

## SCHEDULE 2 – THE SERVICES

### A. Service Specifications

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| <b>Service Specification No:</b> |  |
| <b>Service</b>                   | Children's Cancer Network - Principal Treatment Centres<br>[INDIVIDUAL PROVIDER NAME TO BE INSERTED AT CONTRACT STAGE] |
| <b>Commissioner Lead</b>         | NHS England – National Cancer Programme of Care  |
| <b>Provider Lead</b>             | INDIVIDUAL PROVIDER NAME TO BE INSERTED AT CONTRACT STAGE  |

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| <b>1. Scope</b>   |
| <p><b>1.1 Prescribed Specialised Service</b></p> <p>This Service Specification (the “Specification”) covers the provision of cancer services (the “Service”) for children aged 0 to 15 years, up to the 16<sup>th</sup> birthday at the Children’s Cancer Principal Treatment Centre (PTC) in England. The Specification also describes the purpose and requirements of the Children’s Cancer Network (the “Network”), which is hosted and run by the (PTC).</p> <p>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 the Teenage and Young Adult (TYA) Cancer Service, it may therefore be appropriate for a Children’s Cancer PTC to treat people up to their 19<sup>th</sup> birthday. It may also be appropriate for a TYA Cancer PTC to treat people aged 13 years above, in line with the TYA Cancer Services Service Specification.</p> <p><b>1.2 Description</b></p> <p>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.</p> <p>The Manual states that “specialist cancer services for children and young people include:</p> |

- 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 (service provision covered by other published NHS England Service Specifications);
- 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 Children’s Cancer Network – Paediatric Oncology Shared Care Units (POSCU) Service Specification, together with other published NHS England Service Specifications, in particular those relating to TYA cancer services (Appendix 1); and
- NHS England Clinical Commissioning Policies and Policy Statements.

### **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 children with cancer and is based on the principle that care must be age appropriate, safe, effective and delivered as locally as possible. Each child with suspected cancer should be referred to the PTC, which must make the diagnosis and direct the provision of treatment. The PTC will work in partnership with POSCUs, local specialist cancer services and supra-Network services to ensure that children receive the right care at the right time and in the right place.

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

- Improve integration between different children’s cancer services;
- Improve the experience of care;
- Increase participation in clinical trials, which is currently at around two thirds of patients;
- Increase tumour banking rates;
- Improve the transition between children’s and TYA services, in particular ensuring that there is no age gap between different services; and
- Embed genomic medicine within children’s cancer services.

Securing improved experience, greater pathway integration and increased clinical trial participation may mean that existing shared care arrangements in some Networks in England need to be both/either consolidated in number and/or expanded in terms of scope of practice. It is expected that the PTC, through the Children's Cancer Network, will drive this change, reflecting the unique needs of each Network within the agreed service configuration.

## **2.2 The Children's Cancer Network**

The PTC is responsible for ensuring the provision of high quality care through the effective coordination of integrated, disease specific pathways across different providers, known collectively as the Children's Cancer Network.

The PTC will discharge the Network function through the Children's Cancer Network Co-ordinating Group (CCNCG). 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 clear governance arrangements which have been agreed by the service commissioners and the Cancer Alliance(s) within the Network.

The CCNCG 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 CCNCG should be formed from all local providers of children's cancer services within the Network geography and at a minimum, must include representation from:

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

The CCNCG 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 Network, that will:

- Ensure that Network service configuration enables equitable access to comprehensive and integrated care for all children. This must include POSCU designation, unit age ranges and interaction with TYA cancer services and must be agreed no later than April 2020;
- Monitor POSCU provider compliance with the requirements of the POSCU Service Specification, recommending action(s) where a centre is non-compliant;
- Develop and maintain an operational policy for children's cancer services across the Network;

