

B08/S/a

**2013/14 NHS STANDARD CONTRACT
FOR SPECIALISED SERVICES FOR HAEMOGLOBINOPATHY CARE
(ALL AGES)**

SECTION B PART 1 - SERVICE SPECIFICATIONS

Service Specification No.	B08/S/a
Service	Specialised Services for Haemoglobinopathy Care (All Ages)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

National Context

The majority of haemoglobinopathies seen are Sickle Cell Disease (SCD) and Thalassaemia (SCD&T). Other very rare anaemias requiring lifelong transfusion and chelation, such as Blackfan Diamond anaemia and congenital sideroblastic anaemia amongst others, fall within the scope of this specification. Haemoglobinopathies are complex disorders which although often grouped together and managed by the same specialist team, have distinct clinical manifestations and treatments. Treatment differs significantly for the three main client groups i.e. children, adolescents and adults.

SCD predominantly affects black and African-Caribbean people, whilst thalassaemia mainly affects those of Asian and Mediterranean origin. The prevalence varies according to geographical area, being highest in urban ethnic populations, particularly the Greater London area, where about 60% of SCD patients live

There are about 1,500 patients with thalassaemia and 15,000 with SCD living in England at present. A large number are under 19 years of age. SCD is the most

common inherited condition in England, around 350 babies are born in England each year with SCD compared with 20-30 babies with thalassaemia.

Nearly all SCD affected children born in England, and the majority with thalassaemia, will be identified by the NHS Sickle Cell and Thalassaemia Screening programme. Other new patients may present through migration or late diagnosis.

Life expectancy for both conditions is progressively improving and is now likely to be in excess of 50 years. Maximising quality of life is an important factor in the organisation of care and in treatment decisions.

Haemoglobinopathy services were provided in over 120 acute trusts last year however specialised services are delivered from fewer than 20 centres across England.

The varied prevalence of haemoglobinopathies combined with the known difficulties in delivering care to minority groups has resulted in inequities in both the quality and access to high quality care. Improving the delivery of care for haemoglobin disorders is a challenge which will require close cooperation between all service providers and those commissioning services.

Evidence base

The table below provides a high level summary of standards, guidelines and quality requirements together with other additional evidence.

- The National Haemoglobinopathy Project: A guide to Effectively Commissioning High Quality Sickle cell and Thalassaemia Services (2011), East Midlands Specialised Commissioning Group.
- Quality requirements for health services for adults with haemoglobinopathies (2012) - (adult peer review).
- Quality requirements for health services caring for children and young people with haemoglobinopathies (2009) - (paediatric peer review).
- Royal College of Nursing – Caring for people with sickle cell disease and thalassaemia syndromes – a framework for nursing staff (2011).
- Sickle Cell Disease in Childhood – standards and guidelines for clinical care – second edition (2010). First edition 2006.
- Trans-cranial Doppler Scanning for Children with Sickle Cell Disease – standards and guidance (2009).
- Specialised Services National Definitions Set (SSNDS) 3rd edition – specialised haemoglobinopathy services (all ages) – Definition No. 38 (2009).
- Sickle Cell and Thalassaemia – Handbook for Laboratories (2009) third edition 2012, NHS Sickle Cell and Thalassaemia Screening Programme.
- Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2008) – second edition. First edition, 2005.
- Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (2008).
- Standards for the Linked Antenatal and New-born Screening Programme

Second Edition (2011), NHS Sickle Cell and Thalassaemia Screening Programme.

- Health Technology Assessments (HTAs) – there are a number of HTAs underway with direct relevance to SCD&T. These HTAs have been sponsored by the National Institute for Health Research (NIHR).
- Management of Sickle Crisis, NICE (2012).
- The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, A Sickle Crisis? (2008).
- Understanding the Contribution of sickle cell and thalassaemia specialist nurses: a summary report (2012), NHS Sickle Cell and Thalassaemia Screening Programme.
- Transition: Getting it Right for Young People, improving the transition of young people with long term conditions (2006), Department of Health. Gateway reference 5914.

