

# **Integrating Healthcare Ethical Issues Into IS Education**

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## **ABSTRACT**

Federal initiatives are encouraging the increase of IS graduates to work in the healthcare environment because they possess knowledge of datasets and dataset management that are key to effective management of electronic health records (EHRs) and health information technology (IT). IS graduates will be members of the healthcare team, and as such, they should gain an understanding of bioethics and 'level the playing field' so that they may meaningfully contribute to the healthcare team. Moreover, they should be mindful of professional ethical codes and common ground that healthcare and IS professions share, particularly with regard to ethical principles of beneficence, autonomy, fidelity, and justice. The purpose of this paper is to present ways to integrate healthcare ethical issues within IS education. To this end, we discuss the notion of a mutual understanding of bioethics and present professional codes of ethics as an advance organizer. We also offer an example ("Fidelity and The Case of Two Datasets") that may be used in class to illustrate a specific IS healthcare ethical dilemma. Prepared with the knowledge of ethical problems in healthcare organizations, IS professionals can meaningfully contribute to the deliberations and resolutions of the problems that will emerge as more healthcare facilities employ EHRs.

**Keywords:** Ethics, Health Care, Privacy, Data Management

## **1. INTRODUCTION**

From the 2009 American Recovery and Reinvestment Act (ARRA), about 20 percent (\$19 billion) of the total funds were allocated to the health sector as only about 20 percent of physicians and 10 percent of hospitals had used basic electronic medical records (EHRs) and only about 6 percent of physicians and two percent of hospitals had used them comprehensively (Dentzer, 2010). One ARRA provision was the Health Information Technology for Economic and Clinical Health Act (HITECH), which called for an increase in IT professionals educated in adoption, implementation, and meaningful use of EHRs.

The 2010 Patient Protection and Affordable Care Act (ACA) is expected to increase access of U.S. residents to healthcare visits with providers. In preparation, the North Carolina Institute of Medicine (2011) reported that the State has been awarded over \$10.4 million to expand the healthcare professional workforce, including provisions to focus on IS professionals working in the healthcare environment (NCIH, 2011). Thus, the HITECH Act (of ARRA) and ACA may bring about an expansion in EHRs as well as a surge in the number of patients, estimated at 23 million additional regular users (Harmon, 2010). Accompanying these changes is the importance of

professionals (with IS and health IT competencies) on interdisciplinary healthcare teams that represent clinical, administration, and information systems areas.

Healthcare has continued to experience an ever-burgeoning need for IS graduates, precisely because of the recent focus brought about from the aforementioned federal initiatives. Estimates indicate that from 2011-2016, the U.S. will experience a shortfall of about 50,000 qualified health IT workers (HITECH RegionD, 2011).

IS graduates working on healthcare teams will have opportunities to make valuable contributions to the discussions of ethics in their healthcare organizations, alongside clinical healthcare professionals. For instance, using the Internet as the only method to publicize a healthcare organization's services has ethical implications. It is unjust to implement a strategy that disenfranchises many potential patients simply because they lack Internet access. IS professionals should have important roles in such discussions.

The purpose of this paper is to present and discuss ways to integrate healthcare ethical issues within IS education. To this end, we first present the notion of mutual understanding in which IS educational programs may prepare their graduates by building their knowledge and skills in bioethics. Second, we discuss the professional code of ethics as an

advance organizer for IS students as they consider ethical issues in healthcare. Last, we present an example to illustrate ethical dilemmas that IS professionals may meet as they work in healthcare.

## 2. MUTUAL UNDERSTANDING

Building knowledge and skills in bioethics creates a mutual understanding between IS professionals and health practitioners in the classroom and in the work place. Both sets of professional have ethics in their educations. Prominent accrediting bodies for IS educational programs mandate ethics as a component of the curricula:

- ABET, Inc. (accreditor for college and university programs in applied science, computing, engineering, and technology) requires that curricula result in graduates' having:
  - An understanding of professional, ethic, legal, security and social issues and responsibilities (2011-2012 Criteria for Accrediting Computing Programs. Criterion 3. Student Outcomes) and
  - An understanding of professional and ethical responsibility (2011-2012 Criteria for Accrediting Applied Science Programs. Criterion 3. Student Outcomes. Baccalaureate Programs)
- AACSB International—The Association to Advance Collegiate Schools of Business requires that curricula include learning experiences in the ethical and legal responsibilities in organizations and society (Eligibility Procedures and Accreditation Standards for Business Accreditation. Standard 15)

Moreover, the IS 2002 Model Curriculum for Undergraduate Degree Programs in Information Systems recommends that ethics be included in three core courses (Rogers, 2006). The Model Curriculum is a collaboration of Association for Computing Machinery (ACM), Association for Information Systems (AIS), and Association of Information Technology Professionals (AITP) (Gorgone et al. 2002).

Additionally, reflecting the importance of the IS role as members of teams, the ABET, Inc. accreditation criteria also mandated that curricula include a component that ensures graduates are able to function as members of teams (Criterion 3. Student Outcomes for both Computing Programs and Applied Science Programs). The IS 2002 Model Curriculum recommends that team work be included in five of ten courses.

However, despite this educational preparation, IS graduates may lack confidence in their knowledge of ethics and the tools of ethics, *as they apply to healthcare*. This lack of confidence may undermine their functioning as members of healthcare teams; thus, deterring their participation in the decision making in healthcare organizations. Educational programs in IS, though, can prepare their graduates for this

part of the IS professionals' role by building knowledge and skills in bioethics.

