

Use and 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
DRAFT

General comments:

As the decision made by a medical practitioner to disclose genetic information when consent has been withheld has the potential to cause discord within families that may already have difficult relationships and dynamics, it is vital that the Guidelines clearly convey the steps required to provide support to patients during this process.

It is of concern that there is no process for patients to appeal through an independent arbitrator a medical practitioner's decision to disclose without consent.

There is a need to develop and make available appropriate documents in lay language which outline the steps the medical practitioner will take if a patient withholds consent. These documents should be available in different languages, be culturally sensitive and include the letter their relatives will receive. Time to reflect on this information must be built into the processes required of the medical practitioner.

The summary and practical guide:

Given that the Guidelines state that ethical considerations are to be part of the decision making process (Page 1 summary) it is crucial to develop and include steps to provide support to the patient during the process outlined in the Framework (Page 5).

Inclusion of the following suggested steps would provide vital support for people who:

1. Are likely to have health and emotional issues from being told they have a genetic condition;
2. Are likely to have increased stressors / issues arising from their decision not to share the information with other family members;
3. Are likely to have issues arising from a perceived breaking of trust and confidentiality by their medical practitioner.

Suggested extra steps to be included in the Framework (Page 5):

- Patients must be given supporting information in an appropriate format that addresses their needs i.e. literacy, language, cultural issues.
- Patients must be offered access to timely, appropriate counselling / information services – costs and waiting times must not be a barrier to access.
- Patients must be told of the medical practitioner's decision to inform relatives if consent is withheld.
- Patients must be given time to consider this decision.
- Patients must have the opportunity to appeal this decision with an independent arbitrator i.e. the Federal Privacy Commissioner.
- Include a suggested timeframe for the process

As these steps may be applicable to all genetic relatives if and when the cascade process is used, there is potential to create an unrealistic and unworkable process for busy medical practitioners.

The Guidelines / Framework should make a statement about the steps to be considered if the medical practitioner's decision to disclose without consent creates a hostile situation.

Form Letter to Relative:

- This letter assumes a high literacy level – consideration needs to be given to what process is to be used for people who are illiterate or for whom English is a second language.
- The second paragraph and the last paragraph could be considered contradictory.
- Does receiving a letter like this obligate people to disclose this information when applying for insurance / employment? If so then it must be mentioned in the letter.
- Include details of community support available i.e. genetic support groups.

A copy of the letter for relatives should be included in the consumer information. This may provide reassurance regarding concerns about identity and conditions.