



**Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: methods for a population-based study**

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Complete List of Authors:	O'Connell, Dianne; Cancer Council New South Wales, Cancer Research Division Goldsbury, David; Cancer Council New South Wales, Cancer Research Division Davidson, Patricia; University of Technology Sydney, Centre for Cardiovascular and Chronic Care Girgis, Afaf; Ingham Institute for Applied Medical Research, Translational Cancer Research Unit Phillips, Jane; The Cunningham Centre for Palliative Care, Piza, Michael; South Eastern Sydney Local Health District, Clinical Governance Unit Wilkinson, Anne; Edith Cowan University, School of Nursing and Midwifery Ingham, Jane; The Cunningham Centre for Palliative Care,
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**Title**

**Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: methods for a population-based study**

**Authors**

Dianne L O'Connell, BMaths(Hons) PhD  
Senior Epidemiologist, Cancer Council NSW, Australia  
E: [dianneo@nswcc.org.au](mailto:dianneo@nswcc.org.au)

David E Goldsbury, BSc(Hons) MPH  
Statistician/Data Analyst, Cancer Council NSW, Australia  
E: [davidg@nswcc.org.au](mailto:davidg@nswcc.org.au)

Patricia Davidson, RN BA MEd PhD  
Director, Centre for Cardiovascular and Chronic Care, University of Technology, Sydney, Australia and St Vincent's Hospital Sydney, Australia  
Johns Hopkins University  
E: [pdavids3@jhu.edu](mailto:pdavids3@jhu.edu)

Afaf Girgis, BSc(Hons) PhD  
Executive Director, Translational Cancer Research Unit, Ingham Institute for Applied Medical Research, UNSW Medicine, The University of New South Wales, Australia  
E: [afaf.girgis@unsw.edu.au](mailto:afaf.girgis@unsw.edu.au)

Jane L Phillips, RN BSci(Nur) PhD  
Professor Palliative Nursing, The Cunningham Centre for Palliative Care and School of Nursing, The University of Notre Dame, Australia  
E: [jane.phillips@nd.edu.au](mailto:jane.phillips@nd.edu.au)

Michael Piza, BA(Hons) MPH  
Clinical Epidemiologist, Clinical Governance Unit, South Eastern Sydney Local Health District, Australia and Conjoint Associate Lecturer, School of Public Health and Community Medicine, Faculty of Medicine, The University of New South Wales, Australia  
E: [Michael.Piza@sesiahs.health.gov.au](mailto:Michael.Piza@sesiahs.health.gov.au)

Anne Wilkinson, PhD  
Cancer Council WA Chair in Palliative and Supportive Care

1 School of Nursing and Midwifery, Edith Cowan University, Western Australia, Australia

2  
3 E: [anne.wilkinson@ecu.edu.au](mailto:anne.wilkinson@ecu.edu.au)

4  
5 Jane M Ingham, MB BS FRACP FACHPM

6  
7 Professor, Palliative Medicine, University of NSW Cunningham Centre for Palliative Care,  
8 Australia

9  
10 E: [jingham@stvincents.com.au](mailto:jingham@stvincents.com.au)

### 11 12 13 **Corresponding author**

14 Dianne O'Connell, BMaths(Hons) PhD

15 Senior Epidemiologist, Cancer Research Division

16 Cancer Council NSW, PO Box 572, Kings Cross, NSW 1340, AUSTRALIA

17  
18 E: [dianneo@nswcc.org.au](mailto:dianneo@nswcc.org.au)

19  
20 P: +61 2 9334 1768

21  
22 F: +61 2 8302 3550

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## ABSTRACT

### Objectives

To describe health care utilisation in the last year of life for people in Australia, to help inform health services planning.

### Design/Setting

Linked, routinely collected administrative health data were analysed for all people who died in New South Wales (NSW), Australia's most populous state, in 2007. The data comprised linked death records (2007), hospital admissions and emergency department presentations (2006-2007) and cancer registrations (1994-2007).

### Participants

There were 46,341 deaths in NSW in 2007. The initial analyses were conducted for 45,760 decedents aged 18 years and over.

### Outcome measures

The primary measures address the utilisation of hospital-based services at the end of life, including number and length of hospital admissions, emergency department presentations, intensive care admissions, palliative-related admissions and place of death.

### Results

The median age at death was 80 years. Coded cause of death was available for 95% of decedents and 85% were linked to a hospital admission record. In the greater metropolitan area, where data capture was complete, 83% of decedents were linked to an emergency department presentation. Thirty-eight percent of decedents were linked to a cancer diagnosis in 1994-2007. The most common causes of death were diseases of the circulatory system (34%) and neoplasms (29%).

### Conclusions

This study is among the first in Australia to give such an information-rich census of end of life hospital-based experiences. While the administrative datasets have some limitations, these population-wide data can provide a foundation to enable further exploration of needs and barriers in relation to care. They also serve to inform the development of a relatively inexpensive, timely and reliable approach to the ongoing monitoring of acute hospital-based care utilisation near the end of life and inform whether service access and care are optimised.

## Article summary

### Strengths and limitations of this study

- The data provide powerful information about the hospital-based experiences at the end of life for all people who died in an entire state across a full calendar year, providing a valuable addition to the limited epidemiological information currently available.
- The data cannot be used to identify the “appropriateness” of care patterns or care delivery, and the information about palliative care specialist service use was incomplete.
- Not all emergency department presentations could be captured and not all cause of death information was available.
- The results 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.

## INTRODUCTION

There are more than 45,000 deaths each year in New South Wales (NSW),[1] Australia's most populous state. Despite the NSW population of around 7 million people accounting for 33% of the country's population,[2] there is little epidemiological information available about health care utilisation towards the end of life for these people. This information is important for planning and optimising the availability and appropriateness of health care services across NSW. While there is some related information available for other Australian states, there has been a gap in the evidence base for clinicians and researchers in NSW to develop, implement and monitor patient outcomes.

Worldwide, studies of end of life care have covered population groups ranging from small hospital-based samples to all decedents across several countries.[3-5] Many studies have focused on place of death,[6] palliative care[7] and health services use for specific disease subgroups such as cancer.[8, 9] 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 analysed place of death and, for a subgroup of decedents with terminal illnesses, the use of specialist palliative care. It reported that half of all deaths occurred in hospitals and that death in the usual place of residence was more common for those who accessed specialist palliative care.[10] The other study analysed hospital costs, but did not report specific numbers of decedents in hospital.[11] All other Australian studies of end of life care have been restricted to specific disease types, age groups or population subgroups.

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 and found that 66% of cancer deaths occurred in hospital and a further 8% were in a hospice. Geographical area of residence was the factor most strongly associated with place of death and the investigators proposed that this was related to the uneven distribution of hospice care facilities across the state.[12] The other study focused on hospital costs for decedents aged 65 years and over who died of any cause in 2002-2003. It reported that half of these deaths occurred in hospitals and that 87% of decedents were hospitalised at least once in their last year of life.[13]

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.[14] Another study of people who died in WA during 2000-2002 from selected conditions considered

1 to be potentially amenable to palliative care, reported that it was more common for people who  
2 died of cancer to access palliative care than it was for those dying from other causes.[15] A  
3 more recent study in WA reported that 62% of decedents who had an informal primary carer and  
4 who died of a condition considered to be potentially amenable to palliative care, were in hospital  
5 on the last day of life, that almost all had spent time in hospital in the year preceding death, and  
6 the number of hospitalisations increased markedly during the last three months of life.[16]  
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11 A number of studies from South Australia have addressed epidemiological questions relating to  
12 end of life care. Two studies of cancer deaths between 1990 and 1999 reported an increase in  
13 the utilisation of hospice and palliative care services.[17, 18] Other studies explored various end  
14 of life issues using data obtained through the South Australian Health Omnibus survey – an  
15 annual government-supported health survey. These included information about: unmet care  
16 giving needs;[19] place of death and its relationship to illness and uptake of specialist palliative  
17 care services;[20] factors associated with specialist palliative care service uptake including its  
18 relationship to caregiver perceptions of unmet need,[21] and outcomes of specialist palliative  
19 care services.[22] While informative for those specific purposes, these studies did not address  
20 utilisation of hospitals or EDs towards the end of life.  
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28 The aim of this study was to describe patterns of utilisation of acute hospital-based services by  
29 NSW residents during their last year of life using linked, routinely collected administrative health  
30 data. It included all people who died in NSW in 2007. This study will enhance the existing  
31 evidence base, enabling us to determine the use of acute hospital-based services by this  
32 population including admissions to hospital, time spent in hospital, presentations to ED, types of  
33 services received in hospital and place of death. We also examined variations in use of these  
34 services among groups defined by factors including age group, cause of death and geographical  
35 area. This will provide information that can form a foundation for further analyses and research  
36 studies that aim to address the health services needs of people who are nearing the end of their  
37 life in NSW. In this paper we describe the methods we have used to assemble the study dataset  
38 and provide a description of the study cohort.  
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## 48 **METHODS**

### 49 **Data sources and record linkage**

50 We carried out a retrospective population-based study using de-identified linked health records.  
51 From the NSW Register of Births, Deaths and Marriages (RBDM), we identified all people who  
52 died in NSW during the 2007 calendar year. Coded causes of death were obtained for these  
53 people from the Australian Bureau of Statistics (ABS) Mortality data. We also obtained  
54 information about their hospitalisations between January 2006 and December 2007 from the  
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1 NSW Admitted Patient Data Collection (APDC), information on their presentations to EDs for the  
2 same period through the NSW Emergency Department Data Collection (EDDC), and information  
3 on any cancer diagnoses these people had between 1994 and 2007 from the NSW Central  
4 Cancer Registry (CCR) (Figure 1).  
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9 The RBDM receives notification of all deaths in NSW and the resulting data set contains date of  
10 death and age at death. The ABS Mortality data set contains coded causes of death and  
11 demographic information (e.g. sex, area of residence) for all deaths in NSW. We chose to work  
12 with data for people who died in 2007 as this was the most recent year for which coded cause of  
13 death information was available from the ABS. Further, the ABS releases this information based  
14 on the year in which the deaths were registered, not when they occurred, so deaths occurring  
15 later in 2007 may not have been included in the data released for 2007. The APDC contains  
16 information on all admissions to public, private or repatriation hospitals, private day procedure  
17 centres, or public nursing homes in NSW, including procedures performed, diagnoses recorded  
18 and patients' demographic characteristics. The data are abstracted from medical records  
19 following the patient's discharge from hospital. The EDDC contains information on the majority of  
20 emergency department presentations in NSW, including dates, times and departure status. The  
21 coverage of the EDDC is described in more detail below. The CCR contains information on all  
22 cancers diagnosed in NSW, except for non-melanoma skin cancers, including summary disease  
23 stage and patients' demographic characteristics.  
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33 Linkage of records in these data sets was carried out by the Centre for Health Record Linkage  
34 (CHeReL),[23] using probabilistic matching carried out with ChoiceMaker software  
35 (ChoiceMaker Technologies Inc., New York, US). The CHeReL used a privacy-preserving  
36 process to ensure the separation of personal identifiers and health information. The CHeReL  
37 held no health information, receiving only personal identifiers from data custodians that were  
38 used to generate a linkage key, which was then returned to the data custodians. Researchers  
39 received only health information and a linkage key from the data custodians. Records for all  
40 uncertain matches from the linkage process and a sample of "certain" matches and non-matches  
41 underwent clerical review by linkage officers at the CHeReL, and approximately 0.4% false  
42 positive and less than 0.5% false negative linkages were reported.  
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50 The NSW Population and Health Services Research Ethics Committee approved the study and  
51 the linkage process.  
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### 55 **Characteristics of decedents**

