

# **Connecting Americans to Their Health Care:** *Empowered Consumers, Personal Health Records and Emerging Technologies*



**NATIONAL CONFERENCE  
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WASHINGTON, D.C.**

**Connecting Americans to Their Health Care:**  
*Empowered Consumers, Personal Health Records  
and Emerging Technologies*

**2006**

**PHRs 101**

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## Purpose of today's PHR 101 session

- Provide basic understanding of PHRs
- Assess the current landscape
- Understand key stakeholders
- Discuss key barriers
- Explore possible solutions and the future

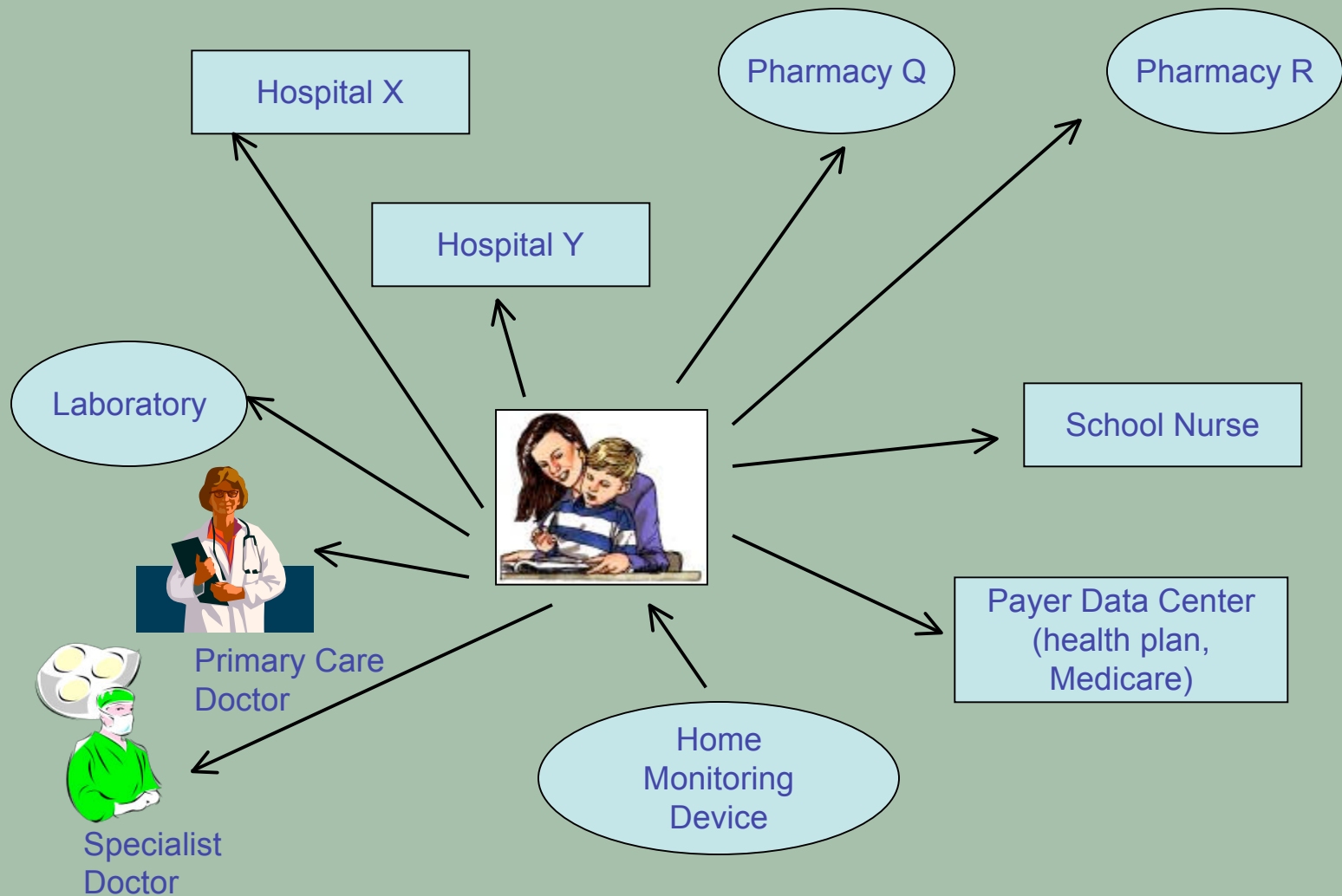
# Examples of consumer-based transformation

- Communications
  - Email, internet calls, cell phones
- Search
  - Google, Yahoo!
- Content
  - Wikipedia, YouTube
- E-commerce
  - Books, travel, real estate, eBay, Craigslist, etc.
- Personal finance
  - Quicken, Online banking
- Entertainment
  - iPod

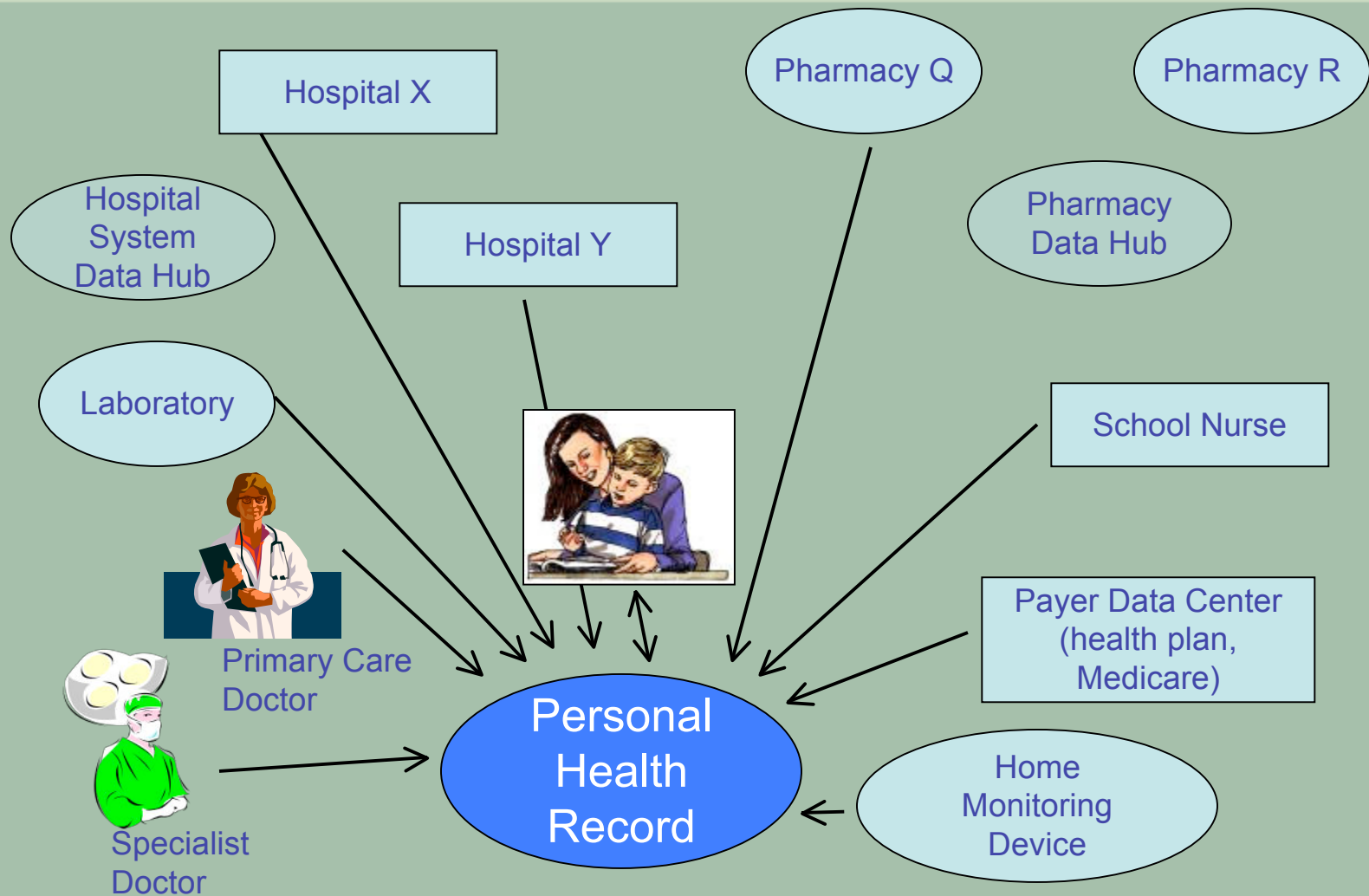
# Consumers can't leverage power of health care networks

