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ARTICLE

Reporting on Australian childhood visual impairment: the first 10 years

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BACKGROUND: Visual impairment is rare but has significant impact on the neurobehavioural development and quality of life of children. This paper presents the key findings from the Australian Childhood Vision Impairment Register, which commenced in 2008 to report on children diagnosed with permanent visual impairment.

SUBJECTS/METHODS: Families consent to completing a data form related to their child and for contact with the child's ophthalmologist. Ophthalmologists complete and return a comprehensive data form on the child's primary and secondary ocular diagnoses, associated disabilities and health conditions, visual acuity and visual fields. Data is stored on a secure database and anonymised data is available to researchers and for planning purposes.

RESULTS: Nine-hundred four children and their families provided informed consent for participation, with 57% males and 43% females. Most children spoke English in their home. Eighty-three percent of children were born full term, with a birth weight of >2500 g (81%). Children were commonly suspected to have visual impairment by a parent, with 68% of families receiving a diagnosis of visual impairment by their child's first birthday. The most common primary diagnoses were retinal dystrophy (17%), CVI (15%) and Albinism (11%). A secondary diagnosis of infantile nystagmus occurred in 33% of children. Additional disabilities and/or developmental delay were reported for 44% of children. Corrected binocular visual acuity was reported for 75% of children, with moderate visual impairment being most common.

CONCLUSIONS: These findings contribute to knowledge of rare diseases affecting the eye and visual pathway and represent Australian childhood visual impairment.

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INTRODUCTION

Although childhood vision impairment (VI) is rare [1, 2], it is widely agreed that it has a significant impact on a child's neurobehavioural development, their quality of life and that of their family [3, 4]. Data describing childhood visual impairment is essential for knowledge building, to identify future trends, to support health, education and social planning [5], and for research that explores the prevention and treatment of eye and visual disorders in children [4]. Some uniquely Australian studies exist such as the Sydney Myopia Study, a prevalence study of myopia and eye disease in Sydney school children [6]; the Sydney Paediatric Eye Disease Study, a study of preschool aged children [7]; and the Birth Defects Registry of Western Australia, which reports on congenital eye anomalies [8]. The Australian Childhood Vision Impairment Register (ACVIR) is a national project that has collected data on Australian children with VI since 2008. ACVIR was initiated and continues to be sponsored by NextSense (formerly the Royal Institute for Deaf and Blind Children), with ethics approval by human research ethics committees (HRECs) across Australia. Uniquely, ACVIR provides detailed data on Australian children with VI and co-morbidities, in areas where national monitoring is currently lacking.

SUBJECTS AND METHODS

To register with ACVIR a child must be aged between 0 and 18 years and have permanent VI in both eyes diagnosed by an ophthalmologist. Inclusion criteria include:

- Corrected binocular visual acuity (CBVA) of 6/18 or less
- 20 degrees or less of intact binocular visual field
- Any form of cortical/cerebral visual impairment (CVI)

The registration process is outlined in Fig. 1. ACVIR materials approved by the HRECs (including the participant information sheet, and consent and parent data forms) are included in registration packs, which are widely distributed to paediatric ophthalmology practices and hospitals that offer paediatric services; to low-vision service providers; and to specialist educators. Families may also access ACVIR information on the VI Family Network (at www.vifamilynetwork.org.au), the website that supports the project. Families are informed that registration is voluntary and that they will not experience any disadvantage if they decline to register their child. There are no incentives offered to families other than to opt in to receive