56 Personal characteristics recorded across the data sources included age at death, sex, marital  
57 status, country of birth, need for interpreter service, and causes of death. Two geographical  
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1 variables were created, both based on local government area of residence at the time of death:  
2 accessibility to services as defined by the Accessibility/Remoteness Index for Australia  
3 (ARIA+)[24] and socioeconomic status quintile based on the ABS index of relative  
4 disadvantage.[25] To date, our analyses have been restricted to people aged 18 years or more  
5 at death, as the experiences of those younger than 18 years (1% of all deaths) were considered  
6 likely to be very different to those of the adult population. Decedents younger than 18 years will  
7 be studied separately. Cause of death was taken from the ABS 'underlying cause of death' field  
8 and each person could also have up to 20 contributing causes of death recorded. Cause of  
9 death was available as a 4-character code using the International Classification of Diseases 10<sup>th</sup>  
10 revision (ICD-10); we summarised these to standard 3-character groupings for analysis.  
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### 17 **Measures of hospital-based services utilisation**

18 We generated indicators of hospital-based services utilisation for each person during the 365  
19 days prior to their death, including the number and length of hospital admissions, the number  
20 and length of ED presentations, the amount of time spent in an intensive care unit (ICU), the  
21 number of admissions with a palliative care component, procedures recorded in hospital and  
22 place of death.  
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28 Several different indicators in the APDC were used to identify palliative care service utilisation.  
29 These indicators were used to create two definitions of palliative-related admissions. The first  
30 definition, which captured people who were clearly documented as having been seen by a  
31 specialist palliative care team, included admissions that had a specific flag indicating that the  
32 patient saw a palliative team, or admissions to the five stand-alone hospice/inpatient palliative  
33 care facilities in the State. The second broader definition included all admissions potentially  
34 related to palliative care, including some decedents who may have received palliative care but  
35 not from a specialist team. This group included those captured by the first definition, together  
36 with admissions where the service unit type was a palliative care bed, admissions where the  
37 service category or service related group or a diagnosis code indicated palliative care, and  
38 admissions where the patient was flagged as having been referred to a palliative care team or  
39 palliative unit or hospice.  
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48 Admission to an intensive care unit was flagged when the number of hours spent in intensive  
49 care at each admission, was recorded in the APDC. The data set did not allow us to determine  
50 whether the person was in an ICU at the time of death, or on the day of death, only whether the  
51 person spent time in the ICU during an admission.  
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56 Deaths in hospitals or EDs were identified from the arrival/separation status recorded in the  
57 APDC and EDDC. The CCR also recorded place of death as either in a hospital, hospice,  
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1 nursing home, or the person's home. If the death was not recorded as being in hospital in the  
2 APDC or EDDC, we used place of death recorded in the CCR where available. Deaths occurring  
3 on the date of separation from a hospital or ED where status on separation was not "died" were  
4 not classified as a death in hospital.  
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8 We also investigated a number of markers that have been proposed as potential indicators of  
9 "aggressive" care for people who died from cancer.[26] Covering the last 30 days of life, these  
10 markers included: having an ICU admission; having more than one hospital admission; spending  
11 more than 14 days in hospital; and having more than one ED presentation. Earle et al[26]  
12 proposed other markers of potentially "aggressive" cancer care in the weeks prior to death  
13 including receiving chemotherapy in the last 2 weeks, starting a new chemotherapy regimen in  
14 the last month, and being admitted to a hospice for fewer than 4 days. However, chemotherapy  
15 and hospice admissions were not reliably recorded in the data set and so these were not  
16 investigated.  
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### 23 **Coverage by the NSW Emergency Department Data Collection (EDDC)**

24 The EDDC only contained information for 46% (n=86) of the 185 EDs in NSW during the study  
25 period. These EDs accounted for 81% of all ED attendances in that time [J. Agland, personal  
26 communication, October 2012] and included care provided in all major metropolitan EDs.[27]  
27 NSW is divided into 15 Local Health Districts (LHDs). The EDDC included 37 of the 39 EDs in  
28 the "Greater Sydney Area", comprising the following LHDs: Central Coast, Illawarra Shoalhaven,  
29 Nepean Blue Mountains, Northern Sydney, South Eastern Sydney, South Western Sydney,  
30 Sydney and Western Sydney. The two EDs in these LHDs not included are relatively small  
31 facilities covering less complex cases.[27]  
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39 We assessed the level of linkage to the EDDC across the 15 LHDs. For each LHD in the Greater  
40 Sydney Area, at least 74% of the NSW adult residents who died in 2007 linked to at least one  
41 record in the EDDC, with 83% linked overall across the region. In the study therefore we  
42 restricted analyses of ED presentations to the decedents from these LHDs (accounting for 62%  
43 of NSW adult deaths) as we believe they have sufficiently complete information on presentations  
44 to the ED. For the decedents in this region who were not linked to the EDDC, we are confident  
45 that this was not due to data availability or linkage issues, but rather because these people did  
46 not present at an ED during the study period. While the proportion linked to the EDDC was also  
47 around 80% for decedents from Hunter New England and Mid North Coast LHDs, there were  
48 three and four EDs in the respective LHDs not covered by the EDDC so these two LHDs were  
49 excluded from analyses of ED utilisation as were the other five LHDs, all covering rural and  
50 remote areas for which ED data capture was incomplete.  
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## Data analysis

The measures of interest (number of hospital admissions, place of death, etc.) were analysed for all adult decedents and separately for selected groups defined by key patient characteristics (age, place of residence, etc.). We analysed these outcomes using descriptive statistics and multivariable logistic regression. Information about marital status and need for an interpreter service was only available from the APDC and EDDC data sets, so if a decedent did not have linked records in either of these then this information was not available. We therefore omitted these variables from analyses where interpretation of the outcome of interest (related to a hospital admission or ED presentation) would have required information about persons who were not in these data sets.

We analysed the data on an admission-by-admission basis, treating each admission record separately. We also aggregated records with overlapping dates for an individual, considering these admissions to be part of the one overall hospitalisation “episode”. Although overlapping dates could reflect a discharge and re-admission on the same day, this was relatively rare. Of the multiple-admission “episodes” that were identified, 78% involved a transfer from one hospital to another, 18% were due to a change in type of service within the same hospital and only 4% reflected a discharge and re-admission on the same day to the same hospital.

The purpose of this paper is to describe the methods of the study and provide descriptive statistics (counts and proportions) for the cohort relating to sociodemographic characteristics and levels of linkage to the data sets of interest. Subsequent publications will report on in-depth analyses for subgroups of the cohort of decedents. All analyses were carried out in SAS version 9.2 (SAS Institute Inc, Cary, North Carolina, US).

## RESULTS

### Sample size and characteristics

There were 46,341 deaths in NSW in 2007 with 45,760 of these people aged 18 years or more. The results that follow refer to decedents aged 18 years or older. The median age at death was 80 years (interquartile range 70-87 years). Around 1% of these decedents had no information on sex, country of birth or geographical location of residence, while 13% had unknown marital status and 17% had no information on need for an interpreter (Table 1).

### Record linkage

Coded cause of death was available from the ABS for 95% of adults who died in 2007. Of the 2,220 decedents who were not linked to records in the ABS Mortality Data, 94% died in

1 December 2007 (representing 59% of all deaths in this month), although around one third of  
2 these people had cause of death information available from the CCR. The vast majority of  
3 decedents were linked to records in the hospital or ED data sets, and 38% had a cancer  
4 diagnosis recorded in the CCR between 1994 and 2007 (Table 2).  
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### 8 **Causes of death**

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10 The most common underlying causes of death were diseases of the circulatory system (34% of  
11 all deaths) and neoplasms (29%) (Table 3). Excluding people who died in December, due to the  
12 relatively large proportion with unknown cause of death, did not substantially alter the distribution  
13 of causes of death.  
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## 17 **DISCUSSION**

18  
19 This study utilises existing health data collections to describe the use of acute hospital-based  
20 services during the last year of life by all adults who died in NSW in 2007. It is the first study in  
21 Australia that will report hospitalisation rates for all adult decedents for the whole State, and only  
22 the second (and first in NSW) to analyse place of death for all decedents state-wide. The study  
23 also describes ED presentations at the end of life for the majority of NSW decedents, giving an  
24 information-rich census of the end of life experience. Further work on this data set is in progress,  
25 including analyses of hospital admissions, time in hospital, ED presentations, place of death and  
26 identification of factors related to these and other outcomes of interest. We are investigating  
27 these factors in relation to specific causes of death such as cancer and cardiovascular disease,  
28 along with the hospital-based experiences towards the end of life for children and very elderly  
29 decedents.  
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40 There are limitations to this study. Due to data not being made available, there was no coded  
41 cause of death information from the ABS for 59% of those who died in December 2007.  
42 However, the distribution of causes of death in December, where the data were available, was  
43 very similar to that for all other months and the CCR data provided cause of death for a large  
44 number of cancer deaths where it was not available from the ABS. In addition, the analyses rely  
45 upon probabilistic record linkage, so it is possible that there were incorrect linkages with hospital  
46 or ED records, although the CHeReL estimated that there were only around 0.4% false positive  
47 linkages and less than 0.5% false negative linkages.  
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54 Other limitations include that the EDDC does not capture presentations to all EDs in NSW, so  
55 we cannot provide a “whole-of-state” description of ED presentations during the last year of life.  
56 We therefore restricted analyses of ED utilisation to decedents living in the geographical area in  
57 which we believe almost all ED presentations were captured. As these were predominantly EDs  
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1 in urban areas, this limited our ability to comment on potentially important differences in the  
2 utilisation of EDs between these and rural settings.  
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5 Another limitation is that the restriction on ABS data availability meant we had to use data that  
6 are now up to 6 years old. The annual number of deaths has increased in that time, and while  
7 trends may be similar for many conditions and in many situations, it is feasible that differences in  
8 patterns of care and practices between that time and now may exist.  
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13 In presenting data from this study, we must highlight that there are limitations in the data set that  
14 limit our ability to accurately reflect service use. The lack of information about palliative care  
15 specialist service use and bed use is problematic. The similar lack of information about the  
16 specific days on which ICU services were accessed also presents problems in relation to  
17 considering ICU use at the end of life. Other gaps include the lack of information about place of  
18 death within the hospital, and demographic factors that could impact service access and use  
19 such as language barriers between health service providers, patients and families. Also, there  
20 are currently barriers to linking any of the hospital-based service data to community-based  
21 service data and therefore the former tell only a “part of the story” in relation to health care  
22 utilisation towards the end of life.  
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30 These data have two further important limitations. There is no subjective, patient, family or carer-  
31 reported information in these administrative data that could serve to shed light on these groups’  
32 perceptions of care and whether their needs are met – a vital outcome if, as a society, we are to  
33 optimise our healthcare. Also, these data sources cannot be used to identify the  
34 “appropriateness” of care patterns or care delivery. While the markers of potentially “aggressive”  
35 cancer care were developed by Earle et al[26] in the United States and have been explored in  
36 various populations since and will be explored in this dataset in subsequent analyses, it must be  
37 acknowledged that these markers may capture care that is quite “appropriate”. Thus, although  
38 these markers could be used as baseline information to prompt further investigations into  
39 “appropriateness”, these should not be interpreted as definite indicators of inappropriate or even  
40 “aggressive” care. For example, admission to intensive care – sometimes deemed as  
41 inappropriate towards the end of a life-limiting illness – may indeed be quite appropriate under  
42 some circumstances. In addition, we do not have any information on the patients where this  
43 “aggressive” care was successful and death was averted. The identification of palliative care  
44 service utilisation is also an important consideration in relation to whether care options are  
45 optimal. Unfortunately, as discussed previously, documentation of the utilisation of these  
46 services is not comprehensive as the dataset did not include complete documentation of hospital  
47 access to palliative care or information about any access to palliative care provided in the  
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1 community setting. Therefore, it does not represent the full array of palliative care service  
2 utilisation.  
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5 Despite these potential limitations, the data we have used provide powerful population-based  
6 information about the hospital-based end of life experiences of all adults who died across the  
7 entire State. Decedents aged less than 18 years, who comprise only 1% of all deaths, will be  
8 studied as a separate cohort.  
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13 The data described in this study are routinely collected for other purposes and the linkage  
14 process is established and ongoing, which makes it possible to routinely update the analyses  
15 undertaken in this study to monitor activity over time, provided the coded cause of death  
16 information is available. Such data will enable an analysis of the effect of relevant characteristics  
17 (e.g. cause of death and geographical location of residence) on acute hospital-based service  
18 utilisation. The gaps in the data, for example in relation to palliative care services, highlight areas  
19 where consideration could be given to additions to routinely collected data to more accurately  
20 reflect service use over time.  
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27 Importantly, the data described in this study will provide a necessary foundation for asking an  
28 important "next set of questions". Such questions, to be addressed in subsequent studies, would  
29 require a data collection approach other than record linkage. These could include investigating  
30 the reasons behind any disease-specific or regional differences identified in acute hospital-  
31 based services utilisation, whether some population groups encounter more barriers than others  
32 in service access, and how all of this relates to the needs of individuals and their "subjective"  
33 experiences of the health system – the latter being an area totally absent from routinely collected  
34 data. With the answers to this next set of questions, the planning of health services can be  
35 based around the goal of meeting clearly quantified needs of all individuals with serious illness  
36 including those who are nearing the end of their life, addressing identified barriers to access to  
37 services, and optimising care at this often difficult time of life for patients, families and carers.  
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## 45 **Conclusions**

