SUMMARY:

13-24 YEAR OLDS WITH CANCER IN ENGLAND: INCIDENCE, MORTALITY AND SURVIVAL (2018)

INTRODUCTION

In 2016 Teenage Cancer Trust funded a data analyst hosted by the National Cancer Registration and Analysis Service in Public Health England in order to gain a greater understanding of the current cancer landscape of teenagers and young adults. Teenage and young adult cancer data has typically been captured across varying age brackets – this report has enabled Teenage Cancer Trust and Public Health England to publish data for the first time about the 13-24 age group that we support.

Information on young people aged 13-24 years diagnosed in England between 2001 and 2015 was extracted from the National Cancer Registration and Analysis Service (NCRAS) and compiled into the report ‘13-24 year olds with cancer in England: Incidence, mortality and survival’ (2018).

This document is a Teenage Cancer Trust summary of the key points outlined within the full report.

HEADLINES

1. Incidence of cancer in 13-24 years olds in England has increased from a crude rate of 233.1 per million in 2001, to 299.7 per million in 2015
2. Mortality rates of all cancers combined in 13-24 year olds have decreased from 42.9 per million in 2001 to 32.3 per million in 2015
3. Five-year survival rates for cancer in 13-24 year olds have risen from 83% females / 80% males in (2001-05) to 87% in females / 84 % males (2007-11)
4. There are statistically significant variations in incidence and survival rates of cancer in 13-24 year olds based on geography and deprivation.
1. INCIDENCE

Incidence rates are about how many people get diagnosed with cancer. In this report cancer incidence is measured per million population.

The types of cancer that affect teenagers and young adults are different to those diagnosed in older adults and they are therefore most usefully presented in terms of morphology (cell/tissue type of origin and type of cancer) than the site of tumour and is known as the Birch Classification Scheme.

Incidence of cancer in 13-24 years olds has increased from 2001-2015

As a proportion of overall cancer incidence in all ages, cancer in young people is rare: less than 1%.

In England, between 2013-2015, on average 2,397 young people in England were diagnosed with cancer.

The study shows that age specific crude rates of cancers in 13-24 year olds has increased in England from 233.1 per million in 2001, to 299.7 per million in 2015.

The reasons for this rise in overall incidence include:

• A near doubling of thyroid carcinoma cases due to a rise in papillary thyroid cancer (continuing a worldwide trend of increasing thyroid cancer incidence evidence since 1970s)
• The reclassification of appendiceal carcinoids from 2011 from non-malignant to malignant
• A dramatic increase in cervical cancer in young women aged 24, coinciding with a lowering of the age at first invitation to cervical cancer screening in 2012 from 25 to 24.5 years (cf. ‘Is the recent increase in cervical cancer in women aged 20-24 years in England a cause for concern?’ Castanon and Sasieni (2018))
• These increases in the Carcinoma diagnostic group means that Carcinomas are now the most common cancer group, overtaking lymphomas, in teenagers and young adults with cancer since 2011
There are gender based variations in incidence of cancer and its type in 13-24 year olds

The study shows that incidence of all cancers in teenagers and young adults is significantly higher in females (1,235 on average between 2013-2015) than in males (1,162 on average between 2013-2015). When we consider the incidence rates together (across genders) young people overall are most likely to get carcinomas (24%) or lymphomas (19%), but when comparing between the sexes the distribution is different.

In females, carcinomas were much more frequent (36%), particularly thyroid carcinomas and carcinomas of the colon and rectum. Skin cancer rates were also significantly higher in females compared to males.

In men, germ cell tumours (21%) were the most common, with testicular cancer making up 93% of these.

Incidence of cancer in the 13-24 years old age group increases with age

Incidence for all cancers combined in 13-24 year olds increased with age, with more than two thirds of diagnoses in 19-24 year olds. Some cancers have relatively even incidence across all ages, some become more common with age, others less common.

Between 2013-2015 the incidence rate for 13-24 year olds was 298 per million overall, however this was down at 171 per million amongst the 13-15 age group, 240 per million amongst 16-18 year olds and up at 379 per million amongst the 19-24 year olds.
2. MORTALITY

Mortality rates were calculated for people aged between 13 and 24 at the time of death, who were resident in England at diagnosis, and who died between 2001 and 2015.

**Mortality rates of all cancers combined in 13-24 year olds have decreased from 2001 to 2015**

In contrast to incidence, the age specific mortality rates of all cancers combined in 13-24 year olds in England have decreased from 42.9 per million in 2001 to 32.3 per million in 2015.

On average, between 2013-2015, there were 255 deaths annually.

The decrease in mortality rates over time has occurred across all of the three inner age bands that the study refers to (13-15, 16-18, 19-24).

