Author's response to reviews

Title: Systematic Analysis of Four Studies in a Comparative Framework Reveals: Consent Rates on British Cohort Studies Higher than on UK Household Panel Surveys

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Version: 4 Date: 5 September 2014

Author's response to reviews: see over
Dear Editor and Reviewers
Many thanks for taking the time to review our work and for helping us improve our manuscript.

We have now made revisions in line with your recommendations. A log of all comments and our responses to them is listed below. We hope you will agree with us that these changes are appropriate and improve the readability of the research.

Best wishes,
Gundi Knies & Jon Burton
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<th>#</th>
<th>Reviewer comment</th>
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<th>Action to be found where?</th>
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<tr>
<td>1.1</td>
<td>The quibble relates to the use of the phrase 'systematic' in the title: I think it may be redundant in that presumably most analysis is systematic??</td>
<td>Word “Systematic” removed from the title.</td>
<td>Title page</td>
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<td>1.2</td>
<td>Provide greater level of demonstration of how health-focused the studies are</td>
<td>This was also suggested by the other referee and we have addressed the issue in the following ways:</td>
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<td>a) We have expanded Table 1 so it incorporates a number of markers of how much health-focused the study is: the branding of the study as indicated by who runs and funds the study; the proportion of questionnaire content which is health-related (we have liaised with the PIs of the studies over this classification); the stage in the life of the panel study when biological specimen were collected.</td>
<td>See Table 1</td>
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<td>b) We have added a sentence describing the type of health data collected in the BHPS</td>
<td>See ll. 203</td>
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<td>c) We make it clearer that the UKHLS does not collect as much information on health and use health services as the BHPS does but that the survey is nevertheless more health-focused</td>
<td>See Table 1, note 3 and ll. 223ff.</td>
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<td>d) We now explicitly mention the rationale for our assessment of how health-focused the four studies are</td>
<td>See ll. 290ff.</td>
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1.3 My main comments relate to the discussion section: This reiterates the differences between studies in the demographic and socio-economic factors that are associated with consent to follow-up but does not offer suggestions as to why this variation in the strength and direction of association may have occurred. This is reasonable as the surveys do not contain the relevant data to answer this question, but it does rather highlight and re-emphasise how little is known about the factors influencing consent and why these vary so much between studies. It does however perhaps offer the alternative suggestion that the variation in consent between studies arises not primarily from a focus on health but on other socio-demographic factors, whether measured or unmeasured.

We agree that the results highlight and re-emphasize how little we know about the drivers of consent. You are, of course, right that other factors than the ones we observe (and include in our models) may be important. We had already pointed out that markers of trust and altruism are factors which have been linked to consent, and that this is consistent across all studies we have seen thus far.

On the basis of the many empirical studies we have seen we have to conclude that socio-demographic factors are not, in all likelihood, driving differences in consent rates.

We made the following changes to the manuscript to make this clearer:

a) We had already mentioned, in endnote 7, that whilst we reported results only for those variables which are available in all three studies we have also undertaken the analysis using any variables that are included in just two of the three studies. We now re-iterate this in the Conclusions.

