Information Technology Research Challenges for Healthcare: From Discovery to Delivery[1]

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Wellness and healthcare are central to the lives of all people, young or old, healthy or ill, rich or poor. The use of information technology is already contributing in significant ways to enhancing healthcare delivery and to improving the quality of life. However, deployments of information technology have only scratched the surface of possibilities for the potential influence of computer and information science and engineering on the quality and cost-effectiveness of healthcare. New computing and behavioral research can lead to *transformative changes* in the cost-effective delivery of quality and personalized healthcare. And beyond the daily practice of healthcare and wellbeing, basic information technology research can provide the foundations for new directions in the clinical sciences via tools and analyses that identify subtle but important causal signals in the fusing of clinical, behavioral, environmental, genetic, and epigenetic data.

Such research is particularly timely now, in light of the national priority to improve human health and the recent passage of healthcare legislation. In addition, we are witnessing dramatic changes in the way care is administered. More and more patients are suffering from chronic illnesses (such as cancer and diabetes) that require continuous attention and care. Of necessity, much of that attention and care takes place outside of hospitals and clinics.

In the sections that follow, we describe some of the opportunities to enhance wellness, healthcare, and the clinical sciences, and the research challenges that must be met to realize those opportunities. Our emphasis is on transformative changes and new directions, but we are mindful as well of the opportunities to strengthen the uses of information technology that are already underway in healthcare and in other domains.

From Data to Knowledge to Action: Enabling Evidence-Based Healthcare

The National Academies' Report "Computational Technology for Effective Health Care: Immediate Steps and Strategic Directions" (Stead and Lin, 2009) details numerous opportunities for improving healthcare processes through leveraging the growing avalanche of data with relevance to healthcare. Data about wellness, illness, and healthcare delivery (including biomedical data), the increasing feasibility of personal data (e.g., 24x7 activity and physiology traces), and the growing availability of relevant contextual data (e.g., indoor and outdoor air quality, exposures to toxins) can collectively better inform multiple healthcare stakeholders including doctors, provider teams, patients, caregivers and payers.

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Advances in methods for capturing and sharing large amounts of data synergize with advances in core analytical, learning, and inferential tools that consume such data. New approaches in applied statistics and machine learning can transform opaque data into knowledge and then into decision policies that can provide guidance on ideal actions by consumers, healthcare providers, and payers. As one direction, large-scale and systematic inclusion of U.S. patients in both observational and interventional research studies promises to greatly accelerate our ability to detect subtle findings that may be small but could nevertheless translate into substantial cost and quality benefits at the population level. Such studies can lead to guidelines on the effective allocation of scarce resources in a context-sensitive manner, identifying how best to make investments that will ideally enhance the quality and cost-effectiveness of healthcare. Studies in support of such goals will often require the extraction, storage, and fusion of multiple classes of data from disparate sources and contexts—data that are drawn in a secure manner in accordance with peoples' preferences about privacy. New computational techniques are needed at multiple steps to meet this challenge, drawing from such sub-disciplines as machine learning and reasoning, systems, databases, cryptography, and human-computer interaction.

A great deal of information with potential relevance to the optimization of healthcare delivery is currently being dropped on the floor. New kinds of data sensing and perception will be necessary to capture and to pool previously uncollected data—and these data may be important for building insights and constructing predictive and causal models. Data must be captured *in situ* and in ways that are automatic, unobtrusive, and easy to use. Networks of small special-purpose sensors and convenient mobile devices are examples of the new technologies that can be brought to bear to capture data. At a higher level, fundamental advances are needed to enable the automated capture and comprehension of context, situations, events, and systems. For example, information about the actions, assessments, and flow of activity among members of a surgical team during a surgery procedure, about the post-surgical course, and about the patient's post-discharge experiences are available to different people at different times—and such data are largely volatile and currently not captured. New kinds of tools for recognition, tracking, and recording could capture and pool such data at low cost and make it available to an analytical pipeline. Also, new kinds of annotations about the sources and reliability of data need to be maintained and relayed with the core data. As an example, the evidence about a heart murmur documented by a cardiologist is different than the evidence provided about that same murmur by a medical student. Advances in the ability to capture information from these multiple sources and synthesize knowledge from them will help to end the chronic hemorrhage of valuable data and experience in health delivery – for individuals and populations.

