

## A Patients' Rights Approach: The New Zealand Perspective

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Being a small country but having a mature democracy, New Zealand has been playing a leading role in the global development of human rights, in particular women's and patients' rights. If the case occurred in NZ, the Code of Health and Disability Services Consumers' Rights 1996 (Code of Patients' Rights) and the Health Information Privacy Code 1994 (Privacy Code) would constitute the key legislation on how related medical information should be handled. As manifested in the Code of Ethics of the NZ Medical Association, the approach in these Codes to patients' rights and their health information has also become the professional norm for healthcare providers.

### 1. Testing the Patient for HIV

The facts suggest that the patient was not aware that his blood sample would be tested for HIV. This would be a breach of New Zealand's Code of Patients' Rights, a regulation issued in 1996 under the Health and Disability Commissioner Act 1994. It gives consumers (patients) rights and imposes on healthcare providers the corresponding duties. Right 7 of that Code stipulates that services may be provided to a patient only if the patient has made an informed choice and given informed consent. Right 6 requires doctors to give their patients the information that a reasonable patient in that patient's circumstance would need

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to make an informed choice about services. So, in New Zealand the patient should not have been tested for HIV without his consent. If he was incompetent to consent and there was nobody legally authorised to give consent on his behalf, then Right 7(4) permits the doctor to do the test if it was in the patient's best interests and the doctor believed that performing the test accorded with the patient's views or the views of other suitable persons interested in his welfare, such as his wife. The other justification for performing the test without the patient's consent is if it was an emergency and the test was necessary to preserve his life. It is not clear from the facts that the doctrine of necessity could legitimately be invoked in this case.

## **2. Disclosing the Result to the Patient**

Right 6 of the Code of Patients' Rights imposes a duty on doctors to give the results of tests performed on the patient. Rule 6 of the Privacy Code, issued in 1994 by New Zealand's Privacy Commissioner under the Privacy Act 1993, gives patients the right to access their health information, subject to limited exceptions that would be most unlikely to apply in this case.

## **3. Disclosing the Result to the Patient's Wife**

Disclosure of a patient's health information is governed by the common law rules on confidentiality and the Privacy Code. Under both rules the patient's HIV status may be disclosed to his wife with his consent. In the absence of his consent, there may be a discretion to disclose the information to his wife, but there is no legal duty to do so. Even though it is a life-threatening infectious disease, HIV is not a notifiable disease in New Zealand. Only AIDS is a notifiable disease under the Health Act 1956. Because of the association of this disease with homosexuality and concerns about discrimination, information about a person's HIV status is seen as being particularly sensitive (Privacy Code, commentary on Rule 4 on pp. 28–9). Nonetheless, Rule 11(2) of the Privacy Code would permit disclosure without the patient's consent if it was not desirable or practicable to obtain his consent and the disclosure is necessary to prevent or lessen a serious threat to the life or health of another individual. While it would be good medical practice to encourage the patient to disclose his HIV status to his wife, the exception in Rule 11(2) would appear to apply in this case. The patient is in the intensive care unit on a ventilator and may not be in a position to inform his wife. Even if he is able to do so, the potential risk of harm to her may justify disclosing her husband's HIV status

to her so that she can receive potentially life-saving treatment and prevent passing it on to others, such as a future partner.

The duty of confidentiality is not absolute either. It is subject to a public interest defence, which might well be met in this case. HIV is an infectious disease and disclosing the patient's status to his wife could protect her and others from this life-threatening disease.

Timing of the disclosure to his wife will depend on the circumstances and, in particular, whether she might have contracted the disease. If there is a risk that she may also be HIV positive, then early disclosure might be important if she is to receive the best chance of effective treatment.

#### **4. Breach of the Codes**

In the event of a breach of either the Code of Patients' Rights or the Privacy Code, a complaint can be made to the Health and Disability Commissioner for a breach of the Code of Patient Rights or to the Privacy Commissioner for a breach of privacy. These Commissioners have the power to investigate complaints and refer any breaches to a Director of Proceedings who may issue proceedings before the Human Rights Review Tribunal. The Tribunal may award damages if it finds that there was a breach. Complaints may also be made to the Medical Council. Complaints are thus handled at the expense of the state rather than the patient.

#### **5. The Historical Socio-Cultural Context**

While the present NZ norm focuses upon patients' rights such as those to privacy and truth-telling, this is a relatively new phenomenon, having a history of three or so decades only. As in other western countries, historically speaking, the standard way was for medical professionals *not* to tell the truth to patients about their terminal medical conditions. Even in the late 1980s, some leading medical professionals in NZ still argued that it was neither ethically sound nor practically feasible for physicians to adequately inform their patients and thus actively engage with them in medical decision-making.

In spite of the country's small size, NZ is a very multicultural society. It has been acknowledged that in honouring the aforementioned patients' rights, medical professionals may conflict with the cultural values and practices of Maori people (the first nationals in NZ), Asian and other ethnic groups who reportedly prefer non-disclosure of terminal illness and emphasize joint decision-making through the direct involvement of family members. The first of ten rights in

the Code of Patients' Rights—the right to be treated with respect—stipulates the right to privacy [1(2)] on the one hand and “the right to be provided with services that take into account the needs, values and beliefs of different cultural, religious, social and ethnic groups, including the needs, values and beliefs of Maori” [1(3)] on the other. But the Code has not specified what should be done if these two are in conflict, which can be a contentious issue.