

The New American Health Citizen – DIY Health Implications for PHRs and Privacy



***Testimony to the NCVHS
Hubert Humphrey Building, Washington, DC***

Jane Sarasohn-Kahn, MA (Econ.), MHSA

THINK-Health

20 May 2009



DECEMBER 25, 2006 / JANUARY 1, 2007

www.time.com

TIME

PERSON OF THE YEAR



Yes, you.
You control the Information Age.
Welcome to your world.

What's Driving the Citizen-Consumer-Patient-Caregiver to H2.0 Tools?

- An online, 24x7 world for more and more people
- People DIY and project-manage other facets of daily life: travel, financial services, entertainment
- Why not health?
 - Transparency
 - Value
 - Knowledge
 - Empowerment.



Welcome to the New World of Participatory Health

Signposts to the New World

Retail clinics



OTCs/supplements replace
and/or complementing Rx's

Medical tourism



Health care gift cards



Health blogging



Consumer self-care tools

patientslikeme™

....and PHRs!



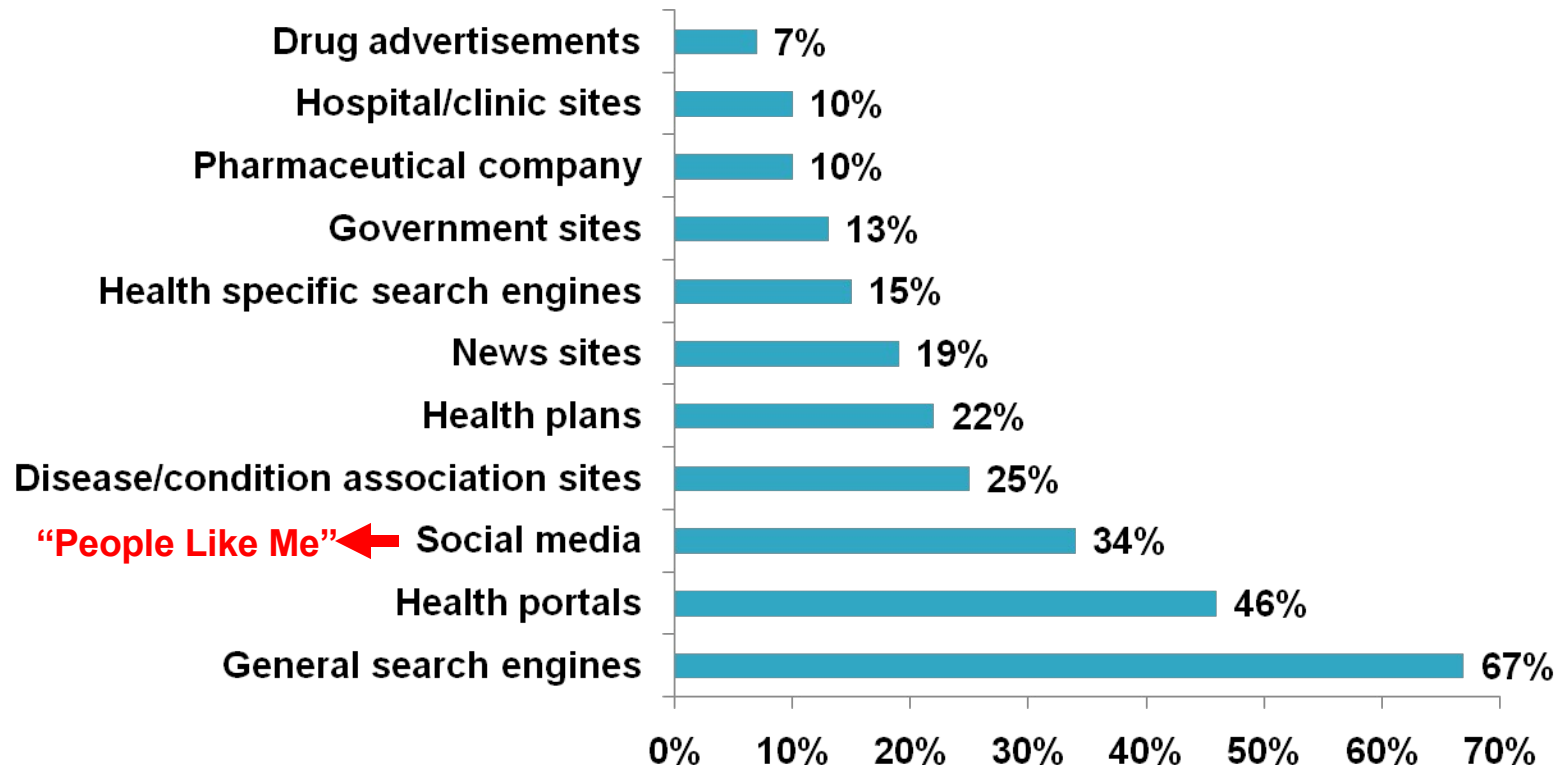
Defining *Participatory Health*

- A cooperative model of health care, actively involving the health citizen as an integral part of the full continuum of care, enabled by:
 - Information, software and community
 - Equal access to all the clinical and scientific data related to the patient
 - A well-defined, shared decision-making process.



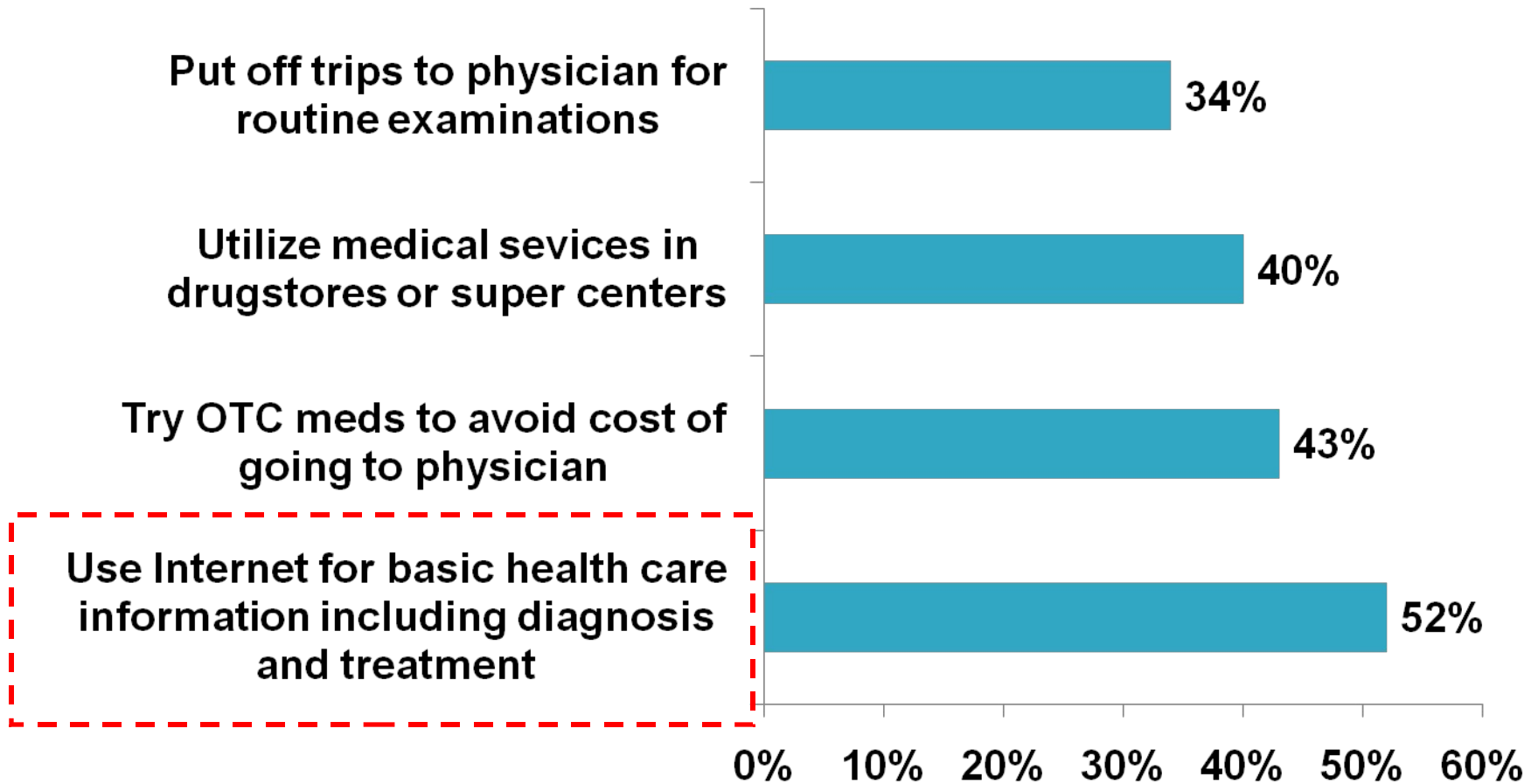
Participatory Health Requires “Information and Community”

