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## Teenage Cancer Trust response to Refreshing the NHS Outcomes Framework 2015-2016

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### Introduction

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and chances of survival 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, bringing young people together so they can be treated by teenage cancer experts in the best place for them.

Cancer is the most common cause of non-accidental death in young people, and five-year survival rates remain lower in teenagers than in children<sup>1</sup>. Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work 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 survival rates.

### Overarching Comment

We welcome the opportunity to comment on the refresh to the NHS Outcomes Framework. In partnership with other tools and levers, such as peer review, patient experience surveys and patient engagement, the Outcomes Framework is a useful device to review and monitor the vital work of NHS England. We welcome the opportunity to consider the indicators within the Outcomes Framework to ensure they deliver for young people with cancer.

The key areas of the refresh of the NHS Outcomes Framework which are important to young people with cancer are:

- **Specialised age appropriate care for children and young people:** We strongly agree with the need for children and young people to have age appropriate care and welcome the proposed addition of an indicator monitoring access to these services. It's vital that all references to amendments to the framework to include indicators for children also include an explicit reference to include young people. Access to age appropriate care for young people with cancer facilitates access to specialised staff and better treatment environments, improving patient experience and outcomes. Furthermore, the specialist nature of the work must continue to have a focus in NHS England through the Teenage and Young Adult Cancer Clinical Reference Group.
- **The continued focus on patient involvement:** This is an important method of improving services, but it's vital that patient engagement and experience measures are extended to those under the age

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

of 16 to ensure the voices of young people are heard and responded to, and that young people up to the age of 24 are included in children and young people's specifically designed tools and surveys.

**Question 1: What are your views on the effectiveness of using outcome measures to drive improvement in the health care system?**

A focus on outcomes is integral to improving the quality care and experience for patients. Outcome measures can be used to drive improvement alongside information collected in other forms. For example, the use of peer review (e.g. National Cancer Peer Review programme), patient experience surveys (e.g. the National Cancer Patient Experience Survey) and stakeholder involvement.

To be effective, outcome measures must be based on consistent information. As recommended by the report of the Children and Young People's Health Outcomes Forum, data should be recorded in five year age bands up 24 years of age, yet this does not yet always occur<sup>2</sup>.

We do have concerns about the indicators which are still placeholders. We feel it would be beneficial to explicitly know the reasons from OFTAG for the rejection of any proposed indicators, and have the opportunity to know the position in the process where new indicators are and proposed times for entry into the outcomes framework. We requested these details from the Department of Health but were informed that a brief overview of this information will be published alongside the refreshed framework. However, having this information available during the consultation process would enable us to better answer questions on the long term direction of travel which are posed within the refresh consultation.

**Question 11: Do you agree with the long term direction that the Department of Health is taking regarding indicators for children and young people in the outcome Framework?**

It's vital that the Department continues to develop and implement indicators on areas that will deliver better care for young people, and so we support the long term direction of travel that the Department of Health is taking. We agree that by continuing to seek improvements in indicators, improvement will be seen in the services provided to children and young people.

However, young people, including those with cancer, have some specific needs and experiences that are not yet appropriately captured by the Outcomes Framework. We continue to support the recommendations of the Children and Young People's Health Outcomes Forum to develop health outcome measures more specifically aimed at young people. These include time from first NHS presentation to start of treatment, better integrated care, effective transition and age appropriate services. It's vital that the NHS Outcomes Framework takes steps to incorporate these recommendations.

**Question 12: What are your views on our selection criteria for inequalities indicators in paragraph 47?**

We support the proposal to include inequalities indicators, and particularly welcome the focus on inequalities due to age. Teenagers and young adults with cancer face reduced access to clinical trials and worse patient experience, in part due to their age and their status as being between paediatric and adult services. Less than 20% of cancer patients aged 15-24 currently access clinical trials in the UK, compared with around 50-70% of children<sup>3</sup>. Also, young people with cancer consistently report worse experience, including

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<sup>2</sup> The Children and Young People's Health Outcomes Forum Report.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216852/CYP-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216852/CYP-report.pdf)

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

communication and information around their treatments. Young people often have little experience of a hospital environment at the beginning of their treatment and are unaware of side effects and late effects that can occur by having treatment<sup>4</sup>.

**Question 17: What are your views on highlighting negative experiences of care for patients rather than only focusing on positive ones?**

It's important that NHS England has an understanding of positive and negative experiences of care in order to improve care. It's vital that all patient groups have their voice heard and that outcome frameworks are able to represent patients' outcomes under the age of 16. Currently, many surveys have age restrictions which can mean the views and experiences of this age range can be missed out or ignored. The National Cancer Patient Experience Survey currently only allows patients over the age of 16 to participate, yet teenagers and young people can have different experiences of healthcare than other age groups and can be a hard to reach group<sup>5</sup>. In order to capture this feedback and drive change, teenagers and young adults should be included in all patient experience and outcomes measurements.

