



Pervasive Health

Editors: Anind K. Dey ■ Carnegie Mellon University ■ anind@cs.cmu.edu
Jesus Favela ■ CICESE ■ favela@cicese.mx
Stephen Intille ■ Northeastern University ■ s.intille@neu.edu

The Future of Pervasive Health

Kay Connelly, Indiana University
Oscar Mayora, Create-Net
Jesus Favela, CICESE
Maia Jacobs, Georgia Tech
Aleksandar Matic, Telefonica Alpha
Chris Nugent, Ulster University
Stefan Wagner, Aarhus University

On 16 May 2016, a group of nearly 15 researchers met at the Future of Pervasive Health Workshop, part of the International Pervasive Health Conference, to discuss the future of the field. Pervasive health as a field started in the late 90s with the promise of integrating innovative health and wellbeing services into everyday life using pervasive computing and communication technologies. After several years of research and development, the field has evolved to a point in which the adoption of ubiquitous computing devices and software is actually starting to become a reality, with patients systematically using such devices and software in coordination with their caretakers and clinical professionals.

The evolution of this field coincides with rapid technology advancements and with researchers' growing interest in defining regulatory frameworks and integrating ICTs into clinical practice, which would increase opportunities for embedding innovative and high-quality pervasive health solutions into our daily lives.¹ Moreover, pervasive health solutions have reached a maturity level such that they're not only prototypes built up from early technologies and tested for usability in a laboratory; they're now deployed with real patients and

clinical professionals to assess the solutions based on their clinical relevance to treating specific diseases.

While the technology and research focus has matured, there remain many challenges and opportunities. During the Future of Pervasive Health Workshop, we identified five general themes related to pervasive health solutions that must be addressed:

- technological challenges and opportunities,
- adoption and adherence,
- open data,
- methods and ethical issues, and
- education.

This list doesn't pretend to be comprehensive, yet there was wide consensus among workshop participants that addressing these issues is paramount for advancing the field.

TECHNOLOGICAL CHALLENGES AND OPPORTUNITIES

Despite the technology and field maturing to the point of being able to deploy technologies with real patient populations for significant periods of time, pervasive health researchers will continue to work on cutting-edge technologies that are often too brittle for

extended, real-world deployments. Given the breadth of work in this field, we identified four important areas for research to allow fast prototype development with both mature and novel technologies.

Personalization and Adaptivity

Pervasive health solutions must support personalization and adaptivity to ensure they meet the needs of heterogeneous patient populations. The definition of new standards and frameworks will facilitate quickly incorporating these aspects into systems.

Appropriation of Technologies

There exist technologies from other domains (such as the communication or entertainment domains) that could be appropriated to the health space (persuasive interaction, exergames, and so on). There is a need to better understand how to assess such technologies and their appropriateness for health.

Real-World Value

As pervasive health research matures to the point of having an impact on current healthcare practices, researchers need to consider how to promote such a transition. It's important to have standard metrics to assess the value of

a technology in real-world settings and provide such information to the appropriate stakeholders, so they can make informed decisions about whether to invest in this technology.

Shared Research Testbeds

Finally, much early research occurs within a single lab or project, with researchers having to create everything from scratch. While this is necessary, there's a need to have shared research testbeds and infrastructures to maximize the investment in infrastructure, instead of having each research lab invest in their own personal testbeds. Although we can borrow lessons learned from other technical domains, we still must investigate case studies and protocols for how to develop, maintain, and share such research testbeds with respect to human health. This applies to software and hardware infrastructure as well as study protocols.

ADOPTION AND ADHERENCE

As pervasive computing technologies pave the way for transforming traditional episodic healthcare into a continuous, user-centered, and preventive healthcare model, the notion of patient adherence needs to be extended to consider an appropriate use of the technologies (which range from self-measurement devices, such as blood-pressure monitors, to wearable trackers and mobile health apps). Limited or selected use of biomedical sensors or fitness trackers could lead to biased results and inaccurate inferences, yielding unpredictable effects of the used technology. Because inappropriate use of health technologies can result in erroneous input information, this can further affect the quality of the service, which can lower the perceived utility and adoption of the technology and lead to a downward spiral of adherence, reliable data collection, and adoption.

However, it's unrealistic to expect perfect adherence from all users, so future pervasive health applications

must explicitly tackle this challenge. Proposed strategies include using context-aware sensors to detect and tag non-adherent behavior during self-measurement activities, using behavior- and activity-estimation algorithms that infer information from incomplete data, and encouraging adherence through various strategies.

The ability to infer adoption is as important as creating more reliable sensors, medical devices, or healthcare infrastructures for self-care settings. In addition to exploiting technological advancements for providing better healthcare services, a parallel focus must be placed on developing mechanisms for determining the data instances that correspond to lower user compliance with the recommended

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technology. In this regard, context tagging and tracking user activities can help in understanding the reliability of the collected data, reducing the noise in the input data, and informing the service logic and models.

