

E03/S/d



**2013/14 NHS STANDARD CONTRACT
FOR PAEDIATRIC MEDICINE: IMMUNOLOGY AND INFECTIOUS DISEASES**

PARTICULARS, SCHEDULE 2 – THE SERVICES, A – SERVICE SPECIFICATIONS

Service Specification No.	E03/S/d
Service	Paediatric Medicine: Immunology and Infectious Diseases
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Paediatric Immunology and Infectious Diseases (PIID) is a paediatric sub-speciality in two parts. Like most sub-specialities there is a group of relatively rare patients with potentially serious and life threatening conditions requiring complex management who are cared for by PIID specialists, such as children with inherited primary immunodeficiencies and rare infectious diseases (such as complex TB). Additionally, PIID specialists provide advice on management of infections to a wide range of colleagues caring for children with many disorders who can all be severely affected by infections. Collaborating with microbiologists, immunologists, and paediatric sub- speciality colleagues, PIID specialists enhance the quality of care and outcomes, prevent unnecessary use of resources and set standards for the management and prevention of infection for a wide range of children in their specialist centres and region- wide.

PIID clinicians manage all primary immunodeficiency including diagnosis, management and ongoing complex care (>150 currently recognised, rare with overall prevalence of 1/10,000). Specialists also investigate those with suspected immunodeficiency (which is managed by specialists not in secondary care). Specialist PIID advice and/or treatment is required where the infectious disease is serious, persistent, unusual, recurrent or drug-resistant. PIID specialists drive research in the biology, treatment and prevention of infection for the benefit of the

NHS. Examples include overwhelming septicaemia, severe or complex TB, unusual fungal infections, and tropical infections including malaria. HIV infection is covered separately in Service Specification B6b but where not designated, lead hub tertiary services are provided by PIID specialists. Primary immunodeficiencies may present not only with infections, but also with severe and often early onset autoimmune and autoinflammatory conditions, or infection-associated cancers. Many of the most complex infections occur in immunocompromised children, the number of whom are increasing as a result of the greater use of immunosuppressant treatments for childhood diseases including cancer, organ and bone marrow transplants and inflammatory conditions, and advances in the management of primary immunodeficiency disorders (defined in Scope, also see appendix 1).

Prevalence

Primary and Secondary Immunodeficiency

Although few children are born with primary immunodeficiencies (approx. 4000 children and adults in UK primary immunodeficient, prevalence estimated 1/3000 to 1/10000), there is an increasing cohort of children with secondary immunodeficiency due to increasing use of disease modifying anti-rheumatic drugs (DMARDs) and chemotherapy. Approximately 50 children per year receive a bone marrow transplant as treatment for primary immunodeficiency and 2,320 received treatment in 2011 for malignancy (1,824 solid organ and 496 leukaemia, source Office for National Statistics). Failure to diagnose primary immunodeficiency promptly leads to avoidable death or long term debilitating and expensive illness so there is a need to screen more patients in clinical services than actually found to have the immune disorder.

Infectious Diseases

Despite infections being extremely common in children, the rates of serious specific infections requiring specialist input is low. For example TB (estimated 557 paediatric TB cases in England, Wales and Northern Ireland in 2004, British Paediatric Surveillance Unit (BPSU); bone and joint infections (1.4-11 cases/1000,000/year, Faust *et al* Arch Dis Child 2012); tropical infections e.g. 290 cases of paediatric malaria in 2005, BPSU Ladhani *et al*, 2010) etc.

The increasing complexity of care in tertiary children's specialities requires antimicrobial stewardship due to increasing use of broad spectrum antibiotics, increasing rates of antibiotic resistance and the increased cost of antibiotic spending in the NHS. Over 10% of all children are admitted to hospital with an infection in their first year of life. Recent Health Protection Agency (HPA) (www.hpa.org.uk) data show the rate of healthcare associated infections overall in the NHS is highest in the 1-23 months group (8.2%) compared to an overall prevalence of 6.4%. There are 1,500 cases of healthcare associated infection bloodstream infections in children each year (around 500 Gram negative of which approx. 15% piptazobactam/gentamicin resistant and 5% meropenem resistant). In 2011 the HPA reported that there had been a 26% increase in multi-drug resistant

TB, at 431, up from 342 the year before.

