

HEALTHCARE INFORMATION SYSTEMS:
DESIGN THEORY, PRINCIPLES AND APPLICATION

by

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A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Department of Management Information Systems
in the College of Business Administration
at the University of Central Florida
Orlando, Florida

Fall Term
2006

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ABSTRACT

Healthcare information systems (HISs), as a class of systems, are not currently addressed in the MIS literature. This is in spite of a sharp increase in use over the past few years, and the uniquely qualified role that MIS has in the development of, impact and general understanding of HISs. In this project the design science paradigm frames the development of a set of design principles derived from the synthesis of the design literature, ethics literature, and professional guidelines, from both the medical and computing professions. The resulting principles are offered to address the design of healthcare information systems. Action research, a widely accepted methodology for testing design principles derived from the design science paradigm, is employed to test the HIS principles and to implement change in a healthcare organization through the use of an HIS. The action research project was a collaborative effort between a Central Florida hospice and the researcher, the result of which was an advanced directives decision support system. The system was design to meet a number of organizational goals that ranged from tracking compliance with federal regulations to increasing the autonomy of the patients that used the system. The result is a set of tested design principles and lessons learned from both anticipated and unanticipated consequences of the action research project.

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LIST OF ACRONYMS

ACM	Association of Computing Machinery
AD	Advanced Directive
ADDSS	Advanced Directives Decision Support System
CAR	Canonical Action Research
CKMS	Churchmanian Knowledge Management Systems
CPM	Principle of the Cyclical Process Model
EIS	Executive Information Systems
EKP	Emergent Knowledge Processes
GDSS	Group Decision Support Systems
HIPPA	Health Insurance Portability Accountability Act
HINARI	Health InterNetwork Access to Research Institute
HIS	Health Information System
LOKMS	Learning Oriented Knowledge Management Systems
MIB	Medical Information Bureau
NHII	National Health Information Infrastructure
PAPA	Privacy, Accuracy, Property and Accessibility
PID	Patient Identification Number
RCA	Principle of the Researcher Profile
RPI	Principle Researcher Profile

CHAPTER ONE: INTRODUCTION

The role of information technology in the practice of medicine has changed significantly over the past 40 years. Initially addressing administrative functions in the healthcare industry, similar to those found in other organization types, the focus was on increased efficiency and reduced costs (Berner et al., 2005). Today's healthcare information systems have grown increasingly complex and span from purely administrative systems to those that are more clinical in nature and therefore have a direct impact on patient treatment and care. Systems such as clinical decision support systems augment physician decisions in their practice of evidence-based medicine. Clinical information systems are available to assist physicians in identifying the most effective course for prescriptions, especially when complex combinations of drugs are required for treatment, for example in pain management or oncology. Information systems are also available that facilitate compliance with changing treatment protocols.

Contemporary healthcare information systems have had a profound impact on both the practice of medicine and the relationships between healthcare providers and their patients. Patients have become more autonomous in the information age, and are increasingly relying on information systems to make healthcare related decisions for themselves or a family member. Patient autonomy is receiving increased attention in both research and practice in the medical field. In the last two decades the term "patient autonomy" has appeared more and more frequently in the medical literature; a text word search in PubMed provided 41 citations for 1980, 324 in 2000 (Stiggelbout et al., 2004) and 687 in 2005. "It is only in the later part of the past century that people have begun to view the physician as an advisor, often one of many, to an autonomous

patient...the center of patient care is no longer in the physician's office or hospital, but rather it is in the home and workplace where people live their lives and make their healthcare decisions" (Sox, 2003, p.243). One evolution of this changing relationship is the introduction of patient decision support systems which address the complex decision making that patients face today.

System designers, in their attempts to design and develop systems that meet the needs of both healthcare providers and patients in today's medical environment, must rely on established guidelines for the design of Healthcare Information Systems (HISs). While the practice of medicine, the relationships involved, and the role of information systems in medicine have changed significantly, the IS design literature has not kept pace with these changes in practice.

As a result there is a need for design theory and guidelines to address the design of contemporary HISs, as the current IS literature in design theory does not support the design and development of these systems. The goal of this work is to address the current void in the literature regarding the design and development of HISs, and to specifically address the research question "Can an effective set of design principles for the design and development of HISs be developed for the new environment for the practice of medicine?"

Design science and action research are employed to develop and test a set of HIS design principles, resulting in a design theory articulated by a set of design principles to guide systems designers and developers in the creation of HISs. The result is a set of validated HIS design principles, based on a synthesis of the ethical and professional guidelines for both the medical and computing professions, offered to guide the design efforts of future HIS systems.

This chapter will proceed as follows. First the theoretical background of design science is presented, followed by a discussion of healthcare information systems and justification for why a new design theory is needed. Second, a description and overview of the contemporary medical environment and the response of the medical profession to its changing environment is presented. The professional and ethical guidelines for both the medical and computing professions then are described. Next, through the guidance of the design science framework, a synthesis of the guidelines and ethics literature results in a set of design principles for the design of HISs. The action research methodology is then introduced and the initial design principles developed under the design science methodology are employed as the basis for specifying system features and a system is developed in a healthcare organization, resulting in a test of the design principles in practice. Specifically, an advance directives decision support system (ADDSS) is developed through a collaborative effort with a mid-sized hospice in Florida. The ADDSS action research project investigates the effectiveness of the design principles as a guide for the development of HISs. A discussion follows illustrating contributions of this project.

Theoretical Background

In this section IS design theory and design science are discussed. Next a theoretically based concept of HISs is offered followed by an explanation of why a new design theory for HISs is needed.

Design Science and Theory Development

Design and design theories are central to the information systems discipline (Walls et al., 1992; Markus et al., 2002; Hevner et al., 2004; Lindgren et al., 2004). Benefits of design theories include providing researchers a basis for making predictions about system use, patterns and impacts; and making problems more manageable for developers (Markus et al., 2002). “A design theory is a prescriptive theory based on theoretical underpinnings which says how a design process can be carried out in a way which is both effective and feasible.” (Walls et al., 1992, p. 37) Walls and his colleagues (1992, p. 17) also suggest “...there is a need for theory development based on paradigms endogenous to the area itself.”

MIS has a long history of examining the role of design theory. Churchman (1971) referred to IS design theory in abstract terms, relying on general systems theory and emphasizing the relationships between the designers, developers, clients and users. Mason and Mitroff (1973) brought inquiring systems theory into the IS literature early on, effectively making it endogenous to the field. Klein and Hirschheim (2001) propose a rational way for thinking about value judgments that underlie design and development and the issues that are involved in choosing and crafting designs, and address selection from a collection of overlapping, sometimes conflicting ideas. Markus et al. (2002) offer design principles for emergent knowledge processes (EKPs) that have unique requirements not supported by familiar classes of systems. Hall et al. (2003) address validity issues and offer an architecture for knowledge management systems based on Churchman’s inquiring systems. Richardson and Courtney (2004) provide an IS design theory based on the Singerian inquirer. And lastly, Richardson (2005) and Richardson et al. (2006) synthesize Boland’s distributed cognition with Habermas’ theory of communicative action and

offer a set of information systems design principles that emphasize communication in distributed cognition.

The role of information technology in healthcare organizations has also been addressed in the medical informatics literature. In 1990 Lorenzi recognized the increasingly important role of information technology in healthcare organizations and examined change management as it related to information technology in the healthcare industry. Ash (1997) went on to examine organizational factors that influence information technology diffusion in healthcare organizations. Patel et al. (1998) proposed that it would be helpful to examine medical informatics as a local science of design; as a local science design principles simplify and explain parts of the domain of interest rather than providing a unifying set of assumptions. Berg (1998) and Kaplan (2001) examine socio-technical issues surrounding patient care and information technology. Several research areas have covered the design of specific aspects of software applications such as interface design for healthcare environments (Patel et al., 1998), the design of web based healthcare systems (Kushniruk et al., 2001) and the design of electronic patient records (Patel and Haux, 2001).

The above summary of the literature in both MIS and the medical informatics literature reveals two things. First there is recognition of the importance of the design of healthcare information systems. And secondly the approach to design of healthcare information systems as a class of systems has not been addressed at all in the MIS literature, and has been addressed in the medical informatics literature as a “local” or specific type of healthcare information system and not as a class of systems itself.

It is suggested here that healthcare information systems are a class of systems with a unique domain and set of characteristics. Furthermore it is suggested that existing IS design theories do not meet the requirements, and cannot generalize, to the development and design of HIS. Nor can the design of HISs be addressed by applying general systems theory because the result would be a general solution and one that would not adequately address the unique requirements of these systems. The goal of this research is to develop a design theory that can provide guidance to system designers and result in more effective HISs that improve the quality of healthcare. This is accomplished through a design theory, characterized by a set of design principles that upholds above all else, patient autonomy, patient welfare, and social justice.

This dissertation project builds upon the MIS literature in order to expand the research in this area. Walls et al. (1992) and Markus et al. (2002) describe the elements of design science as solutions for specialized classes of IS design problems; these elements guide the current project. The framework for design science research offered by Hevner et al (2004) also guides the current work and results in an initial set of HIS design principles. In order to fully realize the need for design guidelines for HIS design it is important to understand more formally what an HIS is. The following section illustrates HISs as a class of systems. The domain in which HIS operate and the unique characteristics these systems embody are described.

Healthcare Information Systems

HISs are interdisciplinary in nature and can be defined as acquiring, storing, distributing, and using information in a healthcare environment, and usually involving the use of information technology. HISs has a unique set of characteristics such as:

- A challenging and unique domain
- Unique user requirement
- Requires knowledge and expertise in both the medical and computing fields
- Requires both general and contextual knowledge
- Challenging information requirements
- A unique impact on users
- Different and conflicting user goals
- Fuzzy boundaries
- An environment of rapid change
- The user of the HIS is often not the final client, the patient is
- The impact of the HIS can have life and death consequences

The environment in which these systems operate is hectic, fast paced, isolated and fragmented, and at the same time collaborative, and inundated with isolated IT applications that are the result of rapid development of applications and has resulted in fragmentation in the industry. All of these characteristics are modified daily by an amazingly rapidly growing body of scientific knowledge.

It is important to remember that these systems not only impact the user on the side of the medical professional, but increasingly impact the patient as a user as well. Advancements in medical knowledge have increased the burden of chronic disease by extending life expectancies (Scott et al., 1997) and making available increased treatment options. As a result today's patients are placed in the difficult position of having to make complex decisions, sometimes while facing a life threatening illness, at a time of crisis in their lives. Deciding between several treatment options with complex tradeoffs involving quality and length of life can be difficult for patients (Scott et al., 1997).

The design science paradigm is the foundation for the current project which builds on prior literature in both the MIS and the medical informatics literature to develop a set of guidelines to guide the design and development of HISs. Synthesis of the professional and ethics literature, for both the medical and computing professions, results in an initial set of design principles for HISs. In the following section the professional guidelines and ethics literature for both the medical and computing professions are introduced.

Professional and Ethics Literature for Medical & Computing Professions

Advancements in technology have changed medical treatment and the relationships between provider and patient. Public policy developments have placed the role of information technology in medicine at the forefront of its current efforts. Recent policy has addressed both the positive and negative consequences of the use of information technology in healthcare as the industry has

changed significantly with the increased use of these technologies. The following sections describe several attempts by the medical community and researchers to address the ethical issues of contemporary medicine. The Charter of Medical Professionalism is one attempt by the medical community to address the changes in healthcare, many of which are the result of the increased use of technology.

Charter of Medical Professionalism

The practice of medicine is changing. Globalization, economic and technological impacts, and the introduction of health maintenance organizations have changed how healthcare providers make treatment decisions. Information technology has had a significant impact on the medical community, one result being an exponential increase in medical knowledge. Information technology has impacted the relationships between healthcare providers and their patients, the treatment decisions for both patients and physicians, and is impacting patient autonomy.

The medical community has responded to its changing environment by developing a new set of practice guidelines, the Charter of Medical Professionalism. Developed by a staff of 18 physicians in 10 countries, the Charter (Table 1.1) is a joint response by medical communities in both America and Europe addressing professionalism in the face of its current environment (Sox, 2002). A set of fundamental principles and professional responsibilities, the Charter both updates and reaffirms the fundamental and universal principles and values of medical professionalism. It addresses both well-established principles and responsibilities in the practice of medicine as well as more contemporary issues. Significant additions include greater

recognition and respect for patient autonomy, and increased concern for social justice. Designed to be universally relevant to physicians across many geographic, cultural, technological, and economic environments, the Charter offers guidance to healthcare professionals in their practice of medicine. However; it doesn't offer guidance to IT professionals in the development of health information systems. While ethical issues, including information security and privacy, are important in any IS application, they are even more important in medical applications. The Health Insurance Portability and Accountability Act (HIPAA) requirements (Deshmukh and Croasdell, 2004), for example, makes this especially important in medical applications where design theory and principles provide the means for developers to cope with situations in which they may not have access to users for determining requirements (Cusumano & Selby, 1995).

The Charter is characterized by three fundamental principles: the principle of primacy of patient welfare, the principle of patient autonomy, and the principle of social justice. The principle of patient autonomy is a new concept in the practice of medicine. The fundamental principles are supplemented by ten responsibilities, and together, guide healthcare providers in the practice of medicine.

Ethics

Healthcare providers rely on ethical guidelines for the resolution of ethical issues that arise with the treatment of patients. The medical ethics guidelines which are called upon to resolve issues that address religious beliefs, family conflicts, futile medical efforts, economic concerns, and respect for the autonomy of a patient and the patient's wishes. It is important to incorporate both

the ethical guidelines that healthcare providers rely on, as well as the ethical guidelines for computing professionals into healthcare systems design theory. In the following sections two widely accepted ethical theories are introduced; Beauchamp and Childress's (2001) principles of biomedical ethics, and the Association for Computing Machinery's ethical guidelines for computing professionals.

Principles of Biomedical Ethics

Beauchamp and Childress (2001) develop a set of principles and rules that are widely accepted by the medical community, and provide guidance for resolution of ethical conflicts. The principles are; (1) respect for autonomy, (2) beneficence (seeking to do good), (3) non-maleficence (avoidance of harm), and (4) justice (fair distribution of resources). There are four rules that supplement these principles: (1) veracity, (2) privacy, (3) confidentiality, and (4) fidelity (faithfully maintaining duty to care).

Ethical Guidelines for the Computing Profession

The Association of Computing Machinery offers computing professionals ethical guidelines for the resolution of ethical conflict (Table 1.2). These guidelines are widely accepted in the computing profession and are characterized by four major categories; (1) general moral imperatives, (2) professional responsibilities (specific issues regarding professional conduct), (3) organizational leadership (specific issues regarding individuals in leadership roles, and (4) compliance with the code.

Each profession has a set of guidelines to both guide professional practice and to assist in the resolution of ethical conflicts that each may face. And, while these guidelines assist each in resolution of conflicts when they arise, neither set alone is sufficient to guide a designer in the design and development of HIS. Therefore a comprehensive set of professional and ethical guidelines to assist developers in the design and development of HIS is needed. A synthesis of the professional and ethical guidelines for both professions results in a design theory, characterized by a set of design principles, to guide the design and development of these uniquely complex systems. These principles are described in the next section.

Table 1: Charter of Medical Professionalism

Charter of Medical Professionalism

Fundamental Principles

1. Principle of Primacy of Patient Welfare: ***Based on a dedication to serving the interest of the patient. Altruism contributes to the trust that is central to the physician-patient relationship. Market forces, societal pressures, and administrative exigencies must not compromise this principle.***
2. Principle of Patient Autonomy: ***Physicians must have respect for patient autonomy and must be honest with their patients, empower them to make informed decisions about their treatment as long as those decisions are in keeping with ethical practices and do not lead to demands for inappropriate care.***
3. ***Principle of Social Justice:*** The medical profession must promote justice in the healthcare system, including the fair distribution of healthcare resources. Physicians should work actively to eliminate discrimination in healthcare, whether based on race, gender, socioeconomic status, ethnicity, religion, or social category.

Professional Responsibilities

1. ***Commitment to Professional Competence:*** Physicians must be committed to lifelong learning and be responsible for maintaining medical knowledge and clinical team skills necessary for provision of quality care.
2. ***Commitment to Honesty with Patients:*** Physicians must ensure that patients are completely and honestly informed before the patient has consented to treatment and after treatment has occurred.
3. ***Commitment to Patient Confidentiality:*** Earning patient trust requires appropriate confidentiality safeguards be applied to disclosure of patient information. This commitment extends to discussion with persons acting on a patient's behalf when obtaining a patient's own consent is not feasible.
4. ***Commitment to Maintaining Appropriate Relations:*** Physicians should never exploit patients for any sexual advantage, personal financial gain, or other private purpose.
5. ***Commitment to Improving Quality of Care:*** Physicians must be dedicated to the continuous improvement in the quality of care.
6. ***Commitment to Improving Access to Care:*** A commitment to equity entails the promotion of public health, preventative medicine, as well as a public advocacy on the part of each physician, without concern for the self-interest of the physician or profession.
7. ***Commitment to Fair Distribution of Finite Resources:*** While meeting the needs of individual patients, physicians are required to provide healthcare that is based on wise and cost effective management of limited resources.
8. ***Commitment to Scientific Knowledge:*** Much of medicines' contract with society is based on integrity and appropriate use of scientific knowledge and technology. Physicians have a duty to uphold scientific standards, promote research, and to create new medical knowledge and ensure its appropriate use.
9. ***Commitment to Maintaining Trust by Managing Conflicts of Interest:*** Physicians have a duty to disclose potentially compromising relationships, such as those associated with industry and opinion leaders, clinical trials, and for profit organizations.
10. ***Commitment to Professional Responsibilities:*** Physicians are expected to work collaboratively to maximize patient care, be respectful of one another, and participate in the process of self-regulation, including remediation and discipline of members who have failed to meet professional standards.

Table 2: Summary of the ACM Code of Ethics and Professional Conduct (ACM, 1997).

<i>Summary of ACM Code of Ethics & Professional Conduct</i>	
General Moral Principles	
	1. Contribute to Society and Human Well Being
	2. Avoid Harm to Others
	3. Be Honest and Trustworthy
	4. Be Fair and Take Action Not to Discriminate
	5. Honor Property Rights
	6. Give Proper Credit for Intellectual Property
	7. Respect the Privacy of Others
	8. Honor Confidentiality
Specific Professional Responsibilities	
	1. Strive to achieve the highest quality, effectiveness & dignity in both the process and products of professional work.
	2. Acquire & maintain professional competence.
	3. Know & respect existing laws pertaining to professional work.
	4. Accept & provide appropriate professional review.
	5. Give comprehensive & thorough evaluations of systems and their impacts.
	6. Honor contracts, agreements & responsibilities.
	7. Improve public understanding of computing & its consequences.
	8. Access computing & communication resources only when authorized.
Organizational Leadership	
	1. Articulate social responsibilities & encourage acceptance.
	2. Manage personnel & resources to build systems that enhance quality of working life.
	3. Acknowledge & support proper and authorized uses of resources.
	4. Ensure that users and those who will be affected by a system have their needs clearly articulated during the assessment and design requirements; later the system must be validated to meet requirements.
	5. Articulate and support policies that protect the dignity of users and others affected by computing systems.
	6. Create an opportunity for members of the organization to learn principles and limitations of computer systems.
Compliance with Code	
	1. Uphold and promote the principles of this Code.
	2. Treat violations of the Code as inconsistent with membership in the ACM.

Initial HIS Design Principles and Guidelines for HIS

In the following sections a set of design principles developed to guide the design and development of HIS's is developed and tested using an action research strategy. The HIS design principles are a result of the synthesis of the professional and ethical guidelines for both the

computing and medical professions. The guidelines are characterized by three dimensions; a set of general moral principles, a set of responsibilities for HIS designers, and a set of technical responsibilities for HIS design. These principles will serve as the foundation for the development of an advanced directives decision support system (ADDSS), and through that collaborative, iterative, development process these initial guidelines will be refined and tested. The result is proposed to be a set of tested and refined set of design principles that guides developers with these unique and complex systems in the healthcare context.

ADDSS Case and HIS Design Theory

Action research is one strategy appropriate for design theory building and testing (Walls et al., 1992; Markus et al, 2002). Characterized by an iterative, collaborative effort between researcher and practitioner in which the researcher is both an instrument and observer (Myrdal, 1975; Markus et al., 2002). The goal of action research is better theory, better understanding and better development of applications for practice.

In the current project, action research provides the mechanism for testing the HIS design principles. Action research begins with the design principles that resulted from the synthesis of the design principles based on kernel theories. These initial principles are used as the basis for specifying the system features; once developed and deployed; the use and impacts of the system are observed and result in the refinement of the initial design principles (Markus et al, 2002). This iterative process is continued until a final set of principles is developed, deployed, and evaluated, and the resulting system achieves the goals of the organization.

The goal of the action research arm of the methodological triangulation is not only to test the design principles but also to develop an HIS through a collaborative effort with a healthcare organization. The HIS is developed to both address the organization's goals as well as to explore the second research question, "Can system design result in a more autonomous user?" In the following section the research context in which the action research study takes place is presented.

Research Context

The test of the initial set of design principles that resulted under the design science arm of the methodological triangulation of this project is carried out through a collaborative effort with a midsized hospice in Central Florida. The hospice is one branch of a large hospital organization. This organization provides healthcare for end of life patients, both independently and in partnership with many healthcare facilities. The patients are characterized as those with terminal illnesses who are no longer pursuing curative treatments and have an estimated life expectancy of six months or less. The patients of the hospice can be cared for by the hospice healthcare providers in their homes, hospital, nursing home, or assisted living facility. The hospice itself has no inpatient facilities. Given the nature and stage of the illness of the hospice patients end of life issues are of extreme urgency.

The hospice has set increased completion rates of advanced directives by its patients as an important organizational goal. Advanced directives (AD) are a tool developed by the medical

and legal communities to facilitate patient autonomy. It is the goal of the hospice to have close to 100% of their patients complete advance directives so that they are able to respect their patient's autonomy with regard to their treatment wishes. Currently the completion rate is about 20%.

Over a year of collaboration, observation of patients and healthcare provider interaction, and meetings with management at the hospice has resulted in requirements determination, systems development, and implementation and testing of the ADDSS. The hospice has also set the goal of updating the physical paper forms for AD's to a computerized system housed on laptops that the nurses currently take with them on patient visits. In addition, the hospice participates in community programs that educate people about AD's and has expressed an interest in having a computerized program that they could eventually use for community education. And lastly, the hospice expressed the goal of having a computerized tracking system to show that they are in compliance with a federal law which states that all healthcare organizations that receive federal funds must expressly ask if a patient has a completed AD.

In order to understand the issues involved in the development of the ADDSS it is important to have an understanding of both the concept of patient autonomy and advance directives. The following sections provide an introduction to each of these concepts.

Patient Autonomy

The principle of autonomy is based on Kant's Principle of Respect for Persons (Beauchamp and Childress, 2001), which holds that individuals have the right to make their own choices and

develop their own life plan, which in a medical setting translates to informed consent (Garrett, 1993). Autonomy is defined as the right of an individual, as a chooser, to act intentionally, with understanding, and without controlling influences that determine their actions (Stiggelbout et al., 2004). There are two dimensions of autonomy; information seeking and decision-making. Patient autonomy refers to the decision making dimension, and enhancing patient autonomy means helping patients make their own decisions (Stiggelbout et al., 2004).

Advanced Directives

Patients frequently cite loss of personal control and autonomy as one of the most unsettling issues faced with regard to terminal illness. Advance directives (AD) are one avenue for patients to have their personal autonomy extended past the time when they are able to voice an opinion regarding their choices. The justification for ADs is grounded in the notion that they extend patient autonomy into future states of incompetency through patient participation in decision making about end of life care (Ikonomidis & Singer 1999).

The complexity of ADs is often overlooked. Many assume that the legal forms will cover all of the necessary issues should the time come when individuals can no longer make decisions on their own. However, this is often not the case. ADs are written or oral statements that communicate choices offer legal protection and are meant to enhance autonomy. Although legally sufficient, difficulties arise in complex situations with ADs as they often lack sufficient detail to provide guidance about patient preferences (Redman, 2006).

It is suggested here that a patient decision support system can assist patients in making decisions

regarding ADs, and that the design of such systems can lead to a more empowered and autonomous patient. Specifically, an ADDSS is proposed as the healthcare information system to achieve all of the hospice's goals, increasing the numbers of patients that complete Ads, and therefore achieving the additional goal of respecting patient's autonomy with regard to treatment wishes.

ADDSS

It is proposed here that ADDSS's can facilitate communication between patients, their families, and their healthcare providers, so that sufficient details regarding their preferences are communicated. An ADDSS can also aid healthcare providers and surrogates in making decisions should a patient become mentally incompetent to do so.

The system includes several options for the patients to choose from with regard to the level of information that they wish to receive. This is achieved by providing links to additional information that the system users can follow or minimize depending on their desired level of information. The framing and amount of information provided by the system is an important consideration. If the user is overloaded with information the user might experience cognitive overload and not complete the AD. If not enough information is provided to the user they user cannot make an autonomous decision with regard to their AD choices. The ADDSS itself while it is in the design process, it is somewhat modeled after the TurboTax© system which guides the user through choices and allows the user to gather the level of information that they desire.

The development process began with the incorporation of the initial HIS design principles and through collaboration with hospice healthcare providers, observation of the interaction of patients, family members and healthcare providers, and initial system development the initial principles have been refined, and tested.

The next chapter provides the theoretical background from both the medical and MIS literature. This background serves as the foundation for the development of the HIS design theory employed in the action research project.

CHAPTER TWO: THEORETICAL BACKGROUND: DESIGN SCIENCE AND HEALTHCARE INFORMATION SYSTEMS

Design and design theories are central to the information systems discipline (Walls et al., 1992; Markus et al., 2002; Hevner et al., 2004; Lindgren et al., 2004). Benefits of design theories include providing researchers a basis for making predictions about system use, patterns and impacts; and making problems more manageable for developers (Markus et al., 2002). “A design theory is a prescriptive theory based on theoretical underpinnings which says how a design process can be carried out in a way which is both effective and feasible.” (Walls et al., 1992, p. 37) Walls and his colleagues (1992, p. 17) also suggest “...there is a need for theory development based on paradigms endogenous to the area itself.”

MIS has a long history of examining the role of design theory. Churchman (1971) referred to IS design theory in abstract terms, relying on general systems theory and emphasizing the relationships between the designers, developers, clients and users. Mason and Mitroff (1973) brought inquiring systems theory into the IS literature early on, effectively making it endogenous to the field. Klein and Hirschheim (2001) propose a rational way for thinking about value judgments that underlie design and development and the issues that are involved in choosing and crafting designs and address selection from a collection of overlapping, sometimes conflicting ideas. Markus et al. (2002) offer design principles for emergent knowledge processes that have unique requirements not supported by familiar classes of systems. Hall et al. (2003) address validity issues and offer an architecture for knowledge management systems based on Churchman’s inquiring systems. Richardson and Courtney (2004) provide an IS design theory

based on the Singerian inquirer. And lastly, Richardson (2005) synthesizes Boland's distributed cognition with Habermas' theory of communicative action and offers a set of information systems design principles that emphasize communication in distributed cognition.

The role of information technology in healthcare organizations has also been addressed in the medical informatics literature. In 1990 Lorenzi recognized the increasingly important role of information technology in healthcare organizations and examined change management as it related to information technology in the healthcare industry. Ash (1997) went on to examine organizational factors that influence information technology diffusion in healthcare organizations. Patel et al. (1998) proposed that it would be helpful to examine medical informatics as a local science of design; as a local science design principles simplify and explain parts of the domain of interest rather than a unifying set of assumptions. Berg (1998) and Kaplan (2001) examine socio-technical issues surrounding patient care and information technology. Several research areas have covered the design of specific aspects of software applications such as interface design for healthcare environments (Patel et al, 1998), the design of web based healthcare systems (Kushniruk et al. 2001) and the design of electronic patient records (Patel and Haux 2001).

The above summary of the literature in both MIS and the medical informatics literature reveals two things. First there is recognition of the importance of the design of healthcare information systems. And secondly the approach to design of healthcare information systems as a class of systems has not been addressed at all in the MIS literature, and has been addressed in the medical

informatics literature primarily as a “local” or specific type of healthcare information system and not as a class of systems itself.

It is suggested here that healthcare information systems are a class of systems with unique a domain and set of characteristics. Furthermore it is suggested that existing IS design theories do not meet the requirements, and cannot generalize, to the development and design of HIS. Nor can the design of HISs be addressed by applying general systems theory because the result would be a general solution and one that would not adequately address the unique requirements of these systems. The goal of this research is to develop a design theory that can provide guidance to system designers and result in more effective HISs that improve the quality of healthcare.

In the following section healthcare information systems will be defined as a class of systems. The unique characteristics of HISs will be described in order to achieve greater insight into the role of, and need for, a design theory to be used in designing and developing these systems.

Healthcare Information Systems

HISs can be defined as the acquiring, storing, distributing, and using of information in a healthcare environment, and usually involving the use of information technology. HISs are interdisciplinary in nature and have a unique set of characteristics such as; potential life and death impact for the patient who is the main client of the system but often not the user of the system; a challenging and unique domain; unique user requirements; requires knowledge and expertise in both the medical and computing fields; requires both general and contextual knowledge; has challenging information requirements; a unique impact on users; different and

conflicting user goals, fuzzy boundaries. The environment in which these systems operate is hectic, fast passed, isolated and fragmented, and at the same time collaborative, and inundated with isolated IT applications that are the result of rapid development of applications and have resulted in fragmentation in the industry. Lastly, HISs have to communicate critical and complex information to a variety of individuals with diverse cultural and educational backgrounds. All of these characteristics are modified daily by a rapidly growing body of scientific knowledge.

It is important to remember that these systems not only impact the user in the medical profession, but increasingly impact the patient as a user as well. Advancements in medical knowledge have increased the burden of chronic disease by extending life expectancies (Scott et al., 1997) and making available increased treatment options. As a result today's patients are placed in the difficult position of having to make complex decisions, sometimes while facing a life threatening illness, at a time of crisis in their lives. Deciding between several treatment options with complex tradeoffs involving quality and length of life can be difficult for patients (Scott, et al., 1997). Current MIS design principles do not address the evolving complexities of HIS design. Therefore there is a need for a new design theory to address the design and development of HISs. In the following sections HISs are described in order to illustrate the need for new design theory in this area.

The Need for a New Design Theory for HIS

In order to understand why there is currently a need for a new design theory for HIS it is helpful to understand the evolution of the use of information systems in healthcare organizations. An

understanding of the history of the use of these systems, as well as the changing impact and use of these systems today will highlight the need for a new theory.

