Developing a Policy & Governance Framework for an Operational Learning Health System

Presentation to the HIMSS Center for Patient and Family-centered Care

November 12, 2014
Background to Current Activities
Core Values Underlying a National-Scale, Person-Centered Continuous Learning Health System (LHS)

Developed at the May, 2012 Learning Health System Summit
Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS)

1. **Person-Focused:** The LHS will protect and improve the health of individuals by informing choices about health and healthcare. The LHS will do this by enabling strategies that engage individuals, families, groups, communities, and the general population, as well as the United States healthcare system as a whole.

2. **Privacy:** The LHS will protect the privacy, confidentiality, and security of all data to enable responsible sharing of data, information, and knowledge, as well as to build trust among all stakeholders.

3. **Inclusiveness:** Every individual and organization committed to improving the health of individuals, communities, and diverse populations, who abides by the governance of the LHS, is invited and encouraged to participate.
Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS)

4. **Transparency:** With a commitment to integrity, all aspects of LHS operations will be open and transparent to safeguard and deepen the trust of all stakeholders in the system, as well as to foster accountability.

5. **Accessibility:** All should benefit from the public good derived from the LHS. Therefore, the LHS should be available and should deliver value to all, while encouraging and incentivizing broad and sustained participation.

6. **Adaptability:** The LHS will be designed to enable iterative, rapid adaptation and incremental evolution to meet current and future needs of stakeholders.

7. **Governance:** The LHS will have that governance which is necessary to support its sustainable operation, to set required standards, to build and maintain trust on the part of all stakeholders, and to stimulate ongoing innovation.
Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS)

8. **Cooperative and Participatory Leadership:** The leadership of the LHS will be a multi-stakeholder collaboration across the public and private sectors including patients, consumers, caregivers, and families, in addition to other stakeholders. Diverse communities and populations will be represented. Bold leadership and strong user participation are essential keys to unlocking the potential of the LHS.

9. **Scientific Integrity:** The LHS and its participants will share a commitment to the most rigorous application of science to ensure the validity and credibility of findings, and the open sharing and integration of new knowledge in a timely and responsible manner.

10. **Value:** The LHS will support learning activities that can serve to optimize both the quality and affordability of healthcare. The LHS will be efficient and seek to minimize financial, logistical, and other burdens associated with participation.
65 Endorsements of the LHS Core Values*  
(As of 10/28/2014)

*To be included on a Learning Health Community public website that will list all organizations that have endorsed the LHS Core Values.
The Learning Health Community: A Grassroots, Self-Organizing, Multi-Stakeholder Movement

Learning Health Community
-------------------------
Steering Committee

ESTEL
Essential Structures to Enable Learning

Policy & Governance Framework Initiative
(Initial Activities)
LHS Components
The Learning Health System:
Improving Personal and Population Health through Knowledge

Community
Data on Individuals & Populations
Problem Definition
Research Plan

Governance
Data Use
Policies & Procedures
Standards Adoption

Education
Communications
Publications
Messaging

Technical
Aggregation
Analysis
Security
Policy & Governance Initiative
The point of departure for the governance initiative will be several working assumptions about the structure of a national-scale LHS.

-- The national-scale LHS will be a **structured, collaborative, multi-stakeholder effort**: a system comprised of sub-systems bound together by a common policy and governance framework agreed to by any organization electing to participate and willing to be legally bound by the **multi-party agreement** that all parties must execute before participating.

-- The sub-systems comprising the LHS will be **heterogeneous**, comprising all stakeholders in the nation’s health sector, including but not restricted to: provider organizations, payer organizations, patient/consumer groups, research organizations, technology companies, professional associations, and government agencies including public health that can comply with the agreement that binds all participants to a common set of expectations and responsibilities.

-- These heterogeneous entities will have different reasons for being part of the LHS. They will contribute in differing ways to the LHS and will derive differing benefits.

-- In order to be stable and sustainable, the national LHS will require some form of governance, likely reflected in a compact or multi-party agreement that all sub-systems will formally endorse. Agreement to comply with the current version of the ESTEL standards will be a key component of this compact along with other standards, policies and procedures that will be a part of the structure. **A draft of the agreement is expected to be the primary deliverable of the governance initiative.**

-- The governance initiative will view the LHS as an ultra-large scale system and will be one that enables growth, evolution, self-repair, and change.

-- While these sub-systems themselves may consist of sub-sub-systems, the governance of the LHS will extend only to its own direct sub-systems but may need to take into account any **chain-of-trust implications** dependent on the data sharing work flow.

-- The governance of a national LHS is expected to be a **public-private partnership**, not residing within the federal government.
Initial Meetings Oct. 26-27, 2014
NCHICA, Research Triangle Park, NC
DATA SUPPLIERS/USERS

- Federal/State Gov't, Penal
- Public Health - State, Local, Regional, National, International
- Researchers - Clinical, Basic Science, etc.
- 3 Levels
- Canopy - Disease, Surveillance, Payers, Information
  - Public Providers - Clinical, Home care, nursing, support community needs
  - Companies - EHR, Pharma, mobile/telecom, Payers, Construction, vendors, analysts
  - Industries - communities
- Key sectors - Energy, environmental, security/defense, professional associations, social services, societal
Contacts

Joshua C. Rubin, JD, MBA, MPH, MPP
Program Officer for Leaning Health System Initiatives
Department of Learning Health Sciences
University of Michigan Medical School
josh@joshcrubin.com

Holt Anderson
Chair, Policy & Governance Framework Initiative
Learning Health Community
lhs@nchica.org

http://www.learninghealth.org