



CONNECTING FOR HEALTH COMMON FRAMEWORK

Resources for Implementing Private and
Secure Health Information Exchange

Connecting *all* the dots...

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What's the goal of HIT?

- Reduce errors, improve quality, increase efficiency?
- Empower consumers with information?
- Create platform for transformation?

Three layers of HIT planning

- Information to care for a patient
- Information to support better decision-making
- Information to help consumers improve own health and their care

Connecting for Health

- Broad-based, public-private collaborative of more than 100 diverse stakeholders
- Founded and supported by **Markle Foundation**, with additional support from **Robert Wood Johnson Foundation**
- **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

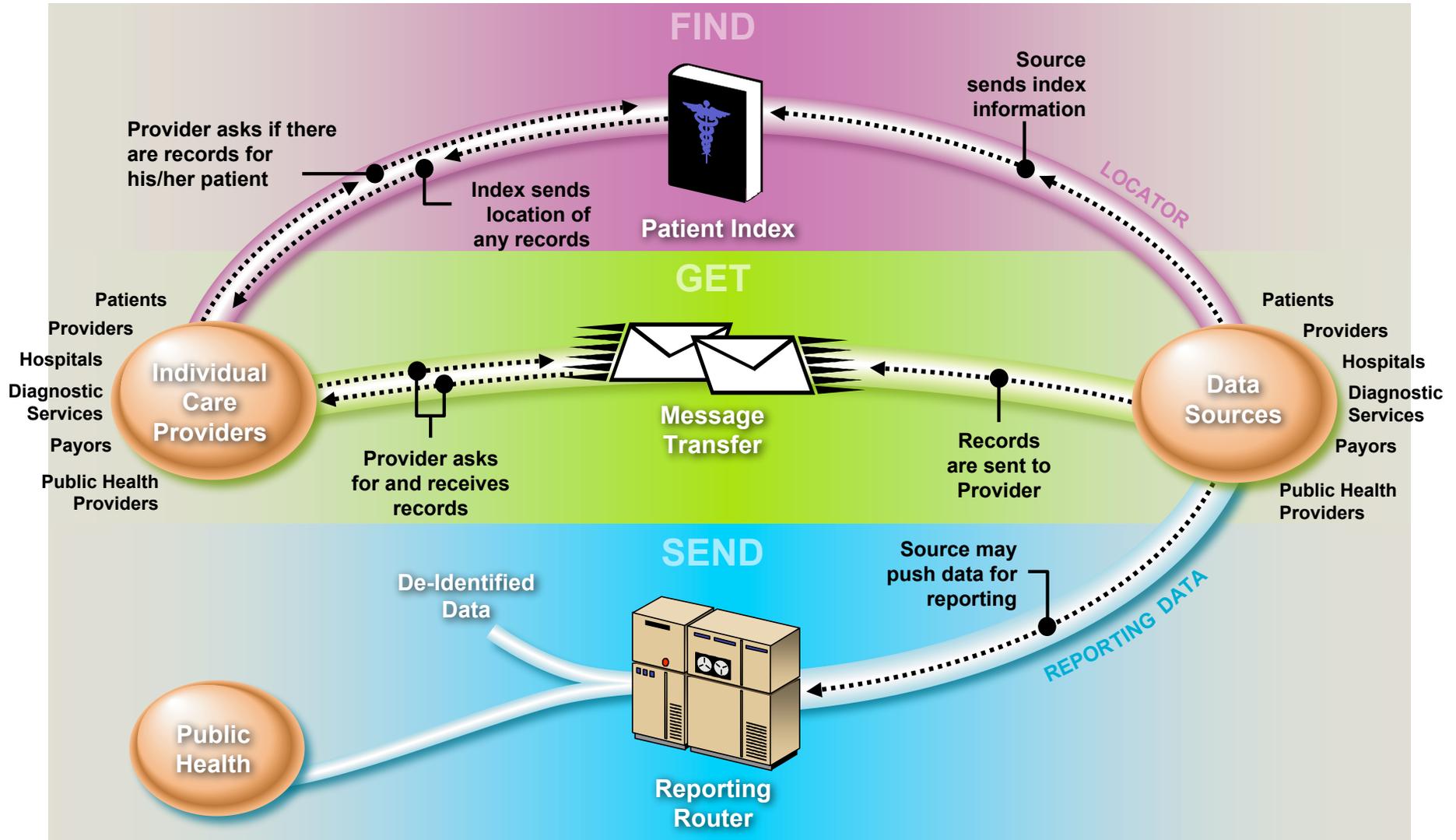
1. Information to care for a patient

Connecting for Health Approach

Architecture *is* Policy
[“code is law”]

The Design Principles

- Designed to safeguard privacy—imposed the requirement first and then designed the functional architecture
- This approach is harder and requires resisting “if only” thinking.
- It does not produce the easiest or simplest technical solutions
- You can't build first and worry about the policies later...



