The role of screening and surveillance in the detection of childhood vision impairment and blindness in the UK

Ameenat Lola Solebo PhD[1,2,3,4], Lucinda Jade Teoh MSc[1,2], Jugnoo Sangeeta Rahi PhD[1,2,3,4] for the British Childhood Visual Impairment and Blindness Study Interest Group*

*A complete list of study group members appears in the Appendix

1. Population, Policy and Practice Research and Teaching Department, UCL GOS Institute of Child Health, London, UK
2. Ulverscroft Vision Research Group UCL GOS Institute of Child Health, London, UK
3. Great Ormond Street Hospital for Children NHS Trust, London, UK
4. National Institute for Health Research Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology, London, UK

Corresponding author

J S Rahi, Population, Policy and Practice Research and Teaching Department, UCL GOS Institute of Child Health, 30 Guilford Street, London WC1N 1EH, UK

j.rahi@ucl.ac.uk

Phone +44(0)20 7905 2250

Word count: 2795

Abstract

Objective: Understanding pathways to detection for childhood visual impairment is critical for planning services. We aimed to describe patterns of detection for childhood visual impairment.

Design and setting: Cross-sectional study using data from British Childhood Visual Impairment and Blindness Study 2.

Patients: Children newly diagnosed with Visual impairment (VI), Severe Vision Impairment or blindness (SVI/BL) – ie visual acuity worse than LogMAR 0.5 in both eyes - were identified through active surveillance, with data collection at diagnosis and one year later.

Outcome measure: Method of detection of vision/eyes problem.

Results: 784 children (45%, 356 girls) were identified, of whom 313 (40%) had VI, 471 (60%) SVI/BL. Additional non-ophthalmic disorders or impairments (VI/SVI/BL 'plus'), were diagnosed in 72% (559/784).

Of the 784, 173 children were detected through routine screening (22%), 248 through targeted examinations (32%), and 280 through family self-referral (36%) Parents and carers had only reported symptoms in 55% of children who manifested them, with evidence that families living in socioeconomically deprived areas were less likely to report concerns. Paediatricians were the professionals most likely to raise initial suspicion of visual disability.

Conclusions: Our findings show that targeted screening and surveillance is important for the detection of full spectrum childhood visual impairment (VI/SVI/BL), as a significant proportion of children will not have symptoms, or their parents or carers will not report symptoms. As paediatricians were the professionals most commonly involved in detection, it would be helpful if their core competencies included the skills needed to undertake simple assessments of vision.

INTRODUCTION

Prompt intervention for sight threatening disorders is needed during the critical periods of visual development to avoid life-long disability.[1,2] Timely intervention also ameliorates the educational, developmental and quality of life impact of untreatable disorders,[3] and early detection enables prompt diagnosis of underlying or associated disease.[4]

In recognition of the importance of early detection, several countries have established whole population screening programmes (table 1).[5] Examples include the United Kingdom's (UK's) Public Health England National Screening Committee Newborn and Infant Physical Examination (NIPE).[2,5,6,7] As in other countries, there are also UK recommendations about surveillance and targeted screening in children at higher risk of sight impairment, due to shared aetiology, or those for whom an additional impairment would be particularly impactful, eg those with sensorineural hearing loss, or preterm infants.[5,8] Detection of serious eye conditions is a shared responsibility across different specialities, as seen in the coordination between neonatology and ophthalmology for retinopathy of prematurity (ROP) screening.[9]

In 2003 the British Childhood Visual Impairment and Blindness Study (BCVIS)[10] reported that for many children newly diagnosed with severe visual impairment or blindness (SVI/BL, ie vision worse than 1.0 logMAR, or '10 fold worse' than normal acuity levels, normal acuity being 0.0 logMAR, or 6/6 in the older Snellen notation)[11], parents were unaware of the child's visual problem.[10] Since then, the NHS Healthy Child Programme has promoted family health education on normal visual development, including guidance on key childhood developmental visual milestones, described within the Personal Child Health Record provided to each newborn's family.[12] Findings from BCVIS1 also helped to formalize the NIPE screening and childhood vision screening at 4-5 years programmes.[13]

The adverse impact of severe visual impairment/blindness on developmental and lifelong socio-economic outcomes is well established,[14,15] with a growing evidence of the impact of 'milder' visual impairment on social, general and mental health outcomes.[14] Visual impairment (VI, or acuity between 0.5 -'5 fold worse' - and 1.0 logMAR) predicts a requirement for additional educational support, such as low vision aids.[16] However the patterns of detection of childhood visual impairment across the full spectrum of severity are unknown.

