



"Peter Sainsbury"

<[redacted]>
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28/03/2008 10:02 AM

To <[redacted]>
cc <[redacted]>
<[redacted]>

Subject Disclosure of genetic information to genetic relatives
[No Protective Marking]

Dear Ms Cooke,

I wish to make the following points as a private citizen about the consultation draft dated 11 February 2008:

- 1 it essential that the title page makes it very clear that these guidelines cover practitioners in the private sector only. I realise that it already says this on the title page but I think that a way needs to be found to make this more prominent in the final version.
- 2 page 3 - are grandparents and first cousins both third degree relatives?
- 3 page 21 - the section headed 'Justice and respect' is somewhat confusing as respect is not mentioned again after the heading. Indeed, it says that the ethical principle underpinning the sharing of information is 'justice or reciprocity'. This raises two issues: 1) why 'justice and respect' in the heading and 'justice or reciprocity' in the text? 2) does 'justice or reciprocity' imply that justice and reciprocity are the same thing or that there are two ethical principles involved here? In either case, greater clarity is required regarding what ethical principles are being invoked and exactly what they involve.
- 4 page 21 - I am not an expert in ethics but it doesn't seem correct to me to say that respect for confidentiality is based ethically on patient choice. These seem like two separate, though obviously connected, principles to me. Although I accept that patients should be able to decide what happens to information about them, one could make a strong case for confidentiality even in the absence of patient choice in general.
- 5 page 34 - in scenario 7 it isn't obvious to me that it would be best practice for a genetics service to be collecting details about a patient's relatives before the result of the testing is known. I wonder if it is advisable to suggest that it might acceptable to do this, particularly as the final dot point states that

disclosure can occur using the details collected beforehand. I think that if I was the patient in this situation I would feel that the genetics service had deceived me.

6 page 37 - I don't share the view that a registered or certified letter could reasonably be perceived as coercive. In my view, this would be an appropriate way to contact relatives.

7 page 39 - 'send' is misspelt in the second paragraph of the scenario.

8 page 40 - I wonder if more guidance is required regarding cascade contact. For instance, should all same-degree relatives be initiated into the cascade at the same time or should one be chosen to start the process?

9 page 40 - scenario 11 does not really illustrate legal obligation 9 as the first woman involved did provide consent, she simply refused to inform her sister and mother herself.

I hope these comments are helpful.

Yours sincerely,

Peter Sainsbury

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