

Ophthalmic Services for Children Guidance

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Contents

Section	Page
Summary	3
1. Background	3
Population	3
Interventions	3
2. Health needs relevant to paediatric ophthalmology	4
3. Staff and the paediatric ophthalmology team (Quality standards 1a & 1k) 5
4. Referrals into hospital	6
A. Referrals into paediatric ophthalmology outpatient services	6
B. Referral Management and Triage	6
5. Paediatric Outpatient Clinics	7
A. The outpatient setting / clinic (Quality Standards 2, 3, 4, 5, 9, 10, 13,19, 22)	7
B. Follow up appointments (Quality Standard 26, 27, 28)	8
6. Communication and Support (Quality Standard 14, 17, 18, 20, 21, 23, 24	& 25)9
6.1 Special School Eye Care Programme	10
7. Extended Roles (Quality standard 7)	10
8. On-call arrangements (Quality standard 8)	10
9. Safeguarding (Quality standard 6)	11
10. Transition (Quality Standards 16, 17)	11
A. Transfer	11
B. Core services	12
C. Non-core services	12
D. Primary ophthalmic long-term conditions	12
E. Children and YP with complex needs	12
F. Resources	12
G. Good practice (Quality standard 13)	12
11. Day case, Surgery and Inpatient care (Quality Standards 11)	13
A. Facilities within theatre environment and recovery	13
B. Paediatric anaesthesia and paediatric trained support staff	13
C. Specialised surgery	13
D. Inpatient management	14
12. Specialised ophthalmic services for children	14
Examples of possible multi-disciplinary team members and services	15

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Summary

This document updates the 2012 Ophthalmic Service Guidance for paediatric ophthalmology. It represents the expert consensus, based on available evidence and national guidance, of the Paediatric Sub-committee of The Royal College of Ophthalmologists (RCOphth) regarding best practice and fundamental standards for children's ophthalmic services. It should be read in conjunction with the RCOphth Quality Standards for paediatric ophthalmology services and RCOphth principles and generic information to inform commissioning of paediatric ophthalmology services.

This document is intended primarily for healthcare professionals and managers working in the Hospital Eye Service (HES) but should be of interest also to those working in community and primary care eye care services including orthoptists, optometrists, general practitioners, and commissioners.

1. Background

Population

The target population to which this guidance applies are infants, children and young people with ophthalmic disorders. Infants include pre-term neonates up to the age of 1 and children refers to those between the ages of 1 year and 10 years. Adolescents are defined from 10-19 years of age. In line with new transition of care guidance, the term "young people" refers to those from 10 years up to 25 years.

The term ophthalmic disorders include ocular and adnexal (surrounding structures) disease, ocular motility or binocular vision problems, visual processing disorders, cerebral visual disorders, and visual impairment.

Interventions

Disease prevention

The HES has a key role in disease prevention, particularly secondary and tertiary prevention.

Secondary Prevention includes the detection and treatment of established disease to reverse, minimise or retard its impact on vision and visual development. To undertake this, hospital services need to be responsive to, and collaborate with, the wider healthcare system for successful delivery of screening programmes including:

- 1. <u>Newborn and Infant Physical Examination (NIPE)</u> at birth and at 6-8 weeks, to detect and treat congenital cataract
- 2. <u>Universal vision screening programme</u> at age 4-5 years (Preschool screening in Scotland), to detect and manage amblyopia
- 3. Other screening and surveillance programmes, e.g., <u>diabetic eye screening</u> commencing from age 12 years, retinopathy of prematurity (ROP) screening, assessment of those with family history of congenital or childhood onset disorders such as retinoblastoma, neurodevelopmental disorders, sensorineural hearing impairment.

Tertiary Prevention is through managing the impact of chronic established eye conditions including the provision of habilitation for example mobility training or use of low vision aids for those with congenital and acquired visual impairment.

2. Health needs relevant to paediatric ophthalmology

Consideration of the effects of ophthalmic disorders, and their treatment, on a child's general development and quality of life should be paramount. A holistic, child-centred approach is required to deliver high quality paediatric ophthalmology services, addressing both the specific needs of children with ophthalmic disorders and the needs of their families. The needs of children differ significantly from those of adults with ophthalmic problems, as a child's health encompasses their physical, emotional, social and educational development. Vision impairment in childhood can significantly impair progress in any or all of these dimensions. Equally, developmental delay will impact on a child's functional vision. Paediatric ophthalmic disorders and their management should always be viewed in the broader context of general health and development.

