PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (see an example) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: methods for a population-based study
AUTHORS	O'Connell, Dianne; Goldsbury, David; Davidson, Patricia; Girgis, Afaf; Phillips, Jane; Piza, Michael; Wilkinson, Anne; Ingham, Jane

VERSION 1 - REVIEW

REVIEWER	Paul Glare Memorial Sloan-Kettering Cancer Center, USA
REVIEW RETURNED	27-Dec-2013

GENERAL COMMENTS	This is an interesting, well-written paper that describes the methodology for linking administrative data sets in the state of New South Wales Australia where the authors claim this kind of work has only been done on a limited basis. It is important because many jurisdictions would be able to repeat this kind of work enabling benchmarking, so having the methodology clarified is crucial. They conclude that they have developed a reliable method, but with a lot of limitations. While the advantages (e.g. representativeness and precision) and disadvantages (e.g. limited variables) of using administrative data sets is well known, there seem to have been a lot of gaps in the data sets raising concerns about the validity of their conclusions and this concern needs more discussion. The introduction is a bit long. The findings of prior studies in other Australian states aren't very relevant to this methodologic paper. they could be omitted or summarised in a table. The issue of the probabilistic matching describes in the Methods needs clarification. I presume this was required because of privacy laws, and is likely to be required by IRB's in other countries. The description is quite technical and I think a figure would help understand how this worked and this would be more helpful than the current Figure which does not add much to understanding how the study was done, and repeats what is in Table 2. Regarding validity of the methodology, why are there so many gaps in the NSW data? Why is the ABS data so incomplete? Why are many ED's not part of the state reporting system? Why is palliative care utilization not routinely collected? In summary, do the results accurately reflect the real situation of end of life care in NSW?

REVIEWER	Lorna Rosenwax Curtin University Western Australia
REVIEW RETURNED	17-Jan-2014

GENERAL COMMENTS	Generally this paper is well written. As the paper is about record linkage, and few places in the world are able to link administrative data for whole populations, the paper is relevant to a limited audience. However I imagine that future papers with results from these linkages will be of greater interest to readers. This is primarily not a research paper but a paper explaining the methods or approach taken to describe acute hospital-based services for a population in their last year of life. The paper offers rudimentary results. The abstract is confusing. It reflects paper(s) that will be written in the future and not what this paper is about. As one example, the objective of this paper is not 'To describe health care utilisation in the last year of life ....'. Rather the objective is to describe the methods used to obtain data, link data, etc. Likewise in the body of the paper, the data analysis explains what will/may be done into the future and not necessarily the analysis for this paper. I believe this needs correcting/clarification. The first half of the paragraph on page 9, commencing line 39, is very difficult to understand and needs to be rewritten. The sentence commencing with ' While there is some related information ...' in the opening paragraph in the Introduction (page 5) would benefit from referencing. The fourth dot point of the Strengths and limitations of this study (page 4) needs rethinking. It is difficult to see how this study will provide a foundation from which to develop an efficient data collection infrastructure.

VERSION 1 – AUTHOR RESPONSE

Reviewer 1

Comment 1 *This is an interesting, well-written paper that describes the methodology for linking administrative data sets in the state of New South Wales Australia where the authors claim this kind of work has only been done on a limited basis. It is important because many jurisdictions would be able to repeat this kind of work enabling benchmarking, so having the methodology clarified is crucial.*

They conclude that they have developed a reliable method, but with a lot of limitations. While the advantages (e.g. representativeness and precision) and disadvantages (e.g. limited variables) of using administrative data sets is well known, there seem to have been a lot of gaps in the data sets raising concerns about the validity of their conclusions and this concern needs more discussion.

Response 1 The Discussion section has been amended as shown below, in response to this and the reviewer's Comment 4. We believe that for each limitation the downside does not diminish the benefit of reporting this information.

