Deloitte Access Economics

Socioeconomic impact of low vision and blindness from paediatric eye disease in Australia

Save Sight Institute
The University of Sydney

15 July 2016

SAVE SIGHT INSTITUTE

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15 July 2016

Dear John

Socioeconomic impact of low vision and blindness from paediatric eye disease in Australia

Attached is our revised final report on the prevalence of low vision and blindness from paediatric eye diseases in Australian children by condition, along with associated health system expenditure, other financial costs and burden of disease impacts.

This revised final report incorporates some editing changes provided by you, which have been incorporated into the final report we provided in August 2015. We note, however, that the quantitative and other content of the report does not reflect any factors that may have altered the analysis that occurred after provision of the final report last year.

Yours sincerely,

Lynne Pezzullo

Office Managing Partner Canberra, Deloitte Touche Tohmatsu
Lead Partner, Health Economics and Social Policy, Deloitte Access Economics

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Glossary

ABS	Australian Bureau of Statistics
ACVIR	Australian Childhood Vision Impairment Register
AIHW	Australian Institute of Health and Welfare
AHS	Australian Health Survey
AR-DRG	Australian refined diagnosis related group
AWE	average weekly earnings
BOD	burden of disease
CVI	cortical/cerebral visual impairment
DALY	disability adjusted life year
DR	diabetic retinopathy
DWL	deadweight losses
GP	general practitioner
JIA	juvenile idiopathic arthritis
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th Revision
IHPA	Independent Hospital Pricing Authority
NF1	neurofibromatosis Type 1
NLTS	National Longitudinal Transition Study
NPV	net present value
NSW	New South Wales
RE	refractive error
ROP	retinopathy of prematurity
SAVES	Sydney Adolescent Vascular and Eye Study
SCES	Sydney Childhood Eye Study
SDAC	Survey of Disability, Ageing and Carers
SPEDS	Sydney Paediatric Eye Disease Study
SMS	Sydney Myopia Study
STEPS	Statewide Eyesight Preschooler Screening
UK	United Kingdom
US	United States
VET	vocational education and training

VI	vision impairment
VSLY	value of a statistical life year
WHO	World Health Organization
YLD	years of healthy life lost due to disability
YLL	years of life lost due to premature death

Executive summary

Children's eye health is an important and challenging issue across the world. The World Health Organization (WHO) has identified childhood blindness and genetic eye diseases as priority eye diseases as part of its global eye health action plan for 2014-2019.[1]

Childhood blindness refers to a group of diseases and conditions that may result in blindness or severe vision impairment. Many of the diseases and conditions in this group are untreatable later in life. Genetic eye diseases are a leading cause of blindness in children in developed countries.[2]

Children's eye health presents challenges as vision impairment may arise from the disorder itself, or from disruption of the normal visual and neurological developmental processes, or a combination of both. Screening programs and early intervention is required to minimise the impact of the eye disorder on the developing visual system.

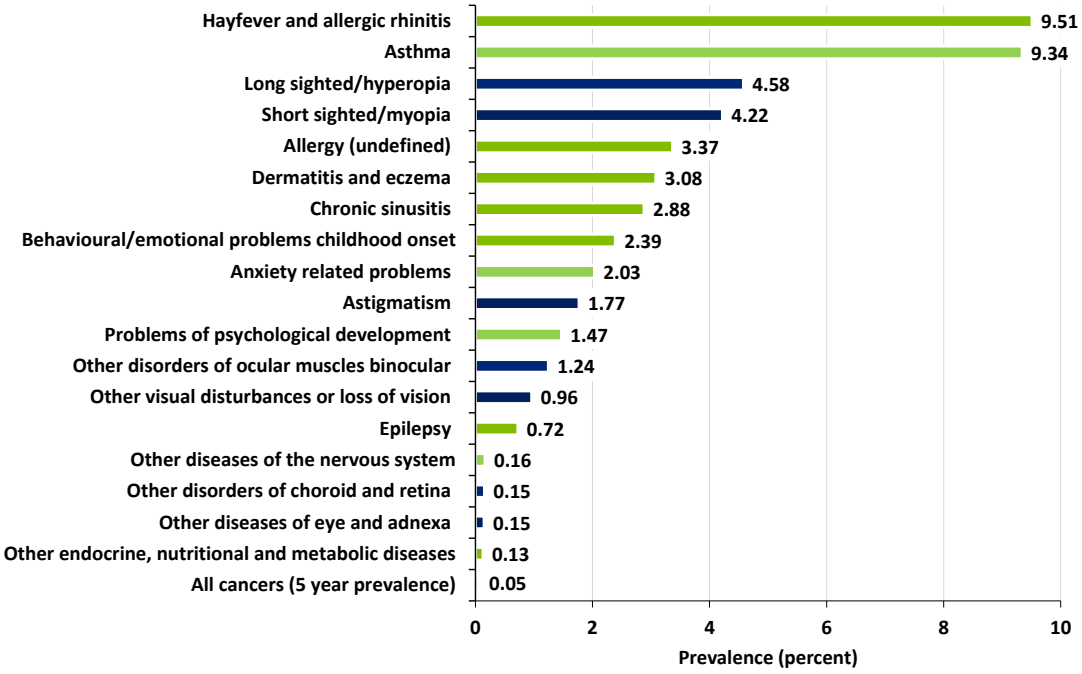
If left untreated, childhood vision impairment (VI) generally continues into adulthood and working life, causing substantial impacts through a child's life. It is estimated that at least half of all children with low vision and blindness also have motor, sensory, or learning impairments or chronic systemic disorders which further impact a child in life (Rahi and Cable, 2003).

While many childhood eye disorders are rare, there are still substantial health system and other financial and morbidity impacts associated with childhood VI. Vision problems also account for a substantial proportion of childhood health conditions. The Australian Bureau of Statistics (ABS, 2012) reports that refractive error (RE) accounts for three of the top ten most common long-term health conditions in under 15 year olds – hyperopia (3rd), myopia (4th) and astigmatism (10th). This also continues into adulthood , as shown in the Economic Impact of Vision Loss in Australia report from 2009 which found that most vision loss in Australians aged 40 years or over was uncorrected refractive error (over 341,000 people) (Access Economics, 2009).

[1] http://www.who.int/blindness/causes/priority/en/index9.html, accessed 28/04/2015.

[2] http://www.who.int/blindness/causes/priority/en/index9.html, accessed 28/04/2015.

Chart i: Select common long-term health conditions in Australian children, by order of frequency



Source: ABS (2012) and AIHW (2014b)

While RE accounts for a large proportion of eye conditions in Australian children, this data also shows that "other disorders of ocular muscles binocular"[3], and "other visual disturbances or loss of vision"[4] are more common than many other childhood conditions such as epilepsy, cerebral palsy, cystic fibrosis and childhood cancer.[5]

There have only been a few paediatric eye health studies in Australia. These studies have been small and have generally only focused on single year age groups. The NSW StEPS (Statewide Eyesight Preschool Screening) program screens many thousands of children each year (>65,000 children in 2011), but only a small amount of high level data from this program has been released. The Australian Health Survey (AHS) (ABS, 2012) covers over 20,000 households, and reports on all age groups across a large range of eye conditions. Accordingly, it is used as the main basis for calculating prevalence of childhood VI, supplemented with estimates for single year age groups from other studies. Congenital eye conditions, and disorders of the optic nerve and visual pathway were not included in the AHS, and so have been separately reported using Australian Institute of Health and Welfare (AIHW) data. The AHS only reports down to two-digit ICD-10 (International Classification of

[3] International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) codes H49-51

[4] ICD-10 code H53

[5] Note: Cerebral palsy is under the category 'Other diseases of the nervous system', and cystic fibrosis is under the category 'Other endocrine, nutritional and metabolic diseases' shown in Chart i.

Diseases, version 10) level and does not report on individual rare conditions. While it is assumed that most rare diseases are captured in the AHS' high level groupings, overall prevalence of VI from rare conditions has been calculated also, based on a range of journal articles.

Based on these sources, Deloitte Access Economics estimates that **there are almost a third of a million (332,936) Australian children with VI or the potential to become visually impaired** in Australia in 2015 (Section 2.3).

Table i: Estimated prevalence of visual impairment in Australian children (under 18), 2015

ICD-10 description	Condition	Prevalence ('000s)		
		Male	Female	Total
Disorders of choroid and retina (H30-H36)	Retinopathy and other disorders of choroid and retina	1.98	5.48	7.46
Disorders of optic nerve and visual pathway (H46-H48)	Disorders of optic nerve and visual pathway	5.48	3.70	9.18
Disorders of ocular muscles and binocular movement (H49-H51)	Strabismus and other disorders of ocular muscles binocular	37.84	27.28	65.12
Hypermetropia (H52.0)	Long sight/ hyperopia (presenting)	40.13	62.29	102.41
Myopia (H52.1)	Short sight/myopia (presenting)	54.96	52.76	107.71
Astigmatism (H52.2)	Astigmatism (presenting)	18.36	19.62	37.97
Visual disturbances (H53)	Amblyopia and other visual disturbances or loss of vision	21.39	47.33	68.72
Visual impairment including blindness (H54)	Blindness (including partial)**	0.19	0.13	0.32
Other disorders of eye and adnexa (H55-H59)*	Nystagmus and other diseases of eye & adnexa	8.19	6.97	15.15
Congenital malformations of eye (Q10-Q15)	Congenital eye anomalies	1.75	0.95	2.70
Total persons		**151.99**	**180.94**	**332.94**

Note: total persons is less than sum of conditions due to comorbidities. Does not include colour blindness. * The AHS category 'Other diseases of eye & adnexa is not directly comparable with the ICD 10 category 'Other disorders of eye and adnexa' since the AHS category is designed to capture all other eye diseases not included under the other headings in the table. ** Blindness is a functional state rather than a condition. The most common conditions for blindness include CVI, oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma and congenital cataract.

Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics calculations.

While RE is treatable through appropriate spectacles or lenses, many children do not have their RE properly corrected. Since most screening programs in Australia do not provide universal coverage, many children are not yet screened. Consequently, under-corrected RE still accounts for the majority of VI in children (53%). Most other VI is caused by conditions such as amblyopia or strabismus, which are managed by occlusion therapy (patching), surgery and medications. Early detection plays a critical role in the management of

paediatric eye diseases. The impact of the condition can be lessened if detected before it affects the normal development of the visual system.

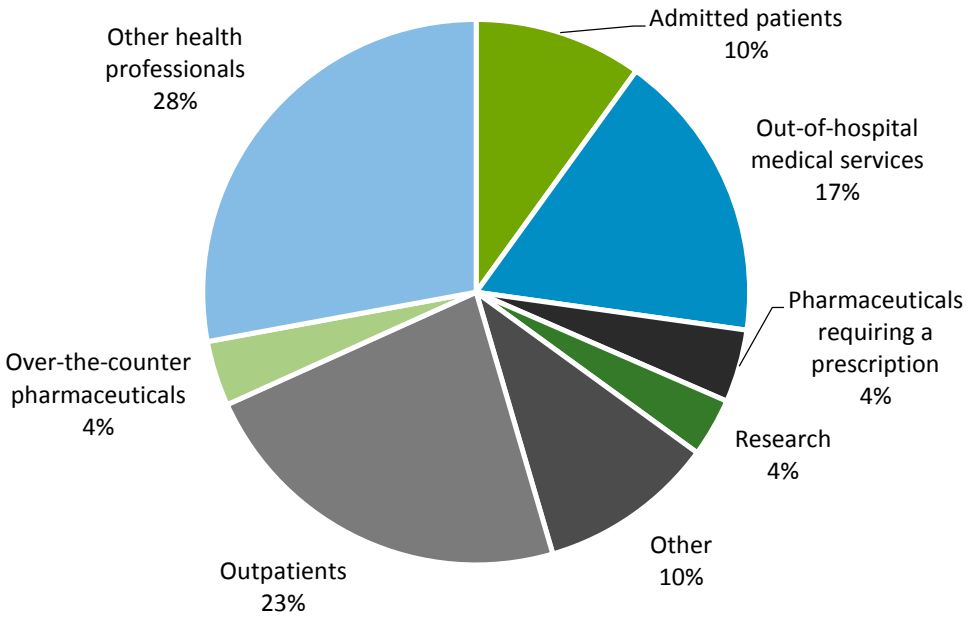
While rare eye conditions only afflict a small number of children, their impact on the children concerned is severe, as most of these disorders are incurable.

Total health costs to treat children with diseases of the eye and adnexa are an estimated **$439 million in 2015, or 11.3% of the total health system expenditure on eye conditions in 2015.**

Consequently, the proportion of total health expenditure for eye conditions in children is much higher compared to their share of health expenditure for all conditions (8.5%) reported at the start of Chapter 3. While some of this increased share of cost represents screening programs and other interventions, this also reflects the increased burden of eye conditions on children.

Almost half of the total health expenditure ($202 million) is for children who are under five years old. More than half of total health expenditure is accounted for by outpatients and allied health services. Hospital admitted patients only comprises 10% of health system costs. This reflects the advances in ophthalmic care enabling children's eye diseases to be managed in the community wherever possible.

Chart ii: Allocated health system expenditure, by cost component, 2015



Note: cost of glasses is under the category 'Other'.

Source: AIHW special request.

The lifetime (real) health system expenditure for a baby born with an eye condition today is $29,200 in net present value terms, assuming life expectancy of 80 years for males and 84 for females (Section 3.3).

With recent improvements in vision support, most vision impaired students are able to complete year 12. This is similar to other young adults (Chapter 5). However, evidence from the United States (US), Canada and Australia shows that having VI causing disability reduces the chance of being employed by almost 50%. Reduced employment due to VI causing disability in children costs the economy an estimated $50 million per year in 2015 in lost productivity (Chapter 4). Including health expenditure, lost productivity, and other financial costs, **the estimated economic impact of VI in children is $624 million per year**, or $1,845 per child.

Long term costs are large. As today's 17 year olds will have to deal with their current eye conditions throughout their adult working lives, they can expect their **lifetime real earnings to be $53,916 (NPV) lower than their colleagues without VI**. Using disability weights and distributions from the AIHW (Begg et al (2007), there are an estimated 6,983 prevalent years of healthy life lost due to disability (YLD) from low vision and blindness in Australian children in 2015 (Section 5.1). Adding in an allowance for mortality - less than one child death per year from eye diseases - **the burden of disease (BoD) is 7,011 disability adjusted life years (DALYs)**. The Office of Best Practice Regulation stipulates that the value of a statistical life year (VSLY) is $187,200 in current dollars. Thus **the total cost of DALYs (lost years of healthy life) amounts to $1.31 billion, or $3,880 per child with VI in 2015.**

Health system expenditure accounts for the majority (70%) of the total financial costs in children caused by VI. Accordingly, governments bear just over half (52%) the total financial costs of childhood VI.

Table ii: Total costs of VI in children, 2015 ($m)

	Individual	Family/ friends	Federal Govt.	State Govt.	Employers	Society/ other	Total
Health system costs	0.0	78.1	181.6	118.0	0.0	61.0	438.7
Productivity costs	23.9	0.0	16.9	0.0	9.0	0.0	49.8
Carer costs	0.0	5.3	2.9	0.0	0.0	0.0	8.2
Other costs	34.2	0.0	0.0	0.0	0.0	0.0	34.2
Dead weight losses	0.0	0.0	0.0	0.0	0.0	92.7	92.7
Transfers*	-1.6	-1.3	2.8	0.0	0.0	0.0	0.0
Total financial	**56.6**	**82.1**	**204.3**	**118.0**	**9.0**	**153.6**	**623.5**
BoD	1,312.3	0.0	0.0	0.0	0.0	0.0	1,312.3
Total with BoD	**1,368.9**	**82.1**	**204.3**	**118.0**	**9.0**	**153.6**	**1,935.9**

Note * transfers here included reduced taxation revenue and increased welfare outlays; this is a negative cost for individuals and family/friends as they receive more net transfers from government.
Source: Deloitte Access Economics' calculations.

Deloitte Access Economics

1 Background

Children's eye health is an important and challenging issue across the world. The WHO has identified childhood blindness and genetic eye diseases as priority eye diseases as part of its global eye health action plan for 2014-2019.[6]

Childhood blindness refers to a group of diseases and conditions that may result in blindness or severe vision impairment. Many of the diseases and conditions in this group are untreatable later in life. Genetic eye diseases are a leading cause of blindness in children in developed countries.[7]

Children's eye health presents challenges as vision impairment may arise from the disorder itself, or from disruption of the normal visual and neurological developmental processes, or a combination of both. Screening programs and early intervention are required to minimise the impact of the eye disorder on the developing visual system (Murdoch Childrens Research Institute, 2009).

If left untreated, childhood vision impairment (VI) generally continues into adulthood and working life, causing substantial impacts through a child's life. It is estimated that at least half of all children with low vision and blindness also have motor, sensory, or learning impairments or chronic systemic disorders which further impact a child in life (Rahi and Cable, 2003).

In determining the long-term outcomes for children with VI, it is important to be aware of and understand the biological, environmental and lifestyle/social influences that impact a child's development (Rahi and Gilbert, 2013). For example, Rahi et al (2011) identify that factors such as increasing births to older mothers and persistence of smoking during pregnancy are associated with the increasing prevalence of Myopia, and suggest that "life course and genetic epidemiological approaches" are applied to Myopia research. While many childhood eye disorders are rare, there are still substantial health system, other financial and morbidity impacts associated with childhood VI.

Childhood conditions, will generally affect those children for the rest of their lives. Combined with developmental impacts, conditions such as congenital cataracts, retinal dystrophies or childhood glaucoma have lifetime health impacts and may reduce productivity over an entire working career.

This report examines the impact that low vision and blindness – caused by paediatric eye diseases – has on government and private funding of a child's medical care, education, disability support, lost income/productivity, informal care and quality of life.

[6] http://www.who.int/blindness/causes/priority/en/index9.html, accessed 28/04/2015.

[7] http://www.who.int/blindness/causes/priority/en/index9.html, accessed 28/04/2015.

The rest of **Chapter 1** defines various levels of vision impairment (VI) and provides some background on the most common – and some rarer - childhood eye conditions.

Chapter 2 discusses the similarities and differences between various sources of prevalence data, the methodology employed, and prevalence for major conditions by age and gender.

Chapter 3 covers health system expenditure, including an analysis of who bears these costs.

Chapter 4 covers other financial costs including estimated future reductions in workforce productivity from both patients and carers, and other costs such as those associated with welfare payments. This chapter also provides a qualitative analysis of educational impacts of childhood VI.

Chapter 5 discusses burden of disease and social and educational impacts associated with childhood VI.

Chapter 6 provides a summary of findings from the above chapters.

1.1 Definitions of low vision and blindness

The legal definition of VI varies internationally. The WHO (2015) defines VI by the categories 'mild or no visual impairment', 'moderate visual impairment', 'severe visual impairment' and three separate classifications of 'blindness'. The classifications and the associated level of visual acuity are shown in Table 1.1.

Table 1.1: WHO classification of severity of visual impairment

Category	Presenting distance visual acuity
Mild or no visual impairment	<6/18
Moderate visual impairment	<6/18 to 6/60
Severe visual impairment	<6/60 to 3/60
Blindness	<3/60 to 1/60
Blindness	<1/60 to light perception
Blindness	No light perception

Source: WHO (2015).

For the purposes of this report, and to maintain comparability with Access Economics (2004), mild VI is further defined as presenting visual acuity of worse than 6/12 but better than 6/18.

Additionally, legal blindness is defined in this report as best corrected visual acuity of <6/60. A person is also legally blind if they have a field of vision less than 10 degrees of arc around central fixation, or cortical blindness. This is to maintain comparability with the level of visual acuity for blindness that is defined by the Australian Government.[8]

[8] http://www.humanservices.gov.au/spw/customer/forms/resources/sa013-1403en.pdf

Figure 1.1 provides a comparison of visual acuity equivalents and levels of vision impairment across countries.

Figure 1.1: Visual acuity equivalents and levels of vision impairment

RANGES (ICD-9-CM)		EQUIVALENT NOTATIONS		TRUE SNELLEN FRACTIONS (numerator = test distance)					*MA*gnification *R*equirement		Visual Acuity Score (letter count)
		Decimal	US	6.3 m	*6 m* (*Britain*)	5 m (Europe)	4 m (ETDRS)	1 m (Low Vision)	MAR (1/V)	Log MAR	
(Near-) Normal Vision	Range of Normal Vision	1.6 1.25 **1.0** 0.8	20/12.5 20/16 **20/20** 20/25	6.3/4 6.3/5 **6.3/6.3** 6.3/8	*6/3.8* *6/4.8* *6/6* *6/7.5*	5/3.2 5/4 **5/5** 5/6.3	4/2.5 4/3 **4/4** 4/5	1/0.63 1/0.8 **1/1** 1/1.25	0.63 0.8 **1.0** 1.25	–0.2 –0.1 **0** +0.1	110 105 **100** 95
	Mild Vision Loss	0.63 0.5 0.4 0.32	20/32 20/40 20/50 20/63	6.3/10 6.3/12.5 6.3/16 6.3/20	*6/9.5* *6/12* *6/15* *6/19*	5/8 5/10 5/12.5 5/16	4/6.3 4/8 4/10 4/12.5	1/1.6 1/2 1/2.5 1/3.2	1.6 2.0 2.5 3.2	0.2 0.3 0.4 0.5	90 85 80 75
Low Vision	Moderate Vision Loss	0.25 0.20 0.16 0.125	20/80 20/100 20/125 20/160	6.3/25 6.3/32 6.3/40 6.3/50	*6/24* *6/30* *6/38* *6/48*	5/20 5/25 5/32 5/40	4/16 4/20 4/25 4/32	1/4 1/5 1/6.3 1/8	4 5 6.3 8	0.6 0.7 0.8 0.9	70 65 60 55
	Severe Vision Loss	**0.10** 0.08 0.063 0.05	**20/200** 20/250 20/320 20/400	**6.3/63** 6.3/80 6.3/100 6.3/125	*6/60* *6/75* *6/95* *6/120*	**5/50** 5/63 5/80 5/100	**4/40** 4/50 4/63 4/80	**1/10** 1/12.5 1/16 1/20	**10** 12.5 16 20	**+1.0** 1.1 1.2 1.3	**50** 45 40 35
	Profound Vision Loss	0.04 0.03 0.025 0.02	20/500 20/630 20/800 0/1000	6.3/160 6.3/200 6.3/250 6.3/320	*6/150* *6/190* *6/240* *6/300*	5/125 5/160 5/200 5/250	4/100 4/125 4/160 4/200	1/25 1/32 1/40 1/50	25 32 40 50	1.4 1.5 1.6 1.7	30 25 20 15
(Near-) Blind-ness	Near-Blindness	0.016 0.0125 **0.01** ---	20/1250 20/1600 **20/2000** ---	6.3/400 6.3/500 **6.3/630** ---	*6/380* *6/480* *6/600* ---	5/320 5/400 **5/500** ---	4/250 4/320 **4/400** ---	1/63 1/80 **1/100** ---	63 80 **100**	1.8 1.9 **+2.0**	10 5 **0** ---
	Blindness	No Light Perception (NLP)									

Source: http://precision-vision.com/Introduction-to-Visual-Acuity-Measurement/a-visualacuity.html#.VRaHWfmUd8E

Although some diseases of the eye and adnexa can cause VI, those that do not are not covered in this report. They include the following (ICD-10 codes in brackets):

- Disorders of eyelid, lacrimal system and orbit (H00-006); and
- Disorders of conjunctiva (H10-H13).

For clarification, the term "sight problems" is used in this report to refer to those conditions which cause sight problems, where it is necessary to distinguish between the condition and the resultant VI. For example, hospital costs are by condition, not severity of VI.[9]

[9] For clarification disorders of eyelid, lacrimal system and orbit (H00-006) and disorders of conjunctiva (H10-H13) would be included in health system expenditure, although it is not possible to remove the expenditure allocated to these groups of eye conditions.

1.1.1 Presenting visual acuity versus corrected visual acuity

The AHS reports on uncorrected visual acuity from RE, meaning people with VI without glasses. However, it does not report on best corrected visual acuity, which means visual acuity with whatever glasses the respondent usually wears, if any.

'Corrected visual acuity' is visual acuity measured according to the most appropriate refractive correction. 'Presenting visual acuity', however, is a measurement of an individual's acuity with the refractive correction which is currently in use by the individual, for example, spectacles or contact lenses.

An individual may qualify as 'not blind' because their vision improves with refractive correction. However, in their daily living, their vision may be poor enough, due to uncorrected or under-corrected RE, that they qualify as 'blind' when measured according to their presenting visual acuity.

Although easily managed, uncorrected RE remains a major cause of vision impairment. In 2006, WHO recognised uncorrected RE as an important cause of vision loss. Broadening its definition of VI to include uncorrected RE effectively doubles the estimated total number of visually impaired people worldwide (AIHW, 2009). It is estimated that 12.8 million children aged 5-15 years are visually impaired from uncorrected RE, representing 8.3% of all VI caused by uncorrected RE (Resnikoff et al, 2008).

Access Economics (2004) determined that nearly two-thirds (63%) of Australians who were visually impaired were so because of under-corrected RE. Based on Australian population eye health studies, Access Economics found that while 22.2% of Australian adults had RE that could be corrected by visual aids, 3.3% of the population still had VI from under-corrected RE. That is, over one in seven people with RE (15%) either did not have glasses, or did but needed better ones.

It is plausible that the ratio may be higher still in Australian children, as screening programs are incomplete and it can be some years into childhood before their need for glasses is diagnosed. The literature supports this argument.

- Robaei, Kifley et al (2006) reporting on the Sydney Myopia Study (SMS) of over 2,000 Australian 12 year old children found that the prevalence of VI from RE was 10.4%. The prevalence of under-corrected VI from RE was 3.7%. That is, over a third (36%) of RE in 12 year old children is under-corrected.
- Blows et al (2014) report that, of preschool children referred for diagnosis after being screened in the 2011 NSW StEPS program, 44% of 'high priority referrals' and 32% of 'routine referrals' were then prescribed glasses.
- Robaei et al (2005) bear out the thesis that the younger children are, the less likely their RE is to be corrected. The SMS found that the prevalence of uncorrected VI from RE in Australian six year old children was 4.1%, while the prevalence of presenting VI from RE was 2.8%. That is, over two thirds (68%) of pre-school children with VI from RE had not yet had it corrected by glasses.
- Qiu et al (2014) in a study of over 12,000 participants in the US National Health and Nutrition Examination Survey reported that the prevalence of correctable RE in 12 to 19 year olds was 38.4%, and the prevalence of under-corrected RE was 9.1%. That is,

around a quarter (23.7%) of RE in young people is under-corrected. In this study, VI results were clinically assessed, rather than being self-reported.

