

turning knowledge into practice

What Consumers Want in Personal Health Records: Findings from Project HealthDesign

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Outline

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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**

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**
- **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**

Project HealthDesign: ActivHealth – Study Approach

- **Phase I – Design Phase**
 - **User-centered design analyses**
 - Facilitated group discussions and structured interviews with consumers (N = 28), healthcare providers (N = 8), and personal trainers (N = 6)
 - **Technology Scan**
 - Identify possible technical solutions to user needs now and in the future
 - **Project HealthDesign Grantee Workshops**
 - **Review of available literature on PHRs**

Project HealthDesign: ActivHealth – Study Approach

- **Phase II – Prototyping**
 - **Systems Development**
 - Develop web-based tools to address behavior mediators
 - **User-centered Testing**
 - Develop prototype scenarios focused on major components and processes
 - Conduct an iterative approach to testing consumers (N = 6) and healthcare providers (N = 2)
 - **Synthesize findings and create an enhanced design statement**

Project HealthDesign: Discussions with Consumers – Desired Features

- **User-friendly design, both in the technology used and in the user interface**
- **Provide appropriate advice regarding physical activities for the individual consumer**
- **Electronic tracking and uploading of physical activity data to the PHR with minimal user involvement**
- **Customizable settings that allow the user to set their own preferences**
- **Consumer control of access to PHR information**
- **Low or no cost to the consumer**
- **Provide up-to-date contact information to all and physical activity reports to some of their healthcare providers**

Project HealthDesign: Discussions with Consumers – Privacy Concerns

- **Many consumers were concerned about who in general might have access to the PHR records**
- **Consumers do NOT want to use their social security numbers in any part of the system**
- **Consumers concerned about possible misuse of PHR data by insurance providers or employers**
 - For instance, can an insurance company use your PHR record against you if it appears that you did not follow medical advice? Can an employer deny you employment if they see something they don't like in your record?
 - Both consumers (and healthcare providers) wanted to restrict insurance companies and employers from gaining access to PHR data

Project HealthDesign: Discussions with Consumers – Data Security

- **Desired data security measures**
 - Strong password protection
 - De-identification of records so that individual consumer information is not revealed (except to the consumer)
 - Access control menu in the preferences on the system to allow the consumer to set permissions to allow access to the system
 - Passwords or other access codes that could be shared by consumers with friends, family members, healthcare providers, or others
- **Many consumers indicated concern about the possible loss of records in the event that a monitoring device is lost or the communication link to the PHR is broken**
 - Consumers want, by design, a system that regularly backs up all data and can recovering or restore accounts

Project HealthDesign: Discussions with Consumers – Cost

- **Consumers agree that some cost is probably necessary to make the system work**
 - Most do not want healthcare providers or insurance company's to bear any cost for providing the system
 - Many consumers indicated they don't value things when they are free
- **Most consumers felt that costs should be around \$10 per month with additional costs for other add-on features**
 - Most consumers felt that a monthly membership fee would work best
 - Many wanted a “take a vacation” option at no cost
 - Basic system costs should meet the average consumer's needs without requiring add-on options (e.g., electronic monitors, virtual coach, etc.)
- **Consumers want incentives for participating in the program**
 - Discounts on income taxes or health insurance premiums were popular
 - Ability to use flexible spending accounts to cover the PHR was desirable

Project HealthDesign: Discussions with Consumers – Working with Healthcare Providers

- **Consumers want to share information with healthcare providers**
- **Consumers want a PHR that can facilitate physical activity planning with their healthcare providers**
 - Most consumers were dissatisfied with the generic advice they receive from their healthcare providers
 - Consumers want a PHR that can provide them with appropriate and specific physical activity options that they can discuss with their healthcare providers
- **Consumers want their healthcare providers to stay informed about their physical activity**
 - Consumers want to see the link between physical activity and their health outcomes—and want their healthcare providers to see this as well
 - Most consumers did not want their healthcare providers to have full and complete access to records—but they like the idea of sending status reports at some regular interval

Summary of Consumer Needs

- **Provide a mechanism for tracking health information to empower consumers to take more active control of their own health**
- **Build a user-friendly but familiar interface**
- **Ensure consumer controlled access**
- **Create PHRs that are flexible and customizable to the individual users needs (easy for all and upgradeable for advanced users)**
- **Enhance the relationship and communication between consumers and their healthcare providers**
- **Protect consumer data**
- **Meet practical needs in helping consumers plan, track, review and change their physical activity behavior**

Recommendations for the Future

- **Explore possible incentives for participation in PHRs that can directly impact many consumers and encourage participation**
 - Tax breaks
 - Insurance discounts
 - Use of Flexible Spending Accounts
- **Pursue legislation that protects PHR information from abuse**
 - Address consumer concerns about possible abuse by insurance companies or employers
- **Industry stakeholders should embrace user-centered design principles and move towards producing products for next-generation PHR systems**

Recommendations for the Future

- **The PHR systems of the future will be...**
 - Tailored
 - Comprehensive
 - Flexible
 - Portable
 - and, above all they will be...

PATIENT-CENTERED

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