

Panel 3

Privacy and Security of Identifiable Health Information in PHRs and Related Technologies: Expectations and Concerns

Moderator: Joy Pritts, J.D.

Chief Privacy Officer

U.S. Department of Health and Human Services



The third panel will provide information on and discuss consumer expectations and concerns related to the privacy and security of identifiable health information in PHRs and related technologies. It will also explore the attitudes of health care providers and industry groups to the privacy and security of PHRs.



Panel 3

- Robert Gellman, J.D.
- Josh Lemieux, Director of Personal Health Technology, Markle Foundation
- Lee Tien, J.D., Staff Attorney,
 Electric Frontier Foundation
- Tresa Undem, Vice President, Lake Research Partners
- Matthew Wynia, M.D., M.P.H., F.A.C.P., Director,
 - The Institute for Ethics, American Medical Association



Data Sources

- The California HealthCare Foundation, Consumers and Health Information Technology: A National Survey (April 2010)
 - http://www.chcf.org/publications/2010/04/consumers-and-health-information-technology-a-national-survey
- Physicians' Views on Using Personal Health Records: Results
 of a National Survey; Matthew Wynia, M.D., M.P.H., Director,
 Institute for Ethics, American Medical Association
- Markle Foundation

http://www.connectingforhealth.org/resources/surveys.html

What Is Useful About a PHR?

Source: Lake Research Partners, national health IT consumer survey, 2009-2010.

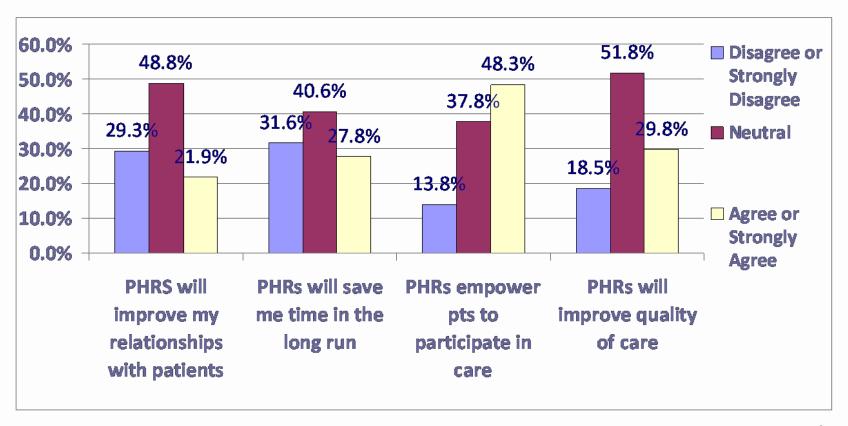
Thinking about the times you looked at your online medical and health info, how useful was...

PERCENT WHO ANSWERED "VERY" OR "SOMEWHAT USEFUL" BASE: PHR USERS (n=266) Making sure info is correct 64% Looking at test results 57% Renewing Rxs online 52% **Emailing providers** 50% Scheduling doctor visit 48% Managing family's health info 44% Reminders for tests 44% Keeping track of child's records* 43% Seeing doctor's instructions 41% Sharing info with your family 38% *Among parents who have a PHR.

CALIFORNIA HEALTHCARE FOUNDATION



All things considered, do you agree or disagree with the following...

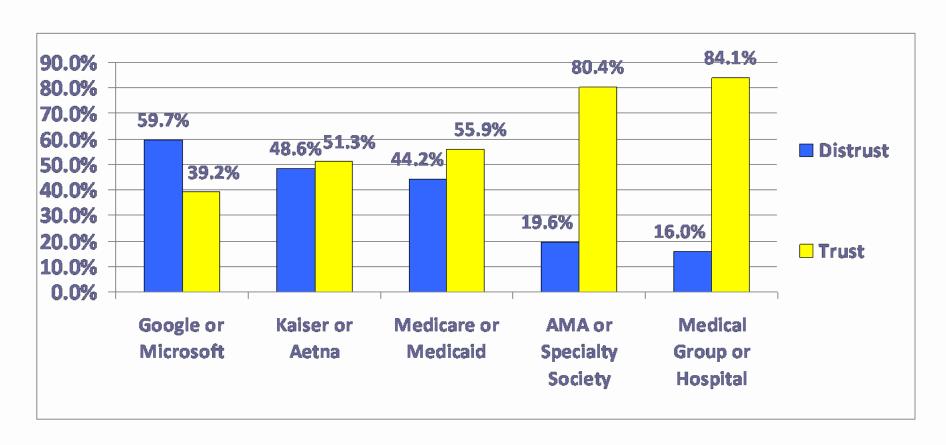


Non-Users' Preferences Toward PHR Source

Would you be interested in using a PHR if it were from... BASE: ADULTS WITHOUT A PHR (n=1,583) The hospital or medical practice you use Your health insurance plan 50% A government group like Medicare 36% A nonprofit group like the American Heart Association 35% A company like Google or Microsoft 25% Your employer 25%



Would you trust a PHR run by...

