

CONSUMER INFORMATICS: DEVELOPMENT OF A MODEL
FOR DOCUMENTING AND MAINTAINING
FAMILY MEDICAL RECORDS

A DISSERTATION
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

COLLEGE OF EDUCATION AND HUMAN ECOLOGY

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AUGUST 1999

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ACKNOWLEDGMENTS

Sincere appreciation is extended to the participants in this study for the tenacity to complete three questionnaires within a short time period. Thank you for spending your valuable time and sharing your expert opinions to design this family medical record.

Thank you to my Aunt, Mrs. Dora Nisby, a librarian extraordinaire, for using your expert search and find skills to locate references for this project.

My deepest gratitude to my parents, husband and children who expressed confidence in my ability to achieve this goal even when I wavered.

Thank you to my committee members, Dr. Jennifer Martin and Dr. William Cissell, for helpful advice and encouragement throughout the process. Special appreciation to my committee chair, Dr. Gladys Hildreth, who was a challenging taskmaster and a nurturing mentor simultaneously.

All praises to almighty God for blessing me with everything I needed to reach this goal. I can do all things through Christ who strengthens me (Philippians 4:13).

ABSTRACT

CONSUMER INFORMATICS: DEVELOPMENT OF A MODEL FOR DOCUMENTING AND MAINTAINING FAMILY MEDICAL RECORDS

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Doctoral dissertation, August 1999

The purpose of this study was to develop a model to guide families in documenting complete health information. Design issues addressed include format, size, arrangement, content, and other elements to improve effectiveness. This model will help patients, parents, and other consumers to maintain their medical records.

The review of literature indicated medical outcomes improve when patients become partners in medical decision-making. Empowering patients with information and assigning responsibility for documentation to them enhances this participation.

Members of the Grand Council for the International Federation of Health Record Organizations and past-presidents of the American Health Information Management Association formed a panel of experts. Three Delphi rounds were facilitated by questionnaires asking the panel to evaluate the importance of choices for each design area. Respondents indicated “not important”, “somewhat important”, or “very important” on a Likert-type scale. Responses were tallied for each round resulting in a ranking of

the choices based on total score for round 2 and mean score for round 3. Items with less than a 2.0 mean score at the conclusion of round 2 were eliminated from consideration for round 3. Participants added design items and made many comments. These items were categorized and used to design questionnaires for rounds two and three.

At the conclusion of the third round, consensus was reached. The best design for a family medical record was defined in terms of format, size, arrangement, and content.

The best format is both electronic and paper. The paper format should be a 3-ring binder and include a computer disk with screens that match the paper forms. A separate record should be developed for each family member. The record should be divided into sections and include entries from providers as well as patients. Record content should include family and personal health history, information on the current health status and records of all healthcare services. Reminders for preventive and routine services should be included. Forms in the record should be designed so users can easily understand how to make entries and locate information.

TABLE OF CONTENTS

COPYRIGHT	iii
ACKNOWLEDGMENTS	iv
ABSTRACT	v
LIST OF TABLES	x
CHAPTERS	
I. INTRODUCTION	1
Statement of the Problem.....	1
Statement of Purpose	2
Rationale for the Study	3
Significance of Study	5
Research Questions.....	7
Conceptual Framework.....	7
Definitions of Terms.....	8
Delimitations.....	9
Summary	9
II. REVIEW OF LITERATURE	
Consumer Informatics.....	12
Patient Empowerment.....	16
Current Medical Record Documentation.....	19
Advantages of Patient Involvement.....	22
Disadvantages of Patient Involvement.....	30
Utilization of Patient-held Records.....	32
Effectiveness of Patient-held Records	38
Format of Patient-held Records	43
Content of Patient-held Records	50
Impact of Patient-held Records.....	55
Summary	59

III.	METHODOLOGY	61
	Selection of Subjects.....	61
	The Delphi Technique	63
	Instrumentation	66
	Round 1 Questionnaire	66
	Round 2 Questionnaire	67
	Round 3 Questionnaire	67
	Pilot Study.....	67
	Collection and Treatment of Data.....	70
	Round 1	70
	Round 2.....	72
	Round 3.....	74
IV.	FINDINGS	79
	The Expert Panel.....	80
	Education	81
	Credentials	81
	Experience	81
	Employment Setting.....	82
	Current Area of Responsibility	83
	Geographic Representation.....	84
	Volunteer Positions.....	84
	Round 1	85
	Format.....	86
	Size.....	87
	Arrangement	88
	Content.....	89
	Design Issues	89
	Round 2.....	92
	Format.....	93
	Size.....	94
	Arrangement	95
	Content.....	96
	Design Issues	97
	Round 3.....	101
	Format.....	103
	Size.....	103
	Arrangement	103
	Content.....	104
	Design Issues	106

V.	DISCUSSION	108
	Summary of Study	108
	Discussion	
	Format	110
	Size.....	111
	Arrangement	113
	Content.....	115
	Design Issues	119
	Conclusions.....	122
	Research Question One.....	122
	Research Question Two	123
	Recommendations.....	124
	Research.....	124
	Healthcare Providers.....	125
	Limitations	125
	REFERENCES	127
	APPENDICES	133
	A. AHIMA forms.....	134
	B. Round 1 Questionnaire	143
	C. Pilot Study Cover Letter	150
	D. Round 1 Cover Letter.....	152
	E. Round 2 Questionnaire	155
	F. Round 2 Cover Letter.....	167
	G. Round 3 Questionnaire	169

LIST OF TABLES

Table	Page
1. Level of Education for Round One Panel of Experts	81
2. Credentials Earned by Round One Panel of Experts	82
3. Years of HIM Experience by Round One Panel of Experts	82
4. Employment Setting for Round One Panel of Experts	83
5. Area of Responsibility for Round One Panel of Experts	84
6. Volunteer Positions Held by Round One Panel of Experts	85
7. Round 1 Scores for Format	86
8. Round 1 Scores for Size	87
9. Round 1 Scores for Arrangement	88
10. Round 1 Scores for Content	90
11. Round 2 Scores for Format	94
12. Round 2 Scores for Size	95
13. Round 2 Scores for Arrangement	96
14. Round 2 Scores for Content	97
15. Round 2 Scores for Family Characteristics	98
16. Round 2 Scores for Completion Issues	99
17. Round 2 Scores for Security Issues	100

18.	Round 2 Scores for Other Content Issues	101
19.	Round 2 Scores for Other Design Issues	102
20.	Round 3 Scores for Format.....	103
21.	Round 3 Scores for Size.....	104
22.	Round 3 Scores for Arrangement	104
23.	Round 3 Scores for Content.....	105
24.	Round 3 Scores for Completion Issues.....	106
25.	Round 3 Scores for Security Issues	107
26.	Round 3 Scores for Other Design Issues	107
27.	Mean Scores for Format.....	112
28.	Mean Scores for Size	113
29.	Mean Scores for Arrangement.....	114
30.	Mean Scores for Content	118
31.	Mean Scores for Security Issues.....	120
32.	Mean Scores for Completion Issues	121
33.	Mean Scores for Other Design Issues.....	122

CHAPTER I

INTRODUCTION

Where once health was defined simply as the absence of disease, health now is defined as the state of complete physical, mental, and social well-being. In this more comprehensive definition, consideration is given to healthcare which includes the prevention of disease and health maintenance, in addition to medical care which is curative or palliative (Huffman, 1994). With these changing attitudes, it is important for health status to be documented in a more comprehensive, longitudinal medical record that spans from birth to death.

Statement of the Problem

Currently, various healthcare providers retain ownership of medical records and individually compile documentation of services. It is increasingly difficult to reconstruct a chronology of health status as patients are served by a variety of healthcare providers in a variety of settings. The mobile society and the nature of the health delivery system exacerbate this fragmentation problem. Patients receive services from multiple providers in varied locations who often do not communicate with each other or share medical records. It is left to the patient to inform present providers of previous and concurrent services (Huffman, 1994).

In this environment, it is critical for families to maintain complete chronological records of their health status and health services received by each member throughout the years. In addition to childhood immunizations, records are needed on illnesses, surgeries, hospitalizations, trauma, and other health problems as well as evidence of physical, emotional, and cognitive development. In this day of fragmented healthcare delivery, it is critical for families to maintain health records to capture the continuous chronology of each family member's healthcare (Johns, 1996).

Availability of health history is especially important at the time of entrance into a school system at any level. Little guidance is available to assist parents with this little-publicized responsibility. Parents need to be made aware of the value of healthcare documentation and process requirements for such information. Equipped with a model to guide them, this knowledge can lead families to maintain complete documentation relating to health problems and services for every member of the household (Johns, 1996).

Statement of Purpose

The purpose of this study is to develop a model to guide families in documenting complete health information. Design issues to be addressed include format, size, arrangement, and content. This model will help patients, parents and others to maintain their medical records. This study also will identify design elements to increase the effectiveness of family health records.

Rationale for the Study

Most studies (Jeffs, Nosser, Bailey, Smith, & Chey, 1993; RACGP, 1982; Young & Fasher, 1994) on parent-held child health records have been conducted in Australia where parents maintain medical records for their children. Researchers reported patient and provider satisfaction as well as improved outcomes and documentation effectiveness. The personal health record has not been widely implemented in the United States. However, the American Health Information Management Association (AHIMA) Past-President, Merida Johns, 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" (Johns, 1996, p. 6).

It is critical that healthcare providers have access to specific information about their patients, including history of chronic disease, allergies, current medications, emergency contacts, and other treating physicians. In emergencies, physicians and other healthcare workers who have specific information about their patients' conditions will be able to provide better healthcare and not have to duplicate diagnostic tests that were done previously (Huffman, 1994).

Many people mistakenly believe a database exists with all of the information that emergency room staff and other providers can access any time. Very few such databases exist, and the ones that do are very limited. Others believe that their physicians keep their records for years or are easily reachable. Physicians retire, sell their practices,

move, and pass away. Moreover, through the years, primary care specialists, allergists, and a host of other specialists may see individuals. No single physician maintains a master record for patients; so, records are kept in more than one place (Johns, 1996).

The circle of health professionals caring for a patient is growing wider, drawing in professionals based both in hospitals and the community, depending on health needs. Each of these groups of professionals keeps their own type of record. Access to the information depends on professional relationships, communication systems, and agreed-upon local policies. Professionals should recognize the potential of the parent-held record as a communication channel with colleagues (Charles, 1994).

This current method of documenting healthcare creates the need for patients to assume more responsibility for maintaining accurate and complete records over time. In the case of children, the responsibility falls to the parents. The record will maintain its effectiveness only if individuals update it regularly, keep copies in their homes, bring it along on medical visits, and take it with them when they travel, according to Johns (1996).

Parents need information to take advantage of positive health opportunities and achieve optimum health for their children and themselves. Parent-held child health records are becoming more popular as a means of responding to this need. This involves not only issuing parents a different type of record, but embraces the concept of partnership with professionals working in an open and participative way with clients (Charles, 1994).

This change in practice means that parents are more involved in decisions about the health and well-being of their child. Evidence has been provided of positive outcome measures from this approach in terms of increased parental knowledge, confidence, and parenting skills (Charles, 1994).

Significance of Study

Child health records given to parents were introduced in one part of the Oxfordshire, England Health Authority in 1982. Studies (Macfarlane & Saffin, 1990; Martin, 1998; Saffin & Macfarlane, 1991) demonstrate that parent-held records are popular with both parents and healthcare professionals once they have had some experience with them. Because of its success, the parent-held child health record was designed for universal application throughout the British National Health Authority. It is designed to be the primary child health record. Its purpose is to give clients information, which enables them to take more responsibility for the health of their child. It also helps to develop the concept of partnership between clients and healthcare professionals (Dauncey, 1991). Studies (Charles, 1994; Macfarlane & Saffin, 1990) show that professionals with experience of parent-held records are in favor of parents' holding the main child health record and consider it an effective means of communication with parents (Charles, 1994).

Parent-held records were introduced in the Newcastle-under-Lyme area of North Staffordshire, Australia in July 1991. A study conducted by Randa Charles of North

Staffordshire evaluated parent-held child health records. A national parent-held record was adopted for the pilot study. The record serves two major functions. First, it is a resource containing information and advice recorded by professionals, outcomes of health checks, and details of immunizations, as well as child-lists (developmental milestones) and observations by parents. Second, the record is a teaching tool that the health provider can use when working with parents, using the basic health education material contained in the record. The important role that parents have in the surveillance of their child's health and development is promoted in the booklet (Charles, 1994).

Audits of parent-held records in the Charles (1994) study revealed more detail was recorded in the parent's record than the traditional medical record. This evidence challenges the belief among many professionals that parents would forget to bring the record to surgery and clinic and when they attended appointments with health and medical professionals.

Examples (Dauncey, 1991; Fierman et al., 1996; Jimison & Sher, 1998; MacFarlane & Saffin, 1990; Yarborough, 1996) demonstrating the value and success of a family health record (FHR) exist throughout the world. Patients were empowered by the additional information to become more involved in monitoring and maintaining their health status and that of their family members. Additionally, health outcomes were improved for patients involved in documenting their healthcare (Dauncey, 1991; Fierman et al., 1996; Martin, 1998; Young & Fasher, 1994).

Research Questions

The purpose of this study is to develop a model to guide documentation in a family-maintained medical record. The following research questions will be addressed:

1. What is the best design for a family-maintained health record?
2. Which design elements will increase the effectiveness of the family-maintained health record?

Conceptual Framework

In the past decade, the term “empowerment” has captured the imagination of people in public health, government, and human services. In public health, empowerment has been largely defined by its opposite, powerlessness. The definition of empowerment most commonly used focuses on changing how people feel about themselves, treating individuals as separate from their social context. A broader definition of empowerment proposes that people gain control of their own lives in the context of participating with others to change their social and political realities. The goals of an empowerment social action process, therefore, are individual and community capacity building, control over life decisions, equity of resources, and improved quality of life (Wallerstein, 1994).

Inspired by Brazilian educator, Paulo Freire, empowerment education involves people in group efforts to identify their own problems, to critically analyze the cultural and socioeconomic roots of the problems, and to develop strategies to effect positive

changes in their lives and in their communities. Community empowerment education would aim to foster healthy individuals in the context of creating healthy communities. Freire originally developed his ideas through highly successful literacy programs for slumdweller in Brazil. In 6 weeks, people gained literacy skills. Freire's educational ideas have been a catalyst for worldwide programs in literacy, English as a second language, health education, worker health and safety, youth programs, and community development. Freire suggested that the hidden agenda for most learning experiences is the teaching of attitudes and behaviors of the dominant society, a practice which ignores the traditions of those on the outside. To equalize the hierarchical relationships and to equally value all cultures, Freire proposed a co-learner approach. While empowerment education does not automatically eliminate power relationships or structural inequities, this approach can encourage community decision-making, community leadership, and community transformation (Wallerstein, 1994).

Definitions of Terms

Medical Record--The medical record houses the medical information that describes all aspects of patient care. Complete information is required by healthcare providers to effectively treat patients. It serves as a communication link among caregivers and protects the legal interests of the patient, provider, and facility. Records are also important for the financial wellbeing of the healthcare facility to substantiate reimbursement claims.

Family-maintained Medical Record--The patient, family members, and/or healthcare providers contribute documentation in a family medical record. It is kept at the patient's residence and carried to each encounter with a healthcare provider. Synonymous terms are parent-held records, personal or patient-held health record (PHR), and family health record (FHR). The researcher chose the term family-maintained to indicate there is an individual record for each family member

Delimitations

This study is subject to the following delimitations:

1. The population of this study will consist of health information management (HIM) professionals.
2. Only those HIM professionals who are currently members of the Grand Council for the International Federation of Health Record Organizations (IFHRO) and past-presidents of the American Health Information Management Association (AHIMA) were invited to participate.

Summary

Chapter one describes the current state of healthcare documentation in medical records. Documentation is fragmented since it is maintained by each healthcare provider who creates information when providing services. The medical record is considered the

property of the healthcare provider; and, although it is accessible to the patient, gaining access can be time-consuming, difficult, and expensive.

The problem addressed in this study results from consumers today being treated by a number of providers who may not have ready access to previous medical records. This creates the need for one comprehensive, longitudinal medical record for each person. The patient can logically assume this responsibility to provide a continuous chronology of healthcare status and services received. Included in this responsibility is the regular updating of entries and carrying the record to each encounter with a healthcare provider.

The conceptual framework is based on the theory of empowerment. Empowerment proposes that people gain control of their own lives in the context of participating with others to change their social and political realities. It decreases power relationships or structural inequities and encourages shared decision-making. Patient involvement in healthcare decisions is enhanced by sharing information.

In addition to increased availability of information for patients, other benefits result from patient-held records. Patients become more involved in decisions about their health and well-being and increase positive outcomes with increased knowledge and participation in healthcare. Patients are empowered to assume responsibility for their health and actively engage in maintaining a healthy status.

Audits of patient-held records reflect more detail recorded than in the traditional medical record. All of the data indicate patient-held records are equally if not more effective than traditional medical records.

The purpose of this study is to develop a model to guide patients, family members, and others in documentation of their own healthcare. The model will be designed based on effectiveness indicators from the literature and a panel of experts. This family-maintained medical record would include entries from the patient, family members, and healthcare providers. Patients are expected to produce the record for each encounter with healthcare providers thereby creating a longitudinal, comprehensive medical record that spans from birth to death.

CHAPTER II

REVIEW OF LITERATURE

The purpose of this study is to design a model that will serve as a guide for patients, parents, and others to document and maintain their own health care record. The design will be based on effectiveness factors identified in the literature and by a panel of experts.

Subtitles to organize the review of literature are consumer informatics, patient empowerment, current medical record documentation, advantages of patient involvement, disadvantages of patient involvement, utilization of patient-held records, effectiveness of patient-held records, format of patient-held records, content of patient-held records, and the impact of patient-held records. The chapter concludes with a summary.

Consumer Informatics

The September 1998 issue of the Journal of the American Health Information Management Association (AHIMA) was dedicated to one topic, consumer informatics. This is a clear indication that it is an issue of major concern (Kloss, 1998). In its Vision 2006 initiatives, AHIMA identifies future roles for health information management professionals. One of the future roles is that of patient information coordinator. This new service function is designed to help consumers manage their personal health

information. The function of consumer educator is included as one of the responsibilities (AHIMA, 1996).

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has included patient and family education in its perspectives. Their goal is to improve patient health outcomes by promoting healthy behavior and involving the patient in healthcare decisions. Patient education is defined as a planned activity initiated by a health professional whose aim is to impart knowledge, attitudes, and skills with the specific goal of changing behavior, increasing compliance with therapy, and, thereby, improving health (JCAHO, 1996).

Consumer health information services (CHI) is becoming a standard department in hospitals. It is seen as an additional service to meet consumer health information needs. Some facilities are sharing the medical library with a patient education library (Lambremont, 1997).

The trend toward consumer information and participation in a variety of industries is coming to healthcare. Providing patients with information about their health empowers them to become involved in decision-making as well as monitoring and maintaining their own health (Kloss, 1998).

Many programs exist to provide patients with information needed to make healthcare decisions. Many advantages to having patients more involved are cited in the literature (Golodetz, Ruess, & Milhous, 1976). Current procedures for documenting

healthcare do not allow for patient participation and do not provide a comprehensive chronology of one's healthcare status or services (Huffman, 1994).

Significant changes in healthcare, coupled with advances in technology, have sharpened interest in health information that can help consumers understand their own health problems and determine treatment options. Research has shown that access to health information can lead consumers to attain better medical outcomes (Golodetz et al., 1976). Health Information Management (HIM) professionals and medical librarians should work together to link clinical information systems to consumer health databases and design easy-to-use interfaces or single entry points to these resources in order to make the best information available that directly benefits consumers and their caregivers (Martin, 1998).

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 (Jimison & Sher, 1998).

Consumerism is emerging as a major force in healthcare. One indicator is the Patients' Bill of Rights being debated by Congress. Policymakers view consumerism as a social trend and a market force capable of bringing about healthcare market reform that could not be achieved through drastic government-controlled reform. Through

Medicare+Choice, Patients' Bill of Rights, and other programs, the government is leveraging consumerism by promoting consumer choice, value, quality, and consumer satisfaction. Consumerism is a general trend in our society, and businesses have been responding to pressures to become more customer-focused for the past decade. Now it is healthcare's turn to become customer-focused (Kloss, 1998).

Three physicians conducted a study to assess the effect of patients' having their own medical records. The study included each patient admitted to the 16-bed Rehabilitation Medicine Service at Medical Center Hospital of Vermont during a seven-month period. Each patient received a carbon copy of the full admission evaluation and discharge summary. The objectives were to improve patient education and to encourage feedback from the patient to the rehabilitation team. The effect was evaluated in four ways: (a) the nurse completed a form indicating the degree of patient acceptance, (b) the attending physician completed a form indicating whether the written note had been expurgated in any way in consideration of the patient's receiving it and commented on the positive and negative effects which occurred from sharing the record, (c) the patient completed a questionnaire which was mailed 2 weeks after discharge, and (d) the rehabilitation team as a whole discussed how the sharing had altered their work. The majority (84%) of patients expressed a strong desire to be well-informed about their conditions. Patients were strongly affirmative with 50% making some addition or correction on point of fact, and 60% 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. Initial fears of the staff were dispelled by the realization that most patients were ready to handle the information and were waiting for this degree of openness. There needed to be no hesitation because a staff member did not know what a patient had been told. Each provider could interact more freely and honestly with the patient. The effect on patient-team relationships was strong, tending away from paternalistic and caretaking relationships toward more collaborative and educational ones. No instance was identified where a patient was harmed by having a copy of his record. The study found the objectives were reached; patient education improved, as did the patient's contribution to the planning of his care. Staff accountability to the patient also improved. Results indicated patients were generally comfortable about reading the record, found it educational, and appreciated the trust implied (Golodetz et al., 1976).

