



PAEDIATRICS

**A NATIONAL MODEL
OF CARE FOR PAEDIATRIC
HEALTHCARE SERVICES
IN IRELAND
CHAPTER 37:
PAEDIATRIC
OPHTHALMOLOGY**



Féidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Clinical Strategy and Programmes Division



**ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND**

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37.0 INTRODUCTION

The planning of ophthalmic services should explicitly account for the following '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.

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.

Disorder specific frequencies are detailed below:

Cataract	3-4 per 10,000 births/year
Glaucoma	5.4 per 100,000
Inherited Retinal Disorders	1.4 per 100,000 children/year (cumulative incidence by age 16 years 22.3/100,000)
Visual Problems of Prematurity	Up to 50% of <750g would need treatment (stage 3)
Neuro-ophthalmic Disorders	Individually rare, collectively commonest cause of severe visual impairment (accounting for about 50%)
Anophthalmia, microphthalmia or coloboma	11.9 per 100,000 by 16 years

The specialised ophthalmology service for children is responsible 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 (pre-cut tissue plasma/serum production, cell culture production), ocular surface stem cells, retinal stem cells, and 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).

Strabismus 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. Complex strabismus cases such as Brown Syndrome, paretic strabismus in which the use of botulinum toxin is occasionally utilised or paediatric strabismus which requires postoperative adjustment is a specialised service. 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.

37.1 CURRENT SERVICE PROVISION

The service has developed in both Temple Street and Crumlin with a significant component of the work also performed in the Royal Victoria Eye and Ear Hospital. Little strategic overlap exists between the two services to date.

Ophthalmology services in Temple Street Children's University Hospital

Mr. Ian Flitcroft has a 0.3 whole time equivalent (WTE) commitment, Professor Michael O'Keefe has a 0.7WTE commitment, and Dr. Susan Fitzsimons has a 0.4WTE commitment to paediatric ophthalmology. In total, there are 1.4WTE paediatric ophthalmologists in Temple Street. The service has significantly increased since 2007:

	2007	2012
Outpatient Attendances	9,088	14,000
Admissions for Surgery	670	740
Referrals for Retinopathy of Prematurity*	1,500	2,068

* Retinopathy of prematurity babies are screened and treated within the neonatal departments.

Ophthalmology Services

Temple Street provides a comprehensive range of secondary and tertiary services in paediatric ophthalmology, and in addition there is significant commitment to inter-disciplinary care through joint management with other specialities (e.g. neurology, neurosurgery, metabolic, infectious diseases and dermatology). A national service for retinoblastoma is provided by Prof. Michael O'Keefe for treatment, monitoring and screening.

Outpatient Workload

There are nine ophthalmology clinics each week with sub-specialist clinics (from weekly-monthly) in motility, metabolic, genetic, cataract, glaucoma, neonatal, low vision, contact lens, ocular prosthetics and an outreach clinic to Child Vision. A comparable throughput of patients, in terms of outpatient attendances exists in the Hospital for Sick Children Toronto, there are 17,000 outpatient attendances per annum and this compares with 14,000 per annum in Temple Street. There is a 1.4WTE consultant complement in Temple Street - there is significant understaffing at consultant level. There is also a significant deficit from a nursing perspective with Ms. Bernie Lanigan being the sole clinical nurse specialist in ophthalmology and proposals have been made to have more clinical nurse specialists in ophthalmology in the future. There are three non-consultant hospital doctors, one senior house officer (SHO) and two registrars, both of whom are shared with the adult service in the Mater.

Ophthalmology Services in Our Lady's Children's Hospital, Crumlin

In Crumlin, there are two paediatric ophthalmologists, Mr. Donal Brosnahan (0.5WTE) and Ms Kathryn McCreery (0.5WTE). The ophthalmology department in Crumlin provides an inpatient consultation service for all paediatric subspecialties which has experienced a significant increase in referrals with growing paediatric subspecialisation, particularly in rheumatology, dermatology, cardiology, endocrinology and genetics. A neuro-oncology multidisciplinary team meeting is held every two weeks at which ophthalmology is represented. Ophthalmology also participates in the tertiary referral joint vascular birth mark clinic in Crumlin and is actively involved in managing patients with capillary haemangiomas and Sturge-Weber Syndrome.

