

General practitioners should allow use of anonymised patient records for research

YES

Medical records have probably been used for research since records began. The earliest medical texts dating back to before 1000 BC contain comprehensive empirical observations, as well as diagnostic paradigms and treatment recommendations.¹ In today's digital age, medical records used for research are mainly electronic.

Electronic medical records provide rich datasets for health researchers. Uniformity of software, consistency of data recording and coding allows for better quality data and, therefore, better research. Electronic medical records open up new research possibilities. New Zealand (NZ) legislation and government policy promote data sharing across agencies for research purposes. Research using electronic records is theoretically acceptable to patients and clinicians. NZ general practitioners (GPs) were world pioneers in the use of electronic medical records, and these records have been used for research purposes for many years.

NZ legislation allows sharing of health information. The sensitivity of health information is recognised, but this does not preclude its use. The Health Act 1956² is held in balance with the principles defined in the Privacy Act 1993.³

These laws recognise situations where disclosure of health information is permissible.

The Health Amendment Act 1993 gives extremely broad scope to the sharing of anonymous health information.

Notwithstanding any enactment, rule of law, or other obligation, any person may supply to any other person health information that does not enable the identification of the individual to whom the information relates (Section 22H).⁴

The Privacy Act 1993 outlines basic principles of collecting and disclosing personal information.³ Personal information should be collected directly from the individual, unless they have authorised another person to pass on their information (as is the case when a patient enrolls with a primary health organisation [PHO] when they enrol with a general practice),⁵ or if it is not reasonably practicable in the circumstances.

Of particular relevance to research, it is also unnecessary to contact individual patients if the information is used in a non-identifiable manner, or if it 'will be used for statistical or research purposes and will not be published in a form that could reasonably be expected to identify the individual concerned.'³ The Health Information Privacy Code 1994⁶ recommends that researchers seeking the disclosure of health information

Sharon Leitch

MBChB, DCH, FRNZCGP
Department of General Practice and Rural Health,
Te Tari Mātauranga Rata
Whānau me te Hauora
Taiwhenua, Dunedin
School of Medicine,
University of Otago,
Dunedin, New Zealand

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While evidence can help inform best practice, it needs to be placed in context. There may be no evidence available or applicable for a specific patient with his or her own set of conditions, capabilities, beliefs, expectations and social circumstances. There are areas of uncertainty, ethics and aspects of care for which there is no one right answer. General practice is an art as well as a science. Quality of care also lies with the nature of the clinical relationship, with communication and with truly informed decision-making. The **BACK TO BACK** section stimulates debate, with two professionals presenting their opposing views regarding a clinical, ethical or political issue.



Sharon Leitch



Katharine Wallis

BACK TO BACK this issue:

obtain ethical approval (if required), and publish only non-identifiable information. Researchers are also advised to consider data security safeguards to protect health information collected.

The NZ government promotes information sharing and considers information as a resource. 'Non-personal information is a public asset that must be open by default for economic and social benefit.'⁷ It may be a justifiable view that completely anonymised medical records contain only non-personal information.

Widespread patient consultation, including NZ patients,⁸ found high levels of support for the use of medical records for non-commercial research purposes, even when prior consent is not specifically obtained.⁹ Individuals balance their 'natural right to privacy' with a genuine commitment to supporting medical research.¹⁰

However, patient support for research using medical records is not unconditional.⁹ Patients are concerned with the privacy of their health information, and want this information to be anonymised and kept secure, particularly from commercial agencies. Patients are generally unaware of the extent of existing health data sharing, research processes and safeguards. Patient education on those topics increases trust in medical researchers, and increases support for research using anonymised patient records without specific informed consent. Some patients want more control over the use of their medical information, and to actively consent to its use in research.

GPs on the whole are less willing than patients to allow their patients' records to be used for research.^{11,12} GPs have similar concerns to patients about data privacy and potential misuse of data, such as it being sold for commercial purposes. Other GP concerns reported include fears that research will conflict with patient care, that electronic records do not reflect reality, and that their practice computer or software may be damaged. Fear of patient complaints about the use of their records may be a disincentive. No research imperative outweighs the impact of a potential patient complaint on a GP's willingness to participate in future research.

GPs already use medical records in a multitude of ways. GPs use their own non-anonymised records for research, in the form of in-house audits to assess data recording and clinical practice. We transfer patient information with variable levels of anonymity to our PHO and district health board (DHB) to obtain funding, knowing full well that these agencies conduct ongoing research with this information, analysing our patient demographics, prescribing, investigations, treatment, and other elements of medical care. In other countries, practice-based research networks use anonymised electronic medical records for collaborative general practice research. All these uses of medical records arguably improve patient care.

There is an inherent tension in this debate. GPs create medical records ostensibly for patient care. We hold firmly to the idea of protecting our patients' privacy, and yet we actually use their records in various ways, some of which have very little to do with the reason the information was collected in the first place (to evaluate the percentage of smokers offered smoking cessation in one PHO compared to another, for example). I contend that there is very little difference between using patient records for PHO or DHB research compared to using records for a specific research project.

This is not to say that researchers should be given access to anonymised patient records *carte blanche*. Both patients and GPs appropriately oppose the use of patient records for commercial purposes. NZ has the safeguards of the law, professional codes of conduct, and human ethics committees for protecting health information. When these safeguards are upheld, then I believe yes, GPs should allow use of anonymised patient records for non-commercial research.

Educating patients about existing medical data sharing, research processes and safeguards is likely to improve public support for this type of research. Empowering patients to participate in research planning and to have more control over their medical records is a laudable aim. Re-establishing a NZ practice-based research network will greatly facilitate research using anonymised patient records.

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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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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