

The prevalence and causes of vision impairment and blindness in Australia: The National Eye Health Survey

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ABSTRACT

Vision impairment (VI) and blindness affect 440 million people worldwide. As most cases can be avoided through evidence-based eye health care interventions, the elimination of avoidable VI and blindness is a global health priority. Nationally-representative population surveys on the prevalence and causes of VI and blindness are required to inform targeted eye health care programs.

This thesis documents Australia's first National Eye Health Survey (NEHS) that aimed to determine the prevalence and causes of vision loss and rates of utilisation of eye health care services for non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.

Multistage random-cluster sampling was used to select a nationally-representative sample of 3098 non-Indigenous Australians and 1738 Indigenous Australians from 30 population clusters across all five geographic remoteness strata (Major Cities, Inner Regional, Outer Regional, Remote and Very Remote). Participants underwent an interviewer-administered questionnaire and a series of standardised eye examinations, including visual acuity assessment, anterior segment assessment, perimetry, fundus photography and intraocular pressure measurement.

The prevalence of bilateral vision loss was 6.5% (95% confidence interval [CI]: 5.4-7.8) in non-Indigenous Australians and 11.2% (95% CI: 9.5-13.1) in Indigenous Australians. The age- and sex-adjusted prevalence of bilateral vision loss was 2.8 times higher in Indigenous than non-Indigenous Australians ($P<0.001$). The prevalence of unilateral vision loss amongst non-Indigenous and Indigenous Australians was 16.0% (95% CI: 14.4-17.7) and 14.9% (95% CI: 13.1-16.8), respectively, but after adjustment, unilateral vision loss was 1.4 times more prevalent in Indigenous Australians ($P=0.003$). Geographic remoteness was associated with a

higher prevalence of bilateral (Outer Regional odds ratio [OR]: 2.02) and unilateral (Very Remote OR: 1.65) vision loss in Indigenous Australians, but not non-Indigenous Australians.

Uncorrected refractive error and cataract were the leading causes of bilateral and unilateral vision loss, accounting for 70.4%-80.9% of all cases. Age-related macular degeneration was the leading cause of bilateral blindness (71.4%) and the third leading cause of bilateral vision loss (10.3%) in non-Indigenous Australians. Cataract was the leading cause of bilateral blindness (40%), and diabetic retinopathy was the second leading cause of bilateral blindness (20%) in Indigenous Australians.

Eighty-two percent of non-Indigenous Australians had undergone an eye examination within the past two years. Forty-seven percent of Indigenous Australians had been examined within the past year, as per national recommendations. Fewer Indigenous than non-Indigenous Australians with diabetes adhered to diabetic eye examination guidelines (52.7% [95% CI: 45.9-59.6] v 77.5% [95% CI: 71.8-83.3], OR: 0.37). Cataract surgery coverage (58.5% [95% CI: 49.8-66.8] v 88.0% [95% CI: 84.5-90.6]) and refractive error treatment coverage rates (82.2% [95% CI: 78.6-85.3] v 93.5% [95% CI: 92.0-94.8]) were significantly lower in Indigenous Australians compared to non-Indigenous Australians (OR: 3.2 and 0.51, respectively).

The NEHS has provided nationally-representative data on the prevalence and causes of vision loss and the utilisation of eye health care services for non-Indigenous and Indigenous Australians. This study has shown that the non-Indigenous population of Australia has a lower prevalence of vision loss than other high-income countries, and that there is a significant excess burden of vision loss in the Indigenous population of Australia. Most vision loss in Australia is avoidable and can be eliminated by utilising the findings of this survey to optimise treatment rates of avoidable causes of vision loss. Improvements in the availability and uptake of eye

health care services in Indigenous communities, particularly in non-metropolitan areas, are required to close the gap in Indigenous eye health. Marginalised and under-served Indigenous populations in other countries may benefit from the execution of similarly stratified nationwide surveys, the results of which may be used to optimise blindness prevention programs for at-risk population groups.

DECLARATION

This is to certify that

- i. the thesis comprises only my original work towards the PhD except where indicated in the preface,
- ii. due acknowledgement has been made in the text to all other material used, and
- iii. the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

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PREFACE

In accordance with University of Melbourne policy, I acknowledge that certain aspects of this work were collaborative.

My primary PhD supervisor, Mohamed Dirani, was the Principal Investigator of this study and successfully obtained funding (in collaboration with Vision 2020 Australia), ethical approval from the Human Research Ethics Committee of the Victorian Eye and Ear Hospital and endorsement from the National Aboriginal Community Controlled Health Organisation. He was also involved in the initial conception of this survey, along with Hugh Taylor and Peter van Wijngaarden. I worked with Mohamed Dirani and Stuart Keel to obtain ethical approval from Aboriginal ethical bodies and a coordinated approach involving Mohamed Dirani, Stuart Keel, Larissa Andersen and myself, was employed to facilitate engagement with Indigenous communities.

Ross Dunn assisted with the participant sampling and site selection protocol outlined in Chapter 3. Stuart Keel, Pei Ying Lee, Alison Schokman, Larissa Andersen, John Komser, Cayley Bush, Benny Phanthakesone, Hiba Wehbe, Rosamond Gilden and Celestina Pham assisted with logistics and the examination of study participants. Peter van Wijngaarden designed the clinical referral protocol.

A total of 27 manuscripts relating to this work have been submitted to journals, of which 25 have been accepted or published and 2 have been provisionally accepted. I am first author on 13, joint first author on one, second author on three and third author on 10 of these manuscripts. This thesis includes ten papers on which I am first author and one on which I am joint first author. The full citation for each included paper is presented below in the order of presentation in this thesis, after which the relative contributions of authors are provided.

1. Foreman J, Keel S, Dunn R, van Wijngaarden P, Taylor HR, Dirani M. Sampling methodology and site selection in the National Eye Health Survey: an Australian population-based prevalence study. *Clin Exp Ophthalmol*. 2017;45(4):336-47.
2. Foreman J, Xie J, Keel S, van Wijngaarden P, Taylor HR, Dirani M. The validity of self-report of eye diseases in participants with vision loss in the National Eye Health Survey. *Sci Rep*. 2017;7(1):8757.
3. Foreman J, Keel S, van Wijngaarden P, Taylor HR, Dirani M. Recruitment and Testing Protocol in the National Eye Health Survey: A Population-Based Eye Study in Australia. *Ophthalmic Epidemiol*. 2017; 24(6):353-363.
4. Foreman J, Xie J, Keel S, van Wijngaarden P, Sandhu SS, Ang GS, Fan Gaskin J, Crowston J, Bourne R, Taylor HR, Dirani M. The Prevalence and Causes of Vision Loss in Indigenous and Non-Indigenous Australians: The National Eye Health Survey. *Ophthalmology*. 2017; 24(12):1743-1752.
5. Foreman J, Xie J, Keel S, Ang GS, Lee PY, Bourne R, Crowston J, Taylor HR, Dirani M. The prevalence and causes of unilateral vision impairment and unilateral blindness in Australia: The National Eye Health Survey. *JAMA Ophthalmol*. 2018.
6. Keel S*, Foreman J*, Xie J, Taylor HR, Dirani M. Prevalence and associations of presenting near vision impairment in the Australian National Eye Health Survey. *Eye*. 2018.
7. Foreman J, Xie J, Keel S, Taylor HR, Dirani M. Utilization of eye health-care services in Australia: the National Eye Health Survey. *Clin Exp Ophthalmol*. 2017.
8. Foreman J, Keel S, Xie J, Van Wijngaarden P, Taylor HR, Dirani M. Adherence to diabetic eye examination guidelines in Australia: the National Eye Health Survey. *Med J Aust*. 2017;206(9):402-6.
9. Foreman J, Xie J, van Wijngaarden P, Crowston J, Taylor HR, Dirani M. Cataract surgery coverage rates for Indigenous and non-Indigenous Australians: the National Eye Health Survey. *Med J Aust*. 2017;207(6):256-261.
10. Foreman J, Xie J, Keel S, Taylor HR, Dirani M. Treatment coverage rates for refractive error in the National Eye Health survey. *PLoS One*. 2017;12(4):e0175353.
11. Foreman J, Dirani M, Taylor H. Refractive error, through the lens of the patient. *Clin Exp Ophthalmol*. 2017;45:673.674.

I conducted the literature review, designed the analysis, interpreted results, authored the first draft, and implemented all author and reviewer feedback for all publications included in this thesis. All authors provided significant intellectual contributions and reviewed all iterations of the manuscripts on which they are listed as authors. Jing Xie contributed to the statistical analysis of each paper on which she is listed as an author. Mohamed Dirani was the Principal

Investigator and senior author on all manuscripts in this list and supervised all aspects of this study.

Publications 1, 2 and 3 are included in the Methods section of this thesis. Prior to the commencement of data collection, I spent six months refining all aspects of the methodology with my supervisors, Mohamed Dirani, Peter van Wijngaarden and Stuart Keel, including study design, logistics, questionnaire and examination procedures, as well as electronic database construction.

Collectively, references 4-10 fulfill the objectives of my thesis and comprise most of the results section. I conceived the ideas for these publications with Stuart Keel and Mohamed Dirani. I designed the statistical analysis, interpreted data, conducted the literature review, authored the first draft of each publication and incorporated author feedback. As trained retinal graders, Lauren Hodgson, Beth Allesandrello, Jessica Alessi-Calandro, Pei Ying Lee, John Komser and Galina Makeyeva graded retinal photographs. As trained ophthalmologists, Sukhpal Singh Sandhu, Ghee Soon Ang and Jennifer Fan Gaskin utilised survey data to determine the main cause of vision loss in those with bilateral vision loss (Publication 4), while Pei Ying Lee and Ghee Soon Ang ascertained the main cause in those with unilateral vision loss (Publication 5). As Stuart Keel generated many of the ideas for Publication 6 and contributed significantly to its production, he has joint 1st authorship.

Reference 11 is an editorial piece commissioned by the Clinical and Experimental Ophthalmology. As first author, I generated many of the ideas for this editorial, wrote the first draft, conducted the literature review, and implemented author feedback and revisions. Mohamed Dirani and Hugh Taylor also provided intellectual input for this publication.

This project was funded by the Department of Health of the Australian Government, and also received financial contributions from the Peggy and Leslie Cranbourne Foundation and

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Stuart Keel deserves a special mention. Ted, your professionalism and unparalleled work ethic were a key motivating force for me to continue to challenge myself. You were truly thrown in the deep end, and seeing how quickly you adapted and how impressively you continued to grow and improve in your research and writing skills inspired me to try to keep up. We made

a brilliant team, and we should both be proud. I wish you only the very best in your undoubtedly bright future. Jing (Sophia) Xie also deserves a special acknowledgment. Sophia, you worked tirelessly under very high pressure, and I thank you for your hard work on this project. I owe a special thanks to Ross Dunn. The sampling methodology and site selection aspects of this study were very steep learning curves for me, and Ross spent hours explaining and clarifying with incredible patience and enthusiasm. Peter van Wijngaarden, thank you for always being available for a chat when I needed a fresh opinion. I was always excited to receive your thorough and meticulous feedback on my papers. Hugh Taylor deserves a special mention. Prof, drawing on your years of experience and wisdom ensured that our study design and community engagement were efficient and culturally appropriate, and your input on all manuscripts was exceptionally insightful. I am grateful for your continued willingness to always help with an air of patience and joviality. I would also like to thank all other authors who contributed to our research outputs.

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RESEARCH OUTPUTS

A total of 27 papers on this work have been submitted to journals, of which 25 have been accepted or published and 2 have been provisionally accepted. I am first author on 13, joint first author on one, second author on three and third author on 10 of these articles. In addition, two reports on the results of this study were commissioned by the Commonwealth Government and were launched at an event at the Australian Parliament on World Sight Day in October 2016. I was first author on both reports.

JOURNAL PUBLICATIONS

1. **Foreman J**, Keel S, Dunn R, van Wijngaarden P, Taylor HR, Dirani M. Sampling methodology and site selection in the National Eye Health Survey: an Australian population-based prevalence study. *Clin Exp Ophthalmol*. 2017;45(4):336-47.
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25. Keel S, Xie J, **Foreman J**, Taylor HR, Dirani M. The prevalence of vision loss due to ocular trauma in the Australian National Eye Health Survey. *Injury*. 2017; 48(11):2466-2469.
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27. Keel S, Xie J, **Foreman J**, Lee PY, Fahy E, Alwan M, Fan Gaskin J, Ang GS, Crowston J, Taylor HR, Dirani M. The prevalence of glaucoma in the Australian National Eye Health Survey. *Br J Ophthalmol*. 2018 (provisionally accepted).

COMMISSIONED GOVERNMENT REPORTS

1. **Foreman J**, Keel, S, Xie, J, van Wijngaarden, P, Crowston, J, Taylor HR, Dirani, M. The National Eye Health Survey 2016: Full 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 2016.
2. **Foreman J**, Keel, S, van Wijngaarden, P, Crowston, J, Taylor HR, Dirani, M. The National Eye Health Survey 2016 summary report. Centre for Eye Research Australia Vision 2020 2016.

CONFERENCE PRESENTATIONS

1. Oral presentation: Asia-Pacific Academy of Ophthalmology Congress, Hong Kong, 2018. Keel S, **Foreman J**, Dirani M. Australia's National Eye Health Survey.
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3. Oral presentation: Invited speaker at Close the Gap for Vision by 2020 National Conference, Melbourne, Australia, 2017. **Foreman J**, Xie J, Keel S, Taylor HR, Dirani M. Utilisation of eye health care services in Australia: the National Eye Health Survey. *Clin Exp Ophthalmol*. 2017.
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5. Oral presentation: World Health Organization Western Pacific Region Regional Meeting on Implementing "Towards Universal Eye Health": A Regional Action Plan for the

- Western Pacific (2014-2019), Manila, Philippines, 2017. Dirani M, **Foreman J**, Keel S. The National Eye Health Survey in Australia: utilisation of eye care services.
6. Oral presentation: World Health Organization Western Pacific Region Regional Meeting on Implementing "Towards Universal Eye Health": A Regional Action Plan for the Western Pacific (2014-2019), Manila, Philippines, 2017. Keel S, **Foreman J**, Dirani M. Data collection and assessment: The Australian National Eye Health Survey.
 7. Oral presentation: Australian Ophthalmic Nurses Association Conference, Melbourne, Australia, 2017. Keel S, **Foreman J**, Dirani M. The National Eye Health Survey.
 8. Oral presentation: Asia Pacific Academy of Ophthalmology Congress, Singapore, 2016. **Foreman J**, Keel S, Xie J, Van Wijngaarden P, Taylor HR, Dirani M. Adherence to diabetic eye examination guidelines in Australia: the National Eye Health Survey. *Med J Aust.* 2017;206(9):402-6.
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 10. Oral presentation: Centre for Eye Research Australia Community Seminar Series, Melbourne, 2017. Keel S, **Foreman J**, Dirani M. Diabetic Retinopathy: Epidemiology
 11. Oral presentation: Invited speaker at the Centre for Eye research Australia Department Meeting, Melbourne Australia, 2016. **Foreman J**, Keel S, Dirani M. Ideal sampling methodology in a population-based survey...and then the real world.
 12. Oral presentation: Invited speaker at the Centre for Eye research Australia Department Meeting, Melbourne Australia, 2015. **Foreman J**, Keel S, Dirani M. Overview and progress report on the National Eye Health Survey.
 13. Poster presentation: Association for Research in Vision and Ophthalmology (ARVO), Baltimore, USA, 2017. **Foreman J**, Xie J, Keel S, Taylor HR, Dirani M. Utilisation of eye health care services in Australia: the National Eye Health Survey. *Clin Exp Ophthalmol.* 2017.
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ABBREVIATIONS

AACG	Acute angle-closure glaucoma
ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Service
AH&MRC	Aboriginal Health and Medical Research Council
AHCSA	Aboriginal Health Council of South Australia
AHCWA	Aboriginal Health Council of Western Australia
AIHW	Australian Institute of Health and Welfare
AIRE	Indigenous Area
ALSA	Australian Longitudinal Study of Ageing
AMD	Age-related macular degeneration
AMS	Aboriginal Medical Service
AMSANT	Aboriginal Medical Services Alliance of the Northern Territory
ANOVA	Analysis of variance
aOR	Adjusted odds ratio
APA	Australian Postgraduate Award
ARIA	Accessibility/Remoteness Index of Australia
ARIA+	Accessibility/Remoteness Index of Australia Plus
ARVO	Association for Research in Vision and Ophthalmology
ASCCEG	Australian Standard Classification of Cultural and Ethnic Groups
ASGC	Australian Standard Geographical Classification
ASGS	Australian Statistical Geography Standard
AusDiab	Australian Diabetes, Obesity and Lifestyle Study
BCVA	Best-corrected visual acuity
BDES	Beaver Dam Eye Study
BMES	Blue Mountains Eye Study
CAOHS	Central Australian Ocular Health Study
CCD	Census Collector Districts
CDR	Cut-to-disc ratio
CERA	Centre for Eye Research Australia
CI	Confidence interval
CO	Corneal opacity

CSME	Clinically significant macular edema
DALY	Disability-adjusted Life Years
DM	Diabetes mellitus
DR	Diabetic retinopathy
DRS	Digital Retinography System
DW	Disability Weight
DYHS	Derbarl Yerrigan Health Service
ETDRS	Early Treatment Diabetic Retinopathy Study
FDT	Frequency Doubling Technology
FTA	Fail to attend
GBD	Global Burden of Disease
GP	General Practitioner
HDI	Human Development Index
HREC	Human Research Ethics Committee
IAPB	International Agency for the Prevention of Blindness
ICD-10	International Statistical Classification of Diseases– 10 th revision
IOL	Intraocular lens
IOP	Intraocular pressure
IP	Indigenous population
IQR	Interquartile range
KRDRS	Katherine Region Diabetic Retinopathy Study
LALES	Los Angeles Latino Eye Study
LE	Left eye
logMAR	Logarithm of the Minimum Angle of Resolution
LP	Light perception
MBS	Medicare Benefits Scheme
mmHg	Millimetres of mercury
NA	Not applicable
NACCHO	National Aboriginal Community Controlled Health Organisation
NATSIEHP	National Aboriginal and Torres Strait Islander Eye Health Program
NEHS	National Eye Health Survey
NFIP	National Framework Implementation Plan
NHANS	National Health and Nutrition Survey

NHMRC	National Health and Medical Research Council
NHS	National Health Survey
NIEHS	National Indigenous Eye Health Survey
NLP	No light perception
NP	Non-Indigenous population
NPDR	Non-proliferative diabetic retinopathy
NPV	Negative predictive value
NS	Non-significant
NSDAC	National Survey of Disability, Ageing and Carers
NSW	New South Wales
NT	Northern Territory
NTEHP	National Trachoma and Eye Health Program
NVI	Near vision impairment
OCT	Optical coherence tomography
OHT	Ocular hypertension
OPSM	Optical Prescription Spectacle Makers
OR	Odds ratio
OU	Oculus uterque (both eyes)
PDR	Proliferative diabetic retinopathy
PH	Pinhole
PPS	Probability Proportional to Size
PPV	Positive predictive value
pt	part
PVA	Presenting visual acuity
QAIHC	Queensland Aboriginal and Islander Health Council
QLD	Queensland
QoL	Quality of life
RA	Remoteness Area
RAAB	Rapid Assessment of Avoidable Blindness
RAAB+DR	Rapid Assessment of Avoidable Blindness plus Diabetic Retinopathy
RACGP	Royal Australian College of General Practitioners
RACSS	Rapid Assessment of Cataract Surgical Services
RANZCO	Royal Australian and New Zealand College of Ophthalmologists

RE	Right eye
REHC	Regional Eye Health Coordinators
RHOF	Rural Health Outreach Fund
RRR	Relative Risk Reduction
RVEEH	Royal Victorian Eye and Ear Hospital
SA	South Australia
SA	Statistical Area
SA1	Statistical Area – Level 1
SA2	Statistical Area – Level 2
SA3	Statistical Area – Level 3
SA4	Statistical Area – Level 4
SAEHP	South Australia Eye Health Program
SD	Standard deviation
TAFE	Technical and Further Education
TAR_IP	Target Indigenous population
TAR_NP	Target non-Indigenous population
TT	Trichomatous trichiasis
TVI	The Vision Initiative
VA	Visual acuity
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VI	Vision impairment
VIC	Victoria
VIP	Visual Impairment Project
VLEG	Vision Loss Expert Group
VTDR	Vision-threatening diabetic retinopathy
WA	Western Australia
WESDR	Wisconsin Epidemiologic Study of Diabetic Retinopathy
WHA	World Health Assembly
WHO	World Health Organization
YLD	Years Lived with Disability

CHAPTER 1: INTRODUCTION

1.1 Overview of this study

This thesis presents the key findings from Australia's first National Eye Health Survey (NEHS), conducted from September 2014 until October 2016. The NEHS was a nationwide cross-sectional population-based survey that aimed to determine the prevalence and major causes of vision impairment (VI) and blindness in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older in Australia. A modified multistage random-cluster sampling methodology was used to select 3098 non-Indigenous Australians and 1738 Indigenous Australians residing in 30 population clusters in Australia from the 11th of March 2015 to the 18th of April 2016. All participants underwent an interviewer-administered questionnaire and series of standardised eye tests.

A wealth of data was collected during this study, and at the time of completion of this thesis, 25 publications pertaining to the NEHS and its findings have been completed (with an additional two publications on the related topic of vision loss in Indigenous peoples of the world). The findings of the NEHS were therefore too numerous to include in a single doctoral thesis. This thesis addresses the primary aims of the NEHS.

1.1.1 Study Aims:

- 1) To determine the prevalence and major causes of unilateral and bilateral VI and blindness in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.
- 2) To determine rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and both cataract surgery coverage and refractive error treatment coverage rates in non-Indigenous Australians aged 50 years or older and Indigenous

Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.

1.2 Thesis chapters

1.2.1 Chapter 2. Literature review

Chapter 2 provides a comprehensive review of the global and Australian literature relevant to the aims of this project, and identifies the major gaps in the literature that demonstrate the need for conducting a nationwide survey on vision loss in Australia. The global burden of vision loss and the major causative eye diseases are discussed, demonstrating the need at a global level to allocate resources and formulate policy to alleviate avoidable vision loss in the context of a growing and ageing population. As this thesis explores vision loss in an Indigenous population, the literature also briefly discusses the paucity of global data on vision loss in Indigenous populations, and the need to include Indigenous groups in population surveys. Subsequently, this chapter describes global initiatives, including the Vision 2020 Initiative and the World Health Assembly (WHA) resolution, ‘Universal Eye Health: a Global Action Plan 2014-2019’ (the Global Action Plan), that call for all Member States to work toward creating “a world in which nobody is needlessly blind” by eliminating global avoidable blindness.¹ A core objective of the Global Action Plan is to provide an evidence base for informing eye health care policy in each country based on well-designed population surveys on the prevalence of VI and blindness.

As a signatory and contributing member to the Global Action Plan, Australia intends to fulfil its obligations to the WHA, and based on the recommendations of the Global Action Plan, Australia therefore requires nationally-representative population data on the prevalence and causes of vision loss. The literature review provides a comprehensive chronological account of ophthalmic epidemiological studies conducted throughout Australia’s history, focusing first on

the literature on the prevalence and causes of VI and blindness in Australia's non-Indigenous population, and then separately describing the available literature on the eye health of Australia's Aboriginal and Torres Strait Islander population. In line with the major objectives of this thesis, the literature on the prevalence and causes of VI and blindness, eye examination frequency, adherence to national diabetic eye examination guidelines, cataract surgery coverage and refractive error treatment coverage is reviewed.

Based on the lack of up-to-date and representative population-based eye health data, this thesis concludes that Australia is ill-equipped to optimally inform nationwide blindness prevention strategies and requires a nationally-representative eye health survey. Thus, the rationale, significance and community benefits of conducting a national survey on the prevalence of VI and blindness are multitudinous. The NEHS provides the evidence base to inform eye health care policies and programmes to allow the eye care sector and the Australian Government to meet the eye health care needs of the Australian population. This study is a core indicator in measuring the progress and impact of eye health care services in Australia and will guide the use of necessary resources in reducing the prevalence of avoidable vision loss in Australia through effective, feasible and cost-effective eye health care services. The results of this study may also aid in developing education, awareness and screening programs in communities, including regional and remote areas for the prevention of eye disease. Furthermore, to fulfil Australia's obligations under the Global Action Plan, nationally-representative data on the prevalence and causes of vision loss are required. Prior to the NEHS, as a signatory, Member State and contributing party to the Global Action Plan, Australia has been insufficiently equipped compared to other countries to fulfil its Vision 2020 obligations, highlighting the need for this study.

1.2.2 Chapter 3. Materials and Methods

Chapter 3 describes the methodology of the NEHS, including the sampling methodology, the participant recruitment protocol, the questionnaire and clinical eye examination procedures, data storage, handling and analysis, and protocols used to attribute the main causes of vision loss. This chapter appraises the various epidemiologic methods used historically to collect population-level data on the prevalence and causes of VI and blindness in other countries, including the use of disease registries, and various types of population survey methods. An account of various types of survey sampling and clinical examination methodologies is provided, with an emphasis on the strengths and weaknesses of various protocols. Two published manuscripts that describe the survey methodology in detail are included in Chapter 3. The first, titled “Sampling methodology and site selection in the National Eye Health Survey: an Australian population-based prevalence study” describes the protocol used to select samples of Indigenous and non-Indigenous Australians from all levels of geographic remoteness in Australia, and provides a detailed account of the challenges encountered during this process and how those challenges were overcome. The second manuscript, titled “Recruitment and testing protocol in the National Eye Health Survey: A population-based eye study in Australia” describes how residents were engaged and recruited to the study, the details of the interviewer-administered questionnaire and clinical eye examination methodology, and sample characteristics, including positive response rates and key demographic information. Because certain information was abbreviated for publication, Chapter 3 expands on some aspects of the methodology to provide a complete account of the survey protocol. This expansion includes an additional publication titled “The validity of self-report of eye diseases in participants with vision loss in the National Eye Health Survey” that demonstrates the unreliability of self-report in population-based eye health surveys, and consequently provides strong justification for the clinical examination methodology included in this study.

1.2.3 Chapter 4. Results

Chapter 4 of this thesis provides the results of the study. Although this chapter focuses principally on presenting the results in line with the objectives of this thesis, in accordance with University guidelines, entire publications have been included in this section. Section 4.2 addresses the primary objective of determining the prevalence and major causes of VI and blindness in Australia and includes three publications: 1) The prevalence and causes of vision loss in Indigenous and non-Indigenous Australians: The National Eye Health Survey; 2) The prevalence and causes of unilateral vision impairment and blindness in Australia: The National Eye Health Survey, and 3) Prevalence and associations of presenting near vision impairment in the Australian National Eye Health Survey. Additional supplementary data are included to provide a more complete account of the epidemiology of vision loss in Australia. Section 4.3 addresses the secondary aim of determining utilisation rates of eye health care services in Australia and contains four publications: 1) Utilization of eye health-care services in Australia: the National Eye Health Survey; 2) Adherence to diabetic eye examination guidelines in Australia: the National Eye Health Survey; 3) Cataract surgery coverage rates for Indigenous and non-Indigenous Australians: the National Eye Health Survey; and 4) Treatment coverage rates for refractive error in the National Eye Health Survey.

1.2.4 Chapter 5. General Discussion

Chapter 5 presents an overall discussion of the results in Chapter 4. Considering that each published manuscript in the results section contains a comprehensive discussion pertaining to the results in the manuscript, to avoid superfluity Chapter 5 does not provide a comprehensive discussion, but rather summarises the significance of this work in the global and national context.

CHAPTER 2. LITERATURE REVIEW

2.1 The global burden of vision impairment and blindness

2.1.1 Vision impairment and blindness as a disability

VI and blindness are major public health problems, costing the global economy well over \$2 trillion per year.² Loss of vision severely affects quality of life (QoL) and contributes significantly to the global burden of morbidity and mortality.³ According to the Global Burden of Disease (GBD) study, in terms of years lived with disability (YLD), VI and blindness constitute the third leading cause of disability worldwide.³ The effects of VI and blindness on QoL and the level of disability they cause depend on their severity (see 2.2 for definitions of each level of severity of VI and blindness). Disability Weights (DW), which reflect the relative severity of disease on a scale from 0 (perfect health) to 1 (equivalent to death) have been assigned to each level of impairment.

2.1.1.1 Bilateral vision loss as a disability

Bilateral blindness causes the greatest level of disability of all levels of vision loss (DW=0.187), followed closely by bilateral severe VI (DW=0.184). These weightings are more severe than the level of disability induced by severe malarial infection with anaemia (DW=0.178) and severe heart failure (DW=0.179), highlighting the profound impediment caused by loss of vision.⁴ Moderate (DW=0.031) and mild (DW=0.003) VI cause lower levels of disability, comparable with the level induced by conditions such as mild angina pectoris (DW=0.033) and mild anaemia (DW=0.004), respectively.⁴

The QoL effects of bilateral VI and blindness are multitudinous and vary from person to person depending on health, social and economic factors. People with VI or blindness are significantly more susceptible to personal injury and falls,^{5,6} have generally poorer health and health-related QoL,⁷ are less capable of engaging with educational and vocational activities, tend to

experience greater levels of poverty,^{8, 9} and have a high level of dependency on others.¹⁰ VI and blindness are also associated with poor mental health outcomes, including high levels of depression and anxiety, social isolation and feelings of hopelessness.¹¹ Apart from the increased disability burden, VI and blindness are also associated with increased mortality.^{12, 13}

2.1.1.2 Unilateral vision loss as a disability

Unilateral VI and blindness, while less severely detrimental than bilateral VI and blindness, also contribute to the global burden of disability. The DW associated with unilateral vision loss is 0.017.⁴ While far less data are available on the epidemiology of unilateral VI and blindness compared to bilateral VI and blindness, evidence suggests that, despite having a functional fellow eye, those with unilateral vision loss may be greatly affected in several functional domains. Loss of stereoscopic binocular vision and the reduction in visual fields result in reduced depth perception, visual-motor coordination, and spatial orientation.¹⁴ Consequently, unilateral VI and blindness are associated with a higher risk of motor vehicle accidents,¹⁵ a greater propensity for falling, increased levels of dependency on others, and poorer physical and mental health than the general population.¹⁰

2.1.1.3 Near vision impairment as a disability

Most studies on the prevalence and causes of VI and blindness have focused on the loss of distance vision and have neglected the pervasive problem of near NVI.¹⁶ Most NVI is caused by the age-related presbyopic loss of the accommodative ability of the eye.¹⁷ NVI is an important cause of disability and productivity loss worldwide, resulting in an estimated total economic loss of \$427 billion per year.¹⁸ The most recent GBD data from 2016 assigned a DW of 0.011 to NVI.⁴ Most of the disability associated with NVI arises from the inability to read, write and engage with new technologies such as computers and handheld devices, which have become indispensable occupational, educational and leisure tools in modern society.¹⁹

2.1.2 The global epidemiology of vision impairment and blindness

In 2015, an estimated 189 million people had mild VI, 217 million people had moderate to severe VI and 36 million were blind, corresponding to 2.57%, 2.95% and 0.48% of the world's population, respectively.¹⁶ These estimates, based on the GBD study that pooled data from 280 population-based surveys on the prevalence of vision loss conducted around the world, illustrate that the number of people with VI and blindness has increased by more than 22% since 2005.³ If preventative measures are not put in place, it is estimated that the number of people with VI and blindness will increase further to 588 million and 115 million by 2050.¹⁶ Considering that approximately 80% of global VI and blindness is preventable or treatable,²⁰ and that the global economic cost of VI and blindness is expected to surpass US\$2.7 trillion by the year 2020,²¹ the global community has a strong incentive to implement public health programmes to eliminate avoidable VI and blindness.

Major reasons for the increasing incidence and prevalence of VI and blindness are the growth and ageing of the population, as well as the influence of certain lifestyle factors such as overweight, smoking and obesity that contribute to the onset of eye diseases.^{22, 23} Regarding the ageing of the global population and the role this plays in the vision loss epidemic, the World Health Organization (WHO) has estimated that more than 80% of all VI and blindness occurs in those aged 50 years or older.¹ As many as 14% of people aged 50 to 69 years and 35% of those aged 70 and above are vision impaired, while 1% of people aged 50 to 69 years and almost 5% of people aged 70 years and above are blind.¹⁶ VI and blindness are more common in older people due to the higher incidence and more rapid progression of the major blinding eye diseases, particularly cataract, glaucoma, diabetic retinopathy (DR) and age-related macular degeneration (AMD) in older populations.²⁰

The prevalence of VI and blindness varies between different countries and regions of the world. Up to 90% of all VI and blindness is estimated to occur in developing countries, mostly due to

a lack of eye health care service availability.²⁴ In 2015, the prevalence of moderate to severe VI and blindness were below 5% and 0.5%, respectively, in those aged 50 years and older in all developed nations. In contrast, the prevalence of moderate to severe VI was as high as 17.5% in south Asia and the prevalence of blindness was as high as 5.1% (10 times higher than the average for developed nations) in western sub-Saharan Africa.¹⁶

Approximately 1.1 billion people were estimated to have presbyopic NVI in 2015, of whom more than 60% were aged 50 years or older.¹⁶ Holden and colleagues (2008) estimated that the global prevalence of presbyopia was between 43.8% and 58.9% in adults aged 40 years or older, while the prevalence was as high as 83% in those aged 45 years or older.¹⁹ Like distance VI and blindness, the prevalence of NVI varies considerably between regions of the world.¹⁹ Despite the ease with which most cases of NVI are treatable with spectacles, it was estimated in 2010 that approximately half of the presbyopic population globally, totalling 517 million people, had no correction or inadequate correction to achieve normal near visual acuity.²⁵ Indeed, 94% of presbyopia cases may be under- or uncorrected in some low income countries.¹⁸

2.2 Definitions of vision impairment and blindness

Various definitions of VI and blindness can be found in the literature. The WHO's International Classification of Diseases 10th Edition (ICD-10) defines bilateral VI as presenting visual acuity (PVA) worse than 6/18 ($<6/18$) but equal to or better than 3/60 ($\geq 3/60$) in the better eye and bilateral blindness as PVA $<3/60$ in the better eye.²⁶ The ICD-10 sub-categorises VI into mild ($<6/12$ - $6/18$), moderate ($<6/18$ - $6/60$) and severe VI ($<6/60$ - $3/60$).²⁶ The United States and some other countries utilise different definitions, with VI defined as best-corrected visual acuity (BCVA) $<6/12$ - $6/60$ and blindness defined as BCVA $<6/60$.²⁷ Some studies utilise United States thresholds for visual acuity, but consider PVA rather than BCVA to be more relevant. Australian definitions of legal VI and blindness use the 6/12 and 6/60 thresholds, and recent

Australian literature has defined VI as PVA<6/12-6/60 and blindness as PVA<6/60 in the better eye.²⁸

2.3 The major causes of vision impairment and blindness

The major causes of VI and blindness vary between populations, however, globally, the five most common causes of vision loss are uncorrected refractive error, cataract, AMD, DR and glaucoma.²⁹ Other important causes of vision loss include trachoma, non-trachomatous corneal opacity (arising from conditions such as corneal dystrophy, keratoconus and iridocorneal endothelial syndrome), ocular onchocerciasis, trauma and myopic macular degeneration.²⁹⁻³²

2.3.1 Defining the main cause of vision impairment and blindness

Population surveys may distinguish between *causes* of vision loss and *the main cause* of vision loss. For example, causes of VI or blindness may be reported without specifying whether these conditions are the *main cause* or whether another condition is more advanced and has contributed more to vision loss.³³ While an individual may have more than one ocular condition that contributes to the impairment of their vision, the condition that is identified as causing the greatest impediment to vision is designated as the main cause of vision loss. However, in cases where there is no obvious or distinct main cause, then the main cause of vision loss may be attributed to combined mechanisms. In the review of the literature on the causes of VI and blindness in 2.3.2 to 2.3.7 below, where conditions are described as causes of VI or blindness, this refers to that condition being the *main cause* of vision loss.

2.3.2 Uncorrected refractive error

Globally, uncorrected refractive error is the leading cause of vision loss.²⁹ The most common refractive error affecting distance visual acuity, myopia, has been shown to result from excessive corneal curvature or an elongation of the eye along its axial length, causing light entering the eye parallel to the optic axis to focus in front of the retina.³⁴ Conversely,

hypermetropia occurs with a reduced corneal curvature or shorter axial length, causing light parallel to the optic axis to focus behind the retina, while astigmatism occurs due to aberrations in the shape of the cornea or lens resulting in distortion of light arriving at the retina.³⁴ Presbyopia is caused by age-related changes in the elasticity of the lens and a consequent reduction in the accommodative amplitude of the eye. This condition usually progressively worsens and interferes with the ability to focus on near objects.³⁴

In 2016, a meta-analysis of 145 studies estimated that the number of people with myopia in 2010 was 1.95 billion, or 28.3% of the global population,³⁵ with a prevalence higher than 90% in some East and Southeast Asian countries such as South Korea. This represented a substantial upward trend from 1.41 billion in 2000 (22.9% of the global population), indicating that both the incidence and prevalence of myopia have increased rapidly. From these data, it was estimated that by the year 2050, half of the global population would be myopic, affecting an estimated 5 billion people.³⁵ Approximately 10% of people with myopia are at risk of developing pathological myopia, which may cause irreversible blindness due to complications such as retinal detachment, glaucoma and myopic macular degeneration.³⁵ The prevalence of hypermetropia varies between populations and across age groups, and tends to be more prevalent during childhood.³⁶ Estimates of the global prevalence of hypermetropia and its contribution to the global burden of vision loss are unreliable due to large differences in spherical equivalent thresholds for diagnosis between studies.³⁶ In most instances, refractive errors do not cause severe disability if they are adequately corrected, however, uncorrected or under-corrected refractive error remains a pervasive problem worldwide.

Surveys on the prevalence and causes of VI and blindness in many countries have defined vision loss based on BCVA, and the contribution of uncorrected refractive errors to the burden of vision has not been quantified in those studies.^{37, 38} Studies that have investigated uncorrected refractive error have consistently demonstrated the considerable magnitude of this

condition as a major public health concern.^{39, 40} Despite the fact that most cases of refractive error can be readily corrected with low-cost spectacles, more than 150 million adults have uncorrected distance refractive error (defined as VI or blindness caused by refractive error).⁴¹ Systematic analyses conducted by the GBD Vision Loss Expert Group (VLEG) in 2013, and again in 2017, demonstrated that uncorrected refractive error was the leading cause of VI worldwide, accounting for 52.9% of moderate or severe VI in 2010 and 52.3% of moderate or severe VI in 2015, and the second leading cause of blindness, accounting for 20.9% of bilateral blindness cases in 2010 and 20.3% of blindness cases in 2015.^{20, 29} Uncorrected refractive error was the leading cause of moderate or severe VI in all 21 major world regions assessed.^{20, 29}

2.3.3 Cataract

Cataracts comprise a diverse array of pathological conditions in the crystalline lens and surrounding structures of the eye that cause lens opacification and the obstruction of the passage of incoming light, thereby resulting in reduced visual function.⁴² While there are various forms of the disease including congenital cataract, juvenile cataract, traumatic cataract and metabolic cataract, by far the most prevalent form is age-related or senile cataract, which in turn is usually subclassified into nuclear sclerotic (the most common type), cortical and subcapsular cataract, depending on the anatomical components of the lens affected.⁴³

Review of the literature on the epidemiology of cataract across studies should be carried out with caution as studies vary greatly in terms of cataract classification, thresholds of diagnosis, testing protocols and age criteria of the sampled populations. Most eye health surveys examine older populations, usually with participants aged above 40 or 50 years, and the majority of people in this age group present with some degree of cataractous opacity.⁴⁴ Consequently, studies typically do not report the overall prevalence of *any* cataract, but rather the prevalence of blinding or vision-impairing cataract, or the proportion of vision loss attributable to cataract.⁴⁵ Nonetheless, a few studies have investigated the prevalence of any cataract, and

estimates vary widely. Pooled data revealed that 34.8% of Australian women and 28.9% of Australian men aged 50 years and over had any cataract,⁴⁶ while rates were comparable between Barbadians aged 40 years and above, Chinese aged 45 years and above and Koreans aged 40 years and above, with prevalence estimates of 41%, 38.1% and 42.3%, respectively.⁴⁷ A 2013 review reported comparatively lower prevalence rates of cataract in European countries, with rates ranging from 5% in those aged 52-62 years to 30% in those aged 60-69%.⁴⁸ The prevalence of cataract can exceed 95% in populations aged over 80 years.⁴⁹

Considering the near ubiquity of cataracts in most older populations, studies that have specifically investigated the epidemiology of vision-impairing and blinding cataracts rather than all cataracts are arguably more relevant to understanding disease burden and are more useful for public health policy. According to the WHO, 90% of people with blinding cataracts live in developing nations, and this inequity results from insufficient cataract surgery service availability in these regions relative to more affluent countries that tend to have affordable, high quality and prolific services that are sufficient to meet the needs of the population.¹

Systematic global analyses that have pooled multinational data have consistently shown that cataract is the second leading cause of VI and the leading cause of blindness in the world.^{20, 29,}

⁵⁰ The most recent available data revealed that 25.2% of moderate or severe VI in 2015 was caused by cataract.²⁹ A 2004 WHO study reported that 47.8% of world blindness was caused by cataract,⁴⁴ and a follow up analysis in 2012 suggested that cataract was responsible for 51% of global blindness.⁵⁰ The former study did not include uncorrected refractive error (now known to be the second leading cause of blindness)²⁰ and therefore probably underestimated the number of people with blindness and overestimated the relative proportion attributable to cataract. This highlights the need for eye health studies to ascertain the contribution of uncorrected refractive error to the global burden of vision loss. While the systematic analyses conducted by the GBD VLEG in 2013 and 2017 corroborated that cataract was the leading

cause of blindness worldwide, its relative contribution to the burden of vision loss was lower than in the WHO studies, causing 33.4% of cases in 2010²⁰ and increasing to 35.2% of cases in 2015.²⁹

Cataract is the leading cause of blindness in most of the world's low and middle-income countries, including in much of Asia, the Caribbean, Latin America, Oceania and all of Africa, due to the lack of cataract surgical services in these regions.²⁹ However, in recent years, cataract has ceased to be the major cause of blindness in some high-income countries, including those of Asia, Western Europe, North America and Australasia, owing in part to substantial improvements in cataract surgery coverage rates (the proportion of individuals who had bilateral cataract causing vision loss, who have received cataract surgery on one or both eyes), as well as the increasing incidence of other ocular diseases such as AMD and DR,³⁰ and their correspondingly greater contribution to the burden of vision loss. This represents a considerable shift from previous decades in which cataract was the major cause of blindness in all regions of the world.²⁹

2.3.4 Glaucoma

Glaucoma comprises a group of conditions with diverse aetiologies and pathophysiological underpinnings that are characterised by damage to the optic nerve and the loss of peripheral vision that can progress to loss of central vision and permanent blindness.⁵¹ The two major types of glaucoma, open-angle glaucoma and angle-closure glaucoma, have a strong genetic basis, and frequencies of each differ between populations of different ethnic/racial composition. For example, angle-closure glaucoma is more common in Asian populations than other populations.⁵² Despite representing 60% of the global population, Asian people comprise approximately 87% of all people with angle-closure glaucoma.⁵³ Conversely, open-angle glaucoma is most prevalent in African populations (4.2%), with people of African descent being 2.8 times more likely than people of European descent to develop the disease.⁵² An

estimated 60.5 million people had glaucoma in 2010, and this number is predicted to increase to approximately 80 million by 2020, due primarily to the growth and ageing of the global population.⁵³

Glaucoma has been identified as the leading cause of irreversible blindness,⁵² and accounts for 8.5% of all blindness globally, corresponding to 2.9 million people.²⁹ The proportion of global VI attributable to glaucoma is substantially lower, at 2.1%, corresponding to 4 million people worldwide. Estimates of the global burden of glaucoma as a cause of vision loss are likely to be less reliable than for more easily diagnosed conditions such as cataract and refractive error. This results from the fact that most global estimates are derived from pooled population survey data, and most surveys employ rapid and simplified ophthalmic examination protocols, the majority of which do not make provisions for glaucoma detection.⁵⁴ Therefore, proportionately fewer surveys have attributed glaucoma as a main cause of vision loss.²⁹ Glaucoma is significantly associated with increasing age, and the ageing of the global population is predicted to be accompanied by an increase in the number of people with VI and blindness from glaucoma to 4.5 million and 3.2 million by 2020, respectively.²⁹ It is therefore of importance that future eye health surveys in each country aim to include testing modalities such as perimetry, intraocular pressure assessment and fundus photography in their protocols to accurately detect glaucoma, thereby better informing blindness prevention strategies.

2.3.5 Age-related macular degeneration

AMD is a blinding eye disease characterised by degeneration of components of the outer retina, including the retinal pigment epithelium, photoreceptors and choriocapillaris, resulting from variable combinations of degenerative and neovascular changes.⁵⁵ The two major subtypes of AMD are wet or neovascular AMD, and dry or non-neovascular AMD. The progression of neovascular AMD may be slowed by a number of different treatments, most notably intravitreal injections of anti-vascular endothelial growth factor drugs.⁵⁶ However, there is no effective

treatment for non-neovascular AMD, and people with this form of AMD are at serious risk of progressing to irreversible VI or blindness.⁵⁷ The strongest risk factor for AMD is older age, with people aged 75 years or older being three times more likely to have AMD than those aged 65-74 years.⁵⁸ Due to the rapid ageing of the global population and the fact that most cases are untreatable, AMD represents a significant and worsening public health crisis that costs the global economy more than \$30 billion annually.⁵⁹

The epidemiology of AMD as a cause of VI and blindness has changed markedly in recent decades. Cataract was previously the leading cause of blindness in all regions of the world, however, AMD has recently become the main cause of overall blindness in many high-income countries.⁶⁰ AMD is responsible for 15-20% of blindness in high-income Australasia, Asia-Pacific, Europe and North America.²⁹ This shift is due in part to improvements in avoidable blindness prevention and treatment programs in high-income countries, and the increasing prevalence of AMD worldwide.⁶⁰ A 2014 meta-analysis of 39 studies showed that the pooled prevalence of AMD in people aged 45 to 85 years was 8.7%, corresponding to just under 200 million people, and due to the growth and ageing of the global population, the number of people with AMD is expected to increase to 288 million by the year 2040.⁶⁰

As with glaucoma, insufficiencies in many population surveys worldwide that have used simplified testing methods have limited the ability of investigators to attribute macular disease as the main cause of vision loss.⁵⁴ Consequently, less data are available for the epidemiology of AMD compared to avoidable causes of blindness, and many countries may be ill-informed to adequately resource programmes for macular blindness, such as low vision services for those with irreversible blindness. Global and national programmes would benefit from accurate data on AMD from surveys that include retinal imaging modalities and appropriately trained staff that are able to identify and categorise AMD.

2.3.6 Diabetic retinopathy

Diabetes mellitus has become a global public health crisis and affects more than 400 million people worldwide.⁶¹ An estimated \$376 billion is spent annually on diabetes care, accounting for up to 12% of global health expenditure.⁶² The dramatic increase in the incidence of diabetes is being driven principally by diet, obesity, and physical inactivity, as well as population growth and ageing.⁶³ As the burden of diabetes increases, so too does the burden of its complications, one of which is DR, the most common microvascular complication of diabetes.⁶⁴ DR is a complex and progressive vascular disease that is usually asymptomatic in its early stages, but if left undetected and untreated, may result in irreversible blindness.⁶⁵

Most surveys that have reported the prevalence of DR have not reported the overall population prevalence of the disease, but rather the prevalence of DR within the diabetic population. A meta-analysis by Yau *et al* (2012) based on 35 studies that included 22,896 participants with diabetes reported a prevalence of any DR of 34.6% and a prevalence of 10.2% for vision-threatening diabetic retinopathy (VTDR).⁶⁶ These prevalence estimates correspond to 93 million people with DR and 28 million people with VTDR worldwide,⁶⁶ all of whom have potentially irreversible vision loss or are at considerable risk of developing irreversible vision loss. Indeed, DR is now the leading cause of blindness in working age adults,⁶⁶ despite most blindness resulting from the disease being preventable.⁶⁷ Among adults aged 50 years and older, DR contributes to 1.3% of moderate and severe VI and 1.06% of blindness, globally.²⁹ DR tends to account for a greater proportion of vision loss in middle- and high-income regions than in low-income regions, ranging from 0.31% of VI in East sub-Saharan Africa to 5.06% of VI in Eastern Europe, and 0.16% of blindness in South Asia and 4.5-4.9% of blindness in Australasia and Eastern Europe.²⁹ However, as developing nations adopt Westernised lifestyles, the influence of DR-related risk factors, including poor diet, obesity, sedentary

lifestyle and poor glycaemic control are expected to increase. Consequently, DR is considered an emerging cause of blindness in the developing world.⁶⁵

2.3.7 Other major causes of VI and blindness

The various diseases and conditions not including uncorrected refractive error, cataract, glaucoma, AMD and DR, that cause VI or blindness constitute a large proportion of all vision loss worldwide. Other conditions including unidentified causes and all conditions not included in the above categories (but excluding trachoma and corneal opacity) were the main cause of 13% of VI and 24.9% of blindness in 2015, and this was demonstrably higher than in 1990, when 9.7% of VI and 18.8% of blindness were due to other causes.⁶⁸ This represents an increase in the number of people with vision loss from other causes from 22 million to 37 million in just 25 years, and as many as 42 million people are expected to have other causes of vision loss by 2020.⁶⁸ Global, regional and national eye health policy would benefit from accounting for other causes of vision loss, firstly because they comprise a quarter of all blindness worldwide, and secondly because many are avoidable or preventable. In particular, the infectious causes of vision loss, including ocular onchocerciasis (not endemic in Australia) and trachoma are endemic in many populations.

Trachoma, caused by infection with the bacterium *Chlamydia trachomatis*, is endemic in over 40 countries where 190 million people are at risk of infection.⁶⁹ Children are at greatest risk of trachoma infection, with the prevalence of active forms of trachoma (follicular trachomatous inflammation and intense trachomatous inflammation) being as high as 90% in some child populations.^{70, 71} Chronic infection results in conjunctival scarring followed by trachomatous trichiasis which, over a prolonged period, causes corneal opacity and blindness.⁷²

Trachoma is a disease of the developing world, and its presence is strongly correlated with poor living conditions, lack of hygiene and flowing water, and a paucity of health care services.⁷³⁻⁷⁶

Almost all high-income countries have eliminated trachoma, while in contrast, 6% of all VI and 7% of all blindness in East sub-Saharan Africa is caused by trachoma.²⁹ In some highly endemic and severely underserved populations such as South Sudan, as much as 47% of VI is caused by trachoma.⁷⁷ Notably, Australia is the only developed nation that has not succeeded in eradicating endemic trachoma, despite ranking 2nd on the global Human Development Index (HDI).⁷⁸ Trachoma is only endemic in Australia's Indigenous population, where up to 5% of children still have active trachoma infection,⁷⁹ and according to a recent survey, 9% of adult blindness was caused by trachoma.²⁸

Surveys aiming to determine the cause-specific prevalence of VI and blindness in low-income populations known to have endemic trachoma have frequently been insufficiently resourced to identify trachoma.^{80, 81} In particular, if study investigators have not utilised standardised diagnostic tools such as the WHO simplified trachoma grading system⁸² and have not possessed the requisite examination equipment, the relative contribution of trachoma to the burden of vision loss may not be adequately quantified. Considering the efficacy with which trachoma-specific public health programmes have alleviated the burden of trachoma,⁸³ inclusion of trachoma screening in population research is valuable for efforts to eliminate this avoidable cause of blindness.

2.4 Risk factors for vision impairment and blindness

2.4.1 Risk factors of blinding eye diseases

Identifying epidemiologic risk factors for vision loss improves the ability of policy-makers and eye health care providers to specifically formulate targeted interventions for population sub-groups most in need. The most obvious risk factor for vision loss is the presence of a blinding eye disease,⁸⁴ and there is an abundance of literature on the risk factors associated with each disease. For example, risk factors for DR include high cholesterol, poor glycaemic control and

duration of diabetes,^{66, 85} risk factors for trachoma include poor hygiene, an unclean face, overcrowding and high environmental temperatures,⁸⁶⁻⁸⁸ and risk factors for AMD include family history, cigarette smoking and excessive alcohol consumption.^{89, 90}

2.4.2 Sociodemographic risk factors

Most surveys that report the prevalence and causes of VI and blindness have not included risk factor analyses to identify demographic and environmental variables that are associated with vision loss. Nonetheless, from the limited studies that have reported risk factors, some demographic factors have been repeatedly identified. For example, gender has been shown to be a risk factor for vision loss in many populations, although this association varies between studies, with both female^{41, 44, 91} and male⁹² gender being identified as risk factors. Gender has also been seen to have no effect on vision loss in other populations.⁹³ Older age, unemployment, fewer years of education and diabetes have also been repeatedly shown to be risk factors for vision loss.^{84, 94-96}

2.4.3 Geographic location as a risk factor for VI and blindness

Geographic location has been identified as an important risk factor for VI and blindness in a small number of studies. In China, municipality of residence has been associated with vision loss, and surveys in a number of countries including Mexico⁹⁷ and India⁹⁸ have demonstrated that people residing in rural areas have a greater risk of vision loss than those living in urban areas. Rural areas are not as well serviced as metropolitan areas with eye health care services, and the consequently lower detection and treatment coverage rates of blinding eye diseases contribute to the higher prevalence of VI and blindness.⁹⁹

Very few studies have interrogated the problem of geographic remoteness thoroughly, and most studies have not stratified their sampling frames to ensure that the relative risk associated with rural residence is quantified. Studies that have implemented some form of remoteness

stratification have considered remoteness as an urban-rural dichotomy,¹⁰⁰⁻¹⁰² but a study conducted in Australia that examined samples from five distinct remoteness strata revealed a significant non-binary remoteness effect across the remoteness spectrum.²⁸ The majority of studies have not stratified sampling by remoteness,¹⁰³⁻¹⁰⁸ have only controlled for remoteness through design effect calculations, or adjusted for remoteness *post hoc* during statistical analysis.¹⁰⁹⁻¹¹¹ The general consequence is that most countries have not quantified the relative risk experienced by millions of people living in remote areas, and may not be capable of optimally designing interventions that reflect the true needs of non-metropolitan vs metropolitan populations.

2.4.4 Limitations of reports on risk factors for VI and blindness

A number of studies that report risk factors have simply compared the prevalence of one group to the prevalence of another group in pairwise or univariate comparisons, without making adjustments for the possible confounding effects of co-variates, or have adjusted only for age and gender.⁹⁶ This is particularly apparent in studies that report gender and age as risk factors for vision loss.¹¹² While these studies have not been incorrect in stating that one group has a statistically significantly higher prevalence of vision loss than another, they have not adequately demonstrated independent and unconfounded associations. Examples of studies that have used more complex statistical models such as multivariable logistic regression to identify independent risk factors include the Los Angeles Latino Eye Study⁹⁴ and the China Nine-Province Survey.⁹⁵ Population risk factors from these studies are likely to be more reliable than those that have not controlled for co-variates, and eye health programmes arising from these data may therefore be more effective in delivering services to those most in need.

2.5 Vision impairment and blindness in marginalised communities

Most population surveys, including many national and sub-national studies that are included in the Global Vision Database managed by the GBD VLEG, report overall population prevalence estimates without accounting for potential differences between subgroups within heterogeneous populations.¹⁶ Considering that the prevalence of vision loss varies between countries and regions of the world due to ethnic, economic and health-related factors,¹¹³ it follows that the prevalence of vision loss may also vary between subgroups within a country's population.

Some literature has shown that vision loss does indeed vary within populations. For example, the Multi-Ethnic Study of Atherosclerosis in the United States has revealed ethnic differences in the prevalence of vision loss, with one study revealing that Chinese Americans had the highest prevalence of 9.8%, followed by Hispanic (7.5%), Black (5.5%) and White (5%) populations.¹¹⁴ Similar racial differences have been observed between Singaporean Malay, Indians and Chinese in the Singapore Epidemiology of Eye Disease study.¹¹⁵ While hereditary factors play a role in the development of certain eye diseases and consequently on the prevalence of vision loss,¹¹⁶⁻¹¹⁸ research suggests that lifestyle and economic factors play a larger part, with vision loss being found at consistently higher rates in socioeconomically disadvantaged communities.¹¹⁹⁻¹²¹ The disparity in vision loss between certain ethnic groups may therefore be due to socioeconomic rather than hereditary factors. Surveys that have assumed homogenous populations and neglected to investigate the stratified prevalence of vision loss in disadvantaged or ethnically diverse communities may have underestimated the burden of vision loss in their populations' most vulnerable groups. Consequently, policy-makers that rely on these data may develop sub-optimal interventions that are insufficient to meet the needs of the population. Surveys conducted within marginalised or socio-

economically disadvantaged groups that are likely to have poor access to care and poorer general and ocular health would benefit from stratifying their sampling frames accordingly.

2.5.1 Vision impairment and blindness in the Indigenous peoples of the world

2.5.1.1 Health inequity in Indigenous peoples

Indigenous people, of whom there are an estimated 370 million residing in 90 countries,¹²² are among the world's most disadvantaged and marginalised.¹²³ This PhD thesis presents a national survey on the prevalence and causes of vision loss in Australia, a country containing a substantial Indigenous community that comprises almost 3% of the national population.¹²⁴ Due to the consistent tendency for Indigenous populations to be poorly serviced with health care, it is of interest to appraise the literature on vision loss in Indigenous populations around the world to provide some context for the current study. While the definition of Indigeneity is contentious, according to the United Nations Permanent Forum on Indigenous Issues, Indigenous peoples may be defined by their: 1) self-identification as Indigenous peoples by individuals and acceptance as such by their community, 2) historical continuity and land occupation before invasion and colonisation, 3) strong links to territories (land and water) and related natural resources, 4) distinct social, economic, or political systems, 5) distinct language, culture, religion, ceremonies, and beliefs, 6) tendency to form non-dominant groups in society, 7) resolution to maintain and reproduce ancestral environments and systems as distinct peoples and communities, 8) tendency to manage their own affairs separate from centralised state authorities.¹²²

As a result of colonial invasion, oppression and exploitation, many Indigenous peoples are severely afflicted by poverty, and social and political exclusion.¹²⁵ The Lancet–Lowitja Institute Global Collaboration study was a multinational project that collected health data from Indigenous populations in 23 countries, and its findings revealed that Indigenous peoples have poorer health outcomes than non-Indigenous populations in most countries.¹²⁶ However, as

with other global literature on Indigenous populations,¹²⁷⁻¹²⁹ this study did not include data on VI and blindness.

2.5.1.2 The prevalence of vision impairment and blindness in Indigenous peoples

Based on the above definition of Indigeneity, 86 articles describing 65 studies from 24 countries that provide eye health data on Indigenous populations since 1990 were found in the literature. Older studies are likely to be less relevant to a contemporary review, and studies conducted before the 1990s are consequently not discussed in this thesis, although there is a wealth of data from much of the early 20th century. Of the studies found, 21 studies reported the prevalence of VI, and 19 reported the prevalence of blindness in Indigenous peoples. Some of these studies were conducted on Indigenous populations in Australia, however, this literature is reviewed later (in section 2.7.2) and will not be reported here. Eye health surveys in Indigenous populations have varied greatly in sampling, recruitment and testing protocols, as well as definitions and visual acuity thresholds of VI and blindness. The prevalence of VI based on PVA has been shown to be particularly high in some Indigenous populations, including the Indigenous people of Tibet aged 50 years or older (48.5%)¹³⁰ and the Indigenous people of East Timor (14.9%).¹³¹ Estimates based on BCVA were high in the Hamar people of Ethiopia aged 40 years or older (14.6%).¹³² The prevalence of blindness was high in Indigenous Tibetans¹³⁰ and East Timorese¹³¹ with PVA-based estimates of 10.9% and 7.7%, respectively, and in the Indigenous Turkana people of Kenya (12.5%)¹³³ and the Hamar people (8.1%).¹³²

Very few studies have statistically compared prevalence estimates between Indigenous and non-Indigenous populations, however most studies that conducted comparisons have revealed a greater burden of vision loss in Indigenous populations.^{68, 134-139} VI was more prevalent in the Indigenous population than the non-Indigenous population of Chiapas State, Mexico (10.0% vs 5.1%, $P<0.001$).¹³⁵ and the Indigenous Kalenjin of Nakuru, Kenya were 2.5 times more likely to be blind than their non-Indigenous counterparts in the same country.¹³⁹ A Malaysian

survey reported a moderately higher prevalence of VI in Indigenous Malaysian peoples (3.3%) than non-Indigenous Malay (2.4%), Indian (2.9%) and Chinese (2.1%) participants, however no statistical comparisons were made.¹⁴⁰

Indigenous peoples do not have universally higher prevalence rates of VI. Countries in which non-Indigenous adults had a higher prevalence of VI than their Indigenous counterparts include Fiji (6.2% vs 9.5%, $P=0.02$)¹³⁴ and Singapore (4.6% vs 3.9%, no statistical comparison).¹¹⁵ In both countries there was no difference in the prevalence of blindness. Notably, surveys on vision loss in child populations revealed that Indigenous children often had a lower prevalence compared to non-Indigenous children. For example, the prevalence of vision loss in native Bedouin was 1.1% compared to 2.9% in non-native urban-dwelling children in Egypt ($P=0.007$).¹³⁶ The tendency for Indigenous children to have better eye health than their non-Indigenous counterparts that deteriorates in adulthood is indicative of the likely influence of environmental factors such as a lack of availability of eye care services.

2.5.1.3 The main causes of VI and blindness in Indigenous peoples

There is a noteworthy paucity of data on the main causes of vision loss in Indigenous populations. A national survey in Timor-Leste focused specifically on cataract-related blindness, and therefore only determined the proportion of VI (25.1%) and blindness (76.1%) attributable to cataract.¹³¹ As with non-Indigenous populations, in studies that defined VI based on PVA, uncorrected refractive error was the main cause of VI in almost all Indigenous populations, accounting for 54-65% of VI.^{68, 134, 141, 142} Cataract was the second leading cause of VI in Indigenous populations where PVA was measured, accounting for a quarter of all VI cases.^{110, 143} Cataract was the most common cause of VI in all studies that defined VI based on BCVA. Cataract caused 72% of VI in both Singaporean Malays¹⁴⁴ and Indigenous people in the Brazilian Amazon¹⁴⁵ and AMD was responsible for 18% of VI cases and 16% of blindness cases in Tibetans.¹³⁰ Cataract has been shown to be the main cause of blindness in most studied

Indigenous populations around the world, including in Tibetans,¹⁴⁶ Melanesian Fijians,⁴⁶ Timorese,¹³¹ the Aeta people of the Philippines,¹⁴⁷ the Turkana people of Kenya¹³³ and Brazilian Amazon tribes.¹⁴⁵ Trachoma has been reported to be a significant cause of blindness in Indigenous populations, contributing to as much as 20% of blindness in the Turkana people of Kenya.¹³³ Similarly, DR was an important contributor to the burden of blindness, with as much as 25% of blindness in Navajo Indians attributed to the disease.¹⁴⁸

Evidently, the literature on the prevalence and causes of vision loss in Indigenous populations is sparse and much of the existing literature is outdated and of questionable methodological rigour. Nonetheless, it may be inferred from the studies above that Indigenous populations around the world have a disproportionately higher burden of vision loss compared to non-Indigenous populations. Consequently, any population surveys on the national burden of vision loss conducted in countries with Indigenous populations, particularly when those populations are known to be marginalised, such as in Australia, should include representative samples of those Indigenous populations. Studies that have not done so may have neglected to quantify the burden of vision loss in their respective populations' most vulnerable groups, thereby limiting the capacity of interventions informed by them to meet the needs of at-risk communities.

2.6 Global initiatives to reduce the burden of vision impairment and blindness

The feasibility of reducing the burden of avoidable VI and blindness globally through the appropriate implementation of eye health care programs has resulted in a multitude of initiatives being launched to address the problem of avoidable blindness. The Global Initiative for Elimination of Avoidable Blindness, also known as Vision 2020 – the Right to Sight, was established by the WHO and the International Agency for the Prevention of Blindness (IAPB)

in 1999.¹⁴⁹ The WHA identified vision loss as a major public health problem and included its elimination as a high priority on its agenda, with numerous resolutions aiming to reduce avoidable blindness being passed since the 56th WHA in May 2003.¹⁵⁰ At the 62nd WHA in 2009, the ‘Action plan for the prevention of avoidable blindness and visual impairment 2009-2013’ was implemented to reduce avoidable blindness globally.¹⁵¹

In an effort to improve upon previous initiatives, resolution WA66.4 ‘Universal Eye Health: A Global Action Plan 2014-2019’ (the Global Action Plan) was endorsed in May 2013 at the 66th WHA.¹ The primary objective of the Global Action Plan was to ‘reduce avoidable vision impairment as a global public health problem and to secure access to rehabilitation services for the visually impaired.’¹ The global target of a reduction of avoidable blindness by 25% from 3.18% to 2.37% was adopted, as the WHA deemed this to be a measurable indicator that the action plan has been successful.

Three core objectives were defined by Member States, international partners and the Secretariat, the first of which emphasised the need to generate an evidence base on the magnitude and causes of VI and blindness. The Global Action Plan highlighted the need to undertake robust population-based epidemiological surveys at the national level to determine the prevalence of VI and blindness, and to assess and identify gaps in eye health care service delivery. Population based studies on the prevalence and causes of VI and blindness have been conducted at the city,¹⁵²⁻¹⁵⁴ state¹⁵⁵⁻¹⁵⁸ and national level^{159, 160} in many countries, and studies vary considerably in their sampling and data collection methodologies. These various methods are described in detail in the Materials and Methods chapter of this thesis (3.3 and 3.4), and their strengths and limitations are discussed.

2.7 Vision impairment and blindness in Australia

2.7.1 Vision impairment and blindness in non-Indigenous Australians

2.7.1.1 Early ophthalmic epidemiology research in non-Indigenous Australians

Non-Indigenous Australians have enjoyed similar standards of health care and comparable health outcomes to the inhabitants of other developed nations, even surpassing most high income countries in some measures.¹⁶¹ This is reflected in most ophthalmic epidemiology research in Australia. Early surveys of the Caucasian Australian population in the 1950s by Mann reported that the burden of the major ophthalmic conditions including glaucoma, DR, and cataract were comparable to Caucasian European populations at that time.¹⁶² While only 0.2% of the population was blind, in contrast to European populations at the time, there was a non-negligible prevalence of trachoma.¹⁶³ This was, however, considerably less severe than in the Indigenous population, affecting approximately 6% of non-Indigenous Australians compared to more than 50% of Indigenous Australians.¹⁶² Just 4% of non-Indigenous children had signs of trachoma infection compared to 58% of Indigenous children.¹⁶⁴

In response to the endemicity and persistence of trachoma in Australia's population (both Indigenous and non-Indigenous populations), the National Trachoma and Eye Health Program (NTEHP) was established in 1976. The NTEHP was a large-scale nationwide mobile eye screening and treatment program conducted between 1976 and 1978 in which more than 100,000 Australians (including 38,616 non-Indigenous and 62,116 Indigenous Australians) underwent an ophthalmic examination and were provided treatment where required.¹⁶⁵ The NTEHP found that the prevalence of blindness was 0.1% in non-Indigenous Australians.¹⁶⁵

2.7.1.2 Non-survey research on the prevalence and causes of vision impairment and blindness

In the period between the NTEHP and the early 1990s, research on the burden of vision loss in non-Indigenous Australians was primarily based on clinical samples and data from Government agencies, rather than population-based surveys. Banks and Hutton (1981) estimated the prevalence of blindness (BCVA<6/60) in New South Wales (NSW) based, in part, on the NTEHP report, as well as data from the Department of Social Security, the Australian Bureau of Statistics (ABS) and the Royal Blind Society.¹⁶⁶ The estimates reported in this study were not reliable, as the data sources themselves were largely unreliable (as acknowledged by the authors). Data from the Department of Social Security reported the number of Australians receiving a blindness pension, which likely underestimated the true number of people living with blindness, while the ABS data were based on self-report rather than a clinical examination, which has been shown to be an unreliable epidemiological tool for quantifying the prevalence of vision loss and eye diseases.¹⁶⁷⁻¹⁶⁹ Furthermore, the NTEHP data pertaining to the non-Indigenous population may have lacked representativeness due to a low response rate, while the Royal Blind Society data were based on extrapolations from a dataset in the United States.¹⁶⁶ Based on these data, the prevalence of blindness in NSW was determined to be 0.14%-0.19%, corresponding to 7000-10000 people in the NSW population.¹⁶⁶ This study also reported the major causes of blindness, but these estimates were only based on 349 new registrants with the Royal Blind Society, and the representativeness of this sample was not verifiable. Macular disease was the leading cause of blindness, accounting for 37.2% of all cases and 81.5% of cases in those aged 60 years and older.¹⁶⁶

Blind pension data were utilised again in a 1986 study by Banks and Kratochvil that reported that the major causes of blindness were AMD, hereditary retinal dystrophies and diabetic eye disease.¹⁷⁰ However, as with the previous study, not all blind persons would have been

registered for a pension, and these estimates were therefore unreliable. Yeates (1983) reported the major causes of blindness in 311 blind patients visiting ophthalmology services in Brisbane, Queensland, and identified genetic causes (unspecified), maculopathy, congenital causes (unspecified), non-diabetic and diabetic vascular conditions, retinitis pigmentosa and glaucoma as leading causes of blindness.¹⁷¹

Collectively, the extent to which the findings of the above studies were representative of the wider Australian population was limited, and significant methodological flaws rendered extrapolations unreliable. Reliably determining the prevalence and causes of vision loss in the population requires robust and representative population survey data to eliminate the risk of selection bias. Consequently, while this research was somewhat helpful in developing eye health care programs, the epidemiology of VI and blindness in Australia was not known in the late 1980s and early 1990s as well-designed surveys had not been conducted. Interventions that aimed to address blindness in the population were therefore likely to be ill-informed and sub-optimal. In contrast, programs in the United States had been, and were continuing to be, informed by the Beaver Dam Eye Study¹⁷² the Baltimore Eye Study,¹⁷³ and an Appalachian study¹⁷⁴ all of which were robust population surveys that collected representative samples. Considering that the Australian population aged over 65 years was expected to double by the year 2020, and that most vision loss was found to occur in this older age group in the US studies, robust investigation of the epidemiology of vision loss in Australia's older non-Indigenous population was becoming of paramount importance.¹⁷⁵

To fulfil the need for a reliable estimate of the prevalence and causes of VI and blindness in Australia, epidemiologists began surveying the non-Indigenous Australian population to derive statistically robust prevalence estimates of vision loss. These surveys included two South Australian studies, one Victorian study and one NSW study. Until now, these studies,

specifically the NSW and Victorian surveys, have remained the most reliable sources of ophthalmic epidemiologic data in Australia.

2.7.1.3 Surveys of vision loss in South Australia

Newland *et al* (1996) conducted the first true population survey of its kind in Australia's non-Indigenous population in 1989 and 1990.¹⁷⁶ Utilising stratified cluster sampling, this survey selected 2115 residents aged 50 years and over from urban and rural areas in South Australia, based on 1986 ABS census data. Participants underwent a standardised ophthalmic examination and the prevalence and causes of VI and blindness were determined. Bilateral blindness was found in 1.3% of participants and unilateral blindness was found in 3.7% of participants.¹⁷⁶ The major causes of bilateral blindness were AMD (50%), cataract (22.2%) and optic atrophy (14.2%), while cataract and amblyopia and AMD were the leading causes of unilateral blindness. Contrasting previous literature,¹⁷³ the prevalence of VI (BCVA<6/18-3/60) was lower than the prevalence of blindness (BCVA<3/60) in this sample (0.85%).¹⁷⁶

Limitations in this study affected the representativeness of the sample and the consequent utility of extrapolating the results to the population. Most notably, the positive response rate was low (41%), and there was therefore a risk of non-response bias. The high proportion of individuals who declined to participate may have varied systematically and unquantifiably from survey participants in variables pertinent to ocular health and visual acuity, such as recentness of having undergone eye examinations or other relevant factors. This may have accounted for the unusually low prevalence of bilateral VI reported for this sample, which has not been replicated in other populations aged 50 years or older. Having used the conservative definition of blindness of BCVA<3/60, rather than the commonly used Australian threshold of 6/60,¹⁷⁷ this study likely underestimated the proportion of Australians eligible to receive disability benefits for their blindness, thereby sub-optimally informing government eye health

programs. Finally, this survey was conducted at a sub-national level, and the representativeness of this South Australian sample to the wider and diverse national population of Australia was unknown, resulting in estimates of VI and blindness of unknown representativeness.

Another South Australian study, the Australian Longitudinal Study of Ageing (ALSA) commenced in 1992 and included visual acuity as one of its measures of the health of elderly Australians aged 70 years and older.¹⁷⁸ The survey randomly sampled 3263 residents of Adelaide, South Australia. The prevalence of bilateral VI (BCVA<6/12-6/60) of 22.5% was considerably higher than other Australian studies,^{103, 176} probably due to the significantly older age distribution in the ALSA sample. A total of 1.2% of participants in this survey had bilateral blindness (BCVA<6/60).¹⁷⁸ As with the study by Newland *et al* (1996)¹⁴⁵, due to its confinement to isolated clusters of the South Australian population, as well as issues of representativeness, this survey could not be relied upon to optimally inform national interventions for VI and blindness.

2.7.1.4 The Blue Mountains Eye Study

2.7.1.4.1 Overview of the Blue Mountains Eye Study

Initiated in November 1991, the Blue Mountains Eye Study (BMES) was a population survey designed to assess visual acuity and the causes of vision loss in an older Australian population.¹⁰³ The survey sampled 3654 non-institutionalised residents aged 49 years or older from two adjacent postcodes in the Blue Mountains, west of Sydney, NSW. A further 134 nursing home residents were sampled to quantify the burden of vision loss in the institutionalised older Australian population.¹⁷⁹

2.7.1.4.2 The prevalence of vision impairment and blindness in the baseline Blue

Mountains Eye Study

The BMES used a variety of different definitions for VI and blindness, reporting prevalence estimates based on PVA and BCVA, and using WHO, US, Australian and other acuity thresholds in different publications. Overall, the crude prevalence of vision loss based on BCVA was 4.7%.¹⁰³ The crude prevalence of vision loss was higher in women (5.7%) than in men (3.2%), with higher rates for women in all sub-classifications of vision loss.¹⁰³ Based on WHO definitions, the prevalence of blindness was 0.27%, whereas the more inclusive Australian definition (BCVA<6/12) revealed a prevalence of blindness of 0.5%.¹⁰³ In contrast, the prevalence of blindness was 11% in participants residing in aged care facilities.¹⁷⁹ Based on the threshold of PVA<6/12, the prevalence of bilateral VI in non-institutionalised residents of the Blue Mountains was 11.1%, while the prevalence of bilateral blindness (PVA<6/60) was 0.6%.¹⁸⁰ Both VI and blindness were substantially more prevalent in older age groups, with more than one quarter of those aged 80 years or more being visually impaired.¹⁸¹

2.7.1.4.3 Main causes of vision impairment and blindness in the baseline Blue

Mountains Eye Study

In the original publication from the 1991-1994 study sample, the main causes of vision loss were reported based on BCVA. The main causes of blindness in the BMES reflected current data in many high-income countries,²⁰ with AMD causing 88% of cases, followed by cataract, occipital infarct and retinal vein occlusion, according to acuity thresholds used in that analysis. According to the Australian definition of blindness (<6/60), AMD was the main cause of blindness in 76% of cases, cataract was responsible for 11.8% of cases and glaucoma was responsible for 5.9% of cases.¹⁸¹ Similarly, AMD was the main cause of moderate VI (38%), while cataract (33%) and glaucoma (10%) were also important causes. Cataract caused the vast majority of mild VI (74%), followed by AMD (17%). Overall, cataract was reported to be the

leading cause of VI (64%), owing to the greater number of cases of mild compared to moderate VI. A major limitation of the older BMES literature was that the proportion of vision loss attributable to uncorrected refractive error was not quantified, as causes of vision loss were not based on PVA. Therefore, both the true prevalence of vision loss and the burden of uncorrected refractive error in the Australian population were underestimated. However, Foran *et al* (2003) retrospectively ascertained that 67.8% of VI and 26% of blindness were caused by uncorrected refractive error (defined as visual acuity correctable to $\geq 6/12$ and to $\geq 6/60$, respectively).¹⁸⁰

2.7.1.4.4 Unilateral vision impairment and blindness in the Blue Mountains Eye Study

The BMES revealed that the prevalence of unilateral VI was substantially higher in the older Australian population than bilateral VI, with 29.6% having PVA and 14.4% having BCVA $< 6/12$ of in their worse eye.¹⁸⁰ As with bilateral vision loss, the prevalence of unilateral vision loss increased dramatically with age, affecting 52.2% of participants aged 80 years or older.¹⁸¹ Major causes of unilateral vision loss based on BCVA differed somewhat from those of bilateral vision loss, particularly in younger participants aged 49-59 years, where amblyopia was the major cause of mild, moderate and severe VI (50%). Overall, cataract was the main cause of unilateral VI in 41.9% of participants, followed by AMD (18.5%) and amblyopia (13.5%).¹⁸¹ When PVA was used, 57.5% of unilateral VI and 20% of unilateral blindness were attributed to uncorrected refractive error.¹⁸⁰

2.7.1.4.5 Follow-up data on vision impairment and blindness in the Blue Mountains

Eye Study

The Blue Mountains community underwent follow-up ophthalmological surveys in 1997-1999,¹⁸² 2002-2004,¹⁸³ and 2007-2010.¹⁸⁴ As a longitudinal study, the BMES was able to report previously unmeasured epidemiologic characteristics, including the incidence and relative mortality risk of vision loss and major eye diseases.^{182, 184-186} Follow-up reports utilised United States and Australian thresholds for vision loss, and defined VI as visual acuity $< 6/12$ and

blindness as visual acuity <6/60 in the better eye.¹⁸⁰ In 1997-2000, the prevalence of bilateral VI decreased by 25% from 11.1% to 8.3%, and the prevalence of bilateral blindness had decreased by 50% from 0.6% to 0.3%.¹⁸⁰ Similarly, the prevalence of unilateral VI and blindness decreased to 25.5% and 3.5%, representing 14% and 22% reductions, respectively. In this cross-section, uncorrected refractive error caused 67% of bilateral VI, 54.6% of unilateral VI, 9% of bilateral blindness and 12.3% of unilateral blindness.¹⁸⁰ Cataract (15.5%), AMD (11%) and glaucoma (1.7%) were main causes of most other bilateral VI cases, while cataract (15.7%), AMD (9.5%), other retinal diseases (8.3%) and amblyopia (5.7%) were the other leading causes of unilateral VI.¹⁸⁰ AMD (45%), other retinal diseases (36.4%) and cataract (9%) were leading causes of bilateral blindness. Unilateral blindness was principally attributed to AMD (28%), other retinal diseases (18%), cataract (11%), amblyopia (10%) and enucleation (9%).¹⁸⁰

The BMES was a landmark study in Australia, and was characterised by significant strengths, including a comprehensive clinical examination methodology and a high positive response rate (82.4%).¹⁰³ Nonetheless, the applicability of the findings of this study to the current Australian population is limited, owing to the fact that the baseline data were collected more than 20 years ago, and that the method of participant sampling was not randomised, thereby limiting the national representativeness of prevalence estimates. Consequently, further population research on the prevalence of vision loss in Australia is required.

2.7.1.5 The Melbourne Visual Impairment Project

2.7.1.5.1 Overview of the Melbourne Visual Impairment Project

The Melbourne Visual Impairment Project (VIP) was initially conducted in 1992 to 1995 as a cross-sectional population survey designed to determine the prevalence and impact of eye diseases including cataract, retinal disorders and glaucoma in the urban community of Melbourne and to establish the need for resources to considerably reduce avoidable

blindness.¹⁷⁵ As with the BMES, the VIP later became a longitudinal study.¹⁸⁷ Data from Australia's 1986 Census were used to select a random sample of nine pairs of population clusters (Census Collector Districts [CCDs]), with an intended sample size of 3500 residents aged 40 years and older.¹⁷⁵ The VIP initially recruited 3266 urban-dwelling participants using a door-to-door survey approach, achieving a response rate of 83%, and all participants underwent a clinical eye examination.¹⁸⁸

2.7.1.5.2 The prevalence of vision impairment and blindness in the Melbourne Visual Impairment Project

Most previous population surveys in other countries had reported the prevalence of VI and blindness according to BCVA, and the relative contribution of under- or un-corrected refractive error to the burden of vision loss had been scarcely quantified. The VIP reported the prevalence of VI and blindness according to PVA and BCVA and found using PVA at WHO thresholds that 1.28% of participants had VI and 0.15% were blind, and after best-correction, 0.70% had VI and 0.12% were blind. Based on Australian thresholds, 3.52% of participants had VI (PVA<6/12–6/60) and 0.37% were blind (PVA<6/60).¹⁸⁸ After age standardisation, the overall prevalence of blindness (<6/60) was 0.34%, and age-standardised rates of vision loss tended to be higher in women than men across all thresholds for both PVA and BCVA.¹⁸⁸

In 1995, the VIP was expanded to include a small sample of 403 institutionalised nursing homes residents,¹⁸⁹ and in 1996 it was further expanded to include a sample of 1473 rural participants from four pairs of randomly-selected adjacent CCDs in four rural communities in Victoria.¹⁹⁰ VanNewkirk and colleagues (2001) reported the population-weighted prevalence of mild, moderate, severe and profound VI in the combined urban and rural sample.¹⁹⁰ The prevalence of mild VI (PVA<6/12-6/18) was 2.5%, the prevalence of moderate VI (PVA<6/18-6/60) was 1.2%, the prevalence of severe VI (PVA<6/60-3/60) was 0.35%, and the prevalence of profound VI – at the WHO threshold for blindness of <3/60 (PVA) - was 0.16%.

Cumulatively, the prevalence of vision loss based on PVA <6/12 was 4.3%, corresponding to approximately 345 000 Australians aged 40 years or older in the total Australian population.¹⁹¹

2.7.1.5.3 Causes of vision impairment and blindness in the Melbourne Visual

Impairment Project

The VIP demonstrated that uncorrected refractive error was the leading cause of vision loss in the older Victorian population, accounting for 56.4% of all cases, with other causes of vision loss being 6-16 times less prevalent than uncorrected refractive error.¹⁹⁰ AMD was the second leading overall cause of vision loss (9.4%), followed by cataract (6.9%), glaucoma (5.4%) and DR (3.5%). When disaggregated, the major causes of VI (PVA<6/12-6/60) were uncorrected refractive error (61.2%), cataract (7.9%) and AMD (7.3%), while DR and glaucoma contributed very little to the burden of VI (3.9% and 3.3%, respectively). Blindness mostly resulted from AMD (25%), glaucoma (21%) and uncorrected refractive error (21%).¹⁸⁹

2.7.1.6 Pooled estimates from the Blue Mountains Eye Study and the Melbourne Visual

Impairment Project

The BMES and the VIP were conducted concurrently and utilised (albeit tenuously) comparable methodologies, providing a rare opportunity to pool estimates from Australia's two largest population centres and calculate a more inclusive and representative snapshot of the eye health of Australia's older population. From the pooled data, the age-specific prevalence of VI and blindness, the proportional attribution of each major cause of VI and blindness, and the total number of people in the population with VI and blindness were reported.¹⁹² The overall age-standardised prevalence of VI or blindness was not provided based on the combined data. Age-specific estimates ranged from 0.67% in those aged 40-49 years to 39.49% in those aged ≥90 years (a 59-fold higher prevalence) for VI, and 0% in those aged 40-49% to 16.94% in those aged ≥90 years for blindness, highlighting the strong influence of age on the prevalence of vision loss.¹⁹² This report also reaffirmed that the majority of VI in Australia was caused by

uncorrected refractive error (62%) and cataract (14%), illustrating the avoidable nature of most vision loss. Conversely, posterior segment diseases (AMD: 48%, glaucoma: 14% and DR: 11%) accounted for most cases of blindness, and efforts to reduce blindness in Australia therefore required screening and early detection programs.¹⁹² At the time of publication, the estimated number of Australians with VI and blindness based on the combined BMES and VIP data were 480,300 and 50,600, respectively, with these numbers expected to increase to 619,700 and 68,800 by the year 2014.¹⁹²

Pooling BMES and VIP data revealed some similarities, including the prevalence of presenting (<6/60) blindness (0.5%) and some of the major causes of vision loss.¹⁹² However important differences were also noted. For instance, when the definition of VI in non-institutionalised adults was standardised across the two studies and defined as PVA<6/12-6/60, the prevalence was 2.75 times higher in the BMES compared to the VIP (11% vs 4%).¹⁹² This considerable disparity likely resulted from the fact that the two studies employed very different sampling methodologies to select study participants and that the two populations differed significantly from each other in factors relevant to the epidemiology of vision loss. The fact that the prevalence of VI differed so markedly between these two otherwise superficially homogenous Australian populations demonstrates that the epidemiology of VI, blindness and the causative eye diseases is likely to vary between other sub-populations in Australia. This non-uniformity likely results from heterogeneity in multiple factors including socio-economic status, demographics, lifestyle factors and eye health service availability and utilisation.

While the BMES and VIP generated previously unprecedented epidemiological data on the burden of vision loss in Australia and contributed substantially to public eye health policy, changes in population parameters and eye health programs since their completion more than 20 years ago have necessitated the acquisition of updated prevalence data. Further, these two geographically distinct studies reported different prevalence estimates for VI, highlighting that

a larger survey with nationwide geographic coverage of Australia's diverse population is required.

2.7.2 Vision impairment and blindness in Indigenous Australians

2.7.2.1 Aboriginal and Torres Strait Islander peoples

The Indigenous population of Australia is composed of a culturally and ethnically diverse array of peoples, broadly referred to as Aboriginal and Torres Strait Islander peoples. There is significant debate surrounding the nomenclature of Aboriginal and Torres Strait Islander peoples in Australia, and no real consensus has been reached in the socio-political discourse regarding the most culturally appropriate, sensitive and inclusive terminology to distinguish Aboriginal and Torres Strait Islander peoples from other ethnic and cultural groups in Australia.¹⁹³ Some community authorities consider 'Aboriginal and Torres Strait Islander people' or 'Aboriginal people' or 'Aboriginal Australians' to be the most appropriate terminology, while others prefer the term 'Indigenous Australians', and still others prefer to be described based on the specific language or cultural group with which they identify. The author of this thesis and the co-authors of published manuscripts herein acknowledge the diverse preferences of persons from various cultural groups. However, to ensure terminological consistency and to facilitate comparisons with Australians who do not identify as Aboriginal or Torres Strait Islander (non-Indigenous Australians), the term 'Indigenous Australians' will be used henceforth.

2.7.2.2 The health of Indigenous Australians

A review of the literature on the eye health of Indigenous Australians should be considered in the context of the complex array of challenges faced by Indigenous communities since the arrival of European colonialists. Indigenous Australians have inhabited Australia for more than 60,000 years and have, over the course of their cultural evolution, developed a deep and complex relationship with their land and natural resources.¹⁹⁴ The arrival of colonialists in the

1770s immediately introduced multiple threats to Indigenous health, culture and life. Indigenous communities that had no previous exposure and therefore no immunological fortitude against pathogens brought by European settlers were ravaged by smallpox, measles and tuberculosis.¹⁹⁵ Countless Indigenous communities that had relied upon and acted as custodians of their traditional lands and natural resources for thousands of years were dispossessed, marginalised and exploited.¹²⁷ As a result of colonisation, Indigenous Australians that had once lived in equilibrium with their environment became heavily afflicted by codified discrimination, poverty, inadequate living conditions, displacement, undernutrition and exposure to environmental contamination.

