Research using electronic health records: not all de-identified datasets are created equal

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We read the article Research using electronic health records: balancing confidentiality and public good by Wallis et al. with great interest. The authors note general practices need to trust de-identification processes when releasing patient records.¹ Patients have also expressed concerns about de-identification practices.² De-identification encompasses a wide range of practices, and there are no universally accepted standards.²,³ We propose here a three-step scheme for judging de-identified health records: (1) the de-identification standards used (2) the performance of the de-identification system and (3) additional security measures taken to prevent re-identification. Such a scheme may be useful to ethics committees, researchers planning a project and health providers deciding whether to participate.

De-identification standards

The United States Health Insurance Portability and Accountability Act 1996 (HIPAA) provides arguably the most user-friendly definition of de-identified. Under HIPAA’s Safe Harbor provision, 18 specific categories of protected health information (PHI) about patients and family members need to be removed from the records.⁴ The New Zealand Health Information Privacy Code requirement that the information is in a form in which the individual is not identified is less specific, but arguably provides researchers greater flexibility.⁵,⁶ However, the European Union’s General Data Protection Regulation (GDPR) is arguably even more stringent than the HIPAA, and has extra-territorial reach. It requires that individuals are not identifiable rather than simply not identified (e.g. through cross-matching with other datasets or publically available information).⁶,⁸

Performance of the de-identification system

De-identification is a two-step process where PHIs are identified and replaced by appropriate surrogates. Recently, there have been significant advances in automating de-identification of health records using machine learning. Several systems have achieved the gold standard of 95% accuracy in identifying HIPAA Safe Harbor PHIs.⁹ However, there are still challenges and concerns in automating the surrogate generation and replacement process. There are also concerns about the usability of records de-identified to this extent, and whether analysis of de-identified records will produce the same results as records that have not been de-identified.

Additional security measures

These include encryption, random noise generation and compartmentalisation of the datasets. Such measures protect de-identified data from being re-identified through cross-matching with other datasets.⁹ A multi-layered protection model based on well-accepted patient safety practices may be useful.¹⁰ In conclusion, de-identification may more accurately be described as difficulty in identifying, and lies on a spectrum from very easy to near impossible. Being specific about where one’s dataset lies allows researchers and health providers to make informed choices.
Competing interests

The authors declare no competing interest.

References


Response

Thank you for putting forward this interesting suggestion. Having a score that rates the level of de-identification of health information could assist communication about de-identification and would potentially be of interest to researchers, patients, and practices. However, the development of such a scoring system is some time away. In the meantime, we need to continue to work to improve the reliability of current de-identification processes.

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