Overview of the Connecting for Health **Common Framework**

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

Why Share Health Information?

- A person's health record can be scattered among:
  - Primary care provider
  - Specialists
  - Former healthcare providers
  - Labs
  - Pharmacies
  - Imaging centers
  - Insurance companies
  - Patient's records/memory
  - Family members

Why Share Health Information?

- To improve quality
  - With more complete information, healthcare providers can give better care
  - Providers need to know
    - Existing conditions
    - Allergies
    - Medications

There are 3 million preventable adverse drug events per year in the US

Why Share Health Information?

- To reduce costs
  - Duplicate tests
  - Lost time
  - Errors have to be fixed

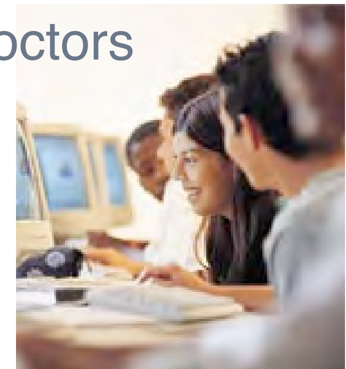
One-third of US healthcare spending is considered wasteful, unnecessary, or duplicative.

Why Share Health Information?

- Patients want access (to their own health information)
  – Based on the findings of two national surveys
    - 800 adults and registered voters
    - September 2005
    - Conducted by Public Opinion Strategies
    - Sponsored by the Markle Foundation

Why Share Health Information?

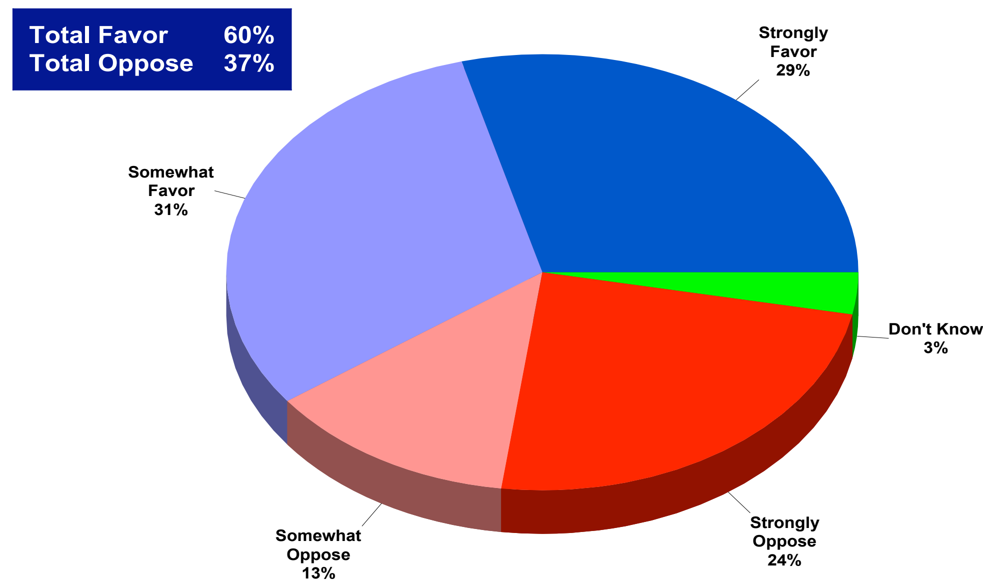
- Patients want access
  - 72% of Americans favor the establishment of a nationwide electronic information exchange
  - 69% would use IT to check for mistakes in their own medical record
  - 68% would use IT to check and fill prescriptions
  - 58% would get test results over the Internet
  - 57% would share private/secure email with their doctors



Why Share Health Information?

- Patients want access

60% of Americans want to use a secure online “personal health record”



Now, overall, would you favor or oppose the creation of this type of secure online "personal health record" service?

