



## Hospital service use in the last year of life by Indigenous Australians who died of heart failure or cardiomyopathy: A linked data study



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### ABSTRACT

**Background:** Aboriginal and Torres Strait Islander peoples experience disproportionate rates of heart failure. However, information regarding their use of hospital services in the last year of life is poorly delineated to inform culturally appropriate end-of-life health services.

**Objectives:** To quantify hospital service use in the last year of life of Aboriginal and Torres Strait Islander peoples who died of heart failure or cardiomyopathy in Queensland, Australia.

**Methods:** A subgroup analysis of a larger retrospective linkage study using administrative health data in Queensland, Australia. Individuals that identified as an Aboriginal and Torres Strait Islander person from their first hospital admission in the last year of life, who died of heart failure or cardiomyopathy from 2008 to 2018, were included.

**Results:** There were 99 individuals, with emergency department presentation/s recorded for 85 individuals. Over 50% of individuals presenting to the Emergency Department were from regional areas (n = 43, 51%). The 99 individuals had a total of 472 hospital admissions, excluding same day admissions for haemodialysis, and 70% (n = 70) died in hospital. Most admissions were coded as acute care (n = 442, 94%), and fewer were coded as palliative care (n = 19, 4%). Median comorbidities or factors that led to hospital contact = 5 (interquartile range 3–9).

**Conclusion:** Acute care hospital admissions in the last year of life by this population are common for those who died of heart failure or cardiomyopathy. Multimorbidity is prevalent in the last year of life, underscoring the importance of primary health care, provided by nurses and Indigenous health workers.

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### Summary of relevance

#### Problem

Heart failure and cardiomyopathy data for Indigenous Australians, including hospital use in the last year of life, are poorly delineated.

#### What is already known

Indigenous Australians experience higher rates of cardiovascular conditions, including heart failure and cardiomyopathy in comparison with non-Indigenous Australians.

#### What this paper adds

In the last year of life, hospital admissions are mostly for acute care for Indigenous Australians.

Multimorbidity was highly prevalent and dying in hospital during a palliative care admission is common for Indigenous Australians.

These data can inform end-of-life care and health service planning for Indigenous Australians living with heart failure and cardiomyopathy.

### Acknowledgment of Country

The authors acknowledge the rich culture and history of Australia's First Peoples. We recognise their continuing connection to land, sea and community and acknowledge that they never ceded sovereignty. We pay our respect to all Elders and ancestors past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

### 1. Introduction

Aboriginal and Torres Strait Islander peoples (hereafter respectfully referred to as Indigenous Australians) are the First Peoples of the lands known as Australia and often experience disproportionate rates of cardiovascular conditions, compared to non-Indigenous Australians (Vos, Barker, Begg, Stanley, & Lopez, 2009). This includes heart failure and cardiomyopathy which predominantly results from cardiovascular disease (Dyck, Raj, Zieroth, Dyck, & Ezekowitz, 2019).

Despite the higher prevalence in Indigenous Australians, heart failure data and information in Indigenous Australians are poorly delineated (Teng et al., 2014). This includes data describing hospital service use in the last year of life and the demographics of Indigenous Australians who died of heart failure or cardiomyopathy. This evidence has the potential to inform the co-design of culturally appropriate end-of-life interventions alongside Indigenous Australians living with heart failure and cardiomyopathy, family, community organisations and service providers.

This study quantifies hospital service use in the last year of life by Indigenous Australians who died in Queensland, Australia, and had heart failure or cardiomyopathy recorded as a primary or underlying cause of death. The demographic and clinical characteristics of individuals who used acute hospital services are also described.

### 2. Methods

#### 2.1. Data sources

A subgroup analysis of a larger retrospective, population-based linkage study was conducted using administrative health data. Data obtained from health administrative sources include the Queensland Hospital Admitted Patient Data Collection (QHAPDC), Queensland Emergency Department Data Collection (QEDDC) and the Queensland Death Registrations. The QHAPDC includes separations from 121 declared public hospitals and 119 private hospitals and day surgery units. The QEDDC includes all presentations at 105 public Emergency Departments (ED) in Queensland and the Queensland Death Registrations document deaths recorded within Queensland.

The datasets were linked using a patient identification number and included data over a decade, from 1st July 2008 to 31st December 2018 (the most recently available data for which death information was available) to capture as many individuals as possible and provide a contemporary snapshot.

