

B06/S/b

**2013/14 NHS STANDARD CONTRACT  
FOR SPECIALISED HUMAN IMMUNODEFICIENCY VIRUS SERVICES  
(CHILDREN)**

**SECTION B PART 1 - SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	B06/S/b
<b>Service</b>	Specialised Human Immunodeficiency Virus Services (Children)
<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**

Human Immunodeficiency Virus (HIV) is a virus that infects and destroys cells responsible for combating infections, leaving the body susceptible to infections it would normally be able to fight. Without treatment, the immune system can be compromised and rare infections and later cancers can develop. In children, infection is almost always vertically transmitted from the mother, meaning that HIV is a disease that can affect the whole or part of a family and care must therefore be family centred. Particular challenges in the care of children include adherence in young children for whom there are limited formulations of drugs, and adolescents, supporting families that are often socially disadvantaged, providing staged information to children about their diagnosis prior to full disclosure and the support of adolescents prior to and during transition to adult care. Multidisciplinary team working is an essential part of paediatric HIV care as is the interface with social care, safeguarding teams and the voluntary sector. Networked arrangements are already in place (The Children's HIV National Network – CHINN) which reduce inequalities in access to specialist paediatric HIV outpatient care.

In the UK there are currently around 1200 children infected with HIV. Approximately half of these children have been born abroad and the median age of the cohort is around 11 years. All children diagnosed with HIV in the UK are reported to the NSHPC (National Study of HIV in Pregnancy and Childhood) and are followed up as the CHIPS cohort (Collaborative HIV Paediatric Study). The data set on these children is updated annually, thus CHIVA (Children's HIV Association) have excellent current information on the epidemiology of paediatric HIV in the UK as well as annual updates on case

management. Recent mathematical modelling (2009) of the UK paediatric HIV population growth over the last 5 years by the CHIPS team has demonstrated a nationally relatively stable population number for the next 5 years ahead (for further information contact [www.chipscohort.ac.uk](http://www.chipscohort.ac.uk)) with slightly more new patients entering the cohort than older children moving to adult care.

The vast majority of children with HIV in the UK are infected through mother-to-child transmission. Distribution of cases within the UK has changed from a predominance of cases in London to an equal distribution between London and the rest of the country. The proportion of children living and receiving care outside London continues to grow. Overall mortality among children with HIV has reduced considerably since the introduction of highly active antiretroviral therapy (HAART). High uptake of antenatal testing, reduced transmission rates from diagnosed women, improved survival following HAART and later age at presentation among those born abroad mean that the average age of perinatally infected children and young people in the UK continues to rise.

HIV has become a chronic condition of childhood with the likelihood of survival well into adult life; therefore, development of appropriate services for long-term paediatric survivors has become an important goal for the 21st century.

Locally, prevalence will vary as will the nature of the patient cohort. Services need to be responsive to these variations.

### **Key Guidelines**

- CHIVA Standards of Care for Infants, Children and Young People with HIV 2013
- BHIVA Pregnancy Guidelines 2012
- 'Don't Forget The Children ' Guidance on the testing of children of HIV positive parents 2009
- [www.chiva.org](http://www.chiva.org)
- PENTA (Paediatric European Network for the Treatment of AIDS) Treatment Guidelines 2009 (and 2013 update due soon)

## **2. Scope**

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

#### **Aims**

The aim of the service is to provide a consistent, effective and appropriate family centred paediatric HIV outpatient and inpatient service which ensures that children remain safe and well (reduced morbidity from the complications of HIV infection and its treatment and continuing low mortality) and have access to the same standards of care wherever they live in the UK. Services must be delivered by a multidisciplinary, consultant led team with networked arrangements informed by and in line with the relevant guidelines and CHIVA standards.

## Objectives

The service will deliver these aims by:

- Ensuring that all children infected with HIV are diagnosed and access care as soon as possible either via an outpatient, or more rarely inpatient, route.
- Providing high quality specialist outpatient and inpatient care for new, stable and complex patients and supporting families to remain engaged with both specialist HIV services and mainstream care services.
- Delivering services by a multidisciplinary, consultant led team with networked arrangements to balance quality of care, productivity and access. Assurances that all requirements for qualifications, revalidation, CPD (Continuing Professional Development) and audit within the network must be demonstrated.
- Ensuring that all pregnant women are recommended to have an antenatal HIV test and those who decline are encouraged to review the decision and be seen by a specialist midwife. Those women who present untested late in pregnancy or in labour should be recommended to have a rapid HIV test and those who have refused an HIV test in pregnancy should be strongly advised to have the infant tested as soon as possible after birth.
- Involving and engaging with other services, including social care, psychology support and the voluntary sector, as appropriate to ensure the holistic needs of families living with HIV are met and to help reduce prejudice and stigma.
- Promoting the testing of all the children of HIV positive adults in a timely fashion which will include taking a careful family history and regularly reviewing the country of residence of the children.
- Ensuring that infants of less than a year of age are started on antiretroviral treatment urgently and that PENTA guidelines for initiation of treatment are followed for older children, with families being offered the chance, where appropriate to participate in PENTA or other treatment trials.
- Contributing to the national surveillance of babies born to HIV positive mothers and new paediatric cases of HIV infection (NSHPC [www.nshpc.ucl.ac.uk](http://www.nshpc.ucl.ac.uk)) and the CHIPS cohort ([www.chipscohort.ac.uk](http://www.chipscohort.ac.uk)). Newly diagnosed young people who are >15 yrs old should be reported to the HIV and AIDS reporting section at the HPA (<http://www.hpa.org.uk/HPA/Topics/InfectiousDiseases/InfectionsAZ/1200660065903/>).
- Participating in and implementing the results of local, regional and national audits.

## 2.2 Service description/care pathway

- This specification identifies the requirements of specialised paediatric HIV services. These services will operate in a pathway which includes other services which will be commissioned at a local level. The effectiveness of the specialised services depends on other elements of the pathway being effectively coordinated.

## Service elements – overview

The paediatric HIV outpatient service comprises the following elements:

- Assessment and support of newly diagnosed children and their families by a multidisciplinary team led by a suitably qualified and trained paediatrician. This may

also include testing of other family members and onward referral to adult services if required.

- Management of infected children according to current PENTA guidelines/ CHIVA treatment pathways with all infants <1yr of age being started on treatment as a matter of urgency due to the risk of rapid disease progression.
- Screening, diagnosis and management of complications of HIV, antiretroviral therapy and non HIV co-morbidities.
- Close assessment and monitoring of children starting or changing treatment. Initiation or changes to treatment shall always be discussed in a treatment meeting either locally or virtually via CHINN.
- Provision of specialist pharmacy services with consideration of formulations suitable for younger children.
- Multidisciplinary support for children and families including paediatricians, specialist nurses, pharmacists, psychologists, physiotherapists, occupational therapists, play specialists, social workers and dieticians to develop knowledge of the child's condition, treatment and support adherence.
- Liaison with social care, safeguarding teams and the voluntary sector for non-specialised HIV care and support needs and services including psychological and peer support.
- Liaison with other teams involved in the care of the child and family including primary care, with the family's permission and adult teams, midwives, obstetricians, health visitors and schools.
- Antenatal counselling and support of pregnant women with HIV infection and postnatal prescribing of antiretroviral therapy (ART) / testing of the infant as part of the prevention of mother to child transmission (PMTCT).
- Provision of advice to other specialties in the Trust regarding HIV testing and management and to GPs / primary care.
- An in depth annual review for each child including HIV disease parameters, growth and development, treatment including adverse events and side effects, family circumstances and educational progress.
- Immunisation of children with HIV in line with PENTA and CHIVA guidance and in partnership with primary care.
- An individual transitional care plan for each young person to facilitate a smooth and timely transition to adult care and developed in consultation with the young person.
- Operate within agreed local documented pathways / networked arrangements.

In addition, services providing complex outpatient services will provide:

- Virtual clinic arrangements for management of children with adherence issues or resistance.
- Management or advice regarding co-infections with TB, Hepatitis or other co-infections or co-morbidities including malignancies.
- Specialist joint clinics depending on local prevalence and cohort including family clinics, adolescent clinics and pregnancy clinics.
- Operation within agreed local documented pathways / networked arrangements.

The paediatric HIV inpatient service comprises the following elements :

- Assessment, diagnosis and management of opportunistic infections related to HIV infection and following CHIVA protocols.

- Assessment, diagnosis and management of complications of HIV therapy such as immune reconstitution syndrome (IRIS) and drug side-effects.
- Initiation of treatment for children presenting with symptomatic HIV requiring inpatient care.
- Provision of specialist advice relating to HIV for inpatients with non- HIV related admissions.
- Facilitation of effective care on discharge.

### **Service elements – networks of care**

All children should have access to the same standard of care across the UK wherever they live and will generally benefit by accessing healthcare closer to home through networked arrangements. Networks for the care of children infected with HIV were established in London in 2004 and for children outside of London in the Children's HIV National Network (CHINN) review in 2005 based on a hub and spoke model.

