Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity

FINAL REPORT FOR TOGETHER FOR SHORT LIVES
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Executive Summary

1 Life-limiting conditions (LLC) describe diseases with no reasonable hope of cure that will ultimately be fatal. For children with these diseases palliative care services should be accessible but little data are available to estimate the burden of these conditions.

2 A study was undertaken at Paediatric Epidemiology Group, University of Leeds in collaboration with Dr Richard Hain, Children's Hospital for Wales to address the information gap on the national and regional prevalence of children with LLC. The project used routinely collected hospital inpatient data to investigate prevalence in terms of diagnosis, geography and demographics including age, sex, ethnicity and deprivation.

3 Children (0-19 years) with LLC were identified within four independent inpatient hospital datasets for England, Scotland, Wales and Northern Ireland by applying a customised coding framework of ICD-10 disease codes. Prevalence per 10 000 population (0-19 years) was calculated by age, diagnostic group, ethnicity and deprivation within each country for each year (from 2000/01-2009/10).

4 The hospital datasets contained data on 175286, 13911, 9916, 7392 children admitted to hospital with LLC in England, Scotland, Wales and Northern Ireland respectively over a ten year period.

5 National prevalence of LLC in children (aged 0-19 years) in England had increased over 10 years from 25 to 32 per 10 000 population with the final year reaching double previous prevalence estimates.

6 National prevalence of LLC in children (aged 0-19 years) in Scotland had increased over time from 32 per 10 000 to 38.6 per 10 000 population (0-19 years) in the most recent year (2009/10).

7 National prevalence of LLC in children (aged 0-19 years) in Wales had increased over time from 34.9 per 10 000 to 44.6 per 10 000 population (0-19 years) in the most recent year (2009/10) but there was year on year fluctuation.

8 National Prevalence of LLC in children (aged 0-19 years) in Northern Ireland had increased over time from 23.5 per 10 000 to 27.8 per 10 000 population (0-19 years) in the most recent year (2009/10) but there was year on year fluctuation.

9 In all four countries prevalence of LLC in children (aged 0-19 years) was highest in the children under 1 year and decreased through the age bands. The prevalence in the male population was significantly higher than in the female population in all years.

10 In all four countries the highest prevalence of LLC in children (aged 0-19 years) was accounted for by congenital anomalies.

11 Associations between higher prevalence in the most deprived areas were seen in all four countries. In England and Northern Ireland a J shaped association between LLC and deprivation was seen with higher than expected prevalence in the most deprived and a small excess in the least deprived categories. In Scotland and Wales a linear association was observed with the highest prevalence in the most deprived areas.

12 Ethnicity was strongly linked to variations in prevalence. In England, prevalence in the South Asian (48 per 10 000), Black (42 per 10 000), and Chinese, Mixed & 'Other' (31 per 10 000) populations were statistically significantly higher compared to the White population (27 per 10 000).

13 Information from our data estimates that 40042, 4463, 3199 and 1307 children and young people are currently living with LLC in England, Scotland, Wales and Northern Ireland respectively.

14 These results clearly identify an escalating need for specialist paediatric palliative care services. When planning services for these increasing needs, the excess prevalence in ethnic minority groups especially in deprived areas needs to be considered.

1 Introduction

Life-limiting conditions (LLC) in children and young people can be defined as conditions for which there is no reasonable hope of cure and from which children or young people will die. Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer[1].

Paediatric palliative care is a clearly different speciality than adult palliative care. The World Health Organisation's definition of palliative care for children includes the statement 'It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease'[2]. Children tend to be cared for over extended time periods; longer than 20 years in some instances[3]. Adult services generally focus on end of life care which can be measured in days or weeks[4].

In 2007 an independent review of children's palliative care services in England [5] highlighted the lack of available data on the number of children and young people who received or who would benefit from palliative care services.

Previous estimates of the prevalence of life-limiting conditions in children and young people have risen from 10 per 10 000 in 1997[6], to 12 per 10 000 in 2003[7] with the most recent estimate of 16 per 10 000 in 2007 (aged 0-19 years)[8]. The most recent estimate was based on death certificate data which has limitations with respect to quality and as children live longer with their condition these figures are likely to be underestimates; anecdotally clinicians working in paediatric palliative care consider the data to under represent the burden of disease. There is no current national database of clinical and demographic information which can provide more accurate figures.

Palliative care is a current priority for the UK Government and a recent independent review has published findings relating to funding of palliative care for adults and children in England[9].

This study used routinely collected NHS data to estimate the prevalence of life-limiting conditions in children and young people and assess trends over time using an empirically derived diagnostic coding framework.

The National Health Service (NHS) Hospital inpatient datasets contain clinical and demographic information about individual's inpatient consultant episodes and the diagnoses are coded in this dataset using the ICD10 disease classification[10]. To identify

children and young people with a life-limiting condition a coding framework of ICD-10 disease codes[10] was developed based on the diagnoses of children seen by clinicians providing paediatric palliative care.

1.1 Definition of Life-Limiting Conditions

A key process was the identification of ICD10 codes that constituted the conditions of interest; this was undertaken prior to accessing the inpatient hospital datasets. Two independent sources of information were used, the Hain Dictionary version 1·0 of ICD10 codes for children seen by palliative care providers (Richard Hain, personal communication) and a listing of written diagnoses for children accepted for care at Martin House Children's Hospice during 1987-2010. A four digit ICD10 code[11] was assigned to 92% of diagnoses on the Martin House list; the 8% not coded were children without clear diagnoses (e.g 'degenerative neurological disease with no firm diagnosis').

Combining both sets of codes produced a provisional list of 801 ICD10 codes for further scrutiny (84% of codes appeared on both lists).

All these ICD10 codes were individually subjected to the following two questions:

1. Are the majority of children with this diagnosis life-limited/life-threatened?
2. Are the majority of sub-diagnoses within the ICD10 code life-limiting/life-threatening?

A list of ICD10 codes which fulfilled the above criteria was compiled and completed by adding all malignant oncology ICD10 codes.

The final ICD10 coding framework consisted of 777 four digit ICD10 codes. Malignant oncology codes accounted for 445 (57%) codes with congenital malformations and chromosomal abnormalities having 87 (12%) codes (Appendix A).

1.2 Population Data

Populations at risk were mid-year estimates by age, sex and ethnic group for local authorities in England and nationally for Scotland, Wales and Northern Ireland were obtained from http://ethpop.org/. This source has been used in preference to the sub-national estimates produced by the Office of National Statistics (ONS) because the cohort component population estimation model [12] incorporates more detailed demographic information by ethnic group in relation to newborns, mortality and most importantly both

sub-national migration and international migration. Indeed, ONS has recently warned about the quality of their estimates.

2 England

2.1 Methods

2.1.1 Patient Data

An extract of inpatient Hospital Episodes Statistics (HES)[13] was obtained from the NHS Information Centre for the 10 financial year time period 2000/01 until 2009/10. The selection captured all episodes for all patients ever coded with one of the defined ICD10 codes and/or the ICD10 code for palliative care (used to capture children with no firm diagnosis). The extract excluded patients aged over 19 years at the start of an episode and those whose country of residence was outside England.

An extract of outpatient HES data was also obtained but the diagnostic coding was of insufficient quality to use for this study.

Age

The start age recorded at the first hospital episode in each year was used to assign the age category for each individual. Age was categorised into five groups: less than 1 year, 1 to 5 years, 6 to 10 years, 11 to 15 years and 16 to 19 years.

Gender

The data for each hospital episode included a code for gender. Gender was coded as male, female or not known. For individuals where more than one gender was recorded they were assigned the most commonly recorded gender.

Diagnoses

There are twenty diagnoses fields in the inpatient HES dataset.

The diagnoses were categorised into 11 groups based on the main ICD10 chapters: neurology, haematology, oncology, metabolic, respiratory, circulatory, gastrointestinal, genitourinary, perinatal, congenital and other. No attempt was made to prioritise multiple diagnoses for individuals therefore individuals may have more than one life-limiting diagnosis.

Ethnicity

The data for each hospital episode included a code for ethnicity. Individuals with more than one ethnicity were assigned the most commonly reported ethnicity unless the most common ethnicity was 'not known'[14]. This ensured that the same code for an individual's

ethnicity was assigned to all episodes (i.e if coded white in 2001/02 data and 2002/03 but not known in 2003/04, they would be counted as white in all years). The 16 census ethnic groups[15] were merged into four super-groups to avoid very small numbers in some groups; White (White: British, White: Irish, White: Other White), South Asian (Asian or Asian British: Indian, Asian or Asian British: Pakistani, Asian or Asian British: Bangladeshi, Asian or Asian British: Other Asian), Black (Black or Black British: Black Caribbean, Black or Black British: Black African, Black or Black British: Other Black) , Chinese & Other ethnic groups (Mixed: White and Black Caribbean, Mixed: White and Black African, Mixed: White and Asian, Mixed: Other Mixed, Chinese and Other Ethnic Group).

Deprivation

An index of multiple deprivation (IMD2007)[16] score was assigned to each individual based upon their local authority of residence (LAD) . The lack of availability of population data by ethnicity at smaller geographical areas meant that lower superoutput area deprivation score could not be used in these analyses. These scores were categorised into five equal categories based on the scores for the whole of England (20% of the local authorities in each category).

2.1.2 Analyses

Prevalence per 10 000 population (aged 0-19 years) were calculated overall, for each year, for each ethnic group per year, for each geographical unit per year and for the age groups per year and the diagnostic groups per year.

Each individual was assigned a local authority district (LAD) and government office region (GOR) of Residence based on their LSOA of residence. These assignments were done per year and if an individual moved local authority within that year the first local authority reported that year was used. This allowed the individual to be assigned new local authorities over the time period but not within a year.

2.2 Results

A total of more than 1.7 million finished consultant episodes for 175286 individuals were included in the final dataset.

Prevalence

Table 1 shows the crude number of patients and prevalence per 10 000 population by age group and the total. Overall prevalence has increased over time from 25 per 10 000 to 32 per 10 000 population (0-19 years) in the most recent year (2009/10).

The prevalence was highest in the under 1 age group and decreased through the age bands. The increase in prevalence over time was seen in all of the age groups but was most marked in the 16-19 years old where there was a 44.8% increase in prevalence over the 10 years, with a 37.9% increase in the 11-15 year olds, 31.9% in the 6-10 year olds, 17.1% in the 1-5 year olds and 7·7% in the under 1 year olds.

The prevalence in the male population was significantly higher than in the female population in all years with the figures for 2009/10: male (35.2, 95%CI 34.7, 35.7), female (29.2, 95%CI 28.8, 29.6)(Figure 1). This difference was constant across age groups and diagnostic groups (data not shown).

Diagnoses

There were 216119 life-limiting diagnoses in the 175286 individuals. Each year between 21·7-29·9% of children had more than one life-limiting diagnosis (data not shown).

The percentages per diagnostic category (overall) were; Congenital anomalies (30.7%), oncology (13.7%), neurological (12.0%), haematology (9·8%), respiratory (8·8%), genitourinary (6.2%), perinatal (7·7%), metabolic (3·8%), circulatory (3·8%), gastrointestinal (2·4%) and the other group (1.1%).

The trends in prevalence shown in Figure 2 are per diagnosis, not per individual patient. The highest prevalence was of congenital anomalies with the lowest prevalence in circulatory and gastrointestinal diagnoses. Oncology diagnoses and the other group were the only groups without a rising prevalence.

Ethnicity

Overall there were 25% of patients with their ethnicity coded as not known. The proportion of unknowns decreased over time from 33% in 2000/01 to 11% in 2008/9 and 9% in 2009/10. Data from the two most recent years was selected for analysis and no assessment of time trends was undertaken.

The highest prevalence was in the South Asian (47.6 per 10 000, 95%CI 46.8, 48.4), Black population (41.5 per 10 000, 95%CI 39.5, 43.5) and the Chinese & other population (30.7 per

10000, 95%CI 29.4, 32.0. These were significantly higher compared to the White population (27.0 per 10 000, 95%CI 26.7, 27.3) (Table 2).

Deprivation

The prevalence per 10 000 population in each deprivation category over time shows an inverse J shaped relationship with deprivation with the highest prevalence in the most deprived category and the lowest in category 4 (Figure 3). All categories are significantly different from each other (χ^2=29.2, p<0.001)

Deprivation by Ethnic group

Figure 4 and Figure 5 show the prevalence and the 95% confidence intervals by deprivation category by ethnic group for the year 2009/10. Similar results were seen for the previous year. A J shaped association with deprivation is seen in all four ethnic groups. In the second most affluent areas (category 4) a significantly lower prevalence was seen for the White population compared to all other categories (χ^2=28.2, p<0.001) and for the Black population compared to the 3 most deprived categories (χ^2=28.2, p<0.001). In the South Asian population prevalence in the most deprived category was significantly higher than the prevalence in all the other categories with category 4 having the lowest prevalence (χ^2=124.2, p<0.001).

The Chinese, Mixed & 'Other' groups were also analysed separately. Although prevalence was higher in the 'Other' group, no significant differences were observed between the deprivation categories for either the Chinese or Mixed or 'Other' groups where small numbers gave wide overlapping confidence intervals.

Figure 5 shows the same data grouped by deprivation category to allow easier comparison between the ethnic groups. The South Asian prevalence is significantly higher than the White population in all deprivation categories apart from category 4.

Geographical Variation

There is some significant geographical variation in prevalence at Government Office Region level illustrated in Figure 6 (2009/10) with the North East, North West, West Midlands and London having higher prevalence than the South West, Yorkshire and Humber and the East Midlands. The prevalence rose uniformly in all Government Office Regions over the ten year period (Figure 7).

Summary for each Government Office Region are shown in Appendix B.

Table 1 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in England

		Prevalence per 10 000 population											
Year	**Number of Patients**	**Total**	**95%CI***	**Age under 1 year**	**95%CI**	**Age 1-5 years**	**95%CI**	**Age 6-10 years**	**95%CI**	**Age 11-15 years**	**95%CI**	**Age 16- 19 years**	**95%CI**
2000/01	**30643**	**24.9**	24.6,25.1	**116.7**	113.9,119.5	**29.1**	28.5, 29.7	**18.8**	18.3, 19.3	**17.4**	17.0,17.9	**16.3**	15.7, 16.8
2001/02	**29443**	**23.8**	23.6,24.1	**105.9**	103.3, 108.6	**28.0**	27.4, 28.6	**18.1**	17.6,18.6	**17.0**	16.6, 17.4	**16.2**	15.7, 16.7
2002/03	**30503**	**24.7**	24.4,25.0	**104.2**	101.6, 106.8	**29.5**	28.9, 30.2	**19.1**	18.6,19.5	**18.0**	17.5, 18.4	**16.5**	16.0, 17.0
2003/04	**31280**	**25.3**	25.1,25.6	**104.1**	101.5, 106.6	**29.9**	29.2, 30.5	**19.6**	19.1, 20.1	**18.5**	18.0, 18.9	**17.5**	17.0,18.0
2004/05	**31639**	**25.6**	25.4,25.9	**102.1**	99.6, 104.6	**29.9**	29.3, 30.5	**20.1**	19.6,20.6	**18.4**	18.0, 18.9	**17.9**	17.3, 18.4
2005/06	**34066**	**27.6**	27.3,27.9	**106.7**	104.2, 109.2	**31.1**	30.4, 31.7	**21.8**	21.3, 22.4	**20.4**	19.9, 20.9	**19.5**	18.9, 20.0
2006/07	**36013**	**29.1**	28.8,29.4	**123.4**	120.8, 126.1	**31.4**	30.8, 32.0	**22.3**	21.7, 22.8	**21.0**	20.5, 21.5	**19.7**	19.2, 20.3
2007/08	**37447**	**30.2**	29.8,30.5	**113.5**	111.0, 116.0	**32.9**	32.3, 33.6	**23.5**	22.9, 24.1	**22.4**	21.9, 22.9	**21.1**	20.6, 21.7
2008/09	**37601**	**30.3**	30.0,30.6	**117.5**	114.9, 120.1	**32.4**	31.8, 33.0	**23.6**	23.0, 24.1	**22.5**	22.0, 23.1	**22.0**	21.4, 22.6
2009/10	**40042**	**32.2**	31.9,32.6	**125.7**	123.1, 128.4	**34.1**	33.5, 34.7	**24.8**	24.2, 25.4	**24.0**	23.4, 24.5	**23.6**	23.0, 24.2

*95% Confidence intervals

Table 2 Prevalence (per 10 000 population) of children with life-limiting conditions in England aged 0-19 years by Ethnic Group (2008/09, 2009/10)

Ethnic Group	Number of Patients	Prevalence per 10000 population 2008/09	95% Confidence Intervals	Number of Patients	Prevalence per 10000 population 2009/10	95% Confidence Intervals
White	25875	24.8	24.5,24.8	28065	27.0	26.7,27.3
Black	1529	37.5	35.6,39.4	1714	41.5	39.5,43.5
South Asian	3987	43.0	41.7,44.3	4520	47.6	46.8,48.4
Chinese & Other	1920	30.2	28.9,31.6	2093	30.7	29.4,32.0
Missing	4290			3650		
Total	37601			40042		

Figure 1 Prevalence of life –limiting conditions in children by gender, England 2000-2010

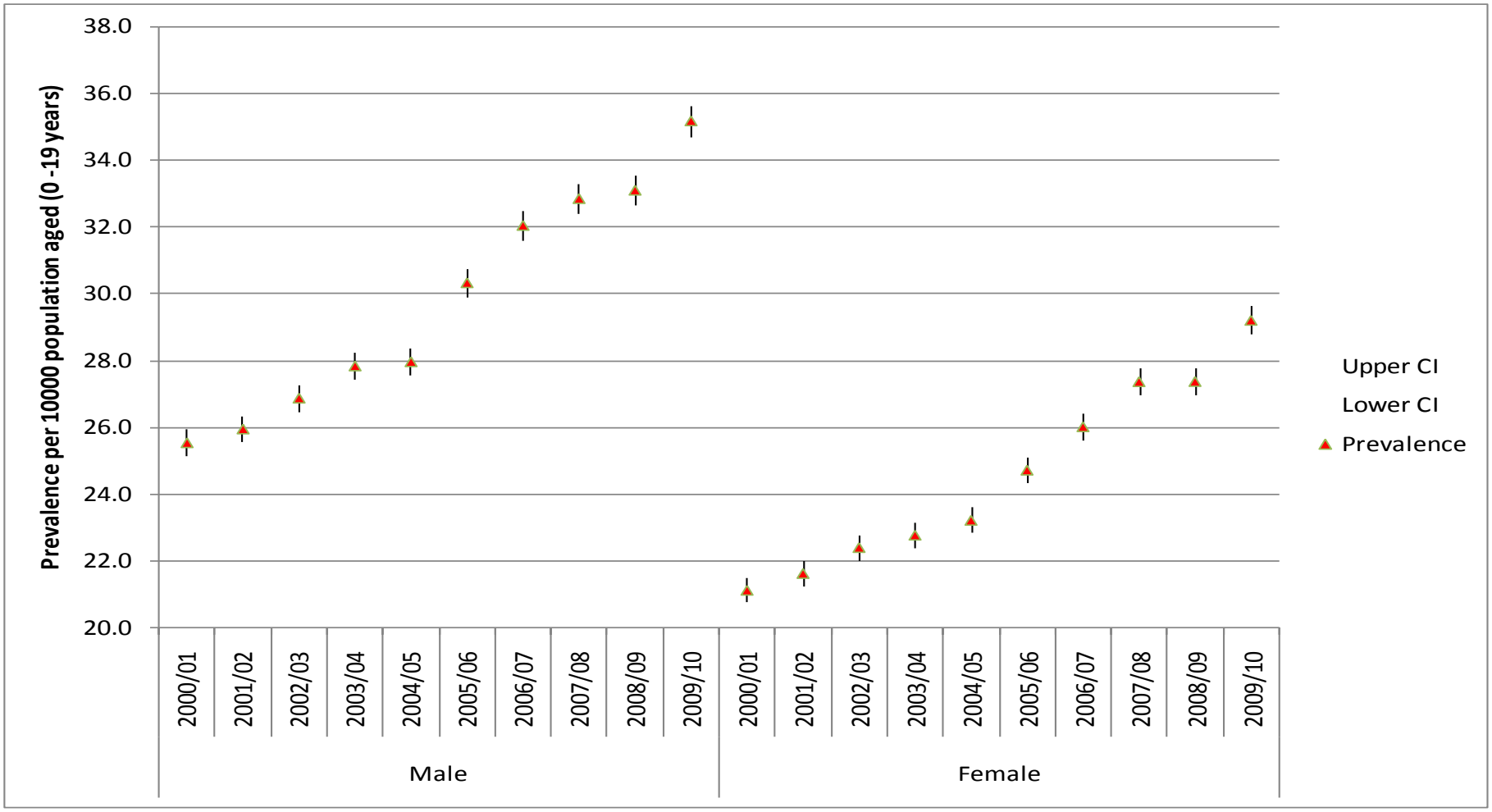


Figure 2 Prevalence of Life Limiting Conditions in Children by major diagnostic group, England 2000-2010

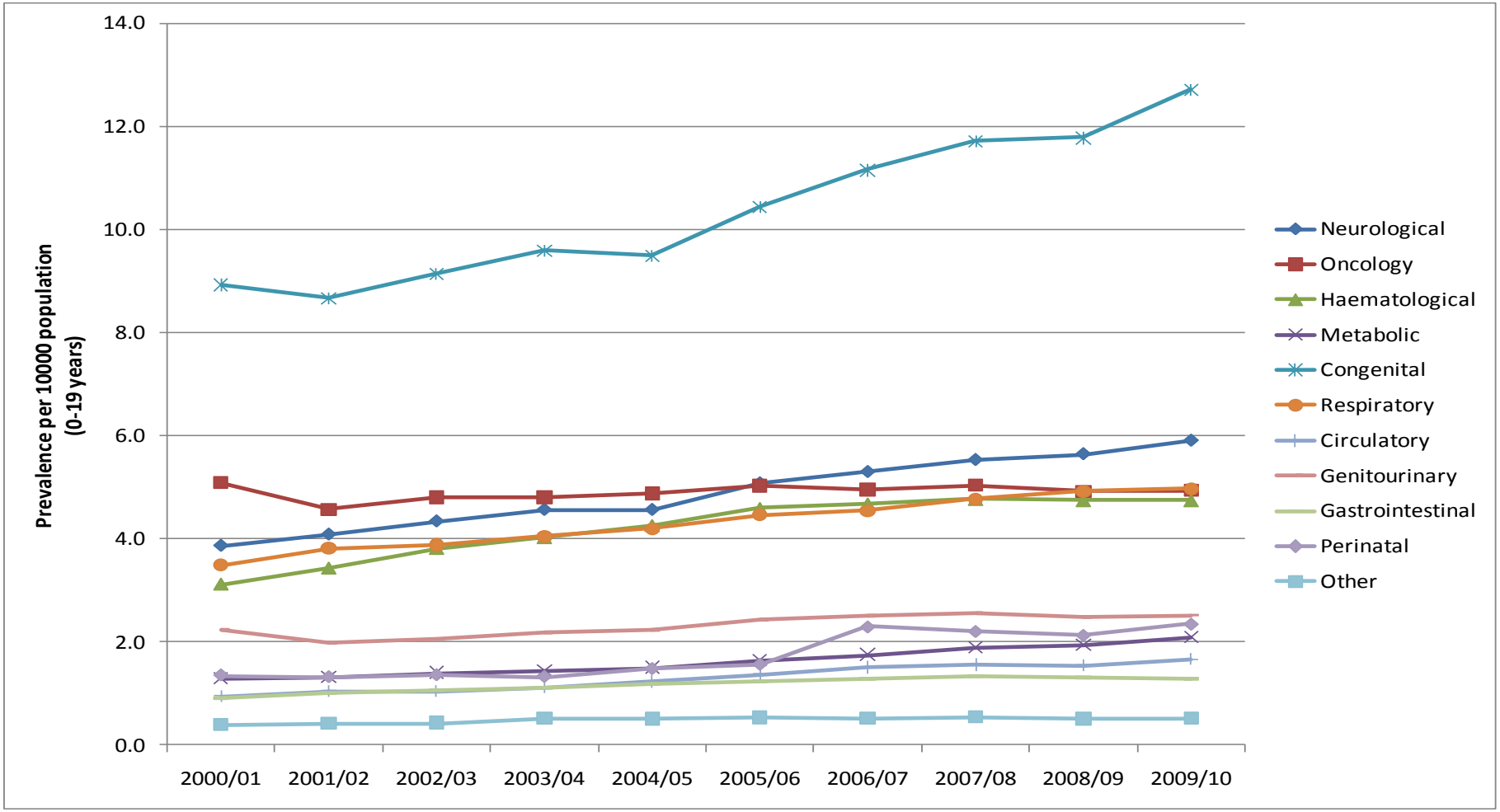


Figure 3 Prevalence of Life-limiting conditions in children by deprivation category, England 2000-2010

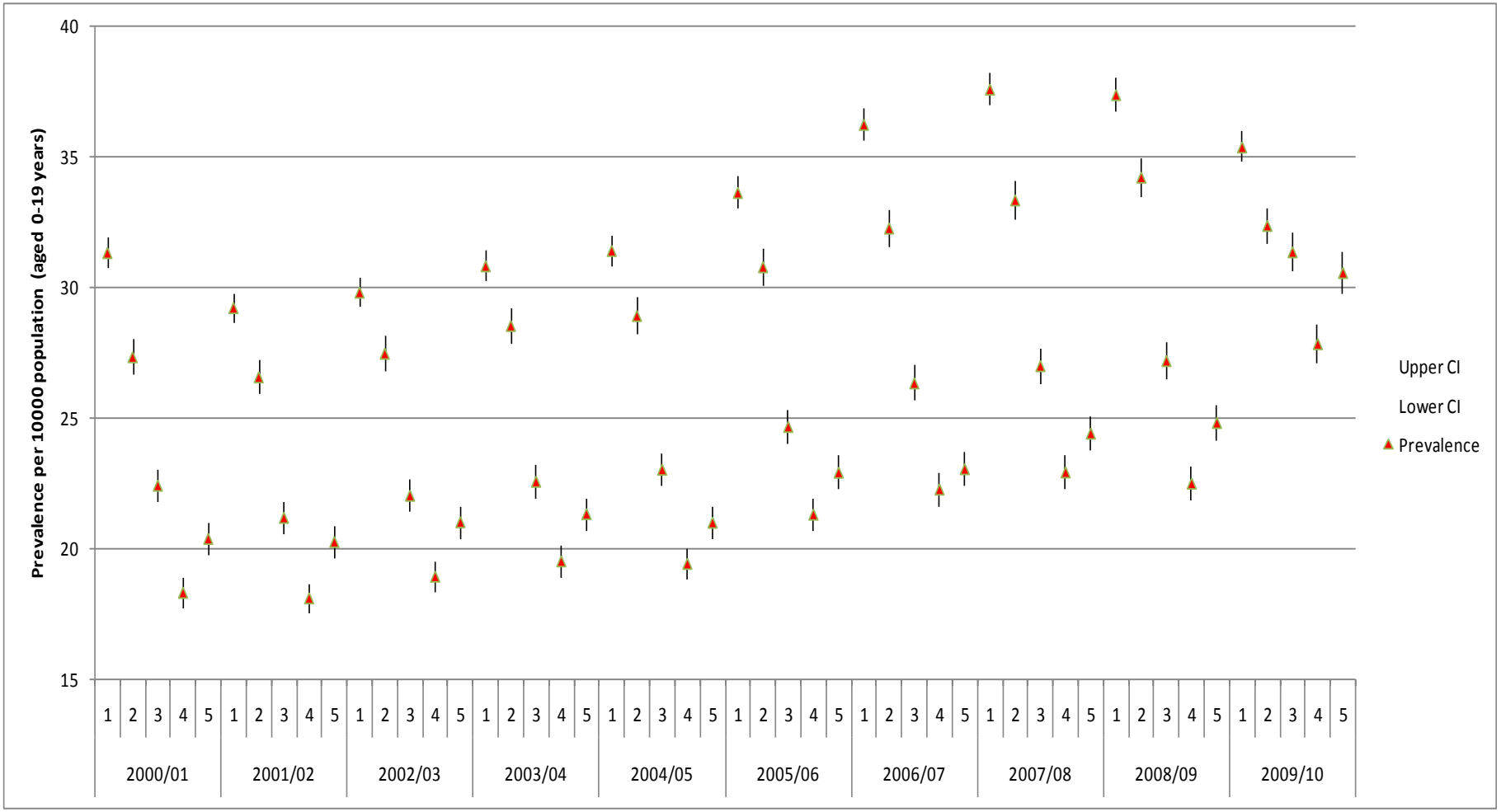


Figure 4 Prevalence of Life-limiting conditions in children deprivation category by ethnic group, England 2009/10

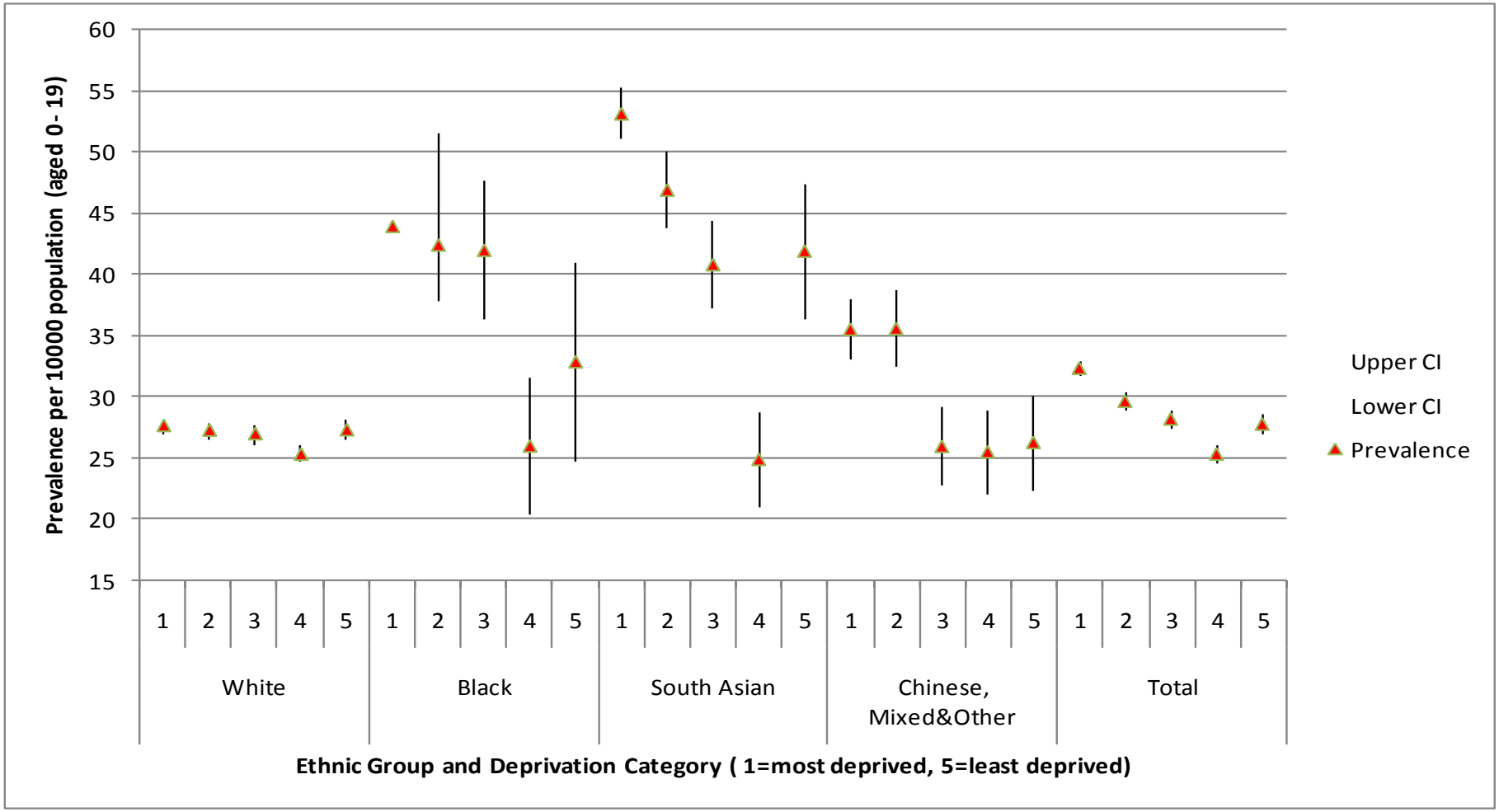


Figure 5 Prevalence of Life-limiting conditions in children ethnic group by deprivation category, England 2009/10

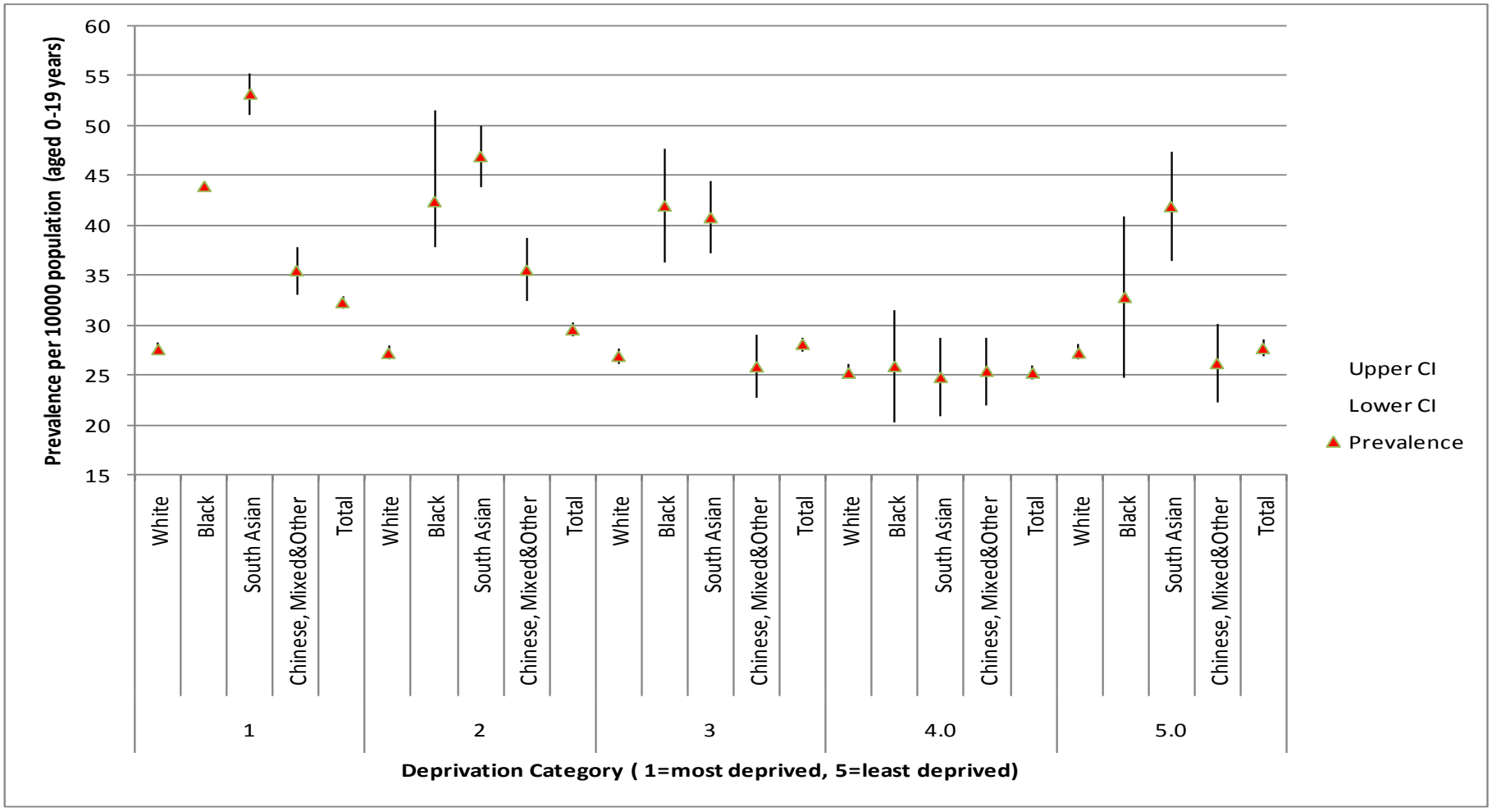


Figure 6 Prevalence of Life-limiting conditions in children by Government Office Region, 2009/10

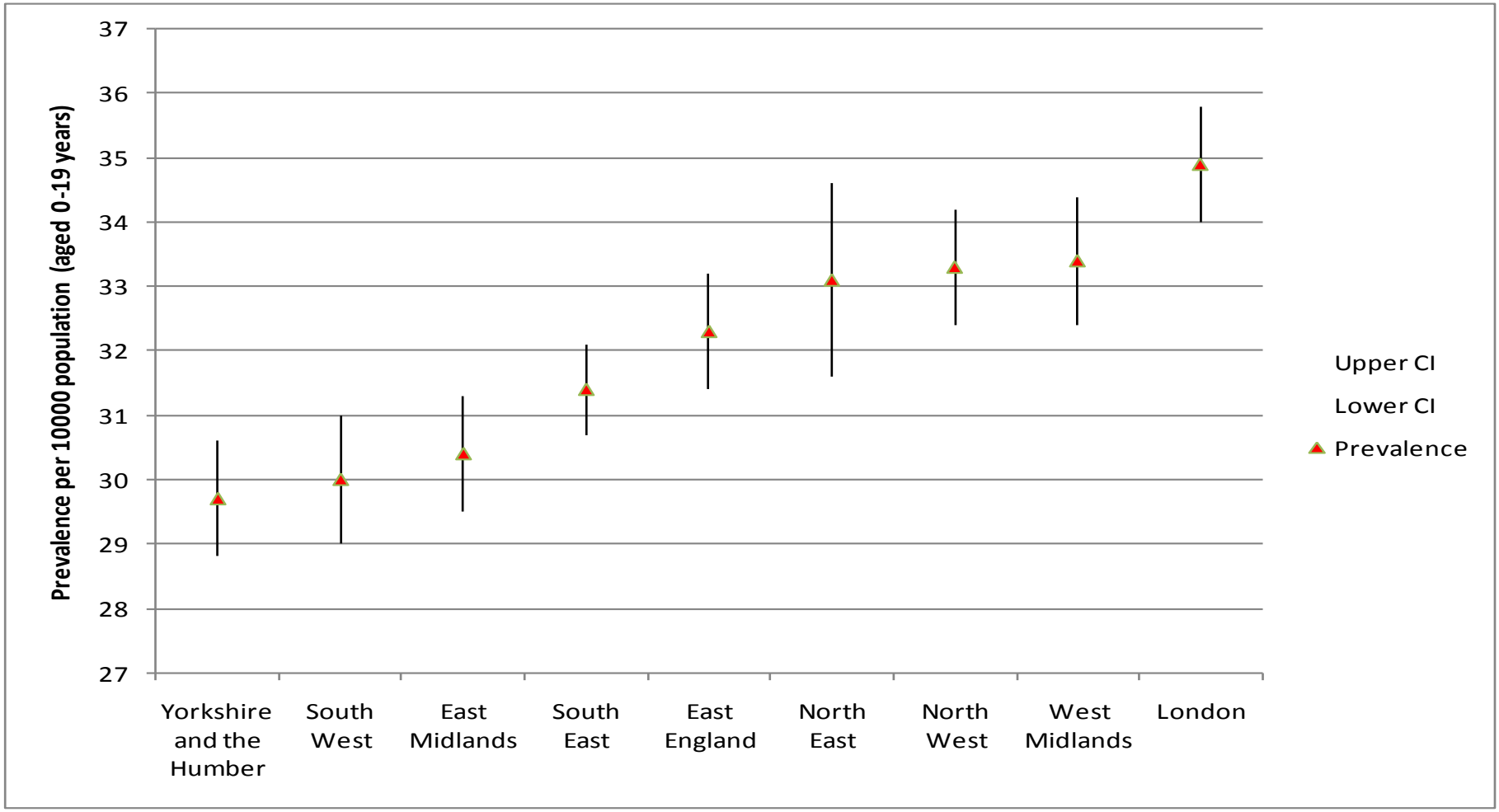
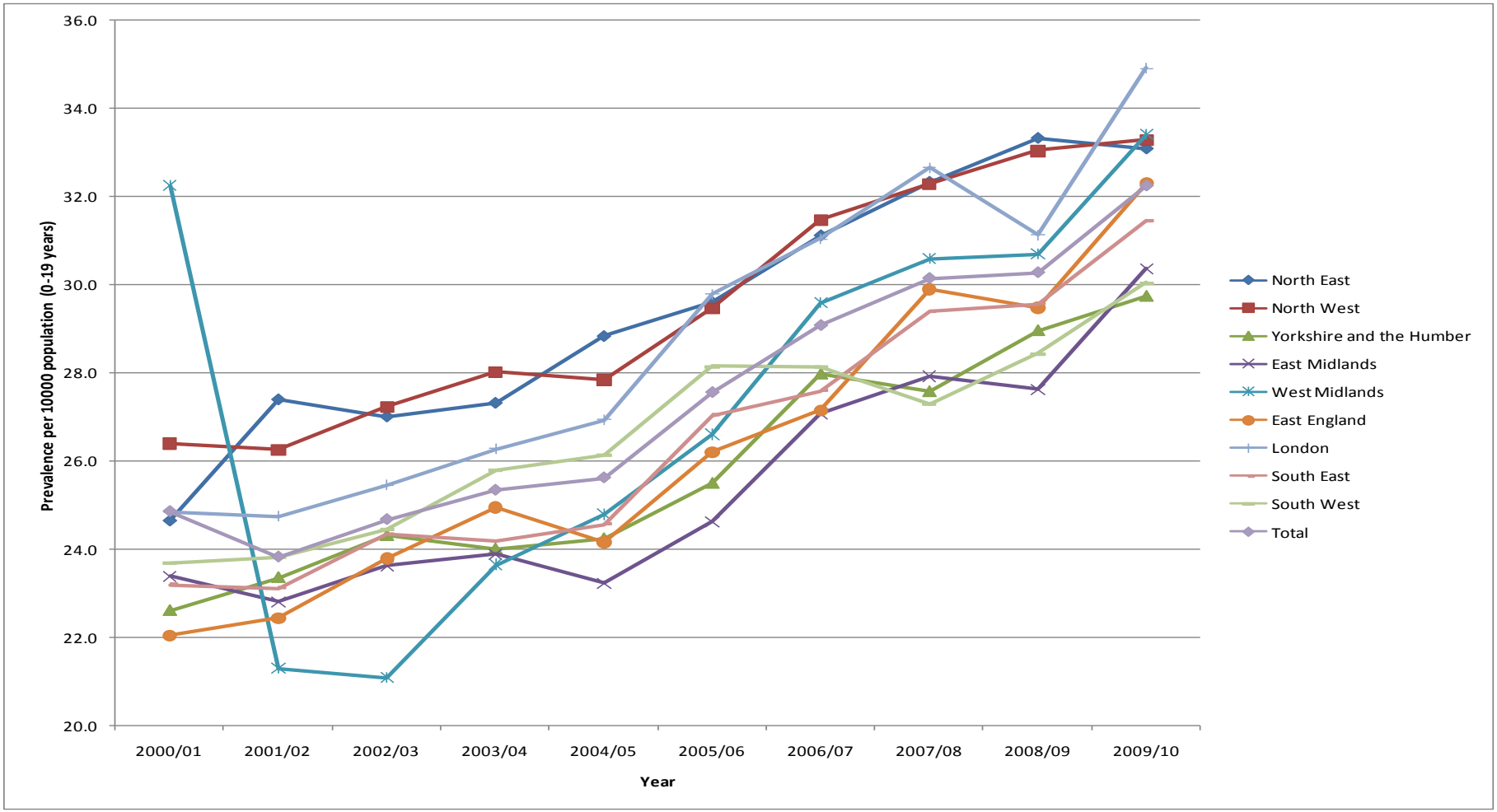


Figure 7 Trends in Prevalence of Life-limiting Conditions in Children by Government Office Region, England 2000-2010



3 Scotland

3.1 Methods

3.1.1 Patient Data

An extract of the Scottish Morbidity Records Inpatient activity database (SMR 01) was obtained from the Information Services Division for the 10 financial year time period 2000/01 until 2009/10. Due to difference in data laws between Scotland and England an application to the Privacy Advisory Committee was required (this application was successful). The selection captured all episodes for all patients ever coded with one of the defined ICD10 codes and/or the ICD10 code for palliative care (used to capture children with no firm diagnosis). The extract excluded patients aged over 19 years at the start of an episode and those whose country of residence was outside Scotland.