Patient Empowerment

Patient empowerment can be defined as the increasing ability of patients to actively understand, participate in, and influence their health status. The same social, economic, and technological forces behind the changes in the organization and financing of healthcare also are linked to increasing demands for patient empowerment (Bruegel, 1998).

The health outcomes of powerlessness and empowerment are often unrecognized says Nina Wallerstein, an Assistant Professor in the Department of Family and

Community Medicine at the University of New Mexico. Powerlessness has been referred to as alienation, victim-blaming, and learned helplessness. Empowerment is a multi-level construct that involves people assuming control and mastery over their lives. They gain a sense of control and purposefulness to exert power as they participate to change their life situation. Participation in decision-making and in gaining control over one's destiny is itself health-enhancing (Wallerstein, 1992).

A number of factors are generating more demands by patients for an increasing role, involvement, and say in their healthcare and health status. These factors include: (a) increase in overall consumer empowerment, (b) shift to chronic disease, (c) impact of cost containment, (d) increase in the availability of health information, (e) incentives for patient education with managed care, (f) move to larger systems of healthcare, (g) continuing legal exposure, (h) access to external sources of information, (i) expectations for customer service, (j) transparent practice, (k) continuity of information from point of care to the internet home page, (l) electronic interaction with both providers and the electronic record, (m) remote monitoring, (n) community linkage, (o) provider-to-provider communications, (p) provider-to-patient/family communications, (q) patients-to-providers/families-to-providers communications, and (r) patient/families-to-other-patient/families communications (Bruegel, 1998).

Health information enables patients to be more active participants in the treatment process, which can lead to better medical outcomes. An increasing trend is to empower consumers to take a more active role in their own healthcare and to provide the necessary

information to enhance their decision-making. Self-care and home care, combined with information and communications technologies, will allow patients to better manage both diseases and overall health. Consumers will have the capability to communicate interactively to acquire health information and even consult with healthcare professionals (Jimison & Sher, 1998).

The growth in consumer use of the Internet has changed the traditional doctor-patient relationship. As patients come to their physicians with information found online, some physicians are spending more time discussing this information. Yet this new consumer enlightenment also can be a boon. It can provide the mechanism for physicians to help patients take control of their own healthcare. This form of empowerment and self-efficacy has been studied in relation to patient education (Jimison & Sher, 1998).

The Internet has opened the floodgates of medical knowledge. Any patient with a computer connected to a telephone line can track down the peer-reviewed articles doctors read in their professional journals. Patients can seek comfort and advice from a cyber-community of people with the same disease or get an on-line second opinion from another physician. This information revolution is helping patients take charge of their own well-being. Patients and doctors are required to play new roles in this information democracy. Some physicians are experiencing feelings of intimidation because they want to be unquestioned oracles of medical wisdom. However, the rewards are more important than the fragile egos of physicians. Better health for the patient and a lighter workload for healthcare providers often result from this new relationship (Lowes, 1997).

Empowerment and self-efficacy are closely linked concepts. In general, empowerment is the process that enables people to own their own lives and have control over their destiny. It is closely related to health outcomes, in that powerlessness has been shown to be a broad-based risk factor for disease. Similarly, self-efficacy is a patient's level of confidence that he or she can perform a specific task or health behavior in the future. Some clinical studies have shown self-efficacy to be the variable most predictive of improvements in patients' functional status (Jimison & Sher, 1998).

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) recently added a requirement that hospitals institute a systematic approach to providing information for patients and their families. Because of this requirement, many hospital librarians have begun offering some kind of consumer health information service. There is no question that consumers need and want access to timely, accurate medical information (Martin, 1998).

Current Medical Record Documentation

The Risk Management Foundation (RMF) at the Harvard Medical Institution provides expert review of medical records when a case goes to court. These records reflect only those situations in which the quality of care provided has been questioned. Nevertheless, what was or was not entered in the medical records frequently has significant bearing on the decision to settle or defend the case. Without accurate documentation, medical reviewers have difficulty being supportive about the care that

was given. The common assumption prevails that “if it was not documented, it was not done.” Documentation issues frequently seen in case review were identified as: (a) inconsistent documentation of breast lumps, (b) unexplained deletions from problem lists, (c) inadequate information regarding intravenous sites, (d) information gaps, (e) unclear dating and timing, (f) incomplete resuscitation information, (g) conflicting labor and delivery information, (h) perpetuating incorrect information, (i) derogatory comments, (j) conflicts among providers, (k) embellishment or overstatement, and (l) misnomers. Poor documentation does not directly cause injury or death, but it can diminish the quality of care. Documentation remains a cornerstone of the review process because reviewers must base their opinion on the written word. Without a clear record, the credibility of the defendant, rather than the facts of the case, will become the central issue (Bierman, Joyce, & Knight, 1995).

The design of the medical records will always play an essential role in influencing the quality of medical care. The structure of the notes is a medical construct and their repeated use reinforces for all readers the values there embodied. To gather information for the medical record, questions are asked in a closed format; and little additional information is obtained. Furthermore, if additional facts surface, there is no place to write them. Consequently, the information goes unrecorded; if there is no place to record how a mother was reacting to her pregnancy, why bother to inquire? A stereotyped medical model is thus perpetuated. When problems arise with recordkeeping, it is often because the notes were too brief. One area that is often neglected is the documentation of

advice given patients. Yet, the design and style of recordkeeping is not conducive to recording the advice given. Cryptic entries are often the result (Kirkham, 1997).

A newspaper article recounted the story of a woman who sought copies of nursing records from her local hospital. The patient was desperately trying to gather information about the rare breast disease that almost caused her death in an earlier hospitalization. The patient was told the records could not be found. The process of obtaining copies of medical records can be frustrating for patients although by law they usually have a right to access. Cost of the paperwork can run into hundreds of dollars. Patients may have to wait because medical professionals are unsure when documents can be released. Release is complicated because separate organizations oversee records and their rules can differ. Patients may have to go to multiple sources to gather all components of healthcare records (Huff, 1999). Maintaining records at home would render them more accessible to patients.

Physicians and consumer advocates say the confidentiality of most Americans' medical histories is disappearing as large employers and their managed care organizations strive to control healthcare costs. Even though the vast majority of the public think their records are private, in most cases they are not. No federal standards exist for the protection of medical records (Ortolon, 1998). Family-maintained records would put control of confidentiality in the hand of the consumers.

In numerous situations a patient is asked to provide a complete medical history. People are moving more and more frequently today, often far from their old

neighborhoods. New doctors need ready access to medical histories, but often have little time to collect them properly. The increased specialization of medicine creates another problem for individuals seeking comprehensive healthcare. Specialists treating patients with problems in a specific area of medicine may not be aware of their patients' other problems unless these are brought to their attention. Another obstacle between a physician and the collection of complete medical information is microfilm. Microfilm allows hospitals and clinics to keep a large number of records in a small amount of space, but many doctors and healthcare professionals find it cumbersome to use. Medical records also may be filed in the wrong place, making finding some of them virtually impossible. (Laumark & Christianson, 1980).

Documentation of medical care is an important function of health professionals; however, retrieval of information is often inefficient. Development of a national computerized system of medical records is impeded owing to the expense and to confidentiality issues. One efficient, inexpensive, and private method to increase the availability of medical information is to encourage individuals to maintain an accurate, up-to-date summary of their healthcare (Tobacman, & Nolan, 1996).

Advantages of Patient Involvement

Preparing in advance for medical appointments can play an important role in effective physician-patient communication. Maintenance of a medical record by the patient is an effective preparation activity. The patient is better prepared to ask pertinent

questions or objectively describe symptoms. Therefore, the patient becomes an active participant and not just a recipient of information (Jimison & Sher, 1998).

The de Madres a Madres Program was started in a Houston inner-city Hispanic community. It is based on the concepts of empowerment of indigenous women through unity. It empowers women as key health promoters, and utilizes acceptance of a community's ability to identify and address its own health needs. The program has become a strategy for mobilizing a total community for health. Outcome data identified the covert functions of the program was the enhancement of individual women's self-esteem and power and the collective enhancement of community self-esteem, power, and economy (McFarlane & Fehir, 1994).

A study was conducted to examine the reactions of general practitioners and health visitors to parents holding the main record of their own child's health and development. For 1 year, parents in part of the Oxfordshire, England district were given their child's records while in the other part of the health district the records remained with the clinic. Questionnaires were sent out to all general practitioners and health visitors in the two areas. A total of 287 questionnaires were mailed to general practitioners, and 239 (83%) replied. Questionnaires were mailed to 127 health visitors with 117 (92%) responses. The results show that over 90% of the general practitioners and health visitors with experience using parent-held records are in favor of them. The results of this study led to parent-held records being introduced throughout the whole

Oxfordshire district in January 1989, with the long-term hope that a standard parent-held record will be introduced throughout the United Kingdom (Macfarlane & Saffin, 1990).

A second study by Macfarlane and Saffin (1990) examined attitudes of parents involved in the experiment. Following the 1 year trial, an audit was made of a sample of parents attending child health clinics in the two areas. The study examined 284 parents who had parent-held records and 168 who did not. Participants in the study were asked who they thought should keep the child health record. Three quarters of parents who had experience with the system thought they should hold the records compared with only one quarter of parents whose clinic held the records. The most common responses for wanting to keep the records were (a) ability to keep themselves and their family informed of the child's progress, (b) being able to give the record to the child when they were older, (c) the convenience of being able to use more than one clinic and have the record available, (d) feeling more involved, (e) reduced secrecy, and (f) having the record to serve as a reminder for preventive services (Saffin & Macfarlane, 1991).

Carrying immunization cards to medical visits is a particularly useful practice in populations that use multiple providers for their primary care. When patients present for a medical encounter and the medical record is not readily available, the immunization card is a suitable alternative (Fierman et al., 1996).

The parent-held record is one of the best ideas in community health practice. Communities using the parent-held child health record are now challenged to expand its application to a health file for life. Advantages cited include (a) health professionals

would be able to work together actively as a team, (b) it would help avoid contradictory verbal advice and misunderstandings, (c) it would guide patients to become more proactive with their healthcare, (d) it would help to share information and health objectives with clients, and (e) it would help people monitor their own health (Fierman et al., 1996).

Charlotte Johnston, Chair of the Department of Health Information Management at the Medical College of Georgia, reported in an interview that keeping a family medical record could help ensure better healthcare for patients and their families. Accessing official medical records in hospitals and doctors' offices can be a slow, cumbersome process; so, it is more effective to have the documentation readily available (Yarborough, 1996).

A personal health record can be carried when traveling. It is a valuable tool for a doctor when diagnosing and treating problems, especially in an emergency situation. A health record also can be a timesaver in getting through the admission process at most hospitals and clinics. As well as preserving medical history for personal needs, it is important to document certain diseases and conditions that occur in one's family for the use of future generations. More and more illnesses are thought to be influenced by heredity. Children and grandchildren should have a record of these illnesses. The easiest way for them to do this is to have it documented in their personal medical records. Besides providing a legacy for children, personal health records are useful in completing school, insurance, and tax records. Each individual should assume the responsibility for

good health. Keeping a health record will make one an active participant in preserving and monitoring one's own well being (Laumark & Christianson, 1980).

A study was conducted at the Center for Ulcer Research and Education, an outpatient clinic at the Wadsworth Veteran's Administration Hospital, in Los Angeles. An experimental and a control group were established. The control group received a 20-minute educational session prior to scheduled appointments with a physician. Patients received information on standardized protocol for reviewing ulcer disease. Copies of these educational materials were given to the patients. The control group was neither shown nor given copies of their medical records. The experimental group also received a 20-minute educational session prior to a scheduled appointment with a physician. The session was designed to inform patients about the logic of the medical care process and to improve their information-seeking skills so they would interact more effectively with their physicians. The intervention included a review of the patients' medical record. Patients in the control group were given a copy of their medical record to take to the visits. The visits for both groups were audiotaped and analyzed by the researchers. Without the intervention, patients behaved passively in the physician-patient interaction. The experimental intervention had a measurable impact on various indicators of patient involvement. Patients in the experimental group were more verbally active. The intervention has a significant impact both on the affect expressed and opinions shared by physicians and patients during the encounter. Patients in the experimental group reported better role and physical functioning after the intervention than did patients in the control

group. The results found that the intervention using medical records increased patient involvement in physician office visits, and the greater involvement was linked to better health outcomes (Greenfield, Kaplan, & Ware, 1985).

Record sharing was tested at the Given Healthcare Center, an outpatient healthcare clinic affiliated with the University of Vermont. The project was in response to the center's goal of making patients more responsible for managing their own healthcare and increasing their ability to use health services intelligently and economically. Physicians attempted to make communication as open as possible, and record sharing was one of the tools used to achieve this goal. Over a seven-year period, records were shared with 7,000 patients. Physicians used the problem-oriented (POMR) documentation approach, which includes a section for plan of care and patient education. Patients received a copy of their record and were asked to audit the content for thoroughness and clarity (Bronson, Rubin, & Tufo, 1978).

The physicians at the clinic learned records can be written in unambiguous lay language or at least with enough clarity so that an intelligent dialogue between patient and physician can take place. Physicians were better able to view problems as they affect the whole patient. The patient's participation in establishing goals for their own care is now considered essential because the patient is more apt to understand the reasons for medical actions. In addition, such participation fosters respect between physician and patient. Physicians also have learned records can be shared without provoking undue fear in patients. The center's experience has shown that record sharing can reduce a patient's

anxiety by removing fear about what may have been hidden or not communicated by the physician (Bronson et al., 1978).

Record sharing also has had an impact on physicians' attitudes. As patients display improved understanding of their health problems and plans, physicians are more comfortable about giving them increased responsibility for self-management of chronic health problems. Physicians have more strictly relied on facts and avoided undue speculation about disease processes and expected outcomes. Patient audit and questions about general care have led to the institution of the health maintenance section, which summarizes the patient's health status, sets priorities among problems and establishes plans for routine care. It also is used to define the responsibilities of the patient, the physician, and other providers. Participation in this process has decreased patients' dependency on physicians while maintaining quality of care (Bronson et al., 1978).

The doctor-patient relationship has many facets but the basis of the whole relationship is trust. The doctor has to trust the patient to tell him everything that may be relevant. The patient has to trust the doctor to treat that information as entirely confidential. A growing number of people with no interest in the health of individual patients are finding that doctors' records are a valuable source of useful information. By letting patients keep their own records, it would deny administrators, policemen, and non-medical personnel the chance of obtaining access to medical records. At the same time, it would give patients the freedom to see exactly what had been written about them. Patients would keep their records at home eliminating the need for filing, storing, and

retrieving thousands of records at the healthcare facility. At St. Mary's Maternity Hospital in Portsmouth, Virginia, patients have been allowed to keep their hospital maternity notes for over 10 years. Records have been kept in good condition, very few have been lost, and much administrative time has been saved. Giving patients charge of their own records is the answer to a growing confidentiality problem (Coleman, 1984).

If patients always had their records with them, records would be available for surgery, home visits, out-of-hours calls and emergencies. Metcalfe indicated patients would not lose their records because, when given responsibility, one acts responsibly. Patients are more cooperative with treatment when they have complete information. Sharing the records symbolizes sharing responsibility for health. It promotes an adult-to-adult relationship that protects and restores the patient's autonomy and dignity. Information is power. To have information about someone which he does not have himself is to be in a powerful, controlling position. This is typical of the adult-child relationship, but inimical to the adult-adult relationship which should be the one used for patient-provider relationships (Metcalfe, 1980).

The emphasis of modern health management is self-care. The days of prescriptive medicine by professionals, with patients obeying orders, are gone. Patients demand to be involved in decisions about their own healthcare. With advances in preventive medicine, the role of the physician now accents advice, support, and education about self-help. The logical extension of this paradigm shift is the personal health record (PHR). The PHR is particularly important for children, the elderly, the housebound, the

disabled, and the chronically ill. The PHR serves as a communication tool when the patient visits another provider. Features of the PHR include: (a) saving time by eliminating repeated history and other important facts, (b) patients may keep all their health documents in one place, (c) the PHR encourages patient compliance especially with medication management, and (d) preventive care is enhanced (Gawthorn, 1983).

Disadvantages of Patient Involvement

Because patient empowerment centers around access to health information, the changes that result from patient empowerment directly affect health information management professionals. Patient empowerment will introduce an entirely new customer, the patient, into the work of HIM professionals. The demands that this new customer will make are likely to conflict with the demands being made by the current customer, such as existing health organizations, insurance companies, government agencies, or health providers. Complicating the issue is a substantial increase in overall concerns about the privacy and confidentiality of health information (Bruegel, 1998).

After ten years of use, the Royal Australian College of General Practitioners (RACGP) reported few disadvantages in the use of patient-held records. Confidentiality was considered; however, with the information in the control of the patients, they can make their own decisions regarding access. The possibility of litigation against doctors was a second concern. The PHR dictates care in incorrect labeling of patients and possibly only recording things that the patient will accept. It was agreed that doctors

should take care with inaccuracies even without use of the PHR. The third concern was erosion of status. The RACGP concluded that providing this service to patients demonstrates care and interest in the patients' welfare. Their experience has shown that status is actually enhanced (RACGP, 1982).

Participants in the Saffin and Macfarlane (1991) study reported why they did not want to keep their child's record. The two reasons focused on worries about losing the record but also raised the issue of access to clinic-held records. The second reason revealed an opinion that the record is the property of the clinic, and they saw no value in keeping it at home. Additional comments related to the size, format, and legibility of entries.

A semi-rural practice in North Oxfordshire, England explored patient-held records. Medical summaries were prepared by a general practitioner for inclusion in the computer system. A representative sample of the practice population of 2500 was sent their summaries. The first 100 families identified in alphabetical order from the practice register were selected. It was decided not to send summaries to 19 of the patients because of family relationships or potential patient reaction to the content. This means that opinions, possible diagnoses, and inaccurate diagnoses assume greater impact when the notes are read by someone other than the person who wrote them. Three patients disagreed with the doctor over a diagnosis and wanted it removed. In these cases, disagreement between doctor and patient could hazard the relationship between them. With 2% of patients, the general practitioner felt that he could not allow them to see even

the summary. The general practitioner felt the need to exclude 11 diagnoses whenever they appeared and to suppress one or more diagnoses in 14% of the patients. The patients' views of the usefulness of the summaries and of their accuracy and completeness were sought by a questionnaire. A majority (91%) reported that they thought the summary was useful. In 18% of cases, the patients requested additions, corrections, or deletions. Only 1% of patients replied that they definitely did not like the idea of a computer containing their medical information. The researcher made several recommendations resulting from the findings: (a) the patient should not have the right to see the whole record, but only the medical summary; (b) this summary should be made available to the patient when the doctor can answer any questions raised; (c) a copy of the summary should be made available to the patient on request; (d) the doctor should have the final say when entries are disputed by the patient; and (e) the rest of the medical record should remain confidential (Sheldon, 1982).

Utilization of Patient-held Records

Studies by the Oxfordshire, England Health Authority found parent-held records are unlikely to get lost, will usually be available at clinic, and are more likely to be completed. This program has been so successful that the Health Education Authority is piloting an adult client-held record. Information will be available to partners, grandparents, and any child caretaker. Traveling families also will find value in the parent-held records (Dauncey, 1991).

Fierman et al. (1996) studied the accuracy of immunization cards maintained by parents as compared to medical record documentation of immunizations. The study was conducted at the Department of Pediatrics for New York University's School of Medicine in New York City. In 85% of 257 cases, the immunization card and medical record immunization dates were identical. Similar results were obtained for identifying patients who were due or were up-to-date with immunizations. The conclusion was that the hand-held immunization card is a suitable alternative to the medical record (Fierman et al., 1996).

Underimmunization has been shown to be a powerful marker for lack of other preventive and primary care supervision. To accomplish the national goals for Healthy People 2000, providers must be able to make accurate assessments of a child's immunization status at every clinical encounter. While the physician or hospital record of immunizations has been considered the gold standard for the assessment of immunization status, such records may not be available at all clinical encounters. In situations where healthcare is fragmented, no single provider may possess a complete record of all immunizations received. Other methods of assessing immunization status, such as parental recall and assessment of risk factors for immunization delay, have been shown to be imperfect when compared with the medical record. The results of Fierman et al.'s study demonstrate that, when patients' hand-held immunization cards are available for review, they provide immunization information comparable with hospital medical records and result in similar assessments of immunization status. This will be of great

potential value in furthering the goals of the National Vaccine Advisory Commission to utilize all clinical encounters to screen for needed vaccines (Fierman et al., 1996).