Paper Isn’t Practical

Compared to an electronic file, a paper file is:

- Easy to destroy
- Expensive to replicate
- Expensive to transport over distances
- Takes up space
- Makes it hard to analyze data
- Makes it hard to track who has seen it
- Environmentally wasteful

A typical hospital visit generates 60 pieces of paper

Information Technology Has Transformed Other Areas…

Examples include:

- Banking
- Travel
- Research

Healthcare is Different

- The healthcare system is very diverse
- Health information is especially sensitive—and privacy spills can't be "fixed"
- Patients/consumers are traditionally less involved than in some other areas

Some Barriers to Electronic Information Sharing in Health

- Technical (eg lack of standards)
- Policy (eg lack or incompatibility of rules about who is allowed to see information and why)
- Financial (eg misalignment of incentives for IT adoption)
- Educational (eg lack of understanding of the benefits and risks of IT)

… and the technology is the *easy* part!

Sharing Health Information = Linking Existing Sources

- 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*

What is the Common Framework?

- A set of critical tools, including technical standards and policies for how information is handled, whose general adoption will enable secure nationwide health information sharing
- Contractual arrangements among members of communities (or SNOs) are a key to implementation

The Common Framework

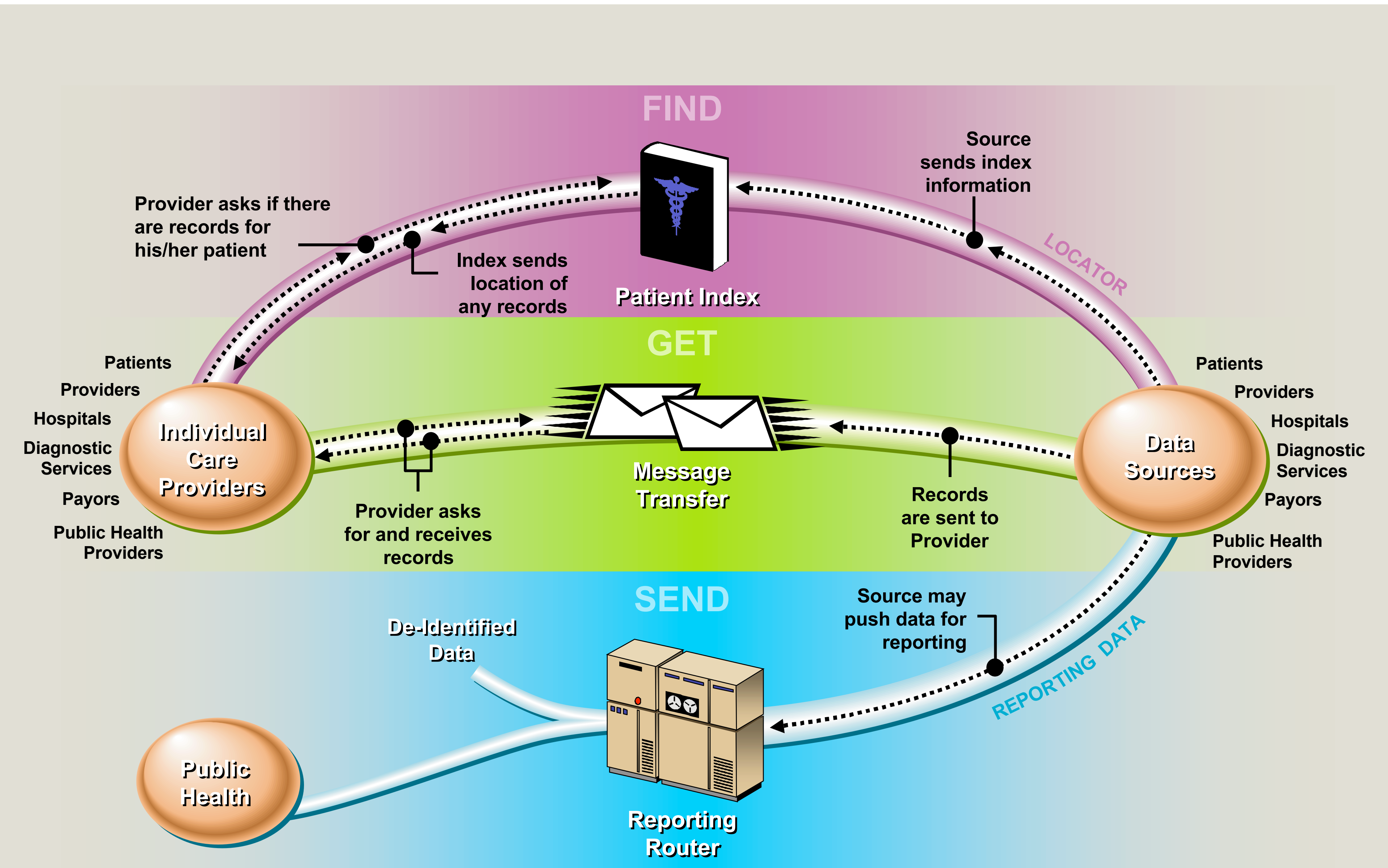
Is like a nationwide set of traffic rules that enable specific pieces of health information to travel when and where they are needed…