![Crude mortality rates per 1,000,000 population for 13-24 year olds by year of death](image)

**The largest reduction in mortality between 2001 and 2015 has been in leukaemia**

The largest reduction in mortality by diagnostic group in England, between 2001 and 2015, came in leukaemias. There were also reductions seen in mortality from CNS tumours, bone cancer and in lymphoma.

**The largest number of deaths were from Central Nervous System (CNS) tumours**

Despite the reduction in crude rates of mortality from Central Nervous System cancers across the time period of this study, this diagnostic groups remains the most likely cause of death by cancer in young people in England.
In recent years, more males died of cancer than females in the 13-24 age group.

Between 2013-15 there were a higher average number of male deaths and a higher crude mortality rate per million in males than in female young people.

There were on average 142 male teenage and young adult deaths annually, with a crude rate of 35 per million, whilst there were 113 female teenage and young adult deaths at a crude rate of 29 per million.

3. FIVE-YEAR SURVIVAL

Five-year survival considers how many young people per million have survived five years after they were diagnosed with cancer.

Five-year survival rates for cancer in 13-24 year olds have improved since 2005

For 13-24 year olds diagnosed in England between 2007-11, five year survival rates have improved against those who were diagnosed between 2001-05.

In 2007-11 five-year survival rates in females were at 87%, whilst they were at 84% in males. This is an improvement from the period of 2001-05 where in females it was 83%, and males it was 80%.

There was significant improvement in five-year survival in certain diagnostic groups

Within the improvements in five-year survival rates for all diagnostic groups combined, there were significant improvements in the leukaemia, lymphoma, bone and carcinoma cancer types for 13-24 year olds who were diagnosed in England between 2001-2005 and 2007-2011.
4. REGIONAL VARIATIONS

To study regional variation, the report breaks the cases down by Cancer Alliance. This was done by assigning the postcode at diagnosis to the Cancer Alliance geographical regions. The study also categorised cases by level of deprivation. This was done by assigning the postcode of residence at diagnosis to its respective ‘Lower Super Output Area’.

There were large regional variations in the number of cases diagnosed when broken down by Cancer Alliance

There was a large variation in the average annual number of cases diagnosed in each Cancer Alliance region with West Midlands and East of England having much larger burdens in this age group. However, it is important to note that this is heavily dependent on the size of the population within the Cancer Alliances.

When considering crude rates there was much less variation by region. However, for the 13-15 year old bracket, the regions with the highest incidence rates, West Midlands (201 per million) and North East and Cumbria (198.6 per million) were almost double those with the lowest rates, South East London (103 per million) and Lancashire and South Cumbria (123.6 per million).

For 16-18 year olds, Wessex (179) and North Central and North East London (202.3) had the lowest rates, with the highest in Cheshire and Merseyside (335.6) and North East and Cumbria (430.45).

For 19-24 year olds Wessex (322.9) and East Midlands (329.6) had the lowest rates, with the highest in North West and South West London (443) and Cheshire and Merseyside (430.5).

As expected, the areas assigned to each Cancer Alliance with the highest incidence of teenage and young adult cancer also had the highest number of deaths due to cancer, but there was some variation in the ratio of death between the three age bands. There were no significant differences in crude mortality rates across Cancer alliances.

Five-year survival improved significantly in certain Cancer Alliance areas

Five-year survival of 13-24 year olds improved significantly from 2001-05 to 2007-11 in the following Cancer alliances: Surrey and Sussex, Cheshire and Merseyside and Greater Manchester. Patients in the Thames Valley had significantly higher five-year survival than nine of the other cancer Alliances for teenage and young adults diagnosed between 2007-11.

These differences may be statistically significant. However, without taking into account distributions of gender, cancer type, ethnicity and deprivation between Cancer Alliances, it is not possible to say these are necessarily caused by service provision within them.

Patients in the least deprived quintile had significantly higher five-year survival

Patients aged 13-24 years diagnosed in England between 2007 and 2011 in the least deprived quintile had significantly higher five-year survival than those in Quintile 2 (second least deprived), and in the most deprived quintiles.
<table>
<thead>
<tr>
<th>Deprivation Quintile</th>
<th>Five-year survival</th>
<th>95% CIs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - least deprived</td>
<td>88%</td>
<td>87% - 90%</td>
</tr>
<tr>
<td>2</td>
<td>85%</td>
<td>83% - 86%</td>
</tr>
<tr>
<td>3</td>
<td>86%</td>
<td>84% - 87%</td>
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<tr>
<td>4</td>
<td>84%</td>
<td>82% - 85%</td>
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<tr>
<td>5 - most deprived</td>
<td>84%</td>
<td>82% - 85%</td>
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There were significant variations in incidence by diagnostic group when grouped by level of deprivation

The study showed that there were some significant variations when cases were grouped by area deprivation quintiles. These variations occurred in the following diagnostic groups: carcinomas, skin cancers and leukaemias.

