D12/S/b

NHS STANDARD CONTRACT
FOR SPECIALISED OPHTHALMOLOGY (PAEDIATRICS)

SCHEDULE 2 – THE SERVICES - A. SERVICE SPECIFICATIONS

Service Specification No.	D12/S/b
Service	Specialised Ophthalmology (Paediatrics)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Bilateral serious visual loss in childhood is uncommon. Six of every 10,000 children born in the UK each year become severely visually impaired or blind by their 16th birthday and, approximately, a further 12 become visually impaired (worse than 0.5 to 1.0 Log Melanoma Associated Retinopathy (MAR) in both eyes). Thus there are at least 4 newly visually impaired children each day in the UK and around 2 per 1000 children in a given population are visually impaired or blind – amounting to around 20,000 at any time.

Children with milder visual loss, unilateral visual problems, or eye diseases which require treatment but do not cause visual impairment, considerably outnumber others within paediatric ophthalmic services and require a disproportionately smaller amount of available resources in the long-term than the minority with bilateral marked visual impairment. The planning of ophthalmic services should explicitly account for these three 'populations' of children: those with visual impairment as an isolated problem, those with visual impairment as well as other impairments/disorders, and those with eye conditions associated with mild or no visual loss.

Disorder specific frequencies are shown in the table below.

Table 1- Frequency

Cataract	3-4 per 10,000 births/yr
Glaucoma	5.4 in 100,000
Inherited retinal disorders	1.4/100,000 children/year (cumulative incidence by age 16 years 22.3/100,000)
Visual problems of prematurity	Up to 50% of <750gm would need treatment (stage 3)
Neuro- Ophthalmic disorders	Individually rare, collectively commonest cause of sever visual impairment (accounting for about 50%)
Anophthalmia, microphthalmia or coloboma	11.9 per 100,000 by 16 years

2. Scope

2.1 Aims and objectives of service

To optimise children's vision and prevent avoidable visual disability of ophthalmic (eye and vision) disorders.

This service aims to provide the investigation and management of children and young people with rare and/or complex visual system, ocular and ocular adnexal disorders.

This service is defined by the population it serves – children, young people and their families – and their specific needs, rather than by the disorders managed, and thus potentially encompasses all ophthalmic sub-specialties. As set out in the Royal College of Ophthalmologists' standing report 'Ophthalmic Services for Children' (Appendix D), the purpose of ophthalmic health services for children remains:

- **Primary prevention:** Preventing the occurrence of visually impairing disease through effective screening and treatment - e.g. screening of premature neonates for retinopathy of prematurity.
- **Secondary prevention:** Reducing the visual impact of established disease - e.g. screening for vision impairment in 4-5 year old children followed by appropriate treatment.
- **Tertiary prevention:** Maximising function in individuals with permanent visual impairment - e.g. provision of low vision aids for children with congenital eye anomalies or habilitation/rehabilitation programmes.

The evidence base for each sub-specialty and each disease will differ. However, all components of the service will be expected to demonstrate good clinical governance.

Treatment is predominantly delivered in an outpatient setting and, where appropriate, as an inpatient (ward or day unit as required), with carefully monitored shared care arrangements in place with referring clinicians.

The service will aim to optimise children’s vision and prevent avoidable visual disability of ophthalmic (eye and vision) disorders by:

- making timely and accurate diagnosis
- timely investigation and management
- providing high quality proactive treatment and care
- providing appropriate counselling and psychological support to children and families
- ensuring smooth and managed transition from children’s to adult care between the ages of 16-19 for patients with long term conditions
- supporting patients to manage their condition independently
- ensuring effective communication between patients, families and service providers
- providing a personal service, sensitive to the physical, psychological and emotional needs of the patient and their family
- provide advice, when appropriate, on Letter of Vision Impairment (LVI), Referral of Vision Impairment (RVI) and Certificate of Vision Impairment (CVI)

2.2 Service description/care pathway

Specialised ophthalmology services for children are provided by both paediatric and adult ophthalmologists working together at different levels (primary/secondary/tertiary), as evidenced by the highly successful clinical research networks through which recent national studies of uncommon paediatric disorders have been undertaken, including cataract, glaucoma, ocular anomalies and inherited retinal disorders. www.rcophth.ac.uk/core/core_picker/download.asp?id=591

Ophthalmology hospital services are provided by multidisciplinary teams (MDT) of ophthalmologists, optometrists, orthoptists, specialist nurses, and technicians. Specialised services are provided by ophthalmologists trained to fellowship standard in the appropriate subspecialty. Ophthalmic specialised services, as in most other clinical disciplines, will overlap with other specialised services. Due consideration must be given to the appropriate care of vulnerable children.

