Author's response to reviews

**Title:** Acute hospital-based services used by adults during the last year of life in New South Wales, Australia: a population-based retrospective cohort study

**Authors:**

- David E Goldsbury (davidq@nswcc.org.au)
- Dianne L O'Connell (dianneo@nswcc.org.au)
- Afaf Girgis (afaf.girgis@unsw.edu.au)
- Anne Wilkinson (anne.wilkinson@ecu.edu.au)
- Jane L Phillips (jane.phillips@uts.edu.au)
- Patricia M Davidson (pdavidson@jhu.edu)
- Jane M Ingham (jane.ingham@svha.org.au)

**Version:** 3  
**Date:** 18 September 2015

**Author's response to reviews:** see over
Responses to reviewers’ comments for End of Life Study all deaths paper

The authors thank the reviewers for their thoughtful and constructive comments.

Reviewer 1

**Comment:** This is an interesting and well written study based on a large set of linked data to provide information of acute-hospital-based services used by adults during the last year of life in NSW, Australia. My only minor comment is that, in relation to cause of death (page 29), it would be interesting to that the authors comment and look at EOL trajectories for “other causes”.

**Response:** The paper describes some of the end-of-life trajectory for the combined “other causes” group (all known causes except diseases of the circulatory system and cancer), including hospital use, emergency department presentations, palliative care and time in intensive care (Tables 2 and 4). In our previous paper we gave a more detailed breakdown of the causes of death, showing that other than diseases of the circulatory system (34% of deaths) and cancer (29%), there is no single disease group that accounts for more than 8% of deaths. We feel that if we went into more detail for other disease groups the analysis would not be informative and the paper extremely long. We have added the following text (underlined) to the Results section to acknowledge this point.

[Page 11, line 228] “The most common underlying causes of death were diseases of the circulatory system (34% of all deaths) and neoplasms (29%) (Table 1). As described previously [2], the next most common disease group (diseases of the respiratory system) accounted for only 8% of deaths, and so in this paper all other known causes of death have been grouped together.”

Reviewer 2

**Comment:** This paper provides a valuable contribution to evidence on healthcare utilization at end of life, focusing on the experience of New South Wales, Australia. This is likely to be useful information for policy-makers and also provides a platform for further research (involving quantitative and/or qualitative methods). It also provides a point of comparison for international studies looking at similar issues in other geographical areas and countries. Given the ease with which the authors suggest the figures can be updated over time, it is therefore of some concern, if I have understood correctly, that data-linkage with mortality records is not possible after 2007. The analyses additionally draw attention to what we do not know, including information about the provision and utilization of palliative care and community-based services, and the characteristics of people accessing these services (evidence gaps that also exist elsewhere).

**Response:** At the time of submission of this paper these were the most recent data available. Pleasingly, the bureaucratic hold-up has cleared very recently and the data are now becoming available. We have adjusted the abstract, Background and Discussion sections to reflect this.

[Page 3, line 52] “Linked administrative health data were analysed, using privacy-preserving principles, for all adults who died in NSW in 2007 (the most recent year for which cause of death information was not available for linkage at the time of this study).”

[Page 5, line 113] “All adults who died in NSW in 2007 were included (as of May 2015 this was the most recent year for which cause of death information was available for all decedents) were included.”

[Page 21, line 502] “An additional limitation of the study is that restrictions on ABS Mortality data availability meant that we had to use were limited to using data that are now around eight years old. … Pleasingly, at the time of submission of this paper, more recent data were beginning to become available.”
Comment: Overall, the research presented in this paper is of high quality, the methods are clear (and supported by a separately written paper on the methods used), the analyses seem robust and data sound, the limitations stated and the paper well written and clearly laid out. However, I do have one ‘minor essential revision’ and several comments that come under the category of ‘discretionary revisions’.

Minor essential revisions

Comment: 1) Remove ‘within’ or ‘in’ in the sentence ‘.. questions, for addressing within in subsequent studies, would require a methodological ..’ in the paragraph just before the ‘Conclusions’ section.