- Agree, and ensure adherence to, Network-wide referral pathways, disease-specific treatment pathways (including pathways for accessing paediatric radiotherapy services and sarcoma care), treatment and supportive care protocols and follow-up pathways. This must include: (i) clear transitional pathways for each tumour type into TYA services and then subsequently into adult services; (ii) access to fertility services in accordance with the National Institute for Health and Care Excellence (NICE) Quality Standard 'Fertility Problems' (QS73); (iii) psycho-social support pathways; and (iv) access to highly specialist maternity units for any patients who may become pregnant during treatment. In some cases, Networks may wish to agree pan-Network / Regional pathways and protocols to make best use of clinical facilities and teams;
- Ensure there are documented clinical pathways and access/referral arrangements in place for each Supra-Network service;
- Ensure good clinical governance systems and policies are in place between PTCs and POSCUs. This must include: (i) quality assurance systems; (ii) regular reporting of outcomes and any safety concerns; and (iii) incident reporting and information sharing between PTC and POSCUs including dissemination of learning from incidents;
- Promote age appropriate care throughout the Network in liaison with TYA cancer services ensuring no gaps in service provision particularly for those aged 16-18 years;
- Co-ordinate and monitor access to research across the Network to increase clinical trial recruitment and ensure every child is offered an opportunity to tumour bank;
- 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;
- Agree workforce contingency arrangements to ensure shared care services are sustained at all locations within the Network either through the PTC or other POSCUs where required;
- Ensure there are dedicated and secure communication systems in place between PTC and POSCUs 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;
- 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 PTCs and POSCUs where required;
- Ensure access to locally commissioned services including community nursing, therapies and palliative care across the Network; and
- Prepare a Network-wide annual report for submission to the Cancer Alliance Board and all commissioners outlining network performance against a set of agreed quality measures with areas identified for improvement. This may include data from the National Cancer Registration and Analysis Service

(NCRAS); Systemic Anti-cancer Therapy Database (SACT); European Group for Blood and Marrow Transplantation (EBMT); and the paediatric cancer quality dashboard.

The CCNCG must take into account both the needs of the local population and the local geography, e.g., 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**

### **2.3.1 Referral**

The PTC must:

- Have an agreed local process and clear pathways for referral to the 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.

If the PTC does not have sufficient capacity to accept the patient, it must:

- Liaise with other centres (ideally the closest alternative PTC) to arrange an alternative admission; or
- Actively support the referring hospital with patient management until transfer is completed (if appropriate).

### **2.3.2 Diagnosis, Treatment and Management of Cancer**

The PTC must diagnose and direct the provision of cancer care for each child diagnosed with cancer within the Network. This means that the PTC must ensure that there is access to diagnostic and therapeutic expertise that is most appropriate to each child's tumour. This includes ensuring timely access to consultations with tumour or site-specific experts.

#### Diagnosis and Decision-making Core Service Requirements

The PTC must:

- Hold a weekly diagnostic and treatment multi-disciplinary team (MDTs). The structure of the MDTs may vary within the PTC dependent on the size and expertise of the PTC but must encompass the core and extended membership as described in Appendix 2. Terms of reference for the MDT must be approved by the Network;
- Hold a weekly psychosocial MDT and ensure that there is a holistic approach to the delivery of care. The psychosocial MDT may be either held as a stand-alone MDT or be incorporated alongside the children's cancer MDT or site-specific MDTs;
- Hold a Late Effects MDT for all children with cancer treated within the Network. The Late Effects MDT must have a single named lead clinician with an agreed list of responsibilities. Core membership and extended membership must be provided in line with Appendix 2;

- For central nervous system tumours, ensure that the operational relationship between neurological, radiotherapy, neuroscience and rehabilitation services and their MDTs is defined and agreed.
- Ensure access to appropriate imaging and image-guided biopsy modalities, as agreed by Network protocols and guidelines;
- Ensure access to pathology services as per 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;
- Develop and agree treatment plans according to the following, as appropriate: (i) appropriate current UK Clinical Research Network (UKCRN) Portfolio protocol; (ii) Children's Cancer and Leukaemia Group (CCLG) guideline; (iii) other guidelines as determined by individual cancer type (e.g., sarcoma); or (iv) in the case of a teenager, clear evidence of better outcomes on an adult guideline or protocol. In exceptional circumstances, children may be treated in line with a locally approved off protocol therapy; and
- Communicate care plans with their relevant POSCUs using a secure electronic system.

Given the trend towards increasingly specialist interventions delivered by supra-Network specialist services, the scope of service provision delivered by each PTC may change over time. These changes may necessitate increased supra-regional working and the establishment of national clinical advisory panels, to ensure equity of access to these new therapies. The PTC will be expected to participate in these panels, as required, and adhere to any stipulated treatment protocols and pathways.

#### Treatment Core Service Requirements

The PTC will provide most of the treatment for child with cancer. 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. Sites delivering HSCT services must be clearly documented in the PTC's operational policy.

The PTC must only undertake treatment for infants aged less than 1 year old if it has specific experience and expertise in the management of cancers in this age group. Where this is not the case, there must be referral pathways and access arrangements with another PTC to ensure appropriate care for this age group where required.

The treatments provided by the PTC may be delivered entirely within the PTC or in partnership, but under the direction of the PTC, with a Paediatric Oncology Shared Care Unit (POSCU) that is located closer to home. The scope of practice and service

requirements for POSCUs are set out within the Children's Cancer Network POSCU Service Specification.

