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## **ETHICAL ISSUES SURROUNDING THE USE OF INFORMATION IN HEALTH CARE**

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### ***ABSTRACT***

*As a result of rapid technological and economic expansion throughout the world, society is confronted with new requirements. For the success of the medical practice, even with the rapid changes in technology and the medical field, practitioners involved in the use of patients' information are obliged to continue to behave ethically. This paper reviews the ethical challenges raised in the use of patients' information for medical and other purposes. It also discusses the values underlining the ethical issues and their importance in the use of patients' information in the doctor and patient context. The issues surrounding the use of patients' information such as secrecy and confidentiality are raised and potential problems in the area, policy issues which must be addressed by those concerned with the confidentiality and secrecy of health information and the germane legal issues are also discussed. Moreover, this is a review of the current status of the health care information ethics with particular reference to the United Kingdom, United States, Canada, Australia and developing countries. Finally, it concludes that the emerging field of health care information ethics will require careful thought and insights from an international collection of ethicists.*

Keywords: Medical information; Patients information; Healthcare information; Medical librarians

### **INTRODUCTION**

Being ethical is not the same as following the law (Mason, Mason and Culnan, 1995). The law often integrates ethical standards to which most citizen pledge. But laws, like feelings, can deviate from what is ethical. Therefore, what is ethics? Ethics and morality are usually closely related. Ethics may be looked upon as the philosophy of morality. Generally, ethics deals with right and wrong behaviour. In other words, ethics refers and describes standards of right and

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wrong that prescribe what human beings ought to do in terms of obligations, benefits to society and rights. Generally, Ethics is a system for governing human behaviour (Mason, Mason and Culnan, 1995).

The information lifecycle is a sequence of functions through which information is handled. The key stages of the information lifecycle are acquiring, processing, storing, disseminating and using information (Figure 1). Anyone can be brought to an ethical crossword at any of these stages. However, the “using stage” conceivably creates the most obvious issues because we all understand that information can be used in ways that either help or harm people.

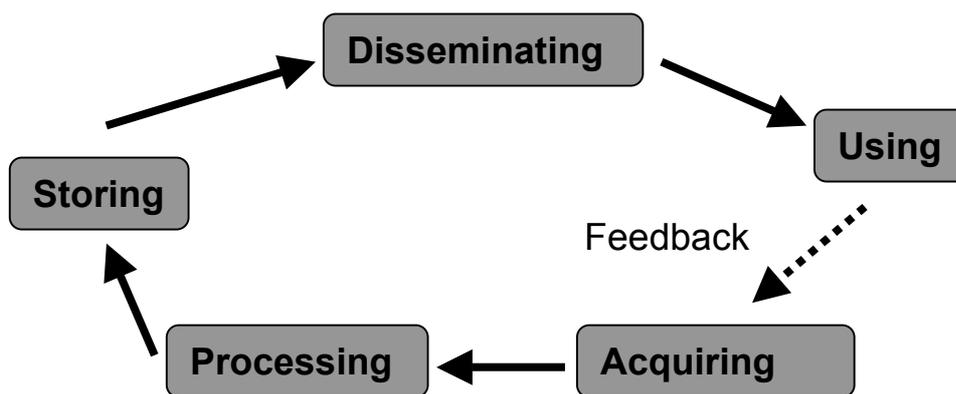


Figure 1: Information lifecycle

Generally, patients’ medical records are used largely by health care professionals such as physicians, health researchers and medical students. Nevertheless, a new trend has emerged whereby the medical information is used routinely for a wide range of other purposes such as life insurance, mortgages, employment, council housing, state benefits and private pension schemes. Therefore, health information plays an increasingly important social function and, as a result, a number of ethical issues have arisen since the confidentiality and privacy of the patients may be ignored. In the meantime, health information is mainly important for the provision of high quality health care such as developing treatments and diagnosing new diseases based on research. Health information is extensively used in medical research to improve the understanding of diseases and treatments across broad populations. On the other hand, the same health information may affect the patients adversely in numerous ways. Sensitive medical information can affect patient’s employment, new employment opportunities or the ability to receive insurance or may lead to other harmful outcomes.