Age

The start age recorded at the first hospital episode in each year was used to assign the age category for each individual. Age was categorised into five groups: less than 1 year, 1 to 5 years, 6 to 10 years, 11 to 15 years and 16 to 19 years.

Gender

The data for each hospital episode included a code for gender. Gender was coded as male, female or not known. For individuals where more than one gender was recorded they were assigned the most commonly recorded gender.

Diagnoses

There were 6 diagnoses fields within the SMR01 dataset.

The diagnoses were categorised into 11 groups based on the main ICD10 chapters: neurology, haematology, oncology, metabolic, respiratory, circulatory, gastrointestinal, genitourinary, perinatal, congenital and other. No attempt was made to prioritise multiple diagnoses for individuals therefore individuals may have more than one life-limiting diagnosis.

Ethnicity

Ethnicity was collected within this dataset but was missing in 63% of all individuals for 2009/10 so no analyses by ethnic group could be undertaken.

Deprivation

A deprivation category (fifths and tenths) had been assigned to the individual records based on health board of residence by the ISD. These categories were population weighted (i.e. a fifth of the population lived in each deprivation fifth and a tenth of the population lived in each deprivation tenth). This allowed proportions of the cases by deprivation category to be interpreted.

Geographical Variation

Due to the relative small numbers of cases no sub national analyses was undertaken.

3.1.2 Analyses

Prevalence per 10 000 population (aged 0-19 years) were calculated overall, for each year, for each ethnic group per year, for each geographical unit per year and for the age groups per year and the diagnostic groups per year.

3.2 Results

Table 3 shows the crude number of patients and prevalence per 10 000 population by age group and the total. Overall prevalence has increased over time from 32 per 10 000 to 38.6 per 10 000 population (0-19 years) in the most recent year (2009/10).

The prevalence was highest in the under 1 age group and decreased through the age bands.

Gender

The prevalence in the male population was significantly higher than in the female population in all years (Figure 8).

Diagnoses

There were 15279 life-limiting diagnoses in the 13911 individuals. Each year between 18 and 21% of children had more than one life-limiting diagnosis (data not shown).

The percentages per diagnostic category (overall) were; congenital anomalies (35.0%), oncology (16.8%), neurological (14.5%), haematology (3.8%), respiratory (11.4%), genitourinary (7.0%), perinatal (1.1%), metabolic (3.3%), circulatory (3·7%), gastrointestinal (2.7%) and the other group (0.7%).

The trends in prevalence shown in Figure 9 are per diagnosis, not per individual patient. The highest prevalence was of congenital anomalies with the lowest prevalence in perinatal and

other diagnoses. Congenital anomaly diagnoses showed a rising prevalence over the time period.

Deprivation

In all years there is a linear association with deprivation with significantly higher percentage of children with life-limiting conditions lived in areas of higher deprivation (Figure 10).

Table 3 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in Scotland

		Prevalence per 10 000 population																
Year	Number of Patients	Total	95%CI		Age <1 year	95%CI		Age 1-5 years	95%CI		Age 6-10 years	95%CI		Age 11-15 years	95%CI		Age 16-19 years	95%CI	
2000/01	**3,908**	**32.0**	31.0	33.0	**108.6**	99.7	117.5	**43.8**	41.3	46.2	**29.0**	30.9	32.9	**23.7**	22.0	25.4	**17.2**	15.6	18.8
2001/02	**4,068**	**33.6**	32.6	34.6	**104.1**	95.4	112.8	**47.2**	44.6	49.7	**29.8**	31.7	33.1	**24.9**	23.2	26.6	**20.1**	18.4	21.8
2002/03	**4,266**	**35.5**	34.4	36.6	**96.9**	88.5	105.3	**51.8**	49.1	54.5	**30.5**	32.5	34.0	**28.9**	27.0	30.7	**20.1**	18.4	21.9
2003/04	**4,391**	**36.8**	35.7	37.8	**98.3**	90.0	106.6	**51.7**	48.9	54.4	**32.7**	34.8	36.1	**28.4**	26.5	30.2	**23.7**	21.9	25.6
2004/05	**4,492**	**37.9**	36.8	39.0	**104.0**	95.6	112.4	**52.3**	49.5	55.1	**33.7**	35.8	37.3	**28.1**	26.3	30.0	**25.7**	23.8	27.7
2005/06	**4,553**	**38.7**	37.6	39.8	**100.5**	92.3	108.7	**51.2**	48.5	53.9	**34.6**	36.7	38.6	**29.3**	27.4	31.2	**28.1**	26.1	30.2
2006/07	**4,536**	**38.7**	37.6	39.8	**95.9**	88.0	103.8	**47.3**	44.7	49.9	**35.5**	37.8	39.9	**30.2**	28.3	32.2	**30.3**	28.1	32.4
2007/08	**4,519**	**38.7**	37.6	39.8	**89.6**	82.1	97.0	**45.8**	43.3	48.3	**36.8**	39.1	40.7	**30.5**	28.6	32.5	**30.5**	28.3	32.6
2008/09	**4,633**	**39.9**	38.7	41.0	**103.1**	94.8	111.3	**45.5**	43.1	48.0	**36.6**	38.9	40.7	**33.0**	30.9	35.0	**30.7**	28.6	32.9
2009/10	**4,463**	**38.6**	37.5	39.7	**88.0**	80.4	95.6	**45.7**	43.2	48.1	**35.0**	37.2	39.3	**32.6**	30.5	34.7	**29.9**	27.8	32.1

Figure 8 Prevalence of life –limiting conditions in children by gender, Scotland 2000-2010

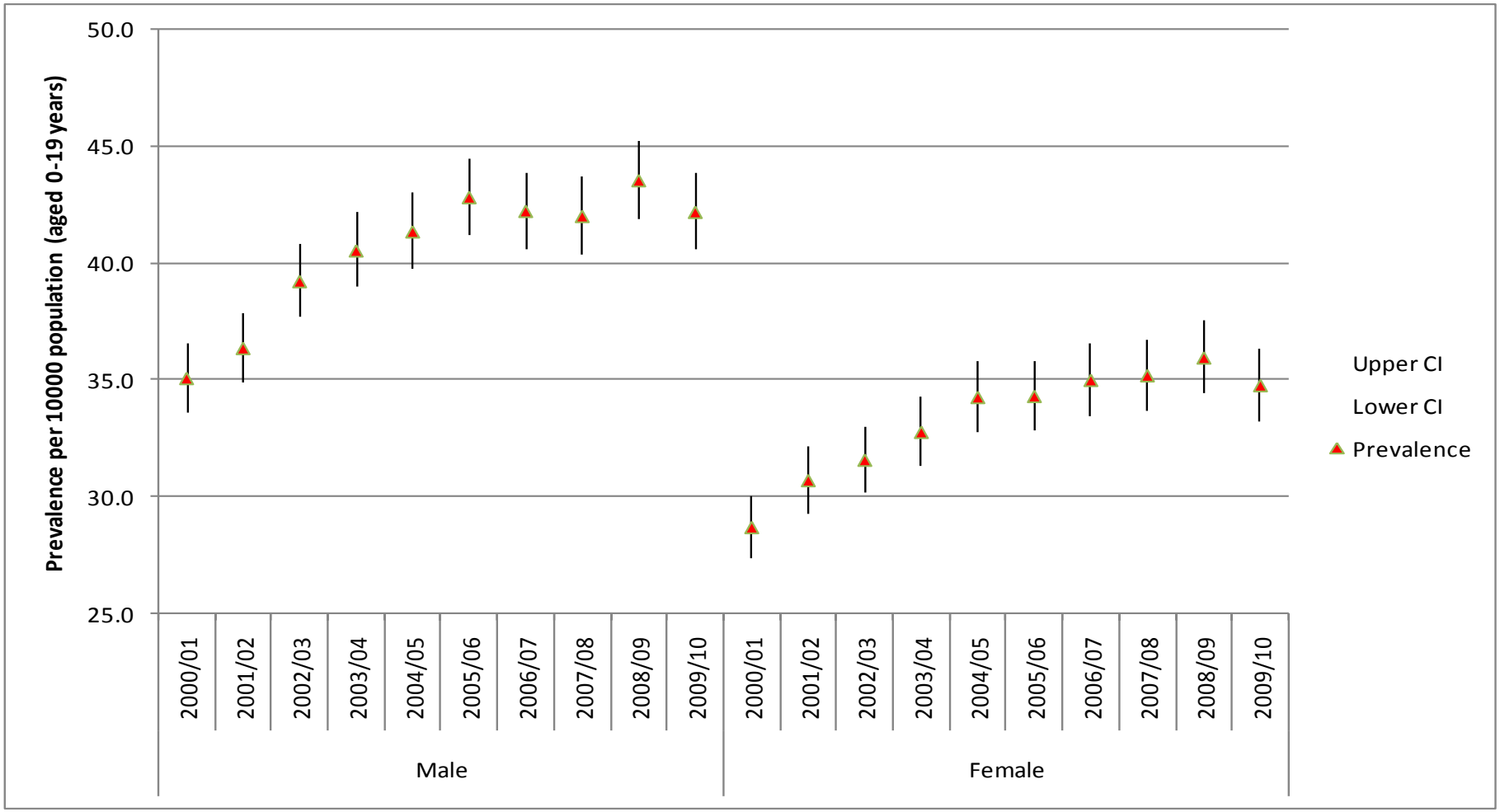


Figure 9 Prevalence of life –limiting conditions in children by major diagnostic group, Scotland 2000-2010

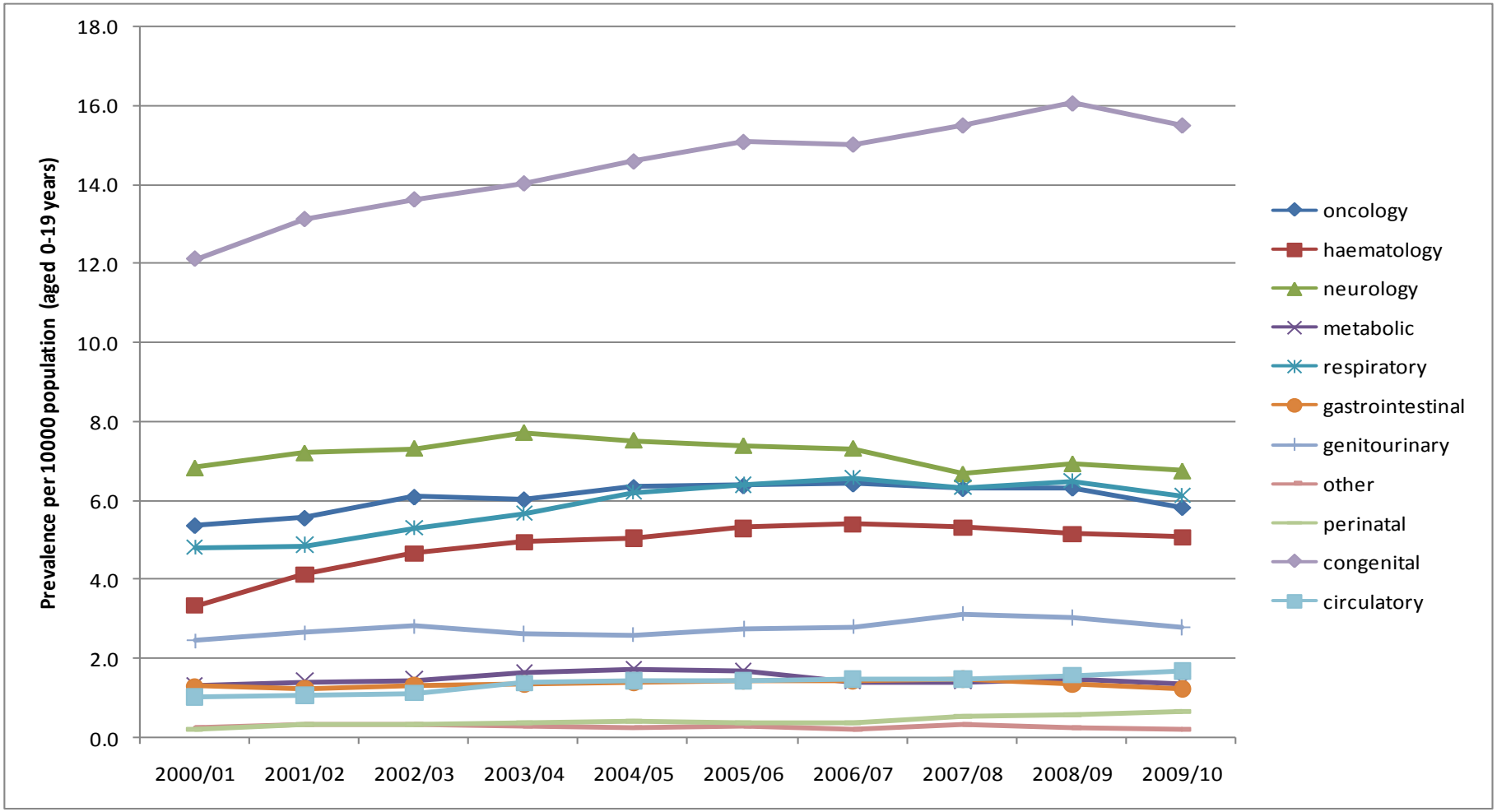
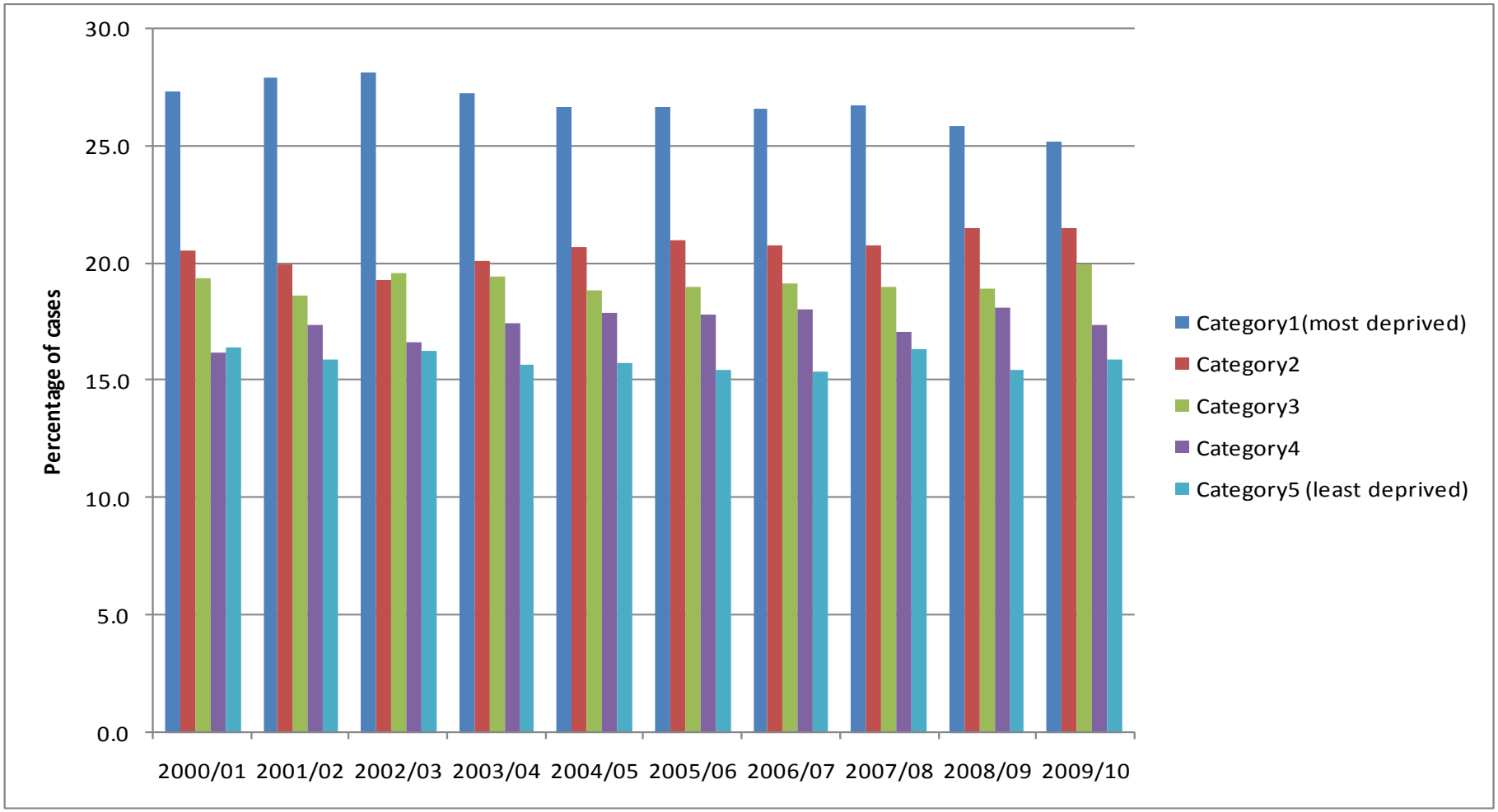


Figure 10 Prevalence of life –limiting conditions in children by deprivation category, Scotland 2000-2010



4 Wales

4.1 Methods

4.1.1 Patient Data

An extract of the inpatient Patient Episode Database (PEDW)[13] was obtained from the NHS Wales Informatics Service the for the 10 financial year time period 2000/01 until 2009/10. The selection captured all episodes for all patients ever coded with one of the defined ICD10 codes and/or the ICD10 code for palliative care (used to capture children with no firm diagnosis). The extract excluded patients aged over 19 years at the start of an episode and those whose country of residence was outside Wales.

Age

The start age recorded at the first hospital episode in each year was used to assign the age category for each individual. Age was categorised into five groups: less than 1 year, 1 to 5 years, 6 to 10 years, 11 to 15 years and 16 to 19 years.

Gender

The data for each hospital episode included a code for gender. Gender was coded as male, female or not known. For individuals where more than one gender was recorded they were assigned the most commonly recorded gender.

Diagnoses

There are 14 diagnoses fields within the PEDW dataset.

The diagnoses were categorised into 11 groups based on the main ICD10 chapters: neurology, haematology, oncology, metabolic, respiratory, circulatory, gastrointestinal, genitourinary, perinatal, congenital and other. No attempt was made to prioritise multiple diagnoses for individuals therefore individuals may have more than one life-limiting diagnosis.

Ethnicity

The data for each hospital episode included a code for ethnicity. PEDW warned that the ethnicity field was unvalidated. Ethnicity was missing for 50% of the patients in the most recent year of data 2009/10 therefore no ethnic group analyses were undertaken.

Deprivation

A Welsh Index of Multiple Deprivation 2008 (WIMD) score was assigned to each individual based upon their lower super output area of residence (LSOA) (census area which contains approximately 1500 individuals). This deprivation score could change over time due to house moves so the mean WIMD score for each individual for each year was used. These scores were categorised into equal fifths based on the scores for the whole of Wales (20% of the local authorities in each fifth). The most deprived fifths is labelled 1 and the least deprived 5.

Geographical Variation

Due to the very small number of cases and small population no geographical analyses were undertaken.

4.1.2 Analyses

Prevalence per 10 000 population (aged 0-19 years) were calculated overall, for each year, for the age groups per year and the diagnostic groups per year.

4.2 Results

A total of 125 633 finished consultant episodes for 9916 individuals were included in the final dataset.

Prevalence

Table 4 shows the crude number of patients and prevalence per 10 000 population by age group and the total. Overall prevalence has increased over time from 34.9 per 10 000 to 44.6 per 10 000 population (0-19 years) in the most recent year (2009/10) but there was year on year fluctuation.

The prevalence was highest in the under 1 age group and decreased through the age bands. The increase in prevalence over time was seen in all of the age groups apart from the under 1 year olds who had a 17% decrease. The increase was most marked in the 16-19 years old where a 70% increase in prevalence over the 10 years, with a 59% increase in the 11-15 year olds, 39% in the 6-10 year olds and 27% in the 1-5 year olds.

The prevalence in the male population was significantly higher than in the female population in all years (Figure 11).

Diagnoses

There were 11160 life-limiting diagnoses in the 9916 individuals. Each year between 19.0-23.0% of children had more than one life-limiting diagnosis (data not shown).

The percentages per diagnostic category (overall) were; Congenital anomalies (36.5%), oncology (14.6%), neurological (12.9%), respiratory (8.5%), perinatal (8.3%), genitourinary (6.1%), haematology (2.2%), circulatory (4.6%), metabolic (3.6%), gastrointestinal (1.9%) and the other group (0.8%).

The trends in prevalence shown in Figure 12 are per diagnosis, not per individual patient. The highest prevalence was of congenital anomalies, neurology and oncology diagnoses with the lowest prevalence in gastrointestinal and metabolic diagnoses. Congenital anomaly diagnoses showed a rising prevalence over the time period.

Deprivation

The proportion of individuals in the highest deprivation category (26%) was significantly higher than the proportion of the population in that category and there were lower than expected proportions of individuals in categories 4 and 5 (least deprived). This pattern was consistent over the time period (Figure 13).

Table 4 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in Wales

		Prevalence per 10000 population																	
	Number of Patients	Total	95%CI		under1 year	95%CI		1-5 years	95%CI		6-10 years	95%CI		11-15 years	95%CI		16- 19 years	95%CI	
2000/01	**2566**	**34.9**	33.6	36.3	**167.4**	153.3	181.6	**43.6**	40.4	46.7	**27.5**	25.1	29.9	**20.1**	18.3	21.8	**18.0**	15.8	20.1
2001/02	**2667**	**36.5**	35.1	37.8	**160.6**	146.7	174.4	**47.6**	44.3	50.9	**28.2**	25.8	30.6	**26.7**	24.4	29.0	**20.8**	18.5	23.1
2002/03	**2764**	**37.9**	36.5	39.3	**153.8**	140.4	167.2	**53.1**	49.6	56.6	**29.8**	27.3	32.3	**26.5**	24.2	28.8	**21.6**	19.3	23.9
2003/04	**2885**	**39.7**	38.3	41.2	**169.1**	155.3	182.9	**53.2**	49.6	56.7	**30.3**	27.7	32.8	**27.1**	24.8	29.5	**24.5**	22.0	26.9
2004/05	**3049**	**42.2**	40.7	43.7	**166.3**	152.9	179.7	**55.5**	51.9	59.1	**33.5**	30.8	36.2	**27.8**	25.4	30.1	**28.3**	25.7	30.9
2005/06	**3201**	**44.3**	42.8	45.9	**171.3**	157.9	184.8	**56.5**	52.8	60.1	**34.7**	31.9	37.4	**30.7**	28.2	33.1	**30.0**	27.3	32.7
2006/07	**3231**	**44.8**	43.3	46.4	**166.6**	153.5	179.6	**55.8**	52.3	59.4	**35.8**	32.9	38.6	**30.5**	28.0	33.0	**31.1**	28.3	33.8
2007/08	**3116**	**43.3**	41.8	44.8	**138.0**	126.4	149.7	**56.5**	53.0	60.0	**35.9**	33.0	38.8	**29.5**	27.0	32.0	**29.2**	26.6	31.9
2008/09	**3288**	**45.8**	44.2	47.4	**152.9**	140.5	165.3	**56.7**	53.2	60.1	**39.6**	36.6	42.7	**32.1**	29.5	34.7	**29.4**	26.8	32.1
2009/10	**3199**	**44.6**	43.1	46.2	**140.3**	128.3	152.3	**55.4**	52.0	58.8	**38.0**	35.0	41.0	**32.0**	29.4	34.6	**30.6**	27.9	33.4

Figure 11 Prevalence of life –limiting conditions in children by gender, Wales 2000-2010

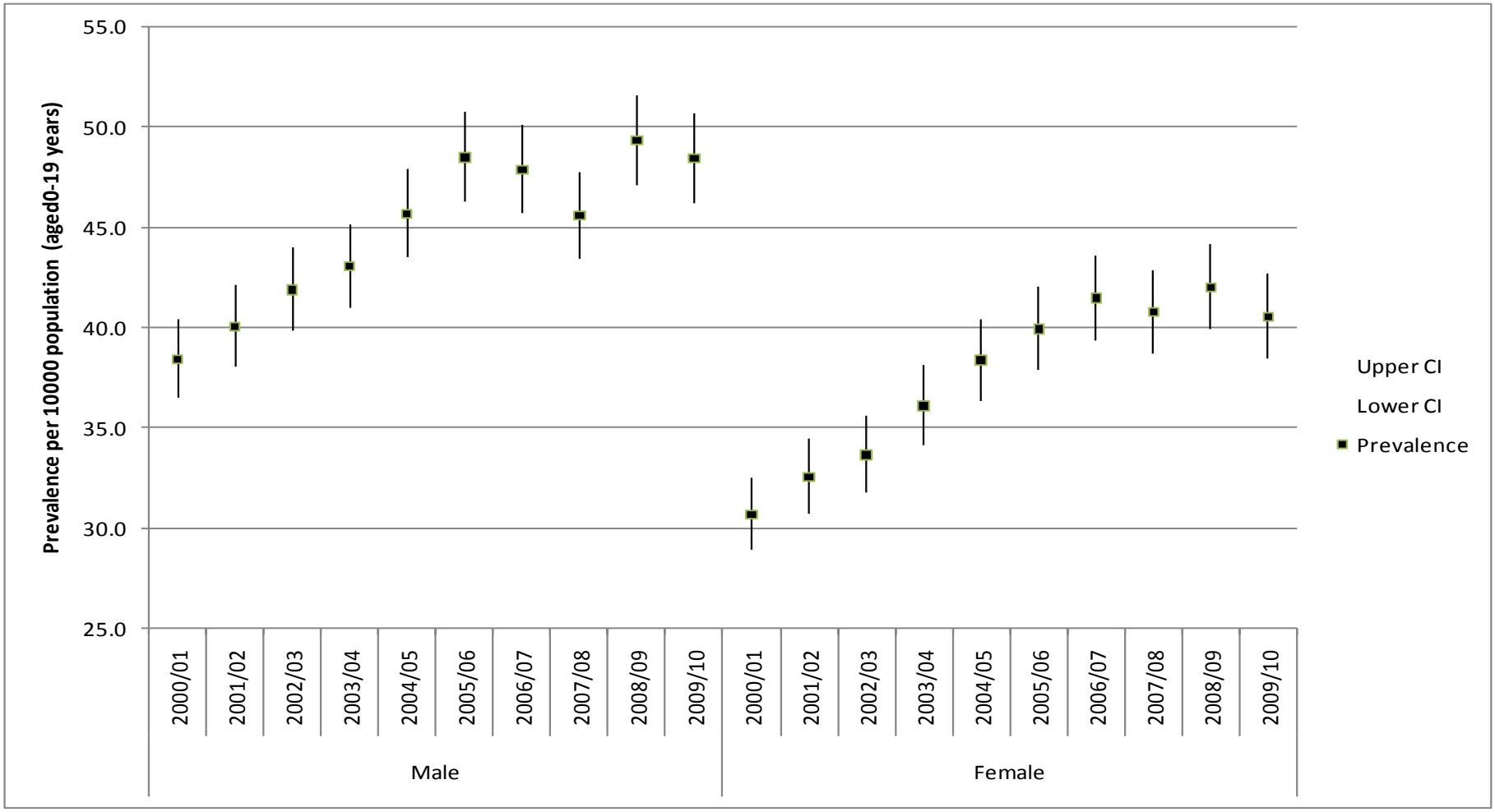


Figure 12 Prevalence of life –limiting conditions in children by major diagnostic group, Wales 2000-2010

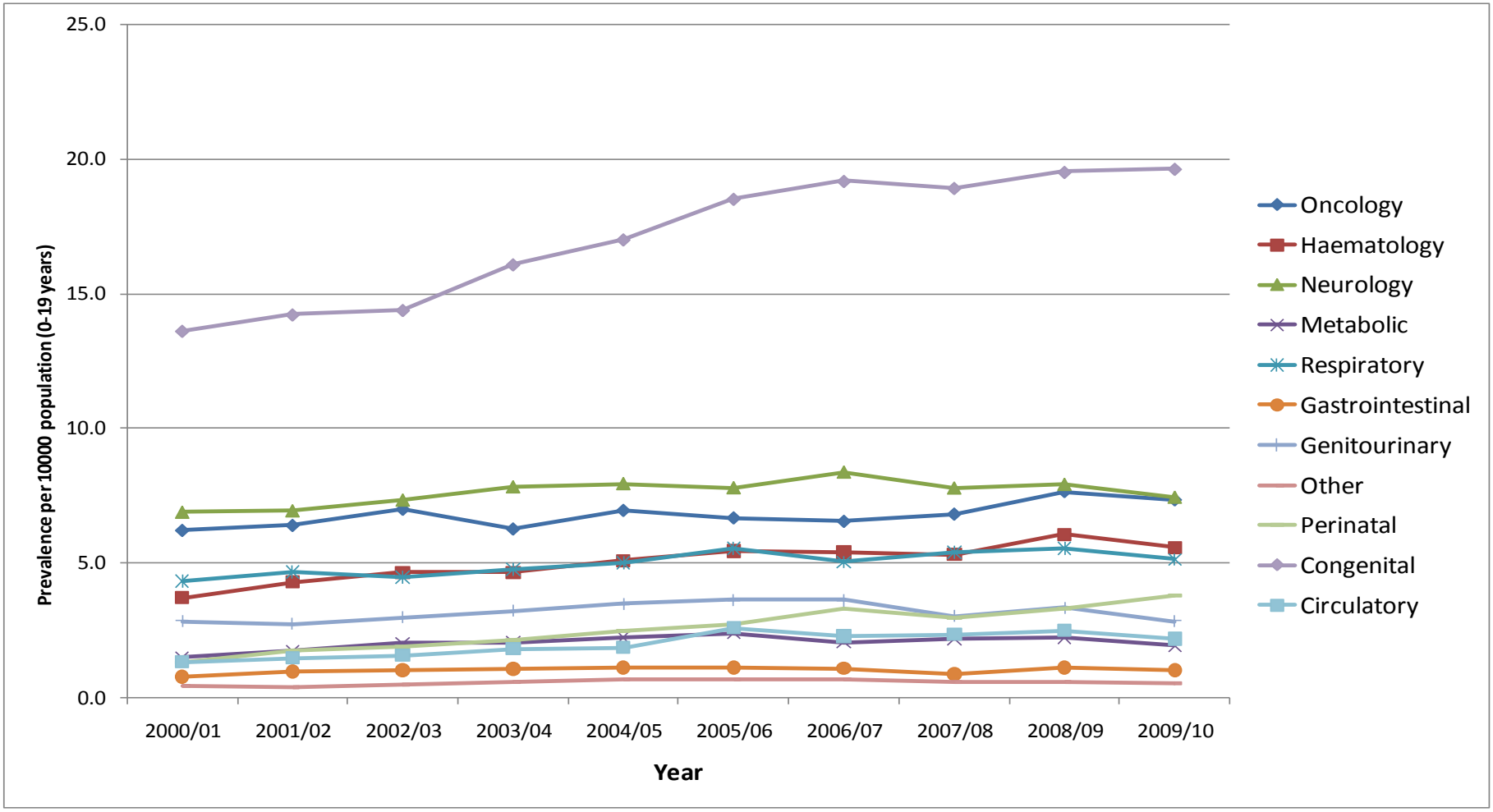
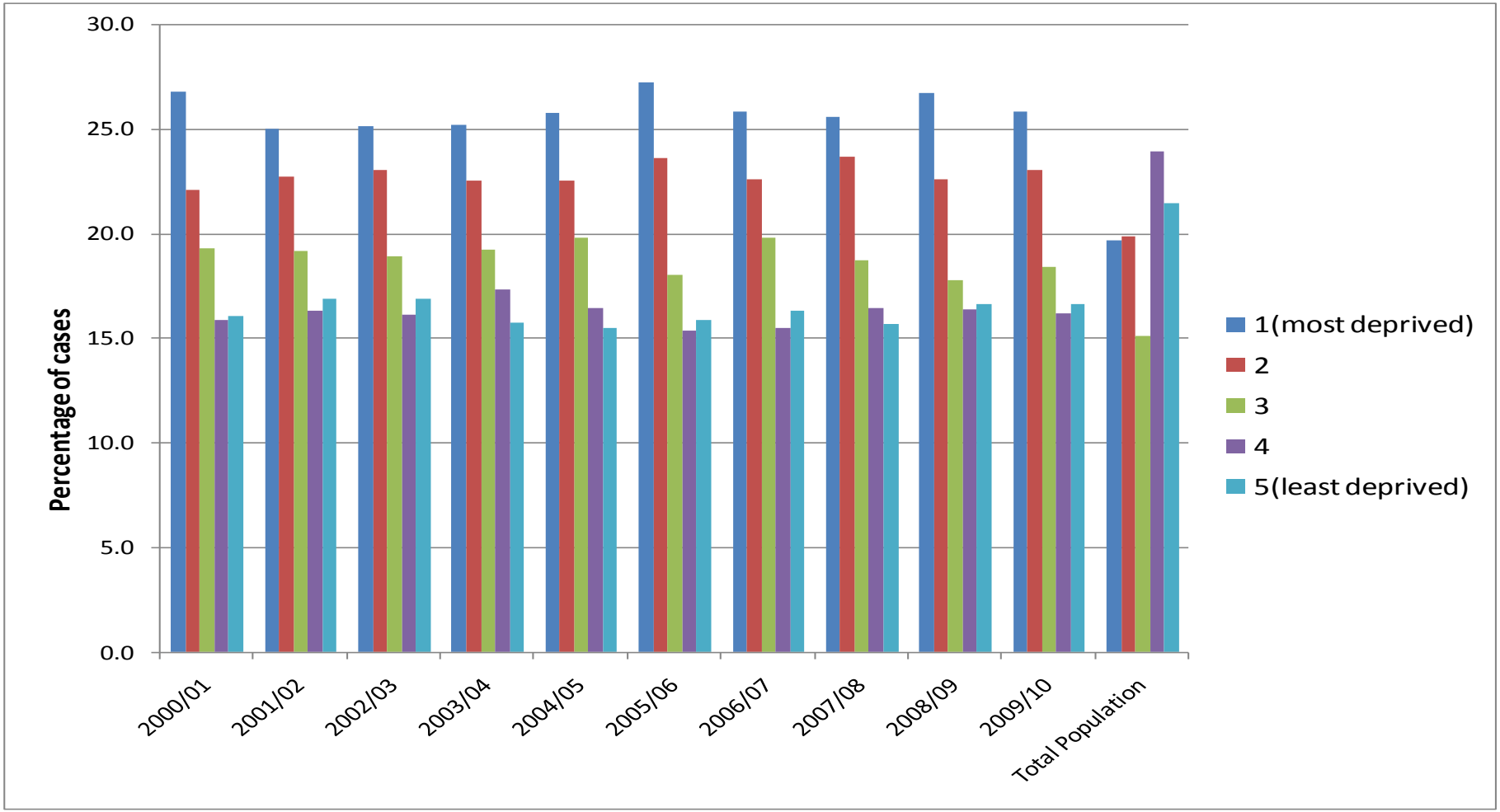


Figure 13 Prevalence of life –limiting conditions in children by deprivation category, Wales 2000-2010



5 Northern Ireland

5.1 Methods

5.1.1 Patient Data

An extract of the inpatient Hospital Inpatient Statistics (HIS)[13] was obtained from Hospital Information Branch of the Department of Health, Social Policy & safety for the 10 financial year period 2000/01 until 2009/10. The selection captured all episodes for all patients ever coded with one of the defined ICD10 codes and/or the ICD10 code for palliative care (used to capture children with no firm diagnosis). The extract excluded patients aged over 19 years at the start of an episode and those whose country of residence was outside Northern Ireland.

