

BRIEFING ON THE 'MAKING EVERY CHILD COUNT' PREVALENCE STUDY

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Background & context

Since the publication in April 2012 of the original prevalence study undertaken by Professor Lorna Fraser¹ there has been anecdotal discussion about a seeming increase in the number and complexity of babies, children and young people living with life-limiting or life-threatening conditions (LLCs). As the national charity for children with life-limiting conditions and their families and the many professionals and services that support them, Together for Short Lives wanted to understand if there was evidence of a higher prevalence in order to inform the ongoing strategic development of the children's palliative care sector. We are grateful to the True Colours Trust for providing funding to enable Professor Fraser to carry out this research. The full report can be accessed [here](#).

What did the study set out to do?

To estimate the current prevalence of life-limiting and life-threatening conditions in children and young people in England, Wales, Scotland and Northern Ireland and to provide a future estimate of what the prevalence will be in 2030.

Methodology

The study used routinely collected Hospital Episode Statistics (HES) data linked to mortality data from the Office for National Statistics (ONS) in England from 1 April 2001 – 1 April 2017 for children aged 0-19 years. As in the previous study, life-limiting conditions were identified through an ICD-10 coding framework and was analysed by age, diagnostic group, sex, ethnicity, Government Office Region and deprivation level.

In Scotland data had been collected through the ChISP Study² from 1 April 2003 – 31 March 2015 and this previous analysis was used. Prevalence for Wales and Northern Ireland were based on the trends in Scotland.

The study's Advisory Committee wanted to see if the inclusion criteria could be narrowed to exclude conditions that were less likely to cause death in childhood and four conditions were excluded (perinatal diagnoses beyond the age of one, oncology five years post diagnosis, non-central nervous system oncology cases five years post diagnosis and early stage renal failure). This reduced prevalence only slightly from 66.4 per 10,000 to 63.2 per 10,000 in 2017/18.

The study looked at length of hospital stays over twenty-eight days as a proxy measure for complexity and also looked at the number of young adults in their nineteenth year.

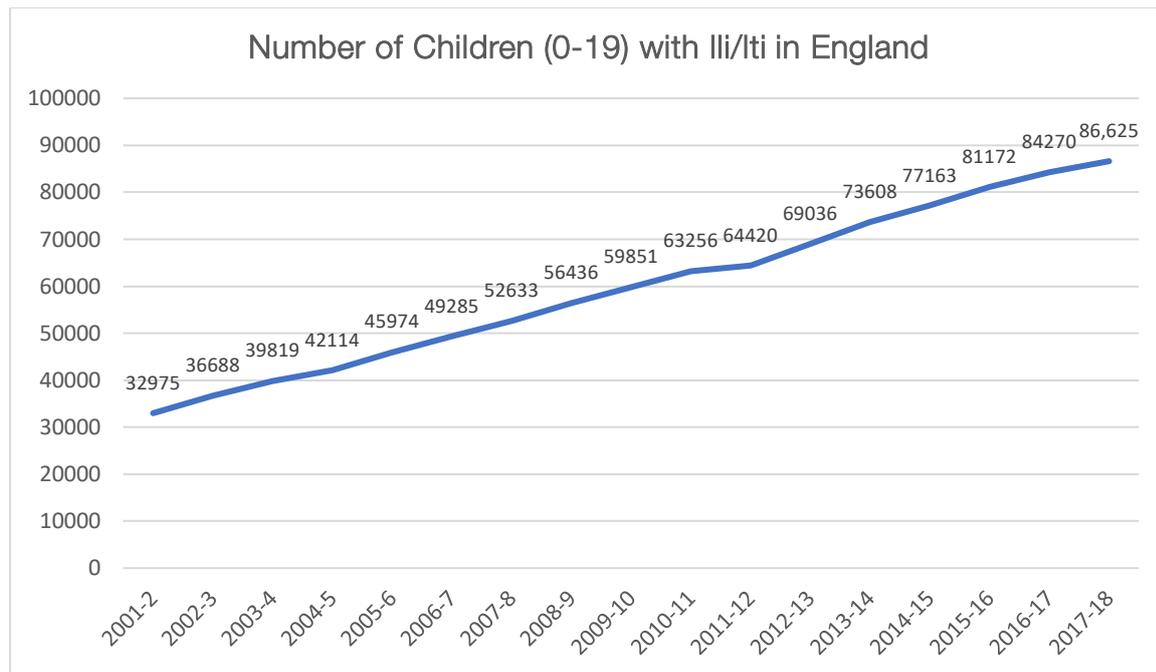
¹ Fraser L K et al (2012). Life-limiting and life-threatening conditions in children and young people in the United Kingdom: Final report for Together for Short Lives.

