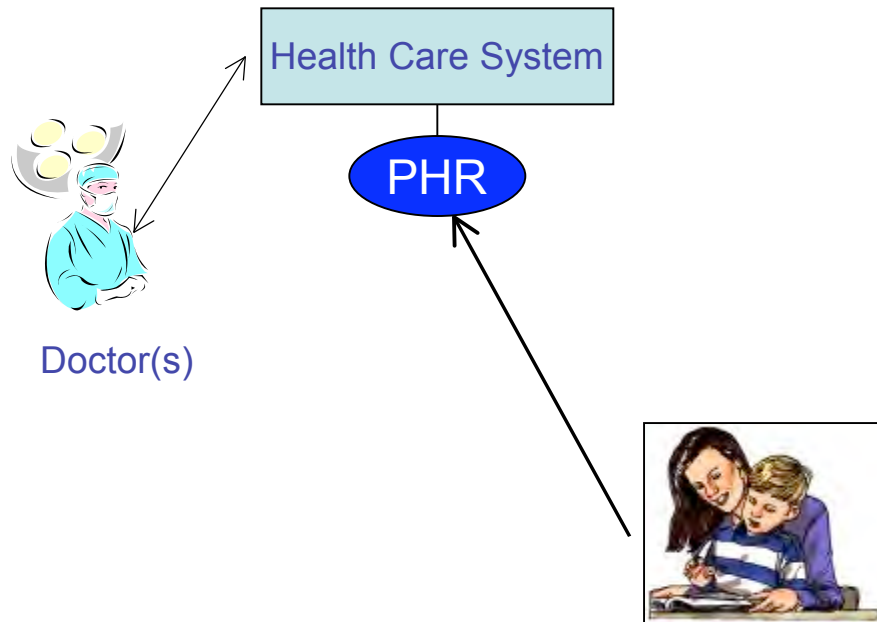# Networked Personal Health Records

Table of Contents

- Potential of Personal Health Records (PHRs)
- What is a PHR?
- Common functions of a PHR
- Ideal attributes
- The PHR environment
- Consumer perceptions about PHRs
- PHR services today
- What do we know about adoption so far?
- A Networked PHR

CONNECTING FOR HEALTH COMMON FRAMEWORK

Potential of Personal Health Records

- Giving individuals access to and control over their personal health information enables:
  - Patients better able to maintain health and manage their care
  - More reliable care; e.g., in emergency situations
  - Greater efficiency, less duplication of tests and quicker access
  - Improved satisfaction, lower cost and greater choice
  - Improved health care quality and safety
  - More effective communication and collaboration between patients, doctors, pharmacies, and others
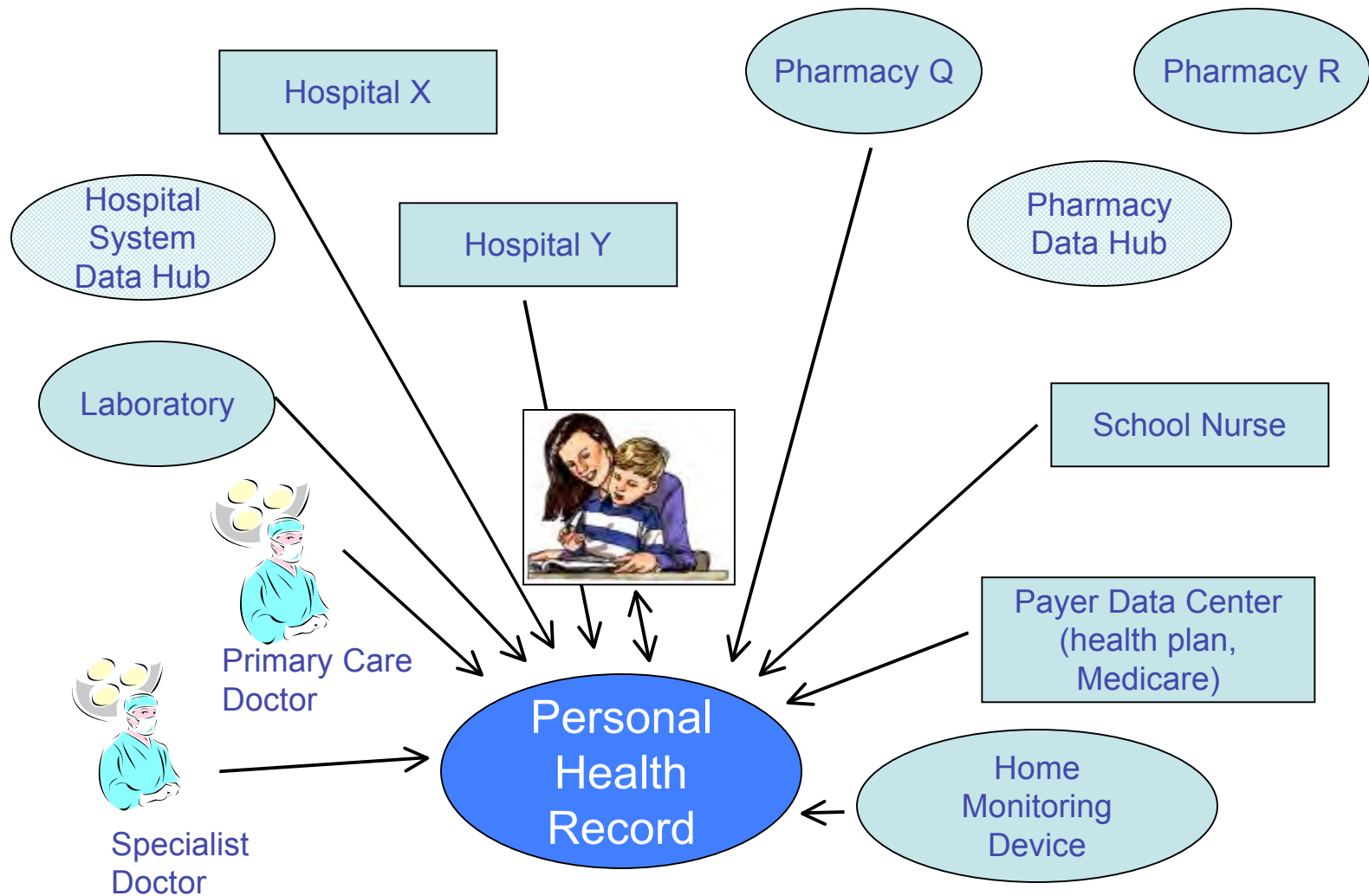
The Simple Case

