

Dear NHMRC Project Officer,

Thank you for inviting me to comment on the draft genetics privacy guidelines as part of the targeted consultation for these recommendations. I fortunately did attend a briefing on this subject given by Dr Graeme Suthers had a national meeting of familial cancer clinics in August this year.

My comments on this draft are as follows:

- Point 5 states that, "In the course of inter professional discussions, the identity of the patient must not be disclosed". In practice knowledge of patient identity may be known to some members of multidisciplinary group. I suggest this point should be worded so that it states, "In the course of inter professional discussions, the identity of the patient should not be disclosed wherever possible."
- Point 7 states that, "Disclosure of genetic information without consent may proceed only when it is necessary to prevent a serious threat to genetic relatives." I suggest deleting this point altogether. There are genetic diseases such as Huntington disease for which no current treatment exists to prevent the disease. This point may prevent a practitioner from disclosing information if interpreted to mean that a proven therapy must already exist. I believe that safeguards in this legal obligation are already covered under Point 6. Removing at least one legal obligation will also simplify the compliance.

Overall I would enthusiastically support the introduction of these recommendations. In particular I note they impose no obligation or duty on health professionals in the private sector to disclose health information to other family members. I also am pleased to note that there is a mechanism by which complaints can be addressed through the Office of the Privacy Commissioner.

I would be grateful if you can keep me informed progress with this issue.

Yours sincerely,

Dr Michael Gattas MB BS FRACP

Brisbane Private Clinical Genetics

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