SCHEDULE 2 – THE SERVICES

Service Specifications

1. Service name	Specialist cancer services for children and young people Sub-Heading: Teenage and Young Adults Principal Treatment Centre Services
2. Service specification number	1747
3. Date published	May 2023
4. Accountable Commissioner	NHS England – Cancer National Programme of Care (NPOC) NHS commissioning » Cancer (england.nhs.uk)

5.	**Population and/or geography to be served**
5.1	**Population Covered**
	The population covered by the Teenage and Young Adult (TYA) Principal Treatment Centre Service (the 'Service') is people aged 16 years up to 25th birthday who are within the commissioning responsibility of NHS England and who have a suspected or confirmed cancer. Within the Specification, the following definitions apply: • Teenager refers to people aged 16 to 18 years, up to the 19th birthday; • Young Adult refers to people aged 19 to 24 years, up to the 25th birthday; and • Teenager and Young Adult refers to people aged 16 to 24 years, up to 25th birthday. It is acknowledged that, in some networks, age criteria may vary 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.
5.2	**Minimum population size**
	The TYA PTC Service (the 'Service') must serve a population sufficient to support a critical mass of infrastructure, specialist and sub-specialist expertise.
6.	**Service aims and outcomes**
6.1	**Service Aims**
	The Service aims are to: • Improve cancer treatment outcomes and survival for all service users. • Deliver age-appropriate care, in age-appropriate settings, taking into account service user choice and the specific disease type. • Enable integrated and timely joint care across the network served by the TYA PTC. • Increase participation in clinical trials. • Increase participation in tumour banking.

- Improve the transition arrangements between children's and TYA services and subsequently to adult services, ensuring that there is no age gap between different services.
- Support the service user and their family throughout their cancer journey in a culturally appropriate and sensitive way.
- Develop high quality data to enable review of the performance of services and share learnings to continuously demonstrate improvements in the quality of services and service user experience.
- Embed genomic medicine within TYA cancer services.

6.2 Outcomes

NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	✓
Domain 2	Enhancing quality of life for people with long-term conditions	✓
Domain 3	Helping people to recover from episodes of ill-health or following injury	✓
Domain 4	Ensuring people have a positive experience of care	✓
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	✓

Service defined outcomes/outputs

No	Indicator	Data source	Domain
115	Proportion of service users aged 16-24 discussed at an age-appropriate MDT.	NDRS/NCRAS	1,2,5
108	Proportion of eligible service users aged 16-24 recruited to a nationally available trial.	Provider submitted data	1,5
110	Proportion of service users aged 16-24 offered the opportunity to tumour bank.	NDRS/NCRAS	1,5
117	Proportion of TYA service users offered fertility preservation where their treatment may impact on fertility.	Provider submitted data	2,3,4,5
116	Median time from onset of fever to administration of antibiotics in neutropenic fever in service users aged 16-24.	Provider submitted data	1,4,5
103	Median time from onset of symptoms to diagnosis.	NDRS/NCRAS	1,3,4,5

7. Service description

7.1	**Service model**
	The Service encompasses the diagnosis, management and follow-up of people aged 16 years up to 25th birthday. The service is led by a TYA PTC which will work in partnership with TYA Designated Hospitals (DHs) to ensure that service users receive the right care in the right place at the right time. The TYA PTC must be an active member of the TYA Cancer Network. The model of care for TYA cancer services requires that: • Each teenager (up to the 19th 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 (see Section 7.7.1). • 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. **(A) Referral** For all teenagers and those young adults who have chosen to have their care delivered at the TYA PTC, the TYA PTC must: • Have an agreed local process and clear pathways for referral to the TYA PTC, including urgent and out of hours referrals. • Respond to referrals on the day received and initiate the admission or any other clinical actions required in line with the protocols for that cancer type. For young adults that have chosen to have their care at a TYA DH or another centre, the TYA PTC must: • Have an agreed process in place for receiving referrals for MDT discussion at the Network (PTC) TYA MDT. • Discuss all cases in the Network (PTC) TYA MDT, within 7 working days of receipt of referral. **(B) Diagnosis, Treatment and Management of Cancer**

	The TYA PTC must diagnose and direct the provision of cancer care for all teenagers and each young adult who has chosen to have their care at the TYA PTC. This means that the TYA PTC must ensure that there is access to diagnostic and therapeutic expertise which is most appropriate to each service user's needs – this is achieved principally via the MDT. This includes ensuring timely access to consultations with tumour or site-specific experts. The TYA PTC must also ensure that each teenager and young adult is supported through diagnosis, treatment and into survivorship. This means that it must: • Ensure that each teenager and young adult has a named key worker. • Ensure that each teenager and young adult has access to a social worker, expert psychological support (if required) and an activities co-ordinator/youth worker to access appropriate activities. • Facilitate access to relevant service user support groups and charities where appropriate. <u>Diagnosis and decision-making core service requirements</u> The TYA PTC must: • Ensure access to appropriate imaging and image-guided biopsy modalities, in accordance with Network guidelines and protocols; • Ensure access to pathology services, in accordance with Network guidelines. This must include access to acute diagnostics services and clinical pathology opinion 24/7; • Develop pathways for Whole Genome Sequencing (WGS) in partnership with the Genomic Laboratory Hub and pathology departments to ensure access to WGS for all eligible service users; • Develop pathways for tumour banking; and • Ensure that site specific MDTs, supported by the Network (PTC) TYA MDT, develop and agree treatment plans according to either: (i) appropriate current UK Clinical Research Network (UKCRN) Portfolio protocol; (ii) relevant paediatric guideline/protocol as determined by individual cancer type; or (iii) relevant adult guideline/protocol as determined by individual cancer type. In exceptional circumstances, some people may be treated in line with a locally approved off-protocol therapy. • Ensure that both site specific MDTs and the TYA Network MDT maintain accurate and auditable recommendation and/or decision records. The TYA PTC is also responsible for hosting the Network TYA MDT, which must: • Meet weekly. • Support the site-specific MDTs to jointly plan care for each service user, including ensuring that each person is offered the optimal treatment strategy for their disease and age and access to all available and appropriate clinical trials. • Work with site-specific MDTs to resolve alternative views relating to treatment plan or trial access. • Review the holistic needs of each service user using a TYA Cancer Network approved TYA specific Health Needs Assessment (HNA). • Make a recommendation to the managing clinician about how the holistic needs may influence the pragmatic aspects of different treatment options. This must include the consideration and comment upon fertility preservation services for

