ECHPI
Evidence for Children's
Palliative Care in Ireland

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Key Findings & Recommendations

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Trinity College Dublin
The University of Dublin

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Irish Hospice Foundation
To die and grieve well wherever the place

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IRELAND'S CHILDREN'S HOSPICE

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All Ireland Institute of Hospice and Palliative Care

ECHPI
Evidence for Children's
Palliative Care in Ireland

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Learn more about the ECHPI project at
https://professionalpalliativehub.com/research/palliative-care-research-studies/childrens-palliative-care/

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.

Contents

Introduction

This document highlights key findings from a national study on children's palliative care in Ireland.

This study aimed to fill important information gaps needed by healthcare policymakers and providers to improve planning and delivery of children's palliative care in the country.

Background to Children's Palliative Care in Ireland

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 and oversight structures including the 2009 National Policy on Palliative Care for Children with Life-Limiting Conditions in Ireland,[1] the Children's Palliative Care Strategic Advisory Group (formerly the National Development Committee for Children's Palliative care), the national paediatric model of care[2], as well as operational and clinical guidelines (e.g., for delivering end-of-life care in the community[3]).

The service is delivered by hospital-based specialist tertiary paediatric palliative teams, clinical nurse co-ordinators for children with life-limiting conditions and Community Specialist Palliative Care Teams (mainly for end-of-life care in the community), specialist hospice care (e.g., through LauraLynn Ireland's Children's Hospice) in addition to the child's general or specialist paediatric team and their General Practitioner.

However, important challenges persist. There are concerns about late or even non-referrals to children's palliative care, as well as uneven and inequitable access to available palliative care across the country.[3,4]

New challenges are also emerging. For example, improvements in medicine and technology mean more children are surviving with complex care needs, including palliative care needs, over long periods of time and possibly into adulthood with implications for service continuity.[5-9]

Why this study was needed

Planning and delivering an effective healthcare service is challenging when there is limited information about the population who might need and use that service.

Until now, little was known about the characteristics of children with palliative care needs in Ireland.[1,2,10-13]

What did this study do

This study filled important information gaps about the population likely to need children's palliative care in Ireland. The key findings and learnings are summarised in three key stages:

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

First, we estimated how many children have a life-limiting condition in Ireland. This is an internationally-recognised first step in counting how many children might need palliative care in the country. Irish policymakers require up-to-date prevalence estimates because available estimates in Ireland are outdated[1,3] and were based on international data.

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

Second, we examined hospital activity for children with life-limiting conditions in Ireland.

This highlighted several important issues for policymakers and providers to pay attention to when planning and furthering the development of paediatric and children's palliative care in the country.

3. What more do we need to know?

   Third, we highlighted information gaps that are more difficult to fill without further analysis, but also without significant improvements in healthcare data systems in Ireland.

Together, the findings 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.[14] The findings also have wider implications for the revision of the national model of care for paediatrics,[2] including general paediatric training and education.

The study

This study was known as the Evidence for Children's Palliative care in Ireland (ECHPI) project and ran from 2023–2026.

The study was led by a collaboration of national and international researchers, knowledge users (including children's palliative care providers, policymakers), as well as public and patient involvement (PPI). 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 research included literature review, qualitative consensus-building, and quantitative secondary data analysis. Detailed study findings have been published in peer-reviewed papers, conference presentations, infographics and other outputs (a full list is provided on the **project webpage**).

The study received ethical approval from the Health Policy and Management and Centre for Global Health Research Ethics Committee at Trinity College, Dublin (Refs: 2969 & 4001). **The full project team and detailed methods are outlined in the appendices**.

What is children's palliative care

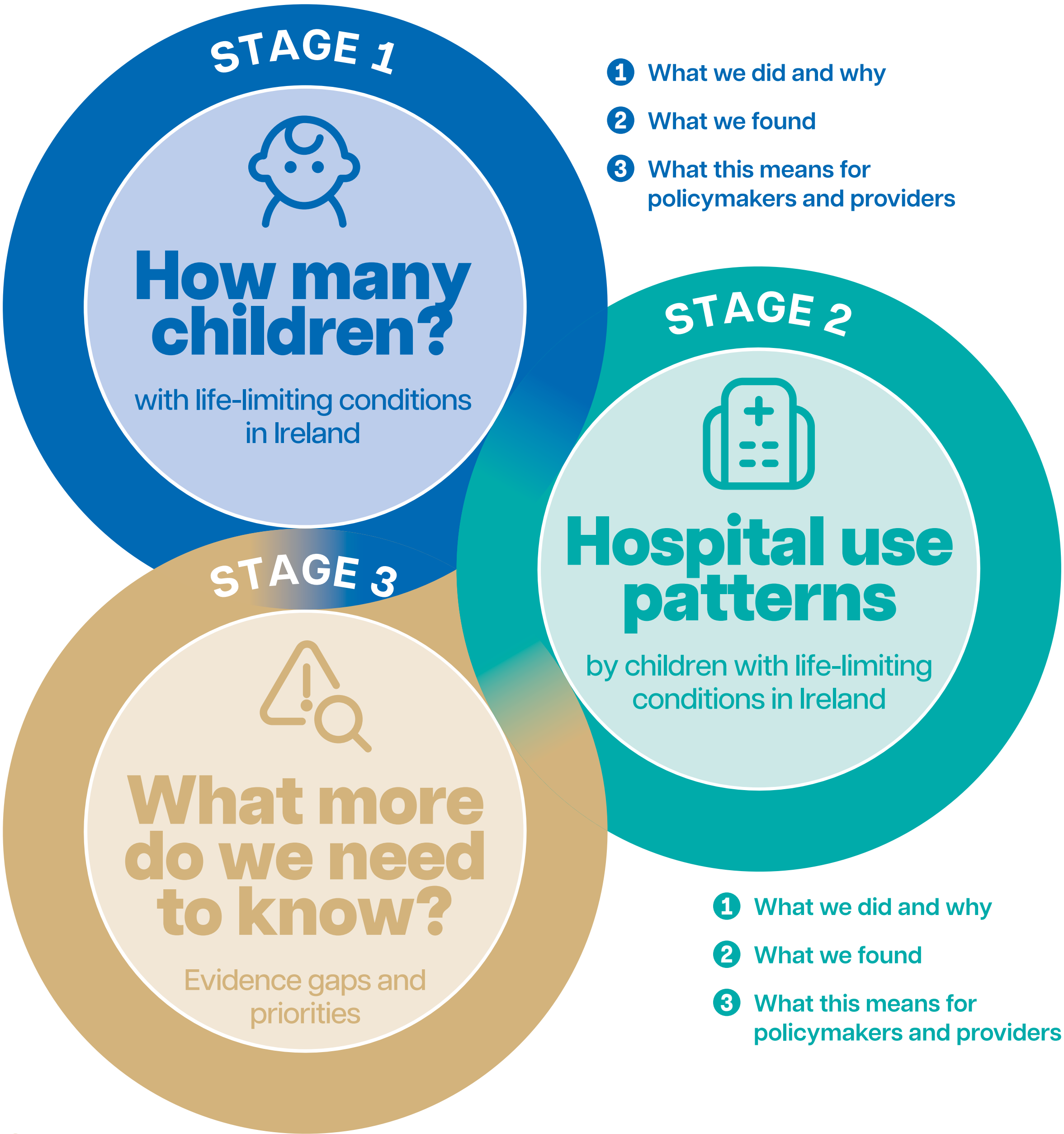
Children's Palliative Care:

1. focuses on enhancing quality of life for children with life-limiting conditions and their families.
2. **includes:** managing distressing symptoms, providing short breaks for the child and family, providing care through death and bereavement.
3. ideally begins at diagnosis or recognition of a life-limiting or life-threatening condition and may be needed for a very short period of time or could extend over many years.
4. can improve symptom control and quality of life for children and their families, potentially reduces the need for hospitalisations, increases the likelihood that the preferred place of death is achieved.[15]

This document

This document highlights the key findings from stages 1, 2 and 3 outlined above and illustrated here.

Document Overview:
The Evidence for Children's Palliative Care in Ireland



STAGE 1

How many children?

with life-limiting conditions in Ireland

1. What we did and why
2. What we found
3. What this means for policymakers and providers

STAGE 2

Hospital use patterns

by children with life-limiting conditions in Ireland

1. What we did and why
2. What we found
3. What this means for policymakers and providers

STAGE 3

What more do we need to know?

Evidence gaps and priorities

1. Data challenges
2. What more do we need to know
3. What this means for policymakers and providers

Prevalence
Section 1

Hospital use
Section 2

Gaps and policy
Section 3

SECTION 1.

STAGE 1

How many children?

with 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

1.1 What we did and why

We estimated the prevalence of life-limiting conditions amongst infants, children, and adolescents aged 0–19 in Ireland in 2019.

[For the rest of the document we use the term ‘children’ to include infants, children and adolescents aged 0–19.]

These are the first estimates of prevalence of life-limiting conditions amongst children in Ireland that have been calculated using Irish-specific data.

