ETHICAL CONSIDERATIONS IN INTEGRATING PERSONAL HEALTH RECORDS INTO CLINICAL PRACTICE

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Objectives

- Review the concept of PHRs and trends of how they are being used.
- Demonstrate common practical tools for managing and monitoring targeted care needs.
- Review common ethical concerns & barriers surrounding the use of PHRs.
- Striking the right balance for service integration for those who can benefit from PHRs.
A Bit of Perspective

- What has changed in the past 15 years with respect to healthcare and the internet?

- What can you imagine over the next 15 years?

"Our future is greater than our past." - Ben Okri
What is a PHR

- Per the Dept. of HHS, a PHR is:
  - "An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual."

- A PHR may include:
  - info about an individual's conditions and ailments
  - medication and dosages & allergies
  - test results (X-ray, labs, etc)
  - immunization history

What’s a PHR, have you heard? [http://What’s a PHR]
Consumer Use of Electronic PHRs Remains Very Low

SOURCE: Markle Foundation Survey—June 2008
Patient Level Components of a PHR System

- Self-Monitoring
- Clinical Records
- Communication
- Decision Support
HIE View – Total System Inter-Operability
Among patients,
- The large majority of patients who had ever used a PHR felt they were valuable but very few had used them.
- Just under half said they would be interested in trying to do so.

Among physicians,
- Half thought PHRs could empower patients to participate in their care.
- 44% said they would be willing to use PHRs in their clinical work.
- Only 22% agreed that using PHRs would improve their relations with patients (one-third disagreed).
- Only 30% agreed PHRs would improve the quality of care.

Other physician concerns included:
- PHRs might contain incorrect information.
- Privacy protections may be inadequate.
- Patients might omit important information from their PHR.
ELECTRONIC RECORDS:
Electronic Health Records, Electronic Patient Records & Personal Health Records

After Stead et al, 2005
PHR for Physicians vs Patients

- Improving health and decreasing cost may be achieved by:
  - Implementing necessary policies and standards to facilitate integration of PHR among stakeholders (e.g. tethering with EHR)
  - Providing incentives to all stakeholders (e.g. tax credits)
  - Offering patient oriented clinical decision support (e.g. alerting drug interactions or reminding patients to take their medication)

- In the future,
  - Research regarding consumer’s behavioral aspects and business models of PHR may increase its penetration among stakeholders
  - In long term, PHRs may be redefined by studies focusing on integrating personalized genomic information into PHR, implementing real-time mass statistical health analysis, encompassing customized health education strategies and utilizing its infrastructure for public health emergencies
  - PHR is/should be more than just a repository of patient data
EHR ADOPTION IS SLOW, PHR SLOW


NOTES: Any EMR/EHR is a medical or health record system that is either all or partially electronic (excluding systems solely for billing). The 2009 data are preliminary estimates (as shown on dashed lines), based only on the mail survey. Estimates of basic and fully functional systems prior to 2006 could not be computed because some items were not collected in the survey. Starting in 2007, the skip pattern after the all or partial EMR/EHR systems question was removed. Includes nonfederal, office-based physicians. Excludes radiologists, anesthesiologists, and pathologists.

SOURCE: CDC/NCHS, National Ambulatory Medical Care Survey.
Experience from those who used PHR

- As a result of their PHR use, users cite:
  - Taking steps to improve their own health
  - Knowing more about their health care
  - Asking their doctors questions they would not otherwise have asked

- Two-thirds of the public remain concerned about the privacy and security of their health information, but the majority of those who are using a PHR are not very worried about the privacy of the information contained in their PHR.

- Most PHR users and non-users say we should not let privacy concerns stop us from learning how health IT can improve health care.

- Those with chronic conditions and less education are more likely to experience greater positive value from a PHR.
Hmm . . .

