# **SCHEDULE 2 – THE SERVICES**

# **Service Specifications**

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

5.	Population and/or geography to be served
5.1	Population Covered
	The population covered by the Teenage and Young Adult (TYA) Designated Hospital Service (the 'Service') is people aged 19 years up to 25 <sup>th</sup> birthday, who are within the commissioning responsibility of NHS England and who have a suspected or confirmed cancer.
	<ul> <li>Within the Specification, the following definitions apply:</li> <li>Teenager refers to people aged 16 to 18 years, up to the 19th birthday;</li> <li>Young Adult refers to people aged 19 to 24 years, up to the 25th birthday; and</li> <li>Teenager and Young Adult refers to people aged 16 to 24 years, up to 25th birthday.</li> </ul>
	It is acknowledged that, in some networks, age criteria may vary and there may be some flexibility in age boundaries of services to enable service users to access optimum disease and age-appropriate services. 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, for example, through the use of joint care models.
5.2	Minimum population size
	The TYA Designated Hospital (DH) must serve a population sufficient to support a critical mass of infrastructure, specialist and sub-specialist expertise. The TYA Cancer Network may undertake a designation programme to ensure that DH services meet the population needs.
6.	Service aims and outcomes
6.1	Service Aims
	The Service aims are to:
	Improve cancer treatment outcomes and survival for all service users.
	Deliver age-appropriate care, in age-appropriate settings, taking into account
	<ul> <li>service user choice and the specific disease type.</li> <li>Enable integrated and timely joint care across the network served by the DH.</li> </ul>
	<ul> <li>Enable integrated and timely joint care across the network served by the DH.</li> <li>Increase participation in clinical trials.</li> </ul>
	<ul> <li>Increase participation in tumour banking.</li> </ul>
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- Improve the transition arrangements between children's and TYA services and subsequently to adult services, ensuring that there is no age gap between different services.
- Support the service user and their family throughout their cancer journey in a culturally appropriate and sensitive way.
- Develop high quality data to enable review of the performance of services and share learnings to continuously demonstrate improvements in the quality of services and service user experience.
- Embed genomic medicine within TYA cancer services.

# 6.2 Outcomes

# NHS Outcomes Framework Domains & Indicators

Domain 1 Preventing people from dying prematurely		✓
Domain 2	Domain 2 Enhancing quality of life for people with long-term conditions	
Domain 3	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		<b>✓</b>

#### Service defined outcomes/outputs

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

#### Service description

#### 7.1 Service model

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The Service encompasses the diagnosis, management and follow-up of people aged 16 years up to 25th birthday. The service is led by a TYA PTC which will work in partnership with TYA Designated Hospitals (DHs) to ensure that service users receive the right care in the right place at the right time. The TYA DH must be an active member of a TYA Cancer Network.

The model of care for TYA cancer services requires that:

- Each teenager (up to the 19<sup>th</sup> birthday) with a suspected diagnosis of cancer must be referred to the TYA PTC for diagnosis and agreement of a treatment plan. The TYA PTC will also deliver most of the care and will co-ordinate referral to supra-network services and local specialist cancer services for specific treatments not provided by the TYA PTC (see Section 7.7.1).
- Each young adult (aged 19-24 years) must be referred to either a TYA PTC or TYA DH for diagnosis and agreement of a treatment plan, having been offered a choice of the two. The choice must be documented in the TYA multidisciplinary team (MDT) referral proforma. The relevant service, either TYA PTC or 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 available within the service.
- Each teenager and young adult, irrespective of where treatment is delivered, must be discussed in the TYA MDT meeting which is hosted by the TYA PTC. The purpose of the TYA MDT is to review the treatment plan made by the site-specific MDTs to ensure that each person: (i) is offered the choice of participating in appropriate clinical trials; and (ii) has their holistic needs identified and met.
- Each teenager and young adult receiving care primarily at the TYA PTC, may have their treatment delivered entirely within the TYA PTC or through a jointcare model with a TYA DH, closer to home. The exceptions to this relate to where some conditions are managed by supra-network services and or local specialist cancer services.

#### (A) Referral

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 service users informed choice of place of care in the referral proforma to the TYA MDT.
- 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 service user through the sitespecific 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.

#### (B) Diagnosis, Treatment and Management of Cancer

The TYA DH must diagnose and direct the provision of cancer care for each young adult with cancer who 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 service user support groups and charities where appropriate.

#### Diagnosis and decision-making core service requirements

#### 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.
- Ensure that site-specific MDTs maintain accurate and auditable decision records.
- 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 service users in line with Network agreed guidelines;
- Ensure samples for tumour banking are sent in line with Network agreed pathways;
- Ensure compliance with all Network agreed pathways and protocols; and
- In partnership with the Network TYA MDT, develop and agree treatment plans
  according to either: (i) appropriate current UK Clinical Research Network
  (UKCRN) Portfolio protocol; (ii) relevant paediatric guideline/protocol as
  determined by individual cancer type; or (iii) relevant adult guideline/protocol as
  determined by individual cancer type. In exceptional circumstances, some
  people may be treated in line with a locally approved off-protocol therapy.