The analyses that convert information to knowledge and then to decisions are challenging: they must accommodate uncertainty, stochastic processes (such as patients typically visiting their doctors only when they feel something is wrong), temporal dependencies, multiple types of data (such as quantitative, textual, spoken, imaging, hand-written and drawn), and an ever evolving understanding of biomedicine. Furthermore, these advances will not occur without significant research progress in such areas as language understanding, cognitive modeling, human dialog, and rhetorical structure of content, as well as on the core perceptual challenges of visual and acoustical scene analysis, and speech and handwriting recognition. Research will also be required on mixes of perception and reasoning such as the interleaving of perception and inference required for effective plan recognition.

With targeted investment in computer science research, we have the potential to greatly enhance our understanding for health and disease, and to enable truly personalized healthcare delivery – not based on biological and genomic information alone, but also incorporating environmental factors, local clinical effectiveness assessments and information on the course of treatment thus far. Without this research, clinicians will remain swamped with spotty data and with few tools to coerce the data into knowledge.

Empowering people – providers *and* consumers – improves healthcare quality

Healthcare requires effective actions by both consumers and providers; thus, transformational influences of information technology on healthcare will come via enabling both providers and consumers to achieve more, both independently and together.

People are living longer, at times via the management of chronic diseases and in the context of physical and cognitive disabilities. Information technologies can play a critical role in helping individuals and communities to stay healthier, in helping those with chronic or acute conditions to manage their disease outside of acute care settings, and in providing clinical research with high fidelity data from natural experiments in the progression of disease and the comparative effectiveness of interventions. However, the vision of "patient-centered medical homes" that emphasizes coherent, coordinated care centered on patients while protecting their privacy is a far cry from the current disease-oriented, transactional systems centered on physicians and payers. Realizing the vision will require research advances in diverse areas of computer science. For example, advances in data analytics, classification, and feature extraction are essential to turn the myriad of 24x7 recordable data streams into meaningful clinical data. Similarly, current privacy architectures do not support rich semantics for patient understanding, control, and selective sharing of these personal data streams according to clinical needs and personal preferences about privacy and sharing. At the same time, systems must be built to support users with a range of language, literacy, numeracy, and cultural backgrounds.

Human-computer interaction research in its broadest sense is needed to accommodate the full spectrum of patients and caregivers. Power users may desire power tools, but not all users are power users. All participants must be able to participate in workflow management, privacy management, and personal health management to the extent necessary to get patients the care they need. Systems must be able to serve patients and caregivers even when they are distracted, fatigued, or partially incapacitated in other ways.

Part of the vision for healthcare involves effectively capturing information revealed in the interactions between patients and caregivers. Consider the discourse between a patient and a doctor, which occurs in natural language. Having the doctor record the information during the conversation interferes with the discourse itself, while recording the information after the conversation introduces error and incompleteness. A software agent would have to accurately represent the discourse between the individuals, correctly attributing each speech part to each actor in the conversation. It would then have to abstract and summarize the salient information. Since much important information is exhibited non-verbally, the agent would also need observational and synthesis capabilities that extend to visual and tactile cues. Substantial research in natural language, in abstraction and inference, in combining of information, and in computer-enhanced observation is needed to make that possible.

Information must be provided to caregivers and patients in forms that are appropriate both to their skills and to the context. Reading text on a screen may not suffice. Advances in visualization, audio delivery, customization to the needs of particular users, the use of multiple natural languages, and interpersonal collaboration are all important. All must be attuned to the needs and demands of healthcare environments. For example, doctors often have only a few minutes to digest all of the salient information about a patient before having to make a treatment decision, explain it to the patient, and move on to the next activity.

Challenges in medical care are also drivers for research on models of cognition in human-computer interaction. For example, we have a poor understanding of the best ways to non-invasively make healthcare workers aware of potentially important, evolving, time-critical situations involving patients at home or in a hospital. Promising research using the automated capture and analysis of video and sensor data to recognize agitation in people with dementia gives a glimpse of what might be possible, but it is only a first step. We do not know how best to remind or how to predict forgetting. We do not know how to detect and counter well-known psychological biases in judgment and decision-making that plague experts and non-experts alike. We do not know how to choose the right level of detail to explain a disease process, a care plan, or discharge notes to a patient or to her daughter or father. We do not know how best to use computing systems to assist healthcare providers with handling the disruption of focus on a patient or situation in rich multitask settings, nor how to support the ideal recovery and continuity of understanding about a patient's situation—critical for baton passing among the many different individuals and whole care teams overseeing each patient, as well as for refreshing the teams' understanding about a patient between encounters.

Information technology can potentially be used not only to assist caregivers, but also to complement their roles. Recent research is exploring robotic-assisted recovery and rehabilitation, and even socially assistive robotics used for behavioral therapy. The initial achievements are relatively modest when compared with human caregivers, but the potential for extending scarce human resources with automation and with complementary approaches that harness both people and computing technology is enormous. A big research challenge in this domain is to automate the understanding of emotional and physiological state, detecting such mental states as depression, anger, fatigue, or lack of attention.