Online Tools and Resources Used to Search Health Information



Source: iCrossing. *How America Searches: Health and Wellness*. January 2008

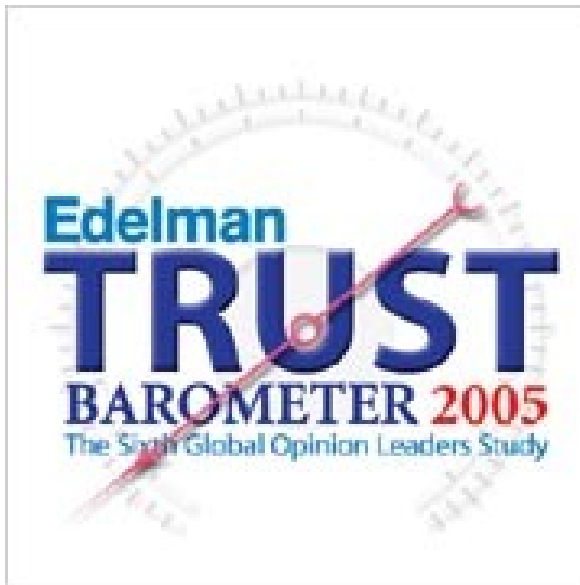
The Recession Is Driving More Americans Toward DIY Health



Source: *Dissecting the Downturn Generation*, IRI, April 2009

Trust MEdia

A Report from Edelman's *Trust Barometer* Spring 2005



- “Trust has shifted from authority figures to ‘average people,’ like you.”
- The average person wants to engage and be engaged in **conversations**.

Source: Trust “MEdia.” Why the Average Person is Finally Getting Heard, The 1.0 Guide to the Blogosphere for Marketers & Company Stakeholders, Edelman and Intelliseek, Spring 2005.

The Six Health Care Consumer Segments According to Deloitte, 2008-2009

Segment	Description	% in 2009	% in 2008
Content & Compliant	Traditional, most likely to prefer authoritarian doctors	28.5%	29.3%
Sick & Savvy	Traditional, but want to be engaged in decision making	25.3%	24.3%
Online & Onboard	Traditional, but open to non-conventional	8.0%	7.3%
Shop & Save	Traditional, but open to non-convention and seek lower-cost services	2.4%	1.6%
Out & About	Alternative, prefer holistic approaches and natural remedies	8.2%	9.1%
Casual & Cautious	Disengaged but currently lean toward traditional, and seek lower-cost services	27.6%	28.4%

The more engaged health segments are growing.

Source: 2009 Survey of Health Care Consumers – Key Findings and Strategic Implications, Deloitte Center for Health Solutions



A growing cadre of Americans are interested in tools and resources to assist with health improvement

- 9% of Americans have a computerized personal health record (8% in 2008)
- 57% want a secure Internet site to enable them to access their medical records, schedule office visits, refill Rx's and pay medical bills
- 42% want access to an online PHR connected to their doctor's office
- Privacy and security of PHI is an issue: 38% are very concerned vs. 24% who are not at all concerned
- 60% believe the government should set standards for how medical information is collected, stored, exchanged, and protected.



