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Estimating national prevalence of life-limiting conditions amongst infants, children, and adolescents using administrative hospital data in the absence of a unique health identifier; evidence from Ireland

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Abstract

Background Estimating the total number of children with a life-limiting, complex chronic condition or serious illness has been identified as an important first step in determining how many children might need palliative care in a country or region. Relevant estimates have not been calculated for Ireland, an exercise complicated by the country's lack of a fully operational unique patient identifier in healthcare data.

Methods This study estimated prevalence of life-limiting conditions amongst children aged 0–19 in Ireland in 2019 and 2024, demonstrating methods in the absence of a unique identifier. Baseline hospital-based prevalence calculated as (estimated) number of inpatients with a life-limiting diagnoses per 10,000 population aged 0–19 in Ireland, 2019 (pre-Covid) and 2024 (most recent year available). Number of inpatients were estimated from discharge-level data under 3 alternative scenarios (E1, E2, E3) adjusting for multiple admissions in the data. In sensitivity analysis, adjusted prevalence estimates further corrected for sources of under-counting in the data.

Results Baseline estimated total prevalence of life-limiting conditions amongst children aged 0–19 in Ireland between 34.8 (E3) and 50.0 (E1) per 10,000 population in 2019; between 32.3 (E3) and 44.5 (E1) per 10,000 population in 2024. In sensitivity analysis, correcting for potential under-counting in the data, adjusted estimated prevalence: between 46.4 (E3) and 66.6 (E1) per 10,000 population in 2019; and between 43.0 (E3) and 59.3 (E1) per 10,000 population in 2024. Prevalence was higher for males than for females, and highest in the age group < 1 for all estimation scenarios.

Conclusions These are the first estimates of prevalence of life-limiting conditions amongst children in Ireland that have been calculated using Irish-specific hospital data. The estimates are in line with prevalence from other similar-income countries based on studies using similar definitions and methodologies. The findings demonstrate

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how careful application of transparent methods to routinely collected administrative hospital activity data can yield important findings even in the context of data limitations.

Keywords Prevalence, Life-limiting, Life-threatening, Palliative, Children, Ireland

Background

Children's palliative care focuses on enhancing quality of life for children with life-limiting conditions and their families, including management of distressing symptoms, providing short breaks, and care through death and bereavement [1]. Children's palliative care (CPC) ideally begins at diagnosis or recognition of a life-limiting/life-threatening condition and may be needed for a very short period of time or could extend over many year [2].

Up-to-date and accurate information on how many children might need palliative care informs decision-making in planning for and delivering palliative care services to the right people in the right places and at the right times.

Defining and quantifying who needs children's palliative care at a population level is challenging because of the diversity of diagnostic, social and family factors that can determine eligibility for palliative care. In the clinical setting, healthcare professionals have access to a wide range of information about the child and their family that inform a palliative care referral decision for that particular child. In contrast, healthcare planning typically relies on a much narrower range of indicators (e.g., demographic, diagnostic) from available administrative data (e.g., mortality, healthcare utilisation data) to estimate who needs palliative care at a national or population level.

While there is no universally agreed definition of population-level need for CPC, there is broad consensus in the literature that need is determined by a combination of diagnostic plus care complexity indicators [3]. In a growing number of studies, the total number of children with a life-limiting or complex chronic condition or serious illness has been estimated as an important first step in determining how many children might need palliative care in a country or region [4–7]. A small number of studies have examined complexity of care needs to further help identify population-level palliative care needs in children [8–10] but challenges persist in selecting and accessing relevant data.

In Ireland, existing estimates of prevalence of life-limiting conditions amongst children have relied on extrapolation from international research rather than use of Irish-specific data.

Aim and rationale

The aim of this paper was to provide a first estimate of prevalence of life-limiting conditions amongst infants, children, and adolescents in Ireland using data specific to the population of the country. We estimated the prevalence of life-limiting conditions amongst the 0–19 age group in Ireland in 2019 and 2024 using Irish public acute hospital administrative data in order to inform policy, planning and delivery of CPC. Additionally, we contributed to international literature on paediatric life-limiting prevalence estimation by demonstrating methods for addressing limitations in population-level healthcare utilisation data, namely the absence of a unique health identifier.

The paper adheres to the RECORD [11] guidelines for studies conducted using observational routinely-collected health data. Life-limiting conditions include life-threatening (where curative treatment may be feasible but can fail) and life-limiting (where there is no reasonable hope of cure) conditions [1], hereafter called life-limiting.

Methodology

Setting

Ireland has a population of 5.46 million people, of which 19.0% are aged 0–19 [12]. CPC is delivered through hospital-based specialist tertiary CPC teams, community specialist palliative care teams (mainly adult-focused but with some paediatric caseload), general practice, clinical nurse co-ordinators for children with life-limiting conditions in the community, and specialist hospice care. However, there is no national register of children (and families) with life-limiting conditions or who are receiving palliative care [13–15]. National CPC planning has relied on life-limiting prevalence estimates based on data from the UK [16]. There have been concerns about delayed referrals to CPC and unequal access to services [17, 18].

Acute hospital inpatient care for infants and children in Ireland is provided primarily in public hospitals (i.e., paediatric units within public acute hospitals, public paediatric hospitals, public maternity hospitals) [14, 19].

Data

The national Hospital In-Patient Enquiry (HIPE) collects data on patients discharged (including deaths) from public acute hospitals in Ireland [20]. Individual-level (anonymised) demographic, administrative, and diagnostic (max 30 diagnoses per discharge) information was extracted for all discharges aged 0–19 for the years 2009–2024 for this analysis, obtained from the Healthcare Pricing Office, Health Service Executive [21].

National population data by age, sex and county were available from the Central Statistics Office [12].

Study population

To contextualise prevalence estimation, descriptive analysis of key characteristics of discharges with life-limiting conditions in public acute hospitals was undertaken for the full time period 2009 to 2024.

Prevalence estimation was conducted on the most recent data available (2024), and for comparison, the year preceding the Covid 19 pandemic (2019).

Discharges were included for prevalence analysis if:

- aged 0–19.
- living in Ireland (i.e., excluding visitors on holiday).
- had a life-limiting diagnosis (in any of the 30 diagnostic fields) from a pre-established list of diagnoses coded in ICD 10 (10th Revision of the International Statistical Classification of Diseases and Related Health Problems) [22].
- inpatients (same day or overnight).
- within the years 2019 or 2024.

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 [14], in practice some adolescents aged 16 + continue to be treated by paediatric services [23–25].

The list of life-limiting diagnoses was adopted from Fraser et al. [26] For application within HIPE, where clinical data are coded using ICD10AM (Australian Modification), the list of ICD10 codes was converted to ICD10AM using a mapping tool [27, 28]. Consistent with established methods [5], no attempt was made to prioritise multiple diagnoses and any discharge could have more than one life-limiting diagnosis.

Modified prevalence methods

Standard methods for prevalence estimation of life-limiting conditions amongst children applied by Fraser et al. [5, 8] calculated hospital-based prevalence as:

$$\frac{\text{Number of children with a life limiting condition}}{\text{Population at risk}} \times 10,000$$

where the numerator included children with a hospital admission in the current year and a life-limiting condition recorded in the current or previous years [5, 8].

