

*This is the pre-peer reviewed version of the following article: [Sypek MP, Dansie KB, Clayton P, Webster AC, McDonald S. Comparison of cause of death between ANZDATA and the Australian national death index. Nephrology 2019;24(3):322-329], which has been published in final form at [<https://doi.org/10.1111/nep.13250>]. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.*

## **COMPARISON OF CAUSE OF DEATH BETWEEN ANZDATA AND THE AUSTRALIAN NATIONAL DEATH INDEX**

Matthew P SYPEK<sup>1,2</sup>, Kathryn B DANSIE<sup>1</sup>, Phil CLAYTON<sup>1,3,4</sup>, Angela C WEBSTER<sup>5,6</sup>, Stephen MCDONALD<sup>1,3,4</sup>

### **Affiliations:**

<sup>1</sup> ANZDATA, Adelaide, South Australia, <sup>2</sup> University of Melbourne, Victoria <sup>3</sup> University of Adelaide, Adelaide, South Australia, <sup>4</sup> Royal Adelaide Hospital, Adelaide, Australia, <sup>5</sup> Sydney School of Public Health, University of Sydney, Australia, <sup>6</sup> Centre for transplant and renal research, Westmead hospital, NSW, Australia

### **Corresponding Author:**

Dr Matthew P Sypek

Epidemiology Fellow

ANZDATA Registry

C/O SAHMRI

PO BOX 11060

Adelaide, South Australia, 5001

p. 08 8128 4767

### **Running title:**

Registry coding of cause of death



## **Abstract**

### **Aim:**

To understand the differences in how cause of death for patients receiving renal replacement therapy in Australia is recorded in The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) compared to the National Death Index (NDI).

### **Methods:**

Data linkage was performed between ANZDATA and NDI for all deaths in the period 1980-2013. Cause of death was classified according to ICD-10 chapter. Overall and chapter specific agreement were assessed using the Kappa statistic. Descriptive analysis was used to explore differences where there was disagreement on primary cause of death.

### **Results:**

The analysis cohort included 28,675 patients. Ninety five percent of ANZDATA reported deaths fell within +/- 3 days of the date recorded by NDI. Circulatory death was the most common cause of death in both databases (ANZDATA 48%, NDI 32%). Overall agreement at ICD chapter level of primary cause was poor (36%, kappa 0.22). Agreement was best for malignancy (kappa 0.71).

When there was disagreement on primary cause of death these were most commonly coded as genitourinary (35%) and endocrine (25.0%) in NDI, and circulatory (39%) and withdrawal (24%) in ANZDATA. Sixty-nine percent of patients had a renal related cause documented as either primary or a contributing cause of death in the NDI.

### **Conclusion:**

There is poor agreement in primary cause of death between ANZDATA and NDI which is in part explained by the absence of diabetes and renal failure as causes of death in ANZDATA and the absence of 'withdrawal' in NDI. These differences should be appreciated when interpreting epidemiological data on cause of death in the Australian end stage kidney disease population.

### **MeSH Key Words**

Cause of Death

Classification

End-stage kidney disease

Registries

Renal Replacement Therapy

### **Abbreviations**

ABS – Australian Bureau of Statistics

AIWH – Australian Institute of Health and Welfare

ANZDATA – The Australia and New Zealand Dialysis and Transplant Registry

CORR - Canadian Organ Replacement Register

ESKD – End Stage Kidney Disease

ICD - International Classification of Diseases

ISQ – *Institut de la statistique du Quebec*

NDI – National Death Index

RRT – Renal Replacement Therapy

## **Main Text**

### **Background:**

Registries provide a valuable source of data for epidemiologic research and help inform policy decisions on resource allocation and health service provision(1–3). However, depending on how data is collected, from whom, for what purpose, and the coding and classification systems used, it is possible that the same variable, such as cause of death, from separate datasets may contain differing information for the same population. It is therefore possible that disparate or even contradictory conclusions may be drawn about the same population depending on the data source used in an analysis. Although considered the standard reference for population cause of death in Australia, the National Death Index (NDI) has been shown to differ substantially from other sources of mortality data (4–6). Disease specific registries, such as the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) often develop more detailed “bespoke” categorisations for cause of death that are specifically relevant to the particular disease process on which they collect data. In order to appreciate the mortality burden for patients with end stage kidney disease (ESKD) in Australia and interpret studies reporting on this outcome, it is important to understand the agreement and differences between the two key national sources of data on mortality in this population.

