

Children in Scotland requiring Palliative Care (ChiSP) 2



Foreword

CHAS has commissioned new intelligence from NHS National Services Scotland about the number of children living with life-shortening conditions. We have done so to further help the development of paediatric palliative care services across Scotland.

This piece of work sets out the number of babies, children and young people in Scotland with a life-shortening condition. This is only the second time such a study has been carried out. While the data is not directly comparable to the Children in Scotland requiring Palliative Care (ChiSP) study of 2015, it does complement and bring our collective knowledge about the need for paediatric palliative care in Scotland up to date and also presents highly detailed local information. CHAS is currently working with NHS National Services Scotland to examine how we can ensure this information is updated regularly.

The research provides data for the years up to 2016-2017 for babies, children and young people aged 0-21. This new data tells us that across Scotland 15,949 babies, children and young people have life-shortening conditions. Of these, 5,671 had contact with a hospital team in the preceding year.

These figures confirm what CHAS already knows - there are many and an increasing number of children in Scotland who are likely to die young. We know the benefits that palliative care brings to babies, children and young people, and their wider families. CHAS's vision is to ensure that support is available to all who need it. We remain committed to reaching every child and family who can benefit from the support and care we provide and our strategic plan for 2017-2020 sets out how we can achieve this ambitious goal.

ChiSP 2 is a key resource for organisations with responsibility for and delivering services to babies, children and young people with life-shortening conditions and their families. I am very grateful to the researchers at NHS National Services Scotland who undertook this complex exercise to describe the numbers and characteristics of children and young people with life-shortening conditions.

There are some important messages in this data.

First is the number of children in Scotland with life-shortening conditions. Many of these children, and their families and siblings, are living with complex care and support needs. Supporting a child who is likely to die young presents as challenging a situation for parents as they are ever likely to encounter. The interventions they need may require to be sustained over a prolonged period. The services available to support them are delivered nationally and locally through integration authorities, territorial health boards, local authorities, and the voluntary sector.

Second is the percentage of babies aged under one who die each year from life-shortening conditions. Of all the deaths from life-shortening conditions each year, nearly 40% died before reaching their first birthday. This reinforces the importance of children's palliative care in neonatal units. Staff in those units, and in community nursing teams, must be confident and skilled in supporting new parents and very young babies who will likely live for only a short period of time. All of us involved in planning and delivering services need to think about the extent to which we can respond not just to the immediate clinical needs of these babies, but also to the emotional and social needs of the family at a time of crisis and beyond.

Third, we see that there is a very strong correlation between poverty and being a child with a life-shortening condition. This is particularly the case for babies, children and young people who have had recent contact with a hospital team - 26.5% of these lived in the most deprived population quintile; the same figure for the least deprived quintile is 15.9%.

Fourth, we see distinct patterns of population prevalence amongst babies, children and young people from certain ethnic backgrounds. Those from South Asian and black ethnic backgrounds are more likely to have a life-shortening condition than those from white backgrounds. This is an important reminder, if it were needed, that organisations, including CHAS, must ensure that services are accessible and culturally competent for the diverse populations they serve.

This document is in two parts. Part 1(a) presents information about the prevalence of paediatric palliative care need with detailed breakdowns by geography, age, deprivation and other characteristics. Part 1(b) provides additional information about the stage of condition.

I hope this data is helpful in understanding the local population need in different parts of Scotland and in planning services. CHAS will continue to work with a wide range of partners across Scotland to develop high quality integrated services that are responsive to babies, children, young people, and their families' needs.

Maria McGill Chief Executive



Children and Young People in Scotland with Life-Limiting Conditions - Phase 1(a)

NHS National Services Scotland (XRB17031) 22 August, 2018

Introduction

In 2015, the University of York published the report 'Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)' (https://www.chas.org.uk/about-us/our-vision/our-publications#Chisp). This report, commissioned by Children's Hospices Across Scotland (CHAS) (https://www.chas.org.uk/), provided an evidence base to inform the planning and design of paediatric palliative care services in Scotland. It provided quantitative data identifying the number of children and young people with life-limiting conditions living in Scotland and describing this population in terms of their ages, conditions/diagnoses, geographical locations and ethnicity. The information and evidence in this report has been used by CHAS to develop its strategic business plans.

Due to the importance of the evidence presented in The ChiSP Study's report to its work, CHAS was keen to see these analyses updated and refined to provide information more tailored to its requirements, and to inform the further development of its palliative care services. As a result, CHAS commissioned the Information Services Division (ISD) of NHS National Services Scotland (NSS) to provide analyses to identify the population and demographic characteristics of children and young people in Scotland with life-limiting conditions.

The commissioned analyses are being carried out in phases, with this report containing the results of Phase 1(a).

Key Definitions

Children and Young People

For the purposes of this work, children and young people are defined as those aged 0-21 years. Please note that this definition varies from that in The ChiSP Study (https://www.chas.org.uk/about-us/our-vision/our-publications#Chisp) which looked at the 0-25 age group.

Life-limiting conditions

For the purposes of this work, 'life-limiting conditions' includes:

- **Life-limiting conditions** (i.e. conditions where there is no reasonable hope of a cure and from which children or young people will ultimately die prematurely), and
- Life-threatening conditions (i.e. conditions where curative treatment may be feasible but may fail).

Life-limiting conditions were identified using a list of ICD10 (International Classification of Disease, Version 10) (http://www.who.int/classifications/icd/en/) codes (listed as an appendix to the Phase 1(a) Technical Report) and categorised into 11 diagnostic groups.

Populations

- NRS Mid-2016 population estimates for Scotland (https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2016) have been used to calculate prevalence by age, gender, NHS Board and Local Authority.
- NRS 2011 Data Zone based population estimates for Scotland (https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/2011-based-special-area-population-estimates/population-estimates-by-urban-rural-classification) have been used to calculate prevalence by 8-fold Urban Rural Classification.

Other

For more information on the definitions and methology used to produce these outputs, please refer to the Phase 1(a) Technical Report.

Prevalence

The prevalence of life-limiting conditions among children and young people in Scotland has been calculated in two ways:

· Hospital-based prevalence

- Scottish Birth Record (SBR) and inpatient (SMR01) data were used to determine hospital-based prevalence.
 These prevalence figures include any child or young person resident in Scotland who had a life-limiting condition and any inpatient episode (within a given financial year).
- o 1 April 2003 31 March 2017

• Complete prevalence

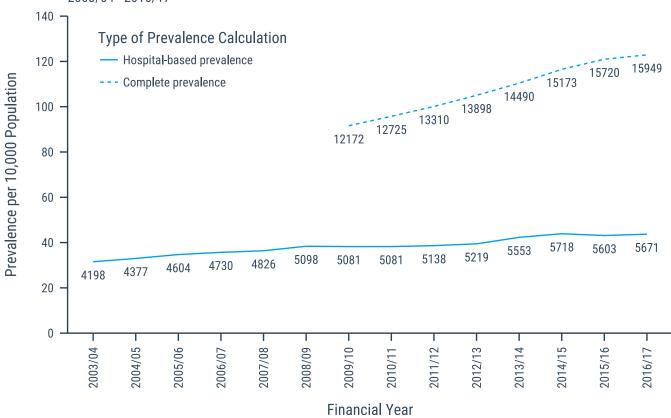
- SBR, SMR01 & community prescribing data were used to determine complete prevalence. These prevalence
 figures include any child or young person resident in Scotland who meets the criteria for inclusion in the
 hospital-based prevalence plus those who appeared in the analysis cohort and on community prescribing
 records (within a given financial year).
- o 1 April 2009 31 March 2017

Overall

Figure 1

Overall

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years Scotland 2003/04 - 2016/17



Overall

Hospital-based and complete prevalence of life-limiting conditions among children and young people;

0-21 years;

Scotland;

2003/04 - 2016/17

Financial Year	Persons	PR	CI-	CI+
Hospital-based preva	alence			
2003/04	4,198	31.5	30.6	32.5
2004/05	4,377	33.0	32.0	34.0
2005/06	4,604	34.7	33.7	35.7
2006/07	4,730	35.7	34.7	36.7
2007/08	4,826	36.4	35.4	37.4
2008/09	5,098	38.4	37.3	39.4
2009/10	5,081	38.2	37.2	39.3
2010/11	5,081	38.2	37.2	39.3
2011/12	5,138	38.6	37.6	39.7
2012/13	5,219	39.4	38.4	40.5
2013/14	5,553	42.3	41.2	43.4
2014/15	5,718	43.9	42.8	45.1
2015/16	5,603	43.1	42.0	44.3
2016/17	5,671	43.7	42.6	44.8
Complete prevalence	!			
2009/10	12,172	91.6	90.0	93.2
2010/11	12,725	95.8	94.1	97.4
2011/12	13,310	100.1	98.4	101.8
2012/13	13,898	105.0	103.3	106.8
2013/14	14,490	110.4	108.6	112.2
2014/15	15,173	116.5	114.7	118.4
2015/16	15,720	121.0	119.1	122.9
2016/17 Note:	15,949	122.9	121.0	124.8

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

By age group

Age has been calculated based on the most commonly recorded date of birth for each individual.

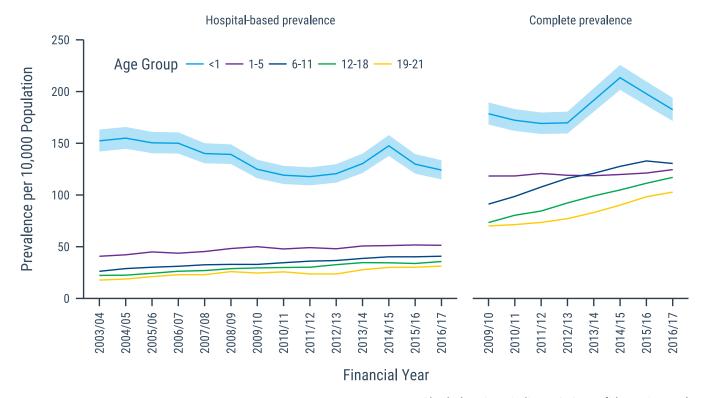
Each individual has been assigned an age in each financial year based on their age at the start of the first record (SMR01 or SBR) in that financial year.

If there was no SMR01 or SBR record, then the individual's age at the date of the first community prescription in the year has been used.

Figure 2

By age group

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by age group Scotland 2003/04 - 2016/17



Shaded regions indicate 95% confidence interval Produced by NHS National Services Scotland (Ref. XRB17031)

By age group

Hospital-based and complete prevalence of life-limiting conditions among children and young people;

0-21 years, by age group;

Scotland;

2003/04 - 2016/17

		Age	<1			Age 1	-5			Age 6	-11			Age 12	2-18			Age 19	-21	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-bas	ed prevaler	ice																		
2003/04	789	152.4	142.0	163.3	1,103	40.8	38.4	43.2	962	26.2	24.6	27.9	1,001	22.2	20.9	23.7	343	17.8	15.9	19.7
2004/05	831	155.0	144.7	165.8	1,124	42.2	39.8	44.7	1,040	28.9	27.1	30.7	1,014	22.5	21.1	23.9	368	18.8	16.9	20.8
2005/06	820	150.5	140.4	161.0	1,193	45.0	42.5	47.6	1,074	30.2	28.4	32.0	1,091	24.3	22.9	25.8	426	21.1	19.1	23.2
2006/07	827	150.0	140.1	160.5	1,164	43.7	41.3	46.3	1,087	31.1	29.3	33.0	1,177	26.3	24.8	27.8	475	23.0	20.9	25.1
2007/08	799	140.1	130.6	150.1	1,222	45.4	42.8	48.0	1,124	32.5	30.7	34.5	1,202	27.0	25.5	28.5	479	23.0	21.0	25.1
2008/09	829	139.2	130.0	148.9	1,328	48.3	45.7	50.9	1,117	32.9	31.0	34.9	1,279	28.8	27.2	30.4	545	25.9	23.8	28.2
2009/10	745	124.9	116.1	134.1	1,412	50.0	47.5	52.7	1,093	32.9	31.0	34.9	1,322	29.5	28.0	31.2	509	24.6	22.5	26.8
2010/11	707	119.2	110.6	128.2	1,373	47.8	45.3	50.4	1,134	34.6	32.6	36.6	1,319	29.9	28.3	31.6	548	25.7	23.6	27.9
2011/12	711	117.8	109.3	126.7	1,420	49.1	46.6	51.8	1,175	36.1	34.0	38.2	1,308	30.2	28.6	31.9	524	23.7	21.7	25.8
2012/13	706	120.6	111.9	129.8	1,413	48.0	45.6	50.6	1,195	36.7	34.6	38.8	1,383	32.6	30.9	34.4	522	23.7	21.7	25.8
2013/14	743	130.4	121.2	140.0	1,504	50.7	48.2	53.3	1,272	38.7	36.6	40.9	1,438	34.6	32.9	36.5	596	27.7	25.6	30.1
2014/15	829	147.6	137.7	157.9	1,510	51.1	48.6	53.7	1,355	40.2	38.1	42.4	1,401	34.5	32.7	36.3	623	30.0	27.7	32.5
2015/16	727	129.8	120.6	139.5	1,518	51.7	49.1	54.4	1,388	40.3	38.2	42.4	1,350	33.8	32.0	35.7	620	30.1	27.8	32.6
2016/17	689	124.1	115.1	133.7	1,507	51.4	48.8	54.0	1,428	40.8	38.7	43.0	1,406	35.7	33.9	37.6	641	31.3	28.9	33.8
Complete pre	valence																			
2009/10	1,065	178.5	168.1	189.5	3,341	118.4	114.4	122.4	3,029	91.2	88.0	94.5	3,284	73.4	70.9	75.9	1,453	70.1	66.6	73.8
2010/11	1,022	172.2	161.9	183.0	3,398	118.4	114.5	122.4	3,237	98.6	95.3	102.1	3,546	80.4	77.8	83.1	1,522	71.4	67.8	75.0
2011/12	1,021	169.1	159.0	179.7	3,491	120.8	116.8	124.8	3,511	107.7	104.2	111.3	3,662	84.5	81.8	87.3	1,625	73.5	70.0	77.2
2012/13	994	169.8	159.5	180.6	3,503	119.0	115.2	123.0	3,788	116.2	112.5	119.9	3,912	92.3	89.5	95.2	1,701	77.1	73.5	80.8
2013/14	1,092	191.6	180.5	203.2	3,519	118.7	114.8	122.6	3,977	121.0	117.2	124.7	4,117	99.1	96.1	102.2	1,785	83.1	79.3	87.0
2014/15	1,199	213.4	201.6	225.7	3,540	119.8	115.9	123.8	4,299	127.7	123.9	131.5	4,263	104.9	101.7	108.0	1,872	90.2	86.2	94.3
2015/16	1.108	197.9	186.5	209.7	3.561	121.3	117.3	125.3	4.582	132.9	129.1	136.8	4.446	111.3	108.1	114.6	2.023	98.3	94.1	102.7
2016/17	1,013	182.5	171.5	193.9	3,654	124.5	120.6	128.6	4,565	130.4	126.7	134.3	4,609	117.0	113.7	120.4	2,108	102.8	98.5	107.3
2010,17	1 ',5'6	102.0	1, 1.0	1,0.,	0,004	121.0	. 20.0	120.0	1,000	100.4	.20.7	10 1.0	1,007	0		120.7	2,130	102.0	70.0	107.0

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

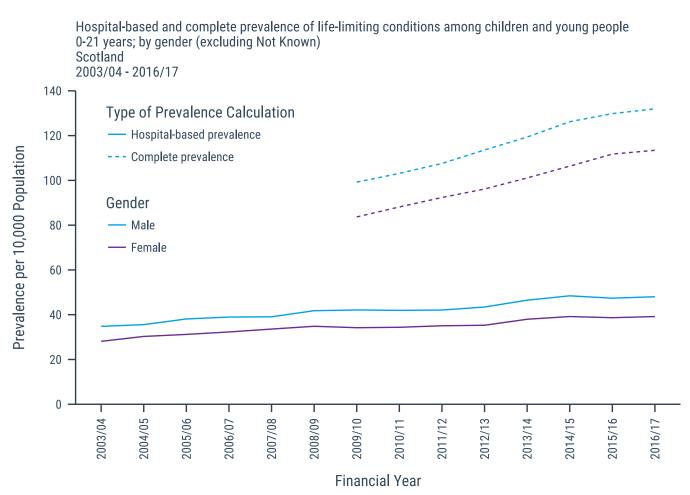
CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

By gender

The following figures and tables excludes those individuals whose gender is not known.

