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 (davidg@nswcc.org.au)
Dianne L O’Connell (dianneo@nswcc.org.au)
Aaf 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: 5 Date: 9 November 2015

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

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, time in intensive care, emergency department presentations and palliative care (Tables 2, 3 and 5). 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 12, from line 246] “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 the analysis all other known causes of death have been grouped together.”

Also, in response to the comments of Reviewer 3, we have added the following to the Results section to describe people who die of external causes.

[Page 17, from line 383] “Deaths due to external causes
Five percent (n=2140) of adult deaths were due to external causes (including falls, self-harm, traffic accidents). These causes were most common for decedents aged 18-59 years, with 20% of this group dying from external causes compared with only 2-3% in other age groups. In all other sociodemographic groups, 3-6% of decedents died from external causes. Compared with those dying from all other causes, lower proportions of people who died from external causes used all forms of hospital care except for ICU where the proportions were the same (12%).

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 up-to-date data available. Pleasingly, refinement of governance processes has ensured data availability is now more timely and more up-to-date data have become available. We have adjusted the abstract, Background and Discussion sections to reflect this.
“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).”

“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.”

“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 25, line 608), 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 135: “… 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 20, from line 452] “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 22, from line 508] “Both of These findings are similar to those from previous international studies of intensive care use by age [25,41,42], for cancer deaths compared with other causes [37,41-43], and for ICU use overall [32] [39-41].”

[Page 22, from line 515] “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 socioeconomic status [27] and palliative care by cause of death [10,11,25,33-38]. 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 [33,38] and accessibility to services [33], differences in intensive care by age [25,41,42] and cause of death [37,41-43], 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.

[Page 21, from line 486] “A recent UK-based review also described potentially inequitable provision of palliative care to various subgroups of decedents, such as those with non-cancer diseases and the very elderly [38]. Again, further work is needed to align these findings with a better understanding of the palliative care needs of this population.”

[Page 22, from line 518] “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.

[Page 20, from line 449] “The proportions in hospital and numbers of hospitalisations in this study are similar to those reported in previous Australian studies for subgroups of decedents aged 65+ years, with around 80% admitted to hospital in their last year of life [5,7], more hospital use for those who died from cancer [8] and very elderly decedents having fewer hospital admissions [5,7].”

[Page 25, from line 583] “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 use of hospital-based end-of-life care services at the end of life including 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 data from Australian studies 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 23, from line 534] “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.”
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 16, from line 372), 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 occurred 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 24, from line 552] “More generally, we cannot use these data sources to identify the “appropriateness” of care, as these data sources do not contain any patient-reported outcomes, nor do they address priorities and needs of the decedents, nor does it address those for or their carer(s). In addition, comorbid conditions are not comprehensively recorded in these data sets and so it is not possible to assess the potentially important impact of these conditions [48]. … 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, from line 176] “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 second indicator 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.

Reviewer 3

Comment: This is a descriptive study presenting data on the use of hospital services by residents in NSW in their last year of life. The study uses linked health administrative databases, and employs a retrospective cohort approach to examine health care use in the last year of life on a census one-year decedent cohort. The paper was well written and easy to read through. It is overall a study on a topical subject, and gives a rare population view of end-of-life health care. There are however, previous similar studies internationally that the authors have not reference or discussed. This would have been helpful to round out a good background/discussion section. One major gap of this study, as pointed out, is the lack of inclusion of community based health care use. However, this is fine given the lack of data in this region.

The data presented, although only from one health sector is quite rich. It is from this richness that the authors had a difficult time with focus and key messages. I would recommend that they cut down on the number of outcomes reported, and discussed more on the significance (e.g., concept, directionality, modifiability, benchmarking, etc.) of each of the chosen indicators. The paper is missing clear 3-5 key messages that are helpful in descriptive studies such as these.

Correspondingly, it is missing hypothesis/exploratory questions that can would be helpful to direct the paper (e.g., those not dying of cancer do not receive adequate care; that the lack of
community resources for palliative and EOL care will lead to high % of hospital deaths and hospital use at the EOL). I do not have a problem at all about the descriptive nature of this paper; but good descriptive papers will have a few clear and interesting angles to view the data. The authors almost get there, but I believe were hampered by the number of outcomes/indicators they were trying to report on in one paper.

