Air Force Institute of Technology AFIT Scholar

Theses and Dissertations

Student Graduate Works

3-21-2008

# A Delphi Study Assessing Long-term Access to Electronic Medical Records (EMR)

Byron D. Nicholson

Follow this and additional works at: https://scholar.afit.edu/etd

Part of the Health and Medical Administration Commons, and the Information Security Commons

#### **Recommended Citation**

Nicholson, Byron D., "A Delphi Study Assessing Long-term Access to Electronic Medical Records (EMR)" (2008). *Theses and Dissertations*. 2859. https://scholar.afit.edu/etd/2859

This Thesis is brought to you for free and open access by the Student Graduate Works at AFIT Scholar. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of AFIT Scholar. For more information, please contact richard.mansfield@afit.edu.





# A DELPHI STUDY ASSESSING LONG-TERM ACCESS TO ELECTRONIC

## **MEDICAL RECORDS (EMR)**

THESIS

Byron D. Nicholson, Captain, USAF

AFIT/GIR/ENV/08-M15

DEPARTMENT OF THE AIR FORCE AIR UNIVERSITY

**AIR FORCE INSTITUTE OF TECHNOLOGY** 

Wright-Patterson Air Force Base, Ohio

APPROVED FOR PUBLIC RELEASE; DISTRIBUTION UNLIMITED



www.manaraa.com

The views expressed in this thesis are those of the author and do not reflect the official policy or position of the United States Air Force, Department of Defense, or the United States Government.



# A DELPHI STUDY ASSESSING LONG-TERM ACCESS TO ELECTRONIC MEDICAL RECORDS (EMR)

## THESIS

Presented to the Faculty

Department of Systems and Engineering Management

Graduate School of Engineering and Management

Air Force Institute of Technology

Air University

Air Education and Training Command

In Partial Fulfillment of the Requirements for the

Degree of Master of Science in Information Resource Management

Byron D. Nicholson, B.S.

Captain, USAF

March 2008

APPROVED FOR PUBLIC RELEASE; DISTRIBUTION UNLIMITED



## AFIT/GIR/ENV/08-M15

# A DELPHI STUDY ASSESSING LONG-TERM ACCESS TO ELECTRONIC MEDICAL RECORDS (EMR)

Byron D. Nicholson

Captain, USAF

Approved:

\_\_\_\_//signed//\_\_\_\_ Alan R. Heminger, PhD, USAF (Chairman) 21 Mar 2008 Date

\_\_\_\_//signed//\_\_\_\_ Jason M. Turner, Maj, PhD, USAF (Member) 21 Mar 2008 Date



#### AFIT/GIR/ENV/08-M15

## Abstract

This research effort addressed the issue of long-term access to electronic medical records as technological generations become obsolete, thereby preventing the access to patient health information. Using the Delphi methodology, experts with experience in electronic medical records and applicable systems provided insight based on their years of hands-on experience managing and/or using records and these systems.

The end result of this research was a collection of ideas that medical institutions and medical informaticians must consider to ensure that patients and hospitals do not lose long-term access to electronic medical records as electronic medical records and technology continually evolves. Results of the study identified the need for more research in this particular area as no definitive solution to long-term access to electronic medical records was revealed. Additionally, the research findings highlighted the fact that a few medical institutions may actually be concerned about long-term access to electronic records.



iv

# Acknowledgments

Although I physically accomplished the work for this thesis, it would not have been possible without the help from God or the emotional, spiritual, and academic support of, family, friends, and faculty. I would like to extend a heartfelt thank you to each of them for their unwavering support on this research effort.

Byron D. "Nic" Nicholson



# Table of Contents

	Pag	ge
Abs	stract	iv
Ack	cnowledgements	.v
Tab	le of Contents	vi
List	of Figuresv	iii
List	of Tables	ix
I.	Introduction	.1
	Background A Call for Change in Healthcare Initiatives Problem Statement	.1
II.	Literature Review	.8
II.	Literature Review Introduction Information Technologya Vital Resource Electronic Medical Records Systems Exactly What is a Medical Record Anyway Electronic Records Principles Strategies for Long-Term Access to Medical Documents	.8 .8 13 16 21 26
	Introduction Information Technologya Vital Resource Electronic Medical Records Systems Exactly What is a Medical Record Anyway Electronic Records Principles Strategies for Long-Term Access to Medical Documents	.8 .8 13 16 21 26 32



## Page

IV.	Results and Analysis	41
	Introduction Round One, Question One Round One, Question Two Round Two Responses for Consolidated Question One Comments Round Two Responses for Consolidated Question Two Comments	41 44 45
V.	Discussions	48
	Conclusions Limitations Recommendations	51
Ap	pendix A. E-mail for Expert Panel	53
Ap	pendix B. Research Synopsis	54
Ap	pendix C. Round One Consolidated Responses	56
Арј	pendix D. Round Two Report	63
Bib	liography	65
Vit	a	71



# List of Figures

	F	Page
Figure 1.	Flow of healthcare information in U.S. system	. 19
Figure 2.	Information life-cycle	. 24
Figure 3.	Model of the life-cycle of a clinical document	. 25
Figure 4.	OAIS model	. 29
Figure 5.	DRS model	. 30



# List of Tables

	Pa	age
Table 1.	Key characteristics of AHLTA	15
Table 2.	Record type and retention criteria	21
Table 3.	Common Digital Preservation Strategies	26
Table 4.	Round 1 Question 1 aggregation of responses by topic	42
Table 5.	Round 1 Question 2 aggregation of responses by expert	44
Table 6.	Round 2 Question 1 Aggregation of comments	45
Table 7.	Round 2 Question 2 Aggregation of comments	46



# A DELPHI STUDY ASSESSING LONG-TERM ACCESS TO ELECTRONIC MEDICAL RECORDS (EMR)

#### I. Introduction

### Background

Patients' medical histories are documented within their medical records and these records must follow them over the course of their lifetimes. Until recently, the majority of medical records were printed on paper and kept in a paper folder. Hospitals, as well as private-sector healthcare providers, are moving away from traditional paper-based records to electronic versions; patients' entire medical histories are recreated in a digital format as the healthcare field incorporates more technology into its daily practices. The increased use of this technology has allowed doctors, nurses, and hospital administrators to perform tasks faster and easier (Harrison & Palacio, 2006).

#### A Call for Change in Healthcare Initiatives

Healthcare market trends indicate that more money is being allocated for medical informatics systems than ever before (Krizner, 2006). In 2006, the Department of Defense (DoD) completed its nationwide rollout for its new electronic medical record (EMR) system Armed Forces Health Longitudinal Technology Application (AHLTA) and has mandated that all of its hospitals (i.e. Wright-Patterson AFB 88<sup>th</sup> Medical Group or Brooke Army Medical Center) begin using the system. The DoD intends to maintain a continuity of care by ensuring a service member's record follows the individual for life.



This change is part of a Pentagon-led initiative to use electronic medical records to eliminate the requirement for service members to hand-carry their records to appointments or to installation reassignments (Swartz, 2006).

An achievement of this magnitude will depend largely on the ability of information technology (IT) to foster the exchange of electronic health information. Although EMR systems facilitate the information sharing process, the use of these systems may present problems with long-term access to the digitally stored information as the technology continually evolves; hospitals and/or patients could lose access to parts or all of their digitally stored records when earlier generations of EMR systems become obsolete and are no longer available. This is a legitimate concern considering the increasing number of healthcare facilities that are now using these systems to collect, store, and share patient health-related information.

#### Collecting Patient Information.

Within the medical community, there seems to be an understanding or a de facto standard of practice that states, "*If it's not written down, then it never happened*." Anyone who has visited a hospital or clinic for a medical appointment might have noticed the physician, the physician's assistant, a nurse, or a medical technician gathering information for patient care orders pertaining to the patient's current health status including any procedures performed or medication(s) issued for health history and insurance purposes. A large portion of a physician's workday is consumed with writing down or explaining everything that has occurred or needs to happen; this helps to explain the profession's notoriety for poor penmanship (Slomski, 2007).



Time consumed writing or translating medical orders, coupled with malpractice lawsuits spurred by errors attributed to illegible handwriting, is driving a change toward a technological solution to handwritten patient order entries (Edwards & Moczygemba, 2004). Hence, the methodologies used to capture patient care orders are changing as many of the nation's larger hospitals and even some smaller, private offices and clinics transition from paper records to the electronic version. Once captured, regardless of method or format, this protected health information (PHI) is included into the patient's medical history.

Whether handwritten or entered electronically, the medical orders become part of that patient's life-long medical record. When done manually, the record is a collection of individual sheets containing specific health-related information and actions and are contained within a folder or series of folders stored in the institution's records department. Once filled with elaborate shelving and filing cabinets, such rooms are now being replaced with server farms and data warehouses. Thus, when records are maintained electronically, the records themselves are simply contained in a computer file that is stored and retrieved according to specific hardware and software protocols. As long as access methods are available based on these protocols, a patient's medical history should always be available when stored electronically.

#### Increased (EMR) Popularity.

Electronic medical records, often referred to and used interchangeably with electronic health records (EHR) or computer-based patient records (CPR), are rapidly replacing their paper predecessors (Schabetsberger, 2006). In many cases, it is the



patients and not the medical professionals who are requesting electronic medical records. A national survey by Kaiser Permanente revealed that the majority of 1000 Americans surveyed would prefer physicians and insurance companies that use electronic medical records to those that do not (Swartz, 2007). Based on these survey results, medical facilities that implement EMR systems might provide better care from the patients' point of view. Because of sentiments like those expressed by the survey participants, regional health information organizations (RHIO) are lobbying for increased EMR implementation.

The Health Information Management Systems Society (HIMSS) defines an RHIO as a "group of organizations with a business stake in improving the quality, safety, and efficiency of healthcare delivery" (Squazzo, 2007). The increasing popularity and use of electronic medical records and their systems has also increased the number of health information exchanges (HIE) as well as RHIOs that operate within the country (Squazzo, 2007). Healthcare providers and patients stand to benefit from implementing these systems if EMRs prove cost-efficient and offer the possibility of providing better service to patients. However, unlike patients, these organizations have financial gain as an additional incentive to implement EMR systems.

Congress took legislative action in 2006 in attempts to boost electronic health (ehealth) initiatives by re-addressing previous bills that supply health providers the necessary grants to implement health IT such as EMR systems (Wechsler, 2007). The intention behind this action was to capitalize on the efficiency and cost-savings offered by using an electronic medical record versus the status quo that is paper records.



However, operating EMR systems and converting medical information into a digital or electronic format garners new concerns for medical institutions concerning such issues as availability and long-term access. Once the data and information are stored, a process for long-term retrieval across multiple technology generations needs to be in place to ensure patients' health histories are not lost and are available for access.

#### Concerns Over Future Access.

With proper care, paper records should be available 50 years from now and can be read by simply looking at them. With electronic records, however, this is not the case. To access EMRs, it is necessary to have both the hardware and software that can retrieve and display the records. As previously mentioned, issues regarding long-term storage and retrieval are looming on the horizon as personal health information is captured in the digital form of an electronic medical record.

### **Problem Statement**

Hospital administrators are realigning business strategies to ensure they have the proper healthcare systems in place to store large amounts of patient-related data and information. Yet, there is no clear answer detailing the manner in which hospitals and private-sector clinics/offices will guarantee the availability of a patient's medical record once it is digital. We know that rapidly evolving generations of computer hardware and software frequently leave older computer files inaccessible to new systems that operate with different designs and protocols. Healthcare institutions and/or patients may lose access to parts or all of digitally stored records as earlier generations of EMR systems



become obsolete. Although many organizations, big and small, are focusing on storing the information in a digital form, relatively few are addressing the continued access of that information in the out years.

One solution, which is presently the de facto standard, involves migrating the information from the existing platform or system to a newer one similar to technology refreshing. Another solution, already in use by the National Archives and Records Administration (NARA), warrants physically storing a functional system in a "technology museum," keeping it operational in order to access the stored information at a later time. Some experts in the field of electronic records management and medical informatics vendors have proposed placing the onus of responsibility on the patient rather than the healthcare providers, or some centrally managed technological solution. Specifically, medical records would be placed in the patient's charge to manage over their lifetime. Regardless of the solution, however, the problem remains the same. Over time, these electronic records are at risk to become unavailable.

The importance of the information contained within a medical record requires a more stringent approach than prior methods of simply storing paper records in filing cabinets to ensure that electronic medical information has continued availability for access spanning multiple technology generations. Thus, the overarching research question to be addressed by this study is: **What should be done to ensure long-term access to patients' electronic medical records as technology changes?** 

This research effort employed a Delphi study to forecast the future issues and concerns associated with long-term storage and access of electronic medical records.



