

E04/S/a

**2013/14 NHS STANDARD CONTRACT
FOR PAEDIATRIC ONCOLOGY**

PARTICULARS, SCHEDULE 2 – THE SERVICES, A – SERVICE SPECIFICATION

Service Specification No.	E04/S/a
Service	Paediatric Oncology
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Epidemiology: Children's Cancer

Paediatric oncology is the term used to encompass all malignant conditions among children with cancer, including blood conditions such as leukaemia. The doctors involved, paediatric oncologists and paediatric haematologists, work within a national framework to ensure they provide the most effective care. Care has become increasingly centralised in specialised treatment centres over the last 30 years, which has helped to improve survival rates. Care is guideline driven and guidelines are developed by the CCLG (Children's Cancer & Leukaemia Group) a national, multi-disciplinary organisation which advances the care of children with cancer through best practice and clinical research.

Most of the cancers affecting children differ from those affecting adults. They occur in different parts of the body; appear differently under the microscope and respond differently to treatment. Treatment is frequently complex and intensive but cure rates among children are much higher than for most adult cancers, and overall more than 70% of children are completely cured (CCLG). A significant proportion of these will experience long-term side effects from their treatment. 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.

In Great Britain, the world age-standardised incidence rate has increased by more than two fifths (43%) since the late 1960s, from 107 cases per million children in 1966-1970 to 152 cases per million in 2001-2005. Between 1966 and 2000 there has been a statistically significant average annual increase of almost 1% per year, although this varies between 0.5% and 2.5% per year by tumour type. The literature suggests a plateau has been reached in childhood cancer incidence rates from the mid-1990s onwards. Whilst some of the worldwide increases are likely to be due to real changes in risk, improvements in the efficiency of systems for the diagnosis and registration of childhood cancers since the 1960s and 1970s will also have played a part.

Cancer in children is rare, about one in 600 children develops a cancer by age 15 years. There are approximately 1,400 new cases of cancer among children 0-15 years in the UK each year; an annual incidence rate of approximately 1:7700. The incidence of cancer in adolescents is less certain due to data collection problems, but rates calculated by Birch (2003) and endorsed by the Children's Cancer and Leukaemia Group 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 to across the UK.

In children, the most common malignancy is leukaemia, followed by tumours of the central nervous system and then a variety of embryonal tumours. As the age of the patient increases, bone sarcoma and epithelial tumours, which are more commonly seen in adults, are found. In addition, patients across this age range will be at different stages of physical and emotional development and the care setting needs to be responsive to the needs/ age of patients.

Cancer-like disease: There are some very rare cancer-like diseases that are treated under paediatric cancer services. These include:

- Langerhans' Cell Histiocytosis (LCH): LCH is a cancer-like condition that may be treated with chemotherapy. In its more serious forms, LCH can behave like a cancer and is therefore usually treated by children's cancer specialists.
- Haemophagocytic Lymphohistiocytosis (HLH): HLH blood disorders are a range of diseases due to a problem with the red or white cells in the blood. Problems can arise when there are too many or too few of these cells, or when their function becomes uncontrollable.
- Craniopharyngioma: A craniopharyngioma is a benign tumour that develops near the pituitary gland at the base of the brain.

Clinical trials are a core part of the way care is delivered for children with cancer, and are often international because of the small numbers involved. Currently clinical trials exist for approximately 60% of children with cancer and this is expected to rise to 80% with the opening of clinical trials which are still in the set up phase. This makes the treatment of childhood cancer the most research-driven of any service within the NHS. The configuration of services needs to take account of this. The National Cancer Research Institute (NCRI) Children's Cancer and Leukaemia (CCL) Clinical Studies Group has several subgroups working on the development of clinical trials

for children with cancer. In some cases, e.g. sarcomas, the development of paediatric clinical trials is combined with adult studies in a single Clinical Study Group. The delivery of clinical trials is the responsibility of the National Institute for Health Research (NIHR) Cancer Research Network (NCRN). Clinical research within CCL is supported strategically within NCRN by a dedicated Associate Director for CCL and an NCRN CCL Lead. The work-stream has been strengthened nationally by the establishment of a single Children's Cancer Research Network hosted by the national cancer research network. Most clinical trials in paediatric oncology are hosted by the Cancer Research UK Clinical Trials Unit at the University of Birmingham, although other trial units may be involved. The UK has an early phase trials paediatric network; the Experimental Cancer Medicine Centre Network (ECMC). Early phase trials may not be opened in all centres so patients may need to travel to access specific trials.

Scale and Provision of Service

The National Institute for Health and Clinical Excellence (NICE) guidance on Improving Outcomes in Children and Young People, with Cancer (2005) recognises cancer in childhood is rare and includes a wide range of cancers with small numbers of patients with each type of cancer. Hence, in order to improve treatment and survival of cancers, the national approach is to commission these services for large populations of at least 2 million to maximise the opportunities for standardising care and evaluating outcomes.

The service model recognises that children with cancer are different to adults because they are children, and because the cancers common in childhood differ from those common in adults. Children's needs differ according to their developmental stage (emotional, social, psychological and physical) and the need to consider the impact on the wider family of a cancer diagnosis. Indeed, across the age spectrum, children are as different from each other as they are from adults. Therefore a holistic approach to needs assessment is an essential part of service design.

Age Range

Very different issues arise depending on the age and maturity of the individuals whose needs are being addressed. Childhood and adolescence is a time of enormous change, physically, psychologically and socially, and this influences the different patterns of malignancy seen, their pathological behaviour, response to treatment and eventual outcomes. Outcomes should encompass more than improved health, in terms of survival, mortality and morbidity, and this is even more of a reality for children, whose outcomes need to include the ability to mature successfully into adulthood. The late effects of treatment are particularly relevant in this context.

The principle that underpins the national guidance is that of age appropriate, safe and effective services delivered as locally as possible, not local services as safely as possible. Specialised care is therefore centralised in Principal Treatment Centres (PTCs) for Children's Cancer to ensure depth and breadth of cancer coverage; specialist clinical support; and age appropriate care across the age range. The PTC

retains overall responsibility for the cancer treatment plan but defined aspects of care are delivered in a Paediatric Oncology Shared Care model provided through designated Units (POSCUs). These services are provided by District General Hospitals (DGHs) outside the centre. The shared care model is not uniform nationally, being more developed in the South and West. In England there are 13 PTCs for children with cancer which have associated shared care services in each area. There are currently 93 shared care services but the proposed strategy is to increase the proportion of POSCUs that can offer higher levels of shared care (Levels 2 and 3) but reduce the overall number of shared care units to facilitate this. It will still be appropriate to offer Level 1 shared care where agreed by both commissioners and the Children's Cancer Network Co-ordinating Group. In most cases the PTC for children and Teenagers & Young Adults (TYAs) is within the same trust and in all cases they should work closely together.

From 2013 the children's cancer pathway delivered through PTCs and POSCUs will be commissioned through NHS England as a prescribed service. Clinical Commissioning Groups (CCGs) and Local Authorities may directly, or through other collaborative arrangements, commission other elements of the pathway. This specification has been developed to enable commissioners and associated commissioners to contract specialised children's oncology services in a way that ensures an equitable and appropriate use of this specialist resource. For 13/14 commissioners will hold the contracts for PTCs and POSCUs services with each provider. In future, a prime contractor role may be implemented but this is dependent on development of a commissioning model and negotiations with providers.

The National Cancer Peer Review Children's Cancer measures (April 2011 v2.1) state that the Area Teams hosting the Principal Treatment Centres (PTCs) for children's cancer have a responsibility for coordinating commissioning responsibilities throughout the patient pathway, including at hospital sites and community services contracted through other commissioners within the named children's cancer network. Area Teams should carry out this co-ordinating function with the local Children's Cancer Network Co-ordinating Group (CCNCG). Local arrangements may mean the CCNCG may be stand-alone or combined with the Teenage and Young Adult Cancer Network Coordinating Group (TYACNGs). The commissioning arrangements for whichever model is in place should be described for the PTC and POSCU catchment area. The PTC and POSCU hospitals within the CCN are required to support the work programme of the CCN, including CCN wide policies, referral and treatment guidelines, annual reports and service development plans.

The evidence base for the service specification is drawn from:

- NICE *National Improving Outcomes Guidance for Children and Young People with Cancer (2005)*.
- *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies 2008*.
- Children's Cancer and Leukaemia Group (CCLG) *guidelines for treating children with cancer*.
- The National Service Framework for children (2004).
- Health Services Commission: *Improving Services for Children in Hospital*

(2007).

- Specialised Services National Definition Set (2010).
- More Than My Illness: Delivering quality care for children with cancer CLIC Sargent 2009.
- “Good Practice Guide for Paediatric Radiotherapy” The Royal College of Radiologists, the Society and College of Radiographers and the Children’s Cancer and Leukaemia Group.
- The Equality Act 2010.

2. Scope

2.1 Aims and objectives of service

The aim of the service is to provide specialist cancer care for children and teenagers aged 0 to 15 years, up to their 16th birthday; to improve cancer treatment outcomes; reduce morbidity arising from treatment; and support the patient and family throughout their cancer journey and beyond. Care will be delivered through PTCs and their associated POSCUs. It is recognised that nationally the age range of patients managed within the children’s and the teenage services may vary in different areas. This specification is for children from 0 - 15 - (up to 16th birthday) but older teenagers may be treated in the service if they so wish, and where this is consistent with local agreements. Hence this specification should be read in conjunction with the specification for Teenage and Young Adult cancer services.

Objectives

The designated PTC and POSCUs should support the Children’s Cancer Network Coordinating Group and work collaboratively with the other named providers to deliver cancer care and improve outcomes in accordance with the NICE Improving Outcomes Guidance for Children and Young People with Cancer (2005) and the National Cancer Peer Review Children’s Cancer measures.

This includes meeting the national standards and quality measures for:

- adhering to and facilitating the cancer specific referral pathways,
- meeting cancer waiting times targets on access to treatment,
- medical, nursing, pharmacy, Allied Health Professional (AHP) and clinical support staff with specialised qualifications and / or training in children’s cancer and which meet required levels of staffing,
- multi-disciplinary Diagnostic and Treatment Teams,
- psychosocial Multi-disciplinary Teams,
- treating patients in line with the nationally agreed (NCRI, CCL, CSG and NCRN) clinical trial protocols within the UKCRN Study Portfolio and guidelines (CCLG) where these exist,
- treating patients in line with CCNCG agreed protocols and guidelines where a national protocol is not available,
- facilitating transition to Teenage & Young Adult services,

- Providing children and families with information appropriate to their needs and treatment pathway,
- supporting integrated shared care services,
- maintaining and developing supportive care guidance,
- delivering and supporting palliative care services across the pathway,
- delivering a long term follow-up model,
- delivery of age appropriate care, in age appropriate settings,
- delivery of care by a workforce specialised in the care of children with cancer,
- supporting national cancer data collection (cancer outcomes and services dataset, COSD) and regional data, where agreed,
- supporting entry of patients to clinical trials.

2.2 Service description/care pathway

Specifically this service is for children and teenagers with cancer requiring specialised intervention and management, as outlined in this specification. The specification includes both care delivered within designated PTCs and POSCU services.

The service model is to be consistent with NICE *Improving Outcomes Guidance for Children and Young People with Cancer* (August 2005). Many of the treatments are complex, intensive and potentially curative. The model of care aims to give access to specific cancer expertise, with access to the range of other paediatric surgical and medical services needed to deliver modern cancer care. One of the main objectives of the national model is to facilitate co-ordination of care for patients between different tiers of health services, and with social services and education services.

The dependence of children and young people on their families and the profound effect severe ill health and/or death of a child or young person has on other family members are additional important factors that significantly affect all service planning and delivery.

General paediatric care

When treating children, the service will additionally follow the standards and criteria outlined in the Specification for Children's Services (attached as Annex 1 to this specification).

Care pathways are based on the principle that all children and teenagers with a suspicion of cancer should be referred to the PTC which will make the diagnosis and direct and provide treatment, except where for clinical reasons the CCNCG has agreed an alternative pathway.

The pathway includes:

- referral with suspected cancer,
- investigations & confirmation of diagnosis,
- cancer staging and treatment,
- shared care and supportive care,
- long term follow up,

- and for some patients palliative care,

Treatment may be delivered entirely within the PTC or in partnership with a POSCU located closer to home. The service should specify the range of cancers and age group of patients covered within the Children's CNCG services as appropriate.

Since the majority of children with cancer are treated within a clinical trial, treatment for each type of childhood cancer follows specifically designed protocols (national & international) or in the minority of cases where there is no clinical trial, a national UK guideline or protocol or in some cases an internationally agreed guideline or protocol. Currently there are around 40 open clinical trials covering the majority of childhood malignancies, with further trials in set up due to open shortly. The CCNCG should have agreed clinical indications, guidelines and clinical protocols to guide professional decision making where national protocols are not available.