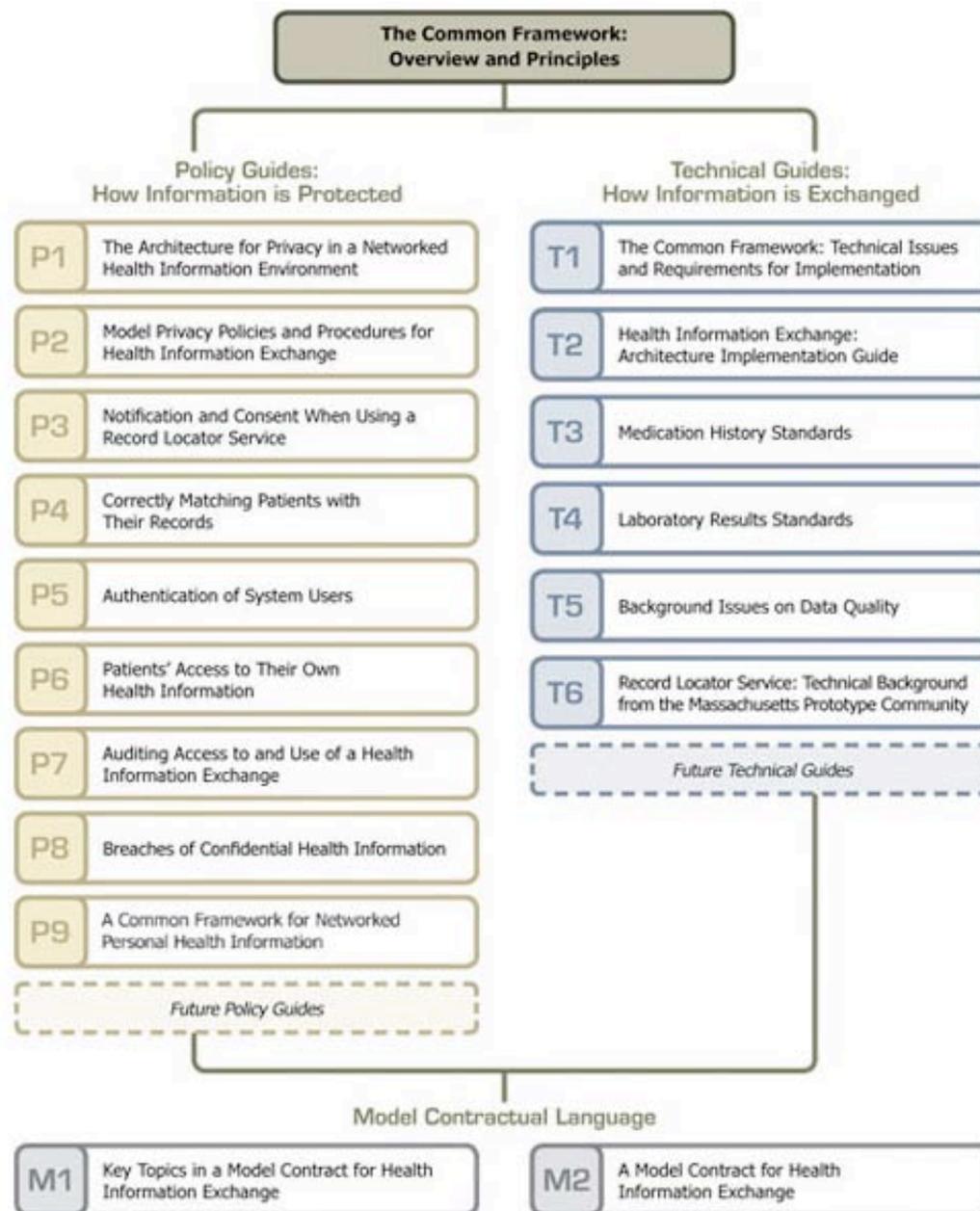
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Over the last three years...

- The most challenging aspects of the agenda are “policy” related: *What rules, business and organizational requirements govern the flow of information?*
 - How is access to your information controlled?
 - Who has access to what, under what circumstances?
 - What protections are in place for information that is shared?
 - Who shares what and who bears the liability for it?
 - Which policies need to be uniform in a health information exchange and which do not?

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*



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

Common Framework is based on a set of Policy 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

Common Framework, p.4

Common Framework is based on a set of Technology 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

Common Framework, p.5

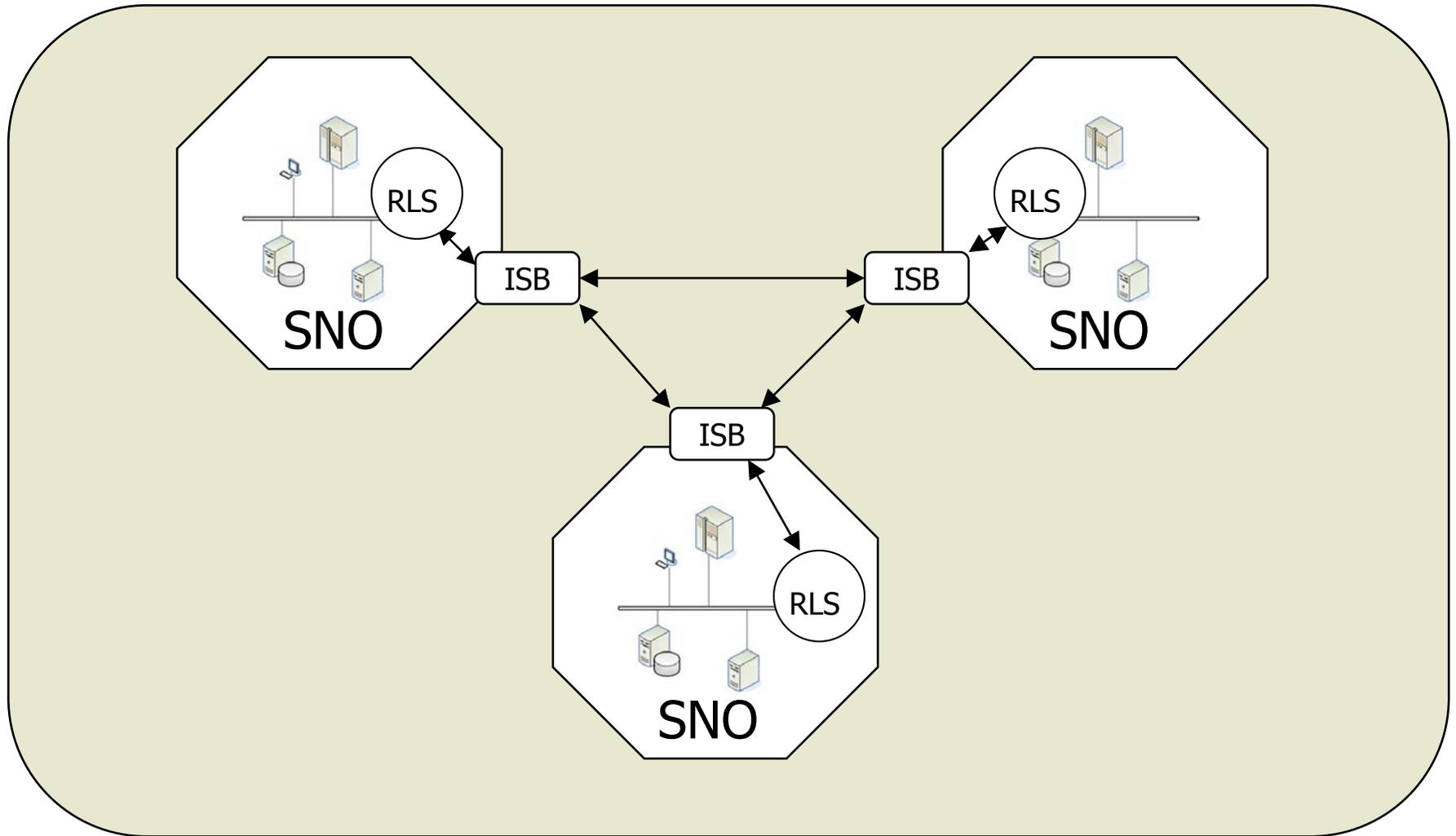
The Connecting for Health Model for Health Information Sharing

- 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
- Implementation and Experimentation are Essential

Connecting for Health Prototype Goals

- Develop a policy and technical framework that enables information sharing to happen for high quality patient care while protecting the privacy and security of personal health information.
- Identify what needs to be common for interoperability and what does not.
- Design and develop the documentation and the materials for communities on issues such as access, control, privacy and security.
- Share and disseminate broadly in order to continue to learn !!!