Specialised services will be provided in a network model that will build on existing strengths and established networks and shared care practices. This will be an operational delivery network model or other network models as appropriate to the particular service. It is anticipated that the network operating model and accountability structure will be similar to that of the operational delivery networks.

The objectives of networks would be to:

- Facilitate patient choice
- Ensure sufficient patient numbers to support training and experience across the range of specialties
- Provide an opportunity to train and retain clinicians in specialised areas
- Enable services to pool expertise
- Support smooth transfer of care across organisations
- Develop standards, guidelines and care pathways to facilitate assessment of care quality and promote consistency of care

- Reduce unwanted variation in clinical practice

The service needs close links with appropriate medical specialities and the national ophthalmic pathology service. Internally the multi-disciplinary team (MDT) links into multiple clinical and administrative teams as a result of the broad composition of the team. Strong links are also required between the clinical and diagnostic teams involved in the service.

Services for children must always be provided in a suitable environment which meets national guidelines for the care of children, providing access to a skilled and trained multi-disciplinary workforce to manage children with ophthalmic problems.

Specialised services are provided by ophthalmologists trained to fellowship standard in the appropriate sub-specialty. Ophthalmic specialised services, as in most other clinical disciplines, will overlap with other specialised services. Staffing levels should include all those involved in the specialist care of the child at primary, secondary and tertiary level. Care should be provided by a MDT including:
- ophthalmologist
- ophthalmology nurse specialist
- paediatrician
- orthoptists
- optometrists
- eye clinic liaison officer
- whenever appropriate
- teachers for the visually impaired
- social worker
- genetic counsellors

All specialist services will provide education and training working closely with the College of Ophthalmologists to determine educational and professional standards and with postgraduate training commissioners and providers. Clear policies should be in place to ensure that staff maintain and develop their specialist skills and knowledge. It is a requirement that medical staff can demonstrate that they are part of a revalidation cycle.

All specialised services will be actively involved with research and innovation to ensure the continued development of their service. All staff involved in specialist services will be required to be involved in education and research, be given appropriate time and funding to undertake these requirements and for medical staff to be supported to provide data for revalidation.

Specialised services are required to keep data to ensure coding is accurate.

Some of these conditions require lifelong surveillance, and potential treatment, to limit visual loss, and which will necessitate a planned transition to adult services.

Discharge policies will be in place for each service.

The most common cause of visual impairment in children is visual pathway damage and paediatric ophthalmologists are involved in the visual assessment and rehabilitation of such children. Other common causes of visual impairment in children include; inherited retinal disorders, congenital eye anomalies (structural abnormalities of the eye comprising anophthalmia, microphthalmia and coloboma), primary or secondary disorders of the optic nerve, congenital, cataract, congenital glaucoma, retinopathy of prematurity and uveitis. Many paediatric ophthalmologists are involved in screening of pre-term infants to detect and treat retinopathy of prematurity. For all of these conditions some cases will involve intensive management and contribute disproportionately to the workload of children's eye departments. Management of these conditions requires access to comprehensive paediatric and genetic services, including neonatology and anaesthesia. The transition of children needing ongoing ophthalmic care into adult services must be carefully planned.

The specialised ophthalmology service for children is commissioned for the following conditions:

- **Orbital disorders**
  Orbital disorders are rare in children, and most significant paediatric orbital disorders are referred for specialist evaluation, either to a predominantly adult orbital service or to a specialist paediatric ophthalmology centre. In addition, all orbital surgery (apart from minor surgery and the management of orbital cellulitis) is a specialised service. Surgery on children may often be undertaken by an (adult) orbital surgeon (i.e. an adult ophthalmic surgeon sub-specialising in orbital surgery) rather than a paediatric ophthalmic surgeon.

  Microphthalmia and anophthalmia are specialised services.

  The provision of ocular prostheses is a specialised service.

- **Oculoplastic and Lacrimal Surgery**
  Except for routine syringe and probing, lacrimal duct intubation and minor lid surgery, paediatric oculoplastic and lacrimal surgery is a specialised service.

- **Cataract and lens disorders**
  Treatment for cataract and lens disorders, where the condition requires surgery within the first few weeks of life, is a specialised service because of both the surgical and anaesthetic requirements for these infants and the demanding process of optical rehabilitation of infants following cataract surgery. Treatment for cataracts in older children can be managed using techniques common to adult cataract surgery. Cataract surgery in children up to the age of 2 years will be considered specialised, however this age limit will remain under review.