Ultimately, it was an effort to outline potential initiatives or policy decisions that might be implemented to ensure that medical professionals and patients do not lose access to electronic medical records. The next chapter will discuss what the current literature highlights about the body of knowledge associated with creating, storing, and retrieving a patient's electronic medical record.



### **II.** Literature Review

"The most incredible feature of the  $21^{st}$  century medicine is that it's held together with  $19^{th}$  century paperwork".

- Former Secretary of Department of Health and Human Services

### Introduction

This chapter discusses the current literature and research pertaining to medical information technology (electronic medical record systems) and its use in the medical field. Furthermore, this chapter discusses the current methods used to store and retrieve paper and electronic records. As discussed in Chapter 1, the potential to lose access to a patient's medical history exists as more healthcare facilities migrate from paper records to electronic records.

#### Information Technology...a Vital Resource

Information technology has proven itself to be a critical enabler and is utilized in nearly every type of organization in various forms. Although widespread use of IT within the medical community was uncommon years ago, that practice has been completely reversed ("Hospital IT use growing strong", 2007). Today, the increased use of technology allows doctors, nurses, and hospital administrators to perform tasks faster, easier, and with less invasive methods to patients. Many administrators have come to view IT as a valued resource and its implementation is often necessary for competition and success. In fact, while conducting research for this literature review, one of the larger hospitals in the surrounding Dayton, Ohio, area was contacted. Despite the best



efforts to convince them otherwise, efforts to discuss EMRs were declined for fear that the hospital's rival campus would learn closely guarded, trade secrets pertaining to its electronic records system. The use of IT systems has proven that, when implemented and utilized correctly, it can enhance an organization's performance.

#### Information Technology within the Medical Profession.

Medical professionals devote a significant portion of their lives to a demanding academic curriculum to master a body of knowledge with life-saving implications (Romano, 2004). Because of such commitments, medical advancements have been achieved by sharing exacting knowledge and lessons learned from one physician to another (Liberatore & Nydick, 2008). Medical progress attained through the use of IT can be seen in such areas as fertility drugs, cancer research, or organ transplants. Even though IT has and continues to foster an environment where the codification of medical knowledge is more easily accomplished and shared with colleagues globally, the use of technology by medical professionals has not always been popular.

The medical field, for various reasons such as cost and time, did not follow the emerging trends of industry and corporate leaders regarding the implementation of technology and its resources. "Health care lags behind other industries in adopting information technology by as much as 10-15 years" (Goldschmidt, 2005). Most people would agree that instituting change is difficult; instituting change that redefines years of medical practice and the potential loss of human life is even more difficult. Although the medical profession did not spearhead major technological developments, it did not completely avoid the use of technology:



Experiments with computerized medical record keeping began in the 1960s. The first electronic health records (EHRs) were designed and deployed starting in the late 1960s and early 1970s. By the mid-1970s, approximately 90% of hospitals used computers for business functions; 174 sites processed electronic data with some medical content. Physicians began adopting EMR systems in the late 1980s, following the introduction of the personal computer (Goldschmidt, 2005).

Albeit in a limited capacity, physicians used medical technology as early as 1960. Due to the costs associated with early systems, it is understandable why widespread use of computer systems might not have been readily adopted among medical professionals. High start-up costs thwart desires or efforts and often delay or discourage the transition from paper to digital records (Stabenow, 2007). Costs aside, it has also been argued that technology might have faced a difficult start in the medical community in part because the personnel did not readily accept it.

#### Medical Technology Acceptance.

Technology adoption research has been performed for nearly 30 years with welltested models attempting to predict or validate the use of IT; in 2002, there were a scarce number of published studies relating to healthcare and technology acceptance (Chismar & Wiley-Patton, 2002). Today however, numerous studies have been conducted specifically targeting technology acceptance within the medical profession. Common reasons cited within the research as to why technology falls into disuse were those such as the amount of time it takes to learn the new system (ease of use) and the users' perceptions as to whether or not the technology actually assisted or hindered their ability to accomplish tasks (perceived usefulness). "Practitioners have often regarded technology as costly, cumbersome, and offering little help for tasks at hand"



(Goldschmidt, 2005). Considering the fact that physicians are constantly under time constraints, it is not surprising that a change impacting their hectic, daily regimes would meet resistance.

One particular study conducted by Paul Hu, Patrick Chau, Olivia Sheng, and Kar Tam (1999) examined physician acceptance of telemedicine, using the technology acceptance model (TAM); the TAM was developed by Fred Davis (1989) to test technology acceptance using constructs based on user perceptions and intention to use. Telemedicine is best described as "the transportation of medical advice or procedures using telephone lines or internet as the medium" (Chau & Hu, 2004). Based on the study's findings, the most significant factor affecting doctors' decisions to use telemedicine technology was their perceptions as to how useful they found the technology (Hu, 1999).

The study further concluded that attitudes might also affect a physician's acceptance of technology. Physicians, more so than non-professionals, tended to focus on the technology's usefulness versus its ease of use (Hu et al., 2002). This might help to explain the slower adoption rate that plagues many hospital chief information officers (CIO) and administrators (Middleton, 2005). Even though adoption rates for technology tapered off, improvements to the technology as well as benefits through its use have really ignited a desire for more implementation (Chow, 2007)



#### Medical Technology Use Increases.

While the types of technology employed in the medical field vary greatly, much of the present talk in the medical community is centered on the use of electronic medical records and their sub-systems (Tang, 2006). In 1991, the National Institute of Medicine declared the computer-based records essential for health care ("Institute of medicine," 1991). Nearly two decades later, the medical community has begun widespread use of this technology. As previously mentioned, the first systems were designed and used in the late 1960s (Goldschmidt, 2005); however, the newer systems of today provide computing power that far surpasses the startup systems of 40 years earlier, and are catapulting the medical field toward a new frontier (Allan, 2002).

Today, geographically separated medical personnel share incredible amounts of patient-related information within seconds without ever physically handling it. Physicians and their staff no longer need to be present in order to address the changing needs of their patients (Bush, 2007). They are linked electronically to their work whether through E-mail, personal digital assistants (PDA), or video teleconferencing (VTC). The ability to rapidly share information through the increased usage of technology gives doctors, nurses, and hospital administrators access to critical and relevant clinical information as well as fostering communication amongst colleagues (Bobb, 2007; Glaser, 2007). Patient health information is among the most shared thanks to the enabling characteristics of EMR systems.



#### **Electronic Medical Record Systems**

An EMR is formally defined as "an electronic medical record that digitally stores healthcare information about an individual's lifetime with the purpose of supporting continuity of care, education and research, and ensuring confidentiality at all times" (Eichelberg, 2005). Therefore, EMR systems can be defined as the group of systems and subsystems used to store, transport, and share digital medical records. An Internet query on the subject of EMRs will return countless hits; scholarly searches in academically refereed journals or practitioner magazines will return an overwhelming amount of information specifically covering both the records and the EMR systems in detail.

Savings achieved through EMR implementation are estimated at nearly \$140B per year, or 10 percent of the health care industry spending ("Iron Mountain," 2006). However, while technology and electronic medical records have become more popular in the recent years, relatively little talk is being done regarding long-term access to the newly digitized patient information stored and accessed electronically using EMR systems. The number of organizations with well-established, functional EMR systems will need to increase before long-term access becomes an issue among current leaders in the technology.

#### Leaders in EMR System Implementation.

In 2004, President George W. Bush set a goal to have all healthcare facilities using electronic health/medical records by the year 2014 (Summers, 2007). Two of the leading U.S. organizations with successfully implemented EMR systems are the DoD and the Veterans Health Administration (VA). One of the largest in the world is that of the



National Health Service in the United Kingdom which plans to have 60,000,000 patients with EMRs by 2010 (Times Online, 2004). The VA has been credited for having one of the U.S.'s most successful EMR systems (Harrison & Palacio, 2006). Until recently, it owned and operated the country's largest system; a Pentagon initiative to provide lifelong records to military members and their families has now pushed the DoD ahead of the VA.

In keeping with the President's goal, the DoD recognized the importance of continued patient care and took necessary measures to ensure that its healthcare facilities followed the trends of their civilian compatriots and increased the use of EMR systems. The DoD's previous system, Composite Health Care System (CHCS-II), was fielded in 2004 and cost approximately \$4B (Goldschmidt, 2005). That system has been replaced with the new system named "AHLTA". When asked, AHLTA administrators consistently claim that "AHLTA" is a name and not an acronym. However, a quick read of its literature suggests that the letters represent the Armed-Forces Health and Longitudinal Technology Application ("Inspector general," 2006). Regardless of what it is called, the system is touted to set a new standard for the military healthcare profession. Table 1 lists the notable features of this system.



# Table 1. Key Characteristics of AHLTA (adapted from Global Information's Nov 2005 AHLTA Announcement)

- 1. Largest electronic health record system in the nation
- 2. Cost \$1.2 billion for acquisition and development
- 3. Designed to serve 9.2 million service members, retirees, and their families worldwide
- 4. Provides 24/7 instant access to medical information
- 5. Protects records from loss due to natural and man-made disasters
- 6. Enables medical surveillance protecting beneficiaries from disease outbreaks
- 7. Provides continuity of care from battlefield to home station for military members
- 8. Provides a single, complete, legible, life-long, portable health record for beneficiaries

Although organizations like the DoD, VA, and larger civilian entities such as Kaiser Permanente possess the financial freedom to purchase EMR systems, they have not yet conquered the problems associated with long-term access. Many organizations appear to be focusing more on system acquisition and implementation. However, if any organization has a great headstart at tackling the storage and retrieval process of patient medical records, it would be the VA (Philpott, 2004).

The VA's system of record keeping, although extensive, has consistently met its intended purpose for handling various types of records including medical records (Harrison & Palacio, 2006). The VA owns a massive Records Center and Vault (VA RC&V) which provides record management and storage within a climate controlled facility that is staffed by archive technicians ("VA Records Center," 2002). According to a 2005 VA Index of Records, these records are stored electronically, in paper folders, on magnetic discs, magnetic tape, and are retrieved using the member's social security number or name at the Health Administrative Center in Denver, Colorado. Archive



technicians work constantly to ensure records are accurate and accessible to patients and healthcare providers nationwide.

Much like hospitals throughout metropolitan areas, the VA is widely dispersed and needs the ability to transfer medical information across the nation. According to R. James Nicholson, former VA secretary, the VA provides care for its members and their families across 1400 locations (Brewin, 2003). Electronic records make it easier to transport information contained within medical records among these different sites. To fully appreciate the VA's level of accomplishment regarding record handling, an understanding of what comprises the medical record is needed.

#### **Exactly What is a Medical Record Anyway?**

Patients' medical histories are documented within their medical records, also referred to as charts. The term "medical record" refers to the folder or chart containing sensitive health documents as well as the collective body of information contained within the folder (Tang, 2006). A typical record might contain removable media such as compact discs and x-ray film, in addition to several sheets of paper containing both computer generated and handwritten notes. Medical records, or any record for that matter, can exist as paper, digital, or a combination of the two known as hybrid (Hobbs, 2005). The type of information contained within a medical record is dependent on the format in which it is created and/or stored.

With paper records, the majority of a patient's medical information is relatively aggregated in one area such as a locked filing system. This information or file type,



which includes such media as radiological outputs (i.e. x-rays, pictures) or paper notes is referred to as a "physical" record because it can be touched (Peterson, 2006). It should be noted that the majority of U.S. healthcare transactions still take place on paper (Scott, 2007). Paper records also consist of a heterogeneous mix of varying, handwritten clinical notes. These records are managed with extensive file-keeping practices that involve human-to-human interaction since the record only exists in one location. With the adoption of EMRs, this is not the case given that records can now exist on multiple systems in a digital form.

An EMR represents a single, physical entity such as a folder containing sheets of paper as a functional view composed from data stored in various data bases (Goldschmidt, 2005). Quite literally, a patient's medical information can now be dispersed across multiple locations through the use of medical networks linked with electronic health record systems. The information contained within an EMR includes the same information found on physical media; it is simply "born digital" or "reborn digital." The major difference between paper and electronic records, aside from the obvious, is the manner in which each is created, stored, and used. Efforts to replace the paper system, a system that has been used throughout healthcare since the 1950s, with a system comprised of digital records has given rise to a new type of record referred to as a hybrid record by preservation experts ("American Health," 2003).