There are four key populations of children with ophthalmic conditions with differing requirements in terms of the balance of professional and service resources:

- 1. Sight impaired or blind children: The cumulative incidence of vision impairment, severe vision impairment (SVI) and blindness (BL) combined is 10 per 10,000 by the age of 18 years: i.e., a child born in the UK has a risk of 1 per 1000 of being diagnosed as VI, SVI/BL by their 18th birthday. Half of these children will be born or become sight impaired infancy. 1,2 The prevalence (number of children and young people ≤16 years in the UK with either VI, SVI or Bl is at any time) is around 2 per 1000. The impact of vision impairment on early development is profound and therefore robust strategies are required for early detection, early intervention and ongoing management, which should be provided by a network of professionals that includes ophthalmologists, community paediatricians, primary eye care professionals and secondary and tertiary paediatricians, specialist educational services, qualified teachers for visual impairment (QTVI) and health visitors. The key intervention points are set out in the Department of Health's publication, "Healthy Child Programme: pregnancy and the first five years of life." Most children have SVI/BI/VI as part of a wider systemic disorder or have other significant impairments. As such, children and young people with VI/SVI/BL require substantial health care resource and time from hospital and community services.
- 2. Children and young people with *common eye conditions that may cause less severe reduction in bilateral vision or unilateral visual loss, particularly amblyopia and strabismus.* These conditions affect approximately 5-10% of all children, with the bulk of care delivered in HES outpatient settings. This high-volume care may be best delivered for some patients through shared care with primary care optometrists and community orthoptics to ensure timely management. Such shared care arrangements require both require robust and agreed pathways with clarity about how and when to transfer in and out of the HES.
- 3. Children with isolated refractive error or with mild / acute or self-limiting conditions. Most, particularly those with refractive error that requires correction (around 20% of all children in the UK), can be managed entirely in community settings such as primary care optometric practices.

4. Rare and complex conditions. Conditions such as congenital cataract, congenital glaucoma, vitreoretinal disease, congenital ocular malformations, orbital disease and complex neuro-ophthalmic disorders, should receive care using networked models or operational delivery networks between secondary and tertiary providers as set out by the Clinical Reference Groups. The tertiary centre has a concentration of expertise and appropriate support services to provide specialist care for these disorders. Appropriate monitoring and advice for shared care arrangements between tertiary and secondary care can be set up to facilitate patient choice and widen access.

Highly specialised services, such as treatment for retinoblastoma, are only delivered in a small number of designated centres.

There is no commissioning system in Scotland and Wales where each Health Board operates within a budget, with arrangements for tertiary referrals within Scotland of varying formality and referral to a centre in England/Wales/Northern Ireland arranged on a case basis.

3. Staff and the paediatric ophthalmology team (Quality standards 1a & 1b)

Secondary care ophthalmic services for children and young people involve a multidisciplinary team of ophthalmologists, orthoptists, optometrists, specialist nurses, technicians, support workers and eye clinic liaison officers (ECLO), who all have appropriate training and skills in delivering ophthalmic care to children.

A senior member of the ophthalmic clinical team should be named as clinical lead for paediatric ophthalmic services. Where this is not a consultant ophthalmologist or autonomously practising Associate Specialist, there must be a clear delegation of this task, with agreed consultant support easily accessible when required. Similarly, depending on size and structure of the department, there should be a dedicated lead from the orthoptic, optometric and nursing team or one lead representing all three non-medical groups.

Children with a confirmed visual disability should have access to an ECLO and subsequent access to local QTVIs within a sensory support service. Signposting families to these supportive services is important (see section 6: Communication and Support). Nursing staff and play specialists also play an important role in supporting children where they may get upset or have other difficulties.

In Scotland, every ophthalmology department should have a designated member of staff, usually an orthoptist, who liaises with Visual Impairment Network for Children and Young People (VINCYP), which logs children with visual impairment onto a clinical audit system (CAS).

All staff working in the core paediatric ophthalmology team should have a common set of core skills, competencies and knowledge for paediatric care including safeguarding training to level 3 (refreshed regularly). Where staff work at multiple sites, there should be agreement to recognise formal training and competencies completed at any site.