Depending on the type of cancer, treatment may include chemotherapy, surgery and / or radiotherapy. Each of these modalities may be used alone or more often in combination, depending on the particular disease. For Acute Lymphoblastic Leukaemia, the most common childhood cancer treatment may be over a two and half to three year period. Other cancers will require shorter treatment protocols.

Care for patients in this age range is mainly provided within inpatient and day care settings and a key difference from adult practice is the smaller proportion of care than can be given in outpatient settings. This is because of the high intensity of the treatment which means children often become acutely ill during treatment and require a high level of medical support.

The PTC directs the aftercare pathway following treatment, and provides long term follow up to manage the late effects of treatment, and these will be in conjunction with other services, as these are developed. Where the patient cannot be cured the service provides palliative and end of life care and bereavement support. The service supports co-ordination of care outside specialist centres through shared care services and in liaison with local community and palliative care services. Reference should be made to the paediatric palliative care service specification.

The PTCs and shared care services are required to work with other specialised services and local services to proactively manage transfers and discharges. Services must ensure timely and appropriate communications with services who are expected to provide other parts of the patient's pathway in compliance with national and children's cancer guidance.

Service Model

Referral

The referral criteria are that a practitioner has concluded from the clinical findings that a child has a suspected cancer, or initial tests have determined a cancer may be or is present.

In all cases there must be an agreed process and pathways for referral to the service, (including urgent and out of hours referrals).

Diagnosis and Treatment Management

PTC Multi-Disciplinary Teams (MDTs)

The PTC must have weekly diagnostic and treatment MDTs and a late effects MDT. MDTs must encompass the core and extended membership in line with national guidance. The number and configuration of MDTs may vary between PTCs but must encompass haematological malignancy, brain & central nervous system (CNS) tumours and solid tumours. Larger centres may operate some supplementary MDTs for rarer tumour types. At diagnosis or relapse the child / teenager is to be treated according to the appropriate current UKCRN Portfolio (NCRI CCL CSG / NCRN) protocol or guidelines (CCLG), where available, unless there is an agreed indication at the appropriate MDT for an off-protocol therapy or, in the case of a teenager, clear evidence of better outcomes on an adult guideline or protocol.

PTCs should also have psychosocial MDTs. This is to ensure patients are discussed in MDTs with the specified cancer expertise, and there is support to provide co-ordination of care throughout the pathway, with the assigned key worker having a major role in ensuring this occurs. Such care includes a holistic approach and joint management of educational needs between health services and education services.

Haematological Cancer: Leukaemia and Lymphoma: As leukaemia and lymphomas make up 35% of all malignant disease in childhood and adolescence, this group of patients will generate the largest caseload.

Central Nervous System Tumours: This group of patients will generate the second largest workload. Patients with brain tumours often have complex long term needs due to the impact of the tumour and / or the intensive medical and surgical treatment required to treat them. The arrangements for the different age ranges should be specified, as should the operational relationship to the Neurosciences Centre. Patients under 16 years old may have neurosurgery at the PTC site and radiotherapy at that or another specified site. In general, chemotherapy and supportive care will be at the PTC. Appropriate cover arrangements should be in place where patients are treated at neuroscience centres which are on a different site from the PTC site. The arrangement for patients aged 16 to 18 years needs to be specified and the relationship between the PTC and the TYA MDT, the Neuroscience Centre MDT and the Network Neuro-Oncology MDT for the geographical area.

Solid Tumours Pathway: Solid tumours comprise a wide range of tumours found in a variety of organs and which normally require management jointly with the relevant medical and surgical team. In the paediatric age group, embryonal tumours predominate with tumours more commonly seen in adults appearing in adolescence and beyond. It is imperative that all the diagnostic and therapeutic skills are tailored

in such a way as to provide expert care in an age appropriate location. Treatment will be provided within a PTC but, where required, appropriate liaison with tumour specific MDTs will be part of the agreed pathway. All suspected solid tumours in children and teenagers aged 18yrs and under are to be referred to the PTC. Referral to a specialist MDT at another site may be necessary for some very rare cancers. Any agreed exceptions to the pathway should be described.

Bone Sarcomas: The complexity of this tumour group is well recognised and it is covered by separate NICE *Improving Outcomes Guidance for Sarcoma*, as well as the NICE *Improving Outcomes Guidance for Children and Young People with Cancer*. Bone sarcoma services are provided in conjunction with one of the nationally commissioned services for diagnostics, surgery and cancer management of these patients. In all cases children are to be treated according to the Children's Cancer Network commissioned pathway and will usually receive treatment at the PTC.

Retinoblastoma: The complexity of this tumour group is well recognised and the NICE *Improving Outcomes Guidance for Children and Young People with Cancer* states a specific MDT should manage these patients who are usually diagnosed in the first year of life. These patients are to be managed in conjunction with the nationally commissioned service. Surgery and specialised radiotherapy are usually undertaken within this service but chemotherapy will usually be delivered at the PTC, but can be within other agreed locations as stated in the "agreed regimens list" for the CCNCG.

Treatment Modalities

Chemotherapy

Chemotherapy services and drugs for children are by definition a specialised clinical activity. Specific facilities are required to prepare chemotherapy and specific training is required to prepare and deliver chemotherapy to children. This includes the management of central venous access devices with defined surgical support at the PTC and at other agreed sites. Specific training is also required to look after children who have received chemotherapy.

The paediatric chemotherapy or "systemic cancer therapy" service specification should be adhered to by all providers in relation to their role in the service. This includes the effective management of febrile neutropenia and other infections according to guidelines.

Intrathecal Chemotherapy

Services undertaking Intrathecal chemotherapy procedures must be compliant with the national measures written to ensure safety when performing this high risk activity.

Radiotherapy

The radiotherapy service for children and adolescents must be at the specified site(s)

agreed by the CCN. The named radiotherapy service should offer a comprehensive range of radiotherapy and access to radionuclide therapy services required for children with cancer. The majority of paediatric PTCs do not have specialised facilities for delivering paediatric radionuclide therapy currently and therefore this is referred on to a specialist centre.

The maintenance and development of the service is critically dependent not just on 'adult' radiotherapy equipment and adequate staffing including clinical oncologists, radiographers and physicists, but also on paediatric oncology support on the PTC site, paediatric nursing and play specialists and paediatric anaesthesia. Currently children requiring Proton Beam Therapy (PBT) will need to be referred to the nationally commissioned service accessed through PBT panel for treatment outside the UK. Proton Beam Therapy services will be nationally commissioned within the UK from 2014/15.