Figure 3

By gender



By gender

Hospital-based and complete prevalence of life-limiting conditions among children and young people;

0-21 years; by gender (excluding Not Known);

Scotland;

2003/04 - 2016/17

		Male	!			Femal	le	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-based	prevalence							
2003/04	2,359	34.8	33.4	36.2	1,838	28.1	26.8	29.4
2004/05	2,402	35.6	34.2	37.0	1,974	30.3	29.0	31.7
2005/06	2,572	38.1	36.6	39.6	2,032	31.2	29.9	32.6
2006/07	2,628	39.0	37.5	40.5	2,102	32.3	30.9	33.7
2007/08	2,639	39.1	37.6	40.6	2,186	33.6	32.2	35.0
2008/09	2,827	41.8	40.3	43.4	2,271	34.8	33.4	36.3
2009/10	2,852	42.1	40.6	43.7	2,229	34.2	32.8	35.6
2010/11	2,839	41.9	40.4	43.5	2,242	34.4	33.0	35.8
2011/12	2,852	42.1	40.6	43.7	2,286	35.1	33.6	36.5
2012/13	2,930	43.4	41.9	45.0	2,289	35.3	33.9	36.8
2013/14	3,110	46.5	44.9	48.1	2,443	38.0	36.5	39.5
2014/15	3,218	48.4	46.8	50.1	2,500	39.2	37.7	40.7
2015/16	3,143	47.4	45.7	49.1	2,460	38.7	37.2	40.2
2016/17	3,183	48.0	46.4	49.7	2,488	39.2	37.7	40.7
Complete preva	lence			-				
2009/10	6,718	99.2	96.9	101.6	5,454	83.7	81.5	85.9
2010/11	6,979	103.1	100.7	105.6	5,746	88.1	85.9	90.4
2011/12	7,289	107.6	105.1	110.1	6,021	92.3	90.0	94.7
2012/13	7,661	113.6	111.1	116.1	6,237	96.1	93.8	98.6
2013/14	7,986	119.4	116.8	122.0	6,504	101.1	98.7	103.6
2014/15	8,385	126.2	123.5	128.9	6,788	106.4	103.9	108.9
2015/16	8,611	129.8	127.1	132.6	7,109	111.7	109.2	114.4
2016/17	8,744	132.0	129.2	134.7	7,205	113.4	110.9	116.1

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

Table 4

North of Scotland

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by NHS Board of Residence 2003/04 - 2016/17

		Gram	pian			Highla	and			Orkn	еу			Shetla	and			Taysi	de		W	esterr	ı Isles	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	ed prevale	nce																						
2003/04	456	32.9	29.9	36.0	265	35.0	30.9	39.4	16	32.2	18.4	52.2	31	50.7	34.4	71.8	289	29.0	25.8	32.6	25	38.6	25.0	56.9
2004/05	446	32.3	29.4	35.4	275	36.0	31.9	40.5	16	31.6	18.0	51.2	32	52.1	35.7	73.5	328	33.0	29.6	36.8	17	26.1	15.2	41.7
2005/06	460	33.2	30.3	36.4	273	35.7	31.6	40.2	16	31.5	18.0	51.1	27	43.9	28.9	63.7	340	34.1	30.5	37.9	25	38.1	24.6	56.1
2006/07	496	35.6	32.6	38.9	296	38.6	34.4	43.3	15	29.3	16.4	48.3	33	54.1	37.3	75.9	338	33.8	30.3	37.6	20	30.6	18.7	47.3
2007/08	451	32.2	29.3	35.3	288	37.5	33.3	42.1	16	31.4	18.0	51.0	25	41.1	26.6	60.6	326	32.5	29.0	36.2	18	27.5	16.3	43.5
2008/09	460	32.8	29.9	35.9	304	39.6	35.3	44.3	14	27.4	15.0	46.0	31	51.3	34.9	72.7	325	32.1	28.7	35.8	13	20.0	10.7	34.2
2009/10	458	32.5	29.6	35.6	291	37.9	33.7	42.6	12	23.6	12.2	41.2	15	24.7	13.8	40.7	344	33.9	30.4	37.6	20	31.0	19.0	47.9
2010/11	450	31.7	28.9	34.8	285	37.2	33.0	41.8	14	27.5	15.0	46.1	18	29.4	17.4	46.4	329	32.2	28.8	35.9	18	28.1	16.7	44.4
2011/12	461	32.4	29.5	35.5	282	36.8	32.6	41.3	16	31.4	17.9	50.9	23	37.6	23.8	56.3	313	30.5	27.2	34.1	18	28.5	16.9	45.0
2012/13	472	33.1	30.2	36.3	267	35.2	31.1	39.7	19	37.7	22.7	58.8	24	39.7	25.4	59.0	316	30.9	27.6	34.5	20	32.0	19.5	49.3
2013/14	523	36.8	33.7	40.1	311	41.2	36.8	46.0	15	30.0	16.8	49.4	17	28.3	16.5	45.3	368	36.4	32.8	40.4	26	42.0	27.4	61.4
2014/15	511	36.1	33.1	39.4	314	42.0	37.5	46.9	11	22.3	11.1	39.9	27	45.4	29.9	66.0	377	37.8	34.1	41.8	19	31.3	18.9	48.8
2015/16	523	37.1	34.0	40.4	306	41.1	36.6	46.0	17	34.8	20.3	55.7	21	35.7	22.1	54.6	394	39.8	36.0	43.9	21	35.0	21.7	53.5
2016/17	544	38.8	35.6	42.2	285	38.5	34.2	43.3	17	35.2	20.5	56.2	21	36.2	22.4	55.3	411	41.9	38.0	46.2	18	30.7	18.2	48.5
Complete pre	valence																							
2009/10	1,181	83.7	79.1	88.6	675	88.0	81.5	94.9	37	72.8	51.3	100.2	57	93.8	71.1	121.3	799	78.6	73.3	84.3	45	69.8	51.0	93.3
2010/11	1,246	87.9	83.1	92.9	681	88.9	82.4	95.9	43	84.4	61.1	113.5	59	96.4	73.5	124.2	809	79.2	73.9	84.8	45	70.3	51.3	93.9
2011/12	1,310	92.0	87.1	97.1	708	92.4	85.7	99.4	49	96.1	71.2	126.8	61	99.7	76.3	127.9	840	81.9	76.5	87.6	47	74.5	54.8	98.9
2012/13	1,384	97.2	92.1	102.4	709	93.5	86.8	100.6	54	107.0	80.5	139.4	67	110.8	86.0	140.5	871	85.1	79.6	90.9	48	76.7	56.6	101.6
2013/14	1,464	103.1	97.9	108.5	727	96.3	89.5	103.5	49	97.9	72.5	129.3	67	111.6	86.6	141.5	954	94.5	88.6	100.6	49	79.1	58.6	104.4
2014/15	1,529	108.1	102.8	113.6	747	99.9	92.9	107.2	48	97.3	71.8	128.8	73	122.8	96.4	154.1	986	98.8	92.8	105.2	51	84.0	62.6	110.3
2015/16	1,626	115.3	109.8	121.0	813	109.2	101.8	116.9	44	90.1	65.6	120.8	68	115.7	90.0	146.5	1,051	106.1	99.8	112.7	52	86.7	64.8	113.6
2016/17	1,651	117.7	112.1	123.4	793	107.2	99.9	114.9	44	91.0	66.2	122.0	69	119.0	92.7	150.4	1,068	108.9	102.5	115.6	49	83.7	62.0	110.5

Note

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

South East Scotland by NHS Board of Residence

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by NHS Board of Residence 2003/04 - 2016/17

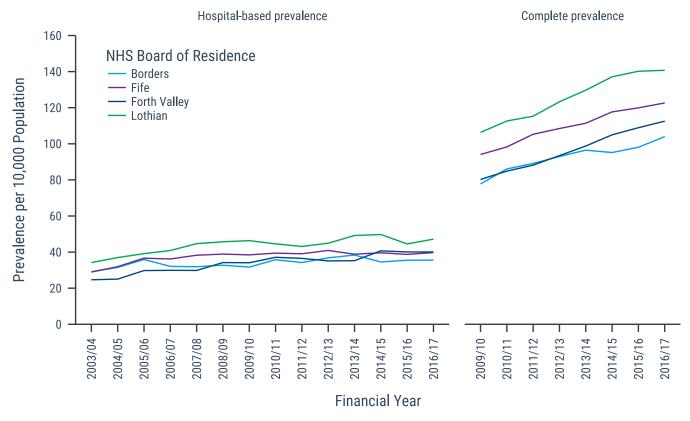


Table 5

South East Scotland

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by NHS Board of Residence 2003/04 - 2016/17

		Borde	rs			Fife	1			Forth Va	alley			Lothia	an	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	ed prevalence															
2003/04	77	29.1	23.0	36.4	271	28.9	25.6	32.6	187	24.7	21.3	28.4	686	34.2	31.7	36.8
2004/05	84	31.5	25.1	39.0	298	31.9	28.4	35.8	189	25.0	21.6	28.9	739	37.0	34.3	39.7
2005/06	96	35.9	29.1	43.8	342	36.6	32.9	40.7	227	29.8	26.0	33.9	787	39.1	36.5	42.0
2006/07	86	32.1	25.7	39.6	337	36.2	32.4	40.2	228	29.9	26.1	34.0	826	40.9	38.2	43.8
2007/08	86	31.9	25.5	39.4	354	38.3	34.4	42.5	229	29.8	26.1	33.9	909	44.7	41.8	47.7
2008/09	89	32.7	26.3	40.3	359	38.9	35.0	43.1	263	34.2	30.2	38.6	939	45.7	42.8	48.7
2009/10	86	31.7	25.4	39.1	356	38.5	34.6	42.7	262	34.1	30.1	38.5	960	46.3	43.5	49.4
2010/11	96	35.8	29.0	43.7	365	39.4	35.5	43.7	286	37.1	32.9	41.7	932	44.5	41.7	47.5
2011/12	91	34.2	27.6	42.0	363	39.1	35.2	43.3	282	36.5	32.4	41.0	910	43.1	40.4	46.0
2012/13	97	36.8	29.9	44.9	379	40.9	36.9	45.2	270	35.1	31.0	39.5	944	44.9	42.1	47.9
2013/14	101	38.4	31.3	46.6	359	38.8	34.9	43.0	269	35.2	31.2	39.7	1,027	49.2	46.2	52.3
2014/15	91	34.5	27.8	42.3	364	39.6	35.7	43.9	309	40.7	36.3	45.5	1,040	49.8	46.8	52.9
2015/16	93	35.5	28.7	43.5	356	38.7	34.8	42.9	305	40.1	35.7	44.8	935	44.5	41.7	47.5
2016/17	93	35.5	28.7	43.5	365	39.8	35.8	44.0	305	40.0	35.7	44.8	997	47.2	44.3	50.2
Complete pre	valence															
2009/10	211	77.8	67.7	88.9	871	94.1	88.0	100.5	617	80.3	74.1	86.8	2,202	106.3	101.9	110.8
2010/11	231	86.1	75.4	97.9	910	98.3	92.0	104.8	654	84.9	78.5	91.6	2,357	112.6	108.2	117.2
2011/12	237	89.1	78.2	101.2	978	105.3	98.8	112.1	681	88.2	81.7	95.0	2,432	115.3	110.8	119.9
2012/13	245	93.0	81.7	105.3	1,005	108.5	101.9	115.3	719	93.5	86.8	100.5	2,591	123.3	118.6	128.1
2013/14	254	96.5	85.0	109.0	1,030	111.4	104.7	118.4	754	98.8	91.9	106.0	2,709	129.7	124.9	134.7
2014/15	251	95.2	83.8	107.6	1,081	117.7	110.8	124.9	797	105.0	97.8	112.5	2,866	137.1	132.2	142.2
2015/16	257	98.1	86.5	110.8	1,103	119.9	113.0	127.2	829	108.9	101.7	116.5	2,945	140.2	135.2	145.3
2016/17	272	104.0	92.0	117.0	1,126	122.6	115.6	130.0	857	112.5	105.2	120.3	2,974	140.7	135.7	145.8

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

West of Scotland by NHS Board of Residence

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by NHS Board of Residence 2003/04 - 2016/17

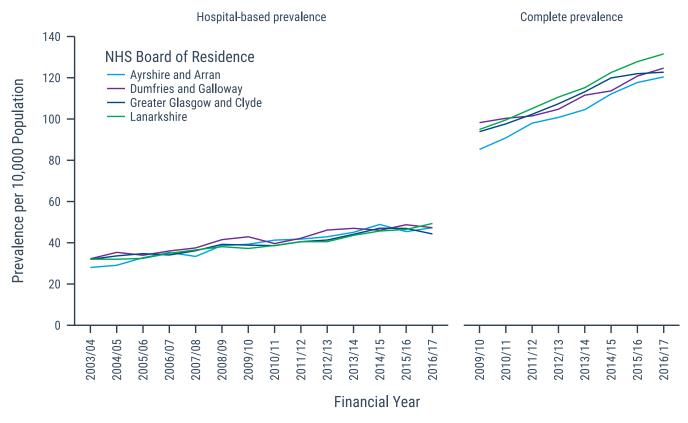


Table 6

West of Scotland

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by NHS Board of Residence 2003/04 - 2016/17

		Ayrshire ar	nd Arran		Du	ımfries and	Galloway		Grea	ter Glasgo	w and Clyd	е		Lanarks	shire	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	ed prevalenc	e														
2003/04	267	28.0	24.8	31.6	116	32.3	26.7	38.7	963	32.0	30.0	34.0	549	32.1	29.4	34.8
2004/05	276	29.1	25.8	32.7	127	35.4	29.5	42.1	1,003	33.6	31.6	35.8	547	32.0	29.4	34.8
2005/06	309	32.7	29.2	36.6	122	34.0	28.2	40.5	1,028	34.7	32.7	36.9	552	32.4	29.8	35.2
2006/07	331	35.3	31.6	39.3	129	36.0	30.1	42.8	1,003	34.1	32.0	36.2	592	34.9	32.1	37.8
2007/08	312	33.4	29.8	37.3	134	37.5	31.4	44.4	1,058	36.1	34.0	38.4	620	36.5	33.7	39.5
2008/09	361	38.7	34.8	42.9	148	41.5	35.1	48.8	1,146	39.2	37.0	41.6	646	38.1	35.2	41.1
2009/10	364	39.3	35.4	43.5	152	42.9	36.4	50.3	1,130	38.9	36.6	41.2	631	37.2	34.4	40.3
2010/11	379	41.3	37.2	45.6	139	39.6	33.3	46.8	1,117	38.6	36.4	40.9	653	38.7	35.8	41.8
2011/12	382	41.8	37.7	46.2	148	42.2	35.7	49.5	1,167	40.5	38.2	42.9	682	40.5	37.5	43.7
2012/13	390	42.9	38.8	47.4	160	46.2	39.3	53.9	1,180	41.3	39.0	43.7	681	40.5	37.5	43.7
2013/14	405	45.1	40.8	49.7	161	47.0	40.0	54.8	1,243	44.1	41.7	46.6	728	43.6	40.5	46.9
2014/15	434	48.9	44.4	53.7	156	46.0	39.1	53.8	1,309	47.1	44.5	49.7	756	45.7	42.5	49.1
2015/16	400	45.4	41.1	50.1	163	48.7	41.6	56.8	1,303	47.0	44.5	49.6	766	46.5	43.2	49.9
2016/17	413	47.3	42.9	52.1	156	47.3	40.2	55.3	1,236	44.3	41.9	46.8	810	49.4	46.0	52.9
Complete pre	valence															
2009/10	790	85.3	79.4	91.4	348	98.2	88.2	109.1	2,730	93.9	90.4	97.5	1,609	94.9	90.4	99.7
2010/11	834	90.9	84.8	97.2	352	100.4	90.2	111.3	2,824	97.6	94.1	101.3	1,680	99.5	94.9	104.4
2011/12	896	98.0	91.7	104.6	356	101.5	91.3	112.5	2,946	102.3	98.7	106.0	1,769	105.1	100.3	110.1
2012/13	916	100.8	94.4	107.5	363	104.8	94.3	116.0	3,067	107.4	103.7	111.2	1,859	110.6	105.7	115.8
2013/14	939	104.5	98.0	111.4	382	111.5	100.7	123.2	3,189	113.2	109.3	117.2	1,923	115.2	110.1	120.4
2014/15	996	112.1	105.3	119.3	385	113.6	102.6	125.5	3,336	119.9	115.9	124.0	2,027	122.5	117.3	127.9
2015/16	1,037	117.7	110.7	125.1	404	120.8	109.4	133.1	3,384	122.0	117.9	126.1	2,107	127.8	122.5	133.4
2016/17	1,051	120.4	113.3	127.9	411	124.7	113.0	137.2	3,425	122.7	118.6	126.9	2,159	131.6	126.1	137.2

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

By 8-fold Urban Rural Classification

Hospital-based and complete prevalence of life-limiting conditions among children and young people; 0-21 years, by 8-fold Urban Rural Classification; Scotland;