In subsequent decades, urbanisation and the introduction of alcohol, tobacco, a Western diet and sedentary lifestyle further contributed to the devastation of Indigenous populations.¹⁹⁶⁻¹⁹⁸ Consequently, the health of Indigenous Australians declined dramatically. Non-Indigenous Australia flourished, with the general population currently ranking 2nd on the United Nations HDI.⁷⁸ In contrast, the health of Indigenous populations continued to decline rapidly creating a substantial health gap, and rates of morbidity in Indigenous communities are now comparable to many developing nations.^{199, 200} Compared to the non-Indigenous population, Indigenous Australians have 1.7 times higher rates of infant mortality, 2.1 times higher rates of maternal mortality and 1.7 times higher rates of adult and childhood obesity and childhood malnutrition.¹²⁶ Indigenous Australians also have higher rates of diabetes, ischemic heart disease, mental illness and substance abuse disorders than non-Indigenous populations.²⁰¹

As recently as 2003, the Australian Government reported that for Indigenous Australians, life expectancy at birth was approximately 20 years younger than in non-Indigenous Australians, and it was estimated that the gap in health outcomes between Indigenous and non-Indigenous populations accounted for 59% of the total health burden in Indigenous populations.¹⁹⁹ A collaborative planning strategy has been developed involving the Australian Government, the

National Aboriginal Community Controlled Health Organisation (NACCHO) and various other stakeholders in an effort to close the gap in health outcomes for Indigenous Australians, and some progress has been made. For example, a recent report in *The Lancet* on the status of Indigenous populations highlighted that the gap in life expectancy has decreased to ten years, with a mean life expectancy of 81.4 years for non-Indigenous Australians and 71.4 years for Indigenous Australians.¹²⁶ Despite improvements in some areas, Indigenous Australians, particularly those residing in non-metropolitan areas, remain under-served and continue to have poorer health and economic outcomes than their non-Indigenous counterparts, illustrating that the gap in Indigenous health persists.²⁰¹

2.7.2.3 Early ophthalmological surveys of Indigenous Australians

Epidemiologic research has quantified the burden of vision loss in various Indigenous populations and at multiple time points around Australia, and has recently revealed that vision loss contributes more than most health problems to the Indigenous health gap.²⁰² Published literature on population surveys investigating vision loss and eye disease in Indigenous Australians dates back to at least the early 1950s, with Mann reporting the prevalence of ophthalmic diseases in the Indigenous communities of the Eastern Goldfields,²⁰³ the Kimberley region²⁰⁴ and the southwest communities of Western Australia.²⁰⁵ From 1953 to 1955, 13,268 Indigenous Australians were surveyed. Mann summarised the findings of her early surveys in a 1957 paper published in the *Bulletin of the World Health Organization*.¹⁶³ In this seminal work, trachoma was identified as a highly prevalent disease and a major cause of blindness in the Indigenous Australian population, and was described as endemic to the entire Australian mainland. Most other eye diseases were reported to be rare in Indigenous populations, with prevalence estimates for senile cataract, glaucoma and amblyopia of 3%, 0.2%, 0%, respectively.¹⁶² In contrast, trachoma was found in 56% and 58% of Indigenous inhabitants of the Kimberley region and the Eastern Goldfields region, respectively, compared to a prevalence

of 8% in the non-Indigenous population.¹⁶³ Approximately 11.5% of infected Indigenous Australians were blinded by the disease in the Kimberley region, while 4.7% of infected individuals in the Eastern Goldfields were blind.

Mann estimated that approximately 3-4% of the Indigenous Australian population was blind, compared to just 0.2% of the non-Indigenous population.¹⁶³ Trachoma was reported to be the leading cause of binocular blindness, while ocular injury was found to be the principal cause of unilateral blindness in Indigenous Australians. The high burden of trachoma in Western Australia was reflected in the Indigenous population of the Northern Territory where the ophthalmologist and missionary Father Frank Flynn reported that 7% of Indigenous Australians were blind from the disease.¹⁶³ Mann posited that trachoma had not been endemic to Australia's Indigenous population prior to the arrival of foreign settlers, and that the pathogen may have been brought by European and Chinese migrants in the 1700s.¹⁶³

2.7.2.4 The National Trachoma and Eye Health Program

Following the revelations from the early surveys of Indigenous populations, sporadic trachoma treatment centres were established with limited success, as demonstrated by the high prevalence of blindness (4%) in the Indigenous population of New South Wales reported by Hollows in 1972, and the persistently high prevalence of trachoma of up to 80% in some communities.¹⁶⁵ The NTEHP was established in 1976, in attempt to address the pervasiveness of blinding trachoma infection in Indigenous communities.¹⁶⁵ Based on examinations of 62,116 Indigenous Australians, the national prevalence of trachoma in Indigenous Australians in the NTEHP was 38%.¹⁶⁵ Early findings of the NTEHP revealed that the overall prevalence of bilateral blindness ($\leq 6/60$) was 1.8% in Indigenous Australians of Central Australia (compared to just 0.1% in non-Indigenous Australians), and this prevalence increased markedly with age to 5.5% in Indigenous Australians aged 50-59 years and 25.1% in those aged 60 years or older.²⁰⁶

Unilateral blindness was also highly prevalent in the NTEHP, affecting 2.5% of Indigenous Australians in Central Australia, with 14.7% of those aged 50-59 years and 22.5% of those aged 60 years or older being unilaterally blind.²⁰⁶ Cataract was the leading cause of bilateral blindness (50%), followed by corneal scarring (14.3%). Trachoma was responsible for 7.1% of blindness. Similarly, senile cataract was the main cause of unilateral blindness (35.1%), followed by corneal scarring (21.6%). Trachoma caused 8.1% of unilateral blindness.²⁰⁶ It was noted that blindness was almost entirely absent from Indigenous Australian children. The NTEHP findings illustrated that, despite Australia's status as a developed country, the eye health of its Indigenous population was similar to that found in severely under-developed countries, and recommendations were made to improve the availability of ophthalmological services to remote Indigenous communities.¹⁶⁵ Although the NTEHP was invaluable to efforts aiming to quantify the eye health burden of Indigenous Australians, important limitations including the lack of random sampling and the fact that it was conducted 40 years ago and there have been dramatic changes in innumerable epidemiologic variables, have rendered the study insufficient to inform current eye health policy.

A number of other ophthalmological surveys of Indigenous Australians took place around the time of the NTEHP. A study that investigated 361 Indigenous adults in remote South Australia reported a prevalence of bilateral VI (<6/9) of 17.7% and unilateral VI (<6/9) of 22%, however age distributions were not reported, so comparisons with other similar studies are not reliable.²⁰⁷ A landmark study by Taylor (1980) reported that Indigenous Australian males and females both had a prevalence of bilateral blindness of 1.1% and a prevalence of unilateral blindness of 2.4% and 1.8%, respectively.²⁰⁸ Bilateral blindness was highly prevalent in older participants, affecting 21.5% of males and 17.5% of females aged 60 years and above, a finding that was comparable to the South Australian study.²⁰⁸ Unilateral blindness affected 25.5% of males and 18.5% of females aged 60 years and above.²⁰⁸ This survey informed eye health

policy for Indigenous Australians at a national scale for many years, however much like the NTEHP, significant changes in Indigenous population parameters, including an increase in life expectancy and diabetes, coupled with a multitude of eye health programs implemented in the decades since its completion, have necessitated an up-to-date survey.

2.7.2.5 Subnational eye health surveys of Indigenous Australians

Despite considerable efforts, later surveys continued to show that the prevalence of blindness in Indigenous Australians was comparable to developing nations. In 1990, a survey of 1514 Indigenous people of Anangu Pitjantjatjara and Yalata lands of South Australia revealed a prevalence of blindness (<3/60) of 1.5%, with women displaying a greater prevalence of 2% compared to a prevalence of 0.8% in men.²⁰⁹ The prevalence of VI (<6/18) and blindness (<3/60) in those aged 60 years and above was 19.6% and 10.5%, respectively.²¹⁰ This represented a decline in the prevalence of VI, but not blindness, in this region compared to the NTEHP survey. The major causes of blindness were cataract, trachoma and trauma, indicating that blinding trachoma continued to be burdensome in the Indigenous community despite an apparently lower prevalence compared to previous research.^{209, 211}

The eye health of Indigenous communities continued to undergo monitoring through epidemiologic surveys, with an emphasis on recording changes in the prevalence of trachoma. Following a 1985 report which suggested a considerable reduction in trachoma in the Indigenous Australian population,²¹² the Commonwealth commissioned a report detailing the status of Indigenous eye health and the quality and effectiveness of eye health services in Indigenous communities.²¹³ This report revealed that Indigenous Australians in rural areas had nearly ten times more blindness than non-Indigenous Australians (1.4% vs 0.16%). Seventeen recommendations for the improvement of eye care services for Indigenous Australians were included.²¹³ The National Aboriginal and Torres Strait Islander Eye Health Program

(NATSIEHP) was subsequently established by the Commonwealth Government to further improve the availability of eye health care services in Indigenous populations.

2.7.2.5.1 The Katherine Region Diabetic Retinopathy Study

A survey conducted in the Katherine Region of the Northern Territory from 1993 to 1996 was one of the first epidemiological studies to identify DR as a major health problem in Indigenous Australians.²¹⁴ This study, known as the Katherine Region Diabetic Retinopathy Study (KRDRS), conducted ophthalmic examinations on Indigenous Australians with known diabetes and identified that 21% had some degree of DR and 13% had maculopathy. It is important to note that DR was not reported to be a major health concern in earlier ophthalmological surveys of Indigenous Australians. Indeed, a study by Wise *et al* in 1976 reported that the prevalence of diabetes was 11% in Indigenous people of South Australia (5.6% previously diagnosed and 5.4% newly diagnosed) and none of the participants in that study were found to have significant retinopathy.²¹⁵ Future research would report further increases in the burden of DR (see section 2.7.2.6),²¹⁶ contrasting starkly with the observations by Mann (1972), who reported that, due to the mostly carbohydrate-free diet of Indigenous populations, DR was rare.¹⁶² However, Mann predicted based on the Westernisation and assimilation of Indigenous communities, that diabetes and its ophthalmic complications would become “a problem in the future,”¹⁶² a foreboding that has been proven correct by recent studies.

2.7.2.5.2 The South Australian Eye Health Program

A survey of 22 remote South Australian communities in which 552 Indigenous children and 1651 Indigenous adults received ophthalmic examinations from 1999 to 2004 as part of the South Australia Eye Health Program (SAEHP) reported that 15.7% of participants had trachomatous scarring, trichiasis or corneal opacification.²¹⁷ While this study added further evidence of the trachoma epidemic to the already extensive literature on this problem in

Indigenous communities, perhaps the most striking finding was that almost half of participants (46.7%) had diabetes.²¹⁷ Of those with diabetes, 22% had DR and half of those with DR had proliferative DR. This survey provided further insight into the increasing severity of the diabetes burden in Indigenous Australian communities and the consequent effects this was beginning to have on the eye health of Indigenous Australians around the country. However, the magnitude of the problem at a national scale was not known.

2.7.2.5.3 The Central Australian Ocular Health Study

From 2005 to 2008, the Central Australian Ocular Health Study (CAOHS) collected eye health data from 1884 Indigenous Australians aged 20 years and older from 30 very remote communities in Central Australia and quantified the prevalence, causes and risk factors of VI, blindness and eye diseases.²¹⁸ This cross-sectional survey utilised a comprehensive examination protocol including visual acuity assessment, subjective refraction, IOP examination, corneal pachymetry, slit lamp examination of the anterior segment, dilated lens grading, slit lamp examination of the fundus and Frequency Doubling Technology (FDT) perimetry.²¹⁸ Since its completion, the findings of the CAOHS have been published prolifically, providing prevalence estimates and risk factors for cataract,²¹⁹ refractive error,²²⁰ trachoma,²²¹ glaucoma,²²² ocular hypertension,²²³ pterygium,²²⁴ pseudoexfoliation syndrome,²²⁵ and DR.²²⁶

In the total sample of adults aged 20 years and above, the prevalence of bilateral VI (PVA<6/12) was 19.4% and the prevalence of bilateral blindness (PVA<6/60) was 2.8%.²²⁷ Proportions were higher in those aged 40 years and older, with VI and blindness affecting 25.1% and 3.6% of individuals respectively.²²⁷ Unilateral blindness (accompanied by normal vision in the fellow eye) was found in 4.8% of all participants and 5.3% of those aged 40 years or older.²²⁷ Contrasting previous studies, the leading cause of both VI and blindness was uncorrected refractive error (56.7% of VI and 35.8% of blindness). Cataract was the second leading cause of both VI (29.3%) and blindness (26.4%), while DR was responsible for 6% of

VI and trachoma was responsible for 13.2% of blindness.²²⁷ The CAOHS provided strong evidence that, despite consistent efforts by both Government and non-government organisations, the burden of VI and blindness remained particularly high in Indigenous communities residing in the most remote parts of the country.

Each of the sub-national studies discussed above provided estimates of the prevalence and causes of vision loss in specific Indigenous communities and populations. However, due to the considerable heterogeneity in Australia's geographically dispersed Indigenous population, none of these estimates could be relied upon to provide an accurate measure of the total national burden of vision loss in Indigenous Australians.

2.7.2.6 The National Indigenous Eye Health Survey

2.7.2.6.1 Background of the National Indigenous Eye Health Survey

In 2008, the National Indigenous Eye Health Survey (NIEHS) was conducted, with the aim of providing an updated nationally-representative estimate of the prevalence and causes of VI and blindness in Indigenous Australian children aged 5-15 years and adults aged 40 years and older.²⁸ This survey was distinct from previous research in that it used a stratified multi-stage random-cluster sampling protocol to randomly select participants from all levels of geographic remoteness at a national scale, including Major City, Inner Regional, Outer Regional, Remote, Very Remote-Coastal and Very Remote-Inland areas, as defined by the ABS Accessibility/Remoteness Index of Australia (ARIA).²²⁸ A total of 1694 Indigenous children and 1189 Indigenous adults were recruited and examined. As with the CAOHS, the findings from the NIEHS have been published extensively. A comprehensive report outlining the key findings of the NIEHS was published in 2009,²²⁹ and the national and remoteness-stratified prevalence of vision loss,²⁸ trachoma (and its subtypes),²³⁰ cataract,²³¹ and DR²³² have been published.

2.7.2.6.2 The prevalence of vision impairment and blindness in the National Indigenous Eye Health Survey

Taylor *et al* (2010) reported that 9.4% of adult participants had VI (<6/12) and 1.9% were blind (<6/60), and after adjusting for differential sampling weights in each remoteness stratum, the weighted prevalence of VI was 8.6% (95% CI, 6.9%–10.7%) and the weighted prevalence of blindness was 1.8% (95% CI, 0.1%– 3.3%) nationwide.²⁸ This may represent a substantial reduction in the burden of vision loss in Indigenous Australians compared to previous literature, where blindness affected 17.5% to 21.5% of Indigenous adults aged 60 years and above in 1980²⁰⁸ and 10.5% of those aged 60 years and above in 1990.²⁰⁹ Comparisons between the NIEHS and previous studies should be considered with caution owing to differences in sample representativeness, demographic factors and definitions of vision loss.

The NIEHS data were age-standardised to the Australian population to facilitate comparisons with prevalence estimates from research in non-Indigenous populations conducted in the early 1990s.^{103, 188} These comparisons suggested that VI was 2.8 times higher (14.42% vs 5.19%) and blindness was 6.2 times higher (2.79% vs 0.45%) in Indigenous adults than non-Indigenous adults.²⁸ These comparisons suggested that, despite the ostensible improvement in Indigenous eye health over recent decades, a significant gap in the burden of vision loss persisted.

The crude prevalence rates of VI and blindness were 1.5% and 0.2%, respectively, in Indigenous children in the NIEHS.²⁸ Following sampling weight adjustment, the prevalence of VI was 2.0% (95% CI, 1.3%–2.9%) and the prevalence of blindness remained at 0.2% (95% CI, 0.01%–0.7%). Age-standardised comparisons with the Sydney Myopia Study,²³³ suggested that VI was almost five times more prevalent and blindness was 1.6 times more prevalent in non-Indigenous children compared to Indigenous children.²⁸ This corroborates previous findings from the NTEHP that suggested that the eye health of Indigenous children tends to be better than that of non-Indigenous children, and that the gap in Indigenous eye health has

resulted largely from lifestyle factors that precipitate blindness later in life. However, the reliability of age-standardised comparisons between the NIEHS and previous surveys is limited due to differences in population representativeness (national and remoteness-stratified vs sub-national urban and peri-urban samples) and changes in population parameters during the time that elapsed between studies. Therefore, direct intra-study comparisons from a representative national survey that includes both Indigenous and non-Indigenous Australians are required to reliably quantify the gap in Indigenous eye health.

The NIEHS reported the prevalence of VI, blindness and eye diseases in Indigenous Australians across all levels of remoteness for the first time, thereby quantifying the burden of vision loss and eye disease in Indigenous Australians with unprecedented geographic resolution. Notably, it was reported that greater geographic remoteness was not associated with a statistically significantly higher prevalence of VI or blindness in Indigenous adults ($P=0.60$), although the prevalence of VI tended to be higher in Remote and Very Remote regions (9.5%-12.7%) compared to Major Cities and Regional sites (6.6%-7.8%).²⁸ Conversely, Indigenous children in Major Cities had the greatest risk of vision loss and those in the most remote parts of Australia had the lowest risk of vision loss.²⁸ As the authors note, this is likely due to the low prevalence of myopia in Indigenous children in remote areas, owing in part to the protective effects of spending more time outdoors and less time inside focusing on near objects.²³⁴

The NIEHS only reported the overall unadjusted prevalence of unilateral VI and blindness, and in contrast to bilateral VI and blindness, did not adjust these estimates to account for sampling weights, performed no age-standardisation to compare with previous literature, and did not stratify the prevalence of unilateral vision loss according to geographic remoteness. The crude prevalence estimates of unilateral VI and blindness in adults were 12.8% and 2.7%, respectively, while 1.9% of Indigenous children had unilateral VI and 0.3% were unilaterally

blind.²⁸ Unilateral vision loss has been shown to be highly prevalent in sub-national Indigenous populations previously,²²⁷ and the fact that the NIEHS did not report adjusted, disaggregated or standardised estimates of unilateral vision loss represents a missed opportunity to provide useful data on this outcome at an unprecedented national scale.

The NIEHS was the first study to report the national prevalence of NVI in Indigenous Australians, and it was found that 40% of Indigenous adults had NVI (presenting near visual acuity <N8).²⁸ Considering that NVI has been associated with significantly reduced productivity and economic participation in later life, this high prevalence likely represents a significant but almost entirely avoidable contributor to the overall health and socioeconomic gap experienced by Indigenous Australians.^{18, 19, 235} However, as with unilateral vision loss, the NIEHS was limited in its reporting of NVI and did not provide disaggregated or weighted prevalence estimates, thereby restricting the utility of the survey findings.

2.7.2.6.3 Causes of vision impairment and blindness in the National Indigenous Eye Health Survey

Reflecting the findings of the CAOHS, the NIEHS reported that the major cause of bilateral VI was uncorrected refractive error (54% in adults and 56% in children).²⁸ The attribution of other main causes of blindness could not be completed in children in this study, but cataract was found to be the second leading cause of VI (27%) and the leading cause of blindness (32%) in Indigenous adults. In contrast to most of the previous literature, trachoma contributed almost insignificantly to the burden VI in adults (2%), but it was still a relatively important cause of blindness (9%). More than one-third (37.3%) of participants in the NIEHS had diabetes,²¹⁶ and DR was responsible for 12% of adult VI and 9% of adult blindness.²⁸ The NIEHS data strongly supported the notion that DR had become a major cause of vision loss in Indigenous Australians at a national level. These findings also added to the growing body of literature that showed that diabetes and its complications had become major contributors to the Indigenous health gap in

general, now accounting for 12% of the health disparity between Indigenous and non-Indigenous Australians.¹⁹⁹

2.7.2.7 The contribution of vision impairment and blindness to the Indigenous health gap

Prior to the NIEHS, knowledge about the prevalence and causes of vision loss in Indigenous Australians was fragmentary and mostly outdated, and the relative contribution of vision loss to the overall Indigenous health gap was not known. Using the NIEHS data, the investigators of that survey quantified the extent to which the national Indigenous health gap could be explained by VI and blindness. Measured using Disability-adjusted Life Years (DALY) and YLD, VI contributed 47% and blindness contributed 53% of the total vision loss burden in the Indigenous Australian population.²⁰² Combined, VI and blindness were responsible for as much as 10.8% of the total all-cause non-fatal health gap.²⁰² From these data, it has been concluded that vision loss is the fourth leading cause of the health gap in Indigenous Australians, after ischaemic heart disease, diabetes and traffic accidents. Considering that as much as 94% of vision loss in Indigenous Australians in the NIEHS was determined to be avoidable or treatable,²⁰² vision loss represents a realistic target that, if prioritised and properly resourced, could contribute greatly to narrowing the Indigenous health gap.

2.8 The utilisation of eye health care services in Australia

The primary objective of this thesis is to determine the prevalence and causes of VI and blindness in Australia. Typically, the causes of vision loss include those diseases and conditions that, through pathological processes in the eye, result in reduced vision. As noted in the description of the literature above, discussion about the causes of vision loss may also include epidemiologic risk factors that are associated with an increased likelihood of eye diseases and vision loss occurring, including demographic and clinical factors.^{90, 236} However, as the above literature has also elucidated, 76% of VI and 65% blindness worldwide,²⁰ approximately 80%

of vision loss in non-Indigenous Australians,¹⁹⁰ and up to 94% of VI and blindness in Indigenous Australians²⁸ are preventable or avoidable. Prevention of vision loss requires engagement with eye health services to ensure that appropriate care is provided, and treatment coverage rates of major eye diseases and the avoidance of VI and blindness therefore depend on both the availability and utilisation of eye health care services. It may therefore be said that a lack of availability and utilisation of eye health care services are also causes of (avoidable) VI and blindness. This thesis will explore rates of utilisation of eye health care services by Indigenous and non-Indigenous Australians, as identifying gaps in services and treatment rates will inform efforts to reduce Australia's burden of vision loss. The aspects of utilisation of eye health care services to be investigated are: 1) frequency with which Australians utilise eye health services, 2) rates of adherence to national diabetic eye examination guidelines, 3) cataract surgery coverage rates and 4) refractive error treatment coverage rates, as well as associated risk factors.

2.8.1 Rates of utilisation of eye health care services

2.8.1.1 Frequency of eye examinations in non-Indigenous Australians

Opinions vary on how frequently older individuals should undergo eye examinations. Many eye diseases are asymptomatic in their early stages and the gradual vision loss they cause may go unnoticed, undiagnosed and untreated.²³⁷⁻²³⁹ To ensure timely detection, health policies in some countries such as the United States recommend 2-4 yearly eye examinations for the general population aged 50 years or above, increasing to 1-2 yearly for those aged 65 years or above.²⁴⁰ Those with established eye diseases and vision loss should undergo more regular examinations and care according to their individual needs, as determined by their health care provider.²⁴¹ In Australia, there is no consensus on the frequency with which older non-Indigenous Australian adults should undergo eye examinations. In the VIP, fewer than 1% of those without prior vision loss developed asymptomatic vision loss at 5-year follow-up and

most (75%) of those with noticeable symptomatic vision changes sought care.²⁴¹ Based on these findings as well as the economic implications of excessively regular eye examinations, Taylor *et al* (2004) suggested that 5-yearly check-ups are sufficient for those without previously diagnosed pathology.²⁴¹ However, Australians are able to undergo more regular rebated eye examinations if they so choose. Medicare rebated eye examinations are available to Australians aged under 65 years every three years, and to Australians aged 65 years and older every year.²⁴²

There is currently a paucity of robust population-based research on the frequency with which older Australians, particularly in the non-Indigenous population, undergo eye examinations. Most data are from the VIP and BMES, and are therefore insufficiently representative of the national population at all levels of geographic remoteness and are likely to be out-of-date. The VIP and BMES reported that 63% and 61.3% of participants had undergone an eye examination within the preceding two years, while 8.9% and 1% had never seen an eye care service provider, respectively.^{243, 244} Another Victoria-based study, The Vision Initiative (TVI), investigated service utilisation in a significantly older population (70-79 years) and reported that 61% of participants had seen an eye care specialist within the past year, and after an eye health care promotion campaign, this increased to 70%.²⁴⁵ The low response rate of 12% in this study necessitates cautious inference regarding true utilisation rates due to the risk of non-response bias.

In the VIP, male gender, lack of private health insurance and under-corrected refractive error were associated with having not undergone an eye examination in the preceding five years, and those who resided in rural populations, as well as those who spoke Greek or Italian were twice as likely as urban dwellers and English speakers to have never undergone an eye examination.²⁴³ In the BMES, men, younger participants, those with lower occupational prestige, lower educational attainment and the absence of diabetes or a major eye disease were

significantly less likely to have undergone an eye examination within the preceding two years.²⁴⁴ Of those who had undergone an eye examination within the past two years, 50.2% had seen an ophthalmologist and 48.6% had seen an optometrist. Women and older participants were more likely to have seen an ophthalmologist, while younger people were more likely to have visited an optometrist for their most recent eye examination.²⁴⁴

2.8.1.2 Frequency of eye examinations in Indigenous Australians

In contrast to the non-Indigenous population, official guidelines have been formulated for the recommended frequency with which Indigenous Australians should undergo eye examinations. NACCHO and the Royal Australian College of General Practitioners (RACGP) have suggested that all Indigenous Australians aged 40 years and older should undergo an annual eye examination as part of their yearly health checkup.²⁴⁶ Despite these recommendations, Indigenous Australians tend to engage with eye health care service providers less frequently than non-Indigenous Australians, and this is thought to be a major cause of the gap in Indigenous eye health.²⁴⁷ Indeed, much of the Close the Gap for Vision guidelines are centred on improving access to, and utilisation of, eye health care services by Indigenous Australians.²⁴⁸

Based on Medicare data, the findings of the NIEHS, as well as hospital inpatient and outpatient data, it has been estimated that populations with a high density of Indigenous Australians (>20% of the population) have rates of optometric and ophthalmological service utilisation that are approximately 66% (95% CI, 0.65-0.66) as high as the rate in populations with negligible Indigenous population density (0-0.1% of the population).²⁴⁹ The NIEHS also revealed that, despite the NACCHO and RACGP guidelines, only 15% of participants had undergone an eye examination within the past year, and only 65% had ever had their eyes examined.²⁵⁰ Major reasons for these low utilisation rates included a lack of Regional Eye Health Coordinators (REHC), insufficient Aboriginal Medical Service (AMS)-integrated optometry services,

insufficient visitation frequency by visiting ophthalmologists, cost-related factors and prohibitively long distances to service centres for those in non-metropolitan locations.^{250, 251}

2.8.2 Adherence rates to diabetic eye examination guidelines

2.8.2.1 National Health and Medical Research Council guidelines

As with most countries, Australia has a significant diabetes burden, with a prevalence of between 5.1%²⁵² and 7.6%,²⁵³ corresponding to well over a million people. The prevalence and incidence of diabetes are increasing markedly in Australia, and there are approximately 280 new cases diagnosed each day.⁶³ The prevention of DR-induced vision loss requires early detection and treatment, and the National Health and Medical Research Council (NHMRC) of Australia has established eye examination guidelines for Australians with diabetes in the form of dilated fundus examinations and visual acuity assessment to facilitate timely detection.²⁵⁴ The guidelines are comprehensive, and recommendations vary based on the level of risk of developing retinopathy, including diabetes duration, glycaemic control, blood pressure, blood lipid concentrations and other factors. In the absence of established retinopathy or known high risk factors, the NHMRC recommends that Indigenous Australians with diabetes undergo an annual examination and non-Indigenous Australians with diabetes undergo a biennial examination.²⁵⁴ More regular examinations are recommended for Indigenous Australians due to their earlier onset, more rapid progression and higher prevalence of DR.^{216, 254}

2.8.2.2 Adherence rates of non-Indigenous Australians

Maintaining high adherence rates to these guidelines is critically important for efforts to reduce Australia's burden of avoidable blindness, but data are sparse and outdated, and particularly for the non-Indigenous population, current adherence rates are not presently known. Of the diabetic participants in the VIP, only 54.8% had ever had a dilated fundus examination, and only 43% of diabetic participants aged 65 years and above had seen an optometrist in the previous two years, although this study did not specify whether dilated fundus examinations

had been performed on all participants.²⁵⁵ TVI reported that 52% of Victorians aged 70-79 years with diabetes had adhered to the guidelines,²⁵⁶ and a small study conducted at a pathology collection centre reported an adherence rate of 65.7% in a sample aged 12 years and above.²⁵⁷ However, small sample sizes and selection bias have limited population inferences from these studies. In 2004, the nationwide adherence rate in the Australian Diabetes, Obesity and Lifestyle (AusDiab) study was reported as 77%, however the findings may be out-of-date.²⁵⁸

2.8.2.3 Adherence rates of Indigenous Australians

An adherence rate of 20% reported for Indigenous participants in the NIEHS was concerning low, especially when considered in the context of the high prevalence of diabetes (self-reported=37.3%) and DR in those with diabetes (29.7%) in that sample.²¹⁶ This low adherence rate demonstrated that a large portion of Australia's Indigenous population was at risk of avoidable diabetes-induced blindness. Since the completion of the NIEHS, strategies have been implemented at a national scale to improve access to and uptake of diabetic eye screening services, including outreach optometry and ophthalmology services and teleophthalmology in remote Indigenous communities.²⁵⁹ An updated appraisal of resultant changes in adherence rates is therefore warranted.

2.8.3 Cataract surgery coverage rates

2.8.3.1 Cataract surgery coverage as a core global eye health indicator

Cataract is the leading cause of blindness and the second leading cause of VI worldwide.²⁰ The prevalence of cataract is strongly age-related, and due to the ageing of the global population, the incidence of cataract is increasing accordingly.⁴⁶ In most cases of age-related cataract, presuming that there is no other primary cause of reduced vision, vision loss can be readily reversed by surgical extraction of the cataract and replacement with an intra-ocular lens (IOL). With the advent of technologies such as phacoemulsification, the safety, tolerability, recovery time, cost and success rates of cataract surgeries have improved, and cataract surgery has

become the most commonly performed surgical procedure worldwide.²⁶⁰ One study in the United States reported a 500% increase in the incidence of cataract surgery over 24 years.²⁶¹ Considering the high proportion of vision loss attributable to cataract, and the cost-effectiveness of dramatically reducing a nation's burden of avoidable blindness through ensuring the large-scale availability of cataract surgery services, the WHO has selected cataract surgery coverage rates as a core indicator of the success of the Global Action Plan and a general measure of the effectiveness of national eye care programmes.¹ The WHO has defined the cataract surgery coverage rate as the proportion of people with both bilateral cataract and VI or blindness (visual acuity <6/18) who have had their vision corrected by cataract surgery on one or both eyes.¹

2.8.3.2 Cataract surgery coverage rates in non-Indigenous Australians

As a signatory and contributing Member State to the Global Action Plan, Australia requires representative estimates of cataract surgery coverage rates. To date, no population-based estimates of cataract surgery coverage rates in non-Indigenous Australians have been reported, and the cataract surgery coverage rate is not known. The incidence and prevalence of cataract surgeries, as a proportion of the population, have been reported based on the BMES, the VIP and hospital data,^{46, 262, 263} and the number of pseudophakic Australians is projected to be 500,000 in 2021, compared to 320,000 in 2001.⁴⁶ However, in order to inform the allocation of cataract surgical services and to monitor progress of eye health care interventions in line with the Global Action Plan and Australian Government policy, the current cataract surgery coverage rate is required. Quantifying national and area-specific surgery requirements is particularly important considering that cataract surgery has greater variation in hospital waiting periods between remoteness strata than all other surgical procedures.²⁶⁴ This may mean that different regions have significant differences in cataract surgery coverage rates and therefore different requirements for improvements in service availability.

2.8.3.3 Cataract surgery coverage rates in Indigenous Australians

The NIEHS reported the cataract surgery coverage rate in Indigenous Australians, both at a national level and for each remoteness stratum. The national cataract surgery coverage rate was 65.3%, and ranged from 50.0% in the Outer Regional population to 81.8% in the Inner Regional population.²³¹ A total of 2.5% of participants were bilaterally vision impaired from cataract and 0.59% were blind.²³¹ It is important to note that the definition of the cataract surgery coverage rate in the NIEHS did not account for those with bilateral cataract and BCVA $\geq$ 6/12, even if PVA was <6/12. In Australia, cataract surgeries are routinely being performed at progressively better visual acuities, and many ophthalmologists may consider these individuals eligible for surgery, as substantial visual symptoms, such as glare which impacts on driving function, may be manifest at visual acuity levels better than 6/12.²⁶⁵ Based on this fact, the NIEHS may have over-estimated the cataract surgery coverage rate. Further, the universal applicability of the WHO definition of the cataract surgery coverage rate may require revisiting. The 6/18 threshold is relevant to developing nations in which cataract surgeries are generally performed with more severe vision loss compared to developed nations. With surgeries being performed at increasingly better acuities (even for those with PVA=6/9) in Australia,²⁶⁵ a different threshold may be warranted.

2.8.4 Refractive error treatment coverage rates

Refractive error is the leading cause of vision loss worldwide and in Australia.²⁰ An Access Economics report estimated that in Australia alone, \$407 million is spent annually on treating refractive error; second only to cataract (\$459 million) for eye health expenditure.²⁶⁶ Nonetheless, approximately 341,000 Australians are still blind or vision-impaired as a result of uncorrected refractive error, more than all other eye diseases combined.²⁶⁶ The prevalence of refractive error (in particular myopia) has increased to epidemic proportions in many industrialised societies,²⁶⁷ and quantifying the proportion of those with uncorrected refractive

error would assist services in keeping up with the changing population needs. Considering the ease and affordability with which most non-pathological cases can be corrected with spectacles, contact lenses and surgery, refractive error represents the most cost-effective target for strategies aiming to have the greatest impact on the national burden of VI and blindness.²⁶⁸

2.8.4.1 Refractive error treatment coverage rates in non-Indigenous Australians

The most recent data on refractive errors and treatment coverage rates in non-Indigenous Australians were based on the VIP and BMES. In the VIP 57% of participants²⁶⁹ and in the BMES 45.6% of participants²⁷⁰ had correctable PVA. However, these rates were based on different definitions. The VIP defined under- or uncorrected refractive error as an improvement of one or more lines in those with PVA <6/6 minus two letters²⁶⁹ and the BMES defined under- or uncorrected refractive error as an improvement of two or more lines on a Logarithm of the Minimum Angle of Resolution (logMAR) chart in those with visual acuity $\leq 6/9$.²⁷⁰ The low treatment coverage rates in both studies can be explained by the fact that the visual acuity thresholds used are better than accepted definitions of VI, and a substantial proportion of those participants, particularly within the 6/9 - 6/6 minus two letters range would not be functionally impaired. These individuals would therefore be unlikely to require refractive correction, and the treatment coverage rates reported by both studies are consequently not meaningfully applicable to VI and blindness prevention strategies. A more clinically and epidemiologically useful definition for treatment coverage rates of refractive error in Australia should be based on the 6/12 threshold as anyone with poorer acuity is excluded from driving in Australia.²⁷¹ Therefore, the treatment coverage rate of refractive error, defined as the proportion of people with refractive error who have had their refractive error adequately corrected to $\geq 6/12$, should be used.

2.8.4.2 Refractive error treatment coverage rates in Indigenous Australians

Refractive errors are uncommon in Indigenous Australians, with the CAOHS reporting myopia in 11.1% and hyperopia in 15.2% of Indigenous Australians,²²⁰ compared to rates of up to 49%³⁵ and 57%²⁷² in other high-income Australasian populations. Despite this low prevalence, the NIEHS reported that uncorrected refractive error was the leading cause of VI and that 5.3% of the adult Indigenous population had uncorrected distance refractive error.²³⁵ To date, a peer-reviewed report on the treatment coverage rate for refractive error in the NIEHS has not been published. However, the number of adults with VI as a result of uncorrected refractive error (n=63) and the number of adults with distance correction (n=186) were provided in an appendix of the Minum Barreng (Tracking Eyes) report from the NIEHS.²²⁹ From these data, the crude treatment coverage rate may consequently be calculated as 74.7%, ranging from 54.1% in Very Remote Inland communities to 84.4% in Major Cities. As a comprehensive analysis (including identifying risk factors associated with treatment) was not conducted, and considering that these rates may have changed due to prioritisation of refractive error by Close the Gap and other initiatives in the years following the NIEHS,²⁴⁸ further investigation of treatment coverage of refractive error in Indigenous Australians is required.

2.9 Major initiatives to promote eye health and reduce vision impairment and blindness in Australia

2.9.1 Close the Gap for Vision

The NIEHS revealed that Indigenous Australians continued to suffer from high rates of VI, blindness and eye disease, and that they had poor access and uptake to eye health care services across the nation.²⁸ Indeed, vision loss was responsible for 11% of the total Indigenous health gap.²⁴⁸ Importantly, the NIEHS also revealed that more than 90% of vision loss was avoidable or preventable, and that closing the gap between Indigenous and non-Indigenous Australians was an achievable and realistic objective, provided the appropriate resources were provided.

Taylor *et al* (2012) outlined a comprehensive framework to guide the closing of the vision loss gap, titled ‘The Roadmap to Close the Gap for Vision.’²⁴⁸ The Roadmap outlined 42 specific recommendations to improve nine key areas; 1) eye care in primary health services; 2) eye health service access for Indigenous Australians; 3) co-ordination and case management; 4) eye health workforce; 5) trachoma elimination; 6) monitoring and evaluation; 7) governance; 8) health promotion and awareness; and 9) financing. It was estimated that if these 42 recommendations were implemented at a cost of \$70 million, the Indigenous health gap could be closed by the year 2020.²⁴⁸ In the intervening years, considerable effort has been put into this initiative, however the national ramifications have not yet been adequately assessed.

2.9.2 National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss

In 2005, the Australian Government drafted and endorsed a policy document titled ‘National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss’ (the National Framework) as the domestic response to the 2003 WHA resolution WHA56.26 which called for Member States to develop national eye health policy.²⁷³ This document aimed to provide a blueprint for nationally coordinated action against avoidable VI and blindness by government, the health sector, non-government organisations and industry. Following the endorsement of the Global Action Plan in 2013,¹ the Department of Health of the Australian Government released the ‘Implementation Plan under the National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss’ (The National Framework Implementation Plan).²⁷⁴ This plan was intended to support the objectives of the National Framework by focusing efforts on three key priority areas; 1) eye health of Indigenous Australians; 2) preventing eye disease associated with chronic conditions; and 3) improving the evidence base. In accordance with priority area 3, the Australian Government

pledged \$1.126 million towards the development of Australia's first National Eye Health Survey (NEHS). This thesis reports key findings from that survey.

2.10 The National Eye Health Survey

2.10.1 Rationale

From the above review of the literature, it is evident that there are significant gaps in our understanding of Australia's eye health, and there is considerable need for reliable and nationally-representative data on the epidemiology of VI, blindness, eye disease and population engagement with eye health care services. In summary, data on the eye health of non-Indigenous Australians are outdated and unlikely to be nationally-representative, while data on Indigenous Australians require follow-up due to the high likelihood that there have been systematic changes in their eye health profile since the completion of the NIEHS. With the ageing of both Indigenous and non-Indigenous populations and the increasing pressures exerted by chronic conditions such as diabetes, the causes of vision loss may have changed. Furthermore, reporting on risk factors for vision loss, eye diseases and reduced engagement with health care services in Australia has previously been scarce, with the exception of some data from the CAOHS,²²⁷ the NIEHS²⁸ and the VIP.^{243, 275} In line with the Global Action Plan, many other countries, including those that are far less resourced than Australia, have conducted national or quasi-national surveys on the prevalence and causes of VI and blindness.²⁰ The result is that dozens of countries have national data to inform policy and to report to the WHO. Prior to the NEHS, as a signatory, Member State and contributing party to the Global Action Plan, Australia has been insufficiently equipped compared to other countries to fulfil its Vision 2020 obligations.

To fulfil Australia's commitment to the Global Action Plan, to meet the objectives of the National Framework Implementation Plan, to provide follow-up data to monitor the progress

of the Close the Gap for Vision initiative, and to generally improve our scientific understanding of Australian eye health, the Centre for Eye Research Australia (CERA) partnered with Vision 2020 Australia to conduct Australia's first NEHS. The NEHS aimed to determine the prevalence of causes of VI and blindness in Indigenous Australians aged 40 years and older and non-Indigenous Australians aged 50 years and older across all levels of geographic remoteness in Australia. The survey also aimed to measure the prevalence, detection and treatment coverage rate of major eye diseases and conditions, including cataract, DR, glaucoma, AMD and refractive error in both Indigenous and non-Indigenous Australian adults. In effect, the NEHS intended to provide a comprehensive cross-sectional account of Australia's eye health, and as this involves a multitude of variables, this thesis will focus on a select few outcomes, described in the Aims below.

2.10.2 Significance and benefits to the community

Epidemiologic studies are indispensable to programs aiming to meet the health care needs of the population. The eye care sector and the Australian Government have endeavoured to meet the eye health needs of the Australian population, and the NEHS provides the evidence base to inform eye health care policy and programs accordingly. The NEHS serves to improve eye health in Australia in multiple ways. Firstly, this study is a core indicator in measuring the progress and impact of eye health care services in Australia. Secondly, the results of the NEHS may guide the use of necessary resources in reducing the prevalence of avoidable vision loss in Australia and assist in developing effective, feasible and cost-effective eye health care services. Finally, the results may aid in developing education, awareness and screening programs in communities, including regional and remote areas for the prevention of eye disease.

Due to the methodological similarities to the NIEHS, the research reported in this thesis provides follow-up data on the status of eye health in the Indigenous population of Australia.

This was not a longitudinal cohort study and did not examine the same participants as the NIEHS. However, by utilising similar methodologies and randomly sampling two cross-sectional populations, the NEHS and NIEHS can be compared to interrogate nationwide and remoteness-stratified changes in eye health-related outcomes, including the prevalence and causes of vision loss, the prevalence of ocular disease, eye health care service utilisation and treatment coverage rates. In turn, these findings will contribute to tracking changes in Indigenous eye health since the NIEHS in 2008, and identify persistent deficits as well as elucidate where improvements have been made. The Indigenous eye health care sector and the Australian Government may then use these data to further refine Indigenous-specific strategies to further close the gap in Indigenous eye health.

The NEHS also provides benefit to the international community. It is evident that many eye health surveys around the world are not nationally-representative. A large proportion of those that claim to be nationally-representative have not collected national population samples, and further to this, in almost all cases no (or insufficient) sample stratification has been conducted. In particular, nations with systematically oppressed or marginalised Indigenous (or other ethnic or cultural) groups have, in most cases, not stratified their sampling frames to account for their Indigenous populations, and may have insufficiently quantified the burden of vision loss in their most severely afflicted sub-populations. The sampling methodology of the NEHS is distinct from surveys in other countries in its collection of stratified samples from all levels of geographic remoteness. Additionally, large samples of both Indigenous and non-Indigenous inhabitants were collected to provide sufficient statistical power to determine and compare the prevalence and causes of vision loss in both groups. From the many publications to come from this research in which a strong emphasis has been placed on this aspect of the study, it is hoped that policy-makers and ophthalmic epidemiologists (and indeed other population health

researchers) in countries with marginalised groups will take care to include those groups in their research in the future.

2.11 Aims

This thesis has two aims:

- 1) To determine the prevalence and major causes of unilateral and bilateral VI and blindness in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.
- 2) To determine rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and both cataract surgery coverage and refractive error treatment coverage rates in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.

CHAPTER 3: MATERIALS AND METHODS

3.1 Overview

The methodology of the NEHS was designed to address the following two aims; 1) to determine the prevalence and major causes of unilateral and bilateral VI and blindness in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia; and 2) to determine rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and both cataract surgery coverage and refractive error treatment coverage rates in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia. To address these aims, we designed and executed a nationwide cross-sectional population-based field survey that utilised a modified multistage random cluster sampling methodology to select samples of non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older from all levels of geographic remoteness in Australia. Participants underwent an interviewer-administered general questionnaire and a series of standardised eye examinations to quantify the prevalence and causes of vision loss and the utilisation of eye health care services in Australia. Field work was conducted between the 11th of March 2015 and the 18th of April 2016.

This chapter begins with an account of the process undertaken to obtain ethics approval and endorsement from the various governing ethical bodies for this study, particularly for conducting research in Indigenous populations. A comprehensive background of various sampling methods used to collect prevalence data is then presented, with an emphasis on the importance of population-based surveys that use reliable sampling protocols. This in-depth discussion is provided to adequately substantiate the methodology chosen for this survey. The

sampling and site selection methodology of the survey is subsequently presented in the form of a publication titled “Sampling methodology and site selection in the National Eye Health Survey; an Australian population-based prevalence study,” with supplementary information provided after this publication to further describe methodological details not published.

The chapter continues with an appraisal of methods used in eye health surveys to recruit participants and collect ophthalmic data to appropriately frame and justify the methods employed in the NEHS. A publication titled “The validity of self-report of eye diseases in participants with vision loss in the National Eye Health Survey,” is presented to substantiate the need for clinical examinations over self-report in surveys on vision loss. The recruitment and clinical examination protocols of the survey are presented in the form of a second publication titled “Recruitment and testing protocol in the National Eye Health Survey: A population based eye study in Australia.” The details of statistical analytical protocols used to address each aim are not provided in this chapter. Instead, because each of the aims and their respective sub-aims are addressed in the Results chapter as complete journal publications, the specific statistical analyses used to address each sub-aim are described within those publications.

3.2 Funding and ethics approval

On the 25th of June 2014, a funding proposal was submitted by CERA and Vision 2020 Australia to the Minister for Health of the Australian Government requesting a total of \$3.32 million to conduct the NEHS. Funding was initially approved to the amount of \$1.126 million, with an additional \$881,242 pledged in in-kind and financial support from partner organisations in the eye health and vision care sector. The Australian Government later approved an additional \$650,000 in Government funding to ensure the completion of the project.

The NEHS received ethical approval from the Human Research Ethics Committee (HREC) of the Royal Victorian Eye and Ear Hospital, Melbourne, Victoria, Australia on the 27th of November 2014 (HREC Reference Number: 14/1199H) (Appendix A). To obtain ethics approval for the Indigenous arm of the NEHS we engaged in consultations with national, state-level and community organisations over 16 months (October 2014 to February 2016) (Appendix B). Obtaining ethics approval was an ongoing process that was conducted in parallel with data collection during the survey, and was coordinated principally by Stuart Keel. Representatives of NACCHO, the peak representative body of over 150 Aboriginal Community Controlled Health Services (ACCHS) in Australia, were consulted to determine the most culturally appropriate and practical methods to obtain ethics approvals within each state and develop relationships with key stakeholders in the Indigenous communities of Australia. NACCHO provided an official endorsement letter in support of the NEHS on the 25th of March 2015.

Endorsement from NACCHO assisted in building partnerships with Indigenous organisations at the State level and within the individual communities in each selected Indigenous population cluster (Appendix C). We cultivated close working relationships with members of the Indigenous community including managers and liaison officers at Indigenous organisations in each site. All research practices and communications were conducted with consideration for individual requirements of each Indigenous community. Ethical approval was required from five HRECs. These were the Aboriginal Health and Medical Research Council (AH&MRC) of New South Wales, the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), the Menzies School of Research (representing the Northern Territory), the Aboriginal Health Council of Western Australia (AHCWA) and the Aboriginal Health Council of South Australia (AHCSA). Prior to the commencement of data collection in Indigenous communities, cultural safety training was undertaken at the VACCHO office in Melbourne on

the 6th of March 2015. Official endorsement was obtained from an additional 32 state-level or community-level organisations. A total of 39 local Indigenous workers were employed to assist with engaging Indigenous communities in 27 of the 30 survey sites.

3.3 Participant sampling and site selection methodology

3.3.1 Background of sampling methods in population research

This sub-section provides a detailed account of various sampling methodologies used in population research, both generally and in ophthalmic epidemiology, as a preface for the NEHS sampling protocol. The advantages and limitations of various methods are presented to provide adequate context for appraisal of the appropriateness of the sampling utilised in this study. Subsequently, section 3.3.2 presents the sampling protocol in the NEHS.

3.3.1.1 Non-survey epidemiologic research methods used to collect eye health data

Population-level health data can be collected by various methods depending on the research question, study design and the nature of the required data. For example, hospital inpatient and outpatient data and insurance company data may be consulted to estimate the number of people with a particular disease, the number of people who have undergone a particular treatment, or other health-related outcomes. Similarly, disease registries may provide data on the number of people with a given illness,²⁷⁶ or for example in the case of blindness, the proportion of blindness attributable to each disease.²⁷⁷

Research that draws inferences from the above-mentioned data sources has some practical utility. For example, blindness registries have been established in some countries, including Israel,²⁷⁷ Canada,²⁷⁸ Denmark,²⁷⁹ and Iceland,²⁸⁰ and these databases provide at least an approximate estimate of the number of people with blindness and the number of people that use low vision services in a population.²⁷⁷ However, this utility is limited for a number of reasons. Most importantly, the patient samples investigated using these methodologies are

unlikely to be truly representative of the population of interest. Attempting to extrapolate the prevalence and causes of blindness (or any disease) from the number of people on a disease registry cannot be relied upon because the number of blind people *not* on the registry is unknown. As an example of the unrepresentativeness of blindness registry-based data, Rearwin *et al* (1997) reported the major causes of blindness in Navajo Indians in the United States based on a hospital blindness registry, and concluded that trauma (29.7%) and congenital/hereditary conditions (14.9%) such as retinitis pigmentosa were the major causes of blindness.²⁸¹ It is conceivable however that traumatic blindness and congenital/hereditary blindness would be disproportionately over-represented in blindness registries due to their severity, likely requirement for hospitalisation and early age of onset, compared to conditions such as uncorrected refractive error or cataract. Reliable epidemiologic studies that have collected more representative samples have shown that trauma and congenital blindness are not typically the most prevalent causes of blindness.²⁰

The second major limitation of disease registry and hospital-based data is a lack of quality control, methodological validation or standardisation. For example, criteria and thresholds for disease diagnosis may vary between hospitals for a given disease, and different tools and equipment may be used to diagnose and treat eye health conditions. The lack of standardisation and comparability resulting from this, and indeed any other potential inconsistencies between sources of data, renders these data unreliable.

3.3.1.2 The benefits of survey methodologies

The most reliable method for accurately and reliably measuring population parameters, including, for example the prevalence of VI and blindness, is the cross-sectional population-based survey.²⁸² Studies that report the prevalence of vision loss, such as those used in the Global Vision Database,¹⁶ employ a cross-sectional survey methodology in which population clusters are selected based on a carefully devised protocol, and all (or almost all) residents

within the selected clusters are sampled. If the survey is properly designed and the sample size is sufficiently large, the proportion of sampled participants with a given health outcome can be taken to reflect the proportion with that outcome in the population. Due to the statistical robustness and the reliability of prevalence estimates inferred from well-designed and representative population-based surveys, they are considered the gold standard method for estimating population prevalence.²⁸³

3.3.1.3 Sampling of participants in eye health surveys

Epidemiologists have devised many types of survey methodologies to measure population parameters. Broadly speaking, survey sampling methodologies can be divided into probability sampling and non-probability sampling protocols. There are various types of probability and non-probability sampling methods, each with their own advantages and disadvantages.

Non-probability sampling includes convenience sampling, quota sampling and focus groups. These survey methods use non-random sampling procedures in which each unit (or person) in the sampling frame that is taken to represent the population does not have an equal or pre-specified proportional probability of being selected.²⁸³ Participants are chosen based on judgments regarding the characteristics of the target population and the needs of the survey.²⁸² In non-probability sampling, some members of the eligible target population have a chance of being chosen and others do not, and this sampling method is therefore characterised by a significant risk of selection bias.²⁸⁴ There is no way of determining the validity and representativeness of the resulting estimates as they relate to the true parameter in the population.²⁸³ Non-probability sampling methodologies are therefore considered to be undesirable for estimating the frequency of health outcomes in populations,²⁸³ and most recently-conducted surveys on the prevalence of vision loss have not employed non-probability sampling methodologies.

Probability sampling, which includes simple random sampling, stratified random sampling, systematic sampling and cluster sampling employs statistical methods to ensure that each member of the target population has a specified, non-zero chance of being sampled.²⁸² Consequently, probability sampling is more likely to select unbiased samples that are truly representative of the target population compared to non-probability sampling. However, even within probability sampling, there is variability in terms of the true randomness and representativeness of selected samples.

3.3.1.3.1 Simple random sampling

Simple random sampling is the most robust method to ensure that a sample is reliably random and representative as all individuals in the population are included in the sampling frame and have equal probability of being selected.²⁸² However, when conducting population surveys, particularly of large populations such as at the national scale, simple random sampling is not practical. The logistical and financial costs involved in randomly selecting people over such expansive geographic ranges are prohibitive, and most population surveys therefore require an alternative methodology.²⁸³

3.3.1.3.2 Cluster sampling

Population surveys typically use random cluster sampling as an alternative to simple random sampling, as cluster sampling is cheaper and less logistically demanding.²⁸⁵ Cluster sampling involves constructing a sampling frame that identifies groups or clusters of people without explicitly selecting the individual people within those clusters. Clusters are typically pre-defined population units, such as census districts, suburbs or towns. A set of clusters (perhaps all the clusters in a country's population if a national survey is being conducted) are included in the sampling frame, and a pre-determined number of clusters is then randomly selected from the list of clusters. Ideally, all (or almost all) individuals within the randomly-selected clusters are surveyed.²⁸⁵ While cluster sampling is preferable to simple random sampling due to

logistical and financial reasons, it is limited by high variance (and hence high standard errors) owing to the design effect, inter-class correlations and potential homogeneity of individuals within clusters.²⁸⁵

There are many variations on cluster sampling, but the commonly used procedure for nationwide surveys is multistage random cluster sampling, in which the population clusters are selected in a stepwise process. First, larger geographic units, such as districts or towns or other specifically defined census locations that contain large populations are sampled. Then, a smaller geographic unit (or a cluster of smaller geographic units) from within each of the randomly-selected larger geographic units is randomly selected. Typically, cluster sampling is at least a two-stage process, however, the procedure can include multiple stages. National surveys that have used multistage random-cluster sampling include those in Trinidad and Tobago,²⁸⁶ Pakistan,¹¹¹ Bangladesh,⁹⁶ Myanmar,²⁸⁷ Fiji,¹¹⁰ and Timor-Leste.²⁸⁸

3.3.2 Sampling of participants in the National Eye Health Survey

The NEHS used a modified multi-stage random cluster approach that was designed to sample approximately 3000 non-Indigenous Australians aged 50 years or older and approximately 1400 Indigenous Australians aged 40 years or older from 30 population clusters across all levels of geographic remoteness in Australia. The sampling frame used population data from the Australian Census conducted by the ABS in 2011.²⁸⁹ To collate and organise Census data, the ABS classified Australia's geography according to the Australian Statistical Geography Standard (ASGS) along various demographic and statistical dimensions (Figure 1). These were: 1) Remoteness Areas, 2) Urban Centres and Localities and Section of State, 3) Indigenous Regions/Areas/Locations, 4) Greater Capital City Statistical Areas, 5) Significant Urban Areas, and 6) Statistical Areas (SA).

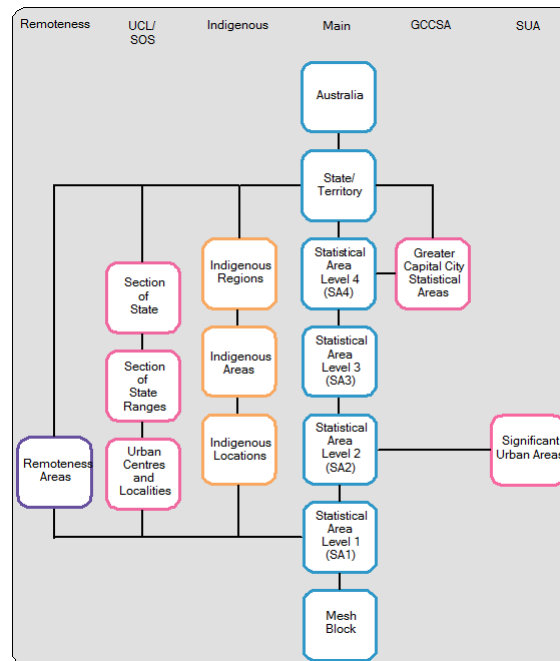


Figure 1. Geographic structures in Australia defined by the Australian Statistical Geography Standard (ASGS). The National Eye Healthy Survey sampled 30 population clusters based on the Main Statistical Area (SA) dimension of the ASGS. The first stage of sampling involved randomly selecting SA2 clusters from all levels of geographic remoteness. SA1s or groups of SA1s were then randomly selected from within each cluster and the constituent population within the SA1 borders were nominated as the survey sample.

The SA dimension was chosen as the geographic sampling unit for the NEHS because; 1) it consisted of enough levels of magnification to allow multistage selection of clusters - Statistical Areas - Level 2 (SA2) could be selected in the first stage of sampling, following which Statistical Areas - Level 1 (SA1) within each SA2 could be selected at the second stage of sampling. This was particularly convenient because population sizes in SA1 clusters were small and approximated cluster sizes that are useful for household surveys; and 2) population data for SAs were more reliable and comprehensive than for the other dimensions and included data on the number of residents, population age distributions, Indigenous/non-Indigenous constituency of the population and geographic remoteness.

It is noteworthy that the NIEHS, conducted in 2008, utilised a similar sampling methodology to that of the current study in that multistage random-cluster sampling was used to select 30

population clusters from all geographic remoteness strata in Australia.²²⁸ The NEHS achieved sufficient similarity in sampling (including the number of clusters, remoteness stratification and inclusion criteria of the adult Indigenous population) to facilitate comparisons between the two studies. However, there were key differences. The NIEHS used 2006 Census data that were based on a different geographic classification system, the Australian Standard Geographical Classification (ASGC). As the intended sample in that study consisted of Indigenous Australians only, Indigenous-centric geographical structures, called Indigenous Areas (AIRE), were the primary sampling unit,²²⁸ whereas in the current survey, a sampling unit that accommodated both Indigenous and non-Indigenous recruitment (the SA2) was required.

3.3.2.1 Publication 1: Sampling methodology and site selection in the National Eye

Health Survey; an Australian population-based prevalence study

The sampling methodology is described in detail below in Publication 1 titled “Sampling methodology and site selection in the National Eye Health Survey; an Australian population-based prevalence study.” The paper provides an account of the sample size calculation, the multi-stage selection of SA2s and SA1s and the stratification of clusters based on geographic remoteness. The paper then details challenges faced during household enumeration and recruitment, including the sparse distribution of Indigenous populations as well as the consistent discrepancies between ABS Census data and the true number of eligible residents in each of the selected sites. Methodological adjustments employed to overcome these challenges are described. This paper was published in *Clinical and Experimental Ophthalmology* in January 2017.



Original Article

Sampling methodology and site selection in the National Eye Health Survey: an Australian population-based prevalence study

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ABSTRACT

Background: This paper presents the sampling methodology of the National Eye Health Survey that aimed to determine the prevalence of vision impairment and blindness in Australia.

Design: The National Eye Health Survey is a cross-sectional population-based survey.

Participants: Indigenous Australians aged 40 years and older and non-Indigenous Australians aged 50 years and older residing in all levels of geographic remoteness in Australia.

Methods: Using multistage, random-cluster sampling, 30 geographic areas were selected to provide samples of 3000 non-Indigenous Australians and 1400 Indigenous Australians. Sampling involved (i) selecting Statistical Area- Level 2 sites, stratified by remoteness; (ii) selecting Statistical Area- Level 1 sites within Statistical Area- Level 2 sites to provide targeted samples; and (iii) grouping of contiguous Statistical Area- Level 1 sites or replacing Statistical Area- Level 1 sites to provide sufficient samples.

Main Outcome Measures: The main outcome measures involved Sites sites selected and participants sampled in the survey.

Results: Thirty sites were generated, including 12 Major City sites, 6 Inner Regional sites, 6 Outer Regional sites, 4 Remote sites and 2 Very Remote sites. Three thousand ninety-eight non-Indigenous participants and 1738 Indigenous participants were recruited. Selection of Statistical Area- Level 1 site overestimated the number of eligible residents in all sites. About 20% (6/30) of Statistical Area- Level 1 sites were situated in non-residential bushland, and 26.67% (8/30) of Statistical Area- Level 1 populations had low eligibility or accessibility, requiring replacement.

Conclusions: Representative samples of Indigenous and non-Indigenous Australians were selected, recruited and tested, providing the first national data on the prevalence of vision impairment and blindness in Australia.

Key words: national survey, population health, random cluster sampling.

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INTRODUCTION

The World Health Organization estimated that in 2012, 285 million people had vision impairment (VI) globally, of which 39 million were blind.¹ The 'Universal Eye Health: a Global Action Plan 2014–2019' was endorsed at the 66th World Health Assembly (WHA) (May, 2013) to reduce the prevalence of avoidable blindness globally by 25% by 2019.² The Global Action Plan emphasized the need for generating population-based prevalence data for VI and blindness at a national level to inform future strategies aiming to reduce vision loss in each country, including Australia.

National population-based surveys differ in their sampling methodologies. Although simple random sampling theoretically provides the most precise and representative sample, the time and resources required render this method unfeasible in most instances. For this reason, multistage random cluster sampling is considered to be the most practical method when conducting population-based surveys to produce representative data at a national level.³ However, not all population-based eye studies conducted locally or internationally adhere to all aspects of this methodology. These shortcomings include a lack of national coverage, absence of stratification and random sampling and the use of suboptimal cluster selection. This is largely due to logistical constraints as well as a lack of population and geographic data. A recent review⁴ of 53 studies from 39 countries that investigated the prevalence of VI and blindness found that studies for only 13 countries had nationwide coverage.^{5–17} There is a paucity of nationwide prevalence studies in VI and blindness in the world, with only six national studies being completed and published since 2012.^{18–22} Furthermore, many studies such as those using the Rapid Assessment of Avoidable Blindness protocol²³ have not stratified their selected populations on the basis of characteristics that may affect the prevalence of VI or have not randomly selected their samples,²⁴ and this contributes to a lack of consistency between surveys globally.

No studies in Australia have estimated the prevalence of VI and blindness in both Indigenous and non-Indigenous Australians using a nationally representative methodology. Two landmark studies, the Melbourne Visual Impairment Project (VIP)²⁵ and the Blue Mountains Eye Study²⁴ conducted in the early 1990s, provided excellent insights into the prevalence of VI and blindness. However, the generalizability of both studies was limited owing to their sampling methods. On one hand, the Melbourne VIP obtained its sample using cluster-stratified random sampling; however, the site selection was not multistaged.²⁶ This study included four rural sites

and nine urban sites from the general population and nursing homes in one state (Victoria), thus limiting the extent to which findings could be extrapolated to a national level. On the other hand, the Blue Mountains Eye Study used a convenience sample, selecting two postcodes in the west of Sydney (New South Wales; NSW) due to the older demographic in the area.²⁷ The National Indigenous Eye Health Survey (NIEHS), conducted in 2008, utilized a highly robust stratified multistage random cluster approach, but although this study included a small convenience sample of non-Indigenous Australians, its focus was on the Indigenous population.²⁸ Despite these limitations, these studies have remained the reference studies for the prevalence of VI and blindness in Australia until now.

The National Eye Health Survey (NEHS) was conducted in order to provide national estimates of VI and blindness in Australia. The NEHS implemented a multistage random cluster sampling methodology, with cluster selection stratified by geographic remoteness, to generate representative prevalence data on VI and blindness. This paper describes the sampling and site selection process in the NEHS.

METHODS

Ethics approval

The protocol for this study was approved by the Royal Victorian Eye and Ear Hospital Human Research Ethics Committee (HREC-14/1199H). Additional ethics approvals were obtained from the Aboriginal Health and Medical Research Council of New South Wales (HREC-1079/15), the Menzies School of Health Research (HREC-2015-2360), the Aboriginal Health Council of Western Australia (HREC-622) and the Aboriginal Health Council of South Australia (HREC-04-15-604). This research was conducted in accordance with the Declaration of Helsinki.

Sampling

The NEHS aimed to recruit and examine a total of 4400 participants. Selection of sites utilized Census 2011 data collected by the Australian Bureau of Statistics (ABS). Using multistage random cluster sampling, 30 randomly selected sites containing approximately 100 non-Indigenous Australians aged 50 years and over and 50 Indigenous Australians aged 40 years and over, stratified by remoteness, were selected. The age criterion of 50 years and over for non-Indigenous participants was chosen to reflect the age group suggested by the World Health Assembly (WHA) Global Action Plan for national prevalence surveys.² The younger age inclusion criterion for Indigenous participants was chosen owing to the

earlier onset and more rapid progression of major eye diseases and diabetes in Indigenous Australians.²⁹ Participants were considered to be Indigenous Australians if they reported that they were (i) Aboriginal; (ii) Torres Strait Islander; or (iii) Aboriginal and Torres Strait Islander.

Sample size calculation

The non-Indigenous sample size calculation was based on previous data on the prevalence of VI from the Melbourne VIP. The sample size was calculated as 1552 with an upper limit of 1799 based on a margin of error of 1.1% using the sample size calculation formula $n = [Z^2 \times p \times (1 - p)]/e^2$, where $p = 0.0515$, $Z = 1.96$ and $e = 0.011$. Assuming a design effect of 1.5 that adjusts for the inter-class correlations between participants within clusters and a 20% non-response rate, the required sample size was 2794 (upper limit: 3238). Using the same calculation with a margin of error of 2% and assuming a similar prevalence to the NIEHS, the Indigenous sample size was calculated to be 1368 (approximately 1400). Therefore, the combined sample size required for this study was 4400. Assuming a cluster size of 150 per sampling site, 30 sites were required.

Site selection

Setting the geographical sampling unit for the first sampling stage

The ABS Census 2011 data were used to inform study site selection. The ABS used a geographical classification system, the Australian Statistical Geography Standard in the 2011 Census, to divide Australia into discrete geographical structures or Statistical Areas (SAs).³⁰ SAs are categorized at different levels, with SA4 the largest SA unit composed of multiple smaller SA3s, which in turn are composed of multiple smaller SA2s that are made up of multiple smaller SA1s. The SA2 was the initial geographic unit for study site sampling in the NEHS.

Constraining the sampling pool

A set of constraints was added to the list of 2097 SA2 sites across Australia. To be eligible for inclusion in the site selection pool, SA2s were required to contain at least 10 non-Indigenous Australians aged 50 and older and either 6 or 10 Indigenous Australians aged 40 years and older in urban and rural SA2s, respectively. This limit was chosen as it was the most suitable criterion to balance the need for a sufficient number of SA2s in the sampling pool while attempting to include sites with appreciable population densities. Consequently, 1842 SA2s containing

a total population of 19 499 171 residents were available for site selection.

Stratifying by remoteness

The ABS assigned a value from 0.00 to 15.00 to each SA2, denoting the level of remoteness according to the Accessibility/Remoteness Index of Australia Plus (ARIA+) system, with ARIA+ categories including Highly Accessible (ARIA+ range: 0.00–0.2), Accessible (ARIA+ range: >0.20–2.40), Moderately Accessible (ARIA+ range: >2.40–5.92), Remote (ARIA+ range: >5.92–10.53) and Very Remote (ARIA+ range: >10.53–15.00). ARIA+ superseded the Remoteness Area (RA) classification system used by the ABS that classified SAs according to discrete numbers of 1 to 5, corresponding to Major City, Inner Regional, Outer Regional, Remote and Very Remote. The ARIA+ groups were converted to the discrete RA groups for NEHS site selection according to Table 1 for ease of interpretation. Twelve Major City sites, six Inner Regional sites, six Outer Regional sites, four Remote sites and two Very Remote sites were chosen to correspond approximately to the population distributions within each of the RAs. Backup sites were selected for each RA, to be used if primary sites were unsuitable owing to logistical or administrative reasons.

To stratify NEHS site selection by remoteness, all 1842 SA2s were grouped into their RA categories and ranked by their ARIA+ scores in ascending order (Table 2). The total progressive population in each RA was divided by the number of sites required in each RA to separate the RA into discrete blocks of equal population size (block size) to ensure that sites were selected from across the whole ARIA+ spectrum.

Selecting the sites

For each stratified RA, the random number function in Microsoft Excel (32-bit version 14.0.7.128.5000) was used to create a 'seed value', which was multiplied by the RA block size to provide a unique population 'selection value' for each RA. The selection value was used to select the same number in the cumulative population in all blocks within the RA, and the SA2 in which that individual in the population was located was selected as the survey site for that block. This was repeated for all RAs to provide 30 primary sites and 10 backup sites.

Setting the geographical sampling unit for the second sampling stage

The SA2s contain non-Indigenous populations exceeding the cluster size required for the NEHS. Therefore, the second stage of sampling required the

Table 1. Conversion of ARIA+ classifications to RAs

ARIA+ [†] category	ARIA+ range	Corresponding RA [‡]	Corresponding RA value
Highly Accessible	0–0.2	Major City	1
Accessible	>0.2–2.4	Inner Regional	2
Moderately Accessible	>2.4–5.92	Outer Regional	3
Remote	>5.92–10.53	Remote	4
Very Remote	>10.53–15.00	Very Remote	5

[†]The Australian Bureau of Statistics endorsed remoteness classification system in the Australian 2011 Census. [‡]The remoteness classification derived from the Australian Standard Geography Classification. ARIA+, Accessibility/Remoteness Index of Australia Plus; RA, Remoteness Area.

Table 2. Distribution of selective SA2 geographical areas across RAs

RA [†]	SA2s [‡]	Tar_IP	Tar_NP	Total Population	Block size	% Pop [§]
Major City	936	43 567	3 632 398	12 627 075	789 192.19	64.8
Inner Regional	464	30 706	1 456 275	4 214 982	526 873	21.6
Outer Regional	322	30 066	688 493	2 042 319	255 290	10.5
Remote	61	11 383	108 372	395 061	49 383	2.0
Very Remote	59	21 610	35 110	219 734	27 467	1.1
Total	1842	ND	ND	19 499 171	ND	ND

[†]The remoteness classification derived from the Australian Standard Geography Classification. [‡]The geographical unit of site preselection. [§]Percentage of the total population within the total SA2 sampling pool distributed within each RA. RA, Remoteness Area; SA2, Statistical Area Level 2; Tar_IP, target Indigenous population; Tar_NP, target non-Indigenous population; ND, no data.

selection of a sub-cluster within each SA2. SA1 population sizes correspond approximately to the required cluster size in the survey; however, their population sizes are variable, and selection of a single SA1 may have produced highly variable cluster sizes. SA2s were therefore divided into blocks of one or more SA1s such that the blocks would be as close as possible to the required cluster size while also allowing each block in the SA2 to contain a similar-sized non-Indigenous target population. The random number function was then used to select a cluster for targeted recruitment. Sampled clusters consisted of one to three SA1s. Some SA1s within a selected SA2 were not contiguous or did not have similar population sizes or could not be divided into clusters with the required number of eligible residents within a reasonable block size. In these cases, selection of the SA1 had to reflect the practicalities of door-to-door recruitment within the time and budget constraints of this study, and SA1s were selected to accommodate these considerations. The geographical boundary of each site was then overlaid on a corresponding image from Google Maps to provide a street-level map to be used for door-to-door recruitment. SA1 sites were not used for sampling of the target Indigenous population because Indigenous populations are sparse and SA1 populations rarely contain sufficient Indigenous residents. Depending on the target Indigenous population size at each

selected site, the SA2-level or SA3-level area was used to obtain the required sampling population.

Door-to-door enumeration and site adjustments

Door-to-door knocking

Recruiters went to each accessible residence in the recruitment site and delivered an information pamphlet outlining the study in each mailbox with a message that recruiters would be returning within 48 h. Recruiters then went door-to-door to enumerate eligible residents and invite them to participate using a standardized script. In cases where residents were absent at the first attempt at recruitment, recruiters returned within 2 days to re-attempt contact. Residents who were not present following two attempts were deemed non-contactable.

Site modifications for non-Indigenous clusters

A systematic approach was implemented to compensate for disparities between the ABS Census data for non-Indigenous residents and population sizes enumerated by survey recruiters. Disparities were likely to occur as (i) some residents were expected to be absent; (ii) not all homes would be accessible; (iii)

sampling was conducted based on Census data from 2011, and eligibility of the constituent populations was likely to have changed during this period; and (iv) population density would be prohibitively low in some sites, including in areas composed almost entirely of farmland or bushland.

The SA1s with low eligibility rates, such as those in which estates were recently built for young families or SA1s located in bushland with low population density, were replaced with the closest SA1 with an acceptable population density. SA1s identified through door-to-door enumeration as having insufficient sample sizes, but with permissive population densities and adequate eligibility rates, were merged with the largest contiguous SA1. Progressively smaller contiguous SA1s were sampled to complete recruitment in the allocated time frame of 3 to 5 days per study location. The ARIA+ scores of the SA2 in which all site extensions or replacements occurred were always within the same RA classification as the original site. All residences visited by recruiters outside of the randomly selected SA1 were documented on an online cloud-based database and overlaid onto a map of their SA1 boundaries to allow adjusted sampling weights to be derived.

Site modifications for Indigenous clusters

The eligible target Indigenous population in the list of available SA2s was expected to comprise only 2.27% of the total eligible population (Table 2). However, the sample size calculation required a 31.81% composition (1400/4400). Therefore, it was expected that SA1 clusters and their surrounding areas would not contain sufficiently large Indigenous populations. In addition, ethical approval from five HRECs and community endorsements from 32 state-level or community organizations were required before recruiters were able to engage Indigenous communities. The nearest Indigenous communities to the sampled SA1 were used for recruitment of Indigenous participants. In cases where community consultations were unsuccessful and NEHS staff were unable to gain access to Indigenous communities in the randomly selected survey site, a backup site was used.

RESULTS

Randomly sampled NEHS survey sites

A total of 30 core sites and 10 backup sites across five states and one territory were selected for the NEHS using multistage random cluster sampling (Table 3). Sites were distributed across RAs as follows: twelve core sites and four backup sites from the Major City RA, six core sites and two backup sites from each of the Inner Regional and Outer Regional RAs, four

core sites and one backup site from the Remote RA and two core sites and one backup site from the Very Remote RA. The ARIA+ distributions for the core SA2 sites in each RA were Major Cities: 0.00–0.13; Inner Regional: 0.37–2.28; Outer Regional: 2.55–5.15; Remote: 6.00–9.00; and Very Remote: 13.28–14.33, indicating that sites were distributed evenly across the ARIA+ spectrum

Modified non-Indigenous clusters

Random selection of SA1 clusters generated 24 sites that were suitable for door-to-door recruitment. However, six SA1s (20%) were located in rural areas containing farmland, bushland or large bodies of water, with very low population densities. Sites affected were Goulburn (NSW), Tomerong–Wandandian–Woollamia (NSW), Ulladulla Region (NSW), Rockhampton Region-East (Queensland; QLD), Eden (NSW) and York Peninsula-South (South Australia). Because of logistical constraints, door-to-door knocking in these areas was deemed unfeasible, and the nearest SA1 with a suitable population density and the same RA classification was selected for recruitment.

Of the 24 SA1 sites suitable for door-to-door recruitment, eight (33.33%) were identified by recruiters as having low eligibility or contactability rates. The randomly selected SA1s in the sites of Springfield (QLD), Parklea–Kellyville Ridge (NSW), Elderslie–Harrington Park (NSW) and Wodonga (VIC) were all situated within newly constructed estates, inhabited predominantly by young families who did not fit the inclusion criteria. South Hedland (Western Australia), established as a mining town, had a particularly low eligibility rate as the town's population was composed almost entirely of young workers operating the mines. The SA1 in Banana (QLD) had a high rate of absent residents. In Wagaman (Northern Territory), a high proportion of residents were inaccessible owing to secured locked gates. For all eight sites, eligible residents were enumerated from adjacent SA1s or SA2s.

Modified Indigenous clusters

Backup sites

A total of five backup sites were used in the NEHS (Table 4). Of these, two were utilized because Indigenous communities in the core sites of Warilla (NSW) and Mount Isa (QLD) declined to participate. NEHS project leads were advised that the Derby-West Kimberley (Western Australia) site would require lengthy community consultation for ethical approval, and because of time constraints, a backup site was used. Two Major City sites selected in NSW had small Indigenous populations, and backup sites were

Table 3. National Eye Health Survey sites: selected SA2 sites and targeted SA1 sites

SA2 data						SA1 data						
Site no	SA2 name	State	RA [†]	ARIA+ [‡]	Area (m ²)	Tar_IP [§]	Tar_NP [¶]	SA1	ARIA+	Area (m ²)	Tar_IP	Tar_NP
Core sites												
Major Cities												
1	Brighton (QLD)	QLD	1	0.00	6 482 055.16	64	2977	3104209	0.00	281 514.20	0	108
2	Springfield ^{††}	QLD	1	0.00	6 673 459.51	32	874	3130301	0.00	590 391.40	0	74
								3130312	0.00	153 075.77	3	38
								Total		743 467.17	3	112
3	Parklea–Kellyville Ridge	NSW	1	0.00	9 877 842.94	36	3169	1131030	0.00	151 915.76	0	88
4	Chipping Norton–Moorebank	NSW	1	0.00	14 490 264.51	48	4851	1152323	0.00	105 418.34	0	121
5	Concord–Mortlake–Cabarita	NSW	1	0.00	6 325 574.85	24	6547	1138341	0.00	115 055.18	0	146
6	Mornington	VIC	1	0.00	21 089 872.96	32	8830	2138032	0.00	222 147.55	0	113
7	Rowville–Central	VIC	1	0.00	8 200 350.36	14	4290	2125620	0.00	142 965.52	0	124
8	Craigie–Beldon	WA	1	0.00	7 131 438.77	25	2561	5107009	0.00	175 983.96	0	85
								5107010	0.00	149 986.20	3	72
								Total		325 970.16	3	157
9	Bassendean–Eden Hill–Ashfield	WA	1	0.00	10 344 501.60	91	4514	5104429	0.00	458 631.67	0	209
10	Kalamunda–Maida Vale–Gooseberry Hill	WA	1	0.00	28 121 619.03	32	5807	5114002	0.00	280 332.42	0	133
11	Elderslie–Harrington Park	NSW	1	0.04	21 533 575.05	85	3772	1143410	0.00	289 357.00	3	91
12	Warilla	NSW	1	0.13	9 480 393.51	204	7266	1114313	0.13	111 417.98	3	169
Inner Regional												
13	Lesmurdie–Bickley–Carmel	WA	2	0.37	219 991 095.83	21	3961	5114125	0.00	385 864.17	0	130
14	Goulburn	NSW	2	0.60	64 644 260.60	185	7411	1100125	0.60	9 219 031.38	0	161
15	Wodonga	VIC	2	0.89	278 809 991.40	92	6257	2107405	0.74	957 416.42	0	80
16	Tomerong–Wandandian–Woollamia	NSW	2	1.14	375 942 158.91	36	1319	1128110	0.94	16 049 084.33	3	162
17	Ulladulla Region	NSW	2	1.88	677 622 119.32	29	2338	1128313	1.51	56 185 123.80	0	117
18	Rockhampton Region-East	QLD	2	2.28	680 170 163.09	35	1094	3121802	2.44	352 559 355.71	6	74
								3121811	1.56	46 332 551.27	6	96
								Total		398 891 906.98	12	170
Outer Regional												
19	Whyalla	SA	3	2.55	40 871 748.87	219	6648	4113660	2.54	340 824.86	6	148
20	Geraldton	WA	3	2.73	21 228 754.27	328	4161	5121007	2.73	780 992.96	3	168
21	Wagaman	NT	3	3.00	837 954.92	39	438	7102802	3.00	191 459.54	14	80
22	Inverell	NSW	3	3.35	207 668 432.14	203	4049	1119127	3.13	518 178.45	15	154
23	Eden	NSW	3	3.71	94 814 149.25	68	1389	1102303	3.73	3 240 030.21	3	98
								1102310	3.73	1 062 545.60	0	5
								Total		4 302 575.81	3	103
24	Katanning Remote	WA	3	5.14	2 646 877 347.64	104	1343	5123013	4.67	558 965.56	10	113
25	Mount Isa	QLD	4	6.00	62 753 989.65	772	3229	3140541	6.00	182 476.25	6	81
								3140544	6.00	237 512.10	19	61
								Total		419 988.35	25	142
26	Daintree	QLD	4	6.27	2 230 932 070.87	244	1766	3116407	4.50	505 717.92	6	108

Table 3. (continued)

SA2 data		SA1 data										
Site no	SA2 name	State	RA [†]	ARIA+ [‡]	Area (m ²)	Tar_IP [§]	Tar_NP [¶]	SA1	ARIA+	Area (m ²)	Tar_IP	Tar_NP
27	Yorke Peninsula-South	SA	4	8.04	2 273 732 701.26	13	2099	4112813	7.37	168 306 923.25	0	86
28	South Hedland	WA	4	9.00	22 287 425.89	500	956	5122419	9.00	177 083.43	22	27
								5122422	9.00	226 979.06	14	41
								5122424	9.00	121 649.26	12	39
								Total		525 711.75	48	107
29	Very Remote	WA	5	13.28	134 986 003 299.42	87	1172	5119705	11.99	610 061.74	4	133
30	Exmouth	WA	5	14.33	110 883 574 518.85	1067	774	5120624	11.52	1 705 340.29	47	146
	Derby–West Kimberley											
	Backup sites ^{##}											
	Major Cities											
Backup 1	Willoughby-Castle Cove-Northbridge	NSW	1	0.00	10 751 553	18	7803					
Backup 2	Seventeen Mile Rocks-Sinnamon Park	QLD	1	0.00	5 389 722	21	2738					
Backup 3	Morphett Vale-East	SA	1	0.00	7 684 247	61	4485					
Backup 4	Ashwood-Chadstone	VIC	1	0.00	6 709 546	15	4618					
	Inner Regional											
Backup 5	Nambour	QLD	2	0.24	54 024 551	117	6113					
Backup 6	Warrnambool-South	VIC	2	1.56	120 194 041	34	4499					
	Outer Regional											
Backup 7	Rosebery-Bellamack	NT	3	3.00	3 176 364	36	336					
Backup 8	Dorrigo	NSW	3	4.23	1 987 708 554	38	1410	1108707	3.51	333 511.58	0	123
	Remote											
Backup 9	Banana	QLD	4	6.78	28 527 048 579	92	2668	3119425	3.18	213 021 792.17	0	100
								3119431	3.04	1 279 878.26	3	79
								Total		214 301 670.43	3	179
Backup 10	Very Remote	WA	5	11.12	55 408 257 147	22	1147					
	Esperance Region											

[†]The remoteness classification derived from the Australian Standard Geography Classification. [‡]The Australian Bureau of Statistics endorsed remoteness classification system in the Australian 2011 Census. Note that the ARIA+ score for the SA2 is the mean ARIA+ score of all constituent SA1s. [§]This corresponds to the number of Indigenous Australians aged 40 years and older residing in the SA according to the Australian 2011 Census. [¶]This corresponds to the number of non-Indigenous Australians aged 50 years and older residing in the SA according to the Australian 2011 Census. ^{||}All sites with two or more rows of SA1 data (Springfield, Craigie-Beldon, Rockhampton Region-East, Eden, Mount Isa and South Hedland) had two or more contiguous SA1s selected to provide a sufficient population size. ^{##}Backup sites were sampled to provide alternative recruitment sites in cases where any of the 30 core sites were unsuitable. Backup sites used were Morphett Vale (SA) (replaced Indigenous testing in Concord-Mortlake-Cabarita), Banana (QLD) (replaced both Indigenous and non-Indigenous testing in Mount Isa), Seventeen Mile Rocks-Sinnamon Park (QLD) (replaced Warilla) and Esperance Region (WA) (replaced both Indigenous and non-Indigenous testing in Derby-West Kimberley). Recruitment of Indigenous Australians from the randomly selected Major City site of Parklea-Kellyville Ridge was unachievable, and owing to logistical concerns, the remaining available Major City backup sites could not be utilized. Ashwood-Chadstone (VIC) was identified as containing insufficient eligible Indigenous residents, and communications with local Indigenous organizations in Willoughby-Castle Cove-Northbridge proved difficult. Consequently, Indigenous organizations were consulted to identify an area with comparable sociodemographic characteristics to be used as a backup site. Consequently, the suburb of Elizabeth Vale (SA) replaced Parklea-Kellyville Ridge. ARIA+, Accessibility/Remoteness Index of Australia Plus; NSW, New South Wales; QLD, Queensland; RA, Remoteness Area; SA, South Australia; SA1, Statistical Area Level 1; SA2, Statistical Area Level 2; Tar_IP, target Indigenous population; Tar_NP, target non-Indigenous population; VIC, Victoria; WA, Western Australia.

Table 4. Backup sites used in the National Eye Health Survey

Replaced site	Replacement site	Reason	Indigenous replacement	Non-Indigenous replacement
Concord–Mortlake–Cabarita (NSW)	Morphett Vale (SA)	Indigenous population size too small	Yes	No
Warilla (NSW)	Seventeen Mile Rocks–Sinnamon Park (QLD)	Declined by Indigenous organization	Yes	No
Mount Isa (QLD)	Banana (QLD)	Declined by Indigenous organization	Yes	Yes
Derby–West Kimberley (WA)	Esperance Region (WA)	Logistical constraints	Yes	Yes
Parklea–Kellyville Ridge (NSW)	Elizabeth Vale (SA)	Indigenous population size too small	Yes	No

NSW, New South Wales; QLD, Queensland; SA, South Australia; WA, West Australia.

used only for Indigenous sampling and recruitment, and the core sites were used for non-Indigenous sampling. Figure 1 displays all core sites sampled in the NEHS, including those that were unsuitable for recruitment, as well as the backup sites used.

Proximity of Indigenous and non-Indigenous clusters

Due to the sparseness of Australia's Indigenous population, all randomly selected SAIs contained insufficient numbers of eligible Indigenous residents. In these instances, the nearest Indigenous communities were selected as recruitment sites under the guidance of local Indigenous organizations at each site. Distances between randomly selected SAIs and areas

where Indigenous participants were recruited ranged from 1 (South Hedland) to 401 km (Exmouth), with the nearest Indigenous population in Onslow.