In the absence of a unique health identifier in HIPE data, we were unable to count the number of children with a life-limiting condition in hospital in any year. Instead, we estimated the numerator in the above equation by adjusting the observed study population (i.e., number of inpatient discharges aged 0–19 with a life-limiting diagnosis) for sources of double counting of patients in the data (e.g., multiple admissions, transfers), under three alternative estimation scenarios.

The 3 alternative estimation scenarios were as follows:

E1: Correction for double counting of care episodes.

In HIPE, hospital-to-hospital transfers are counted as separate discharges even though they refer to the same episode of inpatient care (e.g., a child admitted to a regional hospital subsequently transferred to a tertiary national referral hospital for further care). The initial admission and the subsequent transferred admission are recorded as two separate discharges. E1 excluded from the study population any discharges where the discharge destination involved a 'transfer out' to other hospitals.

E2: Correction for multiple admissions 1.

E2 adopted the number of discharges in E1 and made further adjustment for double counting of children by correcting for estimated multiple hospital admissions in each year using Irish data. Limited available Irish data suggest that 12% of adult discharges are hospital re-admissions [29, 30] and case study evidence suggests a mean number of < 2 readmissions within 12 months amongst a cohort of children with chronic illness [31]. In the absence of paediatric-specific data on hospital re-admissions in Ireland, E2 adjusted the number of discharges in E1 downwards as follows: 12% of discharges were estimated to have 2 admissions in a year.

E3: Correction for multiple admissions 2.

E3 adopted the number of discharges in E1 and corrected for multiple admissions in each year using international data. Co-morbidities or complex chronic conditions are consistently cited as key factors associated with paediatric hospital readmissions [32–36]. E3 adjusted the number of discharges in E1 downwards as follows: any discharges with 2/more chronic conditions [37] were estimated to have 2 admissions in a year.

Analysis

Descriptive characteristics

Baseline demographic characteristics and discharge patterns over time for discharges aged 0–19 with life-limiting conditions were examined between 2009 and 2024.

Baseline prevalence

Prevalence of life-limiting diagnoses amongst children aged 0–19 per 10,000 population at risk was calculated for 2019 and 2024 using each of the three alternative estimated numerators (E1, E2, E3).

Total prevalence (for all ages 0–19) was stratified by sex, age group, location of residence categorised by Community Health Organisation, and diagnostic group (ICD10 chapter headings).

International comparisons

Baseline estimates of prevalence of life-limiting conditions amongst children aged 0–19 in Ireland were compared with international estimates. Comparison studies were selected for consistency in underlying definitions, data and methods as follows:

- Definition: life-limiting conditions defined using Fraser et al. list or related list (e.g., Directory of life-limiting conditions) [8, 26, 38].
- Data & methods: used hospital data as core data source to estimate prevalence (e.g., not incidence estimates based on mortality only data).
- Year of data comparable with the Irish estimates.

Studies were selected from a recent scoping review of the literature on defining and quantifying need for children's palliative care [3] and studies (in English) identified after the review period [39–41].

Sensitivity analysis

In our analysis, we could only count discharges who had an inpatient hospital admission in the current year, and a life-limiting diagnosis recorded during that admission. This contrasts with recent UK analysis by Fraser et al. [5, 8, 42] counting any children with a hospital admission in the current year where their life-limiting diagnosis was recorded either during that admission, or during an earlier year.

Prevalence estimates of the number of children with life-limiting conditions are available for England with and without these 'additional' children, i.e., in hospital in current year, life-limiting diagnosis recorded in earlier year, for the years 2001–2010 [5, 26]. Prevalence increased by between 12.2% and 48.5% in England when these additional children were included, with an average increase of 33.2%. [See supplementary Table S1.]

In sensitivity analysis, we adjusted the E1, E2, and E3 estimates of the number of inpatient children with life-limiting conditions upwards by 12.2% (low uplift), 33.2% (average uplift), and 48.5% (high uplift) and re-calculated prevalence.

All analyses were performed in Stata/MP v. 18.0, tables generated in MS Excel v.2502.

Results

Descriptive characteristics

Table 1 describes demographic characteristics of discharges aged 0–19 with a life-limiting condition between 2009 and 2024. Discharges with a life-limiting diagnosis accounted for 7.7% of all inpatient discharges in public acute hospitals in Ireland 2009–2024.

Before Covid (2009–2019), total inpatient discharges aged 0–19 with a life-limiting condition fell by 7.0% overall. The age profile changed over time, with a decrease in younger discharges (particularly 4 weeks–5 years) and an increase in pre-adolescent (6–15 years) discharges with a life-limiting diagnosis. By 2019, before Covid, discharges aged 6–15 had increased from 30.9% to 38.1% of discharges aged 0–19. A higher proportion of the discharges were male in all years of analysis (ranging from 52.2% to 56.9%).

Consistent with other age groups, inpatient discharges aged 0–19 with a life-limiting condition fell by 18.1% between 2019 and 2020 with the onset of the Covid-19 pandemic and have been recovering an upward trend since then [43].

Baseline prevalence estimation - total

The total number of inpatient discharges meeting the eligibility criteria in 2019 and 2024 was 14,088 discharges (see flowchart in Fig. 1).

Figure 2 illustrates application of the methods under the three alternative estimation scenarios (E1, E2, E3) to discharges in 2019 to estimate the number of inpatient children with life-limiting conditions in that year. From a total of 7,361 discharges aged 0–19 in 2019 with a life-limiting diagnosis, 677 transfers to other hospitals were excluded under E1 (E1: 6,684 patients). Adjustment for multiple admissions using Irish-specific data (E2) lowered the estimated number of patients to 5,968. Adjustment for multiple admissions using international literature on factors associated with paediatric readmissions (E3) lowered the estimated number of patients to 4,656.

Table 2 presents the baseline estimate of the number of children with life-limiting conditions aged 0–19 in Ireland in 2019 and 2024, and estimated prevalence per 10,000 population by estimation method and age group.

Baseline estimated total prevalence of life-limiting conditions amongst children aged 0–19 in Ireland in 2019 ranged from 34.8 (E3), to 44.6 (E2), to 50.0 (E1) per 10,000 population. In 2024, baseline estimated total prevalence of life-limiting conditions amongst children aged 0–19 in Ireland ranged from 32.3 (E3), to 39.7 (E2), to 44.5 (E1) per 10,000 population.

Baseline prevalence estimation - stratified

Stratification of baseline estimated prevalence of life-limiting conditions amongst children aged 0–19 in Ireland by age, sex, disease group and location of residence follow similar patterns for all three estimation scenarios. For ease of presentation, the findings in this section are based on the E2 estimation scenario (E1 and E3 findings available upon request).

Total baseline estimated prevalence of life-limiting conditions amongst individuals aged 0–19 was 44.6 in 2019 and 39.7 in 2024 (E2, Fig. 3a).

