

Chapter 75

Health Information Technology and Human Rights

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ABSTRACT

Information technology has the potential to transform healthcare and eradicate many of the inequities seen in the area. However, the use of electronic means to process sensitive health data poses significant risks. Electronic health records have been designed to be more secure than traditional paper records, but there have been notable cases where data has been lost, stolen, or viewed by unauthorised persons. Misuse of health information technology can result in severe violations of human rights. In particular, the right to privacy can be eroded by inappropriate protections, which still exist in some health systems. This chapter describes the rights framework in healthcare, analyses legal provisions for protection of health data, considers why such protections are necessary, outlines examples of rights violations, and proposes future directions.

INTRODUCTION

Of any area, healthcare ought to be a bastion of human rights protection. But there are notable violations in hospitals every day: from overcrowded wards that are devoid of dignity to paternalistic casting aside of patient autonomy. Healthcare is also concerned with the accumulation of some of the largest quantities of data on individuals. This may include very sensitive personal details. Traditionally the majority of health information has been in paper form but there is a trend towards digitisation. This process is expected to produce many improvements in patient care, including better patient safety and quality of care and better access to up-to-date medical informa-

tion for practitioners. However there are inherent risks involved with this change which need to be foreseen. Maintaining a high level of security is of particular concern as the flow of information increases. It is possible that information may be misused, for example by influencing insurance decisions, or affecting employment prospects. If risks such as these can be managed, then digitisation could be very fruitful. From a consumer point of view, information technology could facilitate access to valuable health data that can help the doctor-patient relationship to blossom. The availability of population level data could help to plan improvements in health services. Better access to healthcare could be achieved by using informatics to provide services according to need. These

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steps would help to advance healthcare as a human right. However, there is much advocacy to be done in order to achieve this. It is necessary to draw attention to the need for work in this area, with a detailed academic, legal and clinical analysis.

HEALTHCARE: A HUMAN RIGHT?

Whether healthcare is a human right has long been debated. Madden (2002) notes that such claims have either been to a “right to health” or a “right to healthcare.” One of the earliest such references was made in the preamble to the 1946 Constitution of the World Health Organisation (WHO) which unequivocally states: “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being” (World Health Organization, 1949). The WHO definition of health is comprehensive: “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

Two years later, the Universal Declaration of Human Rights was published. Article 25.1 states: “everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and necessary social services” (United Nations, 1949). This envisages a right to health as part of a socio-economic aspiration rather than a more quantifiable right to a particular standard of care or health status.

One of the most recently ratified instruments is the Charter of Fundamental Rights of the European Union. When the Treaty of Lisbon was signed in December 2009, the Charter became binding on EU states. It also begins by looking at health mainly from a socio-economic perspective, stating that “every worker has the right to working conditions which respect his or her health” (European Parliament & European Commission, 2001). However Article 35 goes on to say: “Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the condi-

tions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.”

The wording emphasises the importance of preventive healthcare, and seems to suggest that there is no recognised right to *health*, but rather a right to *access* to healthcare.

Health Records

Health records have existed at least since Roman times. They began as an aide-memoire and to help document progression between visits. Relatively little had changed about this process up until modern times. Although information technology is taking hold, many physicians still use paper records for their patients’ medical details (Ford, 2009). One of the drivers for the change to electronic records was medical negligence litigation. The quality of physicians’ handwritten entries has been criticised by the courts (Charatan, 1999). Documentation of clinical activity can be very poor, and there may be little reflection of the decision making process. In addition there is no scope for patients to make their own entries, for example to record their impression of their illness or care. The record has always been physician-centric; being composed, read, and guarded by them. Patient access has traditionally been restricted and they rarely have an opportunity to peruse or correct the entries. All of these factors mean that patients who have been harmed find it difficult to prove their case. Without accurate contemporaneous records, care can never be of the highest standard. Doctors are ethically obliged to maintain accurate, up to date and detailed records. Patients are entitled to demand this. They also have a right to be able to access it – although this operates differently from country to country, and depending on whether a health service is publicly or privately run.

For many years, the doctor was the only person capable of viewing a patient’s record. That situation is changing with the advent of electronic records.

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