

# Making Every Young Person Count: Estimating Current and Future Prevalence of Young People with Life-limiting and Life-threatening conditions in England

Final Report

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## List of abbreviations and definitions

CI	Confidence Interval
HES	Hospital Episode Statistics
GOR	Government Office Region
ICD	Implantable cardioverter defibrillator
ICD-10	International Classification of Diseases version 10
NHS	National Health Service
LLC	Life Limiting Condition
LTC	Life Threatening Condition
LAD	Local Authority District
ONS	Office for National Statistics
SD	Standard Deviation
Children	Individuals up until their 18 <sup>th</sup> birthday
Young people	Individuals aged 14-25 years
Young adults	Individuals aged 18-25 years



## Executive summary

1. Life-limiting and life-threatening conditions (LLC) are terms which have been used to describe the population of children and young adults who may benefit from input from paediatric palliative care services.
2. Many young people with life-limiting or life-threatening conditions are surviving into adulthood and therefore require transition to adult health services which may include adult palliative care providers.
3. This study used routinely collected hospital and death certificate data from England to provide an update of current numbers and prevalence of young people (14-25 years) with a life-limiting condition and estimate future prevalence (up to 2030).
4. Young people aged 14-25 years were identified as having a LLC using a list of diagnostic codes (ICD-10) previously developed to identify children with a LLC. The dataset contained **138,356** individuals over an eight year time period (from 2009/10-2017/8).
5. The number of young people with a LLC identified in this dataset from England rose from 27,316 in 2009/10 to 38,261 in 2017/18. The numbers of young people with a LLC who were diagnosed whilst still in childhood (and therefore eligible for transition)(age <18) rose from 16,107 in 2009/10 to 24,773 in 2017/18.
6. The national prevalence of LLC in young people (aged 14-25 years) in England had increased over eight years from 33.5 per 10,000 in 2009/10 to 46.7 per 10,000 in 2017/18. The prevalence of young people with a LLC who were diagnosed whilst still in childhood (age <18) rose from 19.7 per 10,000 in 2009/10 to 30.2 per 10,000 in 2017/18.
7. The prevalence of LLCs was similar between young people aged 14-17 years and young adults aged 18-25 years although the increase in prevalence was slightly larger in the younger age group resulting a prevalence of 51.9 per 10,000 in 2017/18 compared to 44.6 per 10,000 for young adults. Excluding young adults diagnosed aged  $\geq 18$  years reduced the prevalence of the older age group to 21.2 per 10,000 in 2017/18.
8. The prevalence of LLCs was highest for congenital, oncology and neurology conditions, whose prevalence in 2017/18 was 12.9 per 10,000, 10.1 per 10,000 and 9.6 per 10,000 respectively. Among young people diagnosed as children, congenital disorders were also the most prevalent at 10.6 per 10,000 in 2017/18.
9. The prevalence of LLCs was significantly higher among females (50.8 per 10,000 vs males 42.8 per 10,000 (2017/18)), however after excluding young adults diagnosed aged  $\geq 18$  years there was no significant difference in prevalence up to 2013 and a marginal difference after this point.
10. Prevalence of LLCs was highest amongst young people of Pakistani origin (76.8 per 10,000). This was also true after excluding young adults diagnosed  $\geq 18$  years (56.8 per 10,000). This is important in terms of flexibility of service to meet the needs of all young people.
11. More young people with a LLC than expected lived in areas of higher deprivation (24% most deprived versus 18% in least deprived). The deprivation categories were population weighted with 20% of the general population in each category; therefore it would be expected that  $\sim 20\%$  of young people with a LLC would be in each category.
12. The future prevalence of young people aged 14-25 years with a LLC in England is estimated to be between 46.0 and 62.2 per 10,000 by 2030. There is a range of uncertainty around these estimates. Excluding those

diagnosed as young adults (aged  $\geq 18$  years), future prevalence is estimated to range between 31.0-46.0 per 10,000.

13. More than a third (38%) of hospital episodes for young adults aged 18 years or older between 2009/10-2017/18 were for those diagnosed with a LLC as adults.
14. The age of diagnosis had an impact on the clinical and demographic characteristics of this population. The main differences being that congenital and neurological diagnosis were more prevalent in young adults (aged  $\geq 18$  years) diagnosed as a child, whilst oncology diagnoses are more prevalence in those diagnosed as adults.
15. 6.0% (n=8,301) of the young people with a LLC died (at any age) during the study period.
16. Overall most deaths occurred in Hospital (62%). Home deaths (25% overall) were more common (31%) among young people who died  $>25$  years. The proportion of hospice deaths (9% overall) was higher in young adults aged  $\geq 18$  years diagnosed as adults (10%) compared to young adults diagnosed as children (7%).
17. The diagnostic framework developed to identify children with a LLC should be used with caution in the young adult population. Many cancer diagnoses in the young adult age group e.g. cervical or breast cancer have very good outcomes.
18. These datasets did not have any information on whether palliative care services were involved in the care of these young adults.
19. The planned national data collection in the All Age Palliative and End of Life Care Programme should include information of young people who will require transition from paediatric to adult services.
20. These data did not contain any measure of complexity of the underlying condition or the needs of the young adult or family, future research and data collection should address this gap.

## Background

Life-limiting conditions (LLC) in childhood are those for which there is no reasonable hope of cure and from which children or young people are expected to die (Together For Short Lives 2018). Life-threatening conditions (LTC) in childhood are those conditions for which curative treatment may be feasible but can fail, such as cancer (Together For Short Lives 2018). The population of children with life-limiting and life-threatening conditions (hereafter referred to as LLCs), is a very heterogeneous group with nearly four hundred individual diagnoses classified as life-limiting or life-threatening (Noyes, Edwards et al. 2013).

Previous research has shown that the prevalence of life-limiting conditions in children and adults is U shaped with higher prevalence in the under 1-year and 36–40 -year age groups with the lowest prevalence in the 20–25 -year age group (Fraser, Lidstone et al. 2014). In adults, the higher prevalence is accounted for by patients with an oncology diagnosis (Fraser, Lidstone et al. 2014). That study did not differentiate between the young adults who had a LLC diagnosed in childhood who may have experienced paediatric palliative care services and patients who had been diagnosed with a LLC as a young adult (age  $\geq 18$  years). The life experience of these two groups is likely to be quite different, and the needs and expectations of these two groups of patients may differ considerably. More children with LLCs are surviving into adulthood and therefore will require transition to adult services, a process which involves supporting young people through adolescence and their move from paediatric to adult services which may include adult palliative care providers.

A recent study, utilising the same datasets as this report, has shown that the number of children with LLCs in the UK has been rising with latest estimates showing more than 86,000 children and young people (0-19 years) with a LLC in England in 2017/18 (Fraser, Gibson-Smith et al. 2020). However, this study only included children and young people up to age 19 years, therefore information on young adults is currently not available.

## Aim

To estimate the number and prevalence of young people (aged 14- 25 years) with life-limiting and life-threatening conditions in England.

## Objectives

1. To assess trends in the prevalence of young people with LLCs in England (14-25 years) (2009/10-2017/18) by age group, diagnostic group, sex, ethnic group, deprivation and geographical region using hospital admissions data.
2. To assess trends in prevalence of young people with LLCs in England (14-25 years) (2009/10- 2017/18), excluding young people diagnosed aged  $\geq 18$  years, by age group, diagnostic group, sex, ethnic group, deprivation and geographical region using hospital admissions data.
3. To model the future national prevalence of young people in England (14-25 years) with LLCs utilising ethnic specific population projections data (2018-2030, including and excluding those diagnosed during adulthood ( $\geq 18$  years))

4. To quantify the proportion of young adults (age  $\geq 18$  years) who were first diagnosed as children ( $< 18$  years) or were first diagnosed as adults ( $\geq 18$  years) and compare the prevalence by age group, diagnostic group, sex, ethnic group, deprivation and region (2009/10- 2017/18).
5. To describe the number of young people with a LLC who die in England each year, split by age of death, and to describe their place of death split by age of death and age of diagnosis.
6. To assess trends in prevalence within each Government Office Region in England by age group, diagnostic group, sex, ethnicity, deprivation and Local Authority Region, including and excluding those diagnosed during adulthood ( $\geq 18$  years).

## Methods

### Data Sources

Hospital Episode Statistics Admitted Patient Care (HES) data for the period 2000-2017 linked to the Office for National Statistics (ONS) mortality data were obtained from NHS digital (Health & Social Care Information Centre 2015). HES is a database containing details of all admissions, accident and emergency attendance and outpatient appointments at NHS hospitals in England (Health & Social Care Information Centre 2015). The data include private patients treated in NHS hospitals, patients resident outside England treated in hospitals in England and care delivered by treatment centres funded by the NHS. HES records include information about clinical diagnoses and operations, patient information such as age, sex and ethnicity, dates of admission and discharge and geographical information about where patients live and are treated.

### Life-Limiting Conditions

A list of ICD-10 codes was produced for a previous study in order to identify **children** with a life-limiting or life-threatening condition (Fraser, Miller et al. 2012). This code list was derived as below:

1. Two independent sources of information were used: the Hain Dictionary (Hain, Devins et al. 2013) version 1.0 of ICD-10 codes for children seen by palliative care providers and a list of diagnoses for children accepted for care at Martin House Children's Hospice, Yorkshire, England from 1987 to 2010.
2. A 4-digit ICD-10 code was assigned to 92% of diagnoses on the Martin House list; the 8% not coded were children without clear diagnoses (e.g., "degenerative neurologic disease with no firm diagnosis").
3. Combining both sets of codes produced a provisional list of 801 ICD-10 codes for further scrutiny (84% of codes appeared on both lists).
4. All of these ICD-10 codes were individually subjected to the following two questions:
  - I. Are most children with this diagnosis life-limited/life-threatened?
  - II. Are most sub-diagnoses within the ICD-10 code life-limiting/life-threatening?
5. A list of ICD-10 codes that fulfilled these criteria was compiled and completed by adding all malignant oncology ICD-10 codes (the data source was hospital admissions, so this would not include children "cured" of cancer). The final ICD-10 coding framework consisted of 777 4-digit ICD-10 codes (*Table 1*). Malignant oncology codes accounted for 445 (57%) codes, with congenital malformations and chromosomal abnormalities having 87 (11%) codes. It should be noted that this ICD-10 framework was developed using data from children (<19 years) not young adults.

This ICD-10 coding framework has been shown to be sensitive (i.e. it identifies the children with a LLC) by identifying 75% of children who died in paediatric intensive care units (Fraser and Parslow 2018) but there are some concerns about its specificity (i.e. it may also pick up children who do not have a LLC). This is due to the grouping of diagnoses within ICD-10 and the variation in clinical features of some of these diagnoses. Therefore, in this study an attempt was made to refine this list.

The list of ICD-10 codes was assessed by the independent advisory panel for this study and a group of codes/exclusions were identified where the panel felt that the child may not be always be considered as having a LLC or LTC. As early stage (1-3) renal failure only appeared after 2010, it was decided to exclude these ICD10 codes from all analysis. It was also decided to exclude non-specific acute kidney failure from all analysis, as this is not a Life-limiting condition. For additional categories a sensitivity analysis assessing the impact of removing these codes was undertaken. Thus the following exclusions were explored:

- I. Perinatal diagnoses beyond the age of 1 year, restricting inclusion of perinatal diagnoses to age under 1 (for an individual to be included beyond age 1 a non-perinatal LLC diagnosis is required)
- II. Oncology cases 5 years after first oncology diagnosis (assuming no other LLC is present)
- III. Non central nervous system (CNS) oncology cases 5 years after first oncology diagnosis (assuming no other LLC is present)

Diagnostic Group	ICD-10 Numbers
<b>Neurology</b>	A17 A810 A811 F803 F842 G10 G111 G113 G12 G20 G230 G238 G318 G319 G35 G404 G405 G600 G601 G702 G709 G710 G711 G712 G713 G800 G808 G823 G824 G825 G934 G936 G937
<b>Haematology</b>	B20 B21 B22 B23 B24 D561 D610 D619 D70 D761 D81 D821 D83 D891
<b>Oncology</b>	C D444 D48 (Central Nervous System: C70,C71,C72, D33, D43)
<b>Metabolic</b>	E310 E348 E702 E71 E72 E74 E75 E76 E77 E791 E830 E880 E881
<b>Respiratory</b>	E84 J841 J96 J984
<b>Circulatory</b>	I21 I270 I42 I613 I81
<b>Gastrointestinal</b>	K550 K559 K72 K74 K765 K868
<b>Genitourinary</b>	N170 N171 N172 N178 N172 N18 N19 N258 (Early stage (1-3) renal:N181, N182, N183)
<b>Perinatal</b>	P101 P112 P210 P285 P290 P293 P350 P351 P358 P371 P524 P525 P529 P832 P912 P916 P960
<b>Congenital</b>	Q000 Q01 Q031 Q039 Q040 Q042 Q043 Q044 Q046 Q049 Q070 Q200 Q203 Q204 Q206 Q208 Q213 Q232 Q218 Q220 Q221 Q224 Q225 Q226 Q230 Q234 Q239 Q254 Q256 Q262 Q264 Q268 Q282 Q321 Q336 Q396 Q410 Q419 Q437 Q442 Q445 Q447 Q601 Q606 Q614 Q619 Q642 Q743 Q748 Q750 Q772 Q773 Q774 Q780 Q785 Q792 Q793 Q804 Q81 Q821 Q824 Q858 Q860 Q870 Q871 Q872 Q878 Q91 Q920 Q921 Q924 Q927 Q928 Q932 Q933 Q934 Q935 Q938 Q952
<b>Other</b>	H111 H498 H355 M313 M321 M895 T860 T862 Z515

## Patient data

A pre-existing extract of clinical and demographic information on all hospital episodes for children and young adults aged 0-25 years who had ever had an ICD-10 code for a LLC (*Table 1*) recorded within the admitted patient HES data was received from NHS Digital. These data were available for the period 01/04/2000 until 31/3/2018.

These HES data were linked to the Office for National Statistics (ONS) death certificate data and, if the child, teenager or young adult had died during the period of the study, information on date of death, place of death and cause of death was available (Health & Social Care Information Centre 2015).

## Population data

Population estimates broken down by age, sex, ethnicity and Government Office Regions were obtained from <http://ethpop.org> (Wohland P. 2016). This source has been used in preference to the sub-national estimates produced by the Office of National Statistics because the cohort component population estimate incorporates more detailed demographic information by ethnic group in relation to newborns, mortality, and most importantly, both subnational migration and international migration (Rees P. 2011, Wohland P. 2016). These data were available as mid-year estimates for 2001-2017 and projected estimates up to 2030. ETHPOP includes subnational projections of population by ethnic group, age and sex beyond 2050 based on census estimates for 2001 and 2011. Here we incorporate populations projected to 2030.

## Data cleaning

Young people were only included in this study if they had been diagnosed with a LLC between 01/04/2000 and 31/03/2018. All data from 01/04/2000 were used for diagnoses and demographic information but prevalence was only calculated from 2009 onwards as at that point all individuals had at least two years' worth of data whilst they were a child (< 18 years). Using earlier data for prevalence would have included individuals with little or no time in the dataset when aged < 18 years and so little or no chance of being identified as being diagnosed as a child. The financial year and age at which a LLC was first recorded for each young person was identified using data from 1/4/2000 onwards. Subsequently, hospital episodes outside the study period (01/04/2009-31/3/2018), for young people who resided outside England (identified by Government Office Region code) for young people younger than 14 years of age or older than 25 years, were removed from the extract. Hospital episodes occurring prior to the first recorded LLC were excluded for the prevalence analyses. For the second objective, young people whose first recorded diagnosis was at age 18 years or older were excluded. In the sensitivity analysis hospital episodes were only use for prevalence estimation after a first diagnosis from the more restricted list of LLC-indicative IC10 codes.

Demographic information was derived using all years of available data and was defined as follows:-

**Age** - Age was taken from the age at the start of the first hospital episode in each financial year and grouped into age categories (14 to 17 years, 18 to 25 years) for the main analysis.

**Diagnostic group** - Diagnoses were grouped according to eleven diagnostic groups (neurology, haematology, oncology, metabolic, respiratory, circulatory, gastrointestinal, genitourinary, perinatal, congenital and other) which were mostly based on ICD-10 chapters (*Table 1*) (Fraser, Miller et al. 2012). No priority was given to diagnostic group and individuals were allowed to have more than one LLC diagnostic group.

**Sex** - Sex was recorded as male or female. Individuals with conflicting multiple codings were assigned the most commonly reported sex from records in which sex was not missing.

**Ethnicity** - Ethnicity was reported using the 2001 census groups (NOMIS 2013). Ethnic groups were classified into eight groups by collapsing the 16 Census groups as follows:

- White (White: British, White: Irish, Other White),
- Black (Black or Black British: Black Caribbean, Black or Black British: Black African, Black or Black British: Other Black),
- Indian (Asian or Asian British: Indian),
- Pakistani (Asian or Asian British: Pakistani),
- Bangladeshi (Asian or Asian British: Bangladeshi),
- Chinese, Mixed (Mixed: White and Black Caribbean,
- Mixed: White and Black African, Mixed: White and Asian, Mixed: Other Mixed),
- Other Asian.

Individuals with more than one ethnicity were assigned the most commonly reported ethnicity, excluding records in which ethnicity was 'not known', thereby ensuring that an individual's ethnicity was assigned to all episodes. In the case of a tie for the most common ethnicity, the most recently recorded of the tied ethnicities was used.

**Region & Local Authority-** The HES data provided details of both Local Authority District (LAD) and Government Office Regional (GOR) codes. When an individual had multiple LADs in one year, the first non-missing LAD was used. The Government Office Regional codes referred to one of nine subnational geographical areas (East Midlands, East of England, London, North East, North West, South East, South West, West Midlands and Yorkshire and Humber). For each financial year the first non-missing GOR was used. In event of conflicting GORs for duplicate admission dates, non-missing data (region) was prioritised. Where possible missing GORs were replaced with the GOR from the previous or later year, prioritising earlier GORs.

**Deprivation** - An index of multiple deprivation (IMD2010) (Department for Communities and Local Government 2011) was assigned to each individual based on the 2001 Lower-layer Super Output Area (LSOA) of residence. If there was no known LSOA in a year, but the individual was known from Government Office Region of Residence to be in England then (in preference order) the last known LSOA from preceding years or the next known LSOA from later years was assigned. Five deprivation categories were created, from least (category 1) to most deprived (category 5), based on IMD2010 scores. These were population weighted using mid-year estimates from the ETHPOP data for 2010 so that each category contained approximately 20% of individuals in England aged 14-25 years. Assignment of deprivation code was undertaken each year and if an individual moved during that year the deprivation code associated with the first LSOA in that year was used.

Additionally, separate deprivation categories were assigned **within** regions. Five deprivation categories were created ranking the deprivation status within that region from least (category 1) to most deprived (category 5). The categories were weighted to ensure an even distribution of the overall population within each category using the regional populations. Thus, each category contained approximately 20% of the population (aged 14-25 years) for that region.



## Statistical analysis

### Current prevalence

Young people with an eligible condition were identified and counted each financial year (see case identification criteria below).

The prevalence per 10,000 population (aged 14-25 years) per financial year was calculated according to the formula below. Additionally, the prevalence was estimated broken down by age group, diagnostic group, sex, ethnic group, region and Local Authority District.

$$prevalence = \frac{\text{number of individuals with an eligible condition}}{\text{population at risk}} \times 10000$$

The number of young people in each deprivation category was expressed as a proportion of the number of young people aged 14-25 years with an eligible condition.

Regional summaries presenting prevalence by age group, diagnosis, sex, ethnicity, deprivation (within the region) and local authority district are provided. For the regional summaries, deprivation was expressed as a proportion of the number of young people aged 14-25 years children with an eligible condition.

### Case Identification

An individual young person was included in a financial year during the study period (1/04/2009-31/3/2018) if they fulfilled the following criteria:-

- 1) Had a diagnosis of one of the LLC/LTC ICD-10 codes in the current year or a previous (from 1/4/2000) year;
- 2) Had a hospital admission in the year of analysis
- 3) Were aged 14-25 years for the first hospital admission of the year
- 4) Were resident in England

### Denominator data

The population at risk was estimated using ethnic specific population data sourced from the ETHPOP dataset (Wohland P. 2016). From separate ETHPOP datasets annual population estimates were made by LAD and deprivation category by LAD for 2017. 95% confidence intervals (CI) for the prevalence estimates were calculated using standard methods for Confidence intervals for proportions (Bland 2015).

### Sensitivity analysis

A series of sensitivity analyses were conducted where the definition of a LLC was restricted to exclude the following three sets of diagnoses identified by the advisory board, individually and combined to assess the effect on overall prevalence figures:

- (i) Perinatal disorders were assumed not to be relevant after the first birthday<sup>1</sup>;
- (ii) Oncology cases 5 years after diagnosis after which point they were assumed to be resolved;
- (iii) Non-central nervous system (CNS) oncology cases 5 years after diagnosis after which point they were assumed to be resolved

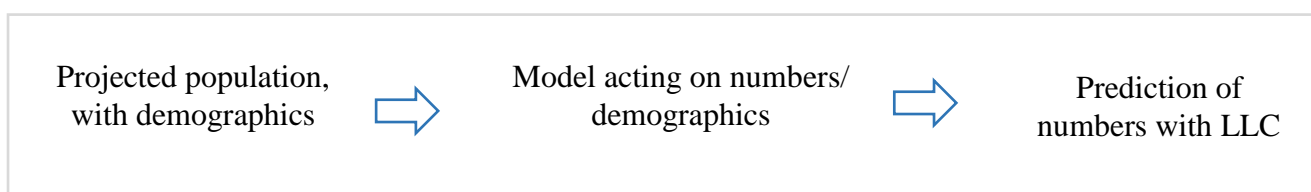
#### Current prevalence: Young people diagnosed <18 years

The overall prevalence calculations included all young people irrespective of the age that they were diagnosed with a LLC. In order to understand the similarities or differences between those diagnosed as children (<18 years) or those diagnosed as young adults ( $\geq 18$  years) these groups were disaggregated in further analyses. This enabled a second set of prevalence calculations which only included those aged 14-25 years who had been diagnosed as a child and who may need to transition between paediatric and adult services. This prevalence was calculated overall (2009/10-2017/18) and broken down by age, diagnostic group, sex, ethnic group and GOR. The proportion of young people in each deprivation category was also calculated. Additionally, the prevalence using the more restricted definition of LLCs was calculated.

#### Modelling of Prevalence to 2030

Modelling future prevalence was estimated using a population based modelling approach (Murrey and Lopez 1997) (Figure 1). This modelling approach automatically adjusts for changing population demographics and does not require separation of incidence, survival and migration. The ETHPOP data was used for the population estimates (Wohland P. 2016).

The number of young people with an eligible condition was calculated by first estimating the annual probability of an individual with each unique combination of demographic characteristics having an eligible condition for the period 2018/19-2030/31, using logistic regression on data on young people aged 14-25 years for 2009/10-2016/17. Age categories, sex, ethnicity and GOR were included as predictive variables in the regression.



**Figure 1: Future projection modelling approach**

Projections of future numbers and prevalence were made for the whole population of young people aged 14-25 years and also excluding young adults first diagnosed  $\geq 18$  years. The predicted number of young people with an

<sup>1</sup> Assumption is that if they had an ongoing LLC after age 1 this would be recoded e.g., a baby with severe birth asphyxia would be recoded as having cerebral palsy

eligible condition was estimated by multiplying the probability of having an eligible condition by the total estimated population for that year. Further information on calculating the future prevalence is detailed in Appendix I

Three models were developed using estimates of the number of young people aged 14-25 years with eligible conditions from 2009-2016. These years were chosen as 2009 is the first year in which it is possible for a young adult aged 25 years to have had early episodes, and hence a LLC diagnosis, as a child within the period covered by the data (i.e. aged < 18 in 2000). The first model (Model 1) assumed trends in incidence and survival for young people with a LLC would continue (i.e. that changes in prevalence year-on-year not explained by changing demographics - and so due to changes in incidence, survival or both - would continue). The second model (Model 2) used similar estimates and the same time period as the first model but used a restricted definition of LLC, i.e. excluding oncology diagnosis 5 years after the 1<sup>st</sup> diagnosis and perinatal diagnosis one year after birth. The third, most conservative model (Model 3) provides a lower boundary of possible future prevalence, albeit not necessarily a realistic scenario. This model assumed no further improvement in survival or increase in incidence.

#### [Age of diagnosis: Young adults diagnosed during childhood compared to adulthood](#)

The longitudinal nature of these data enables some differentiation of young people who have been diagnosed with a life-limiting or life-threatening condition whilst still in paediatric services (<18 years) and those diagnosed in young adulthood ( $\geq 18$  years). The characteristics, and in particular the diagnostic group, of young adults diagnosed aged 18 years or older is likely to differ from young adults who were diagnosed as having a LLC during their childhood (Fraser, Lidstone et al. 2014). In order to understand the distribution of young adults who were diagnosed in childhood, a summary was made of the number of young people who were currently still a child (below the age 18 years), young adults (18 years and older) who were diagnosed <18 years and young adults who were diagnosed as adults ( $\geq 18$  years). The number of individuals who died each year within these three groups was also calculated and compared.

A comparison of characteristics between the two groups of adults (diagnosed <18 years and diagnosed  $\geq 18$  years) was also undertaken. Using data from 2009/10 onwards, a summary of the number and prevalence per 10,000 of young people aged 18-25 years who were diagnosed as a child (<18 years) or an adult ( $\geq 18$  years) was created. The prevalence was also broken down by diagnostic category, sex, ethnic group, and government office region. The level of deprivation for the two groups was compared by calculating the proportion (as a proportion of the total numbers in each individual category) in each deprivation category.

#### [Numbers of young people who died](#)

Using ONS death certificate date of death, the year, age and place of death was assigned to each young person who died. The annual number of young people who died each year was calculated overall and divided into categories according to the age at which they died (14-17 years, 18-25 years, >25 years). Place of death was categorised as hospital, hospice, home, other and missing based on the recorded address of death in the ONS death certificate data. The "other" category included deaths at respite care centres, nursing homes and deaths outside the home (e.g. in a

park or school). Deaths where the street address was not present were recorded as missing. The proportional distribution of place of death within each age group was calculated.

#### Government Office Region Summaries

Regional summaries of the prevalence by age group, diagnosis, sex, ethnicity and local authority district were calculated for all young people and for young people diagnosed < 18 years. Deprivation was expressed as the proportion of young people in each deprivation group.

All data manipulation was undertaken using Microsoft SQL server and statistical analysis was done using STATA version 16 (Stata Corp, Collage Station, TX).

## Results

A little under eight million hospital episodes (7,794,258) were included in the initial dataset for 531,377 individuals.

### Data cleaning

For the prevalence calculations hospital episodes outside of the study period (n=3,085,822) were removed from the dataset along with 3,212,539 episodes for 256,279 individuals younger than 14 years and older than 25 years at the time of the episode (*Figure 2*). Furthermore, 19,476 episodes were removed as they were for individuals not resident in England. A final 129,390 episodes were removed as they occurred before the first recorded LLC diagnosis.

### Missing data

For most variables there were few missing data. Young people with missing sex (n=220 (0.07%)), deprivation scores (n=505 (0.18%)), ethnicity (n= 5,792 (1.9%)) and Local Authority District (n=1105 (0.35%)) were excluded from the prevalence calculations split by those characteristics.

### Number of children

The final dataset for analyses contained information on 296,897 hospital episodes for 138,356 individuals.

A breakdown by financial year and age group of the number of young people with a LLC can be seen in table 2. The absolute number of young people aged 14-25 years with a LLC rose from 27,316 in 2009/10 to 38,261 in 2017/18. After excluding those diagnosed  $\geq 18$  years the number of young people aged 14-25 years with a LLC diagnosed as children rose from 16,107 in 2017/18 to 24,773. The number of children eligible for transition (aged 14-17 years) rose from 8,794 in 2017/18 to 12,495 in 2017/18.

### Prevalence

The prevalence of young people with a LLC rose from 33.5 per 10,000 [95% confidence intervals (95%CI) 33.1-33.9] in 2009/10 to 46.7 per 10,000 [95%CI 46.2-47.2] in 2017/18. After excluding those diagnosed  $\geq 18$  years the prevalence in 2017/18 was 30.2 per 10,000 [95%CI: 29.9-30.6].

The prevalence was similar between 2009/10-2013/14 between the two age groups 14-17 years and 18-25 years (*Table 2*) after which point the prevalence became slightly higher for the younger age group. After the exclusion of young adults diagnosed  $\geq 18$  years, the prevalence of LLCs was higher among young people aged 14-17 years compared to 18-25 year olds (*Table 2, Figure 3*).

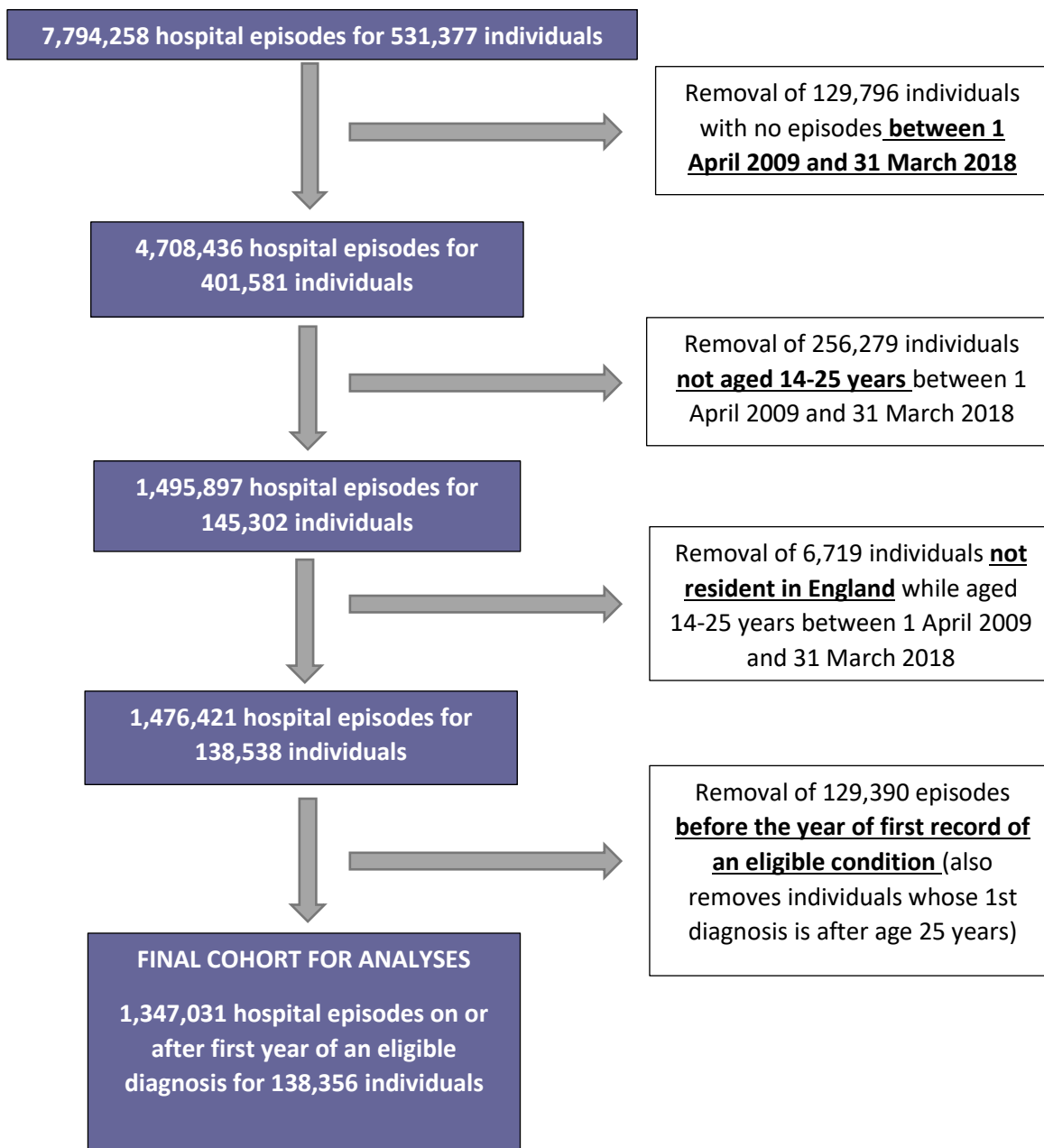


Figure 2: Flow diagram of recruitment criteria

Table 2: Prevalence per 10,000 of young people (aged 14-25 years) with a LLC, overall and by age group for 2009/10-2017/18

Young People aged 14-25 years											
Financial year	Overall			Age 14-17 years				Age 18-25 years			
	Number with a LLC	Prevalence	95%CI	Number with a LLC	Prevalence	95%CI	Number with a LLC	Prevalence	95%CI		
2009	27,316	33.5	33.1 33.9	8,794	33.7	33.0 34.4	18,522	33.4	32.9 33.9		
2010	29,019	35.3	34.9 35.7	9,268	35.7	35.0 36.5	19,751	35.1	34.6 35.6		
2011	30,068	36.3	35.8 36.7	9,532	36.7	36.0 37.4	20,536	36.1	35.6 36.5		
2012	31,556	38.0	37.6 38.4	9,898	38.5	37.7 39.2	21,658	37.8	37.3 38.3		
2013	33,259	40.0	39.6 40.4	10,548	41.2	40.4 42.0	22,711	39.5	39.0 40.0		
2014	34,645	41.7	41.3 42.1	11,227	44.4	43.6 45.2	23,418	40.5	40.0 41.0		
2015	35,780	43.1	42.7 43.6	11,376	45.8	45.0 46.7	24,404	42.0	41.4 42.5		
2016	36,993	44.8	44.4 45.3	11,851	48.6	47.8 49.5	25,142	43.2	42.7 43.8		
2017	38,261	46.7	46.2 47.2	12,495	51.9	50.9 52.8	25,766	44.6	44.0 45.1		
Young People aged 14-25 years excluding those diagnosed ≥18years											
Financial year	Overall			Age 14-17 years				Age 18-25 years			
	Number with a LLC	Prevalence	95%CI	Number with a LLC	Prevalence	95%CI	Number with a LLC	Prevalence	95%CI		
2009	16,107	19.7	19.4 20.0	8,794	33.7	33.0 34.4	7313	13.2	12.9 13.5		
2010	17,284	21.0	20.7 21.3	9,268	35.7	35.0 36.5	8016	14.2	13.9 14.5		
2011	18,355	22.1	21.8 22.5	9,532	36.7	36.0 37.4	8823	15.5	15.2 15.8		
2012	19,272	23.2	22.9 23.5	9,898	38.5	37.7 39.2	9374	16.4	16.0 16.7		
2013	20,653	24.8	24.5 25.2	10,548	41.2	40.4 42.0	10105	17.6	17.2 17.9		
2014	21,906	26.4	26.0 26.7	11,227	44.4	43.6 45.2	10679	18.5	18.1 18.8		
2015	22,819	27.5	27.1 27.9	11,376	45.8	45.0 46.7	11443	19.7	19.3 20.0		
2016	23,668	28.7	28.3 29.0	11,851	48.6	47.8 49.5	11817	20.3	20.0 20.7		
2017	24,773	30.2	29.9 30.6	12,495	51.9	50.9 52.8	12278	21.2	20.9 21.6		

Abbreviations: 95% CI- 95% Confidence intervals

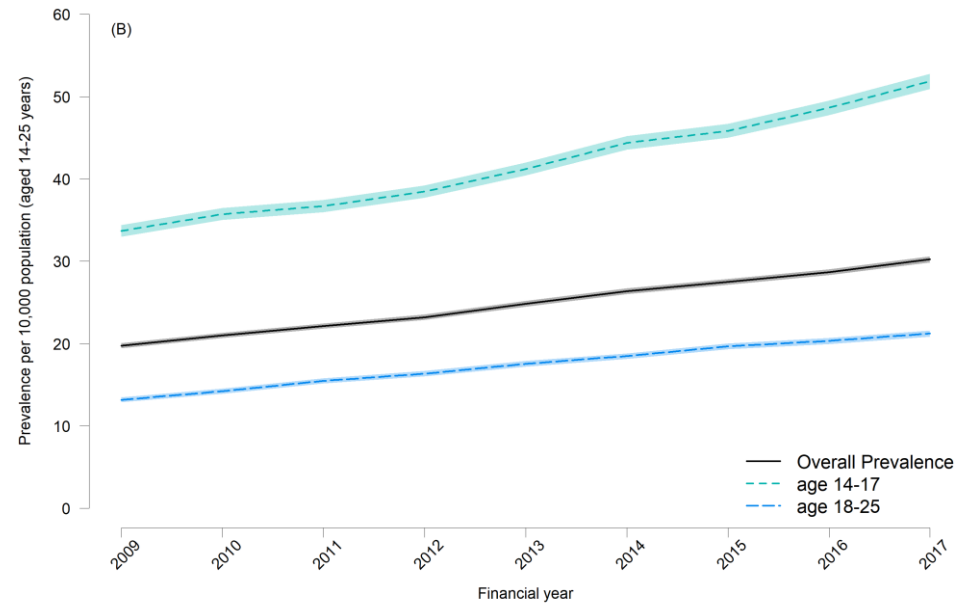
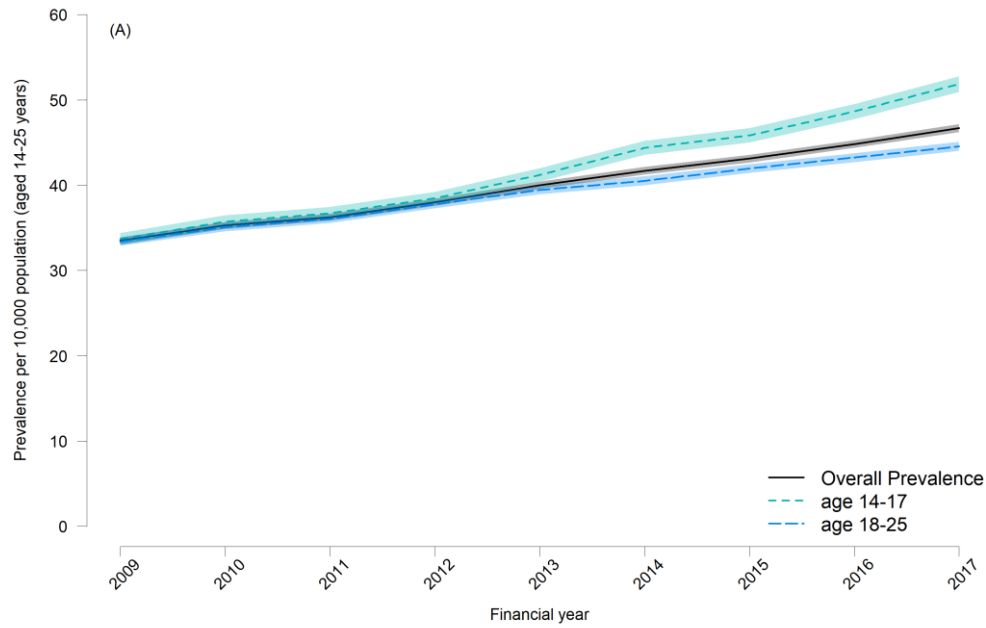


Figure 3: Prevalence per 10,000 of young people (aged 14-25 years) (A) with a LLC diagnosed at any age or (B) with a LLC diagnosed <18, overall and by age group for 2009/10-2017/18



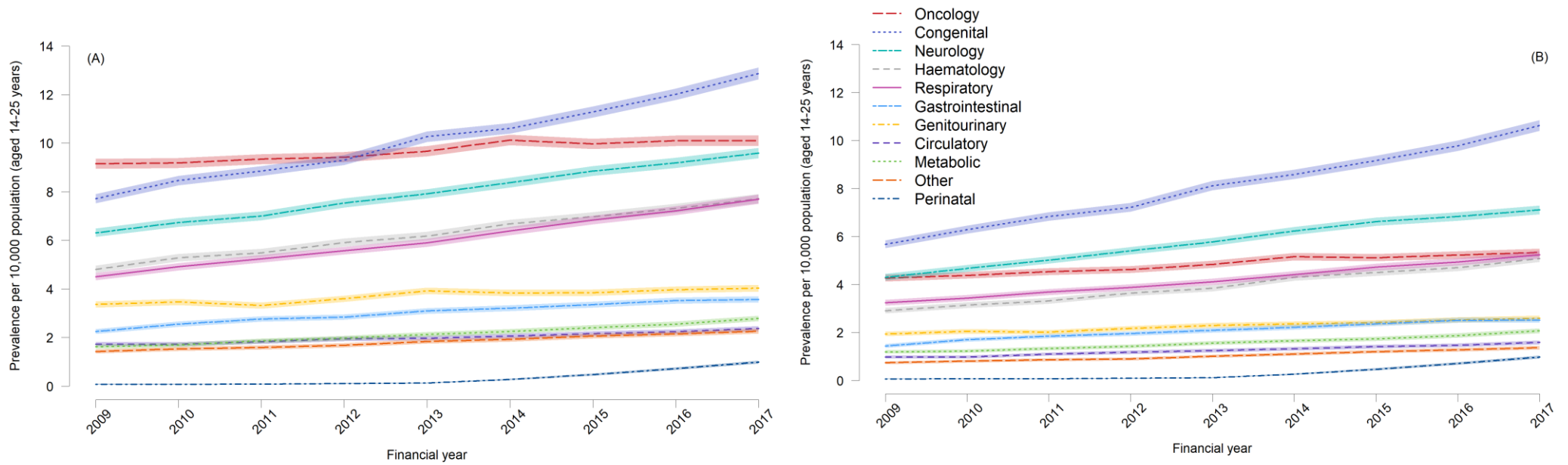


Figure 4: Prevalence per 10,000 of young people (aged 14-25 years) (A) with a LLC diagnosed at any age or (B) with a LLC diagnosed <18, by diagnostic group for 2009/10-2017/18

Figure 4 shows the prevalence per 10,000 population by diagnostic group. The prevalence of LLCs was highest in congenital, oncology and neurological diagnostic groups, whose prevalence in 2017/18 were 12.9 per 10,000 [95%CI: 12.6-13.1], 10.1 per 10,000 [95%CI: 9.9-10.3] and 9.6 per 10,000 [95%CI: 9.4-10.3], respectively. The lowest prevalence was for perinatal disorders at 1.0 per 10,000 [95%CI: 0.9-1.1]. There was an increase in prevalence for all diagnostic groups, with the largest increase (by proportion) being for metabolic and respiratory disorders which had a 70% increase. The smallest increase in prevalence was for oncology diagnosis which only had a 10% increase (Figure 4 (A)).

After young people diagnosed  $\geq 18$  years were excluded, the prevalence of LLCs was highest for congenital, and neurology diagnostic groups, (Figure 4 (B)). The prevalence in 2017/18 was 10.6 per 10,000 [95%CI: 10.4-10.8] for congenital diagnosis and 7.1 per 10,000 [95%CI: 6.9-7.3] for neurological diagnosis. The lowest prevalence was for perinatal disorder at 1.0 per 10,000 [95%CI: 0.9-1.1]. The largest increase in prevalence was for congenital and other disorders which saw a 90% and 80% increase in prevalence respectively.

The prevalence of LLCs was higher in females than males: 50.8 per 10,000 [95%CI 50.1-51.5] in 2017/18 compared to 42.8 [95%CI 42.2-43.4] for males (Figure 5(A)). After excluding young adults diagnosed on or after 18 years, the prevalence of LLCs was similar for both sexes (Figure 5(B)).

Figure 6 shows the breakdown of prevalence by ethnic group. Prevalence was highest among young people of Pakistani origin (76.8 per 10,000 [95%CI 70.4-76.8] in 2017) followed by the Other Asian (54.6 per 10,000 [95%CI 49.5-54.6]) and Black groups (49.8 per 10,000 [95%CI 45.6-49.8]). The prevalence was lowest in young people of Chinese origin (9.4 per 10,000 [95%CI 6.4-9.4] in 2017). The rise in prevalence was similar between all ethnic groups, with the exception of those of Chinese origin whose prevalence remained static. Prevalence was also greatest among young people of Pakistani origin when those diagnosed in adulthood were excluded (56.8 per 10,000 [95%CI 53.9-59.6] in 2017) (Figure 6 (B)) however, the prevalence in all other ethnic groups was considerably lower.

Prevalence of LLCs in young people was lowest in London (43.0 per 10,000 [95%CI 41.9-44.1] in 2017) and highest in the North West (51.3 per 10,000 [95%CI 50.0-52.7]) (Figure 7, Figure 8(A)). Similar to the analysis including young adults diagnosed at any age, the prevalence of LLCs excluding young adults diagnosed  $\geq 18$  years was lowest in London (27.1 per 10,000 [95%CI 26.3-28.0] in 2017) and highest in the North West (33.7 per 10,000 [95%CI 32.6-34.8]) (Figure 7, Figure 8(B)).

As the deprivation categories were population weighted (using the national population), it would be expected that ~20% of young people with a LLC would be in each of the five categories. During the eight year period 23-24% of young people who had a LLC were in the most deprived category, whilst only 17-18% of young people were in the least deprived category. The proportion of young people with a LLC in each deprivation category remained fairly

constant between 2009-2017 (*Figure 9(A)*). After excluding young adults diagnosed  $\geq 18$  years the proportion of young people with a LLC in the most deprived groups was 22% to 23% compared to approximately 19% in the three least deprived groups (*Figure 9 (B)*).

### Sensitivity analysis

In order to assess the impact of excluding certain ICD-10 codes from the definition of a LLC a sensitivity analysis was carried out with the following results (*Figure 10*):

- (i) Exclusion of perinatal disorders after the first birthday made little impact on the prevalence, reducing the overall prevalence in 2017/18 from 46.7 per 10,000 [95%CI 46.2-47.2] to 46.3 per 10,000 [95%CI 45.8-46.8].
- (ii) The exclusion of oncology cases 5 years after diagnosis also made a small impact on the prevalence, reducing it by 1.0 per 10,000 to 45.7 per 10,000 [95%CI 45.3-46.2] in 2017/18.
- (iii) Removal of non-central nervous system (CNS) oncology cases 5 years after diagnosis had a similar effect as the removal of all oncological cases.