Table 1 Number and percentages of discharges aged 0–19 with a life-limiting diagnosis in public acute hospitals, Ireland, 2009–2024, by age & sex

	Year																% change		
	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2009–2019	2019–2020	2020–2024
TOTAL DISCHARGES (with and without LLCs)																			
with LLC	7,914	7,975	8,258	8,289	8,028	8,153	8,171	8,131	7,997	7,705	7,361	6,029	6,296	6,584	6,612	6,727	−7.0	−18.1	11.6
without LLC	96,600	94,004	96,279	100,473	95,481	96,624	96,171	95,982	90,784	90,948	89,164	66,658	73,417	84,675	82,787	89,481	−7.7	−25.2	34.2
Total number	104,514	101,979	104,537	108,762	103,509	104,777	104,342	104,113	98,781	98,653	96,525	72,687	79,713	91,259	89,399	96,208	−7.6	−24.7	32.4
LLCs as % of total	7.6	7.8	7.9	7.6	7.8	7.8	7.8	7.8	8.1	7.8	7.6	8.3	7.9	7.2	7.4	7.0			
AGE GROUP (LLC discharges)																			
Number																			
0–3 weeks	886	977	977	940	974	994	969	895	927	875	886	887	890	812	833	829	0.0	0.1	−6.5
4 weeks-<1 yr	1,009	1,074	1,090	1,084	948	994	913	885	813	883	743	676	721	727	696	780	−26.4	−9.0	15.4
1–5 yrs	2,672	2,669	2,547	2,737	2,779	2,702	2,723	2,642	2,458	2,123	2,108	1,722	1,702	1,842	1,954	1,962	−21.1	−18.3	13.9
6–10 yrs	1,181	1,179	1,498	1,448	1,362	1,510	1,353	1,450	1,526	1,566	1,431	1,002	1,071	1,100	1,169	1,210	21.2	−30.0	20.8
11–15 yrs	1,268	1,286	1,301	1,282	1,270	1,218	1,345	1,239	1,355	1,473	1,377	1,088	1,206	1,349	1,188	1,225	8.6	−21.0	12.6
16–19 yrs	898	790	845	798	695	735	868	1,020	918	785	816	654	706	754	772	721	−9.1	−19.9	10.2
Total	7,914	7,975	8,258	8,289	8,028	8,153	8,171	8,131	7,997	7,705	7,361	6,029	6,296	6,584	6,612	6,727	−7.0	−18.1	11.6
Percentage																			
0–3 weeks	11.2	12.3	11.8	11.3	12.1	12.2	11.9	11.0	11.6	11.4	12.0	14.7	14.1	12.3	12.6	12.3	7.5	22.2	−16.2
4 weeks-<1 yr	12.7	13.5	13.2	13.1	11.8	12.2	11.2	10.9	10.2	11.5	10.1	11.2	11.5	11.0	10.5	11.6	−20.8	11.1	3.4
1–5 yrs	33.8	33.5	30.8	33.0	34.6	33.1	33.3	32.5	30.7	27.6	28.6	28.6	27.0	28.0	29.6	29.2	−15.2	−0.3	2.1
6–10 yrs	14.9	14.8	18.1	17.5	17.0	18.5	16.6	17.8	19.1	20.3	19.4	16.6	17.0	16.7	17.7	18.0	30.3	−14.5	8.2
11–15 yrs	16.0	16.1	15.8	15.5	15.8	14.9	16.5	15.2	16.9	19.1	18.7	18.0	19.2	20.5	18.0	18.2	16.8	−3.5	0.9
16–19 yrs	11.3	9.9	10.2	9.6	8.7	9.0	10.6	12.5	11.5	10.2	11.1	10.8	11.2	11.5	11.7	10.7	−2.3	−2.1	−1.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0			
SEX (LLC discharges)																			
Number																			
Females	3,572	3,512	3,776	3,895	3,740	3,897	3,812	3,838	3,685	3,354	3,341	2,770	2,887	2,906	2,968	2,897	−6.5	−17.1	4.6
Males	4,337	4,460	4,480	4,390	4,284	4,250	4,351	4,290	4,309	4,344	4,016	3,252	3,405	3,678	3,641	3,827	−7.4	−19.0	17.7
Percentage																			
Females	45.2	44.1	45.7	47.0	46.6	47.8	46.7	47.2	46.1	43.6	45.4	46.0	45.9	44.1	44.9	43.1	0.6	1.3	−6.3
Males	54.8	55.9	54.3	53.0	53.4	52.2	53.3	52.8	53.9	56.4	54.6	54.0	54.1	55.9	55.1	56.9	−0.5	−1.1	5.4

Source: Hospital In-Patient Enquiry, Healthcare Pricing Office

Excludes 7,797 visitors on holiday; *LLCs* Life-limiting conditions; Life-limiting conditions defined as per Fraser et al. 2012

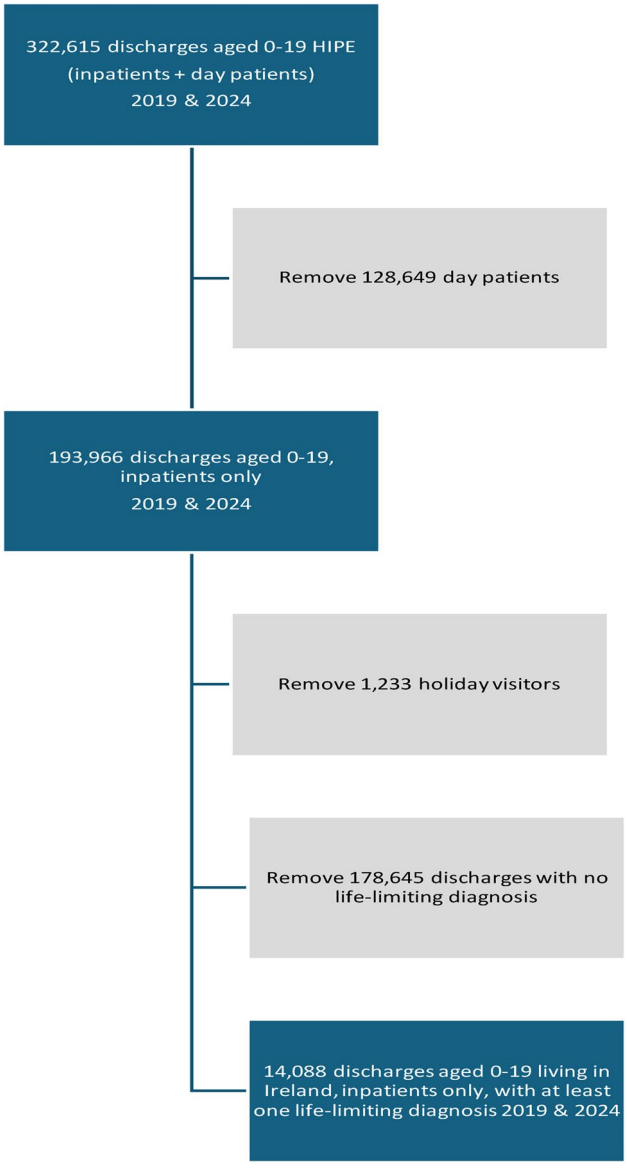

Fig. 1 Study population flowchart

In 2019, baseline estimated prevalence of life-limiting conditions was highest amongst infants aged < 1 year at 185.7 per 10,000 population, followed by 55.2 for ages 1–5, 34.0 for ages 6–10, 33.9 for ages 11–15, and 27.2 per 10,000 for ages 16–19 (Fig. 3a).

The age profile of baseline estimated prevalence followed a similar pattern in 2024, highest for ages < 1 year (201.7 per 10,000, Fig. 3a).

Baseline estimated prevalence was higher amongst males than amongst females aged 0–19 in 2019 (47.6 vs. 41.5 per 10,000) and 2024 (44.2 vs. 35.0 per 10,000) (Fig. 3b).