We aimed to address this evidence gap using data from British Childhood Visual Impairment and Blindness Study 2, the first prospective, population-based observational study of the incidence, causes, and short-term health outcomes for children with all-cause vision impairment, severe vision impairment and blindness[17]

METHODS

Study design

A prospective population based cross-sectional study of children newly diagnosed with visual impairment, severe visual impairment or blindness, referred to as visual disability for brevity.

Case definition

Any child or young person aged ≤18 years resident in the UK and newly diagnosed with impaired acuity as classified using the World Health Organization's International Classification of Disease (ICD-10) taxonomy,[11] ie a level of 0.50 logMAR or worse in both eyes or better seeing eye, or an equivalent vision level as assessed by qualitative measures.[17]

Case ascertainment and data collection and management

Study methods have been reported previously.[17] In summary, cases were ascertained over a 12-month period starting October 2015. Active surveillance was undertaken, simultaneously but independently, through two national surveillance schemes, the British Ophthalmological and Paediatric Surveillance Units (BOSU and BPSU). Clinical and demographic data were

collected at diagnosis and one year later using study specific standardized proforma, and included age at detection of the ocular or vision problem, whether there were symptoms at detection, the context in which detection occurred, and who (parent, carer, paediatrician, ophthalmologist or other professional) first suspected the presence of a vision or eye problem.

Analysis

Children were grouped by absence/presence of other significant non-ophthalmic impairments or conditions, referred to as '*VI/SVI/BL isolated' or 'VI/SVI/BL plus'* respectively. Socioeconomic status was categorized using the area-based (postcode/zipcode) Index of Multiple Deprivation (IMD) and grouped into quintile rankings. Age at detection of vision/eye problem was categorized using the key developmental milestones of the neonatal period (first month), and the ages at which childhood vision screening interventions occur in the UK, i.e. 6-8 weeks (Newborn and Infant Physical Examination) and 5yrs (School-entry Vision Screening) of age (table 1).

We investigated the proportion of children with full spectrum visual impairment and blindness identified through either routine universal (whole population) eyes/vision screening programmes or universal child health surveillance programmes, or through enhanced clinical surveillance comprising targeted examination of higher risk children, or detected in the context of an examination instigated by their parents because they had concerns. We explored differences in detection pathways by the presence/absence of an associated non-ophthalmic disorder or impairment and by severity of visual impairment (visual impairment, VI, versus severe, SVI/BL). We also identified detection pathways for those children with potentially treatable disease, defined as an isolated eye or vision disorder for which there was an effective intervention. Treatable disorders comprised cataract, glaucoma, ocular inflammatory disorders, retinopathy of prematurity, and ocular or visual pathway tumours.

Data were analysed using STATA statistical software (version 14.2, StataCorp LLC, College Station,Texas). Comparisons between two groups and associations with sociodemographic or clinical factors were quantified using the test for differences in proportions and/or odds ratios (ORs) and are reported with 95% confidence intervals and *P* values.

The necessary approvals were granted by the UK Health Research Authority (14/LO/1809; CAG14LO1809).

RESULTS

We identified 784 children/young people newly diagnosed with VI/SVI/BL (45%, 356 girls), of whom 313 (40%) were newly diagnosed with VI and 471 with SVI/BL (figure 1). The sociodemographic characteristics of the cohort have been reported in detail elsewhere.[17] Key aspects comprised increased relative rates of visual impairment and blindness for those from the most socio-economically deprived groups, from any ethnic group other than white, or born preterm or low birthweight, and associated non-ophthalmic disorders and/or other impairments (VI/SVI/BL 'plus') in 72% (559/784) of children. Disorders and impairments included global developmental delay (245, 31%), seizures (177, 23%), and cerebral palsy (74, 9%), and mobility (204, 26%), and speech and language impairments (167, 21%), with details of these disorders reported elsewhere.[17]

Initial detection of a vision/eye problem occurred in the context of routine whole population screening in 173 children (22%), through enhanced surveillance or targeted examination in 248 (32%), and in 280 parental/caregiver concern led the family to self-refer (36%) (table 2). The remaining children were detected incidentally during interactions with health professionals, or by non-health professionals (eg, teachers, social workers). Socioeconomic background and ethnicity were not associated with the mode of detection.

