



Overview of Personal Health Record Trends and Policy Issues

David Lansky, Ph.D.
Markle Foundation

September 8, 2005

CONNECTING FOR HEALTHSM
MARKLE FOUNDATION *A Public-Private Collaborative*

IOM's Six "Aims" for U.S. Health Care

- ▶ **Safe**—avoiding injuries to patients from the care that is intended to help them.
- ▶ **Effective**—providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively).
- ▶ **Patient-centered**—providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- ▶ **Timely**—reducing waits and sometimes harmful delays for both those who receive and those who give care.
- ▶ **Efficient**—avoiding waste, including waste of equipment, supplies, ideas, and energy.
- ▶ **Equitable**—providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

The “Design Rules” that depend on patients

1. *Care based on continuous healing relationships.*
2. *Customization based on patient needs and values.*
3. ***The patient as the source of control.***
4. *Shared knowledge and the free flow of information.*
5. Evidence-based decision making.
6. Safety as a system property.
7. *The need for transparency.*
8. *Anticipation of needs.*
9. Continuous decrease in waste.
10. Cooperation among clinicians.

Potential of a “personal health record”

- ▶ 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

Already happening in diverse ways

PAMF Online
 Your Direct Connection to Personalized Health Care
 8/30/2005- Welcome, Emily My Chart. (** DEMONSTRATION **) [back](#) [home](#) [log out](#) [help](#) [Exit Demo](#)

My Health Record
[Health Summary](#)
[Recent Visits](#)
[Test Results](#)
[Tests Ordered](#)

Prescriptions
[Renew](#)

Appointments
[Request](#)
[Upcoming/Cancel](#)

Messaging
[Inbox](#)
[Messages Sent](#)
[Archive](#)
[Renew Messaging](#)
[Send Msg to MD/RN](#)

Questions
[Billing](#)
[Non-medical](#)

Change/Update
[Address](#)
[Personal Preferences](#)
[Password](#)

Visit Information
 This page may contain links to external health information websites. This information is a supplement to the consultation provided by your physician and health care team. Linked web pages outside of the PAMF web site are not sponsored or endorsed by PAMF, nor does PAMF guarantee the accuracy of the information contained on them.

Please note that any personal information that you enter when visiting an external website is not covered by PAMF privacy policies.

Date	Time	Clinician Seen Today	Department
11/29/04	11:25 AM	Pam F. Sutter, MD	Los Altos Internal Med

Reason for Visit	Visit Type
Cough	Office Visit

Vitals

Blood Pressure	120/80
Pulse Rate	77/minute
Temperature	100 degrees
Temp Source	Oral
Height	5' 2"(1.575m)
Weight	140 lbs(63.504 kg)

Orders
 CHEST PA & LATERAL
 CBC W/AUTO DIFF

Future Orders	Expires	Expected By
LIPID PANEL	05/31/05	03/31/05

Scheduling Instructions
General Imaging
CHEST PA & LATERAL
 You have been referred to the Radiology Department at the Palo Alto Clinic. The department is located Level A of the Lee building. The department is open from 8:30 a.m. to 5:30 p.m. Monday through Friday. Please visit the department or call to schedule an appointment.
 Palo Alto Main number: (650) 853-2955

Already happening in diverse ways

The screenshot shows a web browser window titled "Home - Microsoft Internet Explorer" displaying a personal health portal for Janet McNichol. The portal has a navigation menu with links for Home, Messages, Community, Diary, Graphs, Reports, Education, and Profile. The "Messages" section is active, showing an "Inbox" with two messages from "ACME Health". A secondary window titled "Messaging - Microsoft Internet Explorer" is open, displaying a message from "Dr. Jones" with the subject "Send a graph or report - Dr. Jones".

Confirm and Send

The following information is exactly as your care provider will see it. Please review carefully, then click 'submit' at the bottom to send. If you need to make changes, click the 'back' button until you get to the part you want to change.

Message from: Janet McNichol

Subject:	Blood Glucose Graph	Patient Age:	53
Date:	6/2/2003 7:37 PM	Patient DOB:	4/5/1950
Patient Phone:		Patient Gender:	Female
Provider:	Dr. Jones		

Question

Dr. Jones, my PHR said that taking my aspirin may cause my blood sugars to go low, and now my blood sugars are low. Should I stop taking my aspirin?