Note: HIV is commissioned in the separate service specification B6b Specialised HIV Services for Children (1190 HIV infected children alive and in active follow-up at a Collaborative HIV Paediatric Study (CHIPS) clinic in 2010-11), but where no separate contract exists, HIV activity is provided by PIID specialists commissioned by this service specification)

Integrated sub-speciality care and network service:

Provide consistent, case-by- case basis interactions with other tertiary paediatric specialities (e.g. immunological or infectious investigation of child treated primarily by other speciality group; PICU; system- based specialities e.g. orthopaedics, ear nose and throat (ENT), neurology etc.); secondary general paediatric care (e.g. advice on investigation of child with fever of unknown origin); and primary care (e.g. advice on immunisations); adult speciality colleagues (e.g. microbiology (including diagnostic services); clinical immunology (including diagnostic services); genitourinary medicine (GUM); adult infectious diseases and respiratory physicians.

National Context

Specialist services in PIID are provided in a small number of dedicated units that have highly skilled staff and integrated services for children with complex primary immunodeficiencies and infectious diseases. Delivery of the specialist services requires dedicated multi-disciplinary teams, requiring specialist laboratory-based testing, imaging and medical management. Key interdependencies link other tertiary paediatric and adult specialities and disciplines.

With the emergence of new infections, new diagnostic tools, new antimicrobial treatments, increasing resistance to antibiotics, increased immunosuppressive treatments, the complexity of modern tertiary care and increased global travel, it **has been recognised that paediatric specialist centres should have access to and support from a specialist in PIID** (reference: Department of Health (2008) '*Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Inter-Dependencies*'). In addition, PIID clinical and academic researchers provide NHS patients with access to the latest new diagnosis/treatments for immune problems, infections and vaccines to prevent new and emerging infections (*NHS Constitution* (2009) and seek to ensure that patients from every part of England are made aware of research that is of particular relevance to them; Chief Medical Officer (CMO) statement in National Institute of Health Research Annual Report 2010/11).

Evidence of Standards of Care

General documents

- Pearson, G A (Ed) *Why Children Die: A Pilot Study 2006; England (South West,*

North East and West Midlands), Wales and Northern Ireland.
London:Confidential Enquiry into Maternal Child Health(CEMACH). 2008.
http://www.injuryobservatory.net/documents/why_children_die1.pdf

- Reducing healthcare associated infections: An organisational perspective – A summary of best practice
http://hcai.dh.gov.uk/files/2011/03/Document_Reducing_HCAI_Organisation_Perspective_FIN_AL_100816.pdf
- Antimicrobial stewardship: Start smart - then focus; DoH 2011
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131181.pdf
- Health and Safety Executive: Biological agents: Managing the risks in laboratories and healthcare premises
<http://www.hse.gov.uk/biosafety/biologagents.pdf>
- Recommended standards for NHS HIV services
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4106272
- CHIVA (Children's HIV Association) Standards of Care for Infants, Children, and Young People with HIV, (including infants born to mothers with HIV)
<http://www.chiva.org.uk/professionals/health/guidelines/guidelines/standards.html>
- UK PIN standards for diagnosis and management of primary immunodeficiencies
<http://www.ukpin.org.uk/home/standards.html>
- Therapeutic immunoglobulin will be in accordance with and monitored by the Department of Health Demand Management Programme (<http://www.ivig.nhs.uk>)
- Use of therapeutic monoclonal antibodies (biologics) for patients with autoimmune complications of PID will be in accordance with published evidence (Gobert D et al.Br J Haem 2011;155: 498- 508)
- Guidelines and position statements from the European Society for Immunodeficiencies and other recognised professional bodies such as the Royal Colleges and the Joint Committee on Immunology and Allergy (JCIA) will inform practice.

