Author's response to reviews

Title: Bioethics in Popular Science: Evaluating the Impact of The Immortal Life of Henrietta Lacks on the Biobank Debate

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Author's response to reviews:

We would like to thank the reviewers for their very thorough and helpful comments and evaluation of the manuscripts. As detailed below relevant to each recommendation or criticism, we have significantly revised the manuscript, making for a substantially improved and stronger study.

We also thoroughly edited the manuscript for clarity and brevity, and will do so again at the editor's request pending final acceptance and submission.

CHANGES MADE IN RESPONSE TO REVIEWER KIERAN O'DOHERTY

--Recommendation 1: In the conclusion we include discussion as the reviewer correctly notes that it is not possible to know whether Skloot's book is driving the heavy focus on informed consent or whether background factors are reinforcing that reception and interpretation among reviewers and journalists.

--Recommendation 2: In line with this change to the conclusion, we also include additional discussion of a recent analysis at Nature Methods examining to the extent there is a consensus among experts and the public on preferences relative to informed consent policy at biobanks. We do so in the context of discussing what the implications of a narrow focus on informed consent in media discussion of Skloot's book might mean for broader public understanding.

--Recommendation 3: We agree with Kaufman relative to the need for clarity and greater explication on the relevance of themes in relation to frames. To address this issue, we adopted his advice to build our primary analytical claims around themes only, and were much more cautious in making strong claims relative to framing. To do so, we focused the literature review/introduction on Skloot's choice to focus on some ethics-related themes over others. Later in the results section, we discuss specific correlations among themes, and describe how these linkages provide both a diagnostic and prescriptive interpretation to the issue of tissue donation and research.

--Recommendation 4: We addressed this recommendation by introducing the focus on Skloot's book much earlier in the paper, first introducing this focus in the the 3rd paragraph. It's here that we note, as he recommends, that the Lacks'
case does not directly reflect many practices by biobanks today, but does offer an opportunity to discuss the ethical issues related to biobanks more broadly.

In moving these paragraphs and additional discussion to the beginning of the paper, we believe we aid readers by introducing the main focus of the study earlier on in the paper. We also included sub-headers in the introduction/literature review section which we believe also aid readers and further promote clarity.

CHANGES MADE IN RESPONSE TO DAVID KAUFMAN

MAJOR CRITICISM

--On criticism of media versus consultation exercises: We agree with the reviewer about the important complementary role played between consultation exercises that reach and engage a strongly motivated and interested public and media depictions – especially popular best-selling books like Skloot’s – which reach and inform a much broader, larger, and diverse segment of the public.

We emphasize this complementary role between consultation and the media in the last paragraph of the section of the sub-header Biobanks as a Communication challenge, referencing in note 13 a frequently cited state-of-the-art literature review and synthesis on the subject.

--On criticism of Skloot’s book quelling discussion of other ethical concerns and reducing complexity of discussion: In the conclusion section, we softened the strength of this implication. See conclusion and response to other reviewer.

--On the difference between the book that does not focus on biobanks and the opportunity for bioethicists to raise biobanking-related issues: In the text we discuss Skloot’s focus in her afterward to her book – written in the style of a policy brief – on the implications for biobanks and tissue research generally. We also discuss her prominent NY Times magazine article on the issue. In the conclusion we also close by emphasizing the opportunity that the book and forthcoming film offer bioethicists in structuring and convening consultation exercises and forums that capitalize on the interest generated among a broader public.

--On concerns about statistical analysis: We thank the reviewer for these excellent points and insights. Per his suggestion, we re-ran the correlation table using dichotomous measures of the themes, updating the results. We also deleted Tables 3-4 making use of means, reporting frequency differences among types of articles where relevant in the main text. Since the findings relative to country differences were less relevant, we deleted their discussion from the revised manuscript.

MINOR ESSENTIAL AND DISCRETIONARY REVISIONS

We thank the reviewer for these suggestions since they enhance the quality and clarity of the article.
On statement regarding opinion leaders: This is a well supported finding and process in the field of science communication, though we did not think it was necessary to include in the literature review and therefore deleted, enhancing the focus of the section for readers.

On population and statistical significance: We dropped this reference.

On imprecise numbers: We include precise numbers in the main text.

On public as spectators: See earlier discussion about complementary role between consultation and popular media.

On Figure 1: We deleted this figure from the manuscript since it was redundant with Table 1.

Table 3: We deleted this table, instead reporting frequencies where relevant in the main text.

-Table 4: Same as above.

The other discretionary comments are similarly very helpful and relate to changes we made in the manuscript detailed earlier.