Select date to display: [1/2/2003](#) [1/3/2003](#) [1/4/2003](#) [1/5/2003](#) [1/6/2003](#) [1/7/2003](#) [1/8/2003](#) [All Days](#) [All Days Enlarged](#)

Displaying Glucose Data for : 1/3/2003

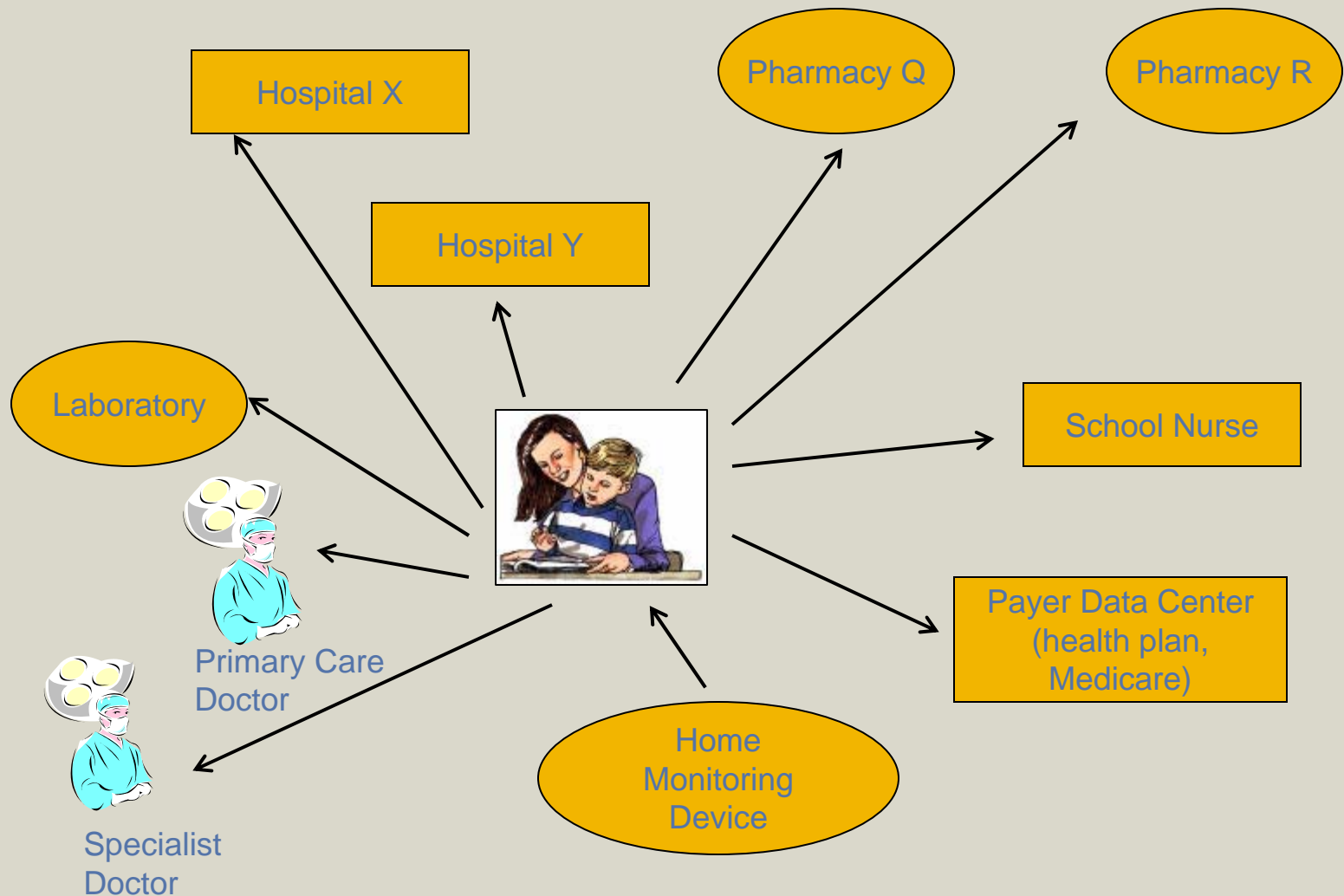
Options:

