

Disclosure of genetic information to at-risk relatives: privacy law and professional guidance in New Zealand

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The practice of medicine is increasingly informed by advances in knowledge arising from the sequencing of the human genome, with implications for new strategies being developed for the diagnosis, prevention and treatment of diseases. It has been observed that almost 2000 different genetic conditions have been determined.¹ The familial and predictive nature of genetic information is relevant not just for a patient or health consumer, but also to family members in terms of consequences for their personal health or family planning. Family members who receive relevant genetic information may be able to use the information to avoid harm or obtain benefit from testing, diagnosis and care for themselves. Hence, a patient's genetic information raises challenging issues about whether the information can or should be disclosed to genetic relatives.

Patients may refuse their genetic information being disclosed to at-risk relatives or they may express the wish for the information to be passed on to them. As observed by Gallo, the reasons given for not disclosing genetic information to family members include: a lack of closeness; a desire to protect family members from troubling information; a perception that the relative has a lower risk of passing on the disorder because she or he is unmarried or childless or plans to have no additional children; test results that were uninformative or negative for specific mutations; a relative's youth or immaturity; family

disagreements; assumptions that information had been imparted by other family members; an antiabortion stance; a lack of 'openness' regarding cancer; and happenstance (it 'never came up'). Nondisclosure decisions may also be influenced by guilt or anxiety.² On the other hand, the most common reasons cited for disclosure within a family include: a perceived need or obligation to disclose; the fear that the relative carries a reproductive risk; a close social relationship with the relative; the need for support; a feeling of responsibility toward the younger generation; and a perceived need to retrieve information about familial risk.² In the context of those at risk for, or diagnosed with, hereditary breast and ovarian cancer, reasons cited for disclosure include their desires to encourage genetic testing, to obtain advice about medical decisions, to provide information about risk and possible discrimination, and to be open about the cancer diagnosis.

Selected developments overseas

The shared nature of genetic information, and respect for the privacy of persons and confidentiality of their personal information, are recognised in key international instruments, for example by UNESCO. The Universal Declaration on Human Genome and Human Rights (1997) states that the human genome underlies the fundamental unity of all members of the human family and that it is symbolically the heritage of humanity. In the In-

The **ETHICS** column explores issues around practising ethically in primary health care and aims to encourage thoughtfulness about ethical dilemmas that we may face.

THIS ISSUE: Richard Wee, former chairperson and legal member of NZ's Multi-Region Ethics Committee, discusses issues around patients sharing their genetic information with at-risk relatives so that they may benefit or avoid potential harm.

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ternational Declaration on Human Genetic Data (2000), genetic information is stated as having special status because it is predictive, familial, and has significance that is cultural and is not necessarily known at the time when samples are collected. Respect for the privacy of persons and the confidentiality of their personal information is recognised in the Universal Declaration on Bioethics and Human Rights (2006) which states that such information should not be used or disclosed for purposes other than those for which it was collected or consent had been given.

At common law, there are exceptions to the duty of a health professional in maintaining patient confidentiality. In the well-known US case of *Tarasoff v. Regents of University of California*,³ the patient killed Tatiana Tarasoff after confiding to his psychologist of his intention to do so. The court held that where the patient presents a serious danger of violence to another, the therapist incurs an obligation to use reasonable care to protect the intended victim against such danger by taking steps that are reasonably necessary under the circumstances.

With disclosures of genetic risks to at-risk genetic relatives, case law is still developing and is not uniform. Two US cases involving issues about disclosures to at-risk relatives regarding hereditary risk for cancer are usually cited: *Pate v. Threlkel*,⁴ and *Safer v. Pack*.⁵ In both cases, the courts held there was a “duty to warn”, but took differing positions as to how the physician’s duty to warn can be satisfied. In *Pate*, the Florida state supreme court held the duty to warn is discharged by informing the patient about potential risks to genetic relatives, with the expectation that the patient pass on the warning to family members. However, in the subsequent case of *Safer*, a lower court in New Jersey held the doctor has a duty to convey the warning directly to genetic relatives. In addition to those cases, the Supreme Court of Minnesota, in *Molloy v. Meier*,⁶ has held that a physician’s duty regarding genetic testing and diagnosis extended beyond the patient, who was a minor with fragile X syndrome, to biological parents who foreseeably may be harmed by a breach of that duty.

