

Children's, Teenage and Young Adult's (TYA) Cancer Services Consultation Guide



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Purpose of this document

NHS England is committed to working with a wide range of patients, patient groups and other stakeholders in the development of its commissioning of specialised services. A public consultation is an opportunity to check whether proposals are right and supported, the public understand their impact, and identify any alternatives before decisions are made.

NHS England has launched a consultation to seek views on proposed changes to:

- **Children's Cancer Services.** These are used by children aged between 0 and 16. In some cases, and with the agreement of Teenage and Young Adult's Cancer Services, they may also treat teenagers up to the age of 18.
- **Teenage and Young Adult's (TYA) Cancer Services.** These are used by teenagers and young people aged between 16 up to the day before their 25th birthday. In some cases, and with the agreement of Children's Cancer Services, they may also treat teenagers from the age of 13.

The consultation will run for 60 days from **Wednesday 5 June to Sunday 4 August.**

This document sets out:

- how care is currently provided;
- the proposed changes and reasons for these; and
- how the proposed changes will be implemented.

The document also has information about how you can share your views with NHS England. At the end of the consultation period, all feedback will be considered and a decision will be made about how services should be delivered in the future.

Conversations will then take place at a local level with services to determine the best way to deliver this care at a local level.

We recommend that you read this consultation guide alongside other documents published as part of the consultation. While a single consultation guide has been produced to summarise the proposals, the remainder of the documentation is service specific.

Children's Cancer Services:

- [Children's Principal Treatment Centre \(PTC\) and Network Service Specification](#)
- [Paediatric Oncology Shared Care Unit \(POSCU\) Service Specification](#)
- [Children's Impact assessment](#)

TYA Cancer Services:

- [TYA Cancer Principal Treatment Centre \(PTC\) and Network Service Specification](#)

- [TYA Designated Hospitals Service Specification](#)
- [TYA Impact assessment](#)

A service specification is a contractual document that describes the clinical service and sets out appropriate standards and quality measures that provider organisations must satisfy. The Impact Assessments set out the potential impact of our proposed changes on both patients and services.

Context

The NHS Long Term Plan (NHS England, 2019) included a number of important commitments for improving the outcomes and experience of children, teenagers and young adults with cancer. The plan, which builds on the National Cancer Taskforce Report (2015) that preceded it, includes commitments to:

- develop and implement networked care to improve outcomes for children and young people with cancer, simplifying pathways and transitions between services and ensuring every patient has access to specialist expertise;
- support children and young people to take part in clinical trials, so that participation among children remains high, and among teenagers and young adults rises to 50% by 2025; and
- put in place more effective consent processes for using data and tissue samples in research will contribute to improving survival outcomes.

This consultation sets out how NHS England proposes to deliver on these commitments. The consultation follows an extensive review undertaken with the support of the Children's and Young People's Clinical Reference Group (CYP CRG). As part of the review, NHS England conducted extensive engagement with patients and their families, clinicians, service providers during September and October 2017. This included a Facebook Live session, conducted by CLIC Sargent, with parents of children and teenagers with cancer, and teenagers and young adults with cancer.

We have also completed a period of formal stakeholder engagement on the draft service specifications. Reports of the findings of stakeholder engagement are available as part of the public consultation documentation.

The results of engagement have provided a rich source of information about the issues affecting service delivery and how services could be improved. It has also confirmed that there is strong consensus about both the issues and the proposed changes.

How is care currently provided?