Regular multidisciplinary paediatric service meetings should be scheduled, with attendance from all members of the team including and where appropriate, involvement of the wider non ophthalmic paediatric medical and support team.

4. Referrals into hospital

A. Referrals into paediatric ophthalmology outpatient services

The majority of paediatric ophthalmology referrals originate from four sources.

1. Screening and surveillance programmes or targeted assessment of groups at high risk of ophthalmic disorders including:

- Neonatal and six week eye (red reflex) screening (NIPE):
- ROP screening
- School entry vision screening (pre-school vision screening in Scotland)
- Uveitis screening
- Neurosensorial hearing loss
- Neurodevelopmental impairments (e.g. Downs syndrome)
- Family history of child onset ophthalmic disorder (retinoblastoma)
- Other systemic conditions and syndromes with risk of ophthalmic disease, such as prematurity or cerebral palsy

2. Referrals from primary care and community practitioners

- These practitioners include GPs, optometrists, health visitors [HV], school nurses [SN], community paediatricians or community orthoptists and Special School Eye Care Programmes (https://www.england.nhs.uk/long-term-plan/) (see section 6.1)
- 3. Referrals from paediatric emergency or ophthalmic emergency departments
- 4. Referrals from paediatric hospital services

B. Referral Management and Triage

There should be ready access for urgent patients when serious visual impairment or high-risk ophthalmic disease is suspected. Every ophthalmic unit seeing children should have agreed pathways for very urgent and emergency referrals. Clear arrangements should be in place for receiving referrals from, and providing prompt advice to, emergency departments, both during normal hours and out of hours. Children requiring emergency ophthalmic care should be seen at the earliest opportunity. Initial contact/assessment can be undertaken by medical staff or trained non-medical clinicians (nurses, orthoptists, optometrists) to whom this role has been clearly delegated. Paediatric inpatient units should be aware of urgent and routine referral pathways for children requiring assessment for ocular issues that should be agreed with the receiving ophthalmic unit. Again, emergency referrals should be seen as soon as possible, and it should be possible to assess children on wards if they are too unwell to be seen in an outpatient clinic.

Non-emergency referrals can be triaged to an appropriate clinic appointment. Triage should be undertaken against documented clinical risk and urgency criteria and appointments offered within an appropriate interval in a clinic with the appropriately trained personnel and facilities. Referrals into paediatric ophthalmology services should be triaged by a consultant ophthalmologist or a designated clinician, to whom this duty has been clearly delegated, such as a clinical fellow, or senior orthoptist / optometrist.

A robust referral system, monitored and actioned by designated staff, should be in place. Where referrals are received via email, there should be a dedicated generic account with failsafe mechanisms in place (such as out of office and who to contact in this instance). Referrals sent to an individual clinician's email should be discouraged to prevent emails

becoming 'lost' or unactioned during periods of absence. Where there is no alternative, it is the responsibility of the referring clinician to ensure any referrals sent to another clinician's personal email account are actioned.

5. Paediatric Outpatient Clinics

A. The outpatient setting / clinic (Quality Standards 2, 3, 4, 5, 9, 10, 13,19, 22) Paediatric ophthalmology services in HES should adhere to the outpatient <u>standards</u> for children

(https://www.cqc.org.uk/sites/default/files/20200317 NHS Acute Core service framewor k for CYP v7.pdf).

The care setting should be appropriate for children, including those with complex disorders, with the ability to make reasonable adjustments for those with learning disability and autistic spectrum disorder.

Specifically, the outpatient area for children, YP and their families should have access to:

- A suitable waiting area that is separate from the adult area
- A waiting area or facilities that offer activities for different ages of children and YP
- Facilities for toileting, infant feeding and changing
- Accessibility for wheelchairs, buggies, low reception counters for checking in, and parking
- Clear signage that is appropriate for children and YP including those who are visually impaired
- Children and YP should be seen in dedicated paediatric ophthalmology or orthoptic / optometry clinics by paediatric trained and experienced clinicians, unless there are circumstances where more specific subspecialty input is required to fulfil the patient's needs, or it is very urgent or an emergency
- Information about conditions, their treatments and to support consenting for children and young people and/or family in age-appropriate language
- Ready access to translation services
- Information about mental health services and public health messages in age / family appropriate language
- Patient experience measures designed for families, children and YP which can be used as part of assessing quality of service and clinical effectiveness
- Clinical equipment and tests required to assess the full age range of paediatric patients
- Clinic appointments should be timed so that long waits are avoided as far as is
 possible; clear communication and information should be sent in advance, and
 displayed in waiting areas, explaining the nature of sequential appointments and
 expected length of the appointment. Patients and families should be kept up to
 date during their attendance on any delays. An active clinic-flow management
 system should be in place to mitigate an unnecessary delay in seeing children in
 a busy clinic.
- Reasonable adjustments for their specific needs. Families of children with learning disabilities, autistic spectrum disorder or those requiring complex services should be offered the opportunity to discuss and record the specific

