SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No:	B17
Service	Teenage and Young Adult Cancer Networks - Principal Treatment Centres [INDIVIDUAL PROVIDER NAME TO BE INSERTED AT CONTRACT STAGE]
Commissioner Lead	*For local completion*
Provider Lead	[INDIVIDUAL PROVIDER NAME TO BE INSERTED AT CONTRACT STAGE]

1. Scope

1.1 Prescribed Specialised Service

This Service Specification (the “Specification”) covers the provision of cancer services (the “Service”) for teenagers and young adults (TYA) aged 16 to 24 years, up to the 25th birthday at the TYA Cancer Principal Treatment Centre (PTC) in England. The Specification also describes the purpose and requirements of the TYA Cancer Network (the “Network”), which is hosted and run by the (PTC).

It is acknowledged that, in some Networks, age criteria may vary and there may be some flexibility in age boundaries of services to enable patients 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 PTC to treat people aged 13 years above.

1.2 Description

The scope of specialised services is set out in within the Prescribed Specialised Services Manual (the “Manual”). The provision described within the Manual relates to children and young people up to the age of 24 years.

The Manual states that “specialist cancer services for children and young people include:

- All specialist care for children within children's Principal Treatment Centres (PTCs);
- All specialist care for teenagers and young adults within Teenage and Young Adult (TYA) PTCs including transitional care;
- All shared care overseen by PTCs;
- All cancer chemotherapy and radiotherapy;
- All specialist cancer palliative care services; and
- Planning after care (as part of the survivorship initiative)".

The Specification must be read in conjunction with:

- The TYA Cancer Networks – Designated Hospital Service Specification, together with other published NHS England Service Specifications (Appendix 1); and
- NHS England Clinical Commissioning Policies and Policy Statements.

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.

1.3 How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners

NHS England commissions all specialist cancer services for TYA at specified centres. Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

2. Care Pathway and Clinical Dependencies

2.1 Service Overview

The Service encompasses the diagnosis, management and follow-up of teenagers and young adults (TYA) with cancer. The service is led by a TYA PTC which will work in partnership with TYA Designated Hospitals (DHs) to ensure that teenagers and young adults receive the right care in the right place at the right time. The model of care for TYA cancer services requires that:

- Each teenager 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 Appendix 1);
- Each young adult 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 MDT referral proforma. The TYA PTC/TYA DH will also deliver most of the care and will co-ordinate referral to Supra-Network services and local specialist services for specific treatments not provided by the TYA PTC/TYA DH;

- Each teenager and young adult, irrespective of where treatment is carried out, must be discussed in the TYA multi-disciplinary team (MDT) meeting which is hosted by the TYA PTC. The purpose of the TYA MDT is to review the treatment plan made by the disease-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; and
- Each teenager and young adult receiving care primarily at the TYA PTC, may have their treatment delivered entirely within the TYA PTC or through joint care 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.

The Specification has been developed, as part of a suite of TYA Cancer Network Service Specifications, to implement the recommendations of the Cancer Taskforce and the NHS Long Term Plan. Specifically, it aims to sustainably:

- Promote age appropriate care, delivered in a safe and effective manner;
- Improve the experience of care;
- Increase participation in clinical trials;
- Increase tumour banking rates;
- 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; and
- Embed genomic medicine within TYA cancer services.

2.2 The TYA Cancer Network

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; and
- Issues in maintaining compliance with treatment protocols.

The purpose of the TYA Network is to navigate these challenges, ensuring optimal operational delivery of safe, effective and efficient TYA cancer services which deliver excellent patient experience, in accordance with this Specification and other relevant standards. This will be achieved through the effective coordination of patient pathways between providers within the Network's geographical area, and sometimes beyond, enabling access to both specialist expertise and locally delivered elements of care, as appropriate.

The Network must be hosted and supported by the designated TYA PTC. The Network function will be discharged through the TYA Cancer Network Co-ordinating Group (TYANCG). 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.

The TYANCG must meet at least quarterly and must be chaired jointly by the Lead Clinician for the Network, together with the Lead Commissioner for the Network. Membership of the TYANCG should be formed from all local providers of TYA cancer services within the Network geography and at a minimum, must include representation from:

- All DHs within the Network;
- Service Commissioners;
- Cancer Alliances within the Network;
- Nursing;
- Allied Health Professionals (AHPs);
- Pharmacy;
- Patient and public voice representatives and local charities (where these exist);
- Local Cancer Research Network; and
- Cancer Lead from the Genomic Laboratory Hub.