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

Life-limiting conditions include both life-threatening conditions, where curative treatment may be feasible but can fail (e.g., cancer), and life-threatening conditions, where there is no reasonable hope of cure.[16]

Up-to-date and accurate information on how many children have life-limiting conditions informs decisions on planning for, and delivering, children’s palliative care in Ireland, so that the right care is delivered in the right place and at the right time.

1.2 What we found

1. 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). See Table 1.

Table 1: *Estimated prevalence per 10,000 population of life-limiting conditions amongst children aged 0–19 in Ireland, by age and sex, 2019 (baseline and adjusted estimates)*

	Baseline Estimate		Adjusted Estimate	
	No. of patients with LLCs	**Prevalence per 10,000**	**No. of patients with LLCs**	**Prevalence per 10,000**
Age group				
Age ≤ 1	1,121	185.7	1,494	247.4
1-5 years	1,779	55.2	2,371	73.6
6-10 years	1,228	34.0	1,636	45.2
11-15 years	1,142	33.9	1,522	45.2
16-19 years	697	27.2	929	36.2
Total 0-19 years	5,968	44.6	7,951	59.4
Sex				
Females	2,710	41.5	3,610	55.3
Males	3,258	47.6	4,341	63.4

Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Notes: Excludes visitors on holiday; LLCs = Life-limiting conditions; Life-limiting conditions defined as per Fraser et al. 2012[17]
Results presented for Estimation Method 2 (E2), see Appendix 1 for more detailed methods.

2. Prevalence was highest amongst infants under the age of 1, between 185.7 (at baseline) and 247.4 (adjusted) per 10,000 population (Figure 1).

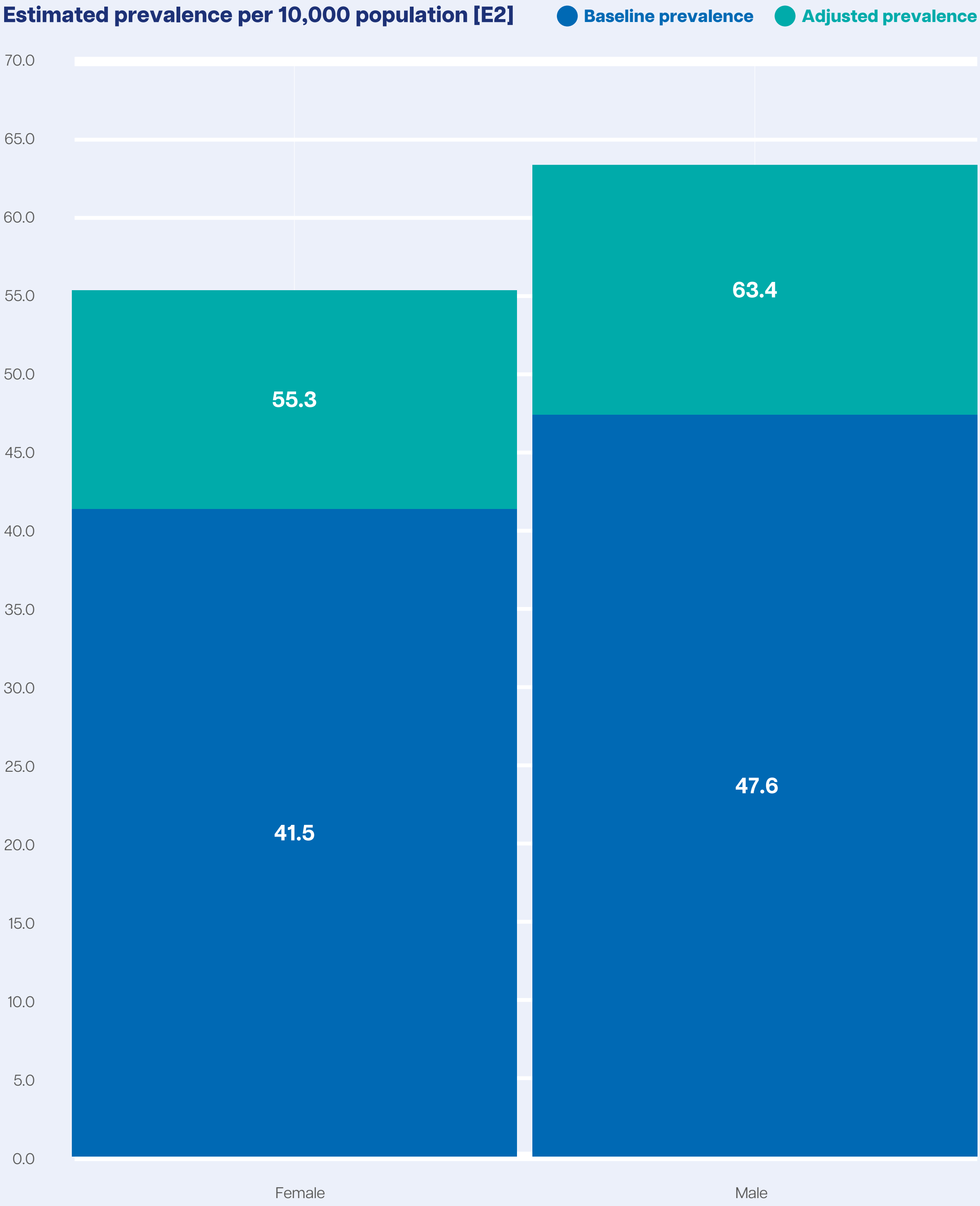
Figure 1: *Estimated prevalence per 10,000 population of life-limiting conditions amongst children aged 0–19 in Ireland, by age group, 2019 (baseline and adjusted estimates)*

Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Notes: Results presented for Estimation Method 2 (E2) see Appendix 1 for more detailed methods.

3. Prevalence was higher amongst males (47.6–63.4 per 10,000 population) than females (Figure 2), and highest for neoplasms and congenital/chromosomal conditions.

Figure 2: *Estimated prevalence per 10,000 population of life-limiting conditions amongst children aged 0–19 in Ireland, by sex, 2019 (baseline and adjusted estimates)*

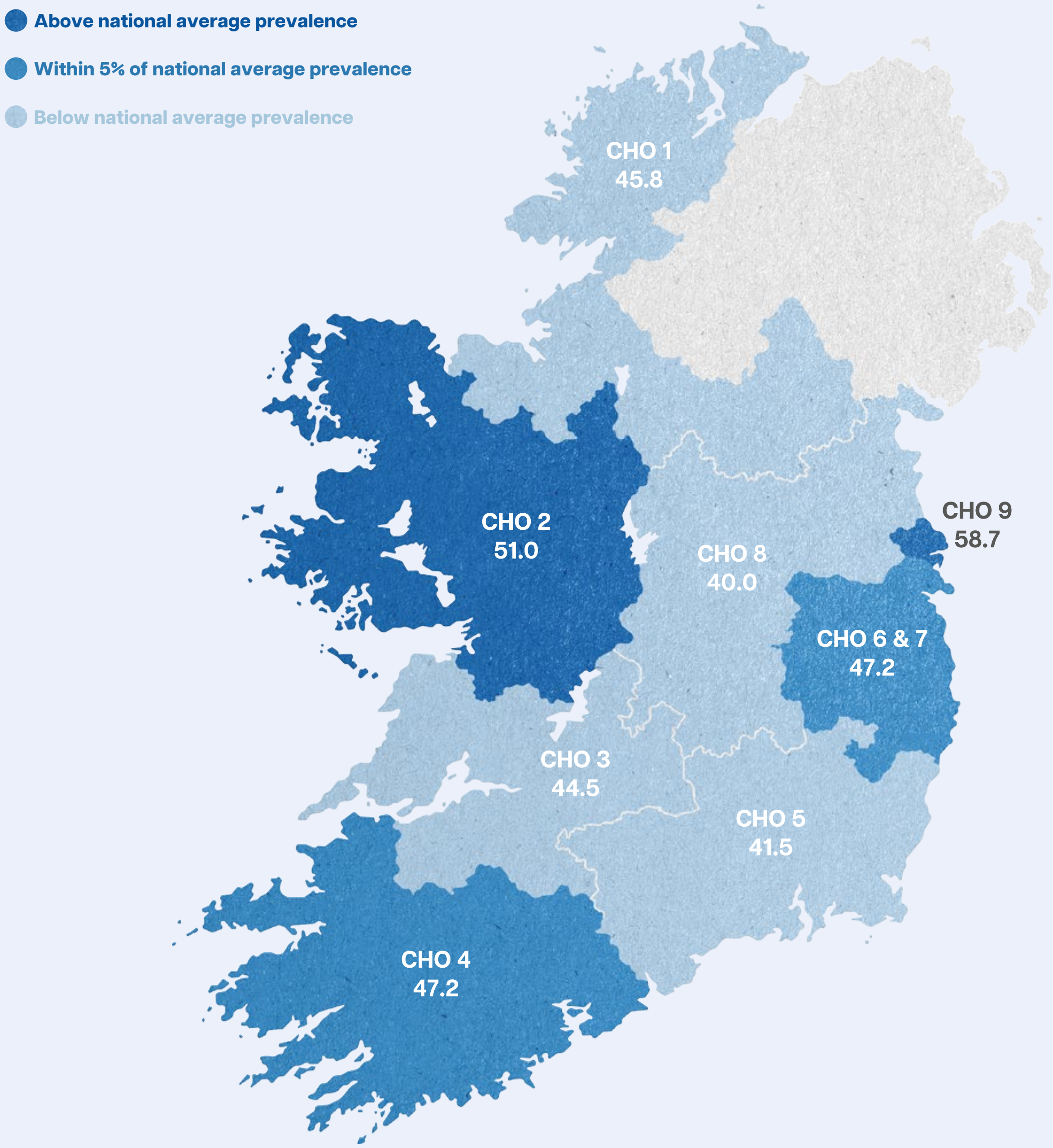


Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Notes: Results presented for Estimation Method 2 (E2) see Appendix 1 for more detailed methods.

