

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



**NATIONAL CONFERENCE  
DECEMBER 7-8, 2006  
WASHINGTON, D.C.**

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**2006**

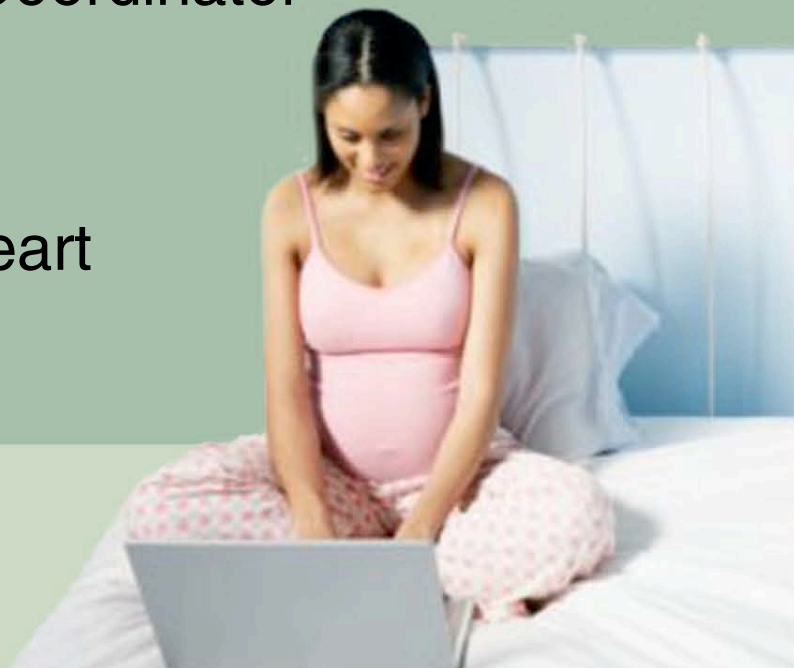
**Consumer Empowerment Use Cases**

David Lansky - Markle Foundation

Kelly Cronin - Office of the National Coordinator  
for Health Information Technology

Kathleen Mahan - SureScripts

Rose Marie Robertson - American Heart  
Association



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## **Consumer Empowerment Use Cases**

Kelly Cronin

Office of the National Coordinator for Health  
Information Technology



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## Consumer Empowerment Use Cases

Kathleen Mahan

SureScripts





# 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...

[Kathleen.Mahan@SureScripts.com](mailto:Kathleen.Mahan@SureScripts.com)

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Department of Health & Human Services  
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# **American Health Information Community**

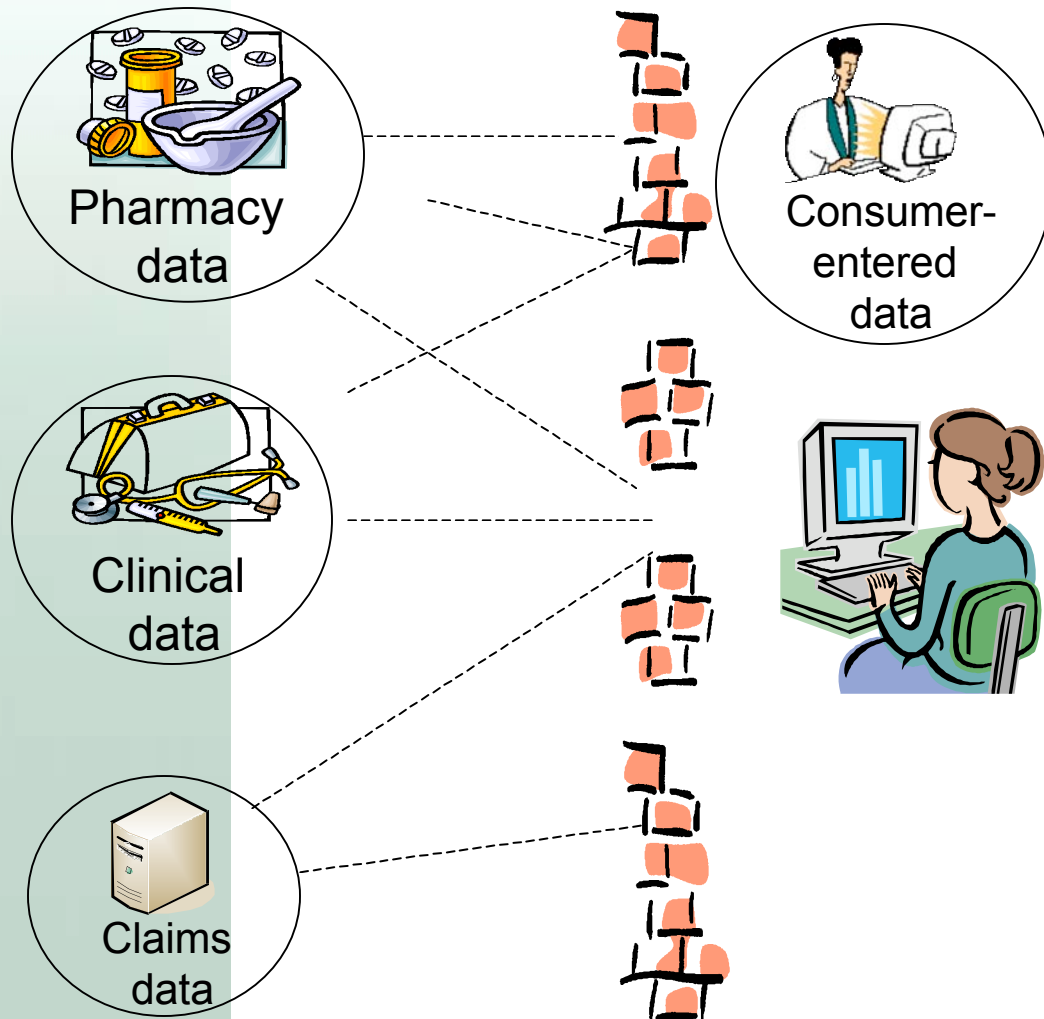
**Consumer Empowerment Workgroup**  
**Rose Marie Robertson, MD, Co-Chair**  
**Vision and Priority Areas**  
**December 7, 2006**

