

Vital signs of privacy:

Old verities in the new world

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Introduction: old verities in the new world

It is easy enough for our memories of events to collapse upon each other. New memories overlay the old and, in doing so, obscure parts of what were apparent before. It can be useful to peel away these layers and consider the earlier events afresh. Recently, in dealing with a file detailing a man's request for health information, I came across a letter written by an experienced medical practitioner. For obvious reasons I omit parts of the letter:

'Over the past several years Mr X has made multiple requests to have copies of aspects of his...Hospital file. I and my two predecessors have photocopied [various] aspects of notes over these years and sent them to him. Most recently...he claimed to have lost some of these photocopies and asked for others, and I have sent him those as requested.

There are many issues regarding this man's case which are difficult. Some years ago he made complaints to the Medical Disciplinary Commit-

tee about Dr A and Dr B...He appears quite paranoid about certain doctors and about his treatment in this hospital and I am in no doubt that this is part of his disorder. Most recently he has requested...a photocopy of all the notes written by Dr A.

I have been considering this for some time as this is a difficult issue for two reasons:

- 1. Dr A is quite adamant that it would be harmful to Mr X to read the clinical information that he specifically has written.*
- 2. Much of the information that Dr A has written has been obtained from Mr X's family. Under the Official Information Act we need to protect them and are not entitled to give Mr X that information.*

I have also discussed this request with Dr C, Chief Medical Advisor to the Area Health Board, and we both feel that it would be inappropriate for us to forward his full file to you for his perusal.

I hope you understand our concerns...'

The letter was written in 1989. I found it instructive because it underlined to me how persistently people seek their own health information and how enduring the dilemma for the practitioner is. The Privacy Act came into force in July 1993 and the Health Information Privacy Code in 1994. It can be tempting to think that some of these health privacy issues have appeared only in the last 10 years or so. The thoughtful comments from

the practitioner in 1989 show that is not the case.

The Health Information Privacy Code

is designed to function as a practical steer to practitioners working their way through health information related issues. But with or without a code governing the collection, use and disclosure of health information, practitioners would be confronted by difficult requests from patients which would require the practitioner to navigate through the thicket to some sort of conclusion. Requests for information are perennial and raise fundamental questions of knowledge and empowerment.

Similarly, the obligation to protect a patient's health information was not created by the Health Information Privacy Code and is not a new concept for practitioners. Practitioners are already guided by the requirement for confidentiality in the Hippocratic Oath and set out in the new Code of Ethics developed by the New Zealand Medical Association.¹ As its fifth principle, the Code of Ethics directs practitioners to:

'Protect the patient's private information throughout his/her lifetime and following death, unless there are overriding public interest considerations at stake, or a patient's own safety requires a breach of confidentiality.'

Complaints about an interference with privacy do not generally arise in a random way, but are often associated with misunderstandings, either



on the part of the patient or doctor or other medical staff. I do not approach health-privacy complaints with the aim of identifying a culprit and singling him or her out for blame. I am conscious, however, from a range of health-privacy complaints over the years, that there are certain factors which affect or contribute to complaints: patient expectations; patient awareness or knowledge, and patient empowerment.

Patient expectations

Patient expectations in terms of information handling are crucial. Surprise is not a positive thing in a surgery or hospital. For most patients, the medical environment is alien and challenging and the unfamiliarity can lead to concern.

Primary concerns in the patient's mind are likely to be medically-related: *'Why am I feeling like this? What is the cause? How serious is it? What is the treatment?'* But secondary concerns include those which are information-related: *'What is the doctor thinking? Why is the doctor asking me about this? What is he or she writing down? Who else will be able to have access to that information?'*

Although these types of concerns are distinct, it is apparent that both may be alleviated by the practitioner taking an open and clear approach in dealings with the patient. As far as is possible, I urge doctors to try and take a 'no surprises' approach to patient information. Patients don't necessarily know what to expect in terms of how their health information will be handled. It is up to the practitioner to inform them.

Sometimes, the patient will have a particular expectation about what should happen with his or her infor-

mation. Those expectations are not predictable. Do not assume. It can be striking how the views of any two people can vary when it comes to their approach to personal information, and perhaps health information in particular. It is simply not realistic to expect all patients to regard their files with the same eye. Sensitivities vary. Therefore openness about information handling will enable the practitioner to gauge individual reactions and thus avoid complaints.

