

Ms Cheryl Cooke
Evidence Translation Section
NHMRC
GPO Box 1421
CANBERRA ACT 2601

8th April 2008

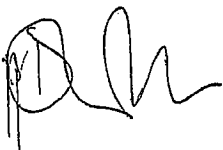
Dear Ms Cooke,

**RESPONSE TO THE NH&MRC GUIDELINES ON THE DISCLOSURE OF
GENETIC INFORMATION TO A PATIENT'S GENETIC RELATIVES**

Please find attached the response from Health Policy and Clinical Reform, Department of Health WA, to the public consultation for the draft document *Disclosure of genetic information to a patient's genetic relatives under section 95AA of the Privacy Act 1988 (Cth)*.

Thank you for the opportunity to comment.

Yours sincerely



Dr Simon Towler

EXECUTIVE DIRECTOR
Health Policy and Clinical Reform
Department of Health Western Australia

Date: 4 April 2008
Reference Number:

ISSUE Disclosure of genetic information without consent

Type of briefing: For information

Reason for briefing: Submission of comments to the NM&MRC re the consultation draft: Disclosure of genetic information of a patient's genetic relatives under Section 95AA of the Privacy Act 1988 (Cth).

BACKGROUND

The *Privacy Act 1988* (Cth) prohibits disclosure of personal information without the person's consent. Exceptions to this occur in special circumstances (eg medical scenarios) where disclosure of information is necessary to protect others against serious and imminent harm. In the context of genetic risk, the adverse health outcomes associated with genetic conditions may be serious and/or preventable but may not occur imminently, limiting the potential for an exception under the *Privacy Act 1988* to be utilised.

Proposed changes to the *Privacy Act* will allow health practitioners in private practice to disclose genetic information without patient consent, if disclosure is considered necessary to lessen or prevent a serious threat to the life, health or safety of genetic relatives of a patient. The *Amendment Act* requires the NH&MRC, in consultation with the Office of the Privacy Commissioner, to develop guidelines for health practitioners to facilitate understanding of the legislation and clarify the circumstances where disclosure without consent is legally justified. The NH&MRC has developed a draft document and invited public submissions.

The Office of Population Health Genomics (OPHG) held a workshop in November 2007 to discuss communication of genetic information within families and disclosure without consent by a health practitioner. The workshop was attended by members of university and hospital human research ethics committees, genetic counselors, medical researchers and members of genetic support groups (a total of approximately 50 people). Three hypothetical scenarios were used to explore the attitudes of members of human research ethics committees, genetic counselors and researchers to the issue of disclosure of genetic information without consent. The OPHG has used data from this workshop to formulate a response to the draft guidelines developed by the NH&MRC.

CURRENT STATUS

The data from this workshop suggest that although most attendees believed there was familial responsibility attached to genetic information (that is, genetic risk information should be shared with genetic relatives) they were unwilling to prioritise this over patient autonomy and preservation of the doctor-patient relationship. Disclosure of genetic information by a health practitioner without consent was not supported, despite the fact that most people believed that genetic information should be shared. Participants stressed the need for education and counselling of patients, in an attempt to ensure patients were fully "enabled" to disclose voluntarily.

Our comments to the NH&MRC can be summarised as follows:

1. We understand that health professionals, if they perceive a need to disclose, will require protection from the possible legal consequences of doing so.
2. Our data suggest that disclosure of genetic information by a health practitioner without consent was not supported, and that the introduction of legislation permitting this may not be well accepted.
3. This lack of support for disclosure without consent may need to be taken into consideration, especially if changes to the National Privacy Principles applying to private health practitioners are replicated by changes to the Information Privacy Principles applying to health professionals in the public sector. There may be a need for public education about the importance of sharing genetic information within families.
4. We suggest that health practitioners disclosing genetic information to family members *with* patient consent could also benefit from the development of guidelines. Guidelines may protect health practitioners from any adverse effects of disclosing and be particularly helpful when the practitioner is not familiar with the nature of the family relationship.
5. We commented on the wording and scope of some specific guidelines.

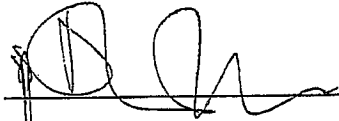
RECOMMENDATION

The Executive Director support the Office of Population Health Genomics response to the NH&MRC on the *Disclosure of genetic information of a patient's genetic relatives under Section 95AA of the Privacy Act 1988 (Cth)*.

CONTACT: Prof Peter O'Leary


DEPT REF:

SIGN OFF:

A handwritten signature in black ink, appearing to be 'S. Towler', written over a horizontal line.

Dr Simon Towler
EXECUTIVE DIRECTOR
HEALTH POLICY AND CLINICAL REFORM