- Changes in other sectors rely on a fresh openness toward consumer access to — and contribution of — information
- Yet, health care today is not “networked”
- Consumers go through the “system” one data silo at a time
- And much of the important information remains on paper or in the consumer's head

# Retrieving your health information



# The person as an information hub



# What are personal health records?

- PHRs enable people to **collect, view, manage, or share** copies of their health information or health-related transactions electronically
- PHRs facilitate an individual's ability to track personal health information and services through an application that the individual (or a designee) controls
- Over 100 such applications on the market



## PHRs are *not* EHRs

- Electronic health records are tools for *health professionals*:
  - Designed to improve upon the paper “chart”
  - Clinicians have a legal and professional obligation to maintain patient records
- Personal health records are tools for *consumers*:
  - Consumers have no similar legal obligation to maintain their health information
  - PHRs do not replace EHRs or paper charts
  - PHRs may include copies of data from EHRs

# Common functions of PHRs

- Patient education, self-care content, 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

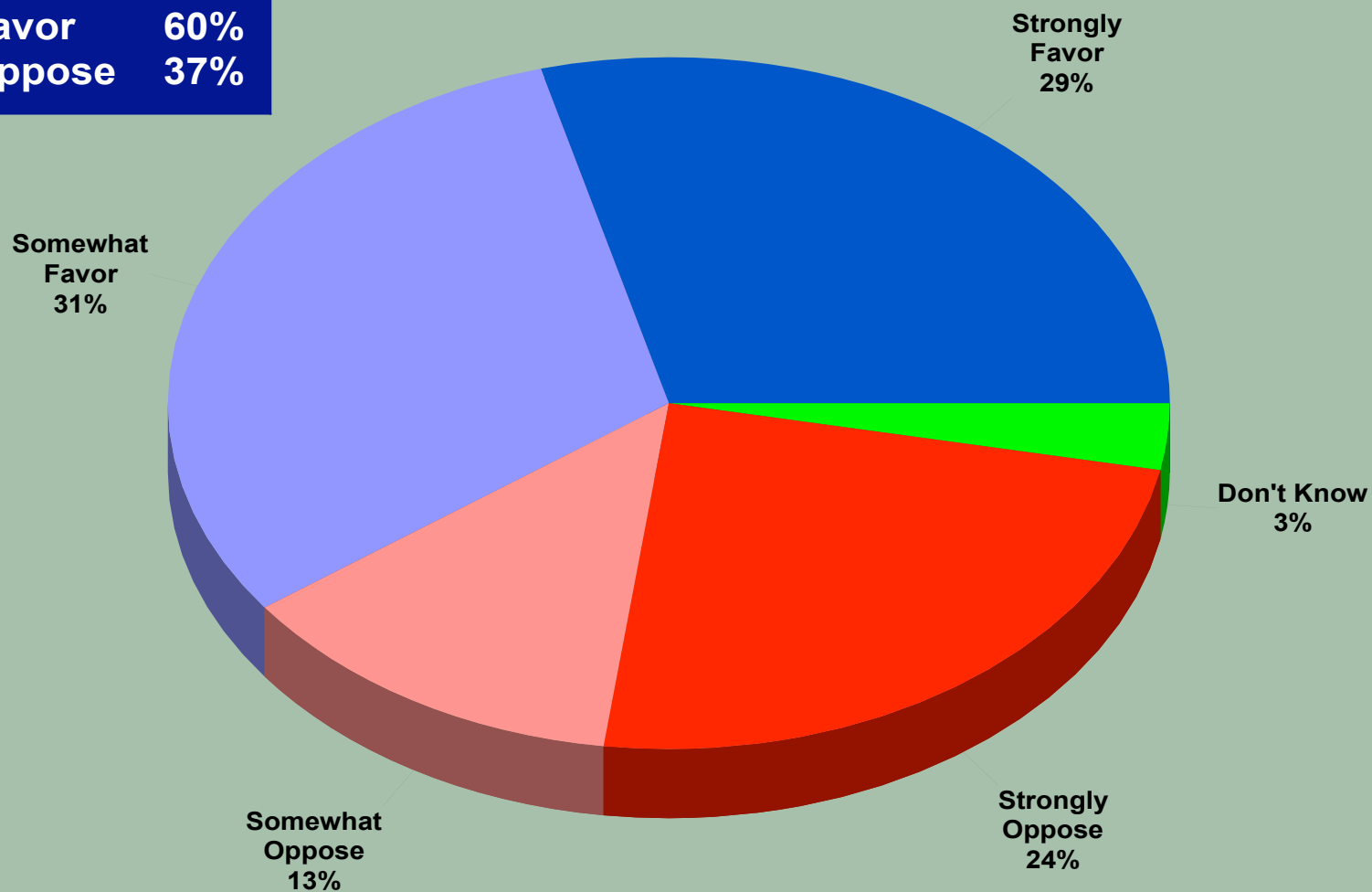
# Consumers want to use information technology to manage their health

Services Tested	% 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%
<b>19%</b> Would not use the service for any of these items.	

