NATIONAL EYE HEALTH SURVEY

The National Eye Health Survey 2016

A summary report of the first national survey to determine the prevalence and major causes of vision impairment and blindness in Australia prepared by the Centre for Eye Research Australia and Vision 2020 Australia.





















Summary report prepared by the Centre for Eye Research Australia and Vision 2020 Australia.
Copies of the full National Eye Health Survey Report 2016 are available from www.vision2020australia.org.au or by calling +61 3 9656 2020.
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Glossary of abbreviated terms

BMES Blue Mountains Eye Study

CERA Centre for Eye Research Australia

NACCHO National Aboriginal Community Controlled Health Organisation

NEHS National Eye Health Survey

NFIP National Framework Implementation Plan

NIEHS National Indigenous Eye Health Survey

NSW New South Wales

NT Northern Territory

QLD Queensland

SA South Australia

VIC Victoria

VIP [Melbourne] Visual Impairment Project

WA Western Australia

WHA World Health Assembly

WHO World Health Organization

Symbols

- < Less than
- > More than
- ≤ Less than or equal to
- ≥ More than or equal to
- / Or
- +/- With or without

Definitions

Age-adjustment	A technique in epidemiology and demography used to allow populations to be compared when the age profiles of the populations are quite different
Age-related macular degeneration	A degenerative disease that affects the central area of the retina called the macula, causing it to thin and in some cases bleed
Blindness	Presenting distance visual acuity <6/60 in the better eye
Cataract	A cloudy area on the eye's lens, formed when protein in the lens is damaged and clumps together, limiting the amount and clarity of light passing through the lens to the retina, causing poor vision
Diabetes	A group of metabolic diseases in which there are high blood sugar levels over a prolonged period
Diabetic retinopathy	Diabetic retinopathy is a complication of diabetes that damages blood vessels inside the retina at the back of the eye. It commonly affects both eyes and can lead to vision loss if it is not treated
Glaucoma	A group of eye diseases in which the optic nerve at the back of the eye is slowly destroyed. In most people this damage is due to an increased pressure inside the eye - a result of blockage of the circulation of aqueous, or its drainage. In other patients the damage may be caused by poor blood supply to the vital optic nerve fibres, a weakness in the structure of the nerve, and/or a problem in the health of the nerve fibres themselves
Intraocular pressure	The fluid pressure inside the eye
Refractive error	A condition in which light that passes through the front of the eye fails to focus precisely on the retina. It causes long or short sightedness and difficulties changing focus
Vision impairment	Presenting distance visual acuity <6/12 in the better eye
Visual acuity	The clarity of vision
Visual field	The total area in which objects can be seen in the side (peripheral) vision as you focus your eyes on a central point

Foreword

It is not often that one has the privilege of being part of something truly ground-breaking, a genuine first. The 2016 National Eye Health Survey (NEHS) falls into that category, being the only nationwide representative population health survey into the prevalence and causes of major eye conditions ever conducted in Australia. Equally impressive is the knowledge it was only made possible by the commitment and determination of so many coming together from across government, non-government and the private sector.

While the objective was simple - to determine the prevalence and causes of blindness and vision impairment in Australia for both Indigenous and non-Indigenous Australians - the goal was profound. In order to eliminate avoidable blindness and vision loss and ensure people living with unavoidable blindness and vision impairment are supported to live the life they choose, we need to have accurate up-to-date evidence to shape policy, direct services and provide a benchmark for monitoring progress.

This is the goal the NEHS partners set out to achieve and this is the driving force behind the collaboration that made the NEHS a reality.

It cannot be overstated that the NEHS would not have been possible without the contributions of so many individuals and organisations providing financial and operational support and expertise at their own expense. I would particularly like to note the tenacity, professionalism and leadership of Mohamed Dirani and the entire NEHS team delivering this report with unparalleled efficiency and care for each participant. The Australian Government for their foresight and commitment to eye health, and the NEHS Steering Committee and particularly Robyn Weinberg from OPSM for always going above and beyond expectations. And I wish to thank Jennifer Gersbeck for her vision, leadership and guidance and Sarah Davies for her unrelenting diligence in supporting the project governance and oversight.