the young person. An outcome must be provided within 7 working days of its team discussion to all relevant clinicians, including a new service user discussion for all clinicians within the diagnostic pathway.

- Ensure that each service user is assessed for psychological need and can access any psychosocial support that is required.
- Ensure that each service user can access information and support which is age-appropriate, including a range of information in different media, peer group support meetings and other approaches support and information.
- Be aware of the TYA Cancer Network portfolio of open clinical trials within their comprehensive local research network and must comment to the site-specific team where there are opportunities for trial entry.
- Ensure there is a documented process in place to allow for urgent TYA MDT advice and input outside of the TYA MDT meeting.
- Receive a referral no later than 7 working days after any site-specific MDT discussion at any location within the Network.
- Submit the TYA data fields to Cancer Outcomes and Services Dataset (COSD).
- Maintain accurate and auditable records of MDT recommendations and/or decisions.

Some TYA MDTs may also review teenagers and young adults with suspected cancer, those with benign brain tumours or non-malignant conditions requiring 'cancer-type' therapies such as Haemopoietic Stem Cell Transplantation (HSCT).

<u>Membership of the TYA MDT</u>

The TYA Network MDT must have:

- Single named Chair of the TYA MDT who fulfils the criteria listed in Section 7.7.2.
- A consultant haematologist with a practice in leukaemias which includes service users in the TYA age range and who is a core member of a site-specific MDT for leukaemia which has an exclusive catchment population for referral for service users with leukaemia, of at least 0.5 million.
- A consultant haematologist or oncologist with a practice in lymphoma which includes service users in the TYA age range and who is a core member of a site - specific MDT for lymphoma which has an exclusive catchment population for referral for service users with lymphoma, of at least 0.5 million.
- A consultant medical oncologist with a practice in germ cell malignancy which includes service users in the TYA age range and who is a core member of a site - specific MDT for testicular cancer which has a catchment population for supra-network referral of testicular cancer of at least 2 million.
- A consultant medical oncologist with a practice in brain and CNS tumours which includes service users in the TYA age range and who is a core member of a brain and CNS neuroscience MDT.
- A consultant medical oncologist with a practice in soft tissue sarcoma which includes service users in the TYA age range and is a core member of a sarcoma MDT which deals with at least 100 cases of soft tissue sarcoma per year.
- A paediatric medical oncologist.
- The PTC lead nurse.
- A specialist nurse in addition to the lead PTC nurse.

- A person agreed as able to offer psychological support to service users to at least Level 3 scope of practice. They should have completed the training necessary to enable them to practice at Level 3 for the psychological support of people with cancer and carers, and should receive a minimum of 1 hours clinical supervision by a Level 3 or Level 4 practitioner per month.
- A young people's social worker.
- A person agreed as performing the role of youth worker/activity co-ordinator.
- An MDT co-ordinator/secretary.
- At least one clinical core member of the team with direct clinical contact, an NHS-employed member of the core or extended team should be nominated as having specific responsibility for users' issues and information for service users and parents/guardians.
- An NHS-employed member of the core team should be nominated as having specific responsibility for late effects issues and information.
- A member of the core team nominated as the person responsible for ensuring that recruitment into clinical trials and other well-designed studies is integrated into the function of the MDT.

Extended membership of the TYA Network MDT should include:

- Clinical oncology

The late effects MDT must include membership from at least:

- TYA haematologist/oncologist
- Clinical Oncologist
- Clinical nurse specialist
- Endocrinologist (core involvement of other specialists may be required depending on the MDT's caseload)
- Psychologist
- Clinical care co-ordinator
- MDT co-ordinator

<u>Treatment core service requirements</u>

There are several different treatment options available for teenagers and young adults with cancer. The most common include: surgery, chemotherapy, radiotherapy, stem cell and bone marrow transplants, immunotherapy, and targeted therapy. Each of these modalities may be used alone or, more often, in combination, depending on the type of cancer.