Health Care System

PHR

Doctor(s)

The Reality…
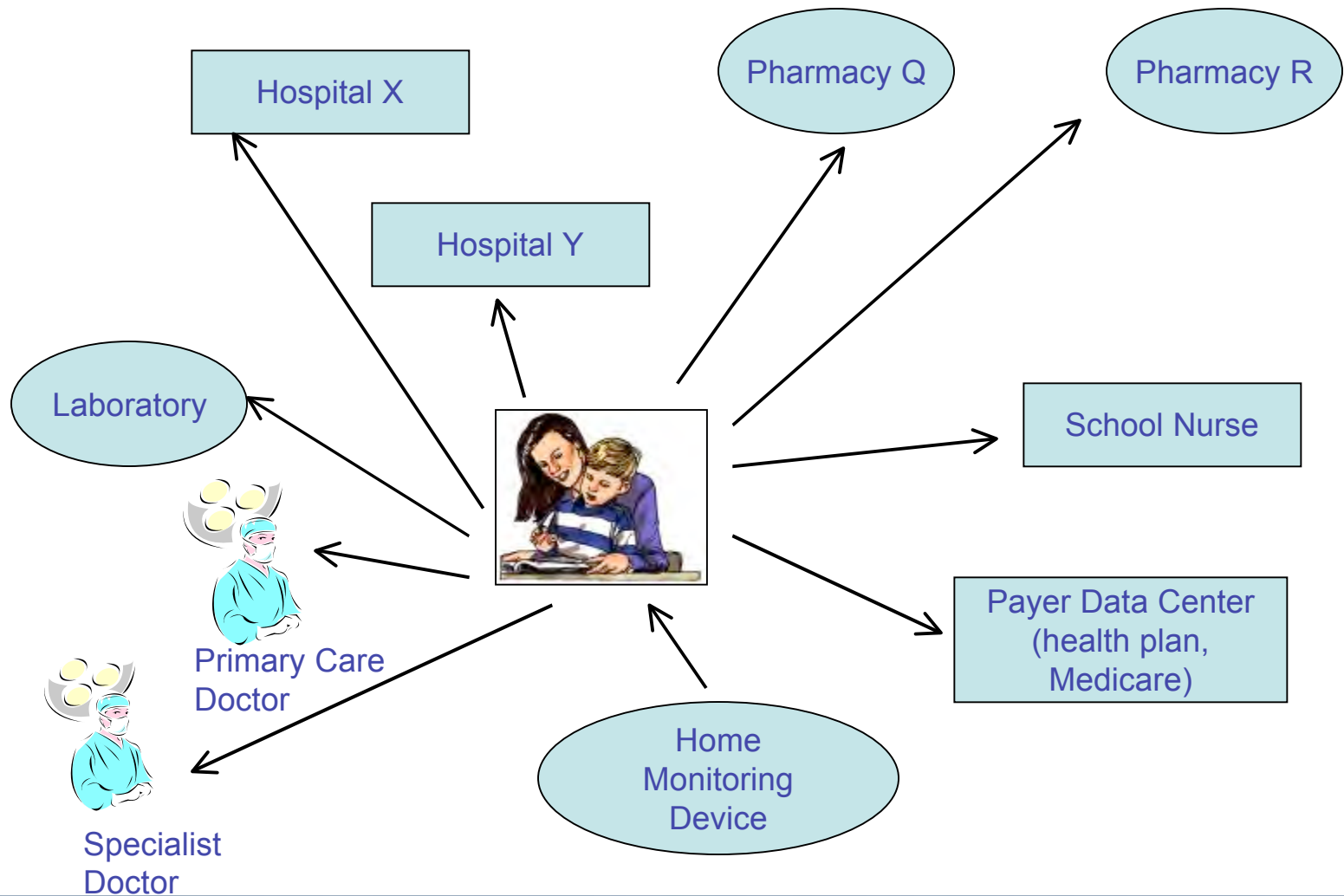
The Networked PHR

What is a Personal Health Record?

