PCHRI2006 – Societal Implications of PHRs

Patricia Flatley Brennan, RN, PhD
Jenna Marquard, MSIE, PhD
Candidate
University of Wisconsin-Madison
October 10, 2006
Potential Societal Benefits of PHRs are Significant

- Public health...
- Prevention...
- Chronic disease management...
- Improved self-care...
- Research participation...
- Economics...

These benefits cannot be realized if patients do not use PHRs or use them inappropriately.
Societal Benefits of PHRs Rest on Two Key Assumptions

- PHR content and control over that content will be *understandable* to patients, especially with personally controlled PHRs.
- PHRs will be viewed as *useful* by patients.
- These assumptions are likely coupled.
We Must Make PHRs Understandable to Patients

- Understanding PHR content
  - Health literacy levels are low

- Understanding control over PHR content
  - We are unsure how literate patients will be in granting access rights to their records
We Must Make PHRs Useful to Patients

- Usefulness is likely to look different for each patient

Diagram:

Understanding
- Content
- Control over content

Usefulness
- Access
- Functionality
- Revenue
We Must Make PHRs Useful to Patients

- Demand for PHRs depends on their perceived usefulness by patients.
- The ‘ideal’ PHR, for the individual and society, is one that has high demand.
Understanding and Usefulness are Levers for Increasing PHR Demand

- If we increase patient *understanding*, and/or *perceived usefulness* of PHRs, we will likely increase demand for PHRs.
- Highly demanded PHRs will likely result in the aforementioned societal benefits:
  - Public health
  - Prevention
  - Chronic disease management
  - Improved self-care
  - Research participation
  - Economics
Increasing Patient Understanding of PHR Content

- **Language**
  - Health Literacy? Health care kindergarten?
  - Tailoring
  - Culture

- **Design**
  - Information structure and layout, etc.
  - Design-for-action
Increasing Patient Understanding of Control Over PHR Content

- Individual preferences for privacy/access
  - Solicited through surveys, case examples, stories?
  - Conveying uncertainties in these choices to patients – what might happen if I grant access to my mental health record to Provider X?
Increasing Perceived Usefulness of PHRs

- **Information access**
  - What can I see, or see more easily, that I couldn’t before?

- **Functionalities**
  - What can I do, or do more easily, with my information that I couldn’t do before?

- **Revenue generation**
  - How can I profit, or profit more easily, from ownership of my information in ways I couldn’t before?
Integration of the PHR into existing health information management behaviors – **Health@Home**

Will what patients demand align with the interest of other stakeholders?

How do we deal with this in making infrastructure choices?