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# Specialist paediatric palliative care delivered to children who died in 2021

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Paediatric palliative care aims to help alleviate symptoms and improve the quality of life of a child with a life-limiting condition and their family. Paediatric palliative care differs from adult palliative care in many ways, including illness trajectories, support requirements, specialist workforce requirements, and the unique considerations for advance care planning in paediatric populations (AIHW 2022). It can be delivered by a wide range of health and community providers, is not limited to any specific condition, can be delivered at any stage of illness and can accompany curative treatments.

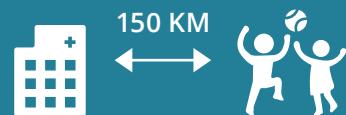
The Paediatric Palliative Care National Action Plan states that every child with a life-limiting condition and their family should have access to at least one specialist paediatric palliative care team. Access to specialist care is associated with improved quality of life, enhanced symptom control, perceived support, fewer hospitalisations, less invasive treatment, and greater use of advance care plans (PCA 2022). To improve the accessibility and quality of paediatric palliative care in Australia, robust data is needed.

Current reporting focuses on adult palliative care as there is a paucity of paediatric palliative care data in Australia (AIHW 2022). Data development is a key activity identified in the Paediatric Palliative Care National Action Plan (PCA 2022), the National Palliative Care Strategy 2018 (Australian Government 2018), and the National Palliative Care and End-of-Life Care Information Priorities report (AIHW 2022).

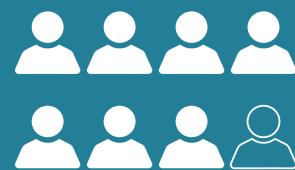
Some data on child demographics and clinical indicators are currently collected by 8 children's hospitals providing specialist paediatric palliative care services. These data are collected via the Paediatric Palliative Care Clinical Indicators survey. This survey is routinely completed by practitioners for the purpose of internal, service-level quality and monitoring following the death of a child. As such, these survey data have not been formally analysed before, and have been collated and analysed for the first time in this report.



Almost 1 in 2 (46%) of all children who died in 2021 with a life-limiting condition received specialist paediatric palliative care from a children's hospital



Children lived an average of 150 KM away from the hospital at which they received care



7 in 8 children died in the family's end-of-life location goal

AIHW

This report aims to build the evidence-base for the specialist needs of children with life-limiting conditions. It describes the characteristics, quality of care and the types of services received by all children (aged 0–20) who have died between 1 January 2021 and 31 December 2021 and received palliative care services from one of 8 participating children's hospitals. This study population was also compared with all children (aged 0–20) with life-limiting conditions who died in 2021. Further details on the data sources and methods used in this report can be found in Appendix. Detailed data tables can be found in the supplementary data tables online.

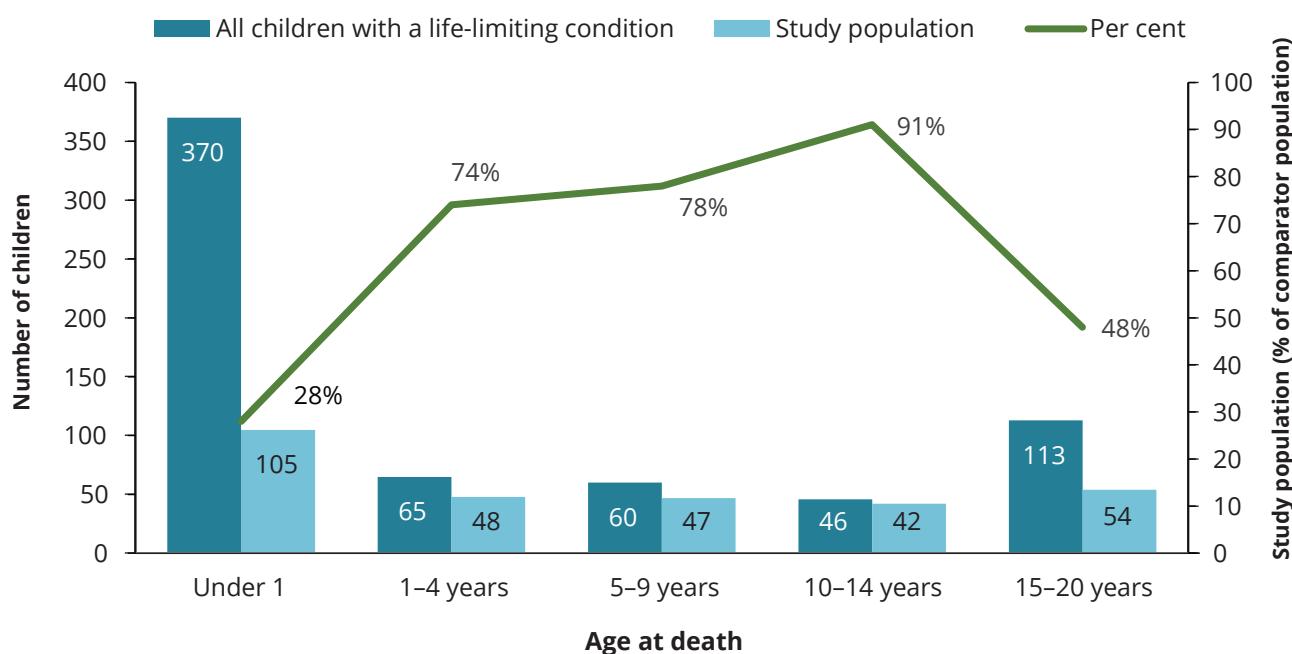
Based on the data provided, a total of 301 children receiving specialist paediatric palliative care from a children's hospital died in 2021. This study population accounts for 15% of all children who died, and an estimated 46% of all children who died from potentially life-limiting conditions in 2021. Due to the small size of the cohort and confidentiality requirements, only high-level aggregated data are presented in this report.

## Key findings

### An estimated 46% of all children who died with a life-limiting condition received specialist paediatric palliative care in 2021

Of an estimated 654 children that died in Australia in 2021 with a life-limiting condition<sup>1</sup>, 46% (or 301 children) received specialist paediatric palliative care from a children's hospital (Supplementary Table 1). This increased with age at death from 28% for infants (those aged less than 1 year at death) to 91% for children aged 10–14 years, before falling to 48% for those aged 15–20 years (Figure 1).

**Figure 1: Age at death of the study population compared with all children who died with a life-limiting condition in 2021**



Note: The line represents the children in the study population as a proportion of children in the comparator population. This estimates the percentage of all children who died in 2021 with a life-limiting condition who received specialist paediatric palliative care from a children's hospital.