Combining all of the restricted definitions reduced the prevalence from 46.7 to 45.3 per 10,000 (95%CI 44.9-45.8) in 2017/18 (*Figure 10 (A)*).

This pattern remained the same after young adults diagnosed  $\geq 18$  years were excluded albeit with an overall lower prevalence (*Figure 10 (B)*). Exclusion of perinatal disorders after the first birthday resulted in a prevalence of 29.8 per 10,000 [95%CI 29.5-30.2] in 2017/18 as opposed to 30.2 per 10,000 [95%CI: 29.9-30.6] without exclusions. The exclusion of oncology cases 5 years after diagnosis reduced the prevalence in 2017/18 to 29.3 per 10,000 [95%:CI: 29.0-29.7]. Applying all the restrictions together resulted in a prevalence of 28.9 per 10,000 [95%CI: 28.6-29.3].

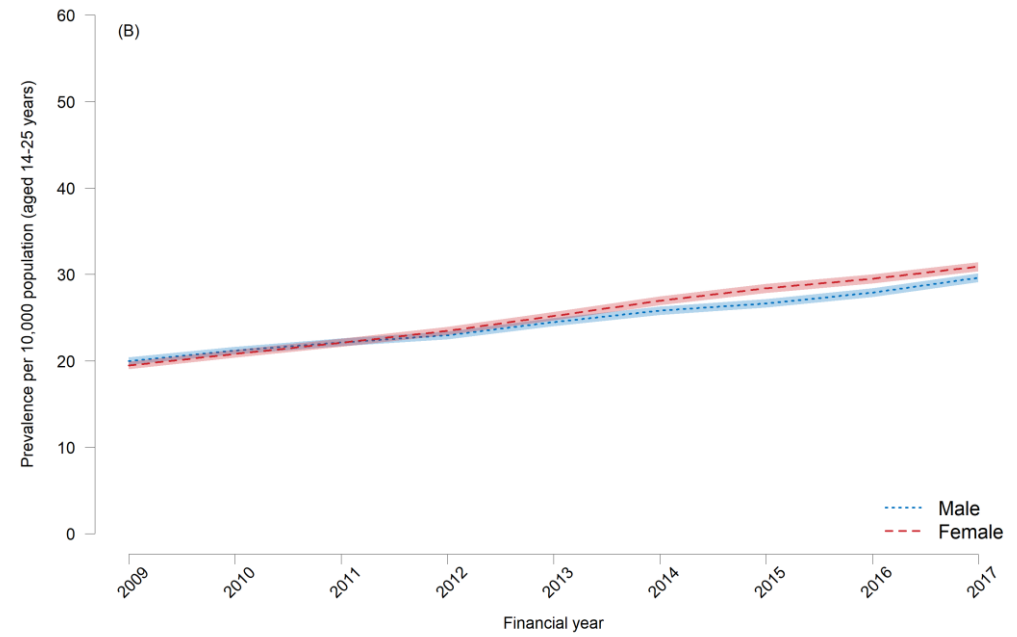
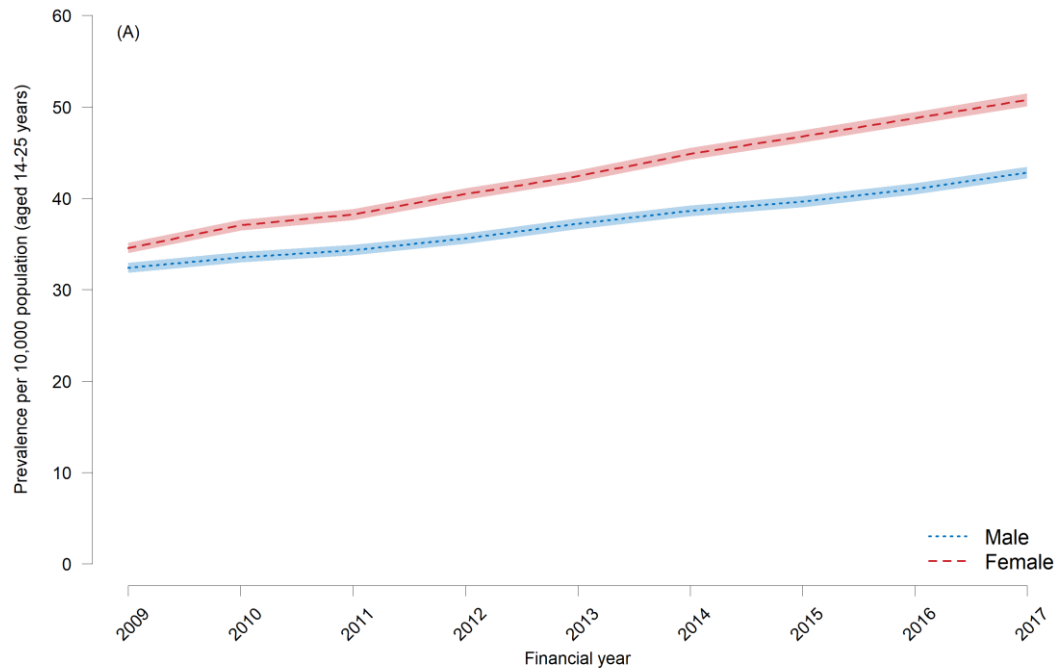


Figure 5: Prevalence per 10,000 of young people (aged 14-25 years) (A) with a LLC diagnosed at any age or (B) with a LLC diagnosed <18, y sex for 2009/10-2017/18

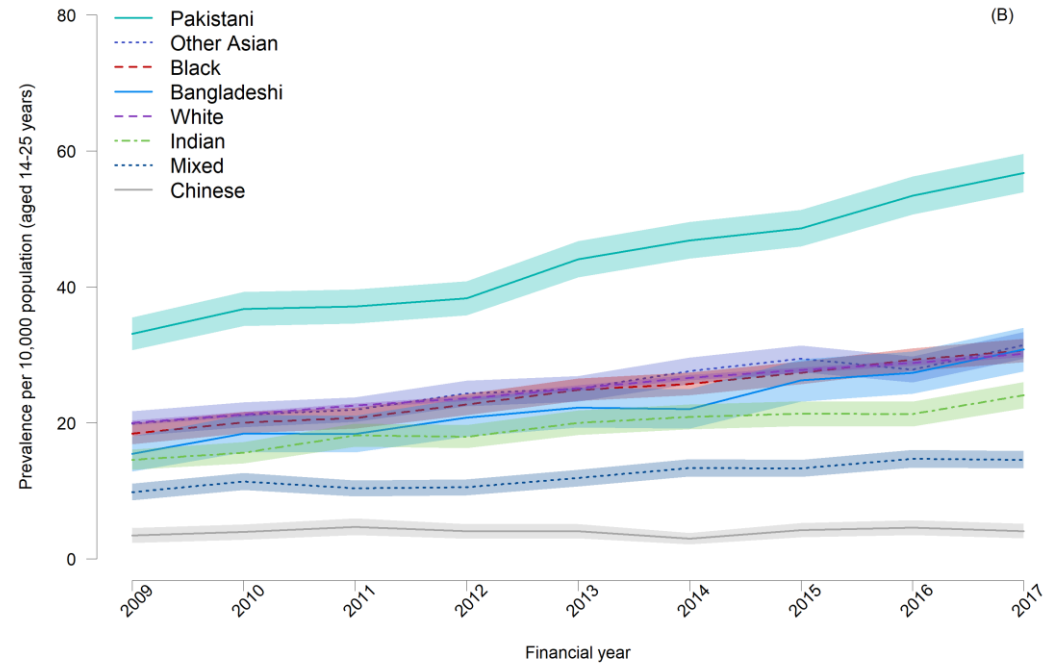
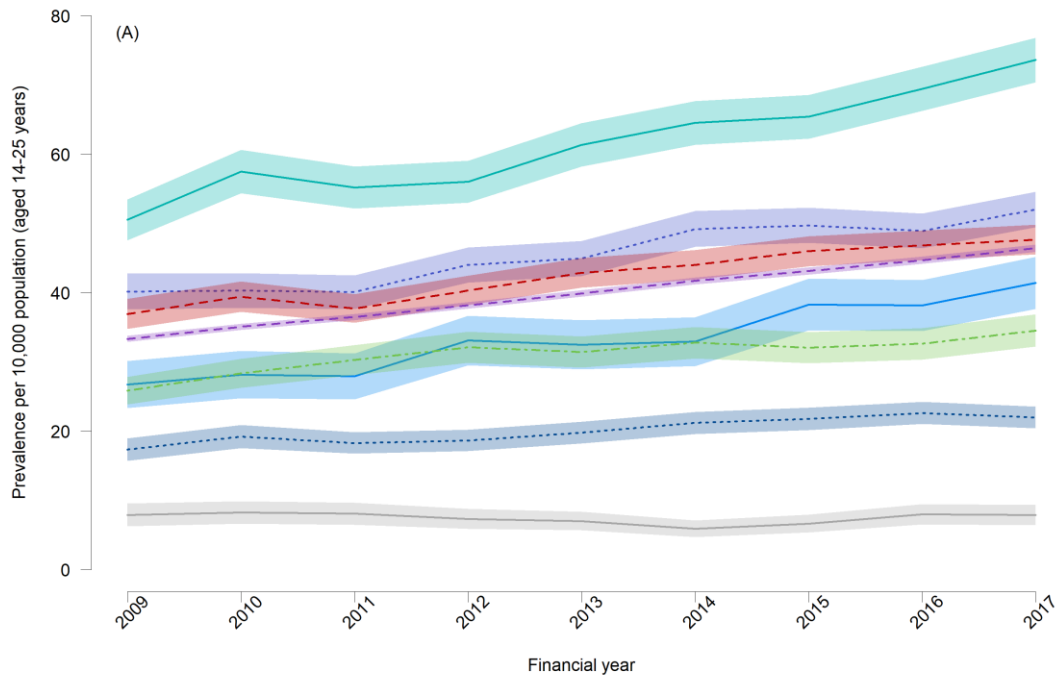


Figure 6: Prevalence per 10,000 of young people (aged 14-25 years) (A) with a LLC diagnosed at any age or (B) with a LLC diagnosed <18, by ethnic group for 2009/10-2017/18

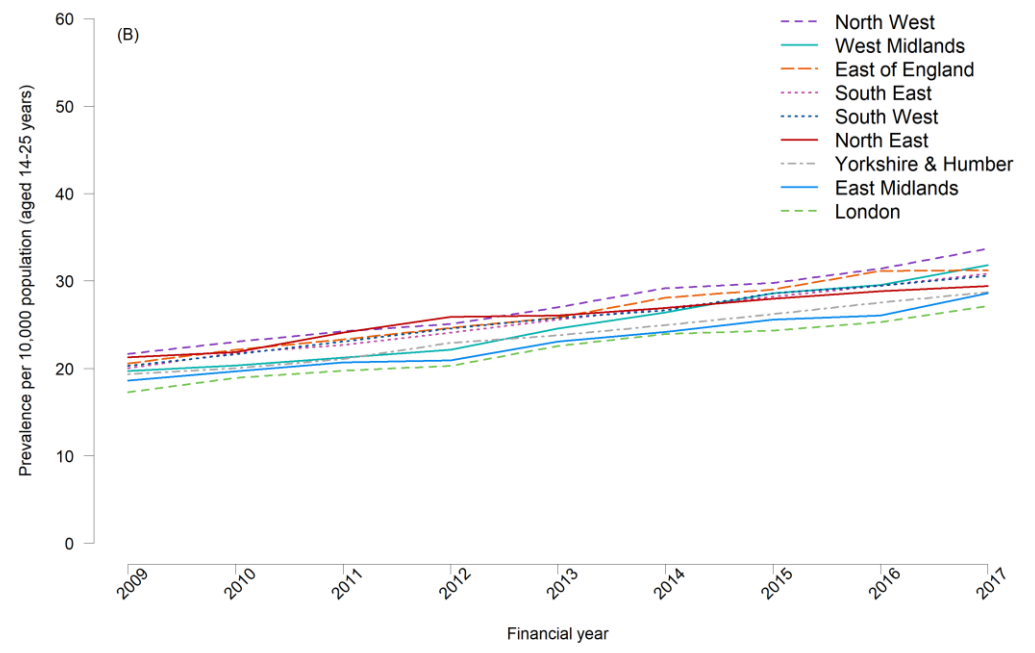
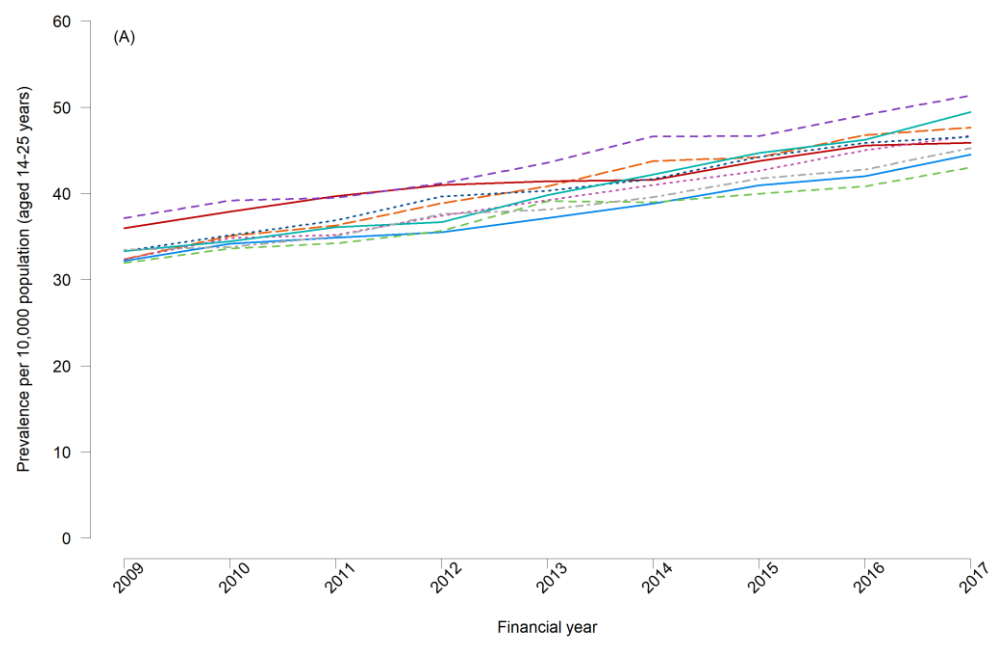


Figure 7: Prevalence per 10,000 of young people (aged 14-25 years) (A) with a LLC diagnosed at any age or (B) with a LLC diagnosed <18, by Government Office Region for 2009/10-2017/18

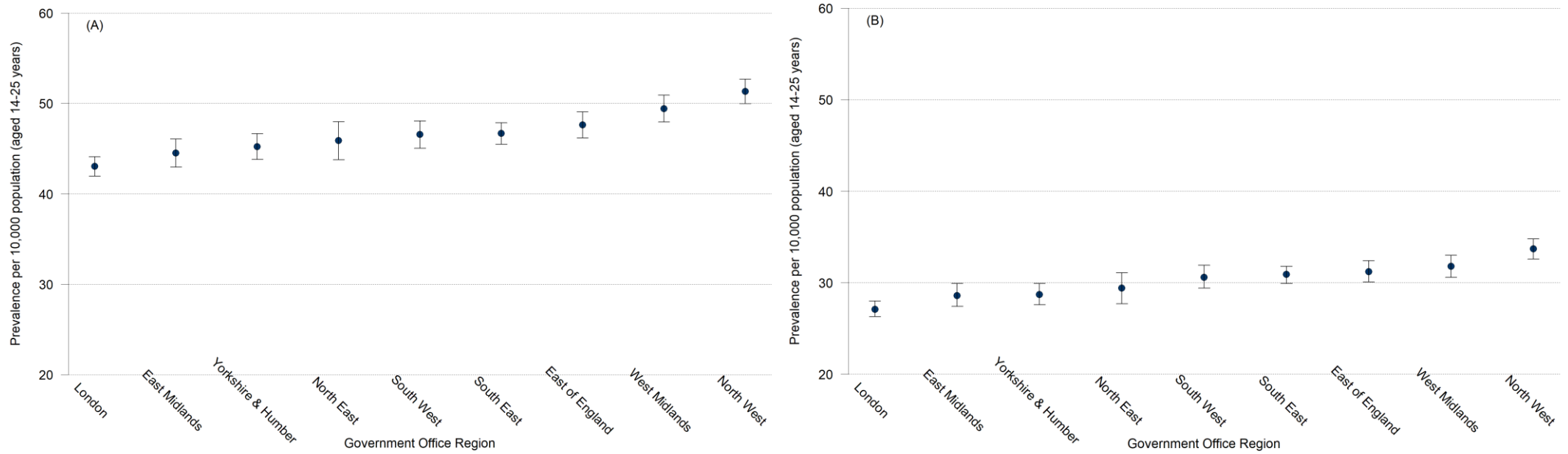


Figure 8: Prevalence per 10,000 of young people (aged 14-25 years) (A) with a LLC diagnosed at any age or (B) with a LLC diagnosed <18, by Government Office Region for 2017

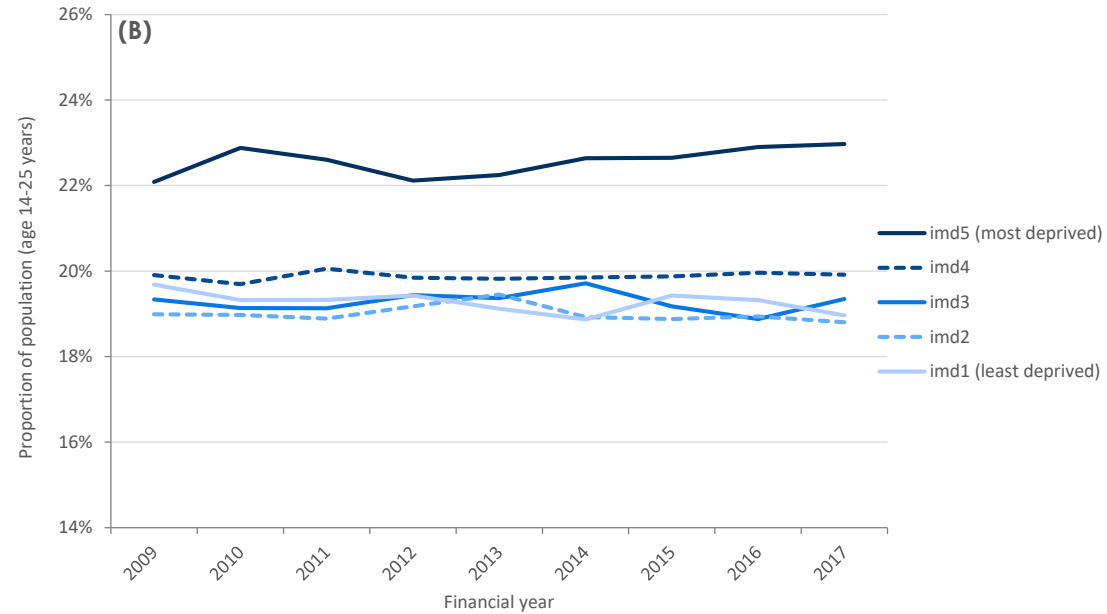
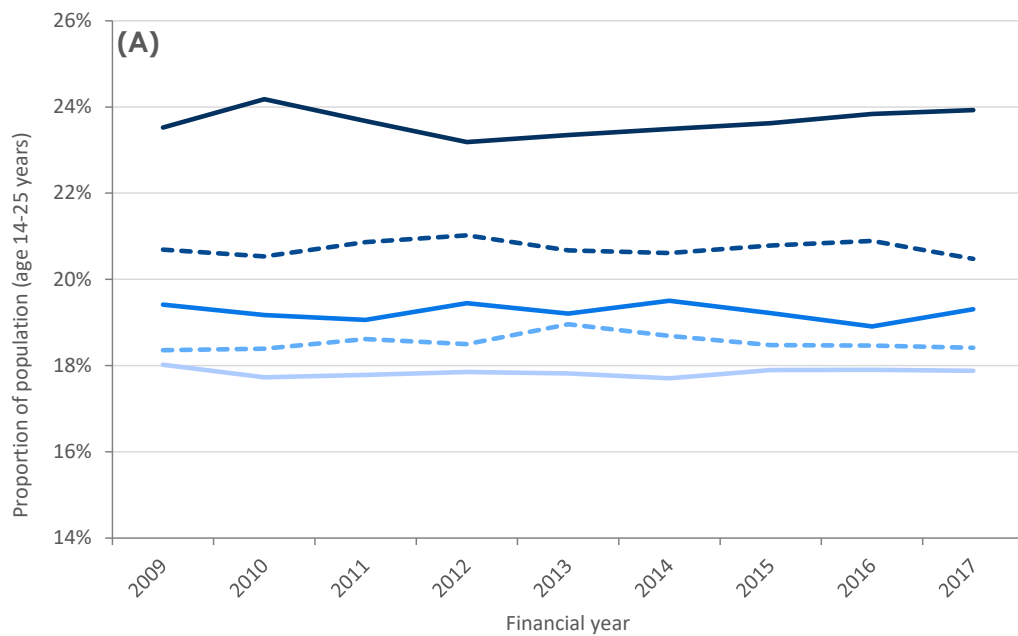


Figure 9: Percentage of young people (aged 14-25 years) (A) with a mental health condition diagnosed at any age or (B) with a mental health condition diagnosed <18, by (population weighted) deprivation group for 2009/10-2017/18



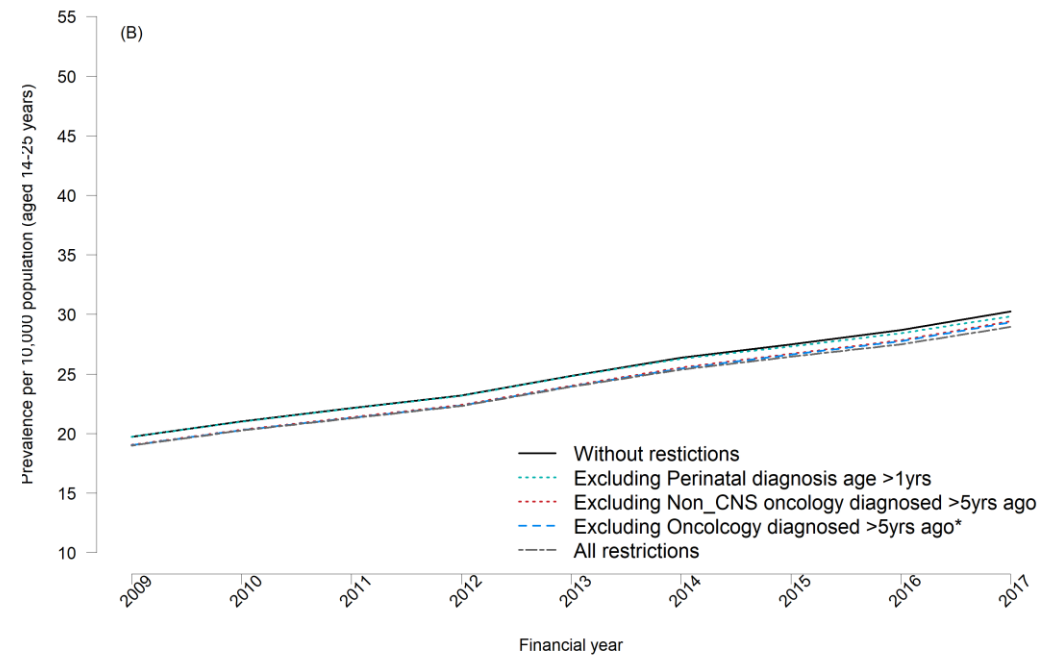
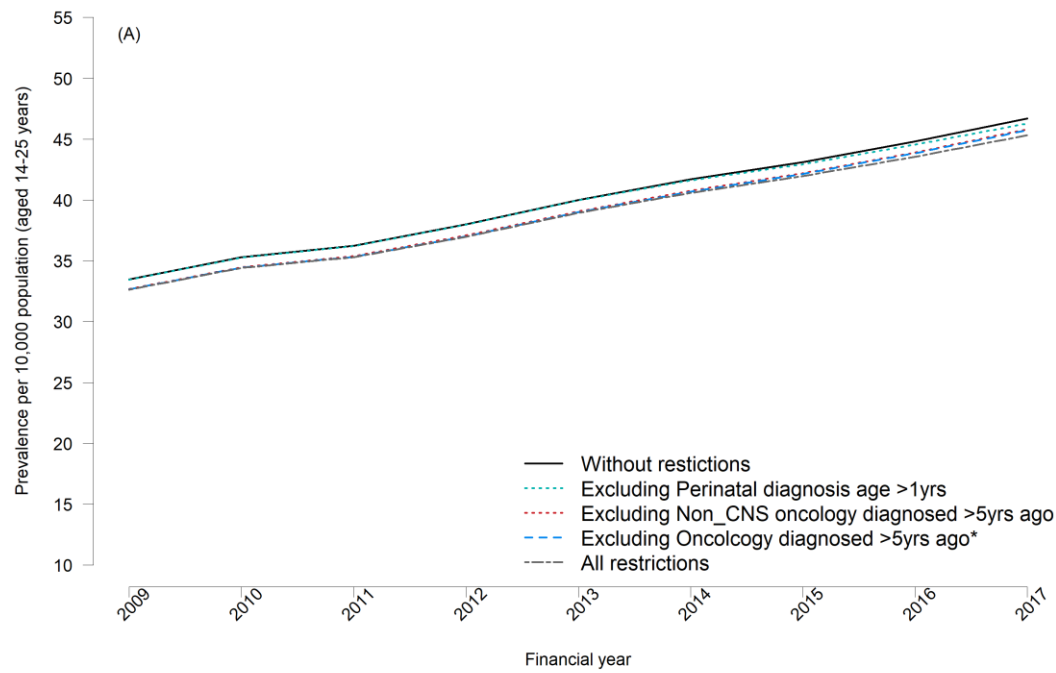


Figure 10: Prevalence per 10,000 of young people (aged 14-25 years) (A) with a LLC diagnosed at any age or (B) with a LLC diagnosed <18, with restricted definitions of life-limiting condition.

\*Lines overlap those of group above

## Modelling of future prevalence

*Figure 11 to Figure 14* show the predicted number and prevalence of young people with a LLC between 2018-2030 regardless of age of diagnosis (*Figure 11 & Figure 13*) and excluding those diagnosed as adults (*Figure 12 & Figure 14*). Including all young people, the most conservative estimates (**Model 3**), in which it is assumed there are no changes in survival or incidence/diagnosis, predicted that the number of young people with a LLC would rise slightly from 37,484 [95%CI 36,838-38,144] in 2018 to 40,530 [95%CI 39,810-41,265] in 2030 This equates to a change in prevalence from 46.0 [95%CI 45.2-46.8] to 46.0 [95%CI 45.1-46.8]. Excluding young adults diagnosed age  $\geq 18$  years the predicted number of young people with a LLC rose from 24,819 in 2018 [95%CI 24,280-25,372] to 27,350 in 2030 [95%CI: 26,739-27,976] (*Figure 11*). This equates to a change in prevalence from 30.4 per 10,000 [95% CI: 29.8-31.1] in 2018 to 31.0 per 10,000 [95% CI: 30.3-31.7] in 2030 (*Figure 13*).

The less conservative model (**Model 2**) which used a restricted definition of LLCs, predicted that the number of young people with a LLC would rise from 37,209 [95%CI 36,179-38,269] in 2018 to 52,646 [95%CI: 40,629-68,188] in 2030. Equating to a prevalence of 45.6 [95% CI 44.4-46.9] and 59.7 [95%CI 46.1-77.3].

Excluding young adults diagnosed age  $\geq 18$  years, the model predicts an increase in the number of young people with a LLC from 24,445 [95%CI: 23,592-25,331] in 2018 to 37,173 [95%CI: 26,731-51,664] in 2030 This equates to an increase in prevalence from 30.0 per 10,000 [95% CI: 28.9-31.1] in 2017 to 42.2 per 10,000 [95% CI: 30.3-58.6] in 2030.

The least conservative estimates (**Model 1**), which used the broadest definition of LLCs, predicted that the number of young people with LLCs would rise to 54,815 (95%CI 42,453-70,745) by 2030 or a prevalence of 62.2 per 10,000 (95%CI 48.1-80.2) per 10,000.

Excluding young adults diagnosed age  $\geq 18$  years, the model predicts that the number of young people with a LLC will increase to 40,552 [95%CI: 29,352-55,991] in 2030 equating to a prevalence of 46.0 per 10,000 [95%CI: 33.3-63.5]

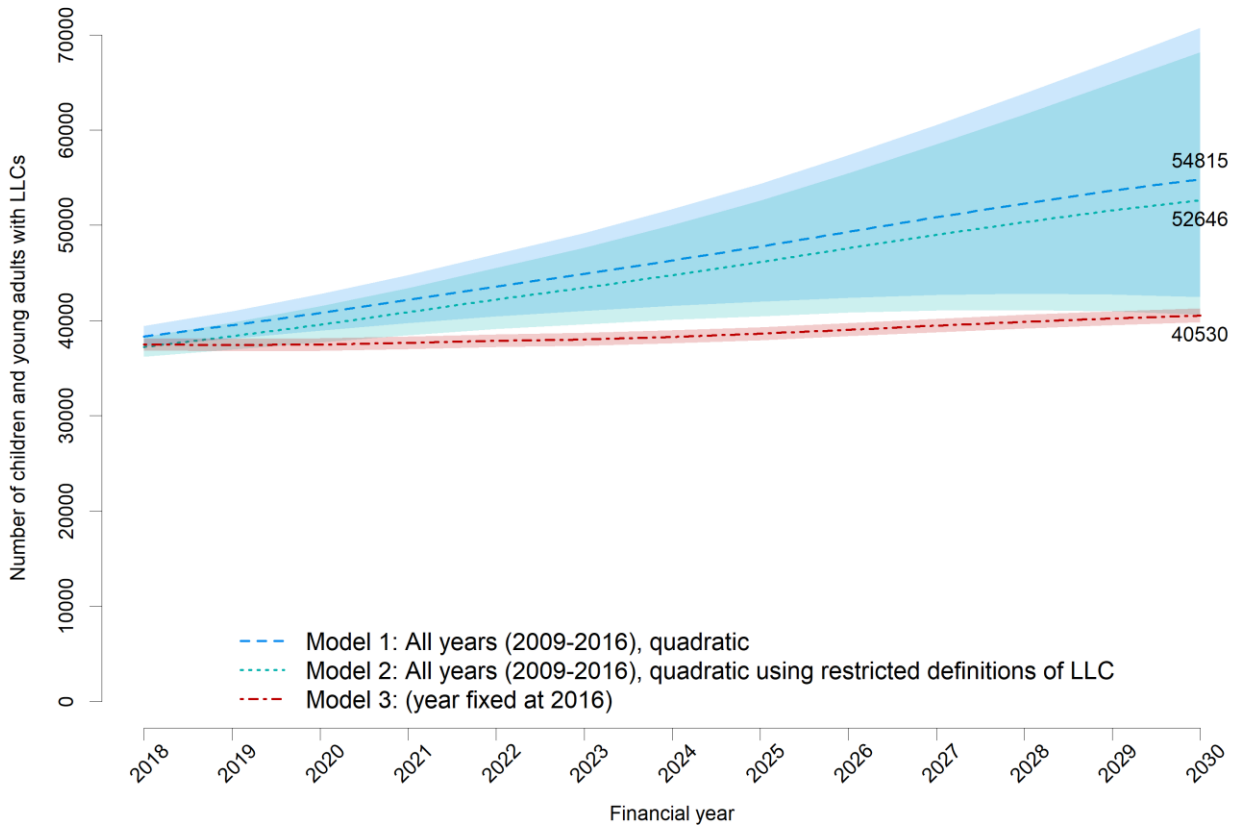


Figure 11: Predicted number (with 95% confidence intervals in lighter shading) of young people (14-25 years) with a life-limiting condition

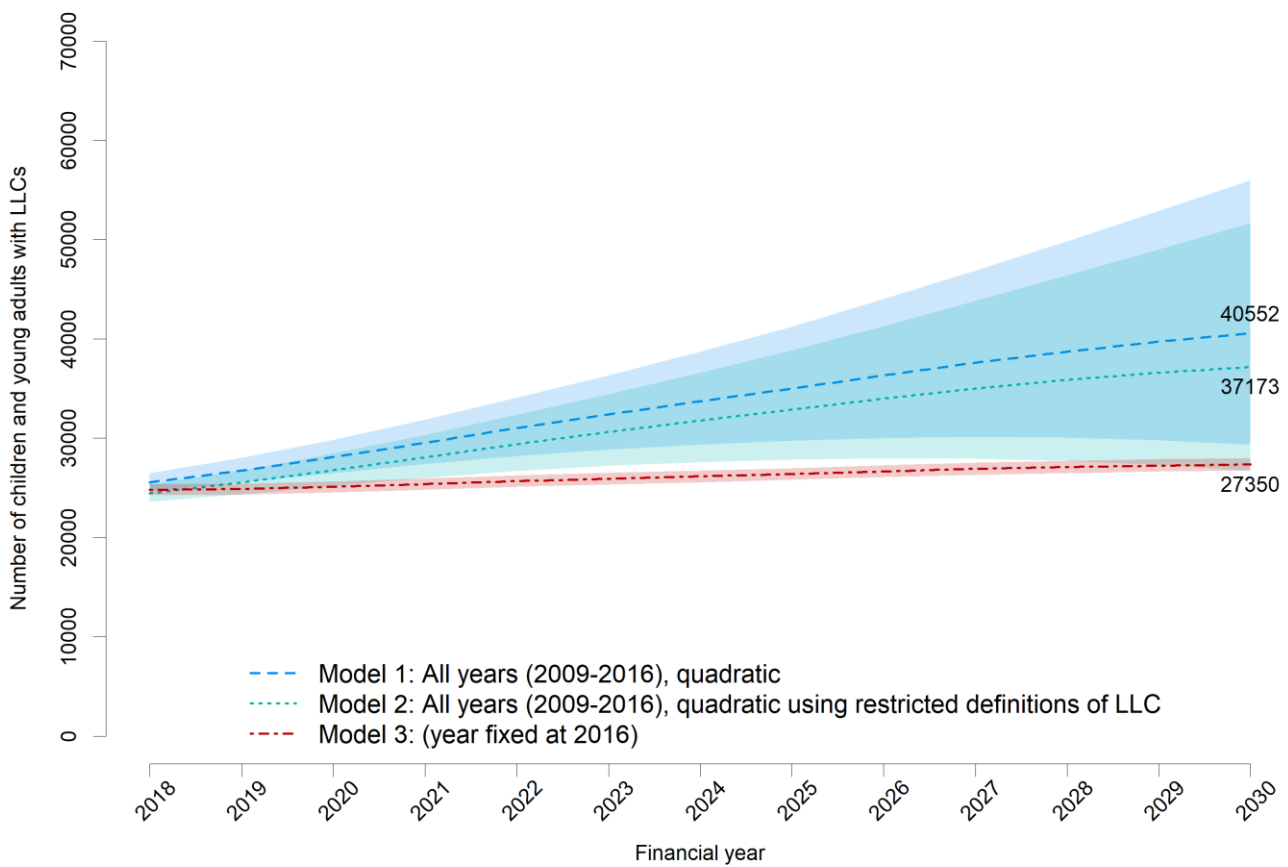


Figure 12: Predicted number (with 95% confidence intervals in lighter shading) of young people (14-25 years) with a life-limiting condition excluding those diagnosed  $\geq 18$  years

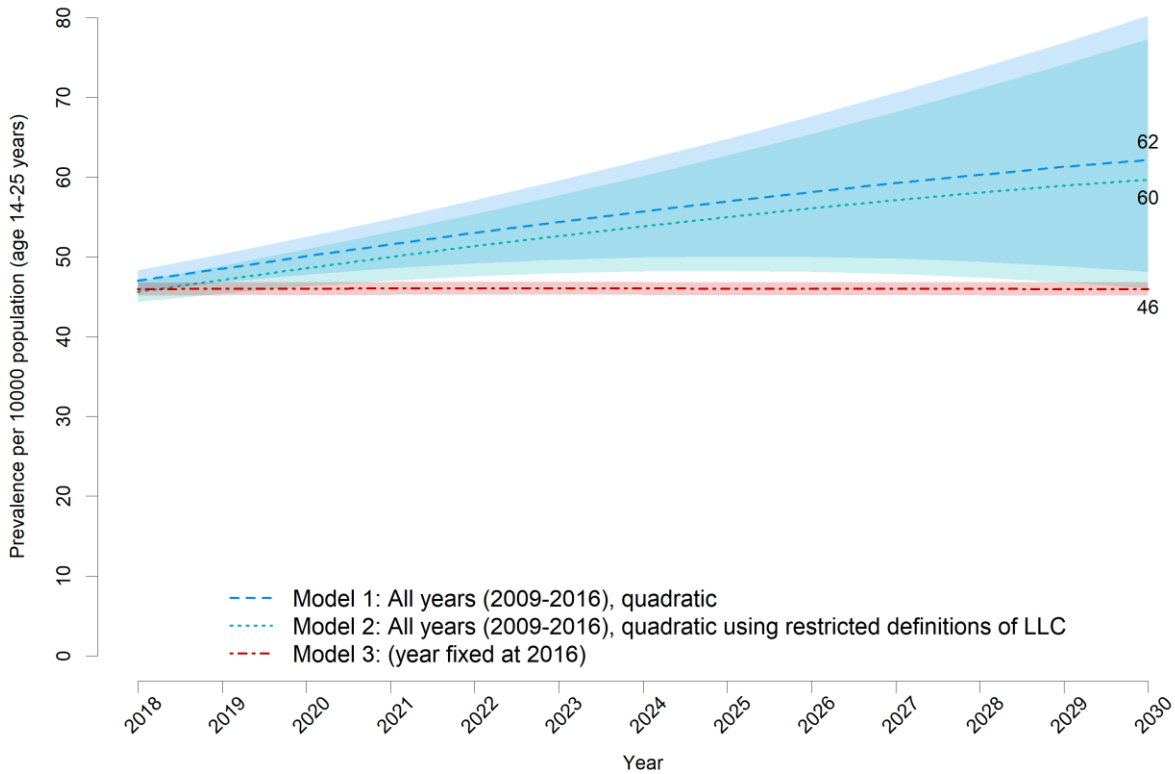


Figure 13: Predicted prevalence (with 95% confidence intervals in lighter shading) of young people (age 14-25 years) with a life-limiting condition

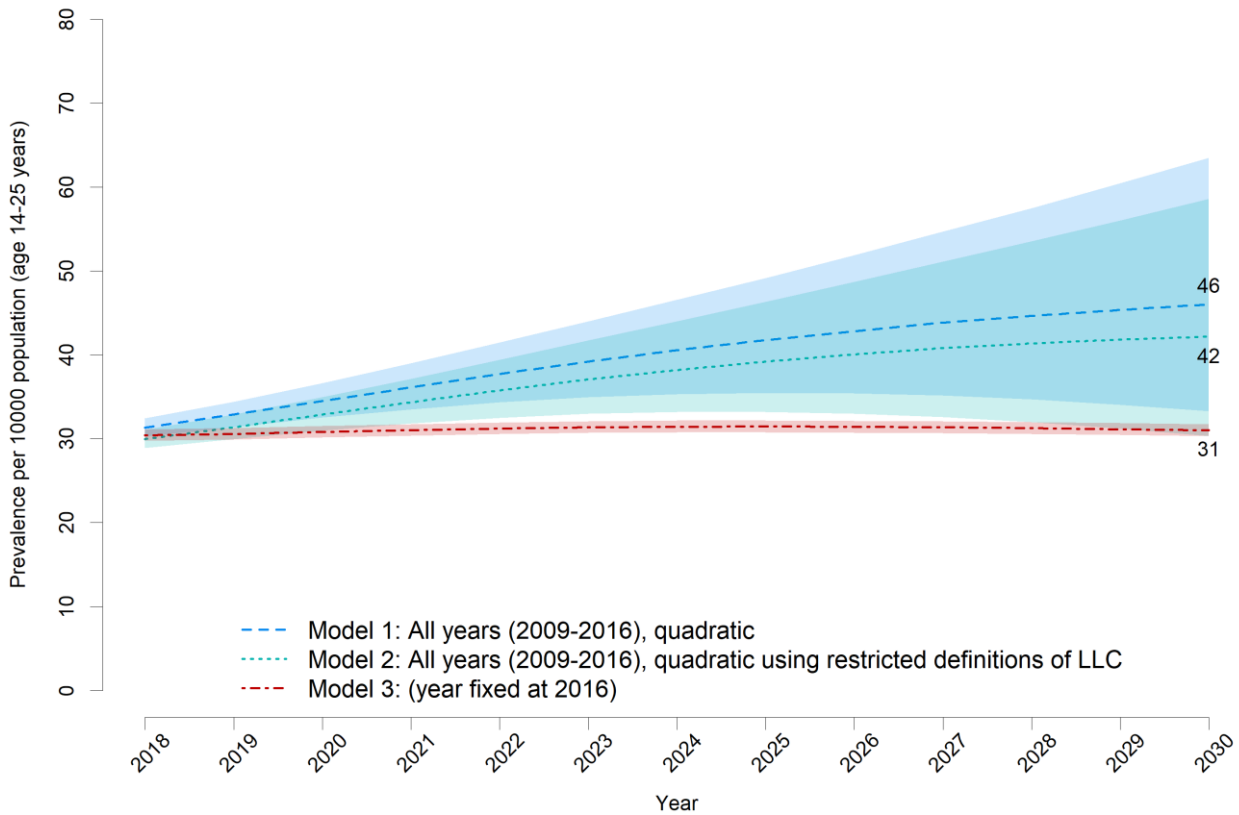


Figure 14: Predicted prevalence (with 95% confidence intervals in lighter shading) of young people (age 14-25 years) with a life-limiting condition excluding those diagnosed ≥18 years

## Age of diagnosis: Young adults diagnosed during adulthood ( $\geq 18$ years) compared to those diagnosed in childhood ( $<18$ years)

Analysing the number of individuals at their entry point in the dataset, the largest group (46%) of young people were adults (aged 18-25 years) who had their first recorded LLC in adulthood (*Table 3*). Just under 40% were aged  $< 18$  years when first appearing in the dataset and the remaining 14% were young adults diagnosed in childhood.

Examining the data on an annual basis from 2009/10 onward showed that around a third of hospital admissions were for young people aged  $<18$  years. Just under a third were adults who had been diagnosed with a LLC whilst under the age of 18 years and just over a third were adults who had only been diagnosed on or after age 18 years.

On an annual basis, the prevalence was highest for young people aged  $<18$  years which was 51.9 per 10,000 [95%CI: 50.9-52.8] in 2017/18 (*Table 3*).

*Figure 15* shows the prevalence of the two groups (diagnosed  $<18$  years, diagnosed  $\geq 18$  years) split by diagnosis. For young adults whose first LLC diagnosis was recorded  $< 18$  years, the highest prevalence was among congenital disorders (7.2 per 10,000 [95%CI: 7.0-7.4] in 2017/18), followed by neurological diagnosis (5.0 per 10,000 [95%CI: 4.8-5.1] in 2017/18). The largest increase in prevalence among young adults diagnosed in childhood was for haematology and congenital diagnosis, which had a 100% and 90% increase respectively. Among young adults who only had a hospital admission for a LLC age  $\geq 18$  years the prevalence was highest for oncology diagnosis (6.8 per 10,000 [95%CI: 6.5-7.0, 2017/18]. The prevalence of young adults with an oncology diagnosis remained consistent over the eight year period. The largest increase in prevalence was for respiratory diagnoses which had just under a 100% increase.

For both groups of young people the prevalence was higher in females compared to males although the difference between the two was greater for those diagnosed aged  $\geq 18$  years (*Figure 16*). The prevalence for male young adults diagnosed  $\geq 18$  years remained static at around 8.4 per 10,000

Among young people diagnosed  $<18$  years, the prevalence of LLCs was largest for those of Pakistani origin 37.9 per 10,000 [95%CI: 35.1-40.7]. This was also the group which saw the largest increase in prevalence, over 100% in the eight year period. For those diagnosed age  $\geq 18$  years, the prevalence was greater than that in the white population in three ethnic minority groups, namely the Other Asian, Black and Pakistani ethnic groups (28.3 per 10,000 [95%CI:26.0- 30.5], 24.9 per 10,000 [95%CI:23.0- 26.7], 25.5 per 10,000 [95%CI:23.2- 27.8] in 2017/18 respectively) (*Figure 17*).

The prevalence of young adults diagnosed with a LLC as a child was greatest in the North West (23.9 per 10,000 [95%CI:22.8-25.0] in 2017/18) and lowest in London (17.9 per 10,000 [95%CI:17.1-18.7] in 2017/18). For those diagnosed in adulthood the prevalence was greatest in the West Midlands (25.4 per 10,000 [95%CI:24.1-26.6] in 2017/18) (*Figure 18, Figure 19*).

The proportion of young adults diagnosed < 18 years with a LLC is largest for those in the most deprived category (23-24%). Likewise for young adults diagnosed age  $\geq$  18 years the highest proportion is also in the most deprived category (25-26%) with a very distinct reduction in proportions between the remaining four groups with only 15-16% of young adults being in the least deprived group (*Figure 20*).

