

turning knowledge into practice

Personal health records: Putting prevention into the hands of the consumer

Presented by

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Session Objectives

- Describe the key features of a personal health record
- Articulate the role of prevention and wellness in the personal health record
- Provide an example of a current initiative in the development of a PHR application focused on prevention

What is a PHR?

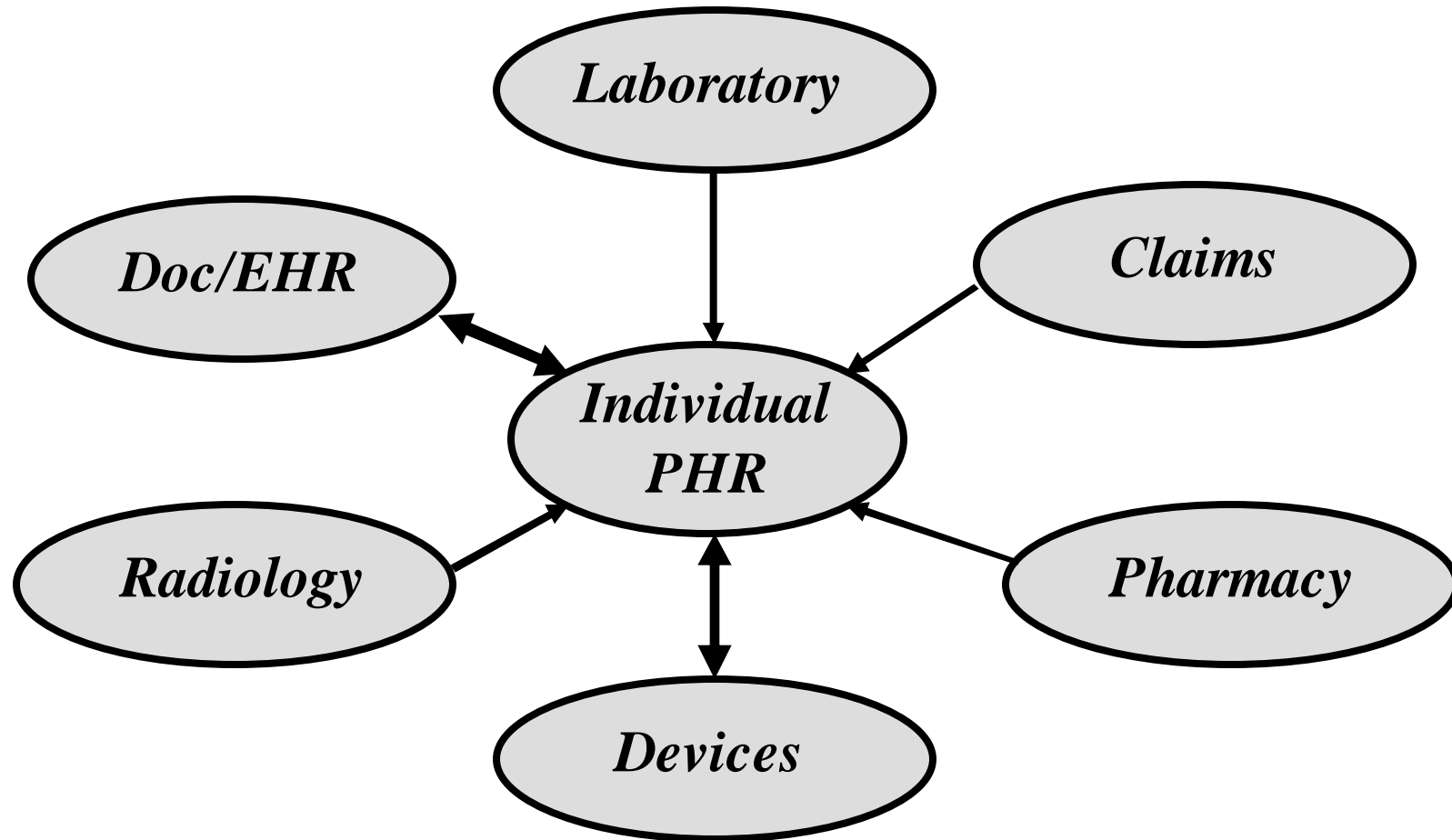
“An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.”

Markle Foundation Connecting for Health, 2003

EHRs versus PHRs

- EHRs - the clinician's/health care institution's record of patient encounter-related information
- PHRs - an innovative tool for individuals allowing them to improve their health and wellness, and better manage their health care