needs of the child when attending for appointments. These should be available for the booking and clinical teams to view and should be reviewed at regular intervals to allow for further adjustments to be made where necessary. Adjustments may include first / last appointment, separate or quiet waiting area, avoidance of known triggers to sensory sensitivities, likes and dislikes, expedited flow through the outpatient pathway and additional evaluation time? An example of this is available.

- Open discussions and as much active involvement of children in their care and condition as possible
- Access to special investigations, tests, and services necessary for the diagnosis, monitoring or management of their condition e.g., electrophysiology, neuroimaging, genetic counselling, low vision assessment. Where this is not available in a unit, there should be pathways developed with other units to enable access.
- Pathways permitting assessment and advice by generalist and specialist paediatricians and psychological support if required supported by the potential for multidisciplinary team (MDT) meetings to review care decisions holistically
- Safeguarding pathways (see section 9: Safeguarding)

B. Follow up appointments (Quality Standard 26, 27, 28)

The managing clinician should ensure a follow up appointment is arranged, in keeping with agreed local risk stratification guidelines or RCOphth / national clinical guidelines where they exist. It is an everyday reality that demand for HES appointments exceeds capacity. This often limits the ability to offer a clinically ideal appointment or may lead to rescheduling of clinic appointments. The decision as to when to book or rebook (after cancellations and where patients do not attend) should always be confirmed by a suitably senior clinician considering key factors including the level of visual impairment, risk of incurring visual impairment or other serious harm from any delay. A process for monitoring of follow up backlogs should be in place and the service should identify cases of significant harm due to delay in follow up through their hospital incident reporting system to ensure that appropriate investigation and preventative actions are instigated. An example case study is available.

Where possible, and where it is clinically safe to do so, children and young people with less complex eye conditions should be considered for orthoptic only or orthoptic / optometry shared care in the HES or community setting. When clinically appropriate, children and young people should be discharged from HES and see their primary care optometrist for follow up refractive care where necessary. For children with special needs, liaison with community optometrists with an interest in paediatric eye care/special school eye care programme can facilitate transition to community services. Senior decision makers should robustly oversee decisions to follow up to ensure the appropriate frequency of follow up and robust discharge of patients who no longer need hospital appointments.

An agreed process for management of children or young people not brought to their clinic appointments should be in place (see section 9: Safeguarding).

6. Communication and Support (Quality Standard 14, 17, 18, 20, 21, 23, 24 & 25)

Effective communication is essential to the progress and wellbeing of children and families.

Parents or guardians remain the most expert advocates for their children. In older children and those undergoing transition (see section 10: Transition), a process should be in place to ensure active involvement of the young person in the management of and decision making for their own eye condition. Parental advocacy and, for those young people going through transition, shared decision making, should be supported and encouraged through provision of information and social and emotional support. This should be undertaken both in the context of the management of individual children or young person, as well as more broadly in relation to the planning of ophthalmic services for children and young people with ophthalmic conditions and visual impairment. Patient information leaflets with appropriate translation should be provided or patients signposted to relevant information (see section 5a: Outpatient Setting). Clinic letters addressed directly to the family and young person, in an understandable and easy to read format are important in this context. Active regular communication to outside agencies, such as visual impairment teachers is important (with the permission of parent, carers or guardians), for the social, educational and emotional wellbeing of the family.

All infants, children and young people with visual impairment should be referred directly to the local authority special education sensory impairment service as soon as sight impairment is identified, with appropriate consent, to enable early intervention and support. The evidence provided by the ophthalmologist is important and frequently incorporated into Education Health and Care plans (EHCP) for children with special educational needs and disabilities. It is important to respond within the appropriate timeframe to draft plans from the local authority.

he placement of an ECLO embedded within the service facilitates linkage between HES, sensory support teams and social services. They can also provide families with information about national support groups. Interhospital and communication between health professionals is important particularly where shared care arrangements are in place or if there are complex needs1. Ophthalmic services will need to ensure that they are part of any digital technology programme development to share information about children and young people, as espoused in "Getting it right for every child", and "Healthy child programme".