Ethics courses in the health professions typically involve several key content areas. These content areas are ethical principles; end-of-life decisions; allocation of scarce resources, such as organs; reproduction, abortion, and genetics; euthanasia and sterilization; and patient informed consent and autonomy. Various ethical philosophies are explained, such as teleology, beneficence, utilitarianism, deontology, principles of justice, virtue, and caring. A working knowledge of these topics 'levels the playing field' for IS students and graduates when they begin to work in healthcare teams.

Mutual understanding of bioethics is especially important when IS graduates are members of interdisciplinary teams. When discussing ethics, health practitioners use a verbal shorthand – a code. Without the decoder, IS team members may feel somewhat intimidated by clinical healthcare professionals and, consequently, be less likely to contribute. IS educators can teach IS students the verbal code and, thus, prepare them for ethical discussions in healthcare organizations. The verbal code involves major documents that set standards for bioethics and notorious cases of breaches of ethics.

### 2.1 Learning the Code

Beginning at the end of World War II, several major documents were published setting standards for bioethics. The documents show an evolution of requirements for the protection of human subjects. This evolution has continued into the 21<sup>st</sup> century. These documents are summarized:

- Nuremberg Code (1947). This international statement is a result of the U.S. Military Tribunal-Doctors' Trial (Shuster, 1997). The tribunals were the trials of Nazi war criminals in the city of Nuremberg. Nazi doctors performed medical experiments on civilian prisoners. These experiments included hypothermia (excessively low body temperature), castration by x-rays and intrauterine injections, high-altitude conditions through decompression chambers, bone transplantation, forced ingestion of saltwater, and injection with typhus and malaria (Bassiouni et al., 1981). The Nuremberg code states that human participation in research must be voluntary and informed.
- Declaration of Helsinki (1964, with amendments in 1975, 1983, 1989, 1996). The Declaration is a guide to physicians conducting biomedical research (Bassiouni et al., 1981). The World Medical Association published this attempt at self-regulation.
- Belmont Report (1979). The National Research Act (Pub. L. 93-348; 1974) created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission was charged to identify the basic ethical principles that should underlie biomedical and behavioral research on human subjects and develop guidelines to assure that research is conducted in

accordance with those principles (National Commission, 1979). The Department of Health, Education, and Welfare (now Department of Health and Human Services) adopted the Report as a statement of its policy.

- U.S. law and regulations. The National Research Act (Pub. L. 93-348; 1974) created the Commission that wrote the Belmont Report. The Code of Federal Regulations (CFR) extended the protections of the Belmont report to research involving substances under the jurisdiction of the Food and Drug Administration (CFR, Title 21, Parts 50 and 56; 1981); the Veterans Administration (CFR, Title 38, Part 16; 1991); and pregnant women, fetuses, neonates, prisoners, and children (CFR, title 45, Part 46; 1981). In 2005, almost all federal agencies adopted these protections which became known as the “Common Rule.”

As early as the 1800s, U.S. researchers were conducting medical experiments (Numbers, 1979). Some of these experiments violated ethics, resulting in the Belmont Report and subsequent regulations. IS students and graduates who enter the healthcare sector should be aware of these notorious cases.

- U.S. Public Health Service Syphilis Study. Commonly known as the Tuskegee Syphilis Study, this case is arguably the most notorious violation of ethics in U.S. human experimentation. Congressional and public outrage from it resulted in the National Research Act of 1974 and the Belmont Report. Researchers from the U.S. Public Health Service (PHS) conducted the study from 1932 through 1972 in rural counties around Tuskegee, Alabama (Reverby, 2001). The purpose of the study was to obtain information about the course of untreated syphilis. The researchers did not tell the 399 African-American men that they had syphilis and, moreover, after the discovery of penicillin (definitive treatment) in the 1940s, blocked the men from being treated. The men’s wives were infected with syphilis and their children were born with congenital syphilis (Jones, 1981). The U.S. PHS researchers did *not* inject the men to infect them, but did prevent them from getting treatment. However, from 1946 through 1948, in another study, the Public Health Service Sexually Transmitted Disease Inoculation Study, the U.S. PHS researchers did deliberately expose poor Guatemalan men and women, through sexual contact or inoculation (injection), to syphilis, gonorrhea, and chancroid (Reverby, 2011). The U.S. PHS Venereal Disease Research Laboratory and the Pan-American Sanitary Bureau conducted the study with four Guatemalan government agencies; the Ministry of Health, the National Army of the Revolution, the National Mental Health Hospital, and the Ministry of Justice (Reverby, 2011). The purpose of the study was to obtain information on

penicillin’s effectiveness as a prophylactic (preventive) treatment after exposure (Reverby, 2011). The subjects were prisoners, prostitutes, and inmates of a mental health asylum. A total of 1560 subjects were exposed to syphilis (696), gonorrhea (772), and chancroid (142) (some subjects were in multiple experiments) (Centers for Disease Control and Prevention, 2010). The number of exposures that were adequately treated ranged from 86 percent to 99.5 percent (Centers for Disease Control and Prevention, 2010).