ANZDATA is a binational database established in 1971 for the purpose of recording, analysing and reporting on outcomes of treatment of those people with ESKD receiving chronic renal replacement therapy (RRT) (7). The database includes records on over 70,000 patients. As well as producing an annual report summarizing dialysis and renal transplantation activity and patient outcomes, the registry also provides health services and government bodies with data to assist with service delivery planning, produces centre specific performance reports, and provides population data for epidemiological and clinical research projects.

The NDI is a Commonwealth database that contains records of deaths registered in Australia since 1980 with data from the Registrar of Births, Deaths and Marriages in each jurisdiction,

the National Coronial Information System and the Australian Bureau of Statistics (ABS)(8). In its guidance to Medical Practitioners on completing Medical Certificates of Cause of Death the ABS states that accurate documentation of cause of death is important to both public health sector and medical researchers for evaluating and developing measures to improve the health of Australians generally, and, to family members in order to know what caused a loved one's death and to be aware of conditions that may occur in other family members(9).

Due to the variation in systems for cause of death coding and the priorities of those entering the data, it is possible that disparate conclusions on the burden of kidney disease in Australia may be drawn depending on the data source. We therefore aimed to compare the agreement in date and cause of death between ANZDATA and NDI and to explore the differences between these two important public health resources.

#### **Methods:**

The study population included all patients who commenced RRT (dialysis or transplantation) in Australia from 1980 and had a date and cause of death recorded in both ANZDATA and NDI during the period 1980-2013. Deaths occurring in New Zealand were not included in this analysis.

Cause of death for patients within ANZDATA is currently recorded using 84 codes (table 1), designed to cover the most common causes of death in this population, with the option of a free text 'other' field. This list was developed specifically for the registry and includes RRT specific causes of death such as "Withdrawal for psychosocial reasons". Cause of death is entered by the patient's treating renal unit, either at the time of death or at the end of the annual survey period. Of note, it is not possible to record a cause of death as "Renal failure" or "ESKD" within the registry, nor does ANZDATA have a cause of death code for "Diabetes" or "Complications of Diabetes". Only a single cause of death can be documented for each patient.

NDI cause of death is based on the diagnosis recorded on the Medical Certificate of Cause of Death, by a registered medical practitioner who was either responsible for the deceased person's medical care during their final illness or who examined the deceased person's body after death, or by the coroner in cases of coronial investigation. Death is subsequently coded according to the International Classification of Diseases (ICD) codes; ICD-9 until 1996 and ICD-10 since 1997. As well as recording underlying cause of death, the NDI allows for multiple additional other causes of death to also be recorded (up to 12 causes).

Data linkage between ANZDATA and NDI was performed by the Australian Institute of Health and Welfare (AIHW) using probabilistic matching. Extensive clerical review was conducted on any ambiguous links by the AIHW, therefore all links were considered true for the purpose of analysis, regardless of link weight.

ANZDATA cause of death codes and ICD-9 codes were mapped to ICD-10 chapters as outlined in table 1. ANZDATA includes a number of death codes related to withdrawal from treatment, which relate to death following the cessation of life sustaining RRT (usually the cessation of dialysis treatment). Where a specific reason for withdrawal was documented this was mapped to the corresponding ICD chapter for that cause (eg. 48 Withdrawal-Malignancy was mapped to chapter 2, Neoplasms). Four ANZDATA withdrawal codes did not have corresponding ICD chapters and were categorized under the heading 'Withdrawal'.