Study participants

A total of 23 235 residences were visited across all 30 sites from 11 March 2015 to 18 April 2016, of which 11 883 had contactable residents. A total of 6760 residents were enumerated as eligible to participate in the survey. Of these, 5764 agreed to participate (positive response rate of 85.27%) and 4836 (3098 non-Indigenous and 1738 Indigenous) attended testing centres and were examined (examination rate of 71.5%). Of the 3098 non-Indigenous participants recruited, 1253 (40.4%) resided in Major Cities, 636

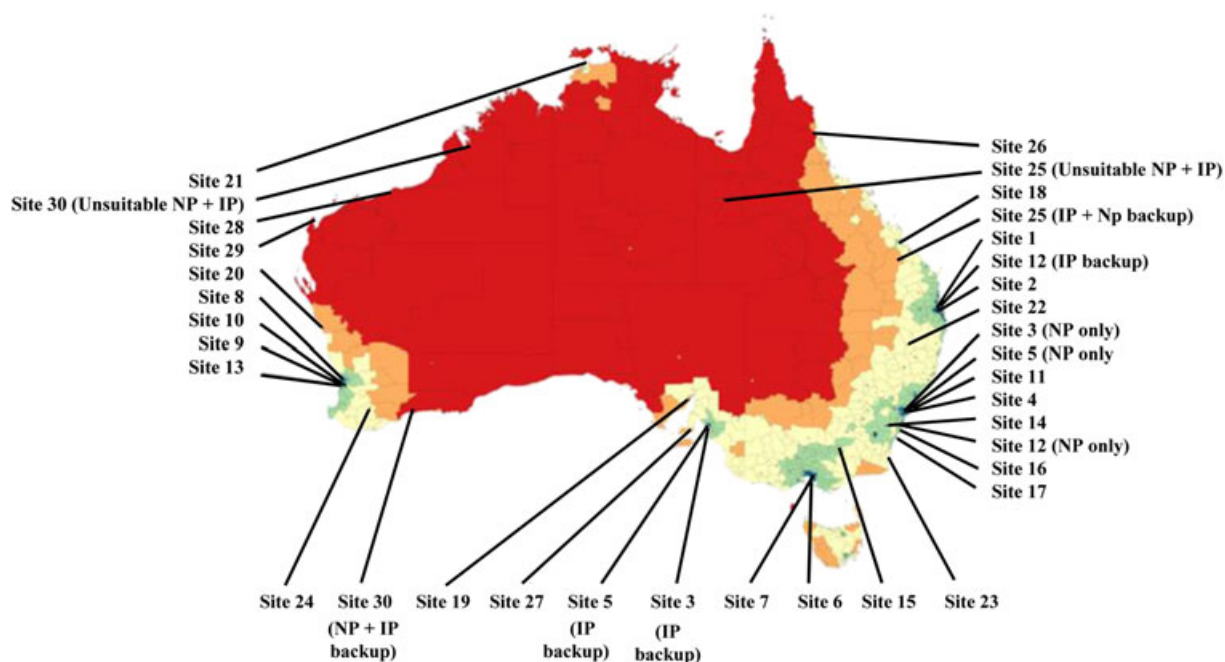


Figure 1. Distribution of sampled core survey sites and backup sites used across Remoteness Areas in the National Eye Health Survey. Boundary lines represent Statistical Area Level 2 boundaries. NP, non-Indigenous population; IP, Indigenous population.

(20.5%) in Inner Regional areas, 625 (20.2%) in Outer Regional areas, 367 (11.8%) in Remote areas and 217 (7.0%) in Very Remote areas. Indigenous participants were distributed across the Remoteness Areas as follows: 741 (42.6%) in Major Cities, 315 (18.1%) in Inner Regional, 405 (23.3%) in Outer Regional, 181 (10.4%) in Remote and 96 (5.5%) in Very Remote sites.

DISCUSSION

This paper describes the sampling methodology in the NEHS and provides details of the selected recruitment sites. The NEHS is the first cross-sectional population-based survey to provide nationally representative data on the prevalence and main causes of VI and blindness in Australia. Multistage random cluster sampling was used to select targeted SA1 recruitment sites, stratified by remoteness, to provide a sample of 3000 non-Indigenous Australians aged 50 years or older and 1400 Indigenous Australians aged 40 years and older. A total of 30 core sites and 10 backup sites were sampled across the ARIA+ spectrum in five states and one territory in Australia. Systematic and consistent site modifications were made where ABS data did not correspond to populations enumerated by survey recruiters or where Indigenous populations were too small in number or inaccessible. Trained recruiters successfully recruited 3098 non-Indigenous and 1738 Indigenous participants through a door-to-door approach, providing a high examination rate of 71.5%.

Nationwide representation

The NEHS was the first population-based eye study in Australia that achieved extensive geographic coverage of the national population, with sites being selected from multiple states and across all levels of remoteness. Previously, population-based surveys investigating the prevalence of VI and blindness in Australia did not generate nationally representative samples as they surveyed residents in only one state each.^{24,26} Many surveys conducted in other countries have also not provided nationally representative estimates of VI and blindness as they have collected samples from subnational geographic areas, such as provinces/states or districts,^{31–38} or collected samples at a national scale but with insufficient sample sizes.³⁹ Although many of these studies have not made claims of national representativeness,^{31–34} a considerable number have extrapolated their findings to national populations.^{35–40} This introduces the risk of uncontrolled population differences between subnationally sampled populations and the wider national populations they intend to represent. By including 1842 SA2s from almost all regions

within all states/territories in the sampling pool, the NEHS achieved national representation that compared favourably with other nationwide surveys.^{41,42}

Stratifying by remoteness

A distinguishing feature of the NEHS sampling methodology was the process by which remoteness was incorporated into the study design. The NEHS employed a robust procedure for stratifying sites by remoteness, ensuring that participants from all levels of remoteness in Australia were selected in proportions that reflected their distributions in the wider population. This is important as the prevalence of vision loss may vary between areas of different remoteness, owing to a lower availability of eye health-care services in more remote areas.⁴³ Although other studies have implemented some form of remoteness stratification,²⁸ most have considered remoteness as an urban–rural dichotomy.^{15,19,21} The majority of studies, both in Australia and globally, have not reported stratifying by remoteness at all,^{18,39,44–47} have only controlled for remoteness through design effect calculations or retrospectively adjusted for remoteness during analysis.^{14,20,41} The ARIA+ system used in the NEHS assigns a remoteness score to all SAs as a function of road distance to the nearest major service centre (including health service centres). Selecting sites from across the ARIA+ spectrum significantly reduced the risk of overall prevalence data being affected by bias associated with confounding effects of remoteness. It should be noted that random selection resulted in the majority of sites being situated in close proximity to the coast. Despite the NIEHS having reported no significant differences in the prevalence of vision impairment across remoteness strata, both inland and coastally, the Central Australian Ocular Health Study suggested that Indigenous Australians residing inland may suffer from particular high rates of eye disease such as trachoma.⁴⁸ Estimates of the prevalence of vision impairment for Australians residing in the coastal Very Remote sites in the NEHS may therefore be somewhat limited in their generalizability to inland Very Remote communities.

Multistage random cluster selection

Although simple random sampling is always preferred owing to the low variance and low bias in the resulting sample, the multistage random cluster method is ideal for national surveys given the cost, time and feasibility issues. Multistage sampling is associated with an increase in sample variance due to interclass correlations and the design effect, but the current study compensated for this in the sample size calculation. The remaining small increase in variance was outweighed by the reduction in sample size and

cost and time requirements, allowing results to be delivered timeously to inform policies in line with the Global Action Plan.²

Site modifications

Merging with contiguous SA1s

Merging contiguous SA1s with randomly selected SA1s was conducted in a systematic and consistent manner and proved indispensable in sample enumeration. Sample size calculations presumed a non-response rate of 20%, meaning that of all eligible residents enumerated in the 2011 Census, only 20% would not be recruited to the survey owing to both absenteeism and declining to participate. Although recruiters achieved a very low decline rate, non-eligibility and non-contactability were higher than expected. Consequently, as measured against the outdated ABS data, absolute recruitment rates were low. As only a 20% non-response was accounted for in determining required cluster sizes, the margin of error was insufficient to accommodate for unpredictable population parameters. Therefore, to ensure the recruitment of a sample size large enough to provide adequate statistical power, it was necessary to expand sites, introducing an element of selection bias. Future population-based surveys in Australia would benefit from using a larger cluster size than a single SA1, containing larger than required populations to allow for higher than expected non-response rates. Comparatively, Indigenous areas of up to four times the required sample were selected in the NIEHS.⁴⁹ Although this may not eliminate the problem of non-response bias, pre-emptively avoiding the need for recruiters to non-randomly select contiguous sites would remove selection bias. Furthermore, the fact that the Australian Statistical Geography Standard data used in NEHS site selection were outdated presents a risk of inaccuracy as population changes may have occurred since the completion of the Census in 2011. Selecting sites based on more current Census data may be beneficial, and future investigators may wish to conduct surveys soon after Census to maximize the accuracy of reference Census data.

Replacement of sites with low population density

Australia has the seventh lowest population density of any country, and the majority of its land is either uninhabited or contains sparse communities.⁵⁰ The exclusion of 255 low-density SA2s (12% of all SA2s) from the sampling frame attempted to generate a list of sites for which door-to-door recruitment was feasible. This process is reflected in previous national survey research in Australia.⁵¹ Despite these

constraints, the current study randomly sampled six sites with populations that were too inaccessible or sparse for recruitment. Replacement of these sites with accessible populations was imperative to ensure the completion of the survey within a specified timeframe.

Oversampling of Indigenous participants

Indigenous Australians have been shown to have poorer eye health than their non-Indigenous counterparts.⁵² Considering this, determining the prevalence of VI and blindness in Indigenous Australians was essential. However, as Indigenous Australians comprised only 2.27% of the target population, if they were sampled in this proportion, an insufficient sample size would have resulted. The survey was designed to provide a sample of 1400 Indigenous participants (31.81% of the total sample), resulting in significant oversampling. The sampling of Indigenous participants was similar to the NIEHS in terms of sample size and remoteness stratification. Therefore, the results of the NEHS can be directly compared with those of the NIEHS, providing follow-up data to ascertain the effectiveness of interventions implemented since that study was completed.

Consequences for sampling weights

As the NEHS intended to report the sampling-adjusted prevalence of VI and blindness, sampling weights from each site were required. However, post-sampling site adjustments resulted in the following consequences: (i) the population of the primary randomly selected SA1 reported by the ABS was insufficient to derive sampling weights, as contiguous areas with additional residents were merged with the SA1; (ii) owing to the differences between the Census and NEHS population numbers, ABS population data could not be used to calculate absolute response rates; and (iii) as some sites required replacement, the Census data pertaining to the original randomly selected SA1 could not be used. Consequently, the use of SA1-level population data provided by the 2011 Census would have significantly underrepresented or misrepresented the size of the actual population visited, enumerated and recruited. This was effectively dealt with by storing all addresses visited by recruiters on a database and overlaying them on maps with their SA boundaries. This allowed for more accurate sampling weights calculation, thereby providing a more reliable basis from which to derive sampling-adjusted prevalence.

In conclusion, the sampling methodology in the NEHS was comprehensive and used a well-designed, multistage random cluster sampling of 30 sites stratified by levels of remoteness across Australia. Minor

adjustments were made to the sampling protocol to overcome challenges resulting from Australia's geographic and population structures. Representative samples consisting of 3098 non-Indigenous Australians and 1738 Indigenous Australians were recruited and tested, providing the first national data on the prevalence of VI and blindness in Australia.

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3.3.2.2 Supplementary information on the sampling methodology

The sampling protocol of this study was complex and further clarification of certain methodological aspects is warranted. First, the protocol for initially selecting the 30 core SA2 clusters and the 10 backup SA2 clusters warrants elaboration. Second, it is also of interest to revisit and elaborate on the rationale behind how SA1s were selected, given the diversity of population densities across Australia. It is evident that it was not possible to develop a uniform methodology for recruiting participants at random from across the country. However, initial efforts to account for this were well considered. An explanation of how heterogeneity was accounted for is provided with example diagrams.

3.3.2.2.1 The first sampling stage

As stated in Publication 1, a listing of the 1842 SA2 geographical areas was assembled, in which the Census 2011 data were included, along with the average ARIA+ score assigned to each SA2. The SA2s were grouped by their RA. Within the RA group, SA2s were listed sequentially in ascending order of remoteness based on their ARIA+ score. An example of this listing is presented in Table 1 where a random extract of six SA2s is shown from the total list of 322 Outer Regional SA2s. The first SA2 in this list of six has an ARIA+ score of 3.00 and the last has an ARIA+ score of 3.02, indicating increasing remoteness as the list progresses. An additional data column provides the ‘progressive population’ (the cumulative number of persons going down the list) for the RA. For the last SA2 listed in each RA group, the progressive population value equals the total population of the RA. The size of the population in each SA2 varies.

Table 1. Extract of six Outer Regional Statistical Area Level-2 areas listed in order of geographic remoteness

Ascending remoteness →	Remoteness Area	ARIA+	SA2 Code	Target Indigenous population	Target non-Indigenous population	Total population	Progressive population
	Outer Regional	3.00	701021023	77	540	2,467	2,467
	Outer Regional	3.00	701021010	58	496	2,123	4,590
	Outer Regional	3.01	701021011	75	527	2,404	6,994
	Outer Regional	3.01	701021012	197	286	2,523	9,517
	Outer Regional	3.02	701021013	35	764	3,053	12,570
	Outer Regional	3.02	701021016	109	625	2,850	15,420

ARIA=Accessibility/Remoteness Index of Australia

SA2=Statistical Area – Level 2

A different total number of sites (core sites + backup sites) was required for each RA. For example, six core sites and two backup sites were required from the Inner regional RA. The cumulative total population in all SA2s in the RA was divided by the total number of required sites to provide equal ‘block sizes’ containing an equal number of persons within each block within each RA. For example, in Table 2, for the Outer Regional RA, the total population in all listed Outer Regional SA2s (n=2,042,319) was divided by 8 to generate eight symmetric blocks each containing a block size of 255,290 from which one site or cluster was picked.

Table 2. Summary population data from the 2011 Australian Census

Remoteness Area	SA2s	Target Indigenous Population	Target non-Indigenous population	Total population	Core sites	Selected sites	Block size
Major City	936	43,567	3,632,398	12,627,075	12	16	789,192.19
Inner Regional	464	30,706	1,456,275	4,214,982	6	8	526,873
Outer Regional	322	30,066	688,493	2,042,319	6	8	255,290
Remote	61	11,383	108,372	395,061	4	5	49,383
Very Remote	59	21,610	35,110	219,734	2	3	27,467

SA2 = Statistical Area – Level 2

As described in Publication 1, the random number function in Microsoft Excel (32-bit Version 14.0.7.128.5000) was used to create a seed value that was multiplied by the block size to provide the population selection value, n . A different random seed value was generated for each RA. The selection value, n , was the number that corresponded to the n^{th} person listed in the population within each of the blocks in that particular RA. The SA2 in which the n^{th} person

resided would be the selected SA2 in that block. This process was repeated for each block in each RA.

Figure 2 represents this process graphically using a simplified version of a RA. In this example, a simplified version of the Very Remote RA with only 18 SA2s containing a total of 62,982 residents is depicted (in reality there are 59 Very Remote RAs with a total population of 219,734, however in this example the population size is reduced for clarity of illustration). In this example, three Very Remote sites were required (2 core + 1 backup). The total Very Remote population of 62,982 was divided by 3 to provide three blocks of equal population sizes, each containing 20,994 persons. Importantly however, it did not follow that there would be an equal number of SA2s in each block, as each SA2 contains a different population size. If all SA2s had the same population size, each of the three blocks would contain six SA2s each with 3499 persons listed. The randomly generated selection value that selected the n^{th} person from each block would have an equal probability of selecting each SA2. However, as the SA2 population sizes differed, and the SA2 itself was not the unit of selection (in which case its population size would not affect its selection probability), but rather the person within the SA2 was the unit of selection, this created an unequal selection probability in each block, whereby SA2s with more persons were more likely to be selected. This is commonly referred to as probability proportional to size (PPS) sampling. Eye health surveys have previously utilised PPS sampling,^{96, 290, 291} however, the methods by which PPS sampling was conducted differed in many cases.

in their component SA1s range from 0 to 44, and their size and layout are highly irregular. In the first selection process, a single SA2 was randomly selected, which theoretically, could have been any of the red bordered areas in the diagram, as long as it fulfilled the minimum population size requirement. The distribution of the target population in the component SA1s within the selected SA2 determined the protocol for the next stage of selection.

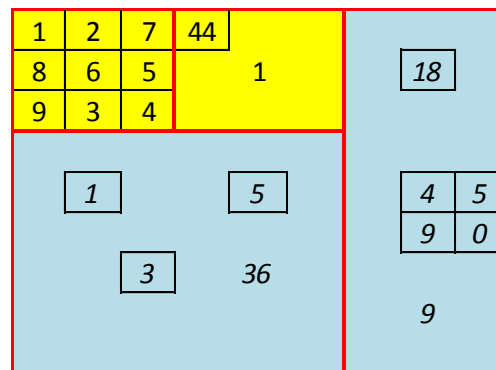


Figure 3. Simplified diagrammatic representation of a Statistical Area – Level 4 (SA4) in Australia. The SA4 contains heterogenous population distributions within its constituent SA3s (uniformly shaded areas), SA2s (red borders) and SA1s (black borders).

In this example, the required cluster size for targeted recruitment is nine people – in the NEHS, the actual required cluster size was 100 non-Indigenous Australians and 50 Indigenous Australians, however smaller numbers illustrate the problem more easily. If, as in this example, the required cluster size was nine, the area selected in the second sampling stage should ideally have contained as close to nine people from the target population as possible. However, many SA1s contained fewer than the required number of people, and depending on how the population was distributed, the selection methodology used to ensure that approximately nine people were sampled, differed. All four of the SA2s in Figure 3 above contain populations with different SA1 distributions, and therefore each represents a different challenge for sampling.

Figure 4A represents an ideal SA2 for randomly selecting a SA1 or cluster of contiguous SA1s containing the required nine residents. The total population of this SA2 is 45 and it is possible to group the component SA1s into 5 clusters that each contain the required cluster size of nine,

as indicated by the different shaded areas. In this case, it is possible to use a random number function to generate a value between 1 and 5 to nominate the required sampling area. This was most typically seen in Major City SA2s. This is the method that was attempted for all sites in this study, however, there were circumstances in which this method could not be applied.

For example, Figure 4B contains two SA1s - a small and dense SA1 with 44 people, and a large SA1 containing only one resident. The only possibility was to non-randomly select the geographically smaller SA1 with the large population. The ASGS did not provide the required population data at greater magnification than the SA1. Therefore, it was not possible to break this SA1 down into smaller units containing the required nine residents. Being unable to randomise a cluster within this type of SA2 introduced the risk of selection bias. This was most typically seen in Outer Regional areas.

Figure 4C presents another problematic population distribution. One of the SA1s contains zero people and would not be included in the sampling frame, while another SA1 contains the required nine people but is too sparsely populated to practically permit door-to-door recruitment. Therefore, the remaining three options are the single small SA1 with nine people (shaded yellow), the adjacent small SA1s containing four and five people which, when clustered, contain the required nine people, or the single SA1 containing 18 people. In this circumstance, one of these three would be randomly-sampled. This distribution was typically seen in Inner Regional areas.

Finally, Figure 4D illustrates the most problematic scenario. This SA2 consists of a few small SA1s with populations well below the required cluster size, while the remaining SA1 has a large enough population, but it is scattered over too large an area. In this type of scenario, any form of randomisation was impossible and local knowledge and practical considerations such as distance to the NEHS testing venue were used to nominate where the sample would be

obtained. In extreme cases, the neighbouring SA2 would be approached if the sample size was insufficient. This was most typically seen in the Remote and Very Remote areas. The 255 SA2s excluded from the original NEHS sampling frame, as described in the above publication contain large numbers of SA1s that had population distributions reflective of the red-shaded SA1 in this example. It was anticipated that enumeration of residents and participant recruitment would be impracticably slow, justifying their removal from the sampling frame. However, as illustrated by the finding that 20% of sites were still too sparse to permit practical recruitment, the sampling methodology might have benefitted from further refinement of the sampling pool to account for Australia's unusually sparse population.

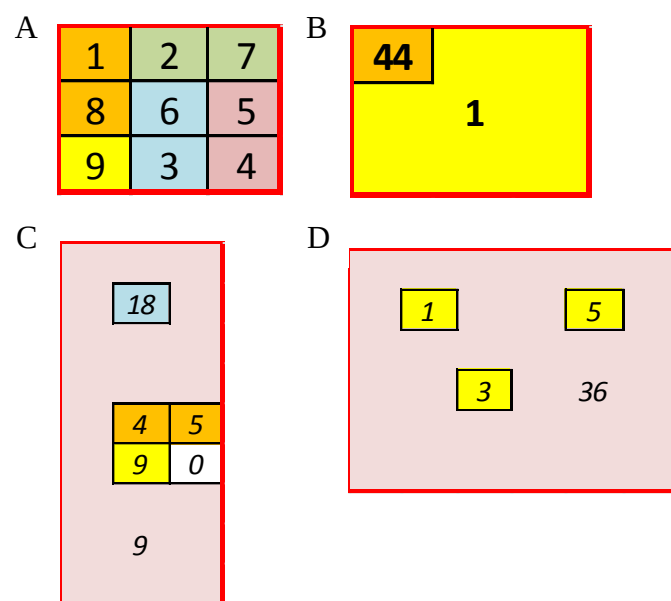


Figure 4. Different distributions of SA1s within SA2s. (A) Ideal SA2 that contains nine SA1s. Contiguous SA1s can easily be grouped to provide five clusters with the required nine residents, denoted by five coloured areas, from which one is randomly sampled. (B) SA2 containing two SA1s, of which one is small but contains more than the required population and one is large but does not contain enough to fulfil the required sample. The only option was to select the SA1 with the larger population. (C) SA2 containing one SA1 with no inhabitants and one SA1 with sufficient inhabitants that are too widely distributed. Neither would be considered for selection. The cluster would be randomly selected from the single SA1 containing 18, the small yellow SA1 containing nine, or the adjoining orange SA1s containing four and five people. (D) SA2 containing three SA1s with insufficient populations and one with a population that is too sparse.

3.4 Recruitment and testing methodology

3.4.1 Background of participant recruitment methods in eye health surveys

Following the sampling of participants for population surveys, investigators construct a recruitment methodology in which selected persons are contacted and invited to participate in the survey. Some studies utilise marketing, advertisements, social media, television and radio to inform and invite the public to participate, however these methods are non-selective and do not accommodate the sampling methodology employed in most surveys on vision loss, including the NEHS. Options for robust surveys are limited mostly to telephone contact, usually from phone books, electoral rolls or other community lists, as well as direct door-to-door recruitment, whereby survey staff visit the place of residence of selected individuals and engage them face-to-face.

Both the BMES and the VIP investigated whether telephone contact or door-to-door contact was the most effective recruitment method. Based on findings from its pilot study, the VIP reported that telephone contact resulted in a substantially poorer positive response rate (47%) than door-to-door recruitment (76%), and all subsequent participant recruitment was conducted through a systematic door-to-door approach.¹⁷⁵ The BMES recruited all participants door-to-door and then retrospectively searched the telephone directory and electoral roll to determine the proportion of recruited participants that were listed. It was found that the telephone directory listed only 82.2% and the electoral roll listed only 84.3% of participants.²⁹² Risk factor analysis revealed systematic non-response biases associated with these recruitment methods, with younger participants, those who did not own their own homes and those born outside of Australia being significantly less likely to be included in either sampling frame. The telephone directory was also more likely to exclude participants with higher occupational prestige, while the electoral roll was more likely to exclude unmarried participants and men.²⁹²

3.4.2 Participant recruitment in the National Eye Health Survey

Owing to its superiority over telephone recruitment, coupled with the lack of availability of telephone numbers in the ASGS database, it was determined that door-to-door recruitment would be utilised in the NEHS. The details of the standardised recruitment methodology are described in Publication 3 titled “Recruitment and testing protocol in the National Eye Health Survey: A population based eye study in Australia” (section 3.4.4.1), along with the clinical examination methodology, following an appraisal of clinical data collection methods used in previous surveys. (See Appendix D and Appendix E for methodological flowcharts illustrating the recruitment process).

In brief, a standardised script (Appendix F) was used to engage residents in each site, determine their eligibility, and invite them to participate in the survey. Residents who agreed to participate were provided with a recruitment pack that explained the study and contained participant instructions (Appendix G). Sociodemographic details and appointment details of each individual were recorded and uploaded onto a customised secure NEHS cloud-based database using a tablet computer (Samsung Galaxy Tab S 10.5, Samsung) (Appendix H). Due to the mobile nature of the survey, particularly during recruitment, Wi-Fi internet connectivity was inconsistent, and all tablet computers were consequently connected to a mobile data plan, allowing continual access to 3G or 4G mobile network coverage. Owing to the risks of data loss associated with disruption of mobile network connections, recruiters carried hardcopy recruitment forms to each recruitment site (Appendix I). During times of loss of connectivity, all data pertaining to the recruitment process were recorded on hardcopies and entered into the database when a reliable network connection was re-established.

3.4.3 Background of methods used to collect eye health data in population

surveys

This section provides a detailed account of the various methods used to collect eye health data in previous population-based surveys. Considering the significant heterogeneity between different surveys, and the vast array of available testing modalities, an appraisal of the different methods used is critical for framing the methodology that was designed to meet the specific objectives of this survey. First, the benefits and disadvantages of self-report questionnaires are discussed, followed by a publication (Publication 2) that demonstrates the unreliability of this method. Second, a description and appraisal of clinical eye examination methods in surveys is presented, with both rapid and comprehensive assessment methodologies being discussed. Following this discussion, section 3.4.4 presents the clinical examination methodology used in the NEHS.

3.4.3.1 Questionnaires and self-report

The use of clinical examinations in eye health surveys is always preferable to self-report questionnaires because they provide standardised data based on direct observation rather than potentially erroneous and biased participant recall.¹⁶⁷ However, clinical examinations in eye health surveys require expensive equipment and technical expertise that are not always available or affordable. In cases where clinical examinations cannot be performed, surveys have used self-report to determine the prevalence and causes of vision loss in populations. However, due to the unreliable nature of this data collection method, the use of self-report survey data to inform public policy for major health issues may result in insufficiencies in public health programmes. Examples of self-report surveys include government census surveys such as the National Health Surveys (NHS) and the National Survey of Disability, Ageing and Carers (NSDAC) in Australia, both of which are major sources of population data on eye disease used by the Australian Government to formulate eye health care policy.^{177, 274}

Typically, self-report surveys ask participants if they have problems with their vision and if they have ever been diagnosed with an eye disease. However, without corroborative standardised clinical examinations, it is impossible to know the reliability of these reports.

Robust surveys have revealed disagreement between self-report of eye disease and the results of clinical examinations, with between only 5% and 46% of those identified through examination as having a major blinding eye disease being aware of their condition.^{167, 168, 238} A Finnish national survey revealed that the correlation between self-reported visual ability and clinically measured visual function was only moderate ($r=0.27-0.40$).²⁹³ To date, the reliability of self-report as a measure of the prevalence of eye diseases has never been investigated in the context of a national eye health survey.

3.4.3.1.1 Publication 2: The validity of self-report of eye diseases in participants with vision loss in the National Eye Health Survey

To demonstrate the indispensability of clinical examinations in nationwide population-based eye health research, a publication is included below that reports the validity and reliability of self-report of eye diseases by participants with vision loss in the NEHS, by comparing self-report with the outcomes of the clinical eye tests used in this survey. To date, this paper represents the most robust statistical analysis on the reliability of self-report of eye diseases in population-based research, and includes kappa coefficients, sensitivity and specificity values, as well as positive predictive values (PPV) and negative predictive values (NPV). This paper provides strong evidence that, for the four major eye diseases, cataract, AMD, diabetic retinopathy and glaucoma, and across almost all measures of reliability, self-report is a highly unreliable research tool, and emphasises the importance of the inclusion of clinical examinations in field research. This paper was published in *Scientific reports* on the 18th of August 2017.

SCIENTIFIC REPORTS

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The validity of self-report of eye diseases in participants with vision loss in the National Eye Health Survey

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We assessed the validity and reliability of self-report of eye disease in participants with unilateral vision loss (presenting visual acuity worse than 6/12 in the worse eye and equal to or better than 6/12 in the better eye) or bilateral vision loss (presenting visual acuity worse than 6/12 in the better eye) in Australia's National Eye Health Survey. In total, 1738 Indigenous Australians and 3098 non-Indigenous Australians were sampled from 30 sites. Participants underwent a questionnaire and self-reported their eye disease histories. A clinical examination identified whether participants had cataract, age-related macular degeneration, diabetic retinopathy and glaucoma. For those identified as having unilateral or bilateral vision loss (438 Indigenous Australians and 709 non-Indigenous Australians), self-reports were compared with examination results using validity and reliability measures. Reliability was poor for all four diseases (Kappa 0.06 to 0.37). Measures of validity of self-report were variable, with generally high specificities (93.7% to 99.2%) in all diseases except for cataract (63.9 to 73.1%) and low sensitivities for all diseases (7.6% in Indigenous Australians with diabetic retinopathy to 44.1% of non-Indigenous Australians with cataract). This study suggests that self-report is an unreliable population-based research tool for identifying eye disease in those with vision loss.

Population-based health studies are indispensable to our understanding of the prevalence and causes of disease, and their findings often direct medical research priorities and inform evidenced-based policy on resource allocation¹. Generally, standardised clinical examinations in which all participants are subjected to the same testing protocol generate the most reliable data^{2,3}. However, logistical constraints and financial costs may render clinical examinations unfeasible, and a large proportion of surveys rely exclusively on participants' self-report to collect data on medical history, disease diagnosis, and other important health-related information⁴⁻⁶.

Research has repeatedly revealed disagreement between self-report of eye disease and the results of clinical examinations in surveys^{7,8}. Studies have attributed this poor awareness of personal eye disease to either a lack of previous diagnoses⁹, or inaccurate recall in those who have been diagnosed resulting from memory failure or poor eye health literacy^{8,10}. A number of surveys including the Beaver Dam Eye Study (BDES)⁸, the Wisconsin Epidemiologic Study of Diabetic Retinopathy (WESDR)¹¹, and the Los Angeles Latino Eye Study [LALES]^{7,9} have demonstrated poor reliability and validity of self-report for age-related macular degeneration (AMD), cataract, glaucoma and diabetic retinopathy (DR), with only 5% to 46% of those identified as having an eye disease, accurately self-reporting their disease. These conditions often require early detection, treatment and management to reduce the risk of vision loss¹². The notably low rates of disease awareness in these studies illustrates that the use of self-report under-estimates both the prevalence and disability weighting of eye diseases¹³, thereby reducing the effectiveness of such measures for resource allocation to reduce the burden of vision loss.

In Australia, self-report data collected by the Australian Bureau of Statistics (ABS) National Health Surveys (NHS) and the National Survey of Disability, Ageing and Carers (NSDAC) are major sources of population data on eye disease, and are used by the Australian Government to formulate eye healthcare policy^{14,15}. There is

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some evidence to suggest that self-report of eye diseases by both Indigenous Australians¹⁶ and non-Indigenous Australians^{17, 18} is unreliable. However, these studies did not conduct thorough agreement analyses and did not report sensitivity, specificity, kappa coefficients and predictive values, suggesting that a more comprehensive analysis is required. Furthermore, previous analyses often were limited to a single disease, had limited geographic or ethnic coverage, or did not investigate risk factors for poor reliability of self-report. Considering that self-report surveys continue to be cited as valuable sources of data in eye disease surveillance in Australia and elsewhere, further investigation of the reliability of this method is warranted.

The National Eye Health Survey (NEHS) collected the first nationally-representative data on the prevalence and causes of both unilateral and bilateral vision loss in Indigenous and non-Indigenous Australians, using both self-report and thorough clinical examinations. This paper assesses the reliability of self-report of major eye diseases in NEHS participants with unilateral or bilateral vision loss by comparing self-report with clinical diagnoses, and presents risk factors for inaccurate self-report. The findings of this study may provide insight into the validity of self-report surveys in Australia as well as the accuracy of current surveillance data on the burden of vision-threatening eye disease.

Materials and Methods

Study design and participant sampling. This study received ethical approval from the Royal Victorian Eye and Ear Hospital Human Research Ethics Committee (HREC-14/1199H) and state-based ethics bodies that govern research on Indigenous Australians. All procedures adhered to the tenets of the Declaration of Helsinki. The study design and sampling methodology of the NEHS have been described in detail and published elsewhere¹⁹. In brief, this study was a nationwide population-based survey that used multistage random-cluster sampling to select population clusters from all remoteness strata in Australia using 2011 Census data²⁰. Thirty clusters were selected in total, each containing approximately 50 Indigenous Australians aged 40 years and older and 100 non-Indigenous Australians aged 50 years and older. A younger age criterion was selected for Indigenous participants to reflect the earlier onset and more rapid progression of disease in this population¹⁴. Trained recruiters went door-to-door in each survey site to recruit participants to the study. Employed personnel and local staff from Aboriginal Medical Services (AMS) assisted in the recruitment of Indigenous Australians in each site.

Survey questionnaire. All study participants provided written informed consent. A standardised questionnaire was administered by trained interviewers. Interviewers slowly read out questions from a standardised questionnaire stored on mobile tablet computers, and input participants' verbal answers directly into the questionnaire to be uploaded to a cloud-based online database. The relevant questions were;

- (1) Personal particulars: name, gender (binary male or female), age and date of birth.
- (2) Ethnicity; country of birth, whether participants were of Aboriginal or Torres Strait Islander origin, and language spoken at home.
- (3) Educational attainment: highest level of education (9 item scale from Grade 0 = No education to Grade 8 = Undertaking/completed post graduate study), as well as number of years of education.
- (4) History of stroke (binary Yes/No)
- (5) Past ocular history: History of having eyes examined (binary Yes/No), time since last examination (months and years) and type of service provider visited (list of options included optometrist, ophthalmologist, local doctor, nurse, technician, other), history of being diagnosed with any of the following diseases; glaucoma, cataract, diabetic retinopathy, age-related macular degeneration (Yes/No/Unsure). Layman terminology was used to describe each disease if participants were unsure of their meaning. All points of ambiguity were clarified and participants were provided with an opportunity to ask any questions.

Clinical examination. The clinical examination protocol of the NEHS has been described in detail elsewhere²¹. In summary, a 30-minute examination that involved a series of standardised eye tests was conducted by trained examiners. Presenting distance visual acuity was assessed using a logMAR chart (Brien Holden Vision Institute, Australia) with each eye tested separately. Participants with either bilateral vision loss (presenting visual acuity worse than 6/12 in both eyes) or unilateral vision loss (presenting visual acuity worse than 6/12 in one eye) underwent handheld autorefraction (Nidek Co., LTD, Japan) in the affected eye(s) and best-corrected visual acuity was measured. Binocular near vision was assessed using a CERA Vision Test E Chart (Centre for Eye Research Australia, Australia). Slit-lamp examination was performed using a Keeler PSL One hand-held slit-lamp (Keeler Ophthalmic Instruments, UK). A Frequency Doubling Technology (FDT) perimeter (Zeiss Humphrey Systems & Welch Allyn, USA) was used to assess visual fields. Two 45-degree, colour fundus photographs were taken, centred on the optic disc and the macula, respectively, using a Digital Retinography System (DRS) non-mydratric fundus camera (CenterVue SpA, Italy). Tropicamide (0.5%) was used to induce mydriasis when image quality was reduced due to small pupil size, and photographs were taken again. The DRS camera was also used to take anterior segment photographs for those with vision loss in one or both eyes. Intraocular pressure was measured using a tonometer (iCare, Finland).

Identification of eye disease. The presence or absence of the major blinding eye diseases, cataract, AMD, DR and glaucoma were determined in participants with either unilateral or bilateral vision loss, regardless of whether any of these conditions were determined to be the primary cause of vision loss. Blinded retinal graders, an optometrist and ophthalmologists graded all retinal images using OpenClinica software (OpenClinica LLC and collaborators, Waltham, MA, USA) and eye diseases including AMD, DR and glaucoma were graded according to protocols that have been described in detail elsewhere^{22–24}. Anterior segment photographs and fundus

	Indigenous (n = 438)	Non-Indigenous (n = 709)
Mean years of age (SD) [†]	59.6 (10.5)	70.5 (10.1)
Mean years of education (SD)	10.1 (3.3)	11.8 (3.8)
	n (%)	n (%)
Gender (male)	184 (42.0)	368 (51.9)
English at home	413 (94.3)	659 (93.0)
<i>Ethnicity</i>		
Oceanian	438 (100.0)	476 (67.1)
European	0	179 (22.3)
Others	0	54 (7.6)
<i>Remoteness</i>		
Major City	163 (37.2)	290 (40.9)
Inner Regional	70 (16.0)	125 (17.6)
Outer Regional	131 (29.9)	150 (21.2)
Remote	39 (8.9)	94 (13.3)
Very Remote	35 (7.9)	50 (7.0)
<i>Years since last eye exam</i>		
≤1 year	228 (52.4)	412 (58.1)
1 <–≤ 2 years	72 (16.6)	143 (20.2)
2 <–≤ 5 years	64 (14.7)	81 (11.4)
>5 years or never	71 (16.3)	73 (10.3)

Table 1. Demographic characteristics of Indigenous and non-Indigenous Australians with unilateral or bilateral vision loss in the National Eye Health Survey. [†]Note the lower age limit for inclusion of Indigenous Australians than non-Indigenous Australians.

photographs were assessed to identify participants with cataracts. In cases where photographs were unavailable, cataracts were identified by using a hand-held slit-lamp.

Statistical analysis. Descriptive statistics including age, number of years of education (continuous variables), gender, language, country of birth, distribution in each remoteness stratum, and time since last eye examination (categorical variables) were calculated for Indigenous and non-Indigenous participants separately. Analyses were performed separately for: (1) those with unilateral vision loss; (2) those with bilateral vision loss and; (3) all those with unilateral and bilateral vision loss combined (the latter group hereafter referred to as *vision loss*). Vision loss was defined as presenting visual acuity worse than 6/12. Due to the stratification of our sample by Indigenous status, reliability and validity analyses were conducted separately for Indigenous and non-Indigenous participants. For each of the major diseases (cataract, DR, AMD, and glaucoma), the numbers of participants with vision loss who (1) correctly reported not having the condition (true negative); (2) incorrectly reported not having the condition (false negative); (3) correctly reported having the condition (true positive); and (4) incorrectly reported having the condition (false positive) were calculated. Reliability of self-report was calculated by deriving Cohen's Kappa coefficients (κ) and confidence intervals. Validity of self-report was quantified by determining sensitivity, specificity, positive predictive values (PPV), and negative predictive values (NPV) for each eye disease. Reliability and validity were ascertained for participants with unilateral vision loss and bilateral vision loss both separately and in combination.

Univariate and multivariable logistic regression analysis was conducted to identify risk factors associated with unawareness of disease by comparing false negative cases with true positive controls. Logistic regression was conducted for AMD, DR and cataract separately. Regression analysis could not be conducted for glaucoma due to insufficient sample sizes. Risk factors investigated in logistic regression included: age, gender, years of education, English spoken at home, Indigenous status, ethnicity of non-Indigenous participants (Oceanian, European, or Other), geographic remoteness, time since last eye examination (categories were ≤1 year, >1–2 years, >2–5 years, >5 years or never). Risk was expressed as odds ratio (OR) and 95% confidence intervals (CI). Analysis was performed by using Stata, version 14.2 (Stata Corp, College Station, TX).

Results

Demographic characteristics. In total, 1738 Indigenous Australians and 3098 non-Indigenous Australians were recruited and examined between the 11th of March 2015 and the 18th of April 2016 from all levels of geographic remoteness in Australia. Of these, 250 (14.4%) Indigenous Australians and 501 (16.2%) non-Indigenous Australians had unilateral vision loss, and a further 188 (10.8%) and 208 (6.7%) had bilateral vision loss, respectively (presenting visual acuity worse than 6/12). The sample of Indigenous Australians with vision loss had a mean [SD] age of 59.6 [10.5] years and 42% were male (Table 1). The mean [SD] age of non-Indigenous Australians with vision loss was 70.5 [10.1] years and 51.9% were male. More than half of participants in both groups reported having undergone an eye examination within the past year. Due to a combination of poor image

quality and missing data, the presence or absence of disease could not be determined for cataract in 19% of participants, AMD in 11% of participants and DR in 11% of participants.

Reliability and validity of self-report of eye disease in participants with vision loss. *Kappa coefficients.* With the exception of $\kappa = 0.75$ (moderate reliability) for glaucoma in Indigenous participants with unilateral vision loss, the reliability of self-report for all four diseases in both Indigenous and non-Indigenous Australians, with unilateral and bilateral vision loss, was poor ($\kappa = -0.09$ to 0.35 for cataract; 0.04 to 0.31 for AMD; 0.11 to 0.39 for DR; 0.20 to 0.35 for glaucoma) (Table 2).

The κ coefficients for cataract were similar for both Indigenous and non-Indigenous Australians (bilateral vision loss = -0.06 vs -0.09 and unilateral vision loss = 0.19 vs 0.20), however, κ for AMD was lower for Indigenous Australians (bilateral vision loss = 0.04 vs 0.31 and unilateral vision loss = 0.07 vs 0.19) while DR was higher for Indigenous Australians (bilateral vision loss = 0.39 vs 0.11 and unilateral vision loss = 0.34 vs 0.15). κ for glaucoma was higher for non-Indigenous Australians with bilateral vision loss (0.31 vs 0.20), but lower for non-Indigenous Australians with unilateral vision loss (0.75 vs 0.25).

Sensitivities and specificities. Sensitivities were almost uniformly low for all eye diseases, with the exception of three Indigenous participants with unilateral vision loss and glaucoma (100% sensitivity) (Table 2). Sensitivities for glaucoma (Indigenous Australians = 33% and non-Indigenous Australians = 52%) and cataract (Indigenous Australians = 33% and non-Indigenous Australians = 45%) were comparably poor. The lowest sensitivities were found for Indigenous Australians with AMD and non-Indigenous Australians with DR. Only 5.4% of bilaterally-impaired and 9.1% of unilaterally-impaired Indigenous Australians with AMD reported that they had the disease. Only 9.4% and 9.5% of non-Indigenous Australians with DR and bilateral or unilateral vision loss, respectively, were aware that they had the disease. Between 93% and 99.7% of participants who were clinically identified as not having AMD, DR and glaucoma correctly self-reported that they did not have each disease, suggesting high specificity for all three diseases. Conversely, specificity for cataract was variable, being low in those with bilateral vision loss (62% for Indigenous and 48% for non-Indigenous Australians), and moderately high in those with unilateral vision loss (88% and 85%, respectively).

Positive Predictive Values and Negative Predictive Values. PPVs for glaucoma were consistently low, with fewer than half (43%) of Indigenous and only one fifth (22%) of non-Indigenous Australians who reported having the disease being diagnosed with glaucoma in this study (Table 2). While PPVs were below 50% for cataract in those with bilateral vision loss, they were moderately high for both Indigenous and non-Indigenous participants with unilateral vision loss (PPV = 81% and 90%). Most Indigenous Australians who self-reported DR were confirmed to have the condition (PPV = 86%), which was considerably higher than 69% for non-Indigenous Australians. Approximately 40% of Indigenous Australians and 76% of non-Indigenous Australians who self-reported AMD were identified as having the condition. Between 93% and 100% of participants who self-reported that they did not have glaucoma were determined to not have the disease, while NPVs for both AMD and DR were lower, with 70–87% accurately reporting that they did not have each disease. NPVs were lowest for participants reporting that they did not have cataracts, with between only one third and one half of those reporting no history of cataracts being cataract-free.

Risk factors for unawareness of eye disease. Multivariable logistic regression revealed that non-Indigenous Australians were less likely to be aware that they had DR than their Indigenous counterparts (OR 0.25) (Table 3). Conversely, Indigenous Australians were at greater risk than non-Indigenous Australians of being unaware that they had cataracts (OR 1.56) and AMD (OR 3.64) in univariate analysis, but this association was not significant in multivariable analysis. Older age was associated with unawareness of AMD (OR 0.89/year) and cataract (0.95/year), but not of DR. Participants with cataracts were at significantly greater risk of being unaware of their cataracts if their last eye examination occurred more than one year earlier ($p < 0.001$ for all time categories measured). While time since last eye examination was not a statistically significant independent risk factor for unawareness of AMD ($p = 0.061$ for 1–2 years) and DR ($p = 0.067$ for more than 5 years) in multivariable analysis, univariate analysis suggested a significantly greater risk of disease unawareness with longer times since the last examination (ORs 3.10 for 2–5 years and 3.46 for 1–2 years compared to less than 1 year for AMD and 6.44 for 1–2 years and 11.11 for 5 or more years compared to less than 1 year for DR). For all three diseases, participants who had visited an ophthalmologist for their last eye examination were significantly more likely to be aware of their eye diseases than those who had visited an optometrist ($p = 0.002$ to $p < 0.001$).

Discussion

This paper examined the reliability and validity of self-report of eye disease in participants with vision loss in Australia's first National Eye Health Survey. To our knowledge, this is the first Australian study to conduct a thorough analysis on agreement between self-report and clinical diagnosis of the four major eye diseases, AMD, DR, cataract and glaucoma. Reliability of self-report was mostly poor for all eye diseases, in both Indigenous and non-Indigenous Australians, with both unilateral and bilateral vision loss. While measures of validity were variable, with mostly high disease specificities and moderate to high predictive values in some instances, the validity of self-report was generally shown to be poor. These results illustrate that self-report of major eye diseases, even in those with vision loss, is an unreliable indicator of the presence or absence of eye disease in the Australian population. The results of surveys such as the NHS and NSDAC that rely on self-report to determine the prevalence of eye disease should therefore be interpreted with great caution.

Sensitivity of self-report by both Indigenous and non-Indigenous Australians was consistently low for all diseases, with the exception of Indigenous Australians with unilateral vision loss and glaucoma. It should be

		True positive [†] n	False negative n	False positive n	True negative n	Kappa coefficient (95% CI)	Sensitivity (%) (95% CI)	Specificity (%) (95% CI)	PPV (%) (95% CI)	NPV (%) (95% CI)
Participants with bilateral vision loss (worse than 6/12) (n = 396)										
Indigenous	Cataract	29	60	38	61	−0.06 (−0.20, 0.08)	32.6 (23.0, 43.3)	61.6 (51.3, 71.2)	43.3 (31.2, 56.0)	50.4 (41.2, 59.6)
	AMD	2	35	3	115	0.04 (−0.07, 0.15)	5.4 (0.7, 18.2)	97.5 (92.7, 99.5)	40.0 (5.3, 85.3)	76.7 (69.1, 83.2)
	Diabetic retinopathy	19	33	3	101	0.39 (0.25, 0.54)	36.5 (23.6, 51.0)	97.1 (91.8, 99.4)	86.4 (65.1, 97.1)	75.4 (67.2, 82.4)
	Glaucoma	3	12	6	167	0.20 (−0.03, 0.44)	20.0 (4.33, 48.1)	96.5 (92.6, 98.7)	33.3 (7.5, 70.1)	93.3 (88.6, 96.5)
Non-Indigenous	Cataract	38	51	62	57	−0.09 (−0.23, −0.04)	42.7 (32.3, 53.6)	47.9 (38.7, 57.2)	38.0 (28.5, 48.3)	52.8 (42.9, 62.5)
	AMD	22	45	6	103	0.31 (0.18, 0.44)	32.8 (21.8, 45.4)	94.5 (88.4, 98)	78.6 (59.0, 91.7)	69.6 (61.5, 76.9)
	Diabetic retinopathy	3	29	3	135	0.11 (−0.04, 0.25)	9.4 (2.0, 25.0)	97.8 (93.8, 99.5)	50.0 (11.8, 88.2)	82.3 (75.6, 87.8)
	Glaucoma	5	7	11	185	0.31 (0.08, 0.55)	41.7 (15.2, 72.3)	94.4 (90.2, 97.2)	31.3 (11.0, 58.7)	96.4 (92.6, 98.5)
Participants with unilateral vision loss (worse than 6/12) (n = 751)										
Indigenous	Cataract	39	75	9	67	0.19 (0.09, 0.30)	34.2 (25.6, 43.7)	88.2 (78.7, 94.4)	81.3 (67.4, 91.1)	47.2 (38.8, 55.7)
	AMD	5	50	7	166	0.07 (−0.04, 0.18)	9.1 (3.0, 20.0)	96.0 (91.8, 98.4)	41.7 (15.2, 72.3)	76.9 (70.6, 82.3)
	Diabetic retinopathy	18	45	3	166	0.34 (0.21, 0.47)	28.6 (17.9, 41.3)	98.2 (94.9, 99.6)	85.7 (63.7, 97.0)	78.7 (72.5, 84.0)
	Glaucoma	3	0	2	245	0.75 (0.40, 1.00)	100 (29.2, 100.0)	99.2 (97.1, 99.9)	60.0 (14.7, 94.7)	100 (98.5, 100.0)
Non-Indigenous	Cataract	114	142	13	76	0.20 (0.13, 0.28)	44.5 (38.3, 50.8)	85.4 (76.3, 92.0)	89.8 (83.1, 94.4)	34.9 (28.6, 41.6)
	AMD	29	125	10	296	0.19 (0.11, 0.27)	18.8 (13.0, 25.9)	96.7 (94.1, 98.4)	74.4 (57.9, 87.0)	70.3 (65.7, 74.6)
	Diabetic retinopathy	6	57	1	394	0.15 (0.04, 0.26)	9.5 (3.6, 19.6)	99.7 (98.6, 100)	85.7 (42.1, 99.6)	87.4 (83.9, 90.3)
	Glaucoma	7	4	32	458	0.25 (0.09, 0.42)	63.6 (30.8, 89.1)	93.5 (90.9, 95.5)	17.9 (7.5, 33.5)	99.1 (97.8, 99.8)
Participants with either bilateral or unilateral vision loss (worse than 6/12) (n = 1147)										
Indigenous	Cataract	68	135	47	128	0.06 (−0.03, 0.15)	33.5 (27.0, 40.4)	73.1 (65.9, 79.6)	59.1 (49.6, 68.2)	48.7 (42.5, 54.9)
	AMD	7	85	10	281	0.06 (−0.02, 0.14)	7.6 (3.1, 15.1)	96.6 (93.8, 98.3)	41.2 (18.4, 67.1)	76.8 (72.1, 81.7)
	Diabetic retinopathy	37	78	6	267	0.37 (0.27, 0.46)	32.2 (23.8, 41.5)	97.8 (95.3, 99.2)	86.0 (72.1, 94.7)	77.4 (72.6, 81.7)
	Glaucoma	6	12	8	412	0.35 (0.13, 0.57)	33.3 (13.3, 59.0)	98.1 (96.3, 99.2)	42.9 (17.7, 71.1)	97.2 (95.1, 98.5)
Non-Indigenous	Cataract	152	193	75	133	0.07 (−0.003, 0.15)	44.1 (38.7, 49.5)	63.9 (57.0, 70.5)	67.0 (60.4, 73.0)	40.8 (35.4, 46.3)
	AMD	51	170	16	399	0.23 (0.16, 0.30)	23.1 (17.7, 29.2)	96.1 (93.8, 97.8)	76.1 (64.1, 85.7)	70.1 (66.2, 73.9)
	Diabetic retinopathy	9	86	4	529	0.14 (0.05, 0.22)	9.5 (4.4, 17.2)	99.2 (98.1, 99.8)	69.2 (38.6, 90.9)	86.0 (83.0, 88.7)
	Glaucoma	12	11	43	643	0.28 (0.14, 0.41)	52.2 (30.6, 73.2)	93.7 (91.6, 95.4)	21.8 (11.8, 35.0)	98.3 (97.0, 99.2)

Table 2. The reliability of self-report of four leading causes of vision loss by Indigenous and non-Indigenous Australians with vision loss [†]True positive: self-report = yes, examination = yes; False negative: self-report = no, examination = yes; False positive: self-report = yes, examination = no; True negative: self-report = no, examination = no 95% CI = 95% Confidence Interval. PPV = Positive Predictive Value. NPV = Negative predictive value. AMD = Age-related macular degeneration.

noted that the number of participants identified with glaucoma was significantly lower than for other diseases, and this small sample size necessitates cautious inference about the wider population. Nonetheless, as few as 8% of Indigenous Australians with AMD, 10% of non-Indigenous Australians with DR, and approximately one third of all participants with cataract were aware of their eye condition, illustrating that self-report of eye disease may dramatically under-estimate true disease prevalence in the population. While still low, the sensitivity for DR in Indigenous Australians (32%) was 3.5 times higher than for non-Indigenous Australians, and this difference was found to be highly significant in logistic regression ($p = 0.004$). With a PPV of 86%, Indigenous Australians who reported that they had DR were more likely to be correct than for all other eye diseases measured. Together, these results signify that increases in uptake of Indigenous Australians to DR screening services, as well as improvements in education and coordinated outreach initiatives to Indigenous communities may be modestly improving disease awareness in the Indigenous population^{25, 26}. Interestingly, higher sensitivities and PPVs for AMD in non-Indigenous Australians than their Indigenous counterparts may reflect better knowledge and literacy of the condition in this group, possibly reflecting the higher prevalence of AMD in the non-Indigenous population²⁷. As we did not have access to participants' medical records, it was not possible to ascertain the proportion of disease unawareness that was due to participants having never been diagnosed versus the proportion who had been diagnosed but failed to recall their eye diseases.

Specificity of self-report was consistently high (above 90%) for AMD, DR and glaucoma, suggesting that participants without each disease were generally able to report that they were disease-free. While high specificities are generally favourable, in this instance when considered in conjunction with very low sensitivities and low to moderate NPVs, these high specificities may result from a cognitive bias where the overwhelming proportion of individuals provide a 'no' self-report due to potential uncertainty, regardless of their true disease status²⁸. Conversely, self-report for cataract was characterised by higher sensitivities and lower specificities than the other diseases. This may reflect a propensity for older Australians with vision loss to more readily attribute their vision loss to cataract over other diseases, perhaps owing to cataract being a better-known and more common disease¹⁰.

As literature on the validity of self-report of eye disease is scarce, and existing studies employed different statistical measures or investigated population sub-groups that differed significantly from the present study^{7, 8, 11, 16},

Factor	AMD (n = 313)		Diabetic retinopathy (n = 210)		Cataract (n = 548)	
	OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p
Indigenous status			0.25 (0.10, 0.65)	0.004		
Age (year)	0.89 (0.84, 0.93)	<0.001			0.95 (0.93, 0.97)	<0.001
Time since last eye test						
≤1 year					1	
1 <– ≤ 2 years					2.62 (1.55, 4.42)	<0.001
2 <– ≤ 5 years					4.33 (2.27, 8.23)	<0.001
>5 years or never					28.96 (6.09, 137)	<0.001
Service provider last used						
Optometrist	1		1		1	
Ophthalmologist	0.32 (0.16, 0.64)	0.001	0.19 (0.08, 0.44)	<0.001	0.47 (0.30, 0.75)	0.002

Table 3. Independent risk factors associated with unawareness of eye disease by cause. OR = Odds ratio. AMD = Age-related macular degeneration Only risk factors that were shown to have independent statistically significant associations ($p < 0.05$) in multivariable logistic regression analysis are shown. Other factors tested included; gender, years of education, English spoken at home, ethnicity of non-Indigenous Australians, and geographic remoteness.

comparison between studies is difficult. The National Indigenous Eye Health Survey (NIEHS) reported PPVs for self-report of eye diseases in Indigenous Australians, ranging from 8.7% for AMD to 48% for cataract¹⁶, all of which were substantially lower than those in the present study, suggesting that improvements in eye health education in Indigenous communities in recent years may have slightly improved the ability of Indigenous Australians to correctly identify their eye diseases²⁹. Overall sensitivities for self-report of eye disease in the NEHS and the BDES were comparably low, with the BDES reporting sensitivities of 38% and 18% for cataract and AMD⁸, and the NEHS reporting sensitivities of 34% to 44% for cataract and 7.6% to 23% for AMD. Even though the BDES findings relate to all members of the study, the current study focused only on those with vision loss, and yet overall agreement as ascertained by κ was substantially lower in the NEHS (0.06 to 0.37) than in the BDES (0.50 to 0.78). The low sensitivity and high specificity of self-report of glaucoma in our study are similar to those of the Melbourne VIP, which was conducted more than twenty years ago¹⁸. However, as our sample included only those with vision loss, validity of self-report for glaucoma is likely to be even poorer in the general population, and therefore lower than that identified in the Melbourne VIP. The poor reliability of self-report in this Australian sample points either to poor eye health literacy or low rates of disease detection and necessitates an intensive public health campaign to increase awareness of eye diseases.

This paper identified risk factors associated with false negative self-reports of eye disease. Those examined more than five years ago were 29 times more likely to be unaware of their cataracts, strongly emphasising the importance of regular eye examinations. Considering that cataract is the second leading cause of reversible vision loss in Australia^{27, 30}, and that approximately two-thirds of participants were unaware of their cataracts, these individuals represent a substantial proportion of Australians with reversible vision loss. Improving self-awareness of disease status in these individuals through education and increased frequency of eye examinations may increase cataract extraction rates and reduce the prevalence of vision loss in Australia. Participants with DR, AMD and cataract who had visited an ophthalmologist were more likely to be aware of their diseases than those who had seen an optometrist, perhaps owing to the fact that those attending ophthalmology clinics may be more likely to have more advanced and symptomatic disease. Lack of disease awareness in those with early stage disease may be mitigated by increasing the frequency of eye examinations and improving referral pathways to ophthalmology services, consequently improving the timely treatment of disease³¹.

It is important to note that most of the risk factors measured, including gender, level of education, spoken language, ethnicity, and geographic remoteness, were not significantly associated with a greater risk of inaccurate self-report. Considered in conjunction with the almost uniformly poor reliability of self-report shown in other studies^{7, 8, 16, 18}, the inaccuracy across most sociodemographic variables in the NEHS, reaffirms that self-report is a universally unreliable measure of the prevalence of major eye diseases. However, the reliability of the risk factor analysis conducted in this survey is somewhat limited and must be considered with caution. Sociodemographic and eye healthcare utilisation data were obtained using self-report. As we have illustrated, the reliability of self-report of eye disease is unreliable, and we therefore cannot rule out inherent inaccuracies in other data collected using self-report. Another limitation of this study was that disease status could not be definitively determined for some participants (19% for cataract, 11% for AMD and 11% for DR). These individuals could not be included in the agreement analysis, and there is therefore a small but unquantifiable risk of over- or under-estimation of agreement between self-report and diagnosed eye disease in this study.

In conclusion, the generally poor reliability of self-report of eye diseases has significant implications for eye healthcare policy and disease surveillance based on this method of data collection. Our findings have demonstrated that, even in a population with vision loss, self-report of eye disease is highly inaccurate, and that surveys relying on self-report are unlikely to generate accurate or representative information on the prevalence of eye disease in the population. Population surveys aiming to collect accurate data on the prevalence of vision-threatening eye disease must include a standardised clinical eye examination protocol. Furthermore, individuals who are unaware of their eye diseases are at particularly high risk of vision loss⁹. Improving eye disease literacy and the frequency of eye examinations in older Australians may improve disease awareness and treatment, thereby reducing Australia's burden of vision impairment and blindness.

Data availability statement. The Royal Victorian Eye and Ear Hospital Human Research Ethics Committee and the numerous state-level Indigenous Ethics bodies have placed stringent ethical guidelines on the investigators of this study. Due to the risk of identifying participants, particularly in remote Indigenous communities, the authors are unable to make the dataset freely available. Interested researchers may contact the Principal Investigator, Dr. Mohamed Dirani, Head of Evaluative Research and Health Services, Centre for Eye Research Australia at mdirani@unimelb.edu.au to request access to the data.

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Author Contributions

J.F., S.K., P.v.W., H.R.T. and M.D. conceived the study design, planning and logistics. J.F., S.K. and M.D. collected data. J.F. and J.X. analysed data. All authors contributed to and reviewed the manuscript.

Additional Information

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3.4.3.1.2 Supplementary data on the reliability of self-report

Publication 2 analysed the reliability and validity of self-report of eye disease in those with vision loss, however, it did not discern the reliability of self-report of eye disease when that disease was the *main cause* of vision loss. Considering the centrality of the main cause of vision loss to the aims of this thesis, it is of interest to extend this analysis to determine the proportion of NEHS participants with vision loss who, when asked, were able to recall that they had the eye condition that was the main cause of their vision loss. Of those Indigenous Australians with vision loss attributed to one of the five main causes, 57.40% reported having not had that condition previously diagnosed (Table 3). Of non-Indigenous participants for whom vision loss was attributed to one of the five main causes, 51.93% reported to have not had that condition previously diagnosed. It is evident that self-report surveys are not sufficient to provide a valid and reliable estimate of the prevalence and causes of vision loss, and the cost and logistical impositions of clinical examinations are justified.

Table 3. Proportion of National Eye Health Survey participants with bilateral vision impairment who were able to accurately self-report that they had the eye condition that was determined through examination to be the main cause of their vision impairment

Eye condition	Indigenous Australians			Non-Indigenous Australians		
	No. with condition	No. true positive	True positive rate (%)	No. with condition	No. true positive	True positive rate (%)
Refractive error	116	64	55.2	124	79	63.7
Cataract	39	27	69.2	28	10	35.7
AMD	2	1	50.0	23	4	17.4
DR	11	4	36.4	3	1	33.3
Glaucoma	1	1	100	3	0	0
Total	169	97	57.4	181	94	51.9

AMD = age-related macular degeneration

DR = diabetic retinopathy

3.4.3.2 Clinical examination methodologies in eye health surveys

3.4.3.2.1 Defining vision impairment and blindness

VI and blindness are typically diagnosed on the basis of a person's visual acuity, which is a measure of the spatial resolution achieved by the visual processing system.²⁹⁴ Visual acuity is measured as the individual's ability to identify optotypes (letters or symbols) on a standardised chart from a specified viewing distance.²⁹⁵ Visual acuity may be measured relative to a reference 'normal' distance, often standardised at 6 metres or 20 feet. Conventionally, normal vision is defined as 6/6 (in metres) or 20/20 (in feet).²⁶ As the current study was conducted in a country that utilises the metric system, all subsequent visual acuities are described based on metres. Visual acuities may be expressed as the fraction 6/x, where the numerator 6 represents the distance between the individual and the vision chart, and the denominator x represents the distance at which an individual with normal vision (6/6) would be able to identify the same optotype that the viewer is able to discern at 6 metres. For example, a visual acuity measurement of 6/9 means that a person with 6/9 vision who is 6 metres from a chart sees what a person with unimpaired or normal (6/6) vision can see from 9 metres away.

The WHO and ICD-10 definition of bilateral VI (PVA<6/18-3/60 in the better eye) and bilateral blindness (PVA<3/60 in the better eye), and its associated sub-categories, including mild (<6/12-6/18), moderate (<6/18-6/60) and severe VI (<6/60-3/60) are commonly used in population surveys, particularly in developing countries.²⁶ The severity of blindness can be further categorised beyond the <3/60 level and includes the ability to count fingers, the ability to perceive light, and finally, no light perception.²⁹⁶ The United States and some other countries utilise different definitions, with VI defined as best-corrected visual acuity (BCVA) <6/12-/60 and blindness defined as BCVA <6/60.²⁷ Australian definitions of legal VI and blindness use the 6/12 and 6/60 thresholds, and recent Australian literature has defined VI as PVA<6/12-6/60 and blindness as PVA<6/60 in the better eye.²⁸

To facilitate comparisons with previous Australian literature (particularly the NIEHS) and to account for the legal driving threshold in Australia, this thesis defines bilateral VI as $PVA < 6/12-6/60$ and bilateral blindness as $PVA < 6/60$ in the better eye. Analyses in this thesis also utilise the term ‘vision loss’, defined as bilateral $PVA < 6/12$, and therefore includes all those with bilateral VI and bilateral blindness. Unilateral VI is defined as $PVA < 6/12-6/60$ in the worse eye and $PVA \geq 6/12$ in the better eye. Unilateral blindness is defined as $PVA < 6/60$ in the worse eye and $PVA \geq 6/12$ in the better eye, while unilateral vision loss includes all unilateral VI and all unilateral blindness ($PVA < 6/12$ in the worse eye and $\geq 6/12$ in the better eye). NVI is conventionally measured using a vision chart at 40cm or at the person’s preferred reading distance. NVI may be defined as an inability to read the N6 or N8 line.^{16, 229} This thesis defines NVI as the inability to distinguish optotypes at the N8 (20/50) level.

3.4.3.2.2 Rapid Assessment methodologies

Historically, the methodologies used in eye health surveys have varied in terms of sampling, recruitment and ocular examination protocols. Surveys have also differed in definitions of VI and blindness, diagnostic criteria for eye diseases and statistical analyses. Surveys on VI and blindness tend to be costly, time-consuming and complex undertakings. To simplify, homogenise and standardise surveys, the WHO conceived the Rapid Assessment of Cataract Surgical Services (RACSS) in 2001.²⁹⁷ This survey methodology was designed for population sub-groups aged 50 years and over, due to the fact that approximately 80% of vision loss occurs in this age group.²⁹⁷ As the vast majority of blindness in this age group was caused by cataract, the RACSS was principally designed to quantify the age- and sex-specific prevalence of vision loss caused by cataract as well as cataract surgical service availability. RACSS surveys used the WHO definition of VI ($BCVA < 6/18$) and blindness ($BCVA < 3/60$) and included visual acuity assessment with pinhole and lens examination by direct ophthalmoscopy, with provisions for more comprehensive examinations where resources permitted.²⁹⁷ RACSS was

particularly useful for surveys in low- and middle-income countries due to its relatively low cost and the ability to survey populations quickly (within as few as 20 days) and with minimal staff and equipment. Countries in which RACSS were successfully performed include Nigeria,²⁹⁸ Cameroon,²⁹⁹ Timor-Leste,¹⁴³ Papua New Guinea³⁰⁰ and Pakistan,³⁰¹ and these surveys provided unprecedented data on the epidemiology of vision loss in those communities.

More recently, in 2006, the Rapid Assessment of Avoidable Blindness (RAAB) was adopted as a modified and updated version of the RACSS.^{54, 302} Methodological improvements on the RACSS included the utilisation of the less biased compact segment sampling technique rather than the random walk technique used in the RACSS, as well as a more comprehensive eye examination (particularly with the later inclusion of the RAAB+DR ophthalmoscopy component that permitted the crude identification of DR as a cause of vision loss).³⁰³ The International Centre for Eye Health has generated an online RAAB Repository that lists the countries that have conducted RAAB surveys on the prevalence and causes of VI and blindness at the national, state and district level, and provides links to RAAB survey reports. At the time of writing, the RAAB Repository had 280 registered studies, illustrating that the RAAB methodology has been widely adopted worldwide.³⁰³ Countries that have used the RAAB to conduct nationwide surveys include (but are not limited to) Bhutan,¹⁰² Cambodia,³⁰⁴ Dominican Republic,³⁰⁵ El Salvador,³⁰⁶ Eritrea,³⁰⁷ Honduras,¹⁰⁵ Moldova,¹⁰¹ Panama,¹⁰⁵ Paraguay,³⁰⁸ Peru,³⁰⁹ The Gambia,³¹⁰ Turkmenistan,¹⁰⁷ Uruguay,³¹¹ Venezuela,³¹² Argentina,¹⁰⁵ Libya,¹⁰⁶ Papua New Guinea,³¹³ Qatar³¹⁴ and Suriname.¹⁰⁸ Numerous other countries have conducted RAAB surveys at the state or district level. With the results of RAAB surveys, many countries are now able to inform eye health policy and contribute to fulfilling the objectives of the Global Action Plan and their own domestic eye health policies.

RACSS and the RAAB surveys are undoubtedly beneficial, particularly in poorly-resourced developing countries, due to their standardisation and relatively low cost, however they have

limitations. First, the RACSS and RAAB methods are designed to collect representative samples from populations of between 0.5 million and 5 million people, typically corresponding to state or province-level populations in countries with large populations, rather than national populations.⁵⁴ Therefore, in countries with more than 5 million people, RAAB studies have unavoidably been conducted at sub-national scales and their findings are not as reliable as RAAB studies conducted in countries with smaller populations.

Secondly, as with most eye health surveys, Rapid Assessment methodologies do not incorporate provisions for sample stratification to account for heterogeneous populations. In most countries, populations have great variability in geographic remoteness, socioeconomic status, ethnicity and geographic distribution of eye health care services, all of which may contribute to variations in the prevalence and causes of vision loss across populations. Without the inclusion of some level of stratification, the RACSS and RAAB are unable to identify population sub-groups with the greatest need for improvements in services.

Finally, RAAB surveys are limited in their capacity to accurately attribute the causes of VI and blindness and determine the prevalence of eye diseases. While the simplified testing protocol is sufficient to identify most avoidable causes of blindness, the lack of inclusion of more comprehensive testing limits their capacity to identify other causes of vision loss and to diagnose disease. For example, the lack of thorough anterior segment examinations, fundus photography, perimetry or ocular tonometry⁵⁴ limit the ability of Rapid Assessment studies to attribute vision loss to posterior segment diseases as well as infectious causes of blindness such as trachoma and onchocerciasis which are still major causes of blindness in some parts of the world.^{1, 315} Although RAAB studies have been indispensable in collecting population-based eye health data worldwide, particularly in developing nations, due to these limitations, the NEHS did not use a RAAB methodology.

3.4.3.2.3 Comprehensive clinical examinations

Most surveys on the prevalence and causes of VI and blindness use rapid and simplified clinical examination methodologies, such as those used by the RAAB described above.^{54, 302} Typically, rapid assessment methodologies are adequate to identify major causes of avoidable blindness, such as uncorrected refractive error and cataract. However, surveys may have additional objectives, such as identifying unavoidable or irreversible causes of vision loss, including glaucoma and AMD. Other objectives may include determining the prevalence of ocular diseases and their subtypes, including DR, AMD, glaucoma, or other diseases not detectable with rapid screening modalities.^{316, 317} In such instances, more comprehensive ophthalmic examinations are required.

Studies that have employed comprehensive examinations include; the Aravind Comprehensive Eye Survey³¹⁷ and the Andhra Pradesh Eye Disease Study³¹⁸ in India; the Reykjavik Eye Study³¹⁹ in Iceland; the Yunnan Minority Eye Study³²⁰ and the Handan Eye Study³²¹ in China; the Meiktila Eye Study³²² in Myanmar; the Baltimore Eye Study¹⁷³ and Salisbury Eye Study³²³ in the United States; the Nigeria National Blindness and Visual Impairment Survey³²⁴ in Nigeria; and the BMES¹⁸⁹ and Melbourne VIP¹⁷⁵ in Australia.

Equipment and testing protocols differ in each comprehensive survey depending on logistical, budgetary and technological constraints. Some surveys have included lens photography to allow for diagnosis and classification of cataract subtypes.^{28, 325} Techniques used to diagnose glaucoma and ocular hypertension have included measurement of intraocular pressure, using various types of tonometers such as rebound or applanation tonometers^{324, 326, 327} and visual field assessment, using FDT^{228, 324, 328} or Humphrey Field Analyzer perimeters.^{317, 323} Studies have also used gonioscopy to assist in the diagnosis of glaucoma.^{316, 317, 322, 329} Many surveys have utilised stereoscopic or monoscopic fundus cameras (with or without pharmacological pupil dilatation), that provide the significant advantage of storing retinal photographs for later

comprehensive inspection and professional grading, thereby allowing for the diagnosis of an array of posterior segment diseases.^{175, 321, 330, 331} While retinal photography has become fairly common in population surveys to assist in disease diagnosis and attribution of the causes of vision loss, optical coherence tomography (OCT) has also been used, although very infrequently.^{286, 318} Other clinical assessments that have been used in surveys include corneal pachymetry, and a variety of slit-lamp examination protocols to examine the anterior segment of the eye for corneal thickness, anterior chamber depth, pterygia and other anterior pathology.^{223, 319, 324, 332, 333} Apart from thorough eye examinations, some surveys have included non-ophthalmic biometry measures in their protocols, including weight, height, blood pressure, and the collection of blood samples.^{317, 318}

Surveys that utilise comprehensive clinical examination methodologies require heavy, fragile and expensive equipment, and the amount of time required to examine each participant increases, and compounds dramatically over the course of the study, with each test added to the protocol. Therefore, comprehensive examinations create geographic, transport and time pressures, and often require specialist training. These studies tend to cover small geographic ranges,^{173, 181, 319} and attempt to answer specific epidemiological questions beyond determining the prevalence and causes of vision loss.³³³ Researchers investigating the prevalence and causes of VI and blindness in largescale national surveys, particularly where expansive geographic ranges are covered, such as in Australia, must select their clinical examination methods carefully by balancing financial, logistical, transport and time factors, while ensuring that the methods are sufficient to accurately address the study objectives.

3.4.4 The clinical examination in the National Eye Health Survey

3.4.4.1 Publication 3: Recruitment and testing protocol in the National Eye Health

Survey: A population based eye study in Australia

The NEHS clinical examination methodology was devised with consideration for all the above factors including consideration of the objectives of the study, as well as time, financial and transport implications. The standardised interviewer-administered questionnaire and eye examination methodology (as well as the recruitment methodology) are presented in detail below in the publication titled “Recruitment and testing protocol in the National Eye Health Survey: A population based eye study in Australia.” Further details of the methodology, including a full list of equipment, the consent form, and protocols for data input (both hardcopy and tablet-based clinical examination user interface), storage, and extraction are provided in Appendix J, Appendix K, Appendix L, Appendix M and Appendix N. As described in the publication below, all participants in this survey were provided with a certificate of participation (Appendix O), and a referral letter (Appendix P) to see a doctor or optometrist if pathology was detected according to a standard protocol (Appendix Q). Clinical data were used to determine the main cause of vision loss based on standardised protocols provided in Appendix R. This manuscript was published in *Ophthalmic Epidemiology* in March 2017.

ORIGINAL ARTICLE

Recruitment and Testing Protocol in the National Eye Health Survey: A Population-Based Eye Study in Australia

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ABSTRACT

Purpose: To present the recruitment and testing methodology of the National Eye Health Survey (NEHS), a population-based study that aimed to determine the prevalence and causes of vision impairment and blindness in Australia.

Methods: Non-Indigenous Australians aged 50 years and older and Indigenous Australians aged 40 years and older were recruited using a door-to-door approach from 30 randomly selected geographical areas, stratified by remoteness. Participants underwent a vision examination, anterior segment assessment, intraocular pressure testing, perimetry, and fundus photography.

Results: In total, recruiters approached 23,235 residences, and 11,883 residents were successfully contacted (51.1%). Of these, 6760 (56.9%) were deemed eligible and 5764 agreed to participate (positive response rate = 85.3%). Of those who agreed, 4836 residents attended the examination (4836/6760 = 71.5%). This included 1738 Indigenous Australians (41.1% male) aged 40–92 years (mean $\pm$ standard deviation = 55.0 $\pm$ 10.0 years) and 3098 non-Indigenous Australians (46.4% male), aged 50–98 years (mean $\pm$ standard deviation = 66.6 $\pm$ 9.7 years).

Conclusions: The NEHS achieved an excellent positive response rate, and the data collected from 4836 Australians will provide the first population-based national estimate of the prevalence of vision impairment and blindness. This data will guide future economic analysis, policy formulation, and eye health service delivery in Australia.

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Blindness; methodology; prevalence; survey; vision impairment

Introduction

The World Health Organization (WHO) estimated that 285 million people have vision impairment (VI) globally, of which 39 million are blind.¹ The “Universal Eye Health: a Global Action Plan 2014–2019” was endorsed at the 66th World Health Assembly (May, 2013) to reduce the prevalence of avoidable blindness globally by 25% by 2019.² The Global Action Plan emphasized the need for prevalence data for VI and blindness to inform future strategies aiming to reduce vision loss. As a signatory to this resolution, Australia requires up-to-date prevalence data on VI and blindness. The annual economic cost of vision loss in Australia of \$16.6 billion highlights the need for evidence-based eye health policies.³

There is a paucity of recent population-based data on the prevalence of VI and blindness in Australia. Two landmark studies, the Melbourne Visual Impairment Project (VIP)⁴ and the Blue Mountains Eye Study (BMES)⁵ conducted in the early 1990s, provided excellent insights into the prevalence of VI and blindness in

nine areas in metropolitan Melbourne, and two urban areas west of Sydney, respectively. Estimates based on the findings of these studies suggested that approximately 400,000 Australians had VI and 50,000 were blind, defined as having presenting visual acuity of $<6/12$ – $6/60$ and $<6/60$ in the better eye, respectively. Projections indicate these numbers will double by 2020.⁶ More recently, a nationwide study—the National Indigenous Eye Health Survey (NIEHS)—was conducted to assess the burden of VI and blindness in Indigenous Australian children and adults.⁷

The BMES and the VIP collected data at a sub-national level and since these studies were completed, there have been major population and disease risk changes, with a general population increase, the ageing of the population and a rise in the prevalence of diabetes-related risk factors.⁸ Since the completion of the NIEHS in 2008, a number of targeted eye health interventions have been implemented across Australia in an effort to close the gap between Indigenous and non-Indigenous eye health.⁹ Population-based research is

required to ascertain the impact of these strategies and to guide further interventions.

The National Eye Health Survey (NEHS) was conducted to provide national data on the prevalence of VI and blindness and to guide future economic analysis, policy formulation, and eye health service delivery in Australia. This paper describes the recruitment and clinical testing methodology of the NEHS and presents recruitment and fundus gradability results.

Materials and methods

Ethics approval

The protocol for this study was approved by the Royal Victorian Eye and Ear Hospital (RVEEH) Human Research Ethics Committee (HREC-14/1199H). Additional ethical approvals were obtained at the state level by the Aboriginal Health and Medical Research Council (AH&MRC) of New South Wales (HREC-1079/15), the Menzies School of Health Research (HREC-2015-2360), the Aboriginal Health Council of Western Australia (AHCWA) (HREC-622) and the Aboriginal Health Council of South Australia (AHCSA) (HREC-04-15-604). This research was conducted in accordance with the tenets of the Declaration of Helsinki.

Sampling

The sample size calculation assumed a similar prevalence of vision loss in non-Indigenous Australians to the pooled prevalence reported in the Melbourne VIP and the BMES of 5.2%⁶ and a prevalence of 17.2% in Indigenous Australians, as reported in the NIEHS.⁷ Assuming a margin of error of 1.1% for non-Indigenous Australians and 2% for Indigenous Australians, a design effect of 1.5 that adjusted for interclass correlations and a 20% non-response rate, the required sample size for the non-Indigenous and Indigenous populations was approximately 3000 and 1500, respectively. Based on this sample size, and an expected cluster of 100 non-Indigenous individuals and 50 Indigenous individuals in each site, 30 recruitment sites were required.

Multi-stage, random-cluster sampling was used to select all 30 geographic areas to provide a sample of 3000 non-Indigenous Australians aged 50 years and older and 1500 Indigenous Australians aged 40 years and older. The younger age inclusion criteria for Indigenous participants was chosen due to the earlier onset and more rapid progression of major eye diseases such as diabetic retinopathy in Indigenous Australians.¹⁰ The first stage of sampling involved selecting sites at the Statistical Area Level 2 (SA2), as defined in the

Australian Statistical Geography Standard developed by the Australian Bureau of Statistics (ABS) to report the 2011 Census data.¹¹ SA2 geographic areas correspond to population clusters of approximately 10,000 residents. SA2 clusters are composed of smaller SA1 geographic units, each of which contains 200–800 persons. Of the 2097 SA2s in Australia, 1842 were included in the sampling pool, while the remaining 255 SA2s were excluded due to insufficient population numbers.

SA2s were then stratified by remoteness according to the Accessibility/Remoteness Index of Australia Plus (ARIA+) into the five distinct Remoteness Areas (RAs), which are levels of remoteness defined by the road distance between the SA and the nearest major service centres.¹¹ In total, 12 Major City, six Inner Regional, six Outer Regional, four Remote and two Very Remote sites were selected, corresponding to the approximate distribution of populations within each RA. Within each selected SA2, a constituent SA1 or cluster of two to three Statistical Areas Level 1 (SA1s) containing approximately 100 eligible non-Indigenous Australians was selected and nominated as the recruitment site. Due to the sparseness of Indigenous populations, and possible inaccuracies in the Census data that were collected four years before commencing the survey, expansion of recruitment sites to the SA2 or SA3 (clusters of contiguous SA2s that have similar regional characteristics), level was required in all sites to obtain sufficient Indigenous sample sizes. In three Major City sites, one Remote site, and one Very Remote site, Indigenous residents were inaccessible to recruiters due to Indigenous communities declining to participate, insufficient population sizes or logistical constraints. In these instances, backup sites were utilized.

Participant recruitment

Household recruitment

Recruiters visited every house in each randomly selected SA1 from March 2015 to April 2016. Pamphlets outlining the study and a statement that recruiters would return to the residence within 2 days were left in each mailbox. Recruiters went door-to-door to recruit participants. Residents who were present were engaged by recruiters using a standardized script and screened for eligibility based on the inclusion criteria of being Indigenous and aged 40 years and over, or non-Indigenous and aged 50 years and over, and living at the residence at the time of recruitment. In cases where residents were absent, recruiters returned within 2 days to re-attempt contact. Residents who were not present following two attempts were deemed non-contactable. Due to a number of factors, including (1) inaccuracies in the available Census

data; (2) low eligibility rates; (3) low population densities; (4) high absenteeism rates; and (5) inaccessibility of target residences, all randomly selected SA1s contained insufficient population numbers. Consequently, when the SA1 was exhausted, recruiters visited contiguous SA1s until 100 participants were recruited. A total of two Major City sites, three Inner regional sites and one Outer Regional site required expansion into an adjacent SA2 site. The level of remoteness of adjacent SA1s and SA2s was always consistent with the originally nominated SA1.

Eligible residents were invited to participate, and those who agreed were provided with an appointment card containing their appointment date, time and venue, and a recruitment pack that consisted of an information booklet, abbreviated testing protocol, and instructions. Socio-demographic information (post-code, age, gender, and date of birth) and contact details were recorded on an online tablet-based database. Individuals who were undecided at the point of recruitment ("Maybe" response) were provided with a recruitment pack and their details were recorded. Where possible, NEHS staff made a tentative appointment followed by a phone call to determine the resident's final response. If a negative response was initially received, recruiters assisted the residents in addressing their concerns and obtained reasons for refusals if objection handling was unsuccessful.

Additional modes of recruitment

Although the primary recruitment methodology involved a door-to-door approach, the recruitment of Indigenous Australians included some modifications to be culturally sensitive and to account for the diversity of local conditions. Further, as Indigenous Australians comprise approximately 2.27% of the target Australian population, relying entirely on door-to-door recruitment was deemed inefficient (Table 1). Collaboration with community elders and local health workers at each site therefore facilitated community acceptance of the survey and assisted recruitment. Alternative methods of recruitment included telephone recruitment from community lists, word of mouth, media and public relations, and recruitment from concurrent Aboriginal Health Service clinics. Telephone recruitment from community lists and recruitment from concurrent Aboriginal Health Service clinics were the most effective modes of recruitment for Indigenous participants.

Reminder calls, text messages, and follow up

To optimize clinical attendance, each individual who agreed to participate was contacted one day prior to their appointment to remind them to attend. Individuals who provided a landline telephone number

were contacted through phone calls, while those who provided mobile telephone numbers were sent an automated text message using 5centsms.com.au. Individuals who failed to attend (FTA) were contacted by phone and encouraged to reschedule. The recruitment coordinator visited the homes of residents who did not answer after three attempts to encourage them to reschedule. If residents were not contactable through this process, they were deemed to have FTA.

Participant questionnaire and testing protocol

Clinical examinations took place in a venue that was within 6 km of the target SA1. Testing venues included community centers, schools, Aboriginal corporations, function centers, land councils, medical clinics, mobile clinics, and town halls. Testing in each site was conducted over 3–8 days. On average, approximately 25 participants attended daily. Participants provided informed consent, following which they underwent a general questionnaire and a series of eye tests. All tests were conducted by orthoptists, optometrists, ophthalmologists or research assistants who were thoroughly trained under a standardized training protocol in all procedures under the supervision of an orthoptist or optometrist. Verbal feedback about test results was provided and participants received referrals to an optometrist or local doctor if abnormalities were detected. The testing protocol took approximately 30 minutes per participant.

Interviewer-administered general questionnaire

Each participant underwent an interviewer-administered questionnaire that collected information about participants' ethnicity (including Indigenous/non-Indigenous status), educational attainment, and history of ocular problems, stroke and diabetes.

Vision Assessment

Presenting distance visual acuity

Presenting distance visual acuity (VA) was assessed using a logMAR chart (Brien Holden Vision Institute, Australia) in well-lit room conditions. Distance refractive correction was worn for those who attended with distance spectacles or contact lenses. VA was assessed first for the right eye and then the left. Light perception was assessed using a pen torch for participants who could not discern the 6/60 letters. VI was defined as a presenting VA of <6/12–6/60, while blindness was defined as a presenting VA <6/60.

Table 1. Population data, positive response rates, and examination rates, for recruitment of Indigenous and non-Indigenous participants by Remoteness Area.

Remoteness Area	SA2s	Selected sites	Target population	Indigenous Australians			Non-Indigenous Australians						
				Number of participants	Positive response rate ^a (%)	<i>p</i> [*]	Examination rate ^b (%)	<i>p</i>	Target population	Number of participants	Positive response rate (%)	Examination rate (%)	<i>p</i>
Major City	936	12	43,567	746	91.2	0.47	73.7	0.09	3,632,398	1253	77.7	62.7	0.004
Inner Regional	464	6	30,706	310	89.1		83.6		1,456,275	636	83.3	68.2	
Outer Regional	322	6	30,066	405	89.6		76.6		688,493	625	85.0	72.6	
Remote	61	4	11,383	181	93.5		83.4		108,372	367	89.3	75.5	
Very Remote	59	2	21,610	96	93.8		85.7		35,110	217	96.3	89.3	
SA2s not included ^c	255		2423						624,115				
Total target population ^d	2097		139,755						6,544,763				

^{*}*p*-values based on Kruskal-Wallis test (non-normally distributed variables) or one-way ANOVA (normally distributed variables) to test whether positive response rates and examination rates differed between Remoteness Areas. Statistical significance was set at $p < 0.05$.

^aThe positive response rate is calculated as the proportion of eligible residents who agree to participate at the point of recruitment.

^bThe examination rate is calculated as the proportion of eligible residents, as determined at the time of recruitment, who undergo the general questionnaire and the eye examination.

^cA total of 255 SA2s were excluded from the sampling pool due to insufficient population numbers.

^dTarget population is Indigenous Australians aged 40 years and older and non-Indigenous Australians aged 50 years and older.

SA2: Statistical Area-Level 2.

Pinhole visual acuity

If presenting VA was worse than 6/12 in one or both eyes, a pinhole test was performed using a multiple pinhole occluder to determine whether refractive error was the likely cause. If VA improved with pinhole testing to $\geq 6/12$, then auto-refraction was performed.

Auto-refraction

Auto-refraction was performed using a Nidek ARK-30 Type-R Hand-held auto-refractor/keratometer (Nidek Co., Ltd, Tokyo, Japan) to objectively measure refractive error of participants whose VA improved with pinhole to $\geq 6/12$. Measurements of refraction were taken and the corresponding spherical and/or cylindrical lenses were placed in a trial frame, and the distance VA protocol was repeated to ascertain auto-refraction-corrected visual acuity.

Presenting near vision

Presenting near vision was assessed in well-lit conditions using the CERA E near vision card (Centre for Eye Research Australia, Melbourne, Australia). Refractive correction was worn during VA testing in those attending with reading spectacles. Near vision was recorded as the smallest line at which the participant correctly identified the direction of at least 3 of the 4 E optotypes.

Anterior segment assessment

Anterior segment assessment of both eyes was conducted using a Keeler PSL One hand-held slit lamp (Keeler Ophthalmic Instruments, Berkshire, UK) at 10 $\times$ magnification for the presence of pterygium and lid abnormalities. Trachoma grading was conducted in Indigenous Australians using the WHO Trachoma Simplified Grading System.¹² Participants with presenting distance VA of $< 6/12$ in one or both eyes had anterior segment photographs taken using a non-mydriatic Diabetic Retinopathy Screening¹³ camera (CenterVue SpA, Padova, Italy). These photographs were used for the grading of cataract,¹⁴ trachoma and other anterior segment pathology.

Visual field assessment

Frequency Doubling Technology (FDT) perimetry (Zeiss Humphrey Systems & Welch Allyn, Dublin, CA, USA) was used to assess visual fields. The N-30-5 screening protocol was used due to its high sensitivity and specificity for detecting glaucomatous field loss and its short testing time (approximately one minute per eye).¹⁵ Participants wore their distance correction if applicable. If the sensitivity was reduced in any of the tested field locations, the test was repeated to determine

the reproducibility of the defect and the best result was graded.

