Draft Genetics Privacy Guidelines

Thank you for the opportunity to view and provide comment on the Draft Genetics Privacy Guidelines.
The rationale and process to be undertaken by the NHMRC is noted.
Unfortunately due to time constraints and other pressing issues, there has not been the opportunity to seek views from across the Department of Health and Human Services. There has, however, been an opportunity for the lead genetic counsellor in the Department to provide input.

Overall, we feel that the guidelines are comprehensive, logical and well illustrate the issues and possible scenarios.

There are two matters we wish to raise:

Legal Obligation No. 8 (particularly the approach detailed on page 34)
While appreciating the potential impact on a person receiving advice that they may be carrying a genetic alteration of note, in practice genetic services advise the recipient of the specifics of the condition, potential risks and mitigating actions; at least in general terms. The rationale here is that providing information that is too general in nature may not be sufficiently effective in leading to the person making contact with the genetic service. We recognise the tension between not identifying the proband, and yet providing sufficient impetus to the relative to pursue the lead. However if the health professionals are sufficiently concerned to make contact with relatives without the proband’s consent, then perhaps the balance should be shifted more towards providing information that will be more likely than not to elicit the desired response.

We feel that consumer bodies would be well placed to provide input on that issue.

Application of the guidelines
The requirement for the guidelines in the context of the recent amendment to the Privacy Act 1988.
We raise the issue of the scope of the guidelines’ applicability.
The majority of genetic services provided in Australia are based in the public sector, and the guidelines should have resonance (if not legal application) with public services where they encounter instances foreshadowed in the legislation and explanatory memorandum.
Importantly, the inevitable caveat regarding the situation of inconsistencies between State and Federal legislation, where the latter will prevail, may lead to confusion for
public sector providers. Therefore the preparation of a companion publication/information sheet for providers of genetic services in all sectors would be worth serious consideration.

Raising these matters is timely for us, as I will review Tasmania's *Personal Information Protection Act 2004* in this light, and with reference to the discussion paper on privacy law recently released by the Australian Law Reform Commission.

Regards, David Boadle

**Dr David Boadle**  
**Chief Medical Officer**  
**Director**  
**Clinical Performance & Emergency Management**  
**Acute Health Services Group**  
**Department of Health and Human Services Tasmania**