Specific pathologies requiring PIID input as defined interdependency with other specialities

- Feverish illness in children – assessment and initial management in children younger than 5 years <http://www.nice.org.uk/CG047>
- Bacterial meningitis and meningococcal septicaemia in children and young people younger than 16 years in primary and secondary care
<http://guidance.nice.org.uk/CG102>
- Neutropenic sepsis
<http://guidance.nice.org.uk/CG/Wave23/11/Consultation/Latest>
- Tuberculosis - Clinical diagnosis and management of tuberculosis, and measures its prevention and control <http://guidance.nice.org.uk/CG117>

- Prevention and treatment of surgical site infection
<http://www.nice.org.uk/CG74>
- British Thoracic Society (BTS) guidelines for the management of pleural infection in children http://thorax.bmj.com/content/60/suppl_1/i1.full.pdf
- BTS guidelines for the management of opportunistic mycobacterial infections
- <http://www.brit-thoracic.org.uk/Portals/0/Guidelines/Opportunist%20Mycobacteria/Guidelines/OpportMyco.pdf>

Specific PIDD managed pathologies

Consensus document for the diagnosis and management of patients with primary antibody deficiency <http://www.rcpath.org/publications-media/publications/consensus-document-for-the-diagnosis-and-management-of-patients-with-primary-antibody-deficiencies#>

C1 inhibitor deficiency: consensus document

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2249.2005.02726.x/pdf>

International Working Group on C1 inhibitor deficiency (Cicardi et al. Allergy 2012;67: 147-57)

2. Scope

The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in 'Who Pays?: Establishing the responsible commissioner' and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

* Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England

2.1 Aims and objectives of service

The aims and objectives of the service are to provide family centred specialist care for children with primary immunodeficiencies and complex infectious diseases as agreed in the service specification (see Appendix 1). The service is centred around four broad activities:

- optimisation of the diagnosis and management of children with primary and secondary immunodeficiency, and severe infections
- co-ordination/overseeing of antibiotic stewardship (with microbiology colleagues)

across tertiary paediatric units and provision of advice on antimicrobial stewardship to the local/regional network

- provision of clinical link between tertiary paediatric services and microbiology infection prevention activities to reduce healthcare associated infections
- Provision of access to National Institute of Health Research (NIHR) portfolio clinical trials in PIID and to lead improvement in child health in the NHS through underpinning research

The broad objectives of the service are to facilitate:

- accurate and timely diagnosis using best practice in the assessment of these rare diseases with protocols to enable rapid access for new and existing patients
- early identification of patients with complex diseases, ensuring that they have timely access to specialist care and appropriate NIHR portfolio clinical trials.
- development and delivery of evidence based treatment plans (or best practice treatment in rare disorders where limited evidence exists). This should lead to improved treatment outcomes (reduced mortality and morbidity) and maximisation of children's development and potential.
- provision of expertise on drug treatments of infections and immunodeficiency disorders including paediatric medication formulation and dosing, and of complex immunisation advice.
- provision of full paediatric infection training and expertise including ability to communicate complex infection issues with children and families, including safeguarding issues
- consistent, evidence-based and equitable decision making about use of off license therapies in refractory or relapsing disease
- appropriate shared care arrangements between specialties for the management of co-morbidities directly associated with the patients' rare disease including but not limited to: linking with a) adult infectious diseases teams for family infections (TB, travel infections, hepatitis, HIV (where not separately commissioned) etc). b) with obstetric/neonatal team – regarding perinatal/ congenital infections; c) with rheumatology and oncology teams regarding complex febrile presentations (fever of unknown origin, haemphagocytic conditions, autoinflammatory conditions, macrophage activation syndromes, malignancy) etc
- detailed audit of patient outcomes and experience, shared with colleagues in other centres, enabling the dissemination of best practice and appropriate benchmarking of quality. For example, entry of Primary Immunodeficiency patients into the ESID (European Society for Immunodeficiency) database, use of national registries such as world-leading paediatric HIV database (CHIPS) in centres where not commissioned in separate specification.
- integration of patient care between regional / national specialised centres and local services through the use of standardised shared-care protocols, ensuring that support is delivered as close to patients' homes as possible, but access to specialist services is maintained e.g. approximately half of all immunoglobulin replacement for primary immunodeficiency is delivered through home care programmes involving a multidisciplinary team.
- increased awareness of best practice in the diagnosis and management of

these rare conditions through active engagement and shared care.

