



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

Teenage Cancer Trust response to Service Framework for Children and Young People consultation

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 Service Framework for Children and Young People 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.

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.

We welcome this consultation and the opportunity to comment on the Service Framework. The Service Framework for Cancer Prevention, Treatment and Care (2011) includes standards which

¹ North West Cancer Intelligence Service (2013)

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

tackle key priorities for young people with cancer, such as the importance of age-appropriate multidisciplinary teams and holistic assessment. This overarching Framework for all Children and Young People is a welcome addition to set standards for young people across Northern Ireland and we particularly support the recognition throughout the document that children and young people are a distinct group, separate to the adult population. However, more can be done to enable the Framework to deliver the best patient experience and outcomes for young people with cancer. The key areas where more actions need to be included are examined in the remainder of this response.

Section 2: Service Framework for Children and Young People

Remit of the Framework

We note that the Framework aims to deliver high standards and outcomes for all children and young people aged 0-19 years. We strongly recommend that the age group covered by the document be expanded up to the age of 24. This would align it with, for example:

- The Service Framework for Cancer Prevention, Treatment and Care where children and young people are defined as all those up until the day before their 25th birthday³
- NICE Improving Outcomes Guidance for Children and Young People with Cancer which covers ages 0-24⁴
- Scotland's Managed Service Network's Cancer Plan for Children and Young People which covers those aged up to 25⁵
- Welsh National Standards for Children, Teenagers and Young Adults which cover ages 0-24⁶
- The United Nations definition of young people as being aged up to 25⁷

Not extending the Framework in this way would lead to it being an outlier and out of step with other Frameworks, including those published by the DHSSPS. Furthermore, England's Chief Medical Officer has set out both scientific and practical arguments for why children and young people up to the age of 25 should be included in service planning and provision⁸.

Monitoring outcomes

We note that many of the Standards include performance indicators to be reviewed through self-assessment, including, for example, 15.6 and 17.1. We feel that these indicators would be strengthened by the introduction of specific data collection or a system of Peer Review to ensure a consistent and high standard of provision.

Section 3: Generics

Removed standards

We understand the rationale for removing the generic standards for adults on healthy eating, physical activity, smoking prevention & cessation, and alcohol, from the Framework as they are targeted at an older population. However, we feel that these themes remain very important for

³ Department of Health, Social Services and Public Safety (2011), Service Framework for Cancer Prevention, Treatment and Care

⁴ National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer

⁵ Managed Service Network for Children and Young People with Cancer in Scotland (2012), Cancer Plan for Children and Young People in Scotland 2012-15

⁶ Welsh Government, National Standards for Cancer in Children (2011) and Teenagers and Young Adults (2012)

⁷ <http://www.unesco.org/new/en/social-and-human-sciences/themes/youth/youth-definition/>

⁸ Annual Report of the Chief Medical Officer for 2012 (2013) Our Children Deserve Better: prevention pays

young people. Furthermore, they have not been fully replaced by the new standards such as those on antenatal health or informing parents about healthy lifestyles.

Promoting healthy lifestyle choices to young people helps improve their overall health, and can reduce the risk of developing diseases such as cancer. Teenage Cancer Trust's pioneering education programme is one route to doing 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 upbeat cancer awareness sessions which empower young people to take control of their own health and speak up when something changes. We'd welcome the expansion of the Framework to recognise the importance of promoting healthy lifestyle choices directly to children and young people.

Retained standards

It's also important to consider how those generic standards which have been retained can be applied to children and young people. For example, Standard 1: Communication states that all patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care, to be measured via the Patient and Client Experience monitoring report. However, it doesn't appear that this report routinely monitors the experiences of patients under 16 and so may not provide an accurate picture of young people's experiences. We recommend that the DHSSPS explores opportunities to include young people in all patient experience and outcomes measures. The upcoming Northern Ireland Cancer Patient Experience Survey is one example where the Department could expand patient experience measures to capture the feedback of young people to ensure their voices are heard and acted upon.

Section 6: Children and Young People with Acute and Long Term Conditions

Cancer is the leading cause of non-accidental death in children and young people, yet 80% of young people diagnosed with cancer now live for five years or more⁹. This means that teenage and young adult cancer can be viewed as both an acute and long term condition.

Age-appropriate care

We strongly agree that all ill children and young people should receive high quality care in appropriate settings. 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 Guidance¹⁰, 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 during cancer treatment, some never meeting another young person with cancer.

The Framework should 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

⁹ Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

¹⁰ National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer

structures in services¹¹. It should further note the positive impact that age appropriate care and facilities can have on patient experience and outcomes¹².

Transition

The current focus of Standard 17 is on transition from paediatric to adult services. However, we'd recommend this be expanded to include adolescent or teenage and young adult (TYA) services which may be accessed in some instances by young people with cancer. Indeed, a TYA service can play a key role in ensuring a successful transition by bringing elements of paediatric and adult services together. It should also be noted that transition also occurs from acute care into long term follow up for many ill young people, including young people with cancer. The needs of young people during this time might include returning to education or employment, adjusting to late effects of treatment, a new body image, and are distinct from those of children or adults yet must be considered and provided for.

¹¹ Annual Report of the Chief Medical Officer for 2012 (2013) Our Children Deserve Better: prevention pays

¹² Futures Company (2010), Exploring the Impact of the Built Environment