E03/S/g

2013/14 NHS STANDARD CONTRACT
FOR PAEDIATRIC MEDICINE: RESPIRATORY

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

Service Specification No.	E03/S/g
Service	Paediatric Medicine: Respiratory
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Respiratory conditions are the most common cause of paediatric hospital admission, accounting for 14% of UK hospital admissions and over 50% of long term illnesses in children. Asthma is the most common cause of school absence, and cystic fibrosis (CF) the most common lethal inherited condition. The incidence of allergic disease and asthma has increased over the last 20 years and this rise may continue. Changing expectations from parents and professionals are increasing the demand for more intensive respiratory intervention in neurological diseases. It is now recognised that several conditions, such as primary ciliary dyskinesia, non-CF bronchiectasis and sleep disordered breathing are currently underdiagnosed, leading to preventable morbidity. The incidence of empyema has increased over the past 10 years and is best treated in tertiary centres; the epidemiology of this and other pneumonic infections may change with changes in the infant immunisation programme. In 2009/10, 933 children under the age of 17 years in 30 regional centres were identified as receiving long term ventilation (LTV) and many other children receive some kind of respiratory support at home.

Paediatric respiratory medicine covers many disorders (see 2.2) and the epidemiology will vary per condition: e.g. each congenital lung disease has a prevalence of 1 in 10,000 -1 in 30,000 live births; primary ciliary dyskinesia occurs in 1 in 16,000 live births; inherited neuromuscular disease has a prevalence of 1 in 3000 but perhaps only 1 in 30,000 will require respiratory intervention.

Evidence on need for and access to tertiary care is available in the British Thoracic Society (BTS) Standards of Care Guidelines for Specific Disorders (Section 3.1) and National Institute of Health and Care Excellence (NICE) guidance:

NICE clinical guideline:
- Tuberculosis, 2011
- Respiratory tract infections, 2008

NICE technology appraisals:
- Asthma (children under 5) – inhaler devices, 2000
- Asthma (older children) – inhaler devices, 2002.
- Asthma (in children) – corticosteroids, 2007
- Asthma (uncontrolled) – omalizumab, 2007.
- Asthma (in children) – omalizumab, 2010.

2. Scope

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.

2.1 Aims and objectives of service:

- To provide optimal family-centred specialised care for children with respiratory illness
- To prevent complications and progression of disease
- To improve and maintain lung function in children
- To minimise hospital admission

The service will:
- provide timely and accurate diagnostic services. provide high quality proactive treatment and care
- ensure appropriate monitoring of condition and treatment liaise with and support secondary and primary care providers
- ensure effective communication between patients, families and primary and

secondary care providers
- support patient and families in independent care of their condition.
- ensure smooth and managed transition to adult care as appropriate.

2.2 Service description/care pathway

Overall:

- Referral from secondary or tertiary care
- Initial outpatient or inpatient assessment
- Diagnostic tests
- Initial management as inpatient or outpatient
- Development of long term management plan
- Review and further management either solely in tertiary care or as part of shared care pathway with secondary care
- Eventual outcome either discharge to secondary/primary care or transition to adult services.

Common paediatric respiratory conditions are managed in local hospitals or primary care settings, but complex and rare conditions are managed in conjunction with a specialist paediatric respiratory centre. These children are assessed and treated on an out-patient, inpatient and day case basis by the specialised multi-disciplinary team (MDT). Treatment and follow up of many of these conditions are life-long and planned transition to adult services takes place via joint and/or hand-over clinics.