Results of the North Staffordshire audits by Charles (1994) found the professionals felt time spent in detailed discussion with parents about the record was a good investment in promoting its effective use. Professionals unanimously agreed that every effort must be made to improve communication with parents.

In most of Europe, the system of pregnant women keeping their own medical records has been in place for some time and works well. The United States has been slow to catch on to the idea. A standardized, uniform data-collection system is sorely needed. A single set of records would be especially useful because so many families move around from state to state. So, why is the United States slow to adopt a similar system? The issue, of course, is control. Ownership of the written record denotes control of the information. Information is power, and some healthcare providers simply do not want to share decision-making power with patients. Others view patients like children and complain that patients will misunderstand the information or get upset by it. "Perhaps healthcare providers should spend less time worrying needlessly about the unproved dangers of laypersons learning about their health conditions and medical treatment, and more time encouraging them to take responsibility for their health" (Young, 1991, p. 3).

Compliance with a physician's recommendations is critical to the long-term care of patients with chronic illnesses. Patients with hypertension who visited the outpatient clinic at Saint Joseph Hospital in Paris during the period from January 1981 to August

1982 were studied. The randomized, controlled study compared the effects of a personal standardized medical record on health. The intervention group received routine care plus their personal medical record. The record consisted of 10 pages with carbon copies to be completed during each consultation with the general practitioner. The use of the record was explained to each patient during a previous visit. The control group received usual care alone. The patients in the intervention group added more comments than did patients in the control group. However, blood pressure control and levels of other risk factors measured after 1 year were comparable in the 2 groups. No differences in clinical end-points emerged. Patients in the intervention group had a greater fall in blood pressure, more frequent visits, less frequent modifications of their antihypertensive treatment, and fewer compliance problems than the nonusers (Billault et al., 1995).

In many instances, patient-retained records would assist in transferring information to other doctors involved with a patient's care. The health identity card is a way to help patients remember information about their past and present health problems and to help doctors to understand the problems of a new patient. The identity card contains a colored passport photograph with demographic information. The second part contains details of current and past medical problems with the treatment given. Space is available for the patient to record the last will and testament and life insurance details. The back half of the card contains a summary of patient-doctor contacts with the problem and treatment. A section is provided for miscellaneous details. The card is folded and enclosed in a clear plastic envelope. A handout accompanies the card to tell the patient

what the card is for and how to use it. Skiba (1984) issued the card to patients over the age of 16 being seen in his practice. The card improved access to information for the physician and the patient. The overall response from patients has been favorable, and there have been few problems. Financial problems include recovering the cost of the card and resistance by patients to paying for cards for which they may not feel a need. Sensitive problems such as terminations of pregnancies, psychiatric illnesses, and venereal disease are difficult to include on the card. Cards can be lost, and confidentiality can be a problem (Skiba, 1984).

The idea of client-held records has been slower to develop in the mental health field than other areas of healthcare. However, Stafford and Hannigan (1997) suggested it might be beneficial both for aiding user involvement and coordination of care. They piloted a client-held record known as a care booklet in one area within Tower Hamlets Healthcare NHS Trust in London. Important concerns raised during design were that the booklet should be easy to carry, easy to use, flexible and hard-wearing. The resulting record was in the form of a small, pocket-sized, plastic ring binder with four main sections: personal details, appointments, notes, and medication. In addition, there was space for a care plan, a crisis page for the user to complete, an early-warning-signs page, and blank pages. The pilot indicated the booklet was useful to both users and professionals and could facilitate greater collaboration and communication (Stafford, & Hannigan, 1997).

A cardiologist in New York has used a wallet card for over 17 years. The card has proved to be life-saving in emergency situations. The physician completes the card that is always carried by the patient. It includes diagnoses, crucial lab data, and information on allergies and medication. A copy of the latest EKG is stapled to the card. Immunizations, most recent physical exam, and X-ray results also are recorded. Patients report having the information makes them feel more secure especially when they are far from home (Leibowitz, 1988).

A study was performed in the General Medicine Clinic of the Department of Internal Medicine at the University of Iowa Hospitals and Clinics (UIHC). The randomly-selected sample consisted of 100 adult patients. A Personal Health Record was given to each study subject, and information was entered with the assistance of investigators. The PHR was the same size as a check registry and fit in a pocket or purse. The same questionnaire was administered by telephone at 2, 7, and 14 months. The purpose of the study was to determine acceptance of the PHR, assess usefulness and clarity, determine impact on availability of documentation, measure the effect on knowledge about health and healthcare, and explore the impact on actual care received. At 14 months, 69% of the subjects knew where the record was located at the time of an unscheduled call; 74% had looked at it since it was started; 66% had added information; and 55% had kept it up-to-date. Findings support the conclusion that an unmet need for a PHR exists for adult general medicine patients (Tobacman, & Nolan, 1996).

Effectiveness of Patient-held Records

After ten years' use of personal health records (PHR), the Royal Australian College of General Practitioners (RACGP) reported the PHR is particularly important for children, the elderly, the housebound, the handicapped, and for patients with chronic conditions. They are especially useful for those travelling with a health problem. Another important use is as a communication vehicle for visits to healthcare providers other than the usual practitioner. The RACGP reports use of the PHR saves time for the patient and the doctor. It also avoids duplication of diagnostic procedures. The RACGP further reports evidence that compliance with management plans and medication is enhanced; and patients have an interest in their own well-documented record (RACGP, 1982).

Parent-held child health records (PHCHR) are widely used in the United Kingdom (UK). They were instituted based on a philosophy of partnership between professionals and parents. Problems existed with the attitude of some professionals toward parents' holding their child's main health record, and doubts were expressed over the reliability and completeness of these records. Emond, Howat, and Evans (1995) studied the effectiveness of the PHCHR as part of the Avon perinatal follow-up study. Each mother was issued a PHCHR at enrollment on the postnatal ward and was asked to present it for completion every time she visited a health professional with her baby. The healthcare providers were informed of the study and asked to use the PHCHR to record

details of any consultations with these infants. The PHCHR was used in parallel to existing hospital, community, and general practice records. A total of 373 infants were included in the study. When the children were 1 year old, they attended a special follow-up clinic to evaluate the results. A total of 360 out of 373 PHCHRs (96%) were recovered, photocopied, and returned to the parents. Upon inspection of the documentation, 12% of the records were considered incomplete; and 88% were sufficiently complete to provide adequate details of health services. This validation confirmed that the short-term loss rate for PHCHRs is very low and indicated that, in the vast majority of cases, the records are adequately completed. These data compare favorably with rates of lost, duplicate, or incomplete hospital records (Emond et al., 1995).

During 1986 and 1987, parents in part of the Oxfordshire district health authority were given their child's health and development records while in the other part of the health district the records remained with the clinic. Between August 1988 and February 1989 an audit of a sample of parents' records was made. At the time of the audit, 7% of parent-held records had been lost or forgotten; however, 5% of clinic-held records were not available for inspection. The audit of records looked at the recording of 15 key items by professionals. A total of 473 parents were approached for the study. Of the 284 who participated, 63% had been given parent-held records; and 168 had clinic-held records. Overall, parent-held records were more likely to have comments contributed by parents

and to be more thoroughly completed by professionals. The results suggest that parent-held records are not only workable but also desirable (Saffin & Macfarlane, 1991).

A study in New York was designed to determine whether patients' hand-held immunization cards provided accurate assessments of immunization status when compared with their corresponding medical records. Of the 263 children in the study, 257 (98%) of the records were available for review. In 218 (85%) of the records, the immunization card and medical record immunization dates were identical. Findings concluded the hand-held immunization card is a suitable alternative to the medical record (Fierman et. al., 1996).

Young and Fasher (1994) conducted a study to investigate the actual use of the parent-held child record (PHR) in a general practice setting. The findings showed an increased use of the PHR was linked to increased patient awareness. The study was conducted in New South Wales, Australia where the PHR had been in use for five years. Previous studies indicated widespread use and acceptance by parents and community health workers. However, private doctors had reported the record was not very useful. When the PHR was audited for 825 patient contacts, records of immunizations were well-kept with 92% complete; the health problems summary was blank in 88% of the records. Health center workers had notations on 92% of the progress notes, and 40% had entries by the doctors (Young & Fasher, 1994).

A standard PHR can make an important contribution to the healthcare of children. Parents are a child's primary caregiver, and their involvement in the monitoring of that

child's health is vital. The PHR aids communication and creates a single source of information for healthcare providers, parents, and teachers (Young & Fasher, 1994).

The Young and Fasher (1994) study revealed a discrepancy between reported and actual use by doctors. Notes made by doctors in the PHR were low compared with parent-reported contacts with doctors. Some doctors saw recording as a duplication of records. However, others saw it as a time-saver by eliminating repeated history giving and providing ready access to important facts. Doctors were not targeted with information about the PHR before and during its launch, unlike the healthcare workers. Increased familiarity and belief in the value of the PHR can lead to increased use (Young & Fasher, 1994).

Twenty patients and four healthcare professionals participated in a 1-year pilot project assessing the impact that sharing the record had on the patient and the provider. The concept of sharing was extended beyond simply issuing a copy of the record to include the active involvement of the patient in the authorship and maintenance of the record. The exploratory study was conducted at Beth Israel Hospital in Boston, Massachusetts, a 432-bed teaching hospital, serving as one of the major educational facilities of the Harvard Medical School. The patient and provider formulated the problem list and co-authored notes. Emphasis was placed on designing a mutually acceptable plan of care. A copy of the co-authored notes was kept in a notebook that the patient brought to all BIAC visits. The researchers measured patients' cognitive,

attitudinal, and behavioral changes through data gathered from pre- and posttests, chart review, and patient interviews (Fischbach, Sionelo-Bayog, Needle, & Delbanco, 1980).

Initially, patients had difficulties assuming their new roles and appeared reluctant to express opinions or disagree openly with their providers. As they became more familiar with terminology and format, they began to focus on more relevant symptoms and became more articulate and effective historians. Participation in the writing process helped eliminate serious misconceptions on the part of patients. It became an effective technique to foster two-way communication. The patient-held notebook served as an effective educational tool and supplement to the patient's recall of material discussed during the office visit. Patients became very attached to their notebooks. Record sharing had a marked effect on the providers as well. Prior to the study, the providers were apprehensive and skeptical about exposing traditionally confidential documents to the scrutiny of patients. With time, experience, and the support of peers, ambivalence and anxieties decreased; and they were able to benefit from the improved communication process. There was marked improvement in appointment keeping. If custody of the medical record seems to symbolize authority and control by the medical profession, then sharing the record may be perceived as symbolic of provider trust and confidence in the patient. Patients often have been grossly underestimated and underutilized. They now seem ready, able and eager to be enfranchised to enter an era of self-determination and equality. The therapeutic alliance achieved by informed sharing of the record can serve

as evidence to patient-consumers that they are the most crucial resource of the healthcare system (Fischbach et al., 1980).

A study was conducted in Melbourne, Australia to assess the effect of giving hospitalized patients access to their problem-oriented hospital records. The experimental group had free access to their records while the control group did not and were treated conventionally. The researchers concluded information exchange was facilitated by access, and patients were able to monitor more objectively their hospital course (Stevens, Stagg, & MacKay, 1977).

Format of Patient-held Records

Several computer programs have been developed to help physician-patient communication by organizing information, educating consumers, and keeping a record of important issues that need to be addressed during the physician-patient encounter. These programs allow a user to maintain a comprehensive medical record at home (Jimison & Sher, 1998). The Royal Australian College of General Practitioners (RACGP) has identified its preference for a folded PHR which is suitable for handbag or pocket (RACGP, 1982).

According to Charlotte Johnston, Chair of the Department of Health Information Management at the Medical College of Georgia, keeping a family medical record can help ensure better healthcare. The family medical record should include a running list of diagnoses, procedures, and medications. Immunizations and episodes of childhood

diseases also should be included. Surgeries, other treatments, and allergic reactions are important to note. A family history is critical to identify risks for heredity disorders. A small notebook is all that is needed, but it can be kept on the computer. The record should be updated whenever there is contact with a healthcare provider. It also should be carried when traveling (Yarborough, 1996).

The record format and ease of use could impact its utilization. The parent-held record implemented in Oxfordshire is in a loose-leaf format so that inserts can be made. It includes an education section to give specific information and care guidelines for the child's specific condition (Dauncey, 1991).

In France, it is the *carnet dematernite*'; in London, it is the Maternity Notes or blue book; in Japan, it is the Maternal and Child Health Handbook; in India and many developing countries, it is the home-based maternal record; and in Utah it is the Baby Your Baby Keepsake Book. The names for the maternal health record are different and the content and format vary, but they share a common goal of promoting the mother's and child's health by providing a medical record that is held by the pregnant woman or mother herself. The woman brings her record with her to prenatal or medical appointments in the clinic or doctor's office. Some versions have space for the mother to fill in the requested information. Most contain facts about risk factors, nutrition, breast-feeding, family planning, developmental signposts, and more. The healthcaregiver fills in sections on medical history, results of examinations and tests, details of pregnancy and birth, growth and development charts, and professional notes and other medical

information. Besides giving the mother and her family valuable information on which to act, home-based records can make a substantial difference to the quality and effectiveness of prenatal care (Young, 1991).

Rehabilitation units are ideal for record-sharing, since the emphasis on patient education is already strong. The patient is expected to be active in his own care. Record-sharing depends on typewritten, well-organized records. The problem-oriented record with its complete problem list and its logical arrangement of data is well suited for a patient's perusal (Golodetz et al., 1976).

Oxfordshire began experimenting with parent-held records (PHR) in 1982. Parents of new babies were given the PHR to keep at home. The record consisted of a four-page card containing details of immunization, birth history, developmental checks, and percentile charts for weight and head circumference. Four additional pages contained advice on managing a fever and when to call a doctor, plus hearing, vision, and development checklists. All this was folded and placed in a plastic wallet. The records were not designed to be user-friendly. However, they have been replaced with a loose-leaf booklet designed with parents' use in mind. A patient reported it was hard to keep the record unless it stayed in her handbag. Another reported the records are too big to keep at home. Other comments included insufficient space and illegibility. Less than 10% of patients made adverse comments compared to the 25% who made comments about the advantages (Saffin, 1990).

Physicians in New Zealand have found it practical for patients to carry a personal medical record card. It is most helpful when patients are treated by a substitute doctor who is unfamiliar with the patient. However, it also helps over-familiarity with patients frequently seen, when minor changes may escape notice, and more remote history may be forgotten or buried under current observations. The card includes biographical information, medical history, and medications. It is pocket-sized and is carried in a transparent plastic protective envelope (West, 1967).

Health card projects like DIABCARD are speeding up the necessary standardization activities on electronic health records. The need is amplified when treating a patient with a chronic illness. The multidisciplinary team can stop the onset of secondary diseases or the disease itself with tight monitoring of the patient's state-of-health. A computer-based patient record (CPR) can provide accurate and complete information. Having the CPR on a smart card makes the patient's up-to-date record accessible when and wherever it is needed. Not only will such a medical smart card provide vital information; it also can have an effect on patient compliance (Engelbrecht, Hildebrand, Brugues, DeLeiva, & Corcoy, 1996).

A search on the Internet revealed several products available for families to document their healthcare. The researcher has documented the most useful ones (Odom-Wesley, 1998).

Vitalworks offers Health Tracker, a personal medical record product to manage a family's health. It is dedicated to helping consumers play a more significant role in their

own healthcare by empowering them with contemporary tools for managing personal healthcare information. These tools give consumers secure access to components of their healthcare records and the means by which to record, store, and understand important healthcare data. Support is expressed for the theory that more informed consumers are healthier, require less care, and cost less to insure (Vitalworks, 1998).

The Lifelinks site guides viewers through three steps; downloading forms for family charts and data sheets, researching missing information, and recording information (Lifelinks, 1998). CapMed offers a PHR in a cost-effective, simple method of maintaining and reviewing family medical records. It is a Windows-based software application that stores personal healthcare information for individuals and families. Users can store health information on a diskette to travel or transport to an encounter with a healthcare provider. Medical facilities that subscribe have the capacity to download and update information (CapMed, 1998).

The home page for Home Medical Records markets a Healthwise Handbook. It recommends a home health center as a good place to keep family medical records. It outlines recommended content and suggests a wire-bound notebook with dividers for each member of the family (Home Medical Records, 1998). A home kit for keeping medical records organized is presented on the homepage for MedCheck Medical Alert Identification. A list of items to be included is given along with an order form (MedCheck, 1998).

A web-based repository of simplified electronic medical records is found on the home page for Virtual Medical Records. It contains the essential personal medical records of the users along with past medical or surgical history, immunization histories, allergy records, and medication records in the form of text, data, and clinical images. Healthcare providers can upload copies of records stored here (Virtual Medical Records, 1998).

The Home and Family Financial Management Personal Home Record system markets software or a record book for the non-electronic user. It is a system designed to record every aspect of home and family activity. Medical records is one of the programs offered (Home & Family Financial Management Personal Home Record System, 1998).

Medifile advertises a permanent medical record solution and specializes in consumer health record services. Repository services meet the need for centralized storage of consumer health records, and consulting is available to healthcare institutions on the topic of consumer health records (Medifile, 1998).

Kathleen DeRemer offers a practical guide for taking control of your health and having medical records always available. The HealthMate Medical Planner is a unique system that allows individuals and families to record and process their medical history in a simple, understandable fashion that is always available (HealthMate Medical Planner, 1998).

The MD WIN Computer Super Store offers a Family Health Tracker to locate personal and family medical records and health-related activities. It can be used to

maintain a diary of exercise and fitness activities, prepare a list of medical expenses, print a record of vaccinations and allergies, and print a list of emergency numbers (MD WIN Computer Super Store, 1998).

Personal Medical Data Records offers a system that makes the patient and physician partners in the control of healthcare. The Medical Data Portfolio answers almost every question a patient is likely to be asked regarding healthcare and services. Pages are kept in a three-ring loose-leaf notebook and can be neatly removed by the perforation (Personal Medical Data Records, 1998). Patient Medical Records, Incorporated offers software for medical practices, student health records, and general use (Patient Medical Records Incorporated, 1998).

The Personal Health Organizer (PHO) is a loose-leaf notebook system to store health information. It is divided into 10 sections. There is a family and an individual edition. The family version provides a place for up to 5 family members to store their information. A study by Duke University found the PHO improves healthcare by helping patients better understand their medical problems and giving them a sense of greater control over their health. The study found that the PHO improved the patients' knowledge of, and feeling of control over, their health problems; increased the availability of information for health providers; enhanced communication between patients and healthcare providers; and improved the patients' perceived quality of healthcare (Personal Health Organizer, 1999).

Content of Patient-held Records

Consumer health information needs to be distinguished from patient education information. Consumer health information tends to focus on prevention, wellness, and treatment options. The consumer initiates the search for information for themselves, friends, or family members. Patient information, on the other hand, encompasses medical instructions from a health professional regarding a treatment option or alternative treatments. Often, the purpose is to change behavior. The information is initiated by the health professional rather than the patient (Martin, 1998).

The prototype of the Royal Australian College of General Practitioners' (RACGP) personal health record (PHR) was designed in 1973. By 1982 over 1000 Australian practices with an estimated 3000 doctors had started using it. Important components of the PHR have been identified. The key to the usefulness of the PHR is a health summary, which must provide a complete and accurate overview of the patient's healthcare activities. Health notes are analogous to the doctors' progress notes and may be structured in a narrative style with date of entry or problem-oriented. The medication list is particularly important for use by geriatric patients. A felt pen was recommended for patients with poor vision. Updating the list ensures supervised compliance with nurses or relatives involved in the care of the elderly. Introduction and notes for users is helpful to give instructions to the patient. Other records available include a flow chart and full

range of pediatric percentile charts, immunization records, and a wide range of health education material (RACGP, 1982).

The American Health Information Management Association (AHIMA, 1998) lists the documents common to most health records. The forms included are identification sheet, problem list, medication record, history and physical, progress notes, consultation report, physician's orders, imaging and x-ray reports, electrocardiogram report, laboratory reports, immunization record, correspondence, and authorization forms. Additional documents common to hospital stays or surgery include operative report, anesthesia report, pathology report, recovery room record, vital signs graphic sheet, and discharge summary.

AHIMA supports maintaining personal health records by consumers. Maintaining a personal health record at home is one of the best ways to assure that you will have access to your health information. Keeping a personal health record can be as simple as maintaining a file folder in which relevant medical data is kept. Copies of operation reports, discharge summaries, and significant tests should be included. The following categories of information should be incorporated: personal identification; person to notify in case of emergency; name and phone number of your personal physician, dentist, optometrist, and pharmacist; current medications; immunizations; allergies; important events and dates in your personal and family medical histories; important test results such as x-rays and EKGs; eyeglass prescription; dental information; copies of advance directives; organ donor authorization; and health insurance information. Sample forms

(see Appendix A) for adults and children are available on the AHIMA home page (AHIMA, 1998).

The usefulness of a record decreases without visible identification. The PHR used in New South Wales is anonymous when closed which creates a problem when more than one is on a doctor's desk. This problem was solved by placing a large white sticker with the child's full name on the cover of each record and on each page of the record. It was further found that a reminder sticker on the front of the PHR telling parents to bring it to all health encounters increased usage (Young & Fasher, 1994).

