SCHEDULE 2 – THE SERVICES

# A. Service Specifications

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| **Service Specification No:** | 1643 |
| **Service** | Small bowel transplantation service (Paediatrics) |
| **Commissioner Lead** | *For local completion* |
| **Provider Lead** | *For local completion* |

## 1. Scope

### 1.1 Prescribed Specialised Service

This service covers the provision of assessment, transplantation and lifelong follow up of paediatric patients requiring small bowel transplantation.

### 1.2 Description

Small bowel transplantation services include services provided by Highly Specialist Small Bowel Transplant Centres. This applies to provision in the paediatric population.

### 1.3 How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners

NHS England commissions small bowel transplantation services for children from Highly Specialist Bowel Transplant Centres.
CCGs do not commission any elements of this service.
Activity is identified via local data flows, which apply to Highly Specialist Small Bowel Transplant Centres only.

## 2. Care Pathway and Clinical Dependencies

### 2.1 Care Pathway

Please note that access to treatment will be guided by any applicable NHS England national clinical commissioning policies.
This specification relates specifically to transplantation and in terms of this specification begins when the patient undergoes assessment for transplantation prior to joining the transplant list. The key components of the service are:

- pre-transplant assessment;
- listing;

- transplant;
- management of complications;
- post-transplant follow up
- longer term follow up

The transplant pathway will be delivered by the specialist small bowel transplant centres. The infrastructure will include the necessary resources of staffing, beds, access to theatres, access to H&I services and the interdependencies described in this specification. This must be supported by an MDT process and a robust clinical governance structure including clinical audit. Patients should have a nominated lead clinician to manage their care at each stage of the pathway.

The specialist MDT should include:
- a paediatric hepatologist
- a paediatric transplant surgeon
- paediatric gastroenterologists/ intestinal failure specialists
- paediatric anaesthetist with experience in small bowel transplantation
- specialist nurses / recipient co-ordinator
- paediatric surgeon (interest in intestinal failure/non-transplant surgery)

With the addition of extended MDT membership as necessary:
- clinical psychologist
- diagnostic radiologists
- interventional radiologists
- transplant histopathologist
- microbiologist with an interest in the care of immunosuppressed patients
- dietitian
- pharmacist
- physiotherapist
- H&I scientist
- nutritional care team
- other paediatric speciality doctors

**Assessment**

It is expected that timely investigation and written referral to the transplant team, together with appropriate information for the patient is provided during the transplant pathway.
All patients will undergo a multidisciplinary assessment prior to be being put on the waiting list. Patients will be placed on, or moved off the waiting list after discussion with the MDT and the patient. The provider is required to copy all correspondence with patients and between consultants and the patient's GP.

**Transplant listing**

When a patient has completed their assessment and is considered a suitable transplant candidate they will be entered onto the waiting list as soon as possible. This will be the responsibility of the recipient transplant co-ordinator (or other named person). Patients will be made aware of their activation status.

**Follow up care**

All transplant recipients require regular follow up post-operative care. Follow up must be patient focused and units should consider shared care arrangements with local blood tests and telephone follow up in addition to clinic visits.

The transplant centre remains responsible for all patient follow up care and any changes in therapy. The management of the patient’s immunosuppression will be managed by the transplant centre. Subsequent follow-up will be on a defined frequency (not less than annually) and will depend on patient need.  Routine follow-up is intended to identify and manage any emerging problems of graft.  Shared care may be initiated with the referrer.

The long term care of transplant recipients will include a holistic assessment of the patient’s progress along with pre-emptive strategies to minimise future health, physical and psychological problems. 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 side effects. Services will have a co-located pharmacy. In addition, patients will have their risk of future cardiovascular and bone disease assessed with steps taken to minimise these risks. Patients will be made aware of their increased risk of malignancy and counselled about appropriate changes in their lifestyle. Post-transplant patients will be encouraged to attend cancer screening programmes if appropriate.