Evolution of Information System Use in Healthcare

Information systems have been used in healthcare organizations for over 30 years. Healthcare information systems made their way onto the landscape of healthcare organizations as data driven administrative organizational systems that mirrored the information systems found in most types of organizations. Historically information systems in healthcare organizations have addressed issues such as admissions and discharge, payroll, billing, insurance, and related tasks. These systems helped healthcare organizations improve efficiency in their operations and achieve cost reduction. Today the role of healthcare information systems has changed with the emphasis turning to information and knowledge management. The information systems that have resulted from this shift include clinical decisions support systems, knowledge management systems, communication systems, and simulation systems for use in teaching and surgery. No longer solely housed in administration, health information systems have found their way into the actual practice of medicine, often in the form of a laptop computer, personalized digital assistant (PDA) or other portable device that travels with physicians and other healthcare workers.

Knowledge management systems have allowed physicians to incorporate evidence-based medicine into their practice of medicine. Evidence based medicine is defined as “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al., 1996, p. 71). Through the use of growing databases such as MedLine which house current scientific research, knowledge management systems allow

physicians' easy access to information which they can incorporate into treatment decisions for their patients. The premise behind these systems is that they set the "gold standard" for medicine and allow physicians to stay on the cutting edge of knowledge by searching and critically evaluating the available research (Villanueva-Russel, 2005). Some other health information systems that are showing up in the medical field include diagnostic expert systems, drug interaction notification systems, telemedicine, and protocol based systems. And, very new to the scene are knowledge management, decision support systems, and communication systems intended for use by the patient in gaining access to medical professionals, information, and for use in facilitating decision making with regard to healthcare decisions.

The evolution of information systems in healthcare has been remarkable. The results have often been not only faster and more efficient systems, but also reduction in treatment errors, improved diagnosis, portable electronic health records to improve communication between healthcare providers, telemedicine that can facilitate treatment in rural areas to those who might otherwise have little or no access to healthcare, and algorithms for improved prescription of medication. These changes have been rapid, and the improvements welcome. The benefits from the use of information technology in the healthcare context have improved the overall delivery of medical treatment. However, technology was arguably unleashed on the healthcare industry with inadequate consideration to issues such as privacy, socio-economic differences and access to and distribution of resources in order to achieve the greatest good for the greatest number. Questions of how to design, develop, and implement these new systems have not kept pace with the development of the technology itself.

Early in the evolution of health information systems, standard organizational decision theory and principles could be applied to systems development because the issues these systems tackled mirrored those of other organizations in other domains. However the landscape is changing and currently there is not a design theory or principles that are applicable for the development of these new systems; therefore today's healthcare information systems require a new IS design theory as explicated by Walls, et al. (1992) and (Markus et al. 2002).

In the following section the problems with the current design theory applied to HISs is discussed. Understanding the poor fit between the current systems design principles and HIS's illustrates the need for new theory to guide the development of these important applications.

Problems with Current Design Theory Applied to HIS

Current views of the practice of medicine as characterized in the medical literature, and as captured in the Charter of Medical Professionalism, seem to be a poor fit to current system design theory and existing classes of systems. This gap seems to be the result of several disconnects between requirements of contemporary healthcare information systems and established classes of systems and their associated design theories and guidelines.

First, there is increased demand for patient empowerment, autonomy, and independence on both the part of the patient and the medical community, HIS design, development, and implementation often ignores the patient's viewpoint in favor of more vocal stakeholders (Millenson, 2006). Healthcare providers, insurance companies, lobbyists, politicians, and the organizations, onto which we have unloaded the financial responsibility of our entire healthcare

industry collectively hold a louder and more powerful voice regarding healthcare than do the individuals, or the collective patients. While battling over costs, liability, privacy, HIPAA, electronic medical records, business opportunities, and related issues that seem so removed from the issues that an individual making personal healthcare decisions considers, they all espouse to one thing: the patient needs to be at the center of our healthcare system.

A patient centric healthcare system is an easy leap, especially if healthcare is “defined as the care of one’s mental and physical condition, wellbeing and vigor through the prevention, treatment, and management of illness” (Wilson-Steele, 2006, pg. 44). However when discussions begin regarding healthcare and its associated costs, payment system, and business opportunities our politicians, lobbyists, hospital executives, and others in power seem to lose sight of the ideal healthcare system that they otherwise support. It only takes attendance at one hospital meeting regarding a patient at the end of life and their associated care to realize that cost control is paramount; that the business model outweighs all else. When the discussion turns to numbers and “moving patients out” there is no way to conceptualize the current system as the system we aspire to have; a patient centric system in which patients are at the center and can chose their healthcare based on their preferences and needs.

If we are truly going to have a patient centric system in our current age of technology driven healthcare, consideration of patient education, consent, and access are paramount to change our current system. The current system is characterized by organizations managing risk, and payers who have little choice over their treatments or the distribution of their private health information. Patients are not true consumers and currently do not have the information or confidence to

manage their own treatment. The current system is more disempowering than empowering. More informed, more involved and overall smarter patients are not in anyone's current budget (Wilson-Steele, 2006).

An HIS design theory is needed to close the disconnect between the current system design and its focus on business and traditional medicine. Systems need to be developed that have the patient in mind as the primary stakeholder, even if he or she is not the actual user of the system. Systems that are designed with a patient centric philosophy will empower patients either directly through their own use, or indirectly through the use of healthcare providers as they administer medical care.

The second gray area that represents a need for an HIS design theory is system fragmentation or granularity. System fragmentation is both a blessing and a curse. The traditional paper based systems created medical records that contained private healthcare information and were stored at a provider's office. Mail, telephones and fax machines were the only technology available to exchange personal health information between providers. The result was a medical record that was a distributed entity. Fragmentation of the information contained in the records was difficult to compile and analyze. This was an inherent safeguard to the privacy of an individual's private health information. However, until recently this inherent fragmentation was not viewed as an asset but rather an obstacle to increased efficiency, effectiveness, and cost control in the healthcare industry. Advancements in information technology have provided the means to overcome much of the fragmentation. The results have been positive in terms of providing information quickly, when and where it is needed. For example, when a patient is presented to

an emergency room a quick and accurate medical record can greatly improve treatment and could make the difference between life and death for the patient.

Other benefits have been realized as well. Lower cost, more timely and accurate information exchange has dramatically decreased costs for many healthcare providers. And, the meta data that integrated databases can provide to departments of public health and researchers have greatly improved our ability to understand public health issues, respond to threats, identify both effective and ineffective treatments, and provide low cost and beneficial health education for members of low socio-economic groups.

The unleashing of information technology on the healthcare industry has brought many positive consequences, however it has brought many unintended negative consequences as well. The loss of fragmentation has provided both public and private healthcare organizations with access to large integrated databases that hold the private health information of millions of individuals. The result has been a significant loss in autonomy through the loss of control of individual private health information.

Insurance companies and other private corporations have taken full advantage of the new applications of information technology to healthcare. Through large integrated databases they have compiled large amounts of data and have developed analytical tools to be able to both identify trends and profile individuals. Often the result is the loss ability for an individual to get or maintain reasonably priced health insurance. This is critical to accessing medical care in our current system.

It is proposed that the ethics discourse in both the medical and computing literatures, contemporary professional guidelines in both disciplines, as well as design science provide a sound theoretical foundation for the development of a design theory for the design and development of HISs. An ethical HIS design theory characterized by a set of design principles can provide guidance for developers in developing systems that adapt to the rapidly changing environment of healthcare in general, the emerging role of the patient, and the role that information technology will play in shaping healthcare in the future.

In the following section the ethical theories both the medical and MIS literature are discussed. These theories will lay the foundation for the development of a theory for HIS design.

Theoretical Background

In following sections the Charter of Medical Professionalism and the Principles of Biomedical Ethics will be synthesized with the existing design science literature and the ethical guidelines in the MIS literature and the Association for Computing Machinery's (ACM) code of ethics. A design theory for HIS design will result from synthesizing these ethical theories. The HIS design theory will be grounded in the principles that guide the practice of medicine as well as the design of information systems, and which also encompasses the moral guidance from both disciplines providing an appropriate moral basis.

In the following chapters the theories that provide the foundation for the HIS design principles are described. The current principles and guidelines for the medical profession are first

described and lay the groundwork for addressing design issues related to information systems in healthcare. Next the MIS literatures in design science as well as professional guidelines for the computing profession are described. A synthesis of these theories will result in a set of design principles derived from the literature in both the computing and medical professions.

CHAPTER THREE: PRINCIPLES, RESPONSIBILITIES AND ETHICAL GUIDELINES FOR THE MEDICAL COMMUNITY

The Charter of Medical Professionalism is an attempt by several influential international organizations of internal medicine to address the ethical dilemmas presented by the use of new technology. The Charter also addresses the increasing influences and impact of corporations on the healthcare industry. It recognizes and responds to the changes resulting from the use of information technology on the provider-patient relationship, differences in treatment with regard to uneven distribution of wealth and cultural differences. The Charter is the first of the ethics literature described in the following sections.

The Charter of Medical Professionalism

The medical community is recognizing the changing environment that it is practicing in today. It is facing issues such as globalization, bioterrorism, problems in healthcare delivery, insurance and institutional issues, changing market forces, and the impact of technology have changed healthcare today. These changes in healthcare systems throughout the industrialized world have threatened the values of medical professionalism (Sox, 2002) and have led medical communities across the globe to call for a renewed sense of professionalism. The result of this outcry has been the Charter of Medical Professionalism, which seeks to “encompass a set of principles to which all medical professionals can and should aspire” (Adam 2003, p. 1). The product of the American Medical Association, The Council of Medical Specialties Societies, The American Board of Internal Medicine Foundation, the American College of Physicians-American Society of Internal Medicine, and the European Federation of Internal medicine, the efforts to develop of

the Charter of Medical Professionals span across continents. Frequently referred to as an updated Hippocratic Oath, the Charter of Medical Professionalism adds two key principles; honoring patient autonomy and social justice (Morse, 2002). Patient autonomy is especially emphasized in this new set of principles to guide physicians in the practice of medicine as shared decision making becomes more and more the reality of today's physician-patient relationship. Shared decision making is at the basis of modern medicine, and the principle of autonomy in the Charter of Medical Professionalism emphasizes patient autonomy by stating that physicians must empower their patients to make informed decisions regarding their treatment course (Picano, 2004).

Characterized by three fundamental principles which provide its foundation and ten professional responsibilities, the Charter is a mix of old and new. The principle of primacy and patient welfare dates from ancient times carried forward from the Hippocratic Oath; principles two and three, patient autonomy and social justice have a more recent history (Sox, 2002). The following is a brief description of each of the principles and responsibilities as outlined in the Annals of Internal Medicine (Sox, 2002).

Three Fundamental Principles

1. *Principle of primacy of patient welfare.* This principle is based on a dedication to serving the interest of the patient. Altruism contributes to the trust that is central to the physician-patient relationship. Market forces, societal pressures, and administrative exigencies must not compromise this principle.

2. *Principle of Patient Autonomy.* Physicians must have respect for patient autonomy. Physicians must be honest with their patients and empower them to make informed decisions about their treatment. Patients' decisions about their care must be paramount, as long as those decisions are in keeping with ethical practice and do not lead to demands for inappropriate care.
3. *Principle of Social Justice.* The medical profession must promote justice in the healthcare system, including the fair distribution of healthcare resources. Physicians should work actively to eliminate discrimination in healthcare, whether based on race, gender, socioeconomic status, ethnicity, religion, or any social category.

Professional Responsibilities

1. *Commitment to professional competence.* Physicians must be committed to lifelong learning and be responsible for maintaining medical knowledge and clinical team skills necessary for the provision of quality care. More broadly, the profession as a whole must strive to see that all of their members are competent and must ensure that appropriate mechanisms are available for physicians to accomplish this goal.
2. *Commitment to honesty with patients.* Physicians must ensure that patients are completely and honestly informed before the patient has consented to treatment and after treatment has occurred. This expectation does not mean that patients should be involved in every minute decision about their medical care; rather, they must be empowered to decide on their own course of treatment. Physicians should acknowledge that healthcare errors do occur and will inform a patient promptly after such an error occurs because failure to do so will seriously compromise the patient

- and social trust. Reporting and analyzing medical mistakes provides the basis for appropriate prevention and improvement strategies and for appropriate compensation to the injured party.
3. *Commitment to patient confidentiality.* Earning the trust and confidence of patients requires that appropriate confidentiality safeguards be applied to disclosure of patient information. This commitment extends to discussions with persons acting on a patient's behalf when obtaining a patient's own consent is not feasible. Fulfilling the commitment to confidentiality is more pressing now than ever before, given the widespread use of electronic information systems for compiling patient data and an increasing availability of genetic information. Physicians recognize, however, that their commitment to patient confidentiality must occasionally yield to overriding considerations in the public interest (for example, when patients endanger others).
 4. *Commitment to maintaining appropriate relations with patients.* Given the inherent vulnerability and dependency of patients, certain relationships between physicians and patients must be avoided. In particular, physicians should never exploit patients for any sexual advantage, personal financial gain, or other private purpose.
 5. *Commitment to improving quality of care.* Physicians must be dedicated to continuous improvement in the quality of healthcare. This commitment entails not only maintaining clinical competence but also working collaboratively with other professionals to reduce medical errors, increase patient safety, minimize overuse of healthcare resources, and optimize the outcomes of care. Physicians must actively participate in the development of better measures of quality of care and the application for healthcare delivery. Physicians both individually and through their

- professional associations, must take responsibility for assisting in the creation and implementation of mechanisms designed to encourage continuous improvement in the quality of care.
6. *Commitment to improving access to care.* Medical professionalism demands that the objective of all healthcare systems be the availability of a uniform and adequate standard of care. Physicians must individually and collectively strive to reduce barriers to equitable healthcare. Within each system, the physician should work to eliminate barriers to access based on education, laws, finances, geography, and social discrimination. A commitment to equity entails the promotion of public health preventative medicine, as well a public advocacy on the part of each physician, without concern for the self-interest of the physician or profession.
 7. *Commitment to a just distribution of finite resources.* While meeting the needs of individual patients, physicians are required to provide healthcare that is based on the wise and cost effective management of limited clinical resources. They should be committed to working with other physicians, hospitals, and payers to develop guidelines for cost effective care. The physician's professional responsibility for appropriate allocation of resources requires scrupulous avoidance of superfluous tests and procedures. The provision of unnecessary services not only exposes one's patient to avoidable medical harm and expense but also diminishes the resources available to others.
 8. *Commitment to scientific knowledge.* Much of medicine's contract with society is based on the integrity and appropriate use of scientific knowledge and technology. Physicians have a duty to uphold scientific standards, promote research, and to create

new knowledge and ensure its appropriate use. The profession is responsible for the integrity of this knowledge, which is based on scientific evidence and physician experience.

9. *Commitment to maintaining trust by managing conflicts of interest.* Medical professionals and their organizations have many opportunities to compromise their professional responsibilities by pursuing private gain or personal advantage. Such compromises are especially threatening in the pursuit of personal or organizational interactions with for-profit industries, including medical equipment manufacturers, insurance companies, and pharmaceutical firms. Physicians have an obligation to recognize, disclose to the general public, and deal with conflicts of interest that arise in the course of their professional duties and activities. Relationships between industry and opinion leaders should be disclosed, especially when the latter determine the criteria for conducting and reporting clinical trials, writing editorials or therapeutic guidelines, or serving as editors of scientific journals.
10. *Commitment to professional responsibilities.* As members of a profession, physicians are expected to work collaboratively to maximize patient care, be respectful of one another, and participate in the process of self-regulation, including remediation and discipline of members who have failed to meet professional standards. The profession should also define and organize the educational standard-setting process for current and future members. Physicians have both individual and collective obligations to participate in these processes. These obligations include engaging in internal assessment and accepting external scrutiny of all aspects of their professional performance.

In addition to the Charter of Medical Professionalism, a response by practitioners to the changing environment, there has been increased attention paid to medical ethics and professional guidelines in the research literature as well. Beauchamp and Childress (2001) have established a set of biomedical ethics principles that are widely accepted by both research and practice. In the following section Beauchamp and Childress's (2001) theory of biomedical ethics is described.

Principles of Biomedical Ethics

In addition to the Charter of Medical Professionalism the practice of medicine is guided by a set of biomedical ethics principles that address professional conduct in the practice of medicine. Beauchamp and Childress (2001) provide four ethical principles for resolution of ethical issues; these include Autonomy, Beneficence, Non-maleficence, and Justice. Reflecting the changing medical environment Beauchamp and Childress (2001) emphasize autonomy as the primary responsibility.

Principles

Autonomy: "Autonomy is based on the principle of respect for persons which holds that individual persons have the right to make their own choices and develop their own life plan" (Garrett et al.1993, p. 28). "This principle translates into the principles of informed consent which states that a physician shall not treat a patient without the informed consent of a patient, or surrogate" (Garrett et al, 1993 p. 29). In order to abide by the principles and affirm autonomy the physician must make every possible effort to discuss treatment options and preferences with

the patient, and document those preferences in the patient's medical chart

(<http://www.erlanger.org>).

Requirements for informed consent, as described in the Erlanger Medical Ethics Manual, include the following. (1) The patient or surrogate must be competent and capable of understanding the consequences of consent, and capable of making a choice free from coercion or undue influence. (2) It is the responsibility of the healthcare provider to express opinions and recommendations without undue pressure. (3) And, it is the responsibility of the physician to make the information understandable to the patient and, through reflective conversation, ensure that the patient or the surrogate understands the information.

Autonomy is also maintained by preserving the privacy of individual patient's health information. Information technology has changed the meaning of securing health information. Data storage, analysis, and distribution have made the information that results from these systems more useful and valuable. Maintaining privacy is often a balancing act in which public and private entities make trade offs between preserving the privacy of information and using the information stored in large integrated databases to learn about public health and effective treatment strategies.

In order to maintain autonomy an individual must be informed. Information systems have the ability to bring mass amounts of information to individuals to facilitate decision making.

However, the information presented by the system must first be accurate. Second, the patient must be able to easily wade through a sea of information and not get lost in information

overload. Lastly, the ways information systems present information can impact an individual's understanding and opinions and influence their healthcare decisions. Therefore the framing of information by information systems can have a significant impact on autonomy.

The notion of autonomy is a recent one in medicine. The use of information systems in healthcare and health education has changed the balance of power healthcare. Historically physicians have been able to rely primarily on their own judgment when providing patient treatment and education. However, in recent years this balance of power has shifted in a couple of ways. First, the civil rights movement of the 60's and 70's brought attention to patient's rights. More recently health education, and therefore treatment decisions, have been increasingly under the control of patients. This has had a significant impact on the balance of power in the physician-patient relationship. The Internet has had played a significant role in bringing health information to patients, resulting in a more empowered patients and increased autonomy.

In addition to the changing relationship between provider and patient, power has also shifted toward business in healthcare. Both private and public organizations are calling for larger integrated databases and authorization to access the information within them. The use of private health information by these organizations often is obtained and used at the price of individual autonomy. In large part this loss of autonomy has been facilitated by the use of information systems in healthcare and the resulting shift from reliance on beneficence to autonomy as the primary ethical principle in medicine. Today the balancing act between beneficence and autonomy is a continuing effort.

Beneficence: The principle of beneficence requires the physician to do good, or what ever will further the patient's interest. While historically this was the primary ethical principle in the practice of medicine cultural changes and the impact of information technology have resulted in significant changes in the medical ethics that guide our healthcare industry today. Today beneficence provides the primary goal of rational medicine while autonomy sets the moral limits on the healthcare professional's actions in pursuit of beneficence (Beauchamp and Childress, 2001).

Non-maleficence: The principle of non-maleficence states that a physician should do no harm, and avoids actions that would be against the patient's wishes. Technology and modern medicine have made causing no harm a more difficult decision for healthcare providers. Treatments that can sustain life often cause significant harm. Decisions about what causes harm is less clear in today's medical environment, especially when considering withdrawing and withholding life sustaining treatments, and extraordinary and ordinary treatments. The medical community is relying more frequently on balancing non-maleficence with autonomy and has created tools such as the living will to address this balance. Placing the decision in the hands of the patient so that his or her wishes can be respected whenever possible.

Justice: The final of the four principles is the principle of justice which requires fair distribution of limited resources, namely medical goods and services. The goal being achieving the greatest good for the greatest number. In the information age social justice and autonomy often conflict, especially when considering the use of individual health information for public good. This

balancing act is a difficult one but invaluable in keeping the rapid changes imposed by information technology in check.

It is essential in designing healthcare information systems that the principles, responsibilities, and biomedical ethics guidelines that govern the practice of medicine be incorporated into the principles which guide systems design. Design theory in MIS has evolved resulting in theories and design principles which address broad social and ethical issues to more detailed principles for the design of specific types of systems. However design of healthcare information systems has not addressed the design of complex, information and knowledge management oriented systems. A synthesis of the principles, responsibilities, and biomedical ethics principles from the medical community with the insights from the evolution of systems design and the code of ethics which guides systems design will result in theory, design principles and responsibilities which will produce systems that instantiate the guidelines from both, resulting in a healthcare information system in line with both disciplines.

In the following sections the MIS design literature will be reviewed, and the Association of Computing Machinery's Code of Ethics and Professional Conduct will be presented for synthesis with those that guide the practice of medicine. In the following section a discussion of the MIS design and ethical literature, and the ethics guidelines for computing professionals are described.

CHAPTER FOUR: MIS DESIGN PRINCIPLES AND ETHICAL GUIDELINES FOR COMPUTING PROFESSIONALS

Design science and ethical considerations related to information technology have been a perennial consideration in the MIS literature since its inception. In the following sections the evolution of design science in MIS is described, as is the literature on the ethical implications of information technology and our responsibilities as computing professionals. The issues involved in this discussion will later be synthesized with the medical literature described previously in order to derive a set of ethically based design principles for the design and development of HISs.

Design Science

“Designing useful artifacts is complex due to the need for creative advances in domain areas in which existing theory is often sufficient...as technical knowledge grows; IT is applied to a new application area that was not previously believed to be amenable to IT support.” (Hevner et al., 2004, p. 76). This is especially true in the healthcare industry today as the industry increasingly adopts information technology for use in new and innovative ways. However, as is often the case in times of great change and innovation, consequences both positive and negative have often been unforeseen. Often it is only after implementation and use of information technology that consequences arise and the need for new guidelines to design future systems grows. Today the healthcare industry is in need of guidelines for development of future healthcare systems.

Fundamentally a problem solving paradigm, this paradigm seeks to extend the boundaries of human and organizational capabilities by creating new and innovative artifacts (Hevner et al., 2004). It is an iterative process that makes design problems more manageable for developers and gives research a basis for making predictions about use, patterns and impacts (Markus et al., 2002). The development of guidelines in design science not only must pass scientific tests of explanatory or predictive power but must also pass the test of practice. In the following sections the design science literature is presented in order to lay the foundation on which to build a set of design principles for HISs. Churchman's inquiring systems, and specifically Singerian systems, are ethical systems and address the complexities of general design. Churchman's theory is especially suited for laying the groundwork in order to address the complexities of design in today's complex healthcare environment.

Churchman (1971) – Inquiring Systems

In *The Design of Inquiring Systems: Basic Concepts of Systems and Organization*, Churchman identifies the necessary conditions of general systems, and he walks through the evolution of general systems theory to develop the theory of inquiring systems. Fundamental to inquiring systems are the notions of purposefulness and responsibility. Churchman takes these ideas and examines them through the lenses of several philosophers incorporating the ideas of each into the general systems theory leading to the creation of inquiring systems. He defines inquiry as activity which produces knowledge, and incorporates the ideas of inquiry into a systems perspective. Churchman's inquiring systems are learning systems that produce knowledge that is relevant to solving present day problems (van Gigch, 1995). With each stage, or each philosophical view, his inquiring systems take on richer meaning. The Singerian inquiring

system is the culmination of earlier introductions of Leibnizian, Lockean, Kantian, and Hegelian philosophies. Singerian inquiring systems promote ethical behavior, and work for the good of all humankind, as paramount in systems design. Singerian inquiring systems will be emphasized in the development of design principles for healthcare information systems. The nine components of Singerian inquiring systems are as follows.

Nine Components of Singerian Inquiring Systems

1. The system has the purpose of creating exoteric knowledge, knowledge with a strong ethical base.
2. The system's measure of performance is the "level" of scientific and educational excellence of all society.
3. The client is mankind, i.e., all human teleological beings.
4. The components of the system have traditionally been "disciplines"; this is incorrect if the goal is "exoteric" knowledge.
5. The system has a cooperative environment, with "fuzzy" boundaries, necessary for cooperation.
6. The decision makers are everyone – in the ideal.
7. The designers are everyone – in the idea. Progress can be measured in terms of the degree to which the client, decision maker, and designer are the same.
8. It is the designer's intention to provide a system so as to maximize its value to everyone.
9. There is built in guarantee which gives a sense of optimism.

Information Systems Design for Vigilant EIS

Walls et al. (1992, pg. 36) define an information systems theory as “a prescriptive theory which integrates normative and descriptive theories into design paths intended to produce more effective information systems.” They state that we should be more concerned with design theory as theory development is one of the major pursuits of IS researchers. Focusing on executive information systems they formalized, justified, and extended traditional IS design practice and used the term IS design theory to refer to solutions for specialized classes of design problems such as decision support systems (DSS), executive information systems (EIS), and group decision support systems (GDSS), describing features and prescribing (Walls, et al, 1992, Markus et al, 2002).

Recognizing “design” as both a noun and a verb, they propose that it is both a product (something to be done or produced) and a process (to plan or proportion the parts of a machine or structure so that all requirements are satisfied) (Walls et al., 1992). The result is a two-part design theory, one part dealing with the process of design and the other with the product; these are described below.

Design Product

- a. *Meta-Requirements*: The first component describes a class of goals to which the theory applies.
- b. *Meta-Design*: This second component describes a class of artifacts hypothesized to meet the meta-requirements.

- c. *Kernel Theories*: Includes a set of kernel theories from natural or social sciences which governs design requirements.
- d. *Testable design product hypothesis*: Used to test whether the meta-design satisfies the meta-requirements.

Design Process

- e. Design Methods: A description of procedures for artifact construction.
- f. Kernel Theories: Theories from natural or social sciences governing the design process itself.
- g. Testable Design Hypothesis: Used to verify whether the design method results in an artifact which is consistent with the meta-design.

The contributions made by Walls et al. (1992) focused designers on developing systems requirements and finding applicable theoretical foundations for system design to achieve these objectives. This was a significant contribution to the evolution of systems design.

Boland et al. (1984) – Designing Information Technology to Support Distributed Cognition

As organizations “globalized” so did information systems. Boland et al. (1994) bring the evolution one step further by recognizing the distributed nature of information systems, and at the same time recognizing the role of the individual in the distributed use of information systems. They produce a set of design principles for distributed cognition, based on a synthesis of Churchman’s inquiring systems and the theory of hermeneutics. They recognized the role of

individuals and their ability to make representations, explore them in a dialog with others, reflect about their implications and incorporate them into action (Boland et al., 1994). They offer a set of design elements for the design of distributed cognition systems. Their resulting design principles are as follows.

Elements

1. *Actors:* The system is oriented toward an individual person, not a group, because only individuals can have hermeneutic understanding.
2. *Interpretations:* The system is oriented toward an actor's interpretations of his or her situation taken as an integral, whole unit of understanding, not toward a database of facts or decision models. An actor's interpretation includes an understanding of the factors at work in a situation and their relationships.
3. *Action:* The system is oriented toward the actions that punctuate the ongoing process of distributed cognition.

Design Principles

1. *Ownership:* An interpretation is always owned by an actor who is responsible for creating and maintaining it.
2. *Easy Travel:* An individual's interpretation should display a hypertext like structure in which any element can be linked to any other, and the links can be followed quickly and easily.

3. *Multiplicity*: Each actor involved in distributed cognition should make her own interpretations and be able to participate in the exchange and critique of representations.
4. *Indeterminacy*: Interpretations are not required to be comprehensive or complete; there is no final or stable understanding in hermeneutics.
5. *Emergence*: New, more abstract concepts and constructs will be developed during the process of interpretation. The hermeneutic circle involves playful experimentation with new concepts, categories, and levels of representations.
6. *Mixed form*: Actors have sometimes radically different modes of expressing their understandings, ranging from pictures and graphs to text.

Klein and Hirschheim (2001) – Choosing Between Competing Design Ideals in Information Systems Development

Klein and Hirschheim (2001) bring value judgments and competing design ideals into the evolution of design theory in MIS, and offer a rational way for thinking about value judgments that underlie design and development. They examine how value judgments impact the choosing and crafting design of ideals during information systems development. This work “contends that advice concerning the design of information systems must not be limited to technical design, but should also address what is good or bad, or right or wrong in any particular situation – a notion termed design ideals” (Klien and Hirschheim, 2001, p.75). The works of Habermas and critical philosophy allowed insights into the question of how information systems can best serve all stakeholders by recognizing that all systems include value judgments. Albert’s “bridging principles” are introduced to incorporate some rules of reasoning with regard to design ideals.

Managing Value Conflict – A Three Part Process

Klein and Hirschheim present a three part process to deal with value conflict through informed discourse, which is described as follows.

1. Clear identification of the pertinent design ideals
2. Collecting information to shed light on the implementation and tradeoffs between conflicting design ideals.
3. Construction of arguments to facilitate the convergence on a preferred design ideal, the one that has survived maximal criticism and is relatively best supported by various kinds of evidence.

Markus Et Al (2002) – A Design Theory for Systems That Support Emergent Knowledge Processes

Markus et al. (2002) propose a set of design principles for emergent knowledge processes (EKP's) that have unique requirements not supported by familiar classes of systems. EKP's are defined as “organizational activity patterns that exhibit three characteristics in combination: an emergent process of deliberations with no best structure or sequence; requirements for knowledge that are complex (both general and situational), distributed across people, and evolving dynamically; and an actor that is unpredictable in terms of job roles or prior knowledge.” (Markus et al., 2002, pg. 179). The EKP principles are developed in line with the Walls et al. (1992) theory and principles regarding systems design and are described as follows.

EKP Design Theory Principles

1. *Design for Customer Engagement by Seeking Out Naïve Users:* The system must be self-deploying; developers should conceptualize each user-system interaction as a customer engagement process and repeatedly seek out “naïve” users through a process of “onion-layering” the design team.
2. *Design for Knowledge Translation through Radical Iteration with Functional Prototypes:* The system must translate expert knowledge into actionable knowledge for non-experts; developers should expect to need many functional prototypes, instead of a few nonfunctional prototypes.
3. *Design for Offline Action:* The system must induce users to take offline action; developers must observe and strive to change a user’s offline, as well as online, action.
4. *Integrate Expert Knowledge with Local Knowledge Sharing:* The system must integrate expert knowledge with local knowledge sharing; multiple needed functionalities must be integrated rather than added.
5. *Design for Implicit Guidance through a Dialectical Development Process:* The system must implicitly, not explicitly, guide users’ deliberations in desirable directions, without restricting them to a prescribed process; developers should use a dialectical development process instead of a consensus seeking approach.
6. *Componentize Everything, Including the Knowledge base.* The system must be extremely flexible; developers should componentize everything, including the knowledge base.

