A Briefing on the Implications of the Report


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Introduction

This briefing considers the findings of the latest report from Dr Fraser et al which looks at the prevalence of life-limiting and life-threatening conditions within the population of young adults aged 18-40 in England. This important study was commissioned by Together for Short Lives and the full report can be viewed at this link:

This key document describes the background and context to the Report and highlight some of the key implications and considerations for those with an interest in supporting your adults with life limiting/life threatening conditions namely service providers, commissioners, national organisations and policy makers.

Background & context

A report by Fraser in 2011 regarding the prevalence of life-threatening conditions in the 0-18 age group in 2011 confirmed a steady increase in the number of young people in the 16-18 age group living with a life-threatening condition. Prevalence of life-threatening conditions increased from 16.3 -23.6 per 10,000 population of 16-18 year olds in England (over a 10 year period from 2000 to 2010). This report was the first to identify the numbers of children living with a potentially life-threatening condition and it highlighted a gap in knowledge relating to similar data about young adults over the age of 18.

Robust information about the numbers of young adults living with a life-threatening condition currently is required by a wide range of stakeholders engaged in supporting this population of young people. It is vital in anticipating and responding to their needs, as highlighted, for example, by the Commission into the Future of Hospice Care which calls for new models based on a population-based assessment of need.

In response to such calls, Together for Short Lives commissioned this new study from Dr Fraser at the University of York to look at the prevalence of life-threatening conditions in the young adult population aged 18-40.

The study should be read alongside other recently published research that helps build a broader evidence base about the complex picture of care required by young adults.
In particular, we recommend consideration of the findings and recommendations from:

- The STEPP Project led by Professor Bryony Beresford at the University of York Social Policy Research Unit which explored the elements of positive practice that supported a good transition from children’s to adult healthcare settings\textsuperscript{iii}.

- The research programme and subsequent report ‘Don’t Let me Down’ led by Marie Curie\textsuperscript{iv} and their most recent publication looking at the palliative care and end of life needs of the Black, Asian and Minority Ethnic populations in the UK\textsuperscript{v} which further adds to the picture.

This data will be useful at local, regional and national levels. The briefing makes some suggestions about its relevance to particular stakeholder groups, but this is simply a starting point. It is hoped that individual organisations will use the research to better understand the levels of need for care and support on the part of young adults and how these are best met.

**Methodology**

The study used routinely collected hospital inpatient data. Patients were identified from the inpatient hospital dataset by using the listing of ICD-10 disease codes that had been developed for the previous data study by Fraser et al. The data was examined to look at diagnosis, geography and demographics (age, gender, ethnicity and deprivation).

It should be noted that the study is looking at prevalence which can be defined as “the total number of cases of disease existing in a population. Prevalence is the total number of cases of a disease existing in a population divided by the total population.”

Data was only readily available for England and this report therefore reflects the prevalence in England only.

**Findings**

The findings from the data study raise as many questions as they answer, and further research is required to build on this learning. There are also some limitations within the methodology that make easy conclusions hard to reach. By way of example, it was not possible to differentiate between those young adults who were diagnosed in childhood and those who were diagnosed in adulthood, and by implication whether they required help in transition or not.

We have highlighted some key messages from the research which we believe are worthy of further reflection on the part of policy makers and service planners, commissioners and providers of services:

1. The numbers of young adults with life-threatening conditions are higher than previously thought. There were 55,721 young adults aged 18-40 living with a life-threatening condition in England in 2009/10. In the 18-25 year age groups there were 12,827 individuals living with a life-threatening condition in England in 2009/10. This is a small but not insignificant number of the total population of adults living with a life-limiting or life-threatening illness.
2. The numbers of young adults with life-threatening conditions are increasing. Over the ten years of data the prevalence increased from 26 – 34.6 per 10,000 population, which is an increase of 33%. Prevalence of life-threatening conditions differed by age group and increased with age. The data for 2009/10 showed the lowest prevalence was in the 22-25 age group (21.8 per 10,000), rising to 58.4 per 10,000 in the 38-40 age group.

3. There were a wide variety of conditions diagnosed in this population. Although oncology was by far the most common of the 11 disease groupings, the total number of young adults with one of the other 10 disease groupings was higher. It should be noted that many young adults with a cancer diagnosis will be cured and therefore may be less likely to need to use hospice or palliative care services.

4. The prevalence of life-threatening conditions was significantly higher in the Black (70.8 per 10,000) and South Asian (31.5 per 10,000) populations, compared to the White (25.7 per 10,000) or Chinese and Other (24.4 per 10,000).

