



## A National Agenda for Personal Health Records? *How will we REALLY empower consumers in the next decade?*

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Markle Foundation

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MARKLE FOUNDATION *A Public-Private Collaborative*

## The politicians' perspective

"To protect patients and improve care and reduce cost, we need a system where everyone has their own personal electronic medical record that they control and they can give a doctor when they need to."

- **President Bush**

**At American Association of Community Colleges Annual  
Convention April 26, 2004**

"We should adopt the model of a 'personal health record' controlled by the patient, who could use it not only to access the latest reliable health information on the Internet but also to record weight and blood sugar and to receive daily reminders to take asthma or cholesterol medication."

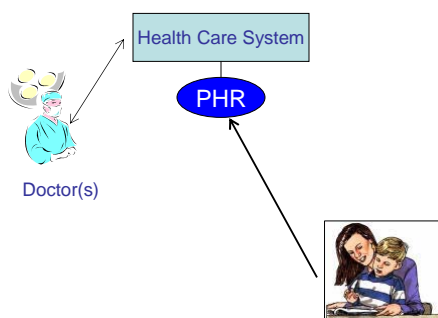
- **Senator Hillary Clinton**

**NY Times, April 18, 2004**

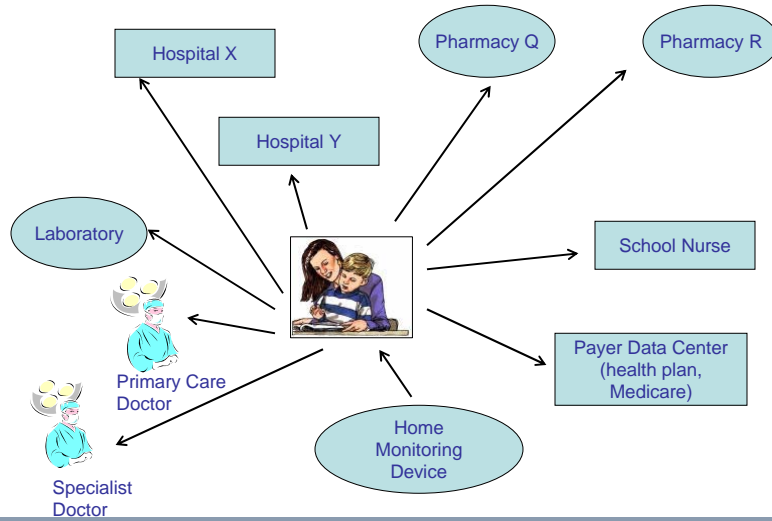
## Potential of Personal Health Records

- Giving individuals access to and control over their personal health information enables:
  - More reliable care; e.g., in emergency situations
  - Patients better able to maintain health and manage their care
  - Greater efficiency, less duplication of tests and quicker access
  - Improved health care quality and safety
  - More effective communication and collaboration between patients, doctors, pharmacies, and others
  - Opportunities for new service delivery models