Consultant Ophthalmic Surgeons	Mr. Donal Brosnahan 0.5WTE Ms. Kathryn McCreery 0.5WTE
Consultant Ophthalmic Physician	Ms. Nikola Brummell Murphy 0.8WTE
Higher Surgical Trainees	0.5WTE (although recognised for training of 1WTE higher surgical trainee)
Clinical Nurse Specialist	Ms. Marie Keegan 0.7WTE ophthalmology trained
Orthoptists	2.6WTE

Staffing Levels in Crumlin

	2013
Ophthalmology Outpatient Attendances	12,624
New Referral Letters Received*	1,782

Activity Levels in Crumlin

* The number of new referrals in 2013 greatly exceeded current service capacity which is 1,000 new patients over a 12-month period. There are currently 798 routine referrals currently awaiting a new appointment. In addition, 300 new outpatient referrals have been transferred to the Special Delivery Unit for evaluation in 2013.

There is currently no eye service in Tallaght. Tallaght Hospital ceased accepting paediatric ophthalmology referrals two years ago and this has resulted in significant increase in paediatric ophthalmology referrals to the services in Crumlin.

Royal Victoria Eye and Ear Hospital (RVEEH)

The RVEEH provides paediatric ophthalmology services – both general paediatric ophthalmology and subspecialty services in paediatric retina, uveitis, oculoplastics and anterior segment. Surgery is undertaken on children over 2 years without co-morbidity and children under 2 by special arrangement. The RVEEH share a number of paediatric anaesthetic posts with Crumlin Hospital. There is a dedicated paediatric ward.

	2013
Ophthalmology Outpatient Attendances	5,307

Activity Levels in RVEEH

Surgical Workload

Temple Street Children's University Hospital

There were 678 operations in Temple Street in 2013. In terms of surgical workload, 20% of the workload relates to strabismus, 25% to retinoblastoma (this is a 32 county service with 3 to 4 referrals per year from Northern Ireland), 20% cataract surgery and 10% glaucoma surgery. The remainder are a miscellaneous group of conditions. Mr. Ian Flitcroft looks after a comprehensive electrophysiology service and the screening of patients with inborn errors of metabolism and mitochondrial disease.

Our Lady's Children's Hospital, Crumlin

There were 317 surgical cases in Crumlin in 2013. A wide range of procedures were undertaken which reflect all areas of paediatric ophthalmology surgery, including strabismus, cataract extraction and IOL implantation, vitrectomy, glaucoma and ROP surgery. Paediatric oculoplastic surgery is also frequently performed including ptosis and nasolacrimal duct stenting.

Royal Victoria Eye and Ear Hospital

260 (56 inpatient, 204 daycases) ophthalmic surgeries were undertaken on children under 16 at the RVEEH in 2013.

Retinopathy of Prematurity

Retinopathy of prematurity (ROP) screening services at the Coombe Hospital are provided by Ms. Kathryn McCreery and Mr. Donal Brosnahan (Mr. Brosnahan provides this service without a contracted sessional commitment). Neonates requiring laser photocoagulation are transferred to Crumlin for treatment. Intravitreal Avastin injections are performed in the Coombe. Professor Michael O'Keeffe provides a similar service for both the Rotunda and National Maternity Hospital.

Retinopathy of prematurity screening should take place in level 3 / level 2 neonatal centres outside of Dublin, i.e. Cork, Limerick, Galway, Drogheda and Waterford. Screening for retinopathy should take place in accordance with international guidelines, however, it is believed that treatment including laser photocoagulation should take place in a tertiary paediatric ophthalmology centres.