The Common Framework

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

The Connecting for Health Model for Health Information Sharing

- Sharing occurs via a network of networks—not a completely new architecture
- The nationwide “network” is made up of smaller communities or SNOs (Sub Network Organizations)
- The model relies on an RLS (Record Locator Service) to locate patient records



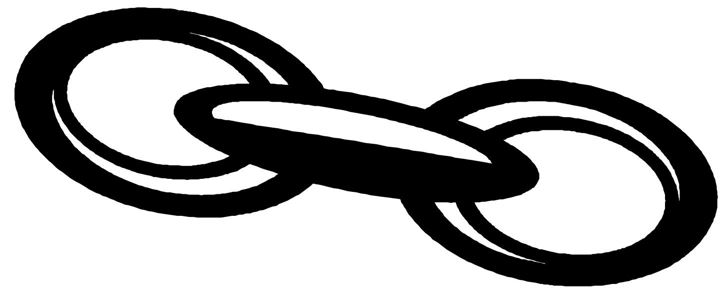
Source: © 2004 The Markle Foundation Graphic adapted from Tom Benthin original.

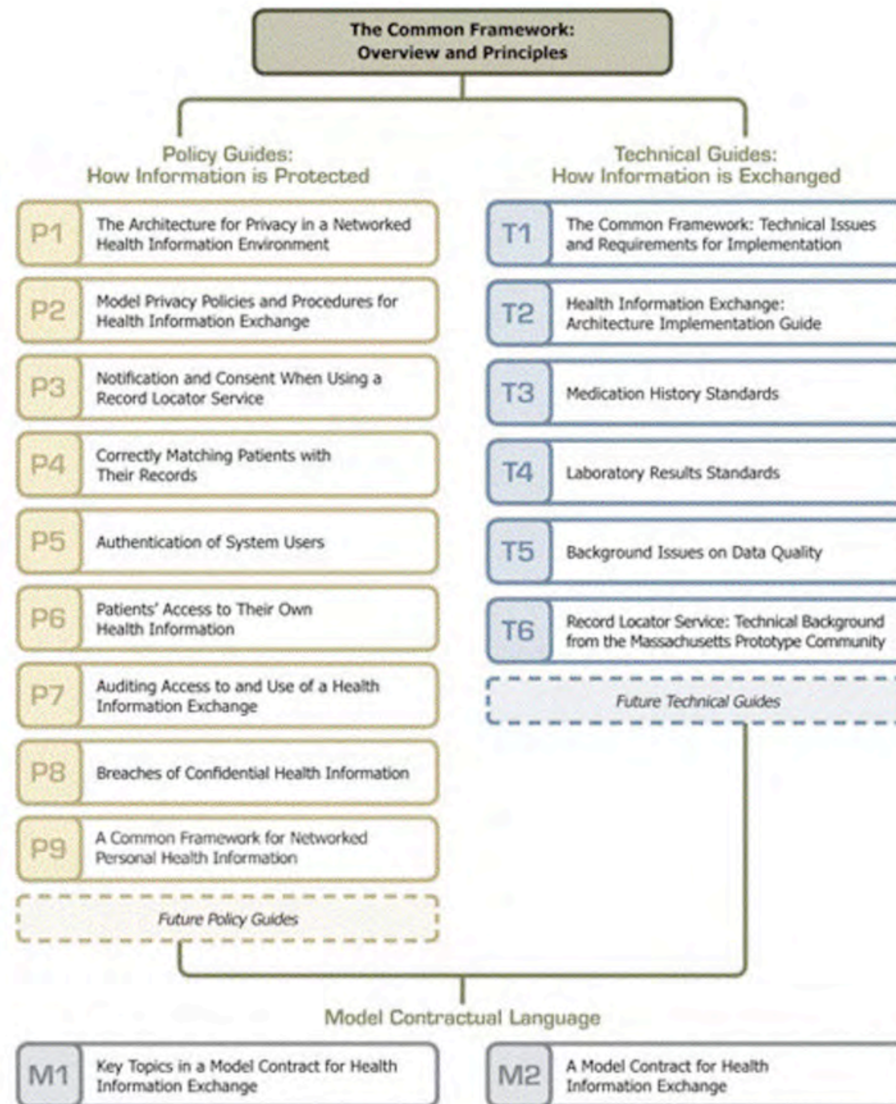
What Do the Common Framework Resources Consist of?

