How to Use WebEx Q & A

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Data Governance Models

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What will we cover today?

• What is data governance?
• Why data governance is vital to interoperability?
• Data governance framework
• Current models of data governance
• What is next?
What is Data Governance?

- Identifies the “rules of engagement” for data sharing, penalties for non-compliance and oversight
- EHR technology is agnostic, it will transfer data without limits
- Users worry about when data can be requested, how is it used, data privacy and security
- Governance is a process, not a board
Why is data governance vital?

Percent of Hospitals That Have Adopted a Certified EHR:

2015 American Hospital Association Survey
Why is data governance vital?

Percent of **Office-Based Physicians** That Have Adopted a Certified EHR:

Source: 2015 National Electronic Health Records Survey (NEHRS)
Why is data governance vital?

• Not something new, we have always had it
• Before digital records, it was manual and point-to-point data exchange where control was easy
• Digital data changed everything!
• Without trust, data will not flow
• Absence of data can compromise delivery of care
• Increasingly difficult to operate without access to data
Data Governance Models

• No “one size fits all” data governance model
• An effective data governance framework includes both Principles and Structure

• **Principles** - what do we believe when it comes to data governance?
  – Data sharing agreements
  – Operating policies
  – Oversight board/committee

• **Structure** - how will we implement our Principles?
Governance Principles

- Where does the authority originate?
  - “top down” or “bottom up”
- Consent of the governed
- Representative governance
- Transparency
- Rules of engagement
- Enforcement
Governance Structure

- Will governance be centralized in a central body or distributed?
- Size of governance bodies?
- How is this memorialized?
  - Organizational documents
  - Trust agreement
  - Legislation or regulations
  - Other
Example 1: eHealth Exchange

- **2005**: ONC project to prove that health information can be successfully exchanged in a safe and secure manner.
- **2009**: I created a first-of-its-kind multi-party data sharing agreement to support nationwide interoperability, the DURSA.
- **2019**: - 120M patients
  - 75% of US Hospitals
  - 70,000 medical groups
  - 8300 pharmacies
  - 5200 dialysis centers
  - 60 state and regional HIEs
  - 4 major federal agencies (DoD, VA, SSA, CMS)
eHealth Exchange Governance

• Principles
  – Authority comes from the eHealth Exchange Participants (consent of the governed)
  – Representative
  – Transparency is more important than protecting business secrets
  – Accountable to Participants
eHealth Exchange Governance

• Structure
  – eHealth Exchange is not incorporated
  – Governance is memorialized in the DURSA which every Participant signs
  – Coordinating Committee is the governing body
  – Powers are listed in the DURSA
Example 2: ConnectVirginia

- Statewide Health Information Exchange
- Started as initiative of the Virginia Dept. of Health pursuant to an ONC award under the ARRA program-public health remains a key focus
- Operates several data sharing initiatives including a legislatively mandated Emergency Department Care Coordination Program that requires every hospital in Virginia to report real-time ED registrations that are matched against a central data base and alerts are fired in real time
ConnectVirginia

- Exchange Trust Agreement (ETA) is the trust agreement signed by all participants
- Modeled on the DURSA but customized
- Same for every Participant for transparency, same rules for everyone
- Details included in operating policies that participants have right to vote on
ConnectVirginia Governance

- 3 distinct phases which show evolution
- **Phase I: 2010-2014 ONC contract**
  - 22-member board with all key stakeholders to support representative governance
- **Phase II: 2014-2019 Non-profit corp.**
  - Corporate board with authority set out in bylaws
- **Phase III 2019 Quasi-governmental**
  - Board specified in statute
Example 3: PULSE

• ONC launched initiative to help disaster health care responders have data on their patients
• Inspired by Katrina when large numbers of folks were displaced and medical information not available
• Currently being deployed in several states using eHealth Exchange as the interoperability platform
PULSE Governance

• Program is “owned” by a state or regional government as part of its EP&R
• PULSE software provided private contractor
• Data sharing supported by eHealth Exchange
• So, governance is multi-faceted
• PULSE Advisory Council is central to this
Example 4: Electronic Case Reporting