Awareness/knowledge

A key factor in preventing 'patient surprise' is to keep them in the information loop. I have noticed that some specialists send copies of reports not only to the patient's general practitioner, but also to the patient. This strikes me as a simple but effective way of ensuring the patient is adequately informed of their own health matters. It is also likely to have the effect of minimising the need for the patient to make a request to access information from his or her own file. Some will dictate a report in front of a patient so corrections and additions can be made on the spot.

By contrast, the GP who relies too heavily upon oral communication is increasing the likelihood that they will receive information access requests. GPs are highly educated, skilled communicators who run the risk of providing

too dense an aural parcel for the patient to unpack. The patient may be in the situation of being unable to take in all the information provided to them. Whether through stress or incomprehension, patients do miss

information, and will make access requests to recover it. Pro-active steps by the GP to jot down and hand over brief notes of their diagnosis or advice for the patient might circumvent some of those requests. The patient then has the opportunity of taking the note home and considering it outside the confines of the 15-minute consultation.

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Empowerment

The third factor I believe is relevant to health information complaints is that of patient empowerment. Patients are unlikely to feel their strongest, either physically or emotionally, when dealing with health matters. As we all know, feeling unwell, for whatever reason, does preoccupy the mind and can make the most robust of characters feel vulnerable and weak.

In addition, the patient is generally lacking in information about his or her own health condition. By contrast, whatever other anxieties and stresses the doctor is facing, the doctor is empowered by the medical knowledge he or she possesses. He or she is at work, going through the familiar consulting routine. The patient is one of many. Similarly, the doctor is likely to hold more information about the patient's health, in documentary form, than the patient herself.

The legal right to access your own health information is one key way in which individuals can gain some knowledge of the information that health agencies hold about them. Having that knowledge is a vital way of gaining a degree of control and, consequently, power. Similarly, an individual is empowered by the ability to request a correction to their health information. This is not an absolute right. The Health Code requires at least a statement of correction to be attached to a patient's file upon request. Unless the practitioner

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or health agency agrees to the correction, there is generally no requirement for the information in the file to be changed.

It is not always desirable to provide an individual with unqualified access to his or her own health information. The example I cited previously with the psychiatric patient is a case in point. There are exceptions structured into the Health Information Privacy Code which cover those sorts of situations depending upon the circumstances of the case.

I have received complaints where it is evident the doctor has refused a request from a patient to have access to the information in his or her file, on the basis that the release of the information would cause the patient to be 'hurt' or upset. While understandable, this is not in itself a basis for withholding information. The practitioner must find one of the withholding grounds within the Privacy Act. In many instances, it may be that the practitioner is willing to release some information to the patient, but is hesitant about releasing too much. Not informing the patient of the existence of the information and the grounds for withholding it, even if inadvertently, will infringe the patient's right of access.

Case examples

For example, my office investigated a case in which a woman made a request to her former GP. The GP withheld some information because he was concerned that the woman was becoming increasingly paranoid and may have been developing some significant psychiatric disorder. The GP considered that the references he had made in the notes to a possible paranoid disorder and a discussion with a colleague about the patient would prove 'unhelpful' to the

woman. The GP failed to inform the woman that he held more of her health information and that he planned to withhold it. This was a fact the woman was legally entitled to know.²

In fact, under the Privacy Act, it seems that the GP would have been entitled to refuse to disclose the notes to the woman. Health information may be withheld if, after consultation with the individual's medical practitioner, the agency is satisfied that disclosure of the information would be likely to prejudice the requester's physical or mental health.³ For the GP to be able to rely upon this withholding ground, he should first have informed the woman that he held some health information about her and the reason he was seeking to withhold it. In failing to do so, the woman was not afforded an opportunity to challenge the GP's view that providing her with access to the information may be likely to prejudice her mental health. Access to one's own health information is a legally enforceable right. If a GP wishes to withhold patient information, he or she must turn to sections 27–29 of the Privacy Act and refer to the withholding grounds set out there.⁴

My staff have noticed that, generally, hospitals are better than GPs at providing individuals with access to their own health information. This may be because the GP is practising largely independently, without the added resources and reference points available to hospital staff. Certainly, while I believe the vast majority of hospitals have Privacy Officers, that role falls to the GP if in sole practice or, in other circumstances, the practice manager. My of-

fice has put out the Health Information Privacy Code with an accompanying commentary to assist practitioners. We have also published a practically-oriented guide, *On the Record*, which contains case examples and guidance. I do encourage practitioners to attend one of the regular Health Code training seminars run by staff from my office.