- Pai et al (2011) reported that only 3 of the 76 children with VI in the worse eye were prescribed spectacles for refractive correction before the Sydney Paediatric Eye Disease Study (SPEDS) examinations. The authors commented that "This low rate of refractive correction in our VI cases reflects the need to improve public awareness of the underlying diagnosis and screening services for common eye conditions in children".

As the SMS is the only study in the literature search that reported specifically on Australian children – the other studies reported on Australian adults, or American children – its results for the proportion of RE that is under-corrected in 12 year olds (36%) are used in this study. Additionally, this estimate approximately represents the mid-range of the literature estimates above for the prevalence of under-corrected RE in children.

1.2 Background information on select eye diseases affecting children

This section provides an introduction to the visual system, rare diseases, childhood blindness and its main causes, and a discussion on the duration of childhood conditions. The rest of the Chapter provides information on select eye diseases that present more commonly in children, and that are discussed later in the chapters on prevalence or costs associated with childhood eye disease. Where possible, information about the condition includes possible signs and symptoms, prognosis for vision and treatment or management options.

1.2.1 Introduction

The substrate for the visual system is laid down before birth, the ongoing maturation and development of the visual system following birth depends on interactions with the environment. The developing visual system is highly vulnerable, and any abnormalities need to be treated in a timely manner or permanent VI may occur. This is a substantial challenge in managing children's eye diseases. Management of the eye disease needs to occur in parallel with managing the developing visual system. The visual system reaches adult configuration around the age of eight years. There are several critical periods (3-9 months and 2-4 years) during this eight years when even minor interruptions can have severe effects on long-term vision. According to the Royal Australian and New Zealand College of Ophthalmology, if clear images are not received in the first eight years from each eye then normal visual development never occurs resulting in permanent untreatable VI.[10]

Many of the ocular conditions that may cause VI have a low prevalence. This makes clinical studies difficult. These disorders with low prevalence fall within the category of rare disorders which are increasingly a group attracting recognition for further investigation and research. Rare diseases are defined as those which affect 5 in 10,000 people or fewer (Commission of the European Communities, 2008).

[10] http://www.eyefoundation.org.au/eyehealth/childrens-vision/262-childrens-eye-health-tips

Most VI is caused by RE and is easily 'treated' by use of appropriate spectacles. Most other VI can be treated by surgery or medication. However, a small proportion of VI is from currently untreatable conditions. These untreatable conditions are largely rare diseases such as congenital cataract, childhood glaucoma and retinal dystrophies.

Since, by definition, rare diseases have a low prevalence, the impact of each disease on its own is small. However, collectively there are about 8,000 rare diseases, which affect approximately 6–10% of the population or 1.2 million Australians (Zurynski et al, 2008).

Many rare diseases begin in childhood and are present throughout life, which means they have a substantial impact on the quality of life of both patients and carers (Zurynski et al, 2008). Since many rare diseases begin in childhood, they are disproportionately represented in the paediatric population. Additionally, as many of these conditions are incurable at present these disorders collectively represent a substantial proportion of the lifetime burden of disease from VI.

Another important aspect of childhood eye conditions is blindness in children. Many of the causes of childhood blindness are avoidable, being either preventable or treatable (Gilbert and Foster, 2001). Only 3% of the world's blind population are children. However, because children have a lifetime of blindness ahead of them, the number of 'blind person years' resulting from blindness starting in childhood is second only to cataract (Gogate and Gilbert, 2007).

Childhood blindness affects approximately 0.03% of all children in high-income developed countries (Gilbert and Foster, 2001). Gilbert and Foster (2001) identify the main causes of childhood blindness as:

- hereditary, due to genetic diseases or chromosomal abnormalities;
- intrauterine, due to rubella or thalidomide;
- perinatal, such as retinopathy of prematurity (ROP), birth injury or neonatal conjunctivitis;
- childhood conditions such as vitamin A deficiency disorders, measles or trauma; and
- unknown / cannot be determined.

In Australia in 2015, the Australian Childhood Vision Impairment Register (ACVIR)[11] , a voluntary registry for children with a diagnosed vision impairment, had 319 registered children with visual acuity of <6/60 – the legal definition of blindness in Australia.

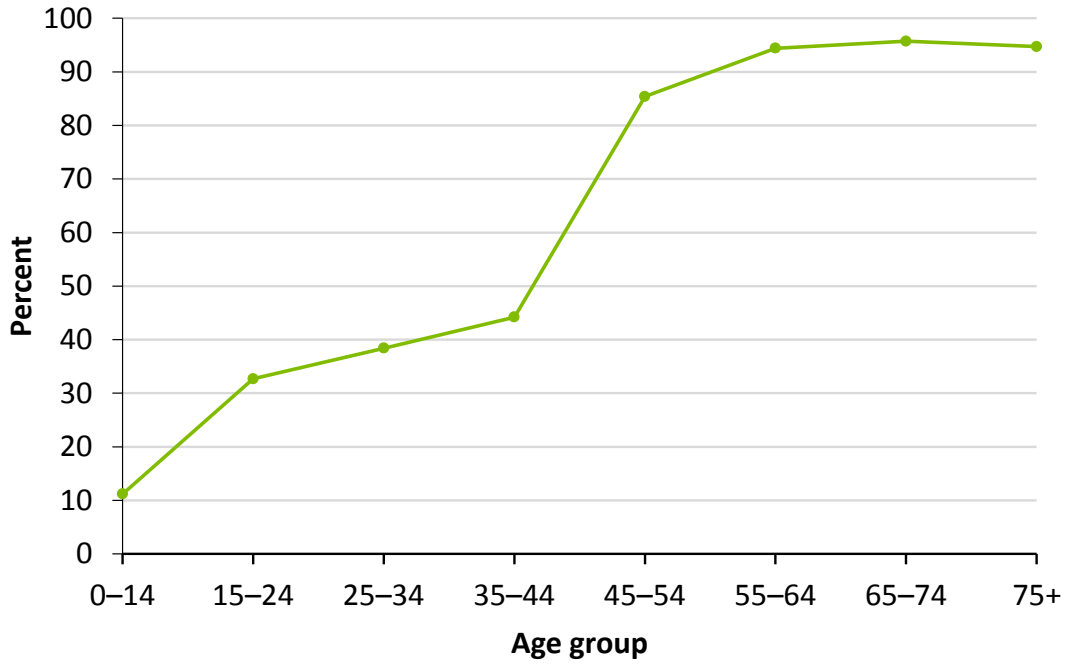
Specifically, the main conditions causing low vision and childhood blindness in children registered with ACVIR are cortical vision impairment (CVI), oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma, and congenital cataract.

For those who contract a condition under the age of 14, they will probably have it for the rest of their lives. Kalloniatis and Johnston (1990) state that while children only constitute a small proportion of the visually impaired population, unlike the elderly, "**children with visual impairment will have to endure a lifelong reduction of normal visual functions**".

[11] http://www.ridbc.org.au/renwick/australian-childhood-vision-impairment-register-acvir

While many congenital eye conditions are identified and managed shortly after birth (where they have been identified), the consequences of genetic eye disorders are often lifelong. For example, congenital cataracts are usually operated on in the first few months of birth, but Chak et al (2006) reporting on the British Congenital Cataract Study found that the average postoperative visual acuity at six year follow up was still only 6/18. Further, in a quarter (24.7%) of cases, there were serious complications post-surgery, including glaucoma (15%), vitreous haemorrhage requiring vitrectomy (8.3%) and retinal detachment (1.7%). As demonstrated in Chart 1.1, there is no decline in prevalence of eye conditions by age after childhood.[12]

Chart 1.1: Prevalence of eye conditions in Australia by age



Source: ABS (2012).

The following sections of this chapter describe the most common paediatric eye conditions, in ICD-10 order. This is the preferred ordering for this report as official sources use it both for disease and expenditure classification. It also has the advantage of being numerical unlike classification by anatomical site, for example.[13]

1.2.2 Disorders of the sclera, cornea, iris and ciliary body (H15-H22)

Corneal opacities are eye problems that can lead to scarring or clouding of the cornea, which decreases vision. Corneal opacities can cause anything from minor irritation to vision

[12] In the AHS, the ABS asks respondents how long they have had their conditions for. This would be helpful for longitudinal tracking of how many adults have had their eye conditions since childhood. Unfortunately, however, the ABS does not release the collated information.

[13] In some cases, conditions in charts are ordered according to frequency of prevalence.

problems and even blindness. Corneal dystrophies are inherited rare conditions that cause changes to the cornea. There are more than 20 corneal dystrophies.

Keratitis occurs when the cornea becomes inflamed. This condition involves a degree of impaired eyesight, accompanied by pain, irritation and itchiness upon blinking. Superficial keratitis does not leave a scar as it only involves damage to the epithelium which can heal. Deep keratitis can leave a scar that will impair vision as it involves deeper layers of the cornea, down to the stroma. Several conditions can cause an infection of the cornea, including conjunctivitis, contact lens-related infection, shingles and ocular herpes.

Diagnosis involves slip-lamp examinations to identify corneal opacification and serologic testing to determine aetiology (Roat, 2014a). Keratitis is usually treated by addressing the underlying condition, although topical corticosteroids can be used.

Uveitis (H20)

Uveitis is a general term describing the inflammation of the uveal tract and may occasionally affect the retina and fluid within the anterior chamber and vitreous (Cunningham Jr., 2014) Uveitis may be caused by isolated ocular conditions, or it can be part of an inflammatory disease affecting other parts of the body.

Symptoms and signs of uveitis vary depending on the site and severity of inflammation. Anterior uveitis tends to be the most symptomatic with symptoms including pain, redness, photophobia and decreased vision. Complications of uveitis can lead to profound and irreversible vision loss if uveitis is unrecognised or inadequately treated. The most frequent complications include cataract, glaucoma and retinal problems.

If treated early, vision loss may be prevented. A retrospective review of cases of paediatric uveitis presenting to Sydney clinics observed 40 cases over a 12 year period (Azar and Martin, 2004). Approximately 60% of the treated cases had visual acuity better than 6/12 at final follow up, leaving just 16 cases with VI. Overseas, Mitry et al (2013) observed 3 cases of uveitis causing VI across England and Wales, which also indicates vision loss being preventable in many cases.

Uveitis is commonly diagnosed with a slit-lamp examination or ophthalmoscopy after pupil dilation. In children, Juvenile Idiopathic Arthritis (JIA) is the most common systemic association. Paediatric uveitis presents particular challenges in diagnosis as it is often asymptomatic till late in the disease, unlike adult presentations.

Uveitis is commonly treated with topical corticosteroids and mydriatics and systemic steroids or steroid sparing agents.

Juvenile Idiopathic Arthritis

JIA is a group of rheumatic diseases that begin at or before age 16. Arthritis, fever, rash, adenopathy, splenomegaly, and iridocyclitis are typical of some forms (Sherry & Pessler, 2013). Symptom manifestations involve the joins and sometimes the eyes and/or skin. The cause of JIA is unknown. Uveitis associated with JIA is the most common cause of uveitis in children (Schieppati et al, 2008). JIA is ranked in the top 20 most common rare disorders

with a prevalence estimated at 25 per 100,000. Up to 40% of children with JIA will develop uveitis.

Regular ophthalmic screening is required in these children as the presentation of uveitis in children differs from adults (Cassidy et al, 2006). In children the uveitis is asymptomatic until late in the disease process when complications of uveitis impair vision (Ravelli and Martini, 2007).

JIA can be treated with drugs that slow disease progression as well as intra-articular corticosteroid injections and non-steroidal anti-inflammatory drugs (NSAIDs).

1.2.3 Cataract (H25, H26)

A cataract is an opacity in the lens that can affect vision. **Paediatric cataract** is a leading cause of childhood blindness in developing countries and contributes to the substantial workload in children's eye clinics. Paediatric cataracts may be hereditary in nature, or have a metabolic or infectious aetiology. Cataracts in children are recognised commonly as an altered appearance of the eye such as a white dot or pupil in the eye.

Symptoms can include cloudy or blurry vision, decreased vision, double vision and faded colours (Boston Children's Hospital, 2015)[14]. Prognosis is hard to predict as some cataracts progress and some do not.

Cataracts may be diagnosed by performing a visual acuity test and/or an ultrasound to check for abnormalities.

Conventional treatment involves removing the lens that has the cataract and replacing it with an artificial lens. This mandates lifelong monitoring for secondary (aphakic) glaucoma (Swamy et al, 2007). In some cases, the placement of the artificial lens may be postponed in order to better predict the lens power the child will require. None of the population eye health studies used in this study reported any specific cases of juvenile cataract.

1.2.4 Retinal disorders (H35, 36)

Retinopathy of prematurity (ROP)

ROP is a potentially blinding eye disorder that primarily affects low birth weight preterm infants. The retinal vascularisation of immature retinas in preterm neonates infants are susceptible to external insults that disrupt normal vascular development, leading to ROP (Hellström et al, 2013). The primary risk factors for developing ROP include birth weight, how early a baby is born and other factors such as anaemia, blood transfusions and respiratory distress (National Eye Institute, 2014)[15].

[14] http://www.childrenshospital.org/conditions-and-treatments/conditions/c/cataracts/treatments

[15] https://www.nei.nih.gov/health/rop/rop

Approximately 10% of births worldwide occur preterm, which is before gestational age of 37 full weeks (Hellström et al, 2013). Of preterm infants with gestational age less than 29 weeks, approximately 10% had severe ROP (Darlow et al, 2005). Depending on the stage of the disorder, ROP can result in severe vision impairment and even blindness if allowed to progress.

Treatment of ROP varies according to the severity of the condition. Laser therapy, intravitreal injection and rarely cryotherapy can be used to destroy the peripheral areas of the retina and slow or reverse the abnormal growth of blood vessels. However, all treatments may have adverse side effects, such as the destruction of some peripheral vision, and are performed only on infants with advanced ROP.

However, the rate of vision threatening ROP has lessened over recent decades due to improvements in neonatal intensive care management of premature infants (Hellström et al, 2013).

Hereditary retinal dystrophies (H35.5)

Hereditary retinal dystrophies are genetic disorders that affect retinal function. They may be stationary (non-progressive) or degenerative. The retinal dystrophies are further divided into Macular dystrophies or retinal dystrophies depending on whether the central vision alone is affected or the whole retina is affected. Hereditary retinal dystrophies may present at birth or within the first year of life or have a gradual onset in the first two decades.

Retinal dystrophy is the term for generalised retinal involvement. This includes retinitis pigmentosa, Cone dystrophy, Cone-Rod dystrophy and Lebers Congenital Amaurosis. The prevalence of hereditary retinal dystrophies is estimated to be around 0.03% (Bocquet et al, 2013).

Retinitis pigmentosa is the most common retinal dystrophy in Australia. It is associated with various inheritance patterns with more than 50 different genetic defects identified (Lions Eye Institute, 2013)[16]. Retinitis pigmentosa manifests most commonly in young adulthood, presenting in the second to third decade as the peripheral vision impairment affects daily activities progressing to legal blindness. Symptoms include loss of side vision, loss of central vision, reduced ability to see at night and increased light sensitivity.

However, expected prognosis is slow development of the condition, with complete blindness being uncommon, but possible.

Diagnosis involves a number of tests to check the functional health of the retina, including:

- Vision test – visual acuity and visual field;
- Electrophysiology test – electro-retinography;
- Retinal photography; and
- Blood test.

[16] https://www.lei.org.au/services/eye-conditions/retinal-dystrophy/

There is no known treatment to cure or slow the progress of retinitis pigmentosa.

Juvenile macular degeneration (JMD) is the term for several inherited eye diseases – including Stargardt's disease, Best disease, and juvenile retinoschisis – that affect children and young adults. Stargardt disease is the most common, affecting approximately 1 in 10,000 children (Riveiro-Alvarez et al, 2009). It accounts for approximately 67% of all retinal disease dystrophies (Blacharski, 1998, Rahi and Cable, 2003).

JMD involves the loss of central vision as a result of choroidal neovascularisation in the macula, the area of the retina at the back of the eye. Symptoms include the gradual loss of all or part of one's central vision, poor night vision, distortion of sight and difficulty identifying colours. JMD usually presents in school age children but is often not diagnosed until later in life (Macular Society, 2013)[17].

While loss of central vision can occur, JMD is painless and does not lead to complete loss of sight as peripheral vision is unaffected by the disorder.

The diagnosis for JMD requires the performance of further tests by an ophthalmologist, which may include:

- Fluorescein angiography;
- Electrodiagnostics;
- Optical coherence tomography; and
- Genetic tests.

There are no treatments for most dystrophies. However, injections may be used to slow the development of choroidal neovascularisation in the eye.

Diabetic retinopathy (H36.0)

Diabetes Mellitus is an increasing health problem in children and adolescents. Two key parameters affecting prognosis are duration of diabetes and degree of glycaemic control. Hyperglycaemia leads to microvascular damage which can lead to diabetic retinopathy (DR). DR is classified into non-proliferative and proliferative diabetic DR which is a continuum of disease severity. There are three stages in this continuum early (mild non-proliferative DR), middle (moderate, severe, very severe non-proliferative DR - typical in paediatric patients with DR) to advanced (proliferative DR - involving aberrant blood vessel growth on the retina).

The earliest signs of background DR rarely occur before the fifth year of disease with the prevalence reaching 50% by year 10. Early diagnosis and treatment can prevent up to 98% of severe vision loss.[18] The first signs of non-proliferative retinopathy are capillary micro aneurysms, dot and blot retinal haemorrhages, hard exudates and cotton-wool spots (Garg,

[17] http://www.macularsociety.org/Resources/Macular%20Disease/Documents/PDF/How%20We%20Help/accss%20Guide%20to%20JMD.pdf

[18] http://www.cera.org.au/community/your-eye-health/diabetic-retinopathy/

2014). Signs in later stages are macular oedema, which is the principal cause of vision loss in non-proliferative DR (Lang, 2007), and venous dilation and intra-retinal microvascular abnormalities. Symptoms of proliferative retinopathy may include blurred vision, black spots, flashing lights and sudden, severe, painless vision loss. **Diabetic macular oedema**, the principal cause of vision loss in non-proliferative DR, can develop at any stage and is defined as clinically significant based on the presence of retinal thickening or the development of hard exudates within 500 µm of the macular centre, or of retinal thickening 1 disc area or larger within 1 disc diameter of the centre.

Diagnosis for DR is by fundoscopy and may include the performance of tests such as colour fundus photography, fluorescein angiography and optical coherence tomography to assess the extent of the retinopathy (Garg, 2014).
Sultan et al (2012) concludes that although clinical DR remains rare among paediatric patients with diabetes, regular monitoring for the appearance of complications is essential given the progressive nature of the disease and the chronic nature of the underlying hyper-glycaemia.

"As early detection is important, all children with diabetes should have an annual dilated ophthalmologic examination. To identify the ocular complications of diabetes early, the International Society for Paediatric and Adolescent Diabetes suggests annual screening for DR in patients aged:

- *11 years (after diabetes of two years duration);*
- *from 9 years (with diabetes of five years duration);*
- *from 10 years or at onset of puberty (after 2-5 years diabetes duration) (Donaghue et al, 2014).*

Treatment for DR primarily involves controlling blood glucose and blood pressure levels to slow the progress of retinopathy[19]. For complicated proliferative retinopathy, patients may be treated with panretinal laser photocoagulation to reduce the risk of severe vision loss and sometimes, vitrectomy to preserve or even restore lost vision in patients. Treatment of macular oedema can include intraocular injection of anti-vascular endothelial growth factor drugs, intraocular corticosteroid implants, focal laser and/or vitrectomy (Garg, 2014).

1.2.5 Glaucoma (H40-42)

Glaucoma is a group of diseases that can damage the optic nerve, resulting in the loss of peripheral vision and possible, eventual blindness (Medline Plus, 2014). In children, glaucoma is a uniquely disabling disease. Glaucoma in children is characterized by the presence of elevated intraocular pressure (IOP) and characteristic optic disc cupping. Glaucoma in infancy is associated with ocular enlargement, or buphthalmos, which results from the biomechanical effects of elevated IOP intraocular pressure in an eye with immature connective tissues (Beck et al, 2014).

[19] https://www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/understanding-eye-conditions-related-diabetes

Childhood glaucoma is classified as primary or secondary. Primary childhood glaucoma is divided into: Primary congenital glaucoma and Juvenile open-angle glaucoma (JOAG). Secondary childhood glaucoma is further classified according to whether the condition is acquired after birth or is present at birth (non-acquired) into the following groups (Beck et al, 2014):

- Glaucoma associated with non-acquired ocular anomalies;
- Glaucoma associated with non-acquired systemic disease or syndrome;
- Glaucoma associated with acquired condition; and
- Glaucoma following cataract surgery.

Non-acquired childhood glaucoma is categorized according to whether the signs are mainly ocular or systemic.

Symptoms of childhood glaucoma may include unusually large eyes, excessive tearing, cloudy eyes and light sensitivity (Lolli et al, 2014).

Without treatment, people with glaucoma will slowly lose their peripheral vision. Over time, straight-ahead vision may decrease until no vision remains. Early diagnosis and appropriate treatment can minimize a lifetime of vision impairment (Lolli et al, 2014).

Diagnosis of childhood glaucoma involves examination of the eye with conventional methods before performing tests such as fundoscopy, tonometry and ultrasonography to determine the condition of the optic nerve and back of eye. A gonioscopy and tonometry may also be conducted under anaesthesia (Lolli et al, 2014).

Treatment for childhood glaucoma is focused on arresting development of vision loss and may include the use of topical eye drops or oral medications and surgical treatments to lower eye pressure by increasing eye fluid drainage (Lolli et al, 2014).

Primary Congenital glaucoma (Q15.0)

Primary congenital glaucoma is the most common non-syndromic glaucoma in infancy. Its worldwide incidence is variable and influenced by consanguinity. Primary congenital glaucoma usually presents in neonates and infants characteristically with symptoms of photophobia and tearing, and physical signs of corneal oedema, ocular enlargement and optic disc cupping. It occurs in eyes with a developmental abnormality of the angle, resulting in decreased aqueous outflow. (Papadopoulos et al, 2014).

If untreated, corneal clouding can progress, resulting in damage to the optic nerve and blindness (Fecarotta & Huang, 2012).

The main treatment for involves early surgical intervention using procedures such as goniotomy, trabeculotomy and trabeculectomy. Approximately 80% of children with primary congenital open angle glaucoma can be cured by trabeculotomy/goniotomy procedures, which are the only form of surgery unique to childhood glaucoma[20].

[20] http://www.glaucoma.org/uploads/grf_childhood_glaucoma.pdf

1.2.6 Disorders of optic nerve and visual pathways (H46-H48)

Light is sensed by the photoreceptor cells in the retina, which transmit impulses to the optic nerve. Visual information is then relayed via the visual pathway for interpretation by the brain. Disruption to the visual pathway results in vision impairment.

Hereditary optic neuropathies are optic nerve disorders, which arise from genetic defects that interfere with normal optic nerve function.

Hereditary optic neuropathies include dominant optic atrophy and Leber hereditary optic neuropathy, which are both mitochondrial cytopathies. Dominant optic atrophy is inherited in an autosomal dominant fashion and is thought to be premature degeneration of the optic nerve leading to progressive vision loss. It is the most common hereditary optic neuropathy with prevalence in the range of 1 in 10,000 to 1 in 50,000 (Garrity, 2014). Children are identified usually in the first two decades. The severity varies between and within families from normal vison to legal blindness. Presentation vision only deteriorates slowly over a lifetime (Chang et al, 2012). Leber hereditary optic neuropathy is due to abnormal mitochondrial deoxyribonucleic acid and has a maternal inheritance pattern. Presentation is between 15 and 35 years of age with sudden profound loss of vision (Garrity, 2014).

Diagnosis of dominant optic atrophy and Leber hereditary optic atrophy is mainly clinical. Damage is irreversible and in some cases, can progress over time.

Currently, there is no effective treatment for hereditary optic neuropathies. Aids such as glasses, magnifiers and large print devices may be of use.

Cortical vision impairment (CVI)

CVI results from damage to areas within the brain that either process or utilise vision. Often the child's eyes may not have any abnormalities, but the brain injury prevents interpretation of visual information. This means the eyes are able to see but the brain cannot interpret what is being seen. CVI is one of the major causes of uncorrectable low vision in the developed world, generally accounting for more than 20% of vision impairment in children presenting to low vision clinics or registers (Bosch et al 2014). (Boonstra et al, 2012; Hatton et al, 2007; Rahi and Cable, 2003). The most common symptoms of CVI include abnormal light response, poor visual acuity and visual field loss.

Common causes of CVI in infants and young children include (Vision Australia, 2012):

- Lack or insufficiency of oxygen (anoxia, hypoxia, ischemia, and asphyxia);
- Developmental brain anomalies;
- Head injury;
- Hydrocephalus; and
- Infections of the central nervous system such as encephalitis and meningitis.

Diagnosis of CVI is indicated for children displaying abnormal visual responses that cannot be attributed to the eyes themselves. A significant finding of the ACVIR is that 47% of children had nystagmus recorded as a secondary diagnosis. Prognosis shows that

improvement in vision can occur with time. Temporary CVI, resulting from meningitis or minor head injuries, may begin to recover a few days or months after the illness. Permanent CVI may recover gradually over months to years after the onset with partial return of vision documented in many cases (Vision Australia, 2012).

Neurofibromatosis Type 1 (NF1)

NF1 is an inherited disorder in which nerve tissue tumours form in the bottom layer of skin, nerves from the brain and spinal cord and skin (Medline Plus, 2012). NF1 causes tissue along the nerves to grow uncontrollably, resulting in pain, severe nerve damage and loss of function in the area served by the nerve. The condition varies from person to person.

It is the most common single gene disorder affecting the nervous system, occurring in approximately 1 in 3000 people (Grigg and Jamieson, 2013; Schieppati et al, 2008). Signs and symptoms of the condition may include "Café au lait" spots on the body as well as blindness, convulsions and tumours (Medline Plus, 2012).

Screening programs for all children with NF1involve at least yearly ophthalmic reviews to detect and monitor these vison threatening tumours. If there are no complications, people with NF1 can expect an almost normal life expectancy (Medline Plus, 2012).

There is no specific treatment for NF1 (Szudek et al, 2000).

