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OPHTHALMOLOGISTS

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# Advice on Commissioning of Ophthalmic Services for Children

Visual Impairment, Eye Conditions and Commissioning

January 2017

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## 1. Introduction

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This is a briefing document on the themes and issues relevant to commissioning of ophthalmic services for children, on behalf of the Paediatric Sub-committee of the Royal College of Ophthalmologists.

## 2. Complex services

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**The population requiring services is complex and comprises three subpopulations with very different profiles and health service needs.**

- A. Population 1: Children with conditions that cause (or may cause) visual impairment (VI), severe visual impairment (SVI) or blindness (BL) (WHO definition i.e. corrected acuity in better eye of LogMAR 0.5 or worse)**

### Key issues:

- **These children require specialist or highly specialist care throughout childhood and in many cases, lifelong care after transition into adult services around 16 – 18 years. Care can be provided in ‘network’ models which could include primary and secondary care.**

Specialist or highly specialist commissioned services exist for some disorders e.g. retinoblastoma. The Ophthalmology Clinical Reference Group has produced a Specification for Paediatric Ophthalmology Services that highlights generic issues/requirements. See <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/d06/>. Recently the CRG developed its first disorder specific guidance comprising of specialist commissioning of biologics in refractory uveitis in children.

ROP screening and treatment services are not nationally commissioned but metrics for this service are included in NHSE Service Specification for Neonatal Intensive Care (<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e08-serv-spec-neonatal-critical.pdf>) and thus feature in regional neonatal services commissioning guidelines.

- **VI, SVI and BL childhood is uncommon (and the individual disorders causing VI/SVI/BL are rare)**

**Prevalence** = *number affected/total population at risk at any point* – reflects incidence of disease, effectiveness of treatment and mortality and provides a snapshot of burden of disease at a specific time point

**Incidence** = *number newly diagnosed/total population at risk during a specified time period*

UK prevalence of **VI** is about **1.5 per 1000 under 16 year olds**.

UK prevalence of **SVI/BL** is about **0.5 per 1000 under 16 year olds**.

UK incidence of SVI/BL is shown below (*from Rahi et al Lancet 2003*)

	SVI/BL plus†	SVI/BL isolated‡	All
<b>Age-group specific incidence</b>			
Age (years)			
<1	3.17 (2.74–3.59)	0.86 (0.64–1.08)	4.04 (3.56–4.52)
1–4	0.26 (0.19–0.31)	0.06 (0.03–0.09)	0.32 (0.28–0.38)
5–15	0.04 (0.03–0.06)	0.02 (0.01–0.03)	0.06 (0.04–0.08)
0–15	0.27 (0.24–0.3)	0.08 (0.06–0.09)	0.35 (0.31–0.38)
<b>Cumulative incidence</b>			
Age (years)			
1	3.17 (2.74–3.59)	0.86 (0.64–1.08)	4.04 (3.56–4.52)
5	4.19 (3.71–4.67)	1.10 (0.85–1.34)	5.30 (4.76–5.84)
16	4.62 (4.12–5.13)	1.26 (1.0–1.52)	5.90 (5.33–6.47)

Values are incidence per 10 000 (95% CI). SVI/BL plus=children with additional non-ophthalmic impairment/disorder. SVI/BL isolated=children with isolated visual loss.

Table 2: **Yearly age-group specific incidence and cumulative incidence of SVI/BL**

Cumulative incidence of 6 per 10,000 can be interpreted as risk to a child born in the UK today of becoming SVI/BL by her 16<sup>th</sup> birthday.

**Note: SVI/BL is most common in the first year of life.** This highlights the fact that in children it is not appropriate to consider sight ‘loss’ but rather **impaired eyesight due to failure to develop normal vision**. This key difference to adults has implications for all aspects of service planning and commissioning e.g. screening in early life to detect serious eye problems. It is also relevant to the language used in advocacy and commissioning discussions where sight loss is the prevailing term.

Currently the UK incidence of VI is unknown but likely to be 2 – 3X incidence of SVI/BL (extrapolating from prevalence). A national study presently underway, **the British Childhood Visual Impairment and Blindness Study 2 (BCVIS2)** which will determine incidence, causes, mode of detection, management and short term outcomes of **VI/SVI/BL** combined (i.e. update and extend BCVIS 1 undertaken in 2000 and restricted to SVI/BL).