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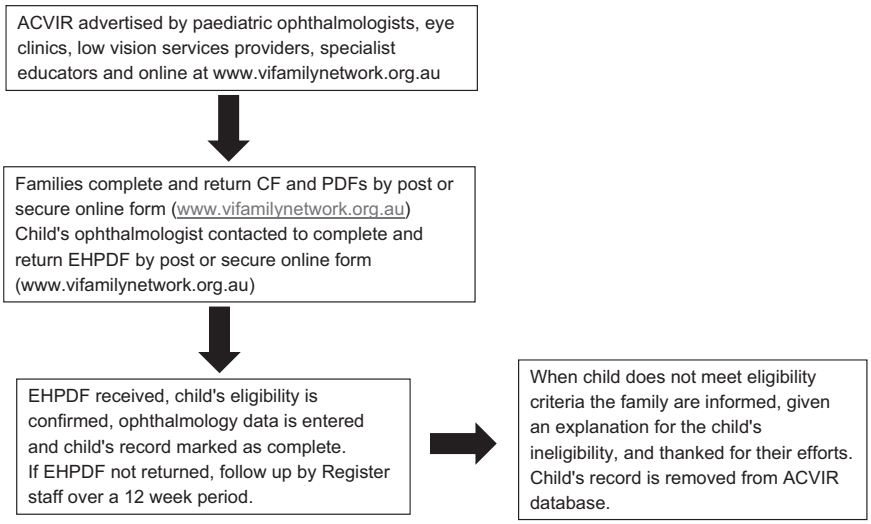

Fig. 1 The registration process. ACVIR is advertised, families complete the Consent Form (CF) and Parent Data Form (PDF) and the child is registered. The child's ophthalmologist is sent and completes the Eye Health Professional Data Form (EHPDF).

the ACVIR newsletter and notification of future research projects related to their child's eye/vision condition.

Families participate in the registration process by completing and returning the consent form (CF) and the parent data form (PDF); both forms are available in hard copy (returned using a postage paid envelope) and online, submitted at www.vifamilynetwork.org.au. The PDF gathers data on the child's demographics, ocular and other diagnoses, and low-vision support. All ACVIR forms are available in accessible formats and in languages, including English, Arabic, Traditional Chinese, Simplified Chinese, Hindi, Spanish and Vietnamese. Online PDFs are received as an encrypted file, with download and access restricted to register staff.

Upon receipt of the CF and PDF, and without the return of the Eye Health Professional Form (EHPDF), the child is registered and if families agree, the child is sent a certificate of registration in their chosen format. Families are also asked to indicate their consent for contact with the child's ophthalmologist. When this consent is provided, ophthalmologists are invited to complete and return the EHPDF in either hard copy (using a postage paid envelope) or using an online data form that has been emailed to a relevant email address. The EHPDF is returned as an encrypted file, with download and access restricted to register staff.

The EHPDF gathers data on the child's primary and secondary ocular diagnoses, associated disabilities, health conditions, and the child's visual acuity and visual fields (if available). Information related to the child's associated disabilities and health conditions is sourced from reporting by paediatricians, and other health professionals involved in the child's care. Ophthalmologists are not obliged to complete EHPDFs or notify families about ACVIR. Despite this, many Australian paediatric eye clinics actively participate by informing families, displaying and distributing ACVIR materials, and completing and returning EHPDFs.

If a child does not meet the eligibility criteria for registration, the child's family are informed by register staff, provided with an explanation for the child's ineligibility, and thanked for their efforts. The child's record is then removed from ACVIR database.

All ACVIR data is stored on a secure database managed by NextSense. Register staff are responsible for monitoring return of PDFs and EHPDFs, with a series of reminders sent to families and ophthalmologists when forms are not returned. Register staff follow up all non-returned PDFs and EHPDFs on a six week cycle. Two attempts are made at following up non-returned PDFs and EHPDFs, and if forms are not returned, follow up is ceased and the child's record remains incomplete. Depending on the data query, incomplete records may be included in certain data analyses.

Stakeholders and researchers are invited to apply for anonymised access to ACVIR data. Register staff also assist researchers by distributing information to families (who have previously indicated their interest) on research related to their child's eye condition.

ACVIR currently has 1336 children registered and this paper presents key findings from 904 children, or those participants who had complete records (i.e., return of both the PDF and EHPDF). The remaining 432 children had only one data form returned, with ~75% being non-returns of EHPDFs, and 24% of PDFs, (where families chose to submit the CF, and did not respond to requests to submit the PDF).

This paper reports on data from both the PDF and EHPDF including demographics; birth and family history; diagnostic journey; primary and secondary diagnoses; additional disabilities and health conditions; levels of VI and visual field loss; and low-vision support. In presenting this data it should be noted that not every question was answered on every child.

RESULTS

Demographics

The child's age at registration was reported by 98% ($n = 889$) of families, with 42% of children aged 0–5 years; 44% aged 6–13 years; and 14% aged 14–18 years. The child's gender was reported by 95% ($n = 861$) of families, with 57% being male, and 43% female. Country of birth was reported for 58% ($n = 523$) of children, with 96% being born in Australia. Other countries of birth included England, Fiji, France, Kenya, Lebanon, New Zealand, Pakistan, Philippines, Qatar, Sudan, United States of America and Vietnam. The first language spoken in the home was reported by 95% ($n = 856$) of families, with 90% speaking English, followed by 1.6% speaking Arabic. A variety of other languages were also reported.

Gestational age and birth weight

Gestational age (GA) was reported for 57% ($n = 519$) of children. When the World Health Organization (WHO) categories for preterm (PT) birth [9] were applied, 83% of children were born full term (FT), and 17% were born PT. Of the PT births, 64% were moderate to late PT (32 to <37 weeks); 15% were very PT (28 to <32 weeks); and 21% were extremely PT (<28 weeks). Birth weight (BW) was reported for 99% ($n = 898$) of children. Only 19% were low BW (<2500 g), with the majority (81%) weighing >2500 g at their birth.

When a family reported both their child's GA and BW (54%), their child's results were applied to the International Newborn Standards (INS) centiles [10]. Approximately half (48%) of PT children with a reported GA and BW (25 males and 15 females), had a BW corresponding with approximately the 50th INS centile. Of the FT children with a reported GA and BW, only 1.7% (4 males, 3 females) had a low BW (i.e., <2500 g) for their term, and 86% of these children were below the third INS centile [10].

Family history

A positive family history of a similar (non-specified) eye condition to the child's condition was reported by 45% ($n = 404$) of families,

with 31% reporting an affected sibling, and 25% reporting an affected parent.

Suspicion of VI

Families were questioned regarding when their child was first suspected to have VI. Of the 91% ($n = 824$) who answered, 30% indicated that their child was suspected within the first month of life. It was most common for a parent (31%), followed by a paediatrician (17%) to raise concern regarding a child's vision. Those health professionals likely to have frequent contact with children, i.e., general practitioners (GPs) and child and family health nurses (CFHNs), were less common notifiers, at 7% for both professions.

Age at diagnosis

The child's age at diagnosis was reported by 89% ($n = 806$). More than half of the children (68%) had been diagnosed by their first birthday, most commonly by 6 months of age (84%).

Mean time interval between suspicion and diagnosis

Data availability allowed the calculation of the mean time interval between suspicion and diagnosis for 91% ($n = 823$) of children. Children aged 0–12 months (72%) had the shortest mean time interval at 2.5 months. However, older children experienced a longer mean time interval including 11.5 months for children aged 13 months to 6 years (22%), and 9 months for those aged 7–18 years (6%).

Primary and secondary diagnoses

Clinicians reported a primary diagnosis on 1725 eyes, and a total of 1061 secondary diagnoses. Secondary diagnoses ranged from 1 to 5 conditions per child, with ~37% ($n = 153$) of children having two or more secondary diagnoses. The British Ophthalmic Surveillance Unit (BOSU) [11] classifications are used in Table 1 to summarise the site affected, and the primary diagnoses per eye, and the number of secondary diagnoses per site.

In the case of the most common primary diagnosis—retinal dystrophy, 40% ($n = 116$) of children with this diagnosis had the dystrophy type reported by their clinician (Fig. 2).

Additional disabilities and health conditions

Co-morbidities were common in children, with 44% ($n = 399$) of families reporting that their child had additional disabilities and/or developmental delay (DD). Children frequently had more than one type of disability, and of the 519 reports related to disability, 11% had hearing loss; 28% had speech disability; 30% had learning disability; and 31% were reported with a physical disability. Of the 274 reports related to DD, 23% had mild DD; 34% had moderate DD; and 43% had severe DD.