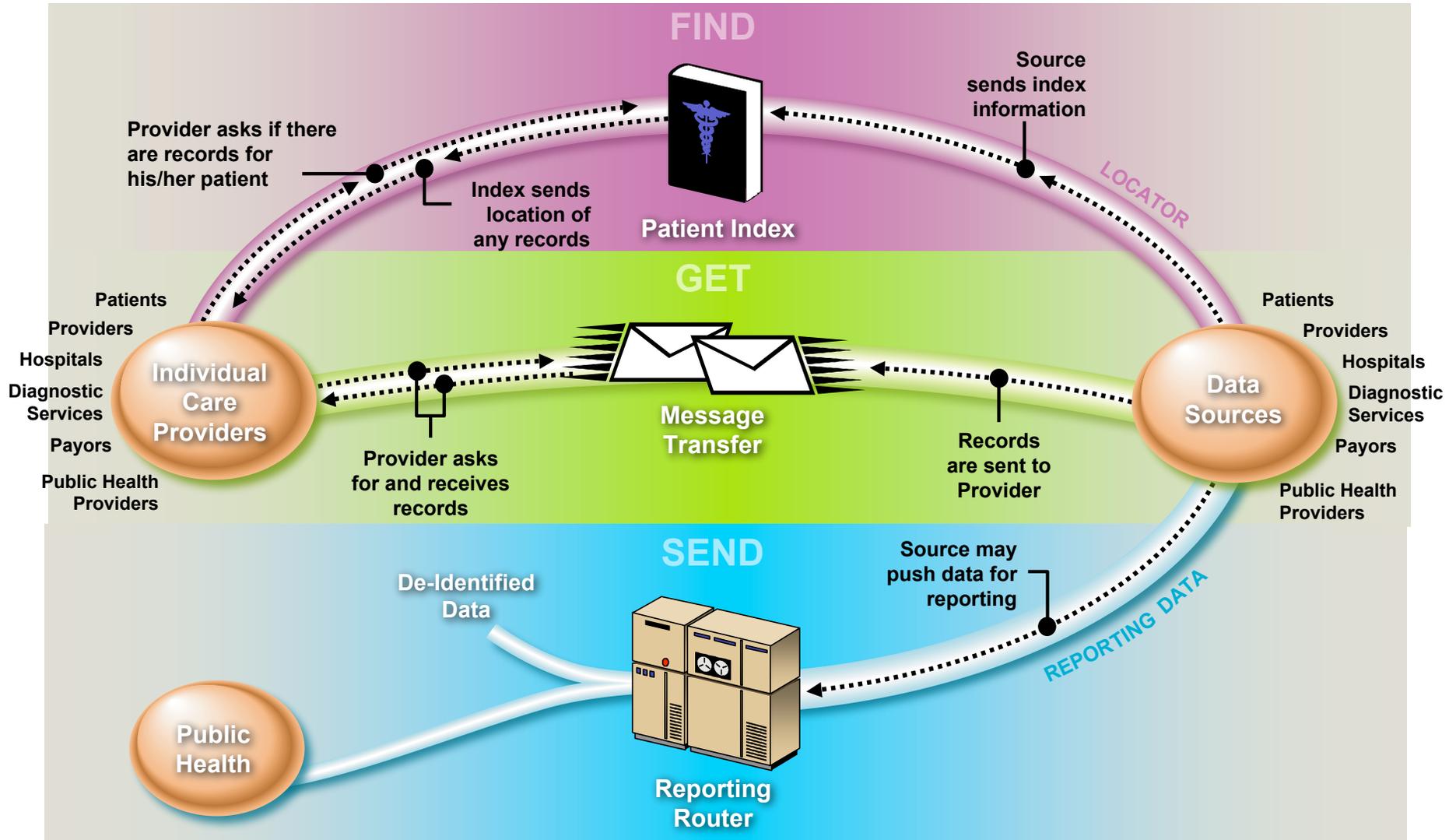
Common Framework architecture



Implications

- Need architecture that anticipates need for interoperability, protects privacy
- Need policies that create trust, are enforceable
- Need incentives to share data with others

2. Information to support better decision making



CONNECTING FOR HEALTH COMMON FRAMEWORK

Why Population Health?

- Population health objectives are realized in at least three distinct domains:
 - bolstering research capabilities and enabling clinical practice to fully participate in and make use of scientific evidence,
 - increasing the effectiveness of our public health system, and
 - empowering consumers with information about cost and quality.
- Each of these requires authorized users to access information housed in many fragmented data sources.

Hypothesis 1: “Gimme the data....please...”

There is an increasing demand from various constituencies for large sets of (frequently the same) population-level health information, created by aggregating patient-level information from clinical sources.

Aggregate Data Requests to a Single CDO

- **National level:**
 - CMS – ORYX indicators
 - UHC
 - NACRI
 - Premier Benchmarking Project
 - Biosense
 - DAWN
 - AHRQ quality data
 - NCQA
 - Leapfrog Group
 - State peri-natal system – some clinical reporting
 - Genetic screening – some selected reporting through the states
 - Quality reporting and AQA pilots
- **State level:**
 - State UB92 reporting (quarterly)
 - Public Health – a variety of reports where requirements mandate reporting
 - Cancer tumor registry – patient-specific at times
- **Local Level:**
 - IRB Approved Research Projects
 - Internal Management reporting
 - Clinical Quality Reporting – infection control, etc.
 - JCAHO Reporting
 - Teaching requests
 - Commercial plans – on-line hospital assessment

Hypothesis 2: “All of these things are just like the others”