1.2.7 Strabismus (H49, H50)

Strabismus, otherwise known as squint or heterotropia involves a misalignment of the eyes. This can result from a condition that affects the eye muscles (extraocular muscles) or the centres of the brain that control eye movement. Children can be born with strabismus or develop it later in life as a result of uncorrected RE, trauma, and other diseases such as raised intracranial pressure or tumours.

As soon as the strabismus develops, meaning the eyes are misaligned, the individual will experience double vision (diplopia). In children, the brain will compensate by suppressing or blocking out the misaligned or strabismic eye. This results in a cessation of visual development in that eye, known as amblyopia. As the eyes are misaligned the child's depth perception (binocular vision) will also be affected.

As with amblyopia, early detection and treatment improves long-term visual outcomes. Additionally, strabismus is a long-term problem that requires commitment from both the child and their family or carer to achieve the best possible outcomes (American Academy of Ophthalmology Pediatric Ophthalmology/Strabismus Panel, 2012a).

The treatment for strabismus includes correcting any RE that is present, facilitating visual development by encouraging the child to wear their glasses (if needed) and occlusion or patching of the better seeing eye. If the strabismus causes cosmetic concern, then surgery may be performed on the extraocular muscles.

1.2.8 Refractive error (H52)

RE occurs when the image of the object a person is looking at is not correctly focussed onto the retina (the light-sensitive tissue in the back of the eye). As noted in Section 1.1.1, RE is a major cause of VI across the world. In 2004, there were estimated to be 12.8 million children worldwide, or 0.96%, with VI caused by RE (Resnikoff et al, 2008).

There are three main types of REs affecting children (and also adults). These are myopia, hyperopia or hypermetropia and astigmatism. They are diagnosed by performing a refraction test, and managed through wearing glasses or contact lenses (hard or soft).

Myopia (H52.1), or short-sightedness, is where the light focuses in front of the retina so distant images are blurred. Myopia is caused either by an excessively steep curvature of the cornea or an excessive axial length of the eye, or both. There is some genetic influence and increasing evidence for environmental influence, such as exposure to natural light (Rose et al, 2008; French et al, 2013). Spectacles or contact lenses enable clear vision by correcting incoming light rays, so they are properly focused on the retina.

Hyperopia (H52.0), or long-sightedness is where the light focuses behind the retina so close images are blurred. The average person is a little hyperopic, however significant hyperopia cannot be overcome and will result in blurred vision. In children, this blur can lead to amblyopia or a delay in visual development. Hyperopia is thought to be genetic. Spectacles or contact lenses enable clear vision by correcting incoming light rays, so they are properly focussed on the retina. Hypermetropia is a significant risk factor for strabismus (Esotropia)

Astigmatism (H52.2) is a focusing error that causes asymmetric blur at all distances, mostly caused by an excessive oval shape of the cornea. The oval (non-spherical) shape results in light focusing at two different locations, rather than to a point resulting in blurred vision. Most people have some mild astigmatism. Astigmatism similar to other REs can be correctable through wearing spectacles and contact lenses.

RE commonly coexists with other paediatric eye disorders. Therefore, it is critical to manage and treat RE as an initial strategy for all other eye conditions (for example, see Section 1.2.9.

1.2.9 Amblyopia (H53.0)

Amblyopia, commonly referred to as lazy eye, is an acquired defect in vision due to an abnormal visual experience during a sensitive period of visual development. It is defined as a decrease in visual acuity caused by pattern deprivation or abnormal binocular interaction for which no causes can be detected by physical examination of the eye and is reversible by appropriate treatment measures (von Noorden and Campos, 2002).

Amblyopia has three main causes:

- Strabismic: caused by misaligned eyes;
- Refractive: caused by uncorrected RE (Hypermetropia, myopia or astigmatism); and
- Deprivational: caused by interference in visual development.

Early detection and treatment are essential for the best chance of correcting amblyopia, although treatment can still be effective in older children (American Academy of Ophthalmology Pediatric Ophthalmology/Strabismus Panel, 2012). In the absence of treatment, the degree of vision loss from amblyopia can range from mild to severe. Treatment involves correcting the RE by wearing glasses or contact lenses, and the use of occlusion therapy (patching or atropine eye drops).

1.2.10 Colour blindness (H53.5)

Colour blindness is a condition which causes decreased ability or complete inability to see colour or identify colour differences within the range of normal lighting conditions. While it does not cause VI per se, it does cause sight problems, and can cause impacts on a child's life. Primarily, colour blindness prevents a driver's license being issued in some countries, and it can prevent participation in certain occupations.

1.2.11 Other disorders of the eye and adnexa (H55-H59)

Nystagmus is the main disorder in this category. Nystagmus, known also as 'dancing eyes', consists of rhythmic ocular oscillations of the eyes and is caused by abnormal function in the areas of the brain that control eye movements (Medline Plus, 2013).

There are two forms of nystagmus – infantile nystagmus syndrome which is present at birth (congenital) and acquired nystagmus, which develops later in life because of a disease or injury. Patients have reduced vision as their eyes are constantly moving. Patients with acquired nystagmus have oscillopsia, the illusion that the environment is moving while those with infantile nystagmus have a stable visual environment (Proudlock and Gottlob, 2013).

Infantile nystagmus syndrome is usually mild and does not become severe. As nystagmus may be caused by congenital diseases of the eye, an ophthalmologist should evaluate any child with nystagmus to check for eye disease.

Treatment options for infantile nystagmus syndrome may include (Medline Plus, 2013):

- Prisms;
- Surgeries such as tenotomy; and
- Drug therapies.

1.2.12 Congenital malformations of the eye (Q10-13)

Throughout embryonic development, the human eye forms through a complex precisely timed process. Problems in this developmental process may lead to congenital eye malformations, as listed below (Boyadijiev Boyd, 2014)[21].

[21] http://www.merckmanuals.com/professional/pediatrics/congenital-craniofacial-and-musculoskeletal-abnormalities/congenital-craniofacial-abnormalities

- **Anophthalmia:** No eye - a complete absence of ocular tissue that is either unilateral or bilateral. Anophthalmia occurs in more than 50 genetic syndromes caused by chromosomal anomalies or mutations in one of several genes (Boyadijiev Boyd, 2014). The eyelids and extraocular muscles are usually present as these structures form independently of the eye. This malformation is often accompanied with other craniocerebral anomalies (Källén and Tornqvist, 2005). It is possible to diagnose anophthalmia prenatally with ultrasounds and amniocentesis and postnatally with a magnetic resonance imaging or computed axial tomography scan and examination (Ragge, 2011)[22]. There is currently no treatment option for regaining vision by developing a new eye but prosthetics and cosmetic surgery can be used.
- **Microphthalmia:** Small eye – the whole eye is small in both axial length and corneal diameter. The eye may be small but structurally normal. It causes sight-threatening complications such as angle-closure glaucoma, strabismus, and amblyopia. Causes include prenatal exposure to teratogens, alcohol and infections and numerous chromosomal or genetic disorders. The condition may affect one or both eyes (Skalicky et al, 2013).
- **Coloboma:** Failure of the optic fissure to close before a child is born resulting in a defect or gap in one of the structures of the eye such as the iris, retina, choroid, or optic disc. Coloboma of the eyelid is frequently associated with epibulbar dermoid cysts and is common in Treacher Collins, Nager, and Goldenhar syndrome. The most common symptom is observing a defect on the iris, or noticing poor vision. Further, patients may experience no vision problems or may be completely blind, depending on the severity of the defect (American Association for Pediatric Ophthalmology and Strabismus, 2013). The condition may affect one or both eyes (Boyadijiev Boyd, 2014).
- **Aniridia:** Absent or partial iris usually involving both eyes. Aniridia can be congenital or caused by a penetrant injury (Lang, 2007). This can cause a reduction in visual acuity and increased sensitivity to light.
- **Optic nerve hypoplasia:** optic nerve hypoplasia is the most common congenital anomaly of the optic disc. It may be an isolated finding or part of a spectrum of anatomical and functional abnormalities, which include partial or complete agenesis of the septum pellucidum, other midline brain defects, or pituitary dysfunction. This condition presents bilaterally 80% of the time (Purvin and Glaser, 2013). Visual acuity can range from no light perception to near-normal vision with variability. There is no treatment for optic nerve hypoplasia.
- **Oculocutaneous albinism**: an inherited defect in melanin formation that causes diffuse hypopigmentation of the skin, hair and eyes (Schalock, 2014). As a result of abnormal development of the retina and abnormal patterns of nerve connections between the eye and the brain, albinism can cause strabismus, nystagmus and decreased vision. Many people with albinism are legally blind, but most can use their vision for near tasks such as reading. There is no treatment for albinism but strict sun protection should be adopted and surgical interventions may lessen strabismus (Schalock, 2014).

Patients with any of the above malformations generally present with an abnormal-looking eye and reduced eye vision, depending on the severity of the condition. Treatment

[22] http://www.cafamily.org.uk/medical-information/conditions/a/anophthalmia/

commonly focuses on maximising vision by using glasses and patching. Surgery and genetic counselling may also be required is complicated by glaucoma, cataract or other anomalies as a result of the malformation.

1.2.13 Injury of eye and orbit (S05)

The AIHW (2008) reported that injuries to the eye and orbit accounted for 12% of child hospitalisations for eye conditions, compared to 2% when looking at all ages. Boys had higher rates than girls for most head injury hospitalisations. Eye injuries are also more common among Indigenous children**,** and are the most common cause of hospitalisation for eye conditions in remote areas. The most common injury, which accounted for over half of such hospitalisations, was for open wounds to the eyelid and area around the eye. The second most common diagnosis was for contusion (bruising) of the eyeball and orbital tissues. A retrospective study of Sydney hospital data showed that approximately 21% of hospitalised eye injury cases resulted in visual acuity <6/15 (Kadappu et al, 2013).

1.3 Summary of background information

The diagnosis, treatment and management of eye diseases in Australia, as in other developed nations, is a complex issue. There are a wide range of childhood eye conditions that have varying treatment methods, and differing prognosis for vision.

Additionally, establishing prevalence of these conditions is difficult as many of these conditions are considered rare – affecting less than 1 in 10,000 people. The prevalence of ocular diseases resulting in VI in Australia is generally agreed to be low. However, these diseases are disproportionately represented in paediatric populations as they often begin in childhood. While the majority of causes of childhood blindness are avoidable, being preventable or treatable, children who contract ocular diseases will often be affected by the condition for the rest of their life.

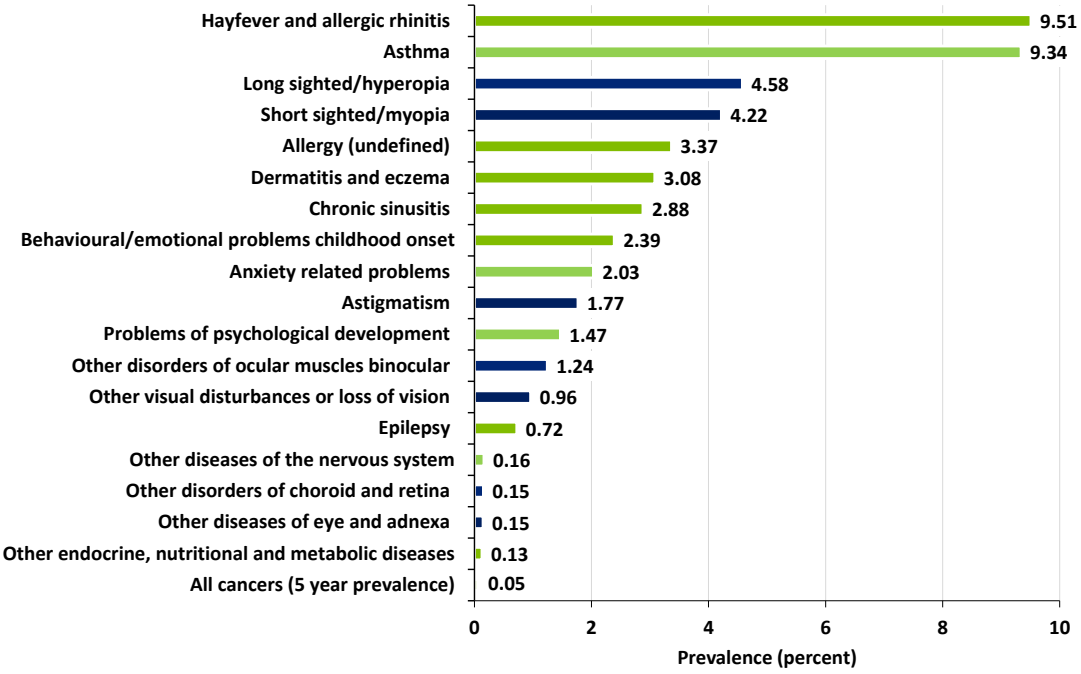
Given the paucity of relevant clinical studies, there is a need for more comprehensive studies to be conducted on rare childhood eye diseases in Australia. The substantial number of 'blind person years' attributed to childhood blindness and the life-long impacts of eye conditions on a child's later productivity and overall welfare make further investigation a matter of particular importance for public health policy and research. Greater attention to the issue would also be conducive to the fulfilment of Australia's international obligations as a member country to the WHO.

The elimination of avoidable blindness is a WHO priority area. In 2013, the World Health Assembly approved its global eye health action plan for 2014-2019 with the aim of achieving a measurable reduction of 25% of avoidable vision impairments by 2019 (WHO, 2014). The WHO has specifically targeted childhood blindness by establishing a global network of 45 childhood blindness centres in 35 countries, in coordination with Lions Clubs International, to combat avoidable childhood blindness.

2 Prevalence of visual impairment (VI) in children

Eye conditions are surprisingly prevalent in Australian children. The ABS (2012) reports that RE accounts for three of the top ten most common long-term health conditions in under 15 year olds – hyperopia (3rd), myopia (4th) and astigmatism (10th).

Chart 2.1: Select common long-term health conditions in Australian children, by order of frequency)



Source: ABS (2012) and AIHW (2014b).

While RE accounts for a large proportion of eye conditions in Australian children, this data also shows that other eye conditions, such as disorders of ocular muscles binocular, and other visual disturbances or loss of vision are more common than many other common childhood conditions such as epilepsy, cerebral palsy and cystic fibrosis.[23] The numerous other eye diseases have a profound impact on children throughout their lives. Some eye diseases are extremely rare and capturing them in epidemiological studies is challenging.

[23] Note: Cerebral palsy is under the category 'Other diseases of the nervous system', and cystic fibrosis is under the category 'Other endocrine, nutritional and metabolic diseases' shown in Chart 2.1.

2.1 Sources

Australia has a relatively large number of data sources from which to draw regarding the prevalence of childhood VI. Although each of these sources has some limitations for the purposes of this report, the data is some of the best available throughout the world.

2.1.1 Australian Bureau of Statistics

The ABS conducts a large nationwide survey of Australians' health every few years, which covers over 20,000 households. The latest survey, the *Australian Health Survey 2011-12* (AHS) is utilised extensively in this report.

In this survey, respondents were asked whether they had problems with their sight, which if they answered in the affirmative, they were then asked to provide which condition(s) caused their sight problems. The primary conditions listed in the survey were:

- Astigmatism;
- Short-sightedness/ myopia/difficulty seeing objects in the distance;
- Macular degeneration;
- Other age related sight problems/ presbyopia;
- Long sightedness/ hyperopia/difficulty seeing objects close up;
- Totally blind in both eyes;
- Totally blind in 1 eye;
- Partially blind in both eyes;
- Partially blind in 1 eye;
- Glaucoma;
- Cataracts;
- Trachoma;
- Lazy eye/ strabismus;
- Retinopathy;
- Colour blind; and
- Other (specify).

Each eye condition reported in the AHS corresponds to a code in the International Statistical Classification of Diseases and Related Health Problems 10th Revision – known more commonly as ICD-10. Table 2.1 provides a comparison of the eye conditions reported in the AHS with the corresponding ICD-10 code.

Table 2.1: Eye conditions included in the AHS

ICD-10 description	AHS category	Primary paediatric eye diseases discussed
Disorders of lens (H25-H28)	Cataract	Paediatric cataract
Disorders of the choroid and retina (H30-H36)	Macular degeneration	Retinal disorders
	Other	
Glaucoma (H40-H42)	Glaucoma	Primary congenital glaucoma
Disorders of the ocular muscles, binocular movement, accommodation & refraction (H49-H52)	Astigmatism	Astigmatism
	Myopia	Myopia
	Hyperopia	Hyperopia
	Other	Strabismus
Visual disturbances and blindness (H53-H54)	Blindness (complete and partial)	Blindness (complete and partial)
	Other	Amblyopia
Other diseases of the eye and adnexa (H55-H59)	Colour blindness	Colour blindness
H00–15, H19–22, H27–32, H43–51*	Other	Nystagmus Keratitis Uveitis Injuries Trachoma

Note: Blindness (H54) is a functional state rather than a diagnosis. * The AHS category 'Other diseases of eye & adnexa is not directly comparable with the ICD 10 category 'Other disorders of eye and adnexa' since the AHS category is designed to capture all other eye diseases not included under the other headings in the table.

Source: ABS (2013)

2.1.2 Australian Institute of Health and Welfare

The AIHW reports on the overall health of Australians every year, the latest example being *Australia's Health 2014* (AIHW, 2014). The Institute also reports frequently on eye health, including specifically on children's eye health, including *Eye health among Australian children* (AIHW, 2008). The AIHW has also reported on the burden of disease for most common conditions including *The Burden of Disease and Injury in Australia, 2003* (Begg et al, 2007). These publications are used to inform various aspects of the analysis in this report.

2.1.3 Australian paediatric eye health studies

This report draws from three population studies of Australian school children, all of which were conducted in Sydney.

- Pai et al (2011) report on the results of a sample of 1,188 children aged 3 to 6 years in the SPEDS.

- Robaei, Huynh et al (2006) report on VI in a sample of 2,353 12 year old children from the Sydney Childhood Eye Study (SCES). This was a cross-sectional population-based study, which examined 2,461 children aged 6 months to 6 years during 2007-09.
- Robaei et al (2005) report on VI in a sample of 1,783 six year old children from the Sydney Myopia Study (SMS), which was conducted between 2003 and 2005. Following on from the SMS, there was a five year follow up study known as the Sydney Adolescent Vascular and Eye Study (SAVES).

2.1.4 Childhood screening programs

In Australia, all states conduct eye screening programs for preschool children. The majority of these rely on the child attending regular health checks, which may have variable participation rates depending on how active a role the parent takes in the child's health. Irregular participation can result in undiagnosed cases, and misrepresentation of the total population prevalence due to sample bias. The NSW StEPS program is an exception, in that it actively identifies and targets all 4 year old children in NSW, and in 2011 had a state wide screening rate of approximately 72%. Published referral outcome data for the StEPS program is based on two NSW Local Health Districts, which are considered representative of metropolitan and rural NSW (Blows et al, 2014).

2.1.5 Other sources

As there are a variety of conditions that are too rare to appear in population eye health studies or state screening programs, a number of registers are used to supplement the information available in those studies.

- The ACVIR is used for the prevalence of various forms of legal and total blindness. [24] Blindness (H54) is strictly a functional state rather than a condition. However, the focus of this report is also a functional state – vision impairment – rather the underlying conditions (since not all conditions that can cause VI necessarily do so). The most common causes of blindness on the register are CVI, oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma and congenital cataract.[25]
- However, the ACVIR reports that over 70 conditions cause VI in children on the register. While these conditions would be classified elsewhere in the table, the number of children with these conditions is not reported. For the purpose of clarity and maintaining separate data sources, this is not broken down further.
- The Australian Congenital Anomalies Monitoring System (AIHW, 2008) is used for data on congenital eye conditions.
- Data from the Kooyong Low Vision Clinic is used for gender splits in individual genetic conditions (Kalloniatis and Johnston, 1990).
- A large number of journal articles are used to cover other relevant aspects of eye conditions.

[24] http://www.ridbc.org.au/renwick/australian-childhood-vision-impairment-register-acvir.

[25] The Register records over 70 conditions that cause blindness.

Details on hospital admissions are nationally comprehensive, and can be the only statistics available for some rare disorders, although they are a poor proxy for prevalence. Each eye disease has different needs for treatment, so the proportion of people requiring hospitalisation varies greatly. For example, one in three children with congenital eye conditions are hospitalised for their condition, but the ratio is less than one in 15,000 for children with RE.[26]

On average, across eye disorders other than RE, there may be around one person in 50 hospitalised in any given year. However, given the variability of this ratio across conditions, this data is not robust enough to reverse engineer population prevalence.

2.2 Choices of primary sources

In an ideal world, the population eye health studies would be the primary source for most conditions as VI is clinically assessed, rather than self-reported. These studies also generally use the same definition of VI as used in this report - <6/12 or equivalent - although some use <6/15 or <6/18, while the definition used in the AHS is not as clear.

However, the sample populations are generally between 1,000 and 2,000 children, which are only large enough to capture the most common conditions. Additionally, these studies only cover discrete, narrow age ranges – for example, six year olds or twelve year olds in the SMS and SCES – and report little information by gender. In contrast, studies of eye health in adult populations such as the Blue Mountains Eye Study, or the Melbourne Visual Impairment Project cover the entire population over 40 years of age in 5 year groups by age and gender.

2.2.1 Australian Health Survey

The sample size of the AHS is around ten times larger than the largest eye health study used in this report.[27] This provides continuous age data from birth to 17 year olds, including by gender. In principle, data are available by single year age-gender cohorts. In practice, the software suppresses small cells for confidentiality reasons, for example, retinal conditions in 9 year old females. Given the large sample size, the AHS is likely to provide more accurate and more complete data for the more obscure diseases affecting childhood VI.

Like the population eye health studies, the AHS reports on VI rather than eye conditions per se. If a respondent identified that they had sight problems, they were then asked what conditions caused that sight problem.

- For example, if a respondent had an eye condition such as stye that did not cause VI, the survey would not report this, except for colour blindness. While colour blindness does not cause VI, it was specifically collected by the survey. Accordingly, the term “sight problems” is used in this report as a collective term covering conditions causing VI and colour blindness.

[26] Ratios of AHS prevalence to AIHW separations.

[27] The sample included 21,000 households, with multiple respondents in most households, however the new ABS data format, TableBuilder, does not report total sample size in persons.

- Cumberland et al (2010) report that only 5% of childhood eye conditions result in VI.
- In this report, it is assumed that economic costs are primarily due to VI, rather than to the presence of a condition which can cause VI. For example, Chapter 4 shows that colour blindness does not impose any discernible productivity impacts.
- That said, health system expenditure (Chapter 3) covers all conditions which can cause VI without distinguishing whether or not the separation is due to VI or the condition.

The main drawback of the AHS is that VI is self-reported, which means it is not necessarily either objective or consistent. However, as an objective measure, 97% of respondents who reported sight problems also wore glasses. This includes 75% of those with sight problems not caused by RE. This fits with the definition of VI in this report, which is visual acuity of <6/12.

Also, it is not unusual in studies of this type to draw the prevalence of VI from one population, and then the economic impacts of VI from a different population. One of the advantages of the AHS is that it is possible to assess the prevalence of sight problems and its economic impacts in the same population.

Accordingly, the primary source used in this report is the AHS. This enables prevalence and its trends to be reported across six year age-gender groups for the population in question. Additional sources are employed for conditions not adequately covered by the AHS as per Table 2.2.

Table 2.2: Disorders and sources used

ICD-10 description	Primary source
Congenital malformations of eye, ear, face and neck (Q10-Q18)	Australian Congenital Anomalies Monitoring System
Disorders of sclera, cornea, iris and ciliary body (H15-H22)	Australian paediatric eye health studies
Disorders of lens (H25-H28)	AHS 2011-12
Disorders of choroid and retina (H30-H36)	AHS 2011-12
Glaucoma (H40-H42)	AHS 2011-12
Disorders of optic nerve and visual pathways (H46-H48)	Australian paediatric eye health studies
Disorders of ocular muscles, binocular movement, accommodation and refraction (H49-H52)	AHS 2011-12
Visual disturbances and blindness (H53-H54)	ACVIR (blindness), AHS 2011-12 (colour blindness), and StEPS (amblyopia)
Other disorders of eye and adnexa (H55-H59)	StEPS

Note: rare disorders appear under each relevant ICD-10 description. The sources for these rare disorders are included as shown in Table 2.8.

By way of triangulation, the results reported by Pai et al (2011) for 3 to 6 year old children, and Robaei et al (2005) for "predominantly" 6 year olds, were reproduced to the extent feasible under TableBuilder.

- An attempt was also made to replicate Robaei, Huynh et al (2006) for 12 year olds. However, most of the less frequent conditions were suppressed by TableBuilder for the single age cohort of twelve years.
- Using an age range of four years (3 to 6) no cells were suppressed. However, a number of the less frequent conditions still had high relative standard errors and so cannot be treated with a high degree of confidence.

While the AHS does not exactly match either of the population studies, there is a small order of difference between them as demonstrated in Chart 2.2. It is to be expected that studies of different populations will produce different, although hopefully similar, outcomes. Accordingly, it is reasonable to conclude that "sight problems" in the AHS represents a similar loss of acuity to VI as defined in Section 1.1.

Adjustments to AHS data were necessary for the prevalence of under-corrected RE. The question asked of AHS participants was "Do you currently wear glasses or contact lenses to correct, *or partially correct*, your eyesight?" (emphasis added). This means the results are of little use for determining the prevalence of under-corrected VI from RE.

- The AHS reports that 75% of those with eye conditions other than RE still wore glasses. At first this appears counter-intuitive, as glasses are designed to correct RE. However, there is substantial comorbidity among eye conditions. Also, the SMS reported – somewhat surprisingly – that over a third of Australian children who wore glasses did not have RE (Robaei, Kifley et al, 2006).

Accordingly, the number of people presenting with RE is adjusted by the proportion of children who have under-corrected VI as discussed in Section 1.1.1.

The AHS category "Other diseases of eye and adnexa" does not correlate exactly with the ICD-10 category of the same name. As both categories explicitly include comparatively common conditions such as nystagmus, there is likely to be high degree of overlap.[28]

However, the AHS category also functions as a catch all for VI from conditions not common enough to warrant their own categories. Accordingly, for ordering purposes, the ICD-10 code H55-59 is assigned to the AHS category "Other diseases of the eye and adnexa".