In spite of its significance for eye health and vision care for Australia, the NEHS is just the beginning and the real work starts now. We must continue the collaboration and increase our efforts across government, non-government and the private sector to respond to what the evidence is telling us and invest in the front-line programs and services for prevention, detection, early intervention, treatment and blindness and vision impairment services needed by all Australians.

Brandon Ah Tong
Director of Policy and Advocacy

Vision 2020 Australia



Message from the Principal Investigator

The completion of the National Eye Health Survey (NEHS) would not have been possible without the unbeatable work ethic, bond and dedication of our research team, who set a new benchmark in delivering top quality data in record time.

Special mention must go to Joshua Foreman and Stuart Keel, who played an instrumental role in the project coordination, data collection and report writing. I am humbled to have led this remarkable team and to have traveled around this magnificent country in the pursuit of helping others.

I would also like to express my gratitude to each of the 4,836 individuals who voluntarily participated in Australia's first ever nationwide eye study. I look forward to using the data gathered as a result of their participation to further the vision of the Centre for Eye Research Australia (CERA) - to save sight and change lives through research that matters.

The success of the NEHS was made possible by taking a collaborative approach, facilitated by Vision2020 Australia, with leaders from the eye health and vision care sector contributing so much to the project throughout its journey.

Special mention must also go to Professor Hugh Taylor and Professor Jonathan Crowston. From first developing the research framework for a NEHS back in 2014, and on every step of the journey that resulted, to delivering the final report, these two individuals have listened, encouraged and empowered me, for which I would like to express my thanks.

Dr Mohamed Dirani

Centre for Eye Research Australia



The National Eye Health Survey team

The NEHS was conducted by investigators at the Centre for Eye Research Australia (CERA) in partnership with Vision 2020 Australia, the national peak body for eye health and vision care in Australia. Project governance and oversight was led by Vision 2020 Australia and the NEHS Steering Committee consisting of representatives from CERA, the Australian Government Department of Health, major contributing partners and the eye health and vision care sector. Sector representatives were elected from the three Vision 2020 Australia national policy committees, including the Prevention and Early Intervention Committee, Aboriginal and Torres Strait Islander Committee and the Independence and Participation Committee. The research planning, data collection, analysis and report writing were managed by the Project Manager, Dr Mohamed Dirani (Principal Investigator, Centre for Eye Research Australia) and his research team, with support from the Steering Committee.

Acknowledgements

CERA and Vision 2020 Australia wish to recognise the contributions of all parties involved in the planning, implementation and completion of the NEHS (Appendix A). The National Eye Health Survey was funded by the Australian Government, with other in-kind and financial contributions coming from CERA, OPSM, Novartis, Zeiss, Brien Holden Vision Institute, Optometry Australia, the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Royal Flying Doctor Service. We also appreciate the governance provided by the NEHS Steering Committee. We acknowledge the commitment of the core CERA research team, the overwhelming support provided by all Indigenous organisations and the contributions from all volunteers.

About the National Eye Health Survey

This summary report provides an overview of the main findings from the NEHS, where data was collected between 11 March 2015 and 18 April 2016. Findings should be read in conjunction with the full NEHS Report.

Global context

It is estimated that globally 191 million people are vision impaired and 32.4 million are blind¹. Recent estimates suggest that 80% of vision impairment and blindness is avoidable through the appropriate implementation of cost-effective prevention and treatment strategies.

The "Universal Eye Health: a Global Action Plan 2014-2019" (the Global Action Plan) was endorsed at the 66th World Health Assembly in late May 2013, with the vision of creating 'a world in which nobody is needlessly vision impaired'². The need to generate reliable evidence of the prevalence and causes of vision impairment and blindness was emphasised. In 2014, the Australian Government Department of Health developed its "Implementation Plan under the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss*". The plan emphasised the need for upto-date, representative prevalence data on eye health conditions from a national survey to inform reporting against the key indicators in the Global Action Plan³.