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The Code of Ethics of the American Medical Association (AMA) states that “a physician shall safeguard a patient’s confidences within the restraints of the law” (AMA, 1996). In addition they emphasise that “patients have a basic right to privacy of their medical information and records. Patients’ privacy should be honoured unless waived by the patient in a meaningful way or in rare instances of strongly countervailing public interest” (AMA, 1998).

#### **PROTECTION OF MEDICAL INFORMATION, PRIVACY AND CONFIDENTIALITY**

The British Medical Association (BMA) (1993) is of the opinion that all information collected in the context of health care is confidential and the activator of its release is the patient context. Usually this information may contain records in the form of computer-based, paper-based, photograph and video-tape. However, it includes not only the visible information but also the patient’s information which is not recorded at all, but held in the doctor’s mind (BMA, 1993). However, in exceptional cases, for example when there is a serious risk to other people, the doctor can dispense with the need for the patient’s context.

Privacy is based on the idea of seclusion and secrecy. From the health care’s perspective, privacy suggests the right of the individual to decide how much information the person desires to disclose to a physician and how much of that information may be exchanged between authorised organizations (Smith, 2000). In this case, information collected about patients is often circulated through the media without the patients’ knowledge or consent. The issue of privacy in the field of medicine is very important for this reason. Usually other people can see a patient’s medical and health information at a clinic or hospital. Patients are very anxious about what happens when they go to the clinic or hospital. They worry about how long this information will be kept, who will see it, what is going to be done with it and what other form of data sharing will take place. Privacy of the patients should be regarded as fundamental human right. Every one must have a right to control his or her personal information and it should not be allowed to be seen or used by unauthorised personnel. This is most visibly substantiated by the fact that the European Union has implemented an Act on data protection. By doing so, the European Union has shown their commitment to protecting privacy as a right of the people. The British Medical Association (1993) claims that privacy is a fundamental right of a patient. Patients must decide the manner and extent to which information about them is shared with other people. However, invasion of privacy in health care has both benefits and detriments to the individual.

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The second issue related to ethics is confidentiality. The ethical and legal principle of confidentiality is anchored in a set of values and assumptions about treatment and the consequences of disclosing private information. While treating mental illnesses or HIV/IDS illnesses, values are enormously important. Confidentiality is also related to the values of privacy and autonomy.

The confidentiality concept goes back to the time of Hippocrates and beyond (BMA, 1993). Since then, the need to ensure the confidence of patients has been a moral and ethical duty of the highest importance. According to the Hippocratic Oath,

*“Whatsoever things I see or hear concerning the life of men, in my attendance on the sick or even apart there from, which ought not be noised abroad, I will keep silence thereon, counting such things to be as sacred secrets”*(Oath of Hippocrates, 4<sup>th</sup>.century,B.C.)

The major principle expressed in the Hippocratic Oath is to recognize the patient’s self-determination as an integral part of their human and civil right. However the importance of the rights to confidentiality is also recognised by the European Convention on Human Rights (Brameley, 2000).

The principle of confidentiality is designed to advance certain values. There are several illnesses, which often call to mind public unease and the victims face unconcealed discrimination. For example, people infected with AIDS often face discrimination. Those who have psychological illnesses also face considerable problems. Therefore, if the information of these individuals is passed on to others apart from the personnel involved in their treatment, it is extremely unethical. In an effort to reduce the risk of disgrace and discrimination, confidentiality laws have contributed substantially to the protection of information of these personnel. All the health care organizations have a common duty of confidentiality towards the protection of personal and health information of their patients and they should not divulge them without prior permission the of individuals concerned. For instance, the International Code of Medical Ethics (BMA, 1993) states that a physician must protect the confidentiality regarding all he knows about his patients even after the death of the patient.

