National Indigenous Eye Health Survey

Minum Barreng (Tracking Eyes)

THE UNIVERSITY OF MELBOURNE

Centre for Eye Research Australia

This report was prepared by Professor Hugh R. Taylor AC and members of the National Indigenous Eye Health Survey Team (NIEHS). The NIEHS team includes Professor Jill Keeffe OAM, Anna-Lena Arnold, Ross A. Dunn, Sarah Fox, Dr Nicolas Goujon, Dr Jing Xie, Rebecca Still, Anthea Burnett, Mitasha Marolia, Dr Tomer Shemesh, Judy Carrigan and Emma Stanford

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Highlights

- Blindness rates in Indigenous adults are 6 times the rate in mainstream.
- Indigenous adults in Very Remote areas have more Cataract and are less likely to have glasses but Diabetic Eye Disease, unoperated Cataract and poor reading vision are problems across the whole country.
- Vision loss in Indigenous children is 5 times less common than in mainstream children.
- Indigenous children in Very Remote areas have better vision and less Refractive Error but still have Trachoma.

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National Indigenous Eye Health Survey Advisory Committee

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National Indigenous Eye Health Survey Steering Committee

Dr Robert Casson, Rowan Churchill, Associate Professor Mark Gillies, Dr William Glasson, Dr Timothy Henderson, Professor Brian Layland, Dr Mark Loane, Associate Professor Ian McAllister, Dr Tharmalingam Mahendrarjah, Dr Richard Mills, Dr David Moran, Dr Nigel Morlet, Helen Morrissey, Dr Henry Newland, Dr Dermot Roden and Gerd Schlenther

Volunteers

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Ethical approval

The Human Research Ethics Committee of the Royal Victorian Eye and Ear Hospital, Aboriginal Health and Medical Research Council of NSW, Aboriginal Health Council of South Australia, Menzies School of Health Research Human Research Ethics Committee, Central Australia Human Research Ethics Committee, Western Australian Aboriginal Health Information and Ethics Committee, ACT Health (12.11.07), Tasmania Scientific Research Advisory Committee, Tasmania Health and Medical Human Research Ethics Committee and the Queensland Aboriginal and Islander Health Council. The protocol was also reviewed and approved by the Board of the National Aboriginal Community Controlled Health Organisation and the appropriate organisation in each community. Permission was obtained as needed at the local, regional or State level to examine children in schools.

Introduction

The National Indigenous Eye Health Survey was undertaken to define:

- the extent of vision loss in Aboriginal and Torres Strait Islander peoples
- the causes of vision loss in Aboriginal and Torres Strait Islander peoples
- the impact of vision loss in Aboriginal and Torres Strait Islander peoples

The last national data came from the National Trachoma and Eye Health Program 1976 – 1980. At that time, blindness rates were 10 times higher than in mainstream.

Key Findings

Adults

- **Blindness rates in Indigenous adults** (1.9%) are **6.2 times the rate in mainstream**
- Low vision rates in Indigenous adults (9.4%) are 2.8 times the rate of mainstream
- **Major causes of blindness** in Indigenous adults are cataract (32%), optic atrophy (14%), refractive error (14%), diabetic eye disease (9%) and trachoma (9%)
- There are about 15,015 Indigenous people with low vision and 3,300 who are blind

Children

- Indigenous children especially in remote areas have better vision than their mainstream peers
- Overall, low vision occurs in 1.4% of Indigenous children (age standardised)
- Vision loss in Indigenous children is 5 times less common than in mainstream children

Cataract

- Overall, 3.1% of Indigenous adults suffer vision loss from cataract
- **Blinding cataract is 12 times more common in Indigenous adults**
- Only 65% of those needing cataract surgery have been operated on
- Regular cataract surgery services with adequate capacity are required

Diabetes

- Diabetic eye disease is the equal third cause of blindness
- Of Indigenous people with diabetes:
  - 36% have diabetic eye disease
  - Only 20% have had a recent eye examination
  - Only 37% have received the laser surgery they need
- Regular screening and accessible laser facilities are required

Refractive Error

- **Half of vision loss** in both adults and children is due to Refractive Error
- **39% of adults cannot see normal print**
- Services to provide distance and reading glasses are needed in every Indigenous community

Trachoma

- Trachoma still occurs in Indigenous people across Australia and still causes blindness
- **60% of very remote communities have endemic trachoma** (defined as a prevalence of active trachoma in 5 – 9 year olds greater than 5%, the highest prevalence was 28%)
- Overall trachoma affects 7% of children (5 – 15 years) in very remote regions
- Adults with scarring and in-turned eyelashes from trachoma were found across Australia
- The Australian Government has in 2009 committed to use the SAFE strategy to eliminate trachoma

Overall, 94% of vision loss is preventable or treatable, but 35% of adults have never had an eye exam.

