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18:02

Subject Re: Submission s95AA guidelines [No Protective Marking]

Submission to the Consultation on the Proposed Guidelines for '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

1. Thank you for the opportunity to comment further on the draft guidelines. I refer to and repeat my previous submission dated 31 March 2008. A copy is attached since it remains relevant.
 2. My major concern is that the draft guidelines are too general and lack the easily achieved rigor and scientific bases of a table or list of major genetic diseases and how to deal with each.
 3. Speaking from both a geneticist's and a lawyer's perspective, the most effective guidelines for health practitioners would be to provide a list of the major or most common genetic conditions stating whether or not relatives should be informed when consent is withheld. That was suggested in my previous submission (sections 2,8). Given its role and expertise NHMRC should be able to prepare such a table. A survey of health practitioners asking if they would like that could be appropriate. The proposed guidelines reflect too many administrators and lawyers and too few scientists.
 4. The emphasis throughout the proposed guidelines on ethics requirements is appropriate and good. It means that failure to act 'ethically' would breach the guidelines and consequently the Privacy Act (as amended). For example, a health practitioner who took the opportunity to generate business by contacting 100 relatives of a patient with heart disease, without consent, would probably act unethically and not in good faith, and breach the guidelines and Act.
 5. It would be better if appropriate NHMRC or other guidelines setting out and defining what is meant by acting ethically in medical practice, were referred to on specific points. Relevant documents include the AMA Code of Ethics and NHMRC National Statement or other HREC documents, given that this issue and human medical research share ethical problems. That would remove some uncertainty.
 6. Section 3.2.5 on non-disclosure is an appropriate and useful addition to the consultation draft. However, I would favour clear statements that many or most individuals, especially when young and healthy, do not want to know and should not be forced to know about such things for most genetic conditions, until the effects are apparent. Forcing a healthy 18 year old to have to plan for, or even think about, a specific late onset disease is simply cruel. Cutting off a healthy young girl's breasts based on a genetic prediction appears obscene and to indulge jack-the-ripper type fantasies, in my
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view. They are entitled to believe in indestructibility. That is particularly so because the risk of something even more nasty occurring prior to onset is at least as likely. Again I refer to my earlier submission (sections 6,7,8) and the need for comparison statistics for accidental serious injury or non-genetic diseases.

7. Section 3.2.5 should clearly state that the possible psychological effects of disclosure on individual relatives should have to be considered by the health practitioners. I note that the proposed guidelines indicate that effects on the family unit is a major consideration, as I understand it.

8. As to aggrieved relatives suing (para 3 p 4; para 5 p 21) I respectfully suggest care should be taken with those statements which look like legal advice. Obviously my position favouring non-disclosure in many circumstances is helped by those statements. Many injured individuals however, sue chasing insurance (most health practitioners have indemnity insurance) and often against lawyers' advice. Lack of binding precedent on point against success would likely encourage many lawyers particularly where persuasive precedents, such as those relating to infectious diseases for example, do support such a claim. Comment by practicing, specialist medical negligence litigation lawyers, or even insurers, may be useful on that aspect. Given the way our adversarial, stare decisis legal system works it is inappropriate to minimize the risks of being sued in guidelines of this nature. That is particularly so where the drafters have preferred subjectivity and uncertainty over specificity. Again I suggest a table.

9. I also found the attempts to define terms valuable if not as extensive as could be; particularly 'lessen', 'necessary', and 'reasonable belief'. However, under guideline 2, what amounts to 'reasonable steps'? Under guideline 3, what is a 'significant role'? Is discussing the case with the original health practitioner enough, for example? What is 'sufficient knowledge'? Is reading the case notes enough? Is the requirement for an expert in human genetics generally or one in the specific disease? Use of the word 'should' suggests guideline 3 has no authority being left up to the health practitioner. Under guideline 4, the phrase 'appropriate expertise' is open to interpretation. Should not a preferred level of genetics education and expertise, such as number of genetics disease patients seen, be specified?

10. In scenario 7, since early miscarriages seem common these days, should not the criterion be multiple miscarriages? Should not the family's attitude to abortion be explored? It is also difficult for NHMRC to use reproduction planning as a reason for disclosure where many or most genetic conditions are not screened for in IVF conducted under NHMRC guidelines.

11. Scenario 4 (2 in the consultation draft) stands out on the bare facts provided as a wrong outcome, in my view (see section 7 of my previous submission). It is an interference with the autonomy of the family unit and undermines the matriachical authority and presumed knowledge of her children. The guidelines themselves stress that it is the family that is to be looked after. As I understand it the one 'benefit' of disclosure to the children is that they can plan for the symptoms. My guess is that if onset was late

in the father (no age is specified) it will be also in any relative with the same mutation. The mother and certainly not the health practitioners involved, is the only person in a position to know whether or not the children who are adults would wish to know under those circumstances. Advising the adult children without the consent of the mother would be a disturbing result and suggests that these guidelines may be flawed. The non-disclosure factors added to the commentary to scenario 7 since the consultation draft are very persuasive, in my view.

12. Also for scenario 9 (4 in the consultation draft), inclusion of factors weighing against disclosure in an important addition because they very much outweigh factors favouring disclosure (see section 5 of my previous submission).

13. I also liked the materials in pp 3 and 4 and 3.2.3 about 'when is disclosure without consent permissible'.

14. It is not clear why the original guidelines 6 and 7 were deleted. They spelt out the key requirements under the amended legislation and NPPs and, although not necessary, were appropriate given that health practitioners may read the guidelines but not the legislation.

15. The form letter to relatives raises serious issues. It should be marked 'private and confidential' with care regarding the identity of the sender.

15.1 First, it must identify the specific condition despite any risk of identifying the patient. That makes it less impersonal, less business like and more caring. It also allows for research and informed discussion with health practitioners, relatives and friends before making a decision whether or not to consider testing. Not to identify the condition simply looks sneaky. It is already an exception to privacy law and would not unreasonably identify the patient because the condition will be revealed by the health practitioner at consultation anyway.

15.2 Secondly, even if for patient identity secrecy reasons the condition is not identified the specific treatments and 'benefits' of knowing for the particular conditions, must be provided. For example, 'If testing shows you have the condition then [all] we can [do] is give you the opportunity to plan for its onset'.

15.3 Thirdly, even if neither of the above details are provided the letter should indicate the symptoms that might show onset of the disease. For example, 'Should you choose not to be tested nor seek medical advice at this time you should do so immediately if you experience the symptoms listed below at some time in the future'.

15.4 I would delete, 'This letter is not intended ... et seq. ... to have more information' and other things to minimize the reading. Too many non-specific words suggests advertising material or spam and is to be avoided in a serious matter of this nature.

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