



AUSTRALIAN MEDICAL  
ASSOCIATION  
ABN 37 008 426 793

T | 61 2 6270 5400  
F | 61 2 6270 5499  
E | info@ama.com.au  
W | www.ama.com.au

42 Macquarie St Barton ACT 2600  
PO Box 6090 Kingston ACT 2604

05/207

S95AA Guidelines Project Officer  
Integrated and Strategic Projects Section  
NHMRC  
GPO Box 1421  
Canberra ACT 2601

Dear Dr Ash

Thank you for providing the Australian Medical Association (AMA) with the opportunity to comment on the National Health & Medical Research Council's (NH&MRC) draft *Disclosure of genetic information to a patient's genetic relatives. Guidelines for health practitioners in the private sector.*

The AMA believes that genetic testing will play an increasingly important role in health care. We commend the NH&MRC for developing these guidelines to assist health care practitioners, usually medical practitioners, who face the very serious ethical and legal dilemma of whether or not to disclose their patient's genetic information to genetic relatives in those circumstances where the patient does not provide consent.

Whilst acknowledging that the guidelines apply to the private sector, the AMA strongly advocates that there must national consistency in the application of the relevant legislation and the guidelines across the public and private sector. The legislation and guidelines must ensure appropriate legal protection for health care professionals who make the very difficult decision to disclose a patient's genetic information to at risk family members without consent.

Further, we advocate that the release of the guidelines themselves must be accompanied by an education campaign, both for the public as well as health care professionals, regarding their application. In particular, it is imperative that the public understand the shared nature of human genetic information and that, in certain circumstances, genetic relatives can benefit from knowledge of the patient's genetic information.

Although the recently amended privacy legislation, and this guidelines, provides for disclosure of a patient's genetic information without consent in certain circumstances, we would certainly not want to see patients refusing to undergo genetic testing because they fear that their privacy may be breached regardless of their wishes. Such fear may have a deleterious impact on the doctor-patient relationship and the health and well-being of the patient. The education campaign needs to be sensitive to these issues.

Yours sincerely

Dr Rosanna Capolingua  
President

12 October 2007