Age

The start age recorded at the first hospital episode in each year was used to assign the age category for each individual. Age was categorised into five groups: less than 1 year, 1 to 5 years, 6 to 10 years, 11 to 15 years and 16 to 19 years.

Gender

The data for each hospital episode included a code for gender. Gender was coded as male, female or not known. For individuals where more than one gender was recorded they were assigned the most commonly recorded gender.

Diagnoses

There are 7 diagnoses fields within the HIS dataset. The diagnoses were categorised into 11 groups based on the main ICD10 chapters: neurology, haematology, oncology, metabolic, respiratory, circulatory, gastrointestinal, genitourinary, perinatal, congenital and other. No attempt was made to prioritise multiple diagnoses for individuals therefore individuals may have more than one life-limiting diagnosis.

Ethnicity

Ethnicity is not recorded within the HIS dataset so no ethnic group analyses could be undertaken.

Deprivation

HIS were unable to release LSOA of residence (potentially identifiable) so the Northern Ireland Multiple Deprivation Measure 2010 (MDM) based on the 1990 ward of residence was used. This deprivation score could change over time due to house moves so the mean MDM score for each individual for each year was used. These scores were categorised into equal fifths based on the scores for the whole of Northern Ireland (20% of population in each fifth). The most deprived fifths is labelled 1 and the least deprived 5.

Geographical Variation

Due to the very small number of cases and small population no geographical analyses were undertaken.

5.1.2 Analyses

Prevalence per 10 000 population (aged 0-19 years) were calculated overall, for each year, for the age groups per year and the diagnostic groups per year.

5.2 Results

A total of more than 50000 finished consultant episodes for 7392 individuals were included in the final dataset.

Prevalence

Table 5 shows the crude number of patients and prevalence per 10 000 population by age group and the total. Overall prevalence has increased over time from 23.5 per 10 000 to 27.8 per 10 000 population (0-19 years) in the most recent year (2009/10) but there was year on year fluctuation.

The prevalence was highest in the under 1 age group and decreased through the age bands. The increase in prevalence over time was seen in almost all of the age groups but was most marked in the 16-19 years old where a 33.3% increase in prevalence over the 10 years, with no increase in the 11-15 year olds, 25.3% in the 6-10 year olds, 12.0% in the 1-5 year olds and 6.5% in the under 1 year olds.

The prevalence of life-limiting conditions in the male population was significantly higher than the female population in all years (Figure 14).

Diagnoses

There were 8110 life-limiting diagnoses in the 7392 individuals. Each year between 15.9-21.0% of children had more than one life-limiting diagnosis.

The percentages per diagnostic category (overall) were; Congenital anomalies (35.6%), oncology (14.4%), neurological (11.6%), respiratory (9.5%), perinatal (7.4%), genitourinary (4.9%), haematology (6.5%), circulatory (3.6%), metabolic (3.1%), gastrointestinal (2.9%) and the other group (0.5%).

The trends in prevalence shown in Figure 15 are per diagnosis, not per individual patient. The highest prevalence was of congenital anomalies with the lowest prevalence in circulatory and metabolic diagnoses. Congenital anomaly diagnoses, neurology and haematology diagnoses showed a rising prevalence over the time period.

Deprivation

The proportion of individuals in the highest deprivation category was significantly higher than the population overall. There were also higher than expected proportions of individuals in the least deprived category (5). There was some fluctuation over time but the most deprived category remained higher than expected (Figure 16).

Table 5 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in Northern Ireland

		Prevalence per 10000 population																	
Year	Number of Patients	Total	95%CI		Age <1 year	95%CI		Age 1-5 years	95%CI		Age 6-10 years	95%CI		Age 11-15 years	95%CI		Age 16-19 years	95%CI	
2000/01	1174	23.5	22.1	24.8	139.9	128.9	161.1	25.8	22.9	28.7	15.4	13.2	17.5	17.3	15.1	19.5	14.4	12.1	16.7
2001/02	1133	22.8	21.5	24.1	130.8	117.9	148.3	25.6	22.6	28.5	14.5	12.4	16.7	14.9	12.8	17.0	16.5	14.1	19.0
2002/03	1083	22.0	20.7	23.3	117.4	103.6	132.2	24.6	21.7	27.5	14.6	12.4	16.7	14.8	12.7	16.9	16.7	14.3	19.1
2003/04	1122	23.0	21.7	24.4	129.3	115.7	145.6	25.6	22.6	28.6	15.2	13.0	17.4	15.3	13.2	17.4	16.0	13.6	18.4
2004/05	1073	22.2	20.9	23.6	130.5	119.8	150.0	23.0	20.2	25.9	14.5	12.3	16.6	14.5	12.4	16.6	15.9	13.5	18.3
2005/06	1092	22.8	21.4	24.1	121.4	110.1	138.7	23.2	20.4	26.1	16.0	13.7	18.3	16.2	13.9	18.4	15.7	13.4	18.1
2006/07	1081	22.7	21.3	24.0	126.5	115.1	143.5	21.5	18.8	24.2	14.6	12.4	16.8	13.8	11.7	15.8	18.6	16.0	21.2
2007/08	1167	24.6	23.2	26.0	127.2	116.4	144.1	25.4	22.5	28.3	17.2	14.8	19.7	13.6	11.5	15.7	18.5	15.9	21.1
2008/09	1310	27.7	26.2	29.2	157.1	148.3	180.4	28.7	25.7	31.8	18.5	15.9	21.0	15.8	13.6	18.1	19.3	16.6	21.9
2009/10	1307	27.8	26.3	29.3	148.1	137.6	168.5	28.9	25.8	31.9	19.3	16.7	21.9	16.7	14.4	19.1	19.2	16.4	21.9

Figure 14 Prevalence of life –limiting conditions in children by gender, Northern Ireland 2000-2010

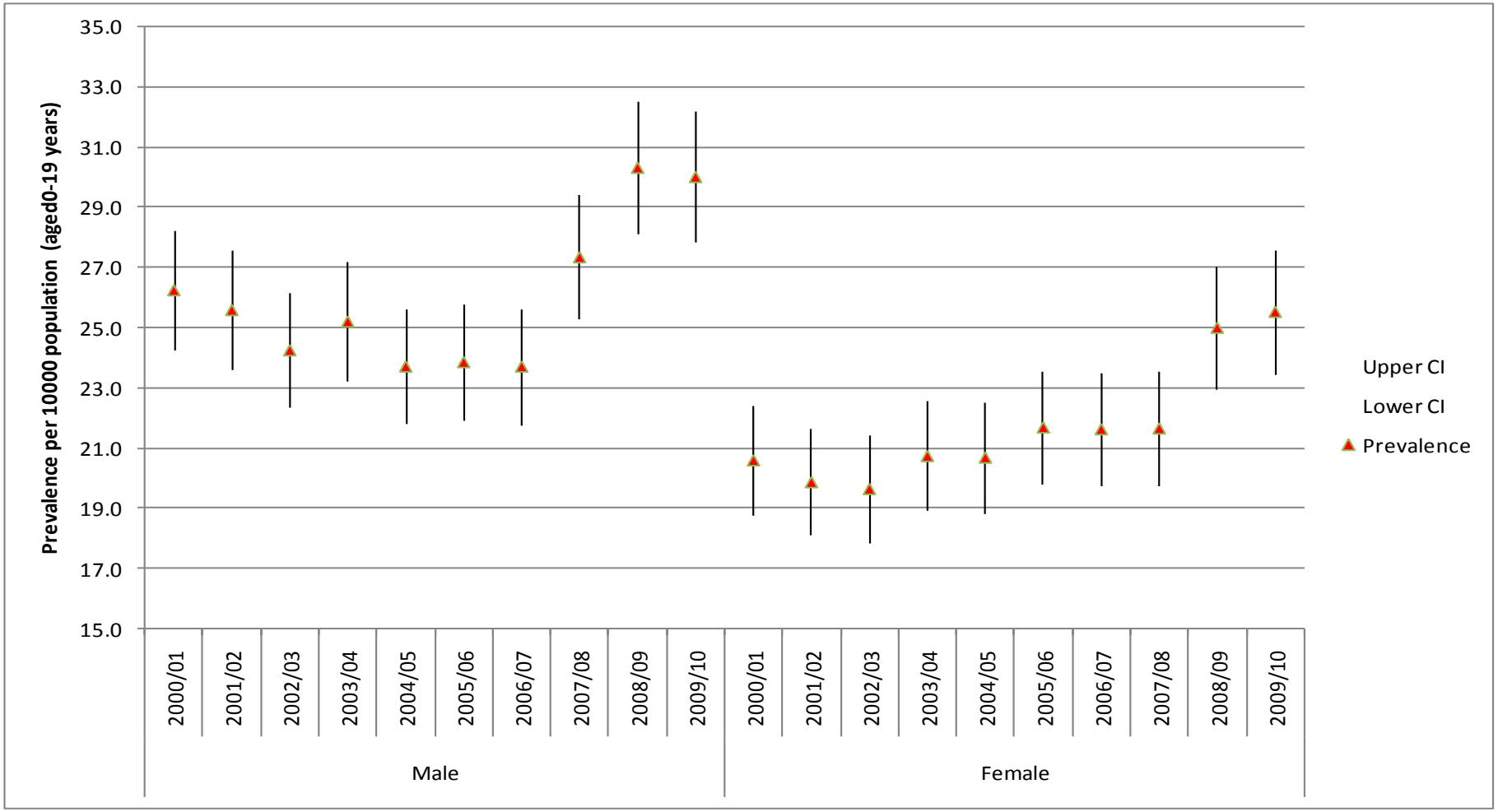


Figure 15 Prevalence of life –limiting conditions in children by major diagnostic group, Northern Ireland 2000-2010

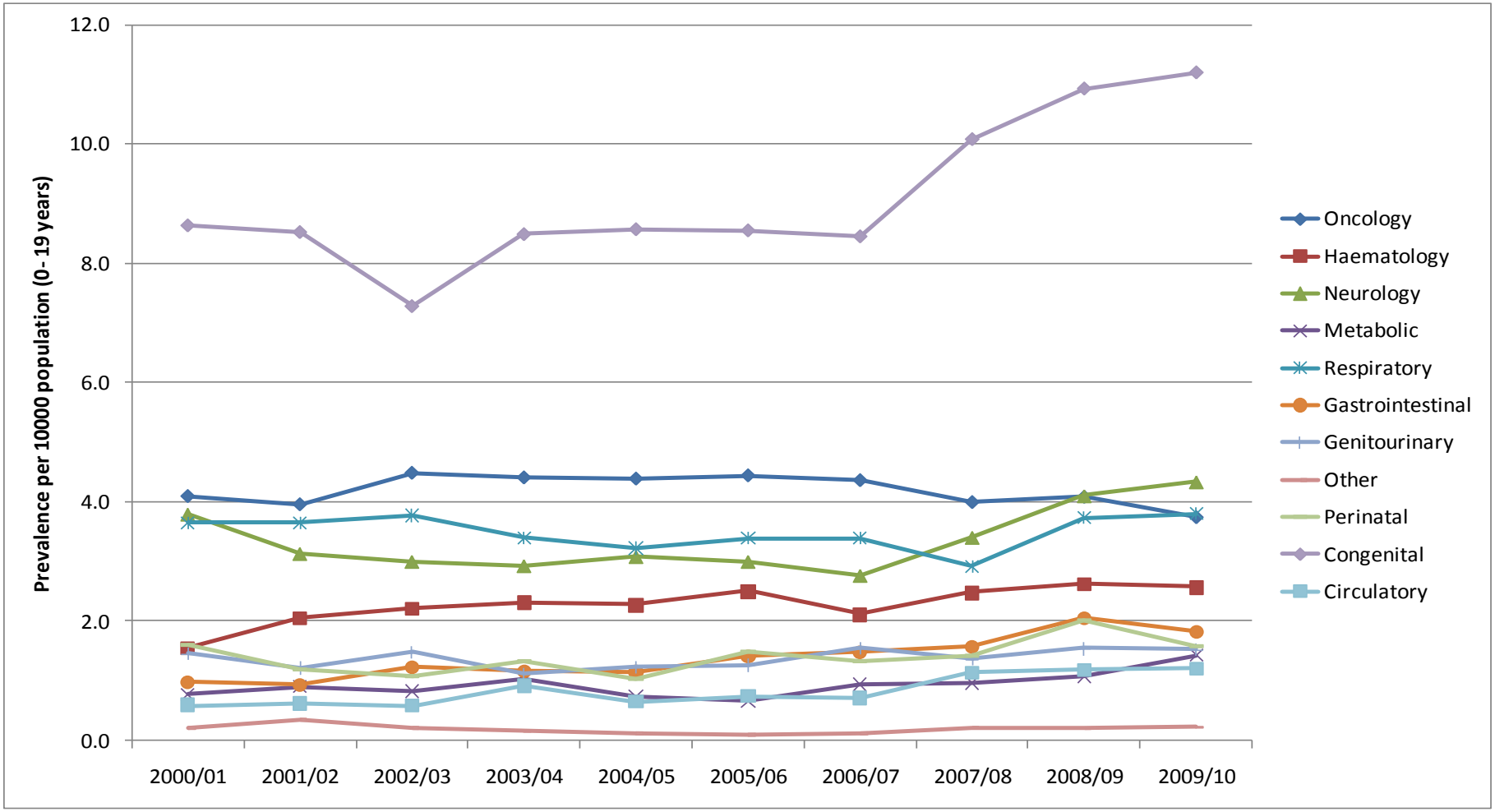
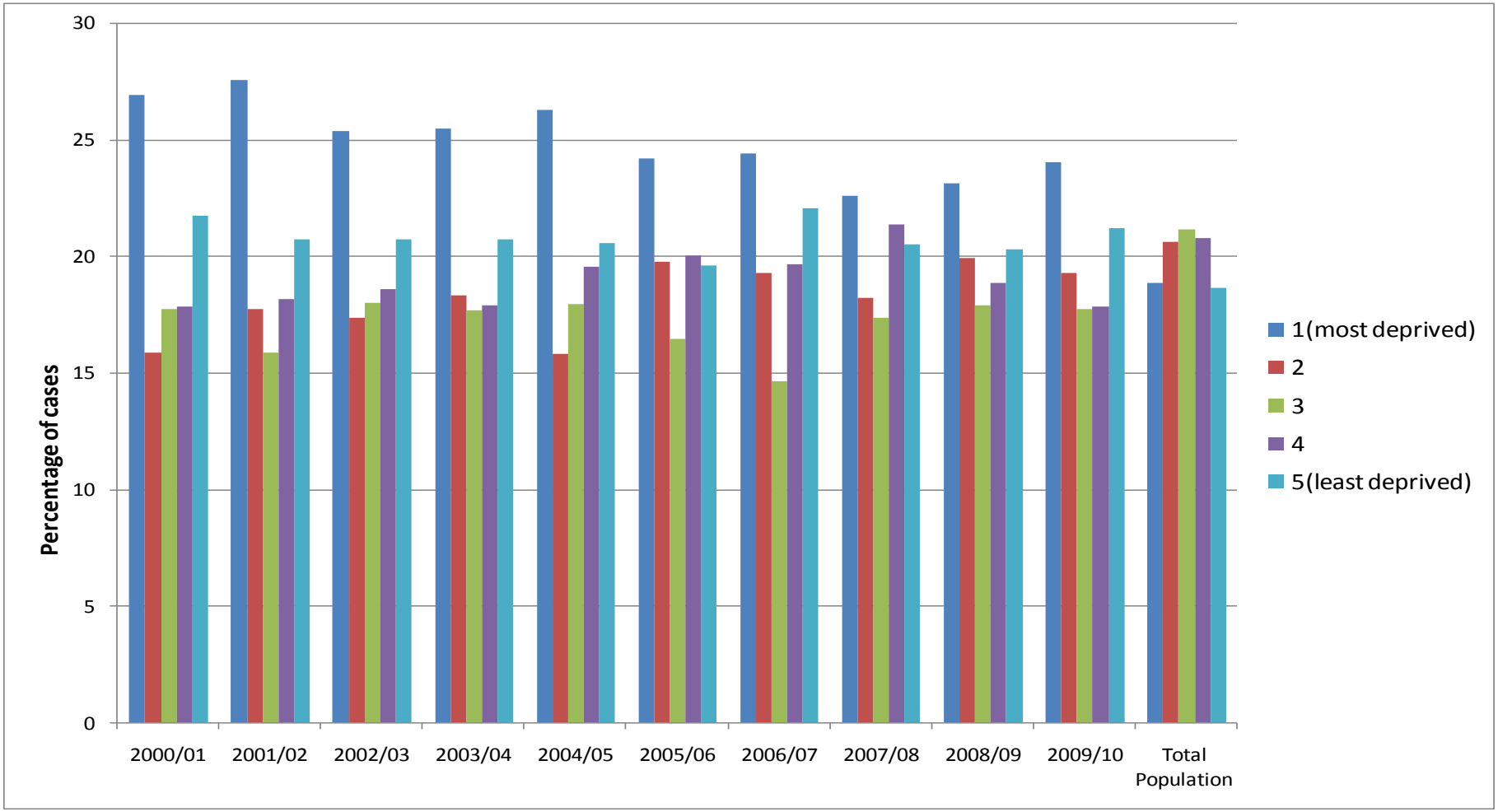


Figure 16 Prevalence of life –limiting conditions in children by deprivation category, Northern Ireland 2000-2010



6 Country Comparisons

The hospital admissions records used for this study are collected and recorded differently for each of the four countries. Direct comparison of figures from each country is not valid due to these differences. However the trends in overall prevalence, prevalence by age, sex and diagnostic groups showed similar results in all four countries.

7 Strengths/Limitations

This study used extremely large routinely collected datasets and robust methodology. The ICD10 coding framework was developed by using more than one data source. There is scope to utilise this coding framework with data from other countries in order to compare and contrast with the UK and also to help service provision.

The prevalence estimates are dependent on the correct identification of individuals with LLC. Some children may not have had an inpatient hospital admission during the study period but in this case we would have underestimated prevalence.

8 Conclusions

1. The prevalence of Life-limiting conditions in children and young people was more than double previous prevalence estimates in England. Figures for Scotland, Wales and Northern Ireland also confirmed higher prevalence.
2. The prevalence of Life-limiting conditions in children and young people was highest in the under 1 age group and this prevalence decreased with age. This was consistent in all countries.
3. The prevalence of Life-limiting conditions in children and young people was significantly higher in the male population compared to the female population. This was consistent in all countries.
4. Congenital anomalies constituted the largest diagnostic subgroup within the Life-limiting conditions in children and young people. This was consistent in all countries.
5. Prevalence of Life-limiting conditions in children and young people was associated with deprivation with the highest prevalence in areas of highest deprivation but this association was not linear with the least deprived areas having higher prevalence than the second least deprived category.
6. The prevalence of Life-limiting conditions in children and young people was significantly higher in the South Asian, Black and other ethnic minority groups compared with the white population. This higher prevalence in these ethnic groups was not accounted for by differences in deprivation status.
7. These results clearly identify an escalating need for specialist paediatric palliative care services. When planning services for these increasing needs, the excess prevalence in ethnic minority groups especially in deprived areas needs to be considered.
8. The ICD 10 coding framework could be used to interrogate other national datasets.

9 References

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10 Research Output

- Poster Presentation at the World Congress of Epidemiology in Edinburgh, August 2011. *Fraser L, Miller M, Hain R, Aldridge J, McKinney P, Parslow R Life-limiting & life-threatening illness in children and young people in England: hospital usage by ethnicity. Journal of Epidemiology and Community Health 65: a109-a109. Aug 2011*
- Academic Paper describing the English data submitted for publication in a peer review journal.

  Fraser L, Miller M, Hain R, Norman P Aldridge J, McKinney P, Parslow R Rising Prevalence of Life limiting conditions in children in England. PEDIATRICS.
- Abstract accepted for an oral presentation at the Palliative Care Congress in Newcastle, March 2012.

  Fraser L, Miller M, Hain R, Norman P Aldridge J, McKinney P, Parslow R Prevalence of Life limiting conditions in children in the United Kingdom

11 Financial Summary

Salary Costs	£16270
Subcontract University of Leeds	£8730
Total Expenditure	**£25000**
Total Grant	£25000
Surplus	£0

APPENDIX A

12

13 ICD10 FILTER CODES to IDENTIFY LIFELIMITING DIAGNOSES IN CHILDREN & YOUNG PEOPLE

A	B	C	D	E	F	G	G	H	I	J
A17	B20-	C00-	D33	E31.0	F80.3	G10	G82.3	H11.1	I21	J84.1
A81.0	B24	C97	D43	E34.8	F84.2	G11.1	G82.4	H49.8	I27.0	J96
A81.1			D44.4	E70.2		G11.3	G82.5	H35.5	I42	J98.4
			D48	E71		G12	G93.4		I61.3	
			D56.1	E72		G20	G93.6		I81	
			D61.0	E74		G23.0	G93.7			
			D61.9	E75		G23.8				
			D70	E76		G31.8				
			D76.1	E77		G31.9				
			D81	E79.1		G35				
			D82.1	E83.0		G40.4				
			D83	E84		G40.5				
			D89.1	E88.0		G60.0				
				E88.1		G60.1				
						G70.2				
						G70.9				
						G71.0				
						G71.1				
						G71.2				
						G71.3				
						G80.0				
						G80.8				
K	**L**	**N**	**P**	**Q**	**Q**	**Q**	**Q**	**Q**	**T**	**Z**
K55.0	M31.3	N17	P10.1	Q00.0	Q21.8	Q39.6	Q78.0	Q93.2	T86.0	Z51.5
K55.9	M32.1	N18	P11.2	Q01	Q22.0	Q41.0	Q78.5	Q93.3	T86.2	
K72	M89.5	N19	P21.0	Q03.1	Q22.1	Q41.9	Q79.2	Q93.4		
K74		N25.8	P28.5	Q03.9	Q22.4	Q43.7	Q79.3	Q93.5		
K76.5			P29.0	Q04.0	Q22.5	Q44.2	Q80.4	Q93.8		
K86.8			P29.3	Q04.2	Q22.6	Q74.8	Q81	Q95.2		
			P35.0	Q04.3	Q23.0	Q44.5	Q82.1			
			P35.1	Q04.4	Q23.4	Q44.7	Q82.4			
			P35.8	Q04.6	Q23.9	Q60.1	Q85.8			
			P37.1	Q04.9	Q25.4	Q60.6	Q86.0			
			P52.4	Q07.0	Q25.6	Q61.4	Q87.0			
			P52.5	Q20.0	Q26.2	Q61.9	Q87.1			
			P52.9	Q20.3	Q26.4	Q64.2	Q87.2			
			P83.2	Q20.4	Q26.8	Q74.3	Q87.8			
			P91.2	Q20.6	Q28.2	Q75.0	Q91			
			P91.6	Q20.8	Q32.1	Q77.2	Q92.0			
			P96.0	Q21.3	Q33.6	Q77.3	Q92.1			
				Q23.2		Q77.4	Q92.4			
							Q92.7			
							Q92.8			

APPENDIX B

14 Government Office Region Summaries

14.1 North East

Table 6 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 17 and Figure 18.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 19 and Figure 20.

Prevalence per Local authority district for 2009/10 is shown in Figure 21 and Table 7.

Table 6 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the North East Government Office Region , 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	Total	95%CI		Age<1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	1560	24.7	23.4	25.9	112.1	99.3	125.0	31.2	28.3	34.1	20.5	18.3	22.7	16.5	14.6	18.4	16.0	13.8	18.2
2001/02	1727	27.4	26.1	28.7	116.6	103.9	129.3	35.2	32.1	38.3	23.1	20.8	25.5	18.7	16.6	20.7	17.0	14.8	19.2
2002/03	1697	27.0	25.7	28.3	115.5	103.0	127.9	33.6	30.6	36.7	21.8	19.4	24.1	20.0	17.9	22.2	16.6	14.4	18.8
2003/04	1710	27.3	26.0	28.6	103.5	91.9	115.1	33.7	30.6	36.7	22.1	19.7	24.4	21.7	19.5	23.9	17.3	15.1	19.5
2004/05	1800	28.8	27.5	30.2	115.0	103.1	126.9	33.9	30.8	36.9	24.0	21.5	26.5	20.8	18.6	23.0	19.4	17.1	21.7
2005/06	1842	29.6	28.2	30.9	116.3	104.5	128.1	33.7	30.7	36.7	24.8	22.2	27.3	22.0	19.8	24.3	19.5	17.2	21.9
2006/07	1935	31.1	29.7	32.5	128.1	115.9	140.3	35.1	32.1	38.1	24.3	21.7	26.8	21.8	19.6	24.1	21.8	19.3	24.2
2007/08	2012	32.3	30.9	33.7	119.1	107.6	130.7	37.5	34.5	40.6	28.2	25.4	31.0	20.9	18.7	23.2	22.3	19.8	24.7
2008/09	2071	33.3	31.9	34.8	130.5	118.1	142.9	37.6	34.5	40.6	25.7	23.0	28.3	24.2	21.8	26.7	23.7	21.1	26.3
2009/10	2053	33.1	31.7	34.5	115.9	104.2	127.6	38.7	35.7	41.7	24.8	22.2	27.3	25.7	23.1	28.2	23.6	21.0	26.2

*95% Confidence intervals

Figure 17 Prevalence of Life-limiting conditions in children by Gender, North East Government Office Region 2000-2010

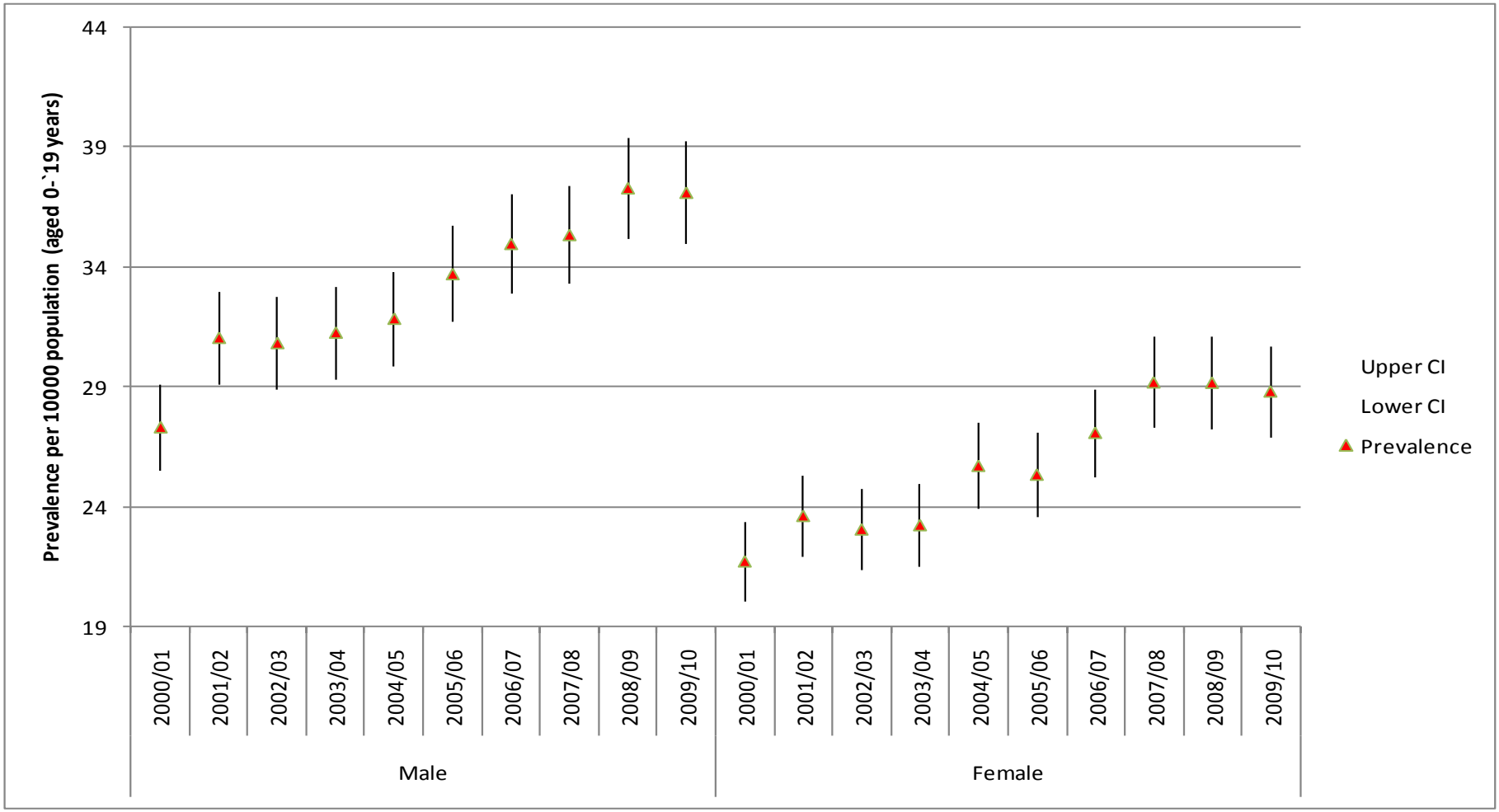

Figure 18 Prevalence of Life-limiting conditions in children by Major Diagnostic Group, North East Government Office Region 2000-2010

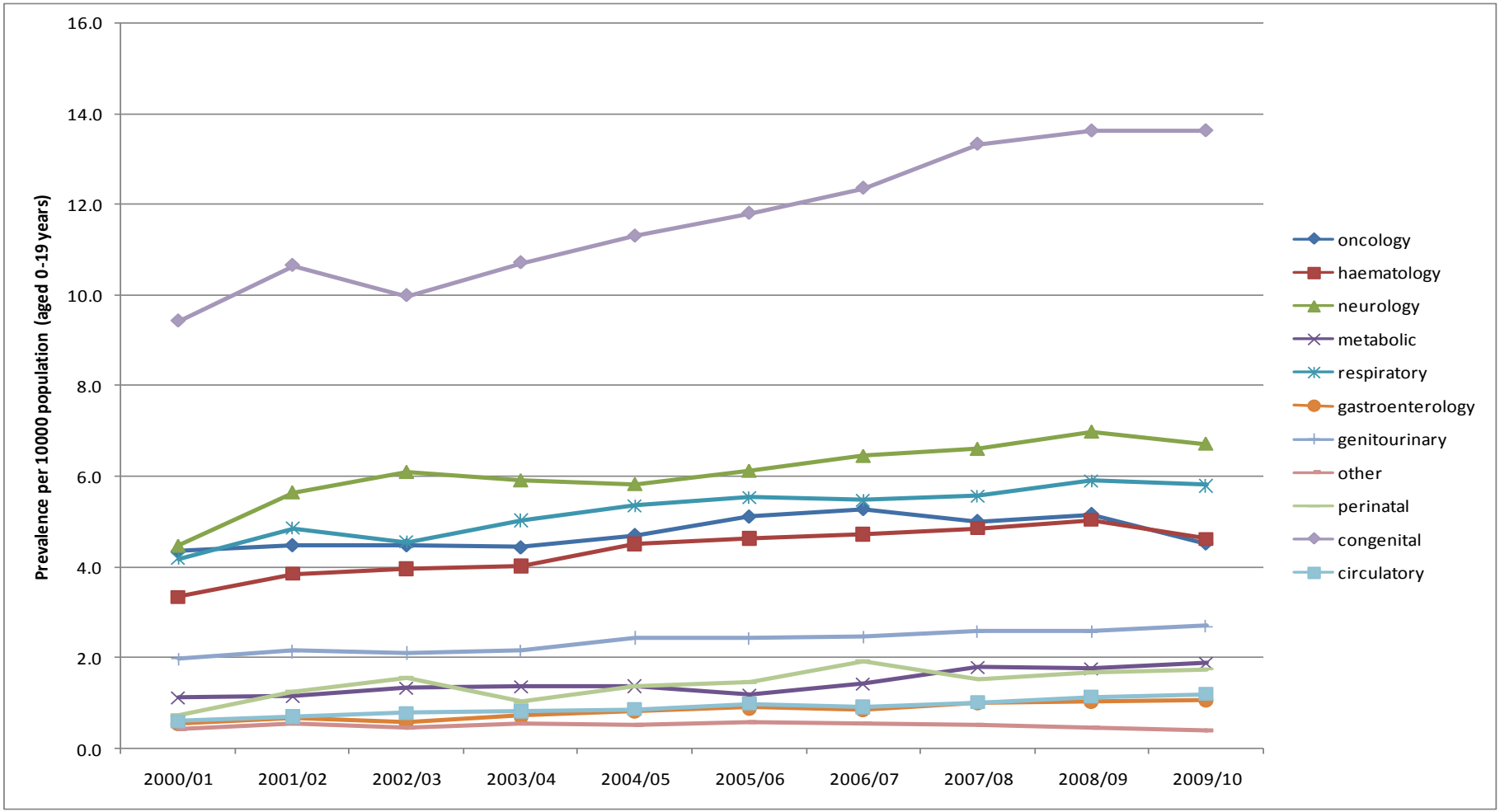

Figure 19 Prevalence of Life-limiting conditions in children by Deprivation category, North East Government Office Region 2009/2010

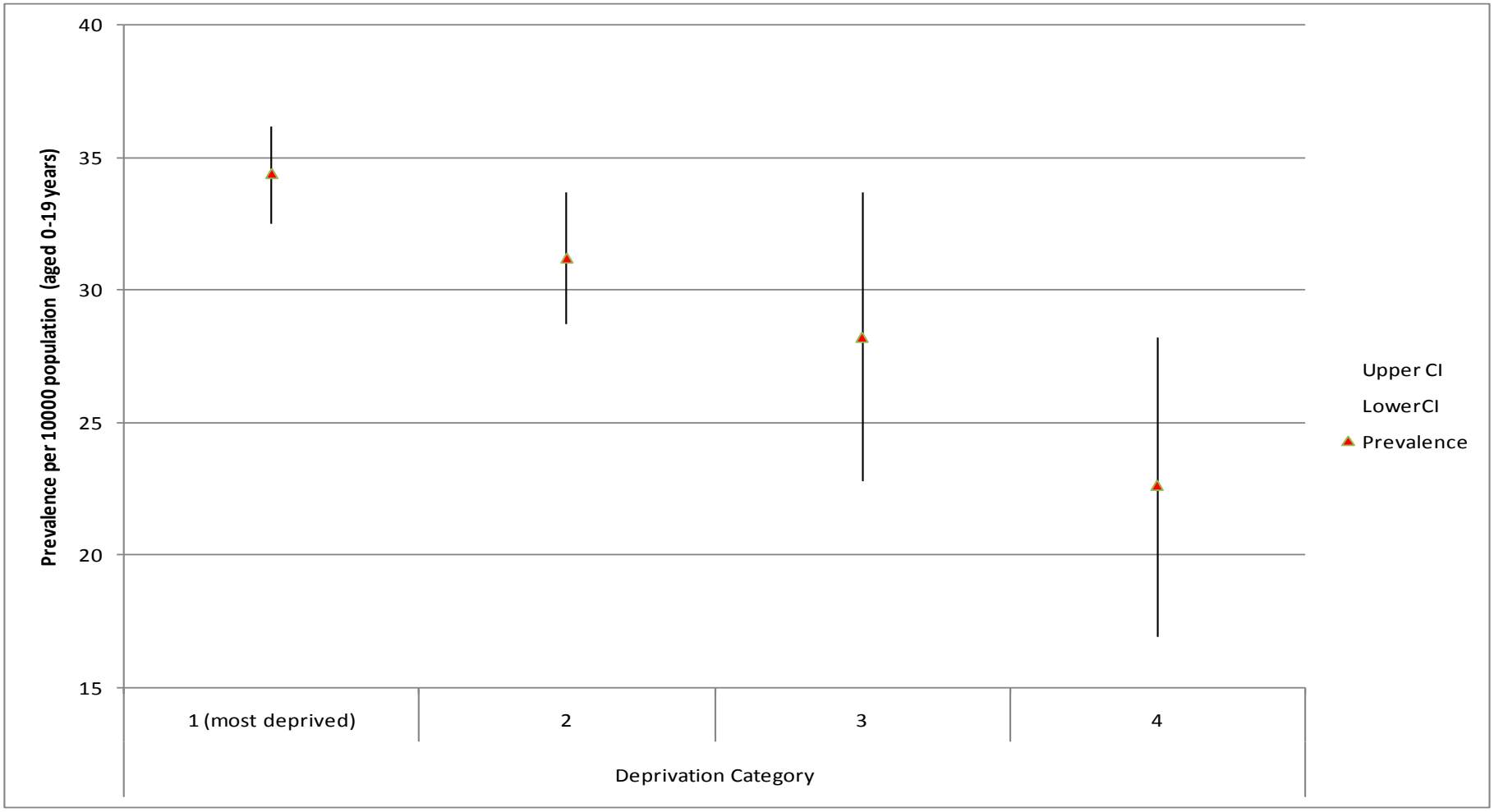

Figure 20 Prevalence of Life-limiting conditions in children by Ethnic group, North East Government Office Region 2009/2010