Source: 2009 Survey of Health Care Consumers – Key Findings and Strategic Implications, Deloitte Center for Health Solutions

Health Citizens Are Seeking Health Engagement

Consumers Embrace Innovations That Enhance Self-Care

- 68% of people are interested in home monitoring devices that enable them to check conditions and send the results to their doctors
- 64% are interested in using an in-home medical device that could help the, know what to do, and when, to improve health or treat a health condition
- 44% are interested in tools such as health diaries to help monitor and improve health
- 37% are interested in using online tools to help assess, monitor and manage health



Source: 2009 Survey of Health Care Consumers – Key Findings and Strategic Implications, Deloitte Center for Health Solutions

Patients See **Conversations with Docs Will Become More Important** Along with Personal and Health Expert Channels



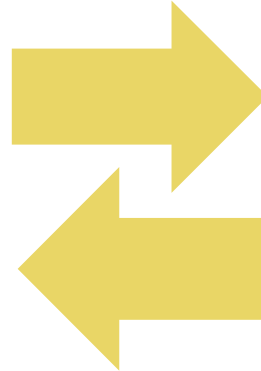
Source: Edelman Health Engagement Barometer, October 2008



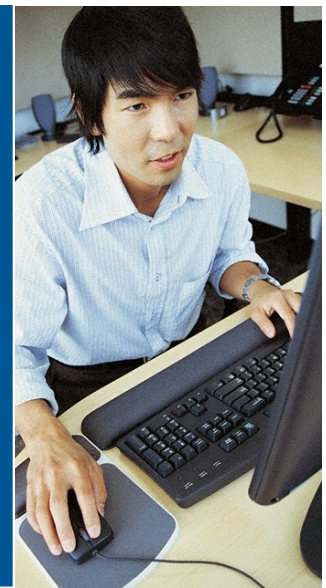
The New Second Opinion among health info-entials



