Reviewer’s report

Title: Health researchers’ experiences, perceptions, and barriers related to sharing study results with participants

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Reviewer: James Gillespie

Reviewer's report:

This is a well written paper that tackles an important issue in research. The survey design is sound, based on a mixture of apriori and emergent themes. In the authors' own account, the main results confirm existing research, although with a larger survey population. The novel aspects of the findings are not as clear to me - the study has unpacked some of the barriers to contacting study participants, but these seem fairly commonsensical - other than the rather bizarre 'systemic' obstacle of a lack of incentives in tenure and career progression. However, overall the paper mainly confirms existing research adding a little to unpack the reasons for researchers behaviour in this area.

Specific points:

Abstract. The journal allows up to 350 words in the Abstract. The one provided (less than 100 words) is inadequate. More details of the research methods could be given and the findings are far too vague and general. The works cited give reasons that are far more specific than a 'general interest'. There are major ethical dilemmas at every point in this debate - some of these emerge in the paper, but it would strengthen it if these were drawn out from the literature at the start. This would move the argument away from what often seems to be an 'all or nothing' position where researchers seem to be either for or against sharing. Recent literature such as Thorogood et al 2014 An implementation framework for the feedback of individual research results and incidental findings in research in BMC Medical Ethics have presented much more nuanced accounts of the levels of dilemma in sharing with participants (in this case in genomic research). If the research problem recognised this ethical complexity from the start, the presentation of the findings could raise more interesting questions.

One surprising aspect of the paper is the assumption that Institutional Ethics committees do not regard participant feedback as a normal aspect of the approval process. In Australia there is a standard question: Outline how feedback will be made available to participants (e.g. via a lay summary or newsletter)? Similar questions are standard in the UK and Canada.

Were participants given a definition of 'research results'? Most of the responses imply that this refers to scientific, population level research, but some of the concerns sound more concerned with the return of individual data eg "may not understand that these data are to be used for research purposes and are not the same as personal health data they receive from their physicians". This should be clarified, at present it reads as though apparent differences
result from readings at cross purposes. It is possible to strongly report reporting of scientific results to participants while being even more strongly opposed to giving any access to individual clinical or other data.

The all or nothing approach is also found in objections around privacy. Here the question is being interpreted not as 'should participants be given access to results' but 'must all participants be given the results'. Again, the Thorogood study shows that there are several layers of consent here. The usual practice has been to invite participants to request information on the study, not to automatically send this to everyone, regardless of preference.

In the conclusion the authors' express concerns with the institutional barriers to sharing knowledge with participants. The inclusion of questions about this type of communication in Ethics clearances would be one way to embed this in institutional practices, and would certainly make it impossible for researchers to say the possibility had not occurred to them.

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