- Some things worth thinking about . . .
## Online Social Networking Adoption

### Boomers catching up with GenX with social networking

Percentage maintaining a page on various social networking sites

<table>
<thead>
<tr>
<th>Social networking site</th>
<th>Ikes</th>
<th>Boomers</th>
<th>Gen Jones</th>
<th>Gen X</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook.com</td>
<td>39%</td>
<td>39%</td>
<td>43%</td>
<td>50%</td>
</tr>
<tr>
<td>Twitter.com</td>
<td>5%</td>
<td>8%</td>
<td>15%</td>
<td>14%</td>
</tr>
<tr>
<td>LinkedIn.com</td>
<td>6%</td>
<td>8%</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>Classmates.com</td>
<td>19%</td>
<td>20%</td>
<td>21%</td>
<td>12%</td>
</tr>
<tr>
<td>Myspace.com</td>
<td>11%</td>
<td>10%</td>
<td>22%</td>
<td>29%</td>
</tr>
<tr>
<td>None of these</td>
<td>50%</td>
<td>47%</td>
<td>45%</td>
<td>32%</td>
</tr>
</tbody>
</table>

Question: On which social networking sites do you maintain a profile? (select all that apply)
Chronic Disease Patients Are Older, Less Educated And Less Computer Literate Than The General Public

<table>
<thead>
<tr>
<th></th>
<th>Living With Chronic Condition</th>
<th>No Chronic Conditions</th>
<th>US Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged 65+</td>
<td>29%</td>
<td>15%</td>
<td>17%</td>
</tr>
<tr>
<td>Less Than High School Education</td>
<td>25%</td>
<td>10%</td>
<td>12%</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>31%</td>
<td>34%</td>
<td>33%</td>
</tr>
<tr>
<td>Some College</td>
<td>27%</td>
<td>26%</td>
<td>26%</td>
</tr>
<tr>
<td>College Degree Or More</td>
<td>18%</td>
<td>29%</td>
<td>28%</td>
</tr>
<tr>
<td>Use Computer At Work, School, Home</td>
<td>52%</td>
<td>75%</td>
<td>71%</td>
</tr>
<tr>
<td>Use Internet Or eMail</td>
<td>51%</td>
<td>74%</td>
<td>70%</td>
</tr>
</tbody>
</table>

SOURCE: Pew Internet & American Life Project
Survey Says . . .

- I wish I knew more about my loved one’s care (among caregivers) - 63%
- I wish my doctors had more time to talk to me - 60%
- I feel like I have to be my own advocate - 55%
- I wish my doctors talked and shared more info with each other - 55%
- I wish my doctor knew me and my health better - 51%
- Keeping track of all of my health info is difficult - 50%

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Searched online for info about a disease or medical problem</td>
<td>67%</td>
</tr>
<tr>
<td>Searched online for info about a doctor</td>
<td>30%</td>
</tr>
<tr>
<td>Entered info on a Web site about your weight, nutrition, or exercise</td>
<td>22%</td>
</tr>
<tr>
<td>Entered info on a Web site about a chronic illness*</td>
<td>21%</td>
</tr>
<tr>
<td>Renewed Rx online</td>
<td>15%</td>
</tr>
<tr>
<td>Sent/received email from doctor</td>
<td>8%</td>
</tr>
<tr>
<td>Used a PHR</td>
<td>7%</td>
</tr>
<tr>
<td>Looked at test results online</td>
<td>6%</td>
</tr>
<tr>
<td>Used a medical device that connects to your computer</td>
<td>6%</td>
</tr>
<tr>
<td>Posted online about your health or health care</td>
<td>5%</td>
</tr>
<tr>
<td>Joined an online group about a health issue</td>
<td>5%</td>
</tr>
<tr>
<td>Used a health-related application for a cell phone</td>
<td>2%</td>
</tr>
</tbody>
</table>

* Among those with chronic illness.
What do patients say they want?

Over 70 percent of on-line respondents would use one or more features of the PHR:

- Email my doctor: 75 percent
- Track immunizations: 69 percent
- Note mistakes in my record: 69 percent
- Transfer information to new doctors: 65 percent
- Get and track my test results: 63 percent

Almost two-thirds (65 percent) of people with chronic illness say they would use at least one of the PHR features today, compared with 58 percent of those without chronic illness.
People vary in their preference for PHR media
Consumer Interest In PHRs, Even When Offered At No Charge, Remains A “Mixed Bag”

SOURCE: Markle Foundation Survey—June 2008
The General Public Thinks **Physicians** Are The Most Trusted Source For Personal Health Records