The TYANCG is responsible for developing and delivering a work programme, which has been agreed by local service commissioners and the Cancer Alliance(s) covered by the TYA Network, that will:

- 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 no later than April 2020;
- 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 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 demonstrate an increase in clinical trial recruitment of at least 10% by March 2021 and 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 and 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. These must be in place by April 2020;
- 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; and
- Prepare a Network-wide annual report for submission to local commissioners and the Cancer Alliance(s) outlining Network performance against a 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 TYANCG must consider both the needs of the local population and the local geography, including travel arrangements, when agreeing local provider configurations and Network agreements. NHS England Specialised Commissioners are responsible for ensuring that individual provider Contracts reflect the agreed Network service configuration and for ensuring that NHS England's public involvement duties are met.

2.3 PTC Service Requirements

The TYA PTC must diagnose, agree the treatment plan and direct the provision of care for teenagers and young adults (that have chosen to have care at the TYA PTC rather than the TYA DH) within the Network. This means that the TYA PTC must ensure that there is access to diagnostic and therapeutic expertise that is most appropriate to each person's tumour.

For young adults that have chosen to have cancer treatment outside of the TYA PTC, either at a TYA DH or an adult cancer service that is not designated to manage TYA cancer, the TYA PTC, through the Network TYA MDT, is responsible for providing expert advice to guide treatment plans, access clinical trials and ensure that holistic needs are met.

2.3.1 Referral

For all teenagers and those young adults that 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; and
- 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 TYA MDT; and
- Discuss all cases in the Network TYA MDT, within 7 working days of receipt of referral.

2.3.2 TYA 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 that 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 patient's tumour. 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; and
- Facilitate access to relevant patient support groups and charities where appropriate.

Diagnosis and decision-making core service requirements
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 patients; and
- Ensure that site specific MDTs, supported by the Network TYA MDT, develop and agree treatment plans according to the 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.

The TYA PTC is also responsible for hosting the Network TYA MDT. The Network TYA MDT must:

- Meet weekly;
- Ensure that membership meets the requirements outlined in Appendix 2;
- Support the site-specific MDTs to jointly plan care for each patient, 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 of the holistic needs of each patient using the Network approved TYA specific 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 at new patient discussion all clinicians within the patients’ diagnostic pathway;
- Ensure that each patient is assessed for psychological need and can access any psychosocial support that is required;
- Ensure that each patient 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 cancer diagnosis at any location (TYA PTC, TYA DH or non-designated providers); and
- Submit the TYA fields to Cancer Outcomes and Services Dataset (COSD).

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).

Treatment core service requirements

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 (Appendix 1). Any service delivering autologous 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, by the end of March 2020.

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

- Offer cryopreservation to each teenager and young adult preparing to have treatment for cancer that is likely to result in fertility problems, considering the diagnosis, treatment plan, 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 patients 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 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. 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 each case that it is directly responsible for to the Network TYA MDT. If a patient 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. Patients 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 patient 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 patients must be offered the opportunity to bank their samples by March 2021; and
- Regular data submissions on research participation are provided to the Cancer Outcomes and Services Dataset (COSD), National Institute for Health Research (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 TYA patients 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;
- 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 (Contract particulars, Schedule 4 – National Quality Requirements). It is acknowledged that some providers may be working towards compliance with this requirement and will therefore have implementation plans in place which have been agreed with local commissioners;
- 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 patients to ensure:
    - Accurate pre-SACT assessment to enable variation from the patient’s baseline to be detected;
    - Pre-course and pre-cycle records meet all requirements of the relevant SACT; and
    - That the patient 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 patients 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 patient’s 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 patients GP and the referring clinician; what treatment has been delivered, the patient's condition and any post treatment arrangements; and
- 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.

Joint Care Core Service Requirements
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 children's cancer paediatric oncology shared care unit (POSCU) in collaboration with the local Children's Cancer Network.

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.

Palliative Care core service requirements
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 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.

2.4 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, 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 patient into one of three levels (supported self-management, a shared care system or hospital-based follow-up for the most complex care needs). All patients must be allocated a risk level which must be documented in the care plan. This process should be overseen by a TYA Late Effects MDT (see Appendix 3 for the defined membership). 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 patient within 6 months of completing treatment and be provided to the patient / family 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 patient 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. At a point along the aftercare pathway, one which will vary between PTCs, a patient's care will be transferred from the disease specific multi-disciplinary team (MDT) 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 patients within the Aftercare pathway. Access to specialist psychological support should be available as required for a minimum of two years post treatment.

