

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from Teenage Cancer Trust – CDP 30



93 NEWMAN STREET
LONDON
W1T 3EZ
T 020 7612 0370
F 020 7612 0371
www.teenagecancertrust.org

Teenage Cancer Trust response to National Assembly for Wales' Health and Social Care Committee inquiry into implementation of the Welsh Government's Cancer Delivery Plan

1. 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, 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.

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.

Around 2,500 young people are diagnosed with cancer each year across the UK. In Wales approximately 114 new patients will be diagnosed annually, while around the same number again will continue to receive care for cancer or relapse¹. 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.

2. Teenage and young adult cancer in Wales: progress so far

In 2012 we welcomed the introduction of a national plan for cancer services in Wales. We believe having a strong focus on the whole of the cancer pathway and supporting those living with cancer is the best way to improve patient experience, outcomes and survival. A plan which is regularly reported against at a local and national level is a strong lever to drive improvements. However, when responding to this new inquiry we faced difficulties in accessing Local Health Board reports on progress against the plan's aims and outcomes.

The publication of the National Standards for Cancer in Children aged 0-15 (in 2011) and Teenagers and Young Adults (TYA) aged 16-24 (in 2012) were further opportunities to drive forward progress for young

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

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people with cancer 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. These were presented alongside monitoring criteria for Local Health Boards to guide their reporting.

We are concerned that the standards for teenagers and young adults have still not officially been launched, are difficult to access, and have not been fully implemented across Wales. As a result, the plans for each Board to monitor and report against their compliance with cancer standards, which are then verified by peer review, have not been realised nor the benefit these standards will bring to young people with cancer in Wales.

3. Teenage and young adult cancer in Wales: the future

80% of young people diagnosed with cancer now live for five years or more², and this, combined with the increasing incidence of cancer in this age group, will mean more young people than ever in Wales will be living with or beyond cancer in future. Health and care services in Wales must be prepared to provide the best possible treatment and survivorship support for these patients in order to meet the vision of Together for Health which recognised that “We must improve the health of everyone in Wales. We must pay particular attention to the young”³.

For teenagers and young adults with cancer this will involve commissioning specialist age-specific services which are made available to every young person with cancer, and complemented by the provision of specialist staff who can communicate effectively with young people, as set out in the NICE Improving Outcomes Guidance for Children and Young People with Cancer (2005). At the same time, services across the cancer pathway must be monitored and reported on regularly and transparently to highlight areas of variation and drive improvements.

The Welsh Government, NHS Wales and Local Health Boards have a unique opportunity to deliver high quality treatment and care for young people with cancer in Wales. The Teenage Cancer Trust unit at University Hospital Wales in Cardiff is a flagship service and the only such unit covering the full 13-24 TYA age range. This investment in facilities and staff is already making a significant impact on the lives of many young people with cancer. Swift diagnosis, access to specialist care, staff and treatment, along with survivorship support, mean that many young people with cancer go on to lead long and productive lives, contributing to society and the economy in Wales.

However, we remain concerned that until the specific needs of teenagers and young adults are addressed within the Cancer Delivery Plan, there is universal implementation of the Teenage and Young Adult cancer standards, and more detailed data is available to robustly measure progress throughout the pathway young people with cancer in Wales will remain at a disadvantage.

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

³ Welsh Government (2011), *Together for Health: A 5-year vision for the NHS in Wales*

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4. Assessment of progress against specific Outcomes in the Cancer Delivery Plan, and recommendations for change in order for these to be met

Outcome 2: Cancer is detected quickly where it does occur or recur

Earlier diagnosis is critical in order to improve the quality of life and outcomes for teenagers and young adults with cancer, yet young people face barriers in securing a swift diagnosis. Teenage Cancer Trust's research has shown that while two thirds of young people with cancer had at least one of the most common cancer symptoms, one in four had to visit their GP four times or more before being referred⁴.

Our most recent research on routes to diagnosis has shown that the picture remains challenging for young people with cancer. In 2013 we found that 37% of young people were diagnosed via A&E, with over a quarter of these having previously presented at their GP⁵.

Recommendation: A system of alerting GPs when they have seen a patient three times with unresolved cancer symptoms will help them to identify and manage these cases appropriately.

Recommendation: More tools should be developed and introduced to doctors in their speciality training which bring to their attention symptoms of rare diseases.

Recommendation: Better data and more regular reporting at a national level on stage at and route to diagnosis will highlight areas of concern and drive improvements.

