

CHANGES TO THE HEALTH SYSTEM: WHAT HAPPENS TO PATIENT INFORMATION?



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Amid the political clamour concerning the National Government's changes to the country's health systems, the question of patient information - how it is protected, what access is required, what is permitted, to whom, and so on - has been very much underplayed. The legislation that will make the principal changes to the law on patient information is the recently enacted Privacy Act and associated changes it makes to the Health Act 1956. These measures have attracted bipartisan support, which is perhaps surprising in the climate of contention over other aspects of the government's health policy. Waiting in the wings is the Health Commissioner Bill, introduced to Parliament in 1990. That may yet require a code of health consumers' rights which would undoubtedly be expected to include provisions concerning patient access to patient information.

This article focuses on how the new law controls access to patient information. I conclude that there are doubts whether appropriate or adequate protection is accorded to patients' interests in privacy. Problems arise from the legislative failure to impose a positive obligation in the Health Act to respect confidentiality. There are many opportunities to disclose health information without patient consent. And there are now duties to disclose without patient consent. The extension of the law to the private sector compounds these problems.

The new statute law: a three Act performance

Under the old law, a complex mix of common law and statute provided differing protection for patient information in the public and private sectors. The old statute law will be swept aside. Three Acts are now relevant to privacy issues in the health sector: the Privacy Act 1993, the Health Act 1956 as amended, and the Health and Disability Services Act 1993. The Health and Disability Services Act repeals the Area Health Boards Act 1983 and relevant parts of the Hospitals Act 1957 which gave statutory protections for patient information in the public hospitals. Amendments to the Health Act 1956 will give extra powers for disclosing health information, and will apply across the public and private sectors. The Privacy Act will apply to people in the health sector as much as to any one else.

The confidentiality requirement: the dog that didn't bark

The ethic of patient confidentiality has a very long pedigree. The common law protected it through the equitable doctrine of confidence. Statute has also bolstered it with protections against giving evidence about doctor-patient relationships in court. So it comes as a real surprise to discover the most significant feature of the new statutory provisions in the Health Act is the absence of any central requirement of confidentiality or privacy. ("Confidentiality" and "privacy" are, perhaps loosely, used interchangeably.)

The old confidentiality requirement in the Area Health Boards Act was, it must be acknowledged, heavily qualified by a large number of exceptions which allowed a wide range

of persons access to patient information, often without patient consent. That will still be the case, and now extends to private sector health care providers. Because the statutes now provide more doctors and other health professionals with opportunities, and in some cases duties, to disclose patient information there will be further inroads into the

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rather limited common law protections. And absent a positive obligation to protect patient confidentiality, or even an express balancing process to weigh confidentiality against interests in disclosure, the total picture means even less control for the patient over personal information.

The old statutory recognition of patient confidentiality, while admittedly flabby, is now traded for the legislators' hope that the Privacy Act can fill the gap.

The Privacy Act

This Act will govern agencies' collection and use of "personal information" (information about an identifiable person). An agency is any body, whether a human person or an incorporated or unincorporated body. The Act will not apply where an individual collects or holds information about that person's personal, family or household affairs; or to the legislative or judicial arms of government; or to the news gathering activities of the news media. These very limited exceptions aside, the coverage of the Act is almost universal.

The Information Privacy Principles

The Privacy Act sets out twelve information privacy principles. The principles govern the collection, use and disclosure of personal information. They do not start from a premise that the person whose information is sought has the right to control access to and use of personal information. Instead, in brief, they require that only information necessary for a lawful purpose is collected (Principle 1); that it is collected only from the individual concerned (Principle 2), who is made aware why the information is sought and who is seeking it (Principle 3); that it is not collected by unlawful, unfair or unreasonable means (Principle 4); and that it is securely held (Principle 5). The person whose information has been collected has a right of access to the information, and to have incorrect information corrected (Principles 6 and 7). Agencies holding personal information must take reasonable steps to ensure that the information is accurate, and that they keep the information for no longer than is necessary (Principles 8 and 9). Generally speaking, the agency may use the information only for the purpose for which it was collected (Principle 10). Agencies must not assign unique identifiers to individuals except to enable the agency to carry out its functions efficiently, and must not in any event assign the same identifier that another agency has already assigned (Principle 12).

