

ECHPI

Evidence for Children's
Palliative Care in Ireland

EXECUTIVE SUMMARY

Evidence for Palliative Care in Ireland

The study

The Evidence for Children's Palliative care in Ireland (ECHPI) project, 2023–2026, was a national study undertaken to fill important information gaps needed by healthcare policymakers and providers to improve planning and delivery of children's palliative care in Ireland.

The work was funded by the Health Research Board with co-funding from the Irish Hospice Foundation and LauraLynn Ireland's Children's Hospice. The study was led by a collaboration of researchers, knowledge users (including children's palliative care providers, policymakers), and public and patient involvement (PPI).

What we did and why

This study examined available national hospital data to find out more about children who might need palliative care in Ireland.

This is because planning and delivering effective healthcare in the right place at the right time is challenging when there is limited information about the population who might need and use that service.

Children's palliative care focuses on enhancing quality of life for children with life-limiting conditions and their families including: managing distressing symptoms, providing short breaks for the child and family, and providing care through death and bereavement.

Children's palliative care ideally begins when the life-limiting condition is diagnosed and may be needed for a very short period of time, or could extend over many years.

We asked:

1. How many children have life-limiting conditions in Ireland?

Why: Estimating the prevalence of life-limiting conditions amongst children is an important first step to estimating how many children might need palliative care.

Irish policymakers require up-to-date prevalence estimates because available estimates in Ireland are outdated (e.g., national children's palliative care policy has not been updated since 2009) and were based on international data.

Life-limiting conditions include both life-threatening conditions, where curative treatment may be feasible but can fail, and life-limiting conditions, where there is no reasonable hope of cure.

2. What are the hospital-use patterns by children with life-limiting conditions in Ireland?

Why: Acute hospitals are important places of care for children with life-limiting conditions. International evidence indicates that children with life-limiting conditions use a lot of acute care but equivalent information has not been generated for Ireland until now.

We examined public acute hospital activity (i.e., hospital discharges) for the age group 0–19 in Ireland between 2009 and 2024. We used 2019 as a pre-Covid-19 benchmark year.

3. What more do we need to know?

Why: To guide future research to focus on policy-relevant information gaps.

What we found

1. How many children have life-limiting conditions in Ireland?

- > There were an estimated 5,968–7,951 children aged 0–19 with life-limiting conditions in Ireland in 2019.
- > Estimated prevalence ranged from 44.6 per 10,000 (at baseline) to 59.4 per 10,000 (adjusting for under-counting in the data).
- > Prevalence varied by age and sex and was highest amongst infants under the age of 1, and higher amongst males than females.

2. What are the hospital-use patterns by children with life-limiting conditions in Ireland?

- > In 2019, discharges aged 0–19 with a life-limiting diagnosis were equivalent to <1% of Ireland's population yet they accounted for 7.6% of inpatient discharges and 24.0% of day cases, and 20% of bed days in public acute hospitals in Ireland.

- > Inpatient discharges aged 0–19 with a life-limiting condition accounted for:
 - › more than 28% of inpatient discharges with the highest resource-use complexity rating
 - › more than 28% of inpatient discharges in hospital between 11–90 days
 - › 54% of inpatient discharges in hospital longer than 3 months
 - › 29% of inpatient discharges in intensive care for 1 month or more
 - › 62% of inpatient discharges in hospital with a tracheostomy/gastrostomy diagnosis or procedure.
- > A high proportion of inpatient hospital activity for children with life-limiting conditions took place within Children's Health Ireland hospitals in Dublin because of their role as national tertiary referral centres for many programmes of care (e.g., cancer, cardiology).
 - › Between 2009 and 2024, more than 50% of inpatient discharges aged 0–19 with a life-limiting diagnoses were treated in Children's Health Ireland hospitals, compared with less than 30% of inpatient discharges without a life-limiting condition.

- › In 2019, inpatient discharges aged 0–19 with a life-limiting condition accounted for approximately 17 out of every 100 inpatient discharges and 38.3% of total bed days within Children’s Health Ireland hospitals.

3. What more do we need to know?

- › More information is needed on the number of non-hospitalised children with life-limiting conditions, and on the future prevalence of life-limiting conditions.
- › Not every child with a life-limiting condition will need specialist palliative care. Need for palliative care is based on a combination of diagnostic and complexity factors. For national estimation of need for children’s palliative care, more information on medical complexity needs to be collected to supplement diagnostic data.

- › National data on supply and use of specialist palliative care is needed including respite, community palliative care, acute palliative care and other supports.
- › More information on the reasons behind very long lengths of stay for some children in hospital is needed, including analysis of potential delayed discharges and identifying where bottlenecks may be occurring.
- › Qualitative analysis of the lived experience of children with life-limiting conditions and their families is needed to supplement the learnings from the quantitative analysis of public acute hospital data.

What this means for Irish healthcare policymakers and providers

1. Prevalence of life-limiting conditions in Ireland

- › The prevalence estimates support the widely held view that the likely number of children with life-limiting conditions in Ireland is much higher than outlined in the outdated 2009 national children’s palliative care policy and the policy should be updated.
- › Prevalence was highest in infants under the age of 1, underlining the importance of measures to further develop perinatal and neonatal palliative care provision in maternity and neonatal units in the country.

2. Hospital activity

- › Hospital care for children with life-limiting conditions is complex and resource-intensive. The findings highlight the vulnerability of these children if their complex needs are not met.
- › Ensuring streamlined hospital care for complex-need patients is essential (e.g., provide non-clinical care/accompaniment for the child to allow parents to take in information

during key meetings with clinical teams; accommodate extra equipment requirements with extra space (e.g., power chairs, access to hoists); accommodate comfort items from home to reassure the child; provide psychosocial support for the child to reduce anxiety; flag the need for extra support on patient chart).

- › Attending hospital with a child with highly complex needs who might rely on almost constant parental/carer supervision (e.g., for communication) is challenging, particularly if far from home support networks. Formal support for accompanying parents/carers needs to be sufficiently resourced to allow basic needs to be met while caring for their child in hospital.
- › Travelling potentially long distances to Dublin-based children’s hospitals adds financial burdens on families and transport challenges, underlining the importance of increasing access to financially supported child-friendly healthcare transport services.

- > Further embedding of education in a palliative care approach in general paediatric training is needed. More widespread expertise in a palliative care approach within paediatrics would ensure that all staff working in an acute setting, no matter what their role or specialty, would have some awareness of, and preparedness for providing appropriate responses and support for any child and family facing life-limiting circumstances.
- > Potential increases in the number of pre-teenage patients with life-limiting conditions have planning implications for managing transition from paediatric to adult healthcare.

3. Data improvements

- > Continued high-quality, policy-relevant research to inform children's palliative care planning and provision relies on secure and protected access to national patient-level data on healthcare use and dataset linkage to examine use across acute and non-acute sectors, longitudinal behaviours (e.g., transition from paediatric to adult services), and outcomes (e.g., linkage with death records, changing survival patterns).

Conclusions

Ireland is at an important juncture in the planning and delivery of children's palliative care.

Over the past 15–20 years, a nationally coordinated service has been established, supported by key policies, oversight structures, as well as operational and clinical guidelines.

The findings from this study are well-placed to inform the next phase of children's palliative care development and delivery in Ireland, including the planned review and revision of the national policy for children's palliative care. The findings also have wider implications for the revision of the national model of care for paediatrics, including general paediatric training and education.

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Learn more about the ECHPI project at

<https://professionalpalliativehub.com/research/palliative-care-research-studies/childrens-palliative-care/>