CONNECTING FOR HEALTH COMMON FRAMEWORK

Resources for Implementing Private and Secure Health Information Exchange

Tackling the Policy Challenges of Health Information Exchange

Carol Diamond, MD, MPH Managing Director, Markle Foundation

What is Connecting for Health?

- A public-private collaborative of 100+ organizations representing all the points of view in healthcare.
- A neutral forum.
- Founded & supported by the Markle Foundation
- Additional support from the Robert Wood Johnson Foundation

What is the Purpose of Connecting for Health?



To catalyze changes on a national basis to create an interconnected, electronic health information infrastructure to support better health and healthcare

The Connecting for Health Model

- Sharing = linking existing sources of information
- Health information can *stay where it is*—with the doctors and others who created it
- Specific information is shared *only* when and where it is needed.
- Sharing *does not* require an all new "network" or infrastructure
- Sharing *does not* require a central database or a national ID
- Sharing *does* require a Common Framework

A Common Framework Is Needed

- The Common Framework is the minimum necessary set of rules or protocols for *everyone* who shares health information to follow.
- Helps organizations overcome the barriers without "reinventing the wheel"
- Enables nationwide interoperability...avoiding isolated islands of information
- Builds *trust*

The Common Framework

Is like a nationwide set of traffic rules that enable specific pieces of health information to travel when and where they are needed...

The Common Framework

...and that put patients and the doctors they trust in the drivers' seat.

What Do the Common Framework Resources Consist of?

- Technical rules and standards—that allow systems to "talk to" each other
- Policies on how to handle information that build trust
- Model contractual language—that holds it all together

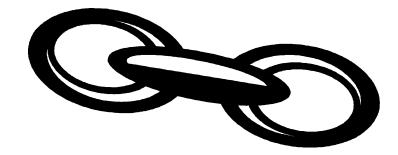
How Was the Common Framework Developed?

Connecting for Health...

- Started with Design Principles
- Wrote a Roadmap
- Built a Prototype
- Developed the Common Framework through field experience and the collaboration of experts

Technology and Policy are Intertwined

- Choices about one necessarily shape the other.
- To build trust, you have to put policy decisions first.



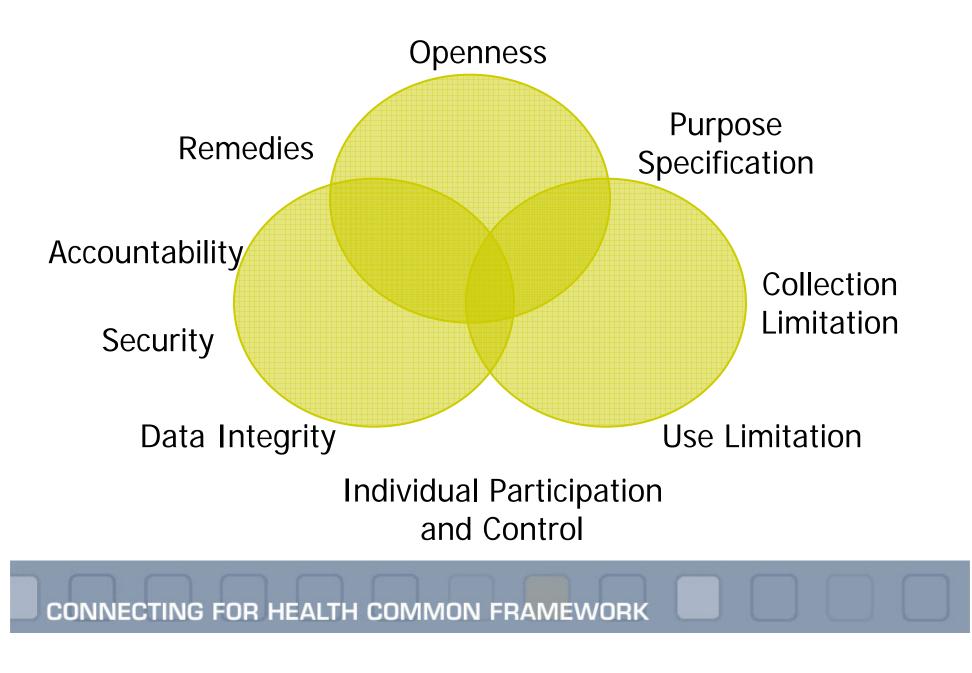
Technical Principles

- 1. Make it "Thin"
- 2. Avoid "Rip and Replace"
- 3. Separate Applications from the Network
- 4. Decentralization
- 5. Federation
- 6. Flexibility
- 7. Privacy and Security
- 8. Accuracy