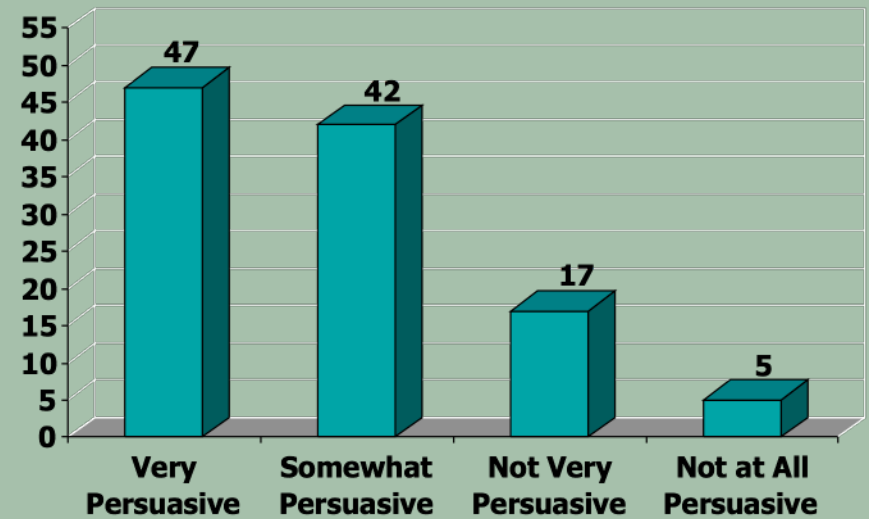
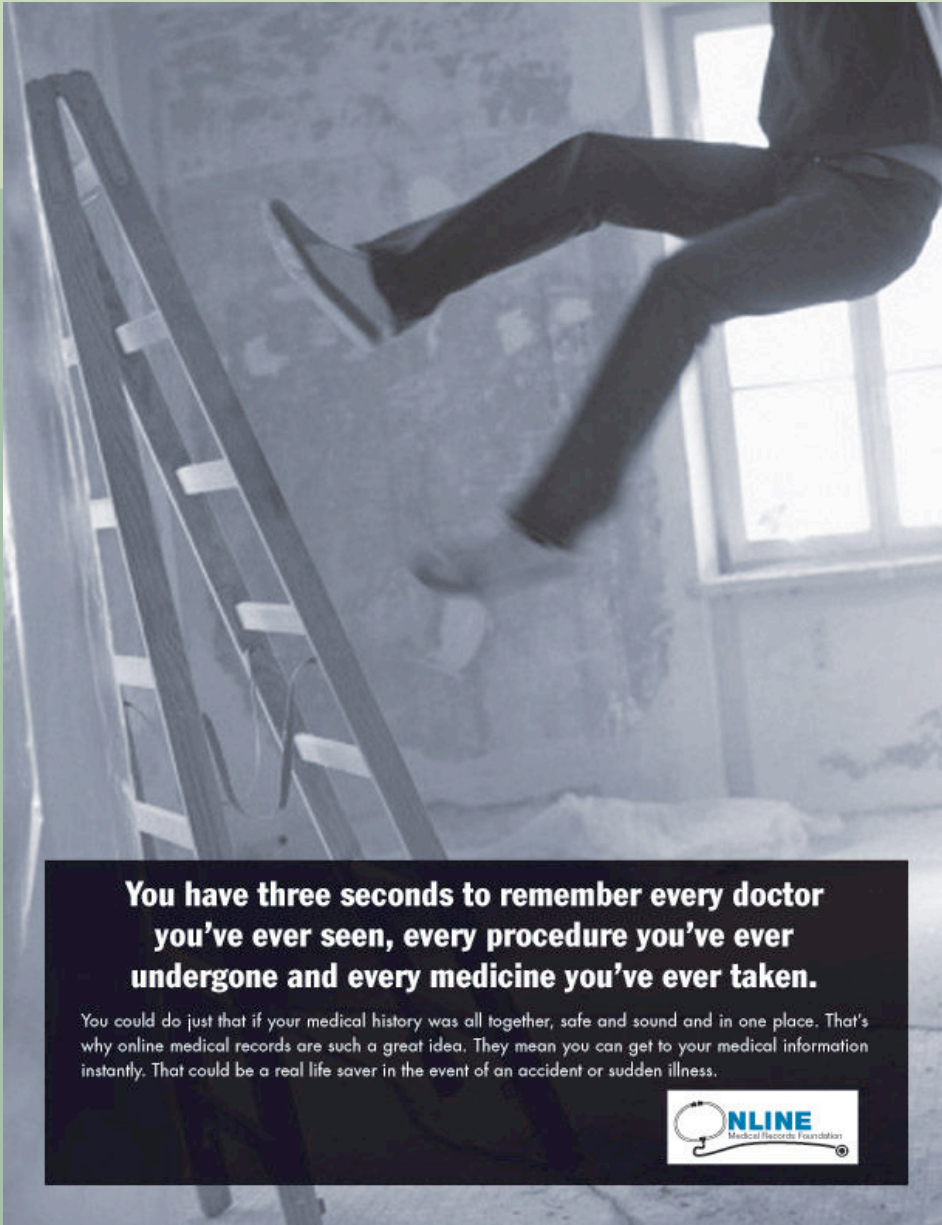
"Now let's imagine that a new secure online service was made available to you allowing you to locate your medical records and view them through your own secure online 'personal health record' account. Now I am going to read you some things this secure online "personal health record" service would allow 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."

# Majority of Americans favor concept of PHR service

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



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



# 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

## Public concerns about PHRs

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

# Maintaining security of PHR data is a public priority

Attribute Statement	% Absolute Top/High 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>

*"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."*



# Attributes of an ideal PHR

1. Controlled by the individual
2. Contain information from one's entire lifetime
3. Contain information from all health care providers
4. Are accessible from any place at any time
5. Are private and secure
6. Are transparent
  - Individuals can see who entered each piece of data, where it was transferred from, and who has viewed it
7. Permit easy exchange of information across health care systems

The Personal Health Working Group Final Report. Connecting for Health, Markle Foundation, July 2003  
URL: [http://www.connectingforhealth.org/resources/final\\_phwg\\_report1.pdf](http://www.connectingforhealth.org/resources/final_phwg_report1.pdf)

# 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

# Consumer- and patient-focused principles

1. Individuals should be guaranteed access to their own health information
2. Individuals should be able to access their personally identifiable health information conveniently and affordably
3. Individuals should know how their personally identifiable health information may be used and who has access to it

Markle Foundation. Personal Health Technology Council letter to Secretary Leavitt, March 6, 2006.  
URL: [http://www.connectingforhealth.org/resources/AHIC\\_Principles\\_PHTC\\_Letter.pdf](http://www.connectingforhealth.org/resources/AHIC_Principles_PHTC_Letter.pdf)

## Consumer- and patient-focused principles (continued)

4. Individuals should have control over whether and how their personally identifiable health information is shared
5. Systems for health information exchange must protect the integrity, security, and confidentiality of an individual's information
6. The governance and administration of health information exchange networks should be transparent and publicly accountable

