

B04/S/b

**2013/14 NHS STANDARD CONTRACT
FOR HAEMATOPOIETIC STEM CELL TRANSPLANTATION (CHILDREN)**

SECTION B PART 1 - SERVICE SPECIFICATIONS

Service Specification No.	B04/S/b
Service	Haematopoietic Stem Cell Transplantation (Children)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Allogeneic haemopoietic stem cell transplantation (HSCT) provides curative therapy for carefully selected patients with a range of malignant and non-malignant haematological disorders and other specific inborn disorders of metabolism and the immune system.

It involves replacing the bone marrow stem cells of a patient following high-dose therapy with stem cells from a tissue-type matched or mismatched donor (termed *allogeneic transplantation* or *allografting*) or using the patient's own bone marrow cells which have been stored before high dose chemotherapy and are returned afterwards to speed bone marrow recovery (termed *autologous transplantation* or *autografting*).

This is a low volume, high risk and rapidly technically evolving specialty in which optimum outcome has been shown to require large, experienced multidisciplinary team assessment and management.

Sophisticated input is also required from numerous paediatric subspecialties, which therefore constitute critical adjacencies in order to achieve best outcomes.

Currently the average annual number of combined paediatric HSCT procedures (allografts and autografts) performed each year falls in the range 310-350 although this is subject to considerable variation due to the small numbers involved.

Evidence of Standards of Care

5th edition, FACT-JACIE (Foundation for the Accreditation of Cellular Therapy and the Joint Accreditation Committee) Cellular Therapy Accreditation Manual; Foundation for the Accreditation of Cellular Therapy (FACT) 2012.

Joint Accreditation Committee EBMT – Euro ISHAGE (JACIE) Standards & Accreditation Manual March 2012.

JACIE Accreditation in Paediatric Haemopoietic SCT, JM Cornish et 2008 (review)

Human Tissue Authority (HTA) Code of Practice 6 on *Donation of allogeneic bone marrow and peripheral blood stem cells for transplantation*

UK Paediatric HSCT Group Indications for HSCT December 2011

NICE National Guidance for Children and Young People with Cancer (2005)

European Blood and Marrow Transplantation Handbook 2012 (EBMT)

British Society of Bone and Marrow Transplants – (BSBMT)

Specialised Services National Definition Set No 2 (2010)

The National Service Framework for Children (2004)

Commissioning safe and sustainable specialised paediatric services-a framework of critical interdependencies, Department of Health, October 2008

Improving outcomes in children and young people with cancer: guidance on commissioning services for young people.

Children and Young People Improving Outcomes Guidance (CYPIOG) Advisory Group, September 2008

The Future of Unrelated Donor Stem Cell Transplantation in the UK, A Report from the UK Stem Cell Strategic Forum, July 2010

Cord blood transplantation: meeting the unmet demand

A report by the All Party Parliamentary Group (APPG) on Stem Cell Transplantation, January 2012

2. Scope

2.1 Aims and objectives of service

This specification aims to define the national context and evidence base for the practice of HSCT, and to outline the nature of specialist children's transplant services, the model of care that they provide and the quality standards that they must satisfy. The principal themes are:

- To ensure that patients requiring HSCT are treated in JACIE accredited units for nationally agreed indications and using consensus operating procedures
- To ensure that parents and children have coordinated care across the whole pathway and feel supported throughout their Blood and Marrow Transplantation (BMT) journey.
- To demonstrate one year and five year survival outcomes in line with national and international standards for children adjusted for case mix.

2.2 Service description/care pathway

Multidisciplinary assessment & management

Comprehensive multidisciplinary team (MDT) care is pivotal for optimisation of patient selection, inpatient and outpatient management, long-term follow-up and quality of survival. These teams must work in a well-defined national framework that crucially includes evidence-based shared protocols, research and critical evaluation of quality. All measures of quality, i.e. patient experience, safety and outcome have to be addressed, audited and presented nationally.

Typical multidisciplinary team members would include, but not be limited to, paediatric consultant specialists with expertise in oncology, haematology, transfusion medicine, immunology, bone marrow transplantation and radiotherapy, nurse and medical transplant coordinators, pharmacist, dietician, physiotherapist and social worker.

