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Brainstorming Design for Health: Helping Patients Utilize Patient-Generated Information on the Web

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Abstract

Researchers and practitioners show increasing sinterest in utilizing patient-generated information on the Web. Although the HCI and CSCW communities have provided many exciting opportunities for exploring new ideas and building broad agenda in health, few venues offer a platform for interdisciplinary and collaborative brainstorming about design challenges and opportunities in this space. The goal of this workshop is to provide participants with opportunities to interact with stakeholders from diverse backgrounds and practices—researchers, practitioners, designers, programmers, and ethnographers—and together generate tangible design outcomes that utilize patient-generated information on the Web. Through small multidisciplinary group work, we will provide participants with new collaboration opportunities, understanding of the state of the art, inspiration for future work, and ideally avenues for continuing to develop research and design ideas generated at the workshop.

Keywords

crowdsourcing; health; patient; online community

Introduction

Health has increased in prominence in the CSCW and social computing communities in the last few years. Workshops¹ and SIGs [1,2] helped practitioners and researchers to share new ideas and challenges, be informed of the current state of the art, and build agenda for future directions. Health encompasses a wide range of specialty areas, from fostering wellness to managing illness. Although it is important to develop a broad community around helping people to manage their health, it is also valuable to create venues that allow people with interest areas within this broader community to collaboratively build tangible and targeted projects. In this workshop, we focus on leveraging a particular type of resource for designing tools that help patients better manage their health: Patient-generated information on the Web. Patient-generated information refers to health-related experiences and expertise shared by individuals on the Web through blogs, Facebook messages, online forum messages, and other social software usages. Harnessing such information is becoming intensely investigated by researchers and practitioners from various backgrounds and fields.

Workshop Goals

The goal of this workshop is to bring together a diverse and interdisciplinary group with a common interest in patient-generated information for collaborative identification of grand challenges and fruitful opportunities in this space. Workshop participants will share their perspectives on patient-generated information through presentations and discussion of design challenges, work in small groups on focused design solutions, and then use those concrete design ideas to collectively develop an interdisciplinary agenda of future opportunities.

The Design Challenges

Although patient-generated information has the potential to help people manage illness and improve their health, we face a number of critical design challenges to reach this goal. Leveraging an interdisciplinary group, we have the opportunity to discuss many such challenges, including:

- Scalable methods for managing increasingly large data sets
- Methods for processing narrative versus numeric data
- Depicting a diversity of opinions and experiences embedded within patientgenerated information
- Working with 'lay' concepts and language and their alignment with complex medical issues
- Being mindful with privacy-enhancing methods for data handling

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¹The Workshop on Interactive Systems in Healthcare

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