- No single answer today
- Some of its attributes:
  - Person who controls own PHR
  - Contains information from entire lifetime
  - Contains information from all providers and self
  - Accessible from any place, at any time
  - Private and secure
  - Transparent – strong audit trail
  - Interactive across one's health care network

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

Idealized Attributes of a PHR

1. Each person controls his or her own PHR. Individuals decide which parts of their PHR can be accessed, by whom and for how long.
2. PHRs contain information from one's entire lifetime.
3. PHRs contain information from all health care providers.
4. PHRs are accessible from any place at any time.
5. PHRs are private and secure.
6. PHRs are "transparent." Individuals can see who entered each piece of data, where it was transferred from and who has viewed it.
7. PHRs permit easy exchange of information with other health information systems and health professionals.

The PHR Environment

- **Paper:** Remains the only available or practical means for many people.

- **Electronic**: Carries much greater potential for rapid, convenient and secure data sharing over time.

  - **Desktop-based:** Consumers may store PHR data locally on the hard drive or within software applications on their personal computer.
  - **Web-based:** Applications may store PHR data on a secure Web server.
  - **Portable devices:** Products that enable consumers to store personal health information on smart cards, personal digital assistants (PDAs), mobile phones or USB compatible memory devices.

- Each data-storage medium may be preferred by different types of patients.

- No matter the electronic data storage medium, a network is the best way to <u>update</u> the PHR with information from professionals and institutions.
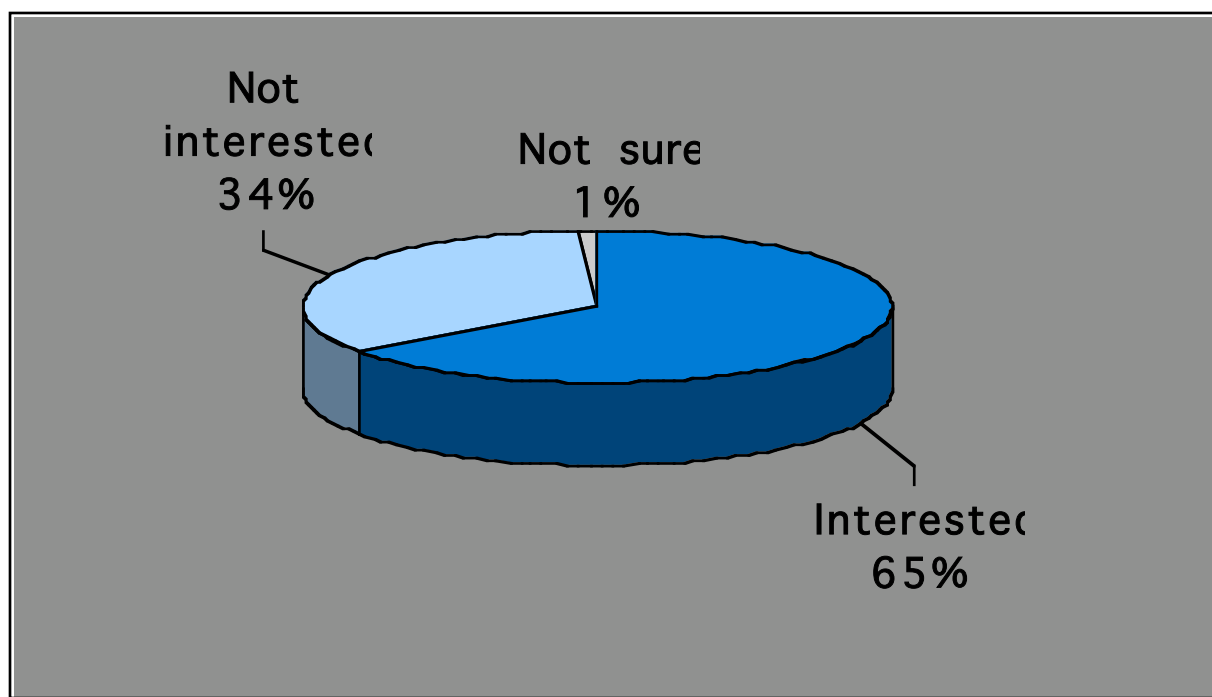
Consumer Perceptions of PHRs

2006 Survey

- National survey of Americans, RDD
- N=1,003 adults 18 and older
- Margin of sampling error: +/- 3.1 %
- Conducted November 11 – 15, 2006
- By Lake Research Partners and American Viewpoint