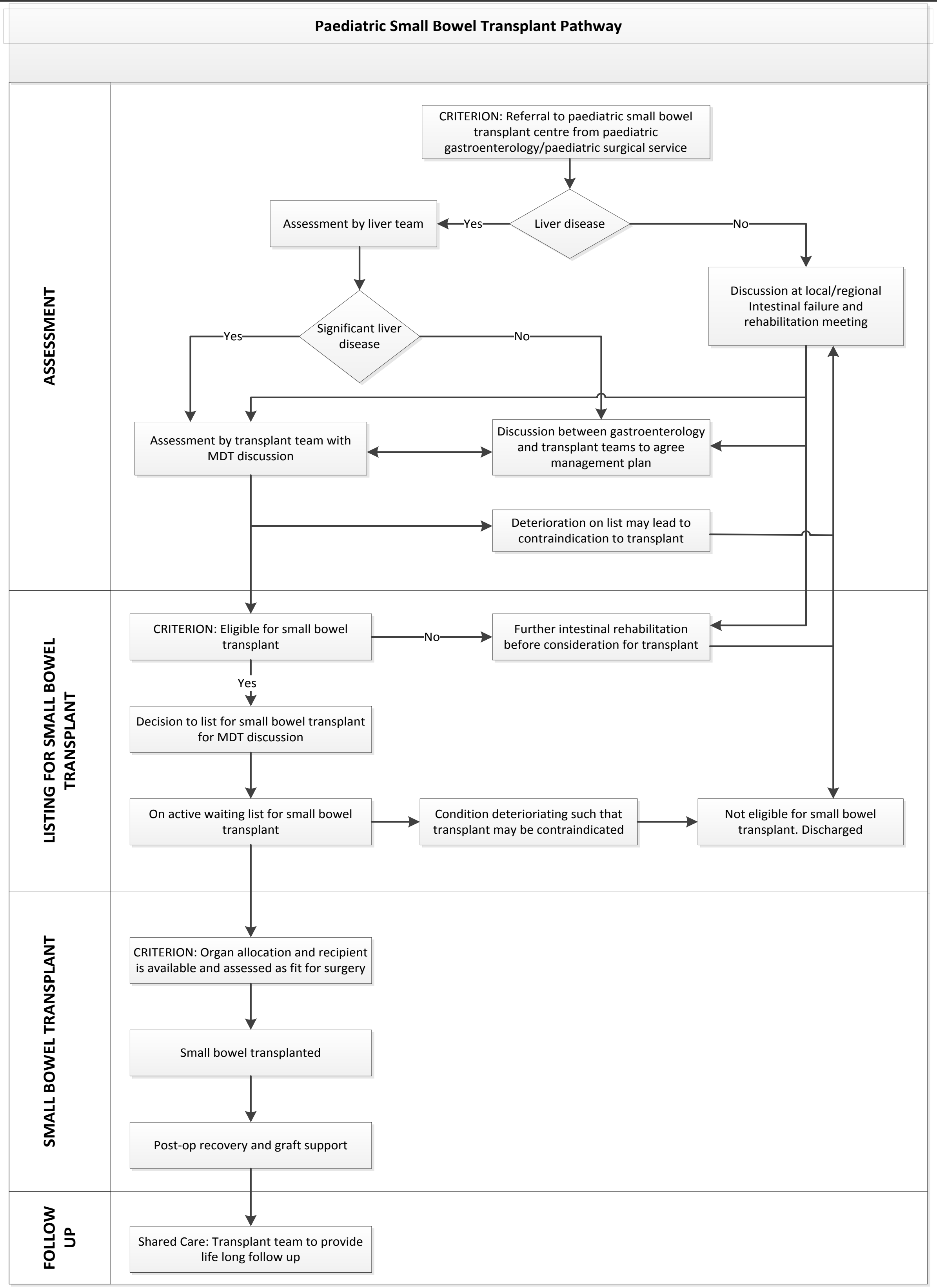
Provision for post-transplant HLA specific antibody monitoring and investigation of humoral rejection episodes will be part of the transplant service. Acute humoral or antibody mediated rejection (AMR) is attributed to the presence of alloantibodies against the graft, which could be either antibodies against human leukocyte antigens (HLA)- class I and/or II, non_HLA antigens or endothelial antigens. Diagnosis of AMR is made through the tissue biopsy and presence of antibodies i.e donor-specific antbodies (DSA). In intestinal transplantation the histopathological changes are not well characterised and lack of sensitivity of immunostaining of C4d has led to diagnostic and treatment dilemmas of humoral rejection. The question of whether humoral rejection/antibody mediated rejection contributes to long term graft damage remains unanswered.  Patients who have a failing transplant will be identified at an early stage as outlined in this specification to ensure that they are prepared for the next stage of treatment.

