

Electronic Patient Records

Prof. Simon Rogerson

**Originally published as ETHcol in the IMIS Journal Volume 10
No 5 (October 2000)**

Healthcare computing or medical informatics is one of the fastest growing areas of information and communication technology (ICT) application. It is a multifaceted application concerned with electronic patient records, performance indicators, paramedical support, emergency service, computer aided diagnosis, clinical governance, research support, and hospital management. Its use should ideally promote and must certainly not be in conflict with the fundamental medical ethical principles of beneficence (a duty to promote good and act in the best interest of the patient and the health of society), nonmaleficence (a duty to do no harm to patients), and respect for patient autonomy (a duty to protect and foster a patient's free, uncoerced choices).

The Electronic Patient Record (EPR) is indicative of the advances in medical informatics and allows providers, patients and payers to interact more efficiently and in life-enhancing ways. It offers new methods of storing, manipulating and communicating medical information of all kinds, including text, images, sound, video and tactile senses, which are more powerful and flexible than paper based systems. The policy of governments appears to favour a national healthcare infrastructure with a longitudinal patient record covering a patient's complete medical history from the cradle to the grave. Such developments raise a number of ethical issues.

EPRs can facilitate the doctor-patient relationship through use of computerised notes which the doctor and patient share and contribute to. However, EPRs can harm the relationship and undermine trust. For example, in the US there are medical data clearinghouses that sell medical patient data to insurance companies, police departments, employers, drug companies, and so on. Consequently, patients are becoming reluctant to tell their doctors everything about their medical symptoms and the causes of them. This is damaging the doctor-patient relationship, which depends heavily upon confidentiality and most importantly threatens to damage quality of care. There is clearly a tension and trade-off between the need-to-know and the right to confidentiality which must be addressed. This is an issue which has been exacerbated by ICT. Violations of medical confidentiality may appear to be easier because of the efficiency of computerised systems. The damage to the patient whose confidentiality is violated may be proportionately greater because of the amount of data held within the EPR.

Electronic access to medical information requires careful scrutiny. A patient's right to informed consent should prevail. A patient should have control over her/his data preventing casual distribution that might be harmful. A patient should also have the right not to be informed of medical facts, for example, genetic data which might affect self

esteem and the way in which one lives ones life. The ability to invoke only partial access is important. For example, a woman who had had an abortion might visit a surgeon for an unrelated ailment. She should have the right to decide whether or not to allow that physician access to data other than what could be termed as her general health status. Electronic access to patient data can be beneficial. For example, the administering of prescriptions via electronic transactions from doctor to pharmacist to patient with the aid of digital signatures for authorisation could improve service significantly.

The movement of EPRs over the Internet, intranets and extranets raises concern, for the further from the original source the greater the risk of inaccuracy, falsification, duplication, manipulation and unauthorised distribution. There is little effective control over data use over computer networks. Ethical practices are not well defined for the vast array of disclosures to secondary users, such as managed care evaluators, insurance companies and so on. For example categorising and profiling patients may engender discriminatory and or exclusionary effects. Data banks of health maintenance organisations, and drug companies are gathering information and storing it in computerised form. By linking their computers these organisations can trade information across computer networks. Information has thus become a tradable commodity. The legitimacy of this medical information trading needs to be established and assurance sought that data is completely anonymised.

A morally defensible approach to EPRs should be adopted and could be based on the following:

- A patient's right to informed consent should be dominant: thus education about these issues should be available to patients, along with information about the existence of all databases with medically relevant information about the patient.
- A patient should normally have effective control over his/her data and the ability to prevent any casual distribution that might be harmful, ensuring EPRs maintain nonmaleficence. There need to be safeguards to ensure that declining to give consent to access records does not harm the patient unduly.
- Patients should have the ability to allow selective access to their records.
- The EPRs of the dead should be treated with the same consideration as those of the living.
- In contemporary industrialised societies, legislation should clearly define the appropriate scope for EPRs, and ownership of patient data. It should clarify what principles should govern legitimate access to and use of personal health and medical data and information, and patients' rights with respect to their own medical information. There should be prohibitions on certain sorts of uses of data. Mechanisms

for the adequate enforcement of applicable laws and oversight of use and access must be in place.

- Healthcare providers and funders and other potential recipients of medical data should understand the range of impacts of all sorts of medical data sharing, including on the requirement for openness in the doctor-patient relationship (both if patients are to be appropriately treated and if accurate data is to be collected).

EPRs are indicative of a society that is increasingly dependent upon ICT. The impact of this morally sensitive application of ICT cannot and should not be ignored. Policy makers, key decision takers and developers involved in the creation, use and promotion of EPRs are urged to consider these suggestions.

This edition of ETHicol is based upon a research paper entitled "A Moral Approach to Electronic Patient Records" by N Ben Fairweather and Professor Simon Rogerson.

Please send your views on ethical and social responsibility issues and cases of ethical dilemmas to:

Professor Simon Rogerson
Director
Centre for Computing and Social Responsibility
Faculty of Computing Sciences and Engineering
De Montfort University
The Gateway
Leicester
LE1 9BH
Tel:(+44) 116 257 7475
Fax:(+44) 116 207 8159
Email:<srog@dmu.ac.uk>
Home Page: (<http://www.ccsr.cse.dmu.ac.uk>)