Vision impairment in Aboriginal and Torres Strait Islander peoples: a toolkit to assess prevalence and impact

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Vision Impairment in Aboriginal and Torres Strait Islander Peoples:

A toolkit to assess prevalence and impact

A thesis submitted in fulfilment for the requirements for the degree of Doctor of Philosophy

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December 2009

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Originality Statement

'I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at UNSW or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by others, with whom I have worked at UNSW or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic ex ion is acknowledged.'

Signed: .....

Abstract

The eye health of Aboriginal and Torres Strait Islander peoples, like many other health outcomes, is far worse than that of non-Indigenous Australians. Accordingly, there is a great need for current epidemiological data on the prevalence, causes and impact of vision impairment. This thesis describes the development and validity testing of a 'Toolkit' to assist in addressing this need.

The Toolkit consists of two components: a) the Rapid Assessment of Blindness and Vision Impairment in Indigenous Communities Protocol (RABVIIC), a methodology designed to detect the common causes of vision loss and tested to ensure validity and cultural acceptability; and b) the Impact of Vision Impairment: Indigenous Peoples Questionnaire (IVI_I), a vision-related quality of life instrument modified for cultural appropriateness and evaluated for psychometric acceptability.

Out of 135 eligible participants, 129 (95.5%) were examined with the RABVIIC and 128 (94.8%) were examined by optometrists. The assigning of cause of vision impairment was very similar for both methods. Vision impairment from non-refractive causes was detected with 75% sensitivity and 98% specificity by the RABVIIC. Vision impairment from refractive error was detected with 72% sensitivity and 99% specificity.

The IVI_I demonstrated internal consistency (Cronbach's α=0.96), cultural appropriateness and discriminated between participants with normal vision from those with vision impairment (U=1231.0, p<.001). Mild vision impairment (<6/12 to 6/18 in the better eye) was associated with difficulty or concern with many activities of daily life.

The RABVIIC is a valid, rapid methodology able to detect vision impairment due to refractive error, diabetic retinopathy, cataract, glaucoma, and trachoma in Aboriginal and Torres Strait Islander populations and was the methodology used by the National Indigenous Eye Health Survey.

The IVI_I has shown that significant improvements in vision-related quality of life may be achievable through correction of refractive errors, cataract surgery or low vision rehabilitation. Also, the IVI_I tool will be useful for clinical practice to evaluate outcomes of intervention programs or rehabilitation.

The (ICEE) Toolkit presented in this thesis will help to design and monitor intervention strategies that will help alleviate the excess blindness and vision impairment in Aboriginal and Torres Strait Islander peoples.

Statement of contribution

The research presented in this thesis used data drawn from three primary sources: the Rapid Assessment of Avoidable Blindness and Vision Impairment in Indigenous Communities (RABVIIC) study conducted in Northern NSW, the National Indigenous Eye Health Survey (NIEHS) conducted Australia wide, and from International Centre for Eyecare Education (ICEE) clinics around NSW.

At the outset of this project the concept of a pilot study for the NIEHS was conceived by Professor Jill Keeffe and Professor Hugh Taylor and then further developed by Professor Brien Holden, Professor Brian Layland and myself. Eye examinations were performed by ICEE optometrists and Ralph Green from the Optometrists Association Australia (Victoria). I was responsible for all other aspects of the pilot study, including ethics approval, training, data collection, data entry and analysis.

Tomer Semesh, Sarah Fox and Anna-Lena Arnold from the Centre for Eye Research Australia were responsible for coordinating the NIEHS including obtaining ethics approvals and coordinating site visits. Nina Tahhan, Mitasha Marolia from ICEE and I coordinated the NSW sites. I was primary coordinator for two NSW sites and assisted with others. I was also site coordinator for two additional NIEHS study sites (Northern Territory and Western Australia) and was a team member for a Victorian site.

IVI questionnaire data was collected from a variety of sources.

I was responsible for all data checking and data entry. The databases used in this research were developed by me using Microsoft Access. I performed all data analysis using SPSS (SPSS Version 17 SPSS Inc., Chicago IL).

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awesome. My final and most profound thanks go to my parents for giving me so much encouragement, support and love.

Abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
AEHCs	Aboriginal Eye Health Coordinator
AHMRC	Aboriginal Health and Medical Research Council
AHSQx	Adult Health Services Questionnaire
AHWs	Aboriginal Health Workers
AMD	Age-related Macular Degeneration
AMS	Aboriginal Medical Service
ARIA	Accessibility and Remoteness Index of Australia
ARMD	Age Related Macular Degeneration
BCVA	Best Corrected Visual Acuity
BDR	Background diabetic retinopathy
BMES	Blue Mountains Eye Study
CCDs	Census Collection Districts
CERA	Centre for Eye Research Australia
CHSQx	Children's Health Services Questionnaire
CRC	Cooperative Research Centre
CSMO	Clinically significant macular oedema
DR	Diabetic retinopathy
ECP	Eye Care Professional
EDTRS	Early Treatment Diabetic Retinopathy Study
EFA	Exploratory Factor Analysis
FDT	Frequency Doubling Technology
HFA	Humphrey Field Analyser
HRQOL	Health-Related Quality of Life
HSQX	Health Services Questionnaire
ICD	International Statistical Classification of Diseases and Related Health Problems
ICEE	International Centre for Eyecare Education
ICF	Classification of Functioning
IVI	Impact of Vision Impairment
IVI_A	Impact of Vision Impairment : Australia
IVI_I	Impact of Vision Impairment : Indigenous
IVI_M	Impact of Vision Impairment : Melanesia
KMO	Kaiser-Meyer-Olkin
KRDRS	Katherine Region Diabetic Retinopathy Study
L	Left
NACCHO	National Aboriginal Community Controlled Health Organisation
NAHS	National Aboriginal Health Strategy
NATSIEHP	National Aboriginal and Torres Strait Islander Eye Health Program
NATSIEHS	National Aboriginal and Torres Strait Islander Eye Health Service
NATSIHSA	National Aboriginal and Torres Strait Islander Health Survey Australia
NEI	National Eye Institute
NEIVFQ	National Eye Institute Visual Functioning Questionnaire
NHMRC	Nation Health and Medical Research Council
NIEHS	National Indigenous Eye Health Survey
NLR	Negative likelihood ratio
NPDR	Non-proliferative diabetic retinopathy
NPV	Negative predictive value
NSW	New South Wales
NTEHP	National Trachoma and Eye Health Program
NTSRU	National Trachoma Surveillance and Reporting Unit

OATSIH	Office of Aboriginal and Torres Strait Islander Health
PDR	Proliferative diabetic retinopathy
PLR	Positive likelihood ratio
PPV	positive predictive value
QOL	Quality of Life
R	Right
RAAB	Rapid Assessment of Avoidable Blindness
RABVIIC	Rapid Assessment of Blindness and Vision Impairment in Indigenous Communities
RACO	Royal Australian College of Ophthalmologists
RACSS	Rapid Survey of Cataract Surgical Services
RE	Refractive Error
RetVIC	Retinal Vascular Imaging Centre
SAEHP	South Australian Eye Health Program
SAFE	Surgery, Antibiotics, Facial Cleanliness and Environment.
SD	Standard Deviation
SEE	Salisbury Eye Evaluation
SPR	Standarised Prevalence Ratio
TVI	The Vision Initiative
URE	Uncorrected Refractive Error
VA	Visual acuity
VI	Vision Impairment
VIHEC	Vision CRC and Institute for Eye Research Human Ethics Committee
VIP	Visual Impairment Project
Vision CRC	Vision Cooperative Research Centre
VRQOL	Vision-related Quality of Life
WA	Western Australia
WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of Life Group

Original publications and presentations related to this project

Oral Presentations

Burnett, A. *Avoidable Blindness in Aboriginal Communities* in 38th Public Health Association of Australia Annual Conference. 2007. Alice Springs.

Burnett, A., *National Indigenous Eye Health Survey: A Pilot Study to validate a rapid methodology*, in IAPB 8th General Assembly. 2008: Buenos Aires.

Poster Presentations

Burnett, A., B. Layland and B. Holden, *Determining the need for vision and eye health services for Aboriginal people in Australia*, in World Refractive Error Congress. 2007, Durban, South Africa.

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Chapter 1 Introduction

1.1 Aboriginal and Torres Strait Islander eye health

Despite progress in improving eye and general health nationally, Aboriginal and Torres Strait Islander peoples are more likely than non-Aboriginal and Torres Strait Islander Australians to have eye health conditions that could be readily prevented or treated.[1-3] Prior to the National Indigenous Eye Health Survey (NIEHS) in 2008, there has been little research into the extent and nature of barriers to Aboriginal and Torres Strait Islander eye health care or the effectiveness of programs to improve access to eye health services, although the importance of culturally appropriate health services has been recognised.

Blindness and vision impairment are additional burdens for individuals, families and communities already challenged with social, health and economic disadvantage. Accessible, appropriate and affordable community-based eye and vision care services delivered to Aboriginal and Torres Strait Islander Australians through Aboriginal community-controlled health centres can help to address these issues. Evidence-based planning can overcome many of the physical and cultural barriers to health service delivery and meet needs with appropriate and sustainable systems for blindness prevention and eye care services.

Prior to 2008, there have been previous surveys and reviews of the eye health of Aboriginal and Torres Strait Islander peoples in Australia which made important recommendations to improve the eye health and vision status of Aboriginal peoples.[2, 4-5] However, Aboriginal and Torres Strait Islander eye health still remains poor, its determinants are under-researched and there has been a lack of current epidemiological data pertaining to the prevalence and causes of vision impairment in Aboriginal and Torres Strait Islander peoples.

Better quality epidemiological data and specific knowledge about the health service barriers is needed on local, regional or national levels to assess eye care needs in

Aboriginal regions and communities. Sound epidemiological studies of eye and vision problems among Aboriginal peoples are required to direct and evaluate appropriate public health and service responses.[2, 6] In order to undertake these studies, sensitive and specific culturally appropriate tools and instruments are required.

1.2 Rapid Assessments

National population-based surveys of eye health are expensive, time-consuming and complicated exercises as large samples are required to determine the prevalence of less common eye conditions that cause vision loss. The Rapid Assessment model of eye health and surgical services has been developed as a simple and rapid survey methodology that uses epidemiologically sound systematic random cluster sampling to collect data on the age group most affected. Initially developed to assess cataract surgical coverage, rapid assessment methodologies have since been utilised to assess avoidable blindness and trachoma in many countries (discussed further in section 2.7.2).

The Rapid Assessment of Avoidable Blindness (RAAB) methodology has been used extensively throughout the world to identify the prevalence of common causes of blindness and vision impairment. RAABs do not, however, include screening techniques for specific posterior-segment conditions such as diabetic retinopathy or glaucoma that can be conducted primarily by non-specialist staff. And they do not usually include assessment for trachoma. As Aboriginal peoples have much higher rates of diabetes and a much younger age of onset than non-Aboriginal Australians,[7-8] there is a great need to determine the extent of retinopathy due to diabetes. The anticipated global diabetes pandemic[9] will also result in a greater need for rapid evaluations of vision impairment due to retinopathies.

1.3 Vision-related quality of life

Quality of Life (QOL) is an important measure to determine the impact of disease and interventions. Vision Impairment has been shown to have negative effects on Health-Related Quality of Life (HRQOL) and a significant impact on daily functioning

(discussed further in section 2.8.2). Many studies have developed instruments to measure both disease specific and generic vision-related HRQOL.