The presence of health conditions other than childhood VI were reported by 47% ($n = 422$) of families. It was common that children had more than one health condition, with 623 health conditions reported, including 14% with epilepsy; 13% with cerebral palsy; 9% with asthma; 7% with autism spectrum; and 8% with low muscle tone.

Levels of VI and visual field loss

Clinicians reported visual function by either indicating the child's CBVA for 6 metres (or equivalent), or by describing the child's visual function by selecting an observable visual behaviour from those categories recommended by BOSU [11]. CBVA was reported on 75% ($n = 681$) with Fig. 3 showing CBVAs according to the WHO classifications for VI [12].

Visual acuity across the seven most common primary diagnoses was analysed. Other than in the case of CVI, the most commonly reported CBVA in the remaining 6 diagnoses was 6/18 to 6/60. In the case of CVI, only 20% of children had their CBVA reported, with the most common visual acuity range being <3/60 to light perception.

Table 1. Primary and secondary diagnoses.

Site affected	Primary diagnosis 1725 eyes	Secondary diagnosis 1061 eyes
Visual pathway and cortex	468 (27%)	350 (33%)
CVI	260 (15.1%)	
Nystagmus	152 (8.8%)	333 (31%)
Other visual pathway	56 (3%)	17 (1.6%)
Whole globe and anterior segment	83 (4.8%)	117 (11%)
Microphthalmos	17 (1%)	48 (4.5%)
Primary glaucoma	16 (0.9%)	29 (2.7%)
Anterior segment anomaly	16 (0.9%)	14 (1.3%)
Anophthalmos	8 (0.46%)	1 (0.09%)
Disorganised globe/phthisis	1 (0.05%)	
Other whole globe and anterior segment	20 (1.2%)	18 (1.7%)
Other glaucoma	5 (0.3%)	7 (0.6%)
Cornea	51 (3%)	47 (4.4%)
Opacity	8 (0.46%)	23 (2.1%)
Dystrophy	4 (0.2%)	3 (0.3%)
Other cornea	39 (2.3%)	21 (2%)
Lens	111 (6.4%)	61 (5.7%)
Cataract	99 (5.7%)	47 (4.4%)
Other lens	12 (0.7%)	14 (1.3%)
Uvea	98 (5.7)	25 (2.4%)
Coloboma	53 (3%)	
Aniridia	34 (2%)	19 (1.8%)
Uveitis	9 (0.5%)	3 (0.3%)
Other uvea	2 (0.1%)	3 (0.3%)
Retina	625 (36%)	72 (6.7%)
Retinal dystrophy	292 (17%)	
Albinism	192 (11%)	
Retinopathy of prematurity	45 (2.6%)	5 (0.5%)
Retinal detachment	30 (1.7%)	27 (2.5%)
Retinitis		6 (0.5%)
Other retina	66 (3.8%)	34 (3.2%)
Optic nerve	236 (14%)	117 (11%)
Optic nerve hypoplasia	122 (7%)	30 (2.8%)
Optic atrophy	78 (4.5%)	56 (5.2%)
Optic nerve glioma	18 (1%)	1 (0.09%)
Neuropathy	6 (0.3%)	2 (0.2%)
Other optic nerve	12 (0.7%)	24 (2.2%)
Other congenital anomaly		4 (0.3%)
Amblyopia	53 (3.1%)	272 (26%)
Refractive	46 (2.6%)	146 (14%)
Deprivation	4 (0.2%)	53 (5%)
Strabismic	3 (0.1%)	73 (6.8%)

The child's CBVA according to the reported level of DD was analysed. In children with mild and moderate DD, moderate VI was most common (61% and 57% respectively had CBVA of 6/18 to 6/60). However, when severe DD was reported, children were more likely to be blind (44% with CBVA of <3/60 to no LP).