- **Glaucoma**
  Infantile and congenital glaucoma in children is rare; glaucoma caused by developmental abnormalities of ocular structure is the commonest cause. Treatment of glaucoma in children is a specialised service and must be provided in a network to ensure long-term care for this chronic disease.

- **Corneal Disorders and Surgery**

Any condition requiring corneal surgery, with the exception of emergency corneal repair is a specialised service. Paediatric corneal transplant is a specialised service.

- **Eye Banking**
  - Tissue processing-i.e. for DSAEK- producing pre-cut tissue
  - plasma/serum production
  - cell culture production- ocular surface stem cells, retinal stem cells
  - amniotic membrane production.

- **Vitreoretinal Surgery**
  Paediatric vitreoretinal management and surgery should be considered a specialised service. This will include both elective and emergency care.

- **Retinopathy of Prematurity**
  Whilst retinopathy of prematurity screening occurs in all neonatal units, treatment needs to be undertaken in specialist centres with appropriate equipment and expertise. This should be within a network arrangement to minimise the need to transfer babies.

- **Medical retinal disorders**
  Children with retinovascular disorders such as Coats disease, familial exudative vitreoretinopathy and the retinopathy of incontinentia pigmenti need access to RETCAM fluorescein angiography, specialist expertise and laser treatment.

- **Paediatric Uveitis**
  Although uncommon, intraocular inflammation in childhood carries a significant burden of blindness, with severe vision loss occurring in 25-33% of cases. This complex group of disorders has a wide range of causes and is often associated with systemic disease. A coordinated multi-specialist approach to care is necessary for severe ocular disease.

- **Ocular Genetic Disorders**
  Ocular genetic disorders are best managed by specialist centres which provide multidisciplinary services including access to electrodiagnostic testing, genetic counselling, molecular genetic testing, specialist imaging, research facilities, and specialist ophthalmologists. This provides patients and families with timely accurate diagnosis, increased knowledge of the nature of the condition, information on prognosis, and access to increasing clinical trials.

- **Neuro-ophthalmology**
  Neuro-ophthalmology includes the evaluation and multidisciplinary care of patients with a range of serious neurological conditions which may first present with visual problems. Adverse patient outcomes are associated with late or delayed diagnosis. Sub- specialist clinical assessment is required to ensure timely access to the best treatment. This requires appropriate, selective diagnostic imaging and other specialised tests.

  There are a large number of children with Cerebral Visual Impairment (CVI) and the underlying brain problem frequently results in other disabilities of varying degree (e.g. cerebral palsy, learning difficulties). Local care is the most appropriate and feasible arrangement for these children, in order to document and manage aspects of basic ocular function. This is considered a non-specialised service. However, infrequent access to a multidisciplinary developmental paediatric clinic for sight impaired children and/or to a clinic with a specialist interest in CVI led by a paediatric neuro-ophthalmologist or paediatric ophthalmologist is extremely helpful and will be considered a specialised service. The care of these children will therefore be within a network of specialised and non-specialised services.

Optic Nerve Sheath Fenestration is a specialised procedure.

- **Stabismus surgery**
  Paediatric strabismus is a common condition managed in most ophthalmic units across the country. It does not generally require specialist or expensive equipment. Surgery is normally already undertaken by consultants with appropriate sub-specialty training and experience. At present paediatric strabismus would therefore not be considered a specialised service requiring central commissioning. There are a few units, however, which offer eye movement recording as an adjunctive investigation for certain patients e.g. some nystagmus patients. Eye movement recording facilities may be considered a specialised service.

  Whilst emergency ophthalmic care will normally be commissioned at Clinical Commissioning Group (CCG) level there will be occasions when it needs to be specially commissioned.

2.3 Population covered

The service outlined in this specification is for patients with conditions included in section 2.2, 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 General Practitioner (GP) practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England.

2.4 Any acceptance and exclusion criteria

The service is accessible to all patients regardless of sex, race, or gender. Providers require staff to attend mandatory training on equality and diversity and the facilities provided offer appropriate disabled access for patients, family and carers. When required the providers will use translators and printed information available in multiple languages.

Specialised commissioners and CCGs must work with clinical networks to ensure that medically necessary transport for patients is commissioned and funded to ensure equity of access for 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.

Criteria will differ for each condition but the upper age limit is 19 years.

