



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

Teenage Cancer Trust response to Draft Northern Ireland Implementation Plan for Rare Diseases

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

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.

Teenage Cancer Trust's current services in Northern Ireland comprise of a Programme Manager and a Regional Education Executive. The jointly funded Programme Manager is working in partnership with the Health Service and all regional stakeholders to scope and propose the best way of meeting the needs of young cancer patients as well as support the establishment of a teenage and young adult cancer service, while the Regional Education Executive works with schools, colleges and universities to deliver cancer awareness sessions across Northern Ireland.

The UK Strategy for Rare Diseases, Northern Ireland Implementation Plan and young people with cancer

Around 2,500 young people are diagnosed with cancer each year across the UK. In Northern Ireland approximately 85 new patients will be diagnosed annually, while around the same number again will continue to receive care for cancer or relapse¹. While many of these patients will access either paediatric or adult oncology services at hospitals in Belfast, a minority will also be treated in local hospitals across Northern Ireland.

Teenage and young adult cancer is a defined rare disease under the Specialised Services National Definition Set. 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.

¹ North West Cancer Intelligence Service (2013)

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 Northern Ireland 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 Northern Ireland, there is much more that needs to be done, particularly in those areas addressed within both the UK Strategy for Rare Diseases and the Northern Ireland Implementation Plan.

We welcome this consultation and support many of the actions set out in the draft plan, such as the creation of an implementation group, the intention to report annually on progress, and the requirement for the plan to deliver for all patients regardless of age. However, more can be done across all themes to enable the plan to deliver the best patient experience and outcomes for 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.

Theme 1: Empowering those affected by rare diseases

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 Northern Ireland cancer patient experience survey, due to be conducted in 2013, has been delayed until early 2015. While we welcome its introduction, this survey will only gather views from patients aged 16 or older and there are currently no tools in place to seek feedback from younger cancer patients. 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 consistent specialist staff and research can be particularly difficult for young people with cancer³.

Service specifications and referral pathways

We support the planned introduction of service specifications for rare disease pathways. The introduction of service specifications and quality standards in England have been instrumental in ensuring that the needs of young people with cancer are more consistently addressed throughout NHS England.

Northern Ireland's Service Framework for Cancer Prevention, Treatment and Care includes Standards 31 and 32 which stipulate that young people with cancer aged 0-24 should be managed by an age-appropriate multidisciplinary team and receive holistic assessment and care. It's important that any service specifications which come about from the rare disease plan support the implementation of existing disease specific plans or standards such as these. In turn, the refresh of the Service Framework which is due to take place in 2015 should also reflect Northern Ireland's commitments from the UK Strategy for Rare Diseases.

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

³ Department of Health (2010, 2012, 2013 and 2014), National Cancer Patient Experience Survey

A Programme Manager, jointly funded by Teenage Cancer Trust and the Northern Ireland Children's Cancer Unit Fund is currently working on mapping and developing referral pathways for young people with cancer in Northern Ireland. It's important that robust diagnostic and referral pathways from primary care to hospitals to specialists are provided to ensure young people can access the support mandated by the Service Framework Standards. To expedite this process there is an urgent need for more and better data to be made available on where patients are receiving their care.

Theme 3: Diagnosis and early intervention

Support in diagnosing rare diseases

We support the focus of the Northern Ireland 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. Delays can also impact on how people cope with their diagnosis and treatment and also how they readjust to life afterwards⁴.

Teenage Cancer Trust has carried out research with young people with cancer across the UK. This 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 referred⁵. 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 GP⁶.

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 expert well-informed staff, able to address the specific needs of young people in their care.

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, sustainable 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

⁴ Gibson et al (2013), Young people describe their prediagnosis cancer experience. *Psycho-Oncology* 10.1002

⁵ Teenage Cancer Trust (2011), Find Your Sense of Tumour Conference Survey [Data available on request]

⁶ Teenage Cancer Trust (2013), Improving Diagnosis Report

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 members⁷. 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 Northern Ireland, 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. In England the Labour Party have committed to funding the expansion of the programme in secondary schools should they be in government in 2015. We currently deliver the programme to 32 schools and over 8,000 pupils each year in Northern Ireland, but are keen to explore opportunities to further promote this important message to teenagers and young adults in schools across the country.

Theme 4: Coordination of care

Integrated care

We support the plan's ambition to deliver coordinated, joined-up care to patients. The treatment and care of teenagers and young adults with cancer can last for as long as 3 years and take place in a variety of settings including specialist units, local hospitals and in the community⁸. A coordinated and integrated approach is therefore vital to ensure a positive patient experience and the best possible outcomes.

Age-appropriate care

We welcome the inclusion of specific information on children and young people within the plan, but note that this only covers young people up to age 15. To ensure a high standard of treatment and care for young people with cancer in Northern Ireland it is important to recognise the unique needs of teenagers and young adults. These needs should be met by delivering age-appropriate services for all 13-24 year olds in line with current recommendations, commissioning that encompasses a range of services from fertility preservation to self-management of issues such as anxiety and fatigue, and the provision of specialist staff who can communicate effectively with young people.

Elsewhere in the UK, specialist care delivered in age appropriate settings, in line with NICE Guidance⁹, has been transformational for young people with cancer. Traditionally treated alongside children or elderly patients at the end of their lives, young people often feel extremely isolated

⁷ University of Stirling (2011), Teenage Cancer Awareness Study

⁸ Pini et al, What effect does a cancer diagnosis have on the educational engagement and school life of teenagers? A systematic review, *Psycho-Oncology* (2012) 21, 7 685-694

⁹ National Institute for Health and Clinical Excellence (2005), *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*

during cancer treatment, some never meeting another young person with cancer. The plan should be amended to recognise that teenagers and young adults are a group which face particular difficulties in accessing appropriate services as they sit between traditional paediatric and adult structures in services¹⁰. It should further note the positive impact that age appropriate care and facilities can have on patient experience and outcomes¹¹.

Theme 5: The role of research

We welcome the recognition in the plan of the importance of research for those with rare diseases, and support the plan's ambition of encouraging greater participation in 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 children¹². 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 children¹³.

It's therefore 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.

¹⁰ Annual Report of the Chief Medical Officer for 2012 (2013) Our Children Deserve Better: prevention pays

¹¹ Futures Company (2010), Exploring the Impact of the Built Environment

¹² 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

¹³ Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer