



Transforming U.S Healthcare: Opportunities and Obstacles

Carol Diamond MD, MPH
Managing Director, Markle Foundation
Chair, Connecting for Health
April 25, 2005

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

The Challenge

Preventable Errors in Hospitals Kill 44,000 to 98,000 People Each Year

- (IOM)

More than 57,000 Americans die needlessly each year because they do not receive appropriate care

- (NCQA)

U.S. Adults Receive Barely Half of Recommended Care

- (McGlynn et al)

U.S. healthcare spending higher, but quality lower, compared with other industrialized countries

One-third of the \$1.6 trillion spent on healthcare each year is wasted on duplicative or ineffective care

- (CECS at Dartmouth)

Why hasn't it happened yet?

- Twenty years of fragmented but noteworthy attempts, with little if any impact
- No organizing force or body existed to change IT policy
- The Institute of Medicine called attention to the problem of medical error and the “Quality Chasm” and called for IT as part of the solution—yet little real impact to date
- No commitment to consumer transparency or control
- Status Quo prevails

Scope of the U.S. Health Care “mess”

- \$1,700,000,000,000 annual spending
- 43 million uninsured (24% of non-elderly workers)
- 60+ million inadequately insured
- Annual medical inflation 4x income (9.8% vs. 2.2%/yr)
- ~100,000 *preventable* hospital deaths/year
- Optimal care provided ~55% of the time
- Knowledge to practice delay ~15 years
- Archaic, inefficient service model

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.

IOM's Ten "Design Rules" for U.S. Health Care

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.

What makes IT a transforming factor in health care?

- Evidence based practice vs. variation
- Communications across fragmented network of providers, patients, families
- Building data resources for evaluation
- Building data resources for continuous feedback and improvement
- Increasing efficient use of increasingly expensive clinical technology: medicines, diagnostics, invasive technologies

Everyone who thinks about this for the first time asks...Why?

- does it take so long?
- do we settle?
- do we continue to tolerate error, waste and inefficiency?
- don't doctors and care providers know about me? (I fill out the clipboard again and again)
- do we pay so much?
- is it so hard?
- do we think about it differently than any other industry?

The Sound Bites

“The health care industry is missing an opportunity, if patients, in order to make sure they get quality care, have to carry files from one specialist to the next. It's like IT, Information Technology, hasn't shown up in health care yet.”

President Bush, in a Conversation on the Benefits of Health Care Information Technology, Department of Veterans Affairs Medical Center

Baltimore, Maryland

April 27, 2004

The Sound Bites

“As paradoxical as it is that advances in medical technology could potentially break our antiquated system, advances in other technologies may hold the answer to saving it. Using a 20th-century health care system to deal with 21st-century problems is nowhere more true than in the failure to use information technology.

Senator Hillary Clinton

“Now Can We Talk About Health Care?”

NY Times, April 18, 2004

Barriers to the Effective Use of IT

- So many...
- Misaligned incentives (piecemeal, service based payment)
- Lack of interoperability
- Privacy and security concerns
- Lack of transparency to the consumer
- Cultural/ Role of the patient and doctor
- Fragmentation of care and information

Scope of the US Health Care “System”

- 300 million people
- 5500 hospitals
- 700,000 physicians – 70% in small groups of < 10
- 2 million nurses
- 1800 health insurers
- 6 million employers
- 50 state Medicaid programs
- EVERY ONE DIFFERENT! NO RULES... no one in charge

Use of Information Technology

- Rapid adoption of clinical technology:
 - Radiology
 - Intensive care units
 - Less invasive surgery (laparoscopic, stents...)
- Business case in Fee-for-service world
 - Increase procedure volumes (angioplasty)
 - Increase service volumes (radiology reading)
 - Reduce operating costs within clinical setting (ICU)

Extent of Clinical IT Adoption

– CDC estimates (3/05)

- Hospital Emergency Depts. 31%
- Hospital Outpatient Depts. 27%
- Physician offices 17%
- Physician CPOE 8%

Where is clinical IT rapidly adopted?

- Significantly...
 - Kaiser Permanente
 - Veterans Health Administration
 - Department of Defense
 - UK National Health Service
- Places where interdependencies are minimized (i.e., narrow silos without need for information exchange)
- Places where liabilities are minimized

Where are we headed?

Alternative Futures

“It's tough to make predictions, especially about the future”

Yogi Berra

- The alternative futures are simplified versions of the extremes
- They force us to think through what happens as we change the environment
- In reality things fall on a continuum but isolating events that change the environment fundamentally alter strategy, policy and operations
- We focused on 2 variables that would change—IT and funding/incentives

High Standards Adoption
and Interoperability



Low Standards Adoption and
Islands of Data

Alternative Interoperability States

- Low
 - Low standards adoption
 - Variable interpretation of standards
 - Little infrastructure for interchange (identity, security, etc.)
 - Difficult or expensive interoperability
- High
 - Widespread adoption of standards
 - Uniform implementation of standards
 - Existing infrastructure for interchange
 - Low cost, low hassle interoperability (“out-of-the-box”)