Survey Sample

A multi stage, random, cluster sample was selected after consultation with the Australian Bureau of Statistics and using data from the 2006 Census

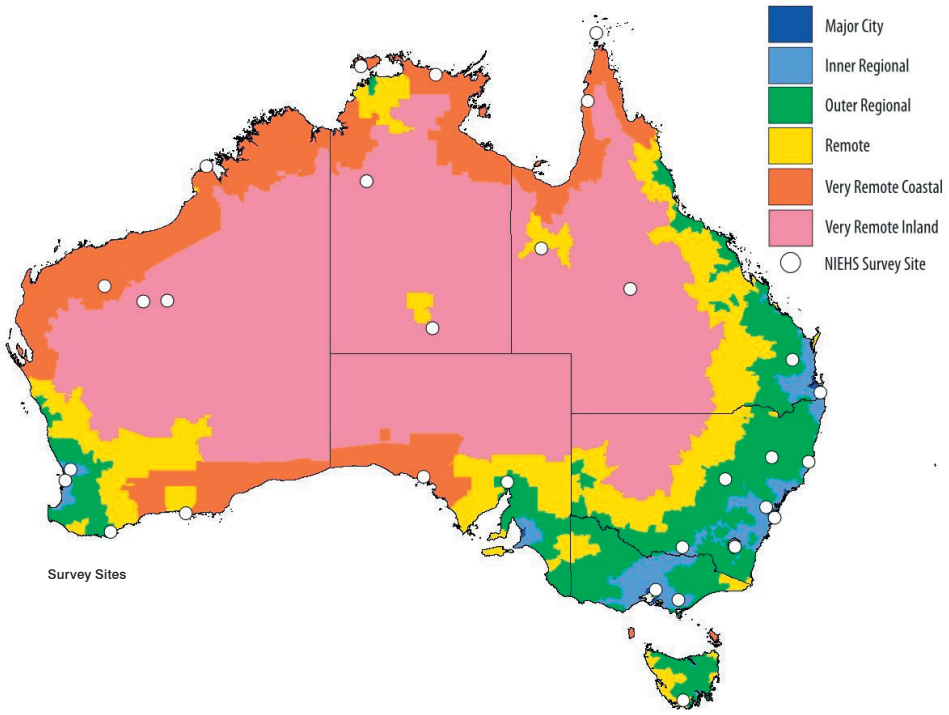
Survey sites

30 clusters containing 300 – 400 people were selected

In each cluster/community, all children 5 – 15 years and all adults over 40 years were examined

Additional ineligible people were examined at their request

In two Remote and two Very Remote communities, a sample of non indigenous adults was examined



State	Aboriginal Population (%)	Total Population	Region	Aboriginal Population (%)	Total Population
NSW	142,377 (2.1%)	6,873,213	Major City	122,311 (1.0%)	12,255,493
NT	53,663 (27.8%)	192,899	Inner Regional	92,947 (2.3%)	4,080,326
QLD	127,581 (3.3%)	3,904,532	Outer Regional	112,398 (4.2%)	2,700,334
SA	25,556 (1.7%)	1,514,337	Remote	41,624 (8.6%)	484,581
TAS	16,770 (3.5%)	476,479	Very Remote Coastal	43,760 (36.3%)	120,623
VIC	30,140 (0.6%)	4,932,419	Very Remote Inland	39,374 (30.4%)	129,421
WA	58,709 (3.0%)	1,959,088	Other*	2,602 (3.1%)	84,510
TOTAL	**454,796 (2.3%)**	**19,852,967**	**TOTAL**	**455,016 (2.3%)**	**19,855,288**

Data from ABS 2006 Census

*Other includes areas such as outlying islands off the coast of Australia

Field Methods

Ethical Clearance

In accordance with the tenets of the Declaration of Helsinki as revised in 2000, all the appropriate ethics approval was obtained. The extensive ethical clearance processes for the National Indigenous Eye Health survey resulted in contact with 73 organisations and groups.[1]

All procedures were field tested prior to starting

Examination Procedures

Standardised Questionnaire

- Background information, age, gender, language spoken at home and education
- Demographics, history vision problems, general health
- Utilisation of eye care services

Standardised eye exam

- Visual acuity, near and far
- Visual fields (adults)
- Refraction if required
- Trachoma grading and photography
- Retinal and anterior segment photography (adults)

Outcome of field work

- All field examinations were conducted in 2008
- Overall 2883 eligible Indigenous people were examined
- This represents 78.7% of those eligible to be included
- This study used standardised procedures that were rapid, reproducible, valid and portable
- A large number of people volunteered and contributed to this field work (see Acknowledgments)