The transition from paper to paperless records allowed organizations to begin combining the two methodologies. A digital compromise was formed when organizations began using hybrid records. Hybrid records are best defined as paper



records that are generated on a computer, then printed and completed manually (Feldhousen, 1989). These records would then be included back into the patient's medical history by either placing the paper media itself in a folder or by either scanning it or recreating it digitally for electronic inclusion. The methodology used depends on whether or not the facility operates with paper or electronic records. This variation in record types is also a large determinant as to which techniques are used to store patient health histories.

#### Storing Electronic Medical Records.

Regardless of the format, patients' medical information must accompany them to each healthcare facility where treatment is delivered. The professional standard is for the record to remain stored and secured in the last facility providing care (Conn, 2008). If the patient visits a facility other than their primary care location and their record is paper, patients can either hand-carry them to the medical facility or the physician can request to have the records delivered prior to the patient's visit. This process requires some level of communication to ensure the records arrive at the correct location when needed.

However, if the record is digital, the healthcare facility only needs to possess the proper hardware, software, and trained personnel to access and manipulate the patient data. Although the healthcare facility providing the care owns the physical record regardless of format, the patient owns the information within the record since it contains their health history (Conn, 2008). This understanding is important since information within a person's medical record is used for various reasons and is often shared among



different organizations. Figure 1 shows the typical flow of medical information in the U.S. medical system.

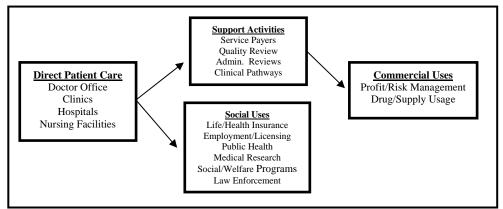


Figure 1. Flow of healthcare information in U.S. system (Rindfleisch, 1997)

Records are stored according to their format at designated areas chosen by the healthcare facility. Whether requesting information on oneself under the Privacy Act of 1974, or requesting information about another individual [relative] under the Freedom of Information Act (FOIA), the system needs to ensure availability to either paper or digital records for disclosure contingent on proper access and authorization. Even though the process performs well using today's technology, the plan to provide the continued access to that very information once the current technology is replaced is unknown.

## Military Medical Records Storage.

In the U.S. military healthcare system, service members' records are stored at the facility [DoD clinic] where care is administered. If a member should leave the military, the record is transferred to a civilian caregiver or the member's record is transferred to the VA for storage or the national center in St. Louis ("VA Enterprise Centers," 2005). Prior to the installation of AHLTA, a disconnect existed between the



DoD and the VA because the two systems used by either were not compatible; transferring that information was a manual process. Now, the two entities have the ability to share information in a near seamless manner electronically versus completely paper (Melvin, 2007). This process is not unlike that used in civilian healthcare. Both paper and electronic records need robust management practices so that organizations can achieve cost-effective and time saving solutions to eliminating its paper processes while maintaining access to the digital information throughout its retention period.

## Medical Record Retention.

The purpose of a record retention program is to make sure the records are available for a specified period of time and to eliminate the accumulation of unnecessary records that are no longer needed (Rothenberg, 1999). For this particular research, longterm is considered long enough to be concerned with the impacts of changing technologies, including support for new media and data formats, or with a changing medical community (Ruotsalainen & Manning, 2007). Maintaining outdated records can prove to be expensive even though they are digital. For instance, to retain electrical engineering records in the U.S., it costs five to seven dollars per megabyte and \$1250 to re-create the same data ("British", 2005). Federal laws state how long certain records must be maintained, but the record retention burden is governed by the state and facility where the record is stored, regardless of format (Calloway, 2005).

According to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Privacy Act Law, patients have the right to their information. The maintaining facility is also responsible for ensuring the proper hardware, software, and



technological needs are available to access that information. In the United Kingdom

(UK), medical records are retained based on the record type (Huston, 2006). Table 2 lists the most common types of medical records and their management schedules in the UK medical system.

Although there is no blanket standard outlining how long a medical record should be maintained in the U.S., HIPAA mandates that a patient's records be retained for at least two years after death (Calloway, 2005).

Table 2. Record type and retention criteria (adapted from NHS health standards)				
Record Type	Retention Length			
General Practice Records	Until 10 years after Patient's Death or patient permanently leaves the country			
General Practice Records (Children)	Until patient's 25 <sup>th</sup> birthday or 10 years after death			
Dental Records	11 yrs for adults, 11 yrs for children (or until patient is 25, whichever is longer)			
Opthamalic (eye) Records	8 years after death			
Immunization and Vaccination Records	For children retain until patients 25 <sup>th</sup> birthday For adults, 10 years after last treatment			
Maternity Records	25 years after last birth			
Mental Health Records	20 years after date of last contact between patient and health care provider, or 8 years after death			
Wiemai meanin Kecorus	ucalli			

Any additional storage is conditional based on secondary uses such as lawsuits or medical research (Calloway, 2005). Again, the area of concern is not how long to retain the records. Instead, the concern lies in providing long-term access to the digital records of living patients whose records' lifecycles outlives the functional use of technology. To accommodate the ensuing changes, lessons learned through extensive electronic record preservation strategies must be incorporated into the medical field.



#### **Electronic Records Management Principles**

Each generation of new technology brings with it newer ways to create and use information (Hobbs, 2005). Technology has simultaneously solved the problems associated with producing, storing, and maintaining massive amounts of paper while introducing an added dilemma of long-term access to the new digital information. The amount of information organizations are creating and storing digitally is more than ever imagined (Jones & Beagrie, 2005; Kelley, 2001). Much like the problems encountered finding ample space for storing immense loads of paper records, storing electronic data is figuratively a growing problem because storage space is considerably cheaper today than it was years ago. Therefore, organizations are storing more and more information electronically. The Paperwork Reduction Act sought to eliminate the amount of paper organizations used and attempted to harness the power of computer technology (Bass & Rubinstein, 1990). Across the globe, record departments that once maintained hordes of paper records have been replaced with server farms and data warehouses (Fletcher, 2002).

Managing electronic records is an undertaking that requires strict guidelines. Without these guidelines or established standards, the process would assuredly fail regardless of preservation strategy. When records are stored digitally they become easier to alter and are at greater risk of content changes, which ultimately affects their authenticity and reliability (King, 2005). Better electronic record management is needed to protect both paper and digital documents. Stored as paper and with the proper care, records could last for several decades (Rothenberg, 1999). This time-tested availability,



barring threats to paper media, is one of the barriers slowing organizations' transition to paperless operations. Digital records have indeed decreased the amount of paper organizations have to store long-term. However, the fact remains that digital records simply have shorter life-spans than do their paper predecessors.

#### Electronic Records Life-cycle.

Unlike paper, electronic information requires both hardware and software in order to read it (Heminger & Robertson, 1998; Rothenberg, 2000). The U.S. Government has produced guidelines such as the Federal Records Act (FRA) 1950 or the Paperwork Reduction Act that regulates the lifecycle of documents deemed worthy of storage (Hobbs, 2005). Even though organizations like the VA own extensive electronic records programs, they continue to store large amounts of paper products. "All records maintained are done so in accordance with records depositions authority approved by the archivists of the United States (2005), NARA" ("VA Index of Records," 2005). Figure 2 highlights the typical lifecycle of a document from creation until its destruction. If deemed necessary, the record is archived. Digital records require different retention and maintenance versus paper records. Active paper records are often maintained by the last facility providing healthcare. Any paper records that are scanned or digitized for viewing electronically are destroyed afterwards ("VA Index of Records," 2005).



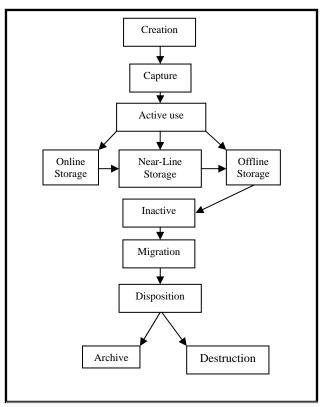


Figure 2. Information Life Cycle (adapted from "Electronic Records Brief", 2005)

#### Clinical Document Lifecycle Model

A team of researchers at the University of Washington developed a model that tracks the lifecycle of clinical documents. Of the growing body of knowledge involving digital document preservation, only a small portion actually pertains specifically to medical documents. Figure 3 shows the model. The model consists of three axes: stage, role, and action, and is designed to describe the lifecycle for clinical documents (Payne & Graham, 2006).



DOCUMENT STAGE	Cognitive	→ Collection →	Draft —	→ Preliminary	→ Final	→Use
ROLE						
Author	•	•	•	•	•	•
Other contributor		•	•	•	•	•
Resident						•
Attending					•	•
Other clinician					•	•
Referring provider						•
Medical information professional						•
Consultant						•
Primary care provider						•
ACTION		•	•			
Туре		•	•			
Copy existing text			•			
Dictate			•			
Edit			-	•		
View			•	•	•	•
Authenticate					•	•
Cosign					•	
Forward					•	
Send to Inbox				•	•	•
Print				•	•	•
Mail				•	•	•
Addend				-		•

Figure 3. Model of the life cycle of a clinical document (Payne & Graham, 2006)

Understanding the lifecycle of a document, or a record in the case of this research, is critical to its preservation because digital preservation is done within the context of a lifecycle (Hedstrom, 2003). By knowing how long a record should legally be kept, regardless of format, the correct preservation strategy can be applied. Although various schools of thoughts exist offering solutions to counter technology obsolescence, no definitive method has yet been identified. For instance, this particular model itself offers no strategy to ensure clinical documents are available in the long-term. However, it does suggest a manner in which to track a clinical document which is ultimately vital to that document's preservation.

### Digital Preservation Techniques.

One fact remains certain; the solution to preserving electronic medical records will involve technology. Ten years ago, digital preservation was considered a new field



(Smith, 1998). Today, a proven technique still does not exist to counter the problems associated with maintaining digital records beyond the lifecycle of their original hardware. However, research indicates that archival experts are intimately aware of the dangers we face if much of our digital information is lost (Rothenberg, 2002). Table 3 lists and defines common methods currently used to preserve digital documents.

Table 3. Common digital preservation strategies				
Methodology	Description			
Migration	Moving data from an older system to a newer system			
Refreshing	Updating software/hardware versions from a previous one			
Software Emulation	Software that mimics older software			
Technology Warehousing	Preserving legacy system to operate their specific medium			

Although each technique has its advantages and disadvantages, migration is often the most utilized and preferred option among some preservation experts (King, 2005). On the contrary, other experts would disagree with the idea of using migration as the standard for digital preservation.

For instance, when migrating information from system to system, some of the data becomes stranded (Rothenberg, 2000). During the process, pieces of data would not successfully migrate as a complete file and would therefore be left behind due to issues with software and/or hardware incompatibility associated with migration. This situation might be acceptable in some technical contexts or record-keeping practices outside of healthcare; however, in the case of a medical record, the stranded data is necessary to ensure record authenticity and accuracy, and its absence could be vital to a patient's



health. Because of such implications, it is necessary to create a strategy that focuses more on the complicated details of handling medical information (Hedstrom, 1993). A number of the aforementioned strategies are currently utilized within the medical profession; still, some medical personnel have begun researching preservation techniques that consider the complexities associated with medical records.

#### **Strategies for Long-Term to Access Medical Documents.**

With the digitization of paper records, it is normal practice for the older information that is recreated or transferred to a newer system or medium to be destroyed once the process is complete (Rothenberg, 1999). As more healthcare facilities convert paper medical records into electronic records, the older paper records are then destroyed according to HIPAA regulations. Creating paper backups to electronic records refutes efforts to limit the need to store massive amounts of paper. Therefore, once a medical record exists in an electronic form, that document must remain accessible to both patients and medical professionals. The following are some of the present strategies and models offered to digital document archiving, preservation, and long-term access to ERMs.

#### Standardization as a Strategy.

The rate at which technology evolves today makes it difficult to tackle technological obsolescence (Hedstrom, 1997). Some archival and preservation experts believe that the answer to long-term access lies in standardizing the format of information to ensure functionality across platforms. Others suggest that a solution lies in making the information system-independent (Rothenberg, 1999). This strategy would require all



healthcare facilities to create medical information using a standard software suite much like Microsoft makes its software system-independent. A [standard] solution would limit the number of EMR systems that presently operate as stand-alone systems which hinders the necessary cross flow of medical information among hospitals and clinics. To combat the problem of inoperable EMR solutions, standards like the Health Level 7 (HL7) Clinical Document Architecture (CDA), Digital Imaging and Communications in Medicine (DICOM), and Integrating the Healthcare Enterprise (IHE) have been developed (Toyoda, 1998).