The specialist respiratory service works as part of a clinical pathway with colleagues in secondary care to provide care for children with difficult or complex respiratory disorders as near to their home as is possible. Much of the work is done on an ambulatory basis with an outpatient and diagnostic service for patients whose care is shared with secondary providers and inpatient services often working closely with other tertiary paediatric specialists *(Department of Health Interdependency Framework). Support via outreach services is often needed for children with complex respiratory disorders, typically those requiring respiratory support from a portable ventilator and those with artificial airways (either tracheostomy or nasopharyngeal tubes). Outreach work by members of the specialist team**extends to:
- shared care outpatient clinics in secondary providers; local paediatrician should be present
- support for ward staff in secondary providers, and community staff as appropriate
- support to patients and staff in palliative care facilities
- support to patients and carers and families in the home
- education and support to secondary care multidisciplinary teams is important
- part of role

A specialist team** would consist as a minimum of:

- Consultant trained in paediatric respiratory medicine
- Specialist respiratory nurse
- Specialist respiratory physiotherapist
- Lung function technician; sleep technician/physiologist; with access to a
- specialist dietician, clinical psychologist, speech & language therapist, occupational therapist, and social worker.

Other infrastructure required

The facilities and ability to perform a range of investigations:

- Flexible bronchoscopy
- Complex pulmonary function testing incl. exercise testing
- Nitric oxide measurement
- Sleep studies (multichannel polysomnography and overnight oximetry and
- capnography)
- Sweat testing
- Allergy testing
- High resolution CT and other complex respiratory imaging

And access to:

- Bronchography
- Open lung biopsy
- Complex immunology tests
- pH study
- Video fluoroscopy
- Echocardiography
- Rigid bronchoscopy

Access to in-patient services: 24 hours / seven days a week Day case: 5 days a week Monday to Friday
Outpatient clinics: 5 days a week Monday to Friday; including outreach activity
Access to tertiary advice for secondary care provider colleagues 24 hours / seven days a week.

Interventions and investigations provided by the specialist respiratory team include:

- flexible bronchoscopy and bronchography
- complex pulmonary function testing (excluding peak expiratory flow rate and
- simple spirometry)
- sleep studies (full polysomnography and overnight oximetry and capnography)
- nasal ciliary brushings

