Author’s response to reviews

Title: Using data linkage to enhance the reporting of cancer outcomes in Aboriginal and Torres Strait Islander people in NSW, Australia

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Author’s response to reviews:

Dear Dr Hu,

Thank you for the opportunity to respond to the reviewers’ comments on our manuscript (BMRM-D-19-00097). We have now revised the manuscript according to these comments. Please find below our point-by-point response.

Reviewer 1

Abstract:
'Conclusions' in abstract should include that 'weight of evidence method' was found most suitable for future analyses of cancer outcomes of Aboriginal people. This may help the reader to select a method of enhancement for their own research.

Response: A statement about the recommended method has been added to the abstract:
"We considered the weight of evidence method to be most suitable for population-level reporting of cancer incidence among Aboriginal people."

Results:

- [Table 3, Figure 1]: make clear in the text that Figure 1 is an illustration of Table 3 and refers to the same data.

Response: The underlying data for Figures 1 and 2 is now stated as being from Table 3 in the figure legends:
"(see Table 3 for underlying data and 95% confidence intervals)".
Discussion:

- typos on p.8, line 6/7: correct to 'the incidence of cervical cancer may be due to ..... but may also be due to other factors.'

Response: Amended.

- p.8, second paragraph: finding that after enhancement results indicated high breast and prostate cancer incidence among Aboriginal than non-Aboriginal people in NSW; This is a major finding and you could explore the possible impact of under-reporting more. E.g. prevention programs might currently not be targeting Aboriginal people as much as they should; we might currently not be aware of the full extent of cancer incidence in Aboriginal people (melanoma, breast, prostate cancer); what does that mean for Australia/ public health programs? More funding necessary to help reduce risk in high risk groups. More targeted interventions / research warranted;

Response: We have now added a paragraph highlighting the need for research in other jurisdictions, cancer as a leading cause of burden of disease in Aboriginal people and the importance of this finding for public health programs (page 9, lines 10-16). Screening programs in Australia are already targeting Aboriginal people since they have lower participation rates.

Reviewer 2

- it is a linkage work submitted to a methodology journal, therefore I would like more information about your linkage strategy and measures of quality of your linkage, how the algorithm was developed, etc.

Response: More information on the linkage methodologies has been added to the methods (page 4, paragraph 2):

"Data linkage was performed by the Centre for Health Record Linkage (CHeReL). The CHeReL uses Choicemaker software to perform probabilistic linkage of personal identifiers using a privacy-preserving protocol (http://www.cherel.org.au). The datasets used in this study are in the CHeReL's Master Linkage Key. The CHeReL implements quality assurance procedures and performs clerical review of a sample records to keep the estimated false positive and false negative linkage rate to less than 5 per 1000. The CHeReL provided a unique and arbitrary "Project Person Number" which enabled the records in each study dataset to be joined for an individual without the researchers accessing personal identifiers."

The CHeReL website, which is now referenced in the Methods, provides information on the technical aspects and data quality of the linkage.

The focus of this study is on identifying a methodology for reporting cancer incidence among Aboriginal people. This study compares existing algorithms that have been developed for use
with linked routinely collected data sources with incomplete Aboriginal status. Sources for these algorithms have now been cited in Table 1 in addition to the Methods to enable readers to get more background on the development of these algorithms should they wish.

- for me it is not clear why the risk of a person being wrongky identified as arbouriginal is very low. You did not convinced me why if they reported as a non arbouriginal and latter on as arbouriginal the negative report is the wrong one.

Response:

If a pathology report is the only notification to the cancer registry then Aboriginal status will be unknown since pathology reports do not contain Aboriginal status (Methods, paragraph 1). Therefore linked records from the study datasets will provide new information on Aboriginal status.

Aboriginal status at NSW health facilities is self-reported which has now been stated in the Methods. Collection of Aboriginal status relies on consistent collection at health facilities and people feeling comfortable to self-identify (Introduction, paragraph 1). There have been policies and programs during the study period to improve the collection of Aboriginal status (such as the identifying question asked in every encounter with health care facilities) and programs to increase cultural safety which are likely to have increased Aboriginal peoples' willingness to self-identify as Aboriginal over the study period. Improved collection of Aboriginal status after diagnosis and in facilities that have not provided cancer care will identify people as Aboriginal compared to the information available on the NSW Cancer Registry. For these reasons we consider it is likely correct that people are newly identified as Aboriginal when previously they were not recorded as such on the NSW Cancer Registry. This has now been elaborated in the Discussion (paragraph 1, lines 21-29).

Incorrect classification of people being Aboriginal on death certificates is considered to low since this information is provided by next-of-kin. This has now been stated in the Methods (page 5, line 16) and Discussion (page 10, line 4): "...if a person was recorded as Aboriginal on the NSWCR or death certificate, this information was accepted, although there is a possibility for positive misclassification this is likely to be low since the information is provided by the next-of-kin."

I would recomend that you submit this paper for a jornal more focus on analysis of health situation than methods.

Response: There are known issues with the quality of Aboriginal status on cancer registries and routinely collected-datasets. This study has demonstrated that different methods for reporting cancer incidence have a profound impact on estimates of cancer incidence among Aboriginal people. Linked data methodologies increased estimates of cancer incidence rates by 17-49% for females and 22-80% for males compared to using the status recorded on the cancer registry. The method for reporting cancer incidence needs careful consideration. This study contributes to the
methodological basis of analysing the health situation of Aboriginal people using better estimates of cancer incidence and therefore is suitable for a methodological journal.

All revisions have been track-changed in the text. We trust the revised manuscript, incorporating the requested changes, will now be suitable for publication in BMC Medical Research Methodology and look forward to your reply. We would be happy to clarify any aspect of our response.

Yours sincerely,

Nicola Creighton