4. Prevalence of life-limiting conditions amongst children aged 0–19 in Ireland varied across the country (Figure 3).

Figure 3: *Estimated prevalence per 10,000 population of life-limiting conditions amongst children aged 0–19 in Ireland by Community Health Organisation, average 2017–2019*



Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Map source: template adapted from Presentation Magazine (**www.presentationmagazine.com**)

Notes: Results presented for Estimation Method 2 (E2) see Appendix 1 for more detailed methods.

CHO = Community Health Organisation

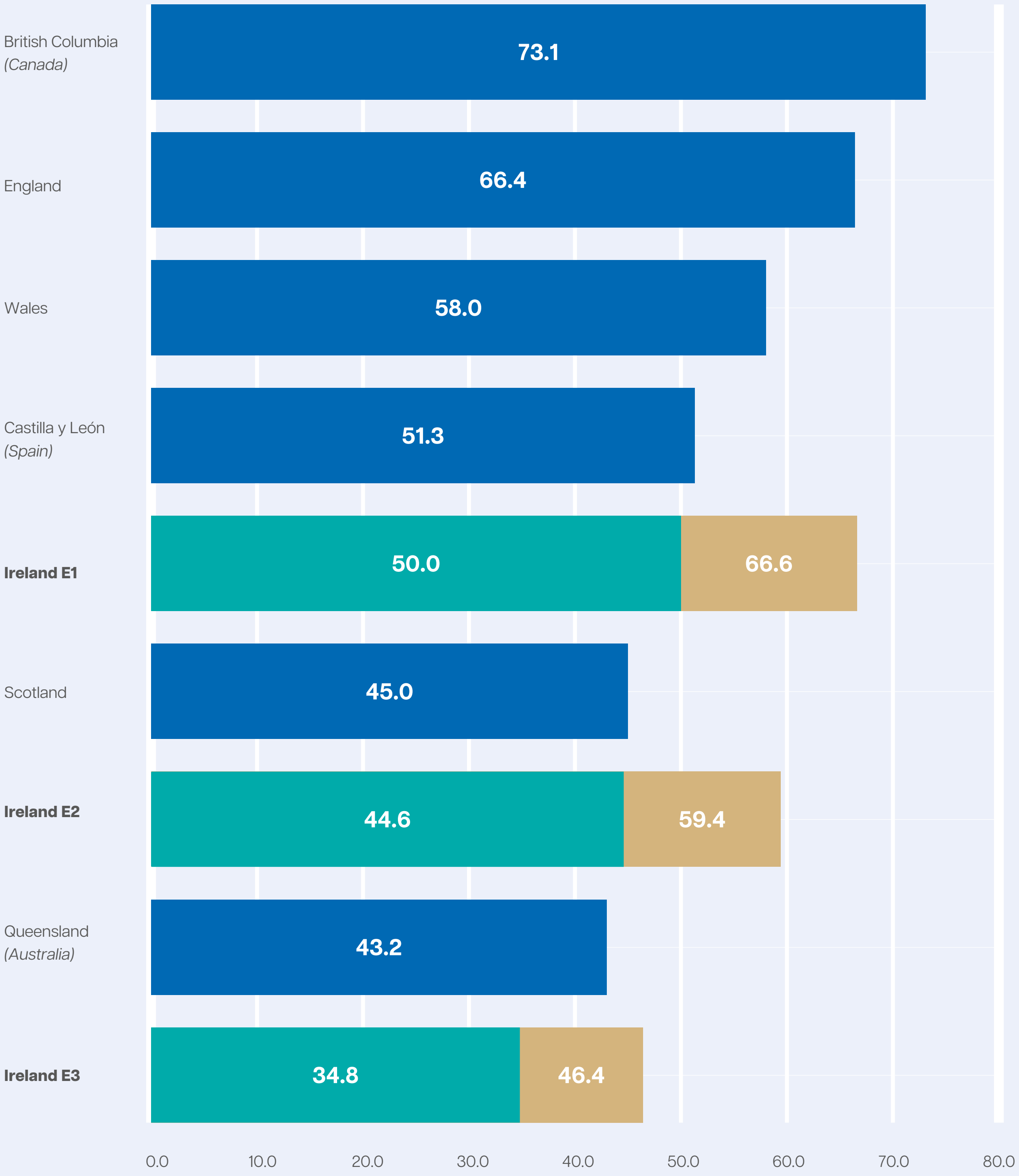
CHO 1: Cavan, Donegal, Leitrim, Monaghan, Sligo; CHO 2: Galway, Roscommon, Mayo; CHO 3: Limerick, Clare, North Tipperary; CHO 4: Cork, Kerry; CHO 5: Wexford, Carlow/Kilkenny, Waterford, South Tipperary; CHO 6 & 7: Dublin South, Wicklow, Kildare; CHO 8: Laois, Offaly, Longford, Westmeath, Meath, Louth; CHO 9: Dublin North

National average prevalence for the time period 2017–2019: 47.0 per 10,000; Above national average prevalence = more than 5% above national average; Below national average prevalence = more than 5% below national average

5. Estimated prevalence of life-limiting conditions amongst children in Ireland was in line with other similar-income countries that used similar data and methods including Australia, Canada, England, Wales, Scotland, and Spain (Figure 4).

Figure 4: *Prevalence of life-limiting conditions amongst children in Ireland, compared with selected countries with similar data and methods*

Prevalence of life-limiting conditions amongst children in Ireland, compared with selected countries with similar data and methods



Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Notes: Results for Ireland based on three estimation scenarios: E1, E2, E3, baseline (green bars) and adjusted for under-counting in the data (brown shaded bars) see Appendix 1 for more detailed methods

Ireland = Age 0-19, 2019; Queensland = Age 0-21, 2016; Scotland = Age 0-21, 2018/19; Castilla y León (Spain) = Age 0-17, 2019; Wales = Age 0-17, 2019; England = Age 0-19, 2017/18; British Columbia (Canada) = Age 0-25, 2017

1.3 What this means for children's palliative care policymakers and providers

National policy revision

The prevalence estimates from this study 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.[1,13,18]

Conservative estimates suggest there were just under 6,000 children with life-limiting conditions in Ireland in 2019. Adjusting for potential under-counting, the total number could have been 7,951.

Development of perinatal and neonatal palliative care

Prevalence of life-limiting conditions was highest in infants under the age of 1. This supports implementation of the Perinatal Palliative Care pathway[19] and the importance of measures to further develop perinatal and neonatal palliative care provision in maternity and neonatal units in the country.

Supply of specialist palliative care providers

Prevalence of life-limiting conditions was not uniform across the country. Planning access to specialist children's palliative care services including respite, specialist palliative input to symptom management and quality of life, end-of-life care and other supports needs to control for regional variations in prevalence.

SECTION 2.

STAGE 2

Hospital use patterns

by children with life-limiting conditions in Ireland

In 2019, discharges with a life-limiting diagnosis accounted for 7.6% of inpatient discharges and 24.0% of day cases aged 0–19 in public acute hospitals in Ireland

2.1 What we did and why

We examined public acute hospital activity for the age group 0–19 in Ireland between 2009 and 2024.

Hospital discharges were categorised into two groups, those with and without a life-limiting condition. We focused particularly on the pre-Covid-19 period (2009–2019), and on 2024 (the most recent post-Covid data available).