Symptoms at detection of vision/eye problem

Symptoms were noted in 552/784 children (65%) at the time of detection. This did not vary by severity of visual impairment (symptoms in children with VI 230/313, 73%, versus SVI/BL, 322/471, 68%, chi^2 P=0.1), but was higher in those with isolated vision impairment versus those with additional non-ophthalmic disorders (VI/SVI/BL isolated, symptoms in 173/219, 79%, and VI/SVI/BL plus, 376/559, 67%, chi^2 *P*<0.01, 95% DIPCI 5% - 19%). Parents or carers had reported symptoms in 288 of these 552 (55%) children.

Delayed vision-dependent developmental milestones (e.g. delayed response to a silent smiling face, delayed reaching for objects) were present in 48% (374 children, noticed by their parents/carers in 190, 57%). The other symptoms at presentation were nystagmus in 18% (143, reported by 75parents, 52%); strabismus (squint) in 7% (58, reported by 28 parents, 48%), corneal clouding in 2% (16, reported by 4 parents, 25%) and leukocoria ('white pupil') in 1% (11, reported by 7 parents, 64%).

Detection through parental concern

Parents self-referred their child to health services (280/784, 36% overall) either because of symptoms (263, 91%), family history of eye or vision disease (14, 5%) or the presence of systemic disorder or syndrome with known ophthalmic and visual manifestations (3, 1%) (table 2).

Parents or carers raised the initial concern more frequently for children with VI than for those with SVI/BL (VI, 136/313, 43%, versus SVI/BL, 156/471, 33%, chi^2 P<0.001), and more frequently for those children with isolated visual disability (VI/SVI/BL isolated, suspicion in 113/225, 50%, versus VI/SVI/BL plus, 177/559, 32%, chi^2 *P*<0.001, 95% DIPCI 10% - 26%). However, parents who lived in areas of relative deprivation were less likely to suspect a problem in symptomatic children with VI (36 parents of the 103 symptomatic children, resident in the areas of highest relative deprivation, 35%, versus 98/206, 48%, of the symptomatic children resident in less deprived areas, chi^2 *P*=0.04, 95% DIPCI 2% - 24%).

This association was not seen in children with SVI/BL (54/109, 50% of families of symptomatic children resident in the areas of highest relative deprivation, and 83/208, 40%, for those in less deprived areas (chi^2 P=0.1).

Detection through targeted examinations/clinical surveillance of those at higher risk

Targeted examinations, through which 248/784, 32% overall were detected, identified a higher proportion of children with SVI/BL than with VI (81/313, 26% children with VI versus 167/471, 36% of children with SVI/BL, chi^2 test for difference in proportions P=0.002, 95% DIPCI 3% - 17%) as well as a higher proportion of those with associated non-ophthalmic impairments (VI/SVI/BL plus 222/559, 40%, versus isolated VI/SVI/BL 20/219, 9%, chi^2 P<0.0001, 95% DIPCI 25% - 37%).

Of these 248 children, 122 (49%) were symptomatic at detection and in 48 (19%) the parents/carers already had concerns about vison/eyes.

Detection through universal childhood screening

Overall, 173 (22%) children were detected via universal screening, comprising 19% (61/313) of children with VI and 23% (112/471) with SVI/BL (chi^2 P=0.2). Of these, 87 were symptomatic and 35 parents/parents reported concerns at the time of the examination (51% and 20% respectively).

The newborn/infant physical examination resulted in clinical suspicion of a vision/eye disorder in 160 children (92 newborn, 31 infant, 37 uncertain if newborn or infant exam). Of 159 children overall with congenital ocular anomalies as the cause of VI/SVI/BL, only 53 (33%) were detected through NIPE. Congenital cataract (the target disorder for NIPE) was diagnosed in 32 children with VI/SVI/BL, with 14/31 detected through NIPE, 11 detected due to parental concern in later infancy or childhood, and 7 detected through targeted examinations (eg family history).