The EKP design theory proposed by Markus et al. (2002) is an important contribution to the evolution of MIS design theory because it addresses the IT support and development process requirements in systems design of an important class of human activities, and it includes the process of strategic planning, new product development, basic research, and academic theory building.

Hall et al. (2003) – Building a Theoretical Foundation for a Learning Oriented Knowledge Management Systems

Following the design theory approaches established by Walls et al. (1992), Hall et al. (2003) integrate open systems theory, Churchman's (1971) theory of inquiring systems, and Simon's (1960) intelligence-design-choice model, to form the kernel theory for learning oriented knowledge management systems (LOKMS). They propose a theoretical foundation for the design of LOKMS and offer a system architecture of 11 basic modules that supports knowledge management and the decision making process which emphasizes verification and validity issues. The components of the LOKMS system architecture are as follows.

Components of LOKMS

1. *The Basis Verifier*: Assess the accuracy of the system basis, as organizations must rely on their knowledge bases as being true in order to make decisions and have faith that decisions made on the system knowledge not be compromised. The basis verifier provides a mechanism for accuracy.

2. *Environmental Verifier*: Ensures the knowledge base is not outdated by frequently reviewing information in the knowledge store and updating the knowledge store.
3. *Self-Adaptation Verifier*: Allows a system to support management by preparing reports of recommended action in the face of new knowledge or changing conditions.
4. *Analysis Integrity Verifier*: Verifies the accuracy of internal models to keep from propagating inaccurate information.
5. *Time Space Assessor*: Provides an ability to mark a system's location in time and space allowing for the ability to follow time-critical missions of the organization; and ensuring that all temporal considerations of the organization are met.
6. *Resource Monitor*: A continual test of dynamic inquiring systems to see if new knowledge candidates can be added to the knowledge store.
7. *Hypothesis Production Manager*: Prevents over-production of candidates.
8. *Best-Fit Analyzer*: Because of the number of potential new candidates, models in the inquiring system test new knowledge candidates for "best fit." This prevents a model from being considered if the model is not performing efficiently.
9. *Executor*: Is the guarantor of the model verification.
10. *Best Measures Guarantor*: Challenges known measures or measure components and guarantees best measures.
11. *System Guarantor*: Challenges known measures or measure components and guarantees an accurate system.

Hall et al. (2003) contribute to the evolution of design theory in the MIS literature by offering a theoretical foundation for the design of LOKM's. Their design principles, based on open

systems theory, inquiring systems, and the intelligence-design choice model, bring an emphasis of verification and validation to design theory to the existing literature.

Richardson and Courtney (2004) – A Churchmanian Theory of Knowledge Management Systems Design

Richardson and Courtney (2004) employ Churchman's inquiring systems as the kernel theory on which to base knowledge management systems design. Using Churchman's nine requirements for a system and his Singerian inquiring system they develop a Churchmanian knowledge management system (CKMS) and principles for their design. CKMS's are defined as a "purposeful and ethical information system that creates exoteric knowledge and provides a link between knowledge and action in an organization." (Richardson and Courtney, 2004, p. 1). Their design principles have a strong emphasis on ethical behavior, success measures, the need to ensure that CKMS enhance the dignity of humankind, a highly participatory design process, the desire to unify the designers, decision makers and clients, and the need for a guarantor to validate knowledge residing in the system. The design principles for a CKMS are as follows.

CKMS Design Principles

1. The CKMS designers, the design process, and the CKMS itself should adhere stringently to ethical and moral principles, for example those espoused by the Association for Computing Machinery in its code of ethics and professional conduct.

2. A CKMS should be a learning system itself and exhibit sustainability by being easily adaptable to changing environmental conditions.
3. CKMS success measures should be developed for specific applications, based on information system and organizational memory success measures existing in the literature.
4. The client of the CKMS should include all salient stakeholders.
5. The CKMS should be designed to encourage the decision maker to manage the system in such a way as to increase the measure of performance to the client, and do so in an ethical manner.
6. The CKMS should do minimal harm.
7. The designer must ensure that the CKMS and knowledge it handles are used to enhance the dignity of humankind, and choose only those clients and decision makers who also abide by this imperative.
8. Design is highly participatory in a CKMS environment, and the client, decision maker, and relevant stakeholders are all swept into the design process along with the CKMS design staff members themselves.
9. Another dimension of success of a CKMS is the extent to which designers, clients and decision makers are one and the same.
10. Each system component should be shaped in relation to the other component and to the system as a whole, so as to co-produce the measure of performance (that is, contribute to the creation of exoteric knowledge) and should not be constrained by organizational boundaries in doing so.

11. The CKMS should include mechanisms for guaranteeing the validity of the knowledge it contains.

Richardson and Courtney (2004) contribute a set of design principles for the development of knowledge management systems that emphasize the goal of creating exoteric knowledge, and at the same time emphasizing ethical behavior and the inclusion of all salient stakeholders throughout the design process. They propose that a CKMS should do minimal harm, and enhance the dignity of those individuals that it affects.

Richardson (2005) – Knowledge Management and the Design of Distributed Cognition Systems

Richardson (2005) recognizes the increasingly important role that knowledge management systems are playing in the strategic advantage of today's organizations, and that this increased reliance on knowledge management systems must be taken into account when designing information technology to support today's organizational knowledge operations. Through the use of philosophy, the role of knowledge management in distributed cognition is examined, and design principles for these systems are proposed. Richardson (2005) modifies the design principles for distributed cognition proposed by Boland et al. (1994) by adding Habermas' (1984) theory of communicative action. The result is a set of design principles proposed as a framework for the design of information technology that emphasizes the role of communication in distributed cognition and knowledge management in organizations. The design principles for these systems are as follows.

Elements

1. *Actors:* The system is oriented toward an individual operating within a social context through discursive communication. The result is merging individual interpretations into organizational knowledge.
2. *Interpretations:* The systems are oriented toward an individual operating within a social context through discursive communication, which provides a mechanism that validates each individual's interpretation.
3. *Action:* Through discursive communication understanding between group members can provide the knowledge for the inquiring system which has the goal of using knowledge as "potential" for action.
4. *Communication:* Through discursive communication the system provides the means for validating and fusing together the interpretations, producing collective organizational knowledge.

Design Principles

1. *Ownership:* Discursive communication provides the mechanisms for moving interpretations owned by individuals into a social context, this is necessary for creating organizational knowledge.
2. *Easy Travel:* Discursive communication provides a mechanism to provide direction, and validates the volumes of information that result from easy travel within the hypertext system.

3. *Multiplicity: Discursive communication provides a forum for open and validated communication to occur – a requirement for exchange and fusion of the representations of individuals in order to form organizational knowledge.*
4. *Indeterminacy: Explicitly leaves room for conversations from separate views and discursive action provides the mechanism for open and validated communication.*
5. *Emergence: Discursive communication provides the forum for bringing together the interpretations of individuals and validates them, as a result interpretations are fused together and new organizational knowledge emerges.*
6. *Mixed Form: Discursive communication provides a mechanism, through validity claims, to ensure that actors are communicating accurately with each other, this is especially important if they are using different forms of expressing their understanding.*

Boland et al., (1994) provided an original set of design principles for distributed cognition that viewed hermeneutics as the mechanism for a group of individual to exchange ideas, and inquiring systems as the mechanism for how to build and test knowledge representations (Richardson, 2005). Richardson (2005) adds to the evolution of design principles by suggesting that there are some missing links in the connection between hermeneutics and inquiring systems and that the addition of Habermas' theory of communicative action provides the link between the two. The addition of the theory of communicative action also provides a validation mechanism by allowing for the creation of validated knowledge to enter the system, and for group knowledge to emerge. Lastly, the notion of a guarantor in inquiring systems is supported through the validity claims of the theory of communicative action.

Design theory has evolved over the past 30 years resulting in guidance for current and future researchers with regard to how to approach systems design. However it is not only the current literature on design theory that guides researchers in the design of information systems, the literature has also included an examination of ethics in MIS as well as the development of an accepted code of ethics, the Association for Computing Machinery (ACM) Code of Ethics and Professional Conduct that guide the behavior of those professionals who design computer systems. In the following sections the MIS literature on ethics in MIS and the ACM's Code of Ethics and Professional Conduct, as published in ACM Computing and Public Policy, and adopted by the ACM Council in 1992 will be reviewed.

Ethics in the MIS Literature

There are two major contributions to the MIS literature with regards to ethical issues in the field. Mason describes four important issues regarding ethics and MIS. He outlines the four issues in his PAPA framework. A discussion of these four ethical issues is included in the following section. This discussion is followed by a description of the ACM's Code of Ethics and Professional Conduct.

PAPA (Mason, 1986)

“Management information systems (MIS) professionals have a central role in technology development, determining how technology is used in organizations and the effects it has on clients and society” (Udas, et al. 1996, p. 721). In a healthcare information system, the

information systems that MIS professionals develop create the “reality” for patients, by controlling the information with which they make complex decisions regarding their healthcare. “Information is the means through which the mind expands and increases its capacity to achieve its goals; thus information forms the intellectual capital from which human beings craft their lives and secure their dignity” (Mason, 1986, p. 5); as such the information distributed by healthcare information systems can change the treatment path a patient takes, altering goals of treatment, and as a result having significant impacts on an individual’s life and dignity.

Mason (1986) addresses four ethical issues in the information age, and the responsibilities we have as members of the MIS community to our society in this information age. He proposes that, though ethical issues are complex and varied, it is helpful to focus on just four, summarized as PAPA (Privacy, Accuracy, Property, and Accessibility).

Four Ethical Issues for the Information Age

1. *Privacy* addresses concerns about what information about one’s self or associations must a person reveal to others and under what conditions can individuals expect safeguards for their information. Privacy issues address surveillance and the combinatory effects of information integration. Also of concern are information selling and inaccurate information.
2. *Accuracy* addresses misinformation which can have a significantly negative impact on an individual’s life. “A special burden is placed on the accuracy of information when people rely on it for matters of life and death; and it is our responsibility to be vigilant in the pursuit of accuracy in information” (Mason, 1986).

3. *Property* is a complex issue with several ethical concerns. While Mason was not specifically considering property of health information it is not much of a leap to apply his general thoughts about the use of information systems, and specifically expert systems, to a medical context. Intellectual property rights are a concern, as is ownership of one's medical records. Who owns information in a medical database is a concern, as "the process of diseminating knowledge from an individual and subsequently emending it into machines transfers control of the property to those who own the hardware and software" (Mason, 1986, p. 9) and with regard to medical records raises the question of ownership.
4. *Accessibility* is the last of the ethical issues. The main avenue to information is through literacy as literacy is a requirement for full participation in today's information society. A person must possess a minimum of three things to be literate; the intellectual skills to deal with information, access to information technologies which store, convey and process information, and access to the information itself (Mason, 1986). This is of special significance with regard to healthcare information systems as patients encompass all socio-economic and cultural groups, not all of which possess these three skills, and the absence of one or more can mean that they do not have full access to the medical information that they require.

The moral imperative for MIS professionals is clear, "we must ensure that information technology, and the information it handles, and are used to enhance the dignity of mankind" (Mason, 1986, p. 11). And, we must assume some responsibility for the social context that is created from the systems that we design and implement and ensure that they are used to create

the kind of world in which we wish to live (Mason, 1986). Specifically, with regard to healthcare information systems, MIS professionals have the responsibility to address and secure whenever possible, information privacy, accuracy, property, and accessibility, as well as patient welfare, autonomy and social justice.

The role of ethics and the professional conduct of the computing professional has been specifically addressed in the MIS literature. The ACM's Code of Ethics and Professional Conduct solidifies these issues and serves as a basis for decision making for medical professionals in their computing work. The ACM's Code will be reviewed in the following section.

ACM's Ethical Guidelines for Computing Professionals

The ACM's Code of Ethics and Professional Conduct is intended to serve as a basis for ethical decision making in the conduct of computing professional work. Derived from more general ethical principles, the general moral imperatives included in the ACM's Code can be relied upon to guide resolution regarding ethical conflict. It is proposed that resolution of questions regarding ethical conflicts can be achieved through thoughtful consideration of the principles included in the code of ethics. The Code of Ethics and Professional Conduct, as published by the ACM (1997) are divided into four major sections as follows; first, general moral imperatives which outlines fundamental ethical considerations; second, professional responsibilities, which address additional and specific issues regarding professional conduct; third, organizational leadership imperatives, address issues specific to individuals with leadership roles; and fourth, compliance, deals with issues concerning compliance with the code. The code is characterized as follows.

General Moral Imperatives

1. *Contribute to society and human well being:* Concerns the quality of life of all people and affirms an obligation to protect fundamental human rights. It is the aim of computing professionals to minimize negative consequences of computing systems, including threats to health and safety. When designing or implementing systems computing professionals must ensure that the products of their efforts will be used in socially responsible ways meet social needs and avoid harmful effects to health and welfare.
2. *Avoid harm to others:* Harm means injury or negative consequences. This principle prohibits use of computing technology in ways that harm any of the following users: users, the general public, employees, and employers.
3. *Be honest and trustworthy:* Honesty is an essential component of trust. Without trust an organization cannot function effectively. The honest computing professional will not make deliberately false or deceptive claims about a system or system design, but will instead provide full disclosure of all pertinent system limitations and problems.
4. *Be fair and take action not to discriminate:* Equal tolerance, respect for others, and principles of equal justice govern this imperative. Discrimination on the basis of race, sex, religion, age, disability, national origin, or other such factors is an explicit violation of ACM policy and will not be tolerated.
5. *Honor property rights including copyrights and patents.*
6. *Give proper credit for intellectual property.*
7. *Respect the privacy of others.* Computing and communication technology enables the collection and exchange of personal information on a scale unprecedented in the

- history of civilization. Precautions should be taken to ensure the accuracy of data, as well as protecting it from unauthorized access or accidental disclosure to inappropriate individuals. Furthermore, procedures must be established to allow individuals to review their records and correct inaccuracies.
8. *Honor confidentiality.* The ethical concern is to respect all obligations of confidentiality to employers, clients, and users unless discharged from such obligations by requirements of the law or other principles of the code.

Specific Professional Responsibilities

1. *Strive to achieve the highest quality, effectiveness and dignity in both the process and products of professional work.* Excellence is perhaps the most important obligation of a professional. The computing professional must strive to achieve quality and to be cognizant of the serious negative consequences that may result from poor quality in a system.
2. *Acquire and maintain professional competence.* Excellence depends on individuals who take responsibility for acquiring and maintaining professional competence. A professional must participate in setting standards for appropriate levels of competence, and strive to achieve those standards.
3. *Know and respect existing laws pertaining to professional work.* Existing laws and policies of the organizations in which a professional works must be obeyed.
4. *Accept and provide appropriate professional review.* Professionals should participate in peer review as well as provide critical review of the work of others.

5. *Give comprehensive and thorough evaluations of computer systems and their impacts, including analysis of possible risks.* Computer professionals are in a position of special trust and therefore have a social responsibility to provide objective, credible evaluations to employers, clients, users, and the public.
6. *Honor contracts, agreements, and assigned responsibilities.*
7. *Improve public understanding of computing and its consequences.*
8. *Access to computing and communication resources only when authorized to do so.*

Organizational Leadership Imperatives

1. *Articulate social responsibilities of members of the organizational unit and encourage full acceptance of those responsibilities.* Leaders in the profession must have recognition on the impact the public, and accept responsibilities to society, in meeting social responsibilities as well as quality performance.
2. *Manage personnel and resources to design and build information systems that enhance the quality of working life.*
3. *Acknowledge and support proper and authorized uses of the organization's computing and communication resources.*
4. *Ensure that users and those who will be affected by a system have their needs clearly articulated during the assessment and design of requirements; later the system must be validated to meet requirements.* Current system users, and potential users, and other persons whose lives may be affected by a system must have their needs assessed and incorporated in the statement of requirements. System validation should ensure compliance with those requirements.

5. *Articulate and support policies that protect the dignity of users and others affected by a computing system.* Computer professionals who are in decision-making positions should verify that systems are designed and implemented to protect personal privacy and enhance personal dignity.
6. *Create opportunities for members of the organization to learn the principles and limitations of computer systems.*

Compliance with Code

1. *Uphold and promote the principles of this Code.*
2. *Treat violations of the Code as inconsistent with membership in the ACM.*

The theories, guidelines, and professional codes of conduct discussed in this chapter provide a solid theoretical foundation from which design principles for HIS's can be derived. By synthesizing theories from both the medical and computing disciplines, and paying particular attention to the ethical foundations of these theories, design principles can be developed to guide designers and developers in creating ethical and effective HIS's that will shape the future of medicine. In the following chapter a set of design principles for the design and development of HIS is offered. A discussion of the ethics literature, which provides the justification for these moral theories, is also offered.

CHAPTER FIVE: DESIGN PRINCIPLES FOR HEALTHCARE INFORMATION SYSTEMS

The role of information systems in healthcare is changing and there is a need for a contemporary set of design principles that will address the behaviors of designers, medical professionals, and other stakeholders, as well as the technical aspect of the information technology in this unique environment. It is proposed here that the principles and responsibilities captured in the Charter of Medical Professionalism which guides the practice of medicine, as well as the principles of biomedical ethics, a universally accepted set of guidelines for the practice of medicine, should be synthesized with existing design theories and principles from the MIS literature which guide information systems design, and the ACM's Code of Ethics and Professional Conduct, an accepted set of guidelines for ethical and professional conduct of computing professionals.

Health information includes information for staying well, preventing and managing disease, and making other decisions related to health and healthcare (Ehealth Ethics Initiative, 2000). A *Healthcare Information System (HIS) is defined as a purposeful and ethical knowledge management system that provides a link between knowledge and action in a physician-patient relationship by creating exoteric knowledge, enhancing communication, supporting patient welfare, autonomy, and social justice in the treatment of patients.* The following principles and responsibilities are the result of the synthesis of these professional principles and responsibilities, as well as the ethical guidelines, for both the practice of medicine and the computing professional, and are proposed as the principles to guide healthcare information system design.

Design Principles and Guidelines for Healthcare Information Systems

General Moral Principles

1. An HIS will be designed with the goal of supporting patient autonomy and empowering patients to make informed healthcare decisions and helping patients communicate effectively with their healthcare providers.
2. A HISs will be designed to promote social justice by facilitating communication and providing information that supports the greater social good, while at the same time attending to the rights of individual patients and balancing difference in power in the traditional patient-physician relationship.
3. An HIS will be designed to support the welfare of the patient. The system will be designed to provide accurate and valid information to the patient, and their healthcare providers, in order to enhance educated and informed decision-making and treatment action, without compromise from external forces, with the goal of achieving the maximum quality of life possible for the patient.

Responsibilities for HIS Designers and Stakeholders

1. The HIS designers will adhere to the ethical and moral principles that guide the medical environment in which the system will be used and to the ethical and moral principles for those in the information systems discipline (i.e., the ACM's Code of Ethics and Professional Conduct).

2. An HIS should be oriented toward patient autonomy, and therefore should exhibit sustainability by being easily adaptable to the changing environmental conditions the users will face. The HIS will be designed for easy modification, improving patients' access to information resulting in improved collaboration with healthcare providers and improved overall decision making and quality of care.
3. HIS success measures should be developed for specific applications, based on knowledge management systems and treatment success instruments existing in the literature. Success measures will primarily relate to patient autonomy and empowerment, how effectively knowledge is created and shared, and the quality of communication.
4. The client of the HIS should include all salient stakeholders. The primary stakeholder is the patient; however, consideration should be given to other stakeholders including family, physicians, nurses, other healthcare providers, hospitals, related organizations and foundations, and the general public.
5. By maintaining trust, facilitating information sharing, communication and managing conflict, the physician and staff should be expected to manage the system in such a way as to increase the measure of performance to the patient.
6. The designer should seek a design that encourages the physician and staff to use the system in a way that maximizes the value to the patient, broadly defined.
7. Another dimension of success is the extent to which the designers, patients, and healthcare providers, become one. Design is a highly participatory process; the patient, healthcare providers, and other relevant stakeholders are all swept into the design process along with the HIS design staff themselves. The utmost in stakeholder cooperation will be sought.

8. System components should be shaped in relation to one another and to the system as a whole, so as to co-produce a measure of performance (that is, contributed to the creation of exoteric knowledge for patient decision making) and should not be constrained by organizational boundaries, or conflicting goals. Knowledge sharing, with the goal of effective patient treatment, will be integrated among all involved (physician, patient, family members, healthcare workers, insurance companies, pharmaceutical companies, etc.) with the privacy of patient information protected.
9. The HIS should include mechanisms for guaranteeing the confidentiality of patient information and the validity of the knowledge it contains.

Technical Responsibilities for HIS Design

1. *Privacy:* Healthcare information systems hold sensitive information and every possible measure to protect the privacy of the patient, family, and healthcare provider should be taken. Current technology, such as firewalls, antivirus programs, encryption technology, password protection, and parsing technology which obfuscates identifiable information (i.e., name, social security number, address, etc.), should be incorporated into the system design.
2. *Accountability:* Patients must be confident that there are measures to enforce professional and organizational integrity in the use of HIS's. Measures such as passwords and logs should be maintained by systems in order to trace the "footprints" of healthcare workers on information held within the system.
3. *Information quality:* The information in a healthcare information system can impact overall healthcare decisions by both the patient and the healthcare worker. Systems

must be designed in such a way as to maintain the integrity of the information within the system through such mechanisms as database normalization incorporated into the overall system design; resulting in elimination of redundancy errors and increased data integrity.

4. *Ease of Use:* The user interfaces should be designed in such a way that is easy for the user to understand and use. The terminology should be simple and clear, resulting in a system that is easy to use at a time when the patient may be under physical and psychological distress, or by a physician under extreme time pressures and addressing complex decisions. Information should be displayed clearly and in a hypertext like structure, where elements are linked together and can be followed quickly and easily.
5. *Portability:* Patients and healthcare providers are often at dispersed locations. Therefore, when applicable, systems should be networked, have web or wireless access, exist on a laptop or a personal digital assistant (PDA), to be easily transported from one location to another.
6. *Non-intrusive:* Computers can be a distraction in the practice of medicine. Every effort should be made to make the system as non-intrusive to the providing of medical care as possible. The computer should not interfere with the conversations between patients and their healthcare providers, or cause the patient undue stress or anxiety. Computers should be easily moved out of the way, such as a laptop on a wheeled care cart; or in smaller form, such as on a PDA.
7. *Mixed Form:* Individuals have different ways of relating and understanding information presented by an HIS. Physicians will relate to information differently than a patient will. Patients may differ in their preferences for the way information is

displayed. Therefore the HIS should provide different modes of expressing understanding, ranging from text, and pictures, to graphical representations.

8. *Multiplicity:* Each individual using the system will have his or her own interpretation of the information. Mechanisms should be placed within the system so that different individuals can participate in the exchange and critique of the information within the system in order to enhance understanding; internal message boards, email, instant messaging, etc. may accomplish this.
9. *Emergence:* More innovative and abstract concepts will emerge as the users employ and learn from the system and the information exchange facilitated by the system. The system will allow for experimentation of new concepts, categories, and levels of representations.
10. *Upholding Regulations:* The practice of medicine in the United States is guided by legal guidelines such as health insurance portability and accountability act (HIPAA). The system will enforce each of the regulations that impact the situation that the system addresses.

The design theory for HIS development, articulated by a set of design principles, encompasses the ethical and professional guidelines from both the medial and computing professions. Each is derived from an history of moral and ethical debates and therefore embodies opposing approaches to solving conflicts in system development in a healthcare context. Theories such as these are usually more credible, and a source of moral insight, if engaged in reflection about the conditions in which they apply. In the following section a moral justification of the three general moral principles for HIS design is offered. In the spirit of Beauchamp and Childress (2001), the

goals of this discussion are, first to engage in abstract reflection about the principles and the context in which they operate. Second, to provide a systematic presentation of the components of the ethical principles that is relevant in a medical context. And, finally to provide an integrated set of principles, and a systematic justification of those principles, for use in developing HISs.

Methods and Moral Justification for HIS Design Principles

The principles and responsibilities described above are the result of a synthesis of the ethical codes of both the medical and computing professions that serve to guide the design and development of healthcare information systems. Given that these principles encapsulate the essence of professionalism in each discipline it is proposed here that a system designed and developed in accordance with these HIS principles and responsibilities will uphold those from its two contributing disciplines. However HIS's are complex and varied, both in the environments in which they operate and the functions that they are to achieve. While the general moral principles apply to all applications, each individual responsibility outlined above may not be applicable in every situation or system design and development project. The responsibilities should be incorporated whenever possible and should the application of the principles result in conflict; the persons involved must exercise their best professional judgment as to which rule should prevail.

In order to best resolve conflicts in HIS development it is helpful to understand the nature of moral and ethical conflict. In the following discussion the roles of moral and ethical theories are

described, as are the history and evolution of these concepts in modern medicine and the development of the information systems used in the medical context.

Beauchamp and Childress (2001) engage in *theory* development through the process of evaluating other ethical theories and engaging in abstract reflection and argument. The result is a theory of biomedical ethics characterized by an organized system of principles. They present justification for the theory they offer by providing a moral justification of the principles they develop. In this current project their process provides the method for justifying the general principles for the development of HISs offered here. In the following sections a discussion of the moral justification of the three general moral principles for HISs is offered.

Moral Dilemma and Ethical Conflict

Before considering the moral justification of each of the three general principles it is important to identify the inherent nature of conflicts and moral dilemmas that exist in the areas of ethics, medicine, and information technology. Beauchamp and Childress (2001) define *ethics* as a generic term that provides various ways of understanding and examining moral life, and *morality* as norms about “what is right and wrong conduct that are so widely shared that they form a stable (although usually incomplete) social consensus” (p. 2).

As we learn and grow over time we incorporate the norms of our culture as the equivalent of moral behavior. However, it is important to understand that morality is inherently a social institution that encompasses many standards of conduct, characterized by moral principles, rules,

rights, and virtues that are grounded in our culture and transmitted across many generations (Beauchamp and Childress, 2001).

It is especially important to understand the cultural dependence of morality in medicine. Both patients and health care providers are characterized by diverse cultural, geographic, religious and educational backgrounds. What one individual sees as a perfectly clear “correct” choice, another may find troublesome and offensive. In situations of complex, and often conflicting, medical treatment decisions, it is important to consider morality from every possible viewpoint.

If it is morality that encompasses our norms and ideas of right and wrong conduct, and morality is based on social and cultural norms, it is important to reflect about the ethics that provide conventions for us to understand these norms that embody a moral life. Ethical theory and moral philosophy refer to reflection about and understanding the justification of moral actions. “These words refer to attempts to introduce clarity, substance, and precision of argument into the domain of morality” (Beauchamp and Bowie 2004, p.1).

Morality and ethics capture a picture in time, defined within a specific cultural moment, and informed by thoughtful reflection and analysis from the past. In order to understand medical ethics today we must not isolate our reflection from the culture in which it resides. Medicine is not an “isolated enclave, but rather resides in our social midst” (Tauber 2001, p. 300). The rules of society inform and direct what is considered ethical in the practice of medicine through governance, politics, community, and business.

If an understanding of medical ethics today cannot be accomplished without considering the external forces that shape it, then the impact of information technology on the practice of medicine should be a forefront consideration. Medical ethics in the 21st century is shaped by the cultural and political environment in which it resides, and cannot be fully understood without explicit attention paid to the technological changes which have so strongly impacted the practice of contemporary medicine.

Information technology has significantly shaped the practice of medicine today. Health information is collected, analyzed, stored, and distributed in ways never before possible. The results often lead to moral dilemmas surrounding issues such as privacy of information, protection of patient autonomy, the use of information technology for the benefit of society, disclosure of information, and how information is framed and presented to individuals. These, and other changes, have created a need for new ethical guidelines to address the use of IT in our current environment

Health information is perhaps “the most intimate, personal, and sensitive of any information maintained about an individual” (Gostin 2001, p. 322). An information infrastructure, as a significant part of our medical and social systems, is well underway. Not a single area of medicine has been left untouched by technology. Information systems in medical care took off before we knew the pros and cons of their use, the impact that these systems would have on individuals, and society. Each of the four generally accepted areas of medical ethics has been significantly impacted by the use of information technology leaving us with unclear social norms from which to address conflicts and to move forward.

In the following sections each of the three general moral principles for HIS development are examined in the light of today's social, technical, political, and medical environment. This discussion is presented as follows. First, the fundamental moral and ethical concepts for each of the three general moral principles for HIS design are described. Mason's (1986) four ethical issues for the information age (PAPA) is offered as a framework for examining the implications of information systems design on the moral and ethical foundations captured in the general moral principles. Next, a discussion of the moral justification for the three general moral principles for HIS development is offered in the spirit of Beauchamp and Childress (2001). Their framework is used to engage in reflection and argument of existing theories in order to develop a systematic and thoughtful set of guidelines to guide developers of HISs. The ethical justifications for the three general moral principles, which form the foundation of the general moral principles in the HIS design theory, are provided in the following sections.

Autonomy

The first general principle for HIS design is grounded in patient autonomy. It states that *HISs will be designed with the goal of supporting patient autonomy and empowering patients to make informed healthcare decisions and helping patients communicate effectively with their healthcare providers.*

Autonomy is defined as "self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevents meaningful choice"

(Beauchamp and Childress 2001, pg. 58). The concept of autonomy has a long history and has

made its way from a primarily a political moral philosophy into many of modern scientific, political, social, legal, and medical moral philosophies.

“Autonomy is always exercised in a context” (Engelhardt 2001, p. 284). The definition of autonomy has changed along with the cultural, political and economic landscapes of the past three centuries. Today the notion of autonomy provides the foundation for much of our moral and ethics theories that guide our social, political, legal, and economic activities.

By many accounts autonomy has become *the* governing principle in biomedical ethics. “Kant’s philosophical concept of autonomy in American bioethics developed within a unique cultural moment and thereby assumed a particular character, a role it was to play as part of a larger social and political drama” (Tauber 2001, p. 304). To fully understand autonomy, and in particular its role in contemporary medicine, it is beneficial to examine its context from an historical perspective.