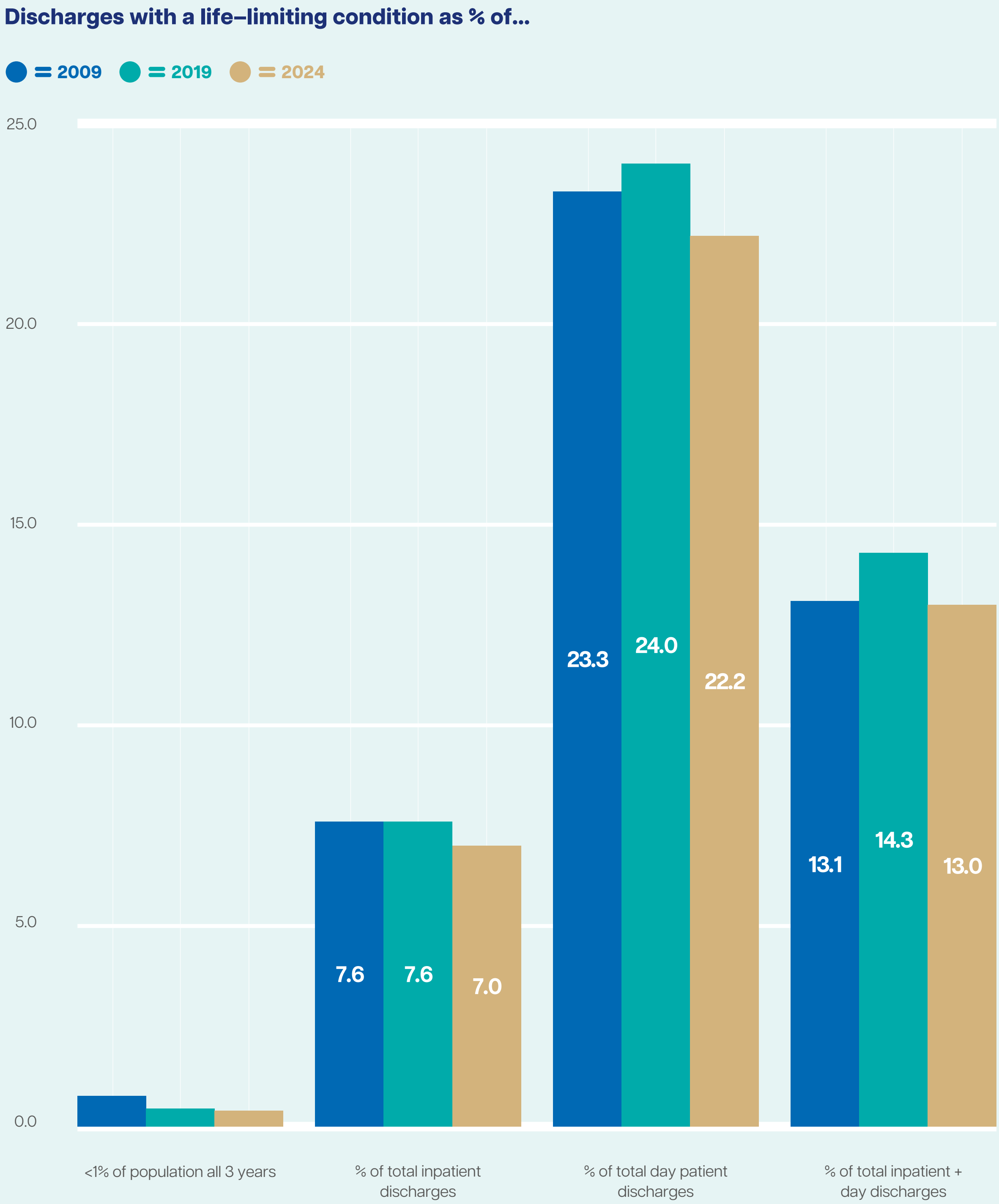
Children with life-limiting conditions have been found to be resource-intensive healthcare users (e.g., hospital admissions, emergency department attendances, prescription medicines) but the evidence is limited to a small number of countries.[20-22] This analysis fills important gaps in information in Ireland on hospital use for the 0–19 age group with and without life-limiting conditions.

Note that the analysis in this section is of hospital activity, counting the number of hospital discharges, not patients, in public acute hospitals in Ireland.

2.2 What we found

1. In 2019, discharges with a life-limiting diagnosis were equivalent to <1% of Ireland's population (aged 0–19) and accounted for 7.6% of inpatient discharges, 24.0% of day cases, and 14.3% of all discharges (i.e., day cases plus inpatients) aged 0–19 in public acute hospitals in Ireland. See Figure 5.

Figure 5: *Discharges with a life-limiting diagnosis as a percentage of the population and public acute hospital discharges aged 0–19 in Ireland, by year and type of discharge (inpatient, day, total)*



Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

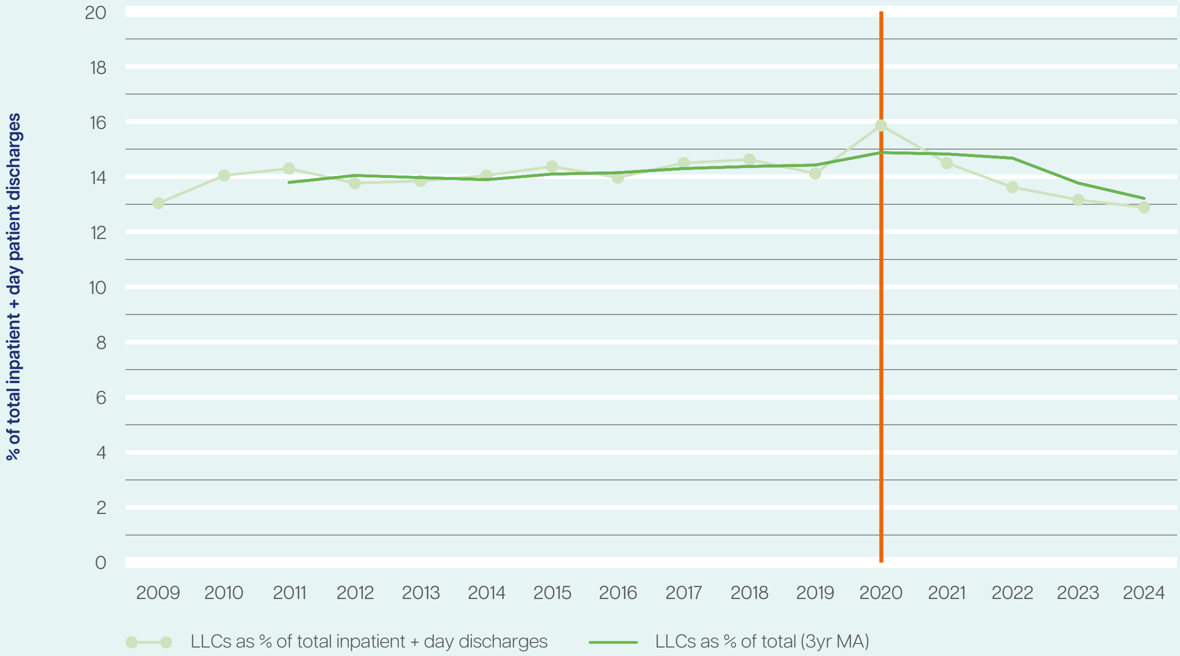
2. **Public acute hospital discharges aged 0–19 with a life-limiting condition increased from 21,290 to 23,100 between 2009 and 2019, growing from 13.1% to 14.3% of total discharges in that age group.**

   This growth was driven mainly by increases in the number of day patients between 2009 and 2019; the number of inpatient discharges fell over the same time-period.

Both day patient and inpatient discharges dropped in 2020 with the onset of the Covid-19 pandemic, but the drop was steeper for discharges without a life-limiting condition (-26.1% vs. -15.1%).

Figure 6: *Total inpatient and day patient discharges aged 0–19 with and without a life-limiting condition (number and 3-year moving average, rate per 10,000 population, % of total), Ireland, 2009–2024*

6c LLCs as % of total inpatient + day patient discharges



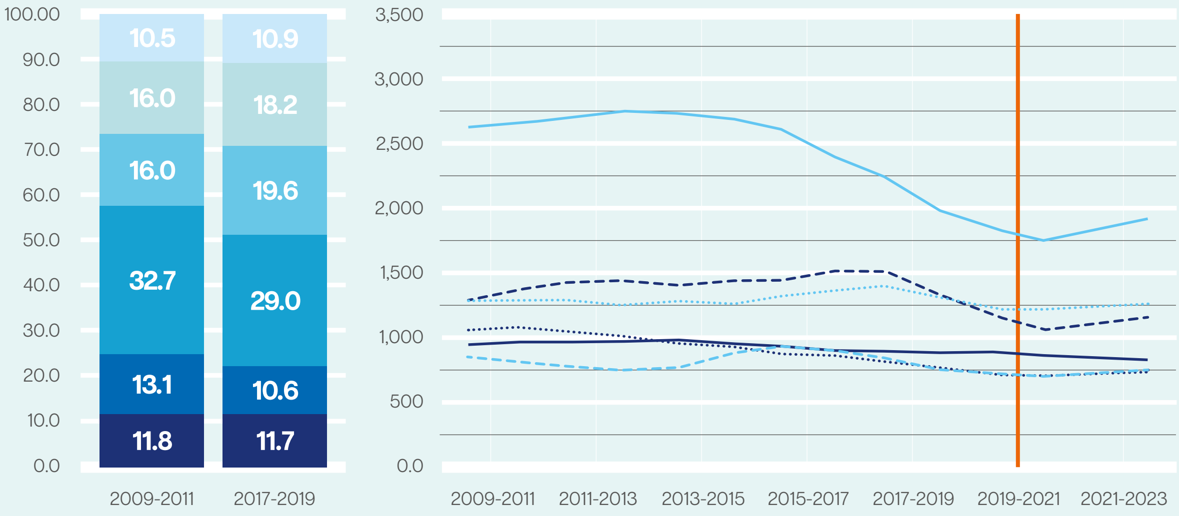
Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]
National population data, Central Statistics Office[23]

Notes: MA = Moving average

3. There was an increase in the proportion of discharges aged 6–10 and 11–15 between 2009 and 2019. The increase in these older age groups was observed in both day and inpatients and for those with and without a life-limiting condition, but the rate of increase was somewhat more pronounced amongst discharges with a life-limiting condition.