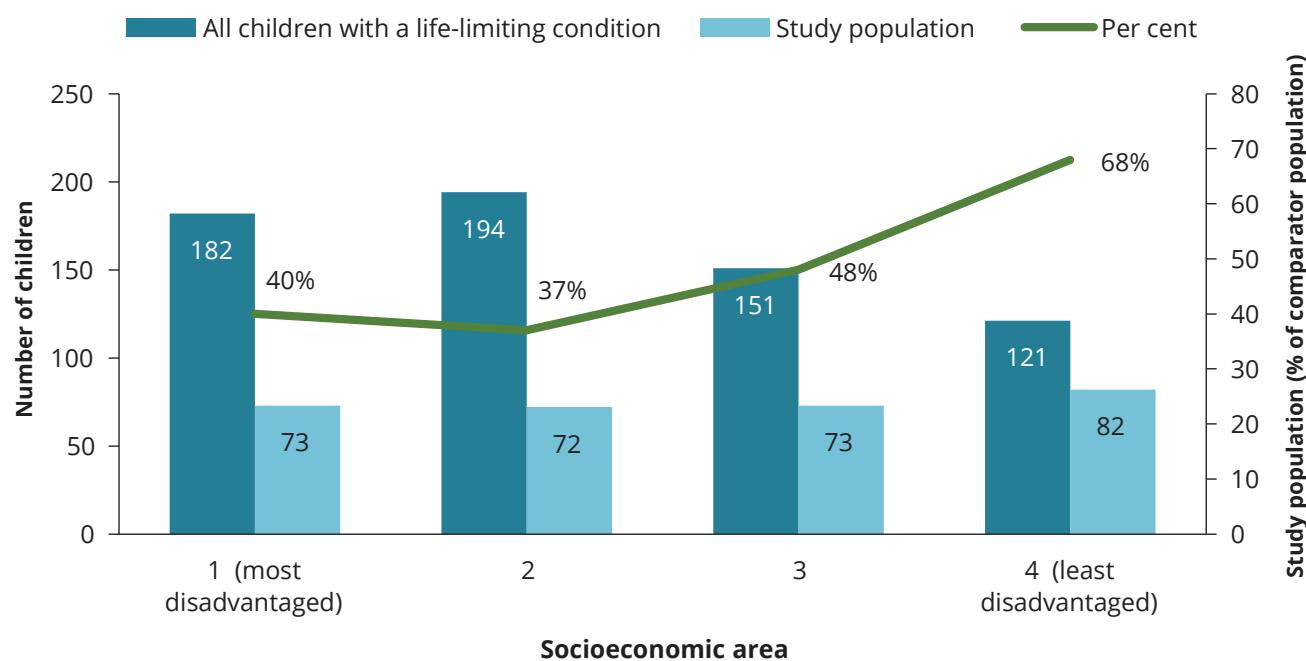
Source: Supplementary Table 1.

<sup>1</sup> The Directory of Life-Limiting Conditions (Hain and Devins 2011) was used to identify conditions eligible for palliative care. See Appendix for more details.

Children who died with a life-limiting condition and lived in a more disadvantaged area were less likely to receive specialist paediatric palliative care from a children's hospital than children in areas with less disadvantage (Figure 2). Two in 5 (40%) children from the most disadvantaged areas received specialist palliative care from a children's hospital compared with 2 in 3 (68%) from the least disadvantaged areas. Further, children with cancer were almost twice as likely as children with non-cancer diagnoses to receive specialist palliative care from a children's hospital (70% compared with 38% respectively).

Interestingly, 11 out of the 15 (73%) children who died in 2021 with a life-limiting condition and were from *Remote and Very remote* areas received specialist paediatric palliative care from a children's hospital. This was compared with around 45% of children from each of *Major cities* and *Inner and Outer regional* areas. See Supplementary Table 1 for further details.

**Figure 2: Socioeconomic area of usual residence of the study population compared with all children who died with a life-limiting condition in 2021**



#### Notes

1. The line represents the children in the study population as a proportion of children in the comparator population. This estimates the percentage of all children who died in 2021 with a life-limiting condition who received specialist paediatric palliative care from a children's hospital.
2. Socioeconomic areas are classified according to the ABS Socio-Economic Indexes for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage (IRSD) and are based on the postcode of usual residence for the study population and Statistical Area Level 2 (SA2) for the comparator population.

Source: Supplementary Table 1.

## Genetic and neurological conditions were more common in infants, while cancer was more common among all other children

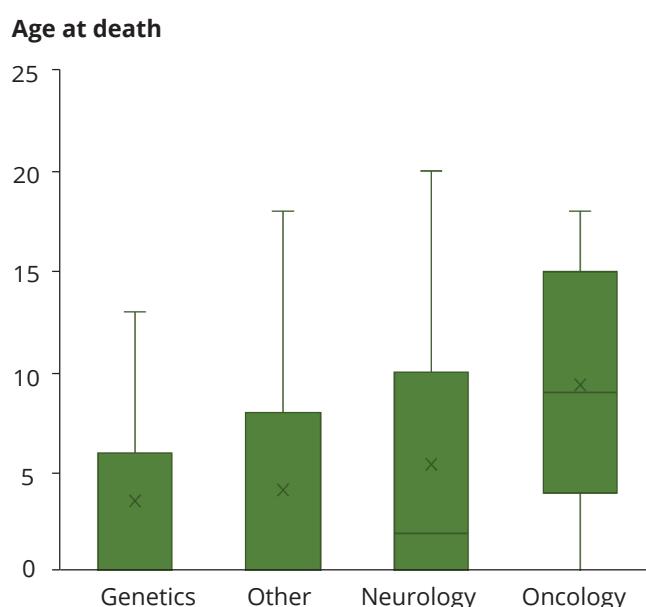
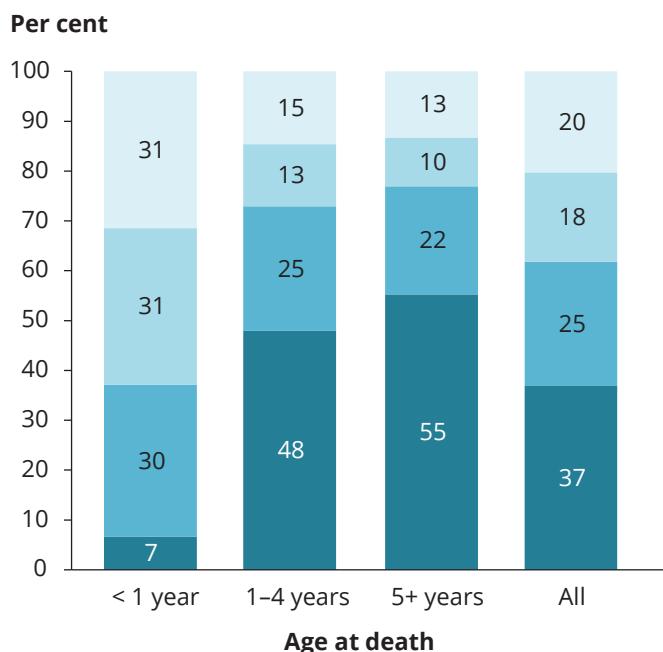
Among the 301 children in the study population, over 1 in 3 had cancer (37%), 1 in 4 had neurological conditions (25%), and 1 in 6 (18%) had genetic conditions (Supplementary Table 1). To increase readability, the term 'cancer' is used in the text while 'oncology' is used in figures and tables as 'oncology' was used in data collection.

These proportions varied considerably by age at death. Among the 105 children who died aged less than 1, genetic (31%) and neurological (30%) diagnoses were much more common than cancer (7%). Whereas almost 1 in 2 children (48%) aged 1–4 years at death, and more than half (55%) of those aged 5 and over at death had cancer.

Similarly, age at death varied by diagnosis (Figure 3). On average, children with cancer died at an older age (median = 9.8) than those with neurological (median = 2.0), genetic (median = 0.2), and other (median = 0.8) conditions.