2.2 Service description/care pathway

Specifically, this service is commissioned to provide the assessment, diagnosis and management of children with primary immunodeficiency and complex infectious diseases fully integrated with clinical research (see Appendix 1) as outlined within this specification, including:

- Service to secondary care centres from tertiary centre:
 - Availability in core hours (e.g. 0900-1800) Monday-Friday for telephone advice for non-urgent cases; 24 hour service for emergency support
 - Timely review/assessment of non-urgent cases in clinic setting (for immediate care see Paediatric Intensive Care (PICU) service specification)
 - For specific infections to provide same-week review service (e.g. fever of unknown origin, HIV drug problems, new cases of suspected TB)
 - Development of guidelines and policies to standardise care across local/regional network (e.g. antimicrobial guidelines, pandemic flu planning etc)
- Service to tertiary interdependent specialities:
 - Core hours (0900-1800) Monday-Friday inpatient service to children admitted under care of PIID and same-day (Mon-Fri) review consult service with 24-hour telephone advice for emergency support to interdependent tertiary specialities
 - Outpatient service for local, regional and national (where appropriate) PIID referrals within national outpatient timelines
 - Implementation/development of guidelines according to national standards and development of agreed quality guidelines where national guidance does not exist
 - Oversee antimicrobial stewardship activities including responsibility for local antimicrobial guidelines (interdependent with clinical microbiology)
 - Provision of clinical link between children's services and hospital infection prevention team
 - Provision of dedicated adolescent transfer service to adult care
 - Close working relationship with designated site specific and national transplant services for primary immunodeficiency disorders
 - Provision of access to NIHR portfolio clinical trials in PIID.

Many serious infections are managed by shared care arrangements between a regional tertiary centre and local hospital. A patient may initially present to their local hospital, be referred to the tertiary centre for specialist investigations and initiation of treatment, and is subsequently transferred back to their local hospital for completion of their treatment. Ongoing advice and support will continue to be provided by the tertiary centre during and after completion of their therapy. In addition, outreach clinics can be offered across the region as well as transition clinics run with the relevant adult specialists (immunologists, HIV physicians etc).

Multi-Disciplinary Team (MDT) membership:

The PIID MDT should have multi-disciplinary teams who have specialist experience in treating primary immunodeficiency and specific complex infectious diseases:

- Consultant(s) in Paediatric Immunology and Infectious Diseases or Immunology and/or infectious disease-specific nurse specialist or Access to specialist paediatric radiology and neuroimaging
- Paediatric Microbiologist or Microbiology Service to Paediatrics
- Immunology laboratory support
- Antimicrobial pharmacy support
- Access to clinical psychologist
- Access to play specialist
- Access to clinical geneticist
- Access to social workers and community support workers (including youth workers and counsellors)
- Access to Anaesthetist or PICU-based peripherally inserted central venous catheter service

Interdependency is key to service delivery:

Paediatric medical specialities in tertiary centres increasingly make use of and rely on PIID clinicians for advice on management of complex infections across the whole range of paediatric sub-specialities. In a tertiary environment, PIID clinicians oversee antimicrobial stewardship and infection prevention activities in association with specialist microbiologists and pharmacists (appendix 1, figure 1). The purpose of specialist PIID assessment is often to “rule out” infection in children with complex inflammation so preventing unnecessary investigations and inappropriate antimicrobials. The conditions listed below should be managed by the specialist PIID centre or by a general paediatrician in a local hospital under a network/shared care arrangement or by another specialist paediatric team (e.g. formal national paediatric HIV network (Gateway ref 4710); immune deficiency shared care networks with PIID centres; TB may be managed by a general paediatrician in a local hospital by, or together with, a PIID specialist, or by a respiratory paediatrician).

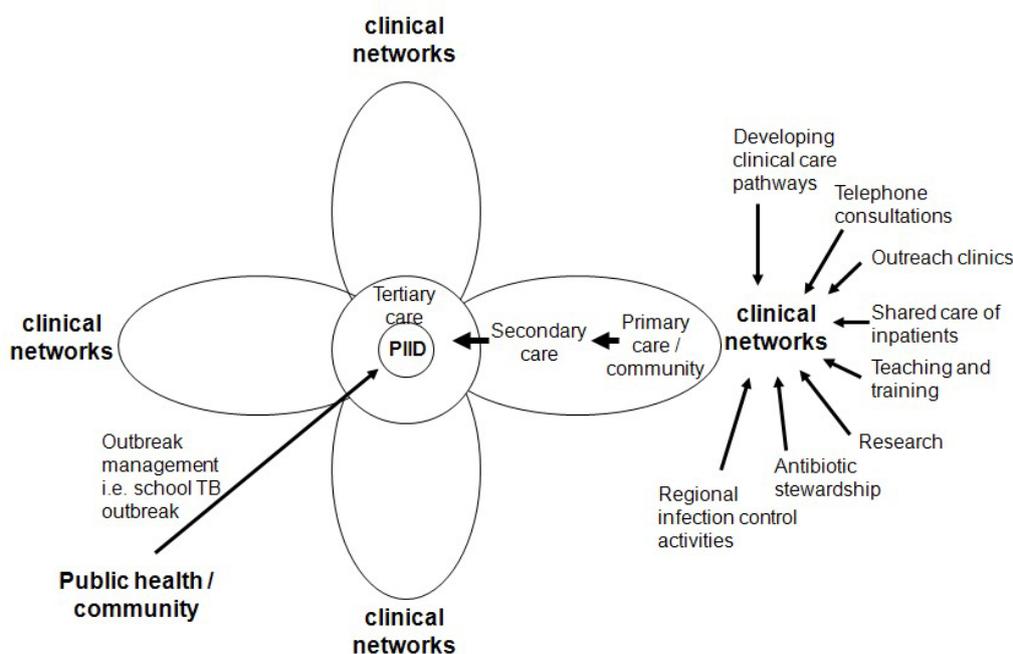
Specialised PIID services may be delivered in the following ways:

- Care within a specialist PIID unit (both in-patient and out-patient including joint clinics,
- e.g. PIID/Rheumatology for auto inflammatory conditions, PIID/Respiratory for immunodeficiency with chronic respiratory infection etc.)
- Expert advice from the specialist in PIID to other paediatric specialists within a tertiary centre - e.g. intensive care, neonatology, oncology, orthopaedics, cardiology, neurology
- Outreach clinics held with the general paediatrician in the local hospital
- Expert advice from the PIID specialist to the local hospital's general

- paediatrician caring for the child or, less commonly, to the GP
- Expert advice from other multi-disciplinary members of the PIID team to other healthcare providers.
- Multi-disciplinary team visits to the patient's home and school to provide training and support to the child, family and other carers.
- Leadership in improving the diagnosis, treatment and prevention of infectious disease in the NHS through research.

The aim is to manage children as close to home as possible with the local hospital delivering the majority of care whenever possible. This is achieved by creating clinical networks across a defined geographical area, with specialists in tertiary centres supporting colleagues in local hospitals (see figure 1 below). For the rarest primary immunodeficiency disorders, home-based care may be provided by the tertiary centres (e.g. specialist nurse support of home-based immunoglobulin service).

Figure 1. Relationship to regional paediatric services: tertiary PIID services play an integral part in coordinating effective clinical networks across wide geographical areas



2.3 Population covered

This service specification covers children up to their 19th birthday with suspected or confirmed primary immunodeficiency, defined secondary immunodeficiency and those with specific serious infections (Appendix 1). To ensure equity of access, access to the service is via primary, secondary or tertiary care (See Figure 1).

2.4 Any acceptance and exclusion criteria

Acceptance criteria:

Origin of Referrals and Criteria for Referral

Referrals will usually be accepted from tertiary sub-speciality or consultants in general paediatrics in secondary care. Referrals from General Practice will be accepted for specific defined conditions, including (but not limited to) high clinical suspicion of suspected primary immunodeficiency, HIV, tuberculosis, Lyme disease, suspected tropical infections in children returning from abroad, and complex vaccine needs.

