

## SCHEDULE 2 – THE SERVICES

### A. Service Specifications

<b>Service Specification No.</b>	E05/S(HSS)/a
<b>Service</b>	Cardiothoracic Transplantation Service (Paediatrics)
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	
<b>Date of Review</b>	

#### 1. Population Needs

##### 1.1 National/local context and evidence base

The service provides a comprehensive transplantation service for infants and children referred with cardiac or respiratory failure who have not responded to maximum conventional treatment and who are candidates for transplantation.

Clinical outcomes are monitored within the UK by NHS Blood and Transplant in collaboration with NHS England. Staff attendance at international meetings ensures that immunosuppression and surveillance are consistent with the best management internationally.

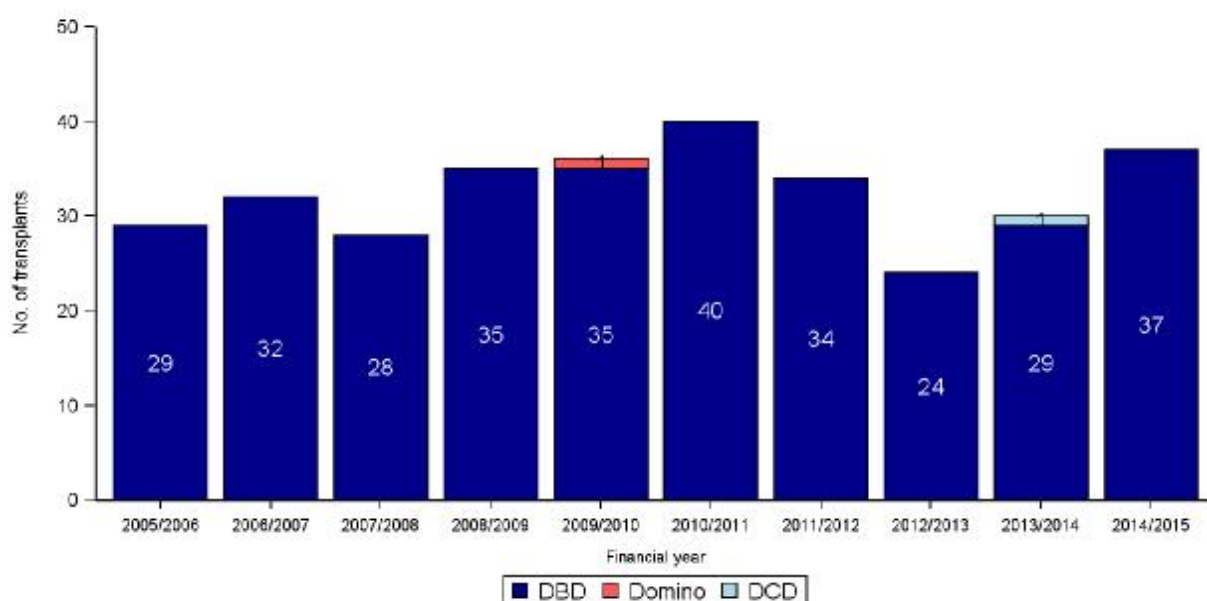
The service integrates smoothly with services for heart failure, cystic fibrosis/ respiratory medicine, and pulmonary hypertension. The service is closely integrated with the Respiratory ECMO for Children and Neonates Service and VADs for Children as a Bridge to Heart Transplant Service which are described in separate specifications published on the NHS England website.