Figure 3: Age at death by diagnosis group for the study population

■ Oncology ■ Neurology ■ Genetics ■ Other



### Notes

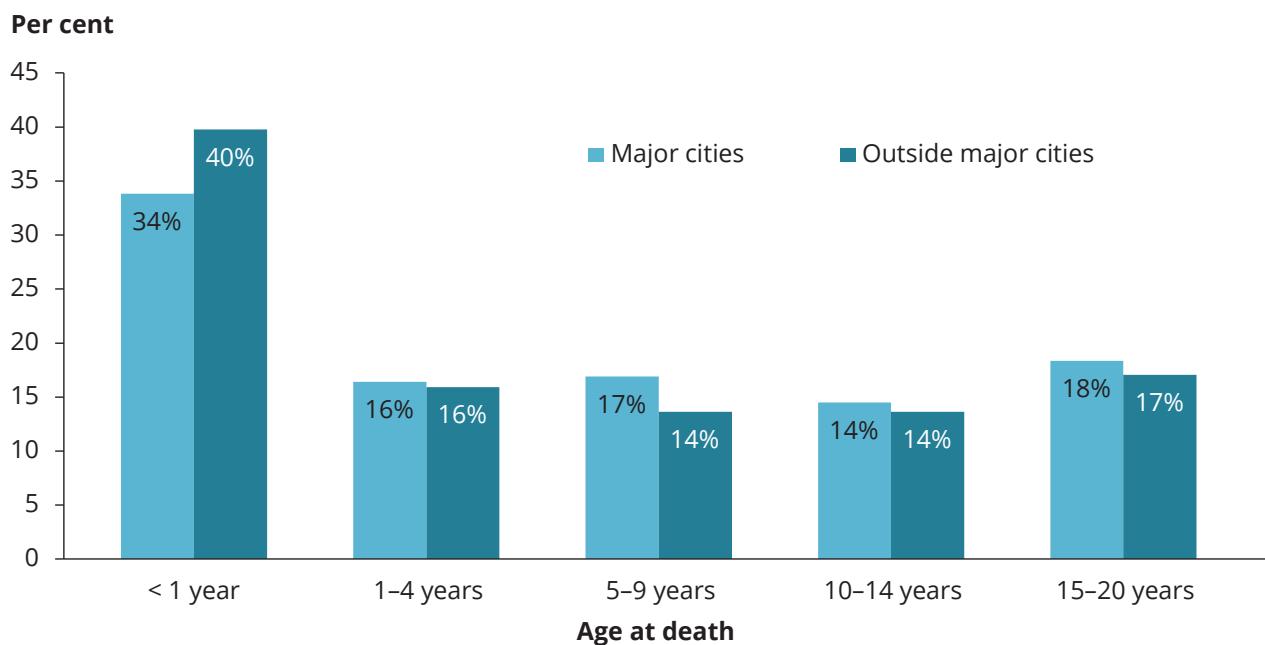
1. 'Other' diagnoses include cardiovascular, metabolic, gastrointestinal, renal, respiratory, rheumatological, and those conditions not further specified.
2. This figure includes a 'Box and Whisker' plot. The extremes of box plot whiskers depict the range of the data, the boxes show the 25th percentile, median, and 75th percentile. The mean of the data is shown by an 'x'.

Source: Supplementary Table 2.

## Children from regional and remote areas tended to die at a younger age than children from major cities

Infants (aged less than 1) accounted for the highest proportion of deaths (35%), with this proportion higher among children living outside *Major cities* (40%) than from *Major cities* (34%; Figure 4). A similar difference was observed in median age at death, varying from 2.9 years among children from outside *Major cities* to 4.9 years among children from *Major cities*. These differences were not statistically significant, however may still be relevant and require further investigation.

Figure 4: Age at death by remoteness area of usual residence for the study population

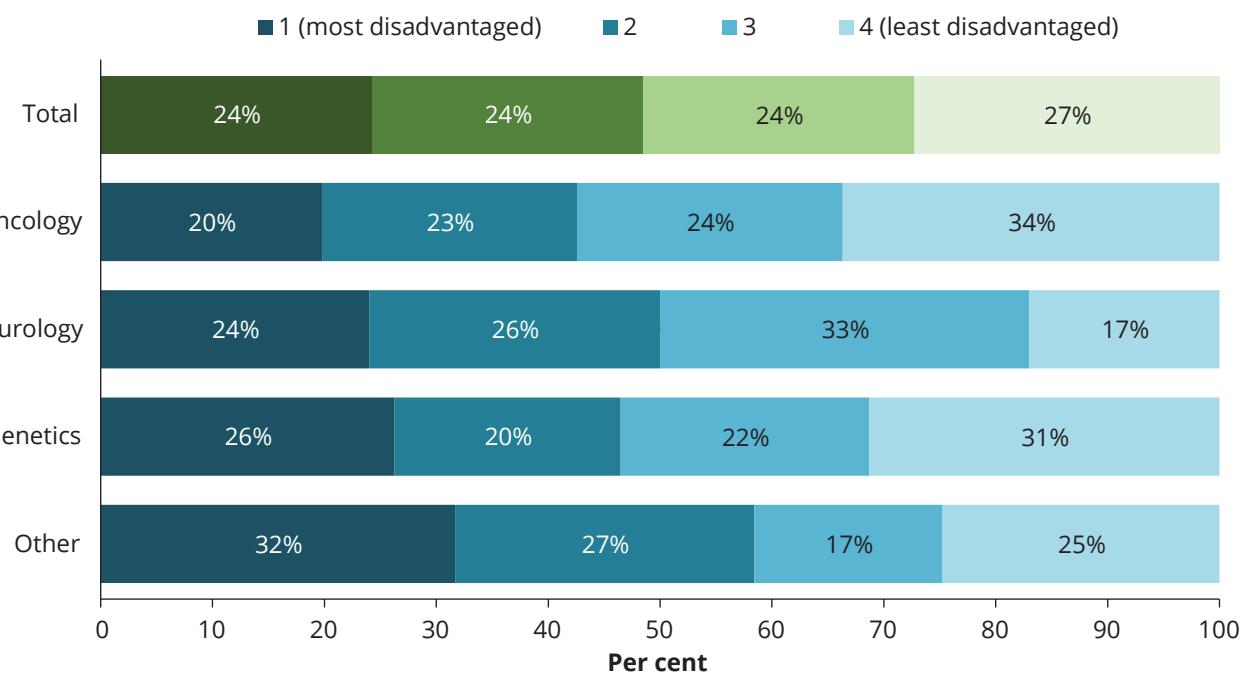


Source: Supplementary Table 2.

## Children with non-cancer diagnoses were more likely to be from disadvantaged areas than children with cancer diagnoses

Generally, the 301 children from the study population were evenly distributed across the four SEIFA quartiles, with only slightly more children residing in the least disadvantaged areas (27%) than the more disadvantaged areas (24% were from each of the 1st, 2nd, and 3rd SEIFA IRSD quartiles; Figure 5). However, this varied by diagnosis group. For example, 34% of children with cancer were from the least disadvantaged areas compared with 17% of children with neurological conditions. These differences were not statistically significant, however may still be relevant and require further investigation.

Figure 5: Diagnosis group by socioeconomic area of usual residence for the study population



### Notes

1. Socioeconomic areas are based on the postcode of usual residence of the child and are classified according to the ABS Socio-Economic Indexes for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage (IRSD).
2. 'Other' diagnoses include cardiovascular, metabolic, gastrointestinal, renal, respiratory, rheumatological, and those conditions not further specified.

