

# Health information privacy: The patient perspective

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## ABSTRACT

Technological advances permitting the electronic storage and transfer of health information come with the promise of improving the quality of health care. This technology also, however, by making private information so readily accessible and transmissible, poses a threat to the privacy of the information and to the confidentiality of the doctor–patient relationship. Confidentiality is fundamental to maintaining trust in doctors and in the medical profession as a whole. Through research surveys, and through complaints, we know that patients consider privacy and confidentiality important. In our move to embrace electronic health systems in the name of quality, we need to be mindful of this if we are to preserve the trust of the public in the medical profession.

## Keywords

Privacy, confidentiality, complaints

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## Background

A patient's private medical details were once kept inside his or her doctor's head or scrawled (illegibly) onto a card. Today, however, things are very different: doctors commonly work in large group practices and 'share' patients (and their private medical details), and doctors are also encouraged to keep detailed computer records documenting everything that takes place in the 'confidential' relationship between a doctor and a patient. A patient's 'private' medical details are now easily accessible to a wide range of people: any staff mem-

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ber can now peruse a patient's private medical details almost at will.

A patient's private medical details may now also be transmitted, at the click of a button, to Government departments or to anyone else who wants the information and is not prevented by law from having it. Government policy supports the move to electronic health systems in the hope that this will lead to an improvement in the quality of health care and to measurable and improved health outcomes.<sup>1</sup> The demand for access to 'private' health information is increasing; in part to satisfy the demand for accountability, and also for research and audit purposes and for the risk management strategies of private insurance companies.

The accessibility of electronic health information, and the ease with which it may be transmitted, pose a threat to the privacy of the information and to the confidentiality, and trust, which exist between a doctor and a patient. But does this matter?

## The ethical notions of health information privacy and confidentiality

The notion of health information privacy stems from a commitment to

autonomy and concerns the right of an individual to control the information about him or herself that is held by others. The right to privacy is about the right to live a life unobserved, free from surveillance and monitoring. Privacy is not an absolute right; in the health context there are many situations when public interest considerations, or the best interests of the individual concerned, outweigh the individual's right to privacy.

The notion of confidentiality, on the other hand, pertains to a relationship between two people: a doctor receives private information in the course of a confidential relationship and has a duty not to disclose that information without the patient's consent. The duty to maintain confidentiality is necessary for the maintenance of trust and has long been considered an important concept in the practice of medicine – at least since the time of Hippocrates (born about 460 BC).

## The legal protection of health information privacy and confidentiality

While a doctor's ethical duty to maintain confidentiality has been present for over 2000 years, the le-

gal protection of privacy and confidentiality has existed for a somewhat briefer period of time. In New Zealand, the Privacy Act 1993 and the Health Information Privacy Code 1996 (HIPC) is the principle guiding legislation. Patient autonomy is central to the Privacy Act: the patient controls the information and practitioners have a duty of non-disclosure. There are, however, many exceptions to this general duty of non-disclosure and these are set out in the HIPC. To complicate matters, the Privacy Act also provides that if another piece of legislation enables disclosure then such disclosure is not a breach of the privacy principles or of the HIPC rules. The HIPC is thus subject to other statutory provisions requiring information disclosure. The rules vary depending on who has the information, who wants the information, the relationship between the parties, the purposes for which the information was initially obtained, whether the information is about an identifiable individual or is anonymous, and whether the information is held in the public or the private sector.<sup>2</sup> In

addition, a doctor's duty to maintain confidentiality may be broader than the scope of the privacy statutes, to the extent that even if the statutes permit disclosure the doctor who discloses may be in breach of his/her ethical or com-

mon law duty of confidentiality and the Code of Health and Disability Services Consumers' Rights 1996 (H&DSCR).<sup>3</sup>

The complexity of a practitioner's ethical and legal obligations with regard to privacy and confidentiality are well recognised. The Law Commission is currently reviewing the privacy legislation and perhaps one outcome to be hoped for from this review would be a clarification and simplification of the rules.