Legend:

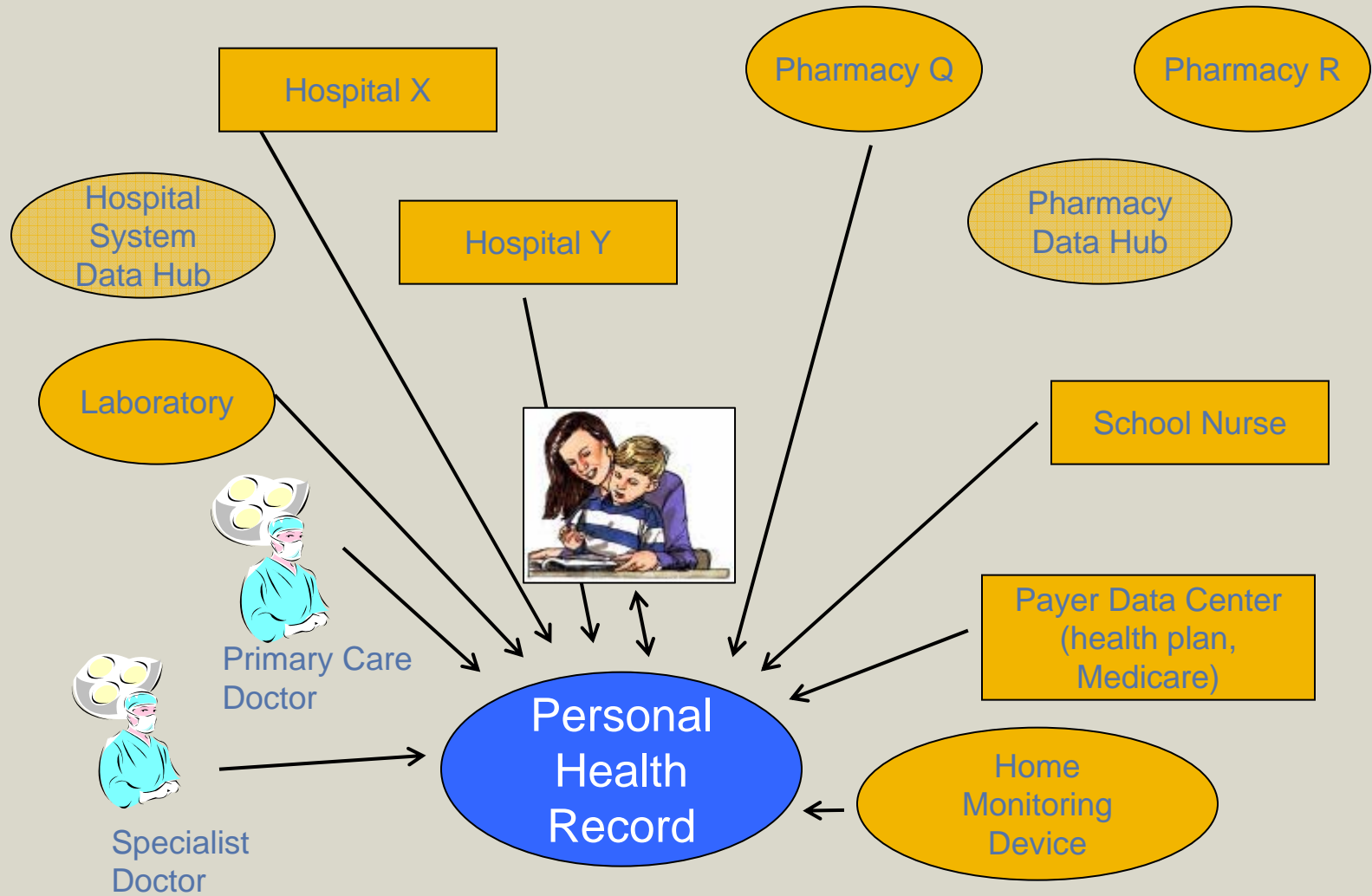
Graph:

Alarm Icons: ■ Elevated Glucose Range > 250 Area of possible sensor error

Retrieving your health information



Having your own information hub



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

Interest in PHR services by online Americans

- Over 70 percent of respondents would use one or more features of the PHR:

Email my doctor	75 percent
Track immunizations	69 percent
Note mistakes in my record	69 percent
Transfer information to new doctors	65 percent
Get and track my test results	63 percent

- Almost two-thirds (65 percent) of people with chronic illness say they would use at least one of the PHR features today, compared with 58 percent of those without chronic illness.
- Thirty-five percent of respondents would use seven or more features of a PHR today if it were available.