² Fraser LK et al (2015). Children in Scotland requiring palliative care. University of York.

Due to the uncertainty around predicting future prevalence, population projections were made to 2030 using three different models. Model one used the estimated numbers of children with LLC from 2004-16, Model two used these figures but with the four exclusions listed above and Model three assumed that there was no further change in survival and incidence.

Summary of the findings

In England, prevalence had risen from 32,975 in 2001/2 to **86,625** in 2017/18³.



In Scotland, the number of children living with LLC in 2018 was estimated to be **5,933**. In Wales, the number was estimated to be **3,650**. In Northern Ireland, the number was estimated to be **2,497**. The figures for Wales and Northern Ireland were extrapolated so not as robust as the data for England or Scotland.

Due to the different data sources being used it's not possible to combine these data for each country to get a robust UK-wide prevalence as was done in the previous study, which showed an overall figure of 49,000 affected children.

10.4% of children with LLC died during the study period and 8.4% of these died before the age of 20 (30,187). Many of these died in infancy (under one) but many were young adults.

It is estimated that there will be between 67.0 and 84.2 per 10,000 children living with LLC in England by 2030. Whilst in Scotland this is estimated to be 51.0-55.8 per 10,000, Wales 50.8-55.6 per 10,000 and Northern Ireland 52.6-56.5 per 10,000.

³ Excluding the four diagnoses (perinatal diagnoses beyond the age of 1, oncology 5 years post diagnosis, non CNS oncology cases 5 years post diagnosis and early stage renal failure) reduced the figure only slightly to 81,712.

Breakdown of data in England only

Male/Female

Prevalence of LLC was significantly higher in boys (72.5 per 10,000 compared to 60 per 10,000 girls).

Diagnostic groups

There was an increase in prevalence in all diagnostic groups. The most common of the 11 diagnostic groups was congenital abnormalities, which accounted for 31.2% of the total and more than twice the next most prevalent group, neurological conditions. The sharpest increase was for perinatal disorders which had a 6-fold increase.

Age groups

There was an increase in prevalence across all age groups. Prevalence was highest in the under one's. There was also a growing number of young people surviving to age nineteen - in 2002 the number was 921 and in 2017 it was 3,075.

Ethnic groups

LLCs were more prevalent in children from Pakistani origin and were lowest in those from Chinese origin. The rise in prevalence was similar across all ethnic groups.

Deprivation level

More children than expected with LLC lived in areas of higher deprivation (13% in the most deprived compared to 8% in the least deprived).

Government Office Region

Prevalence was highest in the North West and Yorkshire & Humber Government Office Regions and lowest in the East Midlands.

What this means for children's palliative care in the UK

The study shows that the overall number of children with life-limiting or life-threatening conditions has increased and is likely to continue to increase slightly year on year over the next decade. Whilst there is evidence that some of the increase is due to better recording of these diagnoses and new coding practice, there is also an increase in survival in this population. The methodology used does not identify the numbers of children who might actively require palliative care, but it does show the growing complexity of this group of children with more children spending longer in hospital.

What is clear is that there is a growth in overall numbers of children who may require some elements of a palliative care pathway and that we need to think about how best to reach these children and their families, especially for those from non-white British backgrounds, who live in more deprived areas of the country. There is also a need to ensure appropriate palliative care support for babies under the age of one and for young people who are negotiating the transition to adult services at a time when their health is deteriorating, as the growth in these two age groups is proportionally greater.

This all points to the need to look at developing models of care that reach out to this growing and more complex population, and their families, looking at how to support them not only clinically but with social and financial issues in a culturally appropriate way. The overall growth of children and young people with LLC/LTC demonstrates the need to develop skills in the core workforce, providing training on some of the core skills needed such as communicating honestly with families

about palliative care options alongside treatments aimed at cure or prolonging life. There is a need to develop closer links between children's palliative care and broader children's disability services.

Together for Short Lives will be looking to support further research that helps us to identify the number of children affected by conditions that mean that they will be actively requiring support from children's hospice and palliative care.