**Research shows that many people are poorly informed about the type of health information that is collected and how this information is, may, or could be used**

## The patient's perspective on privacy and confidentiality: Research surveys

The patients' perspective on privacy and confidentiality has been studied primarily in vulnerable populations, including mental health patients and adolescents.<sup>4</sup> New Zealand researchers have, however, also surveyed the attitudes and knowledge of adult primary care patients.<sup>5,6</sup> Research shows that many people are poorly informed about the type of health information that is collected and how this information is, may, or could be used.<sup>6</sup> It also shows that many patients are concerned about the divulgence of their personal health information within a clinic, as well as being concerned about divulgence to insurance companies and employers, and that many also misunderstand their legal and ethical right to confidentiality protections. A significant minority of patients also distrust confidentiality protections, leading some to report that they delay or forego medical care.<sup>4</sup>

Not surprisingly, research finds that the type of information, the level of anonymity of the information and

the potential recipient of the information all influence attitudes towards the sharing of health information. Thus patients are more comfortable sharing their information with other health professionals than with re-

searchers and administrators, and are increasingly unwilling to share their information as it takes on a more personal nature.<sup>5</sup> Most people surveyed also claim to prefer to be consulted about the use and sharing of their information.<sup>5</sup>

## The patient's perspective on privacy and confidentiality: Complaints

Unsolicited complaints also offer an insight into the patients' perspective

on the respective values of health information privacy and confidentiality. The way that complaints concerning privacy and confidentiality have been handled over the years has changed. Prior to 1996 complaints were dealt with largely by medical disciplinary bodies. These bodies seem to have placed a very high value on confidentiality and seem to have judged defendants somewhat more harshly than would appear the case today. Perhaps confidentiality between a doctor and a patient is, after all, less important today than it once was.

### 1. Complaints dealt with by medical disciplinary bodies prior to 1996

(i) A man, with an established history of aggressive and abusive behaviour, complained when his GP responded to a police inquiry about the man's suitability to possess a firearm. The Medical Practitioners' Disciplinary Committee (MPDC) found the rural GP guilty of '*conduct unbecoming a practitioner*' for disclosing information to the police without the patient's consent. The GP was neither censured nor fined, however he disagreed with the finding, gave up his practice and eventually left the country (MPDC 1996).

The application form for a NZ firearms licence has subsequently been modified and now reads: 'I consent to the Police making inquiries into my fitness to possess or own a firearm and authorise any person approached by the Police in this matter to release or disclose all relevant information' (italics and underlining as quoted).

(ii) A bus driver complained when his general practitioner informed members of the public and the police that, in his opinion, the man was not fit to drive a passenger bus because of a heart condition, despite having clearance to drive passenger vehicles from a cardiac surgeon. The MPDC found the rural GP guilty of '*professional misconduct*' for breaching patient confidentiality and censured him.

The GP then went to the news media with the story. When the driver made another complaint against the doctor he was again found guilty of '*professional misconduct*' for disclosing confidential information and was struck off the medical register. The doctor then sought, unsuccessfully, to have his case reviewed by the High Court and the Court of Appeal (Duncan v MPDC [1986] 1 NZLR 513).

## 2. Complaints dealt with by the Privacy Commissioner

The Privacy Commissioner was established under the Privacy Act 1993 and assesses complaints to determine whether there has been a breach of the HIPC. Most complaints that come before the Privacy Commissioner are settled through conciliation. In the rare situation where a complaint ends up before the Human Rights Review Tribunal (HRRT) an '*interference with the privacy of an individual*' will only be determined if the breach of the HIPC has materially 'harmed' the complainant (Privacy Act s66).

### Breach of the HIPC determined

(i) A seaman complained when the doctor who stitched his finger released information about whether he was fit to work to his employer.

HIPC Rule 11 requires a doctor to seek consent, unless this is not 'practicable', prior to releasing private health information. As the disclosure did not materially harm the seaman the case was closed (Privacy Commissioner (PC) Case Note 35361 [2003]).

(ii) A woman complained when her cervical smear result was disclosed to the National Cervical Screening Register despite her expressed objection to this being done. This complaint was settled with an apology (PC Case Note: 1553 [1994]).

(iii) A woman complained when a company delivered incontinence pads to her house with a large label on the outside stating the contents of the package (PC Case Note: 87729 [2006]).