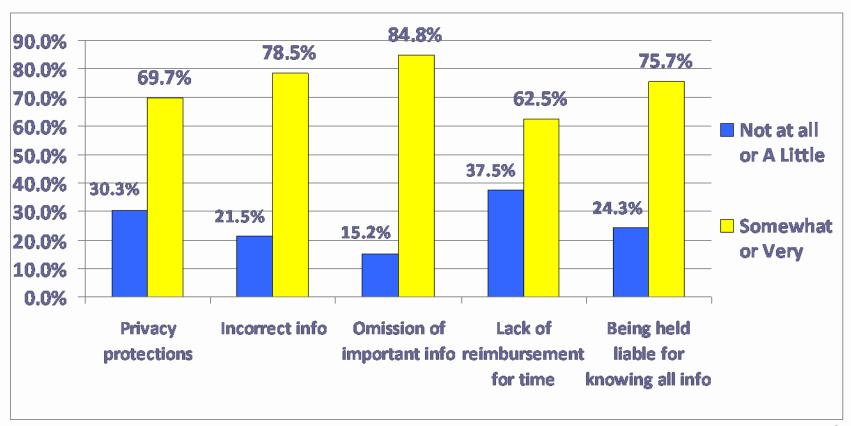


Potential Barriers to Using a PHR

PERCENT OF NON-USERS WHO AGREE BASE: ADULTS WITHOUT A PHR (n=1,583) Worry about the privacy of my information 75% Don't need this to handle my health needs 61% Might cost too much 51% Would take too much time Don't like computers/Internet 26%

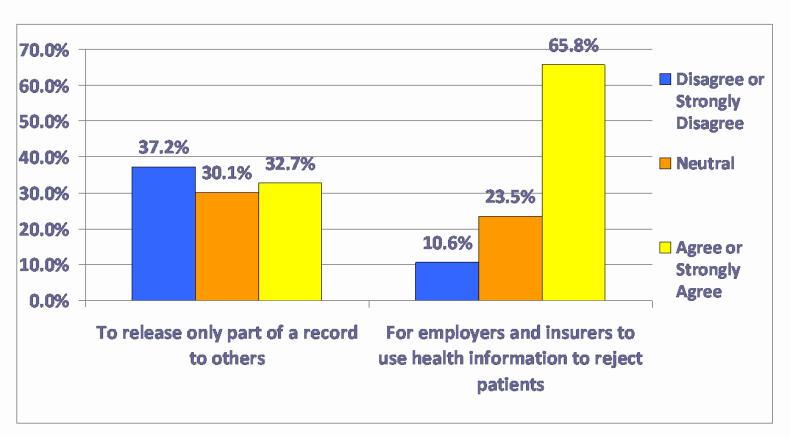


With regard to PHRs, how concerned are you about...





Electronic records would make it easier...



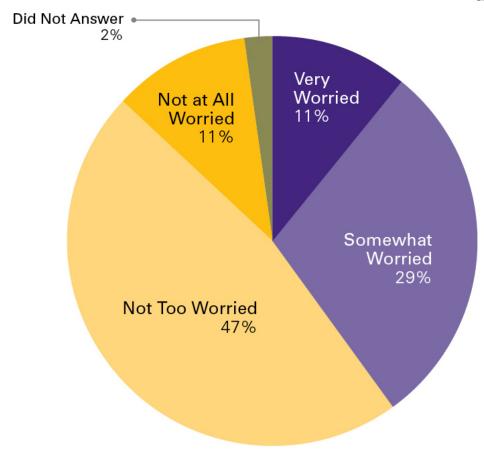
Factors that Would Encourage Signing Up for a PHR

PERCENT SAYING THEY WOULD OR MIGHT SIGN UP IF... BASE: ADULTS WITHOUT A PHR (n=1,583) You trusted the organization 57% There were strong laws and fines for Web sites if they let others look at your info 54% Your doctor told you that your information was safe 52% Web site had detailed privacy policy 51% Your friends or families used it and said info was safe 50% Would be told if anyone looked at info who should not have 50% Seal of approval on Web site, like on banking sites 48% You learned about government privacy rules 46%

PHR Users' Attitudes About Privacy of Information in Their PHR

Now that you have your health information online, how worried are you about the privacy and confidentiality of your information?