Like most standards, their purpose is to structure and markup the clinical content for sharing amongst medical facilities and secondary users (i.e., insurance agencies) (Eichelberg, 2005). The International Organization for Standardization (ISO) Technical Committee on Health Informatics describes its scope as "standardization" in the field of information for health, and Health Information and Communication Technology (ICT) to achieve compatibility and interoperability between independent systems (Eichelberg, 2005). Standardization is a viable solution to interoperability; however, achieving buy-in from all healthcare facilities is an enormous undertaking. Nevertheless, standardized systems have been proven to facilitate electronic document preservation as demonstrated by the ISO model.

*Open Archival Information System.* The ISO's reference model Open Archival Information System (OAIS) was designed "to standardize digital preservation and to provide a set of recommendations for preserving program implementation" ("Consultative," 2002 ). The model itself, Figure 4, proffers the relevant actions



organizations must take to preserve digital documents and provides the applicable bases and frameworks to do so.

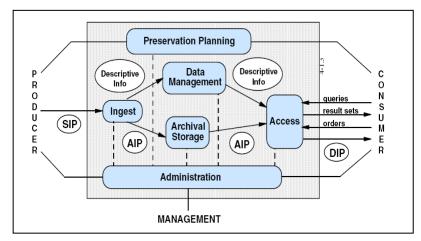


Figure 4 . OAIS model (adapted from CCSDS Blue Book, 2002)

Organizations would still need to possess intimate knowledge of the information to be retained and determine which methods, such as migration or emulation would work best based on administrative and consumer input.

# Digital Rosetta Stone Model.

Metaknowledge and metadata are defined as "knowing what we know" respective to each (Kelley, 2001; Robertson, 1996). It can be viewed as leaving behind the building instructions so that those who come along in the future will "know" how to obtain the information through document reconstruction. The Digital Rosetta Stone model, developed by Heminger & Kelley (2005) does essentially that. This model, Figure 5, outlines a similar method that explains how to access the current information with future technology by preserving the bit streams of information and the accompanying metadata (Kelley, 2001; Robertson, 1996).



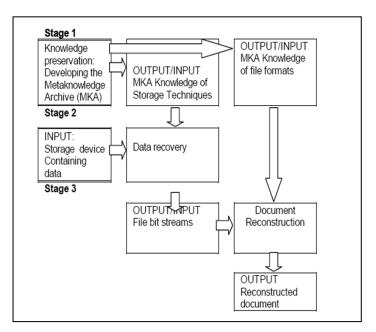


Figure 5. DRS model (Heminger & Kelley, 2005)

The notional model, which could prove useful at reaching back in time to read documents far older than current technology, provided the medical information's data (i.e., bit streams) are preserved, might not be as applicable to medical records considering the life-span or the retention policies governing medical records.

Long-term access to medical records involves more than archiving health information in a data warehouse; it entails data preservation since information that is archived needs to be accessed in the future. "When patient data is recorded electronically, it has to be preserved over long periods in a local database or an external archive" (Ruotsalainen & Manning, 2007). Federal and state laws mandate the exact timelines required to retain health-related information. For this reason, some medical professionals are proposing a system where patients maintain their own health-records.



#### Providing preservation using patient participation.

According to some experts in digital document archiving as well as the medical profession, one way to ensure patients have access to their health information in the long-term is to place the onus of responsibility on the patient (Hansen, 2007; Liu, 2001). Although the patient owns the information contained within a medical record, the healthcare facility providing the care is responsible for the actual record. Justifiably so, physicians and health insurance companies are opposed to this method since they bear a burden of responsibility for a patient's PHI.

On the other hand, software vendors are elated at the opportunity to offer private citizens their version of software that will enable the average citizen to maintain their health information on personal computers or online in record portfolios. Microsoft Corp, noted software giant, has approached the DoD with plans to manage its healthcare; furthermore, the company has developed and tested software that allows people to manage their own medical histories (Lafferty, 2007). If individuals are wary of physically storing their health data at their homes, vendors are using the Internet to provide the same services over the web (Gates, 2007). This, in and of itself, is a rather divisive issue. What a person does with his/her own PHI or EMR is their right. However, the concern lies in long-term access to medical information that is presumed accurate.

It has been shown that a lack of technology and software standardization has created medical "stovepipes." Based on the sheer size of some medical files (i.e. x-rays), how will private citizens be able to store their health information on personal computers?



The overarching concern among medical professionals involves more than record security or availability; the concern lies in authentication and accuracy of the medical record once it is placed in the patient's charge to maintain (Simons, 2005). Physicians face the threat of malpractice lawsuits each time they provide care to a patient. To ensure continuity of care, a physician relies on the accuracy of the information contained within a medical record...electronic or paper.

As noted, some of the aforementioned preservation strategies provide seemingly viable solutions. Considering the importance of the information captured within a medical record and the increasing life-spans of humankind, this topic needs to be addressed so that we do not lose access to critical, medical information. "Currently, there are no internationally accepted digital preservation formats, standards, or strategies to preserve health related data for protracted periods, and broad awareness of this critical issue remains poor" (Scott, 2007). This topic needs to be addressed with a sense of urgency before the loss of electronic medical records become more common.

#### **Chapter Summary**

Information technology is a great enabler and valued resource. Though adoption rates were slower than in most organizations, the medical community has become one of the nation's top users of IT by overcoming barriers such as cost, implementation, and acceptance. Through the use of EMR systems, patients are afforded better care because medical institutions can now share information easier, cheaper, and faster. These systems



link medical information once captured on paper through an intricate network of systems in the form of a digital/electronic medical record.

With care, paper records will be available for several years and only require literacy or understanding of the medical language to interpret. However, it is far more costly, monetarily and time-wise, to operate using paper records. These costs are one of the main reasons why healthcare is transitioning to electronic records; the information is more legible, usable, and flexible in digital form. However, the richness of the record is not the concern; the concern lies in guaranteeing long-term access to digital information as technology that is used to create, transport, retrieve, and store that information continually evolves.



## **III.** Methodology

## Introduction

As previously mentioned, varying ideas exist regarding the best methodology for digital document preservation. This chapter will discuss the materials and procedures used to approach the overall research question of long-term access to electronic medical records.

### Design

This study used the Delphi research method to solicit answers from subject matter experts (SME) to questions created specifically to investigate the overall research question regarding long-term access of electronic medical records. Born from an Air Force-sponsored Rand Corporation initiative referred to as the "Delphi Exercise," the Delphi technique has become a widely recognized and accepted research method in academic circles (Linstone & Turoff, 1975). Although expert opinion is sought, this method does not seek to codify the participating experts' tacit knowledge of a given subject; rather, its intent is to provide the selected experts a forum to independently and anonymously answer questions on a particular topic to forecast trends sans the countering effects of group or social influence and pressures found in similar forums such as committees or focus groups (Robins & Judge, 2005).

This technique was chosen due to its ability to forecast a solution to a speculative research question or questions using a group structure of separated, yet homogenous



experts. The method is iterative in nature in that it requires multiple rounds of questioning which involves moderated reflection on accumulated responses submitted by the experts. Typically, the first round of questioning in a Delphi affords the participants the opportunity to express their initial concerns on the topic (Dalkey, 1969). Subsequent rounds require a more in-depth assessment based on experience in the particular area of interest. For this research, two rounds of questioning were completed. After the first round, responses were aggregated and resubmitted for additional discussion and comments.

#### Materials

#### **Questions**.

Initially, eight questions were generated for this study. They were as follows:

Q1. What methods of digital information storage (migration, technology refreshing, technology museums) are more practical to provide long-term access?

Q2. Are electronic medical records more or less secure than paper records?

Q3. What risks to privacy do patients face with electronic records?

Q4. What are the current threats to a patient's privacy using electronic medical record systems?

Q5. Would a private, outsourced IT company offer more secure solutions?

Q6. How is access by individuals outside the medical institution controlled?

Q7. How will information retention policies be affected by transitioning from paper to electronic records?

Q8. Should companies like Microsoft create software solutions that grant private citizens complete access to their medical history?



After careful analysis by the primary and secondary investigators, it was determined that questions #2, #3, #4, and #5 did not keep with the focus of the study. Each question was subsequently deleted. Questions #6 and #8 were also removed; although these two questions specifically targeted access, the intended focus of long-term access was not clearly stated. Questions #1 and #7 were combined and reworded to ensure they captured the intended scope of the study. The result was the overarching research question and a supplemental question. No other questions were necessary for the initial round.

# **RQ:** "What should be done to ensure that hospitals and/or patients do not lose access to electronic medical records as technology continually evolves?"

SQ: "Do you foresee long-term access to digitally stored health records to be a problem as newer EMR technologies are adopted? Briefly explain why or why or not?"

#### Participants.

One of the strengths of a Delphi study lies in its panel of "experts" (Linstone & Turoff, 1975). Individuals selected to participate in Delphi studies are chosen based on the research topic and purpose. For this particular study, a portion of the participants were selected based on their credentials highlighted during the literature review portion of this thesis. Other experts were drawn from a convenience sample of personnel who manage network systems with EMR subsystems at various hospitals in the Dayton, Ohio, and surrounding areas to include Wright-Patterson AFB (WPAFB), Wright State University's Boonshoft School of Medicine, and the Ohio State University School of Medicine.



Due to the nature of the questions developed for the Delphi, it was determined that these individuals needed to possess more than a technical understanding of the technology and procedures in question; they also needed intimate knowledge of the electronic records archival process and the administration of medical information systems and medical records. Each participant was interviewed either in person or via phone call to ensure they were qualified to serve as a panel member. The high selectivity of participants was used to interest the qualified versus qualifying the interested.

Initially, 12 experts agreed to participate in this study which is more than the ideal number of seven as suggested by Linstone (1978). However, this "surplus" in participants was desired given that some member attrition was expected to occur. One individual, upon receipt of the materials, felt they could not contribute meaningful information to the study and elected to withdraw. Two experts were eliminated because they admitted that they would not be able to answer the questions until a much later date.

Three experts with extensive knowledge of the military system were unable to participate. One member was chosen for a short-notice deployment after agreeing to participate; another became involved in military inspections and could not guarantee timely or meaningful information in the given circumstances. The remaining military member agreed to participate but wanted his contractor to answer the question; the contractor then refused to participate due to potential contract violations. Ultimately, six experts participated in round one questioning. During the discussion and analysis portion of this thesis, each expert will be referred to as Expert A, B, C, D, E, or F for identity purposes.



# Procedures

#### **Question Delivery.**

Another advantage of using a Delphi study is that it eliminates the need for the researcher(s) or the participants to be physically present in the same location when responding (Linstone & Turoff, 1975). As such, the questions for this study were sent to each participant via e-mail. To ensure each participant received their questions, each participant was contacted using the address given during previous conversations to ensure that firewall policies would not prevent electronic communications. Once e-mail confirmation for each participant was received, round one commenced.

### Round One.

For the first round, a research synopsis document (Appendix B) containing the study's background, purpose, participant expectations, and research questions was sent to each participant. Because each expert was aware of the subject and nature of the research, the provided synopsis only gave a brief background that served as a reminder and restated the study's main question and supplemental question. The respondents were also briefed on informed consent and their right to withdraw from the study at any time. A copy of all materials sent in round one is included in the appendices.

During this initial round, the e-mail with attachments (Appendix A) was sent to the panel of experts. To ensure anonymity, each participant received a personally addressed e-mail; blind courtesy copies were not used. The participants were asked to return their responses within 1 week although it was expected to take 2 weeks to receive responses in anticipation of scheduling difficulties and late replies.



#### **Response Time and Receipt.**

All six experts responded in round one. All but one response was received within the 2-week expected response window; an additional response was returned 2 days later. Once received, the replies were aggregated into one document capturing each respondent's answer to the questions. The responses were analyzed for trends in levels of agreement. The aggregated areas of agreement and disagreement from round one were grouped by similar statements and sent back to the participants for their assessment. For example, four people indicated concerns about instituting standards. The participants did not see the entire list of responses from each expert; only the major themes of each response were captured and combined as "Round One report" (Appendix D). The experts were asked to review the statements and provide comments on which suggestion(s) they felt would best ensure long-term access to EMRs as technology evolves. They were also encouraged to add any additional comments they deemed appropriate for discussion. The report was then resubmitted to the participants via e-mail for round two.

#### Round Two.

Only three experts submitted responses for round two. Repeated attempts via email and telephone were made to see if changes to firewall rules impeded receipt of materials. No other responses were received. Of the three responses received, one expert reported that they "had no new comments to make." Based on moderate levels of agreement, convergence, and/or clear patterns of bimodal responses received in the first and second round, as well as the drop in responses, a decision was made not to continue



for a third round of questioning. The next chapter will discuss the results of each round of participation in this study.



