

Parallel National Surveys:

The Similar and Contrasting Views of Consumers and Clinicians Toward Electronic Personal Health Records

Josh Lemieux
Director, Personal Health Technology
Markle Foundation

HIMSS10
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Conflict of Interest Disclosure

Josh Lemieux

Has no real or apparent
conflicts of interest to report.

Markle Survey Methodology

- Questionnaire developed by Josh Lemieux and Alan Westin, with Markle staff input, and Matt Wynia of the AMA Institute for Ethics
- Sample creation, fieldwork and data production by Knowledge Networks
- 1,580 respondents, representative of total adult (18+) population, both on and not on the Net
- Responses collected by special online process, May 13-22, 2008
- Knowledge Networks places error rate at +/- 2.5%
- Estimates of millions represented by results based on Current Population Survey estimate of adult US population at 228M

AMA Survey Methodology

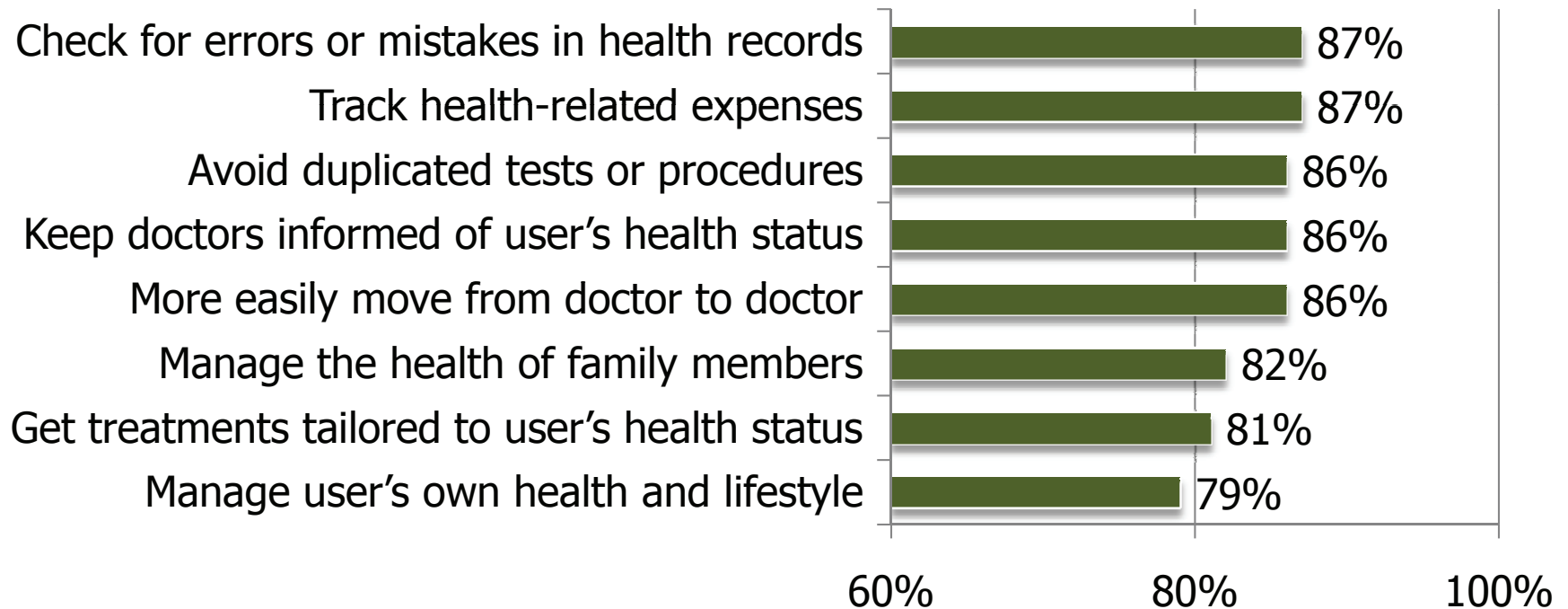
- Survey developed through collaboration between the Institute for Ethics and AMA Health Information Technology Initiatives, with funding from the Markle Foundation
- Results derived from a national survey in 2008–2009 of patient-care physicians, with oversampling of OB/GYNs and psychiatrists
- Analysis based on 856 respondents (response rate: 52.1%) and weighted to reflect the general population of physicians
- 44% willingness to use PHRs also statistically adjusted to account for variations in physician specialty, gender and other demographic variables (unadjusted value is 42%)

Perceptions about PHRs and Demographics of Users and Non-users

No. 1: High Perception of Value

When the general public was asked how use of an online PHR service would affect individual handling of health and health care, large majorities said such services could improve several activities “a great deal” or “somewhat.”

How many believe PHRs would improve their abilities to:



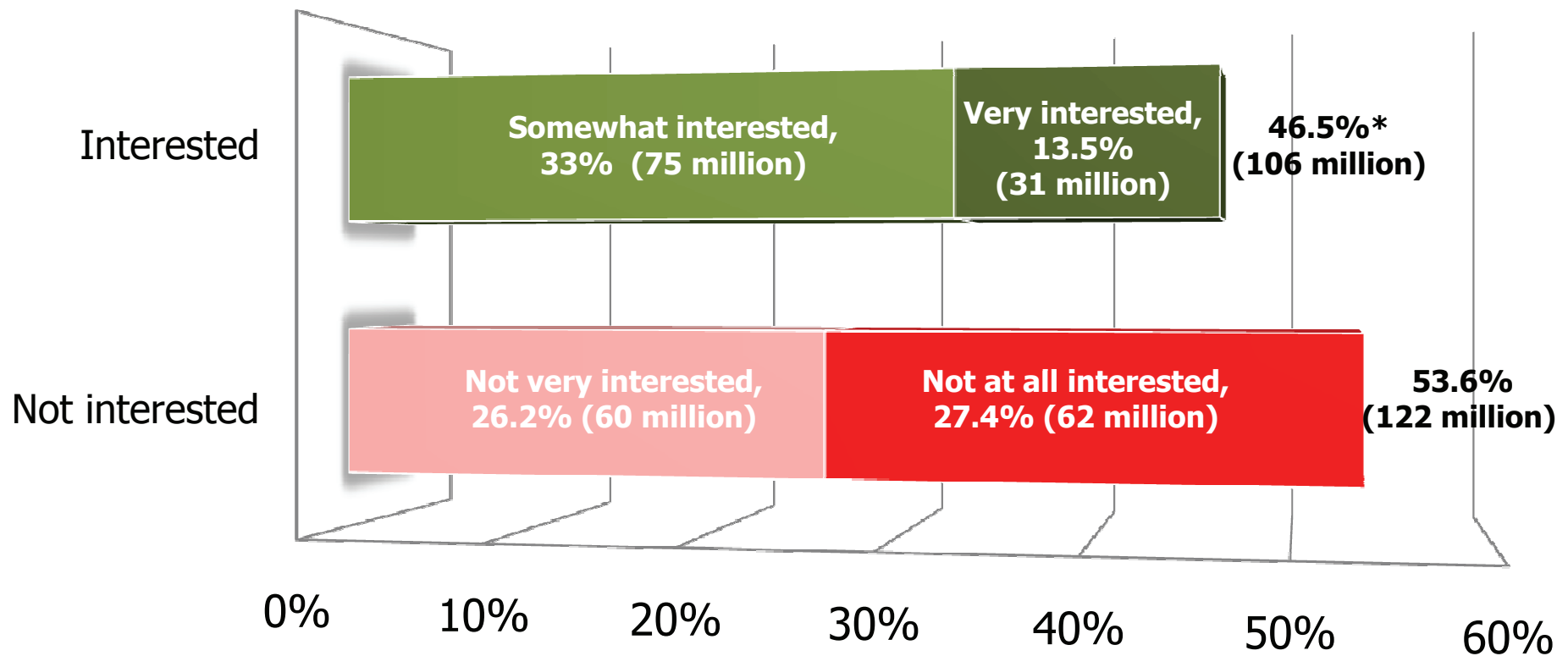
Interest in Joining Online PHR Service – 1