- The ICD 10 category "disorders of the sclera, cornea, iris and ciliary body" (H15-22) does not have a separate heading in the AHS. Instead, component disorders such as corneal ulcers and uveitis/ eye inflammation are specifically included in the AHS "Other" category. There are likely to be few such cases. Robaei, Huynh et al (2006) found no cases of VI from any of these diseases in the SCES. Pai et al (2011) found two children who had corneal scarring which, out of a sample of 1,188 children, represents a prevalence of 0.17%. However, the condition did not result in VI in either case. McKinnon et al (2004) found 14 cases of corneal scarring occasioning VI in infants in South Eastern Australia between 1980 and 2000. This translates to a prevalence rate of 0.0009%.

[28] Sarvananthan et al (2009) estimate the prevalence of nystagmus as around one in every 400 children.

- Trachoma (A71) is also specifically included in the AHS "Other" category. Again, there are likely to be very few cases. The National Trachoma Surveillance and Report Unit (2014) only found 176 cases nationwide in 2014.
- Other ICD-10 categories that may be included in the AHS "Other" category are H00-06 (disorders of eyelid, lacrimal system and orbit), H10-13 (disorders of conjunctiva), and H43–45 (disorders of vitreous body and globe). However, conditions from these groups that cause VI are rare.

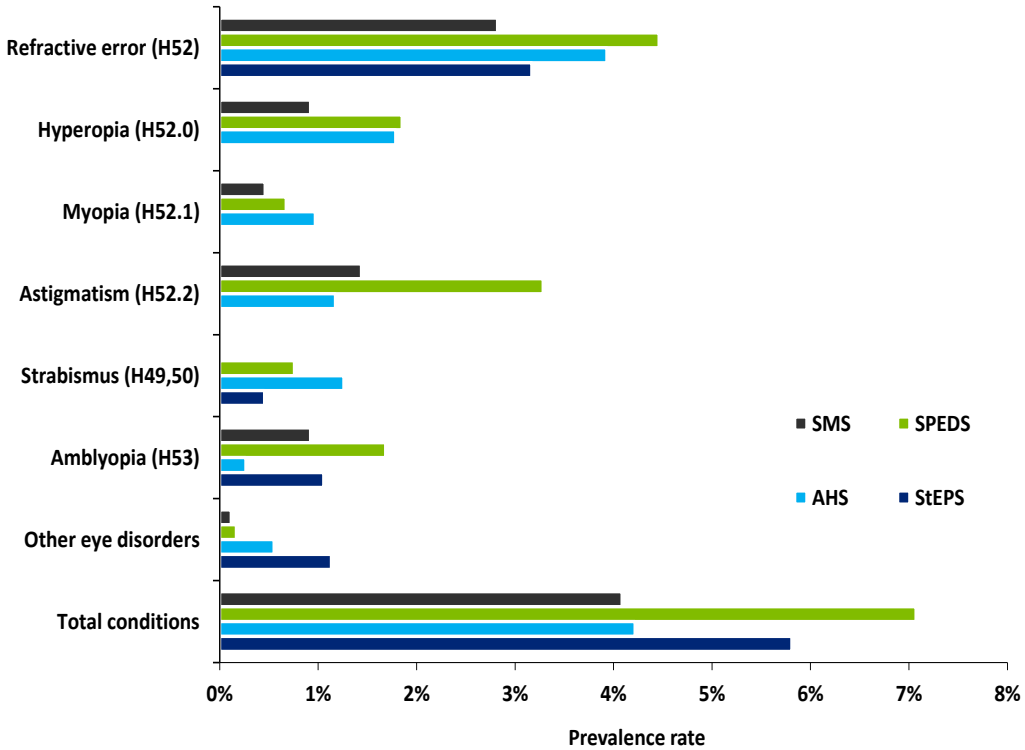
The AHS forms the basis of the prevalence estimates presented in Section 2.3. Where the prevalence is estimated using an alternative source, it is discussed in the following sections.

2.2.2 Screening and eye health studies

Supplementary sources to the AHS are used for "other diseases of eye and adnexa" (H55-59) and "disorders of optic nerve and visual pathway" (H46-48).

As the StEPS program has by far the largest sample of preschool children, AHS results for "other diseases of eye and adnexa" for 0 to 5 year olds were adjusted upwards by the difference between the AHS rates for 3 to 6 year olds and StEPS 4 year olds. Also, as the AHS results for amblyopia in pre-schoolers was substantially lower than in any of the other studies (Chart 2.2), these results were also adjusted upwards by the same margins.

Chart 2.2: Comparison of AHS prevalence with screening eye health studies



Notes: SMS is "predominantly" 6 year olds, StEPS is 4 year olds, AHS and SPEDS are 3 to 6 year olds. VI in SMS is 6/12, in SPEDS 6/15 and in StEPS 6/9; AHS reports "sight problems". Other eye disorders is the category as is included in each relevant journal article, although no further details are provided for breakdown. For the AHS, other eye disorders are conditions not specifically listed on the vertical axis.
Sources: SMS Robaei et al (2005) SPEDS Pai et al (2011), StEPS Blows et al (2014), AHS ABS (2013). Estimates of VI by cause in Australian children in 2015

In NSW, the StEPS program actively identifies and targets all 4 year old children. Blows et al (2014) reports that StEPS managed to screen 65,834 children in 2010-11. Of these, 6,421 (9.8%) were referred to their general practitioner (GP) where they appeared to have a visual acuity of 6/9 or less.[29]

Follow up data was provided for two of the 15 Local Health Districts in NSW (Chart 2.8), which while smaller than the state wide sample, still comprised 12,977 children screened in the two LHDs and was several times larger than other paediatric eye health studies conducted in Australia. This sample of 4 year old preschool children is also larger than the sample of preschool children aged 0 to 5 years in the AHS.

Table 2.3 presents the distribution by condition in NSW preschool children diagnosed with VI after they were screened in the StEPS program in 2011, where VI is defined as visual acuity of <6/9. RE is the most common cause of VI, diagnosed in 54.7% of screened children who are diagnosed with an eye condition.

Table 2.3: VI in NSW 4 year olds diagnosed by the StEPS program in 2011, by condition

ICD-10 description	Condition	% of total
Strabismus, paralytic and other (H49-H50)	Strabismus	8.0%
Disorders of refraction and accommodation (H52)	RE	54.7%
Amblyopia (H53.0)	Amblyopia	18.2%
Other disorders of eye and adnexa (H55-H59)*	Other	19.2%
Total		**100%**

* As with the AHS, the category 'Other' reported in Blows et al (2014) would include conditions outside of this specific ICD-10 description, although no further breakdown is provided.

Source: Blows et al (2014).

As the AHS does not report on the ICD-10 description "disorder of optic nerve and visual pathway" (H46-48) paediatric eye health studies are used instead.

Robaei, Huynh et al (2006) report the results of the SCES, a population based survey of eye conditions among 2,353 12 year old school children[30]. They report that optic nerve hypoplasia accounted for 9.5% of non-correctable impairment, and cerebral visual impairment (CVI) for 4.8%. Translating these results to population prevalence implies that 0.17% of children have VI from optic nerve and visual pathway abnormalities.

These disorders appear to be more prevalent in males. Kalloniatis and Johnston (1990) conducted a retrospective survey of clinical files from the Kooyong Low Vision Clinic. They found 57 cases of optic nerve disorders, of which 60% were in boys. This ratio is used to assign a gender split to these conditions in this report. Both Kalloniatis and Johnston (1990)

[29] Using visual acuity of 6/9 or less would include children with acuity of 6/12 or better, which therefore does not meet the definition of VI used in this report. However, referrals were split into two groups depending on severity of visual acuity. High priority referrals were those with visual acuity of <6/18, and routine referrals were those with a visual acuity of <6/9-2 but better than 6/18 in one or both eyes.

[30] The SCES was the five year follow up to the SMS.

and Boonstra et al (2012) – a similar recent study in Holland – found that optic nerve and visual pathway disorders accounted for 10% to 12.5% of VI presenting to low vision clinics.

Table 2.4: Gender distribution of optic atrophy

ICD-10 description	Condition	Male	Female	All
Optic atrophy (H47.2)	Primary optic atrophy	28	15	43
Optic atrophy (H47.2)	Secondary optic atrophy	6	8	14
Total		**34**	**23**	**57**

Source: Kalloniatis and Johnston (1990)

2.2.2.2 Australian Congenital Anomalies Monitoring System

Congenital malformations of the eye are too uncommon to be separately reported in the AHS. The AHS reports that the prevalence rate of "congenital malformations, deformations and chromosomal abnormalities" across all organs was 0.7% in children aged 0 to 14 in 2011-12.

However, the AIHW maintains the Australian Congenital Anomalies Monitoring System, which reports on individual eye conditions and is accordingly used in this report.

Table 2.5: Average number of congenital eye diseases per 10,000 births, 1998 to 2003

ICD-10 description	Disorder	Number per 10,000 births
Anophthalmos, microphthalmos and macrophthalmos (Q11)	Anophthalmos and microphthalmos	0.9
Congenital lens malformations (Q12)	Congenital cataract and other lens anomalies	1.4
Congenital malformations of anterior segment of eye (Q13)	Congenital anomalies of the anterior chamber	1.0
Congenital glaucoma (Q15.0)	Glaucoma	0.4
All reported eye anomalies		**5.0**

Source: AIHW (2008)

The AIHW (2008) reported an average prevalence of congenital eye diseases of 0.05% in the five years to 2003. Regarding gender distribution, Kalloniatis and Johnston (1990) found 111 cases of congenital disorders in children aged between 6 and 12 years. Two thirds (65%) of the cases were male, which according to the authors "suggests that many ocular conditions are inherited in an X-linked manner." This ratio is used to assign a gender split to congenital anomalies in this report.

Table 2.6: Gender distribution of congenital eye disorders

ICD-10 description	Condition	Male	Female	All
Microphthalmos (Q11.2)	Macular dysplasia	3	2	5
Congenital cataract (Q12.0)	Congenital cataracts	43	19	62
Absence of iris (Q13.1)	Aniridia (glaucoma, cataract)	12	7	19
Congenital malformation of optic disc (Q14.2)	Optic nerve hypoplasia	7	4	11
Congenital malformation of eye, unspecified (Q15.9)	Congenital malformations	7	7	14
Total		**72**	**39**	**111**

Source: Kalloniatis and Johnston (1990)

Advances in neonatal healthcare mean that congenital conditions are likely to increase in prevalence. Boonstra et al (2012) observe that "in the last two decades, treatable or preventable disorders, such as cataract and ROP, have become a less common cause of low vision in children. However, the prevalence of complex (genetic) and untreatable disorders (CVI) has taken its place, as a result of increased survival of pre-term and low birth weight children.

2.2.3 Rare eye diseases

The literature search conducted for this report was unable to find any systematic study of the prevalence of rare diseases in Australia. Accordingly international data are relied on.

Rare diseases are defined as those which affect 5 or fewer people out of every 10,000 people (Commission of the European Communities, 2008). As the paediatric eye health studies conducted in Australia have only had 1,000 to 2,000 subjects, they have not been large enough to capture most of these rare conditions. The AHS, being carefully designed to be a nationally representative survey of over 20,000 households, may be expected to have captured many of these conditions. However, the AHS only reports in broad 2-digit ICD categories, which limits its usefulness for individual rare conditions.

Children with rare severe eye conditions will usually be detected much earlier through vision surveillance. In 2015 approximately 70% of parents on the ACVIR report their child being diagnosed by their first birthday.

The StEPS program, which screens over 65,000 NSW four year olds per year, could potentially contain the most accurate estimate of the prevalence of rare eye conditions in four year olds, because of its large sample size. However, only limited, high level results have been released. Blows et al (2014) report on the results from two Local Health Districts. Out of a total of 12,977 four year olds who were screened, 1.1% had "other vision disorders", where "other" is a catch all for all conditions other than RE, strabismus or amblyopia (Table 2.7).

Table 2.7: Prevalence of VI by condition in a sample of 4 year old children referred for diagnosis by the StEPS program.

ICD-10 description	Condition	Prevalence rate
Strabismus, paralytic and other (H49-H50)	Strabismus	0.5%
Disorders of refraction and accommodation (H52)	RE (6/9 or worse)	3.2%
Amblyopia (H53.0)	Amblyopia	1.1%
Other disorders of eye and adnexa (H55-H59)*	Other vision disorders	1.1%
Total		**5.8%**

* The category 'Other' reported in Blows et al (2014) would include conditions outside of this specific ICD-10 description, although no further breakdown is provided.

Source: Blows et al (2014)

By comparison, the AHS estimates that the prevalence of eye conditions other than RE, strabismus or amblyopia for 3 to 6 year olds is 0.6%[31]. Pai et al (2011) report a prevalence rate for "other" of 0.2% from the Sydney Paediatric Eye Disorder Study (SPEDS) and Robaei et al (2005) report a rate of 0.1% from the Sydney Myopia Study (SMS).

There are numerous other studies around the world that have attempted to capture the prevalence of rare diseases outside Australia. However, as Nagpal et al (2008) state:

> *It is important to acknowledge the limitations of many of these studies. They include referral and selection bias, differences in diagnostic criteria and tools over time and in different parts of the world, recognition of new clinical entities, eradication of certain infectious diseases, environmental and genetic factors, and a greater awareness of certain clinical entities.*

Only two studies found in the literature search were based on truly nation-wide databases, and included all the conditions common enough to appear on such databases[32]. These were Mitry et al (2013) and Rahi and Cable (2003). Rahi and Cable utilised results from national active surveillance schemes in ophthalmology and paediatrics. In the UK, a Certificate of Visual Impairment grants access to a range of government welfare and support services. Mitry et al utilised the database of these Certificates.

The average of Rahi and Cable (2003) and Mitry et al (2013) has been used as the base prevalence for rare eye conditions (Table 2.8). Some confidence can be gained from the fact that two national studies conducted ten years apart yield very similar results. However, while both studies were large and well designed, and a certificate of visual impairment is necessary for certain benefits in the UK, as with all registries, it is likely that not all persons with rare conditions were captured.

[31] Including SCES estimates for visual pathway and optic nerve disorders, which the AHS does not report on separately.

[32] Many other studies investigated only reported the share of rare diseases at individual eye clinics, which cannot be extrapolated to a population basis.

Table 2.8: Estimated prevalence of rare eye conditions per 100,000 persons

Condition	Anatomical site affected	ICD10 code	Rahi and Cable (2003)	Mitry et al (2013)	Average rate	Australia estimate persons
Retinoblastoma	Retina	C69.2	0.02		0.02	1
Ocular-cutaneous albinism	Retina	E70.3	0.16	0	0.08	4
Canavan's disease	Cerebral/visual pathways	E75.2	0.01		0.01	0
Leigh's encephalopathy	Cerebral/visual pathways	G31.8	0.01		0.01	0
Myelinated optic nerve	Optic nerve	G36.0	0.01		0.01	0
Multiple infection	Whole globe and anterior segment	H13	0.01		0.01	0
Sclerocornea and corneal opacities)	Cornea	H17	0.06	0.07	0.07	4
Unspecified macular dystrophy	Retina	H18.5	0.01		0.01	0
Uveitis	Uvea	H20	0.05	0.03	0.04	2
Cyclitic membrane	Whole globe and anterior segment	H21.4	0.01		0.01	0
Lens (cataract or aphakia)	Lens	H25	0.19	0.27	0.23	12
Retinitis/neuroretinitis	Retina	H30.9	0.04		0.04	2
Scar	Retina	H31	0.03		0.03	1
Retinal detachment	Retina	H33	0.04	0.04	0.04	2
Retinoschisis	Retina	H33.1	0.02		0.02	1
Retinopathy	Retina	H35	0.07		0.07	4
Retinopathy of prematurity	Retina	H35.1	0.11	0.17	0.14	8
Retinal and macular dystrophies	Retina	H35.5	0.55	1.47	1.01	54
Cone dystrophies	Retina	H35.5	0.11		0.11	6

Condition	Anatomical site affected	ICD10 code	Rahi and Cable (2003)	Mitry et al (2013)	Average rate	Australia estimate persons
Cone-rod dystrophies	Retina	H35.5	0.08		0.08	4
Retinitis pigmentosa	Retina	H35.5	0.07		0.07	4
Leber's amaurosis	Retina	H35.5	0.13		0.13	7
Storage disease	Retina	H35.5	0.02		0.02	1
Stargardt's disease	Retina	H35.5	0.04		0.04	2
Congenital stationary night blindness	Retina	H35.6	0.02		0.02	1
Myelination of retina	Retina	H35.9	0.01		0.01	0
Glaucoma (primary and secondary)	Optic nerve	H40	0.11	0.1	0.11	6
Primary atrophy	Optic nerve	H44.5	0.08		0.08	4
Secondary atrophy	Optic nerve	H44.5	0.44		0.44	24
Neuritis/neuropathy	Optic nerve	H46	0.06		0.06	3
High refractive error	Other	H52	0.05	0.16	0.11	6
Unspecified neurodegenerative disorders	Cerebral/visual pathways	H47	0.06		0.06	3
Structural abnormalities	Cerebral/visual pathways	H47	0.28		0.28	15
Hypoxic/ischaemic encephalopathy	Cerebral/visual pathways	H47	0.47		0.47	25
Infection	Cerebral/visual pathways	H47	0.11	0.07	0.09	5
Tumour	Cerebral/visual pathways	H47	0.1		0.1	5
Metabolic	Cerebral/visual pathways	H47	0.01		0.01	0
Post operative	Cerebral/visual pathways	H47	0.01		0.01	0
Unknown disorder	Cerebral/visual pathways	H47	0.8		0.8	43

Condition	Anatomical site affected	ICD10 code	Rahi and Cable (2003)	Mitry et al (2013)	Average rate	Australia estimate persons
Idiopathic nystagmus	Other	H55	0.02	0.56	0.29	16
Septo-optic dysplasia	Optic nerve	Q04.4	0.12		0.12	7
Microphthalmia/ anophthalmia	Whole globe and anterior segment	Q11	0.19	0.04	0.11	6
Foveal hypoplasia	Retina	Q11.2	0.02		0.02	1
Dysplasia	Optic nerve	Q11.2	0.03		0.03	1
Coloboma-single site	Uvea	Q12-13	0.02	0.04	0.03	1
Coloboma single site	Retina	Q12-13	0.03		0.03	1
Coloboma single site	Optic nerve	Q12-13	0.01		0.01	0
Coloboma-multiple sites	Whole globe and anterior segment	Q12-13	0.05		0.05	3
Anterior segment dysgenesis	Whole globe and anterior segment	Q13	0.05	0.19	0.12	7
Anidiria	Uvea	Q13.1	0.04	0.11	0.08	4
Persistent hyperplastic primary vitreous	Whole globe and anterior segment	Q14	0.01		0.01	0
Disorganised sclerocornea	Whole globe and anterior segment	Q14	0.01		0.01	0
Dysplasia	Retina	Q14.1	0.04		0.04	2
Isolated Hypoplasia	Optic nerve	Q14.2	0.34		0.34	19
Non-accidental injury	Cerebral/visual pathways	S05	0.01	0.01	0.01	0
Multiple trauma	Whole globe and anterior segment	S05	0.01		0.01	0
Perforated globe	Whole globe and anterior segment	S05	0.01		0.01	0
Retinoblastoma	Retina	C69.2	0.02		0.02	1
Ocular-cutaneous albinism	Retina	E70.3	0.16	0	0.08	4
Canavan's disease	Cerebral/visual pathways	E75.2	0.01		0.01	0
Leigh's encephalopathy	Cerebral/visual pathways	G31.8	0.01		0.01	0

Condition	Anatomical site affected	ICD10 code	Rahi and Cable (2003)	Mitry et al (2013)	Average rate	Australia estimate persons
Myelinated optic nerve	Optic nerve	G36.0	0.01		0.01	0
Multiple infection	Whole globe and anterior segment	H13	0.01		0.01	0
Sclerocornea and corneal opacities	Cornea	H17	0.06	0.07	0.07	4
Unspecified macular dystrophy	Retina	H18.5	0.01		0.01	0
Uveitis	Uvea	H20	0.05	0.03	0.04	2
Cyclitic membrane	Whole globe and anterior segment	H21.4	0.01		0.01	0
Retinitis/neuroretinitis	Retina	H30.9	0.04		0.04	2
No. of children			**439**	**1009**		**338**

Note: total differs from sum due to rounding. Sum of individual causes of CVI, as in Rahi and Cable, is the same as overall CVI rate, as in Mitry et al.
Sources: Rahi and Cable (2003) and Mitry et al (2013).

Applying these prevalence rates to Australia yields an estimate of 338 Australian children with VI from rare diseases, which is intuitive given the relative populations of Australia and the UK. However, this can only be considered a minimum estimate.

Adding estimates from individual condition estimates into the mix – for anophthalmos, microphthalmos and coloboma (Skalicky et al, 2013), corneal opacity and primary glaucoma (McKinnon et al, 2004), cataract (Wirth et al, 2002), uveitis (Nagpal et al, 2008), retinal dystrophy (Monica et al, 1999), optic atrophy (Chang et al, 2012) and injury (Kadappu et al, 2013) – suggests a total of around 1,750 Australian cases of paediatric VI from rare diseases (or 0.5%). Conversely however, most of these authors include sources of variable quality and the overall results do not reflect the consistent distribution shown across the national studies.

As by definition rare conditions affect at most 0.05% of people, the top 20 most prevalent rare eye diseases could not add up to more than 1% prevalence. Eye conditions are very common, affecting more than 50% of the total Australian population. Further, as rarity increases dramatically – the top conditions in the national studies are more than 100 times more common than the bottom ones – it is unlikely that all rare conditions put together would exceed more than 2% of total eye conditions. As this report estimates there are around 300,000 Australian children with VI (Chapter 2) with VI, a 2% upper bound for VI from rare diseases would be in the vicinity of 6,000 cases. [33].

On balance, the mid-range estimate of 1,750 cases of VI from rare diseases is used. It is assumed that the Australian sources used for calculating prevalence in Chapter 2 will have captured representative numbers of most of these rare conditions under their higher level groupings or “other” categories.

2.3 Overall prevalence estimates

Based primarily on the AHS, with additional sources as described in section 2.1 and section 2.2, the estimated prevalence of sight problems in Australian children is 6.99% overall. Prevalence is slightly higher in females (7.02%) than in males (6.97%).

[33] This is calculated using the European definition of rare diseases as those affecting up to 5 in 10,000 (Commission of the European Communities, 2008). Using the Australian definition (Knight and Senior, 2006) of up to 1 in 10,000, the sum of the top 20 conditions would be five times smaller, or around 1,200 cases. This is close to the mid-range estimate of 1,750 people.

Table 2.9: Prevalence rates by condition and gender

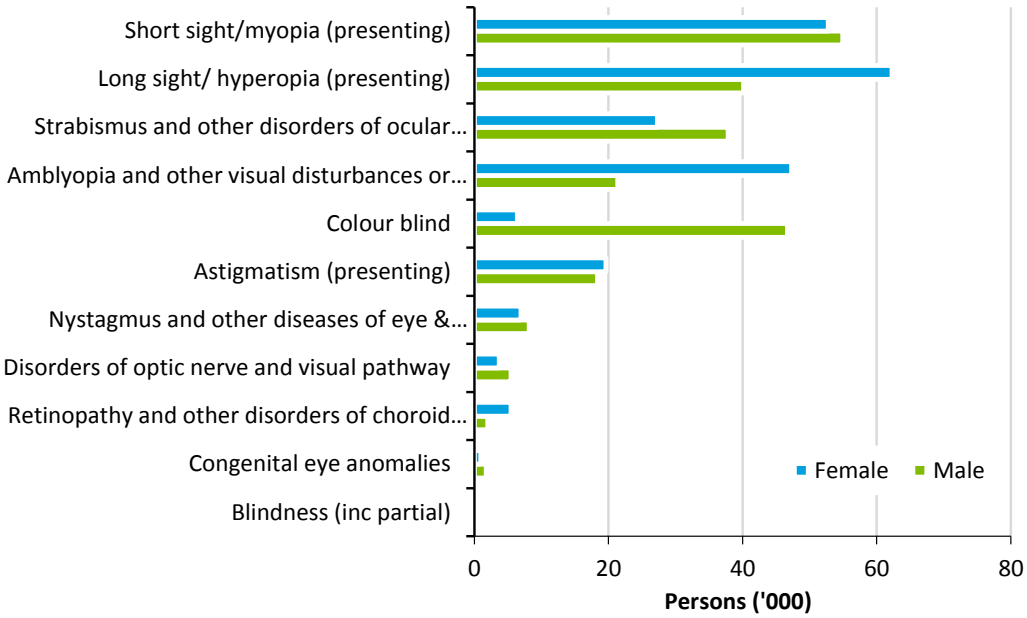
ICD-10 description	Condition	Male (%)	Female (%)	Total (%)
Disorders of choroid and retina (H30-H36)	Retinopathy and other disorders of choroid and retina	0.07	0.16	0.11
Disorders of optic nerve and visual pathway (H46-H48)	Disorders of optic nerve and visual pathway	0.20	0.14	0.17
Disorders of ocular muscles and binocular movement (H49-H51)	Strabismus and other disorders of ocular muscles binocular	1.37	1.04	1.21
Hypermetropia (H52.0)	Long sight/ hyperopia (presenting)	1.45	2.37	1.90
Myopia (H52.1)	Short sight/myopia (presenting)	1.98	2.01	2.00
Astigmatism (H52.2)	Astigmatism (presenting)	0.66	0.75	0.70
Visual disturbances (H53)	Amblyopia and other visual disturbances or loss of vision	0.77	1.80	1.27
Colour vision deficiencies (H53.5)	Colour blind	1.69	0.24	0.98
Visual impairment including blindness (H54)	Blindness (one or both eyes)**	0.007	0.005	0.006
Other disorders of eye and adnexa (H55-H59)*	Nystagmus and other diseases of eye & adnexa	0.49	0.14	0.38
Congenital malformations of eye (Q10-Q15)	Congenital eye anomalies	0.06	0.04	0.05
Total		**6.97**	**7.02**	**6.99**

Note: Total differs from sum due to comorbidity. * The AHS category 'Other diseases of eye & adnexa is not directly comparable with the ICD 10 category 'Other disorders of eye and adnexa' since the AHS category is designed to capture all other eye diseases not included under the other headings in the table. ** Blindness is a functional state rather than a condition. The most common conditions for blindness include CVI, oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma and congenital cataract. Where sources do not report gender splits, ratios from AHS 2011-12 are assumed to apply.

Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations.

There is a substantial amount of difference in prevalence rates between males and females for most conditions.

Chart 2.3: Prevalence of sight problems, in order of frequency



Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations.