Possibly the aim of noting every health visit in the PHR is too optimistic. Material suitable for the PHR may be different from that routinely recorded in doctors' notes. Physicians reported hesitancy about recording sensitive material, mental state, identification of children at risk, and marital discord. Perhaps the PHR should be used to record major health events, hospital admissions, education material, and treatment plans for chronic conditions (Young & Fasher, 1994).

The Family Health History Workbook is designed to explore and record the many and diverse elements that affect the health of the family. The idea for the book grew out of the increased popular interest and participation in healthcare that has developed over the last 15 years. Consumers have discovered that doctors' records are not the complete, precise resources previously imagined. Frequent moves have complicated access to medical records of past care. Increased specialization has relegated healthcare to a number of providers each specializing in a specific area. A conscious and growing health

movement has its roots in the civil rights and women's struggles. Self-help and demand for social change are the two distinct trends. This recordkeeping book reflects thinking from both trends. It serves as a communication tool, gathering information from the family to give the healthcare practitioner and to increase self-awareness. It helps organize information for present and future needs. It is divided into sections which reflect health needs at different life stages. There is a section for adult health, health issues, reproductive health, childbearing, and childhood. There are record-keeping charts to be completed by the patient, parent, or other family member (Mahoney & Lichtman, 1982).

The Lifespan Personal Health Record is a system for entry of health data in a computer-based patient record by lay individuals. Data entry is supported with data clarification and system-supported summarization of the data in context to show relationships, highlight sentinel events, and assist in evaluation of alternative decisions and actions as needed. Specific feature of the system design include: (a) a means to enter past medical and family history, occupational, medication, nutritional, dental, immunization, lifestyle, fitness, functional and travel history, using time lines, (b) event-driven prompts for current health problems, (c) a template for the insertion of diagnostic test results, (d) guidance for the risk interpretation of current health practices, (e) guidance to self-care and to the use of the healthcare system, (f) summarization of the natural history of disorders and implications of alternative modes of management, (g) reinforcement of user awareness of the adverse effects of therapeutic measures, (h)

options for bi-directional linkage of the personal health record to computer records maintained by providers of healthcare, and (i) access to aggregation of elements in databases produced over populations of individuals who are not individually identified (Williams, Imrey, & Williams, 1991).

Health records are only as valuable as the information contained. To be of greatest value a record should meet the following five criteria: (a) the entries must be legible, (b) the information must be accurate, (c) the information must be complete, (d) the information must be relevant to one's health problems, and (e) the information must be organized to assure speedy and easy retrieval (Laumark & Christianson, 1980).

The Personal Health Record System outlines information needed for a complete health record. The items listed include sample forms, and instructions are included for each report. It is divided into eight sections: (a) "Medical Reference Numbers", (b) "Health History and Habits", (c) "For Women Only", (d) "In The Beginning" (childhood), (e) "Test Results", (f) "Special Needs", (g) "Present Illness and Problems", and (h) "Ancillary Health Records" (Laumark & Christianson, 1980).

Shillington (1994) suggested the parent-held records be expanded to a health for life file which would document healthcare into adulthood. In this recommendation, the parent-held under-five record would be expanded to contain all health records. Babies who have the record will hopefully see it develop to become their adult health record. This would promote a healthcare team concept with a communication vehicle. Whenever a professional recommended action or advice, it would be entered on the client-held

record. This would help avoid contradictory verbal advice. Other sections would include health education and first aid and would allow patients to take greater responsibility for their own health (Shillington, 1994).

Impact of Patient-held Records

Parent-held child health records were introduced in the Portsmouth and South Hampshire, England health district on October 1, 1992. Responses from key participants underline the importance of training to prepare staff for the challenge of a new partnership based on the principles of openness and trust. Key issues were identified for the successful implementation of parent-held records: education and training, staff support, and funding. Training was provided to 156 staff members in ten four-day courses. The training focused on fostering a shift in philosophy and practice toward a partnership approach with the goal of empowering clients. The child health record itself was not the object of training. The records are simply a tool or resource for putting partnership with clients into practice (Whitney, Holland, Emms, & Phillips, 1993).

Sharing records with clients is a major change in healthcare practices. It goes against the grain of years of institutionalized nurse training. Two questions arise: first, the method of introduction and the training requirements; second, the legal issues and what other records are needed (Dauncey, 1991).

Skills that enable health professionals to be open and honest with clients need development. Very few adults have ever had the opportunity to write in a professional

record. Clients will need encouragement and training to assume this responsibility. Responsibility for the care of the record lies with the client. This generates concerns about loss of records, mutilation of records, and failure to provide the records during a healthcare visit. Will a duplicate record need to be maintained by the healthcare provider? The Oxfordshire system supports the concept of client-held records as the main record (Whitney et al., 1993).

Using an immunization card to assess immunization status can be of value only if patients bring the card with them to all medical encounters. Several factors are likely to influence patients to carry their immunization cards to all medical encounters. Patients should be asked for their immunization card at every visit and encouraged to carry the card with them at all times. Providers will require training to provide this encouragement (Fierman et al., 1996).

A major concern among healthcare professionals is confidentiality. The Charles (1994) study in North Staffordshire reported most parents were not concerned that someone else might read the information in the parent-held record. In fact, most of the parents said they would share the information in the parent-held record with relatives, friends, and child caretakers. The health professionals reported they would make efforts not to record sensitive information in the record to protect confidentiality. Therefore, additional clerical work was created by having to document in two different sources (Charles, 1994).

Negative comments were fewer than positive in the Charles (1994) study.

Negative responses focused on the size of the record and the additional clerical work its use generated. All the professionals perceived positive benefits in using the record, including improved uptake of preventive services, immunization, and child health surveillance checks. The record also was seen as an opportunity for developing mutual trust and respect between professionals and parents, which is an essential cornerstone if a true partnership between client and professional is to be achieved (Charles, 1994).

Views expressed by parents in the North Staffordshire study indicated the need for more information about their child's health and the wish to be more involved in their child's healthcare. Parents felt that using the parent-held record gave them a better understanding of advice given by professionals. The record helped 99% of parents remember important things because they had been written down (Charles, 1994).

Personal Health Records (PHR) have been issued to babies born in several overseas countries for a number of years. In 1985 the National Health and Medical Research Council endorsed the development of a uniform PHR suitable for issue to all Australian children. PHRs are seen to have a number of potential benefits. These include: (a) adequate documentation of important events in a child's life, (b) improved communication between various health professionals, (c) a readily accessible source of information and advice to parents on child health-related topics, and (d) a greater sense of involvement and responsibility for their child's health among parents and caregivers (Jeffs et al., 1993).

Jeffs et al. (1993) conducted the first extensive study of the retention and use of personal health records in New South Wales, Australia. This was the first large-scale, population-based study on how well the PHRs are retained and how well they succeed in delivering their intended benefits five years after introduction. Eighty-four percent of parents could produce the PHR although 95% claimed to have it. The PHR provided complete documentation of birthweight, Apgar scores, and child development. Parents generally remembered to take the PHR to those healthcare professionals who regularly used the record. Most respondents described the record of immunization, development, and progress notes to be the most helpful sections. These studies confirmed that the PHR adequately fulfills the study objectives and provides most of the intended benefits originally proposed for it. It is relatively inexpensive, easily transportable between different healthcare locations, accepted and valued by parents, and used by and useful to many different healthcare professionals. Most importantly, it makes information about their child's health easily accessible to parents (Jeffs et al., 1993).

Kirkham (1997) is a professor of Midwifery at the University of Sheffield where maternity records are maintained by the clients. Kirkham challenges midwives to make the most of sharing information by making client-held notes genuinely accessible through design and language. The medical records are not evidence that a partnership exists between client and caregiver. The language of the notes is that of obstetrics. Although notes are now client-held, they still consist of medical jargon. The fact that it needs translating emphasizes that this is not shared information but experts' jargon. If a

technology is making it increasingly likely that the outcome will be one of patient empowerment – a situation in which patients are increasingly knowledgeable, demanding clients and where their preferences, concerns, and choices play an increasing role at every level of healthcare decision making. One way of recognizing the stage of any group's empowerment is when the group stops asking permission and simply starts exercising increasing power. In many ways, this has already begun to occur with regard to the empowerment of patients throughout healthcare. As this process accelerates, understanding and anticipating the emergence of this new paradigm will quickly become a key requirement for healthcare professionals to be effective in the new world that patient empowerment is likely to create (Bruegel, 1998).

Programs that have implemented patient-held records report successes and benefits. Families are better informed, conscientious about keeping records up to date and about bringing them to healthcare encounters. Patient-held records are especially beneficial for young children. Immunizations have been recorded more accurately and patients have willingly accepted healthcare documentation as part of their parental responsibility. There are no apparent disadvantages to family-maintained medical records.

The review of literature revealed preferred formats and content requirements to make the patient-held record most beneficial. Implementation of family health records will change the doctor-patient relationship to more of a partnership. Training for healthcare providers is critical to the success of such a project.

CHAPTER III

METHODOLOGY

The purpose of this study was to develop a model for documentation and maintenance of family medical records. A review of the literature indicated medical outcomes improve when patients become partners in medical decision-making. Empowering patients with information and assigning responsibility for documentation to them enhances this participation. Currently, there is no guide for format or content of a family-maintained record. The review of literature further revealed current applications of a Personal Health Record (PHR) and preferred formats and content, based on experience using the system. In this study, a panel of experts provided information to design a model using the Delphi technique.

Selection of Subjects

The International Federation of Health Record Organizations (IFHRO) is comprised of national organizations that focus on medical records and related issues. The American Health Information Management Association (AHIMA) was the first national medical record association and is a member of IFHRO. Early IFHRO members included the Canadian Association of Medical Record Librarians, the Association of Medical Records Officers of Great Britain, and the Australian Federation of Medical Record

Librarians. These national organizations have brought added interest in research in medical records and improvement in the quality of the medical record. It was believed that worldwide participation of medical record personnel would bring about advances in establishment of international standards, the compilation of statistics for international comparison, as well as disease classifications that could be adopted on an international basis. The Federation serves as a means of communication among medical record practitioners in various countries and works to advance the standards of medical record science worldwide. The Federation promotes the development of techniques to improve the quality of medical record services (Huffman, 1994).

Members of IFHRO were chosen to participate in this study because most utilization of patient-held records is outside the United States. A list of members of the IFHRO Grand Council was requested from AHIMA and received. The Council consists of representatives from member countries and an executive board of officers for a total of 23 members. Because of the small number, the researcher decided to add to the participants in order to achieve the convenience sample of 20.

Past presidents of AHIMA also were invited to participate in this study. This group of health information professionals is considered among the most knowledgeable and respected in the HIM field. Past presidents of AHIMA typically serve as liaison to IFHRO during the year immediately following their presidency. A list of past AHIMA presidents was acquired from AHIMA. There are a total of 32 persons on the list.

The IFHRO Grand Council and the AHIMA past-presidents formed a panel of experts with 55 potential participants for this study. The researcher felt confident this group represented experts in the field of health information management and provided a wide range of experience, attitudes, and opinions.

The Delphi Technique

The Delphi method was originally developed at the Rand Corporation by Olaf Helmer and Norman Dalkey in the late 1950s. It is a group communication structure used to facilitate communication on a specific task. The method involves anonymity of responses, feedback to the group as a whole on individual and collective views, and the opportunity for any respondent to modify an earlier judgment (Turoff, 1970).

The Rand Corporation developed the Delphi technique as a forecasting methodology. It is designed as a tool for a group of experts to come to a consensus. The tool works formally or informally, in large or small contexts, and reaps the benefits of group decision-making while insulating the process from the limitations of group decision-making (Cline, 1997).

Delphi was used by the U.S. government to prioritize national funding projects among different states with conflicting goals. The National Cancer Institute used the technique to make project-funding decisions for the American Stop Smoking Intervention Study (ASSIST) (Hall, Hershey, Kessler, & Stotts, 1992).

Delphi has the added advantage that it works as an informal, subjective model when the decisions are based on opinion; and it can be directly converted to a formal model when the data are more knowledge-based. The prioritization process allows experts to produce a list of rankings. The process can be completed in a few short meetings by a panel of experts, in a series of questionnaires, or by a hybrid of the two. The prioritization process follows the following steps: (a) Choose a facilitation leader who is an expert in research data collection, (b) select a panel of experts with intimate knowledge of the topic and criteria for ranking, (c) build a list of criteria, (d) instruct the panel to individually and anonymously rank criteria using a type of Likert scale, (e) calculate the mean and deviation, remove all items with a mean greater than or equal to 2.0, place the criteria in rank order, and share the results with the panel, (f) repeat the ranking process until the results stabilize, [two to four rounds are frequently performed], and (g) analyze results with feedback to participants (Cline, 1997).

The Delphi technique is an idea-generating strategy that does not require face-to-face interaction. This approach is more structured than the nominal group process, using a series of questionnaires and summarized feedback reports from preceding responses. It is useful for generating and clarifying ideas, reaching consensus, prioritizing, and making decisions on alternative actions. Advantages include: (a) anonymity of participants; (b) inexpensive; (c) free of social pressure, personality influence, and individual dominance; (d) allows sharing of information and reasoning among participants; and (e) conducive to

independent thinking and gradual formulation. A well-selected panel can provide a broad analytical perspective. Disadvantages are it: (a) elicits judgements of a selected group of people and may not be representative; (b) is marked by a tendency to eliminate extreme positions and force a middle-of-the road consensus; (c) is more time-consuming than the nominal group process; (d) should not be viewed as a total solution; (e) requires skill in written communication; and (f) requires adequate time and participant commitment, about 30 to 45 days (Carter & Beaulieu, 1992).

Delphi is essentially a series of questionnaires given to a panel of a collection of experts who can interact anonymously, at a distance, through writing, and over an extended period of time. The approach is largely qualitative and inductive, but contains a crucial element of measurement through ordinal ranking and through quantifying ranges and weighting of opinions. The key to the Delphi process is the questionnaire. If the respondents do not understand the initial questions, they may answer inappropriately or become frustrated (Turoff, 1970).

The Delphi technique was chosen for this study to combine ideas from several experts. It will produce a consensus defining the format, size, content, arrangement, and design for a family-maintained health record.

Instrumentation

Round 1 Questionnaire

The review of literature revealed variety in the format, size, arrangement, content, and overall design of patient-held records currently in use. The choices for each design area were listed in a questionnaire to facilitate input from the panel of experts in round 1.

The first section of the questionnaire asked demographic questions to describe the panel. Choices were given for the panel members to respond to their highest level of education, earned credentials, years of experience in HIM, current employment setting, current HIM area of responsibility, geographic location, and volunteer positions held in AHIMA and IFHRO.

The instrument listed choices for format, size, arrangement, and content. Tables were constructed for each design area (i.e., format, size, arrangement, and content). The first column listed the choices followed by columns for “not important”, “somewhat important”, and “very important”. The panel of experts was instructed to indicate their preference for each choice by marking in one of the columns. The panel was encouraged to add additional choices and comments.

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 and what other considerations are important in designing a family medical record? Space was provided for additional comments. The questionnaire for round 1 is in Appendix B.

Round 2 Questionnaire

Choices for each design area were ranked based on the total score received during round 1. A column was added to record the total score for consideration by the panel members. Comments and responses to the open-ended questions were categorized. Additional tables were constructed for panel members to rate the importance of each of these additional items.

Round 3 Questionnaire

The questionnaire for round 3 listed only the choices with a mean score of 2.0 or greater from round 2. Items in each design category were ranked based on the round 2 mean score. The round 2 total score was shared with the panel members along with the mean score. Columns remained for panel members to rate the importance of each choice.

Pilot Study

A pilot study was conducted to evaluate the clarity of the questionnaire and instructions for its completion. The cover letter and the round 1 questionnaire were mailed to the 8 members of the Executive Board of the Texas Health Information Management Association (TXHIMA). An additional cover letter was included to request a response from the Board members and explain the project (see Appendix C). A self-addressed stamped envelope was included for the convenience of the respondents.

A follow-up reminder requesting response was sent by electronic mail to the Board members 2 days prior to the requested response date. Of the 8 mailed

questionnaires, 5 responses were returned for a 62.5% response rate. An additional 2 responses were received too late to be included in evaluation of the instrument.

Respondents indicated their preference for format, size, arrangement and content of a family medical record by selecting not important, somewhat important or very important for each choice. Additional items and comments were encouraged and space provided for entries.

Format. Participants supported their choices with comments. One additional format, credit card/magnetic strip, was added to the existing choices of 3-ring binder, spiral tablet, bound journal, loose-leaf folder, CD-ROM, and computer disk. The questionnaire for round 1 was revised to include this addition.

Size. Choices listed were: 8½ X 11, 5 X 7, wallet-sized, pocket-sized and other. Pilot respondents asked if the intent was to carry the record at all times, to take it to healthcare encounters, or to simply store it at home. Three choices were added for clarification: appropriate to be carried at all times, appropriate to be carried to healthcare visits, and appropriate for home storage only. Notice was made that none of the choices applied to an electronic record; therefore, electronic size was added as a choice. Respondents also felt purse-size needed to be included; it also was added.

Arrangement. The questionnaire offered the following choices: chronological, divided sections, alphabetical, problem-oriented, and other. Several respondents identified the need to separate records by family member to maintain confidentiality.

member?” A second open-ended question was not changed: “What other considerations are important in designing a family medical record?”

Completion time. Pilot study participants were asked in the cover letter to report the time it took to complete the questionnaire. Times reported ranged from 10 to 15 minutes. With this feedback, no changes were needed to the cover letter since it approximated the completion time at 15 minutes.

Collection and Treatment of Data

Data were collected by three questionnaires utilizing the Delphi technique. A cover letter with instructions for completion and return accompanied each questionnaire.

Round 1

A cover letter was written to accompany the questionnaire. The letter gave the qualifications of the researcher and her relationship to the HIM profession. The title and purpose of the study were introduced. Participants were informed that participation was voluntary. Expectations of participants and the procedure for a Delphi study were explained. Participants were assured of confidentiality of responses and invited to request the findings. The last paragraph of the letter invited questions and gave contact information for the researcher, advisor, and Office of Research and Grants at Texas Woman’s University. The cover letter is included in Appendix D.

The initial questionnaire included recommendations from the literature review with opportunity for original input from panel members. Panel members were asked to

respond within 2 weeks of receipt of the questionnaire. A reminder 2 days before the deadline was sent by electronic mail.

The revised (based on pilot study) questionnaire and cover letter were mailed to members of the expert panel by the U.S. Postal Service. A self-addressed, stamped envelope was to be enclosed to expedite responses. However, information was received at the post office that persons in foreign countries had to use their postal system and foreign postage for mail. Therefore, postage for the return envelopes could not be purchased in this country to be returned from another country. Consequently, questionnaires to members of the IFHRO Grand Council included self-addressed envelopes without postage. Postage was on return envelopes for the AHIMA past-presidents. Questionnaires with cover letters were mailed to the entire (55) panel of experts on May 24, 1999 with a requested response date of June 1, 1999.

An e-mail reminder to complete and return the questionnaire was sent after 1 week to 25 panel members who had an e-mail address on the roster. Several respondents replied that it had been mailed. Others replied that it had not been received or that it would be mailed within the next few days. Reminder postcards were mailed to panel members who had not responded by June 3, 1999.

It was discovered that some panel members in foreign countries did not receive the questionnaire for 2 weeks. With this information, it was decided not to use the postal

service for subsequent rounds but to rely on electronic mail or fax to communicate with panel members and transport questionnaires for rounds 2 and 3.

Round 2

Results of round 1 were tallied and frequency of responses used to rank content items in preference order as identified by the panel. A total of 22 (40%) responses were received from round 1. A score of 1 point was assigned for each “not important” mark, 2 points for each “somewhat important”, and 3 points for each “very important” selection. Points were totaled for each choice under format, size, arrangement and content.

A column was added to the table of selections to record the score for each item. Choices were rearranged in order of preference with the highest scored item listed first and the lowest score listed last. Additional choices were added (in order of score) based on comments from round 1. Columns remained for the panel members to indicate their preference using “not important”, “somewhat important” and “very important” for each choice. Space was again provided to add other items and comments. Comments from the panel during round 1 were typed and listed in no particular order following the table for each design topic. The questionnaire for round 2 is found in Appendix E.

A cover letter was written to accompany the round 2 questionnaire. It expressed appreciation to the panel for responding to round 1. The scoring method was explained along with the additional column for score and the ranking of choices. Instructions were reviewed along with contact information. The cover letter for round 2 is in Appendix F.

Because of the inability to provide postage for foreign countries and the slow pace of the postal service, it was decided to use electronic mail or fax for rounds 2 and 3. Of the 22 respondents, 17 reported e-mail addresses on their round 1 questionnaires. Round 2 was e-mailed to these respondents on June 15, 1999. Panel members who did not have e-mail addresses listed fax numbers. The questionnaire and cover letter for round 2 were faxed to these 3 participants. Some additional panel members did not have e-mail addresses or fax numbers. Round 2 questionnaires with cover letters were mailed to these 2 respondents by overnight express mail of the U.S. postal service. Responses were requested from all 22 panel members by June 21, 1999. Participants were asked to use e-mail or fax to return round 2. A self-addressed, stamped envelope for priority mail was included in the two mailed questionnaires.