46 The data from this study provide reliable information about the experiences of those who died in  
47 NSW in 2007. These data can also serve to inform a relatively inexpensive, timely and reliable  
48 approach to the ongoing monitoring of the hospital-based end of life experiences of all adults in  
49 NSW. The study also highlights gaps in existing routine data collection that may also serve to  
50 inform future data collection strategies and thus allow for more comprehensive and informative  
51 future analyses and assessment of health care access and quality. In summary, this study  
52 provides a foundation from which to develop an efficient data collection infrastructure and  
53 provides baseline data for future studies of service access for care towards the end of life in  
54 NSW and other jurisdictions in Australia.  
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## Tables

Table 1. Characteristics of adult decedents in NSW in 2007<sup>a</sup> (n=45,760).

	No. of deaths	% of deaths
<b>Age at death</b>		
18-59	5,723	13
60-79	15,724	34
80-89	16,363	36
90+	7,950	17
<b>Sex</b>		
Female	22,430	49
Male	23,120	51
Unknown	210	0.5
<b>Country of birth</b>		
Australia	33,870	74
Other	11,539	25
Unknown	351	1
<b>Marital status</b>		
Never married	4,120	9
Married (incl. de facto)	18,268	40
Widowed	14,286	31
Separated/Divorced	2,949	6
Unknown	6,137	13
<b>Interpreter required</b>		
No	36,533	80
Yes	1,651	4
Unknown	7,576	17
<b>Accessibility/Remoteness of residence<sup>b</sup></b>		
Major cities	30,908	68
Inner regional	10,993	24
Outer regional	3,176	7
Remote / Very remote	221	0.5
Unknown	462	1
<b>Socioeconomic status<sup>c</sup></b>		
Most disadvantaged quintile	9,047	20
Quintile 2	10,210	22
Quintile 3	10,172	22
Quintile 4	7,879	17
Least disadvantaged quintile	7,945	17
Unknown	507	1

<sup>a</sup> Excludes 580 decedents aged <18 years and 1 decedent with no age information

<sup>b</sup> Based on Australian Bureau of Statistics' Accessibility/Remoteness Index for Australia

<sup>c</sup> Using population-based quintiles of the Australian Bureau of Statistics' index of relative disadvantage

Table 2. Linkage by data source for adult decedents in NSW in 2007 (n=45,760).

Data source	No. of deaths	% of deaths
Australian Bureau of Statistics (mortality)	43,540	95
Admitted Patient Data Collection 2006-2007	38,818	85
Emergency Department Data Collection 2006-2007	35,554	78
Central Cancer Registry 1994-2007	17,315	38
Not linked to any of the above	210	0.5

Table 3. Underlying causes of death for adult decedents in NSW in 2007 (n=45,760).

Cause of death	No. of deaths	% of deaths
A00-B99: Certain infectious and parasitic diseases	728	2
C00-D48: Neoplasms	13,441	29
D50-D89: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	158	0.3
E00-E90: Endocrine, nutritional and metabolic diseases	1,460	3
F00-F90: Mental and behavioural disorders	2,015	4
G00-G99: Diseases of the nervous system	1,619	4
I00-I99: Diseases of the circulatory system	15,501	34
J00-J99: Diseases of the respiratory system	3,718	8
K00-K99: Diseases of the digestive system	1,440	3
L00-L99: Diseases of the skin and subcutaneous tissue	144	0.3
M00-M99: Diseases of the musculoskeletal system and connective tissue	334	1
N00-N99: Diseases of the genitourinary system	1,069	2
Q00-Q99: Congenital malformations, deformations and chromosomal abnormalities	67	0.1
R00-R99: Symptoms, signs and abnormal clinical & laboratory findings, no further classification	334	1
V00-Y98: External causes of morbidity and mortality	2,140	5
Cause of death not available	1,589	3



## Figures

Figure 1. Data sources for analysis of the hospital-based experiences of people who died in NSW, Australia in 2007.

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## Contributorship Statement

DO'C, JI and MP conceived and designed the study. DO'C and DG acquired the data. DG analysed the data with input from DO'C and JI. All authors were involved in drafting the protocol and revising the manuscript. All authors read and approved the final manuscript.

## Data Sharing Statement

No additional data are available.

## Competing interests

None declared.

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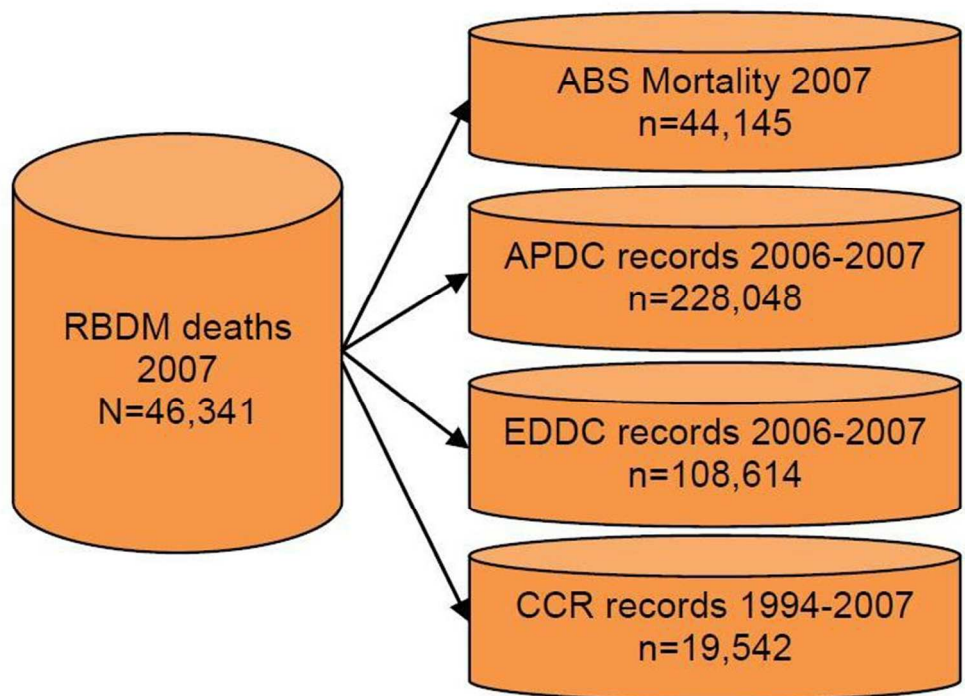
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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cohort studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	3
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	6-7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-7
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6-7
		(b) For matched studies, give matching criteria and number of exposed and unexposed	Not applicable
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-10
Bias	9	Describe any efforts to address potential sources of bias	6-10
Study size	10	Explain how the study size was arrived at	6, 9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-10
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7-10
		(b) Describe any methods used to examine subgroups and interactions	7-10
		(c) Explain how missing data were addressed	9-10
		(d) If applicable, explain how loss to follow-up was addressed	-
		(e) Describe any sensitivity analyses	10-11
<b>Results</b>			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9-10
		(b) Give reasons for non-participation at each stage	9-10
		(c) Consider use of a flow diagram	16
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	14-15
		(b) Indicate number of participants with missing data for each variable of interest	14-15
		(c) Summarise follow-up time (eg, average and total amount)	10-11
Outcome data	15*	Report numbers of outcome events or summary measures over time	10-11, 14-15
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	10-11, 14-15
		(b) Report category boundaries when continuous variables were categorized	14-15
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10-11
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	11
<b>Limitations</b>			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11-13
Generalisability	21	Discuss the generalisability (external validity) of the study results	11-13
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).



**Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: methods for a population-based study**

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**Title**

**Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: methods for a population-based study**

**Authors**

Dianne L O'Connell, BMaths(Hons) PhD  
Senior Epidemiologist, Cancer Council NSW, Australia  
E: [dianneo@nswcc.org.au](mailto:dianneo@nswcc.org.au)

David E Goldsbury, BSc(Hons) MPH  
Statistician/Data Analyst, Cancer Council NSW, Australia  
E: [davidg@nswcc.org.au](mailto:davidg@nswcc.org.au)

Patricia Davidson, RN BA MEd PhD  
Director, Centre for Cardiovascular and Chronic Care, University of Technology, Sydney, Australia and St Vincent's Hospital Sydney, Australia  
Johns Hopkins University  
E: [pdavids3@jhu.edu](mailto:pdavids3@jhu.edu)

Afaf Girgis, BSc(Hons) PhD  
Executive Director, Translational Cancer Research Unit, Ingham Institute for Applied Medical Research, UNSW Medicine, The University of New South Wales, Australia  
E: [afaf.girgis@unsw.edu.au](mailto:afaf.girgis@unsw.edu.au)

Jane L Phillips, RN BSci(Nur) PhD  
Professor Palliative Nursing, The Cunningham Centre for Palliative Care and School of Nursing, The University of Notre Dame, Australia  
E: [jane.phillips@nd.edu.au](mailto:jane.phillips@nd.edu.au)

Michael Piza, BA(Hons) MPH  
Clinical Epidemiologist, Clinical Governance Unit, South Eastern Sydney Local Health District, Australia and Conjoint Associate Lecturer, School of Public Health and Community Medicine, Faculty of Medicine, The University of New South Wales, Australia  
E: [Michael.Piza@sesiahs.health.gov.au](mailto:Michael.Piza@sesiahs.health.gov.au)

Anne Wilkinson, PhD  
Cancer Council WA Chair in Palliative and Supportive Care



1 School of Nursing and Midwifery, Edith Cowan University, Western Australia, Australia

2  
3 E: [anne.wilkinson@ecu.edu.au](mailto:anne.wilkinson@ecu.edu.au)

4  
5 Jane M Ingham, MB BS FRACP FACHPM

6  
7 Professor, Palliative Medicine, UNSW Australia (The University of New South Wales)

8  
9 Cunningham Centre for Palliative Care, Australia

10  
11 E: [jingham@stvincents.com.au](mailto:jingham@stvincents.com.au)

### 12 13 **Corresponding author**

14 Dianne O'Connell, BMaths(Hons) PhD

15 Senior Epidemiologist, Cancer Research Division

16  
17 Cancer Council NSW, PO Box 572, Kings Cross, NSW 1340, AUSTRALIA

18  
19 E: [dianneo@nswcc.org.au](mailto:dianneo@nswcc.org.au)

20  
21 P: +61 2 9334 1768

22  
23 F: +61 2 8302 3550

### 24 25 26 27 **Keywords**

28 End-of-life; hospital-based care; palliative care; population-based; linked administrative health  
29 data  
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### 32 33 **Word counts**

34 Abstract: 299 words

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36 Manuscript: 4059 words  
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## ABSTRACT

### Objectives

The aim of this study is 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.