Overall and chapter specific agreement of primary cause of death were assessed using the kappa statistic. Agreement between ANZDATA cause of death and any NDI (underlying or contributing) cause of death was also conducted. Landis and Koch's qualitative assessment of the kappa statistics was used for interpretation(10). A sensitivity analysis was performed by recoding deaths following *withdrawal* as death due to ESKD (ie *genitourinary* cause of death). A subgroup analysis was also conducted based on last renal replacement therapy prior to death, comparing cause of death agreement in patients treated with transplantation and those treated with dialysis therapy.

Cross tabulation and descriptive analysis were used to explore differences where there was disagreement on primary cause of death. The percentage of patients with at least one renal related underlying cause was calculated.

Ethical approval for this project was granted by the AIHW and the South Australian Department for Health and Ageing Human Research Ethics Committee.

### **Results:**

The linkage process for this study is outlined in figure 1.

There were 51,455 patients who commenced RRT in Australia in the years 1980-2013, 29,008 of whom were matched to records in the NDI. Of note, 1,116 patients with a documented date of death in ANZDATA were not matched to NDI records by AIHW. A small number of patients (n=333) were excluded due to missing data, giving a final analysis cohort of 28,675 patient records.

#### Comparison of documented date of death

The documented date of death was identical in the two data sets for 82% of patients. Agreement increased to 94.5% allowing for a difference of +/- 3 days, and 96.4% allowing for an error margin of one week. 3.6% of death dates differed by more than a week, median difference 21 days (IQR 12-39). Twenty-two dates of death differed by exactly 365 days, suggesting a data entry error in year of death.

#### Comparison of underlying cause of death

Figure 2 shows underlying cause of death by ICD-10 chapter for both ANZDATA and NDI. For NDI the most common cause of death was *Circulatory* (32%) followed by *Genitourinary* (22%) then *Neoplasms* (11%). *Circulatory* (48%) was also the most common cause of death in ANZDATA, followed by *Withdrawal* (16%), then *Neoplasms* (11%). For patients dying



following withdrawal from treatment: 43% withdrew from RRT due to psychosocial reasons; 28% refused therapy; 24% had therapy ceased for 'other reasons' and 5% withdrew due to dialysis access difficulties.

The overall agreement in ICD-10 chapter of primary cause of death was 36%, with a kappa statistic of 0.22, indicating only fair agreement. When agreement was assessed at the level of individual chapters, only malignancy showed substantial agreement with a kappa score of 0.71. Table 2 shows the number of deaths classified under each ICD chapter for both registries as well as the kappa statistic and a qualitative assessment of the level of agreement beyond chance alone.

When both the underlying cause of death and additional causes of death (up to 12 causes) from NDI were included, there was agreement with ANZDATA cause of death in 60% of records. Considering underlying and all additional causes of death, 19,703 (69%) of patients had at least one cause of death classified within the Genitourinary chapter which includes chronic kidney disease and a number of specific causes of renal impairment, this is despite 100% of patients in the study having ESKD.

When there was disagreement on the primary cause of death between the two data sources, NDI death was most commonly coded as *Genitourinary* (35%), followed by *Endocrine* (25%) then *Circulatory* (14%). In cases of disagreement, ANZDATA death was most commonly coded as *Circulatory* (39%), followed by *Withdrawal* (24%) then *Infection* (8%). Table 3 shows a crosstabulation of primary cause of death in the two data sets (note that ICD-10 chapters with <5 deaths are not shown).

If patients withdrawing from RRT are recoded as dying from a Genitourinary cause (ie. ESKD) the kappa statistic for the *Genitourinary* chapter increases to 0.15 (slight agreement), however this accounts for only 26% of patients coded with a *Genitourinary* cause of death in NDI. Of the 4,762 deaths due to Endocrine conditions in NDI, 3,489 (73%) of these had diabetic nephropathy documented as their primary cause of ESKD in ANZDATA.