88%
I usually turn
to my physician
to validate info
I get online

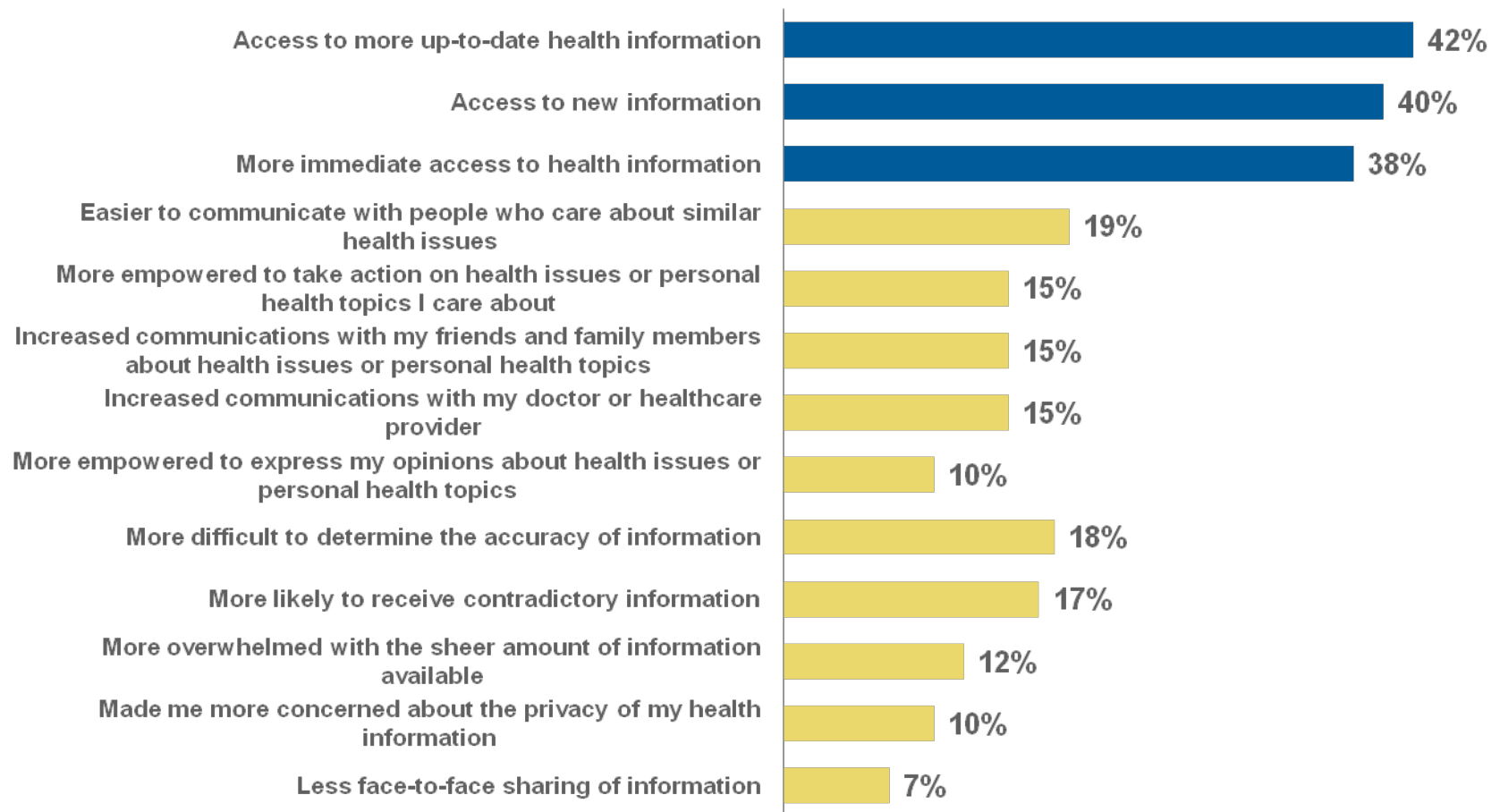


88%
I usually turn
to other sources
to validate info
I get from
my doctor



The New Health Access: Immediate Information

Among health info-entials, which 3 most important ways that digital communications changed how you receive or share information about health issues?



Source: Health Engagement Barometer, Edelman, October 2008

Americans Trust **Health Providers** Above Other Stewards for Handling Health Information

“Data Steward”	Trust (Net)	A Great Deal of Trust	Some Trust	Not Trust (Net)	Not Much Trust	No Trust at All