Certification of children with sight impairment or severe sight impairment is an important task for ophthalmologists to undertake for all eligible children and young people. It creates eligibility to go on local sensory support services register, which helps with local service planning. Additional support from a social care assessment may also be offered following of registration. Children with cerebral visual impairment and reduced vision or visual function, should be referred for a wider multidisciplinary assessment through community paediatricians or developmental paediatric services. Ongoing communication with these agencies is required throughout the period of follow up.

In Scotland, children are not certified with sight impairment until they are 16 years old. Under the age of 16 years they are notified to the VINCYP CAS.

6.1 Special School Eye Care Programme

NHS England has committed to funding a Special School Eye Care Programme (SSECP) to enable children in special schools to access regular community eye care as it is estimated between a quarter and a third of children in special school have a visual impairment. Hospital paediatric eye services may choose to deliver all or part of this service, and are expected to support the local provider with information, advice and facilitate transfer between HES and SSECP where appropriate. There is expectation that hospital paediatric eye services will contribute to SSECP boards alongside special school teachers, QTVI's, optometrists and orthoptists to offer support and agree referral/review criteria for a special school eye care programme and offer virtual support where there is a clinical query. Hospital paediatric eye services will also be expected to provide ongoing liaison with special school eye care programmes to provide information to facilitate community eye care and discussion where queries arise. The SSECP is also an example of a national community programme, which can support long term follow up of patients for whom high street optometry may not be appropriate.

7. Extended Roles (Quality standard 7)

There is increasing interest in the NHS for non-medical clinical professionals, such as orthoptists, optometrists and nurses, to extend their roles through an enhancement process. There are opportunities to increase the depth of their roles by extending their skills or through expanding the breadth of their job by working across traditional professional divides. This may be combined with developing into advanced practitioners through a Masters programme including the non-clinical developmental pillars (research/innovation, teaching, leadership). Examples of extended roles include an orthoptic delivered uveitis screening and a paediatric cataract follow up clinic run by optometrists combined with orthoptists. Such extended clinical services should be under the supervision of an ophthalmology consultant (or autonomous AS) and access to expert advice and guidance from the consultant should be readily available. In establishing these extended roles, non-medical professionals should work collaboratively with their consultant ophthalmologist and experienced non-medical advanced practitioners to devise training packages and recorded competencies, and ensure that appropriate governance arrangements are in place including guidelines, audit and ongoing continuous professional development are embedded.6

8. On-call arrangements (Quality standard 8)

Every ophthalmic unit should have recognised emergency cover arrangements, with access to designated facilities for assessment of children with urgent conditions. Where appropriate, the on-call team may include trained nurses, optometrists, orthoptists, specialist trainees, specialty doctors and staff and associate specialist grade ophthalmologists, as well as a clearly designated on-call consultant. There is no requirement for the on-call team to subspecialise in paediatric ophthalmology.

All members of staff involved in the on-call assessment and management of children must be trained in the appropriate level of child safeguarding. There should be a clearly designated named nurse and doctor identified, in case of safeguarding concerns.

Wherever possible, children should be seen in dedicated areas. There must be suitable facilities for children and their families to wait and be assessed.

Each unit should have agreed pathways for urgent out-of-hours paediatric ophthalmic surgery.

When referring children to other units for urgent sub-specialist ophthalmic surgery, there should be an attempt made to refer to the nearest appropriate unit.

Non-accidental injury: Refer to RCOphth guidelines (https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-292-ABUSIVE-HEAD-TRAUMA-AND-THE-EYE-FINAL-at-June-2013.pdf). Efforts should be made for children with suspected abusive head trauma to be examined within 24 hours of referral. While local services may vary depending on expertise, it is expected that this will be performed by the lower on-call tier. Where positive findings are reported, they should be confirmed by the on-call consultant. There is no requirement for the ophthalmologists to subspecialise in paediatric ophthalmology.

