Update on Report on Federal Roles in PHRs

Cynthia Baur

Office of Disease Prevention and Health Promotion, HHS

Background

- Commissioned by ODPHP

- Project team: David Lansky, Susan Kanaan, Josh Lemieux

- Purpose: Provide ODPHP, other HHS offices and agencies insights and analysis on PHRs and possible Government roles, responsibilities, opportunities and limitations

Sources for Report

- 15 interviews with key informants
  - 13 federal staff
  - 5 non-federal experts
- NCVHS hearings on PHRs
- Connecting for Health reports and meetings
- Project team expertise

Federal Roles tied to Missions

- Health care provider
- Payer
- Participant in standards efforts
- Regulator
- Researcher

- Public educator and knowledge disseminator
- Guardian of public health and public interest
- Employer

Consensus on Roles (interviews)

- **Standardization in data**
  - Facilitate standards-based approaches to health data collection and exchange
- **Experimentation in models**
  - Encourage, coordinate, help disseminate findings from wide range of experiments to find successful PHR applications and models

Critical Federal Contributions to PHR Development (interviews)

- Visioning and strategic leadership
- Leading and facilitating standards-based approaches
- Enforcing laws and creating right the regulatory environment
- Supporting experimentation and facilitating the evolution of PHRs

Critical Challenges for Federal Government (project team)

- What vision of health care and health system reform will inform the Government's involvement with PHRs?
- What is the Government's vision for empowering consumers and how will it translate into policies and programs?
- What is the Government's stance toward the many possible uses of PHRs?

Critical Challenges cont.

- What federal actions are needed to promote population-wide benefits for PHRs?

- How can the coordination of federal policy decisions be strengthened and enhanced and how will progress be assessed?

Recommended Steps
(project team)

- Fundamental: Funding ONCHIT appropriately to carry out necessary coordination in PHRs

- Create a process to clarify objectives and identify research-driven answers to 5 critical challenges

- Strengthen mechanisms and resources for coordinating agencies' PHR activities

Recommended Steps cont.

- Assign responsibilities and specify metrics to evaluate progress
- Nurture a public-private policy framework to address
  - Interoperability
  - Privacy
  - Reimbursement and pricing
  - Patient access and control

PHRs for Prevention and Personal Health Management (ODPHP)

- Emphasis on personal responsibility, behavior and consumer cost-sharing creates a clear public interest in broad access and appropriate tools
  - HP2010 objective on Internet access has received little attention and funding in HHS
- Personal Health Management (PHM) is an under-developed concept that requires research with different intended user groups
  - Consumer capacities to follow prevention recommendations, engage in PHM and use technology effectively vary across the population

PHRs, Prevention and PHM, cont.

- PHRs can make visible many of the intangibles of prevention
  - Example: Estimate personal costs of unhealthy behaviors and inaction
  - Example: Make suggestions about and create new associations among health issues for users
- Proliferation of PHR-type applications from agencies may crowd the field, fragment users' data and confuse users

Core messages

- Federal Government can make critical contributions and has a role in the development of PHRs
- Unique contributions
  - Vision and strategies for the evolution of PHRs as part of a consumer-centric system
  - Fill the gaps for those who would otherwise be left out
- A coordinated, systematic, research-driven and collaborative approach is most appropriate

Unanswered but Critical Questions about the Relationships among Government, Consumers and Providers

- Consumer and provider engagement is critical to the success of PHRs and PHM
- So far, consumers and providers are largely unaware or are wary of PHRs
- Is it appropriate and necessary for the Federal Government to help build public trust as a contribution to the infrastructure?
- If so, what mechanisms could the Government use?