

Together for Short Lives Briefing

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

Final Report: February 2021

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Background and Context

The previous prevalence study undertaken by Professor Lorna Fraser of the numbers of young people with life-limiting or life-threatening conditions was published in 2013. Together for Short Lives commissioned this new research to update the figures, and to provide evidence to support the development of new services to support these young people in transition to adult services. In particular we wanted to support services to develop business cases for sustaining and rolling out some of the models of transition that are being piloted through the Improving Transition for Young People Programme.

This briefing provides a summary of the key findings, mainly relating to those young people who are diagnosed in childhood and who will have made the transition from children's to adult services. You can read the research report [here](#)

What did the study set out to do?

The study set out to estimate the number and prevalence of young people (aged 14- 25 years) with life-limiting and life-threatening conditions in England and:

1. To assess trends in the prevalence of young people with life-limiting conditions in England aged 14-25 from 2009/10 to 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 life-limiting conditions in England, excluding young people diagnosed aged over the age of 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 with life-limiting conditions.
4. To quantify the proportion of young adults over 18 who were diagnosed as children and those who were diagnosed in adulthood and compare the prevalence by age group, diagnostic group, sex, ethnic group, deprivation and region.
5. To describe the number of young people with a life-limiting condition who die in England each year split by age of death, place 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.

Methodology

The 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. Young people aged 14-25 years were identified as having a life-limiting condition using a list of diagnostic codes (ICD-10) previously developed to identify children with a life-limiting conditions. The dataset contained **138,356** individuals over an eight-year time period (from 2009/10-2017/8).

Summary of Key Findings

1. The overall number of young people aged 14-25 with a life-limiting condition identified in this dataset from England rose from **27,316** in 2009/10 to **38,261** in 2017/18. (This includes those diagnosed in childhood and young adulthood.)
2. The numbers of young people with a life-limiting conditions **who were diagnosed whilst still in childhood** rose from **16,107** in 2009/10 to **24,773** in 2017/18.
3. The prevalence of young people with an LLC **who were diagnosed whilst still in childhood** rose from **19.7 per 10,000** in 2009/10 to **30.2 per 10,000** in 2017/18.
4. Prevalence was highest for **congenital, oncology and neurology conditions**. Among young people diagnosed as children, **congenital disorders** are also the most prevalent.

5. Prevalence was significantly **higher among females** (50.8) compared to males (42.8) per 10,000.
6. Prevalence of life-limiting conditions was highest amongst young people of **Pakistani origin (76.8 per 10,000)**. This is important in terms of flexibility of service to meet the needs of all young people.
7. More young people than expected with a life-limiting condition lived in **areas of higher deprivation** (24% most deprived versus 18% in least deprived). The deprivation categories were population weighted therefore you would expect ~20% of young people in each category to have a life-limiting condition.
8. The **age of diagnosis** has an impact on the clinical and demographic characteristics of this population. Congenital and neurological diagnoses are more prevalent in those diagnosed as a child, whilst oncology diagnoses are more prevalent in those diagnosed as adults.
9. **Six per cent** (8,301) of the young people with a life-limiting condition died (at any age) during the study period.
10. Overall, **most deaths occurred in hospital** (55-64%). Home deaths (31%) were more common among young people who died over the age of 25 years. The proportion of hospice deaths was higher in young adults aged 18 or over who were diagnosed as adults (10%) compared to those diagnosed as children (7%).
11. Although it is difficult to predict, it is estimated that the national prevalence of life-limiting conditions in young people (aged 14-25 years) will increase over the next ten years. The number had increased from **33.5 per 10,000** in 2009/10 to **46.7 per 10,000** in 2017/18 and is estimated to increase to up to 62.2 per 10,000 by 2030.

Interpreting the findings

When interpreting these findings, it should be noted that the diagnostic framework used to identify children with a life-limiting condition should be used with caution in the young adult population. Many of the cancer diagnoses in the young adult age group (for e.g. cervical or breast cancer) have very good outcomes. It should also be noted that these data do not indicate whether palliative care services were involved in the care of these young people. In addition, these data did not contain any measure of complexity of the underlying condition or the needs of the young person or family, future research and data collection should address this gap.

Together for Short Lives' Recommendations

1. With the increasing number of young people with life-limiting conditions, services should be developed to meet this growing need. Whether this is providing support to young people and their families from the age of 14 to plan for transition or providing age and developmentally appropriate services that can meet the complex needs of this group of young adults.
2. Services need to be developed to support the specific cultural needs of the population. So with higher prevalence of young people from ethnic minority backgrounds (in particular from Pakistani backgrounds) and those living in more deprived areas, services should take these particular needs into account.
3. In order to improve the availability of data on this population, Together for Short Lives recommends that the planned national data collection in the NHS England **All Age Palliative and End of Life Care Programme** should include information of young people who will require transition from paediatric to adult services.
4. Together for Short Lives calls on national and local governments to use the data to plan and fund the services that are desperately needed by this often-forgotten group of young adults.

Acknowledgements

We would like to thank the funders of the Improving Transitions for Young People Programme who very generously funded this research project, including St James Place and MariaMarina.