### **The Children's HIV network (CHINN)**

The CHINN network established in 2005 provided every hospital in the UK looking after children with HIV with direct access to advice from larger centres in London. In 2013, care is provided directly to children outside London by regional centres with access to regional CHIVA networks ( in England – North East, North West, Midlands, South and South West and London and South East ) with access to national CHIVA guidelines and conferences, regional educational meetings and advice from regional and national centres when required.

The changing nature of paediatric HIV infection, with a possible decline in numbers in the future, means that formal networked arrangements for care will continue to be required to protect quality, improve productivity and continue to enable access relevant to local needs. The arrangements for care must be documented to make it clear to patients and care providers how pathways operate. All patients need to have access to a multidisciplinary team although some parts of this may only be delivered in the lead centres. In some areas centralisation of services may occur whereas in more geographically remote locations hub and spoke arrangements may be more appropriate and commissioning arrangements will be with the lead centres. Greater use of technology may lead to more virtual management of stable patients.

### **Service elements – detailed pathway inclusions – HIV centres / lead hubs**

More specialised aspects of paediatric HIV care will be provided through an HIV centre or lead hub which may be on a single site or may take the form of a 'virtual HIV centre' comprising an interlinked cluster of a small number of providers within a network where the role of each provider will be clearly defined regarding inpatient care and the ability to provide other specialised services.

Ongoing clinical care for children with diagnosed HIV infection will be via a multidisciplinary team led by a consultant qualified to provide such care. Services will include the following, either directly or via networked arrangements:

- Appropriate facilities relevant to the age of the child including a dedicated outpatient waiting area and consultation and treatment rooms which allow

confidentiality.

- Assessment and routine monitoring of children infected with HIV and monitoring of ARV therapy according to current CHIVA treatment pathways / PENTA guidelines.
- Appropriate laboratory services with access to all the relevant tests recommended in CHIVA guidelines for monitoring patients on and off treatment.
- Access to age appropriate written information which can be used in the disclosure process.
- Clearly defined arrangements for network access to all HIV centre services including 24-hour advice and publication of arrangements to local general paediatric services and accident and emergency services.
- Access to specialist nursing within the local area.
- Specialist pharmacist support.
- Access to emotional and psychological assessment and support for the whole family provided by either psychology services or delivered in partnership with community or voluntary sector providers.
- Facilitation of home delivery of drugs where feasible.
- Complete and accurate patient records in line with NHS standards of confidentiality and clinical safety.
- Processes for completion of national surveillance data and audit.

### **Service elements – detailed pathway inclusions – outpatient services**

As a minimum paediatric HIV outpatient services will provide:

- Assessment of newly diagnosed symptomatic children on the day of referral and within 2 weeks for those which are asymptomatic or transferring from elsewhere.
- Assessment, monitoring and management of children by an appropriately qualified MDT under the supervision of a suitably qualified paediatric consultant directly available or through documented networked arrangements.
- Documented network arrangements to achieve 24hr on-call advice which must be available to all general paediatric and emergency departments in the area.
- Cost effective prescribing in line with CHIVA and PENTA treatment guidelines.
- Complete and accurate patient records in accordance with NHS standards of confidentiality and clinical safety and record keeping guidance. This is particularly relevant in children who are transferring care and transfer of records / detailed handover shall occur within 2 weeks.

### **Service elements – detailed pathway inclusions – inpatient services**

Tertiary providers of inpatient care must be staffed by enough qualified consultants to operate a sustainable 24hr rota. HIV centres must be able to ensure that they accept referrals in a timely manner and within 24-48 hrs.

Inpatient care of HIV infected children for general paediatric conditions may take place in the district general hospital setting with advice from the lead hub if required e.g. with regard to drug therapy.

### **Service elements – Staffing and critical mass**

Recommendations regarding staffing levels in lead hub centres, regional hub centres, spoke centres and local centres are outlined in the CHIVA Standards of Care 2013.

Medical staff in the lead hub centres must be able to work across organisational boundaries and support colleagues elsewhere on a 24/7 basis. Requirements for qualifications, training and CPD are set out by the professional bodies relevant to each specialty in the MDT.

### **General Paediatric care**

When treating children, the Service will additionally follow the standards and criteria outlined in the Specification for Children's' Services.

## **2.3 Population covered**

### **Patients covered by NHS England**

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:

[http://www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyAndGuidance/DH\\_127393](http://www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyAndGuidance/DH_127393)

From October 2012, regulations will change to include HIV care and treatment as an exemption to the charging regulations.