Response: This has been corrected (page 23, line 561), removing "within".

Discretionary revisions

Comment: 2) I would include the relevant months, as well as the years, for the data sets.

Response: The months have been added (page 7, line 130: “… and information on any cancer diagnoses for these people between January 1994 and December 2007 …”).

Comment: Beyond this, the authors may judge the value and feasibility of expanding on any of the following.

Comment: 3) The findings presented in the paper are (appropriately) very descriptive. However, notwithstanding an occasional general statement (e.g. ‘population-based studies from other developed countries have reported similar levels of hospitalisation or trends by age or cause of death’), it is difficult to identify which results are in line with existing research or expectations, and which, if any, are at all surprising or note-worthy. It would be good to have more key comparisons included.

Response: Our results are generally in agreement with those from existing research. The Discussion section contains a paragraph with comparisons for each of the following: hospitalisations, ED presentations, palliative care, ICU and place of death. In the Discussion section, we have now provided the references for comparisons as shown below. There were some differences but we didn’t consider them noteworthy, such as 77% being in hospital in the last 6 months of life compared with 61% in a Swiss study [23], as the time in hospital was similar and the other related studies cited were in agreement with our results. Some of the results that we have reported, such as the proportion having allied health procedures, cannot be compared to other studies as they have not been reported elsewhere.

[Page 18, line 411] “Population-based studies from other developed countries have reported similar levels of hospitalisation [19-24] or trends by age [20,25] or cause of death [19,24-26] [19-26]. Over 40% of decedents were admitted to two or more different hospitals, which, together with a previous USA study that reported a median of three healthcare transitions in the last three months of life [24], highlighting the potential value of need for reliable information flow between hospitals for individual patients.”

[Page 20, line 466] “Both of These findings are similar to those from previous international studies of intensive care use by age [25,40,41], and for cancer deaths compared with other causes [36,40-42] [39-41].”
“This is similar to results reported by other Australian studies, which also found that just over half of all deaths occurred in hospital [5-10] and that the proportions of deaths in hospital were higher for people dying from cancer [10] and lower for the very elderly [6,7] [5-10].”

Comment: 4) Equity issues are particularly well highlighted in this study, with clear findings in regard to diagnosis, area deprivation and age. Given it is such a key finding (being rightly presented up front as a key conclusion in the Conclusions section), the authors might want to at least briefly reference key existing research on unequal, and potentially inequitable, provision as it relates to these groups.

Response: As described in the previous response, we have revised the Discussion section to highlight some of the existing research that has been cited. The Discussion section specifically describes existing research relating to differences in ED use by SES [27] and palliative care by cause of death [10,11,25,32-37]. We also describe differences in hospital use by age [7,20,25] and cause of death [8,19,24-26], differences in palliative care by age [32,37] and accessibility to services [32], differences in intensive care by age [25,40,41] and cause of death [36,40-42], together with differences in place of death by age [6,7,13,15] and cause of death [10].

We have revised the Discussion section as follows, including an additional recent reference.

“A recent UK-based review also described potentially inequitable provision of palliative care to various sub-groups of decedents, such as those with non-cancer diseases and the very elderly [37]. Again, further work is needed to align these findings with a better understanding of the palliative care needs of this population.”

Internationally there is wide variation in the distribution of place of death, with the proportion of people dying in acute hospitals generally ranging from 45% to 67% [13-15], and with the same trend of a lower proportion of the elderly dying in hospital [13,15].”

Comment: 5) The authors briefly describe previous studies of hospital use at end of life in NSW/ Australia (in the second paragraph of the Background section). These use somewhat different methods and parameters to the current study, but include studies that also use administrative data and data linkage. While the authors point to the fact that many of these studies have a selective focus (for example, on older people or people with specific conditions), it may still be useful to directly compare findings from the current paper and draw out what taking the approach in the current paper has been able to add.

