Design to Support Personal Health Information Management

Participants:

Xiaomu Zhou, Ph.D, Assistant professor, School of Communication and Information, Rutgers University. Before joining Rutgers, Zhou's research focused on information practice in clinical settings. She has published a number of papers to explore the clinicians' documentation practice, particularly in the change of an adoption of electronic health records and computerized prescriber-order entry system in hospitals. Zhou's recent research is in the area of health information use from the patients' perspective. She is collaborating with doctors from Robert Wood Johnson Medical Group to study chronic patients, investigating their personal health information management and exploring the effectiveness and usability issues of health information technology developed to facilitate patient information access and improve patient-provider communication (e.g., patient portal).

Elizabeth Kaziunas, is a doctoral student at the University of Michigan's School of Information. Her current research examines practices around managing chronic illness in a community context. An ongoing project including patients and healthcare professionals in Flint, Michigan involves exploring challenges in personal health information management for people living with diabetes, hypertension, and kidney disease in a low-income community with significant health disparities. Kaziunas is interested in designing technology to support collaborative health information work in both clinical and nonclinical settings and is presently involved in the development of a personal health application to better connect healthcare professionals, people living with chronic illness, and local resources.

Motivation and Goals

Researchers in human-computer interaction have documented a rich body of knowledge about Personal Information Management (PIM) (Jones, 2007; Jones and Teevan, 2009). To manage information, users take very subjective approaches, based on the principles of classification (subject topics, which in itself is a complex scheme) and the importance or context of the information (Bergman et al., 2003). However, one of the major problems observed in the practice of PIM is information fragmentation, caused by fragmented locations, devices, formats, and media; and users often have to make decisions based on multiple information sources at the same time, such as calendars, emails, websites, archived files, and so on (Karger & Jones, 2006). To address the problem of fragmentation, in a systematic review of PIM practice and research, Jones (2007) synthesizes a list of remedies for integrating information, including integration through emails, folder search (i.e. computer file organization structure), predetermined needs (a goal, task, project, e.g., to-do list), information properties (e.g. time, a good property for integrating family memories), common representation (similar to metadata to integrate all related information), a digital device (to record "everything"), and organizing techniques and strategies recording. Indeed, we have seen many new IT applications or products that reflect the need for information integration.

But what about Personal *Health* Information Management (PHIM)? While personal health information management shares all properties of information management in general, it presents uniqueness and complexity. As perhaps the first group of researchers who have started to explore this topic, Pratt and her colleagues (2006) illustrated that a chronic patient often has to face an overwhelming volume of information, which is generated from or created (by the patient) to respond to multiple clinics or hospitals (involving different healthcare providers), insurance,

home (family members), and workplace (colleagues); the content of information can be very fragmented with diverse forms as well. In particular, they find that patients need to integrate personal, professional, and health-related information, and use this integrated information to make an informed decision (e.g. making a chemotherapy appointment); patients also want to share certain information with their friends, colleagues, and healthcare providers while maintaining privacy.

Further, Civan et al. (2006) identified three major goals for PHIM activities, i.e., "monitoring and assessing health, making health-related decisions and planning preventive or treatment actions, and performing these health-related actions."(p.158) While empirical studies have demonstrated the importance of PHIM to promote a preventative care model, the issues presented by PHIM are still understudied. As Civan et al. argued, lack of a strong body of knowledge on this topic means little guidance to design a better information system for patients.

Informed by this research agenda, the goal of our proposal for this workshop is to explore and understand how future ICTs can be better designed to support patient information and communication needs. We would like to get insights from other PIM researchers on research findings, methodological strategies, and intellectual framings in order to gain a more comprehensive understanding of the range of patient information practices found in daily life. Through generating a richer portrait of PHIM practices, we take the first steps toward the successful establishment of useful models in guiding future design work.

Work to be done

At the workshop (perhaps with the breakout group who are interested in PHIM), if needed, we would like to first briefly introduce our research on chronic illness patients, and present the challenges we are facing, both from the perspective of patient information practice and our research methodologies to study their PHIM activities.

Second, we would maintain that the types of activities and contexts that are understood as "PHIM" needs to be critically examined by the PIM community. As health is integrated into many aspects of daily life, we would like to get input from our participants who study PIM in contexts that are not healthcare specific. The focus here would be on sharing insights on how (and in what situations) general users manage their health related information that researchers may come across during their examination of other types of the personal information. For instance, take for instance the health information sharing that occasionally happens on social media sites, mobile applications, or in various online communities. This will provide a nice opportunity for us to learn how researchers in PIM think about health information issues and explore the relationship of PIM and PHIM. We hope to discover ways in which PHIM might align with more general research findings and design challenges developed in PIM, and where PHIM characteristics and concerns might diverge to generate different types of research questions and designs.

Our third activity would be to discuss the effectiveness of the methodologies. Currently, we largely rely on qualitative approach (observation and interview) to inform design implications and prototypes. We would like to learn from other participants how they study various issues within the PIM research agenda. Questions for the workshop to consider include: How might we extend the scope of PHIM and investigate health practices in a range of contexts beyond clinics and hospitals such as social media sites, faith-based communities, and in family life? Furthermore, how might we incorporate various design methodologies (e.g. design and cultural probes, participatory design approaches etc.) to explore the design space around emergent or future PHIM practices?

Our final goal is to generate a set of research challenges and future design trajectories that takes into consideration a growing diversity of PHIM contexts. This workshop report would also identify connections between PHIM and other PIM research areas in an effort to aid future collaborations.

Potential impact of the work

We would like to draw the PIM research communities' attention to the issues that PHIM is facing, and collectively strategize on methodological approaches, identify understudied contexts, and imagine new spaces for design interventions. The experiences we share and lessons we learn from one another by attending this workshop will help shape the research agenda of PHIM, which is understudied as earlier researchers point out. Particularly, we hope the set of research challenges and future design trajectories we would like to generate will be a useful intellectual framework for future PHIM and PIM exploration.

Statement

If our proposal is selected, all proposers on this document will attend the workshop.