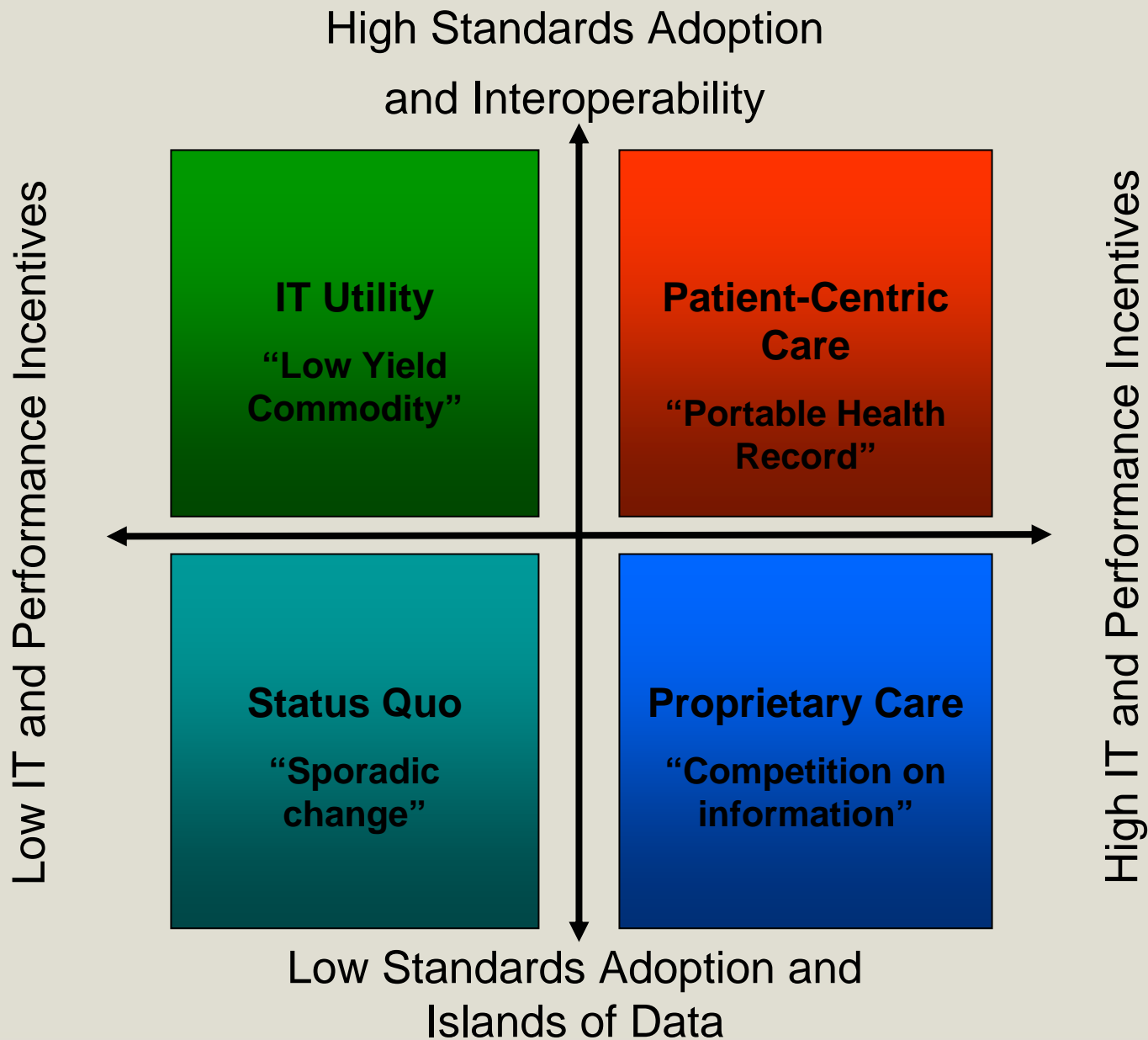
Low IT and Performance Incentives



High IT and Performance Incentives

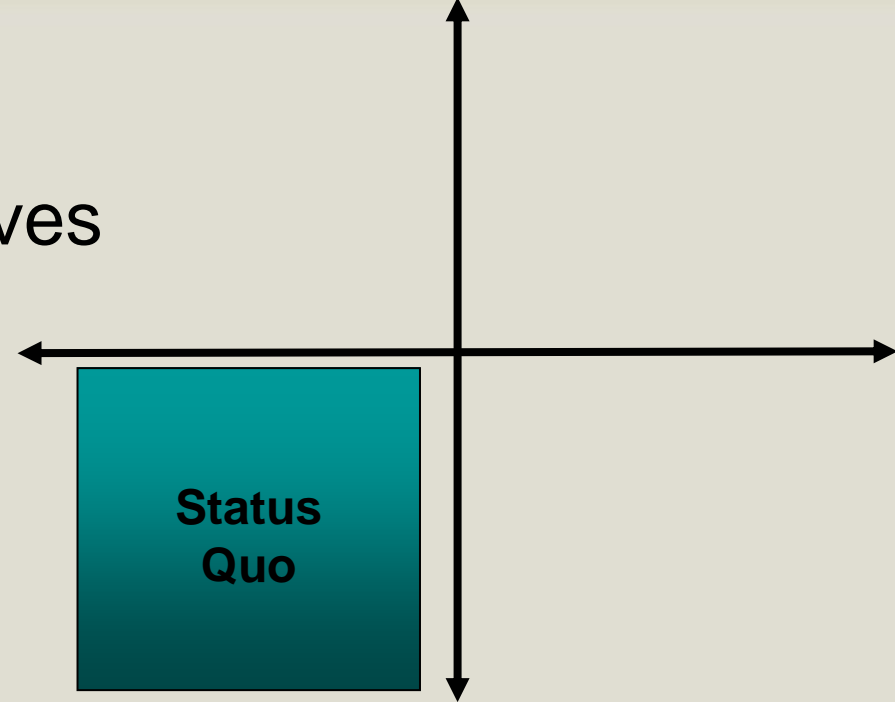
Alternative Funding States

- Low
 - Volume-based
 - Heterogeneous
 - Decapitalized payments
- High
 - Stimulate IT adoption with financial incentives
 - Group purchasing
 - Revolving loan funds
 - Increase reimbursement for CPR
 - Increase incentives for connectivity
 - Pay-for-performance programs to include stretch goals that interoperable IT can uniquely generate



Status Quo:

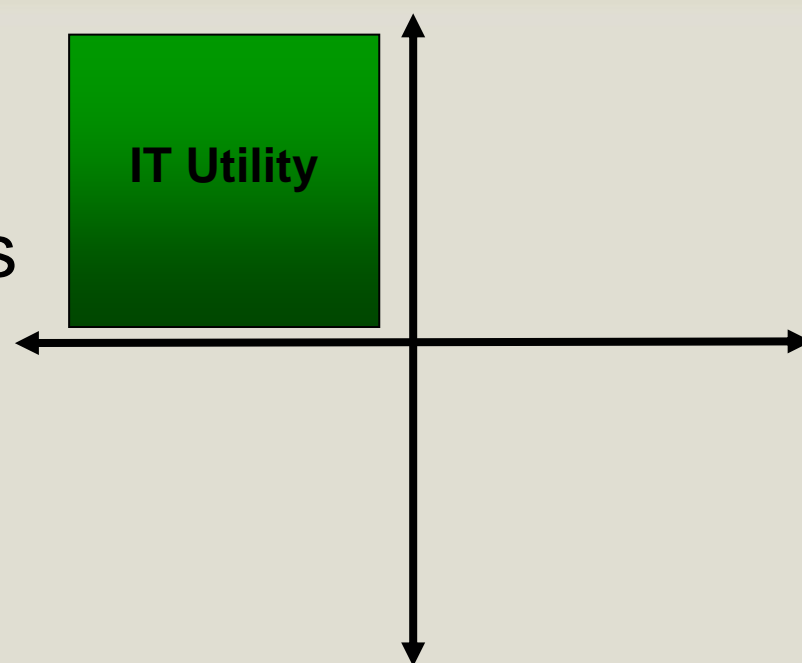
Low standards, low incentives



- Some data standards exist, adoption is voluntary and unrewarded.
- Payment primarily to individual providers for episodes of clinical service without incentives for quality or outcome.
- Rate of IT adoption remains inconsistent, concentrated primarily among large integrated systems.
- Sharing of electronic clinical data almost non-existent outside integrated systems.
- Inadequate capability to measure quality of care or outcomes.
- Limited ability for consumers to access their personal health care information or conveniently provide information to providers

IT Utility:

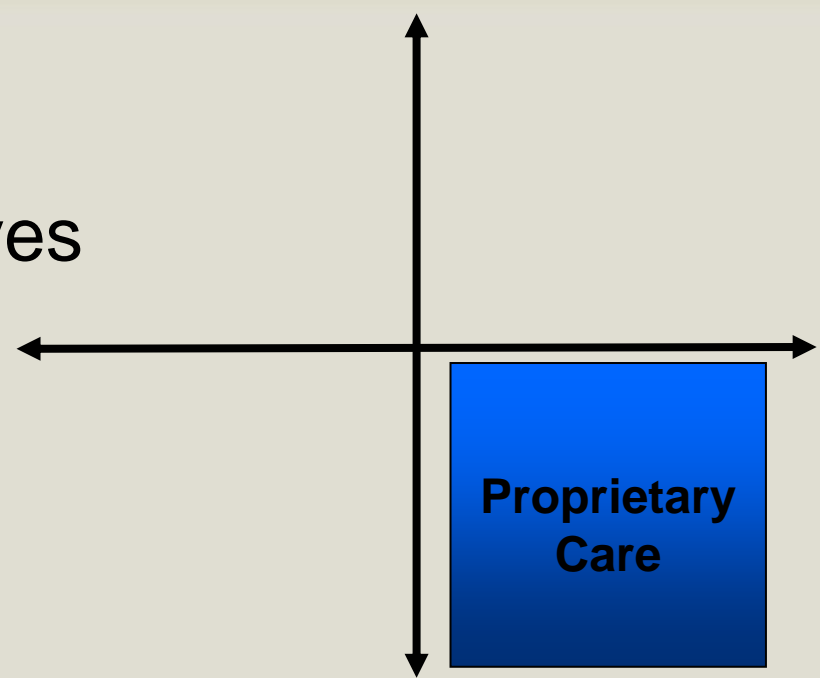
High standards, low incentives



- Governments require adoption of uniform data standards and systems but current payment systems are unchanged.
- Payment provides neither explicit nor implicit support for IT acquisition and standardization.
- Improved potential for care coordination, but few economic incentives for changes in staffing, care management models.
- Technology success, but care delivery remains little changed

Proprietary Care:

Low standards, high incentives



- Payment promotes IT adoption only.
- No change in standards, data exchange and interoperability.
- Consumers/ patients cannot have their personal health information integrated as they move about the system.
- IT vendors compete without data standards to rationalize market
- Health care data is institution-based and compartmentalized
- Provider components face high costs of information exchange

Patient-Centric Care:

High standards, high incentives

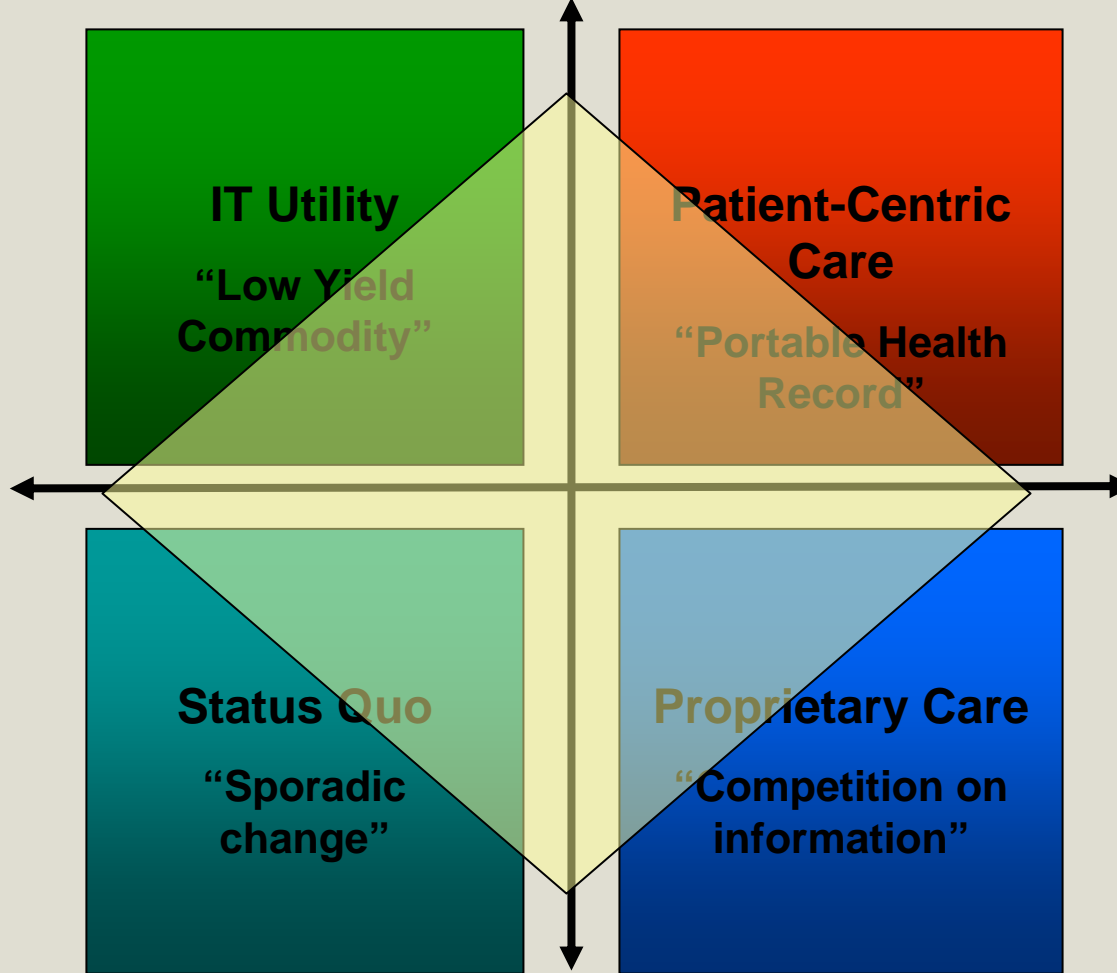


Patient-Centric Care

- Payment rewards IT, interoperability and performance.
- Standards and interoperability are basic features of applications and other information tools including adoption of digital patient identification technology, data standards. Requires public and professional confidence in the privacy and security of the network.
- Patients or agents expect access and control personal information across network, within established community “rules”
- Widespread point-of-care access to patient data for authorized users
- IT vendors compete on implementation, features, cost, service excellence

High Standards Adoption
and Interoperability

Low IT and Performance Incentives



High IT and Performance Incentives

Low Standards Adoption and
Islands of Data

What Needs to Happen?

What is *Connecting for Health*?

- Broad-based, public-private coalition
- More than 100 collaborators
 - Providers
 - Patients
 - Payers
 - Accreditors
 - Government agencies
 - Researchers
 - IT systems manufacturers
- Founded and supported by **Markle Foundation**, with additional support from **Robert Wood Johnson Foundation**
- See www.connectingforhealth.org

The Interoperability Assumptions

- A future of better, more efficient care can be accomplished through “dynamic connectivity” that allows information to move
 - Where it’s needed
 - When it’s needed
 - In a private and secure manner
- Achieving this goal will require public and private sector collaboration
- A ‘roadmap’ is needed to chart the course

Eight Key Areas of Roadmap Recommendations

1. Engaging the American Public

5. Data Standards

2. Designing for Privacy & Security

6. Clinical Applications

3. The Infrastructure—technical architecture & approach

7. Funding & Incentives

4. Accurate Linking of Patient Information

8. Legal Safe Harbors



Three areas of focus:

1. Technology Standards and Adoption
2. Policy Framework for Successful Implementation
3. Role of the Consumer

Three “Legs of a Stool”

Design Principles of the *Connecting for Health Model*

- Designed to safeguard privacy—imposed the requirements and then designed the functional architecture
- Built without a national patient ID
- Leverages both “bottom-up” and “top-down” strategies
- Builds on existing systems (“incremental”) and creates early value for doctors and patients
- Consists of an interoperable, standards-based “network of networks” built on the Internet
- Patient information remains where it is now and is not kept in a central database (“decentralized”)
- Data-sharing initiatives have local autonomy but follow certain ***standards and policies*** to enable interoperability (“federated”)

The System Should...