- Federal experiments on prisoners, 1940s through 1960s. In 1943, at Terre Haute Federal Penitentiary, 241 prisoners were injected with various strains of gonorrhea. During World War II, more than 1300 prisoners at 4 U.S. prisons were part of research on malaria (Baader et al., 2005)
- Experiments on vulnerable people. Between 1823 and 1833, Beaumont conducted experiments on digestion using St. Martin, a French-Canadian voyageur (Numbers, 1979). St. Martin had a chronic, open tract across his abdominal wall from a gunshot wound. From his experimental surgeries on African-American slaves (1840s) and poor Irish immigrants (1850s-1860s), J. Marion Sims, the father of gynecology, invented several gynecological, surgical procedures (Sartins, 2004). In the mid-1950s, researchers exposed severely mentally retarded children, who were residents of Willowbrook State School in New York, to hepatitis (Rothman, 1982). The consent forms that the children’s parents signed were deceitful because the forms were worded to sound as though the children were receiving a vaccine *against* hepatitis (Rothman, 1982). At the Jewish Chronic Disease Hospital in 1963, 22 sick and weak patients were injected with live cancer cells. The patients were told the injection was to test their resistance to disease (Langer 1964).
- Federal research on radiation. Between 1944 and 1974, researchers conducted approximately 4000 human radiation experiments, sponsored by several U.S. federal agencies. Unwitting research participants included children, prisoners, sick patients, and atomic veterans (Advisory Committee on Human Radiation Experiments, 1995). For example, in the late 1940s through early 1950s, at Fernald School, 32 mentally retarded children were fed radioisotopes in milk for their breakfast oatmeal (Mann, 1994). Also, at Fernald School, 17 mentally retarded children were fed radioactive iron (Mann, 1994). The purpose of these experiments was to determine the effects of radiation on the body’s absorption of calcium and iron (Mann, 1994). The researchers, however, deceived the children’s parents into given consent by describing the experiment as participation in “science club” (Buchanan, 1996).

Familiarity with this history of ethical breaches will allow IS students and graduates to understand the context when health practitioners merely say “Tuskegee” or “Fernald.”

Common ethical decisions in healthcare involve obtaining informed consent, maintaining confidentiality, and supporting patients’ autonomy. Today, these decisions have implications for information technologies. Moreover, IS students and graduates apply the ethical principles of justice, fidelity and autonomy when making decisions about the use and allocation of information resources. Ethical discussions occur because technology often advances faster than our philosophical understanding of its implications.

### 3. THE CODE OF ETHICS AS AN ADVANCE ORGANIZER

When discussing the ethics involved with the introduction of IT into the healthcare workplace, a gap exists between what the IS student knows and does not know (Woodward et al., 2007). More importantly, a gap exists between what IS students know and where IT may or may not be used ethically. To bridge this gap, codes of ethics endemic to various professions can be used as an *advance organizer* (West et al., 1991). A code of ethics, when used as an advanced organizer, can act as a bridge between a student’s prior knowledge to situations that directly draw into question the morality behind the use or adoption of IT in specific contextual situations (e.g., the recording of one’s genetic predisposition to cancer within an EHR application).

#### 3.1 Advance Organizer

The concept of advance organizer was developed by Ausubel (1960) who advocated that educators must identify what the student already knows and how that information is organized. To connect new information with prior knowledge, the instructor provides information that acts as a bridge between the new knowledge and prior knowledge. This bridge is the foundation of the advance organizer, identified by:

- A short, abstract textual statement.
- A bridge that connects and organizes new knowledge with a student’s prior knowledge. Similarity must exist between prior and new knowledge
- Used to introduce a new lesson, unit or course.
- Outlines new knowledge; restates prior knowledge.
- Helps students structure new information.
- Encourages the transfer and application of information.
- Provides opportunities for critical thinking and promotes intellectual stimulation.

All of these features are contained in the code of ethics for most U.S. professions.

#### 3.2 Ethical Codes

The *Center for the Study of Ethics in the Professions* reports that there are over 850 ethical codes in existence throughout the world (see <http://ethics.iit.edu>). Most codes may serve as advance organizers because they can structure and organize students’ ability to think ethically about how to respond to

ethical conflicts in their profession. Students have developed a code of ethics based on a set of beliefs (such as ethnicity, and religion). Once in a profession, their personal ethical code may come into conflict with their professions’ code, assuming they recognize their profession has an ethical code, and they choose to adhere to it. Hence, a professional ethical code may help students think about questions such as:

1. Does my personal ethical code guide me towards the supporting the situation under discussion?
2. What is the purpose of a professional code of ethics?
3. Why follow a professional ethical code over my personal code?
4. Am I morally required to uphold a principle in my profession’s ethical code that I may find untenable based on my own set of beliefs?
5. Do I sacrifice my professionalism if I reject a guideline in my profession’s ethical code?
6. Can middle ground be reached between my personal code and that of my profession?

Additionally, a code of ethics acts as an advance organizer as it helps a student think ethically in response to conflict within the profession. Layman (2003, 2008) cautions that as the use of IT increases, IS professionals will be forced to make ethical decisions regarding how and why these technologies are deployed. The ethical use of IT requires IS professionals to think about the principles of beneficence, autonomy, fidelity, and justice. For instance, the use of EHRs is seen by many as a benefit, as it can help increase access to care, improve the quality of medical care, and decrease healthcare costs. However, these benefits come with a price in terms of their influence on ethical principles. As Layman (2003) states, with the introduction of EHRs comes easier access to patient health information, which may result in the loss of autonomy for the individual.

To elaborate, instead of healthcare providers’ relying on the patient for the most up-to- date information, the EHR becomes the record of choice as patients forget, fail to recall properly and, perhaps, even lie about their medical conditions. Autonomy is further eroded when health information, is either inadvertently or unknowingly, shared with insurance companies, and employers.

