Reviewer's report

Title: Biobanking in Israel 2016-17; expressed perceptions versus real life enrollment

Version: 0 Date: 09 Aug 2017

Reviewer: Karen Meir

Reviewer's report:

This is an excellent idea and long overdue in Israel. Some comments for the authors:

1. If available, please provide more detailed information regarding the focus group participants: age, gender, education/income level, whether the focus group members had any previous experience as participants in medical research of any kind.

2. It is worth restating in the results section, that during the "real life" phase, potential donors were approached with the improved consent form.

3. During the "real life" phase of the project, how long did recruiters sit with potential donors? The "real life recruitment" section (page 12) states that on average it took 5-15 minutes to address all queries, however it is not clear how long the entire consent process took, on average.

4. The updated consent form (appendix 2) states that "When medical data will be needed for research, it will be de-identified to assure anonymity". Similar statements reappear in the donor information leaflet (page 27, line 16; page 30, lines 15,16). De-identification by coding is strictly speaking not a form of anonymization. True anonymization definitively removes the link between the sample and the donor such that even Maccabi/"Tipa" staff will not be able to link the samples to the donors, and therefore donors could never be re-contacted for any reason. These statements should be further revised.

5. The donor information leaflet discusses (page 25) Israel's requirement of a Helsinki approval for all projects utilizing material and data stored in "Tipa". An additional line at the end of this paragraph (top of page 26) should make clear that "Tipa" itself will have had to receive a Helsinki approval in order to function. To further "relax" donors, I would suggest the following wording (end of line 3): "In the same fashion, the "Tipa" biorepository was also required to receive ethical approval from the Ministry of Health's
high committee on human subjects research, to store and distribute your de-identified samples and data in future ethically approved research studies".

6. The Withdrawal section of the donor information leaflet (page 34) mentions "Midgam". I would suggest removing these lines - they may confuse potential donors. Midgam is a disease-based biorepository network, conceptually different from the epidemiological biobank the authors are proposing.

Minor comments/editing:

1. Page 8, line 19/20: typographical error in the last word, which should read 'signing', and not 'siNGing'.

2. Page 9, lines 45/46: add a comma between the words "stealing" and "misuse".

3. Page 10, line 22: end the sentence with a period.

4. Page 10, line 48: retranslate from Hebrew: "You never know where can it get" (incorrect English syntax) to "you never know where it can end up".

5. Page 10, line 58, first word: "others", not "other".

6. Page 11, line 19, "participants" (ie. add "s").

7. Page 13, line 52, replace "a larger" with "an expanded".

8. Page 15, line 41, last word typographical error: "rational", correct to "rationale".


11. Page 32, line 26 should read "representative of "Tipa", who is a personnel member trained in the communication of…"

12. Tipa is written in some places with a capital T and in others with a small t. I would keep it capital throughout. It's a (very good) name.

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?
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Yes

Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?
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Not relevant to this manuscript

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