Specifically, 31 children were detected through retinopathy of prematurity (ROP) screening, all had ROP.

Notably antenatal suspicion of a visually impactful disorder was reported in 12 children, due to cerebral anomalies detected through antenatal imaging.

Health professionals involved in the detection of VI and SVI/BL

Overall, a paediatrician was the health professional most likely (300/470, 64%) to suspect/detect or alternatively confirm parental suspicion of a visual problem (table 3). For most children this was a general hospital or community paediatrician, but a range of paediatric subspecialists were also involved.

Pathways to detection for children with treatable disease

Of 784 children overall, 94 had purely isolated treatable eye disorders 56 were children with SVI/BL, and 38 with VI (table 4). The timing of the visually disabling 'insult' to the eye or visual system was identifiable in 87 children, with 79 of them (91%) having VI/SVI/BL due to a prenatal or perinatal disorder. Amongst the 79 children with a congenital but treatable visually disabling disease, the newborn eye examination detected problems in only 21 (27%), for those 57 children with VI/SVI/BL 'plus', the majority of cases were detected through surveillance of a high-risk group.

DISCUSSION

From this population based cross sectional study, we report that amongst 784 children with visual impairment/blindness, the most common trigger for detection was parental concern about their child's age-appropriate visual behaviour. However, parents and carers had only reported symptoms in 55% of the children who manifested them at diagnosis, with families living in socioeconomic deprivation less likely to report symptoms for children with VI (versus SVI/BL). The proportion of children who were symptomatic at presentation was no higher amongst those with SVI/BL than those with VI. The proportion of children with

isolated visual disability with symptoms at detection was higher (79%VI/SVI/BL isolated versus 67% VI/SVI/BL 'plus') whilst enhanced clinical surveillance as the route to detection accounted for a higher proportion of children with non-ophthalmic disorders (40% VI/SVI/BL 'plus' versus 9% isolated VI/SVI/BL) Paediatricians were the professionals most likely to detect a vision/eye problem. Congenital ocular anomalies were the cause of VI/SVI/BL in 159 children overall but only 33% were detected through the UK's newborn and infant physical examination (NIPE) programme.

There are no national registers of disability or other sources with which to formally cross-validate and assess completeness of case ascertainment, but high ascertainment has been achieved for other relevant studies using BOSU and BPSU.[10,17,23] In addition, there was a high level of engagement from the underpinning clinical research network (BCVISG), comprising UK clinicians who manage children with visual disability. The study design precluded direct contact with parents or primary care clinicians to ascertain data on detection. It is possible that we have under-estimated parents' awareness of symptoms before clinical detection. Therefore, we report the more robust measure and clinically meaningful measure of the proportion of families seeking medical attention for their concerns.

A significant proportion of children, particularly those with additional vulnerabilities, are diagnosed through the targeted screening or surveillance of children at higher risk, supporting current national recommendations that children with these additional health needs undergo specialist examinations by ophthalmic professionals to assess visual function, particularly acuity.[5] In contrast, the universal screening programmes were developed in order to reduce the burden of preventable childhood visual impairment due to specific treatable conditions such as congenital cataract (for NIPE)[5] and amblyopia (for the childhood vision screening programme at 4-5 years old).[13] Our study shows that despite being primarily directed to detecting children with unilateral reduced vision due to amblyopia, vision screening at school

entry does also serve to detect a small number of children with bilateral visual disability. The main condition which causes childhood visual impairment in high income countries – cerebral visual impairment - cannot currently be treated so as to fully restore normal vision, although early diagnosis confers other benefits.[3,4] As the incidence of preterm birth is expected to continue to increase, and the long term survival rates for children with multiple disabilities continue to improve,[20,21] we can expect the enhanced pathways to become increasingly important, and more clinically- and cost-effective.

Our findings show policies and services intended to ensure early diagnosis of visual disability need to consider two different populations of children with visual disability differentiated by the presence or absence of non-ophthalmic disorders and impairment. Children with 'VI/SVI/BL plus' are less likely to present due to parental concerns about visual disability. This could be due to greater contact with early detection health services, or, and probably more likely, it may be due to symptoms of poor visual behaviour being less noticeable in a child with other developmental impairments, or because the focus in supporting these parents is not vision/eye problems. We suggest child health professionals outside ophthalmology need to be aware of the normal age-related visual function or concerns, and able to undertake simple assessments of vision for young children. Ophthalmic professionals should support this by including outcomes of vision testing in their clinical correspondence with colleagues. Paediatricians, the health care professionals most commonly involved in the detection of childhood visual impairment, should have within their core competencies the skills needed to undertake simple assessments of vision and visual developmental milestones.

Only a third of visually impaired children with congenital disorders were detected through newborn and infant eye screening. This may represent delayed diagnosis, but as BCVIS2 is unable to report on the clinical findings and symptoms present at the time of screening for those who were 'missed', it is inappropriate to use these data to directly evaluate the

screening programme. We are currently without the population level data on the detection rate and 'false negative' rate of the NIPE programme, which would be needed to contextualise BCVIS findings.

The BCVIS1 study, which identified children newly diagnosed with SVI/BL in 2000, reported that parents and caregivers were the first to suspect a childhood visual problem in almost half of cases (47%, or 195/410), comprising 67% of the children who were symptomatic.[10] Recommendations on educating parents and carers led to the development of a section within UK's Personal Child Health Record (PCHR), on the key milestones in early childhood visual development. The PCHR, developed for use by the family as the main record of growth, development and uptake of preventative health services, has broad uptake and good engagement.[12] However, BCVIS2 findings suggest that almost half of parents and carers are unable to recognise the symptoms of poor vision or sight threatening disease. Of particular concern is the socioeconomic patterning of parental awareness of VI. In the light of the SARS-CoV-2 (COVID-19) pandemic-related widening and hardening of health care access and health and disease outcome inequities,[22] novel, validated health promotion interventions, along the lines of parental interventions to promote other areas of early child development other interventions to similar to those addressing other areas of are likely to be needed to support parents in recognising symptoms of poor vision and monitoring their child's visual development and seek timely health care.

Conflict of interest: The authors have no conflicts of interest relevant to this article to disclose

Funding/Support: This work was funded directly by a Fight for Sight grant (1525/26) and was supported by funding from the Ulverscroft Foundation for the Ulverscroft Vision Research Group. AL Solebo received support from the National Institute for Health Research Biomedical Research Centre (NIHR BRC) based at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology, and an NIHR Lectureship, and is supported by an NIHR Clinician Scientist award (CS-2018-18-ST2-005). JS Rahi is supported in part by the NIHR BRC based at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology, and an NIHR Senior Investigator award. This work was undertaken at UCL Institute of Child Health / Great Ormond Street Hospital for children which received a proportion of funding from the Department of Health's NIHR Biomedical Research Centres funding scheme. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

What is already known on this topic

Understanding pathways to detection for childhood visual impairment is critical for planning services for affected or at-risk children. There is a lack of evidence on the patterns of detection and childhood visual impairment across the full spectrum of severity.

What this study adds

Targeted screening and surveillance of children at higher risk is a particularly important pathway for the growing proportion of visually disabled children who have associated non-ophthalmic disorders. Parents/carers reported symptoms in 55% of the children who manifested them, with families living in socioeconomic deprivation less likely to report symptoms at diagnosis. We suggest that paediatricians, as the professional group most likely to detect a problem, should have within their core competencies the skills needed for simple assessments of vision.

Acknowledgements: This work is presented on behalf of the collaborating clinical research group, the British Childhood Visual Impairment and Blindness Group (BCVISG, membership in appendix). We acknowledge the British Paediatric Surveillance Unit and British Ophthalmic Surveillance Unit for supporting and facilitating the project using their established national surveillance methodologies. We sincerely thank all contributing paediatricians and ophthalmologists to both surveillance units, without whom this research would not be possible. We thank the clinical and administrative teams at the collaborating hospitals for their support.

331 References

332 1. Hensch TK. Critical period plasticity in local cortical circuits. *Nature reviews*
333 *Neuroscience* 2005; 6(11): 877-88.

334 2. Good WV. Vision Screening in Very Young Children-Making Sense of an Inexorable
335 Diagnostic Process. *JAMA paediatrics* 2017; 171(11): 1046-7.

336 3. Solebo AL, Teoh L, Rahi J. Epidemiology of blindness in children. *Archives of disease in*
337 *childhood* 2017; 102(9): 853-7.