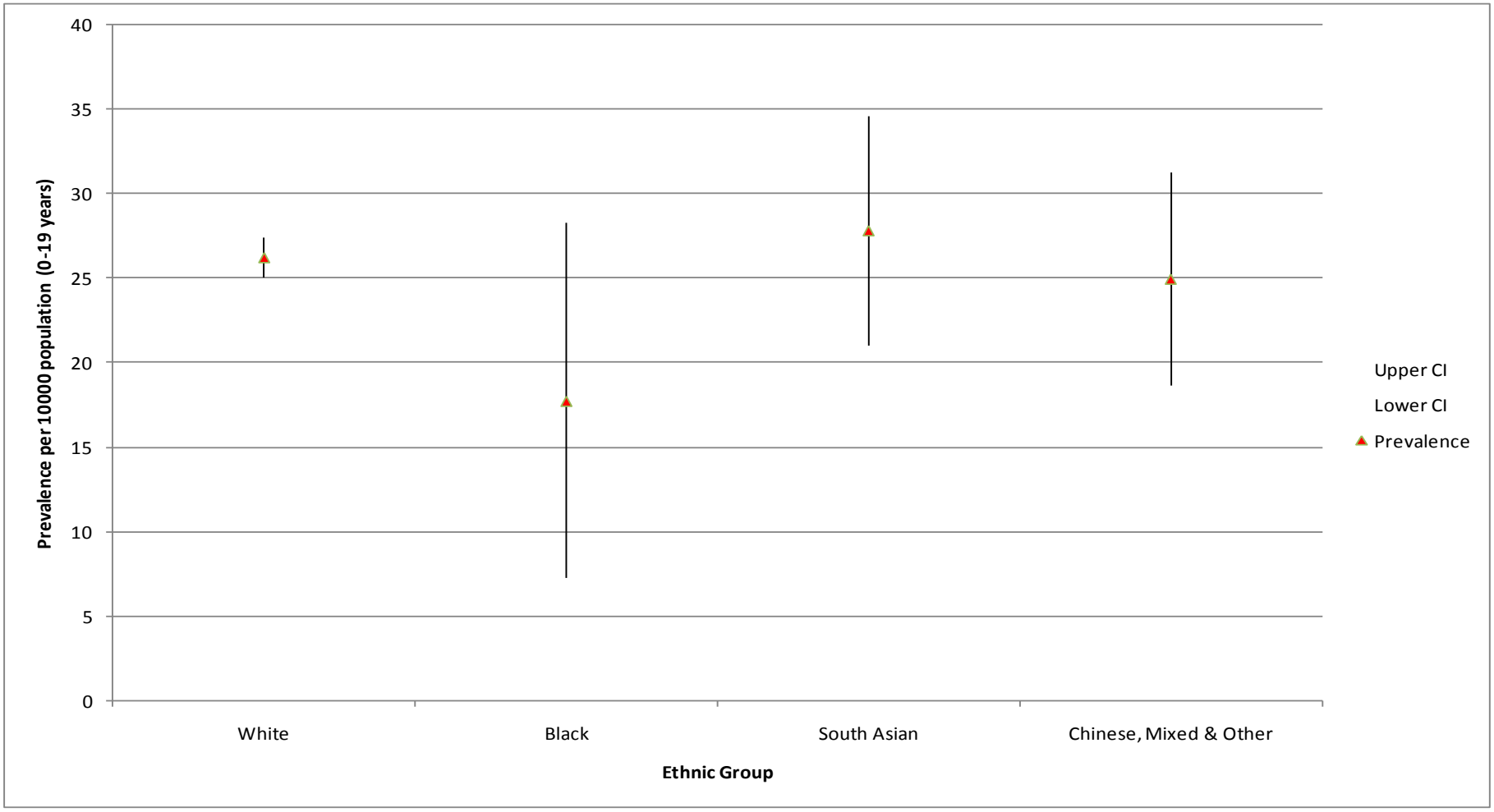

Figure 21 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, North East GOR 2009/10

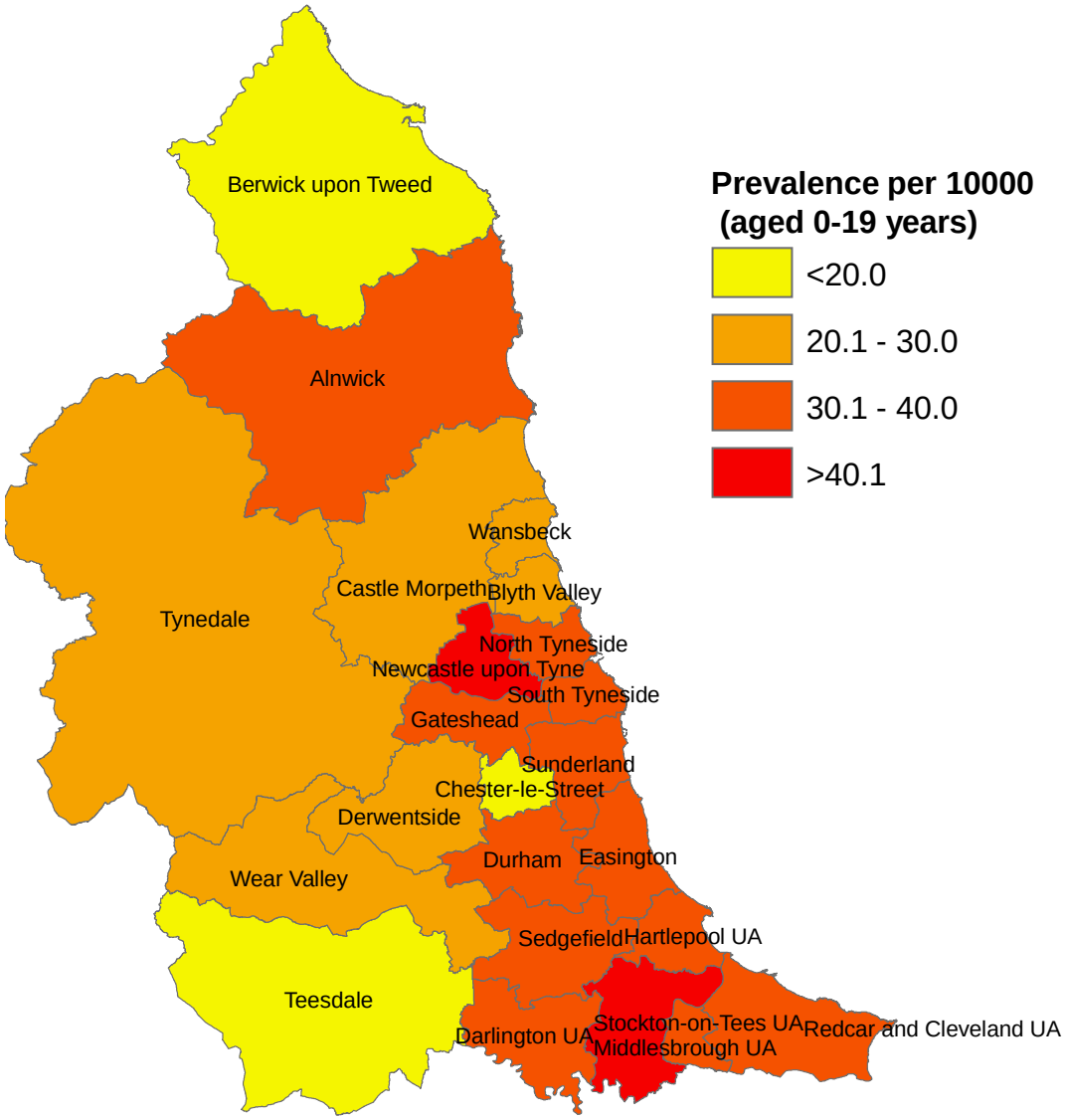

Table 7 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Alnwick	28	8892	31.5
Berwick-upon-Tweed	13	7272	17.9
Blyth Valley	50	20729	24.1
Castle Morpeth	25	11839	21.1
Chester-le-Street	41	24586	16.7
Darlington	82	24989	32.8
Derwentside	63	21840	28.8
Durham	64	20155	31.8
Easington	75	23726	31.6
Gateshead	169	44420	38.0
Hartlepool	72	23756	30.3
Middlesbrough	121	33950	35.6
Newcastle upon Tyne	247	61004	40.5
North Tyneside	145	46005	31.5
Redcar and Cleveland	123	32595	37.7
Sedgefield	75	22286	33.7
South Tyneside	117	35838	32.6
Stockton-on-Tees	205	46461	44.1
Sunderland	202	64889	31.1
Teesdale	12	7781	15.4
Tynedale	37	15179	24.4
Wansbeck	43	17296	24.9
Wear Valley	45	15240	29.5

14.2 North West

Table 8 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 22 and Figure 23.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 24 and Figure 25.

Prevalence per Local authority district for 2009/10 is shown in Figure 26 and Table 9.

Table 8 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the North West Government Office Region , 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	Total	95%CI		Age <1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age 11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	4,597	26.4	25.6	27.2	140.3	131.9	148.8	31.0	29.3	32.8	19.9	18.6	21.2	18.0	16.8	19.2	16.3	15.0	17.6
2001/02	4,560	26.3	25.5	27.0	123.1	115.3	131.0	32.3	30.6	34.1	19.9	18.6	21.3	18.6	17.4	19.9	16.5	15.2	17.9
2002/03	4,709	27.2	26.5	28.0	117.9	110.3	125.5	34.5	32.7	36.4	20.8	19.4	22.2	20.1	18.8	21.4	16.9	15.5	18.2
2003/04	4,814	28.0	27.2	28.8	117.1	109.7	124.5	35.0	33.2	36.9	21.9	20.5	23.3	20.0	18.7	21.3	18.2	16.8	19.5
2004/05	4,756	27.8	27.1	28.6	112.4	105.3	119.5	32.5	30.7	34.3	22.2	20.7	23.6	20.4	19.1	21.7	19.2	17.8	20.6
2005/06	5,010	29.5	28.7	30.3	116.3	109.1	123.5	35.4	33.5	37.3	23.1	21.6	24.6	21.5	20.2	22.9	19.6	18.2	21.0
2006/07	5,329	31.5	30.6	32.3	130.5	123.0	137.9	35.5	33.6	37.3	24.5	23.0	26.1	22.8	21.4	24.2	21.2	19.7	22.6
2007/08	5,449	32.3	31.4	33.1	119.7	112.7	126.8	36.7	34.8	38.5	26.0	24.4	27.6	23.5	22.1	25.0	22.3	20.8	23.8
2008/09	5,544	33.0	32.2	33.9	116.3	109.2	123.5	38.3	36.5	40.2	26.2	24.6	27.8	24.9	23.4	26.4	23.6	22.1	25.2
2009/10	5,554	33.3	32.4	34.2	126.3	118.9	133.8	37.1	35.3	38.9	25.6	24.0	27.2	24.6	23.1	26.1	24.3	22.7	25.9

Figure 22 Prevalence of Life-limiting conditions in children by Gender, North West Government Office Region 2000-2010

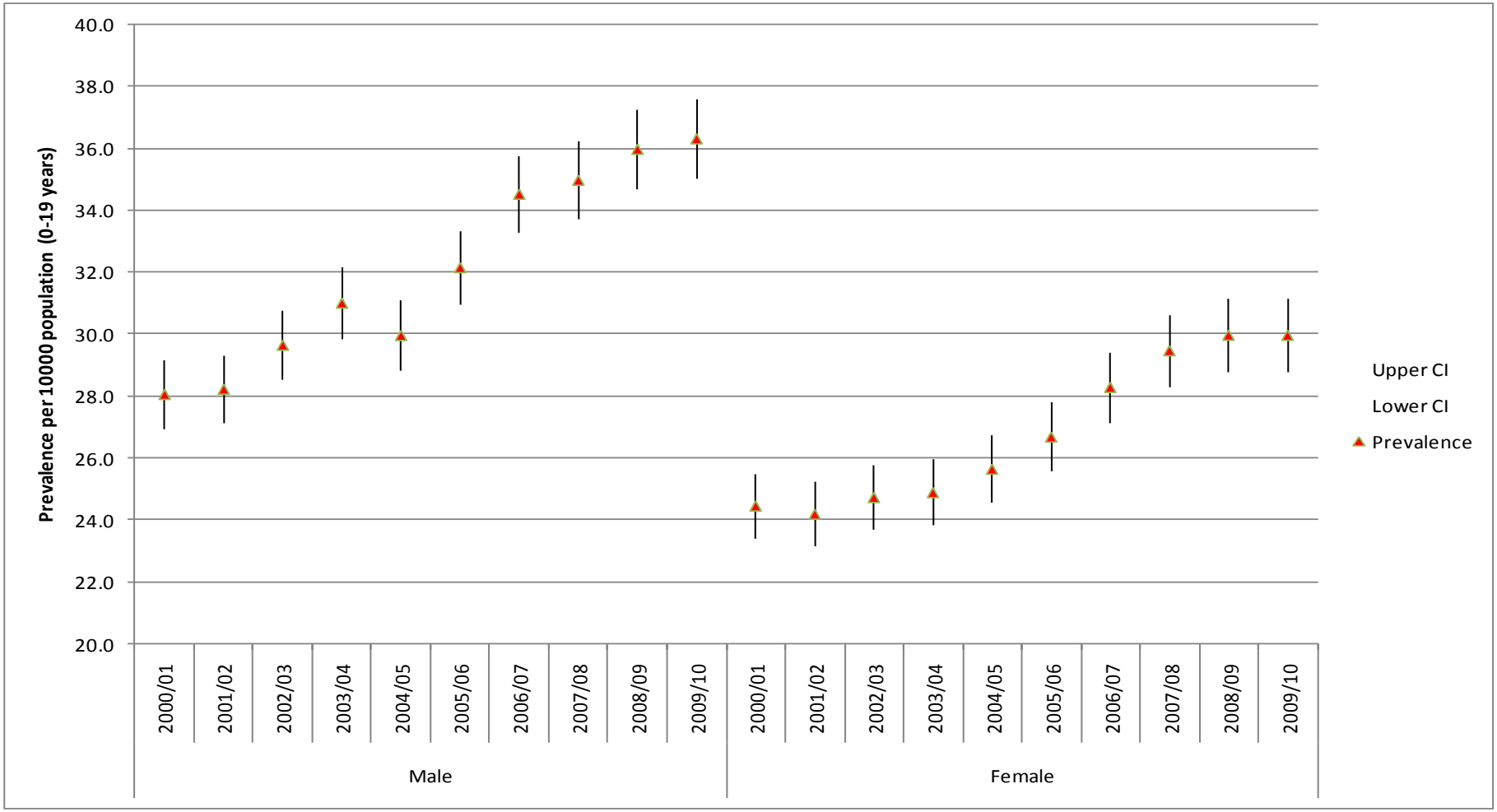

Figure 23 Prevalence of Life-limiting conditions in children by Major diagnostic group, North West Government Office Region 2000-2010

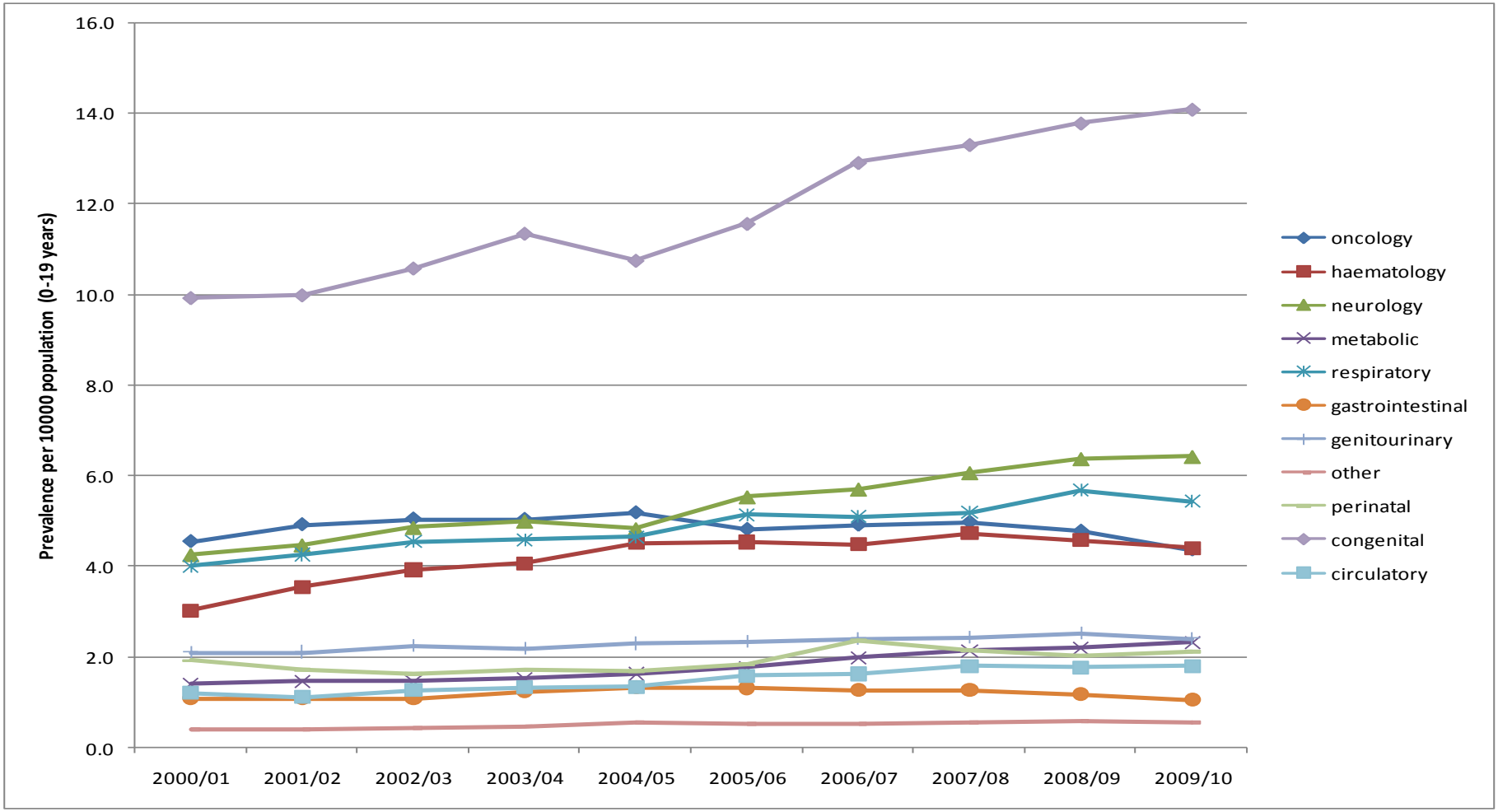

Figure 24 Prevalence of Life-limiting conditions in children by Deprivation Category, North West Government Office Region 2009/10

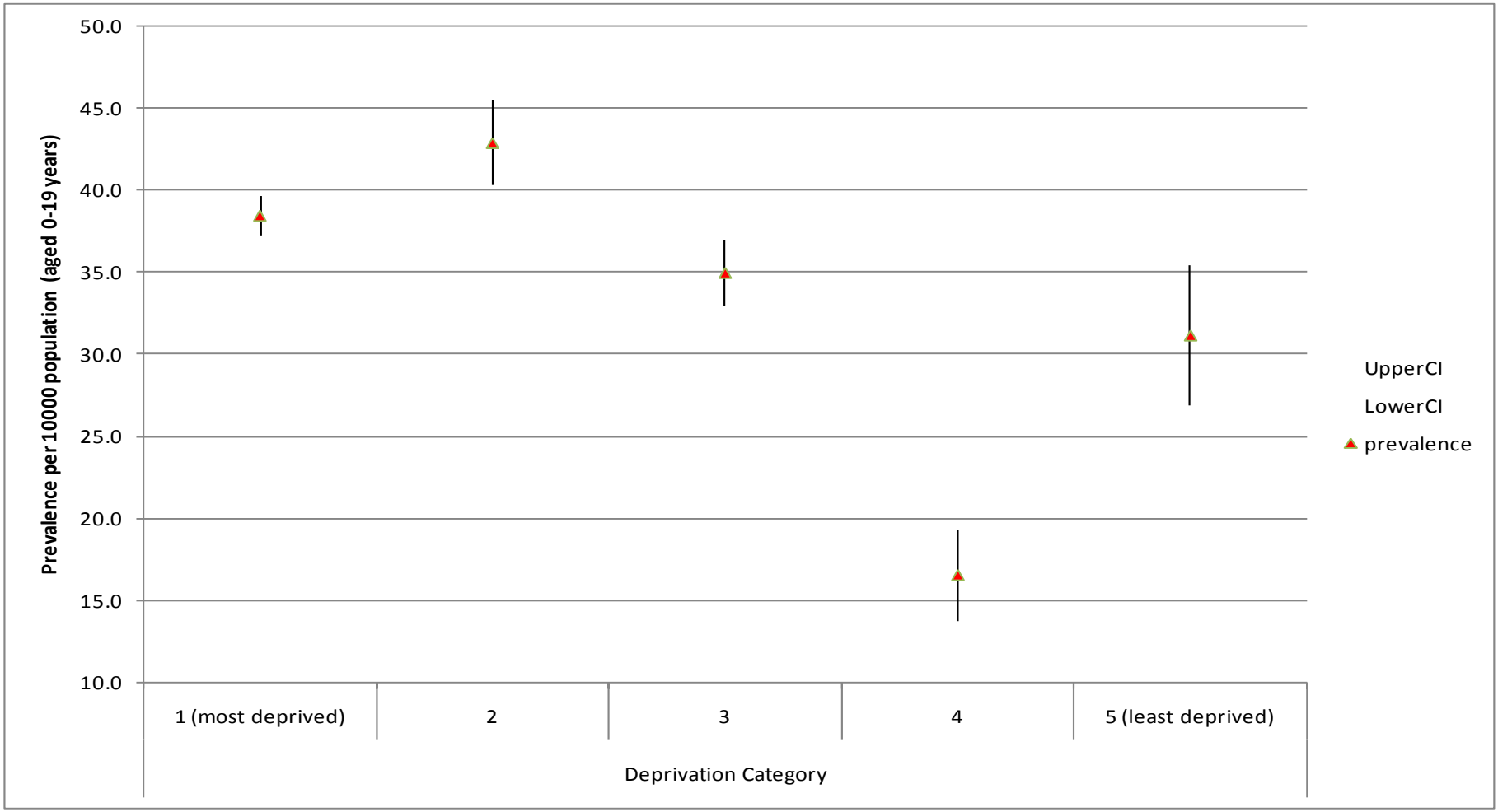

Figure 25 Prevalence of Life-limiting conditions in children by Ethnic Group, North West Government Office Region 2009/10

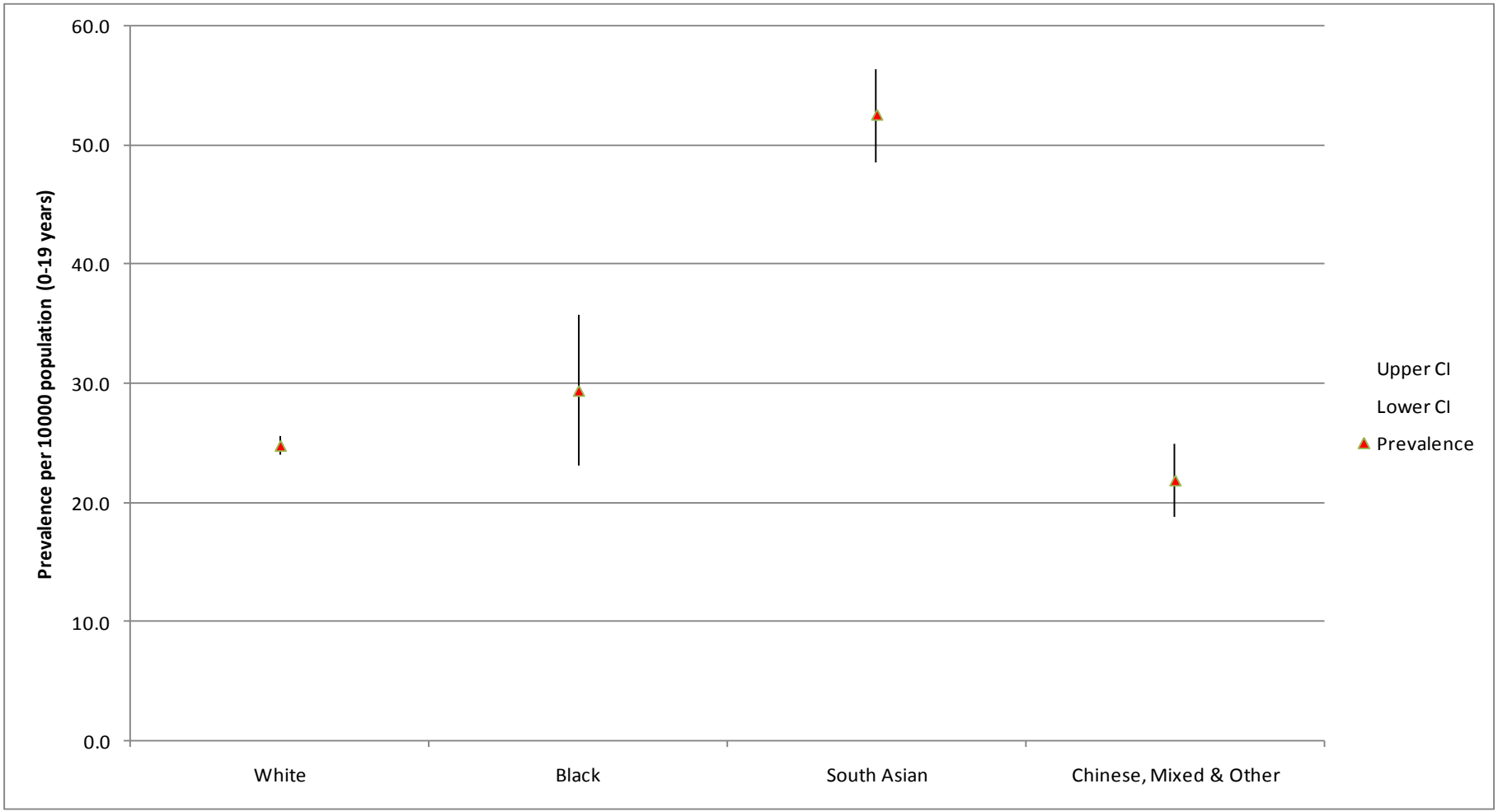

Figure 26 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, North West GOR 2009/10

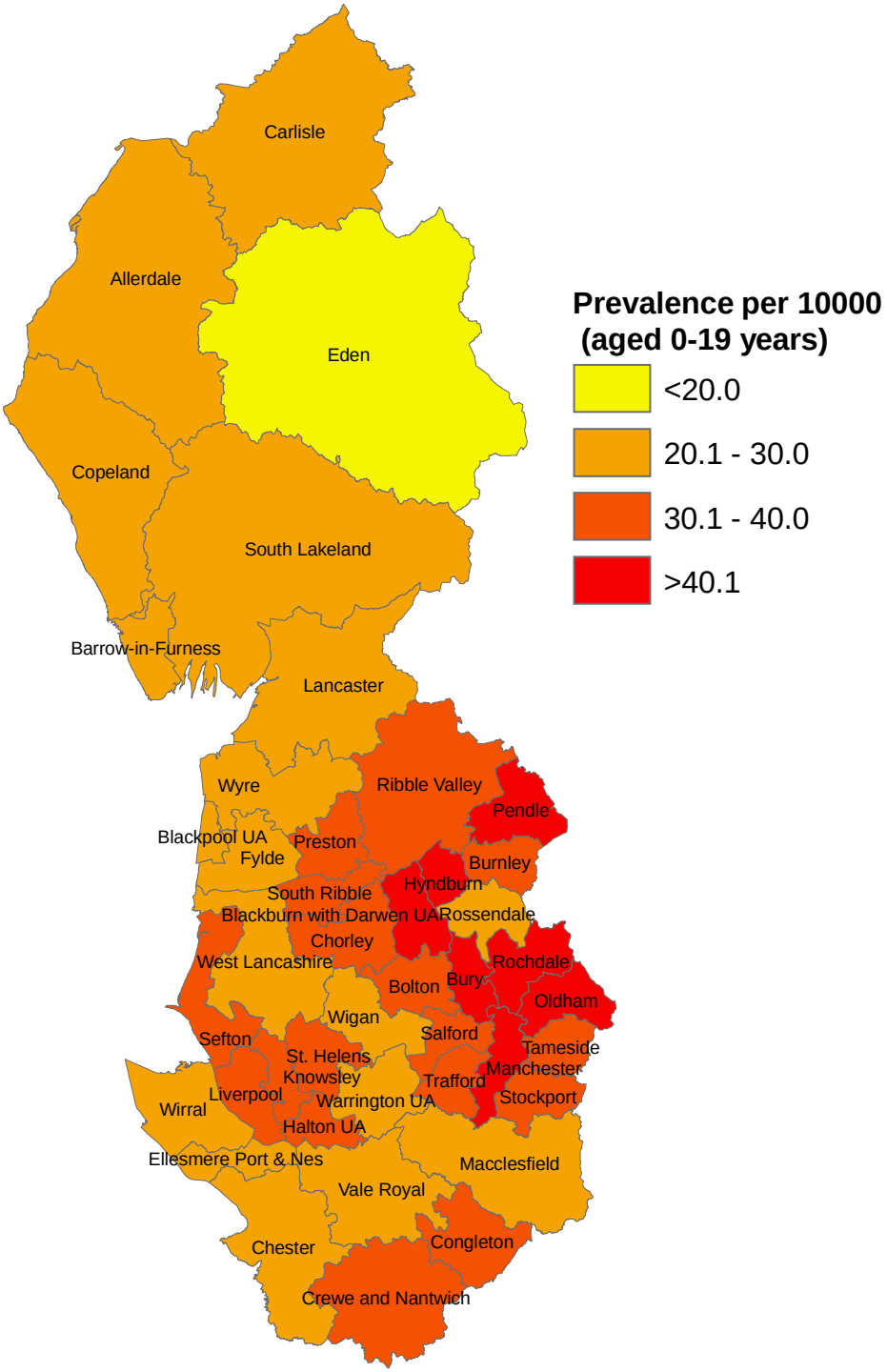

Table 9 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Allerdale	58	21733	26.7
Barrow-in-Furness	46	18633	24.7
Blackburn with Darwen	183	41403	44.2
Blackpool	89	34113	26.1
Bolton	251	68673	36.5
Burnley	84	22863	36.7
Bury	182	44076	41.3
Carlisle	65	24445	26.6
Chester	59	25845	22.8
Chorley	78	25050	31.1
Congleton	63	20882	30.2
Copeland	36	17311	20.8
Crewe and Nantwich	92	30021	30.6
Eden	22	13333	16.5
Ellesmere Port & Neston	51	19321	26.4
Fylde	42	17880	23.5
Halton	110	28292	38.9
Hyndburn	102	22029	46.3
Knowsley	129	38794	33.3
Lancaster	95	32356	29.4
Liverpool	391	103706	37.7
Macclesfield	93	31332	29.7
Manchester	458	113922	40.2
Oldham	240	59860	40.1
Pendle	125	25067	49.9
Preston	125	35007	35.7
Ribble Valley	42	13745	30.6
Rochdale	228	55958	40.7
Rossendale	46	17153	26.8
Salford	196	54804	35.8
Sefton	206	60176	34.2
South Lakeland	49	22878	21.4
South Ribble	79	25203	31.3
St. Helens	146	41004	35.6
Stockport	211	62667	33.7
Tameside	176	53624	32.8
Trafford	191	49002	39.0
Vale of White Horse	72	31450	22.9
Warrington	136	46526	29.2
West Lancashire	69	27061	25.5
Wigan	181	73994	24.5
Wirral	190	72270	26.3
Wyre	61	25086	24.3

14.3 Yorkshire & Humber

Table 10 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 27 and Figure 28.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 29 and Figure 30.

Prevalence per Local authority district for 2009/10 is shown in Figure 31 and Table 11.

Table 10 Number and prevalence (per 10000 population) of patients aged 0-19 years with life limiting conditions by year and age group

		Prevalence per 10000 population																	
Year	Number	Total	95%CI		<1 YEAR	95%CI		1-5YR	95%CI		6-10YR	95%CI		11-15YR	95%CI		16-19YR	95%CI	
2000/01	2,873	22.6	21.4	23.8	103.2	94.8	111.7	26.5	24.6	28.3	17.5	16.0	18.9	14.7	13.4	16.0	17.8	16.1	19.4
2001/02	2,956	23.4	22.2	24.6	105.8	97.4	114.2	26.1	24.3	28.0	18.4	16.9	19.9	16.3	14.9	17.6	17.6	16.0	19.2
2002/03	3,071	24.3	23.1	25.5	97.2	89.2	105.2	29.8	27.8	31.8	19.3	17.7	20.8	17.2	15.8	18.5	17.5	15.9	19.1
2003/04	3,029	24.0	22.8	25.2	95.3	87.6	103.1	28.7	26.8	30.7	17.8	16.3	19.3	17.2	15.8	18.6	18.6	17.0	20.3
2004/05	3,056	24.2	23.0	25.4	84.3	77.1	91.4	29.5	27.5	31.4	18.9	17.3	20.4	17.0	15.6	18.4	19.8	18.1	21.4
2005/06	3,213	25.5	24.3	26.7	89.2	81.9	96.4	29.0	27.1	31.0	21.1	19.4	22.7	18.5	17.0	20.0	19.9	18.2	21.6
2006/07	3,527	28.0	26.8	29.2	108.4	100.6	116.3	30.5	28.5	32.4	21.2	19.6	22.9	21.8	20.2	23.4	20.2	18.5	21.9
2007/08	3,481	27.6	26.4	28.8	104.5	96.9	112.1	30.6	28.7	32.6	20.8	19.2	22.5	20.7	19.1	22.3	19.7	18.0	21.3
2008/09	3,650	29.0	27.8	30.2	113.3	105.2	121.4	34.1	32.1	36.2	24.1	22.3	25.9	22.8	21.1	24.4	20.6	18.9	22.3
2009/10	3,741	29.7	28.5	30.9	114.7	106.6	122.9	33.2	31.2	35.1	22.3	20.6	24.0	21.8	20.2	23.5	21.9	20.1	23.6

Figure 27 Prevalence of Life-limiting conditions in children by Gender, Yorkshire & Humber Government Office Region 2000-2010

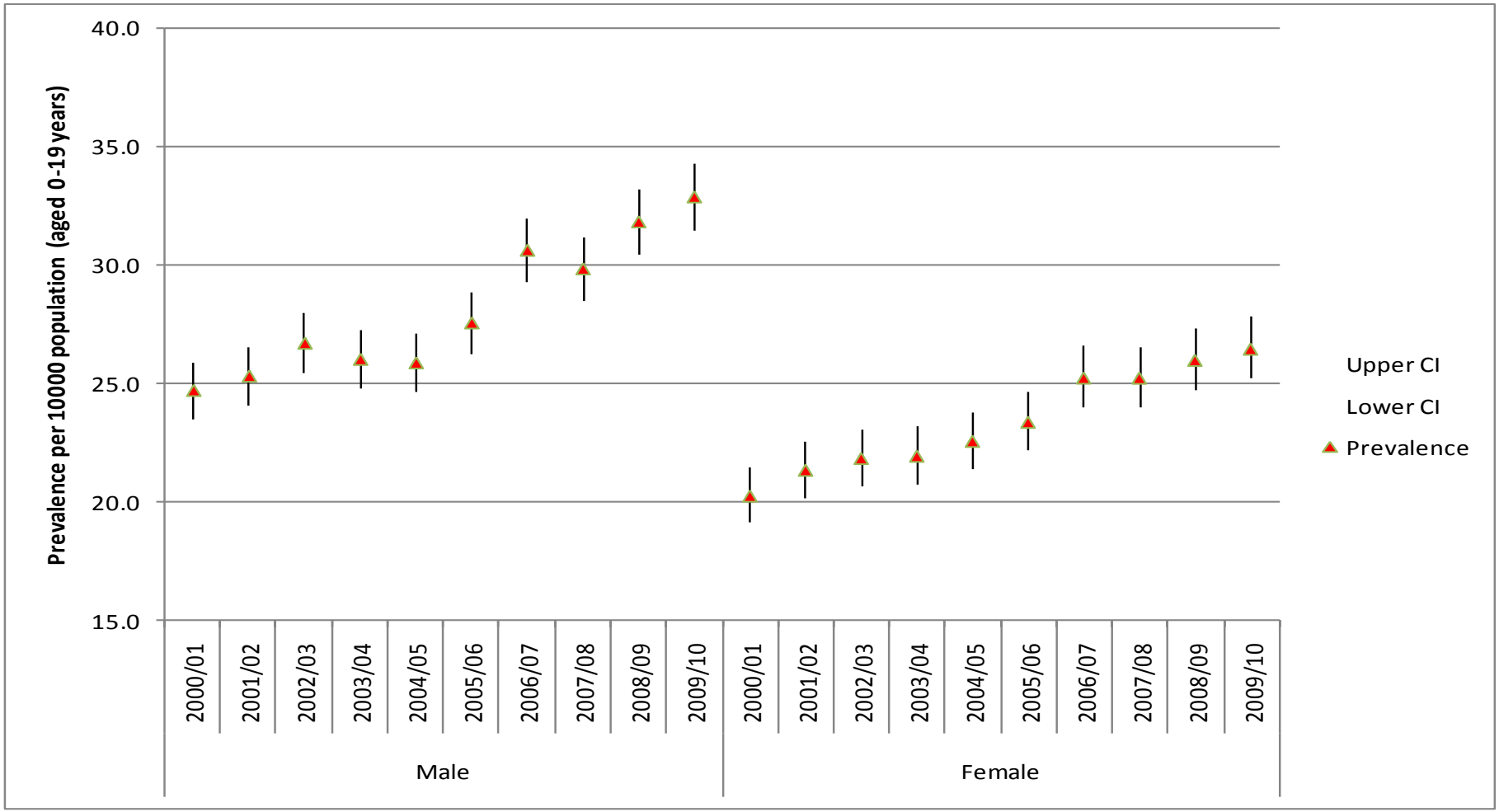

Figure 28 Prevalence of Life-limiting conditions in children by Major Diagnostic Group, Yorkshire & Humber Government Office Region 2000-2010