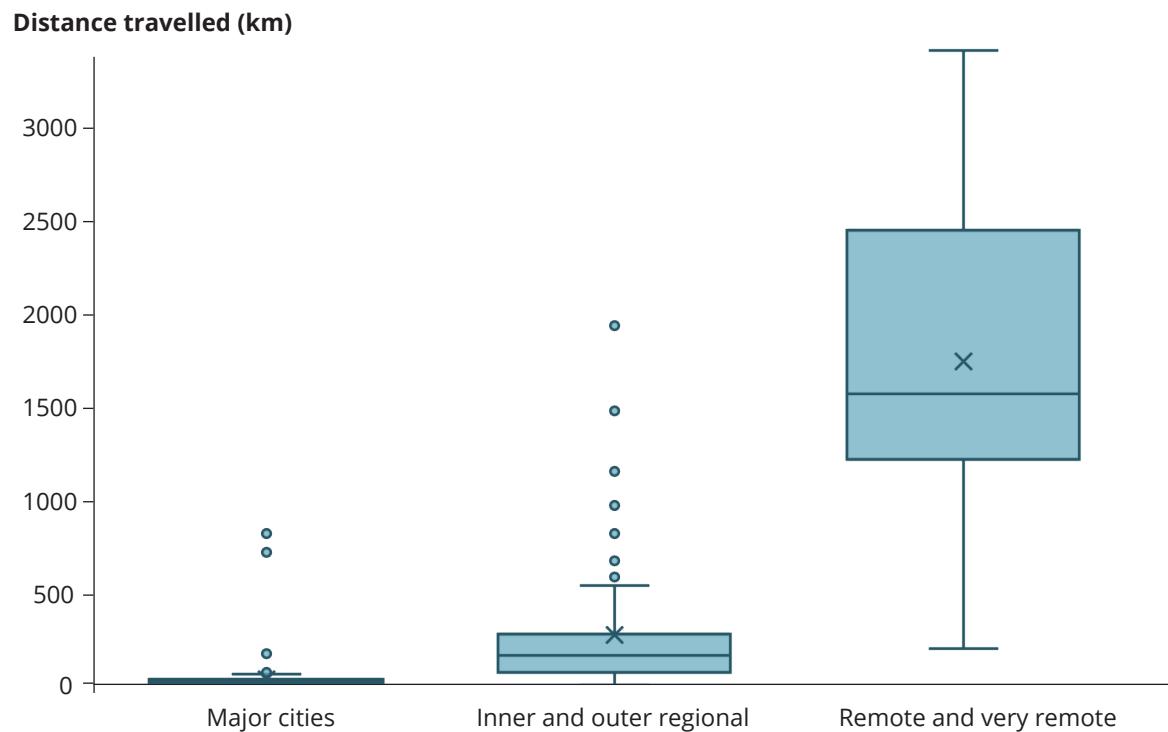
Source: Supplementary Table 3.

## Children lived an average of 150km away from specialist palliative care

Distance analysis revealed that children in the study population lived on average 149km away from the children's hospital at which they received specialist palliative care. This distance ranged from 0km to 3,400km and varied greatly by remoteness (Figure 6). Children living in *Major cities* were an average of 35km from the children's hospital and those in *Inner and Outer regional areas* were an average of 275km. Of the 11 children from *Remote and Very remote* areas, the average distance from their usual residence to specialist palliative care was 1,740km which is roughly the distance from Brisbane to Melbourne.

Note that the distribution of the study population across remoteness categories was generally similar to the Australian population of the same age for *Major cities* (70%) and *Inner and Outer regional areas* (26%). However, for *Remote and Very remote* areas (4%) the proportion was considerably higher. This comparison should be interpreted with caution as there were only 11 children from *Remote and Very remote* areas and the 95% confidence interval for this estimate was [2.1%, 6.4%].

**Figure 6: Distance between usual residence and hospital by remoteness of usual residence of the study population**



Notes

1. The distance refers to the distance in kilometres by road between the postcode of usual residence of the child and the hospital from which they received care.
2. This figure depicts a 'Box and Whisker' plot. The extremes of box plot whiskers depict the range of the data, the boxes show the 25th percentile, median, and 75th percentile. The mean of the data is shown by an 'x', and outliers are plotted as individual dots.

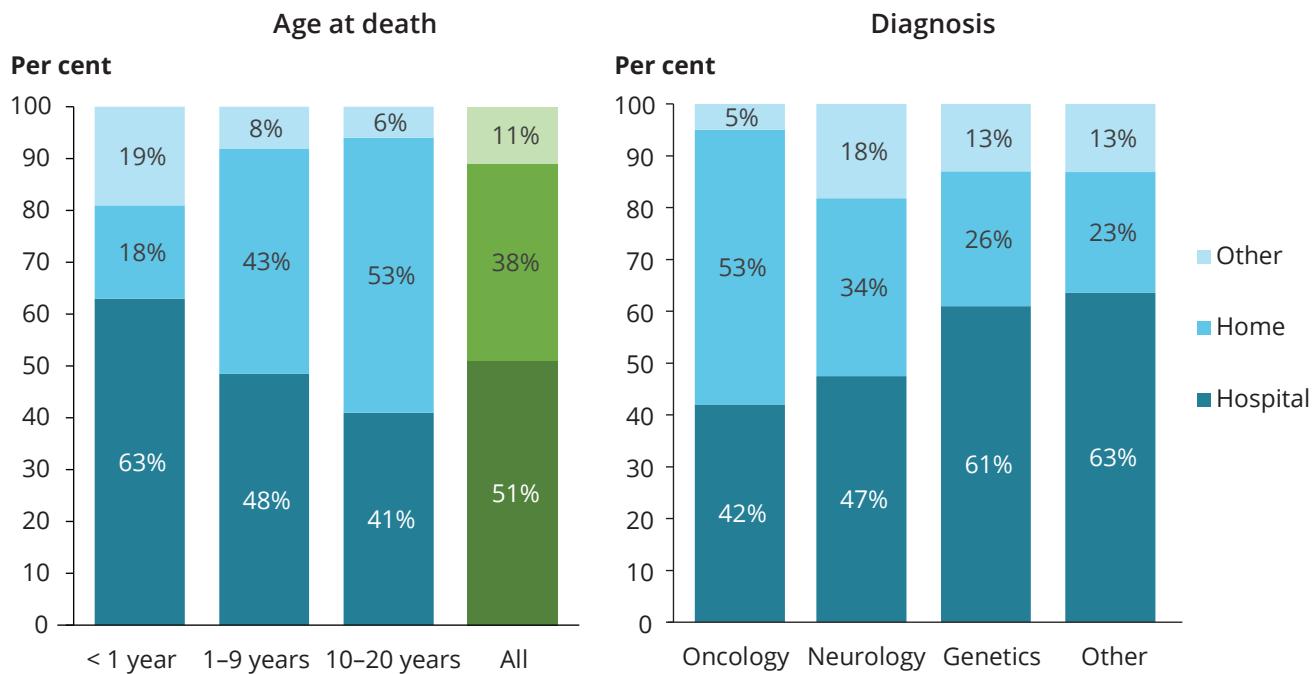
Source: Supplementary Table 4.

## 1 in 2 (51%) children died in hospital

One in 2 children (51%) from the study population died in hospital, 38% died at home, and 11% died in a hospice or other location (Figure 7). These proportions varied by age at death, with the likelihood of dying at home increasing with age. Children who died at ages 10-20 were 3 times as likely to die at home (53%) than children aged less than 1 year at death (18%).

Location of death also varied by diagnosis as shown in Figure 7. Just over half of all children with cancer died at home (53%) compared with 28% of children with non-cancer diagnoses. These findings are consistent with the observed relationship between age and diagnosis among the study population; on average, older children were more likely to die at home and children with cancer tended to die at an older age than those with non-cancer diagnoses.

**Figure 7: Location of death by age at death and by diagnosis group for the study population**



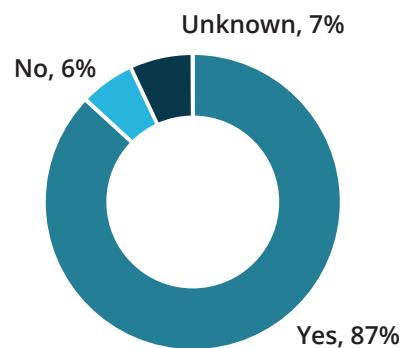
Note: 'Other' diagnoses include cardiovascular, metabolic, gastrointestinal, renal, respiratory, rheumatological, and those conditions not further specified.

Source: Supplementary Tables 5 and 6.