“Some Internet technology companies and health care organizations are inviting individuals to join free online electronic personal health record services. You could obtain, store, and update your health information on a secure web site. You could control which health care providers can see or update your PHR, and you could automatically receive valuable information from the Internet related to the medical and health conditions and interests you indicated in your PHR.”

How interested would you be in joining such a service?

No. 2: High Interest

Almost half the public say they are interested in joining a free online PHR system, with 13.5% saying they are “very interested.”



No. 2: High Interest

Almost half the public (46.5%) say they are interested in joining a free online PHR system.

14% are “very interested” in joining a free online PHR.

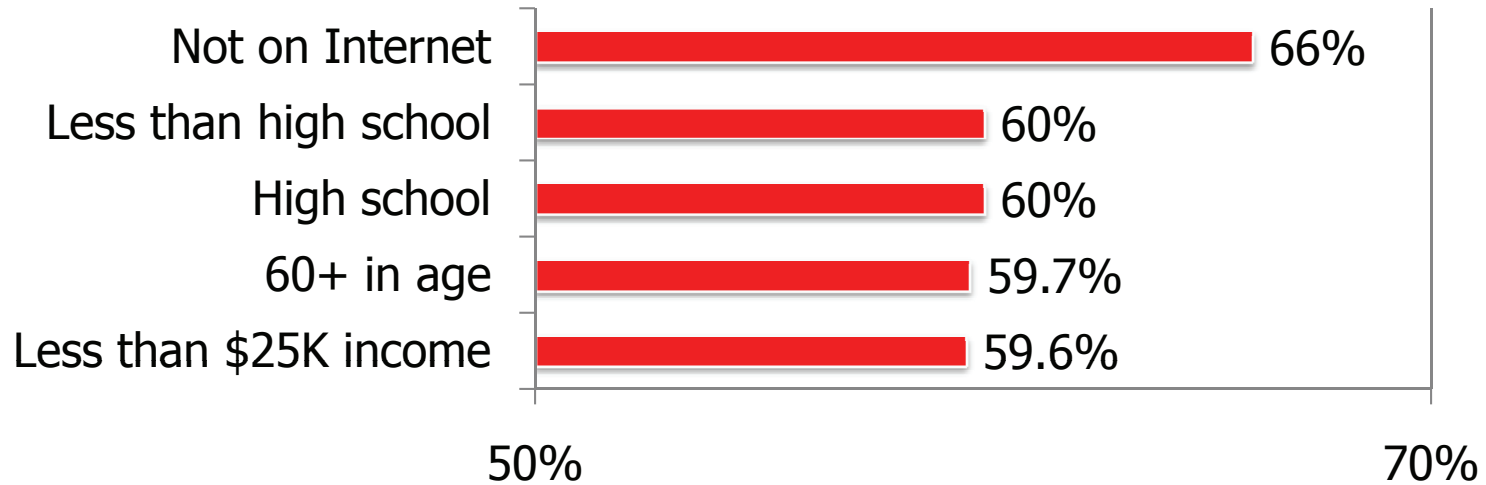
Subgroups with high interest:

- Disability
- Hispanic
- 7+ doctor visits/year
- Have had a serious illness
- Live in the West

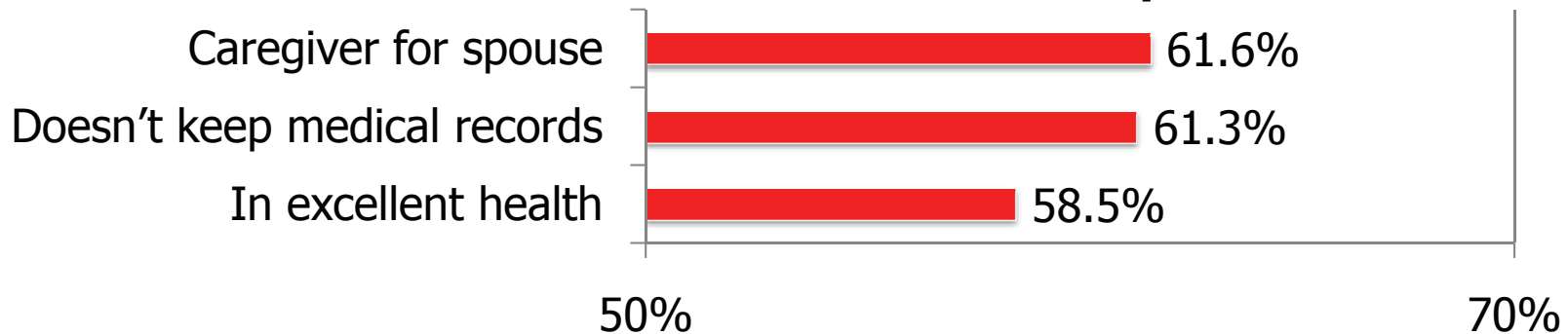
Groups Less Interested in Joining PHR Service

(In total, **53.5%** of the public are not interested)