Table 3: Number, number who died and prevalence per 10,000 of young people (aged 18-25 years) with a LLC by age of diagnosis 2009/10-2017/18

Year	Child in current year (n individuals=54,119 <sup>1</sup> )				Adult in current year diagnosed <18 years (n individuals =20,055)				Adult in current year diagnosed ≥18 years (n individuals =64,182)						
	n	Prevalence	95% CI		Number who died in year <sup>2</sup>	n	Prevalence	95% CI		Number who died in year <sup>2</sup>	n	Prevalence	95% CI		Number who died in year <sup>2</sup>
2009	8,795	33.7	33.0	34.4	201	7,313	13.2	12.9	13.5	213	11,208	20.2	19.8	20.6	286
2010	9,268	35.7	35.0	36.5	188	8,016	14.2	13.9	14.5	197	11,735	20.8	20.5	21.2	285
2011	9,533	36.7	36.0	37.4	171	8,823	15.5	15.2	15.8	207	11,712	20.6	20.2	20.9	292
2012	9,898	38.5	37.7	39.2	155	9,374	16.4	16.0	16.7	215	12,284	21.4	21.1	21.8	272
2013	10,549	41.2	40.4	42.0	146	10,105	17.6	17.2	17.9	226	12,605	21.9	21.5	22.3	269
2014	11,227	44.4	43.6	45.2	167	10,679	18.5	18.1	18.8	245	12,739	22.0	21.7	22.4	277
2015	11,376	45.8	45.0	46.7	167	11,443	19.7	19.3	20.0	263	12,961	22.3	21.9	22.7	263
2016	11,851	48.6	47.8	49.5	160	11,817	20.3	20.0	20.7	273	13,325	22.9	22.5	23.3	269
2017	12,495	51.9	50.9	52.8	182	12,278	21.2	20.9	21.6	222	13,488	23.3	22.9	23.7	250

<sup>1</sup> Number is based on age of the first record within the study period

<sup>2</sup> Number who died is classified according to age at death and financial year of death, and may not necessarily be included in the count of individuals for that year.

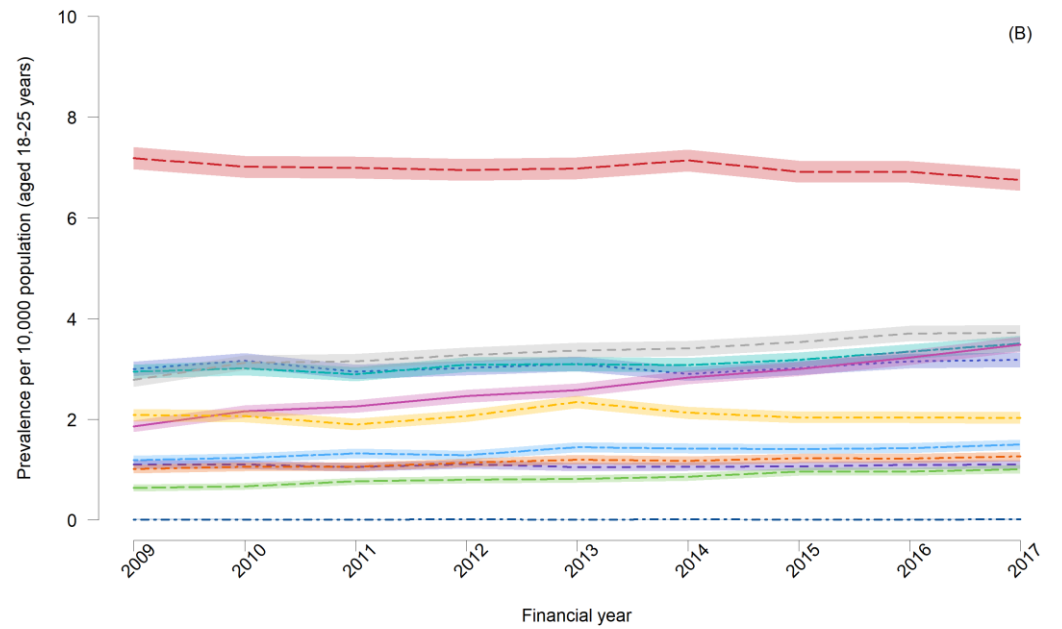
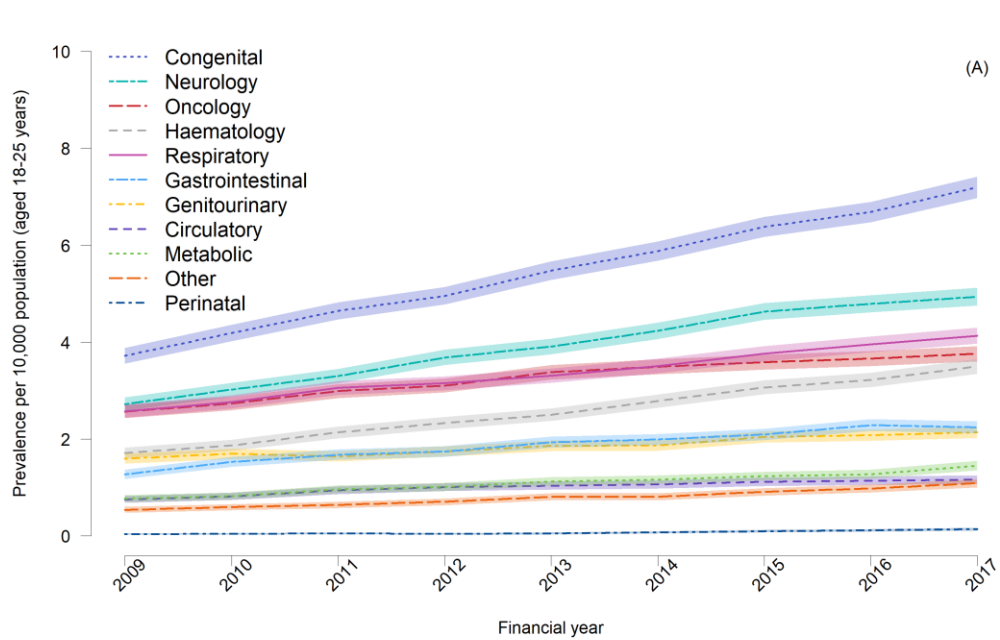


Figure 15: Comparison of the prevalence per 10,000 of young adults (aged 18-25 years) with (A) a LLC diagnosed < 18 years and (B) diagnosed  $\geq 18$  years by diagnostic for 2009/10-2017/18



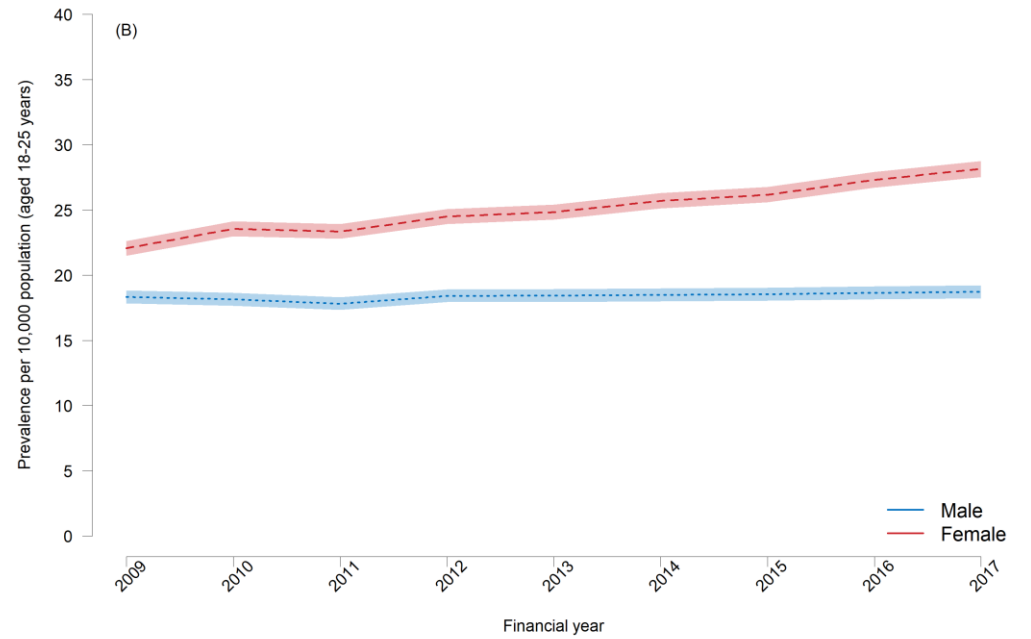
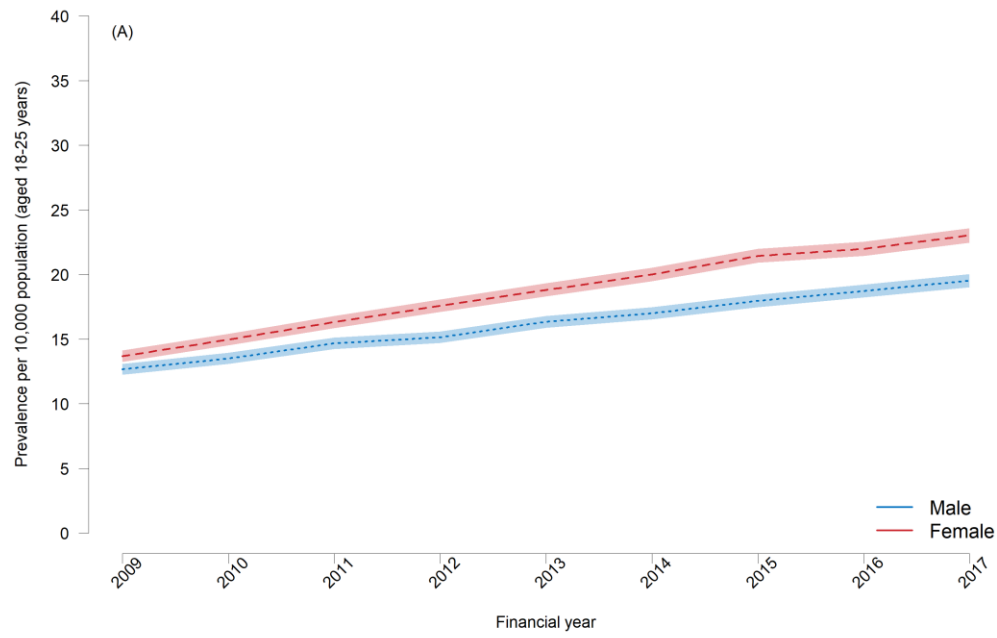


Figure 16 Comparison of the prevalence per 10,000 of young adults (aged 18-25 years) with (A) a LLC diagnosed < 18 years and (B) diagnosed  $\geq 18$  years by sex for 2009/10-2017/18

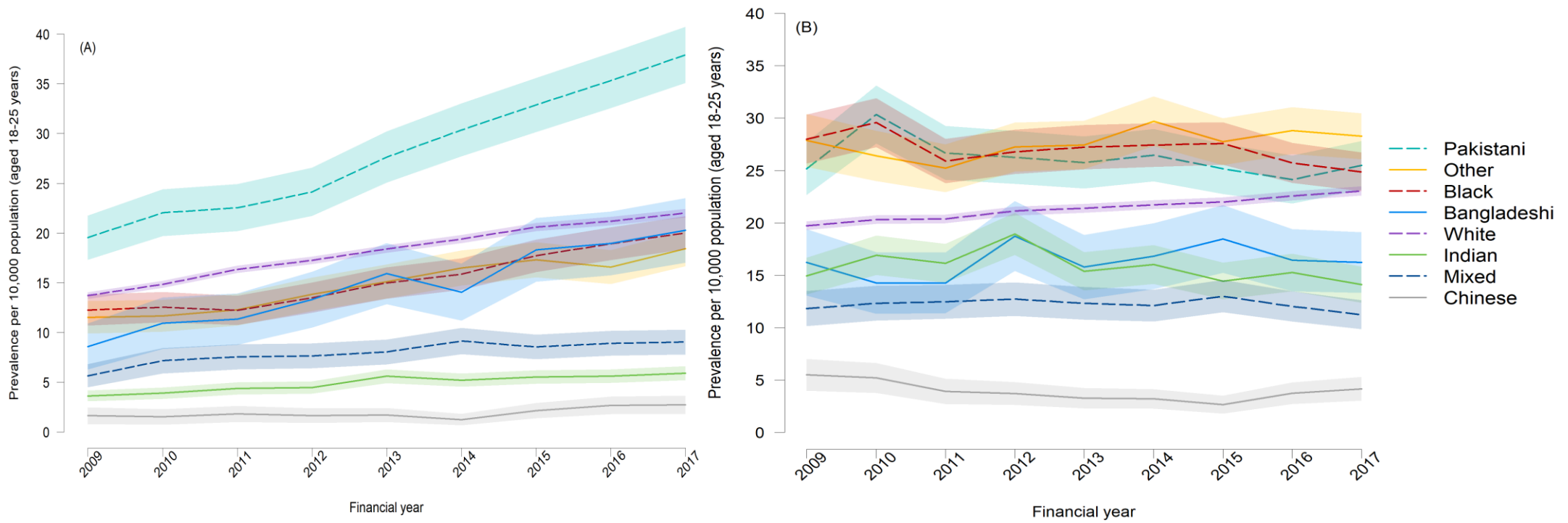


Figure 17: Comparison of the prevalence per 10,000 of young adults (aged 18-25 years) with (A) a LLC diagnosed < 18 years and (B) diagnosed ≥18 years by ethnic group for 2009/10-2017/18

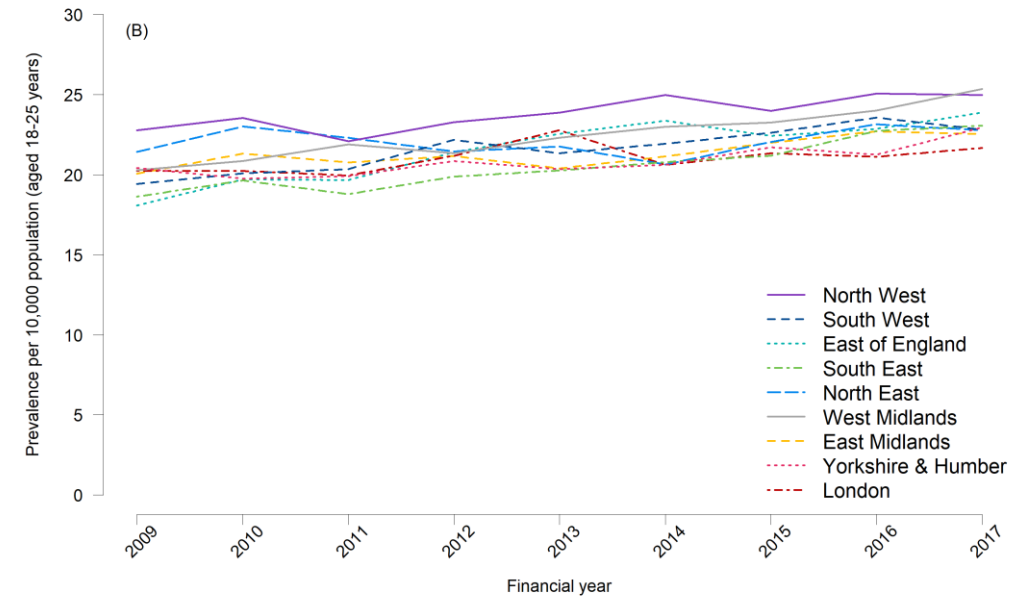
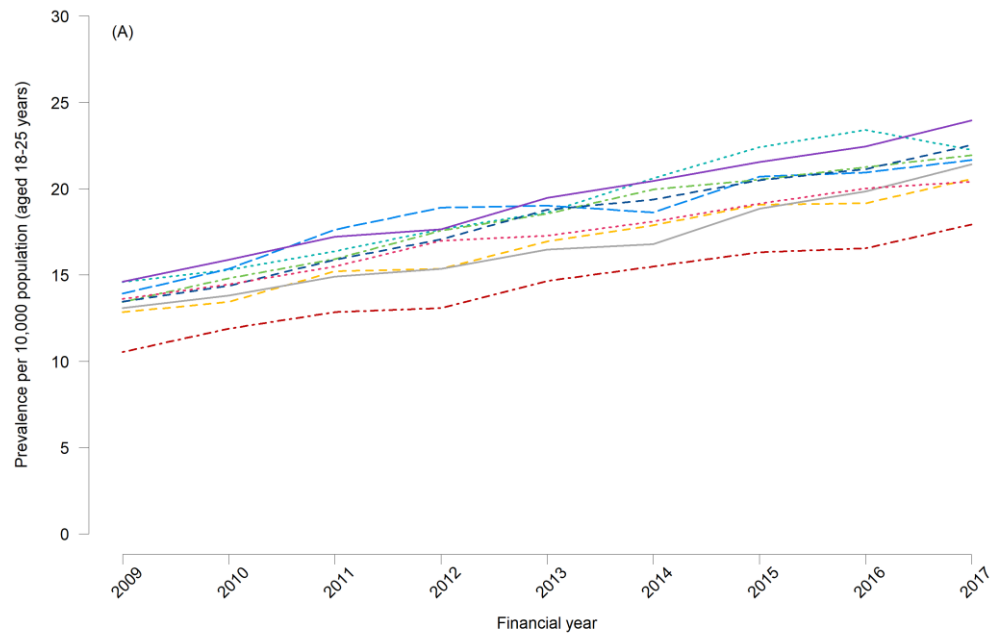


Figure 18: Comparison of the prevalence per 10,000 of young adults (aged 18-25 years) with (A) a LLC diagnosed < 18 years and (B) diagnosed  $\geq 18$  years by Government Office Region for 2009/10-2017/18

Table 4 Number of young people with a LLC by Government Office Region

	Number of young people aged 14-25 with a life limiting condition								
	East Midlands	East of England	London	North East	North West	South East	South West	West Midlands	Yorkshire and Humber
<b>2009</b>	2,256	2,713	4,176	1,489	4,175	4,095	2,575	2,928	2,861
<b>2010</b>	2,420	2,975	4,445	1,577	4,405	4,449	2,741	3,053	2,902
<b>2011</b>	2,486	3,116	4,603	1,653	4,443	4,531	2,900	3,226	3,025
<b>2012</b>	2,531	3,341	4,835	1,696	4,616	4,836	3,123	3,288	3,247
<b>2013</b>	2,652	3,509	5,345	1,704	4,872	5,082	3,176	3,570	3,292
<b>2014</b>	2,762	3,747	5,393	1,694	5,180	5,300	3,271	3,783	3,402
<b>2015</b>	2,906	3,814	5,564	1,774	5,155	5,514	3,456	3,972	3,580
<b>2016</b>	2,959	4,041	5,695	1,830	5,373	5,789	3,552	4,059	3,649
<b>2017</b>	3,107	4,106	6,022	1,819	5,547	5,956	3,567	4,287	3,822
	Number of young people aged 14-25 with a life limiting condition (excluding those diagnosed aged >=18 years)								
	East Midlands	East of England	London	North East	North West	South East	South West	West Midlands	Yorkshire and Humber
<b>2009</b>	1,305	1,725	2,262	880	2,436	2,534	1,569	1,733	1,656
<b>2010</b>	1,392	1,878	2,507	910	2,589	2,780	1,686	1,803	1,721
<b>2011</b>	1,474	2,003	2,658	1,003	2,732	2,919	1,817	1,901	1,822
<b>2012</b>	1,492	2,120	2,752	1,072	2,812	3,112	1,935	1,985	1,981
<b>2013</b>	1,647	2,220	3,085	1,072	3,020	3,317	2,030	2,204	2,054
<b>2014</b>	1,719	2,407	3,313	1,097	3,246	3,484	2,091	2,367	2,146
<b>2015</b>	1,815	2,505	3,389	1,134	3,292	3,651	2,233	2,542	2,250
<b>2016</b>	1,835	2,690	3,532	1,159	3,438	3,787	2,280	2,594	2,349
<b>2017</b>	1,998	2,693	3,799	1,166	3,639	3,938	2,346	2,761	2,428

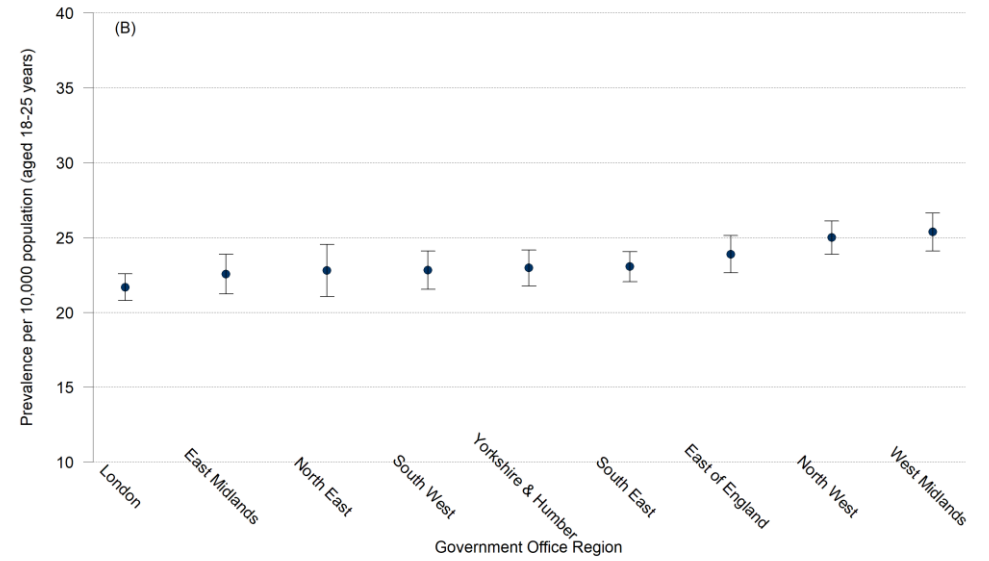
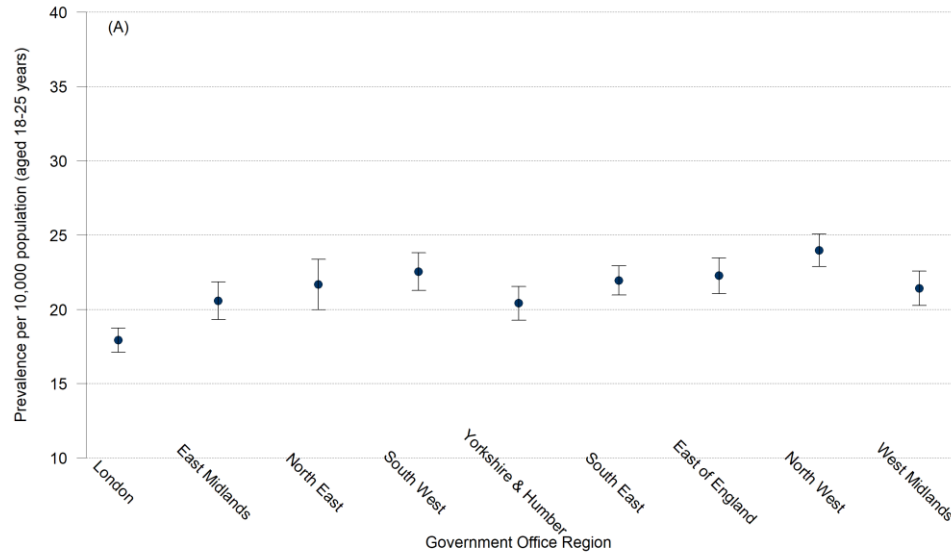


Figure 19: Comparison of the prevalence per 10,000 of young adults (aged 18-25 years) with (A) a LLC diagnosed < 18 years and (B) diagnosed  $\geq 18$  years by Government Office Region for 2017/18

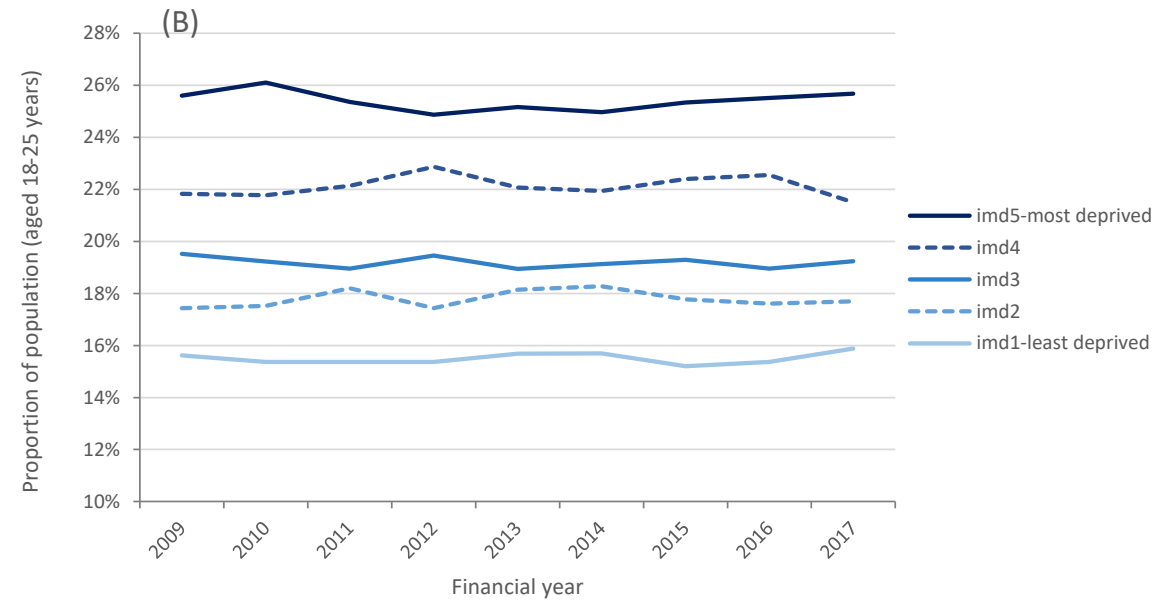
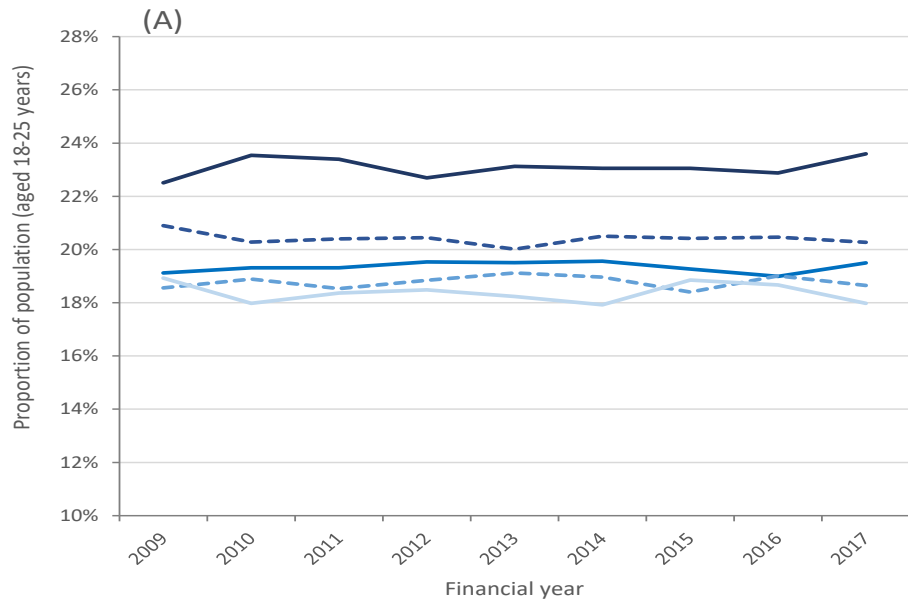


Figure 20: Comparison of the percentage of young adults (aged 18-25 years) with (A) a LLC diagnosed < 18 years and (B) diagnosed  $\geq 18$  years by (population weighted) deprivation and age of diagnosis for 2009/10-2017/18

## Numbers who died

Of the 138,356 young people with a LLC aged 14-25 years identified during the study period, 6% (8,301) died between 31/4/2009-31/4/2018 (at any age) (*Table 5*). As a proportion of all young people diagnosed <18 years, 2.1% died aged 14-17 years. We present the data on those who died >25 years for completeness but many individuals would not have reached that age during the time period of this study.

*Figure 21* shows the proportion of deaths within each setting by age group. Most young people with a LLC continue to die in hospital (57-64%). Young adults aged >25 years and aged < 18 years have the lowest proportion of hospital deaths (55% and 61% respectively). The proportion of home deaths is highest in young adults >25 years (31%) and in young adults diagnosed <18 years (27%), Young adults (≥18 years) who were diagnosed as adults had a higher proportion of deaths in a hospice (10%) compared to young adults (≥18 years) who were diagnosed as children (7%).

Table 5: Number and proportion of young people and young adults who died each year overall and by age group at death.

Year	Overall Died (n)	14-17 years		18-25 years		>25 years	
		Number who died	% of who died overall	Number who died	% of who died overall	Number who died	% of who died overall
<b>2009</b>	758	201	26.5%	545	71.9%	15	2.0%
<b>2010</b>	818	188	23.0%	566	69.2%	66	8.1%
<b>2011</b>	839	171	20.4%	560	66.7%	109	13.0%
<b>2012</b>	850	155	18.2%	540	63.5%	156	18.4%
<b>2013</b>	891	146	16.4%	566	63.5%	180	20.2%
<b>2014</b>	986	167	16.9%	580	58.8%	239	24.2%
<b>2015</b>	1,051	167	15.9%	594	56.5%	294	28.0%
<b>2016</b>	1,096	160	14.6%	612	55.8%	327	29.8%
<b>2017</b>	1,012	182	18.0%	549	54.2%	289	28.6%
<b>Total</b>	<b>8,301</b>	<b>1,537</b>		<b>5,112</b>		<b>1,675</b>	

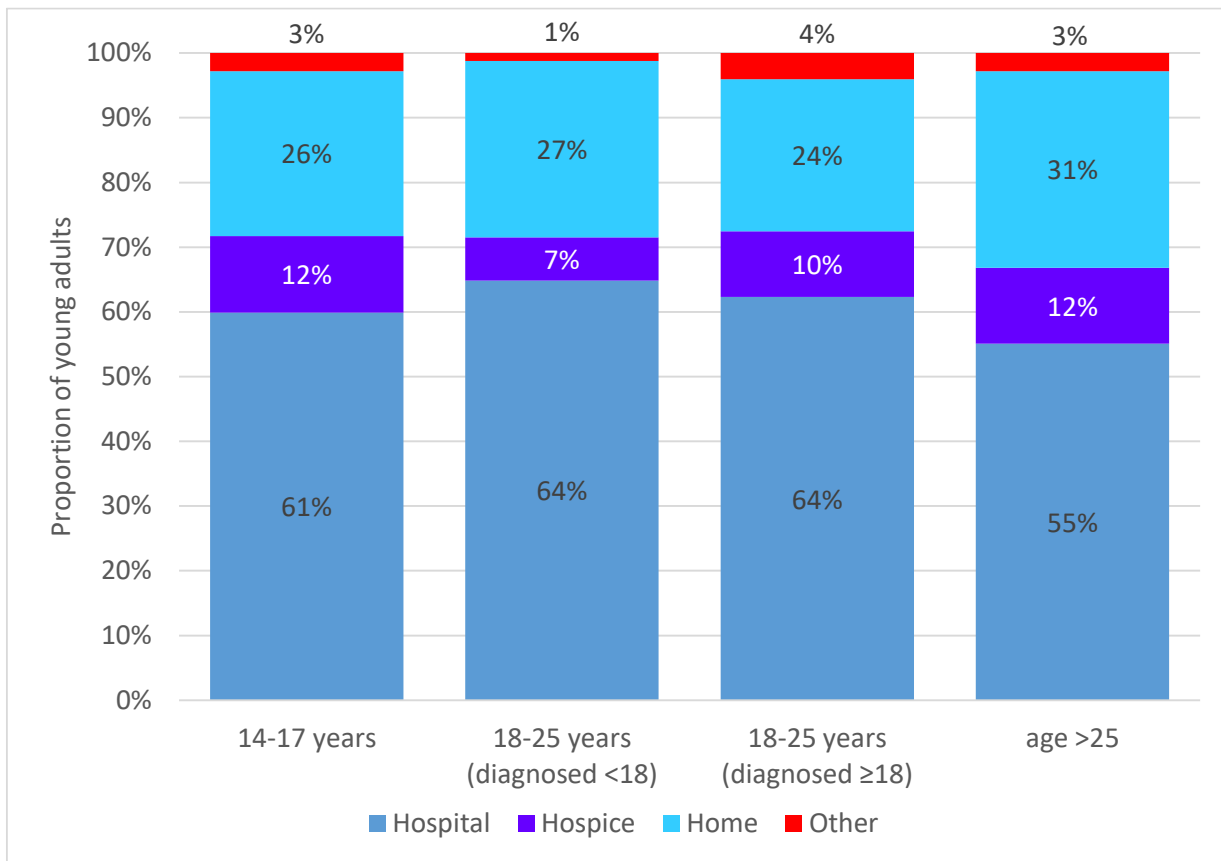


Figure 21: The proportions who died within each place of death by age category between 2009/10-2017/18



## Discussion

The numbers of young people (aged 14-25 years) with a LLC in England has risen by 40% in the past eight years and prevalence has increased by a similar proportion.

This group of young people includes those who are using paediatric health services and who may require transition into adult services and also young adults diagnosed in adulthood. The number of young people with a LLC eligible for transition rose from 8,794 in 2009/10 to 12,495 in 2017/18.

The prevalence of life-limiting conditions in young people was similar between those aged <18 years and those aged ≥18 years with the prevalence being slightly higher in the younger age group for the later years. This compares to previous findings based on one year's worth of data (2009/10) where the prevalence was lower for young adults aged 21-25 (21.1 per 10,000 [95%CI 20.7-21.6] than the prevalence for young people aged 16-20 (23.1 per 10,000 [95%CI: 22.5-23.6])(Fraser, Lidstone et al. 2014). After excluding young adults diagnosed aged ≥18 years, the prevalence in the 18-25 years age group drops significantly, which reflects the fact that many LLC diagnoses are made at age 18 or older.

Prevalence was highest for congenital anomalies and oncology conditions. This pattern differs from the previous report analysing prevalence in 0-19 year olds (L.K., Gibson-Smith et al. 2020) but can be explained by the inclusion of young people aged 20-25 years where oncology diagnoses are more prevalent (Fraser, Lidstone et al. 2014). After the removal of young adults diagnosed ≥18 years, prevalence by diagnosis is similar to the previous report.

The higher prevalence in females than males is similar to previous studies in this age group (Fraser, Lidstone et al. 2014). The fact that the difference between the sexes is greatly reduced when only including young people diagnosed during childhood is also expected as LLC diagnoses that are more prevalent in girls tend to be diagnosed after age 18 (Fraser, Lidstone et al. 2014). The availability of care workers of both sexes is important for supporting transition (Chambers 2015).

Generally, the prevalence of LLCs is greatest among those of Pakistani ethnic origin, although the Other Asian and Black ethnic minority groups also have a higher prevalence compared to the White population. This fits in with previous research which has confirmed that some of the LLC diagnoses likely to be diagnosed in younger age groups, such as genetic conditions and congenital disorders (Sheridan, Wright et al. 2013, Firth, Petherick et al. 2018), are more common in those of Pakistani origin. As part of the person-centred approach to transition it is important to ensure that a person's ethnic background is considered and that any cultural needs are met.

A higher proportion of young people with a LLC lived in the most deprived areas of England. This is important when planning services and accessibility of those services.

Based on previous trends and predicted changes in population, the prevalence in 2030 was predicted to be between 46.0-62.2 per 10,000 population. The predicted prevalence excluding young adults diagnosed in adulthood was, as expected, lower (31.0-46.0 per 10,000 population).

Dividing the population with a LLC into three groups (young people aged <18 years, young adults aged ≥18 years diagnosed <18 years and young adults aged ≥18 years diagnosed aged ≥18 years) showed that young adults (aged ≥18 years) diagnosed in adulthood were proportionally the largest group. Further analysis comparing adults diagnosed in childhood to adults diagnosed in adulthood showed that the most notable difference was in prevalence between diagnostic groups. This implies the type of adult palliative care service provision and condition expertise required will be different between these two groups of young adults. Also notable is the higher prevalence for women diagnosed <18 years, despite childhood LLCs being more prevalent in males. The discrepancy in our data could be explained by the fact that although there are roughly equal numbers of males and females who were diagnosed <18 years, the females have a greater number years of hospital attendance (mean number of years of episodes 2.38 vs 2.16).

The most common place of death was in the hospital setting which could reflect patient preferences or a lack of choice of other services. Interestingly place of death varies according to age of diagnosis with a larger proportion of young adults (aged  $\geq 18$  years) diagnosed  $\geq 18$  years dying in a hospice compared to young adults diagnosed  $< 18$  years who instead have a larger proportion dying at home. This could be a result of the type of diagnoses and care needs that they have.

These analyses provide some evidence that increasing prevalence of LLC is not limited to children but is also evident in young people. These analyses also emphasise how much variation there is in the type of diagnoses a young person has according to their age and age of diagnosis which in turn will impact the type of adult services required to meet their needs.

National data collection that identifies complexity and needs of the young person with a life-limiting or life-threatening condition who may require transition to adult services should be a priority as part of the NHS England All Age Palliative and End of Life Programme

### Strengths and Limitations

This study used a transparent and repeatable methodology over a time period which enabled assessment of longitudinal trends.

Case identification remains challenging. There is large variation in severity and prognosis within some of these diagnoses. This makes it challenging to quantify the needs of the young person purely by their diagnoses. This is compounded by the grouping of some diagnoses within ICD-10, i.e. each diagnoses does not have its own code.

The LLC diagnostic framework used to identify the young people in this study was developed to identify children with a LLC rather than young adults. Some diagnoses may not be life-limiting life threatening when not diagnosed until adulthood.

The hospital data used in this study were primarily collected for financial purposes, rather than for research. However, the key variable for this study was the diagnostic code, which is mandatory for financial purposes and therefore collected to a high standard. Some of the other variables, such as ethnicity, are less well recorded.

If a young person did not have a hospital admission for a particular year, they were not included in the data set for that financial year resulting in an underestimation of the numbers of young adults alive with a LLC for that year. This may partly explain differences over time and between sexes.

Projections, such as those included in this report, involve substantial assumptions about the similarity of future and past trends, including future trends in healthcare improvement that may or may not be valid. Alongside any uncertainties in the numbers diagnosed, the population projections used as denominators are subject to variation from reality, due to variations in population demographics in the future.

## Summaries by Government Office Region

The methods used for these regional summaries are identical to those in the main report apart from the calculation of Deprivation categories which were recalculated for each region rather than nationally as described below:

An index of multiple deprivation (IMD2010) was assigned to each individual based on the 2001 Lower-layer Super Output Area (LSOA) of residence. Five deprivation categories were created, from least (category 1) to most deprived (category 5), based on IMD2010 scores. These categories were population weighted and calculated separately for each region. Thus, each category contained approximately 20% of the population (aged 0-19) for that region.

***Note of caution: for some of these regions data contain relatively small numbers and therefore care in interpretation is required.***

## East Midlands

Table 6: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the East Midlands Government Office Region

Financial year	Overall				Age 14-17 years				Age 18-25 years			
	Number of Individuals with a LLC	Prevalence	95%CI		Number of Individuals with a LLC	Prevalence	95%CI		Number of Individuals with a LLC	Prevalence	95%CI	
<b>Young people aged 14-25 years</b>												
2009	2,256	32.2	30.8	33.5	695	30.6	28.3	32.9	1,561	32.9	31.3	34.5
2010	2,420	34.2	32.8	35.5	744	32.9	30.6	35.3	1,676	34.8	33.1	36.4
2011	2,486	34.9	33.5	36.2	732	32.5	30.1	34.8	1,754	36.0	34.3	37.7
2012	2,531	35.5	34.1	36.9	738	33.2	30.8	35.6	1,793	36.5	34.8	38.2
2013	2,652	37.2	35.7	38.6	812	36.7	34.2	39.3	1,840	37.3	35.6	39.0
2014	2,762	38.8	37.4	40.3	836	38.4	35.8	41.0	1,926	39.0	37.3	40.8
2015	2,906	40.9	39.4	42.4	868	40.6	37.9	43.3	2,038	41.1	39.3	42.8
2016	2,959	42.0	40.5	43.5	886	42.3	39.5	45.1	2,073	41.9	40.1	43.7
2017	3,107	44.5	42.9	46.1	985	47.8	44.9	50.8	2,122	43.1	41.3	44.9
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>												
2009	1,305	18.6	17.6	19.6	695	30.6	28.3	32.9	610	12.9	11.8	13.9
2010	1,392	19.7	18.6	20.7	744	32.9	30.6	35.3	648	13.4	12.4	14.5
2011	1,474	20.7	19.6	21.7	732	32.5	30.1	34.8	742	15.2	14.1	16.3
2012	1,492	20.9	19.9	22.0	738	33.2	30.8	35.6	754	15.4	14.3	16.5
2013	1,647	23.1	22.0	24.2	812	36.7	34.2	39.3	835	16.9	15.8	18.1
2014	1,719	24.2	23.0	25.3	836	38.4	35.8	41.0	883	17.9	16.7	19.1
2015	1,815	25.6	24.4	26.7	868	40.6	37.9	43.3	947	19.1	17.9	20.3
2016	1,835	26.0	24.9	27.2	886	42.3	39.5	45.1	949	19.2	17.9	20.4
2017	1,998	28.6	27.4	29.9	985	47.8	44.9	50.8	1,013	20.6	19.3	21.8

95%CI:95% Confidence interval

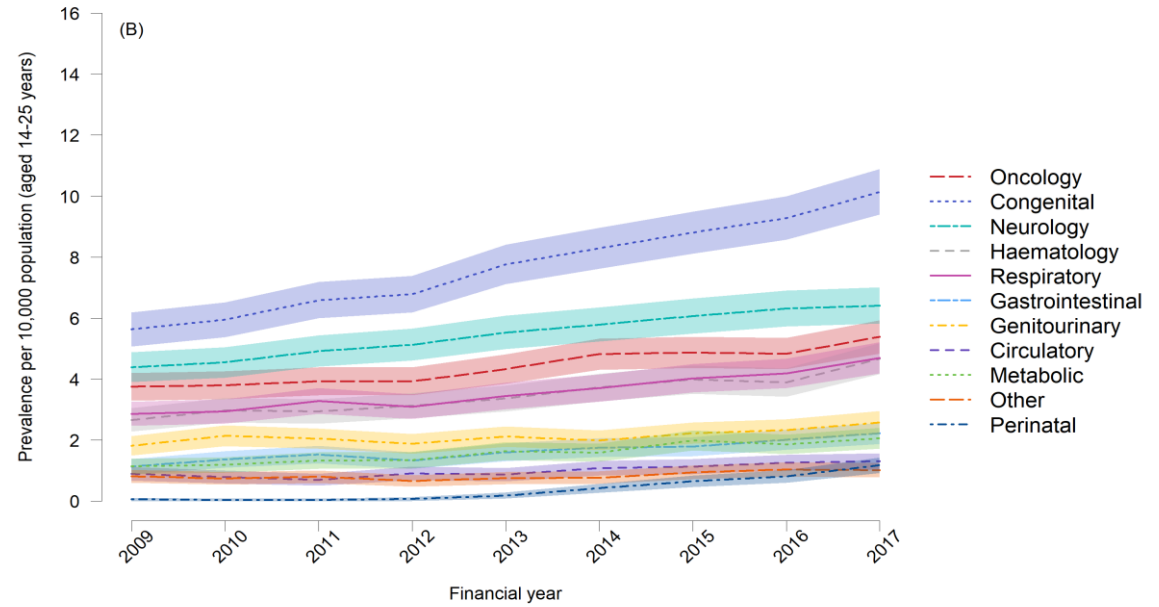
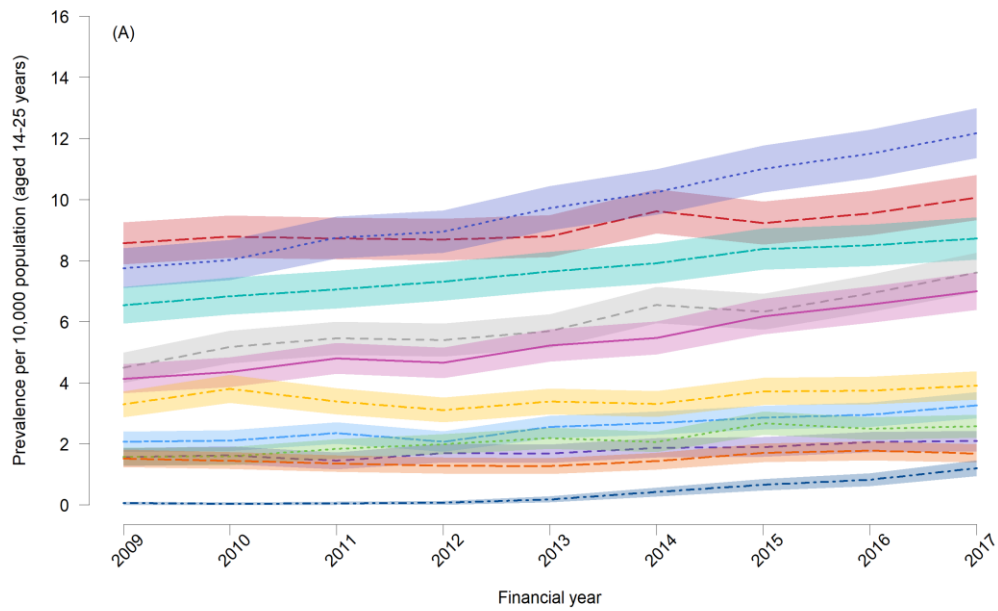


Figure 22: Prevalence per 10,000 of young people (aged 14-25) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in East Midlands Government Office Region for 2009/10-2017/08

