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Teenage Cancer Trust response to Cancer Taskforce consultation on a new Cancer Strategy for England

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Introduction to Teenage Cancer Trust

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them.

Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work to significantly improve their diagnosis experience. And through our own research and working with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people.

The three commitments that you would like to see in a new cancer strategy that would significantly improve cancer services for patients/the health of the public, referencing any relevant evidence and costing information

1. Protect teenage and young adult cancer care specialism

Every year around 2,500 young people aged 13-24 are newly diagnosed with cancer in the UK, around 2,000 in England alone¹. Approximately the same number will continue to receive care or will relapse which makes up for a very distinct group of cancer patients.

Cancer kills more young people in the UK than any other disease and survival varies greatly between cancer types, from 96% 5 year survival for some germ cell tumours to just 56% in bone cancers². The types of cancers that are seen in teenagers and young adults tend to be different to those that occur in children or adults. This combined with the unique psychosocial needs of young people, means that they require and benefit from being viewed as a discrete patient group.

Over the last 10 years there has been increasing recognition of the specific needs of teenagers and young adults with cancer:

- NICE CYP IOG (2005)
- NICE TYA Quality Standard
- NHS England TYA Clinical Reference Group

¹ North West Cancer Intelligence Service (2013)

² Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

As well as growing recognition of the specific needs of young people across all services:

- Chief Medical Officer's 2012 Annual Report 'Our children deserve better: prevention pays'
- Public Health England's framework for improving young people's health and wellbeing

Young people tell us that they have better experiences of care if they have access to specialist staff and services³. We will soon be releasing information about work we've done into aspects of care most important to young people with cancer and can share this work with the taskforce once completed. This work is important because young people under the age of 16 are currently excluded from patient experience measures such as the National Cancer Patient Experience Survey.

It's critical that we listen and respond to what young cancer patients need and that this relatively new specialty is protected so it's embedded in the framework of cancer services. The UK has developed a world leading services for young people with cancer and this should not be lost or eroded.

Recommendation: teenagers and young adults with cancer must be represented in the new cancer strategy as a distinct group requiring distinct services, structures and delivery. This will require continued investment in young people's age appropriate cancer services through specialist commissioning and investment in measuring outcomes from a patient perspective.

2. Improvement areas along the care pathway

Prevention and early diagnosis

1 in 4 young people with cancer have to visit their GP four times or more before diagnosis and 1 in 3 are diagnosed through A & E⁴. It is critical that we equip young people with the knowledge and skills to advocate for their own health needs as well as understanding about how to prevent cancer. As well as equipping GPs and other health professionals with the information, tools and resources they need to recognise and diagnose cancer early.

Educating young people about cancer in schools works; Stirling University have carried out an independent evaluation of Teenage Cancer Trust's education programme and found that the school talks increased the recognition of the number of cancer risk factors and warning signs and improves confidence to seek help when there are concerns⁵. Our education programme provides education and advice about the signs of cancer, cancer treatment and prevention, healthy living and sun safety to 130,000 pupils across the UK each year. Young people also share the information they learn with their families meaning that this one intervention has a huge reach. We will submit findings of the evaluation to the taskforce once completed.

Recommendation: the cancer strategy should include a commitment of educating young people about cancer in schools preparing all young people with skills to help themselves and others.

Age appropriate care and access to treatment

NICE Guidance stipulates that after diagnosis young people with cancer should be notified to their Principal Treatment Centre (PTC) where Teenage Cancer Trust units are located and which host the

³ Teenage Cancer Trust (2012), Young Voices and National Cancer Patient Experience Survey results

⁴ Teenage Cancer Trust (2011), Find Your Sense of Tumour Conference Survey [Data available on request]

⁵ University of Stirling (2011), Teenage Cancer Awareness Study

Teenage and Young Adult Multi-Disciplinary Team (MDT), yet currently on average only around half of all young people with cancer are notified⁶.

Teenage Cancer Trust in partnership with the NHS has successfully trialled an outreach service in the North West of England with huge success. The pilot included the Principal Treatment Centre in Manchester (The Christie) and 18 designated hospitals across the region.

A range of specialist staff were put in place to support young people wherever they were treated, both at hospital and at home. Under the new service model all young people with cancer, wherever they're located, are offered age specific support. As a result patient experience has demonstrably improved, notification to the Principal Treatment Centre has increased, and relationships with designated hospitals have improved.

This service model has been independently evaluated by The Centre for Children and Families Research at Coventry University. The evidence of impact provided will help support roll out of the service nationally, and we've enclosed this with our submission.

Young people with cancer also face specific barriers in accessing clinical trials and new treatments. Only around 30% of young people aged 15-19 and 14% of young people aged 20-24 enter clinical trials for common cancer types in children and young people compared with 50-70% of children⁷.

Recommendation: the cancer strategy must reflect the need for improvements in data about young people with cancer so the NHS can measure access to care, clinical trials and the impact of treatments. It's also critical to have a strong framework for commissioning of new models of care as evidence is generated about their effectiveness.

Support for life during and after treatment

Nearly 17,000 TYAs are living up to 20 years after initial diagnosis of cancer⁸. 50% of young people say they built up debt as a result of cancer, and prolonged absences from education disadvantage young people's educational attainment and career prospects.

We need to ensure that services can provide holistic support for young people with cancer both during and after treatment. Young people who survive cancer will have much to contribute to society and need the right support to ensure having cancer doesn't impede their potential.

Teenage Cancer Trust is now piloting post treatment support programmes in 4 regions across UK. Evidence from young people demonstrates that many are struggling to move beyond cancer and require support to do so.

Recommendation: the cancer strategy should include a survivorship programme that includes the specific needs of young people with cancer and their families, working across public service areas including e.g. benefits, education, employment and health.

⁶ O'Hara C, Khan S, Flatt G, North West Cancer Intelligence Service (2011), How many teenagers and young adults with cancer are being referred to specialist care in England?

⁷ Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

⁸ NCIN and Macmillan (2013), Segmenting the cancer survivor population

3. Work in partnership

We believe it's critical that the NHS recognises the value the voluntary sector brings to cancer services and work in partnership with charities to develop and deliver the best services for people with cancer.

As a charity we have invested millions into the NHS to ensure that together we can deliver the best services for young people with cancer. It's important that this investment and partnership working is recognised and enabled to provide the best for all cancer patients.

Recommendation: ensure the cancer strategy highlights the role of the voluntary sector working alongside public services in delivering cancer services.

Examples of good practice in cancer services that you would like to see replicated across the country

As previously highlighted, Teenage Cancer Trust has just completed an evaluation of a nursing and support model of care which has enabled us to reach all young people with cancer in the North West region. We will submit the report from this evaluation. This is an example of good practice of how the voluntary sector can work alongside the NHS to ensure all patients have access and choice to services that meet their needs.

We have also invested in work around measuring young cancer patient's experiences of services and how they are meeting their needs. This work, carried out by Experience Engineers, is just in the process of being finalised and we will be able to send information about this to the taskforce once completed. Attached is a summary of key findings along with our key messages about our new model of care.

The biggest barrier to improving cancer services

- Lack of good data about young people with cancer
- Lack of national structures to implement better service delivery
- Lack of relevant patient experience measurements:
- Lack of focus provided by a national strategy on cancer