#### <u>Treatment core service requirements</u>

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 (see Section 7.7.1). Any service delivering autologous or allogeneic haematopoietic stem cell transplants at the DH must have accreditation by the Joint Accreditation Committee of the International Society for Cellular Therapy (ISCT) and the EBMT (JACIE), in line with relevant NHS England service specifications, within 18 months of the adoption of this Service Specification.

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

- Offer fertility preservation to each young adult preparing to have treatment for cancer that is likely to result in fertility problems. Consideration should be given to the diagnosis, treatment plan and associated risks of fertility, 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 guideline s; and
- Ensure that each 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 childhood cancers, where around two-thirds of service users are recruited onto trials. Despite this, currently only between 10 to 25% (Fern L, Davies S, Eden T, et al, 2008) of all teenagers and young adults with cancer participate in clinical trials.

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

The role of the TYA 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 discuss every service user in the Network TYA MDT. If a service user is eligible to participate in a clinical trial (early or late phase) which is not available locally 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. Service users 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 service users must be offered the opportunity to bank their samples within 12 months of the adoption of this Service Specification; and

 Regular data submissions on research participation are provided to the Cancer Outcomes and Services Dataset (COSD), 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 must be initiated by the TYA DH and agreed by both the site-specific MDT and Network TYA MDT. All SACT delivered to teenagers under joint care arrangements must have their treatment plan initiated by the TYA PTC.

#### The TYA DH must:

- Ensure that there are arrangements in place to support urgent SACT treatment prior to MDT discussion.
- Ensure that SACT must only be prescribed by staff that have demonstrated their competency and are authorised and registered to prescribe SACT in the 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.
- 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.
- Ensure that SACT is only prescribed by staff that have demonstrated their competency and are authorised and registered to prescribe SACT within the provider.
- Undertake pre-chemotherapy treatment assessments for all service users to ensure:
  - Accurate pre-SACT assessment to enable variation from the service user's baseline to be detected;
  - Pre-course and pre-cycle records meet all requirements of the relevant SACT; and

- That the service user is confirmed to be fit to proceed and all precycle/course investigations are within the limits defined in the protocol.
- Ensure that all female service users of child-bearing age have a pregnancy test prior to initiation of SACT.
- Put in place local arrangements to ensure that, as far as is practicable, highcost items are only reconstituted after the service users blood results are known. All SACT must be prepared in accordance with locally approved policies and protocols.
- Put in place a local policy which sets out that SACT treatment should be commenced during standard 'working hours', wherever possible. This is to ensure that support services and expert advice is available. The policy must also state which, and only which, exceptional circumstances the initiation of administration of chemotherapy may be allowed outside "normal working hours" and the arrangements for administering SACT which then apply.
- Ensure that there are on-site facilities for the management of central venous access devices with defined surgical support at the PTC and at other agreed sites, so that the administering practitioner can ensure appropriate venous access for the chemotherapy to be administered.
- Ensure that the SACT service is delivered safely and that it conforms to appropriate standards, guidance and best practice, including:
  - Manual for Cancer Services: Children's Cancer Measures (National Cancer Action Team, 2013):
  - Improving Outcomes in Children and Young People with Cancer (NICE, 2011);
  - National standards set following National Patient Safety Agency (NPSA) oral and vinca-alkaloid alerts (2008):
  - Systemic Anti-Cancer Therapy: For Better or Worse (National Confidential Enquiry into Patient Outcomes and Death (NCEPOD), 2008);
  - Chemotherapy Services in England: Ensuring quality and safety (National Chemotherapy Advisory Group (NCAG), 2009); and
  - Guidance on the administration of intrathecal chemotherapy (Department of Health, 2008).
- 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 service user's GP and the referring clinician; what treatment has been delivered, the service user's condition and any post treatment arrangements.
- Submit data to the national SACT database.

SACT preparation, in particular chemotherapy, may receive pharmacy support from a pharmacy which has been reviewed as part of the peer review of "adult" cancer services or children's cancer services. If, at such a previous review, there was compliance with the measures regarding preparation facilities and the Control of

Substance Hazardous to Health (COSHH) they will be regarded as compliant for the review of TYA cancer services, provided it is within the timeframes stated in those measures. The remaining preparation measures, as outlined in this Specification, should be applied specifically and separately with regards to the TYA cancer service. The responsibility for review purposes for these measures lies with the lead pharmacist.