Data collection was comprehensive and complete:

- Visual acuity 99.7%
- Visual field 96%
- Questionnaire 96%
- Trachoma grading 99%
- Retinal photography 89%

Numbers examined

State	Indigenous		Non-Indigenous Adults	Region	Indigenous		Non-Indigenous Adults
	Children	Adults			Children	Adults	
NSW	277 (74%)	247 (65%)	-	Major City	156 (81%)	117 (58%)	-
NT	244 (88%)	198 (89%)	-	Inner Regional	271 (87%)	167 (78%)	-
QLD	344 (84%)	259 (68%)	60 (95%)	Outer Regional	204 (75%)	168 (48%)	-
SA	168 (87%)	129 (56%)	56 (79%)	Remote	325 (79%)	245 (74%)	69 (80%)
TAS	32 (97%)	43 (84%)	13 (87%)	Very Remote Coastal	361 (92%)	263 (86%)	-
VIC	33 (94%)	29 (64%)	-	Very Remote Inland	377 (89%)	229 (89%)	67 (87%)
WA	596 (87%)	284 (82%)	7 (50%)	**TOTAL**	**1694 (84%)**	**1189 (72%)**	**136 (83%)**

Additional people seen

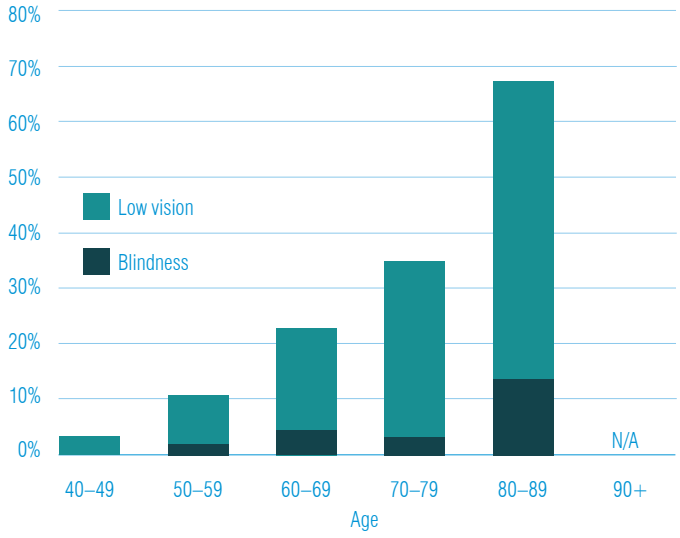
In addition 475 Indigenous children and 736 Indigenous adults were seen who lived outside the sample area and so were not eligible for inclusion in the data analysis.

1. Taylor HR, Fox SS. Ethical hurdles in Indigenous research. Aust N Z J Public Health. 2008;32(5):489-90.

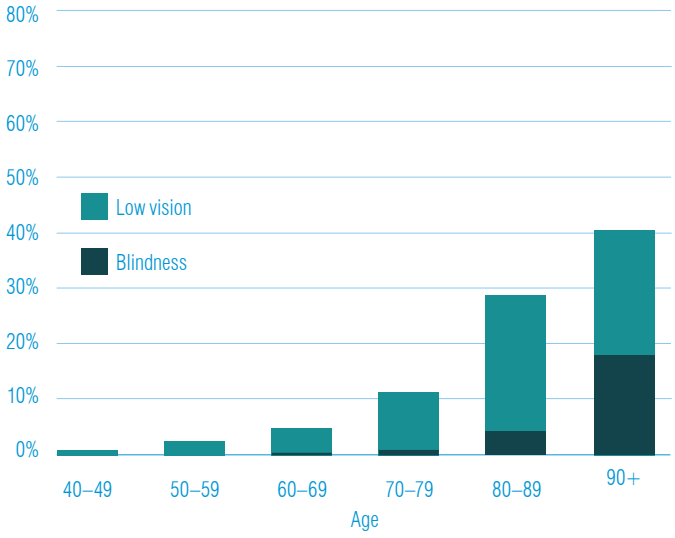
Prevalence of Vision Impairment

There are estimated to be 3,300 Indigenous people who are blind and 15,015 with low vision	Blindness occurs 6.2 times more commonly in Indigenous adults than in non-Indigenous adults
	Vision loss occurs 2.8 times more commonly in Indigenous adults but only 0.22 times as often in Indigenous children

Vision Impairment in Indigenous Adults



Vision Impairment in Non-Indigenous Adults[4]



Age-adjusted prevalence of vision loss[2]

