

Palliative Care Statistics for Children and Young Adults

Health and Care Partnerships Analysis

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Executive summary

This report complements an independent review of children's palliative care services which has been commissioned by the Secretary of State for Health. The review, which includes consideration of the way children's hospices are funded, commenced in October 2006 and is due to report to ministers by the spring of 2007.

This paper provides an analysis of mortality data and hospital admission data, for children and young adults with conditions likely to require palliative care services in England, including information on:

- recent trends in mortality
- the prevalence amongst 0-19 year olds of conditions likely to require access to palliative care services
- cause and place of death
- hospital episodes for 0-19 year olds – including information on:
 - trends in finished consultant episodes
 - admission method
 - regional comparisons of admissions
 - inpatient expenditure by the NHS

Key results

Mortality and prevalence

Prevalence

- Published literature provides some evidence that the prevalence of some conditions requiring palliative care is increasing, probably because of improvements in the survival rate of low birth weight babies and increased life expectancy.
- It is estimated that approximately 20,100 children and young people aged 0-19 years are likely to require access to palliative care services annually in England (18,000 if neonatal deaths are excluded). At Strategic Health Authority level the estimated numbers range from 900 to 2,600 (excluding neonates).
- The estimated prevalence rate for children and young people likely to require palliative care services is 16 per 10,000 population age 0-19 (15 per 10,000 if neonatal deaths are excluded).

Recent trends

- There were 42,400 deaths in England of children and young people aged 0-39 from causes likely to have required palliative care during 2001-05, i.e. an average of 8,480 per annum; this is 50% of deaths from all causes in this age group (including neonatal deaths).
- Over two-thirds of all deaths including neonatal deaths in the 0-19 age group are from causes likely to have required palliative care. The proportion of deaths likely to require palliative care is highest amongst children aged under 1 year and lowest amongst older children (15-19 years) and young adults (20-24 years).
- Non-neonatal deaths from causes likely to have required palliative care have fallen by 45 deaths per year in the 0-19 age group, shown no significant change in the

20-29 age group and fallen by 85 deaths per year in the 30-39 age group over the five-year period 2001-05.

- There have been on average 2,109 neonatal deaths per year from causes likely to require palliative care during 2001-05.

Need for social care

- It is estimated that 63% of children and young people requiring palliative care have a need for social care services i.e. 11,000 age 0-19 years.

Cause and place of death

- The most commonly recorded cause of death category for non-neonatal deaths aged 0-19 years amongst causes likely to require palliative care was congenital malformations, deformations and chromosomal abnormalities.
- Three-quarters of non-neonatal deaths likely to require palliative care amongst children and young people aged 0-19 occurred in hospital. The proportion of deaths in hospital is lower for young adults aged 20-39 (61%) than it is for young children aged under 1 (88%) or 1 - 4 years (74%).
- Almost all (98%) of neonatal deaths occurred in hospital.
- In the years 2002-05, the average proportion of deaths requiring palliative care at age 0-19 (excluding neonates) that occurred at home ranged from 14.5% in London SHA to 25% in the South Central SHA.

Access to children's hospices and specialist services

- Three-quarters (74%) of deaths from causes likely to have required palliative care amongst children and young people occurred within a 40 minute drive of a children's hospice.
- 96% of deaths age 0-19 (including neonates) that are likely to have required palliative care occurred within 30 minutes drive of a specialist palliative care service.

Inpatient hospital episodes

Accurate data on hospital inpatient palliative care is not available at a national level and therefore data from the Information Centre Hospital Episode Statistics database (HES) will over-state the use of inpatient hospital services, as information on severity of patients' conditions is not available. It is however, possible to provide an indication of the upper bound of bed use and expenditure using this data.

The following hospital episode statistics are for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care services:

Trends and summary figures for 2005-06

- In 2005-06 there were 570,500 finished consultant episodes (FCEs) for patients aged 0-39, almost half of which were for patients aged 0-19 years.
- There were 516,000 finished in-year admissions in 2005-06 i.e. 22 admissions per 1,000 population aged 0-39 years.
- Whilst the number of patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care has remained relatively constant throughout the nine years since 1997-98, there has been an increase in the number of FCEs over the period for all age groups, suggesting an increasing demand for palliative care services.

- The average increase over the 11-year period to 2005-06 (FCEs per year) has been: 5,290 for the 0-19 age group, 3,595 in the 20-29 age group and 8,976 in the 30-39 age group
- 65% of FCEs for 0-19 year olds were ordinary admissions, the corresponding proportions for the 20-29 and 30-39 age groups were 36% and 33%.
- 53% of FCEs for 0-19 year olds were elective admissions, whilst the corresponding proportions for the 20-29 and 30-39 age groups were 80% and 83%.

Bed-days

- Of the 3.4 million bed-days in 2005-06 for all patients aged 0-19 years, a third were for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care.
- On average patients in the general population aged 0-19 require 0.3 bed-days per-year, whereas those with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care require 8.9 bed-days per year.
- In 2005-06, of the total bed-days in the year for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, 69% were for patients aged 0-19 yrs, 12% for those age 20-29 and 19% for patients aged 30-39.
- Amongst patients age 0-19, 85% of hospital spells were of 14 days duration or less. 92% of hospital spells in the 20-29 and 30-39 year age groups were 14 days or less.
- 45% of bed-days amongst 0-19 year olds were for disorders relating to short gestation and low birth weight, almost all of which were for babies age under 1 year.
- Cystic fibrosis, Myeloid leukaemia, Sickle-cell disorders and Severe mental retardation were the diagnoses with the highest number of bed-days amongst 20-29 year olds.

Regional comparisons

- an analysis of emergency admissions in five sample regions suggests that there is no straight-forward association between emergency admission rates for children with a diagnosis indicating a condition that may lead to a need for palliative care services, and the reported quality of access to palliative care services in these regions.

Admissions in 12-months prior to death in hospital

- On average children and young people age 0-19 who died in hospital needing palliative care had 2.4 admissions in the 12 months prior to their death, with the majority (78%) having one admission and 13% having three or more admissions.

Inpatient expenditure by the NHS

The NHS inpatient expenditure and bed occupancy attributable to children and young people aged 0-19 years with conditions that may require palliative care account for an estimated one-third of the total expenditure (32%) and bed occupancy (33%) for all patients in this age group.

- Of the estimated £1.7 billion inpatient expenditure on patients aged 0 – 19 in 2004-05, £536.5 million (32%) was attributable to palliative care related diagnoses. Of the palliative care related inpatient expenditure, over a quarter (29%) was on neonates and 16% on cancer patients.

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Context

This report complements an independent review of children's palliative care services which has been commissioned by the Secretary of State for Health. The review, which includes consideration of the way children's hospices are funded, commenced in October 2006 and is due to report to ministers by the spring of 2007.

The review has used complementary analytical work produced by the York Health Economics Consortium within the University of York and Health and Care Partnerships Analysis within the Department of Health. This report summarises the analytical work carried out by Health and Care Partnerships Analysis and includes information on mortality and hospital admissions for children and young adults with conditions likely to require palliative care.

Introduction and policy background

The Government has a manifesto commitment to improve palliative care services:

“In order to increase choices for patients with cancer we will double the investment going into palliative care services, giving more people the choice to be treated at home.”¹

The White Paper “Our health, our care, our say”² states:

“The Government recognises that additional investment is needed to improve end-of-life care and has pledged to increase choices for patients by doubling investment in palliative care services. This will give more people the choice to be treated at home when they are dying, but we must also recognise the wishes of any family members who are caring for dying relatives”

The National Service Framework (NSF) for Children and Young People sets standards for services to disabled children and young people with complex health needs, which includes palliative care. Standard 8 of the NSF states:

Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family –centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.

Further, the NSF states:

“Palliative care is an essential part of care for many disabled children who have complex health needs. For some children and young people, palliative care is needed only for a short time; for others, it will be the only focus of care from the time a life-threatening or life limiting condition has been diagnosed. Palliative care services can include short-term breaks, counselling, family support services, pain management and symptom control. When services are provided, it is particularly important that these are easily accessible, timely and in the setting of the family's choice.”³

¹ Labour Party Manifesto 2005 <http://www.labour.org.uk/manifesto>

² “Our health, our care, our say: a new direction for community services”, Department of Health White Paper, 2006.
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4127453&chk=NXIecj

³ National Service Framework for Children, Young People and Maternity Services: Standard 8: Disabled children and young people and those with complex health needs.

Palliative care is provided for children for whom curative treatment is no longer an option and may extend over many years. There are several definitions of palliative care, including;

*“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial * and spiritual.”⁴*

“Palliative care for children and young people with life limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancements of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite care through death and bereavement.”⁵

For the purpose of the analysis reported in this paper, the need for access to palliative care services has been defined by a set of conditions referenced in Appendix 5.

Methodology and Data Issues

Epidemiological data and service utilisation data identifying how long palliative care was required before death is unavailable. However clinical experience suggests it can be relatively brief (months) for young people with some types of cancer, but very long (perhaps most of their life) for those with severe disability or complex health care needs arising from life limiting illness. Therefore, in attempting to use mortality data to achieve an estimate of the requirement for palliative care, one must take into account that:

- a) The group of children dying with severe disability, though smaller in number than those with some types of cancer, may have had a higher and more intensive requirement for palliative care when expressed in person-years;
- b) The requirement for palliative care will have existed throughout the trajectory of the child’s life/illness, even though the final outcome from their illness occurred in young adult life.

Office for National Statistics (ONS) data is the source of the mortality figures and population mid-year estimates. Queries run against the mortality database search across all cause of death fields: original underlying cause of death, original secondary cause of death, original mentions of cause of death (up to 8 occurrences), counting each death once where any of the selected causes are mentioned, with the exception of Table 7, in which the same death may be recorded against more than one cause. The cause of death codes used for deaths likely to have required palliative care are listed in Appendix 5.

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPAndGBrowsableDocument/fs/en?CONTENT_ID=4094479&chk=ijOZ3N

* Psychosocial support means care that may use formal psychological methods and enhances well-being, confidence and social functioning. It focuses on the individuals needs about the situation they are encountering and emphasizing the individual’s feelings and discusses ways to cope.

⁴ World Health Organisation, 2002

⁵ ACT and Royal College of Paediatrics and Child Health

Hospital admission data used in this analysis has been extracted from the Information Centre for Health and Social Care (IC) Hospital Episode Statistics (HES) database. Queries run against the HES database count hospital episodes with a primary diagnosis that indicates a condition that may lead to an eventual need for palliative care services (i.e. the same conditions as used for the mortality analysis, listed in Appendix 5).

It is not possible to identify episodes in which patients were receiving palliative care in HES as there is no indication of the severity of a condition, and codes indicating a need for palliative care or respite care are not widely used by Trusts. However, counts will provide an upper bound on the number of inpatient palliative care admissions.

See Appendix 6 for notes on HES definitions.

1 Mortality data and prevalence rates

1.1 Trends in life expectancy

Evidence from published sources

A literature review of published research into the life expectancy of children and young adults with one of the conditions most commonly resulting in reduced life expectancy, and a need for palliative care services, suggests that the prevalence of these conditions is increasing probably because of improved survival of low birth weight babies and that life expectancy has increased.

Summary details for some studies covering cerebral palsy, muscular dystrophy and cystic fibrosis are given below, with further details and more references in Appendix 4.

Condition	Source	Year	Summary
Cerebral palsy	Life expectancy in children with cerebral palsy. Hutton et al. BMJ. ¹	1994	Study of life expectancy of children with cerebral palsy born in Mersey region during 1966-84. The survival rates for moderately affected children were not very different from those of normal children for at least the first 20 years. Life expectancy of this cohort of children with cerebral palsy was greater than has been suggested in some previous studies.
	Regional Variation in Survival of People With Cerebral Palsy in the United Kingdom. Hemming et al. Pediatrics. ²	2005	This database consisted of children who were born with cerebral palsy in 5 geographically defined areas in the United Kingdom between 1980 and 1996. Multivariate modelling showed that the severity of impairment had the biggest impact on survival and that additional contributions were made by birth weight and socioeconomic status but that after such adjustments regional differences were no longer significant.
	Life expectancy among people with cerebral palsy in western Australia. Blair et al. Developmental Medicine & Child Neurology. ³	2001	This report describes persons with cerebral palsy using individuals identified by the Western Australian Cerebral Palsy Register born between 1958 and 1994. There is no evidence of any increase in duration of survival since the 1950s.
	Survival of children with cerebral palsy. Children born 1971-1986. Nielsen et al. Ugeskr Laeger. ⁴	2002	Patients in the Danish Cerebral Palsy Register born between 1971 and 1986 were included in study cohort. Persons with cerebral palsy had a lower survival rate than the background population. Compared to earlier studies, the survival rate seems to have improved. The Danish cerebral palsy patients had a survival as good as, and maybe even better, than that of cerebral palsy patients from other countries.

	Children with Long Term Disability in the former Northern & Yorkshire NHS Region. ⁵	2003	The North of England Collaborative Cerebral Palsy Survey (NECCPS) provides data from 1960 to the present. Rates of cerebral palsy in Newcastle, North Tyneside and Northumberland have increased two-fold from 1964-1993. Overall rates of cerebral palsy are relatively constant at 2.0 - 2.5 per 1,000 births. Children flagged at the Office for National Statistics showed that roughly two thirds of children with the severest cerebral palsy now live at least 20 years. ⁷
Muscular Dystrophy	Survival in Duchenne muscular dystrophy. Eagle et al. Neuromuscular Disorders. ⁸	2002	Notes of 197 patients with Duchenne muscular dystrophy from 1967 to 2002 were reviewed, to determine whether survival had improved over the decades. Analyses showed significant decade on decade improvement in survival. Mean age of death in the 1960s was 14.4 years, whereas for those ventilated since 1990 it was 25.3 years. Better coordinated care probably improved the chances of survival to 25 years from 0% in the 1960s to 4% in the 1970s and 12% in the 1980s, but the impact of nocturnal ventilation has further improved this chance to 53% for those ventilated since 1990.
	The multidisciplinary management of Duchenne muscular dystrophy. Bushby et al. Current paediatrics 2005. ⁹	2005	The mean age at death in untreated Duchenne muscular dystrophy (DMD) is 19 years. For many centres, the improvement in clinical care has risen the mean age to the late twenties or beyond. Death in the Newcastle centre has risen from 19 years to at least 25 years. Extrapolating from the experience in other countries where ventilation has been used systematically for longer, survival into the fourth decade and beyond should become the norm.
Cystic fibrosis	Recent advances in cystic fibrosis. Doull. Arch Dis Child. ¹⁰	2001	The median life expectancy for cystic fibrosis is now over 30 years, and it is projected that in newborn infants it will become more than 40 years.
	Cystic fibrosis: review of the decade. Jaffe et al. Monaldi Arch Chest Dis. ¹¹	2001	The median estimated life expectancy of children with cystic fibrosis born in 1990 is 40 years, which represents a doubling in the last 20 years.
	Cystic Fibrosis mortality and survival in the UK, 1947 to 2003. Dodge et al. The European Respiratory Journal. ¹²	2006	All persons with CF born in the UK between 1968 and 1992 were identified up to 1997. The observed survival to 2003 of CF subjects born in 1978 is males 55%, females 49%. For 1988 and 1992, the data are 91% and 88% and 97% and 96% respectively. The continuing improvement in survival of CF subjects in successive cohorts means that the previous prediction of median survival exceeding 50 years for those born in 2000 continues to look realistic.

1-12 See Appendix 4

1.2 National analysis

Children's palliative care is different from that of adults and by comparison the number of children dying is small. However, a child's need for palliative care involves much longer-term provision and increasing complexity of care needs, beginning immediately after diagnosis of a life threatening or life-limiting illness, with the potential for death to occur before adulthood but timing is often uncertain. It is for this reason that the paper includes information on young adults aged 20-39.

There were 42,400 deaths in England of children and young people aged 0-39 from causes likely to have required palliative care during 2001-05, i.e. an average of 8,480 per annum; this is 50% of deaths from all causes in this age group (including neonatal deaths)

Table 1
Population, all deaths and deaths from causes likely to require palliative care, England, 2001-05

	Age Group	2001	2002	2003	2004	2005
Population	0-19	12,327,688	12,334,662	12,350,207	12,365,580	12,367,517
	20-29	6,307,052	6,225,644	6,208,160	6,276,000	6,432,392
	30-39	7,769,534	7,766,824	7,703,035	7,579,826	7,451,618
	0-39	26,404,274	26,327,130	26,261,402	26,221,406	26,251,527
Deaths from all causes	Neonatal ¹	2,148	2,137	2,248	2,239	2,220
	0-19 (including neonatal)	6,062	5,888	5,950	5,807	5,763
	0-19 (excluding neonatal)	3,914	3,751	3,702	3,568	3,543
	20-29	3,987	3,888	3,862	3,700	3,551
	30-39	7,607	7,414	7,343	7,185	6,879
	0-39 (including neonatal)	17,656	17,190	17,155	16,692	16,193
	0-39 (excluding neonatal)	15,508	15,053	14,907	14,453	13,973
Deaths from causes likely to have required palliative care	Neonatal ¹	2,056	2,057	2,152	2,143	2,137
	0-19 (including neonatal)	4,021	3,970	4,084	3,958	3,924
	0-19 (excluding neonatal)	1,965	1,913	1,932	1,815	1,787
	20-29	1,079	1,060	1,099	1,119	1,056
	30-39	3,588	3,443	3,415	3,399	3,185
	0-39 (including neonatal)	8,688	8,473	8,598	8,476	8,165
	0-39 (excluding neonatal)	6,632	6,416	6,446	6,333	6,028
Deaths from causes likely to have required palliative care per 100,000 population	0-19 (including neonatal)	32.6	32.2	33.1	32.0	31.7
	0-19 (excluding neonatal)	15.9	15.5	15.6	14.7	14.4
	20-29	17.1	17.0	17.7	17.8	16.4
	30-39	46.2	44.3	44.3	44.8	42.7
	0-39 (including neonatal)	32.9	32.2	32.7	32.3	31.1
	0-39 (excluding neonatal)	25.1	24.4	24.5	24.2	23.0
¹ Neonatal deaths defined as <28 days.						

The number of non-neonatal deaths from all causes at a national level has been falling since 2001 in all age groups, 0-19, 20-29 and 30-39 by on average 93, 106 and 169 deaths per year respectively. Non-neonatal deaths from causes likely to have required palliative care have fallen by 45 deaths per year in the 0-19 age group, shown no significant change in the 20-29 age group and fallen by 85 deaths per year in the 30-39 age group over the five-year period.

Figure 1
Deaths from causes likely to have required palliative care, by age group

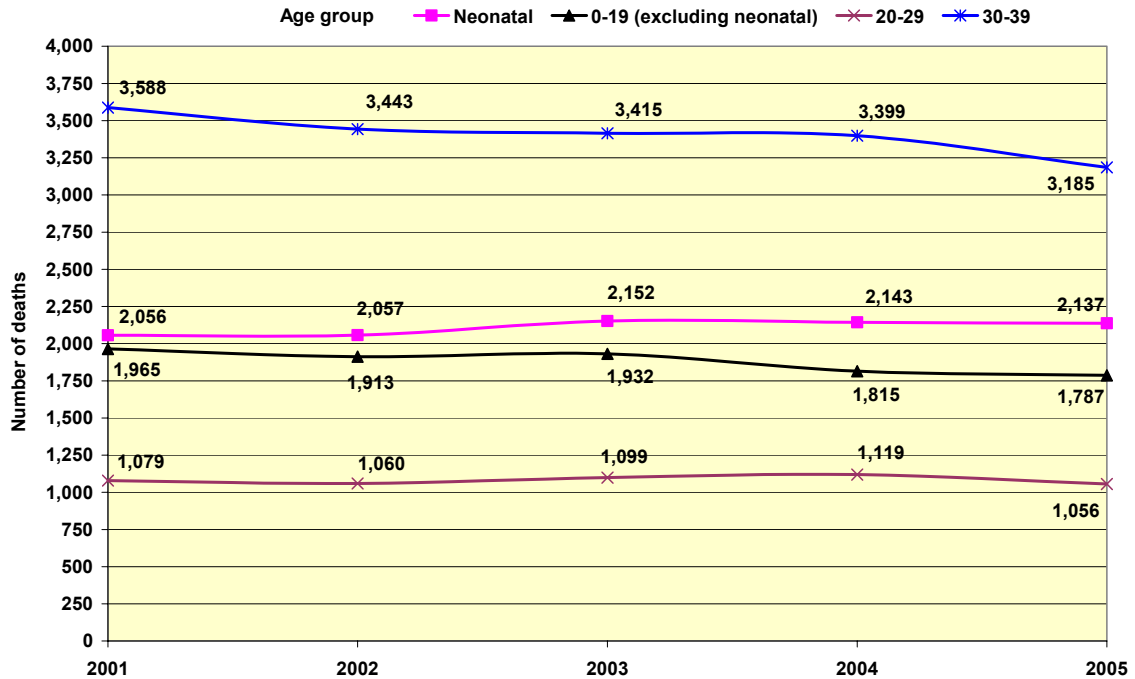
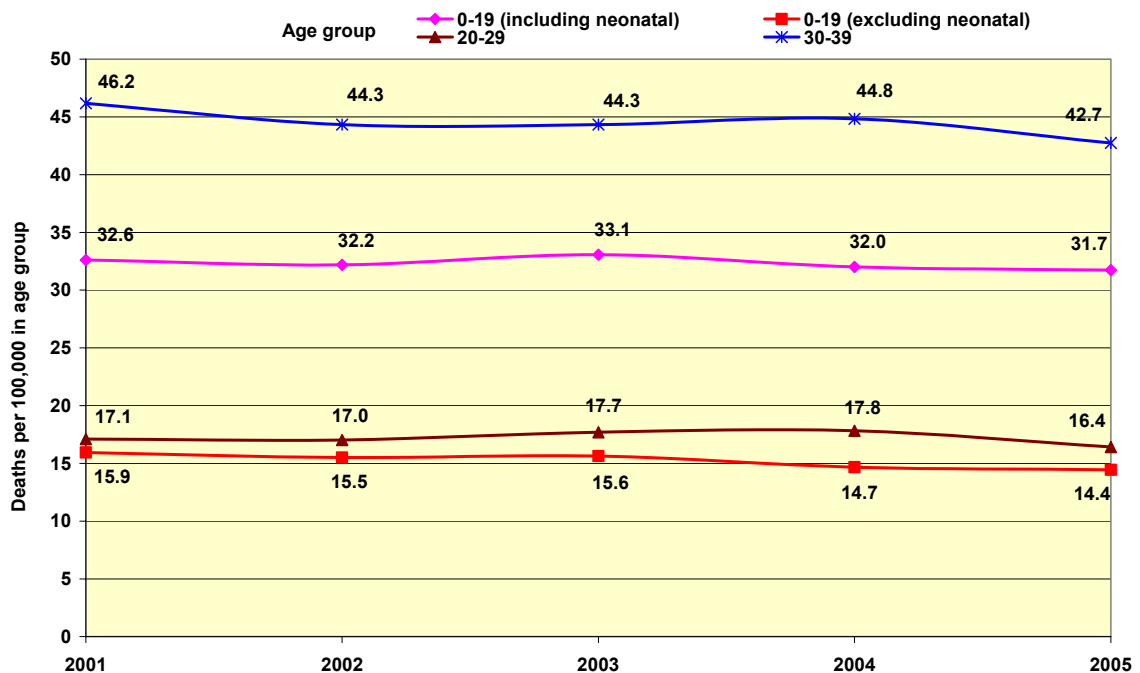


Figure 2
Deaths from causes likely to have required palliative care per 100,000 population in age group



Half of all non-neonatal deaths in the 0-19 age group are from causes likely to have required palliative care. The proportion of deaths likely to require palliative is highest amongst children aged under 1 year and lowest amongst older children (15-19 years) and young adults (20-24 years).

