

**Australasian Society of Genetic Counsellors (ASGC) response to the Consultation  
draft — 11 February 2008**  
**Disclosure of genetic information to a patient's genetic relatives under  
Section 95AA of the *Privacy Act 1988* (Cth)**  
**Guidelines for health practitioners in the private sector**

The Australasian Society of Genetic Counsellors (ASGC) welcomes the opportunity to submit a response to the draft guidelines.

The ASGC represents Human Genetics Society of Australasia certified genetic counsellors and associate genetic counsellors. Although the vast majority of HGSA certified genetic counsellors and associate genetic counsellors in Australia are employed within public health sectors, this document is of relevance to our membership for the following reasons:

- Some clinical genetic health services are administered as private businesses.
- As the profession of Genetic Counselling develops, we anticipate that more certified genetic counsellors will be private practitioners (as has occurred for other allied health professionals such as social workers).
- There is a reasonable expectation that these guidelines for private practice are very likely to be utilised as a basis for future development of similar policies within public health sectors or, in the absence of such policies, to set a standard for 'best practice'.
- It is clear that implementation of the guidelines may lead to increased referral to genetic counselling services in accordance with best practice key points.

**General Comments**

Firstly, we would note that the guidelines are well developed and generally clear in explanation. Secondly, ASGC members support the importance and emphasis of directions related to careful consideration of all essential processes and support options in order to avoid, as far as possible, the ultimate need to disclose genetic information without consent. We are also pleased to note that the guidelines will not create a legal obligation to disclose genetic information. In conjunction with appropriate genetic counselling and support for family communication, we would expect that actual instances of necessary disclosure of genetic information without consent to be rare and even more rarely to be urgent in nature.

**Specific comments:**

## Issue 1

The following sections of the draft all relate to the health professional who will disclose the genetic information as well as who should take responsibility for the final decision to disclose and for the act of disclosure:

### Page 3 "Definition of *Disclosing health practitioner*"

In these guidelines, the person responsible for decision-making and disclosure is referred to as the "disclosing health practitioner". While a range of professionals may be involved in the care of a particular patient, a medical practitioner with the requisite knowledge of the patient's condition or genetics should take final responsibility for decision-making about disclosure and the disclosure itself."

Page 29 "A range of health practitioners may have a role in the disclosure process. However, throughout the process of decision-making one medical practitioner will act as the "disclosing health practitioner"."

Page 29 "It is advisable that a medical practitioner take responsibility for the process even if another professional (eg a genetic counsellor) undertakes the disclosure. It is essential that the range of health practitioners involved in the disclosure process have a clear understanding of their roles."

Firstly, the term "disclosing health practitioner" is somewhat misleading. It suggests that disclosure without consent is the most likely outcome at the end of the process. If the process were to be completed as recommended, one would expect that disclosure without consent would be avoided more often than it would actually be implemented. There is also some contradiction in the contexts above between identifying the medical practitioner as the "disclosing health practitioner" if the actual task is delegated, as may be entirely appropriate, to a certified genetic counsellor. This also relates to the requirement for clear definition / recognition of roles for the different health professionals involved in the process.

It is also necessary to clarify the exact definition of 'responsibility' as used in these contexts. For example, in the public sector, it is not unusual for a certified genetic counsellor to take primary responsibility for a genetic counselling case (in terms of conducting the entire process from consultation to summary letter and follow-up), working within a team that includes a medically qualified professional. Whilst it is recognised that the term 'responsibility' in this document most likely is intended to infer legal significance related to liability, it is important to have this more directly stated in the document and to note that genetic counsellors can take practical responsibility for the act of disclosure.

## Issue 2

### Page 22 "*Benefits of disclosing*"

- If a genetic relative is identified as a carrier of a chromosomal rearrangement, advice can be given about the risk of miscarriage or infertility."

It may be prudent to add 'and / or risk of imbalance in chromosomal constitution of live-born offspring as well as prenatal options to prevent such occurrence.'

Issue 3

Page 8

"• Consider referring patients to a health practitioner with expertise in conveying relevant genetic information or consult such an expert. (p 25)

• Consider arranging for genetic counselling for patients or referring them to an organisation that provides genetic counselling. (p 25)"

The word 'consider' as used in above context is too vague and inadequate under the circumstances. In the endeavour to avoid the need to disclose genetic information without consent, if the private medical practitioner is not successful, then there ought to be a requirement for referral to a genetic counsellor or clinical geneticist. HGSA certified genetic counsellors are particularly skilled and experienced at recognising and ameliorating the barriers (as noted on page 19 and 20) to giving consent for notification of 'at risk' relatives and these skills ought to be utilised to maximise chance of best outcome.

Issue 4

Page 25

#### **"3.1.2 GENETIC COUNSELLING**

In situations where genetic information has implications for individuals and their families, patients may be referred to a genetics unit. This allows a detailed family pedigree to be drawn and promotes open communication, understanding of the situation and identification of at-risk genetic relatives.

If this is not possible within a reasonable time frame, for example because of distance or long waiting lists, the treating health practitioner can seek advice from the genetics unit about an appropriate course of action. If the patient is distressed, referral for locally available counselling may be helpful."

Page 29

"In circumstances where an element of urgency exists, it may not be possible for genetic counselling to be provided (particularly in rural and remote areas) but whatever time is available should be used to provide the patient with as great an understanding of the situation as possible."

Whilst, we acknowledge that many state genetic services have lengthy waiting lists, all services have a protocol for managing urgent referrals (e.g. such as prenatal cases) in a timely manner. In some states there will be provision within clinic appointment allocation systems, in both metropolitan and outreach settings, for urgent case bookings. Telemedicine consultation may be utilised in some states. At the very least, genetic counselling can always be offered by phone in the first instance.

We acknowledge that the process may be expedited by patient contact with a local (non-genetic) counsellor if the issue of concern relates primarily to family dynamics or unresolved personal issues. However, it is preferable to refer the patient to a certified genetic counsellor who can adequately deal with all potential misunderstandings about

the genetic aspects of the disorder as well as the psychosocial issues, which will achieve the greatest level of understanding in this situation.