

# Teenage and Young Adult Cancer Clinical Network Specification

Date May 2023

## Executive Summary

The Teenage and Young Adult (TYA) Cancer Network, (the 'Network') is designed to bring the key teams and personnel together that comprise the clinical and holistic components of the pathway of care for teenagers and young adults with cancer. The goal of the Network is to enable service users to access the right care in the right place and at the right time, including clinical trials, while benefiting from co-ordinated holistic and psychosocial support.

This document must be read in conjunction with the service specifications for TYA Principal Treatment Centres (TYA PTC) and TYA Designated Hospitals (TYA DH).

## 1. Clinical Networks

Clinical Networks are a vehicle for specialty level collaboration between patients, providers and commissioners. They should have a clear line of accountability to Integrated Care Boards (ICBs), and NHS England (NHSE) Regional Teams, to ensure local ownership, alignment and a local mandate.

All networks have an important role in delivering the triple aim, supporting:

- better health and wellbeing of everyone,
- the quality of care for all patients, and
- the sustainable use of NHS resources.

This specification sets out the appropriate scope for the work of TYA Cancer Network. This will inform the development of the annual workplans developed in conjunction with network commissioners. No network will, or could, focus on all aspects of the scope described, at one time.

## 2. Teenage and Young Adult Cancer - Strategic Context

There are a range of very specific challenges in delivering optimal care for teenagers and young adults with cancer, including:

- The unique distribution of tumour types within this age range – these are primarily haematological malignancies, sarcomas, CNS tumours, germ cell tumours and malignant melanoma. However, tumours generally limited to children or cancers primarily seen in adults may infrequently develop in TYA patients – this interface can lead to uncertainty regarding the optimal treatment approach, i.e., 'paediatric' or 'adult' treatment.
- Poorer survival rates for the same tumours, more frequent side effects related to treatment and poorer access to clinical trials than compared to children.
- Poorer experience of care compared to adults, as consistently reported in the National Cancer Patient Experience Survey (NCPES) (Furness et al, 2017).
- Unique psychosocial, information and educational needs consequent on the normal developmental process of adolescence.
- Issues in maintaining compliance with treatment protocols.

The purpose of the Network is to navigate these challenges, ensuring delivery of the NHS Long Term Plan ambitions for the service, as well as optimal operational delivery of safe, effective and efficient TYA cancer services, in accordance with national service standards. This will be achieved through the effective coordination of care pathways between providers within the geographical area served by the Network, and sometimes beyond, enabling access to both specialist expertise and locally delivered elements of care, as appropriate.

For supporting strategy and policy documents, please see:

- Achieving world class cancer outcome – a strategy for England 2015-2020 (see specific recommendations: 43, 44, 45)
- Chapter 3 of the NHS Long Term Plan

Within TYA cancer services, the following definitions are used:

- Teenager refers to people aged 16 to 18 years, up to the 19<sup>th</sup> birthday;
- Young Adult refers to people aged 19 to 24 years, up to the 25<sup>th</sup> birthday; and
- Teenager and Young Adult refers to people aged 16 to 24 years, up to 25<sup>th</sup> birthday.

The model of care for TYA cancer services requires that:

- Each teenager (up to the 19<sup>th</sup> birthday) with a suspected diagnosis of cancer must be referred to the TYA PTC for diagnosis and agreement of a treatment plan. The TYA PTC will also deliver most of the care and will co-ordinate referral to supra-network services and local specialist cancer services for specific treatments not provided by the TYA PTC.
- Each young adult (aged 19-24 years) must be referred to either a TYA PTC or TYA DH for diagnosis and agreement of a treatment plan, having been offered a choice of the two. The choice must be documented in the TYA multi-disciplinary team (MDT) referral proforma. The relevant service will also deliver most of the care and will co-ordinate referral to supra-network services and local specialist services for specific treatments not available within the service.
- Each teenager and young adult, irrespective of where treatment is delivered, must be discussed in the TYA MDT meeting which is hosted by the TYA PTC. The purpose of the TYA MDT is to review the treatment plan made by the site-specific MDTs to ensure that each person: (i) is offered the choice of participating in appropriate clinical trials; and (ii) has their holistic needs identified and met.
- Each teenager and young adult receiving care primarily at the TYA PTC, may have their treatment delivered entirely within the TYA PTC or through a joint-care model with a TYA DH, closer to home. The exceptions to this relate to where some conditions are managed by supra-network services and or local specialist cancer services.