With greater access to health information via EHR applications, the ability to maintain information fidelity becomes problematic. Patient health information has been compromised with recorded information being changed, deleted, and stolen. For instance, a woman received a bill for having her right foot amputated. To prove that she did not receive the operation, she had to send notarized photographs of her toes, intact to hospital administrators (Menn, 2006). Her medical record had been compromised by a hacker, who had stolen her health insurance information, and had obtained the surgery in question.

Finally, in terms of justice, the EHR may present a pervasive problem. Many local, state, and federal agencies require healthcare providers to report information such as births, deaths, diseases and medical procedures. These data may be posted and shared through various government electronic resources. Using several data manipulation

techniques, patients may be identified and linked to shared information. Thus, one person's private healthcare information may be identified through shared sites.

**3.3 Professionals and Their Respective Code of Ethics**

To illustrate how professional codes of ethics can be used to promote ethical thinking, imagine a group of individuals discussing an EHR implementation. Within that group is an IT professional, health information management professional, physician, nurse, and healthcare administrator. Each individual, when considering how the EHR will be implemented, will be influenced by his or her own professional code of ethics.

For the IS professional one of the most common code of ethics is published by the Association of Computing Machinery, while the code associated with the health information management professional is promulgated by the American Health Information Management Association. The physician will be influenced by the American Medical Association's code of ethics, while the nurse will use the code produced by the American Nurses Association. Finally, the healthcare administrator will use American College of Healthcare Executive code of ethics. Canons from the professional code of ethics for each professional, applicable to ethical principles are presented (See Table 1).

<b>Beneficence: The information technology must provide direct benefits to the identified stakeholders.</b>	
<b>Professional</b>	<b>Example From Professional Code</b>
Information Technology	Organizational leaders are responsible for ensuring that computer systems enhance, not degrade, the quality of working life. When implementing a computer system, organizations must consider personal and professional development, physical safety, and human dignity of workers. Appropriate human-computer ergonomic standards should be considered in system design and in the workplace. Current system users, 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. <a href="http://www.acm.org">http://www.acm.org</a>
Health Information Management	Preserve, protect, and secure personal health information in any form and hold in highest regard the record contents and other information of confidential nature, taking into account the applicable statutes and regulations. <a href="http://www.ahima.org">http://www.ahima.org</a>
Physician	A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant technology available to patients, colleagues, and the public, obtain consultation, and use of the talents of other health professionals when indicated. <a href="http://www.ama-assn.org">http://www.ama-assn.org</a>
Nurse	The nurse participates in establishing, maintaining, and improving healthcare environments and conditions of employment conducive to the provision of quality healthcare and consistent with the values of the profession through individual and collective action. <a href="http://www.nursingworld.org">http://www.nursingworld.org</a>
Healthcare Administrator	Conduct both competitive and cooperative activities in ways that improve community healthcare services. <a href="http://www.ache.org">http://www.ache.org</a>
<b>Autonomy: Access to personal health information will be given to only those individuals providing direct care to the patient.</b>	
<b>Professional</b>	<b>Example From Professional Code</b>
Information Technology	This includes taking precautions to ensure data accuracy, 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. <a href="http://www.acm.org">www.acm.org</a>
Health Information Management	Advocate, uphold and defend the individual's right to privacy and the doctrine of confidentiality in the use and disclosure of information. <a href="http://www.ahima.org/">http://www.ahima.org/</a>
Physician	A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy with the constraints of the law. <a href="http://www.ama-assn.org/">http://www.ama-assn.org/</a>
Nurse	The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient. <a href="http://www.nursingworld.org/">http://www.nursingworld.org/</a>
Healthcare Administrator	Comply with all laws and regulations pertaining to healthcare management in the jurisdictions in which the healthcare executive conducts professional activities. <a href="http://www.ache.org/">http://www.ache.org/</a>
<b>Fidelity: All personal health information is maintained in a secure environment.</b>	
<b>Professional</b>	<b>Example From Professional Code</b>
Information Technology	Designing or implementing systems that deliberately or inadvertently demean individuals or groups is ethically unacceptable. Computer professionals who are in decision making positions should verify that systems are designed and implemented to protect personal privacy and enhance personal dignity. <a href="http://www.acm.org">http://www.acm.org</a>

Health Information Management	Preserve, protect, and secure personal health information in any form and hold in highest regard the contents of the records and other information of confidential nature, taking into account the applicable statutes and regulations. <a href="http://www.ahima.org/">http://www.ahima.org/</a>
Physician	A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy with the constraints of the law. <a href="http://www.ama-assn.org/">http://www.ama-assn.org/</a>
Nurse	The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient. <a href="http://www.nursingworld.org/">http://www.nursingworld.org/</a>
Healthcare Administrator	Comply with all laws and regulations pertaining to healthcare management in the jurisdictions in which the healthcare executive conducts professional activities. <a href="http://www.ache.org/">http://www.ache.org/</a>
<b>Justice: Patients are not unjustly treated through the use of health information technology.</b>	
<b>Professional</b>	<b>Example From Professional Code</b>
Information Technology	"Harm" means injury or negative consequences, such as undesirable loss of information, of property, property damage, or unwanted environmental impacts. This principle prohibits use of computing technology in ways that result in harm to: users, general public, employees, employers. Harmful actions include intentional destruction or modification of files and programs leading to serious loss of resources or unnecessary expenditure of human resources such as the time and effort required to purge systems of "computer viruses." To minimize the possibility of indirectly harming others, computing professionals must minimize malfunctions by following generally accepted standards for system design and testing. Furthermore, it is often necessary to assess the social consequences of systems to project the likelihood of any serious harm to others. If system features are misrepresented to users, coworkers, or supervisors, the individual computing professional is responsible for any resulting injury. <a href="http://www.acm.org">www.acm.org</a>
Health Information Management	Advocate, uphold and defend the individual's right to privacy and the doctrine of confidentiality in the use and disclosure of information. <a href="http://www.ahima.org/">http://www.ahima.org/</a>
Physician	A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy with the constraints of the law. <a href="http://www.ama-assn.org/">http://www.ama-assn.org/</a>
Nurse	The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient. <a href="http://nursingworld.org/">http://nursingworld.org/</a>
Healthcare Administrator	Comply with all laws and regulations pertaining to healthcare management in the jurisdictions in which the healthcare executive conducts professional activities. <a href="http://www.ache.org/">http://www.ache.org/</a>