Standard Demographic Groups



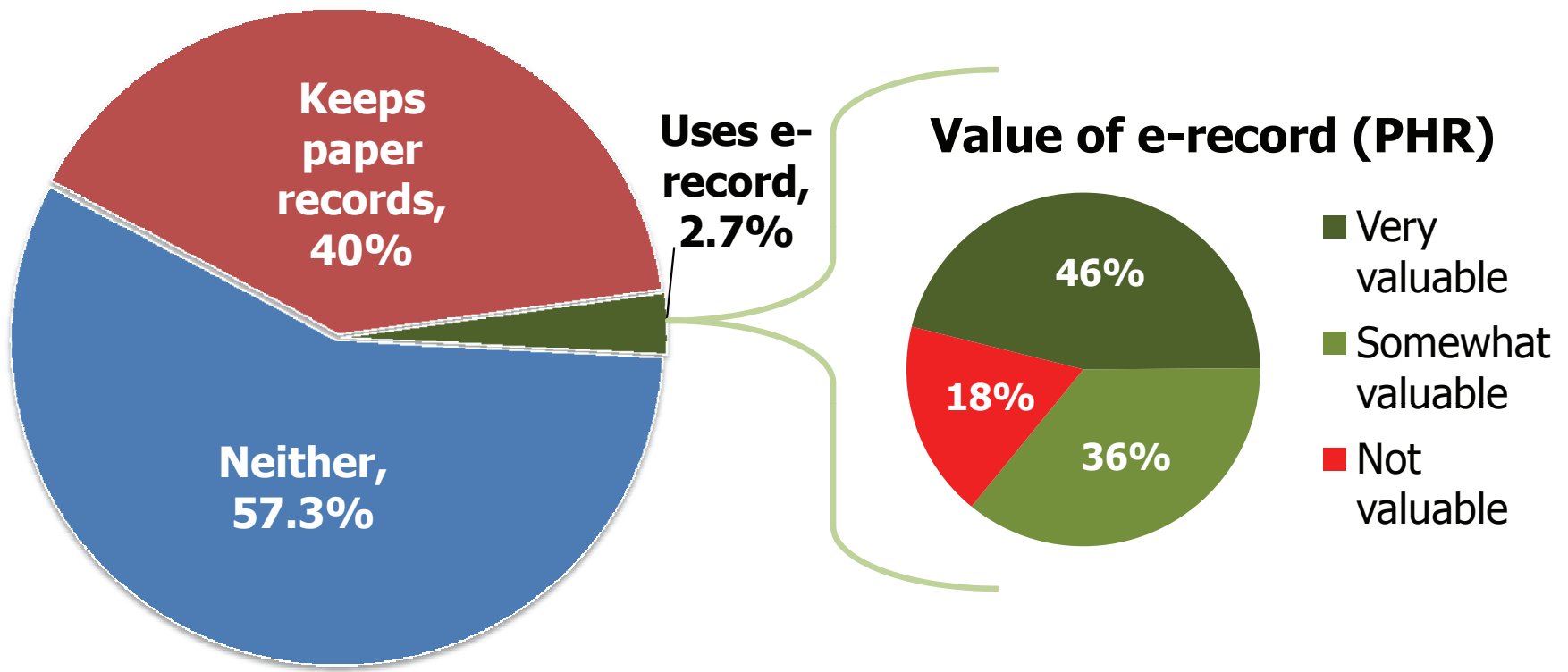
Health-Related Groups



No. 3: Utilization of Electronic PHRs Remains Low

Most Americans do not keep health records at home, while 40% percent keep health records in paper form.

Only 2.7% say they have an electronic PHR today – 4 in 5 of this small group considered them valuable.



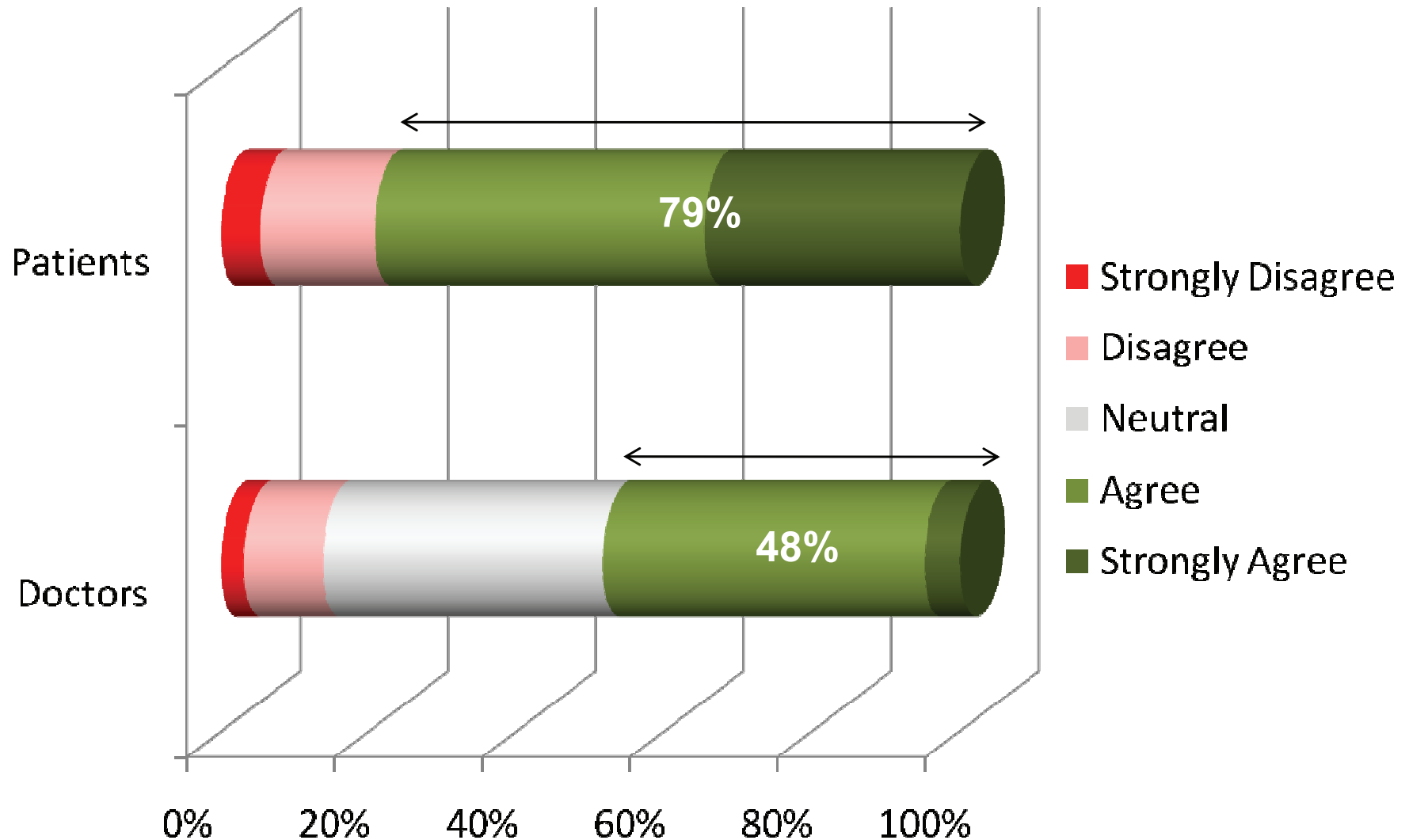
The Small Group Using Electronic PHRs

Only **2.7%** of the total sample say they have a electronic PHR. Although this is too small a cross-section to generalize, we needed there were eight subgroups more likely to have a PHR (by at least **3%**):