Figure 3
Average annual number of deaths from all causes by palliative care need and age group, 2001-05

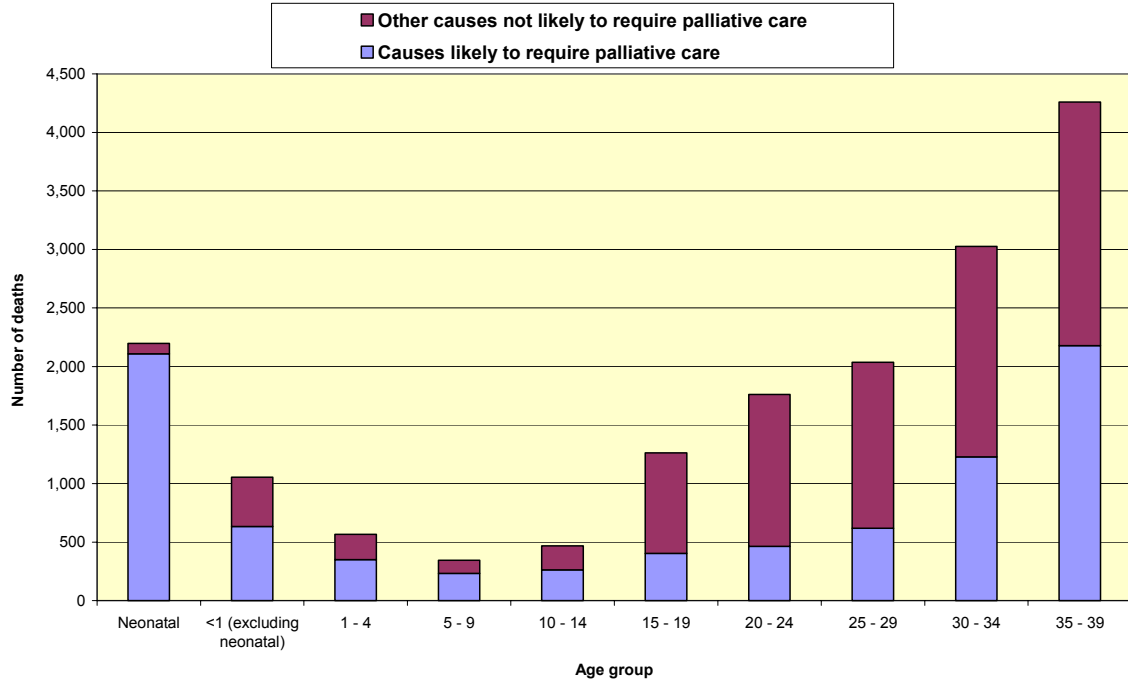


Table 2

Deaths of children and young adults (0-39 yrs) from all causes and from causes likely to have required palliative care, by age group, England, 2001-2005

Deaths from all causes						
Age (yrs)	2001	2002	2003	2004	2005	All years
Neonatal ¹	2,148	2,137	2,248	2,239	2,220	10,992
<1 (excluding neonatal)	1,119	1,031	1,058	1,033	1,028	5,269
1 – 4	601	569	588	554	519	2,831
5 – 9	390	358	362	314	300	1,724
10 – 14	491	490	472	424	461	2,338
15 – 19	1,313	1,303	1,222	1,243	1,235	6,316
0 - 19 (including neonatal)	6,062	5,888	5,950	5,807	5,763	29,470
0 - 19 (excluding neonatal)	3,914	3,751	3,702	3,568	3,543	18,478
20 – 24	1,748	1,777	1,833	1,751	1,695	8,804
25 – 29	2,239	2,111	2,029	1,949	1,856	10,184
30 – 34	3,256	3,151	3,085	2,868	2,771	15,131
35 – 39	4,351	4,263	4,258	4,317	4,108	21,297
0 - 39 (including neonatal)	17,656	17,190	17,155	16,692	16,193	84,886
0 - 39 (excluding neonatal)	15,508	15,053	14,907	14,453	13,973	73,894
Deaths from causes likely to have required palliative care						
Age (yrs)	2001	2002	2003	2004	2005	All years
Neonatal	2,056	2,057	2,152	2,143	2,137	10,545
<1 (excluding neonatal)	630	634	651	631	625	3,171
1 – 4	372	356	374	331	318	1,751
5 – 9	260	247	239	217	199	1,162
10 – 14	284	270	263	238	256	1,311
15 – 19	419	406	405	398	389	2,017
0 - 19 (including neonatal)	4,021	3,970	4,084	3,958	3,924	19,957
0 - 19 (excluding neonatal)	1,965	1,913	1,932	1,815	1,787	9,412
20 – 24	448	453	474	496	451	2,322
25 – 29	631	607	625	623	605	3,091
30 – 34	1,320	1,280	1,257	1,200	1,085	6,142
35 – 39	2,268	2,163	2,158	2,199	2,100	10,888
0 - 39 (including neonatal)	8,688	8,473	8,598	8,476	8,165	42,400
0 - 39 (excluding neonatal)	6,632	6,416	6,446	6,333	6,028	31,855
% of deaths in age group from causes likely to have required palliative care						
Age (yrs)	2001	2002	2003	2004	2005	All years
Neonatal	96%	96%	96%	96%	96%	96%
<1 (excluding neonatal)	56%	61%	62%	61%	61%	60%
1 – 4	62%	63%	64%	60%	61%	62%
5 – 9	67%	69%	66%	69%	66%	67%
10 – 14	58%	55%	56%	56%	56%	56%
15 – 19	32%	31%	33%	32%	31%	32%
0 - 19 (including neonatal)	66%	67%	69%	68%	68%	68%
0 - 19 (excluding neonatal)	50%	51%	52%	51%	50%	51%
20 – 24	26%	25%	26%	28%	27%	26%
25 – 29	28%	29%	31%	32%	33%	30%
30 – 34	41%	41%	41%	42%	39%	41%
35 – 39	52%	51%	51%	51%	51%	51%
0 - 39 (including neonatal)	49%	49%	50%	51%	50%	50%
0 - 39 (excluding neonatal)	43%	43%	43%	44%	43%	43%

¹ Neonatal deaths defined as <28 days.

1.3 Estimated prevalence rate of need for palliative care services

Using data provided by the Association of Children's Hospices (ACH) for 2005-06 and ONS mortality and population data for 2005, the estimated annual number of children likely to require access to palliative care services, excluding neonatal deaths, is approximately 18,000 i.e. 15 per 10,000 population age 0-19. These estimates are similar to those quoted in other sources, for example:

“There are an estimated 15-20,000 children in the UK with conditions which mean they will not reach adulthood.” (The Children's Hospice Service Toolkit, Association of Children's Hospices)

Table 3
Prevalence rate estimation from mortality, population and hospice data, excluding neonatal deaths

		Source
Number of deaths from causes likely to require palliative care, age 0-19, England 2005	1,787	ONS mortality database
Number of children and young people using ACH hospices, 2005-06 (all ages)	4,882	ACH
Number of deaths in 2005-06 (all ages) of children and young people using ACH hospices (including children who used ACH hospices but did not die in a hospice)	486	ACH
Estimated annual number of children age 0-19 requiring palliative care	17,951	ONS mortality database and ACH (=1,787 X 4,882/486)
England population age 0-19, 2005	12,367,517	ONS population statistics database
Estimated prevalence rate for palliative care need age 0-19, per 10,000 population	14.5	

The ACH figures suggest on average there are 10 people requiring palliative care for every death that occurs where palliative care was needed. The figure of 486 deaths is for all places of death and not only for deaths in children's hospices. The ACH were unable to provide a disaggregation of the number of children using ACH hospices by age beyond informing the DH that of the 4,882 clients, 381 were aged 18 or over. The estimated prevalence rate derived above assumes that there is no significant difference between the ratio of service use to deaths in the 0-19 age group when compared with the ratio for all ages using ACH hospices.

The rate of approximately 15 per 10,000 is similar to rates quoted in other sources: the Association for Children's Palliative Care (ACT) give a prevalence rate of 12 per 10,000 aged 0-19⁶, based on a study in the Bath area carried out in 2001. The Lenton et al study⁷

⁶ *A Guide to the Development of Children's Palliative Care Services*, Association for Children's Palliative Care (ACT), September 2003, http://www.act.org.uk/component/option.com_docman/task_cat_view/gid,15/Itemid,26/

⁷ Lenton, S., Stallard, P., Lewis, M., & Mastroiannopoulou, K. (2001) Prevalence and morbidity associated with non-malignant life-threatening conditions in childhood. *Child Care, Health and Development* 27(5): 389-398,

quoted by the ACT and other sources excluded children with malignant life-threatening illness, children with acute conditions leading to death generally of less than one month's duration and children with mental health diagnoses.

Using the list of conditions agreed by medical advisors consulted by DH, almost all neonatal deaths (96%) are regarded as having a need for palliative care. There were 2,137 neonatal deaths from causes likely to require palliative care in 2005 and if these are included in the above calculation by adding them to the 17,950 non-neonatal children requiring palliative care services, the prevalence rate would be 16 per 10,000. Given the relatively large number of neonatal deaths when compared with non-neonatal deaths likely to require palliative care, it is important to distinguish between the different rates and note the effect of including neonatal deaths.

Of the 2,137 neonatal deaths in 2005, 942 (44%) had a first cause of 'Disorders related to short gestation and low birth weight, not elsewhere classified' (ICD-10 P07).

Very few neonatal deaths occur outside hospital. In 2005, 98% of neonatal deaths from causes likely to require palliative care occurred in hospital.

Some other sources of information on prevalence rates are summarised below:

Source	Year	Age Group	Conditions	Prevalence Rate	Methodology
Valuing Short Lives by New Philanthropy Capital	June 2005	0-18 years	Terminal conditions	17.8 per 10,000	Medical research National Statistics
A Guide to the Development of children's palliative care services, (ACT)	Sept 2003	0-18 years	Both malignant and non-malignant conditions	N. Ireland-17.2 per 10,000 Calderdale and Kirklees 16.2 per 10,000 South Glamorgan- 10 per 10,000	District based research studies
Children's Palliative Care Services, Joint Working Party	January 1997	1-19 years	Children with severe disabling conditions	10 per 10,000	Written and oral reports from key individuals, inc hospice workers, paediatricians, researchers
Department of Health	August 2006	Mainly 0-19	Complex conditions needing palliative care	12.3 per 10,000	Questionnaire sent to SHAs. Information on palliative care obtained from 21 PCTs

<http://www.ingentaconnect.com/content/bsc/cchd/2001/0000027/0000005/art00002.jsessionid=1vd342nml1qa.victoria>

1.4 Regional statistics

Regional variations in the number of deaths from causes likely to require palliative care, and in the estimated number of children and young people likely to require palliative care services, are summarised at Strategic Health Authority level in Tables 4 and 5 and Figures 4 and 5. Estimated numbers of children and young adults requiring palliative services have been calculated by applying the estimated national prevalence rate to ONS SHA and PCT population estimates.

Prevalence of palliative care need at SHA and PCT level

The estimated number of children and young adults aged 0-19 years, who are likely to require palliative care services, excluding neonates, ranges from approximately 900 to 2,600 at SHA level and from 40 to 450 at PCT level.

Table 4

Summary statistics for children and young people aged 0-19 years with conditions likely to require palliative care

	Deaths from causes likely to have required palliative care, including neonatal deaths, 2005	Estimated number of people age 0-19 years requiring palliative care, including neonates	Deaths from causes likely to have required palliative care, excluding neonatal deaths, 2005	Estimated number of people age 0-19 years requiring palliative care, excluding neonates
England	3,924	20,088	1,787	17,951
Strategic Health Authorities¹				
Average (mean)	370	2,009	166	1,795
Range	520 (154 - 674)	1,954 (1,002 - 2,956)	210 (79 - 289)	1,746 (895 - 2,641)
Primary Care Trusts¹				
Average (mean)	24	132	11	118
Range	90 (3 - 93)	462 (39 - 501)	55 (0 - 55)	413 (35 - 448)

1. Prevalence rate based on ONS published SHA and provisional PCT population data for the new healthcare organisations created in 2006

There are obviously implications for the way in which palliative care services for children are organised at a regional level given these regional estimates of need.

Further information on the number of deaths by age group and place of death at SHA level is provided in Appendix 1 (Tables A1 and A2).

Table 5
Deaths of children and young adults from causes likely to have required palliative care in 2005 and estimated number of children and young people age 0-19 years requiring palliative care, by Strategic Health Authority of usual residence

Strategic Health Authority of usual residence	Population, age 0-19 years, 2005	Deaths from causes likely to have required palliative care, 2005		Non-neonatal deaths from causes likely to have required palliative care per 100,000 population, 2005	Neonatal and non-neonatal deaths from causes likely to have required palliative care per 100,000 population	Estimated number of people age 0-19 years requiring palliative care	
		Neonatal	0-19 years, excluding neonatal			Excluding neonatal deaths	Including neonatal deaths
East Midlands	1,052,257	162	122	11.6	27.0	1,527	1,709
East of England	1,354,869	164	173	12.8	24.9	1,967	2,201
London	1,819,627	385	289	15.9	37.0	2,641	2,956
North East	616,644	75	79	12.8	25.0	895	1,002
North West	1,715,072	295	241	14.1	31.3	2,489	2,786
South Central	980,619	133	107	10.9	24.5	1,423	1,593
South Coastal	1,017,675	114	119	11.7	22.9	1,477	1,653
South West	1,185,454	159	129	10.9	24.3	1,721	1,925
West Midlands	1,359,395	313	189	13.9	36.9	1,973	2,208
Yorkshire & Humber	1,265,905	233	216	17.1	35.5	1,837	2,056
All SHAs	12,367,517	2,033	1,664	14.4	31.7	17,951	20,088
England total ¹		2,137	1,787				

1. Including deaths in England of people not usually resident in England

Figure 4
Estimated number of people age 0-19 years (including neonates) requiring palliative care, by Strategic Health Authority of usual residence

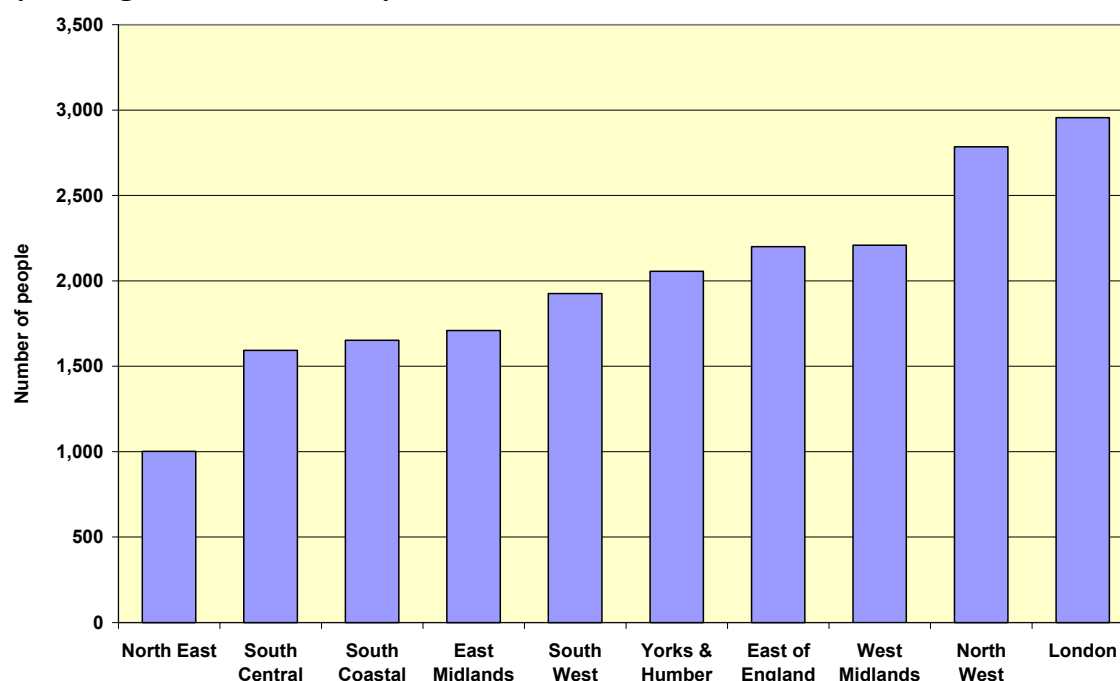
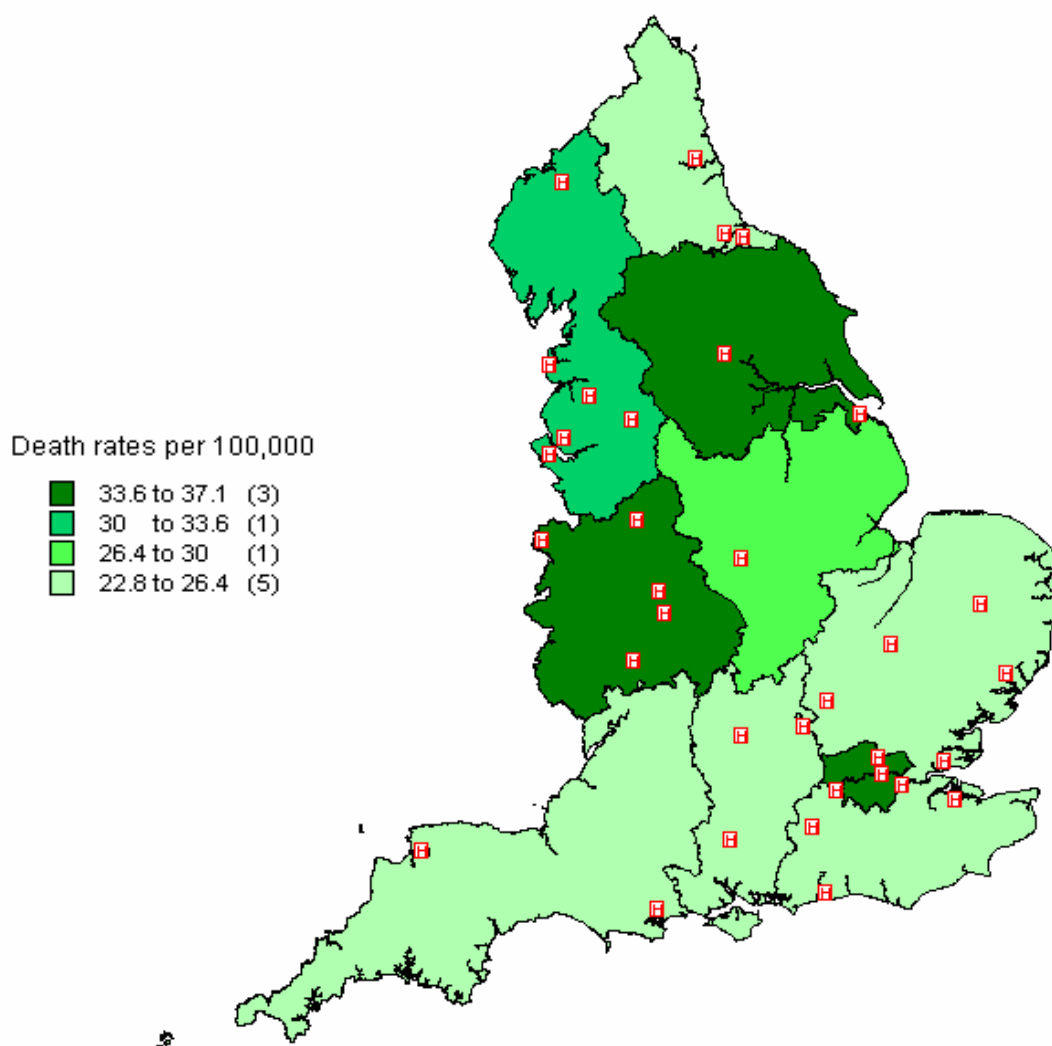


Figure 5
 Death rates¹ in 2005 from causes likely to have required palliative care per 100,000 population age 0-19 years, by Strategic Health Authority of usual residence, and location of children's hospices and hospice at home services².



1. Including neonatal deaths.
2. See Appendix 8 for list of children's hospices and hospice at home services.

1.5 Need for social care

Each of the conditions in the list of causes of death likely to have required palliative care was assigned to one of two categories: those requiring access to health services only and those requiring access to social services.⁸ Using the mortality data for 2005, 63% of deaths in the 0-19 age group from causes likely to have required palliative care had a need for access to social care. This means that of the estimated 18,000 children and young people with palliative care needs, 11,000 are estimated to have a need for social care.

Table 6

Deaths of children and young adults age 0-19 years from causes likely to have required palliative care in 2005 and need for access to social care, by Strategic Health Authority of usual residence (excluding neonates)

Strategic health Authority of usual residence	Deaths by health/social care need			Estimated number needing palliative care	Estimated number needing social care
	Health care need only	Social care need	% with social care need		
East Midlands	48	74	61%	1,527	926
East of England	58	115	66%	1,967	1,307
London	125	164	57%	2,641	1,499
North East	24	55	70%	895	623
North West	90	151	63%	2,489	1,560
South Central	37	70	65%	1,423	931
South Coastal	55	64	54%	1,477	794
South West	51	78	60%	1,721	1,040
West Midlands	64	125	66%	1,973	1,305
Yorks & Humber	74	142	66%	1,837	1,208
All SHAs	626	1,038	62%	17,951	11,198
England total	667	1,120	63%		

⁸ The allocation of conditions to health/social care need was made by DH Medical Advisors. The database was queried looking across all causes of death and where a person died with causes in both categories they have been counted in the social care group.