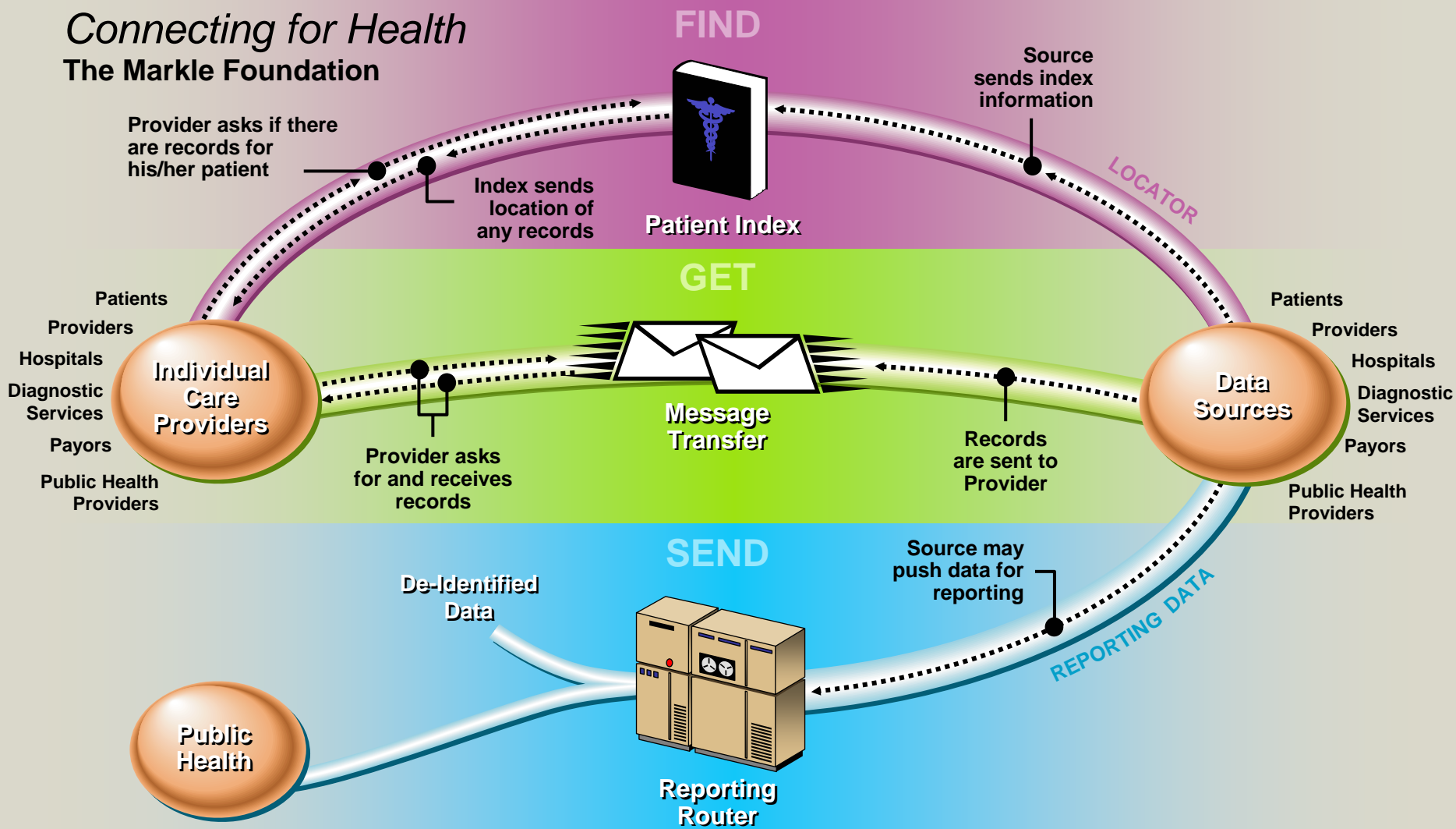
- Provides several layers of security
- Separates 'knowing that' from 'knowing what'
- Leaves the data in local hands
- Leaves privacy controls in local hands
- Allows for variable tech savvy of participants!!
- **Requires** accurate mechanism for matching patient data from disparate sources without relying on a unique patient identifier.
- Learn from and perform at least as well as currently implemented master patient index systems
- Set high thresholds for error

The Roadmap does NOT recommend ...

- A national patient identifier number
- A single proprietary solution
- A single centralized database
- A massive new government program
- A “one-size-fits-all” mandate
- A “rip-and-replace” overhaul

The architecture supports point of care information sharing and population-based reporting

Connecting for Health The Markle Foundation



Source: © 2004 The Markle Foundation. Graphic adapted from Tom Benthin original.

The Collaborative Response to the ONCHIT RFI on NHIN--Participants

1. American Health Information Management Association (AHIMA)
2. American Medical Informatics Association (AMIA)
3. American National Standards Institute-Healthcare Informatics Standards Board (ANSI HISB)
4. Center for Information Technology Leadership (CITL)
5. Connecting for Health (CFH)
6. eHealth Initiative (eHI)
7. HIMSS EHR Vendor Association (EHRVA)
8. Healthcare Information and Management Systems Society (HIMSS)
9. Health Level Seven, Inc. (HL7)
10. Integrating the Healthcare Enterprise (IHE)
11. Internet2
12. Liberty Alliance
13. National Alliance for Health Information Technology (NAHIT)

Element #1: An environment, not a network

U.S. can create an *environment* with specific characteristics, so that any appropriate and authorized entity can participate in information sharing – a doctor, an individual, a pharmacy, a hospital, a public health agency.

Element #2: *A Common Framework*

This environment will be enabled by general adoption of a set of specific, critical tools, including technical standards for exchanging clinical information, explicit policies for how information is handled, and uniform methods for linking information accurately and securely.



Privacy Policy

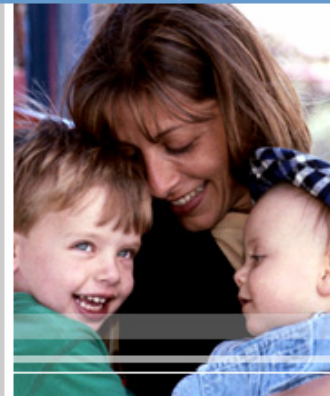
(Last updated 01/04/05)



Protecting privacy is always a ChoicePoint priority. To underscore our fundamental commitment to privacy and our vision that good privacy is good business, we have adopted an online privacy policy for each of our Web sites: www.choicepoint.com, www.choicepoint.net and www.choicepointinc.com. This policy reflects and implements---in an online setting---our corporate privacy principles and Fair Information Practice Principles of notice, choice, access, security, and accountability.

This online privacy policy applies to choicepoint.com, choicepoint.net and choicepointinc.com, which are operated by **ChoicePoint Inc., 1000 Alderman Drive, Alpharetta, GA 30005**, privacy@choicepoint.com, (877) 301-7097. This site is not directed at children. Please note, this policy does not apply to the following subdomains that have their own privacy statements posted: www.findnewcustomers.choicepoint.com; www.minimizebusinessrisk.choicepoint.com; www.employeebackgroundcheck.choicepoint.com.

To demonstrate our further commitment to online privacy, ChoicePoint is a licensee of the TRUSTe® Privacy Program. TRUSTe is an independent, non-profit organization whose mission is to build users' trust and confidence in the Internet by promoting the use of fair information practices. TRUSTe's certification covers the Web sites gathering and dissemination of information not any services or products. We have disclosed the information practices of our Web site to TRUSTe, and TRUSTe has reviewed and approved our online privacy practices for compliance with TRUSTe's online privacy standards. If you have questions or concerns regarding this statement, you should first contact us at:



ChoicePoint Inc.
Office of Privacy Compliance
1000 Alderman Drive
Alpharetta, GA 30005
Telephone: 877.301.7097
Fax: 770.752.5939
Email: privacy@choicepoint.com

If you do not receive acknowledgment of your inquiry or your inquiry has not been satisfactorily addressed, you should then contact TRUSTe at www.truste.org/consumers/watchdog_complaint.php. TRUSTe will then serve as a liaison to resolve your concerns.



