B05/S/a

2013/14 NHS STANDARD CONTRACT FOR HAEMOPHILIA (ALL AGES)

SECTION B PART 1 - SERVICE SPECIFICATIONS

Service Specification No.	B05/S/a
Service	Haemophilia (All Ages)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Bleeding disorders are rare and complex conditions and of these, haemophilia is the most widely recognised. There are two main forms of haemophilia. The most common is Haemophilia A (deficiency of coagulation factor VIII) with a prevalence of between 1:5,000 and 1:10,000 males. Haemophilia B (deficiency of factor IX) is less common with a prevalence of between 1:35,000 and 1:50,000 males and Acquired Haemophilia is even rarer. A deficiency or a defect of the coagulation protein von Willebrand factor is known as von Willebrand Disease. It is a more common but generally milder bleeding disorder affecting both males and females with a prevalence of at least 1:1,000. Other inherited bleeding disorders of clinical importance include deficiencies of other clotting factors (e.g. factor V, factor X, factor XI and fibrinogen) and abnormalities of platelet function*.

(*The management of Idiopathic Thrombocytopenic Purpura (ITP) is not a part of specialised haemophilia services. The latter is an acquired immune condition in which there is excessive destruction of platelets. The clinical management is entirely different to the management of clotting factor deficiencies, and ITP is normally managed within general haematology services).

The following national documents are also of relevance to this service specification:

- Model Documentation for Designation of Haemophilia Services, London Specialised Commissioning Group (June 2010)
- United Kingdom Haemophilia Centre Directors Organisation (UKHCDO) Triennial

Audit Report (2011) http://www.ukhcdo.org/wp/TriennialAuditcommittee.htm

- UKHCDO Clinical Outcomes Group Report (2011) http://www.ukhcdo.org/docs/WorkingPartyReports/AR2011_3_COG_Report.pdf
- All United Kingdom Haemophilia Centre Doctors Organisation (UKHCDO) Guidelines on specific haemophilia clinical issues can be found at www.ukhcdo.org/UKHCDOguidelines.htm
- A National Service Specification for Haemophilia and Related Conditions (The Haemophilia Alliance) [2006] http://www.haemophiliaalliance.org.uk/pdf/Haemophilia_2.pdf

2. Scope

2.1 Aims and objectives of service

The aim of the service is to enable patients with haemophilia and other bleeding disorders to live as normal a life as possible, ensuring optimum treatment with clotting factor to maintain a bleed free existence where possible, whilst maintaining good joint health and general health.

Objectives

- To ensure that all patients have access to specialist, comprehensive care.
- To respond to the complexity and rarity of haemophilia and other bleeding disorders by establishing appropriate adult and paediatric multidisciplinary healthcare systems.
- To deliver care in a way that aims to minimise the complications of haemophilia and other bleeding disorders including the management of pain, incapacity and physical disability
- To ensure that the care of patients is as safe as possible, that it conforms to national clinical guidelines and is monitored by objective external clinical audit.
- To be responsive to the lifelong medical, physical and psychosocial needs of patients with hereditary bleeding disorders and their families.
- To ensure patients are involved in decisions about their treatment and engaged in service developments and improvements.
- To provide an environment in which patients (and their parents/carers where appropriate) are able to make informed decisions about treatment and are enabled to become independent throughout their lifetime, thereby minimising disruption to education, work and social activities.
- To promote the cost effective use of resources available to the service with special reference to clinical management of patients and the nature of service delivery.

2.2 Service description/care pathway

The model of care will ensure patients have access to comprehensive care which includes the following:

- A clinical service provided by healthcare professionals experienced in the treatment of patients haemophilia and other bleeding disorders, including Haematology Consultants with a specialist interest in haemostasis.
- Specialist Nurses trained in line with Haemophilia Nurses Association and Specialist Physiotherapists trained in line with the Haemophilia Chartered Physiotherapy Association.
- Accredited 24 hour laboratory service capable of carrying out all tests necessary for the definitive diagnosis of haemophilia and other bleeding disorders, including the identification and assay of the relevant specific haemostatic factors. These laboratories will be capable of monitoring therapy and screening for inhibitors with quantification of any inhibitor detected in accordance with published UKHCDO guidelines.
- Maintenance of satisfactory quality control and assurance for all laboratory tests offered in relation to clinical services, both by establishing the appropriate level in the UK National External Quality Assessment Scheme in Blood coagulation (NEQAS), or other relevant approved external quality assessment schemes.
- To conduct further investigation of relatives of patients with haemophilia and other bleeding disorders. The services should also include the diagnosis of atypical cases, genotypic analysis, the assay of inhibitors, haemostatic factors, diagnosis of hereditary platelet disorders and molecular diagnostic testing.
- An advisory service to patients and close relatives on matters specific to haemophilia and other bleeding disorders. Advice will also be provided to other healthcare professionals. A Comprehensive Care Centre (CCC) will provide 24-hour advisory service to Haemophilia Centres within their managed clinical network and support to such centres as appropriate.
- Musculoskeletal services to include access to and regular review by experienced specialist physiotherapists.
- Paediatric services to be provided by personnel trained in the care of children.
- 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).
- Access and referral to clinical services for all aspects of haemophilia care including:
  - Orthopaedic Surgical Services.
  - Dental services.
  - HIV and hepatology services.
  - Counselling services, preferably to a named counsellor, who has experience of patients with haemophilia and inherited bleeding disorders
  - Obstetric services, including reproductive counselling.
  - Social care support
- Good quality of medical records will be maintained for all patients, such records must be maintained of all treatment administered and all adverse reactions reported. All relevant patients will be formally registered with the treating Centre and with the UKHCDO National Haemophilia Database.

- Special medical cards will be issued which include details of the patient's bleeding disorder, usual treatment, treatment centre and out of hours contact details for the centre.
- Education facilities and training opportunities for medical staff, nurses, counsellors and other personnel as required, promoting optimal comprehensive care of patients.
- Undertaking research programmes, including the conduct of clinical trials and to establish and participate in suitable regional and national programmes of clinical audit.
- All CCCs must participate in the UKHCDO triennial audit programme for Comprehensive Care Centres.

The above services will be provided by an accredited CCCs or be available through a managed clinical network which must include at least one CCC.

CCCs will normally provide treatment for forty or more severely affected patients per year.

There will be clear and agreed pathways within the managed clinical network to ensure that all patients have access to comprehensive care. The patient pathway must ensure that all patients have access to comprehensive care 24 hours a day, 7 days a week, including protocols for out-of-hours care, emergency management and the treatment of inhibitors.

Patient reviews will take place in accordance with this service specification within a multidisciplinary team. As a minimum all patients with haemophilia and other bleeding disorders must have contact with their centre at least once a year, for those patients not receiving treatment this may be a structured telephone interview. Severe patients must have 6 monthly reviews and small children (<5yrs) must be seen 3-4 times per year.

A home therapy programme should support home treatment for relevant patients across the network including the administration of prophylactic therapy and home and school visits where appropriate.

Providers will purchase clotting factor products via the national framework agreement.

Transfer planning will take place between the paediatric and adult provider to ensure a smooth transition to adult care for adolescents.

Transfer planning should take place to a paediatric provider for the management of neonates with antenatal diagnosis of, or known to be at risk of haemophilia and other bleeding disorders.

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 specialized 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 personalized 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 as 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[1] 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).

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[1] For the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

2.4 Any acceptance and exclusion criteria

Initial referral will be due to a suspected or known bleeding disorder and could come from a GP or as a referral to tertiary care from an acute trust; either route could follow clinical presentation, laboratory investigations showing abnormal coagulation or could be due to genetic diagnosis and/or family studies.

Specifically, all adults and children with the following diagnosis will have access to the service:

- Haemophilia A (Factor VIII deficiency)
- Haemophilia B (Factor IX deficiency)
- Von Willebrand Disease
- Acquired Haemophilia and other related bleeding disorders
- Other rare forms of Inherited Bleeding Disorders

A full list of conditions as ICD 10 codes is included at Annex 2.
There is a spectrum of severity for each of these conditions; however there is no national definition of when a ‘mild’ bleeding disorder requires specialist intervention. The service should therefore cover all severities.

The patient must then be registered at their primary treatment centre (either a CCC or a Haemophilia Centre which is part of a managed clinical network) and also on the National Haemophilia Database.

Exclusion Criteria

Specialist services for haemophilia and other bleeding disorders specifically do not cover the following:

- The use of clotting factor for treatment of trauma or critical care or following surgery or as part of obstetric care (where the patient has no underlying Bleeding Disorder).
- General Haemostasis and Thrombosis services (including stroke services).
- Specialist Haemostasis and Thrombosis unrelated to Haemophilia and Bleeding Disorders (e.g. liver disease).
- Anticoagulation treatment or the reversal of anticoagulant treatment

2.5 Interdependencies with other services

In addition to the specialised elements of care outlined in Section 2.2 there are also a number of general services with varying levels of interdependency with haemophilia and other bleeding disorders.