#### 2.2. Inclusion criteria

Inclusion criteria were individuals living in Queensland who identified as Indigenous Australian in their first hospital record in the last year of life and died aged  $\geq 40$  years. Their underlying or principal cause of death must have been recorded as heart failure or cardiomyopathy, using the International Statistical Classification of Diseases and Related Health Problems 10th revision diagnoses: I50 and I42, including all subcodes ([The International Statistical Classification of Diseases and Related Health Problems, 2017](#)). Analyses were restricted to individuals who identified as Indigenous Australians in their first hospital record in the last year of life to capture a snapshot of individuals who identified at this time, as opposed to individuals who had ever identified as Indigenous Australians. Individuals may legitimately change their indigenous status over time, as a component of the definition for identifying as an Indigenous Australian is acceptance of the person as an Indigenous Australian by the community in which they reside. This component in essence is a social construct that may change over an individual's life (Kennedy, Howell, & Breckell, 2009). Analyses were restricted to individuals who died aged  $\geq 40$  years as this is the time point at which comorbidities peak in Indigenous Australians (Broe & Radford, 2018) and Indigenous Australians aged between 40 and 60 years are at a higher risk of future cardiovascular disease (Calabria et al., 2018).

#### 2.3. Characteristics of the heart failure decedents

Key demographic characteristics included sex, age and principal and co-existing comorbidities. A socio-economic status quintile, the Socio-Economic Indexes for Areas ([Australian Bureau of Statistics, 2018](#)) developed by the Australian Bureau of Statistics using peoples and household data to categorise areas in Australia based on relative socio-economic advantage and disadvantage, was included. Furthermore, an index using road distances to determine the accessibility of areas to goods and services, defined by the Accessibility/Remoteness Index for Australia ([Department of Health, 2001](#)) was utilised.

Comorbidities and factors influencing health service contact recorded in the first hospital admission in the QHAPDC were examined. Comorbidity is any additional disease or injury existing or occurring alongside other disease and injury. Factors influencing health service contact are coded when an individual utilises the health service for a specific purpose (e.g., counselling), which is not a disease or injury, or when a problem (such as tobacco use) is present and influences the person's health status.

#### 2.4. Data extraction

Queensland Statistical Services Branch extracted the data in February 2021 and provided data as four separate datasets, relating to admission data, admission morbidity codes, ED data and death data.

#### 2.5. Data management

Each dataset was checked by two authors (GKS and APB) for errors and data not meeting the inclusion criteria, such as hospital episodes for boarders (individuals who are not admitted but are generally registered at the hospital and include individuals accompanying a patient), were removed. Datasets were merged in IBM SPSS® Statistics (Version 25; IBM Corp: Armonk, NY). Merged records were checked at random for accuracy. Individual records

**Table 1**  
Characteristics of the study sample (n = 99).

Characteristics	n (%)
Sex*	
Male	55 (56)
Female	44 (44)
Cause of death**	
Heart failure	54 (55)
Cardiomyopathy	45 (45)
Age*	
40–49	19 (19)
50–59	16 (16)
60–69	24 (24)
70–79	21 (21)
80+	19 (19)
ARIA+ status (remoteness of home location)*	
Major city	17 (17)
Inner regional	21 (21)
Outer regional	27 (27)
Remote	12 (12)
Very remote	22 (22)
Socio-economic status**	
Most disadvantaged quintile	58 (59)
Quintile 2	23 (24)
Quintile 3–5 (least disadvantaged quintile)	17 (17)

Note. ARIA+ = Accessibility/Remoteness Index for Australia.

\* At first admission recorded in the last year of life.

\*\* Determined by Cause of Death Unit Record File (COD URF), Australian Coordinating Registry.

+ n=98.

matched across the four datasets utilising the patient identification number and if available, the episode or presentation code.

### 2.6. Data analysis

The variables of interest included (a) the number of ED visits, (b) the number of hospital admissions, (c) median length of stay of hospital admissions, (d) the number of individuals who died in the hospital and (e) the proportion of hospital admissions with a ‘palliative’ care type. A care type is the nature of care or treatment provided during an admission. The outcomes were analysed using descriptive statistics in IBM SPSS® Statistics (Version 25; IBM Corp: Armonk, NY).

### 2.7. Ethics

This study was approved by Queensland University of Technology Human Research Ethics Committee (Ref 2000000636) in September 2020, before study commencement.