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

- Offer cryopreservation to patients and their families preparing to have treatment for cancer that is likely to result in fertility problems, taking into account the patient's diagnosis, treatment plan, urgency of treatment initiation, prognosis and likelihood of success of possible fertility preservation methods. The 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 all cancer patients should receive contraception advice prior to treatment if appropriate, depending on age.

Participation in clinical trials is an important component of treatment; currently around two-thirds of children participate in clinical trials. The PTC must ensure that each child is offered an opportunity to participate in a clinical trial, where a clinical trial for their particular cancer is available and it is clinically appropriate to do so. Clinical trials can be either early phase (I, II) or late phase (III). Early phase trials typically involve new therapeutic agents and are only provided by centres that are accredited by the Innovative Therapies in Children with Cancer (ITCC) Europe. Currently, ten PTCs in England are ITCC accredited. All national phase III clinical trials for first line therapy must be open in each PTC and ideally should be available across all PTC sites.

In the event that a child is eligible to participate in a clinical trial (early or late phase) which is not available locally, the PTC MDT must offer referral to an alternative PTC. Furthermore, the PTC must:

- Offer each child (or, where relevant, the persons with parental responsibility over the child) an opportunity at diagnosis to consent – in accordance with the General Data Protection Regulation and the Human Tissue Act - 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 children must be offered the opportunity to bank their samples by March 2021; and
- Provide regular data submissions on research participation 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 children's 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 children should be initiated by the PTC and agreed by one of the PTC MDTs. The PTC must:

- Ensure that there are arrangements in place to support urgent SACT treatment prior to MDT discussion;

- 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;
- 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, in particular the:

- 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 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;
  - Following treatment with SACT, the responsible clinician should confirm to both the patient's 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. 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 children's 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 children's service. The responsibility for review purposes for these measures lies with the lead pharmacist.

#### Palliative Care Core Service Requirements

When the aim of treatment is not curative, the PTC will provide palliative and end of life care and bereavement support. The PTC will also support the co-ordination of care outside specialist centres through shared care services and in liaison with local community and palliative care services. Specialist cancer palliative care advice and treatment is directed by specialist palliative care teams with some palliative care services delivered within POSCUs or at home. Specialist teams provide expert advice on all aspects of symptom control and psychological support for the child and their family and will be part of a wider paediatric palliative care network. It is recognised that these teams will be working with other non-cancer agencies to deliver palliative support e.g. Children's Hospices and Children's Community Nursing Teams, and other community-based services to provide end of life care and bereavement support.

Many children and their families have a preference for end of life care to be delivered at home. End of life care should include access to 24-hour palliative care support,

provided in partnership with paediatric palliative care services in order to deliver 24/7 care to the child and family at home. End of life pathways must be approved by the Network.

### **2.3.3 Survivorship, Long Term Follow-Up and Late Effects Service**

On completion of treatment, the PTC must ensure there is a comprehensive long term follow up package in place for every child or teenage cancer survivor which addresses the following:

- **Clinical risk stratification and follow-up model:** each patient must be allocated a risk level using a clinical risk stratification tool, such as that developed by the National Cancer Survivorship Initiative (NCSI). The risk level must be appropriate for the individual, taking into account psychosocial factors as well as diagnostic and treatment factors and must be documented within the care plan. The NCSI tool allocates patients into one of three levels, supported self- management, a shared care system or hospital-based follow-up for the most complex care needs;
- **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 others 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. In order 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.

### **2.3.4 Transition to TYA and Adult Services**

Transitional care is essential to ensure seamless provision of care from paediatric to TYA and then onto adult cancer / late effects services and should be defined for each tumour specific pathway within the Network. The PTC should ensure that transition to TYA or adult services is:

- Pre-planned and pro-active so that patients know what to expect and when transition is required;
- Occurs at a time of stability in the patient's disease and treatment and may be effectively achieved during therapy and after completion of treatment; and
- Involves close liaison between the referring and receiving teams 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).

### **2.3.5 Information and Consent**

Patient and Carer Information must be provided which covers generic and tumour specific information for children with cancer.

Each provider and health care practitioner must comply with the relevant legislative framework and relevant guidance governing consent. Accordingly, each provider and health care practitioner must ensure that all children and young people who use services are:

- 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 children's consent can be found through the [General Medicine Council](#).

It is important that patients, parents and carers receive clear written guidance when consenting to treatment, this must include the following:

- Treatment intent;
- Prognosis and potential complications associated with their treatment;
- Clear instructions who to contact if they need advice outside working hours including phone numbers for 24/7 advice lines (either at the PTC or POSCU);
- How to proceed in the event of a medical emergency, in particular following SACT; and
- Information on how to manage and care for a central line (where appropriate).

