Evidence-Based Health Informatics E. Ammenwerth and M. Rigby (Eds.) © 2016 The authors and IOS Press. This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License. doi:10.3233/978-1-61499-635-4-237

Realizing the Potential of Patient Engagement: Designing IT to Support Health in Everyday Life

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> Abstract. Maintaining health or managing a chronic condition involves performing and coordinating potentially new and complex tasks in the context of everyday life. Tools such as reminder apps and online health communities are being created to support patients in carrying out these tasks. Research has documented mixed effectiveness and problems with continued use of these tools, and suggests that more widespread adoption may be aided by design approaches that facilitate integration of eHealth technologies into patients' and family members' daily routines. Given the need to augment existing methods of design and implementation of eHealth tools, this contribution discusses frameworks and associated methods that engage patients and explore contexts of use in ways that can produce insights for eHealth designers.

> Keywords. eHealth, community based participatory research, qualitative research, patient engagement.

1. Introduction

Maintaining health or managing a chronic condition involves performing and coordinating potentially new and complex tasks in the context of everyday life. Activities such as medication management, exercise, implementing new dietary recommendations, and monitoring health indicators must be conducted in addition to the pre-existing activities of everyday life, e.g. preparing meals, caring for children, and working. Tools such as reminder apps and online health communities are being created to support patients in carrying out these activities [1, 2]. These tools, referred to as eHealth, have been defined by the World Health Organization in this way [3]:

E-health is the transfer of health resources and health care by electronic means. It encompasses three main areas:

- 1. The delivery of health information, for health professionals and health consumers, through the Internet and telecommunications.
- 2. Using the power of IT and e-commerce to improve public health services, e.g. through the education and training of health workers.
- 3. The use of e-commerce and e-business practices in health systems management.

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Previous studies have documented mixed effectiveness and problems with continued use of eHealth tools [4-9]. Jimison and colleagues [10] showed that more widespread adoption may be aided by design approaches that facilitate integration of eHealth technologies into patients' and family members' daily routines. Given the need to augment existing methods of design and implementation of eHealth tools [11, 12], methods and frameworks are needed that engage patients and explore contexts of use with the goal of producing insights for eHealth designers. Key questions include: Who is acting? What are the activities? How are the activities structured? Which information infrastructures can contribute to informatics solutions?

This contribution reviews two research frameworks and a design method that may be used together or separately to increase the fidelity of design specifications to the actual needs of patients, family members and other participants as they attempt to integrate health-related activities into everyday life.

2. Patient Work: A Focus on Activity

A persistent challenge in patient engagement research methodology is understanding health and chronic illness management *in context*, i.e., as it actually occurs in the patient's home and community. Patients' homes and communities are the "frontlines" of health and illness-related activities. However, due to the difficulty of doing research in these contexts and a lack of methods for doing so effectively, with a few exceptions [13, 14], prior work has taken research on everyday self-management out of context, focusing primarily on the skills and capacities of the individual patient. Thus, our current understanding of self-management inadequately accounts for the full complexity and dynamics of the context in which it is carried out.

One approach for addressing this challenge is to adapt existing methods for studying activity that have been developed and used in the study of work practices in industrial settings. The Patient Work concept [15, 16] has roots in social science [17] and industrial engineering [18], and holds that the health-related activities of patients, family members, and other lay caregivers constitute a type of work, defined as "exertion of effort and investment of time on the part of patients or family members to produce or accomplish something." [19]. Patient work can be similar or analogous to the work of health care professionals. For example, tracking medications and arranging "handovers" to another caregiver are tasks that parents of children with chronic illness routinely perform. Patient work occurs within a *context* (or "work system") that comprises interacting structural components such as task, technology, environment, and community factors. These factors act as constraints, facilitators, or both, with respect to patient work activity.

Methods for Patient Work research include general approaches such as interviews and observation, methods from work sciences such as cognitive task analysis [20] or rapid ethnography [21], and emerging, technologically-mediated methods such as Ecological Momentary Assessment (EMA), a method that involves repeated sampling of participant's activities in real time [22]. Table 1 provides examples of key considerations for application of these methods in Patient Work research.

Table 1. Method	s amenable to	investigating	Patient	Work and	considerations	for their	use in	the pa	atient	work
domain.										