1.6 Cause of death

The most commonly recorded non-neonatal cause of death category for 0-19 year olds amongst causes likely to require palliative care was congenital malformations, deformations and chromosomal abnormalities.

Table 7
Total deaths of children and young adults from causes likely to have required palliative care in years 2001-05, by age group, England

Cause of death ¹	Neoantal	Age group excluding neoantal										
		<1	1 - 4	5 - 9	10 - 14	15 - 19	20 - 24	25 - 29	30 - 34	35 - 39	0-19	0-39
Congenital malformations, deformations and chromosomal abnormalities ²	2,535	1,399	544	182	206	274	270	285	396	453	2,605	4,009
Diseases of the nervous system ³	101	452	503	331	410	605	483	499	741	1,016	2,301	5,040
Neoplasms ⁴	38	74	414	489	543	749	921	1,283	2,746	5,073	2,269	12,292
Certain conditions originating in the perinatal period ⁵	9,160	1,209	88	12	4	11	4	5	5	10	1,324	1,348
Diseases of the circulatory system ⁶	80	392	197	96	131	336	427	710	1,472	2,929	1,152	6,690
Endocrine, nutritional and metabolic diseases ⁷	141	165	200	111	114	166	215	142	160	160	756	1,433
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism ⁸	37	104	89	58	70	78	89	97	207	264	399	1,056
Diseases of the genitourinary system ⁹	5	89	39	26	37	62	88	157	341	522	253	1,361
Diseases of the digestive system ¹⁰	34	97	64	25	20	41	102	187	597	1,319	247	2,452
Diseases of the musculoskeletal system and connective tissue ¹¹	0	4	17	21	55	88	45	69	96	106	185	501
Diseases of the respiratory system ¹²	1	33	25	20	12	31	35	48	94	178	121	476
Injury, poisoning and certain other consequences of external causes ¹³	0	5	23	16	24	45	44	67	77	108	113	409
Certain infectious and parasitic diseases ¹⁴	0	31	13	19	21	19	28	83	186	240	103	640
Mental and behavioural disorders ¹⁵	0	0	3	3	5	3	5	10	10	19	14	58
External causes of morbidity and mortality ¹⁶	0	0	2	1	3	8	19	25	35	49	14	142
Total ¹⁷	12,132	4,054	2,221	1,410	1,655	2,516	2,775	3,667	7,163	12,446	11,856	37,907

Notes

1. ICD codes used for deaths from causes likely to have required palliative care:

2. Q00-Q07,Q20-Q28,Q30-Q34,Q38-Q45,Q60-Q62,Q64,Q77-Q81,Q85-Q87,Q89-Q93

3. G10-G13,G20-G26,G31,G32,G35-G37,G41,G45,G46,G60-G64,G70-G73,G80-G83,G90,G91,G93-G96,G98,G99

4. C00-C26,C30-C34,C37-C41,C43-C58,C60-C85,C88,C90-C97,D17-D48

5. P00-P03,P07,P08,P10,P11,P20-P29,P35-P37,P39,P52-P54,P57,P77,P90,P91

6. I11-I13,I15,I20-I25,I27,I28,I31,I34-I37,I42,I50,I51,I69,I70,I77,I85,I89

7. E22-E25 (excluding E24.4),E31,E32,E34,E35,E70-E72,E74-E80,E83-E85,E88,E90

8. D55-D61,D63,D64,D66-D77,D81-D84,D86,D89

9. N07,N11-N13,N15,N16,N18,N19,N25-N29,N31-N33

10. K72-K77

11. M07,M08,M30-M32,M35,M40,M41,M43,M85,M95

12. J43,J44,J47,J82,J84,J961

13. T86,T90,T91,T94-T98

14. B20-B25,B44,B90-B92,B94

15. F01-F04,F72,F73,F78,F79

16. Y85-Y89

17. Totals in this table are greater than those in other tables, as the same death has been counted in more than one cause category where death registration causes occur in more than one category. In tables that do not give a breakdown by cause of death, each death has only been counted once.

Figure 6
Deaths from causes likely to require palliative care, for ages 0-19 and 20-29, England 2001-05, excluding neonatal deaths

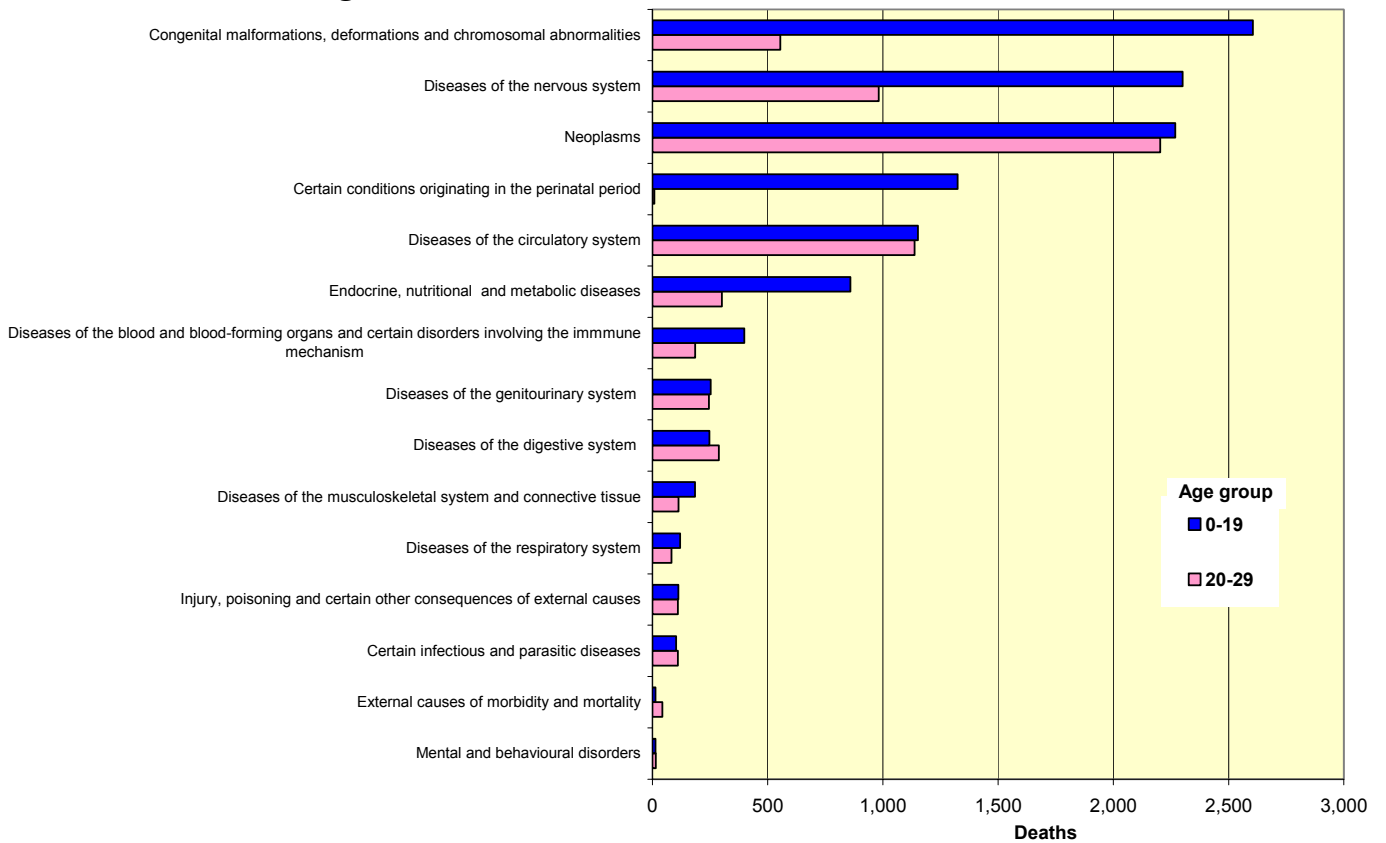
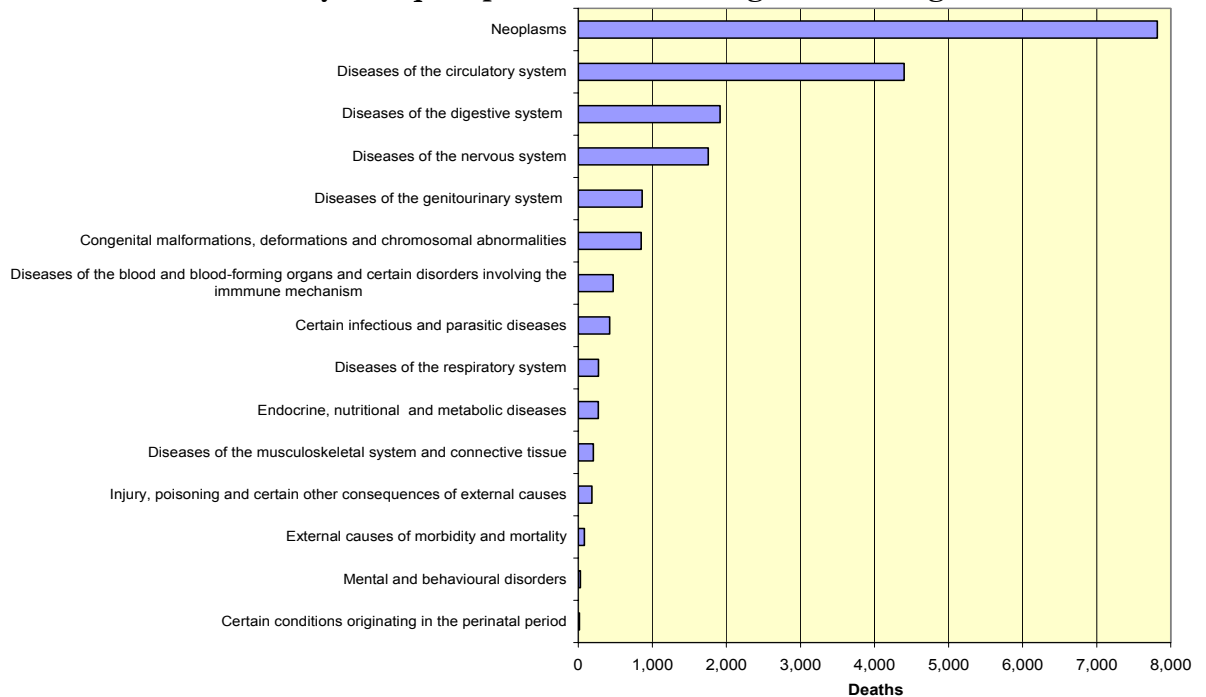


Figure 7
Deaths from causes likely to require palliative care, for ages 30-39, England 2001-05



1.7 Place of death

Three-quarters of non-neonatal deaths likely to require palliative care amongst children aged 0-19 occurred in hospital. The proportion of deaths in hospital is lower for young adults aged 20-39 (61%) than it is for young children aged under 1 (88%) or 1 - 4 years (74%).

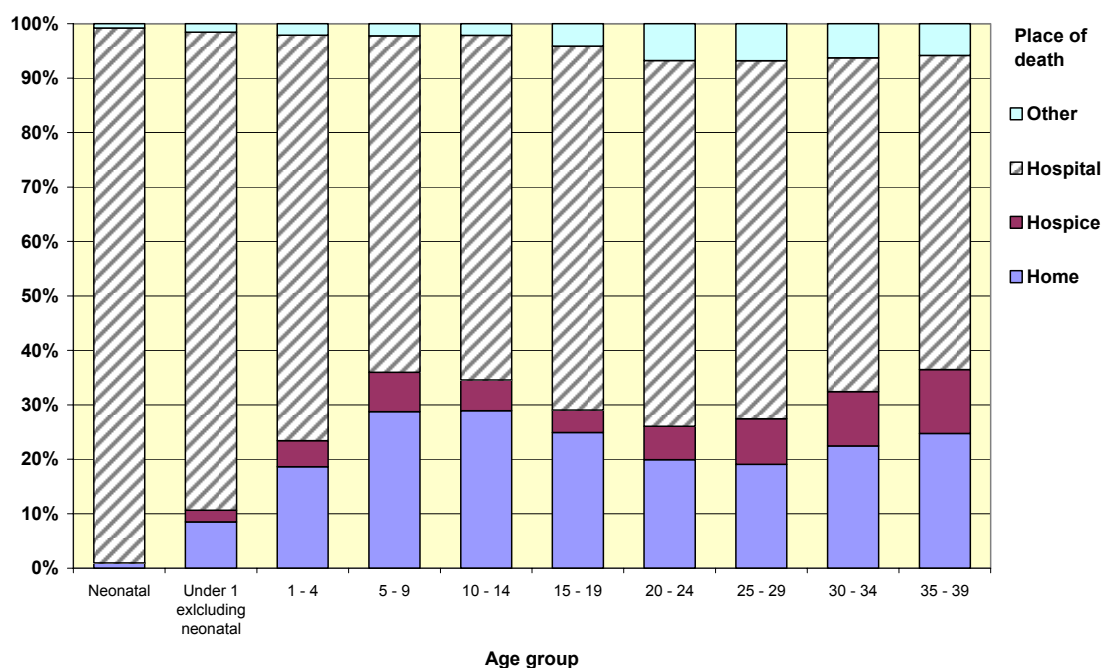
Almost all (98%) of neonatal deaths occurred in hospital.

Table 8
Deaths from causes likely to have required palliative care, by place of death and age group, England 2001-05

Place of death	Age group			
	Neonatal	0-19 excluding neonatal	20-29	30-39
Home	97 (0.9%)	1,811 (19.2%)	1,052 (19.4%)	4,073 (23.9%)
Hospice	7 (0.1%)	393 (4.2%)	402 (7.4%)	1,889 (11.1%)
Hospital	10,357 (98.2%)	6,985 (74.2%)	3,592 (66.4%)	10,048 (59.0%)
Other ¹	84 (0.8%)	223 (2.4%)	367 (6.8%)	1,020 (6.0%)
Total	10,545 (100.0%)	9,412 (100.0%)	5,413 (100%)	17,030 (100.0%)

1. Including for example: psychiatric hospital, nursing home, residential home, private home that is not the usual residence of the deceased.

Figure 8
Deaths from causes likely to require palliative care, by place of death and age group, England 2001-05



In the years 2002-05, the average number of deaths requiring palliative care that occurred at home ranged from 14.5% in London SHA to 25% in the South Central SHA. (see Appendix 1 Table A2). Inferences based on percentages need to be made with caution as the number of deaths requiring palliative at age 0-19 at SHA level are relatively small.

1.8 Access to children's hospices and specialist palliative care services

Using the mortality data for 2005 and the electoral wards of usual residence available within the ONS mortality database extract, the road distance between each death at ward level and the nearest children's hospice was calculated using MapInfo. If a distance of 20 miles is regarded as a reasonable distance to travel on a regular basis, to visit a relative being cared for in a children's hospice, then almost 70% of deaths from causes likely to have required palliative care amongst children and young people occurred within a reasonable distance of a children's hospice that may have been able to provide palliative care. However, there are practical constraints given the much greater drive-times required for the same distances in urban areas when compared to rural regions or the availability of public transport in the latter.

Table 9
Deaths age 0-19 years in England in 2005 from causes likely to have required palliative care, by distance from nearest children's hospice or hospice at home service

Distance from children's hospice (miles)	Number of deaths within given number of miles of a children's hospice or hospice at home service	Proportion of all deaths from causes likely to have required palliative care ¹
5	466	12.6%
10	1,399	37.8%
15	2,095	56.7%
20	2,540	68.7%
25	2,937	79.4%
30	3,128	84.6%
35	3,283	88.8%
40	3,426	92.7%

1. Of the 3,863 deaths in 2005, 3,697 were for people usually resident in England.

An alternative approach to analysing access to children's hospices on a geographical basis is to calculate the estimated time it would take to drive to the nearest hospice. If a drive time of 40 minutes (80 mins. for a return journey) is regarded as a reasonable drive time to travel on a regular basis, then on average three-quarters (74%) of deaths from causes likely to have required palliative care amongst children and young people occurred within a reasonable travelling time of a children's hospice (see Table 10). The region of England with the poorest access to a hospice is the South West, as there is only one children's hospice in the region.

Table 10
Deaths age 0-19 years in England in 2005 from causes likely to have required palliative care, by driving time from nearest children's hospice or hospice at home service

Travel time to nearest children's hospice (minutes)	Number of deaths within given number of minutes drive of children's hospice	Proportion of all deaths from causes likely to have required palliative care ¹
10	209	5.7%
15	582	15.7%
20	1,045	28.3%
25	1,497	40.5%
30	1,925	52.1%
35	2,327	62.9%
40	2,743	74.2%
45	2,993	81.0%
50	3,154	85.3%
55	3,276	88.6%
60	3,357	90.8%
70	3,495	94.5%
80	3,587	97.0%
90	3,617	97.8%

1. Of the 3,863 deaths in 2005, 3,697 were for people usually resident in England.

Using a list of specialist palliative care provider organisations and teams supplied by the Association for Children's Palliative Care (ACT), located at 333 different postcode addresses:

- 86% of deaths age 0-19 (including neonates) that are likely to have required palliative care occurred within 10 miles of a palliative care service, and 98% within 20 miles
- around one half (51%) of deaths age 0-19 (including neonates) that are likely to have required palliative care occurred within 10 minutes drive of a palliative care service, and around 96% within 30 minutes drive.

However, this analysis is of limited value, given that it takes no account of whether the nearest service is actually one that is needed by the family or whether the nearest service has the capacity to provide support.

Table 11
Deaths age 0-19 years in England in 2005 from causes likely to have required palliative care, by distance from nearest specialist palliative care service for children

Distance from nearest specialist palliative care service (miles)	Number of deaths within given number of miles of specialist palliative care service	Proportion of all deaths from causes likely to have required palliative care ¹
5	2,414	65.3%
10	3,166	85.6%
15	3,493	94.5%
20	3,634	98.3%

1. Of the 3,863 deaths in 2005, 3,697 were for people usually resident in England

Table 12
Deaths age 0-19 years in England in 2005 from causes likely to have required palliative care, by driving time from nearest specialist palliative care service for children

Travel time to nearest specialist palliative care service (minutes)	Number of deaths within given number of minutes drive of specialist palliative care service	Proportion of all deaths from causes likely to have required palliative care ¹
10	1,885	51.0%
15	2,744	74.2%
20	3,157	85.4%
25	3,411	92.3%
30	3,556	96.2%

1. Of the 3,863 deaths in 2005, 3,697 were for people usually resident in England

2 Hospital episodes

The analysis of HES data is based on counting finished consultant episodes (FCEs) for inpatients with a primary diagnosis which indicates a life threatening or life limiting condition that may lead ultimately to a need for palliative care, where the age on admission was 0-39 years. The conditions used were the same as those for the mortality analysis summarised above, and are listed in Appendix 5.

The analysis is based on counting hospital episodes for all patient classifications, including ordinary admissions, day cases and regular attenders. Data for the latter patient classification has only been reported by Trusts since 1999-00 and their inclusion is the most likely explanation for the noticeable increase in FCEs between 1998-99 and 1999-00.

2.1 Trend in finished consultant episodes

The following trend analysis is based on FCE counts from 1995-96 to 2005-06. No attempt has been made to look at years prior to 1995-96 due to the change in diagnosis coding from ICD-9 to ICD-10 that came into effect on 1 April 1995.

In 2005-06 there were 570,500 FCEs for patients aged 0-39 years, almost half of which were patients aged 0-19 years.

The largest year-on-year increase in FCEs occurred in 1999-00 when NHS trusts started reporting activity for regular attenders. The number of FCEs has increased by approximately 17,900 FCEs per year over the 11-year period since 1995-96.

Table 13

Finished consultant episodes for patients aged 0-39 with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 2005-06, by patient classification

Year	Ordinary admission	Day case	Regular day attender	Regular night attender	Mother and babies using only delivery facilities	Total
1995-96	253,491	124,029			360	377,880
1996-97	276,110	131,565			229	407,904
1997-98	265,699	147,166				412,865
1998-99	258,025	158,713				416,738
1999-00	253,176	165,613	60,081	890	2,431	482,191
2000-01	245,901	164,480	70,605	838	2,791	484,615
2001-02	244,192	165,809	66,371	620	2,863	479,855
2002-03	256,355	166,988	74,939	922	3,197	502,401
2003-04	266,142	166,184	86,988	624	3,081	523,019
2004-05	264,156	175,185	90,265	125	3,731	533,462
2005-06	273,410	187,022	104,644	1,376	4,038	570,490

Regular day and night attender episodes accounted for almost a fifth of FCEs in 2005-06.

There is a notable difference between age groups when patient classifications and admission method are compared: in 2005-06

- 65% of FCEs for 0-19 year old were ordinary admissions, the corresponding proportions for the 20-29 and 30-39 age groups were 36% and 33%.
- 53% of FCEs for 0-19 year olds were elective admissions, whilst the corresponding proportions for the 20-29 and 30-39 age groups were 80% and 83%.

In figures 9 and 10, mothers and babies using only delivery facilities are included with ordinary admissions and regular day and night attenders are grouped together.