Equally importantly, we must work with colleagues in social science to explore ways in which we can use technologies to incentivize wellbeing. How might we better understand which technologies are most effective in causing patients to "do the right thing" for their long-term health and wellbeing? For example, how might we encourage cardiovascular disease patients to take the stairs, not the elevator, when climbing several floors in a building? We can invent technology to record what a person eats, but how might we convince patients to monitor their eating habits and to respond to recommendations to change patterns of nutrition? How might we get patients to keep track of their medical data, including test results, through personal health records in a way that enables them to identify unusual occurrences that could be indicative of more serious ailments? How might we help patients to recognize anomalies in their conditions? Mobile devices can facilitate information gathering both by and about patients, but how can we increase the likelihood that they are used and used correctly? How can robotic agents be designed to preserve privacy more effectively than human caregivers?

With targeted investment in research that embraces the human component, we have the potential to enhance the effectiveness of clinicians, to support the complexity of coordinated care, and to enable people to better manage illness while preventing debilitating disease; without it, technology improvements will "fall onto deaf ears" as few meaningful improvements will come from automation alone.

Computer-based augmentation of human learning, reasoning, decision-making, and physical motion significantly enhances human capabilities

Basic research in computer-based learning, reasoning, and decision-making is needed to support healthcare. While great strides have been made, we are only at the beginning of the era of understanding how to infer actual causality versus probabilistic association from data and to design efficient studies that identify causal influences. We are also early in our understanding about how to infer and pursue hidden variables within data—variables that might provide new insights and dispel erroneous assumed causality. We need to create algorithms that would enable the construction of predictive models from streams of data representing physiological processes occurring at different time scales. The latter will likely be important across a broad spectrum of applications, from predicting which seemingly healthy people are at risk for sudden death to the real-time monitoring of hospitalized patients to identify who needs to be moved from the ward to the ICU and vice versa. And, as our datasets can invariably be assumed to be incomplete, we need effective "active learning" methodologies that direct the lowest cost and highest value collection of additional data for building better models. Recent basic research on active learning highlights the power of medical challenges to stimulate new basic science in computer learning, but much more needs to be done.

Emerging technology offers the possibility to create probabilistic diagnostic and treatment engines whose largest and most leveraged knowledge base is the full text of the published biomedical literature and their associated data sets. In addition to the challenges stemming from information availability, access, and analysis, these engines must manage evolving knowledge (e.g., rabies used to be a psychiatric disease, ulcers are now an infectious disease) yet still be able to use data from prior knowledge contexts to generate new knowledge. The engines must weigh the information they use. For instance, there must be models of experiments such as clinical trials, to be able to reason about study quality such as biases arising from study design, to resolve conflicting study results, and so forth. These engines must be able to match knowledge from the literature to actual patients, a mapping that is fraught with semantic and inferential challenges, but that could be semi-automated through mapping of knowledge models, decision models, and data. Finally, to be used, these engines must be appropriately combined with the knowledge and judgment of the human caregivers and patients. These engines cannot be black-box solutions; rather they must serve as mechanisms that are responsive, often in real time, to the cognitive needs of users. How can that dialogue be supported? We are a long way from being able to build and apply robust, useful assistive reasoning engines for health care.

Choices and uncertainty are intrinsic to healthcare. Inevitably, decisions must be made under uncertainty. In practice, those decisions and choices are governed not only by incomplete knowledge of the patient, the ailment, and the treatment, but also by considerations of financial cost, abilities of the caregiver, and effects on other aspects of the quality of life. Research is needed on combined modeling of these various aspects. Those models must be updated as information changes. Techniques are needed to update treatment plans as medical knowledge, patient state, and caregiver characteristics change. Those techniques must be informed by information provided interactively by people of varying knowledge and skills.

In order to be beneficial, the fruits of modeling and learning research must be accessible to its users. The right information must be available at the right time, in a cognitively appropriate form. Well-chosen visual and audio presentations must be found. Decision support encompasses not only information, but also human communication. Appropriately capable tools for collaboration and multi-agent decision-making are needed. All of these are research questions that require exploration.

