Will Patients Use Electronic Personal Health Records?
Responses from a Real-Life Experience

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ABSTRACT
The Department of Health and Human Services identifies the electronic personal health record (EPHR) as a fundamental “dimension” of a future national health information infrastructure. Currently thirty-some EPHRs are available on the market. Though the potential advantages for clinical care, patient education, and administrative streamlining are highly touted, they remain speculative, and the core question remains: Will consumers actually use EPHRs?

Upon retirement in July 1999, the author provided 330 patients a commercial EPHR containing clinical office records from the practice’s EMR. One year later, he conducted a mail-in survey that posed a series of relevant yes-and-no questions regarding usage and invited narrative comment and anonymous responses.

This article tabulates the results and synopsizes patients’ opinions. It provides considerable enlightenment regarding patients, who, among other responses, intended to begin or continue keeping records, used the EPHR on medical visits, would rather not store health information on the Internet, wished to use e-mail with the doctor’s office, believed doctors do not keep full records, and strongly believed individuals should keep their own records.

KEYWORDS
- Electronic medical records
- Personal health records
- Internet healthcare
Patients and providers automatically understand the value of having complete health information when and where it is needed. Now, reports are “prescribing” how to bring the disparate and often far-flung fragments of an individual’s health information coherently to the point of care.\textsuperscript{1,2} The National Committee on Vital and Health Statistics makes the case for a future national health information infrastructure, across which the health information for any individual can be collected and assembled into personal, provider, and public health “dimensions” on a computer.\textsuperscript{2}

Such a system could protect patients from the main causes of medical error,\textsuperscript{3,4} offer education in the context of personal conditions,\textsuperscript{5} and streamline administrative information. These advantages could translate into improved care, better clinical outcomes, and greater satisfaction.\textsuperscript{6} Increasingly, patients would enjoy mature interaction with providers and businesslike exchanges with payors.

In the public health dimension, data from personal health records could continuously update state and national data registries (for example, for immunizations, sexually transmitted diseases, and the like). In the opposite direction, push technology could direct national guidelines for preventive clinical services into users’ records.

The goal is desirable, but no one controls fragmented patient records—not health professionals, diagnostic or treating facilities, pharmacies, or government agencies. No one has begun to centralize complete medical information; the job would be gargantuan. Yet patients can accomplish the job for themselves with relative ease. In fact, many are doing just that with electronic personal health records (EPHRs).

There are three compelling reasons for heightened patient interest in keeping personal health records. Patients who are suffering chronic illnesses and those experiencing an unexpected “health event” are particularly interested in recording their care. The availability of inexpensive computers and Internet access is contributing to interest as well. Additionally, HIPAA regulations place the right to access medical information with the patient.\textsuperscript{7}

This opportunity is drawing increased attention. More than thirty EPHRs are available on the Internet.\textsuperscript{8} Many are associated with health information portals. Some Internet-based electronic medical records or EMRs for medical offices (from Epic Systems and MedScape, to name just two) offer patients online viewing of selected medical information. A significant problem, though, in distributing information over the Internet is the risk of exposing patient information.\textsuperscript{9} According to provider participation, standards for sharing information and interoperability of systems are also essential elements of success.\textsuperscript{10}

Offered here is the first report of provider transfer of clinic information from an office-based EMR to a patient computer-based EPHR. This report explores the questions and issues raised by EPHRs.

It was essential first to learn if consumers would actually incorporate personal health records into their health management routines and use them
regularly. Other issues arose about patient attitudes and perceptions. What benefit would they foresee? Is personal control important? Would they trust Internet applications? It was also important to explore the implications for providers who have a wait-and-see attitude toward clinical information technologies.

This study was conducted among a population of generally healthy patients with spinal disorders. The study was not scientifically structured. All patients were invited to participate, regardless of age, gender, type, coexisting health problems, the health status of family members, geography, or educational level. The software was offered free by a “trusted source” to those who chose to participate.

The Setting

A rare confluence of technical capabilities and clinical material made this project both possible and irresistible. It involved a clinic with extensive use of basic information technology, housing of patient records on a commercial EMR (ChartRevolution, from Electronic Healthcare in Birmingham, Alabama) between 1991 and 1999, and availability of an EPHR (CapMed PHR, from CapMed of Wilmington, Delaware) with access to its technical creators. The project was initiated in the office of the author, a neurosurgeon, founder of the Alabama Back Institute (ABI), and cofounder of CapMed, a medical records company. As the author approached retirement in July 1999, he offered to give patients their records in electronic format.