   Figure 7 shows data for inpatients to illustrate.

Figure 7: *Inpatient discharges aged 0–19 with and without a life-limiting condition: % breakdown by age group, and average number (3-year moving average) by age group, Ireland, 2009–2024*

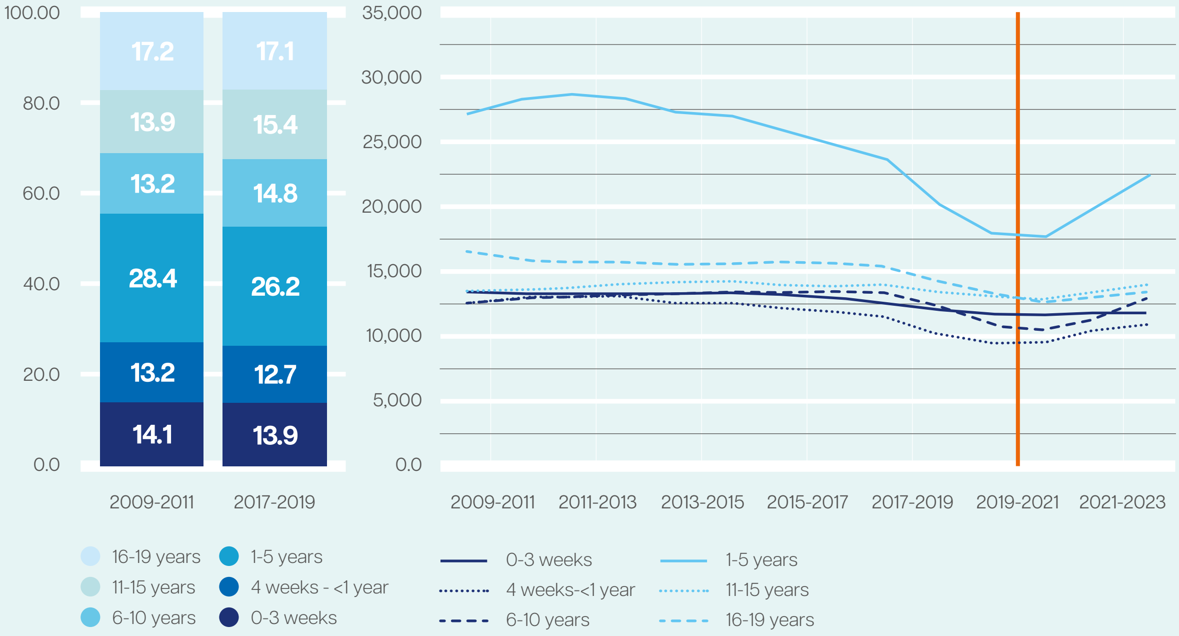


7a Inpatient discharges with a life-limiting condition, % breakdown by age group

7b Inpatient discharges with a life-limiting condition by age group, 2009-2024

7c Inpatient discharges without a life-limiting condition, % breakdown by age group

7d Inpatient discharges without a life-limiting condition by age group, 2009-2024



Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

4. Intensive use of hospital resources: inpatient discharges from public acute hospitals aged 0-19 with a life-limiting condition had longer mean and median lengths of stay, longer mean and median lengths of stay in intensive care, higher resource-use complexity, larger mean numbers of diagnoses and procedures, and higher levels of technology dependence compared with non-life-limited discharges between 2009 and 2024. Table 2 shows data for 2019 to illustrate.

Table 2: *Inpatient discharges aged 0–19 with and without a life-limiting condition: mean number of diagnoses, procedures, length of stay, technology dependence, and resource complexity, Ireland, 2019.*

	2019			
	Discharges with a life-limiting condition		**Discharges without a life-limiting condition**	
Mean number of diagnoses recorded per discharge	4.5		2.5	
Mean number of procedures recorded per discharge	3.0		1.0	
Length of stay (overnight patients only)				
Mean length of stay	9.3		3.3	
Median length of stay	4		2	
Intensive care unit length of stay (for those with an intensive care unit stay)				
Mean length of stay	11.4		6	
Median length of stay	4		3	
Technology dependence				
% of discharges with tracheostomy/gastrostomy	5.9		0.3	
	Number	**%**	**Number**	**%**
Resource complexity (Diagnosis Related Groups):				
A Highest resource consumption	3,677	50.0	11,531	12.9
B Second highest resource consumption	2,928	39.8	58,419	65.5
C Third highest resource consumption	398	5.4	5,258	5.9
D Fourth highest resource consumption	54	0.7	6,485	7.3
Z No complexity split	304	4.1	7,471	8.4
Total	**7,361**	**100.0**	**89,164**	**100.0**

Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Notes: The Diagnosis Related Group (DRG) scheme groups patients into groups with similar treatment processes and similar levels of resource use.[24] Within each DRG, discharges are ranked by complexity into 5 subgroups (A, B, C, D, Z). Subgroup A includes the most complex cases within that DRG, B includes the next most complex cases and so on (Z refers to cases for which there is no complexity split).

5. **Children with life-limiting conditions used disproportionate levels of inpatient hospital resources relative to the size of the cohort (Figure 8). In 2019, within the age group 0–19, inpatient discharges with a life-limiting diagnosis:**
   - accounted for less than 8% of total inpatient discharges but used up almost 20% of total bed days and 23.3% of intensive care unit bed days;
   - accounted for more than 28% of inpatient discharges with the highest DRG complexity rating, more than 62% of inpatient discharges in hospital with a tracheostomy/gastrostomy (diagnosis or procedure), 28% of discharges in hospital between 11–90 days and 54% of discharges in hospital longer than 3 months;
   - accounted for almost 15% of inpatient discharges with an intensive care unit stay, 29% of inpatient discharges in intensive care for 1 month/more, and nearly 56% of inpatient discharges in intensive care longer than 3 months.

Figure 8: *Inpatient discharges aged 0-19 with a life-limiting condition as a percentage of hospital discharges and bed days, Ireland 2009, 2019, 2024*

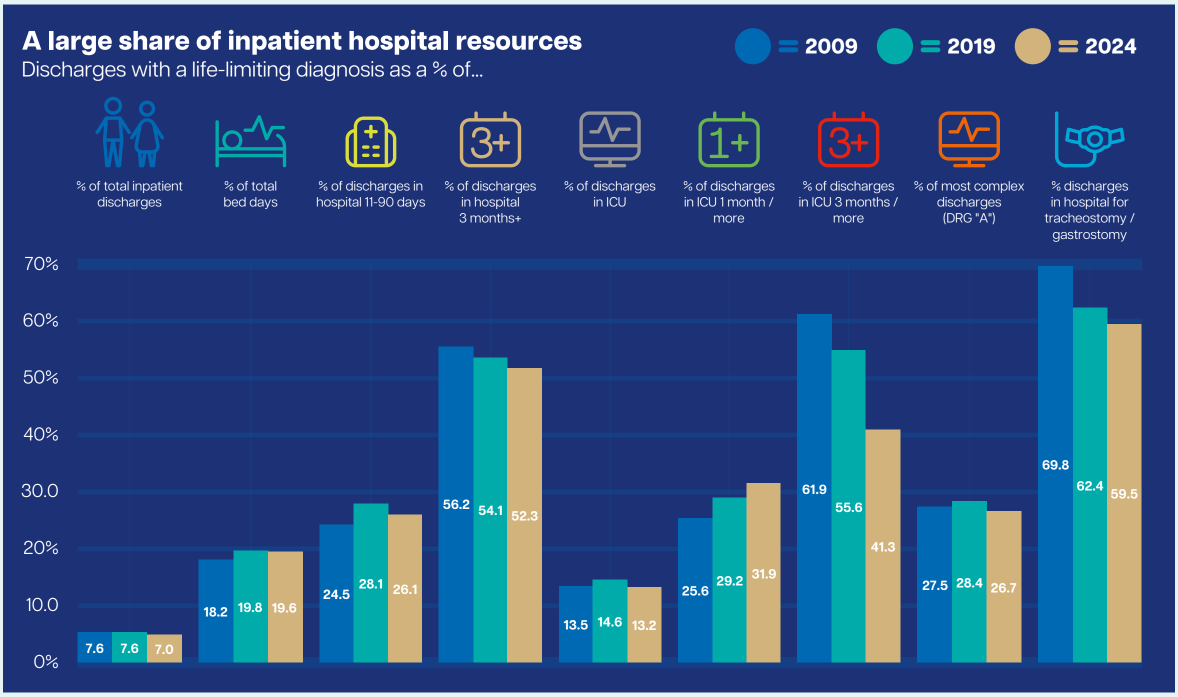
Small cohort. Disproportionate resources. Ireland, 2009, 2019, 2024

Children and young people (0-19) with a life-limiting condition account for a small **proportion of the population** but a **large share of hospital resources**.