(iv) Another woman complained when her mammography films were

sent to her in a large envelope with the clinic logo on it and a red sticker labelling the contents 'X-ray film only' (PC Case Note: 23067 [2003]). These complaints were settled with the companies agreeing to change their practice.

(v) A woman complained when her medical notes were lost between health agencies (PC Case Note: 99263 [2007]).

HIPC Rule 5 stipulates that a health agency must ensure health information is protected, by such security safeguards as it is reasonable in the circumstances to take, against loss or disclosure.

### No breach of the HIPC

(i) A patient complained when his doctor phoned the police and asked them to visit the man after he chose to withdraw from treatment, having earlier expressed suicidal ideas, in favour of keeping a recently purchased gun (PC Case Note: 30372 [2001]).

This disclosure is permitted under HIPC Rule 11(2)(d)(ii) which provides that information may be disclosed to the appropriate body and to the extent that is necessary, if the disclosure '*is necessary to prevent or lessen a serious and imminent threat to public health or public safety or the life or health of the individual concerned.*'

(ii) A man complained when the staff assessing him at a mental health unit approached his doctor for information about him when he refused to cooperate and provide the information himself (PC Case Note: 7454 [1997] NZPrivCmr7).

This disclosure is permitted under HIPC Rule 2(2)(d) which provides that information does not have to be collected directly from the individual concerned if that is 'not reasonably practicable in the circumstances'.

(iii) A man complained that ACC collected information from his son's doctor without the son's consent in relation to a claim for cover (PC Case Note: 15488 [1998]).

This disclosure is permitted as patients, in signing the ACC claim form, give ACC authorisation to collect information about their injury.

(iv) A father complained when a laboratory refused to release his son's blood test results to him, despite having power of attorney, and referred him to his son's GP (PC Case Note 69555 [2006]).

HIPC Rule 11(4)(b)(i) permits the withholding of information when '*the disclosure of the information would be contrary to the interests of the individual.*' The GP is the appropriate person to interpret the result and to determine whether disclosure is appropriate.

## 3. Complaints dealt with by the Health and Disability Commissioner

The Health and Disability Commissioner (HDC) was established under the Health and Disability Commissioner Act 1994 and assesses complaints against health practitioners and determines whether there has been a breach of the Code of H&DSCR.

### Breach of the Code of H&DSCR determined

(i) A woman complained when her surgeon collected data and completed questionnaires without her consent and later published the information (00HDC07593).

H&DSCR Right 6(1)(d) requires notification of any proposed participation in research and Right 7(6)(a) requires informed consent, in writing, prior to collecting research data from a person.

(ii) A woman complained when a radiologist at a public teaching hospital introduced a registrar as a 'colleague' and allowed him to sit in and observe her pelvic ultrasound without asking her permission (00HDC06794).

H&DSCR Right 6(1)(d) requires notification of participation in teaching and Right 7(1) requires prior patient consent.

(iii) A woman complained when, having caught gonorrhoea from her husband, her GP did not tell her that the infection she was being treated for was gonorrhoea and later, when she found out from the nurse that it was gonorrhoea, the GP told the woman that her husband might have caught it from a toilet seat (01HDC03691).

H&DSC Right 4(2) requires services of an appropriate legal, professional and ethical standard, Right 6(1) requires information to be given about the patient's condition and Right 6(3) requires honest and accurate answers to questions.

### Conclusion

These complaints, and the research that has been conducted in this area, tend to indicate that patients do care about their health information and about the confidentiality agreement they have with their doctor. And so while the concept of doctor-patient confidentiality may have slipped somewhat from something approaching an absolute value, it remains nevertheless important. Electronic health systems may provide an opportunity to improve the quality of health care but they also, by making health information so readily accessible and transferable, risk the further erosion of this time honoured concept. While it is important that we take advantage of the opportunities presented by electronic health systems, we should ensure that privacy and confidentiality are not sacrificed along the way. As electronic health systems advance and communication capabilities increase, so too does the need to protect in law the privacy concerns of the individual. The Law Commission is currently reviewing the privacy legislation, and calling for comments. We should also make an effort to improve public awareness of these issues and to involve patients in the debate. Legislation can never provide full protection, and so ethical codes remain important.

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### Competing interests

None declared.

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