Ethical Issues and the Electronic Health Record

Elizabeth J. Layman, PhD, RHIA, CCS, FAHIMA

Ethical issues related to electronic health records (EHRs) confront health personnel. Electronic health records create conflict among several ethical principals. Electronic health records may represent beneficence because they are alleged to increase access to health care, improve the quality of care and health, and decrease costs. Research, however, has not consistently demonstrated access for disadvantaged persons, the accuracy of EHRs, their positive effects on productivity, nor decreased costs. Should beneficence be universally acknowledged, conflicts exist with other ethical principles. Autonomy is jeopardized when patients’ health data are shared or linked without the patients’ knowledge. Fidelity is breached by the exposure of thousands of patients’ health data through mistakes or theft. Lack of confidence in the security of health data may induce patients to conceal sensitive information. As a consequence, their treatment may be compromised. Justice is breached when persons, because of their socioeconomic class or age, do not have equal access to health information resources and public health services. Health personnel, leaders, and policy makers should discuss the ethical implications of EHRs before the occurrence of conflicts among the ethical principles. Recommendations to guide health personnel, leaders, and policy makers are provided. Key words: electronic health record, ethics, data mining, health informatics, medical informatics

ETHICAL ISSUES RELATED to electronic health records (EHRs) confront health personnel, health leaders, and health policy makers. Electronic health records present conflicts among ethical principles. In 2000, Stanberry commented that little published information was available on “info-ethics.” Over the past several years, ethicists and informaticians have rectified this shortage. Today, a substantial body of literature exists on record privacy and ethics. Experts have also extended the body of knowledge to consider ethical issues related to linkages of records, unauthorized sharing of records, unauthorized data mining, and secondary research using record databases. In this article, the conflicts among the ethical principles of beneficence, autonomy, fidelity, and justice, as they relate to EHRs, are examined. Integration of the wide-ranging literature on info-ethics, as it applies to EHRs, supports health personnel, health leaders, and health policy makers as they face the challenges these conflicts among ethical principles present in the care of and services to patients and clients.

BACKGROUND

Functional model of electronic health records (EHRs)

Electronic health record is one term for a computer application that electronically stores individually identifiable health data. Other terms are care record, computer-based patient record, computer-based medical record, electronic patient record, and electronic medical record. Health care organizations that operate at multiple sites can link EHR applications across the individual sites to create an EHR system (also known

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as a computer-based patient record system or electronic medical record system). In the United States, the preferred term has become EHR.  

The preferred functionality of an EHR depends upon its uses. There are 2 sets of uses for EHRs: primary and secondary (see Table 1). In terms of users, these are individuals such as patients, clinicians, and managers and organizations such as hospitals and clinics, insurance companies, governmental health agencies, and universities. The US Institute of Medicine lists 8 core categories of functionality for an EHR system (see Table 2). The Institute of Medicine also lists 6 key capabilities for health care delivery that EHR systems should have to reach their fullest potential (see Table 2).

**Development and diffusion**

Development of EHRs has occurred during the past 40 years. Around the globe, implementation of EHRs is at various stages. In Europe, significant diffusion of EHRs has occurred during the past decade. In June 2000, for example, 90% of general practitioners in Sweden and 88% in The Netherlands used an EHR. The lowest use was in Portugal, with 5%; overall, however, the average use in the European Union was 29%. Diffusion, however, in the United States has been much slower than that in Europe. For example, recent data from the National Ambulatory Medical Care Survey indicate that 25% of office-based physicians were at least partially using an EHR in 2005. Generally, estimates place the United States about a dozen years behind European Union in diffusion of EHRs.

**ETHICAL PRINCIPLES**

**Beneficence**

Some believe that EHRs are justified because they are beneficent; they are purported to do good. In one study in the United Kingdom, 79% of respondents believed that making health records electronic was a “good idea.” In another study in the United Kingdom, patients perceived that EHRs could support continuity of care, especially in emergencies. Examples of “good” include increased access to care, improved quality of medical care and public health, and decreased costs of health care.

Access to care is thought to be increased through online EHRs and associated information technologies. Aspects of access to care are access to health information and convenient communications with health care providers.