## 3. Results

### 3.1. Patient characteristics

From 2008 to 2018, there were a total of 99 individuals who identified as Indigenous Australians in their first hospital admission in the last year of life. Males comprised slightly more than half of the sample (n = 55, 56%) and almost half (n = 45, 45%) were aged between 60 and 79 years (see Table 1).

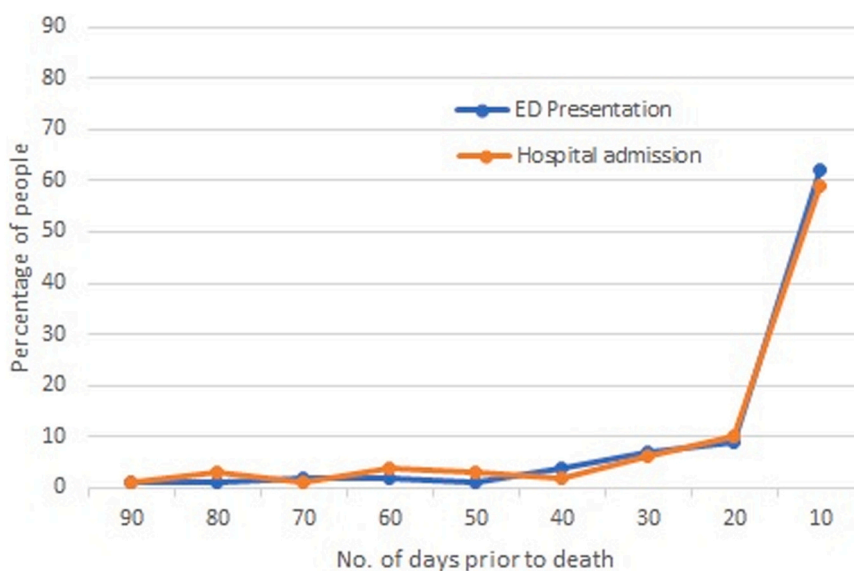
### 3.2. Emergency presentations

Of the 99 individuals, 85 presented to an ED, of which approximately half were male (n = 47, 55%) and from regional areas (n = 43, 51%). Socio-economic status was reported for 84 individuals and of these, the greatest proportion of individuals presenting to the ED was recorded as from the most disadvantaged quintile (n = 49, 57%). The median number of ED presentations in the last year of life was 3 (interquartile range [IQR] 1–7) per individual. Over half (n = 47, 55%) presented to the ED in the last 7 days of life, 79% (n = 67) in the last 30 days of life and 91% (n = 77) in the last 90 days of life (Fig. 1).

Table 2 presents information relating to the 535 emergency presentations. The arrival mode to the ED for over two-thirds of presentations was by ambulance (n = 375, 70%). Over half of the emergency presentations were triaged at 2 (imminently life-threatening) and 3 (potentially life-threatening) (n = 343, 64%) (Table 2).

### 3.3. Hospital admissions and deaths

In the study sample, 70% (n=70) died in hospital and the median length of stay of the hospital admission resulting in death was 4 days (IQR 1–11.25), compared with a median of 3 days (IQR 1–7) for the study sample. The study sample had a median of 4



**Fig. 1.** Proportion of individuals in hospital (n = 99) or presenting to the ED (n = 85) in days before death. ED = Emergency Department.

**Table 2**  
Emergency presentations in the final year of life (n = 535).

Presentation information	n (%)
Mode of transport by which patient arrives at the ED	
Ambulance	375 (70)
Walked in/other transport	160 (30)
Most common principal diagnosis	
Heart failure	84 (16)
Diseases of the circulatory system	67 (13)
Factors influencing health status and contact with health services	64 (12)
Symptoms, signs and abnormal clinical laboratory findings	61 (11)
Diseases of the respiratory system	60 (9)
Triage code	
1 = immediately life-threatening	15 (3)
2 = imminently life-threatening	131 (24)
3 = potentially life-threatening	212 (40)
4 = potentially serious	107 (20)
5 = less urgent	70 (13)
Reason for the patient presenting to ED	
Emergency presentation	499 (93)
Planned returned visit	26 (5)
Inter-hospital transfer	10 (2)
Status of the patient at the end of ED service episode	
Admitted	284 (53)
ED service event completed – discharged	223 (42)
Transferred to another service	17 (3)
Did not wait	11 (2)