Methods	Considerations for the patient work domain					
Traditional Research Methods						
Interviews	If multiple actors are involved, how should the perceptions of each be captured - separate or joint interviews?					
Observation: structured, semi- structured, and ethnographic	Conducting observations of private or infrequent activities.					
Standardized surveys	Appropriate tailoring of language.					
Focus group / group interview	Maintaining comfort and privacy about personal medical issues.					
Document analysis	Are documents available and legible?					
Experimental trial	Isolating behavioral interventions to one group when experimental and control groups are socially connected					
Work Study Methods						
Cognitive task analysis	Determining level of informant expertise.					
Incident/accident analysis	Will self-reported causes be inaccurate or incomplete?					
Process mapping	How to portray complex processes crossing boundaries of health and everyday life?					
Critical incident technique	How will memory of events be preserved in old or young individuals?					
Cognitive work analysis	Where is domain expertise found? Clinicians, patients, lay caregivers, or all?					
Macroergonomic work analyses	Identifying appropriate work system models for application to unpaid, community-based work.					
Simulation modeling	How to handle outside sources of variability, e.g., personal life changes?					
Assessment of workload and situation awareness	How to measure without affecting workload and situation awareness themselves?					
Participatory design	Balancing participants' input and expectations with final design elements.					
Emerging Patient-oriented Methods						
Ecological momentary assessment	How to implement when lacking internet access?					
Diary methods	Overtaxing participants while ensuring participation. Data management of paper and electronic diaries.					
Online group / social network analysis	Maintaining privacy and confidentiality.					
Sensor-based monitoring	Maintaining sensor networks when hardware problems arise. Ethics in research design.					

Methods from the work sciences tend to be too generic or else rooted in their domain of origin (e.g., aviation), requiring adaptation to the patient work domain. For example, interviews may need to be focused based on a theoretic lens such as illness trajectory [23] or illness narrative [24] in order to capture the full relevant experience of a patient and his or her family and friends. Cognitive task analysis for patient work may need to accommodate the possibility that expertise on performing a health-related process such as medication management is distributed across actors and artifacts; thus, a complete task analysis requires observations of patients, informal caregivers, clinicians, and various paper and electronic tools, across many settings [25]. Methods that are being developed specifically for collecting patient data also require further development and adaptation to specific contexts. For instance, using portable accelerometry devices to track the activities and step counts of older adults with physical disabilities is complicated by the relative inactivity of these individuals; the potential disuse of wearable devices due to

loss or forgetting; and variability in gait and pace that may render inaccurate stepcounting algorithms. A different set of issues may affect the use of the same devices to study children, for example, concerns about privacy or disabling of the device due to battery use.

Patient Work research seeks to describe and theorize the activities engaged in by patients and other participants in health or chronic illness management, and in this way is similar to Burden of Treatment Theory [26]. Descriptions and frameworks that emerge from this research can point to a range of eHealth development opportunities, including infrastructural requirements, specific information needs, and interface design needs. For example, designers may use the research to identify data sources to enable offering clinic appointments linked to transportation schedules. This need has been recognized in international research policy development. The 2011 OECD-NSF Workshop on Building a Smarter Health and Wellness Future called for investigators to "look at data outside the health domain and link population data from different sources to better understand environmental determinants of nutritional illness, stress, mental health." [27]

Investigations of Patient Work delineate the roles of specific actors in the overall system. This enables moving beyond traditional classifications e.g. "family" or "spouse" toward more functional roles e.g. "medication administration" or "transportation to clinic appointments." Delineation of specific roles can provide useful input to the design of roles for privacy protection. For example, the person who drives the patient to the clinic may benefit from having access to the patient's appointment times, but may *not* need to know information such as diagnoses or medication prescriptions. These information needs, along with those of formal caregivers and health care providers, produce what the European Science Foundation has referred to as "overlapping domains of confidentiality" [28]. In order for eHealth applications to be regarded and used with trust, these domains must be described and built into systems.

Finally, rich studies of Patient Work can provide insight into relationships among illness activities and structures of everyday life. These relationships can be temporal e.g. the timing of the school day structuring the medication management of a teen with asthma. The relationships can also be spatial, e.g. neighborhood design and physical activity, or functional, e.g. the role of material artifacts (backpacks, medication organizers, inhalers, glucometers) in facilitating everyday adherence.

3. Community-Based Participatory Research: Reaching Under-Represented Individuals

Building a base of robust evidence to support innovative developments in eHealth presents challenges, particularly in access to data and participants. Unlike work practice research conducted in hospitals and ambulatory clinics, researchers studying patient activity do not typically have uncomplicated access to patient homes, schools, workplaces and other community settings. In some cases, prior negative interactions with research institutions can lead to feelings of distrust between community members and academic institutions seeking to conduct research. In addition, individuals from underrepresented groups, such as racial/ethnic minority populations or low socioeconomic status, are often under-represented in research activities, leaving researchers with an incomplete perspective on depth and breadth of patient work [29]. The current result is inadequate published evidence; hence innovators (service developers or technical developers) need to study the requirements – in a way which is robust and unbiased.