Children's Cancer Services

What we know about children's cancer

- ✓ It is rare – around 1,600 children under the age of 15 are diagnosed with cancer each year in the UK.
- ✓ Most cancers affecting children are different to those affecting adults – they occur in different parts of the body, they are biologically different, and they respond differently to treatments.
- ✓ Treatment can be complex and intensive.
- ✓ Approximately two thirds of children receive treatment as part of a clinical trial.
- ✓ Cure rates in children with cancer are much higher than for adults with cancer with more than 80% of children surviving their cancer for 10 years or more (Cancer Research UK).
- ✓ Over the previous 15 years, although cancer survival rates are higher than they have ever been in children and are broadly in line with those of developed countries, they still fall behind countries with the highest survival such as Germany and Canada (Bonaventure et al, 2017).
- ✓ Outcomes can still be improved, specifically in terms of preventing cancer, getting patients a quicker diagnosis, and giving all those with cancer better treatment and care (NHS Five Year Forward View, NHS England, 2014).
- ✓ Despite clinical trial recruitment rates being high for children, it is estimated that currently only around 40% of tumour tissue is banked to support future research studies.

Children with cancer currently receive care primarily from a **Principal Treatment Centre (PTC)**, which provides specialist care. In the current model of care, PTCs work in partnership with **Paediatric Oncology Shared Care Units (POSCUs)**, which provide supportive care and shared care closer to a patient's home. In this arrangement, PTCs hold overall responsibility for cancer diagnosis, treatment and management. Together, a PTC and its associated POSCUs are referred to as a **Children's Cancer Network**.

In this context, supportive care means treatment of the side effects of cancer rather than the treatment of the cancer and includes antibiotics, blood tests and treatment for nausea and vomiting. It also includes emergency care because children with cancer can become sick very quickly and therefore require rapid access to supportive care. For this reason, every POSCU is co-located with a Children's Accident and Emergency unit.

Shared care arrangements mean that children can have some treatments closer to home, minimising the burden of travel. Most, but not all, POSCUs currently deliver

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some elements of chemotherapy, as part of shared care arrangements and under the direction of the PTC. The types of chemotherapy offered by different POSCUs varies significantly. The ability to have chemotherapy closer to home is beneficial because most children with cancer will receive chemotherapy at some point in their treatment journey and chemotherapy usually requires multiple hospital attendances over a long period of time.

There are currently 13 PTCs and 80 POSCUs across England providing shared care to children with cancer, and there are three levels of POSCUs:

- **Level 1** – There are 54 Level 1 POSCUs which are responsible for providing supportive care and basic outpatient chemotherapy.
- **Level 2** – There are 14 Level 2 POSCUs which are responsible for providing Level 1 care together with day-case chemotherapy.
- **Level 3** – There are 12 Level 3 POSCUs. Level 3 is the highest level of shared care and means that the POSCU will provide both Level 1 and 2 services, together with inpatient chemotherapy.

Teenage and Young Adult's Cancer Services

What we know about TYA cancer

- ✓ Cancer in TYAs is rare and accounts for less than 1% of all cancer diagnoses.
- ✓ Approximately 2,200 cancers are currently diagnosed each year in England for patients aged between 15-24 years (Cancer Research UK).
- ✓ Cancer is the leading cause of death from disease in teenagers and young adults in the UK, accounting for 9% of deaths in all males and 15% of all deaths in females aged 15-24.
- ✓ Participation in research is low with only 10-25% of TYAs with cancer participating in clinical trials.
- ✓ Less than 10% of TYAs currently bank tissue to support future research studies.
- ✓ Survival for TYAs is significantly lower than for children in specific cancer types, including bone tumours and soft tissue sarcomas, acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML). Factors relating to diagnosis, different treatment protocols and low levels of participation in clinical trials are thought to explain some of the differences.
- ✓ Some analyses indicate that there is a statistically significant association between TYA cancer incidence and survival and geography and deprivation ([Public Health England, Teenage Cancer Trust, 2018](#)).
- ✓ The needs of teenagers and young adults with cancer differ from younger children and from adults, particularly in relation to emotional and social needs. Therefore, cancer services for TYA are planned and delivered separately to services for children and for adults.

Teenagers and young adults with cancer currently receive care from either a **TYA Cancer Principal Treatment Centre (TYA PTC)** or a **TYA designated hospital**, working as part of a **TYA Cancer Network**. The role of the TYA Cancer Network is to co-ordinate care for young people with cancer across a defined geography.

