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Prevalence of life-limiting and life-threatening conditions in children and young people in England: time trends by area type

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This research used National Health Service (NHS) Hospital Episode Statistics (HES) with the extract informed by a list of International Classification of Diseases (ICD10) codes provided by Richard Hain and Martin House Hospice. The work used Vital Statistics data and mid-year estimates for England provided by the Office for National Statistics and digital boundary data by OSGB. These data are Crown copyright and are reproduced with permission of OPSI.

Prevalence of life-limiting and life-threatening conditions in children and young people in England: time trends by area type

Abstract

Palliative care services in England lack of data on the number of children with ‘life limiting conditions’ (LLCs). Recent research determined that the prevalence of LLCs in children in England was double previous estimates. We analyse time-trends in the prevalence of LLCs by deprivation and geodemographic area types. Prevalence is highest for children aged less than one year but time trends show no increase for the youngest age group but significant increases for older children. These increases are mirrored by a decrease in all cause mortality for children aged less than one year suggesting improved survival. Whilst the majority of children with LLC live within 20km of a children’s hospice this service may still not be accessible due to lack of transport or other factors. Increasing prevalence may require increased paediatric palliative care service provision in the future.

Key words: Life-limiting conditions; Palliative care; Hospital Episode Statistics; Deprivation; ONS Supergroups

Highlights

- Palliative care services lack data on children with life limiting conditions
- Higher prevalences of life limiting conditions are in deprived locations
- Higher prevalences are also in Multicultural and Disadvantaged communities
- Time trends show increases in prevalence for older children but not the youngest
- Coincident decreases in infant mortality suggest improved survival
- Increases in prevalence might impact on the demand for palliative care

Prevalence of life-limiting and life-threatening illness in children and young people in England: time trends by area type

Background

Geographic inequalities in health are regularly found in the UK (Thomas et al., 2010; Norman et al., 2011), with different levels of mortality and self-reported health found in rural and urban areas (Levin and Leyland, 2005; Levin, 2003; Riva et al., 2009; Riva et al., 2011) and in deprived and more affluent areas (Rees et al., 2003; Shaw et al., 2004; Norman et al., 2005; Romeri et al., 2006). Whilst levels of infant mortality are steadily reducing in England and Wales, gradients across differently deprived areas largely persist (Norman et al., 2008).

Classifications based on the sociodemographic characteristics of residents can provide insights about geographic patterns (Abbas et al., 2009). Health varies across geodemographic area types with ‘Accessible Rural Areas’ having relatively low mortality, self-reported health and levels of sickness benefit claims compared with ‘Industrial Districts’ or ‘Principal Metropolitan Cities’ (Norman and Bamba, 2007). Trends in the improvement of infant mortality vary with areas characterised as being ‘Cities and Services’ and ‘London Cosmopolitan’ experiencing relatively large absolute reductions in infant mortality though rates in these areas remain high compared with the national average (Norman et al., 2008).

An independent review of children’s palliative care services in England (Craft and Killen, 2007) highlighted the lack of available data on the number of children and young people who received or who would benefit from palliative care services. Children’s palliative care is concerned with the treatment of children with ‘life-limiting’ or ‘life-threatening’ conditions and aims to maintain and improve quality of life in the weeks, months and years before death not just in the dying stages (Baum et al., 1997; ACT/RCPCH, 2003; ACT, 2011). Children tend to be cared for by palliative care services over extended time periods (Liben et al., 2008, Taylor et al, 2010) while adult services generally focus on end-of-life care, which can be measured in days or weeks (Good et al., 2004). Box 1 provides information on the term ‘life-limiting conditions’.

[Box 1 about here]

Fraser et al., (2012) determined that the prevalence of life-limiting conditions in children and young people in England, at 32 per 10,000 population, was double the previously reported estimate (Cochrane et al., 2007). Variations in prevalence by age, area deprivation and ethnic group were also found. Of note were the findings that increases in prevalence over time were found for older children but not for those aged less than one year old. This suggests increasing survival rather than rising incidence. Higher prevalence was found in more deprived areas but the relationship across the deprivation gradient was less clear, perhaps because the data linkages were to quite large geographic areas. Similarly, higher prevalence was found for minority ethnic groups, particularly people from South Asian backgrounds though time trends have yet to be investigated.

In this paper we use Fraser et al.'s (2012) time trends in prevalence by age as a starting point and then investigate if there are variations when a more local level measure of deprivation is used and whether area type, in particular those locations characterised as being multicultural, have elevated prevalence compared with other area types. Here we will refer to life limiting conditions (LLCs) and take these to include life threatening conditions.

Data and methods

Life limiting / life threatening conditions

For children aged 0-19, data were obtained from the National Health Service (NHS) Hospital Episode Statistics (HES). This dataset contains clinical and demographic information about inpatient consultant episodes by individuals with diagnoses coded using the ICD10 disease classification (WHO, 1992).

A coding framework of ICD10 disease codes was used to be able to distinguish persons age 0-19 with a life-limiting condition. Fraser et al. (2012) detail the development of a list of relevant ICD10 codes. The list was derived by combining the 'Hain directory' of ICD10 codes for children seen by paediatric palliative care providers (ACT, 2011) and a list of diagnoses for children accepted for care at Martin House Children's Hospice during the period 1987-2010. With an 84% overlap between these sources, the provisional list of 801 ICD10 codes was inspected to determine whether the majority of children with a particular diagnosis or sub-diagnosis were life-limited or life-threatened. After this stage and the addition of all malignant oncology

codes, the final list comprised 777 four digit ICD codes which represent life-limiting conditions. 57% of these codes are for malignant oncology and 11% are for congenital malformations and chromosomal abnormalities.

For the 10 year time period for financial years 2000-01 to 2009-10, an extract of inpatient Hospital Episode Statistics (NHS IC, 2011) was obtained from the NHS Information Centre for Health and Social Care. The selection captured all episodes for patients who had been coded with one of the Hain / Martin House based list of ICD10 codes and / or the ICD10 code for palliative care thereby to include persons without a firm diagnosis. The HES extract excluded patients over 19 years of age at the start of a hospital episode and persons whose country of residence was outside England. The start age recorded at the first hospital episode in each financial year was used to categorise age into five groups: less than 1 year of age ('age 0'), 1 to 5 years, 6 to 10 years, 11 to 15 years and 16 to 19 years.

Area type

Each individual's record is linked to their residential Lower Super Output Area (LSOA), a small area geography used for statistical reporting in England (ONS, 2005). This enables analysis of LLC prevalence by LSOA area characteristics with two schemes used here; the Index of Multiple Deprivation (IMD) and the Office for National Statistics (ONS) area classification 'Supergroups'.

The IMD, the government's current preferred indicator of deprivation in England, is an area based score which combines housing, social and economic indicators to indicate the level of deprivation in each LSOA (Noble et al., 2006). The scores for the IMD for 2007 have been divided into five quintiles based on the scores for the whole of England (20% of the LSOAs in each quintile) with quintile 1 the most deprived and quintile 5 the least deprived.

