Workshop Structure and Goals (short)

[A more complete version of this document will be posted at a later time – this is an abbreviated summary.]

The first purpose of the workshop is to identify a rich collection of research challenges and opportunities that should be characterized by:

1. A clear problem statement
2. Promising lines of attack, and
3. Test-beds or demonstrations that would both inform further research and help to transition the results into practice.

The second purpose of the workshop is to grow an interdisciplinary community of collaborators with a common goal of conducting research to advance our shared ability to address these challenges/opportunities, evaluating and then translating the results into the basis for high quality healthcare and long-term health for the populace.

In order to structure the discussions, we will have four sessions. We have introduced themes for the first two sessions and broad topics for the last two sessions. These themes and topics are expanded upon below. The themes are somewhat orthogonal but not independent. They are intended to be suggestive, not limiting; their purpose is to stimulate ideation and creative thinking by the participants.

Session One – Perspectives: Patient, Caregiver, Public Health

Patient/Consumer

- People don't know what symptoms to be concerned about and when they need healthcare.
- Healthcare quality is uneven and not well integrated across providers.
- Hospitalized patients and their families lack important information.
- There would be benefit to people sharing personal data with scientists, epidemiologists, and other patients, but it is difficult to preserve the person's anonymity.
- Technical advances could enable the elderly and the chronically ill to live more independently, and could help people at serious risk of a sudden health emergency to go about their lives. They could assist the disabled.

Caregiver

- Electronic recoding of patient data would have many benefits, yet healthcare providers are reluctant to adopt electronic health record technologies that do not fit their perceived priorities and seriously interfere with their workflow.

- Many care providers find it difficult to remain up to date on latest practices and recommendations, and they are increasingly pressured by the joint demand for increased quality and increased patient volume.
- Geographic distances between underserved populations and concentrations of healthcare providers cause inefficiencies and suboptimal distribution of healthcare resources.

Public health

- The lack of integration of information about the ethnography, health, and healthcare of individuals with population data used in public health surveillance and implementation programs limits the opportunity to learn from millions of patient encounters. Integrated individual and population data could enable the custom-tailoring of healthcare and wellness plans to consumers. Multiple avenues exist for collecting that data.
- The lack of high-quality documentation of clinical encounters slows more fundamental biomedical discoveries that could lead to better treatments, recognition of harmful medications, and identification of public health threats and opportunities.
- The lack of integration of long-term health-related information generated from existing or new measurement technologies creates unnecessary short and long-term blind-spots in our public health initiatives.

Promise of Computer Science and Engineering

These examples frame a rich set of challenges/opportunities for the application of the information, computing, and decision sciences. Numerous advances across computing sub-disciplines could be harnessed, via focused research and engineering, to provide value to consumers, care providers, and to public health researchers. In particular, creative efforts in machine learning and inference, ambient and directed sensing, location-based services, robotics, networking, data visualization, social media, and human-computer interaction could reduce healthcare costs and overall improve the quality and length of peoples' lives.

Session 2 - Process: Prevention, Prediction, Diagnosis, Intervention, Rehabilitation and monitoring

- Understanding the causes of disease, both in individuals and in societies, and the genetic and environmental factors that increase the likelihood of disease, and detecting the agents that put us at risk, would help us to reduce the incidence of various ailments, to anticipate their onset, and to identify their occurrences.

- Although much is already known about both immediate and long-term treatment and care when disease occurs, both higher quality and lower cost intervention and rehabilitation are essential.
- There is a gap between what is potentially possible in the continuum from prevention to best-possible eventual outcomes and what actually occurs.
- Technologic advances such as potentially ubiquitous small accurate sensors and smart robots could change for the better many of the processes traditionally used in all stages of healthcare. What is the research that is needed to realize that impact? While implementing them, what is a good balance between the user's desire and smart systems?
- Today's health care consists of disconnected decisions and processes. This is true across the care spectrum, from health promotion for the populace to diagnosis, treatment, and care coordination for those who are ill. A systems approach to care – one that explicitly recognizes the continuum and effectively manages information as it moves among providers, patients, healthy individuals, and organizations – could shift the balance from individual experts to systems that help people to do the right thing.
- Advances in genomics, imaging, simulation, and integrated and deep data analysis, could enable a profound understanding of the physical and mental condition of an individual. Coupled with an increasingly deep understanding of the symptoms and causes of disease and the efficacy of interventions, there is a new opportunity to know what is the right thing to do.