Figure 9
Finished consultant episodes for patients aged 0-39 with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 1995-96 to 2005-06, by patient classification

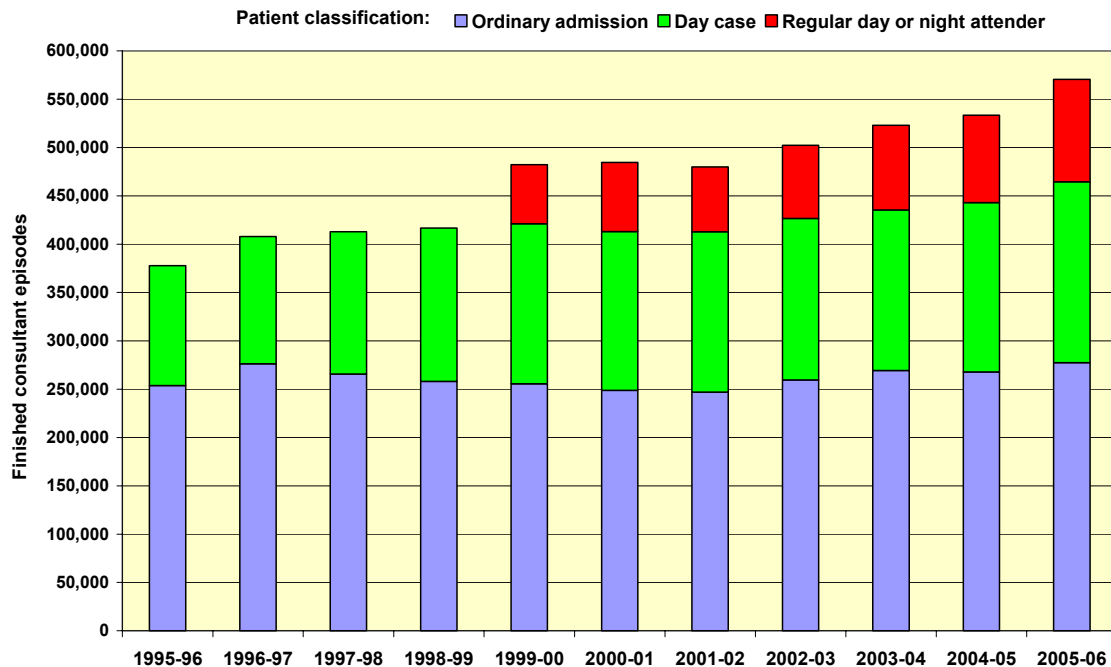
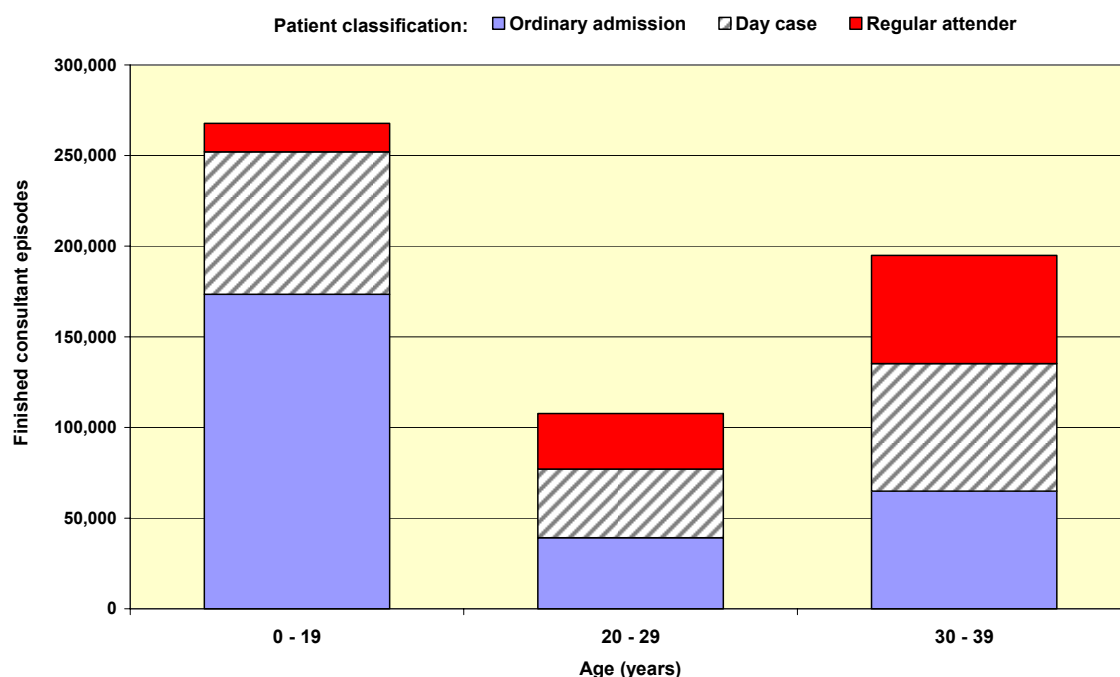


Figure 10

Finished consultant episodes for patients with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 2005-06, by patient classification and age group



Whilst the number of patients with a primary diagnosis indicating a life-threatening or life-limiting illness likely to lead to an eventual need for palliative care has remained relatively constant throughout the nine years since 1997-98, there has been an increase in the number of FCEs over the period for all age groups. The increasing number of FCEs per patient suggests an increasing need for palliative care services. Patient counts are based on the unique patient identifier (HESID) which is not available prior to 1997-98.

Table 14

Finished consultant episodes and patient counts¹ for patients with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 1997-98 to 2005-06, by age group

Year	0 - 19		20 - 29		30 - 39		FCEs per patient		
	FCEs	Patients	FCEs	Patients	FCEs	Patients	0 - 19	20 - 29	30 - 39
1997-98	219,692	128,296	70,447	36,528	122,726	63,548	1.71	1.93	1.93
1998-99	219,475	122,500	70,103	35,657	127,160	64,185	1.79	1.97	1.98
1999-00	228,422	120,543	87,345	34,907	166,424	64,329	1.89	2.50	2.59
2000-01	228,770	120,886	85,751	33,016	170,094	63,398	1.89	2.60	2.68
2001-02	227,921	116,445	85,267	32,271	166,667	62,747	1.96	2.64	2.66
2002-03	242,198	120,865	89,429	33,257	170,774	63,717	2.00	2.69	2.68
2003-04	247,864	120,137	95,028	33,660	180,127	63,940	2.06	2.82	2.82
2004-05	254,742	122,010	97,747	33,888	180,973	62,613	2.09	2.88	2.89
2005-06	267,875	128,048	107,707	36,049	194,908	64,255	2.09	2.99	3.03

1. Patients with episodes in more than one age group within a year have been counted in more than one age group.

Figure 11

Patients with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 1997-98 to 2005-06, by age group

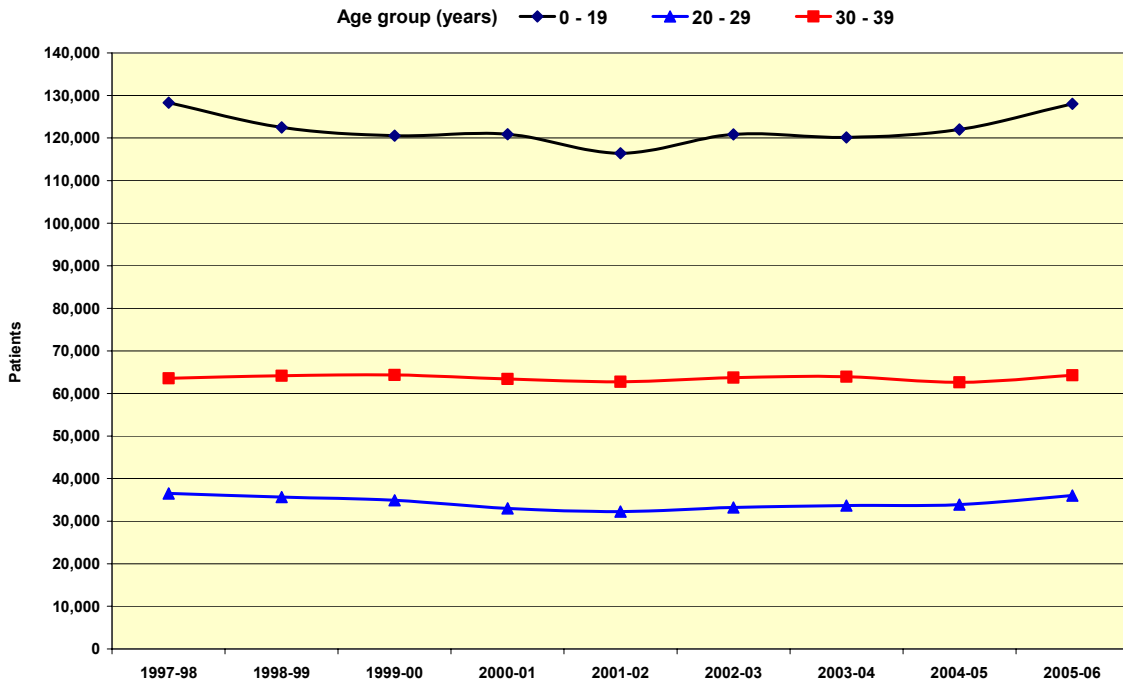
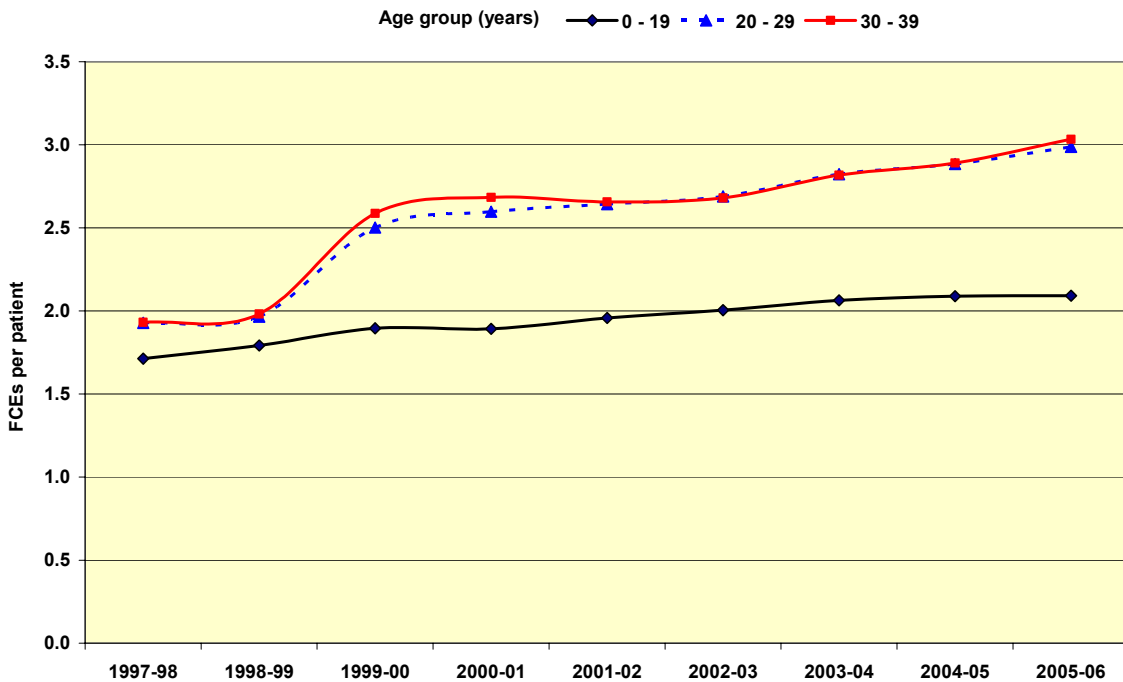


Figure 12

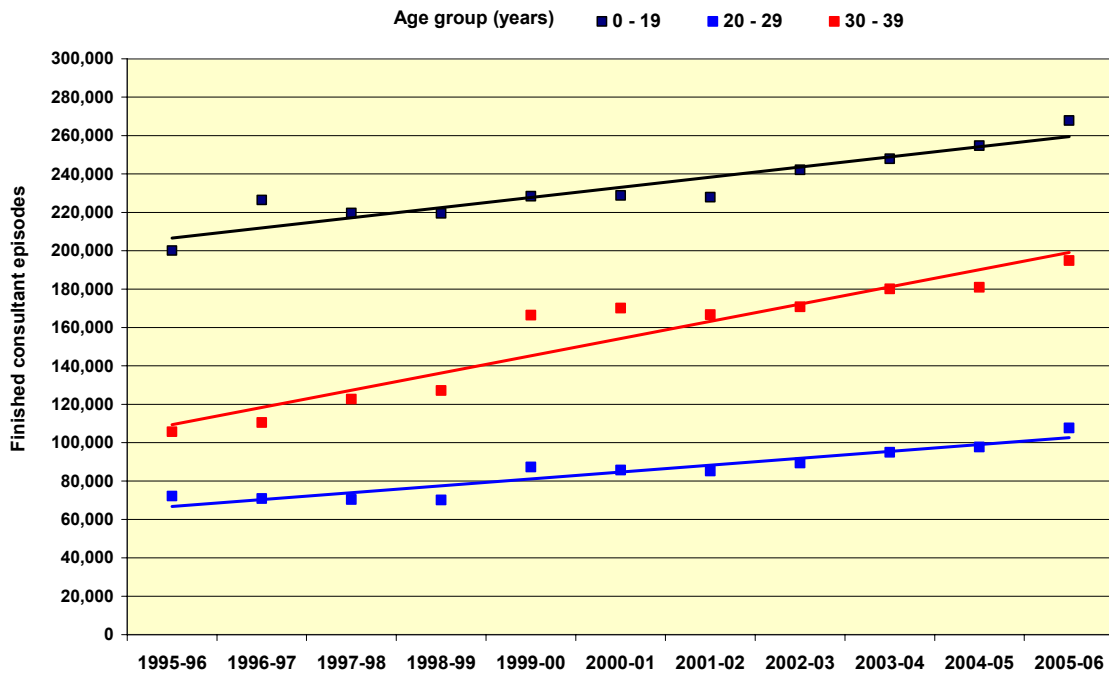
Average finished consultant episodes per patient for patients with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 1997-98 to 2005-06, by age group



The noticeable increase in FCEs per patient between 1998-99 and 1999-00 in the 20-29 and 30-39 age groups is almost certainly due to the inclusion of episodes for regular attenders from 1999-00 onwards – this activity was not included in years up to and including 1998-99.

Figure 13

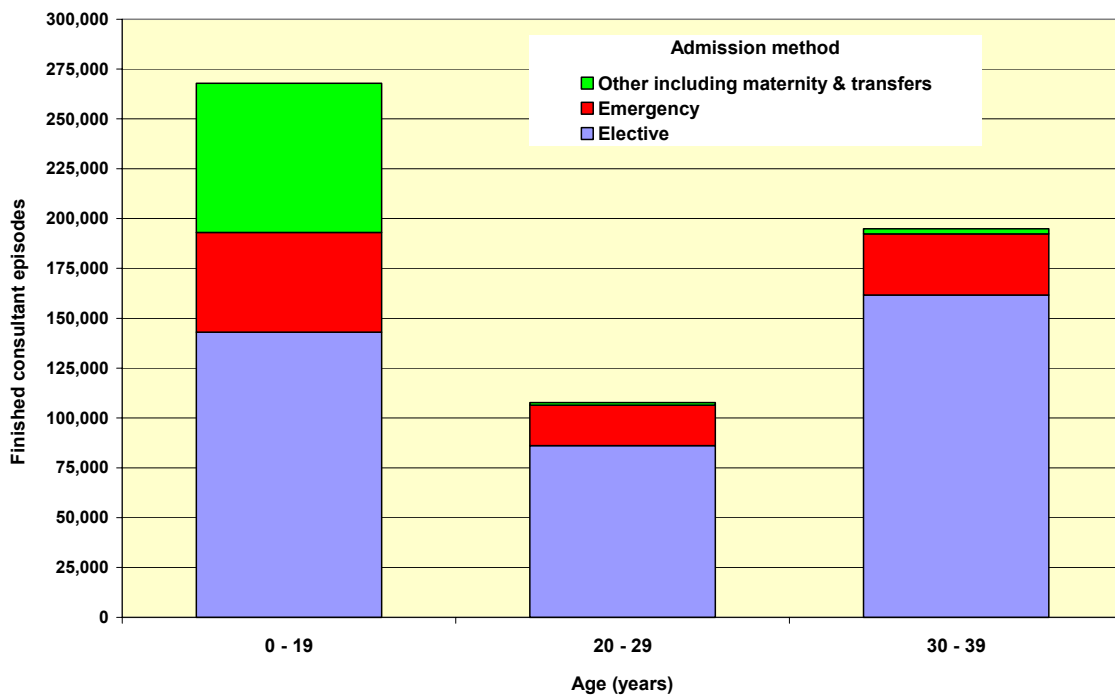
Finished consultant episodes for patients with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 1995-96 to 2005-06, by age group



The average increase (FCEs per year) has been: 5,290 for the 0-19 age group, 3,595 in the 20-29 age group and 8,976 in the 30-39 age group.

Figure 14

Finished consultant episodes for patients with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 2005-06, by admission method and age group



2.2 Admissions and patient counts for 0-19 year olds in 2005-06

2.2.1 National analysis – all admission methods

There were 128,048 patients aged 0-19 years with FCEs in 2005-06, accounting for a total of 267,875 FCEs (this is a count for all admission methods and all patient classifications). The mean number of episodes per patient was 2.1 (range 1 to 160).

Table 15

Finished consultant episodes and patient counts for patient aged 0-19 years, 2005-06

Number of episodes	Number of patients	% of patients
1	93,766	73.2%
2	17,910	14.0%
3	6,051	4.7%
4	2,720	2.1%
5	1,553	1.2%
6	901	0.7%
7	649	0.5%
8	510	0.4%
9	377	0.3%
10	328	0.3%
11 or more	3,283	2.6%

2.2.2 Regional analysis – all admissions and emergency admissions

In order to investigate whether there is a relationship between the emergency admission rate for children with life-threatening or life-limiting illness likely to require palliative care and the reported quality of access to palliative care services in a region, hospital admission were analysed in the following regions, the indicators of service provision were provided by the ACT:

Access to Palliative Care Service

North East London (good)

West Midlands (good)

Brighton (good)

Cumbria (poor)

Cornwall (poor)

Hospital admission counts are based on counting admissions by PCT of responsibility and not by hospital trust, as PCTs are responsible for commissioning palliative care services. For example, a patient registered with a GP in the Brighton region may be admitted as an emergency to a hospital in the North East London region, in which case for this analysis they have been counted within the Brighton figure and not in the North East London total. The list of PCTs used to define each of the regions is given in Appendix 7.

Table 16

Hospital admission and patient counts¹ for patients aged 0-19 with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 2005-06

a) all admission methods

Region	Population age 0-19	All admission methods			
		In-year admissions	Patient count ²	Average admissions per patient	Average admissions per 10,000 population age 0-19
England	12,367,517	232,202	125,929	1.8	188
All sample regions	1,383,310	29,897	15,520	1.9	216
% of England total	11.2%	12.9%	12.3%		
Brighton	128,023	2,269	1,400	1.6	177
Cornwall	117,814	2,159	1,098	2.0	183
Cumbria	147,317	1,864	1,094	1.7	127
N E London	500,784	11,993	6,157	1.9	239
W Midlands	489,372	11,612	5,771	2.0	237

a) emergency admission methods

Region	Population age 0-19	Emergency admissions				
		In-year admissions	Patient count ²	Average admissions per patient	Average admissions per 10,000 population age 0-19	Emergency admissions as a proportion of all admissions
England	12,367,517	43,094	29,098	1.5	34.845	18.6%
All sample regions	1,383,310	5,984	3,742	1.6	43.259	20.0%
% of England total	11.2%	13.9%	12.9%			
Brighton	128,023	411	250	1.6	32.104	18.1%
Cornwall	117,814	406	270	1.5	34.461	18.8%
Cumbria	147,317	476	318	1.5	32.311	25.5%
N E London	500,784	2,872	1,684	1.7	57.350	23.9%
W Midlands	489,372	1,819	1,220	1.5	37.170	15.7%

The results of this analysis do not suggest there is any straight-forward association between the reported quality of access to services within a region and the emergency admission rate. North East London, which is reported to have good quality access to palliative care services, has higher emergency admission rates than Cornwall, where access is reported to be poor. However, West Midlands where access to services is reported to be good does have lower emergency admission rates than any of the other regions considered.

Figure 15

Average emergency admissions per patient for patients aged 0-19 admitted with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 2005-06

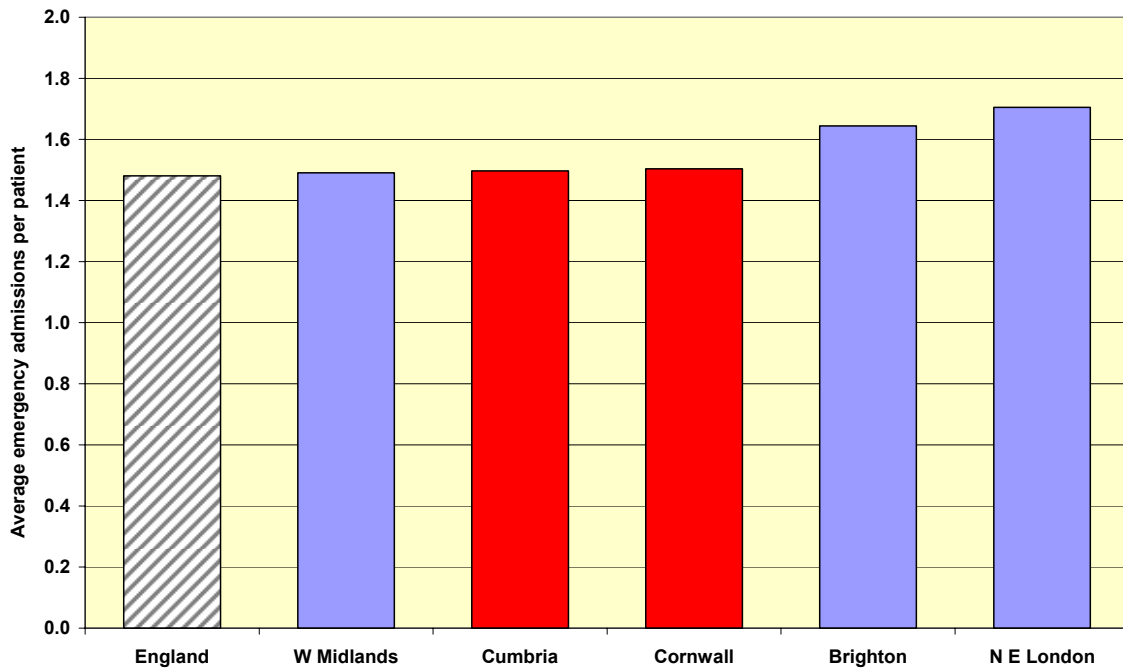
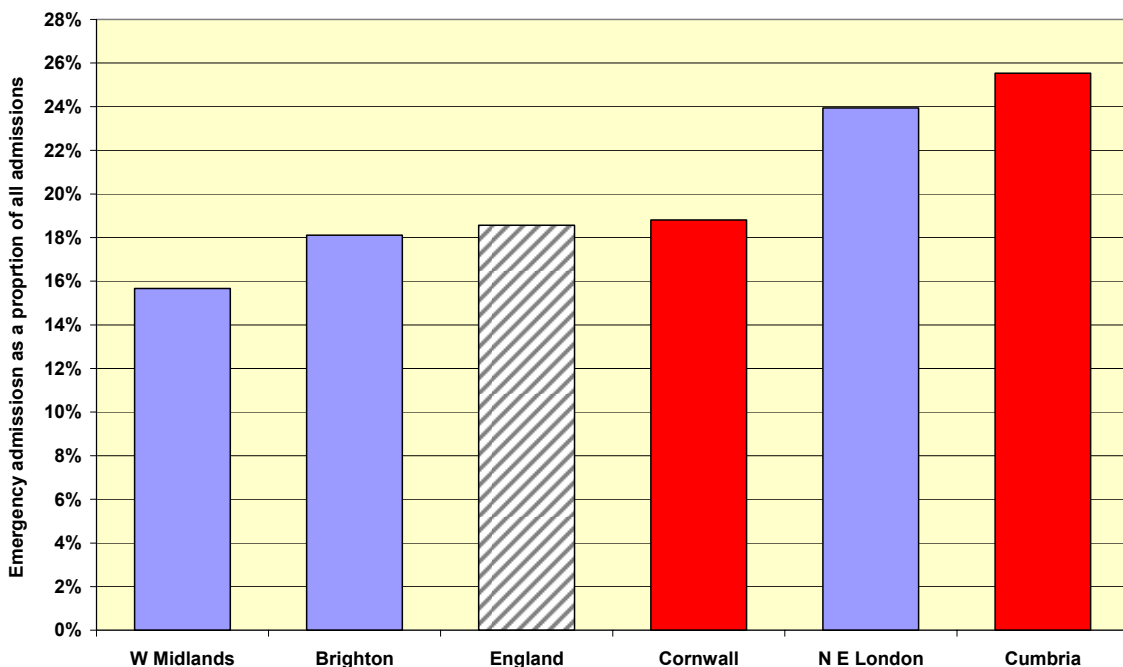


Figure 16

Emergency admissions as a proportion of all admissions for patients aged 0-19 admitted with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, NHS hospitals, England 2005-06



In 2005-06 of the 3,742 patients with emergency admissions in the five regions, 1,084 (29%) had two or more emergency admission and 461 (12%) had three or more emergency admissions.