### **2.3.6 PTC Workforce**

Each PTC must:

- Ensure there is a consultant medical on-call rota in place which fulfils the following requirements:
  - The on-call rota is staffed wholly by named consultants, each of whom is a paediatric oncologist or haematologist employed at the PTC and providing inpatient care as part of their timetable during normal working hours;
  - Cover is provided 24/7;
  - The on-call individual is available to give advice to enquiring clinicians regarding paediatric cancer patients being managed anywhere in the Network, whether in hospital or in the community; and
  - The on-call individual is available to attend hospitals facilities of the PTC when required.

- Ensure there is resident cover rota for the PTC whereby there is 24/7 resident on-call cover from medical staff in paediatrics of Specialty Training (ST) 3 minimum level of seniority;
- Ensure that there is a professional head of the SACT service that is 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;
- Ensure that nurses who administer chemotherapy to children have been assessed as competent to do so, in line with the relevant quality measures;
- Maintain a register of staff that have completed chemotherapy competency-based training;
- Ensure support from a pharmacy team specialising in paediatrics. This must include:
  - A lead pharmacist (team manager) and number of designated pharmacists for the children's cancer service. Sufficient staffing should be in place to ensure that there is a safe and effective service; and
  - A single named designated pharmacist for the aseptic chemotherapy preparation facilities of the pharmacy service.
- 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 5<sup>th</sup> Edition (Beaney, AM. 2017).

Children's cancer services must take a multi-agency approach to support and address the wider social, educational, psychological and emotional needs of the child and family. As a result, all PTCs must ensure that:

- There is ready access to neuropsychology for the assessment and input for children with disease acquired or treatment related brain injury and specialist psychology, and liaison psychiatric services to address more complex psychological morbidity associated with cancer treatment;
- There is ready access to a wider range of services/professionals including:
  - Health play specialists;
  - Social workers;
  - Educational support including teachers;
  - Dietetics;
  - Physiotherapy;
  - Occupational Therapy;
  - Speech and Language; and
  - Rehabilitative support.

All staff should be subject to annual performance appraisal and a policy should be in place to govern this. Clear training policies should be in place to ensure that staff maintain and develop their specialist skills and knowledge which should include:

- Nurse training in line with the Network's internal and external training programme including training in chemotherapy skills and management of its consequences in line with the staff members role (see Appendix 3). It is recognised in national guidance that the nursing contribution in cancer teams is critical to the success of these services;
- Post registration nursing staff will need to develop specialist skills through a combination of in house development programmes, degree pathways or other relevant postgraduate modules. Specialist nurses are needed to support the service in identified roles such as Advanced Nurse Practitioner, and in areas such as long-term follow-up, clinical trials, bone marrow transplant, intravenous therapy, education and nursing research. The nursing teams also need to work effectively outside of hospitals by providing outreach, and support to local POSCU and community teams;
- Medical training in line with above where applicable for chemotherapy.
- Specialist pharmacy training in order to enable: (i) chemotherapy prescription verification; (ii) clinical screening of supportive care prescriptions; (iii) safe implementation of clinical trials and new drugs; (v) safe implementation of electronic prescribing of SACT;
- Access to specialist resource materials; and
- "Good Clinical Practice" in Clinical Trials training.

Time must be allocated for mandatory training and to maintain and develop cancer skills for all staff disciplines.

### **2.3.7 PTC Facilities**

Treatment for children with cancer is complex and intensive, and children can often become acutely ill during treatment, requiring a high level of medical support. As a result, care for children with cancer is mainly provided on an inpatient basis. The Service must be delivered in an age appropriate setting, which means that the PTC must:

- Ensure there are dedicated facilities for children with cancer including:
  - Named wards for inpatient chemotherapy. These must be documented in a written policy and patients must be admitted to these wards in preference to other wards;
  - An agreed number of single rooms (not one room only) for inpatient isolation, each with an en-suite toilet and washing facilities;
  - Separate day care facilities for children with waiting and play areas;
  - Access to dedicated day care recovery beds (i.e., a ward or room(s)). These must be documented in a written policy and on the days that the PTC's day care facility is being used, the rooms must only be used for patients who are resting after day care treatments or after invasive investigation, or for other outpatients who have had clean day care procedures. Paediatric resuscitation equipment must be in all rooms

where day care treatment takes place and this equipment should be checked at least weekly or line with the PTC's protocols; and

- Regular children's outpatient clinics which are exclusive to patients under the care of PTC and are identified as a contact point for referral in the primary care referral guidelines.

The pathology services supporting the Network 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.

