

NSF Learning Health System Workshop: Use Cases

Use Case 1: Health Care Quality and Efficiency

Health systems, regions, states, and the nation as a whole harness the power of clinical information in digital form for ongoing study of health care quality and efficiency. Data from care delivery sites about patient characteristics, prevention, diagnosis, and treatment are routinely collected. Specific clinical regimens and management practices associated with better outcomes are identified and made available to practice sites. Implementation of these “best care practices” creates a virtuous cycle of care improvement through analysis, feedback, and change.

Requirements:

1. A health system, region, state, or nation can continuously generate care quality information without routine human intervention. Care quality measures include both processes (e.g., routine exams and laboratory testing) and outcomes (e.g., lower blood pressure, weight loss, disease-free survival).
2. The system can support analysis at any scale, identifying individuals and populations at risk for harm and whether interventions improved performance.
3. The system can be used to identify when variations in care are associated with better outcomes. “Outcomes” can include clinical, economic, physiological, and psychological measures.
4. The process is HIPAA-compliant.
5. There is a model for all entities to pay their fair share for support of this system.
6. “Best practices” learned by the system can be inserted into the workflow of clinicians as templates.
7. Patients can receive, on request, a report of their own health care experience and how their own experience compares with that of other patients and in relation to best practices.
8. There is appropriate governance over the process.
9. Patients may opt out of inclusion in this system.
10. Patients and providers trust the system.
11. A wide range of stakeholders are incentivized to participate.

Use Case 2: Public Health

The LHS develops the capability to detect disease clusters or outbreaks; maintain a geographical information system capturing the spread of the disease; and convey important information to public health officials, care providers, and the general public.

Requirements:

1. The system will detect unusual rates of naturally occurring diseases, adverse drug reactions, responses to environmental exposures, and other health outcomes that affect all people equally or a vulnerable segment of the population; have temporal clustering that is acute, sub-acute, or chronic; are “expected” or unexpected; and are common or rare. The system can also detect geographically concentrated, or widely distributed events.
2. The system is able to detect an outbreak before it is detected by other means.
3. A nationwide geographic-based disease information system is automatically populated by EHR data as new cases are diagnosed. The system can provide views of varying geographic granularity to local, municipal, state, and national public health agencies.
4. All recently-identified cases, anywhere in the nation, are known to the system.
5. The system can alert clinicians of the likelihood that the condition will affect their practice localities.
6. The system can keep the general public aware of the state of the cluster.
7. Individual members of the public can query the system.
8. The system can “defend itself” against unauthorized intrusions intended to generate panic in the population.
9. The system can integrate data from multiple sources including electronic data sources, Internet search engines, retail sales databases, and others.
10. The system can learn from data variations over space and time that are occurring in the presentation of the disease, or in patients’ responses to treatment.
11. There is a model for public health agencies/entities to pay their fair share of the cost of the system.

Use Case 3: Personal Health

Patients who face difficult health-related decisions want to know the experiences of other “patients like them”, as a function of which decision options they pursued.

Requirements:

1. She can formulate a query to the system to identify “patients like her” and then to request specific aggregated information about this set of patients across a nationwide set of participating entities.
2. The system is multi-lingual and useful to people with different levels of education.
3. The system is HIPAA-compliant.
4. The system accommodates genetic information.
5. The system accommodates personal data streams from the individual’s smartphone, consumer devices, and digital traces to allow the individual to create a more objective, and precise picture of their (a) functional status (activities of daily living), and (b) health behaviors
6. Her use of the system is economically affordable, and not restricted to the affluent.
7. She can play “what if” games with the system, obtaining projections based on a predictive model of what she might expect if she pursues particular options, taking into account information about her that is known to the system without her having to enter it.
8. The system supports data sharing and collaborative decision making between individuals, their significant others, their care providers, and members of their social network.

Use Case 4: Research

Researchers are working to develop new insights and innovations. They want a “rapid learning” system designed to support their work.

Requirements

1. Researchers can access large databases and registries for millions of patients, with individual, longitudinal, clinically rich, standardized data from EHRs and other sources.
 - a. The datasets that can be assembled through the system are large and sophisticated/precise enough to support research for all patient subgroups and conditions and for personalized medicine, including patients often not represented in clinical trials, such as children, seniors, patients with multiple chronic conditions, pregnant women, and patients with rare diseases.
 - b. The system includes information about biobanks (data from archived blood and tissue samples) that can be analyzed for future research. There will be several geographic based population study sites for multi-decade, multi-generation studies. Research projects will be able to gather accurate, detailed, real-time patient data through direct upload from medical devices.
 - c. Available resources include physiologic, genetic, proteomic, metabolomic, environmental, demographic and other data.
 - d. Patients can input data, appropriately tagged as patient-contributed, directly into the repository.
2. The data are curated and indexed on various measures of data quality.
3. An equitable economic/business model supports the operation of the system, allowing stakeholders who can contribute to the enterprise in different ways (data, subjects, money) to be able participate.
4. Patient-level data are privacy-protected, confidential, and available for research, subject to standardized rules and procedures. Research projects can proceed quickly without compromising patients' rights.
5. Software services are available to support efficient search and machine learning from registries and databases, including finding previously unrecognized patterns and relationships, generating and testing alternative hypotheses.
6. For certain research problems, analytic routines run “in the background” to provide real-time analyses of accumulating research data.
7. Predictive, validated models for human physiology and therapeutics make it possible to assess comparative effectiveness of prevention strategies and therapies, formulate and test alternative theories about disease and its treatment via *in silico* research, and to conduct simulated trials for new products.

8. The system can support identification of patients eligible for studies and can facilitate their recruitment. Patients and professional care providers can readily find and contribute data to clinical studies.
9. There will be rapid learning networks and databases that allow all researchers to be in on-going discussions with peers, e.g. weekly virtual “brown bag” videoconferences, to create joint registries and share data, to conduct joint and multi-site projects.
10. There will be opportunities for rapid online dissemination of research results, affording researchers appropriate credit for their work.