- **VI/SVI/BL children comprise a complex population with complex health, education and social care needs**

VI/SVI/BL in childhood impacts on all areas of development and on education. Some advocate profiling VI/SVI/BL a childhood ‘developmental emergency’ emphasising the importance of early detection and timely referral to both health services (ophthalmologists as well as paediatricians for early years developmental support) and specialist education services.

About 70% of SVI/BL and about 50% of VI children have significant non-ophthalmic impairments or disorders – this has significant implications for nature and co-ordination of care and thus for commissioning of services.

There is a significantly increased risk of VISVI/BL in some groups: those born prematurely, born with low birthweight, those from any ethnic minority group, and those from a socio-economically disadvantaged group. These are groups who may warrant targeted services and should be considered specifically in commissioning guidance.

There is an increased mortality associated with SVI/BL with 10% of affected children dying within a year of diagnosis – arguably SVI/BL should be considered a ‘red flag’ for a significant health issue.

## **B. Population 2: Children with common eye conditions that cause (or may cause) unilateral or milder reduction in vision**

### **Key Issues**

- **Epidemiological data on frequency/burden are limited, so planning of services currently relies on data of variable quality.**

Prevalence of individual disorders varies e.g. amblyopia affects about 1 – 2% of children (depending on definition) and strabismus around 3 – 5% of children (depending on type and age). Thus estimates of the size of this population depend on which disorders are included but at a minimum, it would be reasonable to say that this population comprises at least 5% and possibly up to 10% of all children

- **Most children in this population have eye/vision conditions that are not associated with a systemic disorder**

Management of the primary eye/vision condition requires specialist care throughout childhood and in most cases this is provided in secondary (rather than tertiary) care settings.

Longer term follow up depends on the specific condition but, where it is necessary, this may be best provided through a clear community care management plan.

The need for co-ordination of ophthalmic provision with other health services and education is reduced compared to the population with VI/SVI/BL.

## **C. Population 3: Children with isolated refractive error alone or those with mild/acute/self-limiting conditions (e.g. conjunctivitis)**

### **Key Issues**

- **Epidemiological data on frequency/burden are improving but remain limited for some conditions, so planning of services currently relies on data of variable quality**

Prevalence of individual disorders varies.

Data on GP consultations and prescribing in primary care (CPRD and THIN) can potentially be used for assessing service need and for service planning whilst recognising there have been limited investigations using this approach and, where undertaken, have highlighted areas where data quality could be better.

Refractive error (RE) is common e.g. RE requiring correction affects around 20% of children in the UK but prevalence estimates vary considerably reflecting varying definitions (thresholds of spherical equivalent used) of myopia and hypermetropia.

Population based studies over the past 50 years indicate a pattern of:

- a) increasing frequency of myopia in the UK, although not at the rate of change documented in other countries e.g. in Asia
- b) a shifting of distribution of age at onset from 'later onset' myopia i.e. late teens/early adult life to earlier onset myopia.

There is, by comparison, scant literature on the epidemiology of hypermetropia.

- **Robust data on environmental risk factors for myopia remain limited but point to early life influences.**

The most robust associations with risk of myopia in UK studies/populations are with (a) parental/family history (b) higher social class, (c) greater educational attainment and (d) greater 'educational exposure' (using time spent in formal education as the proxy), as well (e) early life (including prenatal) influences reflected in measures maternal/pregnancy health and captured by birth weight, and (f) general growth in childhood. Studies from other populations – which have notably different genetic predisposition – point to time spent outdoors (i.e. distance rather than near viewing) as being 'protective'.

- **The extensive research on interventions for myopia progression has not yet resulted in robust evidence of long term effectiveness**

There is understandably considerable public interest in therapies to prevent myopia onset or progression but limited understanding that interventions remain unproven. It is arguable that until the evidence base is secure, treatment to prevent myopia progression should be offered only in the context of a randomised trial or longitudinal study. This would mirror approaches to innovative treatments in paediatrics/child health more broadly and allow a robust evidence base to develop.