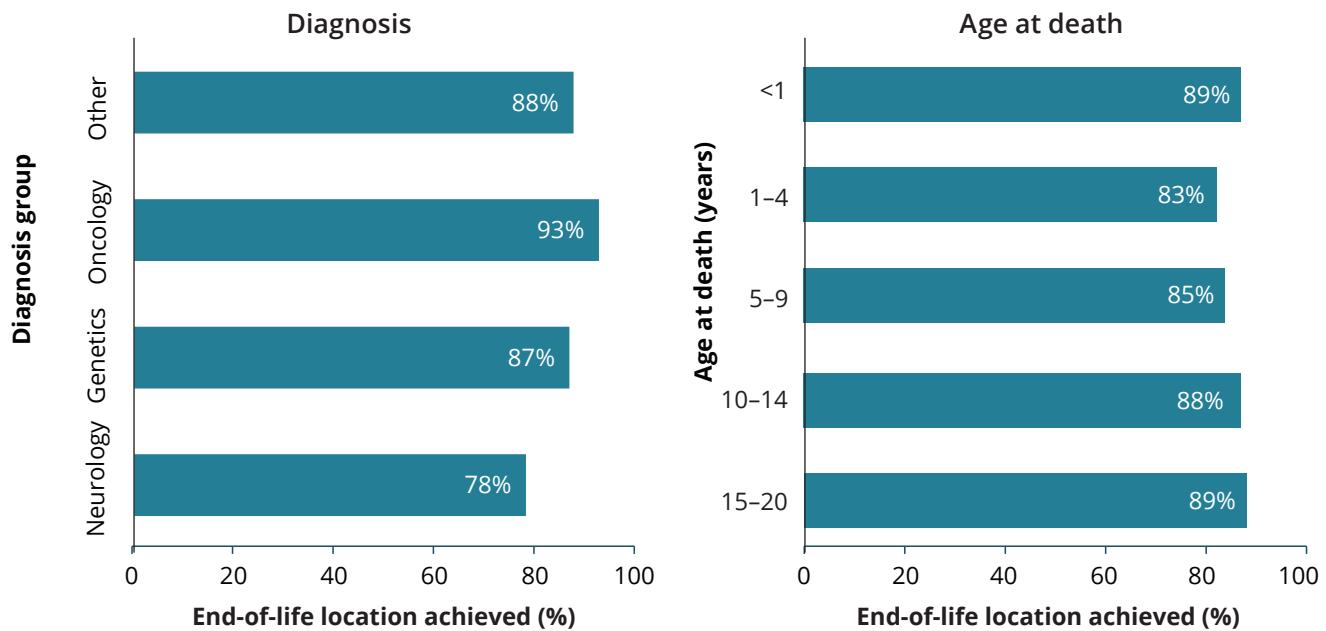
## 7 in 8 children died in the family's end-of-life location goal

Of the 301 children in the study population, 7 in 8 (87%) died in the family's end-of-life location goal. For 7% of children, the responding clinician did not know if the actual location of death was the end-of-life location goal identified by the family. This is consistent with the finding that for 5% of children, family goals and advance care planning were not identified and reassessed as needed, and that preferences for the location of end-of-life care were not discussed with 4% of children and their families. Minor differences in percentages may be due to differences in the clinicians who responded to the survey and those providing care.

Children with neurological conditions were the least likely to die in the family's end-of-life location goal (78%) and children with cancer were the most likely (93%; Figure 8). Excluding infants, the likelihood of achieving the end-of-life location goal increased with age, from 83% for those aged 1–4 years to 89% for those aged 15–20 years. Infants were among the most likely to die in the family's end-of-life location goal (89%). These proportions differed depending on whether 'unknown' responses were included in the denominator, however the patterns were the same.



**Figure 8: End-of-life location goal achieved by diagnosis group and by age at death for the study population**



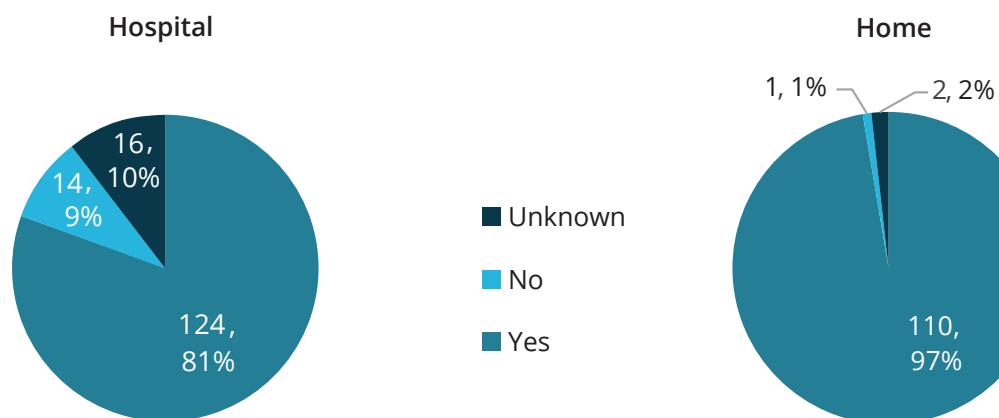
Notes:

1. 'Other' diagnoses include cardiovascular, metabolic, gastrointestinal, renal, respiratory, rheumatological, and those conditions not further specified.
2. The percentages refer to the per cent of all responses to whether a child died in the family's end-of-life location goal that were 'yes', including 'yes', 'no', and 'unknown' responses.

Source: Supplementary Table 7.

Achievement of the end-of-life location goal varied between those who died in hospital and those who died at home (Figure 9). Almost all children (97%) who died at home achieved the family's end-of-life location goal compared to 4 in 5 (81%) of those who died in hospital. The distance between a child's usual residence and the hospital did not impact the likelihood of achieving the end-of-life location goal – children who achieved the end-of-life location goal lived an average of 144km from the hospital and those who did not live an average of 143km from the hospital.

**Figure 9: Achievement of end-of-life location goal for those children who died in hospital and those who died at home among the study population**



Source: Supplementary Table 7.

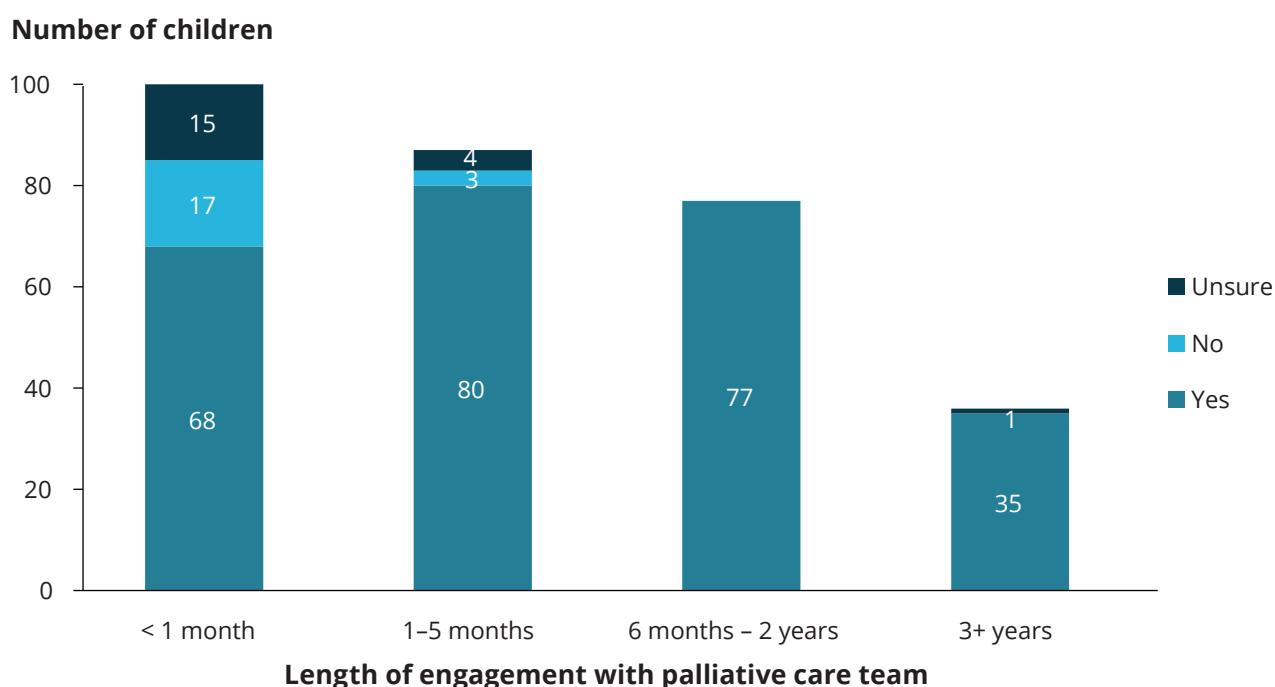
## One in 3 children were engaged with the palliative care team for less than 1 month

Timely referral to a specialist palliative care team is crucial for the delivery of high-quality palliative care. A timely referral allows the palliative care team to adequately assess the needs of the child and their family, build relationships, determine the goals of care, and implement a management plan.