#### **2.4 Interdependencies with Other Services**

PTCs have 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 PTC:

- Paediatric oncology services;
- Paediatric cancer pharmacy services;
- Paediatric haematology services;
- Paediatric radiology services;
- Paediatric critical care (Level 3);
- Paediatric surgery, to include management of emergencies, central lines and biopsy services (where these are not provided by interventional radiology or anaesthetics);
- Paediatric 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 in order to maintain a safe and high-quality service. In particular, the PTC must ensure:

- There are clear standard operating procedures (SOPs) describing the escalation of care for an acutely deteriorating child, the management of acute collapse/arrest and retrieval process to the nearest Level 3 paediatric critical care. These 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;
- Each site must meet the core requirements and SACT standards as outlined in this Specification and facilities of equivalence must be provided across all PTC sites. This must include access to: (i) 24/7 consultant paediatric

oncology/haematology advice; (ii) the full multi-disciplinary team; and (iii) all SACT regimens; and (iv) clinical trials (as defined in section 2.3.2);

- Unplanned transfers between PTC sites are minimised to reduce the need for multiple handovers and complex communications. Network and PTC pathways must demonstrate identification of high risk patients and interventions that may require transfer between sites. Possible transfer points between the PTC sites must be clearly described in Network pathways; and
- The PTC must report the following measures to both the Network and NHS England:
  - The number of unplanned transfers between PTC sites, other units within the Network or another PTC; and
  - The average time taken to transfer from any given PTC site to paediatric intensive care within the Network or another PTC.

On occasion, bespoke service specifications may be put in place that may make on-site co-location with certain clinical services a mandatory requirement.

The following clinical services do not necessarily need to be delivered on-site but PTCs need to ensure the services are readily available at all times (if not delivered on-site):

- Radiotherapy services;
- Endocrinology services;
- Neurosurgery (for centres treating children with neuro-oncological diseases);
- Nephrology services;
- Ophthalmology service;
- Gastro-enterology service;
- Cardiology services;
- Paediatric oncology surgery (other than management of emergencies, central lines and biopsy services);
- Paediatric pathology;
- Genomic testing;
- Paediatric Infectious Disease;
- Palliative care; and
- Other specialist paediatric surgery.

PTCs should ensure there are clear referral and management pathways in place for the following services (if not delivered on-site):

- HSCT (both autologous and allogenic);
- Liver cancer surgery;
- Bone cancer surgery;
- Other specialist surgery;
- Retinoblastoma; and
- PBT.

Other related co-dependent services include:

- Local authority based services for education and social services;
- Child and adolescent mental health services;

- Primary Care;
- Community services; and
- Palliative care services.

Please see Appendix 1 for the full list of NHS England Service Specifications pertinent to children's cancer services.

### **3. Population Covered and Population Needs**

#### **3.1 Population Covered By This Specification**

This Specification is for children 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).

\*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**

Childhood cancer is rare and, in the UK, around 1,600 children (under 15 years) are diagnosed with cancer every year (CCLG). The incidence of cancer in adolescents is less certain due to data collection issues, but rates calculated by Birch (2003), and endorsed by the CCLG, suggest about 1:7000 per year among adolescents 15-19 years. Across the 0-19 age range, the highest incidence of cancer is among children 0-4 years, reducing among children 5-14, and rising again among teenagers over 15 years. The incidence of childhood cancer in each region is similar across the UK.

Childhood cancers are different to cancers affecting adults and tend to occur in different parts of the body. Children are diagnosed with a wide range of cancers in the UK; around 41% are leukaemias and lymphomas, 25% brain tumours, with the remaining conditions comprising a wide range of solid tumours. As the age of the patient increases, bone sarcoma and epithelial tumours, which are more commonly seen in adults, are found.

In the past 40 years, treatment for children with cancer has greatly improved. Cure rates for children with cancer are much higher than adults. On average, 82% (over 8 in 10) of all children can now be completely cured. For some types of children's cancer, the cure rate is much higher (CCLG).

#### **3.3 Expected Significant Future Demographic Changes**

The incidence of paediatric cancer is expected to continue to increase in line with current trends, i.e. approximately 10% more children diagnosed per million population with every decade. The increases are likely to occur in particular tumour types including bone tumours and germ cell tumours, in line with recent trends (Cancer Science 2018, in press). Increased incidence and improved survival rates are

expected to continue to increase the number of patients using adult late effects services.