Note. ED = Emergency Department

**Table 3**  
Admissions (excluding same day renal admissions) in the final year of life (n = 472).

Episode information	n (%)
Mode of separation	
Home/usual residence	317 (67)
Died in hospital	70 (15)
Transferred to another hospital	57 (12)
Other	18 (4)
Residential aged care service	10 (2)
Elective status	
Emergency admission	396 (84)
Not assigned – planned readmission to receive care/treatment for current condition	29 (6)
Elective admission	47 (10)
Care type	
Acute care	442 (94)
Palliative care	19 (4)
Maintenance care	6 (1)
Rehabilitation and geriatric management	5 (1)
Source of referral	
Emergency department – this hospital	338 (72)
Outpatient department – this hospital	35 (7)
Patient transferred from another hospital	41 (9)
Episode change	21 (4)
Private medical practitioner	19 (4)
Other healthcare establishment and community service	12 (3)
Residential aged care service	6 (1)

hospital admissions (IQR 2–7) in the last year of life, excluding same day admissions for dialysis. In the last 7 days of life, 52% (n = 51) had an admission, 75% (n = 74) had an admission in the last 30 days of life and 89% (n = 88) had an admission in the last 90 days of life (Fig. 1).

There was a total of 785 hospital admissions and of these, 313 (40%) were same day hospital admissions for renal dialysis. Of the remaining 472 admissions, 94% (n = 442) were for acute care. Few admissions were for palliative care (n = 19, 2%) and maintenance care (n = 6, 1%) (Table 3) (non-acute care to support a patient with an impairment, due to a health condition not requiring further complex assessment).

### 3.4. Comorbidities and factors influencing health service contact

The study sample had a median of 5 (IQR 3–9) comorbidities and/or factors influencing health service contact recorded in their first admission in the last year of life. Over half (n = 57, 58%) had five or more comorbidities and/or factors influencing health service contact recorded during their first admission (Fig. 2). Table 4 shows the top five comorbidities and factors influencing health service contact. There were 16 individuals (16%) who had all top three comorbidities (heart failure or cardiomyopathy, type 2 diabetes and kidney failure and disease) recorded during their first admission.

### 3.5. Palliative care admissions

Nineteen individuals (19%) had a palliative care admission. Of these, slightly more were females (n = 11, 58%) and two-thirds were aged between 60 and 79 years (n = 13, 68%). Over half (n = 12, 63%) lived in regional areas and 84% (n = 16) were recorded as being in the two most disadvantaged quintiles.

These 19 individuals had a median of 5 admissions (IQR 3–8) in the last year of life (excluding same day admissions for dialysis) when a palliative care admission was recorded and the median length of stay for an admission with a palliative care type was 6 days (IQR 3–17). Most (n = 16, 84%) died in hospital during their palliative care admission and three were transferred home or to other healthcare establishment. Of these 19 individuals, 17 (89%) had not received any previous specialist palliative care treatment.

## 4. Discussion

By linking hospital, emergency and mortality data, this study provides a description of the frequency of hospital service use in the last year of life by Indigenous Australians who died of heart failure or cardiomyopathy. The study findings have the potential to inform policy focused on planning culturally acceptable palliative and end-of-life care services for Indigenous Australians living with heart failure and cardiomyopathy and in rural and remote regions.

Most ED presentations in this study were by individuals residing in regional areas and this is similar to other studies, which has demonstrated a greater proportion of Indigenous Australians present to EDs in regional areas compared to non-Indigenous Australians (Lim, Harrison, Raos, & Moore, 2021). The ED is usually the first contact point for Indigenous Australians (Australian Institute of Health and Welfare, 2015b), especially for those residing in remote areas (Lim et al., 2021). In remote and regional areas of Australia, there is less access to primary and secondary health services and a shortfall in available medical and nursing workforce compared to metropolitan areas (Australian Institute of Health and Welfare, 2018a). Adequately staffed and culturally appropriate EDs are crucial to support Indigenous Australians' health needs (Australian Institute of Health and Welfare, 2018b), including an available Indigenous Australian Hospital Liaison Officer to support individuals to access care (National Aboriginal and Torres Strait Islander Health Council, 2003). Indigenous Australian Hospital Liaison Officers possess valuable insights and knowledge that can influence local ED policies (Thomas & Anderson, 2006).