#### 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.

# (C) 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 through the TYA PTC, 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 service users into one of three levels (supported self- management, a shared care system or hospital-based follow-up for the most complex care needs). All service users must be allocated a risk level which must be documented in the care plan. Long term follow-up may be delivered by a site-specific MDT or by the TYA Late Effects MDT at the TYA PTC depending on the allocated risk level. The allocated risk level must be appropriate for the individual, considering psychosocial factors as well as diagnostic and treatment factors;
- End of treatment summary: this must be prepared for every service user within 6 months of completing treatment and be provided to the service user, parent/guardian and GP (and other as appropriate);
- Individualised care plan: this is a dynamic document which must be reviewed and modified at intervals throughout follow-up and must include: (i) type and planned frequency for surveillance of the original cancer; (ii) potential late effects and recommended surveillance based on national or international standards; (iii) health education; and (iv) psychological assessment and support. The care plan must be shared with the service user and/or parent/guardian 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 access to psychological support, when needed, must be made available.

# (D) Service User Information and Consent

Age-appropriate service user and parent/guardian information must be provided in a

range of different formats which covers generic and tumour specific information for young people with cancer. Information must be provided which covers the treatment plan, how to access care out of hours, information on tumour banking and clinical trials, and the joint care arrangements between the TYA PTC and TYA DH services when appropriate.

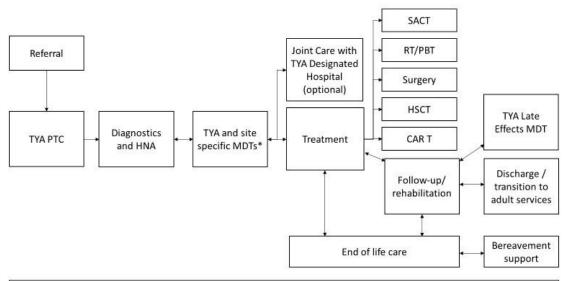
Each young adult using the service must be:

- 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).

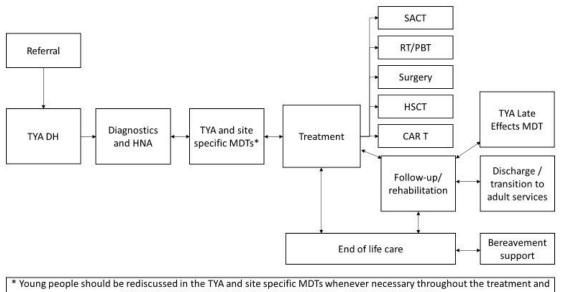
# 7.2 Pathways

Patient pathway – for all teenagers and those young adults that opt to have care at the TYA PTC



 Young people should be rediscussed in the TYA and site specific MDTs whenever necessary throughout the treatment and follow up course e.g., progressive disease, relapse, psychosocial concerns

#### Patient pathway – for young adults that choose to have care at the TYA DH



follow up course e.g., progressive disease, relapse, psychosocial concerns

#### <u>Shared care arrangements – 'joint care'</u>

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.

Under a joint care service, 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)
- Sign-posting to local support services.

#### Transition

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

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

The transition plan should begin well in advance of transition and be pro-active so that each service user knows what to expect. Transition should occur at a time of stability in the service user's disease and treatment and may be effectively achieved during therapy or after completion of treatment. The referring and receiving teams should liaise carefully to ensure that the transition process is seen as a positive step and to minimise the anxiety that service users and families may feel, for example by having joint transition appointments.

#### 7.3 Clinical Networks

There is a requirement for providers of this Service to comply with the provisions of Schedule 2F (Clinical Networks) of the NHS Standard Contract 2022/23 The Particulars. This includes meeting the requirements of the relevant Specialised Services Clinical Network Specification – in this case, the TYA Cancer Network and, as appropriate, the Children's Cancer Network.

# 7.4 Essential Staff Groups

#### 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 service users 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;
- For the purpose of TYA service leadership, the 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 service users at the site;
- Bringing together a team of medical, nursing and AHP staff who have expertise in managing service users 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:
  - o Establishing a pathway for management of each tumour type.
  - Establishing the process for registration of all new service users diagnosed within the Designated Hospital's catchment area.
  - Establishing for each service user, in discussion with the TYA MDT at the PTC, responsibility for each component of the care 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 service users 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;
- For the purpose of TYA service leadership, the DH Clinical Nurse Specialist
  must be employed on a minimum of a 0.5 WTE 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 care 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 service users 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 have access to a 0.5 WTE social worker. However, this should be 0.75 WTE 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 have access to a 0.05 WTE youth worker or activity coordinator.
   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 PTC 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.