The principles are subject to a large number of exceptions and qualifications, important among which are those permitting non-compliance where the person has authorised it, or where the information is collected for research or statistical purposes and is to be published in a non-identifying form. The principles apply unless a code of practice (an approved, legally enforceable modification to the principles) is in force.

In the health context, the statutory core protection for confidentiality was in section 50(2) of the Area Health Boards Act which provided that "no person ... shall disclose to any person any information concerning the condition or medical history of a patient ... without the prior consent of the patient or his representative ...". This applied only to public hospitals. Now principle 11 of the information privacy principles is

expected to do the work of section 50(2). It provides that the agency can disclose the information to someone else only to further the purpose for which it was collected, or if the person from whom it was collected authorises disclosure, or for law enforcement purposes, or to reduce a serious and imminent threat to a person's health, or to facilitate the sale of a business. The first two of these grounds parallel exceptions to section 50(2); the last is new, and may allow a potential buyer of a private hospital pre-purchase access to patients' records.

As far as consent is concerned, there are two aspects in which Principle 11 may impose a lower demand of confidentiality than section 50(2) did: First, section 50(2) required patient

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consent prior to disclosure. Principle 11, by contrast, refers to disclosure "authorised by the individual concerned". This consent *might* not need to be obtained before disclosure. "After the event" consent, if any such concept is meaningful, might be satisfactory; Second, section 50(2) required an explicit consent (although not necessarily in writing), whereas Principle 11 permits disclosure if the "agency believes, on reasonable grounds" that the patient has consented. This might constitute a lower standard.

Processes and remedies

Of the principles, only an individual's right of access to information is directly legally enforceable in a court, and then only if a public sector agency holds the information. Otherwise, individuals can complain about interferences with privacy to the Privacy Commissioner, who can investigate, attempt to conciliate an agreed outcome between the parties, through, if necessary, calling them to a compulsory conference, and if this is unsuccessful, bring proceedings before the Complaints Review Tribunal (formerly the Equal Opportunities Tribunal). The Tribunal can give various remedies, including declarations and orders in the nature of mandatory and prohibitory injunctions, and awards of damages.

The amended Health Act 1956

Over and above the disclosures of "personal information" that the Privacy Act will permit, the new Health Act provisions allow, and in some cases require, purchasers or providers to disclose "health information". The Health Act defines this new term to mean information about an identifiable person concerning (i) that person's health, including the person's medical history; (ii) that person's disabilities, past or present; (iii) any health or disability services that the person has received; (iv) any donations that the individual has made of body parts or substances; and (v) in limited circumstances, information derived from testing or otherwise related to donated body parts or substances. "Health information" is probably narrower than the term "personal information" which operates in the Privacy Act.

Disclosure permitted

i) "I have a little list": extra statutory powers allowing disclosure

Agencies holding health information may disclose it to persons performing statutory functions. There is a list, similar in length and diversity to that in section 50 of the Area Health Boards Act 1983, of government officials who are entitled to access. One hopes that the practice, of dubious legality, under the Area Health Boards Act of treating the old discretion as an almost invariable duty to disclose will not continue. These extra disclosure powers now extend to information that private medical practitioners hold, and thus encroach on the doctor's common law obligation of confidentiality to the patient.

The list includes departments which previously had a similar power under the Area Health Boards Act (such as Health, Social Welfare, Justice, Transport, the Police, and Defence), and the powers are generally more focussed on particular officials for particular purposes (for example, not all officials in Justice can obtain patient information now, only prison medical officers acting under the Penal Institutions Act 1954, or probation officers performing duties under the Criminal Justice Act 1985). One curious inclusion in the list permits officials of the Ministry of Agriculture and Fisheries access to a patient's health information when administering the

Meat Act (which gives powers to test whether butchered meat is fit for human consumption).