9. Safeguarding (Quality standard 6)

Ophthalmologists and other relevant ophthalmic clinic staff are often key professionals in the identification of child abuse and other child protection issues and should be up to date with appropriate level 3 safeguarding in children training. Whilst all ophthalmologists should be familiar with local and national child protection policies and procedures, paediatric ophthalmologists in particular should support multidisciplinary child protection teams in the identification and management of infants or children under their investigation. Clinicians must be aware of the pathways that are in place in their organisation to access named nurses and named doctors for cases where child abuse is suspected. It is important to raise concerns with the consultant where children repeatedly fail to be brought to clinic appointments and clear communication to the families and other involved care providers including health visitors should be made. Consideration for involvement of safeguarding should be made for especially vulnerable children or young people who persistently fail to be brought to clinic appointments. Specific information is available through NICE guideline publications.

10. Transition (Quality Standards 16, 17)

Transition is a process comprising the planned transfer of young people with long-term conditions and/or complex needs from child-centred to adult-orientated health and social care systems. The process of transition can begin by 11 years old and should be a developmentally appropriate process that continues until around 18 years of age or 25 if the young person has an EHCP. The process should align with NICE standards for Transition from Children to Adult services.

A. Transfer

Transfer is the formal event when medical care of a YP is moved from children's to adult services.

B. Core services

Where children and YP services form a part of the core ophthalmic provision in an organisation, the <u>NICE guidance</u> should be used and the overarching principles applied;

- The transition involves young people (which includes a named worker)
- Is developmentally appropriate
- Is strengths based
- Is person centred

C. Non-core services

Where children and YP are seen within a non-paediatric ophthalmology sub speciality such as oculoplastic, vitreoretinal, emergency eye clinics or theatres then standards such as the <u>'You're Welcome' standards</u> should be in place to support YP attending a predominantly adult area.

In England, the guidance from <u>CQC</u> is provided for children and YP in core outpatient and inpatient services.

D. Primary ophthalmic long-term conditions

Some children with complex or chronic primary long-term ophthalmic conditions require ongoing hospital eye care in adult services, and/or care provided by primary care optometrists or community ophthalmic teams. In this situation, the named worker for leading the transition and transfer is usually one of the ophthalmic team and often the Consultant in charge.

E. Children and YP with complex needs

Young people with complex needs requiring complex services who may also have a long-term ophthalmic condition that should be considered as part of the transition arrangements. In this case, the named worker leading the transition and transfer is most often a consultant paediatrician involved in the young person's overall care and familiar with all their needs. The ophthalmic team contribute to and support the transition plan.

<u>Special School Eye Care Programmes</u> also have processes in place for transition for young people with complex needs.

F. Resources

Transition begins as early as 11 years old and by no later than school-year 9 (age 13) but it must be a developmentally appropriate process supporting the needs of the young person. A supportive and structured plan of transition such as the <u>Ready, Steady, Go programme</u> is advised so that all clinical teams have access to the progress of the plan and discussions with the young person. This particular programme also has resources for the transfer to adult services.

G. Good practice (Quality standard 13)

Good practice in core service transition and transfer should include as a minimum:

- All staff involved in transition have received appropriate transition or supporting
 YP training
- Beginning transition at a developmentally appropriate time from age 11
- The clinical team using an agreed set of standards and resources to support transition and transfer
- The young person has a named lead for the process

- All clinicians discussing any aspect of transition with the YP document this clearly in the records
- The letter following the consultation clearly states what was discussed around transition at the appointment
- The young person receives a developmentally appropriate letter which contains the discussions and agreed plans
- The young person is consulted about their future appointments (timing / being accompanied)
- Feedback from young people should be collected and acted upon
- There is a clear process at transfer which supports the young person this should include meeting the receiving clinician prior to transfer and dealing with nonattendance
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- There is a clear process at transfer which supports the young person this should include meeting the receiving clinician prior to transfer and dealing with nonattendance

11. Day case, Surgery and Inpatient care (Quality Standards 11)

A. Facilities within theatre environment and recovery

Most ophthalmic surgery in children can be performed as a day-case procedure. All facilities within the ward, theatre and recovery area must be suitable for children and young people.

Children must be admitted in a paediatric ward be cared for by staff who have the relevant level of mandatory training in relation to working with children and young people e.g., basic paediatric life support, safeguarding level 3.

Where non-medical staff see children and young people independently or in extended or advanced practice roles, appropriate governance arrangements should be in place (see section 7: Extended Roles).