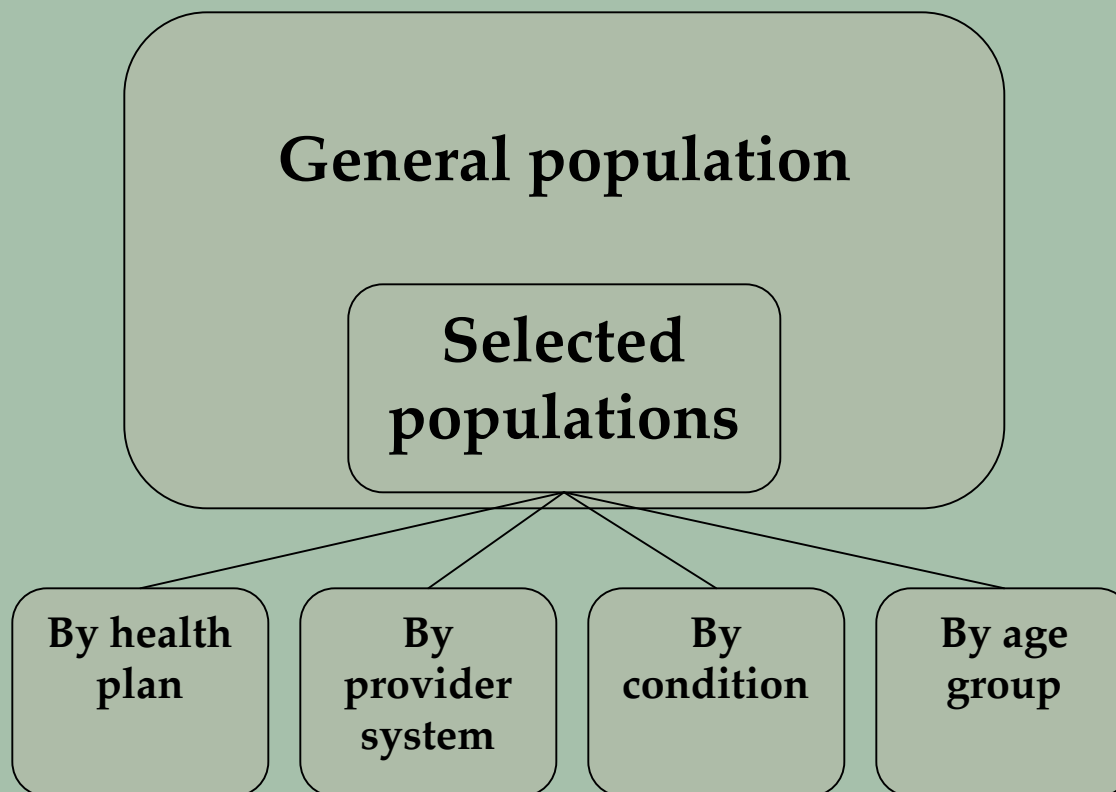
# New Connecting for Health survey

- Results will be released tomorrow

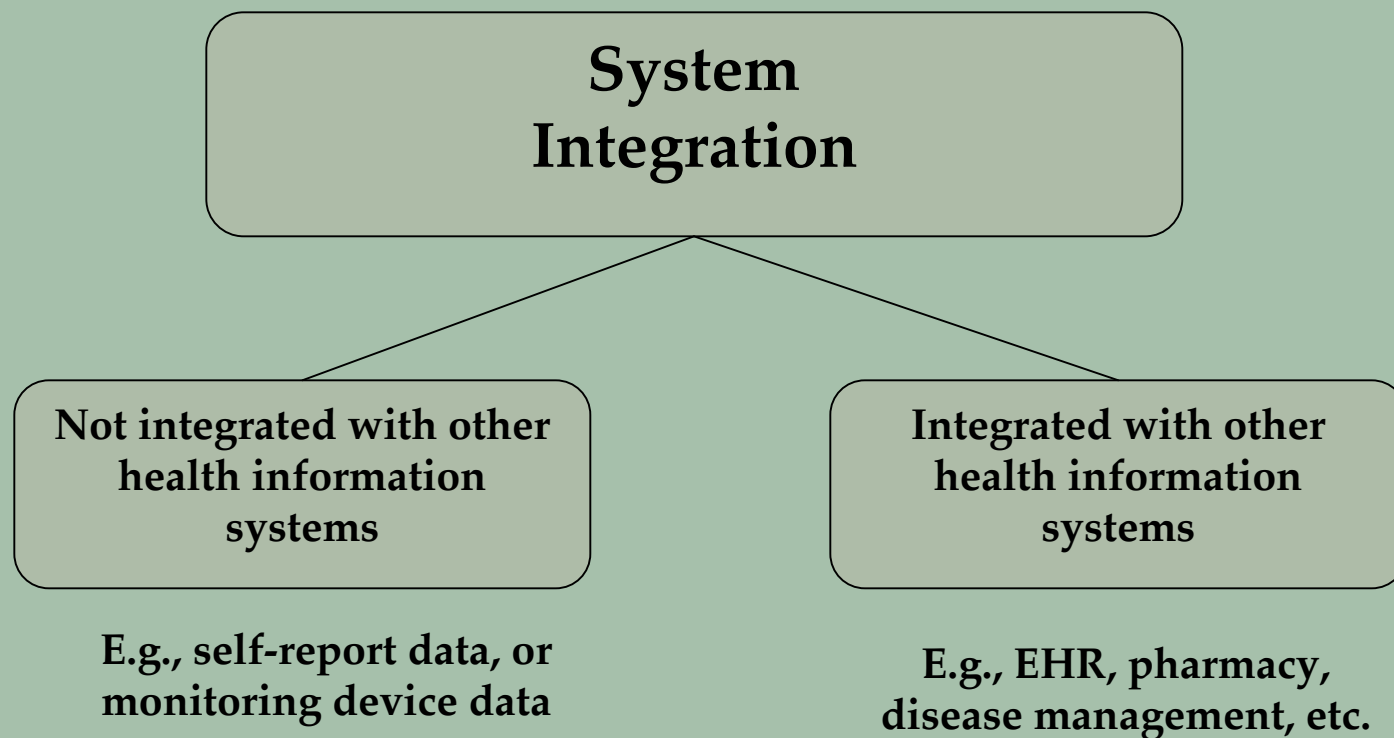
## Six 'dimensions' by which to study PHRs

- *Population* - Who are the targeted users?
- *Integration* - What systems are connected?
- *Data* - What information is stored?
- *Platform* - What type of application is offered?
- *Sponsors* - Who is promoting the application to end users?
- *Business* - What is the financial model or value proposition?

