Personal Health Record Research Topics

NCVHS NHII Workgroup

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Contributors to this review

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Goal

- Promote discussion about PHRs
- Broad categories of issues
- It does not imply who should be responsible for the research agenda
- Next steps
  - confirm the scope and audience(s)
  - suggest the level of granularity that is desired

Evaluation issues for stakeholders and society

- Patients
- Providers
- Payers
- Purchasers
- Intermediaries
- Design issues
- Societal and evaluation issues

Patients

- Define information use cases for patients around a particular health issue.
  - What information do lay persons want? What do they do with it? How do they use it? How much do they need? When do they need it? How often?
- What are differences and similarities in the use of health information across varied population groups?
- How might a PHR/PHS be structured and or used to improve personal health behaviors?
- How does medical information need to be repurposed for the patient?

Providers

- What are key or representative use cases for providers and how their workflow involves providing information to the patient or receiving information from the patient?
- Under what circumstances do providers need or value patient-initiated information?
- What are effects of progressive disclosure?

Payers

- Why are insurance companies and CMS interested in sharing their patient records with the patient?
- What is the payer experience of sharing such data?
- Why might payers be interested in having patient-initiated data as part of their records?

Purchasers

- Why are employers who purchase health insurance interested in their employees having access to their personal health information?
- What kind of information do purchasers wish their employees to have?
- What is the employer expectation of employees' use of information?
- Why might purchasers be interested in having patient-initiated data as part of their records?

Intermediaries Business Case

- Clearinghouses under HIPAA, Third Party Benefit Administrators, and other businesses may become involved in distributing health information to patients.
- Under Health Savings Accounts and stand-alone PHR/PHR-S systems, banks and other third parties have access to and manage the flow of personal health information.

Aggregate Questions

- Who owns what in the EHR and PHR/PHR-S space?
- How is ownership related to the control of access to data within a system?
- What is the scope of logging each and every time that the PHR/PHR-S is touched or accessed by any of the above stakeholders?
- In order to be legally protected will a provider have to maintain a time stamped exact copy of each off-load of health information to the patient?
- Who pays for the PHR/PHR-S?

Design Issues

- What is the basic structure of the PHR/PHS and how is it defined?
- What are the interface issues and other usability issues for each of the potential users?
  - Are specific technology platforms (e.g. pc, web, pda, cell phone etc.) Better suited to different users?
  - How do we best present data for patient use?
- How can we structure the PHR/PHS to take advantage of the semantic web?

Societal and Evaluation Issues

- What are the metrics by which we will measure the process, outcome, and impact of the PHR/PHS?
- What are the major incentives and disincentives?
- How might the PHR/PHS be used to positively impact healthcare quality? Costs?
- How might we measure the long term impact of a PHR/PHS on morbidity and mortality?
- How might we measure the validity and reliability of PHR/PHS data?
- What is the concordance of patient-entered and provider-entered data (e.g., problem list)?
- Does aggregate PHR/PHS data have regional or national relevance?