Overall, 87% of the study population had a timely referral, 7% were not referred in a timely manner, and 7% of responding clinicians were unsure if the referral was timely. This varied by length of engagement with the palliative care team. One in 3 children (33%) from the study population were engaged with the palliative care team for less than 1 month, however 68% of those children were referred in a timely manner. Almost all children (99%) who were engaged with the palliative care team for 6 months or more were referred in a timely manner (Figure 10).

Some differences in the timeliness of referral were observed between children from different remoteness areas; 89% of children who usually resided in *Major cities* were referred in a timely manner compared to 82% of those outside *Major cities*. This difference was not statistically significant, however may still be relevant and require further investigation.

**Figure 10: Length of engagement with the palliative care team by the timeliness of referral to palliative care for the study population**



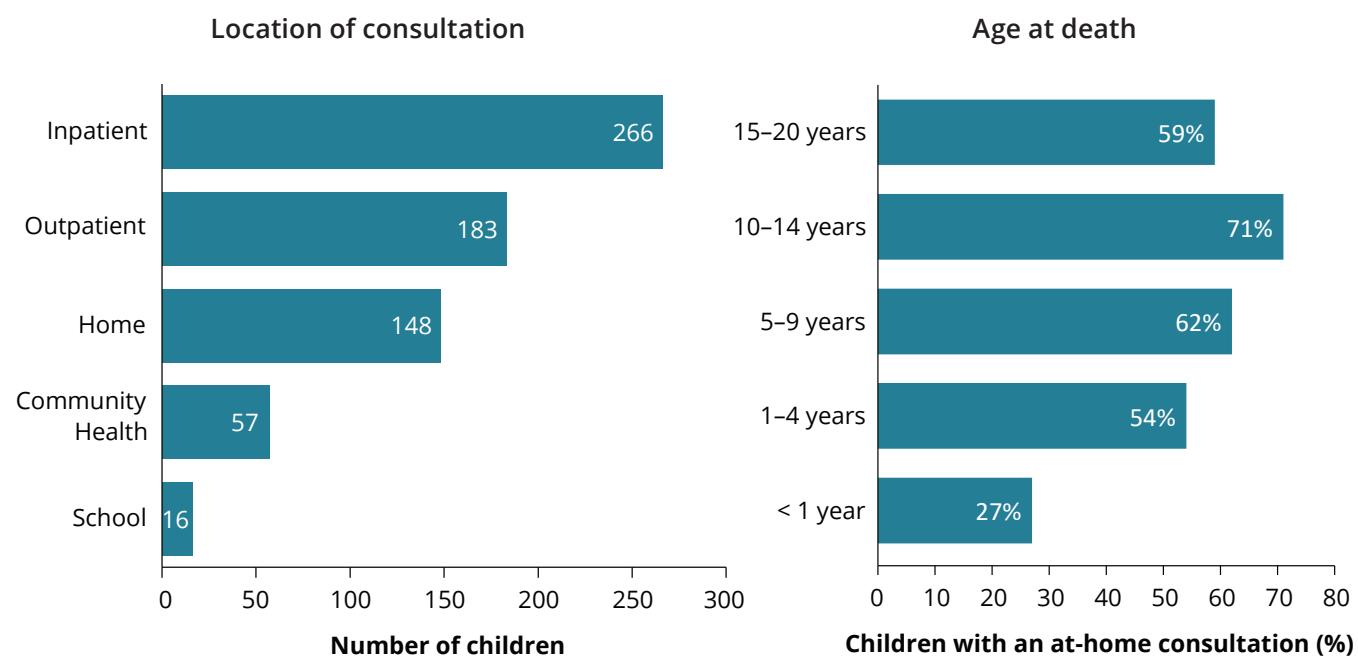
Note: A timely referral was one where the responding practitioner answered yes to the survey question 'was the referral timely?'.

Source: Supplementary Table 8.

## One in 2 children received a care consultation in their home

Palliative care consultations were provided to children in the study population in a range of locations; 88% of children received at least one inpatient consultation, 61% received an outpatient consultation, and 49% received a consultation in the home (Figure 11). Generally, older children were more likely to receive a consultation in the home than younger children. Infants were the least likely to receive a home consultation (27%) and those aged 10–14 years were the most likely (71%; Figure 11).

**Figure 11: Location of palliative care consultations for the study population; and the proportion of the study population that had a home consultation by age at death**



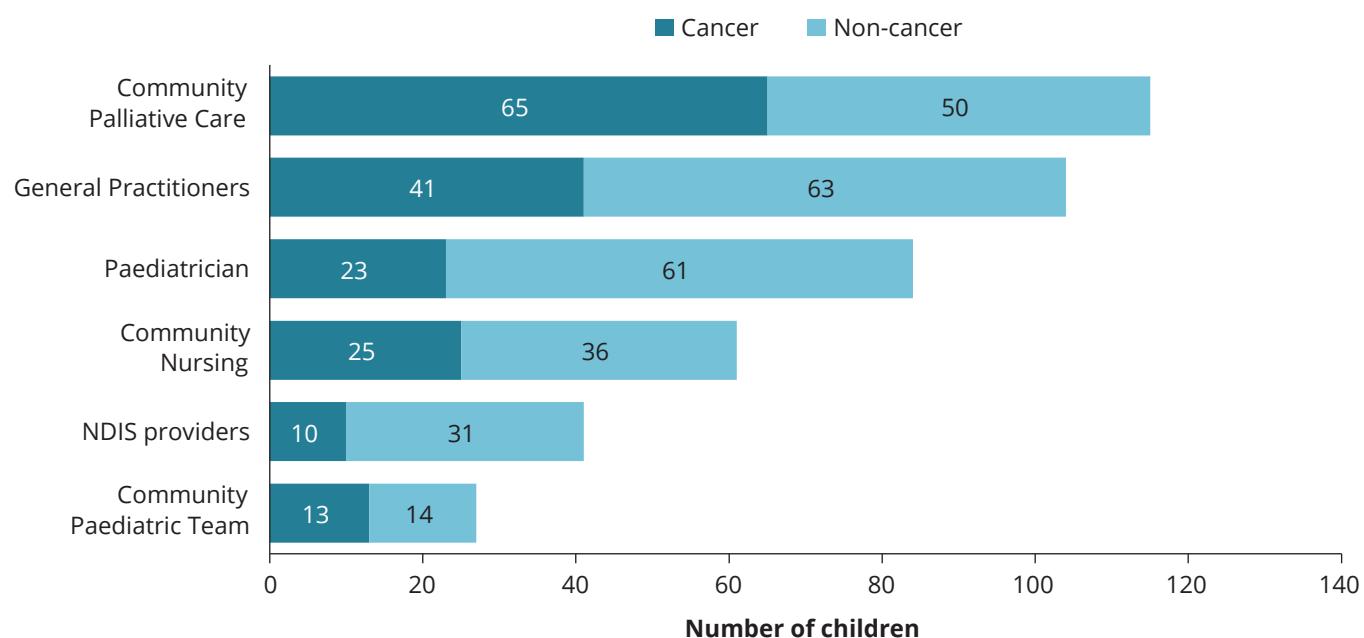
Note: Some children received palliative care consultations in more than 1 location; these children would be counted in more than 1 category.

