

ISSUE BRIEF

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TRENDS IN HEALTH CARE DISPARITIES

Considerations in Designing Personal Health Records for Underserved Populations

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Hurricanes Katrina and Rita brought the utility and importance of electronic, easily portable personal health records (PHRs) starkly to light in fall 2005. With most paper medical records destroyed and evacuees forced to seek care in new environments, many faced medical crises and disruption in treatment for chronic conditions. Furthermore, a large percentage of those affected were elderly people from low-income racial and ethnic minority groups. This issue brief describes (1) the role that PHRs can play in reducing health disparities, (2) barriers to PHR adoption for underserved individuals, (3) reactions of focus group participants to the PHR concept, and (4) implications of the study for reducing health disparities through more widespread use of PHRs.

The Potential of PHRs

PHRs hold potential for reducing health disparities through consumer empowerment. By facilitating timely access to pertinent health data, PHRs allow patients to take a more active role in their health care.

Maintaining an electronic PHR can help patients ensure continuity of health care in situations where they may not have ready access to paper records; for example, if an emergency arises when they are away from home or paper records have been destroyed by a natural or man-made disaster. PHRs can also facilitate management of chronic conditions by tracking use of treatments and lab values (for example, insulin

WHAT IS A PHR?

A PHR is a comprehensive paper- or electronic-based system for recording an individual's relevant health-related information, such as family medical history, insurance coverage, demographic data, immunizations, prescribed and over-the-counter medications, diagnosed diseases or conditions, and diagnostic exams or surgical procedures. Both providers and patients may enter information into the record. However, PHRs differ from provider-maintained clinical electronic health records in that the patient owns the PHR and controls rights of access.

use and blood sugar levels in the management of diabetes). Many physicians, pharmacists, hospitals, and other health care providers are already moving to electronic clinical records systems, so encouraging the use of PHRs can also facilitate communication between patients and providers.

Barriers Exist

Overall, most Americans are unaware of the PHR concept. Low-income elderly individuals from racial and ethnic minority groups are even less likely than other groups to have heard of a PHR. As part of our study, we conducted focus groups with individuals from underserved low-income minority groups to discuss PHRs and their capacity to improve health care (see boxes on pages 2 and 3 describing the study and respondents' characteristics). The results suggest that three primary barriers have limited the diffusion of this technological advance to underserved population groups:

ABOUT THE STUDY

A bilingual moderator conducted three 90-minute focus groups, one for each of the following racial/ethnic and language groups: African Americans (English speaking); Latino (English speaking); and Latino (Spanish speaking). All participants were between the ages of 30 and 80 and resided in a medically underserved area of New Brunswick, NJ.

Discussion themes included:

- How people keep track of their health information
 - Reactions to the PHR concept
 - Desirable qualities of a PHR
- The *digital divide* was clearly a problem because only seven respondents reported that they had access to a computer. Although the local library provides access to computers and the internet, most respondents had never made use of these services because they were unfamiliar with the technology. Among those with access, only two reported using a computer on a regular basis. In addition, respondents were very mistrustful of the concept of storing health records electronically, including software-based PHRs running on a personal computer and those accessed through a password-protected, web-based application.
 - *Low health literacy* was not a serious limitation for most respondents. Only 4 of the 16 were determined to have limited or marginal health literacy based on a question assessing their confidence in filling out medical forms by themselves (a method recently reported as effective and reliable for determining health literacy skills in clinic populations). However, many respondents thought that the information contained in a PHR should be accurate and understandable to both the patient and his or her provider.
 - The need to take into account *cultural differences* when designing PHRs was not directly addressed

in the focus groups. However, Spanish speaking Latinos mentioned that they had experienced language problems when accessing health care and suggested that many doctors do not like to use interpreters due to time and cost constraints. They thought that PHRs could help overcome some of these problems by facilitating information exchange between providers and consumers who do not speak the same primary language.