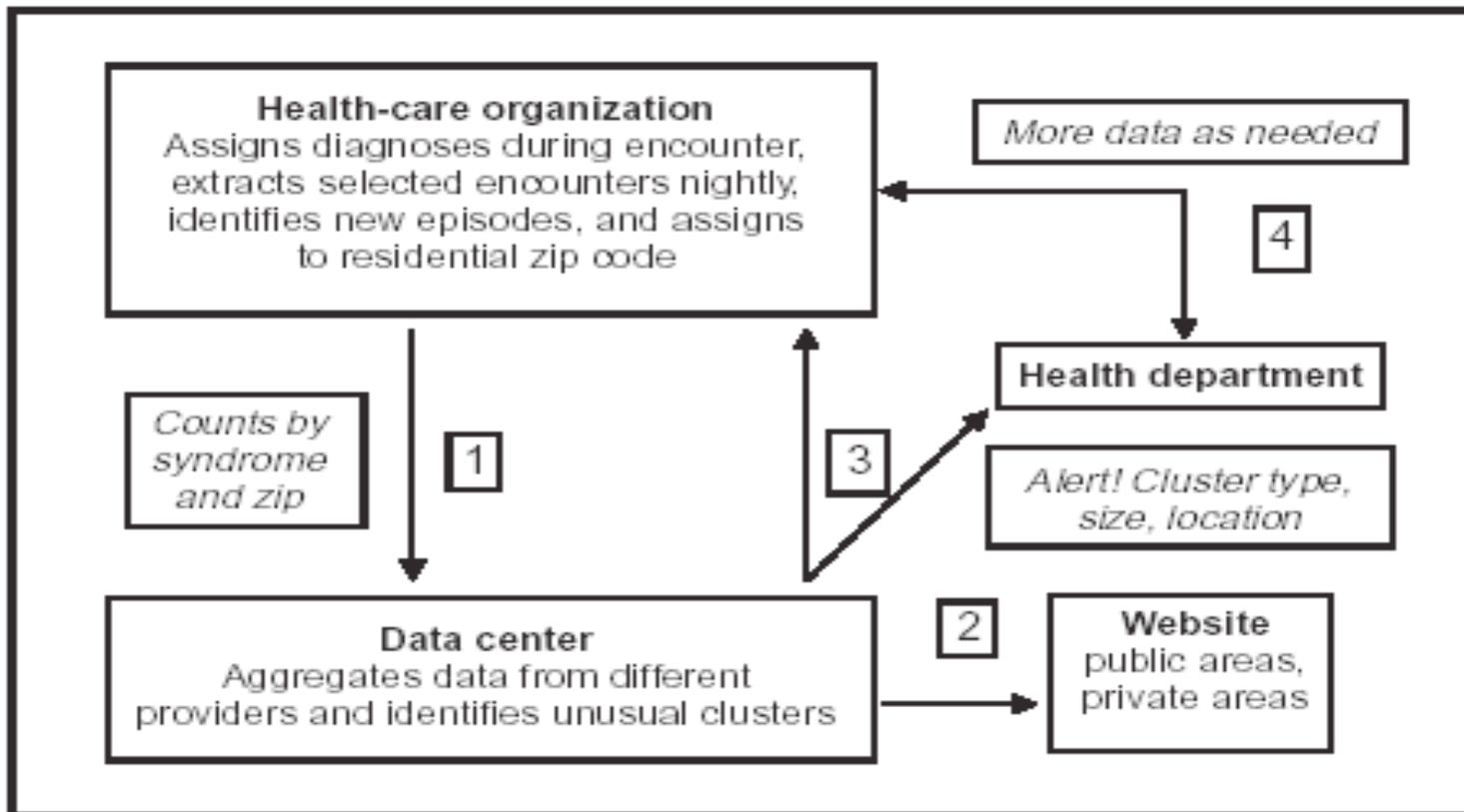
- The problem is large – many requestors, many targets of request, much siloization, little shared infrastructure, cost, or concern for economies of scale or re-use.
- It's going to get larger.
- There's no one 800-lb gorilla, it's 800 gnats. As a result, any action we propose has to introduce systemic change.

Syndromic Surveillance

-CDC-

National Bioterrorism Syndromic Surveillance Demonstration Program (NBSS).

FIGURE. Information flow for the National Bioterrorism Syndromic Surveillance Demonstration Program