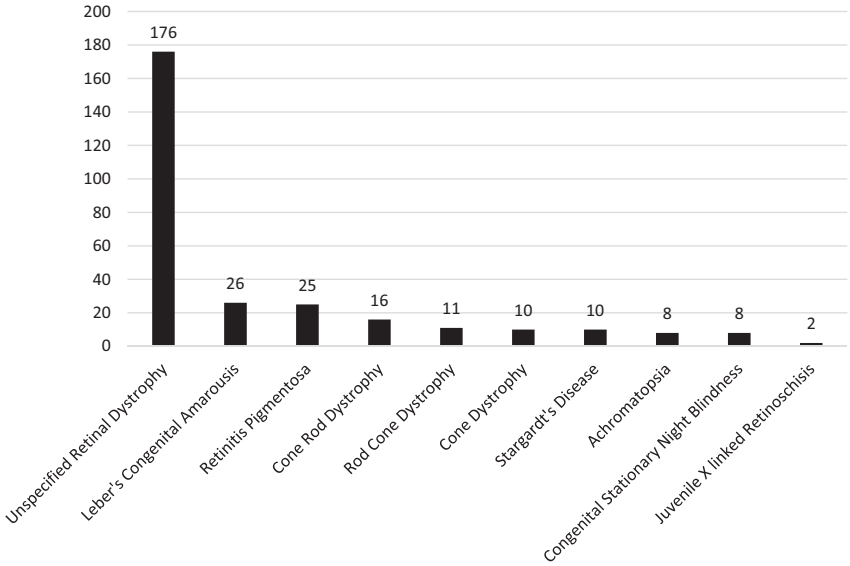

Fig. 2 Types of reported retinal dystrophy in 292 (17%) of children as a primary diagnosis.

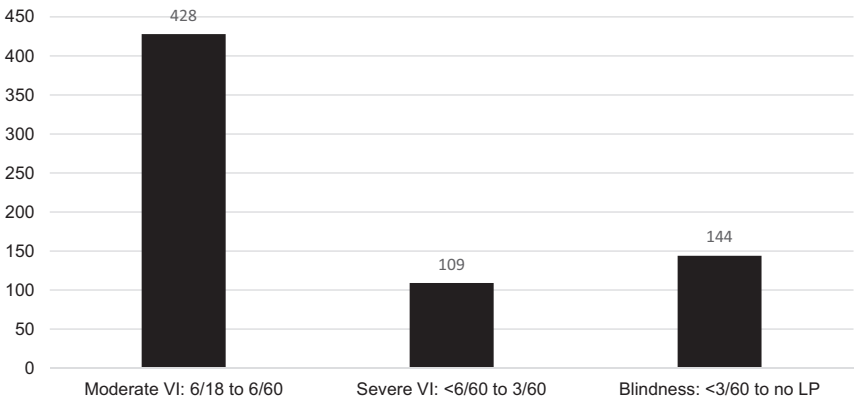

Fig. 3 Correctd Binocular Visual Acuity (CBVA) reported using the World Health Organization (WHO) classification of vision impairment (VI).

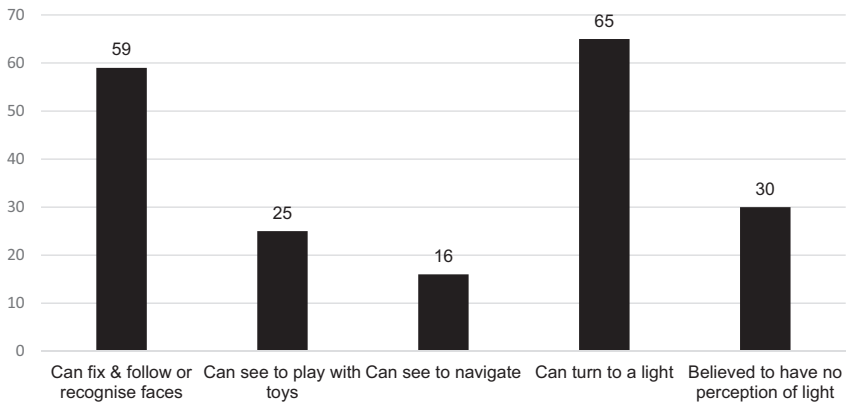

Fig. 4 Visual function reported by observed visual behaviours (using categories recommended by the British Ophthalmic Surveillance Unit) in 22% of children.