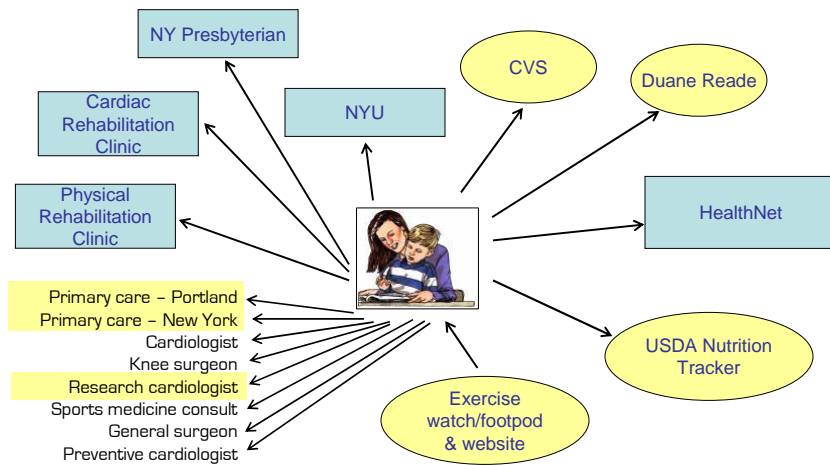
## The simple case



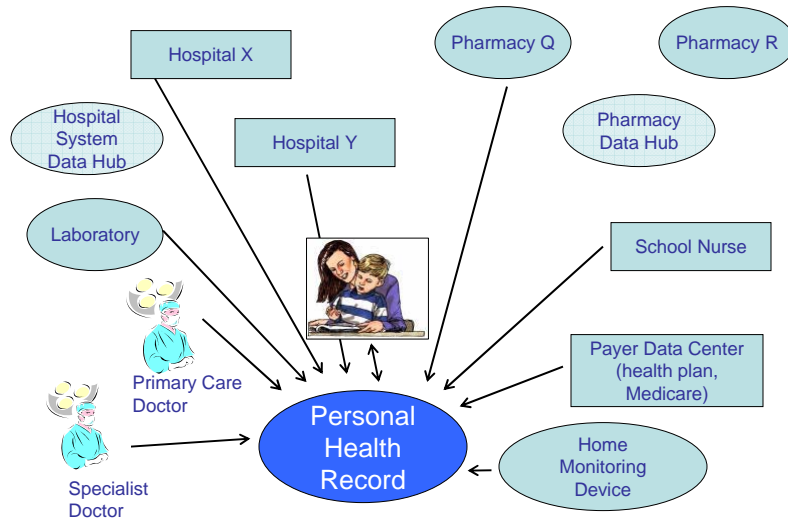
# The reality...



# Retrieving *my*health information - 2006



## The Networked PHR



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## Common Functions of PHRs

- Patient education, self-care content and consensus guidelines
- Secure messaging
- Appointment scheduling and reminders
- Preventive service reminders
- Adherence messaging
- Patient diaries (pain, symptoms, side effects)
- Self-care reminders
- Longitudinal health tracking tools (charts, graphs)
- Drug interactions checking
- Rx refills
- Financial information, such as Explanation of Benefits

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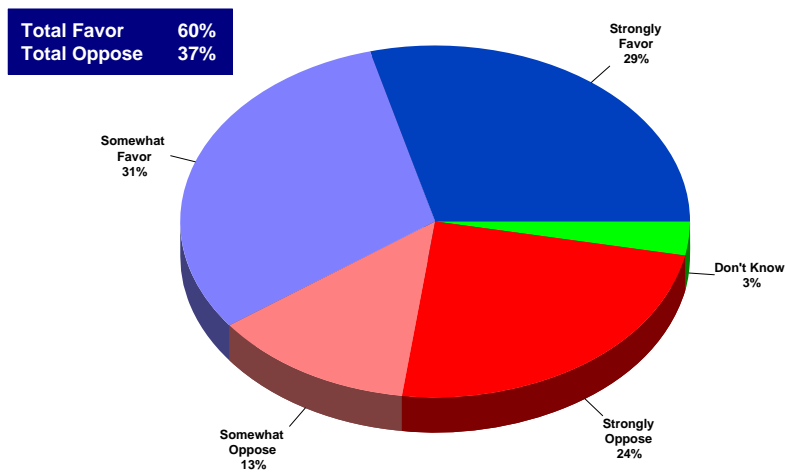
**There is a strong interest among consumers in using health information technology to more fully participate in their own health care.**

Statement	% Yes
Check for mistakes in your medical record.	<b>69%</b>
Check and fill prescriptions.	<b>68%</b>
Get results over the Internet.	<b>58%</b>
Conduct secure and private email communication with your doctor or doctors.	<b>57%</b>

Now let's imagine that a new secure online service was made available to you allowing you to locate your medical records and view them through your own secure online "personal health record" account. Now I am going to read you some things this secure online "personal health record" service would allow you to do after I read each item, please tell me, yes or no, whether or not you would use this secure online "personal health record" service for each activity.