A number of complaints to my office are generated through unintentional lapses on the part of a staff member. Some arise from incidents where, for instance, patient files are left on a reception desk or in a publicly accessible area. In other instances, a staff member discloses information orally.

My office recently settled a complaint from an HIV positive man who complained about the conduct of a hospital phlebotomist. The man regularly attended an outpatients' clinic to have blood tests taken. On this occasion, he was taken into an open cubicle beside the busy waiting room. Upon discovering that he needed an HIV test, a new phlebotomist called out of the room to another staff member: 'I can't do HIV tests'. The man then had to return to a seat in the waiting room until the other staff member was free. While waiting for his test, the man observed the same exchange occur again with another patient. The hospital provided the man with an apology, an assurance, and an ex gratia payment of \$2 000. The hospital also arranged for an external speaker to meet with phlebotomy staff to reinforce the need for sensitivity by staff when dealing with people who are HIV positive.

Mental health policies

The greatest proportion of cases involving GPs relate to situations where a patient has requested access to their file and been refused. Disclosure of health information to a

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third party is another area attracting significant numbers of complaints to my office. In one instance, a man complained to me about a disclosure a doctor had made about him to Police.⁵ The man had been attending hospital clinic for a number of years. He had a complex medical history and had recently expressed suicidal thoughts.

On this particular day, the man failed to turn up to a clinic appointment and left a message explaining that he had been delayed because he had been purchasing a gun. The doctor rang the man and told him that he would only be able to continue to receive treatment at the clinic if he got rid of the gun. The man decided to withdraw from treatment and keep the gun.

The doctor consulted several colleagues involved in the man's care and treatment. All agreed that, in the circumstances, it was appropriate for the doctor to contact the police. The doctor rang the police the same day and asked them to visit the man.

After investigating the man's complaint, I formed the opinion that the doctor was justified in disclosing information about the man to the police because it was necessary to prevent or lessen a serious and imminent threat to the life or health of an individual. There were several factors which were persuasive:

- The doctor knew of the patient's history and had reasonable grounds to believe that the man posed a threat to himself or his immediate family;
- The doctor also had reasonable grounds for believing that disclosing information was necessary to prevent or lessen the threat;
- The doctor disclosed to an agency that was appropriate in

the particular circumstances, the police;

- The doctor disclosed only the information necessary when notifying the police (the man's contact details, a brief overview of recent events and an indication of the man's medical condition).

Cases involving patients with suspected or actual mental health concerns present particular issues and demand careful thought when it comes to privacy. These issues were brought to the attention of the wider public by the deaths of Malcolm Beggs and Lachlan Jones. The Mental Health Commission carried out a review of the way District Health Boards have implemented the Health Information Privacy Code.⁶ The review findings include that DHB staff:⁷ *'...need more training and education to fully understand the requirements of the privacy legislation, other relevant legislation, and the code. They need to have access to specialist advice for more complex situations.*

They need to be supported by clear, comprehensive and user-friendly policies. There needs to be more consistency in the policies and more support provided to services in developing them. The policies need to be specific to mental health services.'

The Ministry of Health is in the process of developing appropriate guidelines with DHBs. The Privacy Act and Health Code require only that agencies devise a reasonable policy, alert people to the policy and then play by those rules. Neither the Code nor the Act prescribes the content of the policy. I see the Health Code functioning as a skeletal guide. It is up to the medical community to flesh out the form by generating appropriate practices and policies. I am sometimes asked to provide specific

rules for practitioners and other health agencies. It would not be appropriate for me to do this. It is something which must be addressed by those familiar with the needs of mental health patients and their families. Even if it were feasible for me to formulate such a policy, I am certain that the medical profession would not unanimously support it.

New technologies: telemedicine

Issues of privacy do, of course, arise in any medium. One of the areas in which my office has been engaged of late is the emerging field of telemedicine. Blair Stewart of my office recently prepared a paper specifically looking at one aspect of telemedicine: web-based health services.⁸ The paper identifies three modes in which health services are delivered over the web:

- Discussion groups, bulletin boards and mailing list;
- The provision of health services from doctor to patient (e-doctor); and
- Using the web as a repository of medical records.