Visual function was reported from observed visual behaviours, when CBVA could not be determined. Observed visual behaviours were reported in 22% of children, with a mean age of 4 years (Fig. 4).

The most common primary diagnoses where visual behaviours rather than CBVA was reported occurred in children with CVI (25%), followed by albinism (9%), optic nerve hypoplasia (9%) and retinal dystrophy (8%). Further, 94 children whose visual function was reported by visual behaviours also had their level of DD reported, with 12% having mild DD, 27% having moderate DD, and 61% having severe DD.

For the remaining 3% of children, no visual function could be reported.

Visual field loss was reported in 4% ($n = 36$) of children, with the most common loss being less than the central 20 degrees of visual field remaining.

Low-vision support

Families were asked whether their child was receiving low-vision support from a non-government agency as commonly occurs in Australia. More than half of all children (68%) were being supported at the time of their registration, with 54% of families indicating this support had begun prior to the child's first birthday. On the other hand, 24% of families indicated that their child was not receiving support and 8% were unsure.

Braille continues to feature as an important method for accessing literacy with 12% of children on the register using braille. Regarding those children using low-vision aids, ($n = 168$) 55% of children used a near magnifier; 19% used a monocular or binocular for distance viewing; and 26% used a CCTV. Use of access technology was not questioned in depth.

DISCUSSION

ACVIR has provided critical data that contributes to the scientific body of knowledge about rare diseases of the eye and visual pathway and forms a snapshot of childhood VI in Australia. The findings are now available for eye care, low vision, education and rehabilitation planning [1]. This is particularly relevant in the Australian context, given the recent implementation of the National Disability Support Scheme, a scheme that funds disability support including individuals with a diagnosis of VI [13].

Ascertainment of the prevalence of Australian childhood vision impairment is challenging. Australia currently conducts vision surveillance and vision screening programmes for children across Australian states and territories, which vary in nature (i.e., age at surveillance and screening, and the chosen protocols). Vision surveillance forms part of the developmental checks conducted by general practitioners and child health nurses, and aims for timely referral of children with a positive family history of eye and/or vision problems; when a child is suspected of an eye and/or vision condition; and when parental or professional concerns exist regarding the child's visual development. Vision screening is typically offered to children aged 3–5 years, with defined referral criteria and clinical pathways to ophthalmic assessment and management. Although evaluation of Australian vision surveillance programmes remains unpublished, reporting on the vision screening programme in New South Wales known as the Statewide Eyesight Preschool Screening Programme (StEPS) revealed a diagnosis of a "vision disorder" (other than amblyopia related to uncorrected refractive error and/or strabismus) in 142 (0.7%) children [14]. However, rates of vision impairment in these children was not reported.

Ascertainment of the prevalence of Australian childhood vision impairment using ACVIR reporting is also challenging. Although somewhat speculative, if prevalence rates for severe childhood VI and blindness of ~4–6 per 10,000 [1] from the United Kingdom (UK) are applied to an average Australian birth rate of 300,000 per annum [15], 120–180 Australian children with severe VI and blindness could meet criteria for ACVIR registration each year. However, based on the cohort of Australian children presented in this paper with severe VI and blindness ($n = 253$), ~25 children are registering per year. Much work needs to be done to improve awareness of ACVIR and the benefits of registration.

A slight gender bias towards boys having childhood VI was found and this appears to be globally consistent. The ACVIR results of 57% boys and 43% girls are similar to data reported from the US Babies Count Register (US register), where in a cohort of 5931 children aged 0–3 years, 55% were boys and 44% were girls [4]. The Norwegian Register of Visual Impairment and Blindness, (Norwegian register) reported on 628 children aged 0–20 years, with similar findings of 55% boys and 45% girls [16]. In addition, The VI Scotland Register (Scottish register) reported on 850 children aged 0–16 years, with 57% boys and 43% girls [5].