Disease specific measurement instruments play an integral role in assessing the level to which vision impairment restricts participation in daily living and QOL. The Impact of Vision Impairment (IVI) questionnaire is a tool designed in Australia to assess how vision impairment restricts participating in daily living and affects QOL. The IVI has been validity tested in Australia, covers a range of issues, and has good discriminative ability, reliability and relevance.[10-15]

1.4 Terminology

In this research reference is to 'Aboriginal peoples', 'Torres Strait Islanders' or 'Aboriginal and Torres Strait Islander peoples' as the traditional owners of Australia and the islands of the Torres Strait. The term 'Indigenous' is generally avoided as it is not specific and some Aboriginal people feel the term diminishes their Aboriginality.[16] However, it has been necessary to use the term when reporting previous work and when referring to the impact of vision impairment questionnaire developed for use in Aboriginal and Torres Strait Islander populations.

National statistics and reports include Aboriginal and Torres Strait Islander peoples, however, the bulk of this research was with Aboriginal peoples from northwest New South Wales and did not include any Torres Strait Islander peoples.

1.5 Researching Aboriginal Health

When performing epidemiological research with Aboriginal and Torres Strait Islander peoples it is important to appreciate how the historical consequences of colonisation in Australia have resulted in negative experiences for Aboriginal and Torres Strait Islander research participants.[17] Although health research has contributed to improving health outcomes in many contexts, research itself has been implicated in the lack of improvement in Aboriginal and Torres Strait Islander health.[18]

It is also important to understand the cultural contexts from which the broader concepts of health and health care arise. Aboriginal and Torres Strait Islander peoples view health in a broad sense, which includes consideration of the physical, cultural and spiritual components of wellbeing.[19]

The 1989 *National Aboriginal Health Strategy* states that:

> *"Health to Aboriginal peoples is a matter of determining all aspects of their life, including control over their physical environment, of dignity, or community self-esteem, and of justice. It is not merely a matter of the provision of doctors, hospitals, medicines or the absence of disease and incapacity."*[20]

In the last two decades many documents, frameworks and guidelines have been developed to assist researchers as a result of the recognised need to improve the performance and accountability of Aboriginal and Torres Strait Islander health research. [17, 21-22]

Understanding the relationship between these guidelines and meeting the communities need in conducting effective research were fundamental aspects in the development of this research.

1.6 Study purpose

This study will provide a toolkit, the 'ICEE Toolkit', to assess the prevalence and impact of vision impairment in Aboriginal and Torres Strait Islander communities. The notion of a 'toolkit' or package of instruments in population-based health studies is not new and has been used in previous significant population-based studies of eye health such as the Blue Mountains Eye Study (BMES),[23-24] the Visual Impairment Project (VIP)[25-26] and the Salisbury Eye Evaluation (SEE).[27] The purpose of this study is to develop the ICEE Toolkit that will be comprised of:

1) A 'rapid assessment' method designed to determine the prevalence and leading causes of vision impairment and avoidable blindness in Aboriginal and Torres Strait Islander populations. The method consists of eye examination procedures and instruments in order to study the presence of eye disease,

causes of vision impairment, barriers to services, attitudes towards and knowledge of eye health services in Aboriginal and Torres Strait Islander populations in Australia.

2) An instrument designed to evaluate the impact of vision impairment in Aboriginal and Torres Strait Islander communities.

Evidence resulting from this research will assist in providing the evidence needed to plan eye care service delivery in urban, rural and remote areas of Australia.

1.6.1 Aim

- To develop the ICEE Toolkit to assess the prevalence and impact of vision impairment in Aboriginal and Torres Strait Islander peoples

1.6.2 Objectives

- To conduct a pilot study to test protocols and procedures, all aspects of the questionnaire design, community acceptability, and the burden on both the participating individuals and the survey staff for the National Indigenous Eye Health Survey.
- To compare a rapid assessment with a comprehensive eye examination
- To adapt, validate and test a vision-related Quality of Life instrument for use in Aboriginal and Torres Strait Islander populations.
- Assess the vision-specific HRQOL instrument in a representative sample of Aboriginal and Torres Strait Islander peoples.

1.6.3 Hypotheses

- That protocols and procedures as developed and modified in this study for the National Indigenous Eye Health Survey (NIEHS) will reliably detect the common causes of Vision Impairment and Blindness in Aboriginal and Torres Strait Islander adults and children in Australia with adequate sensitivity, specificity and examiner agreement.

- That adaptation of an existing quality of life questionnaire will result in an instrument with acceptable psychometric properties and determine the impact of vision impairment on quality of life in Aboriginal and Torres Strait Islander populations.

1.7 Implications and benefits

All participants were provided with optometric care free-of-charge during the study period and uncorrected refractive errors were managed with appropriate prescription or referrals as appropriate at the end of the examination. The study team also provided appropriate counselling and, in conjunction with the relevant Aboriginal Medical Service (AMS), arranged referrals and follow-up to regional and/or visiting ophthalmologists when necessary.

Components of the toolkit as developed in this study, have subsequently been used in a national survey of Aboriginal and Torres Strait Islander eye health to determine the prevalence of eye diseases and vision impairment. The second component developed as part of this toolkit has provided an instrument that provides information on how vision impairment is related to quality of life in Aboriginal and Torres Strait Islander populations.

The rapid examination method presented here also has the potential to be used in different settings where assessment of the prevalence of vision impairment as a result of posterior-segment conditions is required.

Chapter 2 Literature Review

2.1 Background

Blindness occurs 6 times more commonly in Aboriginal and Torres Strait Islander adults than in other adult Australians (relative risk = 6.20). Refractive error (54%) and cataract (27%) are the most common causes of vision impairment in adults, with diabetic retinopathy (9%) and trachoma (9%) significant additional causes of blindness.[1] In Aboriginal and Torres Strait Islander children, 56% of vision impairment is due to refractive error. However, vision loss is much less likely (relative risk = 0.22) to occur in Aboriginal and Torres Strait Islander children than it is in non-Indigenous children,[1] most likely due to the lower prevalence of myopia.[28]

The National Health Survey of Aboriginal and Torres Strait Islanders conducted by the Australian Bureau of Statistics in 2001 and again in 2004-05 stated that eye problems were among the conditions most commonly reported by Indigenous people, with 47% in both surveys reporting having a long term eye or sight condition.[1, 29-30] While the overall rates did not differ markedly with non-Indigenous people, 5% of Indigenous people aged 35-54 years reported being "completely or partially blind" compared to only 3% of non-Indigenous people of the same age. In the group aged 55 years and older, 8% of Indigenous people reported complete or partial blindness compared with only 5% of non-Indigenous people in the same age group.[30]

There have been some significant surveys and reviews of Aboriginal and Torres Strait Islander eye health in Australia, which have made important recommendations to improve the eye health and vision status of Aboriginal peoples.[2, 4-5] These recommendations included the need to overcome cultural insensitivity, limited awareness of eye health problems and treatments, costs of access to both primary and specialist services, gaps in specialist services in remote areas, lack of transport, cost of treatment, lack of Aboriginal Health workers for designated eye health and diabetes programs, and poverty. The surveys and reviews outlined cost-effective interventions

to prevent and/or treat the leading causes of blindness such as correction of refractive error with cataract surgery, early detection and management of Type 2 diabetes/diabetic retinopathy, and the SAFE strategy for trachoma. All surveys and reviews consider or recommend the better use of optometrists and/or appropriately trained auxiliaries for accessible, feasible, cost-effective and sustainable screening for ocular disease and vision problems.[2, 5]

However, prior to the NIEHS the last reliable ***national*** information was obtained 30 years ago by the National Trachoma and Eye Health Program (NTEHP).[4] New, sound epidemiological studies of eye and vision problems among Aboriginal peoples are required to direct and evaluate appropriate public health and service responses.[31] In addition, better quality epidemiological data and specific knowledge about health service barriers are needed on national, regional and local levels. This will enable better assessment of eye care needs to reduce the physical and cultural barriers to health service delivery and provide appropriate and sustainable systems for blindness prevention and eye care services. The impact of vision impairment on the lives of Aboriginal and Torres Strait Islander peoples also needs to be investigated in order to understand the ramifications of vision impairment on quality of life. In order to undertake these studies, culturally appropriate tools and instruments are required.

2.2 Aboriginal and Torres Strait Islander Health

The general population of Australia enjoys good health and a convenient, accessible, and excellent health care system. Australians also have one of the highest life expectancies in the world, surpassed only by the Japanese[32] However, Australia cannot claim to have 100% health care coverage or high levels of health and life expectancy for *all* of its population. In a century marked by dramatic improvements in the health of its people, Australia has failed to provide the same opportunities for health to Aboriginal and Torres Strait Islander peoples.

Compared to other Australians, Aboriginal and Torres Strait Islander peoples die at much younger ages and are more likely to experience disability and reduced quality of life due to ill health. [33-34]

This reduced life expectance is a result of Aboriginal and Torres Strait Islander peoples having significantly worse results than non-Indigenous people on every health indicator.[34-35] Aboriginal and Torres Strait Islander Australians have a life expectancy that is approximately 17 years lower than non-Indigenous Australians.[30] It was reported in 2002 that in one shire in NSW the average age of death recorded for Aboriginal males is 33 years.[36]

Governments have an obligation to provide basic services such as health care, education, and health infrastructure like water and sewerage for their citizens.[37] Accordingly, the Australian Federal Government has asserted the fundamental right for everyone to be free from hunger and for every child to have an adequate standard of living.[38-39] However, many Aboriginal and Torres Strait Islander peoples in Australia do not have access to these basic services and many Aboriginal and Torres Strait Islander children have nutritional deficiencies and are underweight.[40]

The poor health of Aboriginal and Torres Strait Islander peoples has been recognised by the Commonwealth Government as a priority since the late 1960s and since that time many national reports and strategies have been released in an attempt to improve it. While certain strategies have resulted in some improvements to services and facilities for Aboriginal people in a few areas, profound inequities still exist in access to primary health care as well as in many living and social conditions. These inequities have contributed to Aboriginal and Torres Strait Islander populations being one of the least healthy of all Indigenous populations in comparable developed countries.[41] Australia is ranked at the bottom out of a league of wealthy nations working to improve the health and wellbeing of Indigenous peoples, according to a report by the National Aboriginal Community Controlled Health Organisation (NACCHO) and Oxfam Australia.[42] These reports highlight how Australia has failed to improve the health of its Indigenous people, in contrast to the most recent trends in New Zealand, Canada and the USA where life expectancy gaps have been reduced to three and seven years.[42-43]

2.3 Vision Impairment and Blindness

2.3.1 Definitions

Blindness and low vision are defined by the International Statistical Classification of Diseases and Related Health Problems (ICD-10) on the basis of recommendations made by a World Health Organisation (WHO) Study Group.[44] The WHO criterion of low vision is visual acuity from <6/18 to 3/60 in the better eye after best possible correction.[44] Blindness is defined as visual acuity worse than 3/60 in the better eye after best possible correction. As these definitions were developed some three decades ago, higher levels of vision may now be required to complete complex daily tasks. As a result some countries are now using broader definitions.[45]

These definitions also fail to take into account instances where people are blind or vision impaired due to the lack of adequate correction. As a result it is also relevant to examine and define the proportion of presenting vision impairment and blindness that is treatable or correctable, as uncorrected refractive error can represent a significant proportion of the total vision impairment burden.[46-47]

For the purposes of this thesis normal vision will be defined as presenting visual acuity (VA) better than or equal to 6/12 in the better eye, vision impairment as presenting VA worse than 6/12 but better than 6/60 in the better eye, and blindness as presenting VA equal to or worse than 6/60 in the better eye.

