PCHRI2006 – Societal Implications of PHRs

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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
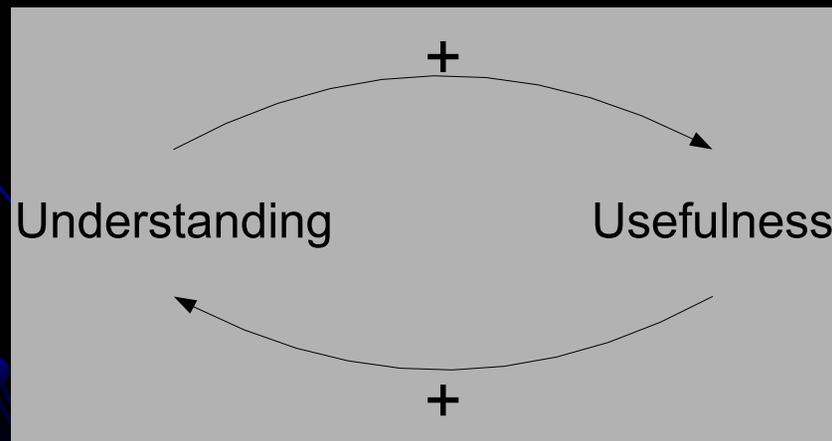
We Must Make PHRs Understandable to Patients

- 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

Understanding   +   Usefulness

+
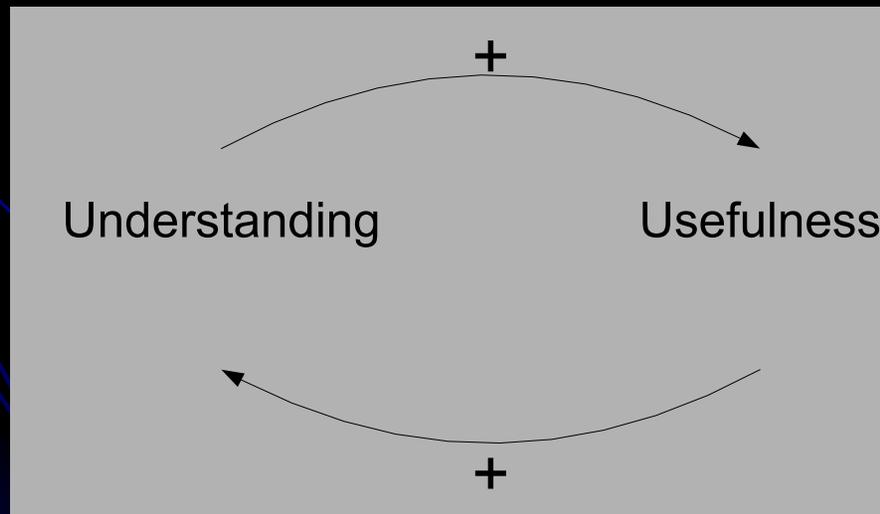
We Must Make PHRs Useful to Patients

- Usefulness is likely to look different for each patient
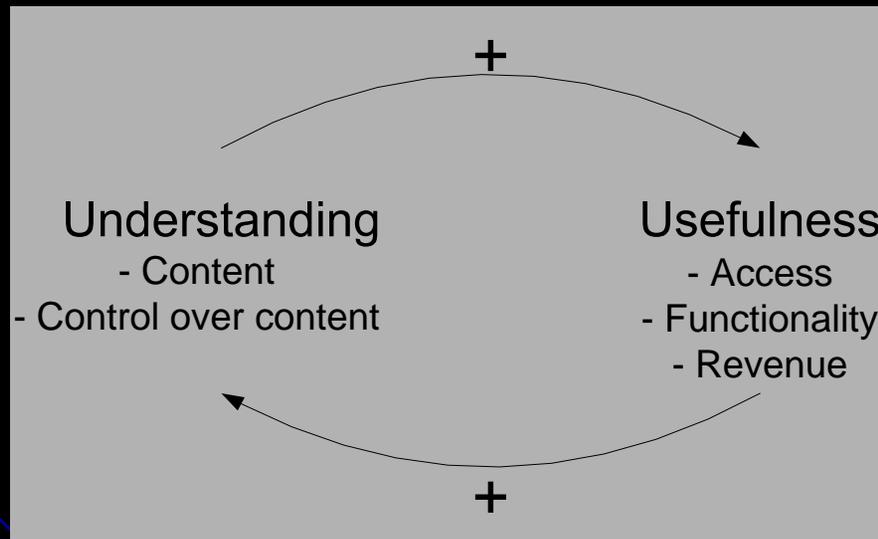
We Must Make PHRs Useful to Patients