In the subgroup analysis, agreement was stronger in the transplantation cohort compared with the dialysis cohort (kappa 0.41 and 0.19, respectively,  $p$  both  $<0.001$ ). However, there was a higher percentage of patients with cause of death *neoplasm* in the transplant cohort, see figure 3, which showed much better agreement compared with other chapters in the primary analysis. If patients with cause of death *neoplasm* in either data source were excluded, the kappa statistic was similar for both cohorts (0.135 vs 0.131, respectively,  $p$  both  $<0.001$ ).

### **Discussion:**

Our analysis of the agreement of cause of death between the ANZDATA registry and NDI demonstrates that when comparing cause of death at the level of ICD-10 chapter, there is only fair agreement between the two databases. Systematic differences between the two databases likely account for some of this disagreement. This finding is consistent with a previous study by Li, Cass and Cunningham, assessing concordance between ANZDATA and the Australian Bureau of Statistics cause of death data in a cohort of patients who died between 1997-1999 (Kappa 0.22 for overall agreement on primary cause of death)(11). Due to limitations in linkage variables, this group were only able to match 65% ( $n=1,117$ ) of deaths recorded in ANZDATA to ABS, compared to 96% of death matched in our study. We were able to confirm the findings of this group in a much larger and more contemporary cohort and explore the underlying differences in greater detail. A similar study of the Canadian Organ Replacement Register (CORR) also found differences in cause of death compared with the *Institut de la statistique du Quebec* (ISQ)(12). Cardiovascular and infectious causes of death accounted for higher proportions of deaths in CORR compared with ISQ. Similarly to ANZDATA, CORR does not record cause of death as either diabetes or kidney failure which accounted for some of the disagreement.

The highest degree of agreement between these two data sources was seen when death was the result of neoplastic disease. This is consistent with previous findings of a high level of agreement on diagnosis of cancer between ANZDATA and the Central Cancer Registry

(CCR) in New South Wales(13) and the level of agreement observed between cancer specific registries and death registries(14,15). We observed better agreement in the transplant population compared to the dialysis population, which may be due to the higher incidence of deaths due to neoplastic disease in this population.

As well as differences in coding, it is important to consider who is entering data, their motivation for recording information and how *cause* can be interpreted to mean a number of different things. The *cause* of death may refer to the mechanism (eg cardiac arrest), the immediate condition that led to the event (eg hyperkalaemia), the clinical decision that led to the immediate condition (eg withdrawal from dialysis), the disease state that necessitated a life sustaining treatment (eg ESKD), the complication of a systemic condition (eg diabetic nephropathy), the underlying systemic condition (eg diabetes) or the contributing factor that led to the disease state (eg obesity). It is possible that the differing perspectives of the clinician completing the death certificate and the renal team submitting information to ANZDATA will influence the primary cause that is documented. Two classification systems can therefore show very little agreement, even if both are accurate, according to their design.

We found that in cases where the two registries differed on primary cause of death, the cause of death was coded in NDI as *Genitourinary* or *Endocrine* in 60% of cases. The vast majority of these specific diagnoses are kidney failure or renal impairment and diabetes or its complications, respectively. Although it is likely a contributing factor in most instances, it is arguably not informative to record the cause of death as kidney failure in a population who by definition all have ESKD unless death occurs due to withdrawal from RRT. It is interesting to note that over 30% of patients on RRT in Australia did not have a kidney related diagnosis recorded on their death certificate at all, either as a primary or secondary cause. Given the influence of chronic kidney disease on incidence and progression of vascular disease and malignancy, this suggests widespread under-reporting. ANZDATA also does not allow for *diabetes mellitus* or *complications of diabetes mellitus* to be coded as a cause of death, although it does allow "Other" and free text entries. While diabetes is a major contributing

factor to mortality in Australia(16), it can be argued that most deaths in diabetic patients are as a result of cardiovascular or infective complications or less directly related causes such as cancer(17). Therefore, the mortality burden of diabetes may be under-represented in a system that emphasises mechanism or event as the *cause* of death, and relatively over-represented in a system that focuses on the primary contributing factor as the *cause*.