### Design/Setting

Linked, routinely collected administrative health data are being analysed for all people who died in New South Wales (NSW), Australia's most populous state, in 2007. The data comprised linked death records (2007), hospital admissions and emergency department presentations (2006-2007) and cancer registrations (1994-2007).

### Participants

There were 46,341 deaths in NSW in 2007. The initial analyses include 45,760 decedents aged 18 years and over.

### Outcome measures

The primary measures address the utilisation of hospital-based services at the end of life, including number and length of hospital admissions, emergency department presentations, intensive care admissions, palliative-related admissions and place of death.

### Results

The median age at death was 80 years. Cause of death was available for 95% of decedents and 85% were linked to a hospital admission record. In the greater metropolitan area, where data capture was complete, 83% of decedents were linked to an emergency department presentation. Thirty-eight percent of decedents were linked to a cancer diagnosis in 1994-2007. The most common causes of death were diseases of the circulatory system (34%) and neoplasms (29%).

### Conclusions

This study is among the first in Australia to give an information-rich census of end of life hospital-based experiences. While the administrative datasets have some limitations, these population-wide data can provide a foundation to enable further exploration of needs and barriers in relation to care. They also serve to inform the development of a relatively inexpensive, timely and reliable approach to the ongoing monitoring of acute hospital-based care utilisation near the end of life and inform whether service access and care are optimised.

## Article summary

### Strengths and limitations of this study

- The study data will provide powerful information about the hospital-based experiences at the end of life for all people who died in an entire state across a full calendar year, providing a valuable addition to the limited epidemiological information currently available.
- The data cannot be used to identify the “appropriateness” of care patterns or care delivery, and the information about palliative care specialist service use was incomplete.
- Not all emergency department presentations could be captured and not all cause of death information was available.
- The results will provide baseline data for future studies of service access for care towards the end of life, along with an indication of the types of information required to develop a more comprehensive data collection infrastructure.

## INTRODUCTION

There are more than 45,000 deaths each year in New South Wales (NSW),[1] Australia's most populous state. Despite the NSW population of around 7 million people accounting for 33% of the country's population,[2] there is little epidemiological information available about health care utilisation towards the end of life for these people. This information is important for planning and optimising the availability and appropriateness of health care services across NSW. While there is some related information available for other Australian states,[3-13] there has been a gap in the evidence base for clinicians and researchers in NSW to develop, implement and monitor patient outcomes.

Worldwide, studies of end of life care have covered population groups ranging from small hospital-based samples to all decedents across several countries.[14-16] Many studies have focused on place of death,[17] palliative care[18] and health services use for specific disease subgroups such as cancer.[19,20] 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.

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.[21] The other study focused on hospital costs for decedents aged 65 years and over who died of any cause in 2002-2003.[22]

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 described palliative care use for people who died from selected chronic conditions in WA during 2000-2002.[6] A more recent study in WA reported on hospitalisations at the end of life for a similar subgroup of decedents who also had an informal primary carer.[7]

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 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

1 government-supported health survey. These included information about: unmet care giving  
2 needs;[10] place of death and its relationship to illness and uptake of specialist palliative care  
3 services;[11] factors associated with specialist palliative care service uptake including its  
4 relationship to caregiver perceptions of unmet need,[12] and outcomes of specialist palliative  
5 care services.[13] While informative for those specific purposes, these studies did not address  
6 utilisation of hospitals or EDs towards the end of life.  
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11 The aim of this study is to describe patterns of utilisation of acute hospital-based services by  
12 NSW residents during their last year of life using linked, routinely collected administrative health  
13 data. It includes all people who died in NSW in 2007. This study will enhance the existing  
14 evidence base, enabling us to determine the use of acute hospital-based services by this  
15 population including admissions to hospital, time spent in hospital, presentations to ED, types of  
16 services received in hospital and place of death. We are also examining variations in use of  
17 these services among groups defined by factors including age group, cause of death and  
18 geographical area. This will provide information that can form a foundation for further analyses  
19 and research studies that aim to address the health services needs of people who are nearing  
20 the end of their life in NSW. In this paper we describe the methods we have used to assemble  
21 the study dataset and provide a description of the study cohort.  
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## 32 **METHODS**

### 33 **Data sources and record linkage**

34 This is a retrospective population-based study using de-identified linked health records. From  
35 the NSW Register of Births, Deaths and Marriages (RBDM), we identified all people who died in  
36 NSW during the 2007 calendar year. Coded causes of death were obtained for these people  
37 from the Australian Bureau of Statistics (ABS) Mortality data. We also obtained information  
38 about their hospitalisations between January 2006 and December 2007 from the NSW Admitted  
39 Patient Data Collection (APDC), information on their presentations to EDs for the same period  
40 through the NSW Emergency Department Data Collection (EDDC), and information on any  
41 cancer diagnoses these people had between 1994 and 2007 from the NSW Central Cancer  
42 Registry (CCR) (Figure 1).  
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51 The RBDM receives notification of all deaths in NSW and the resulting dataset contains date of  
52 death and age at death. The ABS Mortality dataset contains coded causes of death and  
53 demographic information (e.g. sex, area of residence) for all deaths in NSW. We chose to work  
54 with data for people who died in 2007 as this was the most recent year for which coded cause of  
55 death information was available from the ABS. Further, the ABS releases this information based  
56 on the year in which the deaths were registered, not when they occurred, so deaths occurring  
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1 later in 2007 may not have been included in the data released for 2007. The APDC contains  
2 information on all admissions to public, private or repatriation hospitals, private day procedure  
3 centres, or public nursing homes in NSW, including procedures performed, diagnoses recorded  
4 and patients' demographic characteristics. The data are abstracted from medical records  
5 following the patient's discharge from hospital. The EDDC contains information on the majority of  
6 emergency department presentations in NSW, including dates, times and departure status. The  
7 coverage of the EDDC is described in more detail below. The CCR contains information on all  
8 cancers diagnosed in NSW, except for non-melanoma skin cancers, including summary disease  
9 stage and patients' demographic characteristics.

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16 Linkage of records in these datasets was carried out by the Centre for Health Record Linkage  
17 (CHeReL),[23] using probabilistic matching carried out with ChoiceMaker software  
18 (ChoiceMaker Technologies Inc., New York, US). Privacy was preserved through the linkage  
19 process: the CHeReL used personal identifiers for decedents but held no health information,  
20 while the researchers received the health information for the decedents but no personal  
21 identifiers. Records for all uncertain matches from the linkage process and a sample of "certain"  
22 matches and non-matches underwent clerical review by linkage officers at the CHeReL, and  
23 approximately 0.4% false positive and less than 0.5% false negative linkages were reported.

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30 The NSW Population and Health Services Research Ethics Committee approved the study and  
31 the linkage process.

### 32 33 34 35 **Characteristics of decedents**

36 Personal characteristics recorded across the data sources included age at death, sex, marital  
37 status, country of birth, need for interpreter service, and causes of death. Two geographical  
38 variables were created, both based on local government area of residence at the time of death:  
39 accessibility to services as defined by the Accessibility/Remoteness Index for Australia  
40 (ARIA+)[24] and socioeconomic status quintile based on the ABS index of relative  
41 disadvantage.[25] Initial analyses are being restricted to people aged 18 years or more at death,  
42 as the experiences of those younger than 18 years (1% of all deaths) were considered likely to  
43 be very different to those of the adult population. Decedents younger than 18 years will be  
44 studied separately. Cause of death was taken from the ABS 'underlying cause of death' field and  
45 each person could also have up to 20 contributing causes of death recorded. Cause of death  
46 was available as a 4-character code using the International Classification of Diseases 10<sup>th</sup>  
47 revision (ICD-10); we summarised these to standard 3-character groupings for analysis.

### 48 49 50 51 52 53 54 55 56 **Measures of hospital-based services utilisation**

1 We are generating indicators of hospital-based services utilisation for each person during the  
2 365 days prior to their death, including the number and length of hospital admissions, the  
3 number and length of ED presentations, the amount of time spent in an intensive care unit (ICU),  
4 the number of admissions with a palliative care component, procedures recorded in hospital and  
5 place of death.  
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10 Several different indicators in the APDC are being used to identify palliative care service  
11 utilisation. These indicators will reflect two definitions of palliative-related admissions. The first  
12 definition, which captures people who were clearly documented as having been seen by a  
13 specialist palliative care team, includes admissions that had a specific flag indicating that the  
14 patient saw a palliative team, or admissions to the five stand-alone hospice/inpatient palliative  
15 care facilities in the State. The second broader definition includes all admissions potentially  
16 related to palliative care, including some decedents who may have received palliative care but  
17 not from a specialist team. This group includes those captured by the first definition, together  
18 with admissions where the service unit type was a palliative care bed, admissions where the  
19 service category or service related group or a diagnosis code indicated palliative care, and  
20 admissions where the patient was flagged as having been referred to a palliative care team or  
21 palliative unit or hospice.  
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30 Admission to an intensive care unit was flagged when the number of hours spent in intensive  
31 care at each admission, was recorded in the APDC. The dataset does not allow us to determine  
32 whether the person was in an ICU at the time of death, or on the day of death, only whether the  
33 person spent time in the ICU during an admission.  
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38 Deaths in hospitals or EDs are being identified from the arrival/separation status recorded in the  
39 APDC and EDDC. The CCR also recorded place of death as either in a hospital, hospice,  
40 nursing home, or the person's home. If the death was not recorded in the APDC or EDDC as  
41 being in hospital, we are using place of death recorded in the CCR where available. Deaths  
42 occurring on the date of separation from a hospital or ED where status on separation was not  
43 "died" are not being classified as deaths in hospital.  
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48 We are also investigating a number of markers that have been proposed as potential indicators  
49 of "aggressive" care for people who died from cancer.[26] Covering the last 30 days of life, these  
50 markers include: having an ICU admission; having more than one hospital admission; spending  
51 more than 14 days in hospital; and having more than one ED presentation. Earle et al[26]  
52 proposed other markers of potentially "aggressive" cancer care in the weeks prior to death  
53 including receiving chemotherapy in the last 2 weeks, starting a new chemotherapy regimen in  
54 the last month, and being admitted to a hospice for fewer than 4 days. However, chemotherapy  
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1 and hospice admissions were not reliably recorded in the dataset and so these are not being  
2 investigated.  
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#### 4 **Coverage by the NSW Emergency Department Data Collection (EDDC)**

5 The EDDC only contained information for 46% (n=86) of the 185 EDs in NSW during the study  
6 period. These EDs accounted for 81% of all ED attendances in that time [J. Agland, personal  
7 communication, October 2012] and included care provided in all major metropolitan EDs.[27]  
8 NSW is divided into 15 Local Health Districts (LHDs). The EDDC included 37 of the 39 EDs in  
9 the "Greater Sydney Area", comprising the following LHDs: Central Coast, Illawarra Shoalhaven,  
10 Nepean Blue Mountains, Northern Sydney, South Eastern Sydney, South Western Sydney,  
11 Sydney and Western Sydney. The two EDs in these LHDs not included are relatively small  
12 facilities covering less complex cases.[27]  
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21 Eighty-three percent of adult decedents from the Greater Sydney Area who died in 2007 linked  
22 to at least one record in the EDDC. In the study we will restrict analyses of ED presentations to  
23 the decedents from these LHDs (accounting for 62% of NSW adult deaths) as we believe they  
24 have sufficiently complete information on presentations to the ED. For the decedents in this  
25 region who were not linked to the EDDC, we are confident that this was not due to data  
26 availability or linkage issues, but rather because these people did not present at an ED during  
27 the study period. While the proportion linked to the EDDC was also around 80% for decedents  
28 from Hunter New England and Mid North Coast LHDs, there were three and four EDs in the  
29 respective LHDs not covered by the EDDC so these two LHDs were excluded from analyses of  
30 ED utilisation as were the other five LHDs, all covering rural and remote areas for which ED data  
31 capture was incomplete.  
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#### 39 **Data analysis**