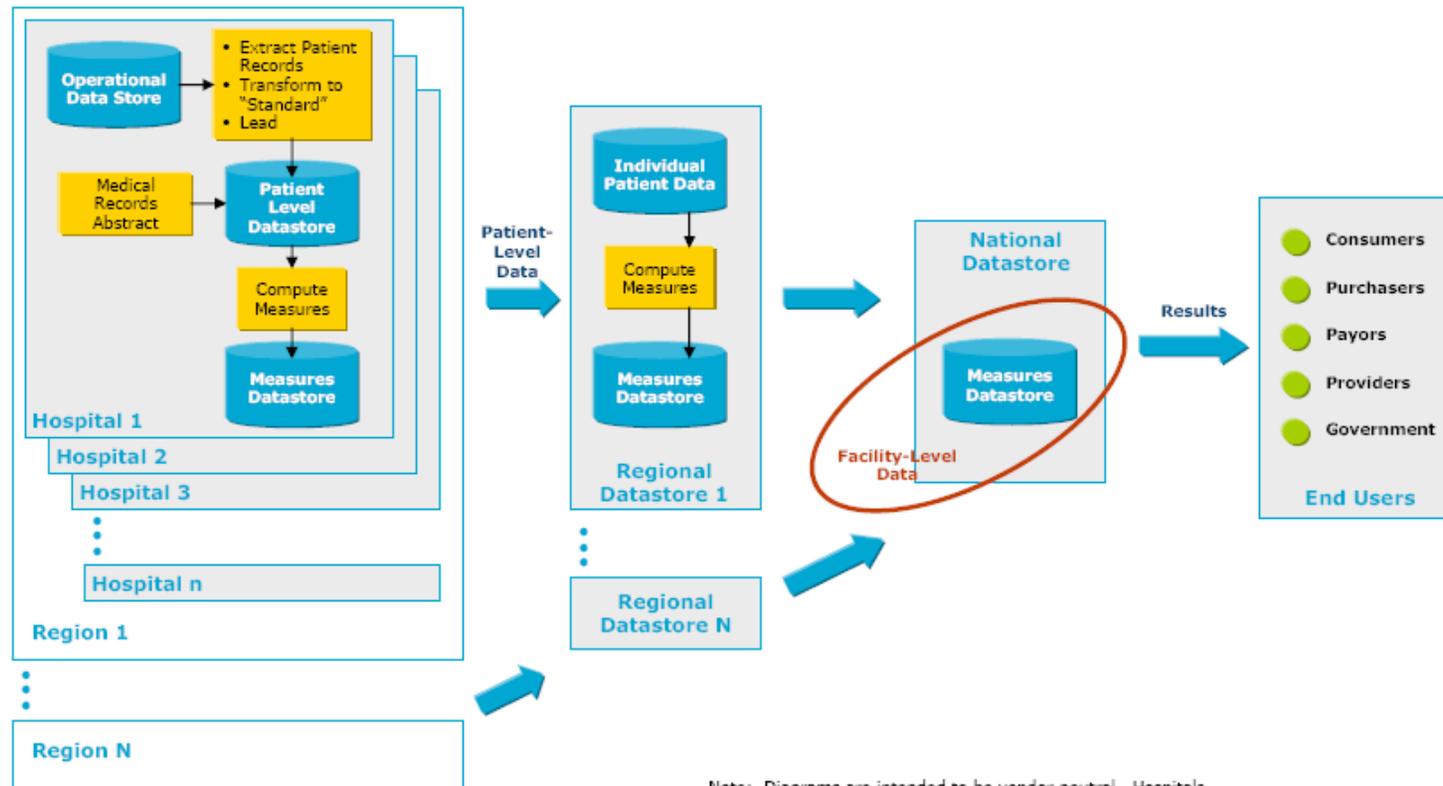


Quality and Performance Measurement

AHA – Quality Reporting Architecture

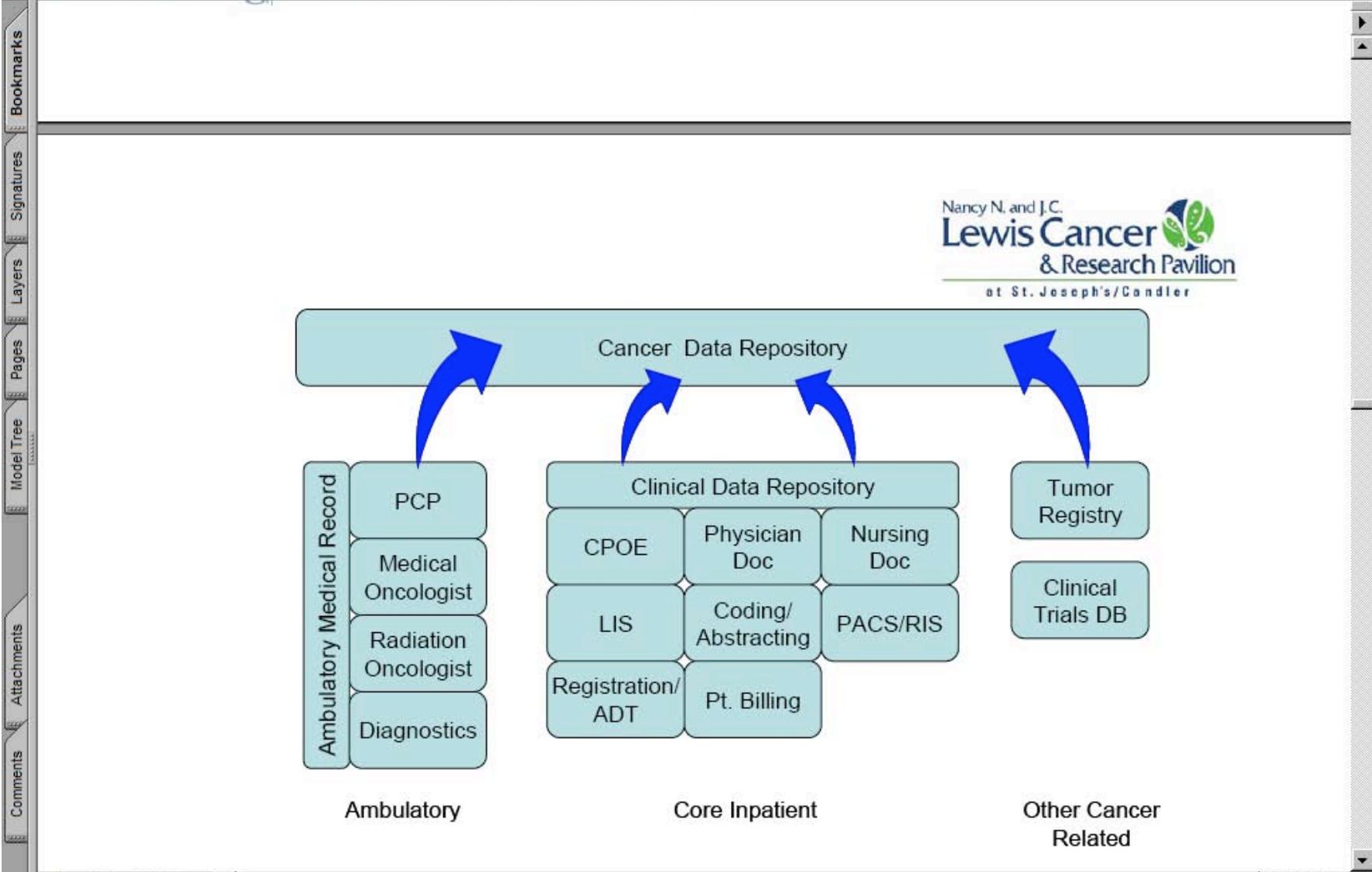
BOOZ | ALLEN | HAMILTON

Exhibit 11 – Technical Architecture: Regional Scenario



Note: Diagrams are intended to be vendor neutral. Hospitals could choose to use vendors for data collection in any model.

Clinical Research



Nancy N. and J.C.
Lewis Cancer
& Research Pavilion
at St. Joseph's/Candler

Hypothesis 3: “So much duplication... so little strategy... deconstructing the data flows”

We must understand the flow of health information for population health, so as to identify where common solutions may be feasible and desirable. We need to identify which areas lend themselves to common solutions across application areas that increase efficiency, and improve privacy protections and public trust.

Hypothesis 4: “Imitation is the sincerest form of flattery”

Because the problem of composite analysis of distributed data is not unique to the healthcare sector, we should examine information technology and policy solutions developed in other sectors.

A Better Solution Would...

Hypothesis 5: “...leverage current investments.”

The business case for clinical IT adoption and information exchange has been weak, except in large delivery systems where local information transfer adds value. However, significant resources – both technical and financial – now being deployed for the capture, aggregation, analysis, and reporting of clinical data could be more efficiently used if a comprehensive clinical information infrastructure existed and were designed to permit appropriate aggregated uses.

Hypothesis 6: “...anticipate changing needs.”

Design of a nationwide health information network should allow for capture of all data that may be pertinent to a high-priority population-level analysis, even though we can not identify all such requirements today. It should permit collection of unanticipated data elements, aggregation across currently untapped information sources, and application of new analysis and distribution techniques.