All teenagers aged between 16 – 18 years of age have their care managed and delivered by the TYA PTC. Young people aged between 19 and 25 years of age can choose whether to have treatment at either a TYA PTC or a TYA designated hospital, which may be closer to home. Unlike for Children's Cancer Services, there is no model of shared care in place that would enable an individual treated by the TYA PTC to have supportive care and/or some elements of treatment delivered closer to home in a designated hospital and under the direction of the TYA PTC.

Another key difference between Children's and TYA Cancer Services is how the diagnosis and treatment planning decisions are made. For teenagers and young people with cancer, they are usually made by the adult cancer team that has the relevant clinical expertise for the specific form of cancer. For example, an individual

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with cervical cancer will be diagnosed and treated by the adult gynaecology cancer team, whilst an individual with a blood cancer will be managed by the adult haematology cancer team. These teams are referred to as 'site-specific multi-disciplinary teams (MDTs)'.

Given the rarity of cancer in this group, all cases should be referred to the specialist TYA MDT for discussion, which is hosted by the TYA PTC. The membership of the TYA MDT has a wealth of experience in TYA cancer and is best placed to ensure that optimal care, including recommending appropriate clinical trials, and holistic support is available to every individual. The full membership of this team is listed in the [TYA Cancer Principal Treatment Centre \(PTC\) and Network Service Specification](#).

There are currently 14 TYA PTCs and 80 TYA designated hospitals across England. The numbers of these services differ between regions.

What changes are being proposed and why?

NHS England is proposing changes to both the existing Paediatric Oncology and TYA Cancer Service Specifications, including replacing these with separate specifications for both PTCs, POSCUs and TYA designated hospitals. Chemotherapy services have also been integrated within each of these specifications.

What is not proposed to change are the:

- number and location of either the Children's and TYA PTCs. This is because PTCs play an important role in co-ordinating care which is set to increase in importance and complexity as both genomic medicine advances and new, increasingly specialist treatments, such as CAR-T cell therapy, are introduced; and
- organisation of services, i.e., both POSCUs and designated hospitals will continue to play an important role in providing care to children and teenagers and young adults with cancer.

Under our proposals, both Children's and TYA PTCs will continue to host the Cancer Networks and will continue to oversee and be responsible for the care provided. They will also receive additional resources to assist with this role.

NHS England are proposing six key changes, of which:

- the first two relate to the function and form of both Children's and TYA Cancer Networks;
- the third and fourth relate to the provision of shared care within Children's Cancer Services; and
- the final two relate to designated hospitals and introduce a model of joint care within TYA Cancer Services.

(1) Both Children's and TYA Cancer Networks will become Operational Delivery Networks with the responsibility for driving improvements within the network and across partner organisations, including recruitment to clinical trials. The exact roles and responsibilities are defined in the relevant service specifications. The Networks will be expected to hold quarterly meetings and have a process in place to ensure that:

- patients are treated in the right place and at the right time;
- consistent transition arrangements, particularly between both Children's and TYA Cancer Services, are agreed and adhered to;
- fertility service arrangements are put in place in accordance with recommendations made by the National Institute of Health and Care Excellence;
- clinical and quality outcomes are reviewed;
- learning is shared across the network;

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- there are training and development opportunities across the network; and
- there are effective access arrangements in place for those specialist services that are not available in every Network, including Proton Beam Therapy and CAR-T cell therapy.

The National Cancer Strategy also highlighted the need to improve pathways and transitions, stating that:

“Transitions continue to pose a problem in some areas, with paediatric services stopping at 16 in some hospitals but adult services not starting until 18. In addition, pathways between specialist centres and shared care units currently cause a great deal of difficulty for patients. This needs to be addressed”.

These issues were also echoed by stakeholders during the engagement programme. During the September 2017 engagement events, and in response to these issues, strong consensus emerged that the Networks needed to be able to make decisions and take appropriate action when standards of care are not what they should be. Furthermore, that they should be able to organise and manage the overall service provision for children and teenagers and young adults. These types of functions go beyond the current remit of the Networks.