National context

Australia lacks up-to-date information on the prevalence of vision impairment and blindness. Two large studies were conducted in the early 1990s, the [Melbourne] Visual Impairment Project (VIP)⁴ and the Blue Mountains Eye Study (BMES)⁵. The VIP and BMES each provided insights into the prevalence of vision impairment and blindness at that time although both studies had limited coverage of the Australian population. Additionally, neither the VIP nor the BMES collected data on Indigenous Australians. In 2008, the National Indigenous Eye Health Survey (NIEHS) was conducted and focussed almost exclusively on Indigenous Australians to investigate the burden of vision impairment and blindness in the Indigenous Australian population, and only recruited a small number of 136 non-Indigenous Australians⁶. However, despite concerns about all three studies; the VIP, BMES and NIEHS have remained the reference studies for vision impairment and blindness in Australia until now.

The need for a National Eye Health Survey

The lack of national information on the burden of vision impairment and blindness in Australia brought about the need to conduct a nationwide study. CERA and Vision 2020 Australia developed a proposal for the Australian Government to fund the NEHS. The Australian Government provided the majority of project funds to Vision 2020 Australia alongside financial and in-kind contributions provided to the project by partner organisations in the eye health and vision care sector.

The NEHS is the first nationwide Australian population-based survey designed to:

- 1. Determine the prevalence and causes of vision impairment and blindness in Indigenous Australians aged 40 years and over, and non-Indigenous Australians aged 50 years and over, by gender, age, and geographical area
- 2. Measure the treatment coverage rate of major eye diseases and conditions

The findings of the NEHS are intended to provide an indication of the effectiveness of existing eye health services in Australia, and will guide future resource allocation, policy development and economic analysis for eye health service delivery in Australia.

Methodology

Thirty geographic areas were selected using Australian Statistical Geography Standard data from the 2011 Australian Census⁷ and were grouped according to the Accessibility/ Remoteness Index of Australia into five remoteness categories: Major City, Inner Regional, Outer Regional, Remote and Very Remote areas. Back-up sites were also selected to be utilised in circumstances in which primary sites were unsuitable due to logistical reasons (Appendix B).

Trained recruiters visited each site and went door-to-door to recruit non-Indigenous Australians aged 50 years and older and Indigenous Australians aged 40 years and older to the study. A total of 23,235 residences were visited (between 11 March 2015 to 18 April 2016) across all 30 sites and 6,760 residents were found to be eligible. Eligible residents were invited to participate and 5,764 agreed (positive response rate of 85.27%). These residents were provided with a NEHS recruitment pack including an information booklet, participant instructions and an appointment card. In total, 4,836 participants were examined (examination rate of 71.54%), including 3,098 non-Indigenous Australians and 1,738 Indigenous Australians.

Each participant completed a general questionnaire to collect information about ethnicity, past eye health, stroke history and diabetes. Participants then underwent a series of eye tests, including: vision assessment, examination of the front of the eye, visual field testing (measuring peripheral or side vision), retinal photography (photographs of the back of the eye) and intraocular pressure test (measuring the fluid pressure in the eye). All tests were performed by eye professionals and CERA trained staff.

At completion (average testing time of 30 minutes), each participant was provided with verbal feedback on their test results and a referral letter was provided to take to their local doctor or optometrist if abnormalities were detected.

Definitions of vision impairment and blindness within the NEHS

A person with vision impairment (visual acuity < 6/12-6/60) cannot read the letters at 6 metres on a vision chart that a person with normal vision can read at 12 metres. A person with blindness (visual acuity < 6/60) cannot read the letters at 6 metres that a person with normal vision can read at 60 metres. Bilateral vision impairment or blindness refers to vision loss in both eyes. As each eye was tested separately, the visual acuity of the better eye was used.