Source: Harris Interactive  Strategic Health Perspectives 2007
The General Public Believes Personal Health Records Are For Doctors and Patients, Not Plans

"Strongly/Somewhat Agree"

- My insurer should have access to my personal health record information
  - 26%
  - 27%
- My personal health record is for my own use and should not be provided to other parties
  - 50%
  - 53%
- All physicians treating me should have access to information contained in my personal health record
  - 83%
  - 80%
- A personal health record would be a valuable tool to track the progress of my health
  - 81%
  - 76%

Source: Harris Interactive, Strategic Health Perspectives 2007, 2008
Integration Of PHRs With Electronic Health Record

76%: More than three-quarters of survey respondents believe that personal health records (PHRs) need to be integrated with an electronic medical record (EMRs) in order to have value in patient treatment.

Source: HIMSS Analytics Vantage Point, May 2008
PHRs Are Evolving . . .
Demonstrate Common Practical Tools

MS HealthVault: [http://MSHV in Action](http://MSHV in Action)  [https://MSHV Login](https://MSHV Login)
PHR: Pay site example

Now you can send faxes from your PC using your mymedicalrecords.com personal health record!

We are excited to announce an important new feature that makes the MMR personal health record even more valuable. From now on, you can send outbound faxes directly from within your account using any internet connected computer. No need for a fax machine! You can send your filed personal health records, medical records and vital documents in your account. Plus, you can send faxes that you upload from your computer hard drive. Read more
MediCard ™ overall advantages includes:

- Always available in the wallet, in Emergency and in daily use
  - Doesn't get lost, forgotten or misplaced
  - Easily found by emergency first responder
- Personalized with high quality printing
- Quick and simple to connect to any USB port
- Enhanced security
  - Strong Encryption
  - Password protection
  - Memory partitioning (Read only part, Secured part, Public part)
- Large memory capacity (up to 8GB), may contain both data and application software
- Double sided USB connector
- High speed data transfer for fast downloading medical images (X-ray, MRI etc.)
Ethical Considerations for PHRs

Okay, so how should I consider when suggesting the use of PHRs?
http://PHR concerns

To encourage PHR use or not to . . . , that is the question.
Key 5 Ethics Values

- Nonmalficence – Do No Harm
- Beneficence – Provide Benefit
- Autonomy – Respect Patient Agency
- Justice – Treat People Fairly
- Fidelity – Act With Integrity
# Ethical Concerns & PHR Models

## PHR Functional and Payment Models

### Functional Models (Endsley)

| (1) | A provider-owned and provider-maintained digital summary of clinically relevant health information made available to patients. EHRs with internet portals and relevant reports. |
| (2) | A patient-owned software program that lets individuals enter, organize and retrieve their own health information and that captures the patient’s concerns, problems, symptoms, emergency contact information, etc. |
| (3) | A portable, interoperable digital file in which selected, clinically relevant health data can be managed, secured and transferred. Platforms for portable PHRs include smart cards, personal digital assistants, cellular phones and USB-compatible (universal serial bus) devices that can be plugged into almost any computer. |

### Payment Models (Gellman)

| (1) | Consumer pays for the service directly. |
| (2) | Advertising pays for the service. |
| (3) | Employer or health plan pays for the service. |

Ethical Considerations

- Ethical considerations around PHRs are varied as the users and will likely be affected by:
  - Computer comfort and use
  - Health care utilization
    - Frequency of doctor visits
    - Number of prescription medications
  - Chronic illness
  - Age
  - Parents and caregivers
- Ethical promotion should consider barriers to effective use
Barriers to Effective PHR Use

- **Missing building blocks.**
  - As of 2008, only 1.5% of hospitals had a comprehensive electronic records system in all major units, and only 7.6% had such a system in at least one clinical unit (NEMJ).
  - Only 17% of physicians use basic or comprehensive electronic records, despite the great merits of adopting this technology (for purposes other than PHRs) and considerable public support.

- **Not reimbursed.**
  - Hospitals questioned the return on investment and cited "inadequate capital for purchase" and "concerns about maintenance costs" as the two most common barriers against the adoption of electronic records (at 74% and 44%, respectively).