Co-located services

Comprehensive Care Centres will have the following onsite services:

- 24 hour laboratory service capable of carrying out all tests necessary for the definitive diagnosis of haemophilia and other bleeding disorders

Interdependent services

Services that are required during the spell of care but where there is no absolute requirement for this service to be based on the same healthcare delivery site are as follows:

- Dental services.
- HIV and hepatology services.
- Counselling services, preferably to a named counsellor, who has experience of patients with haemophilia and inherited bleeding disorders.
- Obstetric services, including reproductive counselling.
- Social care support.

Related services

There are a number of specialised services with a clear inter-dependency for specific patient sub-groups of those with haemophilia and other bleeding disorders as follows:
- Specialised services for Women's Health – this is relevant for Maternity Services and Fetal Medicine for women who are carriers or have a bleeding disorder
- Specialised services for Liver, Biliary and Pancreatic Medicine and Surgery (adult) – this relates to hepatology for Hepatitis infected patients.
- Medical Genetic Services.
- Specialised services for Children – important inclusions are anaesthesia and pain management, dentistry, NIC, PIC, surgery etc.
- Specialised Rheumatology Services (all ages).
- Specialised Pain Management Services (adult).
- Specialised Orthopaedic Services (adult).

Additionally, for the group of infected individuals there is a need for further inter-dependency with the following services:
- HIV/AIDS Treatment and Care and associated services

Whilst the service model needs to describe access arrangements for other Specialised Services, the funding and quality assurance responsibilities lie with the commissioners of those services and not with commissioners of haemophilia services.

3. Applicable Service Standards

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

The standard service model for Haemophilia services was set out in the Health Service Guidance (HSG) (93) 30 Provision of Haemophilia Treatment and Care, this states that there should be two different levels of Haemophilia provision – a Comprehensive Care Centre (CCC) which provides specialist diagnosis and care and a haemophilia centre (HC) which provides a local, shared care service. This Service Specification aims to further develop and strengthen this model of care.

All patients should have access to comprehensive care through a managed clinical network. The clinical service will be provided by healthcare professionals experienced in the treatment of patient’s haemophilia and other bleeding disorders, including Haematology Consultants with a specialist interest in haemostasis, Specialist Nurses trained in line with Haemophilia Nurses Association and Specialist Physiotherapists trained in line with the Haemophilia Chartered Physiotherapy Association.

All CCCs must participate in the UKHCDO triennial audit programme and achieve the accreditation standards. CCCs will normally provide treatment for 40 or more severely affected patients per year.

There will be clear and agreed pathways within the managed clinical network to ensure that all patients have access to comprehensive care. The patient pathway must ensure that all patients have access to comprehensive care 24 hours a day, 7 days a week, including protocols for out-of-hours care, emergency management and the treatment of inhibitors.

All Providers of haemophilia and other bleeding disorders have a contractual responsibility to submit data to the National Haemophilia Database.

4. Key Service Outcomes

Service outcome measures have been agreed as part of the national Dashboard for haemophilia services. The full dashboard can be found at: http://specialisedcommissioning.com/quality-dashboards-2/

Providers must also ensure complete, accurate and timely returns to the National Haemophilia Database.

The UKHCDO triennial audit standards must also be achieved by all CCCs

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

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

The generic aspects of care:
The Care of Children in Hospital (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, 2008

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 continuous professional development.
- All equipment will be optimised for paediatric use and use specific paediatric software.

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training. All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straight forward 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 neurosciences 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, The Royal College of Anaesthetists 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, 2011.

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 4 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, 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, 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 to be 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
- Ensuring that staff handling medicines have the competency and skills needed for children and young people’s medicines management
- Ensures that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability. Providers should ensure that:
- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 1995
- They meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006 London

ANNEX 2

Outpatient activity can be identified by activity under the treatment function code of 309 (Haemophilia) often under a main specialty code of 303 (Clinical Haematology) or 420 (Paediatric Medicine).

Inpatient activity can be identified by the treatment function code AND main specialty codes listed above plus the presence of the following diagnosis codes in the primary position.

D66X	Hereditary factor VIII deficiency
D67X	Hereditary factor IX deficiency
D680	Von Willebrand's disease
D681	Hereditary factor XI deficiency
D682	Hereditary deficiency of other clotting factors
D683	Haemorrhagic disorder due to circulating anticoagulants
D689	Coagulation defect, unspecified
D691	Qualitative platelet defects
D699	Haemorrhagic condition, unspecified