Eye problems increase with age in childhood. Prevalence is just over 2.6% in the first five years of life. By primary school age, this has increased to 8.5%. By high school, prevalence has increased to slightly less than 10%.

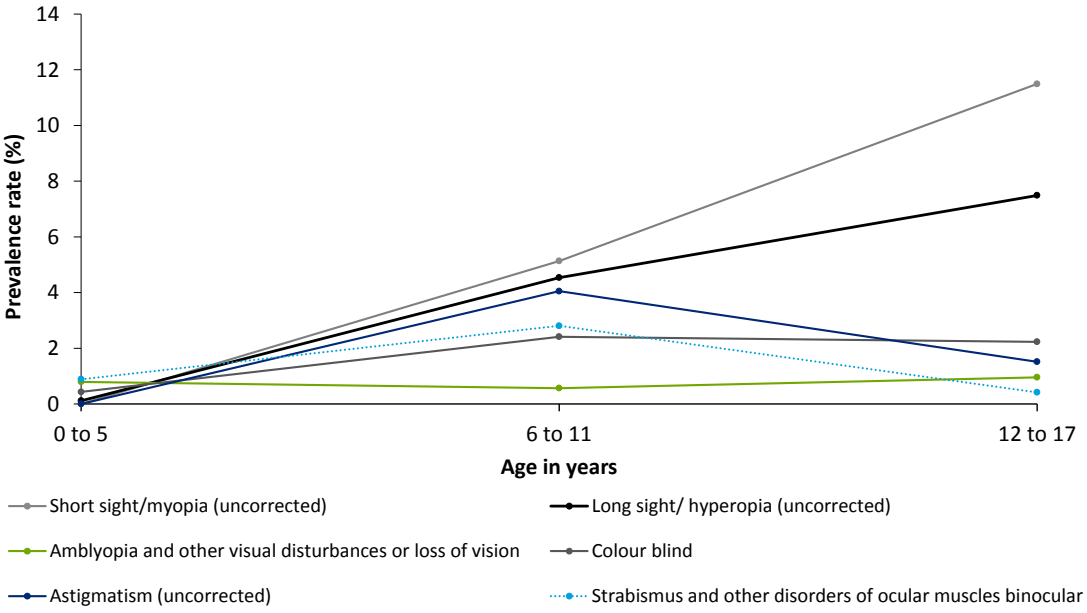
Table 2.10: Prevalence rates by condition and age

ICD-10 description	Condition	Age group (%)			
		0-5	6-11	12-17	Total
Disorders of choroid and retina (H30-H36)	Retinopathy and other disorders of choroid and retina	0.26	0.08	0.08	0.14
Disorders of optic nerve and visual pathway (H46-H48)	Disorders of optic nerve and visual pathway	0.17	0.17	0.17	0.17
Disorders of ocular muscles and binocular movement (H49-H51)	Strabismus and other disorders of ocular muscles binocular	0.92	2.08	0.66	1.21
Hypermetropia (H52.0)	Long sight/ hyperopia (presenting)	0.15	2.36	3.24	1.90
Myopia (H52.1)	Short sight/myopia (presenting)	0.12	1.67	4.25	2.00
Astigmatism (H52.2)	Astigmatism (presenting)	0.01	1.29	0.85	0.70
Visual disturbances (H53)	Amblyopia and other VI	0.79	1.47	1.58	1.27
Colour vision deficiencies (H53.5)	Colour blindness	0.22	1.27	1.50	0.98
Visual impairment including blindness (H54)	Blindness (including partial)**	0.005	0.008	0.005	0.006
Other disorders of eye and adnexa (H55-H59)*	Nystagmus and other disorders of eye and adnexa	0.58	0.19	0.05	0.28
Congenital malformations of eye (Q10-Q15)	Congenital eye anomalies	0.05	0.05	0.05	0.05
Total		**2.62**	**8.51**	**9.95**	**6.96**

Note: Total by age group differs from sum due to comorbidity. * The AHS category 'Other diseases of eye & adnexa is not directly comparable with the ICD 10 category 'Other disorders of eye and adnexa' since the AHS category is designed to capture all other eye diseases not included under the other headings in the table. ** Blindness is a functional state rather than a condition. The most common conditions for blindness include CVI, oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma and congenital cataract.

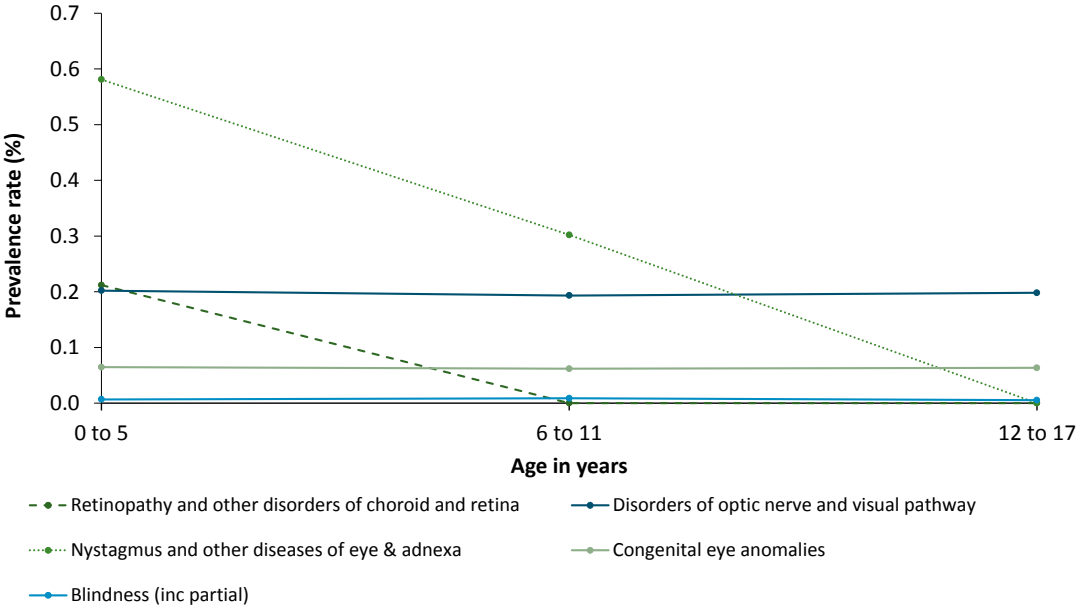
Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations.

Chart 2.4: Prevalence of common sight problems in males by age



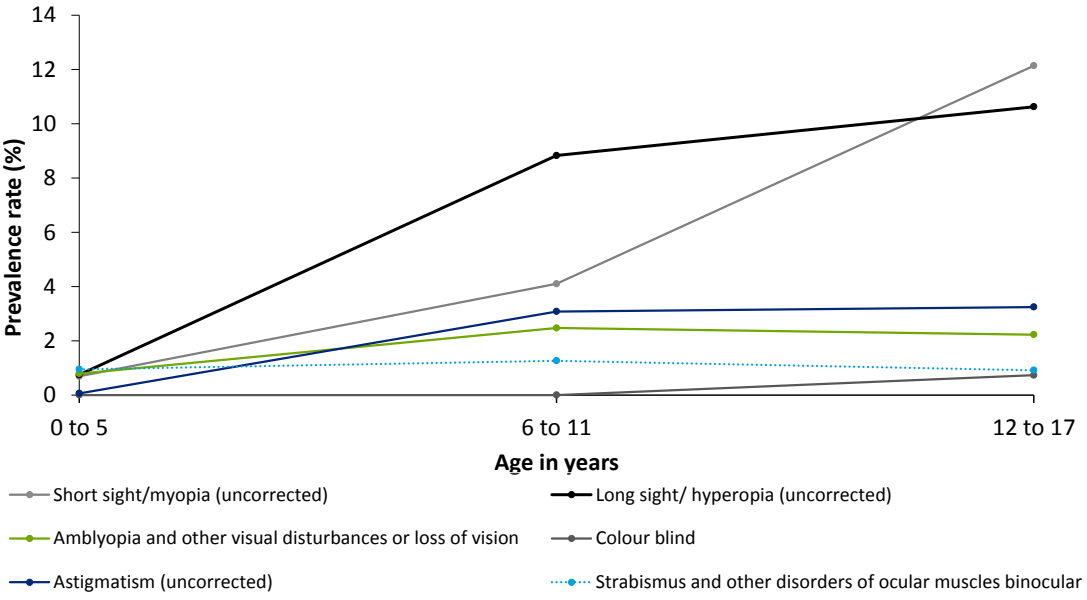
Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations. Where sources do not report gender splits, ratios from AHS 2011-12 are assumed to apply.

Chart 2.5: Prevalence of rare sight problems in males by age



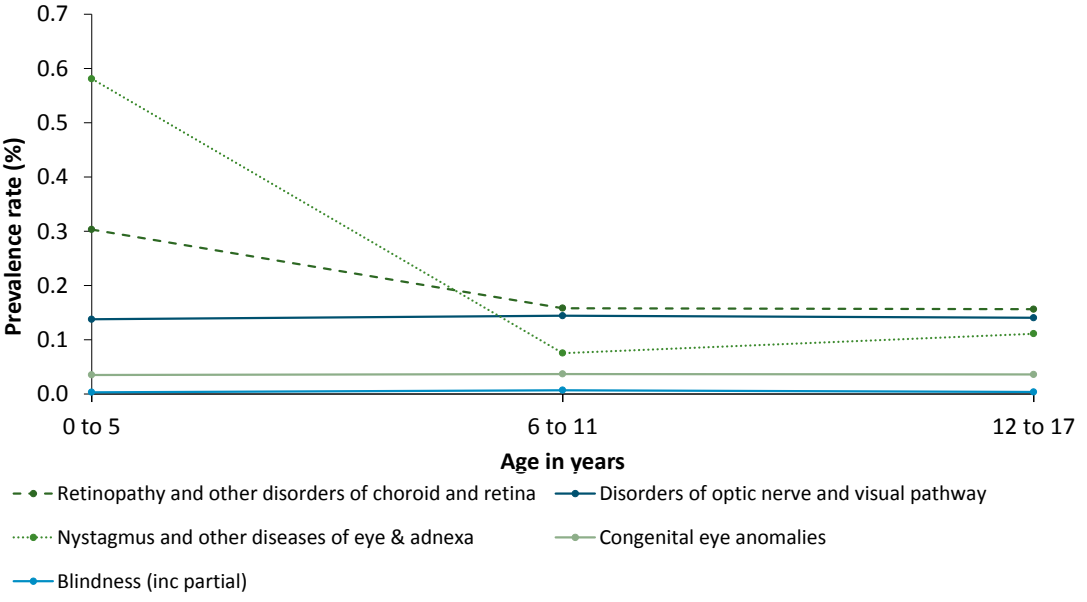
Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations. Where sources do not report gender splits, ratios from AHS 2011-12 are assumed to apply.

Chart 2.6: Prevalence of common sight problems in females by age



Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations. Where sources do not report gender splits, ratios from AHS 2011-12 are assumed to apply.

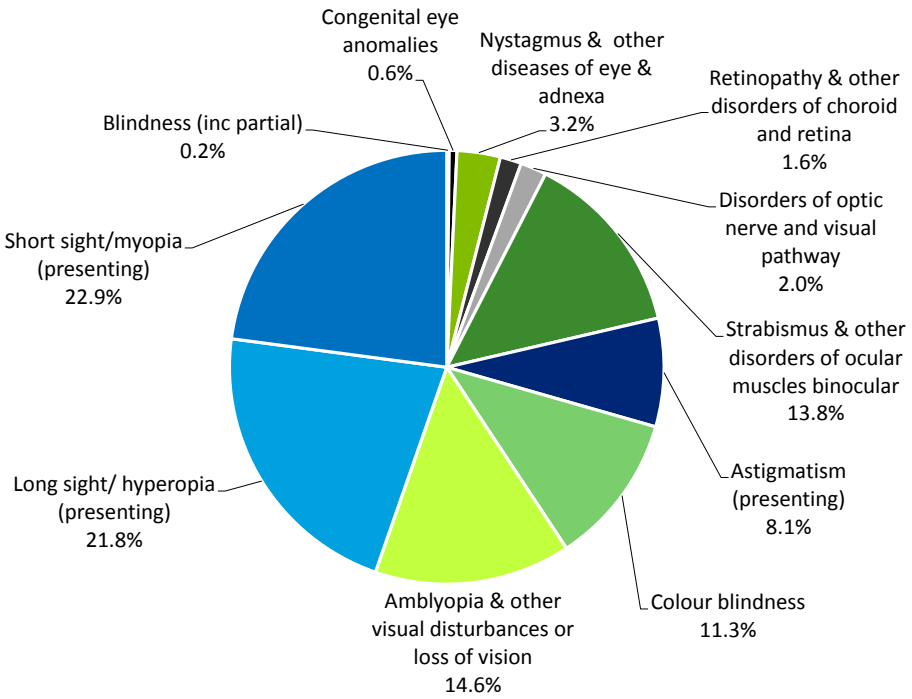
Chart 2.7: Prevalence of rare sight problems in females by age



Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations. Where sources do not report gender splits, ratios from AHS 2011-12 are assumed to apply.

As with adults[34], under-corrected RE accounts for the majority of VI in Australian children. This is demonstrated by the blue shaded wedges in Chart 2.8.

Chart 2.8: Share of sight problems, by order of frequency



Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations. Where sources do not report gender splits, ratios from AHS 2011-12 are assumed to apply.

Overall, there are estimated to be more than 375,000 Australian children with sight problems in 2015. **Of Australian children with sight problems, an estimated 332,936 have VI**.

[34] See Access Economics (2004).

Table 2.11: Prevalence of sight problems by condition and gender, Australia, 2015

ICD-10 description	Condition	Prevalence ('000s)		
		Male	Female	Total
Disorders of choroid and retina (H30-H36)	Retinopathy and other disorders of choroid and retina	1.98	5.48	7.46
Disorders of optic nerve and visual pathway (H46-H48)	Disorders of optic nerve and visual pathway	5.48	3.70	9.18
Disorders of ocular muscles and binocular movement (H49-H51)	Strabismus and other disorders of ocular muscles binocular	37.84	27.28	65.12
Hypermetropia (H52.0)	Long sight/ hyperopia (presenting)	40.13	62.29	102.41
Myopia (H52.1)	Short sight/myopia (presenting)	54.96	52.76	107.71
Astigmatism (H52.2)	Astigmatism (presenting)	18.36	19.62	37.97
Visual disturbances (H53)	Amblyopia and other visual disturbances or loss of vision	21.39	47.33	68.72
Colour vision deficiencies (H53.5)	Colour blind	46.69	6.41	53.10
Visual impairment including blindness (H54)	Blindness (one or both eyes)**	0.19	0.12	0.31
Other disorders of eye and adnexa (H55-H59)*	Nystagmus and other diseases of eye & adnexa	8.19	6.97	15.15
Congenital malformations of eye (Q10-Q15)	Congenital eye anomalies	1.75	0.95	2.70
Total		**189.29**	**186.06**	**375.36**
Total (excl. colour blind)		**151.99**	**180.94**	**332.94**

Note: Totals differ from sum due to comorbidity. * The AHS category 'Other diseases of eye & adnexa is not directly comparable with the ICD 10 category 'Other disorders of eye and adnexa' since the AHS category is designed to capture all other eye diseases not included under the other headings in the table. ** Blindness is a functional state rather than a condition. The most common conditions for blindness include CVI, oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma and congenital cataract.

Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics' calculations.

3 Health system costs

There are 5.4 million children in Australia in 2015, of which, 2.8 million are male. Children account for 22.5% of the total Australian population. Due to substantial spending on health in later years of life, children account for a much smaller share of health system expenditure than the population share suggests. In 2004-05 – the last year data was made available by age, gender and disease – children aged 0-14 accounted for $4.48 billion out of $52.66 billion of allocated health expenditure, or 8.5% of total allocated health expenditure (AIHW, 2010).

Health system costs comprise the costs of running hospitals, GP and specialist services funded through Medicare and patient contributions, the cost of prescribed and over-the-counter pharmaceuticals, optometry and allied health services, research and 'other' direct costs such as health administration.

3.1 Total health system expenditure

The aggregated data on health system expenditure for various eye conditions in 2004-05 were previously obtained from the AIHW by special request (Deloitte Access Economics, 2011).[35] The AIHW derives its expenditure estimates from an extensive 'top-down' process. The data obtained from the AIHW was disaggregated by age, gender and type of cost.

This dataset includes the costs of hospital admitted services, out-of-hospital medical services, pharmaceuticals requiring a prescription and research for eye diseases. The dataset accounts for 70% of total health system expenditure. This is the most recent available data on the health system costs for diseases of the eye and adnexa across Australian health settings. Expenditure on Australian children represents a subset of this data.

However, the AIHW data did not include costs for outpatient services provided by hospitals, over-the-counter pharmaceuticals, and services provided by other health professionals, so adjustments were made to account for these components. A previous special request reported on these additional components, and these data were brought forward using age-gender demographic changes and health inflation to estimate expenditure to current dollars.

Adjustments were then made to account for unallocated health system expenditure. In 2010, the AIHW (2010) reported that outpatient services, over-the-counter pharmaceuticals and services provided by other health professionals comprised 9.2%, 4.0% and 3.4% of total allocated expenditure respectively. The allocated health system

[35] Unfortunately, the AIHW declined our request to obtain the latest expenditure data on diseases of the eye and adnexa by specific causes and age/gender due to internal capacity constraints.

expenditure therefore accounted for 86.6% of all health expenditure including these additional components.

The residual unallocated health system expenditure (13.4%) was incorporated by factoring up health expenditure estimates by 1.15 (=1/(1-0.134)). This adjustment accounts for a proportional share of the costs of capital and administration that would not be incurred if eye conditions did not need to be treated.

The total health system expenditure on eye conditions was $2.25 billion in 2005 (Table 3.1).

Table 3.1: Health system eye condition expenditure, $m, 2005

Age	Male	Female	Total
0–4	79.1	55.2	134.4
5–14	73.3	68.3	141.6
15-24	44.9	56.9	101.8
25–34	75.7	75.0	150.7
35–44	88.4	101.7	190.2
45–54	121.8	135.6	257.4
55–64	143.2	139.8	283.0
65–74	168.1	205.6	373.6
75+	234.2	384.5	618.7
Total	**1,028.7**	**1,222.8**	**2,251.4**

Source: AIHW special data request and Deloitte Access Economics' calculations.

To determine the costs in 2005 relating only to childhood eye condition expenditure, the weighted average of those aged 15-17 in 2005 was applied to the total 15-24 age group. The total health system expenditure on childhood eye conditions was $306.5 million in 2005 (Table 3.2).

Table 3.2: Health system eye condition expenditure in children, by age and gender, $m, 2005

Age	Male	Female	Total
0-4	79.1	55.2	134.4
5-14	73.3	68.3	141.6
15-17	13.5	17.1	30.5
Total	**165.9**	**140.6**	**306.5**

Source: AIHW special data request and Deloitte Access Economics' calculations.

As noted above, the AIHW was not able to provide the latest data on health system expenditure requested, due to limited resources. Consequently, the 2005 data were used as the initial basis of the 2015 estimates, with adjustments to accommodate new information relating to admitted hospital patient data, health inflation and age-gender demographic changes for each age group.

To adjust admitted patient expenditure, Australian refined diagnosis related groups (AR-DRG) separation statistics were obtained from the national hospital morbidity database for 2012-13 (AIHW, 2015), and applied to the 2011-12 costs per episode for each AR-DRG relating to diseases of the eye and adnexa, as reported by the Independent Hospital Pricing Authority (IHPA, 2014).

The average cost per separation for diseases and disorders of the eye was $3,109 in 2011-12. This is broken down further by surgical and medical related treatments for eye conditions. In 2015 prices, $1.2 billion was spent on admitted episodes of diseases of the eye and adnexa in Australian hospitals, of which **$37.8 million was spent on children aged 0-17 years**.

Finally, all costs were brought forward to 2015 using age-gender demographic changes and population growth, and historical health cost inflation from the AIHW to adjust prices to 2015 prices. Health inflation adjustment included:

- Actual historical health inflation data up to 2012-13; and
- 10-year average thereafter.

The total health system expenditure for childhood eye conditions is estimated to be $438.7 million in 2015, or 11.3% of the total health system expenditure on eye conditions in 2015.

Consequently, the proportion of total health expenditure for eye conditions in children is much higher compared to their share of health expenditure for all conditions (8.5%) reported at the start of Chapter 3. While some of this increased share of cost represents screening programs and other interventions, this also reflects the increased burden of eye conditions on children. Only a small proportion (8.6%) of childhood eye condition expenditure occurs in hospital settings.

Table 3.3: Health system costs for childhood eye conditions, by age and gender, in total and per person, 2015

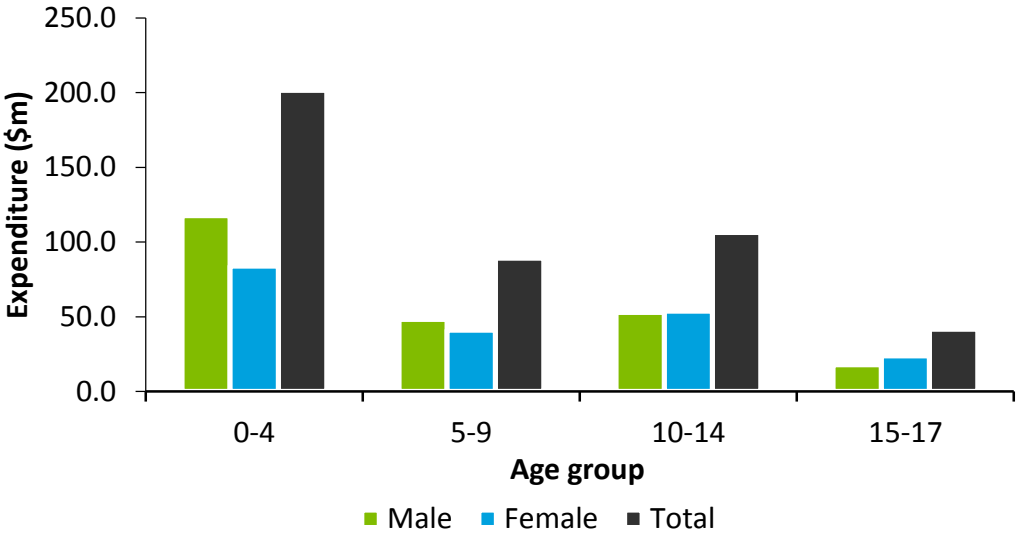
Age	Males		Females		Total	
	Total	per person	Total	Per person	Total	Per person
	$m	*$*	*$m*	*$*	*$m*	*$*
0-4	117.6	5,675	83.9	4,109	201.5	4,898
5-9	48.2	1,006	40.9	801	89.1	900
10-14	52.8	1,006	53.6	801	106.4	891
15-17	17.9	557	23.8	514	41.7	531
Total	**236.5**	**1,543**	**202.2**	**1,094**	**438.7**	**1,298**

Source: Deloitte Access Economics' calculations based on AIHW (2009, 2010) and IHPA (2014).

A large proportion (45%) of health system expenditure is incurred by children aged 0-4 years. This group also experiences the highest per person expenditure, $4,898, compared to the average of $1,298 (see Chart 3.1 and Chart 3.2). Given prevalence rates for eye conditions are not higher in this group than other childhood ages (Table 2.10), this shows

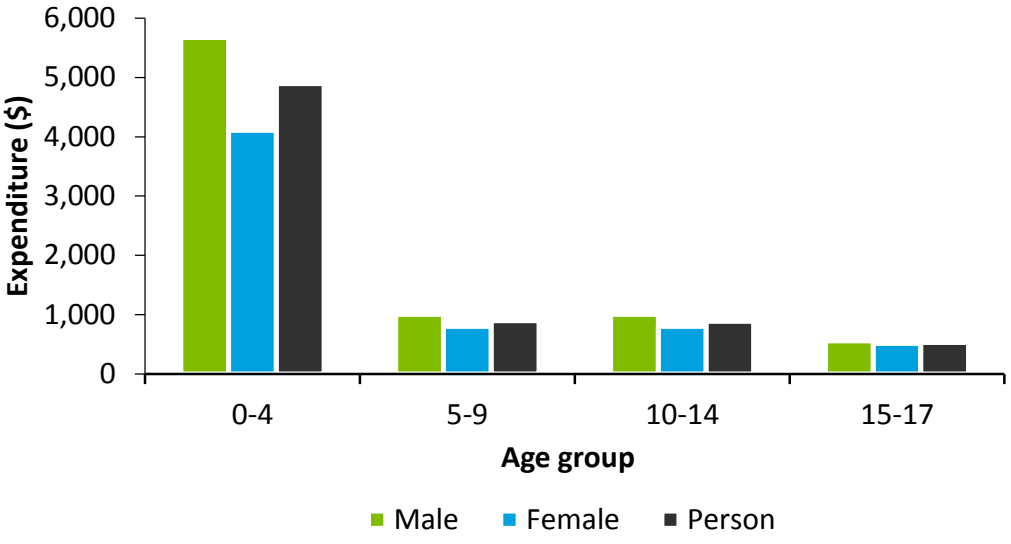
that the youngest children require more frequent and/or more complex interventions. Admitted patients, the only area for which both utilisation rates and overall expenditure are available, shows significantly more frequent admissions in this age group than for older children.

Chart 3.1: Health system expenditure, by age and gender, 2015



Source: AIHW special request and Deloitte Access Economics' calculations.

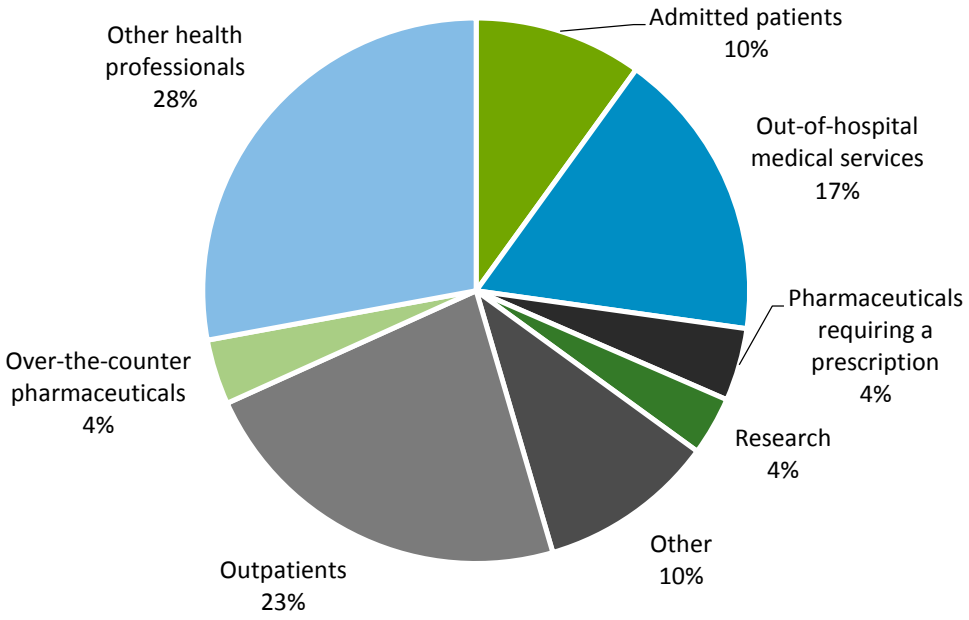
Chart 3.2: Health system expenditure on childhood eye conditions per person, by age and gender, 2015



Source: AIHW special request and Deloitte Access Economics' calculations.