Fundus photography

Two-field, 45° colour fundus photography was performed using a DRS non-mydriatic fundus camera to assess the retina and the optic disc. This was done in a darkened room to allow for pupil dilation and the DRS was programmed to automatically take two photographs of each retina, centred on the optic disc and the macula, respectively. On-site quality checks of photographs were conducted to ensure that the optic disc, macula and surrounding vessels were clearly identifiable. Photographs of reduced quality were taken again without the use of dilating drops if pupil size was sufficiently large (≥ 3.0 mm). If the pupil was small, tropicamide 0.5% was instilled to induce dilation, and photographs were taken. Dilation was used in 13.7% (663/4836) of cases. In order to minimize the risk of inducing anterior chamber angle closure associated with the use of tropicamide, participants requiring dilation underwent Van Herick grading using the hand-held slit lamp to estimate the anterior chamber angle depth.¹⁶ Dilation was not performed where the angle was graded as 1 or 2.

Intraocular pressure

Intraocular pressure (IOP) was measured in both eyes using the iCare tonometer (iCare, Finland). Six consecutive readings were taken, and the average IOP was recorded.

Feedback and recommendation for referral

At the completion of the examination, participants were provided with verbal feedback on the health of their eyes. A strict referral protocol was developed so that when pathology was identified or suspected, participants were provided with a standard referral letter to their local doctor or optometrist outlining the abnormal findings. All participants were provided with a certificate of participation and a free pair of sunglasses.

Grading of ocular pathology

De-identified retinal images were transferred to the retinal graders at CERA. Images were 24-bit colour depth and displayed at a resolution of 5.04 megapixels. Images were converted to JPEG files of approximately 1.2 to 1.8 megabytes in size and stored on a password encrypted external hard drive. OpenClinica software

(OpenClinica LLC and collaborators, Waltham, MA, USA) was used for all retinal grading.

Image quality was assessed by an independent expert grader. Quality grades for each eye were as follows: (1) good quality: both macula-centred and optic disc-centred fields well positioned with good focus (blood vessels and small lesions such as retinal microaneurysms clearly identifiable) and good illumination (no or minimal shadowing across the central part of the image);¹⁷ moderate quality: both fields were present, however, clarity or illumination is decreased in one image (only); (3) poor quality: one field missing or both fields are difficult to grade with certainty; and (4) ungradable: the eye has obscuration of most, or all of the available fields. For an eye to be deemed fully gradable, both macula-centered and optic disc-centered images were required to be of good quality. Eyes were deemed partially gradable when one or both fields were of moderate or poor quality.

Trained retinal graders masked to the identity and clinical characteristics of study participants graded all images. Diabetic retinopathy, age-related macular degeneration and glaucoma were graded according to protocols that have been described in detail elsewhere.^{13,18,19} An ophthalmologist provided weekly adjudication on cases flagged by retinal graders as requiring clarification. Other pathology was noted.

Database and quality assurance

All data were entered into a specialized password-protected online cloud-based database using tablet computers. Each participant was allocated a unique identification code to maintain confidentiality. A checklist was completed for each participant by the examiner to ensure that all data were complete and valid. The data were only accessible to key researchers.

Statistical analysis

Statistical analyses were performed with SPSS (version 24; Chicago, IL, USA). A p -value of 0.05 was used for significance testing. Descriptive statistics were calculated and normality was tested using Kolmogorov-Smirnov or Shapiro-Wilk significance statistic.

Comparisons of positive response and examination rates were performed between RAs using the one-way ANOVA for normally distributed data and the Kruskal-Wallis test for non-parametric data. Spearman rank order correlation was used to test correlations between positive response and examination rates (continuous) and RAs (ordinal). Independent sample t -tests were

utilized to compare positive response and examination rates as well as mean educational attainment between Indigenous and non-Indigenous participants.

Results

Overall positive response and examination rates

A total of 23,235 residences were visited across 30 NEHS sites in five States and one Territory in Australia. Recruitment and examination of all participants occurred over 13 months (11 March 2015–18 April 2016). In all, 11,883 (51.1%) residents were present at the time of recruitment, of which 6760 (56.9%) were eligible to participate. A total of 5764 initially agreed to participate, 127 said “maybe” and 886 declined. Upon follow-up, 17 residents who had responded as “maybe” agreed to participate, giving a total positive response rate of 85.3% (5764/6760). Of these, 4836 residents underwent examinations, resulting in an attendance rate of 83.9% (4836/5764) and a clinical examination rate of 71.5% (4836/6760). The two major reasons for which residents declined to participate were that they were not interested (26.1%) or that they had had a recent eye test (16.7%).

Positive response and examination rates of the target non-Indigenous population

A total of 4520 non-Indigenous residents were identified as eligible at the time of recruitment, of whom 3729 agreed to participate, giving a positive response rate of 82.5%. Of these, 3098 attended and were examined, resulting in an attendance rate of 83.1% (3098/3729) and an examination rate of 68.5% (3098/4520) (Figure 1).

Positive response and examination rates of the target Indigenous population

In total, 2240 eligible Indigenous residents were identified, and 2035 (90.8%) agreed to participate. Of these, 1738 attended and were examined, resulting in a clinical attendance rate of 85.4% (1738/2035) and an examination rate of 77.6% (1738/2240) (Figure 2). The positive response rate was significantly higher in the Indigenous population (mean [SD] = 90.8% [6.5]) when compared to the non-Indigenous population (mean [SD] = 82.5% [9.7]; $p < 0.0001$). Similarly, the examination rate was significantly higher in the Indigenous population (mean [SD] = 77.6% [10.7]) when compared to the non-Indigenous population (mean [SD] = 68.5% [10.3]; $p < 0.0001$).

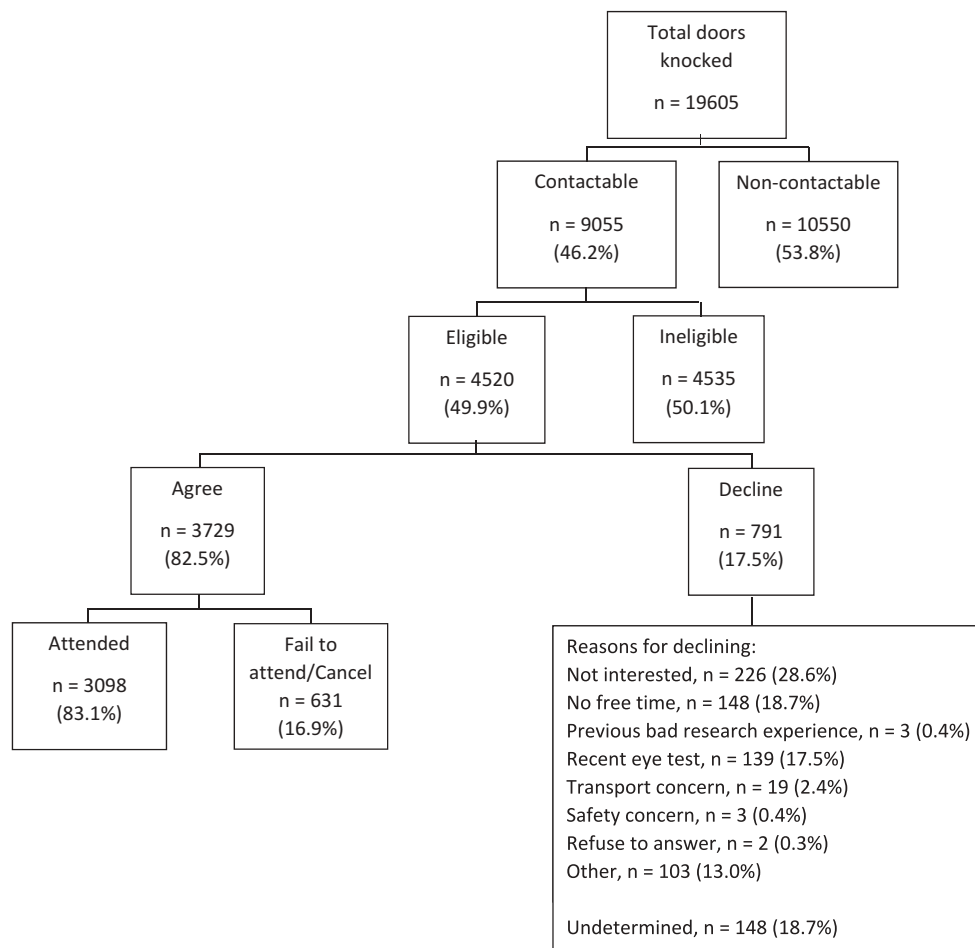


Figure 1. Recruitment statistics of the target non-Indigenous population in the NEHS.

Positive response and examination rates by Remoteness Area

Indigenous positive response rates did not vary significantly amongst RAs ($p = 0.473$) (Table 1). For the non-Indigenous population on the other hand, a significant difference was found between positive response rates among the RAs ($p = 0.011$). Examination rates varied significantly between RAs for the non-Indigenous population ($p = 0.004$), but not for the Indigenous population ($p = 0.09$). Increasing level of remoteness was correlated with higher positive response rates ($r = 0.622$, $p = <0.0001$) and higher examination rates ($r = 0.602$, $p = <0.0001$) in non-Indigenous Australians. Conversely, positive response ($p = 0.60$) and examination rates ($p = 0.17$) were not correlated with RAs in Indigenous Australians.

Key demographics

Of the total sample, 3098 (64.1%) were non-Indigenous and 1738 (35.9%) were Indigenous Australians. The

mean age for non-Indigenous participants and Indigenous participants was 66.6 years ($SD \pm 9.7$; range 50–98 years) and 55.0 years ($SD \pm 10.0$; range 40–92 years), respectively. The mean years of educational attainment were significantly higher in non-Indigenous participants (mean [SD] = 12.5 [3.7] years) compared to their Indigenous counterparts (mean [SD] = 11.0 [3.3] years, $p < 0.001$).

Retinal image quality

Almost all participants had at least one gradable fundus image (4692/4836) (97%). Both macula- and optic disc-centred images were fully gradable in both eyes for 33.3% (1612/4836) of the participants. Images of both fields were fully gradable in one eye and partially or not gradable in the other eye in 26% (1255/4836) of participants. Images were partially gradable for both eyes in 34.2% (1655/4836) of participants and only one eye in 3.5% (170/4836) of participants, respectively. Overall, 1.2% (59/4836) of participants had ungradable images

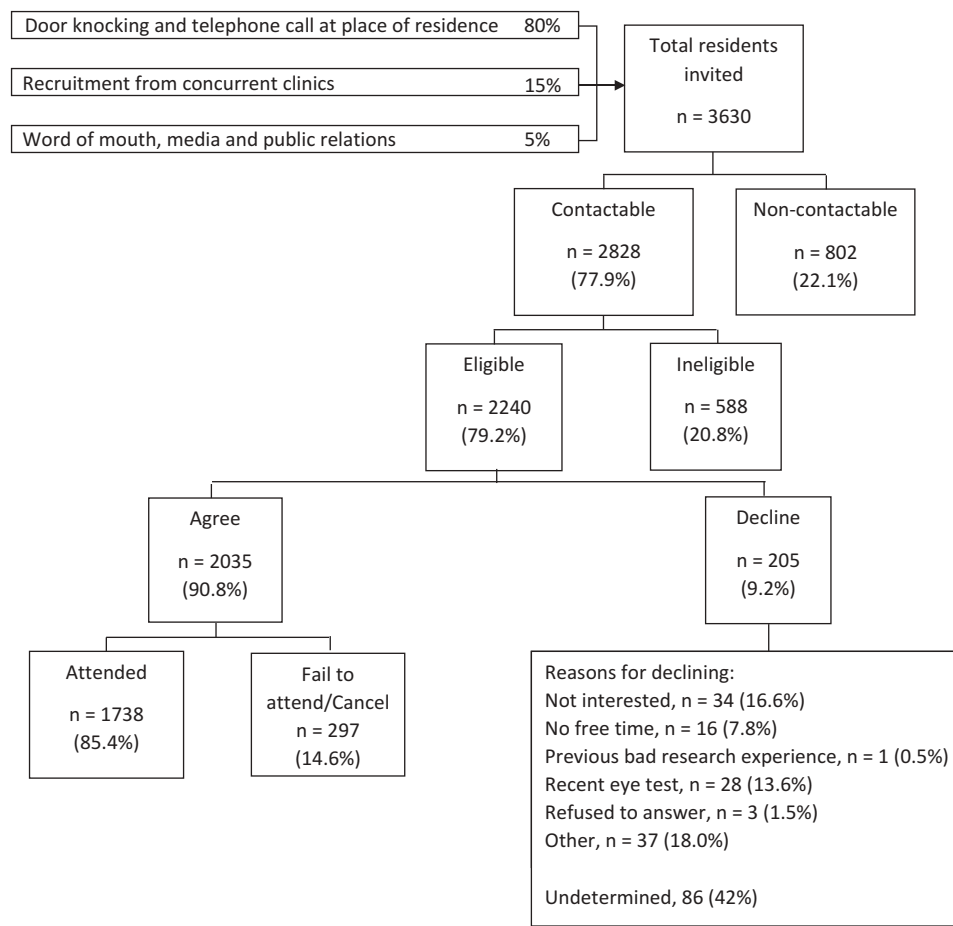


Figure 2. Recruitment statistics of the target Indigenous population in the NEHS.

in both eyes and 1.8% (85/4836) had missing images for both eyes.

Of those participants with missing or ungradable retinal images of both eyes: 60.4% (87/144) were attributed to small pupil size, 14.6% (21/144) were due to poor participant cooperation or mobility, 7.6% (11/144) were a result of significant retinal or optic nerve pathology leading to poor fixation, 6.3% (9/144) were due to corneal or lenticular opacity and 4.2% (6/144) were due to technology malfunction. In the remaining 6.9% (10/144), no reason was attributed.

Discussion

This paper describes the recruitment and testing methodology for the NEHS. It provides positive response rates and examination rates, and presents the quality of fundus photographs obtained. The recruitment methodology employed in the NEHS was highly effective, achieving overall positive response and examination rates of 85.3% and 71.5%, respectively.

The positive response and examination rates achieved in the NEHS compare favorably with those

in other Australian population-based surveys. The Australian Diabetes, Obesity and Lifestyle (AusDiab) Study (1999–2000) achieved a response rate of 70.2% and a clinical examination rate of 55.3%.²⁰ The BMES and VIP achieved positive response rates of 87.9% and 83%, respectively, which are similar to the NEHS.^{4,21} The finding of higher positive response rates for non-Indigenous residents in more remote areas in the current study ($p = 0.01$) is similar to that reported by the VIP, with a 92% positive response rate in rural areas compared to 84% in urban areas.²² These high positive response and examination rates in Remote and Very Remote sites ultimately resulted in more efficient and more representative recruitment. Consequently, future studies may benefit from allocating more resources to recruitment in Major City areas, where non-contactable rates may be higher and residents may be more difficult to persuade due to less time availability, lack of interest and greater availability of services.

The high positive response and examination rates in the NEHS may be attributed to a number of factors. All recruitment staff underwent extensive training on using the recruitment script and handling concerns of

invitees appropriately. Incentivising participation with complimentary sunglasses (valued up to \$AU130), coupled with a free eye examination, also contributed to the high positive response rate. The provision of an appointment card and an informative recruitment pack, and the use of reminder calls and text messages contributed to the high examination rate. Careful selection of testing venues within a desirable proximity to the recruitment site (≤ 6 km of the SA1) was also important.

On average, positive response and examination rates within Indigenous communities were higher than non-Indigenous communities. This was likely due to the support provided by local Aboriginal Health Services, community elders and Indigenous support workers. Establishing and cultivating relationships with local Indigenous organizations allowed NEHS staff to utilize pre-existing relationships between local workers and the community to optimize recruitment. Prior experience in community-based population health research has highlighted that participation is optimized through personalized recruitment strategies that engage trusted community members and peers.^{23,24} Our experience with the recruitment of Indigenous participants in the NEHS confirm these observations.

It should be noted that in population-based surveys, positive response rates can be derived through a number of methods. Conventionally, if census data is used, the randomly selected sample in each site is well-defined. The number of eligible residents residing in each site is enumerated during the census, and an absolute response rate can be calculated as the proportion of the known target sample that responded. Sampling in the NEHS was conducted in the year 2015 based on the most recent available Census data from the year 2011, and socio-demographic characteristics of the constituent populations are likely to have changed during this period. Furthermore, 49.9% of residences were non-contactable after two attempts, and the accuracy of the data pertaining to population clusters provided by the 2011 Census was uncertain. Calculation of absolute response rates was therefore not possible.

The methods used in the present study to calculate positive response and examination rates (positive response rate = the number of eligible residents who agreed to participate divided by the number of residents identified as eligible at the time of recruitment; examination rate = the number of participants examined divided by the number of residents identified as eligible at the time of recruitment) appear to be the most practical. Despite this, a potential limitation of the current study was the number of times recruiters

returned to empty residences to attempt contact. One mail-drop, followed by two attempts at contact may have been insufficient to contact all residents. While increasing the number of times recruiters return to the same SA1 residences, rather than moving to a contiguous SA1, might have increased the absolute response rate, it would have drastically slowed the process of recruitment and reduced the sample size due to time constraints.

The target Indigenous population comprised only 2.27% of the total target population, and it was expected that SA1 clusters and their surrounding regions would not contain the required number of Indigenous residents. While recruiting Indigenous Australians from neighbouring SA2s or SA3s through a variety of alternative recruitment methods ensured that the required sample size was achieved, this resulted in differences in geographic distribution between non-Indigenous and Indigenous participants in each site. While unavoidable due to substantial differences in population density, this may have resulted in some inconsistencies and limitation in comparability between the two populations. However, this limitation was attenuated by ensuring that Indigenous participants were always recruited from within the same RA and as close as possible to the nominated site.

Good quality, gradable macula- and optic disc-centred images of at least one eye were acquired for 59.3% of participants. At least a partial grading could be assigned in 97% of participants, compared with gradability rates 80.3% and 74% in previous studies using non-mydratric fundus photography to screen for diabetic retinopathy.^{25,26} The rate of ungradable images in this study should be considered in light of the older age participants and the rigorous quality standards enforced. A strong relationship between advancing age and poor non-mydratric retinal image quality has been reported previously, typically due to the higher incidence of ocular media opacities and small pupil size.²⁷

Conclusion

The recruitment and testing protocols were feasible, relevant, and well received by participants in the NEHS. The NEHS successfully recruited and examined 4836 participants between March 2015 and April 2016. The recruitment methods utilized in this study achieved high positive response and examination rates for Indigenous and non-Indigenous Australians across all RAs. Indeed these rates compare favorably with the landmark population studies conducted in Australia. Planning and community consultations are imperative during the recruitment of

Indigenous Australians in population-based surveys. A number of factors must be considered, including the sparseness of populations, cultural sensitivity, and the utilization of local community elders, support workers and health services within Indigenous communities. The NEHS provides comprehensive data on the prevalence of VI and blindness in Australia, and the results will inform future planning for eye health care service delivery across the country.

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Declaration of interest

The authors report no conflict of interest. The authors alone are responsible for the writing and content of this article.

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CHAPTER 4: RESULTS

4.1 Overview

This chapter provides the results in line with the two key aims of this thesis:

- 1) To determine the prevalence and major causes of unilateral and bilateral VI and blindness in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.
- 2) To determine rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and both cataract surgery coverage and refractive error treatment coverage rates in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.

In accordance with regulations under the University of Melbourne PhD ‘thesis with publications’ guidelines, most of the results in this thesis are presented in publication format as they appear in journals. This chapter includes seven publications (Publication 4 to Publication 10 below). The methodology papers in the previous chapter provide all population and sample statistics and characteristics relevant to this thesis, including population distributions, response and examination rates, as well as selected sites and summary sample demographics. Additional sample characteristics, including demographics, are reported throughout the results sections of Publication 4 to Publication 10 below.

This chapter is divided into two main sections. The first addresses Aim 1 of this thesis: to determine the prevalence and main causes of unilateral and bilateral VI and blindness in non-Indigenous Australians aged 50 years and older and Indigenous Australians aged 40 years and older from all levels of geographic remoteness, and presents three publications. Supplementary results not included in publications are also provided. The second section addresses Aim 2 of

this thesis: to determine rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and both cataract surgery coverage and refractive error treatment coverage rates in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia. Four publications, also with supplementary results, are presented in this section.

4.2 The prevalence and main causes of vision impairment and blindness

This section presents three publications in line with Aim 1. A brief overview is provided before each publication, followed directly by the published version of the article. Additional results that are relevant to the specific objective are provided immediately after each publication, where appropriate.

4.2.1 Publication 4: The prevalence and causes of vision loss in Indigenous and non-Indigenous Australians: The National Eye Health Survey

4.2.1.1 Overview

The first publication in this section (Publication 4) reports the core findings from the NEHS. This paper principally reports the prevalence and causes of bilateral VI and blindness in Australia. Prevalence estimates are disaggregated by participants' age, gender, place of birth and geographic remoteness, providing unprecedented sociodemographic and geographic resolution of the prevalence of bilateral vision loss at a national scale. Using these disaggregated data, along with ABS population data, the absolute number of Australians with vision loss in each of the disaggregated groups was calculated. Further, multivariable logistic regression was used to identify risk factors that were independently associated with vision loss in Australia's Indigenous and non-Indigenous populations. The major causes of bilateral vision loss are then presented in terms of the percentage of vision loss attributed to each cause. The findings of this manuscript provide the most comprehensive population-based analysis to date

of the prevalence and causes of bilateral vision loss in Australia. This paper was published in *Ophthalmology* in November 2017.

The Prevalence and Causes of Vision Loss in Indigenous and Non-Indigenous Australians

The National Eye Health Survey

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Purpose: To conduct a nationwide survey on the prevalence and causes of vision loss in Indigenous and non-Indigenous Australians.

Design: Nationwide, cross-sectional, population-based survey.

Participants: Indigenous Australians aged 40 years or older and non-Indigenous Australians aged 50 years and older.

Methods: Multistage random-cluster sampling was used to select 3098 non-Indigenous Australians and 1738 Indigenous Australians from 30 sites across 5 remoteness strata (response rate of 71.5%). Sociodemographic and health data were collected using an interviewer-administered questionnaire. Trained examiners conducted standardized eye examinations, including visual acuity, perimetry, slit-lamp examination, intraocular pressure, and fundus photography. The prevalence and main causes of bilateral presenting vision loss (visual acuity <6/12 in the better eye) were determined, and risk factors were identified.

Main Outcome Measures: Prevalence and main causes of vision loss.

Results: The overall prevalence of vision loss in Australia was 6.6% (95% confidence interval [CI], 5.4–7.8). The prevalence of vision loss was 11.2% (95% CI, 9.5–13.1) in Indigenous Australians and 6.5% (95% CI, 5.3–7.9) in non-Indigenous Australians. Vision loss was 2.8 times more prevalent in Indigenous Australians than in non-Indigenous Australians after age and gender adjustment (17.7%, 95% CI, 14.5–21.0 vs. 6.4%, 95% CI, 5.2–7.6, $P < 0.001$). In non-Indigenous Australians, the leading causes of vision loss were uncorrected refractive error (61.3%), cataract (13.2%), and age-related macular degeneration (10.3%). In Indigenous Australians, the leading causes of vision loss were uncorrected refractive error (60.8%), cataract (20.1%), and diabetic retinopathy (5.2%). In non-Indigenous Australians, increasing age (odds ratio [OR], 1.72 per decade) and having not had an eye examination within the past year (OR, 1.61) were risk factors for vision loss. Risk factors in Indigenous Australians included older age (OR, 1.61 per decade), remoteness (OR, 2.02), gender (OR, 0.60 for men), and diabetes in combination with never having had an eye examination (OR, 14.47).

Conclusions: Vision loss is more prevalent in Indigenous Australians than in non-Indigenous Australians, highlighting that improvements in eye healthcare in Indigenous communities are required. The leading causes of vision loss were uncorrected refractive error and cataract, which are readily treatable. Other countries with Indigenous communities may benefit from conducting similar surveys of Indigenous and non-Indigenous populations. *Ophthalmology* 2017;124:1743–1752 © 2017 by the American Academy of Ophthalmology

Globally, approximately 223 million people experience vision loss,¹ in whom 80% of cases are avoidable through early detection, prevention, and treatment.² The feasibility of reducing the burden of vision loss prompted the World Health Assembly to endorse “Universal Eye Health: A Global Action Plan 2014–2019” (the Global Action Plan) in 2013, which aimed to reduce the prevalence of avoidable blindness by 25% before the year 2020.³ The World Health Assembly emphasized the need for population-based survey data on the prevalence and causes of vision loss to inform resource allocation for eye

healthcare services to achieve the objectives of the Global Action Plan.³

Less than 20% of countries have conducted nationwide surveys on the prevalence and causes of vision loss, and existing studies vary in terms of methodological rigor.² In this article, we contend that the methods used in most surveys to date are limited in their ability to provide a sufficiently detailed map of a nation's eye health, particularly in countries with disadvantaged Indigenous groups. The definition of indigeneity is contentious and varies considerably; however, the United Nations

Permanent Forum on Indigenous Issues loosely defines Indigenous peoples on the basis of the following criteria: (1) self-identification as Indigenous peoples by individuals and acceptance as such by their community; (2) historical continuity and land occupation before invasion and colonization; (3) strong links to territories including land and water and related natural resources; (4) distinct social, economic, or political systems; (5) distinct language, culture, religion, ceremonies, and beliefs; (6) tendency to form nondominant groups of society; (7) resolution to maintain and reproduce ancestral environments and systems as distinct peoples and communities; and (8) tendency to manage their own affairs separate from centralized state authorities.⁴ There are 370 million Indigenous people in 90 countries, and they consistently experience significantly poorer health outcomes than their non-Indigenous counterparts.^{5,6} This gap is particularly pronounced in developed nations with historically colonized Indigenous minorities, including the United States, Canada, New Zealand, and Australia, where Indigenous morbidity and mortality rates are higher than in many developing nations.⁷ Considering that vision loss is more prevalent in disadvantaged communities,⁸ it follows that many Indigenous populations are likely to have a higher burden of vision loss. Nationwide studies have been conducted in regions of Asia, Africa, and Europe with Indigenous populations, but none have attempted to collect samples from Indigenous groups.^{9–22} By assuming ethnic homogeneity and neglecting to interrogate Indigenous communities, these surveys may have insufficiently quantified the burden of vision loss in some of their countries' most vulnerable groups. Consequently, they may have underestimated the prevalence of vision loss and generated data that are insufficient to optimally inform national interventions.

With the exception of 2 surveys conducted in Australia,^{23,24} all surveys investigating Indigenous eye health have been subnational and focused on isolated tribes or communities with varying degrees of sampling bias,^{25–33} and most did not make robust comparisons with non-Indigenous groups^{25,27,28,30,33} or collect comprehensive ophthalmic data.^{29,30} Nevertheless, the majority of these surveys, in conjunction with other research, have found that Indigenous communities in Brazil, Ecuador, United States, and Australia have high rates of vision loss^{24,34,35} and eye disease, including trachoma,^{30,36} cataract,²⁵ pterygium,^{25,37} and diabetic retinopathy.²⁴ Therefore, because Indigenous peoples constitute more than 5% of the global population,⁷ identifying the prevalence and causes of vision loss in these groups in conjunction with general populations is critical to inform national eye health programs and to achieve the objectives of the Global Action Plan.

Australia requires national prevalence data on vision loss to fulfill its obligations as a signatory to the Global Action Plan. State-level surveys conducted in the early 1990s in Victoria,³⁸ New South Wales,³⁹ and South Australia⁴⁰ have been the reference studies in Australia until now. We conducted a nationwide study, the National Eye Health Survey (NEHS), to determine the prevalence and causes of vision loss in Australia. This survey has implemented a

novel approach to stratifying its sampling frame according to Indigenous status to produce reliable estimates of the prevalence and causes of vision loss in both Indigenous and non-Indigenous populations. We present the findings of the NEHS and propose that our stratified study design forms the basis for future prevalence studies in all countries with Indigenous groups.

Methods

Study Design and Participants

The sampling methodology of the NEHS has been described in detail.⁴¹ In brief, the target population was stratified into Indigenous Australians and non-Indigenous Australians. In accordance with Global Action Plan guidelines, the NEHS recruited non-Indigenous Australians aged 50 years or older.³ However, because Indigenous Australians have earlier onset and more rapid progression of eye disease and diabetes,⁴² a younger age of 40 years or older was selected. On the basis of the most reliable previous estimates of the prevalence of vision loss in Australia,^{24,43} the required sample size was 2794 non-Indigenous Australians and 1368 Indigenous Australians residing in 30 geographic areas.

Multistage random-cluster sampling was used to select participants on the basis of data from the 2011 Australian Census.⁴⁴ In stage 1 of sampling, the Australian population was stratified into 5 remoteness strata: Major City, Inner Regional, Outer Regional, Remote, and Very Remote. Probability proportional to size sampling was used to select 12 Major City, 6 Inner Regional, 6 Outer Regional, 4 Remote, and 2 Very Remote survey sites, corresponding to the approximate population distribution in each stratum. In the second stage, a smaller cluster containing approximately 100 eligible residents was randomly selected and nominated as the enumeration site. Because of a number of factors including insufficient population numbers, inaccurate Census data, and high absentee rates, a systematic approach was used to make adjustments to some sites, including the use of backup sites and sampling from contiguous geographic areas. The details of this approach have been published.⁴¹ Door-to-door recruitment was conducted until approximately 100 non-Indigenous participants were recruited from each cluster. Although door-to-door recruitment was used for the majority of participants, we consulted Aboriginal elders and local Aboriginal Health Services to ensure that our recruitment methods were culturally appropriate. In some instances, direct door-to-door recruitment was deemed culturally inappropriate, and telephone recruitment from formalized community lists was used as a substitute. Household recruitment, including door-to-door and telephone recruitment, accounted for approximately 80% of Indigenous recruitment. Alternative methods of contact included concurrent Indigenous health clinics and word of mouth.

The protocol was approved by the Royal Victorian Eye and Ear Hospital Human Research Ethics Committee, as well as state-based Indigenous ethics organizations. This study was conducted in accordance with the tenets of the Declaration of Helsinki.

Procedures

The examination protocol of the NEHS has been described in detail.⁴⁵ Participant examinations were conducted in a total of 61 testing venues that included community centers, mobile clinics, town halls, Aboriginal Corporations, schools, and medical clinics, all within 6 km of each recruitment site. Examinations were conducted over 13 months and 7 days, from March 11,

2015, to April 18, 2016. Residents attended testing centers at prespecified appointment times and provided written informed consent. Standardized sociodemographic, stroke, diabetes, and ocular history data were collected using an interviewer-administered questionnaire.

Standardized eye examinations were conducted by researchers, including ophthalmologists, optometrists, orthoptists, and research assistants trained at the Centre for Eye Research Australia (CERA). Presenting distance visual acuity was measured for each eye separately using a logarithm of the minimum angle of resolution chart (Brien Holden Vision Institute, New South Wales, Australia) in well-lit room conditions. Pinhole testing was performed using a multiple pinhole occluder on participants with visual acuity $<6/12$ in 1 or both eyes. If visual acuity improved with pinhole testing, autorefractometry was performed using a Nidek ARK-30 Type-R handheld autorefractor/keratometer (Nidek Co, Ltd, Tokyo, Japan), and autorefractometry-corrected visual acuity was measured. Binocular presenting near vision was assessed using a CERA “Tumbling E” near vision card (CERA, Melbourne, Australia) held at the participant’s preferred reading distance. The smallest line at which the direction of at least 3 of the 4 “Tumbling E” optotypes was correctly identified was recorded. Visual fields were assessed using a Frequency Doubling Technology perimeter (Zeiss Humphrey Systems, Oberkochen, Germany, and Welch Allyn, Skaneateles Falls, NY).

Examination of the anterior segment was performed using a hand-held slit lamp (Keeler Ophthalmic Instruments, Berkshire, UK) at $10\times$ magnification. Because *Chlamydia trachomatis* infection is endemic in Indigenous Australians, but not in non-Indigenous Australians, grading for trachomatous trichiasis and corneal opacity was performed in Indigenous participants using only the World Health Organization Trachoma Simplified Grading System.⁴⁶ If presenting visual acuity was $<6/12$ in either eye, examiners took an anterior segment photo in the affected eye(s) with a Digital Retinography System⁴⁷ camera (CenterVue, SpA, Padova, Italy).

Two-field, 45° color fundus photographs were taken of each retina, centered on the macula and optic disc, respectively, using a nonmydriatic Diabetic Retinopathy Screening camera in a darkened room to allow for physiologic mydriasis. In 663 patients (13.7%) in whom photograph quality was poor because of small pupil size, tropicamide 0.5% was instilled to induce mydriasis if anterior chambers were deemed wide enough to do so safely using the method by Van Herick et al,⁴⁸ and photographs were repeated. Dilation was not performed when the angle was graded as 1 or 2. Intraocular pressure was measured using an iCare Tonometer (iCare, Vantaa, Finland). Participants were provided with verbal feedback on the health of their eyes, and those with suspected pathology were provided with a referral letter to be taken to a local doctor or optometrist.

Blinded retinal graders at CERA graded all retinal images using OpenClinica software (OpenClinica LLC and collaborators, Waltham, MA), and pathology was graded according to protocols that have been described in detail.^{47,49,50}

The main cause of vision loss was determined by 2 independent ophthalmologists, and disagreements were adjudicated by a third ophthalmologist. Data pertaining to participants’ age, gender, and Indigenous status were provided to assist with disease attribution. Uncorrected refractive error was assigned as the main cause of vision loss when distance visual acuity improved to $\geq 6/12$ in 1 or both eyes with pinhole or autorefractometry. For all other cases, ophthalmologists reviewed questionnaire responses and examination results to identify the condition most likely to account for vision loss. When multiple disorders were identified, the condition with the most clinically significant influence was determined to be

the primary cause. For cases in which a single primary cause was not identifiable, vision loss was attributed to combined mechanisms. Cases of vision loss were deemed “not determinable” if no cause of vision loss was identified.

Definitions

Vision impairment was defined as bilateral presenting distance visual acuity $<6/12$ to $\geq 6/60$. *Blindness* was defined as bilateral presenting distance visual acuity $<6/60$. *Vision loss* was defined as bilateral presenting distance visual acuity $<6/12$ and included all cases of *vision impairment* and *blindness*. Participants with presenting visual acuity $<6/12$ in 1 eye but $\geq 6/12$ in the fellow eye (unilateral vision loss) were not considered to have vision loss for the purpose of this article.

Statistical Analysis

The crude prevalence of vision loss was calculated as the percentage of participants with vision loss. Prevalence was then weighted to account for the sampling rate in each remoteness stratum because population sizes varied between strata. This involved dividing the target population recruited from each stratum over the population size in each stratum. This also allowed the absolute number of Australians with vision loss in each stratum to be estimated. To facilitate comparisons between Indigenous and non-Indigenous Australians, the weighted prevalence of vision loss was adjusted for age and gender. Logistic regression analysis was used to identify risk factors for vision loss. Factors associated with vision loss at $P < 0.10$ in univariable analysis were included in subsequent multivariable logistic regression analysis. A plot of the residuals compared with estimates was examined to test linearity and homoscedasticity. The Box-Tidwell model was used to find the best power for model fit based on maximal likelihood estimates. Logistic regression *Model 1* investigated risk factors for Indigenous and non-Indigenous participants together. In *Model 2*, Indigenous and non-Indigenous participants were investigated separately. Analyses were conducted with STATA version 14.2.0 (StataCorp LP, College Station, TX).

Results

Participant Characteristics

Recruiters attempted to contact 23 235 residences within the selected survey areas, of whom 11 883 (51.1%) were contactable. Of these, 6760 (56.9%) were deemed eligible to participate. In total, 3098 non-Indigenous Australians aged 50 to 98 years (mean [standard deviation] = 66.6 [9.7] years) and 1738 Indigenous Australians aged 40 to 92 years (mean [standard deviation] = 55.0 [10.0] years) from 30 geographic areas were recruited and examined. Response rates, defined as the proportion of residents identified as eligible at the time of recruitment who participated in the survey, were 77.6% for Indigenous Australians and 68.5% for non-Indigenous Australians, with a combined response rate of 71.5%. Indigenous participants had fewer years of education ($P < 0.001$), a higher prevalence of self-reported diabetes ($P < 0.001$), and a higher prevalence of self-reported stroke ($P < 0.001$) than their non-Indigenous counterparts (Table 1). Of all 4836 participants, 4692 (97%) had at least 1 gradable fundus photograph, with 67.5% (3265) having gradable images for both eyes. In total, 59 participants (1.2%) had ungradable images in both eyes, and 85 participants (1.8%) had missing images for both eyes.

Table 1. Participant Characteristics

	Indigenous (n = 1738)	Non-Indigenous (n = 3098)	P Value*
	Mean (SD) or Proportion		
Mean age (yrs, SD) [†]	55.0 (10.0)	66.6 (9.7)	—
Gender (% male)	41.1	46.4	<0.001
Educational attainment (yrs, SD)	11.0 (3.3)	12.5 (3.7)	<0.001
English spoken at home (%)	96.1	94.4	0.006
Self-reported diabetes (%)	37.1	13.9	<0.001
Self-reported stroke (%)	8.8	5.0	<0.001

SD = standard deviation.

*P values based on chi-square test for categorical variables or 2 independent samples *t* test for continuous variables.

[†]Comparisons should be interpreted in light of the different age-inclusion criteria between Indigenous Australians (≥ 40 years) and non-Indigenous Australians (≥ 50 years).

Prevalence of Vision Loss

In total, 208 non-Indigenous participants had presenting visual acuity $<6/12$, resulting in a weighted prevalence of vision loss of 6.5% (95% confidence interval [CI], 5.3–7.9). By extrapolating these findings to the entire target non-Indigenous Australian population of 6 544 763, approximately 400 000 non-Indigenous Australians aged 50 years and older were estimated to have vision loss (Table 2). Vision loss increased markedly with age in the non-Indigenous group, from 5.0% (3.6–7.0) in those aged 50 to 59 years to 37.3% (19.2–59.8) in those aged 90 years or more. Of those with vision loss, 7 cases (0.21%, 0.06–0.73) were bilaterally blind ($<6/60$), corresponding to an estimated 12 636 Australians.

With 188 Indigenous participants found to have vision loss, the weighted prevalence in Indigenous Australians was 11.2% (9.5–13.1), corresponding to approximately 15 000 Indigenous Australians aged 40 years or older having vision loss. Bilateral blindness was present in 5 Indigenous participants, corresponding to a weighted prevalence of 0.31% (0.09–1.00) and a total number of 414 blind Indigenous Australians.

After age and gender adjustment of the weighted prevalence of vision loss, the overall prevalence of vision loss in Australia, including both Indigenous and non-Indigenous Australians, was 6.6% (5.4–7.8). Vision loss was 2.8 times more prevalent in Indigenous Australians than in non-Indigenous Australians after age and gender adjustment (17.7%, 95% CI, 14.5–21.0 vs. 6.4%, 95% CI, 5.2–7.6, $P < 0.001$). Vision loss was more prevalent in Indigenous Australians in all age groups, with those aged 60 to 69 years and 80 to 89 years having a greater than 4 times higher prevalence than age-matched non-Indigenous participants.

Risk Factors for Vision Loss

Multivariable logistic regression *Model 1*, which included Indigenous and non-Indigenous participants in a single model, revealed that Indigenous status was associated with an odds ratio (OR) for vision loss of 2.4 (1.80–3.06) relative to non-Indigenous status ($P < 0.001$). Because of this substantial difference, coupled with the different age inclusion criteria for Indigenous and non-Indigenous Australians, we created a stratified model in which risk factors were interrogated in Indigenous and non-Indigenous participants separately (*Model 2*).

The results of *Model 2* are presented in Table 3. In univariable logistic regression analysis, older age was a risk factor for vision

loss in non-Indigenous Australians, with each decade of age being associated with an OR of 1.61 (1.35–1.93). Non-Indigenous participants who reported having not undergone an eye examination within the previous 2 years and those who had never had their eyes examined had a greater risk of having vision loss than those who had an examination within the past year. After adjusting for covariates in multivariable analysis, not having had an eye examination in the past year was shown to be a risk factor for vision loss in non-Indigenous Australians.

Vision loss was associated with most risk factors that were tested in univariable analysis in Indigenous Australians, including older age, female gender, self-reported stroke, self-reported diabetes, and geographic remoteness (Outer Regional and Very Remote residence, specifically) (Table 3). Educational attainment was inversely related to vision loss in Indigenous Australians. When adjusting for covariates, all variables identified as risk factors in univariable analysis remained strongly associated with vision loss apart from self-reported stroke and self-reported diabetes. Because self-reported diabetes was shown to be a strong risk factor in univariable analysis (OR, 2.06; 95% CI, 1.47–2.90), further investigation was conducted to identify its association with vision loss. We identified that the effect of diabetes was dependent on whether participants had previously undergone an eye examination. Self-reported diabetes was shown to not be a risk factor for vision loss in Indigenous Australians who had previously had an eye examination, whereas the OR for those with self-reported diabetes who had never undergone an eye examination was 14.47 (95% CI, 5.65–37.05). Although Very Remote residence was not strongly associated with vision loss in multivariable analysis ($P = 0.054$), univariable analysis revealed an association (OR, 2.05; 95% CI, 1.33–3.17; $P = 0.002$), with the prevalence of vision loss being twice as high as in Major City, Inner Regional, and Remote areas.

Causes of Vision Loss

The leading causes of bilateral vision loss in both Indigenous and non-Indigenous participants were uncorrected refractive error, accounting for 60.8% and 61.3% of cases, and cataract, accounting for 20.1% and 13.2% of cases, respectively (weighted proportions) (Fig 1). This was followed by age-related macular degeneration (AMD) in non-Indigenous participants (10.3%) and diabetic retinopathy in Indigenous Australians (5.2%). Vision loss was attributed to combined conditions for 2.9% of Indigenous Australians and 0.06% of non-Indigenous Australians, whereas the main cause of vision loss was not determinable for 8.1% of Indigenous Australians and 8.7% of non-Indigenous Australians.

Of the 5 Indigenous participants with blindness, 2 cases were due to cataract, and the remaining 3 cases were due to diabetic retinopathy, optic atrophy, and combined mechanisms, respectively. Five of the 7 blindness cases in the non-Indigenous cohort were caused by AMD, whereas 1 participant had optic atrophy and 1 participant was not determinable because of poor retinal image quality.

Discussion

This paper has presented the prevalence and causes of vision loss in Australia's National Eye Health Survey. We have shown that there is a disproportionately large burden of vision loss in Australia's Indigenous population, with a prevalence that is approximately 3 times as high as non-Indigenous Australians. This, coupled with the identification of risk factors and the main causes of vision loss, provides the basis for targeted interventions to reduce the burden of vision loss.

Table 2. Prevalence of Bilateral Presenting Vision Loss (Visual Acuity <6/12) in Indigenous and Non-Indigenous Australians

	Non-Indigenous (n = 3098)				Indigenous (n = 1738)			
	No. with Vision Loss	Unadjusted Prevalence (95% CI)	Weighted Prevalence (95% CI)	Estimated National Population with Vision Loss	No. with Vision Loss	Unadjusted Prevalence (95% CI)	Weighted Prevalence (95% CI)	Estimated National Population with Vision Loss
Total sample	208	6.7% (5.7–7.4)	6.5 (5.3–7.9)	383 897	188	10.8 (9.4–12.4)	11.2% (9.5–13.1)	15 029
Age, yrs								
40–49*	—	—	—	—	34	5.8% (4.1–8.1)	7.2% (5.7–9.0)	3208
50–59	36	4.4% (3.1–6.1)	5.0% (3.6–7.0)	79 213	55	8.7% (6.6–11.2)	8.0% (5.7–11.2)	3910
60–69	51	4.4% (3.3–5.7)	4.0% (2.8–5.7)	90 160	62	17.1% (13.4–21.4)	17.8% (13.1–23.6)	4902
70–79	64	8.4% (6.5–10.6)	8.2% (5.7–11.7)	117 803	25	18.5% (12.4–26.1)	15.5% (9.5–24.3)	1639
80–90	46	14.3% (10.7–18.6)	12.2% (7.8–18.4)	70 222	12	46.2% (26.6–66.6)	56.0% (29.7–79.3)	1370
90+	11	32.4% (17.4–50.5)	37.3% (19.2–59.8)	26 499	—	—	—	—
Gender								
Female	104	6.3% (5.1–7.5)	6.2% (4.5–8.4)	194 704	118	11.5% (9.6–13.6)	12.8% (10.5–15.4)	10 061
Male	104	7.2% (6.0–8.7)	6.9% (5.3–7.9)	189 193	72	9.8% (7.7–12.2)	9.0% (6.8–11.8)	4968
Place of birth								
Oceania	141	6.4% (5.4–7.5)	6.1% (4.7–7.9)	243 622	188	10.8% (9.4–12.4)	11.2% (9.5–13.2)	15 029
Europe	51	7.8% (5.9–10.1)	7.4% (5.1–10.6)	102 899	—	—	—	—
Others	16	7.1% (4.1–11.2)	7.1% (4.9–10.1)	37 336	—	—	—	—
Remoteness								
Major city	85	6.8% (5.5–8.3)	6.7% (5.1–8.8)	233 095	62	8.3% (6.4–10.5)	8.3% (5.7–12.1)	3617
Inner Regional	33	5.2% (3.6–7.2)	5.2 % (3.6–7.3)	74 986	26	8.4% (5.6–12.1)	8.0% (4.6–13.6)	2408
Outer Regional	51	8.2% (6.1–10.6)	8.1% (5.2–12.3)	54 373	68	16.8% (13.3–20.8)	16.6% (13.5–20.2)	4767
Remote	22	6.0% (3.8–8.9)	6.0% (3.0–11.8)	6272	17	9.4% (5.6–14.6)	7.4% (2.4–21.0)	623
Very remote	17	7.4% (4.6–12.3)	7.7% (4.8–12.2)	2534	15	15.6% (9.0–24.5)	15.7% (13.9–17.7)	3201

CI = confidence interval; n = the number of participants with presenting bilateral vision loss (visual acuity <6/12).

*Inclusion criteria differed for Indigenous and non-Indigenous participants. The minimum age for non-Indigenous participants was 50 years. However, because Indigenous Australians are known to have more rapid progression and earlier onset of eye disease and diabetes, a younger age criterion of ≥40 years was selected for the target Indigenous population.

Table 3. Multivariable Logistic Regression Analysis for Risk Factors Associated with Presenting Bilateral Vision Loss (Visual Acuity <6/12) in Indigenous and Non-Indigenous Australians

Risk Factor	Non-Indigenous Australians				Indigenous Australians			
	Univariable [†] OR	P Value	Multivariable [‡] OR	P Value [*]	Univariable OR	P Value	Multivariable OR	P Value
Age (per 10 yrs)	1.61 (1.35–1.93)	<0.001	1.72 (1.40–2.10)	<0.001	1.78 (1.53–2.07)	<0.001	1.61 (1.34–1.95)	<0.001
Gender (male)	1.13 (0.77–1.64)	0.524	—	—	0.67 (0.47–0.97)	0.034	0.60 (0.42–0.84)	0.005
Education (yrs)	0.93 (0.87–0.98)	0.015	0.96 (0.91–1.02)	0.189	0.85 (0.78–0.92)	<0.001	0.91 (0.84–0.99)	0.025
English at home	0.97 (0.62–1.52)	0.905	—	—	0.44 (0.19–1.04)	0.062	0.63 (0.33–1.22)	0.164
Place of birth								
Oceania	1	—	—	—	—	—	—	—
Europe	1.23 (0.76–2.00)	0.384	—	—	—	—	—	—
Other	1.18 (0.75–1.86)	0.464	—	—	—	—	—	—
Remoteness								
Major city	1	—	—	—	1	—	1	—
Inner regional	0.75 (0.47–1.20)	0.223	—	—	0.96 (0.47–1.97)	0.907	0.95 (0.47–1.92)	0.876
Outer regional	1.21 (0.70–2.11)	0.475	—	—	2.18 (1.36–3.50)	0.002	2.02 (1.23–3.31)	0.007
Remote	0.89 (0.41–1.92)	0.752	—	—	0.88 (0.25–3.13)	0.841	0.77 (0.23–2.60)	0.661
Very remote	1.16 (0.65–2.08)	0.608	—	—	2.05 (1.33–3.17)	0.002	1.53 (0.99–2.35)	0.054
Self-reported stroke	1.59 (0.70–3.66)	0.259	—	—	1.93 (1.25–2.97)	0.004	1.17 (0.59–2.33)	0.644
Self-reported diabetes [§]	1.23 (0.78–1.93)	0.354	—	—	2.06 (1.47–2.90)	<0.001	—	—
Time since last eye examination [§]								
Within 1 yr	1	—	1	—	1	—	—	—
1–2 yrs ago	1.35 (0.90–2.03)	0.141	1.61 (1.06–2.42)	0.024	0.71 (0.37–1.36)	0.287	—	—
>2 yrs ago	2.09 (1.23–3.57)	0.008	2.38 (1.33–4.26)	0.005	0.67 (0.36–1.25)	0.197	—	—
Never	3.11 (1.04–9.32)	0.043	4.72 (1.59–13.96)	0.007	1.44 (0.87–2.39)	0.150	—	—
Self-reported diabetes × previous eye examination interaction [§]								
No diabetes × never examined	—	—	—	—	1	—	1	—
No diabetes × previously examined	—	—	—	—	1.53 (0.92–2.52)	0.098	1.46 (0.80–2.67)	0.209
Diabetes × never examined	—	—	—	—	19.86 (8.24–47.92)	<0.001	14.47 (5.65–37.05)	<0.001
Diabetes × previously examined	—	—	—	—	2.49 (1.27–4.87)	0.010	1.57 (0.71–3.43)	0.252

*P values are provided only for factors that were included in multivariable analysis.

[†]The ORs (95% CIs) from a univariable logistic regression model investigating the association between individual factors and the risk of vision loss.

[‡]The ORs (95% CIs) from a multivariable logistic regression model, adjusting for the effects of covariates, investigating the association between factors and the risk of vision loss. This model only included factors with associations in univariable analysis with $P < 0.10$.

[§]There was a strong interaction between self-reported diabetes and a history of having never undergone an eye examination in Indigenous Australians. Without combination, self-reported diabetes was a highly significant risk for vision loss for Indigenous Australians ($P < 0.001$) in univariable analysis, the effect of which was substantially reduced in multivariable analysis ($P = 0.15$). Model building revealed that the risk associated with diabetes was dependent on having never undergone an eye examination.

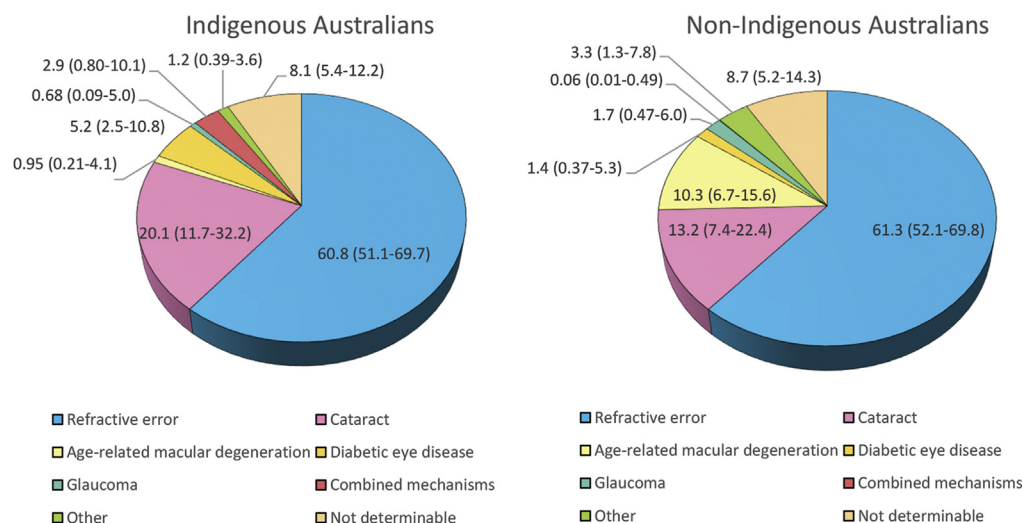


Figure 1. The weighted main causes of vision loss (presenting bilateral distance visual acuity $<6/12$) in Indigenous and non-Indigenous participants. Values are the proportion (%; 95% confidence interval [CI]) of vision loss attributed to each main cause. Values are adjusted for sampling weights. Refractive error is uncorrected or undercorrected refractive error. Combined mechanisms were assigned if there were ≥ 2 causes of vision loss. Other causes of vision loss included retinal dystrophy, optic atrophy, retinochoroidal scarring, retinitis pigmentosa, myopic retinochoroidal degeneration, and keratoconus.

Previously, the best estimate of the prevalence of vision loss in Australia's older population of 5.2% was derived from the pooled prevalence data from the Melbourne Visual Impairment Project and the Blue Mountains Eye Study conducted in 1992–1994.⁴³ These surveys were limited in their geographic coverage, selecting samples from the state of Victoria and a community near Sydney, respectively. Therefore, the estimates of these studies were representative of these populations and could not be confidently extrapolated to the wider Australian population. Furthermore, temporal changes in parameters including population aging and growth, and a higher prevalence of diabetes risk factors, have necessitated updated prevalence estimates. The prevalence of 6.5% reported in the current study is based on nationally representative data and should be considered the most accurate estimate of the prevalence of vision loss in Australia's non-Indigenous population. Estimates from this study will be useful for informing future national eye health policies and may function as the baseline to measure the progress of future interventions. Of particular relevance is the association between the increased risk of vision loss and older age in non-Indigenous participants, with the prevalence of vision loss more than tripling from ages 60–69 years to 80–89 years. Vision loss also was associated with not undergoing regular eye examinations reflecting a missed opportunity to identify and remediate leading causes of vision loss, such as uncorrected refractive error and cataract. These findings, considered in light of the fact that Australia's population is aging rapidly, emphasize the need for individuals to undergo more regular eye examinations as they age to ensure that the prevalence of vision loss does not increase in coming decades.

The weighted prevalence of vision loss of 11.2% for Indigenous Australians in the NEHS was slightly higher than that of the National Indigenous Eye Health Survey (10.4%); however, this may be due to the older mean age of our Indigenous cohort (55 vs. 51 years). More importantly, the prevalence of vision loss was higher in Indigenous

Australians compared with non-Indigenous Australians residing in all geographic remoteness strata and in all age groups measured in this study. This underlines systematic insufficiencies in the delivery of required eye care services to Indigenous communities.⁵¹ The gap in Indigenous eye health has been well established, and the Roadmap to Close the Gap for Vision provides a framework for the improvement of eye care services.^{52,53} This survey identified numerous risk factors for vision loss in Indigenous Australians. The finding that the prevalence of vision loss in Indigenous women was 1.4 times higher than in Indigenous men highlights the need for further investigation into this gender disparity and an urgent need to provide equitable eye health care to all Indigenous Australians.

The finding that uncorrected refractive error and cataract, both reversible, were the main causes of vision loss in both Indigenous (81%) and non-Indigenous (75%) participants is reflected in previous Australian research.^{24,38,54,55} These conditions remain the leading causes of vision loss for a multitude of reasons that are likely to differ between Indigenous and non-Indigenous Australians and across different regions in Australia. For example, the prohibitive distances to spectacle-dispensing services and cataract surgery facilities, coupled with the lack of outreach services, have resulted in insufficient and inequitable treatment coverage for both conditions.⁵⁶ Furthermore, the continually increasing incidence of cataract⁵⁷ and long cataract surgery waiting times⁵⁸ may be further hindering efforts to reduce disease burden, whereas suboptimal coordination of spectacle-dispensing services, cost uncertainty, and affordability particularly for Indigenous Australians⁵¹ may contribute to inadequate treatment of refractive error. Perhaps most importantly, insufficient eye examination frequency in older Australians may result in a lack of detection and correction of refractive error. Consequently, by implementing a well-coordinated nationwide needs-based strategy that addresses these deficits while increasing eye health promotion to

improve service use, Australia would successfully supersede its commitment to the Global Action Plan.

Diabetic retinopathy contributed to 5.2% of vision loss in Indigenous participants, but less than 1.5% of vision loss in non-Indigenous participants. This reflects the substantially higher prevalence of self-reported diabetes in Indigenous participants (37.1% vs. 13.9%) and the higher prevalence of advanced vision-threatening diabetic retinopathy in Indigenous Australians that has been attributed to insufficient use of early detection and treatment services.⁵⁹ Implementing strategies to target risk factors for diabetic retinopathy, including glycemic, lipid, and blood pressure control in Indigenous communities, while also enhancing screening services (supported by the strong association with vision loss in those who had diabetes and had never had an eye examination [OR, 14.47]) may contribute to reducing the burden of vision loss in Indigenous Australians.⁵²

As the leading cause of blindness (71%) and one of the leading causes of vision impairment in Australia and other high income countries, the burden of AMD as a public health concern is likely to increase with the aging of the population.⁶⁰ Because the vision loss induced by AMD is largely irreversible, early detection, treatment, and education on prevention are critical in slowing disease progression.

Many national eye health surveys have used Rapid Assessment of Avoidable Blindness, Rapid Assessment of Cataract Surgical Services or similar methodologies.^{61,62} The strengths of these study designs are their relative inexpensiveness and that they use multistage sampling frames, while permitting rapid identification of obvious ocular disease. However, their practical utility is hindered by a number of weaknesses, including simplified ophthalmic examinations (often consisting of only slit-lamp and ophthalmoscopy, thereby limiting disease attribution) and rigid nonstratified sampling methods that do not account for heterogeneous populations.

Population-based eye surveys that have implemented some level of stratification, however crude, have consistently revealed geographic^{14,15,18} or ethnic^{34,63,64} variations. Therefore, it is likely that nonstratified surveys may not adequately identify regions and ethnic groups most in need of improvements in eye healthcare services. Through our stratified sampling methodology, in which we have collected large samples of both Indigenous and non-Indigenous participants from all levels of geographic remoteness, we have shown that the Indigenous people of Australia, particularly those living in nonmetropolitan areas, have a substantially higher risk for vision loss. These findings will strengthen national programs aiming to reduce the burden of vision loss by assisting policymakers and health providers to allocate limited resources to communities most in need.⁵² On the basis of our findings, future population-based surveys may benefit from using similar stratification methods to identify and investigate Indigenous groups in countries with defined Indigenous populations.

Study Limitations

A limitation of this study resulted from Australia's unique geographic and population structures, including its unusually

low population density.⁶⁵ A systematic protocol was used to reduce the risk of bias when selecting new population clusters imposed by prohibitively low population densities, high absentee rates, and erroneous census data. Nonetheless, the complete elimination of both nonresponse bias and selection bias could not be achieved because nonresponders and absentees may have differed from responders in ways relevant to study outcomes. An additional limitation is that the sample size was calculated to detect the prevalence of vision loss in general, and the study was not powered to achieve precision in the estimates of the causes of vision loss, the prevalence of vision loss by age, or the presumably much lower prevalence of blindness. Future studies may benefit from having larger samples, but the benefit must be weighed against the financial and logistic consequences.

In light of the aim to reduce the prevalence of avoidable vision loss by 25% before the year 2020 under the Global Action Plan, there is an urgent need for more countries to conduct well-designed national eye health surveys to identify at-risk populations to guide domestic strategies in the fight against vision loss. In Australia, uncorrected refractive error and cataract, both reversible, remain the leading causes of vision loss, highlighting that avoidable vision loss can be largely addressed by implementing needs-based nationwide strategies that improve rates of spectacle correction and cataract surgery. Diabetic retinopathy and AMD contribute significantly to the burden of vision loss in Australia, and early detection and treatment are well known to reduce the burden of vision loss from these conditions. Indigenous Australians have a high burden of vision loss, and properly stratified surveys in other countries with Indigenous inhabitants, or indeed other marginalized population subgroups, may reflect these findings in those populations, thereby informing targeted interventions to reduce vision loss in those countries.

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Abbreviations and Acronyms:

AMD = age-related macular degeneration; **CERA** = Centre for Eye Research Australia; **CI** = confidence interval; **NEHS** = National Eye Health Survey; **OR** = odds ratio.

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4.2.1.2 Supplementary data: age-adjusted and sex-adjusted prevalence of bilateral blindness

Age- and sex-adjusted estimates of blindness were not calculated in Publication 4 because the number of participants with blindness was too small in both groups (n=5 for Indigenous Australians and n=7 for non-Indigenous Australians) to conduct meaningful statistical comparisons. While Publication 4 reported the prevalence of blindness (0.31% and 0.21%, in Indigenous and non-Indigenous Australians, respectively), this was only adjusted to account for the sampling weights within each RA. The weighted prevalence of blindness was further adjusted for age and sex for this thesis, and was determined to be 0.23% in Indigenous Australians and 0.04% in non-Indigenous Australians.

4.2.2 Publication 5: Prevalence and causes of unilateral vision impairment and unilateral blindness in Australia: The National Eye Health Survey

4.2.2.1 Overview

The second paper in this section reports the prevalence and major causes of unilateral VI and unilateral blindness in Australia. The majority of reports on the prevalence of vision loss worldwide focus only on bilateral vision loss, and the few studies that do describe the epidemiology of unilateral vision loss usually include it as a secondary and less comprehensive analysis than bilateral vision loss.^{174, 314} Unilateral vision loss, particularly unilateral blindness, has been shown to significantly affect quality of life (QoL) and a variety of functional domains,^{10, 14, 15} and its continual neglect in population-based research is likely to ensure that those with unilateral vision loss are not appropriately considered in eye health care policy. This paper therefore aimed to provide Australia's first nationally-representative data on the prevalence and causes of, and risk factors associated with, unilateral vision loss, in the hope that future planning ensures that resources are available for Australians living with reduced unilateral vision. This paper was published in *JAMA Ophthalmology* on the 25th of January

2018 and it was selected by the Journal Editors for the monthly online *JAMA Ophthalmology* journal club. This article was also selected by the University of Melbourne upon publication for a media release, and featured in news releases including the Australian Science Media Centre and Insight Magazine.

Prevalence and Causes of Unilateral Vision Impairment and Unilateral Blindness in Australia

The National Eye Health Survey

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IMPORTANCE This study determines the prevalence of unilateral vision impairment (VI) and unilateral blindness to assist in policy formulation for eye health care services.

OBJECTIVE To determine the prevalence and causes of unilateral VI and unilateral blindness in Australia.

DESIGN, SETTING, AND PARTICIPANTS This cross-sectional population-based survey was conducted from March 2015 to April 2016 at 30 randomly selected sites across all strata of geographic remoteness in Australia. A total of 1738 indigenous Australians 40 years or older and 3098 nonindigenous Australians 50 years or older were included.

MAIN OUTCOMES AND MEASURES The prevalence and causes of unilateral vision impairment and blindness, defined as presenting visual acuity worse than 6/12 and 6/60, respectively, in the worse eye, and 6/12 or better in the better eye.

RESULTS Of the 1738 indigenous Australians, mean (SD) age was 55.0 (10.0) years, and 1024 participants (58.9%) were female. Among the 3098 nonindigenous Australians, mean (SD) age was 66.6 (9.7) years, and 1661 participants (53.6%) were female. The weighted prevalence of unilateral VI in indigenous Australians was 12.5% (95% CI, 11.0%-14.2%) and the prevalence of unilateral blindness was 2.4% (95% CI, 1.7%-3.3%), respectively. In nonindigenous Australians, the prevalence of unilateral VI was 14.6% (95% CI, 13.1%-16.3%) and unilateral blindness was found in 1.4% (95% CI, 1.0%-1.8%). The age-adjusted and sex-adjusted prevalence of unilateral vision loss was higher in indigenous Australians than nonindigenous Australians (VI: 18.7% vs 14.5%; $P = .02$; blindness: 2.9% vs 1.3%; $P = .02$). Risk factors for unilateral vision loss included older age (odds ratio [OR], 1.60 for each decade of age for indigenous Australians; 95% CI, 1.39-1.86; OR, 1.65 per decade for nonindigenous Australians; 95% CI, 1.38-1.96), very remote residence (OR, 1.65; 95% CI, 1.01-2.74) and self-reported diabetes (OR, 1.52; 95% CI, 1.12-2.07) for indigenous Australians, and having not undergone an eye examination in the past 2 years for nonindigenous Australians (OR, 1.54; 95% CI, 1.04-2.27). Uncorrected refractive error and cataract were leading causes of unilateral VI in both populations (70%-75%). Corneal pathology (16.7%) and cataract (13.9%) were leading causes of unilateral blindness in indigenous Australians, while amblyopia (18.8%), trauma (16.7%), and age-related macular degeneration (10.4%) were major causes of unilateral blindness in nonindigenous Australians.

CONCLUSIONS AND RELEVANCE Unilateral vision loss is prevalent in indigenous and nonindigenous Australians; however, most cases are avoidable. As those with unilateral vision loss caused by cataract and posterior segment diseases may be at great risk of progressing to bilateral blindness, national blindness prevention programs may benefit from prioritising examination and treatment of those with unilateral vision loss.

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← Invited Commentary

+ Journal Club Slides

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The profound impact of bilateral vision impairment (VI) and blindness on quality of life, functionality, and mortality has been well characterized.^{1,2} Despite the comparatively smaller body of literature on unilateral vision loss, there is evidence that, despite having a functional fellow eye, those with unilateral vision loss may be greatly affected in several domains. Loss of stereoscopic binocular vision and the reduction in visual fields result in reduced visual-motor coordination, depth perception, and spatial orientation.³ Consequently, people with unilateral vision loss are more likely to have motor vehicle crashes;⁴ they also have a greater propensity for falling, are more dependent on others, and have poorer physical and mental health than the general population.⁵

Most surveys on VI and blindness report the prevalence of bilateral vision loss and neglect unilateral vision loss.⁶⁻⁹ Systematic reviews, including those by the Global Burden of Disease Vision Loss Expert Group^{10,11} and the World Health Organization,¹² have provided comprehensive global epidemiological data on bilateral vision loss, but not unilateral vision loss. The limited number of surveys that have investigated unilateral vision loss have consistently demonstrated that it is more prevalent than bilateral vision loss, ranging from 1.8 times higher in Cape Verde Islands¹³ to about 4 times higher in Vanuatu¹⁴ and Iceland.¹⁵ This highlights the need for interventions to reduce the burden of unilateral vision loss.

In Australia, there is a paucity of population-based data on unilateral vision loss. Current prevalence estimates for the general population are derived from subnational surveys conducted in the 1990s. These surveys included 1 in Victoria that did not report causes of vision loss,⁵ 1 in New South Wales that reported prevalence based on best-corrected visual acuity (BCVA) rather than on presenting visual acuity (PVA)^{16,17} and 1 in South Australia¹⁸ that provided the prevalence of unilateral blindness but not VI. Nonetheless, these surveys indicated that unilateral VI and unilateral blindness are prevalent in older Australians, affecting up to 11.6%⁵ and 3.7%¹⁸ of the population, respectively.

The 2008 National Indigenous Eye Health Survey reported a prevalence of unilateral VI and blindness of 12.8% and 2.7%,¹⁹ respectively, while the Central Australian Ocular Health Study (conducted from 2005 through 2008) reported the prevalence of unilateral blindness (5.2%)²⁰ in the Australian indigenous population. Changes in population parameters since the completion of these studies may affect the epidemiology of unilateral vision loss, such as population aging²¹ and the increasing incidence of diabetes,²² and this necessitates further investigation.

The National Eye Health Survey (NEHS), conducted between March 2015 and April 2016, collected ophthalmological data from a nationally representative sample of indigenous and nonindigenous Australian adults. This article reports the prevalence, causes, and risk factors of unilateral VI and unilateral blindness in indigenous and nonindigenous participants.

Key Points

Question What are the prevalence and major causes of unilateral vision impairment and unilateral blindness in Australia?

Findings This population-based survey included 1738 indigenous Australians and 3098 nonindigenous Australians and found that the age-adjusted and sex-adjusted prevalence of unilateral vision impairment and unilateral blindness were higher in indigenous Australians than in nonindigenous Australians (18.7% and 2.9% vs 14.5% and 1.3%). Uncorrected refractive errors and cataracts were leading causes of unilateral vision impairment in both populations (70%-75%).

Meaning While unilateral vision impairment and unilateral blindness are highly prevalent in Australia, most cases are avoidable, and health care interventions that address unilateral vision loss are therefore warranted.

Methods

Study Population

Participants were selected using multistage random-cluster sampling, as described previously.²³ Population clusters containing a nationally representative sample of indigenous Australians 40 years or older and nonindigenous Australians 50 years or older were identified from 2011 census data. A younger age was selected for indigenous participants to reflect the earlier onset of diseases, such as diabetes, in this population.²⁴ In the first stage of sampling, a pool of 2097 geographic areas defined by the Australian Bureau of Statistics as statistical areas level 2²⁵ were stratified by remoteness (major city, inner regional, outer regional, remote, and very remote), and a total of 30 clusters were selected. A smaller area (statistical area level 1) from within each statistical area level 2 was selected for participant recruitment.

Recruiters used a systematic door-to-door approach (described elsewhere²⁶) to engage residents. To ensure that indigenous participants were recruited in a culturally appropriate manner, recruiters collaborated with indigenous community members to contact residents through several methods, including door-to-door, telephone, word-of-mouth, and concurrent medical clinics. Recruiters contacted 11 883 residents, of whom 6760 (56.9%) were eligible to participate. Indigenous Australians younger than 40 years, nonindigenous Australians younger than 50 years, and those who did not reside at the residence at the time of recruitment were ineligible.

Ethical approval was obtained from Royal Victorian Eye and Ear Hospital Human Research Ethics Committee and state-based indigenous ethical bodies. This study was conducted in accordance with the tenets of the Declaration of Helsinki as revised in 2013. All participants provided written informed consent.

Procedures

Trained examiners including optometrists, an ophthalmologist, orthoptists, and closely supervised research assistants used a standardised questionnaire to collect data on participants' sociodemographic characteristics, ocular histories, and stroke and

diabetes histories. Examiners conducted a standardised eye examination, described in detail elsewhere.²⁶ Presenting visual acuity was assessed in each eye separately using a logMAR chart (Brien Holden Vision Institute, Australia). Unilateral VI and unilateral blindness were defined as PVA of less than 6/12 and 6/60, respectively, in the worse eye, and 6/12 or greater in the better eye. Pinhole testing was conducted on eyes with PVA of less than 6/12. If visual acuity improved to equal to or greater than 6/12, handheld autorefractometry was performed using a Nidek ARK-30 Type-R handheld auto-refractor/keratometer (Nidek Co. Ltd). Best corrected visual acuity was then measured.

The anterior segment was examined using a handheld slit lamp (Keeler Ophthalmic Instruments). If PVA was less than 6/12 in either eye, anterior segment photographs were taken of the affected eye or eyes using the manual anterior segment photography function on a nonmydriatic Digital Retinography System camera (CenterVue, SpA). This camera was also used to take 2-field, 45° color fundus photographs of each retina, centered on the macula and optic disc. Mydriasis was induced with tropicamide, 0.5%, if physiological mydriasis was insufficient to obtain high-quality photographs. Mydriasis was avoided if anterior chamber angles were deemed too narrow (grades 1 or 2 by the Van Herick method) because of the risk of acute angle closure. For these participants, nondilated photography was reattempted and retinal graders at the Centre for Eye Research Australia used the best quality photographs to identify pathology where possible. Intraocular pressure was measured using a tonometer (iCare, Finland). Examiners provided participants with verbal feedback on their results, a certificate of participation, and free sunglasses.

Determining the Main Cause of Unilateral Vision Loss

Trained retinal graders graded the retinal images using OpenClinica software (OpenClinica LLC) according to validated standard protocols.²⁷⁻²⁹ Cataracts were categorized by 2 independent graders based on anterior segment and fundus photographs into 1 of 3 groups: no cataract, probable cataract, or definite cataract. Graders achieved high interrater reliability (85%) and intrarater reliability (94% and 96% for the 2 graders). Any disagreements were adjudicated by a third independent grader. In cases where photographs were unavailable, a cataract grade was assigned based on the anterior segment examination by a trained examiner. Participants deemed to have probable or definite cataracts were considered to have cataracts for the purposes of this study. The condition causing the greatest limitation to vision based on retinal photographs, grading data, and examination results was assigned the main cause of unilateral vision loss. Uncorrected refractive error was assigned as the main cause of unilateral VI if BCVA was 6/12 or greater in the affected eye. For cases in which more than 1 condition was present and none could be discerned as the main cause, VI or blindness were attributed to multiple mechanisms. The cause of VI was considered “not determinable” if no main cause could be identified.

Statistical Analysis

The prevalence of unilateral VI and unilateral blindness was weighted based on the stratified sampling methods. Because

sampling was stratified by indigeneity, the prevalence in indigenous and nonindigenous Australians were derived separately. Weighted proportions were age-adjusted and sex-adjusted to facilitate χ^2 comparisons between indigenous and nonindigenous groups. Univariable and multivariable logistic regression was used to identify risk factors for unilateral vision loss. To provide adequate statistical power in logistic regression analysis, participants with unilateral VI and unilateral blindness (ie, all participants with PVA of less than 6/12 in the worse eye and PVA equal to or greater than 6/12 in the better eye) were combined into 1 group named *unilateral vision loss*. Tabulated data including disaggregated prevalence estimates and risk factors are presented for the combined unilateral vision loss group. All data were analyzed using Stata software version 14.2.0 (StataCorp). *P* values of .05 or less were considered to be statistically significant.

Results

Prevalence of Unilateral Vision Loss

The study sample consisted of 1738 indigenous Australians with a mean (SD) age of 55.0 (10.0) years (range, 40 to 92 years); 714, or 41.1%, were male. An additional 3098 nonindigenous Australians with a mean (SD) age of 66.6 (9.7) years (range, 50-98 years), participated; of these, 1437 (46.4%) were male. A response rate of 71.5% was achieved.

In total, 214 of 1738 indigenous Australians had unilateral VI, with a weighted prevalence of 12.5% (95% CI, 11.0%-14.2%). This corresponds to 16 739 indigenous Australians in the national population. The weighted prevalence of unilateral blindness was 2.4% (95% CI, 1.7%-3.3%) in indigenous Australians (36 of 1738 participants), equivalent to 3188 people in Australia's national indigenous population. In nonindigenous Australians, the weighted prevalence estimates of unilateral VI and unilateral blindness were 14.9% (95% CI, 13.1%-16.8%; 453 of 3098 participants) and 1.4% (95% CI, 1.0%-1.8%; 48 of 3098), respectively, corresponding to an estimated 866 291 and 80 214 nonindigenous Australians in the national population.

The age-adjusted and sex-adjusted prevalence of unilateral VI in indigenous Australians was 18.7% (95% CI, 15.7-21.8), which was significantly higher than in the nonindigenous group, which had an adjusted prevalence of 14.5% (95% CI, 12.8%-16.2%; *P* = .02). Similarly, the adjusted prevalence of unilateral blindness was higher in indigenous Australians (2.9%; 95% CI, 1.4%-4.5%) than in their nonindigenous counterparts (1.3%; 95% CI, 1.0%-1.7%, *P* = .02).

Risk Factors for Unilateral Vision Loss

The prevalence of unilateral vision loss more than quadrupled from 8.0% in indigenous Australians aged 40 to 49 years to 34.3% in those aged 70 to 79 years (Table 1). This increase was significant in multivariable logistic regression (odds ratio [OR], 1.60/decade; 95% CI, 1.39-1.86) (Table 2). Older age increased the odds of unilateral vision loss in nonindigenous Australians (OR, 1.65/decade; 95% CI, 1.38-1.96), with a tripling of the prevalence from 8.1% in those aged 50 to 59 years to 27.2% in those aged 80 to 89 years. Very remote residence

Table 1. Prevalence of Unilateral Vision Loss by Age, Sex, Ethnicity and Remoteness

Characteristic	Indigenous Participants (n = 1738)				Nonindigenous Participants (n = 3098)			
	No. ^a	Crude Prevalence, % (95% CI)	Weighted Prevalence, % (95% CI)	Estimated National Population With Vision Loss	No.	Crude Prevalence, % (95% CI)	Weighted Prevalence, % (95% CI)	Estimated National Population With Vision Loss
Total study population	250	14.4 (12.8-16.1)	14.9 (13.1-16.8)	19 927	501	16.2 (14.9-17.5)	16.0 (14.4-17.7)	946 505
Age, y								
40-49	47	11.3 (6.0-10.6)	8.0 (5.8-10.8)	3562	NA	NA	NA	NA
50-59	100	15.8 (13.1-18.9)	16.2 (13.2-19.7)	7893	68	8.4 (6.5-10.5)	8.1 (6.5-10.1)	127 414
60-69	57	15.7 (12.1-19.9)	16.4 (12.5-21.2)	4513	194	16.6 (14.5-18.9)	16.2 (13.5-19.4)	367 627
70-79	41	30.4 (22.8-28.9)	34.3 (25.3-44.7)	3621	148	25.5 (22.4-28.7)	19.6 (15.5-24.4)	280 456
80-89	5	19.2 (6.6-39.4)	13.8 (6.3-27.9)	338	84	26.2 (21.4-31.3)	27.2 (21.0-34.5)	157 423
≥90	NA	NA	NA	NA	7	20.6 (8.7-37.9)	19.1 (8.3-38.1)	13 585
Sex								
Female	136	13.3 (11.3-15.5)	13.3 (11.4-15.4)	10 470	237	14.3 (12.6-16.0)	14.3 (12.1-16.8)	452 109
Male	114	13.7 (13.4-18.9)	17.1 (14.1-20.6)	9456	264	18.4 (16.4-20.5)	18.0 (16.0-20.1)	494 395
Place of birth								
Oceania	250	14.4 (12.8-16.2)	14.9 (13.1-16.8)	19 927	335	15.1 (13.7-16.7)	14.7 (12.9-16.6)	586 377
Europe	NA	NA	NA	NA	128	19.5 (16.6-22.8)	19.1 (16.5-22.0)	265 257
Others	NA	NA	NA	NA	38	16.7 (12.1-22.2)	18.0 (11.9-26.3)	94 870
Remoteness								
Major city	101	13.5 (11.2-16.2)	13.6 (11.1-16.6)	5965	205	16.4 (14.4-18.5)	16.4 (14.7-18.1)	594 230
Inner regional	44	14.2 (10.5-18.6)	13.5 (10.4-17.4)	4058	92	14.5 (11.8-17.4)	14.9 (10.7-20.3)	217 026
Outer regional	63	15.6 (12.2-19.5)	15.2 (12.5-18.3)	4470	99	15.8 (13.1-18.9)	15.9 (12.9-19.5)	109 286
Remote	22	12.2 (7.8-17.8)	11.1 (6.3-18.9)	1032	72	19.6 (15.7-24.1)	19.1 (17.2-21.2)	20 744
Very remote	20	20.8 (13.2-30.3)	20.4 (13.8-29.0)	4402	33	15.2 (10.7-20.7)	14.9 (7.2-28.1)	5219

Abbreviation: NA, not applicable.

^a Numbers indicate the number of participants with unilateral vision impairment

or unilateral blindness (defined as presenting visual acuity <6/12 in the worse eye and ≥6/12 in the better eye).

was also a risk factor for unilateral vision loss in indigenous Australians (OR, 1.65; 95% CI, 1.01-2.74), as was self-reported diabetes (OR, 1.52; 95% CI, 1.12-2.07). For nonindigenous Australians, having not undergone an eye examination within the past 2 years was a significant risk factor (OR, 1.54; 95% CI, 1.04-2.27).

The Main Causes of Unilateral Vision Loss

Uncorrected refractive error was the leading cause of unilateral VI in both indigenous Australians (n = 138/214; 64.5%) and nonindigenous Australians (n = 257/453; 56.7%) (Table 3). Cataract was the second leading cause in both groups; it was present in 23/214, or 10.7%, of indigenous Australians with VI and 62/453, or 13.7%, of nonindigenous Australians with VI. Diabetic retinopathy (DR) was responsible for 4.2% of unilateral VI in indigenous Australians (n = 9/214), and age-related macular degeneration (AMD) caused 5.7% of unilateral VI in nonindigenous Australians (n = 26/453). More than 6% of nonindigenous Australians (n = 29/453) and more than 3% of indigenous Australians (n = 7/214) had unilateral VI due to amblyopia.

The combined group of other retinal conditions, including macular scarring, macular holes, epiretinal membranes, and retinal detachment, caused almost one-fifth of unilateral blindness in indigenous Australians. Corneal pathology (n = 6/36; 16.7%), cataract (n = 5/36; 13.9%), DR (n = 3/36; 8.3%), ocular

trauma (n = 3/36; 8.3%), and enucleation (n = 3/36; 8.3%) all contributed substantially to the burden of unilateral blindness in this group. In nonindigenous Australians, amblyopia was the leading cause of unilateral blindness (n = 9/48; 18.8%), followed by trauma (n = 4/48; 8.3%), cataract (n = 5/48; 10.4%), and AMD (n = 5/48; 10.4%).

Age-Specific Causes of Unilateral Vision Loss

The age-specific contribution of uncorrected refractive error to unilateral vision loss remained stable from the indigenous Australian subgroups aged 40 to 49 years to 70 to 79 years, and from the nonindigenous Australian subgroups aged 50 to 59 years to 70 to 79 years, after which this proportion decreased as the age-specific attribution of other diseases increased (Table 4). The proportion of vision loss in indigenous Australians due to cataract increased 5-fold from 40 to 49 years (n = 2/47; 4.3%) to 70 to 79 years (n = 8/41; 19.5%) and then increased sharply to 60% in those 80 years or older (n = 3/5). Similarly, DR was responsible for 5 times as many cases of unilateral vision loss in those aged 60 to 69 years than those aged 40 to 49 years. The increase in AMD as a cause of unilateral vision loss in nonindigenous Australians from 1.5% (n = 1/68; 95% CI, 0.04%-7.9%) in the subgroup aged 50 to 59 years to 28.6% (n = 2/7; 95% CI, 3.7%-71.0%) in those older than 90 years (a 19-fold increase) was the largest relative age-related increase for any condition.

Table 2. Logistic Regression Analysis for Risk Factors Associated With Unilateral Vision Loss in Indigenous and Nonindigenous Australians

Risk Factor	Indigenous Participants				Nonindigenous Participants			
	Univariable ^a OR (95% CI)	P Value	Multivariable ^b OR (95% CI)	P Value ^c	Univariable OR (95% CI)	P Value	Multivariable OR (95% CI)	P Value ^c
Increase in prevalence by decade of age	1.75 (1.49-2.06)	<.001	1.60 (1.39-1.86)	<.001	1.66 (1.42-1.96)	<.001	1.65 (1.38-1.96)	<.001
Male	1.29 (0.99-1.68)	.06	1.20 (0.87-1.66)	.26	1.33 (1.07-1.66)	.01	1.29 (0.99-1.68)	.06
Education, y	0.92 (0.87-0.99)	.02	0.97 (0.91-1.03)	.30	0.93 (0.90-0.97)	.001	0.95 (0.91-1.00)	.05
Speaking English at home	0.69 (0.46-1.03)	.07	0.76 (0.51-1.12)	.16	0.70 (0.49-1.01)	.05	0.89 (0.65-1.21)	.43
Place of birth								
Oceania	NA	NA	NA	NA	1	NA	1	NA
Europe	NA	NA	NA	NA	1.40 (1.13-1.74)	.003	1.27 (1.00-1.61)	.05
Other	NA	NA	NA	NA	1.30 (0.76-2.24)	.32	1.40 (0.79-2.49)	.24
Remoteness								
Major city	1	NA	1	NA	1	NA	1	NA
Inner regional	0.99 (0.70-1.41)	.96	0.95 (0.72-1.26)	.72	0.88 (0.59-1.30)	.50	0.81 (0.55-1.22)	.31
Outer regional	1.28 (0.92-1.78)	.14	1.13 (0.74-1.71)	.57	0.98 (0.75-1.29)	.89	0.91 (0.62-1.32)	.60
Remote	0.79 (0.40-1.53)	.46	0.71 (0.41-1.23)	.25	1.20 (0.99-1.47)	.07	1.18 (0.95-1.46)	.13
Very remote	1.83 (1.10-3.06)	.20	1.65 (1.01-2.74)	.05	0.90 (0.38-2.16)	.81	0.86 (0.45-1.64)	.63
Self-reported stroke	1.74 (1.17-2.59)	.01	1.10 (0.63-1.89)	.73	1.32 (0.81-2.16)	.26	0.99 (0.61-1.63)	.98
Self-reported diabetes	2.04 (1.61-2.58)	<.001	1.52 (1.12-2.07)	.01	1.11 (0.77-1.59)	.56	1.01 (0.70-1.46)	.95
Time since last eye examination								
Within 1 y	1	NA	1	NA	1	NA	1	NA
1-2 y	0.74 (0.49-1.10)	.13	0.78 (0.51-1.19)	.24	0.80 (0.60-1.06)	.12	0.94 (0.73-1.21)	.61
>2 y or never	0.86 (0.54-1.36)	.51	0.97 (0.67-1.39)	.86	1.36 (0.96-1.95)	.09	1.54 (1.04-2.27)	.03

Abbreviations: NA, not applicable; OR, odds ratio.

^a Odds ratios and 95% confidence intervals from a univariable logistic regression model.

^b Odds ratios (95% confidence intervals) from a multivariable logistic regression

model, adjusting for the effects of covariates. This model only included factors with associations in univariable analysis with $P < .10$.

^c P values are provided only for factors that were included in multivariable analysis.

Discussion

We have demonstrated that a substantial proportion of both indigenous and nonindigenous Australians are unilaterally vision-impaired or blind, with almost 20 000 indigenous Australians and 1 million nonindigenous Australians affected. These findings, in conjunction with the main causes of unilateral vision loss and epidemiological risk factors identified in this article, will inform comprehensive eye health care programs that include targeted interventions for unilateral vision loss.

The age-adjusted and sex-adjusted prevalence of both unilateral VI and unilateral blindness were higher in indigenous Australians than their nonindigenous counterparts. Although the gap in indigenous eye health has been well-documented,³⁰⁻³² this is the first time, to our knowledge, that the gap in unilateral vision loss between indigenous and nonindigenous Australians has been quantified.

Despite efforts to improve indigenous eye health in recent years,^{33,34} data from 2008^{19,30} suggest that the prevalence of both unilateral VI and unilateral blindness remained unchanged since that point (unilateral VI, 12.5% in 2015 vs 12.8% in 2008; unilateral blindness, 2.4% in 2015

vs 2.7% in 2008). Refractive error and cataract continue to be the leading causes of unilateral VI in this group. These reversible conditions potentially provide a cost-effective target for three-quarters of unilateral vision loss.^{35,36} Those with cataract-related unilateral vision loss may be at risk of having a less-developed cataract in the fellow eye that has not yet become sufficiently dense to impede vision. If left untreated, these individuals may be at high risk of progressing to bilateral vision loss. Strategies aiming to ensure that those with unilateral vision loss undergo regular eye examinations and receive necessary treatments, including cataract extractions, may ultimately serve to narrow the gap in indigenous eye health.