Table 17

Number of patients aged 0-19 with 1, 2, etc. emergency admissions with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, sample regions 2005-06

Region	number of emergency admissions											Total
	1	2	3	4	5	6	7	8	9	10	11 or more	
Brighton	182	35	12	7	4	6	1	2	0	0	1	250
Cornwall	189	51	18	4	4	3	1	0	0	0	0	270
Cumbria	236	46	16	11	3	2	3	1	0	0	0	318
NE London	1,141	304	113	51	26	13	10	7	6	1	12	1,684
W Midlands	910	187	61	27	13	7	5	3	4	0	3	1,220
Total	2,659	625	223	104	55	37	27	21	19	11	16	3,742

Table 18

Number of patients aged 0-19 with 2 or more and with 3 or more emergency admissions per 10,000 population aged 0-19 with a primary diagnosis indicating a life-threatening or life-limiting illness that may lead to an eventual need for palliative care, sample regions 2005-06

Region	Population 0-19	number of patients with 2 or more and 3 or more emergency admissions		number of patients with 2 or more and 3 or more emergency admissions per 10,000 population	
		2 or more	3 or more	2 or more	3 or more
Brighton	128,023	68	33	5.3	2.6
Cornwall	117,814	81	30	6.9	2.5
Cumbria	147,317	82	36	5.6	2.4
NE London	500,784	543	239	10.8	4.8
W Midlands	489,372	310	123	6.3	2.5
Total	1,383,310	1,084	461	7.8	3.3

Again, this analysis does not suggest there is any straight-forward association between the reported quality of access to palliative care services within a region and the emergency admission rate.

Figure 17
 Number of patients with 2 or more emergency admissions in 2005-06
 per 10,000 population age 0-19

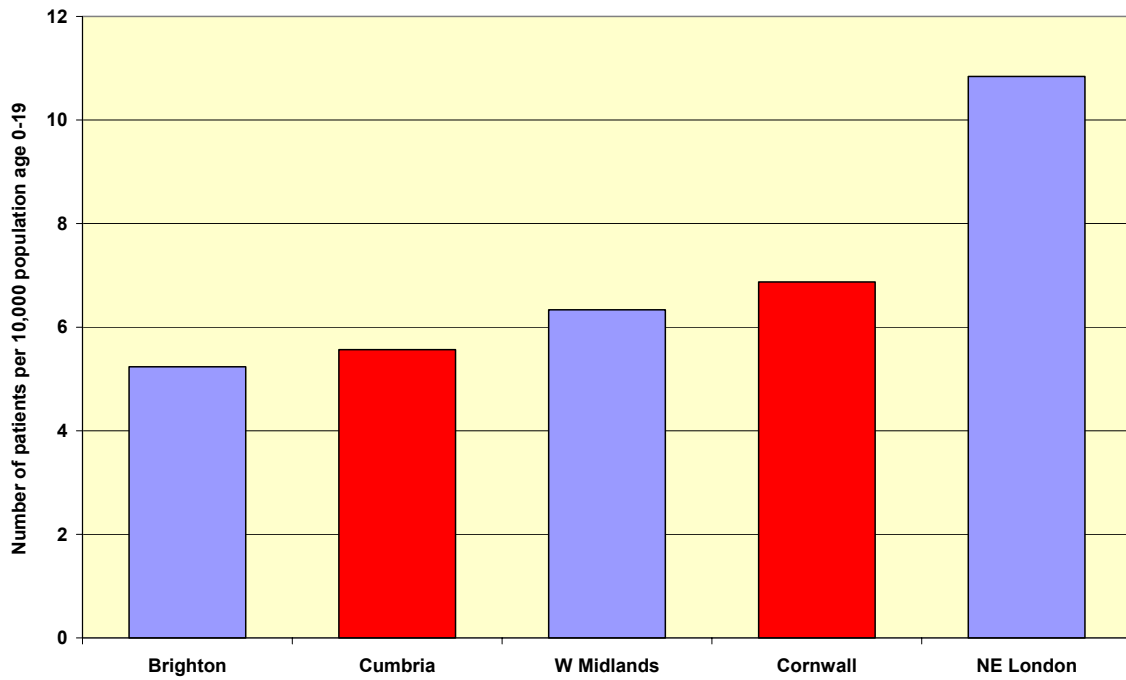
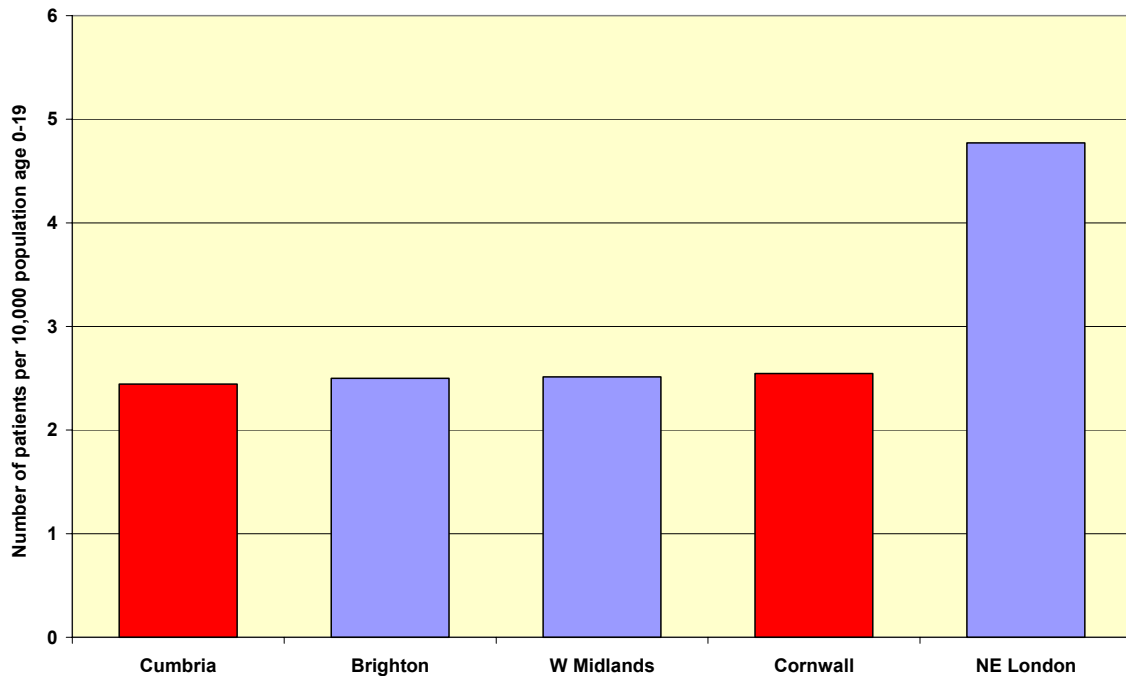


Figure 18
 Number of patients with 3 or more emergency admissions in 2005-06
 per 10,000 population age 0-19



2.3 Length of stay in hospital and bed-days in year 2005-06

A third of the 3.4 million bed-days in 2005-06 for all patients aged 0-19 years were attributable to patients with a diagnosis indicating a condition that may lead to an eventual need for palliative care. For the 20-29 and 30-39 year age groups 'palliative care' bed-days accounted for 7% and 9% of all bed-days in the respective age groups.

On average patients in the general population aged 0-19 require 0.3 bed-days per-year, whereas those with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care require 8.9 bed-days per year.

There is a great deal of variation in bed use - the highest average bed-days in-year per FCE figures when admission methods are compared are for 'other admission methods' amongst the 20-29 age group.

- Of the 714,266 bed-days for patients aged 0-19, with an 'other' admission method, 553, 515 (i.e. 77%) were for babies born in the healthcare provider.
- 50% of emergency admission FCEs were for patients age 0-19 years.
- The patients with the longest average (mean) length of stay are those in the young adult groups (20-29 and 30-39 years). It should be noted that the length of stay analysis is based on the patient's age at the end of their hospital stay and therefore some older patients will have been 0-19 at time of admission.
- Of the total bed-days in the year for all three age groups, 69% were for patients aged 0-19 yrs, 12% for those age 20-29 and 19% for patients aged 30-39.
- Amongst patients age 0-19, 85% of hospital spells were of 14 days duration or less. 92% of hospital spells in the 20-29 and 30-39 year age groups were 14 days or less (Figure 20).

Table 19
Finished consultant episode (FCE) and hospital spell duration statistics for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, by age group¹ and admission method, 2005-06

	Admission method								
	Elective			Emergency			Other including maternity and transfers		
	0 - 19 years	20 - 29 years	30 - 39 years	0 - 19 years	20 - 29 years	30 - 39 years	0 - 19 years	20 - 29 years	30 - 39 years
FCEs (all patient classifications)	143,011	86,122	161,597	49,935	20,282	30,657	74,886	1,261	2,569
FCEs for ordinary admissions ²	48,625	17,523	31,557	49,935	20,282	30,657	74,883	1,260	2,567
Total bed-days in year (days)	195,590	80,194	134,035	227,473	97,977	154,837	714,266	15,720	29,147
Mean bed-days in year per FCE ³ (days)	4.0	4.6	4.2	4.6	4.8	5.1	9.5	12.5	11.4
Median bed-days in year (days)	2	2	2	2	2	2	4	4	4
Standard deviation of bed-days in year (days)	8.609	10.472	9.847	10.008	11.065	10.759	15.702	26.165	27.623
In-Year Discharge FCEs	122,590	54,815	100,684	44,070	16,053	23,538	60,238	1,003	2,070
Total length of stay (LOS) (days)	204,606	99,016	217,387	239,250	111,980	193,824	758,346	19,371	45,134
LOS denominator ⁴	44,167	16,841	30,334	44,070	16,053	23,538	60,238	1,002	2,068
Mean LOS (days)	4.6	5.9	7.2	5.4	7.0	8.2	12.6	19.3	21.8
Median LOS (days)	2	2	2	2	3	3	5	6	5
Standard deviation of LOS (days)	13.006	70.806	132.464	15.505	33.510	72.020	20.534	50.361	160.193

Notes

1. Age group of patient is based on their age at the end of the hospital episode, so FCE counts in this table will not be the same as tables based on age at start of episode.
2. Ordinary admissions and mothers and babies using only delivery facilities
3. Mean bed-days per FCE for FCEs where the patient was an ordinary admission
4. LOS denominator is the number of hospital spells for ordinary admissions that have valid admission and discharge dates

Figure 19
 Hospital spells and length of stay for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, by age group, 2005-06

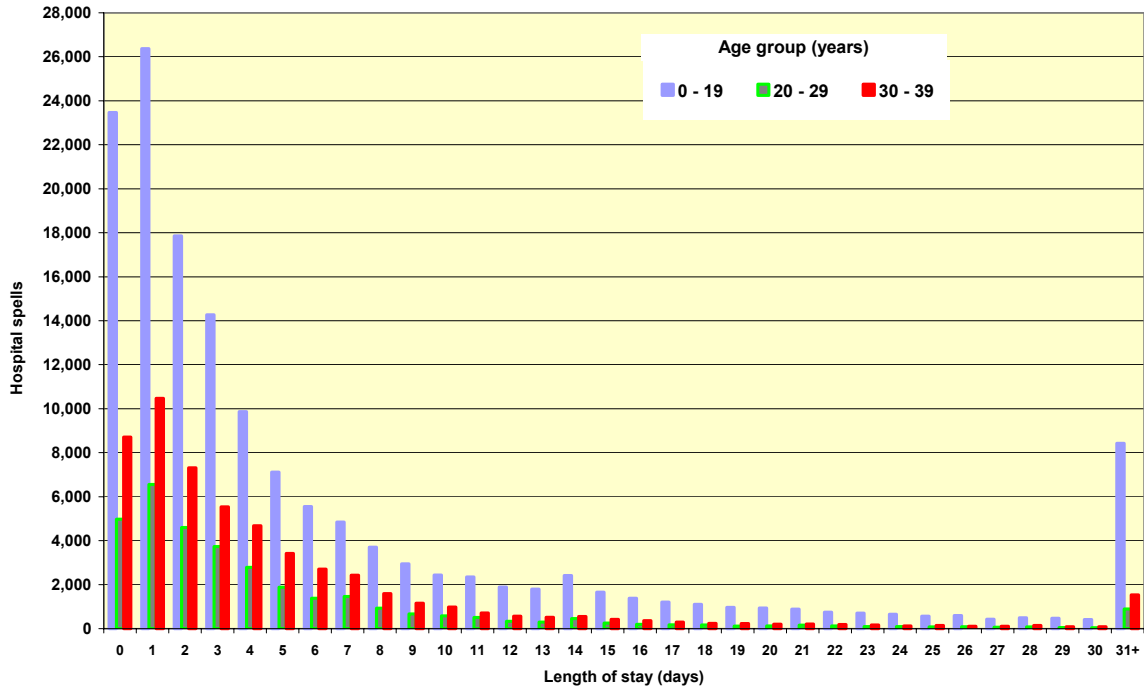


Figure 20
 Cumulative percentage of all hospital spells by length of stay for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, by age group, 2005-06

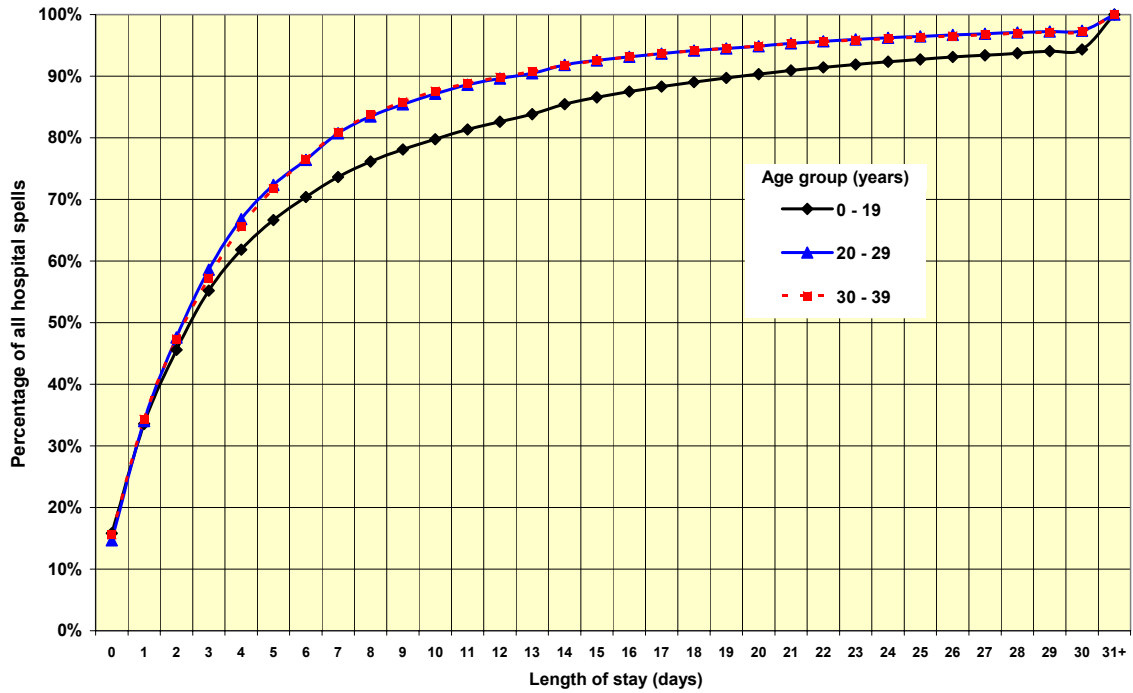


Table 20
Finished consultant episode (FCE) and bed-days statistics for patients age 0-19 years¹ with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, by primary diagnosis chapter, 2005-06

Primary diagnosis ⁴	All patient classifications ²		Ordinary admissions ³						
	FCEs	% of FCEs	FCEs for ordinary admissions	% of FCEs	Total bed-days in year (days)	% of all bed-days in year	Mean bed-days in year per FCE ⁵ (days)	Median bed-days in year (days)	Standard deviation of bed-days in year (days)
Certain conditions originating in the perinatal period	73,802	27.6%	73,485	42.4%	682,210	60.0%	9.3	4	15.007
Congenital malformations, deformations and chromosomal abnormalities	36,641	13.7%	28,478	16.4%	149,606	13.2%	5.3	2	11.765
Neoplasms	70,791	26.4%	23,867	13.8%	105,142	9.2%	4.4	2	9.491
Endocrine, nutritional and metabolic diseases	13,507	5.0%	7,724	4.5%	47,108	4.1%	6.1	3	9.567
Diseases of the nervous system	11,989	4.5%	7,944	4.6%	43,054	3.8%	5.4	2	15.189
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	25,533	9.5%	13,847	8.0%	40,075	3.5%	2.9	1	7.451
Diseases of the musculoskeletal system and connective tissue	9,167	3.4%	4,588	2.6%	21,951	1.9%	4.8	2	9.211
Diseases of the genitourinary system	16,088	6.0%	4,954	2.9%	14,820	1.3%	3.0	2	5.892
Mental and behavioural disorders	4,732	1.8%	4,410	2.5%	11,215	1.0%	2.5	1	6.690
Diseases of the circulatory system	3,017	1.1%	2,108	1.2%	10,073	0.9%	4.8	2	9.570
Diseases of the respiratory system	922	0.3%	815	0.5%	3,833	0.3%	4.7	2	9.906
Diseases of the digestive system	845	0.3%	575	0.3%	3,666	0.3%	6.4	2	13.605
Injury, poisoning and certain other consequences of external causes	483	0.2%	394	0.2%	2,732	0.2%	6.9	3	13.580
Certain infectious and parasitic diseases	315	0.1%	254	0.1%	1,844	0.2%	7.3	4	10.130
Total ⁶	267,832	100%	173,443	100%	1,137,329	100%	6.6	2	12.761

1. Age group of patient is based on their age at the end of the hospital episode, so FCE counts will not be the in this table same as tables based on age at start of episode
2. Ordinary admissions, days cases, regular attenders and mothers and babies using only delivery facilities
3. Ordinary admissions and mothers and babies using only delivery facilities
4. See ICD-10 sheet for code list used for each category
5. Mean bed-days per FCE for FCEs where the patient was an ordinary admission
6. Totals in this table are greater than those in other tables as the same death has been counted in more than one cause category where death registration causes occur in more than one category. In tables that do not give a breakdown by cause of death, each death is only counted once.

Further detail on bed-days by primary diagnosis, by age group, is in Appendix 2.

- 45% of bed-days in the year amongst 0-19 year olds were for episodes with a primary diagnosis of "P07 Disorders relating to short gestation and low birth weight". Of the 511,792 bed-days for P07, 511,382 (i.e. 99.9%) were for babies age under 1 year.
- Cystic fibrosis, Myeloid leukaemia, Sickle-cell disorders and Severe mental retardation were the diagnoses with the highest number of bed-days amongst 20-29 year olds.

- Severe mental retardation, Leiomyoma of uterus, Multiple sclerosis and Myeloid leukaemia were the diagnoses with the highest number of bed-days amongst 30-39 year olds.

2.4 Finished consultant episode counts for cancer patients and non-cancer patients

Around a quarter of FCEs for conditions that may lead to an eventual need for palliative care within the 0-19 age group are for patients with a cancer diagnosis; this proportion is higher for young adults (34% and 41% for the 20-29 and 30-39 age groups respectively).

- The proportion of regular attenders with a cancer diagnosis is higher amongst the 0-19 age group (41%) than it is for young adults.
- Approximately one-fifth of cancer patients (18%) age 0-19 were being treated with chemotherapy; this proportion is slightly higher for young adults (19% and 23% for the 20-29 and 30-39 age groups respectively).

