



## **Teenage Cancer Trust Response:**

### **Consultation on updated Service Specifications for Children with Cancer (August 2019)**

**For more information about our response please contact Ben Sundell, Head of Policy and Public Affairs – [ben.sundell@teenagecancertrust.org](mailto:ben.sundell@teenagecancertrust.org)**

#### **Do you support our proposals to enable hospitals to take greater responsibility for local care pathways through the establishment of Children’s Cancer Operational Delivery Networks?**

Teenage Cancer Trust, as with TYA Operational Delivery Networks, supports proposals to establish Children’s Cancer Networks that will have clear and consistent standards and expectations.

We support a network-based approach to care that will help ensure children with cancer are seen at the right time and in the right place in order to drive forward patients experience of care. We hope that the standardisation of paediatric oncology shared care units (POSCUs) will allow areas currently without shared care to establish services and allow for more sustainable areas where shared care networks already exist.

We particularly welcome the requirement on the CCNCG to develop clear transitional pathways for when patients move from children’s to TYA cancer services.

We are pleased to see the requirement on the CCNCG to promote participation in patient experience surveys and await the development of the Under 16 Cancer Patient Experience Survey. Whilst it is Teenage Cancer Trust’s position a bespoke survey for children and young adults aged 0-25 would be the most effective means of collecting tailored feedback on age appropriate care, in the absence of this, it would be useful for both the Children’s data in the Under 16’s survey, and the TYA data in the adult Cancer Patient Experience survey to be broken down by the Operational Delivery Networks.

Teenage Cancer Trust is supportive of the requirements that these specifications place upon the CCNCG but would like to be assured about what accountability structure will be put in place. We believe that the requirements in the specifications will help to improve the standard of care for children and young people and lead to better outcomes, but there needs to be a clear mechanism in place for ensuring that the Networks deliver on them. This needs to be a national body and we would suggest that the Children and Young Adults with Cancer Clinical Reference Group is best placed to do this.

#### **Do you support our proposals to help improve participation in clinical trials and research? Is there anything more that we could do to encourage and increase participation?**



There is no doubt that successive generations of clinical trials improve survival, as witnessed by substantive improvements in childhood cancer over the past three decades concurrent with high recruitment rates to studies. (Fern & Bleyer - 2018). Whilst this specification is for children's cancer services, Teenage Cancer Trust believes it is especially important to consider here that in the 0-25 age group, that teenagers and young adults have not benefitted from equitable access to potentially lifesaving clinical trials, in the same way that children have.

Teenage and young adult patients are significantly under-represented in cancer research - in the UK accrual rates are between 14-30% in 15-24 year olds, compared to 50-70% of children. This trend is also now reported across multiple healthcare systems.

It is therefore very welcome to see the requirement placed on TYA networks in the TYA Specifications to deliver a 10% increase by March 2021 and the overall participation rate of 50% by 2025, and are pleased to see the urgency with which they must be discussed at the TYA MDT (within 7 days). The proposals in the Children's Cancer Services Specification to continue to improve clinical trials participation in the younger age group is of course, very welcome.

Teenage Cancer Trust is pleased to see the requirement for every child with cancer to have the opportunity to have their data and tissue samples collected for future research. Similar to the point we make in our response to the TYA Service Specifications for young people, here we would say it is very important that there is good communication with children (particularly older children) and their families in order for them to understand what their samples are being used for, and how this could help improve outcomes for others.

### **Do you support our proposals to simplify and standardise shared care through the introduction of Standard and Enhanced shared care units?**

Teenage Cancer Trust is supportive of the position taken by CCLG/TYAC in their response to this consultation:

*'While we support the reorganisation and strengthening of the shared care networks, the current suggested nomenclature of 'standard', 'level A enhanced' and 'level B enhanced' is confusing. If there is a need to differentiate between the current 'levels 1, 2 and 3' and the new model, we suggest 'levels A, B and C'. 'Enhanced' from a point of view of parents may also suggest that a better level of care rather than a different type of service is offered.'*

This is important for TYA care as these are the services that many 13-15 year olds (and in some cases over) will access for their care local to home. The TYA Designated Hospitals will tend to offer their care for over 18s. It is crucial that this gap is considered across the country so that there is absolute clarity about where young people can receive care closer to home. In some places, young people will be considered too old for children's services (with many stopping at 16), whilst also being considered too young for the adult services that start at 18 years old.



**Do you think the proposed quality indicators included in the service specifications are appropriate to measure and monitor this service in the future?**

We support the range of indicators proposed to measure and monitor the service in the future. We are pleased to see an indicator in place to monitor policy being in place for transition.

We would like to see more detail on how the Networks will be held accountable against the requirements in the Services Specifications.

**Are there any changes or additions you think need to be made to the proposed service specifications?**

Teenage Cancer Trust has consistently raised concerns about Section 2.10 – ‘Interdependencies with other services’ because it moves away from the ‘default’ position of critical care (level 3) needing to be on-site. For us, patient safety, patient experience and patient outcomes should always be the top priority and we are concerned that allowing for variation on such a critical service may compromise these. Whilst we acknowledge the mitigations suggested to overcome this in terms of safeguards and enhanced monitoring, we strongly feel that this position still contains risks for patients. Recent press articles published in the HSJ relating to these issues and have highlighted a number of leading clinical and expert views which enforce our position of concern, along with other patient and professional bodies. We appreciate a decision has been made to appoint Professor Sir Mike Richards to undertake a review of responses to this consultation, this is a welcome measure and through which we expect transparency of decision-making based on evidence and clinical advice.