Reviewer’s report

Title: Cancer Patient Perceptions on Biobanking Research

Version: 1 Date: 10 December 2012

Reviewer: Jennifer Harris

Major Compulsory Revisions

This purpose of this study is to examine perspectives of leukemia patients regarding ethics issues in biobanking research and 'to determine whether their experience of receiving treatment and interacting with the physicians and clinic staff might have influenced their views on various ethical and legal issues relative to biorepository research'. Response frequencies and chi-squared test results are reported.

1. A number of conclusions are drawn that are not sufficiently founded based on the analyses conducted or information provided. First, this study did not measure or directly investigate any factors that affected the responses to the 2nd questionnaire; the questionnaire included 9 questions inquiring about perspectives in biobanking and tissue sampling. It did not include a control sample of non-leukemia patients. Therefore, it is erroneous to state that a purpose is to 'determine whether their experience of receiving treatment and interacting with the physicians and clinic staff might have influenced their views on various ethical and legal issues relative to biorepository research'. This confounds an association with causation. From the information provided conclusions about the reasons for differential responses between the original and follow-up questionnaire can not be substantiated.

2. Furthermore, a substantial portion of the sample did not complete the follow-up, but this is not addressed in the ‘limitations’ section which should provide more in depth information about the potential bias due to non-response. Such information may be informed by analyzing the differences between the responders and non-responders (to the follow-up) with regards to how they completed the original questionnaire.

The manuscript purpose and conclusions should be critically reviewed and revised to account for points 1 and 2 above.

3. In the discussion the authors state that this work ‘highlights key differences in the perception of cancer patients as compared to other populations surveyed’. I think this statement needs a cautionary note as they did not study other populations using this questionnaire.

4. Very little background information is provided about the development of the questionnaire or how well it reflects the measures used in other studies. The
manuscript explains that the questionnaire aimed ‘to explore the perspectives of patients undergoing leukemia treatment’ does that mean it was especially formulated for leukemia patients? It does not seem to be. How was the survey developed, is it based on other surveys that have been published? Some questions are poorly worded and not completely relevant to the actual issues that must be addressed in biobanking to inform policy. For example, the question about withdrawing consent asks about withdrawing consent and samples in a single question. This has limited relevance and usability because once samples have been sent to analysis or shared (as they often are) in consortia then residual samples can be withdrawn but certain data can not. Consents have been widely modified to reflect this difference. Thus, it would be more informative to know if participants would still consider donating samples knowing that once their samples are sent to analyses that withdrawal of the data generated from those samples is not always possible. The research questions under investigation here are highly embedded in contextual issues so it is critical to describe more about the basis upon which cross-study comparisons can be made.

5. What is the basis for the conclusion on page 11 stating ‘What is interesting is that more patients indicated that they should have the right to withdraw from research when compared to other surveys and this could be partially explained by the high degree of trust they have in doctors, hospitals and university-based researchers and their views on the importance of biobanking research for leukemia’? Was this based on bivariate analyses between trust and the right to withdraw? If so, where is this presented? Also, several comparisons are being drawn in this one sentence which makes it difficult to interpret. Is this a between-survey difference or a statement about the relationship between trust and withdrawal in this survey?

Minor Essential Revisions

6. The title doesn’t seem to reflect what was actually studied, some thing like…perceptions about ethical issues associated with biobanking research’ seems more accurate, because this study has not investigated perceptions of biobanking research per se.

7. Abstract: What is the distinction between the perception of patients and the perception of the public?

8. Research Setting: The first sentence on page 4 indicates that the patients were randomly recruited, later on the authors explain that patients participant from the Princess Margaret Hospital Hematologica Malignancy Tissue Bank were invited as a convenience sample. Does this mean they were not randomly recruited?

9. There is considerable redundancy in the presentation of the results. Most of the findings could be conveyed in the figures and tables without repeating all percentages in the text.
10. Some reorganization is needed. The Results section includes information that is either relevant for the methods or for the discussion. For example, on page 5, the information about why they limited consent models does not belong in the results, likewise, on page 6 the information defining anonymity and de-identification does not belong in Results.

11. The presentation of the sample numbers is a bit confusing. Apparently, 100 patients were recruited to the first survey but later it states that the recruited number is 78 and later it states that a response rate of 64.1% is equal to 100. Wouldn’t a response rate of 64% be 64 people? It is not clear who was recruited to the second survey, was it the initial sample or just responders to the 1st survey? Can the authors describe the sample in a more straightforward and clear manner.

12. Page 5 refers to 45 participants who completed both initial and follow-up surveys while Table 1 indicates 43 participants who completed both, and on page 6 it states that 44 participants completed the follow up. The authors should correct or explain, these discrepancies.

13. Unanswered questions or multiply answered questions were not counted in the final sample. How much data was lost to this and what is the potential bias? Did particular questions tend to be unanswered?

14. The authors indicate that for their comparative analyses that ‘if a question was left unanswered in the follow-up survey, we considered this as a change in response’. What does this mean and how was it scored?

Discretionary Revisions

15. Abstract: The last sentence of the ‘Results’ and ‘Conclusions’ in the Abstract are nearly fully redundant, consider shortening the results.

16. Page 3, the word ‘tenet’ is misused, a tenet is a principle, the collection of biological materials plus other data is not a principle.

17. References 1 and 2 don’t fully capture the substantial investments made, authors should also refer to the pan-European BBMRI.

18. Page 3, statement that ‘many studies evaluating public and patient perspectives on biobanking’ should be referenced.

Level of interest: An article of limited interest

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

Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests:

I declare that I have no competing interests