The ONS Supergroups is a geodemographic classification of areas. The classification uses cluster analysis to reduce 41 variables from the 2001 Census about the socioeconomic attributes of the residents in each LSOA to a single socioeconomic indicator. The Supergroups comprise seven types which are given a label to typify the population in each area (Vickers and Rees, 2007).

Population data

Populations at risk provided by ONS were mid-year estimates by single year of age for all LSOAs in England for 2001 to 2010 (ONS, 2009). We aggregated these into the age-groups noted above and for the IMD quintiles and Supergroups classification.

Methods

Prevalence and 95% confidence intervals per 10,000 population were calculated for age 0-19 per year and for the age-groups per year aggregated across the IMD quintiles and the ONS Supergroups. For comparison, we accessed Vital Statistics data on the registered deaths for the general population and calculated all cause age-specific mortality rates per 10,000 population by deprivation quintile.

Using the LLC data from 2009/10 (n=40,042) the percentage of children with LLC who live within a 10km and 20km Euclidean buffer of the children's hospices was calculated. To maintain confidentiality the proxy location of residence used was the geometric centroid of the Lower Super Output Area of residence of the individual. These percentages were calculated overall and by the five deprivation categories and the seven ONS Supergroups for comparison of equity of access.

Results

As reported by Fraser et al. (2012), the prevalence for persons aged 0-19 with life limiting conditions increased significantly between 2000-01 and 2009-10 from 25 per 10,000 (CI 24.6,25.1) to 32 per 10,000 (31.9,32.6). In Figure 1 we show that prevalence is highest in the youngest age-group who are less than one year of age. The next highest levels are for persons age 1-5 with prevalence reducing with age. The decreases in prevalences by age are significant but not necessarily between adjacent groups in the older three ages, especially towards the end of the decade.

[Figure 1 about here]

Time-trends in relation to area deprivation

Figure 2a illustrates the prevalence per 10,000 population for ages 0-19 stratified across LSOA quintiles of deprivation. Prevalence is significantly higher in the most deprived quintile and, apart from a slight fall early

in the decade, increases significantly over time. Prevalences decrease with lower area deprivation but the differences between the less deprived quintiles 4 and 5 are not necessarily significant. At all levels of deprivation, prevalence in 2009-10 is significantly higher than in 2000-01.

[Figure 2 about here]

Figure 2b shows the prevalence for those under 1 year of age. The y axis is different to the other graphs in Figure 2 to accommodate the higher prevalence for this age-group. Prevalence is highest in the most deprived quintiles and decreases with lower deprivation but only the two most deprived sets of areas have significantly different levels. Over time, there is an easing of levels in the early 2000s but an increase to 2006-07. Generally, the sets of prevalences can be seen to reduce successively by age in Figures 2c-f. The more deprived quintiles have higher prevalence, still significantly higher at age 1-5 and for the most deprived quintile for ages 6-10. Thereafter, whilst the prevalence of LLC remains relatively high in the most deprived areas, the overall differences in prevalence between the deprivation quintiles reduce over the decade. For all age groups from 1-5 to 16-19, the levels at the end of the decade are higher than at the start.

Rate ratios of the end of the decade to the start can reveal whether prevalence is increasing or decreasing and whether the change is significant. We use two year averages of prevalences for 2000-01 and 2009-10 to reduce the impact of annual fluctuation. Table 1 reports the ratios of prevalence in 2009-10 to prevalence in 2000-01. Since all the rate ratios are above one this indicates an increase in levels. Across deprivation quintiles, rate ratios for the age 0 group are close to one and not significantly different except in the least deprived quintile. With increasing age, the rate ratios increase significantly supporting the observation above that prevalence rises over the decade and this is relatively more for older age groups. There is less of a difference between age-groups in the least deprived areas though a clear and significant increase in LLC prevalence for the oldest group, those age 16-19.

[Table 1 about here]

Time trends in relation to area type

Fraser et al. (2012) found that ethnic groups other than the White group had significantly higher LLC prevalence. Their work was somewhat hampered due to a lack of small area population counts to use as denominators and with LLCs cross-classified by ethnic group only analysed for years between 2008 and 2010. Due to similar data restrictions, whilst we are unable yet to carry out a time-series of ethnic specific

rates we can investigate prevalence for areas typified by the presence of minority groups in a geodemographic classification in comparison with other area types.

Figure 3a has LLC prevalence for all persons aged 0-19 for each of the seven area types in the ONS Supergroups classification. The highest prevalence is in the areas labelled Multicultural City Life where LLC levels are significantly higher than in other area types. The next highest levels are in Disadvantaged Urban Communities. The lowest prevalences are in Urban Fringe and in Countryside though differences between these area types are not significant. For ages 0-19, prevalence increases over the decade in all area types, relatively more in areas where levels are highest.

[Figure 3 about here]

As with Figure 2b, Figure 3b has the prevalences graphed with a different y axis because the levels for age 0 are substantially higher than for the older age groups. For the youngest age-group, prevalences are highest in Multicultural City Life and Disadvantaged Urban Communities with a clear and significant difference to the other area types by the end of the decade. Whilst there are year-by-year variations, levels may only be marginally increasing over time.

Prevalence progressively decreases by age-group through Figures 3c to f but the LLC levels for Multicultural City Life remain significantly higher than the other area types at all ages until age 16-19. LLC prevalence for Disadvantaged Urban Communities is relatively high and largely significantly different to the other area types at ages 1-5 and 6-10 and in the latter part of the decade for age 11-15. For the older age-group, 16-19, there are no significant differences in levels between area types except for areas labelled 'Professional City Life' which has prevalence significantly below those found in the other areas.

Rate ratios by area type reveal whether there has been a significant change in the prevalence of LLC between the start and end of the decade. Table 2 shows that rate ratios for age 0 are close to 1 in four of the area types and significantly above 1 in Multicultural City Life, Urban Fringe and Countryside areas so an increase in rates in these places is found. At all ages and in all area types, rate ratios of LLC prevalence do indicate significant increases in prevalence and these increases themselves are relatively larger with age especially in Multicultural City Life and Countryside area types.

[Table 2 about here]

Does increasing prevalence with age relate to reducing mortality?

Fraser et al. (2012) suggest that the increase in prevalence over time for older children may be due to improved survival times rather than rising incidence of hospital referrals. We cannot readily replicate the geographical and age-group definitions used in the LLC time-series but for local authority districts and ages 0, 1-4 and 5-14 we can calculate mortality rates for the general population aggregated into deprivation quintiles.

Figures 4a-c illustrate mortality rates for these age-groups. Rates are higher for children aged under 1 year than for other two age-groups. In the more deprived areas, rates are steadily reducing over the decade but rates do not appear to reduce so much so that difference in rates between levels of deprivation are reducing. For the older ages 1-4 and 15-14, mortality rates are relatively low with reductions over the decade evident. Whilst the more deprived areas have higher mortality rates than less deprived areas, differences are not necessarily significant. Mortality for these ages is quite rare.

