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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal  
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Ymddiriedolaeth Canser yr Arddegau

Response from: Teenage Cancer Trust



www.teenagecancertrust.org

## Teenage Cancer Trust response to Health, Social Care and Sport Committee consultation on priorities

Contact: Caroline Brocklehurst, Policy Manager, Teenage Cancer Trust  
c.brocklehurst@teenagecancertrust.org  
020 7612 0724

### 1. Introduction to Teenage Cancer Trust

- 1.1 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, including specialist nurses and Youth Support Coordinators. The units bring young people together so they can be treated by teenage cancer experts in the best place for them.
- 1.2 Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we seek 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.
- 1.3 Around 2,500 young people are diagnosed with cancer each year across the UK<sup>1</sup>. In Wales approximately 114 new patients will be diagnosed annually, while around the same number again will continue to receive care for cancer or relapse<sup>2</sup>. These patients will be treated at the Teenage Cancer Trust unit at the Principal Treatment Centre for cancer, University Hospital Wales in Cardiff, or they may receive care within a local hospital.
- 1.4 We are proposing one key area for the Health, Sport and Social Care Committee to consider for its future work programme. Improving access to age-appropriate services for teenagers and young adults with cancer will make a significant, positive impact on the lives of young cancer patients in Wales and we would welcome the Committee's attention on this matter.

### 2. Access to age-appropriate services for young people with cancer

- 2.1 In 2005, the National Institute for Health and Clinical Excellence (NICE) published their guidance on Improving Outcomes for Children and Young People with Cancer<sup>3</sup> which is recognised as best practice across England and Wales. The guidance stipulates that, following diagnosis, all young people with cancer should be notified to the Teenage and Young Adult Multi-Disciplinary Team (TYAMDT) at their nearest Principal Treatment Centre, in order to ensure they can access the best possible treatments and specialist support. The importance of this pathway was also highlighted in the 2012 National Standards for Cancer in Teenagers and Young Adults (TYA) in Wales. Providing a framework for the delivery of NICE Guidance for this age group, the TYA Standard lays out areas for focus across the whole care pathway for young people with cancer, including staffing needs and treatment requirements.

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

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

<sup>3</sup> National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer

- 2.2 Despite these standards being adopted in Wales, we know that currently this referral only occurs in around half of all cases<sup>4</sup>, meaning that many young people are missing out on the care and support they deserve.
- 2.3 Increased notifications and referrals of young people with cancer to TYAMDTs will enable the NHS to deliver against the Wales Cancer Delivery Plan and National Standards, also make a tangible difference to the lives of young people. Referral to the TYAMDT at University Hospital Wales in Cardiff, where Teenage Cancer Trust's unit is based, is the best way for young people with cancer in Wales to access holistic support from specialist staff, be informed of and recruited to clinical trials, and benefit from age-appropriate facilities.
- 2.4 Teenage Cancer Trust and CLIC Sargent have been working together to raise awareness of this issue, and we support their separate submission to the Committee on this topic. We have written together to the Cabinet Secretary for Health, Wellbeing and Sport on this issue (the text of this letter is pasted below).

*Dear Mr Gething*

*Congratulations on your re-election and appointment as Cabinet Secretary, it's great to have someone with your background and knowledge about cancer services in Wales in this important role and we very much look forward to working with you.*

*Teenage Cancer Trust and CLIC Sargent are the two largest charities representing the needs of children and young people with cancer in Wales and across the UK. We are members of the Wales Cancer Alliance and work in partnership to influence policy and deliver in practice to ensure all children and young people with cancer have access to services that meet their needs and support them to live their lives to their full potential.*

*The next few years are critical to embedding changes in Welsh Cancer Services that could make real improvements for young people with cancer and their families; and there is much to be done. There are around 180 new diagnoses of cancer each year in 0-24 year olds, with many more on active treatment at any one time. Although survival rates are over 80% on average cancer remains the single largest cause of death from disease in children in the UK and for some cancers survival is as low as 50%. Very few young people are being picked up by traditional methods of assessing services, like peer review and the Cancer Patient Experience Survey, and many children and young people are having to travel hundreds of miles from home to access support.*

*We've been very disappointed that children, teenagers and young adults have had so little focus in the Cancer Delivery Plan and lack of priority gives to these areas of improvement. This must change in order for young people with cancer to have their needs met.*

*A commitment from the Welsh Government to referring every patient to a paediatric or teenage and young adult MDT should be made a priority for health boards which they are measured against. This one commitment will help NHS services know where each patient is, be able to offer them support and access to research as well as follow up with them after treatment. It will also enable us, as charities, to provide much needed specialist care and support to them through our work with the MDTs are the designated Principal Treatment Centres.*

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<sup>4</sup> 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?

*We call on you to champion the needs of this vulnerable group of patients who too often fall between services and priorities leaving them disadvantaged and missing out on support that is available to them.*

*If you would like to meet to discuss this then we are very happy to do this at your convenience. We're aware the Cancer Delivery Plan is due to be refreshed and so are keen that this one commitment is part of any new plan or strategy.*

2.5 In order to ensure improvements in outcomes for teenagers and young adults with cancer in Wales it is essential that action is taken to ensure that the recommendation for referral to specialist age-appropriate care and support is enforced. This is the single most important action that could be taken on behalf of young people with cancer in Wales. Without proper monitoring and evaluation of Health Board activity to ensure they are held to account for referrals of 16-24 year olds to the appropriate TYA MDT, experience and outcomes cannot be improved for this patient group. Young people will also not be able to access specialist support services or relevant clinical trials until this is achieved.