> [Page 12, paragraph 2] "Other limitations include that the EDDC currently does not capture presentations to all EDs in NSW, so we cannot presently provide a "whole-of-state" description of ED presentations during the last year of life. The EDDC is a relatively new data collection that is currently being expanded to include all EDs in NSW. This expansion will benefit future studies using these data and the methods described in this study will be applicable to future datasets with complete coverage of the State. To ensure accuracy in this analysis, however, we are restrict analyses of ED utilisation to decedents living in the geographical area in which we believe almost all ED presentations were captured. … "

> [Page 12, paragraph 3] “Another limitation is the restriction on ABS data availability. The ABS has limited the release of cause of death information for deaths after 2007. Negotiations are currently underway to re-establish the supply of these data, however it means that we have to use data that are now up to 7 years old. The annual number of deaths has increased in that time, and while trends may be similar for many conditions and in many situations, it is feasible that differences in patterns of care and practices between that time and now may exist.”
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> [Page 12, paragraph 4] “In presenting data from this study, we must highlight that there are limitations in the dataset that limit our ability to accurately reflect all service use. The lack of information about palliative care specialist service use and bed use is problematic. Data on specialist palliative care are collected in other Australian jurisdictions, so it is expected that it would be feasible for this to be undertaken in NSW in the future. The similar … end of life. Importantly, this study will serve to highlight to policy makers the need to review the data that are routinely collected and to consider which data should be collected to facilitate optimal analyses of health service utilisation towards the end of life.”

Comment 2 The introduction is a bit long. The findings of prior studies in other Australian states aren't very relevant to this methodologic paper. They could be omitted or summarised in a table.

Response 2 The Introduction has been amended as follows.

> [Page 5, paragraph 2] “There are no Australia-wide studies of health services use at the end of life and only two Australian studies have addressed this for all decedents within a State, both covering deaths in Western Australia (WA) around 2002. One study described place of death and, for a subgroup of decedents with terminal illnesses, the use of specialist palliative care. [3] The other study analysed hospital costs, but did not report specific numbers of decedents in hospital.[4] All other Australian studies of end of life care have been restricted to specific disease types, age groups or population subgroups.”
>
> [Page 5, paragraph 3] “Two NSW studies have examined patterns of health service utilisation near the end of life, however both were restricted to a subgroup of decedents and did not describe presentations to emergency departments (EDs). One study examined the place of death for people dying of cancer in 1999-2003[22]”
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> [Page 5, paragraph 4] “A study of people in WA aged 65 years and older who died between 1984 and 1994 reported the average number of hospital admissions and length of stay in hospital at the end of life.[5] Another study of described palliative care use for people who died from selected chronic conditions in WA during 2000-2002 from selected conditions considered to be potentially amenable to palliative care, reported that it was more common for people who died of cancer to access palliative care than it was for those dying from other causes.[6] A more recent study in WA reported that 62% of on hospitalisations at the end of life for a similar subgroup of decedents who also had an informal primary carer and who died of a condition considered to be potentially amenable to palliative care, were in hospital on the last day of life, that almost all had spent time in hospital in the year preceding death, and the number of hospitalisations increased markedly during the last three months of life.[7]”
>
> [Page 6, paragraph 2] “A number of studies from South Australia have addressed epidemiological questions relating to end of life care. Two studies of cancer deaths between 1990 and 1999 reported an increase in on the utilisation of hospice and palliative care services.[8,9] Other studies explored various end of life issues using data obtained through the South Australian Health Omnibus survey – an annual government-supported health survey.”

Comment 3 The issue of the probabilistic matching describes in the Methods needs clarification. I presume this was required because of privacy laws, and is likely to be required by IRB's in other countries. The description is quite technical and I think a figure would help understand how this worked and this would be more helpful than the current Figure which does not add much to understanding how the study was done, and repeats what is in Table 2.

Response 3 We have simplified the description in the Methods section as shown below. We feel that Figure 1 is helpful but would be happy to drop it if preferred by the Editor.

