Envisioning the Personal Medical Record

by Barbara Odom-Wesley, PhD, RHIA

Increasingly, patients are becoming interested in maintaining their own personal health records. What should these records contain? A panel of experts offers their recommendations.

When was the last time you or a member of your family moved, changed doctors, or saw a specialist? In these increasingly mobile times, the comprehensive, longitudinal medical record that spans from birth to death is almost nonexistent. Yet, as healthcare becomes more complex, the need for complete records is more urgent than ever.

In recent years, healthcare consumers have become increasingly interested in the concept of keeping track of their own health record. How valuable are these patient-maintained records, and what data elements do they need to contain to be most effective? This article looks at some of the forces driving the personal medical record and offers a model that HIM professionals can use to guide patients, parents, and other consumers to maintain their records.

Why Keep a Personal Medical Record?

No single physician maintains a master record for patients. Therefore, as every HIM professional knows, a patient has as many medical records as providers in multiple locations.

In this environment, it is critical for families to maintain complete chronological records of their health status and health services received by each member. This includes information on childhood immunizations, illnesses, surgeries, hospitalizations, trauma, and other health problems as well as evidence of physical, emotional, and cognitive development.

As healthcare becomes increasingly consumer oriented, the personal health record will no doubt become more important. Patients who have more information about their health are better equipped to become involved in decision making as well as monitoring and maintaining their own health.[1]

Informed medical decision making is at the heart of consumer health informatics. A number of programs have been developed to help patients choose among treatment options for specific diseases. An important feature of these programs is that patients are encouraged to consider quality-of-life issues associated with possible health outcomes and to consider what factors are important to them as they prepare to participate in their treatment decisions.[2]

The Internet also plays an important role. Opening the floodgates of medical knowledge, the Internet's information revolution is helping patients take charge of their own well-being. As a result, both patients and doctors are required to play new roles. While the onslaught of information can be intimidating to some physicians, better health for the patient and a lighter workload for healthcare providers often result from this new relationship.[3]

The patient-held record creates new opportunities for HIM professionals to fulfill new roles, such as the Vision 2006 patient information coordinator role. Consumers need education and information about documenting and maintaining records of their healthcare. Toward this end, AHIMA has made patient health record forms for children and adults available on its Web site (go to www.ahima.org). HIM professionals can help by providing consumers with guidelines that will help them become more active participants in their healthcare encounters.

Because patient empowerment centers on access to health information, the changes that result from patient empowerment directly affect HIM professionals. Patient empowerment will introduce an entirely new customer—the patient—into the work of HIM professionals.

A Model for Patient-held Medical Records

Studies have shown that patient-maintained health records, when maintained appropriately, are useful tools for patients and can enhance communication between patients and providers. (See "How Effective is the Patient-held Record?" below.) But how can families document and maintain their records most effectively? In 1999, the author performed a study to help answer this question, addressing issues such as format, size, arrangement, and content. The resulting model will help patients, parents, and other healthcare consumers maintain their medical records.

The study used the Delphi technique, a consensus-based research technique in which experts answer a series of questions and rank items and concerns. In the study, a panel of HIM experts came to consensus on the best design for format, size, arrangement, content, completion, security, and other design issues. The panel consisted of 55 HIM professionals, including members of the Grand Council for the International Federation of Health Record Organizations (IFHRO) and AHIMA past presidents, and represented six foreign countries and 13 states.

Three Delphi rounds were conducted with the panel of experts to answer these questions:

- what is the best design for a family-maintained health record?
- which design elements will increase the effectiveness of the family-maintained health record?

Participants ranked their preferences for elements related to format, size, arrangement, and content as "not important," "somewhat important," and "very important." In the first round, the panel was asked to respond to two open-ended questions:

- what other design issues should be addressed to facilitate completion by the patient or family member?
- what other considerations are important in designing a family medical record?

Format

A question emerged concerning whether the record should be electronic or paper. Respondents commented on the future of health information management in an electronic environment. They cautioned, however, that in the immediate future, paper would be the most useful format. The majority of homes in the US still do not have computers.

Based on the ranking of the panel and their comments, the best format for a family medical record should be paper-based with an electronic alternative. The computer disk was selected by the panel as the preferred electronic format, and the loose-leaf folder was selected as the best design for a paper format. (See "Format Preferences," below.)