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**Six out of ten Americans say they would favor the creation of a secure online "personal health record" service for their own use.**



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

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## The many flavors of PHR - c. 2006

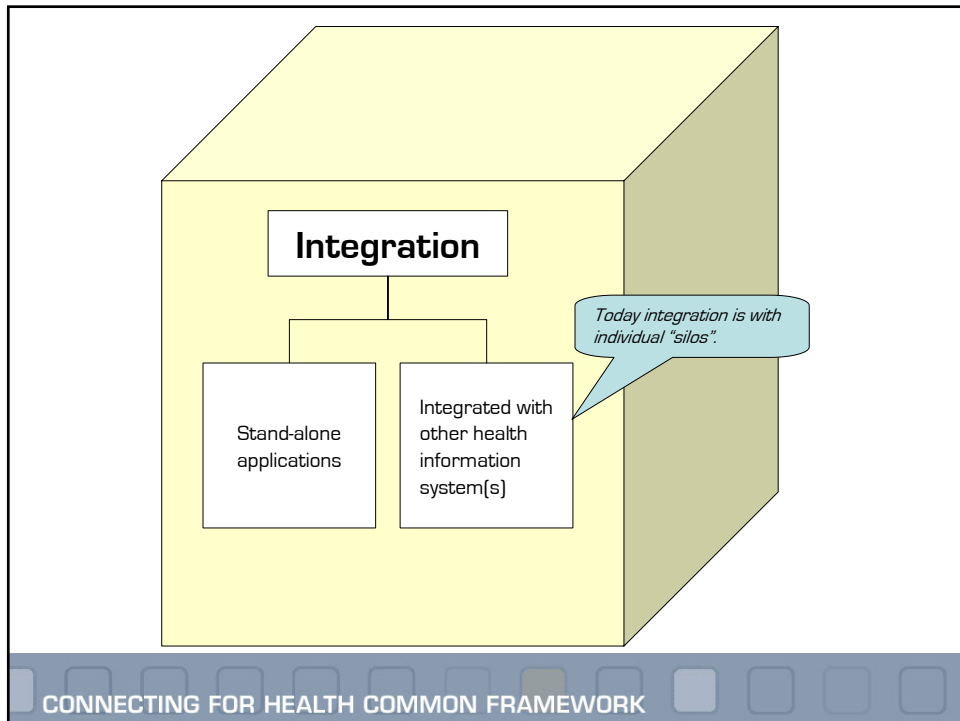
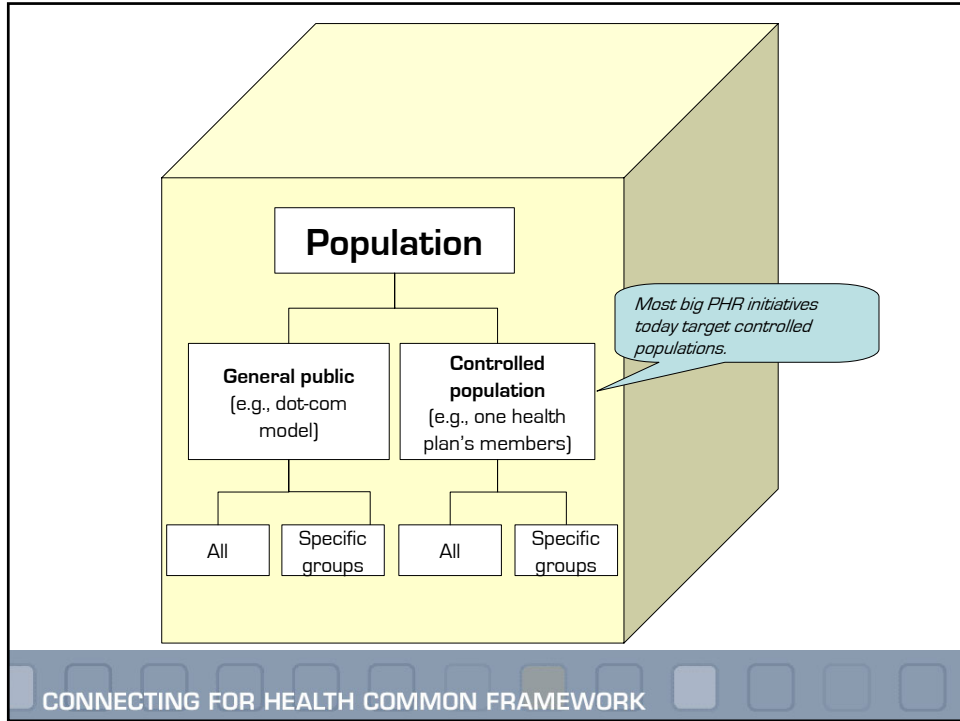
1. Institutional/IDN provider portal
2. Individual provider portal
3. Untethered - USB, desktop, PDA
4. Populated from claims data
5. Population oriented
6. Condition oriented
7. Service oriented