The Act gives the Police a very wide power to require access to *any* person's health information. They can seek access for the purpose of exercising any of their "powers, functions or duties". This could allow, for example, the Police to claim that they required access to the medical records of a group of suspects to ascertain which best fitted the psychological profile of an offender that the Police had developed. This power seems unjustifiably broad and uncontrolled.

Regional health authorities can also access patient information, but only if it is essential to perform their functions.

When any of the people on this list acquire health information under these powers, there is no express statutory obligation on them in the Health Act to maintain any (residual) confidentiality. However, the Official Information Act 1982 will apply, and could justify withholding the information from further disclosure in order to protect personal privacy, or through having been obtained under statutory powers. However, while protection would be likely, it is not mandatory, and is subject to an overriding public interest in disclosure.

ii) Codes of practice and the information privacy principles

As well, providers or purchasers of health services may generally disclose health information where disclosure is permitted under a code of practice issued under the Privacy Act, or under the information privacy principles of the Act if no code applies.

Legally enforceable codes of practice may impose more or less stringent requirements than the information privacy principles themselves. In the health arena, there may be several codes of practice. Each of these may contain differing requirements concerning disclosure of patient information. There may be differences between the codes, as well as departures from the principles. There is thus a real risk of confusion. In the clinical context, the clinical code of practice will apply, but

if the doctor then seeks to use patient information for research, she will have to turn to a different code. And if confusion arises for the health professionals, it is surely compounded for the patients, in whose interests the legislation and the codes have been written in the first place. No longer will doctors have to hire paperhangers to redecorate their waiting rooms: displaying all applicable codes (including the likely code of patient rights under the Health Commissioner Bill) will take several square metres of wall space.

iii) Non-identifying information

Section 22G of the Health Act allows any person to provide health information to any other person so long as it does not enable the identification of the person to whom the information relates. This provision could be particularly important in research contexts, but to enjoy the comparative

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freedom that this offers the information must be completely delinked from identifying material. To rely on this provision would require, for example, that coded lists to link patient information with research data would have to be destroyed.

Section 22G raises an ethical issue which the legislation does not address. Should consent be required to use non-identifying information? One answer is no: if the information is in non-identifying form, there can be no objection, because no privacy interests are at stake. But, arguably, when consenting to the use of her information for any other purpose, a patient should at least know, if not consent to, its possible subsequent, non-identifying uses.

Disclosure required

i) Ministerial powers

The Minister of Health may require any Regional Health Authority or Crown health enterprise to provide

information, in identifying form, concerning the condition or treatment of, or the services provided to, any individuals. The Minister can exercise this power to obtain statistics, or to advance health knowledge, health education or health research. The Minister can require the information in identifying form only if the individual consents, or if identifying information is "essential" for the purposes for which it is sought. The judgment of essentiality will obviously be for the Minister to make. The Minister may also require any Crown health enterprise to provide information concerning donated blood to the newly established Blood Transfusion Trust.

ii) Transfer of information among health carers

Where a patient receives health services from more than one person, any of those persons providing the health services can require any other to provide health information about the patient. This means, for example, that any doctor attending a patient can require a laboratory performing diagnostic tests to provide information about the patient to a consultant (the doctor, the laboratory, and the consultant are all providing health services to the patient).

However, the information does not have to be disclosed if the holder believes on reasonable grounds that the patient does not want the information to be disclosed. So, in our example, if the doctor knew that the patient did not want her blood test results known by any other person, the doctor does not have to disclose them to the consultant.

The effect of this is twofold, and I suspect that neither effect was envisaged. First, this provision could encourage doctors not to ascertain whether the patient wants the information communicated or not. A doctor who is uncertain whether the patient would want information communicated might adopt a paternalistic approach and not inquire what the patient's wishes were. Rather than placing himself in a difficult ethical position by knowing for certain that the patient does not want others, including those who could provide assistance, to know the blood test results, and thus acting against the

patient's expressed interests by telling the consultant, the doctor could decide that he knows best, both what the patient needs, and how the patient's interests are best served.