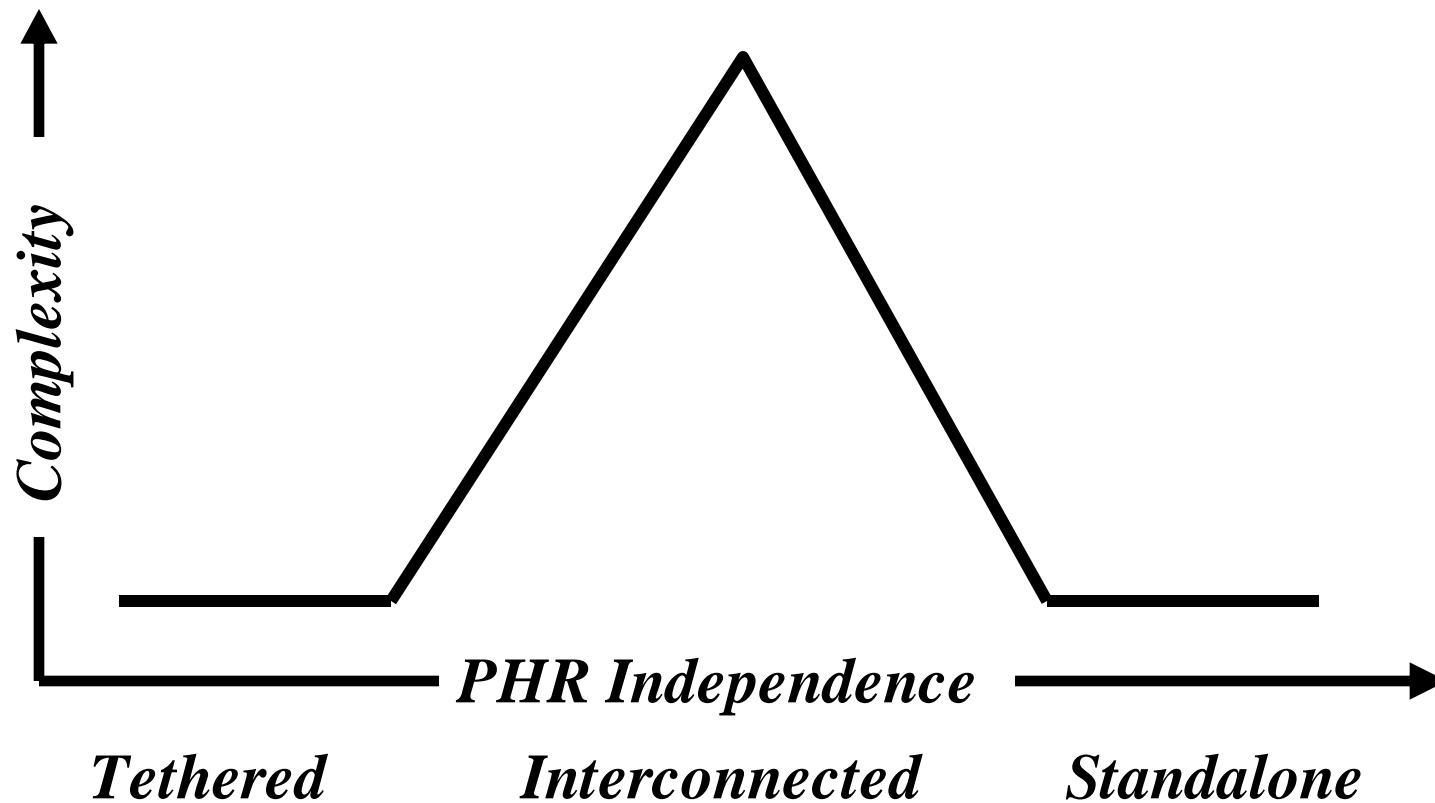
Data Sources for a PHR



PHR Functions

- Access personal health information
- Enhance patient – provider communication
- Decision support tools
- Disease monitoring
- Health reminders/alerts
- Others?

PHR Approaches



Tang, JAMIA, 2007

What PHRs are Today

- Poorly defined
- Narrow range of uses (merely repositories of information)
- Proprietary in nature
- Drawbacks to both institutionally-based as well as free-standing

What could PHRs become?

- Powerful systems of interoperable tools that help individuals improve their health and manage their care
- Americans need access to information about their health, but also need tools to understand and use that information, in order to take charge of their health and healthcare
- PHRs can transform the way patients, health care providers and caregivers access and respond to medical information

PHRs and Public Health

- Potential to impact all levels of prevention
 - Primary – preventing occurrence of disease/injury
 - Secondary – early disease recognition
 - Tertiary – limitation of disability and poor outcomes

PHRs and Primary Prevention

- Increased attention to preventive health behaviors
 - Physical activity
 - Nutrition
 - Spiritual well-being
 - Consumer-focused health information and education
 - Community health monitoring information

PHRs and Secondary Prevention

- Populations with unrecognized, early disease
 - Periodic risk assessment surveys
 - Screening recommendations
 - Environmental and occupational exposure information
 - Information on genetically-related disease risk

PHRs and Tertiary Prevention

- Diseased members of the population
 - Self-monitoring
 - Medication management
 - Decision-support tools
 - Risk management
 - Financial management resources
 - Linking members of affected population

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Project HealthDesign

ActivHealth:

A PHR System for At-risk Sedentary Adults

Project HealthDesign: Background

- 9 multidisciplinary teams of technology, health, and design experts
 - Each received \$300,000 grants to design and test prototypes of bold innovations for PHR system applications
- Collaborating in a structured effort to design and test innovative applications of PHR systems before prototyping tools in communities
- RWJF's Pioneer Portfolio
 - Supports innovative projects that can lead to fundamental breakthroughs in the health and healthcare of Americans