Close working relationships are required with tissue typing experts, quality management, data collection and audit staff. Other critical adjacencies include the full range of paediatric subspecialties with particular emphasis on paediatric intensive care, surgery, anaesthesia, acute pain management, radiology, pathology, respiratory, cardiac, gastroenterology / metabolic, hepatology, ophthalmology, gynaecology, nephrology, dermatology, neurology, immunology/infectious diseases, Ear, Nose and Throat (ENT) medicine and palliative care.

Accreditation Standards & National Oversight

There are defined international standards for all aspects of the transplant process

defined by JACIE/FACT.

5th edition, FACT-JACIE Cellular Therapy Accreditation Manual Produced by the Foundation for the Accreditation of Cellular Therapy (FACT)

Joint Accreditation Committee EBMT- EuroISHAGE (JACIE) Standards and Accreditation Manual March 2012

This is regarded as a minimum standard for HSCT transplant units in the UK. Currently, all paediatric transplant units are also required to participate in a national retrospective audit of outcomes, with reporting of a minimum dataset on indication, donor stem cell source, stem cell manipulations, conditioning therapy, outcomes and complications, with detailed description of serious morbidities and mortality.

In the future, it is an agreed aspiration that all units will contribute to a regular weekly teleconference discussing patient selection/appropriateness of transplantation, optimal approach and ongoing management of complications and waiting lists.

The HSCT Process

Patients require detailed pre-transplant work-up to assess their clinical status and fitness to proceed to transplant. The transplant procedure begins with 'conditioning' or preparative therapy (chemotherapy \pm total body irradiation (TBI)) at a range of doses depending on the type and severity of disease being treated.

The aim of this is to kill leukaemia/tumour cells (in malignant diseases), to eradicate existing bone marrow tissue (in order to provide space for engraftment of incoming donor stem cells) and to immunosuppress the patient so as to minimise the risk of graft rejection. In addition, when transplanting for a malignant indication, it has become evident that a "graft versus tumour" effect is potentially an important component of the success of the procedure in achieving cure of the haematological malignancy. Bone marrow, peripheral blood or umbilical cord blood stem cells may be used as stem cell sources.

Autologous transplantation, which relies on using the patient's own stem cells, is performed as part of dose escalation therapy within many national and international paediatric oncology protocols for solid tumours. It therefore predominantly occurs within tertiary paediatric oncology units subject to their own accreditation and is permissible as long as the stem cell laboratories used and stem cell collection facilities are JACIE accredited for children.

HSCT is an area of rapid technological evolution; as a consequence research and clinical trial work should carry high priority in all units. Concentration of expertise is vital in the proper understanding and management of severe complications which arise following these procedures. This is clearly of the utmost importance to children, their families and their patient support and advocacy groups.

Typical timescales

Conditioning therapy is given over 5-10 days, with the stem cell infusion given at the end of this period (by convention termed Day 0). Recovery from transplantation typically takes 4-8 weeks as an inpatient (although serious complications may greatly extend this), followed by a period of transitional outpatient care in hospital accommodation before return to their referral teams.

Immune suppression is used for between one month and one year post-transplant to prevent immune attack on patient organs (termed graft versus host disease, GVHD). Patients require full revaccination commencing from 12-18 months post-transplant.

Lifelong long-term follow-up is required in view of the high risk of late adverse effects, some of which may be potentially life-threatening.

Conditions Managed By The Specialist HSCT Team

HSCT is indicated in a large number of discrete diseases in paediatric practice, many of these being individually rare. Full listing of the conditions concerned is included in the UK Paediatric HSCT Group Indications, December 2011. These can be broadly classified as follows:

- Malignant diseases, where the aim is to rescue patients with acute or chronic leukaemias or tumours (e.g. lymphoma) from high doses of chemo/radiotherapy which would otherwise render their bone marrow aplastic and to replace their bone marrow with healthy stem cells. There may also be a separate additive "graft versus tumour" or "graft versus leukaemia (GvL)" effect due to donor cells recognising patient cells as foreign.
- Acute leukaemia comprises the largest single indication for transplantation (35-40% of allogeneic procedures), followed by myeloproliferative / myelodysplastic diseases (10-15%), chronic leukaemia (5%) and lymphoma (2%). Very occasional transplants are performed for other solid tumours in exceptional circumstances.