[Figure 4 about here]

Using ratios of rates of the end and beginning of the decade, Table 3 demonstrates that mortality reduces over the time period in each deprivation quintile with all the reductions significant. For age under 1 year, there are greater reductions in the more deprived quintiles 1 to 3 than in the less deprived quintiles 4 and 5. This largely represents that infant mortality is already low in less deprived areas, perhaps bottoming out, and compares favourably with other countries in Europe (Norman et al., 2008). In the more deprived areas, improvements in mortality are found for children age 1-4 and 5-14 years. In the least deprived areas, significant reductions in mortality rates are evident from one age to the next with increasing age of children.

[Table 3 about here]

That mortality rates are reducing for children aged less than one year old is consistent with rising LLC prevalence rates for older children. Larger reductions in infant mortality in more deprived areas are also consistent with larger increases in prevalence in these areas. LLC prevalence may not increase so much over the decade in less deprived areas because survival in these areas may already have been longer.

Are differences in proximity to children's hospices related to prevalence of life limiting conditions?

There are 41 children's hospices in England (Together for Short Lives, 2012). Figure 5 shows these are mainly located on the periphery of urban areas. Over half are located in less deprived areas with twenty in LSOAs classified as either Countryside or Urban Fringe. Only two are in Multicultural City Life areas. Given the differences in prevalence by area characteristics, this suggests that the hospices may not be ideally located. To investigate this further, we estimate the proportion of children with a LLC (alive in 2009/10) living within approximately ten and twenty kilometres of the hospices. Overall 29.7% of the children with LLC lived within 10km and 63.6% within 20km of a children's hospice.

[Figure 5 about here]

Figure 6a shows that whilst the actual locations of the hospices may not be in the more deprived locations, higher percentages of children with LLC in these places live within 10k or 20k of a hospice than in less deprived areas. Similarly, whilst only two hospices are located in areas classified as Multicultural City Life (Newham in London and Walsall in the West Midlands), relatively high percentages of children with LLC live within 10k and 20k of a hospice (Figure 6b). It is possible that the proximity of these populations to hospices, and the care provided, in part explains increased survivorship and therefore rising LLC prevalence over the decade in these area types.

[Figure 6 about here]

Discussion

This study has shown that the prevalence of LLC in children and young people has increased over the ten year time period in all deprivation and geodemographic categories, but not equally. The prevalence of LLC is highest in the more deprived areas and areas characterised as being Multicultural City Life or Disadvantaged Urban Communities. (Note there is a 95% overlap between these area types and the two most deprived IMD quintiles.) Less deprived and more rural areas have lower LLC prevalence. Assessing the time trends by age-group demonstrates that in the age-groups above 6 years old the differences in prevalence across both the deprivation categories and geodemographic groups decreased which may indicate an inequity in survival for those children with LLC living in more deprived areas. This statement is supported by the higher mortality in more deprived areas, albeit all cause rather than LLC specific mortality. Over the decade, prevalence increases for children aged 1-19 with the increase greater for older children. To determine whether the increases are due to improved survival would require individual level longitudinal data.

This data source has shown that the prevalence of LLC in children and young people has risen over the last ten years and should this trend continue there may be a need for further services and geographic location of these services will be important. The independent review by Sir Alan Craft highlighted the variation in service provision for paediatric palliative care services in England (Craft and Killen, 2007) and the need for palliative care to be in appropriate locations has been highlighted (Beecham et al., 2013). Although the proximity analyses showed that a higher percentage of children with LLC who lived in more deprived communities live within 10 and 20km of a children's hospice than children from less deprived areas this does not show that their access to children's hospices are equitable. Straight line buffers were used in this analysis which are a crude measure of proximity but an individual's access is dependent on many other variables including access to a car or the public transport network. Many children with LLC are technology dependent and public transport may not be feasible. Carers of children in more deprived areas are also less likely to have access to a car than those in less deprived areas. The location of children's hospices with the majority being in less deprived areas and only two in multicultural areas may be of concern. Previous research assessing access to adult hospices in England and Wales used more sophisticated access measures and found that rural and relatively deprived areas had poorer access than urban areas (Gatrell, 2012).

Measuring trends in population health at the local area level can be used for the targeting of resources and health education programs and to monitor the impacts of public health and social policies in improving health and reducing health inequalities. Aggregating health rates across different levels of deprivation or by area type can highlight geographic patterns and help avoid small number problems if health events are relatively rare. Increasing prevalence of children and young people with LLC especially in areas of higher deprivation and multicultural and disadvantaged communities may require increased paediatric palliative care service provision in the future. Currently children's hospices tend to be located in areas of lower deprivation and although the majority of children with LLC live within 20km of a children's hospice this service may still not be accessible due to lack of transport or other factors.

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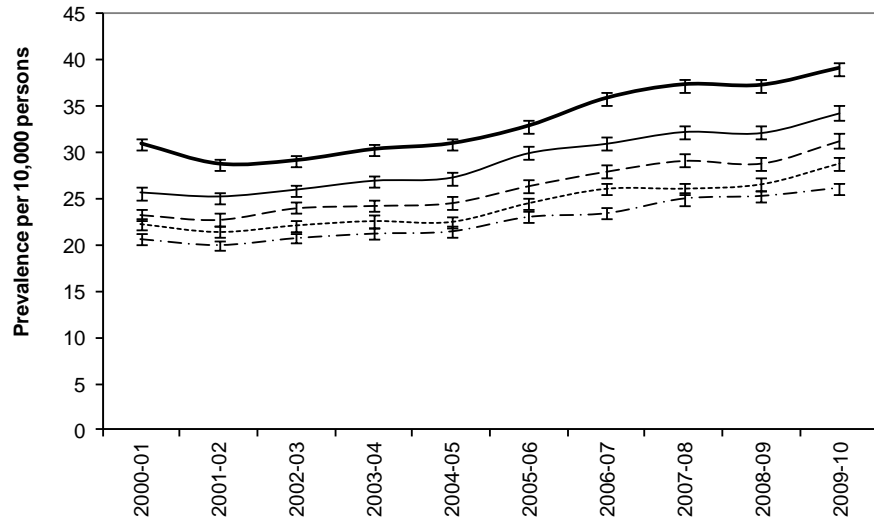
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Figure 1: Age-specific prevalence of life-limiting conditions: England 2000-01 to 2009-10