# Who are the targeted users?

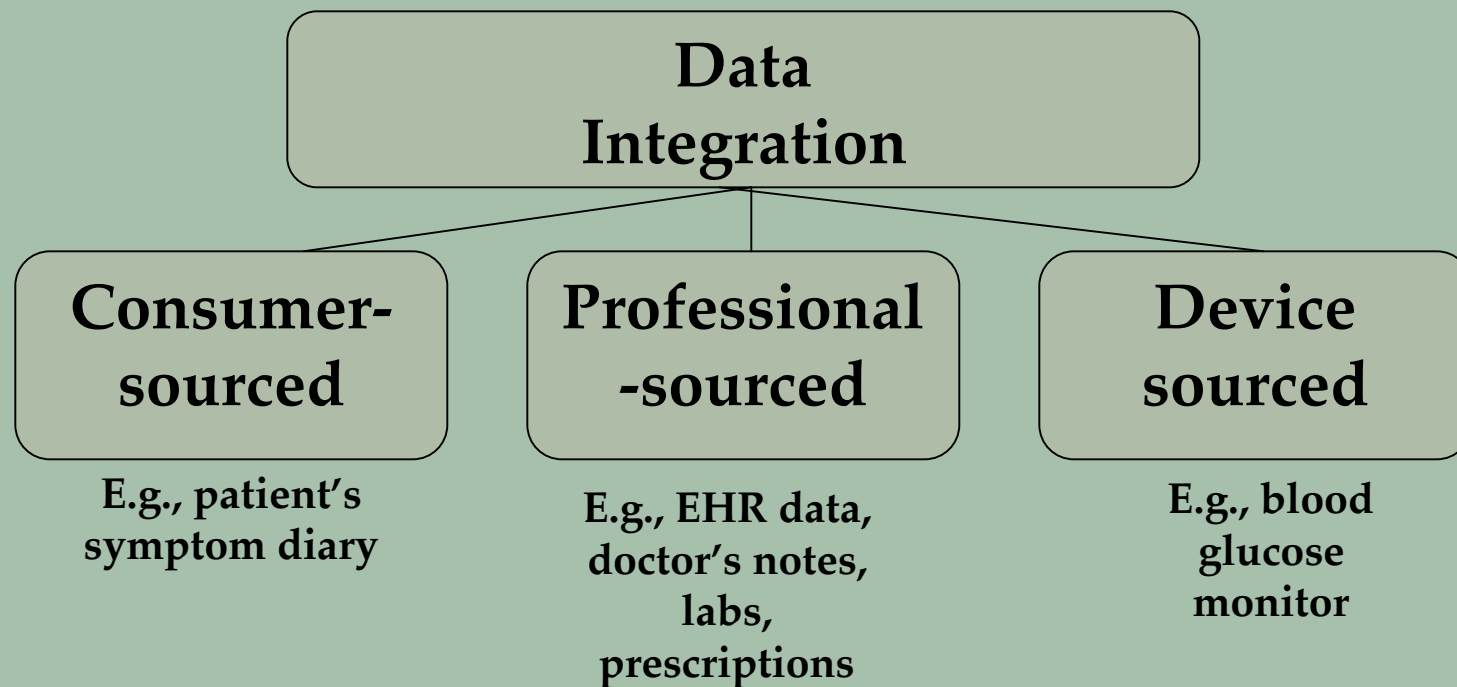


# What systems are connected?

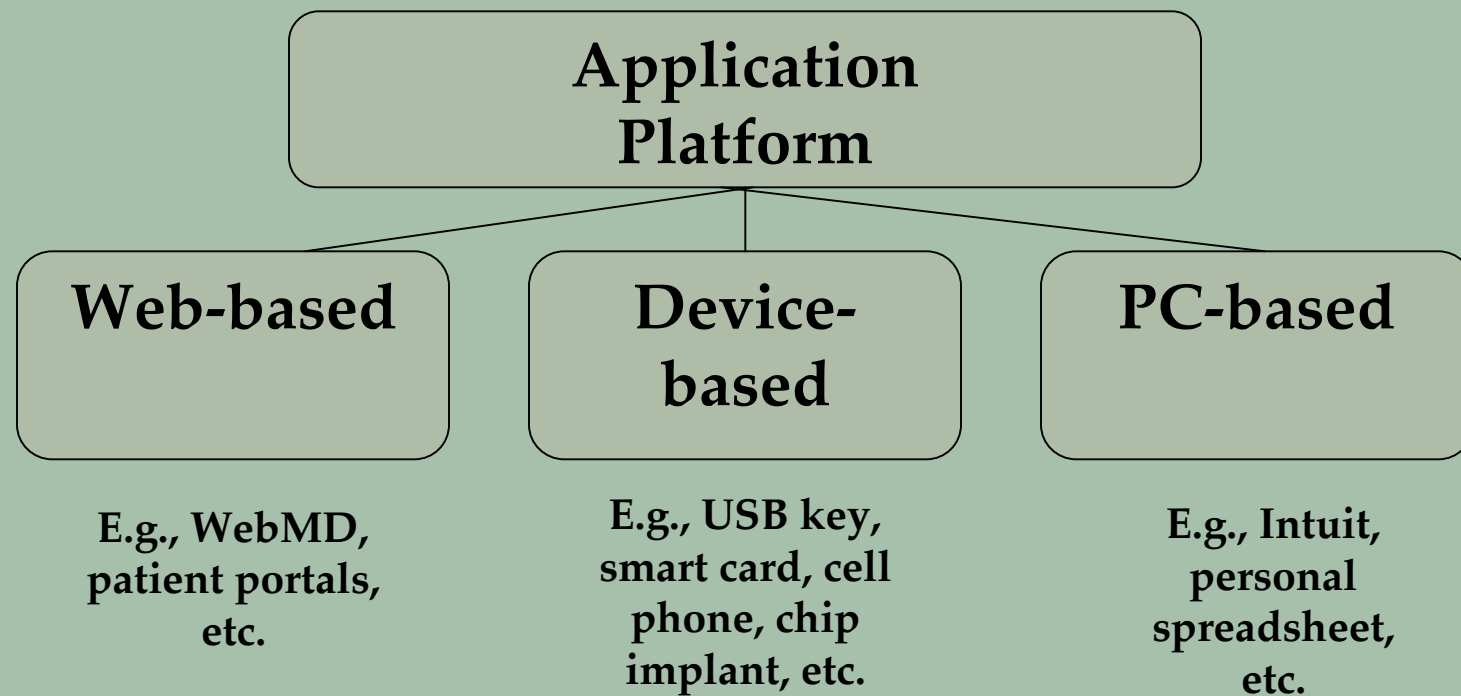




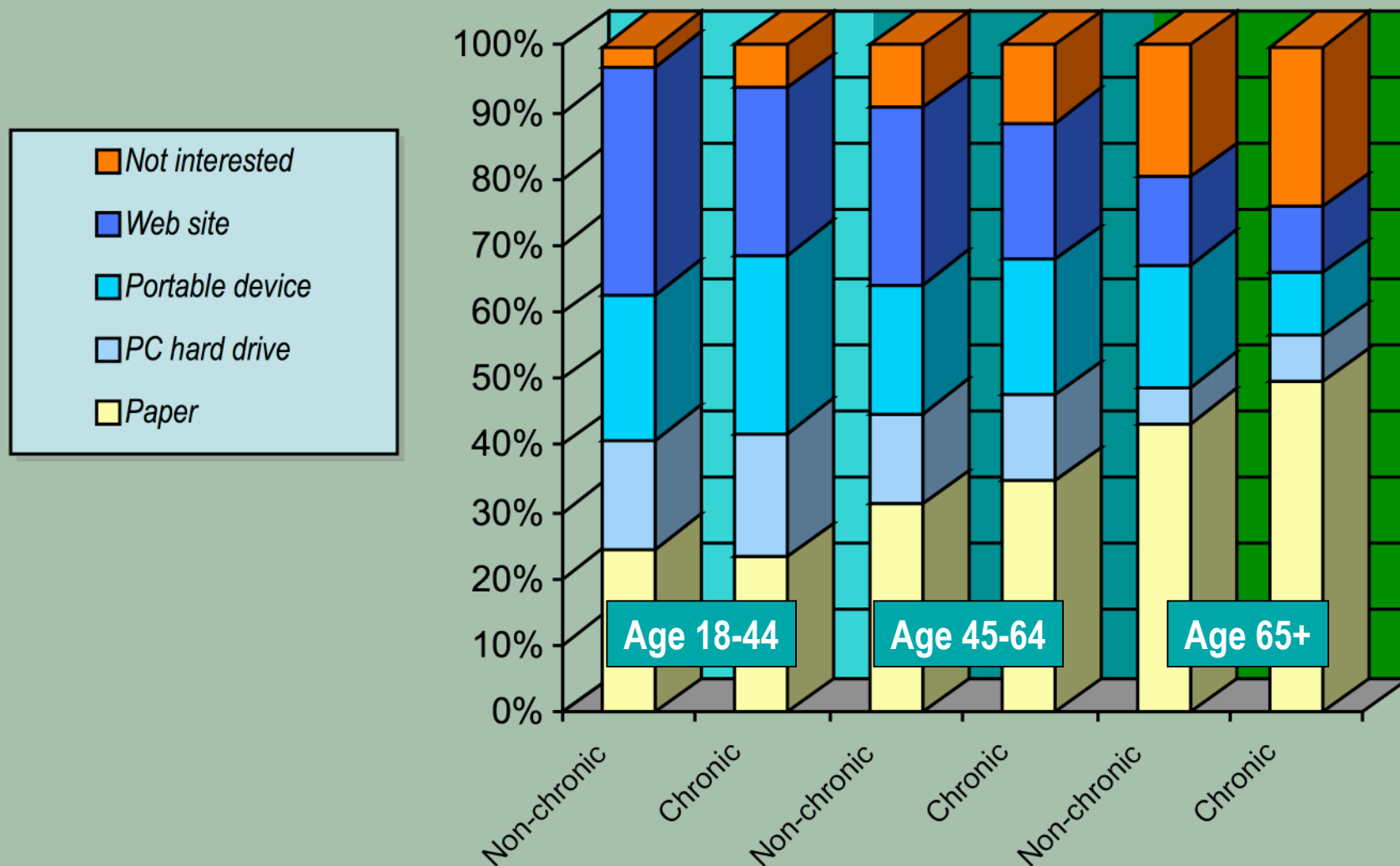
# What information is stored?



