

Etické aspekty používania elektronických zdravotných záznamov v prostredí eHealth

Ethical aspects of electronic health records use in eHealth environment

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Abstract:

Electronic health records (EHR) may represent potential beneficence from different aspects, because they are alleged to increase access to health care, improve the quality of care and health, and decrease costs. Healthcare persons and healthcare institutions are confronted with several ethical questions concerning EHR usage. Using EHR creates conflicts between multiple ethical principles, mainly because eHealth provides a wide range of information sharing among a diverse range of users from patients, health professionals, health insurance institutions to students and researchers. Lack of confidence in the security of patient data in information systems leads them to be cautious in allowing access to their EHR. In terms of EHR sustainability, patients should be confident, that their safety is adequately protected. It is therefore reasonable to discuss ethical principles of EHR use, such : autonomy, fidelity, equality and justice

Keywords

Electronic health record, eHealth, healthcare electronisation, ethical questions, patient

1 Background and Introduction

Computer-based medical records system have become an important part of the health-care delivery system in this age (Irani et al, 2009 pp.553) with its use by different categories of health care professionals such as doctors, nurses, pharmacists, laboratory scientists, etc. Its use by not only the doctors but other health care providers shows its increasing adoption globally in the healthcare system. With the intense competition within the healthcare business, there is an increasing demand for information (internal and external) in order to analyze patients' information speedily and efficiently (Alshawi, Missi, & Eldabi, 2003 pp.286). To meet up with this demand, many healthcare businesses adopt the use of Electronic Medical Records System (EMRS).

Computer-based medical records system is also known as Electronic Medical Records system (EMRS) or Electronics Health Records(EHR). EHR is the storage of patients' data in electronic form. The data is stored in a well secured manner and can be accessed and shared simultaneously by multiple authorized users. It is used for "setting objectives and planning patient care, documenting the delivery of care and assessing the outcomes of care" (Hayrinen, Saranto, & Nykanen, 2008 pp.292). Information in the EHR is obtained during patients' episodes of care by the healthcare providers, and this includes the patients' summary such as the patients' history, allergies, medications, test results, current problems, etc. The EHR is designed to support healthcare providers to provide a quality and efficient continuing care for their patients. (Hayrinen, Saranto, & Nykanen, 2008; O'Connor et al, 2005).

Important ethical questions surround the use of electronic health records, clinical decision support systems, internet-based consumer health information, outcome measurement, and data mining. Electronic health records are changing the way health information is managed, but implementation is a difficult task in which social and cultural issues must be addressed. Empowering health care consumers through readily-available health information is a valuable use of the internet, but the nature of the internet environment raises the spectre of abuse of vulnerable patients. Outcome studies have inherent value judgments that may be hidden. Data mining may impact confidentiality or lead to discrimination by identifying subgroups. All of these issues, and others, require careful examination as more and more health information is captured electronically (Winkelstein, 2005).

Benefits of EHR

The use of EHR promotes the use of guidelines among clinicians while caring for patients (Jerant & Hill, 2000; Delpierre et al, 2004; Peleg, Keren & Denekamp, 2008). It can identify problems and how to resolve such

problems using the computerized clinical guidelines. The clinical guidelines are coded into computer-interpretable format which are then combined to an EHR to enable patient-specific recommendations in the EHR. The clinical guidelines are designed to provide knowledge that the clinicians might need to make decisions concerning the treatment of a particular patient's problem during their clinical practice. They contain information about the evidence and means of diagnosis, prognosis, and treatment combined with other knowledge that will aid physician's decision on patient-specific problems (Peleg, Keren, & Denekamp, 2008). The EHR also has the cleverness of reminding and alerting clinicians on important clinical events. The EHR is designed with reminder and alerting system functions that make clinicians act swiftly on important clinical events like abnormal laboratory result, inter-drug reactions, etc, such that errors in diagnostic processes, medications, etc are reduced (Jerant & Hill, 2000; Garg et al (2005); Bleich & Slack, 2010).

In a healthcare system where EHR is in place, the workflow can be improved efficiently as there will be better coordination with more effective impact on the quality of care the clinicians render. There is better communication amongst staff and the time spent by clinical staff to do clerical work like distributing charts, transcribing, etc is reduced with the use of EHR (DesRoches et al, 2008). With efficient security technologies, EHR offers more security than the traditional paper record systems (Barrows & Clayton, 1996). The access to the EHR is controlled with the use of password, and menus designed for specific roles and specific users. With EHR it is easy to trace who accessed patients' information at a particular time, thereby improving the confidentiality of patients' records.