It is therefore proposed that both the Children’s and TYA Cancer Networks will become Operational Delivery Networks. This will provide each Network with the appropriate authority and responsibility for agreeing and directing patient pathways within their local geography. Further information about Operational Delivery Networks is published on the NHS England [website](#).

The Operational Delivery Network will be hosted by the PTCs which will also receive additional resources to support implementation and to strengthen the Network function. Children’s Networks will be expected to allocate a significant amount of the additional resources to reviewing and improving POSCU provision and ensuring timely access arrangements are in place for specialist treatments that are not available locally. TYA Networks will be expected to allocate a significant amount of the additional resources to ensuring that all cases are discussed in the TYA MDT and that clinical trial participation can be improved.

Strengthening Networks will contribute to the Long Term Plan commitment to increase access to specialist expertise, for both children and teenagers and young people.

(2) All children, teenagers and young adults with cancer will be offered an opportunity to have their data and tissue sample to be collected for future research studies. This aims to make it easier and faster to conduct future research studies. Increasing participation in clinical trials and research is an important aspect

of improving treatments in the future and could help improve cancer survival and quality of life. For these reasons, the new service specifications include this requirement, in accordance with the current legal framework governing consent. Networks will be tasked with overseeing this change and progress will be monitored through the new Specialised Services Quality Dashboards.

As part of NHS England's commitment to introducing genomic medicine, from 2019 all children with cancer will be offered whole genome sequencing which will enable comprehensive and precise diagnosis and access to more personalised treatments. Alongside this, children will also be asked for consent to bank tissue.

(3) POSCUs will be defined as either 'standard' or 'enhanced', depending on whether they provide chemotherapy services. Currently all three levels of paediatric oncology shared care can provide some element of chemotherapy. However, analysis of chemotherapy activity over a four-year period indicates that a fifth of Level 1 POSCUs (11 units) provide no chemotherapy. A further group of POSCUs deliver only very low levels of chemotherapy activity.

The National Cancer Taskforce Report highlighted that the pathways between specialist centres and shared care units needed to be addressed. This was also reinforced throughout our engagement programme, where both clinicians and families of children with cancer communicated the variability of service provision in some POSCUs, with treatments or advice often being very dependent on specific, individual staff members being on-duty. Clinicians also highlighted that this made working effectively with large numbers of POSCUs to safely oversee patient care more difficult for the Children's PTCs.

The experience of shared care was also explored during the Facebook Live session hosted by CLIC Sargent. The views of parents about how services should be configured were mixed; some felt that having fewer, more centralised shared care units might improve the experience of care and service provision, while others were concerned about the impact that this might have on emergency situations and travel.

It is therefore proposed to simplify and standardise the type of care offered by POSCUs, so that shared care arrangements are consistent across England. The proposals are as follows:

- Standard POSCUs – which will provide specialised supportive emergency care for children with cancer. They will not provide chemotherapy services. However, units that also deliver other treatments, for example, children's cancer surgery, will continue to do so; and
- Enhanced POSCUs – which will provide the same specialised supportive emergency care as Standard POSCUs and will be able to deliver chemotherapy services. These will be split into two levels:

- Level A, which will be able to deliver outpatient and day-case chemotherapy.
- Level B, which will be able to deliver the same as Enhanced Level A POSCUs as well as deliver inpatient chemotherapy.

The introduction of a 'Standard POSCU' designation will serve to reinforce the importance of providing supportive and emergency care for children with cancer and normalise the working practice of those POSCUs not currently delivering chemotherapy. This is an essential element of our approach to reducing deaths from bacterial sepsis¹, as is building closer relationships with children's accident and emergency teams where there is no co-located POSCU. It is also expected that some networks will want to expand standard POSCU provision to increase the provision of supportive care, this is particularly the case for the North of England.