2011/12 - 2016/17

	Lar	ge Urba	n Areas		Oth	ner Urba	n Areas	;	Acces	sible Sı	nall Tov	vns	Rem	ote Sma	all Town	s	Very Re	emote S	Small To	owns	Ac	cessible	e Rural		F	Remote	Rural		Very	/ Remo	te Rura	1
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	d prevale	nce																														
2011/12	1,767	38.7	36.9	40.6	2,015	41.8	40.0	43.7	431	33.9	30.8	37.3	100	34.9	28.4	42.4	56	33.0	24.9	42.8	507	34.4	31.5	37.6	158	42.1	35.8	49.2	101	29.8	24.3	36.2
2012/13	1,793	39.6	37.8	41.5	2,050	42.7	40.8	44.5	440	34.7	31.6	38.1	95	33.3	26.9	40.7	54	32.3	24.3	42.1	533	36.2	33.2	39.4	152	40.8	34.6	47.9	99	29.6	24.1	36.0
2013/14	1,924	43.0	41.1	45.0	2,113	44.3	42.4	46.2	457	36.3	33.1	39.8	124	43.7	36.3	52.0	83	50.5	40.3	62.6	591	40.1	36.9	43.5	156	42.4	36.0	49.6	102	30.7	25.0	37.2
2014/15	2,033	46.0	44.0	48.1	2,185	46.1	44.2	48.1	467	37.4	34.1	41.0	101	35.7	29.1	43.4	74	46.1	36.2	57.9	592	40.0	36.8	43.3	163	44.4	37.9	51.8	101	30.7	25.0	37.3
2015/16	1,920	43.5	41.6	45.5	2,194	46.5	44.5	48.4	479	38.6	35.3	42.2	108	38.4	31.5	46.4	52	32.9	24.6	43.2	570	38.3	35.2	41.5	160	44.2	37.7	51.6	117	35.9	29.7	43.0
2016/17	1,934	43.5	41.6	45.5	2,220	47.3	45.3	49.3	511	41.4	37.9	45.2	123	44.1	36.7	52.6	56	36.1	27.3	46.9	590	39.4	36.3	42.7	146	40.9	34.5	48.1	90	28.1	22.6	34.5
Complete pre	valence												•								•											
2011/12	4,501	98.6	95.8	101.5	5,161	107.1	104.2	110.0	1,157	91.1	85.9	96.5	272	94.8	83.9	106.7	146	86.0	72.6	101.0	1,374	93.3	88.5	98.4	401	106.8	96.7	117.8	294	86.8	77.2	97.3
2012/13	4,763	105.2	102.2	108.2	5,392	112.2	109.3	115.2	1,177	92.9	87.7	98.3	284	99.5	88.3	111.7	145	86.7	73.2	101.9	1,430	97.1	92.1	102.2	405	108.8	98.5	119.9	299	89.4	79.6	100.0
2013/14	4,966	111.1	108.0	114.2	5,575	116.8	113.7	119.8	1,256	99.9	94.5	105.5	308	108.4	96.7	121.2	156	95.0	80.7	111.0	1,529	103.8	98.7	109.1	403	109.5	99.1	120.7	294	88.5	78.7	99.1
2014/15	5,186	117.4	114.2	120.6	5,879	124.1	121.0	127.3	1,307	104.8	99.2	110.6	317	112.2	100.2	125.1	164	102.2	87.2	119.0	1,590	107.3	102.1	112.7	437	119.1	108.2	130.7	289	87.8	78.0	98.4
2015/16	5,271	119.4	116.2	122.6	6,126	129.7	126.5	133.0	1,362	109.9	104.1	115.8	328	116.8	104.5	130.0	168	106.4	91.0	123.6	1,716	115.2	109.8	120.7	431	119.2	108.3	130.9	314	96.4	86.1	107.6
2016/17	5,344	120.3	117.1	123.6	6,220	132.5	129.2	135.8	1,438	116.6	110.7	122.8	329	118.0	105.6	131.3	159	102.6	87.4	119.8	1,713	114.5	109.1	120.0	436	122.1	111.0	134.0	308	96.1	85.7	107.4

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

By diagnostic group

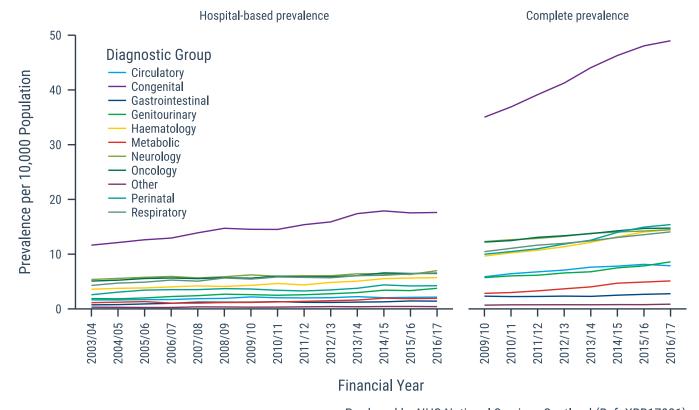
Please refer to the Phase 1(a) Technical Report for details of the ICD10 (International Classification of Disease, Version 10) (http://www.who.int/classifications/icd/en/) codes included in each diagnostic group.

Please note that individuals may be counted in more than one diagnostic group.

Figure 8

By diagnostic group

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by diagnostic group Scotland 2003/04 - 2016/17



Diagnostic Group Set 1

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by diagnostic group Scotland

2003/04 - 2016/17

		Circulato	ory			Congen	ital		(Gastrointes	stinal			Genitourin	nary	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	d prevalence															
2003/04	219	1.6	1.4	1.9	1,551	11.6	11.1	12.2	99	0.7	0.6	0.9	252	1.9	1.7	2.1
2004/05	217	1.6	1.4	1.9	1,608	12.1	11.5	12.7	104	0.8	0.6	0.9	244	1.8	1.6	2.1
2005/06	225	1.7	1.5	1.9	1,675	12.6	12.0	13.2	120	0.9	0.8	1.1	265	2.0	1.8	2.3
2006/07	227	1.7	1.5	2.0	1,715	12.9	12.3	13.6	136	1.0	0.9	1.2	299	2.3	2.0	2.5
2007/08	248	1.9	1.6	2.1	1,843	13.9	13.3	14.5	164	1.2	1.1	1.4	320	2.4	2.2	2.7
2008/09	255	1.9	1.7	2.2	1,956	14.7	14.1	15.4	163	1.2	1.0	1.4	357	2.7	2.4	3.0
2009/10	291	2.2	1.9	2.5	1,932	14.5	13.9	15.2	164	1.2	1.1	1.4	346	2.6	2.3	2.9
2010/11	270	2.0	1.8	2.3	1,929	14.5	13.9	15.2	176	1.3	1.1	1.5	331	2.5	2.2	2.8
2011/12	266	2.0	1.8	2.3	2,046	15.4	14.7	16.1	159	1.2	1.0	1.4	344	2.6	2.3	2.9
2012/13	271	2.0	1.8	2.3	2,103	15.9	15.2	16.6	156	1.2	1.0	1.4	366	2.8	2.5	3.1
2013/14	294	2.2	2.0	2.5	2,285	17.4	16.7	18.1	163	1.2	1.1	1.4	391	3.0	2.7	3.3
2014/15	266	2.0	1.8	2.3	2,331	17.9	17.2	18.6	168	1.3	1.1	1.5	445	3.4	3.1	3.7
2015/16	274	2.1	1.9	2.4	2,279	17.5	16.8	18.3	188	1.4	1.2	1.7	434	3.3	3.0	3.7
2016/17	279	2.1	1.9	2.4	2,286	17.6	16.9	18.4	184	1.4	1.2	1.6	488	3.8	3.4	4.1
Complete pre	valence															
2009/10	780	5.9	5.5	6.3	4,655	35.0	34.0	36.0	309	2.3	2.1	2.6	760	5.7	5.3	6.1
2010/11	854	6.4	6.0	6.9	4,903	36.9	35.9	37.9	299	2.3	2.0	2.5	802	6.0	5.6	6.5
2011/12	900	6.8	6.3	7.2	5,204	39.1	38.1	40.2	302	2.3	2.0	2.5	818	6.2	5.7	6.6
2012/13	938	7.1	6.6	7.6	5,460	41.3	40.2	42.4	309	2.3	2.1	2.6	869	6.6	6.1	7.0
2013/14	1,000	7.6	7.2	8.1	5,784	44.1	42.9	45.2	300	2.3	2.0	2.6	890	6.8	6.3	7.2
2014/15	1,017	7.8	7.3	8.3	6,029	46.3	45.1	47.5	326	2.5	2.2	2.8	977	7.5	7.0	8.0
2015/16	1,057	8.1	7.7	8.6	6,244	48.1	46.9	49.3	346	2.7	2.4	3.0	1,020	7.8	7.4	8.3
2016/17	1,023	7.9	7.4	8.4	6,357	49.0	47.8	50.2	360	2.8	2.5	3.1	1,116	8.6	8.1	9.1

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

Diagnostic Group Set 2

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by diagnostic group Scotland

2003/04 - 2016/17

		Haematology Persons PR CI-				Metabol	lic			Neurolo	gy			Oncolo	JУ	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	d prevalence															
2003/04	479	3.6	3.3	3.9	152	1.1	1.0	1.3	716	5.4	5.0	5.8	677	5.1	4.7	5.5
2004/05	498	3.8	3.4	4.1	163	1.2	1.0	1.4	739	5.6	5.2	6.0	696	5.2	4.9	5.7
2005/06	508	3.8	3.5	4.2	177	1.3	1.1	1.5	765	5.8	5.4	6.2	736	5.5	5.2	6.0
2006/07	533	4.0	3.7	4.4	140	1.1	0.9	1.2	786	5.9	5.5	6.4	748	5.6	5.2	6.1
2007/08	557	4.2	3.9	4.6	140	1.1	0.9	1.2	750	5.7	5.3	6.1	733	5.5	5.1	5.9
2008/09	545	4.1	3.8	4.5	155	1.2	1.0	1.4	780	5.9	5.5	6.3	758	5.7	5.3	6.1
2009/10	573	4.3	4.0	4.7	157	1.2	1.0	1.4	826	6.2	5.8	6.7	746	5.6	5.2	6.0
2010/11	617	4.6	4.3	5.0	169	1.3	1.1	1.5	791	6.0	5.5	6.4	795	6.0	5.6	6.4
2011/12	582	4.4	4.0	4.7	184	1.4	1.2	1.6	806	6.1	5.7	6.5	779	5.9	5.5	6.3
2012/13	640	4.8	4.5	5.2	198	1.5	1.3	1.7	801	6.1	5.6	6.5	775	5.9	5.5	6.3
2013/14	665	5.1	4.7	5.5	212	1.6	1.4	1.8	841	6.4	6.0	6.9	796	6.1	5.7	6.5
2014/15	719	5.5	5.1	5.9	255	2.0	1.7	2.2	835	6.4	6.0	6.9	857	6.6	6.1	7.0
2015/16	733	5.6	5.2	6.1	244	1.9	1.6	2.1	818	6.3	5.9	6.7	841	6.5	6.0	6.9
2016/17	741	5.7	5.3	6.1	250	1.9	1.7	2.2	907	7.0	6.5	7.5	840	6.5	6.0	6.9
Complete prev	/alence															
2009/10	1,283	9.7	9.1	10.2	377	2.8	2.6	3.1	1,635	12.3	11.7	12.9	1,622	12.2	11.6	12.8
2010/11	1,360	10.2	9.7	10.8	397	3.0	2.7	3.3	1,679	12.6	12.0	13.3	1,658	12.5	11.9	13.1
2011/12	1,425	10.7	10.2	11.3	438	3.3	3.0	3.6	1,712	12.9	12.3	13.5	1,739	13.1	12.5	13.7
2012/13	1,503	11.4	10.8	11.9	485	3.7	3.3	4.0	1,756	13.3	12.7	13.9	1,769	13.4	12.8	14.0
2013/14	1,596	12.2	11.6	12.8	528	4.0	3.7	4.4	1,812	13.8	13.2	14.5	1,805	13.8	13.1	14.4
2014/15	1,712	13.1	12.5	13.8	612	4.7	4.3	5.1	1,830	14.1	13.4	14.7	1,857	14.3	13.6	14.9
2015/16	1,828	14.1	13.4	14.7	637	4.9	4.5	5.3	1,849	14.2	13.6	14.9	1,910	14.7	14.0	15.4
2016/17	1,879	14.5	13.8	15.1	663	5.1	4.7	5.5	1,878	14.5	13.8	15.1	1,915	14.8	14.1	15.4

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

Diagnostic Group Set 3

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by diagnostic group

Scotland

2003/04 - 2016/17

		Other				Perinata	al			Respirate	ory	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-based p	revalence											
2003/04	42	0.3	0.2	0.4	345	2.6	2.3	2.9	571	4.3	3.9	4.7
2004/05	38	0.3	0.2	0.4	406	3.1	2.8	3.4	625	4.7	4.3	5.1
2005/06	34	0.3	0.2	0.4	455	3.4	3.1	3.8	648	4.9	4.5	5.3
2006/07	34	0.3	0.2	0.4	466	3.5	3.2	3.8	698	5.3	4.9	5.7
2007/08	49	0.4	0.3	0.5	467	3.5	3.2	3.9	672	5.1	4.7	5.5
2008/09	47	0.4	0.3	0.5	492	3.7	3.4	4.0	750	5.6	5.2	6.1
2009/10	42	0.3	0.2	0.4	483	3.6	3.3	4.0	724	5.4	5.1	5.9
2010/11	44	0.3	0.2	0.4	452	3.4	3.1	3.7	775	5.8	5.4	6.3
2011/12	50	0.4	0.3	0.5	435	3.3	3.0	3.6	766	5.8	5.4	6.2
2012/13	56	0.4	0.3	0.5	459	3.5	3.2	3.8	752	5.7	5.3	6.1
2013/14	51	0.4	0.3	0.5	494	3.8	3.4	4.1	796	6.1	5.7	6.5
2014/15	57	0.4	0.3	0.6	571	4.4	4.0	4.8	800	6.1	5.7	6.6
2015/16	58	0.4	0.3	0.6	544	4.2	3.8	4.6	834	6.4	6.0	6.9
2016/17	54	0.4	0.3	0.5	551	4.2	3.9	4.6	854	6.6	6.1	7.0
Complete prevale	ence											
2009/10	91	0.7	0.6	0.8	1,327	10.0	9.5	10.5	1,389	10.5	9.9	11.0
2010/11	99	0.7	0.6	0.9	1,391	10.5	9.9	11.0	1,470	11.1	10.5	11.6
2011/12	100	0.8	0.6	0.9	1,460	11.0	10.4	11.6	1,549	11.6	11.1	12.2
2012/13	101	0.8	0.6	0.9	1,567	11.8	11.3	12.4	1,584	12.0	11.4	12.6
2013/14	99	0.8	0.6	0.9	1,647	12.5	12.0	13.2	1,632	12.4	11.8	13.1
2014/15	102	0.8	0.6	1.0	1,821	14.0	13.3	14.6	1,700	13.1	12.4	13.7
2015/16	101	0.8	0.6	0.9	1,941	14.9	14.3	15.6	1,762	13.6	12.9	14.2
2016/17	112	0.9	0.7	1.0	1,999	15.4	14.7	16.1	1,826	14.1	13.4	14.7

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

By local authority

Scotland's 32 local authorities have been grouped into the following regions:

- · Aberdeen and North East
 - Aberdeen City
 - o Aberdeenshire
 - Moray
- · Edinburgh and Lothians
 - o City of Edinburgh
 - East Lothian
 - Midlothian
 - West Lothian
- · Glasgow and Strathclyde
 - o East Ayrshire
 - East Dunbartonshire
 - East Renfrewshire
 - Glasgow City
 - o Inverclyde
 - North Ayrshire
 - North Lanarkshire
 - o Renfrewshire
 - · South Ayrshire
 - South Lanarkshire
 - West Dunbartonshire
- · Highland and Islands
 - o Argyll and Bute
 - Highland
 - o Na h-Eileanan Siar
 - Orkney Islands
 - Shetland Islands
- · Scotland South
 - Dumfries and Galloway
 - o Scottish Borders
- Tayside, Central and Fife
 - Angus
 - o Clackmannanshire
 - Dundee City
 - Falkirk
 - ∘ Fife
 - Fife
 - Perth and Kinross
 - o Stirling

Individuals have been assigned to a local authority based on the postcode recorded in their first SMR01/SBR/Community Prescription record in each financial year.