The TYA PTC will provide most of the treatment for each teenager and young adult receiving care within the TYA PTC. However, it may not provide every treatment component and must therefore comply with Network agreed operational and referral arrangements for such services. Such services include: (i) supra-network services; and (ii) local specialist cancer services (see Section 7.7.1). Any service delivering autologous and/or allogeneic haematopoietic stem cell transplants locally must achieve accreditation by the Joint Accreditation Committee of the International Society for Cellular Therapy (ISCT) and the EBMT (JACIE), in line with relevant NHS England service specifications, within 18 months of the adoption of this Service Specification.

Irrespective of where treatment is to be delivered, the TYA PTC must:

- Offer fertility preservation to each teenager and young adult preparing to have treatment for cancer that is likely to result in fertility problems. Consideration should be given to the diagnosis, treatment plan and associated risk of infertility, urgency of treatment initiation, prognosis and likelihood of success of possible fertility preservation methods. The TYA PTC must have a policy defining male and female fertility preservation options available and this must be supported by Network protocols and guidelines; and
- Ensure that each teenager and young adult receives sexual health advice (including contraception) prior to treatment, if appropriate.

Participation in clinical trials is an important component of cancer treatment and is considered to be an important factor behind the higher survival rates seen in some types of childhood cancers, where around two-thirds of service users are recruited onto trials. Despite this, currently only between 10 to 25% (Fern L, Davies S, Eden T, et al, 2008) of all teenagers and young adults with cancer participate in clinical trials.

NHS England's ambition, as set out in the NHS Long Term Plan, is that by 2025, at least 50% of all teenagers and young adults with cancer will be recruited onto clinical trials. The achievement of this ambition will require a step-change in current working practices for each constituent member of the TYA Cancer Network and the Network itself, working collaboratively with Local Clinical Research Networks (LCRNs) representatives, the National Cancer Research Institute (NCRI) and the National Institute for Health Research (NIHR). Each TYA Network constituent member must comply fully with agreed Network-wide research plans and any recommendations set by NCRI, NIHR and appropriate LCRNs.

The role of the TYA PTC is to ensure that each teenager and young adult with cancer is offered an opportunity to participate in a clinical trial, where one (or more) is available and is clinically appropriate. To secure expert clinical trials advice, the TYA PTC must refer every service user to the Network TYA MDT. If a service user is eligible to participate in a clinical trial (early or late phase) which is not available locally, the TYA PTC must offer referral to an alternative provider. In most cases this will be to another TYA PTC, but could also be the Children's Cancer PTC, a supra-network service or an adult cancer service. Service users who have been recruited into a clinical trial will be followed up as defined in the protocol.

Furthermore, the TYA PTC must ensure that:

- Each service user is offered an opportunity at diagnosis to consent – in accordance with the General Data Protection Regulation and the Human Tissue Act 2004 - for their data, a tissue sample and/or a liquid sample, to be collected for use in future research studies and development of services. Where consent is given, these samples must be banked. 100% of TYA service users must be offered the opportunity to bank their samples within 12 months of the adoption of this Service Specification.
- Regular data submissions on research participation are provided to the COSD, NIHR and NHS England.

Systemic anti-cancer therapy (SACT) is an important part of treatment for cancer and includes conventional chemotherapy, monoclonal antibodies/targeted therapies,

	intravenous, subcutaneous, intrathecal, intraventricular, and oral chemotherapy as well as topical treatments for bladder cancer; hormonal treatment is excluded. All SACT delivered to teenage service users should be initiated by the TYA PTC and agreed by both a site-specific MDT and the Network TYA MDT. The TYA PTC must:
	• Ensure that there are arrangements in place to support urgent SACT treatment prior to MDT discussion.
	• Ensure that SACT must only be prescribed by staff that have demonstrated their competency and are authorised and registered to prescribe SACT in the PTC.
	• Agree an approved list of SACT treatment regimens which is updated annually.
	• Ensure that treatment is given in accordance with agreed Network treatment protocols.
	• Assess and secure Network agreement for all new treatments prior to their introduction to ensure that they fit with strategic plans.
	• Agree a policy defining the steps required for use of regimens not on the approved protocol list. Deviations should be recorded and audited on a regular basis.
	• Ensure that there is a robust system of clinical governance in place and that all staff are fully familiar with the treatments employed within the Service and have been trained and deemed competent to deliver them.
	• Ensure that chemotherapy is prescribed using an e-prescribing system.
	• Ensure that SACT is only prescribed by staff that have demonstrated their competency and are authorised and registered to prescribe SACT.
	• Ensure that all SACT prescriptions are checked by a cancer pharmacist who has undergone specialist training, demonstrated their appropriate competence and is locally authorised. Where a pharmacist prescriber (NMP) initiates a prescription a second pharmacist is still required to verify the prescription.
	• Undertake pre-chemotherapy treatment assessments for all service users to ensure:
	  ○ Accurate pre-SACT assessment to enable variation from the service user's baseline to be detected;
	  ○ Pre-course and pre-cycle records meet all requirements of the relevant SACT; and
	  ○ That the service user is confirmed to be fit to proceed and all pre-cycle/course investigations are within the limits defined in the protocol.
	• Ensure that all female service users of child-bearing age have a pregnancy test prior to initiation of SACT.
	• Put in place local arrangements to ensure that, as far as is practicable, high-cost items are only reconstituted after the service users blood results are known. All SACT must be prepared in accordance with locally approved policies and protocols.
	• Put in place a local policy which sets out that SACT treatment should be commenced during standard 'working hours', wherever possible. This is to ensure that support services and expert advice is available. The policy must also state which, and only which, exceptional circumstances the initiation of administration of chemotherapy may be allowed outside "normal working hours" and the arrangements for administering SACT which then apply.
	• Ensure that there are on-site facilities for the management of central venous access devices with defined surgical support at the PTC and at other agreed

sites, so that the administering practitioner can ensure appropriate venous access for the chemotherapy to be administered.

