05/207

S95AA Guidelines Project Officer
Integrated and Strategic Projects Section
NHMRC
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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

[Signature]
Dr Rosanna Capolingua
President