Privacy Policy

(Last updated 01/04/05)



Protecting privacy is always a ChoicePoint priority. To underscore our fundamental commitment to privacy and our vision that good privacy is good business, we have adopted an online privacy policy for each of our Web sites: www.choicepoint.com, www.choicepoint.net and www.choicepointinc.com. This policy reflects and implements---in an online setting---our corporate privacy principles and Fair Information Practice Principles of notice, choice, access, security, and accountability.

This online privacy policy applies to choicepoint.com, choicepoint.net and choicepointinc.com, which are operated by **ChoicePoint Inc., 1000 Alderman Drive, Alpharetta, GA 30005**, privacy@choicepoint.com, (877) 301-7097. This site is not directed at children. Please note, this policy does not apply to the following subdomains that have their own privacy statements posted: www.findnewcustomers.choicepoint.com; www.minimizebusinessrisk.choicepoint.com; www.employeebackgroundcheck.choicepoint.com.

To demonstrate our further commitment to online privacy, ChoicePoint is a licensee of the TRUSTe® Privacy Program. TRUSTe is an independent, non-profit organization whose mission is to build users' trust and confidence in the Internet by promoting the use of fair information practices. TRUSTe's certification covers the Web sites gathering and dissemination of information not any services or products. We have disclosed the information practices of our Web site to TRUSTe, and TRUSTe has reviewed and approved our online privacy practices for compliance with TRUSTe's online privacy standards. If you have questions or concerns regarding this statement, you should first contact us at:

ChoicePoint Inc.
Office of Privacy Compliance
1000 Alderman Drive
Alpharetta, GA 30005
Telephone: 877.301.7097
Fax: 770.752.5939
Email: privacy@choicepoint.com

If you do not receive acknowledgment of your inquiry or your inquiry has not been satisfactorily addressed, you should then contact TRUSTe at www.truste.org/consumers/watchdog_complaint.php. TRUSTe will then serve as a liaison to resolve your concerns.

INFORMATION COLLECTION



ChoicePoint Data Cache Became a Powder Keg Identity Thief's Ability To Get Information Puts Heat on Firm

By Robert O'Harrow Jr.

Washington Post Staff Writer

Saturday, March 5, 2005; Page A01

The man on the phone called himself James Garrett.

Speaking with a lilting accent, the man said he was an executive with a Los Angeles company called M.B.S Financial. He told an employee at ChoicePoint Inc. that he wanted to open an online account with the company to receive electronic reports on people.

It was the kind of request that ChoicePoint, one of the nation's largest information services, gets all the time. Thousands of corporate and government clients rely on the company to provide them with publicly available information on people for help in hiring, fraud

enlarge photo



Element #3: A Standards and Policies Function must exist to make the decentralized environment work

This Standards and Policy Function must develop a toolkit for basic and necessary standards and policies for health information. It must be uniformly adopted, and developed in a way that reflects public and private sector participation, is transparent, accountable, and operates in the public interest.

Element #4 – Record Locator Service (the only novel piece of infrastructure)

New indices that indicate where patient information is stored must be created, particularly within geographic regions. These “Record Locator Services” must be standardized and able to link to other indices that are not regional, such as Medicare, VA, national health plans, public health networks, etc.

Accurate Linking...Our Journey

- Linking of patient information for high-quality care can and should be done without a National Health ID
 - National ID is not a magic bullet—it's just another identifier and would be difficult and costly to implement even if available
 - Political culture in U.S. is not amenable to national identifier
 - Risk of privacy spills is a significant disadvantage
 - No single identifier can be relied on (survey)
- Linking is accomplished by directories pointing to the sources of the records
 - The directory system knows where the records are, not what is in them
 - Patients determine locally with their providers what information to link and disclose, and to whom

Element #5 – *patient control*

To merit the trust of the public, people must have significant personal control over the sharing of their information. The system must also ensure that providers have the information they need to provide high quality, safe care.

Element #6 – *financing and incentives*

1. The national health information environment is funded from both public and private sources.
2. Federal funding is needed to launch the national Standards and Policy Function; and to provide seed grants and for Record Locator Services and regional start-ups.
3. Both should receive private support over time and be self-sustaining.
4. Adoption of compatible IT by end-users (e.g., doctors, pharmacies, hospitals) will be stimulated by incentives built into routine payment that are tied to the use of the Common Framework.

The Role of the Consumer

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

What is a “Personal Health Record”?