Health providers	74%	20%	55%	26%	19%	7%
My email provider	62%	14%	48%	38%	27%	11%
Banks and brokerage companies	59%	15%	43%	41%	28%	13%
State and local governments	56%	10%	45%	44%	30%	14%
The Federal government	54%	13%	41%	46%	28%	18%
Search and portal sites	49%	10%	39%	51%	29%	22%
Social networking sites	23%	5%	18%	77%	31%	46%



Source: *Americans Trust Health Providers to Handle Personal Information in Secure Manner*, BBC America and The Harris Poll, March 30, 2009

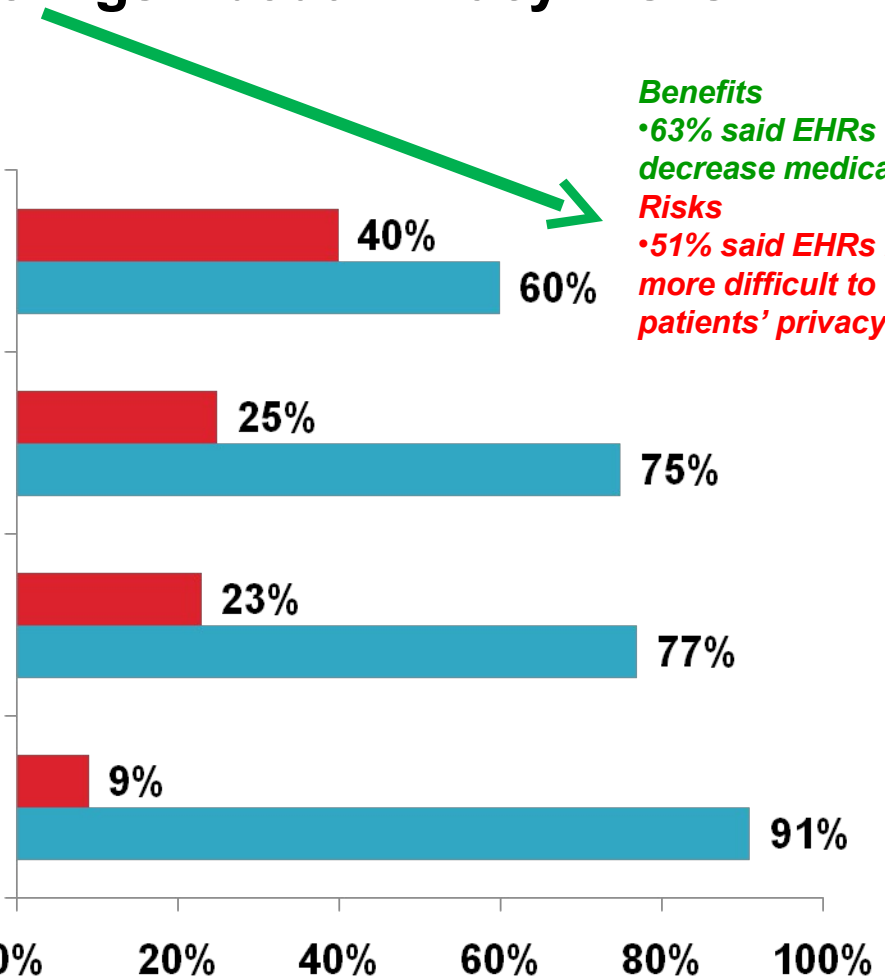
Most Americans Want Access to Electronic Health Records, But Have Mixed Feelings About Privacy Risks

