



Teenage Cancer Trust Response –

Consultation on updated Service Specifications for Teenagers and Young Adults with Cancer (August 2019)

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Do you support our proposals to enable hospitals to take greater responsibility for local care pathways through the establishment of Teenage and Young Adults Cancer Operational Delivery Networks?

Teenage Cancer Trust welcomes the updated Service Specifications as a great step forward to improve the experience and outcomes of young people with cancer.

We support the introduction of Operational Delivery Networks to coordinate the treatment and care of young people with cancer. Teenage Cancer Trust currently has representation on the existing TYA Networks across the country. As the only organisation dedicated to providing the appropriate support and care for 13-24 year olds with cancer across the UK, we would like to be assured that we would have representation on the quarterly TYANCG in every Operational Delivery Network. Ideally this would be written in to the Service Specifications.

In order to be highly effective, the Networks – and their members - need clear responsibilities and accountability, so we are pleased to see the requirement for a formal Memorandum of Understanding which set out the responsibilities of the Network and the constituent members. It is also critical that funding is made available to support the successful establishment of these governance arrangements.

We welcome the comprehensive list of criteria that the TYANCG is responsible for delivering. In particular we would like to comment specifically on the following:

- a) **Monitoring and accountability:** Teenage Cancer Trust is supportive of these Specifications which we believe will help to improve the standard of treatment and care for teenagers and young adults, and lead to better outcomes, but there needs to be a clear mechanism in place for ensuring that the Networks deliver on them. How will we be able to monitor progress of the Networks implementing the updated Specifications? What accountability structure will be put in place? Teenage Cancer Trust believes this function is best performed by a national body and we would suggest the Children and Young Adults with Cancer Clinical Reference Group.
- b) **Holistic Needs Assessment:** We are very pleased to see the requirement for Networks to approve a single TYA specific holistic needs assessment and recommend that the Teenage Cancer Trust Integrated Assessment Map (IAM) is adopted as the standard approach. The IAM is an age-specific, multi-domain framework which provides a structure to support professionals and young people in holistically assessing needs for information and support at any point in their



cancer journey. It is designed to look at the impact of, and adjustment to, their cancer and its treatment within a bio-psycho-social-educational-vocational framework – i.e. what does having this cancer and its treatment mean for this young person and their support network at this point in time. The IAM has been developed for access via a website (www.tyaiam.co.uk) and an app, available on Android and Apple mobile devices. Teenage Cancer Trust is already rolling IAM out to NHS Trusts across the country, with the portal currently live in Cheshire and Merseyside, East Midlands and the South West, whilst we have also begun implementation in South Yorkshire and Scotland.

Some examples of feedback that the IAM and the MDT management tool have received from young people and professionals are:

- *'I liked it because it is just for young people to give their thoughts and ideas. It gave me time to think, everyone should [have] a go... it's really useful'* (Young Person)
- *'Young people have found it helpful – [it is a] useful prompt/trigger to have difficult conversations'* (Professional)
- *'IAM & SWIMMS have improved and re-focused the MDT discussion on the psychosocial needs of our patients'* (Professional)

- c) **Psychological and Social Support:** Teenage Cancer Trust is pleased to see requirements for care pathways to describe the psychological and social support available to patients and families, and for the PTC or DH to facilitate this. Young people with cancer repeatedly report very negative experiences of the psychological support, or lack thereof, that they experienced during or after treatment. Young people consistently tell us that: they did not know there was support available; were not offered support at all; or felt that their support got suddenly cut off at the end of treatment. Other young people have told us that they did not receive a proper end of treatment summary but just a discharge letter. It is absolutely crucial that every young person and their family understands what support is available to them during and at the end of treatment, and that there is rapid re-access to the aftercare pathway should they need it. As discussed above, the best way to coordinate psychological support is through endorsing the IAM Portal as the single holistic needs assessment and ongoing support needs management tool for the TYA Networks.
- d) **Patient Experience Surveys:** We welcome the requirement to promote participation in patient experience surveys. Through analysis of the cancer patient experience survey responses for 16-24 year olds we know that those who receive age appropriate support consistently report better experiences of care. To this end, given that 16-24 year olds are not included in a bespoke survey for children and young adults, it would be useful for the TYA data in the adult Cancer Patient Experience survey to be broken down by the Operational Delivery Networks.
- e) **Prompt Referral to MDT:** We are very supportive of the requirement for every young person to be referred to the TYA MDT within seven days. We believe this will lead to improved outcomes such as increased participation in clinical trials and better, more joined-up psychological support.



In order that all young people are referred in this way, we would like to see data on the current referral rates in each area and a specific action plan to address the issue.

- f) **Fertility Preservation:** We were pleased to see a requirement for the TYA MDT to consider fertility preservation services for every young person. When Teenage Cancer Trust's Youth Advisory Group consulted on the earlier draft of the Service Specifications in February 2019, it was clear that several young people had had very negative experiences of being offered fertility treatment. Some young people said they weren't offered fertility preservation at all, while others felt that it was a 'half hearted' offer, which gave them no room for flexibility. For example, one young person was offered the opportunity on a single day only, and consequently missed out. Another told us that a presumption was made that fertility preservation was not necessary or relevant for him because he is gay and this is a particular concern for us. A repeated theme from those who did have fertility treatment offered was that it felt like it wasn't made out to be a priority to them from their treatment teams, with one young person telling us that they actually received incorrect fertility advice – being told at first that they didn't need preservation, but then after more treatment it turning out they did. One young person responding to our call for evidence for this consultation told us they would have liked to have been spoken to directly rather than via their parents. A number of young people who responded here said they had had no discussion about fertility at all. It is clear that in reality the outlaying of fertility options with professionals at the TYA MDT, and then relaying this directly to young people must improve considerably under these new Specifications. Teenage Cancer Trust would like every young person to be talked to about their fertility options and how their prognosis may or may not affect that. These conversations should take place regardless of whether the treatment plan involves a treatment that will necessarily affect fertility – in order for young people to have a full understanding of their prognosis and what to expect from their treatment.
- g) **Tumour Banking:** We are pleased to see the requirement on the TYA Network to ensure that every young person is offered an opportunity to tumour bank. This is a welcome step that could help to improve cancer survival for young people to come. When consulting the Teenage Cancer Trust Youth Advisory Group about their experiences of tissue banking, the majority of young people said they had been offered this already. However, many struggled to understand what it meant, and they would have appreciated some form of an update on what happened with their samples – or even a conversation more broadly about how them doing this could help others. One young person said that 'I want to know where part of my body has gone'. In conversations with young people about tumour and tissue banking, it is clear that discussing how their sample could lead to improvements and positively impact on other young people in the future should be part of the discussion.