#### 4. Outcomes and Applicable Quality Standards

##### 4.1 Quality Statement – Aim of Service

The Specification aims to:

- Improve cancer treatment outcomes and survival for children with cancer;
- Reduce physical, emotional and psychological morbidity arising from treatment for childhood cancer;
- Support equitable, integrated and timely shared care across the Network;
- Ensure appropriate entry of patients to clinical trials;
- Deliver age appropriate care, in age appropriate settings;
- Delivery and support palliative care services across the pathway;
- Deliver a long term follow-up model;
- Facilitate transition to TYA and/or adult services;
- Support the patient and family throughout their cancer journey; and
- To develop high quality data to enable review of performance of services and share learning 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:

| No.                          | Indicator   | Data source | Domain(s) | CQC Key Question |
|------------------------------|---|-------------|-----------|------------------|
| <b>PTC Clinical Outcomes</b> |   |             |           |                  |
| 101                          | % patients with a solid tumour with a recorded stage of 1 or 2 at diagnosis | NCRAS       | 1,3       | safe effective   |

|     |  |          |       |                 |
|-----|--|----------|-------|-----------------|
| 102 | % patients with metastatic disease at diagnosis  | NCRAS    | 1,3   | safe effective  |
| 103 | Median time from onset of symptoms to diagnosis  | NCRAS    | 1,3   | safe effective  |
| 104 | % patients who progress or relapse for children with Leukaemia   | NCRAS    | 1,3   | safe effective  |
| 105 | % patients who progress or relapse for children with CNS tumour  | NCRAS    | 1,3   | safe effective  |
| 106 | % patients who progress or relapse for children with non CNS solid tumours   | NCRAS    | 1,3   | safe effective  |
| 107 | Number of deaths within 30 days of surgery   | NCRAS    | 1,3   | safe effective  |
| 108 | Number of deaths within 30 days of SACT  | NCRAS    | 1,3   | safe effective  |
| 109 | % readmissions within 30 days of surgery   | NCRAS    | 1,3   | safe effective  |
| 110 | % readmissions within 90 days post-surgery   | NCRAS    | 1,3   | safe effective  |
| 111 | Proportion of eligible children recruited to a nationally available trial  | NCRAS    | 1,3   | safe effective  |
| 112 | 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 | 1,3   | safe effective  |
| 113 | Proportion of patients offered the opportunity to tumour bank  | Provider | 1,3   | Responsive      |
| 114 | Proportion of patients who have had tumour samples banked  | NCRAS    | 1,3   | Responsive      |
| 115 | Proportion of patients admitted into ICU within 30 days of chemotherapy  | Provider | 1,3   | safe effective  |
| 116 | 1 year and 5 year survival   | NCRAS    | 1,3   | safe effective  |
| 117 | Number of emergency transfers from the PTC   | Provider | 1,3,5 | Safe, effective |

|                              |   |                  |       |                     |
|------------------------------|---|------------------|-------|---------------------|
|                              | to another provider within the Network or another PTC   |                  |       |                     |
| 118                          | Average time taken to transfer from the PTC to a paediatric intensive care within the Network or another PTC                  | Provider         | 1,3,5 | Safe, effective     |
| 119                          | Average number of bed days in paediatric intensive care per admission   | HES              | 1,3,5 | Safe, effective     |
| 120                          | Number of PTC referrals refused   | Provider         | 1,3   | Responsive          |
| <b>Patient Experience</b>    |   |                  |       |                     |
| 201                          | There is information for patients and families as set out in the service specification  | Self declaration | 4     | responsive, caring  |
| 202                          | There is a 24/7 advice service for patients and carers  | Self declaration | 4     | responsive, caring  |
| 203                          | There is a mechanism in place to obtain feedback from patients and families   | Self declaration | 4     | responsive, caring  |
| <b>Structure and Process</b> |   |                  |       |                     |
| 001                          | There are networking arrangements and a Children's Cancer Network Co-ordinating Group in place for children's cancer services | Self declaration | 1,3,5 | Well led. Effective |
| 002                          | There is specialist paediatric oncology staffing across all PTC sites in the Network.   | 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 24/7 consultant on call rota and resident on call rota   | Self declaration | 1,3,5 | Safe, Effective     |
| 005                          | There are MDT meetings for diagnosis, treatment and psychosocial management   | Self declaration | 1,3,5 | Safe, Effective     |
| 006                          | There are late effects MDT meetings   | Self declaration | 1,3,5 | effective, caring,  |

|     |  |                  |       |                       |
|-----|--|------------------|-------|-----------------------|
| 007 | There is a network agreed competency based training programme for oncology and SACT  | Self declaration | 1,3,5 | safe effective        |
| 008 | There are specified wards for administration of SACT   | Self declaration | 1,3,5 | safe effective        |
| 009 | There are network agreed clinical guidelines including SACT regimens and protocols in place  | Self declaration | 1,3,5 | safe effective        |
| 010 | There are policies in place for the safe administration of SACT  | Self declaration | 1,3,5 | safe effective        |
| 011 | There are network agreed patient pathways in place.  | Self declaration | 1,3,5 | safe effective        |
| 012 | There is a policy in place for transition  | Self declaration | 1,3,5 | safe effective        |
| 013 | The PTC is submitting all relevant information to the national databases   | Self declaration | 1,3,5 | Responsive            |
| 014 | Clinical trial eligibility is discussed with every patient and family where an appropriate trial is available either at the PTC or at another PTC. | Self declaration | 1,3,5 | Effective, Responsive |