	Indigenous	Non-Indigenous	Relative Risk
Children			
Low vision	1.40 (1.38 – 1.44)	6.36 (6.27 – 6.45)[3]	0.22
Blindness	0.18 (0.17 – 0.18)	0.28 (0.26 – 0.30)[3]	0.64
Adults			
Low vision	14.42 (14.39 – 14.43)	5.19 (5.17 – 5.20)[4]	2.78
Blindness	2.79 (2.78 – 2.81)	0.45 (0.44 – 0.46[4]	6.20

Crude Prevalence rates of Vision Loss in Indigenous Australians

State	Children		Adults		Regions	Children		Adults	
	Low Vision	Blindness	Low Vision	Blindness		Low Vision	Blindness	Low Vision	Blindness
NSW	3.3%	0.4%	5.7%	2.4%	Major City	4.5%	0.6%	7.7%	2.6%
NT	0.8%	0%	9.1%	3%	Inner Regional	2.6%	0%	7.8%	2.4%
QLD	0.9%	0.3%	11.6%	0.4%	Outer Regional	1.5%	0%	6.6%	0.6%
SA	0%	0%	9.3%	1.6%	Remote	0.9%	0%	10.2%	0.8%
TAS	0%	0%	4.7%	0%	Very Remote Coastal	1.1%	0.3%	9.5%	1.1%
VIC	0%	0%	6.9%	6.9%	Very Remote Inland	0.3%	0.3%	12.7%	3.9%
WA	1.9%	0.2%	12%	1.8%	**TOTAL**	**1.5%**	**0.2%**	**9.4%**	**1.9%**

2. Australian Bureau of Statistics. http://www.abs.gov.au/WEBSITEDBS/D3310114/nsf/Home/census.
3. Robaei D, Rose K, Ojaimi E, Kifley A, Huynh S, Mitchell P. Visual Acuity and the Causes of Visual Loss in a Population-Based Sample of 6-year-Old Australian Children. Ophthalmology. 2005;112:1275-82.
   Robaei D, Kifley A, Rose KA, Mitchell P. Refractive Error and Patterns of Spectacle Use in 12-Year-Old Australian Children. Ophthalmology. 2006;113:1567-73.
   Robaei D, Huynh SC, Kifley A, Mitchell P. Correctable and Non-Correctable Visual Impairment in a Population-Based Sample of 12-Year-Old Australian Children. Am J Ophthalmol. 2006;142:112-8.
4. Taylor HR, Keeffe JE, Vu HTV, Wang JJ, Rochtchina E, Pezzullo ML, et al. Vision loss in Australia. Med J Aust. 2005;182):565-8.

Causes of Vision Impairment

Overall, 94% of vision loss in Indigenous Australians is preventable or treatable.

Blindness from trachoma is not seen in other Australians

For Indigenous children:

- 56% of low vision is due to refractive error
- 40% unknown causes
- 4% congenital Nystagmus
- One child was blind from refractive error and two from unknown causes

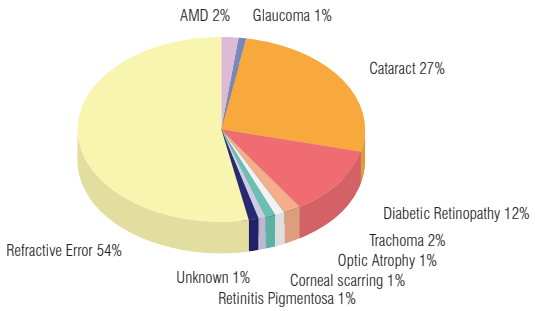
For Indigenous adults:

Overall rates of blindness in Indigenous adults are:

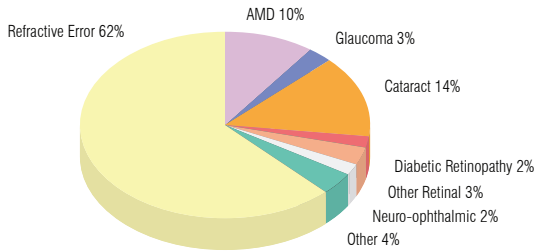
- 12 times higher from cataract
- 14 times higher from diabetes
- 5 times higher from refractive error