<1%

of children and young people aged 0–19 have a life-limiting condition (2009-2024)

Despite being **less than 1%** of the population, children and young people with life-limiting conditions use a disproportionately high share of hospital resources.



A large share of inpatient hospital resources

Discharges with a life-limiting diagnosis as a % of...

Key takeaways – Discharges with a life-limiting condition account for:

Around **7-8%** of all inpatient discharges

Around **1 in 5** total bed days

More than **1 in 2** discharges with a stay longer than 3 months

Nearly **1 in 3** discharges with ICU stay 1 month / more

More than **1 in 2** discharges with ICU stay 3 months / more

More than **1 in 4** discharges with the most complex (DRG "A")

Around **3 in 5** of discharges involving a tracheostomy or gastrostomy

Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Notes: The Diagnosis Related Group (DRG) scheme groups patients into groups with similar treatment processes and similar levels of resource use.[24] Within each DRG, discharges are ranked by complexity into 5 subgroups (A, B, C, D, Z). Subgroup A includes the most complex cases within that DRG, B includes the next most complex cases and so on (Z refers to cases for which there is no complexity split).

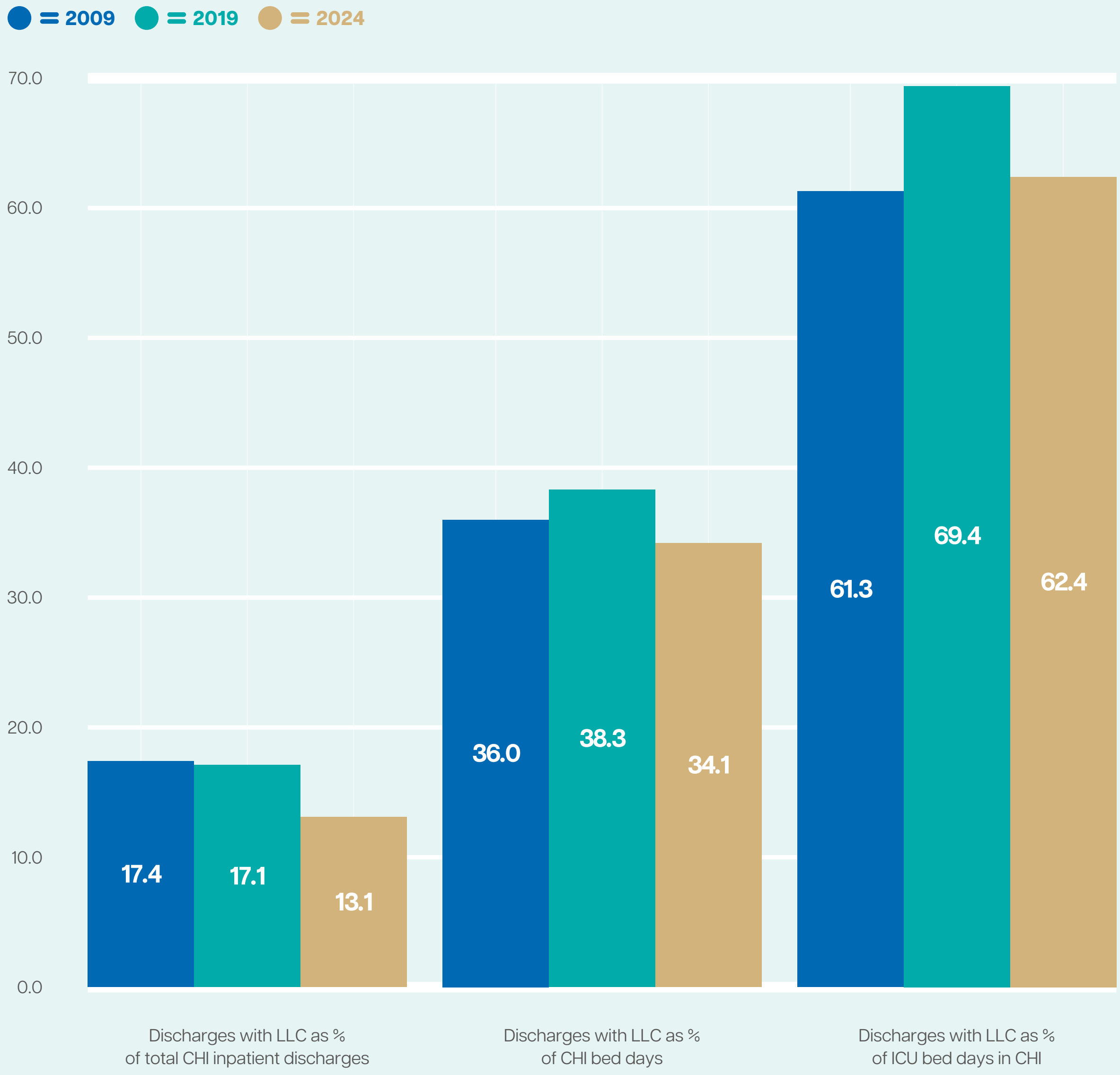
ICU = Intensive Care Unit.

6. A high proportion of inpatient hospital activity for children with life-limiting conditions took place in Children's Health Ireland (CHI) hospitals in Dublin. Between 2009 and 2024, more than 50% of inpatient discharges aged 0–19 with a life-limiting diagnosis were treated in CHI hospitals, compared with <30% of inpatient discharges without a life-limiting condition.

This means that in CHI hospitals, inpatient discharges with a life-limiting condition accounted for a larger proportion of the patient population than in other regions. In 2019, inpatient discharges aged 0–19 with a life-limiting condition accounted for approximately 17 out of every 100 inpatient discharges within CHI, 38.3% of total CHI bed days, and 69.4% of CHI intensive care unit bed days.

Figure 9 Inpatient discharges aged 0–19 with a life-limiting diagnoses as a % of discharges and bed days within CHI hospitals, 2019

Inpatient discharges (0–19) with a life-limiting condition as a % of discharges and bed days within CHI hospitals



Source: Hospital In-Patient Enquiry, Healthcare Pricing Office[16]

Notes: LLCs = Life-limiting conditions; Life-limiting conditions defined as per Fraser et al. 2012[17]
CHI = Children's Health Ireland hospitals: CHI at Connolly, Crumlin, Tallaght, Temple Street
ICU = Intensive Care Unit.

2.3 What this means for Children's Palliative Care policymakers and providers

Complex care needs and resource use

The analysis underlines the complex nature and resource-use intensity of acute hospital care needs by children with life-limiting conditions. The findings highlight the vulnerability of these children if these 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; resource hospital school to optimise continuity of education; ensure prompt and shared communication between CHI and local regional hospital teams; reserved carparking spaces; allow two parents to attend outpatient appointments to facilitate driving, parking, caring for the child).

Lengthy hospital stays

Length of stay is often used as an indicator of hospital efficiency and resource use as well as quality of care.[25,26]

In terms of hospital efficiency and resource use, discharges with life-limiting diagnoses used more hospital resources compared with non-life-limited discharges. Median length of stay for discharges with a life-limiting diagnosis was double that of discharges with no life-limiting diagnosis.

In terms of quality of care, the findings should be interpreted with care. For children with serious illness, a long length of stay may be justified where it is health-replenishing. On the other hand, long lengths of stay bring risks of hospital acquired infections,[27] time away from family, interruptions to schooling and social activities.

Moreover, a long length of stay for a child with a life-limiting condition could represent a considerable portion of their potentially short life with important implications for the quality of their life.

In-hospital supports for parents/carers

A large proportion of inpatient hospital care for children with life-limiting conditions takes place within CHI hospitals. This is expected because the CHI hospitals are national tertiary referral centres for several clinical programmes including cancer care, cardiac care.

Attending hospital with a child is challenging for all parents/carers, particularly if far from home. However, attending hospital with a child with highly complex needs who might rely on almost constant parental/carer supervision (for communication, care of basic needs, etc.) is particularly challenging.

It is important that the new national children's hospital provides for the high complex needs of a notable proportion of its patient cohort. 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.

Travel and transport

Travelling long distances to and from CHI hospitals adds financial burdens for families. Also, transporting children with complex needs to and from hospital is not straightforward and often needs a caregiver with the child as well as a driver, underlining the importance of increasing access to financially supported child-friendly healthcare transport services (e.g., Bumbleance).