2.3.2 Global Burden of Vision Impairment and Blindness

Globally 314 million people are affected by blindness and vision impairment for distance vision, which includes 45 million blind persons with presenting visual acuity less than 3/60 in the better eye.[48] 37 million are blind due to eye disease with the remaining 8 million blind due to uncorrected refractive error.[49] 269 million people have vision impairment globally; 145 million due to uncorrected distance refractive error and 124 million due to eye disease.[48] Vision impairment and blindness have significant costs for both individuals and communities. Distance vision impairment from uncorrected refractive error causes I$269 billion in lost global productivity annually.[50]

Yet the WHO has estimated that up to three-quarters of all blindness worldwide is avoidable and that one-half of the causes in children can be prevented or treated.[51]

Vision impairment predominantly affects adults 50 years of age and older and 82% of all blind people are 50 years and older. Women in every region of the world are 1.5 to 2.2 times more likely to have vision impairment than men. [48]

The largest cause of vision impairment is uncorrected refractive error which can result in lost education and employment opportunities, lower productivity, and reduced quality of life, [48-49] and can be easily corrected with a pair of spectacles. Of the 153 million with vision impairment due to uncorrected refractive error,[48] 45 million are working age adults.[52] Globally 90% of those affected live in low or middle income countries.[53] However, these WHO figures do not include vision impairment as a result of uncorrected presbyopia (diminished ability of the eye to focus at near which occurs with ageing). There were estimated to be 1.04 billion people with presbyopia in 2005, of whom 517 million people were vision impaired because they had no spectacles or inadequate spectacles, with 410 million unable to perform near vision tasks in the way required.[54]

2.4 Aboriginal and Torres Strait Islander Eye Health

2.4.1 Aboriginal and Torres Strait Islander Eye Health Programs

The eye health of Aboriginal Australians prior to European settlement in 1788 was most probably excellent, and certainly better than that of the Europeans of the time.[28, 55] A number of reviews conducted in the 1940s and 1950s found that common ocular abnormalities such as refractive error, defective colour vision and strabismus were rare.[56-60] However, these reviews identified severe preventable problems particularly from trachoma. In 1953 Mann found that nearly 60% of the Aboriginal population in the Kimberleys and Eastern Goldfields showed some signs of trachoma and that 5 to 11.5 per cent of those affected by trachoma were blind.[58-60] While gradual action was undertaken to identify and treat trachoma, the work of Hollows in the early 1970s led to the National Trachoma and Eye Health Program (NTEHP) which provided the first

comprehensive assessment throughout Australia and set out to screen and eliminate trachoma and other eye conditions in rural and remote Australia.[4]

2.4.2 The National Trachoma and Eye Health Program (NTEHP)

From 1976 to 1978 the NTEHP, for the first time, systematically recorded the status of eye health in rural Australia. Teams of eye health personnel travelled the country and examined 100,000 people of whom 62,000 were Indigenous Australians.

The NTEHP, published by the Royal Australian College of Ophthalmologists (RACO) in 1980 found that 38 per cent of Aboriginal Australians showed signs of trachoma compared with 1.7 per cent of non-Aboriginal Australians and that the prevalence of the condition was as high as 80% in some regions of the Northern Territory and Western Australia.[4] The recommendations from the 1980 NTEHP report were wide-ranging and focused on improvements to health amenities and service facilities for all rural Australians. These recommendations included better environmental health conditions, namely improving housing, water supplies, sewage systems, rubbish disposal and better access to a full range of food including fresh fruit and vegetables. The report also called for the continuation of a national program which included regular visits from a range of specialists to rural and remote areas of Australia to monitor, treat, direct and advise on the prevention of a range of skin, ear and respiratory diseases.

2.4.3 The 1985 Trachoma and Eye Health Report

In 1985 the Commonwealth Minister for Indigenous Affairs, the Honourable Neal Blewett, initiated a review of the current ocular health status of Aboriginal Australians so that it could be compared to previous data provided from the NTEHP. It was also designed to assess the effectiveness of the existing anti-trachoma programs and provide plans to deal with trachoma and poor eye health.[61] The 1985 review screened 2,000 Aboriginal people from 20 communities largely within areas found to have a high prevalence and severity of trachoma in the 1980 NTEHP report. Much of the data reported in the 1985 review were not directly comparable to the 1980 report due to

statistical difficulties in the NTEHP baseline report. However, standardised prevalence ratios (SPR), which make allowances for the different age structure of the population in 1985, showed that the SPR of all forms of follicular trachoma had decreased from 100 to 83 in 1985 after adjusting for relative community weightings. Additionally, the SPR of severe follicular trachoma had decreased from 100 to 63. However, the decline in prevalence was not uniform as out of the 17 communities seen at both times the standardised prevalence rates of follicular trachoma had decreased in 12 communities but increased in five. For severe follicular trachoma the standardised prevalence rates had decreased in 11, increased in four and unchanged in two.[62]

2.4.4 The 1997 Taylor Report

Twelve years later in 1997, Taylor was commissioned by the Commonwealth Minister for Health and Family Services to review the eye health in Aboriginal and Torres Strait Islander communities, describe the changing epidemiology of eye disease, and describe and assess the appropriateness and efficiency of current eye care programs. It was also designed to make recommendations on the provision of good quality eye care to Aboriginal and Torres Strait Islander communities. Ocular health data were obtained from existing data collected in areas with treatment programs throughout Australia rather than the collection of new data through specific new field surveys. It was reported that Aboriginal people in rural Australia had nearly ten times more blindness than non-Aboriginal people.[2] The rates of blindness were 1.4% in Aboriginal people compared to only 0.16% in non-Aboriginal people.[2] The 1997 report resulted in 17 recommendations as to how eye care services could be delivered to Aboriginal and Torres Strait Islander peoples and how specific eye conditions could be best managed across three broad themes:

1. The need to develop clinical best practice guidelines for primary eye care in Aboriginal communities and to train Aboriginal Health Workers and nurses to provide primary eye care;

2. The need for all three tiers of government – Commonwealth, State-Territory and Local – to share responsibility for the provision of equipment, training, services and funds for eye health; and
3. The need for a National Information Network to improve the collection and analysis of epidemiological data on Aboriginal eye health.

In response to the 1997 report, the Commonwealth implemented a National Aboriginal and Torres Strait Islander Eye Health Program (NATSIEHP) with three strands: ongoing funding for regional eye health services coordination; supply of initial funding to purchase specialised equipment; and training assistance. The program has been successful in some areas and it is thought that the main success can be attributed to the enthusiasm of the eye health coordinators.[63] Other recommendations were not adopted by the Commonwealth and key stakeholders have mixed responses to the program in general.[63]

2.4.5 Other Studies of Eye Health among Aboriginal Australians

A review of Aboriginal and Torres Strait Islander eye health research conducted in 2003 found that there had only been limited research in Indigenous eye health in the previous decade, despite Australia exceeding the world average in ophthalmic research.[64] This report also identified that the majority of articles were published in journals with low impact, potentially limiting their access. There have, however, been key studies that have contributed to the current understanding of Aboriginal and Torres Strait Islander eye health.

The Katherine Region Diabetic Retinopathy Study (KRDRS) was carried out in the Lower Top End of the Northern Territory between 1993 and 1996 and comprised of two cross-sectional surveys of participants with diabetes.[65] Although the study was limited by the small number of participants, the KRDRS found a potentially lower incidence of diabetic retinopathy among Aboriginal Australians with diabetes compared to the general Australian diabetic population. However, this study did report the highest incidence of vision threatening retinopathy and clinically significant macular oedema (CSMO) in the world.[66] It was also reported that these rates may have

been underestimated because of the relatively short observation time and the low average time since diagnosis.

The South Australian Eye Health Program (SAEHP) was conducted between 1999 and 2004, with visits to 22 remote Aboriginal communities in South Australia. This program found a decline in both active and cicatricial trachoma since the NTEHP and the start of the SAEHP in 1980.[67] However, the active trachoma prevalence in the Red Centre zone of the NTEHP was still 26%. The SAEHP also found that the prevalence of diabetic retinopathy appeared slightly lower than that seen in the Non-Aboriginal Australian population, but again the prevalence of vision-threatening proliferative diabetic retinopathy and CSMO among those with diabetic retinopathy was 24.9% and 8% respectively.[67]

Vision 2020 Australia has recently undertaken a mapping of Aboriginal and Torres Strait Islander eye care services across the country and has collected information on primary (community-based) services and those provided by ophthalmologists and optometrists, either within community medical services or at other locations.[68]

The National Trachoma Surveillance and Reporting Unit (NTSRU) established in November 2006 recently published its third Trachoma Surveillance Report which provides data on trachoma prevalence management and control activities in endemic regions across the Northern Territory, Western Australia and South Australia.[69] Results from the 2008 NTSRU report are presented in section 2.5.2.

Other studies of Aboriginal and Torres Strait Islander eye health have examined the primary eye care needs of Aboriginal and Torres Strait Islander populations across Queensland,[70] visual outcomes for remote Aboriginal peoples after cataract surgery,[71] or various conditions in discrete regions of Australia.[66, 72-79]

2.4.6 ICEE/AHMRC NSW Aboriginal Eye and VisionCare Program

One of the strategies of the NATSIEHP was to increase partnerships between key stakeholders.[3] In NSW, the International Centre for Eyecare Education (ICEE)

collaborated with the Office for Aboriginal and Torres Strait Islander Health (OATSIH, NSW) the Aboriginal Health and Medical Research Council (AHMRC), and Aboriginal Community Controlled Health Services (ACCHS) that provide eye care and vision correction, including the provision of spectacles and other optical aids within the ACCHS environment.[80-81] This program now conducts eye and vision care clinics in 98 Aboriginal community controlled facilities in NSW. The program in NSW has been reported to be cost effective and also provides educational programs to increase health awareness among Aboriginal and Torres Strait Islander populations and Aboriginal eye health workers.[80]

2.4.7 Aboriginal and Torres Strait Islander Health Strategies

The 1989 National Aboriginal Health Strategy was developed after extensive consultation with Aboriginal people and identified major challenges and proposed a range of strategies for improvement.[20] It advocated for a range of new organisational structures for policy development, monitoring, broad resource allocation, and workforce education and training. It sought to address the vast disparity in health standards between Aboriginal people and the general Australian population.[82] Although the strategy was never effectively implemented it still represents a feasible mechanism through which skill shortages can be addressed.

The National Strategic Framework for Aboriginal and Torres Strait Islander Health, which builds on the recommendations of the 1989 National Aboriginal Health Strategy (NAHS), outlines the crucial role that comprehensive primary health care services have in improving the health of Aboriginal people.[83] It confirms that for services to be effective and appropriate they must be available to all Aboriginal people, be adequately funded, have a skilled and appropriate workforce, be seen as a key element of the broader health system, and maximise community ownership and control.[84]

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

The Australian Government's National Eye Health Framework aims to provide a blueprint for nationally coordinated actions by governments, health professionals, non-government organisations, industry and individuals to work in partnership. It represents Australia's response to World Health Assembly Resolution WHA56.26 on the elimination of avoidable blindness in member countries.[85]

This document sets out a strategic National Framework for Action for the promotion of eye health and the prevention of avoidable blindness, and presents key areas for action. It also outlines the greater risks to Aboriginal and Torres Strait Islander peoples of developing avoidable blindness and vision loss. Research projects play a pivotal role in providing an evidence base to enable nationally coordinated action plans. The key research areas outlined in Table 2.1 have been identified as the actions required in order to lead to the prevention of avoidable blindness and vision loss in all Australians.

Table 2.1: National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss, key research action areas

Key area for action	*Action Area*	*Actions*
1. Reducing the risk	Research	Support research programs that contribute to the compilation of an evidence base for population health approaches to reducing the risk of blindness and vision loss
2. Improving access to eye health care services	Rural and remote communities	Explore mechanisms by which low vision and rehabilitation services can be provided to remote and regional areas
	Affordability	Identify effective models of state based programs which provide access to eye health care to disadvantaged and marginalised groups
	Cultural accessibility	Support research into barriers to accessing eye care services by disadvantaged and marginalised groups
	Research	Support further health services research to identify barriers to access and strategies to improve access to health care
5. Improving the evidence base	Research gaps and priorities	Identify eye health research gaps and national priorities in consultation with all key stakeholders

The research actions outlined in this framework also represent mechanisms by which the risk of avoidable blindness among Aboriginal and Torres Strait Islander peoples can be reduced, as well as access to eye health care services can be improved.

2.4.9 Studies of Eye Health among non-Aboriginal Australians

There have been two significant population-based surveys of the eye health in Australia which have contributed greatly to the understanding of the distribution and impact of vision impairment both in Australia and globally.

The Blue Mountains Eye Study (BMES) was a population-based survey of the prevalence and causes of vision impairment and common eye diseases in an older semi-urban Australian community sample with a demography similar in age group to that of the overall Australian population. A detailed assessment of eye disease and other general health measures was conducted on each participant identified through a door-to-door census.[23-24]

The BMES found that under- or uncorrected refractive error is common. After taking into account the effect of age, vision impairment was significantly more common in women than men. At each age women were less likely to achieve 6/6 or 'normal' corrected vision than men. Overwhelmingly, age-related maculopathy was the predominant cause of blindness (all ages over 50) and of moderate impairment affecting persons aged 70 or older. However, cataract was the most common cause of mild vision impairment. Vision impairment affecting only one eye was caused most frequently by amblyopia (poor vision from childhood) in those under age 60. In older age groups vision impairment was due to cataract when mild and caused jointly by age-related maculopathy and cataract when impairment was moderate or severe.[24, 86-87] The cohort of participants in the BMES were examined again 5 and 10 years after the baseline study, which has significantly contributed to the understanding of the long-term consequences and incidence of eye disease and vision impairment as well as the influence of various dietary and other risk factors.

The Visual Impairment Project (VIP) was a population-based study eye of disease in 3500 randomly selected clusters of individuals aged 40 years of age and over,[25-26] and is

reported to be fully representative of the Victorian population.[88] Conducted in urban and rural residential populations and nursing homes, the study was designed to determine the distribution and determinants of eye disease, as well as the impact of eye disease on visual function, activities of daily living, and the accessibility of eye health care services in the community.[25]

VIP found the age-adjusted rate of blindness of 0.34%, with a higher rate of vision impairment observed in women. The VIP also found that the number of people with vision impairment could be halved simply by the provision of new spectacle corrections.[26]

The combined results of these two studies have shown that nearly half a million Australians have vision impairment (either corrected or uncorrected) and the most common causes of vision impairment were under-corrected refractive error (62%) cataract (14%), and age-related macular degeneration (10%).[47] However, neither of these studies represents Aboriginal or Torres Strait Islander peoples.

2.5 Eye Conditions affecting Aboriginal & Torres Strait Australians

2.5.1 Refractive Error

Refractive errors are the main cause of vision impairment and the second cause of blindness globally.[48] The various types of refractive error, including hypermetropia and myopia are easily detected through routine examinations and can easily be corrected with spectacles, contact lenses or refractive surgery. Presbyopia, caused by age-related elasticity changes in the crystalline lens and its capsule,[89] results in the inability to see clearly at near and can also be easily corrected with spectacles. The problem of uncorrected refractive error is now receiving considerable international attention because it has recently been estimated that globally 153 million people over 5 years of age are visually impaired as a result of uncorrected refractive errors.[48] Additionally eight million of these people are blind from uncorrected refractive errors.

Presbyopia affects more than 1 billion people globally, 517 million of whom do not have adequate near vision correction.[54]

In Australia, the BMES and VIP reported that 62% of presenting vision impairment and 4% of presenting blindness (presenting visual acuity <6/60 in the better eye) is caused by correctable refractive error.[47]

Taylor reported in the late 1970s that Aboriginal Australians had a significantly lower prevalence of astigmatism and myopia, particularly high myopia of more than -4.0 D when compared with Australians of European descent.[28, 55] Despite better visual acuity, uncorrected refractive error due to the lack of spectacles was still the most common eye or vision problem documented in the NTEHP.[4] However, the prevalence of uncorrected refractive error in Aboriginal populations now appears to have increased in some populations.[76] A study conducted in 2000 on a similar population found that Aboriginal adults have become significantly more myopic with a shift in the population mean of 1 D.[76] It was suggested that the apparent shift towards myopia may have occurred as a result of increased formal education and higher rates of obesity and diabetes due to diet changes and is common among Aboriginal peoples where existing services do not meet local needs.[76]

2.5.2 Trachoma

Trachoma is a highly contagious disease of the eye and is one of the leading causes of infectious blindness globally. It is caused by *Chlamydia trachomatis*, a bacterium spread from person to person, and is frequently passed within families and households. It is often associated with poverty. Primary risks for its transmission include household crowding, especially where there are flies and poor access to and use of water.[90] With repeated untreated infections the disease can ultimately progress to trichiasis, where the lid margin and eyelashes turn inwards and rub on the cornea leading to damage, scarring and ultimately blindness. This typically results in deepening poverty of individuals and their families. Globally, women experience trachoma-related blindness two to four times higher compared to men[91] and are nearly twice as likely to develop trichiasis.[92] Although there is some evidence of a biological basis for this increased

risk[91] most evidence points to women's increased proximity to affected children.[93] Disparities in the prevalence of trachomatous scarring and inflammatory trachoma have been observed in Central Australia where females are more likely to have trachomatous scarring (OR=3.4) and were 1.8 times (95% CI 1.3, 2.7) more likely to have inflammatory trachoma.[94] However, other studies in the Pilbara and South Australia have not found any associations between trachoma grade and gender.[67, 95]

Previously endemic globally, Australia is now only one of 57 remaining countries with the disease.[96] Trachoma as a cause of blindness has been eliminated in every developed country except Australia where it is found almost exclusively within the Aboriginal population.[97] It has been difficult to determine where trachoma remains endemic, as most surveys have been undertaken as a guide for the provision of services rather than systematic prevalence surveys.[3]

The National Trachoma Surveillance and Reporting Unit (NTSRU) established in 2006 by the Australian Government has confirmed that hyper endemic trachoma (>20%) still exists in rural and remote areas of Western Australia and the Northern Territory. The report also states that active trachoma prevalence in 2008 varied between the states and territory with reported prevalences ranging from 4-67% in the Northern Territory, 0-8% in South Australia and 8-25% in Western Australia.[69] The overall prevalence of active trachoma has not changed substantially since the establishment of the NTSRU although the small numbers examined does result in instability or estimates. Trachoma prevalence in Queensland and New South Wales is currently unknown although it was prevalent in Aboriginal populations in both these States in the 1970s and 1980s[4] and the NIEHS reported inflammatory trachoma in two sites in both states.

Presently there are very few state wide trachoma control programs and a review of the implementation of the NTEHP recommended that trachoma control be the responsibility of government-run and regional public health units and be organised on a regional basis where population mobility is high. The review also recommended that primary health care services be involved in the detection and treatment of trachoma under the coordination of public health units.[63]

2.5.3 Cataract

Cataract, an opacity that develops in the crystalline lens of the eye that can prevent light from reaching the back of the eye, is the leading cause of blindness globally[49] and is the most common cause of vision impairment apart from refractive error in Australia (37%).[47]

It has been reported that in some areas of Australia, Aboriginal and Torres Strait Islander peoples are three times more likely than non-Indigenous Australians to report vision loss due to cataracts, but are four times less likely to have cataract surgery.[75] However, when cataract surgery is performed, the cataract is more likely to be at a more advanced stage compared with non-Aboriginal and Torres Strait Islander Australians.[98] Aboriginal and Torres Strait Islander Australians often also face a variety of difficulties when seeking cataract services, such as distance, lack of transport, lack of medical services, language barriers, and economic disadvantage.[98]

There has been no systematic assessment of the prevalence of blindness and vision impairment as a result of cataract among Aboriginal Australians since the NTEHP, which found a prevalence of 10.5% for the 50-59 year age group and 37% for the >60 year age group. In the same study, rates for non-Aboriginal Australians were lower, particularly for the younger age group: 2.5% for the 50-59 year olds, and 25% for the >60 year olds.[4]

2.5.4 Glaucoma

Glaucoma is a major cause of irreversible vision loss worldwide. It is difficult to detect and treat and its prevalence increases with age [99] Both the BMES and the MVIP have defined glaucoma as the presence of matching optic disc cupping with rim thinning and glaucomatous field defects demonstrated on automated perimetry.[100-101]

While glaucoma is not commonly identified as a problem within Aboriginal communities and was not a major cause of blindness in Aboriginal peoples in the NTEHP study,[4] it has been suggested that it has been overlooked in such studies due to inadequate examination techniques.[70, 78] Studies have also identified a difference in the

cup to disc ratios of youth from a rural Aboriginal and Torres Strait Islander community and a non-Aboriginal community in Brisbane, Queensland indicating the presence of genetically predetermined differences.[78]

2.5.5 Diabetic Retinopathy

Diabetic retinopathy is damage to the retina (retinopathy) caused by complications of diabetes mellitus which can eventually lead to blindness. The main risk factors for diabetic retinopathy are poor glycemic control, the duration of diabetes, systolic blood pressure and urinary albumin.[102-104] In 2002 the AusDiab group reported a diabetes prevalence of 8.0% in men and 6.9% in women from an Australian nationwide cross-sectional survey of adults ≥ 25 years of age.[105]

All people with diabetes mellitus are at risk of developing diabetic retinopathy, however, most of the vision loss and blindness can be prevented through proper and vigilant control of diabetes and regular eye examinations. The National Evidence Based Guidelines for the Management of Type 2 Diabetes Mellitus, which was endorsed by the National Health and Medical Research Council in 2004, recommends that all Aboriginal and Torres Strait Islanders over 35 be tested for diabetes.[106]

There are limited data on the prevalence of diabetic retinopathy among Aboriginal Australians, but anecdotal and service information has suggested that diabetic retinopathy has increased and is now a major vision-threatening condition.[2] According to a review of data from 10 communities studied across Australia, diabetic retinopathy may be present in 8 to 31% of Aboriginal people with diabetes[3] with the lowest rate of diabetes occurring in communities that have maintained more traditional diets and lifestyles.[98] Although the crude prevalence of diabetic retinopathy among Indigenous people may be similar to that documented for the general Australian diabetic population,[107] Aboriginal people have much higher prevalence rates for diabetes and a much younger age of onset than non-Aboriginal Australians.[7] The National Aboriginal and Torres Strait Islander Health Survey Australia (NATSIHSA) in 2004–05, reported that after adjusting for age differences between the two populations, Indigenous people were more than three times as likely as non-Indigenous people to report some

form of diabetes.[30] These estimates are very likely to understate the true prevalence of diabetes in the community as they exclude cases which have remained undetected. Epidemiological studies in Australia and the United States of America using glucose tolerance tests show that for every known case of diabetes there was one undiagnosed case.[8, 108]

Increasing prevalence and trends towards earlier age of onset[7, 105] indicate that retinopathy may become a much more common cause of avoidable blindness among Aboriginal and Torres Strait Islander Australians particularly when other risk factors such as renal disease and hypertension are also present.

