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**APF Response to Draft Guidelines on the Disclosure
of Genetic Information Without Consent**

I write in my capacity as Chair of the Health Sub-Committee of the Australian Privacy Foundation (APF).

The APF welcomes this opportunity to comment on the 'Disclosure of Genetic Information to a Patient's Relatives under Section 95AA of the Privacy Act 1988 (Cth) - Guidelines for Health Practitioner in the Private Sector' (Guidelines). However, our opposition to disclosure of genetic health data without informed consent is steadfast. Our comments must therefore be interpreted from this perspective.

Consent

We were pleased to note the recognition of consent as an ongoing and continual process in the Draft Guidelines. A presentation by David Stokes reported several case studies to this effect at a recent Conference in Brisbane (1). The contextual and changing nature of consent is finally receiving the discussion it warrants.

Cultural diversity

The Guidelines also acknowledge that the Australian community is culturally diverse. Empathy for different world views is important. It empowers many patients' outside mainstream culture to be better informed about their health and well-being.

Documentation

Finally, the APF was particularly gratified by the report's emphasis on documentation. Keeping the individual informed of what is being done with their health information, where it has gone and who has had access to it all of the time is a positive development. Commendable too is explicit attention to matters concerning those who are not able to give consent for themselves. Entrenching the individual's right to information about oneself into health privacy legal frameworks shows the appropriate respect for patients.

Nonetheless, we remain **concerned** by the following:

2. Ethical Considerations

Although we acknowledge the Draft Guidelines are primarily directed at clinicians,

the APF is concerned the **personal** risks to the patient resulting from disclosure and from non-disclosure is not explored as thoroughly as it might. Moreover, the section seems geared toward advising clinicians how to influence patients to disclose information rather than to assist the patient to make an informed choice about consent.

Similarly, boxes outlining the potential benefits and risks of disclosing genetic information on pages 12 and 13 of the Guide are presented in the abstract. The information would be better expressed in language that takes on the patient's perspective as well as those of medical practitioners. By this means, the information in the Guide will specifically assist the patient to make a fully informed decision.

3.2 Following Appropriate Processes When Consent is Withheld: 3.2.2 Taking a Collaborative Approach: Guideline 5

The section refers to the non-disclosure of identity of the patient in inter-professional discussions. The section should explicitly refer to non-disclosure in written records as well as verbal records.

3.2.3 Decision-Making About Use and Disclosure Without Consent: Guideline 6

This section of the Draft Guide is pervaded by tools and script outlines to pressure the patient to consent to information disclosure to genetic relatives. While the affect on patient-doctor relationships for the future receives some attention, why doesn't the patient's mental well-being receive the same kind of attention? The Guide seems to have drafted several ways to influence the patient decision in one way without paying attention to alternative options. For instance, why can't the physician respect the patient decision and move on if the non-consent direction has reached this stage?

Also, why belabour the decision to introduce a genetic counsellor into the process? The Guide is permeated by pressure to consent for someone else's 'good'. That is, the interests of the parties who would be told in the event of non-disclosure seem to receive more attention than those of the patient at the centre of this process. The APF supports an alternative process whereby the counsellor is invited to talk to the patient in a balanced way about the positive and negative aspects of disclosure, should this be required, once diagnosis has been confirmed.

3.2.5 Non Disclosure: When the medical practitioner is unwilling to disclose

The draft guidelines suggest if the decision is not to disclose, the authorising medical practitioner should consult another suitably qualified and experienced health practitioner to support the disclosure of patient information to genetic relatives. Why is the Guide permeated by determination to disclose pertinent information to genetic relatives? It seems that doctors, as with their clients, are being encouraged to disclose the information regardless of patient consent. The APF maintains there needs to be an equal balance of scenarios supporting non-disclosure, particularly given the boxed statement on page 19 of the Guide, which points out that practitioners should call upon their experience, training and expertise to make a decision "in good faith".

3.3.3 Process of Cascade Contact: Guideline 8:

The Draft Guide requires a description of scenarios as to the mental health impact of false positive alarms in the cascade contact scenario. The APF is also concerned about physical and mental dangers faced by genetic relatives. If, in "good faith" an authorising medical practitioner discloses patient information concerning an untreatable condition to genetic relatives, how will dangers to genetic relatives be

managed? The APF has assumed that only manageable conditions will be reported to genetic relatives. Is this the case?

Sex

Sex linked genetic diseases are not mentioned in the Guide. There is no preventative purpose in disclosing a hereditary determiner to the patient's genetic relatives when they cannot possibly pass-on or manifest the condition. Sex linked diseases require explicit analysis in the Guide to prevent needless and useless information disclosures.

Insurance Companies and Employer Medical Checks

The APF maintains the Guide must explicitly prohibit medical practitioners appointed by insurance companies and employers (including prospective employers) from providing access to a patient's genetic information, even in summary form, to anyone other than the patient concerned and their genetic relatives, as appropriate.

Notification to Patients

Information handling practices are currently signposted for patients at every Australian medical practice and health service organisation. Similarly, the APF maintains information about the disclosure of some genetic conditions to genetic relatives without consent should be made available to patients before consulting a medical practitioner. Such information might read as follows: "*This practice sometimes uses and discloses genetic information in order to advise a patient's relatives of a serious health condition under Section 95AA of the Privacy Act 1988 (Cth)*". Alternatively, when ordering tests for certain conditions, medical practitioners will need to inform, either verbally or in writing, patients of the possibility of disclosure without consent and note the caution in the patient's health record. Drawing attention to this aspect of medical practice ensures that the patient is fully informed of the disclosure process.

Conclusion

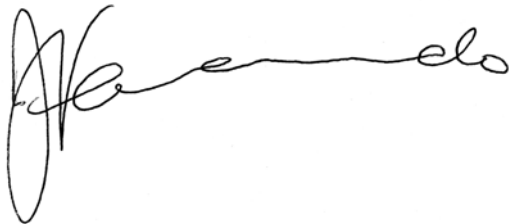
The APF is gratified by the way the Draft Guide acknowledges that consent is an ongoing process, cultural diversity must be respected and patients must be kept informed of what is being done with their health information.

Nonetheless, our opposition to disclosure of genetic health data without informed consent is steadfast. All our views are influenced by this basic tenet. The APF response is summarised below:

1. The Guide does not satisfactorily explore the impact on a patient's health and well-being when genetic information is disclosed without consent.
2. A genetic counsellor needs to be involved earlier on in the process to inform and advise the patient for their own benefit as well as that of their relatives.
3. Similarly, pressure to disclose the genetic information from another medical practitioner brought to bear on the authorising medical practitioner seems to emphasize disclosure rather than any other option.
4. There are no steps to manage danger to the health and wellbeing of genetic relatives either.
5. The APF is concerned the Draft Guide is inadequate with regard to disclosing an individual genetic information to **all** genetic relatives when many conditions apply to only a single sex.

6. Moreover, we wonder whether the scope of the Guide is confined to manageable conditions rather than all conditions, including incurable ones. Disclosures of information about incurable diseases need to be considered more carefully than in the Guide.
7. We assume that medical practitioners appointed by prospective employers or insurance companies will not be able to breach doctor/patient confidentiality laws and so cannot apply this exception to the protection of patient rights to health information privacy.
8. Finally, we believe that patients should be informed prior to testing that their genetic information may be disclosed without consent.

Please do not hesitate to contact us for clarification of any point raised herein.

A handwritten signature in black ink, appearing to read 'Juanita Fernando', with a large, stylized initial 'J'.

Dr. Juanita Fernando

Chair
Health Sub-Committee
Australian Privacy Foundation