Project HealthDesign: Background

- How is Project HealthDesign different?
 - Cooperative design & development of innovative applications
 - Derives core functions as a byproduct of applications development
 - Engages intended users early and often
 - Confronts (and sometimes resolves) ethical, legal & social issues

Project HealthDesign: ActivHealth - Design Vision

- Develop a PHR application to assist sedentary adults in becoming more physically active
- Create tools that will support behavior change mediators within a highly individualized physical activity intervention

Project HealthDesign: ActivHealth - Design Vision

- Construct an easy-to-use environment that has low initial user learning requirements, but is scalable for advanced users
- Integrate user input from a wide variety of sources
- Build a PHR within the modular open-source framework of Project HealthDesign

Behavior Change Mediators

Mediators	Potential Innovation
Goal-Setting	A system that pulls data from a biomonitor and finds time in a person's calendar for exercise
Self-Monitoring	Small biomonitor providing data on activity level and physiological markers
Self-Efficacy	Realistic goal-setting system, instant messages from a virtual friend
Social Support	Supportive instant messages, GPS device locating nearest exercise facility
Rethink Thinking	Podcasts delivering thought-provoking information and instant messages
Reward-Setting	Biomonitor that tracks "points" and reminds people to reward themselves when a certain point level is reached

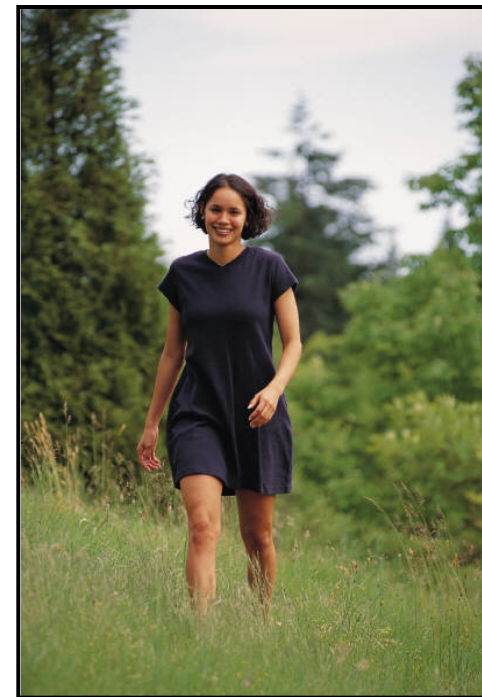
User/Prototype Sample Population

■ Phase I

- **End-user Participants (N=28)**
 - ◆ Adult men (39%) and women (61%)
 - ◆ Sedentary lifestyle
 - ◆ At-risk for (43%) or suffering from (57%) chronic disease
 - ◆ Caucasian (86%), Hispanic (7%), African-American (7%)
 - ◆ Low-middle socio-economic status
- **Healthcare Provider Group (N=8)**
 - ◆ Physicians and nurses from the Dallas area
 - ◆ Family practice and internal medicine boarded
 - ◆ Two physical therapists
- **Personal trainers (N=6)**
 - ◆ Structured interviews

Phase I - Design Analyses

- **User-centered design analyses**
 - Facilitated group discussions and structured interviews with potential users
 - Iterative design that built on past discussion to identify important data features, processes and data needed, for a activity focused PHR application
- **Technology Scan**
 - Identified a wide variety of possible technical solutions to user needs currently available and in the future
- **Project HealthDesign workshops**
 - Participated in discussions with other grantees, the design consultancy, the RWJF and others about PHRs
- **Review of available literature on PHRs**



Possible Tools & Devices

- Web portal for users to access tools, store users' goals and self-monitoring information
- Devices will interface with web tools and include smart phones, PDAs, and iPods®
- Biomonitors to capture data on caloric burn, caloric intake, sleep, physical activity duration, total steps taken, etc
- Context sensitive messaging simulate virtual “coach” with support, incentives, and congratulations

User/Prototype Sample Population

■ Phase II

- **End-user Participants (N=5)**
 - ◆ Adult men and women with a sedentary lifestyle
- **Healthcare Provider Group (N=3)**
 - ◆ Physician, nurse, and a physical therapist

Phase II - Prototyping Plan

■ **Systems Development**

- Develop web-based tools to address behavior mediators
- Populate databases with content
- Creating the business rules to define system functions

■ **User-centered Testing**

- Develop prototype scenarios focused on major components and processes
- Conduct an iterative approach to testing
- Collect feedback from consumers and healthcare providers

■ **Synthesis**

- Update systems to respond to user feedback
- Develop documentation on findings, recommendations, and work yet to be completed

Recommendations for the Future

■ The PHR systems of the future will be...

- Tailored
- Comprehensive
- Flexible
- Portable
- Prevention-oriented
- and, above all they will be...

CONSUMER-CENTERED

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