2.5 Transitional Care

Transitional care applies to those patients 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 patient knows what to expect. Transition should occur at a time of stability in the patient'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 patients and families may feel (e.g. by having joint transition appointments).

2.6 Specialist Psychological Support

Care pathways must describe the psychological and social support available to patients and families to support access to treatment to ensure quality of experience. Services must incorporate a TYA HNA. The provision of specialist psychological and appropriate social support to teenagers, young adults and their families involves multiple agencies and must be available to patients and their carers throughout the entire patient journey from diagnosis, during active cancer therapy and into follow-up or bereavement.

2.7 Service User Information and Consent

Age appropriate patient and carer 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 and, where appropriate, the joint care arrangements between the TYA PTC and TYA DH services.

All young people who use services 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.

2.8 PTC Workforce

The TYA PTC must:

- Ensure there is a single named Lead Clinician for the service who must be a medical consultant, 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 Appendix 4.
- 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 patients 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. Session 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; and
- 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. Recommended staffing levels can be found in Manual for Cancer Services: Teenage and Young Adult Measures Version 1.0 (2011).

- 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; and
- Clinical nurse specialists.

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

2.9 PTC 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 patients within the TYA age range with malignant haematology. This specification recognises that these facilities are also used for TYA patients 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; and
- Provide a framework for staff education.

2.10 Interdependencies with other services

The TYA PTC has a range of critical co-dependencies with other clinical services. 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; and
- 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 patient, the management of acute collapse/arrest and retrieval process to the nearest Level 3 critical care facility. The SOPs must be agreed by the Network and the safety of these pathways must be audited continuously on a prospective basis as part of the Network's audit programme.

A. 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; and
   - Other specialist surgery.

B. 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; and
   - Proton Beam Therapy.

Teenagers and young adults with cancer have complex needs and as a result, a multi-agency approach to supporting patients 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 patients in full time education up to 18 years of age
- Education services for patients in full time/part time education aged 18 to 24 years of age
- Careers and employment services; and
- 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), the services must be delivered in line with the Children's Cancer Network service specification.

3. Population Covered and Population Needs

3.1 Population Covered By This Specification

This Specification is for teenagers and young adults (aged 16 years up to 25th birthday) resident in England* or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?, Establishing the responsible commissioner and other Department of Health guidance relating to Patients entitled to NHS care or exempt from charges).

However, the specification does not prevent patients in the lower part of this age range being treated within children's cancer services or patients younger than 16 years being treated within the remit of a designated TYA PTC if they so wish and if this is clinically appropriate and compatible with local agreements for children's and teenage cancer. The TYA Network will agree initial management, specialised and follow-up pathways for TYA patients across its geographical area. These will be shared with primary and other secondary referrers.

*Note: for the purposes of commissioning health services, this EXCLUDES Patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES Patients resident in Wales who are registered with a GP Practice in England.

3.2 Population Needs

TYA cancer is rare, accounting for less than 1% of cancer in all ages (Teenagers and Young Adults with Cancer (TYAC), 2016). The spectrum of cancer types in this age group is also distinct from those seen in both children and adults. However, tumour types more commonly seen in young children or older adults may occasionally also be seen in the TYA population. The most common tumour types in TYA patients are:

- Lymphomas;
- Germ cell tumours;
- Central nervous system tumours;
- Malignant melanomas;
- Acute leukaemias; and
- Sarcomas.

There were approximately 2,200 patients aged 15 – 24 years diagnosed with cancer annually between 2013 – 2015 in England (Cancer Research UK, 2018); approximately 52% of patients are female and 48% are male, giving a female to male ratio of 11:10. The incidence of cancer within the TYA age group increases with age, with 62% of cases diagnosed in people aged 20 to 24 years.

3.3 Expected Significant Future Demographic Changes

The incidence of TYA cancers has increased over time and incidence rates have grown by 33% since the 1990s (Cancer Research UK, 2018) and has increased at a faster rate than has been observed in childhood cancer, with a 21% increase in the age-specific incidence rate between 2001 and 2015. This trend is expected to continue. Increases in incidence are observed in particular tumour types, including lymphomas, CNS tumours, germ cell tumours and epithelial tumours (specifically thyroid, melanoma and skin carcinoma). The exact reasons are currently unclear and in some cases are due to an increased detection rate of small, early stage cancers.