Response: The reviewer raises two concerns: (1) The large number of measures analysed and reported; and (2) Reasons for the choice of these measures. Our aims were to describe patterns of end-of-life care for a range of measures where, to date, there have been no existing data for this geographical region, as well as to determine the utility of the existing data sets for obtaining an overall picture of end-of-life care. In this context we also sought to identify gaps in data collection so as to inform discussion among stakeholders about optimal data collection. Therefore we examined and reported on a number of measures. For these initial results we believe it is important to provide information on a wider range of measures even if it means having less granular comparisons in order to keep the paper to a reasonable size. Another reason for not focusing on specific measures is that due to the lack of existing data in this geographical region, we had no pre-conceived hypotheses on which the paper could be based.

The specific measures were selected in consultation with key stakeholders in the health system with the aim of describing broadly patients’ experiences at the end of life. In addition a number of measures reported have been analysed in previous studies [12]. The following has been added to the Background and Methods sections to highlight this point.

[Page 5, from line 114] “We present a number of measures based on previous studies [12] and discussed with key stakeholders in the health system, in response to an identified need for information relating to patients’ experiences at the end of life.”

[Page 8, from line 166] “Each measure was selected from those reported previously [12] and in response to needs identified through consultation with health service leaders, administrators and policy makers.”

Major Compulsory Revisions

Comment: 1) Line 132-133 & background: Agree most studies have focused on EOL care for specific diseases, but should review others that have looked at have not. Below are a few. The last one being very similar and relevant to this paper. Also, in Canada, there have been a series of reports from the Canadian Institute for Health Information in several provinces (Saskatchewan, Atlantic Provinces, Manitoba) that have the same perspective. The findings of this paper should be discussed against these international findings


Response: We had referred to the papers by Teno et al and Reich et al, together with a report from the Dartmouth Institute by Goodman et al (2013) which we believe is a more recent update of the suggested Goodman et al (2011) reference. We have now included the paper by Tanuseputro et al.

The main aim of our paper was to describe patients’ experiences at the end of life, using a range of measures where there have been no reported results for this geographical region. Data on costs and expenditures have previously been reported for this region by Kardaminidis et al [5]. Given that this was not a focus of our paper, we have not discussed a number of studies which focussed on costs, including papers (c) to (f) listed by the reviewer. We have added the following to the Methods section to acknowledge this point.

[Page 8, from line 168] “Data on the costs of care are not reported in our study due to the focus being on patients’ experiences at the end of life.”

Comment: 2. In these studies, hospital use is put into perspective against the other health sectors. These studies also use other metrics, such as cost, that are informative. The authors should discuss the findings of this study (including the choice of outcomes) against this literature

Response: Our focus was on patients’ experiences so we decided not to include data on costs as it would add a further level of complexity and additional reporting. This is now acknowledged in the Methods section as described in our response to the previous comment. We did not have access to billing/claims data for care outside of the hospital system (general practitioners, specialists, prescribed medicines), and as described in the paper there are no available data on community-based palliative care, so we could not comprehensively cost service use or compare hospital use with utilisation of services in other health sectors.

Comment: 3. The authors have examined quite a few indicators of health care use. The measures outlined in lines 217-222 include no less than 8 different outcomes. In my opinion, this unnecessarily lengthened the papers as some of these indicators get at the same concepts. I would have much rather they choose half the number of indicators, and went into some detail on the indicator concept (what does it try to capture), directionality (i.e., up/down = desirable/undesirable and for what reasons), modifiability, etc.

For example, the two indicators for palliative care was difficult to interpret. First, I don’t think it was well explained, and perhaps not necessary, why 2 very similar indicators (one narrow, one broad) was presented. It was presented together with indicators where higher prevalence is worse, while I’m assume higher palliative care in hospital is presumed to be better (although I’m not sure it is, since this is still care conducted in hospital, as opposed to in the community)

Response: As stated in our responses to previous comments regarding our choice of measures for inclusion in this paper, we believe that it is important to report on a range of measures with less granular comparisons. Regarding the palliative care measures, we believe that both indicators provide important and different information so both are worthy of reporting. We are also highlighting that these are the best data currently available on palliative care for the population of NSW, with the aim of providing local stakeholders an understanding of the limitations of the existing data. The Methods section now includes the following text to clarify this.
The first indicator captured people who were clearly documented as having been seen by a specialist palliative care team. The second indicator covered all identifiable admissions potentially related to palliative care. Thus the second indicator 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 it may have been delivered by another medical team.