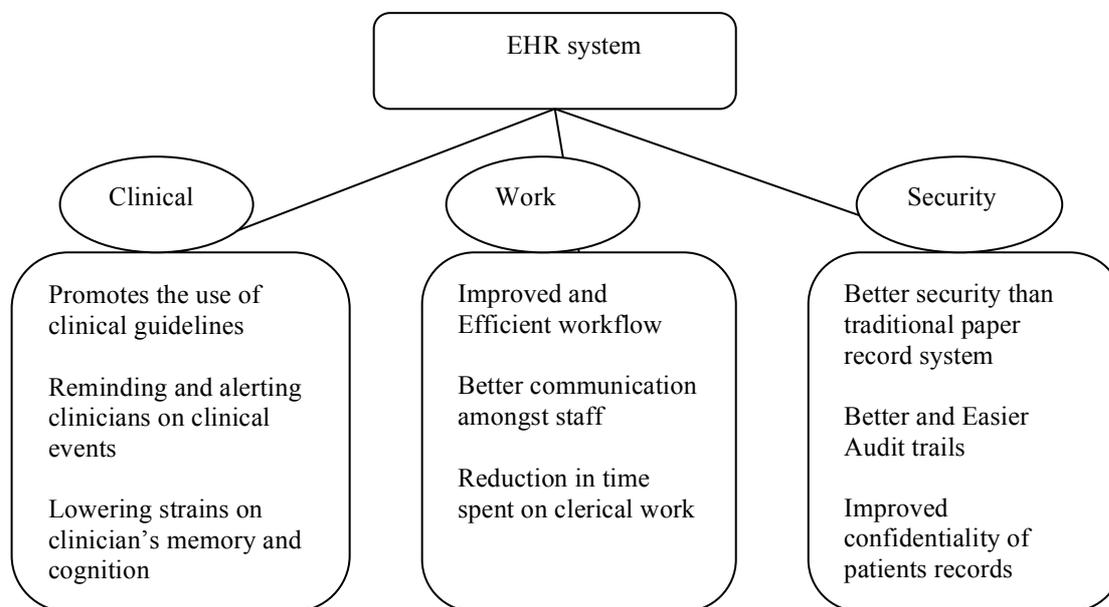


Figure 1: Some roles of EHR system

<i>Core Functionalities of the EHR</i>
Health information and data
Results management
Order entry and management
Decision support
Electronic communication and connectivity
Patient support
Administrative processes
Reporting and population

Table 1. Core Functionalities of the EHR(Layman,

2008)

<i>Key Capabilities</i>
Longitudinal collection of electronic health information for and about individual persons
Interoperability that allows linkages among providers, such as hospitals, physician offices, home health agencies, and individuals' personal health records
Security with access only to authorized users
Immediate electronic access to individual and aggregate health information by authorized users
Connections to external medical and health knowledge, decision support systems, and alerts
Support of processes that enhance quality, safety, and efficiency

Table 2. Core Capabilities of the EHR(Layman, 2008)

Components of EHR

The goal of EHR is to collect data just once and use the same data multiple times. The data is obtained and integrated from various categories of users and used to serve various needs. For each service a patient receives from a healthcare centre, there is a record of it electronically. If a patient consulted a doctor, picked up drugs at the pharmacy, carried out laboratory investigations from the medical laboratory, took an X-ray at the Radiology unit, the patient is being admitted in the hospital, etc; there will be data capture for each of these services. The records are stored in separate systems that have their own patient identification system as well as their users' log-in system. Based on the standard of vocabularies, user identification and patient identification in the systems, a user can gain access through each application to get the patient's information relating to the system desired, and will have to go through all applications if s/he wants the complete record of a patient. Figure 2 represents an example of HER system that integrates health care data from the different systems (Administration, Clinical, Laboratory, Pharmacy, Radiology, and Nursing) for a particular patient (K).