A powerful illustration of the impact of access to health information occurred after Hurricane Katrina in the United States. Within 4 days of Hurricane Katrina, the Veterans Health Administration was able to transfer the records of 50,000 patients from the flooded veterans’ hospital and clinics in New Orleans, Louisiana, to Houston, Texas. At the same time, the US Office of the National Coordinator for Health Information Technology worked with pharmacies to create a medication database for 800,000 people in the region of the storm. This connectivity supported continuity of care and access to care.

A 2001 report of the US Institute of Medicine specifically linked information technology, improved health care delivery, and enhanced patient and clinician communication. Patients’ abilities to manage their own care are increased because they have more information about their health.

Electronic health record software allows patients to access portions of their online EHR

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**Table 1. Uses of electronic health records**

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<th>Primary</th>
<th>Secondary</th>
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<td>Patient care delivery</td>
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<td>Patient care management</td>
<td>Regulation and</td>
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<td>Patient care support processes</td>
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<td>Financial and other</td>
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<td>administrative processes</td>
<td>Public health</td>
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<td>Patient self-management</td>
<td>Public policy</td>
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Adapted from Institute of Medicine, Committee on Data Standards for Patient Safety. *Key Capabilities of an Electronic Health Record System*. Washington, DC: National Academies Press; 2003:5.
and communicate with their physicians’ practice via linked Web messaging. Researchers in Pennsylvania conducted an online survey of members of an integrated health system. Of the 1,421 respondents to the survey, most preferred online interactions to receive information about general medical questions (approximately 50%) and renew prescriptions (approximately 60%). In another survey in California, the patients’ favorite feature was viewing their laboratory results online, and in the comments section of the survey, one of the most common comments was to increase the amount of accessible information in the EHR. In a study in the United Kingdom, patients who reviewed their EHRs for the first time perceived that accessing their electronic records

1. improved their communication with their physician and increased their knowledge about their own health,
2. improved accuracy because they were allowed to correct errors and the electronic record was legible,
3. promoted easier access to health information and continuity of care, and
4. promoted self-managed care.

Electronic health records are believed to be able to promote quality patient care because they remedy the flaws of paper health records. Paper records may adversely affect the delivery of quality care because they can be illegible, ambiguous, incomplete, inaccurate, fragmented, disorganized, often unavailable, and disconnected across sites of care. The flaws of paper records make quality patient care difficult to deliver. Productivity of health personnel is also adversely affected by these characteristics of paper records.

Some studies showed that EHRs addressed these flaws. For example, in a pediatric intensive care unit, a computerized documentation system did result in more legible, complete, and accessible patient records without affecting the time spent in direct patient care. In a study in an urban pediatric primary care setting, use of an EHR was associated with improved quality of care as defined by the documentation of an interim health history, risk assessment, developmental screening, physical examination, and guidance topics. In another study in primary care, patient encounter data were found to be accurate in identifying acute respiratory infections and urinary tract infections in terms of sensitivity, specificity, and positive predictive value. Thus, EHRs are purported to increase the quality of care.

Providing information about public health issues is a core functionality of EHRs. Studies have shown that EHRs can be used to improve public health. One study provided evidence that gender disparities existed in the treatment of coronary heart disease and detailed information about population health characteristics. For the population of US veterans, the EHR system of the Veterans Administration (VA) has improved quality of

<table>
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<th>8 Core Functionalities</th>
<th>6 Key Capabilities</th>
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<tr>
<td>Health information and data</td>
<td>Longitudinal collection of electronic health information for and about individual persons</td>
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<td>Results management</td>
<td>Interoperability that allows linkages among providers, such as hospitals, physician offices, home health agencies, and individuals’ personal health records</td>
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<td>Order entry and management</td>
<td>Security with access only to authorized users</td>
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<td>Decision support</td>
<td>Immediate electronic access to individual and aggregate health information by authorized users</td>
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<td>Electronic communication and connectivity</td>
<td>Connections to external medical and health knowledge, decision support systems, and alerts</td>
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<td>Patient support</td>
<td>Support of processes that enhance quality, safety, and efficiency</td>
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<td>Administrative processes</td>
<td>Reporting and population health management</td>
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Table 2. Core functionalities and key capabilities of electronic health records

Adapted from and data extracted from Institute of Medicine, Committee on Data Standards for Patient Safety. Key Capabilities of an Electronic Health Record System. Washington, DC: National Academies Press; 2003:1, 7. Copyright © 2008 Lippincott Williams & Wilkins. Unauthorized reproduction of this article is prohibited.
Care. Care of veterans compares favorably on multiple performance measures with the care of other US subpopulations.

