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Teenage Cancer Trust response to Health Select Committee Inquiry into Expenditure on Health and Social Care

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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.

Cancer is the most common cause of non-accidental death in young people, and five-year survival rates remain lower in teenagers than in children¹. 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.

Overarching comment

- Teenage and young adult cancer services have been provided by Teenage Cancer Trust in collaboration with the NHS to a world leading standard since 1990
- The services resulting from this partnership deliver outcomes which are important to young people and are aligned with NHS Outcomes and the Mandate
- Successful collaboration between the NHS and the voluntary sector must be supported and maintained despite financial and other pressures on the health system.

Teenage and young adult cancer care and the voluntary sector

Traditionally treated alongside children or elderly patients at the end of their lives, young people often feel extremely isolated during cancer treatment, some never meeting another young person with cancer. To address this, over the past 24 years Teenage Cancer Trust has funded and built age appropriate units in NHS hospitals. The units enable young people with cancer to access the best possible care delivered by specialist staff in an environment suited to their needs. This means that young patients are treated by cancer experts who are used to dealing with teenagers and the types of cancer they get, as well as helping them meet other young people going through the same thing so they can share their experiences and support each other.

¹ Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

In 2005, the National Institute for Health and Clinical Excellence (NICE) published their guidance on Improving Outcomes for Children and Young People with Cancer² which recognised the Teenage Cancer Trust model as the best care option for teenagers and young adults with cancer in England. Similar and complementary guidance is in place across Wales, Scotland and Northern Ireland.

The guidance stipulates that all young people with cancer should be notified to the Teenage and Young Adult Multi-Disciplinary Team (TYAMDT) at their nearest Principal Treatment Centre, where Teenage Cancer Trust units are based, in order to ensure they can access the best possible treatments and specialist support.

As a result, in the last decade our specialist services have grown significantly, from just seven Teenage Cancer Trust units in 2004 to the current 28 at Principal Treatment Centres across the UK. We also fund almost 50 health professionals, including Youth Support Coordinators, Lead Nurses and Clinical Nurse Specialists. These professionals are experts in the delivery of age specific cancer care, and provide support to thousands of young people with cancer every year.

Teenage Cancer Trust's funding for these services ranges from entirely developing a build and service to the value of £3.5million, to contributions of a minimum of £100,000 depending on the infrastructure and needs of the NHS hospital. We also support research services to the value of £300,000 which would be unlikely to exist within the NHS without this funding.

Impact and outcomes

2,100 young people are diagnosed with cancer every year in England, while approximately the same number again will continue to receive care for cancer or relapse³. And there are 26,731 people in the UK living up to 20 years after being diagnosed aged 15-24⁴.

These patients may be treated at Principal Treatment Centres for cancer, or they may receive care within a local or designated hospital. As already highlighted, in line with NICE guidance teenage and young adult specialist care facilities should now be accessible by all 13-24 year old cancer patients, with those aged up to 18 years being managed at a Principal Treatment Centre (PTC) and those aged 19 to 24 years being assessed at a PTC and being given the choice of where they are treated. Yet nationally this only occurs in around half of all cases⁵, meaning Teenage Cancer Trust are providing services for approximately 50% of all young people with cancer.

Age appropriate care for young people can improve their experience and safety outcomes. For example, being treated in a Teenage Cancer Trust unit means young people have expert psychosocial care and support, improved access to clinical trial entry and benefit from effective collaboration and communication between all teams involved in their care.

² National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer

³ North West Cancer Intelligence Service (2013)

⁴ Macmillan and NCIN 'Segmenting the cancer survivor, 1991 -2010' accessed April 2014

⁵ 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?

Young people with cancer say quality of life is just as important to them as survival⁶. These outcomes are now recognised across the NHS with equal weight given to quality of life as well as clinical outcomes⁷. Our units and staff work to provide the best quality of life for young people with cancer during and after treatment.

The services and outcomes delivered by Teenage Cancer Trust services are also in line with NHS outcomes, including those set out in the Mandate and the Outcomes Framework such as ensuring that people have a positive experience of care and supporting people with on-going health problems to live healthily and independently.

Teenage Cancer Trust units and staff directly support access to treatments by providing access to the best treatment as quickly as possible, ensuring there is better adherence to treatment as young people are more engaged and providing the infrastructure to administer and manage clinical trials.

Our units are also a hub of expertise around which a specialty has grown. As a result there is greater focus on how young people with cancer are treated, their response to treatment and development of approaches to treatment specifically for them.

Threats

Teenage Cancer Trust works in partnership with the NHS to deliver our services to teenagers and young adults with cancer, so everything we do is set within the wider context of the resource, care and support provided by the NHS. This means that pressures in the NHS may also impact on the services we deliver, and as a relatively new speciality, teenage and young adult cancer care is particularly vulnerable to changes in the NHS where expertise and focus have changed.

One key concern is NHS England's specialised commissioning budget which is overspent by approximately £400 million. It's critical that the referral pathway for teenagers and young adults continues to be secure in the NHS and 100% of young people are notified to the services at Principal Treatment Centres as part of standard cancer care.

There has also been a loss of focus on cancer at a national level, and political agendas often cite the aging population and managing long term conditions as their focus for the health service. It's important that good practice, whether from the voluntary sector or elsewhere, is embedded in the NHS to ensure that pressures in the system don't lead to a backward direction of travel for young people with cancer.

Furthermore, in order to ensure continued high quality services are delivered whether by the voluntary sector or the NHS, it's vital that robust quality assurance tools are in place. The Cancer Quality Improvement Network system's National Cancer Peer Review programme provides valuable information on patient safety, particularly for areas of specialist care. We have strong concerns that the proposed changes to Peer Review, moving towards focusing on hospitals in special measures and using greater self-review, risks impacting on patient safety. There have been big steps forward in

⁶ Taylor, R. 'Brightlight the 2012 TYA cancer cohort study' presentation given to Teenage Cancer Trust which states that 149 TYAs were asked what were the most important outcomes to them and 73% responded that quality of life and survival are equally important

⁷ For example, the [Cancer Patient Experience Surveys](#) run by the Department's of Health in England and Wales, Patient Experience Quality Performance Indicators in Scotland, the [NHS Outcomes Framework](#) in England which has 2 domains on patient experience and quality of life and 1 domain on survival, and the [NICE Improving Outcomes Guidance](#) with its focus on outcomes not specifically survival

developing services and standards for commissioning specialised services such as those for young people with cancer, and these must be held to account via a robust Peer Review process regardless of who they are provided by.

The future

As experts in the field of teenage and young adult cancer care, we will continue to seek out new opportunities to provide the best care for young people with cancer in partnership with the NHS.

One example of this is Teenage Cancer Trust's Nursing and Support service model in the North West of England, which is providing age appropriate outreach services in line with NICE Guidance to reach 100% of local young people with cancer. Integrated commissioning models for specialised services such as these are vital in providing joined-up care and delivering evidence based interventions which are both clinically effective and economically sound. This service model is currently being evaluated to ensure it meets its aim of reaching all young people with cancer, and we plan to roll it out across other regions in the near future in partnership with local NHS services.

The success of this pilot, and our existing national services for young people with cancer, are testament to the positive benefit that can be achieved when the NHS and voluntary sector work in partnership. It's vital that the significant progress that has been made in teenage and young adult cancer care over the past 25 years is continued in future.