# **IV. Results and Analysis**

# Introduction

This chapter will discuss the comments received during two rounds of a Delphi study. Each question will be listed and the responses from each anonymous expert will be supplied. An analysis of those responses will follow. A discussion of the responses can be found in the following chapter.

# **Round One, Question One Responses**

The first question is discussed below and comments are as follows:

# **RQ:** "What should be done to ensure that hospitals and/or patients do not lose access to electronic medical records as technology continually evolves?"

Many of the experts felt that long-term access would not be lost so long as the records were properly archived or backed up using many of the common techniques in practice today (i.e. refreshing). It was also suggested to use digital preservation techniques such and migration or emulation hardware/software to prevent loss. A number of the experts commented that adopting a standardized system or incorporating a standard EMR format would prevent loss to medical information. The following comments highlight the main points expressed by the experts deemed to be critical to ensure long-term access to EMR:

- Adopt a standardized system to facilitate module integration and avoid implementation cost overruns
- Perseveration will require redundancy: daily back-ups, monthly archiving, annual renewing of archives with state of the art storage and retrieval



- Use migration software/hardware to make existing records forward compatible
- Follow federal, local, state laws for record retention much like paper records so organizations are obligated to provide backups and storage
- EMR formats and standards such as HL7 must be adopted
- Encoding data must be tracked and recorded over time to enable future readers of old EMR to correctly map original meanings into future encodings and terminology
- EMR/EHR data must be copied to new storage media, with strict version control, redundancy, & archival processes

A detailed version of each participant's response to this question is located in the

appendices as Appendix C. Table 4 contains a consolidated view of participant

responses. Each column label represents a topic mentioned by an expert.

Table 4. Round 1 Question #1 Aggregation of responses by topic							
	Standards	Back-ups	Redundancy	Archiving	Patient	Migration	Emulation
	or Formats		(off-site)		Maintains		
Expert A	Х		Х				
Expert B		Х	Х	Х			
Expert C	Х	Х	Х	Х			
Expert D		Х			Х		
Expert E	Х			Х		Х	Х
Expert F	Х					Х	

All of the respondents appeared to understand the questions considering each provided rich material in-line with the questions. Expert A spoke at length of problems associated with implementing medical technology based on his years of experience and recommended using an industry standard and time-proven, successful system such as the



VA. As mentioned in the literature review, the VA is considered to possess one of the nation's top EMR systems.

Expert E had extensive experience in digital document archiving and commented that, "Accepted archival recordkeeping techniques should be applied to ensure the stewardship of EMR." This comment captures the essence of responses for the first round of this research. That is, electronic records management principles used to retain various, non-medical documents might overlap or apply to electronic medical records even though these digital documents contain protected health information.

The results for question one, round one are that the experts shared similarities on multiple topics. Each expert was in agreement with one or more experts when the topic involved standards, back-ups, redundancy, archiving, or migration. Each member touched on these topics either directly or implicitly. However, only two experts (D & E) offered areas different from any of the others. Expert D recommended that patients should become their own record custodians by maintaining them in a fashion similar to online finances. Expert E reported that emulation software should be employed and might prove a better method than other proffered solutions such as migration or refreshing. It should be noted that four of the six respondents agreed that standards or a standardized format for EMR and EMR systems is needed. The fact that half of the respondents agreed that back-ups, archiving, or redundancy would be needed is consistent with the present literature.



# **Round One, Question Two**

The next question proposed to the experts was:

# SQ: "Do you foresee long-term access to digitally stored health records to be a problem as newer EMR technologies are adopted? Briefly explain why or why or not?"

Results from this first round show that the majority of the group reported affirmatively

that long-term access would be a problem as new technologies are adopted. Table 5

contains the summary of responses.

Table 5. Round 1 Question #2 Aggregation of responses by expert					
	Yes	No	Explanation		
Expert A	X		"Unless there is a standardized system for database design and for implementation of EMR without re-inventing the wheel."		
Expert B	X		"Access will be feasible, provided that a careful strategic plan is employed with appropriated emphasis on long-term accessibility."		
Expert C	X		"Across the civilian continuum, this will be problematic due to lack of standardization."		
Expert D	X		"It is an additional expense to import older data into newer systems, and to ensure archiving, backup, and retention occurs."		
Expert E	X		"Short lifespan of technology, deterioration/destruction of paper records, storage problems, conversion, migration, emulation woes."		
Expert F	Х	Х	"Active records will be accessed. However, inactive will prove problematic due to costs associated with migration."		

As noted in the table, the entire panel agreed that long-term access would be a problem; however, one member also answered negatively that it would not be a problem so long as the records are active. Additionally, many of the experts commented that costs would also be a hindrance in long-term access. Although storage media have decreased in cost, the total cost of ownership for maintaining the systems appeared to be a concern. It was offered that technology will not be the main problem; instead, organizational issues and the records' status (inactive/active) would be a problem for long-term access. The results for question one, round one highlighting both standards (66 percent of panel) and the



need for migration, back-ups, archiving, and redundancy (50 percent of panel) show moderate group consensus that this problem might persist unless these measures are taken into consideration.

# **Round Two, Responses for Consolidated Question One Responses**

Consolidated responses from round one were redistributed to each of the experts.

This time, instead of answering a set list of questions, they were asked to provide

comments to the responses of other experts as denoted in the round one report (Appendix

C). Additionally, they were asked to provide any other comments they deemed

appropriate for the discussion. Of the six experts, only two provided any new or

additional comments as depicted in Table 6.

Table 6.	-	uestion #1 Aggregation of comments Comment
	Responded	
Expert A	No	N/A
Expert B	Yes	Looks like there are some common themes here: standardization, redundancy, and maintaining a state of preparedness for future technologies.
		One caveat to keep in mind- the vast majority of information in today's chart will be clinically irrelevant within two years. There may be legal and historical reasons to maintain the data, but there will likely be significant cost savings if we avoid implementing costly solutions for immediate access to old data.
Expert C	Yes	"I have no new comments to make."
Expert D	No	N/A
Expert E	Yes	Migration is not a proven technique and is unlikely to be sufficient. To prevent loss, copies of original records should be stored in their original formats along with copies of whatever application software was originally used to access these records and any operating system software needed to run that application software. Hardware emulation can then be used to run the original software for old records indefinitely, thereby keeping them accessible.
Expert F	No	N/A



Expert B noted that round one produced common themes. Additionally, the expert commented on the relevancy of information that should be considered for long-term access since archiving irrelevant information is both costly and unproductive; this comment was not offered previously by any other expert. Expert E mentioned migration as being a possible solution to long-term access; this technique was mentioned in the literature review and by other members of this study's panel. However, emulation was offered as a better solution. No other comments were received.

# **Round Two, Responses for Consolidated Question Two Comments**

Table 7 contains the comments received for question two. Although only two members responded during this round, they each provided meaningful information.

Table 7. Round 2, Question #2 Aggregation of comments						
	Comments					
Expert B	I still don't agree with the consensus view that long-term access will be a major problem. Establish the standard architecture for data today (CCR/CCD), and require that future systems have the capacity to maintain access to the standard as a necessary condition for certification.					
Expert E	The above statement "Accurately recreating old software behavior is difficult (emulation)" is unsubstantiated and, I would argue, incorrect. Although it is true that using software to emulate obsolete software is indeed difficult, using software to emulate obsolete hardware (on which obsolete software can then be run) is not especially difficult and has proven very successful. Examples of the use of such emulation for what amount to preservation purposes abound throughout the history of computer science, including IBM's provision of 1401 and 7094 emulators for the System 360, Apple's provision of a Motorola 68000 emulator for its PowerPC computers, and Apple's more recent provision of a PowerPC emulator for its Intel computers.					

Expert B asserts that long-term access will not be a problem; furthermore, a solution based on standardization is offered as to why long-term access will not be a problem. Indeed, responses from round one, question one, indicated that four of the six experts



cited standards, and standardized systems as a solution to long-term access to EMRs. Expert E reiterated previous concerns at making emulation a viable solution.

Unfortunately, with only two sets of responses there was less chance of identifying issues

or opinions that were common between experts at the conclusion of the second round.



## V. Discussions

As healthcare facilities continue to implement more and more IT and as this technology evolves through multiple generations of systems, long-term access to EMRs will become problematic. Yet, the research undertaken for this thesis suggests that those responsible for developing and maintaining these systems are not adequately preparing for this problem. From both the literature review and the expert opinions captured in this study, there is some recognition that long-term access is important; yet, there is very little research available that suggests what should be done. This indicates that the medical community is not looking far enough ahead to a point where all current technology has changed so much, that the older data or information cannot be accessed by the new systems.

Among those organizations that currently own and operate EMR systems, the VA has been considered one that has achieved some measure of success with medical records and has managed to keep patients records available. However, the VA's *Cadillac* system does not take all EMR systems into the next generations. The reality is that very few organizations are addressing long-term access based on new generations of technology, including the VA; in 50 years, someone at the VA might discover the need to access a patient's record created and stored using past technology. Present solutions are nil.

Government organizations like NARA or private sector agencies are very concerned about long-term access and are presently researching what will happen once current media is replaced by newer, solid state media. In the medical community, there



does not appear to be the same level of concern over maintaining long-term access to EMRs as found in these organizations. Granted, agencies like NARA use archivists who ensure that records are retained based on guidance that takes into account a digital document's lifecycle and relevance. Both the literature and this study's experts suggested that a retention schedule might be necessary to establish long-term access.

The point of establishing a record retention system is valid since it can clarify how long certain records need to be available. Such a schedule might facilitate the moving of information from older systems to newer ones. However, it does not explain specifically how to address the fact that technologies will become obsolete. In other words, a retention schedule simply does not outline a method to tackling the problem of technology obsolescence.

Proprietary systems purchased now will undoubtedly require a change at a later date. The amount, if any, of information that will be available for access in the future that is created and stored by these systems today is unknown. The suggestions offered by the group of experts did not reveal a viable solution; instead, they advocated the use of methods and techniques in place for access today which most likely will not offer healthcare facilities or patients long-term access to critical information in the out-years.

The solution, if one truly does exist, will not be solely technological. Long-term access to electronic medical records will require some level of collaboration and compromise between policy makers and those hired to oversee healthcare IT. More than half of the experts agreed that a standardized system or the inclusion of standards and formats would help assuage the problems of long-term access. One expert specifically



suggested adopting a system similar to the DoD. This suggestion deals less with the DoD's technological solution and more with the policies governing the use of the technology.

## Conclusions

When specifically asked to address long-term access for electronic medical records, the majority of suggestions received were centered on near-term techniques such as migration, archiving, back-ups, and redundancy. While back-ups and archives have proven successful in cases involving system failures or disasters, they might prove useless as a method for long-term access to medical records considering they will require the availability of the system(s) used to create them.

The unnerving reality, at least based on the inputs received from this research, is that presently, there is little being done to offset the ominous task of accessing electronic medical records across generations of IT. Long-term access to electronic medical records should be at the forefront of medical informaticians and hospital administrators' minds. Instead, it appears that most are still focusing on the problems associated with obtaining an EMR system and not on long-term availability of the information once a system is implemented. Unfortunately, this is a situation that requires a certain level of proactive foresight instead of reactive hindsight.

Perhaps the idea and implementation of EMR systems are so new, that organizations have not had sufficient time to be burdened by this dilemma which will only manifest itself some time in the not-too-distant future. Now is the time to address



this issue and to make plans for moving forward as newer technology comes online. Although the experts shared interesting ideas, most of what they shared is only relevant using today's technology. The real issue lies in what will happen two or three generations beyond this one when either the technology or the record format is not available or understood.

## **Research Limitations**

One limitation identified in this thesis is the Delphi methodology used to conduct the research. Unlike a survey which is used to generalize results to a particular population at large, a Delphi is used to establish theoretical relevance for the selected experts based on some subject. This method was ideal for this study because very little is known about the topic of providing long-term access to EMRs. Unfortunately, by nature of its design, a Delphi is only as good as the experts selected to participate since there is no way to guarantee that this study chose the correct experts. Thus, this study was limited in the fact it employed a few, selected individuals whose expertise was presumed to be representative of the subject for research.

Additionally, this research was theoretically limited in the fact it did not include any members from the US military healthcare system. It was mentioned in the literature review that the DoD owned and operated one of the nation's largest EMR systems. This study might have been enhanced had experts associated with that system been included. The exclusion of personnel with experience using such a system might have revealed suggestions not offered by the selected experts who did participate.



Lastly, the study was limited based on expert attrition, which ultimately affected the number of responses received towards the end of round two. As such, there was little chance to achieve much fidelity on any particular topic because there were so few experts remaining to provide commentary or reflection.

