Reviewer’s report

Title: Healthcare professionals' and patients' perspectives on consent to clinical genetic testing: moving towards a more relational approach

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Reviewer: Amy DeBaets

Reviewer's report:

There is a lot that is valuable in this article, and I hope that the authors will revise and publish it. In their research, they have highlighted some key failings of very common approaches to both bioethics and patient consent. While I will give more specific feedback below, the overall critique that I have is that the authors indicate their three key "virtues" that they believe that physicians should practice but need to clearly define each of the terms they use and give specific indications of how they arrived at each of them within the context of their research study. It is not really clear what they mean, particularly by openness. It is also unclear how honesty differs from the informational perspective they critique and what trust means (which seems to really mean trustworthiness). The authors should also specify why they choose a virtue ethics approach as opposed to other relational ethical perspectives, and what virtues did not arise that may have surprised them in this study (such as epistemic humility, or patience with needing to take multiple appointments and wait for a less emotionally-laden time to go over consent with patients, etc.). What specific process shifts would they recommend in order for clinicians to live out this virtuous approach? And how would they adjudicate between any conflicts between the virtues?

Some additional specific comments:

1) Page 3, paragraph 2 should be edited to highlight how the goals of care matter in determining what information to provide to patients. This should continue in the last section of the text (pages 22-23) as well.

2) Page 4, paragraph 1: The uncertainty inherent in genetic testing should be considered as part of any reasonable information process. We must be straightforward regarding what we do not know. To the extent that this is not currently told to patients, these processes should be updated and highlighted within your study, but it is not clear based on the rest of the draft that this kind of honesty is not the current practice among those who were interviewed.

3) Page 4, paragraph 2: this is where the authors should give some indication as to how they define these three virtues, why they chose their ethical approach, and how the various virtues work together to lead to a different clinical practice. The methodology with regard to the
analysis of the interviews is clear, but the methodology with regard to what ethical approach they recommend is not.

4) Page 5, paragraph 1: There may be a need for a kind of "informational empathy" as another virtue here - what would the HCP want to know in order to make a decision for themselves or their loved ones? It might help to give brief examples.

5) Page 9, paragraph 2: The reliance on any form of principles (including those the authors identify as virtues here) makes it difficult to balance them when they compete. Are they essentially just adding new principles? How would they balance them in conflict? And how does this look differently in practice?

6) Page 10, paragraph 2: It would help to include a list of the common questions as an appendix for the interviews and/or focus groups.

7) Page 15, paragraph 2: It seems that most of the HCPs who were interviewed were already manifesting the virtues that the authors highlight as desirable. What would you recommend to them to help their patients? The interviewees do not seem to be falling into the trap of "bare information."

8) Page 17, paragraph 1: Could this be used to recommend changes to current NHS policy regarding consent for genetic testing? If so, how would you structure the consent process?

9) Page 20, paragraph 3: Patients do seem to assume that their HCPs already have these virtues, but it is not clear from the research why these specific three are chosen or how they are defined, particularly in relation to the actual practices of the people who were interviewed. It would help to give clear, specific definitions for each and give examples from your study where the need for each of them arises, as well as what other common virtues did not arise as needs within the context of the study.

10) Page 21, paragraph 1: What needs to be changed in the process to help patients? It may not be that simply having more virtuous HCPs will make a difference if the people who were interviewed are already practicing in virtuous ways. What concrete steps could be taken to build decision-making partnerships in order to best assist patients? Give some details for how these virtues make a difference in that process.

11) Page 22: It seems that there could be a somewhat different list of virtues here, based on what is identified in the text: trustworthiness and forthrightness (which seem to cover the original three), empathy, epistemic humility, and patience may be likely additions as well.

Overall, the paper has a lot of promise, but the bases for the specific virtues identified and the changes in practice that would ensue really need to be clarified to make this the most useful possible for HCPs and their patients.
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.

Yes

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

No

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.

Not relevant to this manuscript

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