The idea of autonomy was originated by Kant (Beauchamp and Childress, 2001) and provides the fundamental core of his moral philosophy (Beck, 1999). Kant developed the concept of autonomy following the significant political changes of the 17th and 18th centuries. This period was characterized by dramatic changes in the social and political landscape, such as the erosion of monarchical power, the weakening of religious authority, expanding egalitarian rights, and significant gains in scientific knowledge that was not always in line with the powers that be.

It was during this time that liberal democracy arose. This new philosophy of democracy moved society away from religion as the source of moral authority and toward moral independence and individual responsibility (Tauber, 2001). Kant's reaction to this moral shift was to guide us to look within ourselves. He rejected the previously held ideas that individuals were guided by religious beliefs and fear of punishment that promoted individuals to act responsibly toward each other. Denying all philosophies "which held in one form or another, that the ends justified the means" (Tauber 2001, p. 305), he believed that individuals are rational beings, that we all have unconditional worth, and that we all have the capacity to determine our own moral destiny (Kant, 1785).

Kant based his idea of autonomy on respectful action, action that should be based on personal values and beliefs (Beauchamp and Childress, 2001). Also fundamental to his moral philosophy is a deep respect for others to make choices and take action based on their own personal beliefs. He believed that to violate a person's autonomy was to put one's self and personal goals first and to treat other individuals simply as a means to an end. Above all he promoted respect for the individual.

There have been many discussions about autonomy in the literature since Kant placed it central to his moral and political philosophy. Mill expanded on Kant's autonomy and introduced the notion of utility into the debate. Mill proposed that primary concern should be given to individuality of an autonomous agent, but at the same time argued that society should permit individuals to develop according to their individual desires and convictions as long as they do not interfere with similar expressions of freedom by others (Beauchamp and Childress, 2001).

A more contemporary Kantian theory is proposed by Rawls (1971) who challenges utilitarian theories and instead develops the notion that individual rights and just distribution of goods depend less on social factors of majority interest; he develops themes of reason, autonomy and equality (Beauchamp and Childress, 2001). Rawls' recognized the randomness and unfair distribution of talents and abilities in the natural lottery and the need for compensating adjustments (Rawls, 1971). He suggested that we should imagine a hypothetical society in which genetic background, socio-economic status, race, culture, gender, talents or abilities were not known. He proposed that if we get beyond this "veil of ignorance" we could move beyond individual and cultural differences and construct a system that guarantees basic liberties for all, in which all members of society would benefit (Boyd, 2004). He sums up his philosophy by stating that "All social values – liberty and opportunity, income and wealth, and the bases of self respect – are to be distributed equally unless an unequal distribution of any, or all, of these values is to everyone's advantage." (Rawls 1971., p. 62).

In spite of its many revisions over time and varying perceptions, Kant's idea of autonomy has remained a foundation for many aspects of our society. Moral and political philosophy often guides developments in legal and political systems during times of conflict and change. Our culture values individual rights, autonomy, liberty, freedom and independence. Kant's philosophy, with autonomy at its core, has been important to the development of our society and its norms.

The role of autonomy in shaping society is especially clear in more current politics and social movements. Following the influence of the Great Society, the “me generation” of the 1960’s and 70’s evolved. It was a time characterized by suspicion and distrust of constitutional and traditional authority, characterized by familial, education, community, or political institutions (Rothman, 2001). Out of this collective suspicion and distrust of what represented traditional authority in our society rose civil rights, women’s rights, gay right’s, children’s rights, and patient’s rights. “The movements shared an unwillingness to accede to the discretionary authority of whites, men, husbands, parents, clinical investigators, mental hospital superintendents, elected officials, and of course doctors, especially if they males practicing obstetrics, gynecology, or psychiatry” (Rothman 2001, p. 256).

Within the realm of medical ethics, patient rights and the drive to autonomy in the context of the other movements of the 60’s and 70’s illustrates that it was not just chronological coincidence but rather helps us understand that without the momentum from all of these movements patient rights and autonomy would probably not have evolved. Each of these movements has one shared characteristic; each was led by lawyers (Rothman, 2001). This might seem common today but at the time it was a significant departure from the social norm. Philosophers and social scientists had led earlier social movements. The movements of the 60’s were led by lawyers whose orientation, strategy, and presumptions deeply influenced the reform goals of the time and are still very prevalent today (Rothman, 2001). The impact of lawyers on the emergence of a commitment to autonomy and patient rights is “far more critical than the term ‘bioethics’ commonly suggests” (Rothman 2001, pg. 256).

The influence of lawyers has to a large degree defined what it means to be an autonomous patient in our society today. The concepts that define autonomy today are a direct result of the impact of lawyers on this movement. Autonomy today is characterized by legal influences such as an emphasis on consent in the form of written and signed documents (such as advanced directives), mandatory disclosure, waivers, emphasis on the legal formality of medical decision-making, a formal process of establishing capacity for making an informed choice as well as understanding, and a shift in power in the doctor-patient relationship.

The institution of medicine has also shifted as a result of the legal system's impact on the practice of medicine. In recent years issues concerning the care of patients has shifted out of the hands of the physician and into those of the insurance companies and managed care. The principle customer has shifted from the patient to the insurance companies, and the economic motivations of the customer are generally at odds with support for patient self-determination (Woodward, 2001).

Also impacted by these legal influences are the issues of the impact of the prevalence of autonomy over the traditional notion of beneficence in medicine, issues of individual privacy, social justice and utility. These issues have become even more critical with the impact of information technology. Protecting individual privacy against the overall good of collecting and disseminating data from large databases comprised of patient information is an especially important legal debate as we near the governmental goal of standardization of medical records, patient ID numbers, and central databases.

The result of the evolution of autonomy has resulted in several characteristics that impact our current notion of exercising autonomy. Today we analyze autonomous action in terms of individual choosers who act: (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action (Beauchamp and Childress, 2001). Several underlying components influence an individual's ability to act within these three moral requirements, and therefore also contribute to autonomy. These components include truthful disclosure of information, consent, competence, and understanding. In today's medical environment each of these components is greatly influenced, if not controlled, by information technology.

In today's medical environment IT is arguably at the heart of an individual's ability to make an autonomous choice, and specifically impacts each of the underlying components. To this point the discussion of autonomy has primarily concentrated on the history of the concept and its role in a medical context. Understanding autonomy in the contexts of its history and its role in medicine is one important factor in understanding the role of autonomy in HIS development, but it is only half of the picture. At this point it is important to merge the medical understanding with the role of autonomy in HISs.

In the following sections this discussion of autonomy is continued, moving from a consideration in a purely medical environment into the area of management information systems (MIS). The result will be a justification of the first principle for HIS development that upholds autonomy in the development of HISs.

A Justification for Autonomy as an HIS Design Principle

The first, and fundamental, general moral principle for HIS design places patient autonomy at the forefront of system design. It states that *an HIS will be designed with the goal of supporting patient autonomy; and empowering patients to make informed healthcare decisions and communicate effectively with their healthcare providers.* Within the contemporary understanding of autonomy one of the most significant roles of information technology today is to provide information to both healthcare providers and their patients. The role of information in medicine today impacts patient autonomy more significantly than at any other time in medical history, and is arguably at the heart of patient autonomy.

Mason (1986) identifies many of the unique challenges that we face in the information age and provides four ethical issues that the MIS discipline should focus on to help resolve these challenges. He states that “information is the means through which the mind expands and increases its capacity to achieve its goal, often as the result of input from another mind...thus, information forms the intellectual capital from which human beings craft their lives and secure their dignity” (Mason 1986, p. 5). Mason was not specifically addressing the use of information systems in healthcare and the impact on patient autonomy. However, it is not much of a leap from his more general ideas of the nature of information itself and how information technology can impact the lives of individuals to the specific impact on patient autonomy.

Mason goes on to state that people’s intellectual capital is impaired whenever they lose their personal information, when they are precluded from accessing information which is of value to them, when information which they hold intimate has been revealed, or when they find out that

the information upon which their living depends is in error. Again, while he was not specifically addressing patient autonomy specifically these issues are at the heart of the patient autonomy.

“The social contract among people in the information age must deal with these threats to human dignity,” (Mason 1986, p. 5) and nowhere is this a more prevalent concern than in the context of medicine, and specifically patient autonomy. Health information is arguably the most sensitive and personal information about an individual. Information technology may make information more readily available to individuals, boosting their ability to make informed decisions. But at the same time the systems themselves pose enormous threats to the privacy and control of information of one’s autonomy, the very nature of one’s self. The loss of personal information, when a person has not chosen to release information about them is a loss of autonomy. This is just one way in which manipulation of health care information by someone other than the patient can jeopardize an individual’s autonomy. As the nation’s healthcare system “grows in size, scope, and integration, the susceptibility of that information to disclosure will also increase” (Gostin 2001, p. 322).

A breach of one’s autonomy through treatment of his or her health information is an especially complex issue in healthcare. A violation of one’s autonomy by not having the privacy of one’s healthcare information protected is a violation of one’s self. For many patients having one’s healthcare information violated through dissemination of the written word is equivalent to a violation by “unwanted gaze” (Woodward, 2001).

Autonomy is always contextual, and collaborating with others requires freely giving up some of one's freedoms (Engelhardt, 2001). A medical setting, by its very nature, is collaborative and invasive; it is a setting where body, mind and emotions may be revealed, dissected and analyzed (Woodward, 2001). The result is an inherent ethical conflict between many of the stakeholders in a healthcare setting; namely, the patient, physician, healthcare organization, insurance companies, research institutions, government institutions, and society as a whole. Clearly, guidelines are needed for the development of information systems in this setting as many moral and ethical conflicts have and will continue to arise in the future.

Successful treatment within our healthcare system depends on the accuracy, correctness, and trustworthiness of the information, and the rights of the patient to control and disclose his or her health information (Gostin, 2001). Information systems development in a healthcare setting should be guided by ethical principles that respect individual autonomy by protecting the privacy of health information.

It is difficult at best to discuss autonomy in healthcare without addressing the opposing view point, namely the idea of social justice. The concept of social justice in healthcare is grounded in utilitarian theory and supports the belief that while autonomy is important, the overall good of society is paramount. Given that the role of information technology impacts not only individuals but society as a whole it is important to balance autonomy and social justice in HIS design. In the following section a discussion of the utilitarian based social justice theory is offered.

Social Justice

The second general moral principle for HIS design is grounded in the moral philosophy of social justice. The principles states that *HISs will be designed to promote social justice by facilitating communication and providing information that supports the greater social good, while at the same time attending to the rights of individual patients and balancing the difference in power in the traditional patient-physician relationship.*

HISs have an important role in upholding social justice in the healthcare context. For example, information systems can support the good of society by providing information in such a way as to actively eliminate discrimination in healthcare based on race, gender, socioeconomic status, ethnicity, religion, or other social or economic category.

The notion of social justice is grounded in the theories of Utilitarianism, the origins of which are founded in the writings of Jeremy Bentham and John Stewart Mill (Beauchamp and Childress, 2001). Mill expanded on Kant's autonomy arguing that the autonomy of individuals was important; however society should consider autonomy in the context of upholding the greater good of society. In other words, individuals should be free to make autonomous choices as long as those choices do not interfere with like expressions and freedoms of others.

Utilitarianism can be considered conditional or contextual. Supporters of this theory regard it as responsive to changing social conditions, and believe that traditional moral rules cannot handle many of the questions posed by society, especially in light of technological developments (Beauchamp and Childress, 2001). Utility is the goal of this theory, not necessarily in terms of

the individual but rather in terms of maximizing the greatest good for the greatest number of individuals by balancing the interests of all affected persons.

Evaluation of utility is often conceptualized as the best probable outcome and is dependent on judgment (Beauchamp and Childress, 2001). Generally articulated in cost-benefit analysis and other ratios, this theory is often used to develop public health policy. When choices conflict with individual autonomy, and autonomous choices are such that they can endanger public health, potentially harm others, or require uneven distribution of resources, supporters of utilitarian theory would support utility even if it must be exercised in conflict with individual autonomy.

Utilitarian theories hold an important place in public policy, especially in the context of healthcare. In Western societies a basic philosophy underlying the law is the notion that medical information is considered a national resource, hence a kind of collective property (Roscam Abbing, 1999). As a society we benefit from research in health care as this research can result in understanding use, outcomes, and patterns of practice and determinants of the cost of health care (Gostin and Hadley, 1998).

Health is basic to all human activities. Modern medical systems incorporate distributive and social justice, regulated by governmental entities, in order to both obtain and distribute resources in a way that is intended to result in the greater good of society. It is the purpose of the government to attain human goods that individuals alone could not obtain on their own (Walzer, 1982). “Chief among those goods is the assurance of the conditions under which people can be healthy...and while the government cannot assure health, it can, within the reasonable limits of

its resources, organize its activities in ways that best prevent illness and disability, and promote health among its population” (Gostin, 2001).

The healthcare system in the United States is arguably in crisis mode. “Developing a public health information infrastructure is integral to contemporary efforts to reinvent the public health system” (Gostin, et al., 1996).

Traditionally the government and society have placed the burden of healthcare on the backs of organizations and private employers. For these organizations to remain competitive in the current global economy they must operate as efficiently and cost effectively as possible. At the same time the cost of health insurance has skyrocketed, leaving both individuals and private organizations unable to pay for coverage. Concurrent with these changes the United States faces an aging “baby boomer” generation leading to increasing numbers of individuals depending on the federal governments Medicare program for their future medical treatment. As bankruptcy for these social programs is continually projected, the government must intensely consider that “value and effectiveness of its health care system, it must acknowledge that one of the burdens of achieving cost effective and accessible care is a loss of privacy” (Gostin 2001, p. 325). Citizens will, in exchange for continued health care subsidized by the government, have to give up some level of autonomy and privacy. At the same time the government is obligated to create reasonably strong assurances of fair informational practices as it is obtaining the cost benefits of a health information system.

The current use of information systems in health care has provided an infrastructure that supports the systematic collection, analysis, and exchange of the electronic health information of millions of individuals. For society there are many advantages that result from these information systems and the transformation of the way information is handled in health care. Better data allows consumers to make better and more informed decisions about health plans, providers, diagnoses and treatments (Hodge, et al. 1999). These systems allow for the monitoring of the health of entire populations, identifying populations at risk, determining the effectiveness of treatment, assessing prognosis and the usefulness of diagnostic and screening tools, administrative support, and increased efficiency and cost effectiveness (Uphser, et al., 2001).

Supporters of utility theory in health care policy recognize the contradictions with theories such as Kant's which support individual autonomy above all else. For health care information infrastructure to support the greater societal good it must exercise broad collection and use of health data in order to obtain the high quality data that is needed for consumers to make informed choices. These systems facilitate a number of complex choices and activities such as choosing health plans and providers. They also facilitate healthcare providers in administering more effective medical care, assessing quality, cost and effectiveness of healthcare services, monitoring fraud and abuse, and tracking and evaluation access to health services, identifying patterns of morbidity and mortality among underserved populations, and lastly investigating the determination of prevention, and treatment of disease (Gostin, 2001).

Many advocates of utility theory support the creation and implementation of national information systems that can facilitate the analysis and exchange of information of all citizens. The goal of

national systems is to protect public health and national safety. Proponents believe that the government should use technological resources and medical informatics expertise to create a national health information infrastructure (NHII) that provides the underlying information utility that connects local providers and health officials to a national database through networks and national data systems (Tang, 2002).

Proposals of national health information systems are characterized by central coordination on a national level. Necessary components of a national health information system include connectivity between local provider and the national system; standardization that supports effective communication across all levels of individual healthcare providers, local, state, and federal facilities; an Internet based central database; increased public surveillance systems for patients with clinical and behavioral conditions that might be of public health concern; and lastly the use of national identifiers for providers, insurers, businesses and individuals (Tang, 2002). The American Medical Informatics Association has recommended that the federal government support the development of these projects (Tang, 2002).

Supporters of utilitarian philosophies balance autonomy and privacy with the social good that information technology can provide. In the utilitarian view the greater good of society trumps discussions of individual autonomy through the respect for privacy of information. Utility theory identifies privacy, not as holding intrinsic value, but rather as being derived from other, more fundamental ethical principles. In other words privacy is important because of its utilitarian feature as it promotes effective communication and trust, enhances autonomy, and prevents economic harm, embarrassment and discrimination in a healthcare setting (Gostin, 2001). It

would be a “mischaracterization of the ethical arguments to assume the preeminence of privacy because of its normative intrinsic values...equally compelling ethical claims can be made to support more efficient health information systems” (Gostin, 2001). Furthermore, more effective use of health information systems would promote better quality information, better research, and fair distribution of resources across society.

It is virtually impossible to discuss social justice without at the same time discussing autonomy, or visa versa. While there are many aspects of healthcare and the information systems used within a healthcare context that are at odds when viewed through the utilitarian or Kantian autonomy lenses, the issue of privacy is probably the most contentious. The privacy paradox created by these two prominent, yet opposing, ethical philosophies has created a real threat to the realization of a healthcare system that meets the high standards of care and accountability (Upshur, et al., 2001).

Patient welfare is the direct result of the balancing act between autonomy and social justice that is occurring in our healthcare system. Patient welfare is the health, happiness, well-being, and quality of life an individual experiences. Patient welfare is significantly impacted by our decisions made within a healthcare context and is a direct result of the intersection of decisions regarding autonomy and social justice within the healthcare system. The final of the three general moral principles for HIS design is grounded by the concept of patient welfare.

In the following section the third general moral principle for HIS design is described and a discussion of patient welfare the final ethical moral principle for HIS design is offered.

Patient Welfare

The final general moral principle for HIS design is grounded in upholding patient welfare. It states that *HISs will be designed to support the welfare of the patient. The system will be designed to provide accurate and valid information to the patient, and their healthcare providers, in order to enhance educated and informed decision-making and treatment action, without compromise from external forces, with the goal of achieving the maximum quality of life possible for the patient.*

Upholding patient welfare involves promoting health, happiness, good fortune, and well-being. In a healthcare context upholding patient welfare comes down to quality of life. This is a concept included in the medical ethics literature; it is essentially the concept of nonmaleficence. The concept of nonmaleficence guides healthcare providers in times of ethical conflict by stating that it is the health care provider's duty not to inflict evil or harm. This is balanced in the medical ethics literature with the concept of beneficence which refers to the moral obligation of health care providers to act for the benefit of others (Beauchamp and Childress, 2001). There is a constant balance between nonmaleficence and beneficence in the context of healthcare, and sometimes the obligation to do no harm outweighs the obligation to act for the benefit of others.

While there is generally agreement that in a medical context upholding the best quality of life is the goal, there are opposing opinions regarding defining the best quality of life. On one hand, judgments regarding quality of life can be viewed as one's social worth. On the other, quality of life is not viewed in terms of social worth, but rather the value of life for the person who must live it (Beauchamp and Childress, 2001).

Patient welfare decisions in terms of quality of life for the patient are mediated by both the concepts of autonomy and utility. It is the intersection of decisions regarding autonomy, utility, and treatment decision that define quality of life in a health care context.

The treatment issues that relate to quality of life involve the capacity of treatment to cause pain and suffering, reduction in capacity to participate in activities fundamental to experiencing life, imposing undue harm or burden on one's family and as a result diminishing the patient's life, and potentially death. Often quality of life decisions center around death with dignity, and avoidance of over treatment. Generally treatment decisions regarding quality of life involve withholding or withdrawing life sustaining treatment; extraordinary (heroic) and ordinary treatment; artificial feeding and life-sustaining medical technologies; intended effects and merely foreseen effects (Beauchamp and Childress, 2001).

While supporters of autonomy would consider quality of life decisions solely those of the individual. Supporters of a utilitarian or social justice approach to decisions about quality of life would uphold that the patient be the central focus in healthcare decisions. However, at the same time they would note that there are other players including insurance companies, managed care organizations, doctors, unions, the patient's family and friends, hospitals, clinics, and other healthcare providers, pharmaceutical companies, and government programs (Oddo, 2001) that must be taken into account when relevant to quality of life decisions.

It is important to consider both autonomy and utility when considering issues of the use and impact of information systems on both individual quality of life and the overall healthcare system. The goal should be to achieve the best possible balance between autonomy and utility. However; given the sensitivity of health information especially in the context of the use and impact of healthcare information systems, priority should be given to autonomy whenever possible. Quality of life is by its very nature a unique decision for any individual and therefore should rely strongly on promoting autonomy in the decision making process whenever possible.

The discussions of the moral foundations for the three general moral principles for HIS design reveal that these often opposing forces greatly impact decision making in a healthcare context. In the spirit of Beauchamp and Childress (2001) a discussion of the moral justification of each of these principles will follow. The goal of this process is to engage in reflection and argument that results in the systematic presentation of the basic components of the ethical issues included in HIS design. An integrated set of principles, and a systematic justification of those principles also results from this discussion.

The issues of autonomy, social justice, and patient welfare have been discussed in the ethics and medical literatures in great depth. However, these issues, as they intersect with the computing profession in a healthcare context, have not been widely discussed. In order to merge the medical discussion with MIS, Mason's (1986) PAPA framework will be used to discuss each of these ethical issues. The four ethical issues, privacy, accessibility, accuracy, and property will provide the framework for the discussion of autonomy, social justice, and patient welfare as they relate to HIS design. In the following chapter Mason's PAPA framework is discussed.

CHAPTER SIX: FOUR ETHICAL ISSUES FOR THE INFORMATION AGE

Twenty years ago Mason (1986) recognized the potential impacts of information technology on western societies. At that time he called for reflection regarding the society that was evolving as a result of increased usage of technology and asked “is the society being created one we want?” He placed the responsibility on the MIS community to reflect on these changes stating that we are at the forefront of creating this new society. Two decades later we are far from having the answers to the questions that he raised. In fact, if anything we are more aware of the concerns but less convinced of how to address them.

Mason proposes four ethical issues of the information age; privacy, accuracy, property, and accessibility (PAPA). In a healthcare context these four ethical issues focus the attention of the system designer toward aspects of information systems that can uphold or diminish patient autonomy, social justice, or patient welfare.

Mason also offered a set of questions for each of these ethical issues to facilitate reflection about the impact of information systems on society. While he was addressing the general impact of information systems in the information age, and not specifically healthcare, his questions are particularly applicable to our current healthcare system; perhaps even more than when he originally asked them.

In the following sections Mason's four ethical issues will provide the framework for the moral justification of the three general moral principles for HIS design. As illustrated in the discussion of autonomy, social justice, and patient welfare, these three principles are intimately intertwined with the impact of information technology on healthcare. Therefore the discussion of each of the three general moral principles will be described together under each of Mason's four ethical issues.

Privacy and Healthcare in the Information Age

Mason (1986) asked two general questions regarding privacy in the information age in order to address the ethical issues and impact of information technology on society. First, what information about one's self or one's associations must a person reveal to others, under what conditions and with what safeguards? Second; what things can people keep to themselves and not be forced to reveal to others? These are questions that we continue to grapple with when developing public policy regarding healthcare, when defining procedures and policies in both public and private organizations, and in the development of information systems in the healthcare context.

He also identified two forces that threaten our privacy in the information age. First is the growth of information technology, with its enhanced capability for surveillance, communication, computation, storage and retrieval of information. Second, is the increased value of information in decision making. He identified information as increasingly valuable to policy makers. Often these policy makers will covertly acquire information, invading another's privacy.

The two forces that Mason identified 20 years ago have become an even greater threat to privacy today. Advancements in information technology have made storage, analysis, and dissemination of information cheaper, easier, and more efficient. Further advancements are constant, making this technology an even greater threat to the privacy of health information. The information that results from the increased ability to analyze patient records has become of greater value to both policy makers and the business organizations that surround the medical community. These organizations include insurance companies, managed care organizations, government funding organizations (i.e., Medicare and Medicaid), and employers; just as Mason identified 20 years ago.

These questions regarding the impact of information technology, and the issues that impact our privacy in the information age remain relevant, and unresolved, in healthcare today. It is proposed that the general moral principles for HIS design offered earlier will provide guidance for designers and developers in this contentious environment. In order to lend credibility to and establish faith in these design principles it is beneficial to examine the philosophical foundations of each in order to provide a moral justification of each. In the following discussion of privacy, the first of Mason's ethical issues, the foundation of each of the general moral principles for HIS design are balanced together to provide insight into the balancing act that system designers will have to play in the murky environment in which they work today.

Privacy of Health Information

Kant (1785) proposes that autonomy encompasses not only an individual's right to freedom and self determination without undue influence from others, but also the recognition that other

individuals have the same right. In the information age, at the heart of patient autonomy is the respectful treatment of patient health information. To respect the privacy of a patient is to respect their autonomous wish to have their information remain private and not be made available to others. Respecting privacy is an important means of fostering and developing a sense of personhood. It is difficult to envision how a person can form autonomous preferences, make choices, and be self-governing without some level of privacy (Gostin, 2001).

Patient privacy is at the very core of the healthcare profession, dating back to Ancient Greece and the Hippocratic Oath, which states that “all that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal” (Garfinkel, 2001). Privacy “enhances the development and maintenance of intimate human relationships – relations of trust, friendship and love...and the expectation of privacy allows individuals to confide freely in their physicians” (Gostin 2001, p. 324), and other healthcare providers.

The nature of privacy of healthcare information is changing as we move deeper into the information age. Our healthcare system is increasingly characterized by integrated data bases that hold large amounts of data from increasingly numerous and diverse sources. Collections of information “reveal intimate details about a person and thereby deprive the person of the opportunity to form certain professional and personal relationships...this is the ultimate cost of an invasion of privacy” (Mason 1986, p. 6). The ability to establish relationships with healthcare providers is based on trust. These relationships hinge on the privacy of patient health information which facilitates trust that is critical to relationships in a healthcare context.

Health information privacy is fundamentally important to individuals in our society. Recent public opinion surveys reveal that 80% of individuals say that they have lost control over their personal information (Gostin, 2001). Currently there is a push by both private and governmental organizations to develop an information infrastructure in our healthcare system. The move to electronic patient records is accelerating and inevitable (Rindfleisch, 1997). Many are also advocating increased standardization of health information systems to increase communication, central Internet databases to serve as a national health resource directory, more effective public health surveillance systems, and national identifiers (Tang, 2002). While a health information infrastructure will arguably result in less expensive health services, more reliable and generalizable research, and other public benefits (Gostin and Hadley, 1998), the negative impact on patient autonomy is considerable.

Concern about the erosion of privacy reflects important changes in our healthcare system. First there is a transition from written to electronic records. Second, systematic flows of sensitive data throughout employer sponsored health plans, managed care organizations, hospitals, laboratories, and pharmacies. Much of this information is used for non-health or non-treatment related purposes. And lastly, advances in genetic science makes it possible to reveal intimate details about a person's health to families, employers, healthcare providers, and insurers. The inclusion of genetic information medical records transforms our records from primarily beacons into our past to windows into the most intimate aspects of our future (Garfinkel, 2001).

Given these concerns it becomes apparent that the ethical issues concerning privacy that Mason established in 1986 are a very real concern in practice today. Information technology has established very efficient storage, analysis, surveillance, and distribution of health information. The result upholds his second concern, namely that the information that results from the use of information systems will become much more valuable. In a healthcare context it is very clear today that these two predictions have been realized.

Information that can so quickly and efficiently be traded between healthcare organizations, insurance companies, and managed care organizations can have a profound impact on an individual's life. The case of improved identification of genetic identifiers for specific diseases is one example. It is increasingly common to be tested for genetic predispositions for the likelihood of coming down with an illness. This information can prove to be critical in achieving the best possible medical treatment for patients. However, at the same time it will help insurance companies, health management organizations, and employers reduce costs and streamline their role in the overall healthcare system. Therefore sensitive health information is not only easier to obtain but also very valuable for these organizations. Sensitive health information in the hands of insurance companies, or employers, can result in an individual being denied coverage for themselves or their families. An individual might possibly even be denied a job or fired because of a probability that s/he may come down with a significant illness at some future date.

As the push for a national health information infrastructure increases, and becomes closer to being realized, the concern for protection of privacy increases. As we unleash information technology to a greater degree on our healthcare system new issues emerge continuously

regarding the ways that health information can be used against individuals, having a significant negative impact on patient autonomy.

Databases and Patient Privacy

The implementation of a national health information infrastructure is immanent. There are many potential benefits that are likely to result from a national system; more efficient healthcare, reduced cost, reduced errors, and the ability to cross socio-economic and race barriers among others. However the threat to privacy that these systems impose cannot be overstated.

One requirement of a national health information infrastructure is a unique patient identifier, or patient identification number (PID). There are a number of concerns surrounding the issue of the use of PID's. The amount of information that will be associated with a PID and the value of that information to life and health insurance companies, marketers, employers, and other organizations is great, and cannot be over stated. Nor can the amount of damage that can come to an individual if there is a breach of privacy with regard to the PID, or private health information.

One immediate loss of patient privacy is the elimination of the last true outlet that individuals have to maintain the security and privacy of their health information in the current system. Currently individuals can go to a doctor, not provide any identifiable information such as a social security number, and receive treatment with no threat to their personal privacy. For some, the out of pocket expense is worth the protection of privacy. For example in cases such as genetic tests, in which just the fact that the test was performed can negatively impact an individual's

insurability, privacy may be worth the expense. The implementation of PID's would eliminate one of the last ways to be assured of protection of privacy in the current healthcare environment.

Security breaches involving large organizations with financially sensitive data are frequently in the news. We consistently hear of banks and financial organizations struggle with keeping or financial information secure. Recently a breach of security involving 26.5 million U.S. veterans occurred after when a home break was burglarized and a disc containing private information was stolen. The names, dates of birth, and social security numbers of any veteran discharged after 1975 was compromised. The point is much like a social security number, a PID would be very valuable to a number of organizations, and as a result security is always a concern.

With each of these stories of a break in security, the confidence of individuals in the ability to keep information private is diminished. However, in a healthcare setting it doesn't take theft to invade the privacy of an individual. Unfortunately the current system of obtaining medical care is in part reliant on giving away medical information, by taking advantage of informed consent, the tool developed to protect our privacy. Informed consent is intended to protect us from having just anyone be provided authority to access our private health information. Informed consent is a tool that is supposed to provide the individual with some control over sensitive health information. However, informed consent can actually harm the protection of an individual's personal health information. For example, in order to have insurance companies pay for medical claims; patients are required to fill out a claim form. At the bottom of the claim form

is a “contract” that basically eliminates any claim to privacy that an individual holds. These contracts are called consent forms and often say something along the lines of:

I authorize any physician, hospital, or other medically related facility, insurance company, or other organization, institution or person, that has any records or knowledge of me, my dependents, or our health, to disclose, whenever requested to do so by (name of insurance company here), or its representatives, any and all such information. A photo copy of this authorization will be considered as valid as the original (Garfinkel, 2001).

