

Mrs Vesna Cvjeticanin
Director
Evidence Translation Section
National Health & Medical Research Council
GPO Box 1421
Canberra ACT 2601

Dear Mrs Cvjeticanin

I would like to take this opportunity to commend the National Health and Medical Research Council on progressing with this guideline *Disclosure of genetic information to a patient's relatives: guidelines for health practitioners in the private sector*. The following comments are provided to the NHMRC Working Party responsible for finalising the current draft.

1. NSW Health notes that the previous requirement for the threat to the health, life or safety of genetic relatives be 'serious and imminent' in order to justify disclosure has been replaced with 'serious' only. While this change is supported in principle, we would reiterate that this now produces an inconsistency between the standard in these guidelines and the requirements of the *NSW Health Records and Information Privacy Act*. The latter still requires the threat posed to be both 'serious and imminent'. Acting in accordance with these guidelines alone would therefore place NSW health professionals in the private sector at risk of breaching prevailing jurisdictional legislation.
2. The guidelines do not address the ethical issues surrounding informing relatives <18 years of age and the sensitivity required to manage such disclosures. While these guidelines apply to referral for testing and investigation, rather than direct disclosure of the condition to a relative/s, such discussions with minors and parents are nonetheless potentially confronting and sensitive.
3. The definition of 'privacy' is unclear (page vii). An "obligation to the subject of information" is confusing. An alternative might be "Privacy is an obligation to a person about their personal information to ensure that the person can determine....."
4. Under the heading "How does disclosure take place?" (second dot point on p.4 and second paragraph on page 20), notifying the patient should be more strongly expressed i.e. "Where possible, notify the patient"

Should you wish to discuss this matter further, please do not hesitate to contact [REDACTED]
Principal Policy Analyst, Research and Ethics Branch [REDACTED]

Yours sincerely



Dr Kerry Chant
Chief Health Officer and
Deputy Director-General, Population Health

5/3/09