Aberdeen and North East by Local Authority

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by Local Authority 2003/04 - 2016/17

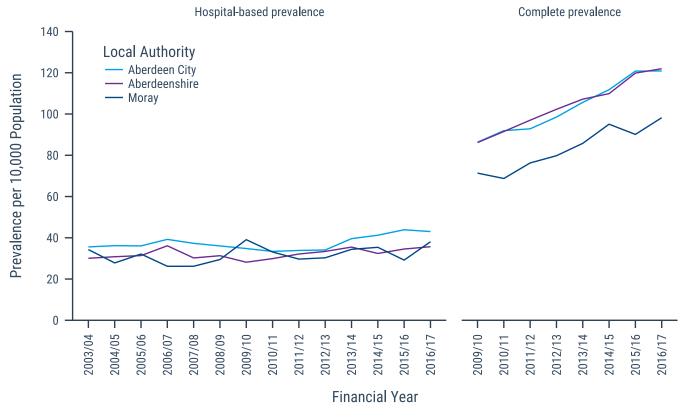


Table 11

Aberdeen and North East

 $Hospital-based\ and\ complete\ prevalence\ of\ life-limiting\ conditions\ among\ children\ and\ young\ people$

0-21 years, by Local Authority

2003/04 - 2016/17

		Aberdeen	City			Aberdeen	shire			Moray	Ī	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-based p	prevalence											
2003/04	187	35.6	30.7	41.0	189	30.1	25.9	34.7	80	34.3	27.2	42.6
2004/05	186	36.2	31.2	41.8	195	30.8	26.6	35.4	65	27.8	21.5	35.4
2005/06	186	36.1	31.1	41.6	199	31.4	27.2	36.0	75	32.1	25.3	40.2
2006/07	204	39.2	34.0	45.0	231	36.1	31.6	41.1	61	26.2	20.0	33.6
2007/08	196	37.3	32.3	42.9	194	30.2	26.1	34.8	61	26.2	20.0	33.6
2008/09	190	36.0	31.1	41.5	201	31.3	27.1	35.9	69	29.5	22.9	37.3
2009/10	185	34.8	30.0	40.2	181	28.2	24.2	32.6	92	39.1	31.5	47.9
2010/11	179	33.4	28.7	38.6	193	29.9	25.8	34.4	78	33.1	26.2	41.3
2011/12	182	33.9	29.1	39.1	209	32.1	27.9	36.8	70	29.7	23.1	37.5
2012/13	183	34.1	29.3	39.4	218	33.4	29.1	38.1	71	30.3	23.7	38.2
2013/14	209	39.6	34.4	45.3	233	35.5	31.1	40.3	81	34.4	27.3	42.7
2014/15	214	41.2	35.9	47.1	214	32.4	28.2	37.0	83	35.4	28.2	43.8
2015/16	227	43.9	38.4	50.0	228	34.5	30.2	39.3	68	29.2	22.7	37.0
2016/17	222	43.0	37.5	49.0	234	35.7	31.3	40.5	88	38.1	30.5	46.9
Complete preval	ence											
2009/10	459	86.3	78.6	94.5	554	86.2	79.2	93.6	168	71.4	61.0	82.9
2010/11	493	91.9	84.0	100.4	591	91.5	84.3	99.2	162	68.7	58.6	80.1
2011/12	499	92.8	84.9	101.3	631	97.0	89.6	104.8	180	76.3	65.6	88.2
2012/13	529	98.5	90.3	107.2	668	102.3	94.7	110.3	187	79.8	68.8	92.0
2013/14	558	105.7	97.1	114.7	704	107.2	99.5	115.4	202	85.8	74.4	98.4
2014/15	580	111.8	102.9	121.2	726	109.9	102.1	118.1	223	95.1	83.0	108.3
2015/16	625	120.8	111.6	130.6	791	119.8	111.7	128.4	210	90.1	78.4	103.1
2016/17	624	120.9	111.6	130.7	800	122.0	113.7	130.7	227	98.2	85.9	111.8

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

Edinburgh and Lothians

Figure 10

Edinburgh and Lothians by Local Authority

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by Local Authority 2003/04 - 2016/17

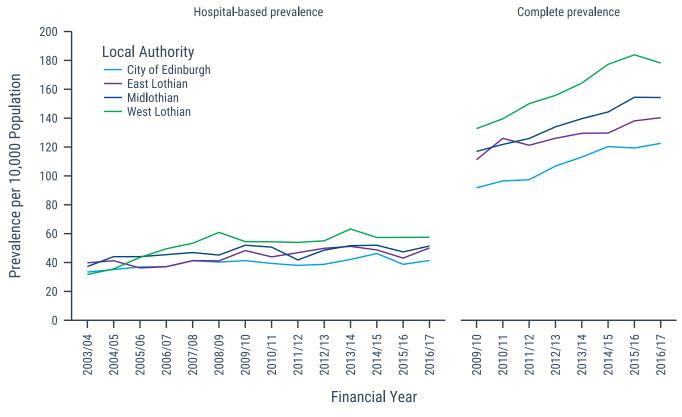


Table 12

Edinburgh and Lothians

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by Local Authority

2003/04 - 2016/17

Financial Year	Persons									Midloth						
		PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-based	l prevalence															
2003/04	362	33.4	30.0	37.0	96	39.8	32.3	48.6	82	37.3	29.6	46.2	146	31.7	26.8	37.3
2004/05	378	35.2	31.7	38.9	100	41.2	33.6	50.1	96	44.1	35.7	53.8	165	35.6	30.4	41.4
2005/06	401	36.9	33.4	40.7	88	36.2	29.1	44.6	95	44.1	35.7	53.8	203	43.5	37.8	49.9
2006/07	405	37.1	33.6	40.9	91	37.1	29.9	45.5	97	45.5	36.9	55.4	233	49.5	43.4	56.3
2007/08	453	41.2	37.5	45.2	103	41.3	33.7	50.1	100	46.9	38.2	57.0	253	53.3	47.0	60.3
2008/09	445	40.3	36.6	44.2	106	41.2	33.7	49.8	97	45.2	36.6	55.1	291	60.9	54.1	68.3
2009/10	462	41.3	37.7	45.3	125	48.3	40.2	57.5	112	52.0	42.8	62.5	261	54.5	48.1	61.5
2010/11	448	39.4	35.8	43.2	114	43.9	36.3	52.8	109	50.7	41.6	61.1	261	54.4	48.0	61.4
2011/12	437	38.0	34.5	41.8	122	46.8	38.9	55.9	91	41.8	33.7	51.3	260	54.0	47.6	60.9
2012/13	441	38.8	35.2	42.5	131	49.9	41.7	59.2	107	48.6	39.8	58.7	265	55.0	48.6	62.1
2013/14	475	42.1	38.4	46.1	134	51.2	42.9	60.6	114	51.7	42.6	62.0	303	63.2	56.3	70.7
2014/15	521	46.2	42.4	50.4	127	48.7	40.6	57.9	116	52.0	43.0	62.3	275	57.3	50.8	64.5
2015/16	440	38.8	35.2	42.5	112	43.1	35.5	51.8	107	47.4	38.8	57.2	275	57.4	50.8	64.6
2016/17	475	41.4	37.7	45.3	130	50.1	41.9	59.5	117	51.4	42.5	61.6	275	57.5	50.9	64.7
Complete preva	alence															
2009/10	1,026	91.8	86.3	97.5	288	111.2	98.8	124.7	252	117.0	103.0	132.2	636	132.8	122.7	143.4
2010/11	1,098	96.5	90.9	102.3	327	126.0	112.8	140.3	262	121.8	107.6	137.4	670	139.6	129.3	150.5
2011/12	1,119	97.4	91.8	103.2	316	121.2	108.3	135.3	274	125.9	111.5	141.6	723	150.0	139.4	161.3
2012/13	1,215	106.8	100.9	112.9	331	126.0	112.9	140.3	295	134.0	119.2	150.1	750	155.8	144.9	167.2
2013/14	1,274	113.0	107.0	119.4	339	129.5	116.1	143.9	308	139.6	124.6	156.0	787	164.2	153.0	176.0
2014/15	1,355	120.3	114.0	126.8	338	129.7	116.3	144.2	322	144.3	129.0	160.8	850	177.3	165.6	189.5
2015/16	1,355	119.3	113.1	125.8	359	138.1	124.3	153.0	349	154.5	138.8	171.4	881	183.9	172.0	196.3
2016/17	1,407	122.5	116.2	129.1	364	140.3	126.3	155.4	351	154.3	138.7	171.1	852	178.2	166.5	190.4

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

CI+ = Prevalence per 10,000 Population (upper 95% Confidence Interval)

Table 13

Glasgow and Strathclyde (Part 1)

Hospital-based and complete prevalence of life-limiting conditions among children and young people
0-21 years, by Local Authority

	ı	East Ayı	shire		East	t Dunbaı	tonshii	e	Eas	st Renfr	ewshire	:		Glasgov	v City		Inverclyde			North Ayrshire				
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	d prevale	nce																						
2003/04	75	23.6	18.6	29.6	68	23.4	18.1	29.6	77	30.5	24.1	38.1	515	33.2	30.4	36.2	63	28.6	22.0	36.6	100	27.3	22.3	33.3
2004/05	85	26.7	21.3	33.0	62	21.6	16.6	27.7	91	36.1	29.1	44.3	530	34.6	31.7	37.6	70	32.3	25.2	40.8	103	28.4	23.2	34.5
2005/06	92	29.1	23.5	35.7	65	23.0	17.8	29.4	82	32.6	25.9	40.4	564	37.0	34.0	40.2	68	31.6	24.5	40.0	121	33.7	28.0	40.3
2006/07	107	34.0	27.9	41.1	76	27.2	21.5	34.1	83	33.1	26.4	41.1	545	35.9	32.9	39.0	77	36.3	28.6	45.3	126	35.3	29.4	42.0
2007/08	105	33.5	27.4	40.6	78	28.4	22.5	35.5	79	31.7	25.1	39.5	570	37.6	34.6	40.9	79	37.8	29.9	47.1	121	34.1	28.3	40.7
2008/09	117	37.5	31.0	44.9	87	32.0	25.6	39.4	90	36.2	29.1	44.5	622	41.1	37.9	44.4	79	38.3	30.3	47.7	147	41.4	35.0	48.7
2009/10	111	35.7	29.4	43.0	86	31.8	25.4	39.3	76	30.6	24.1	38.3	614	40.6	37.4	43.9	79	38.9	30.8	48.4	159	45.1	38.4	52.7
2010/11	124	40.1	33.4	47.8	74	27.5	21.6	34.6	87	35.0	28.0	43.1	640	42.5	39.3	45.9	82	40.9	32.6	50.8	145	41.6	35.2	49.0
2011/12	125	40.7	33.9	48.5	97	36.3	29.5	44.3	90	36.1	29.0	44.3	633	42.2	39.0	45.6	72	36.4	28.5	45.8	144	41.6	35.1	49.0
2012/13	119	38.9	32.2	46.5	90	33.9	27.2	41.6	98	39.4	32.0	48.0	656	44.2	40.8	47.7	75	38.5	30.3	48.3	158	45.9	39.1	53.6
2013/14	137	45.2	38.0	53.5	107	40.9	33.5	49.4	87	34.8	27.9	42.9	685	46.9	43.4	50.5	77	40.2	31.8	50.3	150	44.3	37.5	52.0
2014/15	142	47.4	39.9	55.8	105	40.1	32.8	48.5	96	38.0	30.8	46.4	730	50.9	47.3	54.7	88	46.9	37.6	57.7	164	49.1	41.9	57.2
2015/16	120	40.3	33.4	48.2	117	44.8	37.1	53.7	103	40.7	33.2	49.3	704	49.1	45.5	52.8	97	52.2	42.4	63.7	160	48.4	41.2	56.5
2016/17	149	50.5	42.7	59.2	105	40.1	32.8	48.6	90	35.2	28.3	43.3	665	45.8	42.4	49.4	90	49.1	39.5	60.4	150	45.9	38.8	53.8
Complete prev	valence																							
2009/10	255	82.0	72.3	92.7	202	74.7	64.8	85.7	224	90.2	78.8	102.8	1,509	99.7	94.8	104.8	184	90.6	78.0	104.6	299	84.8	75.5	95.0
2010/11	275	89.0	78.8	100.1	217	80.8	70.4	92.2	232	93.3	81.7	106.0	1,561	103.6	98.6	108.9	190	94.9	81.9	109.3	323	92.8	83.0	103.4
2011/12	290	94.4	83.9	105.9	228	85.4	74.7	97.2	235	94.2	82.5	106.9	1,643	109.6	104.4	115.0	185	93.5	80.6	107.9	349	100.8	90.6	111.9
2012/13	292	95.4	84.8	106.9	231	86.9	76.1	98.8	255	102.5	90.4	115.8	1,693	113.9	108.6	119.5	202	103.8	90.1	119.1	359	104.3	93.9	115.7
2013/14	318	105.0	93.8	117.1	245	93.6	82.2	106.0	267	106.7	94.3	120.2	1,747	119.6	114.1	125.3	211	110.3	96.0	126.1	350	103.4	92.9	114.8
2014/15	315	105.1	93.9	117.3	267	102.0	90.2	114.9	283	112.0	99.4	125.8	1,813	126.4	120.7	132.3	229	121.9	106.7	138.7	392	117.3	106.0	129.4
2015/16	325	109.2	97.7	121.6	278	106.4	94.4	119.6	288	113.7	101.0	127.5	1,830	127.6	121.8	133.5	234	126.0	110.5	143.1	413	124.9	113.2	137.4
2016/17	346	117.2	105.2	130.1	303	115.8	103.2	129.5	279	109.2	96.8	122.7	1,840	126.7	121.0	132.6	246	134.3	118.1	152.0	409	125.1	113.3	137.8

Note:

2003/04 - 2016/17

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

Table 14

Glasgow and Strathclyde (Part 2)

Hospital-based and complete prevalence of life-limiting conditions among children and young people
0-21 years, by Local Authority

North Lanarkshire						Renfrew	shire		\$	outh A	rshire		So	uth Lan	arkshire	9	West Dunbartonshire			
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	ed prevale	nce																		
2003/04	315	34.8	31.1	38.9	148	33.0	27.9	38.8	92	34.1	27.5	41.8	234	29.0	25.4	32.9	91	36.1	29.0	44.2
2004/05	310	34.3	30.6	38.4	148	33.2	28.1	39.0	88	32.8	26.3	40.4	237	29.4	25.8	33.4	102	41.2	33.6	49.9
2005/06	315	34.9	31.2	39.0	151	34.0	28.8	39.9	96	35.7	28.9	43.6	237	29.6	26.0	33.6	98	40.3	32.7	49.1
2006/07	351	39.0	35.0	43.3	138	31.2	26.2	36.8	98	36.8	29.9	44.8	241	30.2	26.6	34.3	84	34.9	27.9	43.2
2007/08	342	37.9	34.0	42.1	147	33.3	28.2	39.2	86	32.3	25.8	39.9	278	35.0	31.0	39.3	105	44.0	36.0	53.2
2008/09	356	39.4	35.4	43.7	166	37.6	32.1	43.8	97	36.4	29.6	44.4	290	36.6	32.5	41.1	102	43.0	35.1	52.2
2009/10	348	38.4	34.5	42.7	160	36.6	31.1	42.7	94	35.7	28.9	43.7	283	35.9	31.8	40.3	115	48.9	40.4	58.7
2010/11	378	41.9	37.8	46.3	136	31.2	26.2	36.9	110	42.2	34.7	50.8	275	35.0	31.0	39.4	98	42.3	34.3	51.5
2011/12	379	42.0	37.9	46.4	164	37.6	32.1	43.8	113	43.3	35.7	52.0	303	38.8	34.5	43.4	111	48.2	39.7	58.1
2012/13	372	41.4	37.3	45.8	160	37.0	31.5	43.2	113	43.7	36.0	52.5	309	39.6	35.3	44.2	101	44.3	36.1	53.8
2013/14	385	43.1	38.9	47.6	182	42.5	36.6	49.1	118	45.9	38.0	55.0	343	44.2	39.6	49.1	105	46.7	38.2	56.5
2014/15	403	45.5	41.2	50.2	178	42.0	36.1	48.7	128	50.4	42.0	59.9	353	45.9	41.3	51.0	112	50.4	41.6	60.7
2015/16	410	46.6	42.2	51.3	160	38.1	32.5	44.5	120	47.5	39.4	56.8	355	46.2	41.6	51.3	122	55.4	46.1	66.1
2016/17	437	49.7	45.2	54.6	178	42.4	36.4	49.1	114	45.5	37.5	54.6	371	48.7	43.9	53.9	110	50.2	41.3	60.5
Complete pre	valence																			
2009/10	870	96.1	89.8	102.6	378	86.4	78.0	95.5	236	89.7	78.6	101.8	739	93.6	87.0	100.6	233	99.1	86.9	112.6
2010/11	927	102.7	96.3	109.5	392	89.9	81.2	99.2	236	90.5	79.3	102.7	753	95.9	89.2	102.9	232	100.0	87.6	113.7
2011/12	963	106.7	100.1	113.7	408	93.5	84.7	103.0	257	98.5	86.9	111.2	806	103.2	96.2	110.5	247	107.4	94.4	121.5
2012/13	1,016	113.0	106.2	120.1	430	99.4	90.3	109.2	265	102.4	90.5	115.5	843	108.0	100.8	115.5	256	112.2	98.9	126.7
2013/14	1,041	116.5	109.6	123.8	443	103.5	94.1	113.5	271	105.5	93.3	118.7	882	113.6	106.3	121.3	276	122.8	108.8	138.0
2014/15	1,076	121.5	114.4	128.9	445	105.1	95.6	115.3	289	113.7	101.0	127.5	952	123.9	116.2	131.9	298	134.2	119.5	150.2
2015/16	1,111	126.2	118.9	133.7	457	108.9	99.2	119.3	299	118.4	105.4	132.5	995	129.6	121.7	137.9	297	134.9	120.1	151.1
2016/17	1,152	131.0	123.6	138.7	465	110.7	101.0	121.2	296	118.1	105.1	132.3	1,007	132.2	124.2	140.6	292	133.4	118.6	149.4