Of allocated health system expenditure, the largest components are other health professionals and outpatients, which account for 51% of total allocated health system expenditure. Costs include the large number of services provided by ophthalmologists (captured in admitted patient, outpatient and out-of-hospital medical services categories), including early childhood screening programs and hospital care requiring surgery, such as for congenital cataracts, congenital glaucoma, ROP, strabismus and other similar conditions (see Section 3.2).

Chart 3.3: Allocated health system expenditure on childhood eye conditions, by cost component, 2015



Source: AIHW special request.

3.2 Health system expenditure by condition

Recent detailed data on hospital separations by cause and by treatment are available from the AIHW's national hospital morbidity database. Thus at least admitted patient costs can be calculated for many eye conditions. On the other hand, only ten year old data for a small number of conditions are available for other components of health expenditure.

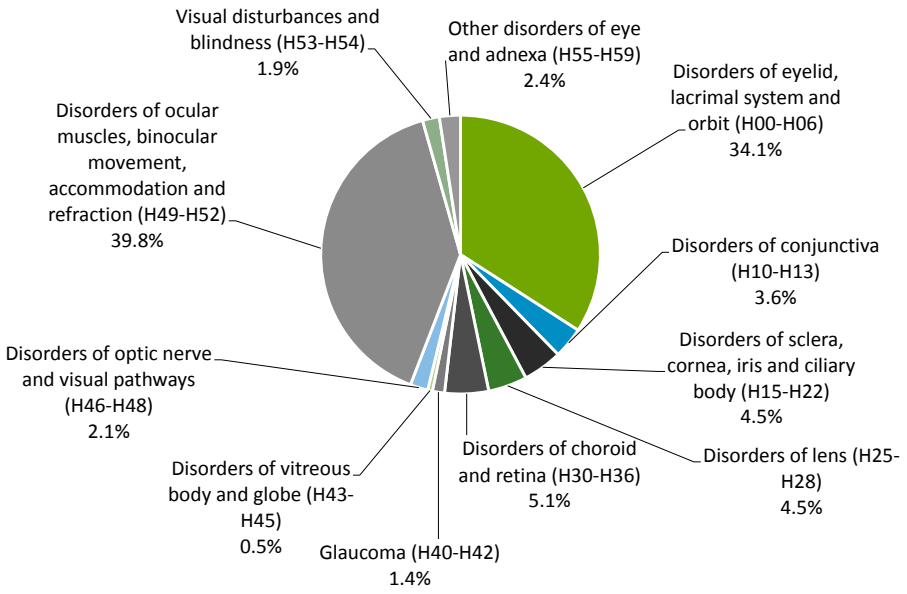
3.2.1 Admitted patient expenditure by eye condition

As outlined in Section 2.3, RE is the most common eye condition causing VI in Australian children and accounts for a large share of health system expenditure. Out of the conditions which cause VI, the ICD-10 description disorders of ocular muscles, binocular movement, accommodation and refraction (H49-52) accounts for the largest share of eye condition admissions. However, very few admissions to hospital are to treat RE – rather, strabismus is the primary reason children are admitted to hospital for eye conditions. Moreover,

strabismus accounted for more than twice as many admissions as all other conditions that cause VI put together[36].

Many rare conditions such as keratitis, juvenile cataract, iridocyclitis and ROP also had a substantial amount of hospital admissions (Chart 3.5).

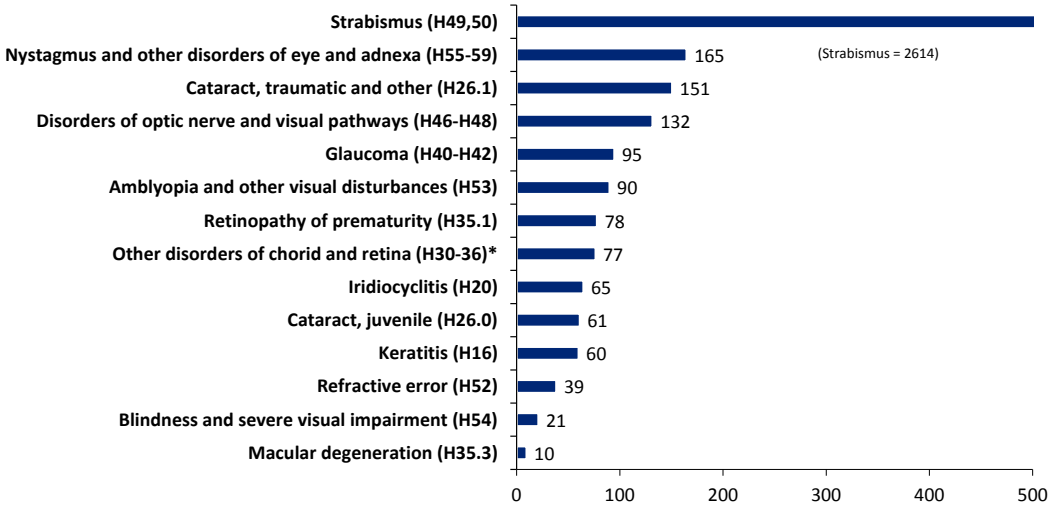
Chart 3.4: Childhood eye condition separations by ICD code, Australia, 2013



Source: AIHW (2015, 2015a).

[36] Conditions H00 to H13 do not cause long term VI.

Chart 3.5: Children admitted for selected eye conditions, by order of frequency, 2012-13



Notes * = disorders of chorid and retina other than ROP and macular degeneration
Source: AIHW (2015a)

Applying AR-DRG cost weights from IHPA (2014) to the 2013 admitted patient separations by principal diagnosis from AIHW (2015a), as shown in Appendix A, indicates that RE cost approximately $170,000 in 2013 (2015 prices). This indicates that almost all health system expenditure for RE occurs out-of-hospital, and that admitted patient expenditure largely relates to rare eye diseases.

When comparing costs and separations, as expected, costs are closely aligned with the number of separations for each ICD-10 code (Table 3.4 and Table A.1). The total estimated admitted patient expenditure by ICD-10 code is $32 million in 2015. As with separations, most expenditure is contained within disorders of eyelid, lacrimal system and orbit, and disorders of ocular muscles, binocular movement, accommodation and refraction excluding RE.

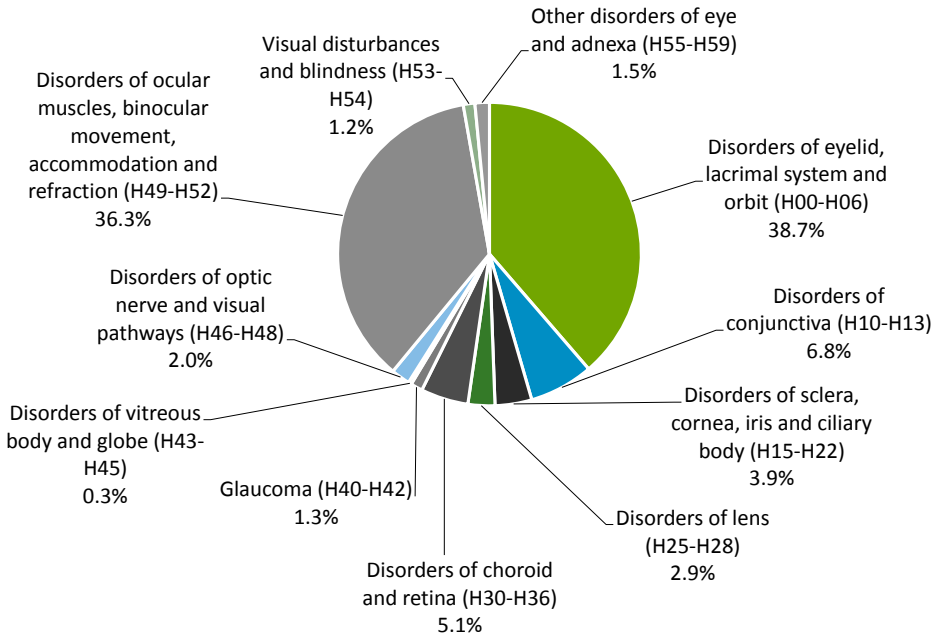
Table 3.4: Admitted separations and costs for childhood eye conditions, 2015

ICD-10 description	Separations		Costs	
	Persons	*%*	*$m*	*%*
Disorders of eyelid, lacrimal system and orbit (H00-H06)	2,420	34.1	12.3	38.6
Disorders of conjunctiva (H10-H13)	255	3.6	2.2	6.8
Disorders of sclera, cornea, iris and ciliary body (H15-H22)	322	4.5	1.2	3.9
Disorders of lens (H25-H28)	319	4.5	0.9	2.9
Disorders of choroid and retina (H30-H36)	360	5.1	1.6	5.1
Glaucoma (H40-H42)	99	1.4	0.4	1.3
Disorders of vitreous body and globe (H43-H45)	39	0.5	0.1	0.3
Disorders of optic nerve and visual pathways (H46-H48)	146	2.1	0.6	2.0
Disorders of ocular muscles, binocular movement, accommodation and refraction (H49-H52)	2,822	39.8	11.6	36.2
Visual disturbances and blindness (H53-H54)	138	1.9	0.4	1.2
Other disorders of eye and adnexa (H55-H59)	173	2.4	0.5	1.5
Total	**7,093**	**100.0**	**31.9**	**100.0**

Note: Estimates of admitted patient costs by ICD-10-AM codes are not directly comparable with the estimate of $37.8 million in Section 3.1. This is due to conditions not directly mapping to AR-DRG codes.

Source: AIHW (2015, 2015a), IHPA (2014) and Deloitte Access Economics' calculations.

Chart 3.6: Share of admitted patient expenditure, by childhood eye condition, 2015



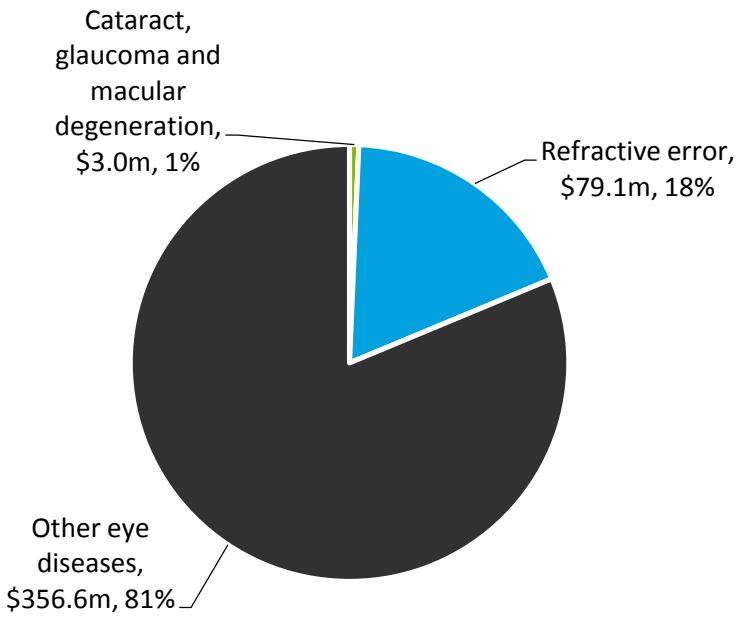
Source: AIHW (2015, 2015a), IHPA (2014) and Deloitte Access Economics calculations.

3.2.2 Total health system expenditure by condition

The largest proportion of health expenditure outside hospital settings is for other eye disease and RE. In 2004-05, the last year for which the AIHW made available expenditure by condition, total expenditure on children for RE was $46.6 million, or 18.0%. Total expenditure on other eye diseases was $210.0 million, or 81.3%. Cataract, glaucoma and macular degeneration – which in children are mostly congenital conditions – accounted for $1.76 million, or 0.7%. The total expenditure on children in 2005 was $258.4 million. Unfortunately, the AIHW data does not allow further breakdown of other eye diseases, although this category represents all other conditions aside from RE, and the likely congenital cataract, childhood glaucoma and macular degeneration.

If these proportions have not changed, then total health system expenditure on RE and other eye diseases would now be $79.1 million and $356.6 million respectively (Chart 3.7).

Chart 3.7: Total health system expenditure by childhood eye condition, 2015



Source: AIHW special data request and Deloitte Access Economics' calculations.

3.3 Lifetime expenditure

Lifetime costs are the sum of those incurred from when a condition is first developed until it is successfully treated or until the end of life. Taking the per person costs, as reported in Table 3.3, and applying these annually to the cohort of newborns with eye conditions as they age, provides an estimate of their total lifetime health costs. The cohort incurs costs of $201.5 million during years 0-4, $37.0 million during years 5-9, $36.7 million during years 10-14, and $21.9 million for each 5 year period thereafter. The total costs for the cohort are $589.9 million over the average expected lifetime of 80.1 years for males and 84.3 years for females (ABS 2014).

3.3.1 Discounting

However, an important concept to understand in economics is that people value consumption today more than potential consumption in the future. The reason people are willing to pay interest on loans is so that they can have the benefits of consumption now, rather than waiting to save up for consumption.

The Australian Government's Office of Best Practice Regulation (Department of Prime Minister and Cabinet, 2014) requires any estimates of the future benefits from policy changes to be discounted at 7% so they can be counted in "net present value" (NPV) terms. In order to enable comparability with returns from other potential investments of public outlays, Deloitte Access Economics also follows this methodology. To illustrate, suppose the government could generate a billion dollars in increased productivity in ten years' time from increased childhood eye interventions today. In NPV terms, there would be no difference for society in earning a billion dollars in a decade or earning $544 million dollars now (=$1 billion / $(1 + 0.07)^9$). In this case, the government could justify spending up to $544 million on interventions now - but not more.

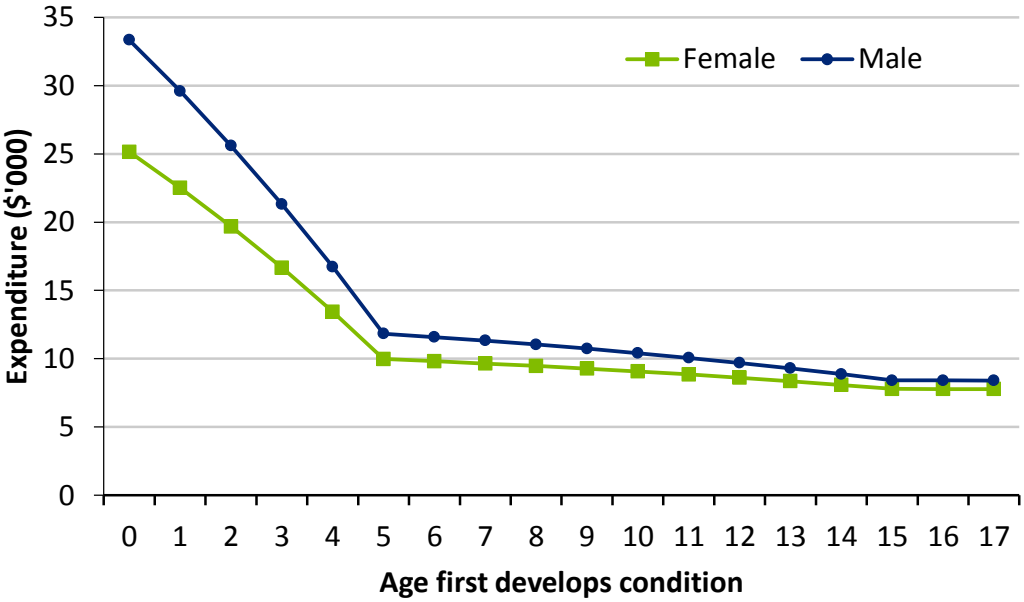
- Another issue to consider regarding future costs is inflation. A hundred dollars today buys a lot less than it did 30 years ago. Similarly, $100 in 30 years time can be expected to buy a lot less than $100 today. Economists deal with this by using real rather than nominal values. For example, suppose a labourer earns enough in a day currently to buy a basket of goods and services worth $100. In the future, it is assumed that they will still earn enough to buy that same basket of goods. However, in 30 years' time, that same basket of goods may cost over $200, if inflation continues to average 2.5% per annum. So the labourer's nominal wages may be $200 per day, but their real wages will still only be $100 per day in today's values.

Discounting real costs back at 7% per annum, the total lifetime costs for today's infants will be $240.3 million in NPV terms. Prevalence for this cohort is 8,225 (41,132/5). This gives per person costs of $29,200 for a baby due to his or her eye condition[37].

The same methodology is applied to children who first develop eye conditions at later ages, with lifetime costs decreasing the later eye conditions are developed. Thus real NPV lifetime costs for those who first contract eye conditions at 17 is only $8,000, for the expenditure due to the condition.

[37] Undiscounted real lifetime expenditure per person is estimated at $69,557.

Chart 3.8: Lifetime health system expenditure per person by age condition is first developed



Source: Deloitte Access Economics' calculations.

The average lifetime health system cost, in discounted 2015 dollars, for a child who has eye disease ranges from $8,000 per person (developed condition at 17 years of age) to $29,200 per person (developed condition in the first year of life). Lifetime costs are higher for males than for females.

This calculation assumes that if someone develops an eye condition during their childhood, then they will have this condition until they die. However, it does not take into account any eye conditions they may develop during adulthood. For example, presbyopia is excluded, because even though it begins in childhood, it does not cause VI until adulthood.

4 Other financial costs

In addition to health system costs, there are other large financial costs associated with VI in children incurred through lost productivity, informal and formal care, aids and modifications, costs of other government programs, and deadweight losses associated with transfers.

4.1 Lost productivity of children in childhood

It would be reasonable to expect that having VI might be a serious impediment to education and thus productivity. Logically, children with VI may take longer to learn to read and write. However, as discussed under the quality of life impacts in Chapter 5, there are relatively small differences between Year 12 completion rates for children with VI and the rest of the population. Year 12 completion rates, and completion rates of post-school education, are typically indicative of employment prospects and lifetime earnings.

While educational attainment is one indicator of lifetime productivity impacts, there is also clear evidence in the US, Canada and Australia showing that having VI directly reduces the chances of being employed (see Section 4.1.1). This may indicate that learning outcomes are affected, while completion rates are not.

In line with requirements in most states that you can only be formally employed if you are over 14 years old, only those children aged 15 to 17 are assumed to be in the potential workforce.[38] Further, most people in this age group will still be studying, so if they do have jobs they will generally be part-time or casual.

Labour market statistics from the ABS (2014d; 2014e) show that 41% of 15 to 19 year old males will have at least some employment, with the average job paying $365 per week. Young females are more likely to have a job (45%) but one that pays less ($251 per week). Average earnings is likely to be strongly influenced by school-leavers (generally 17-19 year olds).

Illness and disease more broadly may lead to productivity losses where they result in higher-than-average absenteeism, and lower-than-average productivity at work (i.e. presenteeism).

- Normally, estimates of productivity losses include lost lifetime earnings due to premature deaths attributable to vision loss, and the 'bring forward' of employers' search and hiring costs resulting from replacing employees lost to premature deaths. However, as the AIHW (2008) reports that only one child died from an eye condition in the decade to 2007, the cost of productivity loss from premature mortality in children due to eye conditions is considered immaterial here.

[38] Some states allow restricted work by children under 15, such as in a family business, or only outside school hours.

- Where possible, estimates of productivity losses also include reduced productivity when at work, or presenteeism. However, no literature was identified that included any parameters for presenteeism from VI. A case study of workers with disabilities, which includes VI, by the Victorian Department of Education (2005) found no differences in productivity between these workers and others in the study.

Short-term impacts of VI were measured using a friction methodology and largely comprise absenteeism costs. The friction methodology measures the cost from the employer's perspective to sustain production until an employee who has VI returns to work or is replaced (e.g. sick leave and overtime premiums for a temporary replacement worker). As is appropriate in developed countries, a human capital approach was adopted to measure long-term productivity losses. The human capital approach, as opposed to the friction method, measures the cost to society of a contraction in the production possibility frontier due to lower labour inputs overall. A review of available literature was undertaken to determine key parameter inputs, including the change in employment participation and productivity associated with VI.

4.1.1 Lower workforce participation

The Vision Australia's Employment Research Survey indicated that only 36% of all people of working age with VI were gainfully employed in 2012 (Vision Australia 2012a), compared to 61.6% in the Australian general population (ABS, 2015). This infers that for a person with VI the chances of being gainfully employed are only 59% as high as someone else who does not have VI. Similar rates of employment for young adults with VI have been have been observed in the US and Canada, with 41.5%[39] and 29%[40] being employed respectively. Both the US and Canada have employment to population ratios similar to those of Australia.

However, these surveys either deal with VI that causes disability, or cover VI which has a distribution by severity that is worse than in the general population. The US study only includes children with disability by default. In the Canadian study, 40% (113/328) of those surveyed were blind. Further, evidence from Britain shows that people with a 'seeing difficulty' who are not disabled have similar levels of employment when compared to people who are not disabled and without a 'seeing difficulty' (Hewett and Douglas, 2011).

Accordingly, employment impacts in this report are adjusted by the proportion of people with VI causing disability. Employment rates were calculated by dividing the number of employed people by the total number of males and females in the corresponding groups from 15 to 17 years. The difference (or excess) between the employment rates for people with VI causing disability and the employment rates for the general population was attributed to VI causing disability. The AHS shows that approximately 15% of people aged 0 to 25 in Australia have VI that causes disability, while the remaining 85% are assumed to have no productivity impacts.

[39] This proportion is for young adults up to 26 years of age. Data obtained from National Longitudinal Transition Study 2 (NLTS2 2003) data tables. Available at: http://www.nlts2.org, accessed on 3 March 2015.

[40] This proportion reflects only those aged between 15-30 years old. Data from Shaw et al (2007).

Data on employment rates and average weekly earnings (AWE) for each respective age-gender group were combined with the proportion of childhood VI causing disability to calculate the lost earnings due to reduced employment.

> Lost earnings due to reduced workforce participation from VI in children, compared to the general workforce, was estimated as $32 million in 2015.

4.1.2 Absenteeism from paid and unpaid work

For people with VI who are employed, the condition can adversely affect work performance through absence from work (absenteeism). Absenteeism is measured by looking at the number of working days missed by people with VI over a 12-month period.

According to the ABS (2014c), people with VI took an average of 7.8 days off work each year. In comparison, those with no long term conditions took an average of 5.2 days off per year. Therefore, the difference due to VI is 2.6 days. For those who do not work, the same number of days was estimated to be lost from their household productivity, which was valued at 30% of the average wage rate.

In the absence of any conditions, it is assumed that people with VI in each age-gender group would participate in the labour force and obtain employment at the same rate as the general population, and earn the same AWE. As such, absenteeism is based on these parameters and incorporates the AWE for each age-gender group.

> The cost of absenteeism and lost home production due to VI was estimated as $17 million in 2015 for children of working age, of which $14 million was paid by employers.

4.1.3 Total lost productivity

The total productivity impact in working aged children is $49.8 million per year ($17.4 million due to absenteeism and $32.4 million due to lost productivity). This translates into $147 per person annually, or $3 per week on average.

4.2 Lost productivity in the future when today's children become adults

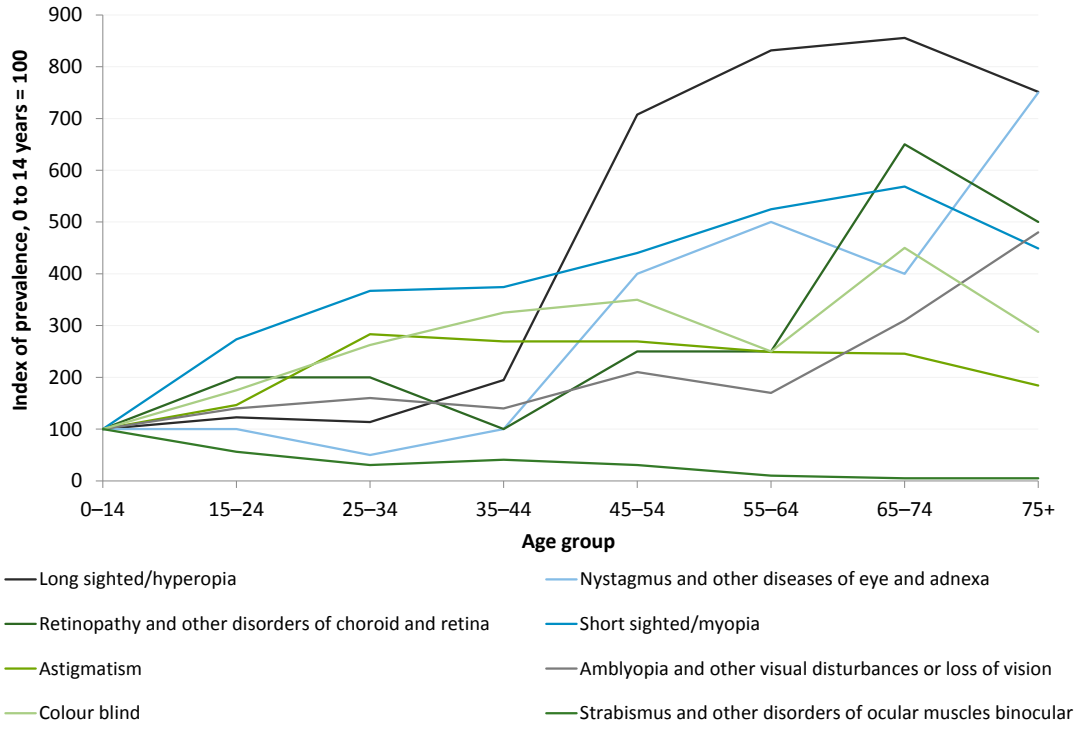
In addition to the small proportion of children with VI who are incurring current productivity losses, there are large potential productivity impacts expected to occur over the working lives of current children with VI. Again, this relates to VI that causes disability.