- Treatment of amblyopia - this is not a specialised service.
- Lacrimal disorders - probing of the nasolacrimal duct is not considered specialised
- The management of orbital cellulitis is not a specialised service
- Oculoplastic surgery - lid lesion surgery (e.g. for chalazia) is not considered specialised
- Treatment of strabismus - this is not a specialised service
- Whilst emergency ophthalmic care will normally be commissioned at
- CCG level there will be occasions when it needs to be specially commissioned.

The over-arching generic referral criterion covering specialised ophthalmology services is as follows:

- The condition is covered by the list in 2.2 of this specification.

Referrals will mainly be from ophthalmology departments in secondary care but will also include referrals from community and hospital paediatricians, established community services, trauma units, medical genetic departments and other disparate groups such as the visiting teacher service. Patients are also referred from general practitioners, hospital consultants for medical or surgical assessment and management of specialised ophthalmology diseases/ conditions. Once referred the patient will be assessed by a specialist multidisciplinary team.

2.6 Discharge criteria

Criteria for discharge from inpatient care:

- No further investigation required
- No adverse outcomes anticipated
- Patient is safe post-surgery
- Clinically appropriate shared arrangements for local care and specialist ophthalmology service follow-up have been discussed and agreed by all relevant parties including the need to continue with regular sight test to identify eye health problems
- Parents / carers have demonstrated competence in any care they will be required to provide in relation to treatment
- Parents / carers understand and have the necessary information to contact their specialist ophthalmology service provider

All discharge planning will be managed by the ophthalmologists in charge of the case with local health and social care providers being fully informed of the patient's condition and any responsibilities they will have to assume. This will be formalised in written communication to the patient's GP and all other relevant parties.

The specialist ophthalmology service works closely together with adult services to develop and implement an adolescent transition strategy to facilitate smooth transition for young people to adult services when necessary.

2.7 Interdependencies with other services

Links with other services include:

- Strategic clinical networks for children
- Specialised Paediatric Surgery
- Specialised Paediatric Medicine
- Specialised Paediatric Cancer Services
- Specialised Paediatric Cardiac Services
- Specialised Paediatric Intensive Care
- Specialised Neonatal Critical Care
- Specialised Paediatric Neurosciences
  Neuroimaging and specialist neuroradiology
- Specialised Services for Blood and Marrow Transplantation
  (management of a cataract is necessary following bone marrow transplantation).
- Cleft Lip and Palate Services for Children
  (detection of associated ocular conditions, e.g. Stickler syndrome, may be required).
- Specialised Immunology Services for Children
  (children with juvenile arthritis are entered into a screening programme to prevent visual loss from uveitis).
- Specialised Services for Infectious Diseases
  (detection and evaluation of Human immunodeficiency virus (HIV) and cytomegalovirus (CMV) associated retinopathy may be required).
- Medical Genetic Services
  (diagnostic confirmation/carrier detection is required for certain ophthalmic conditions for the purposes of genetic counselling).
- Specialised Rheumatology Services
  (children with juvenile arthritis are entered into a screening programme to prevent visual loss from uveitis).
- Specialised Ophthalmology Services (adult)
- Ophthalmic surgery in children should be carried out by consultants with appropriate sub-specialist training and expertise. It is recognised that some specialised conditions will be treated by surgeons who are not primarily paediatric ophthalmologists, e.g. subspecialist vitreoretinal surgeons.
- Retinoblastoma Service
- Ophthalmic Pathology
- Stickler Service

Various other services including:

- Anaesthesia and pain management services e.g. premature infants requiring laser treatment for retinopathy of prematurity
- Cancer services - children with cerebral tumours in and around the visual pathways will be evaluated for evidence of the effect of the tumour on vision and for evidence of tumour recurrence
- Neurosciences services - many visual disorders have a cerebral, rather than an ocular basis and vision assessment is necessary in developmentally delayed/neurologically impaired children to exclude ocular causes of visual impairment and also to inform educational services, etc.
- Neonatal services - infants born at less than 32 weeks gestation or with a birth weight under 1500 grams are entered into a screening programme
- to prevent visual loss from retinopathy of prematurity; infants with congenital eye malformations or syndromes likely to be associated with them are referred for paediatric ophthalmological evaluation; infants with bilateral sensorineural hearing loss are referred for paediatric ophthalmological evaluation to detect any associated ocular manifestations

2.8 Relevant networks and screening programmes

Common referral networks will be between optometrists, ophthalmologists in secondary care and those in the specialised unit.