Note:

2003/04 - 2016/17

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

Highland and Islands by Local Authority

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by Local Authority 2003/04 - 2016/17

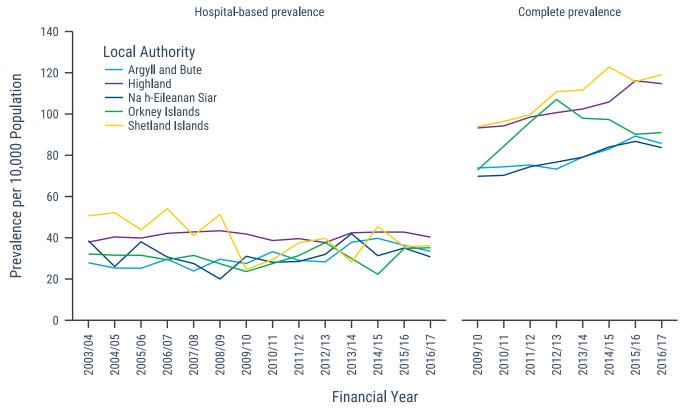


Table 15

Highland and Islands

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by Local Authority

2003/04 - 2016/17

	A	rgyll an	d Bute			Highla	and		Na	h-Eilea	nan Siar	•		Orkney Is	lands		s	hetland I	slands	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-base	ed prevalen	ce																		
2003/04	62	27.9	21.4	35.8	203	37.9	32.9	43.5	25	38.6	25.0	56.9	16	32.2	18.4	52.2	31	50.7	34.4	71.8
2004/05	56	25.3	19.1	32.8	219	40.4	35.2	46.1	17	26.1	15.2	41.7	16	31.6	18.0	51.2	32	52.1	35.7	73.5
2005/06	55	25.2	19.0	32.8	218	39.9	34.7	45.5	25	38.1	24.6	56.1	16	31.5	18.0	51.1	27	43.9	28.9	63.7
2006/07	64	29.6	22.8	37.8	232	42.1	36.9	47.9	20	30.6	18.7	47.3	15	29.3	16.4	48.3	33	54.1	37.3	75.9
2007/08	51	23.9	17.8	31.4	237	42.8	37.6	48.6	18	27.5	16.3	43.5	16	31.4	18.0	51.0	25	41.1	26.6	60.6
2008/09	62	29.6	22.7	37.9	242	43.4	38.1	49.2	13	20.0	10.7	34.2	14	27.4	15.0	46.0	31	51.3	34.9	72.7
2009/10	57	27.5	20.8	35.6	234	41.8	36.6	47.5	20	31.0	19.0	47.9	12	23.6	12.2	41.2	15	24.7	13.8	40.7
2010/11	68	33.3	25.9	42.2	217	38.7	33.7	44.1	18	28.1	16.7	44.4	14	27.5	15.0	46.1	18	29.4	17.4	46.4
2011/12	59	29.0	22.1	37.4	223	39.6	34.6	45.1	18	28.5	16.9	45.0	16	31.4	17.9	50.9	23	37.6	23.8	56.3
2012/13	56	28.3	21.4	36.7	211	37.7	32.8	43.1	20	32.0	19.5	49.3	19	37.7	22.7	58.8	24	39.7	25.4	59.0
2013/14	75	37.8	29.7	47.4	236	42.4	37.2	48.2	26	42.0	27.4	61.4	15	30.0	16.8	49.4	17	28.3	16.5	45.3
2014/15	78	39.7	31.4	49.6	236	42.8	37.5	48.6	19	31.3	18.9	48.8	11	22.3	11.1	39.9	27	45.4	29.9	66.0
2015/16	70	36.3	28.3	45.9	236	42.7	37.5	48.6	21	35.0	21.7	53.5	17	34.8	20.3	55.7	21	35.7	22.1	54.6
2016/17	64	33.5	25.8	42.7	221	40.3	35.2	46.0	18	30.7	18.2	48.5	17	35.2	20.5	56.2	21	36.2	22.4	55.3
Complete pre	valence																			
2009/10	153	73.8	62.6	86.5	522	93.3	85.5	101.6	45	69.8	51.0	93.3	37	72.8	51.3	100.2	57	93.8	71.1	121.3
2010/11	152	74.4	63.1	87.2	529	94.2	86.4	102.6	45	70.3	51.3	93.9	43	84.4	61.1	113.5	59	96.4	73.5	124.2
2011/12	153	75.3	63.9	88.1	555	98.5	90.5	107.0	47	74.5	54.8	98.9	49	96.1	71.2	126.8	61	99.7	76.3	127.9
2012/13	145	73.3	61.9	86.2	564	100.6	92.5	109.3	48	76.7	56.6	101.6	54	107.0	80.5	139.4	67	110.8	86.0	140.5
2013/14	157	79.1	67.3	92.5	570	102.5	94.3	111.2	49	79.1	58.6	104.4	49	97.9	72.5	129.3	67	111.6	86.6	141.5
2014/15	163	83.0	70.8	96.7	584	105.8	97.5	114.7	51	84.0	62.6	110.3	48	97.3	71.8	128.8	73	122.8	96.4	154.1
2015/16	172	89.3	76.5	103.6	641	116.1	107.3	125.4	52	86.7	64.8	113.6	44	90.1	65.6	120.8	68	115.7	90.0	146.5
2016/17	164	85.7	73.2	99.8	629	114.7	106.0	124.0	49	83.7	62.0	110.5	44	91.0	66.2	122.0	69	119.0	92.7	150.4

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

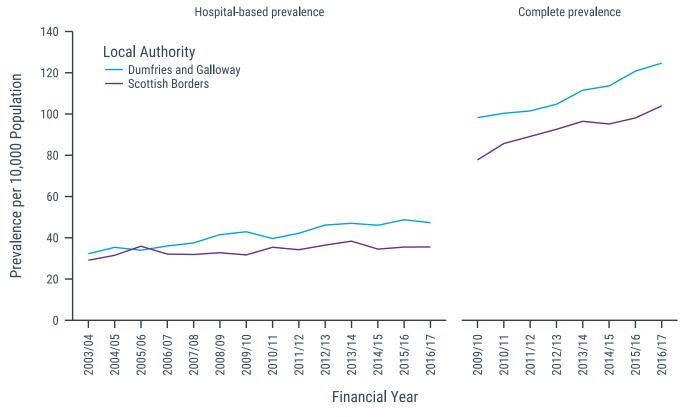
PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

CI+ = Prevalence per 10,000 Population (upper 95% Confidence Interval)

Scotland South by Local Authority

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by Local Authority 2003/04 - 2016/17



Scotland South

Hospital-based and complete prevalence of life-limiting conditions among children and young people 0-21 years, by Local Authority 2003/04 - 2016/17

	D	umfries and	Galloway			Scottish Bo	rders	
Financial Year	Persons	PR	CI-	CI+	Persons	PR	CI-	CI+
Hospital-based	prevalence							
2003/04	116	32.3	26.7	38.7	77	29.1	23.0	36.4
2004/05	127	35.4	29.5	42.1	84	31.5	25.1	39.0
2005/06	122	34.0	28.2	40.5	96	35.9	29.1	43.8
2006/07	129	36.0	30.1	42.8	86	32.1	25.7	39.6
2007/08	134	37.5	31.4	44.4	86	31.9	25.5	39.4
2008/09	148	41.5	35.1	48.8	89	32.7	26.3	40.3
2009/10	152	42.9	36.4	50.3	86	31.7	25.4	39.1
2010/11	139	39.6	33.3	46.8	95	35.4	28.6	43.3
2011/12	148	42.2	35.7	49.5	91	34.2	27.6	42.0
2012/13	160	46.2	39.3	53.9	96	36.4	29.5	44.5
2013/14	161	47.0	40.0	54.8	101	38.4	31.3	46.6
2014/15	156	46.0	39.1	53.8	91	34.5	27.8	42.3
2015/16	163	48.7	41.6	56.8	93	35.5	28.7	43.5
2016/17	156	47.3	40.2	55.3	93	35.5	28.7	43.5
Complete preva	lence							
2009/10	348	98.2	88.2	109.1	211	77.8	67.7	88.9
2010/11	352	100.4	90.2	111.3	230	85.7	75.0	97.5
2011/12	356	101.5	91.3	112.5	237	89.1	78.2	101.2
2012/13	363	104.8	94.3	116.0	244	92.6	81.4	104.9
2013/14	382	111.5	100.7	123.2	254	96.5	85.0	109.0
2014/15	385	113.6	102.6	125.5	251	95.2	83.8	107.6
2015/16	404	120.8	109.4	133.1	257	98.1	86.5	110.8
2016/17	411	124.7	113.0	137.2	272	104.0	92.0	117.0

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

Table 17

Tayside, Central and Fife

Hospital-based and complete prevalence of life-limiting conditions among children and young people
0-21 years, by Local Authority
2003/04 - 2016/17

		Angu	IS		Cla	ckmann	anshir	е		Dundee	City			Falki	rk		Fife			Per	th and	Kinross	;	Stirling				
Financial	Persons	PR	CI-	CIT	Persons	PR	CI-	CIT	Persons	PR	CI-	CIT	Persons	PR	CI-	CIT	Persons	PR	CI-	CIT	Persons	DD	CI-	CIT	Persons	DD	CI-	CI+
			CI-	CIT	reisulis	FN	UI-	CIT	reisulis	FR	UI-	CIT	reisolis	FK	UI-	Ult	reisolis	FK	UI-	Ult	reisulis	FN	GI-	CIT	reisulis	FK	OI-	GIT
Hospital-bas	•																											
2003/04	76	27.6	21.8	34.6	34	26.2	18.1	36.5	130	33.6	28.0	39.8	94	24.4	19.7		271	28.9	25.6	32.6	83	24.9		30.9	59		18.5	31.3
2004/05	86	31.0	24.8	38.2	28	21.6	14.3	31.2	140	36.4	30.6	43.0	103	26.6	21.8	32.3	298	31.9	28.4	35.8	102	30.8	25.1	37.4	58	24.3	18.5	31.4
2005/06	97	34.6	28.1	42.2	41	31.3	22.5	42.4	133	34.5	28.9	40.8	120	30.8	25.6	36.9	342	36.6	32.9	40.7	110	33.1	27.2	39.9	66	27.2	21.1	34.6
2006/07	90	31.9	25.7	39.2	36	28.0	19.7	38.8	132	34.3	28.7	40.6	123	31.7	26.3	37.8	337	36.2	32.4	40.2	116	34.8	28.8	41.7	69	28.1	21.9	35.5
2007/08	96	34.0	27.5	41.5	27	20.4	13.5	29.7	126	32.7	27.3	39.0	132	33.9	28.3	40.1	354	38.3	34.4	42.5	104	30.9	25.2	37.4	70	28.5	22.2	36.0
2008/09	83	29.3	23.3	36.3	43	32.4	23.4	43.6	141	36.4	30.6	42.9	135	34.5	28.9	40.8	359	38.9	35.0	43.1	101	29.7	24.2	36.0	85	34.8	27.8	43.0
2009/10	88	31.2	25.0	38.4	40	30.2	21.6	41.2	152	38.9	33.0	45.6	150	38.1	32.3	44.7	356	38.5	34.6	42.7	104	30.3	24.8	36.7	72	29.7	23.2	37.3
2010/11	91	32.2	25.9	39.5	42	32.2	23.2	43.5	133	33.9	28.4	40.2	168	42.5	36.4	49.5	365	39.4	35.5	43.7	105	30.3	24.8	36.7	76	31.0	24.4	38.8
2011/12	81	28.7	22.8	35.7	46	35.4	25.9	47.2	143	36.2	30.5	42.6	157	39.6	33.6	46.3	363	39.1	35.2	43.3	89	25.5	20.5	31.4	79	32.2	25.5	40.1
2012/13	74	26.4	20.7	33.1	47	36.5	26.9	48.6	136	34.8	29.2	41.2	144	36.3	30.6	42.7	379	40.9	36.9	45.2	106	30.1	24.7	36.4	79	32.3	25.6	40.3
2013/14	104	37.3	30.5	45.2	54	42.0	31.6	54.8	150	39.1	33.1	45.9	137	34.8	29.2	41.1	359	38.8	34.9	43.0	114	32.8	27.0	39.4	78	32.3	25.6	40.3
2014/15	91	32.7	26.4	40.2	58	45.6	34.6	58.9	172	46.2	39.6	53.7	163	41.5	35.4	48.3	364	39.6	35.7	43.9	114	32.8	27.0	39.4	88	36.8	29.5	45.3
2015/16	108	39.1	32.1	47.2	51	40.4	30.1	53.1	150	40.8	34.5	47.8	166	42.4	36.2	49.3	356	38.7	34.8	42.9	136	39.3	33.0	46.5	88	36.2	29.0	44.5
2016/17	117	43.2	35.7	51.7	55	43.7	33.0	56.9	156	42.5	36.1	49.7	170	43.5	37.2	50.5	365	39.8	35.8	44.0	137	40.0	33.6	47.3	80	32.7	25.9	40.7
Complete pro	evalence																											
2009/10	222	78.7	68.7	89.7	100	75.6	61.6	91.9	312	79.8	71.3	89.2	321	81.6	72.9	90.9	871	94.1	88.0	100.5	265	77.2	68.2	87.1	196	80.7	69.8	92.8
2010/11	221	78.1	68.2	89.1	106	81.2	66.5	98.1	332	84.6	75.8	94.2	360	91.1	82.0	101.0	910	98.3	92.0	104.8	256	73.9	65.2	83.5	188	76.7	66.1	88.4
2011/12	231	82.0	71.8	93.2	110	84.6	69.6	101.9	344	87.1	78.2	96.8	365	92.0	82.9	101.9	978	105.3	98.8	112.1	265	76.0	67.2	85.7	206	83.8	72.8	96.1
2012/13	232	82.6	72.4	93.9	122	94.9	78.8	113.2	360	92.1	82.9	102.1	375	94.6	85.3	104.6	1,005	108.5	101.9	115.3	279	79.3	70.3	89.1	222	90.9	79.4	103.6
2013/14	261	93.6	82.6	105.6	133	103.5	86.7	122.5	391	102.0	92.2	112.6	393	99.9	90.3	110.2	1,030	111.4	104.7	118.4	302	86.8	77.4	97.2	228	94.5	82.7	107.5
2014/15	260	93.5	82.5	105.5	137	107.7	90.5	127.2	397	106.7	96.5	117.7	405	103.1	93.3	113.6	1,081	117.7	110.8	124.9	329	94.6	84.7	105.3	255	106.6	94.0	120.5
2015/16	280	101.4	89.9	113.9	137	108.6	91.2	128.2	415	112.8	102.2	124.1	444	113.4	103.1	124.4	1,103	119.9	113.0	127.2	356	102.9	92.5	114.1	248	101.9	89.7	115.3
2016/17	295	108.9	96.9	122.0	140	111.3	93.7	131.2	413	112.5	102.0	123.9	462	118.2	107.7	129.4	1,126	122.6	115.6	130.0	359	104.8	94.3	116.2	255	104.2	91.8	117.7

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

PR = Prevalence per 10,000 Population

CI- = Prevalence per 10,000 Population (lower 95% Confidence Interval)

By Ethnic Group

Ethnicity recorded on SMR01 and SBR records have been collapsed into four main groups:

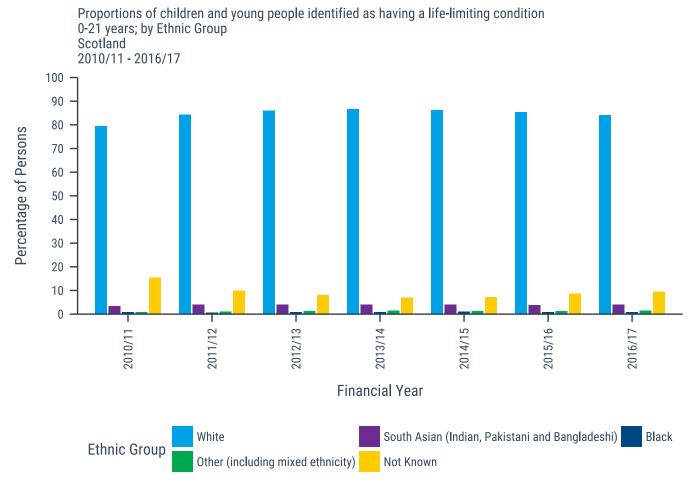
- White
- South Asian (Indian, Pakistani and Bangladeshi)
- Black
- Other (including mixed ethnicity)

Individuals whose ethnicity is not known have been included in a separate 'Not Known' group.