Appropriate facilities for pre-medication and play areas should be provided where possible to minimise pre-operative anxiety and play specialists should be available on request.

The anaesthetic rooms should be child friendly, and theatres should be adequately equipped with portable equipment for examination under anaesthesia.

Access to such facilities should be restricted to authorised staff only. Visitors should undergo appropriate checks or be accompanied by hospital staff at all times.

B. Paediatric anaesthesia and paediatric trained support staff
Children and young people undergoing surgery should be scheduled onto dedicated paediatric lists unless there is a specific clinical reason (e.g., urgent or subspecialty procedure), and <u>anaesthetised by anaesthetists with appropriate training and continuing experience as specified by the Royal College of Anaesthetists.</u>

C. Specialised surgery

All children should be operated on by surgeons with appropriate training and experience.

Surgery should be scheduled in a timely manner according to clinical need.

While most ophthalmologists with continuing experience will be competent to perform uncomplicated strabismus and lacrimal procedures in children, less common procedures such as anterior segment surgery in children should be carried out by consultants with appropriate specialist training and expertise. When experience or equipment is not adequate to manage the condition (either from an anaesthetic or surgical perspective), referral to specialist centre should be considered.

Some specialised cases may require input from surgeons who are not primarily paediatric ophthalmologists, e.g., vitreoretinal, orbital/oculoplastic or corneal surgeons. It is important all surgeons undertaking occasional paediatric surgery have undergone appropriate employment checks and mandatory training and are subject to the governance procedures of the hospital in which the child is being treated.

D. Inpatient management

Children should be cared for onwards appropriate for their age and stage of development. Close involvement of the family is essential because children in hospital who are separated from their parents are more likely to suffer psychological stress and recover more slowly, than if not separated.²

All hospitals with children as inpatients paediatric wards should provide space for parents to stay overnight, wash, make drinks, and to sit in privacy.

Written information for parents and young people should be provided covering policies, facilities, particulars of procedures and contact numbers.

Appropriate arrangements must be in place for shared care with paediatricians, or other paediatric specialties, e.g., paediatric neurology. All relevant clinicians and health professionals should have access to clinical and safeguarding records to ensure key data is not missed.

Units training ophthalmic specialist trainees must ensure that trainees obtain appropriate exposure to paediatric ophthalmology according to the curriculum of The Royal College of Ophthalmologists.

Appropriate arrangements must be in place for timely communication with other health professionals e.g., the general practitioner e.g., discharge letters and e-prescribing. There should be a robust discharge policy to ensure care is followed through in the community.

12. Specialised ophthalmic services for children

These are services provided by specialist paediatric ophthalmology networks including provision in outreach centres when delivered as part of a provider network. The service includes management of rare conditions, complex or high-risk procedures, specialist contact lenses and ocular prosthetics (see table 1). These services are commissioned centrally (e.g.by NHS England) or established in one Board e.g., in Scotland, because:

- The number of individuals requiring the service is small
- The number of doctors and other expert staff trained to deliver the service is small
- The cost of the service is high due to the specialist interventions involved
- The overall cost of treating patients is high, placing a potential financial risk on individual CCG's/Health Boards

Specialised services are provided by multi-disciplinary teams and led by ophthalmologists trained to fellowship standard in the appropriate subspecialty. There is an ongoing requirement for continuing medical education, adherence to professional standards and provision of postgraduate education. Paediatric ophthalmologists and ophthalmologists with adult subspeciality expertise often share care, working together at both secondary and tertiary levels of care provision. Additionally, there is overlap with specialised services in other medical disciplines, in the form of multi-disciplinary teams.

Examples of possible multi-disciplinary team members and services

- Strategic clinical networks for children
- · Paediatric neurosciences service
- Paediatric rheumatology and infectious disease services
- Child development service
- Paediatric oncology service
- Paediatric radiology
- NHS Genomics, medical genetics
- Child psychology
- Ophthalmic pathology
- Intensive care services and neonatology, neonatal networks
- Pharmacy
- Maxillo-facial / ENT / cleft lip and palate / audiology

Specialised ophthalmic services for children are provided within regional networks, these have been constructed from existing clinical expertise and shared care practices within the geographical region, may vary in their delivery structure and may evolve with changes in clinical personnel. In Scotland, there are informal but well recognised pathways for referral to regional specialist services.