## 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?

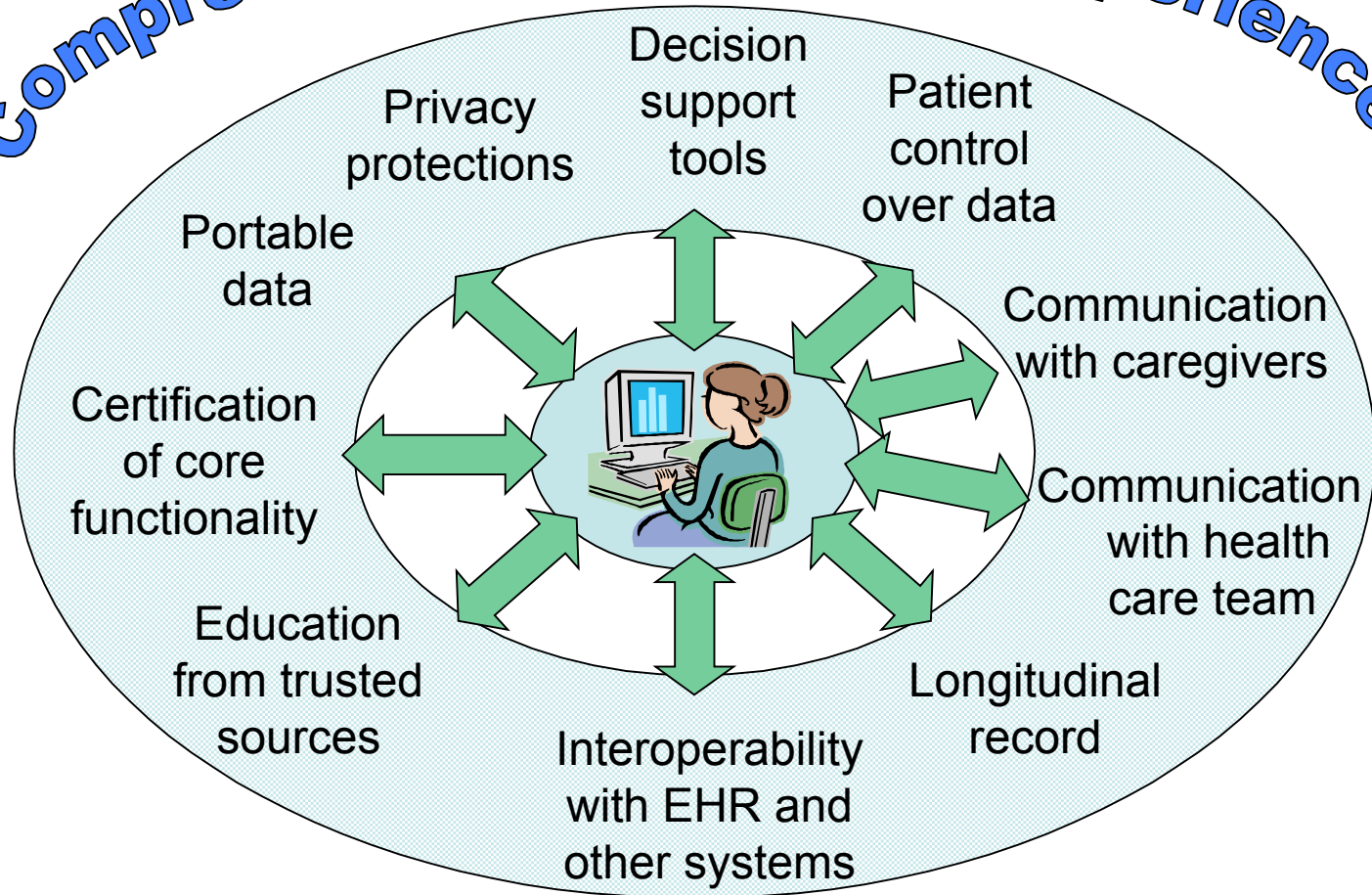


- **Lack of consumer awareness and engagement**
- **Standalone PHRs available, but uptake poor**
  - Manual data entry
  - Lack of interface with clinical data sources
  - Lack of communication tools
- **Good experience with integrated PHR/EHR**
  - Primarily in integrated delivery systems
  - Relatively 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