2. Scope

2.1 Aims and objectives of service

Aim of Specialist Haemoglobinopathy Centre

To reduce levels of morbidity and mortality and improve the experience of all haemoglobinopathy patients by reducing inequities and improving timely access to high quality expert care.

Objectives of Specialist Haemoglobinopathy Centre

The Specialist Haemoglobinopathy Centre (SHC) will agree with their local NHS England Area Team (AT) responsible for specialised services (or AT function in London) and local Clinical Commissioning Groups (CCG) the geographical region (GR) or defined area for which it will take a lead responsibility for managing the care of all patients with a haemoglobinopathy. This will be either directly or as part of a shared-care arrangement. Particular consideration will be given to the arrangements for low-prevalence areas within the GR. (Throughout this document the abbreviation AT will refer to Area Team or Area Team function for London. The abbreviation GR will apply to either geographical region or defined area.)

In conjunction with the AT and patient groups, the SHC will agree and monitor compliance of care pathways and treatment protocols (elective and emergency) for all patients treated within the defined GR. The responsibility for performance management of individual SHCs will sit with the AT.

The SHC will provide and coordinate expert care and advice for all patients with the most complex needs in the defined GR and all levels of care for the SCD&T patients in the SHC's own local catchment area (the local catchment area may vary

depending on the number of centres providing haemoglobinopathy care in the GR).The SHC should consider the use of a regular teleconferenced multidisciplinary team to support care at local centres in the GR where appropriate.

The SHC will be able to provide 24/7 specialist advice for clinical teams in the base unit and defined GR.

Where very specialist services are not available at the SHC (for example stem cell transplantation) the centre will work with the AT to define pathways to an appropriate unit. The individual patient's consultant will remain responsible for the referral in line with the agreed pathway.

The SHC centre will provide routine, non-complex care for its local population.

In recognition of the major impact of non medical determinants of health outcomes in these disorders, the SHC will demonstrate close working with local commissioners and providers to capitalise on the expertise available outside of the specialist centre (including secondary, primary, community and voluntary sectors and existing specialist nurses) when designing the care pathways and including discharge planning. Any shortfalls will be reported to the responsible commissioner.

The SHC will oversee and support the production of a training and development plan for all healthcare staff involved in the delivery of care for haemoglobinopathy patients in the GR. The responsibility for resourcing appropriate training for healthcare staff remains with their employing organisations.

The SHC will register all consented patients in their GR on the National Haemoglobinopathy Register; for patients identified by the screening programme this will be at first paediatric review. The SHC will make sure that the individual records are complete and kept up to date importantly for adverse events and at annual review.

The SHC will be responsible for organising a minimum of two meetings a year for all healthcare staff involved in the delivery of care for haemoglobinopathy patients in the defined GR. This may include morbidity and mortality review, complex case review and other audit.

The SHC will be responsible for ensuring all children from the GR, identified by the screening programme are incorporated into the care system following the relevant guidelines from the screening programme.

The SHC will lead on research and development, audit and educational activities within its GR and ensure such activities are linked in to national programmes.

2.2 Service description/care pathway

Overview

Haemoglobinopathies are lifelong conditions and patients will access both on-going routine, as well as specialist, care throughout their lifetime. Patients' care will be coordinated by the SHC and the majority of care may be delivered outside of the SHC by a range of providers. The configuration of care provision will be based on local prevalence, expertise and availability of service providers; this may include acute hospitals, community care, primary care and the voluntary sector.

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

The SHC(s) within a region will be identified by the responsible AT using the standards in this specification.

Pathway

Referral

The majority of new patients in the future will be identified by the NHS Sickle Cell and Thalassaemia Screening Programme.

The SHC shall be assured that the links between screening and the centre are robust and timely, through an audit process, as specified in the guide to Effectively Commissioning High Quality Sickle Cell and Thalassaemia Services and the Screening Programme standards. However, patients may be identified late or present after migration from abroad and therefore referrals to the SHC may be received from GPs, community services, emergency departments and other consultants.

Initial Care

Newly diagnosed or identified patients will be transitioned into primary and acute care to receive their initial care.