Format. Three additional choices for format were added based on round 1 responses: internet/web page, Intranet access and, classification folder. Comments on format were organized into electronic and paper.

Size. Choices added under size were: appropriate for home computer, A4 (used for Australian records), and appropriate for home storage. The respondent from Australia provided the dimensions of the A4 record in centimeters. The measurement was converted to inches. Both centimeters and inches were printed on the round 2 questionnaire. Comments on size clustered in three categories: carried at all times, carried for healthcare visits only, and other comments.

Arrangement. Round 1 comments fell into two categories: separate record for each family member and other comments. One additional choice was added to the round 2 questionnaire, by medical episode, which was not represented on the first questionnaire.

Content. Round 1 responses provided some additional documents that panel members felt should be included in the family medical record. Items added to the choices for content were: E-mail and phone for healthcare providers; lab and x-ray to diagnostic test results; discharge summary included with hospitalizations; disabilities included with physical assessment; mammograms and pap smear to health maintenance activities; allergies; pathology reports, flow sheets to monitor health problems; history of extended family; summary of old information; health assessment including exercise, nutrition, and health risks; calendar for menstrual history; preventive service reminders; and prosthesis.

Other design issues. Comments written in response to the two open-ended questions were combined and organized into these themes: family characteristics, completion issues, security, content, and design. The comments were placed in a table to parallel the other selection tables. Columns were item, round 1 score, “not important”, “somewhat important”, and “very important”. Items were listed in rank order of preference as indicated by the score received in round 1.

Round 3

Of the 22 questionnaires distributed for round 2, 15 (68%) were returned for round 3. The responses were tallied by assigning 1 point to each “not important” mark, 2

points for each “somewhat important”, and 3 points for each “very important.” The total score for each item was divided by the number of respondents for that item to calculate a mean score. Columns for the total score and the mean score were added to the questionnaire for round 3.

Choices with less than a 2.0 mean score were eliminated from the round 3 questionnaire. This left few choices for each design area. Remaining choices were listed in rank order by mean score for each area (format, size, arrangement, content, completion issues, security, and design). The category of family characteristics was completely eliminated since none of the selections had a mean score of 2.0. Instructions for the round 3 questionnaire explained the ranking and asked participants to indicate their preference for the remaining items by checking the level of importance. A statement was added to the questionnaire asking the panel members to indicate if they would like to receive a copy of the results. The round 3 questionnaire is included in Appendix G.

Round 3 questionnaires were sent to 11 of the 15 round 2 respondents by electronic mail on June 23, 1999. Questionnaires were faxed to 2 respondents and mailed to the final 2. The two mailed questionnaires were sent through the U.S. postal service by express mail with a self-addressed, stamped envelope to be returned by priority mail. Reminders were sent by electronic mail on June 25, 1999. All respondents were asked to respond by June 28, 1999.

Format. Because of the discussion from respondents regarding electronic versus paper formats, this category was divided for round 3 into electronic and paper. The top two choices for electronic were computer disk and CD-ROM. These were included on the questionnaire. The top two choices for paper were loose-leaf folder and 3-ring binder. These were included on the questionnaire although neither achieved the 2.0 mean score. This would allow the panel to indicate the best electronic design and the best design for a paper format. All other items were eliminated from consideration.

Size. Of the 12 choices, 6 had a mean score of 2.0 or higher and were retained for round 3. They were appropriate to be carried to visits, electronic size, appropriate for home computer, appropriate for home storage, appropriate to be carried at all times, and 8½ X 11.

Arrangement. Only two of the seven choices had less than a 2.0 mean score. Therefore, five selections remained on the round 3 questionnaire.

Content. The mean score of 2.0 criteria resulted in removal of 11 choices. The remaining 30 choices were ranked from highest mean score to the lowest.

Other design issues. Completion issues were ranked by mean score, and one of the eight choices was eliminated with less than a 2.0 mean score. All three of the items under security issues remained on the questionnaire because each had a mean score of greater than 2.0. Of the 13 choices under other design issues, 2 were eliminated.

Summary

This chapter describes how the Delphi technique was applied to this study. An expert panel was formed to respond to questionnaires in three rounds. The Delphi technique allowed the participants to interact anonymously, at a distance, through writing over an extended period of time.

The questionnaire for round 1 was designed based on the literature review. It included choices for each design area of format, size, arrangement and content. Participants were instructed to rank each choice as “not important”, “somewhat important” or “very important”. Two open-ended questions asked the panel to identify other design issues to facilitate completion of a family medical record. Additional choices and comments were encouraged. A pilot study was conducted to evaluate the clarity of the instrument and the round 1 questionnaire was revised based on the results.

The round 2 questionnaire included items identified by round 1 responses. Each selection was scored by assigning 1 point to each “not important”, 2 points to each “somewhat important” and 3 points to each “very important” mark. Selections were listed in rank order for round 2. Comments from round 1 were categorized and shared with the panel.

The round 3 questionnaire did not include any items that received a mean score of less than 2.0 during round 2. Choices in each design area were ranked by mean score. The panel was again instructed to rate the importance level of each choice. A mean score

was calculated for each item to identify the best design for a family medical record as determined by the panel of experts in this study.

CHAPTER IV

FINDINGS

The purpose of this study was to develop a model for documentation and maintenance of family medical records. The model then, will be made available to families to record their health history and current health status along with significant health events. The record can be carried to healthcare encounters, and the healthcare providers as well as the patient could make entries.

A panel of experts in the Health Information Management profession was assembled to participate in the study. The panel was queried about their preference for format, size, arrangement, and content of a family-maintained medical record. The Delphi technique was used to bring the panel to consensus, therefore defining the best design for a family medical record. The first round of responses was facilitated with a questionnaire designed based on the review of literature. Preferred design issues (format, size, arrangement, and content) had been addressed in previous applications of patient-held medical records. The various choices for each design area became questionnaire items for round one. A Likert-type scale was used for respondents to rank each item as “not important”, “somewhat important,” or “very important.”

The second round questionnaire included additions made by the panel members during round 1. Items for each design area were ranked based on the total score received

in round 1 with 1 point for each “not important”, 2 points for each “somewhat important” and 3 points for “very important”. Comments from round 1 were categorized and included for panel members to rate the level of importance.

The third round questionnaire listed choices for each design area in order of mean score received in round 2. All items with less than a mean score of 2.0 were eliminated from consideration by the panel. Respondents were instructed to rate the level of importance for each of the remaining choices in each design area.

Results from the third round produced a ranking of choices for each design area using the mean score for round 3. The choices ranked as “very important” by the panel define the best design for a family medical record and identify elements to improve the effectiveness of the record.

The Expert Panel

Members of the Grand Council for the International Federation of Health Record Organizations (IFHRO) and past-presidents of the American Health Information Management Association (AHIMA) were invited to participate in this study. The first section of the questionnaire for round 1 asked for demographic information on the panel members. Responses were received from 22 of the 55 (40%) invited participants. An additional 5 questionnaires were received too late for inclusion in the study. The results describe the panel in terms of education, credentials, experience, employment setting, area of responsibility, location, and volunteer positions.

Education

In response to the highest level of education, the majority (12 or 55%) indicated having earned a master's degree. The bachelor's degree was earned by 6 respondents or 27%. Of the 12 participants, 2 held an associate degree, and 2 had a doctoral degree. A single respondent reported no degree and entered Associate Professor in the other category. Complete results are reported in Table 1.

Table 1

Level of Education for Round 1 Panel of Experts (N = 22)

<u>Highest Level of Education</u>	<u>Number of Respondents</u>
Associate Degree	2
Bachelor's Degree	6
Master's Degree	12
Doctoral Degree	2
Other	1

Credentials

The majority (16 or 73%) of the respondents held the credentials of Registered Record Administrator (RRA). One was an Accredited Record Technician (ART). "Other" credentials were reported by 3 participants since these credentials are not utilized in many foreign countries. Credentials are reported in Table 2.

Experience

Most panel members (12 or 55%) had 21 to 30 years' experience in the Health Information Management profession. Six had 31 to 40 years' experience, and 3 had 41 to

50 years' experience. Of the 22 respondents, 1 had 11 to 20 years' of experience, and 2 wrote in "retired." Table 3 presents a summary of the panel's experience.

Table 2

Credentials Earned by Round 1 Panel of Experts (N = 22)

<u>Credentials Earned by Panel of Experts</u>	<u>Number of Respondents</u>
Accredited Record Technician (ART)	1
Registered Record Administrator (RRA)	16
Other	3

Table 3

Years of HIM* Experience by Round 1 Panel of Experts (N = 22)

<u>Years of Experience for Panel of Experts</u>	<u>Number of Respondents</u>
Less than 10	0
11 - 20	1
21 - 30	12
31 - 40	6
41 - 50	3
51 and over	0
Retired	2

* HIM – Health Information Management

Employment Setting

A variety of current employment settings were indicated in the respondents' answers. Panel members checked as many settings as were applicable. Since many facilities offer multi-levels of care, many choices were selected. Of the respondents, 4 panel members chose inpatient facility, and 4 checked consulting. Of the respondents, 3 each selected outpatient facility and long term care. An additional 3 panel members are employed in the academic setting, and 4 selected "other." The settings written in were

HIM products vendor, Orthopedics/Rehabilitation system, integrated delivery, and professional organization. Refer to Table 4 for complete results on employment setting.

Table 4

Employment Setting for Round 1 Panel of Experts (N = 22)

<u>Employment Setting for Panel of Experts</u>	<u>Number of Respondents</u>
Inpatient Facility	4
Outpatient Facility	3
Home Health	1
Long Term Care	3
Academic	3
Consulting	4
Other	4

Current Area of Responsibility

The panel members were instructed to circle all areas of responsibility that applied. The following selections were made: 10 for Health Information Manager, 4 each for consultant and document and repository manager; 3 each for clinical data specialist and research and decision support; and 2 each for patient information coordinator and data quality manager. A single panel member each chose security officer, risk management, and faculty. Areas of responsibility written in by “other” were CEO, QI consultant, professional organization, COO, financial officer, director, publishing, and compliance and patient accounts. Refer to Table 5 for complete findings on the panel’s current areas of responsibility.

Table 5

Area of Responsibility for Round 1 Panel of Experts (N = 22)

<u>Area of Responsibility for Panel of Experts</u>	<u>Number of Respondents</u>
Health Information Manager	10
Clinical Data Specialist	3
Patient Information Coordinator	2
Data Quality Manager	2
Consultant	4
Document & Repository Manager	4
Research & Decision Support	3
Security Officer	1
Risk Management	1
Faculty	1
Other	9

Geographic Representation

The expert panel members represented 6 foreign countries and 13 states.

Respondents were from The Philippines, Australia, The Netherlands, China, Israel, and Canada. The states represented were Massachusetts, Illinois, Michigan, Florida, Wisconsin, Maryland, Missouri, New York, Minnesota, New Hampshire, Pennsylvania, Indiana, and Georgia.

Volunteer Positions

Panel members reported extensive involvement in local, state and national HIM organizations. The position of State President had been held by 16 members, and 18 have served on a national Board of Directors (AHIMA or other country). The office of AHIMA president had been held by 14 participants, 14 had served as an AHIMA committee chair, and 16 have served on an AHIMA committee. Of the respondents, 12

panel members had served on an AHIMA task force, and 6 had other national committee work. Of the respondents, 4 each have served as AHIMA section chair, IFHRO officer, or performed other IFHRO committee work. Positions listed for IFHRO other were president, vice-president, alternate for Grand Council, speaker, and Director. Positions listed for other AHIMA volunteer service were FORE chair and Board, AHIMA staff, and AOE member. “Retired” was written in by 2 panel members. Refer to Table 6 for complete findings on the panel’s volunteer positions.

Table 6

Volunteer Positions Held by Round 1 Panel of Experts (N = 22)

<u>Volunteer Positions Held By Panel of Experts</u>	<u>Number of Respondents</u>
State President	16
AHIMA Committee Chair	14
AHIMA Committee Member	10
AHIMA Task Force	12
AHIMA Section Chair	4
AHIMA Board of Directors	18
National President	14
IFHRO Officer	4
IFHRO Committee Work	4
IFHRO Other	7
Other AHIMA or IFHRO Committee Work	6
Other AHIMA Position	5
<u>Note.</u> AHIMA – American Health Information Management Association IFHRO – International Federation of Health Record Organizations	

Round 1

The revised questionnaire (see Appendix B) was mailed along with an explanatory cover letter to the panel of 55 experts. The results of the 22 responses (40%)

are presented under format, size, arrangement, content, and other design issues. The score for each choice was calculated by adding 1 point for each “not important” mark, 2 points for each “somewhat important”, and 3 points for each “very important” mark.

Format

Choices for format are arranged in order of preference based on scores listed in Table 7. The top three choices were computer disk, CD-ROM and 3-ring binder. The least preferred choices were Internet/Web page, Intranet access, and classification folder, choices written in under “other.”

Table 7

Round 1 Scores for Format (N = 22)

<u>Format</u>	<u>Total Score</u>	<u>Mean Score</u>
Computer disk	53	2.4
CD-ROM	51	2.3
3-ring binder	45	2.0
Credit card/Magnetic strip	40	1.8
Loose-leaf folder	33	1.5
Bound journal	25	1.1
Spiral tablet	21	1.0
Internet/Web page	6	0.3
Intranet access	3	0.1
Classification folder	3	0.1

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Round 1 comments written in by panel members regarding format were organized into two categories: electronic and paper. All comments were included with the questionnaire for round 2 to be considered by the panel (see Appendix E).

Size

Panel members indicated their preference for the size of the family record by ranking the importance of each choice. Additional choices were written in under “other.”

Complete results are reported in Table 8.

Table 8

Round 1 Scores for Size (N = 22)

<u>Size</u>	<u>Total Score</u>	<u>Mean Score</u>
Appropriate to be carried to visits	56	2.5
Electronic size	47	2.1
Appropriate to be carried at all times	42	1.9
8½ X 11	37	1.7
Wallet-sized	35	1.6
Pocket-sized	34	1.5
Appropriate for home storage only	30	1.4
5 X 7	25	1.1
Purse-sized	22	1.0
Appropriate for home computer	6	0.3
A4 (8.3 X 11.6 inches)	3	0.1
Appropriate for home storage	3	0.1

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Panel members wrote comments during round 1 regarding size. Remarks were organized into three categories: carried at all times, carried for healthcare visits only, and other comments. All comments are included with the questionnaire for round 2 (see Appendix E).

Arrangement

The panel expressed a strong preference to arrange the family record by individual family member first. Comments addressed concerns for confidentiality. Healthcare information is the property of the patient to whom it pertains and is not automatically accessible to any other person including spouse and other family members. Within each individual record the preferred arrangement was by divided sections. An additional choice “by medical episode” was written in as “other.” Complete results are reported in Table 9.

Table 9

Round 1 Scores for Arrangement (N = 22)

<u>Arrangement</u>	<u>Total Score</u>	<u>Mean Score</u>
Separate records for each family member	58	2.6
Divided Sections	58	2.6
By family member	54	2.5
Chronological	50	2.3
Problem-oriented	44	2.0
Alphabetical	26	1.2
By medical episode	3	0.1

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

The panel wrote many comments during round 1 regarding arrangement. The comments were clustered into two categories: separate record for each family member and others. Additional comments related to naming the sections.

Content

Several additions were written in under “other” and some modifications or clarification added to existing choices. Content items added by panel members were: allergies, pathology reports, flow sheets to monitor health problems, history of extended family, summary of old information, health assessment, calendar for preventive service reminders, and prostheses. Electronic mail and telephone were added to names and addresses of providers. Diagnostic test results were clarified to include x-ray and laboratory results. The content item for hospitalizations was clarified to include discharge summaries. Disabilities were included with physician assessment. Mammograms and pap smears were added to health maintenance activities. Complete results for content are reported in Table 10.

Design Issues

Panel members responded to two open-ended questions. One asked “What other design issues should be addressed to facilitate completion by the patient or family member?” The second read “What other considerations are important in designing a family medical record?” Respondents wrote many comments. They were organized into five topics: Family characteristics, completion issues, security, content, and design.

Table 10

Round 1 Scores for Content (N = 22)

<u>Content</u>	<u>Total Score</u>	<u>Mean Score</u>
Family history	62	2.8
Medications	62	2.8
Immunizations	61	2.8
Personal health history	60	2.7
Problem list	59	2.7
Record of healthcare encounters	59	2.7
Operative procedures	59	2.7
End-of-life issues	59	2.7
Name/Address of providers	58	2.6
Diagnostic test results	58	2.6
Hospitalizations	56	2.5
Physical assessment	55	2.5
Growth/Development charts	55	2.5
Eye care	52	2.4
Correspondence about healthcare	50	2.3
Dental care	49	2.2
Financial issues	41	1.9
Health maintenance activities	40	1.8
Health education materials	33	1.5
Allergies	6	0.3
Pathology reports	3	0.1
Flow sheets to monitor health problems	3	0.1
History of extended family	3	0.1
Summary of old information	3	0.1
Health assessment	2	0.9
Calendar for preventive service reminders	2	0.9
Prosthesis	2	0.9

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Family characteristics referred to socioeconomic status of the family and family lifestyle. Respondents wrote that these considerations could influence the family’s ability

to document and maintain health records. Access to computer applications was expressed as a concern by the panel.

Completion issues addressed ways to encourage patients to complete and maintain the health record. Ease of understanding was an underlying theme for these comments. The need to teach patients the importance of maintaining the records was another important concern. Design of forms to guide completion and providing space for ease also were mentioned by the panel.

Security comments addressed storage of the records and computer back-up. Confidentiality and access to other family members' information were written in as concerns.

Content comments identified additional items to be included in the family medical record. The importance of complete history information and tracking current health were underlying concerns.

Other design issues mentioned in the comments related to retrieval of the information. Panel members mentioned the cost of providing such a record for patients and the cost of creating duplicate reports. It was suggested that some duplication could be eliminated by designing a common form for all family members to include and then individualizing the remainder of each record. Comments also addressed the need to keep the record active and useful. A respondent questioned the definition of family and asked who would be included in the family record. These additional design issues were included on the questionnaire for round 2 for evaluation by the panel as "not important",

“somewhat important” and “very important.” The complete list of round 1 comments about other design issues was included on the questionnaire for round 2 (see Appendix E).

Round 2

The second questionnaire (see Appendix E) included the same design for tables as the first round (format, size, arrangement, and content). Choices in each table were ranked according to the score received in round 1. Panel members received all comments from round 1 for their consideration. As prescribed by the Delphi technique, this gives the participants an opportunity to change their first round responses based on comments from other panel members. The total score based on round 1 preferences for level of importance was included on the round 2 questionnaire for each item. The description of the panel of experts as reported in the demographic section also was shared with the panel in round 2. An additional table was constructed for other design issues gleaned from the comment sections (family characteristics, completion, security, content and design). The panel was again instructed to indicate their preference for each choice listed by marking “not important”, “somewhat important” or “very important.”

In addition to the total score for level of importance, the mean was calculated for each item. The score for each item was divided by the number of respondents for the item to calculate the mean score. The results from round 2 are reported for each design area.

Format

The top choices for format were computer disk and CD-ROM. Comments supported the use of automated formats. A participant stated “there was a need to be mindful of the widespread use of technology—what is available and where—use of data and equipment standards to facilitate access to personal health records by a variety of practitioners in a variety of settings and also access by the patient themselves.” Another respondent cautioned against using the electronic format. The comment read, “The loose-leaf folder is probably the more universally accepted format for holding information while all the electronic data evolves; the backup will probably be essential.” Another comment warned, “Systems should be designed to reflect the level of computer sophistication of families and providers and updated as each level of sophistication evolves; we’re still not consistently a computerized nation.” Still another comment recommended the bound journal serve as a back up in case of loss or damage of the computer disk or CD-ROM. Choices with less than a 2.0 mean score were credit card/magnetic strip, bound journal, spiral tablet, internet/web page, Intranet access, and classification folder. Comments suggested key information be carried at all times in a wallet-sized format such as a laminated card. Additional documentation should be 8½ X 11 if paper is used or on computer disk. Complete results are recorded in Table 11.

Table 11

Round 2 Scores for Format (n = 15)

<u>Format</u>	<u>Total Score</u>	<u>Mean Score</u>
Computer disk	34	2.6
CD-ROM	29	2.4
Credit card/magnetic strip	23	1.9
Intranet access	23	1.9
3-ring binder	22	1.8
Loose-leaf folder	22	1.8
Internet/Web page	20	1.7
Bound journal	17	1.4
Classification folder	15	1.3
Spiral tablet	10	1.0

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Size

The number 1 choice for size was appropriate to be carried to healthcare visits. The least selected choice was 5 X 7. The panel expressed the need to base the size on the utility of the record. Three options emerged: carry the record to healthcare visits, carry the record at all times or store the record at home only for reference. The electronic size is preferred by the panel to be carried at all times. The 8½ X 11 is preferred to carry to healthcare visits. The record for home storage could be either electronic for the home computer or paper for home files. The scores for size are reported in Table 12.