The prevalence of diabetes and the resultant vision loss caused by DR are increasing in Australia.³⁷ Therefore, early detection and treatment of DR is becoming an increasingly important component of efforts to reduce the burden of vision loss. This is further supported by the observed association between unilateral vision loss and self-reported diabetes (odds ratio, 1.52; 95% CI, 1.12-2.07; $P = .01$), and the high prevalence of DR-induced blindness (8.3% of all blindness). Considering that most blindness caused by DR is preventable, the high burden of both unilateral and bilateral vision loss³⁸ in indigenous participants in the NEHS with

Table 3. Main Cause of Unilateral Vision Impairment

Cause	Indigenous Participants		Nonindigenous Participants	
	No.	% (95% CI)	No.	% (95% CI)
Unilateral vision impairment				
All causes	214		453	
Uncorrected refractive error	138	64.5 (57.8-70.7)	257	56.7 (52.1-61.2)
Cataract	23	10.7 (7.2-15.7)	62	13.7 (10.8-17.2)
Amblyopia	7	3.3 (1.5-6.7)	29	6.4 (4.5-9.1)
Diabetic retinopathy	9	4.2 (2.2-7.9)	3	0.7 (0.2-2.0)
Age-related macular degeneration	6	2.8 (1.3-6.1)	26	5.7 (3.9-8.3)
Glaucoma	1	0.5 (0.1-3.3)	6	1.3 (0.6-2.9)
Retinal vein occlusion	3	1.4 (0.4-4.3)	5	1.1 (0.5-2.6)
Other retinal ^a	5	2.3 (1.0-5.5)	22	4.9 (3.2-7.3)
Corneal ^a	1	0.5 (0.1-3.3)	2	0.4 (0.1-1.8)
Trauma	1	0.5 (0.1-3.3)	2	0.4 (0.1-1.8)
Combined mechanisms	1	0.5 (0.1-3.3)	8	1.8 (0.9-3.5)
Other ^b	3	1.4 (0.4-4.3)	7	1.5 (0.7-3.2)
Not determinable	16	7.5 (4.6-11.9)	24	5.3 (3.5-7.8)
Unilateral blindness				
All causes	36		48	
Cataract	5	13.9 (5.6-30.3)	5	10.4 (4.3-23.3)
Amblyopia	1	2.8 (0.4-18.7)	9	18.8 (32.9)
Diabetic retinopathy	3	8.3 (2.6-23.9)	0	0
Age-related macular degeneration	1	2.8 (0.4-18.7)	5	10.4 (4.3-23.3)
Glaucoma	0	0	1	2.1 (0.3-14.2)
Vein occlusion	1	2.8 (0.4-18.7)	0	0
Other retinal ^c	7	19.4 (9.2-36.5)	3	6.3 (1.9-18.3)
Corneal	6	16.7 (7.4-33.4)	1	2.1 (0.3-14.2)
Trauma	3	8.3 (2.6-23.9)	4	8.3 (3.0-20.8)
Enucleation	3	8.3 (2.6-23.9)	7	14.6 (6.9-28.2)
Combined mechanisms	1	2.8 (0.4-18.7)	5	10.4 (4.3-23.3)
Other ^c	2	5.6 (1.3-20.8)	7	14.6 (6.9-28.2)
Not determinable	3	8.3 (2.6-23.9)	1	2.1 (0.3-14.2)

^a Corneal causes of unilateral vision impairment include keratoconus and corneal opacity.

^b Other causes of unilateral vision impairment include tumor, stroke, nonarteritic anterior ischemic optic neuropathy, shingles, cataract surgery complication, posterior capsule opacification, asteroid hyalosis, multifocal choroiditis, corectopia, and congenital defect.

^c Other retinal causes of unilateral blindness include retinitis pigmentosa, macular scar, myopic macular degeneration, macular hole, epiretinal membrane, retinal detachment, Best disease, and toxoplasmosis scarring.

self-reported diabetes points to insufficient availability or uptake of diabetes-related eyecare services.³⁹ These findings, along with the finding that almost 20% of indigenous unilateral blindness was caused by other retinal diseases, necessitates integrated and sustainable models to ensure regular retinal examinations for indigenous Australians. The recent inclusion of reimbursement for DR screening in the Australian national Medicare universal health care system will support this process.⁴⁰

The prevalence of unilateral vision loss in nonindigenous Australians in the NEHS cannot be readily compared with previous Australian studies as they defined vision loss based on BCVA rather than PVA.^{16,18} Additionally, most countries with unilateral vision loss data have used World Health Organization definitions of VI (BCVA <6/18) and blindness (BCVA <3/60), rendering comparisons unreliable.^{7,41-43} However, the Icelandic Reykjavik Eye Study used the same definitions as the NEHS and reported a prevalence of 5.45% for unilateral VI compared with a prevalence of 14.6% in the NEHS.¹⁵ This difference may arise in part via sampling differences, with the NEHS selecting participants from all remoteness strata and the Reykjavik Eye Study focusing on metropolitan areas with good access to care. Nonetheless, considering that both Iceland and Australia are developed

nations, the finding that unilateral VI is more than twice as prevalent in Australia supports the need for improved service availability and uptake. It should, however, be noted that the prevalence of unilateral blindness in the NEHS was half of that in Iceland (1.4% vs 3.06%). Considering that, compared with unilateral blindness, VI has minimal detrimental effects on quality of life,⁴⁴ prioritizing Australians with unilateral blindness through the provision of low-vision services and the slowing of disease progression may be beneficial. A significant proportion of those with unilateral vision loss, particularly those with cataract, DR, and glaucoma, are at risk of progressing to bilateral blindness if left untreated due to the bilaterality of these conditions.^{45,46} Therefore, allocating resources to ensure that those with unilateral vision loss undergo regular eye examinations to ensure treatment of progressive eye diseases, may be an effective public health strategy.

With the exception of AMD, causes of unilateral blindness differed from those of bilateral blindness in nonindigenous participants in the NEHS.⁴⁷ Most saliently, amblyopia was the main cause of 6.4% of VI and 19% of blindness. Amblyopia has frequently been shown to be a major cause of unilateral (but not bilateral) blindness in Australia^{16,18} and other countries.^{15,48} Trauma (16.7%) was another important cause

Table 4. Distribution of the Main Cause of Vision Loss by Age

Main Cause of Vision Loss	Age Group, y, No. (%)					
	40-49 ^a	50-59	60-69	70-79	80-89/≥80 ^a	≥90 ^a
Indigenous Participants						
Total affected persons, No.	47	100	57	41	5	NA
Uncorrected refractive error	24 (51.1)	60 (60.0)	31 (54.4)	22 (53.7)	1 (20)	NA
Cataract	2 (4.3)	8 (8.0)	7 (12.3)	8 (19.5)	3 (60.0)	NA
Amblyopia	3 (6.4)	4 (4.0)	0 (0)	1 (2.4)	0 (0)	NA
Diabetic retinopathy	1 (2.1)	3 (3.0)	6 (10.5)	2 (4.9)	0 (0)	NA
Age-related macular degeneration	2 (4.3)	0 (0)	2 (3.5)	3 (7.3)	0 (0)	NA
Glaucoma	0 (0)	1 (1.0)	0 (0)	0 (0)	0 (0)	NA
Retinal vein occlusion	0 (0)	3 (3)	0 (0)	1 (2.4)	0 (0)	NA
Other retinal	2 (4.6)	6 (6.0)	3 (5.3)	1 (2.4)	0 (0)	NA
Corneal	5 (10.6)	2 (2.0)	0 (0)	0 (0)	0 (0)	NA
Trauma	1 (2.3)	3 (3.0)	0 (0)	0 (0)	0 (0)	NA
Enucleation	0 (0)	0 (0)	3 (5.3)	0 (0)	0 (0)	NA
Combined mechanisms	1 (2.1)	1 (1.0)	0 (0)	0 (0)	0 (0)	NA
Other	2 (4.3)	1 (1.0)	2 (3.5)	0 (0)	0 (0)	NA
Not determinable	4 (8.5)	8 (8.0)	3 (5.26)	3 (7.3)	1 (20.0)	NA
Nonindigenous Participants						
Total affected persons, No.	NA	68	194	148	84	7
Uncorrected refractive error	NA	39 (57.4)	107 (55.2)	79 (53.4)	31 (36.9)	1 (14.3)
Cataract	NA	6 (8.8)	27 (13.9)	25 (16.9)	9 (10.7)	0 (0)
Amblyopia	NA	11 (16.2)	17 (8.8)	7 (4.7)	3 (3.6)	0 (0)
Diabetic retinopathy	NA	0 (0)	1 (0.5)	2 (1.4)	0 (0)	0 (0)
Age-related macular degeneration	NA	1 (1.5)	7 (3.6)	6 (4.1)	15 (17.9)	2 (28.6)
Glaucoma	NA	0 (0)	3 (1.6)	3 (2.0)	1 (1.2)	0 (0)
Retinal vein occlusion	NA	0 (0)	1 (0.5)	2 (1.4)	2 (2.4)	0 (0)
Other retinal	NA	2 (2.9)	10 (5.2)	8 (5.4)	4 (4.8)	1 (14.3)
Corneal	NA	0 (0)	3 (1.6)	0 (0)	0 (0)	0 (0)
Trauma	NA	3 (4.4)	1 (0.5)	2 (1.4)	0 (0)	0 (0)
Enucleation	NA	0 (0)	2 (1.0)	3 (2.0)	2 (2.4)	0 (0)
Combined mechanisms	NA	1 (1.5)	4 (2.1)	4 (2.7)	3 (3.6)	1 (14.3)
Other	NA	1 (1.5)	7 (3.6)	2 (1.4)	3 (3.6)	1 (14.3)
Not determinable	NA	4 (5.9)	4 (2.1)	5 (3.4)	11 (13.1)	1 (14.3)

Abbreviation: NA, not applicable.

^a Included age groups were 40 years and older in the indigenous group and 50 years and older in the nonindigenous group. The oldest age group was 80 years and older for indigenous participants and 90 years and older for

nonindigenous participants; thus, the group labeled "80-89/≥80" included indigenous participants 80 years and older and nonindigenous participants 80 to 89 years old.

of unilateral blindness. Amblyopia, trauma, and some corneal conditions are not age-related eye diseases, and their substantial contribution to the burden of unilateral vision loss in this older population may reflect a similarly high prevalence in younger working-aged Australians in whom the disability burden is likely to be greater due to impediments to occupational functioning.

Strengths of this study included the stratified sampling methodology. In addition, the comprehensive ophthalmic examination facilitated disease attribution.

Limitations

Two important limitations should be considered. First, the cause of unilateral VI and unilateral blindness could not be ascertained for 2.1% to 8.3% of participants, and while these participants were included in the calculation for the prevalence

of unilateral vision loss, the cause of their vision loss was recorded as "not determinable" (Table 2). This was often the result of suboptimal retinal image quality owing to small pupil size or inability to fixate. Second, the sample size calculation was not powered to determine the low prevalence of unilateral blindness or disease, but rather the higher prevalence of vision loss in general. Consequently, there is more uncertainty around the cause-specific prevalence estimates and for unilateral blindness.

Conclusions

In summary, while unilateral vision loss has a less severe personal and societal impact than bilateral vision loss, its comparatively higher prevalence in both indigenous and nonin-

igenous Australians supports the inclusion of unilateral vision loss as a target for national eye health care programs. Approximately three-quarters of unilateral vision loss in Australia could be reversed with integrated spectacle dispensing and cataract services. With the increasing prevalence of DR, cataract, glaucoma, and AMD owing to population aging, those with uni-

lateral vision loss are at risk of progressing to bilateral vision loss because of the bilateral nature of these conditions. Therefore, blindness prevention strategies should allocate sufficient resources to ensure that those with unilateral vision loss undergo regular eye examinations to reduce the burden of VI and blindness in Australia.

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4.2.2.2 Supplementary data: Age-adjusted and sex-adjusted prevalence of unilateral vision loss

The overall age-adjusted and sex-adjusted prevalence of unilateral vision loss (unilateral VI and unilateral blindness combined; PVA<6/12 in the worse eye and PVA $\geq$ 6/12 in the better eyes) was not reported and statistically compared between Indigenous and non-Indigenous Australians in Publication 5, but are provided in this thesis. When combined, the age- and sex-adjusted prevalence of unilateral vision loss was 15.9% (95% CI: 14.2, 17.6) in non-Indigenous Australians and 21.8% (95% CI: 18.3, 25.4) in Indigenous Australians. The age- and sex-adjusted prevalence of unilateral vision loss was significantly higher in Indigenous Australians than non-Indigenous Australians ($P=0.003$).

4.2.3 Publication 6: Prevalence and associations of presenting near vision impairment in the Australian National Eye Health Survey

4.2.3.1 Overview

The third and final paper that addresses objective 1 of this thesis reports the prevalence and epidemiological risk factors of NVI in Australia. Historically, much like unilateral vision loss, NVI has been neglected in ophthalmic epidemiological research, with most studies focusing principally on impairment of bilateral distance vision. In Australia, the only estimate of the prevalence of NVI in the general population was provided by the Melbourne VIP in 1997¹⁸⁸ while the NIEHS reported the prevalence of NVI in Indigenous Australians in 2010.²⁸ The VIP reported the distributions of presenting near vision for males and females, while the NIEHS only reported these distributions for the total sample. Neither study provided further disaggregation of near vision data or characterised risk factors for NVI. These gaps, in conjunction with the likely increase in the prevalence of NVI associated with the ageing of the Australian population, necessitate a thorough and up-to-date analysis of the epidemiology of NVI in Australia. This manuscript was published in *Eye* in February 2018 and was chosen by

the Editor in Chief of Eye to be sent to Medscape CME to facilitate the continuing medical education of registered website users, thereby increasing the accessibility of the article.

Prevalence and associations of presenting near-vision impairment in the Australian National Eye Health Survey

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Abstract

Purpose To describe the prevalence and associations of presenting near vision impairment (NVI) in Indigenous and non-Indigenous Australians.

Methods A sample of 3098 non-Indigenous Australians (aged 50–98 years) and 1738 Indigenous Australians (aged 40–92 years) living in 30 randomly selected Australian sites were examined as part of the population-based National Eye Health Survey (NEHS). Binocular presenting NVI was defined as near vision worse than N8 (20/50).

Results In total, 4817 participants (99.6% of the total sample, comprising 3084 non-Indigenous Australians and 1733 Indigenous Australians) had complete data on near visual acuity. The overall weighted prevalence of presenting NVI was 21.6% (95% CI: 19.6, 23.8) in non-Indigenous Australians and 34.7% (95% CI: 29.2, 40.8) among Indigenous Australians. In the non-Indigenous population, higher odds of presenting NVI were associated with older age (OR = 1.68 per 10 years, $P < 0.001$), fewer years of education (OR = 0.95 per year, $P < 0.001$) and residing in Remote geographical areas (OR = 1.71, $P = 0.003$) after multivariate adjustments. Among Indigenous Australians, older age (OR = 1.69 per 10 years, $P < 0.001$), fewer years of education (OR = 0.91 per year, $P = 0.003$) and residing in Inner Regional (OR = 2.01, $P = 0.008$), Outer Regional (OR = 2.17, $P = < 0.001$) and Remote geographical areas (OR = 1.72, $P = 0.03$) were associated with greater odds of presenting NVI.

Conclusions NVI represents a notable public health concern in Australia, affecting approximately 20% of non-Indigenous

Australian and one-third of Indigenous Australian adults.

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Introduction

Near vision impairment (NVI) is an important public health problem in our aging society. The prevalence of NVI increases substantially with age, with the majority of cases attributed to presbyopia. NVI significantly impacts on quality of life (QoL),^{1–3} and poses a considerable financial burden with an estimated global productivity loss of over \$25 billion.⁴ Currently, there is a paucity of reliable data on the prevalence of NVI from population-based surveys conducted in Australia. As the majority of NVI is readily treatable with spectacle correction, this data is useful to quantify Australia's burden of NVI and inform targeted resource allocation.

Until recently, very few countries had estimated the prevalence NVI, with the majority focusing solely on distance visual impairment and its causes. To date, the most robust epidemiological data can be derived from He and co-workers (2014)⁵ who assessed the prevalence of NVI ($\leq 20/40$) across multiple countries, including China, India, Nepal, Niger, South Africa and the United States. The prevalence of best-corrected NVI was reported to range from 10% in urban China to 23% in urban India. More recently, the National Health and Nutrition Survey (NHANS) conducted in the United States reported the prevalence of presenting NVI ($< 20/40$) to be 13.6% among

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adults 50 years and over.⁶ In Australia, only one population-based study conducted in 1992, the Melbourne Visual Impairment Project (VIP), has provided estimates of the distribution of NVI in non-Indigenous adults.⁷ Adopting the slightly more conservative definition than NHANS, $<20/50$, the VIP⁸ reported the prevalence of presenting NVI to be 19% in Australian adults aged 40 years or over. Considerably higher rates have been reported in a nationally representative cohort of Indigenous Australian adults, with Taylor *et al* (2008)⁹ reporting the prevalence of 40% for presenting NVI. Despite this, robust comparisons between these studies are problematic due to differences in testing protocols employed and age distributions of participants. Furthermore, given the continual aging of Australia's population and an increasing reliance on adequate near vision to engage in daily activities such as the use of computers and hand-held devices, up-to-date data on the prevalence of NVI in Australia are warranted.

The National Eye Health Survey (NEHS), with its nationally representative sample stratified by Indigenous status, provides an ideal setting in which to investigate the epidemiology of NVI in the Australian population. Herein, we describe the prevalence and associations of NVI in Indigenous Australians aged 40 years and over and non-Indigenous Australians aged 50 years and over.

Materials and methods

Study population

The NEHS is a population-based, cross-sectional survey conducted between March 2015 and April 2016 with the primary objective of determining the prevalence and causes of vision impairment and blindness in non-Indigenous Australians aged 50 years and older, and Indigenous Australians aged 40 years and older. The sampling, recruitment and clinical testing methodologies has been described in detail elsewhere.^{10,11} In brief, a multi-stage, cluster sampling methodology was utilised to select thirty Australian sites across five Remoteness Areas (RAs) which included; Major City, Inner Regional, Outer Regional, Remote and Very Remote geographical areas. Participants were recruited door-to-door and high overall positive response rates and examination rates were achieved (83.5% and 71.5%, respectively). Ethics approval was obtained from the Royal Victorian Eye and Ear Hospital Human Research Ethics Committee (HREC-14/1199H) and additional ethical approvals were obtained at the State level to conduct research within Indigenous communities. Study procedures adhered to the tenets of the Declaration of Helsinki as revised in 2013 and participants provided written informed consent to participate.

Examination procedures

Sociodemographic data including age, gender, Indigenous status, ethnicity, years of education, language spoken at home, utilisation of eye health services, as well as medical and ocular histories were collected via an interviewer-administered questionnaire. Ethnicity was categorised according to the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG) 2011.¹²

Self-reported use of near, distance or bifocal corrective lenses were recorded at the time of examination. Presenting distance visual acuity was measured in each eye using a logMAR chart (Brien Holden Vision Institute, Australia) in well-lit room conditions. Participants wore their usual distance correction if available at the time of examination. Pinhole testing was performed on participants with visual acuity $<6/12$ in one or both eyes, followed by automated refraction (Nidek ARK-30 Type-R Hand-held auto-refractor/keratometer, Nidek Co., LTD, Tokyo, Japan) if VA improved to $\geq 6/12$ in either eye. Vision loss was defined as a visual acuity of $<6/12$ in the better eye. Participants with vision loss were considered to have uncorrected or under-corrected refractive error if the distance visual acuity improved to $\geq 6/12$ with pinhole testing or auto-refraction in one or both eyes. Vision loss from other causes was defined as a best-corrected visual acuity of $<6/12$ in the better eye. Binocular presenting near vision was assessed using a CERA tumbling E near vision card (Centre for Eye Research Australia, Australia) held at the participant's preferred reading distance. Near correction was worn if normally used and near vision was recorded as N8, N20, N48 or $<N48$. Presenting NVI was defined as near vision worse than N8.

Statistical analysis

Participant demographic characteristics were summarized by mean and SD for normally distributed continuous data, or the median and inter-quartile range for skewed distributed data, and counts and percentages for categorical data. Normality was examined using boxplots, Kolmogorov-Smirnov and Shapiro-Wilks tests. Ninety-five percent confidence intervals (CI), taking into account the sampling design, were calculated for participant demographic characteristics and the prevalence of NVI.

The main outcome was the presence of NVI (yes = 1, no = 0). Key explanatory variables included age, gender, ethnicity, years of education, language spoken at home, remoteness, history of diabetes and history of stroke. Univariate and multivariable binary logistic regression analysis was used to identify factors associated with the

presence of NVI. Lack of multicollinearity between the independent variables in the model was verified by Box-Tidwell transformation. Statistical interaction was tested for all key explanatory variables of NVI. A plot of the residuals compared with estimates was examined to determine whether the assumptions of linearity and homoscedasticity were met. Odds ratios (OR) will be quoted together with their 95% confidence intervals (CI) and *P*-values.

The NEHS employed a multistage cluster sample survey design. Sampling error may be underestimated and the probability of type I error may be increased if the multistage sample design was not taken into consideration in analysis. All analyses were performed by adjusting for stratification and clustering in the sampling procedure, namely incorporating the sampling weights, to obtain unbiased estimates for the NEHS sampling design. Analyses were conducted with Stata version 14.2.0 (Stata Corp, College Station, TX, USA). A two-tailed *P*-value <0.05 was considered statistically significant.

Results

Participant characteristics

A total of 4836 individuals were examined in the NEHS, including 3098 non-Indigenous and 1738 Indigenous Australians, respectively. Of these, 4817 (99.6%, 3084 non-Indigenous and 1733 Indigenous) participants had complete data on near visual acuity. The sample of non-Indigenous Australians had a mean age of 66.7 years (SD=9.7) while the mean age of Indigenous participants was 55.0 years (SD=10). Non-Indigenous Australians were 59% female and Indigenous Australians were 54% female. A total of 91.2% (2807/3084) non-Indigenous and 73.7% (1277/1733) Indigenous participants reported using near vision correction.

Prevalence of near vision impairment

Non-Indigenous population In the non-Indigenous population aged 50 years and over, the overall weighted prevalence of presenting NVI was 21.6% (95% CI: 19.6, 23.8; 707/3084). The weighted prevalence of NVI increased with age, with the following age-specific prevalence rates; 14.2% in those 50–59 years, 19.4% in those aged 60–69 years, 24.5% in those aged 70–79 years and 41.5% in those aged ≥ 80 years (Table 1, *P*<0.001). Presenting NVI was found in 23.9% (95% CI: 21.2, 27.1) of males and 19.6% (95% CI: 16.9, 22.5) of females in the non-Indigenous population (*P*=0.26). Of the total 21.6% of non-Indigenous participants with presenting NVI, 66.1% (467/707) used near correction at the time of examination,

Table 1 Crude and weighted prevalence of presenting NVI (<N8) by Indigenous status, age and gender

Variable	n ^a	Crude % (95% CI)	Weighted % (95% CI)
<i>Non-Indigenous</i>			
Female	338	20.5 (18.5, 22.5)	19.6 (16.9, 22.5)
Male	369	25.8 (23.5, 28.1)	24.0 (21.2, 27.1)
<i>Age, years</i>			
50–59	125	15.4 (13.0, 18.0)	14.2 (11.7, 17.1)
60–69	243	20.9 (18.6, 23.3)	19.4 (16.5, 22.7)
70–79	192	25.5 (22.5, 28.7)	24.5 (21.7, 27.5)
80+	147	41.8 (36.7, 47.0)	41.5 (34.2, 49.1)
Total	707	22.9 (21.5, 24.5)	21.6 (19.6, 23.8)
<i>Indigenous</i>			
Female	320	31.3 (28.5, 34.3)	34.2 (28.0, 41.0)
Male	246	34.6 (31.1, 38.2)	35.5 (29.8, 41.6)
<i>Age, years</i>			
40–49	352	29.1 (26.6, 31.7)	30.8 (25.1, 37.1)
50–59	130	36.0 (31.2, 41.1)	37.9 (29.1, 47.5)
60–69	74	54.8 (46.3, 63.0)	57.7 (48.1, 66.7)
70+	10	38.5 (21.8, 58.3)	52.6 (27.6, 76.4)
Total	566	32.7 (30.5, 34.9)	34.7 (29.2, 40.8)

^an, number of participants with NVI.

and 23.3% (165/707) reported using near correction but did not wear corrective lenses at the time of examination. The remaining 10.6% (75/707) of participants with NVI did not wear near corrective lenses at the time of their examination and reported that they did not use near correction. Among those with presenting NVI, 82.3% (582/707) had normal presenting distance vision (>6/12 in the worse eye), 7.9% (56/707) had uncorrected or under-corrected distance refractive error and the remaining 9.8% (69/707) had distance vision loss resulting from other causes.

Indigenous population Among Indigenous Australians aged 40 years and older, the overall weighted prevalence of presenting NVI was 34.7% (95% CI: 29.2, 40.8; 566/1733). The prevalence of NVI was 35.5% for males and 34.2% for females (*P*=0.59). Similarly to the non-Indigenous population, presenting NVI increased with age (40–49 years = 30.8%; 50–59 years = 37.9%; 60–69 years = 57.7%; >70 years = 52.6%, *P*<0.001). Of those with presenting NVI, 21.2% (120/566) wore near correction at the time of examination and an additional 51.2% (290/566) self-reported using near correction but did not have corrective lenses at the time of examination, with remaining 27.6% (156/566) reporting that they do not use near correction. The majority of Indigenous Australians with presenting NVI had normal distance vision (77.9%, 441/566), with 11% (62/566) having uncorrected or under-corrected refractive error and 11.1%

Table 2 Sampling weight adjusted multivariable logistic regression analysis investigating associations for NVI in non-Indigenous participants

Risk factor	Univariate OR [95% (CI)]	P ^a	Model 1 OR ^b [95% (CI)]	P	Model 2 OR ^c [95% (CI)]	P
Age (10 years)	1.62 (1.42, 1.85)	<0.001	1.68 (1.46, 1.93)	<0.001	1.69 (1.43, 2.00)	<0.001
Gender (male)	1.29 (1.03, 1.63)	0.03	1.14 (0.91, 1.43)	0.26	1.06 (0.83, 1.36)	0.60
Education (years)	0.92 (0.90, 0.94)	<0.001	0.95 (0.93, 0.97)	<0.001	0.95 (0.93, 0.98)	<0.001
English at home	0.58 (0.39, 0.84)	0.01	0.72 (0.43, 1.19)	0.19	0.61 (0.32, 1.15)	0.12
<i>Ethnicity</i>						
Oceanian	1		1		1	
European	1.22 (0.99, 1.49)	0.06	1.08 (0.90, 1.31)	0.40	1.04 (0.83, 1.31)	0.71
Other	1.22 (0.77, 1.92)	0.38	1.12 (0.73, 1.73)	0.58	1.04 (0.65, 1.66)	0.86
<i>Remoteness</i>						
Major City	1		1			
Inner regional	0.99 (0.76, 1.27)	0.91	1.10 (0.79, 1.52)	0.56	1.08 (0.75, 1.57)	0.66
Outer regional	1.36 (0.88, 2.10)	0.16	1.30 (0.70, 2.40)	0.39	1.26 (0.65, 2.47)	0.48
Remote	1.61 (1.10, 2.35)	0.02	1.71 (1.22, 2.40)	0.003	1.65 (1.18, 2.31)	0.005
Very remote	1.05 (0.85, 1.32)	0.60	1.05 (0.57, 1.95)	0.86	0.84 (0.49, 1.45)	0.52
Self-reported stroke	1.67 (1.16, 2.42)	0.01	1.24 (0.80, 1.91)	0.32	1.24 (0.92, 1.66)	0.15
Self-reported diabetes	1.55 (1.23, 1.97)	0.001	1.27 (0.99, 1.22)	0.06	1.45 (0.87, 2.42)	0.14
Time since last eye examination						
Within 1 year	1		1		1	
1 to 2 years	0.80 (0.65, 0.98)	0.03	0.92 (0.70, 1.22)	0.55	0.92 (0.67, 1.28)	0.62
2 to 5 years	1.02 (0.65, 1.60)	0.93	0.89 (0.55, 1.45)	0.64	0.85 (0.50, 1.44)	0.53
>5years or never	1.60 (1.08, 2.38)	0.02	1.23 (0.83, 1.83)	0.30	1.08 (0.68, 1.71)	0.74
Distance vision						
Normal (>6/12 in the better eye)	1		1		1	
Refractive error	3.65 (2.62, 5.08)	<0.001	3.65 (2.43, 5.47)	<0.001	3.96 (2.57, 6.09)	<0.001
Vision loss (<6/12 in the better eye)	16.72 (9.00, 31.03)	<0.001	9.25 (4.33, 19.78)	<0.001	11.21 (3.95, 31.82)	<0.001
Near-vision correction						
Does not have	1		1		1	
Has corrective lenses	0.69 (0.46, 1.02)	0.06	0.57 (0.38, 0.88)	0.01	0.56 (0.37, 0.86)	0.010
Has but did not wear	4.84 (3.06, 7.64)	<0.001	5.57 (3.25, 9.54)	<0.001	—	—

Abbreviations: CI, confidence interval; OR, odds ratio. ^aStatistical significance was set as a *P*-value of ≤ 0.05 (two tailed). ^bModel 1: includes all study participants, adjusted for all factors in the model. ^cModel 2: excluded participants who self-reported using near correction but did not have corrective lenses at the time of examination, adjusted for all factors in the model.

(63/566) displaying distance vision loss from other causes. Table 1

Extrapolating these findings to the Australian population, we estimate that ~1 274 792 non-Indigenous Australians aged 50 years and over and 46 455 Indigenous Australians aged 40 years and over have NVI.

Associations between presenting near vision impairment and selected characteristics

Non-Indigenous population Multivariate logistic regression analysis revealed that older age (OR = 1.68 per 10 years, $P < 0.001$), fewer years of education (OR = 0.95 per year, $P < 0.001$) and residing in Remote geographical areas (OR = 1.71, $P = 0.003$) were associated with presenting NVI (Table 2). Additionally, the prevalence of presenting NVI was higher among participants with

bilateral distance vision loss due to uncorrected refractive error (OR = 3.65, $P < 0.001$) and those with bilateral distance vision loss from other causes (OR = 9.25, $P < 0.001$). After excluding all participants who forgot their near correction, all of these associations remained.

Indigenous population After adjusting for covariates, older age (OR = 1.69 per 10 years, $P < 0.001$), female gender (OR = 0.75, $P = 0.03$), fewer years of education (OR = 0.91 per year, $P = 0.003$) and self-reported stroke (OR = 1.79, $P = 0.004$) were associated with presenting NVI among Indigenous Australians (Table 3). Geographic remoteness was associated with presenting NVI, with participants residing in Inner Regional (OR = 2.01, $P = 0.008$), Outer Regional (OR = 2.17, $P < 0.001$) and Remote areas (OR = 1.72, $P = 0.03$) being more likely to have presenting NVI than those in Major City areas.

Table 3 Sampling weight adjusted multivariable logistic regression analysis investigating associations for NVI in Indigenous participants

<i>Risk factor</i>	<i>Univariate OR (95% (CI))</i>	<i>P-value^a</i>	<i>Model 1 OR^b (95% (CI))</i>	<i>P-value</i>	<i>Model 2 OR^c (95% (CI))</i>	<i>P-value</i>
Age (10 years)	1.50 (1.31, 1.71)	<0.001	1.69 (1.37, 2.07)	<0.001	1.63 (1.26, 2.11)	0.001
Gender (male)	1.06 (0.85, 1.31)	0.59	0.74 (0.56, 0.97)	0.03	0.77 (0.54, 1.10)	0.14
Education (years)	0.87 (0.82, 0.93)	<0.001	0.91 (0.85, 0.96)	0.003	0.90 (0.84, 0.97)	0.01
English at home	0.72 (0.33, 1.59)	0.41	0.93 (0.36, 2.40)	0.88	0.77 (0.35, 1.70)	0.50
<i>Remoteness</i>						
Major City	1		1		1	
Inner Regional	1.57 (0.91, 2.73)	0.10	2.02 (1.22, 3.35)	0.008	1.92 (0.95, 3.87)	0.07
Outer Regional	2.26 (1.62, 3.15)	<0.001	2.17 (1.46, 3.20)	<0.001	2.34 (1.40, 3.92)	0.002
Remote	1.52 (1.05, 2.19)	0.03	1.72 (1.06, 2.80)	0.03	1.65 (0.97, 2.82)	0.07
Very remote	2.47 (0.72, 8.45)	0.14	2.78 (0.46, 16.74)	0.25	3.71 (0.65, 21.30)	0.14
Self-reported stroke	2.19 (1.45, 3.30)	0.001	1.79 (1.23, 2.62)	0.004	1.06 (0.74, 1.51)	0.75
Self-reported diabetes	1.46 (1.09, 1.96)	0.01	0.94 (0.60, 1.47)	0.79	1.40 (0.86, 2.26)	0.17
<i>Time since last eye examination</i>						
Within 1 year	0.82 (0.60, 1.12)	0.21	0.81 (0.61, 1.08)	0.14	1	
1 to 2 years	0.92 (0.69, 1.24)	0.58	0.90 (0.65, 1.26)	0.53	0.79 (0.52, 1.19)	0.24
2 to 5 years	1.08 (0.69, 1.69)	0.73	0.95 (0.62, 1.47)	0.82	0.83 (0.54, 1.27)	0.38
>5years or never					1.19 (0.74, 1.93)	0.46
<i>Distance vision</i>						
Normal (>6/12 in the better eye)	1		1		1	
Refractive error	2.39 (1.56, 3.68)	<0.001	2.13 (1.43, 3.17)	0.001	2.35 (1.37, 4.04)	0.003
Vision loss (<6/12 in the better eye)	21.35 (11.29, 40.38)	<0.001	16.83 (7.39, 38.31)	<0.001	20.50 (7.66, 54.86)	<0.001
<i>Near-vision correction</i>						
Does not have	1		1		1	
Has corrective lenses	0.33 (0.26, 0.42)	<0.001	0.19 (0.13, 0.28)	<0.001	0.22 (0.15, 0.31)	<0.001
Has but did not wear	2.44 (1.57, 3.81)	<0.001	2.56 (1.95, 3.35)	<0.001	—	—

Abbreviations: CI, confidence interval; OR, odds ratio.^aStatistical significance was set as a *P* value of ≤ 0.05 (two tailed).^bModel 1: includes all study participants, adjusted for all factors in the model.^cModel 2: excluded participants who self-reported using near correction but did not have corrective lenses at the time of examination, adjusted for all factors in the model.

Similarly to the non-Indigenous population, participants with bilateral distance vision loss due to uncorrected refractive error (OR=3.65, $P<0.001$) and those with bilateral distance vision loss from other causes (OR=9.25, $P<0.001$) were more likely to have presenting NVI. With the exception of female gender and self-reported stroke, all of the above associations remained after excluding all participants who forgot their near correction.

Discussion

This paper presents the prevalence and associations of presenting NVI in a national sample of non-Indigenous and Indigenous Australian adults. The weighted prevalence of presenting NVI amongst non-Indigenous and Indigenous Australians was 21.6% and 34.7%, respectively. By identifying significant risk factors for NVI, including older age, fewer years of education and residing in regional and remote geographical areas this paper may inform targeted resource allocation to reduce the burden of NVI in high risk groups in the Australian population.

Previous research has suggested that distance visual acuity correlates well with near vision.⁷ In the present study, nearly 90% of all non-Indigenous and Indigenous participants with presenting NVI displayed normal distance vision (>6/12 in the better eye) or uncorrected refractive error. This suggests that a substantial proportion of NVI in Australia may be easily corrected with spectacles.

Among non-Indigenous Australians in the NEHS, the weighted prevalence of presenting NVI (21.6%) was marginally higher than that reported in the Melbourne VIP (19%),⁸ and other population-based reports from developed nations.^{6,13} However, these comparisons must be viewed with caution due to differing definitions of NVI and age distributions of populations. For instance, non-Indigenous NEHS participants were, on average, older (mean age; NEHS=67 years *vs* VIP=60 years) than Melbourne VIP participants. Furthermore, the Melbourne VIP sampled participants from a predominantly urban population, where the availability of eye health care services is highest.^{14,15} Therefore, the higher prevalence reported in the NEHS may be partly attributed to the

well-recognised association between NVI and age, coupled with a more inclusive geographical representation of the Australian population. Nonetheless, it remains that a substantial proportion of adults aged 50 years and over had NVI in the current study, reflecting the need to improve utilisation of eye health services, particularly by those with poorer education and those of older age. This may be achieved, in part, through eye health promotion to improve awareness and eye health literacy within Australian communities.

In recent years, several initiatives have been implemented to close the gap in Indigenous eye health,¹⁶ including those targeted at providing free or subsidised spectacles for refractive errors including presbyopia.¹⁷ For Indigenous Australians aged 40 years and over in the NEHS, the prevalence of presenting NVI (34.7%) was lower than that reported in the National Indigenous Eye Health Survey (2008) (40%).⁹ It must also be noted that among Indigenous NEHS participants with presenting NVI, 51% self-reported using near correction but did not have corrective lenses at the time of examination, suggesting that the prevalence of NVI is likely to be overstated in the present study. This finding, taken in light of the fact that the Indigenous NEHS cohort was, on average, older (mean age; NEHS = 58 years *vs* NIEHS = 50 years) than NIEHS participants, provides evidence for a possible decline in the prevalence of NVI amongst Indigenous Australians. While these findings may point to improvements in the treatment coverage of NVI, it is clear that continued efforts are required to provide equitable access to eye health care services in Indigenous communities.

In the present study, non-Indigenous Australians residing in Remote geographical areas and Indigenous Australians residing in Regional and Remote geographical areas were on average 1.5 to 2.5 times more likely to have presenting NVI than participants from urban areas. This finding is perhaps not surprising given that a disproportionately low availability of services and specialists exists in nonmetropolitan areas of Australia.^{18,19} While considerable emphasis has been placed on providing equitable access to eye health services across remoteness strata,²⁰ our findings suggest that improvements in availability of optometric services in Regional and Remote areas may be warranted. Where feasible, these services should be integrated within Aboriginal Medical Services (AMS) to maximise utilisation within Indigenous communities.²¹ Furthermore, given the simplicity of near vision assessment coupled with the low-cost of near-vision corrective spectacles, improvements in the availability of ready-made glasses for presbyopia correction may be effective within primary care settings.

The strengths of this study include its population-based design, stratification by Indigenous status and nearly complete data (99.6%) for near vision. A number of limitations must also be considered. First, participants with presenting NVI did not undergo binocular refraction for near and as a result we were unable to accurately ascertain the met need among those with correctable NVI. Second, near vision was not assessed at a pre-set standard distance, but rather at participant's preferred reading distance. While this may have resulted in an underestimation of the prevalence of presenting NVI, our method is likely to better reflect normal daily functional requirements. Finally, a large proportion of non-Indigenous (23%) and Indigenous Australians (51%) with NVI self-reported using near correction but did not have corrective lenses at the time of examination. If it were assumed that a large proportion of these participants did not have NVI, we may have overestimated the prevalence of NVI in the Australian population. Despite this, the authors feel that the inclusion of these participants within the definition of presenting NVI better reflects current near visual function and glasses utilisation amongst the Australian non-Indigenous and Indigenous adult population.

In summary, NVI represents a notable public health concern in Australia, with ~20% of non-Indigenous and one-third of Indigenous Australian adults displaying a reduction in their presenting near vision. Our data have identified several high-risk groups that may benefit from focused resource allocation including; older Australians and those with fewer years of education, non-Indigenous Australians residing in Remote locations and Indigenous Australians residing in Inner Regional, Outer Regional and Remote geographical areas. Given the considerable burden of NVI, and its feasibility of treatment in most cases, Australia may benefit from prioritisation of uncorrected presbyopia.

Summary

What was known before

- Currently, there is a paucity of reliable data on the prevalence of near vision impairment from population-based surveys conducted in Australia.

What this study adds

- As the majority of NVI is readily treatable with spectacle correction, this data is useful to quantify Australia's burden of near vision impairment and inform targeted resource allocation.
-

Conflict of interest

The authors declare no conflict of interest.

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4.2.3.2 Supplementary data: Age- and sex-adjusted prevalence and remoteness stratified prevalence of near vision impairment

The age- and sex-adjusted estimates for Indigenous and non-Indigenous Australians were not statistically compared in Publication 6 and are provided here. The age- and sex-adjusted prevalence of NVI was 34.7% (95% CI: 28.8, 40.7) in Indigenous Australians and 21.6% (95% CI: 19.7, 23.6) in non-Indigenous Australians (OR: 3.45, $P<0.0001$) Further, the prevalence of NVI was disaggregated by Indigenous status, age and gender, however the remoteness-stratified data were not included in the final publication. As the prevalence of NVI differed by geographic remoteness for both Indigenous and non-Indigenous Australians in multivariable logistic regression, the inclusion of these estimates is likely to benefit public eye health policy formulation, and are provided in Table 4.

Table 4. Weighted prevalence of near vision impairment in non-Indigenous and Indigenous Australians by geographic remoteness

	Non-Indigenous Australians (n=3098)	Indigenous Australians (n=1738)
Remoteness	Weighted prevalence % (95% CI)	Weighted prevalence % (95% CI)
Major City	20.8 (18.3-23.2)	33.7 (28.2-39.2)
Inner Regional	20.5 (17.1-23.8)	45.1 (32.5-57.6)
Outer Regional	26.0 (18.2-33.9)	54.3 (47.1-61.5)
Remote	29.0 (21.9-36.1)	43.6 (36.4-50.1)
Very Remote	19.1 (13.9-24.3)	51.6 (20.0-83.1)

CI=confidence interval

4.3 The utilisation of eye health care services in Australia

4.3.1 Overview

This section presents results in line with Aim 2 of this thesis: To determine rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and both cataract surgery coverage and refractive error treatment coverage rates in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia. The majority of vision loss cases are

avoidable through appropriate engagement with health care service providers.¹⁶ Most notably, most cases of the leading cause of vision loss, uncorrected refractive error, are correctable with spectacles, contact lenses or refractive surgery,²⁶⁸ while the second leading cause of vision loss, cataract, is generally readily reversible through surgical extraction and intraocular lens (IOL) insertion.^{334, 335} Furthermore, early detection of DR in those with diabetes through regular dilated fundus examinations provides an opportunity for timely treatment before the onset of irreversible blindness.⁶⁷ Consequently, quantifying how the older Australian population engages with eye health care services is equally important as ascertaining the causative diseases of vision loss for optimising efforts to reduce the prevalence of VI and blindness in Australia.

The results pertaining to Aim 2 are presented below in four publications. The first presents the utilisation of eye health care services, including the distribution of times (in years) since participants' last eye examination, the types of eye health care services provider most recently engaged, and variables associated with these behaviours. The second paper presents adherence rates to NHMRC diabetic eye examination guidelines by participants with self-reported diabetes. The third paper reports cataract surgery coverage rates while the fourth reports refractive error treatment coverage rates. Together, these four manuscripts provide a comprehensive account of the utilisation of eye health care services by both Indigenous and non-Indigenous Australian adults.

4.3.2 Publication 7: Utilization of eye health-care services in Australia: the National Eye Health Survey

4.3.2.1 Overview

The fundamental prerequisite for detection and treatment of vision-impairing or blinding eye conditions is an eye examination by a health care provider, and older Australians are therefore encouraged to undergo regular eye examinations to increase disease detection and treatment

coverage rates. However, it has been reported that as many as 9% of older non-Indigenous Australians and 35% of older Indigenous Australians had never had an eye examination, while as few as 61% of non-Indigenous Australians had biennial eye examinations and 15% of Indigenous Australians had annual eye examinations (in accordance with NACCHO and RACGP guidelines).^{245 246, 250}

Older Australians who do not undergo sufficiently frequent eye examinations are likely to be at greater risk of undiagnosed and untreated eye disease, and are therefore at greater risk of avoidable vision loss. To quantify the rates of utilisation of eye health care services in a nationally-representative sample, Publication 7 reports the distributions of times (in years) since participants underwent their last eye examination, disaggregated by sociodemographic variables and self-reported ocular disease status. The results of a multinomial multivariable logistic regression analysis present the associations between each variable and times since participants' last examination to identify those most at risk. The types of eye health care providers last visited by participants and associated risk factors are also presented. This paper was published in *Clinical and Experimental Ophthalmology* on the 6th of September 2017.

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Original Article

Utilization of eye health-care services in Australia: the National Eye Health Survey

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ABSTRACT

Importance: National data on eye health-care service utilization will inform Australia's eye health policy.

Background: To investigate the utilization of eye health-care services by Australians.

Design: Cross-sectional survey.

Participants: Indigenous Australians aged 40 years and older and non-Indigenous Australians aged 50 years and older.

Methods: One thousand seven hundred thirty-eight Indigenous Australians and 3098 non-Indigenous Australians were recruited from 30 randomly selected sites, stratified by remoteness. Sociodemographic, ocular history and eye health-care service utilization data were collected, and an eye examination was conducted.

Main outcome measures: Recentness of eye examinations, types of providers used and associated risk factors.

Results: Approximately 67.0% of Indigenous Australians and 82.5% of non-Indigenous Australians underwent an eye examination within the previous 2 years. Indigenous status ($P < 0.001$), male gender ($P < 0.001$), Outer Regional ($P < 0.001$) and Very Remote ($P < 0.001$) residence

were associated with less recent examinations. Participants with >self-reported eye disease or diabetes were most likely to have been examined within the past year ($P < 0.001$). For Indigenous Australians, older age was associated with recent eye testing ($P = 0.001$). Those with retinal disease and cataract were more likely to see an ophthalmologist ($P < 0.001$), and those with refractive error were more likely to see an optometrist ($P < 0.001$). In Regional Australia, non-Indigenous people were more likely to see optometrists ($P < 0.001$), and Indigenous Australians were more likely to utilize other, non-specialist services ($P < 0.001$).

Conclusions and relevance: Eye examination frequency has improved in Indigenous and non-Indigenous Australians compared with previous population-based research. Further improvements are required in risk groups including Indigenous Australians and those living in Regional and Remote areas.

Key words: eye health care, eye test, indigenous health, national survey, population health.

INTRODUCTION

The International Agency for the Prevention of Blindness classifies Australia as a 'Category A' country (the

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highest rating) for nationwide distribution of eye care services.¹ Service availability is particularly high in metropolitan areas, in which 70% of Australians reside.² Despite this, more than 500 000 Australians aged 40 years and older are estimated to have vision impairment (VI) or blindness, and vision loss persists as a public health concern.³ Almost 80% of vision loss in Australia is caused by uncorrected refractive error and cataract, both of which are readily and affordably reversible through spectacle correction or surgeries.³ The vision loss caused by other major eye conditions including diabetic retinopathy, age-related macular degeneration (AMD) and glaucoma may be better managed through early detection, prevention and treatment strategies.⁴

Population-based studies conducted in Australia have identified insufficiencies in the availability and utilization of eye health services. Indigenous Australians, those with diabetes, those of lower socio-economic status, men, those for whom English is not their main spoken language and individuals with eye disease are under-served.^{5–8} A disproportionately low availability of services has been noted in non-metropolitan areas, with the number of patients per optometrist being 12 700 in Remote areas compared with the national average of 1180.^{2,9} In 2014, the Australian Government developed the National Framework Implementation Plan that aimed to build on existing eye health-care services and programmes to improve access for all Australians in an effort to promote eye health and reduce avoidable blindness.¹⁰ The National Framework Implementation Plan emphasized the need for up-to-date population-based data on the prevalence of vision loss, as well as data on the utilization of eye health services, to inform the implementation of improved eye health strategies.¹⁰

One of the aims of the National Eye Health Survey (NEHS) was to provide up-to-date population-based data on the utilization of eye health services by both Indigenous and non-Indigenous Australians across all levels of geographic remoteness. These data will directly inform the implementation of appropriate eye health service delivery strategies. This paper investigates the utilization of eye health-care services by both Indigenous and non-Indigenous participants in the NEHS, including how recently participants underwent eye examinations, the types of health-care providers used and sociodemographic and clinical risk factors associated with these behaviours.

METHODS

Study design

The NEHS was a cross-sectional, nationwide population-based study conducted from March

2015 to April 2016. The methods used to sample participants and select survey sites have been described elsewhere.¹¹ In brief, cluster sampling was used to select 30 geographic areas stratified by remoteness to provide a sample of Indigenous Australians aged 40 years and older and non-Indigenous Australians aged 50 years and older. A younger age criterion was selected for Indigenous Australians as this group has been shown to have earlier onset and more rapid progression of eye disease and diabetes.¹² Sites were selected using 2011 Australian Census data and were grouped according to the Accessibility/Remoteness Index of Australia into five remoteness areas: Major City, Inner Regional, Outer Regional, Remote and Very Remote.¹³

Recruiters went door-to-door in each survey site and recruited Indigenous Australians aged 40 years or older and non-Indigenous Australians aged 50 years or older. Minor methodological adjustments were made in the recruitment of Indigenous participants, to adapt to local circumstances within diverse communities, including the use of telephone recruitment from Aboriginal Health Services community directories, word-of-mouth and recruitment from concurrent health services. Recruiters recorded reasons for non-participation provided by residents who declined to be surveyed. This study was approved by the Royal Victorian Eye and Ear Hospital Human Research Ethics Committee (HREC-14/1199H). Additional state-level ethical approvals were obtained to conduct the survey within Indigenous communities. This research was conducted in accordance with the tenets of the Declaration of Helsinki.

Participant questionnaire and examinations

Participants provided informed consent and underwent a series of eye examinations described in detail elsewhere¹⁴ and a standardized interviewer-administered questionnaire. Using the questionnaire, participants were asked if they had ever had their eyes examined and if so, how many years and months ago and who had performed the examination. Responses were recorded against a standardized list defined a priori: (i) optometrist, (ii) ophthalmologist, (iii) general practitioner/local doctor, (iv) nurse, (v) health worker, (vi) ophthalmic nurse/technician and (vii) other. Sociodemographic data including age, gender, education, country of birth, main language and Indigenous/non-Indigenous status were obtained. History of stroke, diabetes, glaucoma, AMD, cataract, refractive error and diabetic retinopathy (DR) were recorded. A history of refractive error was determined by asking

participants if they wore distance glasses. These data were used to determine the following outcomes: (i) the proportion of participants who had undergone an eye examination in each of four time categories prior to participation (≤ 1 year, 1 to < 2 years and 2 to < 5 years and > 5 years or never) as well as sociodemographic and self-reported clinical risk factors associated with time since last eye examination; (ii) the proportion of participants who visited an optometrist, an ophthalmologist or other types of eye health service providers for their last eye examination, as well as sociodemographic and self-reported clinical risk factors associated with the type of provider used.

Statistical analysis

Descriptive statistics including age, number of years of education, gender, language and country of birth were calculated for Indigenous and non-Indigenous participants separately in the following groups based on time since last eye examination (four groups): ≤ 1 year, 1 to < 2 years and 2 to < 5 years and > 5 years or never.

Multinomial logistic regression analysis was conducted to identify associations between the time since last eye examination and the following explanatory variables: Indigenous status, age, education, gender, geographic remoteness and self-reported conditions including glaucoma, AMD, DR, cataract, refractive error and diabetes. The referent group (more than 5 years and never) was compared with two or more groups (within 1 year, 1 to < 2 years and 2 to < 5 years) allowing the logits to be calculated simultaneously for each comparison. Because of the small sample of non-Indigenous Australians with histories of AMD and glaucoma, these groups were combined for regression analysis to detect an effect of retinal disease. The association between self-reported DR and the time since examination was not tested in non-Indigenous Australians because of insufficient sample size. The sample size in this model included 1731 Indigenous Australians and 3098 non-Indigenous Australians.

Logistic regression analysis was conducted to identify associations between the outcome variable of the types of eye health-care provider most recently visited. Excluding 'optometrist' and 'ophthalmologist', the list of eye health-care providers was collapsed into the group 'other' because of a small sample size in each group (for Indigenous and non-Indigenous participants, respectively, $n = 44$ and $n = 21$ for general practitioner/local doctor, $n = 13$ and $n = 7$ for nurse, $n = 70$ and $n = 3$ for health worker and $n = 36$ and $n = 21$ for other), resulting in three outcome groups (optometrist, ophthalmologist or 'other' as defined previously). Regression analysis measured associations with the following

explanatory variables: Indigenous status, age, education, gender, geographic remoteness and self-reported conditions including glaucoma, AMD, DR, cataract, refractive error and diabetes. The 'other' group was not included in analysis for non-Indigenous participants because of small sample size ($n = 54$). As the outcome measure for Indigenous participants included three groups, a multinomial logit model was used, and odds ratios were calculated for the non-Indigenous group. A total of 1593 Indigenous participants and 2990 non-Indigenous were included in this model.

Logistic regression analyses included two distinct models. The first model involved analysing Indigenous and non-Indigenous samples in one model to ascertain whether Indigenous status was a significant risk factor. The second model involved testing all explanatory variables on Indigenous and non-Indigenous groups separately, because of differences in sampling procedures and inclusion criteria between these groups. All analyses were calculated using STATA 14.1 software (Stata Corp, College Station, TX, USA), and P -values were significant at < 0.05 .

RESULTS

Study participants

Across all survey sites, 23 235 residences were visited by recruiters, in which a total of 11 883 (51.1%) residents were contactable at the time of recruitment. In total, 2240 Indigenous residents were identified as eligible, of whom 1738 participated in the survey, resulting in a response rate of 77.6%, and 3098 out of 4520 eligible non-Indigenous residents participated (response rate = 68.5%). The most common reasons for non-participation were lack of interest (26.1%) and having had a recent eye test (16.7%). The mean $\pm$ standard deviation age of Indigenous and non-Indigenous participants was 55.0 ± 10.0 years (range 40–92 years) and 66.6 ± 9.7 years (range 50–98 years), respectively. Men comprised 41.1% of Indigenous participants and 46.4% of non-Indigenous participants.

Time since most recent eye examination and associated risk factors

Multivariate analysis revealed that Indigenous status predicted less recent eye examinations (relative risk reduction [RRR] 0.48 and 0.54 for undergoing eye examinations within 1 or > 1 –2 years, respectively, compared with the referent group > 5 years or never). All subsequent analyses interrogated Indigenous and non-Indigenous groups separately because of differences in sampling between groups.

Indigenous Australians

Seven Indigenous Australians had missing data. Of the remaining 1731 Indigenous participants, 1159 reported that they had undergone an eye examination within the past 2 years, and fewer than 50% (814/1731) had undergone an eye examination within the previous year in line with National Aboriginal Community Controlled Health Organisation and the Royal Australian College of General Practitioners recommendations (Table 1).¹⁵ One hundred and forty-two (8.2%) Indigenous participants had never undergone an eye examination.

Each additional year of education was associated with an increased likelihood of having undergone an eye examination within the past 2 years (RRR: 1.05 for <1 year and 1.06 for <2 years) (Table 2). Older age was associated with Indigenous participants having undergone eye examinations more recently (compared with the referent group of >5 years or never, with RRR: 1.03 for <2 years and 1.04 for 2 to <5 years); however, this did not apply to <1 year. Participants with self-reported DR were significantly more likely to have undergone an eye examination within the past year compared with the referent group (RRR: 6.35). Indigenous Australians with histories of cataract, refractive error, DR and diabetes were more likely to have undergone eye examinations within the past year (RRR: 4.17; 6.12; 6.35; and 3.04, respectively) than 5 years ago or never. Similarly, cataract, refractive error and diabetes were associated with participants being more likely to have undergone eye examinations <2 years ago (RRR: 1.99; 3.90; and 1.82), with cataract and refractive error also being associated with participants being more likely to have

had eye examinations 2 to <5 years ago (RRR: 2.32 and 3.81), compared with the referent group. Those residing in Outer Regional (RRR: 0.53 for ≤1 year and 0.55 for <2 years) and Very Remote (RRR: 0.28 for ≤1 year and 0.46 for <2 years) sites were less likely to have their eyes examined in the past 2 years than participants residing in Major Cities.

Non-Indigenous Australians

More than 80% (2555/3098) of non-Indigenous Australians reported that they had undergone an eye examination within the last 2 years, with 59.3% of participants having been examined within the previous year. Only 1.6% of non-Indigenous participants had never undergone an eye examination.

For non-Indigenous Australians, each additional year of education was associated with an increased likelihood of having undergone an eye examination within the past 2 years (RRR: 1.08 for <1 year and 1.06 for <2 years) (Table 2). Those with a history of glaucoma or AMD were significantly more likely to have undergone an eye examination within the past year (RRR: 18.29). Compared with the referent group of more than 5 years or never, histories of cataract, refractive error and diabetes were associated with non-Indigenous participants having undergone eye examinations within the past year (RRR: 8.84; 8.30; and 6.08, respectively), followed by either <2 years (RRR: 3.98; 6.43; and 3.23) and 2 to <5 years (RRR: 2.53; 4.79; and 3.44). Conversely, those residing in Outer Regional areas were less likely to have had an eye examination within the past year than

Table 1. Sociodemographic characteristics of Indigenous and non-Indigenous participants, by time since last eye examination

	Indigenous (n = 1731) [†]				Non-Indigenous (n = 3098)			
	≤1 years n = 814	1 to <2 years n = 345	2 to <5 years n = 256	>5 years or never [‡] n = 316	≤1 year n = 1840	1 to <2 years n = 715	2 to <5 years n = 322	>5 years or never [‡] n = 221
Age, mean (SD)	56.1 (10.0)	55.3 (10.0)	55.7 (9.6)	51.1 (9.1)	67.8 (9.8)	65.1 (9.1)	65.4 (9.3)	62.5 (8.9)
Education (year), mean (SD)	11.0 (3.3)	11.2 (3.7)	10.9 (3.4)	10.9 (2.8)	12.6 (3.7)	12.7 (3.7)	12.2 (3.9)	12.3 (3.7)
Gender (male), n (%)	339 (41.7)	114 (33.0)	100 (39.1)	159 (50.3)	809 (43.9)	304 (42.5)	174 (54.0)	150 (67.8)
English at home, n (%)	786 (95.6)	329 (95.4)	244 (95.3)	306 (96.8)	1736 (94.4)	681 (95.2)	302 (93.8)	204 (92.3)
Ethnicity, n (%) [‡]								
Oceanian	812 (47.0)	344 (19.9)	256 (14.8)	316 (18.3)	1315 (74.5)	58 (3.3)	230 (13.0)	163 (9.2)
European	2 (66.6%)	1 (33.3%)	0	0	388 (59.2)	157 (24.0)	65 (9.9)	45 (6.9)
Others	0	0	0	0	137 (60.4)	50 (22.0)	27 (11.9)	13 (5.7)
History of AMD	30 (3.69)	6 (1.74)	3 (1.17)	5 (1.58)	133 (7.48)	19 (2.75)	6 (1.93)	1 (0.51)
History of DR	89 (10.93)	8 (2.32)	7 (2.73)	3 (0.95)	34 (1.87)	5 (0.71)	4 (1.27)	0 (0)
History of glaucoma	25 (3.07)	6 (1.74)	2 (0.78)	2 (0.63)	131 (7.30)	9 (1.30)	7 (2.26)	0 (0)
History of cataracts	217 (26.66)	45 (13.04)	38 (14.84)	15 (4.75)	852 (47.12)	181 (26.01)	65 (20.57)	17 (8.46)

[†]Seven Indigenous participants had missing data for time since last eye examination. [‡]In the group '>5 years or never', there were 142 Indigenous participants and 49 non-Indigenous participants who reported that they had never had eye examined. AMD, age-related macular degeneration; DR, diabetic retinopathy; SD, standard deviation.

Table 2. Multivariable multinomial logistic regression to examine the associations between recentness of undergoing an eye examination and related risk factors in non-Indigenous and Indigenous Australians

Risk factors	Indigenous (1731) Time since last eye examination			Non-Indigenous (3098) Time since last examination		
	≤1 year RRR (95% CI)	1 to <2 years RRR (95% CI)	2 to <5 years RRR (95% CI)	≤1 year RRR (95% CI)	1 to <2 years RRR (95% CI)	2 to <5 years RRR (95% CI)
Age (year)		1.03 (1.01, 1.06)	1.04 (1.02, 1.06)			
Education (years)	1.05 (1.00, 1.11)	1.06 (1.00, 1.11)		1.08 (1.03, 1.12)	1.06 (1.01, 1.11)	
Gender (male)		0.55 (0.40, 0.77)	0.69 (0.48, 0.97)	0.38 (0.27, 0.52)	0.36 (0.26, 0.50)	0.55 (0.38, 0.79)
Remoteness						
Major City	1	1		1		
Inner Regional	1.22 (0.79, 1.90) NS	1.27 (0.79, 2.06) NS		0.87 (0.56, 1.35) NS		
Outer Regional	0.53 (0.37, 0.76)	0.55 (0.36, 0.83)		0.63 (0.42, 0.94)		
Remote	0.68 (0.42, 1.10) NS	0.92 (0.53, 1.58) NS		0.93 (0.56, 1.56) NS		
Very Remote	0.28 (0.15, 0.54)	0.46 (0.23, 0.92)		0.57 (0.30, 1.07) NS		
History of glaucoma or AMD [†]				18.29 (2.50, 133.79)		
History of cataract	4.17 (2.59, 8.57)	1.99 (1.23, 2.72)	2.32 (1.17, 4.62)	8.84 (4.99, 15.66)	3.98 (2.21, 7.18)	2.53 (1.35, 4.78)
History of RE	6.12 (4.07, 9.21)	3.90 (2.51, 6.05)	3.81 (2.40, 6.03)	8.30 (5.72, 12.05)	6.43 (4.38, 9.45)	4.79 (3.16, 7.26)
History of DR	6.35 (1.46, 27.43)					
Self-reported DM	3.04 (2.12, 4.35)	1.82 (1.23, 2.72)		6.08 (2.75, 13.42)	3.23 (1.43, 7.31)	3.44 (1.47, 8.07)

Statistical significance was set at $P < 0.05$ (two-tailed). [†]Glaucoma and AMD were analysed separately for Indigenous participants, but they were combined for non-Indigenous participants because of small sample size. Only statistically significant RRRs are provided except where indicated with NS. RRRs are provided for non-significant remoteness areas within a time interval column where at least 1 remoteness area was significantly associated to allow comparisons between groups. >5 years or never was the referent group. AMD, age-related macular degeneration; CI, confidence interval; DM, diabetes mellitus; DR, diabetic retinopathy; NS, non-significant; RE, refractive error; RRR, relative risk reduction.

those residing in Major Cities (RRR: 0.63). Non-Indigenous men were also less likely to have had an eye examination within the past 5 years (RRR: 0.36–0.55).

Type of eye health-care service provider most recently visited and associated risk factors

Indigenous Australians

Seventy-five per cent (1195/1589) of Indigenous participants had seen an optometrist, 14.3% (228/1589) had seen an ophthalmologist, 10.3% (163/1589) reported they had seen one of the 'other' eye health-care providers and 0.1% (3/1589) had missing data.

Indigenous Australians of older age (RRR: 1.03/year) and those with a history of glaucoma or AMD (RRR: 5.56), DR (RRR: 4.05), cataract (RRR:

3.38) or diabetes (RRR: 1.61) were significantly more likely to have visited an ophthalmologist than an optometrist for their most recent eye examination (Table 3). Indigenous males (RRR: 1.58) and those living in Inner Regional (RRR: 17.5), Outer Regional (RRR: 2.83) and Remote (RRR: 2.50) areas were more likely to have seen a health-care provider that was not an ophthalmologist or optometrist ('other'), and those in Very Remote areas were likely to have seen either an ophthalmologist (RRR: 2.07) or a provider from the 'other' category (RRR: 2.52) than an optometrist. Indigenous Australians with a history of refractive were more likely to have seen an optometrist (RRR: 0.67 for ophthalmologist and 0.24 for 'other').

Non-Indigenous Australians

A total of 2461 non-Indigenous Australians (81%) had visited an optometrist, 529 (17.4%) reported that

Table 3. Multivariable logistic regression analysis for having seen an optometrist (referent group), ophthalmologist or other eye health-care provider in non-Indigenous and Indigenous participants

Risk factors	Indigenous (<i>n</i> = 1593)		Non-Indigenous (<i>n</i> = 2990)
	Ophthalmologist RRR (95% CI)	Other [†] RRR (95% CI)	Ophthalmologist OR (95% CI)
Age (year)	1.03 (1.01, 1.05)		
Gender (male)		1.58 (1.11, 2.25)	
English-speaking home			0.46 (0.29, 0.72)
Remoteness			
Major City	1	1	1
Inner Regional	0.64 (0.39, 1.05) NS	1.75 (1.05, 2.90)	0.47 (0.34, 0.65)
Outer Regional	1.24 (0.81, 1.90) NS	2.83 (1.80, 4.47)	0.65 (0.49, 0.88)
Remote	1.26 (0.75, 2.10) NS	2.50 (1.41, 4.42)	1.05 (0.75, 1.47) NS
Very Remote	2.07 (1.02, 4.20)	2.52 (1.16, 5.48)	1.13 (0.75, 1.71) NS
History of glaucoma or AMD	5.56 (2.88, 10.74)		4.88 (3.61, 6.63)
History of DR	4.05 (2.36, 6.94)		6.54 (3.04, 14.08)
History of cataract	3.38 (2.29, 5.00)		3.80 (2.90, 4.97)
History of RE	0.67 (0.48, 0.96)	0.24 (0.15, 0.39)	0.64 (0.51, 0.80)
Self-reported DM	1.61 (1.12, 2.44)		
Time since last exam			
Within 1 year			
1–2 years			0.46 (0.33, 0.63)
2–5 years			0.55 (0.36, 0.85)
>5 years			1.91 (1.21, 3.01)

Statistical significance was set at $P < 0.05$ (two-tailed). [†]Other includes: general practitioner/local doctor, nurse, health worker, ophthalmic nurse or other. *n* in each of these categories was too small to provide sufficient statistical power and were collapsed into one group. Even with all categories collapsed into 'other', power was too low for the non-Indigenous group, and 'other' was not included in analysis. AMD, age-related macular degeneration; CI, confidence interval; DM, diabetes mellitus; DR, diabetic retinopathy; OR, odds ratio; RE, refractive error; RRR, relative risk reduction.

they had visited an ophthalmologist and 59 (1.9%) had visited 'other' types of health-care providers for their most recent eye examination. Histories of glaucoma or AMD (RRR:4.88), DR (RRR: 6.54) and cataract (RRR: 3.80) were associated with having seen an ophthalmologist rather than an optometrist in non-Indigenous Australians. Conversely, non-English speakers (RRR: 0.46), those with a history of refractive error (RRR: 0.64) and those residing in Inner Regional (RRR: 0.47) and Outer Regional (RRR: 0.65) areas were less likely to have seen an ophthalmologist than an optometrist. Participants who had their last eye examination more than 5 years ago were more likely to have visited an ophthalmologist (RRR: 1.91). On the other hand, those who had their last eye examination 1–2 years or 2–5 years previously were less likely to have consulted an ophthalmologist than an optometrist (RRR: 0.46 and 0.55, respectively).

DISCUSSION

This paper provides the first nationally representative data on the utilization of eye health-care services by both Indigenous and non-Indigenous Australians across all levels of geographic remoteness. Specifically, we report how

recently participants accessed eye health-care services, the types of services used and sociodemographic and clinical factors associated with the utilization of these services. The results presented in this paper may be beneficial to eye health-care policy and resource allocation.

The lower prevalence of eye examinations in the Indigenous population compared with the non-Indigenous population is consistent with previous research.^{7,16,17} A multitude of factors have resulted in Indigenous Australians using eye health-care services less frequently than their non-Indigenous counterparts. These include insufficient availability of services in areas with large Indigenous populations (particularly in remote locations),¹⁶ prohibitive distances to the nearest service provider, financial cost⁷ and importantly, a lack of well-integrated and culturally appropriate Aboriginal Medical Service-mediated optometry services.¹⁸ Despite this, the NEHS has revealed a substantial increase, when compared with the National Indigenous Eye Health Survey conducted in 2008, in both the proportion of Indigenous Australians who had ever received an eye test (92% vs. 65%) and the recentness of testing (47% vs. 15% within the previous year).⁷ This signifies a noteworthy increase in uptake over the past 7 years, suggesting that programmes aimed at

improving education, availability and utilization of services in Indigenous communities are working.¹⁹ However, a considerable proportion of Indigenous Australians, particularly those of older age and those living in non-metropolitan areas, may be at higher risk for undiagnosed eye disease and vision loss because of the infrequency of eye health service utilization. Since the completion of the National Indigenous Eye Health Survey, the recommended frequency of eye examinations for the general Indigenous population has increased from biennially to annually as part of a routine health check,¹⁵ and initiatives aimed at increasing culturally appropriate optometry or ophthalmology services in Aboriginal Medical Services may further improve adherence to these guidelines.

Blue Mountains Eye Study (62%) and the Melbourne Visual Impairment Project (63%) and was similar to the proportion of participants who had undergone eye examinations (85%) after an extended awareness and education campaign in The Vision Initiative study,²⁰ suggesting that considerable improvements in the uptake of eye health-care services have been made over the past 20 years. It should be noted that potential variations in key sociodemographic variables including cohort age, gender composition and, most obviously, geographic remoteness, between studies necessitates cautious comparisons. Nonetheless, the current study may even have underestimated the proportion of Australians who have undergone eye examinations within the past 1 to 2 years, as one of the leading reasons for non-participation was having had a recent eye examination, and the effect of non-response bias cannot be ruled out. Furthermore, relying on self-report to accurately recall when the participant last underwent an eye examination, and to correctly recall the type of eye health-care service provider consulted, is likely to have introduced the risk of recall bias. Of particular concern are older participants and participants for whom a long time had elapsed since their last examination, as their recall would be likely to be less accurate. Nonetheless, the effect of recall bias on the outcomes measured in this paper cannot be quantified.

In contrast to previous literature, age was not found to be a risk factor for the recentness of use of eye care services in non-Indigenous Australians.⁵ However, older age was associated with a higher likelihood of Indigenous Australians undergoing an eye examination more than 1 year and less than 5 years previously, compared with five or more years previously. It should be noted that the finding that older age did not increase the likelihood that Indigenous Australians underwent an eye examination within the previous year may impact the early

detection of disease. Considering the rapid progression of blinding eye diseases in Indigenous Australians, particularly in those of older age, waiting more than 1 year between eye examinations may be sufficient time for some diseases to cause irreversible damage.¹⁷

Men have been found in many studies to have eye examinations less frequently than women.^{5-7,20-22} Our findings indicate that this continues to be a problem in both Indigenous and non-Indigenous Australians, with men being significantly less likely to have accessed eye health-care services. This may be partly explained by women showing greater awareness of their health and therefore a greater predisposition to engage with health services than men.²²

This study revealed that variations in geographic remoteness were associated with differences in the utilization of eye health-care services. Non-Indigenous Australians residing in Outer Regional areas were significantly less likely to have undergone an eye examination within the past year than their Major City counterparts, and Indigenous Australians residing in both Outer Regional and Very Remote regions were significantly less likely to have undergone eye examinations within the past 2 years than those in Major Cities. Considering that these remoteness strata have been shown to be significantly less equipped than metropolitan areas with optometrists, ophthalmologists and general health services, improvements in service availability and eye health promotion in these regions may improve utilization rates.^{9,16} The Australian Government's Rural Health Outreach Fund (RHOF) and the Visiting Optometry Service provide funding for eye health teams to visit non-metropolitan areas and aim to improve access to eye health services for rural and remote populations. Although the RHOF aims to promote cost certainty for Indigenous Australians visiting outreach clinics by advocating for ophthalmologists to bulk-bill all services at Medicare rebate rates, some practitioners continue to charge additional fees, and this cost uncertainty results in many Indigenous Australians avoiding these services.¹⁹ Increasing funding for the RHOF to meet the population-based needs for service availability while avoiding the practice of charging gap fees by ophthalmologists in outreach clinics will likely improve utilization rates in regional and remote areas.

Participants with a self-reported eye condition or diabetes underwent an eye examination more recently than those who did not report these conditions. Most non-Indigenous participants with AMD or glaucoma (86.6%) and most Indigenous Australians with DR (82.4%) underwent an eye examination within the previous year (derived from Table 1). Contrastingly, those with cataract had a

greater distribution of times since their last eye examination. The observation that those with less readily treatable or reversible retinal conditions (AMD, glaucoma and DR) or a high risk of irreversible retinal disease (diabetes) are considerably more likely to get their eyes examined at least annually and those with easily treatable conditions (refractive error and cataract) are likely to get eye examinations as infrequently as every 5 years or more suggests public awareness of the importance of the annual monitoring of retinal diseases. Although this undoubtedly increases the timely treatment and management of these sight-threatening and irreversible conditions, refractive or cataract-related vision loss should not be neglected. In fact, considering the ease with which these conditions can be reversed and that they account for almost 80% of VI,³ increasing the regularity with which people with these conditions have their eyes examined may drastically reduce the prevalence of VI.²³

Indigenous Australians in Regional and Very Remote areas were between 1.8 and 2.8 times more likely to have had their eyes tested by a local doctor, nurse or technician than by an optometrist. The use of non-optometric services by Indigenous Australians in Regional areas may result from insufficiency in the supply of optometrists in non-metropolitan areas.⁹ Although screening by these health-care providers undoubtedly contributes to early detection and treatment of eye disease, a significant proportion of Indigenous Australians living in remote regions already suffer from advanced eye disease and may require specialist care.²⁴ Sustainable models that ensure that health workers, particularly in Indigenous communities, are thoroughly educated and trained in detection of disease and appropriate referral are indispensable. It should be noted that those living in Very Remote areas were more likely to have seen an ophthalmologist for their last eye check, suggesting that the recent increase in outreach ophthalmology services may be effectively increasing the utilization of these services.^{25,26}

A history of refractive error was associated with a higher likelihood of seeing an optometrist, which is consistent with the fact that refractive error services are provided at a primary care level by optometrists.⁹ This reinforces the point that, considering the overwhelming proportion of VI attributable to uncorrected refractive error,²⁷ improvements in the utilization of optometry services will contribute substantially to tackling vision loss as a public health concern.

Compared with previous population research in Australia, improvements have been made in the frequency of eye examinations in older Australians. However, a significant proportion of those with

potentially undiagnosed eye disease are still not undergoing examinations frequently enough. Improving the utilization of eye health-care services by risk groups including men, Indigenous Australians and those living in non-metropolitan areas, as well as implementing strategies to treat refractive error and cataract in a timely manner, will assist in reducing the burden of vision loss in Australia.

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4.3.3 Publication 8: Adherence to diabetic eye examination guidelines in

Australia: the National Eye Health Survey

4.3.3.1 Overview

With the increasing incidence of diabetes in Australia, the number of people at risk of permanent vision loss from DR is on the rise.⁶³ The NHMRC has published guidelines recommending that Indigenous Australians with diabetes undergo an annual dilated fundus examination, while non-Indigenous Australians should undergo an examination every two years.²⁵⁴ Approximately one third of those with diabetes have some degree of retinopathy, with the number approaching 100% within 20 years after diagnosis of diabetes.³³⁶ With early detection and treatment, most blindness caused by DR is avoidable. However, as Publication 4 demonstrated, as much as 5.2% of vision loss and 20% of blindness in Indigenous Australians is caused of DR, indicating that there may be sub-optimal adherence rates to the NHMRC guidelines and consequent insufficiencies in early detection and treatment of DR.

Publication 8 reports adherence rates to the NHMRC guidelines in both Indigenous and non-Indigenous Australians as well as sociodemographic and geographic risk factors for non-adherence. It is hoped that this paper will form the basis for evidence-based improvements in the provision of ophthalmic services to all Australians with diabetes. This manuscript was published in the *Medical Journal of Australia* on the 15th of May 2017 and was the featured article on the Journal's cover.

Adherence to diabetic eye examination guidelines in Australia: the National Eye Health Survey

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The known Adherence to NHMRC diabetic eye examination guidelines in Australia is reported to be suboptimal, but the accuracy of estimates is questionable, as they are derived from studies with small sample sizes and recruitment bias.

The new In a national sample stratified by remoteness, about half of all Indigenous Australians with diabetes and almost one-quarter of non-Indigenous Australians with diabetes did not have their eyes examined at the recommended frequency, placing them at risk of vision-threatening retinopathy.

The implications Improving the provision and uptake of screening services is needed, particularly in Indigenous communities.

The number of adults with diabetes worldwide has almost quadrupled in the past 35 years, from 108 million in 1980 to 422 million in 2014.¹ This rise is largely attributable to population growth and ageing.² In Australia, about 1.5 million adults have diabetes, and it is estimated that an additional 280 people are diagnosed each day.³ Diabetic retinopathy is a frequent complication of diabetes, and is the leading cause of blindness in working age adults in most developed nations.⁴ This is disturbing, as most blindness caused by diabetes can be avoided by early detection and timely intervention.⁵

The National Health and Medical Research Council (NHMRC) has developed guidelines that recommend annual retinal screening and visual acuity assessment of Indigenous Australians and biennial assessment of non-Indigenous Australians with diabetes but without significant risk factors for retinopathy (longer diabetes duration, poor glycaemic control, elevated blood pressure or blood lipid levels).⁶ The difference in the recommended intervals for Indigenous and non-Indigenous Australians reflects epidemiological evidence that retinopathy is more common in Indigenous than in non-Indigenous Australians.⁷ Rates of adherence to these guidelines are reported to be unsatisfactory, as low as 50% for non-Indigenous Australians and 20% for Indigenous Australians, although the studies providing these estimates may have been limited by small sample sizes and recruitment bias.⁸

Projections for the future prevalence of diabetes in Australian adults have been provided by the Australian Diabetes, Obesity and Lifestyle (AusDiab) study.⁹ If the incidence of diabetes observed during 2000–2005 continues, its prevalence will rise from 7.6% in 2000 to 11.4% by 2025.⁹ As 25–35% of Australians with diabetes have some degree of retinopathy, it follows that a significant increase in the health impact and economic burden of diabetic retinopathy is likely.⁷

The National Eye Health Survey (NEHS) was undertaken to provide national prevalence data on vision impairment and blindness.

Abstract

Objective: To determine adherence to NHMRC eye examination guidelines for Indigenous and non-Indigenous Australian people with diabetes.

Design: Cross-sectional survey using multistage, random cluster sampling.

Setting: Thirty randomly selected geographic sites in the five mainland Australian states and the Northern Territory, stratified by remoteness.

Participants: 1738 Indigenous Australians aged 40–92 years and 3098 non-Indigenous Australians aged 50–98 years were recruited and examined between March 2015 and April 2016 according to a standardised protocol that included a questionnaire (administered by an interviewer) and a series of standard eye tests.

Main outcome measures: Adherence rates to NHMRC eye examination guidelines; factors influencing adherence.

Results: Adherence to screening recommendations was significantly greater among non-Indigenous Australians (biennial screening; 77.5%) than Indigenous Australians (annual screening; 52.7%; $P < 0.001$). Greater adherence by non-Indigenous Australians was associated with longer duration of diabetes (adjusted odds ratio [aOR], 1.19 per 5 years; $P = 0.018$), while increasing age was associated with poorer adherence in non-Indigenous Australians (aOR, 0.70 per decade; $P = 0.011$). For Indigenous Australians, residing in inner regional areas (aOR, 1.66; $P = 0.007$) and being male (aOR, 1.46; $P = 0.018$) were significant factors positively associated with adherence.

Conclusions: More than three-quarters of non-Indigenous Australians with diabetes and more than half of Indigenous Australians with diabetes adhere to the NHMRC eye examination guidelines. The discrepancy between the adherence rates may point to gaps in the provision or uptake of screening services in Indigenous communities, or a lack of awareness of the guidelines. A carefully integrated diabetic retinopathy screening service is needed, particularly in remote areas, to improve adherence rates.

The study also sought to determine the proportion of Australians with self-reported diabetes who adhere to the NHMRC retinal screening guidelines. We report in this article the rates of adherence to the guidelines by Indigenous (aged 40 years or more) and non-Indigenous Australians (aged 50 years or more).

Methods

Study design

Multistage, random cluster sampling was used to select 30 geographic sites in the five mainland Australian states and the Northern Territory, based on data from the 2011 Australian census

by the Australian Bureau of Statistics.¹⁰ In the first sampling phase, Level 2 Statistical Areas (SA2s) were stratified by remoteness into major city, inner regional, outer regional, remote and very remote areas; respectively twelve, six, six, four and two SA2s were randomly selected from these categories. A Level 1 Statistical Area (SA1) or cluster of SA1s containing about 100 non-Indigenous Australians aged 50 years or more and 50 Indigenous Australians aged 40 years or more was selected from within each SA2 and designated as the recruitment site. The lower age criterion for Indigenous Australians was selected because of the younger age of onset and more rapid progression of eye disease and diabetes in this group. Recruiters proceeded door to door to recruit 1738 Indigenous Australians and 3098 non-Indigenous Australians between March 2015 and April 2016. A positive response rate of 82.5% (3729 of 4520) and a clinical examination rate of 68.5% (3098 of 4520) were achieved for non-Indigenous recruitment, while positive response and examination rates for Indigenous participants were 90.9% (2035 of 2240) and 77.6% (1738 of 2240) respectively. Participants were examined with a series of standard clinical eye tests; the results of these examinations are not reported in this article.

Interviewer-administered general questionnaire

Information about ethnic background (including Indigenous status and country of birth), highest educational level, and history of ocular problems, stroke and diabetes was collected by an interviewer administering a questionnaire. Participants were asked whether they had been told by a doctor or nurse that they had diabetes (ie, diabetes in this study was self-reported). The age at diagnosis for those with self-reported diabetes was recorded. Participants were asked whether they had seen an ophthalmologist or optometrist for a diabetic eye examination, and if so, how long ago (in years). This information was used to determine the proportion of participants who adhered to the NHMRC guidelines. Those who reported that they had not undergone a diabetic eye check were asked for a reason, and their answer was recorded according to a standardised list: “I did not know about the guideline”; “I missed the appointment”; “I have no time”; and other.

Statistical analysis

The primary outcome was adherence to the NHMRC diabetic eye examination guidelines. Demographic characteristics were summarised as means and standard deviations (SDs) for normally distributed continuous data, and as medians with interquartile ranges (IQRs) for skewed data. Normality was assessed in boxplots, and with Kolmogorov–Smirnov and Shapiro–Wilks tests. Univariate and multivariable logistic regression analysis was used to identify risk factors associated with adherence. Adjusted proportions were calculated by generalised logit regression models taking into account the sampling weight and non-response rate. A plot of the residuals against estimates was examined to determine whether the assumptions of linearity and homoscedasticity were met. The Stata module NLCHECK was used to test assumptions of linearity after model estimation. A Box–Tidwell model was used to transform a predictor using power transformations to find the best power for model fit based on maximal likelihood estimate. Because of the small numbers of participants with self-reported diabetes from very remote sites (17 Indigenous and 18 non-Indigenous people), the remote and very remote strata were collapsed in the regression analysis. Variables found to be non-significant in univariate analysis were excluded from the multivariable model. All analyses were performed by incorporating sampling weights and non-response rate. Analyses were conducted in Stata 14.2.0 (StataCorp). $P < 0.05$ (two-tailed) was deemed statistically significant.

Ethics approval

The protocol for this study was approved by the Royal Victorian Eye and Ear Hospital Human Research Ethics Committee (reference, HREC-14/1199H). Additional ethics approvals for conducting research in Indigenous communities were obtained at the state level. The research complied with the tenets of the Declaration of Helsinki.

Results

Study participants

A total of 1738 Indigenous Australians (men, 41.1%) aged 40–92 years (mean, 55.0 years; SD, 10.0 years) were examined, of whom 645 (men, 37.5%; mean age, 68.6 years [SD, 8.9]) had self-reported diabetes (crude prevalence, 37.1%; age- and sampling-adjusted prevalence, 42.6%). Of the 3098 non-Indigenous Australians (men, 46.4%) aged 50–98 years (mean, 66.6 years; SD, 9.7 years) examined, 431 had self-reported diabetes (men, 58.3%; mean age, 58.3 years [SD, 9.8]); the prevalence was significantly lower than for the Indigenous participants (crude prevalence, 13.9%; adjusted prevalence, 13.3%; $P < 0.001$). The mean age of non-Indigenous participants who adhered to the NHMRC diabetic eye examination guidelines was 68.4 years (SD, 8.7 years), and the median duration of diabetes since diagnosis was 10 years (IQR, 5–18 years). The mean age of Indigenous Australians who had undergone recommended eye examinations was 58.7 years (SD, 9.7 years), and the median duration of diabetes was 11 years (IQR, 5–20 years) (Box 1).

Adherence to the NHMRC diabetic eye examination guidelines

More than half the Indigenous participants with self-reported diabetes (341 participants; unadjusted rate, 52.9%; age- and sampling-adjusted rate, 52.7%) reported that they had had a diabetic eye examination in the past 12 months, in accordance with the NHMRC guidelines. Of the non-Indigenous Australians with self-reported diabetes, 77.7% (adjusted rate, 77.5%) had had eye examinations in the preceding 2 years (*v* Indigenous proportion: $P < 0.001$; Box 2). In total, 26.2% of Indigenous Australians with diabetes reported that they had never undergone a diabetic eye examination, compared with 15.3% of non-Indigenous participants ($P < 0.001$).

The major reason for non-adherence reported by both Indigenous (72.6%) and non-Indigenous participants (74.3%) was that they were unaware of the need for regular eye examinations.

Effects of associated risk factors on adherence to the NHMRC guidelines

Indigenous and non-Indigenous Australians combined. Univariate logistic regression indicated that Indigenous status was significantly associated with a lower likelihood of having adhered to the NHMRC guidelines (odds ratio [OR], 0.37; $P < 0.001$). After adjusting for covariates, longer duration of diabetes (OR, 1.11 per 5 years; $P = 0.012$) and inner regional residence (adjusted OR [aOR], 1.60; $P = 0.012$) were associated with a greater likelihood of adhering, while Indigenous status remained a strong risk factor for non-adherence (aOR, 0.29; $P < 0.001$) (Box 3).

Indigenous and non-Indigenous Australians separately. Data for Indigenous and non-Indigenous participants were also analysed separately to account for differences in inclusion criteria. In non-Indigenous Australians, univariate and multivariate

1 Socio-demographic characteristics of participants with self-reported diabetes who adhered or did not adhere to National Health and Medical Research Council guidelines for retinopathy screening (unadjusted for age or sampling)

	Non-Indigenous		Indigenous	
	Adherers	Non-adherers	Adherers	Non-adherers
Number of participants	335	96	341	304
Age (years), mean (SD)	68.4 (8.7)	69.6 (9.7)	58.7 (9.7)	57.8 (9.8)
Duration of diabetes (years), median (IQR)	10.0 (5–18)	8.0 (3–14)	11.0 (5–20)	10.0 (5–19)
Education (years), mean (SD)	12.2 (3.9)	11.7 (3.4)	10.7 (3.9)	10.3 (3.2)
Sex (male)	181 (54.0%)	61 (64%)	131 (38.4%)	111 (36.5%)
English spoken at home	298 (89.0%)	85 (88%)	318 (93.3%)	288 (94.7%)
Place of birth				
Oceania	231 (69%)	56 (58%)	340 (99.7%)	303 (99.7%)
Europe	70 (21%)	27 (28%)	1 (0.3%)	1 (0.3%)
Other	34 (10%)	13 (14%)	0	0

analysis showed that older age was a risk factor for non-adherence (aOR, 0.70 per decade; $P = 0.011$), while longer duration of diabetes was associated with greater likelihood of adhering (aOR, 1.19 per 5 years; $P = 0.018$). Among Indigenous participants, adherence was greater for men (aOR, 1.46; $P = 0.018$) and for those in inner regional areas (aOR, 1.66; $P = 0.007$) (Box 3).

Discussion

The adjusted prevalence of self-reported diabetes among participants in the NEHS was more than three times higher for Indigenous than for non-Indigenous participants (42.6% *v* 13.3%). Almost 80% of non-Indigenous participants and half the Indigenous participants with diabetes reported that they had adhered to the NHMRC retinopathy screening guidelines. Longer duration of diabetes was associated with greater adherence and greater age with non-adherence in the non-Indigenous group, while among Indigenous participants those who were men or living in an inner regional locality were more likely to have adhered to the recommendations.