Acute Care

Acute care may be delivered at local hospitals or at the SHC within locally agreed protocols.

Specialist Acute Care

The SHC will have a lead responsibility for the care of all patients with a haemoglobinopathy in their GR and will agree shared-care arrangements which capitalise on locally available services, resources and expertise. The SHC will provide and coordinate expert care for patients with the most complex needs.

The SHC will provide (or delegate) a multidisciplinary annual review for all patients in

its GR either on-site or as an outreach service. This annual review will include Trans-Cranial Doppler screening for all eligible SCD patients and cardiac and liver MRI where indicated for patients with thalassaemia.

On-going Care

The responsibility for planning and overseeing the delivery of on-going care sits with the responsible SHC but may, and should be encouraged, to be delivered outside the SHC where this is safe in settings such as acute hospitals, community care, primary care and the voluntary sector.

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)

Pregnancy

Pregnant women with pre-existing conditions as discussed in this specification require assessment and/or management from highly specialist tertiary maternity care delivered within a dedicated multidisciplinary service staffed by a maternal medicine specialist, a physician, and supporting multidisciplinary team with extensive experience of managing the condition in pregnancy.

In view of this, nationally commissioned condition specific services must have outreach arrangements with highly specialised tertiary maternity units with access to appropriate tertiary medical, surgical, fetal medicine, clinical genetics and level 3 Neonatal Intensive Care services. These specialised maternity services must have a critical mass of activity to maintain expertise, ensure best practice, training opportunities and for the organisational infrastructure, staffing, facilities and equipment to be clinically and economically efficient. They should have robust risk management and performance monitoring processes.

All such women must receive personalised pre-pregnancy and maternity care planning from specialised tertiary maternity services to allow optimal disease management in the context of the pregnancy. This will reduce avoidable morbidity, mortality and unnecessary intervention for mother and baby.

Women with conditions discussed in this specification must be referred immediately once they are pregnant to plan their care. This must include access to termination of pregnancy and specialist advice re contraception. The individualised care plan must cover the ante natal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate including escalation and transfer protocols and clear guidelines for planned and emergency delivery.

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.

Haemoglobinopathies are complex lifetime conditions therefore the population will include all children and adults with SC&T and other very rare anaemias requiring lifelong transfusion and chelation such as Blackfan Diamond anaemia and congenital sideroblastic anaemia amongst others

2.4 Any acceptance and exclusion criteria

Specialist Haemoglobinopathy Services include all care provided by the SHC including in-patient care where the cause of admission is related to haemoglobinopathy. This includes care provided through out-reach in the defined GR. This applies to provision in adults, adolescents and children.

The SHC will provide complex care for patients within the defined GR agreed with commissioners and providers and routine care for patients living locally.

The SHC will comply, and make sure all protocols and pathways within the GR comply, with all national and local policies.

2.5 Interdependencies with other services

Within the GR agreed with commissioners and providers:

- All acute providers.
- Primary care.
- Community healthcare services.
- Antenatal and new-born regional screening laboratories.
- Education providers.
- Social care.
- Voluntary sector.
- Specialist nurse practitioners.
- Genetic counsellors and specialists.
- Local authority and public health.

3. Applicable Service Standards

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

Standards – core and collaborative

Section A: Core standards (mandatory), these are the standards that the SHC must meet directly i.e. they must have the clinical expertise and facilities within their organisation.

A1 Clinical Leadership

- Medical Leadership – the SHC will have a named medical lead at consultant level. This must be a haematologist/paediatric haematologist or a paediatrician with expertise in haemoglobinopathies. Dependent on configuration of acute care within the GR, there may be two medical leads to cover paediatric and adult care.
- All acute units providing routine haemoglobinopathy care within the defined GR will have a named medical deputy at consultant level responsible for haemoglobinopathy care. There may be two deputies i.e. one each for paediatric and adult care.
- Nursing leadership – the SHC will identify a lead nurse from within the GR. The lead nurse will support all nurses across in the GR.
- The SHC will take a lead responsibility for data, audit and outcome monitoring across the GR.