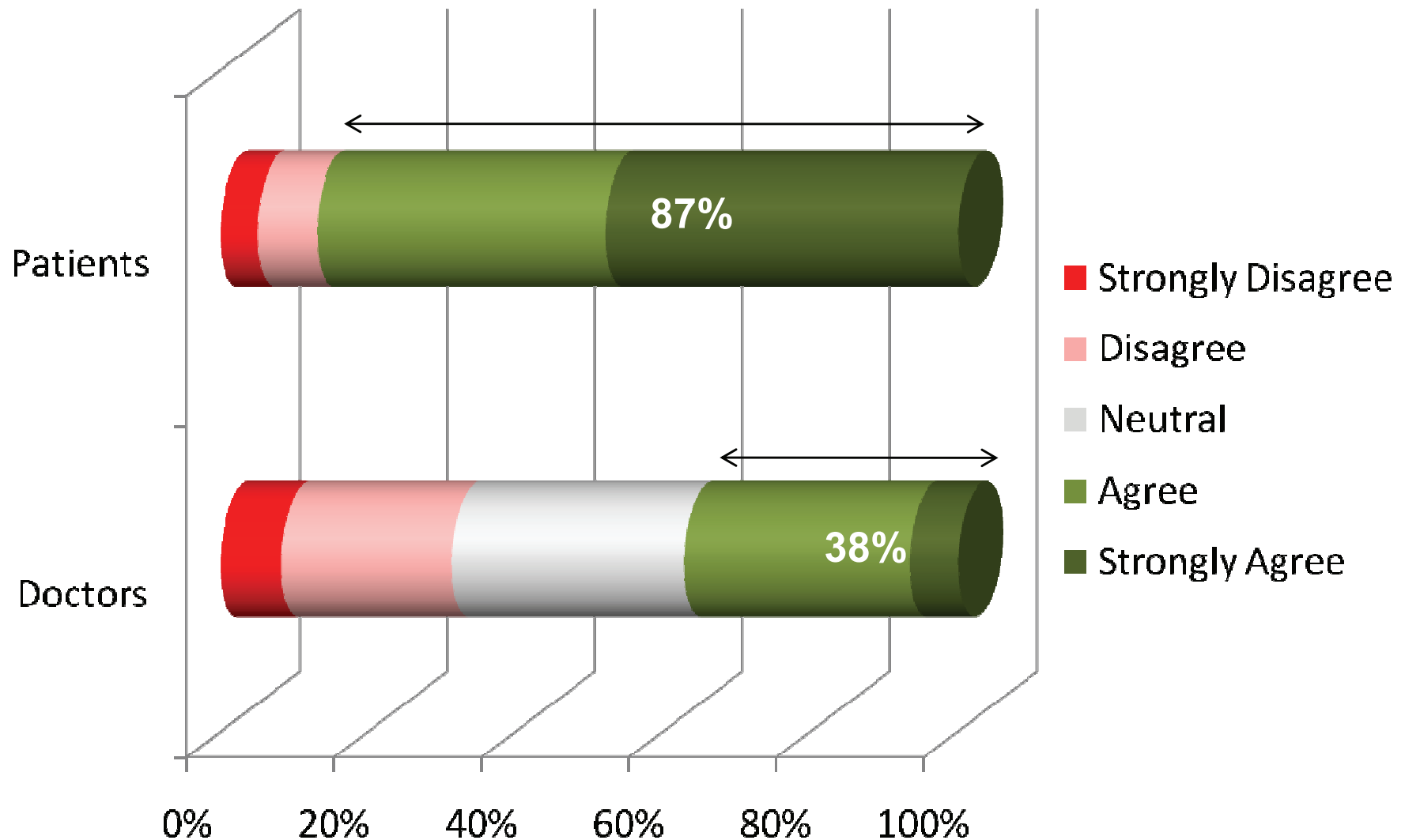
- **visit doctor 7+ times in past year**
- **have long term health condition**
- **have disability**
- **in poor health**
- **use Internet**
- **30-44 years of age**
- **\$100k+ annual income**
- **Hispanics**

Comparison of Doctors' and Patients' Attitudes Toward PHRs

PHRs Empower Patients to Participate in Their Own Health and Health Care



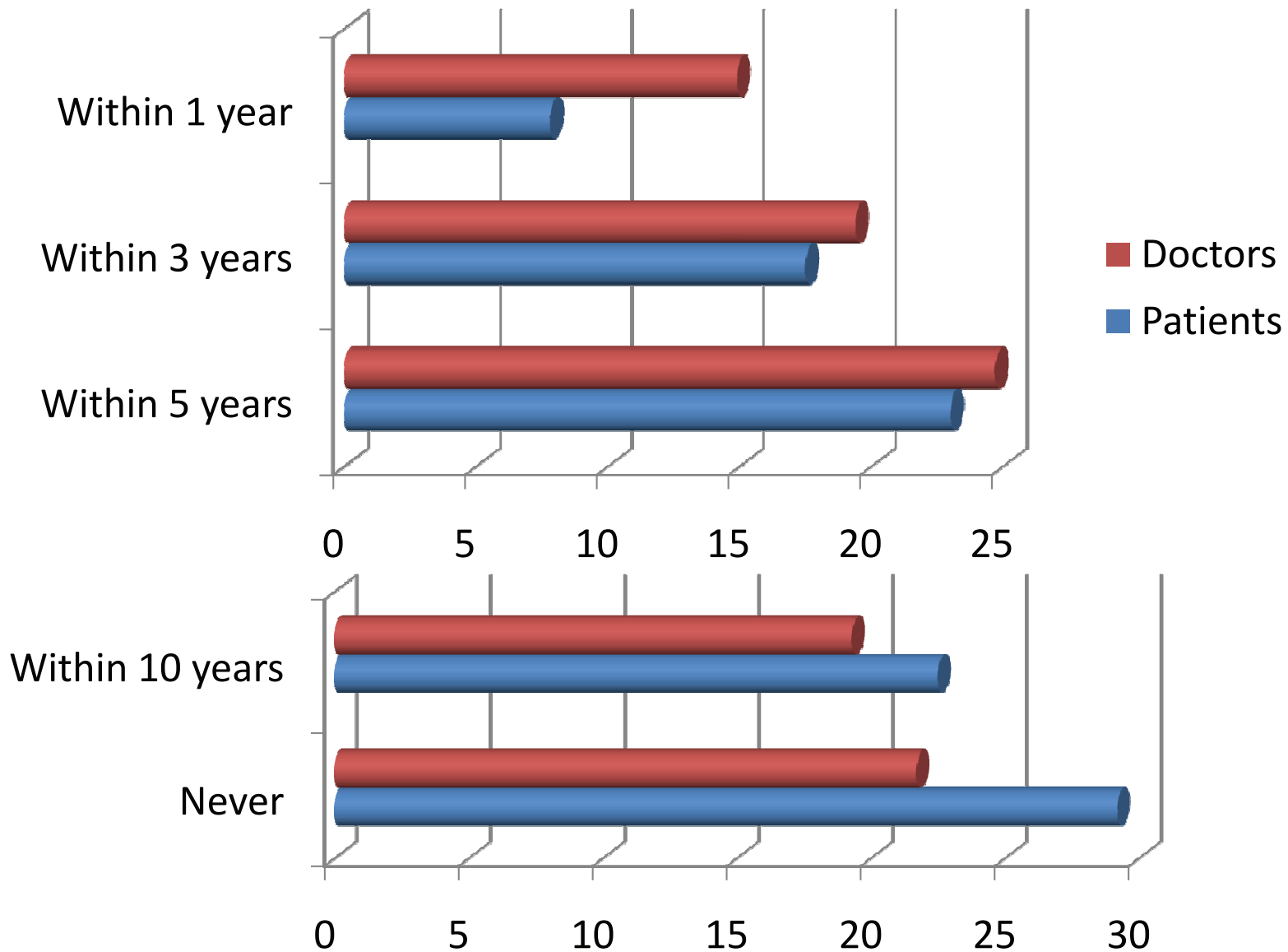
Patient Access to Their Electronic Records Will Improve Record Accuracy