The paper focuses upon the provision of health-based services from doctor to patient. It concludes that the sensitivity of personal medical data means that there must be rigorous adherence to data protection and privacy laws by web-based telemedicine providers. Where such laws do not apply, principles of fair information practice should be followed and all collection, use and disclosure of data should be with the informed consent of the patient. The paper goes on to make the following recommendations:

1. Web-based telemedicine sites must make their information policies clear to users. Part of this will involve posting a clear and explicit privacy policy. Particular attention should be paid to informing patients about aspects of telemedicine practice which may depart from a standard consultation.

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2. Web-based telemedicine sites should not normally collect personal data from users through devices such as 'cookies', unless the patient is aware and consents to that.
3. Medical data should not be used for commercial purposes.
4. Traditional ethical obligations upon doctors and health care professionals must not be diminished by providing services over the Internet.
5. Web-based telemedicine sites should comply with applicable guidelines on consumer protection and professional standards, to ensure that any personal data collected, obtained, used or disclosed is fairly processed.
6. Strong security measures should be taken to protect any stored medical data on a telemedicine site (or data in transit).
7. Professional associations representing doctors and other health professionals should adopt appropriate guidelines for telemedicine.

Human tissue: an information issue

Commonalities in information issues from human tissue collections

I believe there is a degree of commonality in terms of the information issues that arise from human tissue collections of various types and ca-

daveric donations. There are, of course, numerous ethical and clinical conundrums in human tissue collections. These fall outside my purview. I do not intend my comments here to be interpreted as relating to these other areas.

I expect that there are medical or clinical issues related to the procedures themselves. There are certainly various ethical questions that flow from those procedures. There are also legal constraints upon the circumstances in which the collections may be carried out; the requirements for familial involvement; informed consent and so on. I should point out that the legal requirements vary depending upon the type of tissue collection involved, but that is another line of discussion in itself.

There are several varieties of human tissue collections that I am aware of:

- The national cervical screening programme, including later use of the information in epidemiological research;
- The Guthrie 'heel prick' tests;
- DNA tests where there is compulsory collection; and
- Cadaveric organ donations and any subsequent use in research, e.g. brains, eyes, hearts etc.

All of these are distinct and unrelated collections. Despite that fact, there are a various elements which can be identified that crop up across the collections. These elements have some significance when considering how best to handle the *health information* that is involved.

The distinction with which I am concerned is a legal one. It is the distinction between the law governing the actual collection and use of human *tissue*, and the law governing the *health information* connected to those organs or tissue samples. This distinction tends to be overlooked. The law relating to the removal of the body part or tissue is set down by the Human Tissue Act 1964. However, that Act is silent about the transfer of the health information that relates to the organ or tissue sample. On that point, it is necessary to refer to the Health Information Privacy Code.⁹ It is not enough for the practitioner to follow

correct legal procedures in terms of the tissue, but to omit to observe the legal requirements and good practice in terms of the accompanying health information.

If health information is being collected, the individual should be told. They should also be told what the information will be used for and who else will have access to it. If a practi-

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Table 1. Human tissue collection and health information

	DNA tests (compulsory collections)	Guthrie tests	Cervical screening	Cadaveric donations (eyes, brains, hearts) including organs for research
Patient gives authority for collection		parental	■	sometimes
Possible duress or obligation	■			■
Information shared between agencies	■	■	■	■

tioner or health agency wishes to disclose health information to another agency, they must find a way in which that disclosure can be made in accordance with the exceptions to rule 11 in the Health Code. The first and undoubtedly the best exception is where disclosure is one of purposes for having the information. Agencies that wish to rely on that exception must ensure they inform patients, either directly or through appropriate documentation, of the uses to which their information will be put. I stress that 'openness' and 'clear purpose' together form the information rudder which will steer practitioners away from privacy blunders.

Information privacy and informed consent: complementary practices

I have not included the concept of informed consent in the table. That is because informed consent relates to the clinical procedure, rather than

the accompanying health information. I assume that all tissue collections would require informed consent. In the case of cadaveric donations, for instance, the fact that the person concerned, or his or her personal representative, has given informed consent for an organ to be removed, does not determine the sharing of that health information under the Health Information Privacy Code.

Informed consent does have some relevance to information privacy practices however. Establishing consistent and transparent information handling practices will serve to bolster and complement the steps practitioners follow in gaining informed consent. In each process, a key aim is to ensure that the individual patient has been adequately informed.