5. The highest prevalence of young adults with life-threatening conditions is in the most socially deprived areas.

6. The data was analysed by Government Office region and there were marked differences between regions. Highest prevalence was in the North East, North West, Yorkshire and Humber, East Midlands, West Midlands and London. Lowest prevalence rates were in South West, South East and the East of England. The report contains a summary of findings for each region in section 7. Readers should consider regional variation alongside the national picture.

What does this mean?

This new report points to the fact that young adults with life-threatening conditions are a distinct population who have a particular need for age and developmentally-appropriate services. It is unlikely that all these young adults will require access to hospice or palliative care services, but all will need ongoing age-appropriate care and support in a variety of settings. We have set out below some key considerations for services, for commissioners, for the UK Transition Taskforce and other national organisations and for policy-makers:

For Services

This new report provides valuable data that service providers can use in conjunction with their local Joint Strategic Needs Assessment reports to assess the level of need of young adults in their locality. It is critical that this data is used to ensure that services are planned in a way that reflects the age, gender, ethnicity and levels of social deprivation of the local population. Consideration should be given at provider level to ensuring that services meet the needs of their population in economically deprived areas and where there are higher populations of Black and South Asian communities. Services in these contexts will need to consider how their resources are best targeted and services made accessible to people in these areas.

Providers should consider how they can improve their existing services to better cater for the needs of this distinct group. For example, the guidance set out in the STEPP Project
resources about the experiences of young adults in adult health care settings provides useful practice prompts that can be easily implemented to improve the experience of young adults.

For Commissioners

The numbers of young adults with life-limiting conditions are significant and growing, but still represent a minority in terms of overall commissioning for adult palliative and end of life care. Services will need to be commissioned over a large enough footprint to be sustainable. These young adults will need to have their health care needs met, but also their wider social care, educational, employment, leisure and housing needs if they are to live their lives as fully and independently as possible. Consideration needs to be given to joined up thinking about commissioning care and support for these young adults.

There is important demographic data in the study for commissioners and others planning and purchasing services in areas of deprivation.

The evidence relating to higher prevalence in Black and South Asian communities will be of particular relevance for commissioners, who will need to ensure availability and access to relevant services and consider improvements and developments of these services that reflect cultural preferences, working closely with these communities to achieve this.

For the UK Transition Taskforce & other national bodies/charities

This data provides the evidence to reinforce the need for Together for Short Lives and other national partners, such as Help the Hospices and the National Council for Palliative Care to continue to work together through the UK Transition Taskforce to build capacity, skills and resources that improve the experience of young adults, their families and carers. The research provides the Taskforce with the evidence it needs to call for services to be planned, coordinated and developed so that young adults with a range of life-limiting and life-threatening conditions are enabled to live their lives as fully and as independently as they are able.

The UK Transition Taskforce

Over the past year, Together for Short Lives has established a UK-wide Transition Taskforce to improve the experience of young people moving from children’s to adult services, drawing on research and best practice to develop practical advice, promote new partnerships and influence policy. The Taskforce is a collaboration that aims to build bridges and develop new approaches between children’s and adults services to address the needs of this population of young adults. This new study by Fraser will be highly valuable to the Taskforce as it builds greater understanding about this group of people and their needs.

Over the coming months the Taskforce will be continue its programme of work to establish Regional Action Groups across the UK to look at gaps in service provision within regions for this population and to bring children’s and adult service providers together to develop new approaches to adapting and developing services to meet their needs. We will be developing tools and resources, such as a new Transition Care Pathway to ensure that there is a coordinated and young-person centred approach to providing care and support across the spectrum of a young person’s needs. We will also be developing guidance for commissioners about effective commissioning of services for young adults with life-limiting or life-threatening conditions.
Further information about the Transition Taskforce can be found at www.togetherforshortlives.org.uk/professionals/projects/transition_taskforce

To become involved in the Transition Taskforce email transition@togetherforshortlives.org.uk

For Policy Makers

This study provides evidence of the growing number of young adults with life-limiting and life-threatening conditions and is confirmation that their needs should be addressed as a priority. All new government policy relating to children’s and adult palliative care should reflect this new data. National funding support will be needed to enable the development of specific services to support these young adults.

Acknowledgements

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3 Beresford B, SPRU, the University of York: STEPP Project resources http://www.togetherforshortlives.org.uk/professionals/projects/project_two


5 Marie Curie, Palliative and End of Life Care for Black, Asian and Minority Ethnic Groups in the UK http://www.mariecurie.org.uk/en-GB/who-we-are/Diversity-and-inclusion/?Tab=2