

B15/S/b

**2013/14 NHS STANDARD CONTRACT  
FOR NHS STANDARD SERVICE SPECIFICATION TEMPLATE FOR  
CANCER: CHEMOTHERAPY (CHILDREN, TEENAGERS AND YOUNG ADULTS)**

**SECTION B PART 1 - SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	B15/S/b
<b>Service</b>	Cancer: Chemotherapy (Children, Teenagers and Young Adults)
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	12 Months
<b>Date of Review</b>	

**1. Population Needs**

**1.1 National/local context and evidence base**

**1.1.1 National context**

Cancer in children and young people is relatively rare compared to society as a whole (1 in 600 under 16 year olds contract cancer whereas the life time risk for cancer is 1 in 3). There is a wide spectrum of malignancies in this group and a multiplicity of symptoms, many of which are common and non-specific. Many of the treatments are complex, intensive and potentially curative.

Chemotherapy refers to any systemic anti-cancer therapy, this includes monoclonal antibodies/targeted therapies, intravenous, subcutaneous, intrathecal and oral chemotherapy as well as topical treatments for bladder cancer; hormonal treatment is excluded. This service specification is for the treatment of children and young people with cancer requiring systemic anticancer therapy. The delivery of chemotherapy to children, particularly small children, is more complex with a greater potential for errors than in adults.

There are a number of reasons why there are particular risks of error in giving chemotherapy to children:

- All doses have to be carefully calculated and prepared and fluid volume has to be tailored to the size of the child. Standard or upper dose limits are less relevant in children and there is a wide range of dosage, for example, methotrexate.

- Weight loss or gain can significantly alter the correct dosage, requiring close patient observation (this is also an issue for teenagers).
- Many drugs are not licensed for use in children, in particular the very young.
- Many are not routinely prescribed and treatment protocols are often very complex.
- Oral preparations (including suspensions) may not be palatable or may not be available to children and compliance may be difficult.
- Tablets may not be available in sufficiently small sizes, requiring portions of the tablets to be given or necessitating metronomic prescribing.

In August 2005 the National Institute for Health and Clinical excellence (NICE) Guidance on Improving Outcomes (IOG) in Children's and Young People with Cancer (CYPIOG) was published and made recommendations for the treatment and care of children, teenagers and young adults (TYA) with cancer, aged 0 to 24 years. NICE recognises that the needs of children and young people with cancer are different from those of older adults with cancer. For example, during childhood and adolescence, physical changes occur that may affect the type of cancer present, how it needs to be treated, and how well the treatment works. Children and young people also undergo psychological changes that may influence their emotional response during and after treatment.

The key principles of the CYPIOG are:

- All children under 16 years should be referred to a Principal Treatment Centre (PTC) for children.
- All patients aged 16-18 years inclusive should be referred to a Principal Treatment Centre (Children or TYA) for treatment.
- All patients aged 19-24 years inclusive should be offered referral to a Principal Treatment Centre (TYA) for treatment or the locally designated hospital for TYAs (and some will be treated in specialist centres because of their disease - e.g. sarcoma).
- All patients aged 16-24 years inclusive should be discussed at both a site-specific multidisciplinary team meeting and a TYA multidisciplinary team meeting.
- Referral of patients to a PTC (TYA), or review by both a site-specific and a TYA multidisciplinary team should not be allowed to delay the start of urgent cancer treatment.
- For each patient, a lead medical clinician should to be identified, who will have overall responsibility for their treatment.
- The TYA multidisciplinary team at the PTC should have a role in coordinating treatment, psychosocial care and peer contact/support for young people wherever they are treated.
- Robust arrangements should be in place for planned transition between children and young people's services and between young people and adult services.

The CYPIOG also states that all children and young people should have access to "safe and effective care as locally as possible". This is delivered through a network

model of services with agreed PTCs for children and for TYAs and agreed Paediatric Oncology Shared Care Units (POSCUs) for children and designated hospitals for TYAs. This model is set out in more detail in the relevant service specifications.

The CYPIOG deals with the organisation of the whole of cancer services for this group of patients. It is more age specific than disease-specific, although the commonest cancers in this age group comprise a significantly different spectrum from so called “adult” cancers. The oncology practice in the area of children’s malignancy correspondingly has less division into site specialties, with specialists in children’s haemato-oncology, brain & central nervous system (CNS) and specialists in children’s solid tumour oncology. The casemix changes towards the upper end of the age range.

National Health Service policy has further committed to increase patient choice and states that patients, referred for a particular service, should be able to choose where they have it delivered. In the field of cancer for children and young people these services will have been designated as part of an agreed pathway. These services will meet NHS service quality requirements, prices and normal contractual obligations thus ensuring they are appropriately qualified. This allows patients to have the choice of service delivery via Any Qualified Provider (AQP). Guidance exists for commissioners and providers to implement patient choice of AQP for a limited number of services. The Department of Health is developing proposals to extend AQP to community chemotherapy and these will be in place from April 2013.

### **Local context**

The aim of the service is to ensure the provision of consistent high quality care for the patients in the population served, maintaining high standards, equitable access and treatment for all, in line with national standards and requirements that allows access for all children and young people with a diagnosis of cancer to the best possible care.

The chemotherapy service specification is based on the following principles:

- All chemotherapy delivered to children should be initiated by the PTC and agreed by the Diagnostic and Treatment multidisciplinary team.
- All TYAs receiving chemotherapy must have been discussed by both the TYA multidisciplinary team and a site specific multidisciplinary team and a joint treatment plan agreed. Decisions about chemotherapy will therefore sit with the service in overall charge of the patients care which be either the PTC TYA team or the local team, as specified.
- There must be arrangements in place for urgent chemotherapy treatment prior to multidisciplinary team discussion
- There should be access to clinical trials, or treatment on agreed protocols for children & young people.
- All PTC providers delivering chemotherapy should have formal and defined relationships between their services.
- All new treatments should be assessed prior to their introduction to ensure that

they fit with strategic plans developed by clinicians, commissioners and clinically managed networks.