Do you support our proposals to help improve participation in clinical trials and research?

This proposal is of fundamental importance to improving the outcomes for young people with cancer and Teenage Cancer Trust offers its full support.



There is no doubt that successive generations of clinical trials have improved survival, as witnessed by substantive improvements in childhood cancer over the past three decades concurrent with high recruitment rates to studies. (Fern & Bleyer - 2018).

However, it is evident that young people with cancer have not benefitted from equitable access to potentially lifesaving clinical trials, in the same way that children and older adults 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 for all young people with cancer to be discussed at a TYA MDT and we hope that this will be responsible for connecting more young people with available trials. We are pleased to see the requirement placed on the networks to deliver a 10% increase by March 2021 and the overall participation rate of 50% by 2025. We are also pleased to see the urgency with which they must be discussed at the TYA MDT (i.e. within seven days).

Is there anything more that we could do to encourage and increase participation?

However, whilst this will be a positive step in linking young people to existing trials, availability of the trials themselves is the major determinant of research participation, and if no recruiting study exists, there is no possibility of inclusion (Fern & Bleyer - 2018). Teenagers and young adults present with a unique range of cancer types that are typically rare. This has meant historically that trial availability itself has also been generally poor. Comparatively small numbers of the types of cancer young people experience compared with more common cancer types mean that drug development can be unattractive for rare cancers.

It is clear that in addition to TYA MDT discussions, more needs to be done to ensure that the right trials are being opened for young people with cancer. How does NHS England intend to achieve this?

There needs to be a joined-up approach to the delivery of the commitment to increasing young people's access to clinical trials. Teenage Cancer Trust would like to see a single strategy for implementation involving the National Institute for Health Research, NHS England, and continued involvement from third sector partners such as Teenage Cancer Trust. We would also like to be assured that any potential trials opened would be those likely to be most associated with improved survival outcomes and not just those that may be the simplest to run or collect data from.

Do you support our proposals to improve patient experience and care by introducing joint care arrangements between Principal Treatment Centres and designated hospitals to enable more care to be delivered closer to home?

Teenage Cancer Trust agrees with the proposals to develop a network approach to care which enables some elements of supportive care to be delivered closer to home. Wherever it is that young people are treated, they must have access to age appropriate care.



What specific support could NHS England could provide to help hospitals introduce joint care arrangements?

The proposals in the TYA Service Specifications will only be effective if they are adequately resourced.

Teenage Cancer Trust is concerned and would like reassurance about the capacity of staff in designated hospitals as described in the Specifications, due to them not having enough protected time to fulfil the TYA responsibilities set out.

Will resource be dedicated for administrative support for staff in Designated Hospitals? Will there be dedicated administrative or project management support available to the Network as a whole in order to actually drive forward and ensure delivery on the agreed work programmes?

Teenage Cancer Trust welcomes the detail identified about the workforce in relation to the Principal Treatment Centres and Designated Hospitals. In order to understand how Teenage and Young Adult speciality roles will be sustainably funded, we would like to see a TYA specific workforce strategy to sit alongside the Service Specifications and should include the funding sources for all core posts. Currently, Teenage Cancer Trust funds 90 TYA specialist staff across the UK (June 2019) including Nurses Consultants/Lead Nurses, Clinical Nurse Specialists, Youth Support Co-ordinators and MDT co-ordinators. In addition to this, we fund TYA specific training and development for some NHS funded staff.

We would also welcome reassurance on the funding that will be made available particularly to allow Designated Hospitals to increase their workforce in line with the specifications.

Do you support the introduction of service requirements and standards for designated hospitals?

Teenage Cancer Trust welcomes the separate specification for Designated Hospitals. We believe the creation of this framework will be beneficial, giving Designated Hospitals a standard to move towards that we believe will be achievable with the support of the Operational Delivery Network, and providing it is adequately resourced.

However, it is important to recognise that many of the Designated Hospitals may not yet be working to the standards outlined in the Specifications. We would like to understand expectations on them either transitioning to these requirements or to de-designate and what support will be made available.

Teenage Cancer Trust would also welcome clarification on what accountability there will be to ensure that patients are always referred to the Principal Treatment Centre hosted MDT by Designated Hospitals. We are supportive of plans to deliver some elements of care closer to home to improve patient experience, but it is crucial in reality that all cases are discussed at the Network MDT, which is hosted by the PTC in order to ensure the best care is coordinated.



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

Teenage Cancer Trust is broadly supportive of the indicators outlined. However we would like to see the following:

- Staging data to be broken down by age in order to better understand when young people are being diagnosed, and where is most effective to target interventions.
- An indicator that groups cancers by 'Early' and 'Late' stage in order to allow comparisons across cancer groups that are staged in different ways.
- An indicator to track the holistic needs assessment and ongoing psychological support.

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 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.