In cases of disagreement on primary cause of death, ANZDATA was coded as *Circulatory* or *Withdrawal* in around 65% of cases. The burden of cardiovascular mortality in patients on RRT will therefore be higher in studies that use ANZDATA compared to those using NDI. Overall, 4,441 (15%) patients died due to withdrawal. These causes of death were primarily coded in NDI as *Genitourinary* (37%), *Endocrine* (22%) or *Circulatory* (21%). In this setting, the actual cause of death will most likely be the underlying kidney failure, although that may manifest as other mechanistic causes e.g. cardiac arrest due to hyperkalaemia. Defining a patient's decision not to continue RRT as the cause of their death is a delicate area, and the term "withdrawal" is a suboptimal one. A change in focus to palliation and cessation of invasive treatments in the face of a high burden of comorbidity and poor prognosis is an increasingly common part of medical treatment in many areas. However, in the setting of dialysis care there are risks of stigmatizing this decision by implying that a person is actively causing their own death by ceasing therapy rather than dying as a result of disease progression after choosing to cease dialysis treatment. Recording decisions to withdraw from dialysis is a crucial part of assessing the outcomes of renal replacement therapy, however, this should be done in a manner that respects patient decisions to choose a conservative treatment option.

This study provides insights into how ANZDATA's documentation of cause of death compares to the NDI. In some respects, it is not surprising that these two sources have poor agreement – the origin and intent of the two coding systems are different – and variation can in part be explained by the use of a bespoke system for classifying cause of death, and the potential differing perspectives of clinicians completing documentation on the purpose for recording this

information and how *cause* is defined. However, understanding the details of how these two coding systems differ allows the clinician, epidemiologist, policy maker and the broader public to contextualise results from analyses of mortality in the ESKD population. Our results suggest that direct comparison of studies examining cause of death in this population that use different data sources should be undertaken with caution.

### **Acknowledgements**

The ANZDATA Registry is funded by the Australia Organ and Transplantation Authority, the NZ Ministry of Health and Kidney Health Australia. This work was partly supported by NHMRC Program Grant GNT1092958.

Renal units throughout Australia and New Zealand generously contribute untold time and effort in contributing to the Registry.

## References

1. Australian Commission on Safety and Quality in Health Care. Framework for Australian clinical quality registries. Sydney; ACSQHC; 2017.
2. Roder D, Creighton N, Baker D, Walton R, Aranda S, Currow D. Changing roles of population-based cancer registries in Australia. *Aust Heal Rev.* 2015;39(4):425–8.
3. Schmidt M, Schmidt JSA, Sandegaard JL, Ehrenstein V, Pedersen L, Sorensen HT. The Danish National patient registry: A review of content, data quality, and research potential. *Clin Epidemiol.* 2015;7:449–90.
4. Kelman C. The Australian National Death Index: an assessment of accuracy. *Aust N Z J Public Heal.* 2000;24(2):201–3.
5. Chambers B, Dewey H, Frayne J, Giles GG, Mcneil J, Peeters A, et al. Accuracy of national mortality codes in identifying adjudicated cardiovascular deaths. *Aust N Z J Public Heal.* 2011;35(5):466–76.
6. Magliano D, Liew D, Pater H, Kirby A, Hunt D, Simes J. Accuracy of the Australian National Death Index: comparison with adjudicated fatal outcomes among Australian participants in the Long-term Intervention with Pravastatin in Ischaemic Disease (LIPID) study. *Aust N Z J Public Heal.* 2003;27(6):649–53.
7. ANZDATA [Internet]. [cited 2016 May 22]. Available from: <http://www.anzdata.org.au/v1/structure.html>
8. National Death Index [Internet]. [cited 2017 May 22]. Available from: <http://www.aihw.gov.au/national-death-index/>
9. Pink B (Australian Bureau of Statistics). Information Paper: Cause of Death Certification Australia. 2008. ABS Catalogue No. 1205.0.55.001
10. Landis JR, Koch GG. The Measurement of Observer Agreement for Categorical Data. *Biometrics.* 1977;33(1):159–74.
11. Li SQ, Cass A, Cunningham J. Cause of death in patients with end-stage renal disease: assessing concordance of death certificates with registry reports. *Aust N Z J Public Heal.* 2003;27(4):419–27.
12. Lafrance J, Rahme E, Iqbal S, Leblanc M, Pichette V, Elftouh N, et al. Magnitude of discordance between registry data and death certificate when evaluating leading causes of death in dialysis patients. *BMC Med Res Methodol.* 2013;13:51.