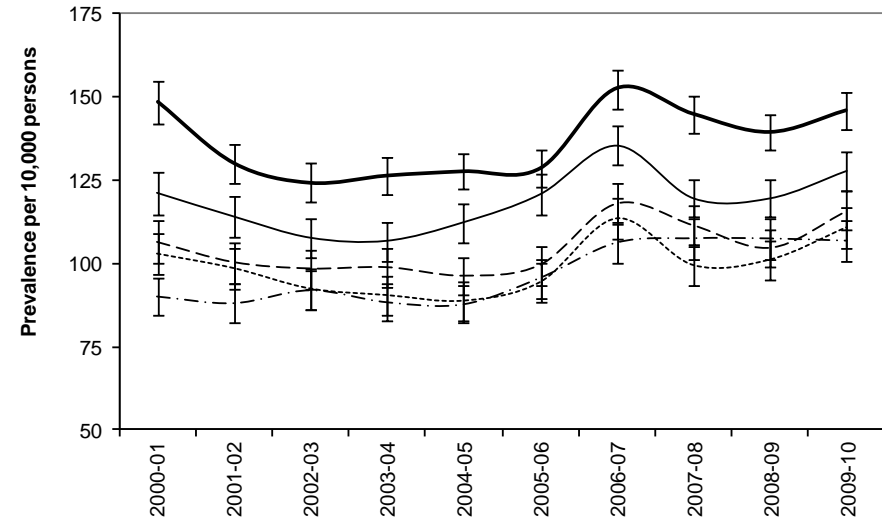


Figure 2: Age-specific prevalence of life-limiting conditions by deprivation quintile: England 2000-01 to 2009-10

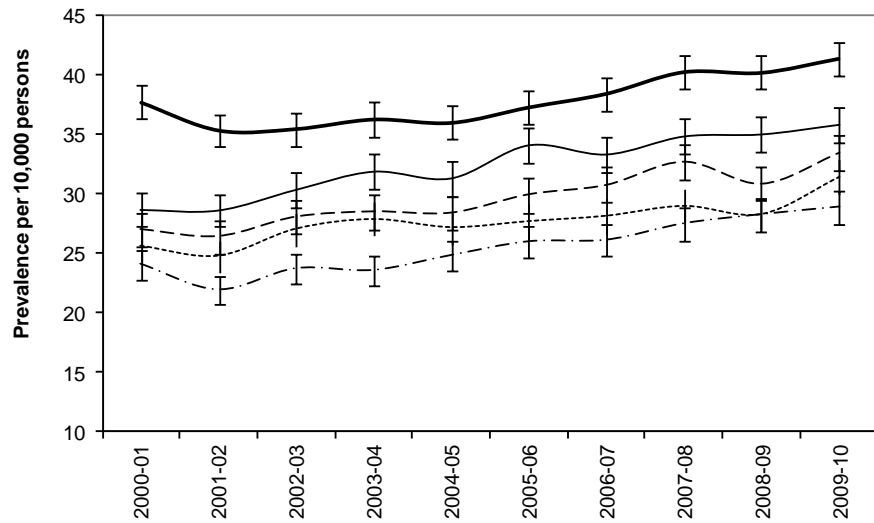
a) Age 0-19



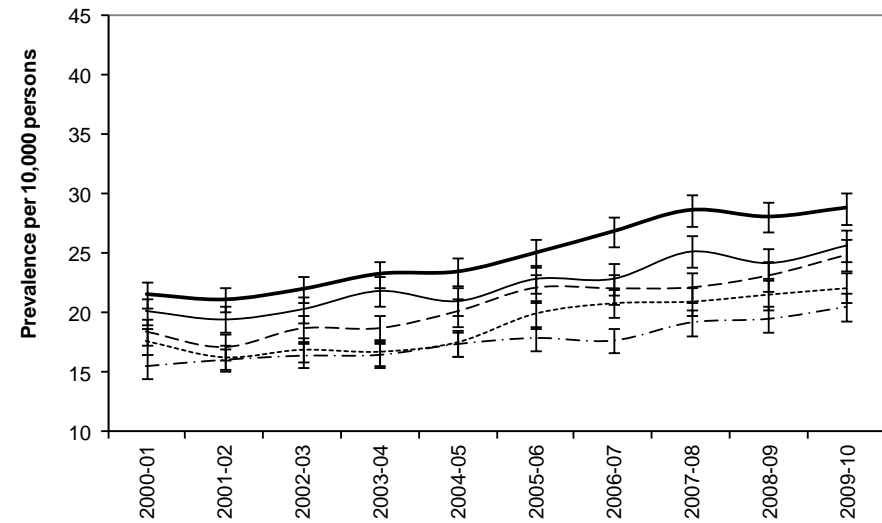
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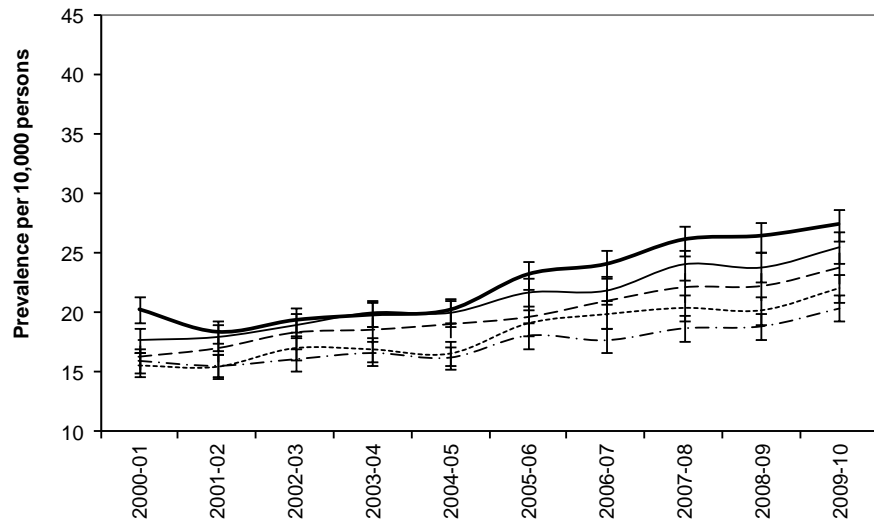
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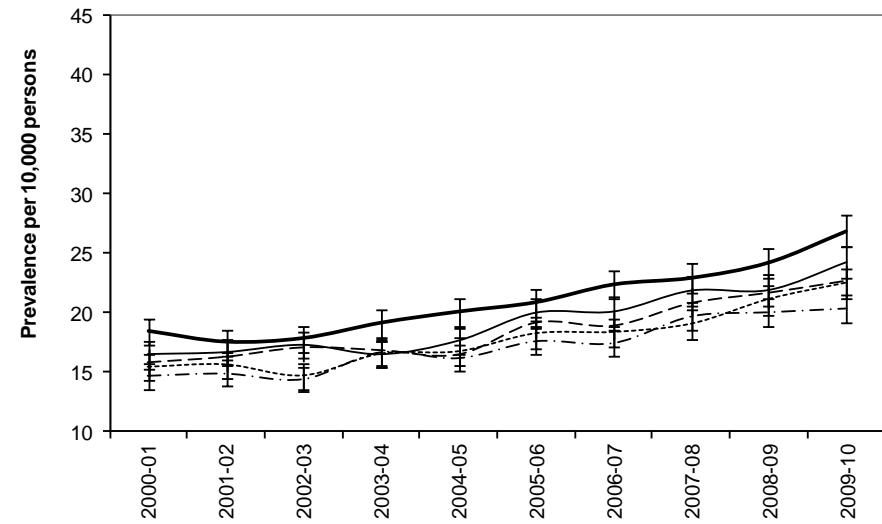
d) Age 6-10