Population data required to calculate prevalence by ethnic group are not available for age group 0-21. Proportions of each ethnic group in each age group have been calculated and presented in the figure and table below.

Figure 15

By Ethnic Group



By Ethnic Group

Proportions of children and young people identified as having a life-limiting condition; 0-21 years: by Ethnic Group:

Scotland;

2010/11 - 2016/17

Financial Year

Ethnic Group	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
White	79.5%	84.3%	85.9%	86.5%	86.3%	85.4%	84.0%
South Asian (Indian, Pakistani and Bangladeshi)	3.3%	4.0%	4.1%	4.0%	4.1%	3.8%	4.0%
Black	0.9%	0.7%	0.8%	0.9%	1.0%	0.9%	0.8%
Other (including mixed ethnicity)	0.8%	1.1%	1.3%	1.5%	1.3%	1.3%	1.5%
Not Known	15.4%	9.9%	7.9%	7.0%	7.2%	8.6%	9.6%

Note:

By SIMD (2016) Quintile

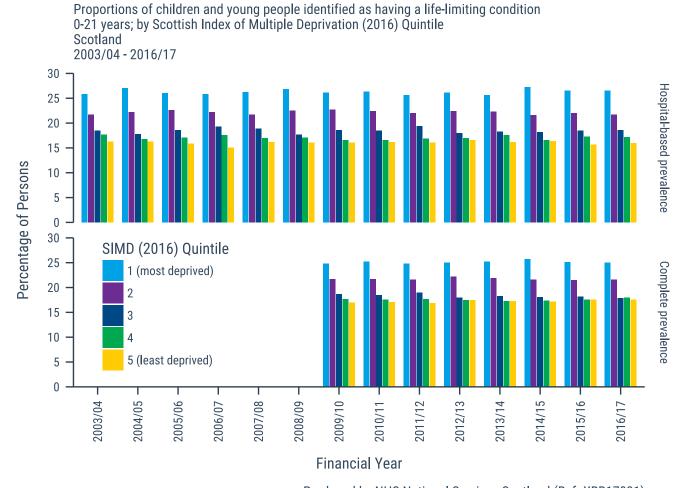
The Scottish Index of Multiple Deprivation (http://www.gov.scot/Topics/Statistics/SIMD) is the Scottish Government's official tool for identifying areas in Scotland concentrations of deprivation by incorporating several different aspects of deprivation (multiple-deprivations) and combining them into a single index. Concentrations of deprivation are identified in SIMD at Data Zone level and can be analysed using this small geographical unit. The use of data for such small areas helps to identify 'pockets' (or concentrations) of deprivation that may be missed in analyses based on larger areas such as council wards or local authorities. By identifying small areas where there are concentrations of multiple deprivation, the SIMD can be used to target policies and resources at the places with greatest need. The SIMD identifies deprived areas, not deprived individuals.

The following figures and tables are based on version 2016 of SIMD.

Individuals have been assigned to an SIMD 2016 quintile based on the postcode recorded in their first SMR01/SBR/Community Prescription record in each financial year.

Figure 16

By SIMD (2016) Quintile



By SIMD (2016) Quintile

Proportions of children and young people identified as having a life-limiting condition; 0-21 years; by Scottish Index of Multiple Deprivation (2016) Quintile; Scotland;

2003/04 - 2016/17

SIMD (2016) Quintile

					SIMD (2016)	Quintile				
	1 (most dep	rived)	2		3		4		5 (least dep	rived)
Financial Year	Persons	%	Persons	%	Persons	%	Persons	%	Persons	%
Hospital-based	prevalence									
2003/04	1,086	25.9	911	21.7	776	18.5	742	17.7	682	16.2
2004/05	1,183	27.0	971	22.2	777	17.8	735	16.8	711	16.2
2005/06	1,198	26.0	1,041	22.6	853	18.5	784	17.0	728	15.8
2006/07	1,223	25.9	1,048	22.2	913	19.3	832	17.6	714	15.1
2007/08	1,267	26.3	1,049	21.7	911	18.9	818	16.9	781	16.2
2008/09	1,366	26.8	1,147	22.5	899	17.6	868	17.0	818	16.0
2009/10	1,326	26.1	1,156	22.8	942	18.5	843	16.6	814	16.0
2010/11	1,339	26.4	1,140	22.4	937	18.4	842	16.6	822	16.2
2011/12	1,319	25.7	1,132	22.0	997	19.4	866	16.9	824	16.0
2012/13	1,364	26.1	1,170	22.4	936	17.9	886	17.0	862	16.5
2013/14	1,421	25.6	1,241	22.3	1,016	18.3	978	17.6	896	16.1
2014/15	1,560	27.3	1,233	21.6	1,040	18.2	949	16.6	935	16.4
2015/16	1,486	26.5	1,231	22.0	1,037	18.5	967	17.3	880	15.7
2016/17	1,505	26.5	1,233	21.7	1,054	18.6	975	17.2	903	15.9
Complete preva	lence							'		
2009/10	3,025	24.9	2,647	21.7	2,275	18.7	2,154	17.7	2,071	17.0
2010/11	3,214	25.3	2,755	21.7	2,345	18.4	2,241	17.6	2,169	17.0
2011/12	3,299	24.8	2,879	21.6	2,531	19.0	2,351	17.7	2,250	16.9
2012/13	3,474	25.0	3,082	22.2	2,493	17.9	2,425	17.4	2,423	17.4
2013/14	3,658	25.2	3,169	21.9	2,647	18.3	2,508	17.3	2,507	17.3
2014/15	3,905	25.7	3,279	21.6	2,741	18.1	2,639	17.4	2,608	17.2
2015/16	3,944	25.1	3,386	21.5	2,864	18.2	2,769	17.6	2,755	17.5
2016/17	3,984	25.0	3,452	21.6	2,849	17.9	2,865	18.0	2,798	17.5
Note:				,						

Note:

Deaths

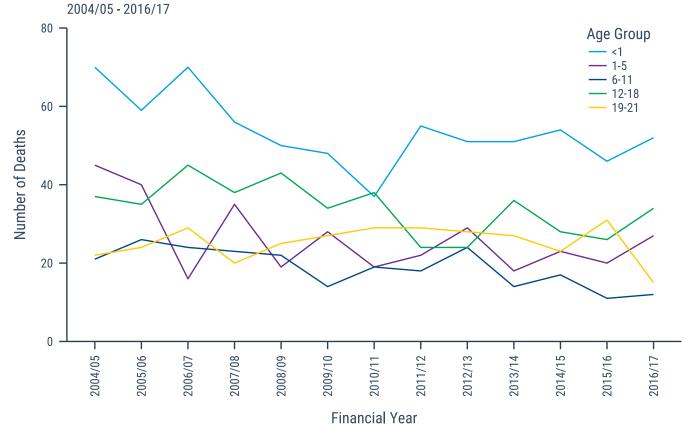
The numbers of deaths and places of death among children and young people in Scotland with life-limiting conditions has been obtained from NRS death registration records.

Numbers of Deaths by Age Group

Figure 17

Numbers of Deaths by Age Group

Numbers of deaths among children and young people identified as having a life-limiting condition 0-21 years, by Age Group Scotland



Numbers of Deaths by Age Group
Numbers of deaths among children and young people identified as having a lifelimiting condition;

0-21 years, by Age Group;

Scotland;

2004/05 - 2016/17

Financial Year	Age <1	Age 1-5	Age 6-11	Age 12-18	Age 19-21
2004/05	70	45	21	37	22
2005/06	59	40	26	35	24
2006/07	70	16	24	45	29
2007/08	56	35	23	38	20
2008/09	50	19	22	43	25
2009/10	48	28	14	34	27
2010/11	37	19	19	38	29
2011/12	55	22	18	24	29
2012/13	51	29	24	24	28
2013/14	51	18	14	36	27
2014/15	54	23	17	28	23
2015/16	46	20	11	26	31
2016/17	52	27	12	34	15

Numbers of Deaths by Place of Death

Deaths have been grouped into the following 3 categories relating to the place of death:

- Hospital
- Hospice
- Home

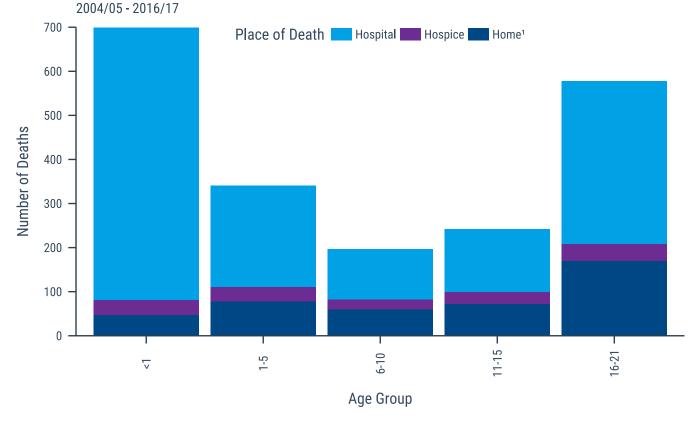
Please refer to the Phase 1(a) Technical Report for details of the institutions assigned to each category.

Note that the 'Home' category includes deaths where the place of death was 'Other' or 'Not Known'.

Figure 18

Numbers of Deaths by Place of Death

Numbers of deaths among children and young people identified as having a life-limiting condition 0-21 years, by Place of Death and Age Group Scotland



¹ Home includes the categories Other and Not Known Produced by NHS National Services Scotland (Ref. XRB17031)

Table 21

Numbers of Deaths by Place of Death

Numbers of deaths among children and young people identified as having a lifelimiting condition;

0-21 years, by Place of Death and Age Group;

Scotland;

2004/05 - 2016/17

Place of Death	Age <1	Age 1-5	Age 6-10	Age 11-15	Age 16-21
Hospital	618	230	114	142	369
Hospice	33	33	22	28	39
Home ¹	48	78	60	72	170

Note:

¹ Home includes the categories Other and Not Known

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Children and Young People in Scotland with Life-Limiting Conditions - Phase 1(b)

NHS National Services Scotland (XRB17031) 10 December, 2018

Introduction

In 2015, the University of York published the report 'Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)' (https://www.chas.org.uk/about-us/our-vision/our-publications#Chisp). This report, commissioned by Children's Hospices Across Scotland (CHAS) (https://www.chas.org.uk/), provided an evidence base to inform the planning and design of paediatric palliative care services in Scotland. It provided quantitative data identifying the number of children and young people with life-limiting conditions living in Scotland and describing this population in terms of their ages, conditions/diagnoses, geographical locations and ethnicity. The information and evidence in this report has been used by CHAS to develop its strategic business plans.

Due to the importance of the evidence presented in The ChiSP Study's report to its work, CHAS was keen to see these analyses updated and refined to provide information more tailored to its requirements, and to inform the further development of its palliative care services. As a result, CHAS commissioned the Information Services Division (ISD) of NHS National Services Scotland (NSS) to provide analyses to identify the population and demographic characteristics of children and young people in Scotland with life-limiting conditions.

The commissioned analyses are being carried out in phases, with this report containing the results of Phase 1(b).

Key Definitions

Children and Young People

For the purposes of this work, children and young people are defined as those aged 0-21 years. Please note that this definition varies from that in The ChiSP Study (https://www.chas.org.uk/about-us/our-vision/our-publications#Chisp) which looked at the 0-25 age group.

Life-limiting conditions

For the purposes of this work, 'life-limiting conditions' includes:

- **Life-limiting conditions** (i.e. conditions where there is no reasonable hope of a cure and from which children or young people will ultimately die prematurely), and
- Life-threatening conditions (i.e. conditions where curative treatment may be feasible but may fail).

Life-limiting conditions were identified using a list of ICD10 (International Classification of Disease, Version 10) (http://www.who.int/classifications/icd/en/) codes (listed as an appendix to the Phase 1(a) Technical Report) and categorised into 11 diagnostic groups.

Other

For more information on the definitions and methology used to produce these outputs, please refer to the Phase 1(b) Technical Report.

Stage of Condition

In this analysis, four stages of condition have been defined:

- · Stable;
- Unstable;
- Deteriorating;
- Dying.

Using record linkage, events recorded on routinely collected data (SBR, SMR01 and Death Registrations) relating to individuals with a life-limiting condition have been used to identify those individuals' transition between the above stages of condition.

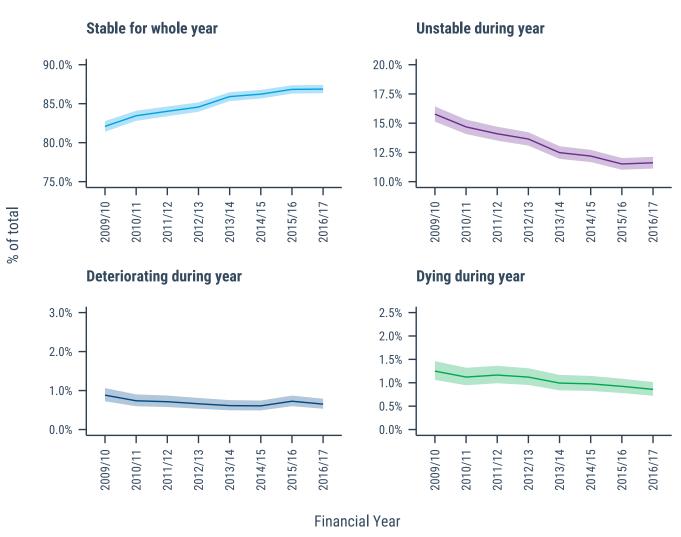
The most severe clinical stage for each individual in each year has been determined, and the results of this analysis are presented in the following charts and tables:

Overall

Figure 1

Overall

Proportions of total children and young people with a life-limiting condition by stage of condition 0-21 years
Scotland
2009/10 - 2016/17



Shaded regions indicate 95% confidence interval Produced by NHS National Services Scotland (Ref. XRB17031)

Overall

Proportions of total children and young people with a life-limiting condition by stage of condition; 0-21 years; Scotland;

2009/10 - 2016/17

	Financial Year	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)
Stable for whole year				
	2009/10	82.1%	81.4%	82.8%
	2010/11	83.5%	82.8%	84.1%
	2011/12	84.0%	83.4%	84.6%
	2012/13	84.6%	84.0%	85.2%
	2013/14	85.9%	85.3%	86.5%
	2014/15	86.2%	85.7%	86.8%
	2015/16	86.8%	86.3%	87.4%
	2016/17	86.9%	86.3%	87.4%
Unstable during year				
	2009/10	15.8%	15.1%	16.4%
	2010/11	14.7%	14.1%	15.3%
	2011/12	14.1%	13.5%	14.7%
	2012/13	13.6%	13.1%	14.2%
	2013/14	12.5%	11.9%	13.0%
	2014/15	12.2%	11.7%	12.7%
	2015/16	11.5%	11.0%	12.0%
	2016/17	11.6%	11.1%	12.1%
Deteriorating during year				
	2009/10	0.9%	0.7%	1.1%
	2010/11	0.7%	0.6%	0.9%
	2011/12	0.7%	0.6%	0.9%
	2012/13	0.7%	0.5%	0.8%
	2013/14	0.6%	0.5%	0.8%
	2014/15	0.6%	0.5%	0.7%
	2015/16	0.7%	0.6%	0.9%
	2016/17	0.7%	0.5%	0.8%
Dying during year				
	2009/10	1.2%	1.1%	1.5%
	2010/11	1.1%	0.9%	1.3%
	2011/12	1.2%	1.0%	1.4%
	2012/13	1.1%	1.0%	1.3%
	2013/14	1.0%	0.8%	1.2%
	2014/15	1.0%	0.8%	1.1%
	2015/16	0.9%	0.8%	1.1%
	2016/17	0.9%	0.7%	1.0%

Note:

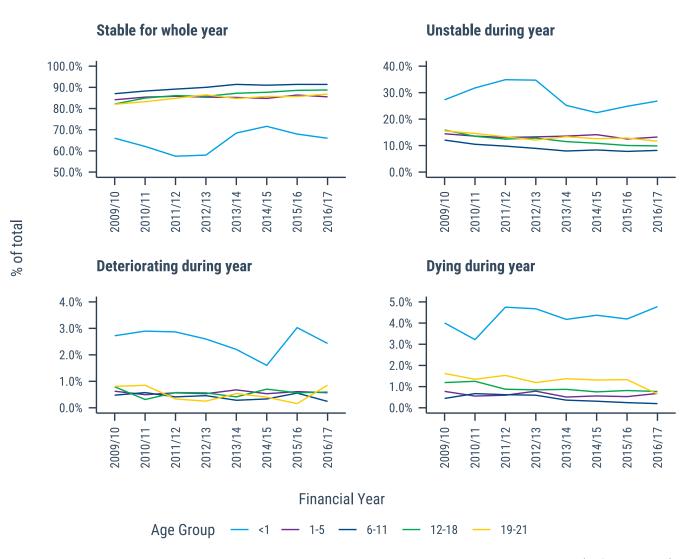
Produced by NHS National Services Scotland (Ref. XRB17031)

By age group

Figure 2

By age group

Proportions of children and young people with a life-limiting condition by stage of condition 0-21 years, by age group Scotland 2009/10 - 2016/17



Produced by NHS National Services Scotland (Ref. XRB17031)

By age group

Proportions of children and young people with a life-limiting condition by stage of condition; 0-21 years, by age group;

Scotland;

2009/10 - 2016/17

		Age <1			Age 1-5			Age 6-11			Age 12-18			Age 19-21	
Financial Year	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)
Stable for wh	ole year														
2009/10	66.0%	63.4%	68.5%	84.1%	82.9%	85.4%	87.0%	85.7%	88.2%	82.1%	80.8%	83.4%	82.0%	79.9%	84.0%
2010/11	62.1%	59.3%	64.8%	85.4%	84.2%	86.5%	88.3%	87.1%	89.4%	84.9%	83.7%	86.1%	83.2%	81.2%	85.1%
2011/12	57.5%	54.7%	60.3%	85.8%	84.6%	86.9%	89.2%	88.1%	90.2%	86.1%	84.9%	87.2%	84.8%	82.9%	86.6%
2012/13	58.0%	55.1%	60.9%	85.4%	84.2%	86.5%	90.0%	89.0%	91.0%	85.8%	84.6%	86.8%	86.5%	84.7%	88.1%
2013/14	68.4%	65.8%	71.0%	85.2%	84.0%	86.4%	91.4%	90.5%	92.3%	87.2%	86.2%	88.2%	84.7%	82.9%	86.4%
2014/15	71.6%	69.1%	74.0%	84.8%	83.6%	85.9%	91.0%	90.1%	91.9%	87.7%	86.6%	88.6%	85.7%	84.0%	87.3%
2015/16	67.9%	65.3%	70.5%	86.4%	85.2%	87.5%	91.4%	90.5%	92.2%	88.6%	87.6%	89.5%	85.7%	84.0%	87.2%
2016/17	66.0%	63.2%	68.7%	85.5%	84.3%	86.6%	91.4%	90.5%	92.2%	88.8%	87.8%	89.7%	86.8%	85.3%	88.3%
Unstable duri	ng year														
2009/10	27.3%	24.9%	29.8%	14.5%	13.3%	15.7%	12.1%	10.9%	13.3%	15.9%	14.6%	17.2%	15.5%	13.7%	17.6%
2010/11	31.8%	29.2%	34.4%	13.6%	12.4%	14.8%	10.5%	9.4%	11.6%	13.5%	12.4%	14.7%	14.6%	12.8%	16.5%
2011/12	34.9%	32.2%	37.6%	13.1%	12.0%	14.2%	9.8%	8.8%	10.9%	12.5%	11.4%	13.6%	13.3%	11.6%	15.1%
2012/13	34.7%	32.0%	37.5%	13.3%	12.2%	14.5%	8.9%	8.0%	9.9%	12.8%	11.8%	13.9%	12.1%	10.5%	13.8%
2013/14	25.2%	22.8%	27.7%	13.6%	12.5%	14.8%	8.0%	7.1%	8.9%	11.5%	10.6%	12.5%	13.4%	11.8%	15.1%
2014/15	22.4%	20.3%	24.7%	14.1%	13.0%	15.3%	8.3%	7.5%	9.2%	10.9%	10.0%	11.9%	12.6%	11.1%	14.2%
2015/16	24.8%	22.5%	27.3%	12.5%	11.4%	13.6%	7.8%	7.0%	8.6%	10.0%	9.2%	11.0%	12.9%	11.4%	14.5%
2016/17	26.8%	24.3%	29.5%	13.2%	12.2%	14.4%	8.2%	7.4%	9.0%	9.9%	9.0%	10.8%	11.7%	10.3%	13.2%
Deteriorating	during year														
2009/10	2.7%	1.9%	3.7%	0.6%	0.4%	1.0%	0.5%	0.3%	0.8%	0.8%	0.5%	1.2%	0.8%	0.4%	1.4%
2010/11	2.9%	2.0%	4.0%	0.5%	0.3%	0.8%	0.6%	0.3%	0.9%	0.3%	0.2%	0.6%	0.8%	0.4%	1.5%
2011/12	2.9%	2.0%	4.0%	0.6%	0.3%	0.9%	0.4%	0.2%	0.7%	0.6%	0.4%	0.9%	0.3%	0.1%	0.8%
2012/13	2.6%	1.8%	3.7%	0.5%	0.3%	0.8%	0.5%	0.3%	0.7%	0.6%	0.4%	0.9%	0.3%	0.1%	0.6%
2013/14	2.2%	1.5%	3.2%	0.7%	0.4%	1.0%	0.3%	0.1%	0.5%	0.4%	0.2%	0.7%	0.5%	0.2%	1.0%
2014/15	1.6%	1.0%	2.4%	0.5%	0.3%	0.8%	0.3%	0.2%	0.6%	0.7%	0.5%	1.0%	0.4%	0.2%	0.8%
2015/16	3.0%	2.2%	4.1%	0.6%	0.4%	0.9%	0.6%	0.4%	0.8%	0.6%	0.4%	0.8%	0.2%	0.0%	0.5%
2016/17	2.4%	1.6%	3.5%	0.6%	0.4%	0.9%	0.2%	0.1%	0.4%	0.6%	0.4%	0.9%	0.9%	0.5%	1.4%
Dying during	year														
2009/10	4.0%	3.0%	5.2%	0.8%	0.5%	1.1%	0.4%	0.2%	0.8%	1.2%	0.8%	1.6%	1.6%	1.0%	2.4%
2010/11	3.2%	2.3%	4.4%	0.6%	0.3%	0.9%	0.7%	0.4%	1.0%	1.3%	0.9%	1.7%	1.3%	0.8%	2.1%
2011/12	4.8%	3.6%	6.1%	0.6%	0.4%	0.9%	0.6%	0.4%	0.9%	0.9%	0.6%	1.2%	1.5%	1.0%	2.3%
2012/13	4.7%	3.5%	6.1%	0.8%	0.5%	1.1%	0.6%	0.4%	0.9%	0.8%	0.6%	1.2%	1.2%	0.7%	1.9%
2013/14	4.2%	3.1%	5.4%	0.5%	0.3%	0.8%	0.4%	0.2%	0.6%	0.9%	0.6%	1.2%	1.4%	0.9%	2.1%
2014/15	4.4%	3.4%	5.6%	0.6%	0.3%	0.9%	0.3%	0.2%	0.5%	0.8%	0.5%	1.1%	1.3%	0.8%	2.0%
2015/16	4.2%	3.2%	5.4%	0.5%	0.3%	0.8%	0.2%	0.1%	0.4%	0.8%	0.6%	1.1%	1.3%	0.9%	2.0%
2016/17	4.8%	3.6%	6.2%	0.7%	0.4%	1.0%	0.2%	0.1%	0.4%	0.8%	0.5%	1.1%	0.7%	0.3%	1.1%
Note:	ı			ı			1			1					

Note:

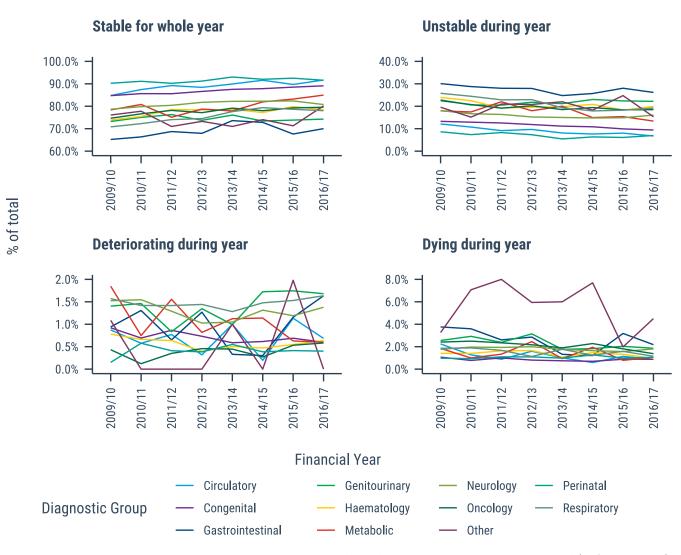
Produced by NHS National Services Scotland (Ref. XRB17031)

By diagnostic group

Figure 3

By diagnostic group

Proportions of children and young people with a life-limiting condition by stage of condition 0-21 years, by diagnostic group Scotland 2009/10 - 2016/17



By diagnostic group

Proportions of children and young people with a life-limiting condition by stage of condition; 0-21 years, by diagnostic group;

Scotland;

2009/10 - 2016/17

	C	irculator	у	c	Congenit	al	Gas	trointest	tinal	Ge	nitourin	ary	На	ematolo	gy	ı	Metaboli	;	ŀ	leurolog	y		Oncology	i		Other			Perinatal		R	espirator	ту
Financial	% of	% of total (lower 95%	% of total (upper 95%	% of	% of total (lower 95%	% of total (upper 95%	% of	% of total (lower 95%	total	% of	% of total (lower 95%	% of total (upper 95%	% of	% of total (lower 95%	% of total (upper 95%	% of	•	% of total (upper 95%	% of	% of total (lower 95%	total	% of	% of total (lower 95%	% of total (upper 95%	% of	% of total (lower 95%	% of total (upper 95%	% of	% of total (lower 95%	% of total (upper 95%	% of	% of total (lower 95%	% of total (upper 95%
Year	total	CI)	CI)	total		CI)	total	CI)	CI)	total	CI)	CI)	total	CI)	CI)	total	CI)	CI)	1	CI)	CI)	total	CI)	CI)	total	CI)	CI)	total	CI)	CI)	total	CI)	CI)
Stable for wh	ole year																																
2009/10	84.8%	82.1%	87.2%	84.7%	83.7%	85.7%	65.2%	59.7%	70.4%	73.2%	70.0%	76.3%	73.9%	71.4%	76.3%	78.4%	73.9%	82.4%	78.7%	76.6%	80.6%	74.7%	72.5%	76.8%	76.1%	66.1%	84.4%	90.2%	88.5%	91.8%	70.8%	68.3%	73.2%
2010/11	87.4%	85.0%	89.6%	85.6%	84.6%	86.6%	66.3%	60.7%	71.6%	75.0%	71.9%	78.0%	75.5%	73.1%	77.7%	80.8%	76.6%	84.5%	79.8%	77.8%	81.7%	76.6%	74.5%	78.7%	77.8%	68.3%	85.5%	91.1%	89.5%	92.6%	72.2%	69.9%	74.5%
2011/12	89.2%	87.0%	91.2%	85.6%	84.6%	86.5%	68.7%	63.2%	73.9%	76.3%	73.3%	79.1%	78.6%	76.3%	80.7%	75.1%	70.8%	79.0%	80.4%	78.4%	82.3%	78.1%	76.1%	80.1%	71.0%	61.1%	79.6%	90.2%	88.6%	91.7%	74.1%	71.8%	76.2%
2012/13	88.4%	86.2%	90.4%	86.6%	85.7%	87.5%	67.9%	62.5%	73.1%	73.7%	70.7%	76.6%	78.4%	76.2%	80.4%	78.7%	74.8%	82.3%	81.8%	79.9%	83.5%	77.2%	75.1%	79.1%	73.3%	63.5%	81.6%	91.2%	89.7%	92.6%	74.5%	72.3%	76.6%
2013/14	89.9%	87.9%	91.7%	87.5%	86.7%	88.4%	73.6%	68.3%	78.5%	76.1%	73.2%	78.8%	78.6%	76.5%	80.6%	77.9%	74.1%	81.4%	82.2%	80.3%	83.9%	79.2%	77.2%	81.0%	71.0%	61.1%	79.6%	93.0%	91.7%	94.2%	77.6%	75.5%	79.6%
2014/15	91.6%	89.7%	93.2%	87.8%	87.0%	88.6%	72.8%	67.7%	77.5%	73.4%	70.6%	76.2%	77.2%	75.2%	79.2%	82.0%	78.7%	84.9%	82.3%	80.4%	84.0%	78.0%	76.1%	79.9%	74.0%	64.5%	82.1%	92.0%	90.7%	93.2%	79.4%	77.4%	81.3%
2015/16	89.7%	87.7%	91.5%	88.5%	87.7%	89.3%	67.6%	62.4%	72.5%	73.8%	71.0%	76.5%	79.8%	77.9%	81.7%	83.2%	80.1%	86.0%	82.4%	80.6%	84.1%	79.3%	77.4%	81.1%	71.3%	61.4%	79.9%	92.5%	91.2%	93.6%	78.6%	76.7%	80.5%
2016/17	91.7%	89.8%	93.3%	89.1%	88.3%	89.9%	70.0%	65.1%	74.7%	74.3%	71.6%	76.8%	78.5%	76.6%	80.3%	85.0%	82.0%	87.6%	80.8%	78.9%	82.5%	79.6%	77.7%	81.4%	80.2%	71.5%	87.1%	91.6%	90.3%	92.8%	78.0%	76.1%	79.9%
Unstable dur	ng year						•									•						•											
2009/10	12.1%	9.9%	14.6%	13.3%	12.3%	14.3%	30.1%	25.1%	35.5%	22.8%	19.9%	25.9%	23.9%	21.6%	26.4%	17.9%	14.2%	22.2%	18.0%	16.2%	20.0%	22.5%	20.5%	24.6%	19.6%	12.0%	29.1%	8.6%	7.2%	10.3%	25.8%	23.5%	28.1%
2010/11	10.7%	8.7%	13.0%	12.9%	12.0%	13.9%	28.8%	23.8%	34.2%	20.6%	17.9%	23.5%	22.5%	20.3%	24.8%	17.5%	13.9%	21.5%	16.7%	14.9%	18.5%	20.8%	18.8%	22.8%	15.2%	8.7%	23.8%	7.4%	6.0%	8.9%	24.4%	22.3%	26.7%
2011/12	9.1%	7.3%	11.2%	12.6%	11.7%	13.5%	28.0%	23.1%	33.4%	20.5%	17.8%	23.4%	19.2%	17.2%	21.3%	22.0%	18.3%	26.1%	16.4%	14.6%	18.2%	19.2%	17.3%	21.1%	21.0%	13.5%	30.3%	8.3%	6.9%	9.8%	22.9%	20.8%	25.0%
2012/13	9.7%	7.9%	11.7%	11.9%	11.0%	12.7%	27.9%	23.1%	33.2%	21.8%	19.1%	24.6%	19.6%	17.6%	21.7%	18.0%	14.7%	21.7%	15.2%	13.6%	17.0%	20.2%	18.4%	22.2%	20.8%	13.4%	30.0%	7.3%	6.1%	8.7%	22.9%	20.9%	25.1%
2013/14	8.1%	6.5%	9.9%	11.1%	10.3%	12.0%	24.8%	20.0%	30.0%	21.2%	18.6%	24.0%	19.8%	17.9%	21.9%	20.0%	16.7%	23.7%	15.0%	13.4%	16.7%	18.5%	16.7%	20.4%	22.0%	14.3%	31.4%	5.4%	4.4%	6.7%	19.3%	17.5%	21.3%
2014/15	7.6%	6.1%	9.4%	10.9%	10.1%	11.7%	25.7%	21.1%	30.7%	23.0%	20.4%	25.8%	20.8%	18.9%	22.8%	15.0%	12.2%	18.0%	14.8%	13.2%	16.5%	19.4%	17.6%	21.3%	18.3%	11.4%	27.1%	6.3%	5.3%	7.6%	17.9%	16.1%	19.8%
2015/16	8.0%	6.5%	9.8%	9.9%	9.2%	10.7%	28.0%	23.4%	33.1%	22.4%	19.9%	25.1%	18.3%	16.5%	20.1%	15.4%	12.7%	18.4%	14.9%	13.3%	16.6%	18.4%	16.7%	20.2%	24.8%	16.7%	34.3%	6.1%	5.1%	7.3%	18.2%	16.5%	20.1%
2016/17	6.7%	5.3%	8.5%	9.4%	8.7%	10.2%	26.2%	21.7%	31.0%	22.2%	19.8%	24.7%	19.9%	18.1%	21.8%	13.4%	10.9%	16.2%	16.1%	14.4%	17.8%	18.5%	16.8%	20.3%	15.3%	9.2%	23.4%	7.0%	5.9%	8.2%	19.2%	17.4%	21.1%
Deteriorating	during y	ear/					•									•						•											
2009/10	0.9%	0.4%	1.8%	0.9%	0.7%	1.2%	0.9%	0.2%	2.7%	1.4%	0.7%	2.5%	0.8%	0.4%	1.4%	1.8%	0.7%	3.8%	1.5%	1.0%	2.2%	0.4%	0.2%	0.9%	1.1%	0.0%	5.9%	0.2%	0.0%	0.5%	1.6%	1.0%	2.4%
2010/11	0.6%	0.2%	1.3%	0.7%	0.5%	1.0%	1.3%	0.4%	3.3%	1.5%	0.8%	2.5%	0.7%	0.3%	1.3%	0.7%	0.2%	2.2%	1.5%	1.0%	2.3%	0.1%	0.0%	0.4%	0.0%	0.0%	0.0%	0.6%	0.2%	1.1%	1.4%	0.9%	2.2%
2011/12	0.8%	0.3%	1.6%	0.9%	0.6%	1.2%	0.7%	0.1%	2.3%	0.8%	0.3%	1.7%	0.6%	0.3%	1.2%	1.6%	0.6%	3.2%	1.3%	0.8%	1.9%	0.4%	0.1%	0.8%	0.0%	0.0%	0.0%	0.4%	0.2%	0.9%	1.4%	0.9%	2.1%
2012/13	0.3%	0.1%	0.9%	0.7%	0.5%	1.0%	1.3%	0.3%	3.2%	1.3%	0.7%	2.3%	0.4%	0.1%	0.9%	0.8%	0.2%	2.1%	1.0%	0.6%	1.6%	0.5%	0.2%	0.9%	0.0%	0.0%	0.0%	0.4%	0.1%	0.8%	1.4%	0.9%	2.2%
2013/14	1.0%	0.5%	1.8%	0.6%	0.4%	0.8%	0.3%	0.0%	1.8%	1.0%	0.5%	1.9%	0.5%	0.2%	1.0%	1.1%	0.4%	2.4%	1.0%	0.6%	1.6%	0.4%	0.2%	0.9%	1.0%	0.0%	5.4%	0.6%	0.3%	1.0%	1.3%	0.8%	2.0%