**Table 1: Ethical Principles and Professional Codes of Ethics**

IS instructors may use codes of ethics to drive discussions regarding the ethical principles of beneficence, autonomy, fidelity, and justice in relation to health IT. For example, consider an IT professional who is in charge of creating physician quality indicators for an orthopedic practice. Over time, this IT professional develops intimate knowledge regarding which surgeons are providing the best care. What actions, in terms of ethical behavior, should he take upon learning that a family member is about to receive care from a surgeon identified as providing low quality of care? Using professional ethical codes as advanced organizer, students can grapple with decisions regarding what they would do. (For a full listing of professional codes of ethics associated with IT professionals, health information managers, healthcare professionals, and healthcare executives, see Table 2.)

**4. AN EXAMPLE TO ILLUSTRATE- FIDELITY AND THE CASE OF TWO DATASETS**

Using the code of ethics as an advanced organizer, students may refer to the principle of fidelity as their responsibility to respect patient confidentiality, privacy and protect patient

health information. IS professionals in health IT are to ensure that personal health information is maintained in a secure environment. However, adhering to the fidelity principle and engaging in health IT practices of reporting data may present ethical risks.

For example, Lamberg (2001) demonstrated that individual patients may be identified by cross-referencing datasets. Although it was not possible to identify a specific patient from each individual dataset, it was possible to re-identify a patient when datasets were linked. Starting with birthdate, sex, and ZIP code, Sweeny (a computer privacy expert) retrieved health data of William Weld (former governor of Massachusetts) from an anonymous database of state employee health insurance claims. Knowing Weld lived in Cambridge, she cross-linked her data with that community's publicly available voter registration records. Only six people shared Weld's birth date. Only three were men. Of these, Weld was the only man in his five-digit ZIP code (Lamberg, 2001, pp. 3075).

Data related to patients are collected, stored, sorted, viewed, coded, shared and analyzed in order to make the right diagnoses or conduct the right treatments. With the nationwide deployment of EHRs, clinical data are stored

Professional	Sources of Professional Codes
Information Technology	<ul style="list-style-type: none"> <li>• Association of Computing Machinery - <a href="http://www.acm.org/about/code-of-ethics">http://www.acm.org/about/code-of-ethics</a></li> <li>• Association of Independent Information Professionals - <a href="http://www.aiip.org/">http://www.aiip.org/</a></li> <li>• American Society for Information Systems - <a href="http://courses.cs.vt.edu/~cs3604/lib/WorldCodes/ASIS.Code.html">http://courses.cs.vt.edu/~cs3604/lib/WorldCodes/ASIS.Code.html</a></li> <li>• Association of Information Technology Professionals - <a href="http://www.aitp.org/">http://www.aitp.org/</a></li> <li>• IEEE-CS/ACM Joint Task Force on Software Engineering Ethics and Professional Practices - <a href="http://ethics.iit.edu/indexOfCodes-2.php?key=6_305_147">http://ethics.iit.edu/indexOfCodes-2.php?key=6_305_147</a></li> <li>• Independent Computer Consultant Association - <a href="http://www.icca.org/index.php">http://www.icca.org/index.php</a></li> </ul>
Health Information Management	<ul style="list-style-type: none"> <li>• American Health Information Management Association - <a href="http://www.ahima.org/">http://www.ahima.org/</a></li> <li>• American Medical Informatics Association - <a href="https://www.amia.org/">https://www.amia.org/</a></li> <li>• Healthcare Information and Management Systems Society - <a href="http://www.himss.org/ASP/index.asp">http://www.himss.org/ASP/index.asp</a></li> <li>• International Medical Informatics Association - <a href="http://www.imia-medinfo.org/new2/">http://www.imia-medinfo.org/new2/</a></li> <li>• Medical Library Association - <a href="http://www.mlanet.org/">http://www.mlanet.org/</a></li> </ul>
Physician	<ul style="list-style-type: none"> <li>• American Academy of Orthopaedic Surgeons - <a href="http://www.aaos.org/">http://www.aaos.org/</a></li> <li>• American College of Emergency Physicians - <a href="http://www.acep.org/">http://www.acep.org/</a></li> <li>• American Academy of Pediatrics - <a href="http://www.aap.org/">http://www.aap.org/</a></li> <li>• American College of Physicians - <a href="http://www.acponline.org/">http://www.acponline.org/</a></li> <li>• American Medical Association - <a href="http://www.ama-assn.org/">http://www.ama-assn.org/</a></li> </ul>
Nurse	<ul style="list-style-type: none"> <li>• American Association of Nurse Anesthetists - <a href="http://www.aana.com/">http://www.aana.com/</a></li> <li>• American Nurses Association - <a href="http://www.nursingworld.org/">http://www.nursingworld.org/</a></li> <li>• Certified Nurse-Midwives - <a href="http://www.midwife.org/">http://www.midwife.org/</a></li> <li>• International Association of Forensic Nurses - <a href="http://iafn.org/">http://iafn.org/</a></li> <li>• International Council of Nurses - <a href="http://www.icn.ch/">http://www.icn.ch/</a></li> </ul>
Healthcare Administrator	<ul style="list-style-type: none"> <li>• American College of Healthcare Executives - <a href="http://www.ache.org/">http://www.ache.org/</a></li> </ul>

**Table 2: Code of Ethics by Profession**

more in electronic format, which is accessible for many patient and public healthcare purposes (e.g. quality management, outcome assessment, or clinical epidemiology). Even though the intent of aggregate data in public databases is beneficent, the protecting of privacy and respecting autonomy may not be secured; thus, violating fidelity.