Electronic health records can positively affect productivity. The previously mentioned report on the VA also showed decreased costs of care. Between 1996 and 2003, the number of veterans treated annually increased by 75% (2.8 million to 4.9 million). In approximately the same period, the VA reduced the cost of care by 25% per patient.

In California, physicians reported that an application allowing patients to see portions of their EHRs and communicate with physicians and nurses resulted in reduced time spent in responding to patients who had previously called the physicians frequently.

Upon further examination, however, beneficence is not assured. Studies show the following:

1. Inequities to access exist.
2. Content does not support basic medical services.
3. Accuracy of EHRs is problematic.
4. Data on productivity are inconclusive.
5. Overly optimistic projections for cost savings are made.

Increased access is not evenly distributed across all demographic groups. In the Pennsylvania survey of access to an online EHR and Web messaging to physicians’ practices, almost all respondents were non-Hispanic whites, with 40% having some college and 27% having a baccalaureate degree or higher. Moreover, although more than half of the respondents preferred online interactions to receive information about general medical questions, less than half preferred online interactions to receive

1. explanations of test results,
2. instructions for treatments,
3. instructions for health monitoring,
4. advice regarding healthy lifestyles, and
5. care for minor problems or routine follow-up.

Thus, online access may not be the patients’ preferred means of access. In Australia, rural populations are least likely to benefit from e-health applications, including EHRs. These researchers noted that rural areas do not have the infrastructure, resources, capacity, or capability to support information and communication technologies.

The longitudinal collection of health data across the continuum of care is believed to support the delivery of quality care. However, this benefit of technology will only be fully realized if health personnel and organizations across the continuum of care can agree on requisite content and share common definitions. This agreement has not yet occurred. Independent of health personnel and organizations, individuals can create their own longitudinal records through personal health records (PHRs). Personal health records are software applications that support the collection and maintenance of health histories and data and provide continuity of care in emergencies or across sites. Researchers evaluated 11 of these PHR softwares. Only 1 of the 11 included all the content needed to complete a clinical history. The researchers concluded that the PHRs were deficient and unlikely to be able to serve as primary sources of medical data.

The accuracy of the data in EHRs has not been shown. A review of the published literature in 1997 found that studies reported highly variable rates of data accuracy. More recent studies also report variable rates of data accuracy. A study of medical documentation available for a preanesthetic clinic showed that 22% of internal information was missing from the organization’s EHRs. The researchers in a study of primary care data on osteoporosis found poor data quality as follows:

1. there were hundredfold differences in interpractice rates of recording relevant data,
2. recording of treatment exceeded recording of diagnosis,
3. clinically important codes were absent,
4. different versions of the diagnostic (Read) codes were used, and
5. manual searches of paper records were required to find some data.

For patients receiving hemodialysis, drug record discrepancies were frequent (38 of 63 patients, 60%), with records on drugs for gastrointestinal (22.1%) and endocrine (15.9%)
disorders accounting for the most of the discrepancies. A study published in 2004 and conducted at the Iowa Veterans Affairs Medical Center showed complete agreement between the electronic list of medications and the patients’ actual medications for 5.3% of the patients. In a study in which patients accessed their primary care EHRs, 70% of the patients found inaccuracies that could be considered trivial, such as outdated addresses and telephone numbers. However, 23% of the patients identified significant omissions. In another study in primary care in which patients accessed their electronic summaries, half of their physicians altered the summaries after discussion. Finally, a commentator on the National Health Service’s EHR in the United Kingdom stated that data quality is questionable because basic principles of health information management are not met.

Little research has been reported on routine monitoring of data accuracy. Moreover, no standard methodology for the study of data accuracy had been established. This lack of standardization makes it difficult to compare results among researchers. In addition, terms, such as accuracy, have not been precisely defined.