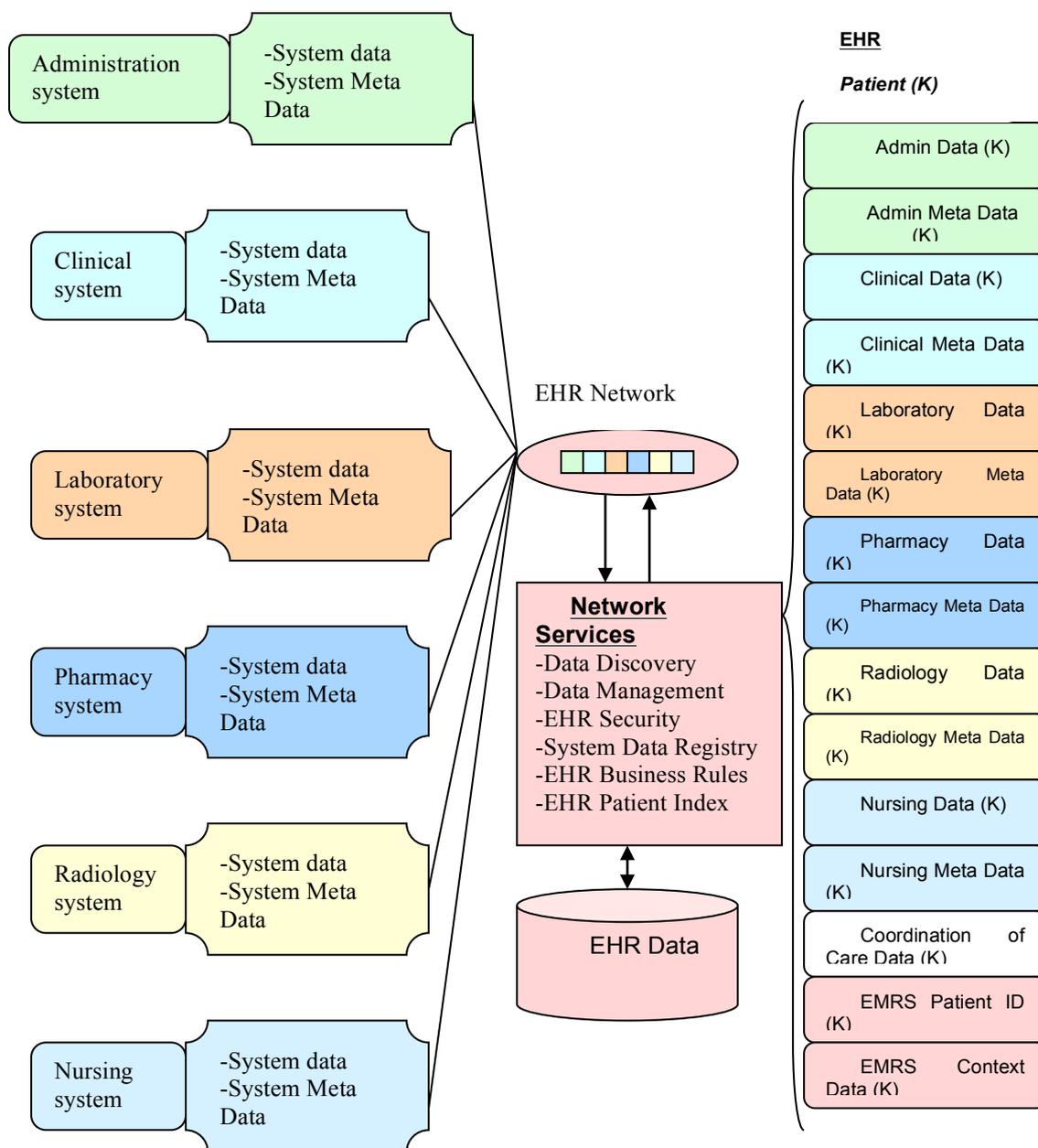


Figure 2 . Concept of EHR (NIH NCRR, 2006)

Confidentiality and security of EHR

Very important factor in EHR system is the confidentiality and security of patients' information.. According to Win (2005), information security deals with the confidentiality, integrity, and availability of patients' records. A breach in security can bring about violation of the patient's privacy, damage or ruin the patient's career, dismissal from workplace, financial loss, etc. The physician or healthcare providers can also be personally liable or face legal sanctions if there is any tampering of records by external parties. But the problem of data security is complicated as it is both an issue of technological capabilities as well as people-management (Huston, 2001; Win, 2005). In fact, the very thing that makes EHRs so attractive to so many people, e.g. students -- easier access to data -- also makes them ripe for a breach of ethical conduct, they added. These "opportunities for misconduct" can include the following:

- Sharing or stealing passwords or other authentication devices
- Misusing procedure codes
- Violating patient information security or privacy
- Excluding patients from participating in the electronic record because the student may fear the patient will choose a treatment that does not benefit the student's educational needs (Kincade, 2012)

As there are developments in EHR for purposes such as Telemedicine, Electronic billing, etc, there is need for improvement in the security technology. Although there are security devices for authentication and verification of users such as automated fingerprints analysis, voice pattern identification, unique identification with electronic tag, Radio Frequency IDentification (RFID) chip, and password checking (that is mostly used by many EHR), the current technologies are inadequate and still need improvement (Huston, 2001; Win, 2005).