The fruits of computing research can enhance not only the mental capabilities of humans, but their physical capabilities as well. Emerging research in bio-devices shows real promise, but it is in its infancy. “Smart” prosthetic devices based on technologies drawn from robotics, sensing, and nanotechnology can help to mitigate even the most challenging physical disabilities. Nano-robots, implanted sensors, and imaging technologies can go where humans cannot, assisting diagnosis, surgical interventions, and the ability of people to monitor their own chronic conditions. Among the computing research challenges are achieving intuitive physical human-robot interaction and interfaces, and understanding the user’s behavior and intent.

With targeted investment, we have the potential to create evolving and dynamic foundations of healthcare knowledge through the creation of predictive models and personalized decision support for clinicians and patients. Further, we have the possibility of increasing the mobility of physically disabled persons and of improving the accuracy of surgical interventions while reducing the invasiveness of those procedures.

Healthcare is a complex, large-scale, adaptive distributed evolving system

Healthcare involves multiple interlocking agents, policies, and practices. Modifications to one part of the system ripple out to unforeseen costs and effects in other parts of the system. The system and its components (including hospitals, nursing homes, care providers, payers, etc.) are already in place; they must evolve without starting over. New solutions must be mixed with existing practice and the consequences of large-scale changes need to be simulated and understood before they are deployed. Research on modeling of these complex dynamic systems is needed.

In considering the computing aspects of the healthcare delivery system, advances must introduce enhanced capabilities in large-scale, distributed systems that seamlessly translate and transport healthcare information while ensuring security and patient privacy among an evolving set of stakeholders (and still managing to work with the legacy systems that will dominate healthcare IT for the foreseeable future). Research in how healthcare systems must be structured to support the complexity, scale, and flexibility they require, together with an improved capability to evolve existing systems to have the necessary attributes, will require ongoing collaborations between computer scientists and systems engineers who understand the healthcare enterprise.

Healthcare team members are often of varying backgrounds, roles, and expertise and they are always shifting. For instance, a new consultant may join the care team when a new problem arises; insurance changes may result in a new home care nurse; or a daughter may move into town and become her father's new caretaker. Roles are often informally negotiated and therefore agents, tasks, and plans are difficult to manage and optimize. To provide effective care, protect privacy, and reduce error, the healthcare system must accommodate the diversity of participants, the hand-off of responsibilities, and the need for consistent care. Therefore, identity management and user-controlled privacy are also essential capabilities.

Representations and machinery for privacy are necessary for managing data in accordance with the preferences of consumers and patients. Privacy must be protected, yet people must be allowed to share data in a willful manner with others for their own healthcare and to promote biomedical science in an altruistic manner. The issues with privacy and sharing in healthcare arise in the context of broader discussions of the promise of cloud computing for consumers and the enterprise—where computation moves outside local machines and protected networks to less understood and distant infrastructure potentially accessible by all. Methods for ensuring the privacy and security of data, while maintaining such services as general search, retrieval, and computational manipulations on the data will be critical not just for healthcare, but for most all applications of cloud computing. We currently do not understand how best to enable these kinds of secure services, with such efforts as searchable encryption still in their infancy.

There is a strong national push towards electronic health records. To maximize the utility of those records, the data contained in them must be reliable and complete, as well as available. But our vision extends beyond electronic health records to information obtained from a vast number of other sources. Both the data obtained from health record systems, medical and biological data banks, observational sensor-based systems, and medical devices and the information derived from it must be efficiently accessible across a wide variety of system components. Basic research is needed in the interchange of information represented in multiple formats and diverse media in a robust and efficient way, within large-scale distributed information systems. Core research in computer systems security, in data provenance, and in fault tolerance is also needed. Adaptive systems capabilities are required, so that new disruptive technologies can be incorporated into existing systems.

Targeted research will enable the healthcare system to be transformed holistically, not just within each individual part – addressing policies, technology, incentives, business models, and core computing. Without this research, improvements will be piecemeal at best and counterproductive at worst.

Research enablers and inhibitors

Advances in information technology for healthcare require both basic research in computer science, engineering, and the social sciences, and "customization" of the fruits of basic research for healthcare purposes. For example, there are generic principles and practices for security of large-scale, distributed, user-centric systems, but there are also characteristics that distinguish national defense and infrastructure protection concerns from healthcare concerns. There are generic privacy issues, there are specific privacy concerns (as in financial systems), and there are special concerns in healthcare systems. Issues important for healthcare must be addressed even in fundamental research. Collaboration between all relevant communities and stakeholders is essential for achieving success and enabling basic research with long-term transformational impact.