Main findings

The prevalence of bilateral vision impairment and blindness

After age-adjustment, the prevalence of vision impairment was three times higher in Indigenous Australians (13.60%) compared to non-Indigenous Australians (4.57%). Similarly, the age-adjusted prevalence of blindness in Indigenous Australians was three times higher compared to non-Indigenous Australians (0.36% versus 0.12%).

In 2016, more than 453,000 Australians are living with vision impairment or blindness. Based on the NEHS and age adjusted population data, it is estimated that this includes up to 432,800 non-Indigenous Australians aged 50 years or older and up to 18,300 Indigenous Australians aged 40 years or older. (a)



THE PREVALENCE OF **BLINDNESS AND VISION IMPAIRMENT AMONG INDIGENOUS AUSTRALIANS** IS THREE TIMES THAT OF **NON-INDIGENOUS AUSTRALIANS**

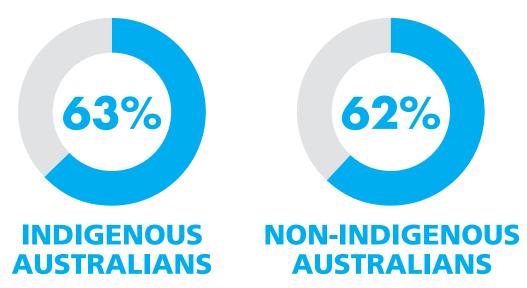
(a). Calculated using the age adjusted prevalence of vision impairment or blindness multiplied by the target population, stratified by remoteness.

The major causes of bilateral vision impairment

The main causes of vision impairment in both Indigenous and non-Indigenous Australians were uncorrected refractive error (63.39% in Indigenous Australians and 61.69% in non-Indigenous Australians) and cataract (20.22% in Indigenous Australians and 13.93% in non-Indigenous Australians). Other notable causes of vision impairment were age-related macular degeneration in non-Indigenous Australians (8.96% compared with 1.09% in Indigenous Australians) and diabetic retinopathy in Indigenous Australians (5.46% compared with 1.49% in non-Indigenous Australians). Glaucoma accounted for 1.49% and 0.55% of vision impairment in non-Indigenous and Indigenous Australians, respectively.

Approximately 90% of vision impairment and blindness among both Indigenous and non-Indigenous Australians is preventable or treatable. (b)

UNCORRECTED REFRACTIVE **ERROR CAUSES ALMOST TWO** THIRDS OF VISION IMPAIRMENT AMONG BOTH INDIGENOUS AND NON-INDIGENOUS AUSTRALIANS

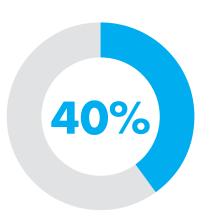


(b). Calculated by combining the five major conditions responsible for the majority of vision impairment and blindness in Australia (age-related macular degeneration, cataract, diabetic retinopathy, glaucoma and uncorrected refractive error) as a percentage of all vision impairment and blindness.

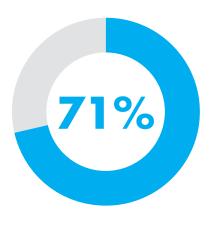
The major causes of blindness

Cataract was the main cause of blindness in Indigenous Australians (40%). Age-related macular degeneration was the leading cause of blindness in non-Indigenous Australians (71.42%).

CATARACT LEADING CAUSE OF BLINDNESS AMONG INDIGENOUS AUSTRALIANS



AGE-RELATED MACULAR DEGENERATION LEADING CAUSE OF BLINDNESS AMONG NON-INDIGENOUS AUSTRALIANS



The prevalence of bilateral vision impairment by gender, age and geographical area

There was no significant difference in the prevalence of vision impairment between males and females for both Indigenous and non-Indigenous groups.

The prevalence of vision impairment increased markedly with age in both groups. Indigenous Australians aged 50-59 years had almost twice the prevalence of vision impairment than non-Indigenous Australians of the same age (8.23% vs 4.42%). This gap increased to a four-fold higher prevalence in those aged 60-69 years (16.85% in Indigenous Australians vs 4.37% in non-Indigenous Australians).