Studies have also shown that patients generally accepted the use of EHR (Masys, et al., 2002; Pyper, et al., 2004). Pyper et al (2004) reported that most of the patients who participated in their online EHR study acknowledged that the system is useful to them, but were also concerned about their information security. On other hands the study by Masys et al. (2002), patients were very satisfied with the level of security in the EHR and agreed that it is highly reasonable. There were multiple checks to the access of the system with the User ID and password, encrypted read-only security diskette, a system 'key', and did not permit any form of external saving to disk.

The first EU eHealth Action Plan from 2004 defined the following measure regarding Confidentiality and security, in general: Specific concerns on privacy and protection of personal data, leading to lack of confidence and wide acceptance: building trust is a prerequisite to the development of an information society as well as eHealth services (eHealth Action Plan, 2012).

Ethical issues

Ethical issues related to EHR confront health personnel. EHR create conflict among several ethical principles. 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. (Layman, 2008) Ethical dilemmas that need additional discussion relate to opt-out provisions that exclude patients from electronic record storage, sale of deidentified patient data by EHR vendors, adolescent control of access to their data, and use of electronic data repositories to redesign the nation's health care delivery and payment mechanisms on the basis of statistical analyses. (Dean and Hardeep, 2011)

Medical Ethics

Some physicians regard the decision to enter medicine as "a calling," similar to that seen in the clergy or in public service. This commitment to help and serve others has traditionally taken precedence over economic interests. Medicine's code of ethics is considered to be far more stringent than the law. Most physicians are governed by their own internal code of ethics and more-formalized codes have been developed by professional organizations to advocate that their members behave ethically. The American Medical Association (AMA), one of the major medical organizations in the United States, established the Code of Medical Ethics for members, which has served as an ethical guideline since the mid 1840's. (Dyer, 2001)

Medicine and Healthcare on the Internet

In stark contrast to typical e-commerce sites, intended for sales of products or services to visitors, medical and healthcare Web sites differ because the sites are frequently dedicated primarily to educating their Web site visitors. Also, with the medical or healthcare Internet the focus is on medical and healthcare interactions, transactions, and research that occur over the Internet. Another difference is the type of content obtained at a medical or healthcare site. This information is often of a very private nature and may result in life-altering and, in some situations, life-and-death decisions (Dyer, 2001)

Insights from professionals in the following diverse groups from countries around the world, should be included when defining this new interdisciplinary domain:

1. Healthcare delivery: physicians, nurses, pharmacists, healthcare professionals, and other healthcare personnel
2. Applied computing: systems developers, database managers, medical software developers, and Web administrators
3. Science and research
4. Government agencies: public-health and regulatory agencies
5. Healthcare services and e-commerce: providers of healthcare transactions conducted over the Internet
6. End users: healthcare consumers and patients
7. Healthcare organizations: insurance companies, management organizations, and societies
8. Administration and healthcare management
9. Medical ethics
10. Law

(Dyer, 2001)

The IMIA Code of Ethics for Health Information Professionals

The reason for constructing a code of ethics for Health Information Professionals (HIP) instead of merely adopting one of the codes that have been promulgated by the various general associations of informatics professionals is that HIPs play a unique role in the planning and delivery of health care: a role that is distinct from the role of other informatics professionals who work in different settings. (IMIA, 2013)

Part of this uniqueness is centred in the special relationship between the electronic health record (EHR) and the subject of that record. The EHR not only reveals much about the patient that is private and should be kept confidential but, more importantly, it functions as the basis of decisions that have a profound impact on the welfare of the patient. (IMIA, 2013)

These fundamental ethical principle, when applied to the types of situations that characterize the informatics setting, give rise to general ethical principles of informatic ethics. General principles of informatic ethics, when applied to the types of relationships into which HIPs enter in their professional lives, and to the types of situations that they encounter when thus engaged, give rise to more specific ethical duties. (IMIA, 2013)

The Ethical Challenges of Remote Access to EHR's

Remote Access: Real time access to hospital based computer applications including EHR via a secure network from a residence, wireless hotspot, office, or university (Best, 2003) Within the principle of beneficence, there was discussion on how remote access to EHR's have the potential to improve: access, communication, efficiency, continuity of care, coordination of care, accuracy, safety and public health. With further examination the literature reveals that many inequalities exist (Layman, 2008).

