Chapter X

Compiling Medical Data into National Medical Databases:
Legitimate Practice or Data Protection Concern?

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Abstract

In recent years, various national medical databases have been set up in the EU from disparate local databases and file systems. Medical records contain personal data and are as such protected by EU and member states' legislation. Medical data, in addition to being personal data, is also defined in the EU legislation as being especially sensitive and warrants special measures to protect it. It therefore follows that various legal issues and concerns arise in connection with these processes. Such issues relate to the merits of compiling a nationwide database, deciding on who has access to such a database, legitimate uses of medical data held, protection of medical data, and subject access rights amongst others. This chapter examines some

of these issues and argues that such databases are inevitable due to technological change; however there are major legal and information security caveats that have to be addressed. Many of these caveats have not yet been resolved satisfactorily, hence making medical databases that already exist problematic.

Introduction

Medical data consists of information used in the provision of healthcare such as observations of patients (e.g., test results), medical histories, symptoms, prescriptions, and treatments. It is essential that such data are properly recorded and accessible in order to support the care of patients. Specifically, medical data can be used for various purposes such as to: create a historical record of a patient, provide a reference for future treatment, provide a communication mechanism among different medical professionals, anticipate future health problems, provide a legal record, and support clinical research (Shortliffe & Barnett, 2001).

The use of information technology in healthcare has created new possibilities including the digitisation of medical data (from passive paper-based patient records). An important consequence of this is the creation of the electronic health record (EHR), which can be defined as:

a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports. (Healthcare Information and Management Systems Society, 2007)

EHRs are generally stored in a database system and their contents can vary according to the specific national legal framework under which they are regulated. They provide many advantages over traditional paper-based patient records leading to an improved quality of healthcare (by facilitating new methods of delivering healthcare and better data management). Some benefits of EHRs include: non-exclusive, continuous and multiple access to a patient's data; improved accuracy, reliability and integrity of data; standardised data record formats; ease of data access; ease of data integration; and stronger protections for confidentiality and security (Hunter, 2002).

Traditionally, EHRs have been stored in database systems that were locally developed, maintained and stored by organisations (such as hospitals, doctors' surgeries and other healthcare providers) in order to improve their quality of service. The advent of new information and communication technologies, improved networks and the