Some General Principles

- Design for decisions
- Design for many users
- Design for distributed environment
- Design for public values
- Design layers of protection
- ... *a virtuous circle of information flow*

Implications

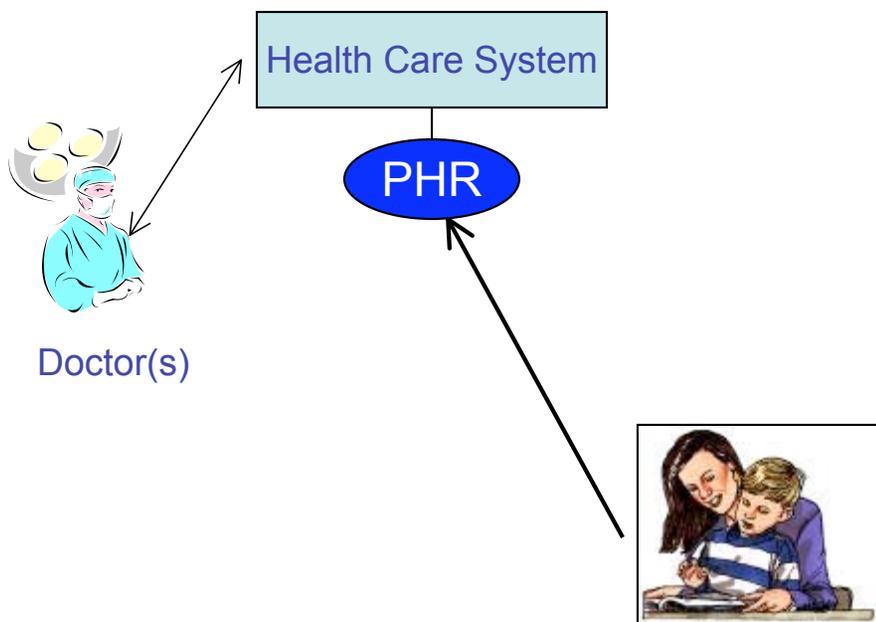
- Need architecture that anticipates need for efficient data acquisition & manipulation while protecting privacy
- Need to “close the loop” by providing value back to contributors

3. Information to help consumers improve own health and their care

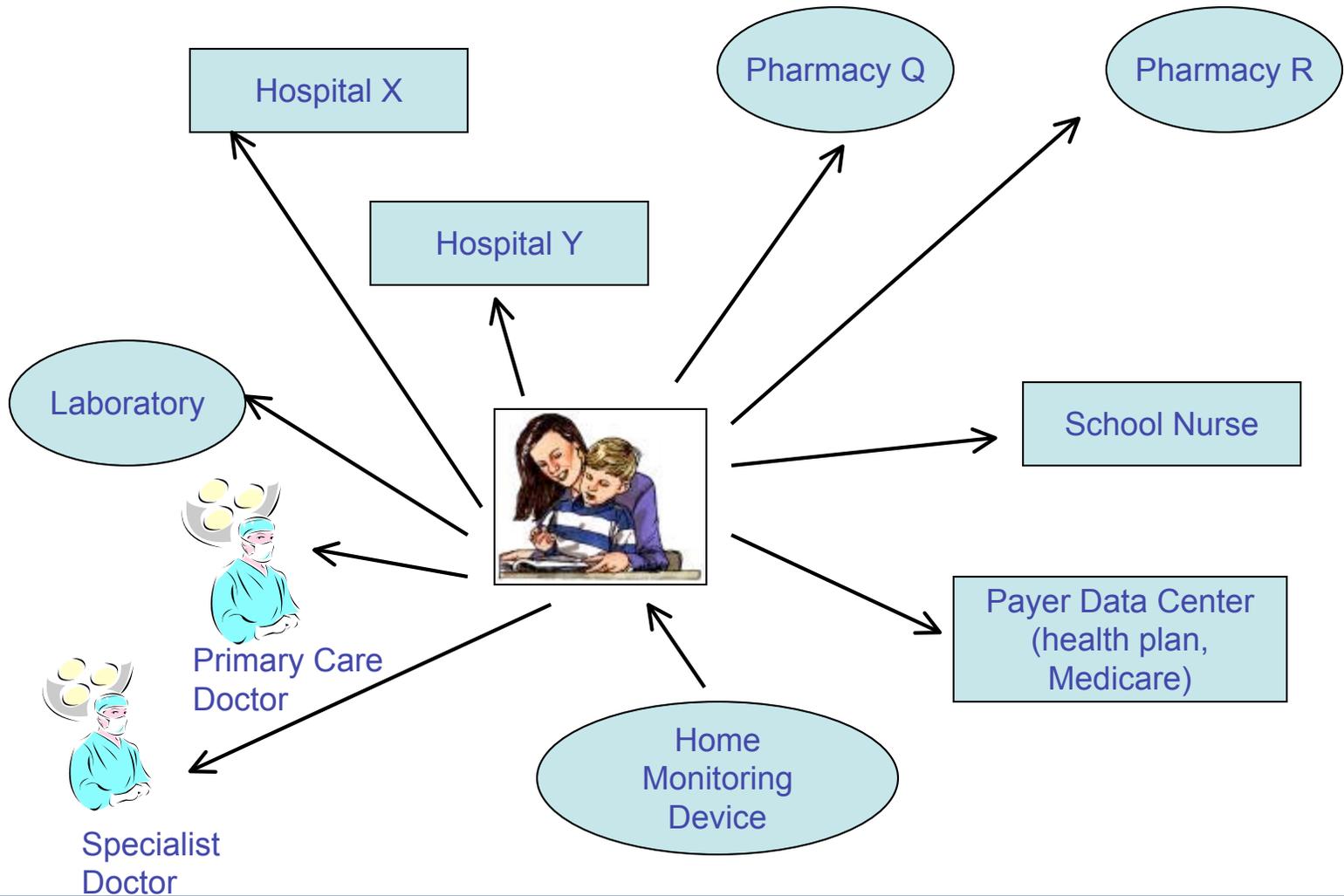
National trends - 2007

- President's 10-year commitment (2014?)
- HHS: American Health Information Community – Consumer Empowerment “Breakthrough”
- Congress – Carper, Porter, Kennedy bills for federal employees, incentives
- AHIP and BCBS – 100 million Americans?
- Major employers – Dossia, IBM, PepsiCo
- Major providers – VA, Kaiser, Partners
- Commercial: Google, Microsoft, Intuit, WebMD
- Health Record Bank (Trust): Brownback, Wash. State ...