Comment: 4. The authors point out that comorbid conditions were not included in the models, which would have made the findings of the models much more compelling. They should justify why this was left out. I presume that they had access to a few years of data of previous hospitalization (i.e., prior to 2007) that they could draw from (e.g., using John’s Hopkins ADG’s or Charlson, etc.). I’m ok if this is not reasonably feasible given the resources they had – but this is a major limitation to the study (at least to the multivariable models) and should be discussed further.

Response: We agree that comorbid conditions are important when describing end-of-life care, however as described in the paper we do not have reliable information on comorbidities available. We have changed the following comment in the Discussion section to acknowledge the importance of this point.

Comment: 5. The main multivariable models are logistic regressions, with the outcome being in the top quartile for 3 of the outcomes: hospital episodes/number of days in hospital/ED visits. The authors should justify why they used this, instead of, for example GLM for continuous outcomes.

Response: In our consultations with key stakeholders prior to this study, health service leaders and administrators expressed a greater interest in describing the frequent users of the health system based on reasonable cut-points, rather than identifying the factors potentially associated with a person having one additional unit of health service use (e.g. one more day in hospital). Therefore, we have focused our analysis on factors relating to being in the top quartile of each measure rather than analysing them as continuous measures. We have included the following comment in the Methods section to clarify this point.

Comment: 6. There were additional outcomes discussed in the results (lines 380-410) that I don’t think were discussed elsewhere (in methods/discussion). “Procedure during hospital admissions” felt out of place; “Final hospital admissions” is interesting, and adds a time component, but wasn’t in any of the tables/models. I would considering including this indicator, in place of one of the other somewhat redundant 8 outcomes.

Response: As described previously, we are reporting on a relatively large number of measures of health care use and for this initial report we believe it is important to include a wider range of measures with less granular comparisons. These two outcomes were added to describe different
aspects of end-of-life care, but due to the length of the paper we did not provide further detail for these particular measures. We have included the following in the Results and Discussion sections to acknowledge the high-level description of procedures.

[Page 18, line 405] “Overall there were 2988 different procedures recorded for people during their last year of life.”

[Page 25, from line 596] “We have also included what we believe is the most comprehensive report to date on ED presentations, and hospital-based palliative care and a description of hospital-based procedures undertaken at the end of life in across NSW”

Minor essential revisions

Comment: 1. Lines 75-77: Fragmented sentence

Response: We agree with the Reviewer that this sentence is not good prose but this was required to cover the key results within the word limit allowed for the abstract. We have made the following adjustments to address this.

[Page 3, from line 60] “Of the 45,749 adult decedents, 82% were admitted to hospital during their last year of life: median 2 episodes; 24% had >3 care episodes (median 2); 47 days median total time spent in hospital; 35% stayed a total of >30 days in hospital (median 17); 42% were admitted to 2 or more different hospitals.”

Comment: 2. Line 79: Would be helpful to separate out in hospital and inpatient hospice death; the former may be undesirable, while the latter appropriate

Response: We agree with the Reviewer but unfortunately we were not able to identify all inpatient hospice admissions in the available data. The following sentences in the Methods section highlight this point, and we have added an explanation to the Discussion section to provide further clarification. The location of death in a hospital, be it in a palliative care bed or an ICU bed, is poorly recorded in the existing data sets and we have included this information to promote local, and indeed broader, discussion about stakeholders’ perceptions of the value of the inclusion of this type of information in future data sets.

[Page 9, from line 193] “Deaths in hospices were only identifiable for the five stand-alone inpatient hospices in NSW that have individual institution codes. Hospice units or beds that are co-located within a hospital do not have a separate institution code so deaths occurring in them have the hospital recorded as the place of death.”

[Page 23, from line 534] “We could not reliably identify all people who were admitted to an inpatient hospice, as there were only five stand-alone 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.”

Comment: 3. Lines 81-83: “Differences” – should state what major findings are.

Response: We have made the following adjustments to the abstract to highlight the major findings.

[Page 3, from line 66] “Differences in the use of hospital-based health services were found including those related to being The very elderly, and those dying from diseases of the
circulatory system cancer or living in a more the least disadvantaged areas generally had lower hospital service use.”

**Comment:** 4. Conclusion of abstract: should give some interpretive statements: what are the major findings? Do the rates of hospitalization seem reasonable? What are the significant variations? I realize this is a descriptive study, but can outline some of the helpful directions that the study point to

**Response:** We have changed the conclusion of the abstract as follows.

[Page 4, from line 71] “These population-wide existing health data collections give a highly informative description of NSW-hospital-based end-of-life service utilisation, providing a reliable, relatively inexpensive and ongoing source of population-wide information. Use of hospital-based services during the last year of life was common, with substantial variation across sociodemographic groups, especially defined by age, cause of death and socioeconomic classification of the decedents’ place of residence. Further research is now needed to identify the contributors to these findings. Gaps in data collection were identified - however are evident, particularly for palliative care and patient-reported outcomes. Our results provide a necessary foundation for the planning and monitoring of health service delivery, and help to identify variability in service use patterns that warrant further study. Addressing these gaps in data collection should facilitate improved monitoring and assessment of service use and care.”