- There must be a robust system of clinical governance in place and all staff must be fully familiar with the treatments employed within the service and be trained and deemed competent to deliver them.
- Service improvement should be shaped by service user and carer involvement.
- Patients, parents and carers must receive clear written guidance when consenting to treatment to include the treatment intent, prognosis and potential complications associated with their treatment, with clear instructions who to contact if they need advice outside working hours and how to proceed in the event of a medical emergency.

In order to demonstrate the effective organisation of CYP chemotherapy services, a number of national requirements will need to be met by providers including:

- Clinical governance
  - Good clinical governance systems and policies must be in place and integrated into organisational governance with clear lines of accountability and responsibility for all clinical governance functions.
- Clinical quality
  - Quality assurance systems must be in place and approved by the commissioning body with regular reporting of outcomes. Providers must provide a report on the quality of the chemotherapy service least once a year and make this public.
  - Compliance with:
    - Cancer Peer Review measures
    - Systemic cancer therapy access targets
    - NICE guidance on anti-cancer medicines
- Data and information management
  - The Provider should have an explicit data and information strategy in place that covers:
    - Types of data
    - Quality of data
    - Data protection and confidentiality
    - Accessibility
    - Transparency
    - Analysis of data and information
    - Use of data and information
    - Dissemination of data and information
    - Risks
    - Electronic prescribing for chemotherapy is highly recommended/mandated
    - Completion and upload of the Mandated Systemic Anti-Cancer Therapy(SACT) Dataset.
- Implemented chemotherapy care pathways
  - Clear children and young person's chemotherapy care pathways and the actions that need to be taken by commissioners and providers to ensure high quality care.

## **Clinical trials**

Wherever possible, patients who are eligible should be offered the opportunity to participate in clinical trials. Treatment on a clinical trial is regarded as the gold standard of care and paediatric trial recruitment has led all other cancers in this area. Every child and TYA with cancer should be enrolled into and treated on a clinical trial, where a clinical trial for their particular cancer is available.

Whilst the majority of children and young people with cancer are cured, a minority relapse and require novel therapies. Phase I and II trials, involving new therapeutic agents, are organised under the auspices of the Innovative Therapies in Children with Cancer (ITCC) Europe. There are nine ITCC accredited centres in the United Kingdom. The Cancer Research UK (CRUK) Clinical Trials Unit based at the University of Birmingham is the main, but not exclusive, sponsor and clinical trials unit for paediatric cancer trials in the UK. Increasingly trials are extending their upper age limit to recruit young adults into combined trials for children and young adults, particularly where outcomes are superior for patients treated on paediatric protocols. Similarly adult trials do not always include young patients. Hence traditionally, teenagers and young adults are less likely to be treated on a clinical trial than children, and the national strategy is to increase development of trials aimed at this age group.

Where a study is only open at one Trust, suitable patients should be referred for trial entry. Patients who have been recruited into a clinical trial will be followed up as defined in the protocol.

When operating clinical trials all providers should ensure training and practice meets those specified in "Good Clinical Practice" (MHRA) in clinical trials. Many cancer trial protocols involve the delivery of complex chemotherapy regimens, not all of which are the focus of the research question, but are instead standard care therapy which must also be delivered to ensure appropriate treatment of the cancer (i.e. 'background' therapy). In assessing which drugs should be designated as IMPs (Investigational Medicinal Products) it is important to identify which drugs are the focus of the research to answer the research questions the trial is designed to answer (i.e. the trial objectives). Careful consideration needs to be given as to whether established therapies are given as standard care in the trial population may be classed Non IMP, considering the objectives of the study.

## **2. Scope**

### **2.1 Aims and objectives of service**

The aim of the children and young person's chemotherapy service is to ensure that children and young people with cancer who require chemotherapy get access to the best possible care and the care that is most appropriate for their age.

The objectives of this children's and young people's chemotherapy service specification is to introduce a national standardised, best practice care for children and young people who are diagnosed with cancer and who require chemotherapy ensuring that the chemotherapy services being delivered offer high quality and best practice services to patients.

Purpose of the service specification:

- To support safe and effective practice with the administration of anti-cancer drugs
- To outline a consistent approach to care.
- To fulfil criteria for chemotherapy related policies in the Manual for Cancer Services: Measures for Children's Cancer Services – National Cancer Peer Review, National Cancer Action Team (2009).

The key objectives are:

- Care to be coordinated across the whole of the NHS and be available as close to the patient's home as possible
- Clinical managed networks to ensure that they meet the needs of children and young people with cancer and that there are sufficient specialist staff
- Provide high quality proactive treatment and careMultidisciplinary teams to provide cancer chemotherapy care
- Each child or young person with cancer to have a key worker
- Care to be appropriate to the child's or young person's age and type of cancer
- Children and young people with cancer to be offered the chance to take part in clinical trials
- Treatment to be based on agreed protocols
- Support to be available to parents and families of children who are undergoing chemotherapy, as well as the affected child.
- Co-ordination and continuity between the PTC and POSCUs (for children) and between the PTC and TYA designated hospitals (for TYA).

## **2.2 Service description/care pathway**

This specification for children and young people with cancer requiring chemotherapy covers both solid tumour oncology and haemato-oncology treatments.