- Ensure that the SACT service is delivered safely and that it conforms to appropriate standards, guidance and best practice, including:
    - Manual for Cancer Services: Children's Cancer Measures (National Cancer Action Team, 2013);
    - Improving Outcomes in Children and Young People with Cancer (NICE, 2011);
    - National standards set following National Patient Safety Agency (NPSA) oral and vinca-alkaloid alerts (2008);
    - Systemic Anti-Cancer Therapy: For Better or Worse (National Confidential Enquiry into Patient Outcomes and Death (NCEPOD), 2008);
    - Chemotherapy Services in England: Ensuring quality and safety (National Chemotherapy Advisory Group (NCAG), 2009); and
    - Guidance on the administration of intrathecal chemotherapy (Department of Health, 2008).
- Put in place a policy detailing the safe reconstitution of SACT including cytotoxic drugs. Manipulating and reconstituting cytotoxics poses the greatest risk, for this reason, cytotoxics should only be reconstituted in an accredited and regulated/audited pharmacy aseptic unit by appropriately trained and experienced staff.
- Put in place regular audit for the aseptic service, carried out by appropriately trained and experienced staff.
- Following treatment with SACT, the responsible clinician should confirm to both the service user's GP and the referring clinician; what treatment has been delivered, the service user's condition and any post treatment arrangements.
- Submit data to the national SACT database.

SACT preparation, in particular chemotherapy, may receive pharmacy support from a pharmacy which has been reviewed as part of the peer review of adult cancer services or children's cancer services. If, at such a previous review, there was compliance with the measures regarding preparation facilities and the Control of Substance Hazardous to Health (COSHH) they will be regarded as compliant for the review of TYA cancer services, provided it is within the timeframes stated in those measures. The remaining preparation measures, as outlined in this Specification, should be applied specifically and separately with regards to the TYA service. The responsibility for review purposes for these measures lies with the lead pharmacist.

<u>Palliative Care core service requirements</u>

Specialist cancer palliative care advice and treatment is delivered by specialist palliative care teams from the PTC TYA. Teams provide expert advice on all aspects of symptom control and psychological support for the young person and their family and will be part of a wider palliative care network. It is recognised that these teams will be working with other non-cancer agencies to deliver palliative support e.g. hospices and community nursing teams, primary care and other community-based services to provide end of life care and bereavement support.

(C) Survivorship, Long-Term Follow-up and Late Effects Service

On completion of treatment, the TYA PTC must ensure there is a comprehensive long-term follow up package in place for TYA cancer survivors and there is access to a Late Effects MDT across the Network, which addresses the following:

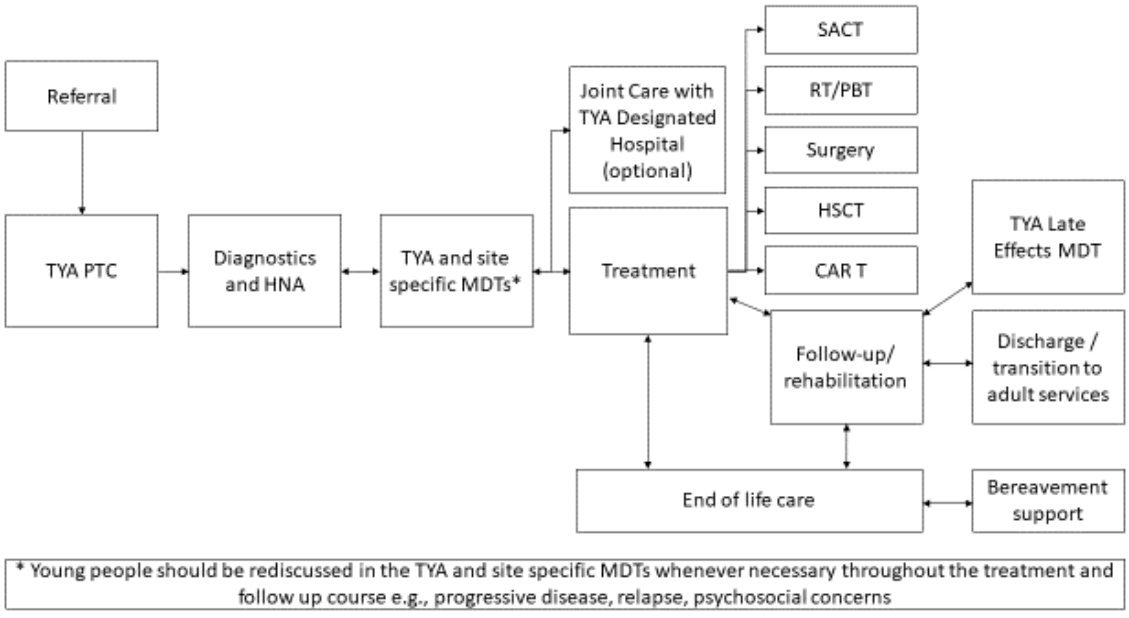
- **Clinical risk stratification and follow-up model:** the clinical risk stratification tool developed by the National Cancer Survivorship Initiative (NCSI) is based upon the original cancer type and the treatment received. The tool allocates a service user into one of three levels (supported self- management, a shared care system or hospital-based follow-up for the most complex care needs). All service users must be allocated a risk level which must be documented in the care plan. Long term follow-up may be delivered by a site- specific MDT or by the TYA Late Effects MDT depending on the allocated risk level. The allocated risk level must be appropriate for the individual considering psychosocial factors as well as diagnostic and treatment factors.
- **End of treatment summary:** this must be prepared for every service user within 6 months of completing treatment and be provided to the service user, parents/guardian and GP (and other as appropriate).
- **Individualised care plan:** this is a dynamic document which must be reviewed and modified at intervals throughout follow-up and must include: (i) type and planned frequency for surveillance of the original cancer; (ii) potential late effects and recommended surveillance based on national or international standards; (iii) health education; and (iv) psychological assessment and support. The care plan must be shared with the service user and/or parent at the end of the treatment and copied to the GP and all involve professionals; and
- **Access to psychological support:** Aftercare pathways commence on completion of treatment and at a point along the aftercare pathway, one which will vary between PTCs, a service user's care will be transferred from the site-specific MDTs to the Late Effects MDT. To facilitate communication and co-ordination of care and ensure rapid re-access into the service, a single point of access must be made available to service users within the aftercare pathway. Access to specialist psychological support should be available as required for a minimum of two years post treatment.