**Comment:** 5. Need to consider excluding or separating deaths from external causes – e.g., for multivariable models – to help interpretation of results. At least for sensitivity analyses.

**Response:** We have carried out the relevant sensitivity analyses and included a sub-section in the Results about deaths from external causes. We added the following in the Methods and Results sections respectively.

[Page 10, from line 220] “A sensitivity analysis was undertaken for each of these measures by excluding all people who died from external causes (including falls, self-harm, traffic accidents), as this group is likely to have a very different health care experience at the end of life.”

[Page 17, from line 383]

**Deaths due to external causes**

“Five percent (n=2140) of adult deaths were due to external causes (including falls, self-harm, traffic accidents). These causes were most common for decedents aged 18-59 years, with 20% of this group dying from external causes compared with only 2-3% in other age groups. In all other sociodemographic groups, 3-6% of decedents died from external causes. Compared with those dying from all other causes, lower proportions of people who died from external causes used all forms of hospital care except for ICU where the proportions were the same (12%).

“When deaths from external causes were excluded from the analyses, estimates of the odds ratios increased for each measure of hospital-based services used by 18-59 year old decedents compared with those aged 60-79 years, and the estimated odds ratios for “other causes” versus circulatory system deaths also increased slightly. For example, after excluding people who died from external causes there was no longer a significant difference between decedents aged 18-59 years and those aged 60-79 years dying in hospital or inpatient hospice (aOR 1.00, 95% CI 0.93-1.07). All other odds ratios for those aged 18-59 years compared with those aged 60-79 years were closer to unity except for time in ICU.
where the odds ratio increased to 1.26 (20% vs 17%, 95% CI 1.15-1.37). The exclusion of external causes of death made very little difference to the remaining associations examined.

Comment: 6. Tables 2 & 4: each of the column should have a total number (n) to go along with the %

Response: We have changed Tables 2 and 4 accordingly. We have added the results for ICU use to Table 2 and moved the results for ED presentations to a new table (Table 3) as the results refer to a subset of the population.

Comment: 7. Table 2 should explain that these are the top quartiles

Response: A footnote has been added to Tables 2 and 3.

[Page 35, line 808] “These groups represent the top quartiles of the distributions for hospital episodes (>3) and length of stay in hospital (>42 days) during the last year of life.”

[Page 36, line 815] “This group represents the top quartile of the distribution for ED presentations (>3) during the last year of life.”

Comment: 8. Table 3’s “Cumulative deaths” column does not add much – I would just put the total respective n’s (i.e., 6,909 and 10,777) in an added Total row. It would have been much more interesting to stratify by a factor (e.g., Cancer versus not, or by period prior to death: <1 month, 1-3 months, etc.) that would have added to a clearly identifiable key message

Response: We included the column with the cumulative percent of deaths to give an indication of the additional decedents included as each potential source of information on palliative care was added as they are not mutually exclusive. Table 5 (previously presented as Table 4) provides information on inpatient palliative care for several decedent groups including cause of death. In addition, we provide information in the Results on palliative care during the last hospitalisation for those who died in hospital.

[Page 19, from line 430] “Twelve percent of decedents died during a hospital episode flagged with palliative care indicator 1 (i.e. in an inpatient hospice or flagged with “saw palliative team”) and 18% died during an episode that had mention of “palliative care”. The corresponding proportions were highest for people who died from cancer: 31% and 46% respectively, compared to 3% and 6% respectively for deaths from diseases of the circulatory system.”

Comment: 9. Figures 1 & 2: missing y-axis figure legend

Response: The y-axis titles have been added.

Comment: 10. The Methods section in the Abstract contains a clear description of the data, but did not mention the statistical/analytical methods that were used or the variables that were examined – e.g., the use of logistic regression models to compute odds ratios, controlling for age, sex, country of birth, etc.
**Response:** As with previous responses, this level of detail was omitted to keep within the word limit allowed for the abstract. We have made the following adjustments to the Methods of the abstract.