Perspectives on the Concept

Attitudes about PHRs were mixed in the focus groups. Respondents were shown an example of a paper-based PHR and told that it was also available in an electronic format. After seeing the example, several said they had their own systems (for example, a notebook or wallet card) for keeping track of their health information, were happy with them, and saw no need to adopt an electronic version. Others thought the example was more comprehensive and better organized than the system they were using and could think of no reason not to use it. Respondents agreed on the following:

- *Nearly all mistrusted the security of electronic records systems.* All respondents recognized that many health care providers already use electronic clinical health records. They all believed their personal physicians would keep their health information private, but they had less trust in the security of records maintained by other providers or other entities (for example, insurance companies and employers). Most participants believed that anyone who wanted to could easily access electronic systems maintained on a personal computer or through the internet.
- *All favored the idea of a “smart card.”* All respondents agreed that a “smart card” (a credit-card-type device that can be carried in a purse or wallet and scanned by health personnel to obtain necessary medical records) could provide secure access to critical personal health information in the event of the owner’s incapacity. Assuming that the card could be read only with a special scanner available to health personnel, they trusted the security of these devices. As one respondent put it, “Everyday people wouldn’t have access to the scanner.”

- *All want to decide who can access their personal health information.* Respondents wanted to limit access to their health records to trusted providers and entities. They also wanted to limit the types of information each could see. For example, few trusted their pharmacist and would only choose to allow a pharmacist to see medication-related health information.

Implications for Reducing Disparities

Most focus group participants saw PHRs as an important tool for improving health care by reducing medication errors, improving patient-provider communication, and producing more appropriate diagnoses and treatments based on more accurate and up-to-date information. For example, some Latino respondents noted that they or people they knew had experienced medication errors because a pharmacist confused one patient with another who had the same or a similar name. They believed that improving the system of personal record keeping would help in identifying and correcting potential medication errors before they occur. All respondents said that consumers would benefit from better PHR systems, and Latino respondents said that consumers would be the primary beneficiaries if PHR systems became widespread.

However, African American respondents expressed a great deal of mistrust of the PHR concept, especially the idea of electronic PHRs. They stated that everyone involved in health care would benefit from the use of electronic clinical records but not electronic PHRs. They expressed concern that electronic records could fall into the wrong hands and be used against them and said that technological developments of this kind were for the benefit of the health care system and “never for the benefit of patients.” They also felt that organizations such as insurance companies and hospitals work to protect their own financial interests and will do whatever they want to, without getting a patient’s permission first. For example, they said that the privacy forms that they sign in a doctor’s office are just a “formality” used to make patients believe that the organization protects their privacy.

African American respondents saw electronic health records as something being forced on them and over which they had no control. For example, one said,

SNAPSHOT OF FOCUS GROUP RESPONDENTS

Total Number	16
Ethnicity	
African American	4
English-speaking Latino	6
Spanish-speaking Latino	6
Health Literacy	
Limited or marginal health literacy	4
Health literate	12
Educational Attainment	
Some college or a college degree	4
High school degree	7
Less than high school degree	5
Responsibility for the Health of Others	
Care for others in their household	7
Care only for themselves/spouse	9
Computer Access	
No access to a computer	9
Has computer access	7

“Whether I want it or not, [my personal health information] is already in the computer” at his doctor’s office. Another said, “[The move to electronic health records] is going to happen whether we like it or not, right?” When presented with the scenario of what happened in the aftermath of Hurricanes Katrina and Rita, respondents reconsidered the potential value of an electronic PHR but, ultimately, found unpersuasive the suggestion that electronic PHRs could have improved the provision of health care to affected individuals. They suggested that an electronic system would only be helpful in a crisis situation if “you wanted to go deep into a person’s background.”

Challenges Ahead

Despite the promise of improved and more equitable health care through the use of electronic PHRs, many barriers remain to their widespread adoption in underserved minority communities. Our study provides the following issues for those involved in developing PHR systems to consider:

- Individuals from underserved minority groups recognize that better record keeping can improve health care and reduce health care disparities, but the digital divide remains a formidable barrier to the adoption of electronic PHR systems.
- Designers and organizations sponsoring the development of PHRs may have to invest in a variety of outreach efforts to overcome consumer mistrust before PHRs will be widely accepted.
- The federal government may have to develop privacy standards that can assure consumers that their records can be accessed only by those the consumer authorizes to do so. The government may

also need to make a better case for how electronic PHRs can help consumers navigate the health care system and make it more affordable.

- Without greater efforts to ensure equal access and use of health information technology, PHRs may actually exacerbate, rather than reduce, racial, ethnic, and class-based health disparities.

This brief is based on a study conducted for the Robert Wood Johnson Foundation. For more information on our research in this area, contact Lorenzo Moreno, (609) 936-2766, lmoreno@mathematica-mpr.com.

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