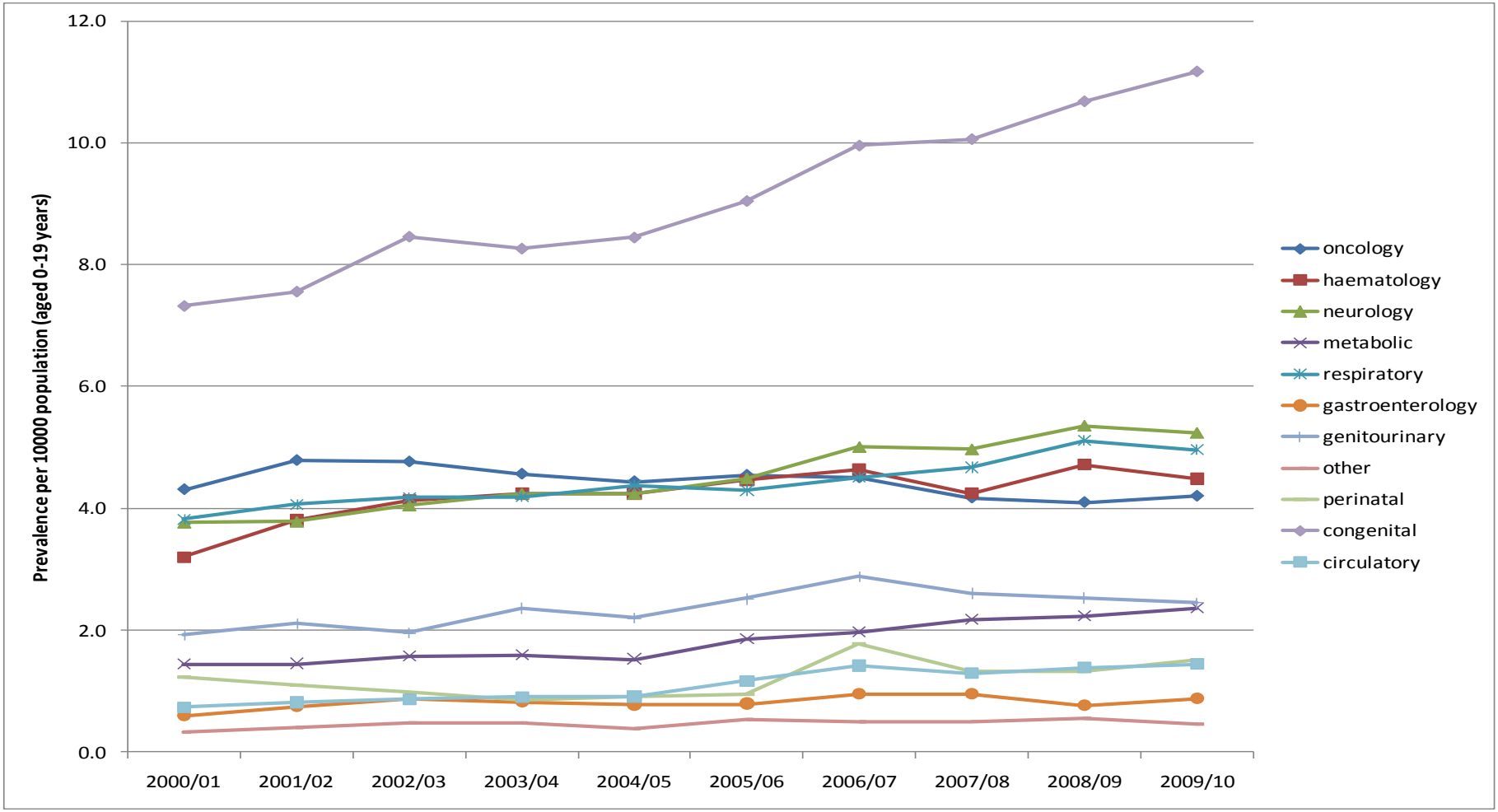

Figure 29 Prevalence of Life-limiting conditions in children by Deprivation Category, Yorkshire & Humber Government Office Region 2009/10

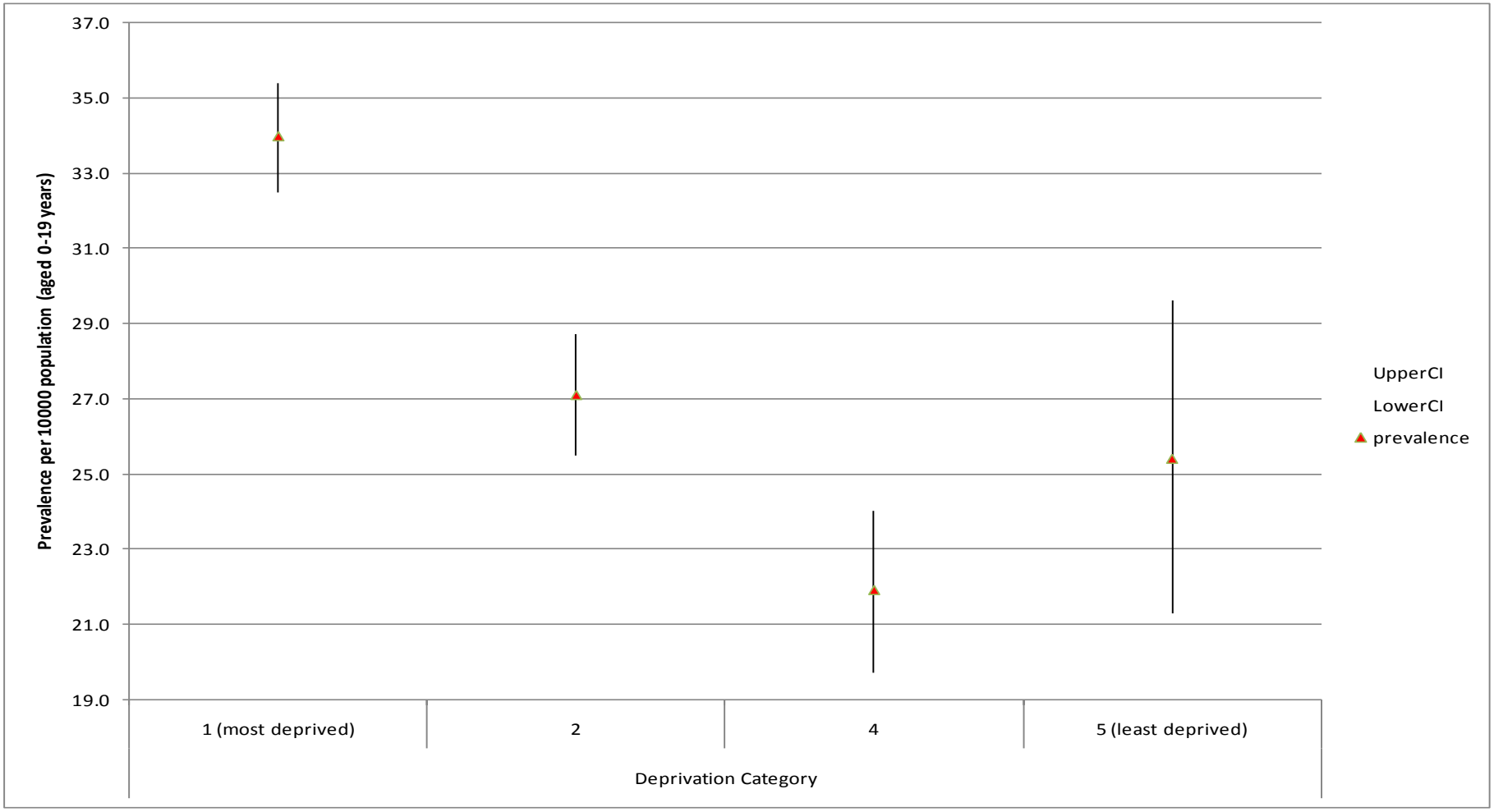

Figure 30 Prevalence of Life-limiting conditions in children by Ethnic Group, Yorkshire & Humber Government Office Region 2009/10

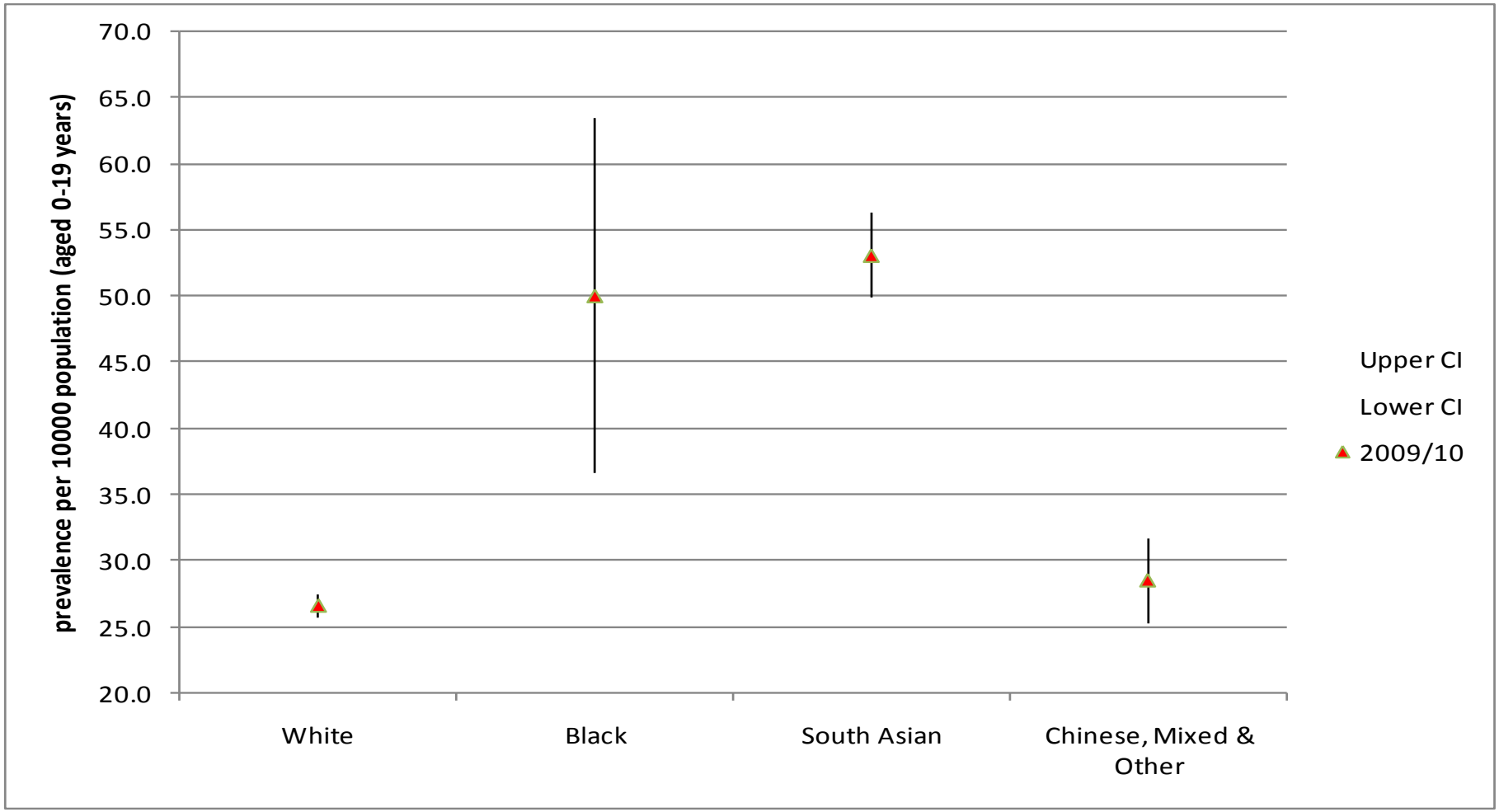

Figure 31 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, Yorkshire & Humber GOR 2009/10

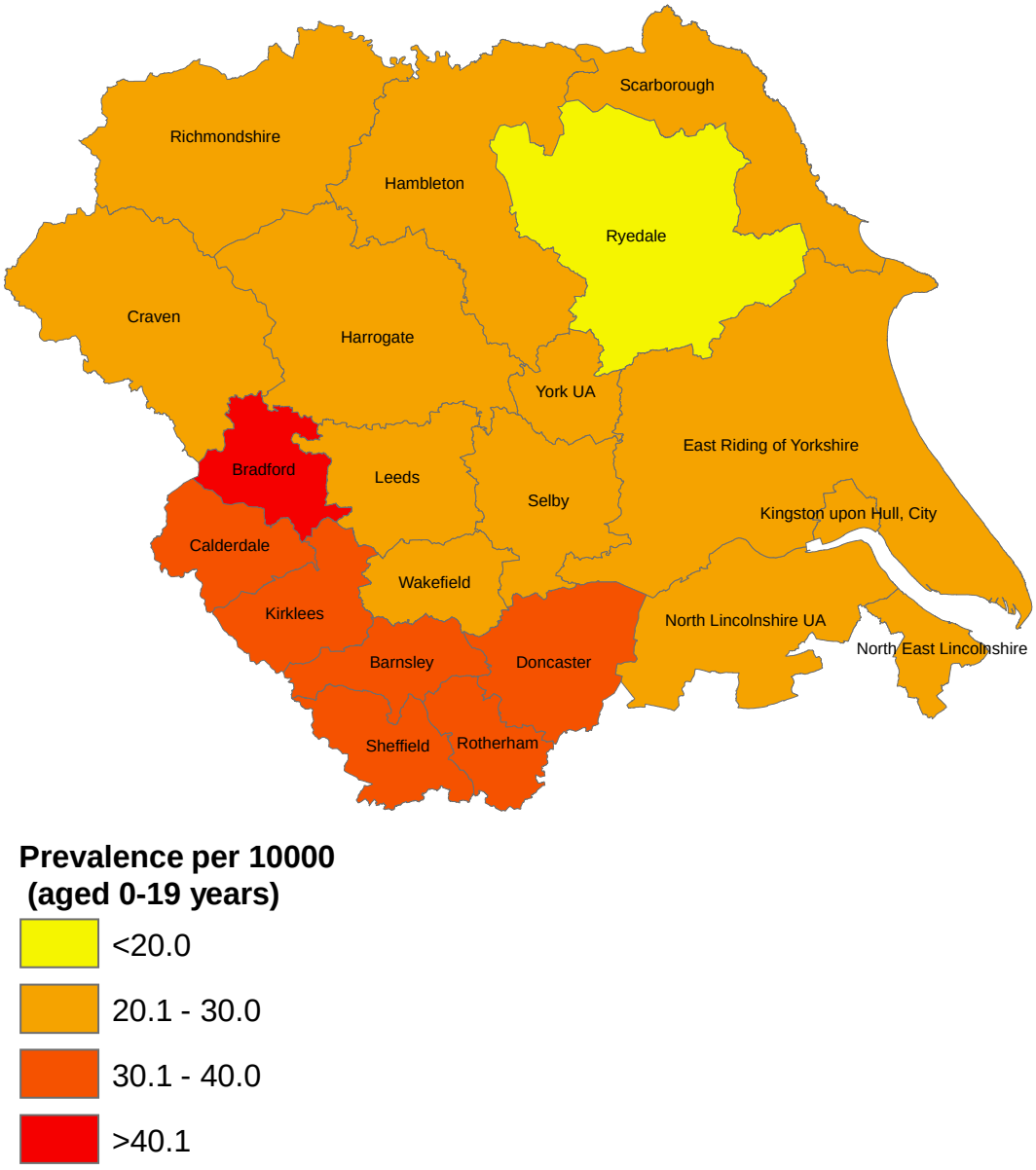

Table 11 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Barnsley	171	54081	31.6
Bradford	595	140403	42.4
Calderdale	158	47879	33.0
Craven	34	14014	24.3
Doncaster	243	71030	34.2
East Riding of Yorkshire	167	75944	22.0
Hambleton	56	19425	28.8
Harrogate	86	36393	23.6
Kingston upon Hull, City of	163	61462	26.5
Kirklees	334	105944	31.5
Leeds	424	176407	24.0
North East Lincolnshire	117	40006	29.2
North Lincolnshire	99	38822	25.5
Richmondshire	30	13028	23.0
Rotherham	192	61885	31.0
Ryedale	26	13088	19.9
Scarborough	51	24332	21.0
Selby	46	20440	22.5
Sheffield	443	123796	35.8
Wakefield	221	78668	28.1
York	85	40909	20.8

14.4 East Midlands

Table 12 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 32 and Figure 33.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 34 and Figure 35.

Prevalence per Local authority district for 2009/10 is shown in Figure 36and Table 13.

Table 12 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the East Midlands Government Office Region , 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	Total	95%CI		Age <1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age 11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	**2446**	**23.4**	22.5	24.3	**111.6**	101.9	121.4	**29.6**	27.5	31.8	**16.3**	14.8	17.8	**16.3**	14.8	17.8	**15.7**	14.0	17.4
2001/02	**2393**	**22.8**	21.9	23.7	**89.6**	81.4	97.8	**27.6**	25.5	29.7	**16.8**	15.3	18.4	**17.5**	16.0	19.1	**15.5**	13.8	17.1
2002/03	**2484**	**23.6**	22.7	24.6	**89.7**	81.7	97.8	**29.1**	26.9	31.2	**18.1**	16.5	19.7	**17.2**	15.7	18.7	**16.4**	14.7	18.1
2003/04	**2514**	**23.9**	23.0	24.8	**84.6**	76.9	92.3	**28.8**	26.7	31.0	**18.7**	17.1	20.4	**18.6**	17.0	20.2	**16.1**	14.4	17.7
2004/05	**2451**	**23.2**	22.3	24.2	**85.5**	77.9	93.1	**26.7**	24.6	28.8	**18.8**	17.1	20.5	**18.3**	16.7	19.9	**14.9**	13.3	16.5
2005/06	**2607**	**24.6**	23.7	25.6	**87.6**	80.0	95.2	**27.4**	25.3	29.4	**18.6**	16.9	20.3	**19.2**	17.5	20.8	**18.9**	17.1	20.7
2006/07	**2878**	**27.1**	26.1	28.1	**117.9**	109.3	126.6	**27.8**	25.8	29.8	**20.5**	18.7	22.3	**19.7**	18.1	21.4	**18.2**	16.5	20.0
2007/08	**2985**	**27.9**	26.9	28.9	**100.4**	92.5	108.4	**30.8**	28.7	32.9	**21.2**	19.3	23.0	**20.6**	18.9	22.4	**21.2**	19.4	23.1
2008/09	**2958**	**27.6**	26.6	28.6	**97.7**	89.9	105.6	**29.2**	27.2	31.2	**21.5**	19.6	23.3	**20.4**	18.6	22.1	**22.0**	20.1	23.9
2009/10	**3257**	**30.4**	29.3	31.4	**113.6**	105.2	122.0	**31.8**	29.7	33.9	**22.7**	20.8	24.6	**21.8**	20.0	23.6	**23.9**	21.9	25.9

Figure 32 Prevalence of Life-limiting conditions in children by Gender, East Midlands Government Office Region 2000-2010

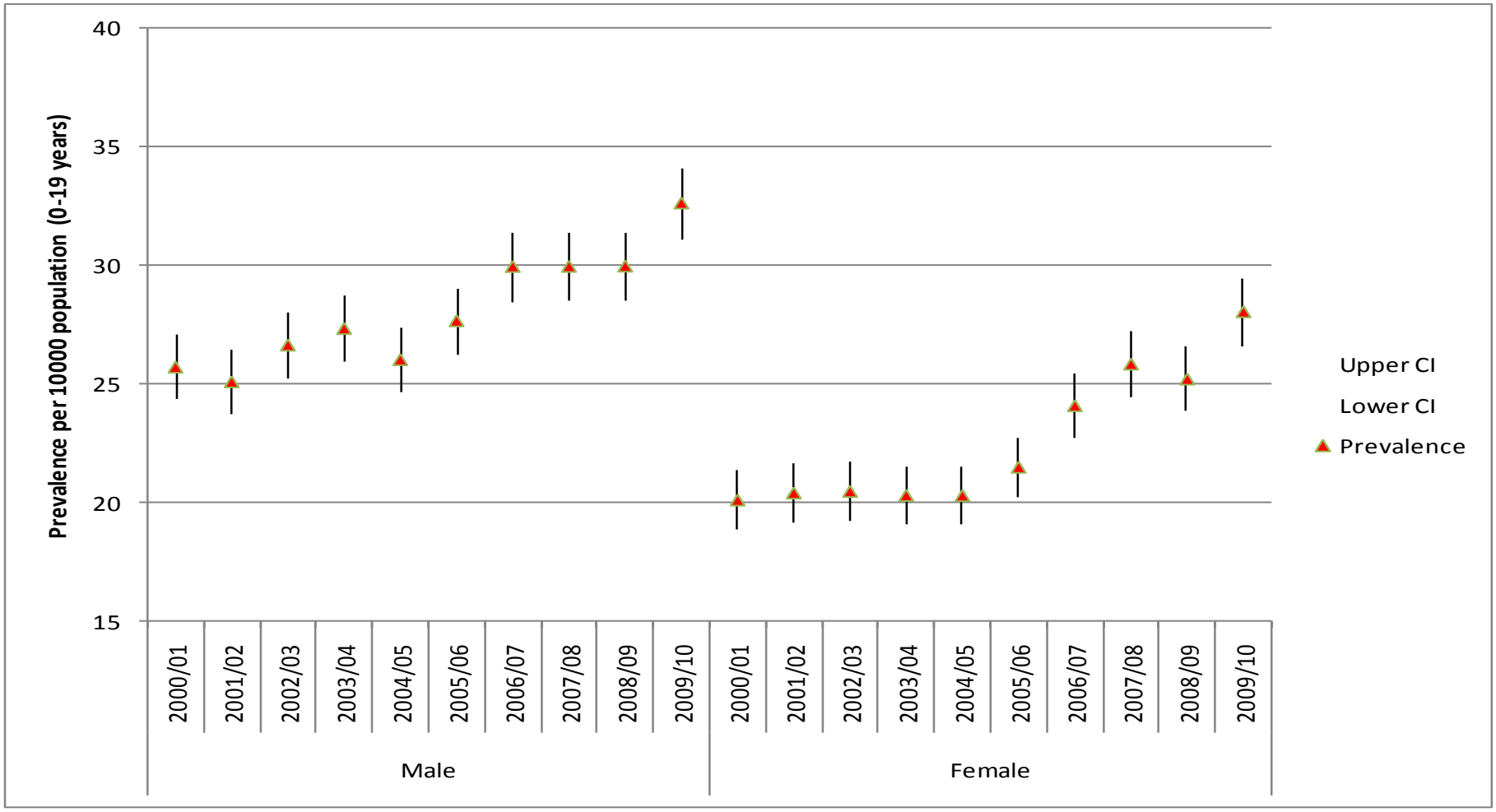

Figure 33 Prevalence of Life-limiting conditions in children by Major Diagnostic Group, East Midlands Government Office Region 2000-2010

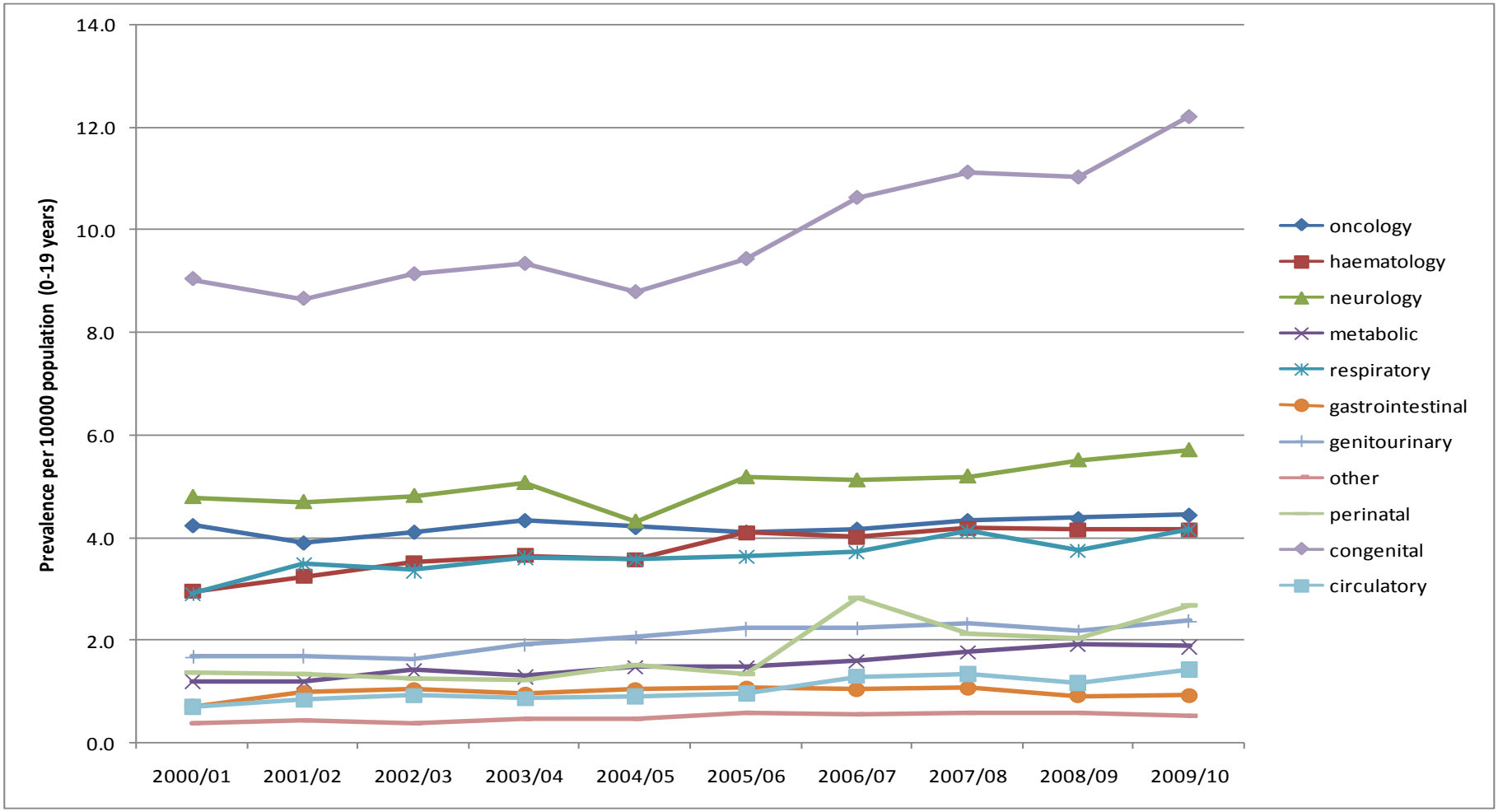

Figure 34 Prevalence of Life-limiting conditions in children by Deprivation category, East Midlands Government Office Region 2009/10

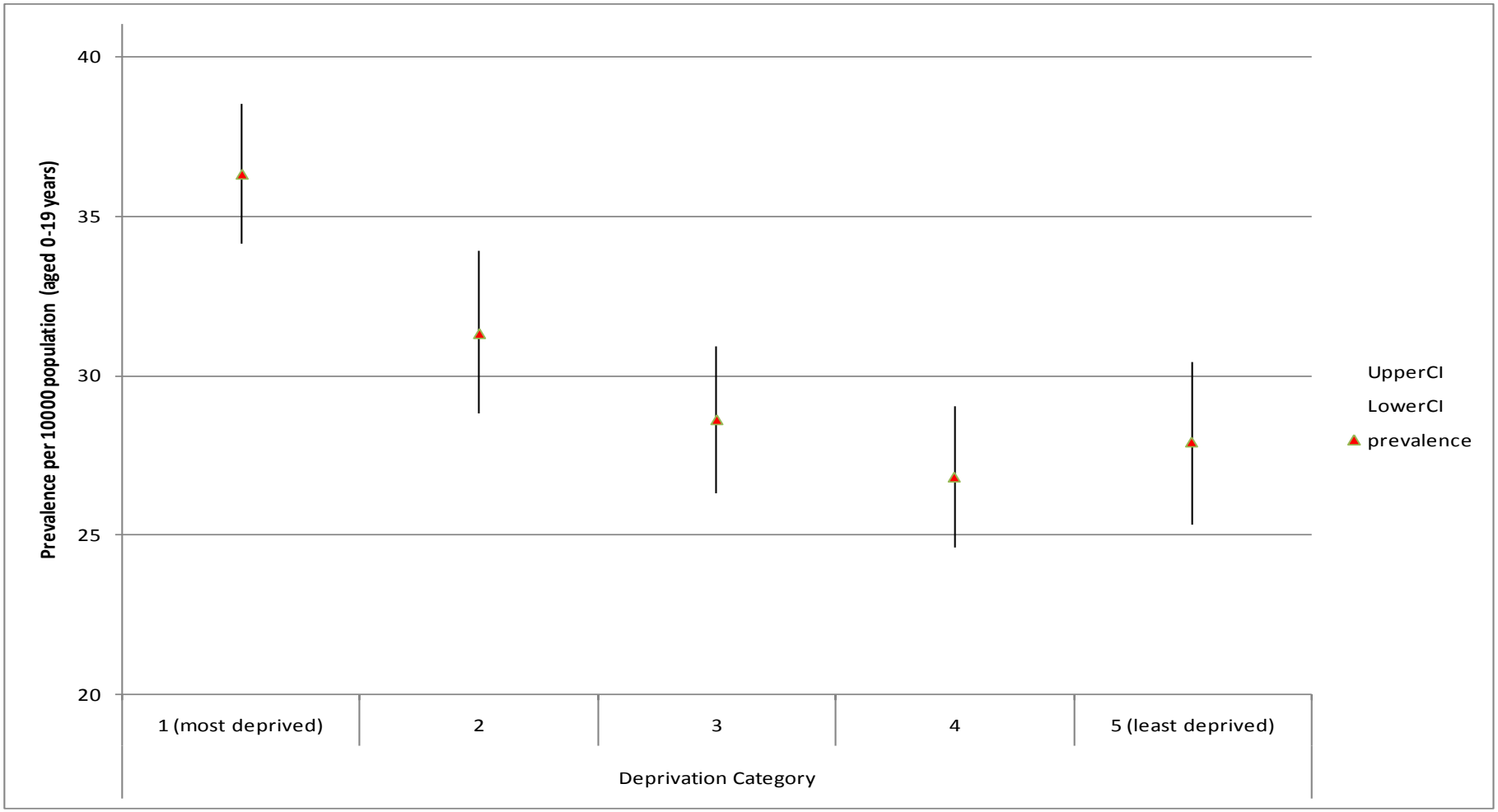

Figure 35 Prevalence of Life-limiting conditions in children by Ethnic group, East Midlands Government Office Region 2009/10

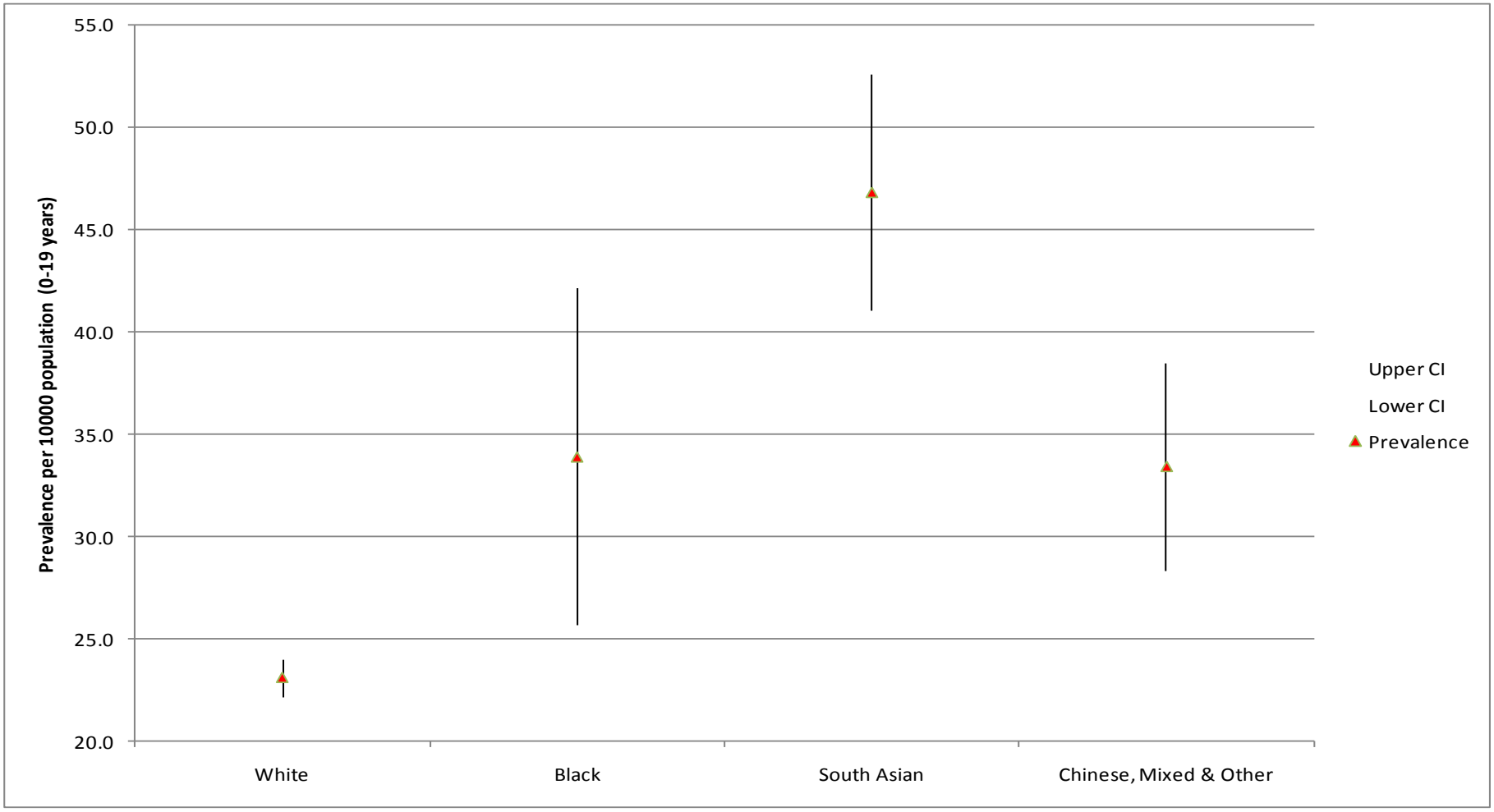

Figure 36 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, East Midlands GOR 2009/10

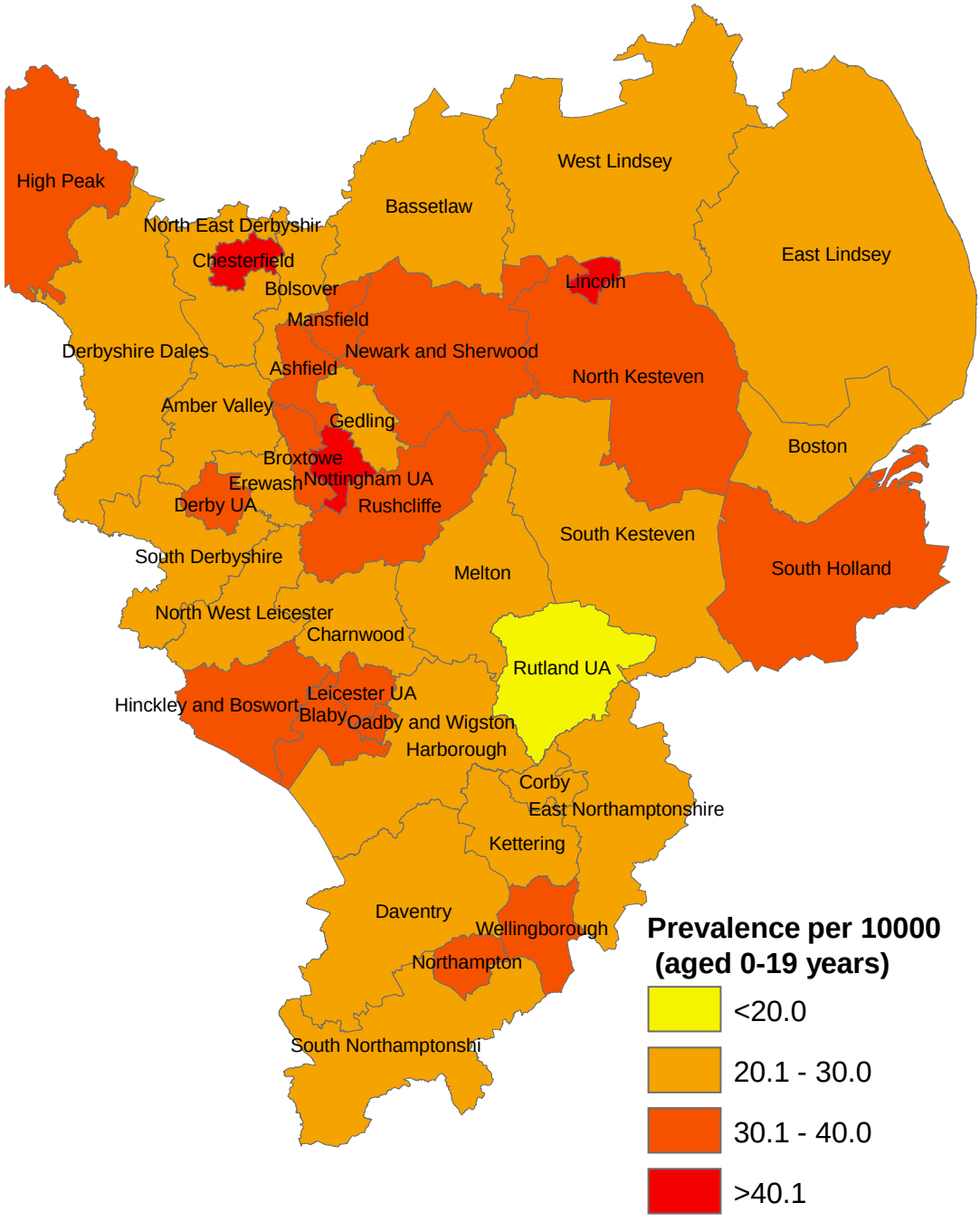

Table 13 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Amber Valley	73	27690	26.4
Ashfield	99	29286	33.8
Bassetlaw	71	27392	25.9
Blaby	65	21627	30.1
Bolsover	48	19857	24.2
Boston	47	16697	28.1
Broxtowe	75	22674	33.1
Charnwood	89	36922	24.1
Chesterfield	75	14434	52.0
Corby	46	15692	29.3
Daventry	49	18993	25.8
Derby	209	60994	34.3
Derbyshire Dales	39	15438	25.3
East Lindsey	68	31493	21.6
East Northamptonshire	52	22318	23.3
Erewash	67	26241	25.5
Gedling	67	24024	27.9
Harborough	45	20662	21.8
High Peak	70	22090	31.7
Hinckley and Bosworth	85	22562	37.7
Kettering	55	24084	22.8
Leicester	316	86122	36.7
Lincoln	90	22414	40.2
Mansfield	75	23243	32.3
Melton	33	13239	24.9
Newark and Sherwood	85	27001	31.5
North East Derbyshire	58	20657	28.1
North Kesteven	81	24639	32.9
North West Leicestershire	58	22453	25.8
Northampton	176	50676	34.7
Nottingham	293	71066	41.2
Oadby and Wigston	41	12519	32.7
Rushcliffe	89	24634	36.1
Rutland	17	9880	17.2
South Derbyshire	48	21438	22.4
South Holland	65	21380	30.4
South Kesteven	87	31448	27.7
South Northamptonshire	46	20317	22.6
Wellingborough	57	18893	30.2
West Lindsey	52	19261	27.0

14.5 West Midlands

Table 14 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 37 and Figure 38.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 39 and Figure 40.