A2 Newborn Screening

- A reporting mechanism for all screen positive blood spot newborn babies to the SHC must be in place. The SHC will work with the Screening Programme to make sure fail-safe mechanisms are in place. Compliance will be audited annually.
- This specification may be subject to amendment as a result of any published revisions to screening standards and specification.
- The SHC will have responsibility for collating and submitting a comprehensive range of data to the screening programme in a manner that is timely, accurate and comprehensive. Details on data collection can be found in appendices 7 and 8 of Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care. 2010. See A13

A3 Prevention and management of neurological complications of SCD through transcranial Doppler (TCD) scanning in childhood; specialised neuro-radiology, neurology and neuropsychology services.

The SHC must be able to demonstrate responsibility for:

- The coordination of access to TCD screening for all eligible children.
- The expert clinical management of those children and adults identified at risk of

stroke and other neurological impairment to minimise the risk.

- The multidisciplinary team management of complex neurological abnormalities.
- Compliance with any national training and quality assurance schemes established to support continuous quality improvement.

A4 Expert Multidisciplinary Care for Complex Patients

- The SHC is responsible for the management of complex patients using a multidisciplinary team approach. Indicators of complexity include but are not limited to:
 - Multi-system disease including organ damage.
 - Mono system disease for example hepatic and renal disease.
 - Abnormal neurology (see standard A3).
 - Psychological and psychosocial problems.
 - Pregnancy (see standard A10).
 - Surgery (see standard A9).
 - Orthopaedic issues.
 - Endocrine complications.
 - Cardiac complications especially related to iron overload.
 - Infection prevention and control requirements.
- The multidisciplinary team should include the following professionals: medical lead, nursing representation (acute and community) and psychology.
- The multidisciplinary team may require input from physiotherapy, neurology, cardiology, radiographer and sonographer.
- All patients to be reviewed at least annually by the SHC or under the supervision of the SHC.
- Multidisciplinary team teams will review and oversee the overall progress of all patients with clinical complexities to optimise overall care. Note: for children this will include growth, development and academic achievement.

A5 Initiation, Modification and Cessation of Long-Term Transfusion Regimes and Preventative Therapy in SCD&T

This standard is associated with standard A6

- The initiation, modification and cessation of long-term blood transfusion regimes should be under the responsibility of the SHC.
- Regular administration and monitoring of transfusions should be carried out locally wherever possible and sessions should be designed to fit around the requirements of patients wherever possible (e.g. evening clinics).

A6 Initiation, Modification and Cessation of Long-Term Iron Chelation. Monitoring of Complications of Chelation

This standard is associated with standard A5

- The initiation and amendment of long-term iron chelation regime is the responsibility of the SHC.
- The regular administration of iron chelation regime can be carried out locally wherever possible.

- The SHC will have access to cardiac and liver scanning.
- The SHC will have access to neuro-psychological, psychosocial and social worker support for patients that struggle with adherence.

A7 Acute Management of Severe and Life Threatening Complications of SCD and Thalassaemia

The SHC will develop guidelines to implement the NICE guidance on the management of acute painful episodes.

The SHC will be able to clinically manage the following range of complications for SCD:

- Fulminant sepsis.
- Acute sickle lung syndrome.
- Acute splenic or hepatic sequestration.
- Ischaemic and haemorrhage stroke.
- Subarachnoid haemorrhage.
- Acute renal failure.
- Multi-organ failure.
- Biliary obstruction.
- Fulminant priapism.
- Post-transfusion hyperhaemolysis.
- Acute ophthalmological complications (for example complications of sickle retinopathy/central retinal artery occlusion).
- Osteonecrosis of major joints (for example hip, shoulder).

The SHC will be able to manage the following complications for thalassaemia:

- Heart failure and cardiac arrhythmias.
- Infection prevention and control.
- Post-splenectomy sepsis.
- Acute endocrine disturbances (for example hypocalcaemic tetany).
- Acute hepatic decompensation.

The SHC will offer formal liaison support to any acute provider within the GR.

