Executive Summary: Research Opportunities and Visions for Smart and Pervasive Health

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The past decade has witnessed tremendous improvements in an expanding number of computing capabilities -- sensors, advanced analytics, networks, data infrastructure, advanced imaging, and cyber-physical systems -- that have, and will continue to, revolutionize health research, and healthcare, with resulting improvements in health and wellness. As the cost of healthcare, the prevalence of chronic disease, and the scope of healthcare disparities increase, so too do emerging paradigms in smart and pervasive health that rely on the growing availability and robustness of sensors, mobile health capabilities and real-time analytics. These paradigms offer holistic approaches to health and healthcare delivery for precision medicine, personalized healthcare, to improve prevention and control the growing expenses associated with chronic disease management and persistent healthcare disparities. This executive summary describes a roadmap for future research in Smart and Pervasive Health based on the conversations at the Computing Community Consortium (CCC) Discovery and Innovation in Smart and Pervasive Health workshop in December 2016. It concludes with a list of recommendations to guide a comprehensive and collaborative approach. A full workshop report is forthcoming.

1.0 24/7 Monitoring for Physiological, Psychological, Environmental and Social Information

Always available health sensing and behavioral monitoring offers the transformational possibility of health and wellness that is bound by neither space nor time. It enables observations of dynamic changes in each individual's health state as well as key physical, biological, behavioral, social, and environmental factors that contribute to health and disease risk, anytime and anywhere that have not been possible in the past.

Although there has been a significant progress in the use of health sensors for remote care for specific diseases (e.g. heart rate monitors), **future strides will come from "holistic" sensing approaches** that integrate wearable, environmental, behavioral, and social network sensors and create new computational models that for human states can, for example, dynamically recognize the influence of environmental factors on human physiology and behavior. With the explosive growth of social media data, it is now possible to obtain temporally varying measurements of interpersonal exchanges, social network structures, and social capital, which can be combined with complementary physiological and psychological measurements of an individual collected by sensors. These dynamic measurements can also reveal network and community effects in health outcomes — quantification of which has been challenging so far due to the paucity of adequate social and community-level data. These approaches also aim to capture the *context* surrounding human behavior to effectively guide healthcare delivery. For example, the noise and bustle of an ICU should affect the content of ICU information displays just as the availability of healthy food and measures of social influence should affect diabetic care and nutritional coaching.

There are several challenging issues in analyzing data, designing decision-support systems, and developing strategic mechanisms for reaching informed responses from holistic sensing approaches:

- How can we measure key environmental variables, such as exposure to cues and triggers for adverse health-related behaviors, and infer a comprehensive characterization of individual behavior?

- How can we model the effect of environmental and social factors on behavior regulation in order to support behavior change and behavior maintenance?
- How do we combine large-scale population "big data" with sparse individual data, controlling for biases in each?
- How do we capture and effectively model the context of and around an individual to guide the "how" of healthcare delivery?
- How can we support decision-making where prioritization of key factors is critical to effective clinical care?
- How can we improve robustness and reliability of these systems operating "in the wild" outside of the traditional confines of healthcare environments.

2.0 Human-Centric System Approaches for Smart and Pervasive Health

Holistic data approaches enable a spectrum of system capabilities that act to integrate data insights and human action. **Fundamental progress will come from systems that actively incorporate input from patients and caregivers and emphasize human engagement** as a whole. These systems must grapple with a host of challenges including balancing human direction and autonomy, integrating real time input and control, creating scalable approaches that manage overlapping layers of input and action, and creating mechanisms for learning.

Mixed Initiative Systems and Closed Loop Systems: Mixed initiative systems balance automation and independent human action including patients, physicians and caregivers. For example, consider a wearable system that helps monitor activities and glucose for diabetic patients. This system might report every week to the clinician a summary of the patient's daily activity and note unusual spikes in glucose, it might offer supportive hints and reminders throughout the day to the patient, and send requests for help or feedback to family members as necessary. Mixed initiative systems must also create a flexible and time-varying division of responsibilities. Decisions that a patient might be capable of making under typical conditions might not be possible under periods of stress, or during episodes of depression or days when dementia symptoms are acute. While traditional mixed-autonomy systems rely on a single, engineered structure for division of task and responsibility, next-generation systems must have the capability to safely support different models of responsibility and risk management for individualized care communities and across changes in the capabilities of individuals. Mixed-initiative systems must have some underlying model of possible human action. Anticipating the range of "random" human action is a challenge, especially when the goal is to create a real-time, closed-loop system.