Researchers investigated the agreement between paper records and EHRs. Methodological problems confounded the findings of these studies. One set of researchers found that paper records and electronic records are complementary, and each type of record contained information that the other did not. Another set of researchers found that structured data entry was more suitable for objective data because the EHRs contained only approximately 65% of the information in the paper records. This finding corresponded with the observation that an overly structured EHR with fixed fields is not representative of the iterative process of delivering health care and, therefore, could impede the provision of quality care. These writers emphasized that the primary purpose of the EHR is to support the work of health personnel, providing direct patient care. Consequently, EHRs should be designed to support the provision of care and not the secondary purposes of administration, regulation, policy making, and research. A comparison of parallel records in paper and electronic versions from the Department of Neurology of a Norwegian university hospital showed that 7% of electronic records varied significantly from the paper records. Between 4% and 13% of documents were missing from the electronic records; 1% of documents were missing from the paper records.

Quality is also affected when patients fail to provide full information. Health services involve highly sensitive information. Patients may censor their medical histories because they doubt the privacy and security of their EHRs. They may decide to withhold certain sensitive data that they believe, if revealed, could incur bias, discrimination, or stigma. For example, in Hong Kong, patients with schizophrenia were more likely to conceal their disease than patients with diabetes do. Moreover, 20.9% of patients with schizophrenia versus 10.9% of patients with diabetes asked their physicians to conceal the diagnosis of schizophrenia in the clinic notes. Given that the technology of EHRs enlarges the magnitude of potential exposures, the likelihood for concealment increases. Accurate data are critical to proper diagnosis and treatment. Moreover, accurate databases are critical to the monitoring of populations’ health. Increased productivity is not guaranteed. A study in The Netherlands found that data in EHRs were insufficient to support the monitoring of performance indicators. Another study explored the patterns of communication between physicians and patients during clinic visits. Although the participant physicians did ask more questions to clarify patients’ information, they also spent more time than did control physicians during the initial visit.

Although studies showed that EHRs could be used to improve the health of populations, one study had an opposite finding. The study investigated the accuracy rate of EHRs in 2 south Australian urban general practices and 2 south Australian rural practices. The original, raw cervical screening rate based on data in the EHRs was 44.9%. After review
with the patients and pathology reports, the final corrected screening rate was 85.7%. The researchers concluded that EHRs do not provide an accurate denominator for cervical screening registers.64

Decreased costs in health care are not assured.65 One critic explained that the annual projected savings of $82 billion in year 2019 and thereafter and the cumulative net savings of $513 billion between 2004 and 2019 represented only miniscule percentages of the trillions of dollars in US health care costs, specifically 1.6% and 1.05%, respectively.66 A review of the literature on the return on investment of health information technology, such as EHRs, concluded that few, rigorous scholarly assessments have occurred.67 Many studies on the topic were case studies.67 The scientific assessments were confined to a few settings or single applications.67 In terms of physicians’ time, a time and motion study preimplementation and postimplementation of an EHR showed no significant difference between the time spent with patients in direct patient care and the time spent to perform activities related to indirect patient care (telephone, paperwork, etc).68 In another study set in 6 community health centers, savings did not offset the cost of EHRs, although quality of care improved substantially.69 Knowledge is limited about the costs and benefits of EHRs.

Thus, the benefits of EHRs remain to be fully demonstrated. However, should society, indeed, decide that EHRs reflect beneficence, the conflicts among beneficence, autonomy, fidelity, and justice still remain. One of the very benefits, ease of access, underlies several of the ethical problems created by the conflicts among the ethical principles. The following paragraphs discuss these conflicts.

**Autonomy**

Autonomy is the right to self-determination. Informed consent is the common example of autonomy. An aspect of informed consent is informed decision making. Electronic health records offer decision support. Researchers in artificial intelligence have created a system that provides information to parents and clinicians in neonatal intensive care units.70 This system helps parents collaborate in decisions about their infants' treatment, such as continuation or termination of invasive therapies.70

Autonomy also includes patients’ rights to access their records themselves, have the opportunity to correct their records, and authorize others who may have access to their records.3 Regarding the right to control access to the EHR, 67.2% of the respondents to a study in the United Kingdom wanted to control access to their EHRs, and 35.6% wanted to add information to their records.28 An example of authorizing access is the special section of the German individual electronic health insurance card.71 This section, under the control of the patient, comprises a personal medical history and pharmacologic and emergency data.71