40 The measures of interest (number of hospital admissions, place of death, etc.) are being  
41 analysed for all adult decedents and separately for selected groups defined by key patient  
42 characteristics (age, place of residence, etc.). We are analysing these outcomes using  
43 descriptive statistics and multivariable logistic regression. Information about marital status and  
44 need for an interpreter service was only available from the APDC and EDDC datasets, so if a  
45 decedent did not have linked records in either of these then this information was not available.  
46 We are therefore omitting these variables from analyses where interpretation of the outcome of  
47 interest (related to a hospital admission or ED presentation) would require information about  
48 persons who were not in these datasets.  
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56 We are analysing the data on an admission-by-admission basis, treating each admission record  
57 separately. We are also aggregating records with overlapping dates for an individual,  
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1 considering these admissions to be part of the one overall hospitalisation “episode”. Although  
2 overlapping dates could reflect a discharge and re-admission on the same day, this was  
3 relatively rare. Of the multiple-admission “episodes” that were identified, 78% involved a transfer  
4 from one hospital to another, 18% were due to a change in type of service within the same  
5 hospital and only 4% reflected a discharge and re-admission on the same day to the same  
6 hospital.  
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11 The purpose of this paper is to describe the methods of the study and provide descriptive  
12 statistics (counts and proportions) for the cohort relating to sociodemographic characteristics  
13 and levels of linkage to the datasets of interest. Subsequent publications will report on in-depth  
14 analyses for subgroups of the cohort of decedents. All analyses are being carried out in SAS  
15 version 9.2 (SAS Institute Inc, Cary, North Carolina, US).  
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## 23 RESULTS

### 24 **Sample size and characteristics**

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26 There were 46,341 deaths in NSW in 2007 with 45,760 of these people aged 18 years or more.  
27 The results that follow refer to decedents aged 18 years or older. The median age at death was  
28 80 years (interquartile range 70-87 years). Around 1% of these decedents had no information on  
29 sex, country of birth or geographical location of residence, while 13% had unknown marital  
30 status and 17% had no information on need for an interpreter (Table 1).  
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### 36 **Record linkage**

37 Coded cause of death was available from the ABS for 95% of adults who died in 2007. Of the  
38 2,220 decedents who were not linked to records in the ABS Mortality Data, 94% died in  
39 December 2007 (representing 59% of all deaths in this month), although around one third of  
40 these people had cause of death information available from the CCR. The vast majority of  
41 decedents were linked to records in the hospital or ED datasets, and 38% had a cancer  
42 diagnosis recorded in the CCR between 1994 and 2007 (Table 2).  
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### 48 **Causes of death**

49 The most common underlying causes of death were diseases of the circulatory system (34% of  
50 all deaths) and neoplasms (29%) (Table 3). Excluding people who died in December, due to the  
51 relatively large proportion with unknown cause of death, did not substantially alter the distribution  
52 of causes of death.  
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## 59 DISCUSSION

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This study utilises existing health data collections to describe the use of acute hospital-based services during the last year of life by all adults who died in NSW in 2007. It will be the first study in Australia to report hospitalisation rates for all adult decedents for the whole State, and only the second (and first in NSW) to describe place of death for all decedents state-wide. The study will also describe ED presentations at the end of life for the majority of NSW decedents, giving an information-rich census of the end of life experience. Work on this dataset is in progress, including analyses of hospital admissions, time in hospital, ED presentations, place of death and identification of factors related to these and other outcomes of interest. We are investigating these factors in relation to specific causes of death such as cancer and cardiovascular disease, along with the hospital-based experiences towards the end of life for children and very elderly decedents.

There are limitations to this study. Due to data not being made available, there was no coded cause of death information from the ABS for 59% of those who died in December 2007. However, the distribution of causes of death in December, where the data were available, was very similar to that for all other months and the CCR data provided cause of death for a large number of cancer deaths where it was not available from the ABS. In addition, the analyses rely upon probabilistic record linkage, so it is possible that there were incorrect linkages with hospital or ED records, although the CHeReL estimated that there were only around 0.4% false positive linkages and less than 0.5% false negative linkages.

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 therefore restricting analyses of ED utilisation to decedents living in the geographical area in which we believe almost all ED presentations were captured. As these were predominantly EDs in urban areas, this will limit our ability to comment on potentially important differences in the utilisation of EDs between these and rural settings.

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

1 similar for many conditions and in many situations, it is feasible that differences in patterns of  
2 care and practices between that time and now may exist.  
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5 In presenting data from this study, we must highlight that there are limitations in the dataset that  
6 limit our ability to accurately reflect all service use. The lack of information about palliative care  
7 specialist service use and bed use is problematic. Data on specialist palliative care are collected  
8 in other Australian jurisdictions, so it is expected that it would be feasible for this to be  
9 undertaken in NSW in the future. The similar lack of information about the specific days on which  
10 ICU services were accessed also presents problems in relation to considering ICU use at the  
11 end of life. Other gaps include the lack of information about place of death within the hospital,  
12 and demographic factors that could impact service access and use such as language barriers  
13 between health service providers, patients and families. Also, there are currently barriers to  
14 linking any of the hospital-based service data to community-based service data and therefore  
15 the former tell only a “part of the story” in relation to overall health care utilisation towards the  
16 end of life. Importantly, this study will serve to highlight to policy makers the need to review the  
17 data that are routinely collected and to consider which data should be collected to facilitate  
18 optimal analyses of health service utilisation towards the end of life.  
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28 These data have two further important limitations. There is no subjective, patient, family or carer-  
29 reported information in these administrative data that could serve to shed light on these groups’  
30 perceptions of care and whether their needs are met – a vital outcome if, as a society, we are to  
31 optimise our healthcare. Also, these data sources cannot be used to identify the  
32 “appropriateness” of care patterns or care delivery. While the markers of potentially “aggressive”  
33 cancer care were developed by Earle et al[26] in the United States and have been explored in  
34 various populations since and will be explored in this dataset in subsequent analyses, it must be  
35 acknowledged that these markers may capture care that is quite “appropriate”. Thus, although  
36 these markers could be used as baseline information to prompt further investigations into  
37 “appropriateness”, these should not be interpreted as definite indicators of inappropriate or even  
38 “aggressive” care. For example, admission to intensive care – sometimes deemed as  
39 inappropriate towards the end of a life-limiting illness – may indeed be quite appropriate under  
40 some circumstances. In addition, we do not have any information on the patients where this  
41 “aggressive” care was successful and death was averted. The identification of palliative care  
42 service utilisation is also an important consideration in relation to whether care options are  
43 optimal. Unfortunately, as discussed previously, documentation of the utilisation of these  
44 services is not comprehensive as the dataset did not include complete documentation of hospital  
45 access to palliative care or information about any access to palliative care provided in the  
46 community setting. Therefore, it does not represent the full array of palliative care service  
47 utilisation.  
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3 Despite these potential limitations, the data we are using will provide powerful population-based  
4 information about the hospital-based end of life experiences of all adults who died across the  
5 entire State. Decedents aged less than 18 years, who comprise only 1% of all deaths, will be  
6 studied as a separate cohort.  
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10 The data being used in this study are routinely collected for other purposes and the linkage  
11 process is established and ongoing, which makes it possible to routinely update the analyses  
12 being undertaken in this study to monitor activity over time, provided the coded cause of death  
13 information is available. Such data will enable an analysis of the effect of relevant characteristics  
14 (e.g. cause of death and geographical location of residence) on acute hospital-based service  
15 utilisation. The gaps in the data, for example in relation to palliative care services, highlight areas  
16 where consideration could be given to additions to routinely collected data to more accurately  
17 reflect service use over time.  
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24 Importantly, the data described in this study will provide a necessary foundation for asking an  
25 important "next set of questions". Such questions, to be addressed in subsequent studies, would  
26 require a data collection approach other than record linkage. These could include investigating  
27 the reasons behind any disease-specific or regional differences identified in acute hospital-  
28 based services utilisation, whether some population groups encounter more barriers than others  
29 in service access, and how all of this relates to the needs of individuals and their "subjective"  
30 experiences of the health system – the latter being an area totally absent from routinely collected  
31 data. With the answers to this next set of questions, the planning of health services can be  
32 based around the goal of meeting clearly quantified needs of all individuals with serious illness  
33 including those who are nearing the end of their life, addressing identified barriers to access to  
34 services, and optimising care at this often difficult time of life for patients, families and carers.  
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## 42 **Conclusions**

43 The data from this study will provide reliable information about the experiences of those who  
44 died in NSW in 2007. These data can also serve to inform a relatively inexpensive, timely and  
45 reliable approach to the ongoing monitoring of the hospital-based end of life experiences of all  
46 adults in NSW. Also, the study will highlights gaps in existing routine data collections that may  
47 also serve to inform future data collection strategies and thus allow for more comprehensive and  
48 informative future analyses and assessment of all aspects of health care access and quality. In  
49 summary, this study will provide a foundation from which to develop an efficient data collection  
50 infrastructure and will provide baseline data for future studies of service access for care towards  
51 the end of life in NSW and other jurisdictions in Australia.  
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## Tables

Table 1. Characteristics of adult decedents in NSW in 2007<sup>a</sup> (n=45,760).

	No. of deaths	% of deaths
<b>Age at death</b>		
18-59	5,723	13
60-79	15,724	34
80-89	16,363	36
90+	7,950	17
<b>Sex</b>		
Female	22,430	49
Male	23,120	51
Unknown	210	0.5
<b>Country of birth</b>		
Australia	33,870	74
Other	11,539	25
Unknown	351	1
<b>Marital status</b>		
Never married	4,120	9
Married (incl. de facto)	18,268	40
Widowed	14,286	31
Separated/Divorced	2,949	6
Unknown	6,137	13
<b>Interpreter required</b>		
No	36,533	80
Yes	1,651	4
Unknown	7,576	17
<b>Accessibility/Remoteness of residence<sup>b</sup></b>		
Major cities	30,908	68
Inner regional	10,993	24
Outer regional	3,176	7
Remote / Very remote	221	0.5
Unknown	462	1
<b>Socioeconomic status<sup>c</sup></b>		
Most disadvantaged quintile	9,047	20
Quintile 2	10,210	22
Quintile 3	10,172	22
Quintile 4	7,879	17
Least disadvantaged quintile	7,945	17
Unknown	507	1

<sup>a</sup> Excludes 580 decedents aged <18 years and 1 decedent with no age information

<sup>b</sup> Based on Australian Bureau of Statistics' Accessibility/Remoteness Index for Australia

<sup>c</sup> Using population-based quintiles of the Australian Bureau of Statistics' index of relative disadvantage

Table 2. Linkage by data source for adult decedents in NSW in 2007 (n=45,760).

Data source	No. of deaths	% of deaths
Australian Bureau of Statistics (mortality)	43,540	95
Admitted Patient Data Collection 2006-2007	38,818	85
Emergency Department Data Collection 2006-2007	35,554	78
Central Cancer Registry 1994-2007	17,315	38
Not linked to any of the above	210	0.5

Table 3. Underlying causes of death for adult decedents in NSW in 2007 (n=45,760).