**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 CHILDREN'S CANCER NETWORK NAME AT CONTRACT STAGE] are as follows:**

## Appendix 1 – Relevant Service Specifications

| <b>NHS England Service Specification</b>   |                              |
|--|------------------------------|
| <b>SUPRA-NETWORK SERVICES</b>  |                              |
| <b>Service Specification Title</b>   | <b>NHS England Reference</b> |
| Paediatric Radiotherapy Services   | TBC                          |
| Proton Beam Therapy Service (all ages)   | 170071S                      |
| Proton Beam Therapy Service - Overseas Programme (adults and children)   | 170012/S                     |
| Haematopoietic Stem Cell Transplantation (Children)  | B04/S/b                      |
| 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                 |
| CAR T-cell Therapy   | TBC                          |
| <b>NETWORK SPECIALIST SERVICES</b>   |                              |
| <b>Service Specification Title</b>   | <b>NHS England Reference</b> |
| Children's Cancer Networks - POSCUs  | TBC                          |
| Teenage and Young Adult Cancer Services  | TBC                          |
| Chemotherapy (Children, Teenagers and Young Adults)  | B15/S/b                      |
| Paediatric Medicine: Endocrinology & Diabetes  | E03/S/e                      |
| Paediatric Neurosciences: Neurosurgery   | E09/S/a                      |
| Paediatric Neurosciences: Neurology  | E09/S/b                      |
| Paediatric Neurosciences: Neurodisability  | E09/S/c                      |
| Paediatric Neurosciences: Neurorehabilitation  | E09/S/d                      |
| Paediatric Medicine: Renal   | E03/S/a                      |
| Paediatric Medicine: Immunology and Infectious Diseases  | E03/S/d                      |
| Paediatric Medicine: Palliative Care   | E03/S/h                      |
| Craniofacial service (All Ages)  | E02/S(HSS)/d                 |
| Paediatric Surgery (& Surgical Pathology, Anaesthesia & Pain)  | E02/S/a                      |
| Paediatric Surgery Chronic Pain  | E02/S/b                      |
| Paediatric Surgery Neonates  | E02/S/c                      |
| NHS Genomic Laboratory Services  | TBC                          |
| 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: PTC MDT Membership

The core team common to all PTC MDTs must include:

- Specialist nurse;
- Cancer pharmacist, from the designated pharmacists of the oncology pharmacy service supporting the PTC's chemotherapy service;
- MDT co-ordinator and secretary.

Extended membership of all PTC MDTs must include:

- Nurse from the oncology ward nursing establishment;
- Nurse from the PTC children's cancer day care facility.

In addition, the following must be included:

1. For a PTC with a single MDT
  - 2 paediatric oncologists with responsibility for solid tumours
  - 2 paediatric haematologists with responsibility for haematological malignancy
  - 2 clinical oncologists with responsibility for paediatric radiotherapy
  - radiologist
  - histopathologist
  - cytogeneticist
  - paediatric surgeon
  - neurosurgeon
  - neuropathologist
  - neuroradiologist
  - neurologist.
2. For a PTC with a separate haematological malignancy MDT
  - 2 paediatric haematologists with responsibility for haematological malignancy
  - histopathologist
  - cytogeneticist

Extended membership for a haematological malignancy MDT must include:

- Clinical oncologists with a responsibility for paediatric radiotherapy
3. For a PTC with a separate non-CNS solid tumour MDT
    - 2 paediatric oncologists with responsibility for solid tumours
    - 2 clinical oncologists with responsibility for paediatric radiotherapy
    - radiologist
    - histopathologist
    - paediatric surgeon
  4. For a PTC with a separate children's CNS tumour MDT
    - 2 paediatric oncologists with responsibility for CNS malignancy
    - 2 clinical oncologists with responsibility for paediatric CNS radiotherapy

- neurosurgeon
- neuropathologist
- neuroradiologist
- neurologist.

An NHS employed member of the core or extended team should be nominated as having specific responsibility for users' and carers' issues and information.

A member of the core team should be 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.