Consent forms illustrate a problem. On one hand they are there to protect the privacy of the individual and their health information. However, on the other hand, without relinquishing your rights and allowing basically anyone access to your medical records you cannot obtain healthcare. So, the current systems do not encourage a patient’s right to privacy, in fact it makes it increasingly difficult to maintain. But it is an individual’s right to forgo medical care to protect information. Information systems play a significant role in making this information easily accessible by others, all one has to do is sign the consent once and the information is out there never to be private again.

The discussion of informed consent illustrates an even greater problem with our healthcare system today. We have placed our healthcare system squarely on the backs of insurance companies and businesses as employers that maintain health insurance for individuals in society. These are profit driven organizations, not balanced by the Hippocratic Oath and the foundations

of medical practice that protect the patient, their autonomy, and privacy in the medical context. Nor do they operate as governmental entities that are concerned with the overall good of society, promoting social justice through the efforts grounded in utility theory.

Insurance companies take advantage of the capability of informed consent tools to coerce individuals into handing over their private health information in exchange for medical coverage. The information that the insurance companies gather as a result is feeding large integrated databases that insurance companies now rely on to analyze data in order to reduce their own costs and boost profits, often at the expense of coverage for individuals. If an individual is identified as having a condition that will be expensive to treat, or even a genetic predisposition for one of these illnesses, insurance companies can either elect not to cover that individual or significantly raise their premiums. Small businesses are also impacted as an increase in insurance rates, due to one individual, can result in a company not being able to afford coverage for any of its employees.

One example of the databases that insurance companies, and other associated organizations, have created to hold large amounts of integrated data that provides them valuable information that can increase their bottom line is the one maintained by the Medical Information Bureau (MIB). The MIB is a 100 year old organization that provides insurance companies with information about individual health and lifestyle information (www.mib.com). The National Networks for Health estimates that there are 15 million records on file and 750 insurance agencies with access to the database (<http://www.uwex.edu/ces/flp/nnh/pdfs/mrpteach.pdf>). The goal of the organization is to help insurance companies identify individuals who have medical or lifestyle conditions that

are not being revealed on insurance applications (Garfinkel, 2001). When an individual completes an application for insurance, and signs the contract at the bottom saying of the application, they are providing informed consent that allows the insurance company to gather any information about them that they desire. And, they are allowing the insurance companies to access and add to the MIB database. A database which most individuals are not even aware exists.

The MIB's combines both medical and lifestyle information to aid medical and life insurance companies in assessing premiums or to offer or deny coverage. Lifestyle information includes driving records, financial information, and participation in hazardous sports, or hobbies. MIB's description of the information it holds in its records includes:

Our records include medical conditions represented by one or more of about 230 codes. Conditions most commonly reported include: height and weight, blood pressure, ECG readings, and laboratory test results if, and only if, these facts are considered significant to health or longevity. There are only a few non-medical codes relating to information that could impact health or longevity including: an adverse driving record, participation in hazardous sports, or aviation activity.

The MIB states that its records are not to be used to deny coverage; rather they are only to be used as the basis for further investigation (Garfinkel, 2001). However, it has been a source of controversy since the 1970's. The MIB has been a part of insurance underwriting for years.

This is controversial because insurance companies were gathering information from the database without telling applicants that they were doing so (Garfinkel, 2001).

Organizations such as MIB, and the insurance companies that use the service, operate in absolute violation of personal autonomy and privacy. And, by its history and very nature MIB characterizes Mason's (1986) suggestion that information systems and their impact simply creep up on us over time.

In the past individuals were somewhat protected from the disregard for privacy and inconspicuous data gathering techniques the MIB currently employs because of information fragmentation. Today, information systems allow individual health information to easily, quickly, and efficiently be combined with a number of other data sources to develop a profile about millions of individuals that could impact their access to affordable healthcare.

The MIB illustrates the impact of information technology on the medical environment today. It specifically illustrates how the two factors that Mason described; increased storage, analysis, and distribution capabilities, and a resulting increased value of information, have impacted our entire healthcare system, and the individuals within the system. The MIB was once reasonably benign. This was due to fragmentation and because it didn't have the analytical capability that information technology provides today. However today, the impacts of technology have crept up on us, allowing organizations like MIB to operate at the expense of personal privacy and erasing the personal autonomy individuals had with regard to their health information and medical treatment.

The loss of privacy regarding health information has a number of potential consequences to an individual. Health information can reveal intimate details about a person's family's life, it can affect one's ability to hold a job, maintain custody of children, secure immigration status, or obtain access to insurance or public benefits (Gostin et al., 1996). In addition to consequences for the individual there can be a negative impact on the medical community as a whole and its ability to provide treatment. In the following section the relationship between privacy and health information, and the impacts on the healthcare community to provide treatment, are discussed.

Impact of Loss of Privacy on Healthcare

The impact of the loss of privacy has profound impacts on the ability of the medical community to provide healthcare to individuals. "Without broad confidence in medical privacy, we know there are consequences" (Rindfleisch 1997, p. 94). For example, as individuals become more aware of the erosion of privacy with regard to their health information they will likely become increasingly reluctant to share important information and concerns with healthcare providers. Another likely outcome is that physicians are forced to lie about a patient's health information. They are forced to lie because they know if they are truthful in their diagnosis and documentation, they may be entering data into patients' health record that will prevent them from obtaining insurance in the future, or possibly employment, even if the documented condition no longer exists when these decisions are made. These reservations on the part of both the patient and physician could inhibit the ability of our healthcare system to treat patients in the future. Information systems are the primary motivation for these changes the privacy and handling of patient information. Therefore designers of these systems are on the hook for

designing systems that place autonomy and privacy that is required in a medical context at the forefront of system design.

The changes that are described above, facilitated by information technology in healthcare, have altered the pact that individuals, and society, held with insurance companies, and consequently with our healthcare system as a whole. When the concept of health insurance was created it was basically a trade off of some individual privacy and autonomy for the greater good. By distributing risk across all of the individuals insured, insurance companies could insure more people and provide affordable coverage all the while making a profit. In its infancy there were safeguards. Information was fragmented and therefore had some inherent protection. Also, in the past there were no information systems that could perform the analysis and predictions that insurance companies are capable of making today. The result has been a removal of the safeguards for privacy, and a shift in the balance between privacy and public good. Now, the system is one that easily allows insurance companies to promote profits above all else.

The role of information technology in these changes cannot be overlooked. Information technology was unleashed on the healthcare system before we knew what the consequences would be. Now that we are aware of many of the consequences, both positive and negative, the designers of HISs are on the hook themselves regarding the ethical issues involved. HISs must be developed that place patient autonomy at the forefront of design and balance patient autonomy, via privacy concerns, with the greatest good for the greatest number along with the

ability of organizations to use information technology to run their business as efficiently and effectively as possible.

Much of the discussion so far regarding patient privacy has been concerned with the use of health information by private and governmental organizations. The results have been questionable with regard to protecting the privacy of individuals, mainly due to the conflict between the business impacts on profits and upholding patient privacy. However there are more subtle concerns regarding maintaining privacy. The primarily involve the use of the Internet.

Health related information is among the most frequently accessed information on the Internet (Roscam Abbing, 2000). This has opened the door for many positive opportunities for the patient. Individuals now have access to information on health and medical treatment issues that they can incorporate into their decisions. They have access to information regarding healthcare services, and clinical trial information and availabilities. And, they have access to online support groups and access to others with whom they can share information and ask questions related to their specific health concerns and experiences. Another growing and inevitable trend is patients having access to their medical records via the Internet.

These are, in general, positive impacts of information systems on healthcare. However, they are not without privacy concerns, such as websites maintaining the anonymity of their visitors and unauthorized individuals accessing electronic patient records.

Historically we have moved very quickly when implementing change with information technology. We have not stopped long enough to adequately contemplate more than the benefits that information technology can bring, not fully considering the threats to individuals, the healthcare system, and society until problems arise. Whether the problem at hand is a breach in security, or an all too lenient policy on exchange and use of information that results from HISs, in many of these cases individual privacy has taken a backseat to profits.

Today, more than ever, there is a need to examine the capabilities that information technology provides, and the increasingly valuable information that results from the use of information technology in healthcare. There is a need for guidelines that uphold privacy of health information above all else. Because, as has been seen all too many times, once that information privacy is lost to an individual, it is lost for good. Therefore, it is proposed here that the design of HISs should hold patient autonomy paramount to all else. One way to achieve this is by maintaining the privacy of patient health information.

At this point many of the concerns with privacy overlap Mason's three remaining ethical issues; accessibility, property and accuracy. These issues will be revisited in the following sections in which accessibility, property and accuracy in relation to HIS development will be discussed in the following sections.

In support of the first general moral principle for HIS design, the argument is made that the design of information systems should place significant emphasis on upholding patient autonomy whenever possible. This argument is made in line with the current emphasis on patient

autonomy within the medical community itself. In concert with current trends in medical ethics the author supports autonomy as the primary principle in medical ethics, especially when considering the use and impact of HISs. This is reinforced by efforts to update medical ethics in the current climate, for example projects like the creation of the Charter of Medical Professionalism. Therefore this discussion has been presented with the goal of supporting autonomy as the primary concern for the HIS designer.

However, any discussion of patient autonomy must include consideration of the opposite point of view, namely utilitarian theory. While generally supportive of autonomy, advocates of utility state that autonomy should take a backseat to the overall good of society. The notion here is that sometimes integration, analysis, and dissemination of information is in the public good, even if it violates an individual autonomy. Therefore, to provide a comprehensive moral justification for the HIS design principles the utilitarian theory of social justice will be offered. In the following section a discussion will be provided for utilitarian theory with regard to the issues discussed in the previous sections.

Utilitarian and Privacy

The previous discussion regarding privacy concerned the impact of information technology on the privacy of the health information of individuals. While the design principles for HIS design promotes autonomy, and concomitantly personal privacy, as being the primary principle, the importance of using health information for both a national program and research are also recognized. It is possible for every member of society to benefit from a health information system that has extensive coverage and linkages. Our privacy rights however are maximized by

restricting access to health information, the better the restrictions the more our privacy is protected. In the end, if protection of privacy was the only concern, health information systems would fail and we would be worse off both as a society and individually. “Trust, cooperation and recognition of the common good are required” (Upshur et al., 2001) in order to achieve the best balance between personal privacy and the good of society.

Many supporters of utilitarianism promote national health systems as of paramount importance, and promote of social good over any individual privacy concerns. A national health information infrastructure would facilitate public health evaluation, identifying populations at risk, determining the effectiveness of treatment, assessing prognosis, and the usefulness of prognosis, diagnostic, and screening tests, and cost effectiveness analysis (Upshur, et al. 2001). The summary data gathered from individual medical records can lead to medical research that leads to discoveries in the areas of cancer, cardiovascular disease, communicable diseases, and public health threats (Gordis and Gold, 1980).

There have been efforts by the government to balance privacy and social systems. The most well known is the Health Insurance Portability and Accountability Act of 1996 (HIPPA). HIPPA is the result of recognition of the need for national health insurance privacy standards balanced in an environment increasingly characterized by linkages and communication of health information. HIPPA is a good first attempt at reflecting on and addressing the consequences of using information technology in healthcare. However, HIPPA does not address all of the potential impacts on autonomy in healthcare. Several loop holes remain.

Insurance companies state the need for large integrated databases, and services such as MIB, as providing a social good. Under our current healthcare system health insurance companies are critical to gaining access to medical care. While mention has been made by different politicians in recent history of the need for national healthcare coverage that goal is far from being realized. So, we continue to rely heavily on insurance companies for access to health care. Insurance companies state that if they did not have access to the information in the databases that they do, they would not be able to operate profitably and would no longer be able to play their current role in providing the foundation for healthcare in this country.

Supporters of national health information systems state that individual healthcare will be greatly improved. Uniform and efficient access to medical records could help emergency care provider's access information critical for the best quality treatment without delay. Currently information is not available when needed. Test results, images, charts, and information about a patient's medical history could be at the fingertips of any healthcare provider treating a patient at any given time. Overall clinical care is improved through faster and more accurate diagnosis, increased checks on medical procedures, prevention of adverse drug events, instantaneous research of medical conditions, and dissemination of medical expert information to areas traditionally underserved (Hodge, et al., 1999).

There are a number of societal benefits from a national health information infrastructure. Public health surveillance is facilitated, consumers are able to make better and more informed decisions about health plans, providers, treatment, and products. Electronic security tools including

personal access codes, encryption programs and audit trails can efficiently monitor health care fraud and abuse and protect data from unauthorized use and disclosures (Hodge, et al. 1999).

The Advancement of Science and Patient Safety Institute identifies clinical error as the second highest cause of death and advise health care providers that these errors are largely due to physicians making decisions with incomplete case histories (Feled, et al., 2004). Systematic use and standardization policies could help to eliminate many of the mistakes made on paper, and fragmented, healthcare information records, leading to overall improvements in healthcare.

From a social justice perspective, the balance should always be tilted in favor of the good of society. Our healthcare system could not exist, and provide the best possible healthcare for our collective society, without considering the overall social good. Information systems play an increasingly important role in making decisions regarding our healthcare system. Those decisions can include national policy level decisions, such as implementation of a national healthcare information infrastructure, as well as treatment decisions at an individual level.

There is no question that when designing HISs, if the public good is to be maximized attention must be paid to social justice. The discussion of the complexities between balancing autonomy and social justice with regard to privacy issues gets to the core of the role of HISs in healthcare today. Both autonomy and social justice theories have been defended as a result of this moral discussion. It has been illustrated that HIS designers will have to balance these two opposing moral ethical theories. In the following sections the balance that should be achieved to best influence and support the overall healthcare system through the use of HISs is discussed.

Privacy: Balancing Autonomy and Utility in HIS Design

This discussion of social justice and utility theory has revealed that there is an effort to balance patient privacy, and therefore autonomy, with the overall benefits for society. However, these benefits come with a cost, a loss of some autonomy via a loss of privacy. This is acceptable in the eyes of utility theory when push comes to shove the balance is always in favor of the greatest good for the greatest number.

In light of the historical problems with information system use in sensitive areas such as in healthcare, upholding autonomy, and therefore the privacy of individual health information, is held here as the primary concern for the HIS designer. Unforeseen security breaches and the use of information systems in newer more effective and efficient ways not yet recognized by the general public can erode autonomy and privacy. Often the negative impacts are not considered before hand, and once privacy is compromised it cannot be fully regained.

It is recognized here that giving autonomy, via privacy, too much weight as the principle design consideration is unrealistic. Social justice issues, from social aspects such as the benefits to the patient, research, and society, are important and must be considered. However, it is maintained here that autonomy must take precedence, especially where maintenance of autonomy through securing personal health information is concerned.

Information systems by their very nature compromise privacy. Relying on databases for efficient storage, analysis and distribution of information compromises the individual nature of the information that these systems retain. It should therefore be of paramount concern to the

designer of HISs to uphold autonomy, through security and privacy of information. And, while the social good is recognized here, it must never outweigh respect for autonomy in design, especially where privacy is concerned.

It is important for HIS designers to design systems that uphold patient autonomy as the primary goal. If system design does not address autonomy as the primary principle, and maintain the privacy of health information, it will difficult if not impossible to regain patient autonomy.

However, if a system that has been designed to maintain the privacy of health information is later viewed as not fulfilling the needs of the healthcare system data can be integrated at a later date.

Information privacy and HIS design are closely related to Mason's remaining three ethical issues; accessibility, accuracy, and property. In the following sections the moral justification of the three general moral principles for HIS design is continued, and strengthened by the discussion of these remaining ethical issues.

Information Accessibility and Healthcare

Access to healthcare facilitated by information technology takes on several forms. First, individuals are able to make better, more informed decisions, as a result of obtaining health information from the Internet. Healthcare providers are better able to provide information to patients over the Internet; either by directing them to quality websites, or sending and exchanging information over email. Electronic medical records provide accessibility to healthcare providers that can improve the efficiency and effectiveness of treatment. And, access to healthcare records by patients gives them control and insight into their medical history.

With each of these the HIS designer has to balance autonomy and social justice when designing systems. While the advantages of Internet access to health related web sites are not disputed there is significant gray area with regard to medical records and who has access. In the following sections each of these will be discussed.

Health Information and the Digital Divide

Accessibility to healthcare information is a hotly debated topic, and one closely related to information privacy. Information and communication technologies have the potential to reduce health disparities and promote public health by preventing disease and supporting clinical care. Unfortunately underserved populations (generally comprised of individuals who are of low socio-economic status, low literacy levels, are elderly, members of ethnic minority groups, and have limited formal education) often have limited access to relevant health information, especially the information widely available over the Internet (Kreps, 2002).

The gap in access to information through technology has long been identified as the digital divide. The digital divide is an especially important issue in healthcare. As we move deeper into the information age, and rely more heavily on tools that provide health information via the Internet, our healthcare system could become one further divided between the “haves” and “have nots.”

The digital divide, with regard to access to health information, is a global issue. The World Health Organization (WHO) has recognized that access to health information is essential for the

development and improvement of health services on a global level (Smith, 2003). In 2001 the WHO launched the Health Internetwork Access to Research Initiative (HINARI) (<http://www.who.int/hinari/en/>) which, in partnership with major publishers, provides biomedical information to developing countries around the world. The program benefits thousands of health workers and researchers, and in turn, contributes to the improvement of world health.

There are several hurdles to overcome in providing access to healthcare information to those without access to information technology. Most discussions regarding access to healthcare information involves access to the technology itself. But, there is an even more fundamental obstacle than the physical access to the required technology - literacy.

Mason states that “our main avenue to information is through literacy...each innovation in information handling, from the invention of paper to the modern computer, has placed new demands on achieving literacy” (Mason 1986, p. 10). He goes on to describe three things that an individual must possess to be literate; (1) the necessary intellectual skills to deal with information; (2) access to the technologies which store, convey and process information; and (3) one must have access to the information itself.

Literacy in terms of accessing healthcare information involves both the literacy level to be able to read the information presented on health related websites and documents, and the literacy to be able to use the technology itself. Historically the American society has been tolerant of a certain level of unequal access to healthcare; we now have a window of opportunity to avert the same inequalities with regard to access to health information (Eng, et al. 1998). Ensuring access

to health information across the digital divide is especially important because it is the same population who is underserved by our total healthcare system, who lack insurance and access to healthcare, and who can most use the information that can be obtained over the Internet at little or no cost.

There are a number of programs that bring Internet access to public places for those that do not have access in their homes. In addition there have been several studies which examined the impact of training on the use of the Internet to access health information. It has been found that those who went through training, and obtained the skills and access to the Internet for health information, benefited from it (Wagner, et al. 2005). In one survey, members of low socio-economic groups (those with annual household incomes of less than \$15,000) wanted the health information that they did not have access to, in fact more than any other income population (Eng, et al. 1998). Programs that provide access and training for health information technology directly address the three criteria for an individual to be considered literate; training provides the necessary technical skills, and programs that support public access to technology are allowing individual access to the technology itself.

There has been some concern about the ability of individuals to process the information once they have obtained it. This is a concern in the healthcare environment as the education levels between healthcare providers, and the patients attempting to understand the information provided to them, is so different. Several suggestions have been made as to designing health information websites to facilitate understanding of complex information by users who have limited education. Websites are primarily text based and are designed for educated, literate, and non-

disabled users. Currently websites are being developed that include video based sites, voice recognition, and touch screen systems, to facilitate use among the less educated and disabled user (Eng, et. al., 1998).

Arguments for programs that support distribution of health information through public access to information, such as found in public libraries, and training to obtain the information desired, are primarily positive. Supporting access to health information supports both the notion of social justice and autonomy. Social justice is supported by the distribution of collective resources to benefit the greater good. Autonomy is supported by making the technology and skills available to individuals so that they can access the information necessary to make informed decisions.

The notion of utility is supported by the social goal of universal access to health information in several ways. One way is by distributing public information which is primarily generated through government grants to everyone. It is estimated that up to 80% of biomedical information is a result of research supported by federal funds (Eng, et al., 1998). Individual health may be improved by access to the information and the resulting quality of health related decisions, and by cost savings. However, no public program is without risk. Some anticipated risks include misappropriation of limited resources, proliferation of inaccurate or misleading health information (Bernhardt, 2000).

To this point the discussion has primarily concerned access to information housed on health information sites on the Internet. There are few that would dispute that the distribution of resources to support this social good is a positive goal. Not only would individuals from all

groups be able to access information, their relationship and treatment resulting from interactions with healthcare providers would improve as well. Healthcare professionals would be able to direct their patients to sources of quality information on the Internet allowing them to think about applicable health information, discuss options with their families, and make better quality decisions regarding their own healthcare.

Accessibility to health information and considerations for the HIS designer also includes electronic medical records. A more controversial issue than access to health related websites, electronic medical records raises a number of questions regarding accessibility. In the following section accessibility of electronic medical records is discussed.

Electronic Medical Records in a Healthcare Setting

Despite many advances in healthcare over the past several decades, on-demand access to clinical information continues to be paper based and inadequate in most settings (Feled, 2004). Clinical care increasingly requires healthcare professionals to access medical records that are currently fragmented and distributed across several locations, and in a mixture of structured and unstructured forms (Kalra and Ingram, 2005). The result is that information is generally not readily available when it is needed. As we move toward a future with electronic medical records the most important first step is to put existing data in the hands of the healthcare providers (Feled, et al., 2004). Bottom line, it is advantageous for healthcare providers to have access to electronic medical records in order to provide the best possible care.

Medical records may be needed on a regular or predictable basis or in the case of an emergency. They may be needed at a time when the patient is psychologically able to provide consent, or at a time when s/he is unconscious and cannot provide consent. “Ideally, the records would be with the patient at all times, but alternative they should be universally available, such as on the World Wide Web...in addition, with the patient’s permission these records should be accessible to and usable by researchers and public authorities” (Mandl, et al., 2001).

The debates that go along with clinical access to electronic medical records mimic those of the privacy debates. At this point accessibility and privacy are inseparable. Few would debate the advantages of having clinical information in the hands of healthcare providers during an emergency situation. Electronic medical records also have the capacity to minimize costs for the overall healthcare system. These records could also contribute to research and an overwhelming growth of medical knowledge. Reduction in medical errors could be achieved through making sure healthcare providers have complete information. However, once again we revisit the cost of these benefits. With every one of these advantages comes an erosion of privacy and control over one’s medical information.

HIPPA is Congress’s response to the balance between the need for access to electronic medical records and the privacy of the information that they contain. However the HIPPA guidelines are not always clear, and not as protective of privacy as many individuals might think. HIPPA does not clearly regulate redisclosure of information to health insurers, workman’s compensation programs, and other associated businesses such as lawyers, accountants, billing companies and other contractors. Rather it states that the rule imposes a duty on these entities to obtain

satisfactory assurances that business associates will comply with privacy standards (Gostin, 2001).

Since the debate between privacy and the public good of distribution of health information was discussed in the privacy section it will not be revisited here. It should be pointed out though that the issue with access to patient medical records by healthcare providers is a clearer cut debate. Most patients would want their records easily accessible by a treating healthcare provider. The question here is not only that the information being used as a public resource, but rather which employees of healthcare facilities should have access to an individual's information. Dozens of employees at hospitals and other healthcare facilities access patient information on a daily basis. The goal of the HIS designer should be to limit the number of healthcare providers and associated employees to the minimum number necessary, and to implement as much control over authorization for access as possible.

Patient control of medical records is an emerging issue in the dialog over access of health information. Patient access to medical records has the potential to improve healthcare by improving communication between healthcare providers and their patients, and also reducing errors contained within the records. However, there is some concern by the healthcare community that routinely providing patients access to their medical records, not intended for a lay audience, may contain information not relevant or possibly troublesome to the patient (Ross and Lin, 2003). This is especially true in the areas of mental health treatment and oncology. In the following section access by patients to their medical records is discussed.

Patient Control of Electronic Medical Records

Patients today expect free access to their medical records to the extent that permits them to play an active role in their healthcare, an issue that is becoming more important as healthcare shifts from specialists to more general providers (Kalra and Ingram, 2006). Problems arise if patients do not have some faith that their medical records are correct and will be used only for the intended purpose.

Recent studies looked at the impact of providing medical records to patients. They found that 68% of those who received their medical records felt more assured and 97% felt less worry about their health (Ross and Lin, 2003). Patients who received their medical records were also likely to feel more in control, and those who carried their records with them perceived an increased sense of autonomy (Ross and Lin, 2003; Draper et al., 1986). Patient accessible medical records were also found to improve recall and understanding of medical conditions (Ross and Lin, 2003). Patients were also able to identify errors in their records and make corrections.

These results illustrate that patient access to medical records can have positive impacts on both the patient's feeling of, autonomy, control and confidence. And improve the relationship between the patient and their healthcare providers. It would seem reasonable to assume that access to patient records could be obtained. HISs should be designed in such a way as to support patient access to medical records whenever possible, the goal being to increase patient autonomy.

HIPPA was imposed, in part, as a response to public concern that individuals did not have access to their medical records. “96% of Americans believe that the right to be able to obtain a copy of their own medical record is important, and 84% believe that it is very important” (Garfinkel, 2001). However many individuals find that when they ask for their medical records, obtaining them is not as simple as they thought it would be. A recent study found that 92% of individuals who asked for their medical records received them. Of those who didn’t 31% were told that the medical record could not be located, and 25% (which represented millions of individuals) were simply denied the request (Garfinkel, 2001). And lastly, currently only 23 states give patients the right to view their own medical histories (Garfinkel, 2001).

The issue of denying a patient access to their medical records is related to the third ethical principle proposed by Mason (1986), property. The property of medical records will be specifically addressed in the following sections. Property and access are closely related and it is apparent that access to one’s medical records can facilitate a feeling of autonomy in the individual and therefore should be promoted in HIS design.

Designers of HISs that involve the use and distribution of electronic medical records should uphold autonomy by providing secure outlets for patients to access their electronic medical records, such as access on the Internet. Access should be provided by healthcare providers as but by limited authority and only when absolutely necessary for treatment. The balance between autonomy and the social benefit in HIS design should emphasize autonomy. Access to medical records can be granted at any time, when needed. However, the negative impact on lenient access policies with regard to medical records can be severe, and as a result patient autonomy might not

be able to be recaptured. HISs should be designed in such a way as to uphold autonomy as foremost while balancing effective and efficient distribution of information and the resulting cost reduction.

With electronic medical records and increased reliance on technology for healthcare a new stakeholder has been introduced into the healthcare environment; the HIS designer. Never before have information and computer specialists played such a significant role in healthcare. Today they are a critical member of the team. In the following section some technological aspects of access to information are discussed.

Problem with Technology and Access to Health Information

Access to health information goes beyond individuals or organizations accessing information for treatment or business related issues. As we become increasingly dependent on information technology for our medical treatment, it is essential that the information be accessible when needed. Information cannot be missing, especially during a critical emergency situation, because the system is down or there are network problems. Patient care is a team sport involving the patient, their families, and healthcare providers (Elder and Hickner, 2005).

HIS developers must ensure that necessary standardization of medical records is included in the design. Network issues, firewalls, and other technological barriers to information flow and communication must be flawless. Systems must be flexible but effective. Security measures must be of the utmost importance in the design and development of HISs. And, revisited and updated regularly. This is necessary because no matter how sophisticated a security system is

someone will always manage to defeat it. At the same time advances in security measures are continually evolving. The widespread adoption of patient access to electronic medical records and more efficient distribution of these records among healthcare providers will require that HIS designers continually monitor and update computer systems and architectures to best protect this sensitive distributed system of records (Mandl, et al., 2001).

It is here that the role of distribution of information, whether it be for public good, or to enhance patient autonomy, falls squarely in the hands of the HIS developer. HIS designers will have to remain vigilant and constantly monitor and update HISs in order to protect the balance between autonomy and utility. If breaches in security are too severe patients will lose faith in the privacy of their health information and will no longer trust or use the entire healthcare system as intended.

This discussion of electronic medical records and access to information is closely related to Mason's third ethical issue for the information age; property. In the following section property and healthcare information will be discussed.

Property

Mason (1986) identifies intellectual property rights as one of the most complex issues we face as a society. He describes information as having an illusive quality, easily reproduced and distributed to others. These qualities make information hard to safeguard because unlike tangible properties once information becomes communicable it is very hard to keep to one's self. Mason

also describes information as initially costly to produce. However, once produced each additional item of information can be produced at very little cost and at increased value.

Mason was not specifically addressing the use of information systems in healthcare. However, it is an easy leap to applying this same description to the current ethical issues that surround the use of information technology in a healthcare context.

The concept of property is especially complex when applied to patient health information. Healthcare providers have traditionally been responsible for the infrastructure and maintenance of patient medical information. A rarely debated issue in the past, information technology has brought ownership of patient health information to the forefront of public policy and patient concern. Given that privacy was discussed in previous sections it will not be revisited here. Issues directly associated with the ownership of health information and the general moral principles for HIS design will be presented in following sections.

The Societal Benefits of an Information Infrastructure

As previous discussions reveal, when information technology meets sensitive information questions of property and privacy arise. Information technology has eroded the trust between patient and physician. Digital channels of communication make easy transmission of information a concern for patients who have little control over the facts about their own health. And, the metadata created by HISs has increased the value of health information opening the doors for further violation of trust.

Historically healthcare providers have been responsible for the infrastructure needed to maintain individual health information. Information input, storage, backup, and distribution of information were all handled by physicians. For the most part patients had trust in their healthcare providers and their handling of private information. There was no question of ownership, it belonged to the provider. Health information was sensitive property placed in the hands of trusted healthcare providers.

A social good developed from traditional arrangement; an information system and exchange of information from one provider to another when required. This primarily paper system provided the backbone for what is now facilitated by information technology. It was safeguarded by fragmentation and difficult channels of communication between interested parties.

Few would argue the benefits that rapid access to health information required for clinical decision making and management of our healthcare system would lead to more efficient use both public and private resources and would improve our current healthcare system. Health information instantly provided to an emergency room doctor can prove critical for effective treatment.

Patient medical records have historically been a dispersed entity. Ideally HISs would bring together information scattered between several collections (computer and paper based) dispersed among various locations and under different numbers, together for more efficient, effective, and cost effective treatment. In order for this to occur several things would have to happen. First the patient and their healthcare providers would have to agree on which clinical information is worth

“risking” for the benefit of making the information available when needed for treatment in the (Schoenberg and Safran, 2000). Standardization of information and communication technology must be established. An infrastructure of hardware and software must be implemented and ownership of patient records must be established as it is unrealistic to expect effective implementation and maintenance of these records without ownership.

Currently many healthcare providers and organizations consider medical records to be their property, whereas many patients argue that the information included in these records is their own (Schoenberg and Safran, 2000). There is a distinction made here between the ownership of the physical record and the right of patients to access the data stored within the records. HIPPA reinforces this notion and provides patients with the right to petition their medical records. This allows the patient access to the information contained in their medical records and provides them with the opportunity to make sure that the record is accurate.