3.4 Evidence Base

The following evidence base has been used to develop this service specification:

- Improving Outcomes Guidance for Children and Young People with Cancer. National Institute for Health and Care Excellence (2005);
- Manual for Cancer Services: Teenage and Young Adult Measures Version 1.0. National Cancer Peer Review (2011);
- National Service Framework for Children and Young People, Standards for Hospital Services. Department of Health (2007);
- "You're Welcome" quality criteria: making health services young people friendly". Department of Health (2011);
- Survival in teenagers and young adults in the UK. North West Cancer Intelligence Service (2012);
- Exploring the Built Environment, The Future's Company Report for Teenage Cancer Trust (2010);
- Report for the National Awareness and Early Diagnosis Initiative Cancer in Primary Care: An Analysis Of Significant Event Audits For Diagnosis Of Lung Cancer And Cancers In Teenagers And Young Adults 2008 – 2009. Mitchell E, Universities of Dundee, Durham & Glasgow;
- Birch JM, Alston RD, Kelsey A, Quinn MJ, Babb P, McNally RJQ. (2002). Classification and incidence of cancers in adolescents and young adults in England 1979-1997. Brit J Cancer, 87, 1267-74. eScholarID:1d6343 | DOI:10.1038/sj.bjc.6600647;
- North West Cancer Intelligence Service (NWCIS). (2012). *Survival in Teenagers and Young Adults with Cancer in the UK.* http://www.ncin.org.uk/publications/reports/survival_in_teenagers_and_young_adults_with_cancer_in_the_uk
- "A Blue Print of Care for Teenagers and Young Adults with Cancer", Teenage Cancer Trust, http://www.teenagecancertrust.org/workspace/documents/Blueprint-of-care.pdf
- Young voices report. Transforming the lives of young people with cancer. Teenage Cancer trust 2012; http://www.teenagecancertrust.org/workspace/documents/Young-Voices-report.pdf
- Throwing light on the consequences of cancer and its treatment http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Throwinglightontheconsequencesofcanceranditstreatment.pdf

- Cancer Research UK Statistics. (2018) *Young people's cancer statistics*. https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/young-peoples-cancers
- More Than My Illness – delivering quality care to young people with cancer. CLIC Sargent (2010);
- Are we nearly there yet? The financial impact of travel on young cancer patients and their families. CLIC Sargent (2018).
- Cancer Costs – the financial impact of treatment on young cancer patients and their families. CLIC Sargent (2016).
- No Child with Cancer Left Out – The impact of cancer on children's primary education. CLIC Sargent (2012);
- No Teenager with Cancer Left Out – the impact of cancer on young people's secondary education. CLIC Sargent (2013);
- Cancer Patient Experience in the Teenage Young Adult Population- Key Issues and Trends Over Time: An Analysis of the United Kingdom National Cancer Patient Experience Surveys 2010-2014. Furness CL, Smith L, Morris E, Brocklehurst C, Daly S, Hough RE. J Adolesc Young Adult Oncol. 2017 May 19. doi: 10.1089/jayao.2016.0058;
- National Career and Competence Framework for TYA Cancer https://www.teenagecancertrust.org/sites/default/files/Nursing%20framework%202017.pdf

4. Outcomes and Applicable Quality Standards

4.1 Quality Statement – Aim of Service

The aims of the TYA cancer service are to:

- Improve cancer treatment outcomes and survival for teenagers and young adults with cancer;
- Deliver age appropriate care, in age appropriate settings taking into account patient choice and the specific disease type;
- Support integrated and timely joint care across the network;
- Ensure appropriate entry of patients to clinical trials;
- Deliver and support palliative care services across the pathway;
- Deliver a long term follow-up model;
- Facilitate transition to adult services;
- Support the patient and their family throughout their cancer journey; and
- To 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 patient experience.