Response: We have revised the Discussion section as follows, based on comparisons with previous NSW/Australian studies.

“The proportions in hospital and numbers of hospitalisations in this study are similar to those reported in previous Australian studies for sub-groups of decedents aged 65+ years, with around 80% admitted to hospital in their last year of life [5,7], more hospital use for people who died from cancer [8] and very elderly decedents having fewer hospital admissions [5,7].”

This study includes covers all adult decedents, whereas most previous studies have been restricted to decedents aged over 65 years or with certain diseases. Our only exclusion was those aged less than 18 years, who comprise only 1% of all deaths. This is the first study in Australia to describe report end-of-life health services utilisation including care service measures such as numbers of hospitalisations and ICU use for all causes of death among all adults for a whole state, and only the second to report on place of death for all adult decedents (the first in NSW). While our results were reasonably similar to those from
previous Australian studies of decedents aged over 65 years, the major difference was that, as we included all causes of death, we found different patterns of hospital and ED use [8], palliative care [10] and place of death [3] compared with studies examining specific causes such as cancer. For example, we found that people who die from cancer are more likely to spend more time in hospital and die in hospital than those dying from other causes. This more comprehensive description is important for understanding the different patterns of hospital-based end-of-life care and resource use.

Comment: 6) The authors say, ‘The importance of having detailed local information is exemplified by a study of people dying from cancer in London and New York, which found place of death varied significantly by patient and area characteristics’. It would be useful to know if any example from this study could be provided where experience in NSW and/or Greater Sydney appeared to differ from experience elsewhere.

Response: As described earlier, our results are generally in agreement with the existing research. There are limited results in Australia with which to compare, which again highlights the importance of reporting this information.

Comment: 7) In the paragraph just before the section headed ‘Procedures during hospital admissions’, deaths for people with cancer in hospital and in inpatient hospice were reported together. However, assuming similar patterns to the UK, I would expect people with cancer to be less likely than people with other conditions to die in hospital but more likely to die in an inpatient hospice. Are separate figures available? If not, this deserves discussion.

Response: Unfortunately we cannot identify all inpatient hospice admissions, only admissions to the limited number of standalone hospice facilities in NSW. Dying in one of these facilities was more common for people who died from cancer compared with people dying from other conditions (10% vs 1%), but we know this is not comprehensive information. We have added the following text to the limitations in the Discussion section.

[Page 21, line 490] “We could not reliably identify all people who were admitted to an inpatient hospice, as there were only five standalone inpatient hospices or inpatient palliative care units in NSW with their own institution codes. Admissions to inpatient hospice beds within larger hospital facilities could not be identified even though such beds are known to be available in a number of hospital facilities throughout NSW.”

While revising this section of the paper we found that in the paragraph describing factors associated with dying in a hospital or inpatient hospice, we had incorrectly included people who were dead on arrival to ED. We have corrected the paragraph in the Results section as shown below. This did not change the results substantially. The authors apologise for any confusion.

[Page 15, line 356] “Of the key patient characteristics of interest, dying in a hospital or inpatient hospice was more common for people who died from cancer (72%) compared with other causes (51%) (aOR 2.18, 95% CI 2.07-2.29) and men (66%) compared with women (55%) (aOR 1.30, 95% CI 1.25-1.35), while it was less common for decedents aged 90 years or more (39%) or 18-59 years (56%) compared with 60-79 years (66%) (aOR 0.46, 95% CI 0.43-0.49 and aOR 0.68, 95% CI 0.64-0.73 respectively).”

Comment: 8) I would also be interested to know the characteristics, including age profile, of the 9 per cent who the authors report died in, or on the way to, an ED.
**Response:** As described in the Results section on place of death (page 15, line 351), the most striking difference for people who were dead on arrival (DOA) to an ED was their age, with 15% of decedents aged 18-59 years being DOA compared with 5% of those aged 60-79, 2% of those aged 80-89 and only 1% of decedents aged 90 years or more. We felt that for the sake of brevity we would only report this result as it was by far the greatest point of difference.

