Connecting Americans to Their Health Care: Empowered Consumers, Personal Health Records and Emerging Technologies

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Consumer Empowerment Use Cases
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Current Progress

- Medication Lists historically have been patient supplied
- Provider demand for informed decision making created initial demand for medication lists.
- Moved industry from patient supplied to provider created.
- Data supply sources began to emerge – i.e. retail pharmacy, claims data, etc.
- Now medication lists can be provided electronically to providers with relative ease.
- Future adoption and cross over use from EHR to PHR greatly depends on overall adoption of prescribers to electronic prescribing, claims processing, etc.
- The final evolution is moving the medication list to the patient via PHR.
- Medication lists traditionally were focused on clinical disease management and NOT a holistic view of the patient
- It’s a paradigm shift that needs education (patient and providers)
AHIC Progress

- Private sector and public sector making advances in Medication lists and PHRs
- Initial concern was speed…will this slow down the progress already being made in private sector?
- A formalized entity enables the coordination of many disparate stakeholders
- The Administration’s push of Healthcare Information Technology has helped gain attention
- AHIC and workgroups have accessed domain experts and coordinated testimony in to public domain
Challenges & Strategies

- Privacy Concerns
  - Balance patient concerns with promotion of PHR adoption
  - All concerned with Identification and Authentication of Individuals
  - Challenge – Find the balance between technological innovation and protection of sensitive data
  - Challenge – Push legislation to keep up with the technology innovations
  - Challenge – Adopt a generally agreed upon Identification / Authentication strategy for PHRs that all can use

- Business Case
  - How will our HealthCare System pay for widespread adoption of PHRs?
  - Patients & Providers have no/low cost tolerance
  - Technology Innovators cannot absorb alone
  - Can incentives be provided?
  - Incentives to patients ($ or other) engage in creation of PHR
  - Announcements like Intel, Wal-Mart, other employers help encourage others
Challenges & Strategies

- Consumer Education on PHRs
  - Focus on overall safety improvements with more informed providers, more informed patients making better and more timely choices.
  - Possible focused approach to chronic disease category patients and caregivers
  - Enable this population & work with them to become ‘champions’
  - Technology itself – must be easy to use for Consumer

- Adoption of PHR without EHR
  - Research shows that only 1 in 4 doctors use the EHR.
  - If doctors have slow uptake on EHRs, can they be counted on to help promote PHRs through EHR Enablement?
  - Challenge: PHR adoption will probably be greater if tied to the patient’s access through providers who utilize EHR technologies.

- Competing thoughts on PHR standards.
  - HITSP established but several standards/models are still emerging in the real world
    - CDA: CCR & HL7 Combined
    - Payer / employer based
    - Must be portable
Future Uses

- PHRs containing medication lists can be a powerful tool in medication therapy management / other disease management.
- Medication lists are the ‘baby step’ to a complete PHR
- Patients can become more involved in their care.
- Caregivers have access to all information on hand.
- Providers receive more information; more information results in better and more timely decisions
- Chronic care patient populations may become the ‘early adopters’.
Thank you…

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Broad Charge
What are we trying to accomplish?

- “Make recommendations to the Community to gain widespread adoption of a personal health record (PHR) that is easy to use, portable, longitudinal, affordable, and consumer centered.”

- The critical components that support widespread adoption are:
  - Functionality
  - Interoperability
  - Consumer awareness
  - Business models
Current State - Where are we today?

- Lack of consumer awareness and engagement
- Standalone PHRs available, but uptake poor
  - Manual data entry
  - Lack of interface with clinical data sources
  - Lack of communication tools
- Good experience with integrated PHR/EHR
  - Primarily in integrated delivery systems
  - Relatively rich functionality, but tethered to single provider organization
  - But -- Lack of portability
- Lack of a sustainable business model for PHR sponsors
End-State Vision
Where do we want to end up?

Comprehensive Consumer Experience

- Decision support tools
- Communication with health care team
- Interoperability with EHR and other systems
- Patient control over data
- Communication with caregivers
- Communication with health care team
- Longitudinal record
- Education from trusted sources
- Privacy protections
- Certification of core functionality
- Portable data
End-State Vision  
Where do we want to end up?

• Widespread adoption of PHRs supporting health and wellness:
  – Comprehensive, longitudinal, “record” about an individual’s health acquired from all relevant sources [data]
  – Timely, understandable, context-sensitive health information from trusted sources [knowledge]
  – Tools that support an empowered consumer taking an active role in managing his/her health
  – Tools to facilitate communication with health care team and caregivers

• Uniform privacy protections for personal health information that follow the data and give patients control of their PHI
Privacy Concerns

• How concerned are you?
  ➢ Very/somewhat – 67%
  ➢ Not very/not at all – 34%

• How concerned are you about employment?
  ➢ ’99 – 36%
  ➢ ’05 – 52%

• Who are you willing to share with?
  ➢ Doctor – 98%
  ➢ Health insurer – 77%
  ➢ Employer – 37%
  ➢ Pharma – 27%
  ➢ Government agencies – 20%

California HealthCare Foundation
NYT, December 3, 2006
End-State Vision
Components Needed

• **Interoperability technical standards**
  – Terminology
  – Health information exchange and data portability (among PHRs and EHRs)
  – Security (including authentication, authorization, data access control)

• **Interoperable policies**
  – Uniform privacy protection that transcends local and state boundaries
  – Authorizations
  – Licensure

• **Widespread adoption of interoperable EHRs**

• **Nationwide Health Information Network** that facilitates sharing of personal health information to authorized users under the control of consumers
Mid-State Vision
Achievable Goals in 4-6 Years

- Majority of consumers aware of the role and value of PHRs as tools to support their health
- Industry standards exist for core functionality of PHRs
- CCHIT certification for EHRs include requirement of PHR interoperability
- Multiple data streams (e.g., lab, pharmacy, EHRs, claims) from health data sources populate PHRs following interoperability standards
- Robust privacy protections exist for personal health information in PHRs
- Business models and incentives emerging to support sustainable operation of PHRs for consumers
Key Enablers for Accelerating Adoption of PHRs

- Public education about PHRs from trusted sources
- Comprehensive privacy protection for portable personal health information
- Certification for core PHR functions, interoperability, security and access control
- Greater adoption of EHRs and electronic prescribing systems among providers
- Automated population of PHRs with clinical data from multiple sources employing interoperability standards
- Development of standards for consumer-focused, evidence-based educational information and decision support tools
## Priorities to Drive PHR Adoption

### Near Term
- Lab results
- List of conditions and allergies
- Prescription refills and renewals
- Administrative features
- Reminders for patients

### Subsequent
- Online consultation
- Summaries of health care encounters
- Endorsed educational information
- Decision support
- Patient health outcomes
End-State Vision
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- Privacy protections
Summary

• Consumer activation and empowerment essential to transforming health care effectiveness
• PHRs have great potential in the important supply of:
  – Personal health data
  – Knowledge to understand and act on personal data
  – Tools to change behavior
• Consumers need to be educated on the value of PHRs, assured of their privacy protection, and empowered to take an active role in their health
Thank you!