b) We added some text to suggest that this inconsistency across the studies we’ve examined here echoes an inconsistency found in the literature for socio-economic variables.
Another interesting factor that perhaps could be commented on is the apparent inverse relationship between participation and consent rates in the BHPS and UKHPS. This leads to the interesting question as to whether it is better to have a high consent rate amongst a select group of participants or a highly select consent rate amongst a more generally representative group of participants. This is an interesting comment, although we are not in a position where we can answer such a question without experimental manipulation. The relationship between response and consent rates for the BHPS and UKHLS is confounded with survey design; the BHPS respondents are being asked consent for the first time in their 18th annual interview, compared to the UKHLS respondents who are being asked as part of their first interview. In response to a suggestion by the other referee, we have added a more explicit discussion of the fact that other design features may be drivers of consent. Therein we mention a publication in which the question of when in the life of a panel to ask for consent (and the associated trade-off between higher consent rates and lower N) is examined in more detail.
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<td>2.1</td>
<td>Title - I would strongly recommend including 'Health Linkage' prior to 'Consent Rates' (or similar) in the title to make it clearer what kind of consent rate is being referred to.</td>
<td>Words added to title.</td>
<td>Title page</td>
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<td>2.2</td>
<td>'Health-focus' - one of the major strengths of the paper is its' ability to compare different studies and it uses the different levels of 'health-focus' to test an important hypothesis. While I agree with the categorisation of the different studies by the degree of health focus, I know these studies well and I wonder it is might be helpful to a reader who is less familiar with them to bring this out more clearly. At the moment, this comes in the study descriptions and could be a bit lost among the rest of the descriptions, so I wondered if the authors could draw this out more clearly e.g. summary table on how 'health focused' each study is. Related to this, there is actually no mention of any health data in the description of BHPS - I assume because there is none, but worth stating this. I wondering if you could use some kind of summary measure e.g. proportion of the questionnaire that is about health - all/most/some/a little/none, or something along those lines.</td>
<td>The other reviewer also suggested that we should draw out more clearly how health-focused the studies are. Please see our response to #1.2</td>
<td>Il. 203ff.</td>
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<td>2.3</td>
<td>Description of NCDS linkage protocol (and Table 1) (lines 176-197) I felt that the description of the protocol could be clearer that an information leaflet about linkage was given, and about when and how this was given. Table 1 states that this was given at the interview by the interviewer but this is not clear from the description.</td>
<td>Made it clearer in the text that the information leaflet was handed over by the interviewer (in all studies as applicable).</td>
<td>Il. 190ff. &amp; Il.212f. &amp; Il.230f.</td>
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2.4 Written versus verbal consent
One of the other main differences between the studies in the protocols was that NSHD and NCDS required written consent whereas for BHPS and UKHLS it was verbal. Is that correct? I think it would be helpful to state this more explicitly and perhaps include in Table 1. All consent was written – the BHPS and UKHLS required written consent, not verbal. This has now been made explicit in the text.

2.5 Level of Interviewer experience of asking consent (Table 1)
Table 1 implies that there are differences in the level of interviewer experience in asking consent and that NCDS, NCDS and UKHLS differ in this regard. I wasn't sure where this information comes from, as this is not discussed in the study descriptions. If this is the case, and is central to the argument of the paper, it should be better evidenced. I would anticipate that these different studies varied in the amount of emphasis they placed on linkage during project-specific interviewer training, but given that they are all using lay-interviewers working for a fieldwork agency, I would be a bit surprised if the interviewers really did vary systematically in this regard. I would suggest considering dropping this from the table. The information on the likely experience of the interviewers in asking consent questions has been dropped from the table as suggested. Since interviewers are generally free-lance and may work for more than one company, have different caseloads etc. we cannot objectively state how much experience they have had asking for consents to data linkage.

2.6 Other differences between studies
As well as their health focus, there are also a number of other differences between the studies. Some of these e.g. everyone same age in cohort studies, is mentioned in discussing the results. But I wonder if some of the others (annual interviews, multiple respondents, baseline vs later wave) need to discussed a bit more, in order to rule them out as the driver of the observed differences in consent rates. This is a good comment and we’ve added some text which raises these issues. Unfortunately, without an experimental design, it is difficult to disentangle the different survey designs from the consent rates.

2.7 Socio-economic vs. health variables
One of major findings is that socio-economic variables are more related to consent in household panel surveys and health are in cohort studies. Though, of course, by design there are more socio-economic data in panel surveys and less in cohort studies, This is a good point. Note that whilst we restricted our analysis to measures which appear across all three studies, we also analysed other measures that were available in any two studies (see Conclusions, specifically: ll. 445ff.
Similarly, there is more health data in cohort studies and less in panel surveys. Ideally you would want all the measures in all of the studies, but you don’t have this. I agree that you have enough of each in all the studies to draw this conclusion, but I would suggest perhaps discussing this issue more directly in the text.

2.8 Implications
I wondered if you could draw out the implications for other studies a bit more clearly? e.g. there is a debate in the literature about the placement of consent questions, do your results speak to this? Or do you feel that you can give any practical advice to studies asking for health linkage consent, particularly if they are not about health i.e. they need to work harder to explain the benefit/rationale.

Our results don’t really speak to the placement in the interview or any other factors which may be manipulated by survey designers to improve consent rates – this is because the differences in consent rates are confounded with study design since the design parameters were not experimentally allocated. Having said that, we believe that “saliency of the request” is the key underlying mechanism for our finding that the more health-focused studies achieve higher consent rates. Hence, any measures that are likely to make the request appear more salient could lead to higher consent rates. We have now added some text to this effect. Thank you for prompting us to think about this more!

2.9 Table 1 - always capitalise 'Hospital' in the final row.
This has been corrected.