Significant concerns about online information

- ▶ Almost all respondents (91 percent) are *very concerned* about their privacy and keeping their health information secure. However, most people believe that technology provides appropriate protections.
- ▶ People who suffer from chronic illness and/or are frequent health care users are less concerned about privacy and security. For example, 41% of the healthy would not want to receive lab results online due to privacy concerns, compared with 36% of those with chronic conditions.

What is a “personal health record”?

- No single answer today
- Some of its attributes:
 - Person 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

The PHR and EHR “Ecosystem” - 2005

- ▶ Slow EHR adoption
- ▶ Slow regional information exchange
- ▶ Slow standards and implementation guide adoption
- ▶ High proportion of standardized, electronic transaction data with national access networks
- ▶ High patient reliance on physician as information source

The PHR Product Environment - 2005

- ▶ **Paper:** Remains the only available or practical means for many people.
- ▶ **Electronic:** We count some 160 products, including:
 - 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, the Internet provides the best potential to update the PHR with information from professionals and institutions.

Major PHR product approaches

▶ **Portals**

- Offered by large provider organizations
- Increasingly common – about 15% uptake rates
- Limited patient-sourced data
- Limited portability or integration
- Limited patient “control”

▶ **Independent, personal tools**

- No major successes
- Migrating towards EHR interoperability
- Specialty audience oriented

▶ **Transaction data-driven**

- Key strategy of health insurance plans
- Some independent PHR models migrating to claims-driven approach

Market accelerators

- ▶ **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
- ▶ **Public policy**
 - Presidential and HHS goals
 - HSAs
 - VA and DoD examples
 - CMS

Market barriers

▶ **Consumer demand limitations**

- Privacy concerns
- Computer skills and health literacy
- Limited portability or integration
- Limited patient “control”
- Low awareness and lack of a trusted, transcendent national “brand”