Table 21

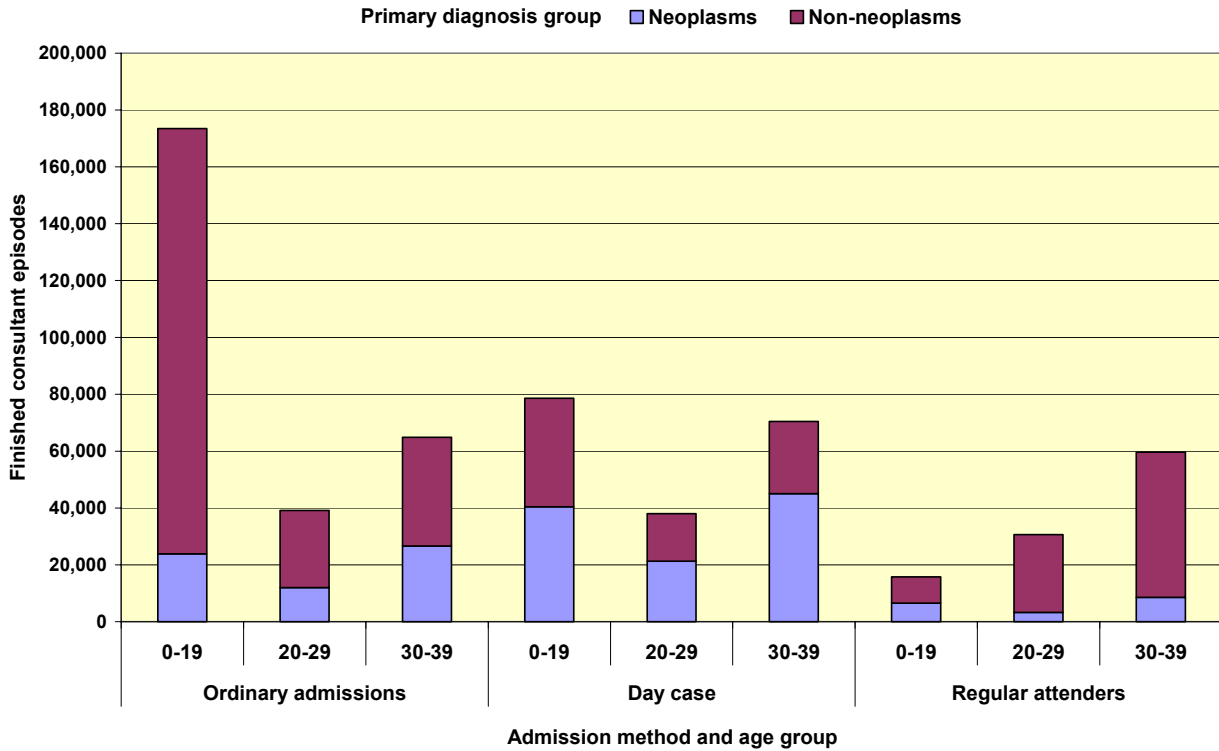
Finished consultant episodes for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, by primary diagnosis (neoplasm) group, age group and patient classification

Primary diagnosis group	0 - 19 years			20 - 29 years			30 - 39 years			Total
	Ordinary admissions ¹	Day case	Regular attenders	Ordinary admissions ¹	Day case	Regular attenders	Ordinary admissions ¹	Day case	Regular attenders	
Neoplasms ²	23,873	40,414	6,513	12,045	21,319	3,263	26,590	45,035	8,567	187,619
of which:										
Neoplasms receiving chemotherapy	4,100	6,840	1,784	2,039	3,755	1,287	2,962	11,469	3,667	37,903
% of neoplasms receiving chemotherapy ³	17%	17%	27%	17%	18%	39%	11%	25%	43%	20%
Non-neoplasms ⁴	149,610	38,213	9,252	27,058	16,676	27,346	38,272	25,365	51,079	382,871
All diagnoses	173,483	78,627	15,765	39,103	37,995	30,609	64,862	70,400	59,646	570,490
% of all diagnoses that are neoplasms	14%	51%	41%	31%	56%	11%	41%	64%	14%	33%

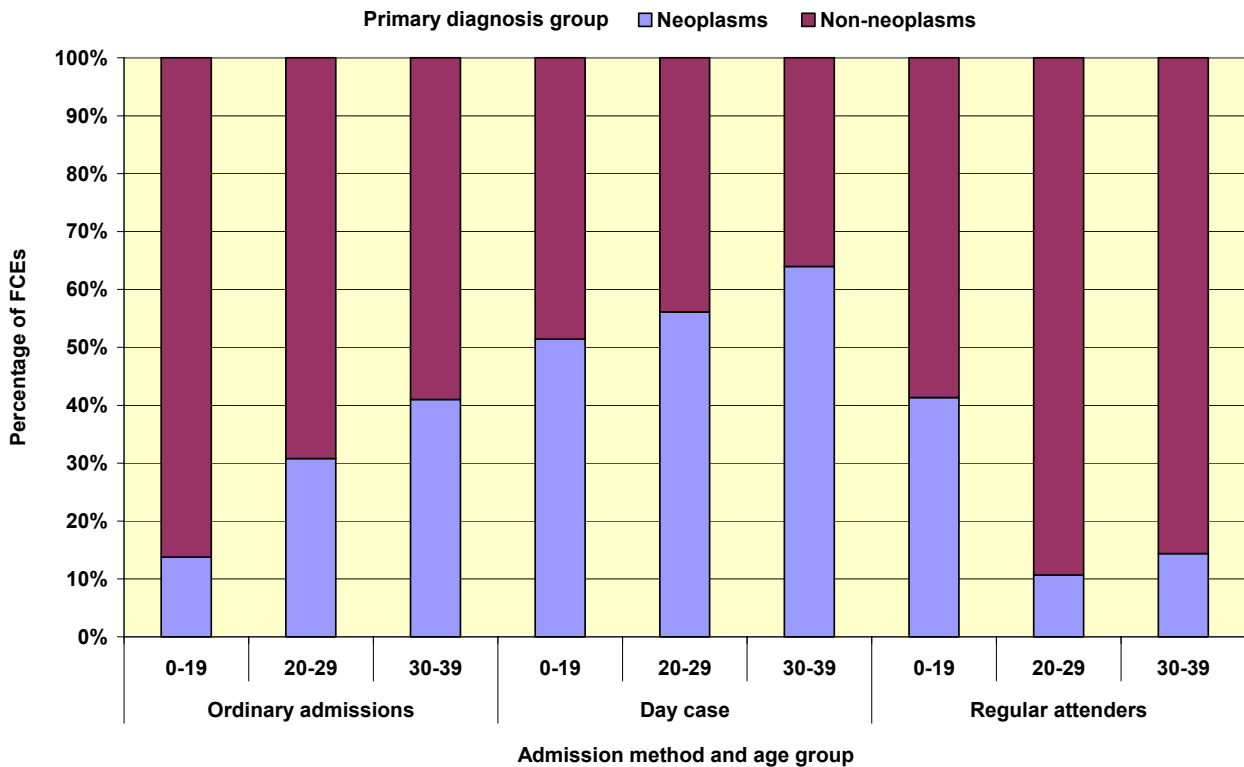
Figure 21

Finished consultant episodes for patients with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, by primary diagnosis (neoplasm) group, age group and patient classification

a) FCEs



b) Percentage of FCEs



2.5 Admissions prior to death in hospital⁹

In order to measure the level of need for inpatient palliative care services in the year prior to death, an analysis of hospital admissions for children and young people who died in hospital was carried out. There were 1,878 deaths in hospital in 2005-06 for children and young people age 0-19 with a diagnosis indicating a need for palliative care. On average children and young people age 0-19 who died in hospital needing palliative care had 2.4 admissions in the 12 months prior to their death, with the majority (78%) having one admission, whilst 241 (13%) had three or more admissions. There were 17 patients who had 30 or more admissions in the 12-months prior to death in hospital and the maximum number of admissions was 156.

Table 22

Number of admissions in 12-months prior to death in hospital¹ for patients aged 0-19, 2005-06

Admissions	Number of patients	% of patients
1	1,455	77.5%
2	182	9.7%
3	67	3.6%
4	35	1.9%
5	23	1.2%
6	14	0.7%
7	11	0.6%
8	10	0.5%
9 or more	81	4.3%
Total	1,878	100.0%

Of the 1,878 patients who died in hospital requiring palliative care, 540 had emergency admissions in the 12-months prior to death. The average number of emergency admissions in the 12-months prior to death was 1.9 for patients who had emergency admissions, 0.6 for all patients, whilst the maximum number was 15.

Table 23

Number of emergency admissions in 12-months prior to death in hospital¹ for patients aged 0-19, 2005-06

Emergency admissions	Number of patients	% of patients with emergency admissions
1	357	66.1%
2	72	13.3%
3	44	8.1%
4	23	4.3%
5	10	1.9%
6	14	2.6%
7	9	1.7%
8	2	0.4%
9 or more	9	1.7%
Total	540	100.0%

1. Patients died in hospital in period 1/4/05 to 31/3/06, admissions may have been in previous data-year

⁹ HES) data cannot be used to determine the cause of death of a patient while in hospital. Deaths recorded on the HES database may be analysed by the main diagnosis for which the patient was being treated during their stay in hospital, which may not necessarily be the underlying cause of death.

2.6 Inpatient expenditure by the NHS

The 254,742 FCEs for children and young adults aged 0-19 with 'palliative care' primary diagnoses in 2004-05 accounted for a total expenditure of £536.5 million. This expenditure is based on 2004-05 Healthcare Reference Group (HRG) reference costs and represents a third (32%) of the estimated £1.7 billion inpatient expenditure on patients in this age group¹⁰.

Of the £536.5m inpatient expenditure:

- over a quarter (29%) was on neonates
- neoplasms and associated treatments account for 16%
- almost all (99%) is attributable to NHS Trusts

Table 24

Finished consultant episodes (FCEs) and inpatient expenditure on patients aged 0-19 years, with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, by healthcare provider type

Organisation type	Expenditure (£)	% of total expenditure	FCEs	% of total FCEs
NHS Trust	532,038,143	99.2%	251,592	98.8%
Primary Care Trust	4,471,089	0.8%	3,146	1.2%
Non-NHS provider ¹	9,296	0.002%	4	0.002%
Total	536,518,528	100%	254,742	100.0%

1. Independent sector organisations providing healthcare funded by the NHS

¹⁰ Expenditure on hospital services for children has been estimated by grossing up data provided by 255 PCTs for the Child health Mapping data collection to obtain national estimates for the 0-19 age group (see <http://www.childhealthmapping.org.uk/index.php>).

Table 25

Finished consultant episodes (FCEs) and expenditure, for the healthcare resource groups accounting for 75% of total expenditure on patients aged 0-19 years with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, ranked by expenditure, 2004-05

Healthcare resource group	Expenditure (£)	% of total expenditure	FCEs	% of total FCEs
All healthcare resource groups¹	536,518,528	100%	254,742	100%
N04 Neonates with Multiple Major Diagnoses	75,008,671	14.0%	17,154	6.7%
N05 Neonates with one Major Diagnosis	49,153,361	9.2%	23,914	9.4%
P07 Neoplasms	40,865,810	7.6%	21,840	8.6%
P98 Chemotherapy with a Disease of Childhood Primary Diagnosis	32,814,164	6.1%	16,517	6.5%
N02 Neonates with Multiple Minor Diagnoses	22,645,039	4.2%	19,648	7.7%
P23 Blood Cell Disorders	22,327,808	4.2%	16,772	6.6%
E43 Congenital Disorders	19,749,297	3.7%	6,349	2.5%
P19 Major Congenital Conditions	18,617,919	3.5%	6,642	2.6%
E41 Other Cardiothoracic or Circulatory Procedures <19	16,857,076	3.1%	3,009	1.2%
P02 Cystic Fibrosis	10,561,688	2.0%	5,404	2.1%
R10 Surgery for Scoliosis or Other Spinal Deformity	8,049,734	1.5%	682	0.3%
P09 Nervous System Disorders	7,959,565	1.5%	3,750	1.5%
S09 Bone Marrow Graft	7,580,937	1.4%	249	0.1%
P18 Developmental Disorders	7,547,158	1.4%	2,001	0.8%
P12 Major Gastrointestinal or Metabolic Disorders	6,972,140	1.3%	3,524	1.4%
J37 Minor Skin Procedures - Category 1 w/o cc	6,862,200	1.3%	7,286	2.9%
N03 Neonates with one Minor Diagnosis	6,353,319	1.2%	6,635	2.6%
S36 Diagnostic Extraction of Bone Marrow	6,059,710	1.1%	2,229	0.9%
Q19 Vascular Access for Renal Replacement Therapy	5,695,715	1.1%	1,369	0.5%
P24 Skin, Musculoskeletal, or Connective Tissue Disorders	5,574,491	1.0%	4,677	1.8%
A34 Miscellaneous Disorders of Nervous System	5,446,031	1.0%	2,519	1.0%
P20 Other Congenital Conditions	4,094,863	0.8%	3,038	1.2%
A03 Intracranial Procedures Except Trauma - Category 3	4,083,925	0.8%	659	0.3%
A04 Intracranial Procedures Except Trauma - Category 4	4,068,217	0.8%	479	0.2%
P04 Lower Respiratory Tract Disorders without Acute Bronchiolitis	4,008,952	0.7%	887	0.3%
E39 Electrophysiological and other Percutaneous Cardiac Procedures <19	3,961,349	0.7%	1,009	0.4%

1. For patients aged 0-19 years with a condition indicating that may lead to an eventual need for palliative care.

Summary

Mortality data and prevalence rates

The estimated prevalence of children and young adults requiring palliative care services (18,000 i.e. 15 per 10,000 aged 0-19 years excluding neonates) derived in this analysis is in line with estimates published in other sources. The estimated number at regional level suggests that the most appropriate geographical area on which services are organised may be at Strategic Health Authority level.

In recent years an average of 8,480 children and young adults aged 0-39 years died per annum from causes likely to have required palliative care; this is 50% of deaths from all causes in this age group (including neonatal deaths).

There is some evidence from recent mortality trends and from published research that life expectancy for people with some conditions that require palliative care is increasing. Further work is needed looking at trends over a longer time period to establish a firmer evidence base.

It is estimated that 63% of children and young people age 0-19 years requiring palliative care have a need for social care i.e. 11,000 children.

Three-quarters of non-neonatal deaths likely to require palliative care amongst children aged 0-19 occurred in hospital. The proportion of deaths in hospital is lower for young adults (61%) than it is for young children aged under 1 (88%) or aged 1 - 4 (74%).

Hospital Episodes

Accurate data on hospital inpatient palliative care is not available at a national level and therefore data from the Information Centre Hospital Episode Statistics database (HES) will over-state the use of inpatient hospital services, as information on severity of patients' conditions is not available. It is however, possible to provide an indication of the upper bound of bed use and expenditure using this data.

Though the number of patients admitted to hospital with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care has remained relatively constant throughout the nine years since 1997-98, there has been an increase in the number of FCEs over the period for all age groups, suggesting an increasing demand for palliative care services.

An analysis of emergency hospital admissions in five sample regions suggests that there is no straight-forward association between emergency admission rates for children with a diagnosis indicating a condition that may lead to a need for palliative care services, and the reported quality of access to palliative care services in these regions.

A third of bed-days for all patients aged 0-19 years were attributable to patients with a diagnosis indicating a condition that may lead to an eventual need for palliative care. For the 20-29 and 30-39 year age groups 'palliative care' bed-days accounted for 7% and 9% of all bed-days in the respective age groups.

On average patients in the general population aged 0-19 require 0.3 bed-days per-year, whereas those with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care require 8.9 bed-days per year.

Expenditure by the NHS on inpatient care for children and young adults aged 0-19 with a condition that may lead to a need for palliative care was in excess of £536m in 2004-05. Over a quarter (29%) of this expenditure was on neonates and 16% on cancer patients.

The NHS inpatient expenditure and bed occupancy attributable to children and young people age 0-19 years with conditions that may require palliative care account for an estimated one-third of the total expenditure and bed occupancy for all patients in this age group.

Appendices

Appendix 1 Mortality data by Strategic Health Authority of usual residence

Table A1

Average annual number of deaths of children and young adults age 0-39 years from all causes and from causes likely to have required palliative care, 2002-05, by Strategic Health Authority of usual residence

Strategic Health Authority of usual residence	Average number of deaths per year from all causes, 2002-05				Average number of deaths per year from causes likely to have required palliative care, 2002-05				Percentage of all deaths that were from causes likely to require palliative care, 2002-05			
	Neonatal	0-19 years, excluding neonatal	20-29 years	30-39 years	Neonatal	0-19 years, excluding neonatal	20-29 years	30-39 years	Neonatal	0-19 years, excluding neonatal	20-29 years	30-39 years
East Midlands	179	298	295	550	173	145	84	241	97%	49%	29%	44%
East of England	180	341	353	655	174	180	102	310	97%	53%	29%	47%
London	398	531	556	1,145	386	301	165	546	97%	57%	30%	48%
North East	83	176	209	350	80	77	58	158	96%	44%	28%	45%
North West	297	503	498	1,055	283	254	150	489	95%	50%	30%	46%
South Central	125	227	244	447	118	121	72	220	94%	53%	29%	49%
South Coastal	135	243	253	506	127	128	78	238	94%	52%	31%	47%
South West	161	276	306	579	154	133	87	263	95%	48%	28%	45%
West Midlands	315	391	362	688	304	189	105	329	97%	48%	29%	48%
Yorkshire & Humber	230	404	402	746	221	205	107	342	96%	51%	27%	46%
All SHAs	2,101	3,388	3,476	6,721	2,018	1,732	1,008	3,135	96%	51%	29%	47%
England total¹	2,211	3,641	3,750	7,205	2,122	1,862	1,084	3,361	96%	51%	29%	47%

1. Including deaths in England of people not usually resident in England

Table A2

Average number of deaths per year of children and young adults age 0-39 years from causes likely to have required palliative care, by Strategic Health Authority and place of death, 2002-05

SHA of usual residence	Neonatal				Non-neonatal											
	Home	Hospice	Hospital	Other	0-19 years				20-29 years				30-39 years			
					Home	Hospice	Hospital	Other	Home	Hospice	Hospital	Other	Home	Hospice	Hospital	
East Midlands	2	0	170	1	32	5	106	2	15	6	57	6	56	26	145	
East of England	1	0	171	2	40	15	122	4	28	10	60	5	77	39	174	
London	2	0	383	1	44	5	247	5	26	12	120	7	104	43	374	
North East	1	0	78	1	17	1	57	2	13	4	37	5	47	16	84	
North West	3	1	275	4	49	16	184	5	30	9	103	9	120	54	294	
South Central	2	1	115	0	31	6	83	2	17	7	45	4	53	33	121	
South Coastal	2	0	124	1	27	5	90	6	16	9	48	6	52	40	130	
South West	1	0	151	2	30	5	95	3	19	8	53	8	70	40	137	
West Midlands	3	0	299	2	31	9	144	5	17	8	74	7	75	29	207	
Yorks & Humber	3	0	216	3	42	12	142	9	22	8	68	9	93	35	187	
All SHAs average	19	2	1,981	16	343	79	1,269	41	202	78	664	63	745	354	1,851	
England average ¹	20	2	2,084	17	362	83	1,372	45	216	82	714	73	801	367	1,990	

Of all deaths within each age group, the percentage that occurred in each place of death category

SHA of usual residence	Neonatal				Non-neonatal											
	Home	Hospice	Hospital	Other	0-19 years				20-29 years				30-39 years			
					Home	Hospice	Hospital	Other	Home	Hospice	Hospital	Other	Home	Hospice	Hospital	
East Midlands	1.0%	0.0%	98.3%	0.7%	22.1%	3.4%	73.1%	1.4%	18.1%	6.8%	68.0%	7.1%	23.2%	10.9%	60.2%	
East of England	0.6%	0.0%	98.3%	1.1%	22.3%	8.0%	67.5%	2.1%	27.5%	9.8%	58.3%	4.4%	24.7%	12.7%	55.9%	
London	0.5%	0.0%	99.4%	0.1%	14.5%	1.7%	82.2%	1.6%	15.6%	7.1%	72.9%	4.4%	19.1%	7.9%	68.5%	
North East	1.3%	0.0%	98.1%	0.6%	22.4%	1.3%	74.4%	1.9%	22.3%	6.0%	63.9%	7.7%	29.7%	10.2%	53.3%	
North West	0.9%	0.3%	97.3%	1.5%	19.4%	6.3%	72.3%	2.0%	20.0%	5.7%	68.4%	6.0%	24.5%	11.0%	60.1%	
South Central	1.5%	0.6%	97.7%	0.2%	25.3%	5.0%	68.5%	1.2%	23.1%	9.4%	62.6%	4.9%	24.1%	15.0%	55.0%	
South Coastal	1.6%	0.0%	97.6%	0.8%	21.2%	3.7%	70.8%	4.3%	20.4%	11.5%	60.7%	7.3%	21.9%	16.6%	54.6%	
South West	0.8%	0.0%	98.2%	1.0%	22.7%	3.9%	71.3%	2.1%	21.4%	9.0%	61.0%	8.7%	26.5%	15.2%	52.1%	
West Midlands	0.9%	0.0%	98.4%	0.7%	16.6%	4.6%	76.0%	2.8%	16.2%	7.1%	70.2%	6.4%	22.6%	8.7%	62.8%	
Yorks & Humber	1.4%	0.1%	97.4%	1.1%	20.4%	6.0%	69.3%	4.4%	20.8%	7.3%	63.9%	8.0%	27.1%	10.2%	54.6%	
All SHAs	0.9%	0.1%	98.2%	0.8%	19.8%	4.5%	73.3%	2.4%	20.1%	7.8%	65.9%	6.3%	23.8%	11.3%	59.1%	
England total ¹	0.9%	0.1%	98.2%	0.8%	19.5%	4.4%	73.7%	2.4%	19.9%	7.5%	65.9%	6.7%	23.8%	10.9%	59.2%	