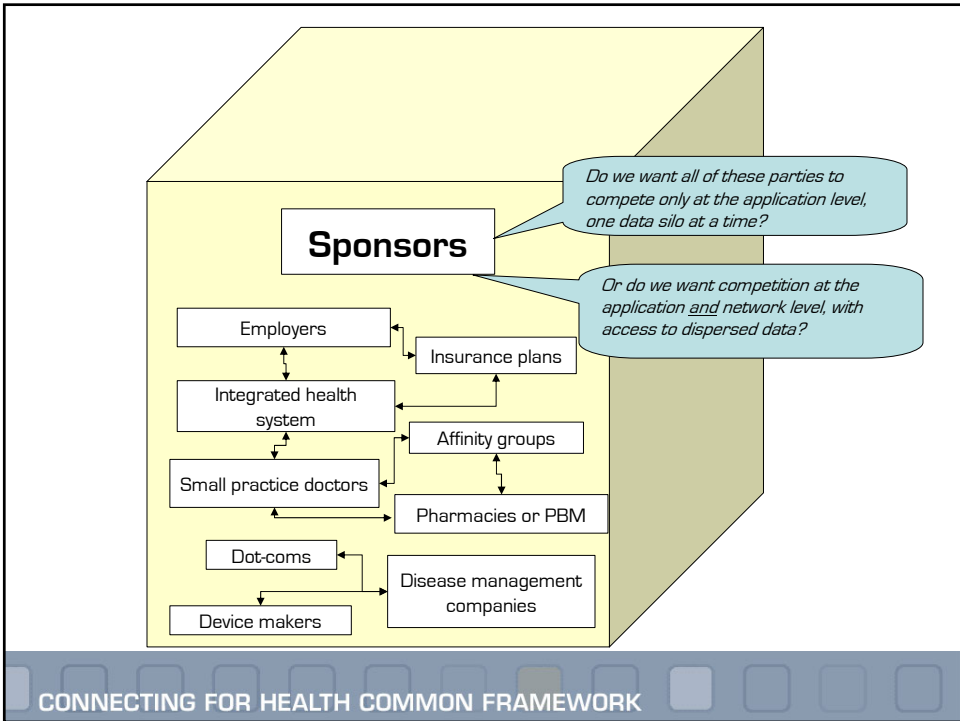
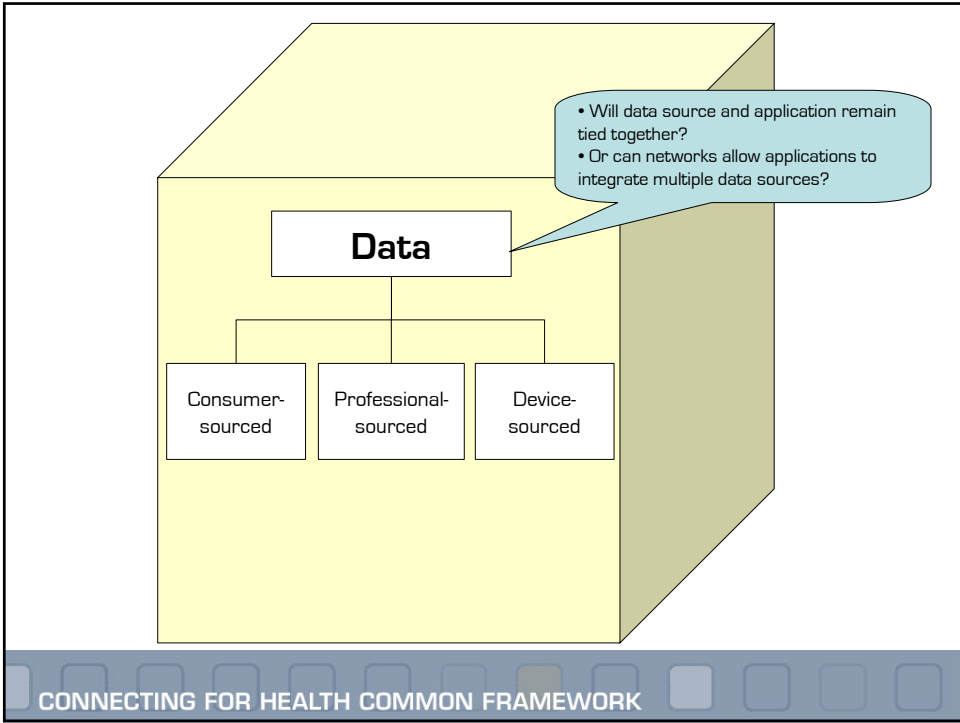
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