Source: Supplementary Table 5.

Part of providing high quality specialist paediatric palliative care is to establish links with other health professionals in a child's local network. The specialist team at a children's hospital often provide local clinicians with support and education so they can effectively care for the child and their family in their own community.

Community palliative care was the most common link established by the hospital for children in the study population (38%); interestingly, more than half (57%) of these children had cancer (compared to 37% for the study population overall). Links were established with general practitioners for 35% of children, and paediatricians for 28% of children (Figure 12).

**Figure 12: The number of children in the study population for which links with other health providers were established, by cancer and non-cancer diagnoses**



Note: Some children had links with more than 1 type of health provider; these children would be counted in more than 1 category.

Source: Supplementary Table 9.

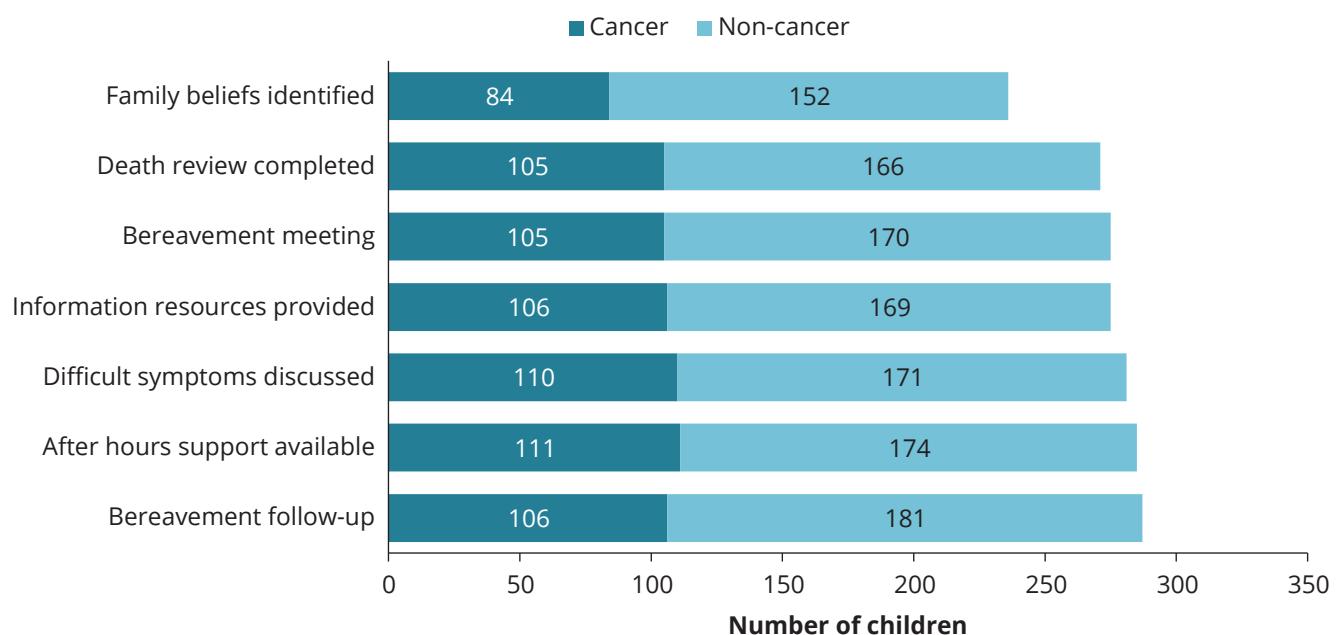
## One in 3 families accessed respite services; 70% had a child who died aged 5 or over

High quality paediatric palliative care embraces the whole family and uses a model of child and family-centred care.

Overall, the families of the children in the study population were well-supported. Almost all families were provided with bereavement follow-up (95%), and the reason most of those who weren't was that the family declined (Figure 13). Similarly, for 96% of children, the needs of their siblings were identified where applicable. Specific practices and beliefs were only identified for 79% of families while caring for the patient; age, socioeconomic area, remoteness, and diagnosis did not appear to influence whether family beliefs were identified or not.

The families of children with cancer were slightly better supported than those with non-cancer conditions; they were significantly more likely to have had discussions about difficult symptoms, and a review completed following the death of their child. It also appeared that they were more likely to have access to afterhours support, however, this requires further investigation as the result may be affected by age at death.

**Figure 13: Indicators of quality care for the families of the children in the study population, by cancer and non-cancer diagnoses**

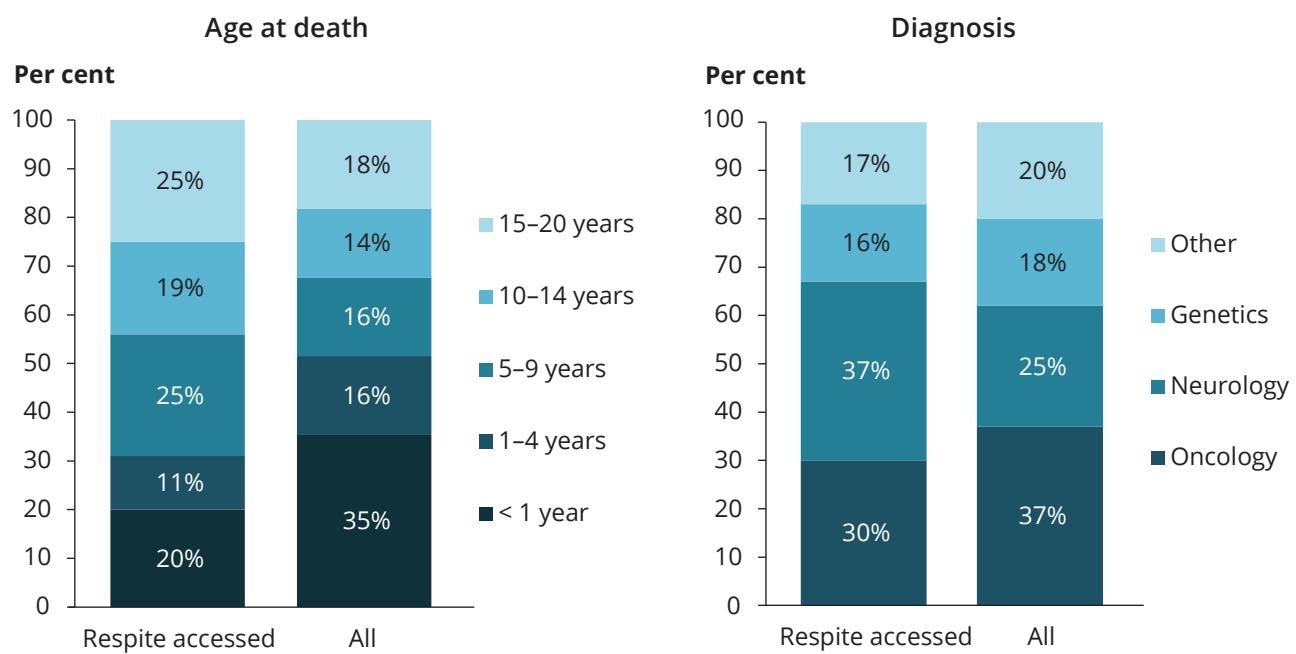


Note: 'Family beliefs identified' means that the specific practices and beliefs of the family were identified while caring for the patient; 'bereavement meeting' means that the family were offered an opportunity to meet/debrief with the palliative care service following their child's death; 'information resources' means that the family was provided with information such as health provider contact details, brochures and factsheets; 'bereavement follow-up' means that the family had a key bereavement support worker to ensure bereavement services were offered.