13. Webster AC, Supramaniam R, Connell DLO, Chapman JR, Craig JC. Validity of registry data : Agreement between cancer records in an end-stage kidney disease registry ( voluntary reporting ) and a cancer register ( statutory reporting ). *Aust N Z J Public Heal.* 2010;15:491–501.
14. Turner EL, Metcalfe C, Donovan JL, Noble S, Sterne JAC, Lane JA, et al. Contemporary accuracy of death certificates for coding prostate cancer as a cause of death : Is reliance on death certification good enough ? A comparison with blinded review by an independent cause of death evaluation committee. *Br J Cancer.* 2016;115(1):90–4.
15. Schaffar R, Rapiti E, Rachet B, Woods L. Accuracy of cause of death data routinely recorded in a population-based cancer registry : impact on cause-specific survival and validation using the Geneva cancer registry. *J Public Heal Med.* 2013;13(609):1–12.
16. Australian Institute of Health and Welfare. *Impact and causes of illness and deaths in Australia 2011.* Canberra: AIHW; 2016.
17. Tancredi M, Rosengren A, Svensson A-M, Kosiborod M, Pivodic A, Gudbjörnsdottir S, et al. Excess Mortality among Persons with Type 2 Diabetes. *N Engl J Med.* 2015;373(18):1720–32.

**Tables:**

Table 1: Details of how ICD-10, ICD-9 and ANZDATA cause of death codes were mapped to ICD Chapters for analysis.

ICD 10 Chapter	Chapter Name	Chapter Label	ICD 10 Codes	ICD 9 Codes	ANZDATA Description	ANZDATA Codes
1	Infectious and parasitic diseases	Infection	A00-B99	001-139	Immunodeficiency due to virus CNS infection Septicaemia Liver infections Other infections	60, 311-315 371-375 381-385 391-395
2	Neoplasms	Neoplasms	C00-D48	140-239	Withdrawal- malignancy Malignancy disease	48 56
3	Diseases of blood and blood forming organs	Blood	D50-D89	240-279	Bone marrow depression	53
4	Endocrine, nutritional and metabolic diseases	Endocrine	E00-E90	280-289	Hyperkalaemia	13
5	Mental and behavioural disorders	Mental Health	F00-F99	290-319	Dialysis dementia (Aluminium)	58
6	Diseases of the nervous system	Nervous System	G00-G99	320-389	-	-
7	Diseases of the eye and adnexa	Eye and Adnexa	H00-H59		-	-
8	Diseases of ear and mastoid process	Ear	H60-H95		-	-
9	Diseases of the circulatory system	Circulatory	I00-I99	390-459	Myocardial ischaemia/infarction Other cardiac conditions Pulmonary embolus Cerebrovascular accident Aortic-aneurysm rupture Withdrawal- cardiovascular reasons	10,11 14-17 21 22 26 45-47
10	Diseases of the respiratory system	Respiratory	J00-J99	460-519	Pulmonary oedema Chronic respiratory failure Lung infections	12 61 321-325
11	Diseases of the digestive system	Digestive	K00-K93	520-579	Gastrointestinal haemorrhage Bowel infarction Hepatic failure Pancreatitis Perforated abdominal viscus Sclerosing peritonitis Infectious peritonitis	23 28 50 52 57 62 361-365
12	Diseases of the skin and subcutaneous tissue	Skin	L00-L99	680-709	Wound infections	341-345
13	Diseases of the musculoskeletal system and connective tissue	Musculoskeletal	M00-M99	710-739	-	-
14	Diseases of the genitourinary system	Genitourinary	N00-N99	580-629	Urinary tract infections	331-335
15	Pregnancy, childbirth and the puerperium	Pregnancy	O00-O99	630-679	-	-
16	Certain conditions originating in the perinatal period	Perinatal	P00-P96	760-779	-	-