This chemotherapy service comprises of the following elements

- Entry to the pathway / service and Initial assessment
  - Access and referral to a consultant paediatric/TYA/clinical / medical oncologist or haematologist
  - Assessment and decision to treat
- Point of intervention

- Prescribing first cycle
- Prescribing subsequent cycles
- Delivery and treatment environment
- Patient and carer information, education support and advice
- Urgent assessment and management of complications
- Preparation of chemotherapy
  - Dispensing and reconstitution
- After treatment
  - End of treatment record and subsequent care plan

### **Entry to the pathway/ service and Initial assessment**

All patients and their carers will be given access to age appropriate verbal & written information during their investigation and treatment, and will be given the opportunity to discuss their management with the treating consultant and a paediatric oncology/TYA trained nurse who is a member of the relevant multidisciplinary team.

Some younger patients will not be given written information but will receive regular verbal information or pre-procedural play just before any procedure and with regularly updated information each time the care is delivered. Post – procedural play with play specialists can also be arranged for traumatic procedures.

The patient / carers will have open access to advice about chemotherapy and side effects & complications via the PTC or their local POSCU chemotherapy trained staff. They will be given phone numbers for the 24hr advice lines at the PTC or local POSCU.

All patients / carers will be given the following written information prior to starting chemotherapy:

- Written information which should cover regimen specific and drug specific information & information on specific side effects applicable to their child's treatment
- Written information covering the action they should take, whom they should contact for advice and the symptoms that should prompt this, with regards to complications of chemotherapy:
- Written information about, and care and management of central line (when applicable)

Pre-chemotherapy treatment assessments:

- Accurate pre-chemotherapy assessment is essential to enable variation from the patient's baseline to be detected.
- Pre-course and pre-cycle records should meet all requirements of the relevant chemotherapy quality measures

## Point of intervention

Supporting children and young people during treatment is essential. Regular review of patients is the responsibility of the medical and nursing team and the pharmacist treating the patient, additionally regular formal review will involve a team approach that requires multiple skills and attention.

Patients during chemotherapy must be given access to a 24 hour helpline (24 hours a day, 7 days a week) for urgent advice about side effects or symptoms of infection from chemotherapy.

Patients receiving treatment at a POSCU or a TYA designated hospital must be able to access the same wide range of expert help as patients receiving chemotherapy at the PTC; this includes timely access back to the PTC if complications of treatment fall outside of the shared care agreement in place.

Nurses who administer chemotherapy to children and young people must have been assessed as competent to do so in line with the relevant quality measures.

The names of staff that have completed competency based training must be kept on a current register of competent staff.

Before a course of chemotherapy is to be given by any route the patient must be clinically assessed to ensure:

- Haematology parameters, particularly neutrophil and platelet counts are sufficient for treatment to proceed.
- Clinical chemistry parameters, appropriate to the treatment and as set out in the treatment protocol, are sufficient for the treatment to proceed.
- Any other investigations e.g. renal function, audiology or cardiology, that impact on whether the treatment can be given and/or at what dose, have been performed, reported and reviewed.
- Investigations listed on the front of chemotherapy prescriptions or as detailed in the clinical trial protocol or national guideline have been carried out and results are within agreed parameters. These investigations should be listed in the case notes for patients following individualised treatment plans.
- The patient is clinically well.

The administering practitioner must ensure appropriate venous access where, appropriate, with regards to:

- Site
- Position
- Patency
- Integrity
- Visibility

Use of aseptic non-touch technique, observation of universal precautions and product sterility are required in all intravenous procedures



## Preparation of chemotherapy

Chemotherapy must be delivered as safely as possible i.e. it must conform to the Manual for Cancer Services CYPIOG measures(2011); and, national standards set following NPSA (National Patient Safety Agency) oral and vinca-alkaloid alerts (2008);NCEPOD report (2008) and NCAG report (2009) recommendations.

The chemotherapy service in the PTC (principle treatment centre) or in a POSCU (paediatric oncology shared care unit) may receive its pharmacy support from a pharmacy which has previously 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 COSHH (The Control of Substance Hazardous to Health) 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 oncology pharmacy measures 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.

Local arrangements should be in place to ensure that as far as practicable high cost items are only reconstituted after the patient's blood results are known. All cytotoxic drugs should be prepared in accordance with locally approved policies and protocols.

Each clinical chemotherapy service must have a policy detailing the safe reconstitution of cytotoxic drugs. The following are the principles and guidelines upon which the local policy should be based. 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. Any staff responsible for reconstituting cytotoxic drugs must have undergone training in line with:

- 1988 Health and Safety Commission approved Code of Practice entitled "The Control of Substance Hazardous to Health" (COSHH).
- Aseptic dispensing for NHS patients: a guidance document for pharmacists in the United Kingdom by Farwell, John .Great Britain. Department of Health, 1993
- Rules and Guidance for Pharmaceutical Manufacturers and Distributors - MRHA 2007- the 'Orange Guide'  
<http://www.mhra.gov.uk/Publications/Regulatoryguidance/Medicines/CON2030291>
- Quality Assurance of Aseptic Preparation Services 2005 Alison M. Beaney

## After treatment

The patient will be given appropriate after treatment care and follow-up including information on post treatment reactions to expect and advice on self management of those reactions.

Patients should be given contact details of the service to support post

treatment reactions and anxieties.

Following chemotherapy the responsible clinician should confirm to both the patient's GP and referring clinician; what treatment has been delivered, the patient's condition and any post treatment arrangements.

Discharge letters must go to the clinician continuing the patient's care – eg the GP or other clinician and a copy placed within the notes. Copies of these should be provided for the patient unless they do not wish to have them.

The patient will receive a treatment summary and care plan.