The findings demonstrate that Indigenous Australians had a high number of comorbidities and/or factors that influenced their health service contact. This is consistent with other findings (Australian Institute of Health and Welfare, 2015a; Lee et al., 2003), where Indigenous Australians are four times more likely to have diabetes, long-term kidney disease, hypertension and higher comorbidities than non-Indigenous Australians, which has an additive effect on heart failure mortality. However, common comorbidities in heart failure, such as type 2 diabetes, hypertension, atrial fibrillation, stroke and chronic obstructive pulmonary disease (Khan et al.,

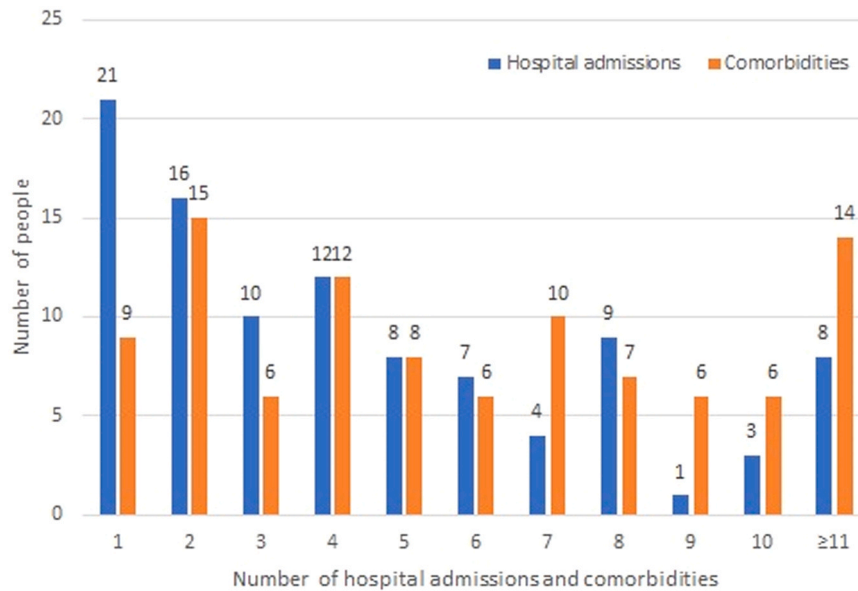


Fig. 2. The number of individuals with hospital admissions and comorbidities (n=99).

Table 4

Top five comorbidities or factors influencing health service contact for the study sample (n = 99).

Comorbidity or factor influencing health service contact	Number of peoples with comorbidity recorded n (%)
Heart failure or cardiomyopathy	44 (44)
Type 2 diabetes	40 (40)
Kidney failure and disease	32 (32)
Hypertension	32 (32)
Current tobacco use*	20 (20)

Note.

\* Factor influencing health service contact.

2020), were under-recorded due to comorbidities not comprehensively recorded in the datasets. For Indigenous Australians, a high number of comorbidities appear early in life and peak by age 40, the time point at which disparities in mortality rates are the highest for Indigenous Australians (Broe & Radford, 2018). A possible solution to addressing the burden of comorbidities is through improving the provision of culturally acceptable, comprehensive primary care for those living with chronic disease (Zhao, Thomas, Guthridge, & Wakerman, 2014). This service model is more effective in Indigenous Australian communities and is delivered by nurse practitioners, remote area nurses and Indigenous Australian health workers, who all have a role in delivering clinical care and enabling health promotion and prevention (Zhao et al., 2014). Nurses working in primary care and Indigenous Australian health workers are well placed to provide monitoring and assistance to peoples with chronic illnesses through encouraging medication adherence and providing advice on self-management (Halcomb, Davidson, & Brown, 2010). Nurses also have a key role in patient advocacy, helping patients to understand their care options and advocating for their preferences (Davoodvand, Abbaszadeh, & Ahmadi, 2016).

Our study showed that 19% of Indigenous Australians had a palliative care admission in the last year of life. This is higher than other studies where approximately 7% of individuals who died of heart failure, access hospital specialist palliative care in the last year of life (Rosenwax, Spilsbury, McNamara, & Semmens, 2016). It is known that the rate of palliative care hospitalisations in Indigenous Australians is two times higher than non-Indigenous Australians (Australian Institute of Health and Welfare, 2019). A possible reason

may be presenting to the hospital in the late stages of the illness, due to difficulties managing medications and heart failure, and an absence of local home-based services (Shahid, Bessarab, Van Schaik, Aoun, & Thompson, 2013). This can result in higher palliative care admissions. Care provided by specialist palliative care nurses and physicians, in collaboration with Elders (an Indigenous Australian recognised as a custodian of knowledge and lore and has approval to divulge beliefs and knowledge) along with Indigenous Australian culture and customs can enable culturally appropriate palliative care in the community (McGrath, Holewa, & Kail-Buckley, 2007). An example initiative is the *Indigenous Program of Experience in the Palliative Approach*, which is working towards increasing the capacity of the Indigenous Australian workforce to provide palliative care, by increasing Indigenous Australian communities' knowledge of palliative care and supporting culturally responsive capabilities of health providers to deliver holistic palliative care to Indigenous Australians (PEPA Education, 2022).