338 4. Rahi JS, Cable N. Severe visual impairment and blindness in children in the UK. *Lancet*
339 2003; 362(9393): 1359-65.

340 5. Solebo AL. Identification of visual impairments. In: Emond A, ed. Health for all Children
341 5th Edition 2019.

342 6. Grossman DC, Curry SJ, Owens DK, et al. Vision Screening in Children Aged 6 Months to
343 5 Years: US Preventive Services Task Force Recommendation Statement. *Jama* 2017;
344 318(9): 836-44.

345 7. Sloot F, Hoeve HL, de Kroon ML, et al. Inventory of current EU paediatric vision and
346 hearing screening programmes. *J Med Screen* 2015; 22(2): 55-64.

347 8. Gulati S, Andrews CA, Apkarian AO, Musch DC, Lee PP, Stein JD. Effect of gestational
348 age and birth weight on the risk of strabismus among premature infants. *JAMA paediatrics*
349 2014; 168(9): 850-6.

350 9. National Institute for Health and Care Excellence. Developmental follow-up of preterm
351 babies: Guideline scope 2015.
352 https://www.nice.org.uk/guidance/ng72/documents/developmental-followup-of-preterm-
353 babies-final-scope2 Accessed 26th Feb 2022

354 10. Rahi JS, Cumberland PM, Peckham CS. Improving detection of blindness in childhood:
355 the British Childhood Vision Impairment study. *Paediatrics* 2010; 126(4): e895-e903.

11. World Health Organization G. ICD-10: international statistical classification of diseases and related health problems: tenth revision, 2004.

12. Walton S, Bedford H. Parents' use and views of the national standard Personal Child Health Record: a survey in two primary care trusts. *Child Care Health Dev* 2007; 33(6): 744-8.

13. Solebo AL, Cumberland PM, Rahi JS. Whole-population vision screening in children aged 4-5 years to detect amblyopia. *Lancet* 2015; 385(9984): 2308-19.

14. Cumberland PM, Rahi JS. Visual Function, Social Position, and Health and Life Chances: The UK Biobank Study. *JAMA ophthalmology* 2016; 134(9): 959-66.

15. Robertson AO, Horvat-Gitsels LA, Cortina-Borja M, Rahi JS. Distribution and associations of vision-related quality of life and functional vision of children with visual impairment. *The British journal of ophthalmology* 2021.

16. Keil S. Survey of educational provision for blind and partially sighted children in England, Scotland and Wales in 2002. *British Journal of Visual Impairment* 2003; 46(6): 93-7.

17. Teoh LJ, Solebo AL, Rahi JS. Visual impairment, severe visual impairment, and blindness in children in Britain (BCVIS2): a national observational study. *The Lancet Child & adolescent health* 2021; 5(3): 190-200.

18. Wilson JMG, Jungner G, World Health Organization G. Principles and practice of screening for disease; 1968.

19. Langmuir AD. The surveillance of communicable diseases of national importance. *The New England journal of medicine* 1963; 268: 182-92.

20. Morgan C, Fetters L, Adde L, et al. Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Reviews. *JAMA paediatrics* 2021; 175(8): 846-58.