In view of the need to ensure that there are no gaps in services, the model of care also allows for some networks to vary age criteria and there may be some flexibility in age boundaries of services to enable service users to access optimum disease and age-

appropriate services. Under agreed network arrangements, and in conjunction with Children's Cancer Services, it may be appropriate for a TYA Principal Treatment Centre (PTC) Service to treat people aged 13 years and above; similarly, for some Children's Cancer PTCs to treat people aged 18 years and younger.

### 3. Network Scope

#### 3.1 Scope

The Network is principally responsible for the co-ordination of care pathways that are delivered by both the TYA Principal Treatment Centre and TYA Designated Hospitals – together, these services deliver diagnostic, treatment, specialist palliative care services and aftercare (sometimes called survivorship). The Network will also be responsible for ensuring seamless pathways to specialist services that are not delivered under the auspices of TYA PTCs and TYA DHs, as follows:

<b>NHS England Service Specification</b>	
<b>SUPRA-NETWORK SERVICES</b>	
<b>Service Specification Title</b>	<b>NHS England Reference</b>
Paediatric Radiotherapy Services	TBC
Proton Beam Therapy Service (all ages)	170071S
Proton Beam Therapy Service - Overseas Programme (adults and children)	170012/S
Haematopoietic Stem Cell Transplantation (Children)	B04/S/b
Haematopoietic Stem Cell Transplantation (Adults)	B04/S/a
Retinoblastoma Service (Children)	E04/S(HSS)/a
Stereotactic Radiosurgery and Stereotactic Radiotherapy (Intracranial) (All Ages)	D05/S/a
Primary Malignant Bone Tumours Service (Adults and Adolescents)	B12/S(HSS)/a
Penile (Adult)	B14/S/b
Testicular (Adult)	B14/S/c
CAR T-cell Therapy	TBC
<b>NETWORK SPECIALIST SERVICES</b>	
<b>Service Specification Title</b>	<b>NHS England Reference</b>
Children's Cancer – Principal Treatment Centres (inc. the Network)	1746
Chemotherapy (Adults)	B15/S/a
External Beam Radiotherapy Services (Adults)	B01/S/a
Brachytherapy and Molecular Radiotherapy (All Ages)	B01/S/b
Soft Tissue Sarcoma (Adult)	B12/S/a
NHS Genomic Laboratory Services	TBC
Oesophageal and Gastric (Adult)	B11/S/a
Brain and Central Nervous System (Adult)	B13/S/a
Specialised kidney, bladder and prostate cancer services (Adult)	B14/S/a
Head and Neck (Adult)	B16/S/a
Complex Gynaecology -Specialist Gynaecological Cancers	E10/S/f
Thoracic Surgery - Adults	170016/S

Child and Adolescent Mental Health Services (CAMHS) Tier 4: General adolescent services including specialist eating disorder services	170022/S
Tier 4 Child and Adolescent Mental Health Services (CAMHS): Children's Services	C07/S/b
Paediatric Medicine: Palliative Care	E03/S/h

### 3.2 Population Covered

All providers of TYA cancer services in England will be required to be part of a TYA cancer clinical network. Each Network has been established such that it has at least one TYA PTC within the population it covers, which, in-turn, have a number of associated TYA Designated Hospitals. The networks are:

#### NORTH EAST AND YORKSHIRE

- Yorkshire & Humber (1) – PTC is Sheffield Teaching Hospitals NHS Foundation Trust
- Yorkshire & Humber (2) – PTC is Leeds Teaching Hospitals NHS Trust
- North East and North Cumbria – PTC is The Newcastle Upon Tyne Hospitals NHS Foundation Trust