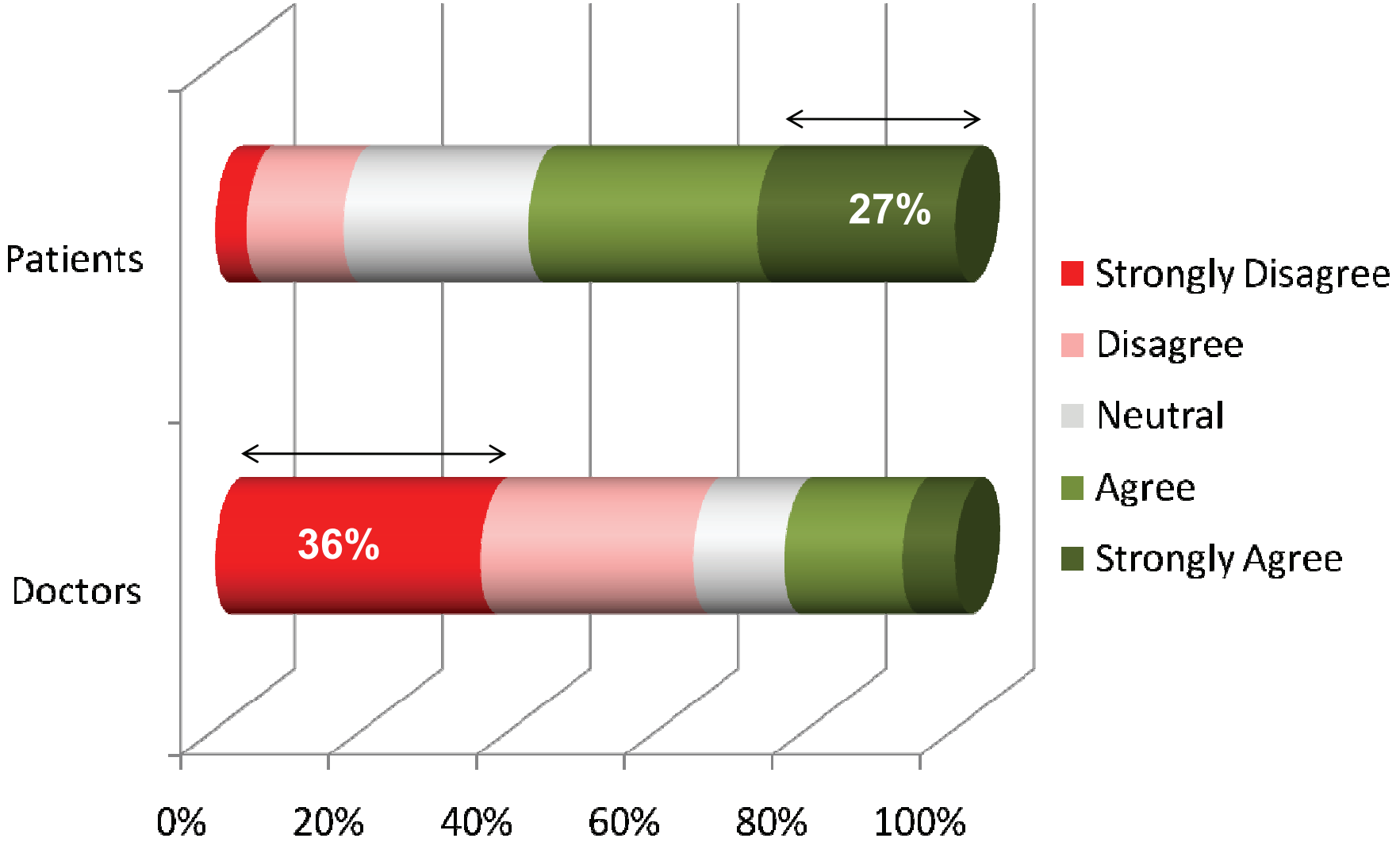
Comparison of Doctors' and Patients' Attitudes Toward Medical Records in General

No. 4: Similar and Contrasting Views:

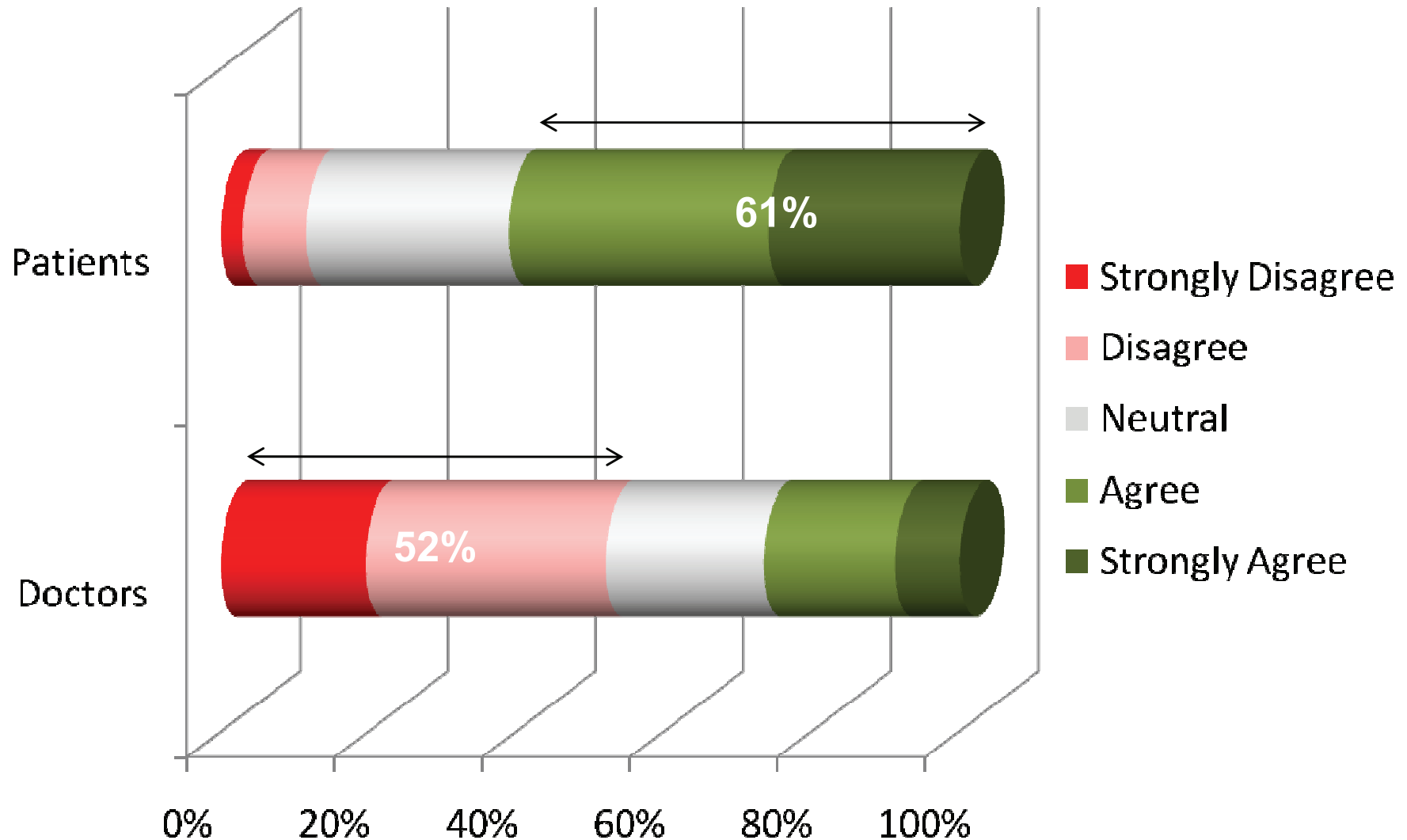
How Long Until Patients and Doctors Regularly Use Electronic Methods to Communicate with Each Other?