Table 12

Round 2 Scores for Size (n = 15)

<u>Size</u>	<u>Total Score</u>	<u>Mean Score</u>
Appropriate to be carried to healthcare visits	36	3.0
Electronic size	32	2.7
Appropriate for home computer	25	2.3
Appropriate to be carried at all times	25	2.1
Appropriate for home storage	25	2.1
8½ X 11	24	2.0
A4 (21 cm X 29.5 cm)	16	1.5
Wallet-sized	17	1.4
Purse-sized	17	1.4
Pocket-sized	15	1.3
Appropriate for home storage only	16	1.3
5 X 7	14	1.3

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Arrangement

The panel agreed that each family member should have a separate, individual record. Comments again mentioned the need to preserve privacy within families. After this provision is met, panel members selected divided sections ahead of chronological or problem-oriented arrangements. However, a dissenting opinion stated, “All family members should be included in the record so they can share some common information; it would be good for the doctor to give care for the family and doing clinical epidemic research.” A respondent observed the problem-oriented format is very similar to medical episode. Results are reported in Table 13.

Table 13

Round 2 Scores for Arrangement (n = 15)

<u>Arrangement</u>	<u>Total Score</u>	<u>Mean Score</u>
Separate records for each family member	35	2.9
Divided sections	35	2.9
By family member	31	2.6
Chronological	30	2.5
Problem-oriented	27	2.3
By medical episode	21	1.8
Alphabetical	13	1.1

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Content

The panel identified past history items as most important along with information on current health status. Health education material was again selected as the least important item to include in the record. Comments supported temporary storage of health education materials in the record as long as needed for a present condition. Some respondents supported the idea of customization for individual patients. All the content items could be available so the provider or patient could select the forms that would be most beneficial for an individual patient. An example mentioned was the development/growth charts, which are very important for pediatric patients and not so important for adults. Comments added information on the manufacturer for any prosthesis (e.g., valves, pacemakers). Another comment stated, “All diagnostic tests should be included; normal could be very significant in some contexts.” Results for content are reported in Table 14.

Table 14

Round 2 Scores for Content (n = 15)

Content	Total Score	Mean Score
Family history	36	3.0
Medications	36	3.0
Personal health history	36	3.0
Immunizations	35	2.9
Operative procedures	35	2.9
End of life issues	34	2.8
Names/address of providers	33	2.8
Diagnostic test results	33	2.8
Health maintenance activities	33	2.8
Problem list	32	2.7
Allergies	32	2.7
Hospitalizations	32	2.7
Record of healthcare encounters	31	2.6
Physical assessment	31	2.6
Growth/Development charts	31	2.6
Eye care	29	2.4
Pathology reports	29	2.4
Dental care	27	2.3
Correspondence about healthcare	24	2.2
Financial issues	25	2.1
Flow sheets to monitor health problems	23	1.9
Summary of old information	20	1.8
Calendar for menstrual history/preventive reminders	20	1.8
Health assessment	22	1.7
History of extended family	20	1.7
Prosthesis	17	1.7
Health education materials	19	1.2

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Design Issues

Comments from round 1 were organized into categories and presented in tables for the panel to evaluate in the second round. The results are presented in Tables 15 to

19. Comments suggested the user should determine who is included in the family.

Strong objection was shared in response to the comment that provider-maintained records should not be duplicated. Instead, it was commented that the patient should get copies of all provider records since the patient is the most important communication link among varied providers and levels of service. Another respondent commented, “Family records should be useable by family and providers.” It also was suggested that “families should provide input into development of a record system that will work for them.”

The category of family characteristics was created from comments made by panel members during round 1. The primary concern was for the socioeconomic status of the family and the family’s ability to maintain medical records. The category of family characteristics was eliminated from the round 3 questionnaire because none of the choices received a mean score of 2.0 or above. Scores for family characteristics are reported in Table 15.

Table 15

Round 2 Scores for Family Characteristics (n = 15)

<u>Family Characteristics</u>	<u>Total Score</u>	<u>Mean Score</u>
The need for a copy of records for the family	25	1.8
Stress on family	26	1.7
Family financial status	25	1.7
Other resources of the family	24	1.6

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

The category of completion issues was created from comments made by panel members during round 1. The focus was on the design of forms for the medical record to facilitate completion by family members. The panel addressed the size of print and the size of spaces for entries. Forms that serve as templates to guide documentation were supported by panel members. Scores for completion issues are reported in Table 16.

Table 16

Round 2 Scores for Completion Issues (n = 15)

Completion Issues	Total Score	Mean Score
Data must be complete and accurate	45	3.0
Ease of understanding for the users	44	2.9
Check-off & easy form completion	42	2.8
Print in native language	40	2.7
Large spaces for handwritten entries	39	2.6
Enough space for kids to self-record	38	2.5
Teach patients the necessity for thoroughness/accuracy	36	2.4
Font size so all ages can easily read	26	1.7

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

The category of security issues was created from comments made by panel members during round 1. The theme of this section is protection of privacy and confidentiality of health information. Panel members expressed the need to protect the family medical record from unauthorized access. Additionally, comments stressed the need for a back up not only for automated storage but also a back up if the patient loses or forgets the record for an appointment. Refer to Table 17 for complete scores on security issues.

Table 17

Round 2 Scores for Security Issues (n = 15)

Security Issues	Total Score	Mean Score
Safe, secure, orderly storage	43	2.9
Computer data must have back-up	42	2.8
Protect confidentiality	32	2.7

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Table 18 reports the scores for comments on additional content considerations identified in round 1. These items were combined with the initial table on content for round 3.

Responses to the open-ended question on other considerations for designing a family medical record were reported under other design issues. The panel emphasized the record be easy to use and locate information. Several comments addressed the cost of the record. A respondent commented whether the record is computerized or manual, it should provide for self-management of chronic illnesses. Another responded that it would be very time-consuming for providers to make entries into a family record and suggested families simply be provided with copies of provider records. Table 19 reports the scores for other design issues.

Table 18

Round 2 Scores for Other Content Issues (n = 15)

Other Content Issues	Total Score	Mean Score
Track when & where services provided	40	2.7
Mental health records	39	2.6
Prescribed & over-the-counter medications	37	2.5
Therapeutic services	36	2.4
Calendar to track health problems	35	2.3
Graph values over time	34	2.3
Upcoming appointments	34	2.3
Only include diagnostic test results when abnormal	33	2.2
Reminders for preventive & routine services	33	2.2
School/Camp physicals	31	2.1
Family tree showing relationships	27	1.8
Family member narratives on health problems	27	1.8
Insurance payments	27	1.8
Temporary storage for health education materials	21	1.4

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Round 3

The questionnaire for round 3 (see Appendix G) was designed based on the results from round 2. Only choices with a round 2 mean score of 2.0 (somewhat important) and above remained on the list. As provided in the Delphi technique, this forces elimination of the least selected choices and clusters responses among the most selected items, therefore bringing consensus on the most important design elements.

Table 19

Round 2 Scores for Other Design Issues (n = 15)

Other Design Issues	Total Score	Mean Score
Ease in finding information	45	3.0
Space for provider-generated reports	41	2.7
Encourage active, continually useful document	41	2.7
Back-up system if patient loses/forgets record	40	2.7
Color-coded to explain sections & expedite filing	36	2.4
Complexity of today's family: Who's included?	36	2.4
Create personal record online, print for visits	36	2.4
Cross reference family members when original disrupted	32	2.3
Don't duplicate provider-maintained records	33	2.2
Design computer screen to match hard copy	32	2.1
Cost of providing copies to patients	32	2.1
Family records share common information & individual	29	1.9
Ability to incorporate reference data	26	1.7

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Questionnaires were received from 13 of the 15 round 2 participants. The participants who responded to all three rounds were from Australia, China, The Netherlands, The Philippines and the United States. Respondents lived in the following states: Maryland, Indiana, Wisconsin, Massachusetts, Missouri, Minnesota, Michigan, New York and Pennsylvania.

The design areas on questionnaire 3 were electronic format, paper format, size, arrangement, content, completion issues, security, and other design issues. Participants were informed of the scoring and removal of choices without a mean score of 2.0.

Results are reported for each area. The round 3 questionnaire is included in Appendix G.

Format

The preferred electronic format was the computer disk. The preferred paper format was the loose-leaf folder. A respondent wrote there is no difference between the paper formats. The round 3 scores for format are reported in Table 20.

Table 20

Round 3 Scores for Format (n = 13)

Format	Total Score	Mean Score
Computer Disk	33	2.8
Loose-leaf folder	27	2.3
3-ring binder	24	2.0
CD-ROM	23	1.9

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Size

“Very important” was selected most often for “appropriate to be carried to healthcare visits.” The panel agreed it is only “somewhat important” for the record to be carried at all times. The second most selected item for “very important” was electronic size. The round 3 scores for size are reported in Table 21.

Arrangement

Panel members affirmed it is most important for the records to be separate for each family member. The second choice was divided by sections. The least important choice was the problem-oriented arrangement. The round 3 scores for arrangement are reported in Table 22.

Table 21

Round 3 Scores for Size (n = 13)

Size	Total Score	Mean Score
Appropriate to be carried to healthcare visits	35	2.9
Electronic size	30	2.5
Appropriate for home computer	29	2.4
Appropriate for home storage	29	2.4
Appropriate to be carried at all times	24	2.0
8½ X 11	24	2.0

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Table 22

Round 3 Scores for Arrangement (n = 13)

Arrangement	Total Score	Mean Score
Separate records for each family member	35	2.9
Divided sections	33	2.8
Chronological	32	2.7
By family member	28	2.3
Problem-oriented	24	2.0

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Content

A respondent added an additional consideration for content in this round:

“Appropriate/qualified website URLs for problem/condition management/treatment.”

The most important content items were: medications, personal health history, and allergies. The least important item was financial issues. The round 3 scores for content are reported in Table 23.

Table 23

Round 3 Scores for Content (n = 13)

Content	Total Score	Mean Score
Medications (prescribed & over-the-counter)	35	2.9
Personal health history	35	2.9
Allergies	35	2.9
Family history	34	2.8
Immunizations	34	2.8
Operative procedures	34	2.8
Health maintenance activities	34	2.8
Diagnostic test results	33	2.8
Mental health records	33	2.8
Pathology reports	33	2.8
End of life issues	31	2.6
Hospitalizations (include discharge summary)	31	2.6
Growth/Development charts	30	2.5
Physical assessment	30	2.5
Names/Addresses of providers	29	2.4
Therapeutic services	29	2.4
Reminders for preventive & routine services	29	2.4
Record of healthcare encounters (include location)	28	2.3
Only include diagnostic test results when abnormal	28	2.3
Problem list	27	2.3
Eye care	27	2.3
Calendar to track health problems	27	2.3
Upcoming appointments	27	2.3
Dental care	26	2.2
Correspondence about healthcare	24	2.0
Graph values over time	23	1.9
School/Camp physicals	22	1.8
Financial issues	20	1.7

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Design Issues

The panel unanimously chose “very important” for “data must be complete and accurate” and “ease of understanding for the users.” The other choices related to form design for the content items. A check-off type form that is easy to complete was deemed very important along with printing in the native language and providing large spaces for handwritten entries. One comment on round 3 was that the native language should be for the patient and the provider. The round 3 scores for these other design issues are reported in Tables 24 through 26.

Table 24

Round 3 Scores for Completion Issues (n = 13)

<u>Completion Issues</u>	<u>Total Score</u>	<u>Mean Score</u>
Data must be complete and accurate	36	3.0
Ease of understanding for the users	36	3.0
Check-off & easy form completion	35	2.9
Print in native language	33	2.8
Large spaces for handwritten entries	31	2.6
Enough space for kids to self-record	29	2.4
Teach patients the necessity for thoroughness/accuracy	28	2.3

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

All of the security items were considered very important by the panel. Protection of confidentiality surfaced as a major concern of the experts.

Table 25

Round 3 Scores for Security Issues (n = 13)

Security Issues	Total Score	Mean Score
Computer data must have back-ups	35	2.9
Protect patient confidentiality	35	2.9
Safe, secure, & orderly storage of records	34	2.8

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

Other design issues that received a rank of “very important” by the panel were ease in finding information; a backup system if the patient loses or forgets the record; and encouraging an active, continually useful document.

Table 26

Round 3 Scores for Other Design Issues (n = 13)

Other Design Issues	Total Score	Mean Score
Ease in finding information	36	3.0
Back-up system if patient loses or forgets record	34	2.8
Encourage active, continually useful document	33	2.8
Space for provider-generated reports	30	2.5
Complexity of today’s family: Who’s included?	28	2.3
Computer input screen design same as hard copy sheets	27	2.3
Create personal record online (print for annual/new)	27	2.3
Cost of providing copies to patients	24	2.0
Don’t duplicate records maintained by provider	24	2.0
Color-coded to explain sections/expedite filing	23	1.9
Cross-reference family when original disrupted	22	1.8

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents.

CHAPTER V

DISCUSSION

The purpose of this study was to develop a model to guide families in documenting and maintaining their medical records. Design issues addressed include format, size, arrangement, and content. The resulting model will help patients, parents and other healthcare consumers to maintain their medical records. This study identified design elements to increase the effectiveness of family health records.

The review of literature indicated medical outcomes improve when patients become partners in medical decision-making. Empowering patients with information and assigning responsibility for documentation to them enhances this participation. The Delphi technique was used to bring a panel of experts to consensus on the best design for format, size, arrangement, content, completion, security, and other design issues.

Summary of Study

Currently, various healthcare providers retain ownership of medical records and individually compile documentation of services. The mobile society and the nature of the health delivery system make it increasingly difficult to reconstruct a longitudinal chronology of an individual's health status. It becomes the patient's responsibility to maintain a complete chronological record of health status and health services

received throughout the years. This study was designed to produce a model, which will guide families to document and maintain their medical records.

Three Delphi rounds were conducted with a panel of experts to answer the research questions: (a) What is the best design for a family-maintained health record? and (b) Which design elements will increase the effectiveness of the family-maintained health record?

The panel of experts consisted of Health Information Management professionals. Members of the Grand Council for the International Federation of Health Record Organizations (IFHRO) and past-presidents of the American Health Information Management Association (AHIMA) were invited to participate for a total of 55 potential participants.

Round 1 was facilitated by a questionnaire based on the review of literature (see Appendix B). A pilot study was conducted to assess clarity of the instrument. The participants ranked choices in each design area as “not important,” “somewhat important,” or “very important.” The responses (22) were tallied by assigning 1 point for every “not important,” 2 points to “somewhat important” selections, and 3 points to each “very important” choice. The panel members were encouraged to make additions under an “other” category and to comment on each design area.

The questionnaire for round 2 listed the choices for each design area in rank order based on the round 1 score. Comments and additions from respondents to round 1 were

organized into categories and included with the round 2 questionnaire. Respondents to round 1 (22) received the round 2 questionnaire (see Appendix E).

The questionnaire for round 3 listed the design choices in each area in rank order based on the mean score calculated from round 2 responses. Choices with a mean of less than 2.0 were eliminated from consideration. Respondents to round 2 (15) received the round 3 questionnaire (see Appendix G). The responses from round 3 (13) were scored and ranked. The resulting preferences from the panel of experts were used to answer the research questions.

Discussion

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. However, they cautioned that, in the immediate future, paper would be the most useful format. Several computer programs are currently available to allow a user to maintain a comprehensive medical record at home (Jimison & Sher, 1998). Of the 13 participants on the expert panel, 2 did not have electronic mail or access to a fax machine. They are both retired and have no need for these, they stated. However, they still have a need to document their healthcare and monitor their health status. A family medical record would be most beneficial to patients with chronic illnesses who are often members of the retirement community (Laumark & Christianson, 1980).

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. Many textbooks today are received with a computer disk or CD-ROM attached for computer use. The same format would accommodate the needs of the population that is actively using electronics while still providing a guide with paper documents for those without such access. The computer disk was selected by the panel as the preferred electronic format.

The panel identified a preference for a loose-leaf folder as the paper format. If forms are not attached, they could easily fall out or get misplaced. Further, without a fastener, the contents are not maintained in any particular order and could make retrieval of the information difficult. The three-ring binder lends itself to the divided sections, which are expressed as the panel's preference for arrangement. The mean scores for format are summarized in Table 27.

Size

The panel discussed through their comments whether the family record should be carried at all times or just to healthcare visits. This determination would influence the preference for size. The final preference was for a size to be carried only to the encounters and not all the time. However, panel members recognized the importance of carrying some vital information at all times in case it would be needed in emergencies.

Table 27

Mean Scores for Format

Format	Round 1 Mean Score	Round 2 Mean Score	Round 3 Mean Score
Computer disk	2.4	2.6	2.8
Loose-leaf folder	1.5	1.8	2.3
3-ring binder	2.0	1.8	2.0
CD-ROM	2.3	2.4	1.9
Credit card/Magnetic strip	1.8	1.9	-
Bound journal	1.1	1.4	-
Spiral tablet	1.0	1.0	-
Internet/Web page	0.3	1.7	-
Intranet access	0.1	1.9	-
Classification folder	0.1	1.3	-

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents. Items with less than 2.0 were dropped from round 3.

Based on the results of the study, each family member should have a record, which is maintained at home and carried to healthcare visits. Additionally, each family member needs a smaller record, perhaps a wallet-sized card, to carry vital information such as allergies, major medical problems, and current medications.

There was a strong preference for an electronic record such as a credit card size with a magnetic strip to be carried at all times. Concerns centered on access to the information since it would require an electronic reader. All providers may not have the equipment. Further, patients would not be able to access or add to the information in this format. The card with a magnetic strip format was eliminated from consideration for the third round.

The consensus for the size of a paper record was 8½ X 11, the standard size of paper in the United States. In other countries, the standard size would need to be used, such as the A4. Using 8½ X 11 makes additions or copies from providers easier. This makes for a larger record to be carried to visits; but it is less likely to get lost than a smaller version.

Table 28

Mean Scores for Size

Size	Round 1 Mean Score	Round 2 Mean Score	Round 3 Mean Score
Appropriate to be carried to visits	2.5	3.0	2.9
Electronic size	2.1	2.7	2.5
Appropriate for home computer	0.3	2.3	2.4
Appropriate for home storage	0.1	2.1	2.4
Appropriate to be carried at all times	1.9	2.1	2.0
8½ X 11	1.7	2.0	2.0
Wallet-sized	1.6	1.4	-
Pocket-sized	1.5	1.3	-
5 X 7	1.1	1.3	-
Purse-sized	1.0	1.4	-
A4 (8.3 X 11.6 inches)	0.1	1.5	-
Appropriate for home storage only	1.4	1.3	-

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents. Items with less than 2.0 were dropped from round 3.

Arrangement

The panel decided each family member should have their own individual medical record rather than keep all records for each family member together in one record. The concern expressed by the respondents was about confidentiality. Family members should

not have access to each other's health information without permission from the patient.

This also would make it easier to separate the records as children become adults so they can carry their own records with them when they leave home. It also simplifies the problem of whose records should be included in a family record.

Each individual record should be divided by sections according to the preferences of the panel. Discussion centered on naming the sections. The names need to agree with the content items selected as very important. The comments went on to specify that the arrangement within each section should be chronological. The ranking for arrangement is reported in Table 29.

Table 29

Mean Scores for Arrangement

Arrangement	Round 1 Mean Score	Round 2 Mean Score	Round 3 Mean Score
Separate records for each member	2.6	2.9	2.9
Divided sections	2.6	2.9	2.8
Chronological	2.3	2.5	2.7
By family member	2.5	2.6	2.3
Problem-oriented	2.0	2.3	2.0
Alphabetical	1.2	1.1	-
By medical episode	0.1	1.8	-

Note. Score represents total of "not important" marks at 1 point each, "somewhat important" at 2 points, and "very important" at 3 points. Mean score is calculated by dividing total score by number of respondents. Items with less than 2.0 were dropped from round 3.

Content

Several content items were consistently selected as “very important”. Past history and information on current health condition were considered as very important. 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 that are maintained by providers.

Health education materials consistently ranked low in importance. The review of literature reported health education materials were an important section to guide the patient in self-care (Charles, 1991; Fierman et al., 1996). Several panel members offered a compromise to temporarily store such materials and discard them when no longer needed. However, both choices were eliminated from consideration for the third round.

The panel emphasized the need to provide for a flexible record that could be customized according to the patient needs. Some items that may seem unimportant to some could be very important to another patient. There was some discussion about including only abnormal lab results. Other panel members pointed out normal results could be significant in some cases.

Medications were modified to include both prescription and over-the-counter drugs. This is important information to have available for a healthcare provider to avoid adverse interactions. This item was consistently ranked as very important. Providers do not have access to information on medications prescribed by other providers nor to patient-selected remedies purchased from the local drug store. The panel was in accord

patient-selected remedies purchased from the local drug store. The panel was in accord with the literature about including medication records. This list is particularly important for use by geriatric patients and improved compliance (RACGP, 1982).

Records of healthcare services ranked as very important. Included are operative procedures, health maintenance activities (i.e., mammograms & pap smears), diagnostic test results (normal & 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 could be significant in individual cases.

The panel recognized the value of involving patients in monitoring and tracking their 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. The panel rejected the idea of including a family tree and family narratives about health issues.

A record of immunizations was deemed very important. The first applications for patient-held records were for immunizations. This also is important information to carry at all times especially when traveling in foreign countries.