#### Recommendations

Although this research effort focused on long-term access to electronic medical records, recommendations for future research include a re-examination of these issues at a later date once additional healthcare facilities have implemented EMR systems and the body of knowledge pertaining to EMRs has grown. Relatively recent mandates from the executive branch and Congress-led e-health initiatives have spurred an increase in EMR system acquisition. At the present, it appears that many organizations are only beginning to purchase and use these systems and are either not concerned with or not yet bothered with long-term access issues.

This study might also be enhanced by looking solely at military operations or the VA system. The DoD has taken necessary measures to ensure that a service member's record is available anywhere in the world using a standard system. An assessment of the military healthcare system or the VA could prove beneficial to finding a solution to long-term access to electronic medical information as technology continually evolves. Even at the end of this study, there is still very little known about long-term access to EMRs. More information about the requirements needed to provide this access is needed and poses a very interesting question for future areas of research.



# Appendix A. E-mail for Expert Panel

Subject: Delphi Study "Long-Term Access to Electronic Medical Records" Round 1 Questioning

# (Title/Name),

Thank you for taking time out of your busy schedule to assist me in completing my research. Considerable thought has been given to your valuable time and steps have been taken to ensure that your participation in this study will be held only to the time required. Conversely, please do not feel restricted in your responses; as a subject matter expert, you are free to elaborate as much as you desire using any resource at your disposal.

Attached to this email are the following items:

1. Research synopsis- provides research background, purpose, methodology, and research question

- 2. A copy of the Privacy Act of 1974
- 3. Researcher Vita

To facilitate your participation, I will state the question below to make it easier for you to respond by simply replying to this email. However, detailed background information to assist you in formulating your response can be found in the attachment named, "Research Synopsis".

# Question:

"What should be done to ensure that hospitals and/or patients do not lose access to electronic medical records as technology continually evolves?"

v/r,

Byron "Nic" Nicholson, Capt AFIT Graduate Student Byron.Nicholson@afit.edu



#### **Appendix B. Research Synopsis**

<u>Background:</u> Electronic medical records are a hot and timely subject. With proper care, a paper record can be preserved for many years and can be read simply by looking at it. However, this is not the case with electronic records considering both hardware and software are needed and require periodic updates. Presently, hospitals and medical facilities have begun the transition from paper-based records to electronic versions where a patient's entire medical history is created/recreated into a digital format. Although an electronic medical record facilitates the information sharing process, it does pose a very interesting question regarding long-term access. To combat the problem of inoperable EMR solutions, standards like the Health Level 7 (HL7) Clinical Document Architecture (CDA) and Integrating the Healthcare Enterprise (IHE) have been developed. Like most standards, their purpose is to structure and markup the clinical content for sharing amongst medical facilities and secondary users (i.e., insurance agencies). However, considering the fact that technology will continually evolve, hospitals and/or patients may lose long-term access to digitally stored records as technologies become obsolete.

<u>Purpose:</u> The DoD envisions a process where a soldier, sailor, airmen, or marine's medical history will be tracked from injury through death all using an electronic record versus the current paper means. To achieve the DoD's goal of lifelong medical records, we must address issues of long-term access to digital information. This study supports the Air Force's overall mission of taking care of airmen by bringing visibility to an area where little comprehensive research has been conducted. The question this research will seek to answer is "What should be done to ensure long-term access to electronic medical records as technology evolves?"

<u>Methodology:</u> Research on this topic will use the Delphi method which is a modification of the panel interview and uses anonymity to solicit answers from a panel designated experts to written questions on an agreed subject matter. Once all the initial responses are received by the designated suspense date, the researcher(s) will compile the answers, analyze responses, and annotate any group consensus. If a clearly defined group consensus is not determined, restructuring of the questions and any expert input will be incorporated into subsequent rounds. Once a clearly defined group consensus is reached, the researchers will desist any subsequent rounds and inform the participants.

<u>Subject Matter Expert Participation/Expectation:</u> Understanding that your time is valuable, I will not seek to belong it with a lengthy survey. Your involvement in this study only requires you to answer the provided questions (not to exceed 5 questions) to the best of your ability. The only limitation placed upon you is the designated suspense in returning your responses. To allow sufficient time for analysis, all responses will need to be e-mailed back to either Captain Byron Nicholson at <u>Byron.Nicholson@afit.edu</u> or <u>Alan.Heminger@afit.edu</u> by January 25, 2008. Thank you for your time and consideration.



# Questions

Several schools of thought exist regarding electronic record archiving and digital document preservation. Popular methods include information migration, software emulation, and technology warehousing. Information migration involves moving the information/data from one technology platform to a newer one. Emulation develops techniques where software is used to mimic a piece of hardware or software so that access to electronic records can be preserved. Technology warehousing consists of preserving the technology in museums and keeping it operational for use in the out-years in order read digital media created specifically for or by it. Several other techniques exist and, like the methods mentioned above, each has its pros and cons. Considering that technology will continue to evolve, there is a risk that parts or all of digitally stored medical records could become lost or inaccessible as more health facilities employ the EMR technology solutions.

**RQ:** What should be done to guarantee long-term access to patients' electronic medical records as technology evolves?

SQ: Do you foresee long-term access to digitally stored health records to be a problem as newer EMR technologies are adopted? Briefly explain why or why or not?



# Appendix C. Round One Consolidated Responses

# **RQ:** "What should be done to ensure that hospitals and/or patients do not lose access to electronic medical records as technology continually evolves?"

**Expert A:** The VA (Veterans Administration) data infrastructure has a proven record of storing medical record data over an extended time period. There is also the experience of the use of these data efficaciously after a disaster, the Katrina disaster where all the patients at the New Orleans VA had to be evacuated and "distributed" to VA facilities across the country. The VA data infrastructure is integrated. There is not the problem of having to "integrate modules". The VA database and EMR system has been selected by the Center for Medicare and Medicaid Services (CMS) to be used as a CMS sponsored EMR – Vista-Office. There are vendors that support this and similar systems, e.g., wxVista. There is a bill in Congress that states the VA database structure should become the basis for the NHII (National Health Information Infrastructure). There are numerous examples in the health care industry of health care systems changing components of their EMR's / EHR's numerous times. For instance, Duke University Health System over the recent past changed its Pharmacy module in its hospital information system five times over six years. There are also examples of health care systems having huge cost overruns when they selected the "best" of the alternative (to the VA system) EHR's (Electronic Health Records). The prime recent example is the Kaiser Permanente System that has had a cost overrun of three billion dollars (estimate = 3 billion dollars; real = 6 billion dollars) for implementation of a system wide electronic medical record system called Epic. There are incompatibilities of the systems. Some of the systems have not had clinicians as major contributors to the basic and applied design phases. The DOD's system is an example of this with the result that the system is increasing separated from the realities of care that the clinicians face on the frontlines. In addition the roll up of these data to the RHIO (Regional Health Information Organization) level should be based on the VA database module (with appropriate modification)

So, the best way to expeditiously address this issue and probably save 3 plus billions or more dollars per year of wasted expenditures on electronic medical record technology is to adopt the VA database and EMR / EHR with modification. There is an open source oriented, national infrastructure available to help support this – <u>http://worldvista.org/</u>.



**Expert B:** Continuous access to patient information is essential. Web-based applications must offer synchronized back-up servers to be activated in the event of system downtime.

Long-term preservation of electronic data will require redundancy. Multiple methods of data backup must be employed, and renewed, along a deliberate strategy to maintain accessibility of records. Daily backups, with monthly archiving and annual renewal of archives with state-of-the-art storage and retrieval are essential in this ongoing process.

**Expert C**: Our goal at a freestanding children's hospital is to create a fully electronic record across the continuum of care. This will take approximately five years and cost about \$35 million. With appropriate archiving and system back up (in the event of a disaster), we should be able to make documentation for every aspect of medical care available "forever". One constraint on the national basis is that there are 5,000+ acute care hospitals in this country. At \$35 million per hospital, the cost of implementation could be \$175 billion. Of note, there are no third party payers prepared to fund these efforts. Federal programs that support implementation would be a significant boost.

**Expert D:** Electronic medical records should be subject to the same retention regulations as paper records so that institutions are obligated to provide backups and storage to continue as technology evolves. Unless required to do so, there is risk that institutions and offices will neglect to address the storage and access requirements in favor of other investments and maintenance costs.

This assumes that state, federal, and local laws regarding record retention are also current and cover EMR technologies in use in their jurisdiction.

Another important measure is to keep copies of essential medical information in the possession of the person to whom it matters the most: the person (or patient).

**Expert E:** Several parallel steps must be taken for this to succeed. EMR formats and standards (such as HL7) must be widely accepted and used in order to standardize the encoding of medical semantics. However, it is naive to imagine that any complex encoding of medical information will remain static and will retain its original interpretation over time. Changes in the meanings and usage of such encodings must therefore be tracked and recorded over time to enable future readers of old EMR to correctly map original intended meanings into future encodings and terminology. In addition, EMR data must be copied to new storage media as old media become obsolete. Ideally, this should be done on a bitwise-verbatim basis to avoid any corruption of the original EMR data. Multiple copies of EMR data should be kept in independent, secure locations, and version control techniques should be used to ensure consistency across such copies. Timestamps, digital signatures, and read-only media should be used to help ensure the validity of EMR data in the future. Accepted archival recordkeeping techniques should be applied to ensure the stewardship of EMR.



Finally, as EMR formats and health information systems evolve over time, a serious archival approach to digital preservation should be employed to ensure that old records remain accessible, readable, valid, and meaningful in the distant future. As discussed further below, format conversion (or "migration") is a doubtful solution for this task. The use of hardware emulation, if augmented with the ability to perform "vernacular extraction" of old data into future EMR environments, may be the most reliable method of keeping old EMR data available and usable.

**Expert F:** As systems evolve, migration software/hardware must be used to translate existing medical records to formats that are compatible with the next generation of hardware/software. Only by spending the time, money, and effort at the time of system conversion will ALL data be continuously available to future generations. Unfortunately, this is probably the only way that all data in active and inactive records will remain accessible to future generations.

With past systems and storage devices this task would appear to be insurmountable. If for no other reason, massive storage requirements hindered this practice simply because medical facilities and businesses could not afford to purchase sufficient storage space. However, with storage media becoming smaller but packing massive amounts of data into these devices (and let's not forget cheap), this is a task that can be more easily accomplished with evolving storage media. Terabyte storage systems that were once a dream are now available and very inexpensive even for home use. As storage capacities continue to get larger and cheaper, migration operations will no longer see storage requirements as a limiting factor.

# SQ: "Do you foresee long-term access to digitally stored health records to be a problem as newer EMR technologies are adopted? Briefly explain why or why or not?"

**Expert A**: Yes, definitely unless there is one standardized system for database design and for implementation of the electronic medical record. Then there can be, for example, a new EMR technology for doing "informed consents" online that can be added to the existing EMR technologies and result in an overall improvement as long as that technology makes use of the proper "hooks" into the standardized system. Otherwise there will be a plethora of technologies that will not integrate well as the data derived from the technologies migrates to the RHIO (Regional Health Information Organization) level. This still allows for entrepreneurship for creation of newer EMR technologies as long as the data infrastructure (the agreed upon NHII) remains the same with planned evolution of that entity. In other words a standardized EMR (such as VA's VisTa) could be replaced with other more efficient and effective technologies but the core data structure remains the same. Add-ons AND complete replacement of the standardized EMR could occur as these technologies evolve BUT the standardized data structure



remains the same (with planned evolution). This would also save money by having a uniform focus on technologies that are the best for quality of care improvement and cost savings rather than spreading developer time across redundant EMR technology development for multiple different EMR systems and data structures. I estimate that this could result in an additional three billion dollars a year or more costs savings because of the focus on clinical functionality improvement rather than redundant systems development. With this progressive clinical functionality improvement comes increased cost-effectiveness of our health care system that is an extremely important goal for the USA's health system to focus upon before the costs of medical care further erode the productive use of funds for other needed purposes (e.g., the DOD could save money that could be applied to its core mission rather than "reinventing the EMR wheel").

**Expert B:** I expect this access to be feasible, provided that a careful strategic plan is employed with appropriate emphasis on long-term accessibility. From the floppy disk, to the hard drive, to external storage devices such as thumb drives, technology has consistently advanced to allow greater volumes of data to be stored in decreasing amounts of physical space. With the appropriate strategy for renewing archival materials, long-term data access should be feasible. As with many other IT issues, the technology is the easy part- organizational issues will be the limiting factor.