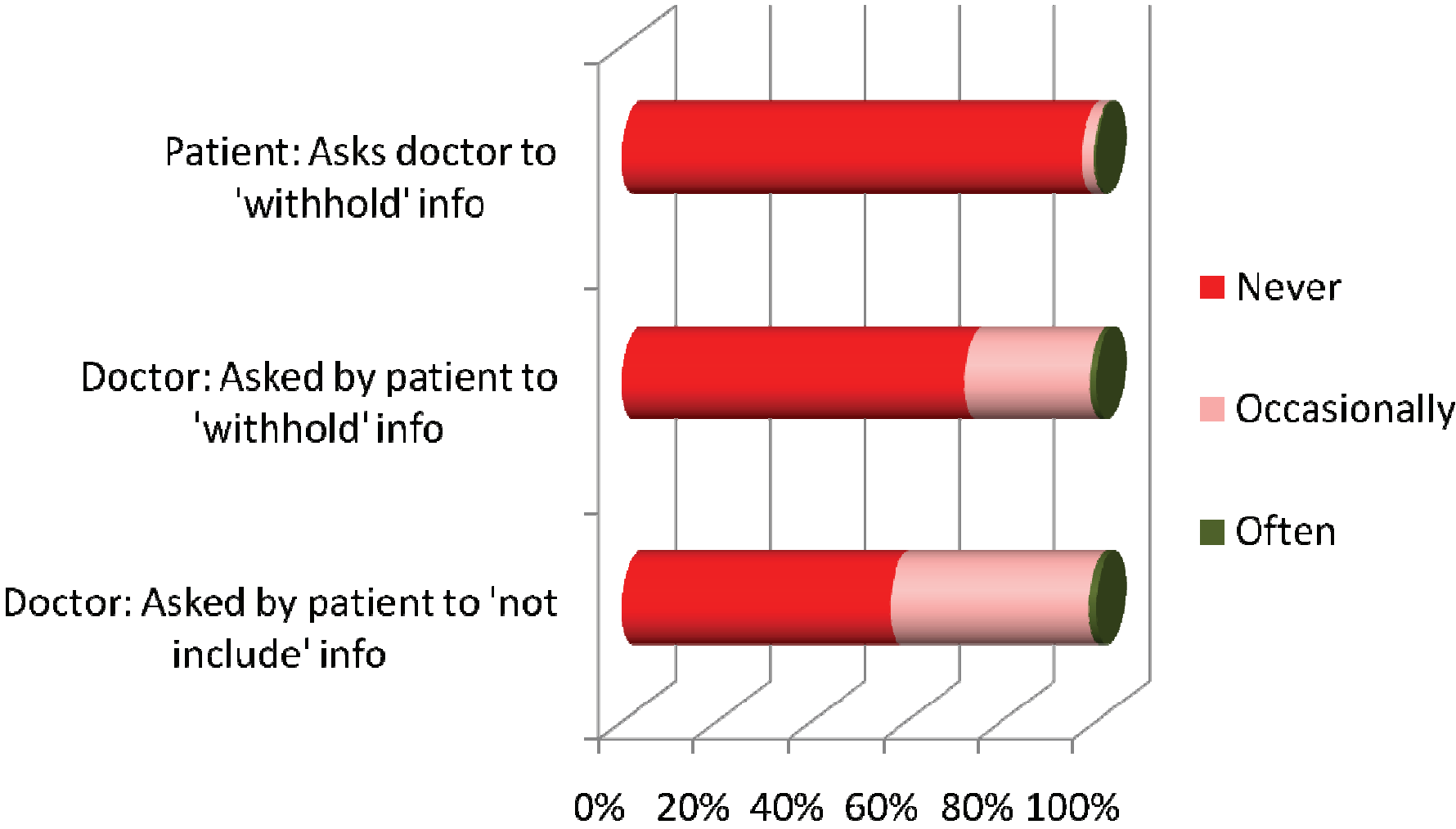
Agree or Disagree: Patients Should Decide Whether Clinicians Receive All or Part of Their Medical Records



Agree or Disagree: Doctors Agreeing to Withhold Sensitive Information Retains or Improves Patient Trust