Beneficence principle

An underpinning ethical principle of all health care workers is beneficence. As discussed, beneficence is the promotion of good or to benefit others (IMIA, 2013)

Autonomy principle

This principle is one of great discussion within the use of EHR's. It includes the patients right to self-determination and control over their health information (MacDonald, 2001). Informed consent is an example of autonomy; sharing without the clients consent violates the principle of autonomy (Layman, 2008).

- There is currently little standardization regarding the process and necessity of consent.
- Many people do not know they have the right to access, correct and authorize who views their records. (Lucas, Rayner, Readman, Waite, 2009)

Fidelity principle

Fidelity relates to the right that patients have to keep their health information confidential and secure (Layman, 2008). France (1998) states "health information should only be accessed by authorized persons, for well defined purposes, taking into account patient interest" (p. 113 as cited in Layman, 2008).

- The easy access to health information enables multiple users at multiple access points to view patient information unbeknownst to the patient.
- With remote access, institutions may vary in their standardization/security of who is allowed access, conflicting with the clients' initial consent.
- Remote access can put patient files at increased risk for breaches, data mining and other security risks. (Lucas, Rayner, Readman, Waite, 2009)

Justice principle

Unequal access to computers, internet or health databases is another ethical issue. A ‘digital divide’ as discussed by Layman , (2008) separates those individuals who have computer/internet and those who do not. Those who have access to online health information or records may be advantaged in their health and health treatment. (Lucas, Rayner, Readman, Waite, 2009)

Sustainability

Investing in quality and containing cost while providing safety and equity care is a mandatory goal for health systems. The use of interoperable EHRs has been identified as a major opportunity for more efficient and better quality healthcare. (eHealth Action Plan, 2012)

EHR sustainability will require more than the physicians to survive. Nurses and Advanced Practice Nurses (APN) will play a vital role in the management of health care records (Goodman, 2010)..

Nurses must understand the boundaries and capabilities of the EHR to assist their clinical colleagues with the necessary help for successful implementation of the EHR system. This is where the NIS is essential to explain the benefits of EHR and its cost effectiveness for the patients, and how the EHR will reduce errors and create a mutual relationship between the provider and the patient. Nurses will guide the development of EHR guidelines and assist the physicians with the transition from paper to computer (Kelly et al., 2011).

Improved care and less medication errors are very important to the sustainability of EHR, but the protection of patient’s privacy is just as important. Placing millions and millions of citizens’ private health information in one location creates risky operations. The Health Insurance Portability and Accountability Act (HIPAA) has established standards of privacy to protect health information (PHI) of patients in US. So any health care facility that stores, receives, or transmits electronic PHI must comply with HIPAA security. Any breaches will result in great fines that will be imposed by the federal government. As EHR grows with the 2014 initiative, so will the HIPAA regulation to protect the patients’ rights to privacy (Madison & Stagers, 2011).

Conclusion

Physicians often find themselves in challenging situations that place extreme demands on their time. Conflicts arise between their ethical inclinations and reality because there are never enough hours in the day, running a business is fraught with complications, and financial expectations run high. Compromises are inevitable. Some save time by writing illegibly. Some abbreviate liberally. Some use forms that have check-off items that are easy to use — so easy that the physician may check the box even if they only did part of what is implied by the presence of the check mark (Daniel, 2012).

The EHR not only reveals much about the patient that is private and should be kept confidential but, more importantly, it functions as the basis of decisions that have a profound impact on the welfare of the patient. The patient is in a vulnerable position, and any decision regarding the patient and the EHR must acknowledge the fundamental necessity of striking an appropriate balance between ethically justified ends and otherwise appropriate means. Further, the data that are contained in the EHR also provide the raw materials for decision-making by health care institutions, governments and other agencies without which a system of health care delivery simply could not function (IMIA, 2013).

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