The Early Treatment Diabetic Retinopathy Study (EDTRS) is still regarded as the gold standard for grading in clinical trials and epidemiologic studies.[109] However, it is limited by relatively complicated rules, multiple severity levels and the need to correlate with standard photographs. Grading of stereoscopic seven-field fundus photography performed by a trained grader is mainly a research tool and is rarely performed in routine practice. Clinical examinations to assess the presence and severity of diabetic retinopathy uses slit lamp biomicroscopy, ophthalmoscopy or retinal photography with pupils either dilated or undilated.[109] In some studies, mydriatic retinal photography has been shown to be more sensitive than non-mydriatic photography (81% vs. 61% sensitivity) to detect moderate non-proliferative diabetic retinopathy (NPDR), severe NPDR, and proliferative diabetic retinopathy (PDR).[109]

The National Health and Medical Research Council (NHMRC) guidelines for the management of diabetic retinopathy report that screening examinations or tests should aim for a sensitivity of at least 60% though higher levels are usually achievable.[109] These sensitivities are based on the reasonable assumption that mild diabetic retinopathy (DR) missed at one visit would likely be detected at the next visit. The guidelines also state that specificity levels of 90-95% and technical failure rates of 5-10% are considered acceptable.

UK and Australian studies have found that optometrists detect any retinopathy with between 67% and 87% sensitivity.[109] Prior studies of Aboriginal and Torres Strait

Islander peoples have been able to obtain gradable retinal photos in at least 90% of eyes.[110]

2.5.6 Other Conditions

Of the five main causes of vision impairment in Australia (refractive error, cataract, diabetic retinopathy, glaucoma and age-related macular degeneration), macular degeneration is the only condition for which there is no information in Aboriginal and Torres Strait Islander populations.[3]

Globally the incidence of hospitalization as a result of eye injury is estimated at 13 per 100,000 of the population per year.[111] A recent study in far North Queensland found the incidence of all eye injuries of 88.2 per 100,000 per year and an incidence of penetrating eye injuries of 21.7 per 100,000 per year. The majority of these cases were in Aboriginal and Torres Strait Islander peoples particularly Aboriginal and Torres Strait Islander females.[112] However, the incidence of ocular trauma varies markedly between Aboriginal and Torres Strait Islander communities and has a variety of casues.[2-3]

Pterygia have also been reported to be more common among Aboriginal and Torres Strait Islander peoples than non-Aboriginal and Torres Strait Islander populations.[2]

2.6 Determinants of Aboriginal & Torres Strait Islander Eye Health

2.6.1 Eye Health Services in Australia

Generally, Australia has very good primary, secondary and tertiary eye care services. However, services are often not as accessible or available in the more rural and remote areas of the country, which is similar to other health fields. In an assessment of eye health in rural Australia, Madden et al found that the number of patients per optometrist was more than 12,700 in remote areas and 2,700 in rural areas, compared with a national average of 1,180.[113] There is also considerable evidence that even current services are not meeting the eye care needs of Aboriginal and Torres Strait Islander peoples, particularly for treatable conditions such as refractive error and for

those living in rural and remote regions of Australia.[2-3, 70] For instance, studies have shown that although there is an adequate coverage of resident ophthalmologists in most non-metropolitan areas of NSW (excepting some areas of the Western regions), Aboriginal and Torres Strait Islander peoples present to ophthalmologists in disproportionately small numbers.[5] This same study highlighted that the most glaring barrier in NSW is a general lack of awareness about eye health problems and the available treatment, both in the Aboriginal community and among primary health care providers. The same study found that there are many barriers which prevent Aboriginal people moving through the referral system such as:

- Low eye health awareness;
- Low eye health awareness among primary health care providers;
- The cost of treatment where GPs and specialists do not 'bulk bill', forcing the patient to pay the scheduled fee 'up front', instead of claiming the cost of service directly from Australia's universal health insurance scheme;
- Limited or absent transport to health facilities;
- Insufficient Aboriginal health workers to provide support and follow-up; and
- Social and economic conditions.[5]

Research into the effectiveness of health services relating to Aboriginal health care emphasises the importance of culturally appropriate health services. A study by Ivers et al[114] concluded that financial barriers are relatively less important than cultural barriers as individuals are often prepared to travel substantial distances to receive more culturally appropriate services that are under community control. Accessible, appropriate and affordable community-based eye and vision care services delivered to Aboriginal Australians through Aboriginal community-controlled health centres, can help to overcome some of the existing barriers.[115] However, the feasibility of providing these services is difficult considering the large geographical dispersion of Aboriginal and Torres Strait Islander peoples throughout Australia.

The most striking conclusion from these studies is the degree to which issues of access to eye health services for Aboriginal and Torres Strait Islander peoples are under-researched. Currently a gap exists in our understanding of what are the most significant barriers faced by Aboriginal and Torres Strait Islander peoples in accessing eye health services, as well as our understanding of how to make them appropriate and accessible.

2.6.2 Aboriginal Community Controlled Health Services (ACCHS)

Canada, the United States and New Zealand have demonstrated that pro-active workforce strategies focused on training Indigenous people, and attention to developing the capacity of the health system to collaborate with agencies outside the health sector, has contributed to the improved health outcomes for their Indigenous populations.[116] Increasing the number of dedicated Aboriginal health workers has thus been identified as a key contributor to improved primary health care access which in turn can impact the health status of Aboriginal people.[83]

The first Aboriginal Medical Service in inner Sydney Redfern was inspired by the Aboriginal Legal Service and established by a collection of Aboriginal leaders and activists. Since then, the ACCHS sector has developed a large pool of knowledge and expertise about Aboriginal health issues enabling it to deliver appropriate care and to advocate for the health interests of Aboriginal people. The most viable and successful community-controlled services have been those initiated by Aboriginal people themselves and shaped by the local needs and perceptions.[117]

The ACCHS have demonstrated a reliable model of improving the health of Aboriginal people through the provision of appropriately skilled staff in community controlled health services. However, these services are still understaffed and/or underfunded. The community-controlled sector is also unsupported with respect to the development of professional leadership, planning, evaluation and research skills, professional development, and information resources.[118] The training of eye health staff in particular is a critical aspect of this workforce in order to encourage awareness, regular eye

screening in their communities, provision of eye examinations, and appropriate referrals.

2.6.3 Social determinants

While a fundamental lack of appropriate health services undoubtedly contributes to poor health outcomes for Aboriginal and Torres Strait Islander peoples there are additional factors relating to underlying inequities. Being able to reduce inequalities and meet basic health needs requires the underlying social, economic, environmental and political causes of poor health to be addressed.

The general health and eye health of Aboriginal and Torres Strait Islander Australians is not only dependent on physical well-being, but also on other key indicators such as education, financial status, adequate housing, sanitation, diet, and access to a range of goods and services.[119] It has also long been recognised that mental illness and stress are significant problems for Aboriginal and Torres Strait Islander peoples and directly impact on physical ill-health.[120-122]

A review of eye health services for Aboriginal Communities in NSW reported that as there are so many more pressing health and social issues which must be addressed on a daily basis, eye problems are often relegated to the "back-burner"

> *"For families in a constant struggle to survive financially and find employment for family members, getting their eyes checked for asymptomatic eye disease is often just too hard."*[5]

The health of Indigenous people in Australia is significantly impacted by economic disadvantage, but the social determinants of health arguably play a greater role in contributing to health inequalities. Reducing these inequalities in health and meeting the health needs of the Australian population is ultimately an issue of social justice. The complexity of the social issues surrounding poor Indigenous health requires multiple strategies and policy approaches over many years to permanently reduce the health inequities, yet clearly these strategies and policies have failed to improve the health status of Aboriginal and Torres Strait Islander peoples in Australia.

Social determinants of health refer to the social gradients that exist in populations and the underlying unequal distributions of power, income, goods and services.[123-124] The recent Commission on Social Determinants of Health has outlined how the unequal distribution of power, income, and goods causes the poor health of poor people.[123] The Commission's three principles for action to close 'the gap' consist of 1) improving the conditions of daily life; 2) tackling the inequitable distribution of power, money and resources; and 3) measuring and understanding the problem and assessing the result of action. These three principles are just as relevant in Australia, particularly for Aboriginal and Torres Strait Islander peoples.

Theoretically, improving the eye health of Aboriginal and Torres Strait Islander peoples can act directly on the broader determinants of health. Addressing avoidable blindness and vision impairment can result in improved education outcomes,[125] allow for greater employment opportunities,[50] and prevent poverty.[126] Additionally, improved vision can also increase the degree to which an individual can participate and function within their society. There are many benefits with improved functioning and participation to both the individual and their social environment, such as greater mobility and independence as well as reductions in safety concerns and the other emotional stresses associated with vision impairment and blindness. A more detailed discussion of the impact of vision impairment on quality of life is presented in section 2.8.

2.7 Epidemiological Methods to assess vision and eye health

2.7.1 Population-based studies

National population-based studies are generally the most accurate way to determine the prevalence and causes of blindness and vision impairment. Sample sizes determined by the disorder with the lowest prevalence are usually very high which contributes to them being complicated, lengthy and expensive exercises. Results usually become available years after the survey was conducted, and thereby lose much

of their validity as planning tools.[127] Blindness surveys often also require expert assistance from epidemiologists or statisticians to produce reports. Because of the high costs and complicated logistics, population-based surveys are unlikely to be repeated after 3-5 years to assess the impact of intervention programmes. This means that full blindness surveys are often not appropriate for planning and monitoring blindness prevention programmes.[128] There have been two previous population-based surveys of blindness and vision impairment in Australia as outlined in section 2.4.5. These two studies have provided a great deal of valuable information on the prevalence and progression of eye disease in Australian people, as well as the role of risk factors in vision and eye health outcomes. However, conducting such a study in Aboriginal and Torres Strait Islander populations would be extremely difficult especially when considering that Aboriginal and Torres Strait Islander peoples constitute only 2.5% of the total population.[129] Additionally, the significant differences in eye health outcomes that are suspected to occur between geographic areas would require even larger samples due to stratification. As such there is a need for a rapid examination methodology that is able to provide the prevalence of the major causes of vision impairment and blindness, including cataract, diabetic retinopathy and trachoma.