e) Age 11-15



f) Age 16-19

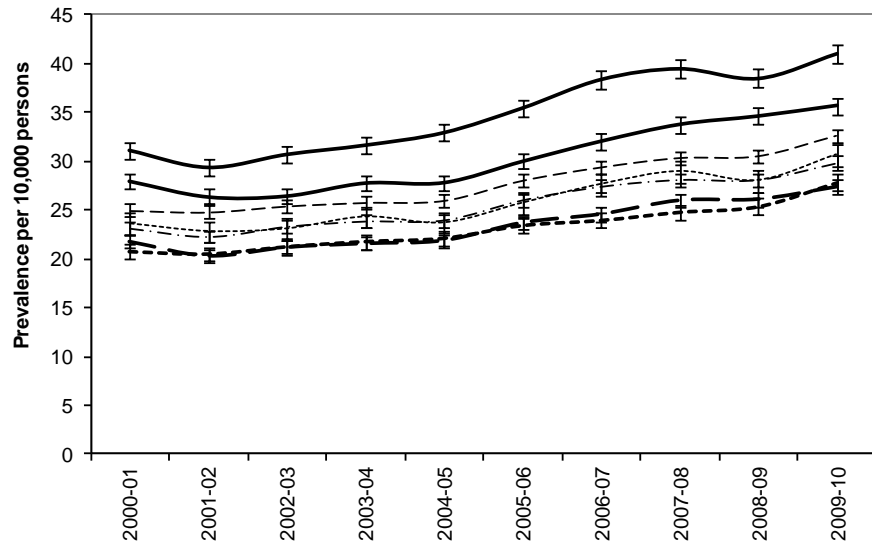


Q1
 Q2
 Q3
 Q4
 Q5
Most Deprived Least Deprived

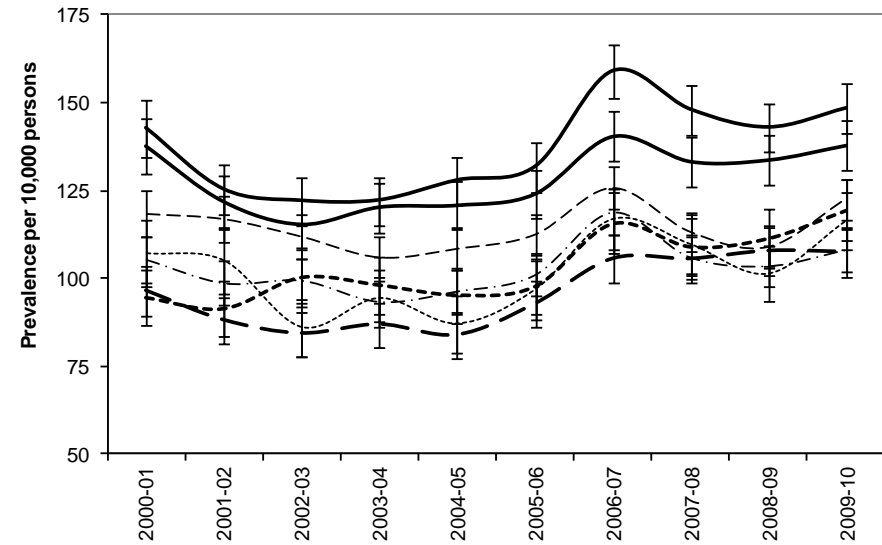
Note: Prevalence per 10,000 persons with 95% confidence intervals as error bars

Figure 3: Age-specific prevalence of life-limiting conditions by ONS Supergroup: England 2000-01 to 2009-10