Majority Interested in Accessing Information Online

**Interest in Accessing Health Information Online**

Not interested
34%

Not sure
1%

Interested
65%

- Majority of all subgroups express interest, even seniors (53%)
- Most interested include:
  - Under 40 (72%)
  - Daily Internet users (71%)
  - Parents (70%)

Online Access as a Way to Gain More Control Over Care

**Health Information Online Will Give People
More Control Over Own Care**

Disagree 27%

Not sure 5%

Agree 68%
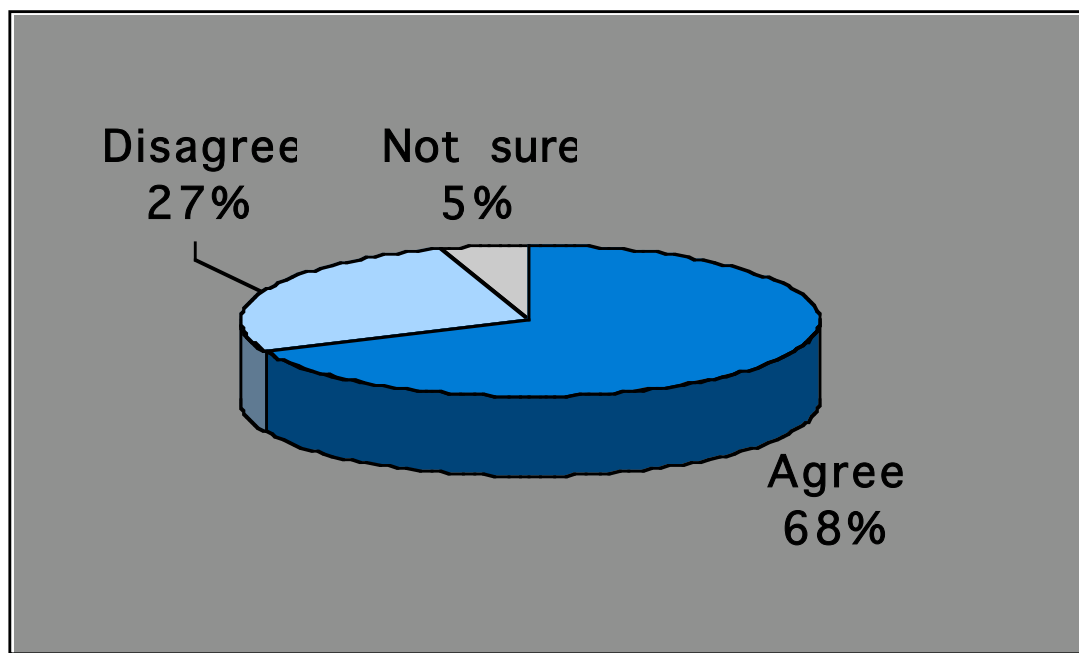
Most likely to agree:

- 18 to 29 year olds (81%)
- African Americans (79%)
- Daily Internet users (76%)
- Parents (74%)
- Frequent users of health care system (74%)

# Ways to Manage Own Care With Secure Network

- Tracking symptoms or changes in health (90% say would be important personally)

- Tracking financial aspects of health care (80% interested)

- Tracking child's health records and services, like immunization dates (82% of parents interested)

Benefits Relating to Quality of Care and Cost

- Checking doctor's chart to make sure situation is understood (91% important)

- Checking medical records for mistakes (84% interested)

- Looking at test results (82% interested)

- Reducing unnecessary or repeated tests and procedures (88% important)