Legislations introduced in the USA have made an enormous contribution to privacy and confidentiality, while at the same time expanding individual autonomy in health care decision-making. A public opinion poll carried out in that country also showed extensive support for the privacy of health care information. About 85% of those responding to a survey characterised protecting the privacy of medical records as essential or very important (Peck, 1994). The

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ethical codes of the health care professions also embrace confidentiality as a major principle (AMA, 1995). The issue has emerged as a major concern for American citizens, many of whom believe that the privacy of mental health care information is not protected as strongly as it should be (Peck, 1994). In recent years the law in Australia has played an increasing role in many medical practitioners' need to have an increasing awareness and knowledge of legal issues that may influence their professional practices (Errington, Nicholson and Powe, 1996).

On the other hand some people have proposed that hospital based case control studies should adopt more ethical deliberation before recruiting subjects for their research. Coggon (2001) stated that a team including himself, has completed data collection in a case-control investigation of infectious pneumonia and occupational exposure to metal fumes centred on ten hospitals in the West Midlands, UK. Cases were identified from hospital records and approached, either in person while still in hospital, or by post after they had been discharged, with an invitation to undergo an interview about their work and lifestyle. They had obtained approval from all the local ethics committees concerning this method, but there were suggestions that the researchers should not have had access to any clinical information about patients without the latter's formal consent. In the UK, various bodies contribute to the definition of which research designs are ethically acceptable, including the General Medical Council, Medical Royal Colleges, BMA, Medical Research Council as well as the research ethics committees.

In 1997, a survey carried out by the Health Information Management System Society (HIMSS) of the USA showed that 41% of the responded information executives have cited internal security breaches as their biggest concern for revealing confidential patients' information to unauthorised users (Conner, 1999). These things usually happen because some of the care providers, such as family members, friends, or co-workers may want to see this information. In the survey, only 37% of health care organizations had taken necessary steps to protect confidentiality and security of their computerised records, 42% expressed that they were beginning to implement steps, but 21% believed that implementing security measures was unnecessary or premature (Conner, 1999).

In the past, confidentiality and privacy of health information was secured by the doctor-patient relationship. Nowadays is not practical since doctors sometimes cannot make sole decisions for complex situations, so patients may have to face various kinds of investigations. Research into causes is needed, so that research into treatment of the conditions can be conducted. The Medical Council in the UK has recognised the importance of research in the field and they have

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presented practicable guidance in order to ensure that ethical considerations are taken into account when research and investigations are carried out.

## **OTHER ISSUES**

Computerised records are more secure than their print counterparts. In paper-based systems, since there is a copy of the patient's record, the whole chart or parts of it can be lost, stolen or damaged, and information can be added, removed, or modified without an audit trail. In fact, advances in medical technology are advantageous to patients with serious conditions, who do not necessarily require hospital in-patient care. They can be monitored from elsewhere by qualified health care professionals through transmission of medical information by telephone, fax or digital media including electrocardiograms, encephalograms, X-rays, photographs and all kinds of medical documents (BMA, 1993). Although these facilities provide high quality and good collaborative care, these technologies raise different problems of ensuring patients' confidentiality. Therefore the British Medical Association (1993) noted that, "It is clear that ethical considerations require the implementation of full safeguards for patient confidentiality prior to the introduction of new technology on a routine basis".

Technology has also emerged as a major issue in privacy debates. Even though computer-based electronic records can in many ways be more secure than paper-based records, the same technology raises trepidation about their privacy because of its capabilities of being copied, stored and disseminated by means of computers quickly when compared to paper based information records. It is generally agreed that access to information and its security are inversely proportional. Thus, routine security mechanisms to protect a patient's confidentiality generally rely on some combination of authentication, authorisation and auditing (Murphy, 1996).