A consultant level healthcare professional will be available for every transplant clinic. Access to a dietician, pharmacist and clinical psychologist are essential. The routes to access social services and other support services will be offered to those patients requiring them.

**Transition**
Transition in health care is recognised as a developmentally mediated process which ensures optimal health and wellbeing outcomes for young people as they move, in partnership with their health care teams, towards and into adult services and lifestyles.

The transition pathway should enable young people (and their parents and carers) to become and remain active partners in their care, prepare for transfer(s) and engage with adult health services, through the provision of a transition process that is based on developmentally appropriate care planning which is introduced in the paediatric service and continued in adult services and described by a transition care pathway which has been co-designed by paediatric and adult services, young people and their parent carers. This is shared with Primary Care to ensure GPs have the relevant information to support young people (and their parent carers) during and after transition.

Patients will transition from paediatric 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 small bowel transplant services will occur in a staged fashion, with the timing and pace to be tailored to the needs of each individual patient. Patients and families should have the opportunity to meet a clinician from the adult team in a supported manner prior to transfer.


Paediatric Small Bowel Transplant Pathway

### 2.2 Interdependence with other Services

The pathway begins when the patient undergoes surgical assessment for transplantation prior to being added to the waiting list. For this section the spell of care is defined at the inpatient episode for the actual transplant surgery. Optimum delivery of the agreed pathways requires effective working relationships with the following services and organisations, but not limited to:

Co-located services (need to be provided on the same site)

- Intensive care
- Theatre and anaesthetic departments
- Radiology (including interventional radiology)
- Pharmacy
- Dietetics
- Allied health professionals (including physiotherapy)
- Histopathology
- Clinical Psychology
- Blood transfusion

Interdependent services (needed during the spell of care)

- Nephrology
- Gastroenterology
- Microbiology/infectious disease
- Cardiology (cardiopulmonary assessment and investigations)
- Histocompatibility and Immunogenetics (H&I) laboratory (accredited by Clinical Pathology Accreditation (CPA) / United Kingdom Accreditation (UKAS))

Related services (preceding or following the spell of care)

- Adult Small Bowel transplantation centres
- Primary care
- Histopathology
- Haematology/oncology for management of patients with post-transplant lymphoproliferative disorders
- NHSBT – listing and allocation

Human Tissue Authority – regulatory approval; competent authority for the EU Organ Donation Directive on the Quality and Safety of Organs.

## 3. Population Covered and Population Needs

### 3.1 Population Covered By This Specification

This service specification covers the population defined as the commissioning responsibility of NHS England. Commissioning arrangements for the devolved nations in relation to this service are as set out in UK-wide Commissioning Arrangements of Highly Specialised Services on the NHS England website.

The NHS England contract includes provision for the service to treat eligible patients from overseas under S2 and aligned referral arrangements. Providers are reimbursed for appropriately referred and recorded activity as part of this contract.

**Acceptance criteria**
The service will accept inward referrals from intestinal failure, gastroenterology, hepatology and other specialist services.

The service will accept referrals for all patients who are medially suitable regardless of gender, ethnicity, disability, faith or sexual orientation.

**Exclusions**
Absolute exclusion criteria for assessment are covered by the listing criteria for transplantation. Patients over the age of 18 are excluded from this service specification.