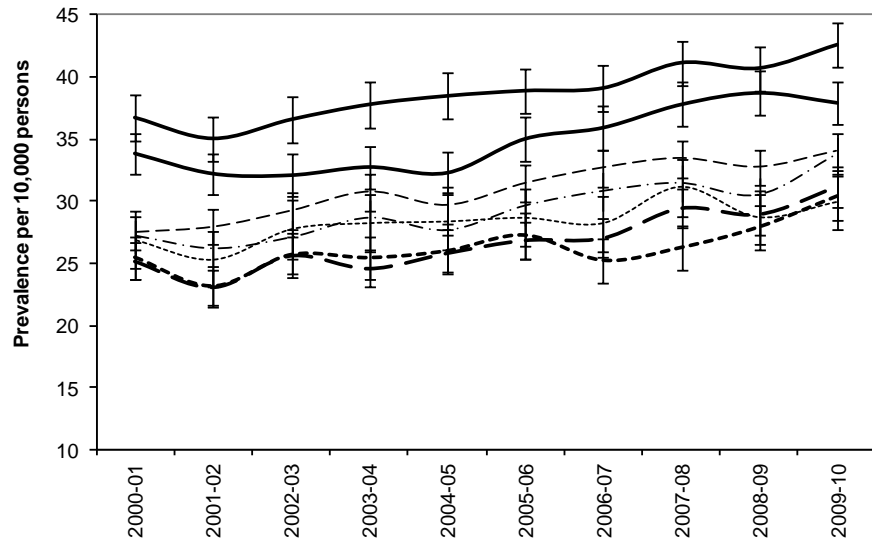
a) Age 0-19



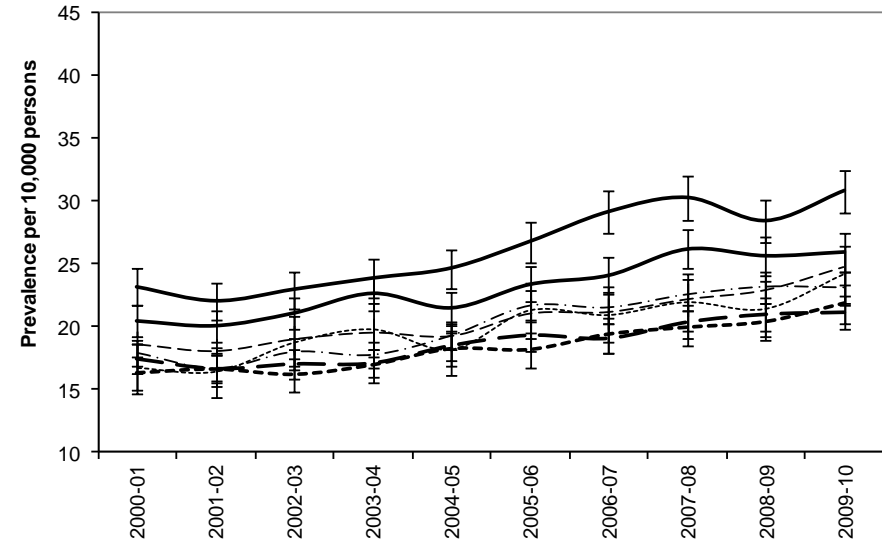
b) Age 0



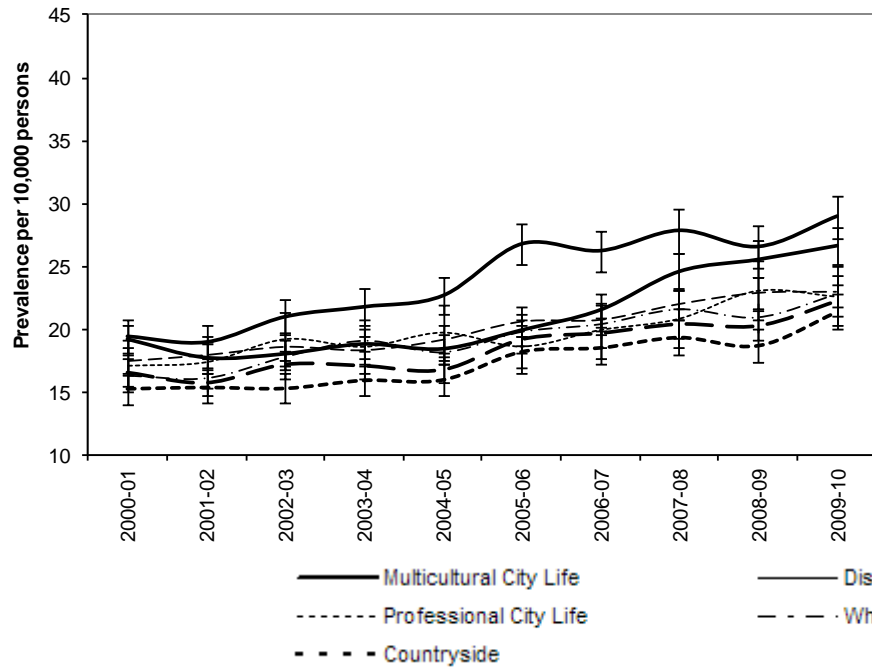
c) Age 1-5



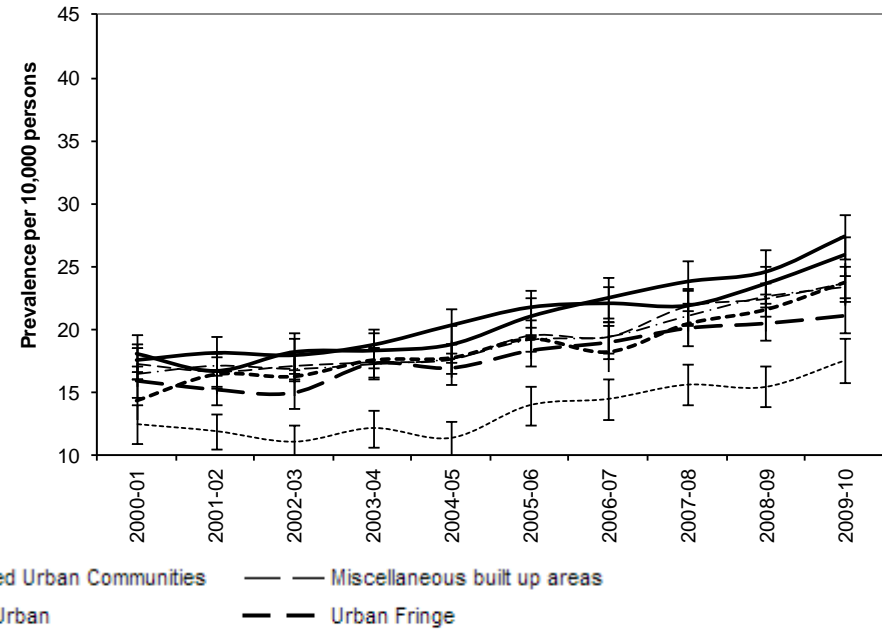
d) Age 6-10



e) Age 11-15



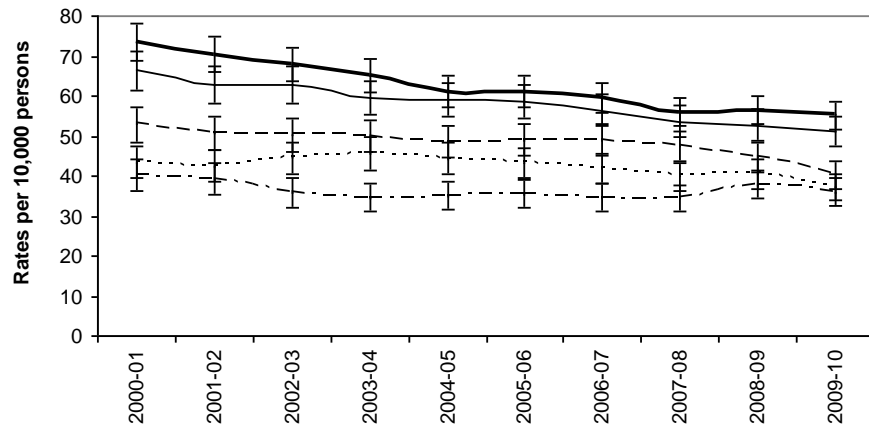
f) Age 16-19



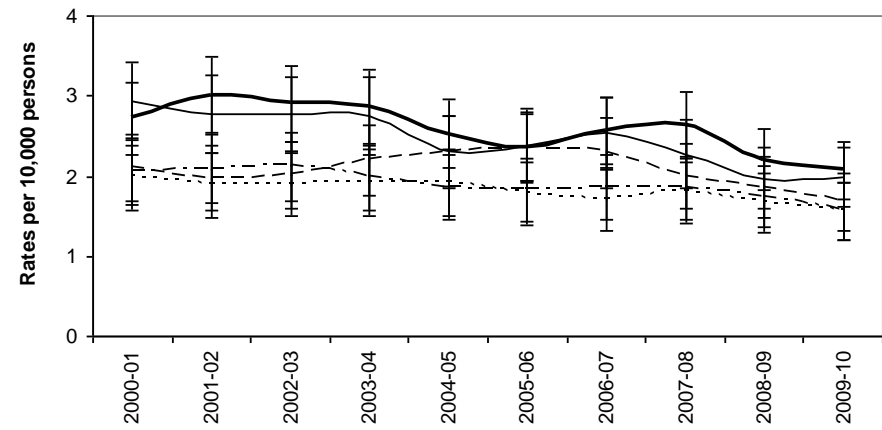
Note: Prevalence per 10,000 persons with 95% confidence intervals as error bars

Figure 4: Age-specific all-cause mortality rates by deprivation quintile: England 2000-01 to 2009-10