<b>17</b>	Congenital malformations, deformations and chromosomal abnormalities	Congenital	Q00-Q99	740-759	-	
<b>18</b>	Symptoms, signs and abnormalities NOS	NOS	R00-R99	780-799	Haemorrhage from dialysis access	24
					Haemorrhage from elsewhere	27
					Cachexia	54
					Unknown	55
					Other	59
<b>19</b>	Injury, poisoning, other external causes	Injury and Poisoning	S00-T98	800-999	Haemorrhage from transplant artery	25
					Accidental death	44
					Uraemia caused by graft failure	51
					Shunt infections	351-355
<b>20</b>	External Causes of Morbidity and Mortality	External Causes	V01-Y98		Suicide	42
<b>21</b>	Factors influencing health status and contact with health services	Health Service	Z00-Z99		-	
<b>22</b>	Withdrawal (ANZDATA only)	Withdrawal	n/a	n/a	Withdrawal – psychosocial reasons	40
					Patient refused treatment	41
					Therapy ceased other reasons	43
					Withdrawal-dialysis access failure	49

Table 2: Frequency of cause of death by ICD-10 chapter for each registry, agreement between the two data sources based on the kappa statistic is shown.

\*The category *Withdrawal* is not an ICD chapter and only present in the ANZDATA registry. It includes the ANZDATA cause of death codes: 40 Withdrawal-Psychosocial reasons; 41 Patient Refused Treatment; 43 Therapy Ceased Other Reasons; 49 Withdrawal-Dialysis Access Difficulties

ICD Chapter	Description	NDI n (%)	ANZDATA n (%)	Kappa	Level of agreement
	Overall			0.22	Fair
<b>1</b>	Infection	687 (2)	1,733 (6)	0.12	Slight
<b>2</b>	Neoplasms	3,270 (11)	3,067 (11)	0.71	Substantial
<b>3</b>	Blood	168 (1)	13 (<1)	0.05	Slight
<b>4</b>	Endocrine	4,762 (17)	203 (<1)	0.01	Slight
<b>5</b>	Mental Health	81 (<1)	11 (<1)	<0.01	Poor
<b>6</b>	Nervous System	218 (1)	0 (0)	<0.01	Poor
<b>7</b>	Eye and Adnexa	1 (<1)	0 (0)	<0.01	Poor
<b>8</b>	Ear	2 (<1)	0 (0)	<0.01	Poor
<b>9</b>	Circulatory	9,163 (32)	12,809 (48)	0.31	Fair
<b>10</b>	Respiratory	835 (3)	1,566 (5)	0.23	Fair
<b>11</b>	Digestive	1,240 (4)	1,855 (6)	0.35	Fair
<b>12</b>	Skin	120 (<1)	282 (1)	0.06	Slight
<b>13</b>	Musculoskeletal	525 (2)	0 (0)	<0.01	Poor
<b>14</b>	Genitourinary	6,440 (22)	49 (<1)	<0.01	Poor
<b>15</b>	Pregnancy	2 (<1)	0 (0)	<0.01	Poor
<b>16</b>	Perinatal	2 (<1)	0 (0)	<0.01	Poor
<b>17</b>	Congenital	462 (2)	0 (0)	<0.01	Poor
<b>18</b>	NOS	56 (<1)	1,302 (5)	<0.01	Poor
<b>19</b>	Injury/Poisoning	110 (<1)	247 (1)	0.11	Slight
<b>20</b>	External Causes	531 (1)	83 (<1)	0.17	Slight
<b>21</b>	Health Service	0	0	n/a	n/a
<b>22*</b>	Withdrawal	0 (0)	4,455 (16)	n/a	n/a

Table 3: Cross tabulation of the number of deaths in each ICD-10 Chapter for ANZDATA and the National Death Index (NDI). Note that chapters with fewer than 5 deaths are not shown (total of 7 patients missing). The 'Withdrawal' category is specific to ANZDATA.