The Objectives

The objectives of the study were to identify patients who would make an EPHR part of their healthcare routine and to determine what would motivate use of such a record. It also sought to explore these patients’ attitudes toward the issues of Internet privacy, medical e-mail, and fragmented medical information—factors that might influence future developments in e-healthcare. Their responses might point to some clinical advantages of electronic record sharing.

The clinical-technical objective was to determine whether transferring information between clinical and personal systems was practical. Finally, the results could be compared against untested hypothetical considerations and marketing claims.

The Patients

The participating patients ranged in age from thirty-five to eighty-five. They were generally healthy and self-selected by accepting the offer. They were distributed equally among a small city noted for its use of high technology and
smaller neighboring towns. From the point of view of healthcare, they appeared to be representative of the population at this practice.

The Electronic Professional and Personal Records

The EMR, ChartRevolution, is the medical record component of an integrated point-of-care system for medical offices and other ambulatory settings. ABI beta tested ChartRevolution and managed all of its patients' records over almost nine years on this system.

Each participant received a copy of CapMed's PHR. Designed for serious record management and interactions with the professional system, this EPHR manages problems, tests, treatments, medications, and preventive interventions in longitudinal sequence, making it possible to view information in time, problem, event, and prevention. Figure 1, comparative views of the medical summaries, illustrates the similarities between the user interface of both EMR and PHR.

The Design

One thousand active patients were offered an electronic personal health record program, along with a floppy disk containing their clinical records exported from the office EMR. The offering letter explained that the EPHR was

Figure 1. Comparative Views of Medical Summaries (EPHR on Right)
computer-based software and that the information from the office could be augmented with information from other providers for themselves and their families. Three hundred thirty patients accepted.

An export routine was written by CapMed’s technical team (full credit for the technical operations goes to Beth Hunter and Judith S. Denton, PhD) to enable transfer of field-level data (no textual comments) from the clinic’s EMR to a floppy disk.

Once the export was completed, the patients received a CD-ROM with the PHR program and a floppy disk containing their office data. This was a one-time input of clinical data, as the office closed soon thereafter. Instructions for installation were included in the package along with a telephone number for help.

Ten months later, a survey was sent to the participants. The survey posed a series of yes-and-no questions regarding usage of the PHR. The survey also invited narrative comments; the respondents could choose to remain anonymous. The responses were compiled and analyzed.

The questions in the survey and the tabulated results are presented in Exhibit 1, the ABI survey form. The sample survey responses in Figure 2 graphically display salient observations remarked upon later in this article.

**Results**

Although commercial personal health records are proliferating, some issues central to their adoption and effective utilization remain unclear. Patients’ perceptions of and attitudes toward their possible role in electronic recordkeeping, along with technical and cost considerations, will determine the ultimate success of the EPHR.

**Adoption and Utilization.** Of the 1,000 patients offered the EPHR, 330 patients accepted and received a record populated with all the health information known about them by the clinic. Of those, 136 patients responded to the mail survey after having their program for ten months. Twelve letters were undeliverable and returned.

Of the respondents, 50 patients (37 percent of the survey’s respondents and 5 percent of the initial 1,000 offered) continued to use the record, and 52 replied they did not. Twenty-five users had taken the record to other medical appointments and judged their doctors found it useful. Three thought doctors did not.

Of the nonusers, 46 planned to do so, commenting typically “when the time comes.” Six will not. Four found the software too difficult to use, while seven claimed not to have realized that they would be dealing with software.

Sixty-eight respondents would recommend the EPHR to friends.

Among those who used the EPHR and those who didn’t, 113 felt patients should keep personal health records. Several stated that they had already devised their own record-keeping systems.
Exhibit 1. ABI Survey Form, with Complete Response Results

Personal Health Record Survey from Alabama Back Institute, May 24, 2000

- 330 questionnaires were mailed
- 136 questionnaires were completed and returned
- 12 returned as “dead letters” by post office
- Many of the yes-no questions were not answered, accounting for discrepancy between the sum of yeses and nos and the total.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
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<tbody>
<tr>
<td>Have you used the Personal Health Record for yourself or your family?</td>
<td>50</td>
<td>52</td>
</tr>
<tr>
<td>If yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was it easy to use?</td>
<td>49</td>
<td>2</td>
</tr>
<tr>
<td>Did your other doctors seem to find your information useful?</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Would you recommend PHR to a friend?</td>
<td>68</td>
<td>0</td>
</tr>
<tr>
<td>Would you rather have this record on the Internet than on your computer?</td>
<td>4</td>
<td>63</td>
</tr>
<tr>
<td>Would you like to exchange record information with your doctors by e-mail directly from your record?</td>
<td>46</td>
<td>20</td>
</tr>
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<th>Comments:</th>
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| If no                                                                   |     |    |
|   I plan to use it but just haven’t gotten around to it.                | 46  | 6  |
|   I didn’t understand that PHR was computer software.                   | 7   | 0  |
|   It seemed too difficult.                                              | 4   | 0  |