**Expert C**: Across the civilian continuum of care, this will be very problematic. Presently, there are at least 8 major vendors in the marketplace for the development, sale, implementation and maintenance of EMRs. These systems do not talk to each other, and do not even have core functions. For example, one of the upcoming players is EPIC. This is a private (not publicly traded) company owned still by its founder. What happens when she retires or a competitor buys out the company? This tends to produce sun setting of products, with the original product now obsolete.

It would be nice if the civilian world could work from one platform, as does the DoD. However, that is not going to happen soon. The next option is the development of core standards and functionality that are standardized across vendors. Attempts to do so are occurring at present. I am not optimistic, however, that such efforts will generate freedom of access.

The DoD has the ability to achieve something that is unlikely in the civilian sector. When you patient moves from Washington D.C to Oakland California, their record goes with them. In our case, their record only travels if they seek care at another EPIC facility that has access to My Chart, or to EPICs latest effort to develop universal access across the EPIC customer line.

**Expert D**: Yes. It is an additional expense to import older data into newer systems, and to assure archiving, backup, and retention occurs. EMRs are new, ad expensive. This is an additional overhead expense that does not provide immediate return. It is akin to renting storage space for paper medical records, except that it is less obvious. The CDs



or tape drives may deteriorate or become hard to load after a decade passes, while the old hart is still readable if it is stored.

**Expert E**: The short answer is yes; however, this should be kept in perspective, since long-term access to paper health records is fraught with problems as well. Physical loss, deterioration or destruction of paper records over the roughly 100-year span of a human life is a significant problem. In principle, EMR enables backup copies to be kept in multiple, secure locations and to be kept consistent and synchronized over time. In practice, however, the technology-dependence of any form of digital representation makes EMR vulnerable.

The most obvious aspect of this is the short lifespan of the physical devices on which the bitstreams of digital objects are stored. The development and use of longer-term storage media, such as platinum or gold CDs, is economically impractical, since the readers for any such medium would become obsolete long before the information carriers themselves (disks, etc.) wore out. It is impractical to keep readers for such obsolete media running long after they are no longer significant in the market, since the expertise needed to maintain them would be expensive and custom interfaces would have to be built to connect them to future computing systems. The current generally-accepted solution to this problem is to copy bitstreams to new storage media as needed over time, thereby allowing the data to "migrate" onto new media that will be accessible by future computers.

However, the storage problem is only the tip of the iceberg. Far more challenging is the fact that all digital information is stored in encoded form that must be interpreted and "rendered" into human-readable form by running software on some computing platform. This is particularly important for EMR data other than "page-images" such as printed reports, handwritten or typed observations, or static 2-D imagery. As more complex and dynamic, non-page-image datatypes are incorporated into EMR, they will require more elaborate interpretation and rendering in order to be made comprehensible. The formats in which such information is encoded become obsolete in a matter of years or at most decades, so that future software is unlikely to retain the ability to interpret and render an old format correctly is insufficient, since future computers are unlikely to be able to run the obsolete software, and obsolete computers themselves cannot be maintained in running condition indefinitely.

Converting information from obsolete formats into new formats ("format migration") is a poor long-term solution, since it must be done repeatedly over time, and each conversion inevitably introduces some loss or corruption. After several such conversion steps, the resulting information is unlikely to retain its original meaning. The use of medical information encoding standards such as HL7 can help by providing a formal representation of medical information; however, even HL7 will evolve and be superseded over time. In addition, the meaning of medical terms evolves over time,



making the correct interpretation of medical information problematic, even if it is encoded in a formalism like HL7.

Retaining the semantics of EMR information over a 100+ year timeframe is therefore a significant challenge.

Emulation of original rendering software is a poor solution, since it requires writing new software for each new generation of computer platforms. Accurately recreating the behavior of obsolete software is quite difficult, so having to do this for every new generation of computers makes it unlikely that future software will correctly emulate the obsolete software needed to render old EMR. A better solution is to save and run the original rendering software to read old EMRs, using hardware emulation programs to enable future computers to "impersonate"

obsolete computers, allowing them to run the obsolete rendering software. If such hardware emulator programs are written to run on virtual machine platforms that can easily be ported to any future computer, then no new software (other than that required to port the virtual machine) need be written over time. This approach would allow viewing old EMR on future computers; however, it would not by itself enable old data to be extracted from old EMR and integrated into a new EMR, especially if that required semantic updating of medical terms, diagnoses, etc. In order to serve this function, an emulation environment would have to support "vernacular extraction" that would enable old EMR data to be extracted into a future computing environment, where it could be translated appropriately and merged into a future EMR.

With this addition, emulation would both preserve original EMRs in their original, uncorrupted form and allow their data to be brought forward into future EMRs as needed.

**Expert F:** I see this as a two part answer. The first part to the answer is "no" there will not be a problem accessing active medical records. As long as records are being actively used by a health care provider, the time and expense to migrate active records will be seen as necessary to move the records to evolving systems.

However, the second part to the answer is "yes" there will be a problem accessing inactive medical records. As records go inactive for whatever reason, health care providers may not want the added expense of migrating inactive records from system (X) to system (X+1) if those records will no longer be used. This is not a problem in the short-term. If records are considered inactive after migration to system (X+1), then it is probably still fairly easy to go back and run the migration software to migrate inactive records to system (X+1). However, there will most likely be serious problems if inactive records from system (X) need to be migrated to systems (X+2), (X+3), etc. At this point, not only do you have problems running the conversion software, but hardware compatibility will also be a problem. Additionally, it is likely that programmers that were familiar with system (X) file formats may no longer be available to write conversion software that will translate files from system (X) to systems (X+2) and beyond. The time and expense necessary to accomplish this task may be deemed too high to make this venture worthwhile, especially if there are only a few records that need to be accessed.



And from a medical perspective, the delay in accessing the records may be overcome by events, so the project may not even be considered.

At this point, the data may be lost to history, like so much of the data that has been stored digitally in the past. Even with my personal files, I have always migrated data files from one medium to the next generation medium. I have data files that are 20+ years old and in their original file formats. However, most of those files are inaccessible by current software. It is only my ability to go into the raw files and manipulate the data at the bit-and byte-levels that allows me to retrieve the portions of the files that I need. It is not feasible for health care providers or other businesses to keep personnel on staff to accomplish this task on the few occasions that it may be necessary.



# Appendix D. Round Two Report

**Q1:** Below is a summation of the responses received to question # 1. Many of you felt that long-term access would not be lost as long as the records were properly archived or backed up. A number of you felt that adopting a standardized system or incorporating a standard EMR format would prevent loss. It was also suggested to use digital preservation techniques such and migration or emulation hardware/software to prevent loss. **Please review the statements below and comment on which suggestion(s) you feel will best ensure long-term access to EMRs as technology evolves (we give up older technology and adopt newer systems). Please feel free to add any additional comments you feel appropriate for discussion.** 

# What should be done to ensure that hospitals and/or patients do not lose access to electronic medical records as technology changes?

- Adopt a standardized system to facilitate module integration and avoid implementation cost overruns
- Perseveration will require redundancy: daily back-ups, monthly archiving, annual renewing of archives with state of the art storage and retrieval
- Use migration software/hardware to make existing records forward compatible
- Follow federal, local, state laws for record retention much like paper records so organizations are obligated to provide backups and storage
- EMR formats and standards such as HL7 must be adopted
- Encoding data must be tracked and recorded over time to enable future readers of old EMR to correctly map original meanings into future encodings and terminology
- EMR/EHR data must be copied to new storage media, with strict version control, redundancy, & archival processes

# **Comments:**



Q2: From the first round, the majority of the group reported affirmatively that long-term access would be a problem as new technologies are adopted. However it was offered that technology will not be the main problem; organizational issues and the records' status (inactive/active) would be a problem with long-term access. Below is a summation of question 2 responses. Based on these suggestions, please comment on the item(s) you feel will be a major barrier to long-term access to digital records as newer technologies are adopted. Please list those you agree with, disagree with, or any additional comments.

# Do you foresee long-term access to digitally stored health records to be a problem as newer EMR technologies are adopted? Briefly explain why or why not?

- Yes. Unless there is a standardized system for database design and EMR implementation. Otherwise there will be a lot of technologies that will not integrate well
- Access will be feasible so long as a plan is in place for long-term access or an appropriate strategy for renewing archival materials. New technology allows greater volumes to be stored more easily. Technology will not be a problem; organizational issues will be the limiting factor preventing access
- Long-term access will be very problematic. There is no standardization amongst vendors; There needs to be a single platform/system or vendor standards and functionality in place
- Yes. It is an additional expense when considering importing old data into new systems as well as archiving, maintaining backups, and retention
- Yes. Technology devices have short life-spans; EMR data types will become more complex and dynamic. Accurately recreating old software behavior is difficult (emulation)
- No and Yes. Accessing an active record will not be a problem since an active record will be in use with the right software/hardware. If the record is inactive, the answer is yes due to costs associated with maintaining the records for the long-term
- Yes. Format migration is a repetitive process and each conversion introduces some loss and/or corruption. Neither is conducive with medical record authenticity or accuracy.

# **Comments:**



# **Bibliography**

- American Health Information Management Association. (2003). *The complete medical record in a hybrid electronic health record environment*. e-HIM task force report, pt. 1. [Chicago, IL.]: American Health Imformation Management Association.
- Bass, G. D., & Rubinstein, G. (1990). Paperwork reduction act: A year for change. *Information Management Review*, 5(3), 69.
- Bobb, A. M., Payne, T. H., & Gross, P. A. (2007). Viewpoint: Controversies surrounding use of order sets for clinical decision support in computerized provider order entry. *Journal of the American Medical Informatics Association*, 14(1), 41-47.
- Brewin, B. (2003). Hospitals CIOs shy away from automating medical systems. *Computerworld*, 37(7), 12.
- British Digital Preservation Handbook. (2001). *Information Retrieval and Library Automation.* 37, 9.
- Bush, H. (2007). Cutting-edge portable devices raise concerns. *Hospitals & Health Networks*, *81*(8), 22.
- Calloway, S.D. (2006). Record Retention Periods. *HIPAAdvisory*. Phoenix Health Systems. <u>http://www.hipaadvisory.com/regs/recordretention.htm</u> (retrieved: Feb. 1, 2008.)
- Chau, P. Y. K., & Hu, P. J. (2004). Technology implementation for telemedicine programs. Association for Computing Machinery. Communications of the ACM, 47(2), 87.
- Chow, A. W., Goodman, B. D., Rooney, J. W., & Wyble, C. D. (2007). Engaging a corporate community to manage technology and embrace innovation. *IBM Systems Journal*, 46(4), 639.
- Conn, J. (2008). Power to the patient. Modern Healthcare, 38(10), 52.
- Consultative Committee for Space Data Systems. (2002). *Reference Model for an Open Archival Information System (OAIS) recommendation for space data system standards ; Blue book.* Washington, DC: CCSDS 650.0-B-1Secretariat.
- Dalkey, N. C. (1969). *The Delphi Method: An experimental study of group opinion*. RAND Corporation. (RM-5888-PR)



- Davis, F. D. (1989). Perceived usefulness, perceived ease of use, and user acceptance. *MIS Quarterly*, *13*(3), 319.
- Edwards, M., & Moczygemba, J. (2004). Reducing medical errors through better documentation. *The Health Care Manager*, 23(4), 329.
- Eichelberg, M. (2005). A survey and analysis of electronic healthcare record standards. *ACM Computing Surveys (CSUR), 37*(4)
- Feldhousen, M. J. (1989). Mainframe-based CAR systems provide document retrieval option. *IMC Journal*, 25(6), 18.
- Fletcher, P. D. (2002). The government paperwork elimination act: Operating instructions for an electronic government. *International Journal of Public Administration*, 25(5), 723.
- Gates, B. (2007, Oct 5). Health care needs an internet revolution. *Wall Street Journal*, pp. A.17.
- Glaser, J. (2007). The electronic health record: A digital divide? *Healthcare Financial Management*, *61*(10), 38.
- Global Information for Quality Care. "Communication messages & questions and answers AHLTA Announcement." 21 Nov 2005.
- Goldschmidt, P.G. (2005) HIT and MIS: Implications of health information technology and medical information systems. *Communications of the ACM*, (48)10.
- Hansen, D. (2007). Microsoft's health vault is the latest entrant in the PHR arena. *American Medical News*, 50(40), 19.
- Harrison, J. P., & Palacio, C. (2006). The role of clinical information systems in health care quality improvement. *The Health Care Manager*, 25(3), 206.
- Hedstrom, M. (1993). *Electronic records management program strategies*. Archives and Museum Information technical report, no. 18. [Pittsburgh]: Archives & Museum Informatics.
- -----. (1997). Digital Preservation: A Time Bomb for Digital Libraries. *Computers and the Humanities*. 31 (3), 189.
- -----. (2003). Report and Recommendations of the NSF-DELOS Working Group on Digital Archiving and Preservation. National Science Foundation's (NSF) Digital Library Initiative & The European Union under the Fifth Framework Programme by the Network of Excellence for Digital Libraries (DELOS).



