

Dr Clive Morris  
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Dear Dr Morris

I would like to take this opportunity to commend the National Health and Medical Research Council on producing 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.

Overall, the guidelines provide clear and practicable advice to health professionals who are considering the difficult issue of disclosure of genetic information under Commonwealth privacy legislation without the consent of the individual to whom it relates. They appear to comprehensively cover the legislative obligations of health care practitioners with particular reference to the two main statutory criteria which must be established – that an identified threat to life, health or safety must be 'serious' and that disclosure must be necessary to 'lessen or prevent' that threat. These sections give measured consideration and sufficient justification, balancing needs of all parties involved.

NSW Health would like to draw your attention to the following. On page 22, it comments that it may not be reasonable or practicable to seek consent where an individual lacks capacity and there is no surrogate decision maker. Firstly, if this is so, it is not clear how consent to the genetic testing would have been obtained in the first place. Secondly, this is a highly unlikely situation, certainly in NSW, because if a person does not have capacity, they would have a guardian. Does this envisage a scenario when a guardian appointed by the guardianship tribunal refuses to give consent to disclose information to genetic relatives because that is not related to the health and well-being of the person under guardianship, but the health of their relative?

The other concept in the guidelines needing better definition is the idea of 'opportunistic' testing of family members (last point on p27, 3.2.4). Perhaps the guidelines should remind medical practitioners that opportunistic testing does not mean surreptitious testing and that consent must still be obtained.

Comments were provided previously to the NHMRC Human Genetics Advisory Committee when the Amendment was in the Bill phase. They drew the Committee's attention to a significant discrepancy between the *NSW Health Records and Information Privacy Act* and the *Commonwealth Privacy Act*: the

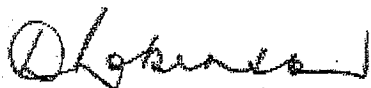
Amendment to the Commonwealth Act permits disclosure of personal genetic information by a health professional to prevent a serious threat to an individual, whereas NSW privacy legislation requires that the threat be both serious and imminent.

NSW clinical geneticists support the 'serious' criterion in the Amendment to the Commonwealth Act as a more workable alternative to the overly restrictive 'serious and imminent' criterion. However it should be noted that the inconsistency that now exists between the privacy principles in the Commonwealth legislation and those in the *NSW Health Records and Information Privacy Act* could result in inequities across different legislative jurisdictions. This situation could also give rise to uncertainty among health practitioners in the private sector, the target audience for these draft guidelines.

In regard to the definition of a 'serious threat' that must exist before disclosure without consent may be contemplated, consideration could be given to including potentially life-threatening situations or where serious illness might occur in an, *as yet, unborn child*.

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

Yours sincerely



Dr Denise Robinson  
Chief Health Officer and  
Deputy Director-General, Population Health

19<sup>th</sup> October 2007