#### NORTH WEST

- Greater Manchester and Lancashire – PTC is The Christie NHS Foundation Trust
- Cheshire and Merseyside – PTC is The Clatterbridge Cancer Centre NHS Foundation Trust

#### MIDLANDS

- West Midlands Children & Young People's Cancer ODN – PTC is University Hospitals Birmingham NHS Foundation Trust
- East Midlands Children's and Young Persons' Integrated Cancer Service – Joint PTCs are Nottingham University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust

#### EAST OF ENGLAND

- East of England – PTC is Cambridge University Hospitals NHS Foundation Trust

#### LONDON

- North Thames Paediatric and TYA Cancer Network – PTC is University College London Hospitals NHS Foundation Trust
- South London – PTC is The Royal Marsden NHS Foundation Trust

## **SOUTH EAST**

- Thames Valley and Wessex – There are two standalone PTCs in this ODN: Oxford University Hospitals NHS Foundation Trust and University Hospital Southampton NHS Foundation Trust

## **SOUTH WEST**

- South West - University Hospitals Bristol and Weston NHS Foundation Trust

**Wales and Scotland:** While some residents of Wales and Scotland receive their care in England, hospitals in these countries are not part of these networks.

Networks in England will work with colleagues in Scotland and Wales to offer mutual aid as appropriate at times of service pressure.

**Crown Dependencies:** Residents of the Channel Islands and the Isle of Man receive their care in England and for this reason hospitals in these territories are also part of these networks.

**Northern Ireland:** While some residents of Northern Ireland receive their care in England, hospitals in Northern Ireland are not part of these networks.

## **4. Network Aims and Objectives**

### **4.1 Network Vision and Aims**

The aim of the Network is to provide a pathway focussed leadership of service delivery ensuring coordination of patient pathways between providers over a wide area to ensure access to specialist support.

Working closely with Cancer Alliances, commissioners, providers and patients, the Network will respond to need through national, regional and local determination, depending on the identified challenges.

### **4.2 Network Objectives**

The objectives of the Network are to:

- Improve the experience of care
- Improve integration between different TYA cancer services within a geographical area
- Increase participation in clinical trials
- Increase tumour banking rates;
- Improve the transition between children's and TYA services and TYA and adult cancer services
- Ensure that there is no age gap between different services, particularly for 16-18 year olds as they may transition between children's cancer services and adult services
- Embed genomic medicine within TYA cancer services.

### **4.3 Network Functions**

The Network is expected to have responsibilities in each of the seven key functions identified below. The balance of functions will be agreed locally taking account of the network scope, local need and network maturity.

#### *Service delivery: plan and manage capacity and demand*

- Support pandemic restoration and recovery planning and delivery.
- Develop and agree an operational policy detailing the range of cancers and age group of patients covered within the service, ensuring that there are no gaps particularly for 16-18 year olds.
- Develop and ensure the operation of common referral, care and transfer pathways and other policies, protocols, and procedures across the network.
- Develop and agree a network-wide, TYA-specific holistic needs assessment (HNA) for use with patients across the whole pathway from diagnosis to treatment completion.
- Undertake capacity planning and activity monitoring to ensure service capacity matches demand requirements, identifying and resolving gaps and blockages in services

#### *Resources: stewardship of resources across whole pathway and minimising unwarranted variation*

- Standardise drugs, devices etc. for best value, using collaborative purchasing arrangements to achieve the best price.
- Reduce unwarranted variation in pathways and processes that lead to inefficiencies.
- Support consistent, network-wide implementation of digital healthcare approaches that offer greater efficiency e.g. remote patient monitoring.
- Support consistent, network-wide implementation of new approaches to outpatient care e.g. phone/video OP clinics, patient-initiated follow-up.
- Improve effectiveness and appropriateness of use of high-cost treatments and consumables.

#### *Workforce: flexible, skilled, resilient staffing*

- Assess future workforce needs for provision of TYA cancer services across the network taking into account projected demand.
- Support providers to develop and implement innovative and extended roles for non-medical staff groups, through training and development and network wide policies and procedures.
- Assess training needs for the network (including baseline skills audit and network maturity assessment) and networked services.
- Develop and agree a network training plan that meets the needs of the network both in the delivery of care and in the functioning of the network.
- Agree with commissioners and providers how the planned training will be resourced and delivered.
- Monitor delivery and assess the effectiveness of the agreed training.