Referrals may go to a named consultant or centres may operate a single list.

Exclusions

Patients who do not have a specific or suspected condition that requires the expertise of a Specialist PIID service (as described above) are excluded from this service.

Paediatric HIV is commissioned in the separate service specification B6b Specialised HIV Services for Children (1190 HIV infected children alive and in active follow-up at a CHIPS clinic in 2010-11), but where no separate contract exists HIV activity is provided by PIID specialists commissioned by this service specification).

Bone marrow transplant for severe combined immunodeficiency and other primary immunodeficiency disorders is commissioned elsewhere and is not covered by this service specification.

2.5 Interdependencies with other services

The investigation and management of children with suspected immunodeficiency specifically involves interdependency with tertiary paediatric subspecialists in respiratory medicine, gastroenterology and haematology.

When children with infectious diseases (ID) are admitted in a specialist centre, they are either managed by the PIID team or by another specialist paediatric team with advice from the ID team (e.g. for bone marrow transplantation (BMT), burns, obstetric & neonatal, neurology & neurosurgery, cardiology & cardiac surgery, renal, hepatology, gastroenterology, dermatology, respiratory, allergy, immunology, trauma & emergency, oncology, intensive care, ear & nose & throat, ophthalmology, paediatric surgery, rheumatology and orthopaedic services) (see table 1 below). The PIID service is also pivotal in antibiotic stewardship activities and infection prevention within a tertiary children's hospital

Table 1. The specialist teams involved in the management of children admitted with serious/complex infections:

Infection / organ system management	PIID management	Joint ID/other specialty
Primary immunodeficiency (all – see above)	Yes	Yes (BMT)
Severe manifestations of common infections (including immunodeficiency)	Yes	
Severe/chronic organ based infections	Yes	Yes (orthopaedics, cardiology, ENT, ophthalmology, surgery, respiratory, PICU etc).
Rare paediatric infections	Yes	
Central Nervous System infections	Yes	Yes (neurology/neurosurgery)
PUO (including Kawasaki Disease)	Yes	Yes (cardiology, rheumatology, oncology)
HIV	Yes	
TB (complex e.g. MDR, military, meningitis)	Yes	Yes (respiratory, neurology, orthopaedics)
Imported infections	Yes	
Opportunistic infections	Yes	Yes (oncology/BMT, cardiology, rheumatology, gastroenterology etc)
STDs	Yes	Yes (GUM)
Congenital infections	Yes	Yes (neonatology, obstetrics)
Hepatitis	Yes	Yes (gastroenterology, hepatology)
Multi-drug resistant infections	Yes	Yes (organ specialists, microbiology, ect.)

3. Applicable Service Standards

Evidence of standards of care contained in the documents as listed in section one.

4. Key Service Outcomes

Key service outcomes are defined both in terms of the service aims and service delivery:

Outcomes for Service Aims

Outcomes for aim to optimise the diagnosis and management of children with primary and secondary immunodeficiency, and severe infections:

mortality rates for specific infections; maintenance of low admission rates of children with recurrent infections; adherence with national guidelines; performance against local/regional network requirements/needs of tertiary/secondary specialists seeking advice/support; performance in enrolling children to NIHR portfolio trials in PIID.

Outcomes for aim to coordinate/oversee antibiotic stewardship across tertiary paediatric units and provide advice on antimicrobial stewardship to the local/regional network:

auditing practice against national/local antibiotic prescribing guidelines and, in future, performance and delivery of paediatric intravenous outpatient antimicrobial therapy services (for hospital: bed days saved and quality indicators of outcome of specific infections (cure without readmission); for children: days in hospital avoided)

Outcomes for aim to provide clinical link between tertiary paediatric services and microbiology infection prevention activities:

adherence/development with/of regional/national guidelines (for example lead for pandemic flu planning) and by comparing rates of healthcare acquired infections (HCAIs) between centres as measure of adherence with infection control recommendations.