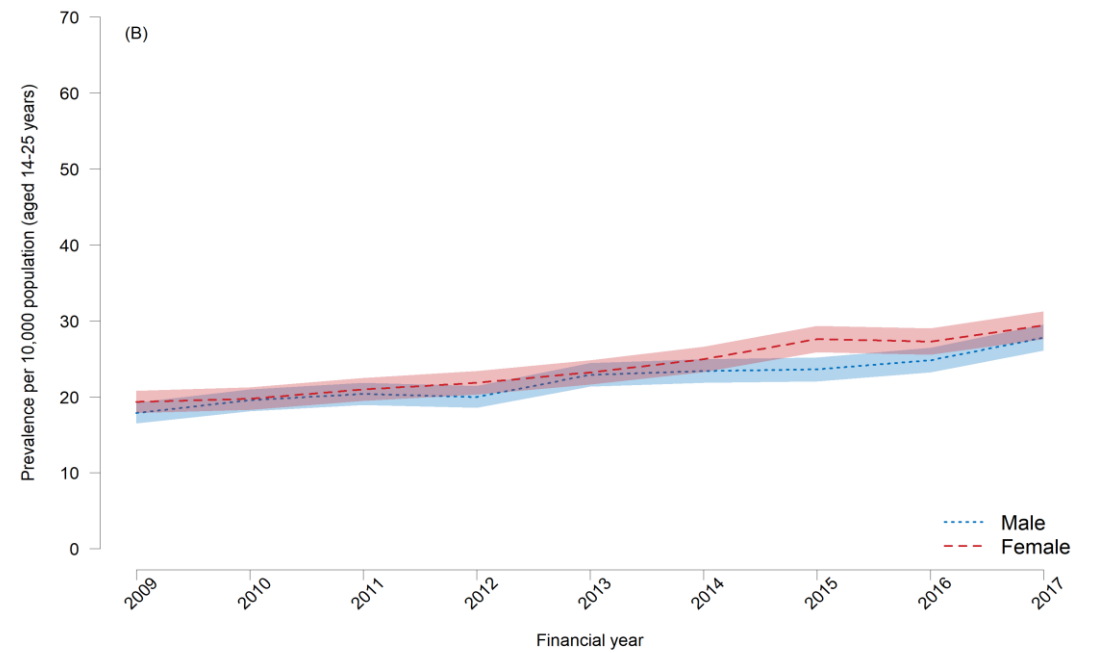
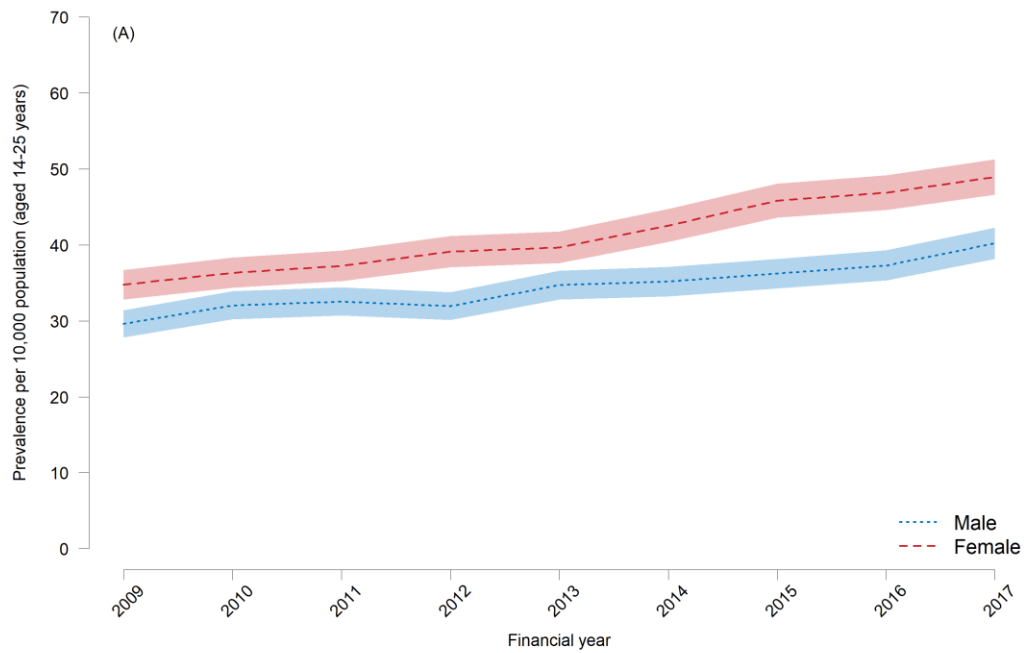


Figure 23: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in East Midlands Government Office Region for 2009/10-2017/08

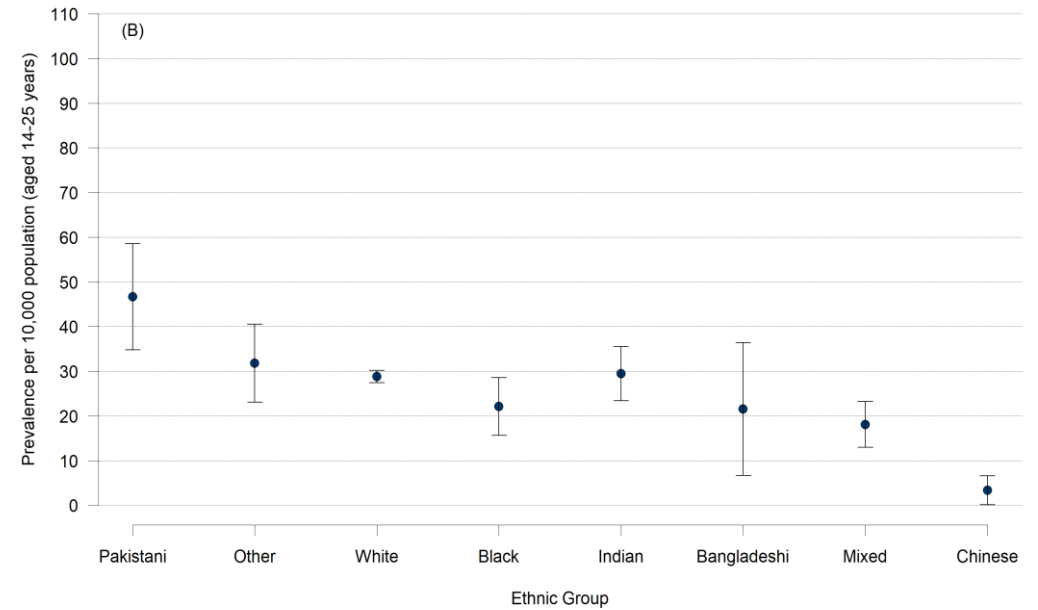
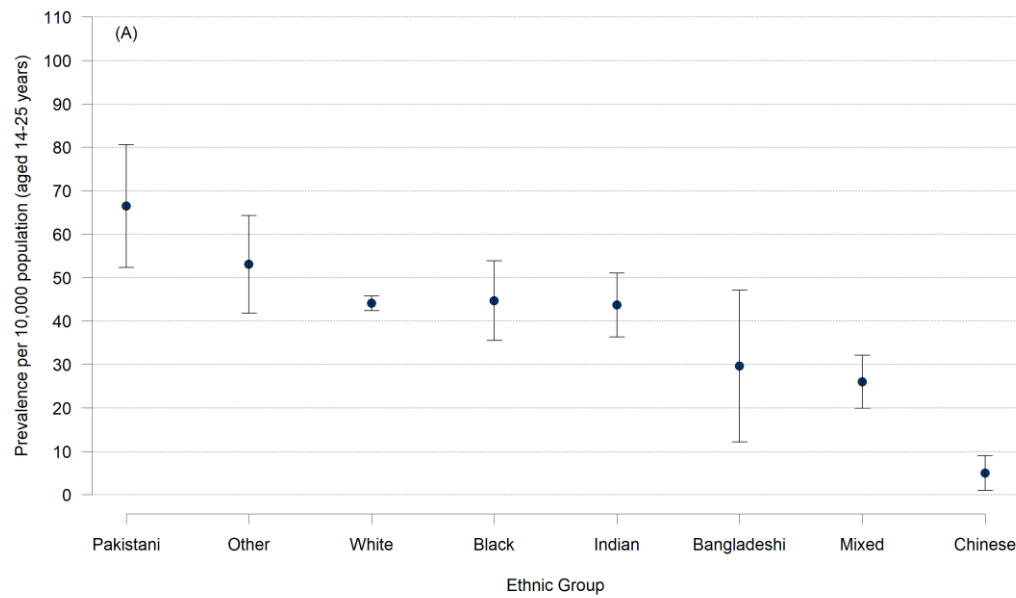


Figure 24: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the East Midlands Government office region for 2017.

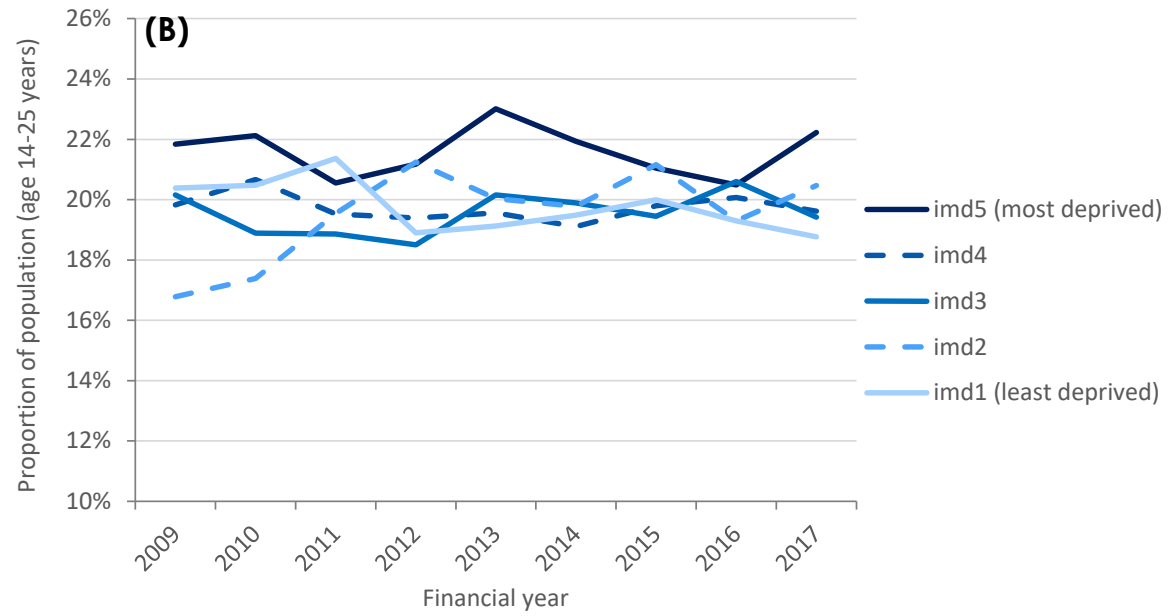
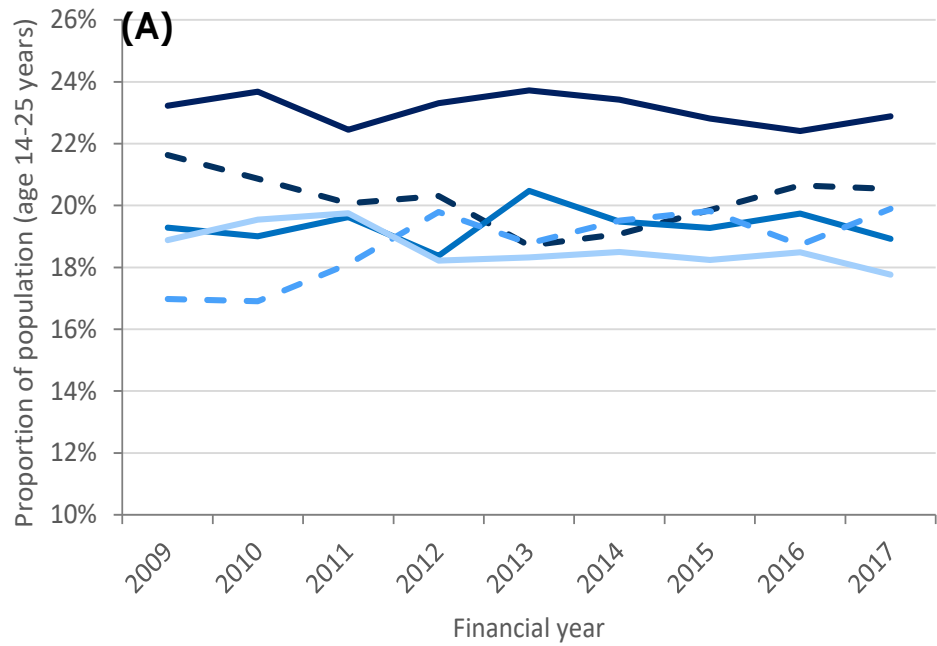


Figure 25: Percentage of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by (population weighted) deprivation group in the East Midlands Government office region for 2009/10-2017/18



Table 7: Prevalence per 10,000 of (age 14-25 years) with a LLC by Local Authority in the East Midlands Government Office Region for 2017/18

Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Amber Valley	15690	69	<b>44.0</b>	33.6 54.3	53	<b>33.8</b>	24.7 42.9
Ashfield	16806	86	<b>51.2</b>	40.4 62.0	51	<b>30.3</b>	22.0 38.7
Bassetlaw	15001	77	<b>51.3</b>	39.9 62.8	55	<b>36.7</b>	27.0 46.3
Blaby	12556	56	<b>44.6</b>	32.9 56.3	39	<b>31.1</b>	21.3 40.8
Bolsover	10233	44	<b>43.0</b>	30.3 55.7	30	<b>29.3</b>	18.8 39.8
Boston	8988	36	<b>40.1</b>	27.0 53.1	25	<b>27.8</b>	16.9 38.7
Broxtowe	15253	64	<b>42.0</b>	31.7 52.2	40	<b>26.2</b>	18.1 34.3
Charnwood	32887	95	<b>28.9</b>	23.1 34.7	53	<b>16.1</b>	11.8 20.5
Chesterfield	13940	76	<b>54.5</b>	42.3 66.7	50	<b>35.9</b>	25.9 45.8
Corby	8901	36	<b>40.4</b>	27.3 53.6	25	<b>28.1</b>	17.1 39.1
Daventry	9930	54	<b>54.4</b>	39.9 68.8	36	<b>36.3</b>	24.4 48.1
Derby	42631	213	<b>50.0</b>	43.3 56.7	115	<b>27.0</b>	22.1 31.9
Derbyshire Dales	7865	26	<b>33.1</b>	20.4 45.7	22	<b>28.0</b>	16.3 39.6
East Lindsey	15258	63	<b>41.3</b>	31.1 51.5	40	<b>26.2</b>	18.1 34.3
East Northamptonshire	11771	62	<b>52.7</b>	39.6 65.8	44	<b>37.4</b>	26.4 48.4
Erewash	14717	79	<b>53.7</b>	41.9 65.5	43	<b>29.2</b>	20.5 37.9
Gedling	14773	79	<b>53.5</b>	41.7 65.2	51	<b>34.5</b>	25.1 44.0
Harborough	10738	42	<b>39.1</b>	27.3 50.9	27	<b>25.1</b>	15.7 34.6
High Peak	11839	70	<b>59.1</b>	45.3 72.9	43	<b>36.3</b>	25.5 47.2
Hinckley & Bosworth	13311	66	<b>49.6</b>	37.7 61.5	42	<b>31.6</b>	22.0 41.1
Kettering	12824	68	<b>53.0</b>	40.5 65.6	48	<b>37.4</b>	26.9 48.0
Leicester	72229	287	<b>39.7</b>	35.1 44.3	179	<b>24.8</b>	21.2 28.4
Lincoln	19782	57	<b>28.8</b>	21.3 36.3	38	<b>19.2</b>	13.1 25.3
Mansfield	14447	74	<b>51.2</b>	39.6 62.9	49	<b>33.9</b>	24.4 43.4
Melton	6397	36	<b>56.3</b>	37.9 74.6	27	<b>42.2</b>	26.3 58.1
Newark & Sherwood	15041	103	<b>68.5</b>	55.3 81.7	70	<b>46.5</b>	35.7 57.4
North East Derbyshire	12049	61	<b>50.6</b>	38.0 63.3	41	<b>34.0</b>	23.6 44.4
North Kesteven	13572	67	<b>49.4</b>	37.6 61.2	53	<b>39.1</b>	28.6 49.5
North West Leicestershire	12178	52	<b>42.7</b>	31.1 54.3	29	<b>23.8</b>	15.2 32.5
Northampton	34222	157	<b>45.9</b>	38.7 53.0	103	<b>30.1</b>	24.3 35.9
Nottingham	79718	281	<b>35.2</b>	31.1 39.4	158	<b>19.8</b>	16.7 22.9
Oadby & Wigston	10290	36	<b>35.0</b>	23.6 46.4	24	<b>23.3</b>	14.0 32.6
Rushcliffe	15107	63	<b>41.7</b>	31.4 52.0	48	<b>31.8</b>	22.8 40.7
Rutland	5541	22	<b>39.7</b>	23.1 56.3	12	<b>21.7</b>	9.4 33.9
South Derbyshire	13193	81	<b>61.4</b>	48.1 74.7	52	<b>39.4</b>	28.7 50.1
South Holland	10873	47	<b>43.2</b>	30.9 55.6	32	<b>29.4</b>	19.2 39.6
South Kesteven	16480	64	<b>38.8</b>	29.3 48.3	44	<b>26.7</b>	18.8 34.6
South Northamptonshire	10153	41	<b>40.4</b>	28.0 52.7	27	<b>26.6</b>	16.6 36.6
Wellingborough	10039	63	<b>62.8</b>	47.3 78.2	43	<b>42.8</b>	30.1 55.6
West Lindsey	11105	50	<b>45.0</b>	32.6 57.5	35	<b>31.5</b>	21.1 41.9

95%CI:95% Confidence interval

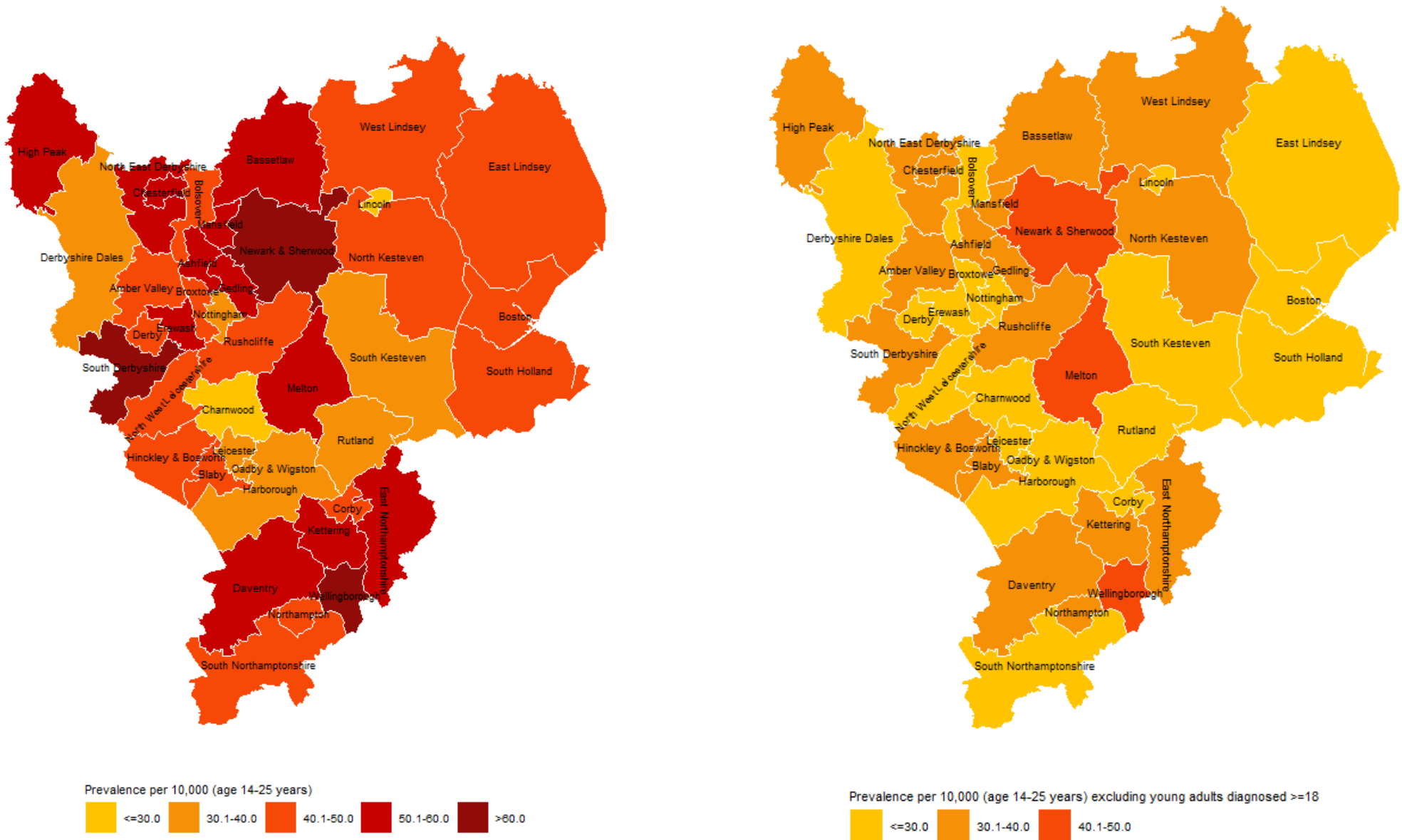


Figure 26: Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in the East Midlands Government Office Region for 2017/18

## East of England

Table 8: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the East of England Government Office Region

Financial year	Overall				Age 14-17 years				Age 18-25 years			
	Number of Individuals with a LLC	Prevalence	95%CI		Number of Individuals with a LLC	Prevalence	95%CI		Number of Individuals with a LLC	Prevalence	95%CI	
<b>Young people aged 14-25 years</b>												
2009	2,713	32.4	31.2	33.6	927	31.8	29.8	33.9	1,786	32.7	31.2	34.2
2010	2,975	35.0	33.8	36.3	1,025	35.1	33.0	37.3	1,950	35.0	33.4	36.5
2011	3,116	36.3	35.0	37.6	1,076	36.8	34.6	39.0	2,040	36.0	34.5	37.6
2012	3,341	38.8	37.5	40.2	1,112	38.4	36.2	40.7	2,229	39.0	37.4	40.7
2013	3,509	40.8	39.5	42.2	1,153	40.2	37.8	42.5	2,356	41.1	39.5	42.8
2014	3,747	43.7	42.3	45.1	1,224	43.3	40.8	45.7	2,523	43.9	42.2	45.7
2015	3,814	44.2	42.8	45.6	1,195	42.9	40.5	45.3	2,619	44.8	43.1	46.5
2016	4,041	46.8	45.3	48.2	1,307	47.8	45.2	50.4	2,734	46.3	44.6	48.0
2017	4,106	47.6	46.2	49.1	1,376	50.9	48.2	53.6	2,730	46.1	44.4	47.9
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>												
2009	1,725	20.6	19.6	21.6	927	31.8	29.8	33.9	798	14.6	13.6	15.6
2010	1,878	22.1	21.1	23.1	1,025	35.1	33.0	37.3	853	15.3	14.3	16.3
2011	2,003	23.3	22.3	24.4	1,076	36.8	34.6	39.0	927	16.4	15.3	17.4
2012	2,120	24.6	23.6	25.7	1,112	38.4	36.2	40.7	1,008	17.7	16.6	18.7
2013	2,220	25.8	24.7	26.9	1,153	40.2	37.8	42.5	1,067	18.6	17.5	19.8
2014	2,407	28.1	27.0	29.2	1,224	43.3	40.8	45.7	1,183	20.6	19.4	21.8
2015	2,505	29.0	27.9	30.2	1,195	42.9	40.5	45.3	1,310	22.4	21.2	23.6
2016	2,690	31.1	30.0	32.3	1,307	47.8	45.2	50.4	1,383	23.4	22.2	24.6
2017	2,693	31.2	30.1	32.4	1,376	50.9	48.2	53.6	1,317	22.3	21.1	23.5

95%CI:95% Confidence interval

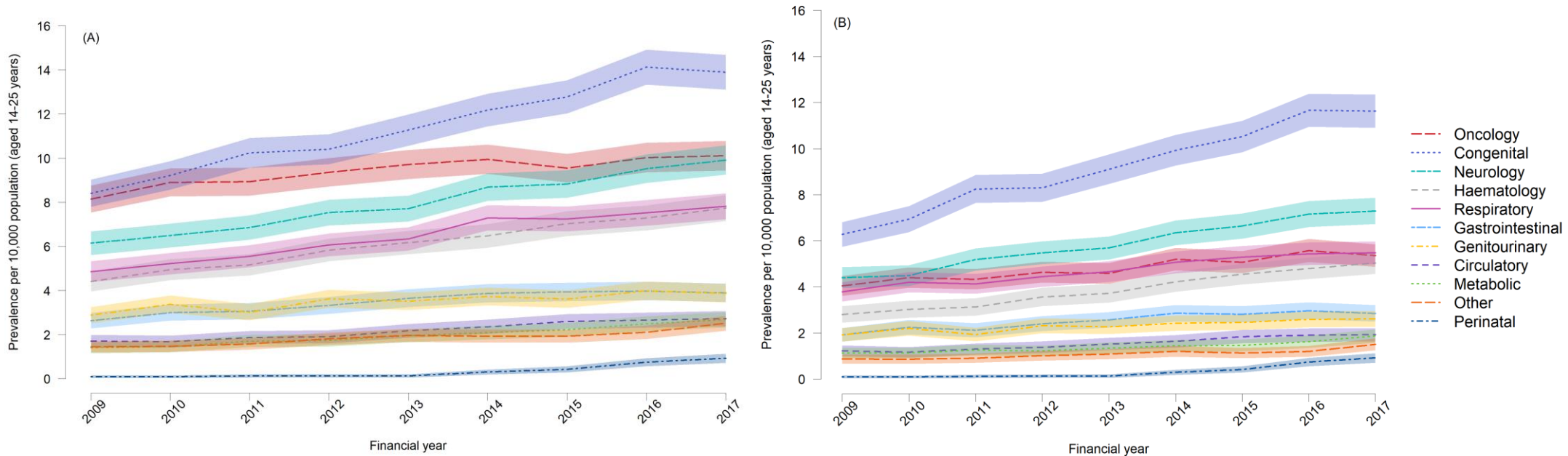


Figure 27: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the East of England Government Office Region for 2009/10-2017/18

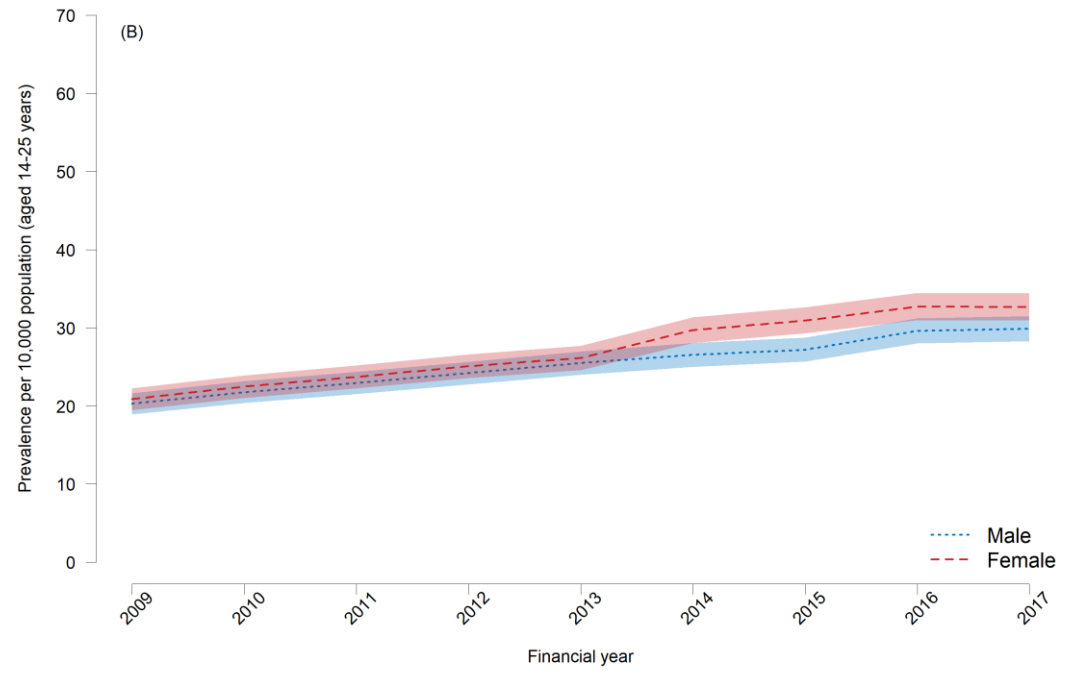
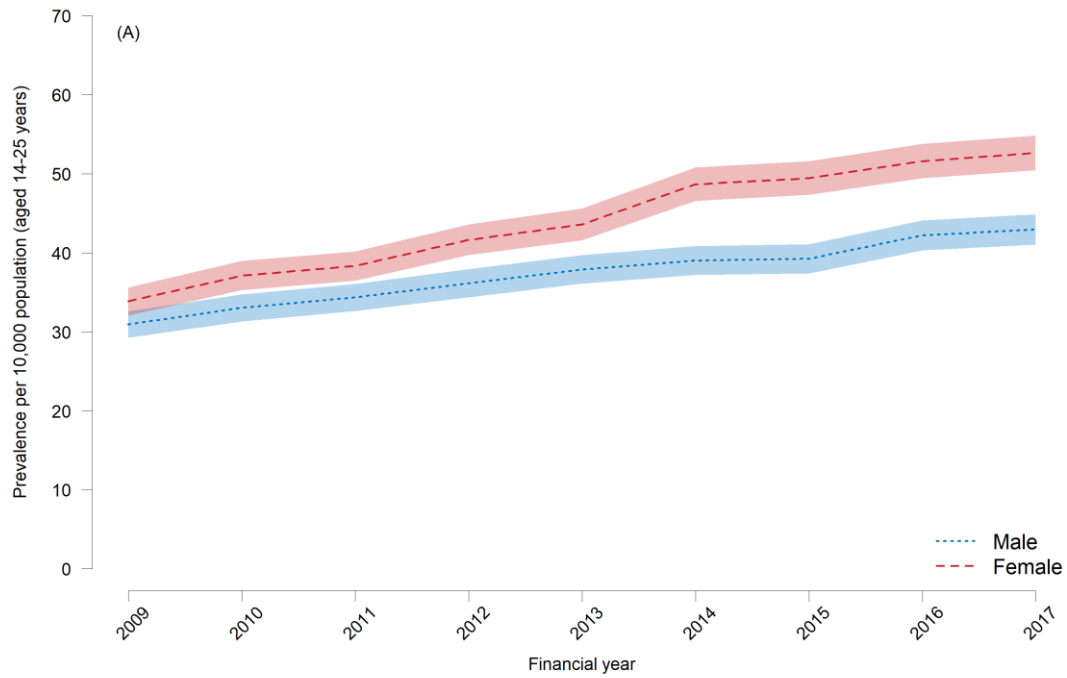


Figure 28: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in the East of England Government Office Region for 2009/10-2017/18

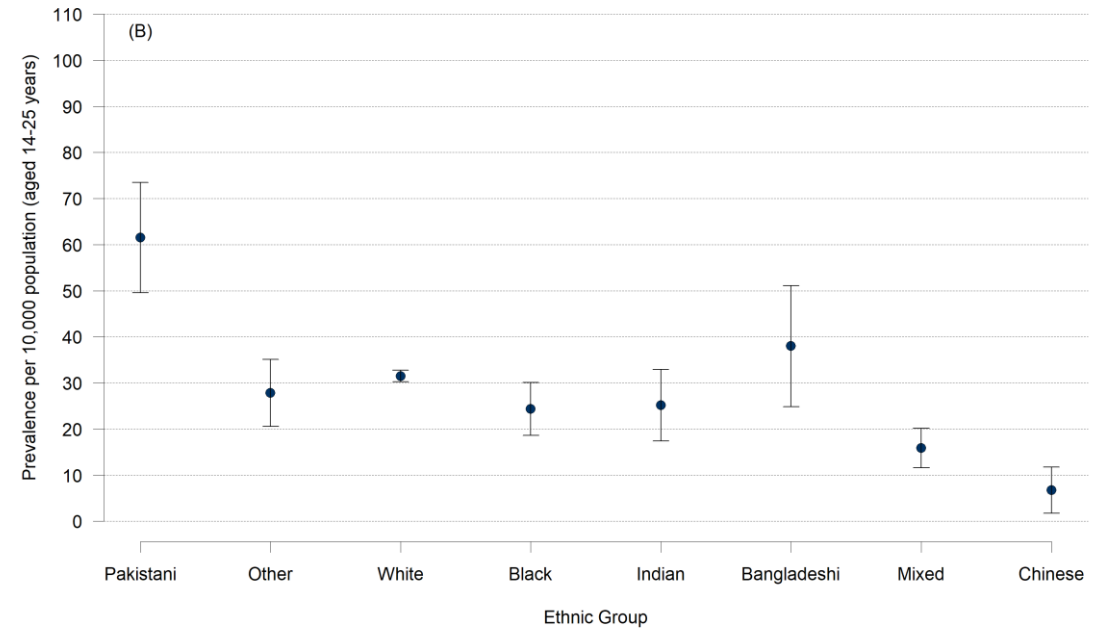
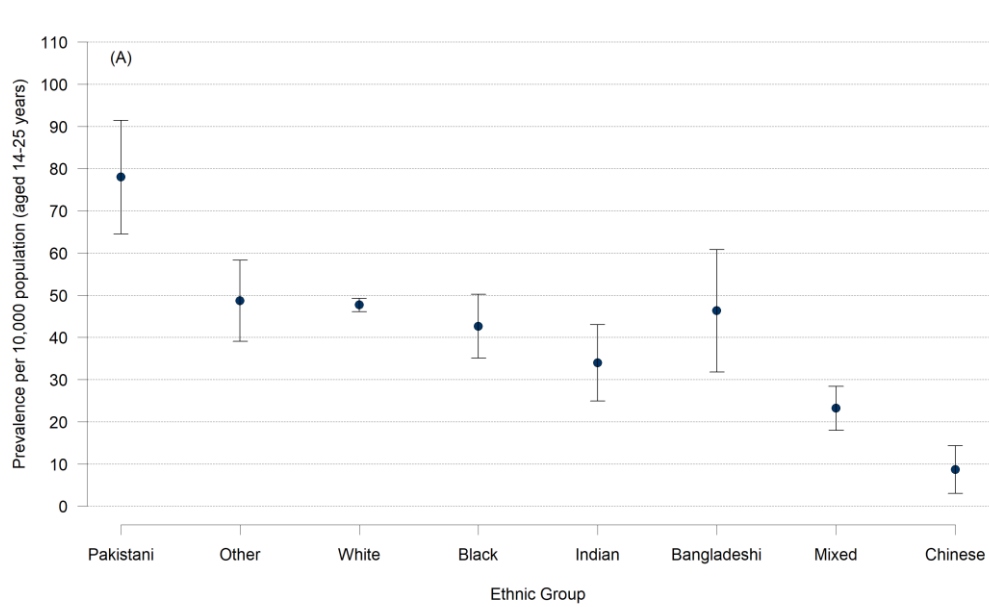


Figure 29: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the East of England Government office region for 2017/18.

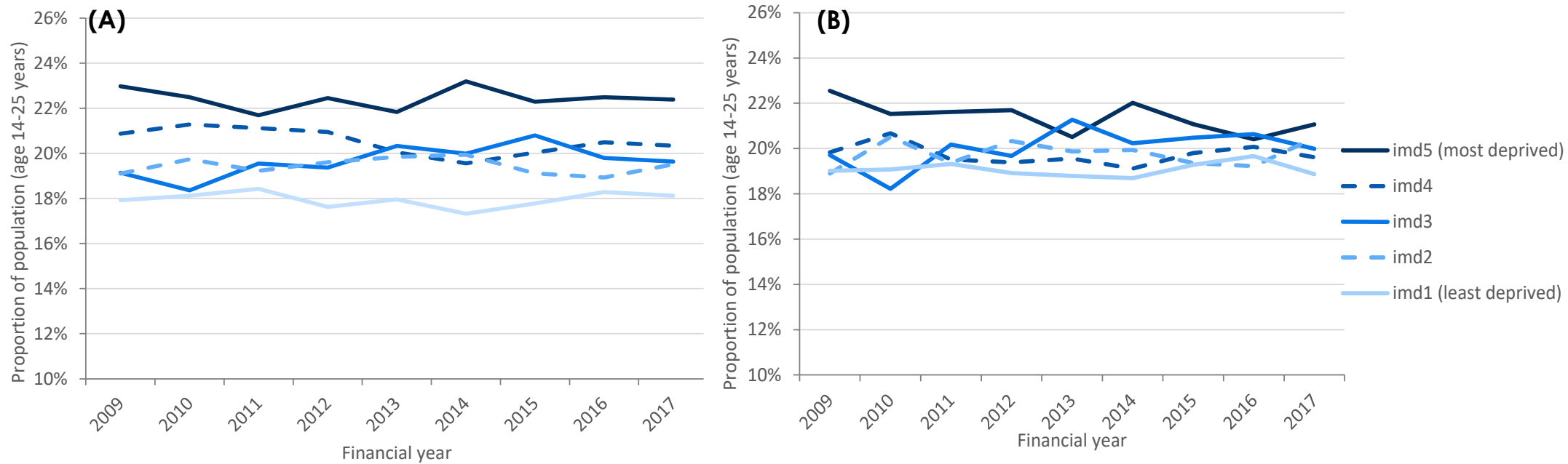


Figure 30: Percentage of young people (aged 14-5 years) with (A) a LEC diagnosed at any age or (B) with a LEC diagnosed <18 by (population weighted) deprivation group in the East of England Government office region for 2009/10-2017/18.

Table 9: Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in East of England Government Office Region for 2017/18

Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Babergh	10718	50	<b>46.7</b>	33.8 59.6	33	<b>30.8</b>	20.3 41.3
Basildon	25376	137	<b>54.0</b>	45.0 63.0	85	<b>33.5</b>	26.4 40.6
Bedford Unitary	24287	125	<b>51.5</b>	42.5 60.5	91	<b>37.5</b>	29.8 45.2
Braintree	19793	87	<b>44.0</b>	34.7 53.2	67	<b>33.9</b>	25.8 41.9
Breckland	17485	89	<b>50.9</b>	40.4 61.4	54	<b>30.9</b>	22.7 39.1
Brentwood	9715	45	<b>46.3</b>	32.8 59.8	28	<b>28.8</b>	18.2 39.5
Broadland	14800	60	<b>40.5</b>	30.3 50.8	39	<b>26.4</b>	18.1 34.6
Broxbourne	14101	69	<b>48.9</b>	37.4 60.5	48	<b>34.0</b>	24.4 43.7
Cambridge	34905	74	<b>21.2</b>	16.4 26.0	42	<b>12.0</b>	8.4 15.7
Castle Point	11536	64	<b>55.5</b>	41.9 69.0	41	<b>35.5</b>	24.7 46.4
Central Bedfordshire	35198	193	<b>54.8</b>	47.1 62.5	137	<b>38.9</b>	32.4 45.4
Chelmsford	24537	117	<b>47.7</b>	39.1 56.3	81	<b>33.0</b>	25.8 40.2
Colchester	31173	136	<b>43.6</b>	36.3 50.9	80	<b>25.7</b>	20.0 31.3
Dacorum	19670	114	<b>58.0</b>	47.3 68.6	79	<b>40.2</b>	31.3 49.0
East Cambridgeshire	10879	32	<b>29.4</b>	19.2 39.6	23	<b>21.1</b>	12.5 29.8
East Hertfordshire	19005	95	<b>50.0</b>	40.0 60.0	67	<b>35.3</b>	26.8 43.7
Epping Forest	16587	82	<b>49.4</b>	38.8 60.1	48	<b>28.9</b>	20.8 37.1
Fenland	13109	54	<b>41.2</b>	30.2 52.2	31	<b>23.6</b>	15.3 32.0
Forest Heath	9598	32	<b>33.3</b>	21.8 44.9	18	<b>18.8</b>	10.1 27.4
Great Yarmouth	13891	73	<b>52.6</b>	40.5 64.6	55	<b>39.6</b>	29.2 50.0
Harlow	12323	74	<b>60.1</b>	46.4 73.7	42	<b>34.1</b>	23.8 44.4
Hertsmere	14427	72	<b>49.9</b>	38.4 61.4	46	<b>31.9</b>	22.7 41.1
Huntingdonshire	23169	124	<b>53.5</b>	44.1 62.9	90	<b>38.8</b>	30.8 46.9
Ipswich	20674	90	<b>43.5</b>	34.6 52.5	55	<b>26.6</b>	19.6 33.6
King's Lynn & West Norfolk	18820	100	<b>53.1</b>	42.7 63.5	71	<b>37.7</b>	29.0 46.5
Luton	41506	211	<b>50.8</b>	44.0 57.7	142	<b>34.2</b>	28.6 39.8
Maldon	7355	45	<b>61.2</b>	43.4 79.0	30	<b>40.8</b>	26.2 55.4
Mid Suffolk	12121	59	<b>48.7</b>	36.3 61.1	41	<b>33.8</b>	23.5 44.2
North Hertfordshire	16287	75	<b>46.0</b>	35.7 56.4	46	<b>28.2</b>	20.1 36.4
North Norfolk	10953	48	<b>43.8</b>	31.5 56.2	33	<b>30.1</b>	19.9 40.4
Norwich	29398	99	<b>33.7</b>	27.1 40.3	51	<b>17.3</b>	12.6 22.1
Peterborough	30082	142	<b>47.2</b>	39.5 55.0	91	<b>30.3</b>	24.0 36.5
Rochford	11101	49	<b>44.1</b>	31.8 56.5	32	<b>28.8</b>	18.9 38.8
South Cambridgeshire	19807	96	<b>48.5</b>	38.8 58.1	63	<b>31.8</b>	24.0 39.6
South Norfolk	15269	76	<b>49.8</b>	38.6 60.9	45	<b>29.5</b>	20.9 38.1
Southend-on-Sea	24408	124	<b>50.8</b>	41.9 59.7	78	<b>32.0</b>	24.9 39.0
St. Albans	18302	117	<b>63.9</b>	52.4 75.5	83	<b>45.3</b>	35.6 55.1
St. Edmundsbury	15497	68	<b>43.9</b>	33.5 54.3	40	<b>25.8</b>	17.8 33.8
Stevenage	12716	62	<b>48.8</b>	36.7 60.9	40	<b>31.5</b>	21.7 41.2
Suffolk Coastal	14858	74	<b>49.8</b>	38.5 61.1	48	<b>32.3</b>	23.2 41.4
Tendring	16609	94	<b>56.6</b>	45.2 68.0	63	<b>37.9</b>	28.6 47.3



Three Rivers	11707	65	<b>55.5</b>	42.1	69.0	40	<b>34.2</b>	23.6	44.7
Thurrock	24275	112	<b>46.1</b>	37.6	54.7	73	<b>30.1</b>	23.2	37.0
Uttlesford	10823	48	<b>44.3</b>	31.8	56.9	31	<b>28.6</b>	18.6	38.7
Watford	14090	70	<b>49.7</b>	38.1	61.3	50	<b>35.5</b>	25.7	45.3
Waveney	14159	89	<b>62.9</b>	49.8	75.9	56	<b>39.6</b>	29.2	49.9
Welwyn Hatfield	24947	87	<b>34.9</b>	27.6	42.2	62	<b>24.9</b>	18.7	31.0
95%CI:95% Confidence interval									

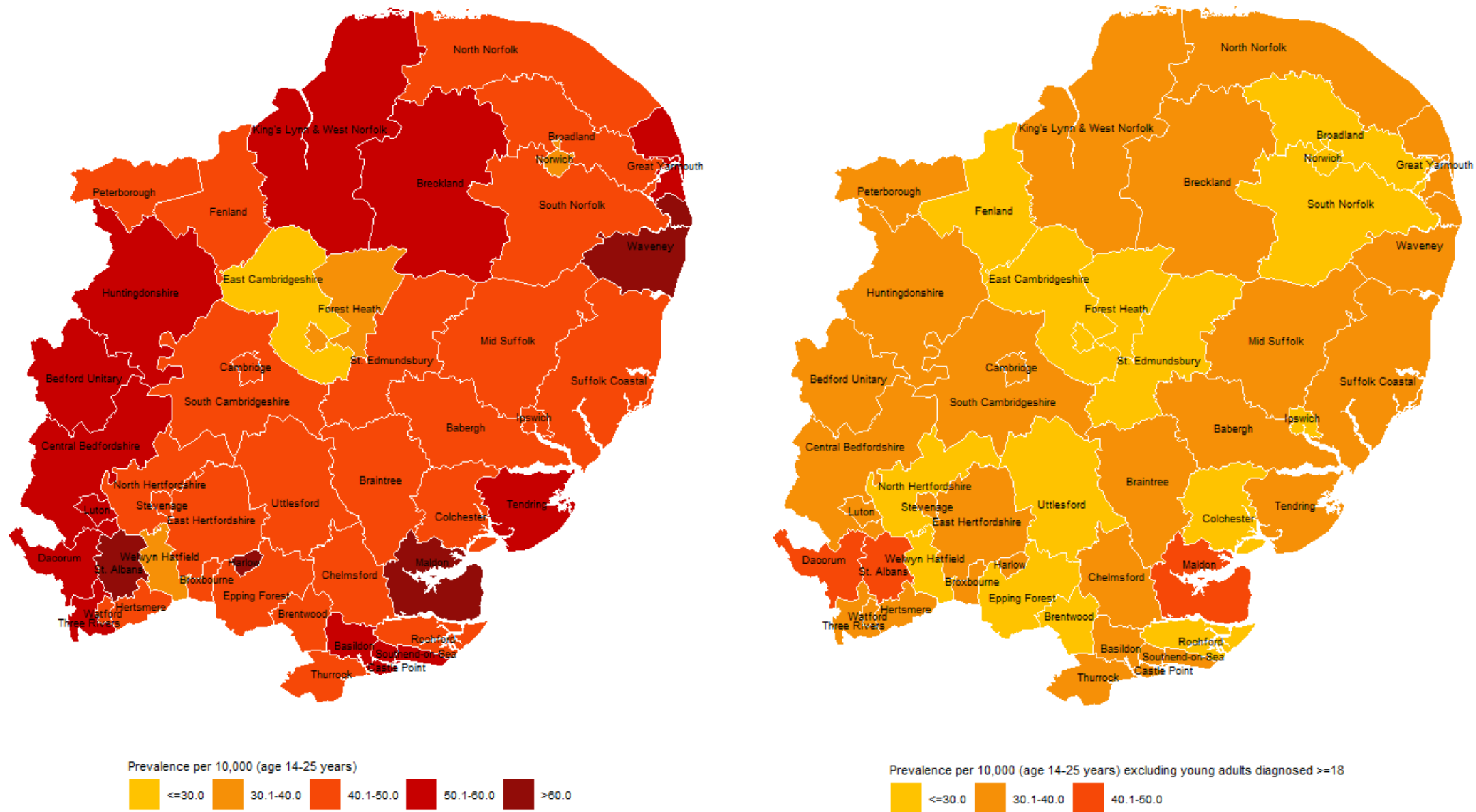


Figure 31 Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in East of England Government Office Region for 2017/18