### **Service model / care pathway**

Children with cancer (i.e. oncological and malignant haematological disorders) require a sustained and integrated network of care involving a variety of organisations, professionals and equipment, often over a prolonged period of time. Care is delivered through multidisciplinary teams identified at different points in the child's care pathway; namely diagnosis and treatment planning, treatment and supportive care, psychosocial care and management of the late effects of cancer treatment.

Chemotherapy services are delivered through this network model with agreed PTCs for Children and for TYAs and agreed Paediatric Oncology Shared Care Units (POSCUs) for children and TYA 'Designated hospitals'. This model is set out in more detail in the relevant service specifications.

The service itself will also have clinical oversight and accountability for governance purposes. Chemotherapy services in a Children's PTC must be compliant with the Children's Cancer Measures. TYA services that are sited within adult services must be compliant with the Chemotherapy measures. There must be a professional head of the chemotherapy service directly responsible for the development, management and ultimate clinical accountability and responsibility for the service. This professional head of service must hold an appropriate qualification to practice and be registered with the Health Professions Council.

Chemotherapy services within PTCs deliver much of the chemotherapy required by children in partnership with POSCUs, which operate at different levels, and provide a chemotherapy service in line with their agreed level of shared care and directed by the PTC. All POSCU services provide some elements of supportive care for children having chemotherapy.

Further details of the three levels of shared care for paediatric oncology services are given in the Department of Health's Children's Cancer Measures set out in the Manual for Cancer Services (2011).

## Shared Care Levels for POSCUs

### POSCU 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.

Allowable options from the above:

1. All the above services
2. Opt out of outpatient IV bolus chemotherapy only
3. Opt out of outpatient IV bolus chemotherapy and inpatient supportive care including care of children with febrile neutropenia
4. Opt out of all chemotherapy and inpatient supportive care including care of children with febrile neutropenia

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

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### POSCU Level 2 Services

- As for level 1 and in addition day care infusional chemotherapy
- Exclusions - inpatient chemotherapy and all exclusions listed in level 3.

### POSCU Level 3 Services

- As for level 2 and in addition inpatient 24-hour chemotherapy
- An intrathecal chemotherapy service in a POSCU is an option for level 3 (only providing the following are fulfilled:
  1. Compliance with HSC 2003-010, as verified by a satisfactory peer review against the ITC measures (Manual for Cancer Services 2004, section 3C-3, or any measures which supersede it);
  2. Paediatric anaesthetic service on site;
  3. Agreement by Children's Cancer Network Coordinating Group.

### Level 3 Exclusions, for instance services which should only be offered in a PTC

- Final diagnosis and determination of treatment plan;
- Chemotherapy regimens or other procedures which would be rendered unacceptably hazardous or have their effectiveness reduced by reason of the

limits of infrastructure or experience available at any of the POSCUs; these regimens and/or procedures should be specified at any one time for the CCN by the CCNCG;

- Stem cell transplantation;
- Recruitment to, and co-ordination of, phase I, II and III clinical trials;
- Radical radiotherapy

The provision of services to TYA patients follows a similar network model, with TYA designated hospitals providing a comprehensive local chemotherapy service for those patients not treated in the PTC.

Once the designation of principal treatment centres and paediatric oncology shared care units through a commissioning process is complete, it is expected that all children with suspected or diagnosed cancer will be referred and treated in one of these hospitals. However, all hospitals that accept children in their emergency departments would be expected to have sufficient knowledge and skill to stabilise a sick child using the principles taught in basic and advanced paediatric life support courses. The patient should then be transferred to a designated centre at the earliest safe opportunity.

PTCs and POSCUs will provide chemotherapy for both solid tumour oncology and haemato-oncology. TYA designated hospitals may provide chemotherapy for solid tumour medical oncology, haemato-oncology, or both.

The service will consist of the provision of chemotherapy by a clinical team using appropriate equipment in the right facilities. It is essential that an agreed and documented consultant paediatric/TYA/clinical / medical oncologist or haematologist retains the responsibility for overall patient care across the whole pathway and will provide care wherever the patient is treated, including homecare, and retains overall responsibility for the management of side effects and complications. A nurse practitioner may provide the link between the PTC and POSCUs or TYA designated hospitals.

All providers must have a professional head of chemotherapy service that is directly responsible for the development, management and ultimate clinical accountability and responsibility for the service at each trust delivering chemotherapy. The professional head of service must hold an appropriate qualification to practice. There must be clear agreements detailing the responsibilities for the development, management and ultimate clinical accountability and responsibility for the service. In conjunction with the cancer centre, the service lead at each trust will have clinical oversight and accountability for governance purposes for issues relating to chemotherapy.

Cover arrangements must be in place for absence and holidays, out of hours and emergencies to ensure continuity of service, and may include links with the  
Children and young people receiving chemotherapy treatment must have direct access to appropriate inpatient care fully equipped to deal with the side effects and acute complications of the treatment, including access to out-of- hours specialist oncologist, and management of emergencies, in accordance with guidelines.

Chemotherapy treatment should be commenced during standard 'working hours' wherever possible when support services and expert advice are available; there should be a local policy to this effect.

All children and young people receiving chemotherapy treatment should be provided with 24 hour contact details, should they require advice on side effects and complications of treatment, and how to obtain help and treatment for them.

There should be a clear pathway for each child and young person from presentation and referral through diagnosis, treatment, supportive care, rehabilitation and palliation, when required.

Where local pathways exist they should be designed to show clearly the links between the PTC and POSCUs or TYA designated hospitals, including how a patient enters, is managed and discharged from the service.

All pathways should include timelines and alert mechanisms for potential breaches, audit processes to ensure standards are met, and specification of provider and commissioner responsibilities. The provider(s) should meet standards for prescribing, adhere to the required competency checks and should foster a responsive and participative approach to including patients' views about their care in the design of care pathways, and should collaborate with other organisations involved in the patient pathway to provide a seamless patient journey.

