

Prerequisites for International Exchanges of Health Information for Record Research: Comparison of Australian, Austrian, Finnish, Swiss, and US Policies

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Abstract

The policies that address health information exchanges for research purposes in Australia, Austria, Finland, Switzerland, and the USA apply accountability and/or adequacy to protect privacy. Specific requirements complicate the exchanges: inform data subjects of data use purposes; assure that the subjects are no longer identifiable; destroy the data in the end; and not to use cloud computing without specific permission.

Keywords:

Electronic Health Records, Health Policy, Privacy

Introduction

A major risk in electronic health records is the possibility of compromising data subjects' privacy, and this is particularly evident in analyzing text (i.e., inability to be fully convinced that all privacy-sensitive information has been removed) or big data (i.e., unforeseen possibilities to infer personal data after record linkages from multiple de-identified sources). Using EHRs for research purposes requires compliance with legislation, and governance.

Methods

We specified the legal frameworks, process of gaining access to EHRs, and restrictions for data exchanges across projects in five countries: Australian Commonwealth, its NSW, Austria, Finland, Switzerland (Valais), USA, and its CA. We used a published method [1] and extended its analysis from Australia and Finland to the EU more widely (Austria), non-EU Europe (Switzerland), and N. America.

Results

Requirements for data access and protection vary (Table 1, [2]). The frameworks apply accountability of the original data creator for regulatory compliance (e.g., Australia and USA) and/or the subsequent information receiver having to protect privacy adequately (e.g., Australia and EU) (Table 2, [2]). ICT can audit compliance with all frameworks [3]. The process of gaining access to EHRs for research has five steps (Table 3, [2]): 1) Preparations include: developing a research

plan, research group, and an ethics protocol. 2) The proper approvals and permissions are furnished. 3) Data are collected and de-identified and an informed consent is obtained from each subject. 4) Research, where the exchanged data are used only for these purposes, takes place. Exchanges of the original or secondary data across borders or projects are permitted if they have been addressed in Steps 1-3; the use of cloud services, which may store data in another country or legislation, without specific permission is not allowed. 5) All data are deleted or returned to their original creator at the end.

Conclusion

Capabilities to exchange health information are critical to accelerate discovery and its diffusion to practice. However, the same ethical and legal policies that protect privacy hinder these exchanges. Both legislation and technologies are available for overcoming these barriers [3].

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