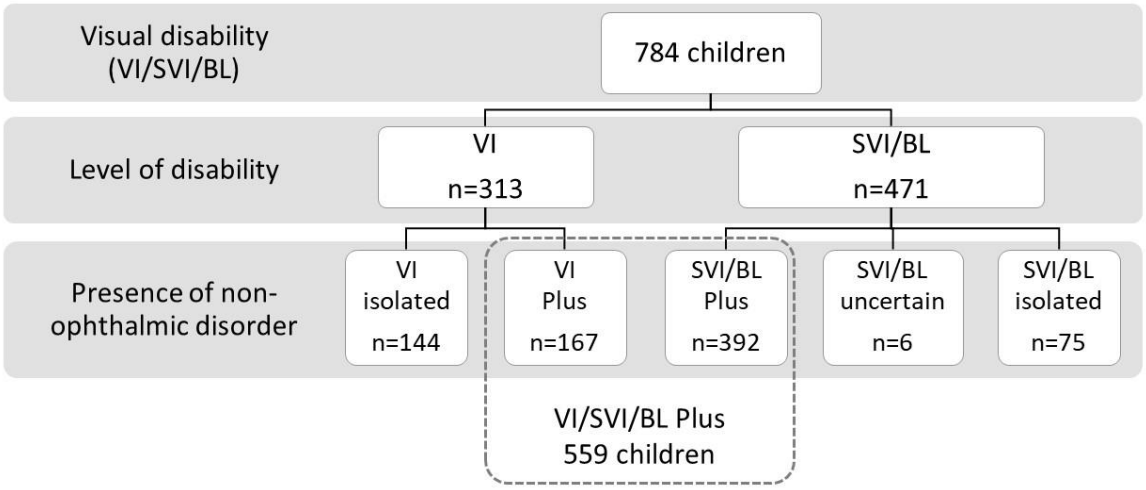
21. Reiner RC, Jr., Olsen HE, Ikeda CT, et al. Diseases, Injuries, and Risk Factors in Child and Adolescent Health, 1990 to 2017: Findings From the Global Burden of Diseases, Injuries, and Risk Factors 2017 Study. *JAMA paediatrics* 2019; 173(6): e190337.

22. After COVID-19, a future for the world's children? *Lancet* 2020; 396(10247): 298-300.

23. Rahi JS, Dezateux C. Measuring and interpreting the incidence of congenital ocular anomalies: lessons from a national study of congenital cataract in the UK. *Invest Ophthalmol Vis Sci* 2001; 42(7): 1444-8.

24. Jeong J, Franchett EE, Ramos de Oliveira CV, Rehmani K, Yousafzai AK. Parenting interventions to promote early child development in the first three years of life: A global systematic review and meta-analysis. PLoS Med. 2021;18(5):e1003602.

391 **Figure 1. Flow diagram of identified cases**



392

Table 1. Vision and eye components within the UK whole population child health programmes[5]

Whole population programme	Age at assessment	Eye and / or vision component	Target disorder(s)	Date of national implementation
Newborn and Infant Physical Examination (NIPE) screening programme	During the first 72 hours of life, and again at 6 – 8 weeks of life	Red reflex test and gross examination of eye performed by health professional	Cataract (primary target) Any other congenital or early infantile ocular disorder	2009¥
Personal child health record (PCHR, 'Red Book') parental information on visual development milestones	From birth to 5 years	Description of key visual milestones (eg "Does your baby look at you when you move your head from side to side?" in first two months)	Reduced vision sufficient to impact on early global development	2009¥
Healthy Child Pathway Health and development review*	At 2-2.5 years	Indirect testing of visual function as part of testing of fine motor skills ('picking up small objects') performed by health professional Also parents asked to report any visual concerns	Reduced vision sufficient to impact on early global development	2013
Childhood Vision screening programme**	4 – 5 years	Assessment of uniocular vision with logMAR chart	Amblyopia (primary target) Any other forms of reduced vision	2016

*in England only; in Northern Ireland: "Health and development review at 2-2.5 years" as part of the Healthy Child, Healthy Future programme; in Scotland: "27- to 30-month child health review" as part of the Scottish Child Health Programme; in Wales: "27-month check" as part of the Healthy Child Wales Programme

**Preceded by the Child Health Promotion Programme which was launched in 2008

¥ Although the current version of these programmes was implemented as stated, there were earlier versions of both (earlier versions of the neonatal and infant eye examination, implemented in 2004, and of PCHR guidance, implemented in 2004)