- 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

Technology and Policy are Intertwined

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




The Common Framework: Overview and Principles
Policy Guides: How Information is Protected
Technical Guides: How Information is Exchanged
P1 The Architecture for Privacy in a Networked Health Information Environment
P2 Model Privacy Policies and Procedures for Health Information Exchange
P3 Notification and Consent When Using a Record Locator Service
P4 Correctly Matching Patients with Their Records
P5 Authentication of System Users
P6 Patients' Access to Their Own Health Information
P7 Auditing Access to and Use of a Health Information Exchange
P8 Breaches of Confidential Health Information
P9 A Common Framework for Networked Personal Health Information
Future Policy Guides
T1 The Common Framework: Technical Issues and Requirements for Implementation
T2 Health Information Exchange: Architecture Implementation Guide
T3 Medication History Standards
T4 Laboratory Results Standards
T5 Background Issues on Data Quality
T6 Record Locator Service: Technical Background from the Massachusetts Prototype Community
Future Technical Guides
Model Contractual Language
M1 Key Topics in a Model Contract for Health Information Exchange
M2 A Model Contract for Health Information Exchange

Sample Policy Documents

Sample policy language

CFH Recommended policy

Incidents to the covered entity.[13] *See relevant sample contract excerpts below:* [14]

Section 8.03 Report of Improper Use or Disclosure. [The SNO] agrees promptly to report to a [Participant] any use or disclosure of the [Participant's] PHI not provided for by this Agreement of which [the SNO] becomes aware.

and

Section 8.14 HIPAA Security Rule Provisions.

(a) ...
(b) [The SNO] agrees promptly to report to a [Participant] any Security Incident related to the [Participant's] ePHI of which [the SNO] becomes aware.

Similarly, each Participant must agree to inform the SNO of any serious breach of confidentiality. It is not necessary for a Participant to inform the SNO of minor breaches of confidentiality (unless there is otherwise a legal duty to disclose such breaches to the SNO). While it is difficult to define what would rise to the level of a "serious" breach, SNOs and Participants might decide that the breaches of