Cause of death	No. of deaths	% of deaths
A00-B99: Certain infectious and parasitic diseases	728	2
C00-D48: Neoplasms	13,441	29
D50-D89: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	158	0.3
E00-E90: Endocrine, nutritional and metabolic diseases	1,460	3
F00-F90: Mental and behavioural disorders	2,015	4
G00-G99: Diseases of the nervous system	1,619	4
I00-I99: Diseases of the circulatory system	15,501	34
J00-J99: Diseases of the respiratory system	3,718	8
K00-K99: Diseases of the digestive system	1,440	3
L00-L99: Diseases of the skin and subcutaneous tissue	144	0.3
M00-M99: Diseases of the musculoskeletal system and connective tissue	334	1
N00-N99: Diseases of the genitourinary system	1,069	2
Q00-Q99: Congenital malformations, deformations and chromosomal abnormalities	67	0.1
R00-R99: Symptoms, signs and abnormal clinical & laboratory findings, no further classification	334	1
V00-Y98: External causes of morbidity and mortality	2,140	5
Cause of death not available	1,589	3

## Figures

Figure 1. Data sources for analysis of the hospital-based experiences of people who died in NSW, Australia in 2007.

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## Contributorship Statement

DO'C, JI and MP conceived and designed the study. DO'C and DG acquired the data. DG analysed the data with input from DO'C and JI. All authors were involved in drafting the protocol and revising the manuscript. All authors read and approved the final manuscript.

## Competing interests

None declared.

## Data Sharing Statement

No additional data available.

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**Title**

**Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: methods for a population-based study**

**Authors**

Dianne L O'Connell, BMaths(Hons) PhD  
Senior Epidemiologist, Cancer Council NSW, Australia  
E: [dianneo@nswcc.org.au](mailto:dianneo@nswcc.org.au)

David E Goldsbury, BSc(Hons) MPH  
Statistician/Data Analyst, Cancer Council NSW, Australia  
E: [davidg@nswcc.org.au](mailto:davidg@nswcc.org.au)

Patricia Davidson, RN BA MEd PhD  
Director, Centre for Cardiovascular and Chronic Care, University of Technology, Sydney,  
Australia and St Vincent's Hospital Sydney, Australia  
Johns Hopkins University  
E: [pdavids3@jhu.edu](mailto:pdavids3@jhu.edu)

Afaf Girgis, BSc(Hons) PhD  
Executive Director, Translational Cancer Research Unit, Ingham Institute for Applied Medical  
Research, UNSW Medicine, The University of New South Wales, Australia  
E: [afaf.girgis@unsw.edu.au](mailto:afaf.girgis@unsw.edu.au)

Jane L Phillips, RN BSci(Nur) PhD  
Professor Palliative Nursing, The Cunningham Centre for Palliative Care and School of Nursing,  
The University of Notre Dame, Australia  
E: [jane.phillips@nd.edu.au](mailto:jane.phillips@nd.edu.au)

Michael Piza, BA(Hons) MPH  
Clinical Epidemiologist, Clinical Governance Unit, South Eastern Sydney Local Health District,  
Australia and Conjoint Associate Lecturer, School of Public Health and Community Medicine,  
Faculty of Medicine, The University of New South Wales, Australia  
E: [Michael.Piza@sesiahs.health.gov.au](mailto:Michael.Piza@sesiahs.health.gov.au)

Anne Wilkinson, PhD  
Cancer Council WA Chair in Palliative and Supportive Care

1 School of Nursing and Midwifery, Edith Cowan University, Western Australia, Australia

2  
3 E: [anne.wilkinson@ecu.edu.au](mailto:anne.wilkinson@ecu.edu.au)

4  
5 Jane M Ingham, MB BS FRACP FACHPM

6  
7 Professor, Palliative Medicine, UNSW Australia (The University of New South Wales)

8  
9 Cunningham Centre for Palliative Care, Australia

10  
11 E: [jingham@stvincents.com.au](mailto:jingham@stvincents.com.au)

### 12 13 **Corresponding author**

14 Dianne O'Connell, BMaths(Hons) PhD

15 Senior Epidemiologist, Cancer Research Division

16  
17 Cancer Council NSW, PO Box 572, Kings Cross, NSW 1340, AUSTRALIA

18  
19 E: [dianneo@nswcc.org.au](mailto:dianneo@nswcc.org.au)

20  
21 P: +61 2 9334 1768

22  
23 F: +61 2 8302 3550

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## ABSTRACT

### Objectives

The aim of this study is 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.

### Design/Setting

Linked, routinely collected administrative health data ~~were~~ are being analysed for all people who died in New South Wales (NSW), Australia's most populous state, in 2007. The data comprised linked death records (2007), hospital admissions and emergency department presentations (2006-2007) and cancer registrations (1994-2007).

### Participants

There were 46,341 deaths in NSW in 2007. The initial analyses ~~were conducted for~~ include 45,760 decedents aged 18 years and over.

### Outcome measures

The primary measures address the utilisation of hospital-based services at the end of life, including number and length of hospital admissions, emergency department presentations, intensive care admissions, palliative-related admissions and place of death.

### Results

The median age at death was 80 years. Cause of death was available for 95% of decedents and 85% were linked to a hospital admission record. In the greater metropolitan area, where data capture was complete, 83% of decedents were linked to an emergency department presentation. Thirty-eight percent of decedents were linked to a cancer diagnosis in 1994-2007. The most common causes of death were diseases of the circulatory system (34%) and neoplasms (29%).

### Conclusions

This study is among the first in Australia to give an information-rich census of end of life hospital-based experiences. While the administrative datasets have some limitations, these population-wide data can provide a foundation to enable further exploration of needs and barriers in relation to care. They also serve to inform the development of a relatively inexpensive, timely and reliable approach to the ongoing monitoring of acute hospital-based care utilisation near the end of life and inform whether service access and care are optimised.

## Article summary

### Strengths and limitations of this study

- The study data will provide powerful information about the hospital-based experiences at the end of life for all people who died in an entire state across a full calendar year, providing a valuable addition to the limited epidemiological information currently available.
- The data cannot be used to identify the “appropriateness” of care patterns or care delivery, and the information about palliative care specialist service use was incomplete.
- Not all emergency department presentations could be captured and not all cause of death information was available.
- The results will 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, along with an indication of the types of information required to develop a more comprehensive data collection infrastructure.

## INTRODUCTION

There are more than 45,000 deaths each year in New South Wales (NSW),<sup>[1]</sup> Australia's most populous state. Despite the NSW population of around 7 million people accounting for 33% of the country's population,<sup>[2]</sup> there is little epidemiological information available about health care utilisation towards the end of life for these people. This information is important for planning and optimising the availability and appropriateness of health care services across NSW. While there is some related information available for other Australian states,<sup>[3-13]</sup> there has been a gap in the evidence base for clinicians and researchers in NSW to develop, implement and monitor patient outcomes.

Worldwide, studies of end of life care have covered population groups ranging from small hospital-based samples to all decedents across several countries.<sup>[314-165]</sup> Many studies have focused on place of death,<sup>[176]</sup> palliative care<sup>[187]</sup> and health services use for specific disease subgroups such as cancer.<sup>[19,208,9]</sup> 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. ~~It reported that half of all deaths occurred in hospitals and that death in the usual place of residence was more common for those who accessed specialist palliative care.~~<sup>[310]</sup> The other study analysed hospital costs, but did not report specific numbers of decedents in hospital.<sup>[414]</sup> All other Australian studies of end of life care have been restricted to specific disease types, age groups or population subgroups.

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 ~~and found that 66% of cancer deaths occurred in hospital and a further 8% were in a hospice. Geographical area of residence was the factor most strongly associated with place of death and the investigators proposed that this was related to the uneven distribution of hospice care facilities across the state.~~<sup>[2112]</sup> The other study focused on hospital costs for decedents aged 65 years and over who died of any cause in 2002-2003. ~~It reported that half of these deaths occurred in hospitals and that 87% of decedents were hospitalised at least once in their last year of life.~~<sup>[2213]</sup>

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.<sup>[514]</sup> Another study ~~of~~ described palliative care use for people who died from selected chronic

1 ~~conditions~~ in WA during 2000-2002 ~~from selected conditions considered to be potentially~~  
2 ~~amenable to palliative care, reported that it was more common for people who died of cancer to~~  
3 ~~access palliative care than it was for those dying from other causes.~~[615] A more recent study in  
4 WA reported ~~that 62% of on hospitalisations at the end of life for a similar subgroup of~~ decedents  
5 who ~~also~~ had an informal primary carer ~~and who died of a condition considered to be potentially~~  
6 ~~amenable to palliative care, were in hospital on the last day of life, that almost all had spent time~~  
7 ~~in hospital in the year preceding death, and the number of hospitalisations increased markedly~~  
8 ~~during the last three months of life.~~[716]

14 A number of studies from South Australia have addressed epidemiological questions relating to  
15 end of life care. Two studies of cancer deaths between 1990 and 1999 reported ~~on an increase~~  
16 ~~in~~ the utilisation of hospice and palliative care services.[8,917,18] Other studies explored  
17 various end of life issues using data obtained through the South Australian Health Omnibus  
18 survey – an annual government-supported health survey. These included information about:  
19 unmet care giving needs;[1049] place of death and its relationship to illness and uptake of  
20 specialist palliative care services;[1120] factors associated with specialist palliative care service  
21 uptake including its relationship to caregiver perceptions of unmet need,[1224] and outcomes of  
22 specialist palliative care services.[1322] While informative for those specific purposes, these  
23 studies did not address utilisation of hospitals or EDs towards the end of life.

31 The aim of this study ~~was is~~ to describe patterns of utilisation of acute hospital-based services  
32 by NSW residents during their last year of life using linked, routinely collected administrative  
33 health data. It includes ~~ed~~ all people who died in NSW in 2007. This study will enhance the  
34 existing evidence base, enabling us to determine the use of acute hospital-based services by  
35 this population including admissions to hospital, time spent in hospital, presentations to ED,  
36 types of services received in hospital and place of death. We ~~are~~ also ~~examined~~ variations in  
37 use of these services among groups defined by factors including age group, cause of death and  
38 geographical area. This will provide information that can form a foundation for further analyses  
39 and research studies that aim to address the health services needs of people who are nearing  
40 the end of their life in NSW. In this paper we describe the methods we have used to assemble  
41 the study dataset and provide a description of the study cohort.

## 51 METHODS

### 54 Data sources and record linkage

55 ~~We carried out~~ This is a retrospective population-based study using de-identified linked health  
56 records. From the NSW Register of Births, Deaths and Marriages (RBDM), we identified all  
57 people who died in NSW during the 2007 calendar year. Coded causes of death were obtained  
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1 for these people from the Australian Bureau of Statistics (ABS) Mortality data. We also obtained  
2 information about their hospitalisations between January 2006 and December 2007 from the  
3 NSW Admitted Patient Data Collection (APDC), information on their presentations to EDs for the  
4 same period through the NSW Emergency Department Data Collection (EDDC), and information  
5 on any cancer diagnoses these people had between 1994 and 2007 from the NSW Central  
6 Cancer Registry (CCR) (Figure 1).  
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11 The RBDM receives notification of all deaths in NSW and the resulting dataset contains date of  
12 death and age at death. The ABS Mortality dataset contains coded causes of death and  
13 demographic information (e.g. sex, area of residence) for all deaths in NSW. We chose to work  
14 with data for people who died in 2007 as this was the most recent year for which coded cause of  
15 death information was available from the ABS. Further, the ABS releases this information based  
16 on the year in which the deaths were registered, not when they occurred, so deaths occurring  
17 later in 2007 may not have been included in the data released for 2007. The APDC contains  
18 information on all admissions to public, private or repatriation hospitals, private day procedure  
19 centres, or public nursing homes in NSW, including procedures performed, diagnoses recorded  
20 and patients' demographic characteristics. The data are abstracted from medical records  
21 following the patient's discharge from hospital. The EDDC contains information on the majority of  
22 emergency department presentations in NSW, including dates, times and departure status. The  
23 coverage of the EDDC is described in more detail below. The CCR contains information on all  
24 cancers diagnosed in NSW, except for non-melanoma skin cancers, including summary disease  
25 stage and patients' demographic characteristics.  
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36 Linkage of records in these datasets was carried out by the Centre for Health Record Linkage  
37 (CHeReL),[23] using probabilistic matching carried out with ChoiceMaker software  
38 (ChoiceMaker Technologies Inc., New York, US). Privacy was preserved through the linkage  
39 process: the CHeReL used personal identifiers for decedents but held no health information,  
40 while the researchers received the health information for the decedents but no personal  
41 identifiers. The CHeReL used a privacy preserving process to ensure the separation of personal  
42 identifiers and health information. The CHeReL held no health information, receiving only  
43 personal identifiers from data custodians that were used to generate a linkage key, which was  
44 then returned to the data custodians. Researchers received only health information and a  
45 linkage key from the data custodians. Records for all uncertain matches from the linkage  
46 process and a sample of "certain" matches and non-matches underwent clerical review by  
47 linkage officers at the CHeReL, and approximately 0.4% false positive and less than 0.5% false  
48 negative linkages were reported.  
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1 The NSW Population and Health Services Research Ethics Committee approved the study and  
2 the linkage process.  
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### 4 5 6 **Characteristics of decedents**