In both 2019 and 2024, baseline estimated prevalence per 10,000 was highest for children with neoplasm (E2 2019: 15.9) and congenital/chromosomal life-limiting conditions (E2 2019: 12.9), followed by blood/blood forming life-limiting conditions (E2 2019: 5.1), endocrine/nutritional/metabolic (E2 2019: 4.8), nervous system (E2 2019: 4.5), genitourinary (E2 2019: 2.7) and perinatal life-limiting conditions (E2 2019: 2.4) and others (see Fig. 4).

Baseline estimated prevalence of life-limiting conditions amongst children aged 0–19 varied by location of residence, categorised by Community Health Organisation (CHO), ranging from 35.7 per 10,000 in CHO 3 to 66.2 per 10,000 in CHO 9 in 2019, and from 31.0 per 10,000 in CHO 8 to 57.4 per 10,000 in CHO 9 in 2024 (Fig. 5). In both years, all but one CHO were either within 5%, or below, national average prevalence.

Sensitivity analysis

Focusing on the 'average uplift' scenario, adjusted estimated total prevalence of life-limiting conditions amongst children aged 0–19 in Ireland was between 46.4 (E3), 59.4 (E2) and 66.6 (E1) per 10,000 population in 2019; and between 43.0 (E3), 52.9 (E2) and 59.3 (E1) per 10,000 population in 2024. Sensitivity results for the low and high uplift scenarios are presented in Supplementary Table S2.

International comparisons

Figure 6 presents Irish estimated total prevalence of life-limiting conditions amongst children aged 0–19 (baseline and adjusted) alongside selected international estimates [3, 5, 8, 29–31, 39–41, 44, 45].

The E3 baseline estimate for Ireland was the lowest in the comparator group and somewhat of a low outlier. The E2 and E1 baseline estimates for Ireland were in line with estimates for Queensland, Scotland (inpatient only) and Castilla y León in Spain ranging from 43.2 (Queensland), 44.6 (Ireland E2), 45.0 (Scotland), 50.0 (Ireland E1) to 51.3 per 10,000 (Spain) for 2019 (or years close to 2019). All of these estimates were based on hospital inpatient/admissions data (Queensland: includes a small number of deaths).

Adjusted prevalence estimates, under the 'average uplift' scenario (E2 and E1) for Ireland (59.4 and 66.6) were in line with Wales (58.0), England (66.4) and to a lesser extent (73.1) British Columbia (Canada), also all based on hospital inpatient data. Prevalence was greater than > 80 per 10,000 in studies that calculated prevalence using hospital inpatient/admissions plus outpatient, emergency or prescriptions data (Taiwan, 81.0; South Korea, 95.5; Scotland, 130.0).

Discussion

Baseline estimates of hospital-based prevalence of life-limiting conditions amongst children aged 0–19 in Ireland were between 34.8 and 50.0 per 10,000 in 2019 and

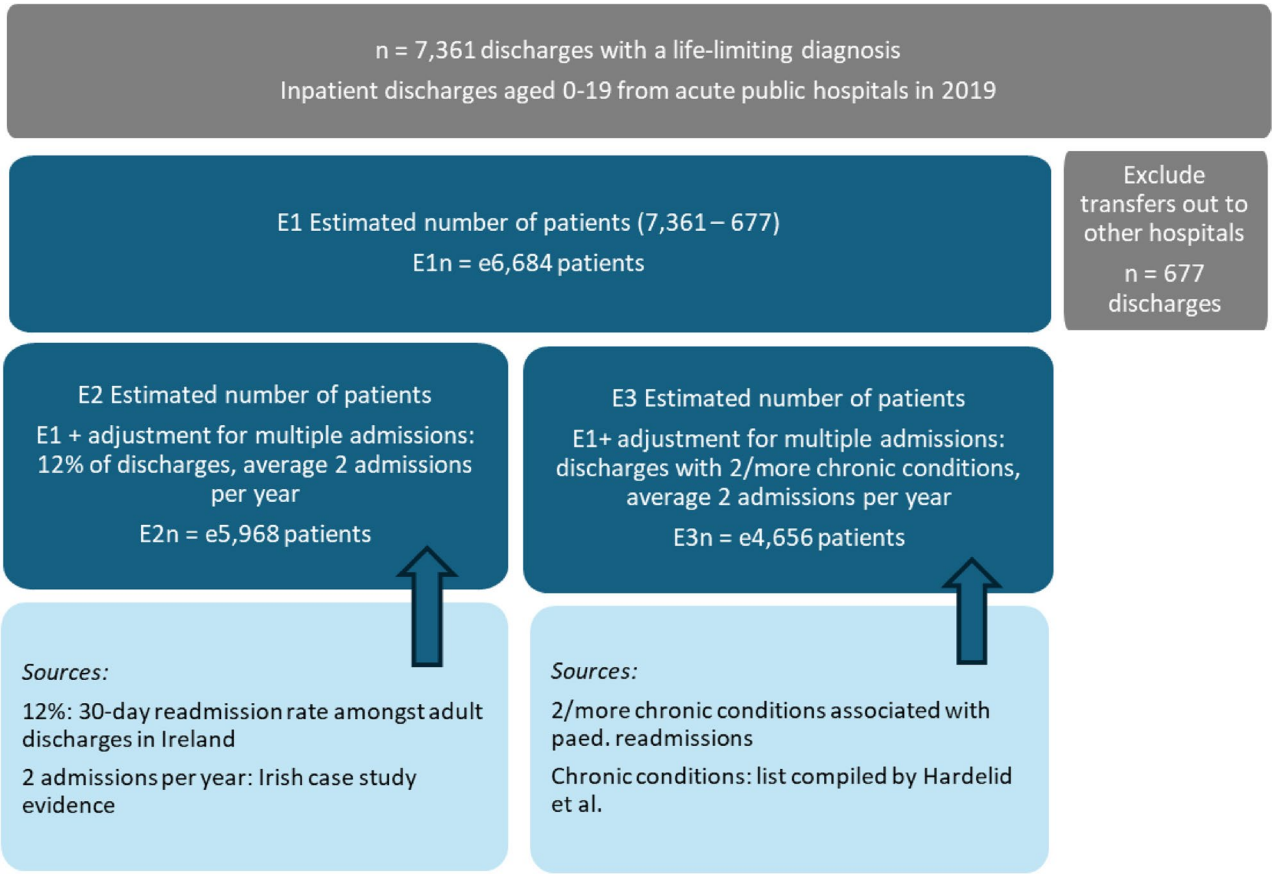

Fig. 2 Alternative scenarios for estimating number of inpatient children in acute public hospitals with a life-limiting condition in Ireland in 2019

Table 2 Baseline estimated prevalence of life-limiting conditions amongst children aged 0–19 in Ireland, 2019 & 2024, by estimation scenario (E1, E2, E3) and age group