- No good 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

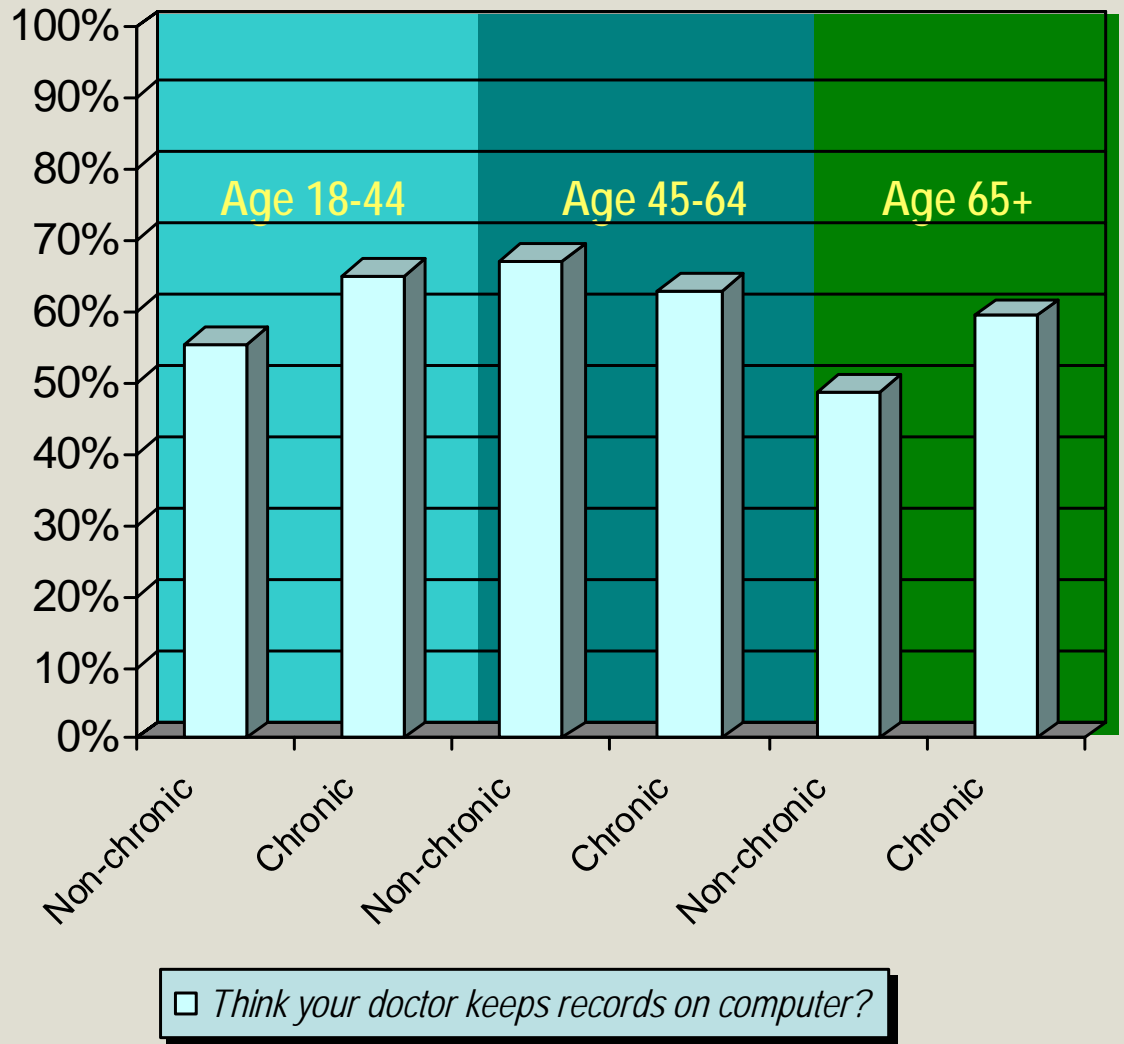
Current state of PHR deployment

- Principal interest by caregivers, frequent health system users (chronic illness, elderly), computer savvy
- Primarily offered as portal by large delivery systems
 - Loyalty marketing
 - Offering only a 'view' of EMR
- “Un-tethered” PHRs not proving viable

Can consumers help us get there? ...

- Need for increased public understanding of the value of connectivity in healthcare
- CFH research has found low awareness of health IT issues ...
 - 50 percent to 75 percent of Americans have not thought about a more connected healthcare system
- But a high receptiveness toward specific services that health IT could offer
 - 75 percent want to email their doctor
 - 69 percent want to track immunizations and check the accuracy of their clinical chart