7 Personal characteristics recorded across the data sources included age at death, sex, marital  
8 status, country of birth, need for interpreter service, and causes of death. Two geographical  
9 variables were created, both based on local government area of residence at the time of death:  
10 accessibility to services as defined by the Accessibility/Remoteness Index for Australia  
11 (ARIA+)[24] and socioeconomic status quintile based on the ABS index of relative  
12 disadvantage.[25] ~~To date, our Initial~~ analyses ~~have been~~ are being restricted to people aged 18  
13 years or more at death, as the experiences of those younger than 18 years (1% of all deaths)  
14 were considered likely to be very different to those of the adult population. Decedents younger  
15 than 18 years will be studied separately. Cause of death was taken from the ABS 'underlying  
16 cause of death' field and each person could also have up to 20 contributing causes of death  
17 recorded. Cause of death was available as a 4-character code using the International  
18 Classification of Diseases 10<sup>th</sup> revision (ICD-10); we summarised these to standard 3-character  
19 groupings for analysis.  
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### 28 **Measures of hospital-based services utilisation**

29 We are ~~generating~~ indicators of hospital-based services utilisation for each person during the  
30 365 days prior to their death, including the number and length of hospital admissions, the  
31 number and length of ED presentations, the amount of time spent in an intensive care unit (ICU),  
32 the number of admissions with a palliative care component, procedures recorded in hospital and  
33 place of death.  
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39 Several different indicators in the APDC ~~were~~ are being used to identify palliative care service  
40 utilisation. These indicators ~~will reflect~~ ~~were used to create~~ two definitions of palliative-related  
41 admissions. The first definition, which captures ~~sd~~ people who were clearly documented as having  
42 been seen by a specialist palliative care team, includes ~~sd~~ admissions that had a specific flag  
43 indicating that the patient saw a palliative team, or admissions to the five stand-alone  
44 hospice/inpatient palliative care facilities in the State. The second broader definition includes ~~sd~~ all  
45 admissions potentially related to palliative care, including some decedents who may have  
46 received palliative care but not from a specialist team. This group includes ~~sd~~ those captured by  
47 the first definition, together with admissions where the service unit type was a palliative care  
48 bed, admissions where the service category or service related group or a diagnosis code  
49 indicated palliative care, and admissions where the patient was flagged as having been referred  
50 to a palliative care team or palliative unit or hospice.  
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1 Admission to an intensive care unit was flagged when the number of hours spent in intensive  
2 care at each admission, was recorded in the APDC. The dataset ~~did~~ does not allow us to  
3 determine whether the person was in an ICU at the time of death, or on the day of death, only  
4 whether the person spent time in the ICU during an admission.  
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8 Deaths in hospitals or EDs ~~we~~ are being identified from the arrival/separation status recorded in  
9 the APDC and EDDC. The CCR also recorded place of death as either in a hospital, hospice,  
10 nursing home, or the person's home. If the death was not recorded in the APDC or EDDC as  
11 being in hospital, we ~~are~~ using place of death recorded in the CCR where available. Deaths  
12 occurring on the date of separation from a hospital or ED where status on separation was not  
13 "died" ~~we~~ are not being classified as ~~a~~ deaths in hospital.  
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19 We are also ~~investigating~~ investigating a number of markers that have been proposed as potential  
20 indicators of "aggressive" care for people who died from cancer.[26] Covering the last 30 days of  
21 life, these markers included: having an ICU admission; having more than one hospital  
22 admission; spending more than 14 days in hospital; and having more than one ED presentation.  
23 Earle et al[26] proposed other markers of potentially "aggressive" cancer care in the weeks prior  
24 to death including receiving chemotherapy in the last 2 weeks, starting a new chemotherapy  
25 regimen in the last month, and being admitted to a hospice for fewer than 4 days. However,  
26 chemotherapy and hospice admissions were not reliably recorded in the dataset and so these  
27 ~~were~~ are not being investigated.  
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### 35 Coverage by the NSW Emergency Department Data Collection (EDDC)

36 The EDDC only contained information for 46% (n=86) of the 185 EDs in NSW during the study  
37 period. These EDs accounted for 81% of all ED attendances in that time [J. Agland, personal  
38 communication, October 2012] and included care provided in all major metropolitan EDs.[27]  
39 NSW is divided into 15 Local Health Districts (LHDs). The EDDC included 37 of the 39 EDs in  
40 the "Greater Sydney Area", comprising the following LHDs: Central Coast, Illawarra Shoalhaven,  
41 Nepean Blue Mountains, Northern Sydney, South Eastern Sydney, South Western Sydney,  
42 Sydney and Western Sydney. The two EDs in these LHDs not included are relatively small  
43 facilities covering less complex cases.[27]  
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50 ~~We assessed the level of linkage to the EDDC across the 15 LHDs. For each LHD in Eighty-~~  
51 ~~three percent of adult decedents from~~ the Greater Sydney Area, ~~at least 74% of the NSW adult~~  
52 ~~residents~~ who died in 2007 linked to at least one record in the EDDC, ~~with 83% linked overall~~  
53 ~~across the region~~. In the study ~~therefore~~ we will ~~restricted~~ analyses of ED presentations to the  
54 decedents from these LHDs (accounting for 62% of NSW adult deaths) as we believe they have  
55 sufficiently complete information on presentations to the ED. For the decedents in this region  
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1 who were not linked to the EDDC, we are confident that this was not due to data availability or  
2 linkage issues, but rather because these people did not present at an ED during the study  
3 period. While the proportion linked to the EDDC was also around 80% for decedents from  
4 Hunter New England and Mid North Coast LHDs, there were three and four EDs in the  
5 respective LHDs not covered by the EDDC so these two LHDs were excluded from analyses of  
6 ED utilisation as were the other five LHDs, all covering rural and remote areas for which ED data  
7 capture was incomplete.  
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### 12 **Data analysis**

13 The measures of interest (number of hospital admissions, place of death, etc.) ~~were~~ are being  
14 analysed for all adult decedents and separately for selected groups defined by key patient  
15 characteristics (age, place of residence, etc.). We are ~~analysing~~ these outcomes using  
16 descriptive statistics and multivariable logistic regression. Information about marital status and  
17 need for an interpreter service was only available from the APDC and EDDC datasets, so if a  
18 decedent did not have linked records in either of these then this information was not available.  
19 We are ~~omitting~~ these variables from analyses where interpretation of the outcome  
20 of interest (related to a hospital admission or ED presentation) would ~~have required~~  
21 information about persons who were not in these datasets.  
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30 We are ~~analysing~~ the data on an admission-by-admission basis, treating each admission  
31 record separately. We are ~~also aggregating~~ records with overlapping dates for an individual,  
32 considering these admissions to be part of the one overall hospitalisation “episode”. Although  
33 overlapping dates could reflect a discharge and re-admission on the same day, this was  
34 relatively rare. Of the multiple-admission “episodes” that were identified, 78% involved a transfer  
35 from one hospital to another, 18% were due to a change in type of service within the same  
36 hospital and only 4% reflected a discharge and re-admission on the same day to the same  
37 hospital.  
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44 The purpose of this paper is to describe the methods of the study and provide descriptive  
45 statistics (counts and proportions) for the cohort relating to sociodemographic characteristics  
46 and levels of linkage to the datasets of interest. Subsequent publications will report on in-depth  
47 analyses for subgroups of the cohort of decedents. All analyses ~~are being~~ were carried out in  
48 SAS version 9.2 (SAS Institute Inc, Cary, North Carolina, US).  
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## 55 **RESULTS**

### 56 **Sample size and characteristics**

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1 There were 46,341 deaths in NSW in 2007 with 45,760 of these people aged 18 years or more.  
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3 The results that follow refer to decedents aged 18 years or older. The median age at death was  
4 80 years (interquartile range 70-87 years). Around 1% of these decedents had no information on  
5 sex, country of birth or geographical location of residence, while 13% had unknown marital  
6 status and 17% had no information on need for an interpreter (Table 1).  
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### 10 **Record linkage**

11 Coded cause of death was available from the ABS for 95% of adults who died in 2007. Of the  
12 2,220 decedents who were not linked to records in the ABS Mortality Data, 94% died in  
13 December 2007 (representing 59% of all deaths in this month), although around one third of  
14 these people had cause of death information available from the CCR. The vast majority of  
15 decedents were linked to records in the hospital or ED datasets, and 38% had a cancer  
16 diagnosis recorded in the CCR between 1994 and 2007 (Table 2).  
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### 22 **Causes of death**

23 The most common underlying causes of death were diseases of the circulatory system (34% of  
24 all deaths) and neoplasms (29%) (Table 3). Excluding people who died in December, due to the  
25 relatively large proportion with unknown cause of death, did not substantially alter the distribution  
26 of causes of death.  
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## 33 **DISCUSSION**