Where chemotherapy is delivered in the community, providers should adhere to local pathways and policies in line with the PTC. The oncology pharmacy will prepare the chemotherapy in the same way that they would at the main oncology centre. The chemotherapy will then be transported safely to the patient. Where private pharmacies are used, they may deliver the chemotherapy directly to the community setting. In some systems, this will involve the nurse collecting the chemotherapy from a central dispensary/store, or be taken home by the patient/parent and with other models, the chemotherapy may be delivered by courier, scheduled to arrive at the planned administration time. All NCAG recommendations relating to the recording and delivery of chemotherapy prescriptions apply whatever the delivery setting. It should be noted that where pharmacy services are outsourced, prescribing, clinical checks and record keeping aspects of the services remain within the NHS.

If any of the chemotherapy activity is sub-contracted to another provider (eg satellite departments, POSCUs, TYA designated hospitals, community teams or external contractor) there must be clear and formal accountability processes and structures in place to ensure continuity of clinical care that is safe and effective. There also a need for there to be a clear mechanism for ensuring treatment information on the patient is captured and provided back to the accountable trust, and that all work processes are protocol led and clearly defined both within the provider and with any other service provider. Any deviation from these protocols will be clearly documented and investigated with regular reviews, and where appropriate updated.

## **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).

### **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.

Specifically, this service is for children and young people with cancer requiring specialised chemotherapy treatment, as part of their planned cancer treatment and support, outlined within this specification. All chemotherapy given to children is defined as specialised.

This specification covers all systemic chemotherapy for children and young people (aged 0 -24 years).

There is a separate service specification for that covers systemic chemotherapy services for adults

### **2.4 Any acceptance and exclusion criteria**

#### **Acceptance criteria**

Referrals for chemotherapy are made to a consultant medical oncologist, clinical oncologist or haemato-oncologist who is a member of the multidisciplinary team. Patients on a chemotherapy pathway must have been discussed by an appropriate multidisciplinary team.

Children are considered to be those patients from birth up to their 16th birthday. Teenagers and Young Adults, for the purpose of this specification are considered to be those patients in the age range from 16 until their 25th birthday.

The age when it is appropriate for an adolescent to move from specialised paediatric services, to TYA services, and on to adult services (whether specialised or non-specialised) will vary according to the individual and the circumstances of their illness,. Appropriate handover arrangements for adolescents requiring

continuing healthcare in adulthood need to be in place; currently the provision of appropriate specialised services in the transitional period, although improving, is still quite variable across the country.

### **Exclusion criteria**

Management of adults chemotherapy– see separate service specification.

## **2.5 Interdependencies with other services**

### **Co-located services**

Children's and TYA chemotherapy services have a range of critical interdependencies with other clinical services – notably intensive care, and (for children) paediatric anaesthesia, and paediatric surgery and (for TYA) Acute Oncology Services (AOS). For children, these interdependencies are set out in the Department of Health report 2008 "Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework for Critical Inter Dependencies".

Clinical and aseptic pharmacy facilities need to be co-located.

### **Interdependent services**

#### **Related services**

Diagnostics. The diagnosis and staging of cancer in children requires specialised diagnostic services. Younger children undergoing imaging will need the support of specialised paediatric general anaesthesia services.

Supportive care (e.g. the management of febrile neutropenia, nausea, vomiting, bowel disturbance and nutrition plus central venous access and blood product support) is provided by the specialist cancer centre during the active treatment period. (Note: supportive care is also provided by shared care units where clinically appropriate and delivered according to clinical guidelines agreed with the cancer centre.)

Psychosocial care comprises the psychological and social supportive care for a child or young person and his/her family during active cancer. The provision of appropriate psychosocial support to children, young people and their families involves multi-agency support and includes particular input from the specialist cancer centre during the active cancer therapy stage.

Occupational therapy, often in conjunction with other services, such as social work, careers and education services, provides support to children and young people with the aim of maximising their physical, emotional, cognitive, social and functional potential.

Palliative care may also be involved in active treatment with chemotherapy,

## **Patient choice and chemotherapy treatment in different clinical settings**

It is important that chemotherapy patients / patients and carers are actively consulted on their choice of therapy and given evidence of where this may be delivered. Liberating the NHS: An Information Revolution and The power of information: putting all of us in control of the health and care information we need (Department of Health 21 May 2012) makes it clear that:

- Patients must have the information they need to make the right choices about their health and treatment;
- The NHS and social care must have the information they need, appropriately analysed by inequality/equality group, to enable them to make the right decisions around commissioning and providing quality services;
- The public must have the information they need to make the right choices about healthy lifestyles.

Liberating the NHS: greater choice and control is based on patients being at the heart of decision-making in the NHS. No decision about me without me should be a guiding principle in the delivery of all treatment. The report envisages a presumption of choice and any willing provider across the majority of NHS-funded services by 2013/14. In cancer, a range of different forms of choice are relevant, including:

- When to have treatment;
- Where to have treatment (some treatments can be given in hospital or in the community);
- Which organisations deliver treatment and care;
- Which teams deliver the treatment;
- What form of clinically appropriate treatment to have.

For children and young people that choice may be limited, both by the requirement of treatment in a PTC, and by the intensity of many of the treatment regimens used. Most children and young people receive treatment administered in hospital under the direct supervision of health professionals. Much of this treatment will be given in PTCs, but some of it will also be given in POSCUs or TYA designated hospitals, depending on local provision. This supports the principle of care closer to home. There are a limited number of treatments which can be administered safely at home, either by community nurses or by other health professionals or patients or families themselves. Patients and families should be given the choice of how these treatments are provided. Some patients also receive prolonged outpatient-based oral maintenance chemotherapy, during which the issue of compliance is important.