However, EHR systems introduce other considerations related to autonomy. One such consideration is the extent to which patients want their data shared across health databases or fed into a national health database. In a recent study in the United kingdom, 16% of respondents (5 of 31) identified health concerns that they did not want shared.72 These 5 persons marked 110 data items related to 19 health concerns in the areas of mental health, sexual health, and genitourinary problems.72 In another study, 50% of respondents were concerned that their records would be linked outside their primary doctor’s office, although 79% of them recorded that they believed making health records electronic was a good idea.28 Patients provide data to health personnel for specific reasons. For these data to be combined to create new information about these same patients without their knowledge or permission violates the principle of autonomy. Many believe that this data mining or secondary use of health data requires informed consent.13

Kluge73 suggests another interesting conflict in which the EHR becomes a constructive person that has rights beyond those of the patient it represents. Kluge explains that corporations are examples of constructive persons. Kluge also explores informatic rights to the information in EHRs. She makes distinctions
between the identifiable health data, such as the diagnosis, that belong to the patient and the decision-making algorithm to make the diagnosis that belongs to the health care provider. If patients have the right to control their data as the principle of autonomy would support, how would they control their EHRs as constructive persons or the informatic rights of their care providers? Creation of EHR rights beyond those of the patient whose information is in the EHR presents a potential conflict with the principle of autonomy.

**Fidelity**

The good that EHRs might bring is in conflict with the ethical principle of fidelity. Persons have a right to have their personal health information kept confidential. France argues that personal health information should “be accessed only by authorized persons, for well defined purposes, taking into account patient interest.” Thus, health personnel have the duty to maintain the confidentiality and security of health information, including the data in health records. Patients concur. In the previously described study in which 79% of respondents agreed that making health records was a good idea, 50% were concerned about the security of their records.

These respondents had good reason to be concerned. Unfortunately, the popular press in the United States is replete with breaches of this duty. In the United States, the organization Privacy Rights Clearinghouse tracks breaches of security, especially those involving the national identifier, the social security number. Between January and November 2006, the organization recorded more than 27 breaches of security for health data involving well more than 900,000 persons. The magnitude of the breaches ranged from the exposure of 3 hospital patients' records to the exposure of thousands of patients' records in 8 states. Of the breaches, 22 involved electronic records, and 5 involved paper records. In terms of the electronic records, most breaches involved stolen laptops and computers or lost external storage, such as computer disks and jump drives (flash or USB drives). Approximately one-third of the breaches involved EHR systems, with the causes being attributed to flaws in software, criminal theft, and hacking. Thus, although personal health data from both electronic and paper records can be inappropriately exposed, the scale and frequency of breaches are greatly increased with electronic records.

Fidelity is also breached when research and epidemiological studies are published. For example, publication of detailed maps of diseases and health statuses can jeopardize confidentiality. The current capabilities of geographic information system software allow such precision that individual house addresses can be identified with 79% accuracy and 100% within 14 m (50 ft). Moreover, the researchers were following the journal publisher's minimum requirements for figure resolution. Given the increasing use of geographic information system data for health research, the researchers recommended that publishers establish policies to protect patients' anonymity.

Another set of researchers, by linking to public databases, showed that it was possible to reidentify data that had been deidentified using deidentification heuristics. Specifically, these researchers demonstrated that it would be possible to identify subpopulations, physicians and lawyers in Ontario, but not the entire population of Ontario. Another set of researchers demonstrated that deidentified or pseudonymized genomic data can be reidentified by combining the genomic dataset with published hospital demographic discharge databases. The unique sets of locations that patients with cystic fibrosis, Friedreich ataxia, hereditary hemorrhagic telangiectasia, Huntington disease, phenylketonuria, Refsum disease, sickle cell anemia, and tuberous sclerosis visit allowed the researchers to reidentify the genomic data in 32.9% to 100.0% of cases, depending upon the number of patients per hospital.

Failure to protect the confidentiality of health data has resulted from multiple situations. Health data are exposed when security measures are inadequate. Persons become identifiable in formats of presentation. Using the capabilities of technology to its fullest
extent, such as mapping software, without consideration of the consequences can also result in inappropriate disclosure. The key responsibility of protecting the privacy of health data has not been fulfilled.