Source: Supplementary Table 10.

One in 3 families (33%) accessed respite services to take a short break from the physical and psychological demands of caring for a child with a life-limiting condition. Families with older children or with a child with a neurological condition were more likely to use respite services – 69% had a child who died aged 5 or over (compared to 48% in the total study population) and 37% had a child with a neurological condition (compared to 25% in the total study population), as shown in Figure 14.

**Figure 14: Families that accessed respite services by age at death, and by diagnosis of their child from the study population**



Note: All refers to all children in the study population.

Source: Supplementary Table 11.

## References

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- The Centenary Hospital for Women and Children, Australian Capital Territory
- Sydney Children's Hospitals Network (Westmead and Randwick), New South Wales
- John Hunter Children's Hospital, New South Wales
- The Queensland Children's Hospital, Queensland
- The Royal Children's Hospital, Melbourne
- Perth Children's Hospital, Western Australia
- Women and Children's Hospital, South Australia.

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# Appendix

## Overview of methodology

A brief overview of the data sources and methods used in this report are presented below.

### Paediatric palliative care study population

The paediatric palliative care study population included all children who died in 2021 and received paediatric palliative care services from at least one of the following 8 dedicated paediatric palliative care services at children's hospitals around Australia:

- The Centenary Hospital for Women and Children, Australian Capital Territory
- Sydney Children's Hospitals Network (Westmead and Randwick), New South Wales
- John Hunter Children's Hospital, New South Wales
- The Queensland Children's Hospital, Queensland
- The Royal Children's Hospital, Melbourne
- Perth Children's Hospital, Western Australia
- Women and Children's Hospital, South Australia.

Responses to the following questions were collected via the Paediatric Palliative Care Clinical Indicators survey. This survey is routinely completed by practitioners when a child dies for internal quality and monitoring purposes. All survey data are stored in a central repository managed by CareSearch.

Demographics	Date of birth Date of death Age at death Referral type Postcode of service Postcode of residence Postcode of death Location of death Location of death was End Of Life Location Goal identified by the family Diagnosis group
Clinical Indicators	Timely referral Length of engagement with palliative care team Intensity of engagement with palliative care team Mode of palliative care consultations Location of palliative care consultations Pop-up intervention provided to local health providers Multidisciplinary assessment completed Information resources for families Links with other health providers established Respite services accessed Specific practices and beliefs of the family were identified

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Clinical Indicators (continued)	<ul style="list-style-type: none"> <li>Sibling needs identified</li> <li>Equipment needs/medical supplies identified</li> <li>Equipment/medical supplies provided in a timely manner</li> <li>Family goals and Advance Care Planning identified</li> <li>Difficult symptoms discussed with family</li> <li>Written palliative care management plan</li> <li>End of life/Advance Care Planning documentation completed</li> <li>Afterhours support available to family during end of life</li> <li>Preferences for location of end of life care discussed</li> <li>Access to the right location at the right time</li> <li>Family offered to meet/debrief with service following child's death</li> <li>Bereavement follow up provided</li> <li>Death review</li> </ul>
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Following all necessary data governance approvals, de-identified survey data was securely transferred to AIHW from each of the 8 participating sites. Data was then cleaned and compiled into one national data set and assessed for quality and comparability across service providers. The survey response rates were very high for all questions with:

- all children having a recorded age, location of death and diagnosis group
- response rates close to 100% for all clinical indicators
- data on place of residence missing for 1 child
- 5 children excluded from all age analyses, due to data quality concerns as date of birth and date of death did not align with age at death.

## Comparator population

The study population was compared with all children (aged 0–20) with life-limiting conditions who died in 2021. This comparator population was identified from the AIHW National Mortality Database (NMD) (AIHW 2023). The NMD comprises information about causes of death and other characteristics of the person. Data for the NMD are provided to the AIHW by the Registries of Births, Deaths and Marriages in each state and territory and the National Coronial Information System (managed by the Victorian Department of Justice). The cause of death data are compiled and coded by the Australian Bureau of Statistics (ABS). All causes of death data from 2006 onward are subject to a revisions process. Deaths registered in 2021 are based on the preliminary version of cause of death data and are subject to further revision by the ABS. For further information, see the methodology notes in ABS Causes of Deaths (ABS 2022).

The comparator population included all children (0–20 years at death) who died in 2021 and had a record of at least one life-limiting condition in the underlying or associated cause of death. Life-limiting conditions were defined according to the Directory of Life-Limiting Conditions which is a list of nearly four hundred ICD10 codes associated with diseases that can limit life in children (Hain and Devin 2011).

# Analysis

## *Descriptive statistics and hypothesis testing*

Descriptive analyses were used to describe the study population by age, geography, socioeconomic area, and diagnosis, and to explore differences between children with favourable and unfavourable clinical indicators. The Kruskal Wallis test was used to determine whether the medians of two or more groups were significantly different at  $p = 0.05$  level. A Chi-Square test of independence was used to examine the statistical significance of any difference in proportions of two or more groups. When examining results, it should be considered that relationships between variables may be influenced by known and unknown confounding factors, and that they do not necessarily reflect underlying causal links.

## *Driving Distance*

ArcGIS Online (geographical information system) was used to calculate the driving distance between each child's usual place of residence and their hospital. Location of usual residence was approximated by taking the population-weighted centroid of the postcode of the child's usual place of residence. Driving distance was calculated between the centroids and the latitude and longitude of the relevant hospital. Two children were excluded from the analysis because driving distance could not be calculated due to their place of residence being out of scope.

## *Index of Relative Socio-Economic Disadvantage*

The Socio-Economic Indexes for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage (IRSD) was used to approximate the socioeconomic status of children. The IRSD was developed by the Australian Bureau of Statistics (ABS) and represents the socioeconomic position of Australian communities by measuring aspects of disadvantage, such as low income, low educational attainment, high unemployment, and jobs in relatively unskilled occupations. Areas are then ranked according to their level of disadvantage. In this report, the rankings were divided into quartiles instead of the more commonly used quintiles due to the small size of the study population. It is important to note that the IRSD reflects the overall or average socioeconomic position of the population of an area; it does not show how individuals living in the same area might differ from each other in their socioeconomic position.

# Considerations

It is important to note that the study population does not necessarily capture all specialist paediatric palliative care provision in Australia. This report does not include any non-specialist paediatric palliative care services, such as care in maternity and neonatal services, and adult-focussed community palliative care services who provide care to paediatric patients in their home. Further, the survey data used in this report may not be complete, meaning that not all children that died in 2021 and received specialist paediatric palliative care from one of the 8 children's hospitals included in this study were captured in the survey data. This may be due to staff resourcing and/or misunderstanding of which deaths should be captured in the survey. It should also be noted that specialist paediatric palliative care services generally provide services only to those aged 0–18 years old, so data for those aged 18–20 years is likely to be incomplete.

Given the nature of life-limiting conditions in childhood, children tend to receive palliative care for longer than adults (PCA 2022). As such, many patients who received specialist palliative care in 2021 from one of the 8 children's hospitals would not have died in 2021, and so are not included in this study. Consequently, the data in this report are not reflective of the total number of children receiving specialist palliative care from these hospitals.

In some cases, only high-level aggregate data are presented in this report due to the small size of the study population and the inherent confidentiality and methodological limitations. Demographic, geographical, and clinical information have been combined into broader groups to ensure that privacy protection provisions are satisfied while maintaining statistical confidence in the data. Many rates and proportions are based on relatively small denominators, potentially undermining the reliability of the estimates due to the volatility in the data. Differences in characteristics of children have been presented even where they are not statistically significant as the study population was small, and the differences may still be relevant.

The diagnosis group of the children in the study population does not necessarily mean this was the underlying cause of death, just that the child died with the specified condition.

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