…than in other Australians

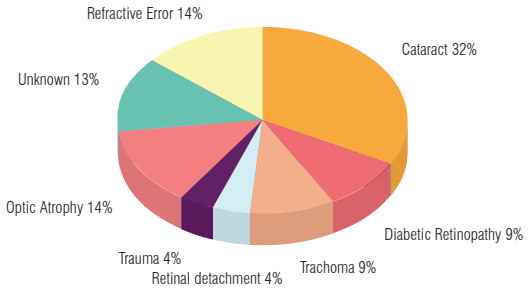
Vision Impairment in Indigenous Adults



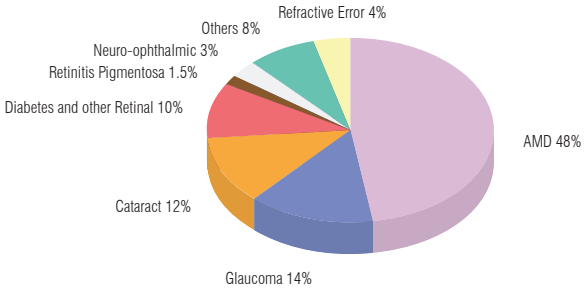
Vision Impairment in Non-Indigenous Adults[4]



Blindness in Indigenous Adults



Blindness in Non-Indigenous Adults[4]



Prevalence of vision impairment by cause for Indigenous Adults and area

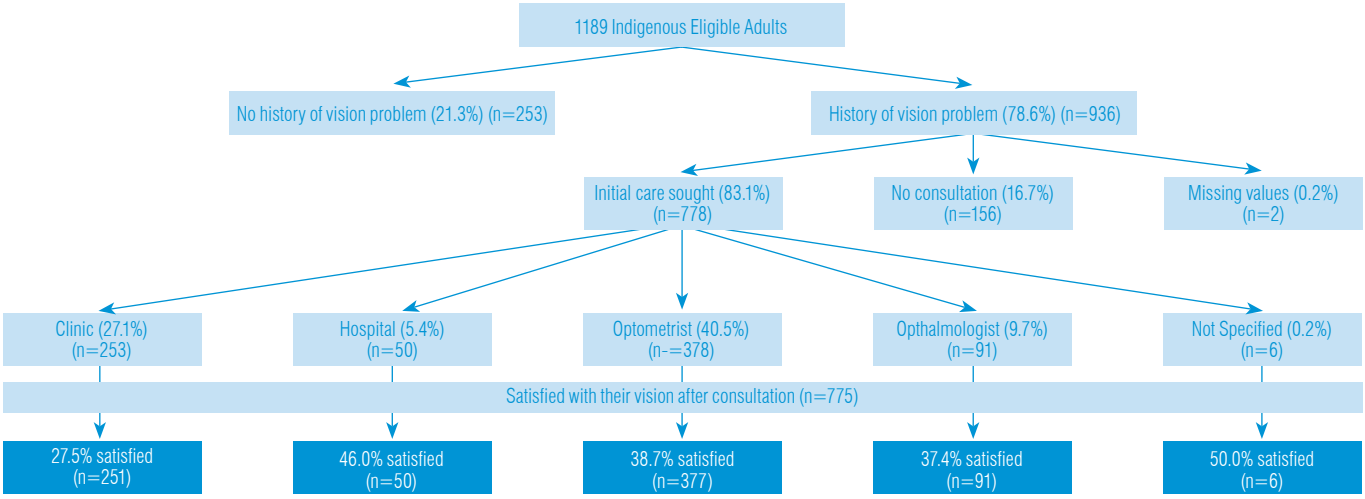
State	Refractive Error	Cataract	Cause Diabetes	Trachoma	Other	Region	Refractive Error	Cataract	Cause Diabetes	Trachoma	Other
NSW	4.1%	1.2%	1.2%	0%	1.6%	Major City	6.0%	2.6%	0.9%	0%	0.9%
NT	6.1%	4.1%	0%	1.0%	1.0%	Inner Regional	4.2%	1.8%	1.2%	0%	3.0%
QLD	6.2%	3.9%	1.5%	0%	0.4%	Outer Regional	3.0%	2.4%	1.8%	0%	0%
SA	6.2%	1.6%	1.6%	0%	1.6%	Remote	6.6%	2.1%	0.8%	0%	1.6%
TAS	4.7%	0%	0%	0%	0%	Very Remote Coastal	4.2%	3.8%	1.9%	0.4%	0.4%
VIC	3.5%	0%	3.5%	0%	6.9%	Very Remote Inland	7.5%	5.3%	0.9%	1.3%	1.8%
WA	5.0%	5.0%	1.8%	0.7%	1.4%	**TOTAL**	**5.3%**	**3.1%**	**1.3%**	**0.3%**	**1.3%**