(\*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)

### **Specific patient group covered**

The provision of HIV outpatient and inpatient care and treatment services for infants, children and young people with HIV infection ( including pregnant mothers with HIV infection and their infants).

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

### **Acceptance / Entry criteria**

The service will accept inward referrals from:

- Adult HIV services – which may include testing of children of positive parents
- General paediatrics
- Primary care
- Obstetrics
- Accident and emergency
- Other specialised HIV services where families wish to transfer care
- Parents of children who move into the area and are already known to be HIV

positive.

All children will have equal access to care and treatment services irrespective of their geographical location, gender, race or disability. Symptomatic children will be seen on the day of referral and may need admission to hospital. Asymptomatic children will be seen by a suitably qualified consultant within 2 weeks of referral.

### **Discharge and exit criteria**

Until transition, children will not be discharged as they need ongoing monitoring and treatment. Discharge will only occur where:

- Families transfer their care between specialist providers or where shared care arrangements are in place – patient information must be transferred within 2 weeks.
- Families become lost to follow-up – services will need to have a policy to demonstrate how they aim to ensure retention in care.
- A child dies or leaves the UK.

### **Transition**

Transition is a critical and complex time for young people who may feel very anxious about the transfer to a new service. Transition shall be effective and planned with each young person having an individualised plan of transition in line with CHIVA and HYPNet (HIV in Young People Network) guidance. Sexual health education shall take place in a timely manner prior to transition and shall be documented.

### **Exclusions**

The following are excluded from the specialised HIV service for children:

- Adults – while adults are usually defined as being 19 yrs or over – some young people of this age may still be completing their transition process. In addition, there will be involvement of the specialised paediatric HIV team in the counselling of HIV positive pregnant women as part of the prevention of mother to child transmission (PMTCT).
- Non HIV care needs of a paediatric HIV patient, recognising that children with HIV have increased need for protection from infectious diseases, including immunisation, as part of their HIV related clinical need.
- Prescribing of ARVs for hepatitis mono-infection – this is commissioned as part of the Infectious Diseases specification.
- HIV treatment and care provided through clinical trials.
- New treatments / ARVs until agreed with commissioners.

For inpatient care, the following exclusions apply:

- Any other activity not covered in the specification must be raised by the provider with the commissioner for prior approval and written confirmation provided by the commissioner that this will be funded. . .



## **2.5 Interdependencies with other services**

### **Co-located services**

For routine paediatric HIV outpatient care there are no essential service location requirements.

For complex paediatric HIV outpatient and inpatient care in the lead centres, the requirements include access to:

- General paediatric care
- Paediatric intensive care
- Hepatology
- Endoscopy
- Specialised microbiology services
- Respiratory medicine including isolation and negative pressure facilities
- Oncology
- Neurology / neurosurgery

### **Interdependent services**

For routine paediatric HIV outpatient care, the interdependent service requirements include:

- A full range of diagnostic imaging and pathology services.
- HIV virology including interpretation of resistance patterns.
- Access to specialist nurses, pharmacists, psychologists, physiotherapists, occupational therapists, play specialists, dieticians, social workers and safeguarding teams. If these services are not available locally, they can be accessed within the network.
- Obstetric and midwifery services.
- Primary care.
- Voluntary sector and other community based services to provide support to children and families.
- Adult HIV and sexual health services.

For complex HIV outpatient care in the lead hub centres, the interdependent service requirements include access to:

- Endocrinology
- Renal medicine
- Haematology
- Oncology
- Dermatology
- ENT services
- Gastroenterology / endoscopy / hepatology
- Cardiology
- Ophthalmology
- Dental / oral medicine
- Psychology

- Obstetrics / midwifery services
- A full range of diagnostic imaging and pathology services
- HIV virology including interpretation of resistance patterns
- Access to specialist nurses, pharmacists, physiotherapists, dieticians, play therapists, social workers and safeguarding teams. If these services are not available locally, they can be accessed within the network
- Primary care
- Voluntary sector and other community based services to provide support to children and families
- Adult HIV and sexual health services

### **Related services**

Specialised HIV services for children are part of a pathway of care for children with HIV. Other parts of the pathway may be commissioned by Local Authorities, Clinical Commissioning Groups, Public Health England and NHS England. The effectiveness of the specialised services will depend on other elements of the pathway being effectively commissioned and co-ordinated. Agreed pathways will be required with the following services to deliver seamless care for children and families:

- Accident and emergency
- Primary care
- Adult HIV services
- Maternity services
- Voluntary sector HIV care and community support services
- Social care
- Psychology services

### **Currencies and coding**

Funding arrangements for specialist paediatric HIV services are currently very variable across the country. The CRG proposes that work needs to be undertaken to develop a national PbR tariff for outpatient services similar to the proposed adult year of care tariff with currencies of new, stable and complex patients. Of concern in paediatrics is the difficulty in applying such a tariff where the staff: patient ratio is high and patient numbers may decrease in the future.

