

8 October 2007

Dr Greg Ash
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Dear Dr Ash

Re: NHMRC targeted consultation: draft genetic privacy guidelines s95AA

Thank you for the opportunity to provide feedback on the draft NHMRC s95AA genetics privacy guidelines.

I wish to endorse the broad thrust of these draft guidelines. They are well structured, detailed, but readable, and the use of case examples is very helpful to elucidate the issues.

I just have a few comments, some of which relate to matters that are not expressly dealt with in the guidelines but which I believe should be covered:

Page 2- outlining the purpose of the guidelines; here or at some other point in these guidelines, I believe some mention should be made of the fact that this statutory exception only relates to privacy obligations under the *Privacy Act 1988 (Cth)* and does not effect common law liability in respect of the health practitioner's duty to maintain confidentiality. (This point is made implicitly by reference to legislation, but the status of the common law is not directly addressed.) Notably, under the heading 'Scope' at p 9, and spelling out what is not included within the scope of these guidelines, there is no reference to the common law obligations, which could confirm the impression that the guidelines are comprehensive with regard to health practitioners' legal obligations.

This will need to be carefully worded, because one would obviously not want to create angst amongst health practitioners about potential liability at common law. However, to omit reference to this altogether runs the risk that health practitioners may rely on these guidelines as the comprehensive statement of their legal obligations and may assume that provided that they comply with the guidelines, they will be acting lawfully when in fact common law liability remains an open issue. There is every likelihood that future application of the common law would take account of this legislative exception and that

the common law would itself evolve accordingly. And whilst in practice it is very unlikely that a health practitioner would be found in breach of the common law duty of confidentiality where such careful steps have been taken, this outcome cannot be guaranteed until case law develops confirming this. The ALRC/AHEC in its Report has expressly limited their recommendations to the amendment of the legislation and stated that the 'Inquiry leaves open the question of whether health professionals may, in the future, require some form of statutory protection for actions for breach of confidentiality based on disclosure of confidential information in order to warn genetic relatives about their genetic risk' (para 21.65, *Essentially Yours* Report).

Page 18 – under the heading 'Ethical Practice' – this section would, in my view, benefit from re-ordering of the subheadings so that the points are presented in a more thematic way. As it is presently presented, the subheading of 'privacy and autonomy' seems a little out of place sandwiched between points that would be supportive of making disclosure ('preventing harm' and 'justice'). Further it may be better if the heading were rephrased to read 'Ethical principles raised by the issue of sharing genetic information' so as to highlight that there are principles in tension here. (The current wording of 'Ethics of sharing genetic information' may be read in a normative sense, creating an expectation that the points which follow will be supportive of making disclosure.) I would suggest that the section could then begin with the point about 'privacy and autonomy' which supports the patient centred-choice position, and then followed by the subheading 'preference not to know'. These points could then be juxtaposed with the other ethical considerations which are generally supportive of making disclosure, namely 'preventing harm' and 'justice'.

The area that I think the guidelines do not yet adequately address is the possibility of a health practitioner who is not willing to make disclosure to genetic relatives against the consent of the patient, even though the guidelines point to disclosure being ethical and appropriate. This is a potentially significant issue. Whilst the legislation and accompanying guidelines do not make it obligatory for health practitioners to disclose, they do set up expectations in respect of best practice. It is quite conceivable, therefore, that health practitioners choosing for their own personal reasons not to disclose, in circumstances where the guidelines would permit them to do so, may be later questioned and criticised by aggrieved genetic relatives who claim that they ought to have been informed of the risk, and have suffered harm as a result of the non-disclosure of relevant information. I believe that the guidelines should more openly address this possibility, thereby alerting health practitioners who are considering whether to make disclosure of the full implications of their decision, particularly where it may be out of accord with community expectations. Related to this is the issue of documenting and being able to substantiate decisions. Reference is made in the draft guidelines to the importance of carefully documenting the steps in the decision-making process: this should explicitly also include circumstances in which a health practitioner decides *not* to disclose, notwithstanding that the legislation and guidelines would permit it. This is important given that the decision not to disclose may also subsequently be subject to challenge by aggrieved relatives, even though at this point in time there is no legal obligation to disclose (either under the legislation or at common law). Moreover, the possible future

development of a duty to warn at common law based on principles of negligence and foreseeable risk cannot be completely ruled out.

Linked with the above point, there should, in my view, be more explicit attention given to possible liability issues associated with both compliance and non-compliance with the guidelines, for example, by expanding on the 'Summary of legal obligations and best practice' at p 5. (This also links with the earlier point in respect of p 2 above and the need to mention that the common law obligations are unaffected by the statutory amendment.)

Further to the above discussion, I think it would be useful to include some discussion in the guidelines of appropriate pathways in circumstances where there is a consensus amongst the consulted experts that from an ethical point of view, there should be disclosure, but the primary health practitioner feels bound to the patient and is not willing to make disclosure without the patient's consent. Would it, for example, be appropriate to then involve another health practitioner in the disclosure process? Failure to provide for such alternative pathways may give rise to fundamental questions about whether it can be ethical and consistent with professional practice for a health practitioner not to disclose where it would be legally and ethically justifiable for the health practitioner to do so. These issues could perhaps be usefully ventilated through a further scenario example??

For your information, I am attaching a link to a paper that was recently published in the Medical Journal of Australia which summaries the effect of these Privacy Act amendments: http://www.mja.com.au/public/issues/187_07_011007/otl10381_fm.html

I would be happy to clarify any matters arising.

Yours faithfully,



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