All oncology units treating children and young people should be compliant with the CYPIOG and the relevant quality measures (i.e. for children, or for TYA) and staffed with adequate numbers of appropriately trained staff to allow good communication and discussion on all aspects of treatment, and its effects and possible toxicity. There should be written protocols covering the administration of chemotherapy



agreed between the principal treatment centre and other treatment sites, and this should clearly define responsibilities and organisational arrangements. Clear accountability should be included in these protocols for the prescription and delivery of chemotherapy, with an agreed route for advice from the principal treatment centre in the event of chemotherapy-related problems.

### **Patient experience**

Minimising disruption to normal family life and limiting time away from home, from other children, from family support from school and from work is important in helping families cope. Despite the intensity and complexity of current cancer treatment, elements of treatment can, and will, be delivered as locally as possible.

The service should be patient centred and should respond to patient and carer feedback. Excellent communication between professionals and patients is particularly important and can avoid complaints and improve patient satisfaction. Patient experience for patients over 16 years is reported in the National Cancer Patient Survey. In this survey patients with a Clinical Nurse Specialist reported much more favourably than those without on a range of items related to information, choice and care. The national programme for advanced communications skills training provides the opportunity for senior clinicians to improve communications skills and all core multidisciplinary team members who have direct clinical contact with patients should have attended this.

### **Community chemotherapy settings (oral/subcut/iv therapies)**

The publication of the 2010 NHS white paper focused the NHS on extending choice for patients and cutting bureaucracy. Extending the choice of chemotherapy service providers from secondary care to include community service providers builds upon previous NHS initiatives.

In children and young people some cancer chemotherapy treatments can be safely delivered away from the PTC – in POSCUs or TYA designated hospitals. A limited number of treatments can be given at home. The National Chemotherapy Advisory Group (NCAG) report, Chemotherapy Services in England: Ensuring quality and safety, which reported in August 2009, concluded that each cancer network should consider whether there were opportunities to deliver chemotherapy closer to patients' homes.

The key drivers for delivering chemotherapy services in the community are:

- Improved patient choice
- Improved experience
- Managing the on-going increasing demand for chemotherapy.

Key issues that need to be addressed are:

- Use of e-prescribing systems
- Commissioning agreed pathways and specifications

- Clinical governance and leadership.

In November 2011 a report was published called Homecare Medicines "Towards a vision for the future". The key recommendations from the report, include:

- The internal governance frameworks of NHS Trusts should be strengthened given the rapid growth of homecare medicine.
- Through collaborative procurement mechanisms between NHS Trusts and commissioners, better value can be delivered for patients and taxpayers to enable high quality, responsive and more cost effective services to the patient and taxpayer.
- Commissioning agencies have a vital role to play in the strategic development of homecare medicine and the management of authorised providers to deliver effective homecare medicine to patients.
- Patients and patient representatives should have a much greater role in the design, operation and monitoring of homecare medicines delivery and services, with the authorised provider organisations delivering them.

In a report on the Dispensing and Supply of Oral Chemotherapy and Systemic Anticancer Medicines in Primary Care published in January 2011, this document sets out the requirements for service delivery of a community based oral SACT service.

### 3. Applicable Service Standards

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

Improving Outcomes in Children and Young People with Cancer, The Manual, August 2005. (National Institute for Health and Clinical Excellence)

The Manual for Cancer Services – Children’s Cancer Measures April 2011

The Manual for Cancer Services: Teenage and Young Adult Measures (2011) - The Teenage and Young Adults Measures reflect the recommendations of the NICE ‘Improving Outcomes in Children and Young People with Cancer’ guidance.

The service will comply with the relevant and current quality standards. This are defined in ‘A Commissioning Framework for Systemic Anti- Cancer Treatment available on the National Cancer Action Team website [www.ncat.nhs.uk](http://www.ncat.nhs.uk).

In line with the Innovation Health and Wealth, Accelerating Adoption and Diffusion in the NHS (5 December 2011) the service will require that all NICE Technology Appraisal recommendations are incorporated automatically into relevant local NHS formularies in a planned way that supports safe and clinically appropriate practice.

Clinical Governance systems and policies should be in place and integrated into organisational governance with clear lines of accountability and responsibility for all clinical governance functions and Providers should produce annual Clinical Governance reports as part of NHS CG reporting system.

The provider is required to undertake annual patient surveys and develop and implement an action plan based on the findings. The National Chemotherapy Implementation group along with the Patient Experience Advisory Group have developed a national survey for use by chemotherapy services in patients over the age of 16 years.

The provider must conform to national guidance and ensure local audits are conducted to ensure standards are being met.

The provider must be able to offer patient choice. This will be both in the context of appointment time and of treatment options and facilities including treatments not available locally.

Reporting of deaths within 30 days of chemotherapy: - Advice from the Coroner's Society of England and Wales reminds all of the clinicians involved in the care of cancer patients who die within 30 days of chemotherapy that patients whose death is caused by or hastened by treatment should be reported to HM Coroner.

The service will comply with the relevant NICE quality standards which defines clinical best practice where they are developed.

### **Mandated systemic anti-cancer therapy dataset**

#### **Standard Number ISB 1533**

In September 2011, the NHS Information Standards Board granted full stage approval to the Systemic Anti-Cancer Therapy (SACT) Information Standard. The standard covers all patients receiving cancer chemotherapy in or funded by the NHS in England. The data standard relates to all cancer patients, both adult and paediatric, in acute inpatient, daycase, outpatient settings and delivery in the community. It covers chemotherapy treatment for all solid tumour and haematological malignancies, including those in clinical trials.