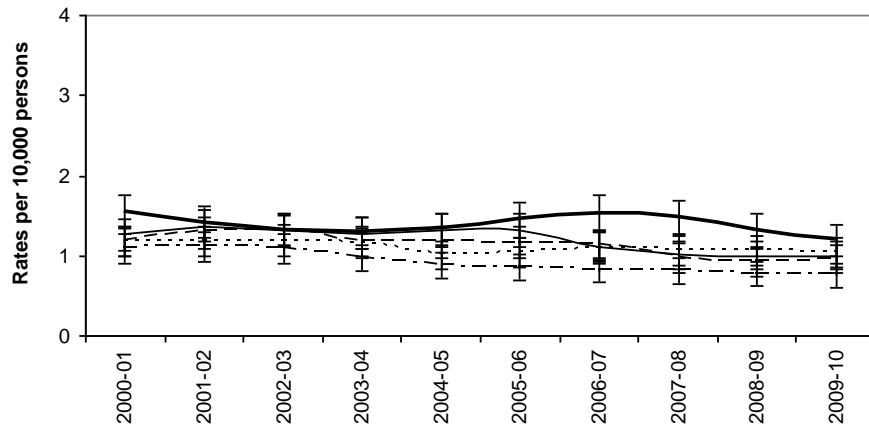
a) Age 0



b) Age 1-4



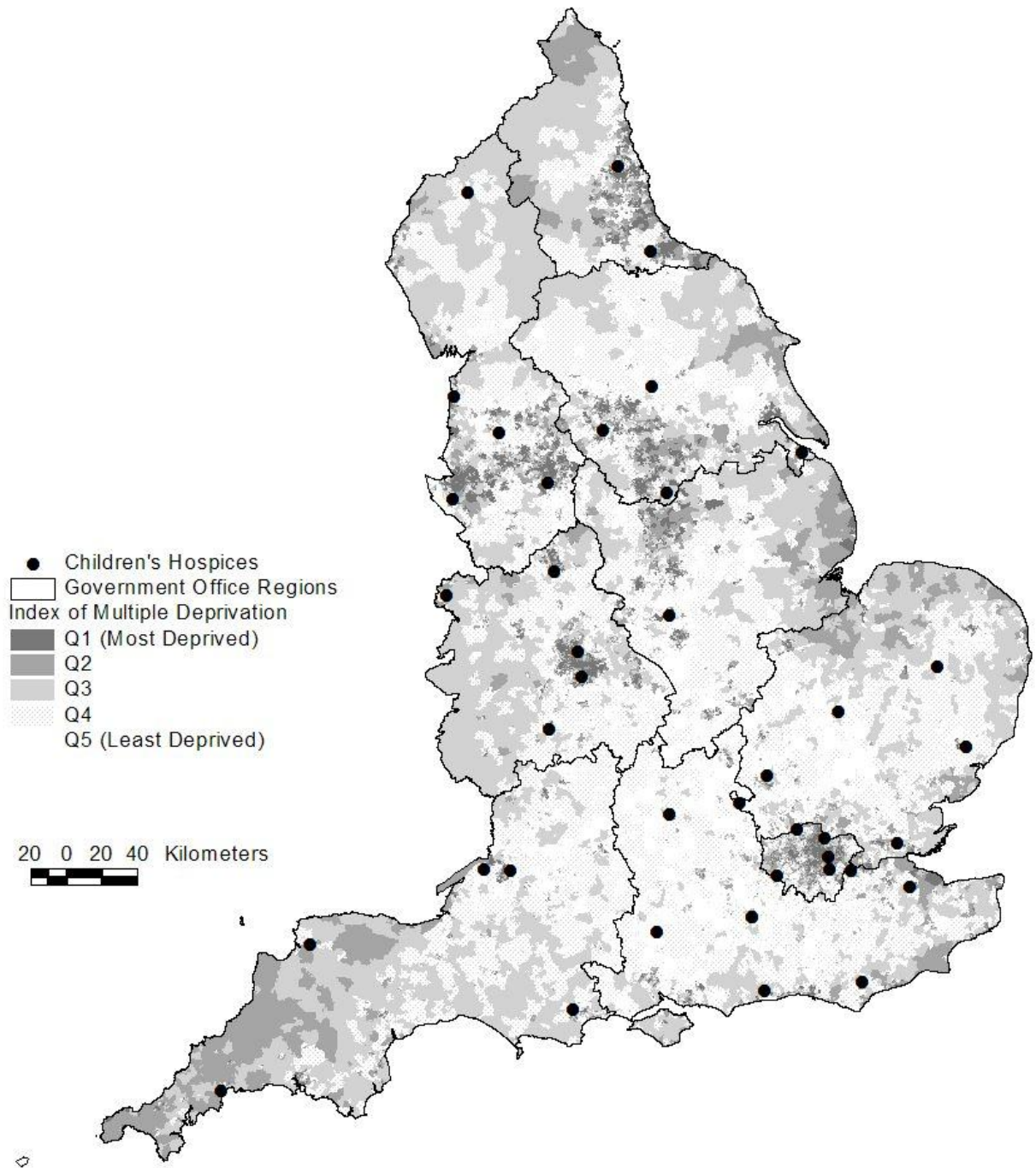
c) Age 5-14



Q1 Most Deprived
 Q2
 Q3
 Q4
 Q5 Least Deprived

Note: Mortality rates per 10,000 persons with 95% confidence intervals as error bars

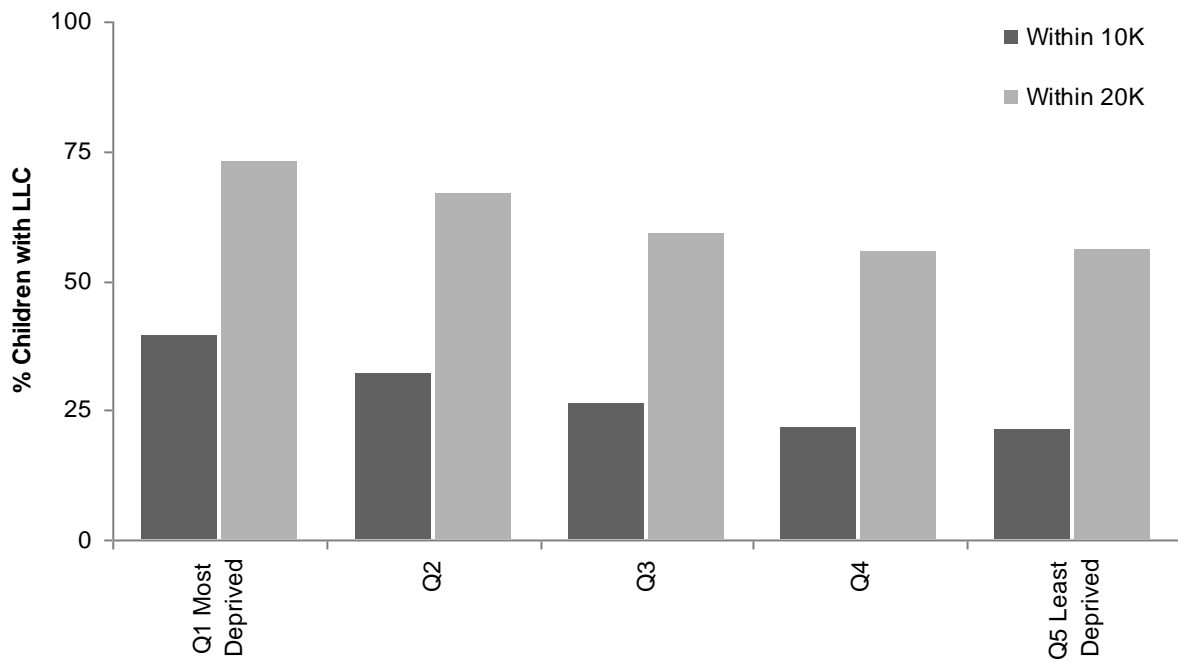
Figure 5: Distribution of children's hospices in relation to area deprivation