Justice

Electronic health records may be used to promote justice. Scholars describe the use of linked health records to discern discrimination, socioeconomic, racial, and geographic, in the delivery of health services. Consequently, once identified, these inequities could be addressed through health policies. However, justice may also be violated in the distribution of electronic resources and inequitable public disclosure of personal health information of certain disadvantaged groups.

Some authors have discussed a “digital divide” between those who have computers and Internet access and those who do not. Those persons with computers and Internet access will be able to use online health information resources.

Personal health records are an example of a health information resource. Personal health records support patient self-management. One proposed use of electronic PHRs is to assist persons who have mild clinical signs. Via an online interface, these persons are guided through a set of questions that helps them to self-diagnosis their illness, determine appropriate over-the-counter medications and dosages, and avoid medications contraindicated by their allergies or prescribed medications.

One set of researchers suggested that the digital divide may not be as insurmountable an obstacle as thought. These researchers conducted a telephone survey of parents of pediatric patients in King County, Washington. Of the respondents, 88% reported computer use of once a week or more, and 83% reported favorable feelings toward computers. For persons who owned a computer, perceptions did not differ by socioeconomic or educational status. However, the characteristics of King County are unique: (1) the population is highly educated, (2) the county is urban and suburban, (3) the county is the 12th largest in the United States by population, and (4) it is one the 100 wealthiest counties in the United States. Not all persons live in this situation. Many persons cannot afford computers or work in jobs without computers. Lack of access to computers decreases these persons’ comfort and familiarity with computers. These persons then have restricted ability to search the Internet for health information or contact health personnel via e-mail.

Economic status is not the only deterrent to the access to information and communication technology. Age also is a factor. A national survey in the United States found that 69% of persons aged 65 years or older have never gone online. Moreover, for persons aged 75 years or older, the percentage increases to 82%. These persons often have chronic diseases and could most benefit from online health information and online communications with health personnel.

Another set of researchers discovered another source of inequity related to governmental health department Web sites. US state governments have used Web sites to provide health information to their citizens. States also allow their citizens to view information such as quality data on health providers and request services such as eligibility requirements, forms, and interpreters, via these Web sites. Researchers found that Web sites did not provide equitable access in terms of readability, accommodations for those with disabilities, translations for non-English readers, and geography. Other researchers found persons who had less income or less education or were African Americans had less access to the Internet. These individuals will be underserved by public health services, especially as states continue to invest in the Web sites.

**PRINCIPLES FOR HEALTH PERSONNEL, LEADERS, AND POLICY MAKERS**

Ethicists recommend principles to guide health personnel, health leaders, health policy makers, researchers, and informaticians. The Central Ethics Commission of the German Medical Association provides realistic and thoughtful principles on the secondary use of
health data. Three principles are particularly relevant to issues raised in this article:
1. “Data must not be exposed in such a way that social discrimination could result.
2. Guarantees must be given that medical confidentiality is maintained even when secondary use is made of person-related data.
3. Data must be made anonymous if possible, using all known technical means and organizational measures to achieve data security and privacy must be used.

Fairweather and Rogerson provide a principle regarding the development of extensive health databases:
4. Patients should have “practical access to information about the existence of all databases with medically relevant information about themselves.”

Discussion of these guidelines can serve as a starting point, as ethicists, health personnel, health leaders, and health policy makers begin to include ethical considerations in their planning for EHRs.

CONCLUSION

Electronic health records have great potential for beneficence, but universal beneficence cannot be assumed. They have the capability of bridging gaps in space and time. Experiences related to Hurricane Katrina demonstrate that EHRs allow patients and health personnel to access health data when and where they need it. Aggregate data in EHRs can detect inequities in provision of public health services and unmet health care needs.

However, lack of certainty in their accuracy can undermine this potential. Autonomy is jeopardized when patients’ health data are shared or linked without the patients’ knowledge. Fidelity can be breached when health organizations do not take proper precautions to maintain the security of identifiable health data. Justice is breached when disparities exist in access to health information and services by income, language, age, geography, literacy, and disability.

Electronic health records present conflicts among the ethical principles of beneficence, autonomy, fidelity, and justice. Health personnel, health leaders, health policy makers, ethicists, and informaticians should continue to examine EHRs and the ramifications of their implementation. Continued discussions need to occur to best use this technology to the benefit of patients and clients and support management and operations.

REFERENCES