# 7.5 Essential equipment and/or 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 service users must be admitted to this ward in preference to other wards. Some DHs may wish to have more than one named ward in order to enable access to site specific expertise. Staff in the named ward must be trained in managing TYA service users. The training requirements should be defined by the TYA Cancer Network and may include local education sessions, network-wide training or more formal national TYA cancer training programmes. These arrangements must be documented in a written policy and agreed by the Network.

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 service users 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.

#### 7.6 Interdependent Service Components – Links with other NHS services

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

- Acute oncology service
- Haematology service
- Cancer pharmacy service
- Radiology
- Anaesthetics and pain management services
- Therapy services (such as psychology, physiotherapy, occupational therapy, dietetics and speech and language)
- Critical care at a level required for the complexity of services provided at that site.

# B. The following clinical services do not need to be delivered on-site, however, the TYA DH must have clear referral and management pathways in place for the following services, if not delivered on-site:

- Endocrinology
- Nephrology
- Cardiology
- Cancer surgery
- Pathology
- Neurosurgery
- Infectious Diseases
- Palliative care
- Other specialist surgery
- Radiotherapy
- Haematopoietic Stem Cell Transplantation (both autologous and allogenic)
- Late effects MDT
- Liver cancer surgery
- Bone cancer surgery (NHS England service specification: Primary malignant bone tumours)
- Onco-fertility/reproductive medicine
- Other specialist surgery
- Proton Beam Therapy
- End of life and hospice services
- Genomic Laboratory Hubs.

# 7.7 Additional requirements

#### 7.7.1 NHS England Service Specifications Relevant to TYA Cancer

NHS England Service Specification			
SUPRA-NETWORK SERVICES			
Service Specification Title	NHS England Reference		
Paediatric Radiotherapy Services	TBC		
Proton Beam Therapy Service (all ages)	170071S		
Proton Beam Therapy Service - Overseas Programme (adults and children)	170012/S		
Haematopoietic Stem Cell Transplantation (Children)	B04/S/b		
Haematopoietic Stem Cell Transplantation (Adults)	B04/S/a		

Retinoblastoma Service (Children)	E04/S(HSS)/a
Stereotactic Radiosurgery and Stereotactic Radiotherapy (Intracranial) (All Age	s) D05/S/a
Primary Malignant Bone Tumours Service (Adults and Adolescents)	B12/S(HSS)/a
Penile (Adult)	B14/S/b
Testicular (Adult)	B14/S/c
CAR T-cell Therapy	TBC
NETWORK SPECIALIST SERVICES	
Service Specification Title	NHS England Reference
Children's Cancer PTC	1746
Children's Cancer POSCU	1746
TYA PTC	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	C07/S/h

# 7.8 Commissioned providers

Services

The list of commissioned providers for the services covered by this specification can be found here. [ADD LINK TO THE COMMISSIONED PROVIDER LIST ONCE AVAILABLE]

C07/S/b

E03/S/h

# 7.9 Links to other key documents

Paediatric Medicine: Palliative Care

Please refer to the <u>Prescribed Specialised Services Manual</u> for information on how the services covered by this specification are commissioned and contracted for.

Please refer to the Identification Rules tool for information on how the activity associated with the service is identified and paid for.

Please refer to the relevant Clinical Reference Group <u>webpages</u> for NHS England Commissioning Policies which define access to a service for a particular group of service users. The specific clinical policies that relate to the services covered by the Specification include:

- Clinical Commissioning Policy: Dexrazoxane for preventing cardiotoxicity in children and young people (under 25 years) receiving high-dose anthracyclines or related drugs for the treatment of cancer.
- Clinical Commissioning Policy: Use of plerixafor for stem cell mobilisation (updated to include paediatrics).

• Clinical Commissioning Policy: Proton beam therapy for children, teenagers and young adults in the treatment of malignant and non-malignant tumours.

# Relevant NICE Guidance (exc. Technology Appraisals)

- NICE: Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer The Manual; August 2005 <u>Child & young people</u> <u>cancer CSG REP (nice.org.uk)</u>
- NICE Quality Standard: Cancer services for children and young people
   <u>Overview | Cancer services for children and young people | Quality standards | NICE</u>
- 3. NICE: Guideline NG12 Suspected cancer: recognition and referral Overview | Suspected cancer: recognition and referral | Guidance | NICE

#### **Relevant National Clinical Guidance**

- Manual for Cancer Services: Teenage and Young Adults Measures Version
   1.0. National Cancer Action Team / Peer Review Programme (2011)
- 2. Advice on provision of age-appropriate care. National Cancer Action Team (2011)
- 3. National Service Framework for Children and Young People, Standards for Hospital Services. Department of Health (2007).
- 4. <u>You're Welcome" quality criteria: making health services young people</u> friendly. Department of Health (2011).
- 5. <u>Cancer in Children, Teens and Young Adults: On the Right Course?</u> National Confidential Enquiry into Patient Outcome and Death (2018)