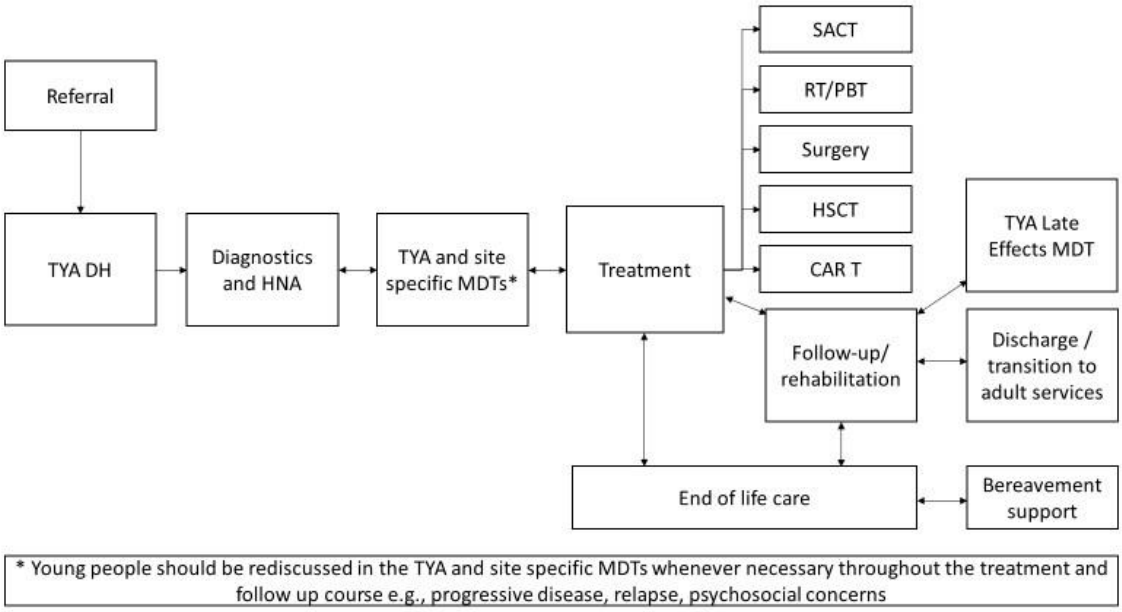
(D) Specialist Psychological Support

Care pathways must describe the psychological and social support available to service users and their families to support access to treatment to ensure quality of experience. Services must use a network approved TYA HNA to facilitate early identification of concerns. The provision of specialist psychological and appropriate social support to teenagers, young adults and their parents/guardians involves multiple agencies and must be available to service users and their families throughout the entire care pathway from diagnosis, during active cancer therapy and into follow-up or bereavement.

(E) Service User Information and Consent

Age-appropriate information must be provided in a range of different formats which covers generic and tumour specific information for young people with cancer. It should address the treatment plan, how to access care out of hours, information on tumour banking and clinical trials, and, where appropriate, the joint care

	arrangements between the TYA PTC and TYA DH services. All young people who use the Service must be: • Fully informed about their care, treatment and support and information must be age-appropriate; • Able to take part in decision making to the fullest extent that is possible; and • Asked if they agree for their parents or guardians to be involved in decisions they need to make. ***(***Guidance for providers on meeting the regulations, Care Quality Commission, 2015***).*** Further guidance on consent for people under the age of 18 years can be found through the General Medicine Council.
7.2	**Pathways**
	<u>Overall patient pathway – for all teenagers and those young adults that opt to have care at the TYA PTC</u>  <u>Patient pathway – for young adults that choose to have care at the TYA DH</u>



Shared care arrangements – 'joint care'

Joint care will enable teenagers and young adults that are receiving cancer treatment at the TYA PTC to receive supportive care and, where agreed, specified chemotherapy, as close to home as possible. Joint care may be provided in either a TYA DH or alternatively at a Paediatric Oncology Shared Care Unit (POSCU), in collaboration with the relevant Children's Cancer Network. The TYA Cancer Network should work with the Paediatric Cancer Network to ensure there are no gaps in service provision, particularly in the 16-18 age range.