- Enable the movement of staff through the implementation of a staff passport.
- Promote workforce resilience through:
  - mutual aid agreements;
  - health and wellbeing support for staff.

**Quality:** *improving quality, safety, experience & outcomes*

- Ensure joined-up clinical governance systems and policies are in place between the TYA PTC and TYA DHs. Establish and maintain systems for the collection, analysis and reporting of key indicators of outcomes, quality of care and patient experience and ensure data is submitted as required.
- Reduce variations in care access, outcomes and experience.
- Run regular clinical forums to review outcomes across the network.
- Develop an active patient engagement strategy, involve patients in their care of and use patient feedback to monitor and improve services.
- Undertake comparative benchmarking, monitoring and audit across the network.
- Produce a network annual report.
- Develop and agree age-appropriate patient and carer information.

**Collaboration:** *working together within individuals and organisations at local, system, regional and national level*

- Engage with all relevant partners to foster a culture of collaboration and promote the development of provider collaborations across the network with a view to improving care pathways.
- Develop and agree arrangements for joint care between constituent TYA DHs and the TYA PTC.
- Share best practice with other TYA Cancer networks across the country.
- Actively participate in and support the national network of networks and participate in national audits.

**Transformation:** *plan sustainable services that meet the needs of all patients*

- Review network configuration and capacity to assure equitable access to comprehensive and integrated care, advising and agreeing a plan with commissioners to assure sustainable services that meet the needs of all patients.
- Work in partnership with ICBs to ensure patients have access to local, non-specialist, services including community nursing, therapies and palliative care.
- Ensure care and care settings are age-appropriate across the whole care pathway.
- Encourage and co-ordinate participation in national, regional, and local research and audit across all clinical disciplines.
- Co-ordinate and monitor access to tumour banking, ensuring that each teenager and young adult is offered an opportunity to tumour bank.

*Population health: assessing need, reducing inequalities in health, access, experience and outcomes.*

- Working with ICBs:
  - understand the needs of the population for TYA Cancer services
- Review service delivery across network against need and identify gaps and variation in services – gaps in overall provision, quality, geographical distribution - and deliver improvements to network services to address these issues.
- Develop specific proposals which mitigate inequalities for the vulnerable groups identified.

#### **4.4 Annual workplan**

The Network board will agree an annual workplan with its commissioners (usually through the joint strategic commissioning committee). This will reflect national, regional and local priorities.

The Network board will publish an annual report detailing its activities, accounts and delivery against the agreed annual plan.

## **5. Governance**

### **5.1 Accountability**

#### Hosting

The Network must be hosted and supported by the designated TYA Principal Treatment Centre (PTC). A Memorandum of Understanding, or other written agreement, must be put in place setting out the responsibilities of the Network and each constituent member, together with the governance arrangements which have been agreed by the service commissioners and Cancer Alliance(s) within the Network.

#### Accountability and responsibility

Network footprints reflect patient flows, provider scale and catchments so will often cut across commissioner boundaries (ICB and regional). Governance arrangements must provide clear accountability to commissioners at system level (with links to all relevant ICSs) and region as appropriate for both network delivery and commissioning responsibilities. Local arrangements to achieve this should be clearly documented within the Network's terms of reference.

The Network will be responsible to ICBs for the management of local pathways and delivery of locally agreed targets. This should be set out in memoranda of understanding between ICBs, providers and the Network. The memoranda of understanding should clearly set out the role of the relevant Cancer Alliance – for example, in contributing to the development, agreement and delivery of the work programme.



The Network will be accountable to the regional team of NHSE via the appropriate board within the Region including any multi-ICB decision bodies established.

The Network's plans and deliverables should be agreed with all ICBs within the geography served by the Network and signed off by the region. The Network will be expected to provide regular reports and have regular reviews with NHSE regional teams.