In Australia, the Law Reform Commission in 2003 recommended that their Privacy Act

should be amended “to permit a health professional to disclose genetic information about his or her patient to a genetic relative of that patient where the disclosure is necessary to lessen or prevent a serious threat to an individual’s life, health or safety, even where the threat is not imminent”.⁷ This recommendation was put into effect in 2006,⁸ with amendments passed to make it discretionary, not obligatory, for health professionals to disclose genetic information to “genetic relatives”. A genetic relative has been defined as “an individual who is related to the first individual by blood including, but not limited to, a sibling, a parent or a descendant of the first individual”.⁹ The amendments provided for the National Health and Medical Research Council to develop guidelines to address circumstances where disclosure to genetic relatives is ethically justified or required, and the need for patients to be counselled about the disclosure of information. The guidelines, contained in a 64-page document, were approved by the Privacy Commissioner and came into effect from 15 December 2009.

New Zealand legal developments

Health professionals in New Zealand can disclose a patient’s genetic information to family members at any time so long as the patient gives consent for that to happen. If the patient does not consent, the law does enable health professionals to make disclosures in limited circumstances, but that would require some preparation beforehand.

In April 2007, the Privacy Commissioner consulted on an amendment that would explicitly provide for health professionals to disclose, in some limited circumstances, genetic information to genetic relatives when that is necessary to prevent or lessen serious threat to their life or health. The consultation took place after Australia had made changes to their Privacy Act. The proposed New Zealand amendment would have provided a new exception to the rule in the Health Information Privacy Code (HIPC) that generally prohibits disclosure of a patient’s health information.

After considering the matter, the Privacy Commissioner decided against proceeding with the proposal. The Privacy Commissioner was of the

opinion that disclosure to at-risk relatives can be made under the existing rule in the HIPC which allows health information to be disclosed if disclosure is one of the purposes for which the information was collected in the first place. This means the patient would have to be informed *before* testing is conducted that under certain circumstances, for example where testing might reveal a serious and treatable genetic condition that may affect a relative, the health professional may pass on the test results to relevant family members if the patient declines to do so. Hence, health professionals will have to be prepared and think ahead so as to discuss with the patient, prior to testing, the possibility that disclosure of the patient's genetic information could potentially be made directly to at-risk relatives. In practice, the issues would be appropriate to raise during informed consent discussions or pre-test counselling.

The general standards and guidelines from the Medical Council of New Zealand can provide guidance about good professional practice. The Council, in *Good Medical Practice: A Guide for Doctors* (2008), states that doctors are to treat all information about patients as confidential and to be prepared to justify their decision if, in exceptional circumstances, they pass on information without patients' consent or against their wishes. In the Council's document *Confidentiality and Public Safety* (revised and reissued, 2002), relevant statements provide helpful guidance that could be applicable in the context of disclosure of genetic information to at-risk relatives. While noting in the context of statutory disclosures under sections 22C–22H of the Health Act 1956 that they are permissive, the Council suggests also that ethical considerations may make it undesirable or improper for disclosure to be made. The Council advises that careful judgment is required when deciding whether to gain consent or inform patients about intended disclosures. The Council states it would be wise to give patients the option of making disclosures on their own account, that any intended disclosures should be discussed with patients, and only the minimum of information should be released to secure the desired result. The Council notes that a clear record of the doctor's reasons should be made and discussion with colleagues is not

essential but would demonstrate that the decision had been made thoughtfully.

Conclusion

Health professionals can disclose the patient's genetic information to family members at any time so long as consent is obtained from the patient for that to happen. As part of good professional practice, health professionals should communicate with the patient about the importance of the patient sharing genetic information with at-risk relatives so that they may benefit or avoid potential harm. Support should be given to the patient regarding how, when and what disclosure should be made to whom. If the patient does not consent, the law in New Zealand allows health professionals to make disclosures in limited circumstances. Under the Health Information Privacy Code (HIPC), health professionals have discretion, but not a duty, to make direct disclosures to at-risk relatives so long as they communicate with the patient, prior to testing, about the risks that test results may reveal for genetic relatives and the possibility of sharing important information with relatives for their benefit. Ethical considerations should be taken into account when health professionals decide whether or not to make disclosures. It is a matter of medical judgment for health professionals to make disclosures directly to at-risk relatives and, if that is intended in the circumstances where the patient declines to consent, it would be a matter of good practice for the health professional to first communicate his or her intention to do so to the patient. Health professionals should be aware that the law, ethics and practice are evolving in this area.

References

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3. 17 Cal. 3d 425, 551 P.2d 334, 131 Cal. Rptr. 14 (Cal. 1976)
4. 661 So2d 278 (Fla 1995)
5. 677 A2d 1188 (NJ Super Ct App Div 1996)
6. 679 N.W.2d 711, 719 (2004)
7. ALRC, *Essentially Yours*, Recommendation 21–1
8. To effect this, amendments were made to the Privacy Act 1988 (Cth).
9. s.95AA of the Privacy Act 1988 (Cth).