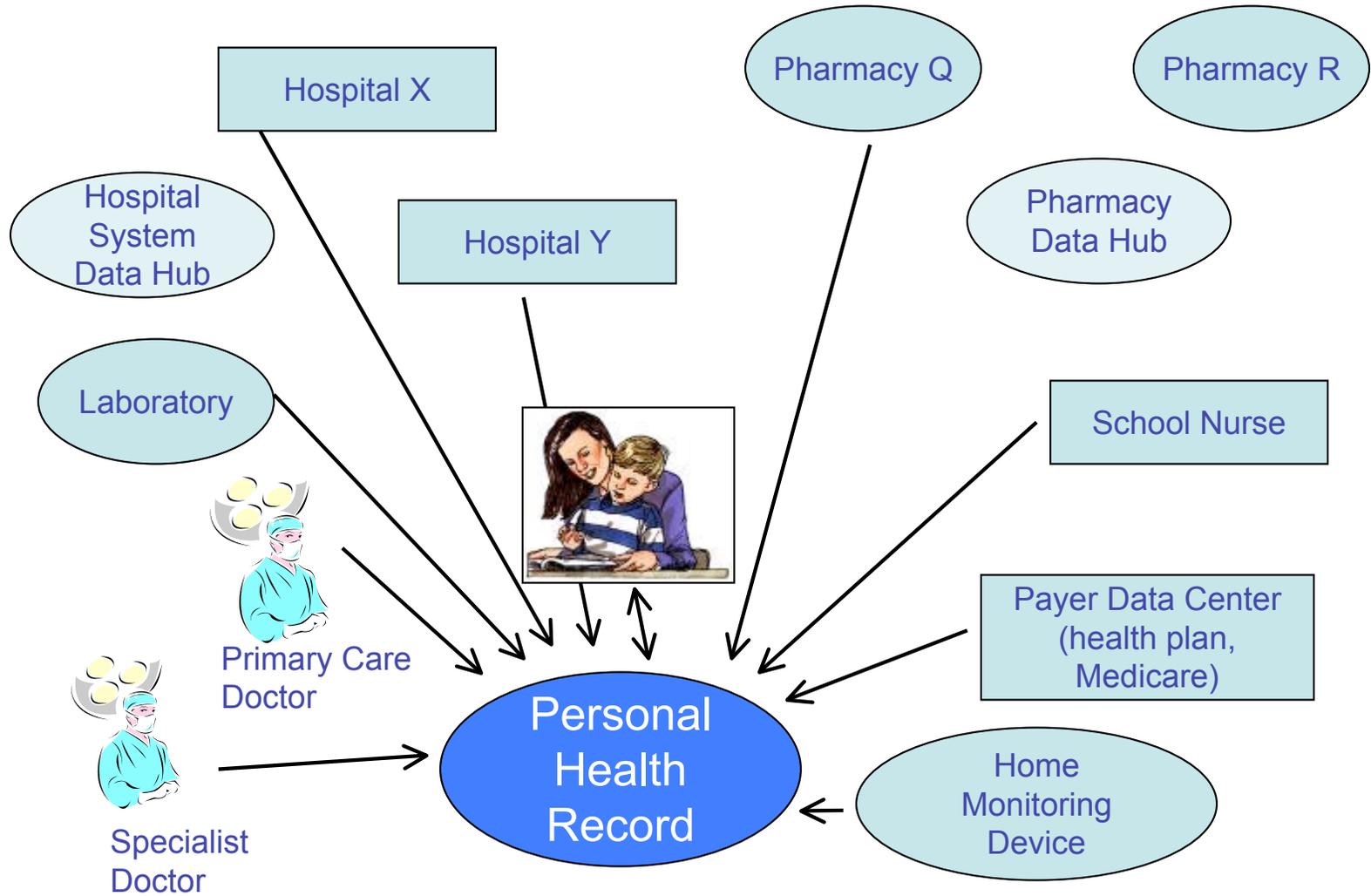
The simple case



The reality...



The Networked PHR

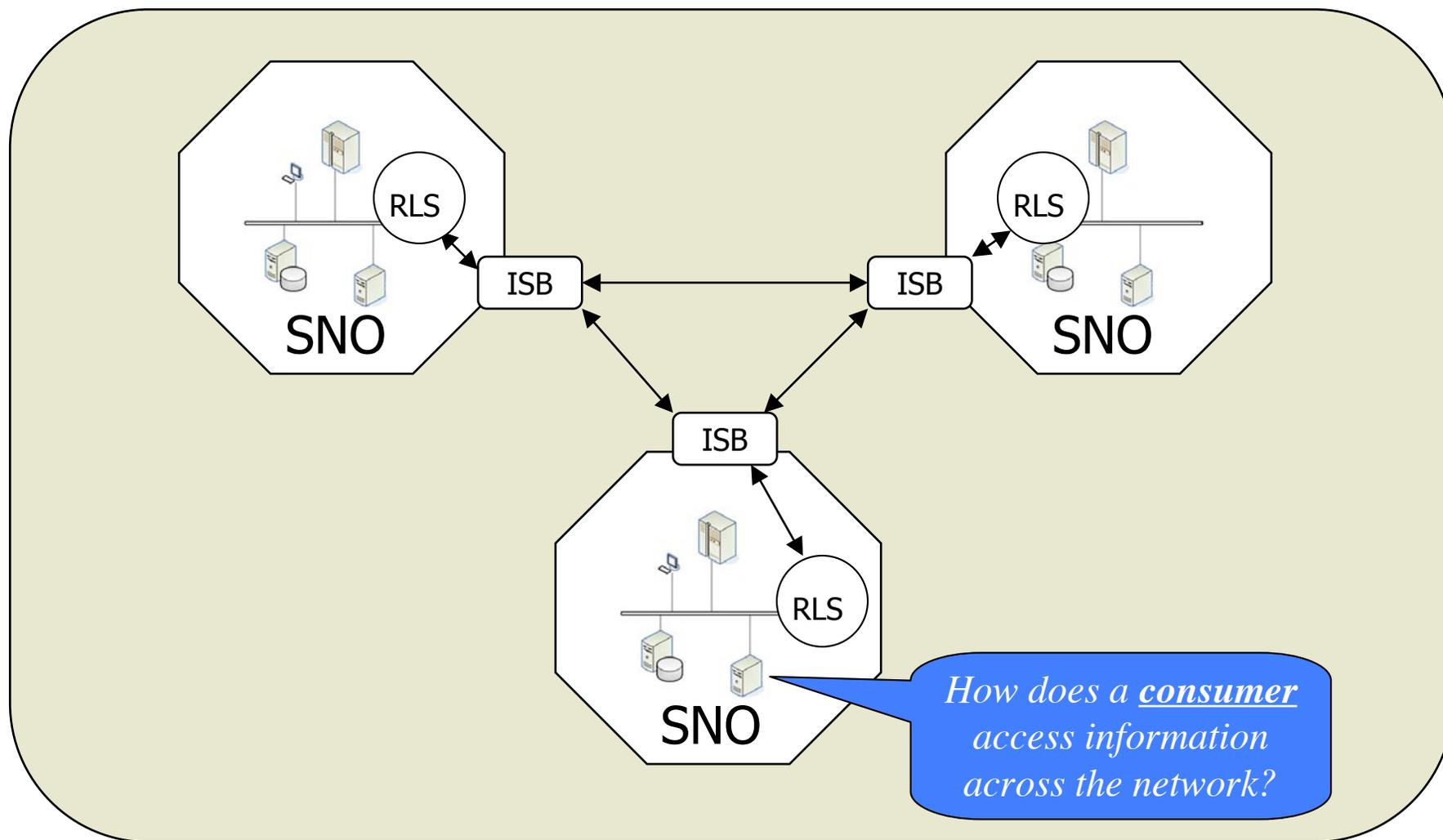


**Are we headed for integration or just
more silos?**

Features of a “networked” approach

- ‘Networked’ consumers drive transformative change in other sectors.
 - Content
 - E-commerce
 - Personal finance
 - Etc.
- A common ingredient is a fresh openness toward consumer access to, and contribution of, information.
- Consumers and health professionals gain opportunities to transform care delivery and roles.
- *A network needs common rules, particularly for privacy.*