The recommendations regarding screening, in order to promote early detection of ophthalmic disorders or reduced vision, are set out in “Health for All Children” and subsequently in the Child Health Promotion Programme and the Healthy Child Programme. This programme comprises the Neonatal and Infant Physical Examinations and Vision Screening at age 4 - 5 years:

(http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107563)

The provider will link with patients’ local healthcare providers to ensure provision of high quality, integrated care, in addition to liaison with employers etc. as necessary to provide support and advice.

Voluntary sector, low vision services and rehabilitation services.

2.9 Location of service delivery

Network models of care will mean that some travelling may be required for specialist care. However, this should be minimised wherever possible. Implementing shared care arrangements should help to offset this.

2.10 Days/hours of operation

Urgent care: 24 hours / seven days a week for new referral of patients and acute referrals. This may include inpatient facilities where appropriate.
Day case: as a minimum 5 days a week, Monday to Friday
Outpatient clinics: as a minimum 5 days a week, Monday to Friday

3. Applicable Service Standards

3.1 Applicable national standards e.g. National Institute for Health and Clinical Excellence (NICE), Royal Colleges

The Royal College of Ophthalmologists is the guardian of excellence in ophthalmology. It aims to set standards in all aspects of the delivery of ophthalmic care in the interests of patients and the public. Guidance is provided under various topics (see below) and is reviewed regularly. The guidance is intended to inform both ophthalmologists and those managing eye services.

Standards of practice are clearly identified. The maintenance of these standards may only be achieved through adequate staffing levels, proper facilities and appropriate managerial support. Ophthalmic care for patients must continuously improve through regular robust audit, professional development, innovation, and training.

The key generic standards of care are set out in The Royal College of Ophthalmologists standing report ‘Ophthalmic Services for Children’ (Appendix D) and in its ‘Quality Statements and Quality Indicators for Paediatric Ophthalmology’ http://www.rcophth.ac.uk/news.asp?section=24&itemid=515&search

These generic standards are in keeping with national standards, in particular those laid out in:

- National Service Framework for Children, Young People and Maternity Services: Change for Children – Every Child Matters (Department of Health)
- National Service Framework for Children, Young People and Maternity Services: core standards. National Service Framework. London: Department of Health, Department for Education and Skills, 2004: 30)
- ‘Healthy lives, Brighter futures’ (Department of Health).
- Getting the Right Start: National Services Framework for Children, Standard for Hospital Services.
- Mental Capacity Act http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf
- www.commissioning foreyecare.org.uk

Other guidance, including clinical management guidance is also available from The Royal College of Ophthalmologists website www.rcophth.ac.uk including:

- Ophthalmic Services for Children: Royal College of Ophthalmologists, August 2012, (Appendix D)
- ‘Juvenile arthritis’, Royal College of Ophthalmologists (2006)
- Vision 2020
- ‘Visual screening in childhood and adolescence’, Health for all Children

4th Ed OUP National Institute of Clinical Excellence (NICE) (2009)

- National Service Framework: Care of Children in Hospital
- The National Framework for action to promote eye health and prevent avoidable blindness and vision loss, 2009
- Standards for the retrieval of human ocular tissue used in transplantation, research and training, The Royal College of Ophthalmologists, October 2008
- UK Retinopathy of Prematurity Guideline, The Royal College of Ophthalmologists, May 2008
- Research and Training, The Royal College of Ophthalmologists, October 2008
- Electrophysiology Eye Service Standards http://www.iscev.org/standards/proceduresguide.html

Revalidation

All medical staff providing specialised services are required to be part of a robust appraisal process. The General Medical Council (GMC) recommends that doctors in specialist practice should consult the supporting information guidance provided by their College or Faculty. This guidance amplifies the headings provided by the GMC, by providing additional detail about the GMC requirements and what each College or Faculty expects relating to this, based on their specialty expertise. These expectations are laid out by the GMC.

For those support staff involved in paediatric eye care, revalidation is also necessary. Orthoptists and other allied health professionals including Operating Department Practitioners must be registered with the Health Professions Council (HPC), optometrists registered with the General Optical Council (GOC), and nurses with the Nursing and Midwifery Council (NMC). These processes require revalidation and proof of competency for those staff who do not require registration to practice appropriate legislation (such as Criminal Records Bureau (CRB) checks and occupational health checks), as well as a robust Knowledge and Skills Framework (KSF) appraisal will be required.