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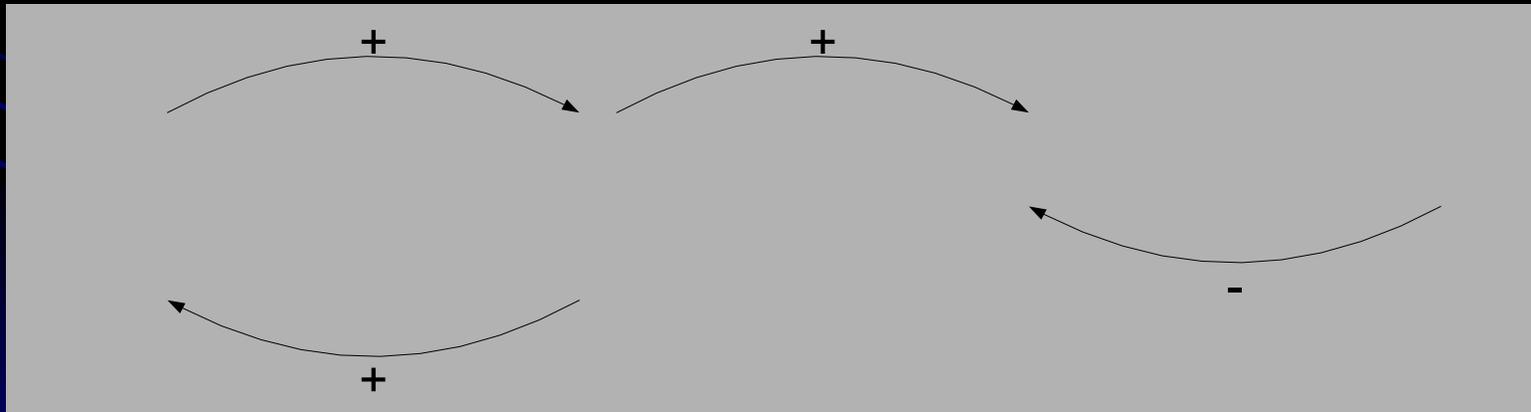
Understanding and Usefulness are Levers for Increasing PHR Demand

- 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 <u>PHR Content</u>

- Language
  - Health Literacy? Health care kindergarten?
  - Tailoring
  - Culture
- Design
  - Information structure and layout, etc.
  - Design-for-action
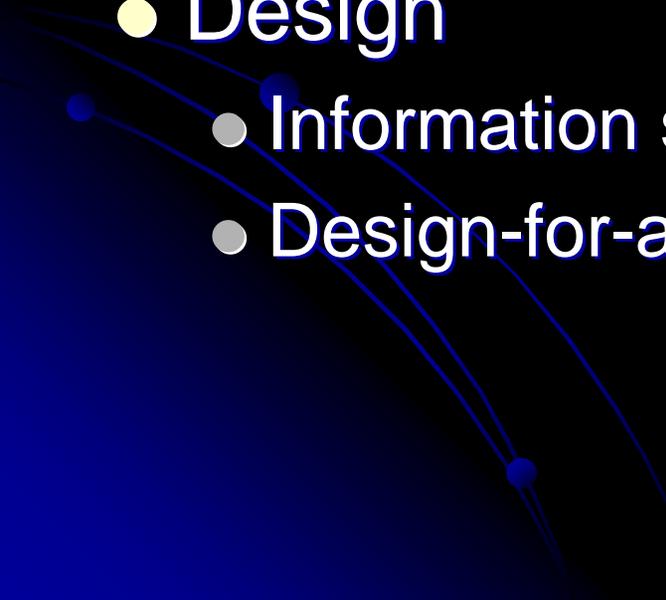
Increasing Patient Understanding of <u>Control Over PHR Content</u>

- 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?
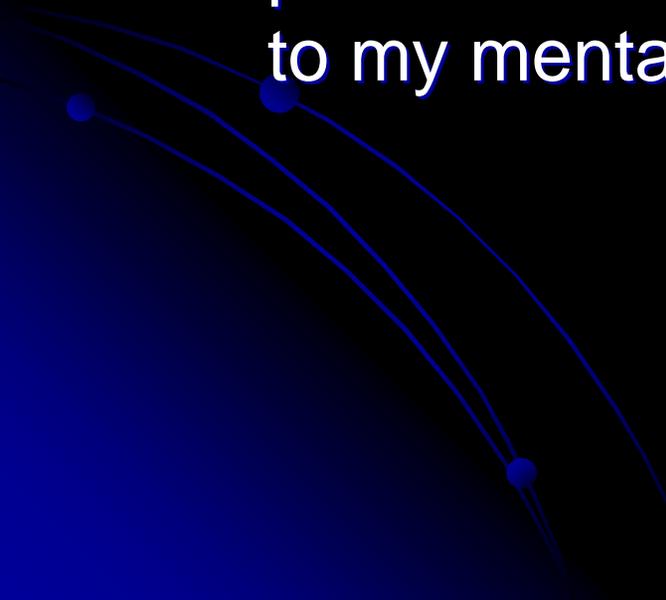
Increasing
Perceived Usefulness of PHRs

- 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?

Leftovers…

- 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?