Reviewer's report


Version: 0 Date: 14 Apr 2019

Reviewer: Heidi Beate Bentzen

Reviewer's report:

General comments:

Topic: The authors have identified a knowledge gap in the scientific litterature, and their study seeks to fill it. It is a valuable and important contribution that I believe can be useful for the establishment and success of biobanks in Egypt. There are a few other studies that have been published about Egyptians views about biobanking, such as those referenced by the authors in this paper (refs 24 and 25 - the latter with this paper's last author as first author), but these supplement each other well.

The method chosen is appropriate for the research question. The study is geographically representative within Egypt, and it is great that the authors have chosen the three main geographical areas of the country in which to conduct the study. The sample is statistically representative (259 research participants).

Language: The language is poor, and needs extensive editing throughout the paper. There are many grammatical errors.

The link to the supplementary files did not work in the PDF I was sent for review, so my comments only apply to the manuscript itself.
Specific comments:

Abstract: You report that «Fifty eight percent were willing to participate in a genetic research project, 45.6% didn't support sharing their sample with pharmaceutical companies, and 32.4% agreed to share their samples with institutions abroad.» and further that «However, they showed concerns regarding participation in genetic research and with sharing their samples across borders or with pharmaceutical companies.» These sentences should be rephrased so that the percentages either all describe the ones who were positive or all the ones who were negative to sharing.

Page 5
Lines 5-7: I would also mention fundamental rights (human rights)

Lines 11-13: Please specify what type of data you have in mind (Demographic data? DNA data? Phenotypic data?)

Page 6
Lines 1-2: Only misconceptions? Can't participants also be hesitant due to a correct understanding of the research methodology? Also, «level of understanding» seems to similarly imply that the problem is a lack of knowledge or understanding, however, well-informed individuals may also choose not to participate in research.

Line 15: Shouldn't this be misunderstanding instead of misinformation?

Page 7
Line 10: From here on, they should be referred to as research participants.
Page 8

Line 9: Please also mention when the study was conducted.

Lines 21-22: Please highlight more of the demographics from the table in the written text, in particular the elements that may distinguish the Egyptian population studied from those studied in similar studies elsewhere in the world. The fact that a quarter of the research participants is illiterate is for instance different from what is typically the case in biobank studies in Western countries.

Page 9

It said on page 7 line 5 that only patients over 18 years of age were recruited. However, in the table on page 9, the age of the participants range from 14-80.

Page 12

Please also explain the other findings from table 3 in the written text regarding international sample sharing and access by pharma, police and others.

Page 13

Please also explain the finding regarding payment from table 4 in the written text.

Page 17

Line 1: Please explain what you refer to by «playing God». Were the participants asked why they answered as they did? Or are these guesses based on the literature?

Page 18

Lines 2-3: Why is sample sharing with Arab countries preferred? Did they say?

Line 7: Interesting. Which authorities?

Line 15: Often such laws make exceptions if the samples have been processed. Does the proposed Egyptian law make any such exceptions?
A lot of research is conducted in collaboration between private and public partners; do you see any challenges with this given your findings? Will such collaborations be difficult?

Line 19: …shared with specific entities or (I would think also) if it is genetic data

Page 19

Line 2: Which sensitive data? Please specify.

Lines 12-13: This is also in line with human rights

Page 20

Line 9: Only one (quite old) reference. This is a much debated issue in the literature so I would add some more references to show the current state of the debate.

Lines 9-11: Yes, and there are also practical issues that have been reported in the scientific literature related to whether it is feasible to feed results back to research participants.

Page 21:

Lines 2-3: I would think that similarly to Islam, one can probably find literature related to principles + to charity as mentioned on line 10.

Page 22:

Lines 7-8: Only verbal consents have been obtained from the research participants, according to the authors because the study did not involve confidential data or intervention. Page 8 line 4 indicates that participants were asked about demographic data and religion, and page 7 line 5 indicates that they were all patients. Both data about religion and health is often considered sensitive data. On page 7 line 17 it says that the verbal consent was documented (How? Recording? Please explain). In the table on page 9, 25.5 % of the participants are described as illiterate, and this may help explain the choice of consent method. I assume that the procedure chosen is in line with Egyptian legislation. I would like to see more thorough information about the Egyptian legislation here and some information about how the rights of particularly the illiterate adult patients who participated in the study were ensured. Please also add information about how data protection was ensured.
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.

Yes

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.

I recommend additional statistical review

Quality of written English
Please indicate the quality of language in the manuscript:

Not suitable for publication unless extensively edited

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