Establishing an information infrastructure that would provide important clinical information in the hands of healthcare providers efficiently and effectively would be a valuable asset for society. Disease registries, health services research, and population epidemiology information registries, could provide valuable information regarding public health. Information technology has the potential to provide life saving information and information that would improve healthcare for individuals and society as a whole.

The threat to patient privacy is ownership of medical records rests in the hands of healthcare providers is not an insignificant issue. However, placing full ownership and responsibility of

health information in the hands of the patient is not a realistic goal. Ownership and cooperation by both private and public organizations is required to pull together adequate resources and handle the workload required to implement the necessary infrastructure. Patients alone do not possess the education, knowledge, or technology to maintain their records. Even so, HIS designers should facilitate patient access to information in order to enhance patient autonomy, control and ownership of their health information whenever possible.

Reconciling issues of ownership of health information places the HIS designer in a balancing act. HIS design should promote social justice. This can be done by designing systems that allow providers to access patient health information at the point of care, providing information only at the lowest level of granularity required. HISs should be designed in such a way as to promote public health including using summary data to identify populations at risk, identifying epidemiological issues and communicable diseases, identifying effective and problematic treatment approaches, and facilitating medical research.

The emphasis on social justice is necessary in HIS design when addressing the complexities surrounding ownership of health information. However, social justice is secondary to promoting autonomy in HIS design on issues of ownership. The complexities of ownership of health information quickly return the designer to discussions of privacy. The fact that an information infrastructure requires that health information is the property of the provider leaves little room for individual's to control their health information and places the autonomy of the individual at risk.

When addressing ownership of health information HIS designers should promote patient autonomy by first facilitating easy access to medical records. HISs should promote patient participation in determining the level of security for the data within their medical record, as well as the granularity of the information communicated to other entities, and allowing the patient some control over the type of data at risk when communicating with other entities (Schoenberg and Safran, 2000).

Currently much of the information contained in medical records is obsolete, redundant, duplicated, or indecipherable and therefore does not benefit the patient or their continued care (Schoenberg and Safran, 2000). Accuracy, the last of Mason's (1986) ethical issues, when specifically addressing patient records and health information in HIS design, is assumed to be the responsibility of the healthcare provider.

Information accuracy is a much broader ethical consideration and extends to areas of HIS design outside of maintenance and property of patient medical records. In the following section information accuracy, Mason's final ethical issue will be discussed with regard to design of HISs.

Accuracy

"Misinformation has a way of fouling up people's lives" (Mason 1986, p.7), this is especially the case in healthcare. "A special burden is placed on the accuracy of information when people rely on it for matters of life and death, as we increasingly do" (Mason 1986, p.8) in the healthcare

context. Patients need access to reliable and good quality health information so that they can take an active role in decisions about their healthcare (Shepperd et al., 1999).

Accuracy is a part of common terminology that facilitates communication between patients and their healthcare providers. The level of accuracy in health information, whether the information is contained in a patient medical record or on a health information web site, can have a significant impact on an individual's autonomy.

Accurate information is essential for effective decision making. On the part of the patient information facilitates understanding which is essential for being able to make an autonomous choice. A person understands if they have been able to acquire pertinent information and have justified beliefs about the nature and consequences of their actions when making decisions (Beauchamp and Childress, 2001). If information is missing, inaccurate, or framed in a way as to sway the user's perception, the individual can be deprived adequate of understanding and therefore deprived of their autonomy.

Information technology, and especially the use of the Internet by patients, has changed the way patients make decisions about their healthcare. The Internet has become an important tool for consumers seeking health information and healthcare services. A recent concern and public health issue is the quality of the health information that consumers find on the Internet (Eysenbach et al., 2002). Seeking useful and valid information on the Internet can be difficult because of the lack of control with which the information is accumulating; as a result judging the information found may be more difficult than the search itself (Jadad and Gagliardi, 1998).

Several issues concern the accuracy of health information that consumers find online. The quality of the content of information found online is important to facilitating understanding and assisting in patient decision making. Quality issues include lack of completeness, difficulty in finding high-quality sites, lack of accuracy (Eysenbach et al., 2002). Readability is also an important consideration of online health information. Readability addresses the vocabulary used and the way the information is phrased. If a website contains technical clinical information some patients may not be able to understand the information. However other patients, especially throughout the course of an illness, may become familiar with complex terminology (Shepperd et al., 1999). Therefore HISs should be designed so that they are flexible and provide different levels of information for the user to access. The information should be hyperlinked for easy travel through the information so that the user can find the level of information appropriate for their skills and knowledge base.

Omission of information is another important issue with regard to the accuracy of information found on health related websites. If any information that would be relevant to an individual's decision is missing then their autonomy is reduced and they cannot make an informed decision with regard to his or her healthcare.

Information systems are critical to the accuracy of information. Presentation quality is a significant aspect of web based health information systems. The following serve as criteria to assess valuable presentation quality; (1) the presence is deemed ethical according to codes of conduct for web publishing (e.g., transparency and accountability criteria, such as disclosure of

authorship); (2) the website helps to create context and avoid misunderstanding; (3) The site empowers users to select the information that is best for them in their individual situation; (4) the site empowers users to validate the information themselves; (5) the site may influence the accessibility of information and facilitate communication with both family and healthcare providers (Eyesenbach, 2002).

The information included on health related web sites should contain complete information and priority should be given to not omitting information. The information should be framed in such a way as to facilitate understanding at the patients level, and provide unbiased information so a patients perception or opinion are not swayed by a web manager or other stakeholders opinion. Websites that could serve to profit the host, such as pharmaceutical companies, medical facilities, and the like, should provide full disclosure.

Advancements in Internet technology and the increased numbers of individuals with access have resulted in a valuable social service. Illustrated previously in the discussion regarding access to information, health information web sites have helped close the socio-economic gap with regard to health education. Because of the Internet health information has been placed in the hands of disadvantaged citizens and consequently has benefited the segment of society who needed the information most.

The increased amount of health information across all members of society has not only provided a public good, it has increased the overall autonomy of individuals as well. The one critical factor with regard to both the social good and the increased autonomy for individual decision

makers is that the information found on these sites must be accurate. If the information found online is inaccurate or misleading it is both a detriment to society, to the overall healthcare system, and to the individual's attempting to make autonomous choices regarding their healthcare.

So far accuracy has been discussed in terms of health information websites. Accuracy of information is also consideration general clinical information used by providers as well as individual patient medical records. Accuracy of health information in patient medical records is of critical importance. Inaccurate information can lead to life altering events, treatments, and potentially death. While inaccuracies in medical is one of the more controversial and widely discussed topics, accuracy as an HIS design consideration extends beyond patient medical records.

Accuracy, in terms of the quality and reliability of information included in electronic medical records is critical to patient autonomy, primarily by protecting privacy. The privacy of medical records was discussed in earlier sections but it is an important overlap when considering accuracy. HISs should be designed in such a way as to protect the accuracy of patient medical records by allowing the patient to have free and easy access to his or her medical records. This would promote opportunity for the patient to review and update any inaccuracies in their health information. Standardization of health information systems would also help increase the accuracy of information within medical records.

Accuracy is the last of the four ethical issues for the information age as suggested by Mason (1986). Mason's four ethical issues have provided the framework for the justification of the three general moral principles for HIS design. Throughout the discussion it is revealed that the HIS designer is continuously balancing between autonomy and social justice, and the result of this balancing act is summed up in patient welfare. It is the management of autonomy and social justice that results in the decisions that impact an individual's quality of life, or patient welfare. In the following section a discussion regarding the moral justification of the HIS design principles, support for the role of autonomy as the primary principle, consideration of the constant balance between autonomy and social justice, and the resulting patient welfare, is offered.

Summary of the Justification of General Moral Principles and HIS Design: A Balancing Act

Advances in information technology have resulted in significant changes in the healthcare industry. Modern integrated databases, and the use of the Internet, have resulted in more efficient collection, storage, analysis and distribution of information. The advancements also brought with them an increased corporate interest, as well as a host of concerns regarding the privacy of individual health information, and changes in the relationships within the healthcare system.

In times of significant change or stress, people and institutions often revisit their core values. This may be why we have seen a resurgence of publications about professional values in the past few years (Pendleton and King, 2002). Information technology is in large part responsible for

the sense of unrest in our healthcare systems and the stress felt by physicians, patients, healthcare organizations, and public and private organizations. As a result HIS design is in a constant state of conflict, and guidance is needed for future HIS design and development.

The abuse of large databases and the fact that patient trust of the organizations who handle their individual health information has been broken has impacted the relationship between the patient and their healthcare providers. The result is often that patients are reluctant to provide information to their provider. And, the provider is often unwilling to include complete information in a patient's medical chart because they are concerned that the information will be used to the patient's detriment. Reluctance on the part of either the provider or the patient is a detriment to the overall healthcare system and to patient autonomy in particular.

As illustrated in the previous discussions in this chapter, health information systems by their very nature present a risk to individual autonomy. Therefore increased attention must be paid to the specific data that is stored in health information systems, and the granularity of that information.

The meta-data that results from HISs needs special consideration. This information is of increased value to corporations, and presents an even greater risk to individual autonomy and privacy for the individual, far above the fragmented information systems of the past.

Historically the voice of corporations outweighs that of the individual with regard to organizational and public healthcare policies. A safeguard for the individual is necessary given the continued uncertainty of the security and use of information resulting from HISs. Therefore

the need to uphold patient autonomy is paramount and is included as the primary moral principle for HIS design.

No discussion of autonomy can be had without giving fair consideration to the beneficial impacts that HISs have had on social justice. Information systems have helped bridge the socio-economic gap and the associated access to health education. These systems also provide a valuable social good in that they can help monitor public health, the effectiveness of treatments, and reduce the overall cost of providing healthcare. Information provided by these systems can aid physicians in providing the best possible care by providing the information that is needed in any given treatment situation quickly and accurately. HISs can get information where it is needed and when it is needed which can mean life or death in many treatment situations.

However these social advantages are often at the expense of individual privacy. The result is a continuous balancing act between autonomy and social justice with regard to HISs. Even with the obvious benefits to both individual and society it is proposed here that social justice must take a backseat to autonomy as the primary design principle. There are countless accounts of information being leaked, used in questionable and unethical ways, resulting in catastrophic consequences to an individual or subset of society. Sometimes very negative results come from the inexperience of all of the stakeholders with the use of information technology in a healthcare context and the unanticipated consequences of these systems.

Therefore social justice must take a backseat to autonomy, not because it isn't equally as important in our overall healthcare system, but rather because autonomy cannot be recaptured

once it has been compromised. But, information can always be combined, analyzed, and distributed later in support of social justice if need be.

The balancing act of HIS design, the resulting systems, and the impact on individuals greatly impacts an individual's welfare. Patient welfare in healthcare includes promoting health, happiness, good fortune, and well being. The basic idea is that the healthcare community will not cause harm. HISs have potential to be of great benefit to both individuals and society, but they also have the potential to cause great harm.

Patient welfare is a very individual concept. The promotion of health in varying degrees of illness and health can present the individual with a number of complex decisions. What makes happiness; good fortune and well being are very individual decisions. By placing autonomy at the forefront of HIS design the individual's ability to express and capture what well-being means to them is increased. At the same time patient welfare is largely influenced by the distribution of public and private resources and knowledge. HISs must be designed in such a way that these are balanced and result in medical care that support the overall welfare of the individual patient.

Currently society as a whole, and in particular our healthcare system, are in a state of significant change. Values, ethics, guidelines, are the necessary tools that society and professionals need to guide the advancement social change due to information technology. There is no question that resources are scarce in our current healthcare system. Therefore it is essential to distribute resources so that they will bring the greatest good to the greatest number. However, the individual must be protected in this process. It is too easy for individual autonomy to get lost in

social good and corporate goals, and therefore it must be maintained as the primary consideration for the HIS designer. Until we know for certain the individual impacts of our HISs on the autonomy of an individual, and their overall health and well being, the principle of autonomy must be paramount. HIS designers must carefully balance autonomy with social justice resulting in the maximization of patient welfare.

These ethical principles for HIS design have been developed as a response to a changing healthcare environment. Information technology has brought about significant change and uncertainty to society as a whole, and specifically the healthcare industry. The principles are intended to aid HIS designers in designing new and innovative systems that reflect the moral and ethical norms of our time. It is proposed that these principles will assist HIS designers in addressing current issues when designing systems that will greatly impact the overall healthcare system and each individual within it.

Action research is a widely accepted strategy for testing theory that result from design science. It is a methodology particularly suited for HIS development in the current environment. Primarily an interventionist and collaborative approach, action research aims to create positive organizational change while at the same time advancing scientific knowledge is an appropriate methodology for testing the HIS design principles. In the following chapter an action research project, completed in partnership with a Central Florida hospice, will be described. As will the use and refinement of the HIS design principles offered here.

CHAPTER SEVEN: A HOSPICE ACTION RESEARCH PROJECT

Action research is a widely accepted strategy for testing theory that results from the use of the design science theory building methodology (Markus et al., 2002; Walls et al., 1992; Lindgren et al., 2004). Ideally suited for the study of technology in its human context, action research is especially suited for exploring design within the information systems discipline because it is a highly applied, almost vocational, field (Baskerville and Wood-Harper, 1996).

Action research is an interventionist approach which aims to solve practical organizational problems while at the same time expanding scientific knowledge (Baskerville and Myers, 2004).

It is characterized by a concern to create organizational change and simultaneously study the process of change; it is change that is the important outcome (Susman and Evered, 1978;

Baskerville and Myers, 2004). It separates itself from other research approaches which are not motivated to change an existing problem, but rather focus on observation and intervention.

Action researchers see merely observing a real world problem as being unhelpful, they take on the responsibility of assisting practitioners by not only developing but also by applying knowledge (Mathiassen 2002; Lindgren et al., 2004).

A collaborative endeavor, action research serves multiple goals, aiming to improve both research and practice. The collaborative nature leads to a deeper level of research goals and activities and when combined with other methodologies can strike a useful balance between relevance and rigor in research (Mathiassen, 2000).

The action researcher is both an instrument and an observer and cannot be separated, or viewed as unbiased, as is assumed in other research methodologies (Myrdal, 1975). The selection of a problem, the construction of an hypothesis, limiting the scope of a study, and defining and classifying data, all involve a choice on the part of the investigator and cannot be free from bias (Myrdal, 1975). Therefore the researchers should be identified and described just as any other instrument of research (e.g., surveys, interviews, statistics, and theories) would be.

Increased attention has been paid to action research in the past few years. As a result there are a variety of approaches to choose from (Baskerville and Wood-Harper, 1998; Susman and Evered, 1978; Lindgren et al., 2002; Davison et al, 2004). Susman and Evered's (1978) cyclical process of action research is widely accepted in the current literature. It characterizes action research as a collaborative effort between practitioner and researcher that is iterative, cyclical, and rigorous. Susman and Evered describe action research in five phases:

1. *Diagnosing*: this phase involves the shared activity between researcher and practitioner in which the organizational problem is identified. Both work together to develop the specific problem to be addressed in the organization and simultaneously formulate an hypothesis that addresses the applicable research phenomena.
2. *Action Planning*: this phase involves considering alternatives, or courses of action, which will be employed to improve the problem.
3. *Action Taking*: this phase involves selecting an alternative or course of action and implementing it in order to improve the problem.

4. *Evaluating*: involves studying the consequences of the alternative that was implemented.
5. *Specifying Learning*: involves identifying the general findings by both the researcher and the practitioner. The outcomes are considered by both the practitioner and researcher and are applied to both organizational knowledge and research.

Both the rigor and relevance of an action research project are enhanced if evaluation criteria are employed (Davison et al., 2002; Lindgren et al., 2004). The principles of canonical action research (CAR) offered by Davison et al. (2004) facilitate the clear and systematic presentation of ideas and findings while simultaneously aiding researchers in justifying their actions, conclusions, and contributions to knowledge. This is a unique form of action research in that it is iterative, systematic, rigorous, and collaborative. The result is a more rigorous presentation in which relevance becomes an essential part of the rigor in the research endeavor (Davison et al., 2004).

Two components characterize CAR; (1) it is a carefully planned iterative process with executed cycles of activity that allows a detailed picture of the organizational problem to develop, while at the same time moving closer to a solution, and (2) it is a continuous process of problem diagnosis in which activities relevant to the problem are planned as it is simultaneously understood and experienced (Davison et al., 2004). Five criteria for evaluation are offered by Davison et al. (2002); these criteria impress a systematic nature to action research. These criteria include the following:

1. *The Principle of the Researcher Client Agreement (RCA)*: A formal contract of sorts, the RCA requires that both researcher and practitioner identify their goals and expectations for the project. Practitioners are informed of how CAR works and together with the researcher identify the benefits and drawbacks for the organization. The RCA is an agreement that promotes a spirit of collaboration by having the practitioner participate in identifying the goals, plans, and actions, and implementing the changes that will result. The resulting contract helps focus the goals for both the practitioner and researcher, and while they may need to be adjusted as the project advances, the RCA also serves as a tool for each to return to should a conflict or misunderstanding arise. In essence the RCA guides the project.
2. *The Principle of the Cyclical Process Model (CPM)*: Once the RCA is established and work begins on the project, the activities should follow the iterative process of CPM. These stages include: diagnosing, planning, intervention, evaluation, and reflection. Primary consideration should be given to progressing sequentially through the stages as this will help to increase the systematic rigor in the project. However, at the same time iterations may be required. If the project deviates from the sequential progression through the steps, the subsequent flow through the five stages should be justified and mentioned explicitly in the project.
3. *The Principle of Theory*: Action research can take place with or without theory, but a clearly articulated theoretical framework is strongly suggested. Theory is a critical part of the planning stage and helps to guide the project activities. Theory helps to focus the problem, guide intervention, prevent the researcher from getting lost in a sea of data, and to aid communication between practitioner and researcher.

4. *Principle of Change through Action:* The goal of CAR is intervention, to take action with the goal of producing change. A lack of change implies that there was no meaningful problem, that the intervention failed to address an existing problem, or the situation could not be altered because of political or practical obstacles that were not identified when the RCA was created.
5. *The Principle of Learning through Reflection:* Learning is the most critical activity in action research. Practitioners will focus on practical outcomes while the research communities will be interested in discovery of new knowledge. Learning from CAR should involve both the internal and external environments. First, learning enables restructuring of organizational norms and reflection about new knowledge gained during the research project. Second, CAR informs further intervention within the current project. Third, CAR contributes to the advancement of knowledge by generating new knowledge or theory, or re-informing existing theory. And fourth, it enables lessons to be elicited for wider application of the methodology.

The principles for evaluation of canonical action research offered by Davison et al. (2004) provide an evaluation methodology which justifies the rigor of an action research project and its findings. Davison et al. (2004) identify action research as being a methodology praised for its relevance but lacking in rigor. In action research the researcher cannot be separated from any aspect of the system and it is this subjective nature of action research that leads to criticism regarding the rigorous nature of the finding.

Myrdal (1975) expands on the subjectivity of scientific methodologies in general and identifies the researcher as a substantial part of a research project, the definition of the phenomena under investigation, and the findings. He states that other, more scientific, methodologies are just as subjective. He identifies the “objective truth” assumed by scientific research as being inseparable from the biases of the scientist himself. It is proposed here that the criticism of action research as lacking in rigor are shared with all research methodologies as they are all subject to the same bias that compromises the rigor of the findings.

The researcher is the culmination of a lifetime of values, experiences, and goals. The application of all of the principles for canonical action research is affected by the individual nature of the researcher. In the case of action research the researcher is an instrument of the research itself and therefore should be explicitly identified as would any other instrument of research (e.g., surveys, interviews, statistics, theories, etc.).

In many methodologies it is often assumed that the subjectivity of the researcher can be removed and the results address an objective reality. Therefore the general convention is not to introduce the individuality of the researcher into the study. However, it is the researcher who chooses from an infinite number of possibilities for the phenomena of study, the definition of the problem, the hypothesis which guides the study of a phenomenon, and the classification of data which describe the findings. Therefore the scientific facts that result from the researcher’s findings are subjective by nature. It is proposed here that omission of information about the researcher is more threatening to the rigorous nature of the findings than if information about the researcher had been explicitly stated. It is also recognized that the individuality of the researcher can also

lead to richer findings if his or her relevant values, goals, and beliefs are explicitly stated. The explicit description of the researcher, from which the research itself cannot be separated, will add rigor to action research projects.

It is with the recognition of the inherent subjectivity of all research, the impact of the researcher him/herself, and in the spirit of Davison's et al. (2004) evaluation of action research that a sixth principle, *the principle of the researcher profile identification (RPI)*, is added to the principles of canonical action research.

6. *The Principle of the Researcher Profile Identification (RPI)*. This principle recognizes the impact of the individuality of the researcher on the action research project. The researcher is an instrument of the research and should be explicitly identified as would any other research instrument.

The Action Research Project Setting

This research project was named the Advanced Directives Decision Support System (ADDSS). It was a 13month collaborative effort between the researcher and the hospice branch of a large Central Florida Hospital. The hospice provides healthcare for terminally ill patients. The patients generally reside in either nursing homes, assisted living facilities, hospitals, or at home. There is no separate onsite care facility at the hospice. When a patient is admitted to the hospice for care, an admission nurse is sent out to see the patient, gather medical records and other information necessary for treatment. The nurses also inquire about any advanced directives that

the patient may already, and if they have not completed the forms, the nurses ask if they would like to upon admission.

The original process of collecting medical records, additional information for treatment, and advanced directives information was formerly completed entirely on paper. The nurses had been provided with laptops, however many did not use them as the paper forms had to be completed in addition to any information entered into the computer. The information system that existed at the start of this project can literally be characterized as milk crates, full of paper forms held in folders, housed in the trunks of the cars driven by the nurses.

The hospice expressed a desire to move the paper based admission process to a fully computerized process. They stated a concern that the computers the hospice had invested in were not being utilized. Another stated problem was lost paperwork. Traveling between departments, and from room to room, in order to compile the necessary admissions information is common; this is especially the case in nursing homes, assisted living facilities, and hospitals. Occasionally paperwork would be misplaced leaving the hospice's patient medical record incomplete. Communication of information between hospice healthcare providers was difficult. And, lastly the procedure that they employed to track compliance with federal regulations was antiquated.

Two months of meetings and conversations with employees of the hospice, from the CEO down to the nurses, resulted in a specific problem area that the hospice wanted to address. Transferring all information and records from the original paper system to a computerized version was a large

undertaking, and currently not realistic for either the researcher or organization. So, the hospice isolated their advanced directives process as the one that they would like to computerize. They envisioned an advanced directives decision support system located on the nurse's laptops. This system would communicate the end of life information captured in advanced directives by direct use by the patient, or facilitate communication with the hospice nurse.

The hospice required that the ADDSS be portable and housed on the nurse's laptops. They wanted a tracking mechanism to document that the hospice was in compliance with the federal regulation that states that all health care facilities that receive federal funds must inquire upon every admission if a patient has an advanced directive. And, lastly the hospice wanted the ADDSS to be an educational tool that would communicate the desired amount of information to the user. They did not want the patient to feel as though they were overloaded with information or that their questions had not been answered as a result of using the system.

The advanced directives project that the hospice identified met the requirements for the researcher in that they (1) required the development of an HIS, (2) involved both the organization and its patients directly, (3) were interested in assessing patient autonomy as one success measure, and (4) would allow for testing the HIS design principles. Hospice personnel had already looked into a couple of different solutions to the problems they were having with advanced directives, but for several reasons were not happy with the systems that were currently available to them.

The hospice was happy with the open-ended option provided to them by the researcher. The main requirement on the research half of the project being that the system would be built in accord with the HIS design principles. The hospice could freely choose the organizational problem that they wanted to address. Through months of conversation, the researcher and hospice employees agreed on the specifics of the organizational problem and the goal of the project.

This chapter archives this action research project, its associated successes and failures, associated activities, and both organizational and theoretical knowledge gained. The goal of this project is to develop an HIS in accord with the design principles offered in the previous chapters, implement the changes requested by the hospice, and document the learning process for both the organizational and theoretical knowledge gained.

Intervention

Action research is an intervention, a partnership between researcher and practitioner. The following sections capture the action research project which followed Susman and Evered's action research cycle. The first step in the cycle is diagnosing.

Diagnosing

Diagnosing is a collaborative effort between researcher and practitioner with the goal being to identify and define the organizational problem. The researcher is from a large Florida university

who is interested in developing HISs with the intent to test a set of ethics-based HIS design principles. The researcher worked in collaboration with a Central Florida hospice which is a relatively small branch of a large Central Florida hospital. In spite of being a part of the hospital it does not have the resources that are generally envisioned when thinking of a hospital. The hospice has experienced rapid growth and increased competition in the area. Many of its procedures are outdated and inefficient.

There were a number of areas that the hospice would like to see change. At first sight it was really difficult to find a starting point or to identify a specific problem. It was decided that the researcher would accompany the nurses to a number of different types of admission visits to identify areas in which an HIS would be helpful to the organization. These visits took place over a two month time period.

The interviews revealed a number of problems with information flow. Many of the problems were characterized in the first admission visit. The patient was an 80 year old woman with dementia; she was living in a nursing home. She had recently been treated at a hospital where she had been placed on a ventilator, in spite of having a complete set of advanced directives stating that she did not want extraordinary measures, and specifically a ventilator. The hospital had no record of the advanced directives and performed the treatment they deemed necessary.

Generally in cases like these the nursing home is not supposed to send a patient to the hospital for this type of extreme care if the patient has advanced directives stating that they want to forego extraordinary treatment. After several visits with nurses on similar cases, and discussions

with nurses at both the nursing homes and the hospitals where the hospice admission cases took place, it was apparent (and explicitly stated) that there was a conflict between nursing homes and hospitals. The nursing home often does not feel that they have the expertise or staff required to make the decision about the urgency of a patient's condition or the type of care that they will need if sent to the hospital. They often err on the side of caution and send patients to the hospital where they have the expertise to care for the patient in an emergency situation. However, often the hospital is not informed of the advanced directives in time during emergency situations.

The hospital receives a patient and must provide care. If they do not have the advanced directives they often provide all necessary treatment to keep the patient alive. In cases like these each side is attempting to provide the best and most appropriate care for the individual patient without full knowledge of the patient's information (either treatment or advanced directives). Both sides also operate in a corporate-medical environment where malpractice is always a concern and they generally err on the conservative side.

Once the woman had returned to the nursing home the family decided to admit the woman to the hospice. The researcher and the admissions nurse went to the nursing home for the admission visit. These visits involve volumes of paper forms and information gathering. The information is often simply duplication of the existing records at the nursing home. However, each of the treating entities (i.e., hospital, nursing home, hospice, etc.) must have their own medical record. Recording the patient's health information into the newly created hospice medical record is a time consuming process that takes from thirty to ninety minutes, on average.

When reading through the patient's medical records at the nursing home it was discovered that the patient had been treated recently for a heart attack and had been diagnosed with breast cancer. However, the documentation for each of these could not be included in the patient's hospice medical record because the treatment took place at a third party hospital in another county. HIPPA laws prohibit transfer of that information directly from the nursing home records to the hospice records; it must be obtained from the treating hospital directly. Given the nature of hospice care, which is generally less than six months, and the bureaucracy that slows the process of information transfer, it is a possibility that the information from the hospital would never become part of the patient's treatment record.

There are risks involved with the patient records being incomplete. Although life saving measures was not part of the ongoing treatment plan, full knowledge is required by the hospice in order to provide the best quality of life for the patient in her final months. Without full documentation, the hospice's ability to provide the appropriate palliative care would be compromised.

Completion of medical forms is an art. This is especially true in when it comes to insurance, Medicare, and Medicaid. Often the forms are precisely worded in such a way as to "justify treatment." Time and time again the nurses would talk about the amount of influence that these forms had on the organization's ability to treat the patient. The type of illness that a patient has greatly impacts the kind treatment coverage, and therefore the care that they can receive. Cancer is a "get out of jail free card" in which there is almost an open ticket for medications and treatments. However, terminal pulmonary conditions, or illnesses involving dementia, for

example have stricter guidelines for the treatments and medications available to the patient. So, the nurses carefully dance around the forms to obtain as much for the patient as possible.

Medical charts are often difficult to read at every type of facility (i.e., hospital, nursing home, hospice, physician, etc.), all included hand written notes. The notes, and documentation of daily medications and health information, were often removed from the chart for review. Occasionally the documentation would not be returned to the chart and a significant amount of time was taken by a number of people to track the information down and return it to the chart.

Upon admission to the hospice an inventory is taken of the patient's current medications. There are usually a significant number of medications; each has to be documented by hand in the patient's hospice chart. Once documented the nurse has to call the hospice pharmacy and read each one off the list, the pharmacy then tells them which are covered and which are not. This process can take anywhere from twenty to forty minutes.

The problems with communication and the time taken to capture information are typical for the visits for the two months spent on admission visits. There were others, but the issues described here surfaced on just about every admission visit.

After the two month time period, the researcher met with several members of the hospice team; the CEO, the Education Director, Director of Nursing, and several nurses. The goal of these meetings was to discuss the findings over the past two months, discuss the problems with

information flows, and to identify a specific area that could be addressed. The result of these meetings was that an ADDSS would be developed.

Many of the problems discovered would require participation by a number of organizations to solve. For example, the process of exchanging information from a hospital in one county, to a nursing home, in another and a hospice in a third was critical. However, it would require participation by all three organizations in three separate counties as well as addressing HIPPA requirements. Not a realistic project at this time. Other issues, like loss of paperwork and the like, also required participation from outside organizations. This process of narrowing down options was an ongoing one for both the hospice and researcher for a number of weeks. Finally a project was chosen, the ADDSS which would aid in the completion of advanced directives.

The ADDSS was chosen because it had a definable scope, it could be completed within the hospice, and it had a reasonably organized and established paper-based process from which to start. The hospice had concerns about documentation that shows they were in compliance with federal regulations regarding advanced directives and they wanted a computer-based documentation process. End of life issues are often intimidating to patients and their families and the hospice wanted an educational tool that could help families and patients, either alone or with a hospice nurse, understand advanced directives information; the goal of the patient education tool being to increase patient autonomy. Another goal was an increase in the completion rates of advanced directives by hospice patients. Only about 20% of patients were currently completing ADs.

The ADDSS also supported investigation of the first research question in this project: can an effective set of design principles for the design and development of HISs be developed for the new environment for the practice of medicine? The first few months of collaboration illustrated the current problems with communication of medical information, the incomplete role that information systems currently have in healthcare today, and the promise that they hold in the future. Also illustrated was a need to put the patient before the bottom line of any of these organizations, as well as the problems that current public policy introduces to the system. The ADDSS provides an opportunity to explore the design of HIS with the design principles presented here, and to see if the result is an effective system in today's healthcare environment.

