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## Teenage Cancer Trust response to Draft Welsh Government Implementation Plan for Rare Diseases

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### Introduction

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. Our 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.

### The UK Strategy for Rare Diseases, Welsh Government Implementation Plan and young people with cancer

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 relapse<sup>1</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.

While this is a significant number, it is important to note that teenage and young adult cancer is considered a rare disease and defined as such in the Specialised Services National Definition Set. When launching the Welsh Government Implementation Plan, Dr Chris Jones, the Deputy Chief Medical Officer for Wales, stated that "rare diseases care in Wales now has a plan on an equal footing to those for cancer and cardiac disease"<sup>2</sup>. It's important for all stakeholders to be aware that many cancer patients, including teenagers and young adults, will also be classed as patients with a rare disease as a result of their cancer type. As such, the rare disease plan must deliver equally for these patients.

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

<sup>2</sup> <http://wales.gov.uk/newsroom/healthandsocialcare/2014/140228rarediseases/?lang=en> [Accessed 28 April 2014]

80% of young people diagnosed with cancer now live for five years or more<sup>3</sup>, 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. Whilst there have been steps forward in the care of teenagers and young adults with cancer in Wales, there is much more that needs to be done, particularly in those areas addressed within both the UK Strategy for Rare Diseases and the Welsh Government Implementation Plan.

We welcome this consultation from the Welsh Government and applaud them for being the only UK country so far to publish a plan in response to the UK Strategy for Rare Diseases. We support many of the actions set out in the Welsh plan, such as the creation of an implementation group and measures to support collaborative working across all stakeholders named in the plan. A plan which is regularly reported against at a local and national level is a strong lever to drive improvements. However, more can and should be done across all themes to enable the plan to deliver the best patient experience and outcomes for patients with rare diseases including young people with cancer.

The key areas where more actions need to be included within the plan are examined in the remainder of this response.

## **Section 1: Empowering those affected by rare diseases**

### **Information provision**

The plan acknowledges the role that third sector and patient organisations can have in providing information and guidance to patients with rare diseases. Yet it's important to note that not all patients will be aware of what patient groups exist to support them, and that third sector organisations themselves need better data in order to reach all those in the patient populations that they support.

For example, 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 cases<sup>4</sup>. This means that many young people are not accessing the holistic support and age-appropriate information provision which is available from specialist staff at Teenage Cancer Trust units. It's important that robust diagnostic and referral pathways from primary care to hospitals to specialists are provided to improve this and enable universal empowerment of patients. In addition, more and better data must be made available on where patients are receiving their care in order for patient organisations to be able to offer support to those treated in local hospitals.

### **Patient experience and outcomes measures**

Key to empowerment is listening to and acting on feedback from patients, and so we welcome the focus on patient experience and patient outcomes measurement within the plan. However, it's important that all patient populations, regardless of age or size, are included when gathering feedback.

The first Welsh cancer patient experience survey conducted in 2013/14 was a key development within this theme, and provided a good baseline against which to measure future progress.

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<sup>3</sup> Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

<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?*

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 patients<sup>5</sup>. We recommend that all future surveys, including those developed following the plan for rare diseases, 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 and other rare diseases, including transition and the long term effects of 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 cancer<sup>6</sup>. 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.

We note with interest the action for the Welsh Health Specialised Services Committee to establish a clinical evidence group for rare diseases, to include patient organisation representatives, by 1 March 2014. We would welcome more details on the remit of this group and ways in which we could support its work alongside the Teenage and Young Adult Cancer Clinical Evidence Reference Group.

### **Section 3: Diagnosis and early intervention**

#### **Support in diagnosing rare diseases**

We support the focus of the Welsh plan on diagnosis and early intervention. 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 referred<sup>7</sup>.

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 GP<sup>8</sup>.

We agree that swifter diagnosis could be supported by tools, developed and introduced to doctors in their speciality training, which bring to their attention symptoms of rare diseases. Furthermore, a system of alerting GPs when they have seen a patient three times with unresolved cancer symptoms would also help them to identify and manage these cases appropriately.

#### **Professional education and training**

We also welcome the plan's focus on education and support for professionals, both in improving rates of diagnosis and throughout the care pathway, and feel that third sector organisations are well placed to support this. Teenage Cancer Trust has been working with Coventry University since 2006 in developing and delivering specialist accredited courses for health care professionals working with this unique group of patients so that teenagers and young adults with cancer are cared for by well-informed staff, able to address the specific needs of young people in their care.

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<sup>5</sup> Welsh Government (2014), *Wales Cancer Patient Experience Survey*

<sup>6</sup> Department of Health (2010 and 2012), *National Cancer Patient Experience Survey*

<sup>7</sup> Teenage Cancer Trust (2011), *Find Your Sense of Tumour Conference Survey* [Data available on request]

<sup>8</sup> Teenage Cancer Trust (2013), *Improving Diagnosis Report*

Like many rare disease areas, teenage and young adult cancer care services are rapidly evolving and it is therefore crucial that care and services are delivered by a skilled and appropriately trained workforce with access to continuing professional development. Teenage Cancer Trust is working with the Royal College of Nursing to develop a competency framework for this area, to capture and describe the knowledge, skills and competencies which are the cornerstone for specialist age-appropriate care delivery.