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

### 3.2 Population Needs

The small bowel and multi-visceral transplant service was established in the UK in the early 1990s. The number of transplants in paediatric recipients has remained fairly stable since the programme was established but fewer than 5 transplants are usually carried out in children each year. Most years there are fewer than 10 patients on the waiting list. So numbers are small but the service should now be routinely considered for patients with life threatening complications of bowel (intestinal) failure which may be caused by one of the following conditions:
1. Short bowel syndrome (which occurs after previous bowel operations in which a large amount of bowel has had to be removed) such as gastroschisis, volvolus and necrotising enterocolitis (NEC)
2. Motility disorders such as hirschprungs disease and intestinal pseudo-obstruction.
3. Mucosal disorders (defective inner lining of the bowel) such as microvillous inclusion disease, and tufting enteropathy.

### 3.3 Expected Significant Future Demographic Changes

It is expected that the service will remain fairly stable in future, with possibly small growth dependent on the number of donor organs made available.

### 3.4 Evidence Base

Intestinal failure (in infants and children is a devastating condition. Total parenteral nutrition (TPN) is the treatment of choice for patients with intestinal failure. Advancements in neonatal care, nutritional support, and surgical techniques have improved the survival of children with intestinal failure. Intestinal and multivisceral transplantation provides an alternative for patients who have life-threatening complications of TPN. The results of bowel transplantation continue to improve but remain somewhat inferior to other common organ transplants such as liver or kidney transplantation. There has been improved survival following intestinal transplantation with advances in surgical techniques and improved understanding of the monitoring and treatment of rejection and opportunistic infections. Approximately two thirds of patients make a long term recovery and around 90% of these patients are off intravenous feeding.

Early referral of the patients for intestinal transplantation yields improved survival results as patients are transplanted in a stable condition. Post-transplant prognosis is also improved when transplantation is performed prior to the onset of liver failure and prior to the exhaustion of all routes of vascular access.

The recovery time is also significantly longer after intestine transplantation. The levels of immunosuppression medicines required after intestinal transplantation are greater than prescribed for other transplants. Acute rejection is commonly seen after transplantation and requires additional treatment with immunosuppression medication, usually with big doses of corticosteroids and early use of monoclonal antibodies. Intestine transplant patients are also more prone to develop some additional complications including opportunistic viral infections, graft versus host disease, post-transplant lymphoproliferative disease and rare forms of haemolytic anaemia. A small proportion of patients develop late onset acute rejection or chronic rejection several months or years after transplantation and sometimes the transplanted bowel needs to be removed. The service includes those patients requiring repeat transplantations.

Trevizol et al studied the procedure over a 5-year period and reported a 1-year patient survival rate of 80%, but survival decreases after the first year to less than 70%..The International Registry for Intestinal Transplantation reports that graft and patient survival rates have improved, with a 80% 1-year patient survival rate and a 65-70% 5 yr patient survival rate.

## 4. Outcomes and Applicable Quality Standards

### 4.1 Quality Statement – Aim of Service

The aim of the service is to provide comprehensive care to patients who either require or who have received a small bowel transplant. The service is commissioned to provide a comprehensive assessment, transplantation and follow up service to eligible patients who are fit enough to undergo the procedure. This service aims to improve the quality and length of life of patients undergoing the procedure and to have outcome figures at least comparable to the best centres internationally.

There are four procedures performed as part of the intestinal transplant programme:

- intestine alone
- liver and intestine;
- multi-visceral - three or more abdominal organs, including liver, stomach, intestine and pancreas;
- modified multi-visceral - two or more abdominal organs, including stomach, intestine and pancreas.

All patients receive an artificial opening of the bowel onto the abdominal wall called a stoma. This allows the transplant team to assess how the transplanted bowel is functioning and allows easy access for biopsies and also for endoscopic examination of the transplanted bowel. Sometimes the patient’s abdomen cannot be closed immediately and it may take several days to achieve closure. During this time the patient remains on the intensive care unit.