Being dead on arrival to an ED (5% overall) was also more common for males (6% vs 3% for females) and less common for people who died from cancer (1% vs 6% for other causes).

With regard to people who died in an ED (4% overall), there were similar trends by age, sex and cause of death, although the differences across sub-groups were not as large. For example, 8% of deaths occurring in an ED for decedents aged 18-59 years, declining to 2% for those aged 90+.

**Comment:** 9) The use of multivariate analysis is important since analyses that do not account for the independent effects of patient characteristics and circumstances are likely to be misleading. Could there, however, be some brief discussion about which other factors it would have been useful to include (and why) if data had been available? This would be helpful for those undertaking future research as well as for those responsible for determining the future content of administrative data sets. There is some reference to priorities, needs and comorbidities in the conclusion but it would be good if this could be drawn out more clearly.

**Response:** A clear gap in the data set available for this study is a lack of information that allowed the investigators to examine patient-reported outcome data related to their needs or their subjective experiences within the health system. It may be possible in the future for innovative health care systems to facilitate the collection and linkage of patient reported experience and outcome measures and information on their carers’ experiences. In addition the absence of community health service data is a very significant gap when exploring service use. The inclusion of such data may further help facilitate analyses that inform health service planning. There is also a lack of information about “appropriateness” of care, priorities and needs of the decedents and their carers, community care, palliative care specialist input, residential aged care, comorbidities and admissions to inpatient hospice beds. Each of these information gaps and the potential benefits of these data are described in the Discussion section as follows:

[Page 22, line 508] “More generally, we cannot use these data sources to identify the “appropriateness” of care, as it does not address priorities and needs of the decedents, nor does it address those for their carer(s). In addition, comorbid conditions are not comprehensively recorded in these data sets and so it is not possible to assess the impact of these conditions [47]. … Clearly access to community care dramatically impacts the experience of the last year of life and these data would be useful to complement our hospital data to provide a more comprehensive overview of dying in NSW. … In addition to the identification of limitations in hospital-based information about palliative care specialist input, the data set did not allow for analysis of palliative care provided in the community setting, so we could not accurately describe primary and specialist palliative care service use in either of these settings. We contend that it is important to address these data gaps in order to provide more comprehensive descriptions of service use at the end of life, particularly palliative care, through administrative health datasets. This may serve to illuminate the discrepancies identified and any anomalous findings.”

**Comment:** 10) In the second paragraph under the heading, ‘Measures of hospital-based service provision’ the authors explain how, in the second of their two definitions of palliative care, they include where the service category, service related group or a diagnosis code indicates palliative care need. I would appreciate more discussion about what is included. Murtagh et al. (2013), for
example, estimated that between 69 per cent and 82 per cent of deaths in high-income countries are likely to have preceding palliative care needs.


Response: One of the key limitations of our paper is the incomplete information about the receipt of palliative care both from inpatient and community services. This limited our ability to undertake useful comparisons and analyses related to this important service need. This has been addressed in the Discussion section, but to indicate that the information is not complete we have revised the Methods sections as follows, also expanding upon one key component of the source data.

[Page 8, line 167] “The second indicator covered all identifiable admissions potentially related to palliative care and comprised all admissions captured in the first indicator, together with those where the service unit type was classified as a palliative care bed, admissions where the service category or service related group or a diagnosis code indicated palliative care (indicating palliative care was the reason for admission or a factor that could have impacted on the hospital stay), and admissions where the person was flagged as being referred to a palliative care team or palliative unit or an inpatient hospice. Thus the latter category included individuals whose admission may have involved the delivery of palliative care. That stated, in this group it was not clear that the palliative care was delivered by a specialist palliative care service and may have been delivered by another medical team.”

Through the available data we could identify any “mention” of palliative care service delivery, but there is no direct information about palliative care “needs”. The paper by Murtagh et al. describes methods for obtaining population-based estimates of potential palliative care needs, but we believe this is beyond the scope of our study.