- **Fear of productivity loss.**
  - More than a third of hospitals studied found resistance to the adoption of electronic records on the part of physicians.
  - A 2007 JMAMIA study of electronic record adoption in Massachusetts found that 81% of respondents identified loss of productivity as a barrier to the adoption or expanded use of electronic records.
    - Reasons cited varied from poor system design to a "lack of clinical capacity to absorb changes during implementation."
Barriers to Effective PHR Use

- **Missing interoperability.**
  - The electronic records that exist at present, for the most part, lack interoperability.
  - Private PHR-like systems such as Google Health and Microsoft HealthVault are directly interoperable with only a few clinics, hospitals, insurers, and pharmacies.
  - Among patient-authorized entities such as personal health record vendors, interoperability rules have yet to be adopted.

- **The risks of incomplete data.**
  - Some health care personnel prefer EHRs over PHRs. The main reason is that with PHRs, individuals choose what to include and what to allow others, even emergency personnel, to access at any given time. Thus, health care personnel who rely on PHRs face the risk of making decisions based on incomplete, partial, or possibly patient-edited data.

- **Privacy concerns.**
  - Privacy and security have been noted as "very important" concerns when it came to online medical records.
  - Private providers such as Microsoft and Google are not subject to the legislation that protects the privacy of an individual's health information and regulates its use and disclosure.
Barriers to Effective PHR Use

- **Aggravate the patients and time-consuming.**
  - When HIPAA was passed in 1996 to allow patients to see their medical records and to request corrections to them, physicians were concerned that they would have to spend a considerable amount of time explaining their records to their patients, particularly if they noted suspicions such as that the patient was neurotic, alcoholic, or the subject of abuse. Others sought to keep notations and interpretations they made out of the accessible record. All these concerns apply, only much more so, to PHRs, because they disclose more and make the records heretofore kept in doctors' offices much more accessible.

- **Defensive medicine.**
  - PHRs are antagonistic to the basic interests of those who practice medicine:
    - Easier for lawyers to determine that
      - some procedures that should have been ordered were not
      - that incorrect procedures were ordered
      - that counterindications to interventions were ignored
      - that proper follow-up was not undertaken
But what if the provider doesn’t wanna share . . .

IC 16-39-2-4

A patient is entitled to inspect and copy the patient's own mental health record. However, if the provider that is responsible for the patient's mental health records determines for good medical cause, upon the advice of a physician, that the information requested under this section is detrimental to the physical or mental health of the patient, or is likely to cause the patient to harm the patient or another person, the provider may withhold the information from the patient. If the provider is a state institution or agency, the patient may appeal the provider's refusal to permit the patient to inspect and copy the patient's own record under IC 4-21.5.

Records may come at a charge: IC 16-39-9
Barriers to Effective PHR Use

- **Not computer-savvy.**
  - The older generation of health care personnel is generally not computer-savvy.
  - Participation in a PHR was positively correlated with education and knowledge, but survey participants expressed a willingness to relinquish privacy for better care.
    - This finding reinforces contentions that vulnerable individuals, such as the poor and those with limited literacy, may not derive the same benefit and may experience unique access and other barriers with respect to PHR.

- **With too much information.**
  - Decisions may be inappropriately delayed.
  - Information overload can occur and some information may be pushed out.
  - Usually, more recently acquired information is retained and used, even if it is not the most relevant.
  - Information will also tend to be retained if it supports a preconceived notion.
  - Mental fatigue or decision fatigue can occur from the labor of sifting through information.
PHRs w/o HIPAA Protections

- Other areas of concern are:
  - Provider privilege
  - Subpoenas
  - Marketing of health care data
  - Linkage of records
  - Security/Privacy policies
  - Ability to correct files
  - Consent/Disclosure issues
“I don’t WANT to be an informed medical consumer. I liked it better when my only medical responsibility was to stick out my tongue.” – Dave Barry
Striking the Balance

- PHRs are still in early development
- PHRs are likely to stay, particularly as consumer bear an increasing proportion of the cost of care
- In general, most patients’ interests will be better served by tethered EHRs and HIEs than by stand alone PHR products
- PHRs can be useful in better managing chronic disease but should be balanced with persons interests and strengths
- Clinicians should be aware of the issues and take an “informed consent” approach to PHR promotion and abide by ethical principles
Questions/Comments

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