As forecasting future incomes over such a long period is difficult, the approach taken in this report is to estimate the productivity impacts in today's adults, from eye conditions they have had since childhood. This serves as a proxy for productivity that will be lost in the future, when today's children with VI enter their working careers.

4.2.1 Future impacts of current childhood prevalence

Although prevalence of VI in children is lower than in old age, children will have to live with their VI for a longer period of time than the elderly will. As discussed in Chapter 1, children are likely to have VI for the duration of their life. Chart 4.1 shows that prevalence rates for all broad eye condition categories continue to increase with age through to retirement age, except for strabismus.

Chart 4.1: Changes in prevalence rates by age and condition



Source: ABS (2013)

Therefore, it is assumed that prevalence rates stay constant from age 18 through to retirement (or death). For example, the increasing rates of myopia by age are assumed to be from people who only need to start wearing glasses during their adult years.

There are three modifications made to prevalence amongst the adult cohort – strabismus and colour blindness are excluded from the adult prevalence cohort when calculating lost productivity amongst adults, and VI caused by RE is adjusted. As noted in Chart 2.4 and Chart 2.6, strabismus rates have already declined to low levels by the time children reach high school, and Chart 4.1 shows that they only continue to diminish thereafter. Since strabismus is declining over time, it is not included in the model after adulthood.

Colour blindness is excluded from the adult prevalence cohort for two reasons. First, colour blindness does not cause VI, although conditions associated with colour blindness may cause VI. Second, the AHS showed that having colour blindness did not lead to an increase

in absenteeism or unemployment compared to the population without long-term health conditions.[41]

Finally, the prevalence of VI from RE is also considerably lower in the adult model. This is not due to a change in the prevalence of the underlying condition; rather, adults have lower ratios of presenting VI to uncorrected VI than children do.

After making these adjustments, 3.4% of adult males, and 5.2% of adult females are assumed to have VI from childhood eye conditions. To calculate lost productivity for this cohort, the same methodology that was employed for children in section 4.1 is applied here. One minor adjustment is made to incorporate increasing severity of VI over time, by using the proportion of VI that causes disability in the working age population, which serves as a proxy for worsening eye sight. This is approximately 20% for this cohort compared with 15% in children as in Section 4.1.

It is estimated that Australians currently in the workforce are losing $3.1 billion dollars per year in terms of reduced productivity due to VI from eye conditions that they contracted during childhood.[42]

- As with the calculations for children, the impact of premature deaths is not included. The AIHW (2008b) reports two deaths in adults under 65 years of age due to diseases of the eye and adnexa in the decade to 2006.

Table 4.1: Current productivity impacts in adults from VI contracted in childhood

Category	Cost ($ billion)
Unemployment	2.51
Absenteeism	0.56
Total	**3.07**

Source: Deloitte Access Economics' calculations.

Assuming that today's children with VI will experience the same productivity impacts as those experienced in current adults of working age who have had VI since childhood, then the productivity losses are expected to be $0.77 billion in NPV terms.

However, the current workforce has a high number of workers who came to Australia when they were older than 17. Accordingly, the estimated future costs have been adjusted to only include the current cohort of 17 year olds as they age. This yields expected total future costs of $0.68 billion in NPV terms (Table 4.2).

[41] However, having colour blindness does prevent participation in some occupations.

[42] For this calculation, it is assumed that everybody has retired before they turn 75.

Table 4.2: NPV of future impacts on current children

Age range	Undiscounted future impact in adults ($bn)	Discount rate, at 7% p.a.	NPV future impacts on current children ($bn)
18-19	0.02	1.00	0.02
20-24	0.21	0.75	0.14
25-29	0.35	0.52	0.15
30-34	0.39	0.36	0.12
35-39	0.36	0.25	0.08
40-44	0.40	0.18	0.06
45-49	0.39	0.12	0.04
50-54	0.36	0.08	0.03
55-59	0.29	0.06	0.02
60-64	0.18	0.04	0.01
65-69	0.09	0.03	0.00
70-74	0.02	0.02	0.00
Total	**3.07**		**0.68**

Note: last column = second column multiplied by third column.

Source: Deloitte Access Economics' calculations.

For each of the estimated 12,561 17 year olds[43] with VI about to enter adulthood, this translates to lost lifetime earnings of $53,916 (0.68 billion/12,561) in NPV terms. Assuming that they will all retire by age 75, that is equivalent to reduced earnings of $946 per year on average. This is mainly a function of the employment gap between people with VI causing disability and their peers without VI.

4.3 Other indirect costs

4.3.1 Informal care

There are two forms of welfare relating to eye conditions. The first is support to children with the eye conditions, such as Disability Support Pension (DSP), Newstart Allowance, Youth Allowance and Sickness Allowance. The second is carer support paid to those who care for others with eye conditions, such as Carer Allowance and Carer Payment.

There is an additional cost for carers, in terms of lost productivity relating to the time that they reduce paid work to care for children with eye conditions.

[43] 150,252 17 year old males * prevalence of 3.4%; 142,232 females * prevalence of 5.2%

4.3.1.1 Support for children with eye conditions

Centrelink data obtained by special request shows that there were 12,750 recipients of Disability Support Pension (DSP) who were considered as 'blind'. There were 284 recipients aged between 15 and 19, of which 170 are estimated to be aged between 15 and 17.[44]

The DSP rate for persons under 18 and living at home is currently $355.30 per fortnight, or $9,328 per year. Accordingly, it is estimated that support directly to children with eye conditions totals $1.6 million per annum. As a transfer payment, this is not considered a cost to society as a whole. However, there are costs imposed on the economy from raising the taxes required to pay for these transfers, referred to as deadweight losses (see Section 4.3.4).

- Centrelink was not able to supply data on how many children with VI were in receipt of Youth Allowance.
- Sickness Allowance and Newstart Allowance are only paid to persons aged 22 years or older.

If a higher proportion of people with a particular condition are on welfare than is the case for the general population (average reliance), then the difference can be attributed to that particular condition. Centrelink data shows that 1.3% of 15 to 17 year olds are in receipt of DSP, which is taken as a proxy for average reliance.

4.3.1.2 Carer support

Carers can also receive support for looking after people with eye conditions including: blindness, low vision, eye anomalies and deafblindness[45]. Assuming that children with VI constitute the same proportions of Carer Allowance and Carer Payment as they do for DSP, then there would be 123 people receiving Carer Allowance, and 43 people receiving Carer Payment for looking after children with VI.

Current rates for Carer Allowance are $122 per fortnight, and $777 per fortnight for Carer Payment. Accordingly, it is estimated that carer support totals $1.3 million per year. As with support for children with eye conditions, there are deadweight losses associated with these transfers.

4.3.1.3 Lost carer productivity

The SDAC (ABS, 2014f) shows that **there were 8,540 carers for people with eye conditions, providing a total of 11.8 million hours of care each year**. As a share of total eye condition prevalence in the AHS, children account for 4% of the total. Similarly, the SDAC shows that children account for 4% of people with eye conditions cared for. Accordingly it is assumed that children also receive 4% of total eye condition carer hours, or 0.47 million hours. Assuming that these carers have the same age-gender distribution as the population at large, and the same wage and employment rates as their (age-gender) peers, then their

[44] 0.6 * 284.

[45] As deafblindness could potentially be counted under both eye and ear conditions, only half of these carers were allocated to eye conditions.

total lost productivity is $8.2 million per year. Unlike the welfare support received by these carers, this lost productivity is a direct cost to the economy.

4.3.2 Aids and equipment

Aids and home or vehicle modifications are those not captured in formal health sector or disability services costs that include equipment and technology in order to assist with daily living.

The AHS reports that almost everybody (97%) with sight problems wears glasses. The consumer magazine CHOICE reported that in 2010, the costs of a pair of single-vision spectacles with standard plastic lenses and anti-scratch coating, and unisex metal frames ranged from $125 to $250[46]. Taking the average price ($188) and allowing for inflation to 2015 gives an average cost of $209. Assuming that most spectacles last for two years, this gives an annual cost of $104 for those who wear glasses. Adjusting for those who do not wear glasses, the average annual cost per person with sight problems is $101.

- People with VI may also require a variety of aids, special equipment and home modifications to function adequately and enhance their quality of life. For example, Lafuma et al (2006) quantified the excess use of resources per visually impaired person in France, Germany, Italy and the United Kingdom. The study found that up to 33.7% more visually impaired people required various devices than in the non-visually impaired population. However, such studies focus on the needs of the elderly e.g. for falls prevention– who account for most VI in the general population. In the absence of any identified studies dealing with need for equipment in children with VI, these costs have not been included in the model.

4.3.3 Funeral costs

The AIHW (2008a) records that there was only one child with diseases of the eye or adnexa as the underlying cause of death in the decade to 2006. Widening the scope to include eye cancers, injuries and congenital malformations, there were seven such deaths over the decade to 2006. Statistically, this is less than one death per year, and given the cost of a funeral is relatively small, the bring-forward of funeral costs are considered immaterial in this model.

4.3.4 Transfers and deadweight losses (DWL)

Transfer payments represent a shift of resources from one economic entity to another. As the act of taxation and redistribution creates distortions and inefficiencies in the economy, transfer payments involve real net costs to the economy.

The Government in Australia provides funding for much of the direct health care system costs, and social security (transfer) payments associated with VI. To achieve a budget neutral position, the government needs to effectively raise sufficient tax revenue. Taxes

[46] http://www.choice.com.au/reviews-and-tests/money/shopping-and-legal/shopping/spectacles-buying-guide.aspx#ixzz3TIRr5AcI

and transfers, such as subsidies and pensions, do not themselves represent a real economic cost because they are payments from one economic agent to another and do not involve a net use of resources. However, the cost of raising revenue to fund transfer payments is not frictionless because tax reduces the efficiency with which the economy's resources are used. For example, an increase in income tax rates will increase the relative price of work compared to leisure and therefore create a disincentive to work. Consequently there is an associated reduction in consumer and producer surplus, which is known as the deadweight loss (DWL), or excess burden, of tax.

This section estimates the size of DWLs associated with having to raise additional taxation revenue to replace taxation revenue lost from lower productivity among children with VI (section 4.3.4.1), welfare and income support payments (section 4.3.4.2) and to fund direct healthcare costs associated with childhood VI.

4.3.4.1 Lost taxation revenue from lower productivity

Reduced earnings due to reduced workforce participation, absenteeism and premature deaths have an effect on taxation revenue collected by the government. As well as forgone income (personal) taxation, there will also be a fall in indirect (consumption) tax, as those with lower incomes spend less on the consumption of goods and services.

There are two sources of lost tax revenue that result from the lower earnings – the personal income tax forgone and the indirect (consumption) tax forgone. The latter is lost because, as income falls, so does consumption of goods and services. Based on parameters from the Deloitte Access Economics macroeconomic model, this study applied an average personal income tax rate of 22.8% and the average indirect taxation rate used of 13.0%. In 2015, reduced productivity attributable to VI in children resulted in $19.8 million of lost potential tax revenue.

These distortionary impacts of taxes on workers' work and consumption choices have been estimated to be 27.5 cents for each tax dollar collected (Productivity Commission, 2003). There is also an additional 1.25 cents in the dollar from government administration costs. Accordingly, there was an associated deadweight loss of $5.7 million.

Table 4.3: Deadweight losses from taxation

Parameter	Cost ($m)
Potential earnings lost ($million)	55.4
Average personal income tax rate*	22.8%
Potential personal income tax lost	12.6
Average indirect tax rate*	13.0%
Average indirect tax lost	7.2
Total potential tax revenue lost	19.8
Deadweight loss from additional taxation	**5.7**

Source: Deloitte Access Economics' calculations. * Deloitte Access Economics Macroeconomics Model

In 2015, around $5.7 million in DWL was incurred from having to raise $19.8 million of forgone taxation due to lost productivity from children with VI.

4.3.4.2 Welfare and income support payments

In total, there are $2.8 million in welfare payments (section 4.3.1.1 and 4.3.1.2), with a corresponding DWL of $0.8 million.

4.3.4.3 Health system costs

As discussed in Chapter 3, the total direct health system expenditure associated with childhood VI is estimated to be $439 million. State and Federal governments funded $300 million of this total. The DWL associated with the provision of services is estimated at $86.1 million.

4.3.4.4 Total DWL

In total, taxes raised to cover welfare payments, health expenditure and lost income cause $93 million in deadweight losses.

Table 4.4: Deadweight losses associated with childhood VI

Category	Outlays	DWL
Health system costs borne by government	299.6	86.1
Lost taxes	19.8	5.7
Welfare payments	2.8	0.8
Total	**322.3**	**92.7**

Source: Deloitte Access Economics' calculations.

4.3.5 Summary of other financial costs

Table 4.5 presents the total financial costs of vision loss from childhood VI, other than health system costs. A substantial proportion of these costs are related to the productivity losses associated with VI in children.

Table 4.5: Summary of other financial costs associated with childhood VI in 2015

Cost items	Total costs ($million)
Productivity costs	49.8
Carer costs	8.2
Aids and modifications	34.2
Deadweight loss	92.7
Total other financial costs	**184.8**

Source: Deloitte Access Economics calculations.

Financial costs, other than health expenditure, associated with childhood VI are estimated to be $184.8 million in 2015.

This study did not include the costs of informal care, lower productivity while at work (i.e. presenteeism) or welfare payments, because of a lack of robust data. The estimate for other financial costs is thus likely to be conservative.

5 Quality of life

This chapter estimates the cost to people with VI of the morbidity their conditions inflict on them. It also assesses the impact of VI on children during their schooling years.

5.1 Disability adjusted life years

Paediatric vision loss imposes a burden that extends beyond health care systems and has broader economics costs. A person with vision loss will experience a lower quality of life due to morbidity and possibly premature mortality.

The 'Burden of Disease' methodology developed by the WHO, World Bank and Harvard University provides a comprehensive measure of mortality and disability from diseases, injuries and risk factors for populations around the world (Murray and Lopez 1996). It uses a non-financial approach, where pain, suffering and premature mortality are measured in terms of disability adjusted life years (DALYs).

DALYs are measurement units that quantify the morbidity aspect as well as the premature death associated with various health conditions. DALY weights are measured on a scale of zero to one, where zero represents a year of perfect health and one represents death. Other health states that result from specific diseases or injuries are given a weight between zero and one to reflect the quality of life that is lost due to a particular condition. A disability weight of, for example, 0.195 for people with blindness, is interpreted as a 19.5% loss in the quality of life relative to perfect health. The disability weights are pre-agreed by a reference group convened at the WHO on the basis of a person trade-off method for measuring health state preferences (Murray and Acharya 1997).

Under the DALY framework, the total burden of disease for an individual with a condition is the sum of the mortality and morbidity components associated with that condition, and includes the years of healthy life lost due to disability (YLDs) and the years of life lost due to premature death (YLLs). Aggregating the DALYs of all people with a particular condition produces the total burden of that disease on society.

The AIHW (Mathers et al, 1999) report disability weights associated with mild, moderate and severe vision loss as 0.004, 0.17 and 0.43 respectively. Taking a weighted average based on prevalence of mild and moderate vision loss in children aged 0-14 as in Begg et al (2007), the disability weight in children aged 0-14 is 0.0203. The disability weight for blindness (0.43) is applied to the prevalence of blindness obtained from ACVIR.[47] It was assumed that the person with VI would experience poor vision for the entire year. The

[47] While the 2010 global burden of disease study provided updated disability weights – 0.004 for mild vision loss, 0.033 for moderate vision loss and 0.191 for severe sight loss (or blindness) (Salomon et al, 2012) – there has been debate over the weights assigned to sight loss and blindness. Taylor et al (2012) argue that the disability weights assigned are too low, and that "investigation and explanation" is required before they can be adopted. As such, we have maintained use of the disability weights used in the 2003 Australian burden of disease study (Begg et al, 2007).

number of YLDs associated with low vision and blindness from paediatric eye disease is estimated as 6,983 in Australia in 2015.

Applying the ratio of multiple causes of deaths due to diseases of the eye and adnexa to the underlying causes of deaths due to diseases of the eye and adnexa gives the attributable fraction of deaths due to VI. Over the five years to 2012, the ABS (2014b) reported 38 deaths (across all ages) were due to diseases of the eye and adnexa, while it was listed as a multiple cause of death 3,228 times, a ratio of 0.0118. Applying this ratio to the expected deaths in children with VI, it is expected that there would be between four and five deaths due to VI over a five year period. The YLLs due to these deaths was estimated for each age-gender group determined via Standard Life Expectancy Table for a single year period. Applying a discount rate of 3%, the total YLL was estimated to be 27 YLLs in Australia in 2015.

> Total DALYs associated with paediatric VI is estimated to be 7,011 years in 2015.

The DALY approach is not financial, and thus not directly comparable with monetary costs and benefits associated with a particular condition. In order to make comparisons, a monetary conversion of the loss in healthy life is usually performed. This allows the determination of the total cost of a condition and also the comparison of this cost to the benefit from a particular health intervention. The monetary conversion involves applying the value of a statistical life year (VSLY) in perfect health to the total number of DALYs estimated for a particular condition. The VSLY essentially estimates how much society is willing to pay to save a statistical healthy life year.

In Australia, the Office of Best Practice Regulation stipulates that public policy proposals should use a VSLY of $151,000 in 2007 dollars (Department of Prime Minister and Cabinet, 2014). This corresponds to $187,200 in 2015 value, after accounting for inflation[48].

- The VSLY is derived by measuring consumers' willingness to pay to avoid risk, largely derived through wage-risk trade-off studies (e.g. higher compensation for working in more dangerous occupations such as underground coal mining) as well as willingness to pay for safety (e.g. to pay more to fly with an airline with the lowest accident rates).
- The WHO (2011) has a similar value for life years lost. It defines an intervention as being cost effective if it saves one year of healthy life for up to three times GDP per capita -which in Australia is also around $187,000. As most people choose to only spend a third of their hours at work, it is intuitive that they value their leisure and sleeping hours as much as their working hours.

[48] Inflated using ABS cat. no. 6401.0, Consumer Price Index, Australia, Dec 2014, and 5 year average between June 2009 to June 2014 to determine the index value in June 2015.

Using this estimated VSLY, the total monetary value of the burden of disease of 7,011 DALYs amounts to $1,312.3 million in 2015. This equates to 0.2 DALYs per child with VI, or $3,880 per child.

It is important to note that this is not a direct financial cost to the economy in the traditional sense; it is the value of a loss in the stock of health capital.

5.2 Educational and social impacts

Limited research has been done on the educational and social impacts of vision impairment in Australia to date. Ideally, Australian research that assessed reading and writing ability, amongst other educational impacts, would highlight the quality of life impacts that having VI during childhood imposes throughout the expected life of each person. However, almost all of the literature focuses on transitional employment outcomes for people with a disability, as captured in Section 4. However, one key study in addition to the AHS was identified in Australia that attempted to highlight educational attainment for those with disability caused by vision impairment. While other Australian research projects appear to collect relevant data, little of the collected information relevant to this project has been published.[49] As such, another three longitudinal studies – from the US, United Kingdom (UK) and Canada – were used to attempt to triangulate these results, and discover impacts of VI on social outcomes (section 5.2.2).

5.2.1 Australian evidence

In Australia, the ABS (2011) reports that students with a disability are less likely to have attained Year 12, however this is not specific to vision loss. Of those with a disability, 62% had completed year 12. By comparison, 78% of those without a disability had completed year 12. This is influenced by severity of disability, with those reporting a moderate or mild disability completing year 12 in 73% of instances, while severe disability is considerably lower. This suggests that only those with severe vision loss would be likely to experience lower educational attainment.

This statement is supported in other Australian studies. Lamb and McKenzie (2001) analysed data from the Longitudinal Surveys of Australian Youth to report on the patterns of success and failure in the transition from school to work in Australia. In this cohort, those with a disability were less likely to be full-time employed as is expected, however, the proportion of those undertaking full-time study in the 7 year follow-up after leaving school was similar for those with and without disability.

Analysis of known outcomes in the ABS' AHS agrees with data reported in ABS (2011) – when considering young adults (aged 25-34) that have recently finished education, the majority of those with diseases of the eye and adnexa have completed year 12 and this is higher than the rate of completion in the general population (82% and 76% respectively).

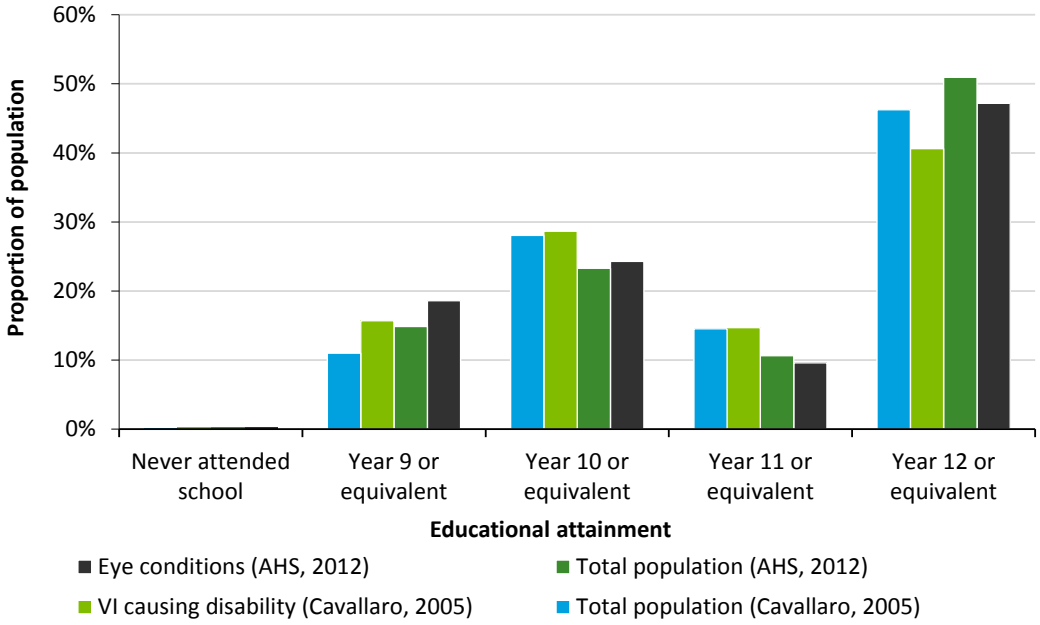
[49] For example, see the Longitudinal Surveys of Australian Youth, available at http://www.lsay.edu.au/index.html.

There are slightly less children with eye conditions leaving school by year 9 compared to those in the general population (2% and 3% respectively).

The only identified Australian study that estimated school completion rates for VI causing disability was a sample of students, across all ages, attending vocational education and training (VET) (Cavallaro et al, 2005). Again, the findings in this study present data only for the known outcomes. Despite this, the proportions of those completing each year of school are remarkably similar to the findings in the AHS for the entire population, as shown in Chart 5.1. However, when comparing this study to AHS when considering only young adults aged 25-34, the educational outcomes are substantially different. Chart 5.2 shows that there are no discernible negative impacts on educational attainment for young adults with VI. This may reflect that a significant proportion of childhood VI is mild (Section 5.1), or the substantial educational support available to those with disabilities and VI in Australia.

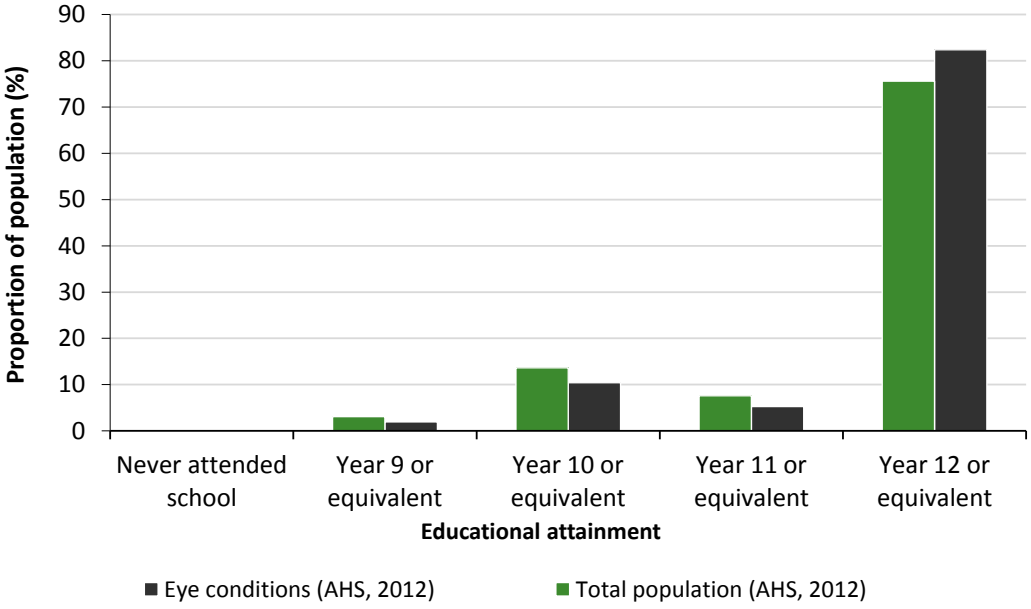
Further, data from the AHS for young adults aged 25-34 indicates that those with eye conditions have obtained a similar or higher level of post-school education compared to those in the general population (Chart 5.3).