	E1		E2		E3	
	No. of patients with LLCs	**Prev**	**No. of patients with LLCs**	**Prev**	**No. of patients with LLCs**	**Prev**
2019						
Age ≤ 1	1,256	207.9	1,121	185.7	873	144.4
1–5 years	1,993	61.9	1,779	55.2	1,412	43.8
6–10 years	1,375	38.0	1,228	34.0	964	26.6
11–15 years	1,279	38.0	1,142	33.9	890	26.4
16–19 years	781	30.4	697	27.2	518	20.2
Total 0–19 years	6,684	50.0	5,968	44.6	4,656	34.8
2024						
Age ≤ 1	1,253	226.0	1,119	201.7	873	157.4
1–5 years	1,846	61.4	1,648	54.8	1,365	45.4
6–10 years	1,158	33.5	1,034	29.9	858	24.8
11–15 years	1,150	29.9	1,027	26.7	815	21.2
16–19 years	687	24.3	613	21.7	510	18.0
Total 0–19 years	6,094	44.5	5,441	39.7	4,420	32.3

Source: Hospital In-Patient Enquiry, Healthcare Pricing Office

Excludes 1,233 visitors on holiday; LLCs = Life-limiting conditions; Life-limiting conditions defined as per Fraser et al. 2012

HIPE adopts revised editions of ICD10AM/ACHI/ACS every 4–5 years: 6th edition was used from 1 st Jan 2009–31st Dec 2014; 8th edition was used from 1 st Jan 2015–31st Dec 2019; 10th edition was used from 1 st Jan 2020–31st Dec 2023; 12th edition was adopted 1 st January 2024

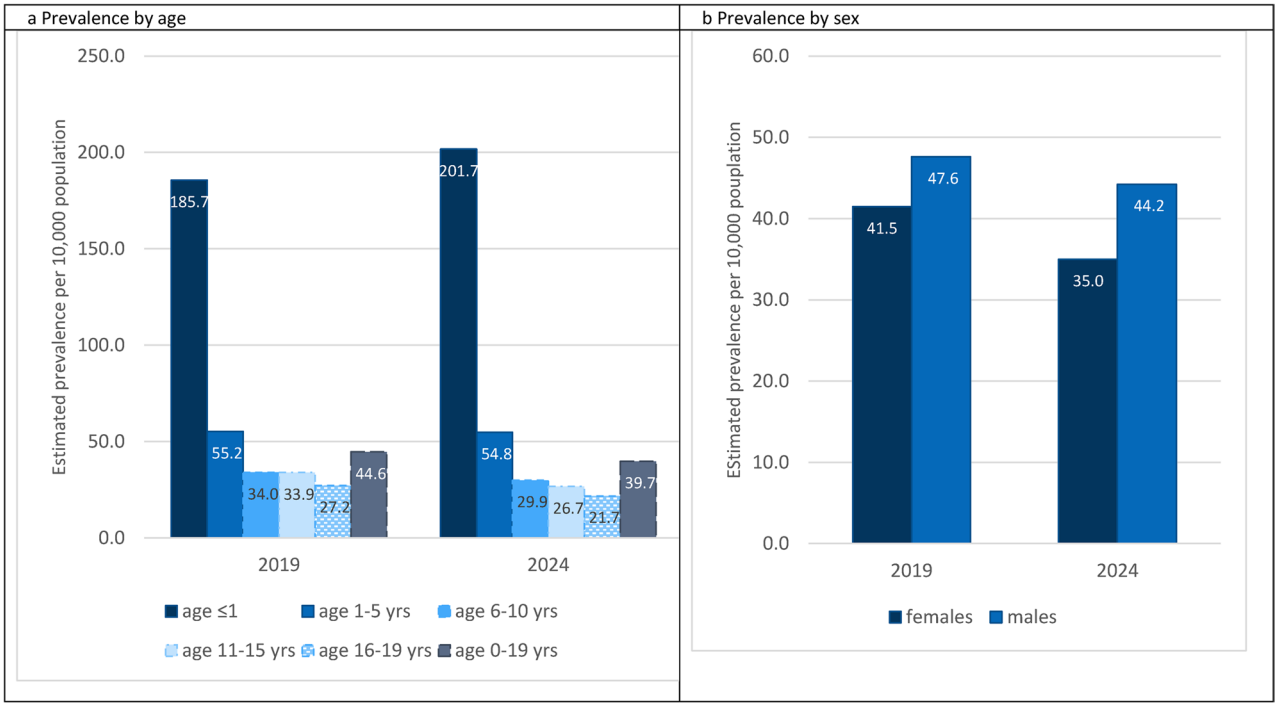

Fig. 3 Baseline estimated prevalence of life-limiting conditions amongst children aged 0–19 in Ireland, 2019 and 2024, by age and sex [E2 estimation scenario]
Source: Authors' analysis of discharge-level HIPE data from Healthcare Pricing Office, Health Service Executive

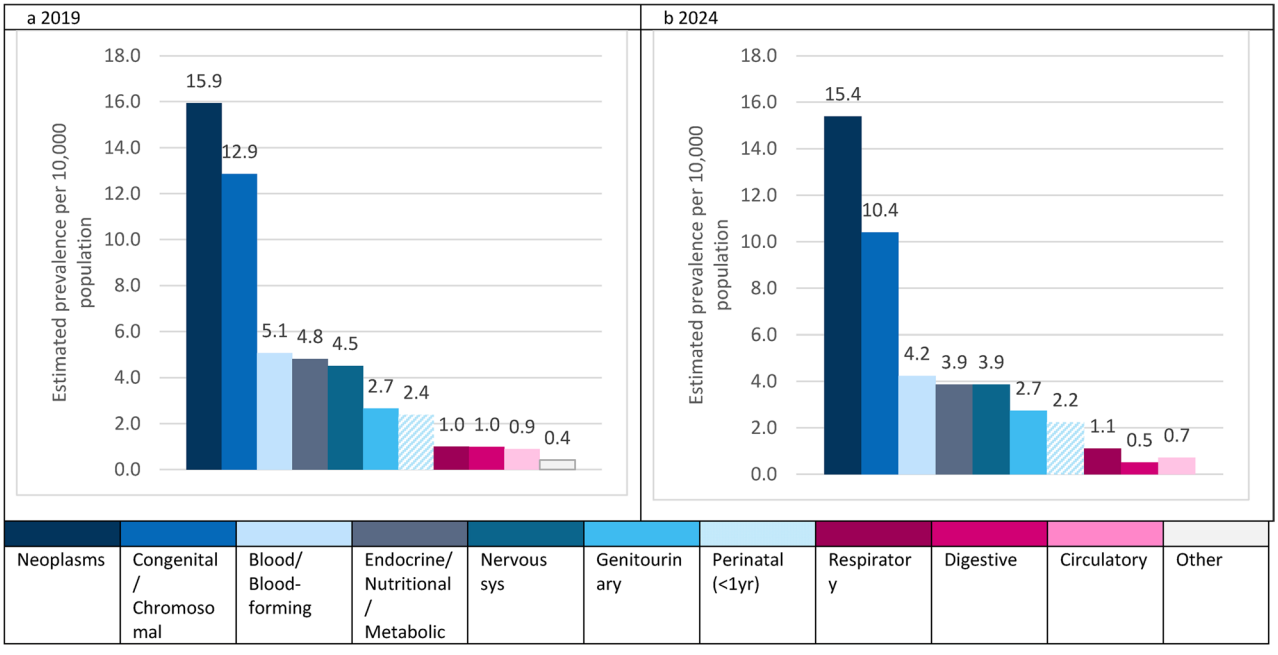

Fig. 4 Baseline estimated prevalence of life-limiting conditions amongst children aged 0–19 in Ireland, 2019 and 2024, by ICD10 chapter [E2 estimation scenario]
Source: Authors' analysis of discharge-level HIPE data from Healthcare Pricing Office, Health Service Executive

between 32.3 and 44.5 per 10,000 population in 2024 using alternative estimation methods. Correcting for potential under-counting in the data, adjusted estimated prevalence under sensitivity analysis was between 46.4 and 66.6 per 10,000 in 2019 and between 43.0 and 59.0 per 10,000 in 2024 ('average uplift' scenario).

