Reviewer’s report

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

Version: 1 Date: 23 October 2012

Reviewer: david kaufman

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This article does one thing that is interesting, which is to categorize ethical issues related to biobanking that are addressed in popular media articles and book reviews related to Rebecca Skloot’s book on Henrietta Lacks. However, some of the conclusions drawn seem completely unwarranted; especially the suggestion that media focus (in this instance) on issues of informed consent, vulnerable populations, and compensation for research will somehow detract from either the public or policymakers ability or willingness to discuss other issues relevant to the ethical governance of biobanks. The demonstrated interest of research funders, evidence by the wide array of funded public engagement projects on biobanking both before and after Skloot's book, suggest keen awareness of these issues among at least some research policymakers. The ability of the public who participating in such engagement studies to raise and discuss many of the issues the author(s) are concerned will be ignored seems to dull the point the authors are making. Since no evidence is provided to support the author's assertion that media focus on consent when writing about Skloot will quell discussions on other issues related to biobanking, this major point should be revisited.

Also while the use of the simple scale to summarize whether an articles address a particular ethical theme (0= does not address; 1=addresses as a minor theme; 2=addresses as a major theme) is an efficient way of creating such a summary, use of this scale as a numerical one to compute means and correlations shown in Tables 3, 4, and 5 and Figure 1 is incorrect. The scale works as a nominal one, and perhaps as an ordinal one; but it is incorrect to assume that the difference between 0 and 1 (not mentioned and minor mention in this case) and 1 and 2 (minor mention and major mention) are equivalent, or that the difference between "not mentioned" and "major mention" is always twice as important as the difference between 0 and 1. These are the assumptions being made when the authors calculate means and correlations, and they are incorrect. The same calculations could be done using a binary scale for "mentioned"(=1) and :"not mentioned". (=0) While this wont capture the emphasis of articles that made a topic their focus, it will present mathematically interpretable and correct results.

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the conclusions drawn seem completely unwarranted; especially the suggestion that media focus (in this instance) on issues of informed consent, vulnerable populations, and compensation for research will somehow detract from either the public or policymakers ability or willingness to discuss other issues relevant to the ethical governance of biobanks. The demonstrated interest of research funders, evidence by the wide array of funded public engagement projects on biobanking both before and after Skloot's book, suggest keen awareness of these issues among at least some research policymakers. The ability of the public who participating in such engagement studies to raise and discuss many of the issues the author(s) are concerned will be ignored seems to dull the point the authors are making. Since no evidence is provided to support the author's assertion that media focus on consent when writing about Skloot will quell discussions on other issues related to biobanking, this major point should be revisited.

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The authors assert that “Embedded within narratives are also specific frames of reference that reduce the complexity of issues or situations to just a few considerations.” Unfortunately the authors do this as well, reducing the complex and myriad ongoing discussions of ethical biobank governance to assert that one book and the media coverage surrounding it will somehow disable these discussions.

Major compulsory revisions

With no evidence to support the assertion that Skloot's book or the media converge (consisting mostly of book reviews, which are not often cited as major policy documents) will somehow thwart public and policy discussions about other ethical and human subjects issues related to biobanking, the authors should, seriously consider revising this point. The effect of the book and the coverage it spawns do not exists in a vacuum. Countless discussions about many of the issues of concern to the authors) have been raised in the near past, starting before Skloot’s books and continuing on as the ethical aspects of biobanks gain substantial attention. These discussions are going on in populations
(researchers, policy makers, research participants, and potential participants) much closer to the issue than the population of those who read book reviews.

While it is interesting and useful to understand the types of discussions Skloot has spawned, these are not the only discussions going on; the authors should consider whether the enormous opportunity that the book has presented ethicists who wish to raise or discuss relevant issues outweighs the fact that the book (which is not about modern biobanking) does not itself raise or engender all the issues underfoot.

If Figure 1 or Tables 3-5, or the findings reported in the text based on these figures is retained, the analysis should be re-done, using a 0/1 scale for not mentioned / mentioned.

Minor essential revisions

- If the authors wish to assert the statement in the second sentence, “the type of informal opinion-leaders who not only read the book but then also find, discuss, and share information online and in person. As voters and consumers, these segments hold greater sway over peers, policymakers, and industry.” They should provide data to back this assertion.

- Authors state that “Since we coded a population rather than a sample of articles identified, all differences displayed in tables, figures, and cells are significant”. DO the authors mean to suggest that the differences are statistically significant? Or significant from a policy perspective? I do not think the claim of statistical significance is a valid one simply because the entire population is being studied. This needs clarification

- There is no need to state imprecise numbers when you have the exact ones at hand “nearly 55 percent” should read “54 percent”. “More than 70 percent” should be “72 percent”

- Authors describe the role of the public as spectators and consumers rather than as active participants in an emerging policy debate. This ignores research efforts funded by the research community to begin including and engaging potential and actual research participants to inform biobank study design and guidance. Surely the book does not completely negate such work? This should be considered.

Discretionary revisions

- Figure 1 does not add appreciably to Table 2; moreover the averages are inappropriate as described above. Could consider removing it.

- Table 3: As described above use of the mean statistic seems inappropriate. However it is interesting to look at what issues “travel” together...perhaps simply redo using a binary scale. If this table is kept, would be great to label factors across the top as well as down the side; also need a key for symbols.

- Table 4: Mean prominence: As described above use of the mean statistic seems inappropriate. If the authors want to keep this table and Table 5, (a) the
standard deviations do not add much since statistical comparisons are not being made and they make the table a little harder to read. It is unclear what the benefit is of international comparisons, especially with such small numbers. Perhaps it would be enough to merely add to the existing text describing findings of these tables the percent in the relevant categories that covered the issue being discussed. With this change authors could consider deleting the tables themselves.

• If the authors wish to write about why simply getting consent isn’t sufficient to deal with issues of biobanking (a strong and valid point), it might be helpful to populate the manuscript with some examples.

• Authors state that “Skloot risked not only obscuring other important ethical issues”. The authors may wish to consider this statement in light of the fact that Skloot is not in fact writing an academic treatise on the comprehensive ethics of biobanks. Is there any evidence that Skloot’s emphasis has led policymakers or the public to view informed consent as a “panacea”. To be sure some researchers and biobankers feel this way, but probably not because of Rebecca Skloot.

• Authors state the book is “limiting reader consideration of deeper questions related to biomedical research and the growing demand for biobanks”. It is not clear how or why such discussions would be limited. In fact since many of the other issues are at least related to consent, it seems equally plausible that such discussions could lead to consideration of some of the other issues.

• Authors state: “Yet, even with increased investment in consultation exercises, the news and entertainment media remain the main forum through which the broadest and most diverse segments of the public are likely to learn about and discuss complex biomedical topics.” [13]. Authors might whether productive focused discussions on issues related to a particular biobank (there are many different contexts) are likely to occur via mass media, or whether biobanks themselves may need to initiate relevant discussions with participant populations about the specific contexts in which they operate.

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Not suitable for publication unless extensively edited

**Statistical review:** Yes, and I have assessed the statistics in my report.

**Declaration of competing interests:**

I declare that I have no competing interests