End-of-life issues such as living will, advance directive, and organ donation were ranked as very important to include in a family medical record. The physical assessment

was considered less important; however, comments noted the importance of an emergency team's being aware of any prostheses or disabilities. This is one of the areas that can be included if it is significant to an individual.

Names and addresses of providers along with telephone and e-mail contact were identified as somewhat important. Perhaps this is because providers change so frequently; a family doctor rarely exists. However, this is information that only the patient can provide.

A problem list was ranked as somewhat important. This is very helpful as a summary of healthcare and serves as a table of contents or index to the medical record. Such documentation would allow a patient to visualize a pattern of problems at a glance. If the patient-held record was going to be reduced to one page, it should be the problem list. A study evaluating the personal health record (PHR) used on Australia, reported the key to its usefulness is the health summary, which must provide a complete and accurate overview of the patient's healthcare activities (RACGP, 1982). Possibly in comparison to the other content choices, the problem list ranked lower in importance.

Business matters such as correspondence about healthcare and financial issues received a low ranking. Possibly this information belongs in other family documents. In general, the panel agreed with items considered most important for inclusion by the American Health Information Management Association (AHIMA, 1998). The mean scores for content items are summarized in Table 30.

Table 30

Mean Scores for Content

Content	Round 1 Mean Score	Round 2 Mean Score	Round 3 Mean Score
Medications (prescribed/OTC)	2.8	3.0	2.9
Personal health history	2.7	3.0	2.9
Allergies	0.3	2.7	2.9
Family history	2.8	3.0	2.8
Immunizations	2.8	2.9	2.8
Operative procedures	2.7	2.9	2.8
Health maintenance activities	1.8	2.8	2.8
Diagnostic test results (norm/abnorm)	2.6	2.8	2.8
Mental health records	-	2.6	2.8
Pathology reports	0.1	2.4	2.8
End of Life issues	2.7	2.8	2.6
Hospitalizations (include disch sum)	2.5	2.7	2.6
Growth/Development charts	2.5	2.6	2.5
Physical assessment	2.5	2.6	2.5
Names/Addresses of providers	2.6	2.8	2.4
Therapeutic services	-	2.4	2.4
Reminders for preventive/routine	-	2.2	2.4
Record of healthcare encounters	2.7	2.6	2.3
Only include abnormal test results	-	2.2	2.3
Problem list	2.7	2.7	2.3
Eye care	2.4	2.4	2.3
Calendar to track health problems	-	2.3	2.3
Upcoming appointments	-	2.3	2.3
Dental care	2.2	2.3	2.2
Correspondence about healthcare	2.3	2.2	2.0
Graph values over time	-	2.3	1.9
School/Camp physicals	-	2.1	1.8
Financial issues	1.9	2.1	1.7
Health education materials	1.5	1.2	-
Flow sheets to monitor problems	0.1	1.9	-
History of extended family	0.1	1.7	-
Summary of old information	0.1	1.8	-
Health assessment (risk factors)	0.9	1.7	-
Calendar for preventive reminders	0.9	1.8	-
Prosthesis	0.9	1.7	-
Family tree showing relationships	-	1.8	-
Family member narratives on health	-	1.8	-
Insurance payments	-	1.8	-
Temporary storage for health materials	-	1.4	-

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents. Items with less than 2.0 were dropped from round 3.

Design Issues

Responses from panel members to the open-ended questions asking for other design issues and concerns to increase the effectiveness of a family medical record created a list of additional design issues. The comments fell into the categories of family characteristics, completion issues, security, content and other design issues.

Family characteristics included issues related to the social characteristics of a family. Included were financial status, resources, need for copy of family records and stress on a family. The primary concern expressed in the comments was access to electronic equipment. However, none of these surfaced as very important concerns and were only included on the round 2 questionnaire.

Security issues were identified as important concerns. The panel expressed a need to protect the confidentiality of the health information by providing security. Storage would be in the hands of the family and out of the control of the healthcare providers. Patients would require education about the value of the information and the right to privacy. This concern was not shared by the patients in the Charles (1994) study. Parents said they would share the information in the parent-held record with relatives, friends, and child caretakers. Health professionals reported they would make efforts not to record sensitive information in the record to protect confidentiality. Table 31 summarizes security comments from the panel.

Table 31

Mean Scores for Security Issues

Security Issues	Round 1 Mean Score	Round 2 Mean Score	Round 3 Mean Score
Computer data must have back-up	-	2.8	2.9
Protect patient confidentiality	-	2.7	2.9
Safe, secure, & orderly storage	-	2.9	2.8

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents. Items with less than 2.0 were dropped from round 3.

Completion issues centered on ways to make the record more effective and to encourage patients to complete the records. These are important concerns to guide the design of forms to be included in the record. Printing the record in multiple languages was one suggestion to increase completion and effectiveness. Having a record that is complete and detailed will make it more valuable for the patient and more useful for the provider. In all things, the user must be paramount. Patients with adverse comments about patient-held records in Australia related to insufficient space for entries and designs that were not user-friendly (Saffin, 1990). The record must be easy to use and maintain. This also appears to emphasize the need for patient education. However, teaching patients did not rank as very important by the panel. Table 32 provides a comparison by rounds for these additional items.

Table 32

Mean Scores for Completion Issues

Completion Issues	Round 1 Mean Score	Round 2 Mean Score	Round 3 Mean Score
Data must be complete/accurate	-	3.0	3.0
Ease of understanding for users	-	2.9	3.0
Check-off & easy form completion	-	2.8	2.9
Print in native language	-	2.7	2.8
Large spaces for handwritten entries	-	2.6	2.6
Enough space for kids to self-record	-	2.5	2.4
Teach patients need for thoroughness	-	2.4	2.3
Font size so all ages can easily read	-	1.7	-

Note. Score represents total of “not important” marks at 1 point each, “somewhat important” at 2 points, and “very important” at 3 points. Mean score is calculated by dividing total score by number of respondents. Items with less than 2.0 were dropped from round 3.

Other design issues to make the record more effective were offered by the panel. It must be easy to find the information in the record once it is 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 since 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. Dauncey (1991) stated the method of introduction and training are major concerns to introduce this change. Whitney et al. (1993) reported patients would need encouragement and training

to assume this new responsibility. These other design issues are summarized and compared in Table 33.

Table 33

Mean Scores for Other Design Issues

Other Design Issues	Round 1 Mean Score	Round 2 Mean Score	Round 3 Mean Score
Ease in finding information	-	3.0	3.0
Back-up system if patient loses/forgets	-	2.7	2.8
Encourage active, useful document	-	2.7	2.8
Space for provider-generated reports	-	2.7	2.5
Complexity of family: Who's included	-	2.4	2.3
Computer input screen same as paper	-	2.1	2.3
Create personal record online (print for visits)	-	2.4	2.3
Cost of providing copies to patients	-	2.1	2.0
Don't duplicate provider records	-	2.2	2.0
Color-coded to explain sections	-	2.4	1.9
Cross-reference family when disrupted	-	2.3	1.8
Family records share common information	-	1.9	-
Ability to incorporate reference data	-	1.7	-

Note. Score represents total of "not important" marks at 1 point each, "somewhat important" at 2 points, and "very important" at 3 points. Mean score is calculated by dividing total score by number of respondents. Items with less than 2.0 were dropped from round 3.

Conclusions

Research Question One

What is the best design for a family-maintained health record? The expert panel provided a response to this first research question. The best design is defined in terms of the format, size, arrangement, and content.

The best format for a family medical record is both electronic and paper. The paper format should be a 3-ring binder and include a computer disk with screens that match the paper forms.

Each family member needs an 8½ X 11 record that is maintained in the home and carried to each encounter with a healthcare provider. Additionally, each person needs a wallet-sized record containing vital information for emergency care to carry at all times.

A separate record should be developed for each family member. The individual records should be divided into sections grouping similar information.

The patient-held record should include entries from providers as well as from the patient. The most important content items are: medications, personal health history, allergies, family history, immunizations, operative procedures, diagnostic test results, mental health records, pathology reports, end-of-life issues, hospitalizations, growth/development charts, and physical assessment. Somewhat important items include identification of providers, therapeutic services, reminders for preventive/routine services, record of healthcare encounters, problem list, eye care, calendar to track health problems, upcoming appointments, dental care, and correspondence about healthcare.

Research Question Two

Which design elements will increase the effectiveness of the family-maintained health record? The second research question was answered by the panel of experts in terms of record security, completion issues, and other design considerations.

Health information is confidential and should be protected from unauthorized access even in the home. Back-up systems must be available for any electronically stored information.

Record forms should be designed so the users can easily understand how to make entries. The data must be complete and accurate. A check-off form or other easy completion method should be used. The space on the forms should accommodate handwritten entries. Record forms should be printed in the patient's native language.

Families need instruction about the necessity of complete and accurate medical records. Family members need encouragement to make the record an active, useful document.

Information in the record must be easily located and retrieved when needed. A back-up should be provided in the event the patient loses or forgets to bring the record to an encounter.

Recommendations

Research

The Delphi technique proved effective in achieving a consensus regarding the best design for a family medical record among a group of experts in the health information management profession. The study should be replicated with a panel of direct healthcare providers to add their perspective. Input also is needed from consumers who will be using the family medical records. Focus groups with various homogeneous

consumer groups could yield helpful information. A prototype of the family medical record should be developed based on input from these various groups.

The model needs to be tested in a variety of healthcare settings. Patients should be issued the record to maintain for a period of time. The results should be studied to determine the effectiveness of the model.

Healthcare Providers

The tested model could be manufactured in mass and distributed widely to consumers throughout the United States. Hospitals could issue the record to mothers of newborns, and Health Maintenance Organizations could issue the record to each member of the health plan. Every healthcare facility could have the records available for patients to begin their documentation.

Training is needed for providers and consumers to revolutionize the patient-physician partnership. An instructional videotape to accompany each record that is distributed could prove helpful.

Limitations

Limitations of this study are consistent with the disadvantages of the Delphi technique. It elicits judgements of a selected group of people and may not be representative (Carter & Beaulieu, 1992). The expert panel included only members of the health information management profession. Their opinions may not represent those of another group.

The Delphi technique is more time consuming than the nominal group process and requires adequate time and participant commitment (Carter & Beaulieu, 1992). The panel of experts was required to respond to three questionnaires. This expenditure of time and effort could have contributed to the small sample size. The small sample size could limit the generalizability of the results.

The Delphi technique typically is conducted during a 30 to 45 day time frame (Carter & Beaulieu, 1992). This study was conducted over a 36-day period. The quick response time could have contributed to the small sample size. The inability to provide postage for respondents from foreign countries also could be a factor, which contributed to the small sample.

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APPENDICES

Appendix A

Health Information Form For Children and Adults

From

American Health Information Management Association



HEALTH INFORMATION FORM FOR ADULTS

Allergic to: _____

IDENTIFICATION

Name		In Emergency Contact:	
Address		Contact Name	Relationship
City	State	Zip	
Date of Birth		Address	
Home Phone	Work Phone	City	State
Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female	Height	Zip	
Weight	Physician	Specialty	Phone
Eye Color	Blood/RH Type		
Languages Spoken			
Primary Health Insurance Carrier	Policy Number		
Secondary Health Insurance Carrier	Policy Number	Dentist	Phone
		Pharmacy	Phone

MEDICAL HISTORY

Date	Mark Appropriate Items
	<input type="checkbox"/> Acquired Immunodeficiency Syndrome (AIDS) or HIV Positive <input type="checkbox"/> Arthritis <input type="checkbox"/> Rheumatism <input type="checkbox"/> Asthma <input type="checkbox"/> Bronchitis <input type="checkbox"/> Emphysema <input type="checkbox"/> Cancer <input type="checkbox"/> Tumor <input type="checkbox"/> Diabetes <input type="checkbox"/> Hypoglycemia <input type="checkbox"/> Dizziness <input type="checkbox"/> Fainting <input type="checkbox"/> Epilepsy <input type="checkbox"/> Seizures <input type="checkbox"/> Eye Problem <input type="checkbox"/> Glaucoma <input type="checkbox"/> Frequent or Severe Headache <input type="checkbox"/> Hearing Impairment <input type="checkbox"/> Heart Condition <input type="checkbox"/> High Blood Cholesterol <input type="checkbox"/> High Blood Pressure <input type="checkbox"/> Jaundice <input type="checkbox"/> Hepatitis <input type="checkbox"/> Kidney Disease <input type="checkbox"/> Hemodialysis
	<input type="checkbox"/> Low Blood Pressure <input type="checkbox"/> Mental Retardation <input type="checkbox"/> Pain or Pressure in Chest <input type="checkbox"/> Palpitations <input type="checkbox"/> Pounding Heart <input type="checkbox"/> Paralysis <input type="checkbox"/> Periods of Unconsciousness <input type="checkbox"/> Rheumatic Fever <input type="checkbox"/> Shortness of Breath <input type="checkbox"/> Smoking (Packs/Day: _____ Number of Years: _____) <input type="checkbox"/> Stomach, Liver, or Intestinal Problems <input type="checkbox"/> Thyroid Problems <input type="checkbox"/> Tuberculosis <input type="checkbox"/> Urinary Tract Infection <input type="checkbox"/> Sexually Transmitted Diseases <input type="checkbox"/> Chlamydia <input type="checkbox"/> Gonorrhea <input type="checkbox"/> Herpes <input type="checkbox"/> Syphilis
	Other: _____

MAJOR ILLNESSES (non-infectious) / OPERATIONS (Include Pregnancies & Childbirth)

Date	Description	Location of Service



MEDICATIONS — Update Regularly

Date Started	Current Prescriptions: Name/Dose/Frequency

INFECTIOUS DISEASES

Disease	Age	Date	Remarks
Chickenpox			
Measles			
Rubella			
Hepatitis			
Mumps			
Polio			
Pneumonia			
Pertussis/Whooping Cough			
Scarlet Fever			
Other			

IMMUNIZATIONS

When planning to travel outside the US, check with your physician to determine what immunizations are necessary

Date	Vaccine	Date	Vaccine
	Hepatitis B		Rubella
	Influenza		Smallpox
	Measles		Tuberculosis
	Mumps		Tetanus/Diphtheria
	Pneumonia		Typhoid
	Polio		Other

HEALTH MAINTENANCE CHART

[illegible]



ADDITIONAL INFORMATION

Electrocardiogram/X-ray — Results/Dates
 Foreign Travel — Location/Dates

Obstetrical History
 Other Significant Information (Tuberculin test)

DEVICES AND PROSTHESES

Date	Item	Date	Item
	Pacemaker		Artificial Heart Valve
	Artificial Joint Implant (Which Joint(s))		
		Contact Lenses	
	Other		

EYE INFORMATION

(Prescription Glasses)

	Sphere	Cylinder	Axis	Prism	Base
Right Eye (OD)					
Left Eye (OS)					

Add: _____ Base Curve: _____

Other: _____

Name of Physician: _____ Phone: _____

IMPORTANT HEALTHCARE DOCUMENTS

Document	Date Signed	Where Filed
Power of Attorney for Healthcare Proxy		
Advance Directive/Living Will		
Organ Donor Card		
Other		



FAMILY MEDICAL HISTORY

	Mother	Father	Maternal Grandmother	Maternal Grandfather	Paternal Grandmother	Paternal Grandfather
<u>Birthplace</u>						
<u>Occupation</u>						
<u>Alcoholism</u>						
<u>Allergies</u>						
<u>Blood/Circulation</u>						
<u>Depression</u>						
<u>Cancer</u>						
<u>Diabetes</u>						
<u>Digestive System</u>						
<u>Drug Sensitivities</u>						
<u>Eye Disorder</u>						
<u>Heart Disease</u>						
<u>Hearing Disorder</u>						
<u>Hypertension</u>						
<u>Kidney Stones</u>						
<u>Liver Disorder</u>						
<u>Musculoskeletal</u>						
<u>Reproductive System</u>						
<u>Respiratory System</u>						
<u>Stroke</u>						
<u>Urinary/Prostate</u>						
<u>Major Surgery</u>						
<u>Alzheimer's Disease</u>						
<u>Other</u>						
<u>Age/Cause of Death</u>						



HEALTH INFORMATION FORM FOR CHILDREN

Child is hypersensitive, allergic or has adverse reactions to: _____

IDENTIFICATION

Name		Date of Birth		Languages Spoken	
Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female	Height	Weight	Eye Color	Blood/RH Type	In Emergency Notify:
Mother's Name			Name Relationship		
Address			Telephone Number		
City	State		Zip		Obstetrician Phone
Home Phone	Work Phone		Pediatrician		Phone
Father's Name			Other Physician		Specialty Phone
Address			Dentist		Phone
City	State		Zip		Pharmacy Phone
Home Phone	Work Phone		Other		

Chronological account of chronic, recurrent, or significant acute illness or injury, including birth defects, surgical procedures, ear infections, etc.

Date	Nature of Health Problem	Remarks (e.g., medications, special tests, x-rays, length of hospital stay, surgery, etc.)

BIRTH DATA

Hospital		
Weight	Length	Physician
Perinatal Problems		
Apgar Score		

[illegible][illegible]



MEDICATIONS — Update Regularly

[illegible]

INFECTIOUS DISEASES

Disease	Age	Date	Remarks
Chickentpox			
Measles			
Rubella			
Hepatitis			
Mumps			
Polio			
Pneumonia			
Pertussis/Whooping Cough			
Scarlet Fever			
Other			

Appendix B

Round One Questionnaire

**Consumer Informatics:
Development Of A Model for
Documenting and Maintaining Family Medical Records**

DESIGN QUESTIONNAIRE: Round 1

I understand that the return of my completed questionnaire constitutes my informed consent to act as a subject in this research.

Respondent _____ Telephone _____
Only summary or aggregate data will be reported, individual responses will remain anonymous

Address _____

E-mail _____ Fax Number _____

DEMOGRAPHICS: Please circle the choice that best describes you

1. What is your highest level of education?

- A. Associate Degree C. Master's Degree
B. Bachelor's Degree D. Doctoral Degree E. Other _____

2. What credentials have you earned? Circle all that apply

- A. ART B. RRA C. CCS D. Other _____

3. How many years have you been in the Health Information Management profession?

- A. Less than 10 C. 21 – 30 E. 41 - 50
B. 11 – 20 D. 31 – 40 F. 51 and over

4. What is your current employment setting?

- A. Inpatient facility C. Home Health E. Academic
B. Outpatient facility D. Long Term Care F. Consulting
G. Other _____

5. What is your current area of responsibility? Circle all that apply

- | | |
|------------------------------------|----------------------------------|
| A. Health Information Manager | E. Document & Repository Manager |
| B. Clinical Data Specialist | F. Research & Decision Support |
| C. Patient Information Coordinator | G. Security Officer |
| D. Data Quality Manager | H. Risk Management |
| I. Consultant | J. Faculty |
| K. Other _____ | |

6. In what state or country do you reside? _____

7. What HIM volunteer positions have you held?

- | | |
|---------------------------|-----------------------------|
| A. State President | E. AHIMA section chair |
| B. AHIMA committee chair | F. AHIMA Board of Directors |
| C. AHIMA committee member | G. AHIMA president |
| D. AHIMA task force | H. Other Committee Work |
| I. IFHRO Officer | J. IFHRO Committee Work |
| K. IFHRO Other _____ | L. AHIMA Other _____ |

Your thoughtful answers to the following questions are most appreciated.

1. Please indicate your preference for the format of a family medical record by rating the importance of each of the choices. Add additional formats that you think should be considered. Any comments are welcome.

ITEM	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
Format			
3-ring binder			
Spiral tablet			
Bound journal			
Loose-leaf folder			
CD-ROM			
Computer disk			
Credit card/magnetic strip			
Other			

COMMENTS:

2. What size should a family medical record be? Indicate your preference by ranking the importance of each choice. Add additional sizes that you think should be considered. Any comments are welcome.

ITEM	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
Size			
8½ X 11			
5 X 7			
Wallet-sized			
Pocket-sized			
Purse-sized			
Electronic size			
Appropriate to be carried at all times			
Appropriate to be carried to healthcare visits			
Appropriate for home storage only			
Other			

COMMENTS:

3. How should a family medical record be arranged? Indicate your preference by ranking the importance of each choice. Add additional arrangements that you think should be considered. Any comments are welcome.

ITEM	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
Arrangement			
By family member			
Separate records for each family member			
Chronological			
Divided Sections			
Alphabetical			
Problem-oriented			
Other			

COMMENTS:

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

[illegible]

COMMENTS:

Appendix C

Pilot Study Cover Letter



TEXAS WOMAN'S UNIVERSITY

DENTON / DALLAS / HOUSTON

151

DEPARTMENT OF
FAMILY SCIENCES
College of Education and Human Ecology
P. O. BOX 425769
DENTON, TX 76204-5769
940/898-2685 FAX: 940/898-2676

May 5, 1999

Dear TxHIMA Board Member:

I have been admitted to candidacy for the Ph.D. in Family Studies at Texas Woman's University. Completion of my dissertation is all that remains to finish degree requirements. In choosing a topic to study I wanted to utilize my 31 years' experience in health information management and my newly acquired knowledge about families. I am excited that my topic allows me to merge the two disciplines: **"Consumer Informatics: Development of a Model for Documenting and Maintaining Family Medical Records"**. The Delphi technique will be used to bring a panel of experts to consensus on the best design for family medical records.