People overestimate the use of EHR

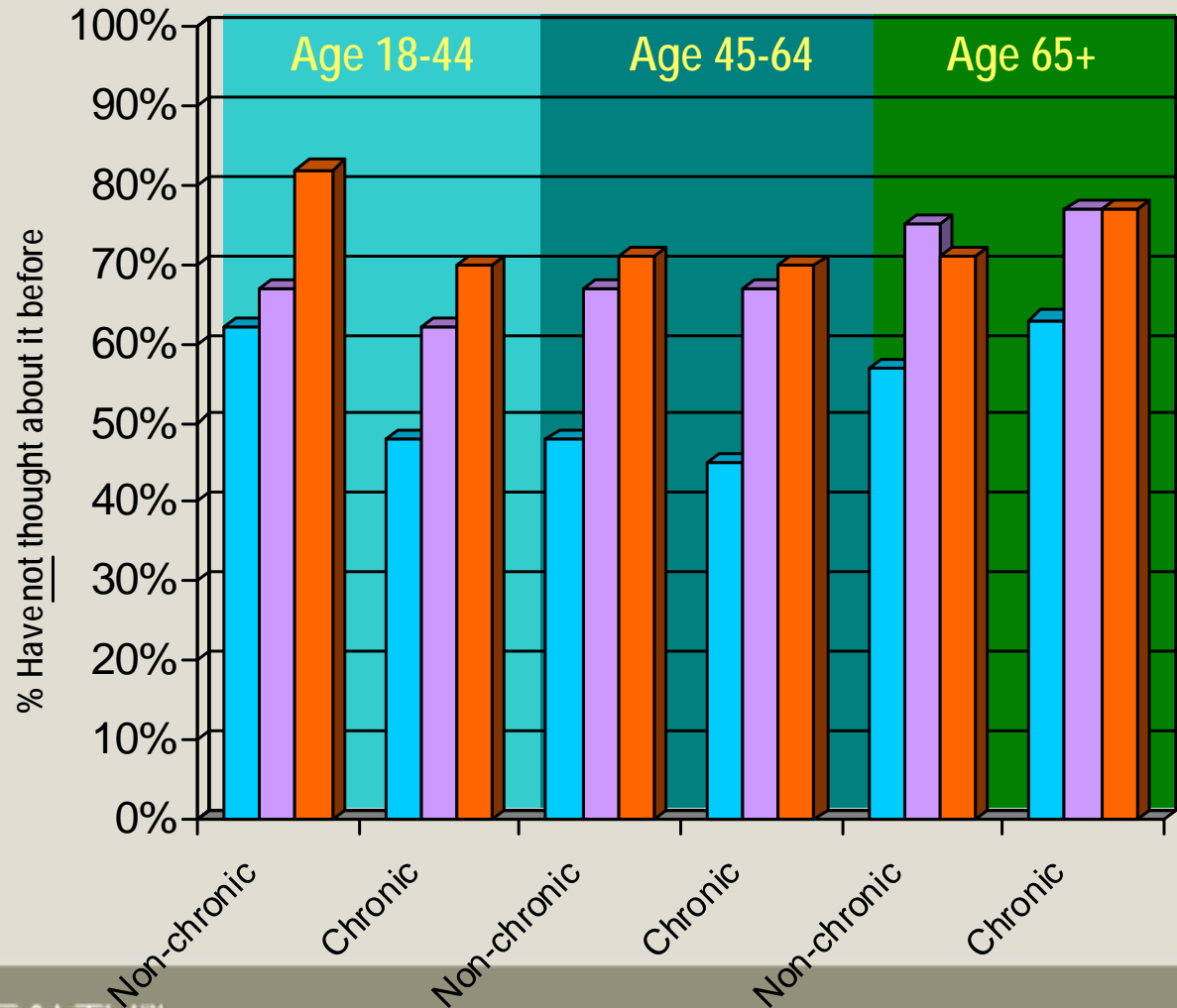


What is the current consumer mindset?

- Modest use of paper health records (40%)
- Extremely low use of electronic personal health records (2-5%)
- High percentage think they “should” (84%)
- Significant concern about privacy and security
 - Harris survey: 66-68%
 - FACCT survey: 91% “very concerned”
 - Strong desire to “control” who sees health information

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*



What works with consumers?

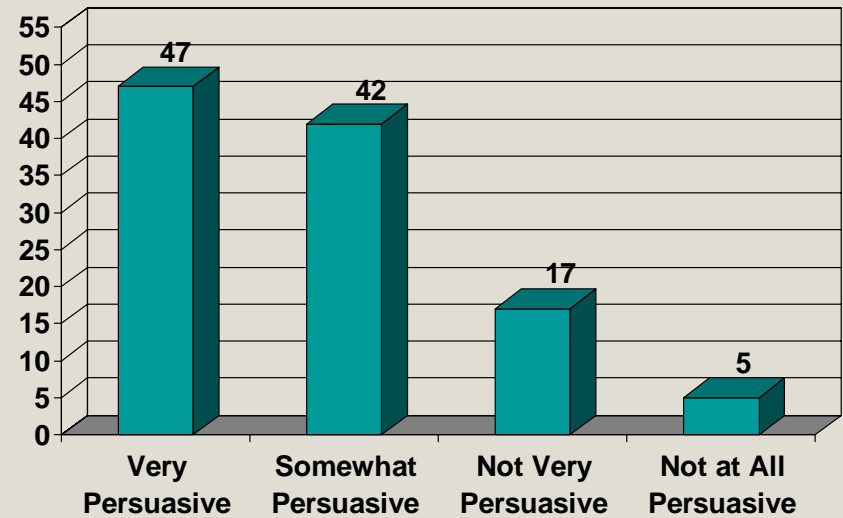
Messaging conclusions

- Messages must be consistent and carefully constructed—not negative
- Messages must be mindful of privacy, while emphasizing convenience and utility
- Most receptive target populations are likely to be:
 - People with chronic conditions, taking multiple medications and people with more than 5 doctor visits a year
 - Patients and families younger than 45 who are more comfortable with computers
 - Those caring for an ill parent or spouse



You have three seconds to remember every doctor you've ever seen, every procedure you've ever undergone and every medicine you've ever taken.

You could do just that if your medical history was all together, safe and sound and in one place. That's why online medical records are such a great idea. They mean you can get to your medical information instantly. That could be a real life saver in the event of an accident or sudden illness.

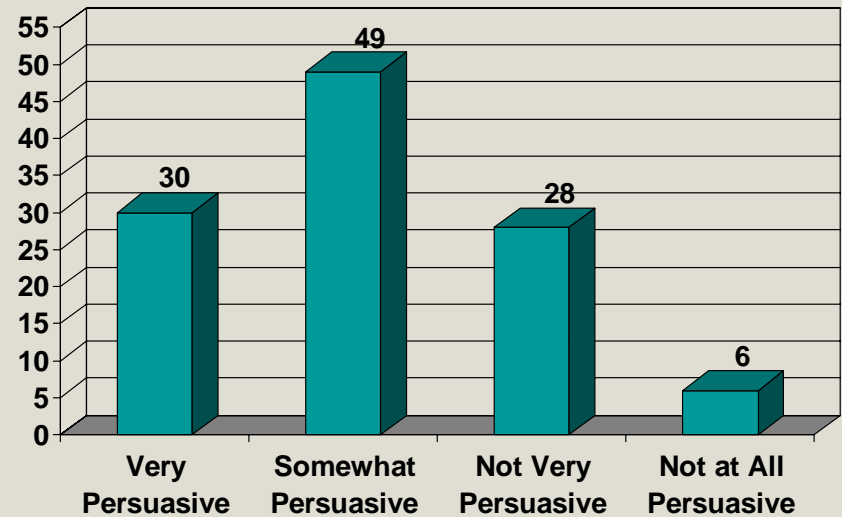


“Anybody can make a mistake. I’d like to double-check what’s in my medical records.”



George Paxton
San Diego, CA

My medical information used to be scattered among many different doctors’ offices, clinics and hospitals. It’s so much better to have everything together in one place, where it’s accessible to me. That’s why online medical records are such a great idea. I really like that I can go online and check that the medical information in my file is accurate and up to date.



We need to get there....the stakes are high

EXHIBIT 3

Net Value Of Health Care Information Exchange And Interoperability (HIEI)

	Implementation, cumulative years 1-10 (\$ billions)	Steady state, annual starting year 11 (\$ billions)
Level 2		
Benefit	141	21.6
Cost	0.0	0.0
Net value	141	21.6
Level 3		
Benefit	286	44.0
Cost	320	20.2
Net value	-34.2	23.9
Level 4		
Benefit	613	94.3
Cost	276	16.5
Net value	337	77.8

SOURCE: Authors' analysis.

NOTES: For explanation of levels, see text. All results are stated to three significant digits.

Source: CITL, *Health Affairs* 1/19/05



Carol C. Diamond MD, MPH.
Cdiamond@markle.org

www.connectingforhealth.org

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