Redsell and Cheater (2001) stated that there is a lack of awareness of the ramifications of the Data Protection Act amongst many staff employed within the health and academic institutions. This is a great barrier against the implementation of health information ethics and looking after the rights of patients.

### **Ownership of Medical Records**

According to the Access to Health Records Act implemented by the UK government, the owner of the medical records is the Secretary of State for Health. In fact, this seems to confuse the ownership of the patients' health

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records, hence the BMA has raised a logical argument stating that because the records are compiled as part of the contract of employment and, in accordance with general law on this subject, it belongs to the employer rather than the creator of the document (Brameley, 2000).

#### **Public Interest**

Brameley (2000) questions whether a patient can be allowed to show his or her record to others. Many doctors have requests from the police to see the records of someone suspected of involvement in criminal activities. To what extent is the obligation to keep someone's medical details private outweighed by a wider obligation to the public? However the BMA has a policy on the release of data to the police, where a serious crime is involved. Nevertheless the decision is solely that of the physician (Smith, 2000).

According to the NHS (Venereal Disease) Regulation 1974 of the UK, the NHS is allowed to reveal information identifying patients with venereal disease to be given to those charged with preventing its spread (SI 1974 no. 29). The UK Misuse of Drugs Regulations 1973 compels clinicians to make available to the Home Office names, addresses and addiction details of patients addicted to certain class of drugs (no. 799). In accordance with the UK Public Health (Control of Disease) Act 1984, it is stipulated that the Department of Health must be notified of any patient having or suspected of having cholera, smallpox, plague or typhoid. The Children's Act 1979 and the Mental Health Act 1983 also coerce clinicians in particular circumstances to co-operate with, and give confidential patients' information to bodies such as the social services. Contrary to popular belief, there is no statutory obligation on doctors to report to the police or UK Vehicle Licensing Authority those patients who are considered medically unfit to drive, but who insist on doing so (Brameley, 2000).

HIV/AIDS information is also sensitive information as it is difficult to determine whether or not it should be revealed to the general public for their safety. However, it is an extraordinarily complex question based on medical and ethical issues surrounding HIV and AIDS. There is an extremely imperative need to keep the right balance between the confidentiality of patients and protecting the public from the disease since HIV can be transmitted to the sexual partners of the particular patient, and also to the general public and health workers in numerous ways.

#### **Access to Information**

Medical information is used for a number of research purposes - to advance biomedical science, understand health care utilization, evaluate and improve

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health care practices, and determine the causes and patterns of diseases. This research is extremely important to provide better treatment and service to the patients. As such, the ethical and legal issues surrounding the use of medical information should be reconsidered.

### **Sharing of Information**

Sharing a patient's information is the main cause for losing the confidentiality and privacy of patients. However, the sharing of information with other health professionals is necessary to give patients effective care. On the other hand, some people argue that it is also an ethical issue affecting the patient's rights. As a result of these points of view, the British Medical Association (1993) states, "Care is provided by interdisciplinary teams and it is important that patients are aware of this and explicitly agree to information being given those who need to know it".

## **LEGAL ISSUES FOR PROTECTION OF PRIVACY AND CONFIDENTIALITY**

### **(a) Access to Health Records Act 1990 (c. 23)**

In UK, the access to Health Records Act 1990 is implemented by the government to give patients a right to inspect information recorded in their medical or health records.

### **(b) Privacy Protection Act (1980)**

In USA, the Privacy Protection Act (1980) was introduced to prevent unwanted searches of offices and files by the government.