Use of Eye Care Services

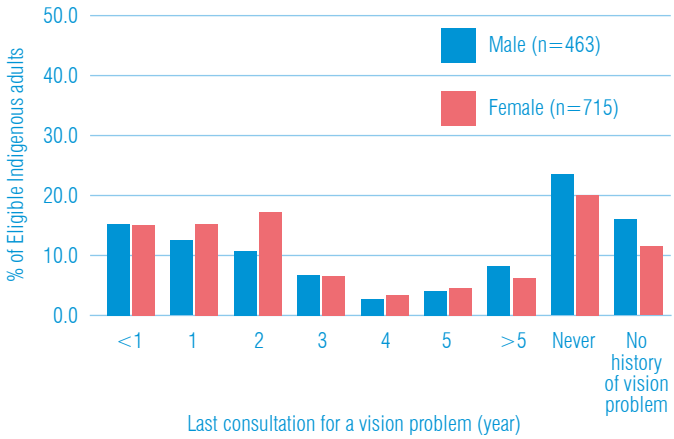
Problems with Vision

35% of adults have never had an eye exam	19% of children reported having had a problem with their vision 58% of these children had seen someone about this › but 40% were still not satisfied with their vision
	79% of adults reported a problem with their vision 17% of adults who had an eye problem had never had an eye exam Most adults (83%) had sought care › but still two thirds (64%) were not satisfied with their vision

Health services utilisation by Adults



Frequency of eye examinations in Adults



Further action:

› Eye care services, whether visiting teams of optometrists or ophthalmologists, or permanent clinics and outpatient services need to be readily accessible for all Australians

Refractive Error

Distance Vision

20% of adults normally wore glasses for distance compared to 56% in mainstream[5]	Uncorrected refractive error caused half the low vision in both children (50%) and adults (54%)
	Uncorrected refractive error caused 14% of blindness in adults

Uncorrected Refractive Error Distance Vision

State	Children		Adult		Regions	Children		Adult	
	VI	Percent with correction	VI	Percent with correction		VI	Percent with correction	VI	Percent with correction
NSW	1.1%	2.2%	4.1%	24%	Major City	2.6%	0%	6.0%	32%
NT	0.82%	0.82%	6.1%	3.0%	Inner Regional	1.1%	2.2%	4.2%	22%
QLD	0.58%	1.5%	6.2%	22%	Outer Regional	0.49%	0%	3.0%	14%
SA	0%	0%	6.2%	13%	Remote	0.92%	1.2%	6.5%	16%
TAS	0%	3.1%	4.7%	30%	Very Remote Coastal	0.55%	0.83%	4.2%	11%
VIC	0%	0%	3.5%	21%	Very Remote Inland	0.53%	1.3%	7.4%	8.7%
WA	1.3%	0.67%	4.9%	9.9%	**TOTAL**	**0.89%**	**1.1%**	**5.3%**	**16%**

Near Vision

Difficulty with Near Vision in Adults (40 years and older)

States	Difficulty with near(<N8)	Have reading glasses	Regions	Difficulty with near(<N8)	Have reading glasses
NSW	43%	74%	Major City	48%	75%
NT	40%	49%	Inner Regional	36%	67%
QLD	22%	68%	Outer Regional	41%	70%
SA	42%	65%	Remote	31%	64%
TAS	14%	83%	Very Remote Coastal	42%	59%
VIC	31%	33%	Very Remote Inland	42%	50%
WA	55%	60%	**TOTAL**	**39%**	**63%**

- Increasing difficulty with near (reading) vision is a normal part of ageing
- Problems are usually noticed around the age of 40
- 62% of Indigenous adults normally wore reading glasses for near work compared to 86% for mainstream[5]
- However, overall 39% could not read normal size print

Further action:

- Both ready-made readers and prescription glasses need to be readily available in Indigenous communities
- Easy access to appropriate refractive services is required for all Australians

5. Taylor HR, Livingston PM, Stanislavsky YL, McCarty CA. Visual impairment in Australia: Distance and near visual acuity and visual field findings of the Melbourne Visual Impairment Project. Am J Ophthalmol. 1997;123:328-37.

Cataract

Everyone will develop cataract if they live long enough	Smoking and high UV-B exposure increase the risk of cataract Cataract surgery can rapidly restore vision Cataract surgery is the most cost effective surgical procedure at $3000 / QALY (quality-adjusted life year)[6] In Australia some 200,000 cataract operations are done (9,500 per million people per year)
Blinding cataract is 12 times more common in Indigenous adults	Cataract causes 32% of blindness and 27% of low vision in Indigenous adults Overall 3% of all Indigenous adults have lost vision from cataract Vision loss from cataract is more common in very remote areas Only 65% of those with vision loss from cataract have actually received surgery

State	Prevalence of vision loss due to cataract	Cataract surgery coverage*	Regions	Prevalence of vision loss due to cataract	Cataract surgery coverage*
NSW	1.2%	57%	Major City	2.6%	57%
NT	4.1%	58%	Inner Regional	1.8%	75%
QLD	3.9%	69%	Outer Regional	2.4%	60%
SA	1.6%	78%	Remote	2.1%	67%
TAS	0%	0%	Very Remote Coastal	3.8%	66%
VIC	0%	100%	Very Remote Inland	5.3%	63%
WA	5.0%	61%	**TOTAL**	**3.1%**	**65%**

* The percentage of people affected by cataract who have had cataract surgery

Further action:

- Cataract surgery needs to be made readily available for all Australians
- Adequate and sustainable funding is required for visiting specialist services
- Visiting services have been confirmed to be cost effective and cost saving[7]
- Proper funding for patient travel to regional hospitals for surgery is required
- Adequate surgical facilities, time and staff must be committed for cataract surgery.