There have been significant developments in the delivery of care for ROP. This involves the use of intravitreal injections which have now become the 'standard of care' in many infants with ROP requiring treatment. This however has significantly added to the burden on clinicians' time. Recent reports have shown that with this new model of care, each child who receives intravitreal therapy will need 16 +/- 6 visits vs. 6 +/- 3 visits for those who have laser therapy (Isaac, 2015). The increased care required per patient effected with ROP (requiring treatment), and the increase survival of at risk infants in our neonatal nurseries, has significantly added to the demand on specialist paediatric ophthalmology services and will need additional resources.

Visual Electrophysiology

Visual electrophysiology is indicated for unexplained visual loss, nystagmus, and to diagnose retinopathy. Visual responses are useful for the management of craniopharyngioma and visual pathway glioma. Visual electrophysiology is available at Temple Street, Crumlin and the Royal Victoria Eye and Ear Hospital.

Ophthalmology Services Outside of Dublin

Paediatric ophthalmology services are provided outside of Dublin, but they are limited to eye probings, strabismus repairs and eye cysts. All other more complex referrals are directly referred to Dublin. In Cork, approximately 70 operations take place per annum, in Waterford 150, in Limerick 30-40, in Galway 40-50 and Sligo 30-40.

Strengths of the Current Service

- High work ethic of the consultant staff
- Excellent working relationships with other departments within the hospital
- The retinoblastoma service in Temple Street is the only service for this condition within all of Ireland and results obtained are comparable to best international norms
- The retinopathy of prematurity service in both Crumlin and Temple Street - this service is delivered on site in the neonatal departments at both screening and therapeutic level and again results are comparable with best international norms.
- Comprehensive electrophysiology service for the diagnosis of complex neurometabolic disease, visual loss and Leber's with significant transfers from all around the country for this service
- Excellent cataract surgery service

Weaknesses of the Current Service

- There has been a significant transfer of the workload from the adult services
- Rolling theatre closures provide significant disruption to theatre lists
- The major component of the workload in theatre is elective surgery as there are frequent cancellations due to lack of bed availability
- Space constraints within clinics in both Crumlin and Temple Street - the current eye clinic is not fit for purpose in terms of its throughput, seeing up to 60 patients per clinic in a very cramped environment is suboptimal. Most equipment additions are via fundraising.
- Understaffing at consultant level

37.2 PROPOSED MODEL OF CARE

Ophthalmology hospital services are provided by multidisciplinary teams (MDTs) of ophthalmologists, 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.

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. Internally, the 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
- Social worker
- Genetic counsellor

In the future, 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

Future vision:

- Use community ophthalmology to see most of the common conditions, and this requires significant strengthening of the community ophthalmology service
- A cross-city on-call rota with subspecialisation in paediatric ophthalmology
- Intra-ocular surgery based in the tertiary centres

New Children's Hospital

Paediatric ophthalmology activity is predicted to increase by approximately 15% by 2020 when the new children's hospital is planned to open, this incorporates factors such as population increase and activity transferred from other sites. In addition to resource increases required to address historical deficits, this further increase will need to be considered in service planning.

Centralisation of all paediatric ophthalmology services at the new children's hospital will create challenges in complex sub-specialist areas such as surgical retina, corneal grafting, difficult glaucoma cases, some uveitis cases and orbital disease. These are currently managed by existing links with adult services at both the RVEEH and the Mater Hospital. To address this, future joint consultant appointments could be created between adult and paediatric services (e.g covering adult and paediatric vitreo-retinal surgery), or contractual arrangements put in place to allow adult ophthalmology sub-specialists from other hospitals to work in the new children's hospital. Appropriate theatre resources and nurse training will also be required for such complex surgical cases. Until such time as appropriate consultant skill mix is available at the new children's hospital to provide a complete service in all subspecialty areas the links with the RVEEH and the Mater Hospital must be maintained. If satellite outpatient ophthalmology clinics are planned outside the new children's hospital, consideration should be given to locating these at sites where staff and facilities already exist.