50-59 YEAR OLD AUSTRALIANS

4.42% NON-INDIGENOUS

8.23% INDIGENOUS

60-69 YEAR OLD AUSTRALIANS

4.37% NON-INDIGENOUS

16.85% INDIGENOUS

Vision impairment in non-Indigenous Australians did not vary significantly between regions of different remoteness. However, remoteness had an effect on vision impairment in Indigenous Australians, with the highest prevalence in Outer Regional areas (21.59%) compared to the lowest prevalence of 10.20% in Inner Regional areas.



THE PREVALENCE OF **VISION IMPAIRMENT IN INDIGENOUS AUSTRALIANS WAS MORE THAN DOUBLE IN OUTER REGIONAL AREAS COMPARED TO INNER REGIONAL AREAS**

Detection and treatment coverage rates of major eye diseases and conditions

Undiagnosed eye disease

Of all participants with vision impairment or blindness attributed to one of the five main causes, 57.40% of Indigenous Australians and 51.93% of non-Indigenous Australians did not report to have had that condition previously diagnosed. This corresponded to 5.58% of all Indigenous participants and 3.03% of all non-Indigenous participants.

MORE THAN 50% OF PARTICIPANTS FOUND TO HAVE AN EYE CONDITION **DIDN'T KNOW THEY HAD THAT CONDITION PRIOR TO TAKING PART IN THE SURVEY**





Diabetes eye checks

52.87% of Indigenous Australians with diabetes underwent the recommended annual diabetes eye check and 77.72% of non-Indigenous Australians with diabetes underwent the recommended biennial diabetes eye check to screen for diabetic eye disease8. Adherence rates in Indigenous Australians were significantly lower in very remote regions, while no remoteness effect was seen in the adherence rates of non-Indigenous Australians.

ALMOST 53% OF INDIGENOUS PARTICIPANTS AND ALMOST 78% OF NON-INDIGENOUS PARTICIPANTS WITH DIABETES HAD THE RECOMMENDED RETINAL **EXAMINATION**





Cataract surgery coverage

The cataract surgery coverage rate was much lower in Indigenous Australians (61.47%) compared to non-Indigenous Australians (87.63%). Coverage rates did not differ by remoteness in either group.

JUST OVER 61% OF INDIGENOUS AUSTRALIANS AND ALMOST 88% OF NON-INDIGENOUS **AUSTRALIANS WHO NEEDED CATARACT SURGERY HAVE HAD** THEIR CATARACTS REMOVED





Treatment of refractive error

The treatment coverage of refractive error was 93.65% in non-Indigenous Australians and 83.28% in Indigenous Australians.

JUST OVER 83% OF INDIGENOUS AUSTRALIANS AND ALMOST 94% OF NON-INDIGENOUS **AUSTRALIANS WHO REQUIRED** TREATMENT FOR REFRACTIVE **ERROR HAD BEEN TREATED**





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- 8. National Health and Medical Research Council, Guidelines for the management of diabetic retinopathy National Health and Medical Research Council, Editor. 2008: https://www.nhmrc.gov.au.

Appendix A: Contributing individuals and organisations

NEHS Steering Committee

Prime Contract Holder and Project Executive Sponsor

Brandon Ah Tong, Director of Policy and Advocacy, Vision 2020 Australia Jennifer Gersbeck, Chief Executive Officer, Vision 2020 Australia

Executing Research Body

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Major contributing partners

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Sector representatives

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Sarah Davies, Policy and Advocacy Officer, Vision 2020 Australia

National Aboriginal Community Controlled Health Organisation representatives

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CERA research team

Stuart Keel, Project Coordinator

Ross Dunn, Sampling Manager

Wei Meng, Database Construction and Administrative Support

Jing (Sophia) Xie, Senior Biostatistician

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Rosamond Gilden, Non-Indigenous Clinical Coordinator/Recruitment Back-up