Non-malignant diseases, where the aim is to replace bone marrow which is:

- Producing defective white blood cells, resulting in immunodeficiency syndromes (15-20%, currently performed in two NHS Specialised Services [NSS] designated centres) OR
- Failing, as in aplastic anaemia or a range of inherited bone marrow failure syndromes (10-15% of all procedures) OR
- Causing histiocytic or haemophagocytic disease (5-10%) OR
- Producing defective red blood cells (e.g. thalassaemia, sickle cell anaemia, hereditary spherocytosis) (5%) OR
- Producing white blood cells which are defective in synthesising critical enzymes necessary for solid organ function (lysosomal storage disorders) (5%) OR
- Producing cells responsible for autoimmune attack on solid organs (e.g. Crohn's disease, juvenile idiopathic arthritis); (1%, currently performed in two NSS designated centres)

Interventions and investigations provided by the specialist HSCT team include:

Donor selection

Ideally, donor stem cells are harvested from a related donor or volunteer unrelated donor who completely or closely matches the human leukocyte antigen (HLA) type of the patient, since this minimises the risks of graft rejection and graft versus host disease (GVHD, a condition where the lymphocytes of the donor attack the skin, liver and/or gut of the patient).

However, it is possible to use family members who match only half of the tissue type (termed haploidentical donors) or unrelated donors who match for at least eight of the 10 HLA antigens routinely tested (maternally and paternally inherited copies of HLA-A, B, C, DR and DQ).

HLA-matched sibling allografts have historically produced the best long-term results but recent published evidence suggests that 10/10 matched unrelated donor transplants produce equivalent outcomes. The use of cord blood for allogeneic transplant is also growing, especially where no HLA matched donor is available or where the transplant is required urgently.

Donor selection requires detailed collaboration with tissue typing laboratories. Optimal donor selection must take into account such varying factors as the size of the patient, disease / disease status, blood group and previous viral infections.

Donor selection protocols require national and international collaboration and research; it has been shown repeatedly in large registry series that the closeness of the donor / recipient match is critical to the patient outcome. Centre size and experience are especially relevant in the context of mismatched donor transplantation (T Klingebiel, JM Cornish et al, Blood, 2010).

Pre-transplant assessment

One or more outpatient attendances for assessment including tissue typing (human leukocyte antigen (HLA) typing), assessment of the state of underlying leukaemia/cancer (where appropriate), accurate classification of disease in genetic disorders and assessment of comorbidities such as organ dysfunction and infection.

Routine investigations include echocardiogram, ECG, respiratory function tests, blood tests to assess kidney, liver and hormonal function, immunoglobulin levels, viral serology and dental review.

Radiology investigations include chest X-ray, wrist X-ray for bone age and CT scan if there is concern about disease status or potential fungal infection. Magnetic resonance imaging/spectroscopy may be required in metabolic diseases.

Highly detailed characterisation of lymphocyte numbers, types and function, of specific cellular mechanisms, of potential causative genes and of attendant infections are required in immune deficiency syndromes. Other disease-specific workup may also be required in other rare genetic diseases.

Bone marrow aspirate and/or trephine and related investigations are usually performed in malignant diseases and osteopetrosis.

Harvest episodes & transplantation

Back-up bone marrow harvest may be performed where there is a higher risk of transplant rejection, in which event the patient's own cells can be returned to speed blood count recovery and potentially negate the risk of death due to infection related to bone marrow aplasia.

Bone marrow or peripheral blood stem cells may be harvested from a sibling or family member who is acting as the donor. This must be performed according to the criteria laid out in the Human Tissue Authority (HTA) Code of Practice on the Donation of allogeneic bone marrow and peripheral blood stem cells for transplantation. Any potential child or adult donor of bone marrow or PBSC who lacks capacity to consent must be assessed by an Accredited Assessor and a report submitted to the HTA for consideration.

Any sibling who lacks the capacity to consent will not be required to donate peripheral blood stem cells or therefore to receive G-CSF for stem cell mobilisation. Siblings with capacity to consent may be allowed to do so, with appropriate information and consent.

Harvesting of volunteer unrelated donors and sourcing of stored cord blood cells are performed by outside agencies in the UK and overseas.

Transplant inpatient episode

Donor cells are administered to the patient in the form of an intravenous infusion and the patients are then kept in hospital until they have recovered adequate neutrophil numbers to reduce the risk of infection (engraftment).

During this period there is intensive requirement for blood product support with packed red cells, platelets and sometimes granulocyte infusions, together with antibiotic, antifungal and antiviral drug prophylaxis and therapy of proven infections. Numerous other acute complications may occur including mucositis, fluid overload, GVHD, haemorrhagic cystitis, veno-occlusive disease, pneumonitis, renal failure and acute neurological problems (e.g. fits, encephalopathy). Specialised paediatric intensive care may be required if these are life threatening.

