Nationwide Trusted Exchange: Are We There Yet?
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Speaker Introduction

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Conflict of Interest

Mariann Yeager, CEO, The Sequoia Project
has no real or apparent conflicts of interest to report.

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Agenda

Nationwide Trusted Exchange: Are We There Yet?

- Components of the Nation’s First Common Trust Agreement
- Extrapolating Benefits from One Network to a Web of Networks
- Lessons Learned
Learning Objectives

1) Identify the **benefits** of common trust agreements for health data sharing

2) Outline **critical components** of an effective common trust framework

3) Evaluate the **efficacy** of a common trust framework
### STEPS™

#### S
**Satisfaction**
- Increase Patient Satisfaction;
- Improve care coordination;
- Eliminate duplicative testing.

#### T
**Treatment/Clinical**
- Increase patient data available to providers; **Better data means better clinical decisions**.

#### E
**Electronic Secure Data**
- Common Expectations for security and a shared security model;
- **Protect data and encourage data sharing**.

#### P
**Patient Engagement and Population Management**
- **Increase Care Coordination**;
- Better manage a population’s health.

#### S
**Savings**
- **Reduce Costs**;
- Avoid duplicative legal agreements & conflicting policies;
- Faster time to connect with less spending.

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*HIMSS17*
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A Vision for a Nationwide Health Information Network

• ONC Nationwide Health Information Network (NHIN) Initiative
• Nationwide network to establish common “dial-tone” for nationwide data sharing across geographies, technology platforms and healthcare settings
• Federated approach consistent with policies in telecom
• Build common trust agreement through a cooperative effort of private sector and government

Goal:
To establish uniform expectations, while minimizing one-off approaches
Nationwide Exchange: A History

- **ONC Conceives the Nationwide Health Information Network (NHIN / NwHIN)**
  - 2006

- **First production exchange between Social Security Administration & MedVirginia**
  - 2009

- **NHIN moves from prototype to production pilot**
  - 2008

- **NHIN transitions from government to private sector & renamed eHealth Exchange**
  - 2012

- **Participation quadruples & expands to all 50 states**
  - 2015

- **New initiatives increase quality & types of content shared**
  - 2016
Scalable Data Sharing Partnership

Point-to-Point Agreement
100 providers = 10,000 contracts

Common Agreement
100 providers = 1 contract
Data Use and Reciprocal Support Agreement (DURSA)

A comprehensive, multi-party trust agreement:

- Establishes Participants’ obligations, responsibilities and expectations
- Creates a framework for safe and secure health information exchange
- Promotes trust among Participants
- Expects Participants comply with Applicable Law

- Protects the privacy, confidentiality and security of the health data that is shared
- Assumes that each Participant has trust relationships in place with its agents, employees and data connections
- Evolves as a living document and modified over time
Components of a Common Agreement

Overview

- Governance
- Clear requirements applicable to all Participants
- Uniform Privacy and Security Obligations
- Equitable Data Sharing
- Exchange only for a Permitted Purpose
- Respect for local policies

- Future Use of Data Received from Another Participant
- Incident Response and Notifications
- Accountability
- Mechanism for updating agreement as legal and policy changes dictate
- Keep agreement flexible and include by reference technical specs, polices and procedures which can be revised more easily
Governance
Components of a Common Agreement

Shared Rules of the Road and Shared Governance
Technical requirements, testing requirements, policies, governance structure and accountability measures, including a process for adding or changing requirements.

Representative Governance
Participants are governed by a committee, which includes representatives from Participants who share data in production.
Uniform Privacy and Security Obligations

Components of a Common Agreement

Requirements to continue complying with existing privacy and security obligations under applicable law (e.g. HIPAA or other state or federal privacy and security statutes and regulations)

Obligations to comply with specified HIPAA Privacy and Security provisions as a contractual standard of performance

Highlights specific requirements which represent the most likely risk to the network, related to: system access policies, identification, authentication, enterprise security, malicious software
Equitable Data Sharing

Components of a Common Agreement

• Participants that allow their respective end users to request data for treatment purposes have a duty to respond to requests for data for treatment purposes.