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35 This study utilises existing health data collections to describe the use of acute hospital-based  
36 services during the last year of life by all adults who died in NSW in 2007. It ~~is~~ will be the first  
37 study in Australia ~~that will to~~ report hospitalisation rates for all adult decedents for the whole  
38 State, and only the second (and first in NSW) to describe place of death for all decedents state-  
39 wide. The study will also describes ~~s~~ ED presentations at the end of life for the majority of NSW  
40 decedents, giving an information-rich census of the end of life experience. ~~Further w~~Work on this  
41 dataset is in progress, including analyses of hospital admissions, time in hospital, ED  
42 presentations, place of death and identification of factors related to these and other outcomes of  
43 interest. We are investigating these factors in relation to specific causes of death such as cancer  
44 and cardiovascular disease, along with the hospital-based experiences towards the end of life  
45 for children and very elderly decedents.  
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54 There are limitations to this study. Due to data not being made available, there was no coded  
55 cause of death information from the ABS for 59% of those who died in December 2007.  
56 However, the distribution of causes of death in December, where the data were available, was  
57 very similar to that for all other months and the CCR data provided cause of death for a large  
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1 number of cancer deaths where it was not available from the ABS. In addition, the analyses rely  
2 upon probabilistic record linkage, so it is possible that there were incorrect linkages with hospital  
3 or ED records, although the CHeReL estimated that there were only around 0.4% false positive  
4 linkages and less than 0.5% false negative linkages.  
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9 Other limitations include that the EDDC currently does not capture presentations to all EDs in  
10 NSW, so we cannot presently provide a “whole-of-state” description of ED presentations during  
11 the last year of life. The EDDC is a relatively new data collection that is currently being  
12 expanded to include all EDs in NSW. This expansion will benefit future studies using these data  
13 and the methods described in this study will be applicable to future datasets with complete  
14 coverage of the State. To ensure accuracy in this analysis, however, we are ~~We~~ therefore  
15 restricting analyses of ED utilisation to decedents living in the geographical area in which we  
16 believe almost all ED presentations were captured. As these were predominantly EDs in urban  
17 areas, this will ~~limited~~ our ability to comment on potentially important differences in the utilisation  
18 of EDs between these and rural settings.  
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26 Another limitation is ~~that~~ the restriction on ABS data availability. The ABS has limited the release  
27 of cause of death information for deaths after 2007. Negotiations are currently underway to re-  
28 establish the supply of these data, however it means that we ~~have~~ to use data that are now up  
29 to 67 years old. The annual number of deaths has increased in that time, and while trends may  
30 be similar for many conditions and in many situations, it is feasible that differences in patterns of  
31 care and practices between that time and now may exist.  
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37 In presenting data from this study, we must highlight that there are limitations in the dataset that  
38 limit our ability to accurately reflect all service use. The lack of information about palliative care  
39 specialist service use and bed use is problematic. Data on specialist palliative care are collected  
40 in other Australian jurisdictions, so it is expected that it would be feasible for this to be  
41 undertaken in NSW in the future. The similar lack of information about the specific days on which  
42 ICU services were accessed also presents problems in relation to considering ICU use at the  
43 end of life. Other gaps include the lack of information about place of death within the hospital,  
44 and demographic factors that could impact service access and use such as language barriers  
45 between health service providers, patients and families. Also, there are currently barriers to  
46 linking any of the hospital-based service data to community-based service data and therefore  
47 the former tell only a “part of the story” in relation to overall health care utilisation towards the  
48 end of life. Importantly, this study will serve to highlight to policy makers the need to review the  
49 data that are routinely collected and to consider which data should be collected to facilitate  
50 optimal analyses of health service utilisation towards the end of life.  
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1 These data have two further important limitations. There is no subjective, patient, family or carer-  
2 reported information in these administrative data that could serve to shed light on these groups'  
3 perceptions of care and whether their needs are met – a vital outcome if, as a society, we are to  
4 optimise our healthcare. Also, these data sources cannot be used to identify the  
5 "appropriateness" of care patterns or care delivery. While the markers of potentially "aggressive"  
6 cancer care were developed by Earle et al[26] in the United States and have been explored in  
7 various populations since and will be explored in this dataset in subsequent analyses, it must be  
8 acknowledged that these markers may capture care that is quite "appropriate". Thus, although  
9 these markers could be used as baseline information to prompt further investigations into  
10 "appropriateness", these should not be interpreted as definite indicators of inappropriate or even  
11 "aggressive" care. For example, admission to intensive care – sometimes deemed as  
12 inappropriate towards the end of a life-limiting illness – may indeed be quite appropriate under  
13 some circumstances. In addition, we do not have any information on the patients where this  
14 "aggressive" care was successful and death was averted. The identification of palliative care  
15 service utilisation is also an important consideration in relation to whether care options are  
16 optimal. Unfortunately, as discussed previously, documentation of the utilisation of these  
17 services is not comprehensive as the dataset did not include complete documentation of hospital  
18 access to palliative care or information about any access to palliative care provided in the  
19 community setting. Therefore, it does not represent the full array of palliative care service  
20 utilisation.

21 Despite these potential limitations, the data we are using ~~will have used~~ provide powerful  
22 population-based information about the hospital-based end of life experiences of all adults who  
23 died across the entire State. Decedents aged less than 18 years, who comprise only 1% of all  
24 deaths, will be studied as a separate cohort.

25 The data being used ~~described~~ in this study are routinely collected for other purposes and the  
26 linkage process is established and ongoing, which makes it possible to routinely update the  
27 analyses being undertaken in this study to monitor activity over time, provided the coded cause  
28 of death information is available. Such data will enable an analysis of the effect of relevant  
29 characteristics (e.g. cause of death and geographical location of residence) on acute hospital-  
30 based service utilisation. The gaps in the data, for example in relation to palliative care services,  
31 highlight areas where consideration could be given to additions to routinely collected data to  
32 more accurately reflect service use over time.

33 Importantly, the data described in this study will provide a necessary foundation for asking an  
34 important "next set of questions". Such questions, to be addressed in subsequent studies, would  
35 require a data collection approach other than record linkage. These could include investigating

1 the reasons behind any disease-specific or regional differences identified in acute hospital-  
2 based services utilisation, whether some population groups encounter more barriers than others  
3 in service access, and how all of this relates to the needs of individuals and their “subjective”  
4 experiences of the health system – the latter being an area totally absent from routinely collected  
5 data. With the answers to this next set of questions, the planning of health services can be  
6 based around the goal of meeting clearly quantified needs of all individuals with serious illness  
7 including those who are nearing the end of their life, addressing identified barriers to access to  
8 services, and optimising care at this often difficult time of life for patients, families and carers.  
9

### 14 Conclusions

16 The data from this study will provide reliable information about the experiences of those who  
17 died in NSW in 2007. These data can also serve to inform a relatively inexpensive, timely and  
18 reliable approach to the ongoing monitoring of the hospital-based end of life experiences of all  
19 adults in NSW. Also, tThe study will also-highlights gaps in existing routine data collections  
20 that may also serve to inform future data collection strategies and thus allow for more comprehensive  
21 and informative future analyses and assessment of all aspects of health care access and quality.  
22 In summary, this study will provides a foundation from which to develop an efficient data  
23 collection infrastructure and will provides baseline data for future studies of service access for  
24 care towards the end of life in NSW and other jurisdictions in Australia.  
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## Tables

Table 1. Characteristics of adult decedents in NSW in 2007<sup>a</sup> (n=45,760).

	No. of deaths	% of deaths
<b>Age at death</b>		
18-59	5,723	13
60-79	15,724	34
80-89	16,363	36
90+	7,950	17
<b>Sex</b>		
Female	22,430	49
Male	23,120	51
Unknown	210	0.5
<b>Country of birth</b>		
Australia	33,870	74
Other	11,539	25
Unknown	351	1
<b>Marital status</b>		
Never married	4,120	9
Married (incl. de facto)	18,268	40
Widowed	14,286	31
Separated/Divorced	2,949	6
Unknown	6,137	13
<b>Interpreter required</b>		
No	36,533	80
Yes	1,651	4
Unknown	7,576	17
<b>Accessibility/Remoteness of residence<sup>b</sup></b>		
Major cities	30,908	68
Inner regional	10,993	24
Outer regional	3,176	7
Remote / Very remote	221	0.5
Unknown	462	1
<b>Socioeconomic status<sup>c</sup></b>		
Most disadvantaged quintile	9,047	20
Quintile 2	10,210	22
Quintile 3	10,172	22
Quintile 4	7,879	17
Least disadvantaged quintile	7,945	17
Unknown	507	1

<sup>a</sup> Excludes 580 decedents aged <18 years and 1 decedent with no age information

<sup>b</sup> Based on Australian Bureau of Statistics' Accessibility/Remoteness Index for Australia



<sup>c</sup> Using population-based quintiles of the Australian Bureau of Statistics' index of relative disadvantage

Table 2. Linkage by data source for adult decedents in NSW in 2007 (n=45,760).

Data source	No. of deaths	% of deaths
Australian Bureau of Statistics (mortality)	43,540	95
Admitted Patient Data Collection 2006-2007	38,818	85
Emergency Department Data Collection 2006-2007	35,554	78
Central Cancer Registry 1994-2007	17,315	38
Not linked to any of the above	210	0.5

Table 3. Underlying causes of death for adult decedents in NSW in 2007 (n=45,760).

Cause of death	No. of deaths	% of deaths
A00-B99: Certain infectious and parasitic diseases	728	2
C00-D48: Neoplasms	13,441	29
D50-D89: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	158	0.3
E00-E90: Endocrine, nutritional and metabolic diseases	1,460	3
F00-F90: Mental and behavioural disorders	2,015	4
G00-G99: Diseases of the nervous system	1,619	4
I00-I99: Diseases of the circulatory system	15,501	34
J00-J99: Diseases of the respiratory system	3,718	8
K00-K99: Diseases of the digestive system	1,440	3
L00-L99: Diseases of the skin and subcutaneous tissue	144	0.3
M00-M99: Diseases of the musculoskeletal system and connective tissue	334	1
N00-N99: Diseases of the genitourinary system	1,069	2
Q00-Q99: Congenital malformations, deformations and chromosomal abnormalities	67	0.1
R00-R99: Symptoms, signs and abnormal clinical & laboratory findings, no further classification	334	1
V00-Y98: External causes of morbidity and mortality	2,140	5
Cause of death not available	1,589	3

## Figures

Figure 1. Data sources for analysis of the hospital-based experiences of people who died in NSW, Australia in 2007.

## Acknowledgements

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## Competing interests

None declared.

## Funding

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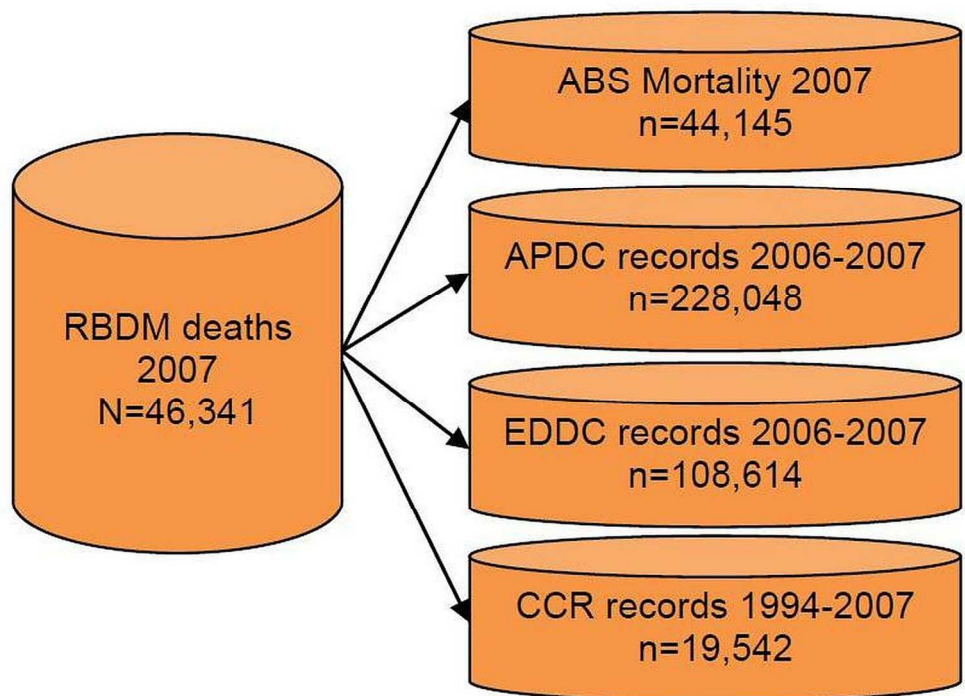
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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cohort studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	3
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	6-7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-7
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6-7
		(b) For matched studies, give matching criteria and number of exposed and unexposed	Not applicable
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-10
Bias	9	Describe any efforts to address potential sources of bias	6-10
Study size	10	Explain how the study size was arrived at	6-10
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-10
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7-10
		(b) Describe any methods used to examine subgroups and interactions	7-10
		(c) Explain how missing data were addressed	9-10
		(d) If applicable, explain how loss to follow-up was addressed	-
		(e) Describe any sensitivity analyses	10-11
<b>Results</b>			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9-10
		(b) Give reasons for non-participation at each stage	9-10
		(c) Consider use of a flow diagram	16
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	14-15
		(b) Indicate number of participants with missing data for each variable of interest	14-15
		(c) Summarise follow-up time (eg, average and total amount)	10-11
Outcome data	15*	Report numbers of outcome events or summary measures over time	10-11, 14-15
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	10-11, 14-15
		(b) Report category boundaries when continuous variables were categorized	14-15
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10-11
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	11
<b>Limitations</b>			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11-13
Generalisability	21	Discuss the generalisability (external validity) of the study results	11-13
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).