The adherence rate of 77.5% for non-Indigenous Australians matches the 77% reported in the AusDiab study.¹² However, AusDiab included participants from a much broader age range (25 years and over) and can therefore be compared with the older NEHS sample only with caution. A more relevant comparison is with the adherence

rate of about 50% in the older population of the Melbourne Visual Impairment Project.¹³ The higher adherence rate we found may indicate improved access to and awareness of diabetic retinopathy screening services among people with diabetes, or improved awareness of the guidelines among health care providers.¹⁴ In any case, adherence rates must improve further to compensate for the expected rise in the incidence of diabetes.³ Australia would benefit from a carefully integrated diabetic retinopathy screening system that ensures coverage for all Australians with diabetes, particularly in underserved remote areas. Combined with improvements in referral pathways for those identified as having vision-threatening retinopathy and increased education of those with diabetes about examination guidelines, an integrated and accessible screening program would increase the uptake of eye examinations. Such programs have been effective in other countries,¹⁵ and would improve the management of diabetic retinopathy in Australia.

The proportion of Indigenous adults with diagnosed diabetes who had had an eye examination during the past 12 months has increased since the completion of the National Indigenous Eye Health Survey (NIEHS) in 2008, from about 20% to more than 50%.^{16,17} This suggests that interventions in Indigenous eye health since the NIEHS may be having a significant impact.¹⁸ Despite this improvement, an unacceptably high proportion of Indigenous Australians with diabetes are not having potentially vision-saving examinations. Coinciding with these findings, the Australian government has allocated \$33.8 million in Medicare rebates to general practitioners for non-mydriatic fundus photography in diabetic patients.¹⁹ Primary health care providers are at the frontline of diabetes care, and integrating regular fundus photography by GPs into their routine management of diabetes should significantly reduce the burden of diabetes-related vision loss. The new Medicare rebate will be of particular benefit to under-resourced Indigenous health services in the most remote regions of Australia. Indigenous Australians in very remote communities are at particularly high risk of diabetic retinopathy, and the lowest adherence rate in the NEHS — 38% in very remote areas — indicates that integrating regular retinal screening into primary care in these communities is essential for improving Indigenous eye health.¹⁷

The positive association between regular eye examinations and disease duration has important implications

2 Rates of adherence to the National Health and Medical Research Council guidelines for retinopathy screening,* by Indigenous status and residential location

	Self-reported diabetes	Adhered to NHMRC guidelines	Adherence rate	
			Crude (95% CI)	Adjusted [†] (95% CI)
Indigenous participants	645	341	52.9% (48.9–56.8%)	52.7% (45.9–59.6%)
Non-Indigenous participants	431	335	77.7% (73.5–81.6%)	77.5% (71.8–83.3%)

* Once a year for Aboriginal and Torres Strait Islander people with diabetes, and at least once every 2 years for non-Indigenous Australians with diabetes.⁹ Adherence rates by geographic remoteness have been published elsewhere.¹¹ † Adjusted for age and sampling, based on multistage random cluster sampling and age weighting. ♦

3 Factors associated with adherence to the National Health and Medical Research Council guidelines for retinopathy screening: univariate and multivariate logistic regression*

	All participants		Non-Indigenous		Indigenous	
	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P
Univariate analysis						
Age (per 10 years)	1.12 (0.93–1.36)	0.24	0.73 (0.56–0.95)	0.021	1.00 (0.68–1.46)	0.98
Duration of diabetes (per 5 years)	1.06 (0.98–1.15)	0.14	1.16 (1.03–1.32)	0.018	1.02 (0.93–1.11)	0.70
Education (per year)	1.06 (0.99–1.13)	0.08	1.02 (0.95–1.09)	0.53	1.06 (0.94–1.18)	0.33
Sex (male)	1.18 (0.85–1.64)	0.32	0.63 (0.37–1.08)	0.09	1.37 (1.02–1.85)	0.033
Indigenous	0.37 (0.25–0.56)	< 0.001				
English spoken at home	0.86 (0.52–1.42)	0.54	1.06 (0.65–1.73)	0.80	1.19 (0.43–3.30)	0.72
Place of birth						
Oceania	1		1			
Europe	1.49 (0.77–2.89)	0.23	0.74 (0.41–1.34)	0.30		
Other	1.03 (0.44–2.45)	0.94	0.51 (0.21–1.26)	0.14		
Remoteness						
Major city	1		1		1	
Inner regional	1.64 (0.94–2.88)	0.08	1.68 (0.89–3.16)	0.10	1.46 (1.02–2.11)	0.038
Outer regional	1.18 (0.61–2.30)	0.60	1.39 (0.77–2.49)	0.26	0.80 (0.46–1.38)	0.40
Remote/very remote	1.55 (0.87–2.74)	0.13	1.49 (0.73–3.04)	0.26	0.87 (0.54–1.39)	0.54
Multivariate analysis						
Age (per 10 years)	0.85 (0.69–1.04)	0.11	0.70 (0.54–0.92)	0.011	1.05 (0.79–1.41)	0.71
Duration of diabetes (per 5 years)	1.11 (1.02–1.20)	0.012	1.19 (1.03–1.37)	0.018	1.03 (0.93–1.13)	0.59
Education (per year)	1.04 (0.98–1.11)	0.23	1.04 (0.96–1.12)	0.31	1.07 (0.96–1.19)	0.24
Sex (male)	0.94 (0.69–1.28)	0.70	0.61 (0.36–1.11)	0.069	1.46 (1.07–1.99)	0.018
Indigenous	0.29 (0.18–0.47)	< 0.001	—	—	—	—
Place of birth						
Oceania	1		1		—	—
Europe	0.75 (0.44–1.27)	0.28	0.74 (0.44–1.24)	0.24	—	—
Other	0.43 (0.13–1.39)	0.15	0.39 (0.09–1.70)	0.20	—	—
Remoteness						
Major city	1		1		1	
Inner regional	1.60 (1.12–2.29)	0.012	1.53 (0.78–3.02)	0.21	1.66 (1.16–2.37)	0.007
Outer regional	1.10 (0.71–1.70)	0.66	1.29 (0.69–2.42)	0.41	0.89 (0.55–1.44)	0.62
Remote/very remote	1.35 (0.83–1.29)	0.22	1.66 (0.86–3.24)	0.13	0.99 (0.56–1.76)	0.98

OR = odds ratio. * Analysis adjusted for sampling weight and non-response rate. ♦

for treating and preventing diabetic retinopathy. The prevalence of diabetic retinopathy increases with duration of disease; 60% of people with type 2 diabetes and almost all with type 1 diabetes develop retinopathy within 20 years of diagnosis.²⁰ Regular screening is therefore particularly important for those who have had diabetes for many years. Lower adherence by people with a shorter duration of diabetes may be noteworthy, as detecting retinopathy early is associated with better treatment outcomes.⁵ That increasing age was associated with a significantly lower likelihood of adherence highlights a clear need to improve the uptake of diabetes eye care services by older people. As our population is ageing, the prevalence of diabetes-related vision loss is likely to increase if older Australians with diabetes neglect their eye health.²¹

The primary limitation of our study was the use of self-reported data for ascertaining diabetes; we cannot exclude the possibility

of self-reporting bias. In addition, recall bias may have led patients to over- or underestimate the time since their most recent eye examination. Similarly, participants may not have accurately recalled whether their fundus had been investigated during this examination. Nevertheless, self-reports are commonly used for diabetes surveillance,^{22,23} and earlier studies have reported excellent sensitivities and specificities for self-reported diabetes when compared with medical diagnoses.^{24,25}

In summary, our findings indicate that adherence rates to the NHMRC diabetic eye examination guidelines are significantly higher than previously estimated in Australia. Despite this encouraging finding, it is important that about half of all Indigenous Australians and almost one-quarter of non-Indigenous Australians with diabetes did not have their eyes examined at the recommended frequency. While the recent allocation by the federal government of funding for screening modalities in general practice

may further improve adherence rates, implementing an accessible integrated screening service is needed to eliminate diabetic retinopathy as a significant public health problem in Australia.

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4.3.3.2 Supplementary data: Adherence to diabetic eye examination guidelines in Australia disaggregated by geographic remoteness

The original submission of Publication 8 to the *Medical Journal of Australia* included a table that disaggregated adherence rates in Indigenous and non-Indigenous Australians by geographic remoteness. However, an editorial decision was made by the Journal to exclude these disaggregated data. Geographic remoteness was shown to be a statistically significant risk factor for adherence in the Indigenous population, and presenting the remoteness-stratified adherence rates is therefore warranted as it may assist policy-makers in allocating screening services more effectively to regions most in need. Adherence rates by geographic remoteness are presented in Table 5. The weighted adherence rates did not differ significantly by remoteness for non-Indigenous Australians ($P=0.13$ to 0.21), but tended to be highest in Remote (82.8%, 95% CI: 78.4, 87.2) followed by Inner Regional (82.6%, 95% CI: 78.3, 86.9) populations, and tended to be lowest in Very Remote populations (64.8%, 95% CI: 58.2, 71.4). Adherence rates were more variable for Indigenous Australians, ranging from 37.8% (95% CI: 28.1, 47.3) in Very Remote areas to 61.3% (95% CI: 51.2, 71.3) in Remote areas. Due to the need to combine Indigenous Australians in Remote and Very Remote areas (due to small samples) for risk factor analysis, it was not possible to determine whether the higher adherence rate in Remote areas was statistically significant. Nonetheless, the similar adherence rate in Inner Regional-dwelling Indigenous Australians of 60.9% (95% CI: 54.0, 67.8) was significantly higher than the referent Major City adherence rate ($P=0.007$).

Table 5. Adherence rates to the National Health and Medical Research Council (NHMRC) diabetic eye examination guidelines by geographic remoteness

	No. with diabetes [†]	No. who adhered to guidelines [‡]	Crude adherence rate (% [95% CI])	Weighted [§] adherence rate (% [95% CI])
Indigenous[¶]				
Major City	268	148	55.2 (49.1, 61.3)	50.3 (43.2, 57.3)
Inner Regional	97	60	61.9 (51.4, 71.5)	60.9 (54.0, 67.8)
Outer Regional	169	84	49.7 (41.9, 57.5)	51.5 (40.7, 62.4)
Remote	63	32	50.8 (37.9, 63.6)	61.3 (51.2, 71.3)
Very Remote	48	17	35.4 (22.2, 50.5)	37.8 (28.1, 47.3)
Total	645	341	52.9 (48.9, 56.8)	52.7 (45.9, 59.6)
Non-Indigenous				
Major City	178	133	74.7 (67.7, 80.9)	75.5 (67.9, 83.0)
Inner Regional	93	77	82.8 (73.6, 89.8)	82.6 (78.3, 86.9)
Outer Regional	93	73	78.5 (68.8, 86.3)	76.4 (69.4, 83.3)
Remote	39	34	87.2 (72.6, 95.7)	82.8 (78.4, 87.2)
Very Remote	28	18	64.3 (44.1, 81.4)	64.8 (58.2, 71.4)
Total	431	335	77.7 (73.5, 81.6)	77.5 (71.8, 83.3)

[†]Self-reported diabetes

[‡]Number of participant who met NHMRC diabetic eye examination guidelines.

[§]Sampling and age adjusted proportions based on multistage random-cluster sampling and age weighting

[¶]Current NHMRC guidelines recommend a diabetic eye examination annually for Aboriginal or Torres Strait Islander persons with diabetes and at least every 2 years for non-Indigenous Australians with diabetes

CI=Confidence Interval

4.3.4 Publication 9: Cataract surgery coverage rates for Indigenous and non-Indigenous Australians: the National Eye Health Survey

4.3.4.1 Overview

Cataract is the leading cause of blindness and the second leading cause of VI globally.²⁰ Most cataract-induced vision loss can be readily reversed through surgical removal of cataracts and replacement of the lens with IOLs. This procedure can be done cheaply, quickly and with a very high success rate in most cases.³³⁵ It therefore follows that the burden of vision loss would be dramatically reduced in countries with high cataract surgery rates.

The NEHS has shown that cataract is the second leading cause of VI in both Indigenous and non-Indigenous Australians and the leading cause of blindness in Indigenous Australians. It is therefore of critical importance to not only quantify the proportion of people with cataract-related vision loss, but to also determine the extent to which cataract surgery needs have been met in the population. Publication 9 presents the cataract surgery coverage rates in Indigenous Australians and, for the first time, in non-Indigenous Australians. Coverage rates are disaggregated by sociodemographic and geographic variables, and logistic regression is used to identify variables associated with undergoing cataract surgery. This manuscript was published in the *Medical Journal of Australia* on the 18th of September 2017. The University of Melbourne External Relations team selected this manuscript for media exposure and it was featured on national ABC talkback radio in September 2017.

Cataract surgery coverage rates for Indigenous and non-Indigenous Australians: the National Eye Health Survey

Joshua Foreman^{1,2}, Jing Xie^{1,2}, Stuart Keel^{1,2}, Peter van Wijngaarden^{1,2}, Jonathan Crowston^{1,2}, Hugh R Taylor³, Mohamed Dirani^{1,2}

The known The incidence of cataract is increasing among Indigenous and non-Indigenous Australians because of the ageing of the population. The burden of vision loss is considerably higher among Indigenous Australians, partly because of a 12-fold higher prevalence of vision loss associated with unoperated cataracts.

The new The cataract surgery coverage rate is significantly lower among Indigenous than non-Indigenous Australians. The difference was greater when using the definition of vision loss as visual acuity worse than 6/12, rather than the WHO definition of best-corrected visual acuity worse than 6/18.

The implications The availability and use of cataract services in Indigenous communities should be improved.

Cataract surgery is the most common elective surgical procedure around the world, with an average annual global treatment cost of US\$573 million.¹ In Australia, 229 693 operations were performed during 2013–14.² Growth in demand for cataract surgery is driven by the increasing prevalence of cataract associated with population ageing, coupled with improvements in the safety and efficacy of the procedure.^{3–5}

As cataract is the leading cause of blindness (51% of cases internationally)⁶ and surgery usually restores vision,⁷ the World Health Organization selected cataract surgery coverage rates as core indicators of the success of its “Universal eye health: a global action plan 2014–2019”, a program that aims to eliminate avoidable blindness.⁸ Consequently, it is imperative that signatory nations, including Australia, document cataract surgery coverage rates. The WHO defines the coverage rate as the proportion of people with both bilateral cataract and vision impairment (VI) or blindness — visual acuity worse than 6/18; that is, not able to read letters on a chart at 6 metres that a person with normal vision (6/6 vision) can read at 18 metres — who have had their vision corrected by cataract surgery on one or both eyes.⁸ However, given that cataract surgery may be clinically indicated for people with visual acuity better than 6/18 and that the definition of VI varies between countries, the definition of the coverage rate may need revision.^{9,10}

Cataract surgery coverage rates may vary across the Australian population. There is significant heterogeneity in the availability and uptake of eye health services, including cataract surgery, for Indigenous and non-Indigenous Australians, and for people in areas of different geographic remoteness.^{11–13} A recent assessment of variations in waiting times for surgery by remoteness found that the disparity for cataract surgery was greater than for any other surgical procedure.² As eye health surveys have not adequately stratified the non-Indigenous population by remoteness, it is unknown whether their cataract surgery coverage rates vary

Abstract

Objective: To determine cataract surgery coverage rates for Indigenous and non-Indigenous Australians.

Design: National cross-sectional population-based survey.

Setting: Thirty randomly selected Australian geographic sites, stratified by remoteness.

Participants: 3098 non-Indigenous Australians aged 50 years or more and 1738 Indigenous Australians aged 40 years or more, recruited and examined in the National Eye Health Survey (NEHS) between March 2015 and April 2016.

Methods: Participants underwent an interviewer-administered questionnaire that collected socio-demographic information and past ocular care history, including cataract surgery. For those with visual acuity worse than 6/12, anterior segment photography and slit lamp examinations were conducted.

Main outcome measures: Cataract surgery coverage rates according to WHO and NEHS definitions; associated risk factors.

Results: Cataract surgery coverage rates calculated with the NEHS definition 1 of vision impairment (visual acuity worse than 6/12) were lower for Indigenous than non-Indigenous participants (58.5% v 88.0%; odds ratio [OR], 0.32; $P < 0.001$). According to the World Health Organization definition (eligibility criterion: best-corrected visual acuity worse than 6/18), coverage rates were 92.5% and 98.9% for Indigenous and non-Indigenous Australians respectively. Greater age was significantly associated with higher cataract surgery coverage in Indigenous (OR, 1.41 per 10 years; $P = 0.048$) and non-Indigenous Australians (OR, 1.58 per 10 years; $P = 0.004$).

Conclusions: The cataract surgery coverage rate was higher for non-Indigenous than Indigenous Australians, indicating the need to improve cataract surgery services for Indigenous Australians. The WHO definition of the coverage rate may overestimate the cataract surgery coverage rate in developed nations and should be applied with caution.

according to geographic location or other socio-demographic and health factors.

In this article, we report the cataract surgery coverage rates and risk factors identified by the first Australian National Eye Health Survey (NEHS). The appropriateness of how cataract surgery coverage rates are defined in the Australian context is also discussed.

Methods

Participant sampling

The sampling methodology of this study is described in detail elsewhere.¹⁴ In summary, Australian census 2011 data were used

to randomly select 1738 Indigenous Australians aged 40 years or more and 3098 non-Indigenous Australians aged 50 years or more from 30 different geographic sites between March 2015 and April 2016. The younger age for selecting Indigenous participants reflects the earlier onset and more rapid progression of eye disease in this population.¹⁵ Population clusters were stratified by remoteness of residence (Major City, Inner Regional, Outer Regional, Remote, and Very Remote). Trained recruiters visited each household and enrolled participants with a standard script. Based on consultations with local Aboriginal medical services and community elders, methodological adjustments (eg, telephone and word-of-mouth recruitment, as well as recruitment from nearby health clinics) were required to adapt recruitment procedures to local circumstances at each site.

Examination protocol

A standardised interviewer-administered questionnaire was used to collect data on socio-demographic factors, stroke and diabetes history, past ocular history, and eye care service history. Examiners asked participants whether they had ever been told by a health practitioner that they had cataracts, whether they had ever undergone cataract surgery, and on which eyes and how long ago (in years and months). A trained examiner then performed a series of eye tests, including visual acuity measurement with pinhole and auto-refraction in those with visual acuity (VA) worse than 6/12, anterior segment assessment, intraocular pressure testing, perimetry, and fundus photography. VI was defined as bilateral presenting visual acuity (PVA) worse than 6/12, measured with a logMAR chart at 3 metres. Participants with VI in either or both eyes had anterior segment photographs of the impaired eyes taken with a Digital Retinography System (DRS) camera (CenterVue) to determine whether vision loss was caused by anterior segment pathology. Verbal feedback about test results was provided, and participants were referred to a local doctor or optometrist if abnormalities were detected.

Identifying cataracts

Two graders independently assessed anterior segment photographs and fundus photographs taken with a DRS camera to categorise participants into one of three groups: no cataract; probable cataract; or definite cataract. High inter-rater reliability (85%) and intra-rater reliability (94% and 96%) were achieved. Discrepancies were adjudicated by an ophthalmologist. In cases where photographs were unavailable, a cataract grade was assigned on the basis of an anterior segment examination by a trained clinician using a handheld slit lamp (Keeler Ophthalmic Instruments). Participants with probable or definite cataract were deemed to have cataracts for the purposes of this study.

Cataract surgery coverage rates

Cataract surgery coverage rates were calculated with the formula:

$$\text{Cataract surgery coverage rate} = \left(\frac{n_1}{n_1 + n_2} \right) \times 100$$

The numerator n_1 was the number of participants who reported that they had undergone cataract surgery on one or both eyes. The value for n_2 , the number of eligible patients with unoperated cataract, varied according to the definition of eligibility for cataract surgery:

- *WHO definition*: participants with bilateral best-corrected visual acuity (BCVA) of worse than 6/18 and bilateral cataracts;

- *NEHS definition 1*: participants with bilateral PVA worse than 6/12 with cataract in one or both eyes;
- *NEHS definition 2*: participants with BCVA of worse than 6/12 with cataract in one or both eyes.

Risk factor analysis could not be undertaken with the WHO definition because the sample size for n_2 was insufficient (nine non-Indigenous and 16 Indigenous Australians). NEHS definition 1 was selected as the most clinically appropriate for the Australian population, as many Australians undergo cataract excision with PVAs better than 6/12,¹⁶ and was applied in our risk factor analysis.

Statistical analysis

Socio-demographic variables were assessed for participants who had undergone cataract surgery and for those with bilateral vision loss and unoperated cataract. For NEHS definition 1 and the WHO definition, coverage rates were disaggregated by age, sex, place of birth, language spoken at home (English *v* other), and geographic remoteness. Associations between cataract surgery and the following covariates were examined in multivariable logistic regression: Indigenous status, age, sex, education, language spoken at home, and geographic remoteness. Given the differences in inclusion criteria for Indigenous and non-Indigenous participants, regression was performed separately for each population. Adjusted coverage rates by age derived from logistic regression were plotted for Indigenous and non-Indigenous participants. All analyses were adjusted for sampling weights and non-response. Associations were deemed statistically significant if $P < 0.05$ (two-tailed). Stata 14.2 (StataCorp) was used for all analyses.

Ethics approval

Ethics approval was obtained from the Royal Victorian Eye and Ear Hospital (RVEEH) Human Research Ethics Committee (reference, HREC-14/1199H). Additional ethics approval was obtained from the Aboriginal Health and Medical Research Council of New South Wales (reference, HREC-1079/15), the Menzies School of Health Research (reference, HREC-2015-2360), the Aboriginal Health Council of Western Australia (reference, HREC-622), and the Aboriginal Health Council of South Australia (reference, HREC-04-15-604). Participants provided written informed consent. This study was conducted in accordance with the tenets of the Declaration of Helsinki.

Results

Study participants

In total, 1738 Indigenous Australians aged 40–92 years (mean, 55.0 years; standard deviation [SD], 10.0 years) and 3098 non-Indigenous Australians aged 50–98 years (mean, 66.6 years; SD, 9.7 years) from 30 sites were examined. Of these, 142 Indigenous Australians (8.2%) and 631 non-Indigenous Australians (20.4%) reported that they had undergone cataract surgery in at least one eye (n_1). Eighty-nine Indigenous Australians (5.1%) and 89 non-Indigenous Australians (2.9%) had bilateral VI or blindness (PVA worse than 6/12) with unoperated cataract in at least one eye (n_2 for NEHS definition 1) (Box 1). For NEHS definition 2, n_2 was 65 for non-Indigenous Australians and 69 for Indigenous Australians, as 20 Indigenous and 24 non-Indigenous participants had BCVA values better than or equal to 6/12. According to the WHO definition, seven Indigenous Australians and nine non-Indigenous Australians were included in n_2 .

1 Demographic characteristics of participants who had undergone cataract surgery (self-report) and participants with vision impairment or blindness and unoperated cataract (National Eye Health Survey definition 1)

	Indigenous participants		Non-Indigenous participants	
	No surgery*	Surgery [†]	No surgery	Surgery
Number of participants	89	142	89	631
Continuous variables				
Age (years), mean (SD)	64.4 (8.9)	66.3 (10.2)	72.7 (9.5)	75.8 (8.7)
Education (years), mean (SD)	9.0 (3.6)	9.5 (3.7)	11.1 (3.8)	11.6 (3.8)
Categorical variables				
Sex (men)	27 (30%)	69 (49%)	45 (51%)	279 (44.2%)
English spoken at home	80 (90%)	135 (95%)	83 (93%)	590 (93.5%)
Self-reported diabetes mellitus	52 (58%)	81 (57%)	12 (14%)	130 (20.6%)
Place of birth				
Oceania	89 (100%)	142 (100%)	56 (63%)	440 (69.7%)
Europe	0	0	27 (30%)	145 (23.0%)
Other	0	0	6 (7%)	46 (7.3%)
Remoteness				
Major city	29 (33%)	49 (34%)	35 (39%)	228 (36.1%)
Inner regional	13 (15%)	29 (20%)	13 (15%)	141 (22.4%)
Outer regional	33 (37%)	44 (31%)	23 (26%)	148 (23.5%)
Remote	7 (8%)	17 (12%)	12 (14%)	74 (12%)
Very remote	7 (8%)	3 (2%)	6 (7%)	40 (6.3%)

SD = standard deviation. * Participants with unoperated cataract in one or both eyes and presenting visual acuity of worse than 6/12. † Participants who have had cataract surgery in one or both eyes. ♦

Overall cataract surgery coverage rates

According to the WHO definition, the cataract surgery coverage rate among Indigenous Australians was 95.3% (sampling-adjusted rate, 92.5%; 95% confidence interval [CI], 74.6–98.1%); among non-Indigenous Australians, it was 98.6% (sampling-adjusted rate, 98.9%; 95% CI, 97.1–99.6%; for difference, $P = 0.01$) (Box 2). According to NEHS definition 1, coverage rates were 61.5% (sampling-adjusted rate, 58.5%; 95% CI, 49.8–66.8%) for Indigenous Australians and 87.6% (sampling-adjusted rate, 88.0%; 95% CI, 84.5–90.6%) for non-Indigenous Australians ($P < 0.001$). According to NEHS definition 2, coverage rates were 67.3% (sampling-adjusted rate, 64.8%; 95% CI, 53.5–74.6%) for Indigenous Australians and 90.7% (sampling-adjusted rate, 91.4%; 95% CI, 88.5–93.7%) for non-Indigenous Australians ($P < 0.001$). The results discussed below are based on rates according to NEHS definition 1.

Factors that influence cataract surgery coverage rates

Indigenous Australians were less likely to have undergone cataract surgery than non-Indigenous Australians (odds ratio [OR]; 0.32; $P < 0.001$). The odds of cataract surgery increased with age for both Indigenous (OR, 1.41 per decade; 95% CI, 1.01–1.99; $P = 0.048$) and non-Indigenous Australians (OR, 1.58 per decade; 95% CI, 1.17–2.13; $P = 0.004$) (Box 3, Box 4). For Indigenous Australians, rates increased from 43% for those aged 40–49 years to 63% for those aged 80 years or more; for non-Indigenous Australians, rates increased from 66% for those aged 50–59 years to 92% for those aged 80 years or more (Box 2). Longer education was associated with higher cataract surgery coverage rates for Indigenous Australians (OR, 1.09 per year; 95% CI, 1.01–1.19; $P = 0.034$), but not for non-Indigenous participants (Box 3).

Geographic remoteness did not significantly affect cataract surgery coverage rates among non-Indigenous Australians, with high rates across all levels of remoteness (Box 2). Greater variation was observed in the coverage rates for Indigenous Australians, from 28% in Very Remote to 78% in Remote areas, although these differences were not statistically significant (Box 2, Box 3).

Discussion

We have reported the cataract surgery coverage rates for Indigenous and non-Indigenous Australians across all levels of geographic remoteness in Australia, and identified socio-demographic factors associated with cataract surgery.

Cataract surgery coverage rates varied according to the definition applied. According to the WHO definition, rates were well above the 85% recommended by the International Agency for the Prevention of Blindness for both Indigenous (92.5%) and non-Indigenous (98.9%) people.⁸ However, the WHO definition is more relevant to developing nations where service availability is poor, rates of vision loss are high, and surgery is not routinely performed on people without profound vision loss. In Australia, cataract surgery is often performed on individuals with visual acuities better than or equal to 6/12,¹⁶ and it is therefore likely that a substantial proportion of the participants who had undergone surgery had better pre-operative vision than the 6/18 BCVA level in the WHO definition.

The NEHS definitions set 6/12 as the threshold VA level. This is consistent with the bulk of cataract surgery research in Australia, and also corresponds with the minimum legal sight requirement for driving a motor vehicle in Australia.^{17–20} NEHS definition 2, which uses BCVA rather than PVA, may be less relevant in the

2 Cataract surgery coverage rates and sampling-adjusted coverage rates according to the National Eye Health Survey (NEHS) and World Health Organization definitions

	NEHS definition 1*						WHO definition†					
	Indigenous			Non-Indigenous			Indigenous			Non-Indigenous		
	<i>n</i> ₂	<i>n</i> ₁ ‡	Adjusted rate§ (95% CI)	<i>n</i> ₂	<i>n</i> ₁ ‡	Adjusted rate (95% CI)	<i>n</i> ₂	<i>n</i> ₁ ‡	Adjusted rate§ (95% CI)	<i>n</i> ₂	<i>n</i> ₁ ‡	Adjusted rate (95% CI)
All participants	89	142 (61.5%)	58.5% (49.8–66.8%)	89	631 (87.6%)	88.0% (84.5–90.6%)	7	142 (95.3%)	92.5% (74.6–98.1%)	9	631 (98.6%)	98.9% (97.1–99.6%)
Age (years)												
40–49	7	7 (50%)	43% (26–62%)	—	—	—	0	7 (100%)	—	—	—	—
50–59	16	32 (67%)	62% (45–77%)	8	22 (73%)	66% (46–82%)	2	32 (94%)	88% (53–98%)	1	22 (96%)	99% (95–100%)
60–69	43	47 (52%)	50% (39–61%)	23	139 (85.8%)	88% (83–92%)	4	47 (92%)	89% (66–97%)	0	139 (100%)	—
70–79	19	43 (69%)	73% (60–83%)	36	230 (86%)	86% (79–92%)	0	43 (100%)	98% (83–100%)	3	230 (99%)	98% (95–100%)
≥ 80	4	13 (76%)	63% (43–79%)	22	240 (92%)	92% (88–95%)	0	13 (100%)	—	5	240 (98%)	99% (96–100%)
Sex												
Women	62	73 (54%)	52% (41–62%)	44	352 (89%)	88% (83–92%)	4	73 (95%)	92% (72–98%)	4	352 (99%)	99% (95–100%)
Men	27	69 (72%)	69% (57–79%)	45	279 (86%)	88% (82–92%)	3	69 (96%)	94% (72–99%)	5	279 (98%)	99% (97–100%)
English spoken at home												
No	9	7 (44%)	43% (31–57%)	6	41 (87%)	85% (76–92%)	1	7 (88%)	94% (63–99%)	0	41 (100%)	—
Yes	80	135 (63%)	60% (51–68%)	83	590 (88%)	88% (85–91%)	6	135 (96%)	92% (73–98%)	9	590 (99%)	99% (97–100%)
Place of birth												
Oceania	—	—	58% (50–67%)	56	440 (89%)	89% (85–92%)	—	—	92% (74–98%)	5	440 (99%)	99% (97–100%)
Europe	—	—	—	27	145 (84%)	85% (79–89%)	—	—	—	4	145 (97%)	98% (95–99%)
Other	—	—	—	6	46 (88%)	87% (75–94%)	—	—	—	0	46 (100%)	—
Remoteness												
Major city	29	49 (63%)	62% (49–73%)	35	228 (87%)	87% (82–90%)	1	49 (98%)	97% (80–100%)	3	228 (99%)	98% (95–100%)
Inner regional	13	29 (69%)	68% (56–79%)	13	141 (92%)	92% (85–96%)	1	29 (97%)	97% (86–99%)	0	141 (100%)	—
Outer regional	33	44 (57%)	57% (37–75%)	23	148 (87%)	87% (78–92%)	1	44 (98%)	98% (90–100%)	3	148 (98%)	98% (95–99%)
Remote	7	17 (71%)	78% (41–95%)	12	74 (86%)	87% (70–95%)	2	17 (90%)	92% (71–98%)	3	74 (96%)	97% (88–99%)
Very remote	7	3 (30%)	28% (4.8–74%)	6	40 (87%)	87% (77–93%)	2	3 (60%)	54% (1.9–99%)	0	40 (100%)	—

CI = confidence interval; NEHS = National Eye Health Survey; WHO = World Health Organization. * *n*₁ = participants who reported cataract surgery in at least one eye; *n*₂ = participants with unoperated cataract in at least one eye and bilateral presenting visual acuity worse than 6/12. † *n*₁ = participants who reported cataract surgery in at least one eye; *n*₂ = participants with unoperated cataract in both eyes and bilateral best-corrected visual acuity worse than 6/18. ‡ Percentage of all participants in group is given in parentheses. ◆

Australian context than NEHS definition 1, as patients with cataracts and corrected VA better than or equal to 6/12 may still undergo surgery;⁹ excluding these individuals from the denominator may therefore lead to overestimating population coverage rates. Consequently, NEHS definition 1, in which all participants with cataract and presenting bilateral VI were included in the denominator, is probably more apposite for analysis, policy formulation, and resource allocation in Australia. According to this definition,

the coverage rate for Indigenous Australians is lower than appropriate.

Earlier research reported a 12-fold higher prevalence of blindness from cataract in Indigenous communities, and it has been suggested that the much lower rates of cataract surgery among Indigenous — nationally, the rate of hospitalisation for cataract among non-Indigenous Australians was more than six times

3 Logistic regression analysis of risk factors associated with cataract surgery in non-Indigenous and Indigenous Australians with vision impairment or blindness and cataract in at least one eye

Characteristic	Indigenous Australians (n = 231)				Non-Indigenous Australians (n = 720)			
	Univariate analysis		Multivariable analysis		Univariate analysis		Multivariable analysis	
	Odds ratio (95% CI)	P	Odds ratio (95% CI)	P	Odds ratio (95% CI)	P	Odds ratio (95% CI)	P
Age (per decade)	1.24 (0.94–1.62)	0.12	1.41 (1.01–1.99)	0.048	1.47 (1.14–1.90)	0.003	1.58 (1.17–2.13)	0.004
Sex (men v women)	2.07 (1.11–3.85)	0.023	1.86 (0.88–3.96)	0.10	0.78 (0.50–1.21)	0.26	0.96 (0.53–1.76)	0.90
Education (per year)	1.06 (0.99–1.13)	0.12	1.09 (1.01–1.19)	0.034	1.04 (0.97–1.10)	0.27	1.03 (0.94–1.13)	0.50
English at home	1.94 (0.99–3.81)	0.06	1.70 (0.56–5.21)	0.34	1.04 (0.43–2.53)	1.291	0.97 (0.39–2.37)	0.94
Place of birth								
Oceania	—		—		1		1	
Europe	—		—		0.69 (0.44–1.08)	0.10	0.66 (0.43–1.01)	
Other	—		—		0.81 (0.37–1.75)	0.57	0.83 (0.33–2.13)	
Remoteness								
Major city	1		1		1		1	
Inner regional	1.34 (0.63–2.84)	0.43	1.31 (0.59–2.88)	0.49	1.68 (0.79–3.57)	0.17	1.43 (0.70–2.96)	0.31
Outer regional	0.83 (0.31–2.18)	0.69	1.08 (0.41–2.85)	0.87	1.01 (0.50–2.03)	0.97	0.95 (0.45–1.99)	0.88
Remote	2.16 (0.40–11.9)	0.36	2.85 (0.61–13.3)	0.18	1.00 (0.34–2.90)	0.88	0.97 (0.33–2.88)	0.96
Very remote	0.24 (0.03–1.88)	0.16	0.26 (0.04–1.55)	0.13	1.05 (0.48–2.31)	0.89	1.01 (0.39–2.60)	0.98

CI = confidence interval. ♦

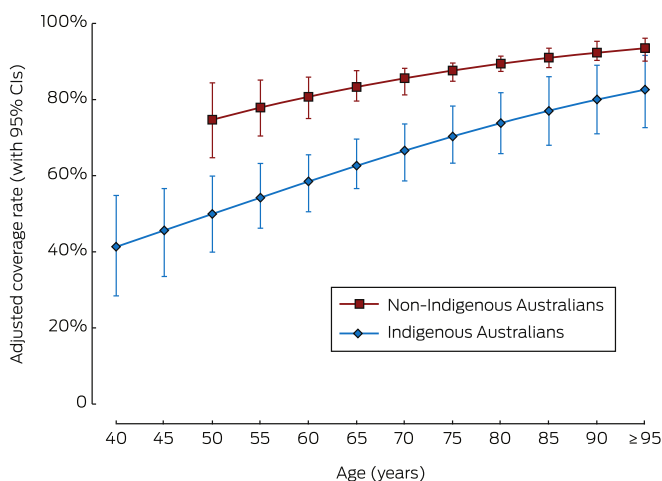
higher than that for Indigenous Australians between 2005 and 2008²¹ — is a major contributing factor to the gap in Indigenous eye health.²² The prevalence of cataract surgery among Indigenous Australians has increased from 6.5% in the National Indigenous Eye Health Survey (NIEHS) in 2008,²³ to 8.2% in our study. The 65% cataract surgery coverage rate reported by the NIEHS was based on visually significant cataract (NEHS definition 2), and is similar to the rate we found when we applied this definition (67%), indicating that the national coverage rate has remained stable. In the context of the increased prevalence of cataract surgery in the Indigenous population, a stable coverage rate may indicate that the prevalence of cataract in this population is increasing. Indeed, the prevalence of visually significant cataract found by the

NEHS — 4.0% (69 of 1738 participants; using definition 2) — was higher than in the NIEHS (2.5%),²³ suggesting that cataract surgery coverage rates need to increase further to compensate for the ageing of the Indigenous population.²²

The cataract surgery coverage rates for Indigenous people we determined were moderately higher than reported by the NIEHS for residents in Major City (63% v 57%), Outer Regional (57% v 50%) and Remote areas (71% v 67%), and moderately lower in Inner Regional areas (69% vs 82%). However, the NEHS rate of 30% for Very Remote communities is much lower than reported by the NIEHS (68%). As these two studies applied different definitions for coverage rates, these comparisons should be considered with caution. Considering the recent improvements in outreach eye health programs for very remote Indigenous communities,²⁴ this difference in coverage is unlikely to represent a dramatic change in coverage in all Very Remote Indigenous communities. It probably instead reflects heterogeneity in service availability and uptake across Indigenous communities in the most remote parts of the country, as well as some sampling variation. We may have inadvertently sampled comparatively underserved Very Remote communities, while the NIEHS may have sampled comparatively well serviced Very Remote communities. Given there were only ten Indigenous Australians in our Very Remote category, the 30% coverage rate found should be regarded with caution. Although this remoteness effect did not achieve statistical significance, such a low coverage rate is unacceptably low in any community, and future planning should identify underserved Indigenous communities in the most remote regions of Australia and develop targeted interventions for improving cataract surgery rates in these areas.

We also provide the first report on cataract surgery coverage rates for non-Indigenous Australians based on a national population-based survey. Previous population-based studies of cataract surgery in non-Indigenous Australians have focused on its prevalence rather than the surgery coverage rate, and have relied on

4 Adjusted cataract surgery coverage rates for Indigenous and non-Indigenous Australians, based on National Eye Health Survey definition 1, by age



extrapolations from subnational population studies, hospital data, or a combination of the two.^{9,11,25,26} The cataract surgery coverage rate among non-Indigenous Australians was high across all geographic region types, with no significant variation between remoteness levels. This suggests that, despite differences in waiting times for surgery associated with remoteness,² the Australian health care system is providing reasonably adequate cataract surgery services for all non-Indigenous Australians. Nevertheless, unoperated cataract still remains a leading cause of reversible vision loss in Australia, and improving cataract services in all regions further will reduce the national prevalence of vision loss.

This is the first study to determine national cataract surgery coverage rates in Australia. Our findings indicate that cataract surgery coverage rate calculations should be adjusted according to

the definition of vision impairment and the thresholds for cataract surgery applied in each country. Our results may inform improvements to cataract surgery services, especially for Indigenous Australians. As cataract is still a leading cause of vision loss and its prevalence will increase in our ageing population,³ sustaining high cataract surgery coverage rates is critical for reducing the burden of vision loss in Australia.

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Competing interests: No relevant disclosures.

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4.3.5 Publication 10: Treatment coverage rates for refractive error in the National Eye Health Survey

4.3.5.1 Overview

Uncorrected refractive error was shown to be the leading cause of VI in both Indigenous and non-Indigenous Australians in the NEHS, a finding that has been reported in most adult populations around the world.^{20, 68} In most instances, apart from cases of severe pathological high myopia, refractive error is treatable and normal or near-normal vision can be restored with a pair of spectacles, contact lenses or surgery.³⁹ Compared to other blinding or vision-impairing ophthalmic conditions, the treatment of refractive error is inexpensive, particularly if a pair of low-cost spectacles is prescribed. This fact, when considered in conjunction with the fact that refractive error is the leading cause of vision loss in Australia, highlights that achieving a high national treatment coverage rate for refractive error represents the most cost-effective, efficient and impactful strategy for reducing Australia's burden of vision loss.

In Publication 10, the treatment coverage rates for refractive error in both Indigenous and non-Indigenous Australians are reported. The proportion of Australians with both uncorrected refractive error (those with bilateral PVA $<6/12$ that improved to $\geq 6/12$ with pinhole or autorefraction, without refractive correction) and under-corrected refractive error (those with bilateral PVA $<6/12$ that improved to $\geq 6/12$ with pinhole or autorefraction, with refractive correction that is insufficient to achieve PVA $\geq 6/12$), are calculated. Sociodemographic, geographic and behavioural risk factors for uncorrected or under-corrected refractive error are provided. This manuscript was published in *PLoS ONE* on the 13th of April 2017.

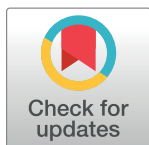
RESEARCH ARTICLE

Treatment coverage rates for refractive error in the National Eye Health survey

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Abstract

Objective

To present treatment coverage rates and risk factors associated with uncorrected refractive error in Australia.

Methods

Thirty population clusters were randomly selected from all geographic remoteness strata in Australia to provide samples of 1738 Indigenous Australians aged 40 years and older and 3098 non-Indigenous Australians aged 50 years and older. Presenting visual acuity was measured and those with vision loss (worse than 6/12) underwent pinhole testing and hand-held auto-refraction. Participants whose corrected visual acuity improved to be 6/12 or better were assigned as having uncorrected refractive error as the main cause of vision loss. The treatment coverage rates of refractive error were calculated (proportion of participants with refractive error that had distance correction and presenting visual acuity better than 6/12), and risk factor analysis for refractive correction was performed.

Results

The refractive error treatment coverage rate in Indigenous Australians of 82.2% (95% CI 78.6–85.3) was significantly lower than in non-Indigenous Australians (93.5%, 92.0–94.8) (Odds ratio [OR] 0.51, 0.35–0.75). In Indigenous participants, remoteness (OR 0.41, 0.19–0.89 and OR 0.55, 0.35–0.85 in Outer Regional and Very Remote areas, respectively), having never undergone an eye examination (OR 0.08, 0.02–0.43) and having consulted a health worker other than an optometrist or ophthalmologist (OR 0.30, 0.11–0.84) were risk factors for low coverage. On the other hand, speaking English was a protective factor (OR 2.72, 1.13–6.45) for treatment of refractive error. Compared to non-Indigenous Australians who had an eye examination within one year, participants who had not undergone an eye examination within the past five years (OR 0.08, 0.03–0.21) or had never been examined (OR 0.05, 0.10–0.23) had lower coverage.

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Data Availability Statement: The Royal Victorian Eye and Ear Hospital Human Research Ethics Committee and the numerous state-level Indigenous Ethics bodies have placed stringent ethical guidelines on the investigators of this study. Due to the risk of identifying participants, particularly in remote Indigenous communities, the authors are unable to make the dataset freely available. Interested researchers may contact the Principal Investigator, Dr. Mohamed Dirani, Head of Evaluative Research and Health Services, Centre for Eye Research Australia at mdirani@unimelb.edu.au to request access to the data.

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Competing interests: The National Eye Health Survey received funding from a commercial source, Novartis Pharmaceuticals. This does not alter our adherence to PLOS ONE policies on sharing data and materials.

Conclusion

Interventions that increase integrated optometry services in regional and remote Indigenous communities may improve the treatment coverage rate of refractive error. Increasing refractive error treatment coverage rates in both Indigenous and non-Indigenous Australians through at least five-yearly eye examinations and the provision of affordable spectacles will significantly reduce the national burden of vision loss in Australia.

Introduction

Refractive error is the most readily treatable cause of vision loss, with a significant proportion of cases being correctable with spectacles or contact lenses [1]. Despite this, uncorrected refractive error is the leading cause of vision impairment (53%) and the second leading cause of blindness (21%) globally, accounting for almost 110 million cases of vision loss [2]. Given its considerable burden in both developing and developed nations, and its feasibility of treatment, uncorrected refractive error has been highly prioritised as a target for interventions in the World Health Organisation's Vision 2020 initiative [3].

Previous population surveys conducted in the early 1990s have reported that the prevalence of uncorrected refractive error may be as high as 10% in Australians aged 40 years and older [4, 5]. While some cases of refractive error are pathological and cannot be treated with spectacles [6], the majority of cases are easily correctable, and the high prevalence of uncorrected refractive error in these studies highlights the need for increased use of spectacles by older Australians. In these studies, higher rates of uncorrected refractive error were associated with a number of demographic and environmental risk factors including country of birth, increasing age, occupation, lower socioeconomic status, and duration since last eye examination [4, 5, 7]. These barriers are considered to be surmountable through targeted interventions aimed at increasing the availability of affordable optometry services, as well as improving community awareness of these services [5, 8].

The National Indigenous Eye Health Survey (NIEHS) reported that 54% of vision loss in Indigenous Australians aged 40 years and older was caused by uncorrected refractive error, and that treatment coverage rates were consistently low in all surveyed communities [9]. However, higher spectacle coverage rates were strongly correlated with better availability of Aboriginal Medical Service (AMS) based optometry practices in communities, highlighting the importance of accessible eye healthcare services in reducing avoidable refractive vision loss [9]. Barriers to obtaining corrective spectacles in Indigenous communities are pervasive, and include insufficient service availability in remote areas and prohibitive travel distances to health services, affordability, and systematic problems with referral pathways [10].

Considering the need for improved treatment coverage of refractive error in both Indigenous and non-Indigenous Australians, a multitude of national and State-based programs have been implemented. The Australian Government's National Framework Implementation Plan (NFIP) involves a coordinated approach to ensure equitable access to eye health care services, with improvements in refractive error treatment being highly prioritised [11]. A number of national and state-based initiatives such as the Visiting Optometrists Scheme have aimed to provide subsidised or free spectacles to improve treatment coverage rates, particularly in Indigenous Australians [10]. However, the efficacy of these programs in improving the treatment of refractive error is not currently known due to a paucity of recent population-based research, and the national treatment coverage rate of refractive error is therefore not presently known.

The National Eye health Survey (NEHS) aimed to provide up-to-date national estimates of the treatment coverage rates of refractive error in both Indigenous and non-Indigenous Australians. Here we present the treatment coverage rates for both groups across all levels of geographic remoteness and provide socio-demographic factors associated with treatment coverage.

Materials and methods

Ethics approval

Ethics Committee approval was obtained from the Royal Victorian Eye and Ear Hospital Human Research Ethics Committee (HREC-14/1199H). Approvals were obtained from the following state-level Indigenous ethics bodies to conduct research within Indigenous communities: Aboriginal Health and Medical Research Council of NSW (HREC-1079/15), the Menzies School of Health Research (HREC-2015-2360), the Aboriginal Health Council of Western Australia (HREC-622) and the Aboriginal Health Council of South Australia (HREC-04-15-604). Participants provided written informed consent. This study was conducted in accordance with the tenets of the Declaration of Helsinki.

Sampling

The sampling methodology has been described in detail elsewhere [12]. In brief, data collection was conducted between March 2015 and April 2016. Probability proportional to size (PPS) multistage random cluster sampling was used to select a representative sample of Indigenous Australians aged 40 years and older and non-Indigenous Australians aged 50 years and older. Population data collected in the 2011 Australian Census were used to select 30 geographic areas across all geographic remoteness strata in Australia. Twelve Major City areas, six Inner Regional areas, six Outer Regional areas, 4 Remote areas and 2 Very Remote areas were selected. In total, 4,520 eligible non-Indigenous residents and 2240 eligible Indigenous residents were enumerated across all survey sites by trained recruiters. Of these, 3098 non-Indigenous participants (68.5% response rate) and 1738 Indigenous participants (77.6% response rate) were recruited to participate in the survey.

Interviewer-administered general questionnaire

Recruited residents in each survey site attended a testing centre within 6km of the selected population cluster and provided written informed consent. Each participant underwent a standardised interviewer-administered questionnaire to collect key sociodemographic data, including gender, age, level of education and ethnicity. Participants were asked whether they were of Aboriginal or Torres Strait Islander origin (Indigenous Australians). The ethnicities of non-Indigenous Australians were categorised according to the Australian Standard Classification of Cultural and Ethnic Groups 2011 based on self-reported country of birth [13]. Stroke and diabetes histories were also recorded. Past ocular history was recorded for all participants, including history of diagnosis of refractive error, cataract, glaucoma, diabetic retinopathy, age-related macular degeneration, or other diseases. Participants were asked if they had ever undergone an eye examination, and if so, how recently. Those who had undergone an eye test were asked who had performed their most recent examination, and responses were recorded against a standardised list defined *a priori*: 1) Optometrist, 2) Ophthalmologist, 3) GP/local doctor, 4) Nurse, 5) Health worker, 6) Ophthalmic nurse/technician, 7) Other. Participants were asked whether they wore spectacles or contact lenses, and if so, whether their refractive correction was for distance or near correction or both.

Eye examination protocol

A series of standardised eye examinations was performed by a trained examiner. Presenting distance visual acuity was measured in each eye separately using a logMAR chart (Brien Holden Vision Institute, Australia) at three metres in well-lit room conditions. If presenting visual acuity was worse than 6/12 in one or both eyes, pinhole testing was conducted. If vision improved to 6/12 or better in one or both eyes, auto-refraction was performed using a Nidek Ark-30 Type-R Hand-held auto-refractor/keratometer (Nidek Co. LTD, Japan). Trial lenses corresponding to auto-refraction measurements were placed in a trial frame and auto-refraction-corrected visual acuity was measured in each eye separately. Binocular presenting near vision was measured in well-lit room conditions using a CERA Vision Test E Chart (Centre for Eye Research Australia, Australia), held at the participant's preferred reading distance. Anterior segment assessment, perimetry, intraocular pressure testing and two-field fundus photography were performed. Examiners provided participants with verbal feedback on their test results, and if abnormalities were detected, a referral letter was provided to be taken to a local doctor or optometrist.

Definitions of uncorrected or under-corrected refractive error and refractive error treatment coverage rates

This analysis focused on participants in whom uncorrected or under-corrected refractive error was the main cause of vision loss. Uncorrected or under-corrected refractive error was determined to be the main cause of vision loss if the distance visual acuity in one or both eyes improved to better than or equal to 6/12 ($\geq 6/12$) with pinhole testing or auto-refraction. The threshold of 6/12 was selected as this is considered the legal threshold for vision impairment in Australia [14]. Participants for whom visual acuity improved with pinhole or autorefraction, but their improvement was below the 6/12 threshold remained bilaterally vision impaired, and were not included as having uncorrected or under-corrected refractive error for the purpose of this analysis. Their vision loss was primarily caused by a different condition, and adequate visual function would not be restored with refractive correction. As participants with presenting visual acuity $\geq 6/12$ did not undergo pinhole testing or autorefraction, those individuals with $\geq 6/12$ vision and mild refractive error who may have improved further with refraction were not identified. These participants were also not considered to have uncorrected or under-corrected refractive error.

Refractive error treatment coverage rates were calculated for participants whose vision loss was caused by uncorrected refractive error using the following formula:

Refractive error treatment coverage rate = $\left(\frac{n_1}{n_1 + n_2}\right) \times 100$. In this formula, n_1 was the number of participants who reported that they wore spectacles and/or contact lenses for distance vision and achieved bilateral presenting distance visual acuity $\geq 6/12$, and n_2 was the number of participants who had refractive error as their main cause of bilateral vision loss ($< 6/12$). Participants in n_2 may have had no refractive correction (uncorrected refractive error) or they may have had refractive correction that was not sufficient to correct their visual acuity to better than 6/12 (under-corrected refractive error).

Statistical analysis

Means and standard deviations (SD) were calculated for normally-distributed continuous sociodemographic variables, and medians and inter-quartile ranges were calculated for skewed data. Counts and percentages were calculated for categorical sociodemographic variables. Refractive error treatment coverage rates were calculated for Indigenous and non-Indigenous participants. Sampling weight-adjusted coverage rates were calculated using logistic regression

models. Treatment coverage rates were disaggregated by age, gender, ethnicity, language spoken at home, and geographic remoteness, and were tabulated as counts and percentages. Multivariable logistic regression analysis was used to examine the association between spectacle or contact lens correction and the following variables: Ethnicity, including Indigenous/non-Indigenous status, age (years), gender, number of years of education, main language spoken at home (English/other), geographic remoteness time since last eye examination and the type of eye health care professional who conducted the examination. Excluding 'optometrist' and 'ophthalmologist', the *a priori* list of eye health care providers was collapsed into the group 'other' due to a small sample size in each group and compared against 'optometrist' and 'ophthalmologist'. Due to differences in inclusion criteria and sampling between Indigenous and non-Indigenous participants, regression analysis was performed separately for each group. For the final fitted logistic regression model, model residuals and delta beta values were examined to determine if potential outlying observations influenced results. The degree to which statistical assumptions were violated was also examined. Associations were considered statistically significant if $p < 0.05$. All statistical analyses were undertaken using Stata version 14.2 (StataCorp, College Station, TX).

Results

Study participants

A total of 4836 participants were recruited and examined from 30 sites across all levels of geographic remoteness in five States and one Territory in Australia. Of these, 3098 identified as non-Indigenous (46.38% male, aged 50 to 98 years, mean age [SD] = 66.6 [9.7] years), and 1738 identified as Indigenous Australians (41.1% male, aged 40 to 92 years, mean age [SD] = 55.0 [10.0] years) (Table 1).

Table 1. Demographic characteristics of participants with corrected refractive error and participants with uncorrected or under-corrected refractive error

	Non-Indigenous (n = 1990)		Indigenous (n = 670)	
	Uncorrected [†] (n = 124)	Corrected [‡] (n = 1776)	Uncorrected [†] (n = 116)	Corrected [‡] (n = 554)
Continuous variables	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age (years)	67.6 (10.5)	67.3 (9.3)	58.5 (10.9)	57.6 (10.0)
Education (years)	11.9 (4.5)	12.7 (3.7)	10.0 (3.0)	11.0 (3.4)
Categorical variable	n (%)	n (%)	n (%)	n (%)
Gender (male)	62 (50.0)	753 (42.4)	46 (39.7)	205 (37.0)
English at home	116 (93.6)	1682 (94.7)	111 (95.7)	541 (97.7)
Ethnicity				
Oceanian	88 (71.0)	1265 (71.2)	116 (100.0)	553 (99.8)
European	26 (21.0)	377 (21.2)	0 (0)	1 (0.12)
Others	10 (8.1)	134 (7.6)		
Remoteness				
Major City	53 (42.7)	705 (39.7)	39 (33.6)	263 (47.5)
Inner Regional	20 (16.1)	388 (21.9)	17 (14.7)	122 (22.0)
Outer Regional	31 (25.0)	358 (20.2)	44 (37.9)	95 (17.2)
Remote	8 (6.5)	196 (11.0)	8 (6.9)	50 (9.0)
Very Remote	12 (9.7)	129 (7.2)	8 (6.9)	24 (4.3)

[†]Participants with uncorrected or under-corrected refractive error determined to be the main cause of bilateral presenting vision loss ($< 6/12$)

[‡]Participants who reported to have distance spectacle or contact lens correction and had presenting bilateral visual acuity $\geq 6/12$.

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Treatment coverage rates of refractive error and the prevalence of under- and uncorrected refractive error

Distance correction was worn by 60.5% (1875/3098) of non-Indigenous participants. Uncorrected or under-corrected refractive error was determined to be the main cause of vision loss in 124 non-Indigenous Australians, resulting in a prevalence of uncorrected refractive error of 4.0%. Of these, 99 participants wore distance correction (under-corrected), while 25 did not wear distance correction (uncorrected). Overall, the number of non-Indigenous Australians with refractive correction and visual acuity $\geq 6/12$ was 1776. The treatment coverage rate for refractive error in non-Indigenous Australians was 93.5% (1776/1900). After sampling weight-adjustment, the coverage rate remained at 93.5% (95% CI 92.0–94.8) (Table 2, Fig 1).

The proportion of Indigenous participants who wore distance correction was 36.2% (630/1738). Under- or uncorrected refractive error was the main cause of vision loss in 116 Indigenous participants, of which 76 wore distance refractive correction (under-corrected) and 40 did not wear correction (uncorrected). Therefore, the prevalence of uncorrected or under-corrected refractive error was 6.7% in Indigenous Australians (116/1738), which was significantly higher than in non-Indigenous Australians ($p < 0.001$). The total number of Indigenous participants who wore distance correction and had presenting visual acuity $\geq 6/12$ was 554, resulting in a coverage rate for refractive error in Indigenous Australians of 82.7% (554/670). The sampling weight-adjusted coverage rate was 82.2% (95% CI 78.6–85.3) (Table 2).

Factors associated with treatment coverage of refractive errors

Multivariable logistic regression revealed that non-Indigenous participants had a significantly higher likelihood of having adequate distance correction than Indigenous participants, with an odds ratio (OR) of 0.51 (95% CI 0.35–0.75, $p = 0.001$) for Indigenous participants. Due to this significant difference, as well as the different age inclusion criteria between Indigenous and non-Indigenous participants (40 years and older versus 50 years and older, respectively), all subsequent risk factor models were performed for Indigenous and non-Indigenous participants separately (Table 3).

In non-Indigenous participants, treatment coverage rates did not vary significantly by age or gender (Table 3). Non-Indigenous Australians who reported that they had not undergone an eye examination within the past five years were less likely to have had their refractive error corrected (OR 0.08, for ≥ 5 years, and 0.05, for those who had never been examined). Participants who reported that they had seen an ophthalmologist were less likely to have had their refractive error corrected (OR 0.49) compared to those who had seen an optometrist.

Numerous factors were associated with a lower likelihood of having corrected refractive error in Indigenous participants. With treatment coverage rates of 68.4% in Outer Regional (OR 0.41) and 75% in Very Remote (OR 0.55) sites compared to the highest rate of 87.2% in Major Cities, geographic remoteness was a risk factor for having under- or un-corrected refractive error. Having never undergone an eye examination (OR 0.08) and having visited a health worker other than an optometrist or ophthalmologist for the most recent eye examination (OR 0.30) were also associated with a decreased likelihood of corrected refractive error in Indigenous participants. Conversely, speaking English at home conferred an increased likelihood of having corrected refractive error (OR 2.72).

Discussion

This paper provides the treatment coverage rates of uncorrected refractive error and associated risk factors in Australia's first National Eye Health Survey. Treatment coverage rates were

Table 2. Refractive error treatment coverage rates.

	Non-Indigenous Australians (n = 1900)				Indigenous Australians (n = 670)			
	Uncorrected [†]	Corrected [‡]	Unadjusted %	Weighted % (95% CI) [§]	Uncorrected	Corrected	Unadjusted %	Weighted % (95% CI)
Total	124	1776	93.5	93.5 (92.0–94.8)	116	554	82.7	82.2 (78.6–85.3)
Age group (years)								
40–49 [¶]	-	-	-	-	29	124	81.0	79.0 (68.9–86.4)
50–59	33	390	92.2	91.0 (87.5–93.6)	35	209	85.7	86.1 (78.9–91.1)
60–69	37	701	95.0	95.3 (93.3–96.8)	34	152	81.7	79.8 (67.3–88.4)
70–79	36	476	93.0	93.5 (88.8–96.3)	14	57	80.3	83.3 (74.2–89.7)
80+	18	209	92.1	92.7 (87.0–96.1)	4	12	75.0	76.0 (35.9–94.7)
Gender								
Female	62	1023	94.3	94.0 (92.2–95.4)	70	349	83.3	82.3 (77.0–86.6)
Male	62	753	92.3	93.0 (90.4–94.9)	46	205	81.7	82.0 (75.0–87.4)
English at home								
No	8	94	92.2	93.5 (88.2–96.5)	5	13	72.2	52.7 (25.7–78.2)
Yes	116	1682	93.6	93.5 (91.9–94.9)	111	541	83.0	82.9 (78.9–86.4)
Ethnicity								
Oceanian	88	1265	93.5	93.5 (90.9–95.4)	116	553	82.7	82.2 (78.6–85.3)
European	26	377	93.6	93.6 (90.4–95.8)	0	1		-
Others	10	134	93.1	93.6 (87.2–96.9)				-
Remoteness								
Major City	53	705	93.0	93.1 (90.9–94.8)	39	263	87.1	87.2 (81.3–91.4)
Inner Regional	20	388	95.1	95.2 (93.2–96.6)	17	122	87.8	88.3 (82.8–92.2)
Outer Regional	31	358	92.0	92.1 (85.6–95.8)	44	95	68.4	69.5 (56.5–79.8)
Remote	8	196	96.1	96.7 (89.6–99.0)	8	50	86.2	87.7 (68.0–96.0)
Very Remote	12	129	91.5	91.6 (87.1–94.7)	8	24	75.0	74.6 (67.1–80.9)
Time since last eye exam								
Within 1 year	56	1167	95.4	95.6 (93.7, 96.9)	56	334	85.6	85.2 (79.4, 89.6)
1–2 years	30	415	93.3	92.1 (89.5, 94.2)	18	113	86.3	83.9 (75.5, 89.8)
2–5 years	17	159	90.3	92.7 (83.2, 97.1)	22	79	78.2	79.6 (63.1, 90.0)
≥5 years	17	31	64.6	63.2 (44.1, 78.9)	12	25	67.6	77.3 (64.0, 86.8)
Never	4	4	50.0	53.2 (18.9, 84.7)	7	3	30.0	28.4 (7.7, 65.5)

Refractive error coverage rate was defined as $(\frac{n_1}{n_1+n_2}) \times 100$, where n_1 = the number of participants who reported that they wear glasses or contact lenses for distance vision, and n_2 = the number of participants with uncorrected or under-corrected refractive error as the main cause of bilateral presenting vision loss.

[†]number of participants with bilateral presenting vision loss (<6/12) and uncorrected or under-corrected refractive error as the main cause.

[‡]number of participants with refractive correction and bilateral presenting visual acuity ≥6/12.

[§] Population-weighted treatment coverage rate: adjusted based on the remoteness-stratified cluster sampling protocol

[¶]The minimum age for non-Indigenous participants was 50 years. However, as Indigenous Australians are known to have more rapid progression and earlier onset of eye disease and diabetes, a younger age criterion of 40 years or older was selected for the target Indigenous population

^{||}Country of birth was not disaggregated for Indigenous participants as only three individuals were born outside of Oceania.

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above 90% in non-Indigenous Australians of all ages, and of both genders residing in all levels of geographic remoteness. Conversely, the refractive error treatment coverage rate in Indigenous Australians varied considerably according to sociodemographic risk factors including spoken language and geographic remoteness, and was significantly lower than that of non-Indigenous Australians.

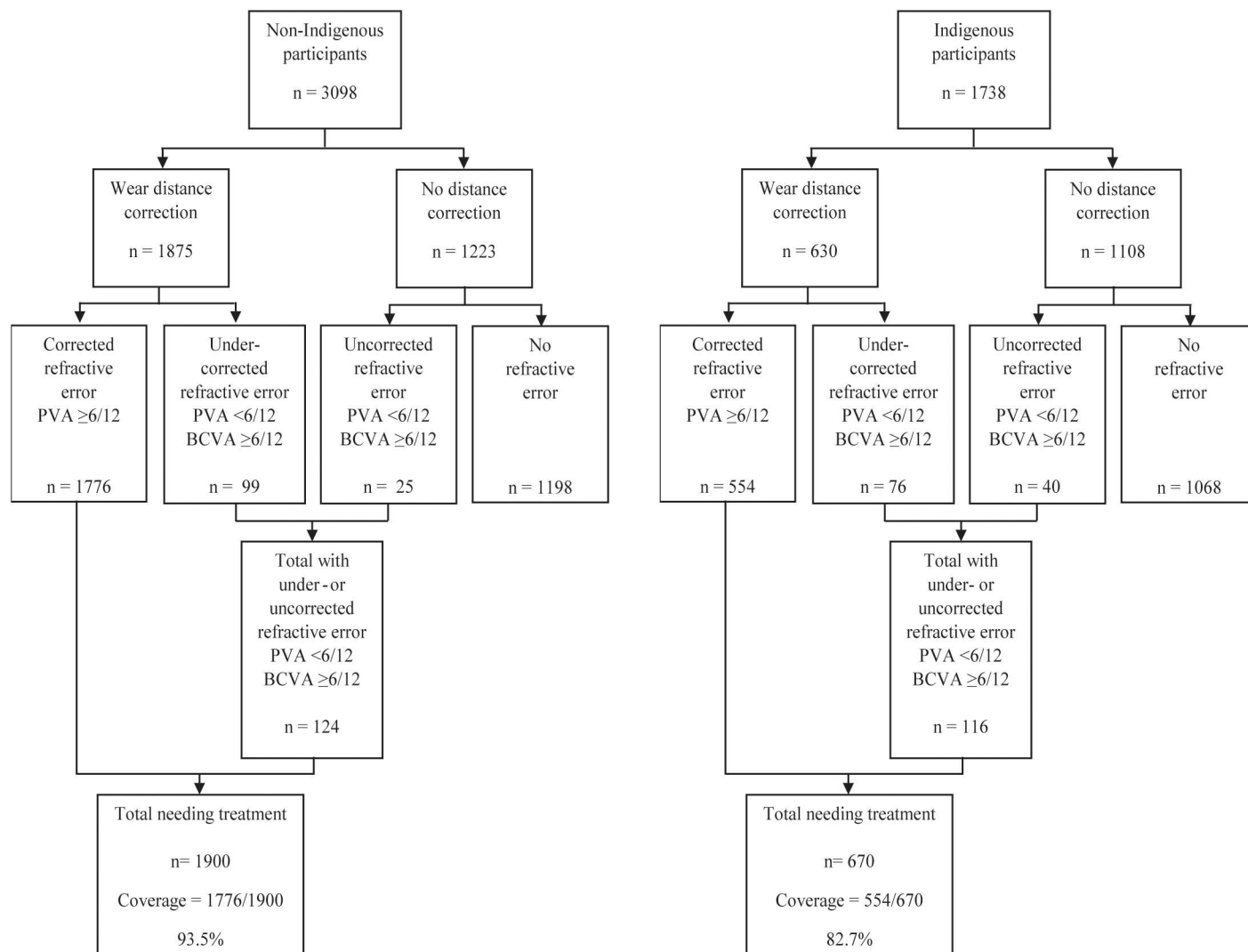


Fig 1. Flowcharts for treatment coverage rates for refractive error in the National Eye Health Survey. PVA = presenting visual acuity; BCVA = best-corrected visual acuity.

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The high refractive error treatment coverage rate of 93.5% in non-Indigenous Australians aged 50 years and older may be explained by widespread accessibility of spectacle-dispensing optometry services. Previously, two surveys in the early 1990s, the Blue Mountains Eye Study (BMES) and the Melbourne Visual Impairment Project (VIP) elucidated that under- and uncorrected refractive error were pervasive, with 45.6% of participants in the BMES and 57% in the VIP having correctable presenting visual acuity [4, 5]. Comparability between the NEHS and these studies is restricted by differences in definitions of under- or uncorrected refractive error, with the BMES defining under-corrected refractive error as an improvement of two or more lines on a logMAR chart in those with visual acuity 6/9 or worse [5] and the VIP considering under-corrected refractive error as an improvement on one or more lines in those with visual acuity worse than 6/6 minus two letters [4]. As such, other parameters including the prevalence of uncorrected refractive error and temporal changes in risk factors must be compared with similar caution. Nonetheless, current national strategies for spectacle coverage appear, on the whole, to have improved coverage in non-Indigenous Australians [11]. Where

Table 3. Multivariable analysis of factors associated with treatment of refractive error in Indigenous and non-Indigenous Australians.

Associated factors	Non-Indigenous Australians (n = 1900)				Indigenous Australians (n = 670)			
	Univariate	p*	Multivariable	p*	Univariate	p*	Multivariable	p*
	OR† (95% CI)		OR† (95% CI)		OR† (95% CI)		OR† (95% CI)	
Age (10 years)	1.10 (0.85–1.43)	0.45	1.17 (0.89–1.55)	0.24	0.97 (0.70–1.35)	0.85	1.04 (0.70–1.53)	0.86
Gender (male)	0.85 (0.56–1.28)	0.42	0.86 (0.54–1.37)	0.52	0.98 (0.55–1.77)	0.95	1.04 (0.57–1.89)	0.90
Education (years)	1.72 (0.76–3.93)	0.19	1.97 (0.81–4.81)	0.13	2.68 (1.33–5.42)	0.008	2.53 (0.90–7.15)	0.08
English at home	1.00 (0.49–2.05)	0.99	0.55 (0.22–1.36)	0.19	4.37 (1.22–15.67)	0.03	2.72 (1.13–6.45)	0.03
Ethnicity‡								
Oceanian	1		1		-	-	-	-
European	1.01 (0.55–1.85)	0.97	1.02 (0.56–1.86)	0.94	-	-	-	-
Others	1.01 (0.40–2.58)	0.98	0.78 (0.23–2.68)	0.68	-	-	-	-
Remoteness								
Major City	1		1		1		1	
Inner Regional	0.54 (0.34–0.86)	0.11	1.35 (0.75–2.44)	0.31	1.11 (0.59–2.10)	0.73	1.01 (0.51–2.02)	0.97
Outer Regional	0.59 (0.22–1.61)	0.69	0.89 (0.46–1.73)	0.72	0.33 (0.16–0.68)	0.004	0.41 (0.19–0.89)	0.03
Remote	0.08 (0.03–0.19)	0.22	2.34 (0.62–8.91)	0.20	1.05 (0.29–3.78)	0.94	1.39 (0.38–5.03)	0.60
Very Remote	0.05 (0.01–0.27)	0.47	0.90 (0.48–1.67)	0.72	0.43 (0.24–0.77)	0.006	0.55 (0.35–0.85)	0.01
Time since last eye exam								
Within 1 year	1		1		1		1	
1–2 years	0.54 (0.34–0.86)	0.01	0.49 (0.32–0.76)	0.002	0.91 (0.47–1.75)	0.76	0.93 (0.51–2.02)	0.81
2–5 years	0.59 (0.22–1.61)	0.29	0.58 (0.22–1.53)	0.26	0.68 (0.24–1.96)	0.46	0.69 (0.23–2.01)	0.49
≥ 5 years	0.08 (0.03–0.19)	<0.001	0.08 (0.03–0.21)	<0.001	0.59 (0.27–1.31)	0.19	0.70 (0.32–1.54)	0.36
Never	0.05 (0.01–0.27)	0.001	0.05 (0.01–0.23)	0.001	0.07 (0.11–0.43)	0.006	0.08 (0.02–0.43)	0.004
Examined by								
Optometrist	1		1		1		1	
Ophthalmologist	0.62 (0.31–1.24)	0.17	0.49 (0.25–0.95)	0.06	0.68 (0.41–1.13)	0.13	0.81 (0.48–1.38)	0.43
Others	0.19 (0.03–1.00)	0.05	0.19 (0.03–1.09)	0.06	0.25 (0.10–0.61)	0.004	0.30 (0.11–0.84)	0.02

†Odds ratio for the association between factors and treatment of refractive error. CI = Confidence Interval

‡ Country of birth was not tested for Indigenous participants as only three individuals were born outside of Oceania

*Statistical significance was set as a p value of <0.05 (two tailed).

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those with poorer education and those of older age were previously shown to be at risk of uncorrected refractive error, the lack of these associations in the NEHS suggests that improvements in availability and utilisation of optometry services in recent years may have contributed to closing these gaps. Interestingly, despite previous reports that regional and remote Australia were severely under-served by optometrists, coverage rates in non-Indigenous participants in our study were stable across remoteness strata, suggesting that outreach programs that incentivise optometrists to practice in remote areas are proving effective for non-Indigenous Australians [15, 16]. Indeed, previous Australian research has suggested that non-Indigenous Australians residing in non-urban areas undergo more frequent optometric examinations than their urban counterparts [17]

The high treatment coverage rate in non-Indigenous participants should be considered in light of the fact that uncorrected refractive error is Australia's leading cause of vision impairment, with even small rates of under-correction (or no correction) contributing significantly to the national burden of vision loss [7, 18]. Indeed, 4% of all non-Indigenous participants had uncorrected refractive error as a main cause of vision loss, corresponding to more than 200,000 Australians. The finding that those who had not undergone an eye examination within the past five

years were at risk for uncorrected refractive error supports previous Australian research and highlights the need for older Australians (specifically those without previously diagnosed eye disease) to undergo a vision assessment approximately every five years [8, 19]. The resulting reduction in the burden of uncorrected refractive error may prove to be a highly cost-effective and efficient method to reduce avoidable vision loss as a public health concern in Australia [14].

The disparity in the treatment coverage rate between Indigenous and non-Indigenous Australians suggests that Indigenous Australians are comparatively under-serviced with eye health care resources. While outreach services have been initiated to close the gap in Indigenous eye health by providing free or subsidised spectacles, previously identified coordination problems and funding deficits may contribute to the lower coverage rate in Indigenous communities [10, 20, 21]. One logistical problem of particular concern that was supported by the results of our survey was the lack of accessibility to spectacles by Indigenous Australians living in remote parts of Australia, with the lowest rates in Outer Regional and Very Remote sites [9, 21]. A well-coordinated and integrated approach involving improvements in availability and utilisation of services in these under-serviced regions, as outlined in the Roadmap to Close the Gap for Vision, is required to improve treatment coverage rates [20]. As Turner et al. showed [9], increasing the availability of optometry services in Indigenous communities is insufficient to increase spectacle coverage rates. However, when increased optometry services were hosted by local AMSs, spectacle coverage rates increased significantly. Therefore, care pathways aiming to improve spectacle coverage in remote communities should increase the role of AMSs in identifying those in need of spectacles and increasing the frequency with which outreach optometry services operate within AMS practices to provide culturally-appropriate services. We also identified that Indigenous participants who received their last eye examination by a health worker other than an optometrist or an ophthalmologist were at greater risk of uncorrected refractive error. This highlights both the indispensable utility of optometrists and ophthalmologists, as well as the need for sustainable models that continue to improve the education and training of health workers in Indigenous communities.

The strengths of this study include; 1) the sampling methodology and large sample size obtained that allowed robust extrapolation of findings to the Australian population, and 2) the comprehensive questionnaire that allowed us to identify important risk factors for uncorrected refractive error. A potential limitation of the study is that we did not ascertain a history of refractive surgery as a treatment for refractive error. This may have resulted in a slight under-estimation of the true treatment coverage rate. Another limitation may be that hand-held autorefraction has been shown to be less accurate than table-mounted autorefraction [22] and subjective refraction [23], and the use of a hand-held autorefractor may have produced inaccurate results in some participants. Nonetheless, the accuracy of hand-held autorefractors has been shown to be sufficient for screening purposes, [22, 24] suggesting that these inaccuracies are unlikely to have substantially affected treatment coverage estimates.

In conclusion, the treatment coverage rate of refractive error was significantly higher in non-Indigenous Australians than in Indigenous Australians. Indigenous Australians living in more remote areas, those who have never had an eye examination, and those who utilise non-optometric eye care services, were at high risk for untreated refractive error. Improvements in AMS-mediated optometry services in remote communities and the provision of affordable spectacles in Indigenous communities are required to increase treatment rates. Given that uncorrected refractive error accounts for a significant proportion of vision loss in Australia, ensuring that older Australians undergo eye examinations every five years will contribute substantially to reducing the burden of vision loss in Australia.

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Investigation: JF SK MD.

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Supervision: MD HRT.

Visualization: JF JX.

Writing – original draft: JF JX SK MD HRT.

Writing – review & editing: JF JX SK MD HRT.

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CHAPTER 5: GENERAL DISCUSSION

5.1 Overview

This study has addressed two core aims: 1) to determine the prevalence and major causes of unilateral and bilateral VI and blindness in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia, and 2) to determine rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and both cataract surgery coverage and refractive error treatment coverage rates in non-Indigenous Australians aged 50 years or older and Indigenous Australians aged 40 years or older residing in all levels of geographic remoteness in Australia.

These aims were addressed through the successful execution of Australia's first National Eye Health Survey - a nationwide cross-sectional population-based survey that utilised a modified multi-stage random-cluster sampling methodology to recruit 3098 non-Indigenous Australians and 1738 Indigenous Australians from all five of Australia's geographic remoteness strata. All participants in this study underwent a standardised interviewer-administered questionnaire and a series of eye examinations, and the resulting data were used to determine nationally-representative estimates for both study aims. This thesis has presented the results of this study in publication format, and aim-specific discussions are reported therein. This chapter provides a general discussion and serves to recapitulate and integrate the numerous findings from this study and to discuss their significance within the broader context of Australian and global eye health.

This chapter begins by discussing the public health, policy and resource implications of the findings of Aim 1 of this study. The Indigenous eye health gap, major causes of vision loss and major population groups at risk of vision loss are discussed in this section. The key findings of

Aim 2 are then contextualised, with an emphasis on how insufficiencies in utilisation of eye care services and disease coverage rates have directly contributed to the burden of avoidable vision loss in Australia. The major findings of the NEHS are then compared with previous Australian and global literature, and the considerable domestic and global impact of this study are discussed. This is followed by an exposition of the major strengths and limitations of the survey as well as suggestions for future research directions. Finally, this thesis concludes with an overall summary of the significance of the NEHS.

5.2 Aim 1: Key findings

5.2.1 The prevalence of vision loss in Indigenous and non-Indigenous

Australians

The NEHS is the first eye health survey to have included and compared national samples of both Indigenous and non-Indigenous Australians in the same study and is therefore the first study to reliably quantify the magnitude of the gap in Indigenous eye health. We found that the weighted prevalence of bilateral vision loss was 6.5%, the prevalence of unilateral vision loss was 16.0%, and the prevalence of near vision loss was 21.6% in non-Indigenous Australians aged 50 years or older. In Indigenous Australians aged 40 years or older, prevalence estimates for the same conditions were 11.2%, 14.9% and 34.7%. The adjusted prevalence of bilateral vision loss was 2.8 times higher, unilateral vision loss was 1.4 times higher, and NVI was 1.6 times higher in Indigenous Australians than non-Indigenous Australians. A recent report emphasised that, despite the consistently higher rates of vision loss in Indigenous Australians, compared to historical findings the results of the NEHS signify that in terms of closing the gap for vision, “we are nearly there”.³³⁷ However, this claim is difficult to verify considering previous estimates have, in part, been predicated on comparisons between incompatible studies.²⁴⁸ Nevertheless, the higher rates of bilateral, unilateral and near vision loss in the Indigenous population identified in this study are substantial and the underlying causes of this

gap warrant discussion to identify specific areas of unmet need. In addition, although vision loss was less common in non-Indigenous Australians, rates of 6.5% (bilateral) to 21.6% (NVI) still represent a significant proportion of the population, and it is similarly important to understand the epidemiologic underpinnings of the vision loss burden in this group and to optimise eye health programs for those with unmet eye health care needs.

5.2.2 Population sub-groups at greatest risk of vision loss

Through the identification of the main causes of vision loss, the stratification of sampling by Indigenous status and remoteness, and the identification of independent risk factors, the NEHS has identified Australian population sub-groups with the greatest burden of vision loss. In logistic regression, older age was seen to profoundly increase the prevalence of bilateral, unilateral and near vision loss in both Indigenous and non-Indigenous Australians. More than 37% of non-Indigenous Australians aged ≥ 90 years had bilateral vision loss, 27% of those aged 80-89 years had unilateral vision loss and 42% of those aged ≥ 80 years had NVI. These proportions were 7.5, 3.4 and 2.9-fold higher, respectively, than for participants aged 50-59 years. The age-related increases in Indigenous Australians were similarly pronounced, with those aged 80-89 years having a prevalence of bilateral vision loss of 56%, those aged 70-79 years having a prevalence of unilateral vision loss of 34%, and those aged ≥ 70 years having a prevalence of NVI of 53%, which were 7.8, 4.3 and 1.7 times higher than those aged 40-49 years. It is important to note that older age groups (≥ 90 years for non-Indigenous Australians and ≥ 80 for Indigenous Australians) were not well represented due to small sample sizes, and the reliability of estimates in this age range should be considered cautiously. Nonetheless, the significant upward trend in the prevalence of vision loss with age reflects the findings of previous studies,^{188, 189} and highlights that both Indigenous and non-Indigenous Australians should receive more frequent eye examinations as they age. The importance of undergoing regular eye examinations is further supported by the observation that participants who had not

undergone a recent eye examination had higher odds of having both unilateral and bilateral vision loss. Considering how rapidly Australia's population is ageing, increasing eye health service uptake by the elderly will improve early detection, prevention and treatment of age-related eye diseases and will prove critical for blindness prevention programs.

For all vision-related outcomes measured in non-Indigenous Australians, NVI was the only factor associated with geographic remoteness, with those living in Remote areas having odds of 1.65 for NVI compared to those in Major Cities. Unilateral and bilateral distance vision loss were relatively uniform across remoteness strata. On the other hand, all measures of vision loss in Indigenous Australians were strongly associated with the level of geographic remoteness. Compared to those residing in Major Cities, Indigenous Australians residing in Inner Regional (NVI only), Outer Regional (bilateral vision loss and NVI), Remote (NVI only) and Very Remote (unilateral vision loss only) areas had substantially poorer vision. There was also a trend indicative of an effect of Very Remote residence on bilateral vision loss (15.7% in Very Remote vs 8.3% in Major City) however, this failed to reach statistical significance ($P=0.054$). Significantly lower eye examination rates in Outer Regional (RRR: 0.53), Remote (RRR: 0.68) and Very Remote (RRR: 0.28) areas, as well as low cataract surgery coverage (27.6%) in Very Remote areas and low refractive error treatment coverage rates in Outer Regional and Very Remote areas (69.5% and 74.6%) contributed to the majority of vision loss in non-urban Indigenous populations. Integrated strategies that prioritise enhancing the provision of optometric and cataract surgical services in regional and remote Indigenous communities are therefore required to close the Indigenous eye health gap.

5.2.3 The major causes of vision impairment and blindness

5.2.3.1 Uncorrected refractive error

The finding that almost two-thirds of bilateral and unilateral vision loss in both Indigenous and non-Indigenous Australians was caused by under- or un-corrected refractive error is one of the

most important observations of this study, because it highlights that the majority of vision loss in Australia is readily correctable with spectacles. Considering that almost 400,000 Australians are bilaterally vision impaired and almost one million are unilaterally vision impaired, it can be inferred that over 200,000 Australians have bilateral vision loss and more than half a million have unilateral vision loss from uncorrected refractive error. This represents a significant and almost entirely avoidable national public health problem. Despite the high treatment coverage rates of refractive error of 93.5% and 82.2% for non-Indigenous and Indigenous Australians, respectively, 4.0% of the total non-Indigenous population aged 50 years or older and 6.7% of the total Indigenous population aged 40 years or older are affected by refractive vision loss, and this group contributes more than any other to Australia's burden of VI.

It is important to consider the economic, socio-cultural and personal context of uncorrected refractive error in order to identify the remaining barriers to obtaining spectacles and to devise strategies to improve treatment coverage rates. As highlighted in Publication 10, barriers are likely to differ for the Indigenous and non-Indigenous populations, and targeted evidence-based interventions should be implemented for each sub-population accordingly. One major reason for the persistence of refractive vision loss in Indigenous communities is the lack of access to (or prohibitive distance to) spectacle-dispensing services in Outer Regional and Very Remote locations, as evidenced by the low treatment coverage rates in these RAs (69.5% and 74.6%), and the correspondingly higher prevalence of both unilateral and bilateral vision loss in these sites. It was also observed that Indigenous Australians who had seen a health care worker other than an optometrist were less likely to have their refractive error treated (OR: 0.30), emphasising the importance of outreach optometry services to non-metropolitan communities. This demonstrates the requirement for sustainable models that improve the training of health workers in Indigenous communities to detect refractive error and refer patients for care.

The high refractive error treatment rates in this study, particularly in the non-Indigenous population, may be approaching the maximum coverage achievable, regardless of further policy, education and service changes. As elaborated upon further in Appendix S, while achieving 6/6 visual acuity is the logical priority of the treating clinician, the situation may be less binary for patients as they may be affected by inconveniences associated with spectacles, contact lenses and corrective surgeries. As identified by Kandel *et al* (2017), deterrents may include cosmetic issues, continual visual and non-visual problems such as poor peripheral vision, and distorted or blurred central vision, ocular pain and dryness from refractive surgery or contact lenses, as well as the financial imposition of recurring the costs of spectacles or contact lenses.³³⁸ Cultural notions regarding the expected deterioration of vision with age and competing health priorities in older age may also result in some individuals not seeking care for their refractive error. Given these considerations, policy makers may benefit from being mindful that further improvement in refractive error treatment coverage may be incremental, and a cost-benefit analysis of the economic implications should be conducted.

Despite the barriers in both the Indigenous and non-Indigenous communities of Australia, Australia's health care system is sufficiently equipped to eliminate uncorrected refractive error as the leading cause of vision loss. Allocating additional resources to programs such as the Victorian Aboriginal Spectacle Subsidy Scheme and the Visiting Optometrists Scheme, and ensuring affordability and cost-certainty for spectacle services nationwide will contribute to improving refractive error treatment coverage rates. This, in turn, may prove to be the most cost-effective and efficient method to reduce avoidable vision loss as a public health concern in Australia.²⁶⁸ The Global Action Plan has prioritised uncorrected refractive error as a major target for low vision and blindness prevention programs,¹ and Australia would exceed the objectives of the Global Action Plan by eliminating uncorrected refractive error alone.

5.2.3.2 Cataract

Cataract was the leading cause of bilateral blindness in Indigenous Australians (40%), and the second leading cause of unilateral and bilateral VI in both Indigenous and non-Indigenous groups, accounting for 13.2% and 20.1% of bilateral vision loss and 13.7% and 10.7% of unilateral vision loss in non-Indigenous and Indigenous Australians, respectively. Cataract was also responsible for 10.4% of unilateral blindness in non-Indigenous Australians and 13.9% of unilateral blindness in Indigenous Australians. When taken with the findings for uncorrected refractive error, these statistics provide further evidence that most VI in Australia is avoidable. The projected ageing of the Australian population will be accompanied by an upward trend in the incidence of blinding cataract, with almost 3 million Australians expected to have cataract by the year 2021.⁴⁶ While the required increase in cataract surgery service availability will put additional pressure on Australia's health care system in terms of cost and human resources, failing to match the increasing incidence of cataract with increased service delivery will result in a greater economic and disability burden.³³⁹

5.2.3.3 Diabetic retinopathy

Successive population health surveys have reported an increasing prevalence of diabetes in Australia, and both the incidence and prevalence of the disease are predicted to increase further unless there is a paradigm shift in public diabetes policy.^{63, 253} The weighted prevalence of self-reported diabetes in non-Indigenous Australians in this study was high, at 13.3%, but comparatively, the 3.2-fold higher prevalence in Indigenous Australians of 42.6% was particularly troubling, especially given the well-established problem of DR in this population.²⁴⁷

While DR did not account for a large proportion of bilateral or unilateral vision loss in non-Indigenous Australians, it was the third leading cause of bilateral vision loss, the (equal) second leading cause of bilateral blindness and the third leading cause of unilateral blindness in

Indigenous Australians. In a publication not included in this thesis, we reported that the prevalence rates of DR and VTDR in those with diabetes were 28.5% and 4.5% for non-Indigenous Australians and 39.4% and 9.5% for Indigenous Australians.³⁴⁰ This demonstrates that; 1) DR is a major contributing factor to the Indigenous eye health gap and; 2) that the problem has become more pronounced since the NIEHS, which reported a prevalence of DR of 29.7% in Indigenous Australians with diabetes.²¹⁶ Almost all blindness from DR is preventable with early detection and treatment, and the increasing burden of DR as a cause of vision loss in Australia's Indigenous population therefore represents another target for avoidable blindness prevention programs.