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 (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 minimise complications and mortality
- families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities
- children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care
- good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; accommodation is provided for them to remain with their children overnight if they so wish

Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through "integrated pathways of care" (*National Service Framework for children, young people and maternity services* (Department of Health & Department for Education and Skills, London 2004))

Interdependencies with other services

All services will comply with *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies* – Department of Health

Imaging

All services will be supported by a three-tier imaging network ('Delivering quality imaging services for children' Department of Health 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
- 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) training² and should maintain the competencies so acquired³ *. 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 magnetic resonance imaging (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. Guideline for Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. RCoA 2010 www.rcoa.ac.uk
2. Certificate of Completion of Training (CCT) in Anaesthesia 2010
3. 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 accreditation/audit/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. National Institute of Health and Care Excellence (NICE), Royal Colleges

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 two RCNs 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 which 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.
- participating in local safeguarding children boards where required and understanding 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 about 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.
- that providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

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

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

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

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

Providers should ensure that:

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability
- Discrimination Act 1995
- They meet the standards set out in Transition: getting it right for young people.

Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006, London

Interim for Adoption from 01/10/13

Appendix 1: Conditions managed by Specialist PIID Services defined in Service Specification:

- Primary immunodeficiency syndromes (including functional disorders of polymorphonuclear neutrophils, hyposplenism, immunodeficiency with predominantly antibody defects, combined immunodeficiencies, immunodeficiency associated with other major defects, common variable immunodeficiency, Other immunodeficiencies e.g. infection-induced cancers hereditary ataxia)
- Common infections (eg Respiratory Syncytial Virus)(in the immunocompromised host
- recurrent infections (investigation and management of)
- inflammatory conditions affecting children including Kawasaki's disease, periodic fever syndromes and autoimmune diseases associated with primary immunodeficiency
- opportunistic infections secondary to: immunodeficiency of unknown aetiology, immunodeficiency due to malignancy, chemotherapeutic drugs, viruses
- severe paediatric infections including those requiring intensive care (meningococcal disease, staphylococcal/streptococcal sepsis and toxic shock syndromes, bacterial meningitis, encephalitis, brain abscess, sinusitis, mastoiditis, ophthalmic infections and inflammatory conditions, empyema, endocarditis, abdominal sepsis and gastrointestinal infections, viral hepatitis, complicated urinary tract infections, complex musculo-skeletal infection, complex skin infections) - these conditions will often be managed in conjunction with the relevant organ-specific specialist.
- fever of unknown origin (greater than 2 weeks duration) nosocomial infections / healthcare associated infection (central line infections, ventilator-associated pneumonia, methicillin resistant Staphylococcus aureus, complicated C Difficile infection and multi-resistant bacterial infection)
- serious post-operative infections and post traumatic infections
- TB (congenital, central nervous system, extra-pulmonary disease, complicated pulmonary disease, drug- resistant TB)
- complex and unusual manifestations of neonatal infections (e.g. candida, multi-resistant organisms, pertussis, meningitis).
- congenital infections (e.g. HIV, Hepatitis, toxoplasmosis, cytomegalovirus, syphilis, rubella, herpes simplex virus, varicella, chlamydia)
- prevention of perinatal infection (e.g. HIV, hepatitis, toxoplasmosis etc) persistent cervical lymphadenopathy and atypical/non-tuberculous mycobacterial infection
- Sexually transmitted infections in children
- Infections with unusual patterns of antimicrobial resistance (bacterial, fungal and viral)
- Complex vaccine advice for passive and active immunisation (non-response, failures, immunocompromised, adverse events)
- Rare, imported and emerging paediatric infections e.g. Lyme disease,

brucellosis, leptospirosis, slow infections of the CNS (SSPE, spongiform encephalopathies), worldwide emerging new infections (dengue, SARS, influenza, chikungunya), imported infections (severe and complicated malaria, typhoid fever, visceral and cutaneous leishmaniasis).

- Zoonosis (eg coxiella, bartonella, brucella, psittacosis etc)
- NB HIV (all care of HIV-infected children/adolescents) is commissioned in the separate service specification B6b Specialised HIV Services for Children but where no separate contract exists HIV activity is provided by PIID specialists commissioned by this service specification).

Interim for Adoption from 01/10/13