Studying patient work poses inherent challenges. Community-based participatory research (CBPR) seeks to address issues of access, trust, and representation through building relationships between researchers and the community throughout all stages of research [30]. While the CPBR model has room for the use of multiple methodologies, the core argument of the approach is that community members and partner community organizations need a voice in research design, implementation, and dissemination. In a CBPR-oriented research project, community partners participate in defining research questions of interest to the community, assist with designing context-appropriate participant recruitment strategies, and may participate in data collection and data analysis activities. In addition, results of CBPR-oriented projects are presented not just in academic venues, but using alternate dissemination approaches such as community meetings and social media. Partners representing community groups might also be involved in presenting research results, both in academic and non-academic venues [31].

Researchers and communities can use CBPR to gain a more complete picture of patient work from diverse perspectives. Approaching patient work research from a CBPR perspective can assist researchers with gaining access to contexts and groups that might be inaccessible when viewing research strictly from an academic perspective.

CBPR is not a specific methodology, but rather a theoretical orientation to research that emphasizes meaningful partnerships between researchers and communities. CBPR in consumer health IT applies methods from user-centered design and participatory design fields² and also approaches from the social sciences and ethnography such as observation and interviews [32]. Unertl and colleagues examined projects that integrated CBPR and informatics design, recommending eight principles: 1) Viewing community as a unit of identity, 2) Understanding the existing strengths and resources within the community, 3) Building collaborative partnerships in all research phases, 4) Integrating research results for mutual benefit, 5) Viewing research and partnership building as a cyclical and iterative process, 6) Empowering both academic and community partners through colearning opportunities, with awareness of social inequalities, 7) Incorporating positive and ecological perspectives into research, 8) Disseminating knowledge to all partners [33]

Although application of CBPR is still in the early stages to health informatics research, studies have shown significant promise for improving the fit between technology interventions and patient needs [34, 35].

4. Participatory Design Methodologies: Listening to the Voices of the Intended Users

Once researchers have access to patient work contexts, identifying appropriate methodologies to gather relevant data is critical. Design Science Research focuses on a systematic view of technology in use, rather than separated from use [36]. Design Science methodologies such as participatory design workshops seek to increase the amount and quality of input from intended end users into technology design processes [37]. A group of methodologies especially well-suited to understanding patient contextual factors are participatory design methods. Using participatory design methods,

² See also: A. Kushniruk et al., Participatory design and health IT evaluation, in: E. Ammenwerth, M. Rigby (eds.), Evidence-Based Health Informatics, Stud Health Technol Inform 222, IOS Press, Amsterdam, 2016.

researchers seek input on the emerging design of an artifact, process, service or other entity [38-40]. Participatory design shares common elements with user-centered design, but places more emphasis on co-designing products, technology, or services with intended end users. Participatory design methods go beyond merely asking patients what they want technology to look like or needed functions. Rather, participatory design methods involve intended end users in hands-on activities to help intended end users think about their needs and how technology products might assist with meeting those needs. The emphasis on collaboration in participatory design methods can result in products tailored to an individual's or group's interests and needs. These approaches seem especially well suited to patient contexts, where researcher- or technology-focussed perspectives inherent in technology can result in a poor fit to patient needs [14].

A commonly used participatory design approach is a design workshop. Design workshops differ from focus groups in the degree of active participation and the collaborative nature of the work [37]. One approach to design workshops incorporates three activities: priming, designing, and debriefing. The priming activity helps to set the stage for the design activity by engaging participants in the topic and encouraging participants to begin thinking about their experiences in new ways. For example, participants could be asked to fill out a worksheet about their experience managing a chronic disease or to take photos of places, people, and resources in their community that either are barriers to or facilitators for healthy behavior choices.

The design activity can take many different formats, such as creating a paper prototype for a human-computer interface or developing ideas for processes that could be used to support health-related activities. The focus of the design activity is on looking beyond narrow constraints and engaging in creative development of solutions to problems or questions. Specific types of design activities serve different purposes, so thoughtful selection of an appropriate design activity for the research questions should be considered. Probing activities [41] can be used to explore current experiences and expectations, while generative activities [42] can be used for the co-design of technology or processes. Generative toolkits are used in design science to provide a set of materials that participants can build on while thinking about how they would design a process or a product [43]. Design activities are typically very hands-on and action-oriented, allow participants to activity engage in design based on their expertise.

Finally, the debriefing activity focuses on understanding participant perspectives about artifacts or concepts created in the design activity. Debriefing activities could take various formats, such as individual or small group interviews or having individual participants reporting back to the full group about the artifacts they have created.