Supportive care services include, but are not limited to, the: (i) management of febrile neutropenia; (ii) management of symptom control (e.g., nausea, vomiting); (iii) central venous access; and (iv) blood product support.

Transition

Transition is defined as a 'purposeful and planned process of supporting young people to move into adults' services. Poor planning of transition and transfer can result in a loss in continuity of treatment, service users being lost to follow up, disengagement, poor self-management and inequitable health outcomes for young people. NHS services, in line with what they are responsible for, must plan, organise and implement transition support and care (for example, holding joint annual review meetings with the service user and their parents/guardians. This should ensure that young people are equal partners in planning and decision making and that their preferences and wishes are central throughout transition and transfer.

In this setting, transitional care applies to those service users who had completed their cancer treatment as children, teenagers or young adults and/or due to relapse, development of a second malignancy, or as part of their ongoing treatment or aftercare plan, they now require transition to a different team due to their maturity.

	The transition plan should begin well in advance of transition and be pro-active so that each service user knows what to expect. Transition should occur at a time of stability in the service user's disease and treatment and may be effectively achieved during therapy or after completion of treatment. The referring and receiving teams should liaise carefully to ensure that the transition process is seen as a positive step and to minimise the anxiety that service users and families may feel, for example by having joint transition appointments.
7.3	**Clinical Networks**
	There is a requirement for providers of this Service to comply with the provisions of Schedule 2F (Clinical Networks) of the NHS Standard Contract 2022/23 The Particulars. This includes meeting the requirements of the relevant Specialised Services Clinical Network Specification – in this case, the TYA Cancer Network and, as appropriate, the Children's Cancer Network.
7.4	**Essential Staff Groups**
	The TYA PTC should: • Ensure there is a single named Lead Clinician for the service who must be a medical consultant (minimum 0.2 WTEs), a single named Chair of the TYA MDT (this may also be the lead clinician) and a single named Lead Nurse who fulfil the roles and responsibilities defined in Section 7.7.2. • Have 0.5 WTEs of time of consultant solid tumour and/or haemato-oncologist(s) with a practice, in one or more of the following malignancies, which includes service users in the TYA age range: (i) Leukaemias; (ii) Lymphomas; (iii) Germ cell malignancy; (iv) Bone and/or soft tissue sarcomas; and (v) Brain and CNS malignancy. Sessions should be identified in job plans. • Have 1.0 WTE of time of medical staff of at least ST3 level in oncology or haematology. • Provide a minimum of two nurses during the day and one nurse at night for all inpatient facilities, who have either: (i) successfully completed a programme of training in cancer for nurses in their specialist area of practice, which has been accredited for at least 20 credits at 1st degree level; or (ii) trained and satisfied the hospital's chemotherapy service competency requirements for the administration of chemotherapy. • In day units, provide a minimum of one nurse on duty during each shift of each working day that the unit is open for chemotherapy who has either (i) successfully completed a programme of training in oncology for nurses in their specialist area of practice, which has been accredited for at least 20 credits at 1st degree level; or (ii) trained and satisfied the hospital's chemotherapy service competency requirements for the administration of chemotherapy. • There must be a professional head of the SACT service directly responsible for the development, management and ultimate clinical accountability and responsibility for the service. This professional head of service must hold an appropriate qualification to practice and be registered with the Health Professions Council. • Any staff responsible for reconstituting SACT must have undergone training in line with:

- Health and Safety Commission approved Code of Practice, The Control of Substance Hazardous to Health (COSHH, 2008);
- Aseptic dispensing for NHS patients: a guidance document for pharmacists in the United Kingdom (Department of Health, 1993);
- Rules and Guidance for Pharmaceutical Manufacturers and Distributors (the 'Orange Guide') (MRHA, 2017); and
- Quality Assurance of Aseptic Preparation Services 5th Edition (Beaney, AM. 2017).

- Nurses who administer chemotherapy must have been assessed as competent to do so in line with the relevant quality measures.
- Ensure support from cancer pharmacists with specialist experience in TYA cancer and include, at a minimum, a lead pharmacist and a designated deputy. Sufficient staffing should be in place to ensure that services are safe and effective. These individuals should receive specialist pharmacy training to enable: (i) chemotherapy prescription verification; (ii) clinical screening of supportive care prescriptions; (iii) safe implementation of clinical trials and new drugs; (iv) safe implementation of electronic prescribing of SACT.
- Ensure there is a lead pharmacist with overall responsibility for the aseptic SACT preparation service and facilities.
- The names of staff that have completed competency-based training must be kept on a current register of competent staff.

The TYA PTC must also have access to the following professionals and must ensure staffing levels are sufficient to meet demands of the individual unit.