Prevalence per Local authority district for 2009/10 is shown in Figure 41 and Table 15.

Table 14 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the West Midlands Government Office Region , 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	total	95%CI		Age <1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age 11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	4,401	32.3	31.3	33.2	136.3	127.0	145.6	42.5	40.3	44.8	25.4	23.7	29.7	24.4	22.8	27.0	16.2	14.7	17.8
2001/02	2,900	21.3	20.5	22.1	94.9	87.5	102.3	23.9	22.2	25.6	16.2	14.9	18.7	14.6	13.4	17.6	15.5	14.0	16.9
2002/03	2,863	21.1	20.3	21.9	82.8	76.0	89.6	25.0	23.2	26.8	16.0	14.7	18.6	15.9	14.6	17.4	14.3	12.9	15.7
2003/04	3,199	23.6	22.8	24.5	99.0	91.7	106.3	28.7	26.8	30.5	16.9	15.5	19.9	17.3	15.9	18.3	15.2	13.8	16.6
2004/05	3,348	24.8	24.0	25.6	87.7	80.9	94.5	31.0	29.0	32.9	19.2	17.7	22.1	18.1	16.7	20.7	16.9	15.4	18.4
2005/06	3,589	26.6	25.7	27.5	102.2	94.9	109.5	30.7	28.7	32.6	20.5	18.9	23.5	18.8	17.4	22.1	19.0	17.4	20.6
2006/07	3,991	29.6	28.7	30.5	124.1	116.1	132.0	33.3	31.4	35.3	22.3	20.6	25.2	20.6	19.1	23.9	19.4	17.8	21.0
2007/08	4,130	30.6	29.7	31.5	110.6	103.2	118.0	34.2	32.3	36.2	24.8	23.1	27.7	22.8	21.1	26.6	20.6	19.0	22.3
2008/09	4,136	30.7	29.8	31.6	118.0	110.3	125.7	32.6	30.7	34.5	24.9	23.1	28.0	21.6	20.0	26.6	22.2	20.5	23.9
2009/10	4,493	33.4	32.4	34.4	125.0	117.1	132.9	34.8	32.8	36.7	27.3	25.5	30.2	23.9	22.2	29.2	24.4	22.6	26.2

Figure 37 Prevalence of Life-limiting conditions in children by Gender, West Midlands Government Office Region 2000-2010

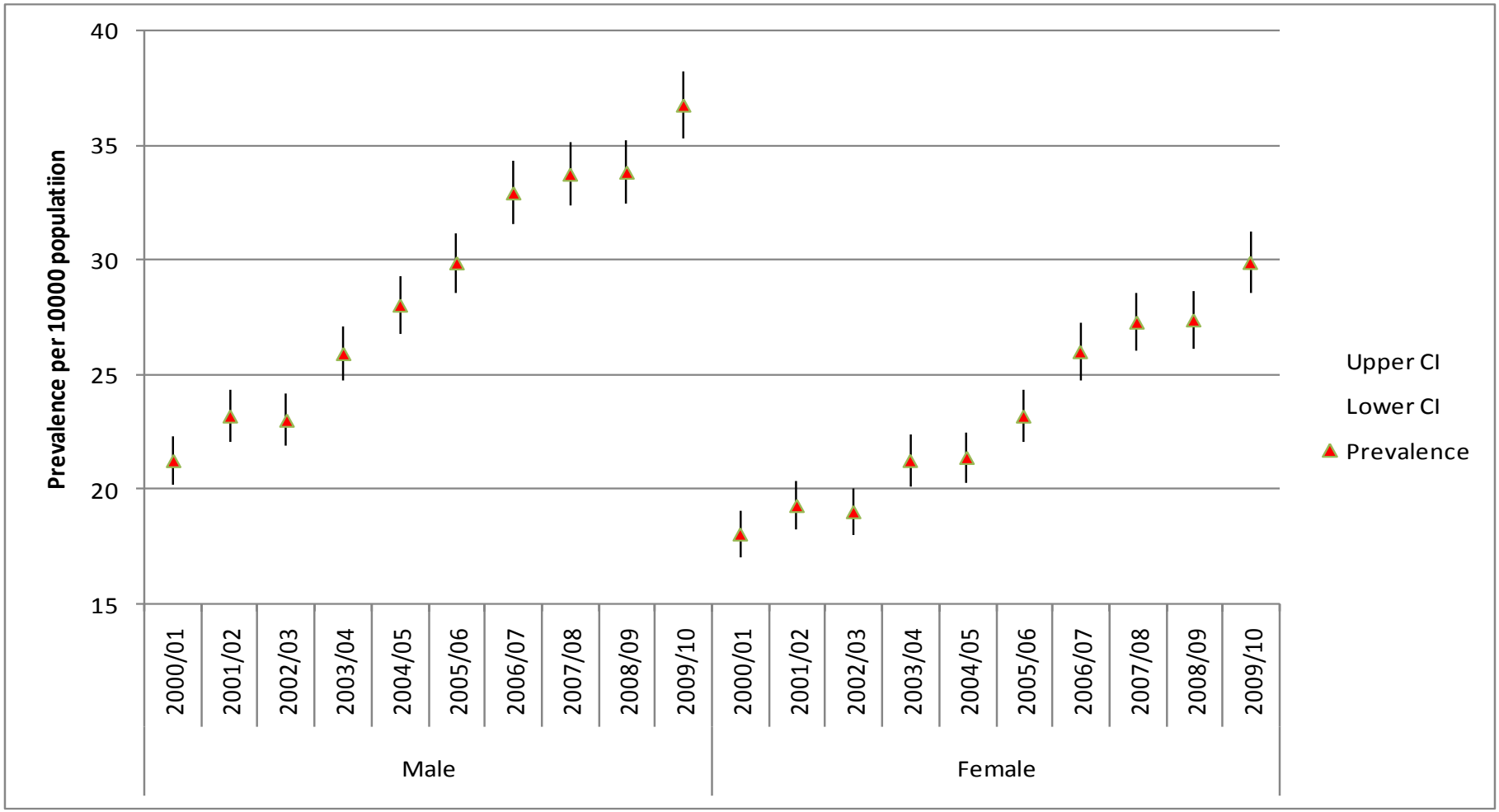

Figure 38 Prevalence of Life-limiting conditions in children by Major Diagnostic group, West Midlands Government Office Region 2000-2010

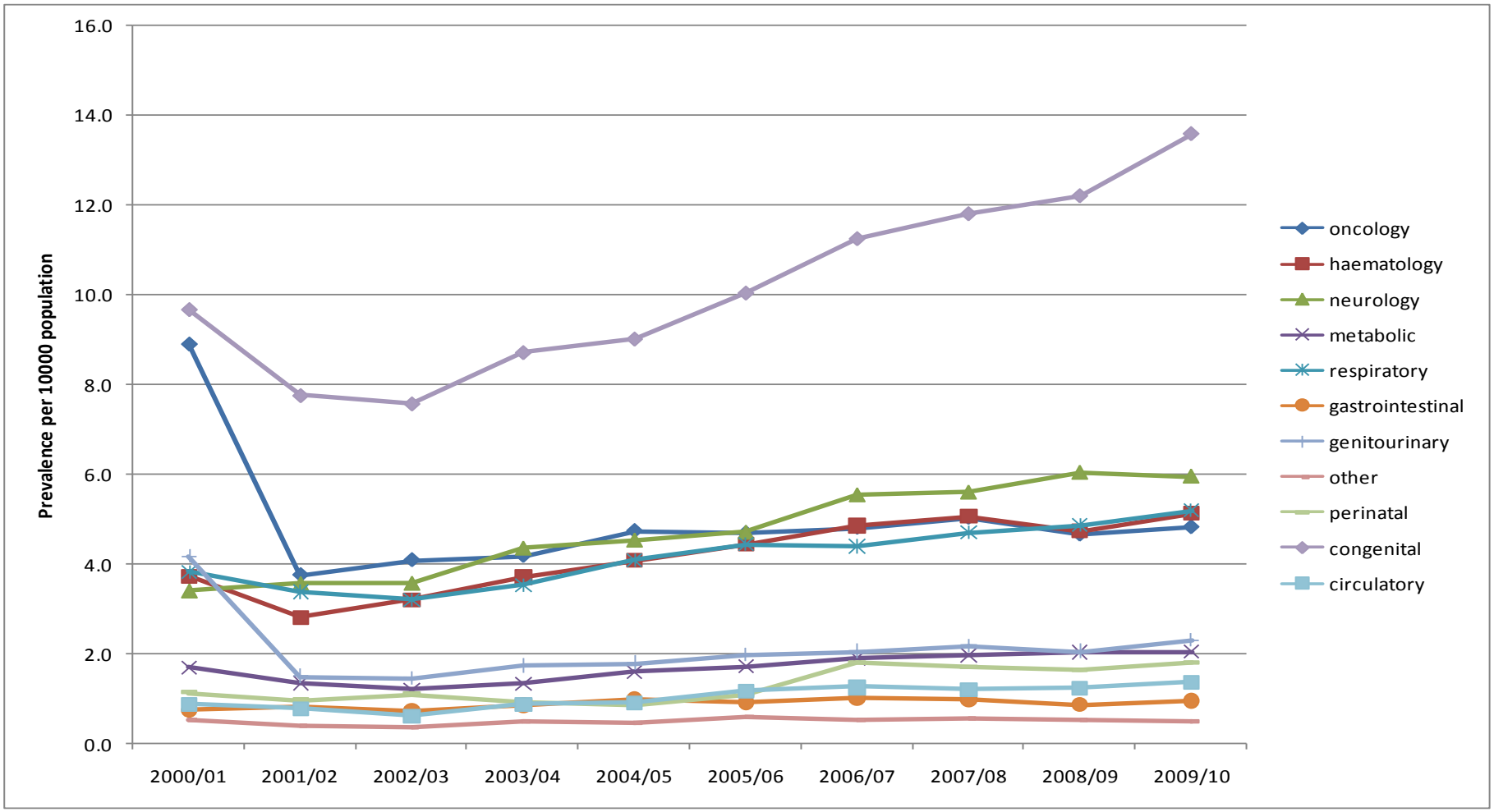

Figure 39 Prevalence of Life-limiting conditions in children by Deprivation category, West Midlands Government Office Region 2000-2010

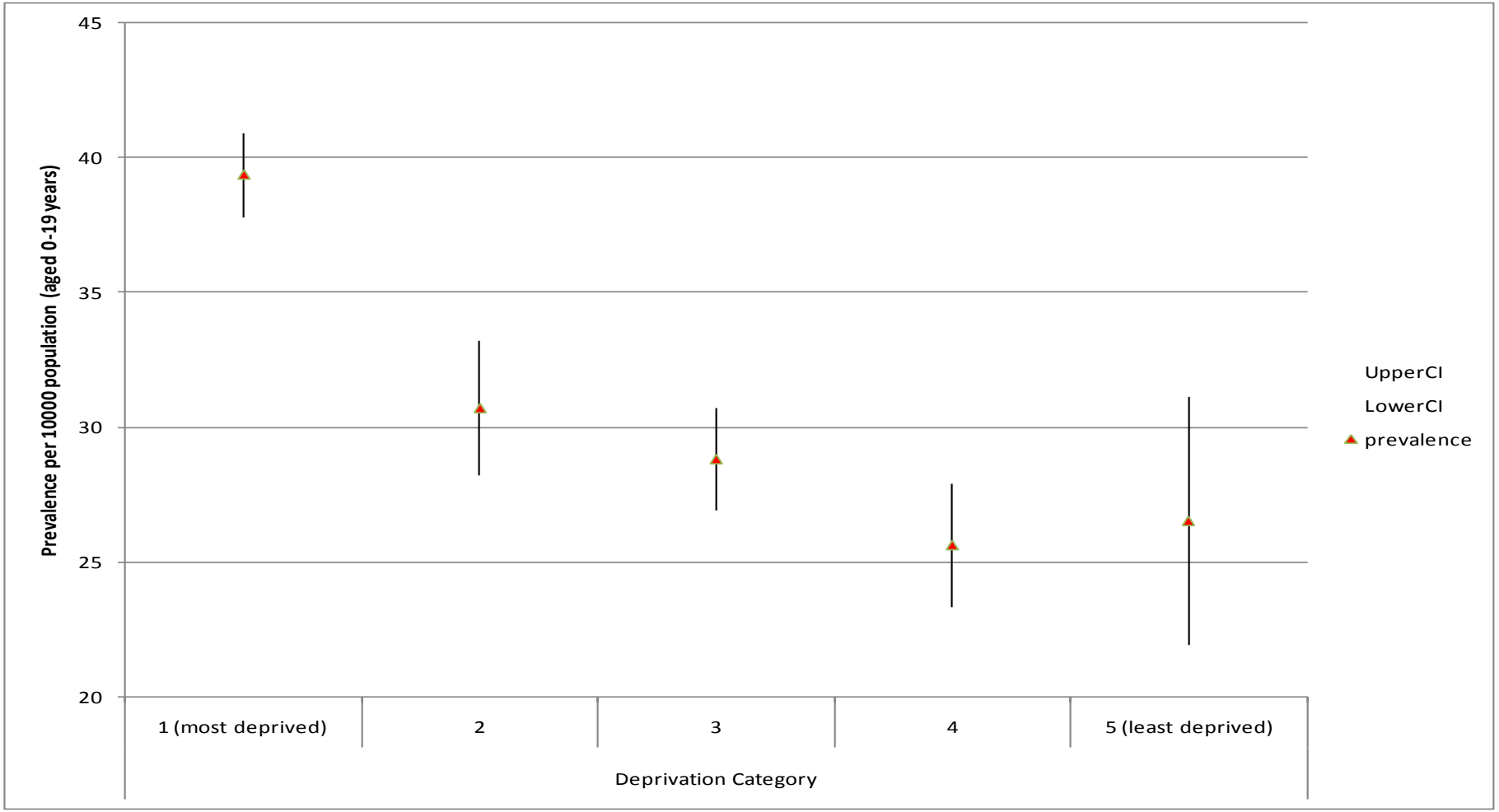

Figure 40 Prevalence of Life-limiting conditions in children by Ethnic group, West Midlands Government Office Region 2000-2010

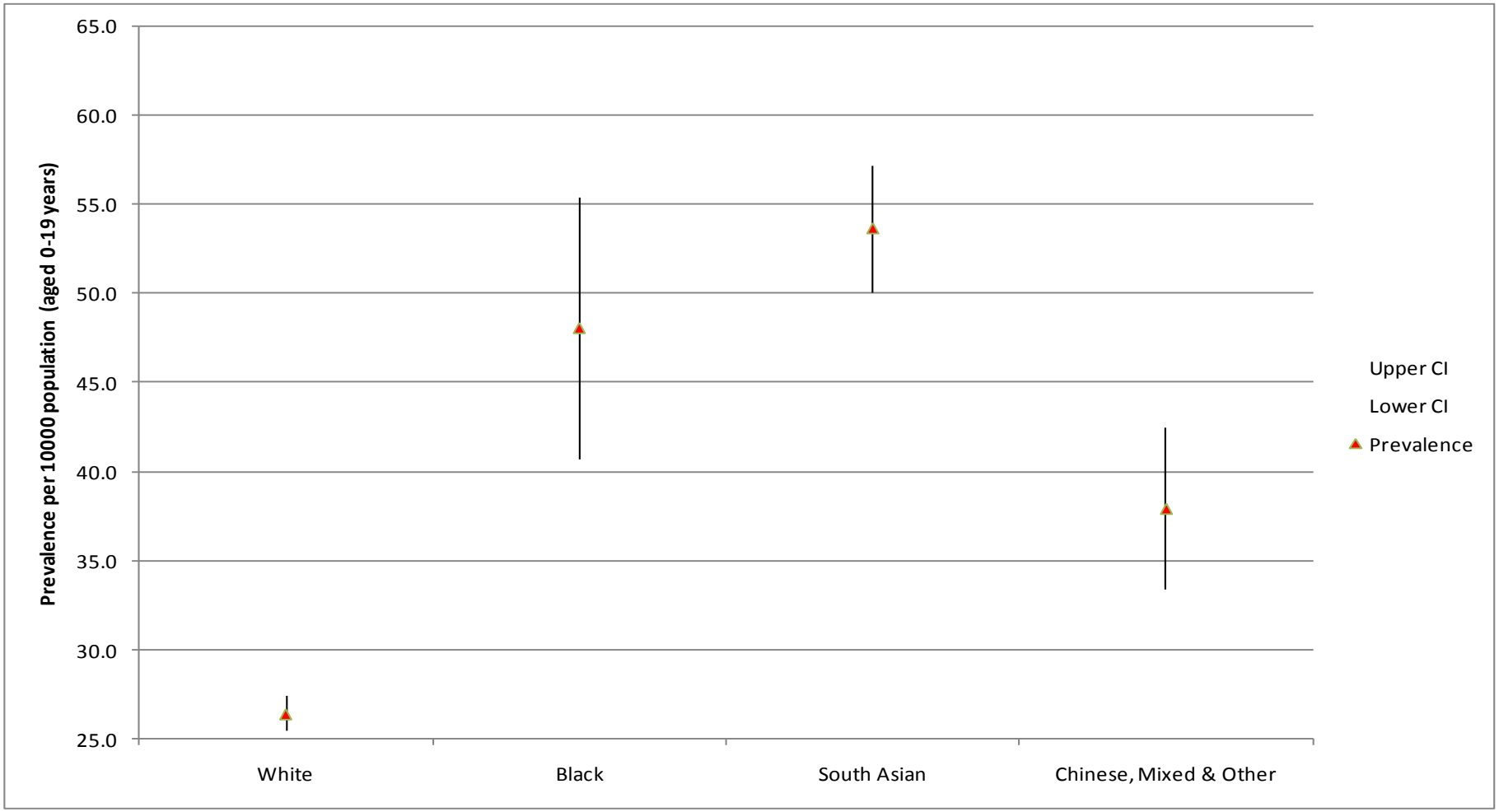

Figure 41 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, West Midlands GOR 2009/10

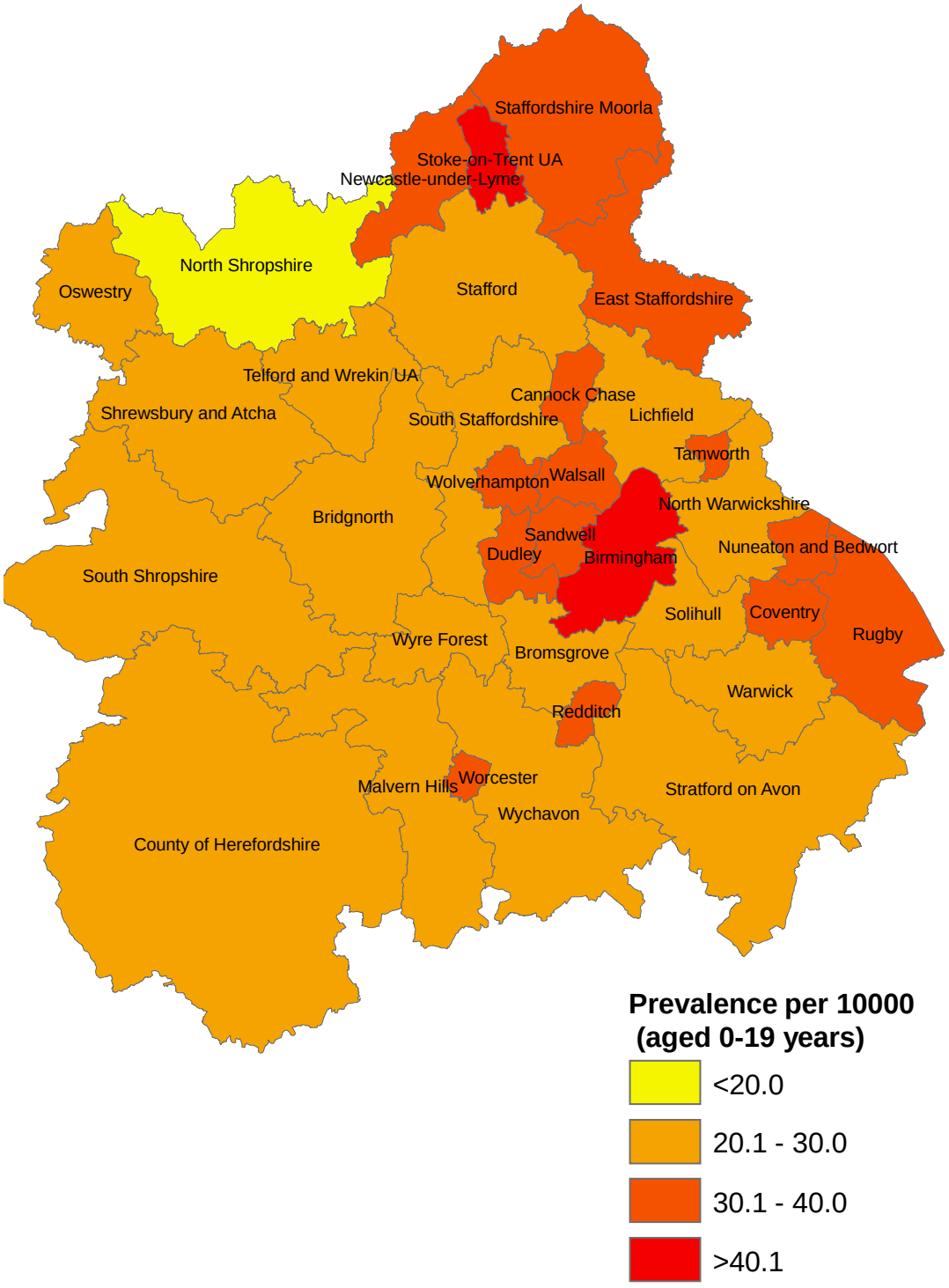

Table 15 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Birmingham	1,138	280031	40.6
Bridgnorth	27	12738	21.2
Bromsgrove	48	21363	22.5
Cannock Chase	78	24161	32.3
Coventry	292	76169	38.3
Dudley	211	69117	30.5
East Staffordshire	88	28454	30.9
Herefordshire, County of	117	42487	27.5
Lichfield	58	21347	27.2
Malvern Hills	39	16442	23.7
Newcastle-under-Lyme	97	26539	36.5
North Shropshire	29	16429	17.7
North Warwickshire	35	14557	24.0
Nuneaton and Bedworth	105	30735	34.2
Oswestry	28	10727	26.1
Redditch	80	20137	39.7
Rugby	72	22941	31.4
Sandwell	293	76731	38.2
Shrewsbury and Atcham	62	23661	26.2
Solihull	124	44437	27.9
South Shropshire	21	10370	20.3
South Staffordshire	68	23590	28.8
Stafford	81	27983	28.9
Staffordshire Moorlands	70	22006	31.8
Stoke-on-Trent	257	60268	42.6
Stratford-on-Avon	78	26607	29.3
Tamworth	68	18783	36.2
Telford and Wrekin	112	46608	24.0
Walsall	214	64300	33.3
Warwick	70	31320	22.3
Wolverhampton	237	59815	39.6
Worcester	78	23798	32.8
Wychavon	59	27799	21.2
Wyre Forest	60	22472	26.7

14.6 East of England

Table 16 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 42 and Figure 43.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 44 and Figure 45.

Prevalence per Local authority district for 2009/10 is shown in Figure 46 and Table 17.

Table 16 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the East of England Government Office Region, 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	total	95%CI		Age <1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age 11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	2,942	22.0	21.3	22.8	92.4	84.8	99.9	24.9	23.2	26.6	17.6	16.2	19.0	15.5	14.2	16.8	16.4	14.8	18.0
2001/02	3,013	23.5	21.6	23.2	89.4	82.0	96.7	25.2	23.5	27.0	17.6	16.2	19.0	16.5	15.1	17.8	17.0	15.4	18.6
2002/03	3,201	24.9	23.0	24.6	94.1	86.7	101.5	26.9	25.1	28.7	19.3	17.9	20.8	17.5	16.1	18.9	16.6	15.1	18.1
2003/04	3,352	26.0	24.1	25.8	96.7	89.3	104.0	28.4	26.6	30.3	19.4	17.9	20.9	18.3	16.9	19.7	18.2	16.6	19.8
2004/05	3,249	25.2	23.3	25.0	101.8	94.4	109.3	27.8	25.9	29.6	17.9	16.5	19.3	16.4	15.1	17.8	17.7	16.2	19.3
2005/06	3,529	27.3	25.3	27.1	94.6	87.5	101.7	30.1	28.2	32.0	21.7	20.1	23.3	19.2	17.8	20.7	18.3	16.7	19.8
2006/07	3,663	28.2	26.3	28.0	105.8	98.4	113.2	29.9	28.0	31.8	21.5	19.9	23.1	20.1	18.6	21.6	18.4	16.8	19.9
2007/08	4,045	31.0	29.0	30.8	113.3	105.8	120.9	31.8	29.9	33.7	23.0	21.3	24.6	23.6	22.0	25.3	20.8	19.2	22.5
2008/09	3,986	30.6	28.6	30.4	113.2	105.6	120.8	30.4	28.6	32.3	22.7	21.0	24.4	22.7	21.1	24.3	21.6	19.9	23.3
2009/10	4,367	33.5	31.3	33.3	121.8	114.0	129.7	34.4	32.5	36.4	24.4	22.7	26.1	24.1	22.5	25.8	23.8	22.0	25.6

Figure 42 Prevalence of Life-limiting conditions in children by Gender, East of England Government Office Region 2000-2010

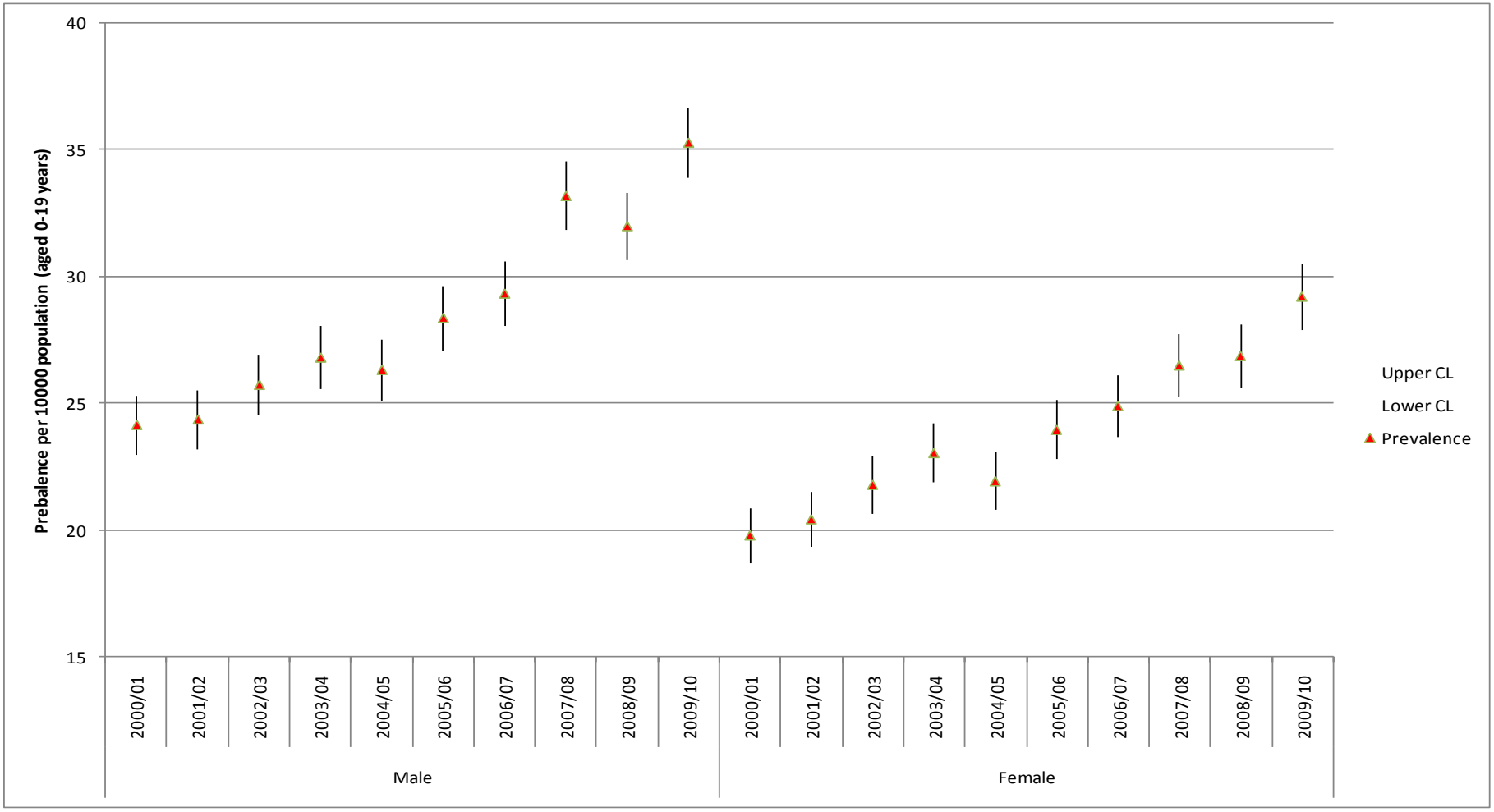

Figure 43 Prevalence of Life-limiting conditions in children by Major Diagnostic group, East of England Government Office Region 2000-2010

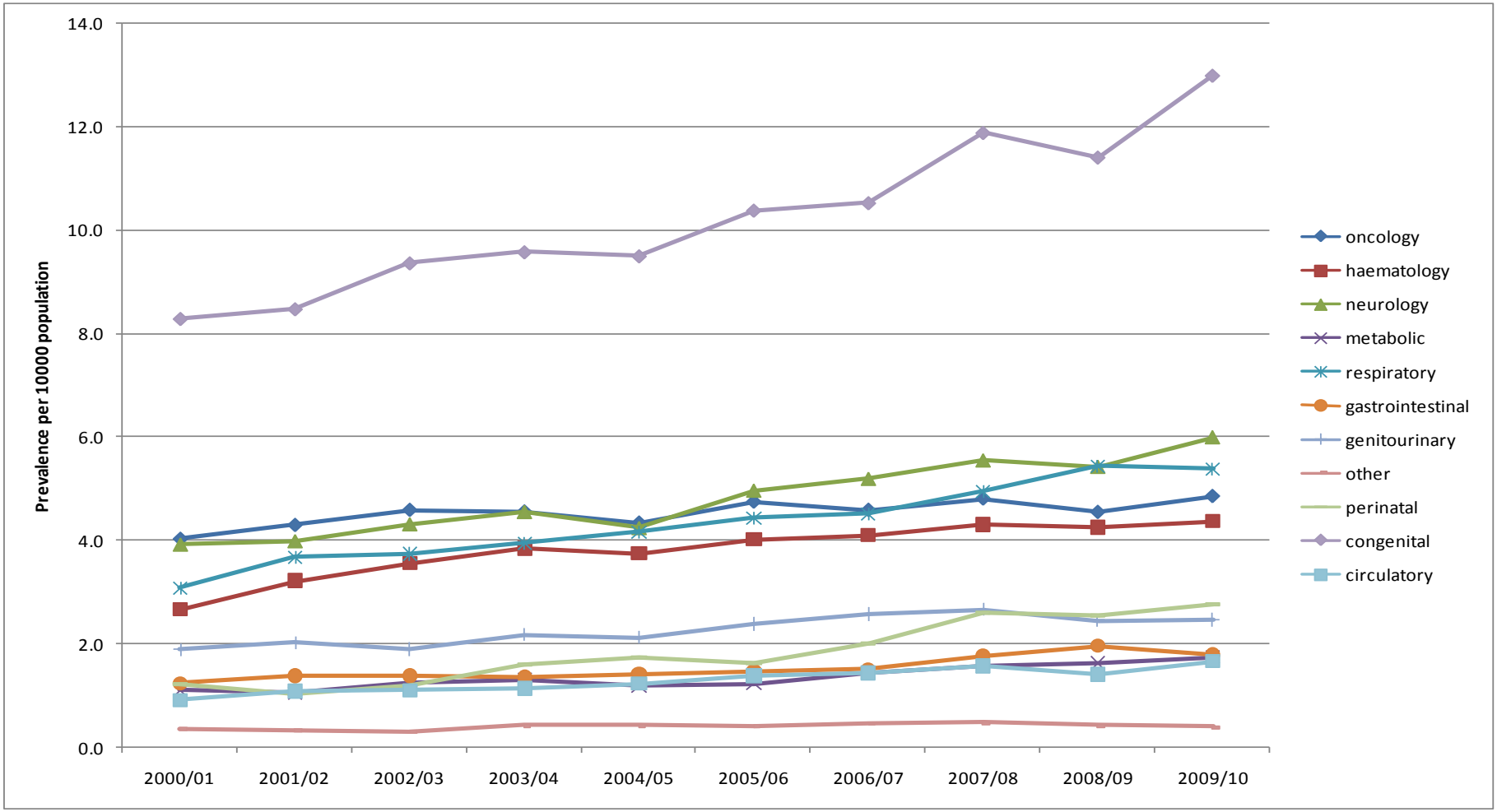

Figure 44 Prevalence of Life-limiting conditions in children by Deprivation category, East of England Government Office Region 2009/10

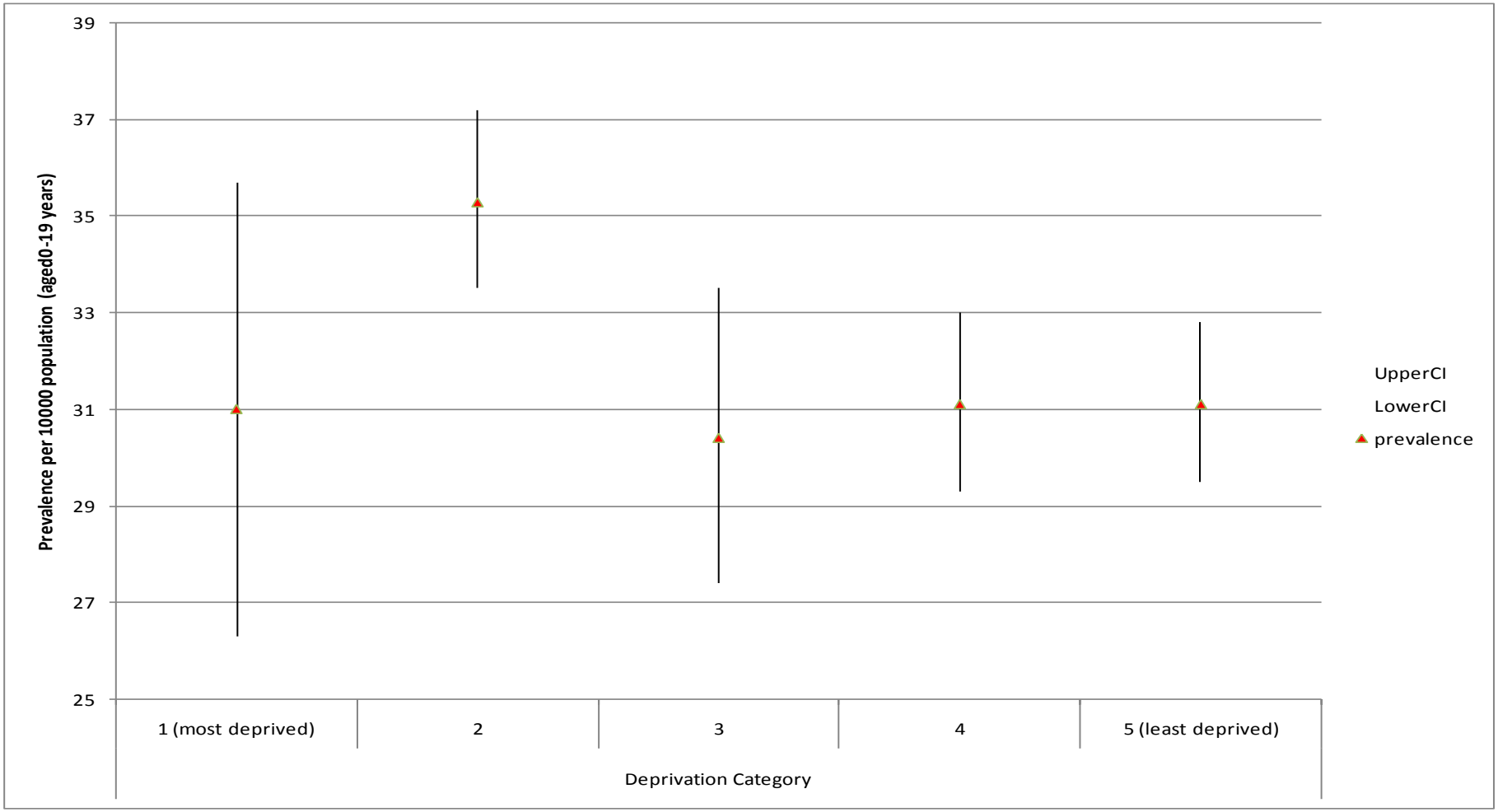

Figure 45 Prevalence of Life-limiting conditions in children by Ethnic group, East of England Government Office Region 2009/10

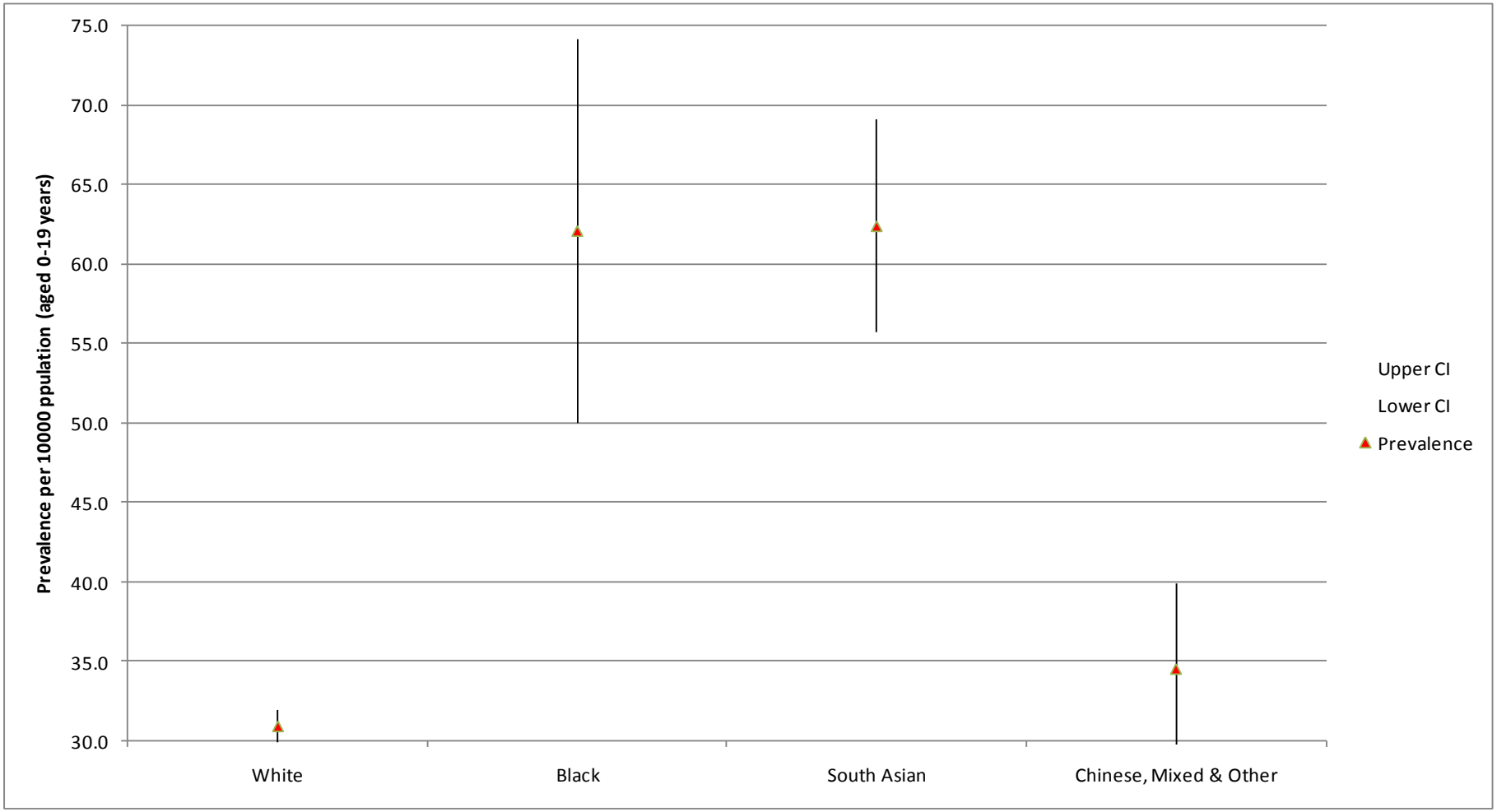

Figure 46 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, East of England GOR 2009/10