The combination of increased volume and access to knowledge, advances with deriving models and inferences from the data, more effective use and wider adoption of information technology, and more ubiquitous decision informatics enhance the possibility of predicting outcomes and susceptibility, reducing error, reducing ineffective and unnecessary interventions, increasing the effectiveness of individual caregivers, and providing better care at all stages.

Sample Challenges – Sessions One and Two

A few high-level directions that might suggest challenges/opportunities are listed below. This list is illustrative but incomplete. Workshop participants will add more.

Modeling, decision making, and discovery

- Machine learning and decision analysis on large patient data sets to develop ideal recommendations, alerting, and warnings for physicians and healthcare organizations to guide medical intake, triage, diagnosis, and disease management.
- Privacy-preserving architectures that support secure and selective sharing of personal health data for research.

- Predictive models that identify drug-related adverse events across the population and characterize those patients at greatest risk.
- Cognitive assistance for healthcare providers making decisions under uncertainty and the pressure of time.
- Self-documenting people and behaviors (ways to discover and record individual attributes and behaviors over time and to associate that information with the individual).
- Automated fault detection (techniques to capture process data during health care and life processes, coupled with statistical techniques for fault detection).

Visualization, summarization, and data availability

- Automated generation of concise, yet informative summaries for patients and patients' families of the health situation, including key uncertainties, pending decisions, and care plan moving forward.
- Automated clinical documentation and communications systems that are efficient, comprehensive, and unobtrusive.
- Leveraging of social networks, social media, and crowd sourcing to support patients' and patient families' questions and concerns.
- Mobile and interactive real-time tools for community health workers to support their roles as providers of healthcare to individuals and communities, and sentinels for emerging health hazards and needs.

Smart sensing, telemetry, and actuation to support patient monitoring and care

- Closed-loop sensing and dosing for fine-grained drug delivery, balancing of endocrine deficiency, etc.
- Development of non-invasive materials and instruments for monitoring physiological signs, drug levels, endocrine levels (e.g., from saliva, perspiration, exhalation).
- Implanted semi-autonomous micro-mechanical devices to survey and report the status of internal structures and function (e.g., coronary arteries in at-risk patients.)
- Robotics, sensing, and automation to support home care for patients currently requiring long-term stays in intensive care units, and assistive care for at-home patients with chronic diseases and disabilities.
- Assistive software agents that support people with cognitive impairments to live independently.

Robotics and vision for diagnosis and surgery

- More sophisticated machine vision for histological and radiological imaging studies.
- Technologies for enabling distributed surgical teams and new forms of surgical collaboration.

- Fully-automated vision-guided precision microsurgery.

Deployment

- Seamless integration of new knowledge, instrumentation, and diagnosis, planning, and intervention into ongoing patient self-assessment and care-giving situations.
- Adaptive insertion of emerging technologies into preexisting healthcare systems, practices, and cultures.

Session 3 –White Space: Everything Else

Rather than using the fruits of information technology to improve the provision of healthcare as it exists today, maybe significantly different processes and practices can be envisioned, serving the needs of the various perspectives in new formats, in new environments and through new mediums of interaction. What ideas might inspire a re-examination of our existing approaches? What adjacent research theories might have immediate relevance here?

Example: What if it were possible to understand the complete genome of an individual, and collect a complete history of that person's vital signs, environmental effects, nutrition, emotions, growth, trauma, etc. from birth on? How might that longitudinal information be synthesized? Against what algorithms could such a multivariate data file be processed to offer policies and clinically actionable results? How would it inform the processes that keep that person healthy? What would be the roles and responsibilities of healthcare providers?

Example: If it were possible to aggregate all the instances of a disease, all the biologic factors, all the ancillary effects (other conditions of the patient, treatments, etc.) and analyze them arbitrarily deeply, what would be the important questions to ask? How would the answers translate to the diagnosis and treatment of an individual?

What are the synergistic research challenges from the first two sessions that have potential to amplify one another? What are we missing?

Session 4 – How does it all fit together?

It's important to have a large collection of potentially transformative and exciting research challenges and to outline the research projects that would enable us to meet those challenges.

It's also important to paint the big picture of the challenges and opportunities in a coherent way that's more focused than a long laundry list – to develop the elevator speech that explains why our vision is not only compelling but also promising.

The purpose of the final session is to develop that story. It will also be a time to brainstorm about next steps in advancing our agenda for research in the use of innovative information technology for improving healthcare.