The Network's authority to act on behalf of its commissioners and members will be set out clearly within the network memorandum of understanding and where necessary clarified within the agreed annual plan.

## **5.2 Network governance and architecture**

### Members and stakeholders

The Network is required to have a formally constituted governing body or board, which is accountable to the Network's commissioners for delivery of the agreed programme, with a line of sight to all ICBs whose patients use the services of providers within the Network.

The Network board should include balanced representation from member organisations and other relevant stakeholders, including patient representatives and third sector organisations.

Clinical representation should cover the whole multi-disciplinary team and pathway of care.

The Network should develop an approach to working with patients and families that ensures patient views inform its whole work programme and ensure optimal service provision for patients.

The board should meet on a regular basis and operate under the oversight of a suitable clinical chair and commissioner co-chair with agreed terms of reference.

The clinical chair will be an appropriately experienced, impartial leader who is credible across the whole network and will be appointed through a fair and open process.

- The Network clinical chair should not be the network clinical lead, and ideally should not have the same main employer as the Network Clinical Lead in order to mitigate the risk of (real or perceived) conflicts of interest.
- There commissioner co-chair must have sufficient seniority to support the implementation of agreed Network objectives.
- They could be a board member or senior clinician from one of the provider organisations in the network (ideally not the host, to underpin the collective nature of these arrangements) or a patient representative where a suitable candidate is available.

The Network must meet at least quarterly. Membership of the Network should be formed from all local providers of TYA cancer services within the geography served by the Network and, at a minimum, must include representation from:

- The TYA PTC
- All TYA Designated Hospitals (DH) within the Network

- Service Commissioners
- Cancer Alliances within the Network
- Nursing
- Allied Health Professionals (AHPs), including expertise in psychological support
- Pharmacy
- Patient and public voice representatives and local charities (where these exist)
- Local Cancer Research Network
- Cancer Lead from the Genomic Laboratory Hub.

### **5.3 Risk Management and risk sharing**

The Network does not manage risk independently but within a system of national, regional and system level arrangements. The Network supports risk identification, assessment, mitigation and may facilitate any agreed response.

Specific local risk management arrangements and governance processes should be managed locally through MOUs/ SOPs etc which are clear and signed off. Escalation processes for risks within a system should be clear and explicit, with any quality concerns escalated through agreed systems and regional processes.

### **5.4 Interdependent Relationships**

- Cancer Alliance(s)
- Children's Cancer Networks

## **6. Resources**

Funding provided to the Network's host is ring-fenced to support the delivery of the agreed programme of work.

The Network should have a team to support its work that provides clinical leadership, management and administrative support. The Network should also have arrangements for analytical and business intelligence support. Commissioners must ensure as part of the annual planning process that the scale of resource made available to the Network is sufficient to support the agreed programme of work. The capacity of the Network to deliver its programme of work does not reside solely in the network team but also in the support of all network members including its commissioners.

Roles such as administration, network management and analytical support may be appropriately combined across networks, with further opportunities to increase the value from these investments, share learning across networks and improve the sustainability of networks through the provision of a pool of staff to support specialised services Clinical Networks across a region.

## **7. Deliverables, Service Indicators & Outcomes**

Three specific categories of metrics must be used: (i) maturity; (ii) nationally derived; (iii) locally derived.

## **1. Maturity - indicators of a well set up, well-functioning network**

A. In their set up phase, the Network should have an:

- Appropriate network management team in post with the skills to deliver the specification
- Agreement outlining the network configuration and membership
- Agreed network host and a signed SLA in place
- Appropriate data sharing agreements between network partners in place
- MOU signed by all constituent members
- Agreed network clinical and commissioner co-chairs in post
- Agreed Network board terms of reference and membership
- Agreed governance, oversight and reporting arrangements with the Network's commissioners. This should include arrangements for managing cross-boundary issues where networks serve multiple ICB populations, and/or where network footprints cross NHSE regional boundaries.