Previous studies have shown that factors such as demographics, culture, lifestyle, and personality represent strong predictors,² which can be automatically captured to build individual adherence models. Moreover, further research is needed to better understand the reasons for non-adherence in specific use cases. This will help us better address user needs and remove potential obstacles to higher compliance—for example, by defining novel strategies for encouraging adoption, such as designing less cumbersome devices, including gamification and persuasion, and so on.

From another perspective, most of the existing healthcare technologies have been designed targeting specific diseases and target groups but without including features for personalization, which might be one of the key reasons for the limited adherence. Although multiple scientific communities have been proposing different concepts of personalization, in practice, there's still a lack of truly individualized technologies that would personalize interaction, adapt better to user's routines, or find the right moment for engaging a user.

OPEN DATA

Mining large datasets and combining them with information from other heterogeneous sources could help advance developments in public health by creating new applications in pervasive and connected health and new strategic policies. In this regard, central to the progression of computational techniques (such as for activity or behavior recognition) in pervasive health is the notion of data sharing and the widespread availability of openly available datasets. Indeed, the need for making health-related data openly available has been strongly endorsed by the Health 8 group of global health organizations.

Models that are being developed to characterize various forms of health and their correlation with behavioral patterns within pervasive health have a fundamental requirement to be developed and tested based on data gleaned from diverse populations covering a range of ethnic, gender, social, and cultural backgrounds. From a technical perspective, we must consider the characteristics of the sensor nodes being used, their locations within the environment, and the constraints that different physical environments impose. Approaches that consider the true multifaceted complexities of the data will inevitably move one step closer toward the development of solutions that work in diverse environments and can produce more generalizable findings.

PERVASIVE HEALTH

Making research datasets available beyond the original research team where they have been generated, in a timely and responsible manner, subject to appropriate safeguards and standards, will offer several benefits. From a data collection perspective, however, generating and collecting such data results is expensive and time-consuming. To date, the seemingly uncoordinated efforts of the research community have further added to the complexities, where many datasets are being unnecessarily duplicated with little or no effort being made to coordinate, consolidate, or share research protocols, leading to the following questions:

- How can we ensure that standards for data management are developed, promoted, and entrenched so that research data can be shared routinely and re-used effectively?
- How can data be collected in an ethical manner, in keeping with best practices?
- What frameworks should be implemented for data sharing to support the creation of an online repository?
- How can challenges around data labeling and ground truth annotation be overcome to ensure the high-quality validation of the data being considered?
- How can data be properly homogenized to conduct studies that include different datasets?
- How can best practices be transferred both to and from other domains?

We must address these issues in making open data repositories for pervasive health.

METHODS AND ETHICAL ISSUES

When addressing the opportunities for innovations in pervasive health, considering the ethical issues associated with these services is critical. Within the conference, two research case studies motivated the discussion around impor-

tant ethical considerations in pervasive health research.

In the first case study, researchers at Indiana University are working with people with rare diseases to understand their needs and lived experiences and to design tools to assist them.³ In the second case study, researchers at the Georgia Institute of Technology are examining how mobile tools can help individuals diagnosed with breast cancer manage the responsibilities and challenges that arise during cancer treatment.⁴ Using these case studies to initiate discussion, researchers at the Pervasive Health Conference deliberated on the ethical questions that arise at each phase of a research study's life cycle. Although we don't offer solutions here, awareness of these issues

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might help researchers develop more ethically mindful studies.

The ethical issues discussed at the conference centered around four points in a research study's life cycle: recruitment, consent, data collection, and end of study. During recruitment, a central ethical concern is reducing added stress placed on both participants and healthcare providers, particularly when working with vulnerable populations. Researchers at the workshop highlighted the need for collaboration between healthcare providers and researchers to develop recruitment strategies that place little burden on existing healthcare services.

Pervasive health research often utilizes participants' personal health data as a tool for promoting behavior change. During consent procedures

for studies involving protected health information, researchers must recognize their responsibility in ensuring that participants understand how their personal data will be used and the risks associated with such data sharing, especially in the context of rapidly changing pervasive health technologies. Future work ought to look at developing best practices for these consent procedures.

Increasingly, pervasive health studies include controlled trials. Although such studies provide stronger evidence, researchers ought to consider the potential detriment to participants who don't receive the intervention. When an intervention might have important health impacts, researchers might need to consider alternative methods that would allow participants in the control group to receive the beneficial intervention, such as running the intervention with the participants in the control group after the experimental study is finished. Conversely, researchers must also consider what responsibility they have for any negative health behaviors that are fostered due to an imperfect intervention.

Finally, when considering the end of research studies, the primary ethical concern we discussed was the return of technical devices. Computing technologies often become ingrained in people's daily lives, and returning devices can thus have negative emotional and health consequences. Researchers should consider what opportunities and barriers exist for allowing study participants to keep devices upon termination of the research study (for example, devices themselves might not be enough; maintenance, technical support, and so on might still be required).