These estimates equated to there being approximately 4,656–6,684 children aged 0–19 at baseline

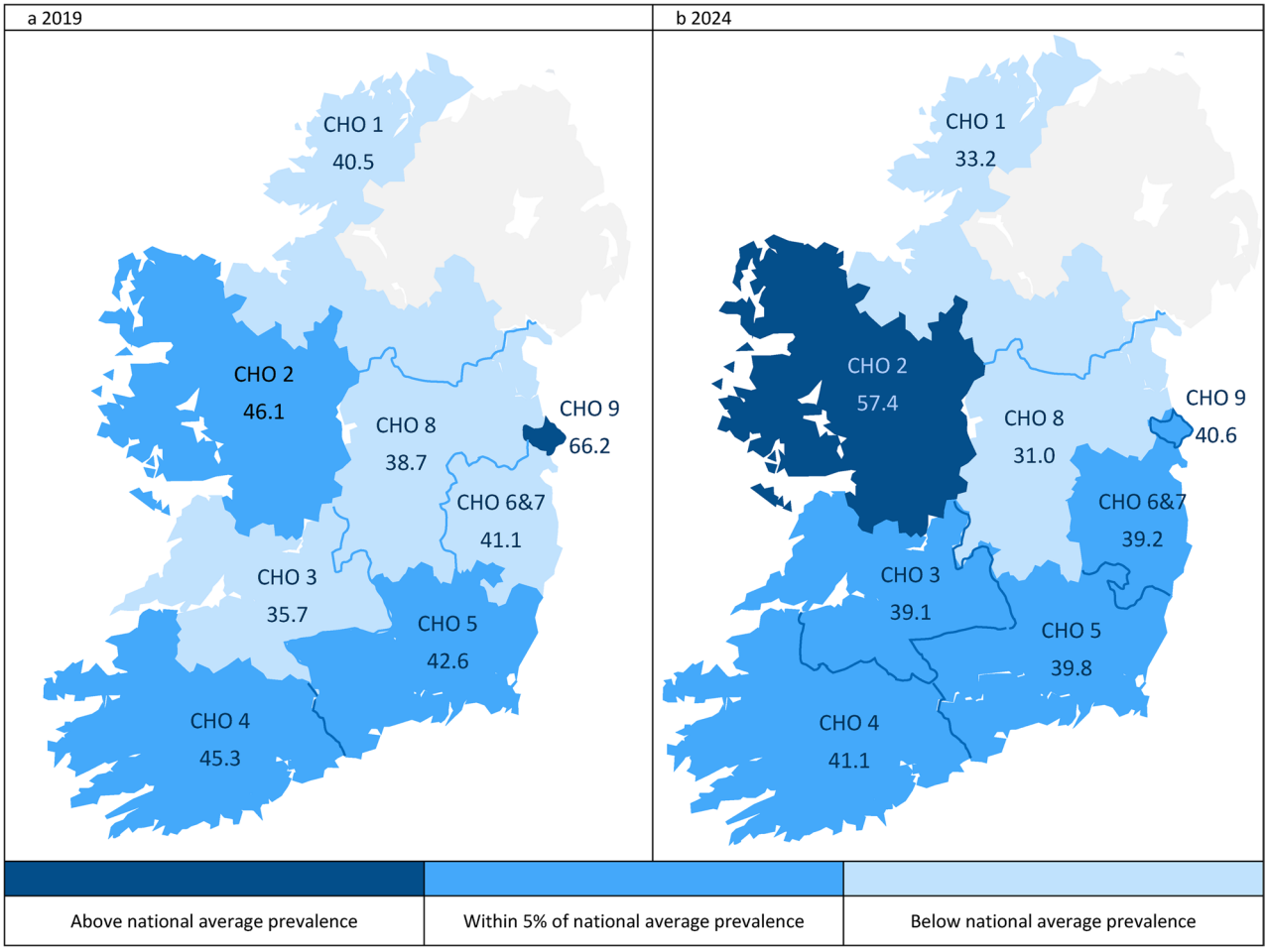

Fig. 5 Baseline estimated prevalence of life-limiting conditions amongst children aged 0–19 in Ireland by location of residence, categorised by Community Health Organisation (CHO), 2019 and 2024 [E2 estimation method]
Source: Authors' analysis of discharge-level HIPE data from Healthcare Pricing Office, Health Service Executive. Map source: template adapted from Presentation Magazine (www.presentationmagazine.com). Notes: CHO 1: Counties Cavan, Donegal, Leitrim, Monaghan, Sligo; CHO 2: Counties Galway, Roscommon, Mayo; CHO 3: Counties Limerick, Clare, North Tipperary; CHO 4: Counties Cork, Kerry; CHO 5: Counties Wexford, Carlow/Kilkenny, Waterford, South Tipperary; CHO 6 & 7: Counties Dublin South, Wicklow, Kildare; CHO 8: Counties Laois, Offaly, Longford, Westmeath, Meath, Louth; CHO 9: Dublin North. Above national average prevalence = more than 5% above national average; Below national average prevalence = more than 5% below national average

with a life-limiting condition in Ireland in 2019, and 4,420–6,094 in 2024. Adjusting for under-counting in the data could mean the number in 2019 was closer to 6,203–8,906.

In both years, prevalence estimates were highest for infants < 1 year, higher for males than for females, and highest amongst children aged 0–19 with a life-limiting condition in the neoplasm or congenital/chromosomal ICD10 chapter.

Importance for CPC policy and planning in Ireland

These are the first estimates of prevalence of life-limiting conditions amongst children in Ireland calculated using Irish-specific hospital data. The need for detailed information on prevalence has been well-documented in Irish palliative care policy and research documentation [47]. The findings are particularly timely because of government commitments to evaluate and revise the outdated 2009 national policy on palliative care for children [16, 48]. Up-to-date estimates of the number of children with life-limiting conditions, together with details on demographic and clinical characteristics, provide valuable evidence to feed into this planning process.