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| Other                                                                   |     |    |
|   Do you think patients should keep their own health records?           | 113 | 3  |
|   Do you think that your doctors all have your complete records and know your full medical history? | 26  | 93 |
|   Would you keep your complete personal records on an Internet-based health record | 43  | 61 |

If you wish to share more about your ideas on personal records, use the back side or please do not hesitate to call me at ______________________. Thank you very much.

Signature (optional) (77 patients signed their names)

Internet-Related Patient Perspectives. Sixty-three respondents reported they would prefer this record to be computer-based rather than housed on the Internet. Four preferred the EPHR to be an Internet application.

In response to the question regarding completing personal information on the Internet, 43 wrote they would, while 61 replied they would prefer not to do so, citing concerns about privacy.
Figure 2. Sample Survey Responses

1. Total responses
2. Continue to use EPHR
3. Plan to begin using EPHR
4. Took EPHR on visit to another MD
5. Believe MDs keep full record
6. Believe MDs do not keep full record
7. Believe patients should keep own EPHRs
8. Believe no need keep own EPHRs
9. Would use Internet with privacy assurance
10. Would not use Internet with privacy assurance
11. Would prefer Web-based records
12. Would not prefer Web-based records
13. Would like to e-mail MDs
14. Would not like to e-mail MDs

Altogether, 48 respondents would “like to exchange medical information” with their doctors, 46 wishing to use e-mail with their physicians to do so. Twenty reported no interest in using medical e-mail.

**Clinical Perspective.** The majority of the respondents do not believe that doctors have their complete medical information. The question was posed, “Do you think that your doctors all have your complete records and know your full medical history?” Ninety-three responded no, 26 yes.

**Technical Process.** On average, transferring clinical information to floppy disks for 330 participants required about three minutes per patient. On a daily patient-by-patient basis, the time costs to a medical office would thus be minimal. With an integrated system, of course, the time cost is entirely negligible. The out-of-pocket material costs were less than an average patient’s copayment.

The capabilities of the EPHR were sufficient to accommodate lengthy and complex records.

**Conclusion and Discussion**

Realizing that medical records are left in the wake of changing locations, jobs, and health plans, many individuals have begun to assemble their personal medical information into electronic health records. Those individuals who do
so can serve as a “personal repository” of a complete record at any point of care or service.

This project looks at a group of patients who received EPHRs containing medical information from a practice that had automated its patient clinical records at the time of the author’s retirement and examines aspects of these patients’ adoption and use of EPHRs and their attitudes toward electronic healthcare. Of the respondents, twenty-eight had taken their EPHRs on a subsequent visit in another office for a continuing update.

The results suggest that 30 percent of patients with spinal conditions will express interest in obtaining EPHRs with their information, and 37 percent of these (5 percent of the original offering) will maintain such records for at least ten months. Individuals who suffer serious chronic illnesses will most likely benefit from keeping personal records and may choose to adopt them readily.

Among the respondents, 90 percent feel they should keep personal health records. This attitude is perhaps motivated by the belief of 69 percent that doctors do not maintain their complete records, and by inference that a central repository does not otherwise exist.

Relative to Internet applications, this group shares privacy and security concerns in roughly the 3:2 ratio of other reports. Public wariness of “fraud operators” and misuse of personal information on the Internet have limited the promise of e-healthcare so far. These respondents’ preferences (sixty-three to four) for the computer-based EPHR reflect that wariness. The FTC says that “fraud on the Internet is an enormous concern for the Federal Trade Commission. . . .”

Patients would like to share e-mail with their personal physicians (forty-three to twenty), even as physicians themselves set about “unlocking the mailbox.” Some doctors and hospitals fear the next step—sharing medical record information with patients—will open a Pandora’s box of potential misunderstanding. Others feel that shared records and decision making strengthen relationships and encourage patient participation. These patients appeared to fall into the latter group.

In addition to gaining new information from informed patients, this project solidly establishes the technical feasibility of transferring information between clinical EMRs and EPHRs.

References

Will Patients Use Electronic Personal Health Records? 259


About the Author

Ira C. Denton, MD, is a board-certified neurosurgeon, founder of the Alabama Back Institute, and cofounder of CapMed, with which he serves as chief medical officer.