There are ongoing requirements for regular viral monitoring (using polymerase chain reaction (PCR) tests for cytomegalovirus (CMV), adenovirus and Epstein-Barr virus (EBV) viruses on blood and other specimens) and for assessing donor engraftment (chimerism tests, based on microsatellite PCR) both during transplant recovery and during ongoing follow-up.

Post-transplant follow-up

In the early stages this concentrates on assessment of post-transplant complications (e.g. GVHD), infection risk (principally viral screening and ongoing prevention or treatment of fungal infection) and immune reconstitution.

Subsequently this concentrates more on monitoring for late effects including growth, cardiac, respiratory, visual, auditory, neuropsychological or hormonal problems and increased cancer risk due to the transplant procedure or underlying disease.

Long term, effective transition to age-appropriate adolescent/young adult care is vital, as is ongoing follow-up in order to manage any late toxicity(ies) and to determine the long term efficacy of the transplant procedures, and hence inform future strategy. The newer service of *Survivorship* is also an adjunct to quality of survival

Outpatient attendances are often shared between the transplant centre and regional/district hospitals. The balance of these activities is highly dependent upon the complexity of the disease transplanted and the severity of any post-transplant complications, as well as the nature and location of the regional / district services. This may be stratified as follows:

- **Simple** = out-patient or day care attendance
- **Complex I** = in-patient admission post allograft without GVHD;
- **Complex II** = in-patient admission with GVHD, and / or anti-fungal therapy, re-infusion of stem cells without additional conditioning, cell therapy for infection, treatment of GvHD and/or disease relapse.

Some patients will require further cellular therapy, most routinely in the form of selected or unselected donor lymphocyte infusions (DLI) to further fight malignant cells or persistent, life threatening post-transplant viral infections. Others may require an additional “top-up” infusion of stem cells if full blood count recovery and immune reconstitution has not occurred. Rarely patients may require a second allogeneic transplant procedure but only after very careful assessment of their disease and clinical status and after careful MDT ± external expert discussion/review.

Shared care

Each paediatric centre has formal shared care arrangements in place with existing referral hospitals. The “JACIE” standards for Blood and Marrow transplant make reference to shared care post-transplant and note that there are risks associated with providing such care, and that assurance for this needs to be demonstrated through formalisation of these arrangements.

Shared care arrangements should work on a hub and spoke basis with relevant stages of the pathway defined. These will operate similarly to how POSCUs operate in paediatric cancer but with specific arrangements determined by the referral pattern, i.e. requiring different arrangements if the centre is referring back to a local district general hospital as compared to a tertiary paediatric haematology/oncology service in the UK.

The shared care arrangements will be incorporated into the BMT service specification with contributions to audit and data collection nationally and internationally. Education programs will be enhanced to support shared care and these will be linked to the national JACIE standards.

It will be appropriate to include the shared care sites in the peer review preparation and visits to the BMT centres.

General Paediatric care

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

2.3 Population covered

This service outline in this specification is for all transplantation for patients under 18 years of age ordinarily resident in England, Wales or Northern Ireland according to nationally agreed indications (UK Paediatric BMT Group HSCT Indications December 2011).

Services for allogeneic HSCT are currently concentrated in 11 centres across the country, accredited for the delivery of safe high-quality care, to ensure a minimum base-line number of cases so as to achieve maximum outcomes. There is therefore a quaternary pattern of referral from regional centres, with carefully co-ordinated aftercare beyond the initial months of the transplant between transplant centres and the referring regional centre, or district hospitals with experience in the management of paediatric haematology and oncology patients (POSCU's). Autologous HSCT is also performed in a further 10 tertiary paediatric oncology centres which do not perform allogeneic HSCT.

2.4 Any acceptance and exclusion criteria

Paediatric HSCT is a quaternary service and all referrals come from Consultant Paediatricians specialising in haematology, oncology, immunology or metabolic diseases.

Acceptance and exclusion criteria are defined by patient age and in accordance with the nationally agreed indication list (UK Paediatric HSCT Group Indications December 2011).

The categories within this classification include four groups:

- **S:** Standard of care, generally indicated in suitable patients
- **CO:** Clinical option, requires careful assessment of the risks and benefits
- **D:** Developmental, further trials are needed
- **GNR:** Generally not recommended

In a minority of cases transplantation will be performed as a component of a clinical trial.

