Reviewer's report

Title: Ethical values supporting the disclosure of incidental and secondary findings in clinical genomic testing: a qualitative study

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Reviewer: Wylie Burke

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This paper provides interesting data on the views of clinical geneticists regarding the return of incidental and secondary findings after exome sequencing. However, the data are difficult to interpret because of what appears to be confusion regarding distinctions between these two types of findings.

Although the authors provide a clear distinction in the introduction, they subsequently refer to both types of findings as "ISFs". The responses of participants are also ambiguous on this point. The paper documents uniform policy in Belgium not to seek secondary findings from exome sequencing. Yet many comments quoted in the paper suggest that the discourse about IFs among Belgian geneticists mirrors discussion of SFs in other venues.

It is worth noting that the distinction between IFs and SFs was muddied at an early stage by the unfortunate decision of the part of the American College of Medical Genetics to use the term "incidental findings" in their first policy statement about the advisability of analyzing additional genes when exome/genome sequencing is undertaken; they subsequently corrected the terminology to "secondary findings" but the confusion in terminology seems to have persisted.

This confusion seems evident in some of the data reported - in particular when participants reflect on or debate whether patient autonomy allows patients to refuse IFs. In the usual understanding of the term, such findings are a part of the medical record and cannot be refused - unless physicians wish to justify deceiving patients about what is present in the medical record. They are generally unwelcome findings, as one participant in this study noted, and patients and physicians may prefer to have them, but the choice whether or not to receive them is not today generally considered debatable in other branches of medical practice.

The confusion in medical genetics, evident in this paper, appears to arise partly from the original mis-use of terminology and partly from a failure to interrogate the ethical implications of laboratory procedure - specifically, the question of whether a laboratory can or should develop a pipeline that automates the production of data not desired by physician or patient - thus making what would otherwise be secondary (and refusable) findings into incidental findings.

The data in this paper suggest that Belgian geneticists find strong ethical arguments against the production of secondary findings from exome sequencing, but accept laboratory procedures that sometimes produce avoidable incidental findings - leading to concern and uncertainty about the role of patient autonomy. However, this point is not explicitly addressed, either in the focus
group guide or in the paper's discussion. As a result, a significant moral and policy issue is not adequately addressed.

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

No

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Yes

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