- The incidence rate for carcinomas was significantly higher in the two most deprived quintiles compared to the least deprived quintile.
- The incidence rate for skin cancers was significantly higher in the two least deprived quintiles when compared to the two most deprived quintiles.
- The incidence rate for leukaemias was significantly higher in Quintile 2 (second least deprived) than in Quintile 4 (second most deprived).

**CONCLUSIONS**

1. Over the period of the study it is clear that there have been improvements in both the mortality and five-year survival rates of 13-24 year olds diagnosed with cancer. These improvements coincide with the publication of NICE Guidelines on ‘Improving outcomes in children and young people with cancer’ (2005). The model of care implemented through the introduction of these Guidelines is one which Teenage Cancer Trust has invested in to ensure every young person with cancer has access to the care and support they need. Teenage Cancer Trust has long supported the policy framework for the best delivery of teenage and young adult cancer services, from the development of the NICE Improving Outcomes Guidelines in 2005, through to representing young cancer patients to the NHS and decision-makers, including being members of the NHS England Clinical Reference Group for Children and Young People with Cancer.

We are committed to continue our work to ensure young cancer patients have access to the services that will best meet their needs and improve their outcomes. As incidence rates continue to rise in line with the research here, we are calling for the teenage and young adult specialty to be sustained and developed to continue to improve outcomes and meet the growing need in future years.
2. The reduction in the number of deaths and improvements in five-year survival is hugely encouraging. In both mortality and survival Acute Lymphoblastic Leukaemia contributed to these changes - coinciding with a clinical trial which improved survival rates by 18% (cf. ‘Are survival and mortality rates associated with recruitment to clinical trials in teenage and young adult patients with acute lymphoblastic leukaemia? A retrospective observational analysis in England’ - Hough et al (2017)). These improvements are significant and demonstrate just how important access to appropriate clinical trials can be to improve outcomes and save lives of young people with cancer.

Figures suggest that currently only around 30% of teenagers aged 15-19 and 14% of young people aged 20-24 enter trials for common cancer types in children and young people. This is compared to a rate of 50-70% of children (cf. ‘Giving more young people with cancer the opportunity to take part in clinical trials’ – Teenage Cancer Trust (2014)). As the study illustrates, some rises in incidence are attributable to the lowering of the age for cervical screening in females in England. If lowering the age of invitation to screening by just half a year can identify cancer earlier then we call for more to be done to investigate opportunities and methods to identify cancers earlier - like self-sampling and awareness campaigns. We appreciate we are yet to see the impact of the roll out of the HPV vaccine and call for further data analysis as the school cohorts for HPV can be tracked.

Teenage Cancer Trust has long called for young people with cancer to have far greater access to clinical trials and we will continue to work with partners to realise further improvements. It is critical that access to clinical trials is championed, and this inequality addressed to drive forward every improvement possible for young people with cancer and ensure that every life that can be saved is saved.

3. With increasing survival there is a greater need to look at the long-term effects of cancer on young people as they move into adulthood. More work is needed to support and service the needs of young cancer patients as they move on with their lives, and more research is needed to understand the ongoing impact of having had cancer for health, social and economic outcomes. It is significant that whenever young people are asked what was most important or lacking in their cancer care, they consistently speak about their post treatment. Teenage Cancer Trust’s Youth Advisory Group (September 2018) identified mental health as the area they were least satisfied with about their care, with the majority saying there was little or no mental health support available for them. Those who had been given mental health support described it as ‘invaluable’. Similarly, a 2018 survey for Teenage Cancer Trust revealed that 8 in 10 young people with cancer found the mental health impact of a diagnosis as difficult as the physical side.

4. This work is the first analysis of the incidence, survival and mortality trends of the 13-24 year old age group specifically, as well as the first publication on teenage and young adults incidence, survival and mortality since Cancer Research UK and the National Cancer Intelligence Network ‘Cancer Statistics Report’ (2013). Whilst this report is based on data from England, it is important that data from Northern Ireland, Scotland and Wales is used in a similar way to give a comprehensive picture of cancer incidence, mortality and survival amongst teenagers and young adults in the United Kingdom.

There are statistically significant variations of incidence and cancer type based upon geography and levels of deprivation. This study is not able to attribute causes to this, nor determine the role that regional services have played either negatively or positively here. Understanding the causes of regional variation and their respective services at a deeper than surface level should be a priority in order to drive long term improvement in outcomes. It is clear that there is a huge need for continued, further analysis of young people’s cancer data and we call for a greater focus on this going forward to ensure we are all doing all we can to improve service delivery, influence service and policy based on evidence.