[Page 3, from line 50] “Linked administrative health data were analysed, using privacy-preserving principles, for all adults who died in NSW in 2007 (after the most recent year for which cause of death information was not available for linkage for this study). The data comprised linked death records (2007), hospital admissions and emergency department (ED) presentations (2006-2007) and cancer registrations (1994-2007). Measures of hospital-based service utilisation during the last year of life included: number and length of hospital episodes, ED presentations, admission to an intensive care unit (ICU), palliative-related admissions and place of death. Factors associated with these measures were examined using multivariable logistic regression.”

**Comment:** 11. Statistical results, such as the IQRs, should be presented within parentheses. The presentation of statistical results should follow conventional formatting, involving the use of mathematical symbols (e.g., aOR = 2.68, 95% CI = 2.54-2.83).

**Response:** We have revised the manuscript with IQRs in parentheses, as shown below. However, in keeping with many of the recent articles in the journal we have not included mathematical symbols in the statistical results quoted in the text.

[Page 12, line 244] “… median age at death was 80 years with (interquartile range [IQR] 70-87).”

[Page 12, from line 253] “… the median number of episodes for each person was 2, (IQR 1-3) (Figure 1) and the median length of each episode was 3 days, (IQR 1-10). During the last year of life, the median time in hospital was 17 days per person, (IQR 3-42)”

[Page 14, from line 307] “…the median time spent in ICU during the last year of life was 3 days, (IQR 2-7).”

**Comment:** 12. Minor grammatical and punctuation errors (e.g., commas around the use of ‘however’, and before the word ‘respectively’).

**Response:** We have changed some instances of these but we believe they are generally acceptable.

**Comment:** 13. Some separation between the discussion of the study’s main findings from its limitations would be helpful in the Discussion section (e.g., with the use of sub-headings).

**Response:** We have added the following sub-headings in the Discussion.

[Page 20, line 440] “Main findings”

[Page 23, line 529] “Limitations”

[Page 25, line 580] “Strengths”

**Comment:** 14. There were some inconsistencies in how sources were referenced.
Response: We have checked the references carefully and made some changes. We believe the referencing style complies with the journal’s specifications.

Discretionary revisions

Comment: 1) Uncertain why the words “use”, “mention” and “next set of questions” were included with quotation marks in the Discussion section (e.g., lines 451-452).

Response: The quotation marks have been removed.

Comment: 2. Line 188-197: I would consider using only one of these palliative care indicators; I would suggest the broader second definition. I’m not sure if one or the other adds to the paper.

Response: Our choice of the two indicators has been addressed in our responses to previous comments.

Comment: 3. I would also consider adding a time element to at least one of the main outcomes/indicators. For example, while acute care hospitalizations 6 months prior to death may be appropriate for curative efforts, if they were able to describe an increasing number of hospitalizations near the end of life they would be able to make a stronger argument about potential preventability. A figure at least (e.g., describing lines 259-261) may be informative.

Response: We have added Figure 3 to show the proportions of people admitted to hospital or presenting to ED by time preceding death.

Comment: 4. Consider making circulatory causes as reference population, as opposed to “other causes” which is difficult to interpret

Response: We have re-run the analyses and updated the relevant tables with circulatory system causes of death as the reference category.

Comment: 5. Table 1: recommend consider adding columns for an interesting stratifying factor (e.g., by cause of death, or by quartiles of whatever chosen main outcome)

Response: This is addressed in Tables 2, 3 and 5 (previously presented as Tables 2 and 4). We believe that adding the suggested outcomes to Table 1 would duplicate the information presented in the subsequent tables.

Comment: 6. Consider presenting unadjusted OR’s in Tables 2 & 3

Response: We feel that including the unadjusted odds ratios and 95% confidence intervals would add multiple columns to each table and take the focus away from the more meaningful adjusted estimates. We do not believe that the unadjusted odds ratios would enhance the usefulness of these tables but would add to the potential for confusion. The percentages with the outcome are reported for each group so readers can calculate the unadjusted odds ratios if they are interested.
Comment: 7. I would remove “Accessibility” from the category “Accessibility/Remoteness” – I think this is presuming too much. Maybe just use Region or Remoteness

Response: We have changed the variable label to “Place of residence”.

Comment: 8. Table 4: I would consider having only palliative care indicator(s) in the table, and moving time spent in ICU in Table 2. This would help in the interpretation of the directionality of the OR’s – that low OR’s are desirable or not

Response: We agree with the reviewer and have moved the results for “time spent in ICU” to Table 2.