**Learning Health System Policy & Governance Framework Initiative**

DRAFT

**Draft Meeting Notes - October 27, 2014**

**NCHICA Office, Research Triangle Park, NC**

This document records the flow of discussion topics as they occurred during the course of the initial Learning Health System (LHS) Governance Framework Taskforce meeting.

Meeting began at **7:30 AM**

Concept of learning cycles

Minimum viable product

Are we going into implementation issues that the governance structure will be struggling with?

Patient as the ultimate source of the data -- and ultimate user (to make decisions)

Need buy-in of CFO, CIO

Need to make the data cheap -- the incremental cost of the next learning cycle is a fraction of the first one

Open data, open government in the Obama administration

Break down barriers between public health, population health, clinical care, research, etc.

ONC Governance Framework for Trusted Electronic Health Information Exchange

90% of adults willing to share data to improve health if identity can be kept private

When ONC talks about exchange and interoperability, it is talking about every tool in the toolbox

AHRQ had done work on governance years ago

JASON report

Utah informatics, Ohio high performance computing, Argon informatics

How much specificity around what the LHS will do is needed to define the governance?

Stan Huff -- Playing basketball on a court without lines, defined hoop size, ball size, etc.

LHS about engendering lots of learning cycles, making them cheaper and easier, infrastructure to enable

Building on data and structures that are byproducts of care and health and what is already happening

Core roles

Provide unfiltered data

Aggregate

Analyze

Feed back what is learned as guidance (what works best, what works and what doesn't work)

LHS is an open ended system engendering these cycles

Minimum viable product

Longitudinal record/story of an individual patient

A person's/individual's health story

Imagine a community of health stories

3-5 years for the DURSA to get federal clearance

Draw on connections to CMS, etc.

Need to consider technical interoperability and policy interoperability

Characteristics

Reliable, secure, cost effective, SLAs, etc.

Look to other sectors

Energy, telecom, finance

ONC national call for LHS

Patient, education, standards and interoperability, national quality strategy, governance, LHS

Defining LHS

IOM definition, table of characteristics

LHS Core Values

A set of information systems which interoperate around the adoption of a learning healty cycle

Different information systems provide different services

Create and capture raw data (EHR, etc.), aggregate (registry, etc.), analyze, learning, improve...

Notion of a culture change too

Try to define four roles/services

Roles may be dynamic

A marketplace for services -- e.g., data analysis

Internet parallels, emergent

Complexity theory, complex adaptive systems principles

Simple rules can govern complex behaviors

Common framework -- how do we make the systems that are emerging work together

Ultra Large Scale Systems -- large scale, decentralized

Entity to identity

Examples

PCORI efforts

South Carolina

Learning how to learn

Specifying the data model

Minimal necessary governance

Enable continued evolution of the system itself

Need trust structures specified

Open architecture

Minimum common data model

PCORI model, learning, ethics

NCATS network model

Requirements for participation (a participant is a system)

Must have a specified, standards-based data structure

Must abide by a trust framework

Lay down rules of the road

Agreements parallel to SLAs but with more flexibility

AHIMA information governance principles

Collaboratives that are geographically dispersed (and hence, do not compete) can share

Must use some standards-based approach to key elements (e.g., privacy)

Do not specify something like "metadata tagging", nudge in those desired directions

How do we sell the concept to companies that have data and do analytics on it themselves?

The LHS as a channel to sell services

Trust framework, privacy framework, framework for SLAs

Societal level of governance (fourth paradigm of health governance for the 21st century by the WHO) -- global

ONC/HHS agreements with Europe, international

Priorities for moving forward

Lots of resources out there

Categories of frameworks

Topics

Data, data management and infrastructure

Legal issues -- consent, privacy, jurisdiction

Outreach and education -- building a trust structure

Implementation -- sustainable, adaptable, administration

Infrastructure -- open data, open architecture, interoperability, networking capabilities, monitoring

Business model -- ROI, agreements, financing

Policy -- security, HIPAA

Other bodies

Who are we operating in conflict or in concert with?

Providing frameworks, not standards

Comprehensive literature review of policy framework for data sharing in health systems

Need to engage the broader community

Gap analysis

What is the value the individual gets

Identify value propositions to various constituencies/stakeholder types

Integrate with ONC 10 year roadmap -- Erica Galvez at ONC

ONC slide deck with 11-point definition of the LHS

Value proposition by stakeholder type group

Coordinate with PCORI and other efforts underway -- look at existing governance structures

Loosely coupled organizations, loosely coupled technologies

Tasks

Funding, social return on investment

Rules of the road

Research on other governance structures

Outreach and education

Press release

Rework mission statement (one page invitation to the initial meeting)

Call for additional participation -- key skillsets and resources

Planning grants to cover future meetings

PCORI grant application idea

Bringing together lots of disparate arenas -- clinical care, patient engagement, public/population health

Coordinate messaging

Need a living example of a story around governance

A culture shift

Press release

What makes this group different

Multi-stakeholder, grassroots

Quotes

What makes this group different

The meeting adjourned at **3:00 PM**