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Personal Health Records: What Do Underserved Consumers Want?

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Growing use of clinical electronic medical records has also sparked interest in personal health records (PHRs). PHRs have the potential to help individuals take a more active role in their health care by allowing them to access and coordinate personal health information and share it with those who need it (see box). The federal government is exploring whether PHRs can be used to address the information needs of medically underserved populations, most of them minorities, who face economic, cultural, or linguistic barriers to health care. This issue brief describes features of existing publicly available PHRs. It also assesses whether these features match the needs and preferences of underserved individuals, who often have low health and computer literacy, as reported in focus group discussions with residents in a medically underserved area in New Jersey.

PHR Features Deemed Desirable

Personal health information is a valuable resource to individuals and their families, as well as health care providers. As the PHR concept gains in popularity, developers of electronic PHRs will be responding with new and enhanced products. But what will patients, especially those from underserved populations, be looking for in a PHR?

Focus group participants from underserved minority groups (see box on page 2) said that any electronic

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 can 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.

PHR system has to be portable, secure, private, simple, and affordable. Several participants used their own systems, most of them paper-based (for example, a notebook or wallet card), to keep track of their health information and were happy with these systems. Nearly all expressed distrust of electronic record systems that would require a personal computer to access their health information or that would store this information on the internet.

Participants agreed on the following:

- ***All favor a "smart card."*** A smart card—a credit-card type device that could be carried in the purse or wallet and scanned by health personnel to obtain necessary health records—could reduce burden to both patients and health care providers. It could provide secure access to critical personal health information in the event of the owner's incapacity, although many focus group participants are concerned about sharing passwords with others.

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

In March 2007, Mathematica conducted a systematic review of web pages of existing PHRs listed in www.myphr.com.

- *All want to decide who accesses their personal health information.* Participants want to restrict access to their health records to providers and entities they trust, such as family members and their own doctors. In addition, they want to limit the information each individual can see. For example, pharmacists could access only medication-related information. They also want an audit feature that shows who accessed their data and why.

- *Most want basic personal health information in their PHR.* Participants want basic health information, such as demographic and health insurance information and lists of conditions, medications, and allergies, in their PHR. If medical information is included, it should be clearly presented and easy to understand (for example, text summarizing laboratory test results instead of numbers). Only a few want content available in languages other than English, despite the fact that one focus group was conducted in Spanish. (Participants may have assumed that any materials available in English would also be available in Spanish.) Almost all participants think health personnel should be responsible for entering data in PHRs.

- *Many would pay set-up and update fees.* Many are willing to pay a modest fee ($25 to $30, but no more than $50) to set up a PHR, although several said insurance companies should pay for this service. In addition, participants are willing to pay a fee (up to $5 per occurrence), perhaps in the form of a co-payment, every time their records are updated. Most participants are reluctant to pay maintenance fees, since they could be charged for services they might not need. All trust their personal physicians to enter information in their PHR in the first place, and keep it up to date and private.

Features of Existing PHRs

On the basis of the focus group feedback, we reviewed 21 existing software-based PHRs, rather than internet- or paper-based PHRs, for three reasons (see table on page 3). First, software-based products often include smart cards, a technology that participants favor. Second, participants distrust systems that require storing personal health data in computers other than their own or those of their physicians, which is the case with internet-based PHRs. Finally, although participants think the paper-based PHRs we showed them are better than their own systems (for example, the paper-based systems are better organized and include information they hadn't thought about), paper-based PHRs would not help them adopt and use new health information technologies.

Most of the software-based PHRs reviewed include a section for a user's general health and demographic information, emergency contact details, and health insurance information. In addition, all but one of the PHRs has a field to record prescription drug use. Some PHRs also include information about over-the-counter drugs, supplements, and vitamins, and most have a section covering family health history, such as chronic conditions and diseases of family members. Another common feature allows the user to write journal entries or make comments on other sections of the PHR. Some include links to educational materials and a fitness and/or nutritional section as part of the journal feature. Finally, the majority of PHRs can store images or documents. In most cases, this feature can display graphs showing weight changes, dietary changes, or other trends. Some PHRs can also display

scanned digital images, such as x-rays and mammogram results.

For the PHRs reviewed, technical and security features vary. Nine PHRs offer smart card or flash drive (USB) technology. Many of the companies advertise these smart cards as conveniently fitting into one's wallet. Other companies offer products that fit on key chains or necklaces, and two companies provide a USB drive on a wristband. Most products require a computer to enter, update, and display the data (for example, laboratory results such as cholesterol levels and thyroid test results).

In addition, manufacturers of roughly half the products reviewed clearly state their security policies on their websites. The most common security devices are password protection and encryption. One product offers fingerprint authentication. The majority store information only on a user's personal computer, personal digital assistant (PDA), or flash drive (and not on the internet or on company servers), so the user is responsible for controlling access. For products that store data on the internet or on company servers, users must enter member IDs and passwords to view data (although the manufacturer's websites do not mention any tracking of how and when the password is used). Some companies simply state that the data are secure and not shared with anyone. However, three manufacturers mention that a user's data can be accessed by others when requested, but not without prior authorization.

Only four products are available in languages other than English. Two products are available in Spanish as well as English; one is provided in English, Spanish, and French. The fourth product, marketed to international travelers, provides information in 10 languages, including French, German, Japanese, Spanish, and English.

The PHRs we examined have been on the market an average of five years. All but two were developed by private companies (one was developed by the U.S. Department of Health and Human Services and another was developed by a nonprofit organization). Several of the private PHR companies were founded by physicians. Finally, for all but 2 of the 21 PHRs reviewed (the government-produced PHR and one from a private firm), the producer charges a fee for the PHR (with an average one-time cost of $64).

FEATURES OF 21 SOFTWARE-BASED PHRS IN OUR REVIEW	
General Features	
Health and demographic information, including medical contacts and health insurance information	21
Drug information, including prescription, over-the-counter, and supplements/vitamins	20
Family health history	20
Patient diary or journal (may include educational materials)	18
Stores documents or images (such as medical reports or x-rays)	17
Other Technical and Security Features	
Relies on smart-card or flash drive technology	9
Clearly states security policy	12
Tracks who accesses data and when (audit)	3
Available in languages other than English	4
Requires computer to enter or update data	18
Displays data in tabular format	19
Commercial Features	
Developed by a private company	19
Time on the market	5 years
Available for free	2
Average one-time cost	$64

Source: Systematic review of PHRs listed in www.myphr.com as software-based products as of March 2007.

Implications for the Future

Rapidly expanding commercial PHR offerings suggest that developers expect strong consumer demand for this technology in the near future. On the basis of our focus groups and a review of current products, it is unclear whether existing PHRs have the features residents of medically underserved areas want. To some extent, this is not surprising because the PHR market is in the early stages of development, and lack of consumer demand is an important barrier to adoption. Furthermore, it is unlikely that underserved populations will demand PHRs any time soon.

PHR developers may be reluctant to adapt their products to specific populations until technical, privacy, and security standards are established and a business model proves successful. In the future, developers may need to step up their efforts to assess the usability of their products by low-income minority populations with limited access to computers and low health literacy. This would require responsiveness to cultural and language needs, even at the cost of sacrificing technological sophistication.

In addition, the federal government may need to make a better case for how electronic PHRs can help consumers navigate the health care system and make it more affordable. A critical aspect of this effort involves allaying concerns of underserved populations about the security of personal health information in public insurance programs, such as Medicaid, and safety net providers, such as community health centers. Similarly, the federal government may need to develop policies to ensure that the financial burden of setting up and updating PHRs does not disproportionately fall on underserved populations.