Open platforms are another powerful research driver. Open platforms encourage sharing and standardization of software, methodologies, data, and analytics. Platforms built with existing state of the art components can deliver application- and technology-relevant data, rapid results (both positive and negative), and a sandbox for next-generation innovations. Platforms create infrastructure that can be tested in a specific context and then adapted to others. They can include reference implementations of modular system components. They can incorporate emerging technologies such as mobile smartphone client applications, wearable devices, etc. They can be used to support novel workflow elements, explore alternate cost models, evaluate new techniques and tools, and compare approaches to the same problem.

Open systems will facilitate adaptation to advances in healthcare and widespread sharing of information, methods, and tools. The current healthcare information technology system is overly reliant on siloed, proprietary systems. Although there is tremendous investment currently through ARRA/HITECH funding, there are no mechanisms in place to transcend these silos. Tools and technologies that catalyze open innovation are needed to enable a healthcare system that can be responsive to continued discovery, invention, evolution, and use. Many of the barriers to deploying open systems are non-technical – but they can only be broken down if the technological foundations of open systems are in place.

Perhaps the most important element of successful development of new technologies that can make a difference in healthcare is a scientific and healthcare workforce that understands in detail the domain and the possible solutions entailed by applications of new or existing information technologies. To this end, far more extensive integrated training and education of fledgling computer scientists in the biomedical domain and "computational thinking" training for biomedical researchers could be highly leveraged. Since the ultimate goal of the research is systems that are used in practice, it is important that researchers can learn from authentic test beds that capture the realities of modern health systems. In some sense, these test beds are "living laboratories" that play the role in information technology research that randomized controlled trials play in pharmacological research. These laboratories produce data that support continued discovery about the people and technology working together while supporting ongoing work. Early examples of such living laboratories are heavily instrumented operating rooms used, for example, for neurosurgery.

Moving this field forward is best done with a real test bed with real drivers, participants, and real-world constraints. Community health is an example of a well-matched driver. A test bed for community health is relevant to many healthcare priorities: chronic disease management, health-behavior change, youth preventative health, mental health monitoring, comparative effectiveness research, community health worker and informal caregiver support.

With targeted research infrastructure development and education, we can create an environment in which scientific and technical advances can occur that will improve health and healthcare in major ways. Those advances can be put into practice through the combined efforts of capable human participants and their interconnection with a global, healthcare network that is responsive to opportunities for continued transformation.

The Importance of Collaborative Government Investment

Improving human health and healthcare delivery is a major U.S. priority. Advances in information technology are at the center of the changes that are needed to realize affordable, reliable, and effective healthcare. Those advances require basic research in computer science, as well as in allied areas of engineering and the social sciences. The mission of the National Science Foundation (NSF) is to support discovery, innovation, learning, and infrastructure in each of these disciplines. As a result, NSF's investment in healthcare research is essential in order for the opportunities outlined in this paper to be realized.

But the basic research cannot be undirected. To achieve advances in health and healthcare, the research must be informed from the outset by the intended domain of use, that is, by expertise and progress in all aspects of biomedicine. As the primary Federal agency for conducting and supporting medical research, continuing investment from the National Institutes of Health (NIH) is also critical.

A number of other Federal agencies are also stakeholders in human health and wellness. The Office of the National Coordinator for Health Information Technology (ONC) and the Agency for Healthcare Research and Quality (AHRQ) within the Department of Health and Human Services are funding the development and deployment of electronic medical record systems to hospitals and clinics around the country. The Centers for Disease Control (CDC) lead national efforts in public health. These efforts stand to be informed by the basic research outlined above. Likewise, as the principal regulatory arm for biomedical devices, the Food and Drug Administration (FDA) could be involved to ensure that new technologies emerging from our nation's research labs arrive on the market in a timely manner and with maximal safety.

The importance of collaboration between information technology researchers, systems engineers, social scientists, *and* biomedical researchers is an essential component of the research agenda we have laid out. That research interaction can be achieved even without the collaboration of NSF, NIH, and other Federal agencies, but the combined effort of those agencies will go far in accelerating this research.

Conclusion

There are many opportunities for enhancing wellness and healthcare in a world where the once exotic notion of *ubiquitous computing* has become the norm. Patients, providers, and payers will soon have access to enormous sets of healthcare data—all at their fingertips, available remotely, anywhere and anytime. There are great opportunities ahead for fundamental computing research to accelerate our understanding of how – in the course of normal daily activities – to sense and collect valuable health and wellness data and indicators, to analyze and use that information for evidence-based healthcare, to stabilize physiology, to modify risky behaviors, to design and field snap clinical trials to advance biomedical knowledge, and to care for people with health challenges. Just as this work requires substantive contributions by computing researchers, it also requires the establishment of highly collaborative, interdisciplinary efforts that span computing as well as engineering, social and behavioral science, and medicine.