Common Framework architecture

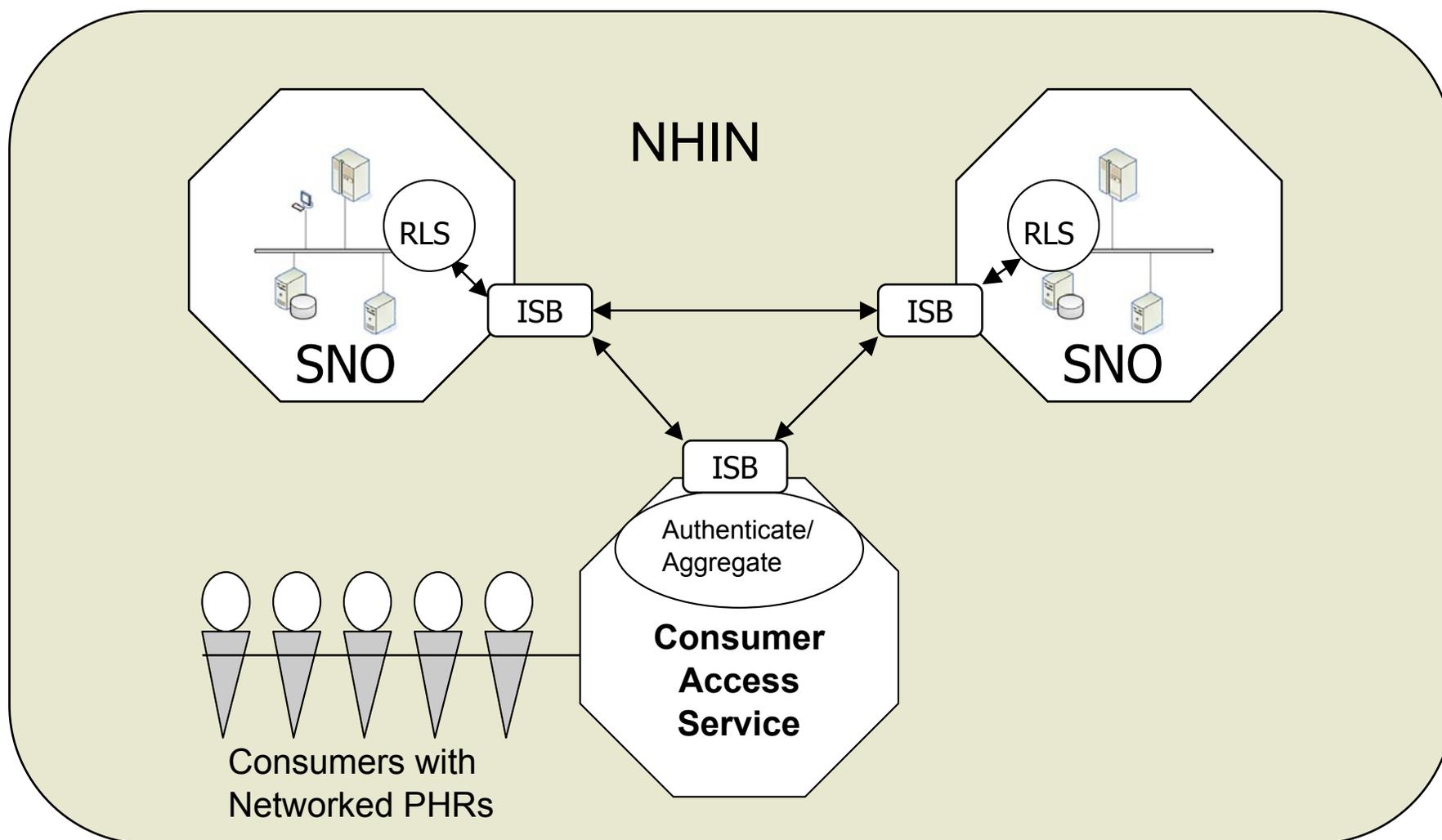


Individual Consumers Will Need Mediating Bodies to Facilitate Their Access to the Network

Functions:

- Distribute services to populations of consumers.
- Issue individuals' identity credentials and "vouch" for them as network users.
- Help consumers access and aggregate their personal health data and connect with various services.
- Assure that network-wide policies (e.g., privacy and information practices) are followed.

Consumer Access Services



Potential Sponsors of Consumer Access Services

- Affinity groups (e.g., AARP, labor unions)
- “Retail” PHR providers (e.g., WebMD, Intuit, Medem)
- Consumer portals (e.g., Google, Yahoo)
- Data clearinghouses (e.g., SureScripts)
- Retail pharmacies (e.g., Walgreens, Wal-Mart)
- Health plans (e.g., AHIP, BCBS)
- Provider organizations (e.g., VA, Kaiser Permanente)

Keys to Success?

- Defining a Consumer Access Service that is trusted by consumers.
- Defining a Consumer Access Service that is trusted by other participants on the network.
- Determining minimum necessary privacy and security policies and practices.

Needed policy framework for CAS

- Does HIPAA address privacy and security concerns?
- Authentication
- Authorization
- Consent and notification
- Consumer control of information sharing, including audit
- Rules for secondary use, data mining
- Consumer annotations and edits to their data
- Data management systems
- Governance, transparency, remedies

Implications

- Need rules that create trust – by data holder and by consumer
- Need interfaces
- Need reason to share data with consumers

Three layers of HIT planning

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- Information to help consumers improve own health and their care

Implications

- The “network” has to support clinical care, population health, and consumer participation
- Implies many new players with a legitimate role
- Adds new business interests, legal questions, ethical questions

Implications for the Infrastructure

- Standards:
- Measures:
- Certification:
- Payment:
- Privacy policy:
- Enforcement of policy:

Implications for where we start

- Can only get there with collaboration
- Can only get there with shared vision as a community
- Can only get there with shared values
- ... and leadership