



HUMAN GENETICS SOCIETY OF AUSTRALASIA

ARBN. 076 130 937 (Incorporated Under The Associations Incorporation Act)
The liability of members is limited

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

27th February 2009

Dear Cathy,

Re Targeted consultations on Draft Genetics Privacy Guidelines (Section 95AA)

The Human Genetics Society of Australasia (HGSA) is the peak body representing Australasian professionals involved in all aspects of human genetics service delivery and research. We thank the NHMRC for consulting us with earlier versions of the Draft Genetics Privacy Guidelines and for this final opportunity to comment. The Guidelines have been considered by members of our Ethical and Social Issues Committee (ESIC).

We commend NHMRC on the approach to development of these guidelines and on this final draft, which is clear, comprehensible and sensible. We had no substantive criticisms of the draft guidelines. Some members of ESIC noted that the guidelines only apply to practitioners in the private sector. In Victoria the major service provider is indeed in the private sector, but in other states many practitioners are employed by public hospitals and are subject to local legislation. Although perhaps outside the scope of these guidelines, this creates practical issues for genetics practitioners about which they will need to be made aware.

We had two specific comments on the wording. The definition of privacy (page vii) sounds a little technical and confusing. One option would be to change it to "Privacy is an obligation to a person about their personal information to ensure that the person can determine".

The second comment relates to the section "How does disclosure take place" on page 4. We thought the second dot point should be expressed more strongly. An option would be to change it to "where possible, notify the patient".

Thank you again for the opportunity to comment and congratulations on this excellent document.

Yours sincerely,

Associate Professor David Thorburn
President, Human Genetics Society of Australasia

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