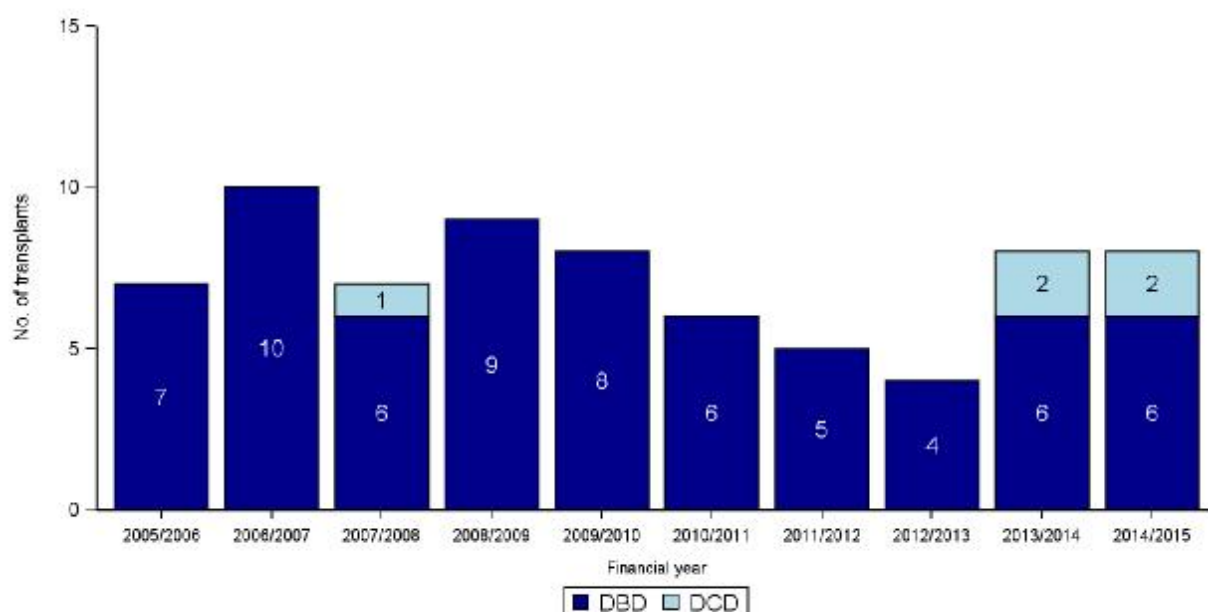
Few paediatric thoracic transplants are performed each year and consequently it is important that the service is limited to a few centres to ensure expertise is maintained.

The demand for heart transplant outstrips the supply of available organs.

Patients are listed for heart transplant if there are no contraindications and when their quality of life and survival are likely to be improved by a transplant. Patients are categorised as urgent or non-urgent. The development of Ventricular Assist Devices (VADs) has enabled some people with end stage heart failure to be supported till such time as a suitable donor heart is identified. VADs may also be used to treat reversible complications of heart failure that are potential contraindications to heart transplantation (e.g. kidney dysfunction, high pulmonary vascular resistance). The overall demand for heart transplantation is likely to increase with the use of this technology.

**Number of paediatric heart transplants in the UK, by financial year, 1 April 2005 to 31 March 2015**





### Number of paediatric lung transplants in the UK, by financial year, 1 April 2005 to 31 March 2015

#### Organ availability

NHS England does not commission organ retrieval. Organ retrieval and allocation is the responsibility for NHS Blood and Transplant (NHS BT).

NHS BT matches donated organs to candidates on the waiting list. Centres must be able to respond without delay. It is expected that individual centres will have fluctuating levels of activity.

The acceptable cold ischemic time for donated hearts is short compared to most other donated organs. This currently makes long distance transport of hearts undesirable, although organ retrieval from Europe is occasionally necessary because of limited paediatric organ supply.

This service aims to transplant all suitable cardiothoracic organs that are matched to recipients on the waiting list.

The service provides life-long aftercare related to the functioning of the grafted organ.

## 2. Outcomes

## 2.1 NHS Outcomes Framework Domains & Indicators

<b>Domain 1</b>	<b>Preventing people from dying prematurely</b>	✓
<b>Domain 2</b>	<b>Enhancing quality of life for people with long-term conditions</b>	✓
<b>Domain 3</b>	<b>Helping people to recover from episodes of ill-health or following injury</b>	✓
<b>Domain 4</b>	<b>Ensuring people have a positive experience of care</b>	✓
<b>Domain 5</b>	<b>Treating and caring for people in safe environment and protecting them from avoidable harm</b>	✓

The service provides assessment, treatment and follow up for children who need cardiothoracic transplantation.

Centres should assess all appropriate referrals and make a decision within 18 weeks on whether to list for a heart transplant. Patients anywhere in the country should have equal access to assessment for a transplant. Urgent referrals must be managed where necessary.

Centres should monitor patients on the waiting list and list for an urgent transplant or use mechanical circulatory support appropriately.

All centres use real time sequential monitoring of 30 day and 90 day mortality rates following cardiothoracic transplantation. This monitoring is conducted by NHS Blood & Transplant in collaboration with the Royal College of Surgeons Clinical Effectiveness Unit, Commissioners and providers are alerted to any trends that might indicate a significant increase in mortality rate.