Blood and Marrow Transplantation

The PTC should state where blood and marrow transplantation (BMT) services are provided and achieve JACIE (accreditation standards for stem cell transplantation) accreditation of the BMT services with unified protocols and guidelines. The service will be managed in age related units, with close interaction between the units and across the sites.

Supportive Care

Children require supportive care during the active treatment period. This includes management of febrile neutropenia, nausea, vomiting, central venous access and blood product support. Outcomes in cancer are dependent not only on the safe and effective delivery of treatment, but also on the timely and effective management of the acute and longer-term side effects; improvements in supportive care have played a key role in increased survival.

Psychosocial Support

Care pathways should describe the psychosocial support available to children and families during and beyond cancer treatment. This involves multi-agency support and addresses the wider social, psychological and emotional needs of the child and family. It requires a holistic approach (starting from a core Holistic Needs Assessment) and continuity of care (requiring the support of an identified Key Worker).

Psychosocial support is provided to families by a range of different health and social care professionals across PTC, POSCU and community sites who require access to appropriate training e.g. Advanced Communications Skills training.

Specialist Psychological Support

There should be ready access to neuropsychology for the assessment and input for children with acquired or treatment related problems and specialist psychology, and

liaison psychiatric services to address more complex psychological morbidity associated with cancer treatment.

Play Specialists

Support from a play specialist can speed up how long a child takes to feel prepared for any procedure, can reduce referrals to psychology and can greatly enhance patient experience. Play specialists play a crucial role in providing information to children, helping to manage pain and providing socio-emotional support and are members of the psycho social MDT. Play is particularly important for those children under 5 for whom there is the highest incidence of cancer.

Social Work

Support from social workers is an essential part of this service. The service may encompass, supporting families, supporting children within complex family situations, formal safe guarding issues, as well as specific and general advice to the family on housing, financial and other support for daily living. Social workers play a crucial role in providing information to families, and as part of the psycho-social MDT.

Educational Support

Educational support is an essential part of this service. The service may be delivered through hospital based schools, links with the child's own school or through facilitating educational support at home. Teachers play a crucial role in ensuring the child's educational attainment is optimized and are key members of the psycho-social-MDT.

Shared Care

Paediatric Oncology Shared Care services are within this specification. The CCNCG has a responsibility to agree the configuration of shared care services and to ensure formal agreements are in place. The children's shared care philosophy is based on the premise that children and teenagers with cancer can benefit from care delivered in partnership with a paediatric oncology shared care unit located closer to home at appropriate times. Shared care can contribute positively to the care of children with cancer, enabling an integrated paediatric oncology service that involves a network of multidisciplinary teams, the paediatric oncology shared care units and in the community. Shared care enables children with cancer to receive supportive care and where agreed specified chemotherapy as close to home as possible and within the home where appropriate, and importantly, facilitates appropriate access to local community support services. It also recognises that shared care units have developed their own local expertise in management of the clinical problems that arise during the treatment of childhood cancer. The PTC will need to support and work with the designated paediatric oncology shared care units to achieve the above in line with the CCNCG "*Paediatric Oncology Shared Care Agreements*". For older teenagers shared care arrangements will be designated in conjunction with the relevant TYACNCG.

The role of the POSCU will vary depending on the clinical expertise and infrastructure available to support paediatric cancer care, but all POSCU services will need to demonstrate compliance with the standards for the Level of its designation or have action plans to meet national guidance, including NICE *Improving Outcomes in Children and Young People with Cancer* (August 2005). There are three levels of POSCU and the IOG's definition should be referred to and the listed options and exclusions before stating the level and extent of service provided.

POSCUs will need to develop the infrastructure commensurate with the level of shared care offered. In the future, POSCUs that develop extended roles would be expected to treat higher numbers of patients to develop and maintain expertise and warrant the use of resources.

It is recognised that Cancer Networks and commissioners will need to take account of critical mass and specific local factors, such as location of acute paediatrics and geography, in recommending designation of POSCU services. If commissioners / cancer networks decide designation of smaller POSCUs is the only option, then a risk assessment should be undertaken to ensure the POSCU can deliver the stated level of service safely and effectively.

Since the majority of children with cancer are treated within a clinical trial the POSCU must have a robust research governance framework in place with the PTC to be able to deliver appropriate elements of the trial activity.

POSCU

- There should be a designated lead consultant paediatrician. There should be written arrangements for cover by a named deputy consultant paediatrician.
- There should be a named lead POSCU nurse. There should be written arrangements for cover by a named deputy senior nurse.
- There should be a named pharmacist responsible for paediatric chemotherapy in the POSCU.
- The nursing skill mix should ensure that sufficient numbers of staff have relevant cancer related training.
- Lead staff should attend appropriate network and local forums relating to children's & young people's cancer services
- Lead staff should identify and liaise with the lead for teenager cancer services

POSCU Full Level 1 Services

- Inpatient supportive care including care of children with febrile neutropenia.
- Outpatient supportive care.
- Outpatient follow up.
- Outpatient oral chemotherapy.
- Outpatient IV bolus chemotherapy.
- Exclusions: day care infusional chemotherapy, inpatient chemotherapy and all exclusions listed in level 3.

NB: The implication of this is that any service that *is* providing outpatient IV bolus chemotherapy should also provide care for children with febrile neutropenia.

POSCU Level 2 Services

- Inpatient supportive care including care of children with febrile neutropenia.
- Outpatient supportive care.
- Outpatient follow up.
- Outpatient oral chemotherapy.
- Outpatient IV bolus chemotherapy.
- Day care infusional chemotherapy.
- Exclusions: inpatient chemotherapy and all exclusions listed in level 3.

POSCU Level 3 Services

- Inpatient supportive care including care of children with febrile neutropenia.
- Outpatient supportive care.
- Outpatient follow up.
- Outpatient oral chemotherapy.
- Outpatient IV bolus chemotherapy.
- Day care infusional chemotherapy.
- Inpatient 24-hour chemotherapy.
- An intrathecal chemotherapy service is an option for level 3 (only) providing the measures for Intrathecal chemotherapy are complied with.

Survivorship

The model of care required by children and teenagers at the end of cancer treatment is evolving nationally as part of the 'National Cancer Survivorship Initiative' (NSCI) supported by NHS Improvement. The developing survivorship model of care risk stratifies the patient's need for long term follow up after cancer treatment. It incorporates planning aftercare pathways including both medical and holistic care. The planning is agreed at the end of treatment. Supported self- management will be included as the care plan for a proportion of patients and may have an increasing role in the future. The model should ensure that access to fertility support is available. Children with the specified cancer-like illnesses will also require transition, and long term follow-up and, where necessary, palliative and end of life care.