6. Taylor HR, Keeffe JE, Mitchell P. Clear Insight: The Economic Impact and Cost of Vision Loss in Australia. Melbourne: Eye Research Australia; 2004.
7. Gruen RL, Bailie RS, Wang Z, Heard S, O'Rourke IC. Specialist outreach to isolated and disadvantaged communities: a population-based study. Lancet. 2006;368:130-38.

Diabetes

All people with diabetes are at risk of developing diabetic eye disease (retinopathy)

Thirty years ago, only 0.03% of Indigenous people had diabetes[8]

With timely diagnosis and treatment, up to 98% of the severe vision loss can be prevented

Overall, 37.4% of Indigenous adults reported having diabetes. There was no significant regional variation

The average age of onset was reported to be 44 years and the duration 11 years

Only 20% of those with diabetes, had had an eye examination within the last year

Overall 13% of those with diabetes have visual impairment

Diabetes was the cause of 13% of low vision and 9% of blindness

Of those with diabetes (444 Indigenous people)

- 25% mild/ moderate non-proliferative retinopathy
- 0.45% severe non-proliferative retinopathy
- 8.6% clinically significant macular oedema
- 2.5% proliferative retinopathy

Overall, only 37% requiring laser treatment had received at least some treatment

State	Prevalence of Diabetes	Number with Diabetes			Regions	Prevalence of Diabetes	Number with Diabetes		
		Vision Loss*	Examined+	Treated§			Vision Loss*	Examined+	Treated§
NSW	24%	13%	22%	25%	Major City	35%	15%	20%	50%
NT	41%	9.9%	17%	25%	Inner Regional	31%	9.8%	18%	46%
QLD	37%	16%	31%	43%	Outer Regional	33%	13%	20%	27%
SA	51%	11%	14%	23%	Remote	38%	8.5%	14%	36%
TAS	14%	0%	0%	0%	Very Remote Coastal	40%	11%	27%	38%
VIC	48%	21%	14%	50%	Very Remote Inland	43%	18%	18%	33%
WA	42%	12%	16%	48%	**TOTAL**	**37%**	**13%**	**20%**	**37%**

* Percent of people who have diabetes and who have vision loss
+ Percent of people with diabetes who have had an eye exam in the last year
§ Percent of people with diabetic retinopathy requiring laser surgery who have been treated

Further action:

- All Indigenous people with diabetes need an eye exam every year (according to the NHMRC) and access to better diabetes education
- The annual examination must include visual acuity and retinal examinations
- Retinal photography is a rapid and easy way to assess the retina
  - but requires sustainable funding for sustainable services
- Prompt referral is required for those found to have diabetic eye disease
- Laser surgery should be available regionally and in the larger communities

8. Royal Australian College of Ophthalmologists. The National Trachoma and Eye Health Program of the Royal Australian College of Ophthalmologists. Sydney: Royal Australian College of Ophthalmologists; 1980.