Size

The panel discussed whether the family record should be carried at all times or just to healthcare visits. This determination would influence preference for size. In the end, the panel preferred a size to be carried only to encounters, not all the time. However, panel members recognized that some vital information should be carried at all times in case of emergencies. Based on the results of the study, each family member should have a record that is maintained at home and carried to healthcare visits. Additionally, each family member needs a smaller record, perhaps a wallet-sized card, for information such as allergies, major medical problems, and current medications.

Many panelists preferred an electronic record to be carried at all times, such as a credit card size with a magnetic strip. But they were concerned with issues of access, and such a card would require an electronic reader that might not be accessible to all providers. Further, patients would not be able to access or add to the information in this format. The card with a magnetic strip was finally eliminated from consideration.

The panel came to consensus on a standard-size 8 1/2 x 11" sheet of paper. (Other countries would need to use their standard-size paper, such as the A4.) Using the standard size makes copying or making additions easier. It is a larger record to carry to visits, but less likely to get lost than a smaller version. (See "Size Preferences," below.)

Arrangement

The panel decided each family member should have an individual medical record, rather than keeping all records together. The panel expressed concerns about confidentiality—family members should not have access to each other's health information without permission from the patient. Keeping separate records also would make it easier to separate the records as children grow up and leave home. It also simplifies the problem of whose records should be included in a family record.

The panel recommended that individual records be divided by sections. Discussion centered on naming the sections. Panelists agreed that names should agree with important content items. Arrangement within each section should be chronological. (See "Arrangement Preferences," below.)

Content

The panel consistently identified several items as very important, such as past history and information on current health condition. (See "Content Preferences," below.) The content items could be categorized into sections, which would dictate the arrangement. The panel preferences would have this family record resemble the popular formats and content of traditional medical records maintained by providers.

The panel emphasized the need to provide a flexible record that could be customized according to patient needs. Some items that seem unimportant to some patients could be very important to others. Medications were modified to include both prescription and over-the-counter drugs.

The panel agreed that patients especially need records of healthcare services, such as operative procedures, health maintenance activities (e.g., mammograms and pap smears), diagnostic test results (normal and abnormal), mental health records, pathology reports, hospitalizations, therapeutic services, and healthcare encounters (including place of services). Eye care and dental care were ranked as less important, but these could be significant in individual cases.

The panel recognized the value of involving the patient in monitoring and tracking health status. Content items included in this area were growth/development charts, reminders for preventive and routine services, calendar to track health problems, and upcoming appointments.

Personal and family history were consistently ranked as very important. Items such as immunization records and end-of-life issues such as living will, advance directive, and organ donation all were ranked as very important.

Names and addresses of providers, along with telephone and e-mail contacts, were identified as somewhat important. Perhaps this is because providers change so frequently; thus, family doctors are rare. A problem list was ranked as somewhat important. Business matters such as correspondence about healthcare and financial issues received a low ranking. This information may belong in other family documents.

The panel noted that security and confidentiality issues are important concerns. Storage would be in the hands of the family and out of the control of the healthcare providers. Patients would need to be educated about the value of the information and the right to privacy.

Other Design Issues

Completion issues centered on ways to make the record more effective and to encourage patients to complete the records. The panel suggested other design considerations to make the record more effective.

The panel noted that information in the record must be easy to find once recorded. This concern supports the selection of divided sections as the preferred arrangement. Dividers with tabs labeled based on content will make retrieval easier.

The forms should be designed to accommodate handwritten entries and machine entry, because it is envisioned that the record will be in both a paper and an electronic format. The record should accommodate entries from the patient and the provider.

The panel agreed it is important to encourage an active, useful document. A good way to do this is through patient education.

Conclusion

In this age of consumer informatics, patient empowerment, and involvement, the patient-provider relationship will likely evolve into more of a partnership. One product of this increased involvement and demand for information will be patient participation in medical record documentation.

HIM professionals will have a critical role to play in designing systems to facilitate consumer involvement in healthcare documentation. Patient information coordinators will be needed at all levels of healthcare and for a variety of consumer groups. Now is the time to seize this opportunity.

Notes

1. Kloss, L. "Consumerism in Healthcare: It's About Time." *Journal of AHIMA* 69, no. 8 (1998): 26-27.

2. Jimison, H.B., and P.P. Sher. "Advances in Health Information Technology for Patients." *Journal of AHIMA* 69, no. 8 (1998): 42-46.

3. Lowes, R. "Here Come Patients Who've Studied Medicine On-line." *Medical Economics* 74, no. 2 (1997): 175-184.

4. Jeffs, D. et al."Retention and Use of Personal Health Records: A Population-Based Study." *Journal of Pediatrics and Child Health* 30, no. 3 (1993): 248-252.