Following discussions about the ADDSS a second research question arose. Can system design result in a more autonomous user?" It was agreed that patient autonomy was a significant consideration in healthcare today and that the ADDSS would be an appropriate tool to test the impact of system design on patient autonomy.

The problem area was identified and agreed upon together between the researcher and the hospice. Once outlined and established, the project moved to phase two; action planning.

Action Planning

The action planning phase involves considering alternatives, or courses of action, which will be employed to improve a problem. Action planning is guided by theory indicating a desired future state, and also the means by which that state will be achieved (Kohli and Kettinger, 2004). The

theoretical selection was motivated by the desire of the researcher to test the HIS design principles described in earlier chapters.

Joint discussions resulted in a number of alternatives for the ADDSS. First was a web-based program that patients and their families could access on their own and would facilitate discussion and lead to completion of advanced directives. This was not realistic for several reasons. First, most of the patients are already in the hospital or nursing home and do not have free access to the Internet. Secondly there were privacy and technical concerns on the part of the hospice. The hospice did not want the information to leap their firewall, or to have any chance of a security breach, and they did not feel they had the expertise or technical resources to manage a web-based program. It was decided that the ADDSS would be housed on the nurse's individual laptops and compiled later over the network.

Next it was decided that the system should be designed in a way that was flexible enough so that the hospice could expand it in the future. They wanted to eventually house the system on the web to be used for community education purposes. Eventually the hospice hoped to have a web-based community wide program that would be used collaboratively between the nursing homes, hospitals, and hospices in the area. They also wanted the system to be available to patients and members of the community so that they could update their advanced directives with changes in their lives. It was agreed that the system would be designed with a forward thinking approach.

It was decided that the system should be flexible with regard to information flow. Patients have varying degrees of educational backgrounds and would require different levels of information.

The system would be flexible enough to provide the user with their desired level of information.

Consideration was given by both sides to security. Protecting the privacy of the patient's information was paramount and would be incorporated into the design of the ADDSS. HIPPA guidelines with regard to security, as well as other applicable issues, would be incorporated into the design of the system.

Lastly, the hospice wanted the system to capture compliance with federal regulations, completion rates, and the impact on user autonomy. Each of these would be built into the design of the ADDSS.

Action taking is the next stage in the cyclical process of action research. In the information gained from the action planning stage is carried forward to this stage.

Action Taking

Action taking is the implementation of from the previous stage (Kohli and Kettinger, 2004). The HIS design principles presented earlier chapters were used to guide the design of the ADDSS. It was proposed then that the entire set of design principles might not be applicable to every system design project. However, the designer is responsible for balancing any conflicting issues during design and employs any principles necessary to guide the development of the HIS system. Table

3 summarizes the use of the three general moral principles for HIS design and ADDSS compliance.

Table 3: Evaluation of Compliance with General Moral Principles of HIS Design Guidelines.

<i>Evaluating Compliance with HIS General Moral Principles</i>	
<u><i>General Moral Principles</i></u>	<u><i>ADDSS Compliance</i></u>
1. HIS will be designed with the goal of supporting patient autonomy.	The ADDSS is a patient education tool to educate patients so that they can make autonomous choices regarding their treatment decisions.
2. HIS will be designed with the goal of supporting social justice.	The completion of advanced directives helps distribute limited resources by not maintaining expensive treatments, while empowering the patient to make the distribution choices. The ADDSS is a community education tool that supports the greater good.
3. HIS will be designed to support patient welfare.	The ADDSS supports patient welfare by educating patients of their treatment choices and allowing the individual to make decisions about their quality of life.

In addition to the general moral principles for HIS design are responsibilities for the designer and stakeholders. Included in Table 7.2 is a summary of the responsibilities for the HIS designer and stakeholders and ADDSS compliance with these principles.

Table 4: Evaluation of Compliance with Responsibilities for HIS Designer & Stakeholders.

<i>Evaluating Compliance with HIS Responsibilities for HIS Designer and Stakeholders</i>	
<i>Responsibilities for HIS Designer & Stakeholders</i>	<i>ADDSS Compliance</i>
1. The HIS designer will adhere to moral & ethical principles guided by both the medical & computing professions.	The ADDSS is designed in compliance with the HIS design principles which incorporates the ethical & moral principles from both professions.
2. The HIS should support patient autonomy by being easily adaptable to the changing environmental conditions the user will face.	The ADDSS is designed with the goal of being modifiable so that the patients can increase their autonomy by incorporating their wishes in their ADDSS, and easily make changes in the future.
3. HIS success measures should be developed for specific applications.	The success measures are clearly stated by both the researcher & hospice and are application specific.
4. The client should include all salient stakeholders.	The primary stakeholder is the patient. Other stakeholders such as the hospice are swept in as applicable (hospital, nursing homes, family etc).
5. By maintaining trust, facilitating communication, & managing conflict the system should be managed to increase the measure of performance to patient.	The ADDSS is designed to capture the details about the patient's treatment wishes & communicate them to healthcare providers. This enhanced communication & control by patients is designed to enhance patient autonomy.
6. HIS designer should seek a design that encourages all providers and staff to maximize value to the patient.	The ADDSS is designed to put information regarding patient treatment wishes in the hands of providers and staff so that they can uphold end of life wishes and therefore provide maximum value to the patient.
7. The HIS designers, patients, and providers should become one in the highly participatory design process.	Design information and requirements were gathered by meeting with and incorporating information from patients, providers, members of the community, and organizations with the goal of incorporating all views into the design process and resulting in a wholly participatory design process.
8. System components should be shaped in relation to one another with the goal of producing exoteric knowledge, and not constrained by organizational boundaries or conflicting goals.	One goal of the ADDSS is to produce a future, expanded version of the system that incorporates lessons learned from the prototype. The motivation is to learn and expand knowledge about communication in a total healthcare system with the explicit intent of moving beyond organizational boundaries to uphold patient autonomy and privacy.
9. The HIS should include mechanisms for guaranteeing the conditionality and validity of the knowledge it contains.	Privacy and confidentiality is at the forefront of HIS design. The system will evolve in a series of changes so that lessons can be learned from its initial use on laptops. These lessons will be incorporated in the future expanded web-based versions with the intent being utmost consideration for the protection of privacy.

The last section of the HIS design principles addresses the technical responsibilities for HIS design. Table 7.3 includes a summary of the technical responsibilities for HIS design and illustrates ADDSS compliance with these principles.

Table 5: Evaluation of Compliance with Technical Responsibilities for HIS Design.

<i>Evaluating Compliance with Technical Responsibilities for HIS Design</i>	
<i>Technical Responsibilities for HIS Design</i>	<i>ADDSS Compliance</i>
1. Privacy	Current technology in the form of firewalls, antivirus protection, password protection, and network restrictions are applied to the ADDSS design.
2. Accountability	Use of the system is accounted for by the nurses responsible for the laptops which house the initial system. The ADDSS is designed to accommodate later versions with passwords and logs.
3. Information Quality	Utmost consideration is given to maintaining the accuracy of the information within the ADDSS. The system supports a flow of information guided by the patient to avoid overload or omission.
4. Ease of Use	The ADDSS is designed with an easily understandable interface, modifiable across all levels of user education. It is clearly structured, linked, and easily followed.
5. Portability	The ADDSS is designed to be forward thinking, adaptable to web-based applications, and easily transported between locations.
6. Non-intrusive	The ADDSS is designed to be as ubiquitous as possible and not to negatively impact the providing of medical care by the hospice nurses. At the same time, it is as apparent as need be to function as a patient educational tool when desired.
7. Mixed Form	The ADDSS provides as many links as possible to display information differently. However, advanced directives are by their nature text based so pictures and graphs were not appropriate in the original design.
8. Multiplicity	The initial version of the ADDSS provides mechanisms to communication information, although it is specifically design for use only within the hospice. However it is designed to be flexible and adaptable so that later versions can incorporate the use of email, links to other sites, and message boards.
9. Emergence	The ADDSS is designed to grow and encourage future innovative uses of this system and others.
10. Upholding Regulations	Every effort was included in the ADDSS design to uphold regulations by the organization, other potential organizations that will use the system, and HIPPA requirements.

An ADDSS prototype was developed and demonstrated to the hospice. The hospice employees were given the chance to experiment with the system and suggest changes or identify any problems that they found. The nurses were especially interested in the opportunity to take a more hands on approach to the project and were excited to see it move from an abstract idea to something that they could use.

As the project progressed the nurses became more excited about the potential of the ADDSS. As a result they provided a lot of useful information for modification of the original prototype. They added some information link ideas and ideas about reformatting which were incorporated into the design of the final prototype that would be used for testing and evaluation.

Several members of the hospice were excited about the potential of the ADDSS. They expressed excitement that the system would help them capture information for patient advanced directives. They saw the ability to easily change and update forms on the system as a particular advantage and they also stated that they expected there to be fewer errors on the forms. It was stated that the communication of information included on the forms would be improved and there would no longer be questions regarding forms that were hard to read because of illegible handwriting.

There was also enthusiasm about the future use of the system in the community and across organizations. And there was a general enthusiasm about the direction that the implementation of the first of these systems would take the organization.

The completed prototype begins with a menu of options regarding the advance directives forms. The user has a choice of exploring each of the forms, and with each stage they can navigate through desired levels of educational information. The ADDSS options interface is captured in Figure 7.1.

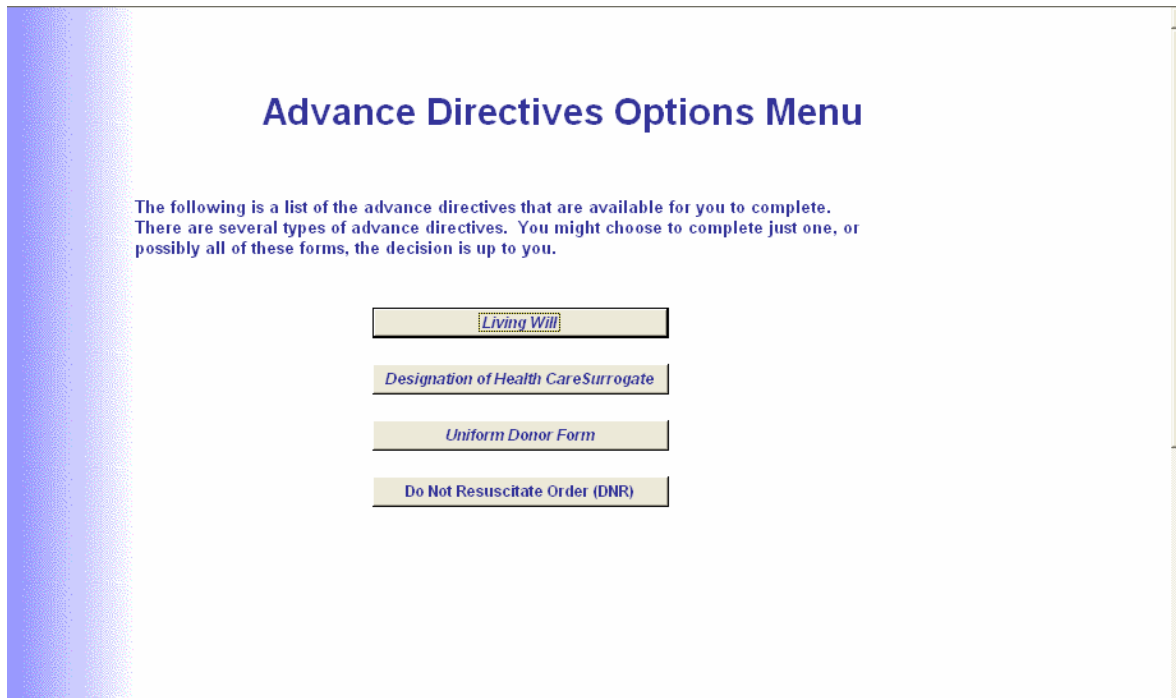


Figure 1: ADDSS Advanced Directives Option Menu

From the ADDSS options menu the user can navigate through the different advanced directives forms; Living Will, Designation of Healthcare Surrogate, Uniform Donor Form, and the Do Not Resuscitate form. When the user selects a form to explore it will bring the user to a screen that guides them through the completion of the form, as well as allowing them to select different links that will provide additional information if desired. Figure 7.2 shows the next step in the completion of a living will.

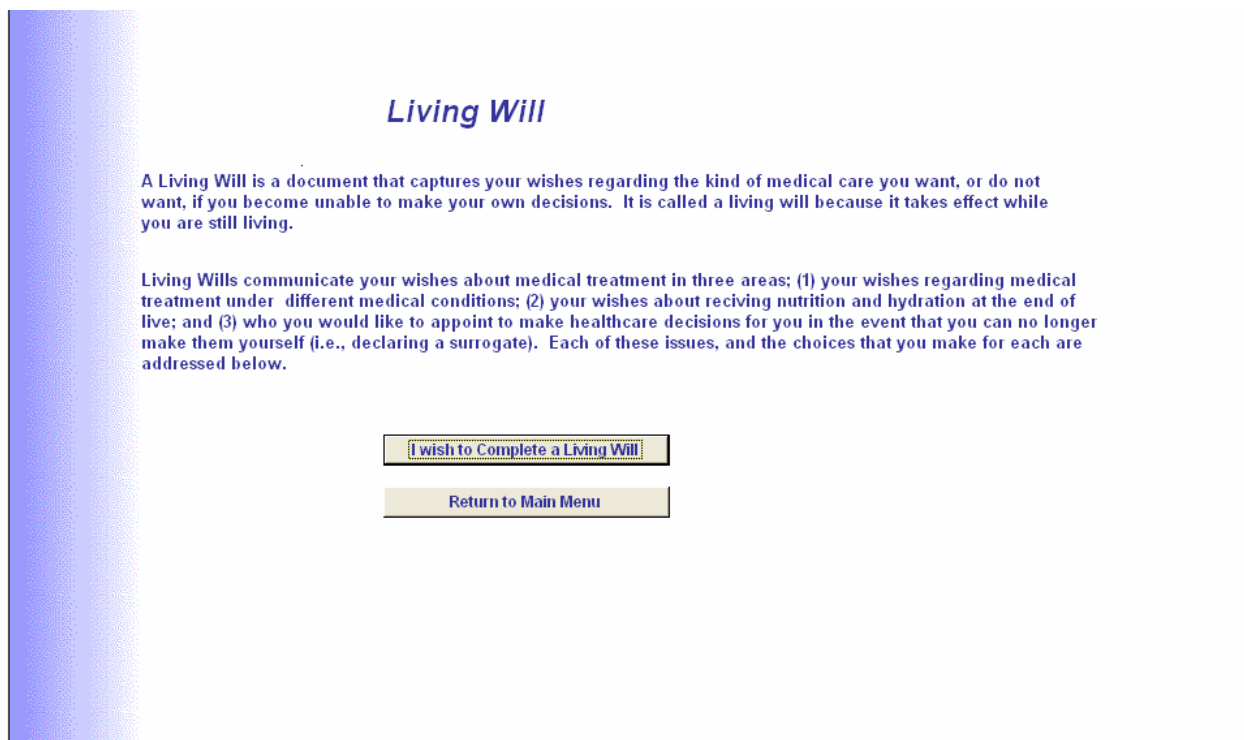


Figure 2: Living Will Introduction Interface

Here users can read general information about what a living will is. If they decide that they want to complete a living will they can navigate in that direction. If the living will is not what they wanted, they can navigate away and back to the main menu to decide upon another path. Figure 7.3 shows the next step in the completion of a living will.

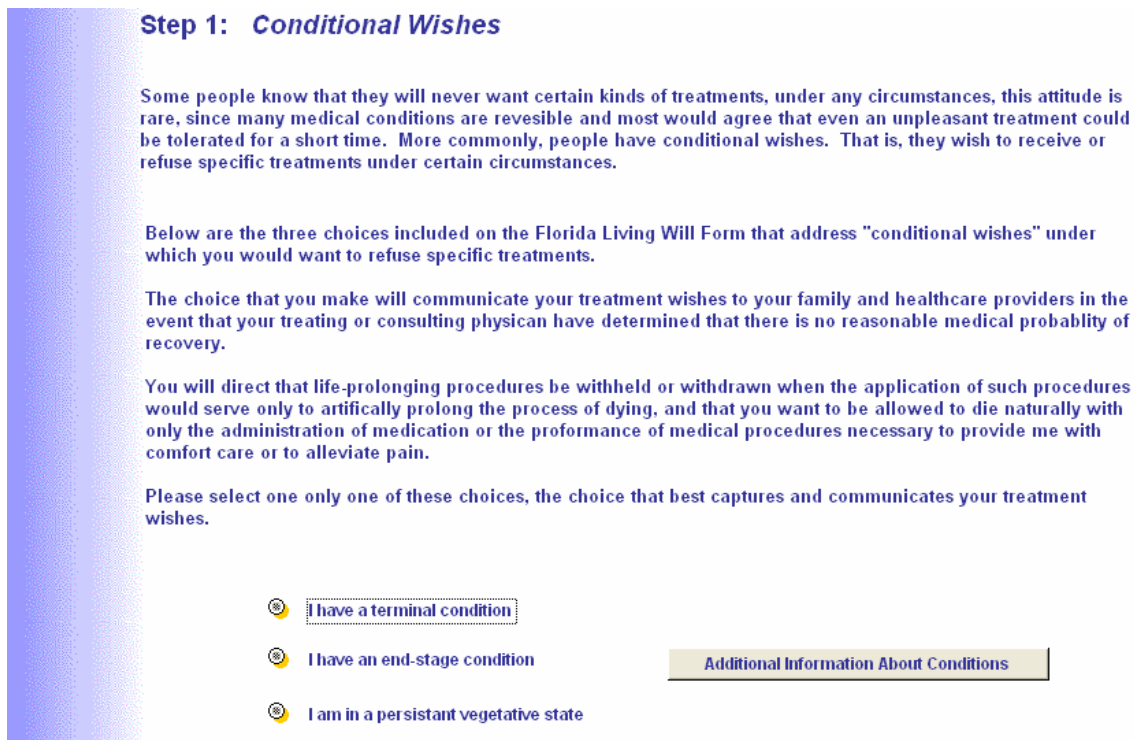


Figure 3: Step 1 of Living Will Interface

In step 1 of completing a living will, the patient makes decisions regarding treatment if they were to have a terminal illness, end-stage condition, or are in a persistent vegetative state. If they are unsure about what any of those conditions mean, they can click the “additional information about conditions” button. This allows them to navigate to additional information if they desire, or continue on with completion of the forms if they do not want more information. Figure 7.4 illustrates the additional information that the user will receive if they decide to navigate in that direction.

Additional Information About Conditions

What is a Terminal Condition?

A "terminal condition" means an incurable condition caused by injury, disease, or illness that according to reasonable medical judgement there is no medical probability of recover and which, without treatment will produce death within six months.

Many serious illnesses may be considered irreversible early in the course of the illness, but they may not be considered terminal until the disease is fairly advanced. In thinking about terminal illness and its treatment, you may wish to consider the relative benefits and burdens of treatment and discuss your wishes with your family, physician, or other persons in your life.

What is an End-Stage Condition?

An "end-stage condition" is defined as a condition that is caused by injury, disease, or illness which has resulted in severe and permanent deterioration, indicated by incapacity and complete physical dependency, and for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.

What is a Persistent Vegetative State?

A "persistent vegetative state" is defined as a permanent and irreversible condition of unconsciousness in which there is both the absence of voluntary action or cognitive behavior of any kind; and there is an inability to communicate or interact purposefully with the environment.

[Return to Living Will](#)

Figure 4: Additional Information Interface

After the user has the opportunity to review the additional information they can return to the living will and continue completing the forms at the point where they left off. There are additional navigation opportunities throughout the process of completing each of the forms.

The ADDSS was implemented in early 2006 after several months of development. Patients, in partnership with the nurses, began using the system immediately after implementation. The experiences that both the patients and the nurses had with the system are captured in the evaluation phase of the action research cycle.

Evaluation

The evaluation stage involves examination of the theorized effects, if they were realized, and if the effects solved the organizational problem identified (Kohli and Kettinger, 2004). The sources for evaluation included the patients and nurses who used the ADDSS. Information obtained during observation by the researcher of system use under a number of different scenarios that naturally evolved in the course of hospice admission visits. Informal interviews of the nurses, patients, and hospice employees, revealed relevant information. Lastly completion of the Advanced Directive Acceptability Questionnaire (Singer et al, 1995) by both system users and non-users were compared to reveal information about the success of the system.

After the system was implemented and had been used by the admission nurses for a few months five nurses were interviewed to elicit responses about the ADDSS prototype, specifically whether they found it useful in their work and how it compared to the paper version. The nurses were asked if the ADDSS was useful during the admission process and specifically in completing advanced directives. Generally the nurses were positive about the impact of completing the advanced directives on the computer. However, while most said it was helpful for its intended task, several stated that it was sometimes disruptive to have to bring the computer out for just one aspect of the admission process. This is how one nurse described the situation:

If you'd put the whole process on the computer it would be better. Right now most of the process is on paper and it would be just as easy to finish the directives that way since my pen is already out. Pulling out the computer when I'm not

already using it? is a little bit of a pain. But if you put the whole admission process on the computer I started the computer up first thing and did it all on there that would be great!

If the entire process had been switched from a paper version to the computer they would have been more comfortable with the entire process. However, most of the nurses kept in mind that this was a prototype and that full computerization was a goal, but not realistic at this point. It should be mentioned that one nurse did state that she did not like computers and did not want to see the admission process head in that direction.

When asked if the ADDSS facilitated communication with the nurses and family members about completing advanced directives, unforeseen and very revealing information surfaced. One nurse responded by saying:

When the patient is lucid, the computer program is really helpful. It can be a novelty for patients who are alert and still feeling well and not in pain. A couple of my patients thought using the system was a lot of fun. One even compared it to filling out the forms with her lawyer and said that using the system together with her family and me was really neat. But a lot of my patients are really very ill and everything they do takes a lot of effort and energy that they do not have. Most of those did not want to use the thing....for those who were pretty far gone they didn't seem to care one way or another and their family is tired too. It was just a job that had to be done and it didn't matter how.

What this nurse's statement reveals is something that was also observed by the researcher, and mentioned by several hospital nurses during admission visits. The patients in hospice care are often very close to dying. They have often fought long, difficult, and painful battles with a long-term illness and they are tired, and often no longer coherent. This particular population might be too ill for a tool like the ADDSS to be as useful as it could be in another population. One nurse practitioner who had worked in palliative care for over 20 years, and was now working in an oncology office, stated that:

This would be great for our patients (oncology), and it would be great for the palliative care patients in the hospital who are more aware than the hospice patients who are at the end of the road without anything left. Maybe you should test this thing in our office, or in the hospital, I bet you'll see a bigger difference there.

Several patients were also asked if they felt that the system made discussing their wishes with family members and the admissions nurses easier and most said that they thought the system was good. A couple of patients were very interested and enthusiastic. One was comfortable with it but more out of resignation that computers were here to stay, he said: *"I thought young people used computers for everything now days...there probably isn't any other way...I learned already that everyone has to get used to them being everywhere."*

When asked if they thought that the ADDSS would be a beneficial education tool for community education programs, all of the nurses agreed that the program would be very beneficial for community efforts. The consensus was that it would be especially helpful for individuals in the community if the system were online and easily accessed on an individual's own schedule.

When the nurses were asked if they thought that the patients felt more autonomous with regard to their treatment the general response was yes. They felt that the computer system helped issues come up that might not otherwise surface. One nurse in particular was excited about the fact that the ADDSS broke the routine of offering advanced directives, she stated:

I have been doing this for a long time and I have my way of getting through the forms and information. Ya know...the same speech over and over. That might lead to me not bringing things up that the patient might be wondering about. With this they can see information and it might trigger something inside of them that I would have just passed right by.

Observation of the interaction between patients and nurses illustrated the same thing. After months of going on admission visits it was obvious that there was a routine. Each nurse was different but they all had their set of instructions and information that they gave for each form, including the advanced directives. Once the ADDSS was implemented the routine did change and there seemed to be more discussion about advanced directives when the patient was completing them.

The nurses were asked if they felt that the system would help them document compliance with the federal regulations that states that upon admission the patient must be asked if they have an advanced directive. They were also asked if they thought that the ADDSS would help them document that they had complied with the hospice's requirement that they ask upon admission if a patient has an advanced directive, and if not would they like to complete one. To both questions the nurses all agreed that it would help them document that they had done their job and asked the appropriate questions.

The interviews and observations revealed consistent, however somewhat informal, insight into the impact of the ADDSS on both the patients and the organization. The Advanced Directive Acceptability Questionnaire (Singer et al, 1995) provided somewhat more formal analysis of the impact of the ADDSS on patient autonomy. The questionnaires were completed by 20 patients; 10 who used the system and 10 non-users. The comparison between the users and non-users was to reveal differences between the two groups and therefore the impact of the ADDSS.

Overall the evaluation efforts revealed both anticipated and unanticipated consequences of the ADDSS. The nurses and patients who were the primary users of the system seemed to value the system and thought that it was a positive addition or at least a step in the right direction for the hospice overall. This evaluation highlighted that the HIS design principles resulted in a system that generated both anticipated and unanticipated consequences. The negative consequences generally revolved around the uncontrollable aspects of the environment. For example, the fact

that overall the organization had a paper-based process and that any introduction of a computer-based process, if not a full process, would not be ubiquitous or routine.

In sum, the ADDSS was widely received as a beneficial tool, but there was uncertainty as to its fit within this particular population. Testing of the system in another environment, with patients or members of the community not at the end stages of a terminal illness, might find the system more beneficial.

Further evaluation of this action research project is conducted by assessing compliance with Davison's (2004) principles of canonical action research. These principles, described in earlier sections, facilitate a clear and systematic presentation of ideas and findings while helping researchers justify their actions and their contributions to both organizational and scientific knowledge. They impress a systematic approach to action research projects and thereby heighten both rigor and relevance in action research.

In the following section, the ADDSS action research project is compared with Davison et al's (2004) principles. The evaluation reveals that the current research project satisfies all of the criteria described by Davison et al.

Compliance with Principles of Canonical Action Research

The *principle of researcher-client agreement* (RCA) results in a contract of sorts that serves two purposes. First, it facilitates communication between the researcher and practitioner and results in a mutual understanding of the goal, scope, focus, and processes

of the research project. It also promotes a sense of collaboration and shared spirit between both parties. The initial stages of the project were characterized by a shared understanding and enthusiasm for the project, its goals, and potential positive impacts for patient education and organizational goals.

The CEO took a personal interest in the project. He was interested in biomedical ethics and with regard to this project he was especially interested in the development and testing of the ethical guidelines for HIS design. The director of education was the first contact made at the hospice and the main contact for the project. She was very enthusiastic about the educational aspects of the project and from first contact was extraordinarily helpful. The nurses were all very interested and helpful throughout the process.

Initial conversations about the project were primarily conducted between the researcher, director of education, and CEO. Together these parties came to what initially seemed to be a fairly solid agreement on both sides with regard to the organizational and research goals and the process of carrying out the action research project.

Once a formal project had been defined and admission visits were to start, the researcher wrote a summary of the RCA, both the organization and the researcher had copies. The director of operations passed the RCA on to other members of the organization who would be participating at varying levels on the project. The goal being mutual understanding by all parties involved.

Initially everyone at the hospice who was given the RCA was excited about the project. However, just as the researcher was to begin the initial admission visits with the nurses, the compliance officer contested the entire project. This was the first experience with a University related researcher or project of this sort at the hospice and the compliance officer was uncomfortable from the start. Her initial objections seemed at first to be potentially project ending. She was not happy about the addition of this project to her already busy schedule and did not want to see it pass. She tossed out a number of road blocks, but together with the researcher and relevant members of the hospice, each of the issues were discussed and resolved.

At first the interactions with the compliance officer were frustrating and at times seemed pointless other than just to end the project and lighten her workload. However in the end her objections, and the resulting discussions, resulted in a stronger understanding and agreement between the organization and the researcher. After several weeks of discussion all parties were working well together, the RCA was revised and resubmitted to the organization. All members of the project team, both on the side of the organization and the researcher were happy with the outcome of these discussions, and the revised RCA.

In the later stages of the project the RCA was tested again when the director of education became ill and was forced to retire. She had been the main contact, and the person who organized activities on the side of the organization for more than 6 months. Upon her departure the project stalled and it appeared again to be project ending. Other members

of the organization who had not been as involved in the project initially seemed disinterested and unsure of what had taken place since the RCA discussions. The loss of the director of education also left everyone with additional work and less time to work on this project. After several weeks of meeting with other members of the hospice and revisiting the RCA everyone was back on track and the project took off from where it was when the director of education left.

Throughout the project the RCA proved to be a very valuable tool. It reinforced the understanding of the expectations and goals on both sides and built camaraderie between the hospice and the researcher in the process. When the organization was disrupted by the loss of one of its key employees the impact on the project was substantial. The RCA proved once again a valuable tool for communication and rebuilding of trust and a spirit of collaboration between different members of the hospice and the researcher.

The primary goal of the RCA is to provide a foundation of agreement and collaboration between both parties and to resolve any differences that might come up throughout the life of the project. In the current project the RCA proved a critical resource, without which the project would have suffered.

The *principle of the cyclical process model (CPM)* encourages the project to progress linearly through the Susman and Evered's (1978) five cycles of action research as sequentially moving through the cycles adds rigor to the project findings. Although it is

recognized that at times iteration can lead to additional learning. In such cases the CPM requires explicit justification of the iterations on the project report.

The early stages of the current project were iterative. The first pass through the evaluation phase resulted in what at first appeared to be a clear problem identification and statement of goals. However, when the project moved into the action planning stage, it was revealed that the problem needed to be further defined. The iteration between the first two phases of the project resulted in a solid problem definition and statement of goals, and an enriched understanding and sense of collaboration on both sides.

The solid foundation that resulted from the iterations early in the project proved to be invaluable later in the project. The significant disruption caused by the loss of a key member of the project team returned the remaining members to the RCA that was a result of those passes through the first two stages of the cycle.

Once the ADDSS had been defined and the project moved into the action taking phase the project continued to move sequentially through the five stages. The experience of moving sequentially through the majority of the five cycles resulted in a clearly defined problem and a shared understanding of the project goals. Moving forward on each stage resulted in a feeling of accomplishment and excitement on both sides and enhanced the collaborative spirit of the project.

The *principle of theory* stresses the importance of using theory to guide research activities and relate the findings of the project to existing theory. The HIS theory, articulated by a set of guidelines for system development offered in earlier chapters, provided the central theoretical foundation for the project. The guidelines were used to guide the design and development of the ADDSS, and the analysis of the system in use. Through the use of the HIS theory it became possible to relate insights gained from the action research project for MIS researches working in design and development of information systems for use in the general healthcare context.