2.7.2 Rapid Assessment Methods

Rapid assessment methodologies have been developed recently to undertake comprehensive assessments of public health issues within a minimum amount of time, using minimum resources. These methodologies initiated out of the cluster survey design of childhood immunisation programs.[130] First used in the ophthalmic world in the assessment of cataract blindness,[131] rapid assessments were developed into a methodology for a Rapid Assessment of Cataract Surgical Services (RACSS),[132] and more recently to a Rapid Assessment of Avoidable Blindness (RAAB).[133] RAABs have been used in many countries around the world including Rwanda,[134] Bangladesh,[135] China,[136] India,[137] the Philippines[138] and Kenya.[139] The main aims of the RAAB are to:

- estimate the prevalence and causes of avoidable blindness and vision impairment (blindness due to cataract, refractive errors, onchocerciasis,

trachoma, other corneal scarring and posterior disease) in people aged 50 and over;

- assess cataract surgical coverage;
- identify the main barriers to the uptake of cataract surgery; and
- measure outcome after cataract surgery.

Rapid assessments methods that focus on uncorrected refractive errors have also been developed and conducted recently.[140]

Rapid examinations do not provide the prevalence of individual conditions. Instead, rapid assessments provide the prevalence of vision impairment and blindness and its cause (Table 2.2). Rapid assessment teams can be significantly smaller than for comprehensive examinations and do not require as many eye health professionals or pieces of equipment. As more than 80% of all blindness occurs in people of 50 years and older, a much smaller sample size is required for a survey covering people aged 50 years and above only. Sample sizes may be one third to one sixth of that needed for a survey covering all age groups depending upon the proportion of people aged 50 and older in the survey area.[128]

2.7.3 Comprehensive Eye Examinations

The VIP and the BMES both used comprehensive eye examinations to determine the prevalence of causes of vision impairment and blindness in Australia. Comprehensive eye examinations are designed to determine the prevalence of a range of conditions regardless of whether they are a cause of vision impairment or blindness. They are generally lengthy and require highly trained optometrists or ophthalmologists as research team members.

A comparison of rapid and comprehensive eye examinations is shown in Table 2.2.

2.7.4 Toolkits

It is commonplace for population based surveys to develop a 'toolkit' of methods, protocols, instruments and questionnaires in order to obtain a complete picture of the

vision and eye health of the target population. The BMES, VIP and SEE studies are just three examples of significant population based studies of eye health that have used a standardised examination to detect cases and have combined this with a vision-related quality of life (e.g., Activities of Daily Vision Scale, National Eye Institute Vision Function Questionnaire) or general health-related quality of life instrument (e.g. SF-36) to assess the impact of vision impairment on quality of life.

The need for more recent epidemiological data on the state of vision and eye health in Aboriginal and Torres Strait Islander populations is evident. In order to complete the toolkit or package an appropriate instrument to assess the impact of vision impairment on quality of life is also required. This will be discussed in further detail in section 2.8.

Table 2.2: Comparison between a comprehensive eye examination and a rapid assessment

Component	***Comprehensive***[23, 25]	***Rapid***[141-142]
Current optical correction	Measured with automatic lens analyser	Type of correction recorded
Distance Visual Acuity	LogMAR visual acuity chart	Simplified tumbling E chart
Refractive Errors	Subjective refraction and objective with Automatic Refractor	Pinhole, handheld autorefraction and best corrected visual acuity
Near Vision	LogMAR word reading card	Simplified tumbling near E chart
Visual Fields	HFA 24-2 Threshold test	Frequency Doubling Technology
Intraocular pressure	Tonometry	NA
Retinal examination	Mydriatic retinal photography	Non-mydriatic retinal imaging
Lens examination	Slitlamp examination	Digital imaging
Cornea examination	Slitlamp examination	Digital imaging
Staffing requirements	4-5 specialist staff	3-4 non-specialist staff/ 1 specialist staff
Average time per person	1.5 hours minimum	30 minutes

2.7.5 Assessing new methodologies

In order to assess the diagnostic accuracy of assessment methods, pre-existing gold standards are compared with new diagnostic tests or methodologies. The gold standard is defined as the best existing test used to categorise the disease state.[143] The result produced by the gold standard is then compared to the outcome of the new

diagnostic test or methodologies. Accuracy is generally reported as sensitivity (the proportion of participants with the disease who have a positive diagnostic test) and specificity (the proportion of subjects without the disease who have a negative test).[144] Cohen's kappa (κ) is also used to assess the levels of agreement between raters by providing a measure of the degree to which two raters concur in their respective sorting of ratings items into mutually exclusive categories.[145-146]

2.8 Vision-Related Quality of Life

2.8.1 Quality of Life

The World Health Organisation defines health as:

> *"a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity"*[147]

This definition extends beyond the traditional Western biomedical paradigm which treats body, mind and society as separate entities and reflects a more holistic understanding of health. Indigenous peoples have a similar understanding of health, which defines well-being as the harmony that exists between individuals, communities and the universe.[148] The WHO definition also suggests that the views of the individual are required in order to understand health status. The challenge then becomes looking past the clinical functional measures and developing indices that reflect this broad definition of health. Knowing how a disease affects one's functioning enables better planning of services, treatment, and rehabilitation for persons with long-term disabilities or chronic conditions.[149]

While it is possible to measure many physiological and biological markers of disease and its treatment, which in turn provide a great deal of information to clinicians, this does not provide insight into how the disease or illness impacts the broader definition of health. Nor are we able to understand how disease or illness limits or stresses the 'quality of life' of the individual. As well as observing changes in visual acuity outcomes it is also necessary to assess the success of vision correction and

rehabilitation programs through improvements in vision-related quality of life outcomes.

Quality of life refers to an individual's emotional, social and physical wellbeing, including their ability to participate in the ordinary tasks of living, and is an important measure to determine the impact of disease and interventions. However, it exists only in the mind of the person whose life is affected and as such it cannot be directly observed. Instead, attitudes of the participant must be obtained.[150]

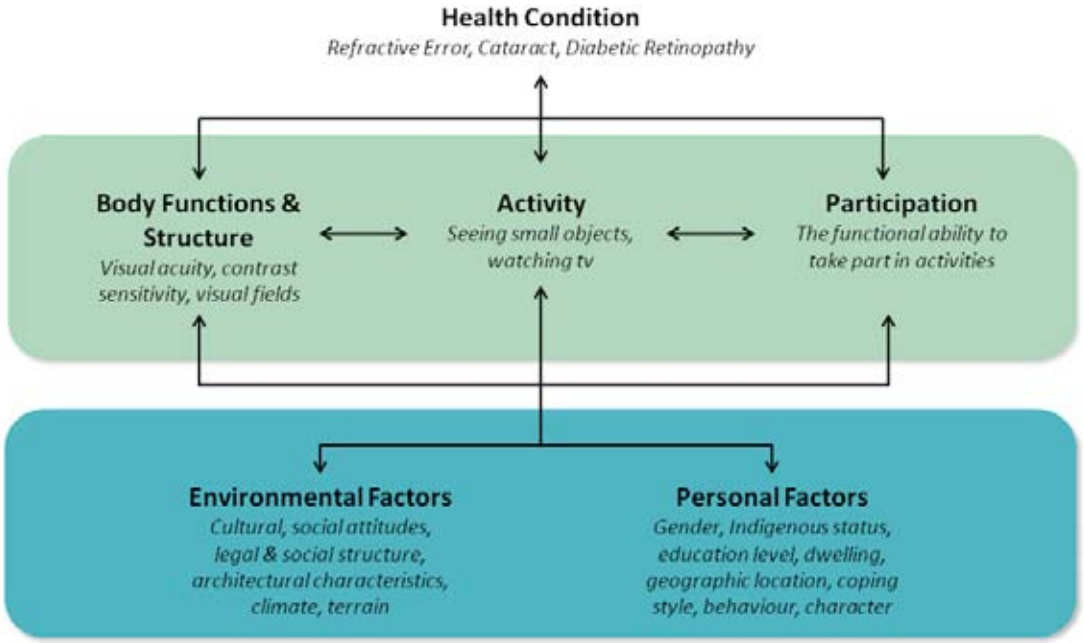
The WHO's International Classification of Functioning (ICF) aims to provide a unifying framework to classify the health components of functioning and disability. It encompasses and describes all aspects of human health and the interactions between the components of the ICF are demonstrated in Figure 2.1, with the addition of vision-related examples.

This framework focuses on the outcomes of health and functioning rather than disability which makes it a very appropriate model to examine the impact of vision impairment on the restriction of participation.

One method of assessing how health relates to quality of life is to use Health-Related Quality of Life (HRQOL) instruments. These instruments have been developed to investigate the effects of numerous disorders, short- and long-term disabilities, and diseases in different populations in four broad health contexts:

- Measuring the health of populations;
- Assessing the benefit of alternative uses of resources;
- Comparing two or more interventions in a clinical trial; and
- Making a decision on treatment for an individual patient.[151]

Figure 2.1: International Classification of Functioning, interactions between components with vision-related examples[152-153]



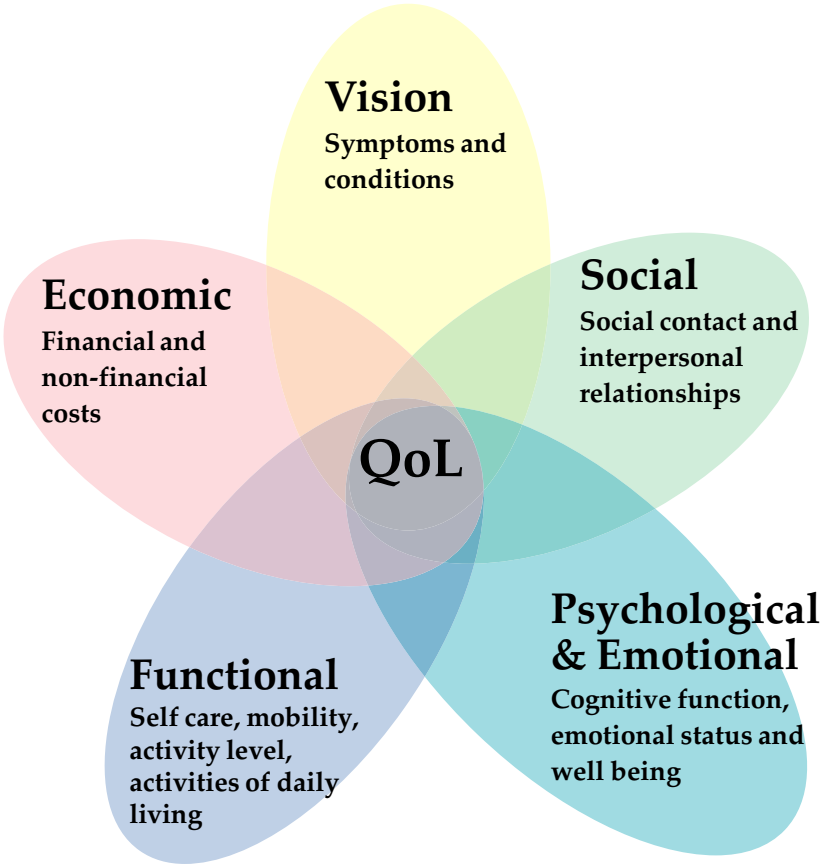
2.8.2 Quality of Life in Vision and Eye Health

Vision impairment has been shown to have negative effects on Health-Related Quality of Life.[154-155] Subsequently, understanding the impact of vision impairment on needs for rehabilitation and restriction of participation can assist in presenting a broader and more meaningful picture of health both for individuals and populations.[12] Indeed, a patient-centred measure, which considers the impact of eye disease in conjunction with the person's views on their own visual performance, can be considered a more accurate indication of the success of any vision intervention. However, the effects of different cultural setting should not be underestimated.