5. Royal Australian College of General Practitioners. "Introducing The Personal Health Record: RACGP Health Record System." Brochure. 1982.

6. Young, S., and M. Fasher. "An Observational Study of the NSW Parent-Held Record in a GP Setting." *Australian Family Physician* 23, no. 4 (1994): 704-712.

7. "Resolve to maintain your health records in the new year: AHIMA proposes New Year's resolution for 1997." AHIMA press release, December 19, 1996.

8. Charles, R. "An Evaluation of Parent-Held Child Health Records." *Health Visitor: The Journal of the Health Visitors' Association* 67, no. 8 (1994): 270-272.

9. Dauncey, J. "Introducing Parent-Held Child Health Records." *Health Visitor: The Journal of the Health Visitors' Association* 64, no. 7 (1991): 229-230.

10. Fierman, A. et al. "Immunization Status as Determined by Patients' Hand-held Cards vs. Medical Records." *Archives of Pediatrics & Adolescent Medicine* 150, no. 8 (1996): 863-866.

11. Martin, E.R. "Consumer Health Informatics: The Medical Librarian's Role." *Journal of AHIMA* 69, no. 8 (1998): 38-40.

12. Young and Fasher.

13. Golodetz, A., J. Ruess, and R. Milhous. "The Right to Know: Giving The Patient His Medical Record." *Archives of Physical Medicine Rehabilitation* 57 (1976): 78-80.

14. Jimison and Sher.

15. Royal Australian College of General Practitioners.

16. Dauncey, J.

17. Bruegel, R. "Patient Empowerment—A Trend That Matters." *Journal of AHIMA* 69, no. 8 (1998): 30-33.

References

AHIMA. "Inventing the Future: Vision 2006, The Vision Continues." Brochure. Chicago: AHIMA, 1996.

AHIMA. "Knowing What's in Your Health Records." Available online at www.ahima.org/consumer.

Huffman, E. *Medical Record Management.* Berwyn, IL: Physician's Record Company, 1994.

Macfarlane, A., and K. Saffin. "Do General Practitioners And Health Visitors Like Parent Held Child Health Records?" *British Journal of General Practice* 40 (1990): 106-108.

Odom-Wesley, B. "Webliography for family health records." Available at http://venus.twu.edu/~j_odomwesley/WebFHR. html.

How Effective Is the Patient-Held Record?

Because the personal health record has not been widely implemented in the United States, most studies on parent-held child health records have been conducted in Australia, where parents maintain medical records for their children.[4,5,6] In recent years, however, the idea of family health records has received more attention in the US. (Former AHIMA president Merida Johns, PhD, RHIA, proposed a New Year's resolution for 1997 that "all Americans should resolve to create their and their families' personal health records in the new year."[7])

In the Australian studies, researchers reported patient and provider satisfaction as well as improved outcomes and documentation effectiveness. Additionally, audits of parent-held records in a 1994 study showed that parents' records often recorded more details than the traditional medical record.[8] This evidence challenges the belief among many professionals that parents would forget to bring the record to appointments with health and medical professionals. Numerous studies throughout the world demonstrate the value and success of a family health record. One benefit was empowerment, which allowed patients to become more involved in monitoring and maintaining their health status and that of their family members. And some studies have shown improved health outcomes for patients involved in documenting their healthcare.[9,10,11,12]

As far back as 1976, studies have demonstrated the value of patient involvement in documentation. At that time, three physicians at the Rehabilitation Medicine Service at Medical Center Hospital of Vermont assessed the effect of patients' having their own medical records. During a seven-month period, each patient admitted to the 16-bed facility received a carbon copy of his or her full admission evaluation and discharge summary. The study assessed patient acceptance, positive and negative effects of sharing the record, and how the sharing process altered the encounter.

The results were striking. Most patients (84 percent) expressed a strong desire to be well informed about their conditions. In fact, 50 percent made some addition or correction on point of fact, and 60 percent asked questions on vocabulary or meaning. Patients often expressed a feeling of relief at having the secrecy removed from their records and were pleasantly surprised to be treated as adults. And the staff, who had initially been wary, realized that most patients were ready to handle the information and were waiting for this degree of openness. Patient education improved, as did patient contribution to the planning of care. Staff accountability to the patient also improved. In general, the study found, patients were generally comfortable reading the record, found it educational, and appreciated the trust it implied.[13]

How Do Patients Benefit?