Source: Hospice locations <http://www.childhospice.org.uk>

Figure 6: Percentage of children with a life limiting condition 2009/10 within 10k and 20k of a children's hospice

a.) Index of Multiple Deprivation



b.) ONS Supergroups

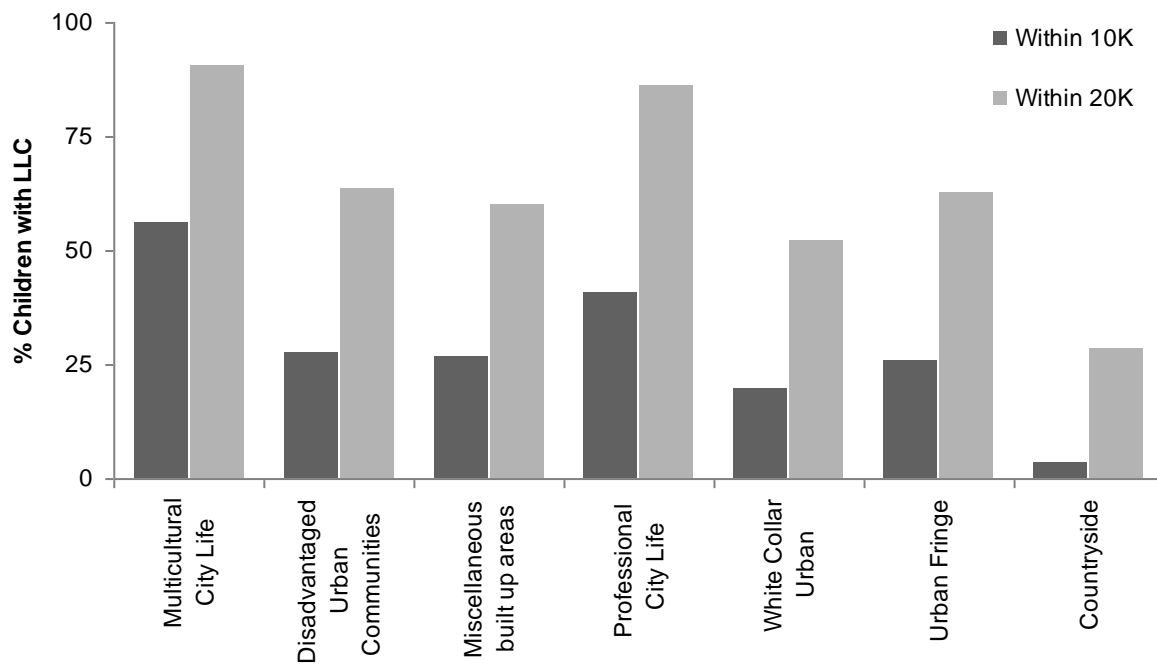


Table 1: Rate ratios of life-limiting conditions prevalence by deprivation quintile and age, England 2009-10 : 2000-01

	Most Deprived				Least Deprived
	Q1	Q2	Q3	Q4	Q5
Age 0	<i>1.03 (0.97-1.08)</i>	<i>1.05 (0.99-1.12)</i>	<i>1.07 (0.99-1.14)</i>	<i>1.05 (0.98-1.12)</i>	1.20 (1.12-1.28)
Age 1-5	1.12 (1.07-1.16)	1.24 (1.18-1.29)	1.21 (1.15-1.26)	1.19 (1.13-1.24)	1.24 (1.18-1.30)
Age 6-10	1.33 (1.27-1.39)	1.26 (1.19-1.32)	1.35 (1.28-1.42)	1.29 (1.22-1.36)	1.27 (1.20-1.34)
Age 11-15	1.39 (1.33-1.45)	1.38 (1.31-1.45)	1.39 (1.31-1.46)	1.36 (1.29-1.43)	1.25 (1.18-1.31)
Age 16-19	1.42 (1.35-1.49)	1.39 (1.32-1.47)	1.38 (1.30-1.46)	1.40 (1.32-1.48)	1.36 (1.28-1.44)

Note: Rate ratios with 95% confidence intervals in brackets. Non-significant rate ratios are in italics

Table 2: Rate ratios of life-limiting conditions prevalence by ONS Supergroup and age, England 2009-10 : 2000-01

	Multicultural City Life	Disadvantaged Urban Communities	Miscellaneous built up areas	Professional City Life	White Collar Urban	Urban Fringe	Countryside
Age 0	1.09 (1.03-1.16)	<i>1.05 (0.98-1.12)</i>	<i>0.99 (0.92-1.05)</i>	<i>1.03 (0.93-1.12)</i>	<i>1.04 (0.97-1.11)</i>	1.17 (1.08-1.25)	1.24 (1.14-1.34)
Age 1-5	1.16 (1.11-1.21)	1.16 (1.10-1.21)	1.21 (1.15-1.26)	1.12 (1.04-1.21)	1.20 (1.15-1.26)	1.24 (1.18-1.31)	1.20 (1.12-1.28)
Age 6-10	1.31 (1.24-1.38)	1.27 (1.20-1.35)	1.30 (1.23-1.37)	1.38 (1.35-1.52)	1.33 (1.26-1.40)	1.24 (1.16-1.31)	1.28 (1.20-1.37)
Age 11-15	1.44 (1.36-1.53)	1.41 (1.34-1.49)	1.30 (1.23-1.36)	1.33 (1.20-1.46)	1.35 (1.28-1.42)	1.32 (1.24-1.39)	1.31 (1.22-1.40)
Age 16-19	1.49 (1.40-1.59)	1.39 (1.30-1.47)	1.36 (1.28-1.44)	1.35 (1.22-1.48)	1.37 (1.29-1.45)	1.34 (1.35-1.42)	1.47 (1.37-1.57)

Note: Rate ratios with 95% confidence intervals in brackets. Non-significant rate ratios are in italics

Table 3: Rate ratios of all-cause mortality rates by deprivation quintile and age, England 2009-10 : 2000-01

	Most Deprived			Least Deprived	
	Q1	Q2	Q3	Q4	Q5
Age 0	0.77 (0.71-0.84)	0.78 (0.71-0.85)	0.77 (0.68-0.85)	0.85 (0.76-0.95)	0.89 (0.80-0.99)
Age 1-4	0.76 (0.61-0.91)	0.68 (0.53-0.83)	0.80 (0.61-0.98)	0.79 (0.60-0.98)	0.76 (0.57-0.95)
Age 5-14	0.77 (0.64-0.90)	0.79 (0.64-0.94)	0.81 (0.65-0.96)	<i>0.89 (0.73-1.05)</i>	0.70 (0.55-0.86)

Note: Rate ratios with 95% confidence intervals in brackets. Non-significant rate ratios are in italics