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Many of you will have heard of the post-mortems that were carried out on children at Alder Hey Children's Hospital in Liverpool between 1988 and 1995.¹⁰ In the course of post-mortems, organs were removed from children and retained by the hospital without the parents being made aware of that fact. There is little doubt that this was done (at least in the majority of cases) without the informed consent of parents. Although Alder Hey Hospital stands out as a salutary example, it is not an isolated case. Similar issues came to the fore in New Zealand last year in relation to the retention of hearts at Greenlane hospital.

The lack of parental informed consent was one key lapse at Alder Hay. Behind the lack of consent at Alder

Hey, however, was another failing. The records that had been kept were so inadequate, parents were unable to be certain what had occurred to their child or the destination of the child's organs. The shock of being told of the events that happened without their knowledge or consent was undoubtedly aggravated by the unreliable and incomplete information the hospital held.

The Alder Hey case is a graphic example of the way in which good clinical practices and good information practices inter-relate. I am hopeful that practitioners, researchers and administrators will become better at recognising not only the significance of informed consent for families and patients, but the importance of careful and open handling of health information.

Genetic issues

The increasing use of genetic testing and diagnosis has led to an awareness and examination of the privacy issues that arise from the testing. In New Zealand, the issue is being considered by the Independent Biotechnology Advisory Council.¹¹

From a privacy perspective, one of the key issues raised by the Advisory Council is that of the balance that

must be struck between the right of an individual to know of a genetic predisposition and the right of relatives not to know. Conversely, there is a balance to be struck between an individual's right *not to know* of a genetic link or predisposition that might exist, and the competing right of a relative to find out. The added influence of information technology has made the situation something of a crossroads, according to one legal commentator:¹² *'Developments in genetic science allow the creation of different*

kinds of highly sensitive personal data, while information technology encourages the transmission and sharing of personal data on a national and global basis. The critical issue is how the legal order should structure the application of personal genetic data by government and private enterprise alike.'

The approach taken in the United Kingdom by the Human Genetics Commission is that there should be a law change to prohibit the taking of genetic material except for authorised medical or investigative purposes.¹³

The issue is currently being considered in Australia by the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC).¹⁴ The inquiry aims to find *'a sensible path between the beneficial uses of genetic information, and*

*protecting people's privacy, rights and interests.'*¹⁵ The Commission came up with 105 proposals, including a suggested change to Australia's privacy laws:¹⁶ *'Privacy laws should be revised to cover genetic samples as well as genetic information, and au-*

thorisation should be given to health professionals to disclose otherwise confidential personal genetic information to a genetic relative, where failure to disclose would place at serious risk the health or life of that relative.'

Australia, like New Zealand, has a Human Tissue Act and separate privacy laws. The proposal to extend the Privacy Act to cover genetic samples as well as genetic information would have the result of avoiding the fine distinctions that I discussed earlier between 'health information' and 'tissue samples'.

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References

1. See <http://www.nzma.org.nz>
2. Privacy Act 1993, section 40(1)(b) and section 44.
3. Privacy Act 1993, section 29(1)(c).
4. Practitioners should also refer to the Health Act 1956, particularly sections 22C, 22D, 22F, 22G and 22H.
5. Privacy Commissioner case note 30372, June 2001.
6. Mental Health Commission. Review of the Implementation of the Privacy Act 1993 and the Health Information Privacy Code 1994 by District Health Boards' Mental Health Services (Wellington, February 2002). The report is available at <http://www.mhc.govt.nz>
7. *ibid*, p 8.
8. Stewart B. Web-Based Telemedicine Working Paper. Paper presented to the 31st Meeting of the International Working Group on Data Protection in Telecommunications, Auckland, 26/27 March 2002.
9. If there were to be any direct conflict between the Human Tissues Act and the Health Code, the provisions of the Human Tissue Act should prevail.
10. The Economist. The return of the bodysnatchers. February 3, 2001.
11. Independent Biotechnology Advisory Council, Genetic Testing: Some issues to consider (Wellington, June 2002).
12. Schwartz PM. European data protection law and medical privacy' in genetic secrets: Protecting privacy and confidentiality in the genetic era (Mark A. Rothstein ed). New Haven: Yale University Press; 1997. p 392-417, 392.
13. NewsQuest. British Commission recommends tightening genetic privacy rules. 21 May 2002.
14. ALRC Discussion Paper 66, Protection of human genetic information (DP 66). The report is available on the Australian Law Reform Commission website: <http://www.alrc.gov.au>.
15. <http://www.alrc.gov.au/media/2002/mr0828a.htm>
16. <http://www.alrc.gov.au/media/2002/mr0828a.htm>