Designing, Developing, and Evaluating the Future Internet of Personal Health

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Abstract

Ubiquitous computing technologies have the potential to revolutionize the support of chronic health conditions: improving quality of life, reducing costs and optimizing health outcomes. Wearable networks of connected devices and sensors offer the prospect of personalized support and contextually aware advice, for those with specific chronic health conditions. However, there are many obstacles and concerns that need to be addressed before the full potential can be realized. This workshop aims to bring together those interested in developing ubiquitous health management and related personal decision support systems to identify how gaps in knowledge can be addressed and design practices can be improved to better support key communities and contexts of use in this rapidly growing field.

Author Keywords

Health management; smartphone apps; healthcare, wellbeing; sensors; Internet of Things; Internet of Personal Health; Quantified Self

ACM Classification Keywords

H.1.2 [User/Machine Systems]: Human factors, Human information processing, Software psychology.

Introduction

Chronic diseases and quality-of-life impacting conditions such as obesity, diabetes, asthma, and

hypertension have placed tremendous stresses on healthcare systems worldwide. While self-management is essential, lifestyle alterations remain challenging for people to put into practice: even highly motivated individuals can struggle to maintain the required behaviors. More advanced ubiquitous systems could be of benefit to those living with these conditions, building on such accepted technologies as insulin pumps and continuous glucose monitors (CGMs). However, many questions remain regarding the ability to meet user needs without compromising self-determination. Rogers and Marsden [2] proposed that, to address such problems, HCI research should move away from third person thinking and instead embrace the design of flexible tools for self-empowerment and re-appropriation. Such promotion of user autonomy becomes especially relevant where algorithms and fully autonomous systems have the potential to dispense medication and offer advice based on standards not necessarily understood nor desired by the user.

Affordable consumer personal informatics technologies have already become pervasive with products such as Fitbit, Jawbone, LifeSum, HealthKit, smartphone and smartwatch apps assisting with the measuring, tracking, and communicating of personal biometrics and trends. And connected devices already exist for: epilepsy [5], ulcer prevention [6], hypertension [7], asthma [8], diabetes [4] and diverse other chronic conditions. The resulting collections of highly targeted and personalized data could potentially help guide better treatment decisions. In some cases it is only with the quantities of data afforded by sensor integration across data sets and services that predictive analysis becomes effective. However, such practices raise serious challenges in terms of data ownership,

privacy, and data siloing. In response to proprietary device standards, groups such as Tidepool.org have been working with industry to open up device APIs, while citizen-initiated groups like Nightscout.org have hacked the data protocol of continuous glucose monitors (CGMs) to allow utilization of collected data on diverse cloud-based platforms.

Such systems could be thought of as early stages of an *Internet of Personal Health* (IoPH) or ubiquitous systems of connected sensors and devices, which assist an individual in the management of a chronic or quality-of-life impacting health condition(s). As these systems become more capable of using methods such as big data analytics and machine learning, they will allow for personalized and contextually aware decision support [3]. However, assessing both short and long-term effects of such technologies on the ecology of an individual's life will be challenging and research methods to measure and analyze these effects are not well developed. In addition, there are many situations in which automated data collection is far from sufficient to ensure any benefit to the user, especially when it is dependent on user data interpretation [1]. Thus there is need for such systems not only to gather data, but also to translate data into motivational feedback to support users in attaining their individual health goals. However, most people have diverse priorities in life such as family, career, or lifestyle that sometimes take precedence over what clinicians might consider "ideal" disease management. Therefore, it is ethically important that these systems do not erode user self-determination. Understanding of these complex user/system relationships will become increasingly important as we carry and embed ever more powerful technologies within our personal sphere.

Goals of This Workshop

This one-day workshop will bring together UbiComp researchers, medical professionals and other stakeholders to share knowledge and improve practice in the design of wearable technologies for enhanced personal health care. We will examine key obstacles, concerns and issues, and seek strategies for refining theory and improving both design practice and research methodologies. Particular attention will be paid to finding ways to empower individuals to take personal control of their personal health devices and systems, and to improve their own health.

Potential Topics for this workshop

- User studies of current digital technology adoption and engagement for chronic conditions.
- Methods of prototyping, evaluating, assessing wearability and usability of IoPH systems.
- Interface design for IoPH systems.
- Data structures and methods for integrating and analyzing diverse personal data.
- The role of behavior change models in IoPH design.
- Embedding autonomy, personalization and customization into IoPH systems.
- The benefits and limitations of AI, analytics and machine learning in health management.
- Novel methods of capturing user data.
- Privacy and Security for personal health data.
- Mapping and exploring the ecosystems of user/devices interactions.