Until now, children's palliative care policy and planning in Ireland relied on application of prevalence from the UK to Irish population data. While these estimates provided a useful ballpark for estimating total prevalence, detailed demographic or clinical stratification was not feasible. The estimates ranged from 1,361 children with life-limiting conditions in the 2009 national policy on children's palliative care [16], to 3,840 in a subsequent 2016 CPC policy evaluation [18], to a more recent

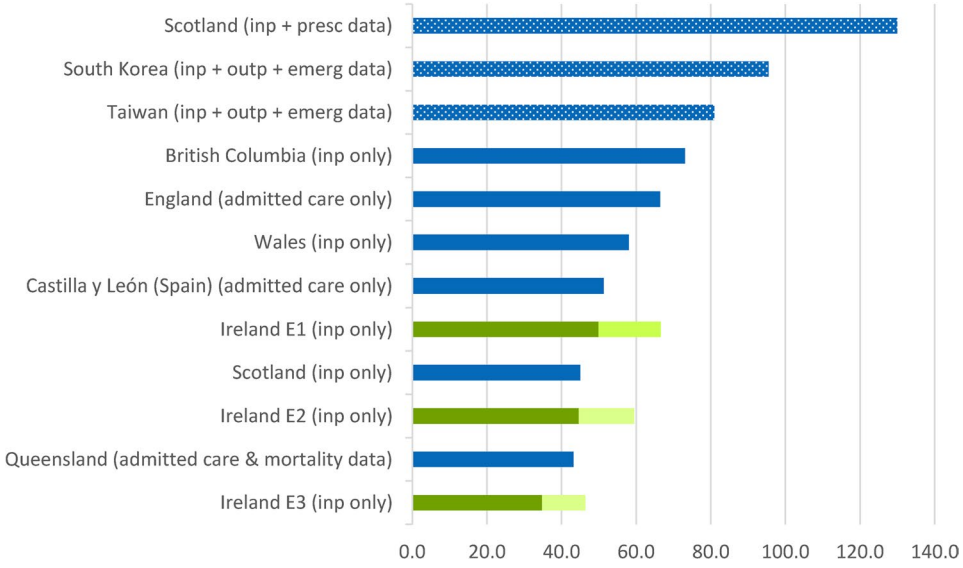

Fig. 6 Total estimated prevalence of life-limiting conditions amongst children aged 0-17+ by country/region(years vary by country between 2015–2019) Source: Authors' analysis of discharge-level HIPE data from Healthcare Pricing Office, Health Service Executive. Notes: Ireland: dark shaded bars = baseline estimation scenarios; light shaded bars = 'average uplift' scenario from sensitivity analysis. Inp only = data on hospital inpatients only; Admitted care + mortality data: data on hospital admissions and mortality data; Inp + outp + emerg data = data on hospital inpatients, outpatients and emergency; Inp + presc = data on hospital inpatients and prescriptions. Ireland = Age 0–19, 2019; Queensland [44] = Age 0–21, 2016; Scotland [45] = Age 0–21, 2018/19; Castilla y León (Spain) [40] = Age 0–17, 2019; Wales [8] = Age 0–17, 2019; England [5] = Age 0–19, 2017/18; British Columbia (Canada) [39] = Age 0–25, 2017; Taiwan [41] = Age 0–25, 2017; South Korea [46] = Age 0–24, 2015

estimate of 8,311 cited in a 2020 clinical governance plan [17]. Our findings support the conclusion that the estimated number of children with life-limiting conditions in Ireland was much higher in 2019/2024 than outlined in the current 2009 national policy. Even our most conservative estimator, E3, suggests there were more than 4,400 children aged 0–19 with life-limiting conditions in the country in 2019/2024 and that the numbers underpinning service planning need to be substantially increased.

It is also important to remember that the focus in this paper is on counting the number of children with life-limiting conditions which can be used in population-planning as a baseline indicator of need for children's palliative care. However, not every child with a life-limiting condition will need specialist palliative care and additional information is needed on the complexity of care needs. Further work is underway on identifying useful indicators of complexity, which, when combined with a life-limiting diagnosis, could signal a need for palliative care in population-level data [8, 49].

Which estimate?

Given the absence of a unique health identifier in the Irish public acute hospital inpatient data, it is important to acknowledge that point estimates of prevalence of life-limiting conditions amongst children in Ireland are not possible. However, the following indicators can help put the available estimates into context.

First, analysis of underlying hospital 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-Covid 19 levels. Thus, there is a valid argument for focusing on prevalence estimates based on 2019, pre-Covid, hospital activity until 2025/2026 data are available. A similar observation of the impact of the pandemic on hospital utilisation, and consequently, prevalence estimates, was made in a study of prevalence of life-limiting conditions amongst children aged 0–17 in Spain [40].

While the adjusted estimates rightly focused on correcting for under-counting in the data, English data were used to inform the adjustment method. The adjustments were aimed at counting any children who may have been in hospital within a given year but whose life-limiting condition was not counted at that time. Further information on coding of co-morbidities in Irish hospital data would be needed to fully understand the extent to which a child with a life-limiting condition may be admitted for inpatient acute hospital care and not have their underlying condition coded during that hospital admission. Thus, caution is advised in over-reliance on the adjusted estimates.

Nonetheless, the adjusted estimates play a role in flagging the uncertainty inherent in estimating prevalence of life-limiting conditions amongst children in Ireland and allow for other potential sources of under-counting in the data. For example, there are known gaps in the number of neonatal deaths in hospital that are reported in

HIPE compared with mortality records, because not all cases where a newborn is cared for at the mother's bedside and dies in a very short space of time are formally admitted and recorded in HIPE. To illustrate, a total of 90 early neonatal hospital deaths (i.e., deaths within 7 days) were reported for the year 2022 in the National Perinatal Mortality Clinical Audit [50], with comparable data in HIPE showing 51 early neonatal deaths (i.e., 51 deaths of infants formally admitted to HIPE with length of stay less than 7 days). Thus, the HIPE dataset understates the numbers of neonates with life-limiting conditions and further investigation is needed to determine the extent of these discrepancies.

Overall, the three alternative baseline estimation scenarios worked well to generate a range of lower, middle and upper prevalence estimates. The E1 baseline estimate provided an upper limit to the estimates, controlling for double counting of hospital episodes (i.e., by excluding transfers to other hospitals), but not for multiple hospital admissions in the data. E2 and E3 corrected for double counting of hospital episodes and also double counting of children (i.e., by estimating multiple admissions). The E2 method relied on Irish-specific data to control for multiple admissions, providing a mid-point between the other two estimators.

International comparisons

The international comparisons show that even after controlling for consistency in terms of definitions (of life-limiting conditions), data, methods and time period, the estimated prevalence of life-limiting conditions varied across a sample of high-income countries from 43.2 in Queensland to 73.1 per 10,000 in British Columbia (Canada) for those calculating hospital (inpatient) prevalence.

Focusing on the European countries within that sample, the Irish estimates (with the exception of the E3 baseline estimate) were in line with the prevalence range of 45–66 per 10,000 (Scotland, England, Wales, Spain). These results provide valuable evidence on comparability of prevalence across similar countries and are consistent with recent work investigating epidemiological cross-national transferability of paediatric life-limiting prevalence from the UK to Germany [51].

In these European countries, prevalence was highest amongst infants aged < 1, and in the Irish setting at least these findings underpin the importance of fostering greater collaboration between maternity-hospital based care and specialist CPC services. The general pattern of prevalence across age groups from high (infants) to low (teenagers) was consistent across these countries although more detailed conclusions about prevalence patterns amongst the age groups 17–21 were not possible because of varying age ranges across the studies.

Estimated prevalence was unsurprisingly highest for the three studies examining prevalence using additional data (but still with similar underlying methods) including outpatient and emergency hospital data (Taiwan, South Korea) and prescriptions data (Scotland) ranging from 81.0 to 130 per 10,000 population. In addition, the studies in Taiwan and South Korea included older ages up to 25, finding high prevalence amongst the young adult age groups 20–24 (South Korea) and 21–25 (Taiwan) in these countries which further set these estimates apart within the sample of countries.