I hope to identify the best design for families to use for documentation and maintenance of their own medical records. This subject is timely as consumers are being empowered with access to more and more information. It also supports the AHIMA Vision 2006 and the new role for HIM professionals as a patient information coordinator or consumer educator/advocate.

I need your help to evaluate the initial questionnaire prior to distribution to the expert panel. Please complete the questionnaire to determine if instructions are clear and the length of time required completing it. Any comments you want to make regarding the process will be helpful to insure the research design will yield the desired results. I will be presenting preliminary findings at the TxHIMA annual convention June 12, 1999 in Houston.

Please return the questionnaire with any comments by May 12, 1999. Call or send E-mail with questions. A self-addressed, stamped envelope is enclosed for your convenience. Thank you for helping with this study.

Yours truly,

Barbara Odom-Wesley, M.A., RRA
Ph.D. Candidate, Texas Woman's University
1100 Ascott Court Arlington, TX 76012-5360
Phone/Fax 817/261-9101 E-mail medprobw@flash.net

Appendix D

Round One Cover Letter

TEXAS WOMAN'S UNIVERSITY

DENTON / DALLAS / HOUSTON

153

DEPARTMENT OF
FAMILY SCIENCES
College of Education and Human Ecology
P. O. BOX 425769
DENTON, TX 76204-5769
940/898-2685 FAX: 940/898-2676

May 24, 1999

As a member of the IFHRO Grand Council or a past-president of AHIMA, you have been selected to participate in a research study. I have been an RRA since 1968 and am a past-president of the Texas Health Information Management Association. Currently, I am a Doctoral candidate at Texas Woman's University. I wanted to utilize my 31 years' experience in health information management and my newly acquired knowledge about families. I am excited that my topic allows me to merge the two disciplines: **"Consumer Informatics: Development of a Model for Documenting and Maintaining Family Medical Records"**. I need your expert opinion to design a family medical record.

The purpose of this study is to develop a model to guide families in documenting complete health information and maintaining this medical record at home. The literature reveals that consumers become empowered and active participants in their medical care decisions through increased and more effective access to healthcare information. Programs throughout the world that have implemented patient-held records report successes and benefits. Families are better informed, conscientious about keeping records up to date and about bringing them to healthcare encounters. Patient-held records are especially beneficial for young children to track development and for the elderly with chronic illnesses. The literature revealed a variety of designs being used for these family records. This study is designed to identify the best design, which will result in complete, current healthcare documentation that is a valuable addition to family documents.

Your participation is completely voluntary; you may withdraw from the study at any time. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. Should you agree, please complete the enclosed questionnaire and return it in the envelope provided within one week. The Delphi technique will be used to reach consensus among a group of experts about the best design for a family medical record. Within three weeks, you will receive a second questionnaire incorporating the results of the first. It will need to be returned within one week. A third and final round will be sent with results from the second round and a final questionnaire. You will have the opportunity to request a copy of the findings when the final questionnaire is returned. Each questionnaire takes about 15 minutes to complete.

The Delphi technique is designed as a tool for a group of experts to come to a consensus. The prioritization process allows experts to produce a list of rankings. The steps are (a) build a list of criteria, (b) panel individually and anonymously ranks criteria using a type of Likert scale, (c) calculate the mean and deviation, remove all items with a mean greater than or equal to 2.0, place the criteria in rank order, and share the results with the panel, (c) repeat the ranking process until the results stabilize, and (d) analyze results with feedback to participants.

Individual responses will remain anonymous. Only summary or aggregate data will be reported with the results. Questionnaires with responses will be stored in a locked file cabinet for two years. After two years, all forms will be destroyed by shredding.

There are no direct benefits to participants in the study. You will receive access to information about maintaining medical records for family members. You will also receive the findings if requested using a card included with the last round of the Delphi. This information could better prepare you to fulfill one of the new roles identified in AHIMA's Vision 2006, consumer advocate/educator.

Your participation is vital to design this family medical record which will empower patients to become more involved in their healthcare decisions. This could revolutionize the patient-provider relationship to a partnership.

If you have any questions about the research study, you should ask the researcher. My address is 1100 Ascott Court, Arlington, TX 76012-5360 or call 817/261-9101 or E-mail medprobw@flash.net. My advisor, Gladys Hildreth, Ph.D., can be reached at 940/898-2694. If you have questions about your rights as a subject or the way this study has been conducted, you may call Ms. Tracy Lindsay in the Office of Research & Grants Administration at 940/898-3377.

Your participation is greatly appreciated. Please respond by June 1, 1999. A self-addressed, stamped envelope is enclosed for your convenience.

Sincerely,

Barbara Odom-Wesley, MA, RRA
Ph.D. Candidate in Family Studies

Appendix E

Round Two Questionnaire

**Consumer Informatics:
Development Of A Model for
Documenting and Maintaining Family Medical Records**

Results for Round One

Description of Expert Panel

Round 1 questionnaires were mailed to the 23 members of the IFHRO Grand Council and to 32 past presidents of AHIMA. Eight Council members and 14 past presidents responded. The results were tallied from the 22 (40%) responses.

Education – In response to the highest level of education, the majority (12 or 55%) have earned a Master's Degree. The Bachelor's Degree has been earned by six respondents or 27%, Two participants have an Associate Degree and two have a Doctoral Degree. One respondent reported no degree and entered Associate Professor in the "other" category.

Credentials – The majority (16 or 73%) of the respondents hold the credentials of Registered Record Administrator (RRA). One is an Accredited Record Technician (ART). Three participants reported other credentials since the choices are not utilized in many foreign countries.

Experience – Most panel members (12 or 55%) have 21 – 30 years' experience in the Health Information Management profession. Six have 31 – 40 years' experience and three have 41 – 50 years' experience. One had 11 – 20 years' of experience and two have retired.

Employment Setting – A wide variety of current employment settings were indicated in the respondent's answers. Panel members checked as many as were applicable. Since many facilities offer multi-levels of care, many choices were selected. Four panel members chose inpatient facility and four checked consulting. Three each selected outpatient facility, and long term care. Three are employed in the academic setting and four selected other. The settings written in for other were HIM products vendor, Orthopedics/Rehabilitation system, integrated delivery and professional organization.

Current area of Responsibility – The panel members were instructed to circle all that apply. The following selections were made, 10 for Health Information Manager, 4 chose consultant and document & repository manager, 3 selected clinical data specialist and research & decision support, Patient information coordinator, and data quality manager were each selected by two panel members. One panel member chose security officer, risk management and faculty. Areas of responsibility written in by other were CEO, QI consultant, professional organization, COO, financial officer, director, publishing and compliance & patient accounts.

Location – The expert panel members represented 6 foreign countries and 13 states. Respondents were from The Philippines, Australia, The Netherlands, China, Israel and Canada. The states represented were Massachusetts, Illinois, Michigan, Florida, Wisconsin, Maryland, Missouri, New York, Minnesota, New Hampshire, Pennsylvania, Indiana and Georgia.

Volunteer Positions – Panel members reported extensive involvement in local, state and national HIM organizations. The position of State President has been held by 16 members and 18 have served on a national Board of Directors (AHIMA or other country). The office of AHIMA president has been held by 14 participants and 14 have served as an AHIMA committee chair with 16 having served on an AHIMA committee. Twelve panel members have served on an AHIMA task force and 6 have other national committee work. AHIMA section chair, IFHRO committee work and IFHRO officer each had four participants from the panel. Positions listed for IFHRO other were president, vice-president, alternate for Grand Council, speaker, and Director. Positions listed for other AHIMA volunteer service were FORE chair and Board, AHIMA staff, and AOE member. Two panel members are retired.

**Consumer Informatics:
Development Of A Model for
Documenting and Maintaining Family Medical Records**

Questionnaire: Round Two

Your thoughtful answers to the following questions are most appreciated.

1. Please indicate your preference for the **format** of a family medical record by rating the importance of each of the choices. Add additional formats that you think should be considered. Any comments are welcome.

ITEM	ROUND 1 SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
Format				
Computer disk	53			
CD-ROM	51			
3-ring binder	45			
Credit card/magnetic strip	40			
Loose-leaf folder	33			
Bound journal	25			
Spiral tablet	21			
Internet/Web Page	6			
Intranet Access To doctor's office	3			
Classification Folder	3			
Other				

COMMENTS:

COMMENTS ON FORMAT FROM PANEL OF EXPERTS:

Electronic:

- "Website to enroll family and members in"
- "Computer/magnetic formats pose difficulties in updating and in accessing by patient/family"
- "CD-ROM requires some standardization of information input; too advanced technologically to be universal"
- "Computer disk: Some of the same concerns about wide access and socioeconomic status issues, etc., but more attractive than CD-ROM"
- "My personal preference would be for a format similar to Quicken. I'd like it PC based so I could update it and track the family. My second preference would be for a smart card, but I think this is more limited to the essentials."
- "Direction should be computerized records for reasons that are familiar to all: database updates, accessibility, ease of retrieval, stats., and portability"
- "Many people are not computer-oriented"
- "Most providers would not have the technology to access the information on a credit card/magnetic strip other than the initial issuer."
- "CD-ROM can hold more information and is easy to take care of. Sometimes it cannot open because of destruction or compatibility problems."
- "Interactive database; PC based"
- "Computer medium cannot be read by family members"

Paper:

- "Bound journal if structured health record."
- "Paper choices are no better or worse than the 3 ring-binder, just the package is different"
- "3-ring binder is not common in other countries"
- "Paper records will still have a place in the near future"
- "Because of the varied forms and most record copies are hardcopy, paper is most practical"
- "One could use an internet-based format to keep the record updated yourself, but in the present/near future, paper is still practical."
- "The holder must allow inserts in some way with easy access in the event of emergency."
- "Should be tailored to the individual family"
- "Paper records are most reliable. It should allow new documents to add up easily but not easy spreading out or losing."
- "Needs to be a robust format, but one that can be used in multiple settings – either in places well-equipped with technology or places where technology is not used."
- "Consider maintenance & safekeeping, handling, and confidentiality."

2. What **size** should a family medical record be? Indicate your preference by ranking the importance of each choice. Add additional sizes that you think should be considered. Any comments are welcome.

ITEM	ROUND 1 SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
Size				
Appropriate to be carried to healthcare visits	56			
Electronic size	47			
Appropriate to be carried at all times	42			
8½ X 11	37			
Wallet-sized	35			
Pocket-sized	34			
Appropriate for home storage only	30			
5 X 7	25			
Purse-sized	22			
Appropriate for home computer	6			
A4 (21cm X 29.5cm) 8.3 X 11.6 inches	3			
Appropriate for home storage	3			
Other				

COMMENTS:

COMMENTS ON SIZE FROM PANEL OF EXPERTS:

Carried at all times:

- “If on CD-ROM come with zippered holder”.
- “I find it useful to maintain two records: a letter-size classification folder which I only take to a healthcare visits and a pocket-size card with basic data (e.g., medications, immunizations) that I carry at all times.
- “Meds and allergies only”
- Small size is easier to carry

Carried for Healthcare Visits Only:

- “8½ X 11 or A4, which is standard for Australian records.
- “I expect in the future to be able to e-mail doctors, transfer information electronically so I don’t necessarily need to carry.”
- “8½ X 11 is easier for the doctor to write on”

Other Comments:

- “Size will depend on the option a family or individual elects.”
- “Size is not important if we assume an electronic record”
- “If paper-based, then all sizes would be important”
- “If electronic, size should be configurable based on a print function”
- Record size will need to accommodate all socioeconomic levels; therefore basic paper that can be scanned is most important.
- Paper 8½ X 11 fits into notebooks and can be scanned into a computer.
- Data should be readable for users
- Should be small, lightweight & versatile

3. How should a family medical record be **arranged**? Indicate your preference by ranking the importance of each choice. Add additional arrangements that you think should be considered. Any comments are welcome.

ITEM	ROUND 1 SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
Arrangement				
Separate records for each family member	58			
Divided Sections	58			
By family member	54			
Chronological	50			
Problem-oriented	44			
Alphabetical	26			
By medical episode	3			
Other				

COMMENTS ON ARRANGEMENT FROM PANEL OF EXPERTS:

Separate record for each family member:

- By family member for privacy
- The important aspect is some methodology to link records from one family if needed.
- I question the importance of a family vs. individual records (e.g., parent & adult children)
- Each member of the family should have a separate record. In this way children can take their records when they leave the family.
- Whether the record is completely separate or a section in a larger record would depend on the volume.

Other Comments:

- A combination of divided sections, with chronological records within each section – and a problem list as an index would be best.
- Depends on number of problems and extent of treatment (divided sections)
- Sections could be by type (i.e., preventive, immunizations, childhood, chronic illnesses, surgeries, screenings, injuries, ordinary wear & tear, etc.)
- Divided sections help organize the data and within each section chronological order is helpful.

4. What information should be **included** in a family medical record? Indicate your preference by ranking the importance of each choice. Add additional information that you think should be included. Any comments are welcome.

ITEM	ROUND 1 SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
Content				
Family History	62			
Medications	62			
Immunizations	61			
Personal Health History	60			
Problem List	59			
Record of healthcare encounters	59			
Operative Procedures	59			
End of Life Issues Organ Donation Advance Directives Living Will	59			
Names/addresses of providers e-mail, phone	58			
Diagnostic Test Results (includes lab & x-ray)	58			
Hospitalizations (include discharge summary)	56			
Physical Assessment (include disabilities)	55			
Growth/Development Charts	55			
Eye Care	52			
Correspondence about Healthcare	50			
Dental Care	49			
Financial Issues	41			
Health Maintenance Activities Includes mammograms & pap smear	40			
Health Education Materials	33			
Allergies	6			
Pathology Reports	3			
Flow Sheets to monitor health problems	3			
History of extended family	3			
Summary of old information	3			
Health assessment: exercise, nutrition, risks	2			
Calendar for menstrual history & preventive service reminders	2			
Prosthesis	2			
Other				

OTHER DESIGN ISSUES IDENTIFIED BY PANEL OF EXPERTS:

Please rate the level of importance for each item.

ITEM	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
FAMILY CHARACTERISTICS			
Family Financial Status			
Other resources of the family			
The need for a copy of the records for the family			
Stress on Family			
COMPLETION ISSUES			
Ease of understanding for the users			
Data must be complete and accurate			
Font size so all ages can read it easily			
Enough space for kids with chronic problems to self-record			
Check-off & easy form completion			
Teach patients the necessity for thoroughness, accuracy			
Print in native language			
Large spaces for handwritten entries			
SECURITY			
Safe, secure, and orderly storage of the records			
Protect confidentiality			
Computer data must have back- ups			

CONTENT			
Family Tree showing relationships			
Prescribed and over-the-counter medications			
Only include diagnostic test results when abnormal			
Upcoming appointments			
Reminders for preventive & routine services			
Calendar to track health problems			
Graph values over time			
Family member narratives on health problems			
Track when & where services provided			
Temporary storage for health education materials			
School/Camp Physicals			
Mental Health records			
Insurance Payments			
Therapeutic Services (Occupational/Physical Therapy)			

DESIGN			
Ease in finding information			
Color-coded to help explain sections & expedite filing & retrieval			
Complexity of today's family: Who's included?			
Space for provider-generated reports			
Encourage active, continually useful document			
Don't duplicate records maintained by health provider			
Create personal record online & print copy for annual or new provider visit.			
Computer input screen design same as hard copy data collection sheets			
Cost of providing copies to patients			
Way to cross-reference family members when original family disrupted			
Ability to incorporate reference data (e.g., from Internet)			
Family records share common information and individual			
Back-up system if patient loses or forgets record			

Appendix F

Round Two Cover Letter

Texas Woman's University
Department of Family Sciences
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Ph.D. Candidate
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E-mail medprobw@flash.net

Thank you for responding to the first round questionnaire to design a family medical record. The participants in this study comprise an expert panel based on education, and extensive experience. The time and effort you are donating to this important topic is invaluable. Your selections and comments have provided a wealth of information on this subject. I have summarized the results for your consideration.

Expert panel members were asked to evaluate the importance of a list of choices for format, size, arrangement, and content using a Likert scale. One point was assigned for each "not important" response, 2 points for each "somewhat important" mark and 3 points for each "very important" mark. The points for each item were added for a total score for each choice. Items were ranked in order of preference determined by the score.

Respondents were also asked to identify other design issues in an open question format. These additional items were organized by topic to be included on the questionnaire for Round 2.

Because of difficulties with the postal service and the foreign countries, electronic mail or fax machines are being used to transmit the questionnaire for round 2 and 3. Please follow the same instructions from round 1. Indicate your preferences by marking the level of importance for each item. I hope to receive your responses by Monday, June 21st. I will tally the results of round 2 and send the third and final round for your completion.

If you have any questions about the research study, please contact me. My address is 1100 Ascott Court, Arlington, TX 76012-5360 or call 817/261-9101 or E-mail medprobw@flash.net. My advisor, Gladys Hildreth, Ph.D., can be reached at 940/898-2694. If you have questions about your rights as a subject or the way this study has been conducted, you may call Ms. Tracy Lindsay in the Office of Research & Grants Administration at 940/898-3377.

Please use E-mail or Fax so I can receive your results by Monday, June 21, 1999. Your participation is greatly appreciated.

Sincerely,

Barbara Odom-Wesley, M.A., RRA
Ph.D. Candidate in Family Studies

Appendix G

Round Three Questionnaire

**Consumer Informatics:
Development Of A Model for
Documenting and Maintaining Family Medical Records**

Questionnaire: Round Three

Items that did not receive a mean score of 2.0 in Round 2 have been eliminated from consideration. Remaining choices are ranked based on the results from Round 2.

Please indicate your preference for the remaining items by checking not important, somewhat important or very important. THANK YOU

ITEM	ROUND 2 SCORE	MEAN SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
ELECTRONIC FORMAT					
Computer Disk	34	2.6			
CD-ROM	29	2.4			
PAPER FORMAT					
Loose-leaf Folder	22	1.8			
3-ring Binder	22	1.8			
SIZE					
Appropriate to be carried to healthcare visits	36	3.0			
Electronic Size	32	2.7			
Appropriate for home computer	25	2.3			
Appropriate to be carried at all times	25	2.1			
Appropriate for home storage	25	2.1			
8½ X 11	24	2.0			

ITEM	ROUND 2 SCORE	MEAN SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
ARRANGEMENT					
Separate records for each family member	35	2.9			
Divided Sections	35	2.9			
By Family Member	31	2.6			
Chronological	30	2.5			
Problem-oriented	27	2.3			
CONTENT					
Family History	36	3.0			
Medications prescribed & over-the-counter	36	3.0			
Personal Health History	36	3.0			
Immunizations	35	2.9			
Operative Procedures	35	2.9			
End of Life Issues	34	2.8			
Names/Addresses of Providers e-mail & phone	33	2.8			
Diagnostic Test Results Includes lab & x-ray	33	2.8			
Health Maintenance Activities Includes mammograms & pap smear	33	2.8			
Problem List	32	2.7			
Allergies	32	2.7			
Hospitalizations (include discharge summary)	32	2.7			
Record of Healthcare Encounters (include location)	31	2.6			
Physical Assessment Include disabilities	31	2.6			

ITEM	ROUND 2 SCORE	MEAN SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
CONTENT CONTINUED					
Growth/Development Charts	31	2.6			
Mental Health Records	39	2.6			
Eye Care	29	2.4			
Therapeutic Services	36	2.4			
Occupational/Physical Therapy	29	2.4			
Pathology Reports	27	2.3			
Dental Care	35	2.3			
Calendar to track health problems	34	2.3			
Graph values over time	34	2.3			
Upcoming Appointments	33	2.2			
Only include diagnostic test results when abnormal	33	2.2			
Reminders for preventive & routine services	24	2.2			
Correspondence about Healthcare	31	2.1			
School/Camp Physicals	25	2.1			
Financial Issues					
COMPLETION ISSUES					
Data must be complete and accurate	45	3.0			
Ease of understanding for the users	44	2.9			
Check-off & easy form completion	42	2.8			
Print in native language	39	2.6			
Large spaces for handwritten entries	38	2.5			
Enough space for kids with chronic problems to self-record	36	2.4			
Teach patients the necessity for thoroughness, accuracy					

ITEM	ROUND 2 SCORE	MEAN SCORE	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT
SECURITY					
Safe, secure, & orderly storage of records	43	2.9			
Computer data must have back-ups	42	2.8			
Protect patient confidentiality	32	2.7			
DESIGN					
Ease in finding information	45	3.0			
Space for provider-generated reports	41	2.7			
Encourage active, continually useful document	41	2.7			
Back-up system if patient loses or forgets record	40	2.7			
Color-coded to help explain sections/expedite filing & retrieval	36	2.4			
Complexity of today's family: Who's included?	36	2.4			
Create personal record online print copy for annual/new provider v	36	2.4			
Cross-reference family when original family disrupted	32	2.3			
Don't duplicate records maintained by provider	33	2.2			
Computer input screen design same as hard copy sheets	32	2.1			
Cost of providing copies to patients	32	2.1			

I would like to receive a copy of the results for this study YES _____ NO _____

Signature

Thank you for your valuable time and thoughtful consideration in completing the questionnaires for this study.