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Larissa Andersen, Indigenous Clinical Coordinator/Recruitment Back-up

Benny Phanthakesone, Clinical Officer/Recruitment Back-up

Celestina Pham, Clinical Officer/Recruitment Back-up

Alison Schokman, Recruiting Officer/Clinical Back-up

Megan Jackson, Recruiting Officer/Clinical Back-up

Hiba Wehbe, Clinical Officer

John Komser, Research Optometrist/Pathology and Referrals

Cayley Bush, Clinical Officer

Lauren Hodgson

Beth Allesandrello

Jessica Alessi-Calandro

Galina Makeyeva

Organisations and individuals by state/territory

Victoria

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State-level or community representatives

Susan Forrester, Victorian Aboriginal Community Controlled Health Organisation Mitchell D Anjou, School of Population and Global Health, University of Melbourne Michael Cutmore, Mungabareena Aboriginal Corporation Andrew Gardiner, Dandenong and District Aborigines Co-operative Karinda Ritchie, Dandenong and District Aborigines Co-operative Kirsty Bell, Willum Warrain Aboriginal Association

Local Indigenous support workers

Margaret Murray Tarni Cooper Sharon Kilpatrick Trevor Mobourne Kylie Armstrong

Belinda Armstrong

Volunteers

Eleni Gilden Chloe Gilden Ranelle Gilden Nathan Gilden Eamonn Fahy Sobhee El Dirani

South Australia

State-level or community representatives

Dr Rosie King, Aboriginal Health Council of South Australia Desley Culpin, Aboriginal Health Council of South Australia Chris Rektsinis, Aboriginal Health Council of South Australia Cindy Zbierski, Nunyara Aboriginal Health Service Theresa Francis, Southern Adelaide Local Health Network Tracie Turnbull, City of Onkaparinga Christine Thyer, Watto Purrunna Aboriginal Health Services

Local Indigenous support workers

Geraldine McNamara Rebecca McNamara Lekesha Keelan **Danny Sevallos**

Volunteers

Jenny Slade Annette Giaretto Lisa Pigliafiori Harley Dutschke Candice Riccio

Northern Territory

State-level or community representatives

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Local Indigenous support worker

Nadia Clements

Volunteer

Shaun Tatipata

New South Wales

State-level or community representatives

Colina Waddell, Brien Holden Vision Institute

Wendy Hermeston, Aboriginal Health and Medical Research Council of New South Wales

Melinda Bell, Tharawal Aboriginal Corporation

Tallulah Lett, Tharawal Aboriginal Corporation

Nathan Jones, South Western Sydney Local Health District

Leslie Jenkins, Budyari Community Health Centre

Aaron Day, Goulburn Community Health Centre

Simon Sadler, Grand Pacific Health

Jade Hansen, Katungal Aboriginal Corporation Community & Medical Services

Donna Wade, Katungal Aboriginal Corporation Community & Medical Services

Sharleen Dodd, Armajun Aboriginal Health Service

Athol Lester, Aunty Jean's Aboriginal Chronic Care Program

Joseph Stewart, Eden Community Health Centre

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Vicki Devries

Teigan Aldridge

Latoya Thomas

Kelvin Brown

Brian Donnelly

Bridgett Jerard

Malcolm Timbery

Pat Seymore

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Volunteers

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Western Australia

State-level or community representatives

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Local Indigenous support workers