> [Page 7, paragraph 3] “Linkage of records in these datasets was carried out by the Centre for Health Record Linkage (CHeReL),[23] using probabilistic matching carried out with ChoiceMaker software (ChoiceMaker Technologies Inc., New York, US). Privacy was preserved through the linkage process: the CHeReL used personal identifiers for decedents but held no health information, while the researchers received the health information for the decedents but no personal identifiers. The CHeReL used a privacy-preserving process to ensure the separation of personal identifiers and health information. The CHeReL held no health information, receiving only personal identifiers from data custodians that were used to generate a linkage key, which was then returned to the data custodians. Researchers received only health information and a linkage key from the data custodians.”

Comment 4 Regarding validity of the methodology, why are there so many gaps in the NSW data? Why is the ABS data so incomplete? Why are many ED's not part of the state reporting system? Why is palliative care utilization not routinely collected? In summary, do the results accurately reflect the real situation of end of life care in NSW?

Response 4 This has been addressed as described in Response 1. We believe that the results of this study will reflect accurately the use of acute hospital services by the whole of the population at the end of life in NSW.

Reviewer 2

Comment 1 Generally this paper is well written. As the paper is about record linkage, and few places in the world are able to link administrative data for whole populations, the paper is relevant to a limited audience. However I imagine that future papers with results from these linkages will be of greater interest to readers. This is primarily not a research paper but a paper explaining the methods or approach taken to describe acute hospital-based services for a population in their last year of life. The paper offers rudimentary results.

The abstract is confusing. It reflects paper(s) that will be written in the future and not what this paper is about. As one example, the objective of this paper is not 'To describe health care utilisation in the last year of life ....'. Rather the objective is to describe the methods used to obtain data, link data, etc. Likewise in the body of the paper, the data analysis explains what will/may be done into the future and not necessarily the analysis for this paper. I believe this needs correcting/clarification.

Response 1 The Abstract has been amended as shown below.

> [Page 3, paragraph 1] “Objectives: The aim of this study is to To describe health care utilisation in the last year of life for people in Australia, to help inform health services planning. The methods and datasets that are being used are described in this paper.”

We agree with the reviewer about the use of the past tense. We have amended the manuscript with a combination of present tense and future tense to describe the work we are doing and work we will do. These are noted using track changes in the manuscript file, including the examples given below, but we have not listed all of the individual changes in this response.

> [Page 3, paragraph 1] “Linked, routinely collected administrative health data were are being analysed for …”

> [Page 6, paragraph 3] “The aim of this study was is to describe … We are also examininged … ”

<u>Comment 2</u> The first half of the paragraph on page 9, commencing line 39, is very difficult to understand and needs to be rewritten.

<u>Response 2</u> The Methods section has been amended as shown below.

> [Page 9, paragraph 5] “We assessed the level of linkage to the EDDC across the 15 LHDs. For each LHD in <u>Eighty-three percent of adult decedents from</u> the Greater Sydney Area, at least 74% of the NSW adult residents who died in 2007 linked to at least one record in the EDDC, with 83% linked overall across the region. In the study therefore we <u>will</u> restricted analyses of ED presentations to the decedents from these LHDs (accounting for 62% of NSW adult deaths) as we believe they have sufficiently complete information on presentations to the ED. … ”

<u>Comment 3</u> The sentence commencing with ' While there is some related information ...' in the opening paragraph in the Introduction (page 5) would benefit from referencing.

<u>Response 3</u> References cited in the remainder of the Introduction have been included in this sentence.

<u>Comment 4</u> The fourth dot point of the Strengths and limitations of this study (page 4) needs rethinking. It is difficult to see how this study will provide a foundation from which to develop an efficient data collection infrastructure.

<u>Response 4</u> The dot point has been amended as shown below.

> [Page 4] “The results <u>will</u> provide a foundation from which to develop an efficient data collection infrastructure, along with baseline data for future studies of service access for care towards the end of life<u>, along with an indication of the types of information required to develop a more comprehensive data collection infrastructure</u>.”

VERSION 2 – REVIEW

REVIEWER	Paul Glare Memorial Sloan Kettering Cancer Center USA
REVIEW RETURNED	24-Feb-2014

GENERAL COMMENTS	Thank you for addressing my comments.