- Social worker
- Youth worker/activity co-ordinator
- Dietician
- Physiotherapy
- Occupational therapy
- Speech and language therapy
- An individual trained in providing psychological support
- An individual with responsibility for providing education or liaising with schools and universities
- Clinical nurse specialists

The recommended AHP staffing levels, as set out in the Manual for Cancer Services: Teenage and Young Adult Measures Version 1.0 (2011), are that there should be:

- 2.0 WTEs of social worker time
- 1.0 WTEs of youth worker/activity co-ordinator time
- 0.8 WTEs of dieticians' time
- 1.0 WTE of physiotherapists' time
- 0.2 WTEs of occupational therapists' time
- 1.0 WTE of time of a person agreed as providing psychological support

All staff groups working in this field should undertake TYA-focussed education and training, such as formally accredited education opportunities or informal learning opportunities with an expectation of TYA focused CPD during an appraisal cycle.

7.5	**Essential equipment and/or facilities**
	The PTC must have dedicated inpatient and day-case facilities that offer age-appropriate care and are covered by a management policy governing use. These facilities must be reserved for the use of service users within the TYA age range with cancer. This Specification recognises that these facilities are also used for TYA service users with non-malignant haematology, though this Specification does not cover such cases. The pathology services supporting the TYA PTC must: • Comply with Clinical Pathology Accreditation (UK) Ltd (CPA) and the Human Tissue Authority (HTA). • Comply with Royal College Minimum Dataset. • Provide acute diagnostics services and clinical pathology opinion 24 /7. • Have access to digital pathology and networked services, including remote working. • Have in place blood management guidelines. • Participate in and encourage clinical trial activity. • Provide a framework for staff education.
7.6	**Interdependent Service Components – Links with other NHS services**
	The TYA PTC has a range of critical co-dependencies with other clinical services. **A. The default position is that the following clinical services should be delivered on-site at every TYA PTC:** • Oncology • Cancer pharmacy • Haematology • Radiology • Critical care (Level 3) • Surgery, to include management of emergencies, central lines and biopsy services (where these are not provided by interventional radiology or anaesthetics) • Anaesthetics and pain management • Therapy services (such as psychology, physiotherapy). It is acknowledged that some PTC functions are shared across more than one site. Where this is the case, a PTC must clearly demonstrate how they will mitigate all potential risks to maintain a safe and high-quality service. In particular, the PTC must ensure that where Level 3 critical care is not available on-site, there must be clear standard operating procedures (SOPs) describing the escalation of care for an acutely deteriorating service user, the management of acute collapse/arrest and retrieval process to the nearest Level 3 critical care facility. The SOPs must be agreed by the TYA Cancer Network and the safety of these pathways must be audited continuously on a prospective basis as part of the Network's audit programme. **B. The following clinical services do not need to be delivered on-site, however, the TYA PTC must ensure the services are readily available at all times (if not delivered on-site):**

	• Endocrinology • Nephrology • Cardiology • Cancer surgery (other than management of emergencies, central lines and biopsy services) • Pathology • Neurosurgery • Infectious Diseases • Palliative care • Other specialist surgery. **C. The TYA PTC must ensure that there are clear referral and management pathways in place for the following services (if not delivered on-site):** • Radiotherapy • HSCT (both autologous and allogenic) • Late effects MDT • Liver cancer surgery • Bone cancer surgery (NHS England service specification: Primary malignant bone tumours) • Onco-fertility/reproductive medicine • Other specialist surgery • Proton Beam Therapy • Genomic Laboratory Hubs. **D. Teenagers and young adults with cancer have complex needs and as a result, a multi- agency approach to supporting service users is required. The TYA PTC must ensure there are formal working relationships with the following services:** • Local authority-based services for social services • Adolescent and adult mental health services • Primary Care • Community services (such as physiotherapy, speech and language therapy and dietetics) • Education services for service users in full time education up to 18 years of age • Education services for service users in full time/part time education aged 18 to 24 years of age • Careers and employment services • End of life and hospice services. In addition, the TYA PTC must have close working relationships with adult site-specific MDTs, partner TYA DHs and paediatric cancer services. Where the TYA PTC is involved in treating younger teenagers (aged 16 below), there must be age appropriate access to the co-dependent services defined in theChildren's Cancer Network service specification.
7.7	**Additional requirements**
	7.7.1 NHS England Service Specifications Relevant to TYA Cancer

NHS England Service Specification	
SUPRA-NETWORK SERVICES	
Service Specification Title	**NHS England Reference**
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
NETWORK SPECIALIST SERVICES	
Service Specification Title	**NHS England Reference**
Children's Cancer PTC	1746
Children's Cancer POSCU	1746
TYA DH	TBC
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

7.7.2 PTC Lead Role Requirements

TYA PTC Lead Clinician

- There must be a single named lead clinician for the PTC who should be a consultant. The time available should be at least 0.2WTEs.
- The purpose of the TYA PTC lead clinician role is to provide leadership and support to the health professionals in the provision of specialist and age-appropriate care within the TYA PTC and across its partner TYA DHs.
- The lead clinician must work in close collaboration with the TYA lead nurse, the site - specific MDT chairs and the TYA lead clinicians at TYA DHs.
- The lead clinician must work in partnership with the lead cancer clinician in the TYA PTC and the TYA Cancer Network to contribute to the strategic development of TYA cancer services.