# London

Table 10: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the London Government Office Region

Financial year	Overall			Age 14-17 years				Age 18-25 years				
	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI			
<b>Young people aged 14-25 years</b>												
2009	4,176	31.9	31.0 32.9	1,265	34.9	33.0 36.9	2,911	30.8	29.6 31.9			
2010	4,445	33.6	32.6 34.6	1,369	37.4	35.5 39.4	3,076	32.1	31.0 33.3			
2011	4,603	34.2	33.2 35.2	1,406	37.9	35.9 39.8	3,197	32.8	31.7 33.9			
2012	4,835	35.7	34.7 36.7	1,465	39.3	37.3 41.3	3,370	34.3	33.1 35.4			
2013	5,345	39.1	38.0 40.1	1,630	43.6	41.4 45.7	3,715	37.4	36.2 38.6			
2014	5,393	39.0	37.9 40.0	1,749	46.7	44.5 48.9	3,644	36.1	34.9 37.3			
2015	5,564	40.0	38.9 41.0	1,726	46.3	44.1 48.5	3,838	37.7	36.5 38.8			
2016	5,695	40.8	39.7 41.8	1,835	49.4	47.1 51.7	3,860	37.7	36.5 38.9			
2017	6,022	43.0	41.9 44.1	1,961	52.5	50.2 54.8	4,061	39.6	38.4 40.8			
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>												
2009	2,262	17.3	16.6 18.0	1,265	34.9	33.0 36.9	997	10.5	9.9 11.2			
2010	2,507	18.9	18.2 19.7	1,369	37.4	35.5 39.4	1,138	11.9	11.2 12.6			
2011	2,658	19.7	19.0 20.5	1,406	37.9	35.9 39.8	1,252	12.8	12.1 13.6			
2012	2,752	20.3	19.5 21.1	1,465	39.3	37.3 41.3	1,287	13.1	12.4 13.8			
2013	3,085	22.6	21.8 23.4	1,630	43.6	41.4 45.7	1,455	14.7	13.9 15.4			
2014	3,313	23.9	23.1 24.8	1,749	46.7	44.5 48.9	1,564	15.5	14.7 16.3			
2015	3,389	24.3	23.5 25.2	1,726	46.3	44.1 48.5	1,663	16.3	15.5 17.1			
2016	3,532	25.3	24.5 26.1	1,835	49.4	47.1 51.7	1,697	16.6	15.8 17.3			
2017	3,799	27.1	26.3 28.0	1,961	52.5	50.2 54.8	1,838	17.9	17.1 18.7			

95%CI:95% Confidence interval

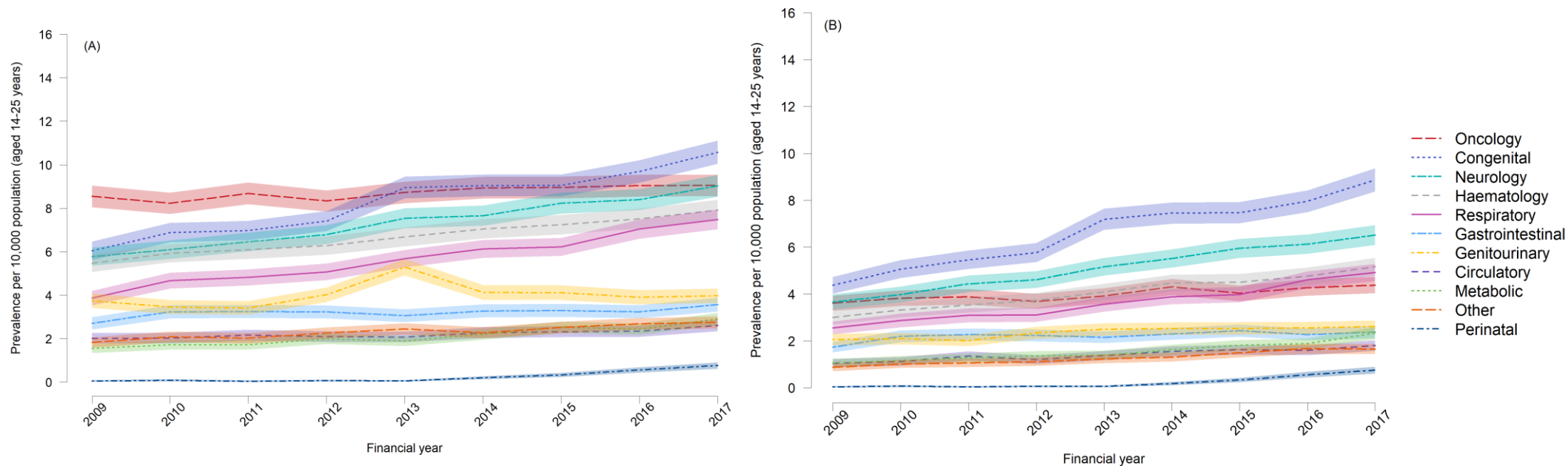


Figure 32: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the London Government Office Region for 2009/10-2017/18

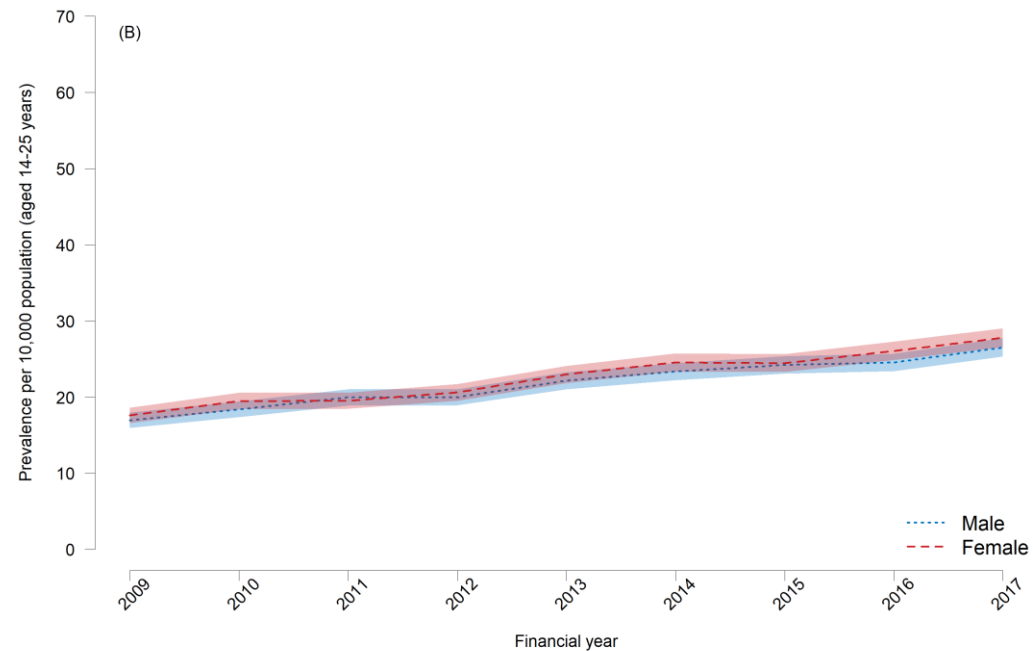
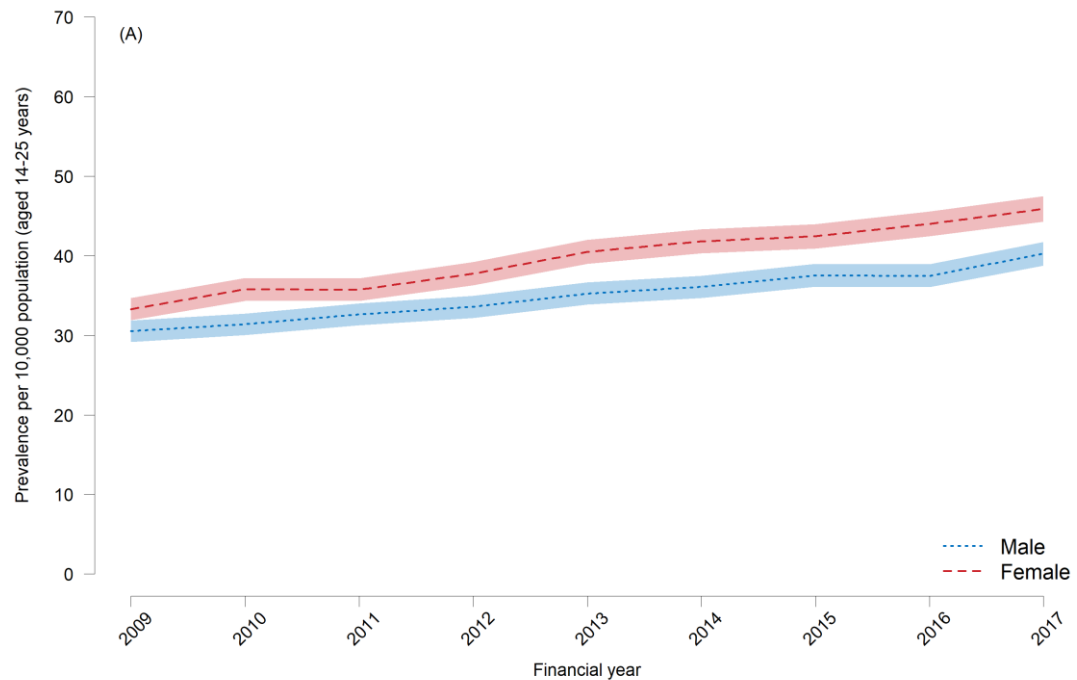


Figure 33: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in the London Government Office Region for 2009/10-2017/18

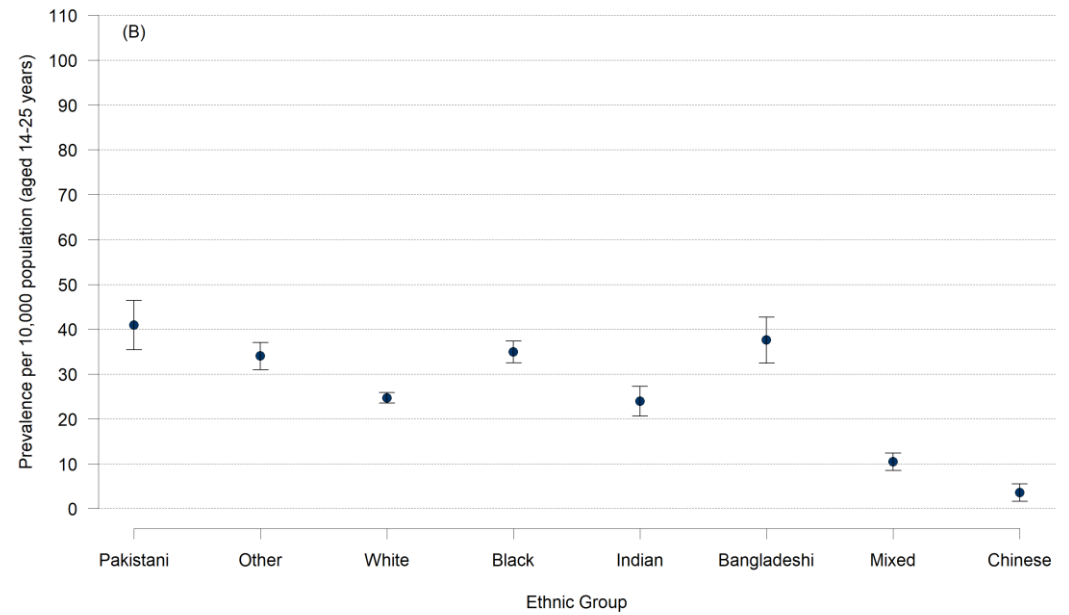
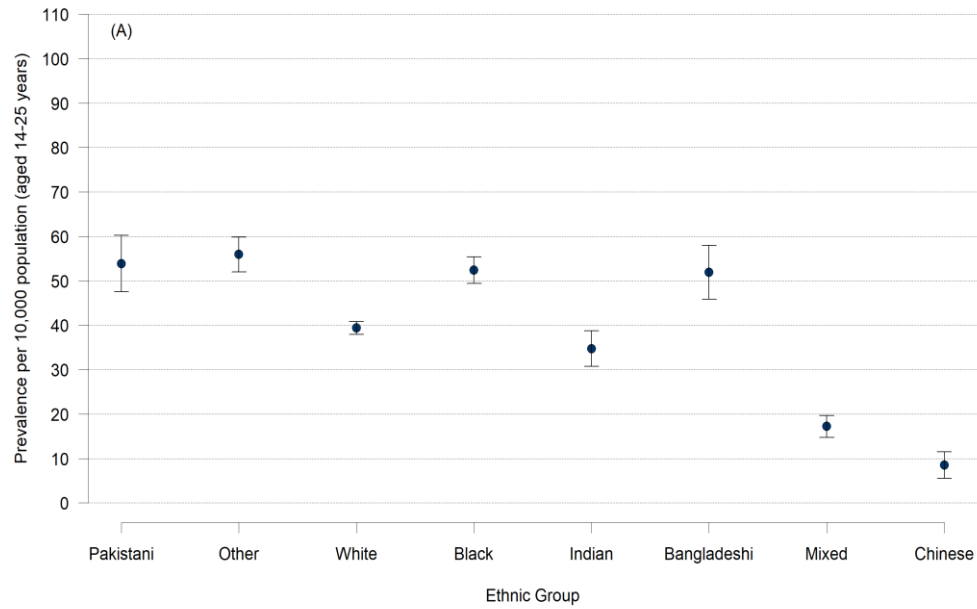


Figure 34: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the London Government office region for 2017/18.

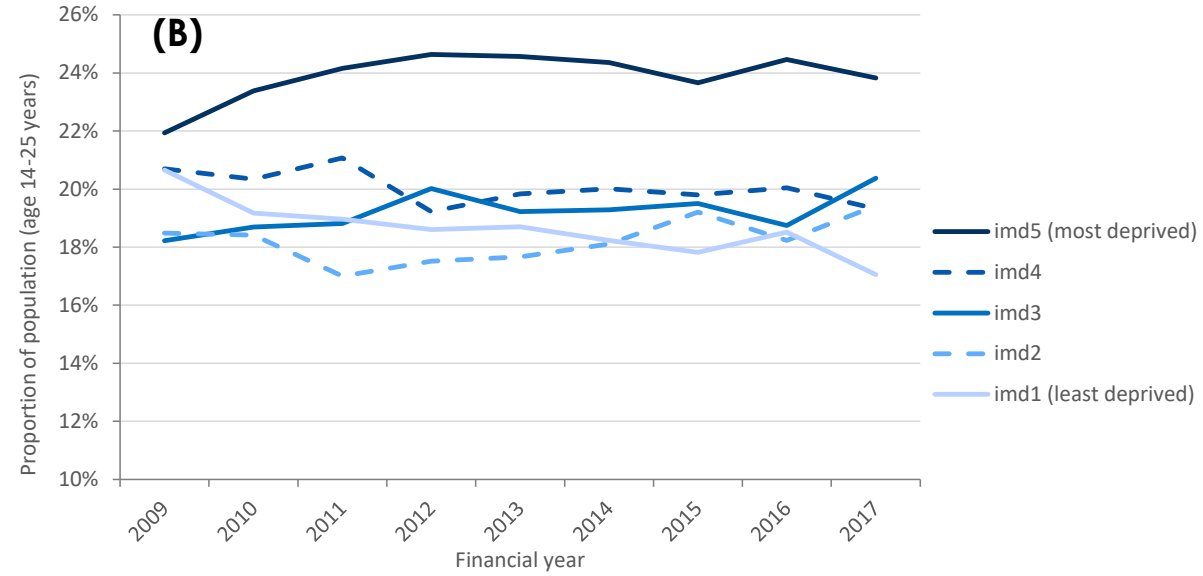
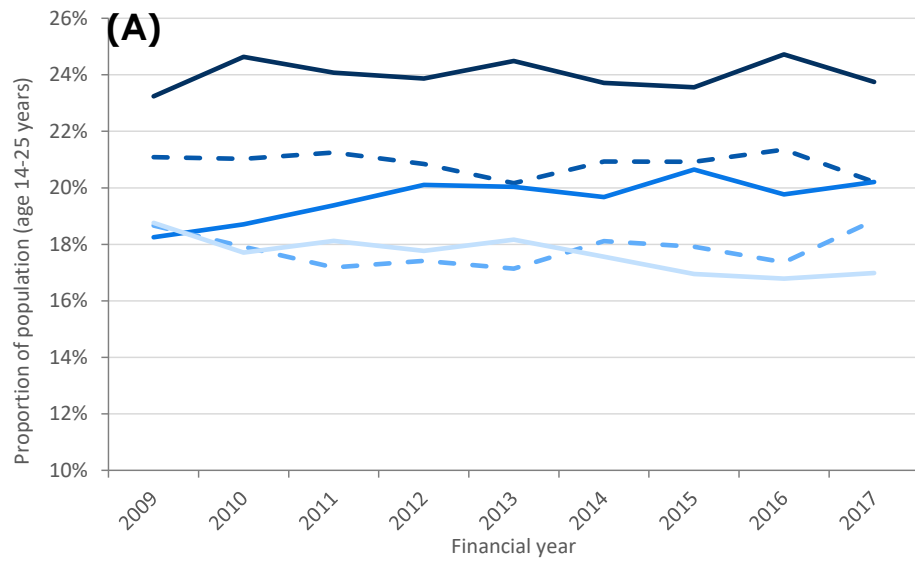


Figure 35: Percentage of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by (population weighted) deprivation group in the London Government office region for 2009/10-2017/18.

Table 11: Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in London Government Office Region for 2017/18

Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Barking & Dagenham	33978	<b>155</b>	45.6	38.5 52.8	<b>101</b>	29.7	23.9 35.5
Barnet	57871	<b>240</b>	41.5	36.2 46.7	<b>162</b>	28.0	23.7 32.3
Bexley	36536	<b>153</b>	41.9	35.3 48.5	<b>98</b>	26.8	21.5 32.1
Brent	53882	<b>244</b>	45.3	39.6 51.0	<b>141</b>	26.2	21.9 30.5
Bromley	41822	<b>201</b>	48.1	41.4 54.7	<b>127</b>	30.4	25.1 35.6
Camden	44395	<b>155</b>	34.9	29.4 40.4	<b>91</b>	20.5	16.3 24.7
Croydon	58755	<b>291</b>	49.5	43.9 55.2	<b>193</b>	32.8	28.2 37.5
Ealing	55245	<b>264</b>	47.8	42.0 53.5	<b>148</b>	26.8	22.5 31.1
Enfield	53892	<b>210</b>	39.0	33.7 44.2	<b>149</b>	27.6	23.2 32.1
Greenwich	45566	<b>165</b>	36.2	30.7 41.7	<b>110</b>	24.1	19.6 28.6
Hackney	42457	<b>184</b>	43.3	37.1 49.6	<b>125</b>	29.4	24.3 34.6
Hammersmith & Fulham	30696	<b>115</b>	37.5	30.6 44.3	<b>71</b>	23.1	17.8 28.5
Haringey	43240	<b>178</b>	41.2	35.1 47.2	<b>110</b>	25.4	20.7 30.2
Harrow	39854	<b>185</b>	46.4	39.7 53.1	<b>126</b>	31.6	26.1 37.1
Havering	35195	<b>192</b>	54.6	46.9 62.2	<b>120</b>	34.1	28.0 40.2
Hillingdon	52754	<b>241</b>	45.7	39.9 51.4	<b>154</b>	29.2	24.6 33.8
Hounslow	40226	<b>188</b>	46.7	40.1 53.4	<b>133</b>	33.1	27.5 38.7
Islington	40616	<b>145</b>	35.7	29.9 41.5	<b>87</b>	21.4	16.9 25.9
Kensington & Chelsea	22207	<b>88</b>	39.6	31.4 47.9	<b>53</b>	23.9	17.4 30.3
Kingston upon Thames	29973	<b>110</b>	36.7	29.9 43.5	<b>71</b>	23.7	18.2 29.2
Lambeth	51863	<b>230</b>	44.3	38.6 50.1	<b>137</b>	26.4	22.0 30.8
Lewisham	46224	<b>207</b>	44.8	38.7 50.9	<b>121</b>	26.2	21.5 30.8
London & Westminster	44112	<b>143</b>	32.4	27.1 37.7	<b>82</b>	18.6	14.6 22.6
Merton	28967	<b>135</b>	46.6	38.8 54.4	<b>84</b>	29.0	22.8 35.2
Newham	67454	<b>259</b>	38.4	33.7 43.1	<b>165</b>	24.5	20.7 28.2
Redbridge	49946	<b>233</b>	46.7	40.7 52.6	<b>157</b>	31.4	26.5 36.3
Richmond upon Thames	23460	<b>97</b>	41.3	33.1 49.6	<b>58</b>	24.7	18.4 31.1
Southwark	53391	<b>235</b>	44.0	38.4 49.6	<b>140</b>	26.2	21.9 30.6
Sutton	26759	<b>135</b>	50.4	42.0 58.9	<b>88</b>	32.9	26.0 39.7
Tower Hamlets	54160	<b>250</b>	46.2	40.5 51.9	<b>144</b>	26.6	22.3 30.9
Waltham Forest	45245	<b>185</b>	40.9	35.0 46.8	<b>126</b>	27.8	23.0 32.7
Wandsworth	48602	<b>194</b>	39.9	34.3 45.5	<b>118</b>	24.3	19.9 28.7

95% CI: 95% Confidence intervals



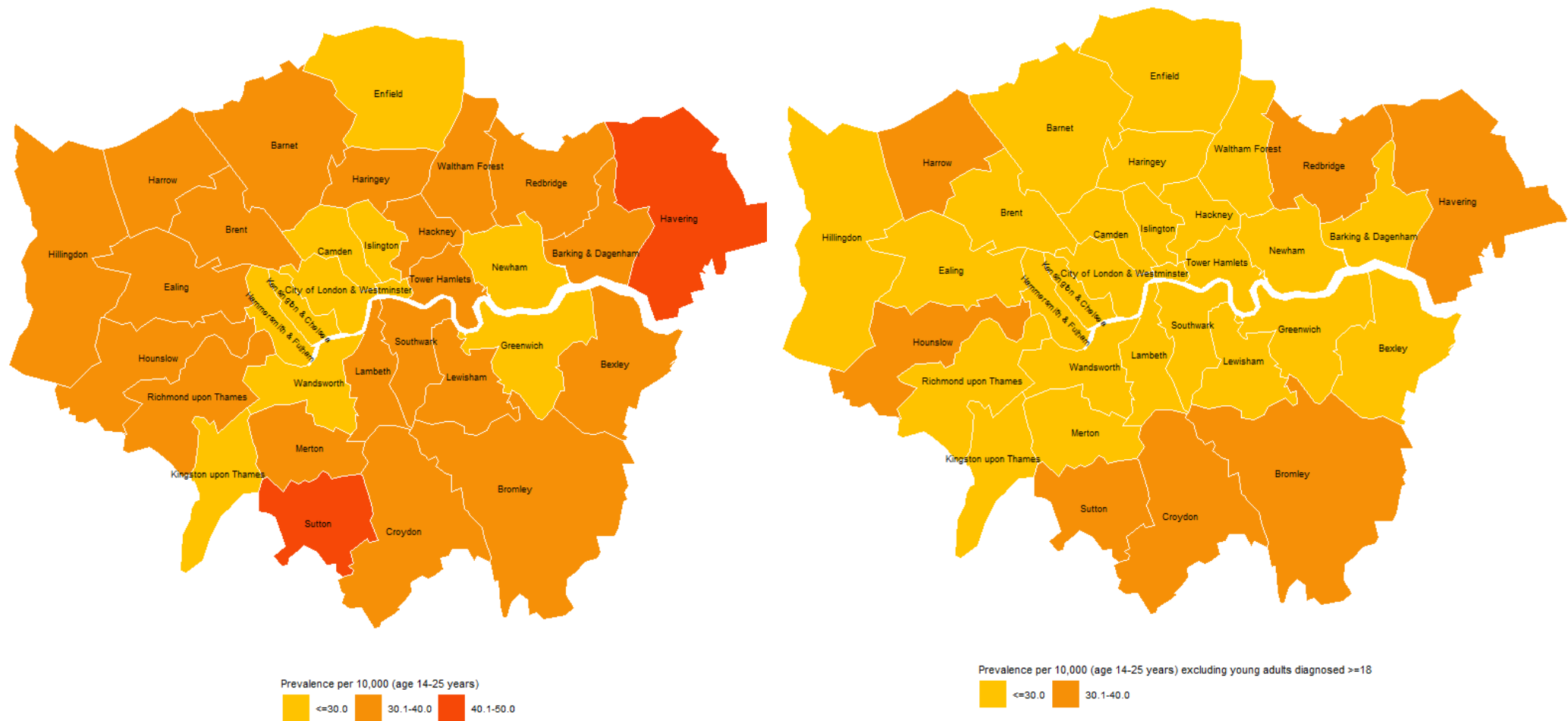


Figure 36 Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in the London Government Office Region for 2017/18

## North East

Table 12: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the North East Government Office Region

Financial year	Overall			Age 14-17 years				Age 18-25 years				
	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI			
<b>Young people aged 14-25 years</b>												
2009	1,489	36.0	34.1 37.8	484	37.3	34.0 40.6	1,005	35.4	33.2 37.6			
2010	1,577	37.9	36.0 39.8	465	36.8	33.5 40.1	1,112	38.4	36.1 40.6			
2011	1,653	39.7	37.8 41.6	489	39.1	35.7 42.6	1,164	39.9	37.6 42.2			
2012	1,696	41.0	39.0 42.9	522	42.4	38.8 46.1	1,174	40.4	38.1 42.7			
2013	1,704	41.4	39.5 43.4	520	42.9	39.3 46.6	1,184	40.8	38.5 43.1			
2014	1,694	41.5	39.6 43.5	558	47.1	43.2 51.0	1,136	39.3	37.0 41.5			
2015	1,774	43.7	41.7 45.8	532	46.3	42.4 50.2	1,242	42.7	40.4 45.1			
2016	1,830	45.6	43.5 47.6	552	49.4	45.3 53.5	1,278	44.1	41.7 46.5			
2017	1,819	45.9	43.8 48.0	545	49.7	45.5 53.8	1,274	44.4	42.0 46.9			
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>												
2009	880	21.3	19.9 22.7	484	37.3	34.0 40.6	396	13.9	12.6 15.3			
2010	910	21.9	20.4 23.3	465	36.8	33.5 40.1	445	15.4	13.9 16.8			
2011	1,003	24.1	22.6 25.6	489	39.1	35.7 42.6	514	17.6	16.1 19.2			
2012	1,072	25.9	24.4 27.5	522	42.4	38.8 46.1	550	18.9	17.3 20.5			
2013	1,072	26.1	24.5 27.6	520	42.9	39.3 46.6	552	19.0	17.4 20.6			
2014	1,097	26.9	25.3 28.5	558	47.1	43.2 51.0	539	18.6	17.1 20.2			
2015	1,134	28.0	26.3 29.6	532	46.3	42.4 50.2	602	20.7	19.1 22.4			
2016	1,159	28.9	27.2 30.5	552	49.4	45.3 53.5	607	20.9	19.3 22.6			
2017	1,166	29.4	27.7 31.1	545	49.7	45.5 53.8	621	21.7	20.0 23.4			

95%CI: 95% Confidence interval

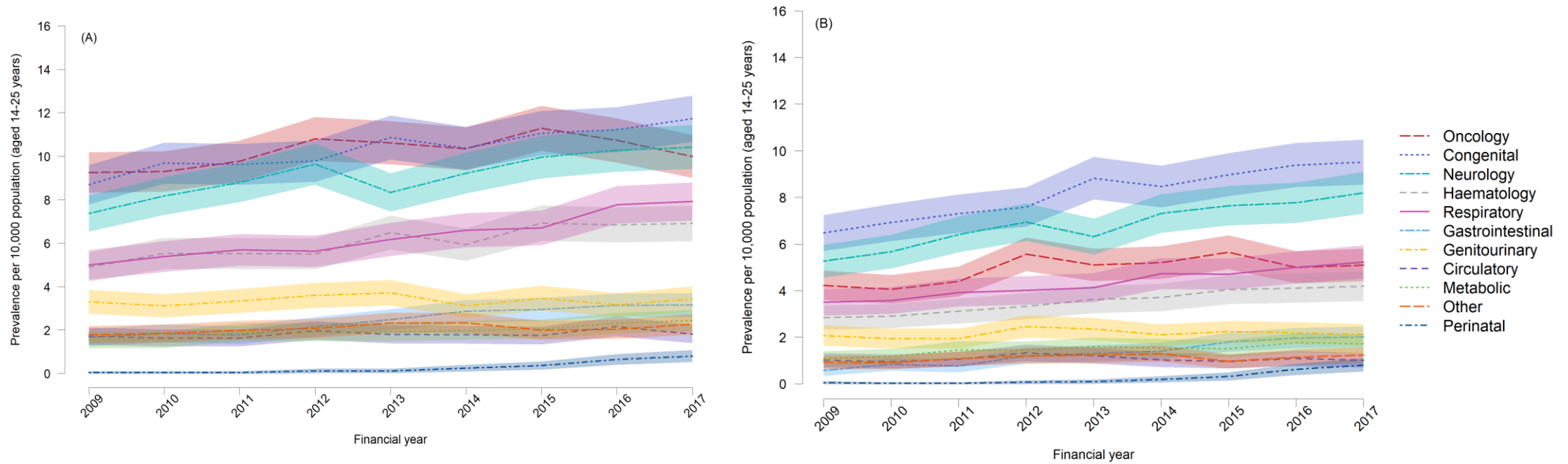


Figure 37: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the North East Government Office Region for 2009/10-2017/18

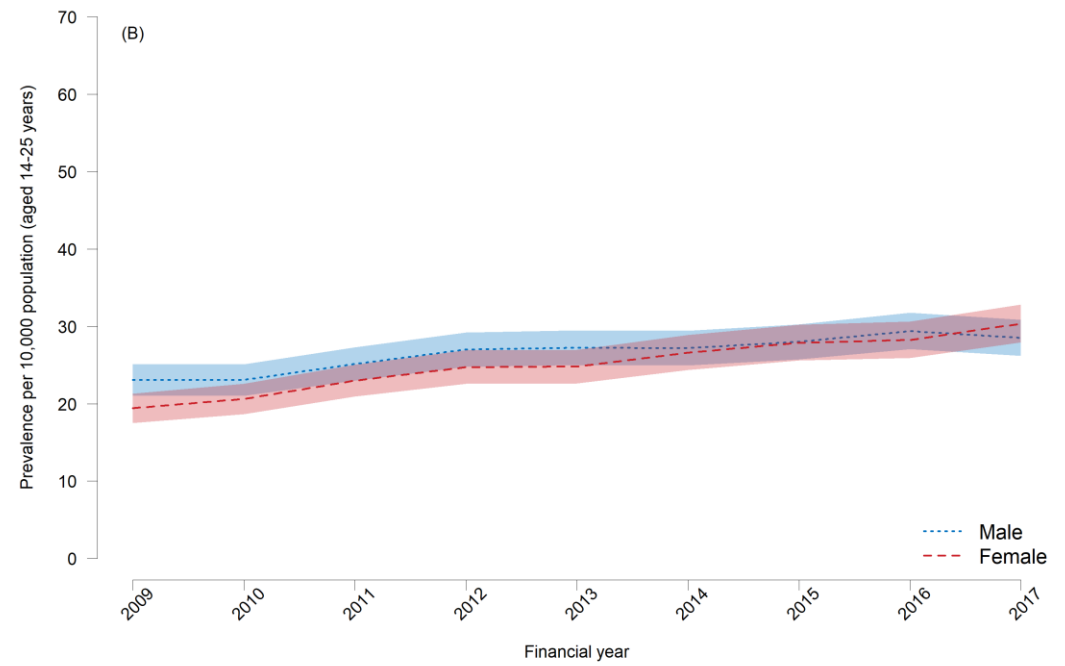
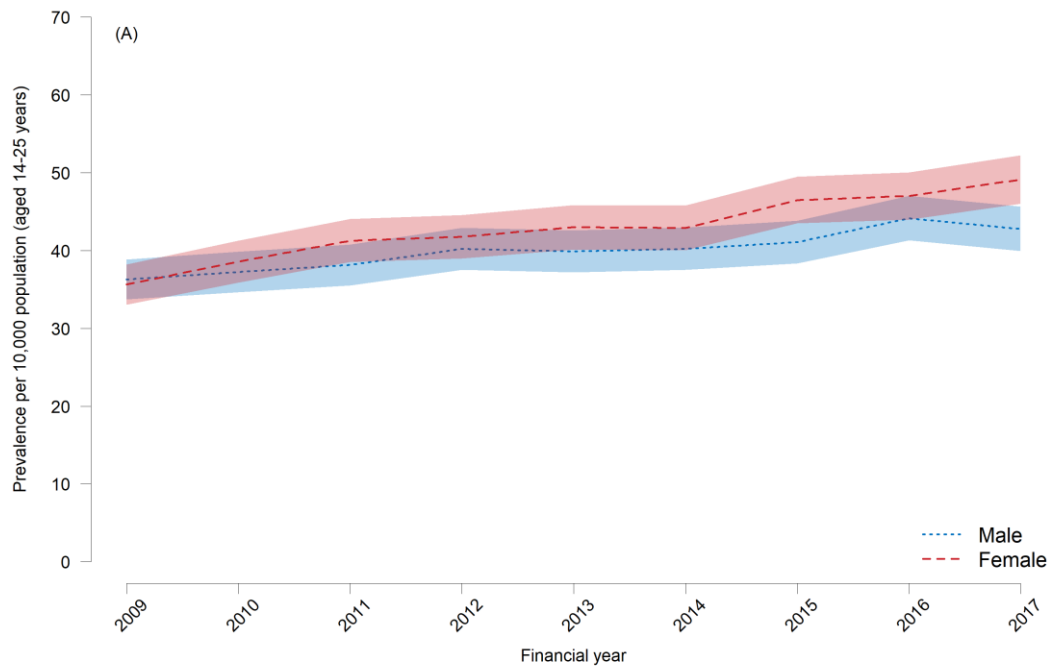


Figure 38: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in North East Government Office Region for 2009/10-2017/18

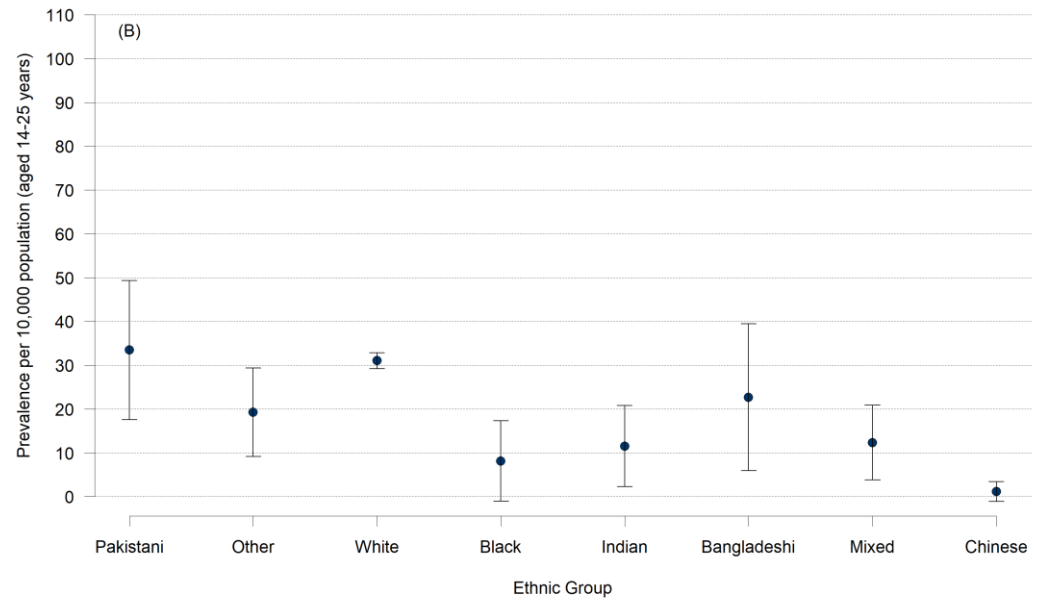
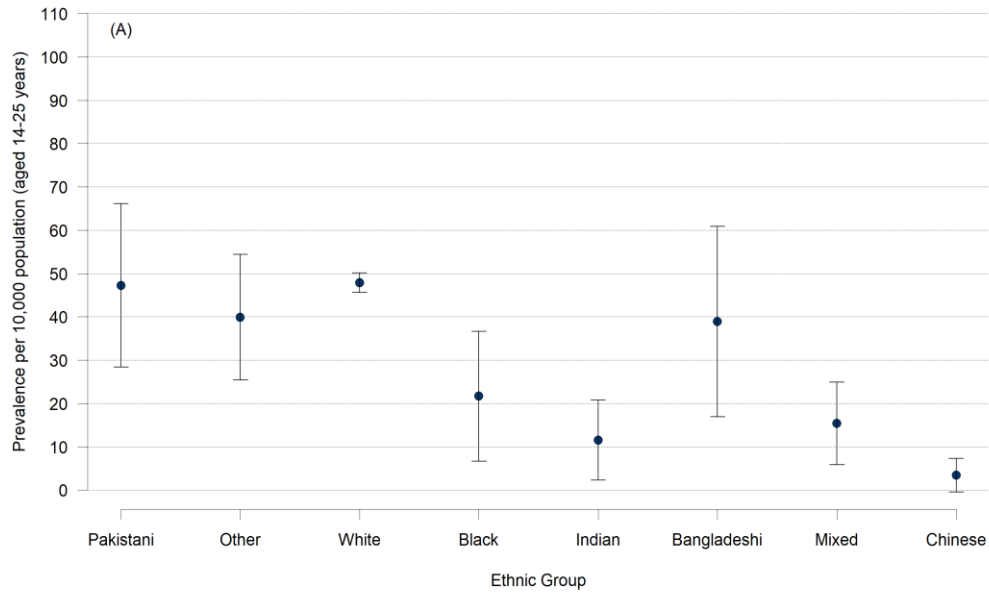


Figure 39: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the North East Government office region for 2017/18

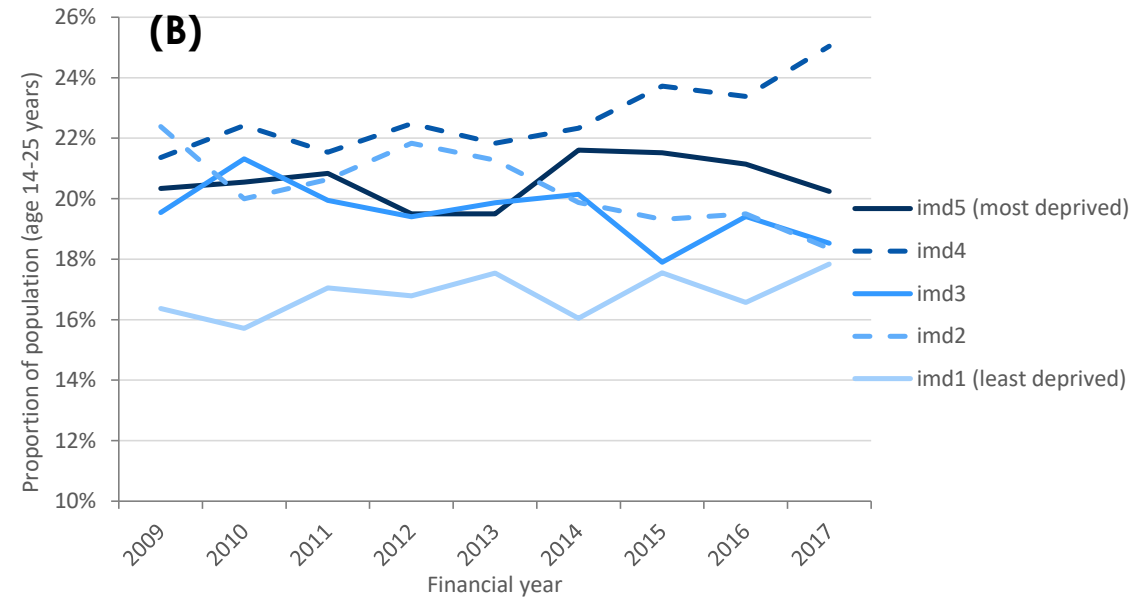
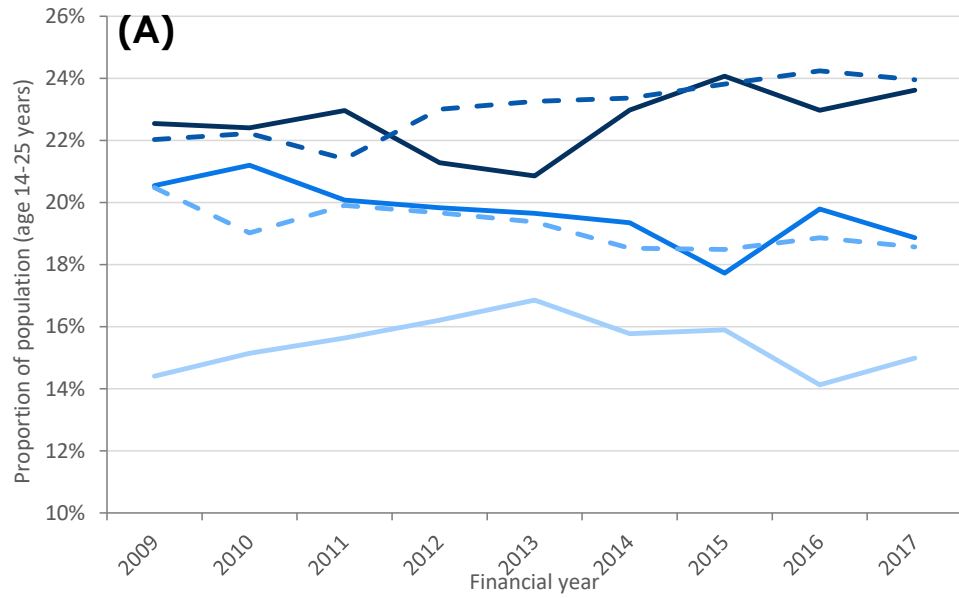


Figure 40: Percentage of young people (aged 14-25 years) with (A) a mental health condition diagnosed at any age or (B) with a mental health condition diagnosed <18 by (population weighted) deprivation group in the North East Government office region for 2009/10-2017/18

Table 13: Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in the North East Government Office Region for 2017/18

Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Darlington	14420	62	<b>43.0</b>	32.3 53.7	45	<b>31.2</b>	22.1 40.3
Durham County	74253	356	<b>47.9</b>	43.0 52.9	224	<b>30.2</b>	26.2 34.1
Gateshead	28129	130	<b>46.2</b>	38.3 54.1	77	<b>27.4</b>	21.3 33.5
Hartlepool	13177	68	<b>51.6</b>	39.4 63.8	41	<b>31.1</b>	21.6 40.6
Middlesbrough	26157	130	<b>49.7</b>	41.2 58.2	86	<b>32.9</b>	25.9 39.8
Newcastle upon Tyne	68532	216	<b>31.5</b>	27.3 35.7	130	<b>19.0</b>	15.7 22.2
North Tyneside	25912	115	<b>44.4</b>	36.3 52.5	72	<b>27.8</b>	21.4 34.2
Northumberland	38982	191	<b>49.0</b>	42.1 55.9	131	<b>33.6</b>	27.9 39.4
Redcar and Cleveland	17828	93	<b>52.2</b>	41.6 62.7	61	<b>34.2</b>	25.6 42.8
South Tyneside	20004	109	<b>54.5</b>	44.3 64.7	70	<b>35.0</b>	26.8 43.2
Stockton-on-Tees	28096	150	<b>53.4</b>	44.9 61.9	93	<b>33.1</b>	26.4 39.8
Sunderland	40853	191	<b>46.8</b>	40.1 53.4	131	<b>32.1</b>	26.6 37.5