In the sphere of vision and eye health, quality of life instruments have historically been used to demonstrate improvement in functioning and quality of life among patients who have undergone cataract surgery.[156] Since then a plethora of questionnaires and instruments have been designed to assess a wide range of eye conditions. Instruments have been designed to investigate specific diseases[157-162] and treatments[163-164] and also to

investigate broader vision impacts regardless of cause.[15, 165-167] Disease specific measurement instruments play an integral role in assessing the level to which vision impairment restricts participation in daily living and quality of life.

Figure 2.2: Key dimensions of Quality of Life (QOL)[153]



These instruments are able to provide data from the patients' perspective about their symptoms, ability to participate in daily activities and satisfaction related to their vision. The key dimensions of vision-related quality of life,[153] shown in Figure 2.2 and adapted from Aaronson (1988),[168] illustrate how the combination of visual, functional, psychological, social and economic factors collectively shape individual experience.

2.8.3 Quality of Life in Different Cultural Settings

The least developed regions of the world carry the largest burden of vision impairment,[49] but the largest proportion of vision-related quality of life instruments by far have been developed in the more developed countries, particularly the United States among non-minority and well educated participants. The bulk have also only been developed and validated for administration in English only. When examining vision-related quality of life improvements that occur with vision treatment, correction and rehabilitation in different cultural settings, instruments that have been specifically adapted for use in different cultural settings are required. However, merely translating the questionnaire for different cultural, ethnic or language groups is not sufficient to produce reliable and valid outcome measures or to avoid conceptual or psychometric errors.[169-170] When this approach was taken in a cross-cultural study of cataract patients, significant international variations were found in the degree to which participants reported having "trouble with vision" that could not be explained by clinical or socio-demographic factors.[171] It was suggested that these variations may be a result of cultural differences. Indeed, there are differences in participation and vision-related quality of life that are not explained by vision function or capacity, but are related to cultural and environmental differences. For instance, during the adaptation and validity test of the Australian Impact of Vision Impairment instrument (IVI_A) for use in Melanesia, the importance of 'community', such as attending community meetings and church gatherings, was clearly found to be a relevant factor when considering the impact of vision impairment.[167, 172] Whereas these aspects of vision impairment were not found to be relevant in Australian contexts.

As a result of concerns with translation, guidelines have been developed for cultural and language adaptation[173-174] and goals of 'equivalence' have been established. Equivalence refers to conceptual, item, semantic, operational, measurement, functional and cognitive equivalence between questionnaires.[175-176] However, there can be many difficulties with achieving equivalence when there are vastly different concepts and expectations of health and well-being and differing impacts of disease and disorders on groups. These goals of equivalence are also complicated by vast literacy and

comprehension differences. Literacy and comprehension of questionnaire techniques are also an important consideration when conducting cross-cultural instrument adaptation as literacy is often associated with both low income and poor health.[177-178]

Three reviews of vision-specific instruments have been conducted since 2002 (Table 2.3). Although it was not the primary purpose of these reviews to examine them for cultural and language adaptations it was still reported for each instrument in all reviews. Two of the three reviews did not examine any original articles that were not written in English. The one review that did reported that only 13% of instruments developed were translated into languages from less developed countries or validated for use in other cultures.

Table 2.3: Review of vision-related quality of life instruments, language and cultural adaptations

Review	Languages Examined	Language and Cultural Adaptations
Margolis (2002)[154]	English only	No reported translation and/ or cultural validation psychometric studies.
De Boer (2004)[179]	Any	Out of 31 instruments reported, four (13%) were translated into languages from less developed countries (Indian, Chinese or Malawian language)
Lundström & Wendel (2006)[180]	English only	Out of 35 instruments reported six (17%) were translated or assessed for performance in a less developed country context (Chinese, Korean, Hindi, Telegu, or Tamil).

More cross-cultural adaptations of existing vision-related quality of life questionnaires are needed to show that vision intervention strategies are successful. Ideally, instruments should be carefully translated and adapted for the local language or dialect and culture for which the instrument is targeted.

2.8.4 Criticisms of Quality of Life measures

Measuring the quality of life of individuals is not without its criticism. In addition to the difficulties in measuring vision-related quality of life in cross-cultural settings, particularly when there may be varying levels of comprehension and concepts of health, there are broader concerns about the fundamental notion of quantifying health states. *"Many fear that, instead of indicating a goal for improved health, the designation of quality of*

life (QOL) might be used as a threshold or triage principle in the allocation of resources, which could be used to justify reducing or withholding medical care."[181] There has also been criticism of the lack of ability to precisely measure the concept of QOL.[182] While it is important to understand how these measures can be used counterproductively, the bulk of research demonstrates that quality of life measures are an effective tool in evaluating and ultimately improving quality of life components in a wide variety of settings.

These broader concerns about using QOL assessment as a means of determining who should and should not be eligible for services may be valid, particularly when instruments are used without due consideration of setting, administration or appropriateness. More so, they highlight the need to ensure that not only are the psychometric properties of the instrument rigorously tested, but that the instrument development includes comprehensive investigation and understanding of the multi-dimensionality of disability, participation and functioning.

2.8.5 Vision-Related Quality of Life in Australia

Population-based studies of the impact of vision impairment on the quality of life of Australians were performed by the BMES[183] and the VIP.[184] These studies have used a variety of instruments and were able to show that vision impairment impacts on health related quality of life. There have been numerous other studies (Table 2.4) also showing various associations between specific eye conditions and health related quality of life.

However, only one of these studies has used Aboriginal and Torres Strait Islander participants.[71] It was able to show that cataract surgery not only improves visual acuity outcomes but also results in improved health-related quality of life. In that study the instrument was based on previous vision function and quality of life studies in Southern India and Britain. It was adapted for use by replacing each example in the original question with suitable local examples and simplifying the wording. However, the instrument was not assessed for psychometric performance so its validity remains undetermined.

Table 2.4: Previous studies of Vision Related Quality of Life (VRQOL) in Australia

Instrument	Study Details	Indigenous Population in sample	Reference
Myopia Quality of Life Scale	Measures success of myopia correction	None	[185]
VF-14	Risk of AMD following cataract surgery	Unspecified	[186]
VF-14	Impact of cataract surgery on VRQOL	None	[187-188]
VF-14	Influence of photodynamic therapy for ARMD on VRQOL	None	[189]
VF-12	Impact of cataract surgery on VRQOL	Yes	[71]
Vision Quality of Life Index	Comparison of refractive error corrections on VRQOL	None	[164]
LVQOL	Design of a Low Vision VRQOL instrument	None	[190]
NEI-VFQ25	Correlation between VRQOL and HRQOL	None	[191]
NEI-VFQ25	Effect of vision screening on VRQOL	None	[192]
NEI-VFQ25	Effect of endophthalmitis on VRQOL after cataract surgery	None	[193]
SF-12	Impact of DR on HRQOL	None	[194]
SF-12	Investigate determinants of participation in daily activities with vision impairment	None	[195]
SF-36 & functional assessment	Risk of AMD following cataract surgery	Unspecified	[186]
SF-36	Impact of vision loss on QOL	None	[184]
SF-36	Correlation between VRQOL and HRQOL	None	[191]
SF-36	Impact of cataract surgery on VRQOL	None	[187]
SF-36	Impact of bilateral vision impairment on HRQOL	None	[183]
SF-36	Impact of cataract surgery on HRQOL	None	[163]
SF-36	Associations between age-related vision and hearing impairments HRQOL	None	[196]
EQ-5D	Effect of endophthalmitis on HRQOL after cataract surgery	None	[193]
Vision outcomes	Impact of vision loss on QOL	None	[184]
IVI	Development of instrument	None	[10, 12, 15]
IVI	Impact of visual field loss on participation in daily activities	None	[197]
IVI	Impact of DR on participation in daily activities	None	[194]

Table 2.4: Previous studies of Vision Related Quality of Life (VRQOL) in Australia

Instrument	Study Details	Indigenous Population in sample	Reference
IVI	Investigate determinants of participation in daily activities with vision impairment	None	[195]
IVI	Impact of ARMD on VRQOL	None	[157]
IVI	Further psychometric evaluation with Rasch and Factor analysis	None	[13-14]
IVI	Effectiveness of rehabilitation on VRQOL	None	[198]
IVI	Impact of ARMD on participation	None	[161]
IVI	Validation of instrument in cataract population	None	[199]
IVI-C	Content for VRQOL instrument for children	None	[165]

The incredible discrepancy in vision and eye health experienced by Aboriginal and Torres Strait Islander peoples compared to other Australians necessitates specific vision-related quality of life measures. Cultural differences and different concepts of health and well-being[200-201] increase the need to determine whether both the content of an intended questionnaire and its expression through language are appropriate for use with Aboriginal and Torres Strait Islander peoples.

There are around 100-120 distinct Aboriginal and Torres Strait Islander languages still currently in use around the country.[202] However, Aboriginal and Torres Strait Islander languages are only spoken in the home by 12% of Aboriginal and Torres Strait Islander Australians aged five years and over, the majority of whom (83%) are also proficient English speakers.[34] As a result it can be considered impractical and potentially unnecessary to translate instruments for use in Aboriginal and Torres Strait Islander settings into the local language.

2.8.6 The Impact of Vision Impairment Questionnaire

The Impact of Vision Impairment (IVI) questionnaire is a tool that has been used to assess how vision impairment restricts participating in daily living and affects QOL. It also includes items that examine the emotional reaction to vision loss, which is an important aspect of vision-related quality of life.[12]

The IVI differs from the existing National Eye Institute Visual Functioning Questionnaire (NEI-VFQ)[203] or the disease-specific clinical tools related to treatment such as the VF-14[162] which measure symptoms and functioning. The IVI questionnaire was designed for use in rehabilitation programmes and measures the impact of the vision impairment on a person's ability to participate in their society. The IVI focuses on how impaired vision has had an overall impact on what people want or need to do—as it is not the 'seeing' but the 'doing' that is ultimately important in many situations.[10] This approach is espoused in the WHO's universal model of human functioning and disablement which guided the IVI development approach.

Initial validity testing was performed in Australia which showed the instrument demonstrated a good range of issues, discriminative ability, reliability and relevance.[10-12, 14-15] Subsequent Rasch analysis has proven the IVI is likely to provide a valid and reliable assessment of restriction of participation, which allows for detailed measurements of different types of eye care rehabilitation programs.[13-14, 161, 194, 198, 204] The IVI can be either self administered or interviewer administered. Responses to the IVI items are rated as "not at all" (3), "a little" (2), "a fair amount" (1), "a lot" (0) or "don't do for other reasons" (8). Items scored with an "8" score are not included in the final analysis.