NHS Trusts providing cancer chemotherapy services in England are required to collect and submit chemotherapy data. The SACT website is operational ([www.chemodataset.nhs.uk](http://www.chemodataset.nhs.uk)) where all the relevant documentation, data submission guidance, schedules for submission and FAQs can be found. The website will also provide access to the upload portal for the SACT data submissions. There is also best practice advice from the MHRA and in the BNF (British National Formulary) regarding the prescribing of bio-similar medicines by brand name (as opposed to chemotherapy where generic prescribing is the standard). This would facilitate appropriate reporting and monitoring of safety data on bio-similar SACTs.

Full compliance under this agreement is expected with the mandated SACT

dataset and reported with the required format and timelines. All trusts with e-prescribing systems should currently be submitting monthly chemotherapy data to the Chemotherapy Intelligence Unit (CIU) via the upload portal on the website. Those without e-prescribing systems should be uploading at least the mandatory fields and have an action plan and timetable agreed with the CIU for uploading the entire dataset.

#### 4. Key Service Outcomes

##### See Section B part 8.1 Quality requirements

Listed below are the key service outcomes for the chemotherapy service. Local and national Commissioning for Quality and Innovation (CQUIN) can be found in Section B Part 9.1 and 9.2: Table 1: CQUIN Scheme (some examples of chemotherapy local CQUINs 9.2)

N.B These are suggested standards derived from standard adult practice and require further discussion in the paediatric chemotherapy setting.

Quality Domain	Performance indicator	Indicator	Method of measurement	Frequency of monitoring
Domain 4 – ensuring that people have a positive experience of care	4.1 Uptake			
Domain 4 – ensuring that people have a positive experience of care  Domain 5 – treating and caring for people in a safe environment	4.2 Access	Due to increase in chemotherapy treatments and to improve the Clinical trial entry rates of children, teenagers and young adults.	Ensure that target of 100% of cancer patients discussed at the multidisciplinary team is met % of patients or parents/carers receiving written treatment plan % cancer patients getting chemotherapy treatment as recorded at multidisciplinary team	
Domain 4 – ensuring that people have a	4.3 Capacity	Due to increase in chemotherapy	The results of service monitoring	

positive experience of care		treatments and to improve the experience of children, teenagers and young adult's receiving chemotherapy all providers should undertake service monitoring. This should also include capacity plans for out-patient services and should be clearly documented.	should be discussed at least six monthly and documented evidence of capacity planned.	
Domain 4 – ensuring that people have a positive experience of care				
Domain 4 – ensuring that people have a positive experience of care  Domain 5 – treating and caring for people in a safe environment				
Domain 1 – preventing people from dying early				
Domain 1 – preventing				

<p>people from dying early</p> <p>Domain 2 – enhancing quality of life for people with LTCs</p> <p>Domain 4 – ensuring that people have a positive experience of care</p> <p>Domain 5 – treating and caring for people in a safe environment</p>				
<p>Domain 1 – preventing people from dying early</p> <p>Domain 2 – enhancing quality of life for people with LTCs</p> <p>Domain 3 – helping people recover from episodes of ill health</p> <p>Domain 4 – ensuring that people have a positive experience of care</p> <p>Domain 5 – treating and</p>				

caring for people in a safe environment				
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## 5. Location of Provider Premises

The provider's premises are located at:

### Principal Treatment Centres (PTCs)

Trust Code	Hospital
RW3	Central Manchester University Hospitals NHS Foundation Trust
RBS	Alder Hey Children's NHS Foundation Trust
RR8	Leeds Teaching Hospitals NHS Trust
RCU	Sheffield Children's NHS Foundation Trust
RQ3	Birmingham Children's Hospital NHS Foundation Trust
RP4	Great Ormond Street Hospital for Children NHS Foundation Trust
RPY	The Royal Marsden NHS Foundation Trust
RA7	University Hospitals Bristol NHS Foundation Trust
RTH	Oxford University Hospitals NHS Trust
RHM	University Hospital Southampton NHS Foundation Trust
RGT	Addenbrookes Hospital, Cambridge University Hospitals NHS Foundation Trust
RTD	Newcastle Upon Tyne Hospitals NHS Foundation Trust
RX1	Nottingham University Hospitals NHS Trust

### Teenage and Young Adults PTCs

Trust Code	Hospital
RBV	The Christie NHS Foundation Trust
REN	The Clatterbridge Cancer Centre NHS Foundation Trust
RR8	Leeds Teaching Hospitals NHS Trust
RHQ	Sheffield Teaching Hospitals NHS Foundation Trust
RRK	University Hospitals Birmingham Foundation Trust
RRV	University College London Hospitals NHS Foundation Trust
RPY	The Royal Marsden NHS Foundation Trust
RA7	University Hospitals Bristol NHS Foundation Trust
RTH	Oxford University Hospitals NHS Trust
RMH	University Hospital Southampton NHS Foundation Trust
RGT	Addenbrookes Hospital, Cambridge University Hospitals NHS Foundation Trust
RTD	Newcastle Upon Tyne Hospitals NHS Foundation Trust
RX1	Nottingham University Hospitals NHS Trust

### Paediatric Oncology Shared Care Units (POSCU's)

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 Calwaladr University HealthBoard	1
RT9	North West Wales, Betsi Calwaladr University Health Board	1
RT9	Conwy & Denbeighshire, Betsi Calwaladr 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 Hertfordshire 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	QE, Woolwich – now 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	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
	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 NHS Trust	3
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	Cambridge Community Services NHS 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

## SECTION B PART 6 - NON-TARIFF AND VARIATIONS TO TARIFF PRICES

The following national currency has been mandated for chemotherapy delivery from April 2012 Onwards. It is expected that a national tariff will be adopted in 2013/14.