Methodological considerations

Two broad estimation approaches have been identified in the literature on quantifying need for CPC, including incidence studies focusing on numbers of deaths with end-of-life care needs, and studies estimating prevalence of CPC needs amongst children living with life-limiting illness [3]. As discussed in the literature, relying only on mortality data to estimate CPC needs risks under-estimating the number of children who could benefit from palliative care, because CPC needs arise across the full trajectory of a child's illness and not just at the end of life [3, 52–55].

This study contributes to a growing body of work making use of hospital inpatient data [5, 8, 26, 39, 41], allowing us to estimate prevalence of life-limiting conditions amongst children, and potential needs for palliative care throughout their lives, compared with studies analysing deaths only, restricting the analysis to incidence of end-of-life care needs.

Data limitations typically limit the choice of estimation approach in this field. This study shows that even in the absence of a unique health identifier, available national administrative data on hospital utilisation can still be used to estimate prevalence of life-limiting conditions amongst children. The approach in this paper has demonstrated application of systematic and transparent methods for controlling for double counting in discharge-level hospital inpatient data, providing a set of prevalence estimates for comparison internationally and that can feed into national policy and decision making. Transparency is key, allowing for adjustments to be made to the underlying assumptions as and when better data come available (e.g., on multiple admission rates for children aged 0–19).

Limitations

One of the main limitations in the analysis stems from applying one-off static adjustments to correct for double counting of patients in the discharge-level hospital inpatient data. We applied the same correction for multiple admissions to both 2019 and 2024 and the main purpose for comparing these two years was to control for the

continuing impact of the Covid-19 pandemic on healthcare utilisation patterns. Beyond that, in the absence of more information on trends in multiple admissions in Irish hospitals over time, it was not possible to examine changes in prevalence over time. Given the consistency in estimated prevalence of life-limiting conditions amongst children across the sample of European countries examined in this analysis, it is likely that the same trends of increasing prevalence observed in the European counterparts have also been occurring in Ireland. Future analysis of multiple admissions within paediatric hospitals using a hospital-specific (i.e., not national) patient identifier could contribute to this analysis, improving on this paper's use of adult data on hospital re-admissions, and allowing preliminary assessment of changes in prevalence over time in Ireland.

However, while the methods applied in this paper make the best use of available data and make important contributions to informing new national policy on children's palliative care in Ireland, further planning and organisation of palliative care into the future will require more detailed analysis of trends in prevalence across regions and over time, both of which are made more difficult in the absence of a unique health identifier. A unique health identifier is currently being rolled out in Ireland [56] but the timeline for inclusion within national hospital data is not yet known. Analysis by region in this paper focused on 9 Community Health Organisations (CHOs). Planning and delivery of health services in Ireland has since been reorganised into 6 new Health Regions, and this regional analysis of prevalence can be updated when access to more detailed regional HIPE data is feasible.

The analysis adopted a conservative approach to calculating prevalence by using three alternative estimation scenarios. Confidence intervals around the estimates that allowed for uncertainty in the assumptions (e.g., uncertainty around the percentage of multiple admissions, skewed distributions of hospital admissions for children with chronic conditions) would have further strengthened the analysis but was not feasible without further background data.

As noted, there were known sources of under-counting in the data including patients who may have been in hospital but their life-limiting condition was not coded and early neonatal deaths not coded in HIPE. Additional sources of under-counting include children with life-limiting conditions who may not have had a hospital admission in the years of analysis. Evidence from the study in British Columbia indicated that only 25% of patients aged 0–25 with a life-limiting condition required a hospital admission in each year of a 6-year time period [39], and prevalence estimates from Scotland took into account prescriptions data in an attempt to capture children who may not have had a hospital admission in the year of analysis [45]. Future analysis can examine prescription medications dispensed at community-based pharmacies in Ireland to capture some of this under-counting. Detailed data on private adult hospital activity are not currently available in Ireland and thus it is possible that some private hospital inpatient activity for the age group 16–19 is missing from this analysis.

Conclusions

Best available data indicate that estimated prevalence of life-limiting conditions amongst children aged 0–19 in Ireland was between 34.8 and 50.0 per 10,000 population in 2019, with higher estimates under sensitivity scenarios adjusting for under-counting in the data.

These are the first estimates of prevalence of life-limiting conditions amongst children in Ireland that have been calculated using Irish-specific hospital data. The evidence can support the evaluation and development of a new national policy for children's palliative care in Ireland.

The prevalence estimates are in line with prevalence from other similar-income countries based on studies using similar definitions of life-limiting conditions, data sources, and methodologies. The findings demonstrate how careful application of transparent methods to routinely collected administrative hospital activity data can yield important findings even in the context of data limitations.

Abbreviations

CPC	Children's Palliative Care
HIPE	Hospital In-Patient Enquiry
ICD10	10th Revision of the International Statistical Classification of Diseases and Related Health Problems
ICD10AM	Australian Modification of ICD10
LLCs	Life-limiting conditions
CI	Confidence interval

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12887-026-07003-1.

Supplementary Material 1.

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Authors' contributions

SS and JB designed and secured Health Research Board funding, and co-funding from the Irish Hospice Foundation and LauraLynn Ireland's Children's Hospice for the overall Evidence for Children's Palliative care in Ireland (ECHPI) project. Estimating the prevalence of life-limiting conditions

amongst children in Ireland formed a large part of the planned work in the ECHPI project. SS, JB, LF, TD, OM, PM, FMcE, MD (Mary Devins), MR, TH, SG, and MD (Maurice Dillon) contributed to the conceptualisation and consideration of methodological approach for the analysis in this paper. SOH contributed to data curation. SS undertook the formal analysis and drafted the original manuscript. All authors reviewed the findings and all authors approved the final draft of the manuscript.

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LF is an NIHR Research Professor [NIHR304252]. The views expressed are those of the author(s) and not necessarily those of the Health Research Board, Ireland, or the NIHR or the Department of Health and Social Care, UK.

Data availability
There were two data sources used for this paper: The national population data that support the findings of this study are available from the Central Statistics Office, Ireland. County-level population estimates, disaggregated by age and sex, were provided under licence for the current study, and so are not publicly available. Population data requests can be submitted to the Central Statistics Office at demography@cso.ie, https://www.cso.ie/en/statistics/population/populationandmigrationestimates/ [last accessed 15/01/2026].*Population metadata: *Years: 2019 & 2024 Population counts: by sex, age, county. The public hospital inpatient data that support the findings of this study are available from the HIPE dataset controlled by the Healthcare Pricing Office, Health Service Executive in Ireland. Restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. HIPE data requests can be submitted to the Healthcare Pricing Office at https://hpowp.com/data-requests/ [last accessed 15/01/2026] and are assessed on a case-by-case basis.*HIPE metadata: *Years: 2009–2024 Age group: 0–19Individual-level (anonymised) variables: sex, diagnoses (max 30 diagnoses per discharge), inpatient/day case, county of residence.

Declarations

Ethics approval and consent to participate
The project received ethical approval from the Health Policy and Management and Centre for Global Health Research Ethics Committee at Trinity College, Dublin (Ref: 2969). The hospital inpatient data used in this study were secondary non-personal data. The extract of non-personal data was provided by the Healthcare Pricing Office and no informed consent was required. The population data used in this study were secondary non-personal data. The extract of non-personal data was provided by the Central Statistics Office and no informed consent was required.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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