From P8 – Breaches, p. 4

Model Terms and Conditions	Notes
4.7 Participant's Other Rights to Terminate Registration Agreement. *How a Participant may cease to be a Participant, generally.* **Alternative One: Participant may terminate at any time without cause.** A Participant may terminate its Registration Agreement at any time without cause by giving notice of that termination to [SNO Name]. **OR** **Alternative Two: Participant may terminate without cause with prior written notice.** A Participant may terminate its Registration Agreement at any time without cause by giving not less than _______ days prior notice to [SNO Name]. **OR** **Alternative Three: Participant may terminate as of the next anniversary of having entered into the Registration Agreement.** A Participant may terminate its Registration Agreement at any time without cause effective as of the next anniversary of the effective date of the Participant's Registration Agreement, by giving not less than _____ days prior notice to [SNO Name]. **OR** **Alternative Four: Participant may terminate for cause (may be combined with Alternatives Two or Three and/or Five).** A Participant may terminate its Registration Agreement upon [SNO Name]'s failure to perform a material responsibility arising out of the Participant's Registration Agreement, and that failure continues uncured for a period of sixty (60) days after the Participant has given [SNO Name] notice of that failure and requested that [SNO Name] cure that failure. **OR** **Alternative Five: Participant may terminate for specified cause (may be combined with Alternatives Two or Three and/or Four).** A Participant may terminate its Registration Agreement upon a Serious Breach of Confidentiality or Security, as described in Section 9.3 (Reporting of Serious Breaches), when such Serious Breach of Confidentiality or Security continues uncured for a period of sixty (60) days after the Participant has given [SNO Name] notice of that failure and requested that [SNO Name] cure that breach.	The SNO may wish to allow Participants to terminate their participation freely at any time, or to require that termination be preceded by a substantial period of advance notice, or to require that Participants maintain their participation for a year (or longer) at a time. If the SNO wishes to limit further certain Participants' (*e.g.*, certain data providers) rights to terminate their participation, the SNO may provide for such special terms in written Registration Agreements described in Section 4.2 (Registration by Agreement). If the SNO places limits upon the Participant's right to terminate, the SNO may wish to provide for the Participant's right to terminate based on the SNO's failure to perform. The Model provides a simple "termination for cause" provision. The SNO may wish to qualify a Participant's right to terminate, *e.g.*, by providing in addition that if the SNO's failure to perform is one that the SNO cannot reasonably cure within the specified period, then the termination will not take effect so long as the SNO commences and diligently pursues work to cure the failure.

From M2 – Model Contract, p. 10

Sample Technical Documents (T2)

