SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No:	B17
Service	Teenage and Young Adult Cancer Networks – Designated Hospitals [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 TYA Designated Hospitals (DHs) in England.

The principle that underpins the provision of TYA cancer services is that they must be age appropriate, safe, effective and delivered as locally as possible. It is acknowledged that, in some Networks, age criteria may vary and there may be some flexibility in age boundaries of services to ensure that patients access the optimum disease and age appropriate services.

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 Teenage and Young Adult PTC 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 children 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 PTC for diagnosis and agreement of a treatment plan. The TYA PTC will deliver most of the treatment and care and will co-ordinate referral to Supra-Network services and local specialist cancer services (Appendix 1) for specific treatments not provided by the TYA PTC. The role of the TYA DH is to refer teenagers with a suspected cancer diagnosis to the TYA PTC;
- 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 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

The TYA DH must be part of a TYA Cancer Network. In some geographies the TYA DH may work with more than one TYA PTC. Where this occurs, the TYA DH is required to form part of one Network only.

The TYA DH must:
- Agree and sign a Memorandum of Understanding, or other written agreement, setting out the role of the Network and each constituent member, together with the agreed governance arrangements;
- Participate fully in the TYA Cancer Network Co-ordinating Group (TYACNCG);
- Actively contribute to service governance at TYA Network meetings;
- Provide reports of clinical and quality outcomes across the network, including any incidents or safety concerns;
- Provide agreed workforce indicators;
- Report patient experience survey results;
- Contribute to service improvement projects within the Network;
- Report activity across their local site-specific cancer teams to the Network;
- Provide timely clinical trial portfolio and recruitment data to the TYA Cancer Network Board;
- Provide cancer pathway concordance data for TYA they manage to the TYA Cancer Network Board;
- Contribute actively to reviews of problems with concordance to network pathways;
- Contribute to the development of joint care pathways within the Network;

- Contribute to the iterative measurement and improvement in travel time and out-of-pocket cost, which will be led by the cancer charities;
- Comply with any Network guideline, protocol or plan; and
- Provide regular data to the TYACNCG to support the operational delivery and improvement of TYA cancer services. This will include, but not be limited to: (i) compliance against Network agreed treatment protocols; (ii) participation in research including clinical trials and tumour banking; and (iii) results and associated action plans for any local patient experience surveys.

2.3 Designated Hospital Core Requirements

2.3.1 Referral

The TYA DH must:

- Have an agreed local process and clear pathways for external referral to the TYA DH including urgent and out of hours referrals;
- Document the information provided when giving patients informed choice of place of care in the referral proforma to the TYA MDT; and
- Have an agreed local process and clear pathway in place to notify the TYA team at the DH of a cancer diagnosis in a TYA patient through the site-specific MDTs. This must include a locally agreed process with the TYA PTC to allow for urgent TYA MDT advice and input outside of the TYA MDT meeting.

2.3.2 Diagnosis, Treatment and Management of Cancer

The TYA DH must diagnose and direct the provision of cancer care for each young adult with cancer that has chosen to have their care within the TYA DH. This means that the TYA DH must ensure that there is access to diagnostic and therapeutic expertise which is most appropriate to each young adult's tumour. This includes ensuring timely access to consultations with tumour or site-specific experts.

The TYA DH must also ensure that each young adult is supported through diagnosis, treatment and into survivorship. This means that it must:

- Ensure that each young adult has a named key worker;
- Ensure that each 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.

<u>Diagnosis and Decision-Making Core Service Requirements</u>

The TYA DH must:

- Ensure that each young adult's case is discussed by a site-specific MDT and by the Network TYA MDT. Referrals to the Network TYA MDT should be sent within 7 days of diagnosis;
- Perform a TYA-specific Holistic Needs Assessment (HNA) and provide these data to the TYA MDT. The HNA tool used must be approved by the Network;

- Develop and agree treatment plans in line with the relevant approved Network protocol for the tumour and in accordance with the advice of the Network TYA MDT.
- 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;
- Ensure appropriate referral for Whole Genome Sequencing (WGS) for all eligible patients in line with Network agreed guidelines;
- Ensure compliance with all Network agreed pathways and protocols; and
- In partnership with 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.

Treatment and Management Core Service Requirements

There are several different cancer treatment options available for young adults, the most common of which are: 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 specific disease.