Palliative care approach

Further embedding of education in a palliative care approach is needed in general paediatric training. While the discharges with life-limiting conditions were easy to spot as a group in formal data analysis, in the day-to-day clinical setting, they are small in number and could be found in any subspecialty within the acute setting.

Increased education and training in a palliative care approach 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.

Increased palliative care skills at levels 1 (palliative care approach) and level 2 (general palliative care) could also allow for earlier initiation of conversations about advance care planning and earlier referral to specialist children's palliative care (level 3) where needed.

Day case activity

The patterns of discharges over time suggest that hospital care will continue to shift towards day case activity in the age group 0-19, for all discharges. This is a positive trend particularly in the case of children with complex healthcare needs. Evidence suggests a scheduled day case can be easier to manage in terms of caregiving needs, travel burden and involves less disruption to family life, schooling etc., including for children with complex conditions.[28]

Transition from paediatric to adult services

Potential increases in the number of pre-teenage patients with life-limiting conditions have planning implications for managing transition from paediatric to adult healthcare. Projections of discharges aged 0-19 over the next 5–10 years will be important to examine the likely changes in the age profile of patients.

SECTION 3.

STAGE 3

What more do we need to know?

Evidence gaps and priorities

Rapid improvements in healthcare data systems are essential to support further Children's Palliative Care policy and development in Ireland

3.1 Data challenges

Detailed analysis of national public acute hospital activity for children aged 0–19 with life-limiting conditions has filled several important information gaps that can inform policymakers, paediatric and children's palliative care providers in Ireland.

Other information gaps remain and are difficult to fill without significant improvements in national healthcare data systems in Ireland.

3.2 What more do we need to know?

Number of non-hospitalised children with life-limiting conditions

This study focused on hospital-based prevalence, estimating the number of children with a life-limiting condition and an inpatient hospital admission in 2019. There may have been other children who didn't have a hospital admission in 2019 but were in a stable phase of a life-limiting condition at home.

Other national-level data need to be analysed to capture these additional cases, for example, national data on prescription medicines, specialist paediatric out-patient services (e.g., cardiology, oncology, and neurodisability) and Childrens Disability Network Teams.

Future prevalence of life-limiting conditions amongst children

This study focused on prevalence data for 2019 (i.e., pre-Covid-19 pandemic) but projecting future prevalence is also important for planning future children's palliative care. Projecting future prevalence would involve analysis of past trends in prevalence (and other factors such as demographic change). Analysis of trends in prevalence over time was not possible in this study without a unique health identifier within national hospital data.

Prevalence and supply by Health Region

Future workforce planning for specialist palliative care requires geographic assessment of supply, controlling for geographic variations in prevalence of life-limiting conditions amongst children (and other factors).

First, detailed data on supply of specialist palliative care including respite, community palliative care inputs, and other supports are needed to give a complete assessment of geographic variations in supply controlling for variations in prevalence. Second, this study examined variations in prevalence by Community Health Organisation, reflecting the way in which community-based healthcare was organised in 2019. Secure access to more detailed geographic data within national hospital data is needed to examine variation in prevalence across the newly established Health Regions.

Population-level need for specialist children's palliative care

Not every child with a life-limiting condition will need specialist palliative care. Ideally, when assessing population-level need for children's palliative care using national-level datasets, need is estimated by combining information on diagnosis with information on complexity of need. In other words, population-level planning ideally estimates, from national level data, how many children with life-limiting diagnoses have additional indicators of medical complexity which together would suggest need for specialist palliative care.

More information on medical complexity needs to be collected in national routine administrative healthcare data in Ireland. Evidence from this study[29] suggests a set of core medical complexity indicators that should be considered.

Who is receiving specialist children's palliative care?

Available analysis focuses on the number of children with specified life-limiting conditions. Analysis of the characteristics of children who have used specialist palliative care in Ireland would supplement this information, capturing cases where palliative care needs occur in the absence of a recognised/listed life-limiting diagnosis and variation in delivery of specialist palliative care to children nationally.

A purpose-built patient-level register of children using specialist palliative care in Ireland would provide valuable information on service use, population need and longitudinal data.

Further development of the palliative care flag within the HIPE dataset is also required to capture specialist children's palliative input in acute care settings. It is important to develop awareness amongst paediatric clinicians on how to document specialist palliative input on hospital charts/discharge summaries so that the flag captures data that are useful for specialist children's palliative care planning.

Factors influencing acute inpatient length of stay

Further analysis of the patterns of length of stay and the reasons behind very long lengths of stay is needed. It is important to examine potential delayed discharges and identify where bottlenecks may be occurring both within the acute system (e.g., lack of coordination between teams, waiting times for specialist reviews), and outside of the system (e.g., delays to establishing links with step-down supports and clinical multidisciplinary teams in the community).

Introducing a unique health identifier into the national HIPE dataset would allow analysis of patient hospital use over time, and of hospital re-admissions, linkage to death records etc. to gain a richer understanding of patterns of acute hospital use allowing more targeted responses to address challenges identified.

Lived experiences of families using acute care

It is important to supplement the learnings from the quantitative analysis of public acute hospital data with qualitative investigation of lived experiences of children with life-limiting conditions and their families navigating Irish healthcare. Understanding the full impact (e.g., financial, psychological, etc.) on families of attending for lengthy hospital stays, or for day case visits far from home etc. can better inform the process of finding appropriate solutions to identified challenges.

Pandemic effects

During the Covid-19 pandemic, hospital activity amongst discharges aged 0-19 dropped by 24.5% overall in 2020 but the drop was much greater for discharges without a life-limiting condition. Further investigation of the patterns of hospital activity during 2020 and in the post-pandemic period is important to understand the extent to which care was protected for patients with life-limiting conditions.

3.3 What this means for Irish healthcare policymakers and providers

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 including specialist palliative care use by children,
- dataset linkage to examine health system integration (e.g., acute and community care linkage), longitudinal behaviours (e.g., transition from paediatric to adult services) and outcomes (e.g., linkage with death records, changing survival patterns).

Conclusions

The prevalence of life-limiting conditions amongst children in Ireland was estimated to lie between 5,968 and 7,951 children aged 0–19 (using 2019 data) and national policy on children's palliative care needs to be updated accordingly.

Collectively, acute public hospital discharges with a life-limiting diagnoses aged 0–19, who represent less than 1% of the total population in that age group, accounted for just under 8% of total inpatient discharges and 24% of day cases within one year (using 2019 data).

These discharges have complex needs and use high levels of hospital resources, accounting for almost 20% of total bed days in this age group. Together the findings highlight important lessons for children's palliative care policy and provision as well as wider paediatric care, training and education to support these children and their families.

Improvements in healthcare data systems are required to further advance the evidence that feeds into children's palliative care policy and development.

Appendix 1

Detailed methods

A1.1 Prevalence estimation

Datasets used

- National public acute hospital inpatient discharge records from the Hospital In-Patient Enquiry (HIPE) dataset.[16]
- Population data from the Central Statistics Office.[23]
- List of life-limiting conditions developed by Lorna Fraser and colleagues.[17] The life-limiting diagnoses are coded using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD10).[30] For application in HIPE, where clinical data are coded using ICD10AM (Australian modification), the list of ICD10 codes was converted to ICD10AM using a mapping tool.[31,32]

Study population

The following discharges in HIPE were included for prevalence estimation:

- Living in Ireland (i.e., excluding visitors on holiday)
- Life-limiting diagnosis (in any of 30 diagnostic fields)
- Inpatients (same day or overnight)
- Year 2019 (for main analysis)
- Aged 0–19 (For this analysis, the term 'children' included infants, children and adolescents aged 0–19. Although the formal cut-off age for treatment of children in paediatrics in Ireland is 16,[2] in practice some adolescents aged 16+ continue to be treated by paediatric services.[33-35])

Methods

We followed standard methods for estimating hospital-based prevalence of life-limiting conditions amongst children, adapting them for use with Irish national hospital data.

Standard hospital-based prevalence has been calculated as:

$$\frac{\textit{Number of children with a life-limiting condition}}{\textit{Population at risk}} \textit{ x10,000}$$

where the numerator includes children with a hospital admission in the current year and a life-limiting condition is recorded in the current or previous years.[8,17,20]

In Ireland, HIPE includes data on hospital discharges from public acute hospitals. There is no unique health identifier in the national dataset so it was only possible to count the number of discharges (i.e., not patients) that met the study population inclusion criteria.

Some patients have more than one inpatient stay in hospital within a year so the number of discharges was expected to be higher than the number of patients. To calculate prevalence, we estimated the numerator in the above equation by adjusting the number of discharges in the study population (i.e., inpatient discharges aged 0–19 with a life-limiting condition in 2019, excluding holiday visitors) for sources of double counting of patients in the data. Sources of double counting included: multiple hospital admissions within a year, hospital-hospital transfers within an episode of care. We applied three different estimation scenarios to provide low, middle, and high estimates of prevalence (E1, E2, E3).

We also undertook sensitivity analysis, adjusting the baseline estimates of prevalence for potential undercounting in the data (e.g., children in hospital in 2019 but life-limiting condition not recorded).