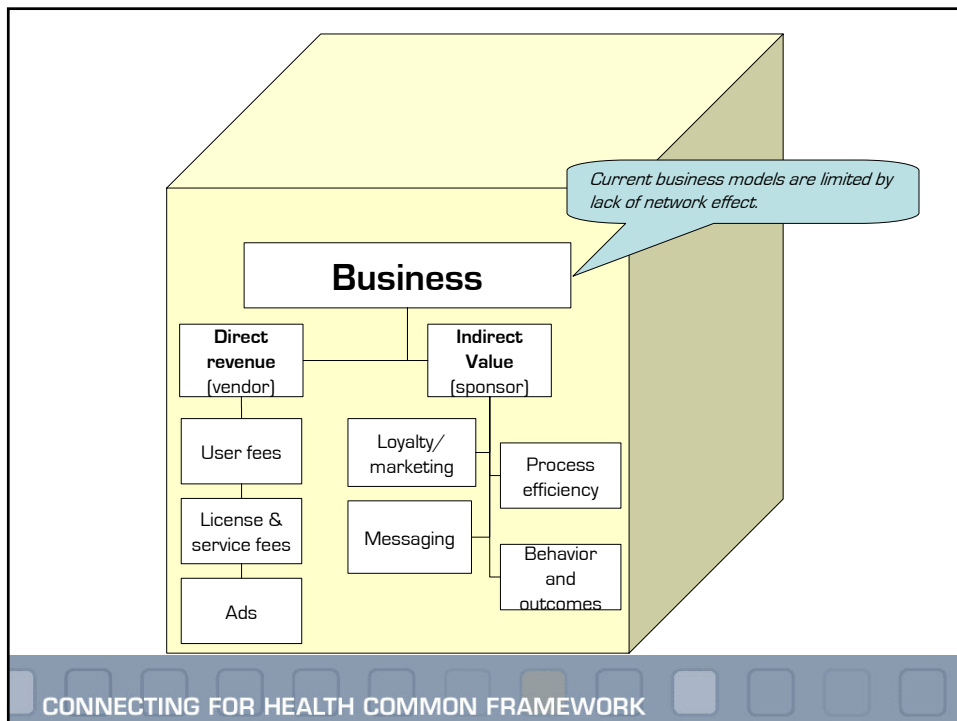
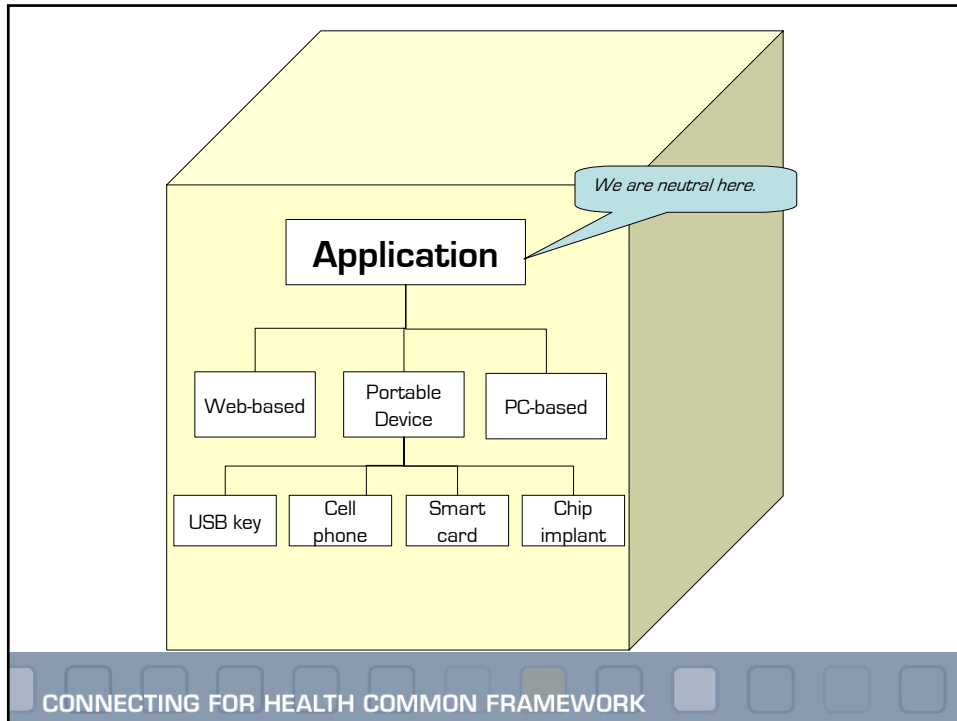
## Six dimensions of PHR designs