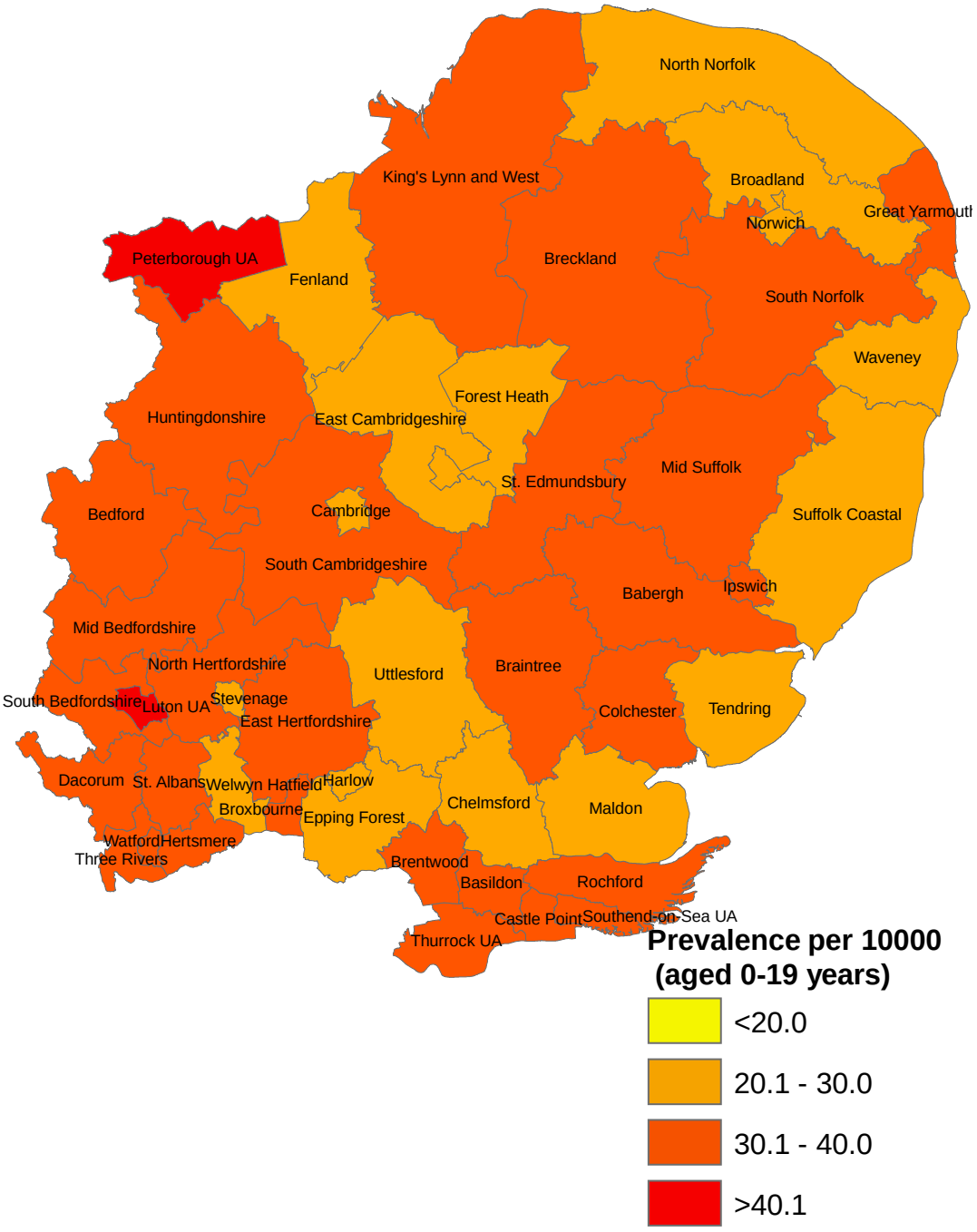

Table 17 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Babergh	65	20079	32.4
Basildon	148	42253	35.0
Bedford	120	38727	31.0
Braintree	113	35452	31.9
Breckland	101	31622	31.9
Brentwood	57	15142	37.6
Broadland	73	28192	25.9
Broxbourne	79	22565	35.0
Cambridge	65	23417	27.8
Castle Point	62	19580	31.7
Chelmsford	103	36920	27.9
Colchester	128	37226	34.4
Dacorum	107	32913	32.5
East Cambridgeshire	55	20517	26.8
East Hertfordshire	92	30245	30.4
Epping Forest	82	29131	28.1
Fenland	57	22861	24.9
Forest Heath	39	16531	23.6
Great Yarmouth	77	23463	32.8
Harlow	56	20817	26.9
Hertsmere	83	22583	36.8
Huntingdonshire	125	39301	31.8
Ipswich	102	29908	34.1
King's Lynn and West Norfolk	120	33085	36.3
Luton	274	56719	48.3
Maldon	45	15945	28.2
Mid Bedfordshire	96	29812	32.2
Mid Suffolk	68	22314	30.5
North Hertfordshire	89	29430	30.2
North Norfolk	57	23185	24.6
Norwich	88	29768	29.6
Peterborough	210	45353	46.3
Rochford	60	18139	33.1
South Bedfordshire	90	27810	32.4
South Cambridgeshire	107	31695	33.8
South Norfolk	79	25589	30.9
Southend-on-Sea	137	41765	32.8
St Albans	108	30044	35.9
St Edmundsbury	86	24440	35.2
Stevenage	56	20524	27.3
Suffolk Coastal	79	26611	29.7
Tendring	98	33513	29.2
Three Rivers	66	19077	34.6
Thurrock	129	39978	32.3
Uttlesford	41	16525	24.8
Watford	68	19921	34.1
Waveney	66	28409	23.2
Welwyn Hatfield	63	23026	27.4

14.7 London

Table 18 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 47 and Figure 48.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 49 and Figure 50.

Prevalence per Local authority district for 2009/10 is shown in Figure 51 and Table 19.

Table 18 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the London Government Office Region , 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	Total	95%CI		Age <1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age 11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	4,437	24.8	24.1	25.6	113.0	106.4	119.7	26.2	24.8	27.7	17.6	16.4	18.8	17.3	16.1	18.6	16.7	15.3	18.1
2001/02	4,475	24.7	24.0	25.5	104.3	98.0	110.5	27.7	26.2	29.2	17.7	16.4	18.9	18.0	16.7	19.2	15.5	14.2	16.9
2002/03	4,631	25.4	24.7	26.2	99.2	93.1	105.4	28.1	26.5	29.6	18.8	17.6	20.1	19.0	17.7	20.3	17.8	16.4	19.2
2003/04	4,796	26.3	25.5	27.0	107.7	101.4	114.1	29.6	28.0	31.1	19.2	17.9	20.5	18.2	16.9	19.4	18.0	16.6	19.4
2004/05	4,947	26.9	26.2	27.7	110.9	104.5	117.2	30.8	29.2	32.4	19.3	18.1	20.6	18.8	17.5	20.1	17.2	15.8	18.5
2005/06	5,509	29.8	29.0	30.6	118.4	112.0	124.8	33.1	31.5	34.8	21.0	19.6	22.3	21.1	19.8	22.5	20.8	19.3	22.3
2006/07	5,781	31.0	30.2	31.8	140.2	133.3	147.1	32.0	30.4	33.6	21.6	20.2	22.9	20.5	19.2	21.9	20.8	19.3	22.3
2007/08	6,132	32.7	31.8	33.5	131.4	124.9	137.8	35.2	33.6	36.9	22.5	21.1	23.9	22.9	21.5	24.3	21.7	20.2	23.2
2008/09	5,870	31.1	30.3	31.9	132.3	125.6	139.0	32.8	31.3	34.4	21.9	20.5	23.3	21.7	20.3	23.0	20.7	19.3	22.2
2009/10	6,616	34.9	34.1	35.8	145.6	138.6	152.6	35.8	34.2	37.4	25.9	24.4	27.4	24.2	22.7	25.6	23.8	22.2	25.4

Figure 47 Prevalence of Life-limiting conditions in children by Gender, London Government Office Region 2000-2010

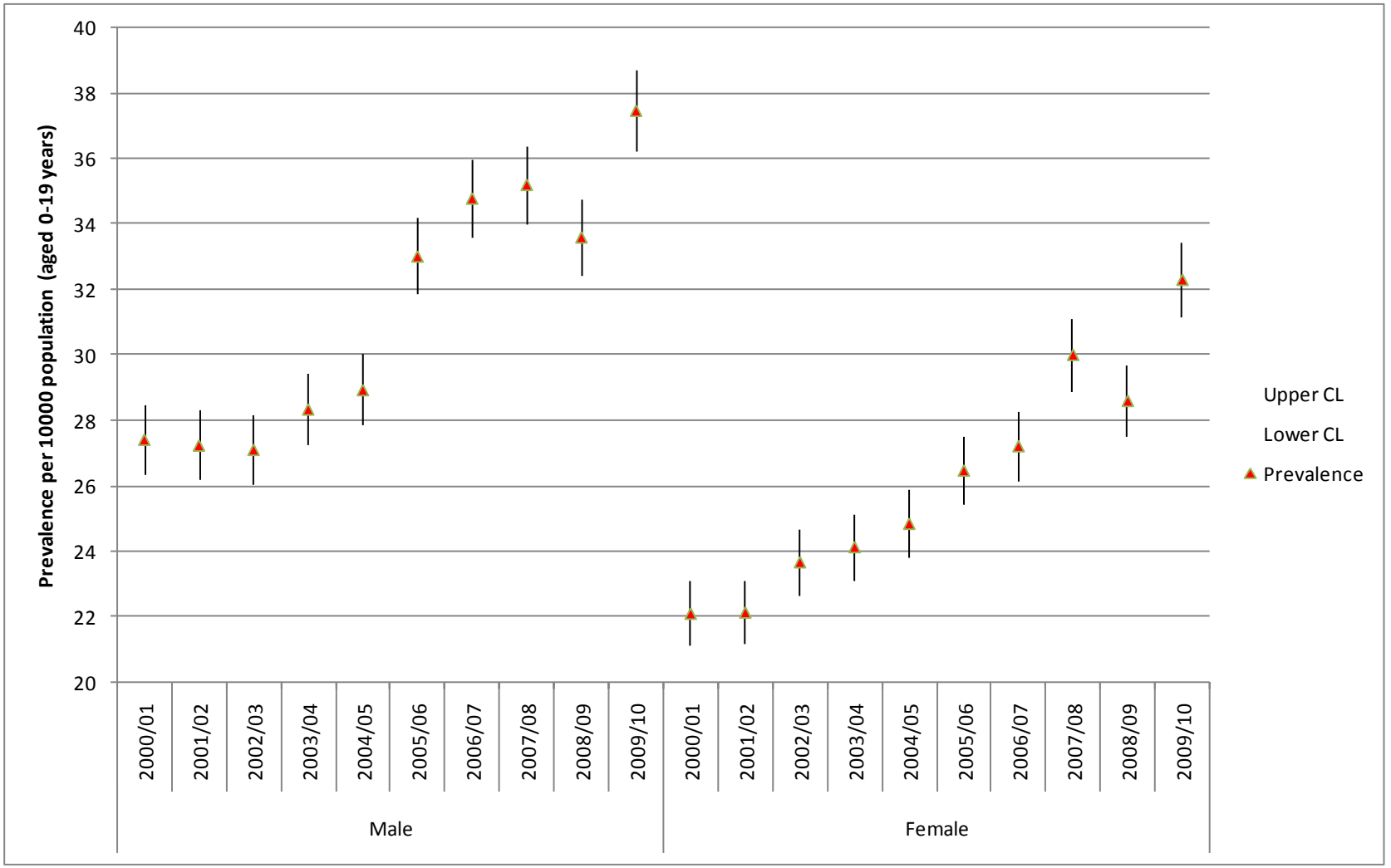

Figure 48 Prevalence of Life-limiting conditions in children by Major Diagnostic group, London Government Office Region 2000-2010

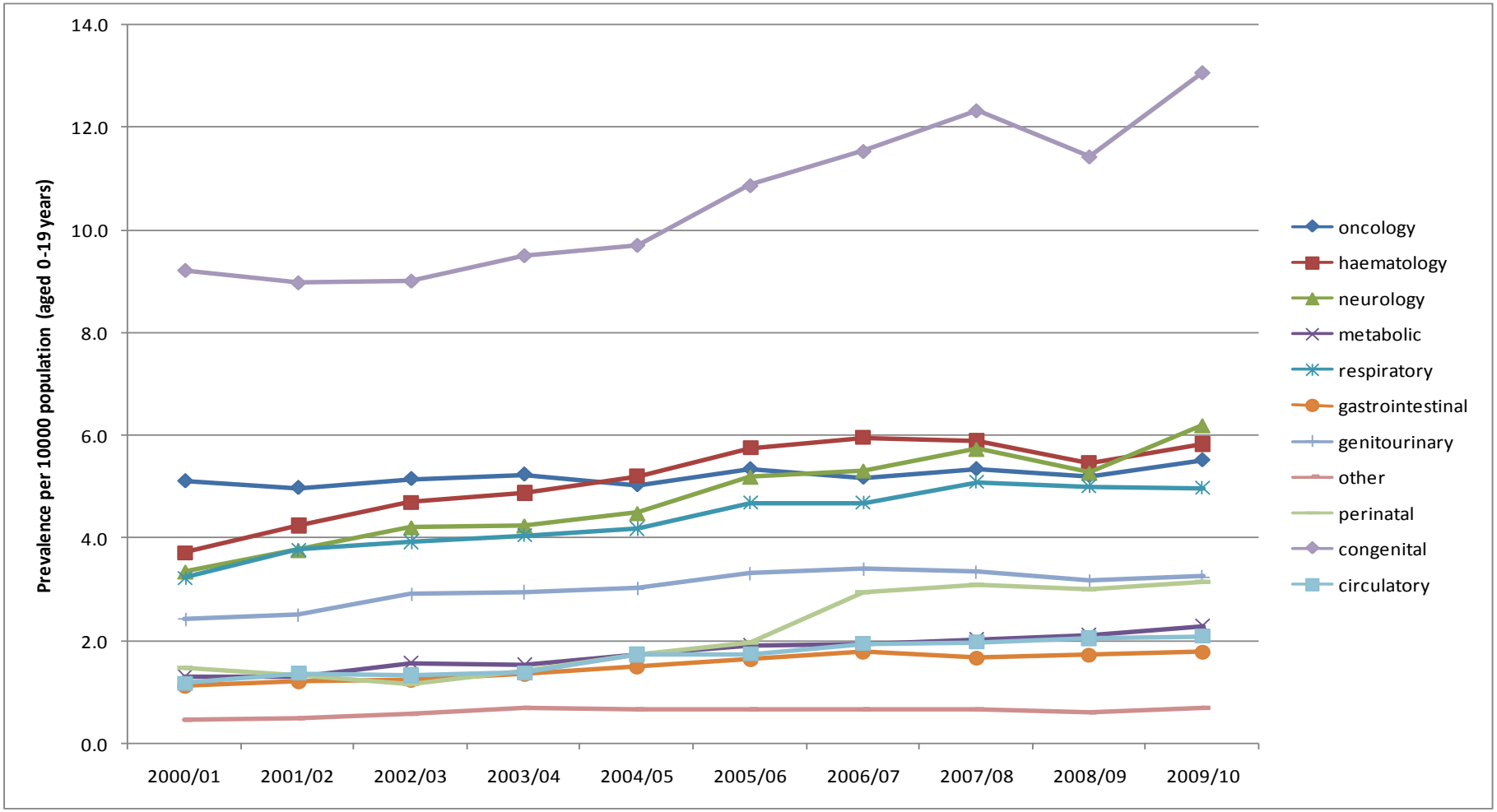

Figure 49 Prevalence of Life-limiting conditions in children by Deprivation Category, London Government Office Region 2009/10

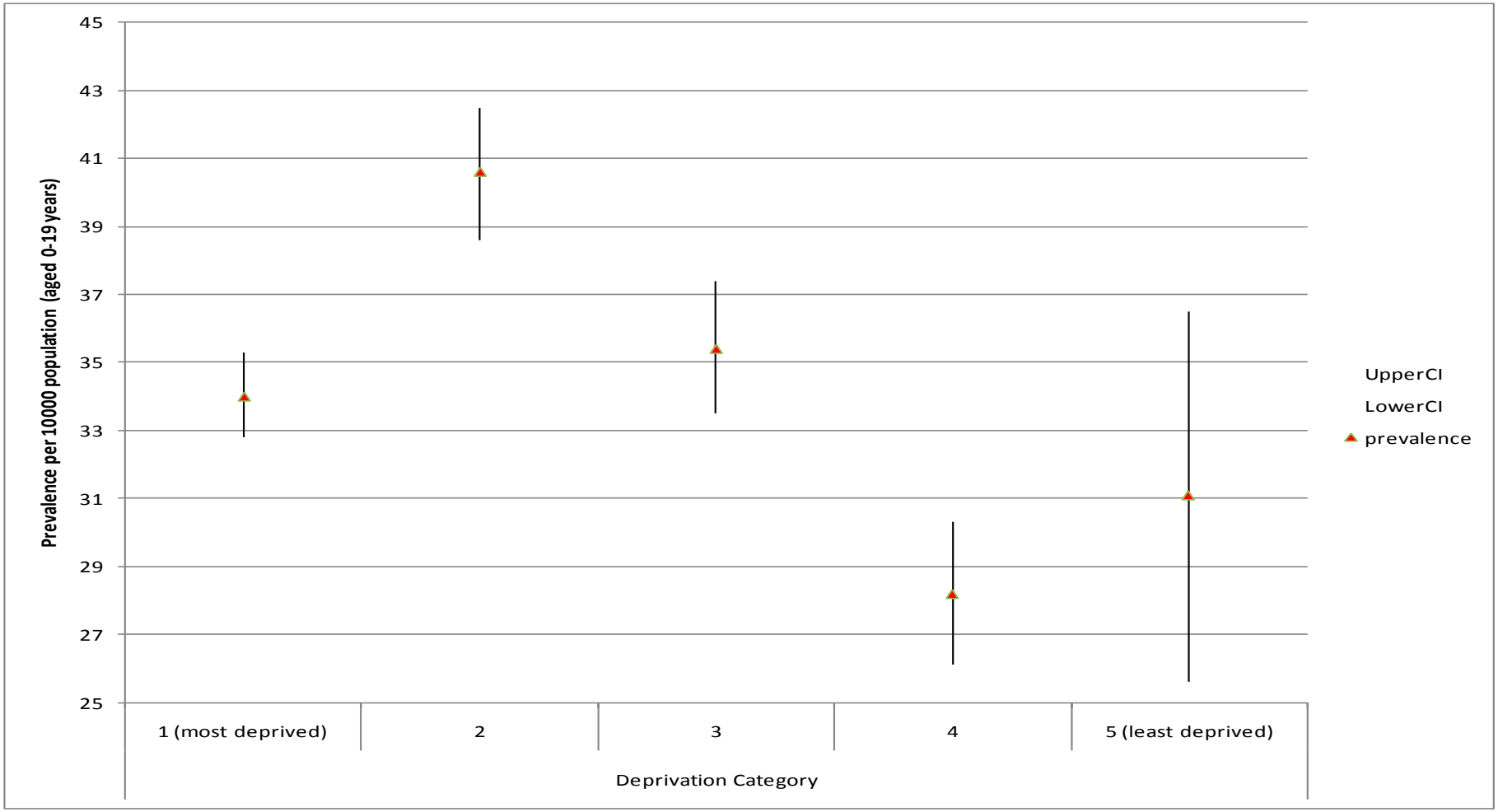

Figure 50 Prevalence of Life-limiting conditions in children by Ethnic group, London Government Office Region 2009/10

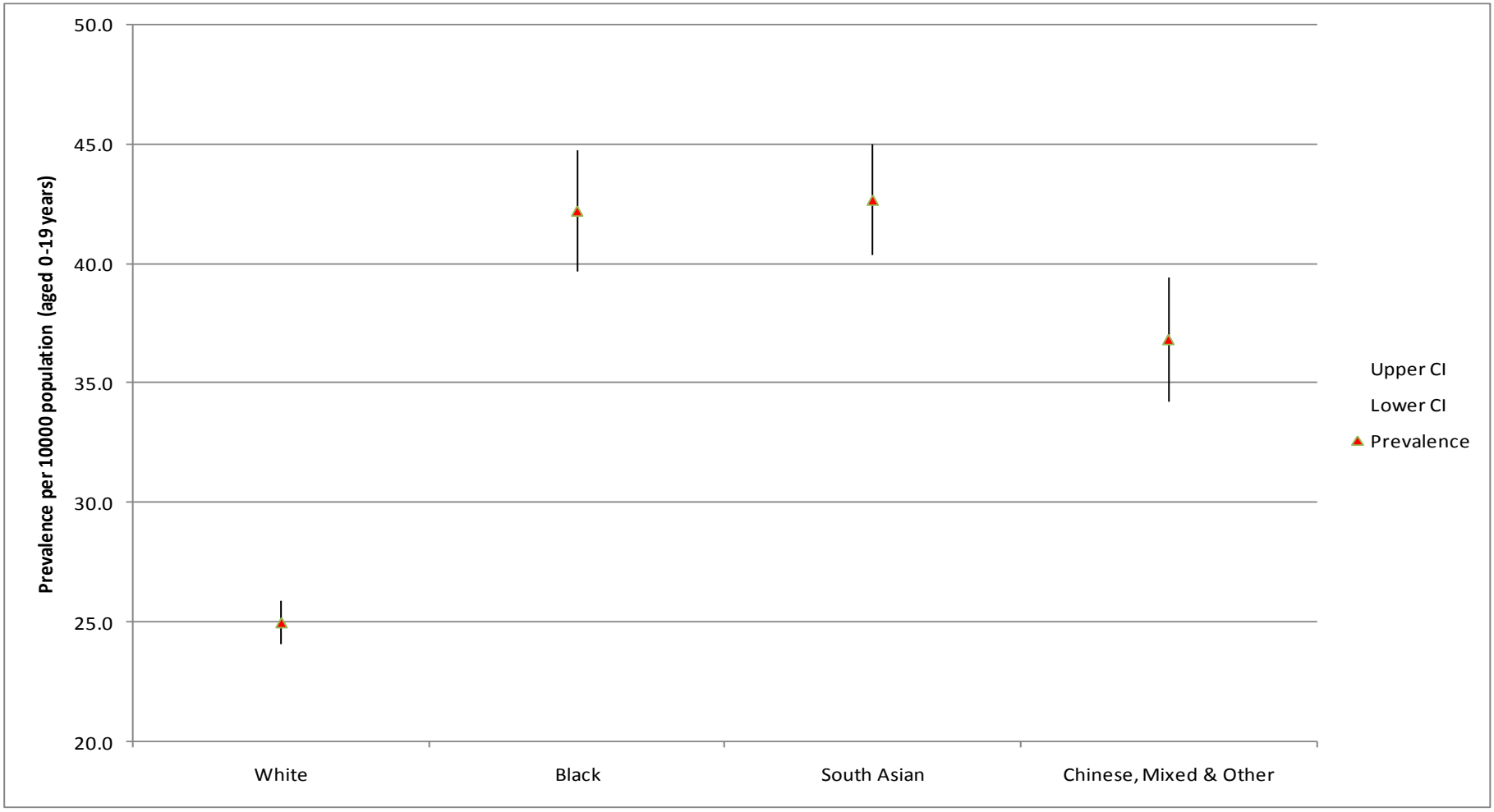

Figure 51 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, London GOR 2009/10

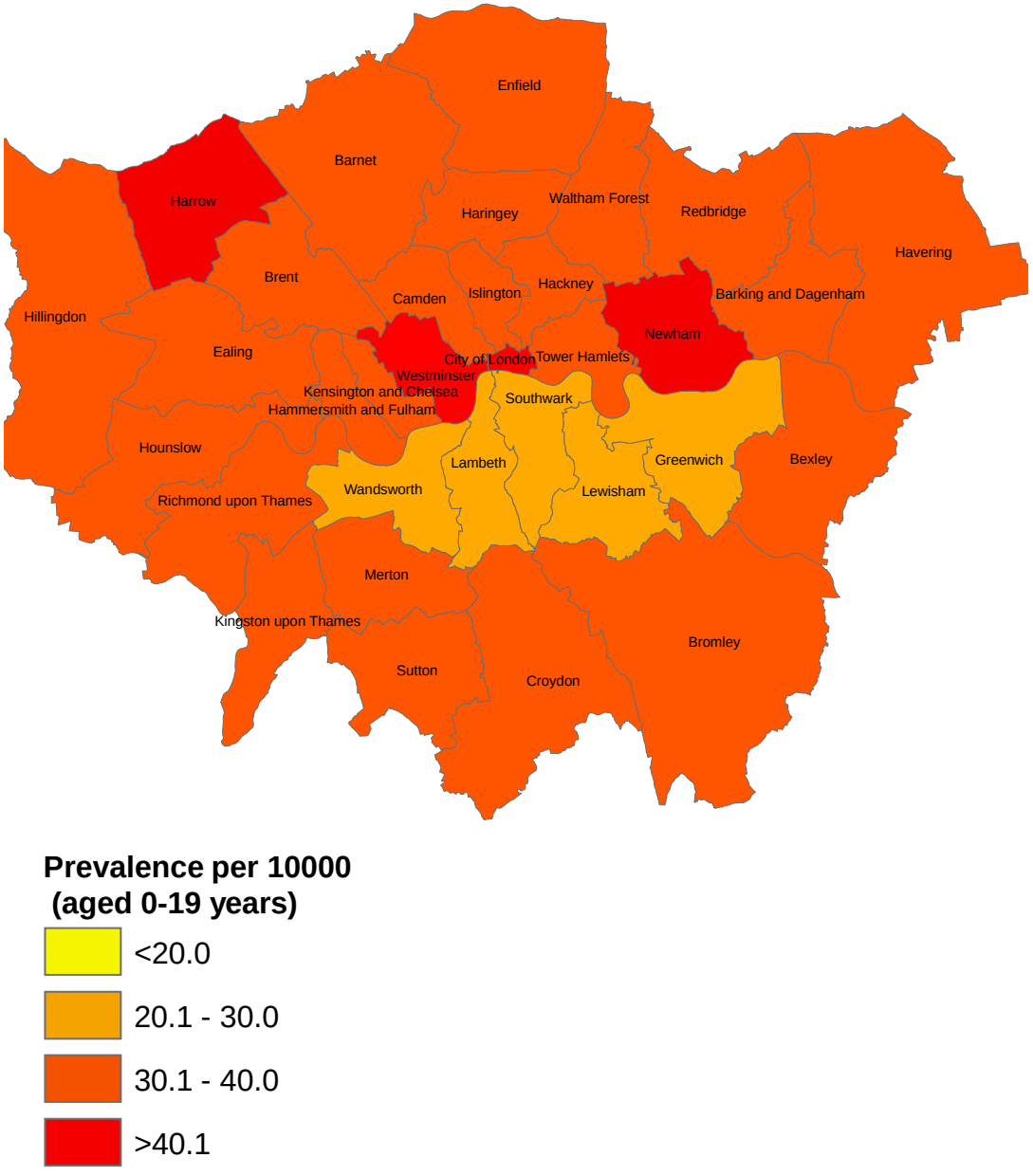

Table 19 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Barking and Dagenham	183	52408	34.9
Barnet	285	82519	34.5
Bexley	165	53032	31.1
Brent	245	69598	35.2
Bromley	219	70520	31.1
Camden	179	46977	38.1
City of London & Westminster	225	40706	55.3
Croydon	314	90374	34.7
Ealing	298	77765	38.3
Enfield	267	72185	37.0
Greenwich	176	61554	28.6
Hackney	200	60798	32.9
Hammersmith and Fulham	120	39385	30.5
Haringey	208	58229	35.7
Harrow	217	50118	43.3
Havering	177	50201	35.3
Hillingdon	244	65008	37.5
Hounslow	183	57936	31.6
Islington	147	41562	35.4
Kensington and Chelsea	105	31953	32.9
Kingston upon Thames	124	37908	32.7
Lambeth	218	76557	28.5
Lewisham	188	70069	26.8
Merton	156	46929	33.2
Newham	356	82083	43.4
Redbridge	249	67289	37.0
Richmond upon Thames	123	39902	30.8
Southwark	201	68092	29.5
Sutton	176	45339	38.8
Tower Hamlets	223	60923	36.6
Waltham Forest	252	63059	40.0
Wandsworth	186	63849	29.1

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Table 20 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 52 and Figure 53.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 54 and Figure 55.

Prevalence per Local authority district for 2009/10 is shown in Figure 56 and Table 21.

Table 20 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the South East Government Office Region, 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	Total	95%CI		Age <1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age 11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	4,594	23.2	22.5	23.9	112.0	105.1	118.9	26.0	24.6	27.5	17.7	16.5	18.8	16.9	15.8	18.0	14.8	13.6	16.0
2001/02	4,581	23.1	22.4	23.8	95.0	88.9	101.2	28.0	26.5	29.5	17.3	16.1	18.4	17.0	15.8	18.1	15.1	13.9	16.3
2002/03	4,818	24.3	23.7	25.0	103.8	97.5	110.2	28.2	26.7	29.8	18.9	17.7	20.1	17.8	16.7	19.0	15.3	14.1	16.5
2003/04	4,770	24.2	23.5	24.9	95.1	89.2	101.1	27.4	25.9	28.9	19.5	18.3	20.7	17.6	16.5	18.8	16.6	15.4	17.9
2004/05	4,841	24.6	23.9	25.3	91.8	86.0	97.6	28.5	26.9	30.0	20.0	18.8	21.3	17.6	16.5	18.7	17.3	16.1	18.6
2005/06	5,329	27.0	26.3	27.8	97.1	91.2	103.0	30.3	28.7	31.8	21.9	20.5	23.2	20.9	19.7	22.2	19.1	17.7	20.4
2006/07	5,443	27.6	26.9	28.3	112.9	106.6	119.1	29.1	27.6	30.7	21.9	20.6	23.3	20.4	19.1	21.6	18.6	17.3	19.9
2007/08	5,808	29.4	28.6	30.1	110.2	104.1	116.4	31.2	29.6	32.8	22.9	21.5	24.2	22.5	21.2	23.8	21.4	20.0	22.7
2008/09	5,832	29.6	28.8	30.3	107.9	101.8	114.1	30.3	28.8	31.8	23.7	22.3	25.1	22.5	21.1	23.8	22.8	21.4	24.2
2009/10	6,196	31.4	30.7	32.2	112.7	106.5	119.0	31.9	30.4	33.5	25.7	24.3	27.2	24.7	23.3	26.2	23.0	21.5	24.4

Figure 52 Prevalence of Life-limiting conditions in children by Gender, South East Government Office Region 2000-2010

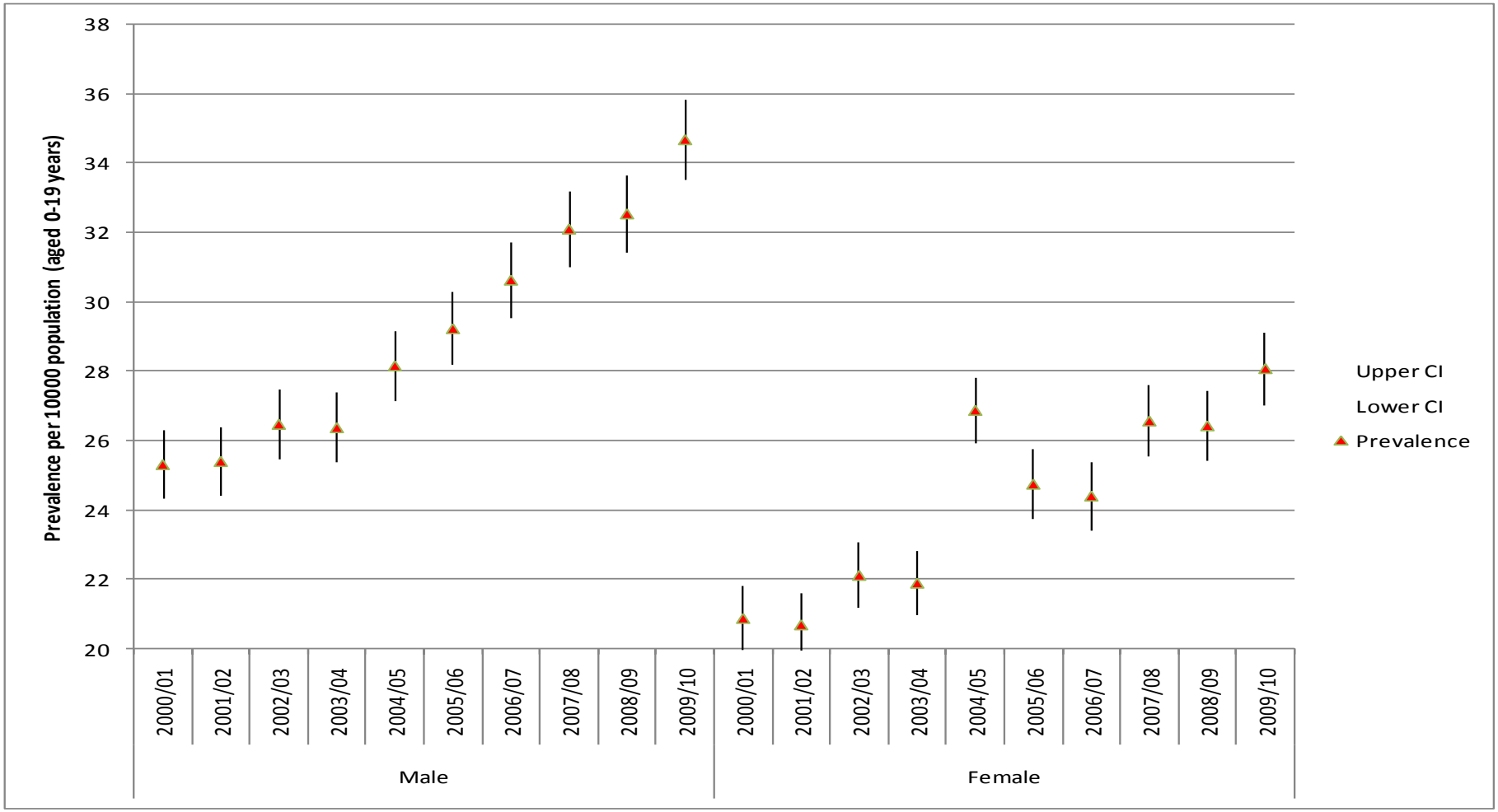

Figure 53 Prevalence of Life-limiting conditions in children by Major Diagnostic group, South East Government Office Region 2000-2010

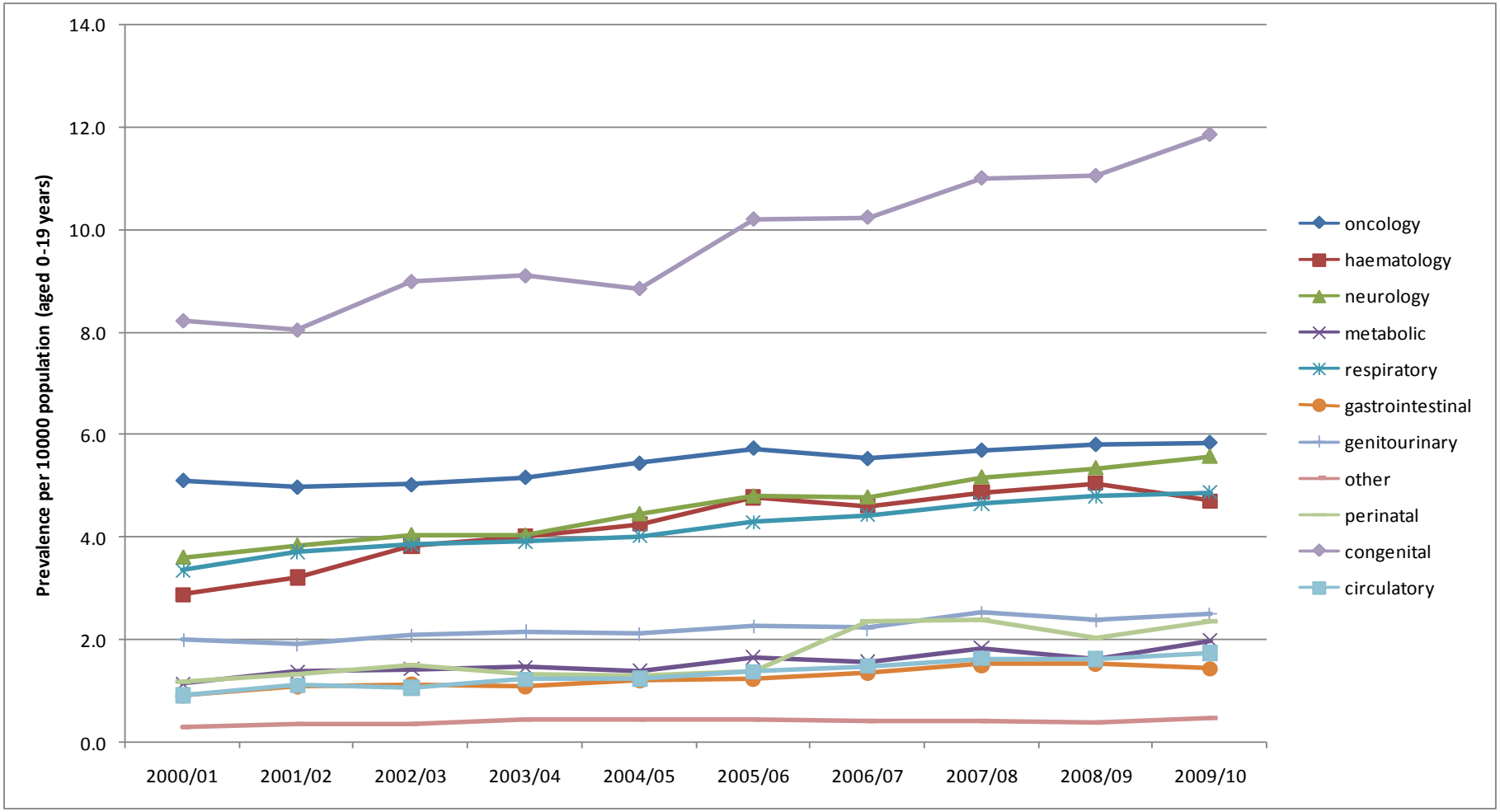

Figure 54 Prevalence of Life-limiting conditions in children by Deprivation category, South East Government Office Region 2000-2010