"The benefits of electronic medical records outweigh the privacy risks"

"Patients should be able to email their doctors as part of their overall care, with no additional charge"

"Medical offices should provide patients with the ability to schedule appointments via email or on the Internet"

"Patients should have access to their own electronic medical record maintained by their physician"



Benefits
 •63% said EHRs can decrease medical errors

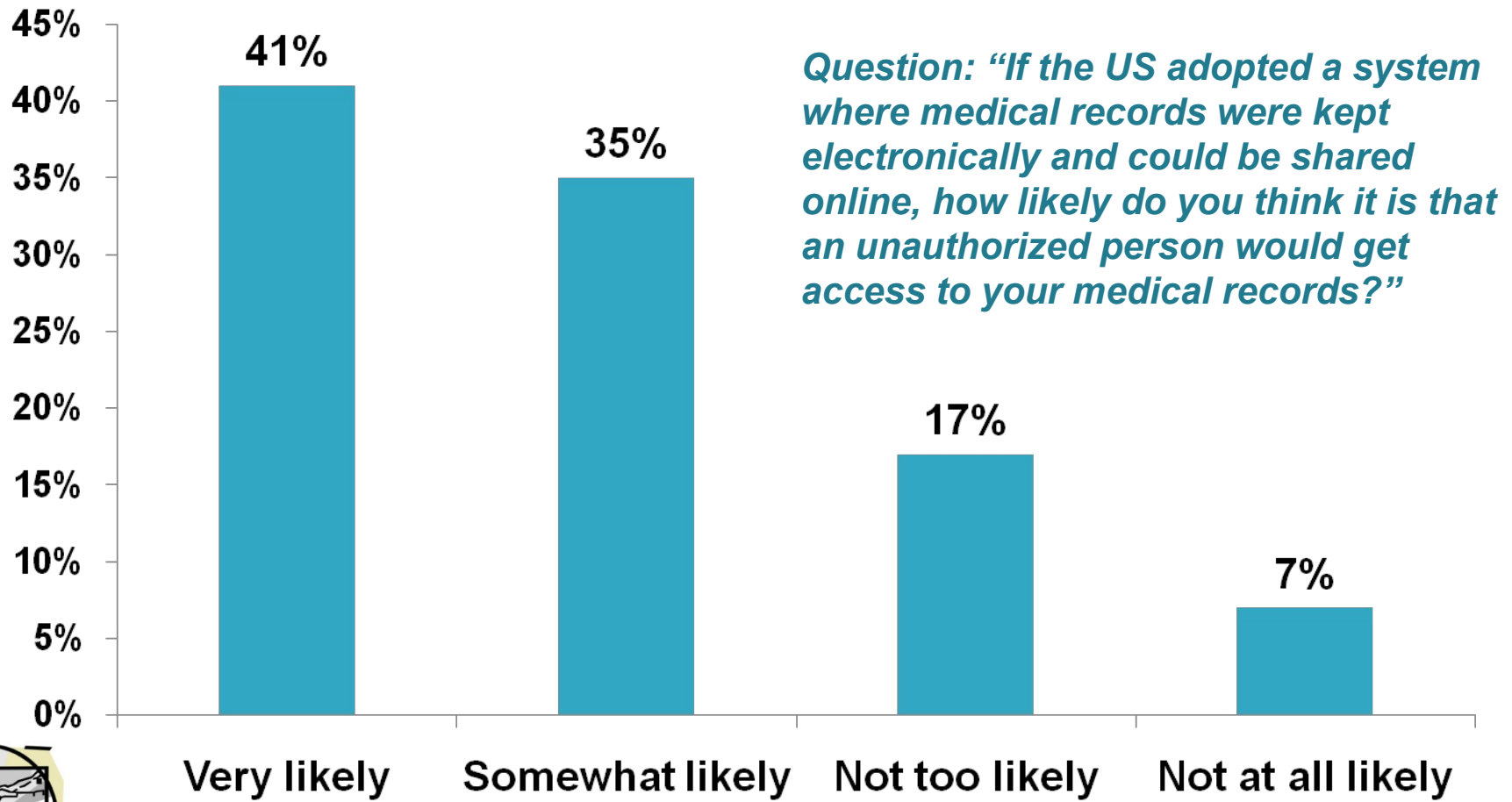
Risks
 •51% said EHRs make it more difficult to ensure patients' privacy.