1. Population served
2. Integration with other systems
3. Data sources accessed
4. Sponsors of the service
5. Application and platform
6. Business model (and motive)

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## What do we know about adoption and use so far?

- Provider portals reach 15-20% of patients to whom offered
  - Computer skilled
  - High users (visits, meds)
- Most other approaches with small uptake, except incentivized (e.g., IBM - \$150)
- Transactions heavily used
- Specialized products seem to have more user interest

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## National trends

- President's 10-year commitment (2014?)
- HHS: American Health Information Community – Consumer Empowerment “Breakthrough”
- Congress – Carper, Porter, Kennedy bills for federal employees
- AHIP and BCBS – 100 million Americans
- Major employers – IBM, PepsiCo, Intel consortium
- Major providers – VA, Kaiser, Partners
- Consumer organizations – AARP, National Health Council
- Internet companies – Intuit, Microsoft, Google, WebMD

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# PHR landscape

- **Key question:** Are we headed for integration or just more silos?
- **Key wildcards:**
  - Public reaction to data spills
  - Congressional privacy debate
  - Public perceptions defined by one approach

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The collage features several key elements:
 

- Google Logo:** The multi-colored logo is prominently displayed on the left side.
- AIM Logo:** The AIM logo, featuring a yellow stick figure holding a red speech bubble with the letters 'AIM' in white, is positioned in the center.
- Craigslist Screenshot:** A screenshot of the Craigslist website interface, showing various job listings and search filters.
- iPod Advertisement:** An advertisement for the new iPod, showing four different models and text that reads: "The new iPod. 15,000 songs, 25,000 photos, 150 hours of video."