# What type of application?



# Heterogeneous preferences for PHR platform



# Who is promoting the application to end users?

## Possible sponsors

Employers

Integrated delivery system

Small practice doctors

Dot-coms

Regional Health Information Orgs

Insurance Plans

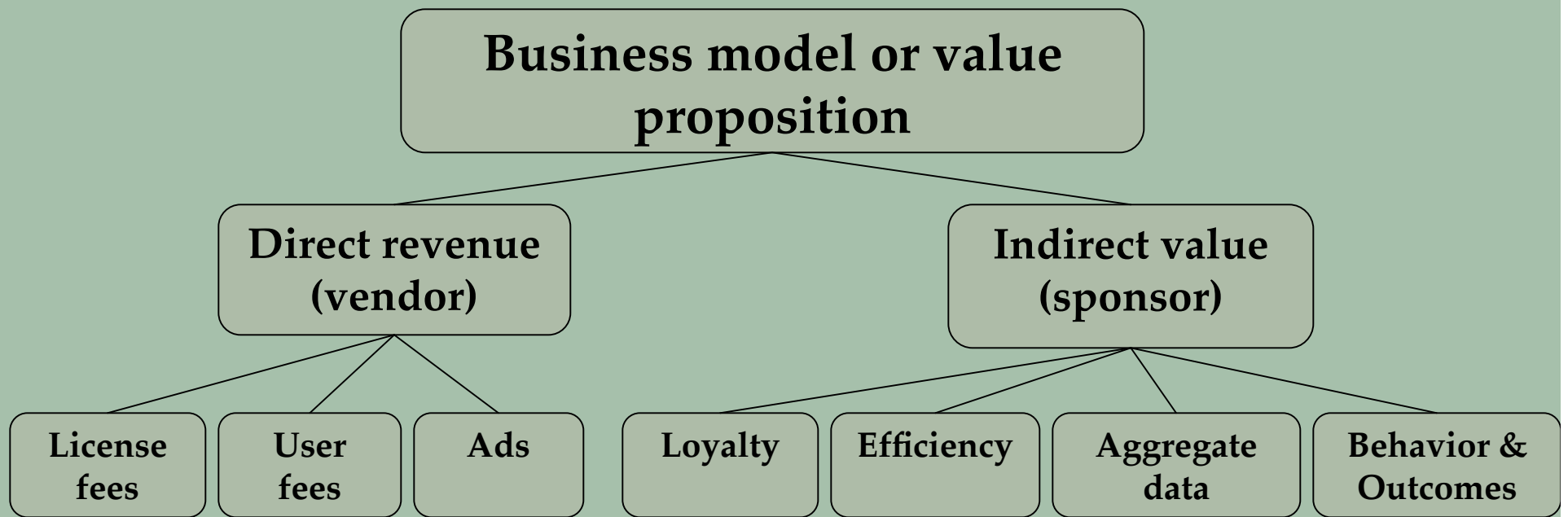
Affinity groups

Pharmacies or PBMs

Disease management or device companies

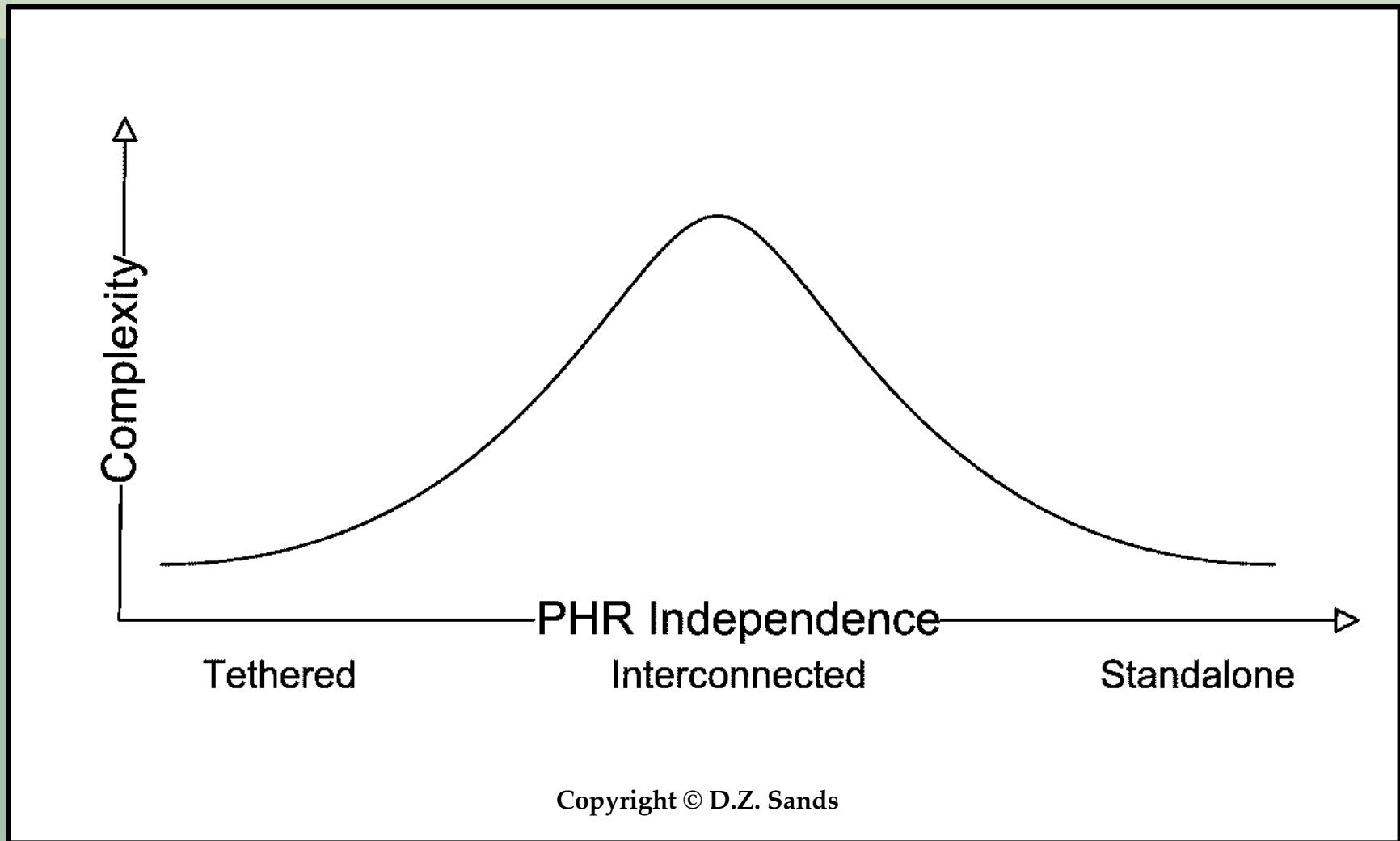
Search engines

# What is the financial model or value proposition?



## Categories not mutually exclusive

- Many existing models are blended
- For example, a PHR can have all three types of data sources or have several different business objectives