A nationally integrated and coordinated approach is required to control the DR epidemic in the Indigenous population, and to ensure that it does not become a comparable epidemic in the older non-Indigenous population (given that DR is already the leading cause of blindness in working-age populations³⁴¹). Most obviously, adherence rates to NHMRC diabetic eye examination guidelines must increase further. To improve adherence rates, particularly in the Indigenous population, the frequency and geographic coverage of outreach ophthalmology services should improve, and services should be well coordinated with local AMSs and health workers. Aboriginal Health Services should be adequately equipped with fundus cameras and local residents should be encouraged to undergo regular screening to facilitate the timely detection of DR. In many instances where screening services are available, detection rates and management of DR may be poor owing to insufficient staff training and referral pathways,³⁴² and models aiming to reduce DR blindness must include better training for health workers as well as teleophthalmology services such as those being implemented by the Lions Outback Vision initiative in non-metropolitan Western Australia.²⁵⁹

5.2.3.4 Age-related macular degeneration

Compared to non-Indigenous Australians, AMD contributed minimally to vision loss in Indigenous Australians. In non-Indigenous participants, however, AMD was the third leading cause of bilateral vision loss (10.3%) and it was the single leading cause of bilateral blindness, accounting for 5 out of 7 cases (71%). Adding to this problem was the finding that, for non-Indigenous Australians, 5.7% of unilateral VI and 10.4% of unilateral blindness was caused by AMD. Further, according to NEHS data not published in this thesis, the population prevalence of early, intermediate and late AMD, respectively, in non-Indigenous Australians was 14.8%, 10.5% and 0.96%.³⁴³ A 2011 report estimated that the direct annual costs associated with AMD were approximately \$750 million,³⁴⁴ however due to the growth and ageing of the population²⁵² and the associated increase in the incidence of the disease, coupled with the lack of treatability of most cases,⁵⁷ the current economic burden, both direct and indirect, is likely to be much greater. Strikingly, the prevalence of intermediate AMD was six-fold higher in those aged ≥ 80 years than in those aged 50-59 years, late AMD was 29-fold higher in those aged ≥ 80 years than those aged 60-69 years,³⁴³ and as a main cause of unilateral vision loss, AMD was 19 times more prevalent in those aged ≥ 90 years than those 50-59 years. Considering the projected increase in life expectancy in Australia, incorporating these age-dependent increases into public health policy will be critical for determining the future need for anti-VEGF and other treatments, as well as for the allocation of low vision services for those with untreatable forms of AMD.

5.2.3.5 Other main causes of vision impairment and blindness

Collectively, uncorrected refractive error, cataract, DR and AMD cause the majority of vision loss in Australia and it therefore follows that prioritising the allocation of resources to these conditions would address most vision loss in Australia, with particular benefit to those with bilateral VI and blindness. Nonetheless, an array of other diseases and pathologies were the

main cause of 3% of bilateral VI, 14% of bilateral blindness, 18% of unilateral VI and 77% of unilateral blindness in non-Indigenous Australians, as well as 5% of bilateral VI, 40% of bilateral blindness, 10% of unilateral VI and 67% of unilateral blindness in Indigenous Australians, and neglecting these patient groups in blindness prevention policy would place hundreds of thousands of Australians at risk of vision loss. Many of these causes of vision loss may be unavoidable and untreatable, including amblyopia (only treatable during early childhood), retinal dystrophy, retinitis pigmentosa, myopic retinochoroidal degeneration, Best Disease and ocular trauma, while others are difficult to treat. The non-trivial prevalence of these conditions in our sample is an important reminder that not all vision loss in Australia is avoidable, and that a comprehensive national eye care policy should include funding for research programs to develop novel treatments. Other less common causes of vision loss are treatable, and if detected and managed in a timely fashion, vision may be saved. Examples include glaucoma which caused 0.7% of bilateral vision loss, 1.3% of unilateral VI and 2.1% of unilateral blindness in non-Indigenous Australians, and retinal vein occlusions which caused 2.8% of unilateral blindness in Indigenous Australians.

5.3 Aim 2: key findings

5.3.1 The importance of measuring utilisation rates of eye health care services for blindness prevention

The rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines and treatment coverage rates for cataract and refractive error reported by the NEHS provide a nationally-representative evidence base on which improvements in eye health care delivery should be built to reduce the prevalence of vision loss. The outcomes pertaining to Aim 2 of this survey are inextricably linked to the outcomes of Aim 1, and only through a comprehensive understanding of the gaps in uptake to sight-saving eye health services, can Australia's eye health sector hope to optimise the allocation of resources to eliminate avoidable

blindness. This thesis and the publications herein have disaggregated each of the outcomes of Aim 2 by sex, age, language, place of birth and geographic remoteness, and in some instances further disaggregation has been included. Disaggregated variables were subjected to multivariable logistic regression to identify whether they were associated with a significantly greater risk of insufficient service utilisation or a lack of cataract surgery or refractive error treatment. Policy-makers will benefit from founding decisions about resource allocation and service delivery for both Indigenous and non-Indigenous Australians on these data.

5.3.2 Insufficient uptake to eye health care services and the Indigenous eye health gap

Of major importance was the observation that for all four measures of eye health service utilisation (frequency of examinations, adherence to NHMRC guidelines, cataract surgery coverage and refractive error coverage), rates were significantly lower for Indigenous Australians than their non-Indigenous counterparts. After adjusting for co-variables, Indigenous Australians were half as likely as non-Indigenous Australians to have undergone an examination within the past year (RRR: 0.48) and within the past 1-2 years (RRR: 0.54). More than 80% of non-Indigenous participants had had their eyes examined within the past two years, while only 47% of Indigenous Australian participants had their eyes examined within the previous year in accordance with NACCHO and RACGP recommendations.²⁴⁶ Similarly alarming was the finding that five times more Indigenous than non-Indigenous Australians had never undergone an eye examination (8.2% v 1.6%). Indigenous participants with a history of self-reported eye disease were 3-6 times more likely to have had an eye examination within the past year. The potentially positive implication is that there may be a tendency for Indigenous Australians with the greatest need (those with advanced disease) to be undergoing regular treatment and monitoring. Conversely, this association may actually point to the following underlying problem: participants who had not undergone a recent eye examination would be

less likely to be aware of having an eye disease, particularly if their disease was asymptomatic. Consequently, those individuals who self-reported that they did not have an eye disease and that they had not undergone an eye examination within the past year represent the portion of the population to whom eye health promotion programs should be directed, as they are at risk of undiagnosed disease and avoidable blindness. Early disease detection in these individuals will be essential in efforts to reduce the excess burden of vision loss in Indigenous Australians.

The finding that Indigenous Australians had poorer adherence rates to NHMRC diabetic eye examination guidelines, coupled with the finding that Indigenous Australians with self-reported diabetes who had never had an eye examination had a 14-fold increased risk of having vision loss, signifies the urgent need to improve screening rates in Indigenous communities. The discrepant adherence rates between Indigenous and non-Indigenous Australians may be partly accounted for by the fact that Indigenous Australians were considered to have adhered to the guidelines if they had undergone an examination in the past year, compared to the past two years for non-Indigenous Australians. Nonetheless, 65% of Indigenous Australians with self-reported diabetes had undergone a retinal examination within the past two years,³⁴⁵ and this was still considerably lower than for non-Indigenous Australians in this time period (77.5%). The recommendation for annual screening for Indigenous Australians reflects the higher risk of blindness from DR in this group,²⁵⁴ as corroborated by the greater contribution of DR to the burden of bilateral and unilateral vision loss in Indigenous compared to non-Indigenous participants in the NEHS.

Along with the lower adherence rates to NHMRC guidelines, the comparatively low cataract surgery coverage (58.5%) and refractive error treatment coverage (82.2%) rates in Indigenous Australians were the greatest contributors to the greater prevalence of VI and blindness in the Indigenous population. Treatment coverage rates for blinding eye conditions can only improve if more Indigenous Australians undergo regular eye examinations, as an examination is the

prerequisite to diagnosis and treatment of any disease. In order to improve eye health service utilisation rates in Indigenous communities, accessible and culturally appropriate services are required, as reflected in the Roadmap to Close the Gap for Vision.²⁴⁸

5.4 Comparisons with previous literature

5.4.1 Comparisons with previous Australian literature

With the exception of the NIEHS, comparisons with previous Australian surveys should be made with caution due to fundamental methodological differences between the NEHS and previous population-based studies in Australia. These differences are most notable in the sampling procedures, geographic coverage and participant age distributions between previous Australian studies and the NEHS.^{103, 175, 176, 178, 209, 214, 217, 218} In addition, clinical methodologies, diagnostic criteria and definitions of VI and blindness varied between studies. Even so, comparisons may be useful for elucidating temporal changes in aspects of Australian eye health while concurrently emphasising the relative strengths and weaknesses of methodological differences between studies.

5.4.1.1 Comparisons with previous literature regarding non-Indigenous Australians

Based on the definitions used in the NEHS, the prevalence estimates of bilateral VI and blindness in the baseline BMES were 11.1% and 0.6%, respectively, and the prevalence of unilateral VI was 29.6%.¹⁸⁰ Compared to the crude prevalence of 6.5% for bilateral VI, 0.23% for bilateral blindness and 16.2% for unilateral vision loss in the NEHS, the BMES estimates were considerably higher. Despite both studies having samples with similar mean ages (NEHS=66.7 years vs BMES=66.2 years), the BMES had an over-representation of those aged 80 years or older (comprising 26% of the total sample),¹⁰³ whereas only 11.5% of non-Indigenous NEHS participants were aged 80 years or older. As our study confirmed through multivariable logistic regression, each decade of older age increases the odds of having vision

loss by 1.72 times in non-Indigenous Australians, which is likely to partially account for the disparity between the two studies. This discrepancy may also be accounted for by the differences in geographic and remoteness coverage and sampling methods used between the two studies. The VIP reported a prevalence of bilateral vision loss of 4.3% (PVA<6/12), which was slightly lower than the present study, perhaps owing in part to the younger age inclusion criterion in that study (≥ 40 years), as well as the fact that the VIP did not include samples from Outer Regional and Very Remote Australian populations which, in our study, tended to have slightly higher rates of vision loss (although not statistically significantly so).¹⁹¹

Based on pooled data from the BMES and the VIP, Taylor *et al* (2005) estimated that 480,300 Australians were vision impaired and 50,600 were blind, and it was predicted that in the year 2014, one year prior to the commencement of the NEHS, those numbers would increase to 619,700 and 68,800.¹⁹² Extrapolating to the 2011 ABS populations within each RA, based on the remoteness-weighted prevalence in our study, we estimated that the number of non-Indigenous Australians with bilateral vision loss was 383,897, of whom 12,636 were blind. Compared to our projections, the projections from Taylor *et al* over-estimated the expected number of people with vision loss by almost 300,000. A number of factors may account for these differences, including better national representativeness of the current study, owing to the greater geographic coverage. It is also possible that some of the disparity between the forecasted number of those with vision loss and the number estimated on the basis of the NEHS findings are due to the success of the many blindness and low vision prevention programs implemented by the Australian Government and the eye health and vision care sector since the completion of the baseline VIP and BMES studies.^{79, 99, 248, 259, 273, 346}

There is some evidence to support this supposition. For example, a follow-up study of BMES participants reported a reduction in the prevalence of bilateral VI by 25% from 11.1% to 8.3%, and the prevalence of bilateral blindness by 50% from 0.6% to 0.3% in six years.¹⁸⁰ Other less

direct evidence can be seen in the findings pertaining to Aim 2 of this study. Compared to previous studies, the NEHS has revealed considerable improvements in the frequency with which older Australians undergo eye examinations, with 82.5% of non-Indigenous Australians having undergone an eye examination within the past two years, compared to 61%-63% in TVI, the VIP and the BMES.²⁴³⁻²⁴⁵ The increased regularity of eye examinations may have improved disease detection and treatment rates. Adherence rates to NHMRC diabetic eye examination guidelines also appear to have improved from 52% in the VIP to 77.5% in the NEHS. Despite the worsening of Australia's diabetes epidemic over recent decades, the DR-specific prevalence of vision loss was only 1.4% in the NEHS, compared to 3.9% in the VIP, signifying that improved adherence rates may have facilitated higher rates of early detection, intervention and blindness prevention.¹⁸⁹

Increased utilisation of eye health care services may also have improved the cataract surgery coverage rate and refractive error treatment coverage rates in the non-Indigenous population, although this cannot be directly compared with previous studies as they did not report comparable coverage rates.^{269, 270} Upon follow-up, the BMES reported an increase in the uptake of cataract surgery services, and based on the VIP, the number of people undergoing cataract surgeries was predicted to increase significantly from 320,000 in 2001 to 500,000 in 2021.^{46, 262, 263} The high cataract surgery coverage (88%) and refractive error treatment coverage (93.5%) in our study may reflect improvements from previous years and may account for a reduction in the national prevalence of vision loss. Many of the programs that have contributed to the potential reduction in the burden of vision loss were directly informed by the findings of the BMES and the VIP, highlighting the importance and practical benefits of eye health surveys.

5.4.1.2 Comparisons with previous literature regarding Indigenous Australians

Comparisons between the findings of the NEHS and historical literature on the Indigenous population of Australia suggest that there have been improvements in Indigenous eye health and engagement with eye health services by Indigenous Australians in recent years. Direct comparability with most previous studies is limited due to methodological differences. However, the similar sampling, recruitment and examination methodologies of the NIEHS and the NEHS provide a unique opportunity for direct temporal comparisons.²²⁸ Prior to the NEHS, trends indicated that the eye health of Indigenous Australians has been gradually improving,²²⁹ and the findings of this study provide evidence of further improvements in some (but not all) important outcomes.

Most notably, bilateral blindness was less prevalent in the NEHS than previous studies, with only 0.31% of Indigenous adults aged 40 years or older being bilaterally blind. In contrast, the early studies by Mann in the 1950s reported that up to 4% of the Indigenous population of Western Australia (of all ages) was blind,¹⁶³ and based on near-nationwide coverage, the NTEHP reported a prevalence of 1.8%, based on BCVA for Indigenous Australians of all ages.¹⁶⁵ If the NEHS definition of blindness and participant inclusion criteria had been utilised, the prevalence of blindness would undoubtedly have been far higher. Taylor (1980) found that the prevalence of blindness was between 17.5% and 21.5% in those aged 60 years or older in 1980,²⁰⁸ and studies in South Australia in the early 1990s reported a significant burden of bilateral blindness, with up to 10.5% of those aged 60 years or older affected.²⁰⁹ Notably, Indigenous Australians in the CAOHS aged 40 years or older residing in very Remote Central Australia had a prevalence of bilateral blindness of 3.6%,²²⁷ which was high compared to the 1% in Very Remote Indigenous communities in the NEHS (this comparison should be considered with a high degree of caution due to the comparatively small sample size in our Very Remote samples and the lack of inclusion of Central Australian communities in our

sample). As recently as 2008, the NIEHS reported a prevalence of bilateral blindness of 1.8%.²²⁹ Given the methodological similarities between the two studies, this prevalence may be compared with the prevalence in the NEHS (0.31%), and this provides evidence that the prevalence of bilateral blindness in Indigenous Australians may have decreased.

The comparatively lower prevalence of bilateral blindness in Indigenous participants in the NEHS compared to the NIEHS may be considered in conjunction with significant changes in engagement with eye health care services between the two studies. The proportion of Indigenous Australians who had undergone an eye examination within the past year more than tripled from 15% in the NIEHS to 47.5% in the NEHS, and the proportion who had ever had an eye examination increased from 65% to 91.8%.²⁵⁰ Similarly, the improvement in adherence rates to NHMRC diabetic eye examination guidelines from 20% to 52.7% may have contributed to the reduction in blindness (albeit very slightly). Indeed, 0.17% of NIEHS participants had DR-related blindness compared to 0.03% of Indigenous NEHS participants.²⁸
²¹⁶ Improved cataract surgery coverage rates in Major City (63% v 57%), Outer Regional (57% v 50%) and Remote areas (71% v 67%), are likely to have alleviated the burden of cataract blindness,²³¹ further contributing to the reduction in bilateral blindness.

These apparent improvements in the prevalence of blindness and rates of utilisation of eye health care services are encouraging, however, we found more modest improvements in some measures, and possible worsening of others. Most saliently, the prevalence of bilateral VI was higher in the NEHS than the NIEHS. Based on unadjusted estimates, 10.5% of Indigenous participants had bilateral VI, compared to 9.4% in the NIEHS.²⁸ Sampling weight adjustments of the total NEHS sample with bilateral vision loss resulted in a prevalence of 11.2% (of whom approximately 0.3% were blind), whereas similar adjustments resulted in a prevalence of bilateral VI of 8.6% in the NIEHS.²⁸ Despite this, compared to studies undertaken prior to the NIEHS, such as the CAOHS,²²⁷ the survey of Anangu Pitjantjatjara and Yalata lands of South

Australia²⁰⁹ and the NTEHP,¹⁶⁵ the prevalence of bilateral VI in the NEHS was substantially lower, suggesting that VI is likely to have decreased in the Indigenous population over the past few decades.

The NIEHS,²⁸ the CAOHS,²⁸ the NTEHP²⁰⁶ and the survey by Taylor in 1980²⁰⁸ all reported the prevalence of unilateral vision loss, but their comparability with the NEHS is limited due to methodological differences or a lack of statistical adjustments of estimates in those studies. Nevertheless, comparisons tend to show that the prevalence of unilateral blindness was only slightly lower in the NEHS than in the NIEHS (crude prevalence= 2.1% v 2.7%, respectively), and unilateral VI was slightly more prevalent in the NEHS than the NIEHS (crude prevalence=14.4% v 12.8%).²⁸ The relative contribution of each major cause to the burden of unilateral vision was similar between the two studies, and the locus of the higher prevalence in the NEHS is therefore not identifiable without proper adjustment of the NIEHS data. Indeed, comparisons of adjusted data may reveal that the prevalence was not higher in the NEHS.

The finding that the prevalence of bilateral blindness was lower in the NEHS than in the NIEHS, but that unilateral blindness may not have been lower, warrants consideration. It might be expected that reductions in both measures would track together if the cause of reduced bilateral blindness was improved service uptake. The lack of a corresponding reduction in unilateral blindness might point to the perceived reduction in bilateral blindness being due to insufficient statistical power in our estimates for bilateral blindness, rather than a true change in the population. Alternatively, the possible lack of change in the prevalence of unilateral blindness may have resulted from those affected being less motivated to seek care, owing to the lower level of impairment, or that a greater proportion of unilateral blindness is due to unavoidable causes such as trauma.

Another important difference between the NIEHS and the NEHS was the finding that geographic remoteness was statistically significantly associated with a higher prevalence of vision loss in Indigenous adults in the NEHS, but not in the NIEHS. This difference was significant for those living in Outer Regional areas (multivariable OR=2.02, $P=0.007$), and although the prevalence of 15.7% in Very Remote residence was not significantly higher than Major City (8.3%) in multivariable analysis ($P=0.054$), the difference was significant in univariable analysis $P=0.002$. While a difference cannot be reliably claimed on statistical grounds, this trend is noteworthy, and it is possible that the lack of significance after adjusting for co-variables may have been due to the small sample in Very Remote residence.

It is tempting to consider this emergent remoteness effect that was not found in the previous study to be indicative of a growing divide in urban (and peri-urban) dwelling Indigenous Australians and their non-metropolitan counterparts. While this may be true, this finding may also be partly attributable to heterogeneity even within each remoteness stratum. As outlined in Publication 9, the cataract surgery coverage rate was far lower in Very Remote sites in the NEHS than the NIEHS (27% v 68%)²³¹ and the refractive error treatment coverage rate was low in the Outer Regional communities that we surveyed (69.5%). However, the cataract surgery coverage rate is unlikely to have more than halved in all Very Remote areas in the past seven years, and the refractive error treatment coverage rate may not be as low in all Outer Regional communities (although this is not impossible given that large numbers of Indigenous Australians are residentially mobile and may relocate to regions of differing geographic remoteness in short timeframes.³⁴⁷ Considering recent improvements in outreach eye health programs for regional and remote Indigenous communities, the observed remoteness effect (and the associated poor treatment coverage rates) may reflect the possibility that we inadvertently sampled comparatively underserved Very Remote and Outer Regional communities, while the NIEHS may have sampled comparatively well serviced communities

in the same strata. It follows that future national blindness prevention programs should prioritise identifying specific communities in each RA with the greatest need and develop targeted programs accordingly. The National Eye Care Equipment Inventory Project (discussed later in 5.5.1) that aims to ensure that Indigenous Australians have equitable access to eye health care regardless of their geographic location may contribute to homogenisation between, and within, RAs.³⁴⁸

5.4.2 Comparisons with global literature

Comparable global data on most outcomes addressed in this thesis are sparse. For example, there are no aggregated global or regional estimates on refractive error treatment coverage rates, cataract surgery coverage rates or the prevalence of presenting unilateral VI, and placing the NEHS in the global context with respect to these measures is consequently difficult. However, it is possible to place the primary outcome measures of the NEHS, the prevalence and causes of bilateral vision loss, in the global context, owing to the GBD VLEG having published global and regional age-standardised estimates of VI and blindness and their causes for the year 2015 in the Global Vision Database in 2017.^{16, 29}

5.4.2.1 The prevalence of vision impairment and blindness

The GBD study utilised WHO definitions of VI and blindness only.¹⁶ Therefore, the NEHS definition of blindness ($<6/60$) is not comparable with the Global Vision Database estimates of blindness. Similarly, the GBD study definition of moderate to severe VI ($<6/18-3/60$) is not comparable with our definition of VI ($<6/12$). Fortunately, however, the supplemental data provided by the GBD VLEG has provided estimates of blindness, moderate to severe VI and mild VI ($<6/12-6/18$), which, when summed, encompass all cases of PVA $<6/12$ (equivalent to our definition of vision loss). Therefore, we can compare our overall age- and sex-adjusted prevalence of vision loss with the summated age-standardised estimates of the GBD database at the global and regional level. While these comparisons are not perfectly standardised, they

provide important insight into the global context of vision loss in Australia. The most recent GBD study provided the first reliable global estimates of VI that have included mild VI, and this is therefore the first opportunity for Australian vision loss estimates that utilise the 6/12 threshold to be compared with aggregated global data.

The weighted, age-adjusted and sex-adjusted prevalence of bilateral vision loss in non-Australians of 6.4% and Indigenous Australians of 17.7% was lower than the global aggregated prevalence of 20.3% in men and 21.5% in women aged 50 and over (GBD estimates are disaggregated by sex).¹⁶ Encouragingly, the prevalence of bilateral vision loss in non-Indigenous Australians, as well as the overall prevalence in Australia (6.6%), was lower than for all major world regions reported in the GBD study. Summated and aggregated estimates for Australasia were 10% for men and 11.2% for women, while the summated prevalence in the region of Oceania (which excluded Australia) was estimated to be 24.4% for men and 25.3% for women.¹⁶ The prevalence of bilateral vision loss in Australia was notably lower than comparable high-income regions of the world, including high-income Western Europe (8.1% in men and 9.2% in women) and high-income North America (9.3% in men and 10.5% in women). While comparisons with other studies should always be made with caution (especially given that we did not standardise our results to the global population), the lower prevalence of bilateral vision loss in the general population of Australia compared to all other world regions demonstrates the relative effectiveness and positive impact of Australia's eye health care services, at least for our non-Indigenous population.

Concerningly, while the prevalence of bilateral vision loss in Indigenous Australians was lower than the global aggregate, it was considerably higher than for other high-income regions of the world. The NEHS inclusion criteria permitted the sampling of Indigenous Australians in the age category of 40-49 years in whom the prevalence of bilateral vision loss was 7.2%. Consequently, the weighted prevalence in the whole Indigenous sample was 11.2%, but after

adjusting for age (and sex), the prevalence was 17.7%. Considering that Australia ranks 2nd on the HDI and is renowned for its inclusive near-universal health care system, the finding that Indigenous Australians had a prevalence of bilateral vision loss comparable to developing regions such as Central Latin America (17-18%) and Southern Sub-Saharan Africa (17-20%) reaffirms the magnitude of the Indigenous health gap and highlights the fact that Indigenous Australians experience health outcomes similar to those of some of the most poorly resourced regions of the world.

5.5 Impact of the National Eye Health Survey

5.5.1 Impact in Australia

As the first population-based survey to report nationally-representative data on the prevalence and causes of vision loss, as well as eye care service utilisation and disease treatment coverage rates in both Indigenous and non-Indigenous Australians, the NEHS has already begun to have a significant impact on Australia's eye health care sector. This study was funded by the Australian Government Department of Health under the Chronic Disease Prevention and Service Improvement Fund to fulfil a core objective of the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss*.²⁷⁴ Accordingly, the Department of Health commissioned a summary report on the findings of the NEHS. To meet and surpass this objective, we authored two reports; one comprehensive 214-page report³⁴⁵ and a summary report³⁴⁹ on the key results of the study. We launched these reports at a Parliamentary Friends Group for Eye Health and Vision Care event held at Parliament House, Canberra, on World Sight Day on the 11th of October 2016, an event that was attended by numerous Government and non-government sector stakeholders. These reports comprised a large component of the knowledge base discussed at a Parliamentary session in December 2017 on the future of Indigenous eye health. Further, since the completion of data collection in April 2016, we have authored 25 journal publications on the results of the NEHS. Together, the data

included in these reports and manuscripts have been used extensively by the sector to inform policy, planning and resource allocation for eye health care services.

Examples of the translation of the results of this survey into changes in policy and service delivery are numerous. For example, the NEHS report functioned as a key information source for the report titled *Indigenous Eye Health Measures 2016*, prepared by the Australian Institute of Health and Welfare (AIHW) of the Australian Government that comprehensively reported on the status of Indigenous eye health in Australia as well as key areas in need of improvement.³⁵⁰ Subsequently, the Australian Health Ministers' Advisory Council utilised findings from the NEHS extensively in its official *Aboriginal and Torres Strait Islander Health Performance Framework 2017 Report* that detailed the current status of all aspects of Indigenous health and highlighted key areas requiring policy change.³⁵¹

Vision 2020 Australia, the peak body for Australia's eye and vision care sector, and the major advocacy group for almost 50 member organisations, has utilised the findings of the study extensively in policy documentation and recommendations to the Australian Government. Based largely on the poor refractive error treatment coverage and cataract surgery coverage rates for Indigenous Australians reported by the NEHS, in its *Closing the Gap in Eye Health and Vision Care by 2020* report, Vision 2020 Australia has recommended that the Australian Government allocates additional annual funding of \$1.06 million to the Visiting Optometrists Scheme and \$1.01 million to specialist outreach ophthalmology services for Indigenous Australians.³⁵² Similarly, the comparatively low adherence to diabetic eye examination guidelines by Indigenous Australians (52.7%) was instrumental in informing the collaborative call by CERA, Vision 2020 Australia and Diabetes Australia for a national diabetes blindness prevention program.³⁵³ The significant age-related increase in vision loss (7 to 8-fold increase over 5 decades of life) for both Indigenous and non-Indigenous Australians also compelled Vision 2020 Australia and its member organisations to submit recommendations to the

Department of Health on the Aged Care Legislated Review that the aged care system should be adequately funded and administered to address the current unmet demand of older people who are blind or vision impaired.³⁵⁴ It is hoped that Government policy-makers will be compelled to implement these recommendations as they will benefit hundreds of thousands of Australians nationwide who have vision loss or are at risk of vision loss.

Specific activities catalysed by this study have included a nationwide audit of eye testing equipment in AMSs under the National Eye Care Equipment Inventory Project to ensure that Indigenous Australians have equitable access to eye health care regardless of their geographic location. This audit was inspired by; 1) our observation that some Indigenous health centres in which our own testing centres were set up were insufficiently equipped and 2) the finding in the survey that Indigenous Australians consistently under-utilise eye health services and have lower disease treatment coverage rates. In turn, the findings of this audit will be used by the Department of Health to assist in identifying locations most in need of new retinal cameras and slit lamps, as well as maintenance of existing equipment and the provision of training.³⁴⁸

Additional translational utility of the NEHS has included consultations by our research group with the Royal Australian and New Zealand College of Ophthalmologists (RANZCO) to advise on strategies for distributing ophthalmic and optometric services nationwide. The survey findings have also been reported and used to directly inform updated strategies in line with the Close the Gap for Vision initiative.³³⁷ The results of the survey have also been reported by numerous key stakeholders in the eye health and vision care sector, including Glaucoma Australia and Optometry Australia, as well as numerous media outlets including ABC National talkback radio and local radio and television stations around Australia. This extensive coverage may contribute to health promotion and education within Australian communities, thereby motivating older Australians to undergo regular eye examinations, which in turn will lead to improved disease detection and treatment rates.

5.5.2 Global impact

The global impact of the NEHS is manifold. The use of a remoteness-stratified sampling design that provided equitable community research participation for a systematically marginalised Indigenous sub-population at a national scale, has provided a novel methodology from which studies in other countries may benefit. The NEHS has achieved significant international exposure through publication of the methodology and key findings on the prevalence of vision loss and eye diseases in the top-ranking international ophthalmology journals, including *Ophthalmology*,^{68, 340} *JAMA Ophthalmology*,^{343, 355} *British Journal of Ophthalmology*³⁵⁶ *Ophthalmic Epidemiology*,³⁵⁷ *Acta Ophthalmologica*³⁵⁸ and *Clinical and Experimental Ophthalmology*.^{359, 360} These publications have placed great emphasis on the unmet needs of the Indigenous population of Australia. Further, I presented the major findings of this study to an audience of key global eye research personnel at the ARVO annual conference in the United States in 2017 and emphasised the importance of including disadvantaged and marginalised population groups (Indigenous or otherwise) in ophthalmic epidemiologic research. It is the hope of the NEHS team that continued research outputs and wider dissemination of the key findings of the study will play a role in shaping and directing similar studies in the future. Specifically, it is hoped that the inclusion of marginalised and minority groups are central considerations in study design as this may result in targeted eye health programs for more vulnerable communities.

The NEHS has provided support for the effectiveness of evidence-based and targeted programs that deliver eye care services to Indigenous populations. Our findings indicate that since the completion of the NIEHS and the implementation of the Close the Gap for Vision initiative and a multitude of other Indigenous-specific initiatives, the age-adjusted prevalence of bilateral blindness in Indigenous Australians has decreased, the burden of blinding trachoma has been dramatically attenuated, and rates of eye health service utilisation have increased markedly in

both the general and diabetic populations. With this in mind (but also with the recognition that Indigenous Australians continue to suffer from significantly poorer eye health than non-Indigenous Australians despite these improvements), we were motivated to further increase the global reach of this Indigenous-centric eye health message through the publication of a systematic review on the epidemiologic data on vision loss in the Indigenous peoples of the world. This review, accepted by *JAMA Ophthalmology* (in press) (and a detailed methodological description thereof published by the prestigious Joanna Briggs Institute³⁶¹) demonstrated that, from the very limited available data, Indigenous peoples tend to suffer from almost ubiquitously poorer eye health than non-Indigenous populations worldwide.

In this review, we make two recommendations: 1) that future studies in countries inhabited by Indigenous populations should collect sufficiently large samples of Indigenous persons to quantify the prevalence of vision loss in those groups, and; 2) specialised programs that target under-serviced Indigenous populations should be created and funded in countries inhabited by Indigenous peoples. Improvements in both the frequency and quality of research in Indigenous populations should provide the evidence base for these Indigenous-specific eye care programs to optimise their impact. Evidence for the positive impact of Indigenous eye health initiatives has been reported elsewhere, with the Onchocerciasis Elimination Program of the Americas having eliminated onchocerciasis transmission in 11 of 13 endemic disease foci in Latin America³⁶² and almost eliminating the disease from the Indigenous Yanomami of Venezuela.^{363, 364} It is hoped that our systematic review and its recommendations will further contribute to the alleviation of the burden of vision loss in the world's most underserved populations.

In recognition of the robust sampling and examination protocol of the NEHS, coupled with the efficiency with which it was completed, our research team has consulted extensively with international stakeholders to assist in designing similar surveys in other countries. These

researchers are drawing on our stratified sampling design to ensure that marginalised population sub-groups are appropriately represented in future studies.

5.6 Strengths of this study

5.6.1 Strong sector collaboration

A major reason for the success of the NEHS was the strong partnerships formed with stakeholders in the eye health and vision care sector. Our partnership with Vision 2020 Australia, the sector's peak advocacy body, contributed to the successful acquisition of funding directly from the Department of Health. Aligning with other key sector stakeholders, including the Brien Holden Vision Institute, Optometry Australia, and Royal Flying Doctors Service, and ensuring that their branding was displayed on all survey documentation and recruitment material is likely to have contributed to trust and acceptance by the community. Further beneficial relationships included those with OPSM who provided free sunglasses for all participants. This incentive contributed immeasurably to the high positive response rate of this survey. The receipt of in-kind donations from other partners, such as Zeiss, were also most helpful.

5.6.2 Community engagement

Conducting randomised population-based surveys is challenging, particularly when household engagement is the primary mode of recruitment, and when surveys are conducted over multiple sites. As noted by Studdert *et al* (2010) in relation to the NIEHS, in a publication titled "Ethics review of multisite studies: the difficult case of community-based Indigenous health research." this process is rendered still more challenging when recruiting participants from the Indigenous population of Australia.³⁶⁵ Indigenous Australians constitute less than 3% of the total target population and participants are thus significantly more difficult to locate through door-to-door

knocking. In addition, there are unique and elaborate ethical approvals, endorsements and community engagement process involved.

Considering these unique circumstances, a major strength of the NEHS was the culturally appropriate and considerate manner in which all communities, Indigenous and otherwise, were engaged by survey investigators. Having comprehensively researched the ethical implications of working with Indigenous communities, and having undergone the requisite cultural sensitivity training, we were well-equipped from early on in the planning phases of this study to navigate the community-engagement process. As a result, obtaining official endorsement from NACCHO, as well as ethical approval and further endorsement from state-based bodies facilitated the cultivation of strong working relationships with Indigenous communities at each site. This allowed us to establish testing venues within AMSs and Aboriginal Corporations, providing direct access to members of the Indigenous community, while also allowing us to provide casual employment to Aboriginal Liaison Officers whose assistance was instrumental in the successful completion of the study. The high positive response rate (90.8% for Indigenous Australians and 82.5% for non-Indigenous Australians) and examination rate (77.6% for Indigenous Australians and 68.5% for non-Indigenous Australians) achieved in this study are evidence that our recruitment and population engagement strategies were well-received by Indigenous and non-Indigenous communities around Australia.

5.6.3 The sampling methodology

The sampling methodology of the NEHS was characterised by a number of strengths when considered in light of other surveys, as described in Chapter 3. Most importantly, the NEHS was nationally-representative, and the sampling method therefore allowed us to extrapolate our findings to the national population of Australia. The additional benefit of this was that the absolute number of persons in the population with VI and blindness could be projected. The

national representation of this study will prove indispensable for resource allocation for eye health service programs nationwide.

An additional strength of the NEHS sampling protocol was the stratification of the sampled population, first by Indigenous status, and second by geographic remoteness. As discussed throughout this thesis, the stratification by Indigenous status has provided a unique and unprecedented opportunity to quantify the excess burden of vision loss in Indigenous Australians. Remoteness stratification ensured that participants from all levels of remoteness in Australia were selected in proportions that reflected their distributions in the wider population. This provided the geographic resolution needed to identify that Indigenous Australians living in Very Remote and Outer regional areas tended to have the poorest eye health outcomes, corroborating previous claims that vision loss and service utilisation may vary between areas of differing remoteness.³⁶⁶

5.6.4 Clinical data collection methodology

The NEHS utilised a robust and standardised clinical examination methodology that was comprehensive compared to most recent eye health surveys around the world. The inclusion of an array of tests, including distance and near visual acuity assessment, auto-refraction, perimetry, anterior segment examination, 2-field retinal photography and tonometry, was noteworthy considering the logistical and transport difficulties imposed by the distances travelled in this national survey. While some previous studies have included additional tests, such as subjective refraction,^{220, 269} pachymetry,^{223, 319, 324, 332, 333} lens photography,³⁶⁷ full threshold perimetry,³¹⁶ wider field fundus photography,³⁶⁸ gonioscopy,^{316, 317, 322, 329} and OCT,^{286, 318} these studies tended to be sub-national with few sites, had comparatively few travel and transport requirements, and they mostly aimed to address objectives that differed from those of the current study^{317-319, 322, 323} The exclusion of these tests may have impacted on accurate disease classification in some instances, and had time and resources permitted their

inclusion, they would have enhanced this study. Nonetheless, the primary objectives of this thesis are unlikely to have been significantly affected, and the clinical examination protocol of this study was well-designed to address these aims.

The inclusion of a standardised referral protocol within the scope of the clinical examination methodology was an additional strength of this study. As we reported in a publication not included in this thesis,³⁶⁹ 1.4% of participants were referred for urgent follow-up due to the finding of symptoms or signs warranting urgent review, including elevated IOP (>30mmHg), retinal tears, uveitis, or periorbital cellulitis. An additional 3.2% of participants were provided with semi-urgent (1 week) referrals due to poor visual acuity or enlarged vertical optic cup-to-disc ratios and elevated IOP (>21mmHg).³⁶⁹ Our referral protocol also ensured that participants with signs potentially indicative of glaucoma (20.2%), macular drusen or pigment changes (20.7%), and those that had not adhered to general or diabetic ocular examinations (19.9%) were referred. Having provided free eye examinations to 4836 Australians, a considerable proportion of whom were referred for follow-up care, the NEHS is a good example of research with service and has set a precedent for future studies to refer participants in need of medical intervention.

5.7 Limitations of this study

The findings of this study should be considered in the context of several limitations. While the study design and execution of this logistically challenging project were robust, each aspect of the study, including the sampling and clinical data collection methodology contained some areas of weakness.

5.7.1 High absenteeism, low eligibility and low population distributions in randomly-selected SA1s

A limitation of this study arose from the array of challenges encountered during the door-to-door enumeration and participant recruitment. This issue was discussed in Chapter 3 of this thesis, including in Publications 1 and 3. In summary, ABS Census data used for cluster selection were collected four years before the commencement of this study and were therefore inaccurate in some instances, due to changes in population distributions and the fact that constituent populations were often younger than expected. Further, we encountered high rates of absenteeism in this study, with 49.9% of residences being non-contactable. Despite initial constraints placed on the sampling pool whereby 12% of all SA2s were excluded due to sparsely distributed populations, we still encountered populations with prohibitively low densities. The result of these challenges was that recruitment sites had to be expanded to include contiguous population clusters to ensure that we recruited sufficiently large samples within the time and budgetary constraints of the survey. Although we utilised a systematic and consistent site-modification approach, the risk of selection bias resulting from this process is a limitation of this study. The high positive response rates may have ameliorated some of the resulting bias and demonstrate that the problem occurred due to circumstances resulting from Australia's unique population and geographic characteristics (including its low population density and high employment rate, resulting in high rates of residents being absent from their homes during the day), rather than parameters that were within the control of the study design. The consistent and systematic approach to site modifications and initial randomness of SA2 and SA1 site selection are likely to have attenuated most of the risk of sampling bias.

As described in Publication 3, the problem of high non-contactable rates may have been avoided by increasing the number of attempts to contact each resident in the target SA1. While this would be likely to increase the contact rate, it would have dramatically increased the

amount of time required in each survey site. Considering the logistical implications and daily costs of this study, this would have imposed impractical and unsustainable delays. A better solution would have been to select a larger population cluster at the second stage of site selection, rather than one SA1 or a small cluster of SA1s that contained approximately the correct number of persons from the target population. The selection of our SA1s was based on a cluster size of 100 non-Indigenous participants with a non-response rate (including declines and absenteeism) of only 20%, which was demonstrably insufficient given the high absenteeism rate and inaccuracy of the ABS data. Therefore, while the selection of larger clusters of SA1s containing at least three or four times the required population (similar to the protocol of the NIEHS), would not improve the overall response rate, it would eliminate the need to non-randomly select contiguous areas after exhausting the SA1, thereby mitigating selection bias.

5.7.2 Different recruitment methods for Indigenous versus non-Indigenous participants

The methods employed to sample and recruit Indigenous participants differed from those for non-Indigenous participants, as described in detail in Chapter 3. Non-Indigenous participants were recruited almost exclusively through household recruitment whereby each residence in the selected population cluster was doorknocked, and in most cases, contiguous SA1s were approached when required to recruit enough participants (with some modifications to account for inaccurate ABS data and householder absenteeism as described in 5.7.1 above). However, because Indigenous Australians comprise less than 3% of the national population and are sparsely distributed, spatially confining recruitment of Indigenous participants in a manner similar to that for non-Indigenous Australians would not have yielded the required sample. For the same reason, doorknocking could not feasibly be relied upon as the sole method to enumerate an Indigenous sample of sufficient size. Adding to this challenge, consultations with

Indigenous workers revealed that culturally acceptable recruitment methods would need to be tailored to account for local requirements in each survey site. Therefore, although door-to-door recruitment was used as frequently as possible, much of the recruitment relied upon telephone calls from formal AMS community lists, word of mouth and other methods.

Statistical comparisons between outcomes for Indigenous and non-Indigenous Australians were central to this thesis, and the potential for differential recruitment methods to affect the reliability of these comparisons must be acknowledged. In some instances, the location for recruitment of Indigenous participants was dictated by the presence of more densely concentrated Indigenous communities outside of our selected sites, while in other cases, the decision regarding where participants would be recruited was based on the judgement and knowledge of local Indigenous workers. Consequently, the expansive geographic range and non-randomness of some Indigenous participant recruitment may have introduced an unquantified risk of selection bias, and direct comparisons with outcomes for non-Indigenous participants might have been affected.

This risk of bias was an unavoidable consequence of Australia's diverse population and unique geographic landscape. Nonetheless, this risk was accounted for during the study planning phase and systematic strategies were implemented to reduce the risk of bias. These strategies included limiting the geographic range of intra-cluster recruitment as much as possible, thoroughly training Indigenous recruitment staff on the necessity of maintaining randomness as opposed to seeking out those who may benefit from eye examinations, closely supervising recruitment to reduce the risk of non-randomness, and conducting recruitment ourselves where possible. A number of statistical adjustments were also applied, including the use of remoteness-stratified sampling weights for all prevalence estimates. To facilitate comparisons between Indigenous and non-Indigenous groups, each weighted estimate was further adjusted for age and sex

differences, and ORs for the relative risk associated with Indigenous status were always adjusted for co-variables to reduce the effects of confounders.

5.7.3 Sample size

The prevalence of bilateral presenting vision loss in the VIP and the NIEHS were used in the sample size calculations of this study to determine that 2794 non-Indigenous Australians and 1368 Indigenous Australians should be examined. Therefore, our collected samples of 3098 and 1738, respectively, possessed sufficient statistical power to detect the prevalence of bilateral vision loss in both populations, presuming the true population prevalence was not substantially different from the estimates used in the initial calculation. The age-adjusted prevalence estimates in the NEHS of 6.4% and 17.7% were indeed similar to the previous studies, and our sample size therefore had sufficient statistical power. However, the sample size was not calculated to power other point estimates. Most notably, very few participants were bilaterally blind (weighted prevalence = 0.21% for non-Indigenous Australians and 0.31% for Indigenous Australians), and the certainty surrounding the representativeness of these estimates as well as estimates of the main causes of blindness, was affected. Due to the low prevalence of blindness and the larger sample size required to accurately detect the prevalence in populations, most surveys worldwide have been inadequately powered, presenting a significant challenge for researchers and policy makers. To supplement survey data, consulting additional data sources may be of benefit, including low vision services and pension data to assist in determining the number of people in the population with blindness. Although people with blindness may be relatively well represented in these services owing to the profound level of impairment and high likelihood of engaging with services, representativeness cannot be quantified. More accurate data may be obtained from national blindness registries, such as those in Israel,²⁷⁷ Canada,²⁷⁸ Denmark,²⁷⁹ and Iceland,²⁸⁰ and

future policy in Australia may benefit from establishing such a registry. Resource allocation for blindness would be optimised by considering all of these data sources.

Other estimates that may have been underpowered include cause-specific prevalence estimates of bilateral vision loss for diseases such as glaucoma (1.7% and 0.68%) and DR in non-Indigenous Australians (1.4%). Similarly, in some instances, small sample sizes in some subgroups resulted in multivariable logistic regression failing to detect significant associations despite large differences between point estimates – for example the low cataract surgery coverage rate in Very Remote Indigenous communities of 27.6% (95% CI: 4.8, 74.1%) compared to Major Cities (61.9%, 95% CI: 49.4, 73.0) was not significantly different at the $\alpha=0.05$ level ($P=0.13$). For some estimates, a larger sample size of at least an order of magnitude greater would have been required to provide the requisite statistical power. However, considering the financial, temporal and logistical implications of recruiting significantly larger samples, this was not considered feasible for this study. Nonetheless, it is commonly acknowledged that reliably estimating the prevalence of rare conditions often requires unfeasibly large sample sizes and the sample collected in this survey was comparable with, and in many instances larger than, other studies conducted in Australia^{28, 189} and in other countries.^{101, 110, 322}

5.7.4 No representation from Central Australian communities

Another limitation of the sampling methodology was that, as an unavoidable consequence of random sampling, no SA2s from within the most inland regions of Very Remote Australia were selected. Resulting purely from random chance, almost all selected sites were within 100 km of the coast, with the exception of Wodonga (VIC), Inverell (NSW), Katanning (WA) and Banana (QLD). While this was unlikely to have significantly affected estimates of vision loss for the non-Indigenous population, the lack of Indigenous participants from Very Remote inland communities may have affected estimates for the Indigenous population residing in Very

Remote areas. This may have contributed to the finding that trachoma was not a leading cause of blindness in our sample. Despite this limitation, the NEHS achieved better geographic coverage than previous surveys in Australia. Approximately 85% of the Australian population resides within 50 km of the coastline,²⁸⁹ and our sampling frame therefore included the vast majority of the population. Nonetheless, to account for Australia's unique geography and population distribution, future studies may benefit from further sub-stratifying Very Remote cluster selection into Very Remote-Coastal and Very Remote-Inland in a manner similar to the NIEHS in 2008.²²⁸

5.7.5 Self-report

The major limitation of the clinical methodology of this study was the use of self-report to collect sociodemographic data, ocular, diabetes and stroke histories, and data about the utilisation of eye health care services. The questionnaire was standardised, and interviewers were well trained to clarify any points of uncertainty for participants. Nonetheless, as Publication 2 in this thesis demonstrated, self-report is a poor epidemiologic data collection instrument, as it is characterised by poor validity and reliability. Low validity and reliability resulting from self-report may be due to memory failure or poor health literacy, or a combination of these factors.^{167, 370} While we were able to ascertain that self-report was inaccurate for reporting a previous diagnosis of the four major blinding eye diseases through direct comparisons with our standardised clinical examination results, the accuracy of self-report could not be quantified for other measures.

Outcomes in this study that may have been affected by self-report bias included sociodemographic factors used in logistic regression analysis. However, not all risk factors were measured using self-report; most notably, geographic remoteness was assigned by the ARIA+ system.²⁸⁹ Most other factors are reliable in self-report, including gender and age, and were therefore not likely to have significantly biased the logistic regression analyses in this

study. However, a few variables may be more prone to self-report bias, including diabetes history, educational attainment, and previous engagement with eye health care services (including recentness of examinations, and types of service providers visited).³⁷⁰ The AusDiab study reported that approximately half of diabetes cases in that study were undiagnosed prior to study participation,³⁷¹ and the absence of glycaemic testing and the reliance on self-report in the NEHS may have therefore resulted in an under-estimation of the prevalence of diabetes. While the potential influences of self-report bias cannot be denied, it is a commonly utilised tool for diabetes surveillance³⁷²⁻³⁷⁵ and several studies have reported high sensitivity and specificity for diabetes self-reporting as an indicator of medically diagnosed diabetes.³⁷⁶⁻³⁷⁸ Considering that a medical diagnosis is a prerequisite to adherence to the NHMRC diabetic eye examination guidelines, this suggests that the use of self-report for diabetes in the NEHS was probably sufficient to fulfil the study aims.

5.8 Future directions and recommendations

5.8.1 Projecting the future of vision impairment and blindness in Australia

Owing to the collection of incidence data, investigators from the BMES and the VIP built predictive models that have forecast the number of people who will have vision loss,¹⁹² glaucoma,³⁷⁹ cataract, and cataract surgeries in coming decades.⁴⁶ These projections have been particularly useful for future planning of resource distribution. However, some predictions based on the BMES and VIP data were not corroborated by the current NEHS data, partly due to significant changes in population parameters and the potential effectiveness of eye health interventions since their completion more than 20 years ago.¹⁹²

With the completion of the NEHS, it is now possible to forecast the future burden of vision loss and blinding eye diseases for Indigenous and non-Indigenous Australians residing in all levels of geographic remoteness based on stratified, nationwide data. With these predictions,

as well as nationally-representative predictions about rates of utilisation of eye health care services, adherence rates to diabetic eye examination guidelines, and cataract surgery and refractive error treatment coverage rates, policy-makers will be better-equipped to allocate resources and plan for the future of eye care in Australia. However, forecasting models must be dynamic and account for more than just the growing and ageing population. Similar to previous projections on the burden of diabetes in Australia,⁶³ models must account for the incidence of vision loss, age-specific relative mortality risk from vision loss, recovery from vision loss, overall population mortality rates, net migration rates, and the expected impact of interventions. Many of these measures require longitudinal data, and therefore the VIP and BMES continue to yield value for this purpose.²⁵³

5.8.2 Monitoring, evaluation and follow-up

Projections based on the cross-sectional estimates ascertained in this study will undoubtedly have utility for modelling future trends in VI and blindness in Australia. However, all predictive modelling depends on potentially unreliable assumptions and are unlikely to provide entirely accurate projections. This is almost certainly the case for models that attempt to forecast vision loss in Australia, owing to the lack of nationwide cohort studies required for nationally-representative incidence, mortality risk and recovery data. One potential solution is to conduct a longitudinal cohort study that involves re-examining the participants from the NEHS over regular time intervals. The benefit of this would be the acquisition of nationally-representative disease and vision loss incidence data. On the other hand, cohort studies are typically limited by high attrition and mortality rates, particularly when the target population comprises the elderly.¹⁸⁴ The attrition rate of a longitudinal study may be further exacerbated by both the logistical challenges associated with following up a nationwide sample and maintaining the engagement of Indigenous participants given cultural acceptability considerations and competing health and socioeconomic priorities.

Given these challenges it is recommended that the Department of Health of the Australian Government endorses and funds a follow-up cross-sectional National Eye Health Survey. A second survey that samples a new nationally-representative cross-sectional sample of Australians based on a similar study design to the NEHS, but with minor methodological adjustments based on the lessons learnt and limitations of this study, will be invaluable for tracking the progress of interventions implemented after the first survey. Vision 2020 Australia and various stakeholders in the eye health and vision care sector endorse the funding of a second National Eye Health Survey, and have appealed to the Australian Government to provide funding accordingly.³⁸⁰ If Australia intends to eliminate avoidable blindness in accordance with its obligations under the Global Action Plan, evidence-based service delivery programs must be formulated and implemented based on the findings of the current study, and their effectiveness should be subsequently monitored and evaluated through regular follow-up and surveillance.

5.9 Conclusions

The NEHS has fulfilled an urgent need for reliable and nationally-representative data on the prevalence and causes of VI and blindness and rates of utilisation of eye health care services in older Indigenous and non-Indigenous Australians. The successful completion of this logistically challenging and complex study has fulfilled a core objective of Australian eye health policy and has provided the data required to formulate targeted blindness prevention programs at a critical time when Australia's population is ageing rapidly and the threat of blindness looms. Notwithstanding improvements in some key areas, the gap in Indigenous eye health persists. Considering that non-Indigenous Australians have a lower burden of vision loss than all other world regions and that Australia's health care system is equipped to close this gap, the finding that vision loss is three times more prevalent in our Indigenous population is unacceptable and must be urgently addressed. In the words of Fred Hollows, "it's obscene to

let people go blind when they don't have to." This study has recapitulated the already well-established fact that most vision loss in Indigenous communities is avoidable. The year 2020 is fast approaching, and Australia has a duty to its Indigenous population that has already borne an unjustifiable burden, to utilise the findings of the NEHS and to intensify efforts at a national scale so that the gap for vision can finally be closed.

The NEHS has fulfilled a core objective of the WHO Global Action Plan and it is hoped that key decision-makers in countries with marginalised and underserved Indigenous peoples draw inspiration from this study and investigate and prioritise the elimination of vision loss in their populations' most vulnerable peoples. The cornerstone of the Global Action Plan is that all people of the world have the "right to sight," and that equitable eye health care services should be provided to everybody. There has been an undeniable positive shift in recent years, with a dramatic increase in the number of surveys on the prevalence of vision loss, owing in part to the development of the RAAB methodology. However, more research that investigates the burden of vision loss in disadvantaged population groups at a national scale is urgently needed so that eye health care programs can be optimised. Only then, will the global community be in the position to create a world in which nobody is needlessly blind.

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Appendices

Appendix A. Ethical approvals and endorsements received in the National Eye Health Survey



The Royal Victorian Eye & Ear Hospital

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27 November 2014

Dr Mohamed Dirani
Research Fellow
Centre for Eye Research Australia
Box No. 2

Dear Dr Dirani

HREC Reference Number: 14/1199H

National Eye Health Survey

Thank you for submitting the above research project for ethical review and attending the meeting to discuss your project. I acknowledge receipt of your letter dated 24 November 2014 responding to the questions raised by Reg Thorpe from the Victorian Aboriginal Health Service.

I am pleased to inform you that ethical approval has now been granted for this project. This letter constitutes ethical approval only. You must not commence this research project at any site until separate research governance authorisation from that site has been obtained.

The project number **14/1199H** was allocated, and this number should be used in all future correspondence. The following documents have been reviewed and approved:

- Participant Information and Consent Form (Version 1, 12 Sept 2014)
- National Eye Health Survey

The following Researchers were approved: (subject to RVEEH appointments and scope of practice for researchers where required):

- Dr Mohamed Dirani
- Prof Jonathan Crowston
- Ms Jennifer Gersbeck
- Dr Sophia Xie
- Dr Peter van Wijngaarden
- Prof Hugh Taylor
- Mr Ross Dunn

The Human Research & Ethics Committee of the Royal Victorian Eye & Ear Hospital is constituted and operates in accordance with the National Health & Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research (2007) and the NHMRC Australian Code for Responsible Conduct of Research (2007).

The Committee requires an annual progress report, and must approve any proposed amendments to the protocol. All serious or unexpected adverse effects on participants or any unforeseen events that might affect continued ethical acceptability of the trial must be reported to the Committee.

The Committee requires you to preserve the confidentiality of information about research subjects, and to ensure the confidentiality of records. Information obtained for your research that is confidential or personal must not be used for purposes other than those specified in the approved protocol.

Ethics – All Sites

Organisation	Corresponding NEHS site/s	HREC Ref#	Submitted	Approved
Royal Victorian Eye and Ear Hospital (RVEEH)	All Australian non-Indigenous sites	14/1199H	27/08/14	27/11/14

Ethics - Indigenous

Organisation	Corresponding NEHS site/s	HREC Ref#	Submitted	Approved
Aboriginal Health Council of South Australia (AHCSA)	Whyalla, Yorke Peninsula-South, Morphett Vale and Elizabeth Vale	04-15-604	13/02/15	22/04/15
Menzies School of Health Research	Wagaman	2015-2360	13/03/15	18/05/15
Aboriginal Health & Medical Research Council (NSW)	Concord-Mortlake-Cabarita, Parklea-Kellyville Ridge, Chipping Norton-Moorebank, Elderslie-Harrington Park, Warilla, Goulburn, Tomerong-Wandandian-Woollamia, Ulladulla Region, Eden and Inverell	1079/15	29/03/15	19/05/15
Aboriginal Health Council of Western Australia (AHCWA)	Craigie-Beldon, Bassendean-Eden Hill-Ashfield, Kalamunda-Maida Vale-Gooseberry Hill, Lesmurdie-Bickley-Carmel, Katanning, Esperance Region	622	16/04/15	26/11/15

Endorsement letter - Indigenous

The National Aboriginal Community Controlled Health Organisation (NACCHO)	All Australian Indigenous sites	N/A	-	26/03/15
Victorian Aboriginal Community Controlled Health Organisation (VACCHO)	Rowville-Central, Mornington and Wodonga	N/A	28/01/15	04/06/15
The Aboriginal Medical Services Alliance of the Northern Territory (AMSANT)	Wagaman	N/A	08/04/15	03/06/15
The Queensland Aboriginal and Islander Health Council (QAIHC)	Springfield, Brighton, Seventeen Mile Rocks-Sinamon Park, Rockhampton Region East, Banana, Daintree	N/A	-	18/08/15
The Western Australian Country Health Service	Katanning	N/A	-	15/09/15
Geraldton Regional Aboriginal Medical Service (GRAMS)	Geraldton	N/A	-	15/09/15
Wirraka Maya Health Service	South Hedland	N/A	-	05/10/15
Buurabalayji Thalanyji Aboriginal Corporation	Onslow	N/A	-	08/10/15

Derbarl Yerrigan Health Service (DYHS)	Craigie-Beldon, Bassendean-Eden Hill-Ashfield, Kalamunda-Maida Vale-Gooseberry Hill, Lesmurdie-Bickley-Carmel	N/A	-	09/10/15
Bega Garbiringu Health Service	Esperance Region	N/A	-	26/10/15



ABORIGINAL HEALTH
RESEARCH ETHICS COMMITTEE

22 April 2015

Dr Mohamed Dirani
Centre for Eye Research Australia
Level 1, 32 Gisborne Street
EAST MELBOURNE VIC 3002

RE: National Eye Health Survey (NEHS)
REFERENCE NO: 04-15-604

Dear Mohamed

Thank you for submitting your research project *National Eye Health Survey (NEHS)* on the 9 April 2015 for ethical consideration.

I am pleased to inform you that this proposal has met with support and that the committee has decided that your application be recommended for approval. The duration of approval is from 9 April 2015 until the expected completion date of your project indicated as 30 June 2016.

In accordance with the NHMRC guidelines, *National Statement on Ethical Conduct in Human Research* (2007), we require at regular periods, at least annually, reports from principal researcher(s). An 'Annual Progress or Final Report' template is available at: <http://ahcsa.org.au/research-overview/ahrec/>

If you require any further information please do not hesitate to contact the Executive Officer or myself. We wish you well with the project and look forward to receiving a copy of your report.

Sincerely yours

MS KIM MOREY
CHAIRPERSON

Ref: Proposal/Approval/ 9April2015



AHREC is a sub-committee of AHCSA

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File Reference Number: HREC-2015-2360
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Email: ethics@menzies.edu.au

18 May 2015

Dr Mohamed Dirani
Centre for Eye Research Australia
Level 1, 32 Gisborne Street
East Melbourne Vic 3002

Dear Dr Dirani,

HREC Reference Number: 2015-2360
Project Title: The National Eye Health Survey (NEHS)

Thank you for letter dated 15/05/2015 and taking the time to respond to the issues of concern identified by the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC) at its meeting held on the 15/04/2015.

I am pleased to advise that the Chair of the HREC has granted **full ethical approval** of this research project. Please note that HREC approval applies only to research conducted after the date of this letter.

This approval will be ratified at the next meeting of the Human Research Ethics Committee.

The nominated participating site in this project is:

- Wagaman, Northern Territory

Approved Project Timeline: 18/05/2015 – 20/07/2016

Approval is granted for a maximum period of twelve months. An annual progress report or final report is required on or before the 18/05/2016.

APPROVAL IS SUBJECT TO the following conditions being met:

1. The Coordinating Principal Investigator will **immediately report anything that might warrant review** of ethical approval of the project.
2. The Coordinating Principal Investigator will notify the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC) of any event that requires a **modification or amendment to the protocol or other project documents** and submit any required amendments in accordance with the instructions provided by the HREC. These instructions can be found on the Menzies' website, or by [clicking here](#).

3. The Coordinating Principal Investigator will submit any necessary reports related to the **safety of research participants (e.g. protocol deviations, protocol violations)** in accordance with the HREC's policy and procedures. These guidelines can be found on the Menzies' website, or by [clicking here](#).
4. The Coordinating Principal Investigator will **report to the HREC annually** and notify the HREC when the project is completed at all sites using the specified forms. Forms and instructions may be found on the Menzies' website, or by [clicking here](#).
5. The Coordinating Principal Investigator will notify the HREC if the project is **discontinued at a participating site before the expected completion date**, and provide the reason/s for discontinuance.
6. The Coordinating Principal Investigator will notify the HREC of any plan to **extend the duration of the project past the approval period listed above** and will submit any associated required documentation. The preferred time and method of requesting an extension of ethical approval is during the **annual progress report**. However, an extension may be requested at any time.
7. The Coordinating Principal Investigator will notify the HREC of his or her **inability to continue as Coordinating Principal Investigator**, including the name of and contact information for a replacement.
8. The safe and ethical conduct of this project is entirely the responsibility of the investigators and their institution(s).
9. Researchers should immediately report anything which might affect continuing ethical acceptance of the project, including:
 - Adverse effects of the project on subjects and the steps taken to deal with these;
 - Other unforeseen events;
 - New information that may invalidate the ethical integrity of the study; and
 - Proposed changes in the project.
10. Approval for a further twelve months, within the original proposed timeframe, will be granted upon receipt of an annual progress report if the HREC is satisfied that the conduct of the project has been consistent with the original protocol.
11. Confidentiality of research participants should be maintained at all times as required by law.
12. The Patient Information Sheet and the Consent Form shall be printed on the relevant site letterhead with full contact details.
13. The Patient Information Sheet must provide a brief outline of the research activity including: risks and benefits, withdrawal options, contact details of the researchers and must also state that the Human Research Ethics Administrators can be contacted (telephone and email) for information concerning policies, rights of participants, concerns or complaints regarding the ethical conduct of the study.

14. You must forward a copy of this letter to all Investigators and to your institution (if applicable).

This letter constitutes ethical approval only. This project cannot proceed at any site until separate research governance authorisation has been obtained from the CEO or Delegate of the institution under whose auspices the research will be conducted at that site.

Should you wish to discuss the above research project further, please contact the Ethics Administrators via email: ethics@menzies.edu.au or telephone: (08) 8946 8687 or (08) 8946 8692.

The Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research wishes you every continued success in your research.

Yours sincerely,



Dr Lewis Campbell
Deputy Chair
Human Research Ethics Committee
of Northern Territory Department of Health
and Menzies School of Health Research
NHMRC Registration No. EC00153
http://www.menzies.edu.au/page/Research/Ethics_approval/

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*. The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.

Dr Stuart Keel
Project Coordinator
National Eye Health Survey
University of Melbourne

Emailed to: stuart.keel@unimelb.edu.au

17th June 2015

Dear Sir/Madam,

Letter of Support: National Eye Health Survey 2015/2016.

This letter is a support letter for the National Eye Health Survey (NEHS), which sets out to determine the prevalence and causes of vision impairment and blindness in Indigenous Australians and non-Indigenous Australians, by gender, age, and geographical area.

In partnership with Vision2020 Australia, the Centre for Eye Research Australia (CERA) secured Federal Government funding to undertake the NEHS. The final project report will be presented to the World Health Organisation (WHO) as part of the global initiative to eliminate avoidable blindness by the year 2020.

Led by the Principal Investigator, Dr Mohamed Dirani, a random selection of regions representing urban, regional and remote Australia will be defined using sophisticated methodologies to ensure a representative sample of Australians are recruited into the study's sample population. Through random stratified sampling, the Northern Territory site of Wagaman has been selected, where 50 Indigenous participants will be recruited and examined.

Survey participants will complete a short interviewer-administered questionnaire to collect information on demographics and medical history, and complete a series of eye tests. These tests include a vision examination, digital photography of the back of the eye, eye pressure measurements and an assessment of peripheral vision. Adequate testing (30-45) will allow for some detection of major eye disease, including diabetic eye disease, glaucoma, age-related macular degeneration and refractive eye conditions.

Danila Dilba is the major Aboriginal community controlled service in Darwin. We understand that the investigators have consulted Danila Dilba and they are supportive of this eye survey occurring in Wagaman and that any relevant results will be fed back to the persons PHC service including Danila Dilba. AMSANT's support does not imply that any individual members will support a particular research proposal. We are pleased that the researchers have consulted with our member on this proposal/

Yours sincerely



John Paterson
CEO, AMSANT



AH&MRC ETHICS COMMITTEE

19th May 2015

Dr Mohamed Dirani
Centre for Eye Research Australia
Level 1, 32 Gisborne Street
East Melbourne VIC 3002

Dear Dr Dirani,

RE: 1079/15 - National Eye Health Survey (NEHS)

The Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee has considered your original application received on 29th March 2015 for ethics approval for the above project. Additional information received on 13th May 2015 is considered to form part of the application.

The Committee agreed to approve the application, subject to the Standard Conditions and Special Conditions of Approval below:

Standard Conditions of Approval (where applicable to the project)

1. The approval is for a period from **19th May 2015** until **19th May 2016** (12 months after), with extension subject to providing an Annual Progress Report on the research by **19th May 2016**.
2. All research participants are to be provided with a relevant Participant Information Statement and Consent Form in the format provided with your application.
3. Copies of all signed consent forms must be retained and made available to the Ethics Committee on request. A request will only be made if there is a dispute or complaint in relation to a participant.
4. Any changes to the staffing, methodology, timeframe, or any other aspect of the research relevant to continued ethical acceptability of the project must have the prior written approval of the Ethics Committee.
5. The AH&MRC Ethics Committee must be immediately notified in writing of any serious or unexpected adverse effects on participants.
6. The research must comply with:
 - the *AH&MRC Guidelines for Research in Aboriginal Health – Key Principles*;

Supported by the NSW Ministry of Health

Location
Level 3, 66 Wentworth Avenue
Surry Hills NSW 2010

Postal Address
PO Box 1565
Strawberry Hills NSW 2012

Contact
Phone: +61 (2) 9212 4777
Fax: +61 (2) 9212 7211
e-Mail: ahmrc@ahmrc.org.au
web: www.ahmrc.org.au

ABN
ABN 66 085 654 397

- *National Statement on Ethical Conduct in Research Involving Humans* (April 2007 – updated March 2014);
 - the *NSW Aboriginal Health Information Guidelines*.
7. The final draft report from the research, and any publication or presentation where data or findings are presented, must be provided to the AH&MRC Ethics Committee to be reviewed for compliance with ethical and cultural criteria prior to:
 - any submission for publication; and/or
 - any dissemination of the report.
 8. A copy of the final published version of any publication is to be provided to the AH&MRC Ethics Committee.

Special Conditions

9. Please provide a support letter from the AH&MRC when this becomes available to you. The Committee is granting this approval with notice that any additional revisions to the project as advised by the AH&MRC, as the peak representative body on Aboriginal health in NSW, may need to be considered as an amendment to the project.

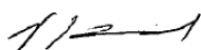
Please acknowledge receipt of this letter and your acceptance of the above conditions within fourteen (14 days).

Please find attached an Annual Progress Report pro forma for use at the end of the approval period.

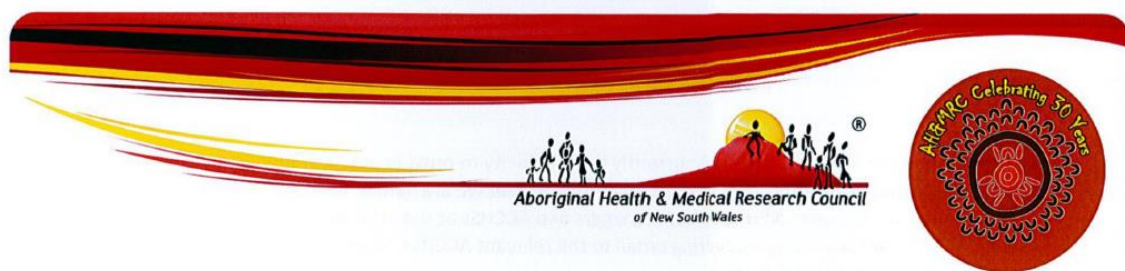
We appreciate your agreement that the research findings will be made available in order to assist the future development of policy and programs in Aboriginal health.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely,



Val Keed
Chairperson
AH&MRC Ethics Committee



9 July 2015

Dr Mohamed Dirani
Centre for Eye Research Australia
Level 1, 32 Gisborne Street
East Melbourne VIC 3002

Dear Dr Dirani

Re: National Eye Health Survey

Thank you for your request for AH&MRC support regarding the above project.

It is a condition of AH&MRC involvement that researchers seek and obtain the approval of the AH&MRC Ethics Committee and I understand that approval has been obtained for this project.

As you are aware, the AH&MRC review process is separate from that of the AH&MRC Ethics Committee, and I note the Committee's approval letter for our records. Further, it is our practice to notify the AH&MRC Ethics Committee if ever we have any concerns about a project. In your correspondence, you requested:

- The AH&MRC has reviewed the information you provided with your correspondence, and is generally supportive of your plans. Aboriginal community governance is an important principle of ethical and effective Aboriginal health research and it is a condition of AH&MRC support that there is an appropriate level of Aboriginal community governance for each project it supports.

We note that the Board of National Aboriginal Community Controlled Health Organisation (NACCHO) has endorsed the intent of the National Eye Health Survey and that you have obtained support for the project from NACCHO Affiliates including the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), Aboriginal Health Council of South Australia (AHCSA) and Aboriginal Medical Services Alliance Northern Territory (AMSANT).

We acknowledge that you intend to consult with ACCHSs at each recruitment site regarding engagement and testing. We wish to highlight the importance for this project of connecting with ACCHSs that operate in the local communities where the project will be conducted, to ensure they are fully informed about the project and have opportunities for input and involvement should they wish to do so.

Supported by the NSW Ministry of Health

Location	Postal Address	Contact	ABN
Level 3, 66 Wentworth Avenue Surry Hills NSW 2010	PO Box 1565 Strawberry Hills NSW 2012	Phone: +61 (2) 9212 4777 Fax: +61 (2) 9212 7211 e-Mail: ahmrc@ahmrc.org.au web: www.ahmrc.org.au	ABN 66 085 654 397

At this time, the AH&MRC does not currently have capacity to provide practical support to the project in terms of meeting with the researchers. However we are able to facilitate communication between NEHS project managers and ACCHSs at the local level in the recruitment sites in NSW, by forwarding a covering email to the relevant ACCHSs, along with an attached letter of introduction developed by you.

It would be appreciated if you could provide the AH&MRC with copies of any reports that are generated.

The AH&MRC point of contact for this project is Wendy Hermeston, Senior Project Officer, Research Support (researchsupport@ahmrc.org.au) should you have any further queries.

Yours sincerely,



Sandra Bailey
Chief Executive Officer



24th November, 2015

Dear Mohamed,

HREC Reference number: 622

Title: National Eye Health Survey (NEHS)

Thank you for submitting the above research project which was considered by the WAAHEC at its meeting held on *18th November, 2015*. I am pleased to advise that the WAAHEC has granted approval of this research project from date of the meeting held, pending your agreement of the following conditions:

1. Conditions

The WAAHEC will be notified, giving reasons, if the project is discontinued before the expected date of completion.

- The coordinating Investigator will provide a Progress Report every 30th June each year in the specified format. This form can be found on the AHCWA website (www.ahcwa.org).
- The approval for studies is for three years and the research should be commenced and completed within that period of time. Projects must be resubmitted if an extension of time is required.
- Publications that arise from this research are to be provided to the WAAHEC for review prior to submission for dissemination.
- That the Aboriginal and Torres Strait Islander community are formally acknowledged for their contribution to this research project.

Amendments

- If there is an event requiring amendments to be submitted you should immediately contact ethics@ahcwa.org for advice.

450 Beaufort Street, Highgate WA 6003 / PO BOX 8493, Stirling Street, Perth WA 6849
Phone: (08) 9227 1631 **Fax:** (08) 9228 1088 **Email:** ethics@ahcwa.org **Web:** www.ahcwa.org
ABN: 48 114 220 478 ACN: 114 220 478



Should you have any queries about the WAAHEC's consideration of your project please contact ethics@ahcwa.org.

The WAAHEC wishes you every success in your research.

Kind regards

Tara Pierson

For

Vicki O'Donnell

Chair, WAAHEC

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, *NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. The process this HREC uses to review multi-centre research proposals has been certified by the NHMRC.

450 Beaufort Street, Highgate WA 6003 / PO BOX 8493, Stirling Street, Perth WA 6849
Phone: (08) 9227 1631 **Fax:** (08) 9228 1088 **Email:** ethics@ahcwa.org **Web:** www.ahcwa.org
ABN: 48 114 220 478 ACN: 114 220 478



DERBARL YERRIGAN HEALTH SERVICE INC.

ABN 60 824 221 416

156 Wittenoom Street, East Perth W.A. 6004

Phone: (08) 9421 3888 Fax: (08) 9421 3884

Email: dyhs@dyhs.org.au Website: www.dyhs.org.au

14 October 2015

Dr Mohamed Dirani
Principal Investigator
Baker IDI
Level 4, 75 Commercial Road
Melbourne VIC 3004

Dear Dr Mohamed,

RE: The National Eye Health Survey

Derbarl Yerrigan Health Service understands that the Centre for Eye Research wishes to conduct a population based research project to determine the prevalence and causes of vision impairment and blindness in Indigenous Australians aged 40 years and over, by gender, age, and geographical area.

We have read the proposal and have been given the opportunity to provide feedback on this. We support this study and are willing for our East Perth clinic to be a research site.

Yours Sincerely

Barbara Henry – Chief Executive Officer
Derbarl Yerrigan Health Service Inc
PH 9421 3814 Fax 94213873
henryb@dyhs.org.au - www.dyhs.org.au

15th September, 2015

Dr Mohamed Dirani
Principal Investigator
Baker IDI
Level 4, 75 Commercial road
Melbourne VIC 3004

Dear Mohamed,

RE: The National Eye Health Survey

Geraldton Regional Aboriginal Medical Service (GRAMS) understands that the Centre for Eye Research Australia wishes to conduct a population based research project to determine the prevalence and causes of vision impairment and blindness in Indigenous Australians aged 40 years and over, by gender, age, and geographical area

We have read the proposal and have been given the opportunity to provide feedback on this. We support this study and are willing for GRAMS to be a research site.

We will require a copy of all materials produced in relation to reporting and outcomes generated from this project for our records and our Boards perusal. This is also in line with our own ethics process.

Yours Sincerely,

A handwritten signature in black ink, appearing to read 'Juli Coffin'.

Dr Juli Coffin
GRAMS Aboriginal Research Co-ordinator



Government of Western Australia
WA Country Health Service

Your Ref: Leave blank if none
Our Ref: File Reference
Enquiries to: Name of contact and telephone number

Dr Mohamed Dirani
Principal Investigator
Baker IDI
Level 4, 75 Commercial road
Melbourne VIC 3004

Dear Dr Dirani,

The National Eye Health Survey

Great Southern Aboriginal Health Service understands that the Centre for Eye Research Australia wishes to conduct a population based research project to determine the prevalence and causes of vision impairment and blindness in Indigenous Australians aged 40 years and over, by gender, age, and geographical area.

We have read the proposal and have been given the opportunity to provide feedback on this. We support this study in principle in the Katanning area.

Yours Sincerely

Juan Clark
A/MANAGER GSAHS

13TH September 2015

GREAT SOUTHERN ABORIGINAL HEALTH SERVICE
Tel: (08) 98927222
ABN 28 680 145 816
www.wacountry.health.wa.gov.au

Working together for a healthier country WA
Our Values: Community | Compassion | Quality | Integrity | Justice



Wirraka Maya Health Service Aboriginal Corporation

[ICN 1855] – [ABN: 65 321 646 985]

17 Hamilton Road / PO Box 2523 South Hedland 6722

Phone: Clinic (08) 9172 0400 / Administration (08) 9172 0410 / Wellbeing (08) 9172 0444

Fax: Clinic (08) 9140 2966 / Administration (08) 9140 2295 / Wellbeing (08) 9172 3719

5th October 2015

Dr Mohamed Dirani
Principal Investigator
Baker IDI
Level 4, 75 Commercial road
Melbourne VIC 3004

Dear Mohamed,

RE: The National Eye Health Survey

We understand that the Centre for Eye Research Australia wishes to conduct a population based research project to determine the prevalence and causes of vision impairment and blindness in Indigenous Australians aged 40 years and over, by gender, age, and geographical area and that South Hedland has been selected as a research site for this project.

I have read the proposal and on behalf of Wirraka Maya Health Service Aboriginal Corporation, I am pleased to inform you of our support for this study and that we are willing for Wirraka Maya Health Service to participate as a research site.

Yours Sincerely,

June Councillor
Chief Executive Officer



Bega
Garnbirringu
HEALTH SERVICE

BEGA GARNBIRRINGU HEALTH SERVICE

"Sickness Gets Better"

16-18 MacDonald Street

PO Box 1655, Kalgoorlie WA 6430

Telephone: (08) 9022 5500 Facsimile: (08) 9091 1302

29th October 2015

Dr. Mohamed Dirani
Principal Investigator
Baker IDI
Level 4, 75 Commercial Road
Melbourne VIC 3004

Dear Mohamed,

RE: The National Eye Health Survey

Bega Garnbirringu Health Service understands that the Centre for Eye Research Australia wishes to conduct a population based research project to determine the prevalence and causes of vision impairment and blindness in Indigenous Australians aged 40 years and over, by gender, age, and geographical area

We have read the proposal and have been given the opportunity to provide feedback on this. We support this study and are willing for the Bega Mobile Clinic to be used as a research site whilst on outreach in Esperance.

Yours Sincerely,

Wayne Johnson
CEO
Bega Garnbirringu Health Service

5 October 2015

Dr Mohamed Dirani
Principal Investigator
Baker IDI
Level 4, 75 Commercial Road
Melbourne VIC 3004

Dear Mohamed,

RE: The National Eye Health Survey

On behalf of the Burrabalayji Thalanyji Aboriginal Corporation, I understand that the Centre for Eye Research Australia wishes to conduct a population based research project to determine the prevalence and causes of vision impairment and blindness in Indigenous Australians aged 40 years and over, by gender, age, and geographical area

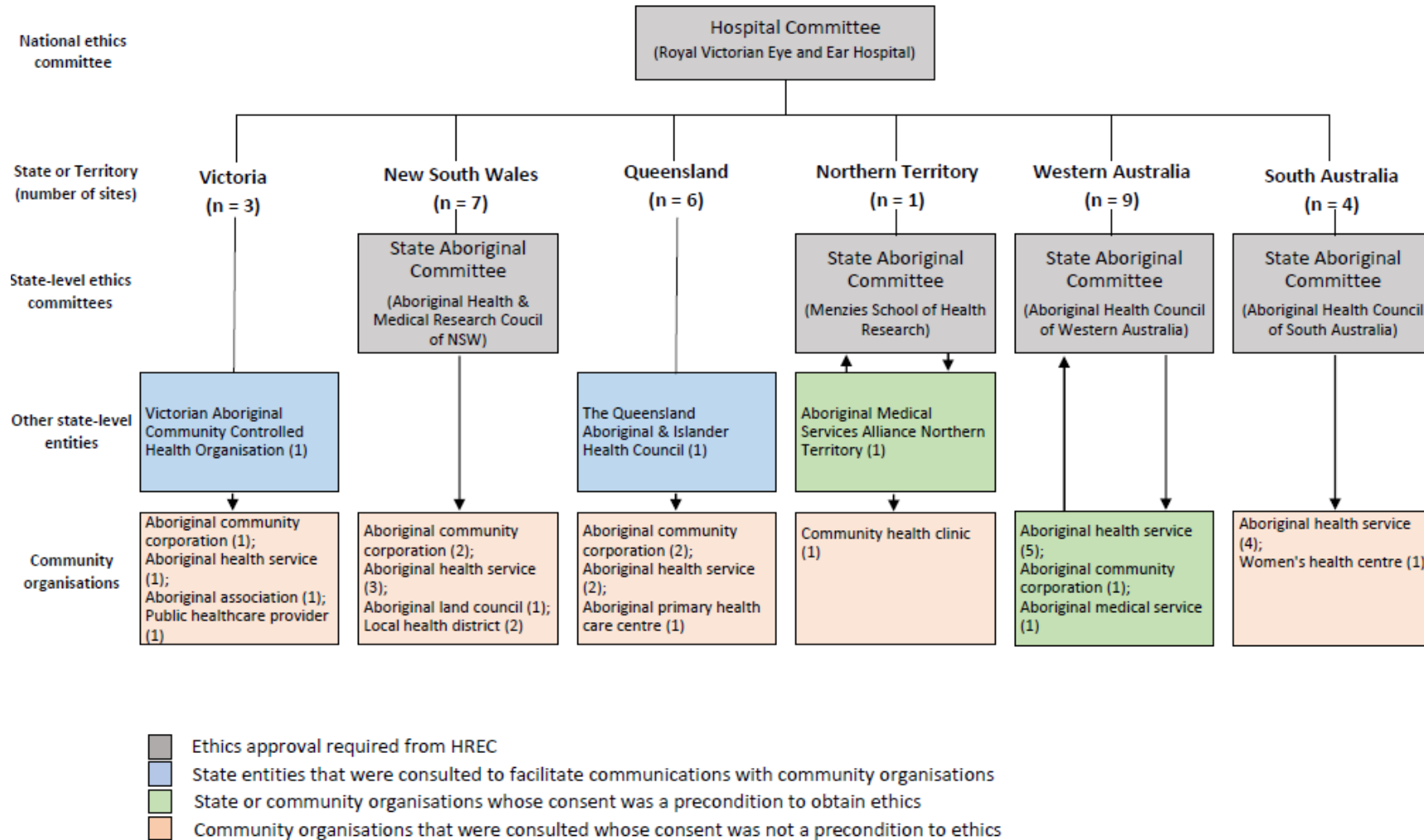
We have read the proposal and have been given the opportunity to provide feedback on this. We support this study and are willing for Onslow to be a research site.

Yours Sincerely,



Tim Milsom
Chief Executive Officer

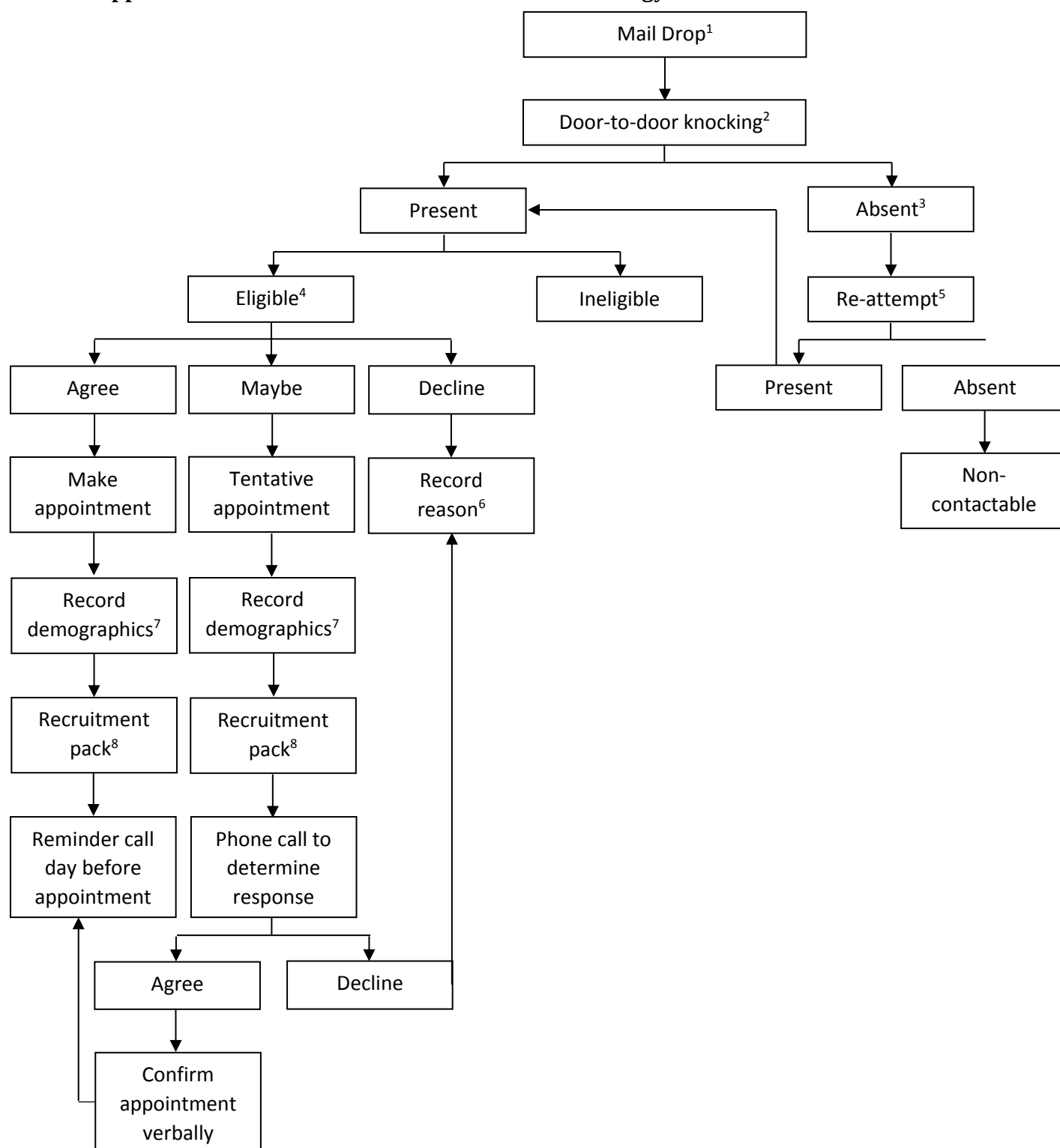
Appendix B. Indigenous ethics approvals and community consultations for the National Eye Health Sur



Appendix C. Primary Indigenous organisations consulted in each site

RA	Site	Indigenous Organisation
Major City	Brighton	Institute for Urban Indigenous Health, Deception Bay
	Springfield	Kambu Aboriginal and Torres Strait Islander Corporation
	Elizabeth Vale	Muna Paiendi Primary Health Care Services
	Chipping Norton-Moorebank	South Western Sydney Local Health District
	Morphett Vale	Southern Adelaide Local Health Network
	Mornington	Willum Warrain Aboriginal Association
	Rowville-Central	Bunurong Health Service
	Craigie-Beldon	Derbarl Yerrigan Health Service, Mirabooka
	Bassendean-Eden Hill-Ashfield	Derbarl Yerrigan Health Service, Midland
	Kalamunda-Maida Vale-Gooseberry Hill	Derbarl Yerrigan Health Service, Midland
	Elderslie-Harrington Park	Tharawal Aboriginal Corporation
	Seventeen Mile Rocks-Sinnamon Park	Kambu Aboriginal and Torres Strait Islander Corporation
Inner Regional	Lesmurdie-Bickley-Carmel	Derbarl Yerrigan Health Service, Midland
	Goulburn	Goulburn Community Health Centre
	Wodonga	Mungabareena Aboriginal Corporation
	Tomerong-Wandandian-Woollamia	Grand Pacific Health, Nowra
	Ulladulla Region	Grand Pacific Health, Nowra
	Rockhampton Region-East	Bidgerdii Health Service, Rockhampton
Outer Regional	Whyalla	Nunyara Aboriginal Health Service
	Geraldton	Geraldton Regional Aboriginal Medical Service
	Wagaman	Bagot Community Health Clinic
	Inverell	Armajun Aboriginal Health Service
	Eden	Katungul Aboriginal Corporation, Bega
	Katanning	The Western Australian Country Health Service, Albany
Remote	Banana	Bidgerdii Health Service, Mt Morgan
	Daintree	Mossman Primary Health Care Centre
	Yorke Peninsula-South	Yorke Peninsula Community Health Service
	South Hedland	Wirraka Maya Health Service
Very Remote	Onslow	Buurabalayji Thalanyji Aboriginal Corporation
	Esperance Region	Bega Garbiringu Health Service

Appendix D. Flowchart of the recruitment methodology



¹Mail contains information about the NEHS and advises residents to expect contact from door-to-door recruiters within 1 day.

²Note: minor adjustments were made to Indigenous participant recruitment strategies. Modes of recruitment included: Door-to-door knocking, word of mouth, telephone recruitment, media releases and public relations, and recruitment from concurrent Aboriginal Health Service clinics.