NHS Outcomes Framework Domains

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**	✓

4.2 Indicators Include:

Number	Indicator	Data Source	Outcome Framework Domain	CQC Key question
Clinical Outcomes				
101	% patients with a solid tumour with a recorded stage of 1 or 2 at diagnosis	NCRAS	1,2,3	Safe, Effective
102	% patients with metastatic disease at diagnosis	NCRAS	1,2,3	Safe, Effective
103	Median time from onset of symptoms to diagnosis	NCRAS	1,2,3	Safe, Effective
104	% patients who progress or relapse	NCRAS	1,2,3,5	Safe, Effective
105	Number of deaths within 30 days of surgery	NCRAS	1,2,3,5	Safe, Effective
106	% readmissions within 30 days of SACT	NCRAS	1,2,3,5	Safe, Effective
107	% readmissions within 90 days post-surgery	NCRAS	1,2,3,5	Safe, Effective
108	Number of deaths within 30 days of SACT	NCRAS	1,3	safe effective
109	Proportion of eligible patients recruited to a nationally available trial	NCRAS	1,2,3	Safe, Effective
110	Proportion of patients completing treatment, who receive an end of treatment summary and follow-up care plan, within 6 months of the end of treatment.	Provider	1235	Safe, Effective

111	Proportion of patients offered opportunity to tumour bank	NCRAS/self declaration	1,2,3	Safe, Effective
112	Proportion of patients who have had tumour samples banked	NCRAS	1,2,3	Safe, Effective
113	% patients discussed at a TYA MDT	NCRAS	1,2,3	Safe, Effective
114	% patients who have had fertility preservation	Self declaration	1,2,3	Safe, Effective
Patient Experience				
201	There is information for patients and carers	Self declaration	4	Responsive, Caring
202	There is a mechanism in place to obtain feedback from patients and families	Self declaration	4	Responsive, Caring
Structure and Process				
001	There are networking arrangements and a TYA Cancer Network Co-ordinating Group in place for TYA cancer services	Self declaration	1,3,5	Well led, Effective
002	There is a specialist multidisciplinary team	Self declaration	1,3,5	Well led, Effective
003	There is a SACT head of service and a lead and designated pharmacists	Self declaration	1,3,5	Well led, Effective
004	There is a network agreed competency-based training programme for oncology and SACT	Self declaration	1,3,5	Safe, Effective
005	There are specified wards for administration of SACT	Self declaration	1,3,5	Safe, Effective
006	There are policies in place for the safe administration of SACT	Self declaration	1,3,5	Safe, Effective
007	There is a TYA MDT	Self declaration	1,3,5	Effective
008	There are late effects MDT meetings	Self declaration	1,3,5	Effective, Caring,
009	There are network agreed clinical guidelines including SACT regimens and protocols in place	Self declaration	1,3,5	Safe, Effective

Detailed definitions of indicators, setting out how they will be measured, is included in schedule 6.

4.3 Commissioned providers are required to participate in annual quality assurance and collect and submit data to support the assessment of compliance with the service specification as set out in Schedule 4A-C

4.4 Applicable CQUIN goals are set out in Schedule 4D

5. Designated Providers (if applicable)

The designated providers for the [INSERT INDIVIDUAL TYA CANCER NETWORK NAME AT CONTRACT STAGE] are as follows:

Appendix 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**
TYA Cancer Networks - Designated Hospitals	TBC
Children's Cancer Networks	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

Appendix 2 – TYA Network MDT Membership

The TYA Network MDT must have:

- Single named Chair of the TYA MDT who fulfils the criteria listed in Appendix C
- A consultant haematologist with a practice in leukaemias which includes patients 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 patients with leukaemia, of at least 500 thousand;
- A consultant haematologist or oncologist with a practice in lymphoma which includes patients 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 patients with lymphoma, of at least 500 thousand;
- A consultant medical oncologist with a practice in germ cell malignancy which includes patients 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 two million;
- A consultant medical oncologist with a practice in brain and CNS tumours which includes patients 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 patients 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 for patients at, at least Level 3. They should have completed the training necessary to enable them to practice at level 3 for the psychological support of cancer patients 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 patients and carers;
- 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

Appendix 3 – Late Effects MDT

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

Appendix 4 – Staffing

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 patient 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.
    - Ensure that the TYA MDT NCRAS data are reported for all new patients diagnosed within the network

Chair of the TYA MDT

- 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 patients 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 patient, in discussion with other MDTs, responsibility for each component of the patient pathway.
    - Ensure that each new patient has a TYA holistic assessment
    - Ensure that all new patients 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 patients into clinical trials, subject to patients giving fully informed consent;

    - 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.

TYA PTC Lead Nurse

- 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 patient 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;
    - Is responsible for contributing to the strategic development of the TYA Cancer Network.