Our following example, “Fidelity and The Case of Two Datasets,” serves to show students the risk of re-identifying a patient by linking together two publicly accessible datasets with de-identified patients/personal data. Professionals in health IT, often as part of their job requirements, manage large datasets with data collected from patients. These datasets may be released and shared for other purposes such as research or disease surveillance. A common practice is to de-identify patient data elements (e.g., SSN, names, and address) with the expectation that patients’ personal information will not be re-identified without these removed data elements. However, the risk of re-identifying a specific patient still exists because it may be linked with other public available datasets.

One can access datasets containing de-identified data with limited costs. As with Lamberg’s (2001) example, it is not possible to identify a specific patient from each individual dataset, but it is possible to re-identify a patient if we link both datasets. To understand to what extent that patient/personal information is removed or suppressed from both datasets, we searched the data dictionaries and data release agreements related to two datasets in North Carolina.

**4.1. The Datasets**

The first dataset is the North Carolina Discharge Database, housed at the Cecil G. Sheps Center, Health Services

Research, University of North Carolina, Chapel Hill. The Sheps Center stores, maintains and analyzes the discharge database. Although the dataset is not a public record, access is available to researchers at the Center (at no charge) as well as the public for a fee (\$1500.00 annually). Data elements include age, sex, race, patient state, patient county, five digit ZIP code, admitting diagnosis, birth weight in grams, length of stay, diagnosis codes, facility id, HCFA DRG, HCFA MDC procedure code, days from admission to procedure, service line, source of admission for newborns, source of admission for non-newborns, patient status, admission type. To ensure fidelity, one of the three elements (ZIP code, facility id or primary diagnosis) is suppressed when releasing the data (see [http://www.shepscenter.unc.edu/research\\_programs/hosp\\_discharge/data\\_request/NCDischarge\\_Overview\\_10-1.pdf](http://www.shepscenter.unc.edu/research_programs/hosp_discharge/data_request/NCDischarge_Overview_10-1.pdf)).

The second dataset is the North Carolina Voter Registration Data. North Carolina State Board of Elections collects and manages data about registered voters. Data collected include the voter’s name, mailing address, ZIP code, birthdate, date of registration, party affiliation, voting history, voting districts, polling place assignment, voter identification number, race, ethnicity, and gender, (North Carolina Voter Registration Data, see <http://www.sboe.state.nc.us/content.aspx?ID=55>). These data are also accessible to the public; a \$25.00 fee is charged for a CD, which is mailed to the requester.

**4.2 Running the Random Number Generator**

IS students should note common fields in both datasets (e.g., age, sex, race, county, ZIP code) that provide the basis for linking the two databases. We used Microsoft Excel to

simulate the process and calculated the probability that a patient could be identified through such an operation. We simulated the hospital discharge dataset (Hospital\_1000) with 10,000 cases with age, race, gender and diagnosis as the fields. We used random number generator in Excel to create the dataset. Sheets 2 (Zipcode\_200) and 3 (Zipcode\_2000) contains simulated voters demographic data for a zip code with a population of 200 or 2000. Because both are voter registration datasets, the range of age is from 18 to 85. Again, a random number generator was used to create data for age, race and gender. So that the instructor may use this example, we have uploaded the datasets in Microsoft Excel 2010 as well as a tutorial for instructors and students (<http://jise.org/Volume22/22-3/Campbell-SpecialIssue.zip>).

One patient (Patient ID No. 10 in the Patient Discharge Data Set) was set with information also included in the voter registration dataset (Voter ID No.1 in the Voting Record dataset). The rest of the data were generated randomly. We used the Excel MATCH function to link the two datasets and identify any matching records based on age, race and gender. We also used the first 200 cases in the hospital discharge data to simulate a dataset containing ZIP code information (that is, those cases in which the ZIP code had not been suppressed when being released). We ran the simulation ten times for each combination of numbers of discharges (200, 10000) and numbers of residents in a specific ZIP code (200, 2000). The probability that a patient's information would be re-identified was calculated by using the average of the ten simulations.

The probability of a patient's personal information being re-identified is higher when the person comes from a low population density ZIP code area (see Table 3). Even for someone residing in a ZIP code area with a population of 2000, the chance to get re-identified is about 8-9%. In North Carolina, 3.96% of the ZIP code areas have populations with fewer than 200 residents, and 27.24% of the ZIP code areas have populations less than 2000. The fidelity violation is not a small matter when it comes to patient health data even when the professionals have adhered to practices designed to protect patient privacy.