95% CI: 95% confidence intervals

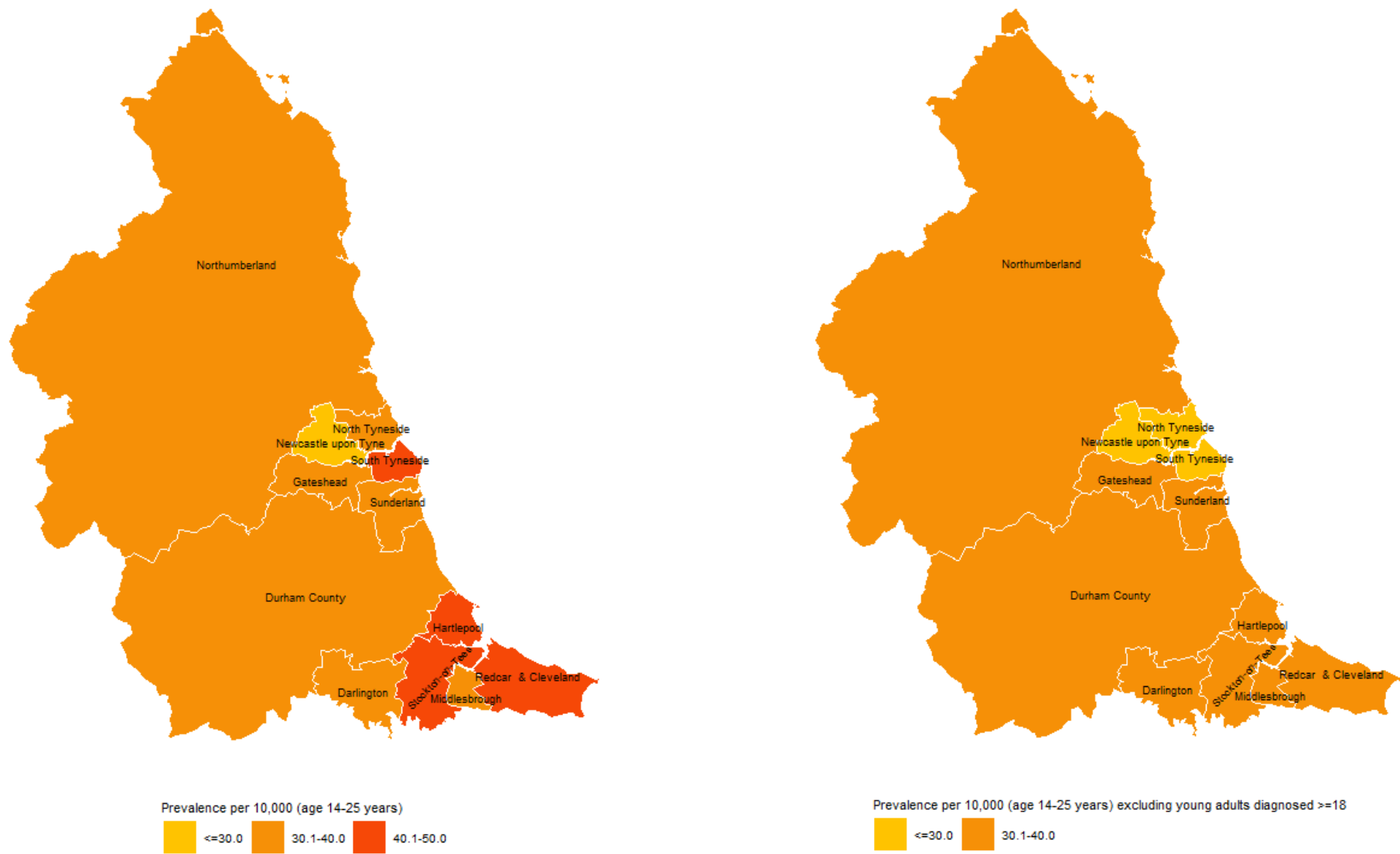


Figure 41: Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in the North East Government Office Region for 2017/18



## North West

Table 14: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the North West Government Office Region

Financial year	Overall			Age 14-17 years				Age 18-25 years				
	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI			
<b>Young people aged 14-25 years</b>												
2009	4,175	37.1	36.0 38.2	1,320	36.6	34.6 38.6	2,855	37.4	36.0 38.7			
2010	4,405	39.2	38.0 40.3	1,363	38.6	36.6 40.7	3,042	39.4	38.0 40.8			
2011	4,443	39.5	38.3 40.6	1,397	39.8	37.7 41.9	3,046	39.3	37.9 40.7			
2012	4,616	41.2	40.0 42.4	1,444	41.7	39.6 43.9	3,172	40.9	39.5 42.3			
2013	4,872	43.6	42.3 44.8	1,510	44.0	41.8 46.3	3,362	43.4	41.9 44.8			
2014	5,180	46.6	45.3 47.9	1,661	49.3	46.9 51.7	3,519	45.4	43.9 46.9			
2015	5,155	46.6	45.4 47.9	1,618	49.3	46.9 51.7	3,537	45.5	44.0 47.0			
2016	5,373	49.1	47.8 50.4	1,705	53.0	50.5 55.5	3,668	47.5	46.0 49.0			
2017	5,547	51.3	50.0 52.7	1,808	57.1	54.5 59.7	3,739	48.9	47.4 50.5			
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>												
2009	2,436	21.7	20.8 22.5	1,320	36.6	34.6 38.6	1,116	14.6	13.8 15.5			
2010	2,589	23.0	22.1 23.9	1,363	38.6	36.6 40.7	1,226	15.9	15.0 16.8			
2011	2,732	24.3	23.4 25.2	1,397	39.8	37.7 41.9	1,335	17.2	16.3 18.2			
2012	2,812	25.1	24.2 26.0	1,444	41.7	39.6 43.9	1,368	17.6	16.7 18.6			
2013	3,020	27.0	26.0 28.0	1,510	44.0	41.8 46.3	1,510	19.5	18.5 20.5			
2014	3,246	29.2	28.2 30.2	1,661	49.3	46.9 51.7	1,585	20.5	19.4 21.5			
2015	3,292	29.8	28.8 30.8	1,618	49.3	46.9 51.7	1,674	21.5	20.5 22.6			
2016	3,438	31.4	30.4 32.5	1,705	53.0	50.5 55.5	1,733	22.4	21.4 23.5			
2017	3,639	33.7	32.6 34.8	1,808	57.1	54.5 59.7	1,831	24.0	22.9 25.1			

95%CI: 95% Confidence intervals

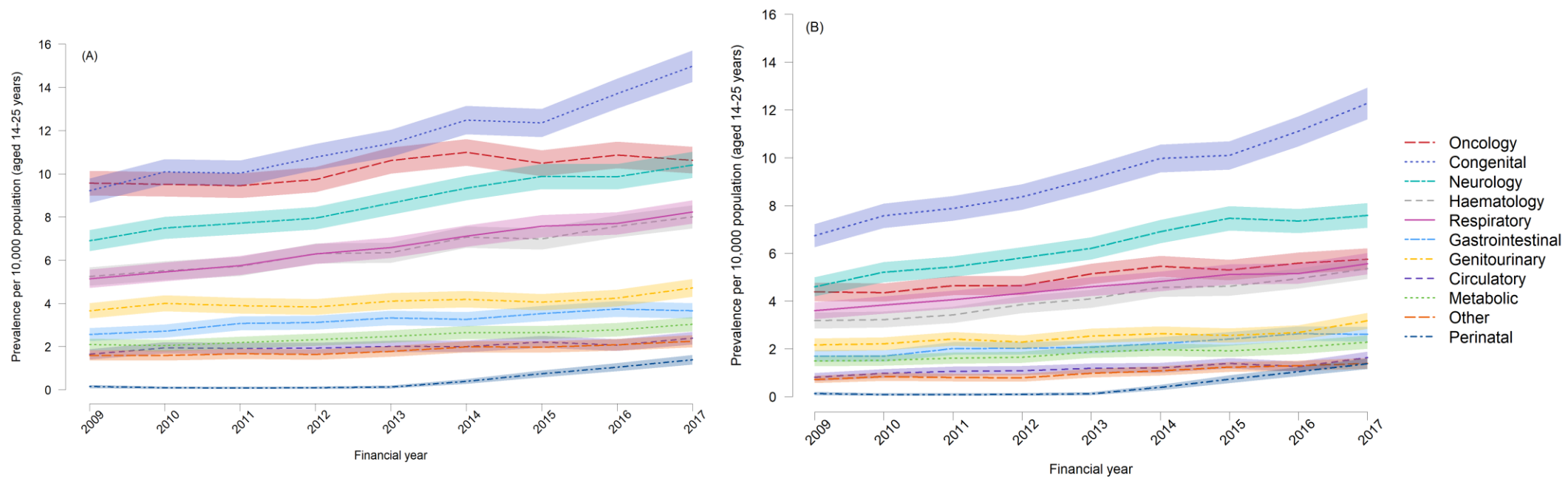


Figure 42: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the North West Government Office Region for 2009/10-2017/18

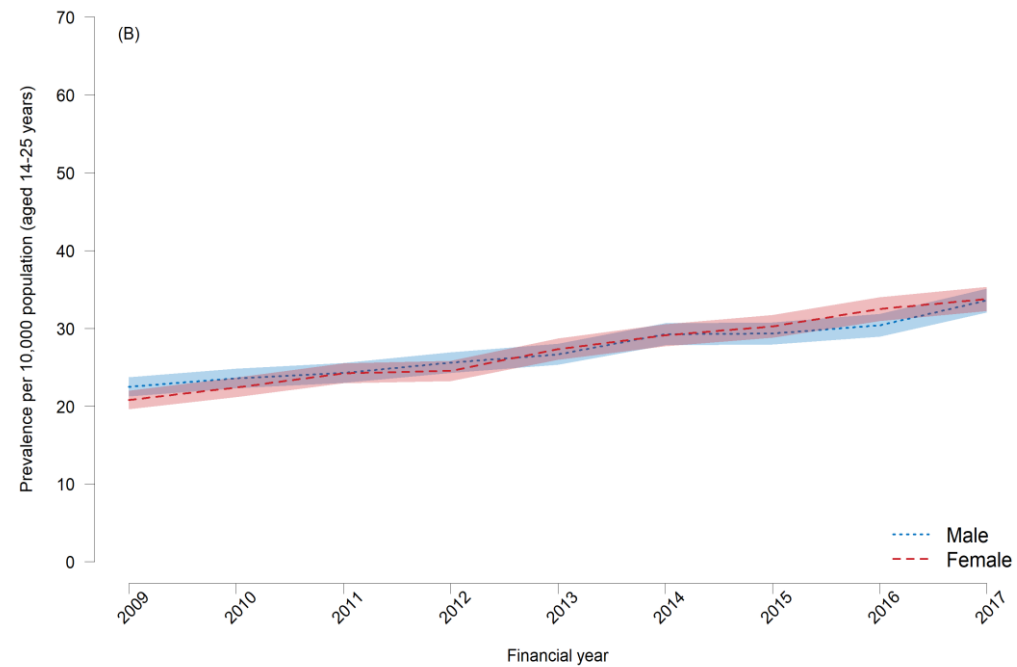
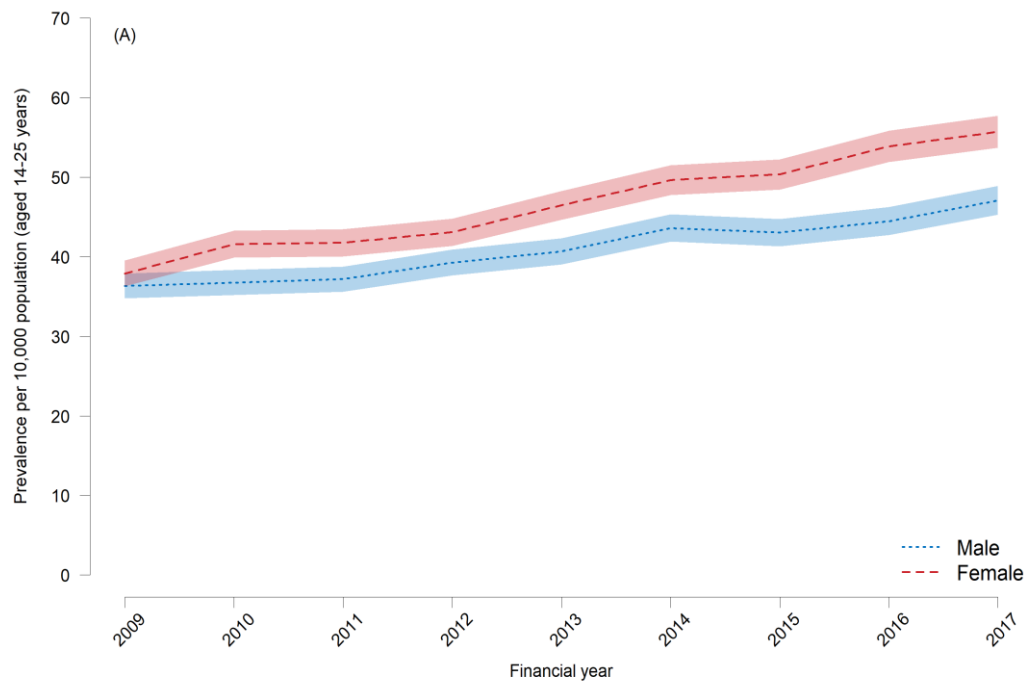


Figure 43: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in the North West Government Office Region for 2009/10-2017/18

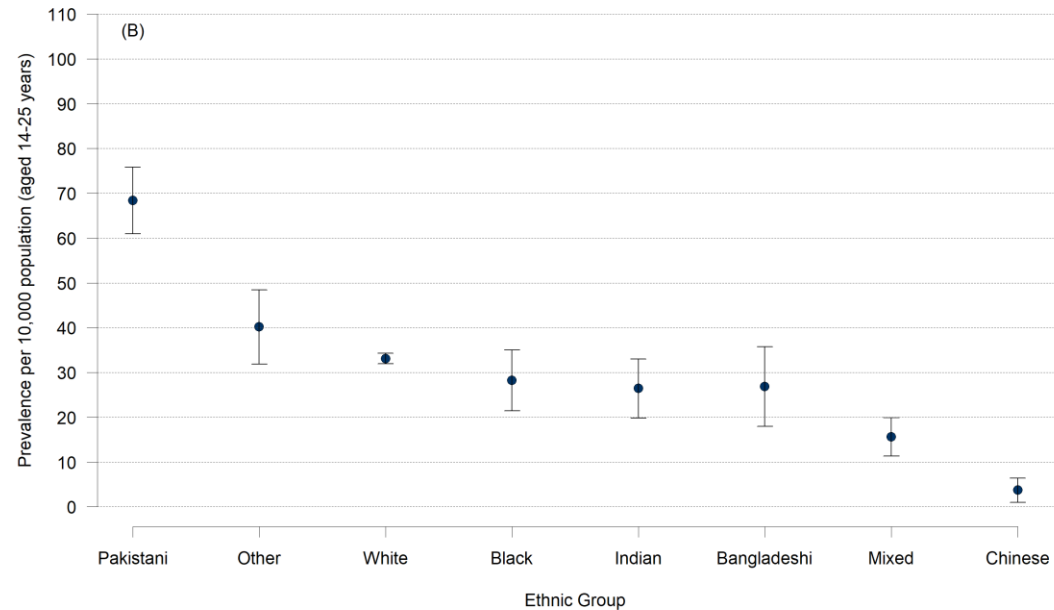
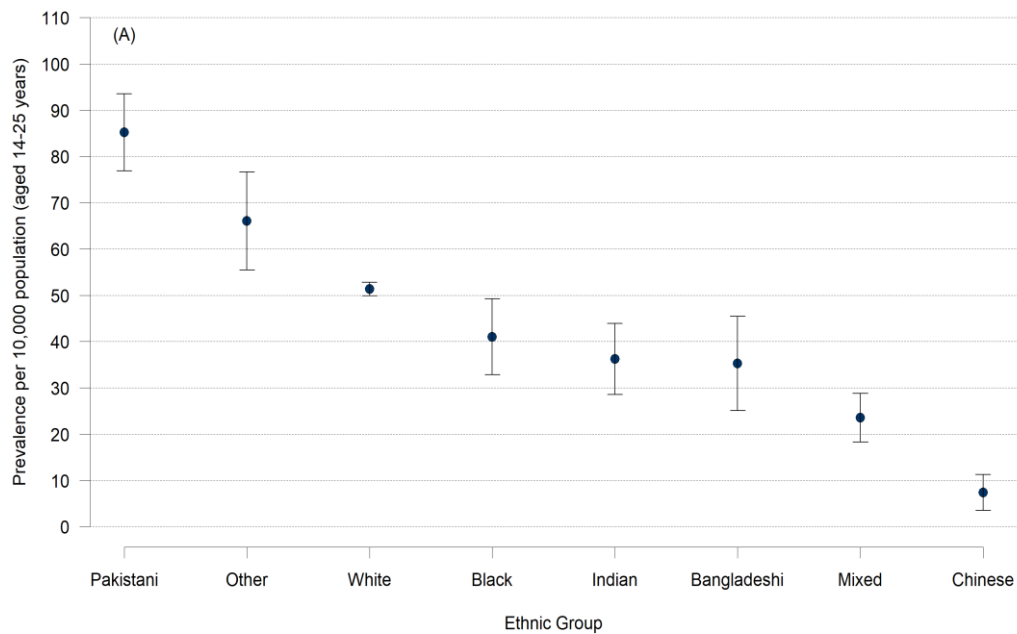


Figure 44: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the North West Government office region for 2017/18

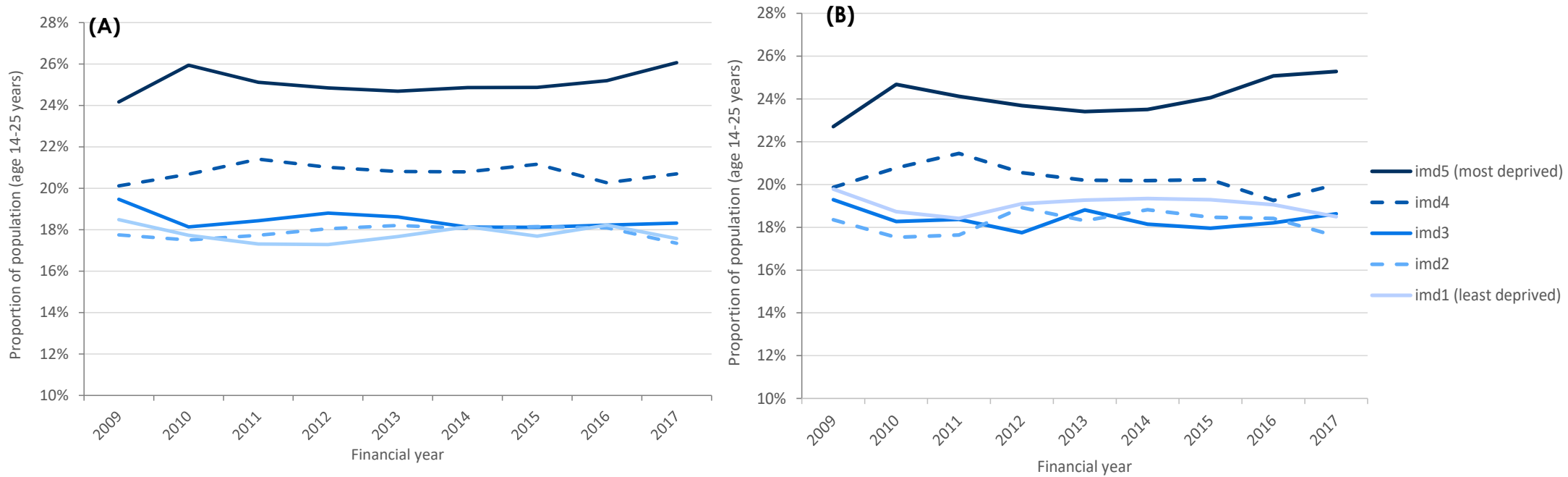


Figure 45: Percentage of young people (aged 14-25 years) with (A) a LSC diagnosed at any age or (B) with a LSC diagnosed <18 by (population weighted) deprivation group in the North West Government office region for 2009/10-2017/18.

Table 15: Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in the North West Government Office Region for 2017/18.

Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Allerdale	11620	52	<b>44.7</b>	32.6 56.9	37	<b>31.8</b>	21.6 42.1
Barrow-in-Furness	8999	57	<b>63.3</b>	47.0 79.7	42	<b>46.7</b>	32.6 60.8
Blackburn with Darwen	24022	162	<b>67.4</b>	57.1 77.8	110	<b>45.8</b>	37.3 54.3
Blackpool	19591	130	<b>66.4</b>	55.0 77.7	86	<b>43.9</b>	34.6 53.2
Bolton	42516	227	<b>53.4</b>	46.5 60.3	155	<b>36.5</b>	30.7 42.2
Burnley	11904	68	<b>57.1</b>	43.6 70.7	50	<b>42.0</b>	30.4 53.6
Bury	25570	158	<b>61.8</b>	52.2 71.4	119	<b>46.5</b>	38.2 54.9
Carlisle	15556	69	<b>44.4</b>	33.9 54.8	42	<b>27.0</b>	18.8 35.2
Cheshire East	46614	240	<b>51.5</b>	45.0 58.0	161	<b>34.5</b>	29.2 39.9
Cheshire West and Chester	44417	213	<b>48.0</b>	41.5 54.4	124	<b>27.9</b>	23.0 32.8
Chorley	14005	74	<b>52.8</b>	40.8 64.8	47	<b>33.6</b>	24.0 43.1
Copeland	8559	39	<b>45.6</b>	31.3 59.8	24	<b>28.0</b>	16.8 39.2
Eden	6140	30	<b>48.9</b>	31.4 66.3	22	<b>35.8</b>	20.9 50.8
Fylde	8487	42	<b>49.5</b>	34.6 64.4	31	<b>36.5</b>	23.7 49.4
Halton	17727	120	<b>67.7</b>	55.6 79.8	76	<b>42.9</b>	33.3 52.5
Hyndburn	11435	66	<b>57.7</b>	43.8 71.6	43	<b>37.6</b>	26.4 48.8
Knowsley	21291	163	<b>76.6</b>	64.9 88.3	94	<b>44.2</b>	35.2 53.1
Lancaster	26703	99	<b>37.1</b>	29.8 44.4	65	<b>24.3</b>	18.4 30.3
Liverpool	93609	419	<b>44.8</b>	40.5 49.0	262	<b>28.0</b>	24.6 31.4
Manchester	128657	508	<b>39.5</b>	36.1 42.9	310	<b>24.1</b>	21.4 26.8
Oldham	36096	190	<b>52.6</b>	45.2 60.1	127	<b>35.2</b>	29.1 41.3
Pendle	12314	89	<b>72.3</b>	57.3 87.2	68	<b>55.2</b>	42.1 68.3
Preston	28177	122	<b>43.3</b>	35.6 51.0	78	<b>27.7</b>	21.5 33.8
Ribble Valley	7429	31	<b>41.7</b>	27.1 56.4	20	<b>26.9</b>	15.1 38.7
Rochdale	32523	205	<b>63.0</b>	54.4 71.6	156	<b>48.0</b>	40.5 55.5
Rossendale	8851	45	<b>50.8</b>	36.0 65.7	32	<b>36.2</b>	23.6 48.7
Salford	42079	190	<b>45.2</b>	38.7 51.6	115	<b>27.3</b>	22.3 32.3
Sefton	34660	186	<b>53.7</b>	46.0 61.4	130	<b>37.5</b>	31.1 43.9
South Lakeland	11249	49	<b>43.6</b>	31.4 55.7	35	<b>31.1</b>	20.8 41.4
South Ribble	14461	76	<b>52.6</b>	40.8 64.3	49	<b>33.9</b>	24.4 43.4
St. Helens	23171	155	<b>66.9</b>	56.4 77.4	113	<b>48.8</b>	39.8 57.7
Stockport	36510	219	<b>60.0</b>	52.1 67.9	141	<b>38.6</b>	32.3 45.0
Tameside	31019	175	<b>56.4</b>	48.1 64.8	106	<b>34.2</b>	27.7 40.7
Trafford	31323	143	<b>45.7</b>	38.2 53.1	104	<b>33.2</b>	26.8 39.6
Warrington	28172	148	<b>52.5</b>	44.1 61.0	91	<b>32.3</b>	25.7 38.9
West Lancashire	16482	69	<b>41.9</b>	32.0 51.7	51	<b>30.9</b>	22.5 39.4
Wigan	43814	199	<b>45.4</b>	39.1 51.7	125	<b>28.5</b>	23.5 33.5
Wirral	41942	241	<b>57.5</b>	50.2 64.7	144	<b>34.3</b>	28.7 39.9
Wyre	12904	74	<b>57.3</b>	44.3 70.4	52	<b>40.3</b>	29.4 51.2

95% CI: 95% Confidence intervals

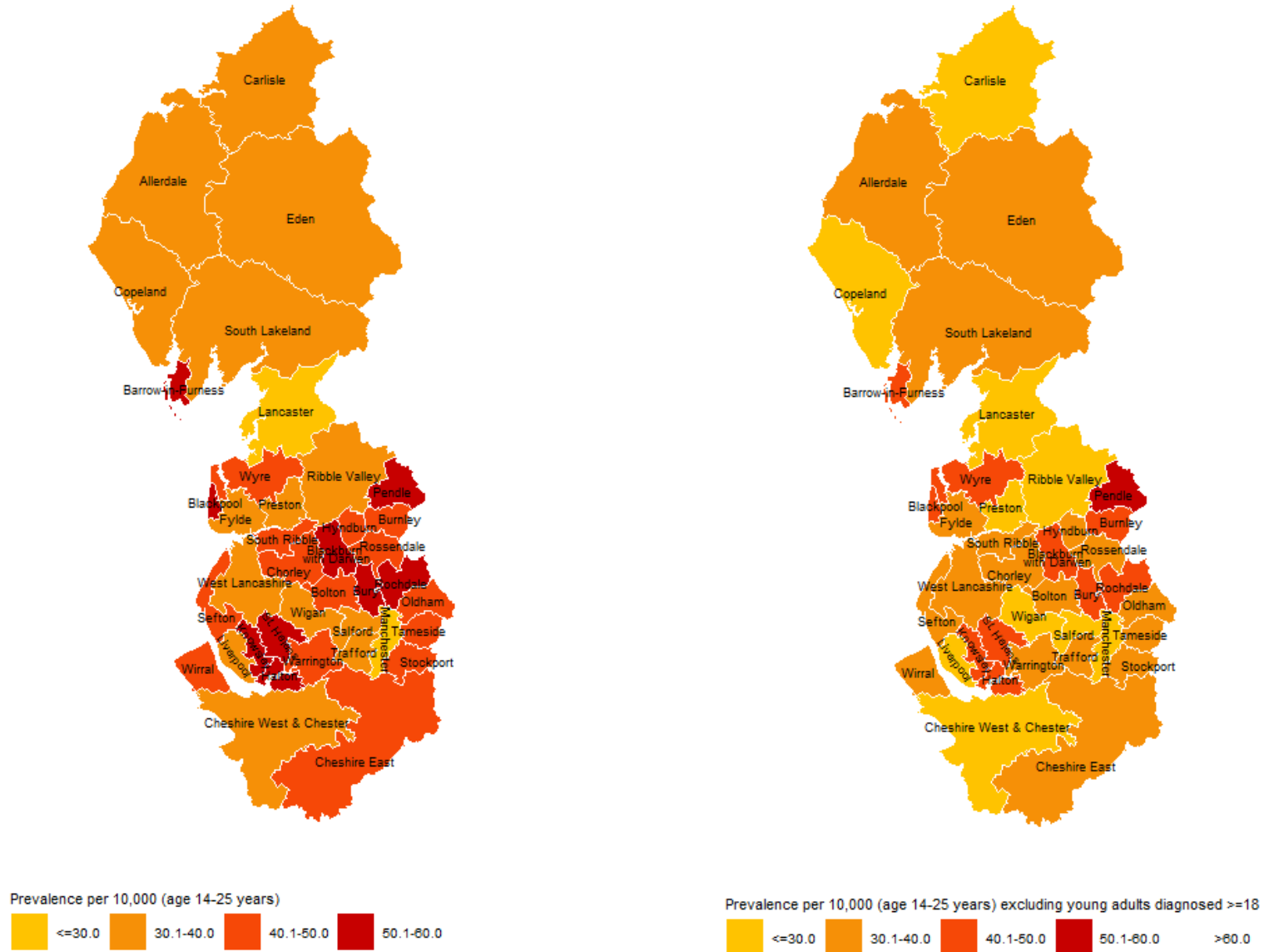


Figure 46 Prevalence per 10,000 of young people (age 14-25 years) with a LLC by Local Authority in the North West Government Office Region for 2017/18

## South East

Table 16: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the South East Government Office Region

Financial year	Overall			Age 14-17 years			Age 18-25 years			
	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	
<b>Young people aged 14-25 years</b>										
2009	4,095	32.4	31.4 33.3	1,410	32.9	31.2 34.6	2,685	32.1	30.9 33.3	
2010	4,449	34.8	33.8 35.9	1,521	35.6	33.8 37.4	2,928	34.4	33.2 35.7	
2011	4,531	35.2	34.2 36.2	1,551	36.2	34.4 38.0	2,980	34.7	33.5 35.9	
2012	4,836	37.4	36.4 38.5	1,589	37.3	35.5 39.2	3,247	37.5	36.2 38.8	
2013	5,082	39.2	38.2 40.3	1,701	40.1	38.2 42.0	3,381	38.8	37.5 40.1	
2014	5,300	41.0	39.9 42.1	1,740	41.4	39.4 43.3	3,560	40.8	39.4 42.1	
2015	5,514	42.6	41.5 43.7	1,845	44.6	42.5 46.6	3,669	41.7	40.4 43.1	
2016	5,789	45.0	43.9 46.2	1,915	47.2	45.1 49.3	3,874	44.0	42.6 45.4	
2017	5,956	46.7	45.5 47.8	2,016	50.4	48.2 52.6	3,940	45.0	43.6 46.4	
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>										
2009	2,534	20.0	19.2 20.8	1,410	32.9	31.2 34.6	1,124	13.4	12.6 14.2	
2010	2,780	21.8	21.0 22.6	1,521	35.6	33.8 37.4	1,259	14.8	14.0 15.6	
2011	2,919	22.7	21.8 23.5	1,551	36.2	34.4 38.0	1,368	15.9	15.1 16.8	
2012	3,112	24.1	23.2 24.9	1,589	37.3	35.5 39.2	1,523	17.6	16.7 18.5	
2013	3,317	25.6	24.7 26.5	1,701	40.1	38.2 42.0	1,616	18.5	17.6 19.5	
2014	3,484	26.9	26.0 27.8	1,740	41.4	39.4 43.3	1,744	20.0	19.0 20.9	
2015	3,651	28.2	27.3 29.1	1,845	44.6	42.5 46.6	1,806	20.5	19.6 21.5	
2016	3,787	29.4	28.5 30.4	1,915	47.2	45.1 49.3	1,872	21.3	20.3 22.2	
2017	3,938	30.9	29.9 31.8	2,016	50.4	48.2 52.6	1,922	21.9	21.0 22.9	

95% CI: 95% Confidence intervals



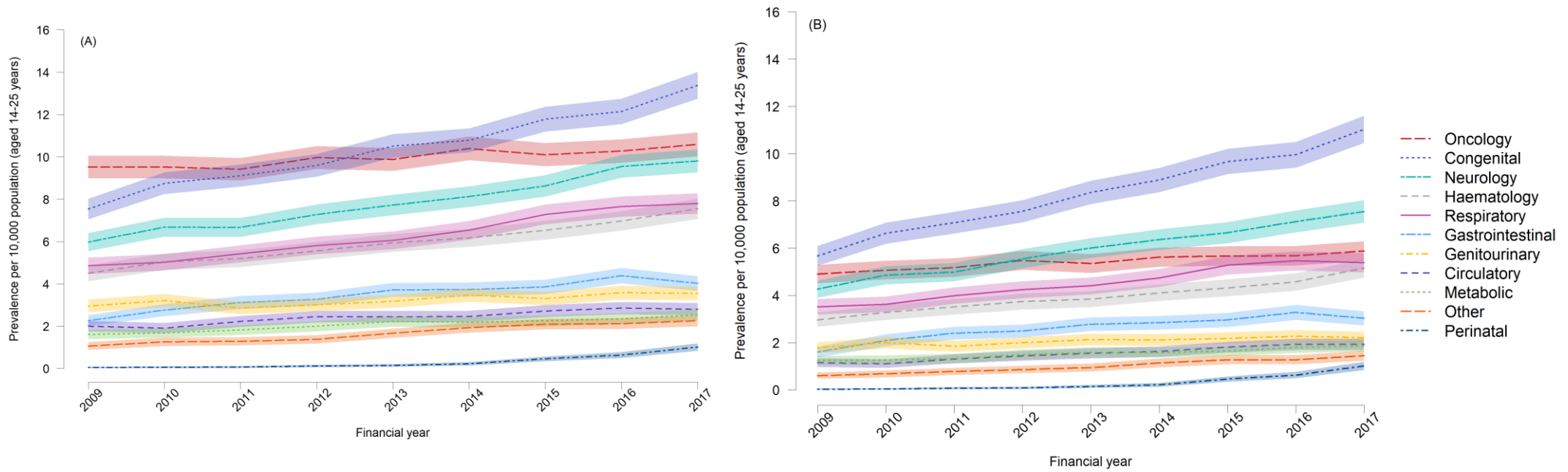


Figure 47: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the South East Government Office Region for 2009/10-2017/18

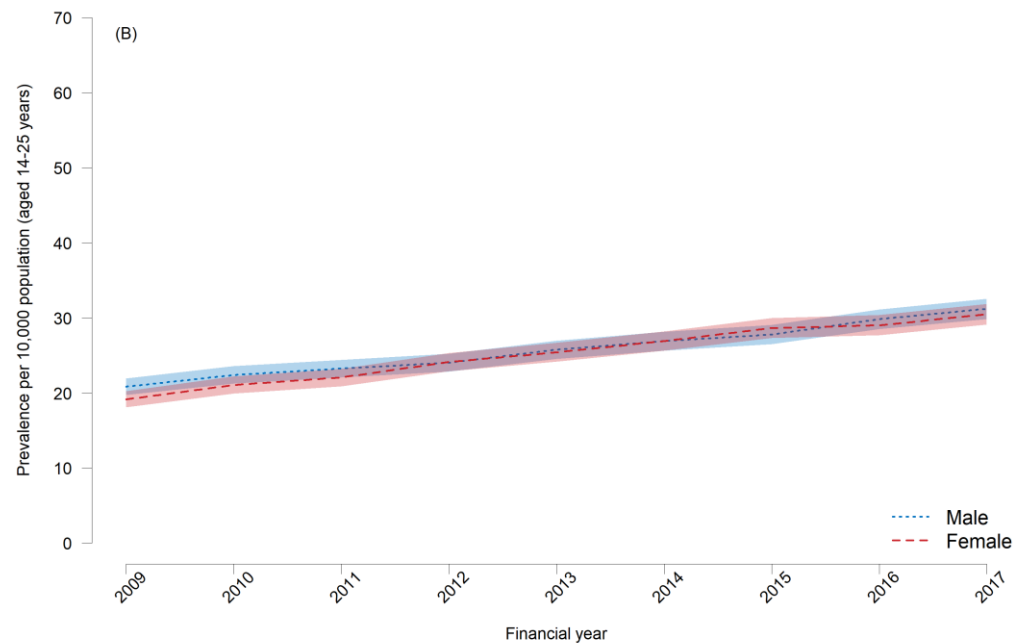
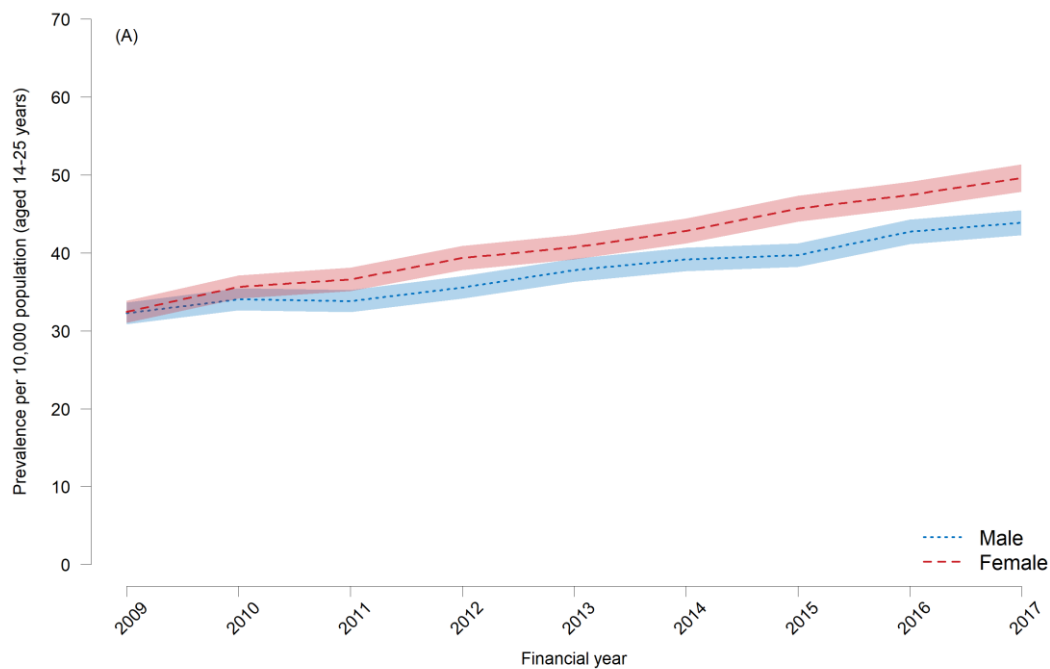


Figure 48: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in South East Government Office Region for 2009/10-2017/18

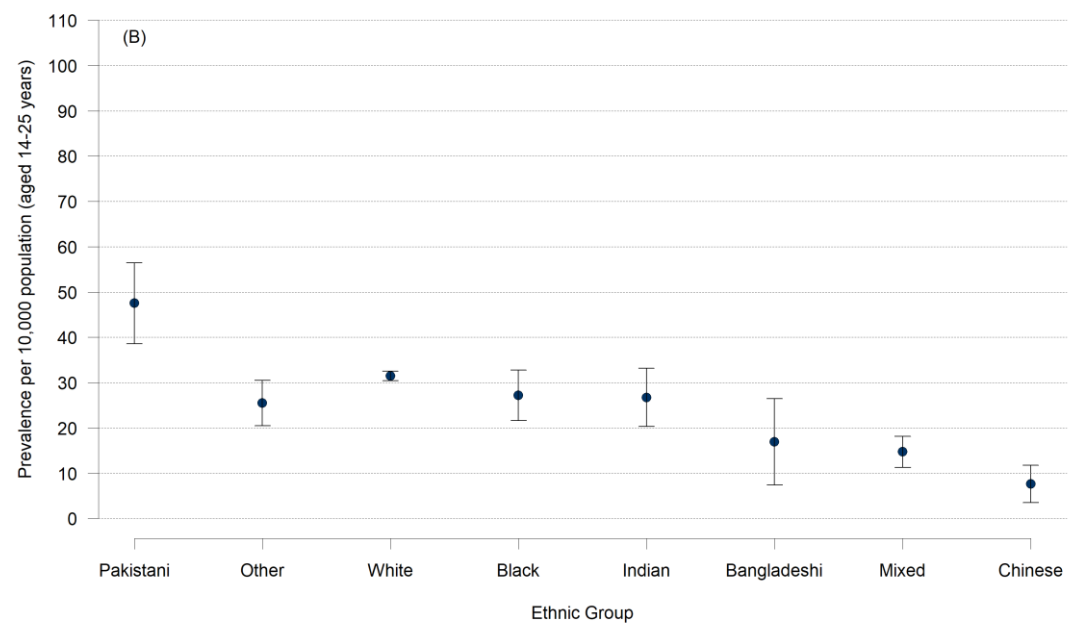
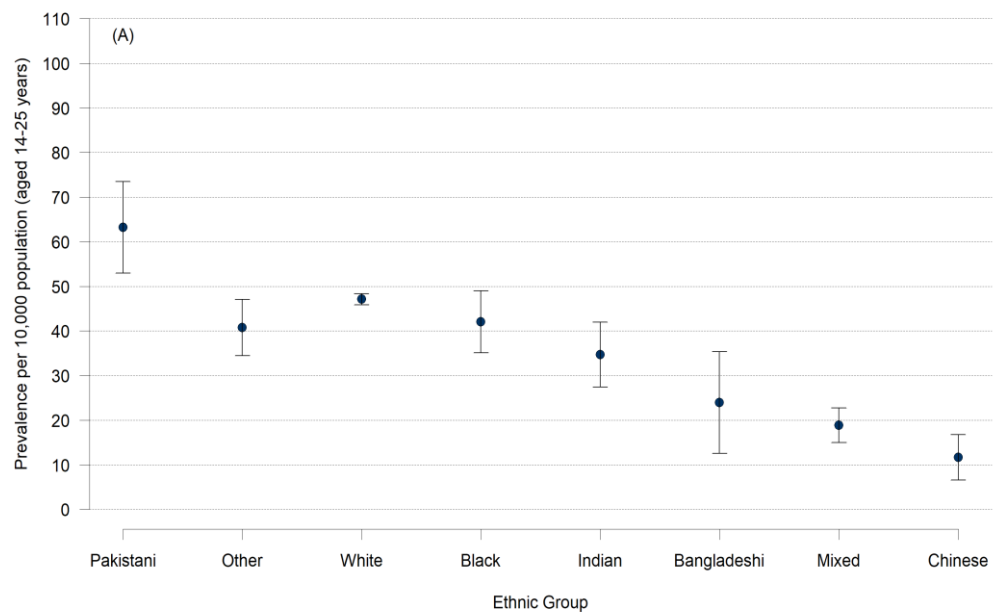


Figure 49: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the South East Government office region for 2017/18

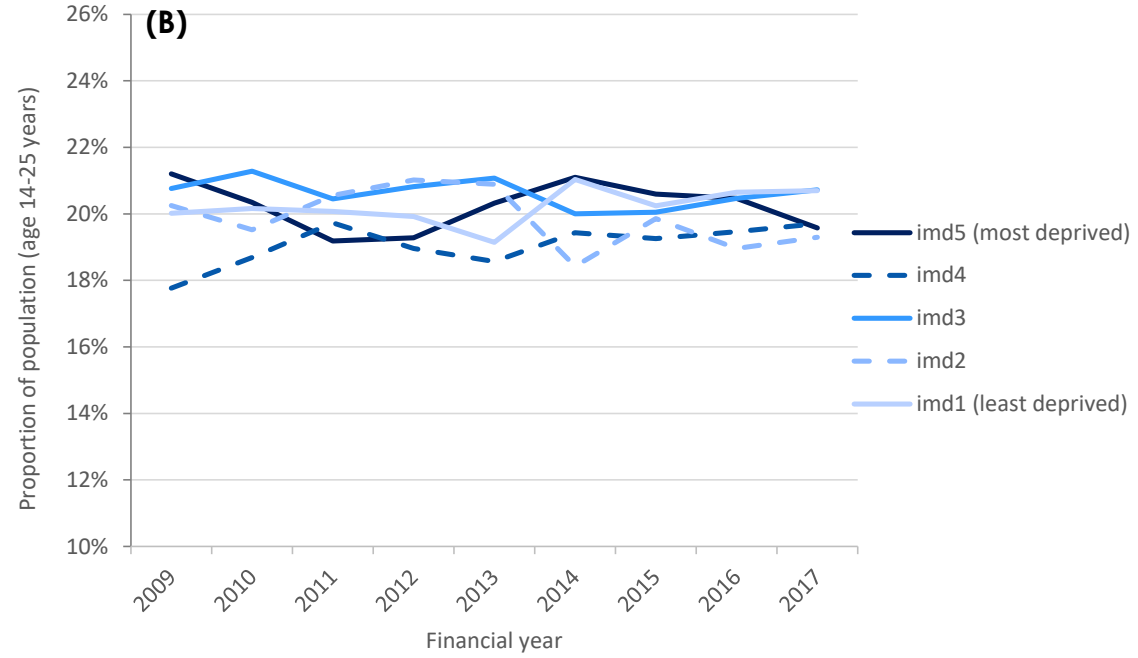
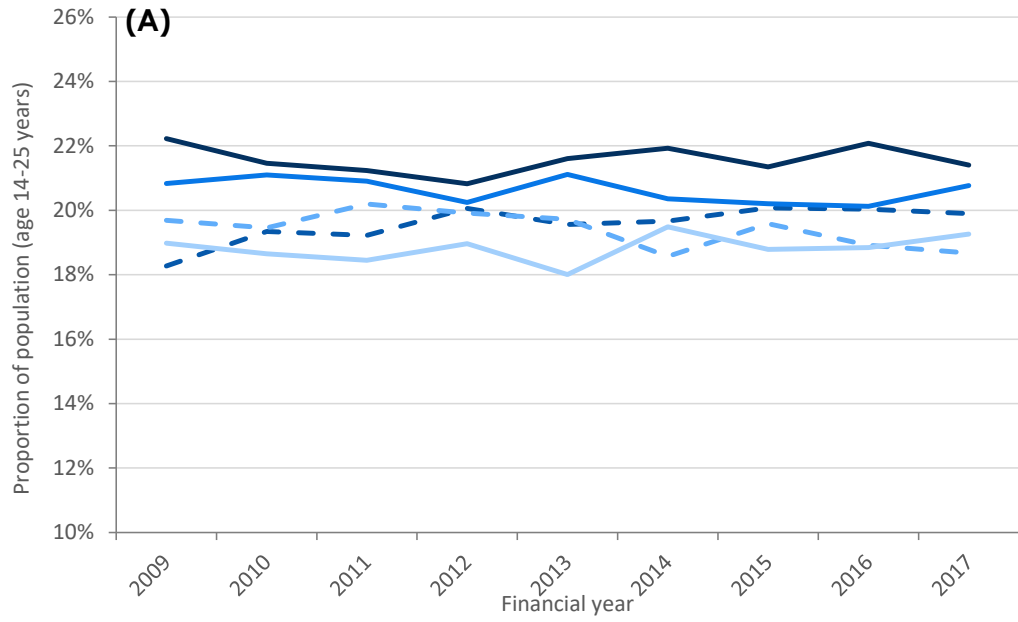


Figure 50: Percentage of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by (population weighted) deprivation group in the South East Government office region for 2009/10-2017/18

Table 17: Prevalence per 10,000 of young people (aged 14-25 years) with a LLC by Local Authority in South East Government Office Region for 2017/18

Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Adur	7329	49	<b>66.9</b>	48.2 85.5	32	<b>43.7</b>	28.6 58.8
Arun	17280	97	<b>56.1</b>	45.0 67.3	74	<b>42.8</b>	33.1 52.6
Ashford	17217	83	<b>48.2</b>	37.9 58.6	61	<b>35.4</b>	26.6 44.3
Aylesbury Vale	24635	109	<b>44.2</b>	36.0 52.5	73	<b>29.6</b>	22.8 36.4
Basingstoke & Deane	22372	115	<b>51.4</b>	42.0 60.8	74	<b>33.1</b>	25.6 40.6
Bracknell Forest	16329	59	<b>36.1</b>	26.9 45.3	38	<b>23.3</b>	15.9 30.7
Brighton & Hove	18749	157	<b>28.8</b>	24.3 33.3	99	<b>18.2</b>	14.6 21.7
Canterbury	54480	99	<b>30.1</b>	24.2 36.0	58	<b>17.6</b>	13.1 22.1
Cherwell	32924	99	<b>50.7</b>	40.8 60.7	69	<b>35.4</b>	27.0 43.7
Chichester	19519	80	<b>56.4</b>	44.1 68.7	44	<b>31.0</b>	21.9 40.2
Chiltern	14184	51	<b>42.6</b>	30.9 54.3	38	<b>31.7</b>	21.7 41.8
Crawley	14526	78	<b>50.6</b>	39.4 61.8	50	<b>32.4</b>	23.4 41.4
Dartford	14667	73	<b>50.3</b>	38.8 61.8	49	<b>33.7</b>	24.3 43.2
Dover	14835	88	<b>60.0</b>	47.5 72.5	57	<b>38.9</b>	28.8 48.9
East Hampshire	14542	99	<b>66.7</b>	53.6 79.8	74	<b>49.9</b>	38.5 61.2
Eastbourne	16669	74	<b>50.9</b>	39.3 62.5	47	<b>32.3</b>	23.1 41.5
Eastleigh	15707	97	<b>58.2</b>	46.6 69.7	67	<b>40.2</b>	30.6 49.8
Elmbridge	11191	75	<b>47.7</b>	37.0 58.5	52	<b>33.1</b>	24.1 42.1
Epsom & Ewell	14219	68	<b>60.8</b>	46.4 75.2	51	<b>45.6</b>	33.1 58.1
Fareham	12148	74	<b>52.0</b>	40.2 63.9	55	<b>38.7</b>	28.5 48.9
Gosport	15303	51	<b>42.0</b>	30.5 53.5	32	<b>26.3</b>	17.2 35.5
Gravesham	25627	66	<b>43.1</b>	32.7 53.5	42	<b>27.4</b>	19.2 35.7
Guildford	11638	100	<b>39.0</b>	31.4 46.7	59	<b>23.0</b>	17.2 28.9
Hart	12551	64	<b>55.0</b>	41.6 68.4	39	<b>33.5</b>	23.0 44.0
Hastings	16141	81	<b>64.5</b>	50.5 78.5	47	<b>37.4</b>	26.8 48.1
Havant	16070	83	<b>51.4</b>	40.4 62.5	57	<b>35.3</b>	26.2 44.5
Horsham	17068	91	<b>56.6</b>	45.0 68.2	67	<b>41.7</b>	31.7 51.7
Isle of Wight	11960	95	<b>55.7</b>	44.5 66.8	73	<b>42.8</b>	33.0 52.6
Lewes	21663	75	<b>62.7</b>	48.6 76.9	53	<b>44.3</b>	32.4 56.2
Maidstone	42478	107	<b>49.4</b>	40.1 58.7	68	<b>31.4</b>	23.9 38.8
Medway	17823	234	<b>55.1</b>	48.0 62.1	142	<b>33.4</b>	27.9 38.9
Mid Sussex	36799	80	<b>44.9</b>	35.1 54.7	49	<b>27.5</b>	19.8 35.2
Milton Keynes	10376	190	<b>51.6</b>	44.3 59.0	129	<b>35.1</b>	29.0 41.1
Mole Valley	20076	45	<b>43.4</b>	30.7 56.0	32	<b>30.8</b>	20.2 41.5
New Forest	42634	111	<b>55.3</b>	45.0 65.5	76	<b>37.9</b>	29.4 46.4
Oxford	44374	114	<b>26.7</b>	21.8 31.6	67	<b>15.7</b>	12.0 19.5
Portsmouth	11969	135	<b>30.4</b>	25.3 35.5	76	<b>17.1</b>	13.3 21.0
Reading	30410	91	<b>29.9</b>	23.8 36.1	52	<b>17.1</b>	12.5 21.7
Reigate & Banstead	17660	111	<b>62.9</b>	51.2 74.5	74	<b>41.9</b>	32.4 51.4

Rother	9866	59	<b>59.8</b>	44.6	75.0	40	<b>40.5</b>	28.0	53.1
Runnymede	14482	51	<b>35.2</b>	25.6	44.9	33	<b>22.8</b>	15.0	30.6
Rushmoor	14802	55	<b>37.2</b>	27.4	47.0	30	<b>20.3</b>	13.0	27.5
Sevenoaks	14037	73	<b>52.0</b>	40.1	63.9	43	<b>30.6</b>	21.5	39.8
Shepway	14720	84	<b>57.1</b>	44.9	69.2	50	<b>34.0</b>	24.6	43.4
Slough	23445	136	<b>58.0</b>	48.3	67.7	86	<b>36.7</b>	28.9	44.4
South Bucks	8181	43	<b>52.6</b>	36.9	68.2	38	<b>46.4</b>	31.7	61.2
South Oxfordshire	16989	74	<b>43.6</b>	33.7	53.5	55	<b>32.4</b>	23.8	40.9
Southampton	15424	202	<b>37.4</b>	32.2	42.5	113	<b>20.9</b>	17.1	24.8
Spelthorne	54066	60	<b>48.7</b>	36.4	61.0	40	<b>32.5</b>	22.4	42.5
Surrey Heath	12310	62	<b>56.3</b>	42.3	70.3	40	<b>36.3</b>	25.1	47.5
Swale	11016	102	<b>51.9</b>	41.8	61.9	71	<b>36.1</b>	27.7	44.5
Tandridge	19662	64	<b>60.4</b>	45.7	75.2	50	<b>47.2</b>	34.2	60.3
Test Valley	10589	92	<b>64.3</b>	51.2	77.4	59	<b>41.2</b>	30.7	51.7
Thanet	14307	96	<b>51.2</b>	41.0	61.4	70	<b>37.3</b>	28.6	46.1
Tonbridge & Malling	16691	82	<b>49.1</b>	38.5	59.7	53	<b>31.8</b>	23.2	40.3
Tunbridge Wells	15291	62	<b>40.5</b>	30.5	50.6	48	<b>31.4</b>	22.5	40.3
Vale of White Horse	16246	72	<b>44.3</b>	34.1	54.5	44	<b>27.1</b>	19.1	35.1
Waverley	16244	70	<b>43.1</b>	33.0	53.2	40	<b>24.6</b>	17.0	32.2
Wealden	17364	88	<b>50.7</b>	40.1	61.2	62	<b>35.7</b>	26.8	44.6
West Berkshire	20663	87	<b>42.1</b>	33.3	50.9	57	<b>27.6</b>	20.4	34.7
West Oxfordshire	12899	72	<b>55.8</b>	43.0	68.7	54	<b>41.9</b>	30.7	53.0
Winchester	17939	74	<b>41.3</b>	31.9	50.6	53	<b>29.5</b>	21.6	37.5
Windsor & Maidenhead	19745	82	<b>41.5</b>	32.6	50.5	57	<b>28.9</b>	21.4	36.4
Woking	12738	53	<b>41.6</b>	30.4	52.8	35	<b>27.5</b>	18.4	36.6
Wokingham	21734	108	<b>49.7</b>	40.3	59.0	83	<b>38.2</b>	30.0	46.4
Worthing	13066	79	<b>60.5</b>	47.2	73.8	50	<b>38.3</b>	27.7	48.9
Wycombe	25714	120	<b>46.7</b>	38.3	55.0	82	<b>31.9</b>	25.0	38.8

95% CI: 95% Confidence Intervals

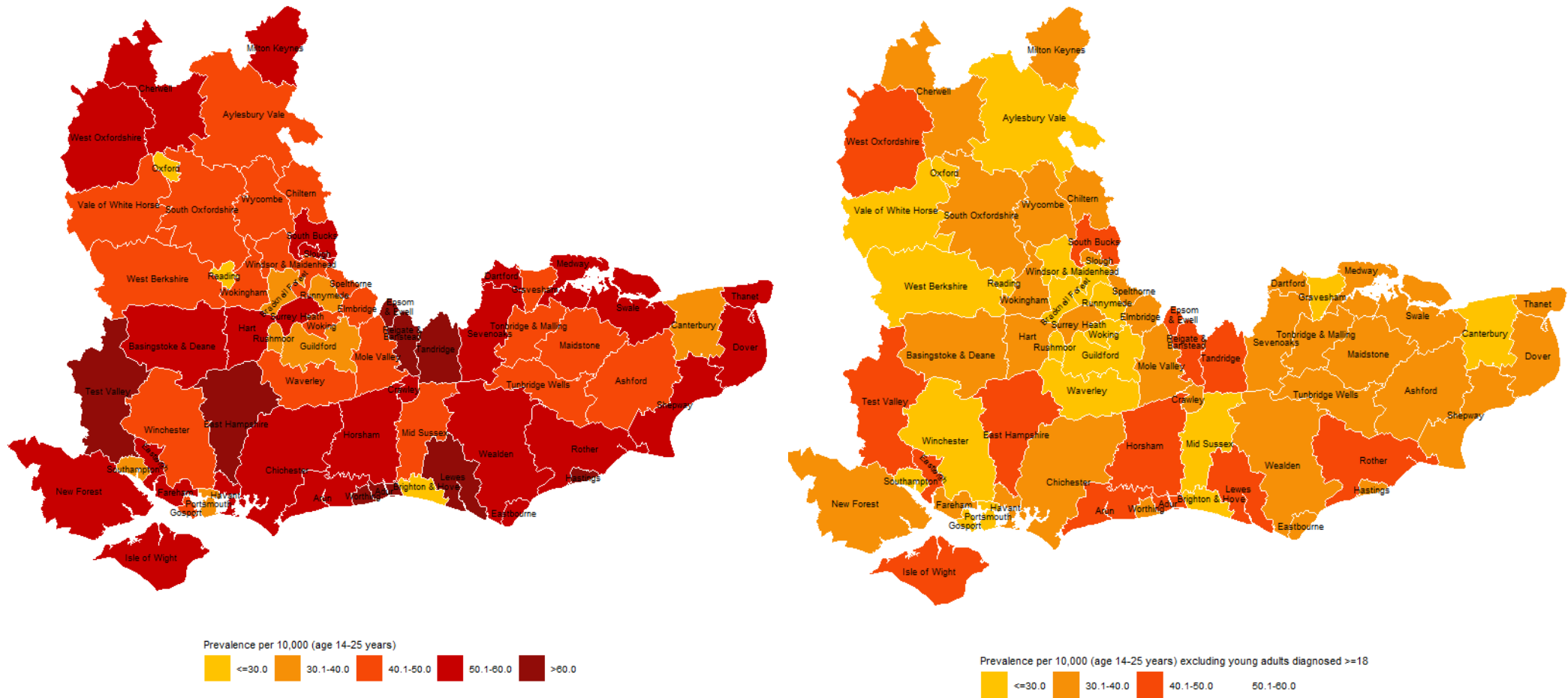


Figure 51: Prevalence per 10,000 of (aged 14-25 years) with a LLC by Local Authority in the South East Government Office Region for 2017/18

## South West

Table 18: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the South West Government Office Region

Financial year	Overall			Age 14-17 years				Age 18-25 years			
	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI		
<b>Young people aged 14-25 years</b>											
2009	2,575	33.3	32.0 34.6	872	34.1	31.9 36.4	1,703	32.9	31.3 34.4		
2010	2,741	35.2	33.8 36.5	931	36.6	34.2 38.9	1,810	34.5	32.9 36.0		
2011	2,900	36.8	35.5 38.2	972	38.1	35.7 40.5	1,928	36.2	34.6 37.9		
2012	3,123	39.6	38.2 41.0	1,020	40.5	38.0 43.0	2,103	39.2	37.5 40.9		
2013	3,176	40.3	38.9 41.7	1,021	40.8	38.3 43.3	2,155	40.1	38.4 41.8		
2014	3,271	41.7	40.3 43.1	1,049	42.5	39.9 45.1	2,222	41.3	39.6 43.0		
2015	3,456	44.2	42.8 45.7	1,125	46.8	44.0 49.5	2,331	43.1	41.4 44.9		
2016	3,552	45.9	44.4 47.4	1,140	48.6	45.8 51.4	2,412	44.7	42.9 46.5		
2017	3,567	46.5	45.0 48.1	1,139	49.4	46.5 52.2	2,428	45.3	43.5 47.1		
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>											
2009	1,569	20.3	19.3 21.3	872	34.1	31.9 36.4	697	13.5	12.5 14.5		
2010	1,686	21.6	20.6 22.7	931	36.6	34.2 38.9	755	14.4	13.3 15.4		
2011	1,817	23.1	22.0 24.1	972	38.1	35.7 40.5	845	15.9	14.8 17.0		
2012	1,935	24.5	23.5 25.6	1,020	40.5	38.0 43.0	915	17.1	16.0 18.2		
2013	2,030	25.8	24.7 26.9	1,021	40.8	38.3 43.3	1,009	18.8	17.6 19.9		
2014	2,091	26.7	25.5 27.8	1,049	42.5	39.9 45.1	1,042	19.4	18.2 20.6		
2015	2,233	28.6	27.4 29.8	1,125	46.8	44.0 49.5	1,108	20.5	19.3 21.7		
2016	2,280	29.5	28.2 30.7	1,140	48.6	45.8 51.4	1,140	21.1	19.9 22.4		
2017	2,346	30.6	29.4 31.9	1,139	49.4	46.5 52.2	1,207	22.5	21.3 23.8		

95% CI: 95% Confidence Intervals



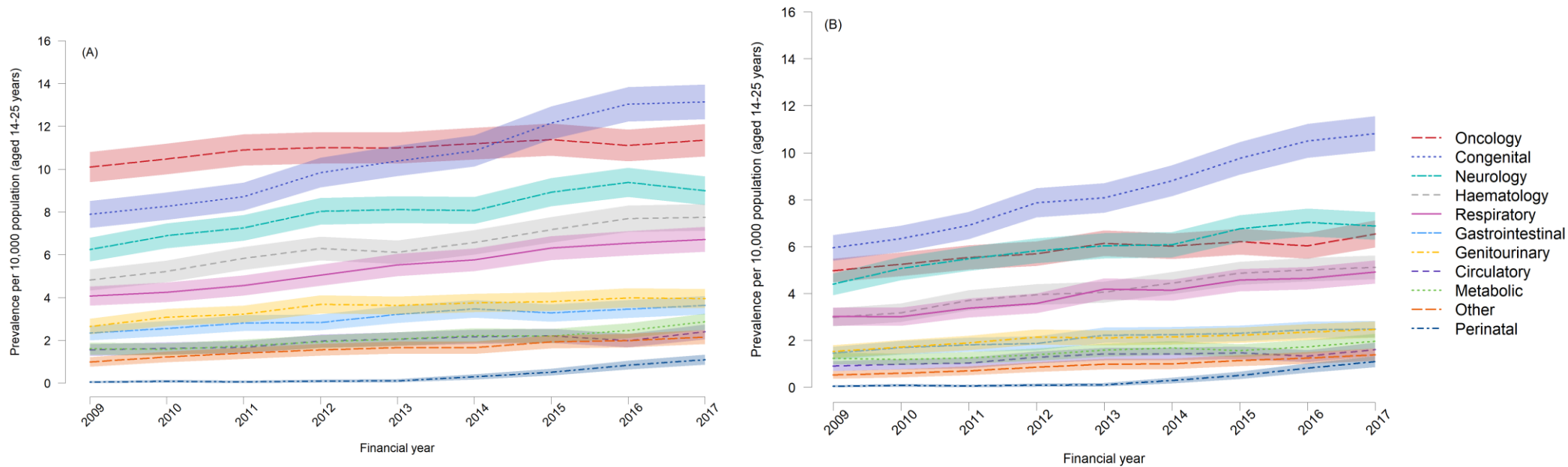


Figure 52: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the South West Government Office Region for 2009/10-2017/18

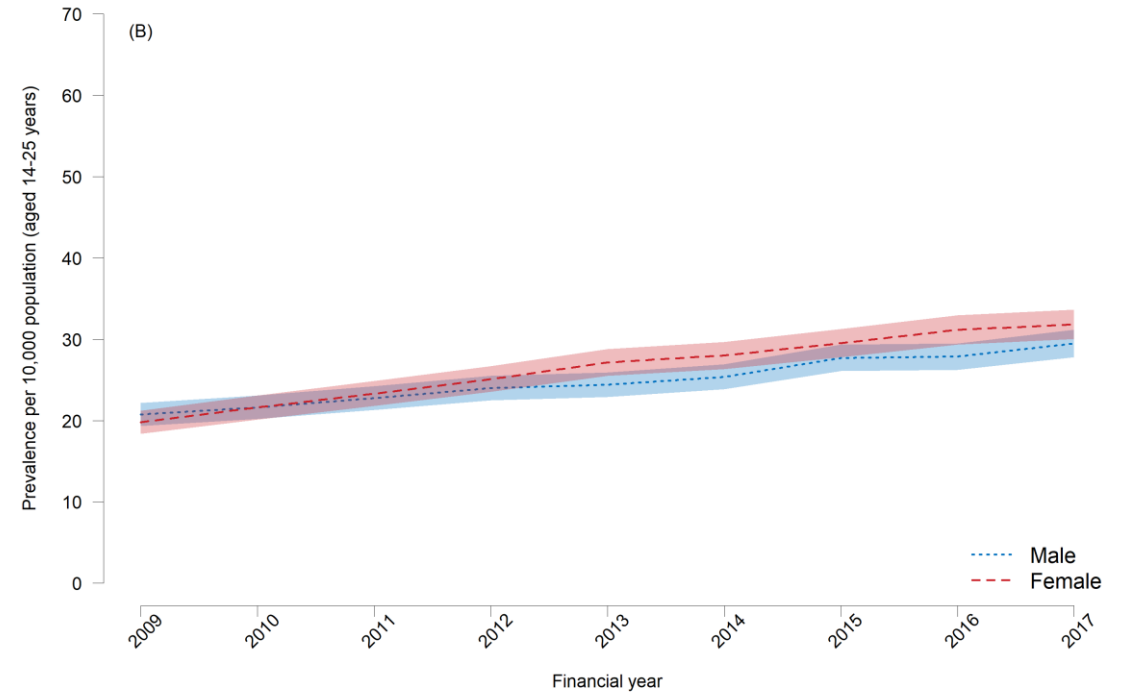
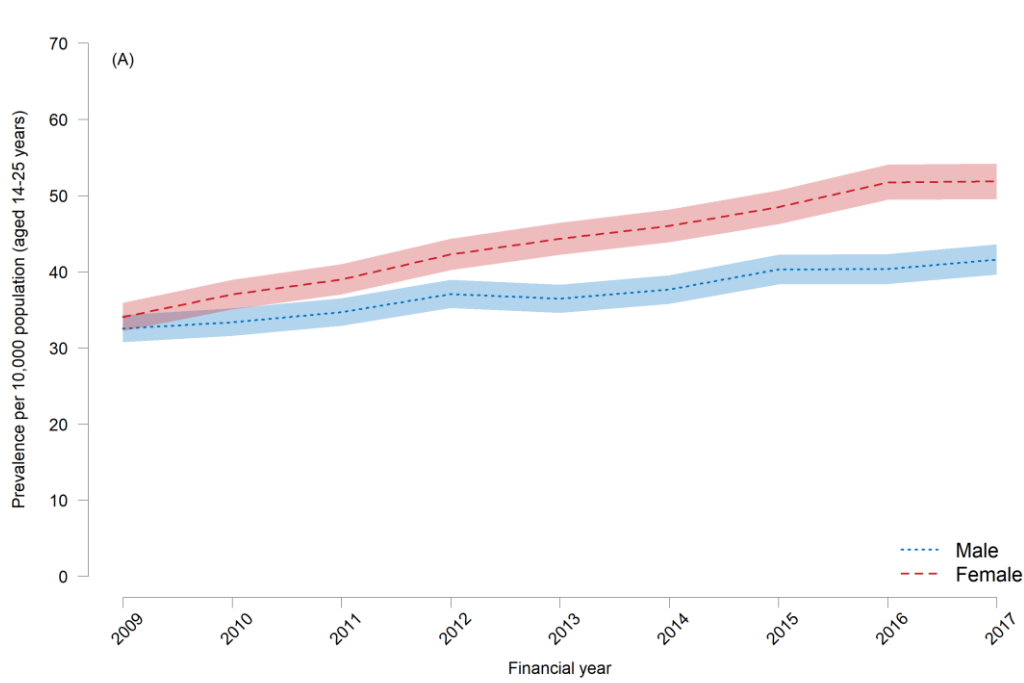


Figure 53: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in the South West Government Office Region for 2009/10-2017/18

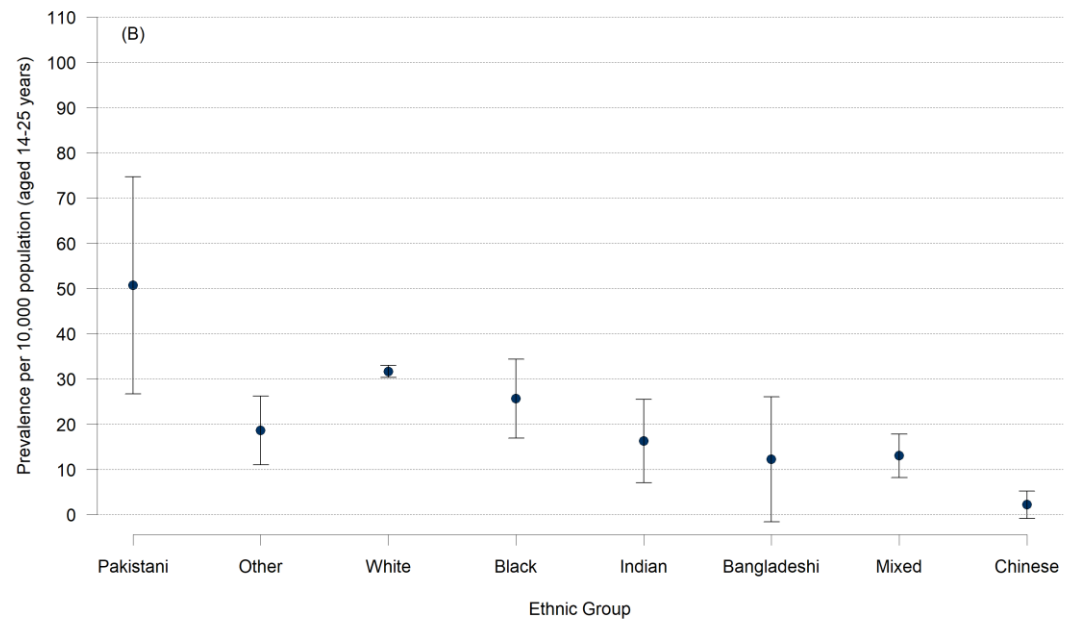
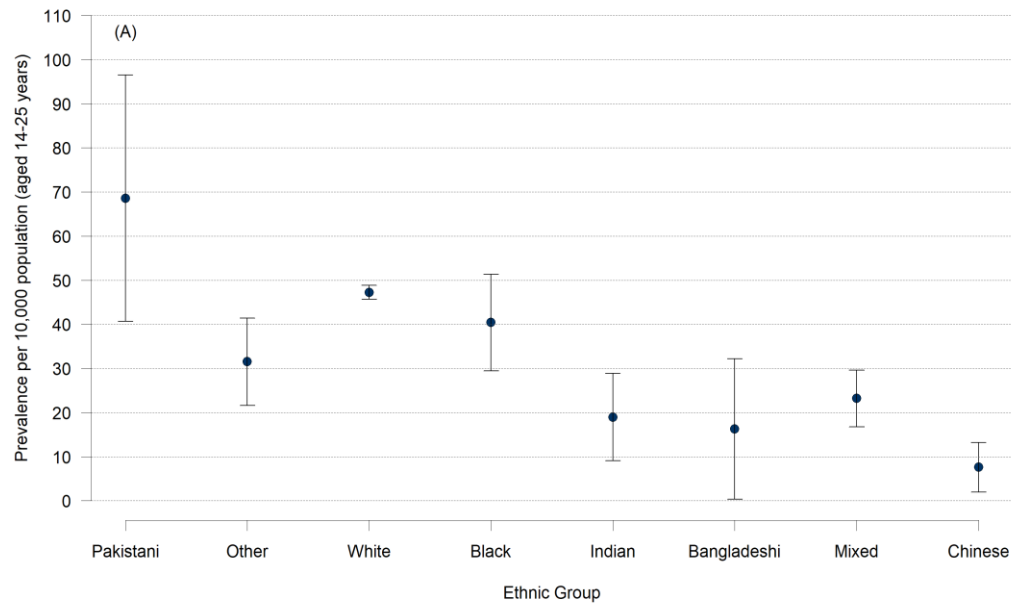


Figure 54: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the South West Government office region for 2017/18

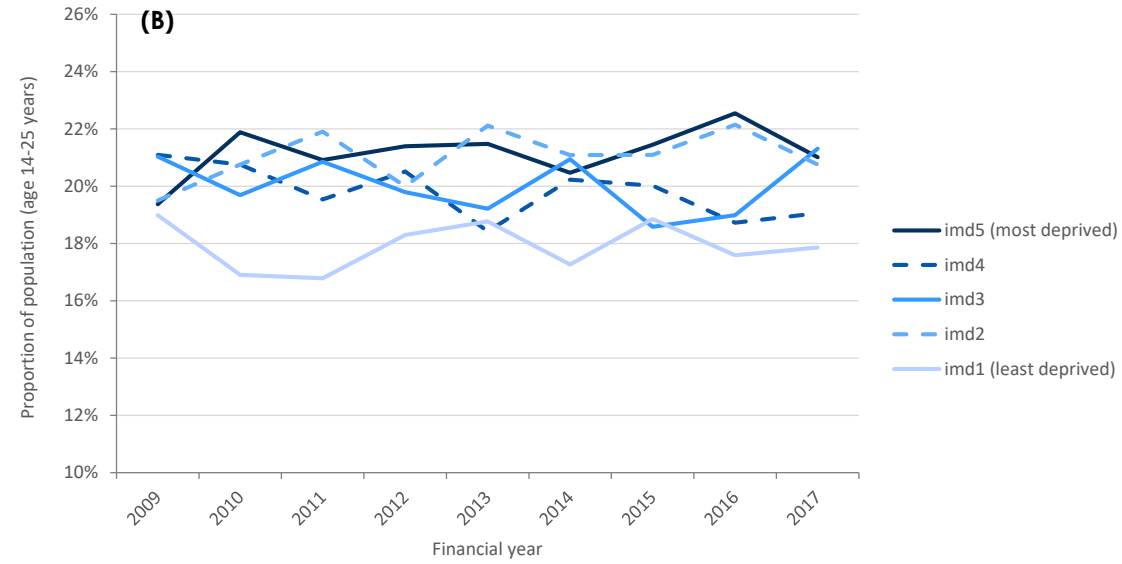
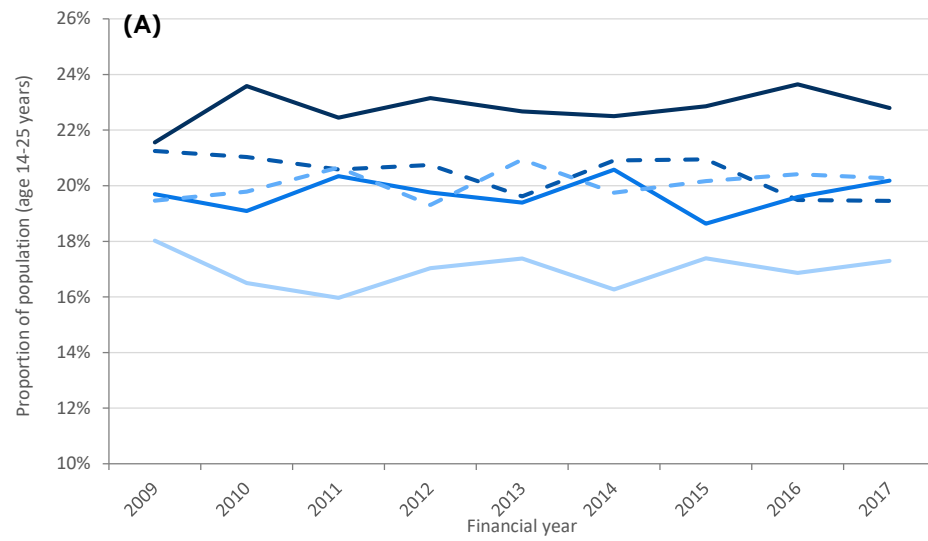
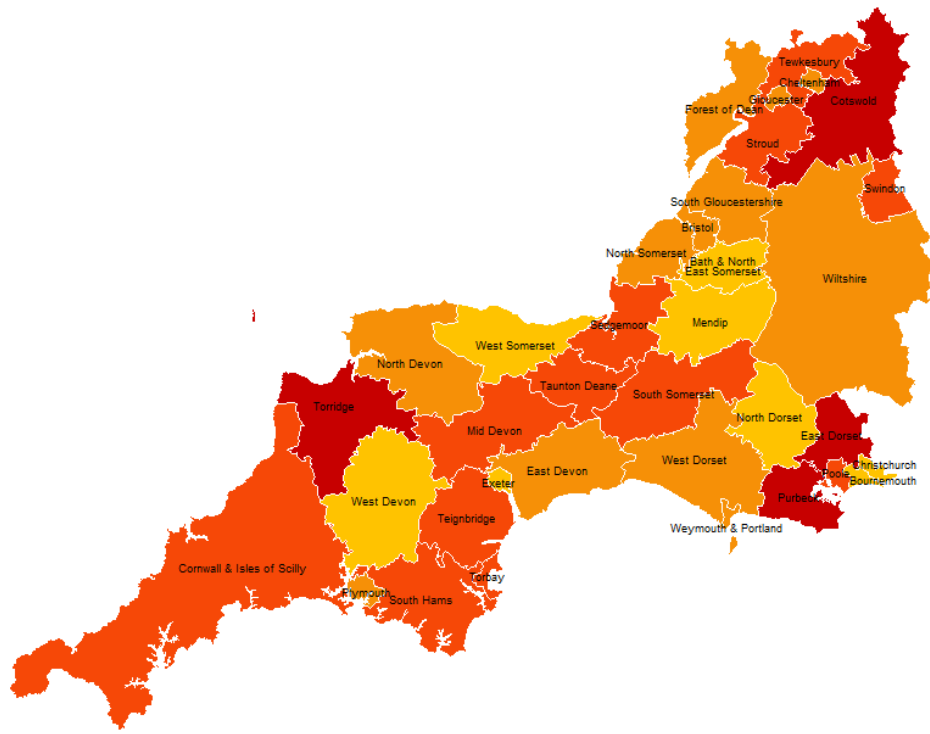


Figure 55: Percentage of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by (population weighted) deprivation group in the South West Government office region for 2009/10-2017/18.

Table 19: Prevalence per 10,000 of young people (aged 14-25 years) with a LLC by Local Authority in the South West Government Office Region for 2017/18

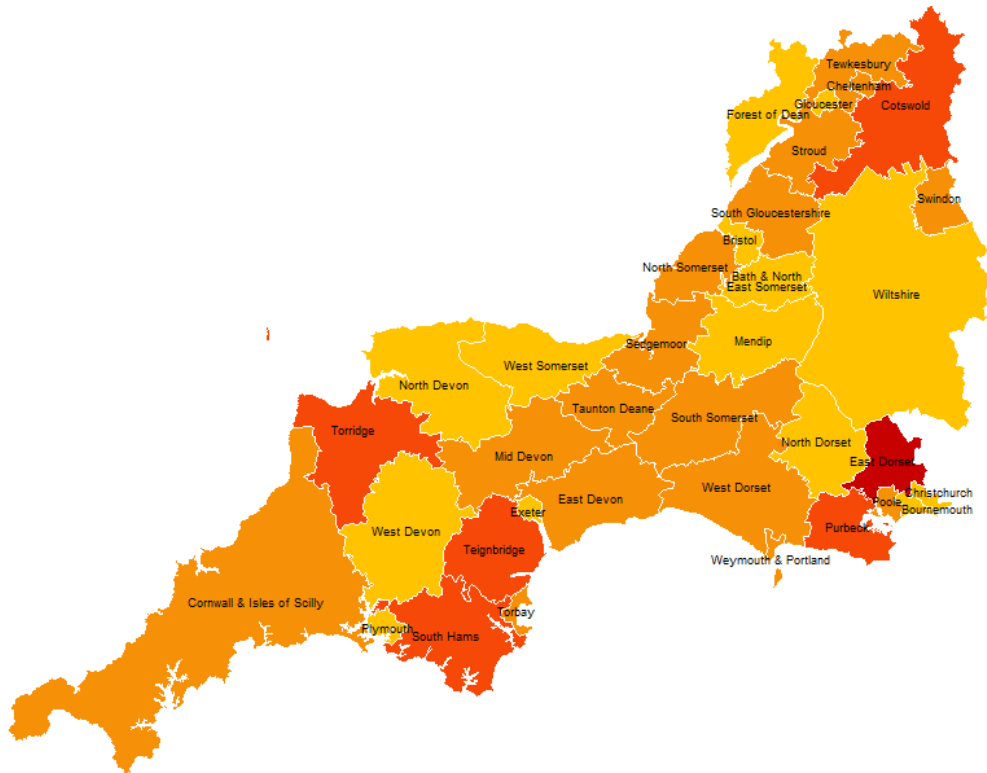
Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Bath & North East Somerset	33766	113	33.5	27.3 39.6	75	22.2	17.2 27.2
Bournemouth	34446	117	34.0	27.8 40.1	81	23.5	18.4 28.6
Bristol	5332	349	41.1	36.8 45.4	202	23.8	20.5 27.1
Cheltenham	84890	82	42.1	33.0 51.2	60	30.8	23.0 38.6
Christchurch	19464	18	33.8	18.2 49.3	12	22.5	9.8 35.2
Cornwall & Isles of Scilly	9807	397	57.6	52.0 63.3	245	35.6	31.1 40.0
Cotswold	14902	64	65.3	49.3 81.2	42	42.8	29.9 55.7
East Devon	9393	74	49.7	38.4 60.9	56	37.6	27.8 47.4
East Dorset	26357	70	74.5	57.1 91.9	52	55.4	40.4 70.4
Exeter	10972	97	36.8	29.5 44.1	68	25.8	19.7 31.9
Forest of Dean	19069	48	43.7	31.4 56.1	31	28.3	18.3 38.2
Gloucester	14628	92	48.2	38.4 58.1	56	29.4	21.7 37.0
Mendip	9738	57	39.0	28.9 49.1	39	26.7	18.3 35.0
Mid Devon	11440	49	50.3	36.3 64.4	35	35.9	24.1 47.8
North Devon	9261	47	41.1	29.4 52.8	32	28.0	18.3 37.7
North Dorset	24900	35	37.8	25.3 50.3	25	27.0	16.4 37.6
North Somerset	48505	123	49.4	40.7 58.1	80	32.1	25.1 39.2
Plymouth	68909	197	40.6	35.0 46.3	113	23.3	19.0 27.6
Poole	20028	107	53.4	43.3 63.5	73	36.4	28.1 44.8
Purbeck	5187	34	65.6	43.6 87.5	25	48.2	29.4 67.1
Sedgemoor	15110	83	54.9	43.1 66.7	55	36.4	26.8 46.0
South Gloucestershire	39807	188	47.2	40.5 54.0	125	31.4	25.9 36.9
South Hams	9577	54	56.4	41.4 71.4	43	44.9	31.5 58.3
South Somerset	20476	109	53.2	43.3 63.2	72	35.2	27.1 43.3
Stroud	13723	69	50.3	38.4 62.1	50	36.4	26.4 46.5
Swindon	30340	158	52.1	44.0 60.2	99	32.6	26.2 39.0
Taunton Deane	15238	79	51.8	40.4 63.2	52	34.1	24.9 43.4
Teignbridge	14254	74	51.9	40.1 63.7	62	43.5	32.7 54.3
Tewkesbury	9683	55	56.8	41.8 71.8	38	39.2	26.8 51.7
Torbay	16125	84	52.1	41.0 63.2	49	30.4	21.9 38.9
Torrige	7357	48	65.2	46.8 83.6	34	46.2	30.7 61.7
West Devon	5982	18	30.1	16.2 44.0	10	16.7	6.4 27.1
West Dorset	11575	48	41.5	29.8 53.2	37	32.0	21.7 42.3
West Somerset	3838	14	36.5	17.4 55.6	9	23.5	8.1 38.8
Weymouth & Portland	8788	43	48.9	34.3 63.5	30	34.1	21.9 46.3
Wiltshire	63435	272	42.9	37.8 48.0	178	28.1	23.9 32.2

95% CI: 95% Confidence intervals



Prevalence per 10,000 (age 14-25 years)

Yellow	Orange	Red-Orange	Dark Red
≤30.0	30.1-40.0	40.1-50.0	50.1-60.0



Prevalence per 10,000 (age 14-25 years) excluding young adults diagnosed ≥18

Yellow	Orange	Red-Orange	Dark Red
≤30.0	30.1-40.0	40.1-50.0	50.1-60.0

Figure 56: Prevalence per 10,000 of young people (aged 14-25 years) with a LLC by Local Authority in South West Government Office Region for 2017/18

## West Midlands

Table 20: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the West Midlands Government Office Region

Financial year	Overall			Age 14-17 years			Age 18-25 years			
	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	
<b>Young people aged 14-25 years</b>										
2009	2,928	33.3	32.1 34.5	962	33.1	31.0 35.2	1,966	33.4	31.9 34.8	
2010	3,053	34.4	33.2 35.7	975	34.0	31.8 36.1	2,078	34.7	33.2 36.2	
2011	3,226	36.0	34.8 37.3	997	34.6	32.4 36.7	2,229	36.7	35.2 38.3	
2012	3,288	36.7	35.4 37.9	1,047	36.6	34.4 38.8	2,241	36.7	35.2 38.2	
2013	3,570	39.8	38.5 41.1	1,194	42.1	39.7 44.5	2,376	38.7	37.2 40.3	
2014	3,783	42.2	40.8 43.5	1,332	47.5	45.0 50.1	2,451	39.7	38.2 41.3	
2015	3,972	44.7	43.3 46.1	1,383	50.5	47.9 53.2	2,589	42.1	40.5 43.7	
2016	4,059	46.2	44.8 47.6	1,383	51.6	48.9 54.3	2,676	43.8	42.2 45.5	
2017	4,287	49.4	47.9 50.9	1,471	55.5	52.6 58.3	2,816	46.7	45.0 48.5	
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>										
2009	1,733	19.7	18.8 20.6	962	33.1	31.0 35.2	771	13.1	12.2 14.0	
2010	1,803	20.3	19.4 21.3	975	34.0	31.8 36.1	828	13.8	12.9 14.8	
2011	1,901	21.2	20.3 22.2	997	34.6	32.4 36.7	904	14.9	13.9 15.9	
2012	1,985	22.1	21.2 23.1	1,047	36.6	34.4 38.8	938	15.4	14.4 16.3	
2013	2,204	24.6	23.5 25.6	1,194	42.1	39.7 44.5	1,010	16.5	15.5 17.5	
2014	2,367	26.4	25.3 27.5	1,332	47.5	45.0 50.1	1,035	16.8	15.8 17.8	
2015	2,542	28.6	27.5 29.7	1,383	50.5	47.9 53.2	1,159	18.8	17.8 19.9	
2016	2,594	29.5	28.4 30.7	1,383	51.6	48.9 54.3	1,211	19.8	18.7 21.0	
2017	2,761	31.8	30.6 33.0	1,471	55.5	52.6 58.3	1,290	21.4	20.2 22.6	

95% CI: 95% Confidence intervals

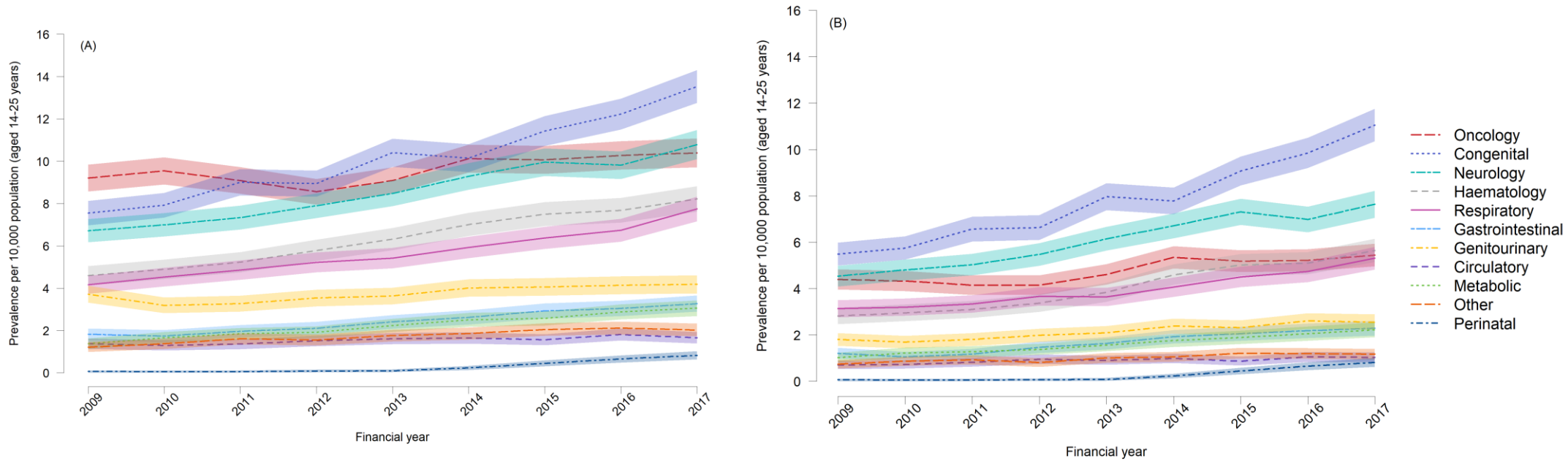


Figure 57: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the West Midlands Government Office Region for 2009/10-2017/18



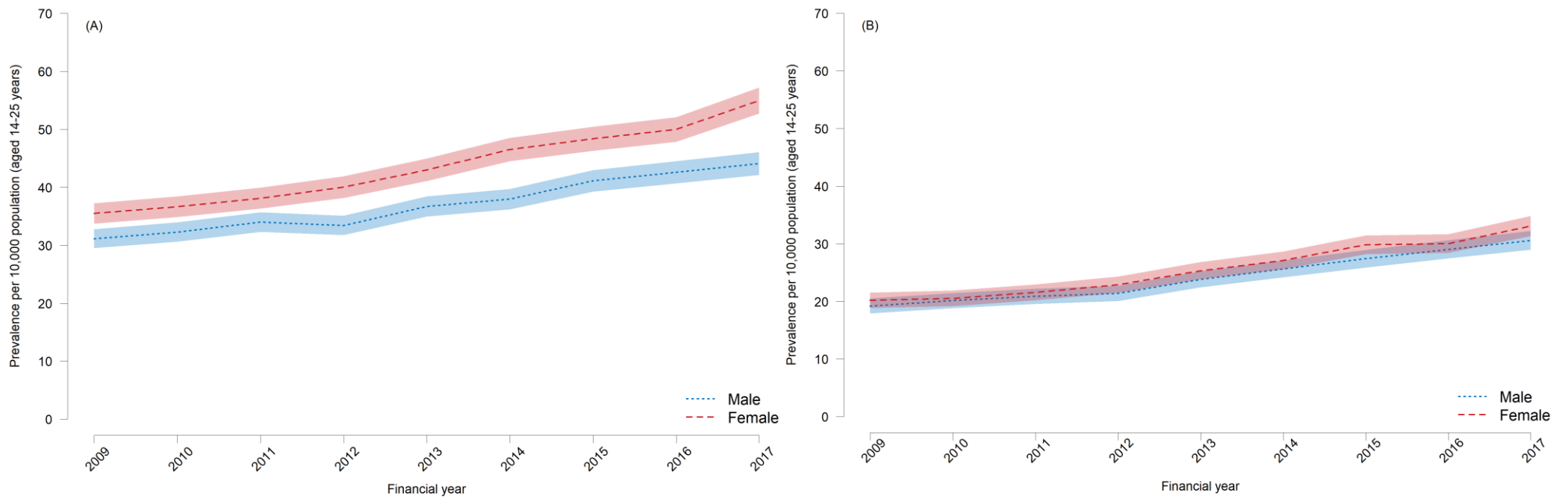


Figure 58: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in the West Midlands Government Office Region for 2009/10-2017/18

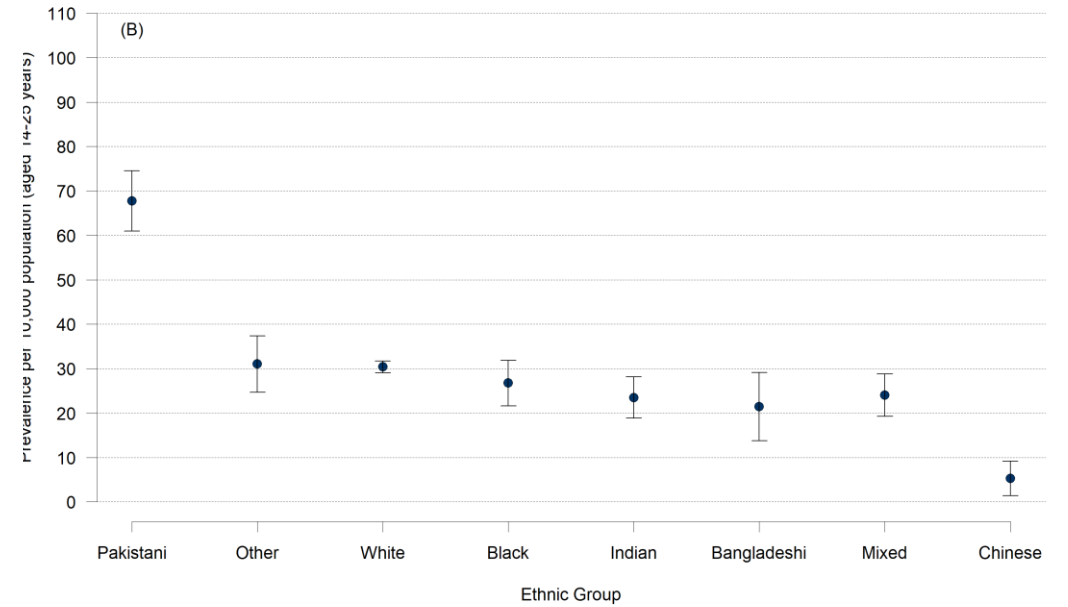
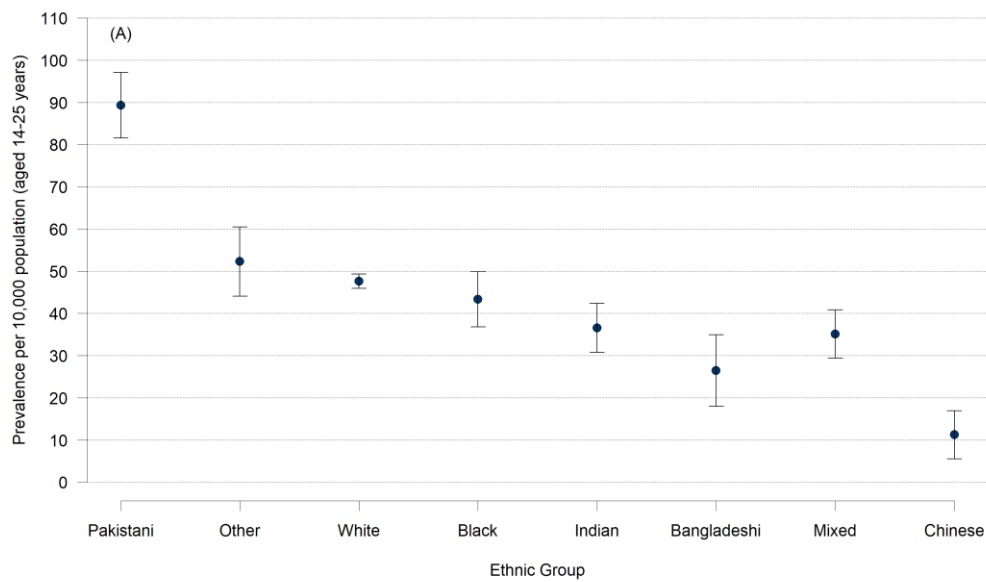


Figure 59: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the West Midlands Government office region for 2017/18.