# 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%

# 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

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- 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

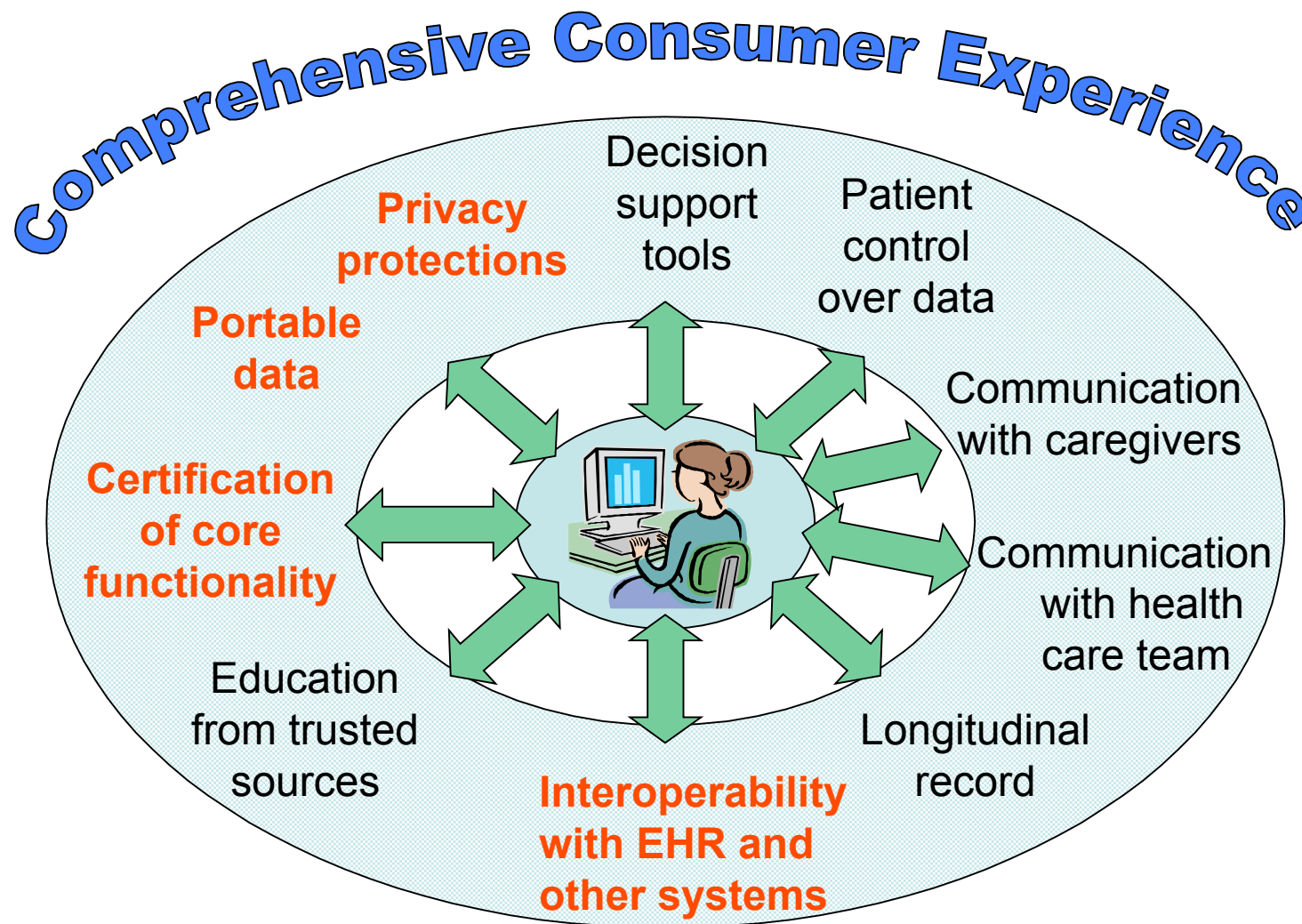
- Lab results
- List of conditions and allergies
- Prescription refills and renewals
- Administrative features
- Reminders for patients

## Subsequent

- Online consultation
- Summaries of health care encounters
- Endorsed educational information
- Decision support
- Patient health outcomes

# End-State Vision

## Where do we want to end up?



## 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



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***Thank you!***



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