**Question 18: Do you agree on the Department's plans for the long term direction for improving patient experience?**

We support the long term direction for improving patient experience for young people set out by the Children and Young People's Health Outcomes Forum, and we continue to recommend that outcome measures should be used that effectively collect information from all ages. Outcome measures should be used to improve patient experience but they are most effective when part of a group of tools used in improving healthcare. We hope outcome measures will continue to be used in line with peer review, national surveys and stakeholder involvement.

**Question 19: What are your views on more effective methods to assess patient safety other than incidence reporting?**

Patient safety is important in the care of the patients and we agree with Lord Darzi's 2008 Report that patient safety is a fundamental aspect of quality. We believe that two key tools are important alongside incidence reporting in assessing patient safety and addressing concerns.

Patient concerns about safety should be easily logged and escalated via an advocacy system that is accessible and user friendly to all patient groups, including young people. As noted in our response to Question 12, young people with cancer can struggle to engage with areas of the health system due to a lack of previous experience of healthcare, and so it's vital that they are able to voice their concerns easily and effectively.

The Cancer Quality Improvement Network system's National Cancer Peer Review programme provides valuable information on patient safety, particularly for areas of specialist care. We have strong concerns that the proposed changes to Peer Review, moving towards focusing on hospitals in special measures and using greater self-review, risks impacting on patient safety. There have been big steps forward in developing services and standards for commissioning specialised services such as those for young people with cancer, and it's vital that these are now held to account via a robust Peer Review process.

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<sup>4</sup> Department of Health (England) (2010, 2012 and 2013), National Cancer Patient Experience Survey

<sup>5</sup> Department of Health (England) (2010, 2012 and 2013), National Cancer Patient Experience Survey

**Question 25: Do you agree with the government’s plan to work towards further alignment between the Outcome Frameworks?**

We understand the importance of aligning outcome frameworks for better integration of care for patients however we feel the current alignment of outcomes is not sufficient to represent the needs and experiences of young people with cancer. Teenagers and young adults are a recognised group which face particular difficulties in accessing appropriate services as they sit between traditional paediatric and adult structures in services<sup>6</sup>. Young people with cancer can be vulnerable, at risk patients, have recognised protected characteristics under the Equality Act, and have greater need for social care, public health and health outcomes which are appropriate to this age range.

We believe that the creation of a separate children and young people’s framework, extending up to age 25, would be a viable approach to addressing these issues. Such an approach may better reflect the healthcare needs of this group and mitigate the high risk of ignoring or missing essential outcomes. However within such a framework there would have to be an alignment with the adult outcome framework to help the transition of patients from paediatric care and to adult care.

**Question 27: What are the biggest issues regarding accessibility to NHS Outcomes Framework data?**

As noted in our response to Question 1, the report of the Children and Young People’s Health Outcomes Forum suggests the use of five year age ranges to report data as this would better capture ‘significant’ transition points<sup>7</sup>. Yet the five year age range is not consistently used to report data. This affects the NHS Outcomes Framework data by making the data inconsistent.

**Question 44: What are your views on effective ways of measuring patient experience or safety outcomes related to access to appropriate care for**

- i. Children and Young people

We welcome the addition of an indicator to measure patient experience or safety outcomes related to access to age-appropriate care.

Access to age appropriate, person centred care for teenagers and young adults with cancer was identified as a priority in the NICE Improving Outcomes for Children and Young People with Cancer Guidance<sup>8</sup>, and reflecting the importance of this in the Outcomes Framework will be a welcomed step to ensure such care is delivered to patients. In line with this guidance, teenage and young adult specialist care facilities should now be accessible by all 13-24 year old cancer patients, with those aged up to 18 years being managed at a Principal Treatment Centre (PTC) and those aged 19 to 24 years being assessed at a PTC and being given the choice of where they are treated. Yet nationally this only occurs in around half of all cases<sup>9</sup>.

Age appropriate care for young people can improve their experience and safety outcomes. For example, being treated in a Teenage Cancer Trust unit at a Principal Treatment Centre means young people have

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<sup>6</sup> Annual Report of the Chief Medical Officer for 2012 (2013) *Our Children Deserve Better: prevention pays*

<sup>7</sup> The Children and Young People’s Health Outcomes Forum Report.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216852/CYP-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216852/CYP-report.pdf)

<sup>8</sup> National Institute for Health and Clinical Excellence (2005), *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*

<sup>9</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?*

expert psychosocial care and support, improved access to clinical trial entry and benefit from effective collaboration and communication between all teams involved in their care.

We understand the importance of indicators being feasible, cost effective with data routinely collected and available. We suggest a potential indicator for a proxy for the use of age appropriate care could be the number of patients in England diagnosed with cancer being notified to a Principal Treatment Centre or Children's Cancer and Leukaemia Group (CCLG) centre in England. This data is already collected by the North West Knowledge and Intelligence Team within Public Health England and could be used to show the referral of individuals to an appropriate care setting.