• This duty to respond means that if actual data is not sent in response, the Participant will at a minimum send a standardized response to the requesting Participant.
Exchange Only for Permitted Purposes

Components of a Common Agreement

- Treatment
- Uses and disclosures pursuant to an Authorization
- Payment activities of a health care provider
- Any purpose to demonstrate Meaningful Use
- Limited Health care operations
- Public health activities and reporting
Respect for Local Policies

Components of a Common Agreement

**Autonomy Principle**
Each Participant can apply its own local access policies before requesting data from other Participants, releasing data to other Participants, or otherwise transacting data.
Future Use of Data

Components of a Common Agreement

Once the Participant or Participant’s end user receives data from another Participant (i.e. a copy of the other Participant’s records), the recipient may incorporate that data into its records and retain that information in accordance with the recipient’s record retention policies and procedures.

The recipient can re-use and re-disclose that data in accordance with all applicable law and the agreements between a Participant and its end users.
Incident Response & Notifications

Components of a Common Agreement

• Required notification to governing committee and affected Participants if “unauthorized acquisition, access, disclosure, or use of Message Content while Transacting such Message Content pursuant to this Agreement.”

  Sample requirements from the eHealth Exchange DURSA:

  – Limited circumstances (e.g. gateway compromised, “man in the middle” attack)
  – Within 1 Hour - Suspected
  – Within 24 hours - Confirmed
Accountability

Components of a Common Agreement

- Mandatory, non-binding dispute resolution
- Clear allocation of liability risk among participants
- Mandatory flow down provisions
Mechanism for Updating Agreement

Components of a Common Agreement

• Agreements will need to be updated as legal and policy changes dictate

• Process must be transparent and fair with an opportunity for participants to review changes prior being presented for approval

• Must accommodate advance notice to participants with opportunity to object to changes

• Thresholds for objections assures equitable governance
Legally Binding Doesn’t Mean Static

- Agreement has appendix which points to technical specifications and operating policies and procedures which can be amended through change management process
- eHealth Exchange has evolved to accommodate new technology and new use cases without changing the DURSA
- Predictability doesn’t preclude flexibility to grow and evolve
- Operational change process maintains stability for participants, without changing the underlying agreement

eHealth Exchange

Exchange began in 2008, Today's the Network Supports:

- ~65% of US Hospitals
- 4 Federal Agencies
- 50,000 Medical Groups
- 3,400+ Dialysis Centers
- 8,300 Pharmacies
- 47 Regional & State HIEs
- Supporting 109M Patients
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A Changing Landscape

A Shifting Marketplace from 2008 to 2015

• Greater EHR adoption

• MU, MACRA and Consumer Directed Exchange driving need for widespread exchange

• HIEs have evolved and many new types of data sharing networks have developed

• Evolving role of EHR vendors

• New types of services for data sharing (e.g RLS)

• Growing pressure from policy makers to connect “health data silos” that are still prevalent

State EHR Adoption Rates have Increased from 2008 to 2014

The Situation

Communities of data sharing partners have formed, brought together by specific needs.

Some are geographically based, but many other types of data sharing communities also exist.
Carequality Interoperability Framework
Public and private stakeholders develop a trusted exchange framework and common legal agreement to enable data sharing across different networks
A Multi-Faceted Approach

Diverse Stakeholders – Collaborative Process:

- Physicians
- Consumers
- Government Agencies
- Data Sharing Networks
- Payers
- Behavioral Health
- Acute Care
- Long Term/Post-Acute Care

- Hospice and Home Care
- Research
- Public Health
- Vendors
- Standards Development Orgs.
- Pharmacies
- EMS Services
The Network Effect
How do you get nationwide connectivity? Clinic by clinic, hospital by hospital?