405 **Table 2. Context of first detection of vision/eyes problem**

	Isolated visual disability			Associated non-ophthalmic disorder(s)			
	VI isolated n=144	SVI/BL isolated n=75	VI/SVI/BL isolated n=219*	VI plus n=167	SVI/BL plus n=392	VI/SVI/BL plus n=559*	Total n=784*
Routine universal child health screening							
Newborn exam	10	15	25	18	47	65	92
6 – 8 week exam	12	8	20	7	7	14	31
4-5 year vision screen	8	1	9	1	1	2	11
Other / unclear	3	4	7	8	23	30	37
Total	**33**	**28**	**61 (28%)**	**34**	**78**	**112 (20%)**	**173 (22%)**
Detected through screening or surveillance of a high risk group							
Preterm / low birth weight	0	0	0	3	26	29	31
Neurodevelopmental disorder (ND)	-	-	-	30	87	117	117
Structural disorder	-	-	-	*3*	*24*	*27*	*27*
Seizure disorder	-	-	-	*3*	*8*	*11*	*11*
Hypoxic Ischaemic Encephalopathy	-	-	-	*2*	*16*	*18*	*18*
Hearing loss	-	-	-	*14*	*6*	*20*	*20*
Other ND	-	-	-	*8*	*18*	*26*	*26*
Family history	12	5	17	7	12	19	36
Cataract	*1*	*0*	*1*	*4*	*1*	*5*	*6*
Retinal dystrophy	*11*	*5*	*16*	*3*	*4*	*7*	*23*
Other family history	*0*	*0*	*0*	*0*	*7*	*7*	*7*
Systemic disorder	-	-	-	8	21	29	29
Other	2	1	3	14	29	43	50
Total	**14**	**6**	**20 (9%)**	**62**	**160**	**222 (40%)**	**248 (32%)**
Family concerns leading to presentation to health professional for confirmation							
Presentation to primary care provider	30	13	43	16	17	33	76
Presentation to Paediatrician	25	6	31	12	73	85	116
Presentation to emergency eye care	6	3	9	11	5	16	25
Presentation to other health service	17a	12	29	16	18	34	63
Total	**78**	**34**	**112 (51%)**	**55**	**113**	**168 (30%)**	**280 (36%)**
Other	**19**	**7**	**26**	**16**	**41**	**57**	**83**

406 *For 6 children there was clinical uncertainty around the co-existence of other abnormality /
407 impairment
408

Table 3. Professional roles involved in initial detection of an eye or vision problem

	By presence of non-ophthalmic disorder*		By age at detection of VI/SVI/BL			Total n=784*
	VI/SVI/BL isolated n=219	VI/SVI/BL plus n=559	0 -1yr n=402	1 – 4yrs n=200	5yrs+ n=182	
Health Professional	99 (45%)	365 (65%)	254 (63%)	127 (64%)	83 (46%)	470 (60%)
Community Paediatrician	*43*	*93*	*72*	*48*	*16*	*136*
Neonatologist	*4*	*23*	*27*	*0*	*0*	*27*
Other hospital paediatrician	*1*	*131*	*95*	*31*	*11*	*137**
Obstetrician / midwife	*0*	*3*	*3*	*1*	*0*	*4**
Health Visitor	*4*	*8*	*10*	*2*	*0*	*12*
Ophthalmologist	*3*	*52*	*26*	*16*	*13*	*55*
Optometrist	*8*	*1*	*0*	*0*	*9*	*9*
Orthoptist	*6*	*5*	*2*	*3*	*6*	*11*
General practitioner	*13*	*3*	*13*	*2*	*1*	*16*
Hospital nurse	*0*	*2*	*2*	*0*	*0*	*2*
Unspecified health professional	*17*	*44*	*4*	*24*	*27*	*61*
Other professional	12 (%)	7 (%)	3 (1%)	3 (2%)	6 (3%)	12 (2%)
Social worker	*2*	*1*	*2*	*1*	*0*	*3*
Teacher / nursery staff	*10*	*6*	*1*	*2*	*6*	*9*

*For 6 children there was clinical uncertainty around the co-existence of other abnormality / impairment

413 **Table 4. Context of detection for treatable disorders**

	VI/SVI/BL isolated n=30		VI/SVI/BL plus n=57		Total n=87
	Prenatal / perinatal insult n=27	Childhood insult n=3	Prenatal / perinatal insult n=52	Childhood insult n=5	
Routine health screening	14 (52%)	0	17 (33%)	0	31 (36%)
Newborn	*10*	-	*11*	-	*21*
6 – 8 week	*3*	-	*1*	-	*4*
2 – 2.5yr check	*0*	*0*	*2*	*0*	*2*
4-5yr vision screening	*0*	*0*	*0*	*0*	*0*
Other	*1*	*0*	*3*	*0*	*4*
Screening / surveillance of a high risk group	2 (7%)	0	22 (42%)	3 (60%)	27 (31%)
Symptoms	11 (41%)	2 (67%)	8 (15%)	2 (40%)	23 (26%)
Other	0	1	5	0	6

414