## **3. Applicable Service Standards**

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

Key guidelines relevant to this specification can be found at [www.chiva.org.uk/professionals/health/guidelines](http://www.chiva.org.uk/professionals/health/guidelines) and include:

- CHIVA Standards of Care for Infants, Children and Young People with HIV (including infants born to mothers with HIV) 2013
- BHIVA UK National guidelines for HIV testing 2008
- HIV testing guidelines for children of HIV positive parents or siblings – testing pathway 2011

- 'Don't forget the Children' Guidance on the testing of HIV positive parents 2009
- Guidelines for the testing of looked after children at risk of blood borne infection
- Baseline investigations for children with HIV 2011
- Dietetic annual assessment form 2012
- Disclosure process recording chart 2011
- Talking to children 2011
- Management of dyslipidaemia in HIV infected children 2011
- Monitoring neurological and developmental outcomes 2011
- Influenza antiviral interactions 2011
- Baseline investigations for an infant/child starting on ART 2011
- PENTA Treatment guidelines 2009
- Vaccination of HIV infected children 2011
- Vaccination of HIV infected children with uncertain or incomplete immunisation status 2011
- Post exposure prophylaxis 2011
- Protocol to enhance adherence 2011
- Taking medication: A factsheet for parents 2011
- You and your medicine : A factsheet for young people 2011
- Pill swallowing technique 2011
- Treating opportunistic infections in HIV infected children – updated in 2013
- The child with HIV and a fever –updated in 2013
- The child with HIV and gastroenteritis 2011
- The child with HIV and respiratory illness 2011
- Guidance on the management of sexual and reproductive health for adolescents living with HIV 2011
- HIV in schools: Good Practice for Supporting Children Infected or Affected 2005
- CHIVA Guidance on Transition for adolescents living with HIV 2011
- BHIVA Guidelines for the management of HIV infection in pregnant women 2012
- Position statement on Infant Feeding in the UK
- Recommended perinatal care 2011

HIV surveillance reporting is required and mandatory

#### 4. Key Service Outcomes

##### Overview of outcome measures

The aim of the paediatric HIV specialised service is to provide a consistent, effective and appropriate family centred paediatric HIV outpatient and inpatient service which ensures that children remain safe and well (reduced morbidity from the complications of HIV infection and its treatment and reduced mortality) and have access to the same standards of care wherever they live in the UK.

Delivery of outcomes will be measured through CQUIN measures – yet to be determined, Quality Dashboard indicators / Public Health Outcome measures – yet to be determined and Key Performance Indicators.

Measurement of outcomes will rely on continuing complete data reporting to CHIPS. Outcome measures will be reported on an annual, quarterly or monthly basis to commissioners as per contract requirements and will be subject to annual review.

### **Key performance indicators**

Key performance indicators will relate to the CHIVA Standards of Care 2013—and will include process measures which are a proxy for the quality of outcome to be achieved. They may include the following:

- VL and CD4 data
- All infants on treatment
- Documentation of adherence
- Disclosure by secondary school age
- Evidence of psychological and emotional support
- Evidence of timely sexual health education
- Pregnancy / infant care plans
- Completion of growth charts
- Neurodevelopmental assessment
- Assessment of psychological health screening
- Annual review
- Documentation of immunisations including HPV and Hepatitis B
- Participation in PENTA trials
- Speed of access into care after diagnosis
- Suitably qualified MDT with evidence of qualification and CPD
- Reduction in treatment associated complications and development of drug resistance
- Improved adherence and compliance with treatment
- Evidence of testing of the UK resident children of HIV infected adults

## **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 shall 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 – DH

## Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' DOH 13732 March2010). 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 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 shall 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 shall 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 shall apply (<http://www.rcpsych.ac.uk/quality/quality accreditationaudit/qnic1.aspx>)
- Staffing profiles and training - essential QNIC standards shall 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 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 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 shall 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 shall 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 shall 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 shall meet the Standards for the Care of Critically Ill Children (Paediatric Intensive Care Society, London 2010).

There shall 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 shall 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 shall 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 shall 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 shall 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