Providers of small bowel transplant services will ensure that as a minimum the following care is provided:

- Equity of access to transplantation regardless of point of referral and location
- Clear and unambiguous care pathways, supported by the provision of culturally appropriate information; specifically in relation to :
- – The counselling of patients and relatives/carers regarding the risks and benefits of transplantation
- – Explanation of tests, procedures and results
- – Outcome of assessment and review to be documented in a letter to the patients detailing discussions and agreed shared decision reached, including those patients who are not suitable
- – Information and education about immunosuppressive therapy

Safe, effective, evidence-based care, delivered through effective pathways of care, in particular through the provision of:

- Detailed recipient assessment (including cardiac assessment) and annual transplant focused review whilst on the transplant list
- A surgical assessment of each patient prior to being placed on the national transplant list
- H&I assessment pre- and post-transplant
- Timely operating theatre and relevant staffing availability to ensure optimal cold ischaemia times
- Effective immunosuppressive therapy
- Effective preventive therapy to control infections
- Prevention/management of long term conditions and co-morbidities particularly with respect to cardiovascular disease, infection and cancer
- post-transplantation follow-up
- long term follow up

Specialist transplant centres will have a process/system to ensure patients are added to the waiting list and that the list is regularly reviewed and updated; small bowel offers from NHSBT are reviewed in a timely manner; and ensuring the requirements of the European Union (EU) Organ donation Directive are met.

**NHS Outcomes Framework Domains**

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

## 4.2 Indicators Include:

| Number | Indicator | Data Source | Outcome Framework Domain | CQC Key question |
|---|---|---|---|---|
| **Clinical Outcomes** | | | | |
| 101 | Number of paediatric patients on intestinal transplant list | NHSBT | 1,2, | effective |
| 102 | Number of paediatric transplants | NHSBT | 1,2,3 | effective |
| | Median time from referral to being added to waiting list | NHSBT | 1,2,3 | effective |
| 103 | Median time on list | NHSBT | 1,2,3 | effective |
| | % of donor offers declined | NHSBT | 1,2,3 | effective |
| 104 | Median cold ischaemia times | NHSBT | 1,2,3 | effective |
| 105 | 90-day patient survival (%) for paediatric elective first intestine transplants | NHSBT | 1,2,3 | effective |
| 106 | 1 year patient survival (%) for paediatric elective first intestine transplants | NHSBT | 1,2,3 | effective |
| 107 | 5 year patient survival (%) for paediatric elective first intestine transplants | NHSBT | 1,2,3 | effective |
| 108 | % graft survival at 90 days | NHSBT | 1,2,3 | effective |
| 109 | % graft survival at one year | NHSBT | 1,2,3 | effective |
| 110 | % graft survival at 5 years | NHSBT | 1,2,3 | effective |
| 111 | Length of stay for transplant episode | HES | 1,2,3 | effective |
| **Patient Experience** | | | | |
| 201 | There is a communication policy | Self declaration | 4 | Responsive, caring |
| 202 | Patients are provided with information | Self declaration | 4 | Responsive, caring |
| 203 | Patient experience is reviewed | Self declaration | 4 | Responsive, caring |
| **Structure and Process** | | | | |
| 001 | There is a specialist multidisciplinary team | Self declaration | 1,2,3,5 | Well led, effective, Safe |
| 002 | There is a MDT assessment /listing meeting | Self declaration | 1,2,3,5 | effective, Safe |
| 003 | There are patient pathways in place | Self declaration | 1,2,3,5 | effective, Safe |
| 004 | There are pathways in place for transition from children's to adult services | Self declaration | 1,2,3,5 | effective, Safe |

| | | | | |
|---|---|---|---|---|
| 005 | There are clinical guidelines in place for assessment preparation and transplant | Self declaration | 1,2,3,5 | effective, Safe |
| 006 | There are clinical guidelines for follow up in place | Self declaration | 1,2,3,5 | effective, Safe |

When considering which patients should be offered intestinal transplantation, the factors are complex, but can in the main be distilled down to survival advantage and quality of life. Both are influenced by the underlying disease, complications of parenteral nutrition and the aspirations and psychological attitude of the patient.