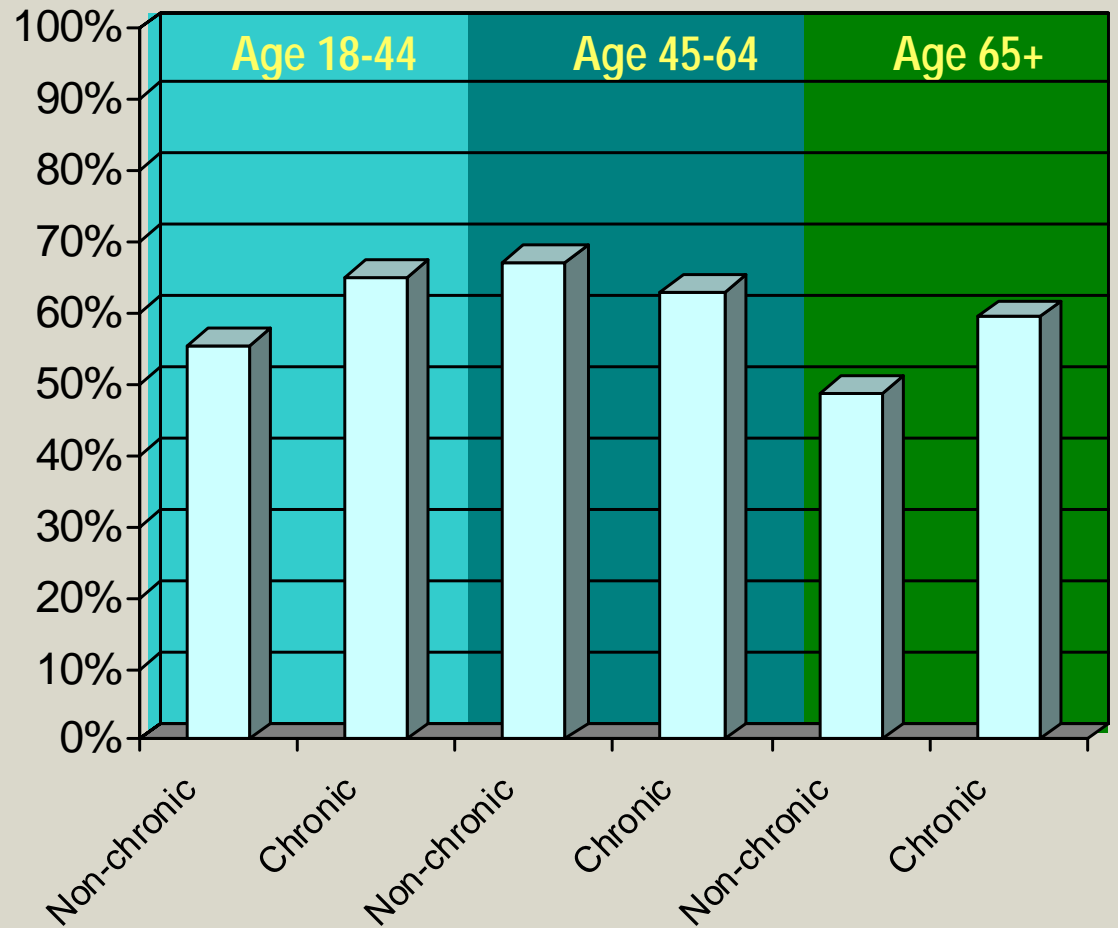
▶ **Physician barriers**

- Lack of EHR
- Lack of reimbursement for supplying PHRs
- Perceived workflow concerns
- Perceived liability concerns
- Traditional paternalism, preference for “passive” patients