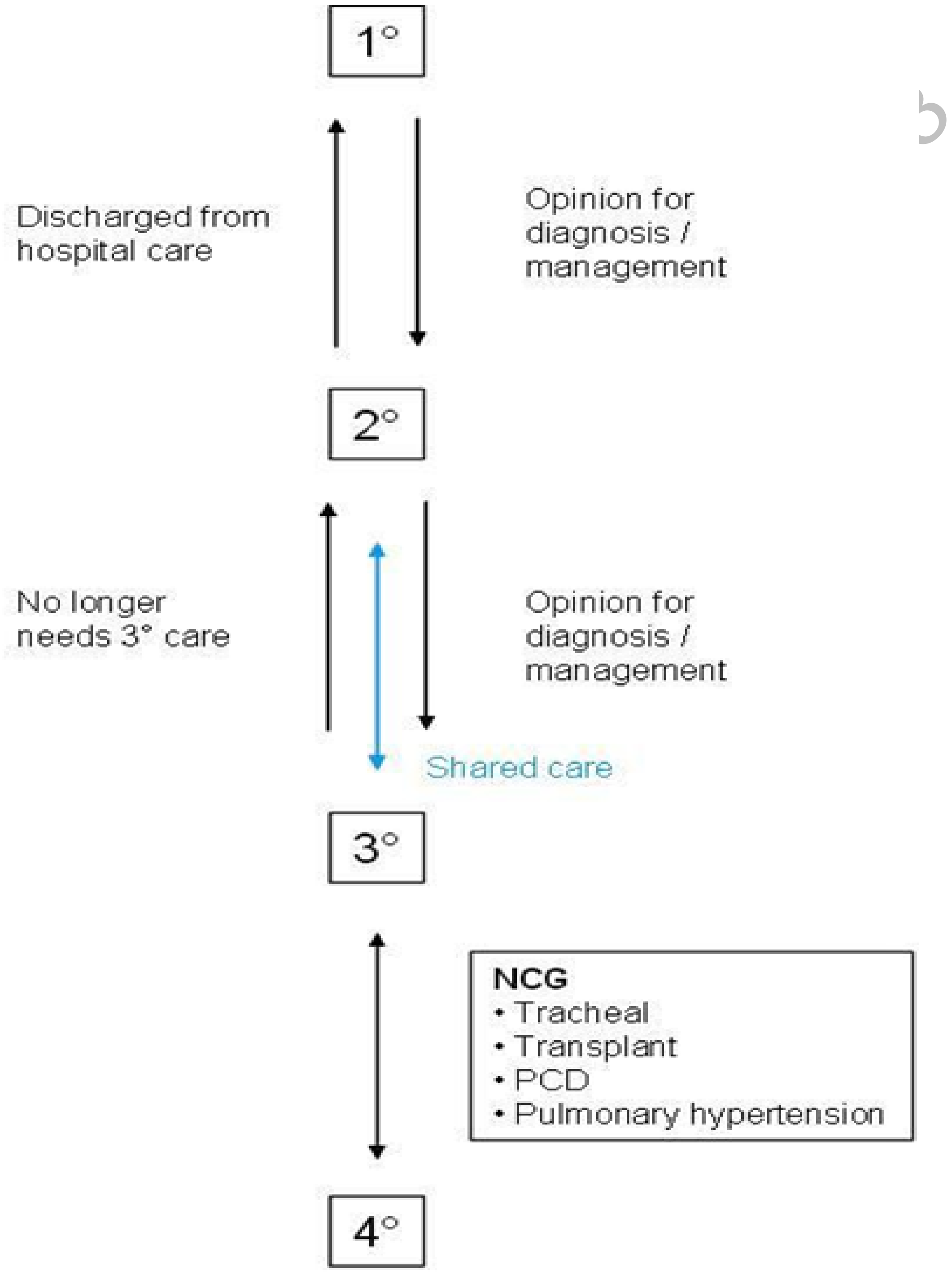
- exhaled and nasal nitric oxide
- sweat testing
- high resolution CT and other complex respiratory imaging.
- investigation of pulmonary hypertension
- lung biopsy
- chest drain insertion and management
- access to rigid bronchoscopy and airway intervention
- training in the use of assistive technologies such as use of cough assist
- machines, invasive and non-invasive ventilators etc

Specific devices, the use of which should be initiated and monitored by tertiary care:

- Ventilators for use at home via tracheostomy
- Ventilators for use at home via mask (non invasive ventilation)
- Cough-assist devices for use at home

Ventilators, and cough-assisted devices and their maintenance, will be provided within the contract. Community care packages will be planned in conjunction with community teams but the funding for the packages will not be covered by this contract.

The pathway from secondary to tertiary care and then to shared care or discharge will vary with the condition and is illustrated below:


1°
Discharged from hospital care
Opinion for diagnosis / management
2°
No longer needs 3° care
Opinion for diagnosis / management
Shared care
3°
NCG
• Tracheal
• Transplant
• PCD
• Pulmonary hypertension
4°

Some examples of pathways –

Difficult to control asthma:

1° ⇨ 2° ⇨ 3° ⇔ 2° shared care and acute admissions. Majority of cases looked after in 1° or 2° care. Difficult asthma e.g. stage 3 or 4 but still symptomatic esp. if high dose inhaled corticosteroids, and all stage 5 (aged 5+ yrs) or stage 4 (<5 yrs) as per SIGN/BTS 2011 guideline.

Congenital lung and airway disease:

2° ⇨ 3°. Referral sometimes from antenatal service for prenatal counselling, or from neonatal unit once baby born. Investigation e.g. computerised tomography(CT) scan performed at 3° unit with decision for surgery or conservative treatment. Follow-up depending on condition initially at tertiary unit then either shared/secondary or discharge to primary care

Rare lung disease e.g. Interstitial lung disease, Obliterative Bronchiolitis, pulmonary haemosiderosis:

2° ⇨ 3° Initial referral for diagnosis. May include open lung biopsy at 3° centre. May be another referral for 2nd opinion. Will usually then involve shared care 2° ⇔ 3°.