	Number of Discharges	
Number of Residents in the Zip Code	200	10000
200	99.4%	97.5%
2000	9.17%	8.11%

**Table 3: Probabilities that a Single Patient could be Re-identified**

It is important to note that the random data function in Excel generates data using a uniform probabilistic distribution that does not reflect the real world distribution of either discharge or the voter registration data. In fact, both datasets should contain more data from older populations, which may actually increase the chance that patient's information being re-identified. Sweeney (2000) estimated

that 87% of the U.S. population could be re-identified based upon ZIP code, sex, and date of birth.

#### 4.3 Implications

The implications are threefold. First, students may discuss that patients who come from a low density ZIP code area had a higher risk of being re-identified when linking several public datasets together. Therefore, not only was fidelity violated, but the higher odds of re-identification by low density region may also spur a class discussion regarding the principle of justice and best practice of releasing and managing data. This example illustrates that while we adhere to our code of ethics, we must be mindful of outcomes and potential harm resulting from seemingly innocuous acts. IS students may discuss how data from the low density ZIP code areas need to be merged to reduce the risk of such re-identifications and identify the right criteria for such merges. They could also discuss how to prohibit data linkage of different datasets from a policy perspective.

Second, students should discuss technical options of more advanced computational methods since re-identification is possible even though methods have been employed to de-identify patient information (e.g., k-anonymity, k-unlinkability or binning). K-anonymity is a data protection model defined by Sweeney(2002) as a data release provides *k*-anonymity protection if the information for each person contained in the release cannot be distinguished from at least *k*-1 individuals whose information also appears in the release (<http://dataprivacylab.org/projects/kanonymity/index.html>). Malin (2008) proposed another formal data protection model called *k*-unlinkability that prevents trail re-identification in distributed data to ensure sensitive data trails are linkable to *n* less than *k* identities to the identities of individual records. Binning is a data pre-processing technique that can be used to reduce the effects of data exposure -- original data values which fall in a given small interval, a bin, are replaced by a value representative of that interval, often the central value like means. Students can use the datasets to discuss the size of *k* or bins in the database and how to maintain the integrity of the data while maintaining the anonymity of individuals.

Finally, students may achieve a level playing field so to mandate that administrative policies be created and enforced when releasing patients' data. Health IT professionals, especially those involve in data management and release, must be vigilant when data releases are requested. Such releases need to be reviewed with caution. In an electronic connected healthcare environment, protecting patient's privacy has become a daunting task.

#### 5. CONCLUSION

The purpose of this paper was to present ways to integrate health care ethical issues within IS education. To include in classes what has been presented, instructors may lecture on learning the code, have students read about the notorious cases, and elaborate on the importance of leveling the field when they participate on healthcare teams. Then, applying advance organizer, instructors may ask students to discuss how they would respond to the dilemma introduced regarding the IS professional's knowledge of a poorly

performing surgeon. Last, instructors could work through “Fidelity and The Case of Two Datasets” to illustrate the ethical issues involved in data release and generate discussion about how the issues may be dealt with effectively and ethically (see <http://jise.org/Volume22/22-3/Campbell-SpecialIssue.xlsx>).

Armed with the knowledge of ethical problems in healthcare organizations, IS graduates can be better informed and more effective healthcare team members. They may meaningfully contribute to the deliberations and to the resolutions of the problems that will emerge as more healthcare facilities employ EHRs, which result in creating new and to be addressed ethical dilemmas.

#### 4. REFERENCES

AACSB International—The Association to Advance Collegiate Schools of Business. (2011), “Eligibility Procedures and Accreditation Standards for Business Accreditation.” Retrieved September 7, 2011 from <http://www.aacsb.edu/accreditation/standards-2011-revisions-jan2011.pdf>

ABET, Inc. (2010), “Curricular Standards for Ethics Education,” Retrieved April 5, 2011, from <http://www.abet.org/forms.shtm>.

Advisory Committee on Human Radiation Experiments. (1995), “Final Report of the Advisory Committee on Human Radiation Experiments.” Retrieved April 10, 2011 from <http://www.hss.energy.gov/HealthSafety/ohre/roadmap/acre/index.html>

Ausubel, D.P. (1960), “The Use of Advance Organizers in the Learning and Retention of Meaningful Verbal Material.” *Journal of Educational Psychology*, Vol. 51, pp. 267-272.

Baader, G., Lederer, S., Low, M., Schmaltz, F., and Schwerin, A. (2005), “Pathways to Human Experimentation, 1933-1945: Germany, Japan, and the United States.” *Osiris, 2<sup>nd</sup> Series, Politics and Science in Wartime: Comparative International Perspectives on the Kaiser Wilhelm Institute*, Vol. 20, pp. 205-231.

Bassiouni, M. Cheriff, Baffes, T., and Evrard, J. (1981), “An Appraisal of Human Experimentation in International Law and Practice: The Need for International Regulation of Human Experimentation.” *Journal of Criminal Law & Criminology*, Vol. 72, No. 4, Winter, pp. 1597-1666.

Buchanan, A. (1996), “Judging the Past: The Case of the Human Radiation Experiments.” *Hastings Center Report*, Vol. 26, No. 3, pp. 25-30.

Centers for Disease Control and Prevention. (2010), “CDC Report on Findings from the U.S. Public Health Service Sexually Transmitted Disease Inoculation Study of 1946–1948, Based on Review of Archived Papers of John Cutler, MD, at the University of Pittsburgh.” Retrieved April 10, 2011 from [http://www.hhs.gov/1946inoculationstudy/std\\_inoc\\_study.pdf](http://www.hhs.gov/1946inoculationstudy/std_inoc_study.pdf)

“Codes of Ethics Online” (2011) Retrieved June 8, 2011 from <http://ethics.iit.edu>.