- Currently, public health disclosures are largely a paper-based process.
- Utilizing established electronic connections with public health authorities, electronic case reporting (eCR) is possible.
Platform Background

• APHL Informatics Messaging Service (AIMS) Platform
• Developed over a period of 10+ years using CDC and other federal grant funding
• Originally created to promote interoperability among CDC and state public health labs (PHLs)
  – Focused solely on flu reporting
AIMS Platform Today

• Now includes data transmission and messaging services between state and select local PHLs, CDC and other data exchange parties
  – Current uses include
    • Vaccine preventable disease (VPD) and rabies reporting services
    • Electronic laboratory reporting services among CDC, PHLs and commercial labs
    • Electronic vital event exchange
    • Immunization data state-to-state exchange
    • Technical support services
Example 4: TEFCA

• Trusted Exchange Framework and Common Agreement
• Established by 21st Century Cures Act
• “single on-ramp” nationwide for interoperability
• ONC selected The Sequoia Project to serve as the Recognized Coordinating Entity
• RCE works with ONC to develop the Common Agreement over next year
TEFCA Goals

GOAL 1
Provide a single “on-ramp” to nationwide connectivity

GOAL 2
Electronic Health Information (EHI) securely follows you when and where it is needed

GOAL 3
Support nationwide scalability
Benefits of TEFCA

Consumers: Access, share and control their own records

Providers and health systems: Obtain complete picture of care across all settings to improve care and coordination with fewer connection points

State programs and public health: Enhance understanding of health metrics, ease burden of public health reporting and program management

Payers: Get and share data needed for care management, value-based care, etc.
RCE Key Milestones

• Year 1
  – Planning and ramp up
  – Engage stakeholders and enlist input
  – Develop the Common Agreement
  – Update the QHIN Technical Framework (QTF) for production use
  – Develop a process to designate and monitor Qualified Health Information Networks (QHIN)

• Subsequent Years
  – Facilitate ongoing stakeholder engagement and input
  – Maintain Common Agreement
  – Maintain QTF
  – Designate and monitor QHINs
  – Propose sustainability strategies
Status Update – Work Completed

• Grant awarded 8/29/19 and announced 9/3/19
• Kickoff meeting 9/11/19
• RCE web site launched 9/30/19 [https://rce.sequoiaproject.org/](https://rce.sequoiaproject.org/)
• Public Kickoff call 10/7/2019
• QTF Scoping Discussion with ONC 10/31/19
• Minimum Required Terms and Conditions (MRTC) review calls with ONC Oct-Nov
• Stakeholder engagement strategy and implementation plan approved - Nov
• Started targeted stakeholder feedback re: Summary of Disclosures - Nov
• Additional Required Terms and Conditions (ARTCs) drafted and initial review with ONC – Nov ‘19 and Jan ‘20
• Approval to form Common Agreement Work Group - Dec
What is The Common Agreement?

The **Common Agreement** will provide the governance necessary to scale a functioning system of connected HINs that will grow over time to meet the demands of individuals, clinicians, and payers.

The Common Agreement will be a legal document that QHINs sign. Some provisions of the Common Agreement will flow down to other entities (including providers) via contracts.

**Stakeholders will be able to comment on the draft Common Agreement.**
What is next?

• Past the tipping point, data sharing is mandatory
• Information Blocking rule will break down data silos
• Effective data governance is essential for a learning healthcare system
• Public health key part of the ecosystem
• Your clients will want to become part of data sharing networks and governance is vital
All In: Data for Community Health

Current Program Partners

- BUILD Health Challenge
- Data Across Sectors for Health
- Network for Public Health Law
- New Jersey Health Initiatives
- Public Health National Center for Innovations
- Population Health Innovation Lab

Past Partners

- Community Health Peer Learning Program
- Connecting Communities and Care

150+ COMMUNITY COLLABORATIONS ARE ALL IN!
Affinity Groups

» Navigating Law for Data Sharing

» Community Collaborative dashboards

» Health and Housing

» Substance use data sharing, integration and planning

Interested? Email info@allindata.org and complete the short form to sign-up.
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