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## 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.
- Truly “networked” PHRs would stimulate innovation.
- Consumers and health professionals gain opportunities to transform care delivery and roles.
- *A network needs common rules, particularly for privacy.*

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## Public concerns about PHRs

- Security of the data system
- Keeping data private
- Keeping data accurate and current
- Controlling and monitoring who has access
- Business motives of sponsor

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**Despite these high levels of support for health information technology, keeping electronic medical information private and secure remains chief consumer concerns.**

Statement	% Absolute Top Priority
The identity of anyone using the system would be carefully confirmed to prevent any unauthorized access or any cases of mistaken identity.	<b>91%</b>
An individual would be able to review who has had access to their personal health information.	<b>81%</b>
Only with an individual's permission could their medical information be shared through this network.	<b>79%</b>
Employers would NOT have access to the secure health information exchange networks.	<b>68%</b>

*I am going to read you different attributes that could be part of this exchange or network and I would like you to rate the importance of each. As you respond, please keep in mind that not every attribute can be a top priority.*

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## Principles released in October 2005

1. Individuals should be able to access their health and medical data conveniently and affordably.
2. Individuals should be able to decide (i.e., authorize) when their health data are shared, and with whom. Individuals should be able to refuse to make their health data available for sharing (i.e., opt-out).
3. Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their records are shared.
4. Individuals should receive easily understood information about all the ways that their health data may be used or shared.
5. Individuals should be able to review which entities have had access to their personal health data.
6. Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information.
7. Independent bodies, accountable to the public, should oversee the electronic health data exchanges.

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## Consumer and Patient Principles Endorsements

- AARP
- ACOR – Association of Cancer Online Resources
- AFL-CIO
- American Hospice Foundation
- Center for Medical Consumers
- Consumers Union
- Families USA
- Health Privacy Project
- International Association of Machinists and Aerospace Workers
- Maternity Center Association
- National Coalition for Cancer Survivorship
- National Consumers League
- National Partnership for Women and Families
- SEIU – Service Employees International Union

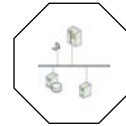
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*Creating a networked PHR  
environment that achieves  
sustainable consumer confidence*

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# HIT Networking Glossary

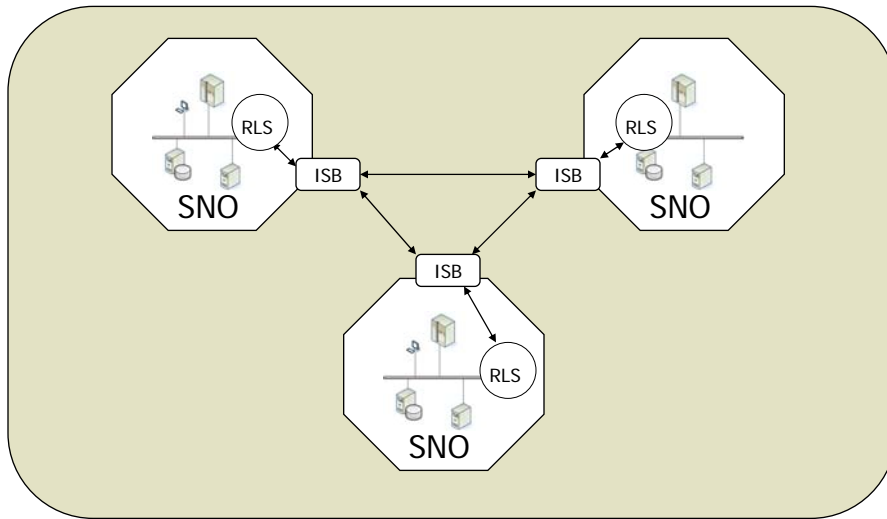
- Sub-network organization (SNO): A regional (e.g., a RHIO) or non-regional (e.g., the VA) health information exchange network.
- Record Locator Service (RLS): A service that matches identity and locates records within a SNO.
- Inter-SNO bridge (ISB): A conduit for data exchange between SNOs.
- National Health Information Network (NHIN): A nationwide network of interconnected SNOs.
- Common Framework: A set of standards and policies for secure electronic health information exchange.