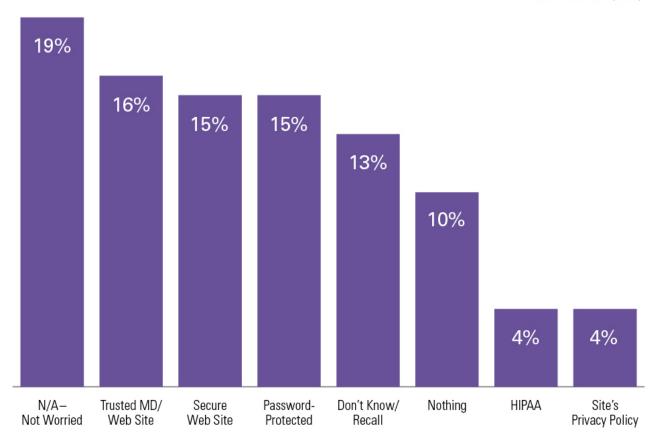
BASE: PHR USERS (n=266)



What Reassures PHR Users About Privacy Concerns?

Think back to when you were first able to look online at your health information, like lab tests. What made you feel that information would be kept safe and private?

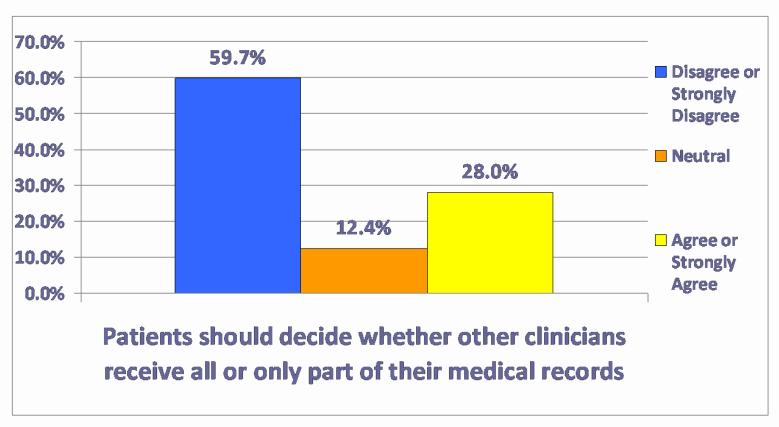
BASE: PHR USERS (n=266)



Note: This was an open-ended question.



Do you agree or disagree with the following...





Panel 4

Perspectives on Privacy and Security Requirements for PHRs and Related Technologies

Moderator: Leslie Francis, Ph.D., J.D.

Distinguished Professor of Law and Philosophy and Alfred C. Emery Professor of Law

University of Utah



The final panel will address the need for privacy and security requirements for PHRs and related non-covered entities, in accordance with the study required by Congress. It will provide a forum for different views on the appropriate regulation, if any, or other requirements that should be applicable to non-covered entities PHRs and related service providers and technologies.



Panel 4 will have two sub-panels.

- Panel 4(A) will include representatives of federal and state agencies with current enforcement authority.
- Panel 4(B) will explore whether there is a need for regulation and other requirements and the pros and cons of different approaches to government regulation and private sector oversight.



Panel 4(A)

- Loretta Garrison, J.D., Senior Attorney, Bureau of Consumer Protection, Federal Trade Commission
- Adam Greene, J.D., M.P.H., Senior Health IT & Privacy Specialist, HHS Office for Civil Rights
- Joanne McNabb, CIPP/G, Chief,
 California Office of Privacy Protection



Panel 4(B)

- Robert Hudock, J.D., Counsel, EpsteinBeckerGreen
- Frank Pasquale, J.D., Schering-Plough Professor in Health Care Regulation and Enforcement, Seton Hall Law School
- Nicolas Terry, B.A. (Hons) Law, LL.M, Chester A. Myers Professor of Law,
 - Saint Louis University School of Law



Public Comment Period

 There will be a 30-minute period for oral comments.

Each comment will have a two-minute time limit.



- Live webcast attendees who wish to make a comment by telephone should dial 1-866-363-9013. The Conference ID number is 28762819. This is an operator-assisted call.
- Roundtable attendees may use the microphone in the center room to make a comment.
- If the number of speakers requesting to comment is greater than the number that can be reasonably accommodated during the scheduled PHR Roundtable, ONC will take written comments at the What Do You Think? Public Comment Table until close of business today.



Closing

Joy Pritts, J.D.

Chief Privacy Officer

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 Public comments may be submitted to ONC through ONC's PHR Roundtable Website:

http://healthit.hhs.gov/blog/phr-roundtable/?page_id=18

 The online public comment period will close on Friday, December 10, 2010.