Similarly, the introduction of an 'Enhanced POSCU' designation provides a consistent framework for service delivery and clearly sets out the infrastructure required to be in place. By also empowering Operational Delivery Networks to manage and develop local children's cancer pathways, in partnership with Cancer Alliances and commissioners, it is our expectation that more children will be able to access a greater range of chemotherapy treatments, including clinical trials, outside the PTC.

The approach set out above is largely unchanged from that set out during stakeholder engagement which was supported, subject to some clarifications as to specific service standards which are reflected in the consultation versions of the Specifications. For further details, please see the Children's Engagement Report.

(4) POSCUs delivering chemotherapy should expect to treat a minimum number of patients per year. Treating very low numbers of patients with chemotherapy is considered to present significant challenges in terms of staffing levels and skill-mix, sustainability and, sometimes, service quality. Low volumes of chemotherapy activity may also be a barrier to investing in children's chemotherapy e-prescribing systems, which are known to improve service safety and remain a mandatory requirement for providers.

This proposal builds on the new POSCU categories and is designed to support improvements in pathways between specialist centres and shared care units for patients. The proposal should help to ensure that more consistent chemotherapy services are provided, which was a key concern expressed by stakeholders, including from children's family members.

¹ [National Confidential Enquiry into Patient Outcomes and Death \(December, 2018\)](#)

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As with our proposal to amend the categories of POSCU provision, the recommendations made in relation to minimum chemotherapy volumes are unchanged from those presented during Stakeholder Engagement. The response from stakeholders indicated that the proposal was supported. For further details, please see the Children's Engagement Report.

Our proposals are that:

- enhanced Level A POSCUs will be expected to manage, on average over a five-year period, a caseload of at least 10 new patients each year; and
- enhanced Level B POSCUs will be expected to manage, on average over a five-year period, a caseload of at least 20 new patients each year.

The standards are based on the advice of the CYP CRG in relation to the expected activity volumes required to be able to consistently offer the different types of chemotherapy treatments to patients.

It is important to note that these standards are a guide for Operational Delivery Networks to consider, alongside several other important factors. They are neither 'must do' standards, nor are they intended to act as a 'one size fits all'. Furthermore, because the incidence of children's cancer is increasing, it is our expectation that many Networks will want to consider expanding the role of some POSCUs so that they can offer a greater range of chemotherapy treatments outside the PTC. This may also help to release capacity in PTCs for more complex cases.

For these reasons, an early task for the newly formed Children's Cancer Operational Delivery Networks will be to review POSCU service provision and make recommendations where it is considered that changes are required to improve the care and experience of care offered to patients.

Networks will be required to balance the recommendations about chemotherapy volumes against other important factors, including ease of travel and travel time and whether lower volume POSCUs also have a critical mass of related services, e.g., Blood and Marrow Transplantation and CAR-T cell services and whether they have e-prescribing systems in place. In some areas it is expected that this will mean that Networks will opt to retain local access to chemotherapy services, even where activity may be lower than recommended.

(5) Clear standards for TYA designated hospitals will be introduced. These standards clarify both the facilities that need to be available for teenagers and young people with cancer, the structure of the clinical teams delivering care and the relationship between the designated hospital, the TYA Cancer Network and, critically, the TYA MDT.

The standards have largely been taken from existing guidance, including Improving Outcomes Guidance and Peer Review measures and, as such, are not brand new. However, for the first time they have been included in a standalone TYA Designated Hospital Service Specification. This is intended to serve as the contractual framework to support the designation / de-designation of units, as recommended within the National Cancer Strategy. This means that there will be a framework that can be used to support Operational Delivery Networks to either commission new TYA designated hospitals or, in rare circumstances, de-commission existing facilities.

The Cancer Taskforce recommendation was not intended to trigger a programme of decommissioning TYA designated hospitals. The aim was to codify universal service standards and empower TYA Networks to drive service improvements. For this reason, both the immediate and overall impact of the changes on the provider landscape is expected to be minimal. The focus of implementation will be on supporting designated hospitals to improve the care and support offered and not on de-designation.