	ANZDATA Chapter														Total
	Infection	Neoplasms	Blood	Endocrine	Mental Health	Circulatory	Respiratory	Digestive	Skin	Genito-urinary	NOS	Injury / Poisoning	External	Withdrawal	
<b>NDI Chapter</b>															
<b>Infection</b>	187	18	0	0	0	207	75	71	15	4	29	6	0	75	<b>687</b>
<b>Neoplasms</b>	71	2,362	1	5	0	332	89	69	9	0	58	2	0	272	<b>3,270</b>
<b>Blood</b>	25	10	5	1	0	48	19	20	1	0	17	2	0	20	<b>168</b>
<b>Endocrine</b>	303	99	2	56	1	2,631	161	186	83	9	249	21	4	957	<b>4,762</b>
<b>Mental Health</b>	1	1	0	0	0	29	7	4	0	0	11	0	0	28	<b>81</b>
<b>Nervous System</b>	37	8	0	1	0	88	17	10	4	0	29	3	2	19	<b>218</b>
<b>Circulatory</b>	352	166	1	51	2	6,596	329	304	61	6	327	41	3	924	<b>9,163</b>
<b>Respiratory</b>	47	26	0	1	0	291	307	15	5	1	50	1	0	91	<b>835</b>
<b>Digestive</b>	137	28	0	2	0	266	49	588	5	1	39	4	2	119	<b>1,240</b>
<b>Skin</b>	30	2	0	1	0	35	6	11	14	0	4	0	0	17	<b>120</b>
<b>Musculoskeletal</b>	68	15	1	5	0	184	49	32	12	1	40	4	1	113	<b>525</b>
<b>Genitourinary</b>	388	295	3	71	8	2,658	386	474	62	23	361	61	9	1,641	<b>6,440</b>
<b>Congenital</b>	37	19	0	5	0	185	30	38	4	2	28	6	0	108	<b>462</b>

<b>NOS</b>	3	1	0	1	0	33	3	1	0	1	6	4	1	2	<b>56</b>
<b>Injury/Poisoning</b>	6	2	0	2	0	29	6	10	2	0	3	20	20	10	<b>110</b>
<b>External Causes</b>	37	15	0	1	0	196	32	21	5	1	51	72	41	59	<b>531</b>
<b>Total</b>	<b>1,729</b>	<b>3,067</b>	<b>13</b>	<b>203</b>	<b>11</b>	<b>13,808</b>	<b>1,565</b>	<b>1,854</b>	<b>282</b>	<b>49</b>	<b>1,302</b>	<b>247</b>	<b>83</b>	<b>4,455</b>	<b>28,668</b>

## Figure Legends

Figure 1: Linkage process performed by the Australian Institute of Health and Welfare (AIHW). † Excluded due to failed linkage or missing data.

Figure 2: Underlying cause of death by ICD-10 chapter for the ANZDATA and NDI registries. Bars are labelled with percentages for the top three categories of cause of death in each registry. \*The 'Withdrawal' chapter has been included for causes of death in ANZDATA relating to cessation of renal replacement therapy for social or other reasons for which there is no corresponding ICD-10 chapter.

Figure 3: 3(a) Underlying cause of death by ICD-10 chapter for the ANZDATA and NDI registries for patients treated with transplantation at time of death. 3(b) Underlying cause of death by ICD-10 chapter for the ANZDATA and NDI registries for patients treated with transplantation at time of death. Note that the y axes are on different scales. \*The 'Withdrawal' chapter has been included for causes of death in ANZDATA relating to cessation of renal replacement therapy for social or other reasons for which there is no corresponding ICD-10 chapter.