Very High Concern About Unwanted Access

Privacy and Access Concerns
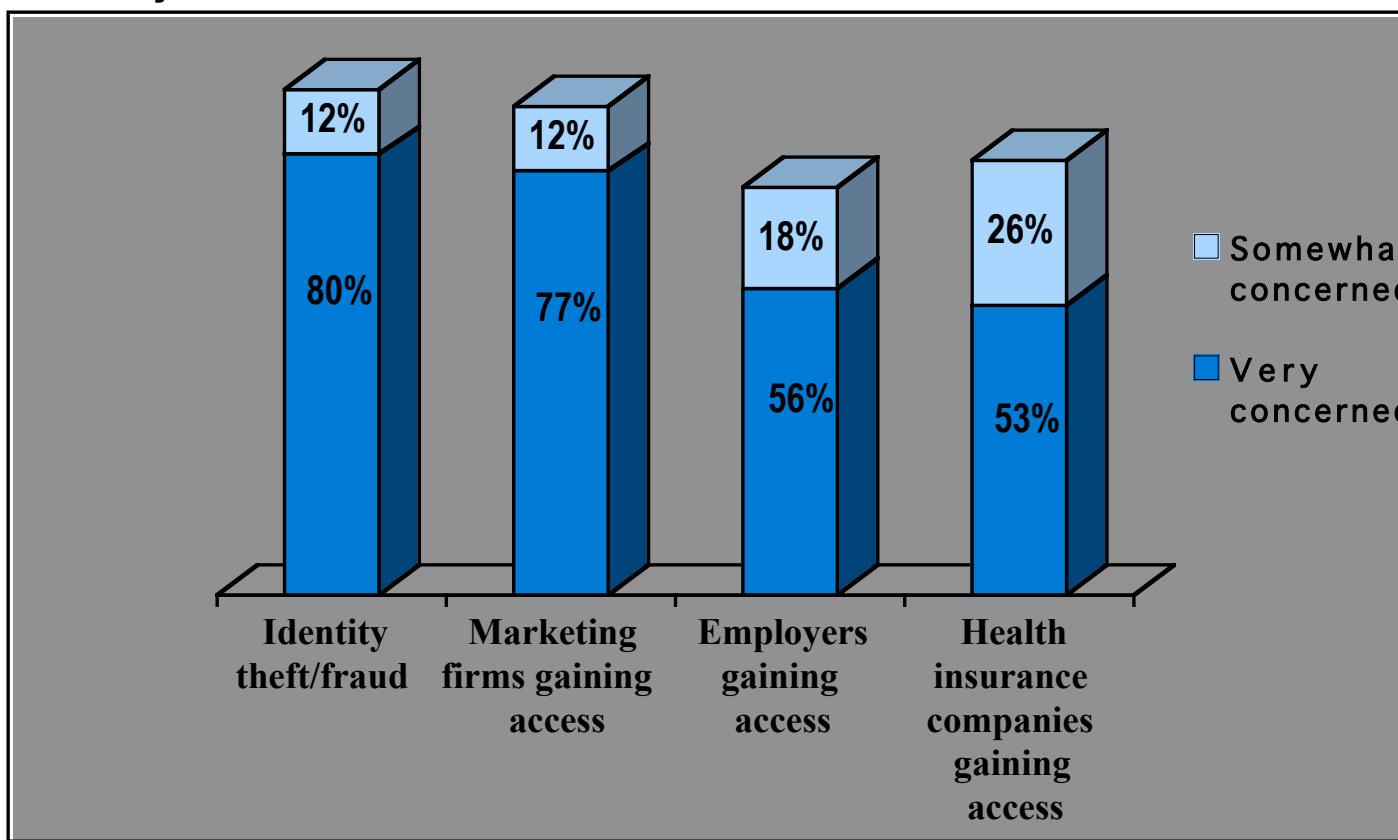
Other Polls Show Similar Results

- Harris Interactive Survey on Medical Privacy (Feb. 2005)
  - Between 62% and 70% are worried about weak security; sharing without consent; increased errors, and privacy rules will be reduced in name of efficiency.

- California Health Care Foundation Survey (Nov. 2005)
  - 67% remain concerned about privacy of PHI.