The service will be expected to provide accurate timely data to NHS Blood and Transplant (NHSBT). This will enable NHS England to monitor outcomes. Adult outcomes in the service are monitored continuously by NHSBT and discussed at its bowel advisory group (BAG) to make recommendations on future management. The provider is expected to action any such recommendations in a timely manner.

The provider will ensure that practitioners are compliant with continuous professional development requirements.

By exception providers should alert commissioners to difficulties in succession planning.

**Detailed definitions of indicators, setting out how they will be measured, is included in schedule 6.**

**4.3 Commissioned providers are required to participate in annual quality assurance and collect and submit data to support the assessment of compliance with the service specification as set out in Schedule 4A-C**

**4.4 Applicable CQUIN goals are set out in Schedule 4D**

## 5. Applicable Service Standards

### 5.1 Applicable Obligatory National Standards

Human Tissue Authority (HTA) guidance for Transplant Teams and Independent assessors (2014)

- Providers will meet standard NHS governance requirements.
- Providers will comply with the agreed transplantation policies and guidance of NHS Blood and Transplant and the Multivisceral and Composite Tissue 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 GPs.
- Equity of access to services.
- Learning from peer review.

### 5.2 Other Applicable National Standards to be met by Commissioned Providers

EU Organ Donation Directive (2010)

### 5.3 Other Applicable Local Standards

Not applicable

## 6. Designated Providers (if applicable)

Birmingham Children’s Hospital NHS Foundation Trust

Kings College Hospital NHS Foundation Trust

## 7. Abbreviation and Acronyms Explained

The following abbreviations and acronyms have been used in this document:

NHS BT – NHS Blood and Transplant
H&I - Histocompatibility and Immunogenetics
HLA – Human leukocyte antigen
CCGs – Clinical Commissioning Groups
HPN - Home parenteral nutrition
TPN = Total parenteral nutrition
MDT – Multi-disciplinary team
NASIT - National Adult Small Intestinal Transplantation forum
CPA – Clinical Pathology Accreditation

Date published: *<insert publication date>*

## 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 are 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

### Imaging

All services will be supported by a 3 tier imaging network (‘*Delivering quality imaging services for children*’ Department of Health 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
- 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.[1] 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[2] and should maintain the competencies so acquired[3] *. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example MRI scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

*The Safe and Sustainable reviews of paediatric cardiac and neuro- sciences in England have noted the need for additional training and maintenance of competencies by specialist anaesthetists in both fields of practice.

### References

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

- CPD matrix level 3

**Specialised Child and Adolescent Mental Health Services (CAMHS)**

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in- patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following:
- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply (http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family are allowed to visit at any time of day taking account of the child / young persons need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child/young persons care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child/ young person.

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

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)
- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of 2RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes HBN 23 Hospital Accommodation for Children and Young People NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce

Development Council Induction standards (Outcome 14b Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002).”Facing the Future” Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking Consent: working with children Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.
- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- Having effective means of receiving and acting upon feedback from people who use services and any other person
- Taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
    - having clear procedures followed in practice, monitored and reviewed that
    - take account of relevant legislation and guidance for the management of alleged abuse
    - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
    - reporting the alleged abuse to the appropriate authority

    - reviewing the person’s plan of care to ensure that they are properly supported following the alleged abuse incident.
- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission’s Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010.

All children and young people who use services must be:
- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

**Key Service Outcomes**

Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking
cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Poorly planned transition from young people’s to adult-oriented health services can be associated with increased risk of non adrernce to treatment and loss to follow-up, whichcan have serious consequences. There are measurable adverse consequences in terms of morbidity and ortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services are moving to access adult services (for example, during transition for those with long term conditions), these should be organized so that:
- All those involved in the care, treatment and support, provide robust hand-over

arrangements from one specialist to another and participate actively in 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, play specialists and CAMHS services within nationally defined access standards.

All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

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

Many children with long term illnesses have a learning or physical disability.
Providers should ensure that:

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