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Dear Colleagues,

In relation to the teleconference on the 95AA guidelines. On reading the guidelines, I was concerned at the lack of content in the guidelines, especially guidelines one, two and six. It seemed to me that with minor modification, they could include the needed content.

The reference to "ethical considerations" in guidelines one seemed to me to be vacuous and needed detail.

The lack of reference to representatives in guideline two is an obvious lack.

The lack of reference to the actual conditions of serious threat, necessity and effectiveness in guideline six meant that it failed to communicate the central content.

This I would suggest revising the guidelines thus:

For the purposes of National Privacy Principle 2.1(ea):

Guideline 1 The decision to use and disclose genetic information without consent must take into account the duty of confidentiality to the patient and be based on the overriding obligation to the wider family, and be sensitive to the individual cultural issues, the requirements of effective communication, the setting and family situation, the difference between diagnostic and predictive testing, and the risks and benefits of disclosure and non-disclosure. (pp 8–13)

Guideline 2 Reasonable steps must be taken to obtain the patient's consent or that of his representative to use and disclose genetic information before resorting to disclosure without consent.

(pp 14–17)

Guideline 3 The authorising medical practitioner should have a significant role in the care of the patient and sufficient knowledge of the patient's condition and its genetic basis to take responsibility for decision-making about use and disclosure.

(p 17)

Guideline 4 Decision-making concerning use and disclosure without consent must involve medical practitioners with appropriate expertise to assess the specific situation.

(pp 17–18)

Guideline 5 Where practicable, the identity of the patient should not be apparent or readily ascertainable in the course of inter-professional discussions.

(pp 17–18)

Guideline 6 Decision-making about use and disclosure without consent must take into consideration the nature of the threat to genetic relatives, the potential for the threat to be lessened or prevented, and whether disclosure is required to achieve this outcome. The nature of the threat must be serious and the disclosure must be necessary and it must be effective in lessening the risk.

(pp 18–22)

Guideline 7 Genetic information disclosed to genetic relatives should be limited to that which is necessary for communicating the increased risk and should avoid identifying the patient.

(p 22)

Guideline 8 Disclosure of genetic information without consent should generally be limited to relatives no further removed than third-degree relatives.

(p 22)

Guideline 9 All stages of the process must be fully documented, including how the decision to use or disclose without consent was made.

(p 23)

Nicholas

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