Dentzer, S. (2010), “One Year after the Stimulus, Will We Get Health IT Right?” *Health Affairs*, Vol. 29, No. 4, p. 582.

Gorgone, J.T., Davis, G.B., Valacich, J.S., Topi, H., Feinstein, D.L., and Longenecker, H.E. (2002), “IS 2002 Model Curriculum and Guidelines for Undergraduate Degree Programs in Information Systems.” Retrieved September 7, 2011 from [www.acm.org/education/is2002.pdf](http://www.acm.org/education/is2002.pdf)

Harmon, K. (2010), “The Future of Your Medical Data.” Retrieved March 18, 2011, from <http://www.scientificamerican.com/article.cfm?id=future-of-medical-data&print=true>.

HITECH RegionD., “What is the Future for HIT?” (2011), Retrieved June 7, 2011, from <http://hitregiond.pittcc.edu/index.html>.

Jones, J. H. (1981), *Bad Blood: The Tuskegee Syphilis Experiment*. Free Press, New York.

Lamberg, L. (2001), “Confidentiality and Privacy of Electronic Medical Records.” *Journal of the American Medical Association*, Vol. 285, No. 24, pp. 3075-3076.

Langer, E. (1964), “Human Experimentation: Cancer Studies at Sloan-Kettering Stir Public Debate on Medical Ethics.” *Science, New Series*, Vol. 143, No. 3606, pp. 551-553.

Layman, E. (2009), “Human Experimentation, Historical Perspective of Breaches of Ethics in US Healthcare” *The Healthcare Manager*, Vol 28, No 4, pp. 354-374.

Layman, E. (2008), “Ethical Issues and the Electronic Health Record,” *The Healthcare Manager*, Vol 27, No. 2, pp. 165-176.

Layman, E. (2003), “Health Informatics Ethical Issues,” *The Healthcare Manager*, Vol 22, No 1, pp. 2-15.

Malin, B. (2008), “k-Unlinkability : A privacy protection model for distributed data,” *Data & Knowledge Engineering*, Vol 64, pp. 294-311.

Mann, C. (1994), “Radiation: Balancing the Record.” *Science, New Series*, Vol. 263, No. 5146, pp. 470-473.

Menn, J. (2006), “Id Theft Infects Medical Records” Retrieved May 13, 2011 from <http://articles.latimes.com/2006/sep/25/business/ft-medid25>.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979), “The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research.” Retrieved April 9, 2011 from <http://ohsr.od.nih.gov/guidelines/belmont.html>

NCIH--North Carolina Institute of Medicine (2011), “Implementation of the Patient Protection and Affordable Care Act in North Carolina: Interim Report.” Retrieved June 8, 2011 from <http://www.ncmedicaljournal.com/wp-content/uploads/2011/03/HR-Interim-Report.pdf>.

North Carolina Voter Registration Data (2011), Retrieved March 25, 2011 from <http://www.sboe.state.nc.us/content.aspx?ID=55>

Numbers, Ronald L. (1979), “William Beaumont and the Ethics of Human Experimentation.” *Journal of the History of Biology*, Vol. 12, No. 1, pp. 113-135.

Reverby, S. (2001), “More Than Fact and Fiction: Cultural Memory and the Tuskegee Syphilis Study.” *Hastings Center Report*, Vol. 31, No. 5, pp. 22-28.

Reverby, S. (2011), "'Normal Exposure' and Inoculation Syphilis: A PHS 'Tuskegee' Doctor in Guatemala, 1946-1948." Journal of Policy History, Vol. 23, No. 1, pp. 6-28.

Rogers, C. (2006), "Ethics in the IS Curriculum: A Summary of Directives from AACSB, IS2002, and ABET." Proceedings of the Southern Association for Library Systems (SAIS). Paper 16. Retrieved September 7, 2011 from <http://aisel.aisnet.org/sais2006/16/>

Rothman, D. (1982), "Were Tuskegee and Willowbrook 'Studies in Nature'?" Hastings Center Report, Vol. 12, No. 2, pp. 5-7.

Sartins, J. (2004), "J. Marion Sims, the Father of Gynecology: Hero or Villain?" Southern Medical Journal, Vol. 97, Issue 5, pp. 500-505.

Sheps Center. (2011), Retrieved March 25, 2011 from [http://www.shepscenter.unc.edu/research\\_programs/hosp\\_discharge/data\\_request/NCDIScharge\\_Overview\\_10-1.pdf](http://www.shepscenter.unc.edu/research_programs/hosp_discharge/data_request/NCDIScharge_Overview_10-1.pdf)

Shuster, E. (1997), "Fifty Years Later: The Significance of the Nuremberg Code." New England Journal of Medicine, Vol. 337, No. 20, pp. 1436-1440.

Sweeney, L. (2002), "k-Anonymity: A Model for Protecting Privacy." International Journal on Uncertainty, Fuzziness and Knowledge-based Systems, Vol. 10, No. 5, pp. 557-570.

Sweeney, L. (2000), Uniqueness of Simple Demographics in the U.S. Population. Carnegie Mellon University, Laboratory for International Data Privacy, Pittsburgh, PA.

West, C., Farmer, J., Wolff, P. (1991) *Instructional Design: Implications from Cognitive Science*, Allyn and Bacon, Needham Heights, MA.

Woodward, B., Davis, D. and Hodis, F. (2007), "The Relationship Between Ethical Decision Making and Ethical Reasoning in Information Technology Students." Journal of Information Systems Education. Vol 18, No. 2, Pp. 193-202.

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