Our approach formed part of the proposals considered during stakeholder engagement and was supported by stakeholders. For further details, please see the TYA Engagement Report.

(6) 'Joint care' between TYA PTCs and designated hospitals will be introduced.

This will mean that both teenagers and young adults will have the option to receive supportive care at both a TYA PTC and a TYA designated hospital, closer to home. In some TYA Cancer Networks, it may also be possible for teenagers aged between 16 and 18 years of age, being treated by the TYA PTC, to receive some elements of treatment, such as chemotherapy, closer to home in TYA designated hospitals. This will need to be decided at a local level and reflect the infrastructure and staffing levels at individual TYA designated hospitals to ensure these services are delivered safely.

As with proposals for Children's Cancer Services, it is important to be able to access supportive and emergency care quickly². This means that it is essential for TYA PTCs and TYA designated hospitals to strengthen their relationships with Accident and Emergency teams and improve the advice given to TYA patients and their families about the possible complications of treatment.

How will these proposed changes be implemented?

Implementation of these proposals will be led by the new Operational Delivery Networks with the support of Cancer Alliances and NHS England. It is anticipated

² [National Confidential Enquiry into Patient Outcomes and Death \(December, 2018\)](#)

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that in the first year of implementation, which is expected to be 2019/20, the networks will complete an assessment of compliance of PTCs, POSCUs and TYA designated hospitals against service standards. Following this, networks will need to finalise the service provision for their local geography, in partnership with Cancer Alliances and commissioners.

It is important to note that any changes to local services that impact on access and travel times will be carried out in line with NHS England's public involvement duties and standard processes. This means that they may be subject to further public consultation. As a result, full implementation of the proposals may not occur till the end of March 2021.

What do you think of these proposed changes?

NHS England would like to hear what the public think about these proposed changes to both Children's and Teenage and Young Adult's Cancer Services. Specifically:

Children's Cancer Services

1. 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?
2. Do you support our proposals to help improve participation in clinical trials and research?
 - a. Is there anything more that we could do to encourage and increase participation?
3. Do you support our proposals to simplify and standardise shared care through the introduction of Standard and Enhanced shared care units?
4. Do you support the Children's Cancer Operational Delivery Networks taking a greater role in shaping how chemotherapy is delivered across the Network to improve outcomes and patient experience?
5. Do you think the proposed quality indicators included in the service specifications are appropriate to measure and monitor this service in the future?
6. Are there any changes or additions you think need to be made to the proposed service specifications?

Teenager and Young Adults

1. 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?
2. Do you support our proposals to help improve participation in clinical trials and research?
 - a. Is there anything more that we could do to encourage and increase participation?

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3. 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?
4. What specific support could NHS England could provide to help hospitals introduce joint care arrangements?
5. Do you support the introduction of service requirements and standards for designated hospitals?
6. Do you think the proposed quality indicators included in the service specifications are appropriate to measure and monitor this service in the future?
7. Are there any changes or additions you think need to be made to the proposed service specifications?

The consultation is set to run from **Wednesday 5 June to Sunday 4 August 2019**. There are a number of ways you can share your views with NHS England.

- Complete the online surveys for [Children's cancer services](#) and [Teenager and Young Adult's services](#).
- Email – england.npoc-cancer@nhs.net.
- Write – Children & TYA Cancer Consultation, NHS England, Floor 3B, Skipton House, 80 London Road, London, SE1 6LH
- Join a webinar – (details included on the consultation landing page)
- Invite NHS England – we are happy to attend meetings or events that you may be hosting to talk about the future of either Children's and/or Teenager and Young Adult Cancer Services. Please email – england.npoc-cancer@nhs.net

Your views will help NHS England to further shape and refine the plans for both Children's and Teenage and Young Adult Cancer Services and will ensure that we are delivering safe and high quality care which meets the needs of patients and their families.