A personal health record is a useful tool in preparing in advance for medical appointments, and it can play an important role in effective physician-patient communication. Because they have maintained their own medical records, patients are better prepared to ask pertinent questions or objectively describe symptoms. They become active participants, not just recipients of information.[14]

What Are the Possible Disadvantages?

After 10 years of use, the Royal Australian College of General Practitioners (RACGP) reported few disadvantages in the use of patient-held records.

Confidentiality was a possible consideration; however, patients who were in control of their information made their own decisions regarding access. The possibility of litigation against doctors was a second concern, in terms of risks such as incorrectly labeling patients or possibly only recording things that the patient will accept. But, the researchers agreed, doctors should take care to avoid inaccuracies even without use of the personal health record. And while there had been initial concern about "erosion of status" for physicians, the RACGP concluded that providing this service to patients demonstrated care and interest in the patients' welfare—and actually enhanced the providers' status with patients.[15]

Other studies by the Oxfordshire, England, Health Authority found that parent-held records are unlikely to get lost, will usually be available at the clinic, and are more likely to be completed.[16]

While these findings may go a long way toward dispelling initial concerns, there are still other issues yet to be resolved. Consumer informaticist Robert Breugel, writing in the Journal of AHIMA in 1998, noted that the issue is complicated by a substantial increase in overall concerns about the privacy and confidentiality of health information. Doubtlessly HIM professionals will be key players in unraveling these concerns. As they do, Breugel noted, HIM professionals may find that patients who maintain their own records are a new kind of customer. "The demands that this new 'customer' will make are likely to conflict with the demands being made by current 'customers,' such as existing health organizations, insurance companies, government agencies, or health providers," Breugel wrote.[17] How these conflicts would play out remains to be seen.

Participants ranked each item according to this scale: 1=not important; 2=somewhat important; 3=very important. Mean score is calculated by dividing total score by number of respondents. Items with less that 2.0 were dropped.

Format Preferences	**Mean Score**
Computer disk	2.8
Loose-leaf folder	2.3
Three-ring binder	2.0
CD-ROM	1.9
Credit card/magnetic strip	-
Bound journal	-
Spiral table	-
Internet/Web page	-
Intranet access	-
Classification folder	-

Size Preferences	**Mean Score**
Appropriate to be carried to visits	2.9
Electronic size	2.5
Appropriate for home computer	2.4
Appropriate for home storage	2.4
Appropriate to be carried at all times	2.0
8 1/2" X 11"	2.0

Wallet-sized	-
Pocket-sized	-
5" X 7"	-
Purse-sized	-
A4 (8.3" X 11.6")	-
Appropriate for home storage only	-

Arrangement Preferences	**Mean Score**
Separate records for each member	2.9
Divided sections	2.8
Chronological	2.7
By family member	2.3
Problem-oriented	2.0
Alphabetical	-
By medical episode	-

Content Preferences	**Mean Score**
Medications (prescribed/OTC)	2.9
Personal health history	2.9
Allergies	2.9
Family history	2.8
Immunizations	2.8
Operative procedures	2.8
Health maintenance activities	2.8
Diagnostic test results (normal/abnormal)	2.8
Mental health records	2.8
Pathology reports	2.8
End of life issues	2.6
Hospitalizations (include discharge summary)	2.6
Growth/development charts	2.5
Physical assessment	2.5
Names/addresses of providers	2.4
Therapeutic services	2.4
Reminders for preventive/routine	2.4
Record of healthcare encounters	2.3
Only include abnormal test results	2.3
Problem list	2.3
Eye care	2.3
Calendar to track health problems	2.3

Upcoming appointments	2.3
Dental care	2.2
Correspondence about healthcare	2.0
Graph values over time	1.9
School/camp physicals	1.8
Financial issues	1.7
Health education materials	-
Flow sheets to monitor problems	-
History of extended family	-
Summary of old information	-
Health assessment (risk factors)	-
Calendar for preventive reminders	-
Prosthesis	-
Family tree showing relationships	-
Family member narratives on health	-
Insurance payments	-
Temporary storage for health materials	-

What You Can Do

How can HIM professionals best position themselves to promote and develop the patient-held record? Here are some things you can do:

- Study the available information about patient-held medical records
- Inform your own family members about the value of documenting their healthcare
- Maintain documentation of your immediate family's healthcare activities
- Take advantage of opportunities to inform consumer groups of the need to document and maintain their medical records
- Participate in efforts to design and distribute a model family medical record to consumers

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