The *principle of change through action* specifies that interventions must be designed to address a specific organizational problem and its causes. The principles also reflect the indivisibility between action and change, as well as the researcher and organization (Davison et al., 2004). It is concerned with the degree of practitioner involvement throughout the life of the project (Lindgren et al., 2004). In the case of this project the degree of practitioner involvement went through several peaks and valleys. On average it was high and there was significant interest on the practitioner side, but at times practitioner involvement was very low. It was the ADDSS itself that brought life back to the project and regained the involvement of the hospice. When the nurses would report their excitement about the use of the system and other members of the organization would either hear about or revisit the system, the enthusiasm returned and the project picked up steam again.

The loss of the director of education was a difficult emotional and functional loss for the hospice. It just seemed to knock the steam right out of the place. After a while they regained interest and the original spark and involvement in the project returned.

The *principle of learning through reflection* specifies the importance of drawing conclusions from the research as well as identifying both the contributions to organizational knowledge and the overall knowledge that contributes to theory and research.

Currently HIS design has not explicitly been addressed in the MIS literature. This research describes HIS as a unique class of systems and introduces ethics-based design principles to guide future design and research in the use of information systems in a healthcare context. The findings of this project suggest that the HIS guidelines offered here can successfully guide the design of future systems.

Learning through reflection highlights that it is central to investigate the sustainability of research efforts over time, as well as to balance the theoretical demands of action research with the problem-solving demands of the practitioner (Lindgren, 2004). With regard to sustainability, it is difficult to know what the hospice will do with the ADDSS over time. However, members of the hospice have explicitly stated that they intend to expand the system as discussed in earlier phases of the project and include the ADDSS in their community education efforts. They also stated that they would continue use of the system for compliance tracking and to introduce the practice of having the nurses use the

computer during their admission visits. The ADDSS was also successful in facilitating communication between the patient, family members, and nurses.

Through this project, the use of theory in general, and specifically the use of the HIS design theory, was made accessible to practitioners. The collaborative nature of creation of the ADDSS made the theoretical concepts more understandable, familiar, usable, and concrete for the organization.

The HIS design principles were useful in that they ensured that the ADDSS contributed to both knowledge generation and the implementation of change. This project tested a set of HIS design principles and furthered the understanding of and development of these principles for future use in systems design.

“The development of design principles is not simply about operationalizing theory into neat principles for normative action, but it also involves an assessment of available tools and situated conditions such that these principles render to technically and organizationally feasible solutions” (Lindgren et al, 2004). In many ways the operationalization of the design principles resulted in technologically and organizationally successful solutions. Overall the ADDSS met the organization’s goals. However, the situational conditions for which the system was designed might not have been as well suited for the ADDSS. As mentioned earlier, the system might have made more of a difference in a “pre-hospice” population where the patients are not in advanced stages of illness.

The *principle of the researcher profile (RPI)* identifies the researcher as an instrument of the research, and as such it is required that the researcher should be described as would any other instrument of research. By explicating stating the values, expectations, and goals of the researcher, the researcher profile adds rigor to the findings of action research and to the contribution to both knowledge generation and organizational change.

The researcher on the current project is a Ph.D. candidate in an MIS program at a large university in Central Florida. She also holds a B.S. in Psychology from the University of New Mexico, an M.S. in MIS from Texas Tech University, and over ten years of industry experience. Both the development of the ethics-based HIS design theory and the ADDSS action research project that tests the HIS theory were designed by the researcher and are part of her dissertation.

The researcher had over ten years of industry experience prior to enrolling in the Ph.D. program, several years of that time was spent on the “business side” of medicine. That experience made the researcher aware of the healthcare industry in general, and of both the advantages and disadvantages that have been recognized by the medical community because of the implementation of information systems in healthcare. It also made her aware of some areas that could benefit greatly from the use of HISs but to date have received little attention.

In addition to being aware of the business aspects of information system use in healthcare, the researcher had experience with the healthcare system first hand as a caretaker for several family members and friends who experienced serious illness. Throughout these experiences she was employed at a large university research hospital in the Southwest, surrounded by the latest technology, experts in oncology, access to clinical trial information, and other benefits that come along with working in a well known research hospital. In spite of the fact that she had access to all of the latest medical technology, experts, and research pulling relevant information together to assist her family in making healthcare decisions was difficult; sometimes impossible. This experience led to a desire to apply information technology in a healthcare setting resulting in systems that would help patients' access information in order to make decisions when confronted with complex treatment options especially when facing life threatening illness. Several years later this interest would lead to a dissertation that involved the development of an ethics-based design theory for the development of HISs in healthcare.

Years spent observing medicine in action has left the researcher with values and beliefs with regard to the system as a whole. She believes that in spite of advances in medical treatments many of these treatments are brutal. Treatments are painful and depleting, and often do as much harm as good. The healthcare system in general values a treatment as successful if it prolongs life; death is often seen as failure. Therefore, the healthcare system generally pushes curative treatments. The treatments greatly impact the quality of life for the patient both in positive and negative ways. The researcher values the notion

that the patient should have the ability to decide which treatments to try and which to pass. She believes it is the individual who can best balance the choices and situations that the treatment options will have on his or her own quality of life and that of their family. The HIS design principles offered and tested in this current project reflect not only the current literature and ethics guidelines in both the medical and computing professions, but those of the researcher as well.

It is the goal of the researcher to study the intersection of MIS and healthcare for the purpose of advancing the understanding of the impact that these systems have on the ability of providers to treat patients, on the advancement of public health and access to health information, and to facilitate the individual patient in making autonomous choices with regard to treatment decisions that will help them achieve the best quality of life as possible in all conditions of health. She is also interested in the ethical issues that arise at the intersection of the two professions and believes that design principles for HISs should be firmly grounded in the moral and ethical philosophies that have guided their advancement throughout history and in the future.

The HIS principles that were employed in this action research project were the result of exploration by the researcher, and of those in the medical and computing fields who developed the ethical theories and guidelines that were synthesized into this HIS design theory. The principles were developed to address the complex issues faced at the intersection of the medical and computing professions as well as the specific issues that arise with the application of information technology in a specific healthcare context. The

ADDSS action research project provided the opportunity to test the principles. By employing the action research methodology to test the HIS principles, knowledge is gained through collaboration with organizations, implementation of change, and testing the principles in context. In the following chapter the contributions of the action research project are discussed, and specifically the contributions to knowledge in both practice and research are summarized.

CHAPTER EIGHT: DISCUSSION

In this project an HIS design theory was developed by bringing centuries of thought on medical ethics and the practice of medicine together with the modern phenomena of information technology and the literature and professional guidelines for computing professionals. The result is a set of ethical guidelines that guide the HIS system design in the complex context of contemporary healthcare.

Biomedical ethics evolved over centuries of thought about complex issues in medicine and have resulted in a progression of ethical guidelines, each capturing a specific cultural moment, a picture in time. Historically lessons of the past have been incorporated into current ethical philosophical thinking and result in a progression of guidelines that moves the medical community forward. This fairly steady progression is occasionally punctuated by significant societal and technological changes. It is during these unsettled times that we seek guidance to progress through the unknown and we turn our attention turns to ethical and moral philosophy for guidance.

Information technology has introduced significant change; global change that has significantly impacted societies, religion, education, business, cultures and the daily lives of individuals. The impact of information technology on the practice of medicine has been profound. Remarkable contributions have advanced the practice of medicine in ways that would have been incomprehensible in the past. The use of information technology in healthcare has also had destructive consequences as well; many of which came about because of the novelty of

information systems and the fact that designers and stakeholders simply didn't anticipate the problems that might arise from their use. The results illustrate that society in general, and our healthcare system in particular, is currently experiencing significant change. We have turned to the established ethical literature for guidance; however the issues that are faced in HIS design today have not here-to-fore been addressed. The HIS design theory offered here is an attempt to address this void. Arguably information technology and the practice of medicine can no longer be addressed separately, they have merged in practice and therefore should be merged in the literature that contains the ethical discourse from which we seek guidance. It is hoped that this theory will be the next step in the progression of ethical discourse regarding the complexities of the use of information technology in medicine today. And, that by articulating the theory in a set of guidelines for HIS designers this theory will have a positive impact on the practice of medicine as well.

The ADDSS action research project provides a first step in validating the HIS design theory. The action research methodology provides the opportunity to implement change in practice and at the same time advance general knowledge. It is hoped that this project is the first of many that begin to test and refine theories such as the HIS design theory offered here. The results of ADDSS project resulted in contributions for both practice and research. These contributions are discussed in the following sections.

Contributions and Implications for Research

This study began as part of a dissertation research project with the goal of testing the HIS design theory described in earlier chapters. Applying the HIS design principles in the ADDSS action research project extended the knowledge of the design of information systems for use in the healthcare context.

The use of information technology in healthcare is growing exponentially and MIS is uniquely suited for addressing the design issues that will arise. To date, information systems design at the intersection of healthcare and MIS has not been addressed in the MIS literature. The ADDSS action research project contributes to the literature seeking to understand the relationship between MIS and healthcare, and how to design ethical, effective, and efficient information systems in a healthcare context.

The hospice was a unique opportunity with regard to examining the relationship between MIS and healthcare. Given their limited use of information technology for the admissions process, the hospice proved to be a blank slate from which to study the HIS phenomena. The organizational changes that resulted from the ADDSS could be attributed directly to the system itself.

The HIS design theory provides a conceptual framework for incorporating information technology into our understanding of the use of information systems in complex healthcare contexts. It was originally anticipated that the action research project would result in a reduction of the design principles, however in the end each of the principles

proved valuable in the design of the ADDSS. Collaboration with the hospice, discussions with healthcare providers at the facilities visited during admissions visits, and especially meeting with patients and their families, transformed the researcher's understanding of the implications of the ethical design theory for HIS. The diversity of education, culture, and background of each of the individuals who used the ADDSS revealed the complexity of HIS design. Illustrated was the need for a number principles that span across the entirety of the individuals and organizations that would use the system. Developing the ADDSS with the guidance of the HIS design principles resulted in a system that was able to achieve multiple goals across multiple stakeholders with varying educational and cultural backgrounds within a healthcare setting. This is a common goal in a healthcare context, and a very difficult goal to achieve. The ADDSS achieved this goal and can provide insight into future design of similar systems.

The ADDSS successfully focused the design and the resulting functionality of the system on the patient, while simultaneously achieving organizational goals. In accord with the design principles, the ADDSS enhanced patient autonomy both by providing an education tool for the patient directly, and also by facilitating communication between the hospice nurses and the patient. The system facilitated patient decision making and allowed the patients to choose the treatment options that would best enhance their quality of life. These results illustrate the successful balance of patient autonomy, social justice (by achieving organizational goals), and patient welfare (the balance between the patient and the organization's goals that result from the ADDSS).

The impact of the advanced nature of the illnesses that characterize hospice patients was unexpected. As a result it proved very difficult to find patients within the hospice population that were able to use the system at all. Data collection proved difficult, as roughly sixty percent of the admissions visits that the researcher and nurses attended were with patients who were either no longer conscious, or still conscious but too ill to answer the questions to complete an advanced directive regardless of the medium in which it was offered (e.g., conversation with the nurse, computer, or paper). While overall the impact on patient autonomy was a positive one, it seems that the ADDSS would be better suited for a population that was not in advanced stages of terminal illness. The ADDSS will most likely prove to be a valuable tool for the hospice in their future community education efforts.

The HIS design principles tested in this project were applied successfully tested in the ADDSS action research project. The results of this project lend credibility in the ability of the design principles to support future applications of HISs. This is a contribution to knowledge in that the design theory is intended to address the design of a class of systems; therefore successful testing by the ADDSS project supports the contention that the HIS design principles will be applicable for design of future applications within this class of systems.

This project resulted in additional criteria for evaluation of action research projects. The *principle of researcher profile identification (RPI)* was added to Davison et al. (2004) criteria for evaluation of CAR. This principle highlights the inherent bias that the

researcher brings to any research methodology. The historical criticisms of action research as being relevant but not rigorous because of researcher involvement are specifically addressed in this principle by recognizing the researcher as an instrument of the research. This requires that the researcher's values, goals and beliefs be explicitly stated adding to the rigor of action research.

It is the goal of action research to contribute to both theoretical and practical knowledge. The ADDSS action research project resulted in the contributions to research mentioned above, as well as to a successful intervention at the hospice that resulted in organizational change. The organizational implications resulting from this research project are discussed in the following section.

Implications for Practice

The hospice stated several goals with regard to the ADDSS action research project. The hospice wanted to increase its role in the community both by participating in research and by providing end of life education for the community. By collaborating with the researcher they accomplished the first goal of participating in research. The ADDSS that was designed as a result of this collaborative effort will be a powerful tool to aid the hospice in achieving the second goal of providing end of life education for the community.

It was revealed very early on in the discussion between the researcher and the hospice that, while the hospice recognized the positive impact and growing need to include information technology in their admissions process, their attempts to accomplish this had not been successful. The initial investment for the hardware had already been made. However, when the researcher first visited with the nurses, she found that they rarely took their computers with them on admissions visits. Instead they would complete the admission process on paper. If there was information for which input into the computer was required, the nurses would input the information from the forms when they returned to their office, leaving as much of the process as possible to reside on paper.

Implementation of the ADDSS onto the nurses computers forced the nurses to begin to use their laptops. The initial reaction was interest in the ADDSS itself, but reluctance to use the computer in general. It didn't take long for the majority of the nurses to see the long term benefits of using the ADDSS, and information systems in general. The result was a learning process in HIS use in general at the hospice, as well as specifically the ADDSS. This was a beneficial process for the organization. It allowed for insight by the nurses regarding the ability of information systems to help them with their work and increased interest in using the computer, the ADDSS, and additional applications.

The hospice had wanted to design a system that would facilitate communication about advanced directives between patients in hopes that it would facilitate autonomy for the patient and enhance the quality of life during a difficult period. They also wanted an ADDSS that would result in an increase in the numbers of advanced directives

completed. Given the difficulties of working with end of life patients and their ability to complete advanced directives, it could not be determined during the life of this project if the ADDSS resulted in an increased completion rate. However, the nurses consistently stated that the system helped refresh their approach to talking with patients about advanced directives and recognized that as a positive outcome of the application. The result of the enhanced conversations is a more autonomous patient for those patients who were physically able to complete the advanced directives.

The hospice stated that the ADDSS would have a positive impact on the ability of the organization to track its compliance with federal regulations. In this case, the application helped the hospice implement a positive change.

Overall the results of the ADDSS action research project led to an increased understanding by the organization of the role of information technology during its admission process. The hospice also had the ADDSS as a result of this project, an application that they explicitly stated that they would continue to use and employ in other areas of their operations.

This project also left the hospice with an increased understanding of the benefits of research. The CEO in particular was glad that the organization was able to test the ethical design theory, and include an understanding of the availability and use of research in an application that the organization can use in practice.

REFERENCES

- “ACM Code of Ethics and Professional Conduct,” *ACM*, 1997.
- Adam, M.B., (2003) Comments on the Charter of Medical Professionalism. *The Center for Bioethics and Human Dignity*. [Http://www.cbhd.org/resources/healthcare/adam_2003-03-28.htm](http://www.cbhd.org/resources/healthcare/adam_2003-03-28.htm) (accessed April 9, 2005).
- Ash, J.S., and West. E., (1977). Journal Evaluation Study at the University of Connecticut Health Center. *Bulletin of the Medical Library Association*, Vol. 62., pp. 95-104.
- Baskerville, R.L., Wood-Harper, A.T., (1996) A Critical Perspective on Action Research as a Method of Information Systems Research. *Journal of Information Technology*, Vol. 11, pp. 235-246.
- Beauchamp, T.L, and Bowie, N.E., (2004). *Ethical Theory and Business*, 7th Edition. Pearson Prentice Hall, Upper Saddle River, New Jersey.
- Beauchamp, T.L., and Childress, J.F., *Principles of Biomedical Ethics*, 5th Edition, Oxford, 2001.
- Beck, G., (1999). Autonomy, History and Political Freedom in Kant’s Political Philosophy. *History of European Ideas*, Vol. 25, pp. 217-241.
- Berner, E.S., Detmer, D.E., and Simborg, D., (2005) Will the Wave Finally Break? A Brief View of the Adoption of Electronic Medical Records in the United States., *JAMIA*, Vol. 12, No. 1, pp. 3-7.
- Bernhardt, J.M., (2000). Health Education and the Digital Divide: Building Bridges and Filling Chasms. *Health Education Research*, Vol. 15, pp. 527-31.
- Boland, R., J., Tenkasi, R., and Te’eni, D., (1994) Designing Information Technology to Support Distributed Cognition, *Organizational Science*, Vol. 5, No. 3.
- Boyd, A., (2004). Tensions between Autonomy and Justice. *Medicine and Philosophy*, Vol. 25, No. 2, pp. 34-36.
- Churchman, C.W., (1971) *The Design of Inquiring Systems*. New York, NY: Basic Books, Inc.
- Code of Medical Ethics of the American Medical Association (1847)*. American Medical Association Press. Chicago, IL.
- Cusumano, M. and R. Selby (1995). *Microsoft Secrets*, New York: Free Press.

- Davison, R.M., Martinsons, M.G., and Kock, N., (2004). Principles of Canonical Action Research. *Information Systems Journal*, Vol. 14, pp. 65-86.
- Deshmukh, P. and Croasdell, D., (2001). HIPPA: Privacy and Security in Healthcare Networks. *Information Ethics: Privacy and Intellectual Property*. Information Science Publishing, Hershey, PA.
- Draper, J., Field, S., Thomas, H., and Hare, M.J., (1986). Should Women Carry Their Antenatal Records? *BMJ*, Vol. 292.
- Elder, N.C., and Hickner, J., (2005). Missing Clinical Information: The System is Down. *JAMA*, Vol. 293, No. 5.
- Eng, T.R., Maxfield, A., Patrick, K., Deering, M.J., Ratzan, S.C., and Gustafson, D.H., (1998). Access to Health Information Support: A Public Highway or a Private Road? *JAMA*, Vol. 280, No. 15.
- Englehardt., H.T., (2001). The Many Faces of Autonomy. *Health Care Analysis*, Vol. 9, pp. 283-297.
- Eysenbach, G., Powell, J., Kuss, O., and Eun-Ryoung, S., (2002). Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web. *JAMA*, Vol. 287, No. 20.
- Feled, C.F., Jonahntan, H.A., Smith, M.S., Gillam, M., Kanhouwa, M., Rothenhaus, T., Conover, and K., Shannon, T. (2004). Clinical Information Systems: Instant Ubiquitous Clinical Data for Error Reduction and Improved Clinical Outcomes. *Clinical Information Systems*, Vol. 11, No. 11.
- Garfinkel, S., (2001). *Database Nation: The Death of Privacy in the 21st Century*.
- Garrett et al., (1993). Health Care Ethics. Prentice Hall, 2nd Edition.
<http://www.utcomchatt.org/Docs/biomedethics.pdf>.
- Gordis, L., and Gold, E., (1980). Privacy, Confidentiality and the Use of Medical records in Research. *Science*, Vol. 207.
- Gostin, L.O., Lazzarini, Z., Neslund, V., and Osterholm, M., (1996). The Public health Information Infrastructure: A National Review of the Law on Health Information Privacy. *JAMA*, Vol., 275, pp. 1921-1927.
- Gostin, G.L., (2001). Health Information: Reconciling Personal Privacy with the Public Good of Human Health. *Health Care Analysis*, Vol. 9, pp. 321-335.

- Gostin, G.L., (2001). National Health Information Privacy: Regulations under the Health Insurance Portability and Accountability Act. *JAMA*, June 2001, Vol. 285, No. 3.
- Gostin, G.L., and Hadley, J., (1998). Health Services Research: Public Benefits, Personal Privacy, and Property Interests. *Annals of Internal Medicine*, Vol., 129, No. 10, pp. 833-835.
- Habermas, J (1984). *The Theory of Communicative Action: Reason and the Rationalization of Society*. Beacon Press Books, Boston, MA.,
- Hall, D., Paradice, D., and Courtney, J.F., (2003) Building a Theoretical Foundation for a Learning-Oriented Knowledge Management System, *JITTA*, Vol. 5, No. 2, pg. 63.
- Health Internetwork Access to Research Initiative (HINARI). <http://www.who.int/hinari/en/>, last accessed May 25, 2006.
- Hevner, A.R., March, S.T., and Park, J., (2004) Design Science in Information Systems Research, *MISQ*, Vol. 28, No. 1, pp.75-105.
- Hickner, N.C., and Hickner, J., (2005). Missing Clinical Information: The System is Down. *JAMA*, Vol. 293, No. 5.
- Hodge, J.G., Gostin, L.O., and Jacobson, P.D., (1999). Legal Issues Concerning Electronic Health Information: Privacy, Quality, and Liability. *JAMA*, Vol. 282, No. 15.
- Ikonomidis, S., and Singer, P.A., (1999) Autonomy, liberalism, and advance care planning. *Journal of Medical Ethics*, Vol. 25, p. 522.
- Jadad, A.R., and Gagliardi, A., (1998). Rating Health Information on the Internet: Navigating to Knowledge or Babel? *JAMA*, Vol. 279, No. 8.
- Kalra, D., and Ingram, D., Electronic Health Records (<http://eprints.ucl.ac.uk/archive/00001598/01/A22.pdf>) last accessed May 25, 2006.
- Kant (1785) "Foundation for the Metaphysics of Morals", in *Classics of Philosophy*,(Louis P. Pojman, ed., New York: Oxford University Press, 1998, 820-857.
- Kaplan, B., Evaluating Informatics Applications, *IJMIA*, Vol. 64, pp. 39-56.
- Kohli, R., and Kettinger, W.J., (2004). Informing the Clan: Controlling Physicians' Costs and Outcomes. *MISQ*, Vol. 28, No. 3, pp. 363-394.
- Klein, H.K., and Hirschheim, R., (2001) Choosing between Competing Design Ideals in Information Systems Development, *Information Systems Frontiers*, Vol. 3, No. 1.

- Kreps, G.L., (2002). *Enhancing Access to Relevant Health Information*. Shaping the Network Society: Patterns for Participation, Action, and Change. CPSR, Palo Alto, CA.
- Lindgren, R., Henfridsson, O., and Schultze, U., (2004). Design Principles for Competence Management Systems: A Synthesis of Action Research Study. *MISQ*, Vol., 28, No. 3, 435-472.
- Lorenzi, N.M., M.I. Mantel and R.T. Riley. "Preparing Your Organization for Technological Change." *Healthcare Informatics*. 7:(12) 33-34, December, 1990
- Mandl, K.D., Szolovits, P., and Kohane, I.S., (2001). Public Standards and Patients' Control: How to Keep Electronic Medical Records Accessible but Private. *BMJ*, Vol. 322.
- Markus, M.L, Majchrzak, A., and Gasser, L., (2002), A Design Theory for Systems That Support Emergent Knowledge Processes. *MISQ*, Vol. 26, No. 3, pp. 179-212.
- Mason, R.O., (1986) Four Ethical Issues of the Information Age, *MISQ*, March, 1986.
- Mason, R.O., Mitroff, I., (1973). A Program for Research on Management Information Systems. *Management Science*, Vol. 19, No. 5., pp. 475-487.
- Mathiassen, L., (2000) *Collaborative Practice Research, Organizational and Social Perspectives on Information Technology*. Baskerville, Stage and DeGross (eds) pp. 127-146. Kluwer Academic. Boston, MA.
- Mathiassen, L., (2002). Collaborative Practice Research. *Information Technology & People*, Vol. 14, No. 1, pp. 321-345.
- Mill, J. S. (1861), "Utilitarianism," in *Classics of Philosophy*, Louis P. Pojman, ed., New York: Oxford University Press, 1998, 913-945.
- Millenson, M.L. (2006), "A Patient's View of Health IT." *Trustee*, March 2006.
- Morse, S. (2002) Hippocratic Oath. *The Washington Post*, March 12, 2002, pg. F.03.
- Myrdal, G., (1975). *An American Dilemma: The Negro Problem and Modern Democracy*. Transaction Publishers, New Brunswick, N.J.
- National Networks of Health, Medical Records Privacy
(<http://www.uwex.edu/ces/flp/nnh/pdfs/mrp teach.pdf>) last accessed May 23, 2006.
- Oddo, A.R. (2001). Healthcare Ethics: A Patient-Centered Decision Model. *Journal of Business Ethics*, Vol. 29., No. ½., pg. 125134.

- Patel, P.L and Haux (2001). Studies in Health Technology and Informatics. *Proceedings of the 10th World Congress on Medical Informatics* Vol. 84. IOS Press, Amsterdam, Netherlands.
- Patel, P.L. and Kaufman, D.R. (1998) Science and Practice: A Case for Medical Informatics as a Local Science of Design, *JAMIA*, Vol. 5, No. 6.
- Pendleton, D., and King, J., (2002). Education Debate: Values and Leadership. *BMJ*, Vol. 325.
- Picano, E., (2004) Informed Consent and Communication of Risk from Radiological and Nuclear Medicine Examinations: How to Escape from a Communication Inferno, *BMJ*, Vol. 329, pp. 849-851.
- Rawls, J. (1971). A Theory of Justice. Cambridge MA: Harvard University Press.
- Redman (2006). Review of measurement instruments in clinical and research ethics, 1999–2003. *BMJ*, Vol. 32, pp. 153-156.
- Richardson, S.M., and Courtney, J.F., (2004) A Churchmanian Theory of Knowledge Management Systems Design. *Proceedings of the 37th Annual Meeting of the Hawaii International Conference on Systems Sciences, IEEE Computer Society.*
- Richardson, S.M., (2005) Knowledge Management and the Design of Distributed Cognition Systems,” Proceedings of the 38th Annual Meeting of the Hawaii International Conference on System Sciences, IEEE Computer Society.*
- Richardson, S.M., Courtney, J.F. and Haynes, J.D., (2006). “Theoretical Principles for Knowledge Management System Design: Application to Pediatric Bipolar Disorder,” *Decision Support Systems (Forthcoming).*
- Rindfleisch, T.C. (1997). Privacy, Information Technology, and Health Care. *Communications of the ACM*. August 1997, Vol. 40, No. 8.
- Roscam Abbing, H. (2000) Internet, the Patient and the Right for Health. *European Journal of Health Law*, Vol. 7, pp. 221-228.
- Roscam Abbing, H. (1999). Central Health Database in Iceland and Patient’s Rights. *European Journal of Health and Law*, Vol. 6, pp. 363-371.
- Ross, S.E. and Lin, C., (2003). The Effects of Promoting Patient Access to Medical Records: A Review. *JAMIA*, Vol. 10.
- Rothman, D.J., (2001). The Origins and Consequences of Patient Autonomy: A 25 Year Perspective. *Health Care Analysis*, Vol. 9, pp. 255-264.

- Sackett, D. L., Rosenberg, W., William, M. C., Gray, J. A., Haynes, B., and Richardson, W. S. (1996). *Evidence-based medicine: What it is and what it isn't*. *British Medical Journal*, 312, 71–72.
- Schoenberg, R., and Safran, C., (2000). How to Use an Internet-Based Medical Records Repository and Retain Patient Confidentiality. *BMJ*, Vol. 321.
- Scott, G.C., Cher, D.J., and Lenert, L.A. (1997) Second Opinion: interactive Web-based access to a decision model. *Proc AMIA Annual Fall Symposium*, pp. 769-73.
- Simon, H. (1960). *The New Science of Management Decision*. Harper Brothers, NY.
- Singer, P.A., Theil, E.C., Naylor, R.M.A, Richardson, Llewellyn-Thomas, H., Goldstein, M., Saiphoo, C., Udall, P.R., Mendelssohn, D.C., (1995). Life-sustaining Treatment Preferences of Hemodialysis Patients: Implications for Advance Directives. *Journal of the American Society of Nephrology*, Vol. 6, pp. 1410-1417.
- Shepperd, S., Charnock, D., and Gann, B., (1999). Helping Patients Access High Quality Health Information. *BMJ*, Vol. 319.
- Smith, Richard (2003). Closing the Digital Divide. *BMJ*, Vol. 326, No. 238.
- Sox, H., (2002) Medical Professionalism in the New Millennium. *Annals of Internal Medicine*, Vol. 136, No. 3.
- Stiggelbout, A.M., Molewijk, A.C., Otten W., Timmermans, D.R., van Bockel, J.H., and Kievit, J., (2004) Ideals of patient autonomy in clinical decision making: a study on the development of a scale to assess patients' and physicians' views. *Journal of Medical Ethics*, vol. 30, No. 3, 268-74.
- Tang, P.C., (2002). AMIA Advocates National Health Information System in Fight Against National Health Threats. *JAMIA*, Vol. 9, No. 2.
- Tauber, A.I., (2001). Historical and Philosophical Reflections of Patient Autonomy. *Health Care Analysis*, Vol. 9, pp. 299-319.
- Udas, K., Fuerst, W.L., and Paradice, D.B., (1996). An Investigation of Ethical Perceptions of Public Sector MIS Professionals, *Journal of Business Ethics*, Vol. 15, pp. 721-734.
- Upshur, R.E.G., Morin, B., and Goel, V., (2001). The Privacy Paradox: Laying Orwell's Ghost to Rest. *CMAJ*, Vol. 163, No. 3.
- Van Gigch, J.P., "The Paradigm of the Science of Management: In Celebration of C.W. Churchman's 80th Birthday", *Interfaces*, Vol. 25, No.2, March-April 1995 (pp.81-88).

- Villanueva-Russell, Y., (2005). *Evidence-based medicine and its implications for the profession of chiropractic. Social Sciences & Medicine, 60, pp. 545-561.*
- Wagner, T.H., Bundorf, M.K., Singer, S.J., and Baker, L.C., (2005). Free Internet Access, the Digital Divide, and Health Information. *Medical Care, Vol. 43, No. 4.*
- Walls, J.G., Widmeyer, G.R., and El Sawy, O.A., (1992) Building an Information Systems Design Theory for Vigilant EIS. *Information Systems Research, Vol.3, No.1.*
- Walls, J.G., Widmeyer, G.R., and El Sawy, O.A., (2004). Assessing Information System Design Theory in Perspective: How Useful Was Our 1992 Initial Rendition? *JITTA, Vol. 6, No.2.*
- Walzer, M. (1983). *Spheres of Social Justice: A Defense of Pluralism and Equality.* Basic Books, USA.
- Wilson-Steele, G. (2006), "Transforming Healthcare through Patient Empowerment." *Health Management Technology, April 2006.*
- Woodward, B., (2001). *Confidentiality, Consent and Autonomy in the Physician-Patient Relationship. Health Care Analysis, Vol. 9, pp. 337-351.*