Closing the loop is ultimately the objective of any smart health system – using data, analytics, and interaction with patients and providers to adapt to the situation. However, adding real-time elements introduces the additional complexity of trading automation/autonomy against oversight, filtering, and feedback through a human. Furthermore, creating closed-loops systems typically involves choosing an objective to optimize, but in smart health, which objectives do we chose, and how do we measure them? For example, rehabilitation may be accelerated by "pushing the system" to the limit, but at the risk of patient comfort; coaching may lose effectiveness if it does not respect patient education, experience, bias, etc., things that are hard to measure and predict; decision-support may not be effective if it cannot take provider context into account.

Many of these systems are distributed – e.g. an ICU is really a complex cyber-physical system-of-systems with multiple controllers (decision makers) that either decide independently on different aspects of the overall system or collaboratively for the entire system, which raises the overall complexity level.

Multi-Tiered Sensing, Modeling and Control Systems: Multi-tier SMC system approaches create the foundation for mixed initiative systems that flexibly balance automation and human action and closed loop systems that integrate real-time data to optimize for specific health outcomes**.** Healthcare data, computed inferences and associated models have a natural multi-tier structure, with varying levels of rate, time-scales, abstraction and specificity. Therefore, it is natural to design "smart health" systems that mirror this multi-tier structure. Multi-tier SMC framework opens various opportunities for:

- Using different models at different time scales and abstraction to flexibly integrate different sources of data, from real time sensors to public health data.
- Creating techniques that help transition from cold models (population) to hot models (personalized).
- Dynamically assigning different roles to humans, e.g. across a coordinated care team or between patients and informal caregivers.
- Managing tradeoffs in sensing, model prediction, data sharing, and privacy.
- Engineering systems to optimize resources across multiple data gathering, modeling, and decision-making processes.

JITAI Systems: JITAI systems, just-in-time adaptive interventions, integrate mobile health applications with dynamic information about an individual's emotional, social, physical and contextual state to facilitate the adoption and maintenance of healthy behaviors and to discourage and prevent negative health behaviors and outcomes. They are designed to provide the right type and amount of support at the right time in person's natural environment by adapting to the person's changing internal state and context. For example, most (93%) unaided smoking cessation attempts fail in first week and 95% of lapses lead to a relapse to smoking. Stress, craving, alcohol, and proximity to tobacco outlets are some major precipitants. The challenge is how to monitor them in real-time to trigger timely interventions. Again, data analytic challenges arise as each JITAI intervention is optimized for individual behavior and his/her environmental context.

Overarching concerns for these human-centric systems include:

- How are inferences and predictions created, how is uncertainty represented, and how can humans understand the rationale and limits of these systems? For example, a neural net may produce outstanding predictions, but without clear justification or "error bounds"; an explicit model may be more explainable and, although it has reduce prediction performance, may be more "convincing" to a provider or patient.
- Ideally these systems should learn over time, but there is not a single loop in most cases, but rather multiple loops at different levels of reaction time and generality. "Inner loops" typically being more traditional real-time control loops (e.g., technology assessing and adjusting prosthetics in real-time based on use), "mid-tier loops" being more human-controlled loops (e.g., adjustment of prosthetics settings by physician) and also much slower or less frequent, and "outer loops" producing generalized knowledge (e.g. likely outcomes for different types of prosthetics)

3.0 Supporting New Healthcare Paradigms

Advances in smart and pervasive health research create opportunities to support new paradigms in healthcare delivery and to address persistent healthcare disparities in the US. Specifically these new holistic and human-centric approaches can provide the foundation for accountable and patient-centric care and for addressing systemic healthcare disparities based in inequities in environments, resources, education and access to healthcare.