A8 Long-Term Specific Therapy for Severe Complicated SCD and Thalassaemia (Complex Long-Term Conditions Management)

This standard links to standard A3 relating to annual reviews and multidisciplinary team management of complex patients.

SHC will be able to clinically manage a range of progressive and often irreversible complications in both outpatient and in-patient settings. In SCD, these include:

- Stroke.
- Chronic sickle lung syndrome.
- Pulmonary hypertension.

- Chronic renal impairment.
- Avascular necrosis of the hips, spine and shoulders.
- Retinopathy.
- Chronic ankle ulceration.
- Chronic pain.

In thalassaemia major and intermedia, these complications include:

- Endocrine dysfunction (growth hormone deficiency), hypogonadotrophic, hypogonadism, hypothyroidism, hypoparathyroidism, diabetes, (which may require insulin treatment).
- Cardiac dysfunction.
- Chronic liver disease (cirrhosis portal hypertension, hepatic failure, hepatocellular carcinoma, often associated with transfusion-transmitted hepatitis B or C).
- Bone problems (avascular necrosis, osteoporotic fractures of the hips and spine, disc disease).
- Gallstones.
- Ankle ulceration.
- Iron overload.
- Pulmonary hypertension.
- Thrombosis.
- Retinal damage.
- Pseudoxanthoma
- Chronic pain.

The SHC must be able to initiate, modify and cease long-term medication regimes. For instance, to prevent or mitigate against sickle painful episodes. The monitoring of such drug regimes is not a specialised function but any modification based on the outcomes of that monitoring remains specialised.

The SHC must be able to provide psycho-social/psycho-neurological support to complex patients struggling to manage their condition.

A9 Peri-Operative Management of Sickle Cell and Thalassaemia Patients Requiring Surgery

In principle all elective surgery, and where possible all emergency surgery, should be carried out in at the SHC. For practical purposes this may not be possible or desirable and it will be for the LAT and SHC to agree surgical pathways.

The SHC will demonstrate close liaison between haematologists, paediatricians, surgeons and anaesthetists. Surgeons and anaesthetists will have experience in the effective peri-operative management of SCD&T patients.

Where a local acute provider is required to deliver an emergency operation, they should liaise with the SHC.

The SHC is required to have pathways in place to manage emergency scenarios.

A10 Management of Pregnant Women with SCD and Thalassaemia

Complex pregnancy refers to any pregnant woman that has SCD or thalassaemia. A high risk carrier couple identified by the Antenatal Screening Programme do not require specialised care during the pregnancy unless a specific complicating factor has been identified.

- The GR will have a named obstetric lead to advise on complex pregnancies. This obstetric lead may or may not be part of the SHC.
- All GRs will have a named midwife to advise on complex pregnancies. The named midwife may or may not be employed by the SHC.
- All high risk pregnancies to be managed by multidisciplinary team approach between obstetricians and haematologists. Management plans to be agreed by the SHC.
- The SHC is required to have pathways in place to manage emergency scenarios.

A11 Clinical Governance and Audit

On behalf of the GR, the SHC will adopt a clinical governance and leadership function. This will include

- Reporting all adverse events to commissioners and the National Haemoglobinopathy Registry (NHR)
- Undertaking an agreed number of clinical/quality audits as agreed with the AT.
- Participating in any peer review process.
- Reviewing all clinical guidelines and protocols within the GR including those produced by community providers.
- Reviewing and amending pathways to promote integrated care.
- Ensuring the quality of care provision and delivery.
- Supporting local and national benchmarking.

A12 Patient and Carer Engagement

The SHC will take the lead on public and patient engagement (PPE). This will involve the following:

- User or user group representation at meetings.
- User involvement in service planning and development.
- User involvement in reviewing and standardising any clinical information contained in patient literature across the GR.

To promote user feedback and engagement with all healthcare providers.

A13 Data Collection, Management and Submission

The data collection should represent the whole clinical pathway and not just the specialised element.

The SHC will be responsible for complete and timely submissions onto the NHR.

The SHC will be responsible for collating and submitting a range of data to the Screening Programme in a manner that is timely, accurate and comprehensive. Details on data collection can be found in appendix 7 of Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care. 2010. See A2.