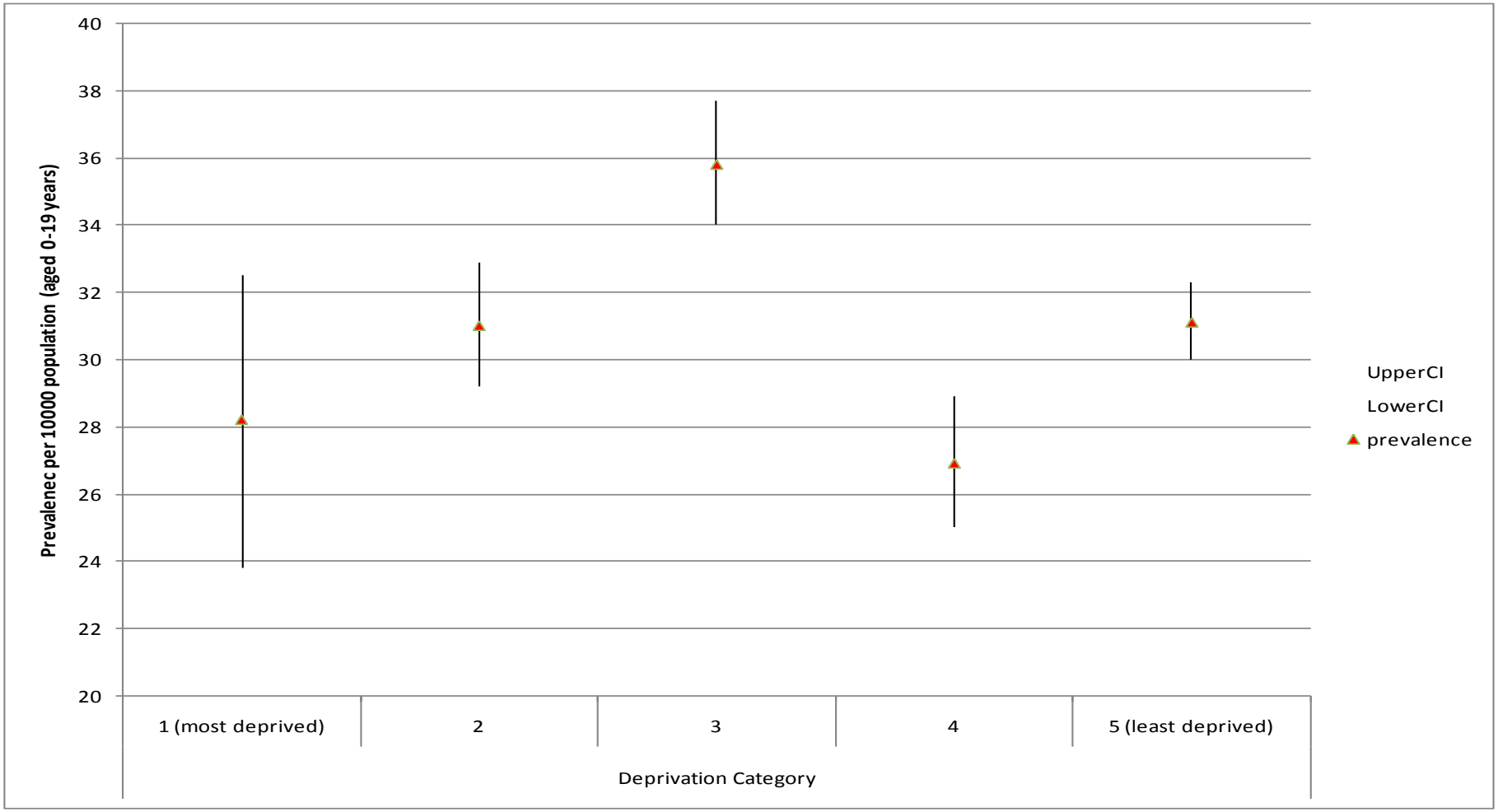

Figure 55 Prevalence of Life-limiting conditions in children by Ethnic group, South East Government Office Region 2000-2010

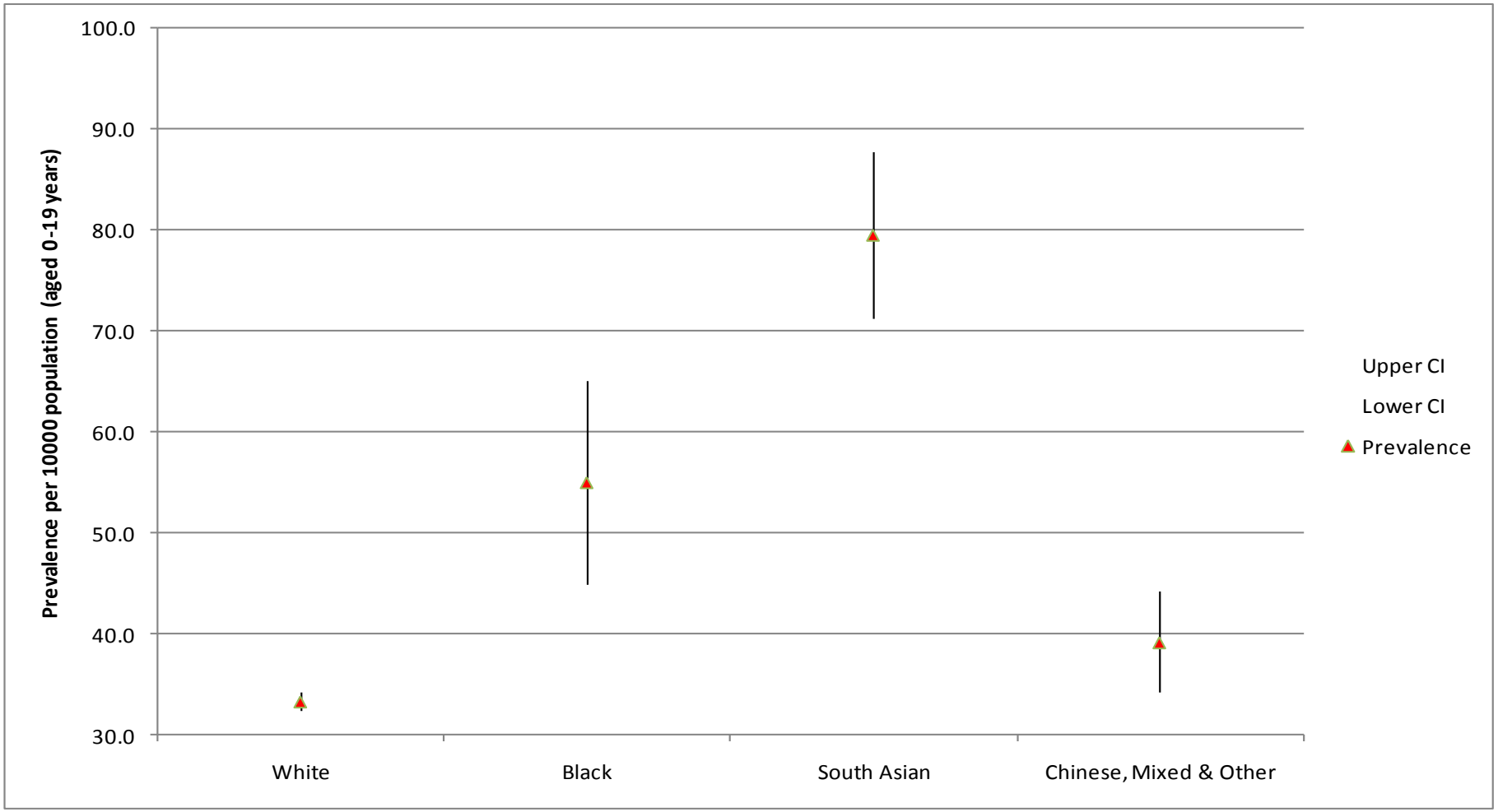

Figure 56 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, South East GOR 2009/10

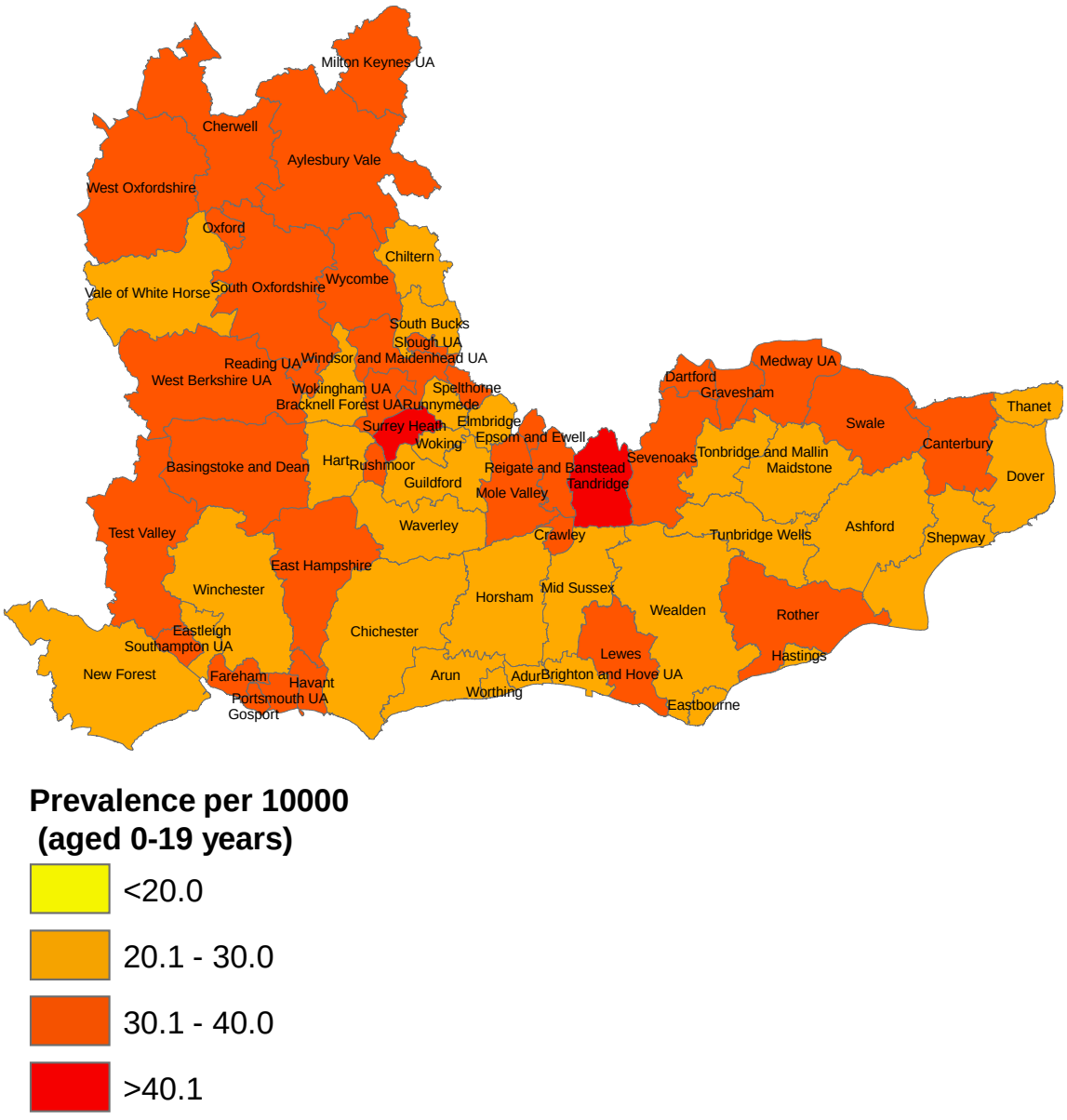

Table 21 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Adur	42	15210	27.6
Arun	99	34322	28.8
Ashford	82	29251	28.0
Aylesbury Vale	134	42517	31.5
Basingstoke and Deane	128	37491	34.1
Bracknell Forest	85	26072	32.6
Brighton and Hove	158	60179	26.3
Canterbury	104	31470	33.0
Cherwell	110	35257	31.2
Chichester	72	24146	29.8
Chiltern	50	19593	25.5
Crawley	99	26500	37.4
Dartford	78	22299	35.0
Dover	70	26609	26.3
East Hampshire	101	26632	37.9
Eastbourne	68	23773	28.6
Eastleigh	81	27762	29.2
Elmbridge	83	29098	28.5
Epsom and Ewell	57	15704	36.3
Fareham	86	24997	34.4
Gosport	65	20118	32.3
Gravesham	85	23497	36.2
Guildford	83	29893	27.8
Hart	58	19919	29.1
Hastings	68	24780	27.4
Havant	97	26591	36.5
Horsham	81	28923	28.0
Isle of Wight	82	32220	25.5
Lewes	64	20903	30.6
Maidstone	97	33730	28.8
Medway	238	65678	36.2
Mid Sussex	80	29139	27.5
Milton Keynes	214	61800	34.6
Mole Valley	59	18067	32.7
New Forest	108	37671	28.7
Oxford	109	30692	35.5
Portsmouth	163	48642	33.5
Reading	138	37702	36.6
Reigate and Banstead	117	31547	37.1
Rother	69	19830	34.8
Runnymede	49	18189	26.9
Rushmoor	83	23051	36.0
Sevenoaks	73	23997	30.4
Shepway	68	25224	27.0
Slough	128	37101	34.5
South Bucks	40	13888	28.8

South Oxfordshire	109	31123	35.0
Southampton	207	56717	36.5
Spelthorne	63	20878	30.2
Surrey Heath	70	17408	40.2
Swale	106	34815	30.4
Tandridge	82	18104	45.3
Test Valley	87	25771	33.8
Thanet	94	32705	28.7
Tonbridge and Malling	74	27016	27.4
Tunbridge Wells	66	24475	27.0
Vale Royal	81	28701	28.2
Waverley	73	25823	28.3
Wealden	88	32382	27.2
West Berkshire	111	33792	32.8
West Oxfordshire	67	22184	30.2
Winchester	69	26423	26.1
Windsor and Maidenhead	95	29636	32.1
Woking	63	22755	27.7
Wokingham	96	33980	28.3
Worthing	65	24244	26.8
Wycombe	133	39731	33.5

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Table 22 shows the crude number of patients and prevalence per 10 000 population by age group and the total.

Prevalence by gender and major diagnostic group are shown in Figure 57 and Figure 58.

Prevalence by deprivation and ethnicity for 2009/10 are shown in Figure 59 and Figure 60.

Prevalence per Local authority district for 2009/10 is shown in Figure 61 and Table 23.

Table 22 Number and prevalence (per 10 000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the South West Government Office Region, 2000-2010

		Prevalence per 10000 population																	
	Number of Patients	Total	95%CI		Age <1 YEAR	95%CI		Age 1-5YR	95%CI		Age 6-10YR	95%CI		Age 11-15YR	95%CI		Age 16-19YR	95%CI	
2000/01	2,777	23.7	22.8	24.6	124.3	114.6	134.0	27.1	25.2	29.0	17.3	15.8	18.8	15.9	14.5	17.3	16.8	15.1	18.4
2001/02	2,817	23.8	23.0	24.7	110.6	101.6	119.6	28.5	26.5	30.5	18.4	16.9	20.0	15.9	14.5	17.3	17.0	15.4	18.6
2002/03	2,906	24.5	23.6	25.3	107.4	98.7	116.1	29.7	27.7	31.8	19.3	17.7	20.9	16.7	15.3	18.1	16.8	15.2	18.4
2003/04	3,073	25.8	24.9	26.7	98.4	90.2	106.6	30.3	28.3	32.4	21.5	19.8	23.2	18.8	17.3	20.4	18.6	16.9	20.2
2004/05	3,128	26.1	25.2	27.0	104.9	96.7	113.2	29.3	27.3	31.4	21.8	20.1	23.4	19.3	17.8	20.8	18.1	16.5	19.7
2005/06	3,386	28.1	27.2	29.1	112.8	104.4	121.2	28.4	26.4	30.3	24.5	22.7	26.3	22.3	20.6	23.9	19.4	17.7	21.0
2006/07	3,409	28.1	27.2	29.1	113.1	104.9	121.3	29.5	27.6	31.5	23.1	21.3	24.9	21.4	19.7	23.0	19.4	17.7	21.0
2007/08	3,335	27.3	26.4	28.2	93.5	86.3	100.8	28.2	26.3	30.1	23.5	21.7	25.3	21.8	20.2	23.5	19.6	17.9	21.3
2008/09	3,492	28.4	27.5	29.4	103.2	95.5	111.0	28.7	26.8	30.6	23.2	21.4	25.0	23.1	21.4	24.8	21.3	19.6	23.1
2009/10	3,709	30.0	29.1	31.0	109.9	101.9	117.8	30.2	28.3	32.1	22.5	20.8	24.3	24.8	23.1	26.6	23.8	21.9	25.6

Figure 57 Prevalence of Life-limiting conditions in children by Gender, South West Government Office Region 2000-2010

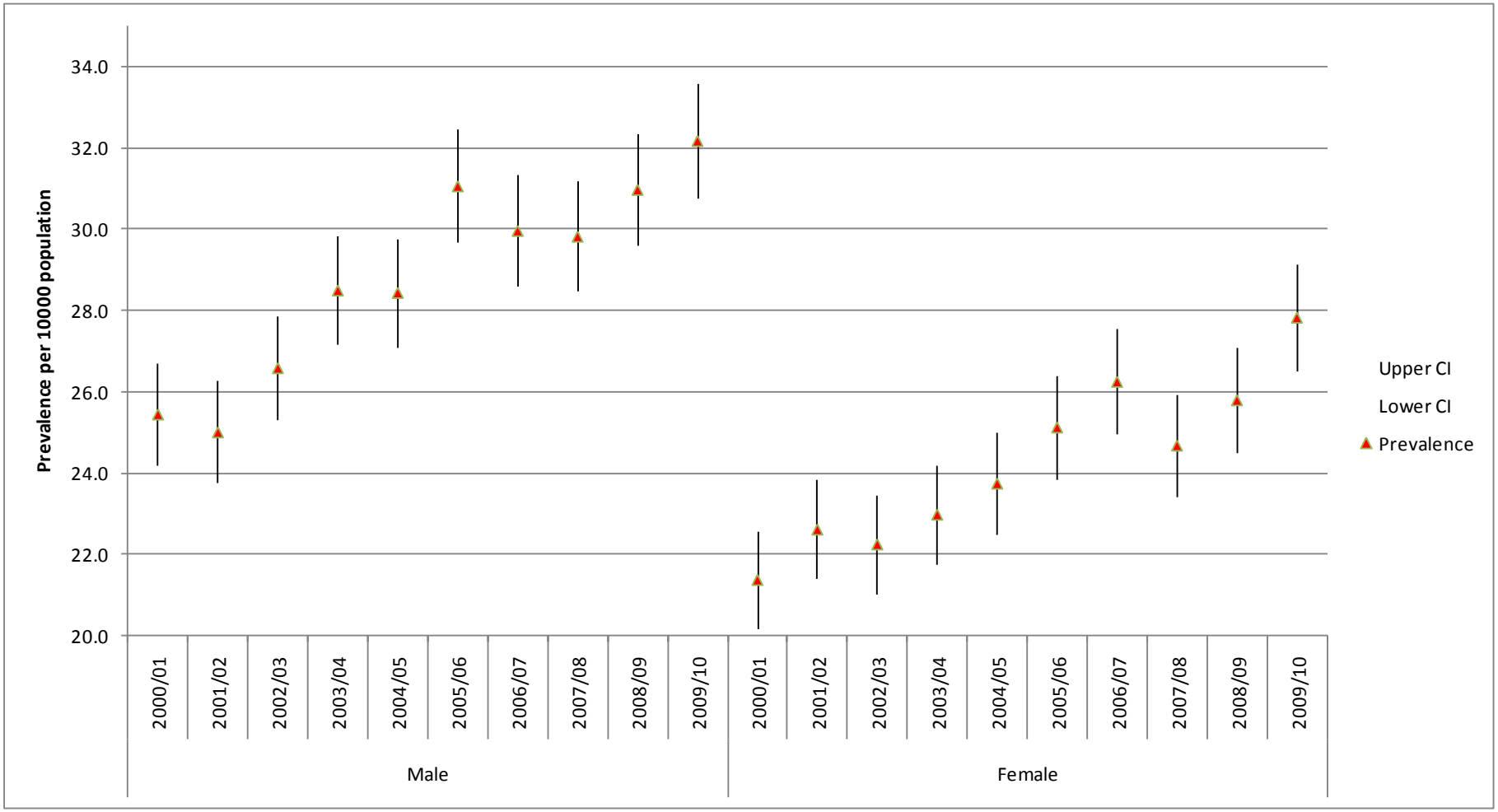

Figure 58 Prevalence of Life-limiting conditions in children by Major Diagnostic group, South West Government Office Region 2000-2010

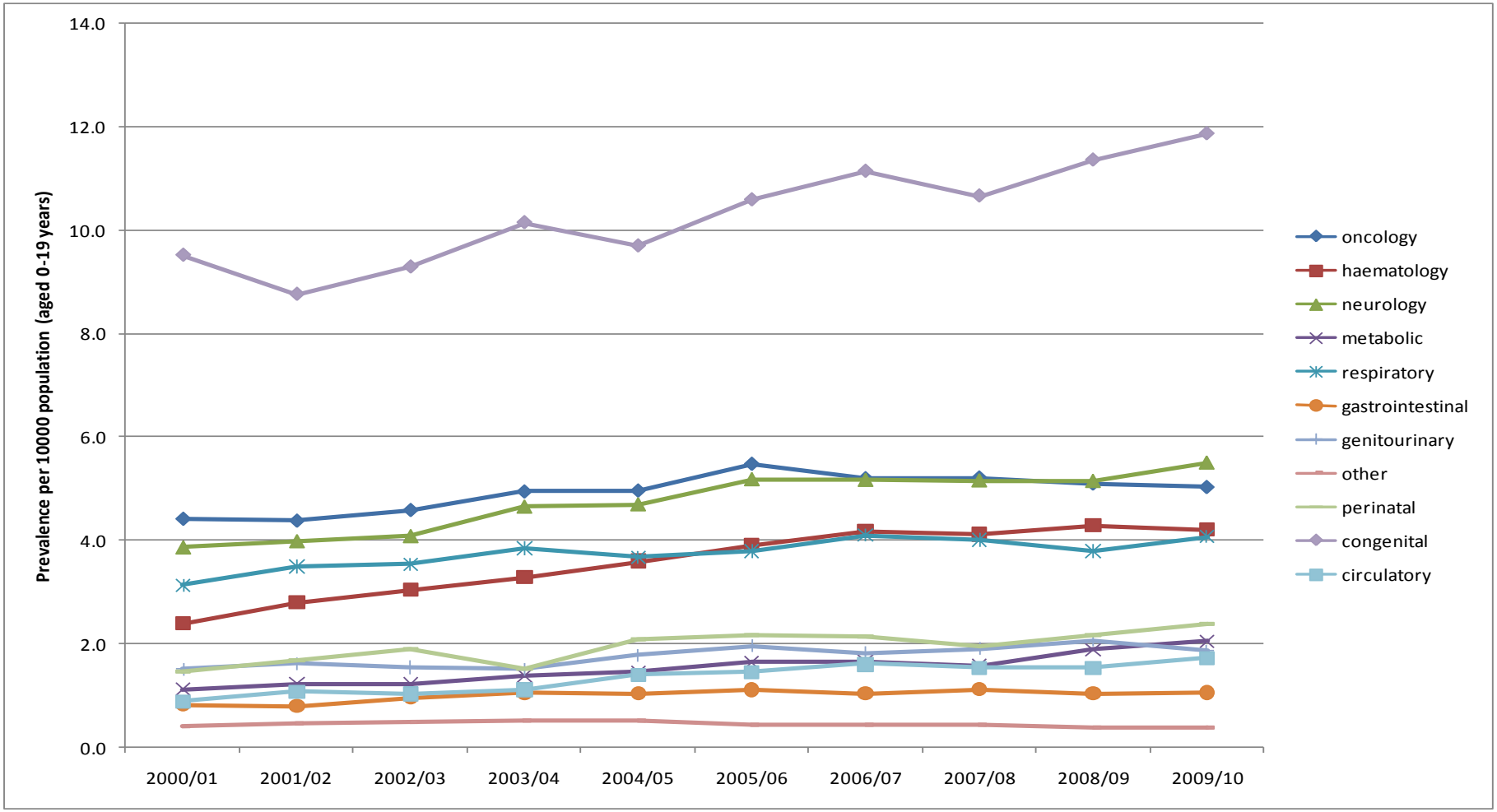

Figure 59 Prevalence of Life-limiting conditions in children by Deprivation category, South West Government Office Region 2009/10

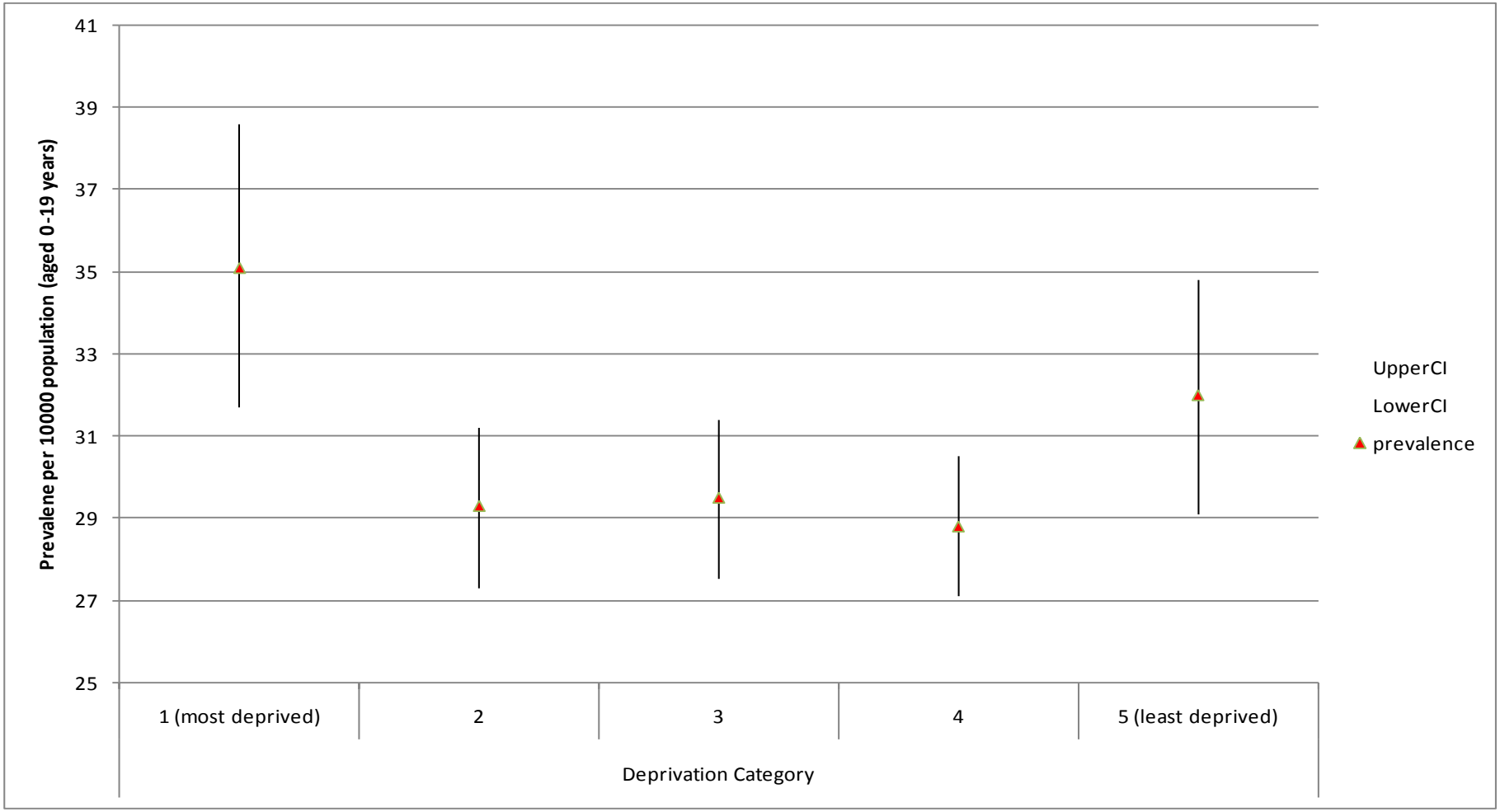

Figure 60 Prevalence of Life-limiting conditions in children by Ethnic group, South West Government Office Region 2009/10

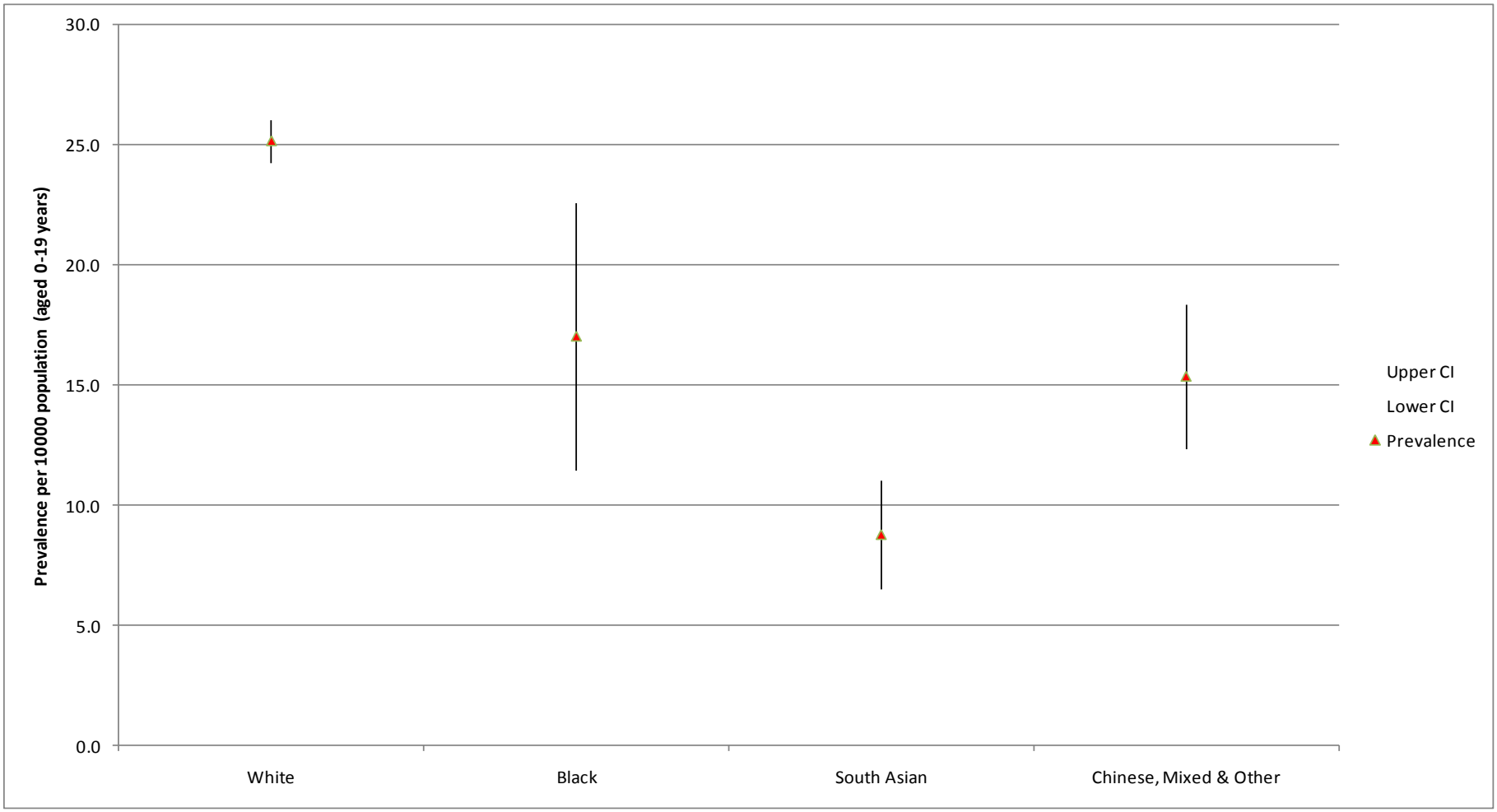

Figure 61 Prevalence of Life-limiting conditions in children (0-19 years) by Local Authority District, South West GOR 2009/10

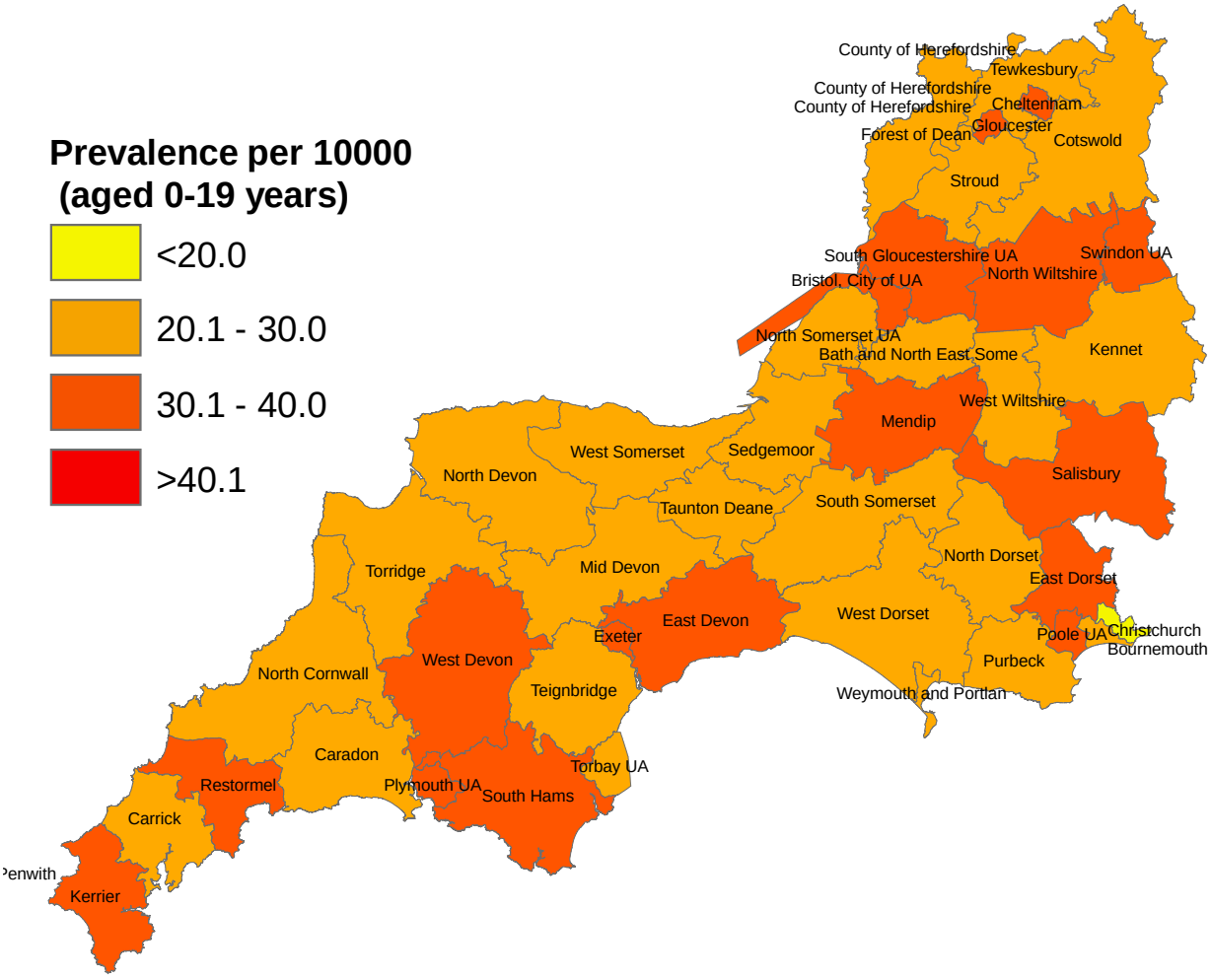

Table 23 Number of Cases of children with Life-limiting Conditions by Local Authority District 2009/10.

Local Authority	Number of cases	Population	Prevalence per 10000 population
Bath and North East Somerset	112	37584	29.8
Bournemouth	104	40732	25.5
Bristol, City of	344	95596	36.0
Caradon	47	18757	25.1
Carrick	61	21066	29.0
Cheltenham	81	26875	30.1
Christchurch	20	11681	17.1
Cotswold	52	18816	27.6
East Devon	98	30564	32.1
East Dorset	67	19742	33.9
Exeter	95	27703	34.3
Forest of Dean	46	20343	22.6
Gloucester	93	28585	32.5
Kennet	52	18395	28.3
Kerrier	87	23207	37.5
Mendip	81	25613	31.6
Mid Devon	57	19248	29.6
North Cornwall	56	21170	26.5
North Devon	60	22698	26.4
North Dorset	50	16857	29.7
North Somerset	133	46626	28.5
North Wiltshire	117	30940	37.8
Penwith & Isles of Scilly	53	16812	31.5
Plymouth	192	60744	31.6
Poole	120	32870	36.5
Purbeck	31	11233	27.6
Restormel	74	24471	30.2
Salisbury	84	27921	30.1
Sedgemoor	82	27522	29.8
South Gloucestershire	190	62009	30.6
South Hams	61	19142	31.9
South Somerset	95	36153	26.3
Stroud	65	25704	25.3
Swindon	158	47010	33.6
Taunton Deane	73	27251	26.8
Teignbridge	84	29297	28.7
Tewkesbury	46	18398	25.0
Torbay	99	33612	29.5
Torridge	47	16861	27.9
West Devon	42	12626	33.3
West Dorset	62	22386	27.7
West Somerset	21	9877	21.3
West Wiltshire	79	32648	24.2
Weymouth and Portland	37	17128	21.6

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