Data sharing networks have already connected many participants within communities. The connections grow exponentially by connecting these networks.

- If you connect six clinics, you might reach a few dozen physicians.
- If you connect six communities, you can reach thousands of physicians.

Case Study Example: Exchange began in 2016, connecting in just a few months:

- 17,000+ Clinics
- 600+ Hospitals
- 210,000 Clinicians
- 100% Increase Monthly in Clinical Records Exchanged
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Hindsight is 20/20

Lessons Learned

• Some challenges weren’t so challenging after all
  – Patient consent
  – Privacy and security

• Some challenges are still a challenge
  – Patient identity matching – although progress
  – C-CDA/ Content: lack of consistency with which CDA is being produced by a variety of stakeholders, which throws off providers and vendors when aggregating docs
  – Lack of provider directory

• Other Learnings
  – EHR adoption and maturation of HIE in general are essential precursors to widespread interoperability
  – Role of vendors played increasingly important role in data sharing models
What Mattered Then, Matters Now

Lessons Learned

• Representative and transparent governance essential to engender public trust

• Open and inclusive consensus-building with government as an active participant assures alignment with public policy goals
  – “Pay to play” rules limits stakeholder engagement to those who can afford membership dues

• Foundational set of universal principles for trusted exchange consistent with 2008 foundation and in alignment with ONC Principles of Governance

• Solid foundation of trust, with a process to adapt to changes in technology and operational policy, is enduring
Common Legal Agreement Benefits

**Lessons Learned**

- Creates **clear expectations** for participants
- **Saves money** with uniform contracts, policies and governance
- **Eliminates** need for point-to-point trust agreements
- Clear **dispute resolution** and consequences for non-compliant behavior
- Provides **transparency** and advances interoperable trust for new partnerships
- Supports more rapid adoption and **accelerates network development**
Industry Needs to Lead But Partner with Government

Lessons Learned

Private Sector Must Lead the Charge

- Health IT technologies maturing
- Workflow improvements being made
- Exploring additional uses of the connectivity
- Private sector is actually many different stakeholders with different objectives and constraints
- Consumers are a major stakeholder group

Government Supporting the Market

- Fed agencies are key consumers of clinical data and have mandatory reporting requirements
- State engagement is key for access to 90-10 funding and other financial support; mandatory reporting for communicable diseases and Medicaid reporting
The Golden Rule for Exchange

Lessons Learned

Non-Discrimination
Treat everyone the same

Equitable Exchange
Reciprocal obligations for treatment based exchange
One-to-Many Model is an Accelerant

“We’ve brought 40 new health data sharing partners online in just two weeks. That would have been impossible before common agreements, like Carequality.”
ROI of Nationwide Trusted Exchange
Proven Efficacy of Common Agreements Approach

$60M
Shared Savings
for first 75 participants of eHealth Exchange

More than 120 participants now, with exponential shared savings for each

Reduced legal costs
Reduced investment
Reduced time to launch

$360M
Expected Shared Savings for 6 Networks under a framework

Estimated intial ROI for nationwide network-to-network exchange framework implementation

Reduced one-off legal agreements
Reduced staff hours
Reduced legal expenses
Nationwide Trusted Exchange: Are We There Yet?

Yes!

There are several national-level common agreements available today that continue to work well.

However a trusted exchange framework and common legal agreement are not the total solution...
Recipe for Success

• Industry led, public-private collaboration
  – Progress can be accelerated when industry and government are working together toward a more unified direction

• Capability doesn’t guarantee use
  – Capability to interoperate doesn’t guarantee high utilization of interoperable data sharing; value of the data helps

• Trust is the foundation; a viable business case and endurance are essential
  – A trust framework is a critical foundation for nationwide data sharing, but is not sufficient without a business case to share data (e.g. value-based payment models)
Learning Objectives

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Questions

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