A14 Education and Research

- The SHC will oversee any clinical education and training across the GR .
- Any training will be offered to clinical staff in all providers across the GR to support integrated working.
- The SHC will be able to provide practical training to relevant clinical staff including junior doctors and nurses.
- Any training to nurses must be compliance with the Royal College of Nurses (RCN) Competencies Framework for nursing staff caring for SCD&T patients.
- All counsellors or healthcare professionals who counsel couples at risk of an affected pregnancy should have undertaken the PEGASUS programme or its replacement.

SHC must demonstrate a research portfolio – possibly linked to clinical and cost effectiveness of certain aspects of care.

A15 Timely Access to Critical Care (Adult)

Unless a Children's Trust, the SHC must have an adult Intensive Therapy Unit (ITU) on site.

A16 Transition

The SHC should develop, provide and oversee a protocol for adolescents transitioning between paediatric and adult services with adequate facilities and staff trained to be sensitive to the special needs of this group of patients.

SECTION B: Collaborative standards (mandatory) – these are standards that the SHC may deliver in collaboration with other SHCs to ensure clinical and cost effectiveness. In addition, some elements will be super-specialised and will be limited to a very small number of providers nationally.

B1 Timely Access to Critical Care (Paediatric)

If the SHC does not have a Paediatric intensive Care (PICU) on site, they must demonstrate formal arrangements with either other SHCs or other acute Trusts with PICU.

B2 Access to a Comprehensive range of Clinical Specialists Experienced in Treating Haemoglobinopathy Patients

The SHC must have demonstrable arrangements in place that recognise the challenges that patients face in travelling long distances, access to the following specialists:

- Experienced nurse specialising in the conditions.
- Acute and chronic pain team.
- Consultant cardiologist.
- Consultant respiratory physician.
- Consultant teams with experience in managing pulmonary hypertension.
- Consultant nephrologist and access to renal replacement therapy and transplant.
- Consultant hepatologist.
- Consultant urologist with expertise in managing priapism, erectile dysfunction.
- Consultant neurologist and acute stroke service.
- Consultant ophthalmologist.
- Consultant endocrinologist.
- Contraception and sexual health services.
- Genetic counselling and fertility services.
- Consultant obstetrician.
- Consultant general surgeon.
- Tissue viability service/leg ulcer clinic.
- Psychologist and other mental-health services.

B3 Access to Bone Marrow and Stem Cell Transplantation

Both of these interventions are deemed super-specialised and will be available at only a few centres nationally. The SHC will have formal processes in place to refer patients for such clinical interventions

SECTION C: Additional quality standards (non-mandatory)

C1 Appropriate Adolescent In-Patient Facilities

The SHC should have appropriate adolescent in-patient facilities in line with national best practice

C2 Development of a GR wide patient hand held record

The SHC is encouraged to develop a single and integrated patient hand held record that covers the entire pathway for their GR.

4. Key Service Outcomes

Note: This section is to be informed by the Haemoglobinopathy Clinical Reference Group development of the quality dashboard and compliance with standards in Section 3.

However, as a minimum in 2013/14 all centres will report on:

- The percentage of patients registered on the National Haemoglobinopathy Register
- The percentage of eligible patients offered and received TCD screening.
- The percentage of patients receiving an annual review.
- Compliance with the Screening Programme referral requirements.

5. Location of Provider Premises

The AT (or AT function) will be responsible for the identification of centres in their region and the completion of the table.

On request, the Haemoglobinopathy Clinical Reference Group will provide advice to the ATs. This advice will be based on the outcomes of the Peer Reviews, the experience of the Screening Programme and clinical and commissioner expertise, experience and opinion.

Region	Specialist Haemoglobinopathy Centres	Adults / Children	Local Haemoglobinopathy Centres Supported	Geographical Region

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, 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 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. 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 and should maintain the competencies so acquired. 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

- GPAS Paediatric anaesthetic services. RCoA 2010 www.rcoa.ac.uk
- CCT in Anaesthesia 2010
- 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 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 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:

- 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, 2006, London