- The Role of the PTC Lead Clinician includes:
    - Leadership of the TYA MDT, ensuring that objectives of MDT working are met. The role of Chair of the TYA MDT may be delegated to another clinician. However, the TYA PTC lead clinician must retain oversight of the MDT;
    - Ensure that TYA MDT outcomes/recommendations are discussed or communicated in a timely manner to site-specific MDTs to achieve a jointly- agreed treatment plan for each service user and seek to resolve differences in opinions if these arise;
    - Agree treatment policies with the TYA Cancer Network;
    - Provide the link to the TYA Cancer Network either by attendance at meetings or by nominating another MDT member to attend;
    - Tumour types to be treated, both to deliver primary treatment and on a joint care basis;
    - Agreeing appropriate treatment protocols for each tumour treated and clarity regarding age criteria for paediatric or adult approaches;
    - Clinical trials to be open for recruitment (with R&D approval) and delivery at which hospitals (PTC and TYA DHS), for each tumour type;
    - Liaison with the TYA DHs;
    - Have oversight of a pathway for management of each tumour type, including joint care where appropriate; and
    - Ensure that the TYA MDT NCRAS data are reported for all new service users diagnosed within the network.

<u>Chair of the TYA MDT</u>

The Chair of the TYA MDT must:

- Ensure that designated specialists work effectively together in teams such that decisions regarding all aspects of diagnosis, treatment and care of individual service users and decisions regarding the team's operational policies are multidisciplinary decisions.
- Ensure that care is given according to recognised guidelines (including guidelines for onward referrals) with appropriate information being collected to inform clinical decision making and to support clinical governance/audit.
- Establish for each service user, in discussion with other MDTs, responsibility for each component of the service user pathway.
- Ensure that each new service user has a TYA holistic assessment.
- Ensure that all new service users have an identified keyworker, and whether support is to be provided by the PTCs TYA team or DHs team, or a combination of the two.
- Ensure that mechanisms are in place to support entry of eligible service users into clinical trials, subject to service users giving fully informed consent.
- Ensure that service users are offered the opportunity to have the tumour samples banked and sent for WGS
- Fertility preserving measures are offered where appropriate
- Have overall responsibility for ensuring that the MDT meetings and team meet the standards outlined in this service specification.
- Ensure that attendance levels of core members and quoracy of the MDT are maintained.

	• Ensure that MDT's activities are audited and results documented.
	• Ensure that the outcomes of the meeting are clearly recorded, clinically validated and that appropriate data collection is supported.
	
	<u>TYA PTC Lead Nurse</u>
	
	• The purpose of the TYA PTC lead nurse role is to provide professional and clinical leadership and support to nursing staff within the Principal Treatment Centre. Post - holders will be responsible for all elements of the nursing services and will also be expected to contribute to the strategic development of the whole service in line with the individual hospital trust.
	• The Lead Nurse:
	  ○ Is an expert in the care of young people with cancer;
	  ○ Advances the development and practice of evidence-based TYA cancer nursing in the trust, in line with national recommendations where available;
	  ○ Collaborates with all members of the multidisciplinary team in ensuring the advancement of service user focused cancer care and support;
	  ○ Develops and implements communication arrangements with nursing and members of the multidisciplinary team across the network;
	  ○ Works clinically on a regular basis, (this should be a least 20%) thus demonstrating expert clinical practice, professional competence, authority and credibility;
	  ○ Provides professional advice, leadership and support on haematology / oncology issues to the designated hospitals within the region; and
	  ○ Is responsible for contributing to the strategic development of the TYA Cancer Network.

7.8	**Commissioned providers**
	The list of commissioned providers for the services covered by this specification can be found here. [ADD LINK TO THE COMMISSIONED PROVIDER LIST ONCE AVAILABLE]
7.9	**Links to other key documents**
	Please refer to the *Prescribed Specialised Services Manual* for information on how the services covered by this specification are commissioned and contracted for. Please refer to the Identification Rules tool for information on how the activity associated with the service is identified and paid for. Please refer to the relevant Clinical Reference Group webpages for NHS England Commissioning Policies which define access to a service for a particular group of service users. The specific clinical policies that relate to the services covered by the Specification include: • Clinical Commissioning Policy: Dexrazoxane for preventing cardiotoxicity in children and young people (under 25 years) receiving high-dose anthracyclines or related drugs for the treatment of cancer. • Clinical Commissioning Policy: Use of plerixafor for stem cell mobilisation (updated to include paediatrics).

	• Clinical Commissioning Policy: Proton beam therapy for children, teenagers and young adults in the treatment of malignant and non-malignant tumours. **Relevant NICE Guidance (exc. Technology Appraisals)** 1. NICE: Guidance on Cancer Services - Improving Outcomes in Children and Young People with Cancer The Manual; August 2005 Child & young people cancer CSG REP (nice.org.uk) 2. NICE Quality Standard: Cancer services for children and young people Overview | Cancer services for children and young people | Quality standards | NICE 3. NICE: Guideline NG12 Suspected cancer: recognition and referral Overview | Suspected cancer: recognition and referral | Guidance | NICE **Relevant National Clinical Guidance** 1. Manual for Cancer Services:Teenage and Young Adults Measures Version 1.0. National Cancer Action Team / Peer Review Programme (2011) 2. Advice on provision of age-appropriate care. National Cancer Action Team (2011) 3. National Service Framework for Children and Young People, Standards for Hospital Services. Department of Health (2007). 4. You're Welcome" quality criteria: making health services young people friendly. Department of Health (2011). 5. Cancer in Children, Teens and Young Adults: On the Right Course? National Confidential Enquiry into Patient Outcome and Death (2018)