▶ **Business models**

- Revenue sustainability still not established

Public attitudes towards PHRs: People overestimate the use of EHR

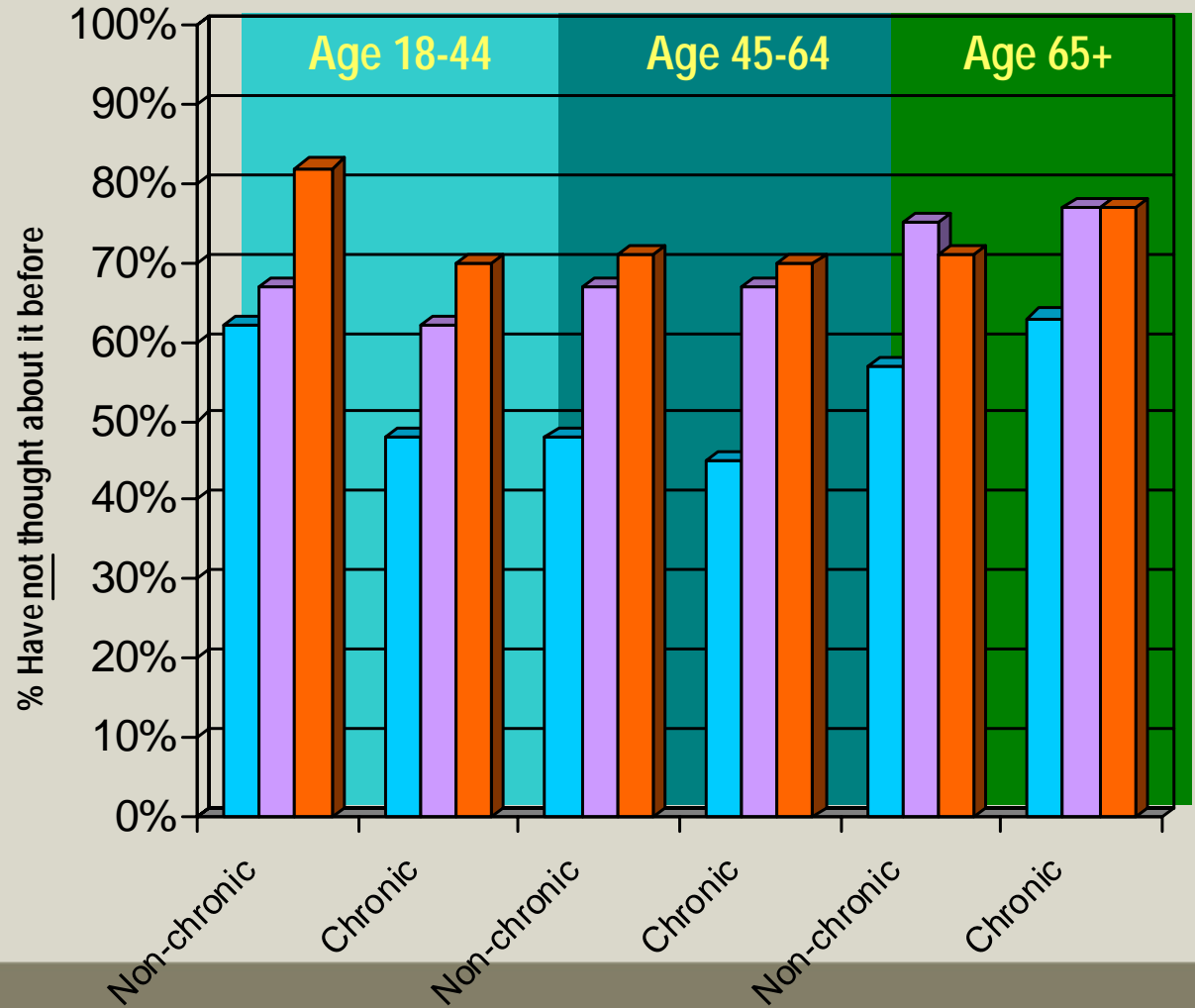


Think your doctor keeps records on computer?

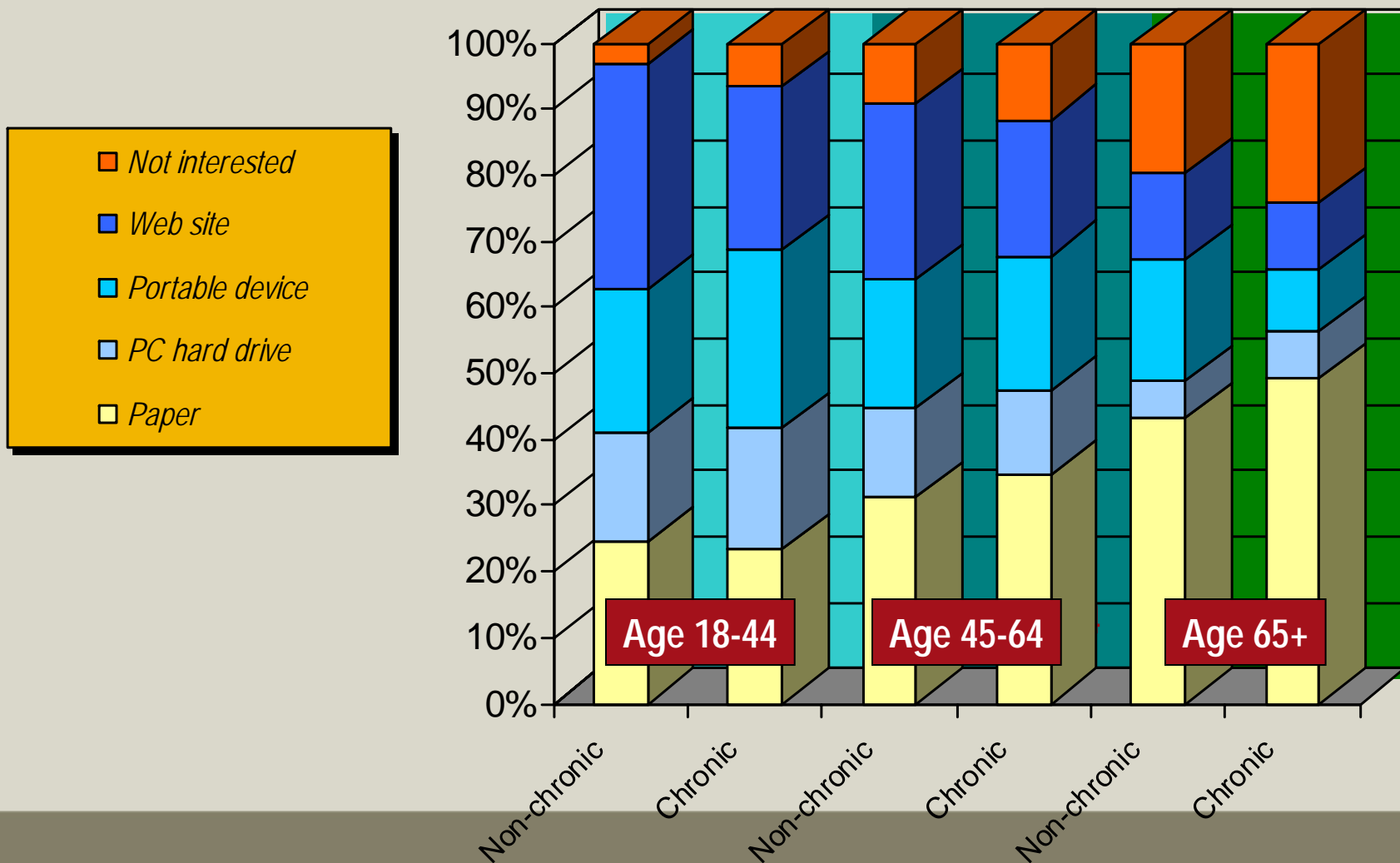
Public attitudes towards PHRs:

Most people have not thought about their health record

- *It's my health information. I should have access to it anywhere, any time.*
- *I'm tired of playing 'telephone tag' with doctors and filling out the same forms. Why can't I do some of this stuff online?*
- *I've often felt the health care system has all the power. Having my own online health record seems to even it out a little bit*



People vary in their preference for PHR media



Research findings about public messaging

- ▶ People have a limited and inaccurate understanding of health information technology issues today. The American public is largely unaware of, but receptive toward, the potential value of PHRs.
- ▶ Most people want convenient access to and control over their health information, and many express a desire to check the accuracy of the records that clinicians keep on them.
- ▶ Most people do want certain healthcare services and information available electronically, particularly when it represents a convenience.
- ▶ The preferred medium of a PHR varies by age, with younger people more receptive to electronic tools and older people more receptive toward paper.
- ▶ People prefer to work with their doctors to access these services.

Policy challenges

- Federal roles in personal health records
- Privacy and HIPAA
- Personal control over health information
- Standards

Rationale for Federal Role in PHR

- ▶ The President has set a national goal of universal “personal electronic health records” within a decade.
- ▶ PHRs are an important tool in achieving the widely espoused health care and public health goals of:
 - patient-centered care
 - greater consumer control and empowerment
 - improved chronic care management
 - fuller translation of the knowledge base.
- ▶ PHRs represent a natural extension of many current federal roles.
- ▶ PHRs provide a new means for achieving federal policy goals.
- ▶ Federal government has unique leadership role, including NHII.
- ▶ Federal government has unique public interest role cutting across market-based health care activity.
- ▶ The need for connectivity (including that between EHRs and PHRs) has been recognized in both policy and health care environments.

Diverse roles for Federal agencies

- ▶ Health care provider: military and veterans; American Indians; provider of last resort (DoD, VA, IHS, HRSA clinics)
- ▶ Payer (CMS)
- ▶ Regulator (FDA, OCR)
- ▶ Researcher (AHRQ, NCI, CDC)
- ▶ Disseminator of the knowledge base (NLM, AHRQ)
- ▶ Public educator (CDC, NLM, ODPHP, AHRQ)
- ▶ Leader, facilitator, policy-setter (ASPE, ONCHIT)
- ▶ Employer (OPM)

The Roles of Federal Agencies in PHR

- ▶ Three forms of federal engagement with PHRs:
 - The PHR extends and enhances current agency activities; a new platform for business-as-usual.
 - The PHR enables new agency roles and activities; the agency moves into new areas with an eye to the wider environment.
 - The PHR is part of implementing a transformational vision for health care and population health.