### **Public health campaigns**

Public awareness of rare diseases plays a key role in diagnosis and early intervention, although this is not currently reflected within the plan. Teenage Cancer Trust's pioneering education programme is one example of this. The programme provides education and advice about the signs of cancer, cancer treatments and prevention as well as healthy living and sun safety, via free, up-beat cancer awareness sessions which 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 members<sup>9</sup>. We would welcome greater detail in the plan on the role of campaigns in raising awareness of rare diseases, their symptoms and prevalence.

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

### **Care pathways**

We agree that primary, secondary and specialist services all have a role to play in the management of rare diseases in Wales. Swift diagnosis and referral to specialist treatment will have a positive impact on patient experience for young people with cancer, and in some cases a delayed diagnosis can affect survival rates.

As already noted, 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, yet currently this only occurs in around half of all cases<sup>10</sup>. It is critical that this referral pathway continues to be secured in the NHS in Wales and 100% of young people are notified to the service as part of standard cancer care.

## **Section 4: Coordination of care**

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<sup>9</sup> University of Stirling (2011), *Teenage Cancer Awareness Study*

<sup>10</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?*

### **Service specifications**

We support the planned introduction of service specifications for rare disease pathways. Service specifications and quality standards for young people with cancer have been instrumental in ensuring that the needs of young people with cancer are more consistently addressed throughout NHS England. However, it's important that where service specifications and standards are introduced, they are effectively promoted and endorsed in order to make an impact on patient care.

For example, 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 key opportunities to drive forward progress for young 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. More must be done to support the implementation of existing standards and plans, while new plans and service specifications should be designed and implemented to avoid these problems reoccurring.

### **Specialist centres**

We agree that it is critical for expert centres to be linked to networks of local hospitals, and for integration to exist across all levels of care. It's also important for expert centres to be looking at outreach work in order to support patients with rare diseases by providing the best specialist care as locally as possible. Where expert centres are already designated, such as the Principal Treatment Centre for young people with cancer at University Hospital Wales in Cardiff, it's vital that the referral pathways to such centres are secure and followed in all cases.

We note with some concern the suggested that "patient organisations are ideally placed to liaise between newly diagnosed patients and the centre of excellence to ensure that all patients are aware of the centre's existence and that they are accessing the services that the centre is able to provide". As noted earlier, there is an urgent need for more and better data to be made available on where patients are receiving their care in order for patient organisations to be able to offer support to those treated in local hospitals. The plan should not assume that patient organisations are able to locate, support and refer patients with rare diseases to the appropriate specialist centre; rather this should be the responsibility of the local hospital or referring primary care professional.

### **Data and reporting**

Accurate reporting and data collection is vital to ensuring coordinated care. Registration is also critical to ensuring that services can be planned for appropriately and commissioning meets the needs of patients with rare conditions. Data collected following the plan should be comparable across the UK in order for it to lead to effective planning and drive improvements in services.

### **Accountability**

It will be vital for the final plan to include details on lines of accountability and reporting requirements for rare disease provision in Wales. As noted earlier, we have concerns about the current system of Local Health Board reporting in relation to the cancer plan. As the plan for rare diseases depends on actions from a variety of stakeholders including Local Health Boards, the Welsh Government, UK bodies and others, it will be important for clear lines of responsibility to be

publicised from the outset. More details are needed on the role of the UK Rare Disease Advisory Group, currently part of NHS England, and how they will work across the four UK countries in overseeing progress against the Rare Disease Strategy.

## **Section 5: The role of research**

We welcome the recognition in the plan of the importance of research for those with rare diseases, and all patients in Wales, and support the plan's ambition of overcoming barriers to such research. Teenagers and young adults with cancer currently face some significant difficulties in accessing new and better treatments through clinical trials. In fact, less than 20% of cancer patients aged 15-24 are getting access to clinical trials in the UK, compared with around 50-70% of children<sup>11</sup>. 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 children<sup>12</sup>.

In order to address these barriers, we recommend that realistic targets be set for trial recruitment for patients with rare diseases. This includes reviewing the targets in the Cancer Delivery Plan for clinical trials access (currently 10% across all ages) in light of the much higher potential for accrual to trials in young people. More detail is also needed on the secondary target in that Delivery Plan 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<sup>13</sup>.

It's also important that improvements in access to research resulting from the rare disease plan are felt by all patients regardless of age or condition, including young people with cancer. Reporting on clinical trials and research access should include analysis by age of patient to ensure transparency.

In order for research to be easily transferred into practice, there needs to be more support to enable collaboration between research centres. For example, applications for collaborative research need to be simplified and streamlined to allow for research centres to join up more easily.

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<sup>11</sup> 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

<sup>12</sup> Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

<sup>13</sup> While government and charity funders spend over £500m annually on cancer research, only 33% goes toward cancers that affect young people, and without leukaemia this drops to 18%. Cancer Research UK (2012), *Research Strategy Progress Report 2011/12*