

NZ law, government policy, and NZ patients support the use of anonymised patient records for medical research. Electronic medical records open up new possibilities for large, collaborative, and multi-centre studies that could never have been completed with paper records. This type of research holds enormous potential for improved patient care. Let GPs abandon our misapprehensions about sharing anonymised electronic medical records, and embrace the massive research opportunities this digital age offers us.

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General practitioners should allow use of anonymised patient records for research

NO

Confidentiality is not a decrepit concept

The canon of Hippocrates of Cos (460 BC – ca 370 BC) included the famous Hippocratic oath, a social statement about the role of the doctor in society.¹ Under the oath, for centuries doctors have promised to keep secret 'all that may come to my knowledge in the exercise of my profession'. General practice, in particular, has taken this promise to heart—even today, when asked, most general practitioners (GPs) identify confidentiality as the primary ethical concern.² However, in recent years, the nature of medical records and the delivery of care by teams has led some to question whether confidentiality is a con, a decrepit concept.^{3,4}

Today, the knowledge that doctors promise to keep secret forms part of a detailed electronic record of health information about a patient. This information may be accessible to many people in a group practice; some of the information (including referral letters, correspondence, classifications, medications, allergies, and laboratory and radiology test results) may be accessible to many people in external agencies, including hospitals and pharmacies, and anonymised information is regularly transmitted from practices to funding, monitoring and research agencies.

The detail, accessibility and transmissibility of the information have the potential to improve patient care by both facilitating communication between providers, and by creating new opportunities for research.⁵ However, the accessibility and transmissibility of the information also poses a threat to privacy and confidentiality.

Katharine A Wallis

MBChB, PhD, MBHL, Dip Obst, FRNZCGP
Department of General Practice and Primary Health Care, The University of Auckland, Auckland, New Zealand
k.wallis@auckland.ac.nz

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The legal protections of health information privacy

The right to privacy concerns the right of an individual to live a life unobserved and to control use of information about him or herself. In New Zealand law, this right is protected under the Privacy Act 1993, and specifically regarding health information, the Health Information Privacy Code 1994 (HIPC). The HIPC stipulates that information gathered for the purposes of providing health care cannot ordinarily be used for other purposes (such as research) without patient consent. But the right to privacy, while important, is not an absolute right. There are many exceptions when doctors can share private health information without consent; that is, when the best interests of the patient or public interest considerations outweigh the right to privacy. For example, somewhat controversially, the law permits auditors of the National Cervical Screening Programme to access a patient's entire medical record without consent.⁶

Rule 11 of the HIPC sets out the exceptions that override the right to health information privacy. Regarding research, Rule 11 stipulates that a practitioner may disclose health information to researchers without patient consent if it is 'either not desirable or not practicable to obtain authorisation' and the information is anonymised or the information is to be used for 'research purposes (for which approval by an ethics committee, if required, has been given) and will not be published in a form that could reasonably be expected to identify the individual concerned'.⁷

Confidentiality: protecting a relationship based on trust

Health information is governed by the rules of both privacy and confidentiality: a health practitioner receives private information in the course of a confidential relationship. Notwithstanding the law permitting doctors to share their patients' private health information for research, doctors have an enduring ethical duty to maintain confidentiality: to keep secret all that comes into their knowledge in the exercise of their profession.

The time-honoured duty of confidentiality is important for protecting the doctor-patient relation-

ship, a relationship based on trust. Patients need to trust their doctor because they are not self-sufficient. But trust entails risk. Trust is about keeping promises; when promises are broken, trust is diminished; And when trust between two people is diminished, the relationship between them is damaged.⁸ Relationships are important in general practice. General practice is about delivering a service through a relationship; when the relationship is broken, we struggle to deliver our service. If we cannot be trusted to protect patients' secrets, patients might withhold important information, hindering our ability to help.

Obviously the law is important, but a doctor's ethical duties are also important. It can be distressing for practitioners when the two are not aligned, when the law undermines our ethical obligations, potentially damaging that which is important: relationships and trust.⁶ Practitioners might attempt to circumvent the (legal) threat to privacy and to protect confidentiality by refraining from documenting and/or communicating sensitive information, potentially compromising patient care.

Research: seeking to improve patient care

Relationships and trust are not all that are important. Research to improve patient care is also important. Improving patient care is in our patients' best interests. Doctors have a duty to share information to improve patient care.

Sophisticated data anonymisation and extraction systems today promise to extract health information from the electronic health record (including the daily record, letters, and test results) and transmit the information to researchers in such a way that researchers will not be able to identify the practice, practitioner or patient. If the data anonymisation processes are reliable, research to improve patient care is possible while posing minimal threat to privacy and confidentiality. Researchers will come to know our patients' secrets but they won't know whose secrets they are. Researchers, although not involved in the care of the patient, are professionals too and have an obligation to respect the nature of the information they come to know.

But is a secret still a secret if it is shared, even if the recipient does not know whose secret it is? While sharing patient information for research is not the worst sort of breach of confidentiality—as releasing identifiable patient information to the media would be—it is nevertheless a breach: the secrets are no longer entirely secret. New Zealand is a small country; there is always the chance that the detail of the information may enable researchers to identify practices, practitioners or even patients.

In deciding whether to share patient information for research, we must balance the potential harms and benefits. Protecting relationships is important, but good sharing of information is important too. In the case of research using anonymised patient health information, the potential benefits (improved patient care) may be great and the potential harms (loss of privacy/confidentiality) may be minimal, but they are not zero. In deciding, we need to assess both the threat to confidentiality and the potential benefits of the proposed research. While we might fear the research leading to discovery of our incompetence or having accountability repercussions, these are ignoble and unfounded concerns given our ethical obligation to work in our patients' best interests and the rules governing research and ethical committee oversight.

In conclusion, while the detail, accessibility and transmissibility of information in the electronic health record create new opportunities for research to improve the quality of health care, they also pose a threat to the patient's right to control access to information about her or himself, and to the doctor's duty to maintain confidentiality. Confidentiality might be no longer sacrosanct, but it nevertheless remains an important ethical principle. On balance, so long as data anonymisation processes are robust, the loss of privacy and confidentiality is likely minimal, making the sharing of anonymised patient information for research the right thing to do.

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String of PEARLS

Practical Evidence About Real Life Situations

about older patients

PEARLS are succinct summaries of Cochrane Systematic Reviews for primary care practitioners—developed by Prof. Brian McAvoy for the Cochrane Primary Care Field (www.cochraneprimarycare.org), New Zealand Branch of the Australasian Cochrane Centre at the Department of General Practice and Primary Health Care, University of Auckland (www.auckland.ac.nz/uo), funded by the Ministry of Health (www.health.govt.nz), and published in *NZ Doctor* (www.nzdoctor.co.nz).

- Vitamin D supplementation may reduce mortality in elderly patients
- Exercise effective for osteoarthritis of the hip
- Variety of interventions improve safety and effectiveness of medicines use
- Psychosocial interventions reduce antipsychotic medications in residential care homes
- Limited evidence for maintenance treatments for depression in older people
- Exercise programmes beneficial for people with dementia
- Withdrawing antipsychotics in older people with dementia can be beneficial

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