Service user/carer information

As set out in The Royal College of Ophthalmologists's 'Ophthalmic Services for Children' and 'Quality Statements and Indicators for Paediatric Ophthalmology', every patient and family / carer must have the opportunity to discuss their diagnosis, prognosis and treatment, and receive information about their condition in an accessible format clearly understood by patients and free from jargon.

The information must cover:

- a description of the disease
- the life-long implications of the disease
- the prognosis for retention of sight
- management of the disease within the scope of the commissioned service as described in the specification, clinical pathways and service standards
- details of appointments including expected duration, requirement for pupil dilatation etc

- details of who to contact in between appointments if the condition changes
- diagnostic procedures and methods of investigations during assessment
- any requirements for on-going monitoring
- drugs and other treatments commissioned in the clinical pathway including any available compliance aids, drop instillation technique, drug storage etc
- treatment options including mode of action, frequency and severity of side effects, as well as benefits of treatment so that people are able to be active in the decision making process
- a realistic assessment of predicted outcome
- the importance of self-management and care
- dietary and nutrition information
- the availability of genetic counselling for inherited ocular conditions
- information about support organisation and internet resources
- advice, when appropriate, on Letter of Vision Impairment (LVI), Referral of Vision Impairment (RVI) and Certificate of Vision Impairment (CVI)
- details of who the patient's lead clinician is
- contact details for the patient's allocated named nurse.

The service must also provide education to patients and carers about:

- the symptoms of disease
- contact details in case of concern.

Patient Groups

Services should work with patient groups to ensure patient input into the development and provision of the services provided.

4. Key Service Outcomes

4.1 Governance

Generic quality standards for Paediatric Ophthalmology Services have been established by the Royal College of Ophthalmologists
http://www.rcophth.ac.uk/news.asp?section=24&itemid=515&search

- Providers will support clinical teams to routinely collect outcome data to demonstrate quality standards
- Providers will ensure that clinical teams will have inbuilt time and resources for continuous professional development, education, revalidation and service developments
- The facilities and environment are required to be safe and appropriately staffed to deliver and care for these complex cases
- All patients will have a lead clinician responsible for the management of their care within the clinical network
- Clinical incidents should be recorded and investigated
- Annual report of morbidity and mortality produced
- Annual report of complaints and outcomes of recommendations produced

4.2 Specific Service Outcomes

To be agreed by condition, national and international standards but generic Quality Standards have been set out by The Royal College of Ophthalmologists.

There will be a continual audit cycle across the service. This will include feedback from patients and their families, for example through regular questionnaire surveys or routine use of patient reported experience measures.

There is a need to develop routine data collection systems to allow standardised outcomes assessment and audit in services.

Continual Service Improvement Plan

Service improvement will be continually ensured through areas such as:

- the appropriate investigation and management of complaints
- monitoring information about the effectiveness of interventions
- regular feedback to commissioners regarding patient outcomes
- learning good practice from other specialist services
- service user feedback/patient and public involvement through regular surveys
- continued research within the service and publication of the results of research
- the development of appropriate policies and guidance on best practice in modifying the service, such as additional outreach clinics in new locations as needed

Service improvement may be stimulated through other areas such as:

- needs assessments
- other communication with stakeholders
- external peer reviewed research

This must be an ongoing and dynamic process. Providers and Commissioners have a commitment to work together to continually improve the service and react to innovative and dynamic ideas. They have a responsibility to continually review and redesign services and consider and act upon requests of the other party.

ANNEX 1 TO SERVICE SPECIFICATION: PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

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

The generic aspects of care:
The Care of Children in Hospital (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 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 (DOH) & 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 – DOH

Imaging

All services will be supported by a 3 tier imaging network (‘Delivering quality imaging services for children’ DOH 13732 March2010). Within the network;

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer for review by a specialist

radiologist, these will be supported by appropriate contractual and information governance arrangements
- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists, and radiographers will have appropriate training, supervision and access to Continuing Professional Development (CPD)
- All equipment will be optimised for paediatric use and use specific paediatric software

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training.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 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 on the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (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,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 Publication.
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

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

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

Key Service Outcomes

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

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:

- All those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

The National Minimum Standards for Providers of Independent Healthcare, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the Standards for the Care of Critically Ill Children (Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs;
- Food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- Support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
- For the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

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

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

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

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

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

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

Appendices

- E01/S(HSS)/a E01 Stickler syndrome diagnostic service
- E04/S(HSS)/a E04 Retinoblastoma service
- D12/S(HSS)/b D12 Specialised Ophthalmology Services Ophthalmic pathology service
- Ophthalmic Services for Children