Second, the converse is that patients might be able to impose a near veto on the transmission (and possibly the recording) of health information about themselves. This could mean that a patient might insist that information not be recorded on a hospital record, on the assumption that others are likely to see and use the information on that record - this is, in fact, almost certain in the hospital context. The patient's immediate doctor would thus have reasonable grounds under the Act for believing that the patient did not want the information to be disclosed, and might feel obliged to comply with the patient's expressed wishes.

Neither of these consequences fits with currently accepted standards of practice. The section empowers but does not *require* the person holding the information to act in accordance with the patient's desire for confidentiality. It does not, however, give guidance on what interests should outweigh the patient's expressed or inferred wishes when a doctor decides to disclose in these circumstances.

Furthermore, anyone who is refused information under this provision can complain to the Privacy Commissioner. This means that where an osteopath and a general medical practitioner are both treating a patient, and the doctor refuses the osteopath access to the patient's information, the osteopath can seek the intervention of the Privacy Commissioner, in what is surely a novel function for the Commissioner, who is ordinarily limited to investigating complaints made by persons who are in the patient's position. Here the patient whose privacy interests are at stake is not part of the dispute over access to her information.

A person holding information can also refuse a request if they have a lawful excuse for not disclosing the information, or if a code of practice under the Privacy Act authorises refusal. "Lawful excuse" is potentially very broad. An obvious example of lawful excuse would be to refuse a

request from the patient himself on the criteria that the Privacy Act itself contains (such as the unwarranted disclosure of another person's affairs). A doctor's duty of confidentiality to the patient would also constitute a "lawful excuse" for refusing to give the patient's information to a requester.

iii) Patient right of access

Under section 22E of the Health Act, patients now have a right of access to *health* information. Public hospital patients have a legally enforceable right of access, formerly under the Official Information Act 1982 but now under the Privacy Act, to any *personal* information that is held about them. Private patients now have a similar right of access to personal information under the Privacy Act, but this is not legally enforceable in the same way. However, the private patient could exercise their rights to complain to the

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Privacy Commissioner, and possibly through to the Complaints Review Tribunal. But if the patient seeks *health* information, which is more narrowly defined than *personal* information, there is a legal right of access whether the information is held in the public or in the private system. This residual discrepancy between the public and private systems is unfortunate and unnecessary.

iv) Audit functions

Finally, those who contract with the Public Health Commission or a Regional Health Authority to provide services must allow their records to be inspected for what are essentially audit purposes. The inspector can take notes or copies from the records. As with section 22C, there is no further express obligation on the inspectors to observe any residual confidentiality, but withholding would be justified under the Official Information Act.

Criminal sanctions

The Health Act will create a new offence of destroying a medical record. This offence will be punishable by a fine of up to \$2000. A medical record is, however, curiously defined for this section only to mean a document containing health information which needs to be retained in order to provide health services to the person whose record it is. Dead people do not need health services, so it will not be an offence to destroy a dead person's medical record. This section will expire on 30 June 1994, by which time regulations providing procedures for destroying health information are expected to be in place.

It is noteworthy that this is the only offence provision specifically concerning health information that is created by the new legislation. Under the old Area Health Boards Act, wrongful disclosure of patient information (for example, without patient consent) could result in a six month prison sentence or a \$2000 fine. (This provision is currently in the news as a result of Sydenham MP Jim Anderton's disclosures concerning patients in the Canterbury Area Health Board's thoracic unit).

Conclusion

People working in the health sector will have to comply with the Privacy Act or any applicable code of practice. Through amendments to the Health Act 1956, they will have more powers to disclose information than the Privacy Act alone would permit. Sometimes they will also be under a duty to disclose patient information. There is now no core statutory obligation to protect patient confidentiality. Patients do, on the other hand, have greater rights of access to their own health information than before. Previously, they only had a right of access to information held about them in the public hospital system. Now that right extends to information that the private health care provider holds. But patients have fewer legally reinforced assurances that their confidential information will be held confidentially.

(Grant Liddell is co-author of *Freedom of Information in New Zealand*, Oxford University Press, 1992, lxiii, 661 pp)