Role for Government in Establishing Protections
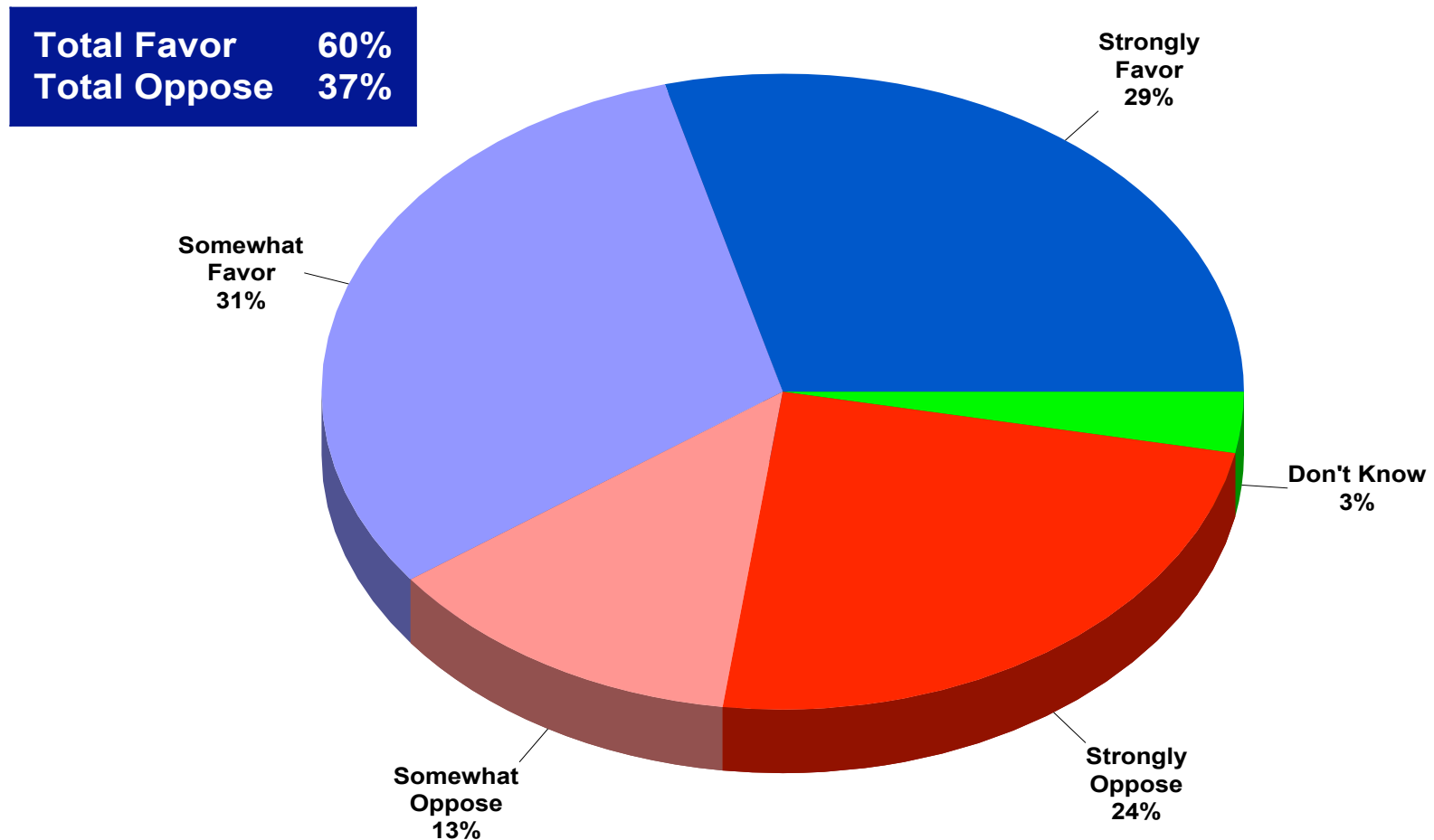
Role for Government in Protections
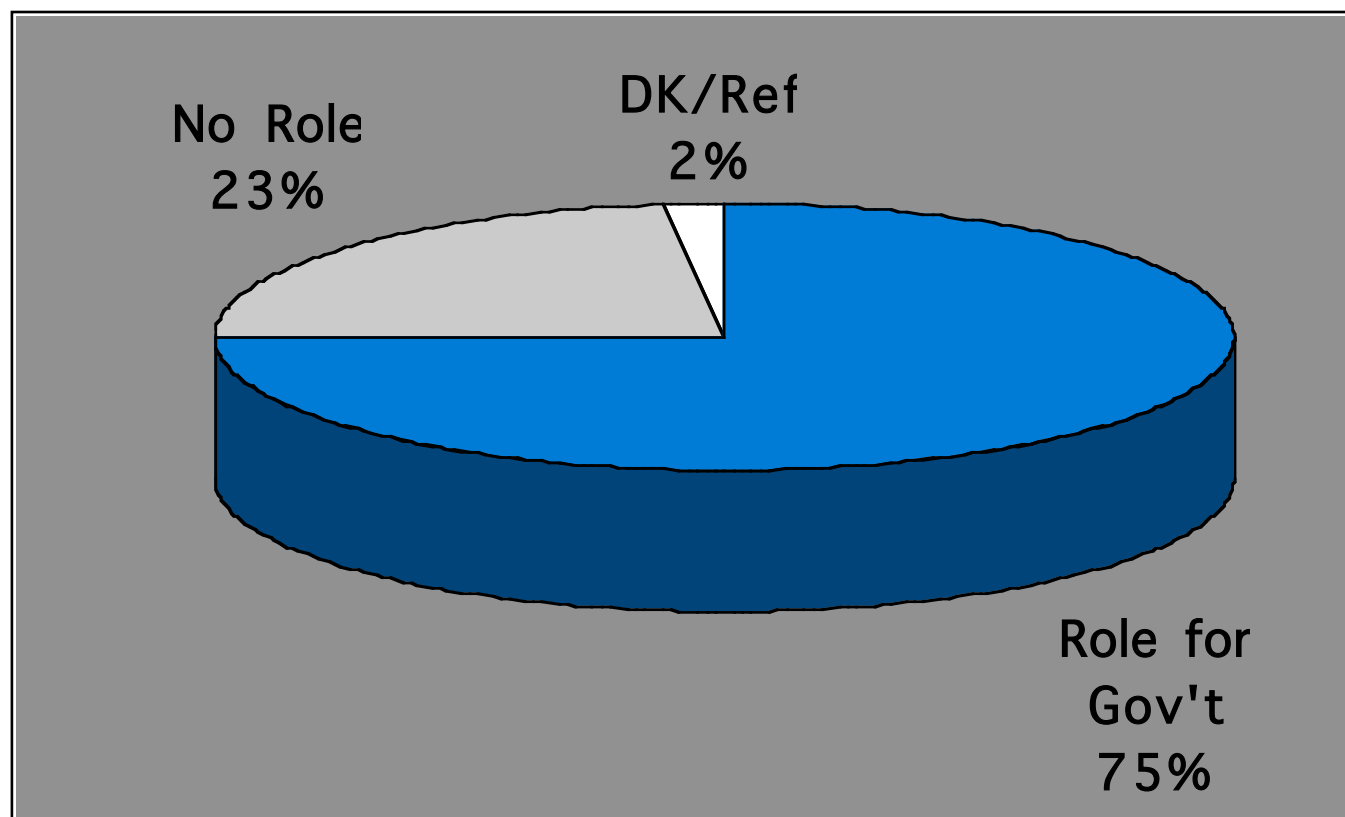
- Three-quarters see a role for federal government in establishing rules to protect the privacy and confidentiality of online health information

2005 Survey

- 800 adults and registered voters
- September 2005
- Conducted by Public Opinion Strategies
- Sponsored by the Markle Foundation

Six Out of Ten Americans Say They Would Favor the Creation of a Secure Online "Personal Health Record" Service for Their Own Use.