### **(c) The Data Protection Act (1998)**

In UK, the Data Protection Act (1998) was introduced in response to the European Community Data Protection Directive (1995). "The eight data protection principles cover the use of 'personal data' held on manual as well as computer records. Briefly the principles cover the use of 'personal data' should be processed fairly and lawfully; that subject must have given explicit consent to the processing of data; that data should only be obtained for one or more special purpose; that it should be accurate and contemporaneous and disposed of once it is no longer necessary" (Redsell and Cheater, 2001). However the main defect of this Act is that it does not permit an individual or institution holding a database

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of personal information to pass any details about individuals directly to a researcher and legal risks are incurred (Flaherty, 1995)

#### **(d) Patient's Bill of Rights**

In 1973, the American Hospital Association (ASA) formalized a list of hospital patients' rights, known as the Patient's Bill of Rights (Columbia University College of Physicians and Surgeons, 1997). The objectives of this Bill are

- i) To meet the demands of consumer-protection groups for greater accountability from health care providers
- ii) To turn back the rising tide of malpractice suits by making the hospital experience less impersonal and therefore more satisfactory.

This Bill emphasised the privacy and confidentiality of all records pertaining to the patient's treatment, except as otherwise provided by law or third-party payment contract.

### **SOLUTIONS**

Three types of solutions are proposed for the protection of the confidentiality, privacy and security of patients' records.

#### **Legal solution**

If the organization cannot control what happens to information once it is released to an authorised outside agency, legislation is required. Legislations are intended to ensure that all organizations obey the same rules and give patients equal protection.

The European Union has promulgated two directives on data protection, and these have been translated into national law in UK through the Data Protection Acts of 1984 and 1998. The main target of the legislation is information used commercially, and it makes some exceptions for data handled in medical research. However, the exact scope of these exceptions in UK is as yet undefined, and an important impact of the laws has been to raise doubts about the legality of certain established research methods. This in turn has caused some people to question the ethics of the method (Coggon, 2001).

In USA, the Health Insurance Portability and Accountability Act (HIPAA) 1996 (P.L. 104-109) called for the protection for the privacy of medical information. Bills related to the privacy of medical records introduced in the 105th and 106th Congresses have provisions to address uses of medical information for a variety

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of purposes, including research (Centre for Medicare and Medical Services, 1996). The various bills attempt to provide for the conduct of medical research whilst offering privacy protection, and some have called for the extension of the current requirements of the common rule, including the use of IRBS, to research which is not federally supported or regulated. Most western countries enacted legislation designed to protect personal data from unreasonable collection, storage, use and dissemination. Until now, most of the developing countries do not have a policy on information privacy or data protection laws.

### **Organizational solution**

The organizational issue for protecting confidentiality is the most successful methodology. Most sources recommend the use of multilevel, individual passwords for all users as a safeguard for the protection of ethical issues in health information.

### **Technological solution**

Technological issue can also help authorised bodies to protect the confidentiality of their patients. For internal use, computerised cards similar to automated teller machine cards, known as “smart cards” are useful.

## **CONCLUSION**

Permission for the disclosure of patient’s information to other parties or those who have direct responsibility for patients’ health care may be inferred. It should not be explicitly sought. On the other hand, the physician cannot conjecture his/her patient’s context to the patient’s identifiable medical information being made available to the other parties or those who do not have a direct relationship (such as police, insurance companies and researchers) with his/her medical care without the patients’ formal authorization or endorsement. If a doctor discloses patients’ information without a prior approval from the patient, it would be in a violation of the human right to respect a patient’s privacy.

It is a mandatory requirement of a hospital to ensure the confidentiality of patient information, which includes medical records, medical test results and diagnoses. Patient information should not be disclosed to unauthorised person without a court order or proper authorization from the patient or his/her respectable guardian.

Even within the organization, the confidentiality of the patient should be strongly upheld. There should be a high fortification for the confidentiality of all patient

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documents particularly while transiting information to others or other places by Intranet, Internet or other means of communication technology.

An independent regulatory body is necessary to see that data protection is carried out properly. It would be extremely beneficial if the relevant bodies could establish some authorised sectors where the victims or general public can complain, and the authorised bodies can perform audits, and verify that fair information practices are being complied with. However the violation of ethics in the use of medical information can be accidental, but the authorities should take the necessary steps to minimise such kinds of occurrences since the privacy of patients is extremely important.

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