Centres are compared to the national average mortality rate. The national audit also provides 1 year, 5 year and ten year outcome for each centre. The International Society for Heart and Lung Transplantation publishes figures for these outcomes that can be used for benchmarking as can the Paediatric Heart Transplant Study Group data. Waiting list deaths are monitored by NHS Blood and Transplant. The data on primary graft failure and use of ECMO and ventricular assist devices after transplant is also collected by NHS BT. The outcomes for bridge to transplant with mechanical support are submitted to NHS BT and to the Intermacs registry.

## 3. Scope

### 3.1 Aims and objectives of service

The national paediatric cardiothoracic transplantation service aims to provide heart transplantation to improve survival and quality of life for children with advanced heart failure and terminal lung disease who meet the service inclusion criteria.

This specification describes the national cardiothoracic transplantation service for children (17 and under) commissioned by NHS England.

The cardiothoracic transplantation service includes:

- Assessment of suitability of patients for transplantation
- Registration of appropriate patients with UK transplant authority
- Heart and/or lung transplantation including
  - pre-operative assessment,
  - hospital based care,
  - post-transplantation follow-up
  - long term follow up.

### 3.2 Service description/care pathway

The service is responsive to the availability of organs and recipients, and is able to operate 24 hours per days, every day of the year.

The service provides heart transplant and lung transplant assessment, surgery and life-long follow up for children (17 and under). The service operates closely with the bridge to heart transplant service for adults and the cardiothoracic transplantation service for adults.

A standard episode of care will include:

- pre-transplant assessment, immunology and tissue-typing of recipient
- follow- up of patients on the waiting list with repeat assessments as required
- admission
- transplant
- routine follow-up, including re-admission if necessary.
- Long-term lifelong follow-up at varying intervals (not less than 6 monthly); the frequency will depend on shared care arrangements with local cardiothoracic services. Readmission for allograft complications as required.

#### Pre-transplant assessment

### Pre-transplant assessment

Referrals are from paediatric cardiologists or paediatric respiratory physicians. Infants and children referred with end stage heart or lung disease who have failed to respond to maximum conventional treatment and who are candidates for transplantation. This broadly encompasses a group of patients with the diagnoses of cardiomyopathy, congenital heart disease, cystic fibrosis and primary pulmonary hypertension.

For any urgent listing there must be agreement between the two paediatric centres. This should involve the clinical leads or in their absence an appointed deputy. If there is disagreement this should be noted at the time of discussion with the chair of the Cardiothoracic Transplant Advisory Group (CTAG).

The patient must be deemed likely to survive the transplant procedure in order to be a candidate.

The service follows the *National Protocol for Assessment of Cardiothoracic Transplant Patients*. A summary is given below:

- Multi-disciplinary involvement: The assessment should involve a whole spectrum of healthcare professionals, including physicians, surgeons, radiologists, nurses, transplant co-ordinators, pharmacists, occupational therapists, dieticians, physiotherapists, social workers, psychologists (if indicated psychiatrists).
- Assessment stages:
- Referral letter and/or proforma with details
- Pre-assessment outpatient clinic when appropriate
- In patient assessment (including management of advanced heart failure)
- Decision
- Waiting List

### **Objectives of assessment procedures:**

- To assess the patient's clinical, social and psychological suitability as a transplant recipient
- To modify therapy as appropriate.
- To impart factual information to the patient and his/her family concerning all aspects of transplantation
- To meet hospital staff and transplant patients
- To provide an opportunity for the patient, and his or her family, to begin to come to terms with the prospect of transplantation, and to be informed about the procedure and its aftermath
- The general condition of the patient is such that cardiothoracic transplantation will allow the patient a realistic chance of prolonging a good quality of life.

### **Assessment outcome:**

- If the patient and family decide to go forward for transplantation, he or she is then

registered with NHS Blood & Transplant and placed on the waiting list.

- If the patient is not deemed suitable and/or declines the option of transplantation the clinician explains to the patient and their family the options available to them.
- The GP and referring clinicians are informed of the outcome of the assessment.

### **Waiting times**

- This Service Specification does not cover care received by the patient whilst waiting for a suitable organ to become available. This may involve a period of intensive care unit (ICU) inpatient care (often on inotropes, and/or ventilated and/or mechanical support). Others will require outpatient visits and repeat assessments depending on their clinical condition.
- NHS Blood and Transplant has operated an urgent heart allocation scheme since 1999. This enables centres to register patients with a rapidly deteriorating condition as a higher priority than patients with a stable condition.
- Waiting times are influenced most significantly by a patient's body size, blood group and primary diagnosis (NHS Blood and Transplant International Society for Heart and Lung Transplantation). Pre-school children who are dependent on paediatric organ donation have long waits. Access to the urgent list in children under 15kg is limited to those ventilated or on mechanical support.