Total Favor	**60%**
Total Oppose	**37%**

- Strongly Favor 29%
- Somewhat Favor 31%
- Don't Know 3%
- Strongly Oppose 24%
- Somewhat Oppose 13%

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

CONNECTING FOR HEALTH COMMON FRAMEWORK

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.	**69%**
Check and fill prescriptions.	**68%**
Get results over the Internet.	**58%**
Conduct secure and private email communication with your doctor or doctors.	**57%**

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.

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.	91%
An individual would be able to review who has had access to their personal health information.	81%
Only with an individual's permission could their medical information be shared through this network.	79%
Employers would NOT have access to the secure health information exchange networks.	68%

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
Individuals would NOT be denied care or penalized financially based on whether they decide to provide certain medical information or choose to participate in a health information exchange network.	72%
An individual's complete health and medical history would be accessible to that person over the internet in a secure account.	53%
Individuals control what information from their medical records is made available through the health information exchange network. For example, an individual with a history of mental health treatment could decide NOT to include information about treatment for that problem.	50%
Independent bodies, accountable to the public, would govern health information exchange, and consumer representatives would participate as full voting members.	38%

PHR Services Today

- 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)

- Longitudinal health tracking tools (charts, graphs)

- Drug interactions checking

- Rx refills

- Financial information, such as Explanation of Benefits

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 when incentivized
- Transactions heavily used
- Specialized products seem to have more user interest

Lessons From Early Adopters

Clinicians

- Physician promotion is key to getting high consumer adoption in most places.

- Physician acceptance requires large up-front efforts to gain buy-in.

- If PHR is viewed as beneficial <u>only</u> to patients, it's hard to get physician support.

- PHR is not likely to be incorporated into clinical workflow without addressing EHR integration.

Lessons From Early Adopters

Patients

- Patient-provider secure messaging, online refills, lab results, medication lists, and disease management plans are among the functions that consumers single out as particularly useful.

- Patient-provider messaging wins over an enthusiastic <u>subset</u> of both patients and doctors, and does not overwhelm the inbox of doctors.

- Patients feel more empowered when they have access to their office chart information, and many early physician adopters find that helpful.

- People with chronic conditions are most likely to need and use PHR-type applications.

The Many Flavors of PHR – c. 2007

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

Creating a Networked PHR Environment that Achieves Sustainable Consumer Confidence

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.*

Individual Consumers Will Need 'Consumer Access Services' 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.

Potential Sponsors of Consumer Access Services

- Affinity groups
- "Retail" PHR providers
- Consumer portals
- Data clearinghouses
- Retail pharmacies
- Health plans
- Provider organizations