1. Including deaths in England of people not usually resident in England

Appendix 2

Table A3

Finished consultant episodes and bed-days in year for primary diagnoses accounting for 75% of bed-days in year for patients aged 0-39 years with a primary diagnosis indicating a condition that may lead to an eventual need for palliative care, 2005-06

a) 0-19 years

Primary diagnosis	FCEs (all patient classific'ns)	% of all episodes	FCEs (ordinary admis'ns)	% of ordinary admission FCEs	Bed-days in year	% of all bed-days in year
P07 Disorders relating to short gestation and low birth weight	35,624	13.3%	35,597	20.5%	511,792	45.0%
P22 Respiratory distress of newborn	8,221	3.1%	8,206	4.7%	57,896	5.1%
E84 Cystic fibrosis	7,026	2.6%	4,961	2.9%	36,526	3.2%
C91 Lymphoid leukaemia	23,546	8.8%	6,035	3.5%	24,747	2.2%
Q21 Congenital malformations of cardiac septa	5,248	2.0%	4,822	2.8%	21,946	1.9%
P20 Intrauterine hypoxia	7,450	2.8%	7,450	4.3%	18,299	1.6%
P28 Other respiratory conditions originating in the perinatal period	6,104	2.3%	6,080	3.5%	17,032	1.5%
Q79 Congenital malformations of the musculoskeletal system NEC	1,465	0.5%	1,372	0.8%	15,578	1.4%
C71 Malignant neoplasm of brain	5,718	2.1%	2,477	1.4%	13,369	1.2%
C92 Myeloid leukaemia	3,015	1.1%	1,161	0.7%	13,367	1.2%
Q25 Congenital malformations of great arteries	3,302	1.2%	3,085	1.8%	13,174	1.2%
M41 Scoliosis	1,857	0.7%	1,608	0.9%	11,653	1.0%
D70 Agranulocytosis	2,681	1.0%	2,350	1.4%	10,800	0.9%
Q20 Congenital malformations of cardiac chambers and connections	1,878	0.7%	1,749	1.0%	10,744	0.9%
G80 Infantile cerebral palsy	4,381	1.6%	2,148	1.2%	10,451	0.9%
Q43 Other congenital malformations of intestine	1,853	0.7%	1,553	0.9%	10,268	0.9%
P21 Birth asphyxia	2,023	0.8%	2,018	1.2%	9,673	0.9%
P36 Bacterial sepsis of newborn	1,604	0.6%	1,590	0.9%	8,985	0.8%
P27 Chronic respiratory disease originating in the perinatal period	500	0.2%	393	0.2%	8,171	0.7%
D57 Sickle-cell disorders	4,090	1.5%	2,847	1.6%	7,884	0.7%
Q23 Congenital malformations of aortic and mitral valves	1,195	0.4%	1,102	0.6%	7,553	0.7%
G93 Other disorders of brain	1,271	0.5%	985	0.6%	7,002	0.6%
C40 Malignant neoplasm of bone and articular cartilage of limbs	2,101	0.8%	1,499	0.9%	6,656	0.6%
All diagnoses total and percentage of total accounted for by above diagnoses	267,832	49.3%	173,443	49.3%	1,137,329	75.1%

b) 20-29 years

Primary diagnosis	FCEs (all patient classific'ns)	% of all episodes	FCEs (ordinary admis'ns)	% of ordinary admission FCEs	Bed-days in year	% of all bed- days in year
E84 Cystic fibrosis	3,215	3.0%	2,111	5.4%	18,270	9.4%
C92 Myeloid leukaemia	2,257	2.1%	764	2.0%	10,053	5.2%
D57 Sickle-cell disorders	3,866	3.6%	2,747	7.0%	7,907	4.1%
F72 Severe mental retardation	675	0.6%	675	1.7%	7,467	3.9%
N12 Tubulo-interstitial nephritis not specified as acute or chronic	3,109	2.9%	3,089	7.9%	7,143	3.7%
C91 Lymphoid leukaemia	2,524	2.3%	609	1.6%	6,147	3.2%
G93 Other disorders of brain	1,206	1.1%	756	1.9%	6,044	3.1%
G35 Multiple sclerosis	1,247	1.2%	615	1.6%	4,518	2.3%
F79 Unspecified mental retardation	840	0.8%	840	2.2%	4,348	2.2%
C71 Malignant neoplasm of brain	1,013	0.9%	512	1.3%	3,679	1.9%
G82 Paraplegia and tetraplegia	158	0.1%	119	0.3%	3,555	1.8%
C62 Malignant neoplasm of testis	1,963	1.8%	1,159	3.0%	3,481	1.8%
N18 Chronic renal failure	25,024	23.2%	880	2.3%	3,467	1.8%
C81 Hodgkin's disease	4,593	4.3%	825	2.1%	3,381	1.7%
N13 Obstructive and reflux uropathy	1,082	1.0%	982	2.5%	3,330	1.7%
M32 Systemic lupus erythematosus	725	0.7%	390	1.0%	2,675	1.4%
C40 Malignant neoplasm of bone and articular cartilage of limbs	535	0.5%	466	1.2%	2,490	1.3%
C41 Malignant neoplasm of bone and articular cartilage of other and unspecified sites	532	0.5%	383	1.0%	2,144	1.1%
D27 Benign neoplasm of ovary	699	0.6%	645	1.7%	2,128	1.1%
T86 Failure and rejection of transplanted organs and tissue	381	0.4%	300	0.8%	2,112	1.1%
C83 Diffuse non-Hodgkin's lymphoma	739	0.7%	241	0.6%	2,028	1.0%
D70 Agranulocytosis	472	0.4%	357	0.9%	2,017	1.0%
G81 Hemiplegia	322	0.3%	301	0.8%	1,954	1.0%
I42 Cardiomyopathy	308	0.3%	291	0.7%	1,939	1.0%
B20 Human immunodeficiency virus (HIV) disease resulting in infectious parasitic diseases	249	0.2%	219	0.6%	1,916	1.0%
C85 Other and unspecified types of non-Hodgkin's lymphoma	1,148	1.1%	297	0.8%	1,745	0.9%
I12 Hypertensive renal disease	3,828	3.6%	343	0.9%	1,724	0.9%
C49 Malignant neoplasm of other connective and soft tissue	484	0.4%	399	1.0%	1,702	0.9%
G61 Inflammatory polyneuropathy	230	0.2%	188	0.5%	1,651	0.9%
G41 Status epilepticus	305	0.3%	304	0.8%	1,416	0.7%
K75 Other inflammatory liver diseases	246	0.2%	214	0.5%	1,296	0.7%
G37 Other demyelinating diseases of central nervous system	303	0.3%	171	0.4%	1,267	0.7%
D64 Other anaemias	1,482	1.4%	595	1.5%	1,212	0.6%
I31 Other diseases of pericardium	519	0.5%	515	1.3%	1,182	0.6%

b) 20-29 years cont.

Primary diagnosis	FCEs (all patient classific'ns)	% of all episodes	FCEs (ordinary admis'ns)	% of ordinary admission FCEs	Bed-days in year	% of all bed- days in year
D69 Purpura and other haemorrhagic conditions	1,392	1.3%	426	1.1%	1,175	0.6%
D25 Leiomyoma of uterus	531	0.5%	391	1.0%	1,138	0.6%
C53 Malignant neoplasm of cervix uteri	722	0.7%	323	0.8%	1,108	0.6%
M41 Scoliosis	141	0.1%	121	0.3%	1,057	0.5%
C56 Malignant neoplasm of ovary	385	0.4%	212	0.5%	1,050	0.5%
B24 Unspecified human immunodeficiency virus (HIV) disease	152	0.1%	104	0.3%	975	0.5%
J47 Bronchiectasis	197	0.2%	151	0.4%	960	0.5%
G80 Infantile cerebral palsy	257	0.2%	126	0.3%	944	0.5%
D61 Other aplastic anaemias	1,497	1.4%	221	0.6%	936	0.5%
G95 Other diseases of spinal cord	87	0.1%	79	0.2%	930	0.5%
C73 Malignant neoplasm of thyroid gland	352	0.3%	332	0.8%	903	0.5%
D43 Neoplasm of uncertain or unknown behaviour of brain and central nervous system	157	0.1%	139	0.4%	869	0.4%
M95 Other acquired deformities of musculoskeletal system and connective tissue	733	0.7%	626	1.6%	860	0.4%
K72 Hepatic failure not elsewhere classified	157	0.1%	155	0.4%	824	0.4%
C18 Malignant neoplasm of colon	557	0.5%	205	0.5%	811	0.4%
C79 Secondary malignant neoplasm of other sites	241	0.2%	161	0.4%	808	0.4%
C78 Secondary malignant neoplasm of respiratory and digestive organs	266	0.2%	179	0.5%	805	0.4%
D48 Neoplasm uncertain or unknown behaviour of other and unspecified sites	382	0.4%	212	0.5%	799	0.4%
N11 Chronic tubulo-interstitial nephritis	276	0.3%	274	0.7%	772	0.4%
All diagnoses total and percentage of total accounted for by above diagnoses	107,665	69.4%	39,065	71.0%	193,891	74.8%

b) 30-39 years

Primary diagnosis	FCEs (all patient classific'ns)	% of all episodes	FCEs (ordinary admis'ns)	% of ordinary admission FCEs	Bed-days in year	% of all bed- days in year
F72 Severe mental retardation	780	0.4%	780	1.2%	13,626	4.3%
D25 Leiomyoma of uterus	4,952	2.5%	3,661	5.7%	12,712	4.0%
G35 Multiple sclerosis	4,062	2.1%	1,951	3.0%	12,144	3.8%
C92 Myeloid leukaemia	3,355	1.7%	940	1.5%	10,438	3.3%
C50 Malignant neoplasm of breast	14,378	7.4%	2,896	4.5%	9,666	3.0%

b) 30-39 years cont.

Primary diagnosis	FCEs (all patient classific'ns)	% of all episodes	FCEs (ordinary admis'ns)	% of ordinary admission FCEs	Bed-days in year	% of all bed- days in year
N18 Chronic renal failure	48,598	24.9%	1,946	3.0%	8,219	2.6%
C71 Malignant neoplasm of brain	1,802	0.9%	973	1.5%	7,557	2.4%
D57 Sickle-cell disorders	3,227	1.7%	2,062	3.2%	7,410	2.3%
E84 Cystic fibrosis	1,230	0.6%	783	1.2%	6,690	2.1%
B20 Human immunodeficiency virus (HIV) disease resulting in infectious parasitic diseases	752	0.4%	676	1.0%	6,553	2.1%
G93 Other disorders of brain	1,108	0.6%	778	1.2%	6,131	1.9%
I21 Acute myocardial infarction	1,595	0.8%	1,587	2.4%	5,792	1.8%
F79 Unspecified mental retardation	629	0.3%	629	1.0%	5,397	1.7%
N13 Obstructive and reflux uropathy	1,510	0.8%	1,370	2.1%	4,669	1.5%
N12 Tubulo-interstitial nephritis not specified as acute or chronic	1,904	1.0%	1,885	2.9%	4,659	1.5%
C53 Malignant neoplasm of cervix uteri	2,267	1.2%	1,209	1.9%	4,484	1.4%
C81 Hodgkin's disease	4,465	2.3%	788	1.2%	3,973	1.2%
C62 Malignant neoplasm of testis	2,181	1.1%	1,224	1.9%	3,908	1.2%
I12 Hypertensive renal disease	7,058	3.6%	778	1.2%	3,726	1.2%
C91 Lymphoid leukaemia	1,717	0.9%	339	0.5%	3,543	1.1%
G82 Paraplegia and tetraplegia	259	0.1%	213	0.3%	3,426	1.1%
D27 Benign neoplasm of ovary	1,036	0.5%	956	1.5%	3,396	1.1%
I42 Cardiomyopathy	636	0.3%	558	0.9%	3,391	1.1%
C85 Other and unspecified types of non-Hodgkin's lymphoma	2,172	1.1%	599	0.9%	3,280	1.0%
I20 Angina pectoris	1,959	1.0%	1,814	2.8%	3,239	1.0%
C83 Diffuse non-Hodgkin's lymphoma	1,397	0.7%	393	0.6%	3,178	1.0%
I25 Chronic ischaemic heart disease	1,550	0.8%	1,081	1.7%	3,157	1.0%
G61 Inflammatory polyneuropathy	548	0.3%	313	0.5%	3,015	0.9%
M32 Systemic lupus erythematosus	980	0.5%	530	0.8%	3,003	0.9%
C79 Secondary malignant neoplasm of other sites	1,159	0.6%	551	0.9%	2,979	0.9%
D70 Agranulocytosis	713	0.4%	605	0.9%	2,969	0.9%
G81 Hemiplegia	526	0.3%	476	0.7%	2,968	0.9%
C18 Malignant neoplasm of colon	1,825	0.9%	495	0.8%	2,954	0.9%
C56 Malignant neoplasm of ovary	1,287	0.7%	562	0.9%	2,840	0.9%
I50 Heart failure	430	0.2%	399	0.6%	2,756	0.9%
C78 Secondary malignant neoplasm of respiratory and digestive organs	1,426	0.7%	668	1.0%	2,701	0.8%
B24 Unspecified human immunodeficiency virus (HIV) disease	418	0.2%	322	0.5%	2,519	0.8%
G37 Other demyelinating diseases of central nervous system	531	0.3%	289	0.4%	2,483	0.8%

b) 30-39 years cont.

Primary diagnosis	FCEs (all patient classific'ns)	% of all episodes	FCEs (ordinary admis'ns)	% of ordinary admission FCEs	Bed-days in year	% of all bed- days in year
T86 Failure and rejection of transplanted organs and tissue	465	0.2%	376	0.6%	2,427	0.8%
D64 Other anaemias	2,594	1.3%	892	1.4%	2,268	0.7%
G95 Other diseases of spinal cord	215	0.1%	189	0.3%	2,082	0.7%
G91 Hydrocephalus	149	0.1%	141	0.2%	1,981	0.6%
D32 Benign neoplasm of meninges	230	0.1%	215	0.3%	1,962	0.6%
C73 Malignant neoplasm of thyroid gland	663	0.3%	632	1.0%	1,905	0.6%
G41 Status epilepticus	419	0.2%	419	0.6%	1,830	0.6%
B21 Human immunodeficiency virus (HIV) disease resulting in malignant neoplasms	429	0.2%	187	0.3%	1,828	0.6%
C49 Malignant neoplasm of other connective and soft tissue	518	0.3%	328	0.5%	1,828	0.6%
C80 Malignant neoplasm without specification of site	578	0.3%	318	0.5%	1,801	0.6%
K75 Other inflammatory liver diseases	343	0.2%	279	0.4%	1,755	0.6%
I85 Oesophageal varices	685	0.4%	426	0.7%	1,727	0.5%
K76 Other diseases of liver	531	0.3%	348	0.5%	1,648	0.5%
C34 Malignant neoplasm of bronchus and lung	760	0.4%	349	0.5%	1,592	0.5%
D48 Neoplasm uncertain or unknown behaviour of other and unspecified sites	534	0.3%	278	0.4%	1,570	0.5%
C64 Malignant neoplasm of kidney, except renal pelvis	281	0.1%	208	0.3%	1,546	0.5%
I31 Other diseases of pericardium	716	0.4%	708	1.1%	1,468	0.5%
K72 Hepatic failure not elsewhere classified	246	0.1%	245	0.4%	1,420	0.4%
D43 Neoplasm of uncertain or unknown behaviour of brain and central nervous system	225	0.1%	187	0.3%	1,396	0.4%
Q21 Congenital malformations of cardiac septa	546	0.3%	421	0.6%	1,366	0.4%
C20 Malignant neoplasm of rectum	1,019	0.5%	270	0.4%	1,346	0.4%
F73 Profound mental retardation	73	0.0%	73	0.1%	1,329	0.4%
J44 Other chronic obstructive pulmonary disease	462	0.2%	451	0.7%	1,327	0.4%
G62 Other polyneuropathies	451	0.2%	259	0.4%	1,313	0.4%
C41 Malignant neoplasm of bone and articular cartilage of other and unspecified sites	234	0.1%	201	0.3%	1,283	0.4%
All diagnoses total and percentage of total accounted for by above diagnoses	194,823	71.8%	64,781	71.7%	318,019	74.7%

Appendix 3

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Appendix 4

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Appendix 5

International Classification of Diseases¹¹ conditions used for deaths likely to have required palliative care and for hospital admissions analysis

Diagnosis Group	Diagnosis code	Diagnosis description
Human immunodeficiency virus (HIV) disease	B20	Human immunodeficiency virus (HIV) disease resulting in infectious parasitic diseases
	B21	Human immunodeficiency virus (HIV) disease resulting in malignant neoplasms
	B22	Human immunodeficiency virus (HIV) disease resulting in other specified diseases
	B23	Human immunodeficiency virus (HIV) disease resulting in other conditions
	B24	Unspecified human immunodeficiency virus (HIV) disease
Other viral diseases	B25	Cytomegaloviral disease
	B44	Aspergillosis
Sequelae of infectious and parasitic diseases	B90	Sequelae of tuberculosis
	B91	Sequelae of poliomyelitis
	B92	Sequelae of leprosy
	B94	Sequelae of other and unspecified infectious and parasitic diseases
Malignant neoplasms of lip, oral cavity and pharynx	C00	Malignant neoplasm of lip
	C01	Malignant neoplasm of base of tongue
	C02	Malignant neoplasm of other and unspecified parts of tongue
	C03	Malignant neoplasm of gum
	C04	Malignant neoplasm of floor of mouth
	C05	Malignant neoplasm of palate
	C06	Malignant neoplasm of other and unspecified parts of mouth
	C07	Malignant neoplasm of parotid gland
	C08	Malignant neoplasm of other and unspecified major salivary glands
	C09	Malignant neoplasm of tonsil
	C10	Malignant neoplasm of oropharynx
	C11	Malignant neoplasm of nasopharynx
	C12	Malignant neoplasm of pyriform sinus
	C13	Malignant neoplasm of hypopharynx
C14	Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx	
Malignant neoplasms of digestive organs	C15	Malignant neoplasm of oesophagus
	C16	Malignant neoplasm of stomach
	C17	Malignant neoplasm of small intestine
	C18	Malignant neoplasm of colon
	C19	Malignant neoplasm of rectosigmoid junction
	C20	Malignant neoplasm of rectum
	C21	Malignant neoplasm of anus and anal canal
	C22	Malignant neoplasm of liver and intrahepatic bile ducts
	C23	Malignant neoplasm of gallbladder
	C24	Malignant neoplasm of other and unspecified parts biliary tract
	C25	Malignant neoplasm of pancreas
C26	Malignant neoplasm of other and ill-defined digestive organs	
Malignant neoplasm of respiratory and intrathoracic organs	C30	Malignant neoplasm of nasal cavity and middle ear
	C31	Malignant neoplasm of accessory sinuses
	C32	Malignant neoplasm of larynx
	C33	Malignant neoplasm of trachea
	C34	Malignant neoplasm of bronchus and lung
	C37	Malignant neoplasm of thymus
	C38	Malignant neoplasm of heart, mediastinum and pleura
C39	Malignant neoplasm of other and ill-defined sites in the respiratory system and intrathoracic organs	
Malignant neoplasm of bone and articular cartilage	C40	Malignant neoplasm of bone and articular cartilage of limbs
Melanoma and other malignant neoplasms of skin	C41	Malignant neoplasm of bone and articular cartilage of other and unspecified sites
	C43	Malignant melanoma of skin
Malignant neoplasms of mesothelial and soft tissue	C44	Other malignant neoplasms of skin
	C45	Mesothelioma
	C46	Kaposi's sarcoma
	C47	Malignant neoplasm peripheral nerves and autonomic nervous system
	C48	Malignant neoplasm of retroperitoneum and peritoneum
Malignant neoplasm of breast	C49	Malignant neoplasm of other connective and soft tissue
	C50	Malignant neoplasm of breast
Malignant neoplasms of female genital organs	C51	Malignant neoplasm of vulva
	C52	Malignant neoplasm of vagina
	C53	Malignant neoplasm of cervix uteri
	C54	Malignant neoplasm of corpus uteri
	C55	Malignant neoplasm of uterus, part unspecified
	C56	Malignant neoplasm of ovary
	C57	Malignant neoplasm of other and unspecified female genital organs
	C58	Malignant neoplasm of placenta

¹¹ International Classification of Diseases (ICD-10), <http://www.who.int/classifications/icd/en/>

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Malignant neoplasms of eye, brain and other parts of central nervous system	C69	Malignant neoplasm of eye and adnexa
	C70	Malignant neoplasm of meninges
	C71	Malignant neoplasm of brain
Malignant neoplasms of thyroid and other endocrine glands	C72	Malignant neoplasm of spinal cord, cranial nerves & other parts of central nervous system
	C73	Malignant neoplasm of thyroid gland
	C74	Malignant neoplasm of adrenal gland
Malignant neoplasms of ill-defined, secondary and unspecified sites	C75	Malignant neoplasm of other endocrine glands and related structures
	C76	Malignant neoplasm of other and ill-defined sites
	C77	Secondary and unspecified malignant neoplasm of lymph nodes
	C78	Secondary malignant neoplasm of respiratory and digestive organs
	C79	Secondary malignant neoplasm of other sites
	C80	Malignant neoplasm without specification of site
	C81	Hodgkin's disease
	C82	Follicular [nodular] non-Hodgkin's lymphoma
	C83	Diffuse non-Hodgkin's lymphoma
	C84	Peripheral and cutaneous T-cell lymphomas
	C85	Other and unspecified types of non-Hodgkin's lymphoma
	C88	Malignant immunoproliferative diseases
	C90	Multiple myeloma and malignant plasma cell neoplasms
	C91	Lymphoid leukaemia
	C92	Myeloid leukaemia
	C93	Monocytic leukaemia
	C94	Other leukaemias of specified cell type
	C95	Leukaemia of unspecified cell type
	C96	Other & unspecified malignant neoplasm lymphoid, haematopoietic & related tissue
	Malignant neoplasms of independent (primary) multiple sites	C97
Benign neoplasms	D17	Benign lipomatous neoplasm
	D18	Haemangioma and lymphangioma any site
	D19	Benign neoplasm of mesothelial tissue
	D20	Benign neoplasm soft tissue of retroperitoneum and peritoneum
	D21	Other benign neoplasms of connective and other soft tissue
	D22	Melanocytic naevi
	D23	Other benign neoplasms of skin
	D24	Benign neoplasm of breast
	D25	Leiomyoma of uterus
	D26	Other benign neoplasms of uterus
	D27	Benign neoplasm of ovary
	D28	Benign neoplasm of other and unspecified female genital organs
	D29	Benign neoplasm of male genital organs
	D30	Benign neoplasm of urinary organs
	D31	Benign neoplasm of eye and adnexa
	D32	Benign neoplasm of meninges
	D33	Benign neoplasm brain and other parts of central nervous
	D34	Benign neoplasm of thyroid gland
	D35	Benign neoplasm of other and unspecified endocrine glands
	D36	Benign neoplasm of other and unspecified sites
Neoplasms of uncertain or unknown behaviour	D37	Neoplasm of uncertain or unknown behaviour oral cavity and digestive organs
	D38	Neoplasm of uncertain or unknown behaviour of middle ear and respiratory and intrathoracic organs
	D39	Neoplasm of uncertain or unknown behaviour of female genital organs
	D40	Neoplasm of uncertain or unknown behaviour of male genital organs
	D41	Neoplasm of uncertain or unknown behaviour of urinary organs
	D42	Neoplasm of uncertain or unknown behaviour of meninges
	D43	Neoplasm of uncertain or unknown behaviour of brain and central nervous system
	D44	Neoplasm of uncertain or unknown behaviour of endocrine glands
	D45	Polycythaemia vera
	D46	Myelodysplastic syndromes
	D47	Other neoplasms of uncertain or unknown behaviour of lymphoid, haematopoietic and related issues
	D48	Neoplasm uncertain or unknown behaviour of other and unspecified sites