SNO



## Common Framework architecture



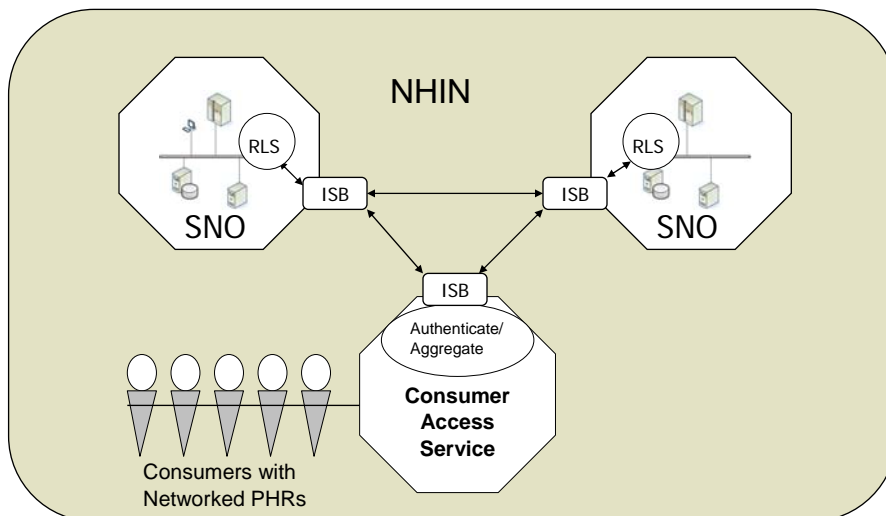
## Individual Consumers Will Need Mediating Bodies to Facilitate Their Access to the Network

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.

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## Consumer Access Services



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## 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)

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## Privacy/Confidentiality Policy

- Role of HIPAA
- What if Consumer Access Services are supplied by entities not covered by HIPAA?
- Are there privacy policies needed beyond HIPAA?

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## Authentication

- How to be sure that consumer-users are who they say they are?
- “Chain of trust”?
- Need uniformity across U.S.?
- Need risk levels corresponding to types of users or types of data?

## Disclosure, Notification, and Consent

- Disclosure
- Marketing policies
- Authorization and permission

## Access and Control of Information

- Consumer access to whole record
- Consumer ability to annotate, correct or purge record
- Granularity of control

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## Core data management functions

- Security
- User rights
- Caching
- Data messaging standards
- Mapping, reconciliation
- Data quality
- Consumer Access Services' rights to analyze data
- Auditing

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## Release of data to 3rd parties

- Law Enforcement demands (homeland security, law enforcement)
- Public health demands
- Business demands (contract partners, health plans, creditors, life insurers)
- Commercial requests (marketers, disease management)

## Governance and openness

- Governance
- Liability considerations
- Breaches
- Sanctions and remedies
- Validation

## Challenges to Empowering Consumers with ALL of their Information

- Inability to locate patient information across multiple care settings
- How to authenticate each individual
- Significant segmentation of consumer market (small, diffuse populations with highly specific needs)
- Significant privacy concerns about internet and health information access by government, plans, employers
- Low level of public trust in health information services not connected to personal physician

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## Challenges (continued)

- Few EHRs to connect to
- No standards for information contributed by patient
- No established business model for consumer-facing applications
- Health information is complex and unfamiliar
- Significant barriers for people with low literacy, poor access to technology, lack of experience with health decision-making

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## Conclusions

- High public interest in PHR features and services coupled with concern about privacy
- There's no "it" out there yet - diverse, complex market
- Many significant offerings in the works
- All will face common challenges accessing data across the "network":
  - Standards issues
  - Architecture issues
  - Policy issues
- A common policy and technical framework will be essential to achieved "networked" personal health record
  - and avoid another set of silos

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