Long Term Follow Up / Late Effects Services

Long term follow-up applies to those patients who have completed their treatment as children and teenagers, and whose aftercare plan will require long term follow- up to treat or manage the late effects of their cancer treatment e.g. risk of endocrine dysfunction, impaired cardiac function or impaired fertility, and impaired neurological function due to the chemotherapy or radiotherapy treatments required to combat the original cancer. The type of intervention required will be linked to disease type and the type of treatment they have received for their cancer, and therefore the likely late effects of that treatment. In some cases other specialist services will need to be

involved such as cardiology to manage the effects of anthracyclines, or endocrinology to manage hormone deficiencies after cranial irradiation or services to manage impairment of fertility. These pathways will need to be embedded in the functioning of late effects MDTs. Some patients will also require cancer surveillance for relapse or for development secondary malignancy according to agreed policies, depending on their original cancer type.

Transitional Care to Teenage & Young Adult / Adult Services

Transitional care applies to those patients who had completed their cancer treatment as children but due to relapse, development of a second malignancy, or as part of the aftercare plan, they now require transition to a different team due to their age. The transition plan should be pre-planned and pro-active so that patients know what to expect if and when transition is required. This may be to a service led by a PTC TYA cancer team or an adult cancer team. In both cases there is a joint responsibility for the referring service and the receiving service to ensure effective transition occurs.

Specialist Palliative Care

Specialist cancer palliative care advice and treatment is directed by specialist palliative care teams from the PTC but palliative care services may also be delivered within POSCUs. 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 non-specialist 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. Most children with terminal cancer, in line with the families' wishes, die 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 hour, 7 day a week care to the child and family at home.

Specialist Therapies and Rehabilitation

Therapy services to support children and teenagers with cancer are specialised, these include Dietetics, Physiotherapy, Occupational Therapy and rehabilitative support. These specialist staff should be available as a minimum in line with the standards set in the children's cancer measures to support MDT working and to provide ongoing support to children and teenagers with the aim of maximising their physical, emotional, cognitive, social and functional potential.

Research

In line with national guidance PTCs will be expected to have clinical trials open to patients which are approved by the National Cancer Research Institute Children's Cancer and Leukaemia Clinical Studies Group and adopted by the NIHR Cancer Research Network (NCRN) into the UKCRN study Portfolio and to deliver these trials locally, managed by the NCRN. The PTC as a specialised service has an important

role in research and development of the evidence base for effective treatment interventions. In some cases this will be through formal academic links, in others as part of NHS research and development activity. Involvement in clinical research will be recognised as an integral part of the service.

Third Sector Organisations

The pathway of support for children and young people with cancer is enhanced and supported by a number of charities who provide a holistic approach and a range of services including specialist social care provision, specialist paediatric oncology nurses, information services and grants. Whilst these services are not commissioned directly but provided by charitable funding, they are important in supporting families and patients and in providing commissioners with comprehensive information and guidance around services.

2.3 Population covered

The service outlined in this specification is for patients ordinarily 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.

The Children's Cancer service includes the treatment of children aged 0 to 15 years (up to 16th birthday). It may also include the treatment of older children up to their 19th birthday, who wish to be treated within children's cancer services. This is acceptable as long as these arrangements are consistent with the agreed regional cancer model for children and teenagers. Referral pathways for children, teenagers and young adults must be agreed between the Children's Cancer Network and the Teenage and Young Adult Cancer Network.

The PTC will be required to respond to referrals on the day received and initiate the admission process, or put in train any other clinical actions required in line with the protocols for that cancer type.

Cancer in children is rare and hence the national model is to have centralised services treating over 70 new patients a year. This means some patients may travel significant distances for specialist care. This can be offset to a degree by the shared care model in place. Where agreed, community based nurses also provide care under the direction of the PTC or POSCU.

The relevant CCNCG will as part of its remit agree common referral pathways, treatment management policies for the CCN catchment area by tumour type.

Referral Criteria and Sources

The referral criteria are that a practitioner believes a child has a suspected cancer or initial tests have determined a cancer is present.

If the PTC does not have capacity to accept the patient the service must liaise with other PTCs to arrange an alternative admission to a PTC or specialist service or if appropriate to actively support the POSCU with patient management until transfer is completed.

There are five main referral routes:

- GP referral to a local paediatric service or direct to the PTC under the two week wait rule.
- Referral from a DHG paediatric service.
- Acute referral from an A&E department.
- Acute referral from another specialist children's cancer or non-cancer service.
- Occasionally from an adult cancer or other adult clinical service.

Leukaemia

All patients in whom a diagnosis of leukaemia is suspected will be referred to the consultant paediatric haematologist or oncologist on call at the PTC who will then arrange admission for initial investigations – history and physical examination, haematological and bone marrow examination and lumbar puncture where indicated.

Central Nervous System Tumours

The referral route may depend on the age of the patient and the location of the Neuroscience Centre. Hence patients may have surgery either within the PTC or designated Neurosciences Centre but will have inpatient care for non-surgical treatment within the PTC. Radiotherapy will be at the specified site for the Network. The consultant paediatric neuro-oncologist and consultant paediatric neurosurgeon will inform each other of any referrals and the relevant MDT.

Solid Tumours

All patients in whom a diagnosis of malignant solid tumours is suspected will be referred to the consultant paediatric oncologist on call. He/she will then arrange for out-patient, day care or in-patient admission at the PTC for initial assessment.

Bone Tumours

For all patients in whom a diagnosis of bone sarcoma is suspected referral should be made directly to the designated Sarcoma Centre for primary malignant bone tumours for biopsy, diagnosis, joint treatment planning and surgery. The on-call consultant paediatric oncologist will facilitate this if the referrer requires advice. Treatment planning and subsequent non-surgical therapy will be carried out at the specified site.

Blood and Marrow Transplantation

Patients referred for blood and marrow transplantation will be discussed at the Paediatric BMT MDT meeting and patients treated within services designated to care for children requiring this procedure.

Cancer-like Disease

There are some very rare cancer-like diseases that are treated under paediatric cancer services – these are Langerhans' cell histiocytosis (LCH); Haemophagocytic Lymphohistiocytosis (HLH); and Craniopharyngioma.

The service will describe the referral areas covered by the relevant CCNCG.

2.4 Any acceptance and exclusion criteria

Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in England; or otherwise the commissioning responsibility of the NHS in England.* 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.