Transplantation is required for patients who have end stage heart or lung disease and have failed to respond to maximum conventional treatment and who are suitable candidates for transplantation. Consequently many paediatric transplant patients require mechanical support prior to transplantation. Some mechanical support prior to heart transplantation is commissioned by the NHS England under separate specifications. ECMO is also commissioned and is used to support to transplant. Mechanical support to lung transplant has not been used in children in the UK because of the long waiting times for transplant.

### **Admission**

- It is the patient's responsibility to make themselves available to be contacted by the transplant centre at any time.
- Once an available organ has been matched to a recipient:
- The relevant centres should respond to the offer within one hour.
- The patient is alerted and asked to make their way to the transplant centre.
- Every effort should be taken to minimise the occasions on which a patient is admitted but a transplant operation does not proceed because:
  1. the patient is not medically fit,
  2. or the necessary clinical resources (e.g. staff, operating theatres) are unavailable.

### **Transplantation**

- Individual centres should provide assurance that individual surgeons are working at safe and sustainable levels, avoiding risks associated with excessive hours and

with occasional practice.

- Mechanical support of the graft post-transplant is commissioned by NHS England within this specification.

### **Initial follow-up**

- There should be arrangements for direct 24 hour emergency access after discharge.
- The follow-up process must run for the period of time agreed with the referring clinician but will need to be lifelong in most patients as expertise in managing immunosuppression is not normally available at referring centres.
- The follow-up process must be based in the transplant centre for the first year.

### **Long-term follow-up**

- Subsequent follow-up will be on a defined frequency (not less than six monthly) and will depend on shared care arrangements with local cardiothoracic services and patient need.
- Routine follow-up is intended to identify and manage any emerging problems of graft function and complications associated with immunosuppression:
- Shared care arrangement may be developed for routine investigations which may be administered without specialist centre input (see clinical standards);
- And if necessary, a patient may need to be reassessed for transplantation.
- Clear arrangements should be in place for the safe planned transition from child to adult follow-up services.
- Each centre should ensure that patients are offered a choice of transplant centre at which to receive routine follow-up care, and this will be important to review if a patient changes their home address.
- NHS England commissions the supply of post-transplant immunosuppressants from the transplant centre. Long-term prescribing of these drugs will come under the control and responsibility of the Centres
- Consideration needs to be given to the availability of generic immunosuppressants and the importance of maintaining consistent supply of the same “brand”. Hence, immunosuppressants (both the innovator brand and branded generics) will be prescribed by brand and referred to by that brand in all correspondence (see Medicines and Health products Regulatory Agency guidance).

### **Transition**

- Patients transition from child to adult services between 16 and 18 years of age, when considered appropriate by the patient, family and clinical team. Transition from child to adult cardiothoracic transplant will occur in a staged fashion, with the timing and pace to be tailored to the needs of each individual patient

### **Risk Management**

- Service providers are responsible for managing the logistical arrangements for on-call teams, clinical resources, and recipient coordination. UK units to work towards



a safe and sustainable number of consultant surgeons capable of undertaking heart or lung transplantation and involved as part of a left ventricular assist devices (LVAD) programme. A department may have different surgeons in each team but must have a sufficient number to publish a robust on-call rota. It is recommended that all service providers work towards a minimum of two heart failure and transplant cardiologists per unit and 2 paediatric chest physicians to provide a sustainable service.

- The staff and facilities covered by the baseline investment for cardiothoracic transplantation should not be used to cross-subsidise local services. There must be a priority given to nationally commissioned referrals for transplant/VAD over general cardiothoracic work. The latter can be provided in the designated centres in the UK. Adequate capacity to accept all emergency heart failure and potential VAD/ECMO referrals should exist in the 2 paediatric transplant units.
- When surgical teams treat patients who have, or are at risk of having transmissible spongiform encephalopathies (including variant Creutzfeldt-Jakob disease, vCJD), there is a risk of contaminating the instruments used during their surgery and hence transmitting the infection to subsequent patients in whom the same instruments are used. Special decontamination measures are required by Department of Health policy. Some instruments cannot be fully decontaminated, in which case policy requires destruction of the instrument. The full guidance is set out at. Patients with or at risk of vCJD present to all parts of the NHS and the same precautions are needed. Hence costs of treating patients with this condition, including destruction of surgical instruments where necessary, are included in average costs.
- This service specification does not limit the pharmacological treatment options available with regard to transplant care, provided they are met within the existing level of investment. This includes desensitisation due to graft-recipient mismatch.
- All providers offering a service to patients less than 18 years of age should ensure compliance with the standards set out in Annex 1, Provision of Services for Children.