Privacy Principles

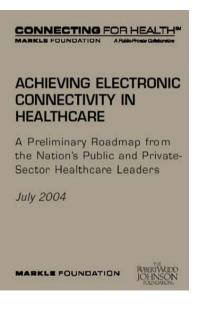
- 1. Openness and Transparency
- 2. Purpose Specification and Minimization
- 3. Collection Limitation
- 4. Use Limitation
- 5. Individual Participation and Control
- 6. Data Integrity and Quality
- 7. Security Safeguards and Controls
- 8. Accountability and Oversight
- 9. Remedies

The Privacy Principles are Interdependent



The Roadmap Report

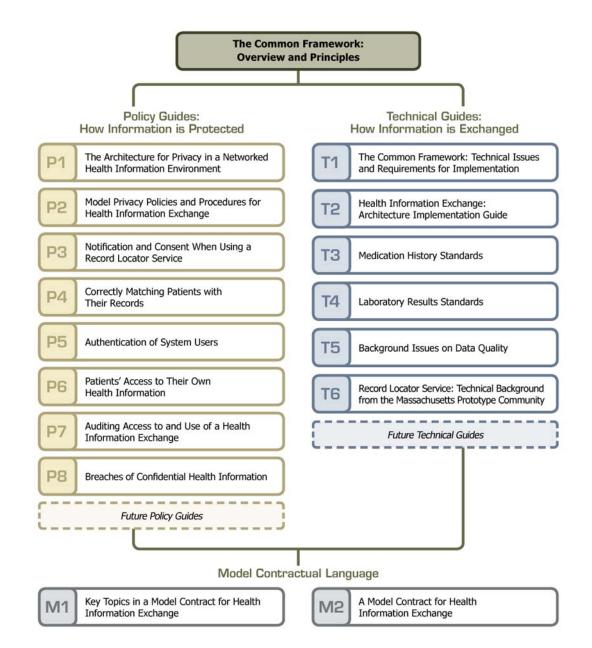
- Laid out the vision in 2004
- More than 60K copies in circulation



The Prototype

- Three sites
 - Boston
 - Indianapolis
 - Mendocino County, CA
- Diverse architectures
- Diverse organizational structures

If these 3 can all use the Common Framework...anyone can!



Who Developed the Prototype and the Common Framework?

- Connecting for Health Steering Group
- Policy Subcommittee: Co-Chairs Bill Braithwaite and Mark Frisse
- Technical Subcommittee: Chair: Clay Shirky
- Three communities and teams:
 - **Boston**: MA-SHARE and technical partner CSC
 - Indianapolis: Regenstrief Institute and Indianapolis Health Information Exchange (IHIE)
 - **Mendocino**: Mendocino HRE and technical partner Browsersoft, Inc.

Tackling the Policy Challenges

- Who has access to what, under what circumstances, and with what protections?
- Who shares what and who bears the liability?
- How can you control access to your information?

What is Available?

Policy Documents: 3 Categories

- 1. <u>Background Document</u>
 - P1: Privacy Architecture for a Networked Health Care Environment
- 2. <u>Specific Policy Documents</u>
 - P2-P8: Model privacy policies, notification and consent, correctly matching, authentication, patient access, audits, and breaches
- 3. <u>Sample Contract Language</u>
 - M1: Contact Topic List
 - M2: Model Contract

Connecting for Health Policy Subcommittee

- Looked at HIE in the context of HIPAA and existing state laws
- Developed a list of significant topics from

 Members' experience with early information
 exchange networks
 - Members' own expertise

Common Framework Policy Topics Addressed

- Notification and consent
- Uses and disclosures of health information
- Matching patients with their records
- Authentication
- Patient access to their own information
- Audit
- Breaches of confidential information

Model Contract for Health Information Exchange

- Purpose of Model SNO Terms and Conditions
 - To create a mechanism of enforcement
 - To assist SNOs prepare their own Terms and Conditions
 - 60-40 solution
 - Identify issues and alternatives
 - Raise questions

The Common Framework is Still Evolving

- Improving the resources to better meet the needs of communities
- Exploring how patients/consumers can access their own information
- Exploring how researchers and public health can benefit from health data

Common Framework Resources

- All available free at <u>www.connectingforhealth.org</u>
- Policy and technical guides, model contractual language
- Registration for AHRQ/NORC Common Framework discussion forum
- Software code from regional prototype sites: Regenstrief, MAShare, OpenHRE
- Email to info@markle.org