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Ms Cathy Mitchell  
A/g Executive Director  
Health Evidence and Advice Branch  
National Health and Medical Research Council  
GPO Box 1421  
CANBERRA ACT 2601

Dear Ms Mitchell

Thank you for providing the Australian Medical Association (AMA) with the opportunity to comment on the Draft Genetic Privacy Guidelines '*Disclosure of Genetic Information to a Patient's Relatives under Section 95AA of the Privacy Act 1988 (Cth) – Guidelines for Health Practitioners in the Private Sector*'.

We commend the National Health and Medical Research Council's (NH&MRC) efforts in developing Guidelines on such an ethically challenging issue that health practitioners will increasingly face as genetic testing plays a greater role in health care.

### **Style and format**

As far as the style and format of the Draft Guidelines, they are very comprehensive; however, it is important that they are practical in format for busy medical practitioners. It may be useful to accompany the finalised Guidelines with short, summary educational materials and an education campaign for medical practitioners.

The scenarios described at the end of the document are quite useful in exemplifying at least some of the situations that health care practitioners are likely to face when considering whether or not to disclose a patient's genetic information to genetic relatives without consent.

### **Legal issues**

We find that the Guidelines may be useful for assisting medical practitioners in their interpretation of the privacy legislation. If followed, the Guidelines may reduce the exposure of medical practitioners from statutory liability in cases of disclosure of a patient's genetic information to genetic relatives. For example,

- Guideline 1 requires the medical practitioner to take reasonable steps to obtain a patient's consent to the disclosure.

relative, the patient, and the patient's wider family. Although this scenario is unlikely to occur very often, it may eventuate on occasion and should be acknowledged in the Guidelines.

4. There are several statements throughout the document that advise practitioners to '*consider* arranging timely genetic counselling for patients or referring them to an organisation that provides genetic counselling' (page 2) (emphasis added). The AMA advocates that genetic testing **should not** be undertaken in the absence of appropriate (pre and post-test) counselling; therefore, the word '*consider*' should be removed.

5. It is important throughout the document to consistently emphasise throughout the Guidelines that medical practitioners may wish to contact their medical defence organisations (MDOs) before disclosing a patient's genetic information without consent;

6. The Guidelines state that 'if disclosure without consent takes place, consideration should be given to notifying the patient of this decision' (page 22). The Guidelines do not address this issue in any particular detail. We recommend that the Guidelines advise that, in most circumstances, the patient should be informed of the decision to disclose their genetic information without consent and this should be documented in the patient's record.

Thank you again for the opportunity to comment on these Guidelines and we look forward to their further development.

Yours sincerely

Dr Rosanna Capolingua  
President

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