### **Discharge planning**

Patients may be removed from the waiting list if their clinical status has changed and transplantation is no longer the appropriate treatment. Patients may also be removed from the waiting list if they no longer wish to be considered for transplantation. The clinician would explain to the patient and their family the options available to them. The GP and referring clinicians will be informed.

The management of the patient's immunosuppression is ideally done by the transplant cardiologist; all patients should ideally be reviewed by the transplant centre at least annually with more frequent visits if complications arise. This will include a regular review of their immunosuppressive therapy which will be tailored to prolong the life of their transplant whilst minimising the risk of drug related side effects.

### 3.3 Population covered

NHS England commissions the service for the population of England. Commissioning on behalf of other devolved administrations is reviewed annually, and a current list is available from NHS England commissioners.

NHS England contract includes provision for the service to treat eligible overseas patients under S2 [Under EU regulations, patients can be referred for state funded treatment to another European Economic Area (EEA) member state or Switzerland, under the form S2 (for EU member states) or the form E112 (for Iceland, Norway, Liechtenstein and Switzerland)] referral arrangements. Providers are reimbursed for appropriately referred and recorded activity as part of NHS England contract.

Trusts performing procedures on EU-based patients outside of S2 arrangements will need to continue to make the financial arrangements directly with the governments involved, separately from their contract with NHS England.

### 3.4 Any acceptance and exclusion criteria and thresholds

All centres must be able to respond to the offer of a suitable organ within agreed protocols. Transport of patients to the transplant centre is not funded as part of this service.

#### Acceptance criteria

See the National Protocol for Assessment of Cardiothoracic Transplant Patients.

The Provider has a duty to co-operate with the commissioner in undertaking Equality Impact Assessments as a requirement of race, gender, sexual orientation, religion and disability equality legislation

Evidence suggests that age, gender, year of registration and cytomegalovirus status were not significant in determining waiting times once someone had been accepted on to the transplant list.

An audit of geographical access will be completed no less than once every two years.

#### Exclusion criteria

See the National Protocol for Assessment of Cardiothoracic Transplant Patients.

Patients aged 16 or older may be accepted by the cardiothoracic transplantation service for adults.

The cardiothoracic transplantation service for children accepts patients up to the age of 17 at the point of transplantation.

Post transplant patients over the age of 16 may have responsibility for their care transferred from child to adult cardiothoracic transplantation providers.

### **3.5 Interdependencies with other services/providers**

Heart transplant is an intervention for the treatment of end stage heart failure. The national service has interdependencies with cardiothoracic services, ventricular assist device services. The service for Ventricular Assist Devices is defined in a separate service specification. The increasing number of paediatric heart and/or lung transplant survivors creates interdependencies between the adult and child programmes for life-long follow-up.

Patient and survivor groups include:

- British Heart Foundation
- British Lung Foundation
- British Congenital Cardiac Association
- Patient groups at each hospital

Trusts commissioned to provide paediatric cardiothoracic transplant services must also have been commissioned to provide level 1 paediatric congenital heart disease surgery.

## **4. Applicable Service Standards**

### **4.1 Applicable national standards**

- All providers will meet standard NHS governance requirements.
- All providers will comply with transplantation guidance and policies as agreed by the NHS Blood and Transplant Cardiothoracic Transplant Advisory Group.
- There is a requirement to hold national audit meetings involving all designated centres on an annual basis.
- Each centre must ensure that:-
  1. All practitioners participate in continuous professional development and networking

2. Patient outcome data is recorded and audited across the service
3. All centres must participate in the national audit commissioned by NHS England. Audit meetings should address:
  - Clinical performance and outcome
  - Process-related indicators e.g. efficiency of the assessment process, prescribing policy, bed provision and occupancy, outpatient follow-up etc.
  - Stakeholder satisfaction, including feedback from patients, their families, referring clinician and General Practitioners doctors and GPs.
- Clinical teams are expected to participate actively in clinical networks to improve the national cardiothoracic transplantation service

#### 4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

There are no current guidelines related to paediatric heart or lung transplantation published by the British Royal colleges.