The methods used in design science and participatory design often produce extensive amounts of multimedia data, requiring careful consideration of efficient and effective approaches to data analysis. Although workshop participants are experts on the topic being explored (e.g. self-management of a chronic disease; use of technology in managing health), eliciting theoretical concepts from the dataset and acting on the design concepts developed by participants are the responsibility of researchers. Participatory design research is also frequently iterative, with future design workshop cycles building on experiences from participants in prior workshops.

There are multiple examples of applying design science and participatory design approaches to health information technology design and development. Byrne and Gregory reported on a large-scale participatory design project in rural South Africa in which "shared ground" was achieved through design shops among national government officials, local community members and researchers in order to build a system of indicators that reflected child health in the region [44]. Other projects have used PD in both small-scale [45] and large-scale projects [46].

5. How can eHealth IT stakeholders benefit from participatory and patientengaged methods?

Stakeholders in eHealth include patients, their families and caregivers, health care providers (including hospitals, clinics, pharmacy, etc.), health care purchasers, technology developers and device manufacturers, and policy makers. All of these can benefit from patient-engaged approaches to research and design of eHealth tools.

Patients, families and caregivers – rigorous and detailed description of barriers and facilitators to the everyday routines of health maintenance and chronic illness management creates opportunities for technology designers to develop tools that can be tailored to the needs of these actors. Better understandings of the information infrastructures involved in these activities can enable time-saving, safety-enhancing links between them, e.g. health care records, transportation schedules, school systems, pharmacies, grocery stores, family members, social media, and medical such as glucometers, pill boxes, and inhalers.

Health care purchasers – governments and other purchasers gain benefits from patient engagement technologies through improved tailoring of and adherence to therapeutic goals and resulting reduced cost to organizations and society, and also through improved efficiencies gained by automation of previously manual tasks such as filing insurance claims.

Technology developers and device manufacturers – these stakeholders gain through increased acceptance and use of tools that are co-designed to meet users' needs.

Policy makers – these stakeholders will be presented with new challenges from eHealth. While the potential financial benefits of a healthier population are real, policy makers will be required to engage in challenging analysis of issues related to the ongoing digitization of health and related information. Capitalists in data science will push for increased access to the details of life and health of individuals. Simultaneously, privacy and security will be increasingly at risk of malicious attack.

6. Challenges in implementation

Methodologies

As with any instance of field research, the above approaches require not only valid and reliable methods but also an appropriate implementation [47]. An analysis of implementation challenges from two studies of Patient Work in home and community setting [48] found four categories of challenges, related to:

- Researcher-participant partnership (e.g., mutual trust, common ground)
- Participant characteristics (e.g., patients' cognitive limitations, lack of participant transportation for research visits)
- Research logistics and procedures (e.g., travel distances, problems recruiting); and
- Scientific quality and interpretation (e.g., combining data from multiple sources).

In CBPR and participatory design, issues of partnership and balancing the researcher-participant relationship are especially important, given the responsibilities held by community stakeholders [49]. In our experience, the presence of a third party such as a healthcare delivery entity or local nonprofit makes for an even bigger challenge, introducing additional regulations, priorities, and institutional history with the community.

Translation into design

While examples of effective use of the methods exist, skills for translating results of participatory design and Patient Work studies into actionable eHealth design and implementation specifications are not widespread. Findings from these studies can potentially impact interaction design, information infrastructure negotiation and access, security and privacy design elements, connectivity with traditional EHR data, and dissemination strategies. Such skills can be developed and disseminated through professional and educational networks.

7. Conclusion

Developing a base of evidence to support design and implementation decisions in eHealth is essential for ensuring the safe, effective, and efficient deployment of these technologies. Stakeholder engagement through participatory methods and user studies that focus on Patient Work activities produce information that can be disseminated and used as guidance for design. Funders that support these activities may include corporate and government entities. We recommend that funders and professional societies support the further development of frameworks, methods, and training and dissemination infrastructure to enable widespread adoption of these approaches, which will in turn provide the best representation of a range of patient needs to the designers and implementers of tools.

Recommended further readings

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- 4. J. Corbin, A.L. Strauss, Managing Chronic Illness at Home: Three Lines of Work, *Qualitative Sociology* **8(3)** (1985), 224-47.
- 5. P. Carayon (Ed.), *Handbook of human factors and ergonomics in health care and patient safety*, CRC Press, Boca Raton, 2011.

Food for thought

- 1. How is a patient work approach to consumer health informatics design different from biomedical and behavioral change approaches?
- 2. You are developing a smartphone app to help teens with asthma manage their medications. What skills do you need on your development team?
- 3. Consider a health problem that you or a friend lives with. What are the Patient Work tasks involved in managing the health issue? Where does the information come from to make decisions? What are the cues to action?
- 4. Who are the stakeholders of eHealth technology, and what are their priorities?

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