37.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

The future visions relate to additional manpower, overcoming space constraints within the clinic and additional theatre time.

The on-going treatment of retinopathy in prematurity needs to continue, this is an expanding service of both screening and therapeutic aspects and happily there have been no cases of blindness due to retinopathy of prematurity in the service for the past 20 years.

Manpower Issues

A new joint appointment between Temple Street and Crumlin of 1WTE consultant ophthalmic surgeon, with access to surgery and anaesthetic support, is required. With the impending retirement of Prof. O'Keeffe in Temple Street, a replacement post is being progressed. The ROP service provided by Mr. Brosnahan to the Coombe Hospital should be formalised within his contract.

Fulltime specialist registrars in ophthalmology are required at Crumlin (Irish College of Ophthalmologists have recognised the post for a full time higher surgical trainee in Ophthalmology). Currently there is only a 0.5WTE sessional commitment to the RVEEH and 0.5WTE to Crumlin. It is recommended that there is a further 0.5WTE sessional commitment to the RVEEH and 0.5WTE to Crumlin, and that this is matched with Temple Street. A full time basic specialist training post should be established at Crumlin. This represents a valuable training opportunity which is not being utilised, and will not be possible to obtain anywhere other than Temple Street where there is a basic specialist trainee post in place.

The current service is overly reliant on one clinical nurse specialist in both sites, and the clinical nurse specialist numbers need to be increased up to two in each. This will potentially in the future allow for nurse led clinics within paediatric ophthalmology.

Staffing	Current (WTE)	Proposed (WTE)
Consultant ophthalmologist	Temple Street: 1.4WTE Crumlin: 1WTE	1.9WTE 1.5WTE
Specialist registrars	Temple Street: 1WTE Crumlin: 0.5	1.5WTE 1WTE
BST	Temple Street: 1WTE Crumlin: 0WTE	1WTE 1WTE
Clinical nurse specialists	Temple Street: 1WTE Crumlin: 0.7WTE	2WTE 2WTE

Infrastructure

Both Crumlin and Temple Street require two additional clinics per week and one additional operating session per week, to relieve immediate pressure on the system. The current clinical space in both Temple Street and Crumlin is wholly unacceptable and needs to be urgently addressed.

Education and Training

Guidance, including clinical management guidance, is available from the Royal College of Ophthalmologists website www.rcophth.ac.uk including:

- Ophthalmic Services for Children: Royal College of Ophthalmologists (August 2012)
- 'Juvenile arthritis' (2006)
- Vision 2020
- 'Visual screening in childhood and adolescence', Health for all Children
- Standards for the retrieval of human ocular tissue used in transplantation, research and training (October 2008)
- UK Retinopathy of Prematurity Guideline (May 2008)
- Research and Training (October 2008)
- Electrophysiology Eye Service Standards:

<http://www.iscev.org/standards/proceduresguide.html>

37.4 PROGRAMME METRICS AND EVALUATION

Clear policies should be in place to ensure that staff develop and maintain their specialist skills and knowledge. 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. 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.

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>)

- Clinical teams to routinely collect outcome data to demonstrate quality standards
- 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

37.5 KEY RECOMMENDATIONS

- Strengthen community ophthalmology services to see most of the common conditions
- Increase outpatient clinics and operating sessions in Temple Street and Crumlin to address current demands, and improve clinic infrastructure at both sites
- Additional consultant staffing is required in both Crumlin and Temple Street to meet growing demands on service
- Provide full time specialist registrar posts in both Crumlin and Temple Street
- Develop clinical nurse specialist roles in ophthalmology

37.6 ABBREVIATIONS AND ACRONYMS

CVI	Cerebral Visual Impairment
DSAEK	Descemet's Stripping Automated Endothelial Keratoplasty
MDT	Multidisciplinary Team
RVEEH	Royal Victoria Eye and Ear Hospital
SHO	Senior House Officer
WTE	Whole Time Equivalent

37.7 REFERENCES

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