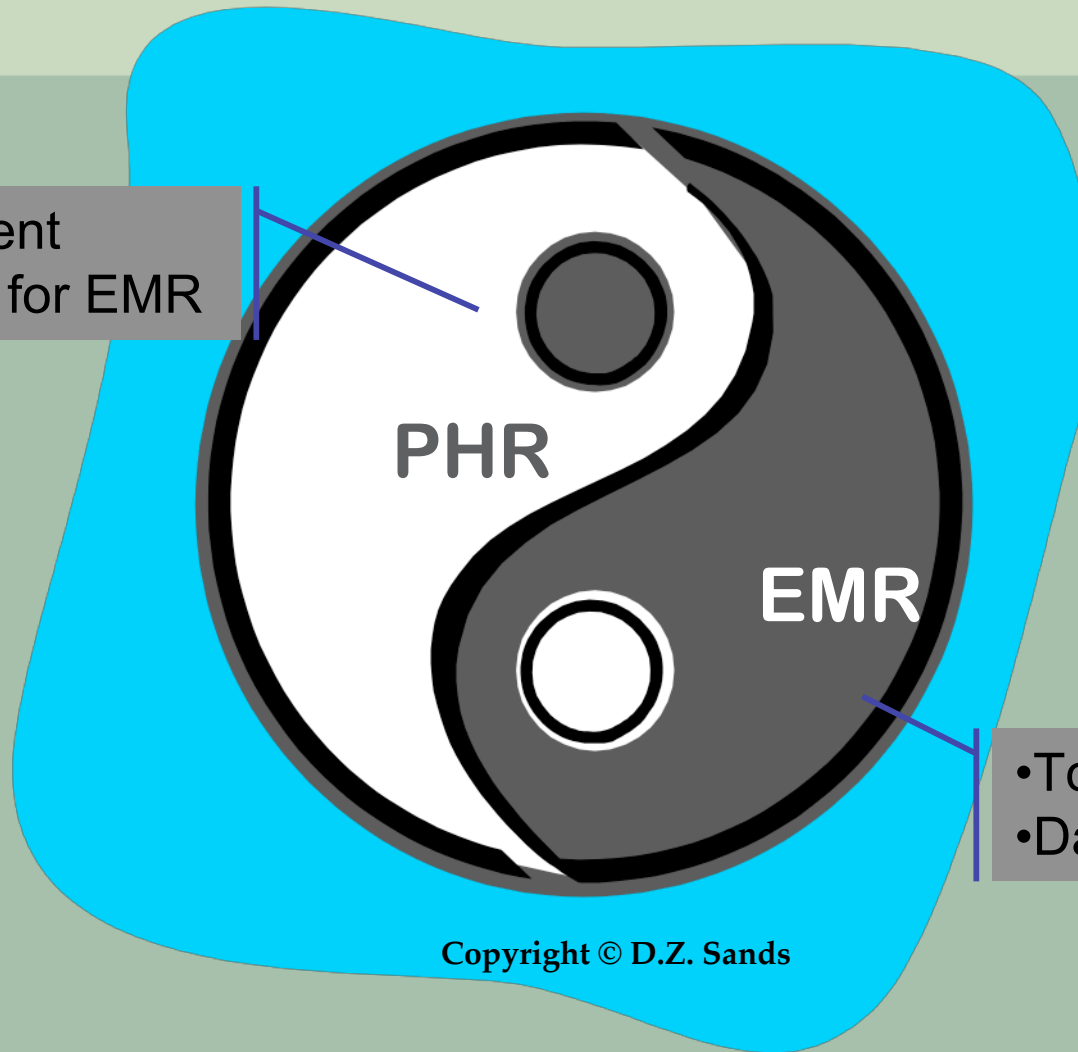
# Type 1: Integrated with EHR

- **Population** - Patients of a practice or health system
- **Integration** - Direct “tether” to EHR
- **Data** - Mostly read-only from EHR
- **Platform** - Web portals
- **Sponsors** - Physicians, health systems, possibly RHIOs
- **Business value** - Loyalty, marketing, service, messaging, behavior, process efficiency



# PHR vs. EHR


- Tool for patient
- Data source for EMR



- Tool for clinician
- Data source for PHR

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Beth Israel Deaconess Medical Center  
**PatientSite**  
 Your Health. Online.

Home 

**Services**

- Mail
- Prescriptions
- Appointments
- Referrals
- Links
- Account Statement

**About Me**


- Records
- Personal Profile

**Support**

- Tech Support
- FAQ / Tutorial

Privacy Policy

• Sign Out

 Help

**Mail:**

- Secure
- Automated routing
- Task assignment

**Services:**

- Prescription refills
- Appointment requests
- Referrals
- View bill

**Records:**

- Secure
- All CG records
- Upcoming appointments
- Meds/Problems/Results...
- Personal records

**Education:**

- Info prescriptions
- Patient selected links
- Predefined collections
- Videos

David Delaney MD have a nice day!  
 John D. Halamka MD-Allergy season is here!

**Learning Center Links**

- [Sleep](#)
- [Sleep](#)
- [General Health Information](#)
- [Children and Child Development](#)
- [Multiple Sclerosis](#)
- [Searching the Literature](#)
- [Womens Health](#)
- [Eye Disease](#)

**General Links**

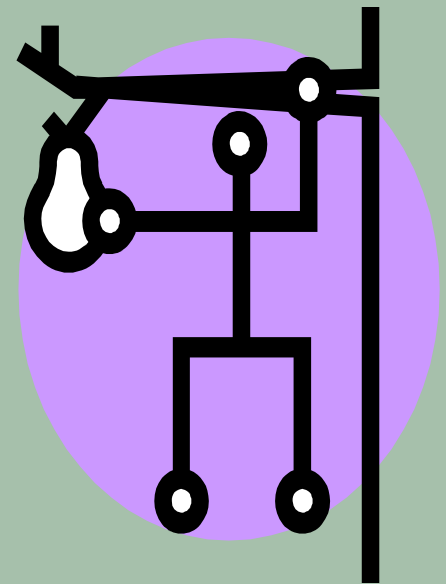
- [David Delaney MD's Web Site](#)
- [John D. Halamka MD's Web Site](#)
- [Find a Doctor](#)
- [Medical Dictionary](#)

## Type 2: Integrated with other health information systems

- **Population** - Members of health care services
- **Integration** - Direct “tether” to a specific service or database
- **Data** - Mostly read-only from specific database, e.g., pharmacy data, claims data
- **Platform** - Web portals
- **Sponsors** - Payers, employers, pharmacy services, software companies, not-for-profits
- **Business value** - Aggregate data, messaging, behavior change, outcomes, impact utilization, process efficiency

# Data strategy: Low-hanging fruit

- Claims data: medications
- Claims data: diagnoses
- Home monitor interfaces
- Immunization registries
- Pharmacies?
- Commercial labs?



