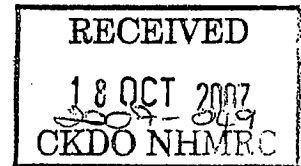




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Dear Clive

Thank you for the opportunity to comment on the targeted NHMRC consultation document: *"Disclosure of genetic information to a patient's genetic relatives - Guidelines for health practitioners in the private sector"*. After reviewing this document, which for convenience shall be referred to as the "Disclosure Guidelines" WA Health would like to submit the following comments for consideration:

- **DEFINITIONS AND SCOPE OF THE DISCLOSURE GUIDELINES.**
- Throughout the document, there are references to "seeking advice of *health professionals* or *health practitioners*". While it is recognised by informed readers that the 'professionals' in question will be, for the most, geneticists, genetic counsellors and general practitioners, who as professionals are fully cognisant of their duties and obligations - for clarity it would be useful to define "health professionals" and "health practitioners" in this context. It may also be appropriate that these professionals are specifically referred to in the "Summary of Legal Obligations and Best Practice" Furthermore, the Disclosure Guidelines also frequently refer to seeking advice from "colleagues" of the disclosing health care professional. Again for clarity it would also be useful to define this term.
- The Scope of the Disclosure Guidelines (p9) indicates the document "does not include the use of genetic information in human research (this is discussed in Chapter 3.5 of the *National Statement on Human Research*)". However, the NH&MRC *National Statement on Ethical Conduct in Human Research* indicates in Section 3.5.2b that "(w)hen participants or their relatives are to be given or notified of genetic information... ..advice and counselling should be provided by *professionals with appropriate training, qualifications and experience*". From this it appears the

'National Statement' is referring to the same health professionals these guidelines are designed for and effectively the two documents are linked. It would be helpful if there was clarification of the link between these two documents and how the practice of disclosing genetic information obtained through research should occur. As mentioned above, it would be useful if the term 'professionals' in the 'National Statement' was defined in alignment with the definition for 'health professionals' in these guidelines.

- Chapter 2.3.1 in the Disclosure Guidelines outlines the ethical considerations underpinning the practice of sharing genetic information.
- The basis for this ethical discussion is derived primarily from the four principles; autonomy - respect for an individual to make his or her own decisions; non-maleficence - to do no harm; beneficence - to do good and justice.

While these four principles have traditionally been applied to the ethical interpretation of health care issues, the view that genetic information should be considered as *shared information* within a family or ethnic group is gaining acceptance. The paper "*Communication of Genetic Information within Families: The Case for Familial Comity*"[1], where "comity" is considerate behaviour towards others, develops the concept that "information gained through genetic testing should be seen to belong to a family rather than an individual alone".

The inclusion of this ethical viewpoint, derived from the principles of *justice* and *reciprocity*, may provide health professionals with a more substantial ethical argument for the disclosure of genetic information without patient consent.

The Davey et al paper identifies that both patient autonomy and confidentiality issues are ethical concepts prioritised by genetic counsellors and clinicians. An ethical argument that provides some balance to this professional dilemma may be of benefit.

The application of "familial comity" as a concept supports the development of these guidelines and the proposed framework for disclosure of genetic information without patient consent.

- Recent studies reported a reticence of health care professionals to breach a duty to patient confidentiality[1]. The inclusion of a specific checklist in the Disclosure Guidelines, in addition to the flowchart "Framework for legal and ethical disclosure of genetic information to genetic relatives when patient consent is withheld" may provide a more objective basis for identifying when the step of contacting genetic relatives without patient consent may be appropriate for health care professionals.

Chapter 3.3.1 of the Disclosure Guidelines discusses how disclosure should take place.

- "Written contact has the advantage of giving the recipient time to consider whether to seek further information, and in this sense can be perceived as non-coercive." This approach is supported by the findings of Molster *et al* which showed 76% of

respondents to a telephone survey did not consider the receipt of a letter requesting participation in research to be an invasion of privacy [2].

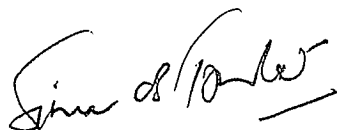
▪ **GENERAL COMMENTS RELATING TO LEGISLATIVE CONSIDERATIONS**

The following comments are confined to the legislative particulars of the Guidelines as they may relate to the Western Australian and take into consideration the *Information Privacy Bill 200* (IPB) currently before the Legislative Assembly of the WA Parliament.

- The guidelines appear to be comprehensive in their application to the Privacy Act and emphasize the extreme sensitivity of this type of information which WA believes will offer assistance and guidance to health practitioners working in the area.
- While the structure and intent of the IPB is similar to the *Privacy Act*; the IPB has the advantage of having been drafted more recently. The IPB affords health information with a higher level of privacy than other confidential information. Information that is private, for the purpose of the IPB, is divided into personal and health information.
- The emphasis on Health Information is contained in a separate set of principals known as the Health Privacy Principles (HPP), which include specific requirements for the collection and disclosure of genetic information.
- The Privacy Act contains reference to the development of Guidelines by the NH&MRC (s95AA). The IPB has no similar clauses but does allow for the development of "codes of practice" with regard to health information. The IPB (at HPP 1.1 and HPP 2.1) however, acknowledges the excellent contribution of the NH&MRC in requiring that individuals or organisations are to take note of guidelines approved by the NH&MRC where no other code exists.

Thank-you for considering these comments; we look forward to continuing our involvement in the development of these guidelines as the consultation process progresses.

Yours sincerely



Dr Simon Towler  
EXECUTIVE DIRECTOR  
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11 October 2007

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**REFERENCES**

1. Davey A, Newson A, and O'Leary P, *Communication of Genetic Information within Families: The Case for Familial Comity*. *Journal of Bioethical Inquiry*, 2006. 3(3): p. 161-166.

2. Molster C, Bower C, and O'Leary P, *Community attitudes to the collection and use of identifiable data for health research - is it an invasion of privacy?* Australian and New Zealand Journal of Public Health, 2007. 31(4): p. 313-317.
3. Information Privacy Bill 2007 (Bill No. 193)  
<http://www.parliament.wa.gov.au/web/newwebparl.nsf/iframewebpages/Bills+-+Current>