Most children on the register with a reported gestational age were born FT (83%), with only 17% of children falling in the extremely PT to PT range (<28 weeks to <37 weeks). Data from the Finnish Register of Visual Impairment on (556 children aged 0–17 years) showed a similar finding with 78% of children born FT [17] and 23% born PT [18].

Few children on the register would be considered small for their age, i.e., a low BW for gestational age [19]. Only 1.7% of FT children had a BW of <2500 g, however, 86% of these children were below the third centile according to the INS [10]. In the PT cohort, 48% had a BW that approximated with the 50th INS centile. Other Australian studies have reported that low BW and PT birth may be associated with ophthalmic morbidity [7, 20]. As ACVIR registrations increase, analysis of the risk of VI in small for age children is planned.

There is no doubt that reaching a diagnosis of childhood VI is challenging and complex, given the nature of children, their ability to participate in clinical assessment and the likelihood of co-morbidities [21]. However, a diagnosis is key information for families to allow them to regain control, and to develop active coping strategies [22]. In this study 68% of children were diagnosed with VI by their first birthday. This diagnostic age aligns with reporting by the British Childhood Vision Impairment Study (BCVIS) where 65% of children with severe VI and blindness received a diagnosis by 12 months of age [23].

Children on the register under 12 months of age experienced a mean delay of 2.5 months between being first suspected and subsequently diagnosed. This minimal delay may reflect efficiencies in the Australian paediatric ophthalmic referral pathway, at a time when visual development is critical and timely interventions are essential. Yet, children aged 1–6 years who were also in a critical phase of visual developmental experienced longer delays (mean 11.5 months), and the mean delay in diagnosis for older children (7–18 years) was 9 months. Given the need for prompt treatment and low-vision support, and the potential impact on families when delay occurs [22], the diagnostic journey for children with VI over 12 months of age warrants review.

The need for non-ophthalmic health professionals to competently observe areas of child development is acknowledged in the literature [24]. Therefore, it is concerning in this study that the two health professionals likely to have regular contact with Australian children—GPs and CFHNs—were less frequently reported by families as those professionals who raised the suspicion of VI. Targeted training programmes for non-ophthalmic health professionals regarding risk factors and red flags for childhood VI are therefore recommended.

Global variation exists when reporting the affected site related to childhood VI. In the current study the retina was the most affected site (36%), closely followed by the visual pathway and visual cortex (27%). However, earlier reporting by BCVIS ($n = 439$ with 6/60 or less) showed otherwise, with the visual pathway primarily affected (47.8%), followed by the retina (28%) [23].

Global variation also exists in the reported aetiologies of childhood VI. For example, data from the current study revealed the three most common primary diagnoses as Retinal Dystrophies (17%), CVI (15%), and Albinism (11%). This finding was similar to rates of Retinal Dystrophies reported in the UK in 2010 at 14% [23], and then again in 2017 at 15% [25]. However, data from the Scottish register reported Retinal Dystrophies at ~7%, CVI at 21%, and Albinism at 8% [5]. The Scottish register reporting was similar to findings in the US schools for the blind, showing Retinal Dystrophies at 5%, CVI at 18%, and Albinism at 4% [3]. Further, the US register reported Retinal Disorders at 5.5%, CVI at 24.9%, and Albinism at 4.5% [4].

In the children on the register diagnosed with Retinal Dystrophy, 40% had the specific dystrophy reported, with the most common types being Leber's Congenital Amaurosis (22%) and Retinitis Pigmentosa (21%). This was a similar finding to that reported by the Danish Registry for the Blind and Partially Sighted Children, with Leber's Congenital Amaurosis at 31% and Retinitis Pigmentosa at 23% [26].

A large number of secondary diagnoses were reported with many children having more than one. The most reported secondary diagnosis was Infantile Nystagmus ($n = 333$). Although the prevalence of nystagmus has previously been recognised in the literature [27, 28], its presence is functionally significant given the impact of nystagmus on the maintenance of quality vision over time [29], and the impact on essential near activities such as reading [29]. Also, worth noting were the reported cases of Amblyopia ($n = 272$ cases), which were mainly refractive in nature. This finding should act as a salient reminder to clinicians that both correction of refractive error and treatment of underlying aetiologies are essential to maximise visual function in all children.