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
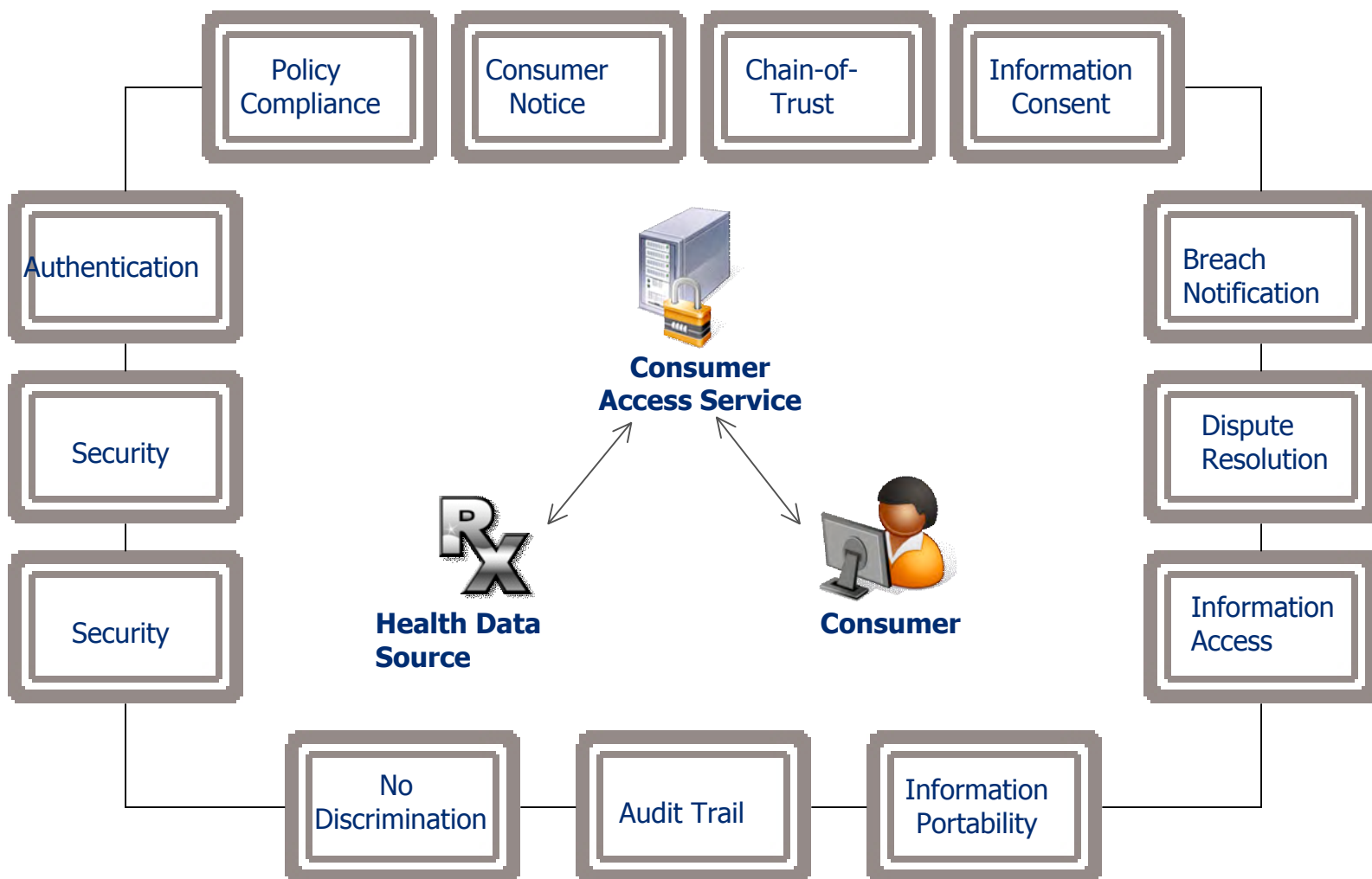
Challenges (continued)

- 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

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

Policy Compliance

Consumer Notice

Chain-of-Trust

Information Consent

Authentication

Security

Security

Consumer Access Service

Health Data Source

Consumer

Breach Notification

Dispute Resolution

Information Access

No Discrimination

Audit Trail

Information Portability

Road to a Networked PHR

- High public interest in PHR features and services coupled with concern about privacy
- Many significant offerings in the works, with risk of creating new information silos
- 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

For more information
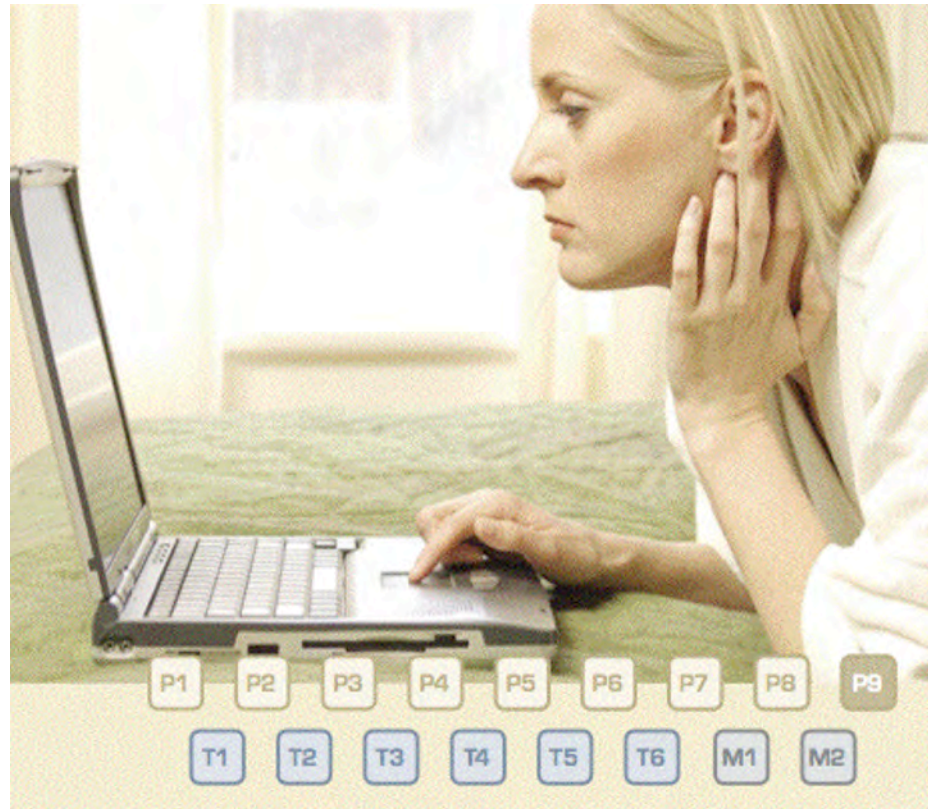
http://www.connectingforhealth.org/commonframework/docs/P9_NetworkedPHRs.pdf