### 3. Scope

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**The scope and thus approaches to prevention of vision/eye conditions and promotion of good visual health require very different approaches to those used in services for adults**

For details, see:

RCOphth Ophthalmic Services for Children at: [https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2012\\_PROF\\_182\\_Ophthalmic-Services-for-Children.pdf](https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2012_PROF_182_Ophthalmic-Services-for-Children.pdf)

RCOphth Quality Statements and Quality Indicators for Paediatric Ophthalmology Services at: [https://www.rcophth.ac.uk/wp-content/uploads/2014/12/Paediatric-Ophthalmology-Quality-Standards-July-2013\\_2013\\_PROF\\_139.docx](https://www.rcophth.ac.uk/wp-content/uploads/2014/12/Paediatric-Ophthalmology-Quality-Standards-July-2013_2013_PROF_139.docx)

## Key Issues

### **A. The WHO nomenclature for disease prevention strategies sets out 3 types of 'prevention':**

#### **1. Primary Prevention = prevention of the occurrence of disease/condition**

For example:

Rubella immunisation programmes that prevent congenital rubella syndrome (which includes congenital cataracts and retinopathy)

**Note: scope to increase primary prevention in the UK is currently very limited given our knowledge of aetiology.**

#### **2. Secondary Prevention = treatment of established disease to reverse, minimise or retard its impact on vision and visual development. Relies on early detection (including specifically screening) and appropriate treatment including monitoring to avoid relapses or deal with occurrence of secondary conditions or complications.**

For example:

- Management of congenital cataract through a) screening of all infants at birth and again at 6 – 8 weeks via the National Screening Committee's Newborn and Infant Physical Examination Programme, NIPE, followed by prompt referral of babies with abnormal findings on screening to specialist ophthalmology services and b) timely surgical intervention with subsequent specialist optical and visual rehabilitation including management of amblyopia and long term surveillance for late complications (often in network/shared care arrangements).
- Management of amblyopia through a) universal vision screening at age 4 – 5 years in an orthoptic-led service as per the National Screening Committee guidance and prompt referral based on pre-agreed criteria for children who are 'screen positive' for specialist care (various referral pathway models exist, many combining primary and secondary care provision) and surveillance till treatment completed.

Note: The National Screening Committee recommends only the NIPE Programme (a mandated national programme) and 4 – 5 years/school entry vision screening (part of the recommended Healthy Child Programme) for screening for eyes/vision in childhood.

Based on its regular rigorous evidence reviews, the NSC does not advocate or support any other eyes/vision 'screening' activities in childhood.

#### **3. Tertiary prevention = management of impact of established/chronic disease/conditions (including 'untreatable' conditions) to minimise impact of impaired vision on development, functioning and quality of life.**

Examples:

Timely referral of affected children for: expert vision habilitation, developmental interventions, low vision aids, mobility training and special educational services.

Note: Best practice models of a 'key worker' service (as recommended by Warnock) exist in various Trusts – commonly the ECLO model – to provide information, support and liaison as a means of delivering tertiary prevention. But this is not universal and advocacy to ensure this provision for children and families is included in service commissioning would be very valuable.

Note: Certification as SI or SSI (NB all with SVI/BL but only some with VI are eligible) can be the way to ensure adequate provision by Local Authorities but is not a pre-requisite. For example certification / registration are not necessary (but likely to be helpful) for an Education, Health and Care Plan. The current consultation on CVI has included multisector input to improve the accuracy and quality of certification data on children for public health monitoring (e.g. through using an appropriate taxonomy for childhood causes) and to improve the use of registration data for improving provision by Local Authorities (e.g. including data on specialist education)

**B. Transition of care of young people with eyes/vision disorders from child to adult services is a critical event.**

The importance of good planning and provision in transition of care to adult services is well recognised, as is the impact of poor quality transition on health trajectories of young people with chronic conditions. There is limited literature on best practice in relation to young people with eye/vision disorders and transition arrangements are generally dictated by existing service provision. Advocacy to ensure good transition provision is included in service commissioning would be valuable.

## 4. Author

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