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Arthur Ugle

Kayleen Pickett

Peggy Michael

Jeff Farmer

Kyanne Heyward

Colleen Frost

Roslyn Rivers

Eric Delgety

Trevor Farrell

Donna Wright

Trevor Beasley

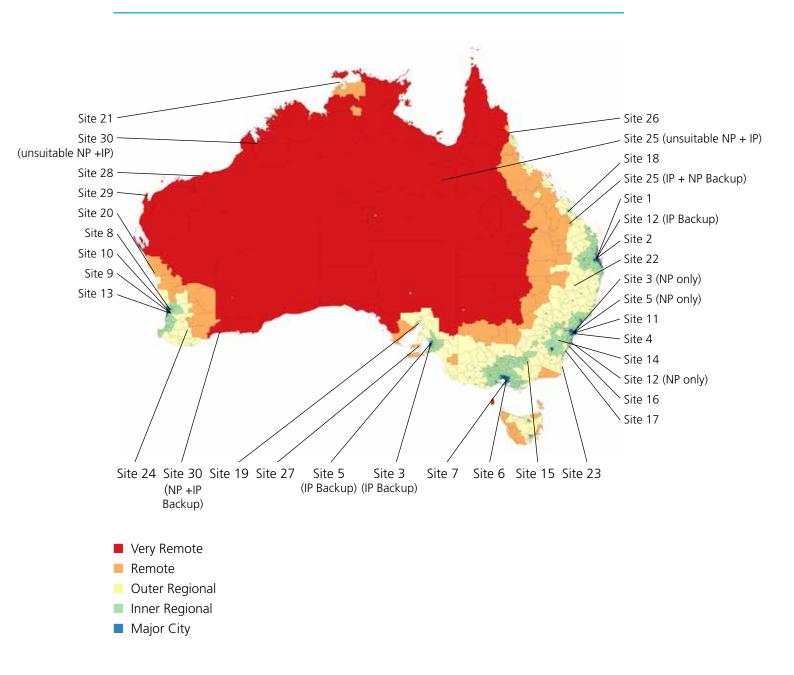
Chloe Kleehammer

Karen Hayes

Anne Hayes

Shirley Hayes

Appendix B: Selected sites in the National Eye Health Survey



Note: IP is the target Indigenous population. NP is the target non-Indigenous population. In cases where Indigenous communities declined to participate or Indigenous populations were too small, backup sites were used. In some instances, backup sites were used for both Indigenous and non-Indigenous recruitment (IP +NP backup), while in others, a backup site was used only for Indigenous recruitment (IP backup) and non-Indigenous participants were recruited from the primary site (NP only).

Site No	Site name	State
1	Brighton (Qld)	QLD
2	Springfield5	QLD
3	Parklea - Kellyville Ridge	NSW
4	Chipping Norton – Moorebank	NSW
5	Concord - Mortlake – Cabarita	NSW
6	Mornington	VIC
7	Rowville - Central	VIC
8	Craigie – Beldon	WA
9	Bassendean - Eden Hill – Ashfield	WA
10	Kalamunda - Maida Vale - Gooseberry Hill	WA
11	Elderslie - Harrington Park	NSW
12	Warilla	NSW
13	Lesmurdie - Bickley – Carmel	WA
14	Goulburn	NSW
15	Wodonga	VIC
16	Tomerong - Wandandian – Woollamia	NSW
17	Ulladulla Region	NSW
18	Rockhampton Region – East	QLD
19	Whyalla	SA
20	Geraldton	WA
21	Wagaman	NT
22	Inverell	NSW
23	Eden	NSW
24	Katanning	WA
25	Mount Isa	QLD
26	Daintree	QLD
27	Yorke Peninsula - South	SA
28	South Hedland	WA
29	Exmouth	WA
30	Derby - West Kimberley	WA

Back-up Sites

Site No	Site name	State
Bck 1	Willoughby-Castle Cove-Northbridge	NSW
Bck 2	Seventeen Mile Rocks-Sinnamon Park	QLD
Bck 3	Morphett Vale-East	SA
Bck 4	Ashwood-Chadstone	VIC
Bck 5	Nambour	QLD
Bck6	Warrnambool-South	VIC
Bck7	Rosebery-Bellamack	NT
Bck8	Dorrigo	NSW
Bck9	Banana	QLD
Bck10	Esperance Region	WA

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National body working in partnership to prevent avoidable blindness and improve vision care

The National Eye Health Survey is supported by funding from the Australian Government under the Chronic Disease Prevention and Service Improvement Fund