Our study showed that most (84%) died in hospital during a palliative care admission. This is higher than Australian Institute of Health and Welfare's report where 52% of palliative care hospitalisations end with the patient's death in hospital (Australian Institute of Health and Welfare, 2019). This finding may be due to the greater likelihood that there is less support and services for care at home for Indigenous Australians following palliative care provision (Australian Government Department of Health, 2019). There is also a cultural imperative to die on Country, which may mean not accessing palliative care and treatment to avoid not being able to return home and community displacement (Australian Government Department of Health, 2019). Our study showed that 82% of the study sample were recorded as residing in regional and remote regions, which is where Indigenous Australians are more likely to reside (Teng et al., 2014). Culturally appropriate specialist palliative care is minimal or nonexistent in regional and remote regions (Australian Government Department of Health, 2019), and this may explain why many individuals in this study had not received specialist palliative care previously. To enable local, culturally acceptable palliative care, which maintains connection with family and land, resources and infrastructure must be increased (McGrath et al., 2007) or Indigenous Australians will continue to rely on acute hospital services. As many services are nurse-led in rural and remote locations, nurses represent the largest group of health care

professionals in these areas (Australian College of Nursing, 2019) and are pivotal to informing resources and infrastructure needed to improve the health and health outcomes of both Indigenous and non-Indigenous Australians.

#### 4.1. Strengths and limitations

This study's major strength is the linkage of valuable statewide population datasets that include information on all hospital admissions and ED presentations recorded in Queensland hospitals. The study captures individuals who died over a ten-year time frame and provides information on end-of-life experiences and hospital-based palliative care use. Additionally, two authors checked the data to ensure the findings were reliable. These data provide foundational evidence for future research, including examining reasons and factors influencing care-seeking in hospitals to address illness-related needs. The data have limitations, such as comorbidities not being comprehensively recorded in linked administrative datasets (Goldsbury, Armstrong, Simonella, Armstrong, & O'Connell, 2012), so the impact of these conditions cannot be assessed. The analyses were restricted to individuals who died aged  $\geq 40$  years and therefore do not capture individuals who died of heart failure or cardiomyopathy aged  $< 40$  years. While the data from this study provide insight into hospital utilisation for Indigenous Australians who died of heart failure or cardiomyopathy in Queensland hospitals, the data do not capture community care or palliative care provided in the community. The study includes individuals with an underlying or principal cause of death recorded on their death certificate as heart failure or cardiomyopathy, and not individuals who only had heart failure or cardiomyopathy recorded as an associated cause of death. This is to avoid capturing individuals where heart failure or cardiomyopathy is a risk factor, comorbidity, or contributed to the events leading to death.

#### 5. Conclusion

Hospital admissions for acute care are common in the last year of life by Indigenous Australians who died of heart failure or cardiomyopathy. Multimorbidity is highly prevalent, underscoring the importance of culturally appropriate, comprehensive primary health care. Nurses and Indigenous Australian health workers are key members of a comprehensive primary health care team. The findings of this study provide quantitative information on health service use to plan culturally acceptable, end-of-life health services for Indigenous Australians living with heart failure and cardiomyopathy.

#### CRedit authorship contribution statement

GKS, APB, CF and LDH were involved in initial planning and drafting of the paper. GKS and APB had a key role in the data preparation and formal analysis. JM, SEI and SC had a role in editing and revising the paper critically. GKS and SC were responsible for data collection and ethics application. JM, a proud descendant of the Cabrogal Clan of the Darug First Nations Peoples, played a key role in ensuring the paper was respectful throughout. All authors made critical revisions and final approval of the paper.

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#### Ethical statement

The submitted paper involves human research. This research study was approved by Queensland University of Technology Human

Research Ethics Committee (Ref 2000000636) on 21st of September 2020, before study commencement.

#### Conflict of interest

The authors declare that they have no conflicts of interest.

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