The objectives of these regional specialist service networks are to:

- Pool expertise to ensure quality of care and reduce unwanted variation in clinical practice
- Concentrate referrals to the service with expertise to support training and clinical governance
- Provide an opportunity to train and retain clinicians in specialised conditions
- Support smooth transfer of care across organisations and facilitate shared care

Table 1: Examples of conditions managed by non-specialised versus specialised services.

Non-specialised service	Specialised service
Orbital Minor orbital disorders e.g., dermoid cysts Typical and responsive pre-septal / orbital cellulitis	Orbital tumours and rare orbital conditions Atypical or non-responsive orbital cellulitis Microphthalmia / anophthalmia Ocular prosthetics
Oculoplastic / lacrimal Lid cysts, benign lesions & minor procedures Congenital nasolacrimal duct obstruction	Ptosis and complex lid surgery Dacryocystorhinostomy
Cataract and lens disorders Cataract surgery over 2 years of age	Lens surgery in children 2 years and under Complex lens surgery Genetic evaluation of lens anomalies Contact lens fitting
Glaucoma	All cases of childhood glaucoma (with shared care within networks)
Corneal disorders Primary corneal repair Common forms of keratitis	Management of corneal dystrophies Corneal grafting Eye banking
Vitreoretinal and retinal conditions Minor, sporadic retinal conditions	Management of retinal vascular disease Vitreo-retinal surgery
Retinopathy of prematurity Screening	Second opinion and treatment
Paediatric Uveitis	Investigation and management of uveitis Immunosuppression therapy
Ocular Genetic disorders	Investigation and counselling for genetic disorders within the NHS genomics service framework
Neuro-ophthalmology Cerebral visual impairment	Multi-disciplinary evaluation for CVI Acquired neuro-ophthalmological conditions Electrophysiology and eye movement recording Optic nerve sheath fenestration
Strabismus Noncomplex/concomitant squint management	Incomitant and complex squint management
Emergency care Non-complex cases Specialised services should undertake regular at	Complex cases requiring specialised evaluation or surgery

Specialised services should undertake regular audit to ensure quality of care with comparison to outcome standards in the specialised ophthalmic services for children manual (see section 13: Audit).

13. Audit (Quality Standards 12 & 29)

Audit is a key component of modern paediatric ophthalmic practice and is included in CQC inspections. Regular audit of clinical practice is important to ensure patient safety. The RCOphth has a role in developing national datasets such as the national cataract dataset and similar programs relevant to paediatric ophthalmology (such as a national strabismus surgery dataset). It is expected that paediatric ophthalmology services will contribute to these datasets, permitting large scale audits and audit standard development for local teams and that these and future datasets will be based largely on good quality EPR systems in every centre. Local audit is also key to running a good service and it is expected that services will run audits on new services and services which have undergone change in addition to rolling audits of key services to compare with national standards or national datasets (such as intraoperative strabismus surgery complications) and established evidence-based guidelines.

A culture of engagement in audit and improvements to services based on their findings is expected in line with that in other ophthalmic and non-ophthalmic specialties.

<u>Patient Reported Outcome Measures (PROMs)</u> are recognised as providing services with information which can help improve and shape clinical services and a review of some of those specific to paediatric ophthalmology is available3. In Paediatric Ophthalmology, these metrics can be used in conjunction with clinical outcome data to help shape and continuously improve services involving children. It is expected that paediatric ophthalmology services engage and actively collect and evaluate PROM data. <u>Examples of developing PROMS in paediatrics are available</u>.

14. Research

Clinical research is now a metric in CQC evaluations are made, in recognition of the growing evidence that patients in research active Trusts have better clinical outcomes. Indeed, clinical research was a key component of the NHS 'Five Year Forward View' 2014.

Clinical research can take many forms and it is not envisaged that many paediatric ophthalmologists will be leading large, multicentre clinical trials.

Research training is part of the OST programme for all ophthalmic trainees. Once this is embedded, it is expected that all ophthalmologists will be appropriately trained to be involved in clinical research at some level, whether this be leading research studies, identifying potential studies which could improve clinical practice or identifying patients for studies run by others.

Trusts and employers are under increasing pressure to recognise clinical research activity on job plans as 'core activity' and therefore direct clinical care (DCC). It is therefore expected that all paediatric ophthalmologists actively seek and contribute to clinical research opportunities and promote a culture by which research is considered part of their core activity, in the interest of their patients.

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16. Authors

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