All referrals are discussed by the local multidisciplinary teams. If a patient's disease and clinical status satisfies the criterion of category **S** the procedure will be routinely commissioned.

There is some evidence to support the use of some of the procedures within category **CO** in carefully selected patients, and they will be commissioned but audited by commissioners on an individual patient basis.

When appropriate IT infrastructure is available in the future, the intention is that these will be discussed in a national videoconference MDT in order to improve consistency of approach to utilise all available expertise in order to achieve best outcomes.

New proposals for activity in category **D** must be made in advance to NHS England. Upon agreement from NHS England, procedures in this category up to the value of 5% of the contracted sum may be supported subject to (i) clarity on the Research and Development basis and funding related to NHS service costs and (ii) sufficient funds are available within the budget for '**S**' work.

A procedure falling within the **GNR** category of the classification is not supported by research evidence of clinical and cost-effectiveness. It will therefore be commissioned by NHS England only in exceptional circumstances. Such cases will not be funded within the contract and authorisation must be sought from NHS England in each case as exceptional treatment requests through NHS England's Individual Funding Request (IFR) process.

2.5 Interdependencies with other services

- Radiotherapy services
- Adult BMT services
- Teenage cancer services
- All paediatric tertiary specialties including intensive Care

3. Applicable Service Standards

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

5th edition, FACT-JACIE Cellular Therapy Accreditation Manual

Produced by the Foundation for the Accreditation of Cellular Therapy (FACT).

JACIE accreditation in paediatric haemopoietic SCT (review) JM Cornish, Bone Marrow Transplantation (2008) 42, S82–S86

Commissioning safe and sustainable specialised paediatric services-a framework of critical interdependencies, DOH, October 2008

Improving outcomes in children and young people with cancer: guidance on commissioning services for young people.

Children and Young People Improving Outcomes Guidance (CYPIOG) Advisory Group, September 2008

The Future of Unrelated Donor Stem Cell Transplantation in the UK

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4. Key Service Outcomes

Mortality rates should be recorded at one and five years.

- Autologous day 100 treatment mortality should be less than 5%
- Allogeneic day 100 treatment mortality should be less than 30%

This requirement is in order to ensure the services can demonstrate one year and five year survival outcomes in line with national and international standards for children adjusted for case mix.

The level of progression free survival and overall survival will depend on a number of factors, including the disease group, the condition of the patient, the type of transplant offered and the degree of stem cell match. The service should demonstrate survival rates in line with national and international standards for children adjusted for case mix.

The service should demonstrate their processes to minimise the risk of and the management of treatment related complications, such as infections and graft versus host disease.

The service should provide long term quality of life monitoring and allogeneic transplant services should aim to provide a late effects service.

Transplant centres shall inform the lead commissioner of patients being entered into clinical trials and as HSCT is an area of rapid technological evolution; centres are expected, as a consequence to give research and clinical trial work a high priority.

The provider will agree with the commissioner on how outcomes of care will be

assessed by the provider. There will be an agreed basis for monitoring and sharing patient specific outcomes, both long term and short term with all providers.

Regular and documented clinical audit should be carried out. A planned programme for future clinical audits should be made available to the commissioner on an annual basis.

Each provider must share the results of the BMT programme with all referring clinicians with education and audit reviews (with emphasis on improving communication and collaboration between cancer centres and units).

All transplants should be registered with the BSBMT and the European Bone Marrow Transplant Register via the BSBMT Data Office.

There should also be arrangements in place for selective call back of patients by the provider on a long-term basis.

As a minimum commissioners will want to monitor by each provider separately for:

- 100 day survival post transplant.
- Overall survival rates.

Providers will be expected to provide full data to populate the national BMT dashboard, either directly or via the BSBMT registry as agreed with commissioners.

Additional relevant information will be agreed and may be a by-product of major trials of e.g. leukaemia, myeloma and lymphoma treatments.

Interim for Adoption from 01/10/13

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 – 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 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

1. GPAS Paediatric anaesthetic services. RCoA 2010 www.rcoa.ac.uk
2. CCT in Anaesthesia 2010
3. Continuous Professional Development 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:

- Ensures the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- Ensuring that staff handling medicines have the competency and skills needed for children and young people's medicines management
- Ensures that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability.

Providers should ensure that:

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

Interim for Adoption from 01/10/13