Diagnostics e.g. recurrent infections, chronic cough:

2° ⇨ 3° * For diagnosis incl. investigations e.g. CT scan, bronchoscopy etc., as per British Thoracic Society (BTS) guidelines on chronic cough 2008 and non-CF bronchiectasis 2010. Depending on diagnosis, may stay 3°, shared care with 2°, or back to 2°/1°.

Complicated pneumonia/other infection:

2° ⇨ 3° for complicated pneumonia e.g. empyema, necrotising pneumonia as per BTS guidelines for pleural infection 2005 and community acquired pneumonia 2011. Usually discharged home with short 3° follow-up, unless underlying disease diagnosed.

Sleep disordered breathing:

2° ⇨ 3° for diagnostics and sleep studies. Depending on diagnosis and management, may require further sleep studies and 3° care or back to 2°

e.g. for ear, nose and throat (ENT) surgery. Some children may be diagnosed with a disorder that requires long term ventilator support.

Long term ventilatory support (non-invasive or via tracheostomy):

For cases requiring ventilation, 3° ⇔ 2° shared care. 3° for sleep studies and adjustments of non-invasive ventilation (NIV) mode etc, but 2° for initial assessment and most acute admissions e.g. during infective exacerbation.(sometimes 3°) For those ventilated via tracheostomy 3° may be necessary for infective exacerbations. As per Royal College of Paediatrics and Child Health (RCPCH) Standards for services for children with disorders of sleep physiology 2009. Long term care and eventual transition to adult services.

Chronic neonatal lung disease:

2° /3° ⇨ 3°. Referral usually from Neonatal Service either while baby still on neonatal intensive care unit (NICU), or post discharge. Former tends to be those with the most severe disease, especially if require home NIV/tracheostomy. Latter tends to be baby still requiring home oxygen after prolonged period, as per BTS guidelines on Home Oxygen in Children 2009, which recommends referral after 1 year to rule out concomitant diagnoses. Then shared care and eventual discharge to 2° or 1° care.

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 with respiratory conditions requiring specialised intervention and management, as outlined within this specification. Each tertiary service will provide support for the surrounding childhood population in partnership with their local secondary care services.

2.4 Any acceptance and exclusion criteria

Acceptance criteria

- This service will accept inward referrals from secondary or other tertiary care
- clinicians. The service will also accept referrals from highly specialised services
- for shared care of patients including: complex tracheal disease; primary ciliary dyskinesia; pulmonary hypertension; lung transplantation .
- The service will accept referrals for any of the conditions listed in the scope above.
- The service will operate on a shared care multi-disciplinary basis

Exclusion criteria

- Shared care protocols will specify exclusion criteria along with the standard age limit of up to day before the 19th birthday
- Highly specialised services include those for complex tracheal diseases; primary ciliary dyskinesia (PCD) service; heart, lung and heart & lung transplantation service; ventricular assist devices (VAD) service; and/or extracorporeal membrane oxygenation(ECMO)
- (ECMO) as a bridge to heart transplant service is also a highly specialised service
- Highly specialised services are covered by a separate service specification
- Cystic fibrosis is commissioned separately and is not included in this service

2.5 Interdependencies with other services

A specialist respiratory service provides services to and is co-dependent on a number of other paediatric services, Department of Health Report, 2008, “Commissioning a Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies.”

Co-located services:

- High quality paediatric radiology
- paediatric critical care
- paediatric surgery
- paediatric ear nose and throat (ENT)
- paediatric anaesthesia (as described in the Department of Health report above)

Interdependent services:

- Paediatric cardiology
- Paediatric neurology

- Paediatric gastroenterology
- Paediatric endocrinology
- Paediatric infectious diseases
- Paediatric immunology
- Paediatric psychology

Related services:

- Paediatric oncology
- cleft lip and palate
- craniofacial and spinal services
- palliative care, secondary and primary care providers

3. Applicable Service Standards

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

The service will be provided from a child facility with equipment to national standards and co-location with other paediatric specialties. DH Report 2008 "Commissioning a Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies."

