



## Department of Human Services

Incorporating: Health, Community Services, Mental Health, Senior Victorians and Housing

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23 October 2007

Dr Clive Morris  
Chief Knowledge and Development Officer  
National Health & Medical Research Council  
GPO Box 1421  
Canberra ACT 2601

Dear Dr Morris

Thank you for your letter dated 12 September 2007 seeking comments on the draft genetics privacy guidelines. As you would know, all clinicians in the field of genetics have struggled for some years with the potential consequences of disclosure/non-disclosure of genetic information.

The draft is well written and thoughtful and I provide the following comments for your consideration:

1. Definitions

- Genetic relative: this includes 1st, 2nd and 3rd degree relatives. In reality, disclosure may be required beyond first cousins.
- Genetic information: this is very broad and has great room for interpretation. If Mr X has an increased cholesterol (i.e. a reliable phenotypic biomarker for a genetic disorder of lipid metabolism) should this be disclosed?
- Health practitioner: is this to be limited to those handling genetic information as usual business, or rather include general practitioner with whom patient may have a long term relationship? Should panels be convened, e.g. clinical ethics committee?
- Cascade contact: There appears to be a generational effect in disclosure - information is shared within a generation (horizontal) but not across a generation (vertical), i.e. siblings are told, but responsibility to their children is their own.

2. Predictive genetic testing (p15) - comment also needs to be made to highlight the differences in penetrance and expression of genes

3. Telephone answering machines (p32) - This note of caution is excellent point. To help it may be worth mentioning that the caller does not know who else might hear the message.

4. Scenario 8 (p33) – neonatal myotonic dystrophy is often lethal. It would be worth stating this to underline the potential seriousness of non-timely disclosure.

With the process of disclosure being inconsistent right across Australia, I am pleased that the NHMRC is developing these guidelines. I look forward to the public consultation process early next year.

Yours sincerely

A handwritten signature in black ink, appearing to read 'John Carnie', written in a cursive style.

DR JOHN CARNIE  
Chief Health Officer