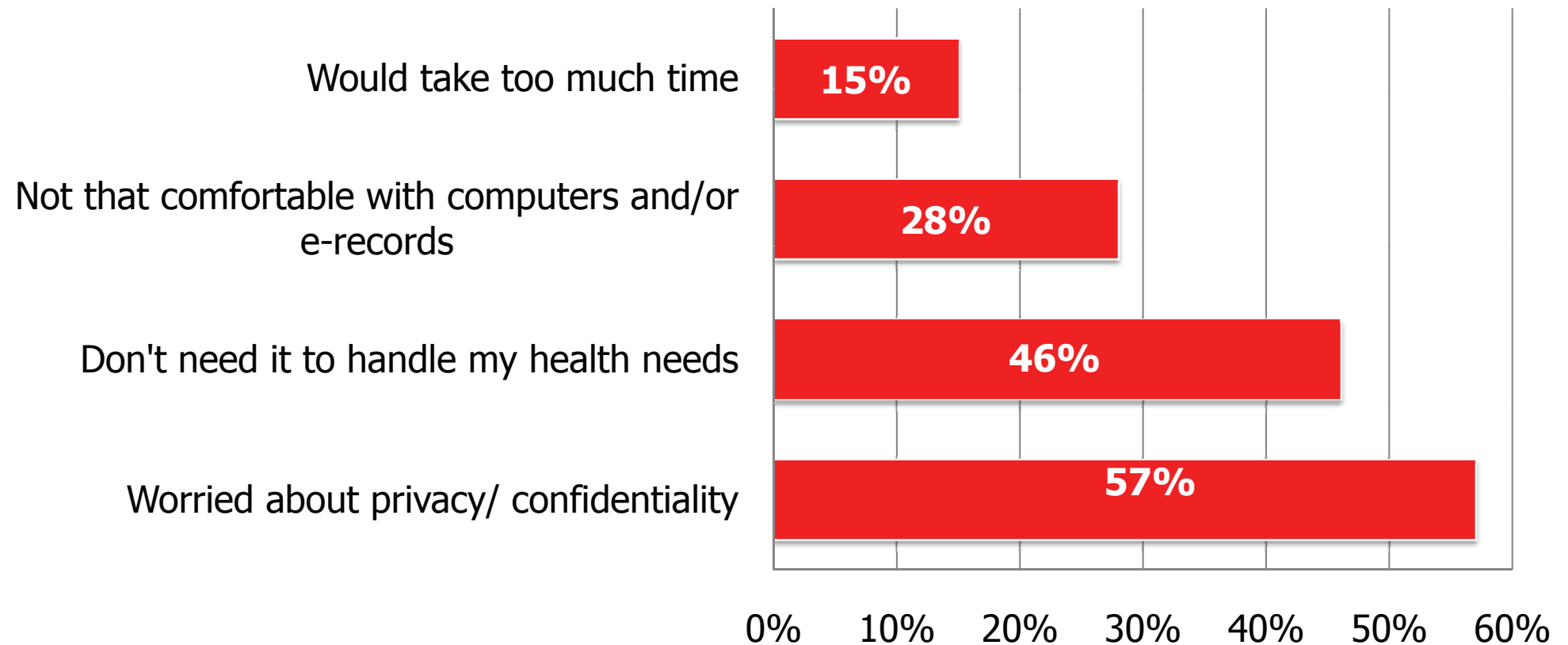
Frequency Doctor is Asked to Withhold Patient Health Information From Medical Record



Consumer Perceptions of Privacy- Protective Practices for Personal Health Information Services

No. 4: Privacy Concerns

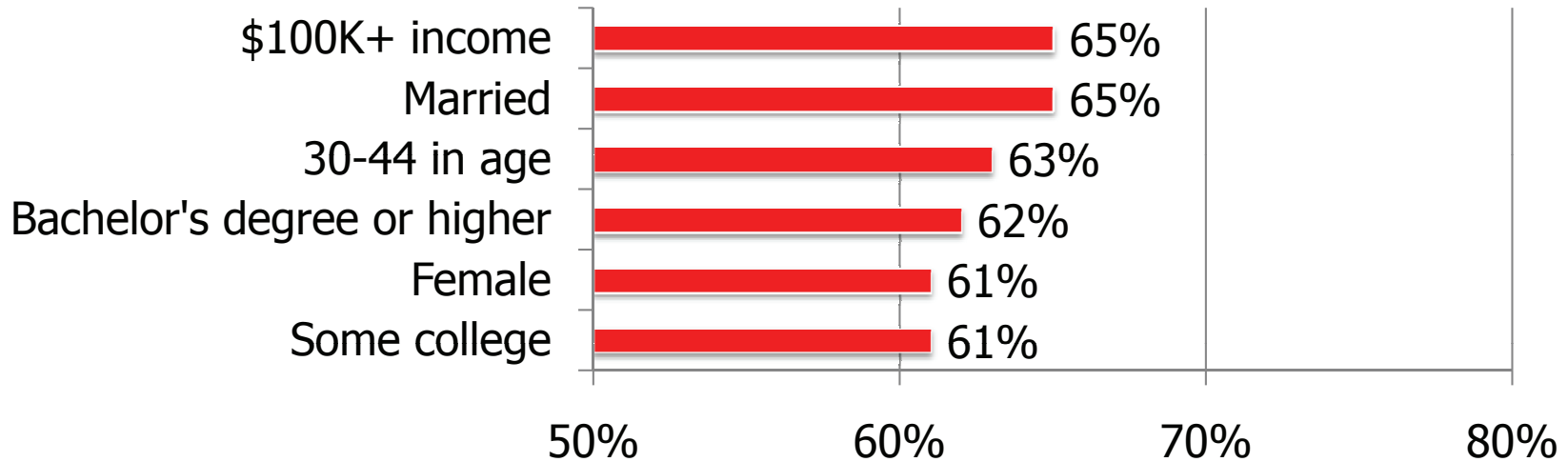
'Not interested' – Why not? More than half of these respondents not interested in PHRs cited "worries about privacy and confidentiality."



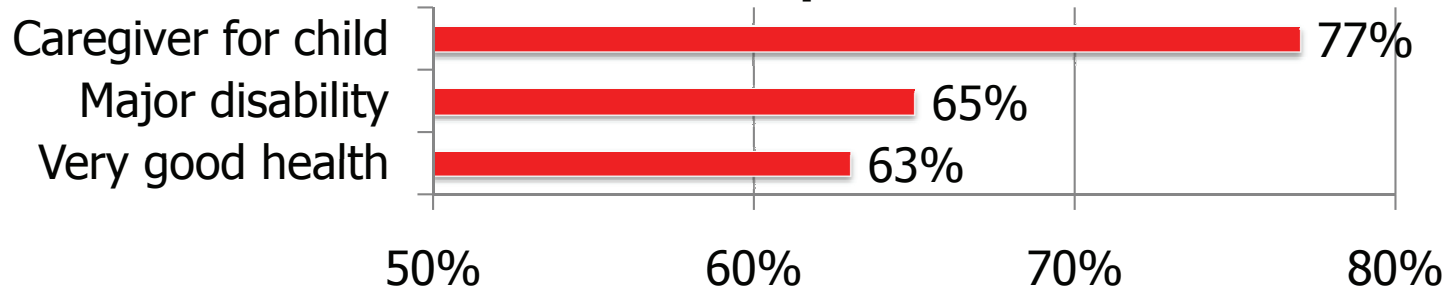
Groups Higher in Citing Privacy Concerns

(57% of those not interested in joining PHR service cited privacy concerns)

General Demographics



Health-Related Groups



What Policies Considered Essential

“Here are some policies that could be adopted by organizations managing your personal health information online. For each policy below, please indicate its potential importance to you. Would it be ...”