It is expected that most of the treatments for each young adult with cancer will be provided by the TYA DH. However, the TYA DH 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 DH must:

- Offer cryopreservation to each 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 DH 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 young adult receives contraception advice 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 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 DH is to ensure that each young adult 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 DH 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 within the TYA DH, the TYA DH must offer referral to an alternative provider. In most cases this will be to a 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 must be followed-up as defined in the trial protocol.

Furthermore, the TYA DH must ensure that:

- Each young adult 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) plays an important role in the treatment of TYA cancers. It 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 young adults (and teenagers under agreed joint care arrangements) must be initiated by either the TYA PTC/TYA DH and agreed by both the site-specific MDT and Network TYA MDT.

The TYA DH 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 TYA DH;
- Agree an approved list of SACT treatment regimens which is updated annually. This list should be in line with Network agreed regimens and protocols.
- 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;
- 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).
- Have 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 cancer 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 treatments, within the TYA DH as close to home as possible. Where there is an agreed joint care pathway between the TYA PTC and TYA DH, the TYA DH must comply with this.

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. The TYA DH must provide as a minimum:

- Outpatient supportive care and follow-up (e.g., blood product support);
- Emergency management of teenagers and young adults with cancer (e.g., febrile neutropenia emergency treatment) and inpatient supportive care (e.g., pain management and symptom control); and
- Sign-posting to local support services.

Palliative Care Core Service Requirements

Specialist cancer palliative care advice and treatment is delivered by specialist palliative care teams from the TYA DH or the TYA PTC. 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, DHs 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. 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 and. 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.

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, when transition is required. 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 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. Patient and Carer information must be provided which covers the treatment plan, how to access care out of hours and the joint care arrangements between the TYA PTC and TYA DH services when appropriate.

Each young adult using 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**).

2.7 TYA DH Workforce

Lead Clinician

- There must be a single named lead clinician for TYA cancer within the TYA DH;
- The lead clinician must have a practice, worked in the designated hospital, in one or more of the following malignancies which includes patients in the TYA age range:
  - Leukaemias;
  - Lymphomas;
  - Germ cell malignancy;
  - Bone and/or soft tissue sarcomas; and
  - Brain and CNS malignancy.
- The purpose of the role is to provide leadership and support to health professionals in the provision of specialist and age-appropriate care within their trust and in collaboration with the TYA MDT at the TYA PTC;

- The TYA DH lead clinician must work in partnership with the PTC to contribute to the strategic development of TYA cancer services in line with the individual hospital Trust and TYA Cancer Network; and
- The TYA DH lead clinician must be employed on a 0.05WTE (0.5 Programmed Activities) basis. If the hospital manages more than 25 TYA patients per year, this should be a 0.1WTE (1 Programmed Activities).

The role of the lead clinician is to support the delivery of age-specific care for TYAs with malignant disease within the host hospital's catchment area. This will include:

- Having oversight of all TYA patients at the site;
- Bringing together a team of medical, nursing and AHP staff who have expertise in managing patients in the TYA range treated at the hospital;
- Liaising with all relevant site-specific leads in the area served;
- Agreement of treatment policies with the TYA Cancer Network Board including:
  - Tumour types to be treated, both to deliver primary treatment and on a joint care basis;
  - Appropriate treatment protocols for each tumour treated; and
  - Clinical trials to be open for recruitment (with R&D approval) and delivery at the Designated Hospital, for each tumour type.
- Liaising with the TYA PTC, including the need to:
  - Establishing a pathway for management of each tumour type.
  - Establishing the process for registration of all new patients diagnosed within the Designated Hospital's catchment area.
  - Establishing for each patient, in discussion with the TYA MDT at the PTC, responsibility for each component of the patient pathway. Including who is the most appropriate Key Worker and whether support is provided by the DH team and/or the outreach team from the PTC.

TYA DH Clinical Nurse Specialist

- There must be a named Clinical Nurse Specialist at the TYA DH;
- The TYA DH Clinical Nurse Specialist role is to provide local coordination of TYA care, liaison with the TYA MDT at the PTC, and leadership and support to provide age-appropriate care to TYA cancer patients within their Trust;
- The TYA DH Clinical Nurse Specialist must work closely with the local TYA clinical lead and the PTC lead TYA nurse;
- The TYA DH Clinical Nurse Specialist must contribute to the strategic development of TYA cancer services within the individual hospital trust;
- The TYA DH Clinical Nurse Specialist must be employed on a 0.5WTE basis for sites managing an average of 25 patients per year. This should be 1.0WTE if the site manages an average of 50 patients per year;
- Provide ongoing advice, support and care to young people from diagnosis across the patient pathway;
- Undergo and/or have completed recognised TYA cancer education in line the National Career and Competence Framework (Royal College of Nursing);
- Advance the development and practice of evidence-based TYA cancer nursing in the Trust, in line with national recommendations where available;

- Collaborate with the TYA MDT in ensuring all patients are reviewed and agreed plans for nursing care and support are delivered at local level; and
- Develop and implement communication arrangements with nursing and members of site-specific MDTs in their Trust regarding TYA cancer care.

