Author’s response to reviews

Title: The Best Interests of the Child and the Return of Results in Genetic Research: International Comparative Perspectives

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Author’s response to reviews: see over
## Responses to the Peer-Reviewer’s Comments

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<th>Peer-Reviewer’s Comments</th>
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<td>p. 2-3: “the best interests of the child framework remains the foundation for all decisions concerning children in research....” This is not the case. Minimal risk research can offer no prospect of direct benefit. One may argue it is not in the child’s best interest but still within the purview of parental decision-making. If the authors remove the word “all”, the sentence works and allows for the small amount of research that may not be in the child’s best interest (but not against the child’s interests).</td>
<td>Agree. The word “all” has been removed.</td>
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| On page 11, they cite the ESHG, “[i]n the rare case that information about a preventable or treatable early-onset disease is found, [parents] should be notified regardless of their wishes providing the findings are subject to assessment of clinical validity and utility.” They then make the claim: this goes to the notion of giving greater weight to parental authority when the seriousness of the matter increases.  
  a. First to whom does their refer “regardless of their wishes”. I think it refers to the parents.  
  b. Second If it refers to the parents, then this says, we ignore not only the child but the parents when the seriousness increases. Please clarify. | We’ve removed the confusing sentence “this goes to the notion of giving greater weight.” An earlier mention in the text was also removed as it was not deemed pertinent after revision. |
| 3) I am still concerned about conflating clinical care with research. All of the British references on pages 13-14 are clearly about clinical care. The same is true in Spain.                                                                 | We agree with the point made about the UK, but we specifically mention this difference in that section by contrasting the studied examples to the field of research:  
  e.g. “p. 13 It cannot be presumed that ethics review committees and UK courts would judge that the threshold for capacity to consent to research is the same for treatment, especially considering the risks |
and benefits of the later”

“Though this report was not specifically aimed at research…”

As for the section on Spain, the discussion surrounding the Law 14/2007 of 3 July 2007 on Biomedical Research only pertains to biomedical research.

The last part of Article 4(5) was cited in our article. The full article explicitly refers to biomedical research:

“4(5) Every person has the right to be informed of his or her genetic data and other data of a personal nature that are obtained in the course of a biomedical research, in accordance to the terms that he or she assented. The same right is recognised to the person who has provided, with the aforementioned purpose, biological samples or when other biological materials are obtained from these.

There shall be an observance of the right of the person not to know that data, which is referred to in the former paragraph, including unexpected findings that could arise. Nonetheless, when this information, according to the criteria of the doctor in charge, is necessary in order to avoid serious damage to his health or that of his biological family members, a close family member or a representative shall be informed, after consulting with the clinical ethics committee, if it exists. In any case, the communication shall exclusively be limited to the necessary data for these ends.”

While the use of the word “doctor” and “clinical ethics committee” is misleading, this is taken verbatim from the official English translation of the law.

Page 15 Canada, they discuss “concerning Many thanks for the comment. In Quebec,
a child shall be taken in light of the child’s interests. And the respect of his rights.” I am not sure if the authors mean to be saying interests or best interests. This is a big difference and if the code only focuses on interests, then it is not necessarily consistent with best interest. Please review and clarify.

article 33 is interpreted as describing the best interests of the child. We have added a new reference that supports this.

1) On page 3 you use Convention on the Rights of the Child. You need to state that this will be referred to as CRC, which you start to use on page 4. You also refer to this document as the Convention. For some readers who are less familiar with the documents you cite, this is confusing so you need to explain that this is another shorthand (or just use of these consistently throughout the whole paper).

Done.

You do not reference #27

Reference 29 should be Ross LF, Saal, HM, etc. when you refer to it in the text it is (page 8) according to the American College of Medical Genetics and Genomics and the American Academy of Pediatrics. I have highlighted the words you are missing.

Many thanks. We do, in the endnotes.

Changed. Many thanks.

P. 18: To this triangular structure, we could add a fourth actor. Change the word could: we suggest adding a fourth actor. Or we propose adding a fourth actor. As written, I could say, you could but you don’t need to. Since you want to, make it a stronger claim.

Done. Thanks.