Note:

Produced by NHS National Services Scotland (Ref. XRB17031)

	С	irculatory	,	С	ongenita	ıl	Gast	trointest	inal	Ger	nitourina	ry	Ha	ematolo	gy	N	/letabolio	:	N	leurolog	y	(Oncology	•		Other		ı	Perinatal		Re	espirator	у
Financial Year	% of	% of total (lower 95% CI)	% of total (upper 95%	% of	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of	% of total (lower 95% CI)	% of total (upper 95% CI)	% of	% of total (lower 95% CI)	% of total (upper 95% CI)	% of	% of total (lower 95% CI)	% of total (upper 95% CI)	% of	% of total (lower 95% CI)	% of total (upper 95% CI)	% of	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	95%
	total	. ,	- '	total		- '		- '	,	total	,	. ,	total	- ,	- '			- /	total		- /	total	,	,			- /	total	• •	- '		•	CI)
2014/15	0.2%	0.0%	0.7%	0.6%	0.4%	0.8%	0.3%	0.0%	1.7%	1.7%	1.0%	2.7%	0.5%	0.2%	0.9%	1.1%	0.5%	2.3%	1.3%	0.8%	1.9%	0.3%	0.1%	0.6%	0.0%	0.0%	0.0%	0.4%	0.2%	0.8%	1.5%	1.0%	2.2%
2015/16	1.1%	0.6%	2.0%	0.7%	0.5%	0.9%	1.2%	0.3%	2.9%	1.7%	1.0%	2.7%	0.5%	0.3%	1.0%	0.6%	0.2%	1.6%	1.2%	0.7%	1.8%	0.5%	0.3%	1.0%	2.0%	0.2%	7.0%	0.4%	0.2%	0.8%	1.5%	1.0%	2.2%
2016/17	0.7%	0.3%	1.4%	0.6%	0.4%	0.8%	1.6%	0.6%	3.5%	1.7%	1.0%	2.6%	0.6%	0.3%	1.1%	0.6%	0.2%	1.5%	1.4%	0.9%	2.0%	0.6%	0.3%	1.0%	0.0%	0.0%	0.0%	0.4%	0.2%	0.8%	1.6%	1.1%	2.3%
Dying during	year .								•																					•			
2009/10	2.2%	1.3%	3.5%	1.1%	0.8%	1.4%	3.8%	2.0%	6.5%	2.6%	1.6%	3.9%	1.4%	0.8%	2.2%	1.8%	0.7%	3.8%	1.8%	1.2%	2.5%	2.4%	1.7%	3.3%	3.3%	0.7%	9.2%	1.0%	0.5%	1.7%	1.9%	1.2%	2.7%
2010/11	1.3%	0.6%	2.3%	0.8%	0.5%	1.1%	3.6%	1.8%	6.3%	2.9%	1.9%	4.3%	1.4%	0.8%	2.2%	1.0%	0.3%	2.5%	2.0%	1.4%	2.7%	2.5%	1.8%	3.4%	7.1%	2.9%	14.0%	0.9%	0.5%	1.6%	1.9%	1.3%	2.7%
2011/12	0.9%	0.4%	1.7%	1.0%	0.7%	1.3%	2.6%	1.1%	5.1%	2.4%	1.5%	3.7%	1.6%	1.0%	2.4%	1.3%	0.5%	2.9%	1.9%	1.3%	2.7%	2.3%	1.7%	3.2%	8.0%	3.5%	15.2%	1.1%	0.6%	1.8%	1.7%	1.1%	2.4%
2012/13	1.6%	0.9%	2.6%	0.8%	0.6%	1.1%	2.9%	1.3%	5.4%	3.1%	2.1%	4.5%	1.7%	1.1%	2.4%	2.5%	1.3%	4.2%	2.0%	1.4%	2.8%	2.2%	1.5%	3.0%	5.9%	2.2%	12.5%	1.1%	0.6%	1.7%	1.1%	0.7%	1.8%
2013/14	1.0%	0.5%	1.8%	0.7%	0.5%	1.0%	1.3%	0.4%	3.3%	1.8%	1.0%	2.8%	1.1%	0.6%	1.7%	0.9%	0.3%	2.2%	1.8%	1.2%	2.5%	1.9%	1.3%	2.6%	6.0%	2.2%	12.6%	1.0%	0.6%	1.6%	1.8%	1.2%	2.5%
2014/15	0.6%	0.2%	1.3%	0.7%	0.5%	0.9%	1.2%	0.3%	3.1%	1.8%	1.1%	2.9%	1.5%	1.0%	2.2%	2.0%	1.0%	3.4%	1.6%	1.1%	2.3%	2.3%	1.6%	3.1%	7.7%	3.4%	14.6%	1.3%	0.8%	1.9%	1.2%	0.8%	1.9%
2015/16	1.1%	0.6%	2.0%	0.9%	0.7%	1.1%	3.2%	1.6%	5.6%	2.0%	1.3%	3.1%	1.3%	0.8%	1.9%	0.8%	0.3%	1.8%	1.6%	1.1%	2.2%	1.8%	1.3%	2.5%	2.0%	0.2%	7.0%	1.0%	0.6%	1.5%	1.6%	1.1%	2.3%
2016/17	0.9%	0.4%	1.7%	0.9%	0.7%	1.1%	2.2%	0.9%	4.2%	1.9%	1.2%	2.8%	1.0%	0.6%	1.5%	1.1%	0.4%	2.2%	1.8%	1.3%	2.5%	1.4%	0.9%	2.0%	4.5%	1.5%	10.2%	1.1%	0.7%	1.6%	1.1%	0.7%	1.7%

Note:

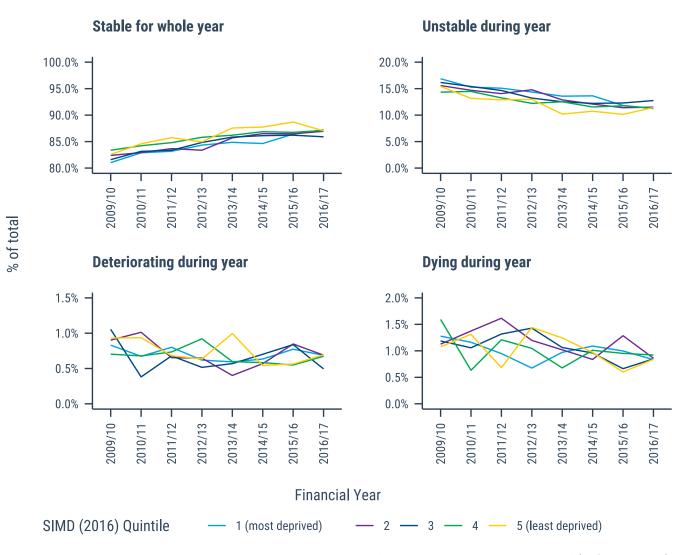
Produced by NHS National Services Scotland (Ref. XRB17031)

By SIMD (2016) quintile

Figure 4

By SIMD (2016) quintile

Proportions of children and young people with a life-limiting condition by stage of condition 0-21 years, by SIMD (2016) quintile Scotland 2009/10 - 2016/17



By SIMD (2016) quintile

Proportions of children and young people with a life-limiting condition by stage of condition; 0-21 years, by SIMD (2016) quintile;

Scotland;

2009/10 - 2016/17

1 (most deprived)					2			3			4		5 (least deprived)			
Financial Year	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	% of total	% of total (lower 95% CI)	% of total (upper 95% CI)	
Stable for wh	ole year															
2009/10	81.0%	79.6%	82.4%	82.4%	80.9%	83.8%	81.6%	79.9%	83.2%	83.4%	81.7%	84.9%	82.6%	80.8%	84.2%	
2010/11	82.9%	81.5%	84.2%	82.9%	81.5%	84.3%	83.2%	81.6%	84.6%	84.2%	82.6%	85.7%	84.6%	83.0%	86.1%	
2011/12	83.2%	81.9%	84.4%	83.7%	82.3%	85.0%	83.4%	81.8%	84.8%	84.8%	83.3%	86.2%	85.7%	84.2%	87.2%	
2012/13	84.3%	83.1%	85.5%	83.4%	82.0%	84.7%	84.8%	83.4%	86.2%	85.8%	84.3%	87.2%	85.0%	83.4%	86.4%	
2013/14	84.9%	83.7%	86.0%	85.7%	84.4%	86.9%	85.8%	84.5%	87.2%	86.2%	84.8%	87.5%	87.6%	86.2%	88.9%	
2014/15	84.6%	83.5%	85.7%	86.5%	85.3%	87.6%	86.1%	84.8%	87.4%	86.9%	85.5%	88.2%	87.8%	86.4%	89.0%	
2015/16	86.4%	85.3%	87.5%	86.5%	85.3%	87.6%	86.2%	84.9%	87.5%	86.7%	85.4%	88.0%	88.7%	87.4%	89.9%	
2016/17	87.2%	86.2%	88.2%	86.9%	85.8%	88.0%	85.9%	84.6%	87.2%	87.1%	85.8%	88.3%	87.0%	85.7%	88.3%	
Unstable duri	ing year															
2009/10	16.9%	15.6%	18.2%	15.6%	14.2%	17.0%	16.2%	14.7%	17.7%	14.3%	12.9%	15.9%	15.4%	13.9%	17.1%	
2010/11	15.3%	14.1%	16.6%	14.7%	13.4%	16.1%	15.4%	14.0%	16.9%	14.5%	13.0%	16.0%	13.2%	11.8%	14.7%	
2011/12	15.1%	13.9%	16.3%	14.1%	12.8%	15.4%	14.7%	13.3%	16.1%	13.3%	11.9%	14.7%	12.9%	11.5%	14.4%	
2012/13	14.4%	13.2%	15.6%	14.8%	13.6%	16.1%	13.2%	11.9%	14.6%	12.2%	10.9%	13.6%	13.0%	11.6%	14.4%	
2013/14	13.6%	12.5%	14.7%	12.9%	11.7%	14.1%	12.5%	11.3%	13.8%	12.5%	11.2%	13.9%	10.2%	9.0%	11.5%	
2014/15	13.6%	12.6%	14.8%	12.1%	11.0%	13.2%	12.2%	11.0%	13.5%	11.5%	10.3%	12.8%	10.7%	9.6%	12.0%	
2015/16	11.8%	10.8%	12.9%	11.4%	10.4%	12.5%	12.3%	11.1%	13.5%	11.8%	10.6%	13.0%	10.1%	9.0%	11.3%	
2016/17	11.2%	10.3%	12.2%	11.5%	10.5%	12.6%	12.8%	11.5%	14.0%	11.3%	10.2%	12.5%	11.4%	10.3%	12.7%	
Deteriorating	during year															
2009/10	0.8%	0.5%	1.2%	0.9%	0.6%	1.3%	1.1%	0.7%	1.6%	0.7%	0.4%	1.2%	0.9%	0.6%	1.4%	
2010/11	0.7%	0.4%	1.0%	1.0%	0.7%	1.5%	0.4%	0.2%	0.7%	0.7%	0.4%	1.1%	0.9%	0.6%	1.4%	
2011/12	0.8%	0.5%	1.2%	0.7%	0.4%	1.0%	0.7%	0.4%	1.1%	0.7%	0.4%	1.2%	0.7%	0.4%	1.1%	
2012/13	0.6%	0.4%	0.9%	0.6%	0.4%	1.0%	0.5%	0.3%	0.9%	0.9%	0.6%	1.4%	0.6%	0.4%	1.0%	
2013/14	0.6%	0.4%	0.9%	0.4%	0.2%	0.7%	0.6%	0.3%	0.9%	0.6%	0.3%	1.0%	1.0%	0.6%	1.5%	
2014/15	0.6%	0.4%	0.9%	0.6%	0.3%	0.9%	0.7%	0.4%	1.1%	0.6%	0.3%	1.0%	0.5%	0.3%	0.9%	
2015/16	0.8%	0.5%	1.1%	0.8%	0.6%	1.2%	0.8%	0.5%	1.2%	0.5%	0.3%	0.9%	0.6%	0.3%	0.9%	
2016/17	0.7%	0.5%	1.0%	0.7%	0.4%	1.0%	0.5%	0.3%	0.8%	0.7%	0.4%	1.0%	0.7%	0.4%	1.1%	
Dying during	year															
2009/10	1.3%	0.9%	1.7%	1.1%	0.8%	1.6%	1.2%	0.8%	1.7%	1.6%	1.1%	2.2%	1.1%	0.7%	1.6%	
2010/11	1.2%	0.8%	1.6%	1.4%	1.0%	1.9%	1.1%	0.7%	1.6%	0.6%	0.3%	1.1%	1.3%	0.9%	1.9%	
2011/12	0.9%	0.6%	1.3%	1.6%	1.2%	2.1%	1.3%	0.9%	1.8%	1.2%	0.8%	1.7%	0.7%	0.4%	1.1%	
2012/13	0.7%	0.4%	1.0%	1.2%	0.8%	1.6%	1.4%	1.0%	2.0%	1.0%	0.7%	1.5%	1.4%	1.0%	2.0%	
2013/14	1.0%	0.7%	1.3%	1.0%	0.7%	1.4%	1.1%	0.7%	1.5%	0.7%	0.4%	1.1%	1.2%	0.8%	1.8%	
2014/15	1.1%	0.8%	1.5%	0.8%	0.6%	1.2%	1.0%	0.6%	1.4%	1.0%	0.7%	1.5%	1.0%	0.6%	1.4%	
2015/16	1.0%	0.7%	1.4%	1.3%	0.9%	1.7%	0.7%	0.4%	1.0%	1.0%	0.6%	1.4%	0.6%	0.3%	1.0%	
2016/17	0.8%	0.6%	1.2%	0.9%	0.6%	1.2%	0.8%	0.5%	1.3%	0.9%	0.6%	1.3%	0.8%	0.5%	1.3%	
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