Teenage Cancer Trust's Education and Advocacy Team deliver a pioneering education programme across the UK, providing education and advice about the signs of cancer, cancer treatments and prevention as well as healthy living and sun safety. We visit over 90 schools each month, with each session attended by between 100 and 200 pupils – that's around 130,000 pupils a year.

The education programme's free, up-beat cancer awareness sessions empower young people to take control of their own health and speak up when something changes. Evaluation of the programme found that a visit from Teenage Cancer Trust increased the number of cancer warning signs that teenagers recognised, and also that the education talks serve as an effective means for disseminating information about cancer to other members of the public including family members⁶.

Teenage Cancer Trust is also committed to the wider agenda of healthcare in Wales, including promoting a healthy lifestyle for young people in order to improve overall health and help reduce the risk of cancer. To this end the education programme contains further information on the impact of smoking, drinking and exposure to the sun while encouraging positive choices about diet and exercise.

In Scotland, the Government's Detect Cancer Early initiative has provided funding for the programme to support its continued expansion and evaluation. We currently deliver a limited programme in Wales, but are

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

⁵ Teenage Cancer Trust (2013), *Improving Diagnosis Report*

⁶ University of Stirling (2011), *Teenage Cancer Awareness Study*

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keen to explore opportunities to further promote this important message to teenagers and young adults in schools across the country.

Outcome 3: People receive fast, effective treatment and care so they have the best possible chance of a cure

In 2005, the National Institute for Health and Clinical Excellence (NICE) published their guidance on Improving Outcomes for Children and Young People with Cancer⁷ 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. Yet currently this only occurs in around half of all cases⁸.

Recommendation: In line with the National Standard for Teenagers and Young Adults with Cancer, increased notifications and referrals of young people with cancer to TYAMDTs will enable the NHS to deliver against many of the outcomes of the Cancer Delivery Plan. 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.

Furthermore, teenagers and young adults with cancer are at a significant disadvantage in accessing new and better treatments through clinical trials. Less than 20% of cancer patients aged 15-24 are currently getting access to clinical trials in the UK, compared with around 50-70% of children⁹. This in turn may account for why cancer continues to be the most common cause of non-accidental death in young people, and five-year survival rates remain lower in teenagers than in children¹⁰.

Recommendation: The targets in the Cancer Delivery Plan for clinical trials access (currently 10% across all ages) should be reviewed in light of the much higher potential for accrual to trials in young people.

The Welsh cancer patient experience survey also found that only 29% of patients were asked about taking part in research¹¹, yet the National Standard for Teenagers and Young Adults with Cancer stipulates that all patients must be given the opportunity to enter clinical trials.

Recommendation: Reporting on clinical trials access should include analysis by age of patient to ensure transparency, as without age specific data it is impossible to ascertain if any progress has been made against the National Standard or the plan. All patients, regardless of age, should be offered the chance to take part in suitable clinical trials.

⁷ National Institute for Health and Clinical Excellence (2005), *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*

⁸ 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?*

⁹ Fern et al (2008), *Rates of inclusion of teenagers and young adults in England into National Cancer Research Network clinical trials*, British Journal of Cancer: 99 (12), 1967-1974

¹⁰ Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

¹¹ Welsh Government (2014), *Wales Cancer Patient Experience Survey*

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Recommendation: More detail is also needed on the secondary target to double research activity in rarer cancers, as there continues to be a lack of innovation and investment in drug development for many rare cancers which are prevalent in teenagers and young adults.

Outcome 4: People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer

The first Welsh cancer patient experience survey conducted in 2013/14 was a key development for this outcome, and provided a good baseline against which to measure future progress. However, only 17 responses, less than 1%, were from 16-25 year olds and there are currently no tools in place to gather feedback from younger cancer patients¹².

Recommendation: Future surveys should ensure more young people are asked about their experiences, and tools should be developed to measure the experience of those under 16. More consideration should be given to those issues which specifically impact on young people with cancer, including transition and returning to education after treatment.

We know from cancer patient experience surveys in England, and Teenage Cancer Trust's own research, that late diagnosis, communication with professionals, access to specialist staff and research can be particularly difficult for young people with cancer¹³.

Recommendation: Notification to the TYAMDT at University Hospital Wales in Cardiff, in line with NICE Guidance and the National Standard for Teenagers and Young Adults with Cancer, will ensure young people benefit from the best possible care to improve outcomes including patient experience.

¹² Welsh Government (2014), *Wales Cancer Patient Experience Survey*

¹³ Department of Health (2010 and 2012), *National Cancer Patient Experience Survey*