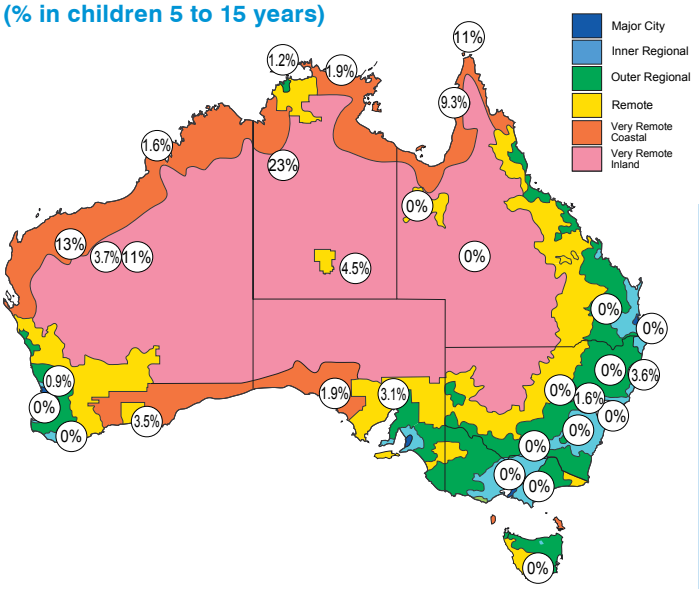
Trachoma

Trachoma is a blinding infectious eye disease	Trachoma occurs in areas with poor hygiene and living conditions **Australia is the only developed country to still have trachoma**
Trachoma disappeared from mainstream Australia 100 years ago	Trachoma affects 7% of children in very remote regions The highest prevalence in children 5 to 15 years was 23% Late scarring and inturned eyelashes (trichiasis) affects older Indigenous people across the country
The Australian Government has recently committed to eliminating trachoma	Over the last 30 years rates of trachoma and blindness from trachoma have fallen nationally However, blinding endemic trachoma still occurs unabated in many outback communities

The Distribution of Active Trachoma in Children (5 to 15 years) across Australia

Region	Active Trachoma (TF) in Children (5–15 years)	Communities with Endemic Trachoma	Scarring in Adults (TS)	Inturned Eyelashes in Adults (TT)	Corneal Blindness in Adults (CO)
Major City	0.6%	0/5	5.2%	0%	0%
Inner Regional	1.1%	0/5	4.8%	0%	0%
Outer Regional	1.0%	0/5	13%	0.6%	0%
Remote	1.6%	0/5	17%	0.4%	0%
Very Remote Coastal	7.2%	3/5	7%	0.4%	0%
Very Remote Inland	7.3%	2/5	40%	5.7%	1.3%
TOTAL	**3.8%**	**5/30**	**16%**	**1.4%**	**0.3%**

TF Prevalence in Indigenous Children
(% in children 5 to 15 years)



Further action:

- Trachoma can be prevented with the SAFE Strategy:
  - **S**urgery for trichiasis,
  - **A**ntibiotic therapy,
  - **F**acial cleanliness and
  - **E**nvironmental improvements
- The extent of trachoma needs to be clearly mapped
- All children at risk need to be checked regularly with follow up treatment
- Elderly people across the country need to be checked for inturned lashes (TT) as part of the Healthy Adult check and if needed, referred for surgery

Glossary

Term	Definition
Age-Related Macular Degeneration(AMD)	- an ageing change at the back of the eye (in the retina) that results in a loss of the fine central vision
Blindness	- presenting visual acuity of less than 6/60
Cataract	- a clouding that develops in the lens of the eye that affects vision
Congenital Nystagmus	- a form of involuntary eye movement present since birth
Diabetic Retinopathy	- diabetic eye disease – damage to the retina caused by the complications of diabetes
Glaucoma	- group of diseases that affect the optic nerve that can progress to blindness
Low Vision	- presenting visual acuity of less than 6/12 but better than 6/60
Macular Oedema	- a collection of fluid in the central retina (macular) causing it to thicken and swell. The swelling may distort a person's central vision
Neuro-Ophthalmic	- a grouping of diseases that affect the nervous system and cause a loss of vision
Non-Proliferative Retinopathy	- diabetic eye disease that has not yet caused new blood vessels to grow in the retina
Optic Atrophy	- loss of some or more of the fibers of the optic nerve resulting in vision loss
Refraction	- the use of lenses to help focus light rays on the retina
Refractive Error	- an error in the focusing of light by the eye that can be corrected with spectacle lenses
Retina	- the fine membrane at the back of the eye that detects light and sends nerve messages to the brain
Retinal and Anterior Segment Photography	- retinal – photographs of the back of the eye - anterior – photographs of the front of the eye
Retinal Detachment	- a disorder of the eye in which the retina peels away from its underlying layer of support tissue
Retinitis Pigmentosa	- a group of genetic eye conditions causing atrophy of the retina
Trachoma	- an infectious eye disease and a leading cause of infectious blindness
Trichiasis	- inturned eyelashes from scarring caused by trachoma, usually seen in older people
Visual Acuity	- sharpness of central vision usually tested with a letter chart
Visual Field	- a map of a person's central and peripheral vision
Visual Impairment (VI)	- low vision and blindness combined

Contact

Professor Hugh R. Taylor AC,
Indigenous Eye Health Unit,
Melbourne School of Population Health,
The University of Melbourne,
Level 5, 207 Bouverie St,
Carlton, Victoria 3053
Website: www.iehu.unimelb.edu.au

Centre for Eye Research Australia,
32 Gisborne St, East Melbourne,
Victoria 3002
Website: www.cera.org.au

Authorised by the Harold Mitchell Chair of Indigenous Eye Health, Melbourne School of Population Health.

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