TYA DH Social Worker

- Should be employed on a 0.5WTE basis. However, this should be 0.75WTE for a site that manages more than 25 TYA patients per year;
- Could be employed by the PTC with a peripatetic contract to enable them to work at the TYA DH or employed by the TYA DH; and
- Should be core members of the TYA MDT.

TYA DH Youth Worker/Activity Coordinator

- Should be employed on a 0.05WTE basis. However, if the site manages more than 25 patients a year, this should be 0.1WTE;
- Could be employed by the TYA PTC with a peripatetic contract to enable them to work at the TYA DH or be employed by the TYA DH; and
- Should be core members of the Network TYA MDT.

TYA DH Pharmacy

- There should be support from cancer pharmacists with specialist experience in TYA cancer.
- As a minimum this should include a lead pharmacist and a designated deputy.
- Sufficient staffing should be in place to ensure that the service is safe and effective.
- Pharmacists 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.

SACT services

- 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;
- The names of staff that have completed competency-based training must be kept on a current register of competent staff; and
- There must be a lead pharmacist with overall responsibility for the aseptic SACT preparation service and facilities.

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.

In some Networks, access to TYA experts in the TYA DH may be provided across the Network from the wider MDT at the TYA PTC or another DH. These DHs must have the appropriate contractual and service level agreements in place to support this model.

2.8 Designated Hospital Facilities

Treatment for young adults with cancer is complex and intensive, and people in this age range can often become acutely ill during treatment, requiring a high level of medical support. As a result, care is mainly provided within inpatient, ambulatory care and day care settings. The DH must ensure that there is a named ward for the delivery of chemotherapy for TYA patients and patients must be admitted to this ward in preference to other wards. Staff in the named ward must be trained in managing TYA patients. These arrangements must be documented in a written policy.

When either outpatient or day-case chemotherapy is being given in wards/areas other than those specified above, these must be specified in local policies. On the days that chemotherapy is being given, the room(s) should only be used for this purpose and for TYA patients only.

The pathology services supporting the TYA DH 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 (e.g. blood tests) 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.

2.9 Interdependencies with other services

Each TYA DH must have co-located on-site the following clinical services:

- Acute oncology service;
- Haematology service;
- Cancer pharmacy service;

- Anaesthetics and pain management services;
- Therapy services (such as psychology, physiotherapy);
- Critical care at a level required for the complexity of services provided at that site;
- Access to those services listed in Section 2.10 B and C of the TYA PTC Service Specification; and
- End of life and hospice services.

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

Cancer in TYA patients 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 distinct from those seen in children and adults. Tumour types more commonly seen in young children or older adults may occasionally also be seen in TYA population. The most common tumour types in TYA patients are:

- Lymphomas
- Germ cell tumours
- Central nervous system tumours
- Malignant melanomas
- Acute leukaemias
- 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 specific 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);
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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 considering 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	1235	Safe, Effective
105	Number of deaths within 30days of surgery	NCRAS	1235	Safe, Effective
106	% readmissions within 30 days of SACT	NCRAS	1235	Safe, Effective
107	% readmissions within 90 days post-surgery	NCRAS	1235	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				
301	There is information for patients and families	Self declaration	4	Responsive, Caring
302	There is a mechanism in place to obtain feedback from patients and families	Self declaration	4	Responsive, Caring
Structure and Process				
401	There is a lead consultant and lead nurse for the TYA service	Self declaration	1,3,5	Well led, Effective
402	The TYA DH participates in the network TYACNCG	Self declaration	135	Effective
403	There is a network agreed competency based training programme	Self declaration	1,3,5	Safe, Effective
404	There are clinical guidelines in place	Self declaration	1,3,5	Safe, Effective
405	There are network agreed pathways and joint care arrangements in place	Self declaration	1,3,4,5	Safe, Effective
406	The DH is submitting all relevant information to the national databases	Self declaration	1,3,4,6	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 - Principal Treatment Centres	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