- Heminger, A. R., & Kelley, D. M. (2005). Assessing the Digital Rosetta Stone Model for Long-Term Access to Digital Documents. *Journal of Management Information Systems*. 21 (4), 11-35.
- -----. & Robertson, S. B. (1998). Digital Rosetta Stone: A Conceptual Model for Maintaining Long-term Access to Digital Documents. *Proceedings of the Hawaii International Conference on System Sciences*. 31 (2), 158-167.
- Hobbs, Brian G. Barriers to Electronic Records Management (ERM): An Exploratory Case Study Evaluating ERM in the Deployed Environment during Operations Enduring Freedom and Iraqi Freedom. MS Thesis, AFIT/GIR/ENV/05M-07. School of Engineering and Management, Air Force Institute of Technology (AU), Wright-Patterson AFB OH, March 2005.
- Hospital it use growing strong.(2007). *Trustee : The Journal for Hospital Governing Boards*, 60(4), 4.
- Hu, P. J., Chau, P. Y. K., Sheng, O. R. L., & Tam, K. Y. (1999). Examining the technology acceptance model using physician acceptance of telemedicine technology. *Journal of Management Information Systems*, 16(2), 91.
- Hu, P. J.-H., Chau, P. Y. K., & Sheng, O. R. L. (2002). Adoption of Telemedicine Technology by Health Care Organizations: An Exploratory Study.
- Huston, J. L. (2006). EHR in the UK shedding some light from a manager's perspective. *The Health Care Manager*, 25(4), 335.
- Inspector General Department of Defense (2006). Information Technology Management: Acquisition of the Armed Forces Longitudinal Technology Application. Arlington, VA: (ADA472015).
- Institute of Medicine: *The computer-based patient record: an essential technology for health care.* Dick RS, Steen EB (ends). Washington DC: National Academy Press, 1991.
- Iron Mountain. (2006). Reaping the benefits of Comprehensive Health Information Management. White Paper. Boston
- Jones, M., & Beagrie, N. (2001). *Preservation management of digital materials: a handbook*. The British Library.
- Kelley, Don M. A Delphi Assessment of the Digital Rosetta Stone. MS Thesis, AFIT/GIR/ENV/01M-10. School of Engineering and Management, Air Force Institute of Technology (AU), Wright-Patterson AFB OH, March 2001.



- Krizner, K. (2006). Provider IT spending on the rise in north america. *Managed Healthcare Executive*, *16*(2), 11.
- Lafferty, L. ". (2007). Medical identity theft: The future threat of health care fraud is now. *Journal of Health Care Compliance*, 9(1), 11.
- Liberatore, M. J., & Nydick, R. L. (2008). The analytic hierarchy process in medical and health care decision making: A literature review. *European Journal of Operational Research*, 189(1), 194.
- Linstone, H. A., & Turoff, M. (1975). *The Delphi method: techniques and applications*. Reading, Mass: Addison-Wesley.
- Linstone, H. A. (1978). The Delphi technique, in Fowles 1978, 273–300.
- Liu, C., Long, A., Li, Y., Tsai, K., & Kuo, H. (2001). Sharing patient care records over the world wide web. *International Journal of Medical Informatics*, *61*(2-3), 189-205.
- Mandl, K., Szolovits, P., & Kohane, I. (2001). Public standards and patients' control: how to keep electronic medical records accessible but private. *British Medical Journal*. 322 (7281), 283-287.
- Melvin, V.C. (2007). Information Technology: VA and DOD Are Making Progress in Sharing Medical Information, but Are Far from Comprehensive Electronic Medical Records. Testimony Before the subcommittee on Oversight and Investigations, Committee on Veterans' Affairs, House of Representatives. May 8, 2007. United States GAO.
- Middleton, B., Hammond, W. E., Brennan, P. F., & Cooper, G. F. (2005). Accelerating U.S. EHR adoption: How to get there from here. recommendations based on the 2004 ACMI retreat. *Journal of the American Medical Informatics Association*, 12(1), 13-19.
- Peterson, H. E. (2006). From punched cards to computerized patient records: A personal journey. *IMIA Yearbook of Medical Informatics*, 45, 180-186.
- Philpott, T. (2004). The VA's big makeover. Air Force Magazine, 87(1), 52-54.
- Rindfleisch, T. C. (1997). Privacy, Information Technology, and Health Care. *Communications of the ACM*. 40 (8), 92.
- Robbins, S.P., & Judge, T.A. (2007). *Organizational Behavior*. New Jersey: Pearson Prentice Hall.



- Robertson, Steven. B. Digital Rosetta Stone: A Conceptual Model for Maintaining Longterm Access to Digital Documents. MS Thesis, AFIT/GIR/LAR/96D-8. School of Logistics and Acquisition Management, Air Force Institute of Technology (AU), Wright-Patterson AFB OH, March 1996.
- Romano, M. (2004). Making the best better. Modern Healthcare, 34(34), 18.
- Rothenberg, J. (1999). Ensuring the longevity of digital documents. *Scientific American*, 272(1), 42.
- -----. (2000). Long-term preservation of digital information: Challenges and possible technical solutions. NEDLIB talk presentation. December 12, 2000. RAND Corp.
- -----. (2002). Preservation of the times. Information Management Journal, 36(2), 38.
- Ruotsalainen, P., & Manning, B. (2007). A notary archive model for secure preservation and distribution of electrically signed patient documents. *International Journal of Medical Informatics*, 76(5-6), 449-453.
- Schabetsberger, T., Ammenwerth, E., Andreatta, S., Gratl, G., Haux, R., Lechleitner, G., et al. (2006). From a paper-based transmission of discharge summaries to electronic communication in health care regions. *International Journal of Medical Informatics*, 75(3-4), 209-215.
- Scott, R. E. (2007). e-records in health—Preserving our future. International Journal of Medical Informatics, 76(5-6), 427-431.
- Simons, W. W., Mandl, K. D., & Kohane, I. S. (2005). The PING personally controlled electronic medical record system: Technical architecture. *Journal of the American Medical Informatics Association*, 12(1), 47-54.
- Slomski, A. (2007). Could you read that? Medical Economics, 84(7), 68.
- Squazzo, J. D. (2007). The state of regional health information organizations: Health data exchange on the rise. *Healthcare Executive*, 22(5), 8.
- Stabenow, D. (2007). The price of paper. *Trustee : The Journal for Hospital Governing Boards*, *30*(30), 30.
- Summers, M. (2007). Medical Technology: Electronic Medical Records-The move towards standards. *Tracker*. Summer 2007.
- Swartz, N. (2006). Pacific bases begin move to EMR system. *Information Management Journal*, 40(4), 13.



- -----. (2007). Americans prefer electronic health records. *Information Management Journal*, 41(4), 8.
- Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 13(2), 121-126.
- Times Online (2004-03-20). <u>NHS is world's biggest employer after Indian rail and</u> <u>Chinese Army</u>. Retrieved on 2008-02-13.
- Toyoda, K. (1998). Standardization and security for the EMR. *International Journal of Medical Informatics*, 48(1-3), 57-60.
- VA Enterprise Centers FY 2002 Annual Report. (2002). Working Together to Achieve Extraordinary Performance in Government.
- Wechsler, J. (2007). Health IT implementation slows down. *Managed Healthcare Executive*, 17(7), 12.



#### Vita

Captain Byron D. "Nic" Nicholson was born in Waynesboro, Mississippi. He graduated from Southern Choctaw High School in Silas, Alabama in 1994. After graduation, he enlisted in the Air Force and became a crew chief on the U-2 Dragonlady high-altitude spy plane. He was encouraged to apply to the United States Air Force Academy in Colorado Springs, Colorado, where he was accepted. While there, he was a member of the varsity basketball team and earned a Bachelor of Science Degree in Psychology. He was commissioned in May 2001.

His first officer assignment was as a minority enrollment counselor for the Academy where he traveled the country speaking to high school students about the opportunities the Academy offered. In 2002, his next assignment took him to Wright-Patterson AFB Ohio where he served as a crew commander and then Integration Chief in Air Force Materiel Command's Network Operation and Security Center. In 2004, he moved to the Aeronautical Systems Center as an Executive Officer to the Director of Plans and Programs, (ASC/XP).

In October 2006, he entered the graduate school of engineering and management, at the Air Force Institute of Technology (AFIT) where he graduated with a Master of Science in Information Resource Management. Following graduation in March of 2008, his next assignment was the 543d Intelligence Group at Lackland AFB in San Antonio, Texas.



		ORT DO	Form Approved OMB No. 074-0188					
						ne for reviewing instructions, searching existing data omments regarding this burden estimate or any other		
aspect of the	collection of inform	nation, including s	suggestions for reducing this b	ourden to Departmen	of Defense, Washing	ton Headquarters Services, Directorate for Information		
						nts should be aware that notwithstanding any other display a currently valid OMB control number.		
PLEASE D	O NOT RETURN	VYOUR FOR	N TO THE ABOVE ADDR					
	T DATE (DD-I	MM-YYYY)	2. REPORT TYPE			3. DATES COVERED (From – To)		
	27032008		Mast	ter's Thesis		October 2006 – March 2008		
	E AND SUBT			CONTRACT NUMBER				
	Study Assess	sing Long-te	erm Access to Electro	onic Medical Re	ecords			
(EMR) 5b.						GRANT NUMBER		
			PROGRAM ELEMENT NUMBER					
					•••			
6. AUTI	HOR(S)				5d.	PROJECT NUMBER		
	_							
Nichols	son, Byro	n. D., Ca	aptain, USAF		5e.	TASK NUMBER		
					5f.	WORK UNIT NUMBER		
7 PEREO		ΔΝΙΖΔΤΙΟΝ	NAMES(S) AND ADD	RESS(S)		8. PERFORMING ORGANIZATION		
	orce Institu					REPORT NUMBER		
			0.					
		•	neering and Man	agement (A	FIT/EN)	AFIT/GIR/ENV/08-M15		
2950	Hobson W	'ay, Build	ling 640					
WPA	FB OH 45	433-8865	5					
			GENCY NAME(S) ANI	DADDRESS(E	5)	10. SPONSOR/MONITOR'S		
					-,	ACRONYM(S)		
	T.	1	1- I - A D1 1-					
	Ir	itentional	ly Left Blank			11. SPONSOR/MONITOR'S REPORT		
						NUMBER(S)		
12. DISTR	BUTION/AV	AILABILITY	STATEMENT					
A DI				DIGTDID				
API	ROVED	FUR PUI	BLIC RELEASE	; DISTRIB	UTION UN	LIMITED.		
	LEMENTARY	NOTES						
13. 30FF		NOTES						
14. ABST	-							
This re	search effe	ort addres	ssed the issue of	long-term a	ccess to elec	ctronic medical records as		
technol	ogical gen	erations h	pecome obsolete	thereby pre	eventing the	access to patient health		
	technological generations become obsolete, thereby preventing the access to patient health information. Using the Delphi methodology, experts with experience in electronic medical							
		0	1 0		-			
records and applicable systems provided insight based on their years of hands-on experience								
managing and/or using records and these systems. The end result of this research was a								
collection of ideas that medical institutions and medical informaticians must consider to ensure								
-	that patients and hospitals do not lose long-term access to electronic medical records as electronic							
medical records and technology continually evolves. Results of the study identified the need for								
more research in this particular area as no definitive solution to long-term access to electronic								
medical records was revealed. Additionally, the research findings highlighted the fact that a few								
medical institutions may actually be concerned about long-term access to electronic records.								
15. SUBJECT TERMS								
Delphi Techniques, Information Technology, Physicians, Migration, Records, Digital Storage,								
Standards, Veterans, Digital								
16. SECURITY CLASSIFICATION 17. LIMITATION 18. 19a. NAME OF						F RESPONSIBLE PERSON		
OF:			Alan R. He	eminger, Civ, USAF (ENV)				
a.	b.	c. THIS	ABSTRACT	OF		ONE NUMBER (Include area code)		
REPORT	ABSTRACT	PAGE		PAGES		3636, 7405		
	U	U	UU	71	Alan.Heminger@afit.edu			



Standard Form 298 (Rev. 8-98) Prescribed by ANSI Std. Z39-18