B. Once established, the Network should:

- Ensure that service configuration enables equitable access to comprehensive and integrated care across the Network. This must include TYA PTC/TYA DH designation, unit age ranges and interaction with children's cancer services and adult cancer services. This must be agreed within 12 months of the implementation of this Service Specification.
- Develop and maintain an operational policy for TYA cancer services across the network, detailing the range of cancers and age group of patients covered within the service.
- Agree, and ensure adherence to, Network-wide referral pathways, disease-specific treatment pathways (including diagnostic pathways, access to critical care, linkages with the TYA MDT, site-specific MDTs and adult cancer services), treatment and supportive care protocols and follow-up pathways. This must include: (i) clear referral pathways for primary care and other secondary care providers to whom TYA patients may present; (ii) clear transitional pathways for each tumour type into adult services; (iii) access to fertility services in accordance with the National Institute for Health and Care Excellence (NICE) Quality Standard 'Fertility Problems'(QS73); and (iv) psycho-social support pathways.
- Develop and agree arrangements for providing TYA joint care services across the Network. These agreements, and the level of support provided (e.g., supportive care, SACT) must be reflected in any memorandums of understanding between constituent TYA DHs and the TYA PTC and the Network operational policy.
- Ensure access to locally commissioned services including community nursing, therapies and palliative care.
- Promote age-appropriate care throughout the Network, in liaison with children's cancer services as described below.

- Co-ordinate clinical trial access across the Network and develop strategies to increase clinical trial recruitment. Each Network must achieve an overall participation rate of 50% by 2025.
- Co-ordinate and monitor access to tumour banking, ensuring that each teenager and young adult is offered an opportunity to tumour bank.
- Approve a single, TYA-specific holistic needs assessment (HNA) for use across the Network when a teenager or young adult is on a cancer diagnostic pathway, receiving cancer treatment or completing treatment.
- Ensure a co-ordinated approach to workforce planning and development of training opportunities across the Network to ensure local services have access to specialist care. This must include regular review of key workforce performance indicators such as vacancy rates and compliance against mandatory training.
- Ensure there are dedicated and secure communication systems in place between the TYA PTC and TYA DHs including secure e-mail systems and electronic systems that should share information on the delivery of chemotherapy, reporting of toxicity and the ability to transfer key diagnostic information between providers. This must be done within 12 months of the adoption of this Service Specification.
- Ensure good clinical governance systems and policies are in place between the TYA PTC and TYA DHs. This must include: (i) quality assurance systems; (ii) regular reporting of outcomes and any safety concerns; and (iii) incident reporting and information sharing between the TYA PTC and TYA DHs including dissemination of learning from incidents.
- Promote participation in clinical audit and patient experience surveys. The results from these surveys must be reviewed regularly and joint action plans must be developed between the TYA PTC and TYA DHs where required.
- Ensure age-appropriate patient and carer information is provided across the Network and provided in a range of different formats which covers generic and tumour specific information for teenagers and young adults with cancer.
- Prepare a Network-wide annual report for submission to local commissioners and the Cancer Alliance(s) outlining Network performance against the set of agreed quality measures with areas identified for improvement. This may include data reports to National Cancer Registration and Analysis Service (NCRAS); Systemic Anti-Cancer Therapy Database (SACT); European Group for Blood and Marrow Transplantation (EBMT); and the TYA cancer quality dashboard.

The Network must consider both the needs of the local population and the local geography, including travel arrangements, when recommending local provider configurations and Network agreements to commissioners, for onward decision and implementation.

**2. Nationally agreed indicators and outcomes for all networks of this specialty, for example as defined by a national transformation programme, or included in the service specification and delegated to network leadership.**

For details of the relevant quality outcomes and quality metrics, please see the TYA PTC Service Specification and the TYA DH Service Specification, as well

as the relevant Specialised Services Quality Dashboards. The Network should regularly review Quality Dashboard, taking action where necessary.

**3. The Network's individual locally agreed annual workplan, which should build in metrics and indicators for each element.**

The Network board will agree an annual workplan with its commissioners which will include the expected in year deliverables along with the indicators that will demonstrate effective network operation.

**8. Further support and information**

All references and support will be made available via the NHS Futures page:  
<https://future.nhs.uk/about>