Referrals should be accepted from any referrer where a child or teenager is suspected of having cancer or the specified cancer like diseases.

Patients will need to remain within a specialised cancer centre and shared care services during the period of active treatment for their cancer and where the care they require for long term follow up needs to be managed by these services.

National guidance on the referral of children with suspected cancer is provided and incorporated into local network referral and treatment pathways.

Exclusions

Exclusions are patients who should be treated under nationally commissioned cancer pathways for children where a service is located at a specified hospital other than a PTC, or where an agreed referral pathway, usually neurosurgical may be located at another site. The PTC and shared care units will work in conjunction with these other hospitals and the role of these other hospitals should be incorporated into the contract with that provider.

2.5 Interdependencies with other services

Co-located Services and Interdependent Services

Children's cancer services have a range of critical interdependencies with other

clinical services – notably Paediatric Infectious Diseases, Paediatric Intensive Care, Paediatric Anaesthesia and pain management, Paediatric surgery and Clinical Haematology and Blood and Marrow Transplant.

These co-located services and interdependencies are set out in full in the Department of Health report 2008 “*Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework for Critical Interdependencies*”.

The recommendations of the national Review of Paediatric Neurosurgery (2011) will also need to be complied with, once finalised. It is understood this review will recommend that the pathways for children with brain tumours are described and commissioned, including the relationship between cancer centres and neuroscience networks services.

Local arrangements may mean the Children’s Cancer Network may be stand- alone or combined with the Teenage and Young Adult Cancer Network. In most cases the PTC for children and TYAs is within the same trust and in all cases formal working relationships should be in place. The service arrangements for whichever model is in place should be described for the PTC catchment area.

Related Services

- Local Authority-based services for education and social services.
- Child & Adolescent Mental Health services.
- Strategic Clinical Networks for children and cancer.
- Paediatric Palliative Care Networks.

Whole System Relationships

These are to include one or more of the following:

- Specialist children’s surgery and specialist medical specialities.
- Paediatric Oncology Shared Care Units.
- The Teenage & Young Adult Cancer service.
- Radiotherapy services.
- Palliative Care services
- Community services.

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

The children’s cancer service should be compliant with the National Children’s Cancer Peer Review measures (v2 April 2011) derived from the NICE Guidance on *Improving Outcomes in Children and Young People with Cancer* (2005). These measures include requirements for the PTC core facilities, for the facilities at POSCUs and measures applicable to the Children’s Cancer Network.

Facilities

Inpatient, Day Care, Outpatient, Surgical, Diagnostic, Intensive Care, Chemotherapy and Radiotherapy, Imaging & Pathology.

Inpatient Care

The hospital and wards should be stated which are providing inpatient cancer diagnosis, cancer treatment expertise, psycho-social support and surgical cancer therapy for children. The relationship to the inpatient care of young people aged 16 – 24 years ward(s) should be described to demonstrate consistency with these arrangements.

Day Care Facilities

There will be separate day care facilities for children with waiting and play areas. Day care will include outpatient chemotherapy, blood transfusion, patient assessment, bone marrow examinations, administration of intrathecal chemotherapy and preparation for bone marrow harvest. General anaesthetic facilities for children and young people undergoing painful procedures (bone marrow examination and administration of intrathecal chemotherapy) will be provided at the PTC. Some of these services can be provided at shared care sites in line with the Shared Care Agreement.

Outpatient Facilities

There will be separate outpatient facilities for children and teenagers.

Cancer Surgery

The site of surgery for children with solid tumours will be stated for each tumour pathway. Surgery for children and adolescents with primary malignant bone sarcoma will be undertaken at a nationally commissioned bone sarcoma centre. Surgery for retinoblastoma will be undertaken at a nationally commissioned retinoblastoma service with delivery of other parts of the pathway to be specified. Surgery for central nervous system tumours will take place in a Children's Neurosurgical Centre, which within the proposed model of care will be part of a Children's Neurosurgical Network.

The Chemotherapy Pharmacy service

The oncology pharmacy service supporting each chemotherapy service will be reviewed against the national cancer measures, some of which are derived from measures applicable to pharmacy services reviewed as part of the peer review of "adult" cancer services.

Radiotherapy treatment will be provided at a named site specified as suitable to treat children with cancer. Where general anaesthesia is required this is provided by specifically trained staff and in facilities suitable for paediatric anaesthesia.

High Dependency Care / Intensive Care

Children requiring high dependency / intensive care will be rapidly assessed by the 24 hour on site paediatric and anaesthetic teams and transferred to the PICU as required.

Imaging

- The service should ensure that all appropriate imaging and image- guided biopsy modalities are available to patients in a timely manner.
- The service should agree imaging modalities and their specific indications.
- Where specific investigations are not available in a particular trust, clear and timely arrangements should be made for them to be carried out in other centres as agreed by the commissioners.

Pathology

- The aim should be to achieve histological confirmation of tumour before treatment with chemotherapy or radiotherapy, although it is recognised some clinical scenarios will require treatment in advance of this.
- The pathology team should have access to a full range of appropriate immuno-histochemical stains and, in difficult cases, advice from a panel of highly specialist pathologists.
- The pathology services should comply with Clinical Pathology Accreditation (UK) Ltd (CPA)¹ and the Human Tissue Authority (HTA).²

Training / Education

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:

- To deliver nurse training in line with the CCNCG internal and external training programme in line with cancer measures, including training in chemotherapy skills and management of its consequences in line with the staff members role. It is recognised in national guidance that the nursing contribution in cancer teams is critical to the success of these services.
- To work in this area 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.

¹ CPA, the principle accrediting body of clinical pathology services and External Quality Assessment (EQA) Schemes in the UK. Modernising Pathology Services. Department of Health (2004)

² HTA Regulatory body for all matters concerning the removal, storage, use and disposal of human tissue. www.hta.gov.uk

- Medical training in line with above where applicable for chemotherapy.
- Access to specialist resource materials.
- “Good Clinical Practice” in Clinical Trials training.
- Time allocated for mandatory training and to maintain and develop cancer skills for all staff disciplines.

Patient and Carer Information

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

The information provided must be age appropriate to the age of the patient and must be provided in a variety of formats. It should follow the principles of the national “Information Prescription”

Patient and Carer Information must be provided which covers the treatment plan, how to access care out of hours and the shared care arrangements with “POSCU” services.

4. Key Service Outcomes

A detailed list of patient and service outcome measures derived from the initial key service outcomes should be listed here. This will be informed by the work of the Clinical Reference Groups (CRGs) on quality.