This report presents the baseline and adjusted estimates under the mid-range estimation scenario (E2 baseline, E2 adjusted).[36]

Analysis

Total estimated prevalence of life-limiting diagnoses amongst children aged 0–19 (per 10,000 population) in Ireland was stratified by sex, age group, and place of residence. Place of residence was categorised by Community Health Organisation. The prevalence findings were also compared with estimates from similar-income countries that used consistent data and methods (Australia, Canada, England, Wales, Scotland, Spain).

Why 2019?

Prevalence was calculated using hospital inpatient data. Hospital inpatient admissions in Ireland (and internationally) were significantly impacted by the Covid-19 pandemic. In 2020, the number of inpatient discharges aged 0–19 in HIPE dropped by 24.7% from the previous year.

Analysis of discharge activity in HIPE from 2009 to 2024 suggests that patterns of hospital activity for the 0–19 age group are still recovering to pre-pandemic levels. Thus, until data from 2025 onwards are available, it is useful to focus on prevalence estimates from the most recent pre-pandemic year available, 2019.

Population-level planning and need for palliative care

What do we mean by population-level?

The analysis in this project focused on counting the total number of children with a life-limiting condition in the country, i.e., at a population level. Population-level analysis and planning rely on definitions of life-limiting conditions that can be easily found in nationally representative datasets (e.g., national administrative hospital data, large survey data).

It is not easy to define a comprehensive list of life-limiting diagnoses that will cover every eventuality where a child's life is threatened or limited. Fraser's list of life-limiting conditions was developed from the perspective of population-level planning, capturing diagnoses and conditions that in most cases result in life-limiting circumstances and are thus broadly representative of the population with life-limiting conditions.[17] *In the clinical setting at the level of the individual, where there is a lot of information available on a given child and family, there may be cases where the child's life is limited but the scenario is not captured in the list.*

Who needs palliative care?

Counting the number of children with life-limiting diagnoses at a population-level is an internationally recognised first step towards estimating population-level need for children's palliative care.[37]

However, it is also important to note that not every child with a life-limiting condition will need specialist palliative care. To understand how many children with a life-limiting condition may need specialist palliative care requires further information on the complexity of their care needs and wider family and social circumstances. Information on complexity of care needs is challenging to capture in population-level data and researchers are increasingly turning their attention to this challenge.[20]

In our study, we examined views of healthcare professionals who were experts in the field of children's palliative care in Ireland on which indicators of medical complexity could be combined with diagnostic data to determine population-level need for children's palliative care (e.g., a life-limiting diagnosis plus a resuscitation treatment agreement form).[29] *This information can guide future data collection and estimation of need for children's palliative care.*

A1.2 Analysis of hospital activity

Datasets used

- National public acute hospital inpatient discharge records from HIPE.[16]
- Population data from the Central Statistics Office.[23]
- List of life-limiting conditions developed by Lorna Fraser and colleagues[17] and mapped to ICD10AM as outlined above.

Study population

The following discharges in HIPE were included for analysis of hospital activity:

- Living in Ireland (i.e., excluding visitors on holiday)
- Day patients & inpatients
- Years 2009–2024
- Ages 0–19

The study population was further refined to focus on inpatients only (same day or overnight). Inpatient discharges were divided into two groups: with and without a life-limiting diagnosis. A discharge was assigned to the life-limiting group if a life-limiting diagnosis[17] was recorded in at least one of the 30 diagnostic fields for that discharge.

Methods

Public acute hospital discharges aged 0–19 with and without life-limiting conditions were examined by day/inpatient status. Patterns over time were summarised using 3-year moving averages to smooth year-on-year fluctuations. For clarity, a vertical orange line in each graph highlights the beginning of the Covid-19 pandemic period (2020+).

Detailed analysis of hospital activity amongst inpatient discharges with and without a life-limiting diagnosis focused on the following characteristics:

- Demographic: age, sex
- Clinical and complexity: diagnoses, procedures, complexity of resource use, dependence on medical technology
- Hospital use: hospital location, length of stay, bed days, intensive care use.

Appendix 2

Project information

A2.1 Glossary

Term	Definition
Bed days	Total number of days spent in hospital by all inpatient discharges
Child	Ages 0-19 inclusive, for the purposes of this report
Children's Palliative Care	Care that 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 at diagnosis or recognition of a life-limiting or life-threatening condition and may be needed for a very short period of time or could extend over many years.
Day case	Patient is admitted to a hospital on an elective basis for care which does not require use of a hospital bed overnight and who is discharged as scheduled
Diagnosis Related Group (DRG)	Patients are grouped into homogenous groups which are expected to undergo similar treatment processes and incur similar levels of resource use
Gastrostomy	Procedure for inserting a feeding tube to allow for long-term nutrition, hydration, and medication delivery
Hospital In-Patient Enquiry (HIPE) scheme	National clinical and administrative data on discharges from, and deaths in, public acute hospitals in Ireland
Inpatient	Patient is admitted to a hospital, on an elective or emergency basis, for care which requires use of a hospital bed, typically for one night or longer
Length of stay	Number of days between admission date and discharge date (not including the final day)
Life-limiting	Conditions where there is no reasonable hope of cure. In this document, the term life-limiting also incorporates 'life-threatening' conditions: conditions where curative treatment may be feasible but can fail. To assist population-level analysis, lists of life-limiting (encompassing life-threatening) conditions have been developed covering a wide range of diagnoses such as malignant cancers, severe neurological impairment, organ failure, rare metabolic diseases, and others.[17,38]
Neonatal palliative care	Neonatal Palliative Care is an active and total approach to care, for a fetus, neonate or infant with life limiting conditions, from diagnosis or recognition, throughout the child's life, death and beyond.

Term	Definition
Palliative care levels[1]	Palliative care approach (Level 1): engagement in the principles of palliative care, where required, by all healthcare professionals. At this level, many patients will have their care needs met without needing to be referred for specialist palliative care. General palliative care (Level 2): intermediate level of expertise in palliative care. At this level, those providing palliative care will have additional training and expertise, engagement in palliative care is part of their caring role but does not define it. Specialist palliative care (Level 3): provided by healthcare professionals whose core activity is focused on the provision of palliative care. Caring for patients with complex and demanding palliative care needs requiring a higher level of specialist palliative care training.
Perinatal palliative care	Perinatal palliative care is defined here as multidisciplinary care for both baby and family in the event of a perinatal diagnosis of a life-limiting condition, providing optimal symptom control and end-of-life care to the baby as well as specialized support to families from diagnosis through to birth, death, and bereavement.
Respite	Care provided by appropriately trained individual(s) for a specified period of time for children with life-limiting conditions, thus providing temporary relief to their usual caregiver
Same day inpatient	Patient is admitted and discharged on the same day (allocated a length of stay of 0.5 in HIPE).
Tracheostomy	Procedure to create opening into the windpipe to facilitate breathing, either temporarily or permanently

A2.2 ECHPI Collaboration

Knowledge Users & PPI	Job Title	Institution
Joanne Balfe (Lead Knowledge User)	Consultant Paediatrician	Children's Health Ireland; School of Medicine, Trinity College Dublin; LauraLynn Ireland's Children's Hospice*
Irish Hospice Foundation	Sara Leitão, Director of Research & Policy Neil Fullerton, Research & Policy Officer	Irish Hospice Foundation
Orla Murphy	PPI Representative, & Palliative Care Nurse (Adults)	Milford Care Centre, Limerick
Maurice Dillon* (succeeded by Sean McArt)	National Lead for Palliative Care	Health Service Executive
Tyrone Horne	Clinical Nurse Co-Ordinator for Children with Life-Limiting Conditions	Cork University Hospital
All Ireland Institute of Hospice and Palliative Care	Mary Rabbitte, Research Programme Manager Busra Ertugrul, Research Support and Knowledge Translation Lead	All Ireland Institute of Hospice and Palliative Care

Knowledge Users & PPI	Job Title	Institution
Fiona McElligott	Consultant in Paediatric Palliative Medicine	Children's Health Ireland; The Rotunda Hospital, Dublin; University College Dublin
Mary Devins	Consultant in Paediatric Palliative Medicine	Children's Health Ireland; The Coombe Hospital, Dublin; School of Medicine, Trinity College Dublin
Department of Health	Paul Rowe, Principal Officer Rory Egan, Assistant Principal	Department of Health, Older Persons Strategy Unit

Researchers	Job Title	Institution
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Tara Delamere	Research Fellow	Centre for Health Policy and Management, School of Medicine, Trinity College Dublin*
Peter May	Senior Lecturer in Health Economics	Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London; Centre for Health Policy and Management, Trinity College Dublin
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Suzanne Guerin	Professor of Research Design and Analysis	School of Psychology, University College Dublin; Research at LauraLynn

Data Controllers		
Sinéad O'Hara	Senior Statistician	Healthcare Pricing Office, Health Service Executive
Cliona McGarvey	Paediatric Programme Manager	National Office of Clinical Audit

Funders	
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Notes: *Moved since project completion

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