



American Health Information Community

Consumer Empowerment Workgroup

http://www.hhs.gov/healthit/ahic/ce_main.html

Workgroup Membership

- **Co-chairs:**

- Nancy Davenport-Ennis National Patient Advocate Foundation
- Linda Springer Office of Personnel Management

- **Members:**

- Jodi Daniel Office of the National Coordinator
- Lorraine Doo Centers for Medicare and Medicaid Services
- Kevin Hutchinson Surescripts
- Robert Kolodner Veterans Health Administration
- David Lansky Markle Foundation
- Ross Martin Pfizer
- Susan McAndrew Department of Health and Human Services
- David McLean RxHub
- Davette Murray Tri-Service Infrastructure Management Program Office
- Nancy Nielsen American Medical Association
- Lynne Rosenthal National Institute of Standards and Technology
- Charles Safran American Medical Informatics Association
- Scott Serota Blue Cross Blue Shield Association
- Steve Shihadeh Microsoft
- Robert Tennant Medical Group Management Association
- Myrl Weinberg National Health Council

- **Office of the National Coordinator:**

- Kelly Cronin

Workgroup Charges

- **Broad Charge for the Workgroup:**
 - Make recommendations to the Community to gain wide-spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered.
- **Specific Charge for the Workgroup:**
 - Make recommendations to the Community so that within one year, a pre-populated, consumer-directed and secure electronic registration summary is available to targeted populations. Make additional recommendations to the Community so that within one year, a widely available pre-populated medication history linked to the registration summary is deployed.

This presentation is focused on the Specific Charge.

Principles of Consumer Empowerment

- The Workgroup is reviewing draft principles for consensus:
 - Individuals should be guaranteed the right to access their own health information
 - Individuals should be able to access their personally identifiable health information conveniently and affordably
 - Individuals should know how their personally identifiable health information may be used and who has access to it
 - Individuals should have control over whether and how their personally identifiable health information is shared
 - Systems for electronic health data exchange must protect the integrity, security, privacy and confidentiality of an individual's information
 - The governance and administration of electronic health information networks should be transparent and publicly accountable

Policy Issues and Barriers to Breakthrough Models

- The Workgroup is exploring barriers and policy implications for breakthrough models
- Issues to be considered:
 - Need to raise consumer awareness of PHRs
 - Confidentiality of Personal Health Records (PHR)
 - Need for patient proxies
 - Liability of providers
 - State laws as barriers
 - Data standards not yet consistent
 - Lack of interoperability when sharing information

Breakthrough Models

- Potential breakthrough models:
 - Use of existing regional health information exchange with a consumer interface
 - PHR vendor(s) linked to one or more intermediaries to get updated registration and medication information
 - Payer- or employer-based portals that supply information to PHRs

Potential Target Populations

- Patients who frequently utilize the system such as those with chronic conditions
- Under consideration:
 - Pediatric population
 - Older (45+) population with high drug usage
 - Possible local/regional geographic location with plans/providers

Open Issues

- Policies are needed to ensure patients are in control of their health information and trust the network
- Patients must be guaranteed the right to access their own personal health information
- Policies are needed to enable authorized caregivers and family members to access a patient's record
- PHRs, EHRs and relevant data sources (claims, pharmacy data) are not interoperable
- Mechanisms are needed to prohibit inappropriate or unauthorized secondary uses of data
- Clarification is needed on how, under current laws, personal health information in PHRs is protected
- Liability - inaccurate information from PHRs could lead to medical decisions associated with bad health outcomes
- Need a standardized approach to matching and authenticating patients to their records

Next Steps

- Refine and streamline principles for the specific breakthrough models
- Refine the scope of the breakthrough models
- Analyze the policy, technical and other barriers through additional research and public input