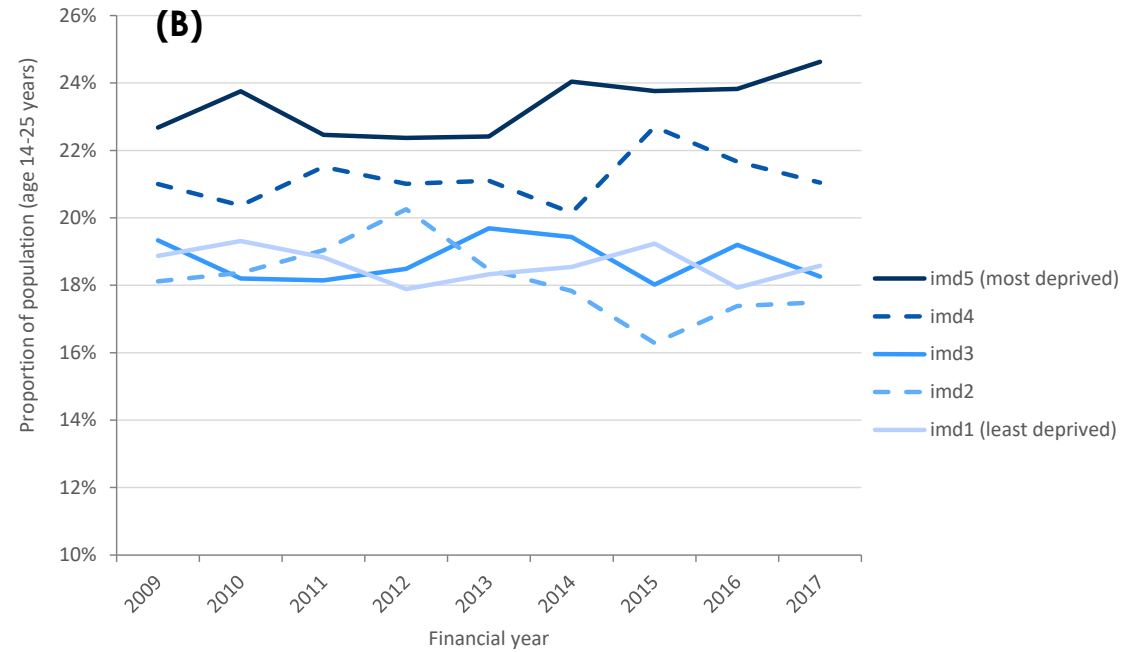
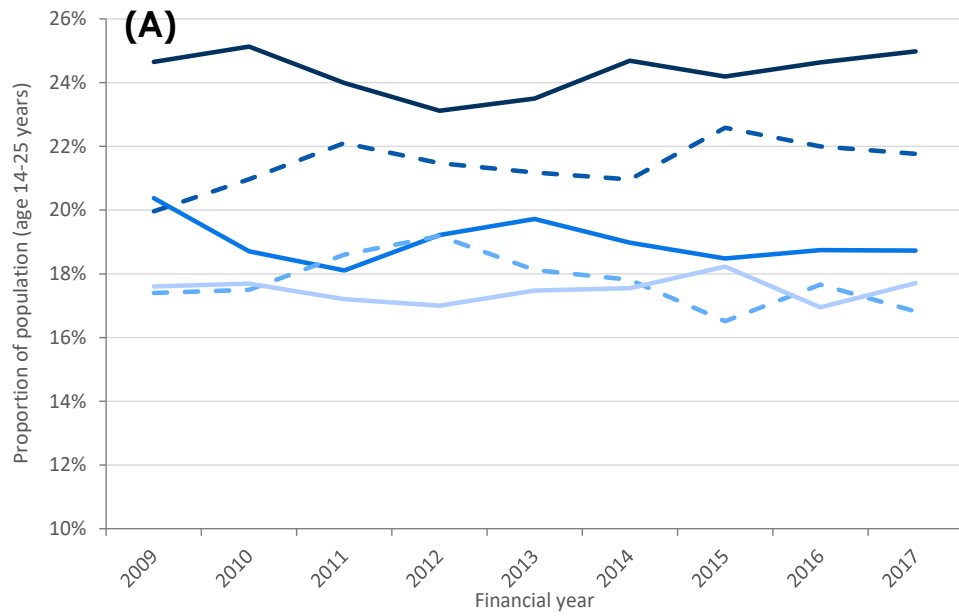


Figure 60: Percentage of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by (population weighted) deprivation group in the West Midlands Government office region for 2009/10-2017/18

Table 21: Prevalence per 10,000 of young people (aged 14-25 years) with a LLC by Local Authority in the West Midlands Government Office Region for 2017/18

Local Authority	Total population	Young Adults (14-25 years)			Young Adults (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Birmingham	213703	1059	<b>49.6</b>	46.6 52.5	681	<b>31.9</b>	29.5 34.3
Bromsgrove	11650	57	<b>48.9</b>	36.3 61.6	40	<b>34.3</b>	23.7 45.0
Cannock Chase	13746	66	<b>48.0</b>	36.5 59.6	41	<b>29.8</b>	20.7 38.9
County of Herefordshire	21824	111	<b>50.9</b>	41.4 60.3	75	<b>34.4</b>	26.6 42.1
Coventry	61897	239	<b>38.6</b>	33.7 43.5	151	<b>24.4</b>	20.5 28.3
Dudley	43496	225	<b>51.7</b>	45.0 58.5	146	<b>33.6</b>	28.1 39.0
East Staffordshire	15715	65	<b>41.4</b>	31.3 51.4	46	<b>29.3</b>	20.8 37.7
Lichfield	12500	65	<b>52.0</b>	39.4 64.6	37	<b>29.6</b>	20.1 39.1
Malvern Hills	8878	31	<b>34.9</b>	22.6 47.2	25	<b>28.2</b>	17.1 39.2
Newcastle-under-Lyme	20420	92	<b>45.1</b>	35.9 54.2	58	<b>28.4</b>	21.1 35.7
North Warwickshire	7937	36	<b>45.4</b>	30.6 60.1	25	<b>31.5</b>	19.2 43.8
Nuneaton and Bedworth	17178	108	<b>62.9</b>	51.0 74.7	65	<b>37.8</b>	28.7 47.0
Redditch	11577	64	<b>55.3</b>	41.8 68.8	50	<b>43.2</b>	31.2 55.1
Rugby	13707	64	<b>46.7</b>	35.3 58.1	41	<b>29.9</b>	20.8 39.1
Sandwell	49032	266	<b>54.3</b>	47.7 60.8	165	<b>33.7</b>	28.5 38.8
Shropshire	39390	187	<b>47.5</b>	40.7 54.3	108	<b>27.4</b>	22.3 32.6
Solihull	28075	156	<b>55.6</b>	46.9 64.3	106	<b>37.8</b>	30.6 44.9
South Staffordshire	13526	57	<b>42.1</b>	31.2 53.1	33	<b>24.4</b>	16.1 32.7
Stafford	17812	64	<b>35.9</b>	27.1 44.7	48	<b>26.9</b>	19.3 34.6
Staffordshire Moorlands	11480	65	<b>56.6</b>	42.9 70.3	52	<b>45.3</b>	33.0 57.6
Stoke-on-Trent	39186	194	<b>49.5</b>	42.6 56.5	113	<b>28.8</b>	23.5 34.1
Stratford-on-Avon	13587	88	<b>64.8</b>	51.3 78.3	61	<b>44.9</b>	33.7 56.1
Tamworth	10638	52	<b>48.9</b>	35.6 62.1	35	<b>32.9</b>	22.0 43.8
Telford & Wrekin	25270	147	<b>58.2</b>	48.8 67.5	94	<b>37.2</b>	29.7 44.7
Walsall	41409	230	<b>55.5</b>	48.4 62.7	148	<b>35.7</b>	30.0 41.5
Warwick	22715	68	<b>29.9</b>	22.8 37.0	47	<b>20.7</b>	14.8 26.6
Wolverhampton	40539	222	<b>54.8</b>	47.6 61.9	134	<b>33.1</b>	27.5 38.6
Worcester	15381	81	<b>52.7</b>	41.2 64.1	54	<b>35.1</b>	25.8 44.5
Wychavon	13348	61	<b>45.7</b>	34.3 57.1	34	<b>25.5</b>	16.9 34.0
Wyre Forest	12031	62	<b>51.5</b>	38.7 64.3	43	<b>35.7</b>	25.1 46.4

95% CI: 95% Confidence intervals

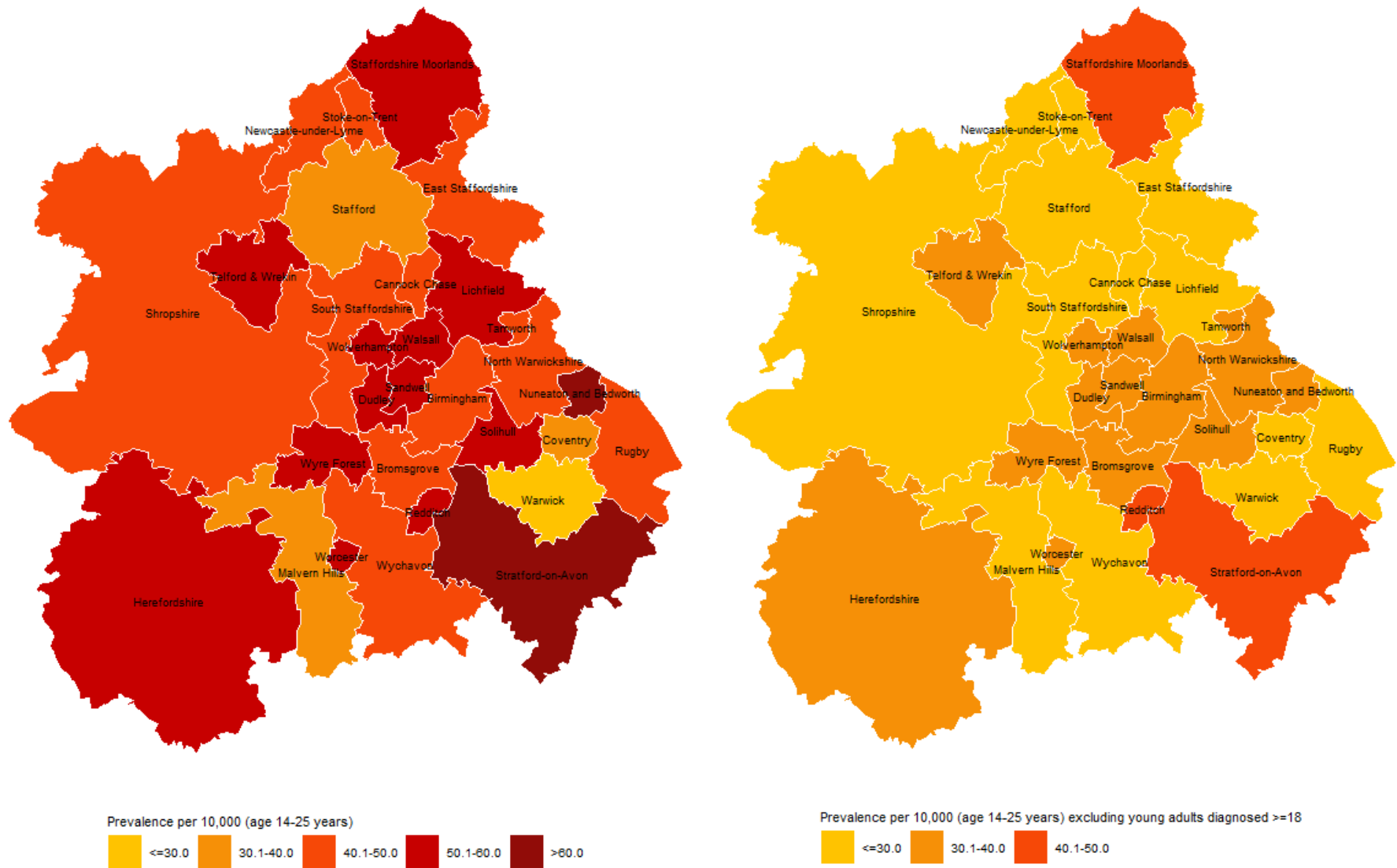


Figure 61: Prevalence per 10,000 of young people (aged 14-25 years) with a LLC by Local Authority in the West Midlands Government Office Region for 2017/18

## Yorkshire and Humber

Table 22: Number of cases and prevalence (per 10,000 population) of young people (aged 14-25 years) with a LLC overall and by age group for the Yorkshire and Humber Government Office Region

Financial year	Overall			Age 14-17 years				Age 18-25 years				
	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI	Number of Individuals with a LLC	Prevalence	95%CI			
<b>Young people aged 14-25 years</b>												
2009	2,861	33.5	32.2	34.7	852	32.2	30.0	34.3	2,009	34.0	32.5	35.5
2010	2,902	33.8	32.5	35.0	857	32.8	30.6	34.9	2,045	34.2	32.7	35.7
2011	3,025	35.0	33.8	36.3	886	34.1	31.9	36.4	2,139	35.4	33.9	36.9
2012	3,247	37.6	36.3	38.9	950	37.1	34.7	39.4	2,297	37.8	36.3	39.4
2013	3,292	38.1	36.8	39.4	1,003	39.3	36.9	41.7	2,289	37.6	36.1	39.2
2014	3,402	39.5	38.2	40.9	1,042	41.7	39.1	44.2	2,360	38.7	37.1	40.2
2015	3,580	41.7	40.4	43.1	1,076	43.9	41.3	46.5	2,504	40.8	39.2	42.4
2016	3,649	42.8	41.4	44.2	1,124	46.7	44.0	49.4	2,525	41.3	39.7	42.9
2017	3,822	45.2	43.8	46.7	1,189	50.0	47.2	52.8	2,633	43.4	41.7	45.0
<b>Young people aged 14-25 years excluding those diagnosed ≥18years</b>												
2009	1,656	19.4	18.4	20.3	852	32.2	30.0	34.3	804	13.6	12.7	14.6
2010	1,721	20.0	19.1	21.0	857	32.8	30.6	34.9	864	14.5	13.5	15.4
2011	1,822	21.1	20.1	22.1	886	34.1	31.9	36.4	936	15.5	14.5	16.5
2012	1,981	22.9	21.9	23.9	950	37.1	34.7	39.4	1,031	17.0	15.9	18.0
2013	2,054	23.8	22.8	24.8	1,003	39.3	36.9	41.7	1,051	17.3	16.2	18.3
2014	2,146	24.9	23.9	26.0	1,042	41.7	39.1	44.2	1,104	18.1	17.0	19.2
2015	2,250	26.2	25.1	27.3	1,076	43.9	41.3	46.5	1,174	19.1	18.1	20.2
2016	2,349	27.5	26.4	28.7	1,124	46.7	44.0	49.4	1,225	20.0	18.9	21.1
2017	2,428	28.7	27.6	29.9	1,189	50.0	47.2	52.8	1,239	20.4	19.3	21.5
<i>95% CI: 95% Confidence intervals</i>												

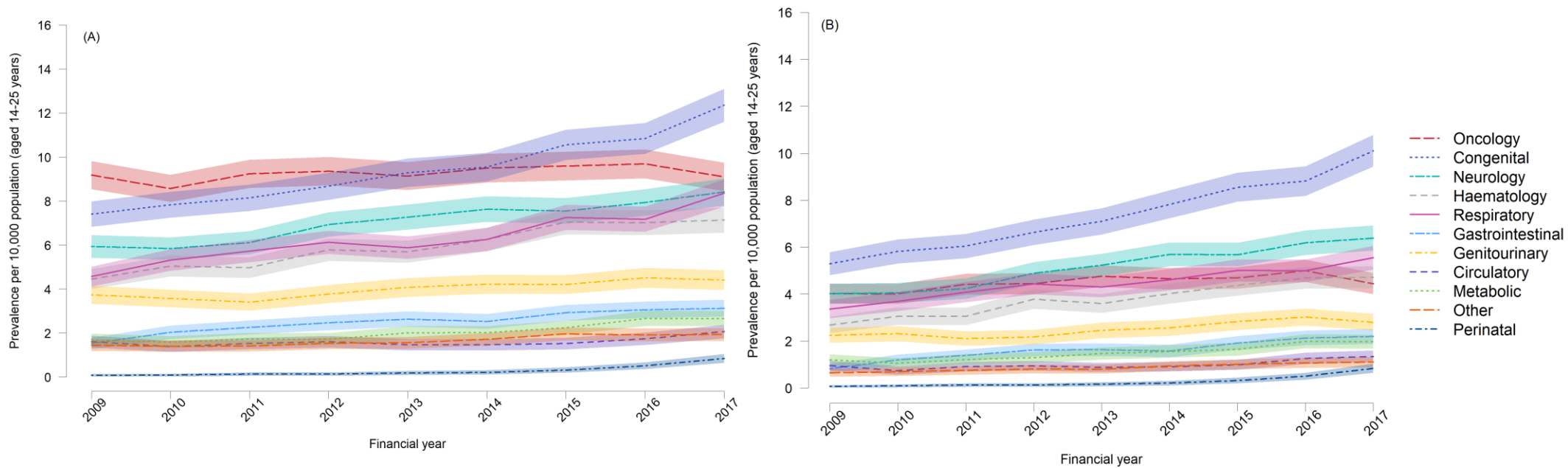


Figure 62: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by diagnosis in the Yorkshire and Humber Government Office Region for 2009/10-2017/18

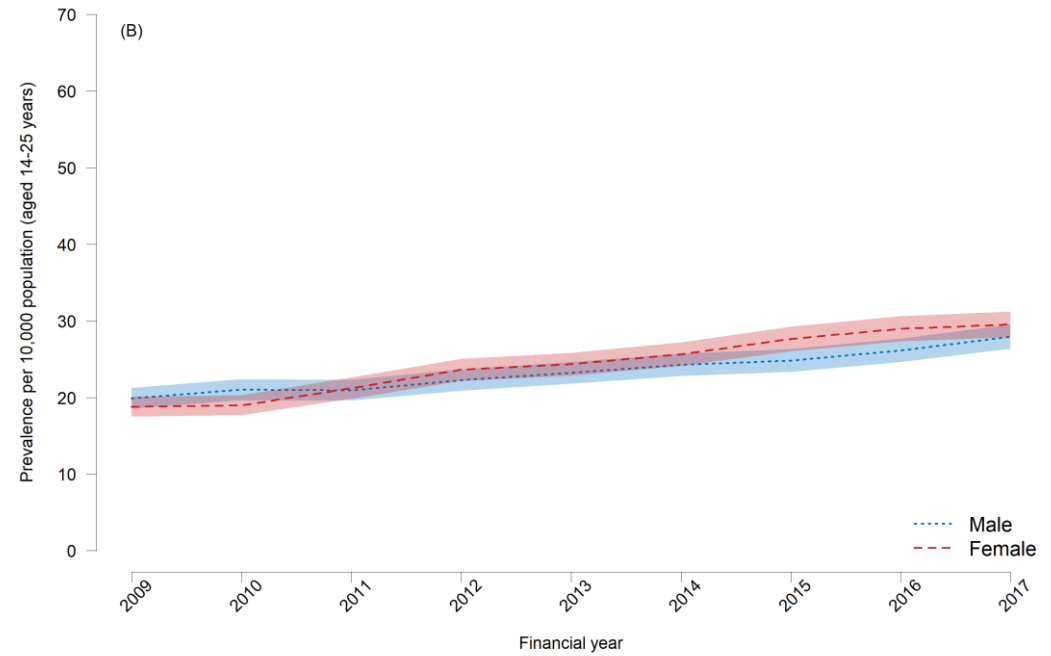
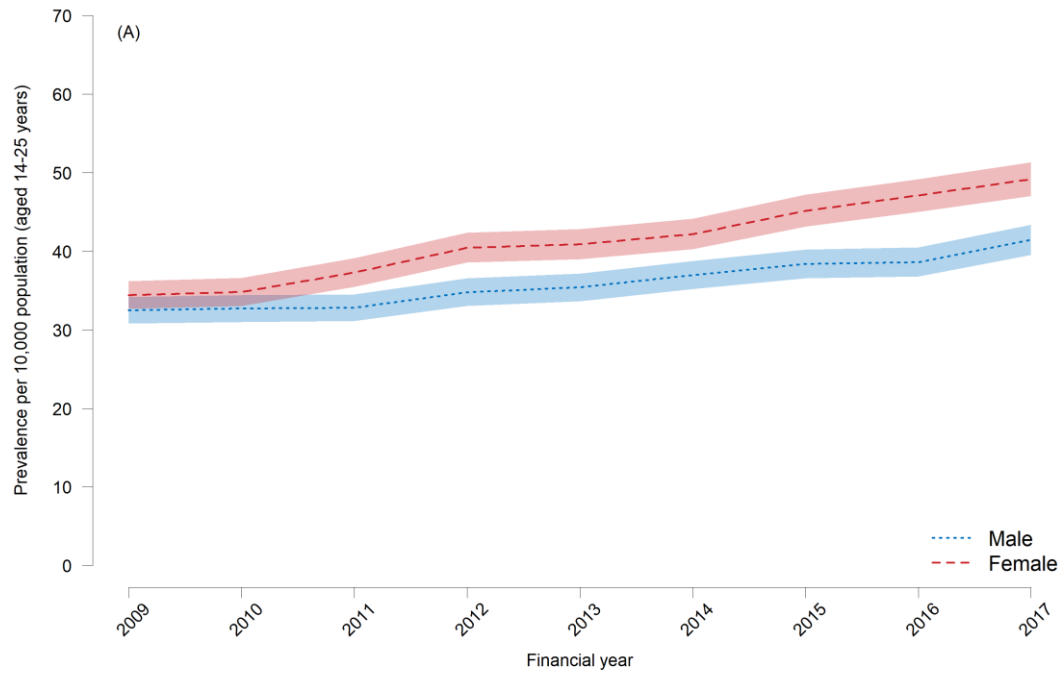


Figure 63: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by sex in the Yorkshire and Humber Government Office Region for 2009/10-2017/18



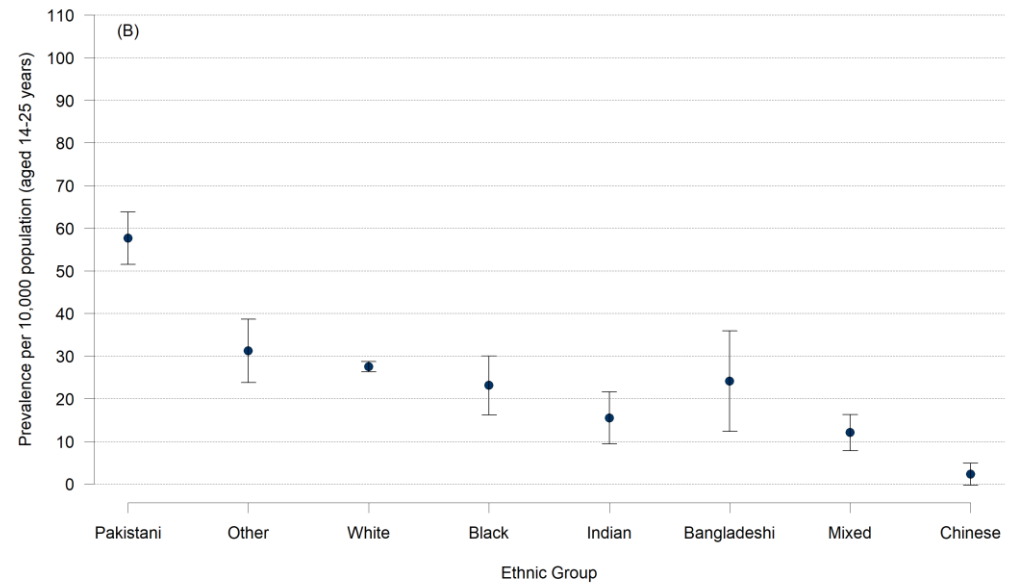
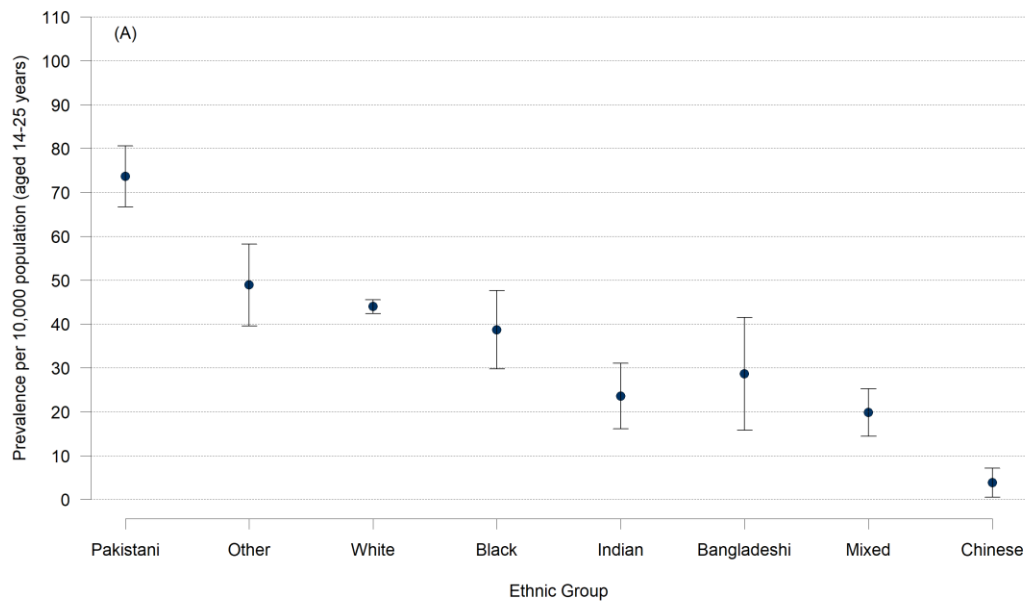


Figure 64: Prevalence per 10,000 of young people (aged 14-25 years) with (A) a LLC diagnosed at any age or (B) with a LLC diagnosed <18 by ethnic group in the Yorkshire and Humber Government office region for 2017/18.

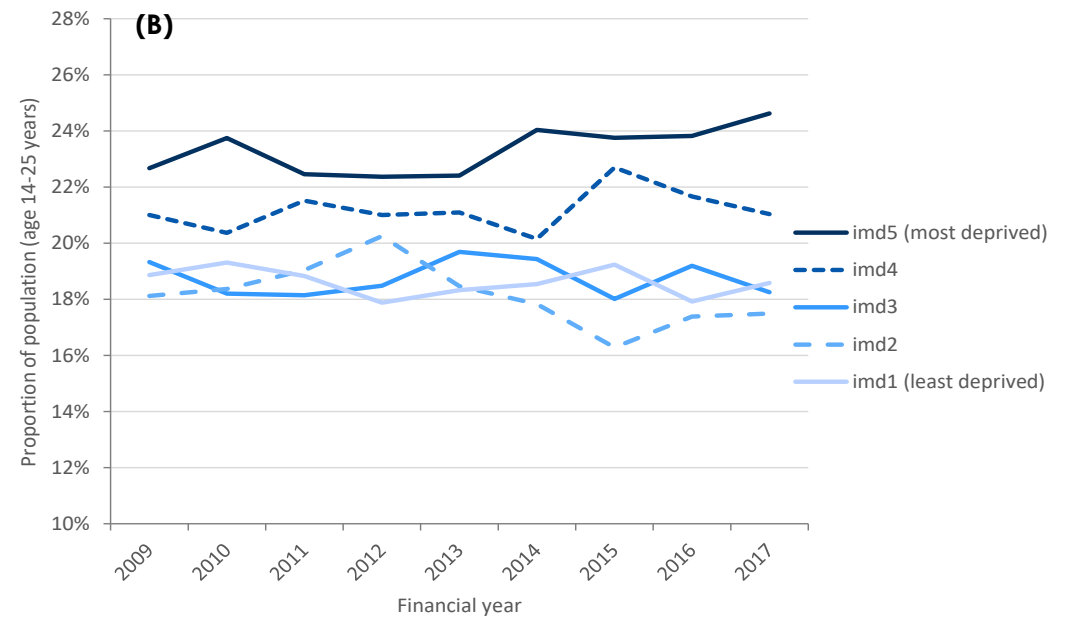
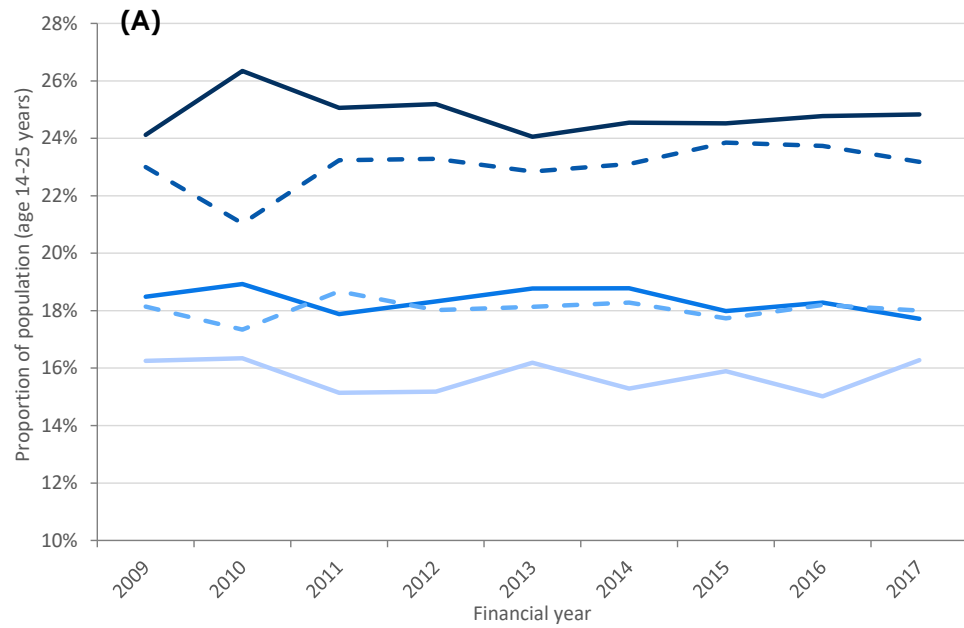


Figure 65: Percentage of young people (aged 14-25 years) with (A) a mental health condition diagnosed at any age or (B) with a mental health condition diagnosed <18 by (population weighted) deprivation group in the Yorkshire and Humber Government office region for 2009/10-2017/18

Table 23: Prevalence per 10,000 of young people (aged 14-25 years) with a LLC by Local Authority in the Yorkshire and Humber Government Office Region for 2017/18

Local Authority	Total population	Young people (14-25 years)			Young people (14-25 years) excluding those diagnosed ≥18 years		
		Number of cases	Prevalence per 10,000	95% CI	Number of cases	Prevalence per 10,000	95% CI
Barnsley	31768	178	<b>56.0</b>	47.8 64.2	109	<b>34.3</b>	27.9 40.7
Bradford	93965	548	<b>58.3</b>	53.5 63.2	378	<b>40.2</b>	36.2 44.3
Calderdale	28082	124	<b>44.2</b>	36.4 51.9	80	<b>28.5</b>	22.3 34.7
Craven	6436	28	<b>43.5</b>	27.4 59.6	17	<b>26.4</b>	13.9 39.0
Doncaster	41642	194	<b>46.6</b>	40.0 53.1	117	<b>28.1</b>	23.0 33.2
East Riding of Yorkshire	41163	136	<b>33.0</b>	27.5 38.6	82	<b>19.9</b>	15.6 24.2
Hambleton	10746	51	<b>47.5</b>	34.5 60.5	33	<b>30.7</b>	20.2 41.2
Harrogate	19867	97	<b>48.8</b>	39.1 58.5	62	<b>31.2</b>	23.5 39.0
Kingston upon Hull	45228	190	<b>42.0</b>	36.0 48.0	123	<b>27.2</b>	22.4 32.0
Kirklees	68305	322	<b>47.1</b>	42.0 52.3	210	<b>30.7</b>	26.6 34.9
Leeds	145759	485	<b>33.3</b>	30.3 36.2	304	<b>20.9</b>	18.5 23.2
North East Lincolnshire	21680	128	<b>59.0</b>	48.8 69.2	76	<b>35.1</b>	27.2 42.9
North Lincolnshire	21877	104	<b>47.5</b>	38.4 56.7	64	<b>29.3</b>	22.1 36.4
Richmondshire	8618	19	<b>22.0</b>	12.1 32.0	13	<b>15.1</b>	6.9 23.3
Rotherham	35841	205	<b>57.2</b>	49.4 65.0	134	<b>37.4</b>	31.1 43.7
Ryedale	5946	25	<b>42.0</b>	25.6 58.5	18	<b>30.3</b>	16.3 44.2
Scarborough	13965	71	<b>50.8</b>	39.0 62.6	45	<b>32.2</b>	22.8 41.6
Selby	10466	56	<b>53.5</b>	39.5 67.5	26	<b>24.8</b>	15.3 34.4
Sheffield	111781	461	<b>41.2</b>	37.5 45.0	303	<b>27.1</b>	24.1 30.2
Wakefield	44317	274	<b>61.8</b>	54.5 69.1	162	<b>36.6</b>	30.9 42.2
York	37589	122	<b>32.5</b>	26.7 38.2	69	<b>18.4</b>	14.0 22.7

95% CI: 95% Confidence intervals

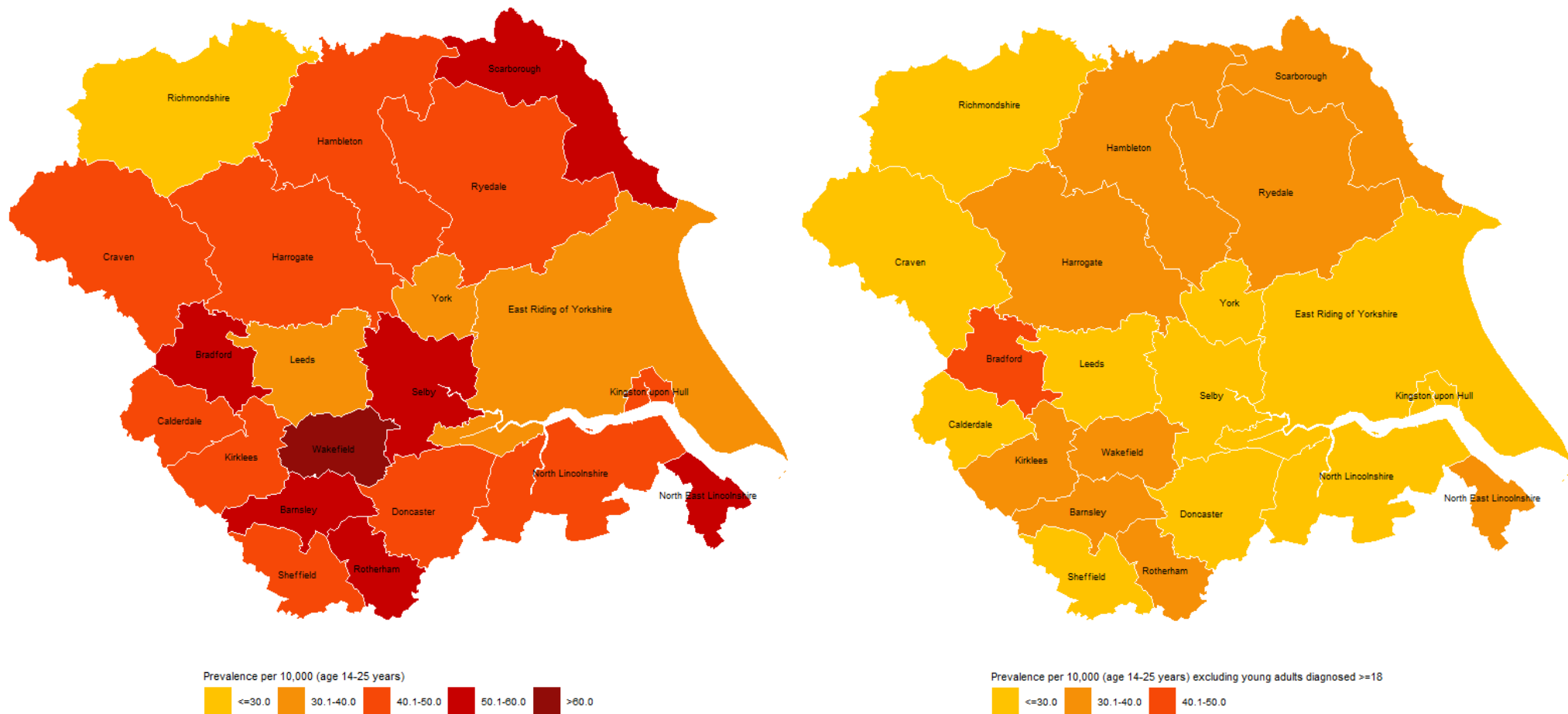


Figure 66 Prevalence per 10,000 of young people (aged 14-25 years) with a LLC by Local Authority in the Yorkshire and Humber Government Office Region for 2017/18

## Appendix 1

The annual probability of having an eligible condition was estimated using logistic regression. Age categories, sex, ethnicity and GOR were included as predictive variables. The regression formula is as follows:-

$$\log_e \left( \frac{P}{1-P} \right) = C + \beta_1 x_i + \dots \beta_i x_i + \beta_{y1} year + \beta_{y2} year^2$$

Where P is the probability of an individual of having an eligible condition, and  $x_i$  are the predictive variables, age group, sex, ethnic group and GOR.

In order to calculate the probability, a dataset was created with counts of individuals aged 14-25 years per year with an eligible condition for each unique permutation of sex, ethnicity, age group and GOR. This number was added to the dataset as variable "n". Each of these rows of data were flagged as eligible condition = 1/yes.

A similar process was followed to create counts of the population without an eligible condition. Thus, the number of individuals for each permutation of gender, ethnicity, age, GOR and were calculated for each financial year between 2009-2016 using the ETHPOP data. The count of individuals without an eligible condition was then calculated by subtracting the number of individuals with an eligible condition for that permutation from the population total for that same permutation. Replica rows of the demographic combinations were added to the dataset with the exception that the LLC flag was set to 0/No. The variable "n" was set as the weighting (the difference between the number of children in the whole population and those with an eligible condition for each demographic combination).

Logistic regression was used to estimate the probability of an individual, for each unique demographic combination, having an eligible condition in that year. Subsequently the regression model was used to predict the numbers with each unique demographic combination of individuals in years 2018-2030.

By multiplying the probability of having an eligible condition by the total estimated number of children with that unique combination of demographics from the ETHPOP data it was possible to predict the number of children with an eligible condition. The number of children in each unique demographic combination were summed to give annual totals of expected individuals with an eligible condition as per the formula below where  $N_{LLC}$  is the annual predicted number of individuals with an eligible condition,  $P_d$  is the probability of an individual of having an eligible condition for that unique demographic permutation (d) and  $N_d$  is the number of individuals predicted to be in that unique demographic permutation (from ETHPOP data).

$$N_{LLC} = \sum_d P_{LLC,d} \times N_d$$

Year terms were added to the model to reflect changes in probability of an individual having an eligible condition not explained by demographics, i.e. increases in survival and/or incidence rates of an eligible condition over time. Inclusion of a linear year term alone would result in predicted numbers with an eligible condition being forced to be monotonic with year (i.e. always increasing or always decreasing). Hence a quadratic year term was included.

A second model was made where a fixed year term (2017) was used. This model assumed that there were no further changes in survival or incidence.

The predicted prevalence (per 10,000) of young people with an eligible condition was calculated by dividing the predicted number of children with an eligible condition by the total population estimate and multiplying the result by 10,000.

## Bibliography

- Bland, J. M. (2015). Standard error and confidence interval for a proportion. An introduction to medical statistics. Oxford, Oxford University Press: 105-106.
- Chambers, L. (2015). Stepping up: A guide to developing a good transition to adulthood for young people with life-limiting and life-threatening conditions. Bristol, Together for Short Lives.
- Department for Communities and Local Government. (2011). "Indices of deprivation ", from <http://www.communities.gov.uk/communities/research/indicesdeprivation/deprivation10/>.
- Firth, C., E. Petherick and S. J. Oddie (2018). "Infant deaths from congenital anomalies: novel use of Child Death Overview Panel data." Archives of Disease in Childhood **103**(11): 1027-1032.
- Fraser, L. K., D. Gibson-Smith, S. W. Jarvis, P. Norman and R. C. Parslow (2020). "Estimating the current and future prevalence of life-limiting conditions in children in England." Palliative Medicine (In Press).
- Fraser, L. K., V. Lidstone, M. Miller, J. Aldridge, P. Norman, P. A. McKinney and R. C. Parslow (2014). "Patterns of diagnoses among children and young adults with life-limiting conditions: A secondary analysis of a national dataset." Palliative Medicine **28**(6): 513-520.
- Fraser, L. K., M. Miller, R. Hain, P. Norman, J. Aldridge, P. A. McKinney and R. C. Parslow (2012). "Rising national prevalence of life-limiting conditions in children in England." Pediatrics **129**(4): e923-929.
- Fraser, L. K. and R. Parslow (2018). "Children with life-limiting conditions in paediatric intensive care units: a national cohort, data linkage study." Archives of Disease in Childhood **103**(6): 540-547.
- Hain, R., M. Devins, R. Hastings and J. Noyes (2013). "Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions." BMC Palliative Care **12**(1).
- Health & Social Care Information Centre (2015). A Guide to Linked Mortality Data from Hospital Episode Statistics and the Office for National Statistics, Health & Social Care Information Centre.
- Health & Social Care Information Centre (2015). Hospital Episode Statistics - Admitted Patient Care - 2014-15.
- L.K., F., D. Gibson-Smith, S. W. Jarvis, P. Norman and R. C. Parslow (2020). 'Make Every Child Count' Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom. York: University of York. York, University of York.
- Murrey, C. L. J. and A. D. Lopez (1997). "Alternative projections of mortality and disability by cause 1990–2020: Global Burden of Disease Study." The Lancet **349**(9064): 1498-1504.
- NOMIS (2013). Census 2011 - Ethnic group by sex by age, NOMIS.
- Noyes, J., R. T. Edwards, R. P. Hastings, R. Hain, V. Totsika, V. Bennett, L. Hobson, G. R. Davies, C. Humphreys, M. Devins, L. H. Spencer and M. Lewis (2013). "Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar." BMC Palliative Care **12**(1): 18.
- Rees P., W. P., Norman P., Boden P. (2011). "A local analysis of ethnic group population trends and projections for the UK. Journal of Population Research." Journal of Population Research **28**: 149-183.
- Sheridan, E., J. Wright, N. Small, P. C. Corry, S. Oddie, C. Whibley, E. S. Petherick, T. Malik, N. Pawson, P. A. McKinney and R. C. Parslow (2013). "Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study." The Lancet **382**(9901): 1350-1359.
- Together For Short Lives (2018). A Guide to Children's Palliative Care. Bristol.
- Wohland P., B. M., Norman P., Rees P., Boden P., Durham H. (2016). ETHPOP database