A specialist team would consist as a minimum of:
- Consultant trained in paediatric respiratory medicine
- Specialist respiratory nurse
- Specialist respiratory physiotherapist
- Lung function technicial
- Sleep technician/physiologist

With access to a specialist dietician, clinical psychologist, speech & language therapist, occupational therapist, and social worker.

Standards of Care

Available from the British Thoracic Society (BTS) - www.brit-thoracic.org.uk
- BTS asthma guidelines 2011
- BTS assessment and management of cough in children guidelines 2008
- BTS community acquired pneumonia in children guidelines 2011
- BTS air travel guidelines 2011
- BTS pleural infection in children guidelines 2005
- BTS spontaneous acquired pneumothorax guidelines
- BTS neuromuscular disease guidelines 2012
- BTS Guideline for non-CF bronchiectasis. 2010.

- BTS Guideline for home oxygen in children. 2009.

Working party on sleep physiology and respiratory control disorders in childhood, Royal College of Paediatrics & Child Health, 2009. Discharge processes must ensure timely and appropriate communications with services who are expected to provide other parts of the patient’s pathway in compliance with national guidance.

4. Key Service Outcomes

General outcomes

- To minimise mortality and morbidity by providing the most appropriate care for children with respiratory disease
- To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children with respiratory disease.
- To ensure children with respiratory disease are treated in line with national guidelines and agreed local pathways.

Specific outcomes

Maintenance or improvement in lung function (in the conditions where this is measurable) to enable normal activities of daily life. Each service to maintain disease specific database of patients. A national model database will be developed to permit national registry of respiratory disorders with annual outcomes to permit comparison between services and patients and to facilitate future research. Each service to take part in national audits eg BTS Asthma and Pneumonia Audit.

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 fundamental to all services.

The generic aspects of care:
The Care of Children in Hospital (Health Service Circular (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 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 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(CPD)
- 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. Guidline for Providios of Anaesthetics(GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists RCoA 2010 www.rcoa.ac.uk
2. Certificate of completed training (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,accreditationaudit/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 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 which 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 about 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

Appendix 1

Conditions managed by the specialist respiratory team include:

- Difficult to control asthma (patients who remain symptomatic on Step 3-4 or are on step 5 of BTS asthma guideline)
- congenital lung and airway disease (congenital cystic adenomatoid malformation, sequestration, congenital lobar emphysema, diaphragmatic hernia, tracheo-oesophageal fistula) including follow up of surgically treated patients
- rare lung disease e.g. chronic/obliterative bronchiolitis, other interstitial lung diseases, pulmonary haemosiderosis, pulmonary alveolar proteinosis
- empyema, parapneumonic effusion and pneumothorax
- bronchiectasis and obliterative bronchiolitis
- chronic cough (i.e. as defined in British Thoracic Society guidelines
- chronic neonatal lung disease with comorbidity
- lung disease associated with primary and secondary immunodeficiency
- complicated pulmonary tuberculosis (in conjunction with infectious diseases specialist)
- restrictive and chronic lung disease associated with thoracic dystrophy, severe scoliosis and neuromuscular disease
- sleep disordered breathing - disorders of respiratory control and those caused by upper airway obstruction
- acute and chronic airway problems including management of artificial airways (in conjunction with paediatric ENT, cleft and craniofacial specialists)
- home respiratory support i.e. invasive and non invasive ventilation and home oxygen
- shared care of patients covered by the highly specialised service specification including: complex tracheal disease; primary ciliary dyskinesia; pulmonary hypertension; lung transplantation.