#### 5. Late Effects MDT at the PTC

The Late Effects MDT must have a single named lead clinician with an agreed list of responsibilities. Core membership must include:

- Clinical Nurse Specialist
- Endocrinologist
- Paediatric or TYA oncologist/haematologist
- Psychologist
- Clinical care co-ordinator
- MDT co-ordinator

Extended membership of the Late Effects MDT may include representatives from additional clinical services and allied health professionals who may have a role in the management of patients within the Aftercare pathway. These members may include:

- Clinical oncologist
- Social worker
- Allied health professionals
- Fertility specialist
- Cardiologist
- Nephrologist
- Gynaecologist
- Representative from memory service
- Gastroenterologist

The extended membership list is not exhaustive and membership of the Late Effects MDT may be extended in agreement with the Network and in line with Network guidelines.

### Appendix 3: Standards for Children's Nursing

The Network should agree a nurse training programme in oncology skills and chemotherapy administration covering certain core competencies specified below (internal training). The Network may or may not choose to extend this programme to provide more comprehensive training, but it is not primarily intended, by these measures, to initiate new, university accredited courses in paediatric oncology.

Where additional training beyond the internal training is required for compliance with these measures it is intended that the Network should use these currently existing courses (external training). There should be named and experienced paediatric oncology nurses for each Network who should be responsible for the internal training and assessing the core competencies of staff. The Network may choose to share the provision of such an internal training programme and the employment of trainers and assessors with one or more Networks.

#### External training

- University accredited course in children's cancer care and/or chemotherapy to 20 credits at first degree or 15 credits at Masters level. Individuals may follow a modular pathway based on local provision. Reviewers should exercise judgement over this.

#### Internal training

- Network agreed, RCN competency based
  - 'Full' – chemotherapy administration and oncology skills. The competencies should include at least those specified in "Competencies: an education and training competency framework for administering medicines intravenously to children and young people" (Royal College of Nursing; publication code 003 005 Domains 1-5) and "Competencies: an integrated competency framework for training programmes in the safe administration of chemotherapy to children and young people" (Royal College of Nursing; publication code 002 501);
  - 'Foundation' – oncology skills for nurses not administering chemotherapy. The competencies should cover at least the following: (i) management of central venous access devices; (ii) care of a child who is febrile and neutropenic; and (iii) administration of blood products.
  - 'Low Risk' – chemotherapy competencies focused only on administration of Network agreed limited list of low-risk regimens.

External is intended to be at greater depth than internal, to provide exemption from 'full internal' training and from foundation and low risk training. Full internal encompasses and provides exemption from foundation and low risk training.

Foundation and low risk are tailored to their specific nurse roles and of themselves provide no exemption from another complete training type. However, nurses should be able to move between roles within the internal training programme by acquiring, and being assessed for, just those additional competencies which would then complete the required training type.

#### PTC Nursing Standards

The number for the oncology nursing establishment for the oncology ward should be based on the nurse numbers for the operational oncology beds, as recommended by the Royal College of Nurses document (RCN) 'Defining Staffing Levels for Children's and Young Adult's Services' (2003, sections 7 and 5). All such nurses should be Registered Sick Children's Nurses (RSCN or RN [child]).

A minimum of two, day and night, of the nurses allocated to the operational oncology beds should be trained at least to the 'full internal' training level. Once the minimum of two, day and night, trained nurses measure is met then where the number of nurses allocated increases with increasing numbers of operational beds, 70% of the overall number allocated to the operational oncology beds should be trained at least to the 'internal foundation' training level. All the nurses of band 6 or above working on the oncology ward should be trained to the 'external' training level.

A minimum of two nurses on duty during each shift of each working day that the day care facility is open for chemotherapy should be trained at least to the 'full internal' training level; 70% of the nurses overall allocated to the day care facility should be trained at least to the 'foundation internal' level. All the nurses of band 6 or above allocated to the day care facility should be trained according to the 'external' training level.

Each diagnostic and treatment planning MDT should have a Nurse as a Core Member of the MDT. Their responsibilities should include:

- Contribution to multi-disciplinary discussion and care planning at the MDT meeting;
- Provision of expert nursing advice and support to other health professionals when care planning decisions are made;
- Ensuring that all patients discussed by the team have a key worker allocated;
- Ensuring that the results of the holistic needs assessment of the child and family undertaken by the key worker are considered in MDT decision making;
- Supporting communication pathways and coordination of care between the MDT and all components of the service at the PTC and local POSCU MDTs.

There must be a named Lead Nurse at the PTC. The role of the Lead Nurse is to provide professional and clinical leadership and support to nursing staff within the PTC. Post-holders should be responsible for all elements of the nursing service and will be expected to contribute to the strategic development of the whole service in line with the individual hospital trust and relevant national targets and quality measures.