SB11Z	Deliver exclusively Oral Chemotherapy
SB12Z	Deliver simple Parenteral Chemotherapy at first attendance
SB13Z	Deliver more complex Parenteral Chemotherapy at first attendance
SB14Z	Deliver complex Chemotherapy, including prolonged infusional treatment at first attendance
SB15Z	Deliver subsequent elements of a Chemotherapy cycle
SB16Z	Procure Chemotherapy drugs for regimens not on the national list
SB17Z	Deliver chemotherapy for regimens not on the national list

## SECTION B PART 8 - QUALITY

### Section B Part 8.1: Quality Requirements – chemotherapy

Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
	Clinical trial entry rates of children, teenagers and young adults.			
	Ensure that target of 100% of cancer patients discussed at the multidisciplinary team is met	100%		
	% of patients or parents/carers receiving written treatment plan	100%		
	% cancer patients getting chemotherapy treatment as recorded at multidisciplinary team	80%		
	The results of service monitoring should be discussed at least six monthly and documented evidence of capacity planned.	100%		
	100% 31 day targets being met for patients receiving chemotherapy as a first Treatment	100%		
	100% 62 day target being met for patients receiving chemotherapy as a first treatment	100%		
	100% patients to wait no longer than a maximum 31 day wait for second or subsequent treatment – anticancer drug regimens	100%		
	Proportion of treatments commenced within 30 minutes of	80%		

	appointment			
	100% of cancer patients/parents and carers are involved in decisions about chemotherapy treatment available.	100%		
	% use/ uptake of CDF against allocation			
	Minimum 80% compliance taken from CQUINS (Cancer Quality Information System), reviewed against the Manual for Cancer Services Chemotherapy Services	80%		
	100% of cancer patients have access to services required in toxicity management 24 hours a day.	100%		
	Audit of 30 mortality of chemotherapy audit results to be available and discussed on a quarterly basis.	100%		
	Audit Proportion of patients needing admission for complications of chemotherapy			
	Neutropenic pathway achievement of 1 hour door to needle time for antibiotics in and out of hours			

### Section B Part 8.2: Nationally Specified Events

Technical Guidance Reference	Nationally Specified Event	Threshold	Method of Measurement	Consequence per breach
PHQ03-05	Proportion of patients receiving first definitive		Review of monthly Service Quality Performance	2% of the Actual Outturn Value of the service

	<p>treatment for cancer within 62 days of</p> <ul style="list-style-type: none"> <li>- an urgent GP referral for suspected cancer</li> <li>- referral from an NHS Cancer Screening Service</li> <li>- following a consultant's decision to upgrade the patient priority</li> </ul>	<p>Operating standard of 85%</p> <p>Operating standard of 90%</p>	Report	line revenue
PHQ06	Percentage of patients receiving first definitive treatment within one month of a cancer diagnosis	Operating standard of 96%	Review of monthly Service Quality Performance Report	2% of the Actual Outturn Value of the service line revenue
PHQ07	Proportion of patients waiting no more than 31 days for second or subsequent cancer treatment - surgery	Operating standard of 94%	Review of monthly Service Quality Performance Report	2% of the Actual Outturn Value of the service line revenue
PHQ08	Proportion of patients waiting no more than 31 days for second or subsequent cancer treatment – drug treatments	Operating standard of 98%	Review of monthly Service Quality Performance Report	2% of the Actual Outturn Value of the service line revenue

PHQ09	Proportion of patients waiting no more than 31 days for second or subsequent cancer treatment (radiotherapy treatments)	Operating standard of 94%	Review of monthly Service Quality Performance Report	2% of the Actual Outturn Value of the service line revenue
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### Section B Part 8.3: Never Events

Never Events	Threshold	Method of Measurement	Never Event Consequence (per occurrence)
Wrongly prepared high-risk injectable medication	>0	Review of reports submitted to National Patient Safety Agency (or successor body)/Serious Incidents reports and monthly Service Quality Performance Report	In accordance with applicable Guidance, recovery of the cost of the procedure and no charge to Commissioner for any corrective procedure or care
Wrong route administration of chemotherapy	>0	Review of reports submitted to National Patient Safety Agency (or successor body)/Serious Incidents reports and monthly Service Quality Performance Report	In accordance with applicable Guidance, recovery of the cost of the procedure and no charge to Commissioner for any corrective procedure or care
Wrong route administration of oral/enteral treatment	>0	Review of reports submitted to National Patient Safety Agency (or successor body)/Serious Incidents reports and monthly Service Quality	In accordance with applicable Guidance, recovery of the cost of the procedure and no charge to Commissioner for any corrective

		Performance Report	procedure or care
Intravenous administration of epidural medicine	>0	Review of reports submitted to National Patient Safety Agency (or successor body)/Serious Incidents reports and monthly Service Quality Performance Report	In accordance with applicable Guidance, recovery of the cost of the procedure and no charge to Commissioner for any corrective procedure or care

## **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 (HSC 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 minimize 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 Inter-Dependencies – 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 the network.
- 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.<sup>1</sup> 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) training<sup>2</sup> and should maintain the competencies so acquired<sup>3</sup> \*. 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 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. GPAS Paediatric anaesthetic services. RCoA 2010 [www.rcoa.ac.uk](http://www.rcoa.ac.uk)
2. CCT in Anaesthesia 2010
3. 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 persons 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 persons 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 College**

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 a 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 2RCNs 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.
- Participates 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.
- 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:

- Ensures the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability ensuring that staff handling medicines have the competency and skills needed for children and young people's medicines management
- Ensures 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

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