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

  

- 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](http://www.connectingforhealth.org/resources/surveys.html)
What Is Useful About a PHR?

*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=208)

- Making sure info is correct: 64%
- Looking at test results: 57%
- Renewing Rx 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.
All things considered, do you agree or disagree with the following…

Unpublished data – do not cite or circulate
Non-Users’ Preferences Toward PHR Source

Would you be interested in using a PHR if it were from…

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The hospital or medical practice you use</td>
<td>58%</td>
</tr>
<tr>
<td>Your health insurance plan</td>
<td>50%</td>
</tr>
<tr>
<td>A government group like Medicare</td>
<td>36%</td>
</tr>
<tr>
<td>A nonprofit group like the American Heart Association</td>
<td>35%</td>
</tr>
<tr>
<td>A company like Google or Microsoft</td>
<td>25%</td>
</tr>
<tr>
<td>Your employer</td>
<td>25%</td>
</tr>
</tbody>
</table>

Would you trust a PHR run by...

Unpublished, raw data – do not cite or circulate
Potential Barriers to Using a PHR

PERCENT OF NON-USERS WHO AGREE

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 38%

Don’t like computers/Internet 26%

With regard to PHRs, how concerned are you about…

Unpublished data – do not cite or circulate
Electronic records would make it easier…

Unpublished data – do not cite or circulate
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?

Did Not Answer: 2%

Not at All Worried: 11%

Not Too Worried: 47%

Somewhat Worried: 29%

Very Worried: 11%

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=286)

- N/A – Not Worried: 19%
- Trusted MD/Web Site: 16%
- Secure Web Site: 15%
- Password-Protected: 15%
- Don’t Know/Recall: 13%
- Nothing: 10%
- HIPAA: 4%
- Site’s Privacy Policy: 4%

Note: This was an open-ended question.
Do you agree or disagree with the following...

Patients should decide whether other clinicians receive all or only part of their medical records

Unpublished data – do not cite or circulate
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.
PHR Roundtable

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
PHR Roundtable

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
PHR Roundtable

Public Comment Period

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

• Each comment will have a two-minute time limit.
PHR Roundtable

- 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.
PHR Roundtable

Closing

Joy Pritts, J.D.
Chief Privacy Officer
U.S. Department of Health and Human Services
PHR Roundtable

• 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.