Reviewer's report

Title: Public's attitudes on participation in a biobank for research: An Italian survey.

Version: 2  Date: 28 July 2014

Reviewer: Kyle Brothers

Reviewer's report:

Major Compulsory Revisions

1. You refer repeatedly to the "availability" of respondents to donate biosamples or participate in a biobank. This is ambiguous: Does this refer to willingness to participate? Or perhaps availability to donate biosample? You could consider using a different word (willingness?) or define explicitly what you mean when you refer to "availability".

2. You make comparisons between survey of the public and survey of EC members. Therefore, you should state in the methods section whether the questionnaires used in this study and your earlier study with ECs was identical, or how this earlier study was different. You should state the sample size of the earlier study. Also, you should explicitly reference your earlier work in the methods section.

3. Papers of this sort typically have a section immediately before the Conclusion section with the title "Limitations". I believe this study does have a few limitations, and it would be helpful to discuss them explicitly.

Minor Essential Revisions

1. Introduction section of the paper: You refer frequently to "people". This is ambiguous because, of course, others involved in biobanks, such as healthcare providers and members of ethics committees, are "people". I think you want to speak here of "Laypersons" or, perhaps, "research subjects."

2. Introduction section, Line 19: The phrase "Existing in our institute a biobank for research on dementia and psychiatric disorders..." is awkward and unclear. Revision recommended here.

3. Methods section, Page 5: There are a few statements here that are confusing or ambiguous. Please consider revising the following phrases:

   Line 12: "Consecutive family members were invited to participate..."

   Lin2 15: "Three questionnaires were submitted to the participants by an independent researcher" What does it mean that the research "submitted" three questionnaires to the participants? Perhaps you mean "administered"? In what way was the research independent?

4. Methods section: Were their patients at these clinics who were not suffering from cognitive impairment? How did you assess whether they were or were not?
5. Perhaps the information on the performance of the first questionnaire found in the methods section should instead be moved to the results section? Also, Since you indicate this questionnaire came from another source, it would be helpful to state explicitly whether principal component analysis was performed in the original study from which this questionnaire was derived.

6. Page 9, Line 7: You refer to "the three types of genetic research" here, but it is not clear what those three types are or their order, and therefore it is impossible to interpret the 77%, 75%, and 77% that are listed immediately afterwards.

7. Page 10, Lines 8-9: "The full questionnaire was completed by 122/125 subjects: from point 2 “Protection of confidentiality”, the percentage of answers is calculated based on those subjects." This sentence is confusing and should be revised.

8. Page 11, Line 4: Earlier you stated that more than one option could be selected, but here you say that "(although public participants chose only one answer)". Does this mean that respondents only provided one response even though they were allowed to provide multiple answers? If so, perhaps this indicates that they did not understand the question?

9. Page 13, Line 10: I would be more precise with the statement "It also assures that our sample’s opinion is representative of the target population." If by "target population" you mean the general public, then this is not the case, since this is a very specific population (i.e. family members of a loved one with dementia). I think you mean that your sample is representative of those who have a loved one with dementia. If that is the case, you should state it this way.

10. Table 5: Although the text provides more information, Table 5 is confusing. What do the percentages represent? Are these the conditions that participants think client studies should meet in order to access data and samples stored in a biobank, or are they conditions that participants would consider important when deciding whether to allow their own samples and data to be included in a biobank?

11. Figure 1: I believe you mean "Utilitarianism" rather than "Utilitarism". Also, this figure should have a more detailed caption. Even though the text of the manuscript provides some information about this, the figure should have a descriptive caption.

Discretionary Revisions

1. The conclusions section of the abstract should be revised to reflect the implications of the empirical findings of this study. For example, you could say something about the fact that the views of lay persons are quite different from those of ECs. As it is, the conclusion section states, essentially, that people should pay attention to results from studies like yours. I wouldn’t consider this a conclusion of the findings from the current study.

2. Introduction section of the paper: You have several sentences here that state how "biobanks should be regarded" and that people's perceptions "need to count". However, you provide no justification for these statements. I think it is OK not to provide a detailed justification, but it would be helpful to give reasons
rather than simply stating "this is the way it should be".

3. Page 12, Lines 3-5: "Forty-three subjects (35%) want the research results of value for themselves as donors to also be communicated to family members; 34 (79%) of them ask for communication to family members in any case." This is just a little confusing. What is the difference between these two categories?

4. Page 12, Lines 20-22: "Regarding donors' remuneration to take part in a biobank, the large majority (87%) think this should not be the case; the others agree with remuneration, but exclusively as a flat refund and refund for documented expenses." Just two comments on this sentence:

   (1) What does "this should not be the case" mean? I suspect you mean to say, "The large majority (87%) think donors should not be remunerated for taking part in a biobank."

   (2) "Refund" refers to the circumstance when a person pays for something and then gets some of that money back. In this case I think it would be more accurate to say "as a flat payment plus reimbursement for documented expenses"

5. Page 15, Line 7: "Our work was also finalised to collect lay subjects' opinion..." I think you mean "Our work was designed to...

6. Table 3: There are a large number of items on this table, so it would be helpful if they were organized in some way. For example, they could be listed in order from most important to least important based on the responses of the public. Alternatively, they could be grouped by domain.

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

   **Quality of written English:** Needs some language corrections before being published

   **Statistical review:** Yes, but I do not feel adequately qualified to assess the statistics.

   **Declaration of competing interests:**

   I declare that I have no competing interests