Reviewer's report

**Title:** Consenting to Health Record Linkage: Evidence from a Multi-purpose Longitudinal Survey of a General Population

**Version:** 1  **Date:** 13 December 2011

**Reviewer:** Don Willison

Reviewer's report:

Overview

This is a well-written paper on a topic that provides important insights into the potential biases introduced through obtaining consent for the linkage of survey information with existing administrative health data. The Background and Methods sections provide a very clear description of the context for the reader not familiar with the British Household Panel Survey (BHPS) and the methods used for the consent process for record linkage, which is the subject of this paper. Analyses are straightforward. Most of the revisions suggested are minor.

Major Compulsory Revisions

(1) The most striking finding is the overall low consent rate to record linkage (41%). Most of the paper focuses on predictors of who consented. Little is said of the actual low rate of consent. The Discussion section would benefit greatly if the authors were to provide some data on consent rates for comparable projects in other countries. In Canada, for example, Statistics Canada has had a much higher consent for similar linkages – in excess of 90%. It may be that this information is not generally in the public domain.

(2) In addition, in the Discussion section, the authors could look beyond the sociodemographic data under consideration to consider what might be the cause for this overall low consent rate. For example, there have been several media headlines in the UK in recent years over the loss of large amounts of personal data on various media. This may have created a general mistrust of how data are managed and, therefore, a reluctance to have this information linked. On the other hand, this is a sample that has already agreed to sharing sociodemographic data that are generally considered quite sensitive (income, education, health conditions). So, an exploration of these issues would add considerable depth to the paper.

Minor Essential Revisions

(3) As mentioned above, the Methods section generally explains well the sequence and chronology of events in relation to Wave 18 of the BHPS. However, the actual time window when the invitations to have one’s survey linked with administrative records appears to be absent. This is important, especially if one were to consider how the consent rate may relate to the media.
reporting events, raised in comment (2).

(4) From the description on page 5, it appears that the consent decision was made at the time of the visit by the surveyor. It would be helpful to be explicit whether or not people were given additional time to consider this request and provide their consent at a later date (e.g. by mailing in the consent form). That would make more explicit whether any of the 59% of non-consenters were simply non-responders.

(5) Some of the results are actually presented in the Methods section. This includes the overall consent rate (p.6) and the reporting of the concordance of reported hospitalizations with administrative data (bottom of page 6 and top of page 7). These should be in the Results section.

(6) There was a substantially higher consent rate among those classified as not living in standard household types (50%). It would bee helpful to know what types of household arrangements were lumped into this category.

(7) Table 2 summarizes regression analysis results. Under “has higher degree” (row 16), the comparison group need to be stated. In Table 1, the greater outlier group appears to be “commercial qualification” more than “higher degree”. So, it is unclear how “higher degree” came to become the variable of interest. Perhaps there is actually a gradient effect.

Discretionary Revisions

(8) It would be interesting to know if there has been any change in participation rate in the BHPS over time. This may help inform the low consent rate for record linkage.

Additional comments

(9) In the last paragraph of the Discussion section, the authors indicate that it is planned to re-approach non-consenters and new entrants with the consent question to get a better sense of who is more reluctant to consent. It would also be helpful for them to solicit (in a way that does not pressure the respondent) the reason why they do not wish to have their files linked. This could also be correlated with the demographic factors that predict decision to consent to linkage.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

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.