³Addresses with absent residents are recorded in the database and followed up within 24 hours.

⁴Inclusion criteria: Resident at time of recruitment and either Indigenous aged 40 years and older or non-Indigenous aged 50 years and older.

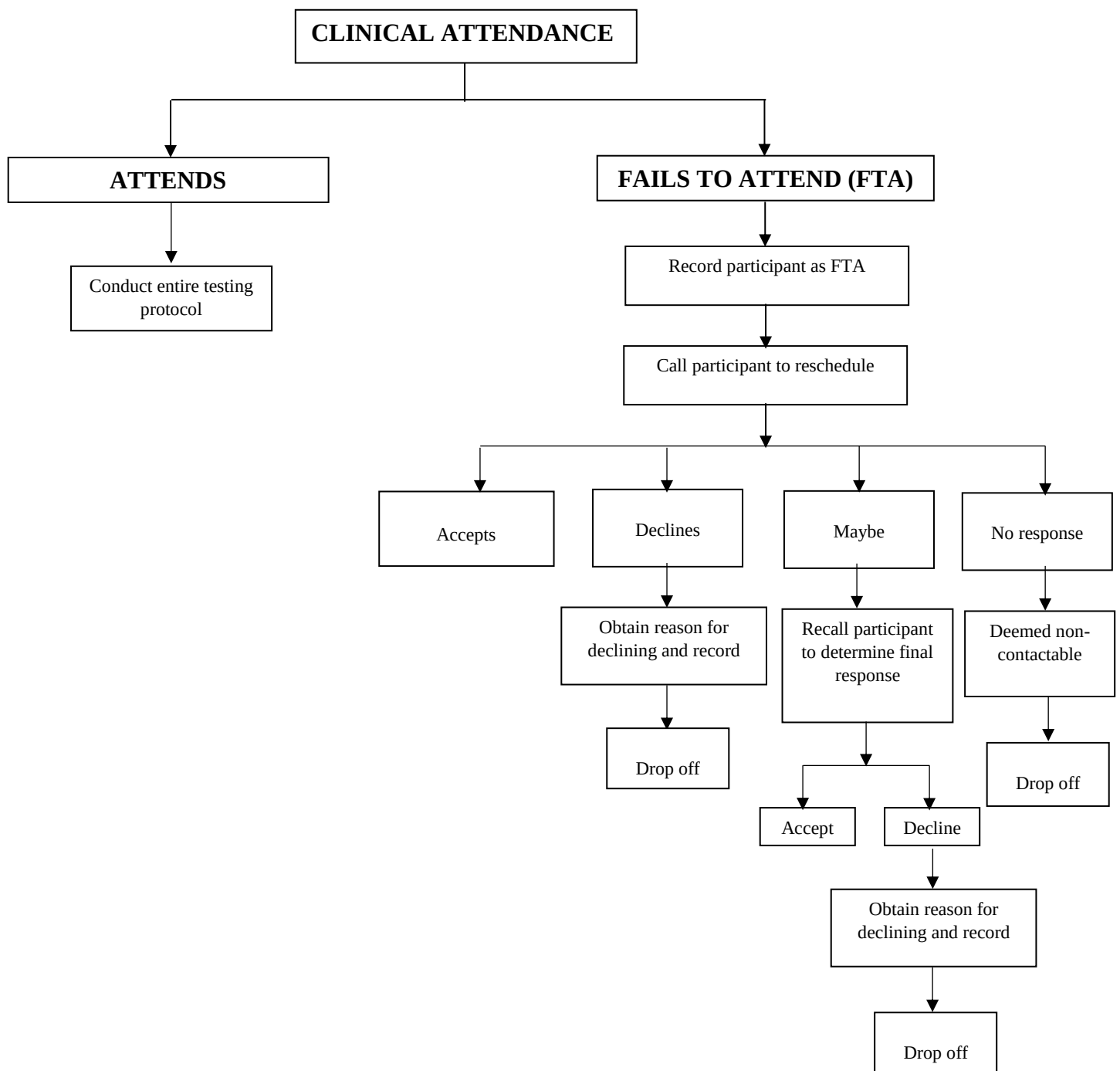
⁵Re-attempt at least 1 day later.

⁶Reasons for declining: Not interested, no free time, previous bad research experience, recent eye test, transport concern, safety concern, refuse to answer, other.

⁷Demographic details: Address, gender, age, date of birth.

⁸The recruitment pack contains an information booklet, participant instructions, an outline of the testing protocol and an appointment card.

Appendix E. Protocol for handling those who failed to attend their appointments



Appendix F. Standardised script used to screen and recruit participants

The following script was used to relay critical study information, increase the positive response rate and ensure a consistent recruitment methodology:

“Hi, I am Joshua from the Centre for Eye Research Australia, based in Melbourne. I am part of a new team that is collecting important vision and eye information as a part of the first ever national eye health survey that is endorsed by the Government. We want to understand how common vision impairment and blinding eye diseases are in our communities. Any person living here that is 50 years of age or older is invited to be part of this important project, where we will offer free eye tests and collect some simple information using a questionnaire. The testing will take approximately 30 minutes, and we will offer you some verbal feedback on your results on the day of the tests as well as a free pair of sunglasses valued at \$130 from our industry partner OPSM. We will be conducting the tests at the [testing venue] over the next 5 days. We would love for you to be part of the Government funded national eye health survey. What day are you available?”

Appendix G. National Eye Health Survey participant recruitment pack

NEHS

NATIONAL EYE HEALTH SURVEY





Level 1, 32 Gribben Street
East Melbourne VIC 3002
t: +61 3 9298 8190 e: nehs@crera.edu.au w: www.cera.org.au



THE RIGHT TO SIGHT



CENTRE FOR
Eye Research
Australia

FREQUENTLY
ASKED QUESTIONS

Are there any potential risks involved?

The eye tests involved in the survey are all non-invasive. A small number of participants may require dilating drops during one of the tests. If used, the initial instillation of the drops might cause a stinging sensation for several seconds. Also, dilation of the pupils may cause light sensitivity and will blur vision for 2-3 hours.

Where will the test be conducted?

The testing centre will be located near to your residence so that it should be easy for you to attend.

WANT
MORE
INFO?

The recruitment pack provided contains all the relevant information about the NEHS, including an appointment card with your appointment details, a frequently asked questions sheet, an appointment instructions page and an information pamphlet.

If you require further information, the research team will be happy to answer any questions. Please feel free to contact the NEHS team:

General Enquiries
Centre for Eye Research Australia
Telephone: (03) 99298190

Partners:





















NATIONAL EYE HEALTH SURVEY

What is the survey about?

You are invited to take part in the National Eye Health Survey (NEHS) which will determine, for the first time, the proportion of Indigenous and non-Indigenous Australians with vision impairment and blindness. Participants will be required to complete a short general questionnaire and undergo several routine eye tests.

The NEHS will play a critical role in planning eye health service delivery, policy development and resource allocation for Australians with vision loss. The results of the survey will also be presented to the World Health Organisation in support of the Global Action Plan which aims to reduce avoidable blindness globally by 25% before the year 2020.



Who is eligible?

All Indigenous Australians aged 40 years or older and non-Indigenous Australians aged 50 years or older who live in the target area will be invited to participate in the NEHS.

Even if you do not have eye problems or if you have had a recent eye exam we still want to see you.



What does the survey involve?

As a participant, you will attend one of our testing centres to complete an interview-administered questionnaire and have several routine eye tests.

The questionnaire will ask simple information about your personal details and medical history.

The eye tests include:

- Distance and near vision
- Assessment of the front of the eye
- Peripheral (side) vision
- Eye pressure
- Photographs of the back of the eye

Will I be told the results of my eye tests?

A trained eye examiner will tell you about the results of all of your eye tests. If there are any abnormalities detected, they will give you a referral letter.

Who will be performing the tests?

All tests will be performed by eye examiners trained by the Centre for Eye Research Australia.

How much time will the questionnaire and examination take?

The questionnaire and eye tests will take about 45-60 minutes.

Do I need to bring anything?

If you wear glasses for distance vision (driving or watching TV) or for near vision (reading), please bring them along with you to the testing centre on the day of your examination. If you usually wear contact lenses, please do not wear them on the day of your appointment but bring your most current glasses instead.

Will I be compensated for my time?

You will not receive any cash payments in exchange for participation. However, a free pair of sunglasses will be provided to you by one of our industry partners, OPSM.

My vision is good. Am I still eligible?

You are still eligible to participate in the NEHS. We need to see everyone. We are conducting a nationwide prevalence study and therefore it is essential to also capture those individuals with healthy vision.



TESTING PROTOCOL

The following is an outline of all the eye tests that you will undergo on the day of your examination. The testing process is expected to take 45-60 minutes.



E Chart

Distance Vision Assessment

Distance vision assessment is a test of how well you can see in the distance. During the test, the examiner will hold a chart with the letter 'E' printed at various sizes and facing in different directions (see image). You will be asked to correctly identify the direction of the letter 'E' (up, down, left or right). The examiner will be able to determine your distance vision based on the smallest set of 'E's for which you are able to identify the direction.



Occluder

Pinhole

If the distance vision in one or both of your eyes is reduced, a pinhole test will be performed. A pinhole test determines whether the reduced distance vision is a result of refractive error (a need for glasses) or eye disease. For this test, you will be handed an occluder that contains small holes (see image). You will be required to peek through one of the holes and correctly identify the direction of the letter 'E' (up, down, left or right) to assess whether your vision improves.



Auto-refractor

Auto-refraction

If your vision improves with pinhole testing, a test will be done to see what sort of glasses might help. This uses a machine called an auto-refractor (see image).



Trial Frame

The examiner will ask you to look into the window of the machine and focus on a target. The machine will take several measurements automatically. When all measurements are done, the relevant lenses will be placed in a trial frame (see image) and your vision will be reassessed to determine whether there has been any improvement.



E Chart

Near Vision Assessment

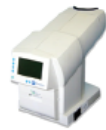
The examiner will ask you to hold a reading card (held at a comfortable reading distance) with the letter 'E' printed at various sizes and facing in different directions (see image below). You will be asked to correctly identify the direction of the letter 'E' (up, down, left or right). The examiner will be able to determine your near vision based on the smallest set of 'E's for which you are able to identify the direction.



Hand held slit lamp

Anterior Segment Assessment

The anterior segment assessment is performed using a hand-held slit lamp (see image). A light will be shone over the front part of your eye to assess your general eye health and to look for any signs of disease or injury.



FDT

Peripheral/Side Vision

Your peripheral vision will be tested using a machine called Frequency Doubling Technology (FDT) (see image). Each eye will be tested separately. You will be instructed to look at a screen which will have a black square located in the centre. Throughout the test you will see flickering patterns or lightning appearing around the screen. You will be required to press a buzzer whenever you see a flickering pattern or lightning. The test takes about 45 seconds for each eye.

Intraocular Pressure

Intraocular pressure is the fluid pressure inside the eye. It is elevated in some diseases such as glaucoma. We will use a device called an iCare tonometer (see image) to measure the pressure inside your eye. It will not cause any pain or discomfort.



iCare Probe

Retina Photography

The retina is the film at the back of the eye. This part of the eye can be damaged by diseases such as diabetes, macular degeneration and glaucoma. A trained examiner will use a machine called a Digital Retinography system (DRS) (see image) to take photos of your retina through your pupil.



DRS

Anterior Segment Photographs

If the distance vision in one or both of your eyes is reduced, you will have a photograph taken of the front part of your eye to see if the vision loss is caused by changes in the front of the eye.

APPOINTMENT INSTRUCTIONS

Please read the list of instructions below before coming to the testing centre.

- 1** Please carefully read all materials provided in the recruitment pack.
- 2** Please come to the testing centre at the time and date as indicated on your appointment card.
- 3** If you need to reschedule your appointment, please call one of our recruiters using the contact details provided in the recruitment pack.
- 4** If you wear glasses, whether for distance vision (watching TV or driving) or for reading, please remember to bring them with you on the day of your examination.
- 5** If you wear contact lenses, please do not wear them on the day of your examination as vision will be assessed using your current glasses.



CENTRE FOR
Eye Research
Australia

NEHS APPOINTMENT CARD

For queries please contact:
t: +61 3 9929 8190

Saving sight. Changing lives.

NEHS APPOINTMENT

Name: _____

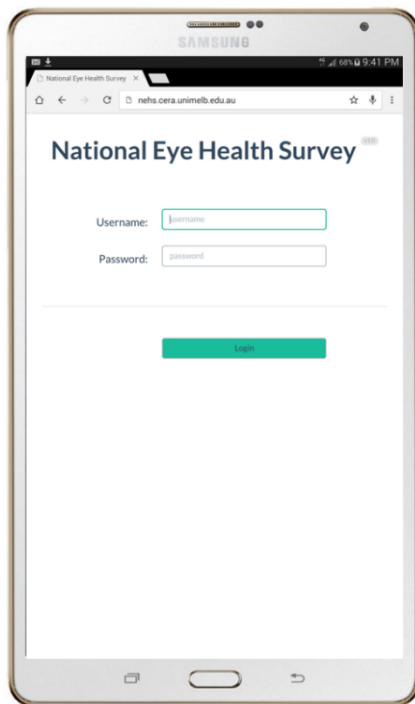
Venue: _____

Day: ☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday
☐ Friday ☐ Saturday ☐ Sunday

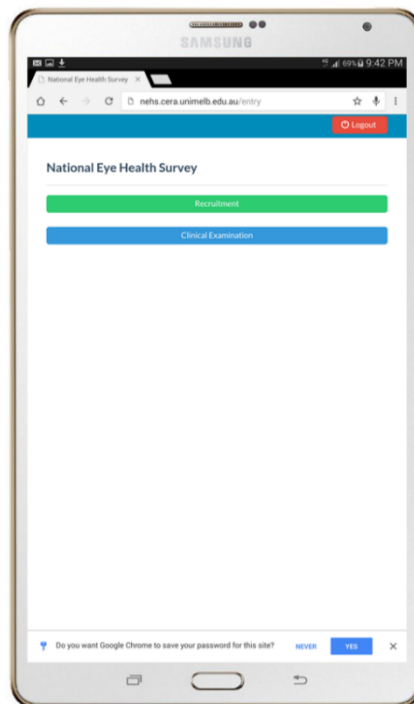
Date: ____/____/____ Time: _____

Initials of Recruiter: _____

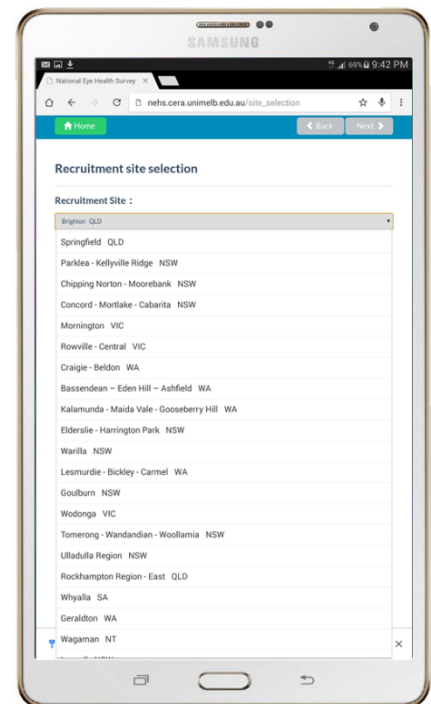
Appendix H. Recruitment user interface of the NEHS cloud-based database



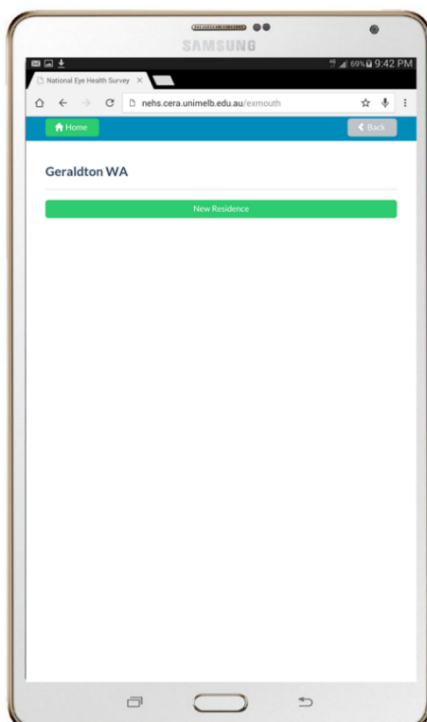
Log in to secure online database



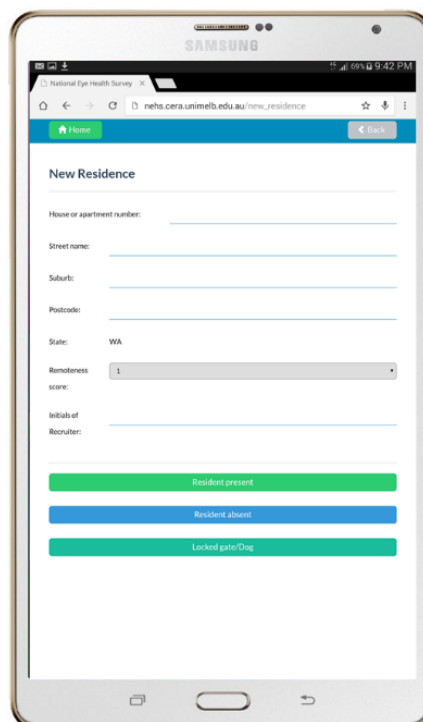
Select 'Recruitment' tab



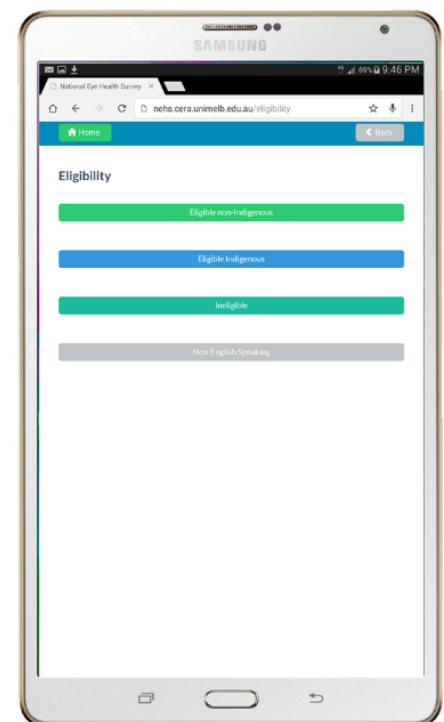
List of 30 sites appears
Select current site
All subsequent data stored in directory
for this site



Select 'New Residence' tab to enter
residence details.



Use touchscreen keyboard to enter address,
RA and recruiter initials.
Select 'Resident absent', 'Resident present'
or 'Locked gate/dog'.
Selecting 'Resident absent' or Locked
gate/dog returns to the 'New Residence'
screen



Selecting 'Resident present' prompts the
'Eligibility' screen.
Select 'Eligible non-Indigenous', 'Eligible
Indigenous', 'Ineligible' or 'Non-English
Speaking'.
Selecting 'Ineligible' or 'Non-English
Speaking' returns to the 'New Residence'
screen.

Select 'Agree', 'Maybe' or 'Decline' depending on resident response

If eligible resident declines, select the reason for declining from dropdown list

If eligible resident provides an 'Agree' or 'Maybe' response, sociodemographic details are recorded

Appointment date, day and time are recorded

Appendix I. Hardcopy household recruitment form

Recruiter initials: _ _ _

Recruiter Code: NEHS _ _

Recruitment date: _ _ (dd) / _ _ (mm) / _ _ _ _ (yyyy)

1. New Residence

Number: _____ Street name: _____

Suburb: _____ Postcode: _____

State: (Tick the correct option)

NSW ☐ NT ☐ QLD ☐ SA ☐ VIC ☐ WA ☐

Remoteness score: _____

Resident present ☐ Resident absent ☐ (Tick the correct option)

2. Eligibility (Tick the correct option)

Eligible non-Indigenous ☐ Eligible Indigenous ☐ Ineligible ☐

3. Resident Response (Tick the correct option)

Agree ☐ Maybe ☐ Decline ☐

a. If decline has been selected please specify:

Not interested ☐ No free time ☐ Recent eye test ☐ Previous bad research experience ☐
Safety concern ☐ Transport concern ☐ Refuse to answer ☐
Other (please specify) ☐

4. Sociodemographic Information

a. What is your given name? _____

b. What is your surname? _____

c. What is your gender? (Tick the correct option)

Male ☐ Female ☐

d. What is your age? _____ years

e. What is your date of birth? _ _ (dd) / _ _ (mm) / _ _ _ _ (yyyy)

f. What is your best form of contact? (Tick the correct option and enter details)

☐ Home phone: +61() _____

☐ Work phone: +61() _____

☐ Mobile phone: _____

☐ Email: _____

5. Appointment Details

a. Venue: _____

b. Day: _____

c. Date: _____

d. Time: _____

e. Has an appointment been made? (Tick the correct option)

Appointment confirmed ☐ Appointment tentative ☐ Appointment not yet made ☐

Appendix J. Examination equipment

Major eye testing equipment items				
Equipment	Manufacturer	Supplier	Model & Year	Function
LogMAR chart	Brien Holden Vision Institute	Brien Holden Vision Institute		Presenting Distance Visual Acuity
Pinhole Occluder				Pinhole Test for those with vision <6/12
Trial lens set	Weidir Impex	Designs for Vision	WD-260MF	Corrected Visual Acuity for those with vision < 6/12
Trial frame	Inami	Designs for Vision	K-0391	Corrected Visual Acuity for those with vision < 6/12
CERA VISION TEST E chart	Centre for Eye Research Australia	Centre for Eye Research Australia		Presenting Near Visual Acuity
Trial frame	Inami	Designs for Vision	K-0391	Corrected Visual Acuity for those with vision < 6/12
Nidek ARK hand-held auto-refractor	Nidek Co., LTD, Japan	Designs for Vision	ARK-30 Type R 2008	Auto-refraction for those with vision equal to or worse than 6/12
Keeler PSL – portable slit lamp - (10x) magnification	Keeler Ophthalmic Instruments, UK	Designs for Vision	3010-P-2001	Anterior segment assessment & trachoma grading
Frequency Doubling Technology (FDT)	Zeiss Humphrey Systems & Welch Allyn, USA	Carl Zeiss Meditec	00710-9, 2000	Visual field Examination
Digital Retinopathy Screening (DRS) non-mydratic fundus cameras	CenterVue SpA, Italy	Ellex	DRS, 2012	Macular and optic disc photos
iCare tonometer	iCare, Finland	Designs for Vision	T	Intraocular pressure

Comprehensive list of clinic items	
Procedure	Item
Registration and consent	Tablet computer
	Appointment sheet
	Stapler
	Participant log
	Folders
	Information and consent form
General Questionnaire	Tablet computer
	Pens
	Questionnaire hardcopy
	Folders
Presenting Distance Visual Acuity	logMAR vision chart
	Tablet computer
	Participant's distance glasses
	Occluder
	Tape measure
	Examination hardcopy
	Alcohol swabs
Pinhole test	logMAR vision chart
	Tablet computer
	Participant's distance glasses
	Alcohol swabs
	Tape measure
	Examination hardcopy
	Pinhole occluder
Auto-refraction	Nidek Hand-held auto-refractor
	Extension cord
	Trial lens set
	logMAR chart
	Tablet computer
	Alcohol swabs
	Auto-refractor print rolls
	Trial frame
	Tape measure
	Examination hardcopy
Presenting Near Visual Acuity	CERA Low Vision E Chart
	Alcohol swabs
	Examination hardcopy
	Participant's reading glasses
	Tablet computer
Anterior segment assessment	Keeler PSL One Hand-held Slit Lamp
	Antiseptic hand wash
	WHO Simplified Trachoma Grading System
	Examination hardcopy

	Extension cord
	Digital Retinography System (DRS)
	Tablet computer
Visual Field Test	Zeiss Frequency Doubling Technology (FDT)
	Alcohol swabs
	Examination hardcopy
	FDT printer rolls
	Tablet computer
	Extension cord
Fundus Photography	Digital Retinography System (DRS)
	Extension cord
	Keeler PSL One Hand-held Slit Lamp
	Tropicamide 0.5% dilating drops
	Tissues
	Tablet computer
	DRS adjustable platform
	Alcohol swabs
	Pen torch
	Alcaine drops
	External hard drive
	Examination hardcopy
Intra-ocular Pressure	iCare Tonometer
	Alcohol swabs
	Examination hardcopy
	iCare Tonometer probes
	Tablet computer
Feedback	Tablet computer
	Referral letter
	Free OPSM sunglasses
	Examination hardcopy
	Certificate of participation

Appendix K. National Eye Health Survey participant consent form



The Royal Victorian
Eye & Ear Hospital
32 Gisborne Street
East Melbourne
Victoria 3002 Australia
Locked Bag 8
East Melbourne
Victoria 8002 Australia
Telephone +61 3 9929 8666
TTY +61 3 9929 8052
Facsimile +61 3 9663 7203
Info@eyeandear.org.au
www.eyeandear.org.au

ABN 81 863 814 677

ROYAL VICTORIAN EYE & EAR HOSPITAL PARTICIPANT INFORMATION AND CONSENT FORM (PICF)

Version: 1.0 – Dated 12th September 2014

Title	<i>National Eye Health Survey</i>
Short Title	<i>Australian Eye Survey</i>
Protocol Number	
Project Sponsor	<i>Vision2020 Australia</i>
Principal Investigator	<i>Dr Mohamed Dirani</i>
Associate Investigator(s)	<i>Professor Hugh Taylor, Professor Jonathan Crowston, Dr Peter van Wijngaarden, Dr Sophia Xie, Mr Ross Dunn, Ms Jennifer</i>
Location	<i>Royal Victorian Eye and Ear Hospital</i>

This Participant Information and Consent Form is **11** pages long. Please make sure you have all the pages.

1. Introduction

You are invited to take part in this research project, ***National Eye Health Survey***, as you have been identified as an eligible participant who meets the criteria for inclusion in this project. The research project is aiming to **determine the prevalence of major eye disease in Australians living in urban, regional and rural areas.**

This Participant Information and Consent Form tells you about the research project. It explains the tests and research involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether you take part or not.

If you decide to take part in the research project, you will be asked to sign the consent section. By signing it, you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project;
- Consent to the tests and research that are described;
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. Purpose and Background

The purpose of this project is to ***provide national estimates of the causes and prevalence of the leading eye diseases and conditions in Australia. The following are the objectives and significance of the study:***

Objectives

1. To 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. To measure the detection and treatment coverage rate of major eye diseases and conditions, including cataract, diabetic retinopathy, glaucoma, age-related macular degeneration and refractive error in both Indigenous and non-Indigenous Australian adults by:
 - a) Determining the proportion of Australians with undiagnosed major eye diseases and uncorrected refractive error.
 - b) Determining the proportion of Australians with known diabetes who adhere to the recommended retinal examination timeframes set by the National Health and Medical Research Council (NHMRC); once every two years for non-Indigenous Australians and once per year for Indigenous Australians.
 - c) To determine an estimation on the rate of cataract surgery and the treatment of uncorrected refractive error in Australia.

Significance

Eye researchers, health professionals and policy makers still rely on prevalence data of blinding eye diseases from two landmark studies that date back to the early 1990s. Both studies, the Blue Mountains Eye Study (BMES) and the Melbourne Vision Impairment Project (VIP), were conducted between 1992-1994, where participants were recruited from selected regions within two Australian States (NSW and VIC), only included non-Indigenous Australians and did not include all levels of remoteness defined by the Australian Bureau of Statistic's Accessibility/Remoteness Index of Australia (ARIA) regions. This is problematic as policy development,

resource allocation and economic analysis of eye diseases and management still utilise these data that are over 20 years old and sub-national.

Our study findings will be presented to the World Health Organisation (WHO), alongside the data from our fellow countries who we actively work with to eliminate the burden of avoidable blindness worldwide. The current NEHS will define the principles and methods to assess the extent of eye disease, provide useful information for policy planning and better direct the allocation of funds.

The NEHS will assist in eye health care in multiple ways, including:

- (1) being a core indicator in measuring the progress and impact of eye health care services in Australia;
- (2) guiding the use of necessary resources in reducing the prevalence of avoidable vision impairment in Australia;
- (3) assisting in developing effective, feasible and cost-effective eye health care services in Australia;
- (4) aiding in developing education, awareness and screening programs in communities, including regional and remote areas for the prevention of eye disease.

The NEHS will contribute to achieving the global target of reducing the number of people with avoidable blindness and vision impairment by 25% by the year 2019.

A total of **4500 Australians** will participate in this project.

Participant will be identified using sampling methods determined by the Accessibility and Remoteness Index of Australia to obtain a representative sample of Australians across urban, region and rural regions.

The National Eye Health Survey is the first nation-wide survey to determine the prevalence of major eye disease in Indigenous and non-Indigenous Australians. This survey will also provide follow up data for the National Indigenous Eye Health Survey (NIEHS) that was conducted in 2008.

You are invited to participate in this research project because ***you meet the criteria for inclusion of the survey.***

This research is being led by Dr Mohamed Dirani from the Centre for Eye Research Australia, in association with Professor Hugh Taylor from the University of Melbourne, Professor Jonathan Crowston, Dr Peter van Wijngaarden, Mr Ross Dunn and Dr Sophia Xie from the Centre for Eye Research Australia, and with Jennifer Gersbeck, the CEO of Vision2020 Australia, who is the project sponsor.

This research has been funded by the Federal Government, with contributions from our major industry partners, including Novartis Pharmaceuticals, Luxottica (OneSight) and Optometry Australia.

Research coordinated outside the Centre for Eye Research Australia will be coordinated by the Lead Researcher Dr Mohamed Dirani, in collaboration with industry contributors, Luxottica and Optometry Australia.

3. What is Involved?

If you agree to participate in this survey, and you meet the inclusion criteria of the survey determined by age and residence, you will be invited to attend one of the Survey testing sites to complete a short questionnaire and undergo a series of eye tests.

Testing will take approximately 30 to 45 minutes to complete.

General Questionnaire

The general questionnaire will obtain information on person particulars, including age, gender, ethnicity, and a thorough history on your general and eye health will be collected.

Eye Tests

There will be a number of eye tests that will be conducted, these include:

- Testing of your vision for both distance viewing and reading
- In those with reduced vision as determined by the protocol (less than 6/12 vision), a further test to determine the level of short-sightedness, long-sightedness or astigmatism using a non-invasive automated machine
- Digital photographs of the back of the eye will be taken using a special camera which is used in routine optometry and ophthalmological clinics
- To obtain measurements of your peripheral (side) vision, you will undergo a visual field test in each eye using Frequency Doubling Technology (FDT) Perimetry.
- An examination of the front part of your eye will be taken using a handheld slit lamp to obtain a general overview of the health of your eyes and eye lids.

All participants will be provided with verbal feedback on their eye test results at the completion of the clinical examination. Any participant with undiagnosed eye disease that can be detected through the survey's testing protocol will receive a letter of recommendations for referral to an appropriate eye care professional.

Dilating Eye Drops

It is very important that we have a clear view through to the back of your eye to obtain high quality photographs. This is typically determined by the size of your pupil. At first instance, we will attempt to achieve the necessary pupil dilation by darkening the examination room, however if this is not achieved, standard dilating drops (Tropicamide) will be used to increase pupil size. These drops will be administered by trained staff 20 to 25 minutes before photographs are taken.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this research, however if an eye condition is identified by the survey you will be provided with an appropriate referral recommendation to an eye care professional.

Possible benefits may include better guidance on eye care interventions for the broader community determined by this survey's results. Also the Government will be better informed on the allocation of necessary eye services in Australia.

5. Possible Risks

While this research does not involve any interventional treatment, you may be receiving medical treatments that cause side effects. You may have none, some or all of the effects listed below, and they may be mild, moderate or severe. If you have any of these side effects, or are worried about them, talk with your study researcher. Your study researcher will also be looking out for side effects.

There may be side effects that the researchers do not expect or do not know about and that may be serious. Tell your study researcher immediately about any new or unusual symptoms that you get.

Many side effects go away shortly after treatment ends. However, sometimes side effects can be serious, long lasting or permanent. If a severe side effect or reaction occurs, your study researcher may need to stop your involvement with the study. Your study researcher will discuss the best way of managing any side effects with you and a doctor if necessary.

Possible risks, side effects and discomforts include:

With the initial instillation of the drops, you may experience a stinging sensation for several seconds. Also, dilation of the pupils may cause light sensitivity and will blur your vision for several hours. In rare situations (studies estimate it at 3 in 10000 people), the use of these drops can trigger a condition called angle closure glaucoma. If such an event occurs, eye care specialist services will be required immediately so that the condition can be treated. We do not advise you to drive after the use of these drops and other arrangements for transport should be put in place. We also advise you to bring sunglasses to the examination for comfort in daylight. Please note that these drops are only expected to be used in less than 20% of participants and you may decline administration of them.

To avoid any physical discomfort with seating positions during eye testing, examiners will ensure that you are comfortable at all times, however if you feel any discomfort at all during the testing please inform one of the examiners. Also, you will be offered frequent breaks to ensure optimal comfort during the entire course of the testing.

With some of the tests, particularly the camera used to take photos of the back of the eye, discomfort may be experienced with the flash used with the camera. This flash is the same as what you would experience using a regular camera. You will be given regular breaks to minimise any eye discomfort from these types of tests, but please do not hesitate to inform the examiner if longer breaks are required.

Participants can suspend or even end their participation at any time in the project if distress occurs.

There may be additional unforeseen or unknown risks that the researchers do not expect or do not know about. Tell a member of the research team immediately about any new or unusual symptoms that you get.

6. New Information Arising During the Project

Sometimes during the course of the research project, new information becomes available about the treatment that is being studied. If this happens, your study doctor will tell you about it and discuss with you whether you want to continue in the research project. If you decide to withdraw, your study doctor will make

arrangements for your regular health care to continue. If you decide to continue in the research project you will be asked to sign an updated consent form.

Also, on receiving new information, your study doctor might consider it to be in your best interests to withdraw you from the research project. If this happens, he/she will explain the reasons and arrange for your regular health care to continue.

7. Other Treatments Whilst on Study

While you are participating in this research project, you may not be able to take some or all of the medications or treatments that you have been taking for your condition or for other reasons. It is important to tell your study doctor and the study staff about any treatments or medications you may be taking, including over-the-counter medications, vitamins or herbal remedies, acupuncture or other alternative treatments. You should also tell study staff about any changes to these during your participation in the research. Your study doctor should also explain to you which treatments or medications need to be stopped for the time you are involved in the research project.

It is not expected that you will need to stop any treatment whilst involved in this study.

8. Alternatives to Participation

There is no standard procedure or treatment that is being withheld as a result of your participation in this study. You do not have to take part in this research project to receive treatment at this hospital.

9. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with the Royal Victorian Eye & Ear Hospital.

Before you make your decision, a member of the research team will be available so that you can ask any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to discuss any health risks or special requirements linked to withdrawing.

If you do withdraw your consent during the research project, the study doctor and relevant study staff will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the sponsor up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

10. Results of Project

Participants will be informed via their preferred form of contact of the results when the research project is complete and the data is published. Also, media release, progress reports and associated newsletters will be accessible to all participants online.

11. Privacy, Confidentiality and Disclosure of Information

By signing the consent form you consent to the study doctor and relevant research staff collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to your information collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, as or required by law.

13. Injury

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

14. Who is organising and funding the research?

This research project is being conducted by ***Dr Mohamed Dirani from the Centre for Eye Research Australia and Ms Jennifer Gersbeck from Vision2020 Australia. The Federal Government has funded the project with contributions from industry and not-for-profit partners.***

There are no financial benefits that might arise from the conduct of the research. You will not benefit financially from your involvement in this research project even if, for example, your results (or knowledge acquired from analysis of your samples) prove to be of commercial value to the ***Centre for Eye Research Australia***. In addition, if knowledge acquired through this research leads to discoveries that are of commercial value to the ***Centre for Eye Research Australia***, the study doctors or their institutions, there will be no financial benefit to you or your family from these discoveries. ***The Centre for Eye Research Australia*** will receive a payment from ***Vision2020 Australia*** for undertaking this research project. No

member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

15. Additional costs and reimbursement

There are no costs associated with participating in this research project, nor will you be paid.

16. Ethical Guidelines

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the Royal Victorian Eye & Ear Hospital.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

17. Who can I Contact?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any medical problems which may be related to your involvement in the project (for example, any side effects), you can contact the principal study doctor on **9929 8115** or any of the following people:

Study contact person

Name	<i>Dr Mohamed Dirani</i>
Position	<i>Principal Investigator</i>
Telephone	<i>03 9929 8190</i>
Email	<i>dirani@unimelb.edu.au</i>

For complaints

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Position: HREC Secretary

Telephone: (03) 9929 8525

You will need to tell the Secretary the name of one of the researchers listed above.

Reviewing HREC:

The reviewing HREC approving this research and contact details of the Executive Officer are:

Reviewing HREC name: Royal Victorian Eye & Ear Hospital

Position: HREC Secretary

Telephone: (03) 9929 8525

Email: ethics@eyeandear.org.au



CONSENT FORM - ADULT PROVIDING OWN CONSENT

Version: 1.0 – Dated 12th September 2014

Title	<i>National Eye Health Survey</i>
Short Title	<i>Australian Eye Survey</i>
Project Sponsor	<i>Vision2020 Australia</i>
Principal Investigator	<i>Dr Mohamed Dirani</i>
Associate Investigator(s)	<i>Professor Hugh Taylor, Professor Jonathan Crowston, Dr Peter van Wijngaarden, Dr Sophia Xie, Mr Ross Dunn, Ms Jennifer Gersbeck</i>
Location (where CPI/PI will recruit)	<i>Royal Victorian Eye and Ear Hospital</i>

Declaration by Participant

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the study without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Participant's Name (printed)

Signature

Date

Witness (where required – see Note for Guidance on Good Clinical Practice CPMP/ICH/135/95 at 4.8.9)

Name of Witness* to Participant's Signature (printed)

.....

Signature

Date

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older.

Declaration by study doctor/senior researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's Name (printed)

Signature

Date

* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.

Version: 1.0 – Dated 12th September 2014

Title	<i>National Eye Health Survey</i>
Short Title	<i>Australian Eye Survey</i>
Project Sponsor	<i>Vision2020 Australia</i>
Principal Investigator	<i>Dr Mohamed Dirani</i>
Associate Investigator(s)	<i>Professor Hugh Taylor, Professor Jonathan Crowston, Dr Peter van Wijngaarden, Dr Sophia Xie, Mr Ross Dunn, Ms Jennifer Gersbeck</i>
Location (where CPI/PI will recruit)	Royal Victorian Eye and Ear Hospital

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to the participant taking part in this research project as described and understand that I am free to withdraw them at any time during the project without affecting their future health care.

I understand that I will be given a signed copy of this document to keep.

Participant's Name (printed)

Name of Person Responsible giving consent (printed)

.....

Relationship of Person Responsible to participant:

.....

(as defined by the Guardianship and Administration Act 1986)

Signature

Date

Witness

Name of Witness to Person Responsible's Signature (printed)

.....

Signature

Date

Declaration by study doctor/senior researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the person responsible for the participant has understood that explanation.

Researcher's Name (printed)

Signature

Date

* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.



Eye & Ear Hospital
caring in every sense

FORM FOR WITHDRAWAL OF PARTICIPATION

It is recommended that this form NOT be included as part of the PICF itself, but that it be developed at the same time and made available to researchers for later use, if necessary. Note that a participant's decision to withdraw their separate consent to the use and storage of tissue will need to be documented separately and linked to the PICF used for that purpose.

On Institution's Letterhead

Title	<i>National Eye Health Survey</i>
Short Title	<i>Australian Eye Survey</i>
Project Sponsor	<i>Vision2020 Australia</i>
Coordinating Principal Investigator/ Principal Investigator	<i>Dr Mohamed Dirani</i>
Associate Investigator(s)	<i>Professor Hugh Taylor, Professor Jonathan Crowston, Dr Peter van Wijngaarden, Dr Sophia</i>

Declaration by Participant

I wish to WITHDRAW from participation in the above research project and understand that such withdrawal WILL NOT affect my routine treatment, my relationship with those treating me or my relationship with the Royal Victorian Eye & Ear Hospital.

Participant's Name (printed)

Signature

Date

In the event that the participant's decision to withdraw is communicated verbally, the Study Doctor/Senior Research will need to provide a description of the circumstances below.

Declaration by study doctor/senior researcher*: I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Researcher's Name (printed)

Signature

Date

member of the research team must provide the explanation and provision on concerning the research project.

Note: All parties signing the Consent Form must date their own signature.

ROYAL VICTORIAN EYE & EAR HOSPITAL EXPERIMENTAL PARTICIPANT'S STATEMENT OF RIGHTS

The Royal Victorian Eye and Ear Hospital considers it important that you know:

Any patient who is asked to participate in a research study involving medical experiment, or who is requested to consent on behalf of another, has the right to:

1. Be informed of the nature and purpose of the experiment.
2. Be given an explanation of the procedures to be followed and any drugs used in the medical experiment.
3. Be given a description of discomforts and risks reasonably expected from the experiment, if applicable.
4. Be given an explanation of any benefits to the participant reasonably to be expected from the experiment, if applicable.
5. Be advised of appropriate, alternative procedures, drugs, or devices that might be advantageous to the participant, and their relative risks and benefits.
6. Be informed of the avenue of medical treatment, if any, available to the participant after the experiment if complications should arise.
7. Be given an opportunity to ask questions concerning the experiment or the procedures involved.
8. Know that consent to participate in the medical experiment may be withdrawn at any time, and that the participant may discontinue participation in the medical experiment without prejudice.
9. Be given a copy of the signed and dated written consent form when one is required.
10. Be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence.

Appendix L. Interviewer-administered questionnaire and examination hardcopy

National Eye Health Survey questionnaire (hard copy)

Interviewer Initials: _ _ _

Interviewer Code: NEHS _ _

Date of Examination: _ _ (dd) / _ _ (mm) / _ _ _ _ (yyyy)

Time of Examination: _____ am/pm

Participant Unique ID: NEHS _ _ _ _

1. Personal Particulars:

a. What is your given name? _____

b. What is your surname? _____

c. What is your gender? Tick the correct option

☐ Male

☐ Female

d. What is your age? _____

e. What is your date of birth? _____ (dd) / _____ (mm) / _____ (yyyy)

2. Ethnicity:

a. What is your country of birth? Tick the correct option

☐ Australia

☐ England

☐ New Zealand

☐ China

☐ India

☐ Italy

☐ Vietnam

☐ Philippines

☐ South Africa

☐ Other, please specify _____

b. If Australia was not your place of birth, how many years have you been in Australia? Record as a whole number

c. Are you of Aboriginal or Torres Strait Islander origin? Tick the correct option

- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, Aboriginal and Torres Strait Islander
- ☐ No

d. What is the main language you speak at home? Tick the correct option

- ☐ English
- ☐ Italian
- ☐ Greek
- ☐ Cantonese
- ☐ Arabic
- ☐ Vietnamese
- ☐ Indigenous language, please specify_____
- ☐ Other, please specify_____

3. Educational Attainment:

a) What is your highest level of education? Tick the correct option

- ☐ Grade 0 = No education
- ☐ Grade 1 = Primary education incomplete
- ☐ Grade 2 = Completed primary education
- ☐ Grade 3 = Completed primary and some years of secondary education
- ☐ Grade 4 = Completed primary and secondary education
- ☐ Grade 5 = Attending/completing trade school or TAFE
- ☐ Grade 6 = University student
- ☐ Grade 7 = Completed university degree
- ☐ Grade 8 = Undertaking/completed post graduate study

b) Total number of years of education _____ years Record in years

4. Stroke:

a. Have you ever had a stroke? Tick the correct option

- ☐ Yes
- ☐ No

5. Past Ocular History:

a. Have you ever had your eyes examined? Tick the correct option

- ☐ Yes
- ☐ No (Proceed to d)

b. If yes, how long ago? Record in years and months
 _____ years _____ months

c. Who did you see for your eye examination? Tick more than one

☐ Optometrist

☐ Eye Doctor/Ophthalmologist

☐ GP/Local Doctor

☐ Nurse

☐ Health Worker

☐ Ophthalmic Nurse/Technician

☐ Other, please specify _____

d. Have you ever been told that you have any of the following eye conditions?
Tick the correct option for **each** eye condition.

Eye Condition	Yes	No	Unsure
Glaucoma (high pressure in the eye)	☐	☐	☐
Diabetic Retinopathy (diabetic eye disease)	☐	☐	☐
Age-related macular degeneration (loss of your central vision)	☐	☐	☐
Refractive error (wear glasses)	☐	☐	☐
Cataracts (cloudiness of the lens resulting in decreased vision)	☐	☐	☐

☐ Other, please specify:

e. Have you ever had cataract surgery? Tick the correct option

☐ Yes

☐ No (Proceed to Question 6)

f. If yes, to which eye? Tick the correct option

☐ Right

☐ Left

☐ Both eyes

g. If yes, how long ago (please specify for each eye)? Record in years and months

R) _____ years _____ months

L) _____ years _____ months

6. Diabetes and Duration:

- a. Have you been told by a doctor or nurse that you have diabetes? Tick the correct option.
☐ Yes
☐ No (Proceed to Question 7)
- b. If yes, at what age were you first told that you had diabetes? Record in years _____ years old
- c. Have you seen an Eye Doctor/Ophthalmologist or Optometrist for a diabetes eye check? Tick the correct option
☐ Yes
☐ No (Proceed to e)
- d. If yes, how long ago? Record in years and months
_____ years _____ months
- e. If no, why? Tick the correct option
☐ I did not know
☐ I was not told
☐ I missed the appointment
☐ I have no time
☐ Other, please specify _____

7. Refractive error:

- a. Do you wear the following? Tick more than one
☐ Glasses
☐ Contact lenses
☐ I currently do not wear glasses or contact lenses (Questionnaire complete)
- b. If you do wear glasses or contact lenses, are they for: Tick the correct option
☐ Distance (driving or watching TV)
☐ Near (reading or computer work)
☐ Both
- c. At what age did you first wear glasses? Record in years
_____ years old

National Eye Health Survey Eye Examination (Hard Copy)

1. Distance Visual Acuity

Tick the correct option

- a. VA R) ☐ 6/6 ☐ pt
☐ 6/7.5
☐ 6/9
☐ 6/12
☐ 6/15
☐ 6/18
☐ 6/24
☐ 6/36
☐ 6/60
☐ LP
☐ NLP

- L) ☐ 6/6 ☐ pt
☐ 6/7.5
☐ 6/9
☐ 6/12
☐ 6/15
☐ 6/18
☐ 6/24
☐ 6/36
☐ 6/60
☐ LP
☐ NLP

☐ Test not completed

2. Pinhole (PH)

Tick the correct option

- a. VA R) ☐ 6/6 ☐ pt
☐ 6/7.5
☐ 6/9
☐ 6/12
☐ 6/15
☐ 6/18
☐ 6/24
☐ 6/36
☐ 6/60

- L) ☐ 6/6 ☐ pt
☐ 6/7.5
☐ 6/9
☐ 6/12
☐ 6/15
☐ 6/18
☐ 6/24
☐ 6/36
☐ 6/60

☐ Test not completed

3. Auto-refraction

- a. R)

Sphere	Cylinder	Axis
	-	°

- L)

Sphere	Cylinder	Axis
	-	°

b. **Auto-refraction-corrected distance visual acuity**

Tick the correct option

VA R) ☐ 6/6 ☐ pt
☐ 6/7.5
☐ 6/9
☐ 6/12
☐ 6/15
☐ 6/18
☐ 6/24
☐ 6/36
☐ 6/60

L) ☐ 6/6 ☐ pt
☐ 6/7.5
☐ 6/9
☐ 6/12
☐ 6/15
☐ 6/18
☐ 6/24
☐ 6/36
☐ 6/60

☐ Test not completed

4. Near Visual Acuity

a. Is the participant wearing near correction?

Tick the correct option

☐ Yes
☐ No

b. Both Eyes Open

☐ N< 48
☐ N48
☐ N20
☐ N8
☐ Test not completed

5. Trachoma grading (Indigenous only)

Tick the correct option

a. R) ☐ Absent
☐ Present

L) ☐ Absent
☐ Present

b. If present, what is the grade?

Tick the correct option

R) ☐ Trachomatous Trichiasis (TT)
☐ Corneal Opacity (CO)
☐ Test not completed

L) ☐ Trachomatous Trichiasis (TT)
☐ Corneal Opacity (CO)

6. Ocular Health

- a. Are there any lid abnormalities? Tick the correct option
 R) ☐ Absent L) ☐ Absent
 ☐ Present ☐ Present
- b. If yes, what is the abnormality? Tick the correct option
 R) ☐ Chalazion L) ☐ Chalazion
 ☐ Styel ☐ Styel
 ☐ Eyelid lesion ☐ Eyelid lesion
 ☐ Mechanical disorders ☐ Mechanical disorders
 ☐ Other _____ ☐ Other _____
- c. Is a pterygium/pterygia present? Tick the correct option
 R) ☐ Absent L) ☐ Absent
 ☐ Present ☐ Present
- ☐ Test not completed

7. Frequency Doubling Technology (FDT) Tick the correct option

- a. Have you completed a FDT test?
☐ Right
☐ Left
☐ Test not completed
- b. Have you taken a photo of the FDT results?
☐ Yes
☐ No

8. Digital Retinography System (DRS)

- a. Have you captured images for the following? Tick the correct option
- i. Anterior segment (Perform only in participants with VA<6/12)
- ☐ Right
☐ Left
☐ Test not completed
- ii. Nasal (Optic Disc)
- ☐ Right
☐ Left
☐ Test not completed

iii. Central (Macula)

- ☐ Right
- ☐ Left
- ☐ Test not completed

b. Did you obtain good quality images for **all** photographs?

- ☐ Yes (Proceed to h)
- ☐ No

c. If no, which photographs were of poor quality?

- ☐ Right Nasal (Optic Disc)
- ☐ Right Central (Macula)
- ☐ Left Nasal (Optic Disc)
- ☐ Left Central (Macula)

Note: If you have selected **no**, conduct a Van Herick Assessment.

d. What is the Van Herick grade?

- R) ☐ Grade 0
☐ Grade 1
☐ Grade 2
☐ Grade 3
☐ Grade 4

- L) ☐ Grade 0
☐ Grade 1
☐ Grade 2
☐ Grade 3
☐ Grade 4

☐ Test not completed

e. Did you instill dilating drops?

- ☐ Yes
- ☐ No (proceed to h)

f. In which eye(s) did you instill dilating drops?

- ☐ Right
- ☐ Left

g. What time did you instill the drops?

h. Did you obtain good quality images for **all** photographs?

- ☐ Yes

☐ No

i. Have you backed up all photos?

☐ Yes

☐ No

9. Intraocular Pressure

a. R) _____ mmHg

L) _____ mmHg

☐ Test not completed

10. Verbal Feedback

a. Have you provided verbal feedback?

Tick the correct option

☐ Yes

☐ No

11. Recommendation Letter

Tick the correct option

a. Is a recommendation letter required?

☐ Yes

☐ No

12. Checklist

Complete the following checklist:

ITEM	Task	Y	N	N/A	Comments
1	Consent form signed				
2	Questionnaire completed				
3	Distance VA				
4	Pinhole (Perform in participants with VA < 6/12)				
5	Auto-refraction (Conduct when VA in either one or both improves with PH)				
6	Near VA				
7	Trachoma Grading (Indigenous only)				
8	Ocular Health				

9	RE FDT				
10	LE FDT				
11	RE Macular photo				
12	LE Macular photo				
13	RE Disc photo				
14	LE Disc photo				
15	RE Anterior segment photo (Perform in participants with VA <6/12).				
16	LE Anterior segment photo (Perform in participants with VA <6/12).				
17	Backup Photographs				
18	IOP obtained				
19	Verbal Feedback				
20	Recommendation Letter				

Appendix M. Clinical examination user interface of the NEHS cloud-based database

All data pertaining to the clinical examination process were entered into the clinical examination interface of the online database during participant examinations using a touch-screen interface on Samsung Galaxy Tab S 10.5 tablet computers, including Participant ID codes, interviewer-administered general questionnaire responses, vision screening results and referral information. The database user interface allowed easy input of examination results and minimised data entry errors by using a conditional logic branching function. These logic branches ensured that options to input results for particular tests, such as pinhole and auto-refraction, were provided only under the precondition that the examiner selected that VA was $<6/12$. Similarly, logic branching was utilised to ensure that subsets of questionnaire items were only available under preconditions that previous subsets were answered in a manner that required further questioning. The clinical examination interface included a function that allowed photographs to be taken of FDT result printouts using the tablet computer camera. The photograph was uploaded to a web address, with each photograph possessing its own URL for later download. All information entered into the clinical examination interface was automatically uploaded to the cloud-based database after which it was viewable, amendable and exportable.

Log in to secure database.

Select 'Clinical Examination'.

Filter participant list by date or search participant by name
Select 'Start' to begin

Enter Participant ID.
Select 'Attended' and 'Consent'
Use touchscreen keyboard to enter examiner initials.
Select 'Next'.

Provide personal particulars:
Name, gender, age, DOB, country of birth, Indigenous status, and main language spoken at home

Select highest level of education
Enter number of years of education achieved
Select 'yes' or 'no' depending on history of stroke

Grade 8 - Understanding/Completed post graduate study

What is your total number of years of education?

_____ years

4. Stroke

Have you ever had a stroke?

☐ Y ☐ N ☐ Unsure

5. Past Ocular History

Have you ever had your eyes examined?

* Y

If yes, how long ago?

_____ years _____ months

Who did you see for your eye examination?

☐ N

Have you ever been told that you have any of the following eye conditions?

Glaucoma (high pressure in the eye)

☐ Y ☐ N ☐ Unsure

Diabetic retinopathy (diabetic eye disease)

☐ Y ☐ N ☐ Unsure

Age-related macular degeneration (loss of your central vision)

☐ Y ☐ N ☐ Unsure

Refractive error (wear glasses)

☐ Y ☐ N ☐ Unsure

Cataracts (cloudiness of the lens resulting in decreased vision)

☐ Y ☐ N ☐ Unsure

☐ Other

Have you ever had cataract surgery?

☐ Y ☐ N

Select 'Yes' or 'No' depending on whether participant's eyes have been examined.
 Enter number of years/months since examination
 Select professional title of examiner from dropdown list
 Select Y/N/Unsure for previous diagnosis of major eye conditions: glaucoma, diabetic retinopathy, age-related macular degeneration, refractive error, cataract and Other

☐ Y ☐ N ☐ Unsure

Diabetic retinopathy (diabetic eye disease)

☐ Y ☐ N ☐ Unsure

Age-related macular degeneration (loss of your central vision)

☐ Y ☐ N ☐ Unsure

Refractive error (wear glasses)

☐ Y ☐ N ☐ Unsure

Cataracts (cloudiness of the lens resulting in decreased vision)

☐ Y ☐ N ☐ Unsure

☐ Other

Have you ever had cataract surgery?

* Y

How long ago (please specify for each eye)?

☒ Right _____ years _____ months

☒ Left _____ years _____ months

☐ N

6. Diabetes and Duration

Have you been told by a doctor or nurse that you have diabetes?

* Y

If yes, at what age were you first told that you had diabetes?

Have you seen an Eye Doctor/Ophthalmologist or Optometrist for a diabetes eye check?

☐ Y ☐ N

Do you wear the following?

☐ Glasses ☐ Contact lenses ☐ Glasses and contact lenses ☐ I don't currently wear glasses or contact lenses

7. Refractive Error

Select Y or N depending on if participant has had cataract surgery
 Select 'Right' and/or 'Left' depending on which eye(s) underwent surgery
 Enter years/months since surgery
 Select Y or N depending on history of diabetes diagnosis
 If Y selected, enter age at which diagnosis occurred
 Select Y or N if participant received diabetes eye check – If Y selected, enter years since last check. If N, select reason from dropdown list.
 Select 'Next'.

NEHS_0001 26 1989-04-24

Distance Visual Acuity

VAR: _____

VAL: _____

6/6

6/6 pt

6/7.5

6/7.5 pt

6/9

6/9 pt

6/12

6/12 pt

6/15

6/15 pt

6/18

6/18 pt

6/24

6/24 pt

6/36

6/36 pt

6/60

6/60 pt

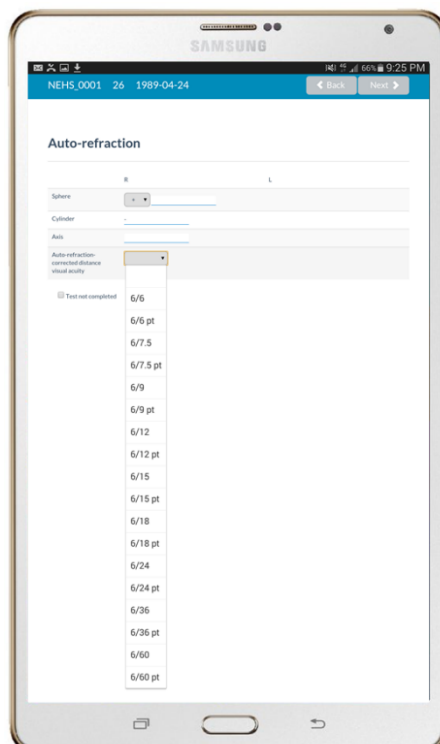
LP

NLP

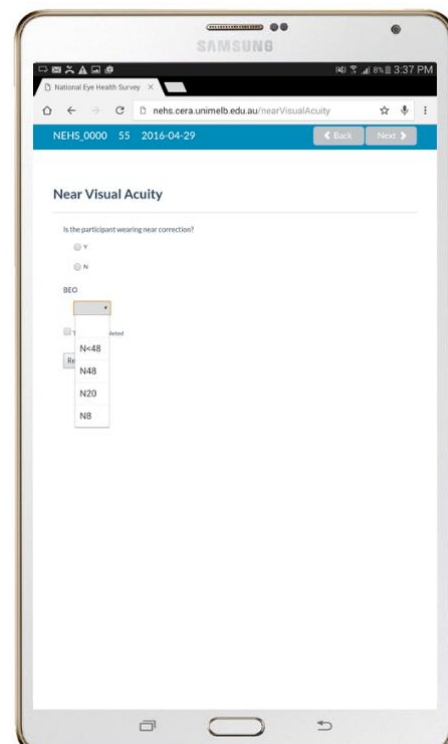
Click the dropdown list to select the presenting distance visual acuity for each eye.
 Select next.
 Click the dropdown list to select the presenting distance visual acuity for each eye.
 Select next.



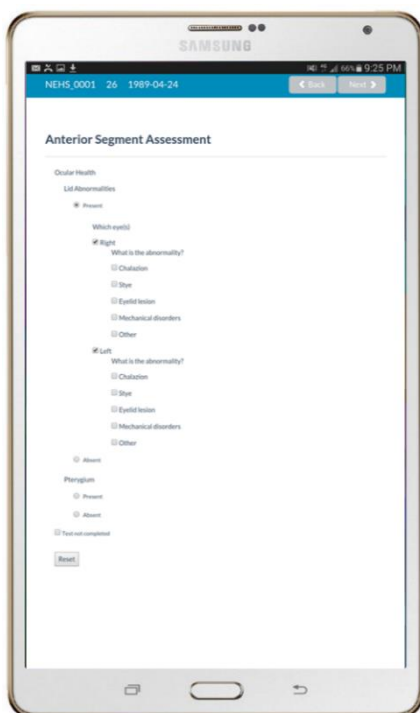
'Pinhole' page appears if visual acuity was less than 6/12 on the 'Visual Acuity' page in either or both eyes. Dropdown boxes appear for any eye with VA <6/12. Click dropdown box and select pinhole visual acuity for either or both eyes. Select 'Next'.



'Auto-refraction' page appears if visual acuity improved with pinhole testing on the 'Pinhole' page in either or both eyes. Input the spherical, cylindrical and axis readings from the auto-refractor. Click dropdown box and select the visual acuity for either or both eyes corrected by auto-refraction. Select 'Next'.



'Near Visual Acuity' page appears either after 'Distance Visual Acuity', 'Pinhole' or 'Auto-refraction' depending on conditional logic branching. Select 'Y' or 'N' depending on if participant is wearing near correction. Click dropdown list and select option for participant's near VA. Select 'Next'.



‘Anterior Segment Assessment’ page appears.

Trachoma grading appears for participants for whom ‘Y’ was selected in ‘Are you of Aboriginal or Torres Strait Islander origin?’ question.

Select ‘Absent’ or ‘Present’ depending on if trachoma is observed.

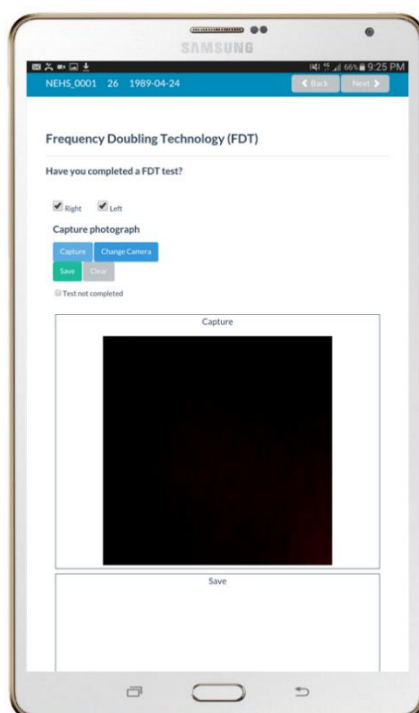
Select ‘CO’ or ‘TT’ for trachoma grade if ‘Present’ was selected.

For all participants, select “Absent” or ‘Present’ depending on if lid abnormalities are observed.

If ‘Present’ was selected, select checkboxes for observed conditions. If other is selected, use keyboard to describe.

Select ‘Present’ or ‘Absent’ if pterygium is observed. If ‘Present’ is selected, select which eyes are affected.

Select ‘Next’.



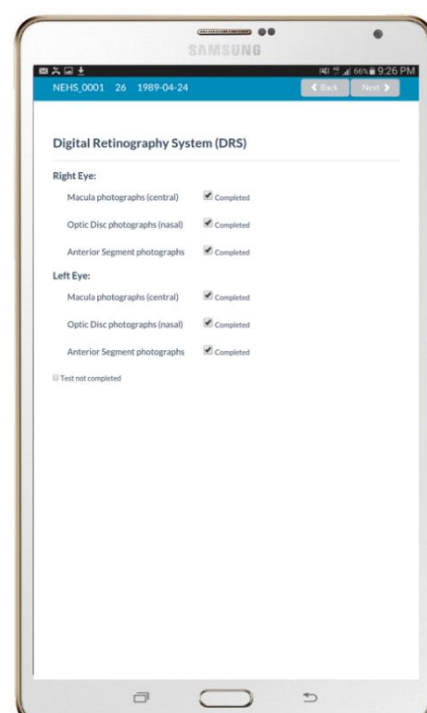
‘Frequency Doubling Technology (FDT)’ page appears.

Select ‘Right’ and/or ‘Left’ for eyes tested.

Select ‘Capture’ to activate tablet camera.

Select ‘Save’ to capture image of FDT printout. (Select ‘Capture’ again if inadequate image quality.)

Select ‘Next’.



‘Digital Retinography System (DRS)’ page appears

Checkboxes appear for macula and disc fundus photographs for both eyes

Checkboxes appear for anterior segment photographs for either or both eyes for which VA was less than 6/12

Select checkboxes for photographs that have been taken.

Select ‘Next’.

'DRS Image Quality' page appears.
 Select 'Good' if all fundus photographs are gradable.
 Select 'Poor' if any fundus photographs are ungradable.
 Select checkboxes of ungradable photographs.
 Select 'Next'.

'Dilation' page appears if 'Poor' was selected for DRS image quality.
 Dropdown lists appear for Van Herick grades for either or both eyes if their selection boxes were ticked for poor image quality.
 Select Van Herick grade
 Select 'Y' for 'Will dilation be performed?' if 'Grade 3' or 'Grade 4' were selected.
 Select 'Next'.

'Intraocular Pressure' page appears.
 Use touch-screen keyboard to enter intraocular pressure readings.
 Select 'Next'.

'Verbal Feedback' page appears.
Select 'Completed' if feedback was provided.
Select 'Next'.

'Recommendation Letter' page appears.
Select 'Y' if a recommendation for referral is required.
Select 'N' if no recommendation for referral is required.

ITEM	Task	Y	N	N/A	Comments
1	Participant Name	☒	☐	☐	
2	Questionnaire	☒	☐	☐	
3	Distance Visual Acuity	☒	☐	☐	
4	Pinhole	☒	☐	☐	
5	Auto-refraction	☒	☐	☐	
6	Near Visual Acuity	☒	☐	☐	
7	Anterior Segment Assessment	☒	☐	☐	
8	FDI	☒	☐	☐	
9	DRS	☒	☐	☐	
10	Anterior Segment photographs	☒	☐	☐	
11	DRS Image Quality 1	☒	☐	☐	
12	Dilation	☐	☒	☐	
13	DRS Image Quality 2	☐	☒	☐	
14	Backup Photographs	☒	☐	☐	
15	ICP	☒	☐	☐	
16	Verbal Feedback	☒	☐	☐	
17	Recommendation Letter	☒	☐	☐	

'Checklist' page appears.
Check that all relevant items have been completed.
Select 'Next'.

'Certificate of Participation' page appears.
Select 'Provided' if a certificate of participation was provided to the participant.
Select 'Finish'

Appendix N. Data management

Online tablet-based database

All data collected during the recruitment and clinical examination processes were recorded, stored, backed-up, extracted, cleaned and analysed using a standardised data management protocol. All data were entered into the specialised online, cloud-based database using tablet computers (Samsung Galaxy Tab S 10.5, Samsung).

The database interface was composed of three main user interfaces:

1. Recruitment interface

All data collected during participant recruitment were entered into the database through this interface

2. Clinical examination interface

All data collected during clinical examinations were entered into the database through this interface

3. Administration interface

All data modifications and data exports were conducted through this interface

Hardcopies

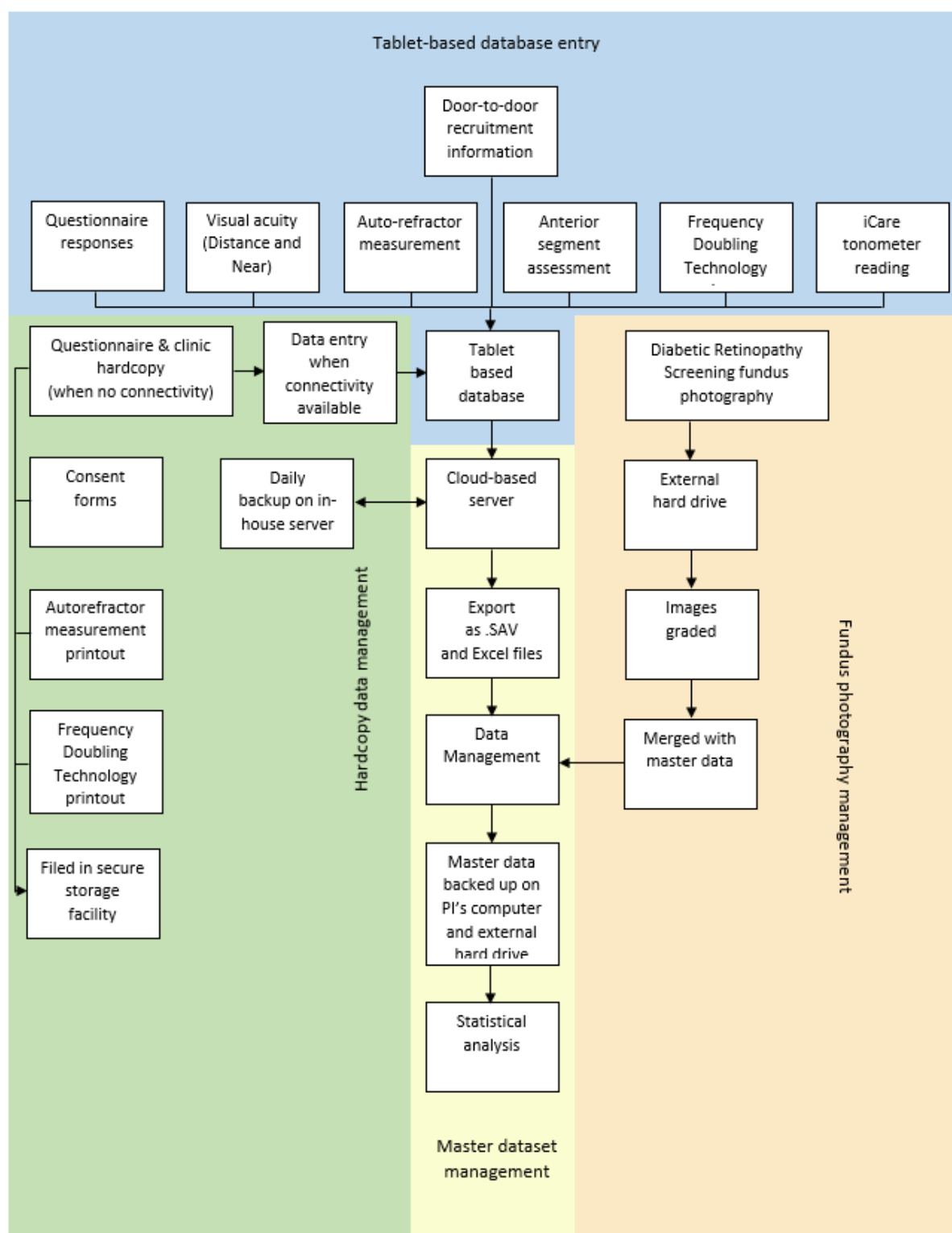
Hardcopy questionnaires and examination forms were taken to all clinics for use during data network inaccessibility. Hardcopy data obtained from each participant including: consent forms, auto-refraction result printouts, FDT printouts, and questionnaire and examination hardcopies (where applicable) were securely stored in a locked filing cabinet at CERA that was only accessible to key study personnel.

Online database data backup and export

All data uploaded to the NEHS online cloud-based database were backed up every 24 hours onto a local server housed at CERA. Data were exported as SAV files from the administration interface of the NEHS database weekly and cleaned. Cleaned data were merged with an existing master dataset and stored.

Management of Digital Retinography System camera photographs

A folder was created for each NEHS participant on the internal DRS hard drive, labelled with the participant ID code, date of birth and gender. All fundus and anterior segment photographs were automatically saved into each participant's folder. In addition, all photographs were manually saved onto an external portable hard drive connected to the DRS. DRS photographs were then transferred to the retinal image grading centre at CERA for retinal grading. Grading data were then merged with the master dataset for analysis.



Appendix O. NEHS certificate of participation

*This certificate of participation
is awarded to*

*In recognition of his/her valuable participation in the
National Eye Health Survey*


Date


Signature

Appendix P. National Eye Health Survey Referral Letter

Date: _____

Dear _____,

As you may be aware, the Centre for Eye Research Australia (CERA) and Vision2020 Australia, in conjunction with participating state and national organisations, is conducting a National Eye Health Survey. The survey is designed to assess the prevalence and main causes of vision impairment and eye diseases, as well as barriers to health and the impact of vision impairment in Indigenous Australians over the age of 40 and non-Indigenous Australians over the age of 50.

_____ participated in the National Eye Health Survey today. During the eye examination, we detected a *potential* abnormality, and are therefore referring the participant to you for further assessment.

For this participant:

Centre for Eye
Research Australia
ABN 72 076 481
984

32 Gisborne Street
East Melbourne,
VIC 3002

Postal Address:
Locked Bag 8
East Melbourne
VIC 8002, Australia

Tel: +61
Fax: +61

www.cera.org.au



Presenting Visual Acuity

Right Eye: _____

Left Eye: _____

Pinhole Visual Acuity

Right Eye: _____

Left Eye: _____

Auto-refraction Visual Acuity

Right Eye: _____

Left Eye: _____

Right eye	Left eye
☐	☐
☐	☐
☐	☐
☐	☐
☐	☐
☐	☐
☐	☐

An abnormality was detected on FDT (visual field instrument)

There was evidence of trachoma _____

There was evidence of retinopathy _____

There was evidence of high intra-ocular pressure _____

There was evidence of pathology in the anterior segment _____

Other _____

If you have any queries or concerns, please do not hesitate to contact the study team on

Thank you in anticipation of your cooperation.

Sincerely,

Dr Mohamed Dirani (Principal Investigator)

Appendix Q. Participant referral protocol

Test	Findings	Timing of Referral
Visual acuity	Presenting BCVA <6/12 in either eye	1-2/12 (unless longstanding and existing eye care) Urgency dictated by onset and severity of vision loss (Within 1/52 if VA <6/12 OU and participant is driving)
FDT	≥2 points missed in either eye (for best result)	1-2/12
Retinal photos	• DR	• Haemorrhages & exudates, refer in 1/12 if eye health care provider has not been seen in the last 3/12 • Central exudates & reduced vision (macular oedema) = 1/52 • Any proliferative retinopathy = 1/52 NB: At least yearly checks for <u>all</u> with DM (guidelines recommend review around 6/12)
	• AMD	• Large drusen, pigment change or atrophy = 1/12 • Any sub-retinal blood in macula = 1-2/7 • Any new symptoms (distortion, scotoma, vision loss) = 1-2/7
	• Glaucoma (≥0.4 C:D)	1/12 (unless remains under care of eye health care provider in last 6/12 and has follow up planned)
	• Pigmented lesion (naevus or choroidal melanoma)	Naevus = 1/12 Melanoma = 1/52
	• Vitreous haemorrhage	Same day
	• Retinal vascular occlusion	Same day
	• Retinal tear or detachment	Same day
Trachoma grading	TT/CO	1/12
Unilateral red eye	Especially if acute and painful; photophobic	Same day (exclude corneal opacity and AACG)
IOP	IOP>21mmHg (non-urgent) IOP>30mmHg (urgent) [#]	2/52 (sooner if advanced cupping >0.8) Same day
Van Herrick	≤Grade 2 in either eye	1/12 (check for symptoms of iACG – urgent referral if so)

Other	Any other issue the examiner feels should be addressed by an eye care practitioner, e.g.:	
	Symptoms:	
	• Flashing lights (persistent , recent onset)	Same day
	• Transient visual obscuration (amaurosis) [@]	Same day
	• Recent headaches (if severe; or temporal ache) [@]	1-2/7
	• Red colour desaturation	1-2/7
	• Photophobia (marked light sensitivity)	1-2/7
	• Recent history of significant eye trauma	1-2/7
	Signs:	
	• Reddening of the peri-ocular skin (cellulitis)	Same day
	Urgent if double vision; reduced motility or proptosis	
	• Corneal ulcers or opacification;	Same day
	• Lid lesions	If raised, irregular lid margin & vascularised, 1/52 If longstanding, regular review at eye health care provider
	• Pterygium encroaching visual axis;	VA >6/12 = 1/12 VA <6/12 = 1/52 (if participant driving and VA <6/12 OU)
	• Significant cataract	1/12
	• Conjunctival lesions;	If raised & vascularised, 1/52 If longstanding, regular review at eye health care provider
	Other issues on history:	
	• Using unspecified eye drops/naturopathy eye drops etc;	1/12
	• Strong family history of eye disease	1/12

Acute glaucoma: if marked elevation of IOP and other symptoms and signs of acute angle closure glaucoma the patient needs to be seen by an eye health professional **immediately** as any delay in treatment could result in permanent loss of vision. **Symptoms may include:** blurred vision; seeing “haloes around lights”; a dull ache around the eye/orbit or unilateral headache; nausea; vomiting. **Signs include:** a red eye (conjunctival injection); corneal oedema (glassy or cloudy appearance); pupil often mid-dilated and non-reactive to light; anterior chamber appears shallow (peripheral iris close to the endothelium). **This warrants a phone call for referral.**

@ Any history of transient visual disturbance (blacking or greying out of vision) in a person over the age of 50; particularly in the setting of ache on the side of the head, temples tender to touch or cramping in the jaw while chewing food should be regarded as an eye emergency – these are warning signs for temporal/giant cell arteritis. Often vision is reduced in one eye; acutely the optic disc may appear pale and swollen, however this does not need to be present to make a presumptive diagnosis of this condition. The patient needs urgent review (ie same day) by their GP or the local hospital for blood tests and anti-inflammatory steroid treatment. This condition is usually managed by ophthalmologists, so it may be advisable to call the local ophthalmologist. Missed giant cell arteritis can cause profound irreversible bilateral blindness. You need to make it clear in the referral that this diagnosis needs to be excluded. **This warrants a phone call for referral.**

Appendix R. Protocols for determining the cause of vision impairment and blindness

The main cause of vision loss was determined by two independent ophthalmologists and disagreements were adjudicated by a third ophthalmologist. Data pertaining to participants' age, gender and Indigenous status were provided to assist with disease attribution. Uncorrected refractive error was assigned as the main cause of vision loss when distance visual acuity improved to $\geq 6/12$ in one or both eyes with pinhole or auto-refraction. For all other cases, ophthalmologists reviewed questionnaire responses and examination results to identify the condition most likely to account for vision loss. When multiple disorders were identified, the condition with the most clinically significant influence was determined to be the primary cause. For cases in which a single primary cause was not identifiable, vision loss was attributed to combined mechanisms. Cases of vision loss were deemed 'not determinable' if no cause of vision loss was identified. Protocols for identifying and grading the five major causes of vision loss are presented below:

Refractive error

Vision loss was attributed to refractive error when VA improved to $\geq 6/12$ on pinhole testing or following refraction.

Cataract

Anterior segment images were taken in all participants with PVA $< 6/12$. Two experienced graders independently assessed digital anterior segment photographs and posterior segment photographs to categorise participants into one of three groups; no cataract, probable cataract or definite cataract. Both graders reported high levels of inter-grader reliability (85%) and intra-grader reliability (94% and 96%, respectively). When the grading differed, the photographs were adjudicated by an ophthalmologist. A high sensitivity and specificity of detecting visually significant cataract as a cause of VI with a non-mydratic fundus camera compared with dilated slit-lamp grading has been reported in the literature.³⁸¹ Where photographs were unavailable,

a clinical grade was assigned based on anterior segment examination by a trained clinician using a hand-held slit lamp.

Diabetic retinopathy

The following protocol was published as it appears below in “Keel S, Xie J, Foreman J, et al. The Prevalence of Diabetic Retinopathy in Australian Adults with Self-Reported Diabetes: The National Eye Health Survey. *Ophthalmology* 2017”³⁴⁰

Trained retinal graders from the Centre for Eye Research Australia masked to the identity and clinical characteristics of study participants graded fundus photographs for retinopathy and other retinal disease. The Early Treatment Diabetic Retinopathy Study (ETDRS)³⁸² grading standards were used to establish the severity of DR lesions, including: microaneurysms, haemorrhages, hard exudates, venous beading, intraretinal microvascular abnormalities, cotton-wool spots, neovascularisation, as well as preretinal or vitreous haemorrhage. A retinopathy severity score was assigned according to the modified Airlie House Classification, described in detail elsewhere.³⁸³ In brief, DR was categorised as minimal non-proliferative DR (NPDR; level 15-20), mild NPDR (level 31), moderate NPDR (level 41), severe NPDR (level 51), or proliferative retinopathy (PDR; level more than 63). Criteria used for the diagnosis of macular oedema were hard exudates in the presence of microaneurysms and/or intraretinal haemorrhages within one disc diameter of the foveal centre, or the presence of focal photocoagulation scars in the macular area. Clinically significant macular oedema (CSME) was considered present when oedema was within 500 microns of the foveal centre or if focal photocoagulation scars were present in the macular area. Vision-threatening diabetic retinopathy (VTDR) was defined as the presence of severe NPDR, PDR or CSME based on the Eye Diseases Prevalence Research Group definition.³⁸⁴ The DR grade was assigned on the basis of the worse of the two eyes. If an eye was ungradable, the grade for the fellow eye was

assigned. Treatment coverage rates were calculated as a proportion of participants with PDR and/or CSME who had evidence of retinal scatter/focal laser treatment on retinal images.

Age-related macular degeneration

The following protocol was published as it appears below in “Keel S, Xie J, Foreman J, et al. Prevalence of Age-Related Macular Degeneration in Australia: The Australian National Eye Health Survey. *JAMA Ophthalmol* 2017;135(11):1242-9.”

Retinal images were deemed to be gradable for AMD if field 2 was present and two-thirds of the macular area was visible. A transparent grid was placed over field 2 of each eye and centred on the fovea.³⁸⁵ The grid included 3 concentric circles with radii of 500, 1500, and 3000 μm and had 4 radial lines that divided the retinal image into superior, inferior, nasal, and temporal quadrants. Any AMD lesions outside the margins of this grid were excluded from analysis. Age-related macular degeneration was graded according to the Beckman classification system as early, intermediate, or late AMD.³⁸⁶ In brief, early AMD was defined as the presence of medium drusen 63 to 125 μm in diameter. Intermediate AMD was characterized by large drusen greater than 125 μm in diameter and/or definite AMD pigmentary abnormalities, defined as any definite hyperpigmentary or hypopigmentary abnormalities associated with medium or large drusen but not associated with known disease entities. Late AMD was defined as neovascular AMD or atrophic AMD. Neovascular AMD consisted of retinal pigment epithelium detachment or intraretinal, subretinal, or sub-retinal pigment epithelium haemorrhages or subretinal fibrous scars. Atrophic AMD was defined as the presence of visible choroidal vessels and a central zone of retinal pigment epithelium atrophy 175 μm or larger in diameter. The AMD grade was assigned on the basis of the worse of the 2 eyes. If an eye was ungradable, the grade for the fellow eye was assigned. Two independent ophthalmologists reviewed relevant questionnaire and clinical data to determine the main cause of vision

impairment or blindness. For cases in which a single primary cause was not identifiable, vision loss was attributed to combined mechanisms. Any disagreements were adjudicated by a third senior ophthalmologist.

Glaucoma

An experienced grader from the Centre for Eye Research Australia, masked to the identity and clinical characteristics of study participants, graded each image for possible glaucomatous signs, including vertical cup to disc ratio (CDR) >0.6 , CDR asymmetry of >0.2 , disc haemorrhage, disc rim thinning, cup notching and nerve fibre layer defects. Following this, records of those persons who were regarded as glaucoma suspects were compiled and two fellowship-trained glaucoma specialists independently assigned a diagnosis ranked on a scale of certainty; none, possible, probable, or definite glaucoma. Each expert used their own clinical judgement to classify each case and no specific criteria were used. Any cases with a difference of two or more steps were adjudicated by a third senior glaucoma specialist. Ocular hypertension (OHT) was defined as an IOP greater than 21 mmHg in either eye after excluding cases graded as probable or definite glaucoma. The main cause of vision loss was determined by two independent ophthalmologists and disagreements were adjudicated by a third ophthalmologist.

Appendix S. Publication 11. Refractive error, through the lens of the patient

The NEHS research group was invited by the journal *Clinical and Experimental Ophthalmology* to write an editorial piece on the topic of the treatment of refractive error in Australia, with a discussion about the impact of refractive error and its treatment on the quality of life (QoL) of the individual. This piece was intended, in part, to be a commentary on an original article published in that edition of the Journal that utilised a qualitative approach to identify QoL issues in people that have had their refractive error corrected. This publication also provides insight into why uncorrected refractive error remains the prevalent despite its treatability. This editorial was published on the 10th of October 2017.



Editorial

Refractive error, through the lens of the patient

More than 150 million people suffer from uncorrected distance refractive error, and over 500 million have uncorrected presbyopia.^{1,2} Refractive error remains the leading cause of vision loss globally, accounting for 53% of all vision impairment and 21% of all blindness.¹ According to the World Health Organization (WHO), the annual global economic loss resulting from refractive vision impairment may be as high as \$427 billion.³ As half of the world's population is expected to be myopic by 2050, the overall economic, social and personal burden of refractive error is likely to increase dramatically.⁴ Despite the global magnitude of this problem, refractive error is often not given the same urgency and priority as other vision disorders, owing partly because it is so common and, in theory at least, so readily corrected.⁵ Nonetheless, refractive error can have a profound impact on quality of life (QoL) and sense of well-being.^{6–8} It is important for the clinician to understanding the impact refractive error has on their patients' QoL. It also is important for policy makers to understand this and to allocate resources for refractive services and so reduce the prevalence of avoidable vision loss and improve the quality of life.

The impact of uncorrected refractive error on QoL and functionality has been well established. Severe vision impairment and blindness due to uncorrected refractive error carry disability weightings that are comparable to severe heart failure.⁹ Multiple studies have shown that those with uncorrected refractive have poorer QoL outcomes than those whose vision has been adequately corrected.^{10–12} These effects include poorer perception of one's own visual health, general physical health, mental health, confidence, happiness, and occupational and social functionality.

In the current issue of this Journal, a study by Kandel *et al.*¹³ provides new insight into the effects of refractive error has on QoL. This Australian study breaks new ground as it investigates the impact on QoL in people whose refractive error is already corrected; all participants had corrected presenting visual acuity $\geq 6/12$. Further, this study used a qualitative approach rather than quantitative measures. The authors point out the often stark disparity between the clinician's perception of an acceptable

outcome of 6/6 vision with correction and the patient's perception of a good outcome.

The well-being of the patient must be the ultimate outcome in any clinical setting. It is important to go beyond the recommendation for spectacles, contact lenses or laser surgery and to understand the complex contextual, personal, experiential and psychosocial outcomes that the patient values. Indeed, understanding and addressing these personal factors are likely to improve uptake to services and patient compliance.

Important QoL measures that were identified by Kandel *et al.* included concern about the condition itself, cosmetic issues associated with spectacle use, fear for their own safety, continual visual and non-visual problems such as peripheral visual issues, distorted vision, blurring, lack of confidence in reading and driving, and pain and dryness of the eyes after laser surgery or contact lenses. Other issues that were reported related to the use of glasses or contact lenses in certain work places and in leisure activities such as swimming and sports. General inconvenience and difficulty in handling and cleaning glasses and contact lenses were frequently reported. Many also reported the financial imposition of recurring the costs of spectacles and contact lenses, and also the cost of laser surgery. Qualitative studies like this one are important as they illuminate the actual experience of patients, rather than reducing these issues and the human experience to bald statistics. They cast some light too as to why uncorrected refractive error remains the leading cause of vision impairment. Although the study by Kandel *et al.* provides insight into the issues faced by adults with properly corrected refractive error, further research is required on the experience of children.

The recent National Eye Health Survey (NEHS) found that one in five Indigenous adults aged 40 years or older had distant vision loss from uncorrected or under-corrected refractive error, compared to just 1 in 15 in the non-Indigenous population.¹⁴ This corresponds to 6.7% of Indigenous adults with vision loss from uncorrected refractive.¹⁴

Uncorrected refractive error makes a major contributor to the gap in Indigenous eye health and its detrimental effects on QoL and well-being undoubtedly

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permeate into the social and economic lives of affected Indigenous Australians. Functional vision is required for full participation in educational, vocational and economic activities, and without addressing the problem of uncorrected refractive error in Indigenous communities, these pervasive effects will continue. It is therefore critical that Australia fully addresses the need for the correction of refractive error for Indigenous Australians. The Roadmap to Close the Gap for Vision¹⁵ documents a list of interlocked improvements that are needed. They include well-coordinated regional services, providing eye care in Aboriginal Medical Services, outreach services provided to meet population-based needs, nationally consistent low-cost spectacle services in each jurisdiction,¹⁶ cost certainty of services, and regular monitoring and evaluation.

Given these findings there is a clear need for us to focus more attention on the correction of refractive error, both as clinicians and as health policy advocates. We need to address patients' needs both individually and on a population basis. Remember, vision loss from uncorrected refractive error is something we can essentially correct right away, but we have to be mindful of the patients' perspective too.

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