

[REDACTED]
27/02/2009
04:16 PM

To [REDACTED]
cc.

Subject Re: Fw: s 95AA Guidelines for Council
[SEC=UNCLASSIFIED]

Our comments are given below:

Overall well written and clearly expressed. It is made very clear that the use of the Guidelines is obligatory, that the decision to disclose the genetic information is not mandatory, but discretionary. Both decisions, to disclose or not to disclose, must be documented with a rationale for the decision. There is strong emphasis on a collaborative approach with experts and other health professionals, and a clear "test" for when a decision to disclose may be justified:

- . The threat to genetic relatives must be serious;
- . The threat must be able to be prevented or lessened via a disclosure
- . That no other alternative to disclosure for preventing or lessening the threat can be identified.

The only question we have is based on page vii:

"In instances where there are no medical or scientific means of reducing a recognised serious threat, there is some doubt that it could be said that the use or disclosure of genetic information could lessen that threat in the relevant sense. In circumstances where a contemplated use or disclosure would not lessen a serious threat to life, health or safety to a noticeable extent or assist in reducing that threat, the exception (to keeping confidentiality) will not apply"

What about a case where there is not cure or good treatment for a genetic condition, relatives might still need to be informed so that in the intervening period, they could put plans etc in place and organise their lives in light of what may happen, that is, disclosure would still lead to "optimal management" of a situation.

Further reading (P3) confirmed that "optimal management" is still a relevant consideration.

Dr John Carnie