Reviewer’s report

Title: Disclosure to genetic relatives without consent – Australian genetic professionals’ awareness of the health privacy law

Version: 0 Date: 24 Nov 2019

Reviewer: Tracey Elliott

Reviewer's report:

This article is an original piece of empirical research relating to the knowledge and understanding of American genetic professionals in relation to the issue of disclosure of genetic information to relatives without consent. This area is highly topical and, although the study was relatively small (37/44 valid responses), in my view this article is a valuable addition to the literature in this field and I enjoyed reading it. It provides an illuminating snapshot of the awareness and knowledge of genetic health professionals in New South Wales. The attached tables and supplementary material are clear and helpful, particularly the summary of the guidelines provided in Table 1. The methodology used appeared to me to be sound, but I am not a statistician and the editors may wish to check statistical findings. In my opinion, the article is well written.

There are, however, a few minor matters which should be attended to before publication.

(i) Line 122: The actual case citation should be provided here, but a secondary reference. The citation for the first High Court hearing is: [2015] EWHC 1394 (QB), and the Bailii webpage: https://www.bailii.org/ew/cases/EWHC/QB/2015/1394.html. The Court of Appeal citation is: [2017] EWCA Civ 336, and the Bailii webpage: https://www.bailii.org/ew/cases/EWCA/Civ/2017/336.html. The authors should be aware that the trial of this case is currently taking place in the High Court.

(ii) Line 329: A reference should be provided to these studies.

(iii) Lines 358 -365: Your account of ABC is not wholly accurate. Disclosure was made to ABC, but by accident and only after she had given birth. There is no 'current appeal'. Initially the case was struck out as disclosing no reasonable cause of action (see [2015] EWHC 1394 (QB)). The Claimant appealed to the Court of Appeal, who allowed the appeal, deciding that she did have an arguable case in negligence (and under the Human Rights Act 1998 - see [2017] EWCA Civ 336). Because this was an appeal against the striking out, the Court of Appeal did not determine whether she was likely to succeed- they sent the matter back to the High Court for trial. The trial is currently in process. Any discussion of this case should be accurate.
Although it appears that necessary controls were followed, I do have a query in relation to the issue of consent. In relation to the consent of the participants, it is stated (Line 142) that consent was implied by submission of the questionnaire. I feel that this should be clarified. The information on the questionnaire does not make it clear that, by clicking 'submit' the participant consents to the data submitted being used. It may be this this information was available on the website elsewhere, or that this meets any requirements imposed with regard to ethical approval and consent, but I feel that this should be confirmed.

**Are the methods appropriate and well described?**
If not, please specify what is required in your comments to the authors.

Yes

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

Unable to assess

**Are the conclusions drawn adequately supported by the data shown?**
If not, please explain in your comments to the authors.

Yes

**Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?**
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

I recommend additional statistical review

**Quality of written English**
Please indicate the quality of language in the manuscript:

Acceptable

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