Outcomes

- To ensure patients with cancer are referred and supported in line with the named Children’s Cancer Network Coordinating Groups (CCNCG) agreed pathways.
- To ensure patients with cancer are treated in line with cancer waiting times targets.
- To ensure patients with cancer are treated in line with the national or international children’s cancer protocols (UKCRN Study Portfolio managed by NCRN) or CCNCG agreed treatment guidelines.
- To ensure suitable patients with cancer have access to all clinical trials that are available for their tumour type.
- To ensure that parents and children have integrated and co-ordinated care across the whole pathway and are supported during their cancer journey.
- To demonstrate one year and five year survival outcomes in line with national and international standards for children with cancer adjusted for case mix.
- To demonstrate responsiveness to patient experience in line with CCNCG and national feedback from families and children with cancer.
- This document needs to be read in conjunction with Network Guidelines and Referral pathways.
- This document is one element of a number of documents that together provide

evidence of strategy for this age group; an agreed specification; and guidance on delivery of care.

Service Monitoring

The Children's Cancer Network require contracts and/or service monitoring criteria to include the following as relevant to the part of the patient pathway and the part of the CCN in question:

- National Cancer Peer Review Quality measures for Children's Cancer,
- performance against waiting times,
- cancer registration,
- specified clinical outcome audits,
- clinical trial entry rates,
- patient reported outcome measures,
- collection of Systemic Anti-Cancer Therapy (SACT) dataset.

Audit and Clinical Governance

Providers should have an active audit programme and be able to demonstrate that they have implemented the NICE Improving Outcomes (IOG) for children and young people with cancer.

Effective multi-disciplinary working should be in place

The PTC providers should record and audit:

- lengths of stay and discharge destination,
- capacity and staffing in line with national measures,
- safe use of chemotherapy in line with national measures,
- multi-disciplinary training undertaken,
- how users and carers are involved,
- information provided to patients and carers,
- adverse and near miss incidents and complaints,
- Cancer Outcomes Strategy Dataset (COSD) appropriate to this patient group.

5. Location of Provider Premises

List of Children's Cancer Principal Treatment Centres offering care for patients 0 to 15 years inclusive.

The location of services for teenagers are included for reference

Region	City	Trust(s)	Role
North	Newcastle	Great Northern Children's Hospital	Children & Teenage

	Liverpool	Alder Hey Children's Hospital / WUTH: Clatterbridge	Children & Teenage / Teenage & Young Adult
	Leeds	Leeds Teaching Hospitals Trust: Leeds General Infirmary / St James Hospital	Children & Teenage / Teenage & Young Adult
	Manchester	Central Manchester University Hospitals: Royal Children's Hospital	Children / Teenage
	Sheffield	Sheffield Children's Hospital / Weston Park	Children / Teenage and or Young Adult
Midlands & East	Leicester / Nottingham	Leicester Royal Infirmary / Queen's Medical Centre	Children & Teenagers
	Birmingham	Birmingham Children's Hospital NHS Foundation Trust/ UHB: Queen Elizabeth Hospital	Children & Teenage / Teenage & Young Adult Unit
	Cambridge	Addenbrooke's Hospital	Children / Teenage Young Adult
London	London	Great Ormond Street Hospital / University College London UCLH Royal Marsden Hospital / St George's Hospital RMH	Children / Teenage Teenage & Young Adult Children / Teenage Teenage / Young Adult Children
South	Oxford	Oxford University Hospitals: Churchill	Teenage / Young Adult Unit
	Southampton	Southampton University Hospital	Children / Teenage & Young Adult Units
	Bristol	University Hospitals Bristol: Royal Children's Hospital / Southmead Hospital	Children / Teenage & Young Adult Units

The list below has not been fully verified with commissioners so may be subject to amendment post consultation

Paediatric Oncology Shared Care Units (POSCU's) 2012			
Principal Treatment Centre	POSCU Trust Code	Hospital	Level of Service
	RXN	Lancashire Teaching Hospitals NHS Foundation Trust	1
	RXL	Blackpool Teaching Hospitals Trust	1
	RXR	East Lancashire Hospitals NHS Trust	1
	RBT	Mid Cheshire Hospitals NHS Foundation Trust	1
	RJR	Countess of Chester Hospitals NHS Foundation Trust	1
	RT9	North East Wales, Betsi Cadwaladr University Health Board	1
	RT9	North West Wales, Betsi Cadwaladr University Health Board	1
	RT9	Conwy & Denbighshire, Betsi Cadwaladr University Health Board	1
	RCF	Airedale NHS Trust	1
	RWY	Calderdale and Huddersfield NHS Foundation Trust	1
	RCB	York Hospitals NHS Foundation Trust	1
	RWA	Hull and East Yorkshire Hospitals NHS Trust	1
	RCC	Scarborough and North East Yorkshire NHS Trust	1
	RJL	North Lincolnshire and Goole Hospitals NHS Foundation Trust	1
	RKB	University Hospitals Coventry and Warwickshire NHS Trust	3
	RWH	Lister Hospital, East and North Hertfordshire NHS Trust	1
	RC9	Luton and Dunstable Hospital MHS Foundation Trust	1
	RWG	Watford General, West Herfordshire Hospitals NHS Trust	2
	RAS	The Hillingdon Hospital NHS Trust	1
	RV8	Northwick Park, North West London Hospitals NHS Trust	1
	RYJ	St Mary's Hospital, Imperial College Healthcare NHS Trust	2
	RQM	Chelsea and Westminster Hospital NHS Foundation Trust	1
	RAP	North Middlesex University Hospital NHS Trust	1
	RKE	The Whittington Hospital NHS Trust	1
	RVL	Barnet and Chase Farm Hospitals NHS Trust	1