- (1) So important that you would not allow your information to be used without it
- (2) One factor helping you decide whether to participate
- (3) Nice to have but not essential

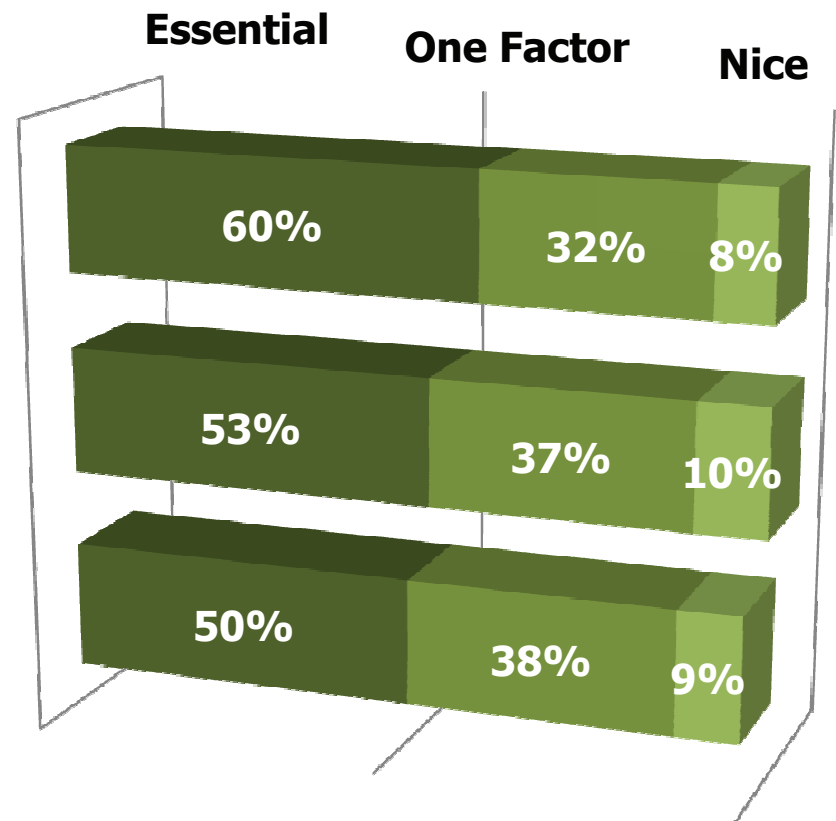
No. 5: Practices Matter

When asked how important a set of privacy and information practices would be in their decision whether to sign up for an online PHR service, large majorities said each of these would either be “essential” or “a factor in making their decision.”

Affected people would be notified if their information falls into unauthorized hands in a way that could compromise their identity or expose their health information.....

Individuals would be able to review who has had access to their personal health information.....

Individuals would have a clear process to request corrections or dispute the way their information is handled.....



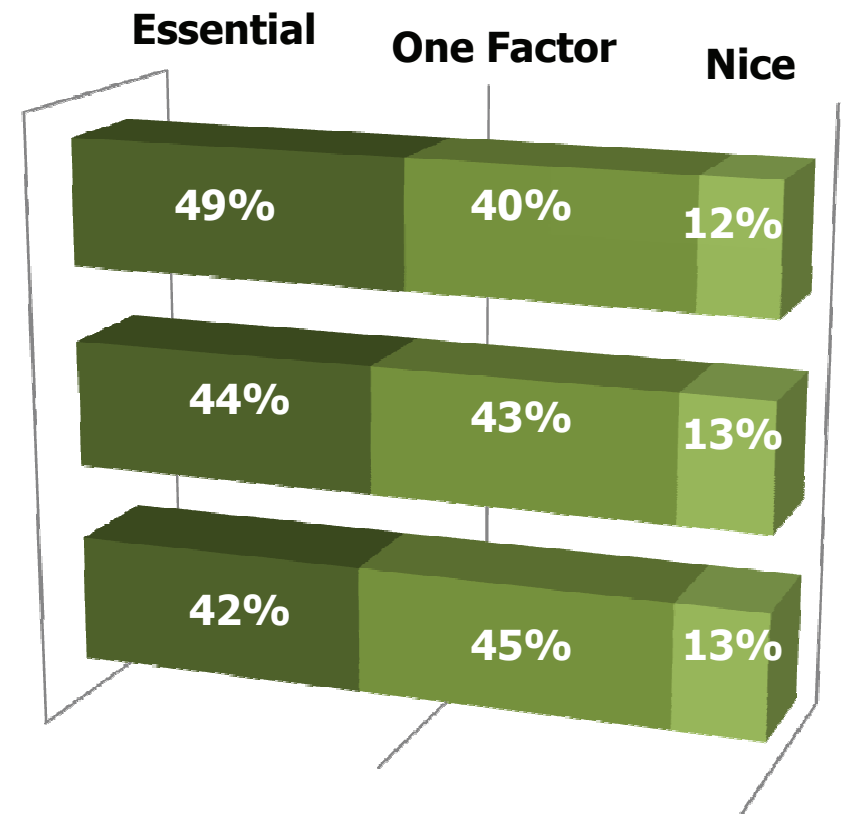
No. 5: Practices Matter (continued)

When asked how important a set of privacy and information practices would be in their decision whether to sign up for an online PHR service, large majorities said each of these would either be “essential” or “a factor in making their decision.”

Individuals would NOT be denied care or penalized financially based on whether they decided to provide certain medical information to an Internet-based service...

Having individuals control what information from their medical records is made available to others. For example, an individual with a sensitive medical condition could decide NOT to include information about treatment for that condition.....

Individuals could make informed choices about how their information is collected and used.....



Attitudes Toward Online Privacy Policies

85% believe:

“No matter what policies I click ‘I agree’ to when I sign up, my information should not be disclosed or sold to third parties unless I say ‘yes’ separately and specifically to it.”

(This is generally not the online world today.)

Key Findings

Key Findings: Similar Views Toward PHRs

Benefits and privacy concerns:

- Half of doctors and 4 in 5 consumers agreed that online tools can empower individuals in managing their health.
- 4 in 5 U.S. adults believe that online PHRs would provide major benefits in managing their health and health care services. 44 percent of doctors are willing to make use of PHRs as part of their clinical work.
 - Nearly half the public are interested in using a free online PHR system.
 - Yet less than 3 percent of the general adult population has an electronic PHR today.
- Among people not interested in using PHRs, concern for privacy is the most frequently cited reason why.
 - Majorities of 87 percent to 92 percent say six key privacy practices are factors in their decision to use an online PHR.
 - 70 percent of doctors also cited privacy concerns.

Key Findings: Contrasting Attitudes

Control of information

- Fewer doctors (38 percent) compared to consumers (87 percent) agree individual access to personal electronic records will improve the accuracy of medical records.
- Only 1 in 5 doctors agree that giving patients more control over who sees what parts of their medical records is a good idea.
- Higher proportions of patients (58 percent) than doctors (23 percent) agree that patients should decide whether clinicians receive all or only part of their medical records.
- Higher percentages of patients (61 percent) than doctors (27 percent) believe that to retain patient trust, physicians need to honor patient requests to withhold sensitive information when transferring records.

For more information

www.connectingforhealth.org