Additional disabilities and health conditions are known to be common and diverse in nature in children with VI [30, 31]. In the current study, 44% of families reported that their child had additional disabilities and/or DD. This finding is similar to Norwegian register, which found that more than half of children had additional impairments, mainly cerebral palsy and cognitive impairments [15]. The US Register reported a higher rate of additional disabilities (65.3%) [4], as did the Scottish register (71%) [5].

The most common level of VI in children on the register who were able to undergo CBVA assessment was moderate VI (63%). Both the Scottish [5] and Norwegian registers [15] also reported moderate VI as the most common level of impairment, however, the ACVIR finding was higher than that reported by Scotland (~38%) [5] and Norway (42.5%) [15]. The figure for children on the register reported as blind was slightly lower (21%) than reporting by Scotland (~5%) [5] and Norway (31%) [15].

Developmental delay and the child's age can challenge their capacity to actively participate in vision assessment [31, 32]. Approximately one-third (30%) of children on the register were reported to have DD and this may have contributed to non-reporting of CBVA in 22% of children, where the level of DD was most commonly severe. Further, this group had a mean age of 4 years. However, it could be argued that skilled clinicians would have adapted their assessment approaches to limit the impact caused by the child's young age.

Literature highlights the risk of VI being overlooked in children with DD, as the focus may be on co-morbidities other than vision [33, 34], and when visual function is not reported, the risk of missing VI is known to increase [35]. Therefore, clinicians participating in this study are commended for reporting visual function from observed visual behaviours, rather than opting for non-reporting when CBVA could not be determined.

Significant levels of visual impairment should act as developmental red flags for all clinicians. Previous literature has reported that the severity of VI corresponds with a rise in the severity of DD [31], and that an association exists between severe levels of VI and poor developmental outcomes [36]. In the current study, 37% of children with a reported CBVA ranged from severe VI to blindness. Further, approximately half (44%) of children with severe DD were reported to be blind (<3/60 to no light perception). Therefore, robust referral pathways should be developed to ensure the availability of comprehensive ophthalmological examination for all children suspected and/or diagnosed with DD.

Given the level of VI and co-morbidities evident in the current study cohort, all children on AVCIR qualify for low-vision support. It is therefore concerning that only 68% of families indicated that their child was being supported by a non-government agency. Low-vision support should be offered as early as possible to children to minimise the impact of VI on their development [37]. Further work is indicated to better inform families regarding their child's right to access support.

STUDY LIMITATIONS

Inherent limitations exist in the data gathered in registers such as ACVIR [1]. As registration with ACVIR is not compulsory, reporting is limited to those children whose families have consented to registration. Therefore, not all Australian children with VI are represented on ACVIR, making accurate ascertainment of prevalence challenging.

CONCLUSION

ACVIR data reveals a group of children who have varied diagnoses, disabilities, health conditions and levels of VI. With near equal numbers of children with CVI—who are complex children often with multiple health and communication issues—to children with Retinal Dystrophy and Albinism who have few other health issues, the diagnostic and management needs are varied. Awareness of this diversity is vital when meeting the challenges of planning and delivering essential services for children with visual impairment.

SUMMARY

What was known before

- Children with visual impairment require tailored support to minimise the impact of visual impairment. In Australia, no published data has been available to ensure this support meets specific needs such as level of visual impairment and co-morbidities.

What this study adds

- This study provides the first data on Australia children with vision impairment, revealing demographics, levels of visual impairment, common primary and secondary diagnoses and co-morbidities.

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The authors agreed that each has made a significant contribution to this paper, including analysis, interpretation, and writing; deciding on the journal for potential publication; reviewing and agreeing on all versions of the paper; agreeing on all changes made at the proofing stage; agreeing to take responsibility and be accountable for the contents of the article; and agreeing to share responsibility for resolving any questions raised about the accuracy and integrity of the published work. SS: 70%, FM: 10%, MF: 10%, HR: 10%.

COMPETING INTERESTS

The authors declare no competing interests.

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