Value-Based Treatment Plans: Currently, much of medicine is moving toward "outcomes-based" approaches to enhancing value – get the "best" outcome for the resources expended. However, this premise assumes there is a global and uniform definition of "value" – but value can be interpreted at many levels – patient value, family value, provider value, health system value, and economic value. For example, end of life is a focus point for value – a time of high expenditure with a perception of high value related to treatments (or lack thereof). What are lacking are tools that model "quality of life" alongside predictive models for healthcare treatments. Value-based treatment plans could also foreground the use of incentives in chronic disease management. For example, systems that coach diabetic patients to sustain life goals such as outdoor activity and interaction with family members could prove much more effective than the more abstract task of managing glucose levels.

Accountable and Patient-Centered Care

Multi-tiered SMC systems can provide the foundation for accountable and patient-centric care by integrating complementary models for data collection, decision-making and collaborative, coordinated care. Likewise, systems that integrate more holistic information about patients' lives and information about networks of informal caregivers have the potential to shift current models of patient-centric from supporting physician collaboration to centering care around a patient's behavioral, social and environmental context.

Decreasing Healthcare Disparities

Different groups have been subject to and suffer from inequities in environments, resources, education, access to health care amongst other challenges, which can all adversely impact health outcomes such as quality of life and life expectancy. Smart and pervasive healthcare systems have the potential to reduce disparities by creating systems that are situated in specific socio-economic contexts, for example providing nutritional and exercise guidance in the context of local resources and economic constraints. Moreover, pervasive rates of smartphone use create a more equitable playing field for access to mobile sensing and healthcare expertise.

5.0 Recommendations

In addition to pursuing the research and development paths described in this paper, we want to call out these specific recommendations for the successful implementation of an impactful smart and pervasive health agenda that results in improved health outcomes, cost-effective healthcare delivery, and improved patient satisfaction, engagement and utilization:

1. New health data platforms are needed to support holistic and unconventional data streams. Current industry platforms under development are either proprietary or implement a limited range of physiological data fields, severely limiting the platforms' utility beyond their immediate application goals. New platforms need to accept data produced from both internal and external sources (including both wearables and traditional health monitors) with varying levels of noise, fidelity, and sampling rates. These platforms need to provide a level of data triage to ensure that they are being representing appropriately in statistical models for a particular person given data quality can vary from person to person and device to device
2. As mobile 24/7 technology is brought to bear on personalized human centric care, new efforts are required that fundamentally address human-in-the-loop participation based on principled psychological, behavioral, and physiological models which are exposed as explicit as components of feedback loops. New multidisciplinary research efforts among control theorists and health professionals are recommended.
3. Mobile technology offers unprecedented opportunities to improve prevention of chronic diseases. Realizing this promise requires development of new models and theories for just-in-time intervention. In particular, the timing, content, and delivery modalities need to be optimized so as to effect sustained behavior change in the long-term.
4. With the proliferation of healthcare apps and in-home technology, individuals are becoming more involved with their own health decisions, especially in rural communities. Due to many confounding factors, possible simultaneous treatments, and lack of medical expertise of patients there is a great potential for unsafe actions due to conflicts in treatments, including drug-drug interactions. New population-based solutions must be developed to create sound, evidence-based methodologies and to ensure safety in human centric systems.

5. Rapid progress in infrastructure to support human centric healthcare can only occur if a standardized, architecture for integrating devices and data is developed. Further, instantiations of this architecture must support privacy, security, dependability, safety, reusability, and be useable by non-experts. Significant new research efforts in achieving these goals are recommended.
6. Substantial and sustained collaboration is needed between healthcare practitioners and smart and pervasive health researchers to fully understand the potential of these approaches for new paradigms of healthcare delivery and to identify and address barriers to successful implementation.
7. We encourage the funding agencies to consider health disparities as an integral consideration in their scientific research portfolios and agendas, and to encourage appropriate methods for design, deployment, and continued engagement for the intended target populations, being acutely aware of groups who have been and are affected by disparities.

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