	RQW	The Princess Alexandra Hospital NHS Trust	1
	RF4	Queens Hospital, Barking, Havering and Redbridge University Hospitals NHS Trust	1
	RGC	Whipps Cross University Hospital NHS Trust	1
	R1H	Newham University Hospital, Barts Health NHS Trust	1
	RNJ	Barts and the London NHS Trust	2
	RJZ	Kings College Hospital NHS Foundation Trust	2
	RYQ	PRUH – South London Healthcare NHS Trust	1
	RVR	Epsom and St Helier University Hospitals NHS Trust	1
	RAX	Kingston Hospital NHS Trust	1
	RJ6	Mayday Healthcare NHS Trust	1
	RK9	Plymouth Hospitals NHS Trust	3
	REF	Royal Cornwall Hospitals NHS Trust	3
	RH8	Royal Devon and Exeter NHS Foundation Trust	3
	RD3	Poole Hospital NHS Foundation Trust	1
	RBD	Dorset County Hospital NHS Foundation Trust	1
	RA4	Yeovil District Hospital NHS Foundation Trust	3
	RD1	Royal United Hospital Bath NHS Trust	3
	RBA	Taunton and Somerset NHS Foundation Trust	3
	RTE	Gloucestershire Hospitals NHS Foundation Trust	3
	RWP	Worcestershire Acute Hospitals NHS Trust	1
	RLQ	Wye Valley NHS Trust (Hereford County Hospital)	1
	RD7	Heatherwood and Wexham Park Hospitals NHS Foundation Trust	2
	RD8	Milton Keynes Hospital NHS Foundation Trust	2
	RHW	Royal Berkshire NHS Foundation Trust	2
	RN3	Great Western Hospitals NHS Foundation Trust	2
	RXQ	Buckinghamshire Healthcare NHS Trust	2
	RHU	Portsmouth Hospitals NHS Trust	2
	RN5	Royal Hampshire County Hospital, Hampshire Hospitals NHS Foundation Trust	1
	RN5	Basingstoke and North Hampshire Hospital, Hampshire Hospitals NHS Foundation Trust	1
	R1F	Isle of Wight Healthcare NHS Trust	1
	RNZ	Salisbury NHS Foundation Trust	1
	RYR	Western Sussex Hospitals NHS Trust	1
	RTK	Ashford and St Peters Hospital NHS Trust	1
	RTP	Surrey and Sussex Healthcare NHS Trust	1
	RDU	Frimley Park Hospital NHS Foundation Trust	1
	RA2	Royal Surrey County NHS Foundation Trust	1
	RXH	Brighton and Sussex University Hospitals	3

		NHS Trust	
	RXC	East Sussex Healthcare NHS Trust	1
	RPL	Western Sussex Hospitals NHS Trust	1
	RVV	Kent and Canterbury Hospital, East Kent Hospitals University NHS Foundation Trust	1
	RPA	Medway NHS Foundation Trust	1
	RWF	Maidstone and Tunbridge Wells NHS Trust	1
	RL4	Royal Wolverhampton Hospitals NHS Trust	2
	RXW	Shrewsbury and Telford Hospital NHS Trust	3
	RJE	University Hospital of North Staffordshire NHS Trust	3
	RGP	James Paget University Hospitals NHS Foundation Trust	1
	RM1	Norfolk and Norwich University Hospitals NHS Foundation Trust	2
	RYV	Hinchingbrooke Healthcare Trust	1
	RGN	Peterborough and Stamford Hospitals NHS Foundation Trust	1
	RGR	West Suffolk NHS Foundation Trust	1
	RCX	Kings Lynn NHS Foundation Trust	1
	RGQ	Ipswich Hospital NHS Trust	2
	RAJ	Southend University Hospital NHS Foundation Trust	1
	RDD	Basildon and Thurrock University Hospitals NHS Foundation Trust	1
	RDE	Colchester Hospital University NHS Foundation Trust	1
	RQ8	Mid Essex Hospital Services NHS Trust	1
	RNL	North Cumbria University Hospitals NHS Trust	1
	RNS	Northampton General Hospital NHS Trust	3
	RJF	Burton Hospitals NHS Foundation Trust	1
	RWD	United Lincolnshire Hospitals NHS Trust	1

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would be fundamental to all services.

The generic aspects of care:

The Care of Children in Hospital (Health Service Circular 1998/238) requires that:

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimise complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through "integrated pathways of care" (*National Service Framework for children, young people and maternity services* (Department of Health & Department for Education and Skills, London 2004))

Interdependencies with other services

All services will comply with *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Interdependencies* – Department of Health

Imaging

All services will be supported by a three-tier imaging network (*'Delivering quality imaging services for children'* Department of Health, 13732 March 2010). Within the network;

- it will be clearly defined which imaging test or interventional procedure can be performed and reported at each site,
- robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements,
- robust arrangements will be in place for patient transfer if more complex imaging or intervention is required,
- common standards, protocols and governance procedures will exist throughout,
- All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development,
- All equipment will be optimised for paediatric use and use specific paediatric software.

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training.¹ All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training² and should maintain the competencies so acquired³ *. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example magnetic resonance imaging (MRI) scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

*The Safe and Sustainable reviews of paediatric cardiac and neuro- sciences in England have noted the need for additional training and maintenance of competencies by specialist anaesthetists in both fields of practice.

References

1. Guidelines on the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCOA) 2010, www.rcoa.ac.uk
2. Certificates of Completion of Training (CCT) in Anaesthesia 2010,
3. Continuing Professional Development (CPD) matrix level 3.

Specialised Child and Adolescent Mental Health Services (CAMHS)

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in-patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply,
- (<http://www.rcpsych.ac.uk/quality/quality accreditation/audit/qnic1.aspx>)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family are allowed to visit at any time of day taking account of the child / young person's need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child/young person's care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child/ young person.

Applicable national standards e.g. NICE, Royal Colleges

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in

the staff establishment of two RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes *HBN 23 Hospital Accommodation for Children and Young People* NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce Development Council Induction standards (Outcome 14b *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002). "*Facing the Future*" Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (*Seeking Consent: working with children* Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them,
- ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed,
- ensuring that people who use services are aware of how to raise concerns of abuse,
- having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern,

- having effective means of receiving and acting upon feedback from people who use services and any other person,
- taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
 - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse,
 - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider,
 - reporting the alleged abuse to the appropriate authority,
 - reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.
- using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance,
- working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies,
- participating in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004,
- having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding,
- taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications,
- ensuring that those working with children must wait for a full CRB disclosure before starting work,
- training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010.

All children and young people who use services must be:

- fully informed of their care, treatment and support,
- able to take part in decision making to the fullest extent that is possible,
- asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

Key Service Outcomes

Evidence is increasing that implementation of the national *Quality Criteria for Young People Friendly Services* (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:

- all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

The *National Minimum Standards for Providers of Independent Healthcare*, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult Patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this.
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the *Standards for the Care of Critically Ill Children* (Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- a choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs,
- food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background,
- support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs,
- for the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed,
- that providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- ensure the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability,
- ensure that staff handling medicines have the competency and skills needed for children and young people's medicines management,
- ensure that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability.

Providers should ensure that:

- they are supported to have a health action plan,
- facilities meet the appropriate requirements of the Disability Discrimination Act 1995,
- they meet the standards set out in *Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services.* Department of Health Publications, 2006, London