Chart 5.1: Educational attainment for those with eye conditions and general population



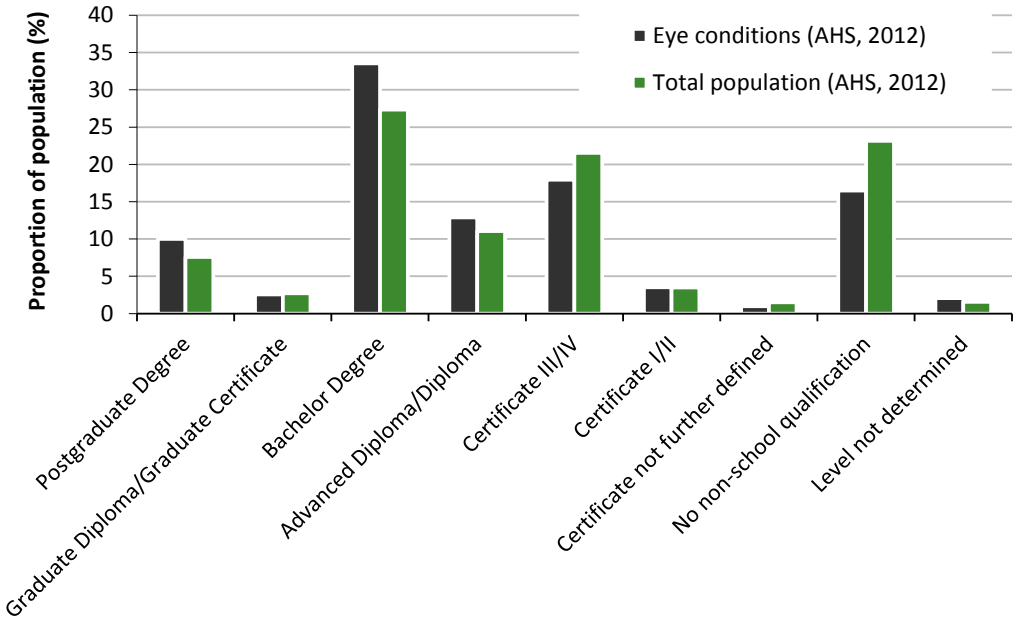
Source: ABS (2014), Cavallaro et al (2005) and Deloitte Access Economics' calculations.

Chart 5.2: Educational attainment by condition, ages 25-34



Source: ABS (2014).

Chart 5.3: Post-school educational attainment, age 25-34



Source: ABS (2014).

Within students undertaking VET, Cavallaro et al (2005) found that subject completion rates for those with VI causing disability were similar to but slightly lower than the sample without a disability (79.5% and 81.9% respectively). Additionally, the proportion of students completing an Australian qualifications framework accredited subject was slightly

lower (15.6% and approximately 18% respectively). In general, slightly lower educational participation underscores the employment impacts for those with VI causing disability estimated in Section 4, due to the links between educational and employment participation.

5.2.2 International evidence

Evidence from other English speaking countries was also reviewed to assess the impact of VI on educational outcomes.

UK

A UK study attempted to establish the effects, if any, that amblyopia had on educational, health and social outcomes (Rahi et al, 2006). This included factors such as unintended injury, sport participation, social activities, behavioural activities as well as education impacts, employment impacts and mortality.

Compared to the general population (those with normal vision) and after adjusting for other factors, those with VI from amblyopia were:

- More likely to have completed higher education;
- Less likely to have participated in social activities such as sport, dancing or going to the cinema; and
- More likely to report poorer health.

However, due to a small sample size, none of these results were statistically significant. Whether a larger sample would yield similar results is to be determined, however this study presents no evidence to contradict what is observed in Australia as in Section 5.2.1.

US and Canada

The National Longitudinal Transition Study (NLTS) in the US has been following students with a disability for a number of years. Publications from the NLTS commonly present the employment and educational outcomes for young adults transitioning to a work environment in the US.

For students with VI and no other disability, grades were comparable to those of students without disabilities. They also had similar patterns of attending college. As with the findings presented in Section 4, the greatest difference between those with VI and those without VI was found in employment rates (Shaw et al, 2007). There was no independent impact on social involvement, and those with VI had higher reading and mathematics scores compared with other disabilities (Wagner et al, 2003).

A similar study in Canada observed that, of young adults with VI, educational attainment was comparable to those without a disability (Shaw et al, 2007).

5.2.3 Summary of educational and social impacts

As there is limited data pertaining to educational and social impacts that are caused by disability associated with vision loss, no separate estimates of the quality of life lost

associated with factors such as reduced reading ability are estimated here. It is important to note that the productivity cost of lower employment calculated in Section 4 would capture any potential financial impacts resulting from lower educational and social outcomes, and the general impacts on quality of life are captured in section 5.1.

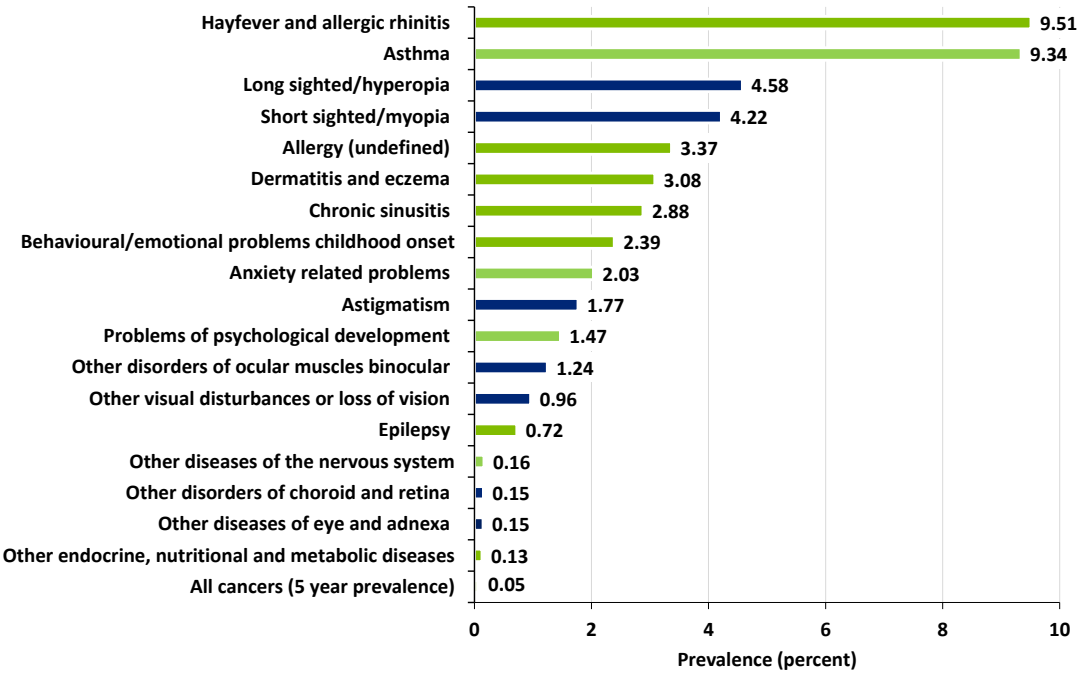
6 Conclusion

While children may only account for a minority of VI in Australia, there are still substantial associated health system, productivity and morbidity impacts. For the most part, these children will continue to have sight problems throughout their working careers, which will cause large and ongoing productivity costs.

6.1 Prevalence

Eye conditions are highly prevalent in Australian children. The ABS (2012) reports that RE accounts for three of the top ten most common long-term health conditions in under 15 year olds – hyperopia (3rd), myopia (4th) and astigmatism (10th). This also continues into adulthood , as shown in the Economic Impact of Vision Loss in Australia in 2009 which found that most vision loss in Australians aged 40 years or over was uncorrected refractive error (over 341000 people) (Access Economics, 2009).

Chart 6.1: Prevalence of select long-term health conditions in Australian children, by order of frequency



Source: ABS (2012) and AIHW (2014b).

While RE accounts for a large proportion of eye conditions in Australian children, this data also shows that other disorders of ocular muscles binocular, and other visual disturbances

or loss of vision are more common than many other childhood conditions such as epilepsy, cerebral palsy, cystic fibrosis and childhood cancer.[50]

Drawing principally on the AHS, and supplemented by Australian paediatric eye health studies and screening programs, Deloitte Access Economics estimates that there are almost a third of a million (332,936) Australian children with VI in Australia in 2015 (Section 2.3).

Table 6.1: Estimated prevalence of VI in Australian children (under 18), 2015

ICD-10 description	Condition	Prevalence ('000s)		
		Male	Female	Total
Disorders of choroid and retina (H30-H36)	Retinopathy and other disorders of choroid and retina	1.98	5.48	7.46
Disorders of optic nerve and visual pathway (H46-H48)	Disorders of optic nerve and visual pathway	5.48	3.70	9.18
Disorders of ocular muscles and binocular movement (H49-H51)	Strabismus and other disorders of ocular muscles binocular	37.84	27.28	65.12
Hypermetropia (H52.0)	Long sight/ hyperopia (presenting)	40.13	62.29	102.41
Myopia (H52.1)	Short sight/myopia (presenting)	54.96	52.76	107.71
Astigmatism (H52.2)	Astigmatism (presenting)	18.36	19.62	37.97
Visual disturbances (H53)	Amblyopia and other visual disturbances or loss of vision	21.39	47.33	68.72
Visual impairment including blindness (H54)	Blindness (including partial)**	0.19	0.13	0.32
Other disorders of eye and adnexa (H55-H59)*	Nystagmus and other diseases of eye & adnexa	8.19	6.97	15.15
Congenital malformations of eye (Q10-Q15)	Congenital eye anomalies	1.75	0.95	2.70
Total persons		**151.99**	**180.94**	**332.94**

Note: total persons is less than sum of conditions due to comorbidities. Does not include colour blindness. * The AHS category 'Other diseases of eye & adnexa is not directly comparable with the ICD 10 category 'Other disorders of eye and adnexa' since the AHS category is designed to capture all other eye diseases not included under the other headings in the table. ** Blindness is a functional state rather than a condition. The most common conditions for blindness include CVI, oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma and congenital cataract.

Source: AHS 2011-12, ACVIR, Australian Congenital Anomalies Monitoring System, Australian paediatric eye health studies, StEPS, and Deloitte Access Economics calculations.

While RE is by far the most common sight problem, it is equally the most easily corrected. Unlike other conditions that require surgery (e.g. cataract) or are untreatable (e.g. visual pathway disorders), RE requires appropriate spectacles or lenses for correction. However, many children do not have their RE corrected. Consequently, under-corrected RE still accounts for the majority of VI in children. Most of the remaining VI is caused by conditions

[50] Note: Cerebral palsy is under the category 'Other diseases of the nervous system', and cystic fibrosis is under the category 'Other endocrine, nutritional and metabolic diseases' shown in Chart 6.1.

such as amblyopia or strabismus, which are managed by occlusion therapy (patching), surgery and medications. The high levels of under-corrected VI in Australia highlight the need for more complete screening programs across Australia, especially since normal visual development may not occur if this remains untreated in the first eight years of life.

There are also a large number of rare eye disorders, which by definition affect less than five out of every 10,000 people[51]. While very rare, these disorders tend to be severe and lifelong – for example, anophthalmia is the complete absence of an eye. Most paediatric eye health studies in Australia have not been large enough to capture more than a few cases of such diseases. The AHS covers over 20,000 households, which is sufficiently large, but it only reports down to the two digit ICD level. The NSW StEPS program easily screens enough people to provide comprehensive data. However, the data has not been released, except for two Local Health Districts and then only as RE, strabismus, amblyopia and "other" (Blows et al, 2014). Drawing from a UK national database of vision impairment, adjusted in the light of individual disease studies, it is estimated that around 0.5% of VI in Australian children is caused by rare disorders.

Given the paucity of relevant clinical studies, there is a need for more comprehensive studies to be conducted on rare childhood eye diseases in Australia. The substantial number of 'blind person years' attributed to childhood blindness and the life-long impacts of eye conditions on a child's later productivity and overall welfare make further investigation a matter of particular importance for public health policy and research. Greater attention to the issue would also be conducive to the fulfilment of Australia's international obligations as a member country to the WHO.

6.2 Health system costs

Costs to the Australian health system are approaching half a billion dollars per year to treat children with diseases of the eye and adnexa. **Total health costs were $439 million in 2015, or 11.3% of total health system expenditure on eye conditions in 2015.**

Consequently, the proportion of total health expenditure for eye conditions in children is much higher compared to their share of health expenditure for all conditions (8.5%) reported at the start of Chapter 3. While some of this increased share of cost represents screening programs and other interventions, this also reflects the increased burden of eye conditions on children.

[51] Commission of the European Communities, 2008

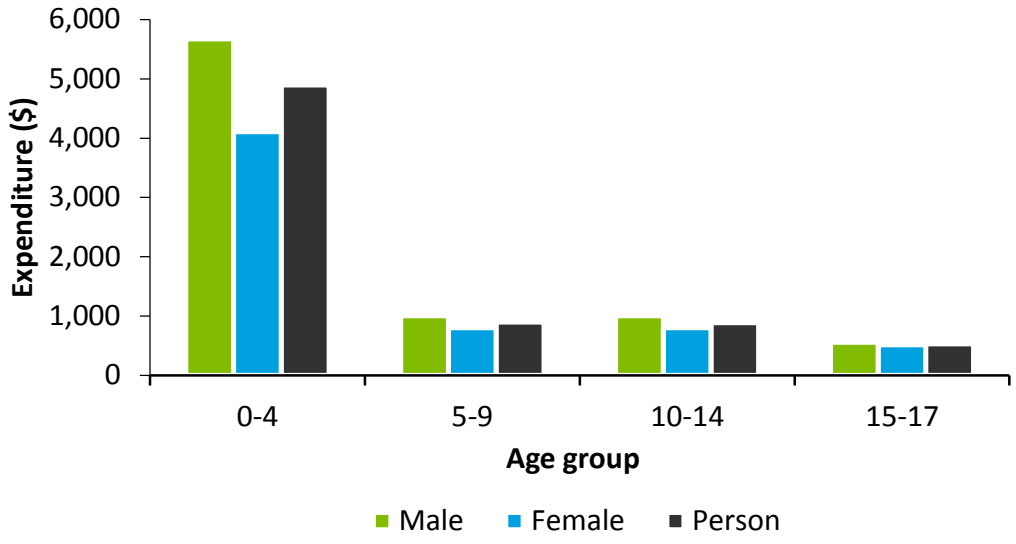
Table 6.2: Health system costs, 2015

Age	Males		Females		Total	
	Total	per person	Total	Per person	Total	Per person
	$m	*$*	*$m*	*$*	*$m*	*$*
0-4	117.6	5,675	83.9	4,109	201.5	4,898
5-9	48.2	1,006	40.9	801	89.1	900
10-14	52.8	1,006	53.6	801	106.4	891
15-17	17.9	557	23.8	514	41.7	531
Total	**236.5**	**1,543**	**202.2**	**1,094**	**438.7**	**1,298**

Source: Deloitte Access Economics' calculations based on AIHW (2009, 2010) and IHPA (2014).

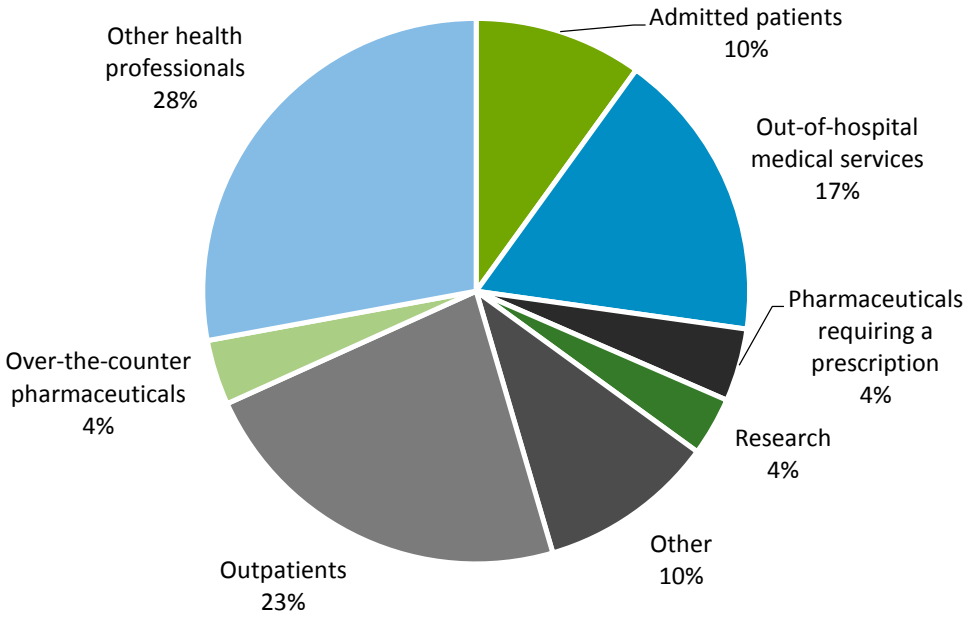
Almost half of this health expenditure ($202 million) is for children who are under five years old. Given prevalence rates for eye conditions are lower in this group than in older children (Table 2.10), this shows that the youngest children require more frequent and/or more complex interventions. Average expenditure per 0-4 year old with an eye condition is $4,898, compared to the average for all children of $1,298.

Chart 6.2: Health system expenditure per person, by age and gender, 2015



Source: AIHW special request and Deloitte Access Economics' calculations.

Chart 6.3: Allocated health system expenditure, by cost component, 2015



Note: cost of glasses is under the category 'Other'.
Source: AIHW special request.

The lifetime (real) health system expenditure for a baby born with an eye condition today is $29,200 in net present value terms, assuming life expectancy of 80 years for males and 84 for females (Section 3.3).

6.3 Productivity impacts

It would be reasonable to expect that having VI might be a serious impediment to education. The less one can see, the harder it could be to learn to read. As discussed under quality of life impacts in Chapter 5, having VI does not reduce Year 12 completion rates in young adults compared to their sighted peers.

However, evidence from the US, Canada and Australia shows that having VI that causes disability reduces the chances of being employed by almost 50%. This may reflect that educational outcomes are lower for those with VI, despite completion rates being comparable, although the reason for this is unclear.

Thus, even though most children do not work, reduced employability in children with VI costs the economy almost $50 million per year in lost productivity (Section 4.1). This translates into $147 per year for every child with VI.

Including health expenditure, lost productivity, and other financial costs, **the estimated economic impact of VI in children is $624 million per year** (Table 6.3), or $1,845 per child (Table 6.4).

Long term productivity costs are large. As today's 17 year olds will have to deal with their current eye conditions throughout their adult working lives, they can expect their **lifetime real earnings to be $53,916 (NPV) lower than their fully sighted colleagues**. Thus, any intervention which could fully correct VI in a child for up to this amount would be worth public investment.

6.4 Burden of disease

Diseases of the eye and adnexa do not cause many deaths. The AIHW (2008) reports that these conditions were the underlying cause of death for only one child over the ten years to 2007. Allowing an attributable fraction of those cases where eye conditions were an associated cause of death (ABS, 2014b), there is still statistically less than one death per year, with an expected (discounted) future total of 27 years of life lost (YLL).

Given how long today's children will have to live with their eye conditions, morbidity is a substantial issue. Mathers et al (1999) report disability weights associated with mild, moderate and severe vision loss as 0.004, 0.17 and 0.43 respectively. Taking a weighted average based on prevalence of mild and moderate vision loss in children aged 0-14 as in Begg et al (2007), the disability weight in children aged 0-14 is 0.0203. This translates into 6,983 prevalent years of life lost to disability (YLD) from low vision and blindness in Australian children in 2015 (Section 5.1).

Thus in total the burden of disease is 7,011 disability adjusted life years (DALYs). The Office of Best Practice Regulation stipulates that the value of a statistical life year is $187,200 in current dollars. Thus **the total cost of lost years of healthy life amounts to $1.31 billion, or $3,880 per child with IV in 2015.**

6.5 Overall costs

Health system expenditure accounts for the majority (70.4%) of financial costs caused by VI in children (Chart 6.4). As noted in Section 3.1, almost half of this expenditure goes to children under 5 years old. In most cost of disease studies, lost productivity is the largest financial impact. However, as most children do not work, current productivity costs are less than health system expenditure, accounting for 8% of total financial costs.

Given that health expenditure makes up the majority of total costs, it is not unexpected that governments bear most of the total costs (52%). Individuals and their families bear the second largest share of total costs (22%), largely through employment opportunities forgone and other financial costs.

Table 6.3: Total costs of VI in children, 2015 ($m)

	Individual	Family/ friends	Federal Govt.	State Govt.	Employers	Society/ other	Total
Health system costs	0.0	78.1	181.6	118.0	0.0	61.0	438.7
Productivity costs	23.9	0.0	16.9	0.0	9.0	0.0	49.8
Carer costs	0.0	5.3	2.9	0.0	0.0	0.0	8.2
Other costs	34.2	0.0	0.0	0.0	0.0	0.0	34.2
Dead weight losses	0.0	0.0	0.0	0.0	0.0	92.7	92.7
Transfers*	-1.6	-1.3	2.8	0.0	0.0	0.0	0.0
Total financial	**56.6**	**82.1**	**204.3**	**118.0**	**9.0**	**153.6**	**623.5**
BoD	1,312.3	0.0	0.0	0.0	0.0	0.0	1,312.3
Total with BoD	**1,368.9**	**82.1**	**204.3**	**118.0**	**9.0**	**153.6**	**1,935.9**

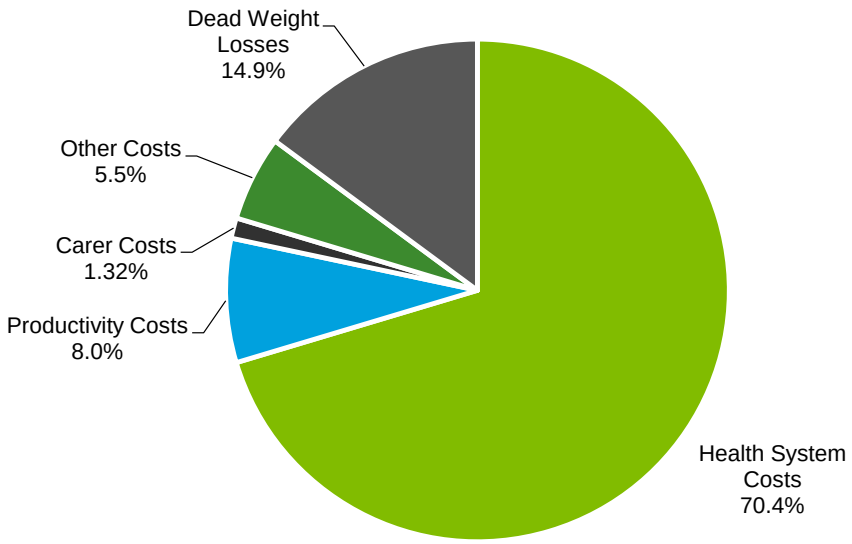
Note * transfers here included reduced taxation revenue and increased welfare outlays; this is a negative cost for individuals and family/friends as they receive more net transfers from government.
Source: Deloitte Access Economics' calculations.

Table 6.4: Per person costs of VI in children, 2015 ($)

	Individual	Family/ friends	Federal Govt.	State Govt.	Employers	Society/ other	Total
Health system costs	0	231	537	349	0	180	1,298
Productivity costs	71	0	50	0	27	0	147
Carer costs	0	16	9	0	0	0	24
Other costs	101	0	0	0	0	0	101
Dead weight losses	0	0	0	0	0	274	274
Transfers	-5	-4	8	0	0	0	0
Total financial	**167**	**243**	**604**	**349**	**27**	**454**	**1,845**
BoD	3,882	0	0	0	0	0	3,882
Total with BoD	**4,050**	**243**	**604**	**349**	**27**	**454**	**5,727**

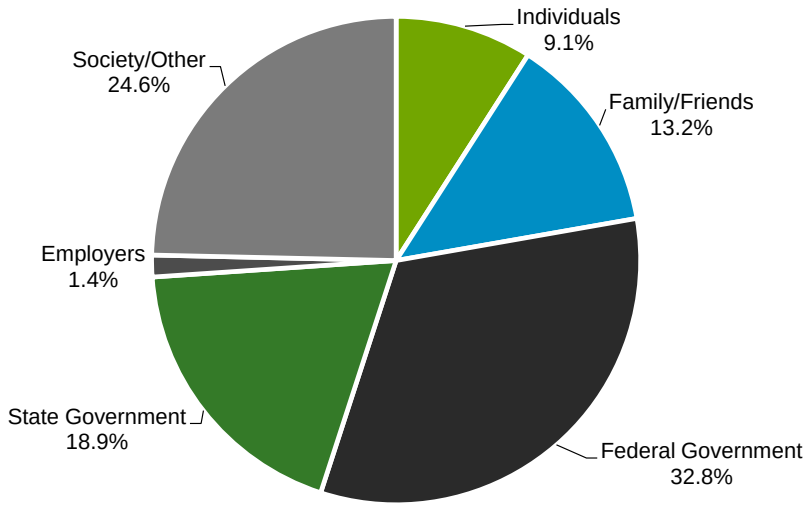
Source: Deloitte Access Economics' calculations.

Chart 6.4: Share of financial costs, by type



Source: Deloitte Access Economics' calculations.

Chart 6.5: Share of financial costs, by bearer



Source: Deloitte Access Economics' calculations.

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Appendix A

Table A.1: Mapping of AR-DRG version 6.0x to ICD-10-AM

ICD-10-AM	AR-DRG version 6.0x	Weighted cost
74 Disorders of eyelid, lacrimal system and orbit (H00-H06)	C11Z Eyelid Procedures, C13Z Lacrimal Procedures, C05Z Dacryocystorhinostomy, C02Z Enucleations and Orbital Procedures, C60B	5,168
75 Disorders of conjunctiva (H10-H13)	C60A Acute and Major Eye Infections W CC, C60B Acute and Major Eye Infections W/O CC	8,669
76 Disorders of sclera, cornea, iris and ciliary body (H15-H22)	C12Z Other Corneal, Scleral and Conjunctival Procedures	3,927
77 Disorders of lens (H25-H28)	C16Z Lens Procedures, C15A Glaucoma and Complex Cataract Procedures, C15B Glaucoma and Complex Cataract Procedures, Sameday	2,899
78 Disorders of choroid and retina (H30-H36)	C03Z Retinal Procedures	4,552
79 Glaucoma (H40-H42)	C15A Glaucoma and Complex Cataract Procedures, C15B Glaucoma and Complex Cataract Procedures, Sameday	4,141
80 Disorders of vitreous body and globe (H43-H45)	C14Z Other Eye Procedures, C63Z Other Disorders of the Eye	2,886
81 Disorders of optic nerve and visual pathways (H46-H48)	C61A Neurological and Vascular Disorders of the Eye W CC, C61B Neurological and Vascular Disorders of the Eye W/O CC	4,454
82 Disorders of ocular muscles, binocular movement, accommodation and refraction (H49-H52)	C10Z Strabismus Procedures	4,157
83 Visual disturbances and blindness (H53-H54)	C14Z Other Eye Procedures, C63Z Other Disorders of the Eye	2,886
84 Other disorders of eye and adnexa (H55-H59)	C14Z Other Eye Procedures, C63Z Other Disorders of the Eye	2,886

Source: IHPA (2014) and Deloitte Access Economics' calculations.

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