Computing Community Consortium (CCC) Response to NITRD "Draft Federal Health Information Technology Research and Development Strategic Framework"

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The Computing Community Consortium (CCC) prepared this response. The mission of the CCC is to catalyze the computing research community and enable the pursuit of innovative, high-impact research. Our goal is to call attention to major research opportunities for the computing community. The draft NITRD framework highlights several key research areas, but it misses others that are critical and falls short in laying out an ambitious agenda that will maximize the long-term success and broad impact of major health IT investments.

We applaud the comprehensive approach taken by the working group to capture the range of critical topics to the future of our nation's health and healthcare system. Indeed, the framework does a terrific job in establishing the motivators for increased investment and attention to Health IT research and development. While this plan lays out a comprehensive, multi-agency approach for health IT, we want to call attention to advanced research topics that receive scant attention in the framework.

As a resource, we offer a recent white paper by the CCC, "Research Opportunities and Visions for Smart and Pervasive Health," that reflects a community led visioning activity involving over 60 researchers engaged through multiple rounds of discussion and debate. This activity was initiated through a research-visioning workshop in December 2016. Subsequent drafts of this agenda were then presented and discussed at forums including AAAS and ACM meetings. The agenda also received comments and edits from NSF and NIH leadership as well as additional members of the research community.

In our discussions of the NITRD draft Health IT framework, three key issues rose to the forefront:

Human-Centric Complex Systems for Health IT While the framework calls attention to "advanced analytics" and cyber-physical systems," we posit that additional attention needs to be paid to complex system modeling. Notably complex systems are not limited to cyber-physical systems and the ability to leverage the capabilities of advanced analytics will require complex systems to manage, prioritize and act of data insights. Many of these systems will be interactive, multi-tiered systems. Simply pointing to "human in the loop" capabilities does not include the needed computing and engineering research to create effective multi-tiered systems. For example, in our white paper, we point to open opportunities for these systems that:

- Adaptively select different models at different time scales and abstraction to flexibly integrate multiple sources of data, from real time sensing to public health data.

- Enable transitions from population models of behavior, seeded with data accrued at a population level, often static and based on sparse measurement, to individual, dynamic, learning models of behavior that incorporate temporally dense, contextualized data accrued the individual level.
- Enable transitions from interventions that operate on population-based data to those that gradually incorporate more individual data and shift to personalized interventions based on dynamic, learning models of the person.
- Balance tradeoffs in sensing, model prediction, data sharing, and privacy needs.
- Optimize resources across multiple data gathering, modeling, and decision-making processes.
- Dynamically and iteratively gather information as needed, such as incrementally gathering contextual information as a person's activity changes throughout the day.

In our paper, we provide two examples of these envisioned systems, one in distributed healthcare delivery and the other focused on adaptive mobile health.

Security and Privacy

We strongly concur with the framework's inclusion of cyber-security and privacy. We argue that health IT is a particularly challenging area due to the vast number of possible security points of failure coupled with the sensitivity of private health information. This area needs greater attention beyond monitoring and logging.

Many of the security and privacy vulnerabilities found in traditional computing technologies apply in the health setting, but they are amplified through the significant use of legacy systems, out of date operating systems, and many entry points for malicious activity. This range of entry points for attack is further complicated by the fact that personal health monitoring devices are constantly entering and leaving homes and clinics, thus moving away from isolated infrastructures and making classic technologies like firewalls and antivirus less effective.

Security and privacy in health is also about risk management and research is needed in how we balance the risk and benefits of these digital systems. Best practices in security and privacy also need to be re-considered for providers, patients, and developers given the workflows in healthcare. As the number and connectivity of such devices increases, the challenge of managing these collections of devices also becomes exponentially more difficult. Making a single device secure and safe is already a difficult problem. Safety issues are increasingly important for connected devices, as many of these emerging systems are capable of physical control. Health sensing solutions are especially vulnerable as many of these systems reside near or on the body of a user. Past work has already shown the security vulnerabilities of implantable medical devices. However, research is needed to aid healthcare professional, and patients, in balancing security risks against potential health outcomes.

Person-Centered Health IT

Perhaps unsurprisingly, the NITRD framework primarily focused on the healthcare ecosystem and healthcare delivery. What is lacking is a more concerted focus on person / citizen / consumer driven needs as individuals, families, and communities seek to improve health and wellness, often outside of the traditional healthcare system.

For example, on a routine basis, people seek out medical and health information from their favorite search engine or voice assistant. The organizations behind these online tools live in fear of litigation — perhaps legitimately so, as the line between medical fact and medical advice is often blurred. Keyword search on the web returns many links and a person may click long and deep before identifying an answer that contextualizes to their situation (pre-existing conditions, race, gender, etc.). Voice assistants create the expectation of a dialog, but currently under-deliver. Doctors have little time to spend teaching patients about their illness. Patients on the other hand have much time to learn about their disease, particularly those with chronic conditions. Patients in underprivileged segments of the population or living in rural areas distant from hospitals may lean more heavily on these online tools. These people are presently underserved by our research and development efforts.

Beyond chronic conditions, the value of information is sometimes in the moment. Examples include time-critical scenarios such as what to do minutes after a head injury, how to help someone who is choking, or unconscious and not breathing. Search engines/voice assistants are the new first responders. They achieved this prominence with sub-second response time, and continuous presence in almost everyone's pocket or purse or home. How can we help people find the medical information they seek? Most people are not familiar with medical jargon. The gap between colloquial and medical terminology must be effectively bridged. Contextualizing information to an individual's medical conditions, prescriptions, demographics, etc. is crucial for presenting effective support. Dialogs that ask people clarifying questions and allow patients to ask follow-up questions can facilitate this information search process.

Finally, we would like to call attention to the need for research and development that enables "Value-Based Treatment." 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 patients with diabetes 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.

We welcome the opportunity to work with NITRD to help further develop these critical research visions.