Chapter 7.6
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

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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 need for new data processing capabilities (e.g., demographic healthcare studies) have resulted in the creation of (or attempt to create) national medical databases. For example in June 2002, the United Kingdom (UK) Government (Department of Health) published a National Strategic Programme for the use of information technology in the National Health Service (NHS). Amongst key elements outlined in the strategy was the delivery of core national services that can be used throughout the NHS such as an electronic health record service (having core data and reference links to local medical databases) accessible nationally for out of hours reference, (Department of Health, 2002).

A national medical database can be described as the aggregation of various disparate local medical registries/databases compiled at the national level. Such databases are characterised by their extensive coverage/storage of medical data, both in terms of their content (they integrate different medical databases) and geographic coverage (they integrate data from an entire country). They can lead to improved healthcare services coordinated (and planned) at a national level. Improvements are due to factors such as: the provision of medical information (e.g., for an emergency) anytime and anywhere, nationally standardised medical records generally leading to an improved quality of medical data, access to a large volume of medical data for clinical research, the ability to undergo epidemiology research, the central control of medical data, the ability to plan services for populations, and better management of scarce national medical resources (see Department of Health, 2003). The nature of national medical databases (compared to local databases), especially the fact that they are accessible nationally raises greater legal concerns regarding the protection (and potential unauthorised disclosure and use) of medical data. This is especially poignant for

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