■ Disagree ■ Agree

Source: U.S. Adults Not Very Confident That Physicians Have the Complete Picture, According to a New WSJ.com/Harris Interactive Survey, December 5, 2007, Volume 6, Issue 18

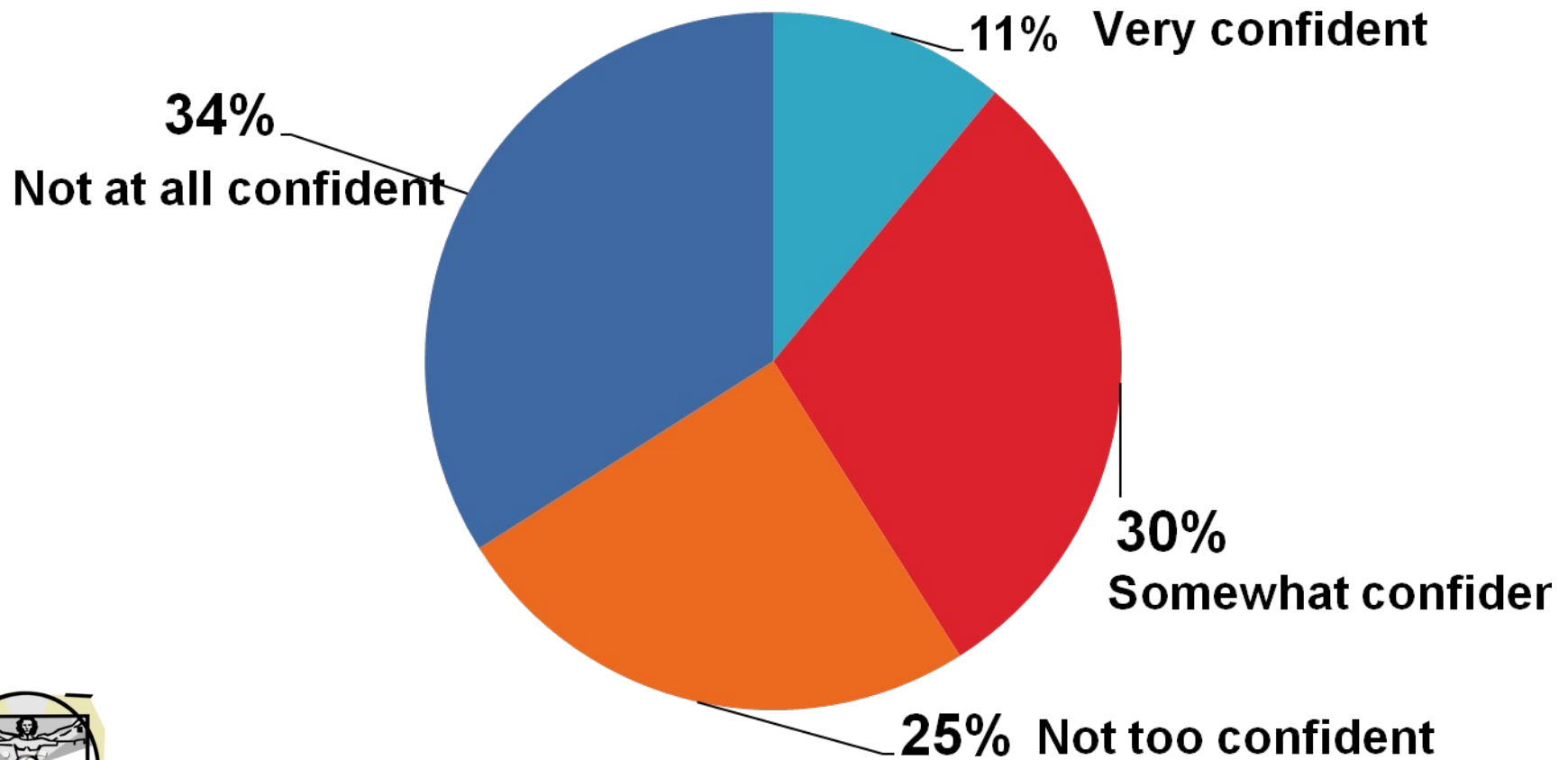


3 in 4 Americans Believe It Is Likely That An Unauthorized Person Would Get Access to EMRs



Source: *The Public and the Health Care Delivery System*, NPR/KFF/HSPH survey, April 2009

Over One-Half of Americans Are Not Confident in the Confidentiality of Electronic Health Information



Source: *The Public and the Health Care Delivery System*, NPR/KFF/HSPH survey, April 2009



A Significant Number of Americans Believes Their Personal Medical Information Has Been Compromised by Organizations Holding It

Question: "Whether or not you have read or heard about medical records or information being lost or stolen, which form of medical records do you think is lost or stolen most often?"

Type of medical information	Total that believe type of record would be more likely lost or stolen	Have heard about medical information being lost or stolen		Have had medical information lost or stolen	
		Yes	No	Yes	No
Computerized medical records	47%	51%	39%	54%	50%
Paper and computerized medical records are lost or stolen about equally	23%	25%	18%	26%	25%
Paper medical records	16%	15%	17%	12%	16%
Not sure	14%	9%	26%	8%	9%

Source: Millions Believe Personal Medical Information Has Been Lost or Stolen, The Harris Poll, #74, July 15, 2008

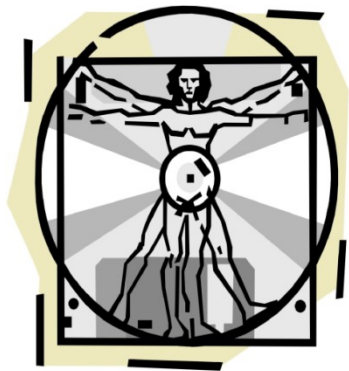


Summary and Implications of Participatory Health on PHRs and Privacy

- Growing number of American health citizens are engaging in DIY health care.
- Trust drives health engagement, and health engagement leads to better health outcomes.
- Conversations with physicians are becoming increasingly important to health citizens.
- Physicians and providers are seen as most trusted health data steward.
- Americans continue to be challenged by the balance of the benefits of electronic PHI and the privacy risks.
- Americans are interested in accessing and using tools that help them better manage health.
- HIPAA won't solve PHR privacy challenges; consumers who use PHRs will seek control of PHI in terms of who can access their PHI, and what pieces of data these parties can access.



Source: *THINK-Health*



Jane Sarasohn-Kahn, MA (Econ.), MHSA
Health Economist and Management Consultant
THINK-Health

610.933.5727 v

jane@think-health.com

www.think-health.com

www.healthpopuli.com Blog

