

ECHPI

Evidence for Children's Palliative care in Ireland

How many children in Ireland have life-limiting conditions?

Estimating the prevalence of life-limiting conditions amongst children in Ireland using Irish data

Counting the number of children with life-limiting conditions is an important first step to estimating how many children might need palliative care. We provide the first estimates of prevalence of life-limiting conditions amongst children in Ireland using Irish-specific data, improving on earlier estimates based on international data. This informs decisions around policy, planning and delivery of children's palliative care in Ireland.

Key Definitions

Life-limiting conditions in children include conditions where curative treatment may be feasible but can fail (i.e., life-threatening) or where there is no reasonable hope of cure.

Children: for this analysis the term 'children' included infants, children and adolescents aged 0-19. In practice some adolescents aged 16+ continue to be treated by paediatric services even though the formal cut-off age is 16.

What Did We Do?

The Data

- National public acute hospital inpatient discharge records
- Population data
- List of life-limiting conditions from international literature
- Year 2019 (pre-Covid-19 benchmark)

The Methods

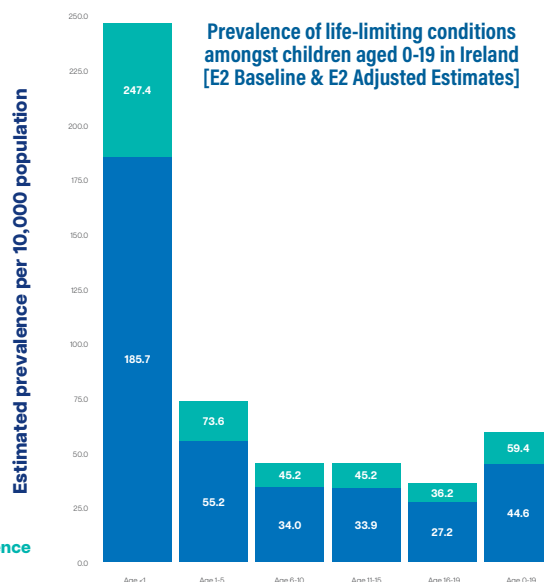
- We calculated low, middle and high estimates of the number of children in hospital with a life-limiting condition in 2019 (E1, E2, E3)
- We also adjusted the baseline estimates for undercounting in the data (E1adj, E2adj, E3adj)
- Prevalence calculated as:

$$\frac{\text{Estimated number of hospital inpatients aged 0-19 with a life-limiting condition in 2019}}{\text{Population aged 0-19}} \times 10,000$$

What We Found

- 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 population (at baseline) to 59.4 per 10,000 population (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.

● Baseline prevalence ● Adjusted prevalence



What This Means

- The likely number of children with life-limiting conditions in Ireland is much higher than outlined in the outdated 2009 national children's palliative care policy and should be updated.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.

What More Do We Need To Know

More information is needed on:

- Any children who were in a stable phase of a life-limiting condition and didn't have a hospital admission in 2019.
- Trends in prevalence over time to project future prevalence, requiring a unique health identifier in national hospital data to be able to count, rather than estimate, the number of patients in hospital.
- Detailed national profile of specialist palliative care supply (respite, community and hospital-based palliative care inputs, etc.) to compare geographic variations in both palliative care supply and prevalence of life-limiting conditions amongst children.
- Indicators of care complexity within national hospital data to combine with diagnostic information to determine how many children will need specialist palliative care (because not every child with a life-limiting condition will need specialist palliative care).

Who's Involved?



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



This project was funded by the Health Research Board [APA-2022-003], co-funded by the Irish Hospice Foundation and LauraLynn Ireland's Children's Hospice.

If you would like to find out more about the overall ECHPI Project, scan the QR code or visit the ECHPI webpage:

<https://palliativehubresearch.com/research-updates/palliative-care-research-projects/childrens-palliative-care/>