Emerging issues facing Federal agencies

- ▶ How do anticipated roles in and uses of PHRs relate to **overarching federal, HHS and agency objectives**?
- ▶ What **financial costs** are associated with government assuming different types of responsibilities? How will they be borne?
- ▶ Assuming the existence of **standards** and interoperability, how much consistency and standardization of the PHR model is necessary for 1) the country and 2) government programs? Should government define requirements for PHRs? If so, using what criteria?
- ▶ What particular **privacy concerns** and issues are associated with a federal repository of personal health data, and how should they be addressed?
- ▶ Can/should there be a government-wide stance toward **encouraging innovation** in this field? What would this stance mean for government activity? What is the potential impact of VA, DoD & CMS vendor requirements? How can such requirements serve the public interest?
- ▶ What decisions are needed regarding **regulation and certification**? How will they be made? Should a consensus process be used?
- ▶ **Additional considerations** for federal roles: internal capacity, track record, consistency with agency and wider federal objectives, intra/ and inter-agency coordination, and public and industry trust.

Privacy and HIPAA

- ▶ Privacy is key public concern; trust is essential
- ▶ HIPAA provides framework for analysis and discussion
- ▶ Did not anticipate electronic records or consumer use
- ▶ Emerging questions:
 - Is individual's right to access records an enabler of PHR?
 - Does individual have right to receive record in interoperable formats?
 - How to provide privacy protection where PHR supplier is not covered entity or in business associate relationship with CE?
 - Do HIPAA "personal representative" provisions apply to caregivers and other proxies accessing PHR?
 - Is HIPAA notification and consent meaningful as it applies to PHR?
 - Are "stronger than HIPAA" protections needed for PHR information, e.g., fewer exceptions?

Personal control over health information

- ▶ Markle 2003 survey of on-line Americans:
 - 87% said it was “very important” to be able to control who saw their medical record.
 - 62% said it was “very important” to be able to grant a person access to only parts of their medical record.
 - 25% would not use any electronic health record due to security and privacy concerns.
- ▶ “Control” in the aggregate or at a granular level?
- ▶ “Control” in the context of technical architecture?
- ▶ “Control” and patient safety, physician support?
- ▶ Technical difficulty of implementing “control”
- ▶ Fear of secondary uses: prevention or consequences?

Standards

- ▶ Need foundation of EHR and interoperability standards
- ▶ Enable re-transmission of PHR data across platforms and suppliers?
- ▶ Standards for patient-supplied information?
 - Symptoms
 - Medication use
 - Lifestyle & health behaviors
- ▶ Uniform policies
 - Security of PHR data
 - Privacy policies, including HIPAA-like

Implications for Medicare role in PHR

- ▶ Focus on benefits, not features
- ▶ Prescription drug benefit is opportunity
- ▶ Migrate the portal to become personal medication list
- ▶ Become data supplier to private PHRs by 2008
- ▶ Experiment with authentication, portability, integration issues
- ▶ Educate beneficiaries about:
 - Value of seeing own information
 - Expectation that all providers share info
 - Specific risks associated with medications

Where does PHR policy framework go from here?

- ▶ All parties will benefit from a “roadmap”
 - Including better understanding of the ecosystem
 - Analysis of accelerators and barriers
- ▶ Need to closely watch next generation of innovations
- ▶ Need to seed specific experiments
- ▶ Identify appropriate policy actions
 - Privacy policy
 - Structure for exercising patient control
 - Interoperability and standards
 - Public investment

Potential PHR policy actions

- ▶ The Secretary and/or AHIC designate a public-private panel to design and guide rapid deployment of PHR pilots by CMS and other federal agencies.
- ▶ Employers, plans, FEHB, CMS develop common incentives and contracting clauses that reward doctors who provide PHRs.
- ▶ Broad federal push on medication interoperability, from e-prescribing to patient access to standardized med list protocols.
- ▶ Make PHR-like functionality a requirement for AHRQ, CMS and other federal grants
- ▶ Create awards for state PHR pilots with the Medicaid program.
- ▶ Create PHR certification process.
- ▶ Increase the resources for ONCHIT to coordinate federal PHR activities, with a strong emphasis on public-private collaboration in carrying out this role.

Connecting Americans to Their Health Care:

Empowered consumers, Personal Health Records and Emerging Technologies

- ▶ **October 11 in Washington, DC**
- ▶ **Topics:**
 - PHRs and other emerging technologies
 - Health IT design principles to put more power into the hands of patients
 - Legislative and private sector proposals
 - New research on public attitudes toward health IT



David Lansky, Ph.D.
Dlansky@markle.org

www.connectingforhealth.org

CONNECTING FOR HEALTHSM
MARKLE FOUNDATION *A Public-Private Collaborative*