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Haemolytic anaemias	D55	Anaemia due to enzyme disorders
	D56	Thalassaemia
	D57	Sickle-cell disorders
	D58	Other hereditary haemolytic anaemias
	D59	Acquired haemolytic anaemia
Aplastic and other anaemias	D60	Acquired pure red cell aplasia [erythroblastopenia]
	D61	Other aplastic anaemias
	D63	Anaemia in chronic diseases classified elsewhere
	D64	Other anaemias
Coagulation defects, purpura and other haemorrhagic conditions	D66	Hereditary factor VIII deficiency
	D67	Hereditary factor IX deficiency
	D68	Other coagulation defects
	D69	Purpura and other haemorrhagic conditions
	D70	Agranulocytosis
Other diseases of blood and blood-forming organs	D71	Functional disorders of polymorphonuclear neutrophils
	D72	Other disorders of white blood cells
	D73	Diseases of spleen
	D74	Methaemoglobinaemia
	D75	Other diseases of blood and blood-forming organs
	D76	Certain diseases involving lymphoretic tissue and reticuloendothelial system
	D77	Other disorders of blood and blood-forming organs in diseases EC
	D78	Other disorders of blood and blood-forming organs in diseases EC
Certain disorders involving the immune mechanism	D81	Combined immunodeficiencies
	D82	Immunodeficiency associated with other major defects
	D83	Common variable immunodeficiency
	D84	Other immunodeficiencies
	D86	Sarcoidosis
Disorders of other endocrine glands	D89	Other disorders involving the immune mechanism NEC
	E22	Hyperfunction of pituitary gland
	E23	Hypofunction and other disorders of pituitary gland
	E24	Cushing's syndrome (exclude E24.4 Alcohol-induced pseudo-Cushing's syndrome)
	E25	Adrenogenital disorders
	E31	Polyglandular dysfunction
	E32	Diseases of thymus
	E34	Other endocrine disorders
	E35	Disorders of endocrine glands in diseases classified elsewhere
	Metabolic disorders	E70
E71		Disorders of branched-chain amino-acid metabolism + fatty-acid metabolism
E72		Other disorders of amino-acid metabolism
E74		Other disorders of carbohydrate metabolism
E75		Disorders sphingolipid metabolism and other lipid storage disorders
E76		Disorders of glycosaminoglycan metabolism
E77		Disorders of glycoprotein metabolism
E78		Disorders of lipoprotein metabolism and other lipidaemias
E79		Disorders of purine and pyrimidine metabolism
E80		Disorders of porphyrin and bilirubin metabolism
E83		Disorders of mineral metabolism
E84		Cystic fibrosis
E85		Amyloidosis
E88		Other metabolic disorders
E90		Nutritional and metabolic disorders in diseases classified elsewhere
Organic, including symptomatic, mental disorders	F01	Vascular dementia
	F02	Dementia in other diseases classified elsewhere
	F03	Unspecified dementia
	F04	Organic amnesic syndrome, not induced alcohol other psychoactive substances
Mental retardation	F72	Severe mental retardation
	F73	Profound mental retardation
	F78	Other mental retardation
	F79	Unspecified mental retardation
Systemic atrophies primarily affecting the central nervous system	G10	Huntington's disease
	G11	Hereditary ataxia
	G12	Spinal muscular atrophy and related syndromes
	G13	Systemic atrophies primarily affecting CNS in diseases
Extrapyramidal and movement disorders	G20	Parkinson's disease
	G21	Secondary parkinsonism
	G22	Parkinsonism in diseases classified elsewhere
	G23	Other degenerative diseases of basal ganglia
	G24	Dystonia
	G25	Other extrapyramidal and movement disorders
G26	Extrapyramidal and movement disorders in diseases classified elsewhere	

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Other degenerative diseases of the central nervous system	G31	Other degenerative diseases of nervous system NEC
	G32	Other degenerative disorders of nervous system in diseases classified elsewhere
Demyelinating diseases of the central nervous system	G35	Multiple sclerosis
	G36	Other acute disseminated demyelination
	G37	Other demyelinating diseases of central nervous system
Episodic and paroxysmal disorders	G41	Status epilepticus
	G45	Transient cerebral ischaemic attacks and related syndrome
	G46	Vascular syndromes of brain in cerebrovascular diseases
Polyneuropathies and other disorders of the peripheral nervous system	G60	Hereditary and idiopathic neuropathy
	G61	Inflammatory polyneuropathy
	G62	Other polyneuropathies
	G63	Polyneuropathy in diseases classified elsewhere
	G64	Other disorders of peripheral nervous system
Diseases of myoneural junction and muscle	G70	Myasthenia gravis and other myoneural disorders
	G71	Primary disorders of muscles
	G72	Other myopathies
	G73	Disorders of myoneural junction and muscle in diseases classified elsewhere
Cerebral palsy and other paralytic syndromes	G80	Infantile cerebral palsy
	G81	Hemiplegia
	G82	Paraplegia and tetraplegia
	G83	Other paralytic syndromes
Other disorders of the nervous system	G90	Disorders of autonomic nervous system
	G91	Hydrocephalus
	G93	Other disorders of brain
	G94	Other disorders of brain in diseases classified elsewhere
	G95	Other diseases of spinal cord
	G96	Other disorders of central nervous system
	G98	Other disorders of nervous system, not elsewhere classified
Hypertensive diseases	I11	Hypertensive heart disease
	I12	Hypertensive renal disease
	I13	Hypertensive heart and renal disease
	I15	Secondary hypertension
	I20	Angina pectoris
Ischaemic heart diseases	I21	Acute myocardial infarction
	I22	Subsequent myocardial infarction
	I23	Certain current complication following acute myocardial infarction
	I24	Other acute ischaemic heart diseases
	I25	Chronic ischaemic heart disease
	I27	Other pulmonary heart diseases
Pulmonary heart disease and diseases of pulmonary circulation	I28	Other diseases of pulmonary vessels
	I31	Other diseases of pericardium
Other forms of heart disease	I34	Nonrheumatic mitral valve disorders
	I35	Nonrheumatic aortic valve disorders
	I36	Nonrheumatic tricuspid valve disorders
	I37	Pulmonary valve disorders
	I42	Cardiomyopathy
	I50	Heart failure
	I51	Complications and ill-defined descriptions of heart disease
	I69	Sequelae of cerebrovascular disease
	I70	Atherosclerosis
Diseases of arteries, arterioles and capillaries	I77	Other disorders of arteries and arterioles
	I85	Oesophageal varices
Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified	I89	Other noninfective disorders of lymphatic vessels and lymph nodes
Chronic lower respiratory diseases	J43	Emphysema
	J44	Other chronic obstructive pulmonary disease
	J47	Bronchiectasis
Other respiratory diseases principally affecting the interstitium	J82	Pulmonary eosinophilia, not elsewhere classified
	J84	Other interstitial pulmonary diseases
	J96.1	Chronic respiratory failure
Diseases of liver	K72	Hepatic failure not elsewhere classified
	K73	Chronic hepatitis not elsewhere classified
	K74	Fibrosis and cirrhosis of liver
	K75	Other inflammatory liver diseases
	K76	Other diseases of liver
	K77	Liver disorders in diseases classified elsewhere
Inflammatory polyarthropathies	M07	Psoriatic and enteropathic arthropathies
	M08	Juvenile arthritis
Systemic connective tissue disorders	M30	Polyarteritis nodosa and related conditions
	M31	Other necrotizing vasculopathies
	M32	Systemic lupus erythematosus
	M35	Other systemic involvement of connective tissue

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Deforming dorsopathies	M40	Kyphosis and lordosis
	M41	Scoliosis
	M43	Other deforming dorsopathies
Disorders of bone density and structure	M85	Other disorders of bone density and structure
Other disorders of the musculoskeletal system and connective tissue	M95	Other acquired deformities of musculoskeletal system and connective tissue
Glomerular diseases	N07	Hereditary nephropathy, not elsewhere classified
Renal tubulo-interstitial diseases	N11	Chronic tubulo-interstitial nephritis
	N12	Tubulo-interstitial nephritis not specified as acute or chronic
	N13	Obstructive and reflux uropathy
	N15	Other renal tubulo-interstitial diseases
Renal failure	N16	Renal tubulo-interstitial disorders in diseases classified elsewhere
	N18	Chronic renal failure
Other disorders of kidney and ureter	N19	Unspecified renal failure
	N25	Disorders resulting from impaired renal tubular function
	N26	Unspecified contracted kidney
	N27	Small kidney of unknown cause
	N28	Other disorders of kidney and ureter NEC
	N29	Other disorders of kidney and ureter in diseases EC
Other diseases of the urinary system	N31	Neuromuscular dysfunction of bladder NEC
	N32	Other disorders of bladder
	N33	Bladder disorders in diseases classified elsewhere
Foetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery	P00	Fetus and newborn affected maternal conditions that may be unrelated to present pregnancy
	P01	Fetus and newborn affected by maternal complications of pregnancy
	P02	Fetus and newborn affected by complications of placenta, cord and membranes
	P03	Fetus and newborn affected by other complications of labour and delivery
Disorders related to length of gestation and foetal growth	P07	Disorders relating to short gestation and low birth weight
	P08	Disorders related to long gestation and high birth weight
Birth trauma	P10	Intracranial laceration and haemorrhage due to birth injury
	P11	Other birth injuries to central nervous system
Respiratory and cardiovascular disorders specific to the perinatal period	P20	Intrauterine hypoxia
	P21	Birth asphyxia
	P22	Respiratory distress of newborn
	P23	Congenital pneumonia
	P24	Neonatal aspiration syndromes
	P25	Interstitial emphysema and related conditions originating in the perinatal period
	P26	Pulmonary haemorrhage originating in the perinatal period
	P27	Chronic respiratory disease originating in the perinatal period
	P28	Other respiratory conditions originating in the perinatal period
	P29	Cardiovascular disorders originating in the perinatal period
Infections specific to the perinatal period	P35	Congenital viral diseases
	P36	Bacterial sepsis of newborn
	P37	Other congenital infectious and parasitic diseases
	P39	Other infections specific to the perinatal period
Haemorrhagic and haematological disorders of foetus and newborn	P52	Intracranial nontraumatic haemorrhage of fetus and newborn
	P53	Haemorrhagic disease of fetus and newborn
	P54	Other neonatal haemorrhages
	P57	Kernicterus
Digestive system disorders of foetus and newborn	P77	Necrotizing enterocolitis of fetus and newborn
Other disorders originating in the perinatal period	P90	Convulsions of newborn
	P91	Other disturbances of cerebral status of newborn
Congenital malformations of the nervous system	Q00	Anencephaly and similar malformations
	Q01	Encephalocele
	Q02	Microcephaly
	Q03	Congenital hydrocephalus
	Q04	Other congenital malformations of brain
	Q05	Spina bifida
	Q06	Other congenital malformations of spinal cord
Congenital malformations of the circulatory system	Q07	Other congenital malformations of nervous system
	Q20	Congenital malformations of cardiac chambers and connections
	Q21	Congenital malformations of cardiac septa
	Q22	Congenital malformations of pulmonary and tricuspid valves
	Q23	Congenital malformations of aortic and mitral valves
	Q24	Other congenital malformations of heart
	Q25	Congenital malformations of great arteries
	Q26	Congenital malformations of great veins
	Q27	Other congenital malformations of peripheral vascular system
	Q28	Other congenital malformations of circulatory system

Congenital malformations of the respiratory system	Q30	Congenital malformations of nose	
	Q31	Congenital malformations of larynx	
	Q32	Congenital malformations of trachea and bronchus	
	Q33	Congenital malformations of lung	
	Q34	Other congenital malformations of respiratory system	
Other congenital malformations of the digestive system	Q38	Other congenital malformations of tongue, mouth and pharynx	
	Q39	Congenital malformations of oesophagus	
	Q40	Other congenital malformations of upper alimentary tract	
	Q41	Congenital absence/atresia and stenosis of small intestine	
	Q42	Congenital absence/atresia and stenosis of large intestine	
	Q43	Other congenital malformations of intestine	
	Q44	Congenital malformations of gall bladder, bile ducts & liver	
	Q45	Other congenital malformations of digestive system	
	Q60	Renal agenesis and other reduction defects of kidney	
	Q61	Cystic kidney disease	
	Q62	Congenital obstructive defect of renal pelvis and congenital malformations of ureter	
Congenital malformations of the urinary system	Q64	Other congenital malformations of urinary system	
	Q77	Osteochondrodysplasia with defects of growth, tubular bones and spine	
	Q78	Other osteochondrodysplasias	
	Q79	Congenital malformations of the musculoskel system NEC	
	Congenital malformations and deformations of the musculoskeletal system	Q80	Congenital ichthyosis
Q81		Epidermolysis bullosa	
Q85		Phakomatoses not elsewhere classified	
Q86		Congenital malformation syndromes due to known exogenous causes, NEC	
Q87		Other specified congenital malformation syndromes affecting multiple systems	
Q89		Other congenital malformations, not elsewhere classified	
Other congenital malformations		Q90	Down's syndrome
		Q91	Edwards' syndrome and Patau's syndrome
		Q92	Other trisomies and partial trisomies of the autosomes
	Q93	Monosomies and deletions from the autosomes NEC	
	Chromosomal abnormalities, not elsewhere classified	T86	Failure and rejection of transplanted organs and tissue
T90		Sequelae of injuries of head	
Complications of surgical and medical care, not elsewhere classified	T91	Sequelae of injuries of neck and trunk	
	T94	Sequelae of injuries involving multiple and unspecified body regions	
	T95	Sequelae of burns, corrosions and frostbite	
	T96	Sequelae of poisoning by drugs, medicaments and biological substances	
	T97	Sequelae of toxic effects of substances chiefly nonmedicinal as to source	
	T98	Sequelae of other and unspecified effects of external causes	
	Y85	Sequelae of transport accidents	
	Y86	Sequelae of other accidents	
	Y87	Sequelae of intentional self-harm, assault and events of undetermined intent	
	Y88	Sequelae of surgical and medical care as external cause	
	Y89	Sequelae of other external causes	
	Sequelae of injuries, of poisoning and of other consequences of external causes	T90	Sequelae of injuries of head
		T91	Sequelae of injuries of neck and trunk
		T94	Sequelae of injuries involving multiple and unspecified body regions
		T95	Sequelae of burns, corrosions and frostbite
T96		Sequelae of poisoning by drugs, medicaments and biological substances	
T97		Sequelae of toxic effects of substances chiefly nonmedicinal as to source	
T98		Sequelae of other and unspecified effects of external causes	
Y85		Sequelae of transport accidents	
Y86		Sequelae of other accidents	
Y87		Sequelae of intentional self-harm, assault and events of undetermined intent	
Y88		Sequelae of surgical and medical care as external cause	
Y89		Sequelae of other external causes	

Appendix 6

Notes on HES data

Finished Consultant Episode (FCE)

An FCE is defined as a period of admitted patient care under one consultant within one healthcare provider. Please note that the figures do not represent the number of patients, as a person may have more than one episode of care within the year.

In-year admissions

An in-year admission is the first period of in-patient care under one consultant within one healthcare provider, excluding admissions beginning before 1 April at the start of the datayear. Periods of care ongoing at the end of the datayear (unfinished admission episodes) are included. Please note that admissions do not represent the number of in-patients, as a person may have more than one admission within the year.

Discharges

A discharge episode is the last episode during a spell, where the patient is discharged from the hospital (this includes transfer to another hospital).

Deaths

Hospital Episode Statistics (HES) data cannot be used to determine the cause of death of a patient while in hospital. Deaths recorded on the HES database may be analysed by the main diagnosis for which the patient was being treated during their stay in hospital, which may not necessarily be the underlying cause of death. For example, consider a patient admitted for a hernia operation (with a primary diagnosis of hernia), but who died from a heart attack. The Office for National Statistics (ONS) collect information on the cause of death, wherever it occurs, based on the death certificate and should be the source of data for analyses on cause of death.

Diagnosis (Primary Diagnosis)

The primary diagnosis is the first of up to 14 (7 prior to 2002-03) diagnosis fields in the Hospital Episode Statistics (HES) data set and provides the main reason why the patient was in hospital.

Patient counts

Patient counts are based on the unique patient identifier HESID. This identifier is derived based on patient's date of birth, postcode, sex, local patient identifier and NHS number, using an agreed algorithm. Where data are incomplete, HESID might erroneously link episodes or fail to recognise episodes for the same patient. Care is therefore needed, especially where duplicate records persist in the data. The patient count cannot be summed across a table where patients may have episodes in more than one cell without double counting patients.

Ungrossed Data

Figures have not been adjusted for shortfalls in data (i.e. the data are ungrossed).

Source

Hospital Episode Statistics (HES), Health and Social Care Information Centre
Further information on HES is available from the Information Centre for Health and Social Care website at <http://www.hesonline.org.uk>

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Appendix 7

Primary Care Trusts used for regional analysis of hospital admissions

Region	PCT code	PCT name
Cornwall	5FM	West of Cornwall PCT
	5KR	North and East Cornwall PCT
	5KT	Central Cornwall PCT
Cumbria	5D4	Carlisle and District PCT
	5D5	Eden Valley PCT
	5D6	West Cumbria PCT
	5DD	Morecambe Bay PCT
West Midlands	5MW	North Birmingham PCT
	5MY	Eastern Birmingham PCT
	5MX	Heart of Birmingham Teaching PCT
	5M1	South Birmingham PCT
	5M3	Walsall Teaching PCT
	5MV	Wolverhampton City PCT
	5MG	Oldbury and Smethwick PCT
	5MH	Rowley Regis and Tipton PCT
	5MJ	Wednesbury and West Bromwich PCT
Brighton	5LR	Eastbourne Downs PCT
	5LT	Sussex Downs and Weald PCT
	5LQ	Brighton and Hove City PCT
N.E London	5C3	City and Hackney Teaching PCT
	5C5	Newham PCT
	5C4	Tower Hamlets PCT
	5C2	Barking and Dagenham PCT
	5A4	Havering PCT
	5K7	Camden PCT
	5K8	Islington PCT
	5NA	Redbridge PCT
5NC	Waltham Forest PCT	

Appendix 8

Children's hospices and hospice at home services

	Strategic Health Authority	Hospice	Hospice address	Primary Care Trust
1	East Midlands	Rainbow Children's Hospice	Loughborough LE11 2HS	Leicestershire County and Rutland PCT
2	East of England	Pasque Hospice (Keech Cottage Children's Hospice)	Luton LU3 3NT	Bedfordshire PCT
3	East of England	Iain Rennie Hospice at Home Service	Tring, Herts. HP23 4BB	West Hertfordshire PCT
4	East of England	Little Haven Children's Hospice	Benfleet SS7 2LH	South East Essex PCT
5	East of England	East Anglia Children's Hospice	Quidenham, Norwich NR16 2PH	Norfolk PCT
6	East of England	East Anglia Children's Hospice	Quidenham, Norwich NR16 2PH	Cambridgeshire PCT
7	East of England	East Anglia Children's Hospice	Quidenham, Norwich NR16 2PH	Suffolk PCT
8	London	Haven House	Woodford Green IG8 9LB	Waltham Forest PCT
9	London	Richard House Children's Hospice	Beckton, London E16 3RG	Newham PCT
10	London	The Shooting Star Children' Hospice	Hampton, Middlesex TW12 3RA	Richmond and Twickenham PCT
11	North East	Butterwick Hospice Children's Unit	Stockton on Tees TS19 8XN	North Tees PCT
12	North East	Zoe's Place	Normanby, Middlesbrough TS6 9DA	Middlesbrough PCT
13	North East	St. Oswald's Children's Hospice	Newcastle upon Tyne NE3 1EE	Newcastle PCT
14	North West	Claire House Children's Hospice	Bebington, Wirral CH63 4JD	Wirral PCT
15	North West	Zoe's Place (baby hospice)	Liverpool L12 9HH,	Liverpool PCT
16	North West	Derian House Children's Hospice	Chorley PR7 1DH	Central Lancashire PCT
17	North West	Eden Valley Hospice (Day Care)	Carlisle CA2 4SD	Cumbria PCT
18	North West	Trinity – The Hospice In The Fylde (Brian House)	Bispham FY2 0BG	Blackpool PCT
19	North West	Francis House	Manchester M9 8PB	Manchester PCT
20	South Central	Naomi House Children's Hospice	Winchester SO21 3JE	Hampshire PCT
21	South Central	Helen House and Douglas House	Oxfordshire OX4 1QT	Oxfordshire PCT
22	South Coastal	Demelza House Children's Hospice	Sittingbourne ME9 8DZ	Eastern and Coastal Kent PCT
23	South Coastal	Ellenor Shining Lights (hospice at home service)	Dartford, Kent DA1 1SA	West Kent PCT
24	South Coastal	Chestnut Tree House	Arundel BN18 9PX	West Sussex PCT
25	South Coastal	Christopher's Children's Hospice (Chase Hospice)	Guildford GU3 1HS	Surrey PCT
26	South West	Julia's House (hospice at home service)	Broadstone, Dorset BH18 8DX	Dorset PCT
27	South West	Children's Hospice South West	Barnstaple EX31 2PZ	Devon PCT
28	West Midlands	Acorns Children's Hospice	Birmingham B29 6HZ	South Birmingham PCT
29	West Midlands	Acorns Children's Hospice	Birmingham B29 6HZ	Sandwell PCT
30	West Midlands	Hope House Children's Respite Hospice	Oswestry SY10 9BX	Shropshire County PCT
31	West Midlands	The Donna Louise Trust	Stoke on Trent ST4 8TN	South Staffordshire PCT
32	West Midlands	Acorns Children's Hospice	Birmingham B29 6HZ	Worcestershire PCT
33	Yorks & Humber	St. Andrew's Children's Hospice	Grimsby DN32 9RP	North East Lincolnshire PCT
34	Yorks & Humber	Martin House	Wetherby LS23 6TX	Leeds PCT

The following hospices do not appear to be registered with the Healthcare Commission:

Brian House, Blackpool; Ellenor Shining Lights, Dartford Kent - Hospice at Home; Ian Rennie Hospice at Home, Tring; Julia's House Children's Hospice, Broadstone Dorset- Hospice at Home; Shooting Star House, Hampton Middx.; Zoe's Place, Middlesbrough