<http://www.ncbi.nlm.nih.gov/pubmed/20643330>

Costanzo MR, Dipchand A, Starling R, Anderson A, Chan M, Desai S, Fedson S, Fisher P, Gonzales-Stawinski G, Martinelli L, McGiffin D, Smith J, Taylor D, Meiser B, Webber S, Baran D, Carboni M, Dengler T, Feldman D, Frigerio M, Kfoury A, Kim D, Kobashigawa J, Shullo M, Stehlik J, Teuteberg J, Uber P, Zuckermann A, Hunt S, Burch M, Bhat G, Canter C, Chinnock R, Crespo-Leiro M, Delgado R, Dobbels F, Grady K, Kao W, Lamour J, Parry G, Patel J, Pini D, Towbin J, Wolfel G, Delgado D, Eisen H, Goldberg L, Hosenpud J, Johnson M, Keogh A, Lewis C, O'Connell J, Rogers J, Ross H, Russell S, Vanhaecke J; International Society of Heart and Lung Transplantation Guidelines.

J Heart Lung Transplant. 2010 Aug;29(8):914-56. doi: 10.1016/j.healun.2010.05.034.

Relevant National and International Guidelines on adult lung transplantation which has relevance for children are:

1. UK Guidelines for Lung Transplantation Referral (available via NHSBT).
2. International Guidelines for the Selection of Lung Transplant Candidates: 2006 Update-A Consensus Report from the ISHLT Pulmonary Scientific Council (Consensus Document) (J Heart Lung Transplant 2006;25(7):745-755)
3. A Review of Lung Transplant Donor Acceptability Criteria (Consensus Document) (J Heart Lung Transplant 2003;22(11):1183-1200)

## 5. Applicable quality requirements and CQUIN goals

### 5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

There is a requirement to hold national audit meetings involving all designated centres on an annual basis.

Each centre must ensure that:-

1. All practitioners participate in continuous professional development and networking

2. Patient outcome data is recorded and audited across the service

3. All centres must participate in the national audit commissioned by NHS England. Audit meetings should address:

- Clinical performance and outcome
- Process-related indicators e.g. efficiency of the assessment process, prescribing policy, bed provision and occupancy, outpatient follow-up etc.
- Stakeholder satisfaction, including feedback from patients, their families, referring clinician and General Practitioners doctors and GPs
- National access to the service

## 5.2 Applicable CQUIN goals (See Schedule 4 Part E)

To be agreed with the Commissioner.

## 6. Location of Provider Premises

The Provider's Premises are located at:

Provider	Paediatric
The Newcastle upon Tyne Hospitals NHS Foundation Trust	Yes
Great Ormond Street Hospital, London	Yes

## 7. Individual Service User Placement

Not applicable.

## Appendix Two

## Quality standards specific to the service:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
<b>Domain 1: Preventing people dying prematurely</b>			
Heart and lung transplant (children) Y 30-day mortality Y 90-day mortality	CUSUM trigger	CUSUM monitoring	Agreed escalation policy for CUSUM triggers
<b>Domain 2: Enhancing the quality of life of people with long-term conditions</b>			
Document refused admissions	All referrals should be transferred to one or other unit within 24 hrs of referral. If both units are full then liaison with adult VAD units / funded paediatric ECMO units should be the responsibility of the transplant centre		To be addressed in annual service audit meeting
Length of wait on waiting list	In line with heart availability	Waiting list analysis NHS Blood and Transplant report every 6 months	
<b>Domain 3: Helping people to recover from episodes of ill-health or following injury</b>			
Proportion of patients receiving annual review at transplant centre	95%	Annual audit	To be addressed in annual service audit meeting
<b>Domain 4: Ensuring that people have a positive experience of care</b>			
Audit of patient experience questionnaire	Patient experience to be audited at least every 3 years.	Report produced	To be addressed in annual service audit meeting
<b>Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm</b>			
SUI and never events	Zero	STEIS .	Root cause analysis

## **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 (Health Service Circular 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 (DH)

#### Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' DH 13732 March 2010). Within the network:

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements



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- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists and radiographers will have appropriate training, supervision and access to continuing professional development
- 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.<sup>1</sup> All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training<sup>2</sup> and should maintain the competencies so acquired<sup>3</sup> \*. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing 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. Guidelines for the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. RCoA 2010 [www.rcoa.ac.uk](http://www.rcoa.ac.uk)
2. Certificates of Completion of Training (CCT) in Anaesthesia 2010
3. Continuing Professional Development (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 person's 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).

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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

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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 is contacted if necessary.
- A18.10 There are written procedures for the assessment of pain in children and the provision of appropriate control.

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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:

- 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.