Conclusion

Developments in ubiquitous computing offer potentially life-changing advances in the management of personal health and wellness, especially for those with chronic quality-of-life impacting conditions. However, designing mobile, connected, and potentially invasive technologies creates a complex ecology of issues that technology alone cannot solve. We believe that from every perspective it is essential that these systems be designed primarily to meet the needs of the patients rather than those of any other stakeholder group, and that the human requirements have primacy over the machine requirements. This will require deeper and more thorough understanding of these interactions and their psychosocial, experiential and physiological impact as well as development of new techniques and systems to understand the interaction process. Due to the enormous potential complexity and negative effects of system error, this necessitates both education and exchange between diverse disciplines. It is our goal that this workshop will facilitate these inter-disciplinary collaborations.

Organizers

Eirik Arsand is a Professor at the Arctic University of Norway and Chief Researcher at the Norwegian Centre for eHealth Research, Tromsø, Norway.

Nick Dalton is a Senior Lecturer in Human Computer Interaction At Northumbria University, researching human computer interaction with ubiquitous computing.

Simon Holland is a Senior Lecturer in Computing at The Open University. Interests include Human Computer Interaction, Assistive Technology, Mobile, Wearable and Whole Body Computing.

Dmitri Katz is a PhD student at the Open University, researching UI/UX for supporting chronic disease self-management.

Clare Martin is a Principal Lecturer in Computing with research interests in the usability of healthcare technology and formal methods for computer science.

Carl Magnus Olsson is a Senior Lecturer and Researcher in the Internet of Things and People Center at Malmö University, Sweden.

Blaine Price is a Senior Lecturer in Computing at The Open University researching ubiquitous computing, privacy, wearables, and QS within a health context.

Website
www.IoPHealth.org

Pre-Workshop Plans
Before the workshop, we will focus on constructing the website, which will feature the CfP, abstract, and additional materials. The workshop will be publicized through relevant news groups such as CHI-Announcements, BCS-HCI list, and UbiComp Announcements. Targeted invitations will be sent to people in academia and industry. All chosen submissions will be posted along with short profiles of participants. All participants will be requested to pre-read accepted submissions, in order to be prepared for critical discussion.

Workshop Structure
9:00-9:45: Introduction, presentation of schedule, and identifying the key objectives for workshop.

10:00-12:30 Short presentations of the accepted materials from all participants.

12:30-1:30 Lunch Break

1:30-1:45 Introduction to the Design Fiction, a method of using stories to experiment with new or imagined technologies and their social implications [9,10].

1:45-2:45 Participants will form small groups, working together to create short stories using Design Fiction methodology. The focus will be on future IoPH systems in the context of chronic conditions and life events.

3:15-4:30 Presentation and discussion of key ideas emerging from Design Fiction segment.

4:45-5:45 Group discussion on likely directions of research based on presentations and Design Fictions. Identify future action.

5:45-6:30 Open discussion and networking

Post-Workshop Plans
- Curate Alt.chi paper describing concepts that emerged from workshop, and a roadmap of future approaches for research.
- Create online forum, allowing an informal and inclusive exchange of ideas and experiences with development and implementation of IoPH systems. This site will also serve to identify potential funding sources, and support multi-partner interdisciplinary grant applications.
- All accepted papers will be submitted for inclusion in the ACM Digital Library and supplemental proceedings of the conference.

Call for Participation

"Designing, Developing, and Evaluating the Internet of Personal Health"
http://www.IoPHealth.org

We are seeing the growth of wearable systems supporting people with the management of chronic health conditions. With the merger of mobile health, internet of things (IoT) technologies, and patient centric design, we are seeing the development of a new area we are calling the Internet of personal health (IoPH). These wearable networks of connected devices have the potential to offer contextually aware personal support, interactions, and advice.

The goal of this one-day event is to bring together those interested in developing these systems to (1) provide a platform for designing autonomy into these systems, (2) establishing a forum for discussion of technologies, techniques and measures of effectiveness, and (3) building and extending the IoPH community.

Potential Topics for this workshop
- User studies of digital technology adoption and engagement for chronic conditions.
- Methods of prototyping, evaluating, assessing wearability and usability of IoPH systems.
- Interface design for IoPH systems.
- Embedding autonomy, personalization and customization into IoPH systems.

- The benefits and limitations of AI, analytics and machine learning in health management.
- Novel methods of capturing user data.
- Privacy and Security for personal health data.

We invite contributions of research on UX, interface design, user needs, methods, algorithms, and hardware/software for IoPH systems. Participants are welcomed from a range of disciplines including but not limited to: personal informatics, computing, HCI, medicine, engineering, interface design, cognitive sciences, interaction and experience design.

Authors are asked to submit a 4-page position paper in the SiGCHI extended abstracts format and supporting materials. Please send to participate@iophealth.org by June 7, 2016. Papers may describe ongoing work, recent results, or opinions and approaches related to the workshop topics. Please include a short biography of the author(s), max. 150 words. Papers will be peer-reviewed and the organizing committee will select up to 20 participants according to relevance, diversity of opinions, and probability of creating dynamic discussion. If accepted, at least one author must register for the workshop and for one or more days of the Ubicomp 2016 conference. Papers will also be presented on the workshop website, and be submitted for inclusion in the ACM Digital Library and supplemental proceedings of the conference.

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