EDUCATION

In the past decade, several efforts have been carried out to formalize pervasive health as a discipline to be integrated into the educational paths. In this rapidly evolving context, where technology, regulations, and clinical practice

are reaching a more clear intersection, the curricula in pervasive health must be revised.

As a starting point, creating common pervasive healthcare terminology will allow researchers and students across the field to collaborate and share results and methods more readily, letting us reproduce experiments in different countries and settings. This will also lead to better collaboration between universities, industry, and user organizations and will help us avoid and mitigate common practical problems faced by the community.

Recognizing the fast-moving nature of our field, we don't recommend locking down the number of topics and technologies to use in training new professionals and researchers. Rather, we'd like to identify and describe a common backbone of knowledge in the shape of one or more courses on pervasive healthcare that we would encourage universities to provide to their students. Also, best practices, described in standardized formats, should be included—such as how to build and evaluate clinical decision support systems, determine which sensors to deploy and how, and even understand how to use open source and open datasets. Moreover, the multidisciplinary nature of the field will require promoting interdisciplinary courses with curricula related not only to HCI and signal processing but also mechanical engineering, nursing, and medicine, among others.

Furthermore, we propose developing a high-quality course e-book that would be continuously updated and enhanced. The only available course book in the field dates back to 2006,⁵ and although it's high-quality and homogenous, the field has evolved considerably since then. Rather than merely revising this book, we suggest creating a community-based repository, where the entire community can provide input and share content about the different aspects of pervasive health. In addition, the traditional sharing of reading material and of

teaching modules, exercises, code, and tutorials would be possible, including access to open source projects and open datasets. Another relevant milestone in the direction of consolidating this field would be the creation of an open access *Journal of Pervasive Healthcare*.

The curriculum covered in the proposed e-book could contain—but wouldn't be limited to—the sample topics discussed here.

Motivation for Study

Students must learn about the forces shaping healthcare and wellbeing in the coming years, including population aging and the rise in chronic diseases. There's also the need for academic research in a field that's already fast-moving based on industrial innovation and marketing efforts.

Background

Students must gain an understanding of ubiquitous and pervasive computing concepts, methods, and history. They should also be proficient about the state of the art in research methods, technologies, systems, and interventions.

Related Fields

Several fields are at times indistinguishable from pervasive health, including telehealth, telemedicine, telecare, medical informatics, mHealth, uHealth, and ambient assisted living. Such fields are highly related and, oftentimes, these are the fields recognizable by our clinical collaborators and other stakeholders, including funding agencies.

Research and Design Methods

It's important to cover inter- and multidisciplinary research topics and best practices, field work and participatory design methods, and interview and usability methods. Students should also learn about ubicomp-style proof-of-concept prototyping methods, clinical proof-of-concept prototyping, and the road to evidence-based medicine methods, including how and when to perform randomized control trials and

when to encourage open source, open-data, and international open collaboration (such as protocol sharing and co-clinical study designs).

Technology Methods

Statistical modeling and reasoning, clinical decision support systems, sensor systems and architectures, and designing for context awareness are also critical methods that must be covered.

State-of-the-Art Pervasive Enabling Technologies

Students should learn about ambient sensors, as well as sensors that enable context awareness. They should also gain an understanding of smart spaces, smart homes, smart hospitals, and other intelligent environments, wearables, and mobile devices. Other topics of interest include bio sensors, distributed computing, and cloud computing.

Security Principles and Practices

International and national regulatory issues, best practices, and technologies for secure pervasive healthcare are all important topics to address.

Here, we've identified a set of challenges and opportunities as a good starting point for evolving the pervasive health research area. However, the list of topics presented here is not exhaustive, and future discussions should occur within the pervasive health community to define a thorough roadmap of actions required for evolving the field. A good opportunity to continue these discussions would be organizing dedicated workshops during relevant events, such as the Pervasive Health Conference, to maximize participation and the dissemination of ideas for the future of this field. ■

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Kay Connelly is an associate professor at Indiana University. Contact her at connelly@indiana.edu.



Oscar Mayora is head of the Ubiquitous Health Group at Create-Net. Contact him at omayora@acm.org.



Jesus Favela is a full professor at CICESE. Contact him at favela@cicese.mx.



Maia Jacobs is a PhD candidate at Georgia Tech. Contact her at mjacobs30@gatech.edu.



Aleksandar Matic is a lead researcher at Telefonica Alpha. Contact him at aleksandar.matic@telefonica.com.



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Chris Nugent is full professor and director of the Computer Science Research Institute at Ulster University. Contact him at cd.nugent@ulster.ac.uk.



Stefan Wagner is an associate professor at Aarhus University. Contact him at sw@eng.au.dk.