# Issues with claims data

- Medications (see MedsInfo-ED experience)
  - Limited history duration
  - No instructions
  - No self-pay
  - No OTCs
  - May require filtering due to legal restrictions
- Diagnoses
  - May not reflect reality
  - May not have secondary diagnoses
  - May require filtering due to legal restrictions
- Tests
  - No results

*Claims data is not perfect...*



*But it can prime the pump*

## Type 3: Independent

- **Population** - General population or specific segments, e.g., diabetes
- **Integration** - Generally little integration with health care entities
- **Data** - Mostly consumer self-reported
- **Platform** - Web portals, devices, PC-based
- **Sponsors** - Software companies, not-for-profits, affinity groups
- **Business value** - User fees, license fees, advertisements, messaging, behavior change

# Accelerators of PHR trend

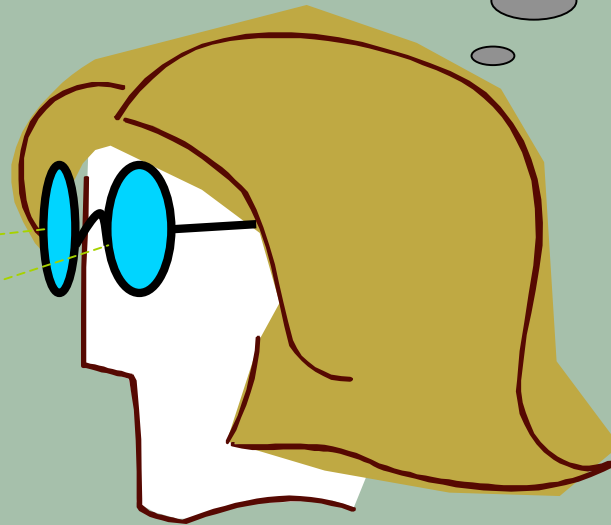
- Internet, digital lifestyle increases information demand
  - E.g., DTC ads, online banking, “Googling,” iPods, wi-fi
- Demographics
  - “Baby Boomers”
  - Chronic diseases
  - “Sandwich Generation” (particularly females)
- Competitive pressures
  - Most big EHR vendors now have a PHR portal product
  - Many health care institutions, payers, and employers now offer PHRs
- Market forces
  - “Consumer driven” plan designs



# Consumer demand limitations and barriers

- Privacy concerns — access by government, plans, employers, marketers, identity thieves, etc.
- Small, diffuse populations with highly specific needs
- Low literacy, poor access to technology, lack of experience with health decision-making
- Limited portability or integration
- Limited patient “control”
- Low awareness and lack of a trusted, transcendent national “brand”
- Low level of public trust in health information services not connected to personal physician.

**Hypertension**

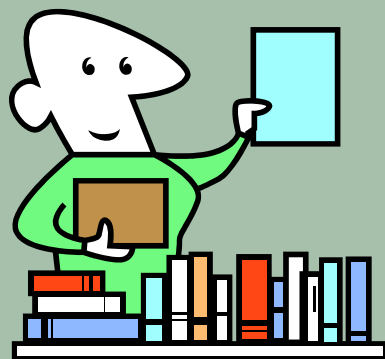


High blood  
pressure

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# Facilitating Patient Understanding



Reference Libraries

The patient's [hypertension](#) is poorly controlled...

*Hypertension* is another name for *High blood pressure*...

Context-sensitive hyperlinks and help

The patient's high blood pressure is poorly controlled...

Automatic Translation (appropriate to patient literacy)

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# Health professional barriers to PHR trend

- Limited number of EHRs with which to connect
- Lack of reimbursement for:
  - Adopting health IT in general
  - For supplying PHR data
  - For incorporating PHR data into practice.
- Workflow concerns
- Liability concerns
- Paternalism and preference for ‘passive’ patients

# Major barriers to consumer health IT in general

- Revenue sustainability still not established
- Data sharing not rewarded
- Inability to locate patient information across multiple care settings.
- Authenticating each individual
- No standards for patient-contributed info.
- Health information is complex
- Lack of an iconic brand or market winner

# Major new initiatives

- Healthcare providers
  - Delivery systems
  - Pharmacies and “retail” services
- Health insurers
  - Individual health plans
  - AHIP / BCBSA
- Government
  - National use cases, AHIC
  - CMS
  - VA
  - Congress

# Major new initiatives

- Regional initiatives & RHIOs
- Employers
  - Intel-led coalition
  - Other major employers (IBM, American Airlines, etc.)
- New entrants?
  - Software companies
  - Consumer organizations

# AHIC “Breakthroughs”

- ↔ Consumer empowerment (medication list and ‘clipboard’)
- ↑ Biosurveillance (data to identify disease outbreaks, bioterror)
- ↔ Electronic health records (lab results)
- ↔ Chronic care coordination (messaging)
- ↑ Quality
- ↓ Privacy, security, confidentiality
- ↔ *Personalized medicine*



# Medication summary

Privacy Policy [Sign Out](#)

## Records of Kermit Frog

[Security Audit] [Help](#)

[BIDMC](#) [MtAUBURN](#) [WEST](#) [MyEntries](#)

[Problems](#) [Meds](#) [Allergies](#) [Visits](#) [Reports](#) [X-rays](#) [Labs](#) [Micro](#)

[Check Drug Interactions](#)

02/22/2000	<a href="#">FOLIC ACID 1 MG PO</a> [#30 R5]	ONE TABLET BY MOUTH EVERY DAY	RIND,DAVID	<a href="#">Refill</a>
03/28/2000	<a href="#">IBUPROFEN 400 MG PO</a> [#40 R0]	ONE BY MOUTH THREE TIMES A DAY AS NEEDED -- TAKE WITH FOOD	MITCHELL,NANCY	<a href="#">Refill</a>
02/22/2000	<a href="#">NITROGLYCERIN 400 MCG (1/150 GR) SL</a> [#100 R2]	ONE UNDER THE TONGUE AS NEEDED FOR CHEST PAIN, MAY REPEAT EVERY 5 MINUTES X 2, THEN GOT TO ER IF PAIN PERSISTS	RIND,DAVID	<a href="#">Refill</a>
08/28/2000	<a href="#">LEVOTHYROXINE 50 MCG PO</a> [#30 R5]	ONE TABLET BY MOUTH EVERY DAY	LOONEY,MAUREEN	<a href="#">Refill</a>
08/28/2000	<a href="#">PREDNISONE 2.5 MG PO</a> [#100 R5]	2 BY MOUTH EVERY MORNING AND ONE BY MOUTH EVERY EVENING	LOONEY,MAUREEN	<a href="#">Refill</a>
02/22/2000	<a href="#">ASPIRIN E.C. 325 MG PO</a> [#30 R5]	ONE TABLET BY MOUTH EVERY DAY	RIND,DAVID	<a href="#">Refill</a>
08/28/2000	<a href="#">FLUOXETINE 10 MG PO</a> [#30 R5]	ONE BY MOUTH EVERY DAY	LOONEY,MAUREEN	<a href="#">Refill</a>
08/28/2000	<a href="#">VERAPAMIL SR 240 MG PO</a> [#30 R5]	ONE TABLET BY MOUTH EVERY DAY	LOONEY,MAUREEN	<a href="#">Refill</a>
08/28/2000	<a href="#">ATORVASTATIN CALCIUM 10 MG PO</a>	ONE TABLET BY MOUTH EVERY DAY	LOONEY,MAUREEN	<a href="#">Refill</a>

# Some of the high priority policy issues

1. Patient notification and consent
2. Authentication
3. Authorization for access and proxies
4. Patient ability to control sharing of data
5. Data standards
6. Data integrity
7. Application requirements
8. Clinician workflow, financial and liability concerns
9. Secondary uses and breaches
10. Consumer awareness and value proposition

# Status of PHRs today

- High public interest in 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:
  - Standards issues
  - Architecture issues
  - Policy issues
- Common policy and technical framework will be essential to achieved "networked" personal health record—and avoid another set of silos

# Charting a path forward

- Each stakeholder must make a commitment to enable portability of personal health data with the consumer in control.
- Organizations should make the data that they hold available — at the consumer's request — to applications offered by other entities, as long as those entities comply with a common set of rules and practices for information stewardship.

# Charting a course forward

- A networked PHR environment cannot be achieved without collaborative efforts and consensus agreements among all stakeholders
- We need to agree on the characteristics of the network and the means by which personal health information will be shared and managed
- We must create an environment of trust and confidence
- Without a common set of policies for information stewardship, even a thousand interesting projects and product offerings are not likely to produce a trustworthy, interoperable PHR

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