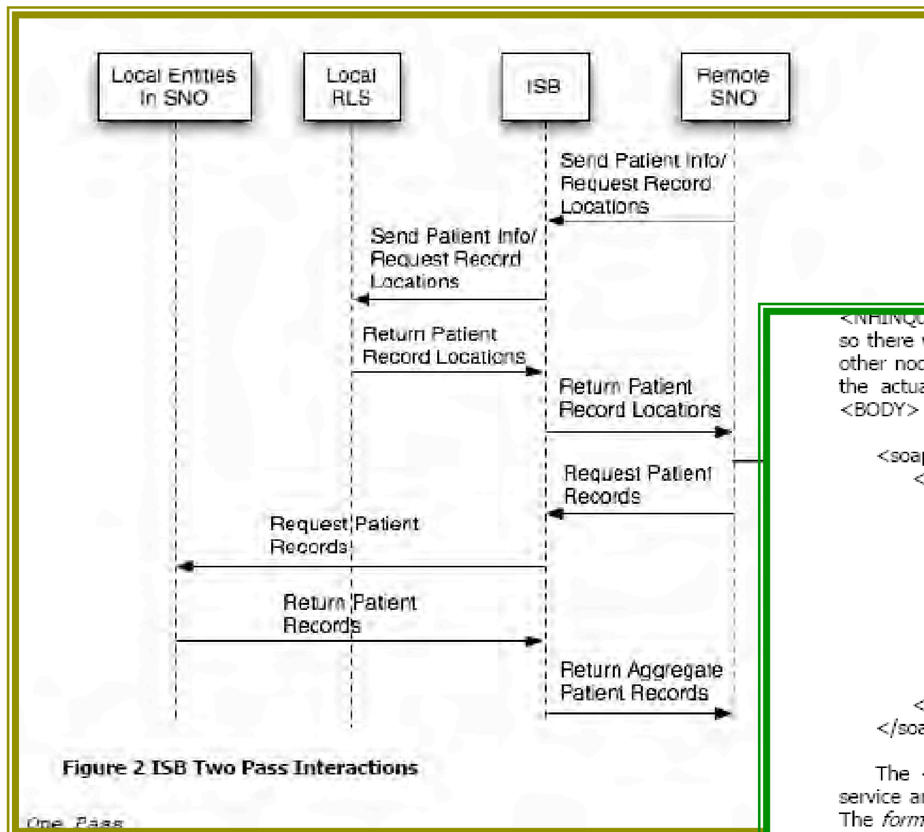


Figure 2 ISB Two Pass Interactions

<NHINQuery> node. The WS-Basic Profile 1.0 requires a single node within the SOAP <BODY>, so there will never be a second node at this level. Within the <NHINQuery> node, we find two other nodes. One contains control information about the query settings and the other contains the actual query. For example, the topmost level of the *PatientDataQuery* SOAP message <BODY> looks like:

```
<soapenv:Body>
    <nhin:NHINQuery>
        <nhin:EvaluationSettings>
            <nhin:MaxResponseInterval>60</nhin:MaxResponseInterval>
            <nhin:ResponseStyle>I</nhin:ResponseStyle>
        </nhin:EvaluationSettings>
        <nhin:Query format="HL7" version="2.4">
            <QBP_Z01 xmlns="urn:hl7-org:v2xml">
            ...
            </ QBP_Z01 >
        </nhin:Query>
    </nhin:NHINQuery>
</soapenv:Body>
```

The <Query> node defines the information that is actually being requested. The SOAP service and operation are merely wrappers in which to pass this generic "query" specification. The *format* and *version* attributes define the format in which the query is expressed. Currently, only HL7 version 2.4 queries are supported. NHIN is considering support of HL7 version 3.0 as its use becomes more widespread.

At the topmost level of the SOAP message <BODY>, each response message also contains a single node. The <NHINResponse> node contains two data-bearing nodes, just like the

The Common Framework is Not a "RHIO in a box"

- It provides different models to consider—not one "right answer."
- It is intended as a partial solution. It does not address finance, governance, etc.
- There are topics (like how to aggregate data for research and public health) that Connecting for Health is still working on…

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

Technical Principles

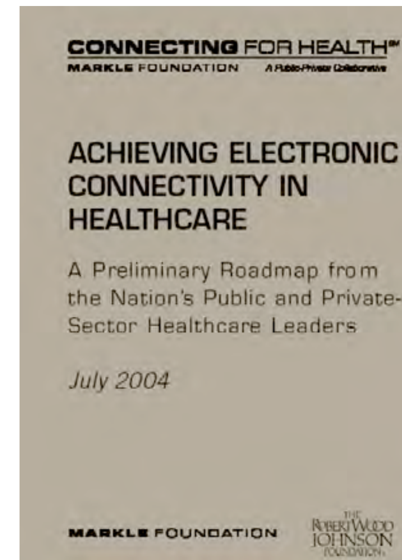
1. Make it “Thin”
2. Avoid “Rip and Replace”
3. Separate Applications from the Network
4. Decentralization
5. Federation
6. Flexibility
7. Privacy and Security
8. Accuracy

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 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 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.

What is Available?

Technical Documentation: 3 Categories

1. Background Documents
   - T6: Record Locator Service Design
   - T5: Data "Cleanliness" and Quality
2. Specific Technical Documents
   - T1: Technical Overview and Implementation Requirements
   - T2: NHIN Message Implementation Guide (Record Locator Service/Inter-SNO Bridge)
   - T3-T4: Standards Guides
     - Medication History: Adapted NCPDP SCRIPT
     - Laboratory Results: ELINCS 2.0, with modifications
3. Technical Code and Interfaces
   - Test Interfaces: CA, IN, MA
   - Code base: CA, IN, MA

What is Available?

Policy Documents: 3 Categories

1. Background Document
   - P1: Privacy Architecture for a Networked Health Care Environment
2. Specific Policy Documents
   - P2-P9: Model privacy policies, notification and consent, correctly matching, authentication, patient access, audits, breaches, and networked personal health records
3. Sample Contract Language
   - M1: Contact Topic List
   - M2: Model Contract

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
- Connecting for Health needs the input of organizations nationwide….

Common Framework Resources

- All available free at www.connectingforhealth.org
- Policy and technical guides, model contractual language
- Software code from regional prototype sites: Regenstrief, MAShare, OpenHRE
- Email to info@markle.org