The IVI questionnaire has three domains:[14]

- Reading and accessing information
- Mobility and independence
- Emotional well-being

The IVI has also since been translated and adapted culturally for use in a variety of other settings, such as Melanesia[172] and Timor-Leste,[166] and in school-aged children.[165]

The cross cultural adaptation and translation in Melanesia produced an instrument that exhibited commonality with the Australian version in 19 of the 22 items. This confirms the usefulness of adapting an existing validated instrument for use in cross-cultural research and future comparison rather than developing new instruments.

There were, however, Australian items that were irrelevant to the Melanesian context (items related to reading and independent living) and additional items (religious, community and cooking activities) were added.[167]

2.8.7 Quality of Life Instrument Development

2.8.7.1 Definitions

When designing QOL instruments it is helpful to clarify that the *instrument* or *tool* refers to the entire set of questions and that *items* are the individual questions. *Domains* or *subscales* are groups of questions that are hypothesised to be related or thought to be measuring the same component of quality of life. *Impairment* is the temporary or permanent problems in body structure or function causing significant deviation or loss. *Functioning* is an umbrella term encompassing all body functions and activities. Similarly, *disability* serves as the umbrella term for activity limitations or participation restrictions.[152] *Participation* is involvement and functioning of the person in the social context. *Activity* is the execution of a task or action by the individual.

2.8.7.2 QOL Instrument Development

The methodology for vision-related QOL instrument development is similar to the methodologies used for instruments in psychology, social health or other health related QOL fields. The three basic phases of development are:

1. Generation of content, item identification and format,
2. Initial validity testing and item reduction,
3. Instrument evaluation and optimization.

A literature review will develop an understanding of the nature and concepts(s) of what the instrument is trying to measure and define, and identify the population of interest. New content can be developed through semi-structured, open-ended and in-depth interviews or focus groups.

Initial face validity testing identifies problems in acceptability, relevance and comprehension using participants clinically and demographically representative of the target population.[205-206]

It is also relevant to emphasise the need to limit the burden placed on Aboriginal and Torres Strait Islander research participants. While vision impairment and blindness are significant issues for the Indigenous peoples of Australia, repeatedly conducting preliminary and development studies using Aboriginal and Torres Strait Islander peoples as participants could be considered inappropriate. Aboriginal and Torres Strait Islander peoples have been 'over researched',[207-208] and are distrustful of non-Indigenous health researchers.[17] As a result it was a deliberate strategy of this research to minimise impact on participants where possible. This is discussed further in section 2.10.

2.8.8 Assessment of VRQOL Instruments

There are a number of key criteria that are used to assess the instruments' validity, reliability and responsiveness. Among the criteria for assessment are: reliability, validity, responsiveness, comprehension, respondent and administrative burden, alternative forms, and cultural and language adaptations.[209]

2.8.8.1 Sample size

Instrument validation generally requires a large and comprehensive sample from the target population. While there is some debate in the literature as to the appropriate sample size when validating questionnaires, an appropriate sample size is based on the number of items in the questionnaire, as well as the number and strength of factor loadings in principal component analysis. It is difficult to find a consensus of the issue of how many participants constitutes a 'large' sample, although the sample should be sufficiently large to eliminate participant variance and instability as a significant concern.[206] Tabachnick and Fidell (2001) suggest that a ratio of five cases to one item is adequate.[210]

2.8.8.2 Validity: Construct/Content

The validity of an instrument is defined as the degree to which the instrument measures what it purports to measure. Self-reported health status assessment is commonly classified by the following criteria:

1. Content-related: Evidence that the content of the instrument is appropriate, relative to its intended use and population; and
2. Construct-related: Evidence of discriminative validity, supported by the proposed interpretation of scores, based on the constructs being measured [209]

2.8.8.3 Validity: Responsiveness

Responsiveness refers to an instrument's ability to detect change, even if those differences are small, and is sometimes referred to as sensitivity to change. [211] No agreement or consensus exists on the preferred statistical measure, although assessment or responsiveness involves estimation of an effect of size statistic.[209]

2.8.8.4 Cultural appropriateness and language adaptations/translations

When an instrument is intended for use in a population different from the original, instruments are adapted or translated. In each case the measurement properties of each cultural or language adaptation ought to be judged separately for evidence of reliability, validity responsiveness, interpretability, and burden.[209] The adaptation of an instrument involves two primary steps: (1) assessment of conceptual and linguistic equivalence, and (2) evaluation of measurement properties.[209]

2.8.8.5 Reliability: Internal Consistency

Internal consistency is the extent to which all items measure the same construct and is assessed using Cronbach's formula for coefficient alpha.[212] A Cronbach alpha of 0.70 to 0.90 is commonly accepted to suggest adequate reliability, item homogeneity and internal consistency.[154]

2.8.8.6 Reliability: Reproducibility

Reproducibility is the degree to which an instrument yields stable scores over time among respondents who are assumed not to have changed on the domains being assessed.[211] It is concerned with the instrument's internal consistency, temporal stability (test-retest) and consistency in varied conditions, including different environments, observers or modes of administration

2.8.8.7 Administration

Finally it is important to carefully consider the administration of the questionnaire itself in terms of respondent time burden, respondent cognitive requirements, complexity of respondent scoring, and whether the instrument can be self-administered, or requires interview administration either in person or by phone. In the case of the latter, interviewer variation needs to be minimised.

2.9 National Indigenous Eye Health Survey

This work contributed to the National Indigenous Eye Health Survey (NIEHS), organised by the Centre for Eye Research Australia (CERA), in association with the Vision CRC, CRC for Aboriginal Health, RANZCO Eye Foundation and peak Aboriginal bodies across Australia. The objective of the NIEHS was to determine the status of eye health, prevalence and causes of vision impairment, the distribution and severity of trachoma, knowledge of eye care service utilisation and barriers to eye care service utilisation of Aboriginal and Torres Strait Islander peoples in Australia. The survey has provided an essential evidence base to plan and prioritise for the effective delivery of eye care to Aboriginal and Torres Strait Islander Australians in urban, rural and remote areas.

2.10 Researching Aboriginal General Health and Eye Health

When performing epidemiological research with Aboriginal and Torres Strait Islander peoples, it is essential that the research is guided by the various documents, frameworks and guidelines that have been developed to improve the performance and accountability of Aboriginal and Torres Strait Islander health research.[19, 22, 213]

Historically there has been a great deal of mistrust of non-Indigenous researchers and of research itself.[214] Research has been conducted without consultation or benefit to Aboriginal peoples and non-Aboriginal researchers have been perceived as being more concerned with "career advancement, publications, or educational qualifications" than the welfare of the community.[215]

As a response to these concerns there are calls for community-based participatory research. There is also a growing body of work examining and outlining principles for undertaking research with Aboriginal peoples[216-223] and calling for decreasing the concentration of 'description only' research.[224] These guidelines have been developed to ensure that Aboriginal people are equal partners in research. The principles outlined in these guidelines minimised the risks of harm, discomfort and identification in all aspects of the research process including the reporting of research findings.[21]

The NHMRC (Australia's peak body for supporting health and medical research) guidelines were developed with guidance from Aboriginal people and are written around a framework of Aboriginal and Torres Strait Islander values and principles namely:

- Reciprocity
- Respect
- Equality
- Responsibility
- Survival and protection
- Spirit and integrity[22]

These guidelines guided the researcher in this thesis in operating in a manner with utmost respect when developing research relationships with Aboriginal peoples.

2.11 The Significance of the Study

As discussed in section 2.2, there is great need and urgency to improve health outcomes for Aboriginal and Torres Strait Islander peoples both in terms of life

expectancy and health outcomes. One component of this development can be achieved through improved vision and better eye health. New and thorough evaluations of the status of Aboriginal and Torres Strait Islander eye health are needed[31] to plan and prioritise effective eye care service delivery as outlined by the National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss.[85] Evaluations that are needed include research into the extent and nature of barriers to eye health care and the effectiveness of programs to improve access to health services.

The research presented in this thesis resulted in valid eye examination procedures and instruments that facilitated studies of the presence of eye disease, barriers to services, knowledge and attitudes and impact of vision impairment in Aboriginal and Torres Strait Islander populations in Australia. Ultimately this will help to provide accessible, appropriate and affordable community-based eye and vision care services delivered to Aboriginal and Torres Strait Islander Australians.

This research program supported the recommendations from the WHO Commission on Social Determinants of Health by undertaking specific research studies designed to measure and understand 'need'.[123] Cultural adaptation of a vision-related quality of life instrument culturally is an appropriate measure to assess real life change.

This research project also contributed directly to the action areas presented in the national framework for action to promote eye health and prevent avoidable blindness and vision impairment (Table 2.1). It contributed to the evidence base for approaches to reducing the risk of avoidable vision impairment as well as supporting research into identifying barriers to access and into strategies to improve access to eye health care.

Finally, this research provided a valid, reliable and culturally appropriate methodology that can rapidly assess the prevalence of the main causes of vision impairment in Aboriginal and Torres Strait Islander populations. An adapted instrument investigated the restriction of participation by Aboriginal and Torres Strait Islander with vision impairment from a variety of causes which aids rehabilitation prioritisation strategies. While similar instruments and methodologies have been used

elsewhere previously, this was the first specific adaptation and validation for use in Aboriginal and Torres Strait Islander populations in Australia.

2.12 Benefits to the community

All optometric care was provided at no cost to participants during this component of the study. Uncorrected refractive errors were managed with appropriate prescription or referrals as required at the end of the examination. The study optometrist also provided counselling as needed and arranged follow-up and referrals with the AMS or ACCHS for regional and/or visiting ophthalmologists when necessary.

Where possible efforts were made to recruit local staff, particularly Aboriginal and Torres Strait Islander staff, in an effort to ensure that the study contributed directly to the community in terms of providing education, employment and the opportunity to become involved in studies of Aboriginal and Torres Strait Islander health.

Chapter 3 Methods

3.1 Purpose

The primary purpose of this thesis was to develop the ICEE Toolkit to assess the prevalence and impact of vision impairment in Aboriginal and Torres Strait Islander peoples. This toolkit consisted of two distinct components that were developed and assessed independently. The first of these; Rapid Assessment of Blindness and Vision Impairment in Indigenous Communities (RABVIIC) Protocol was a rapid assessment methodology that can be conducted by non-specialist staff, modified to detect common posterior-segment conditions and tested to ensure validity and cultural acceptability in Aboriginal and Torres Strait Islander communities. The second component, Impact of Vision Impairment: Indigenous (IVI_I) was a vision-related quality of life instrument, modified for cultural appropriateness and evaluated for acceptability of its psychometric properties.

This chapter outlines the methodology for the development and evaluation of these components, data collection processes, sources from which the data was drawn and the analyses performed. The intent was to provide a methodology to assess the prevalence of common causes of vision impairment, as well as assess how well, in terms of validity and scale reliability, the IVI_I could be used to understand the impact of vision impairment in Aboriginal and Torres Strait Islander peoples in Australia.

3.2 Background

When examining eye health in any population it is necessary to ensure that the examination procedures demonstrate reliability, sensitivity and specificity to detect the common causes of vision impairment. One of the key elements of the RABVIIC Protocol is that it can be conducted mainly by non-specialist study staff. As a result it is also essential to have procedures that are effective and can be accurately documented so that they can be replicated by multiple teams across the country.

In order to reduce the sample size in population-based surveys it is important to determine which age groups in the population are most likely to have the highest burden of eye conditions and vision impairment, and restrict the examination to only that population group.

Conducting a survey of Aboriginal and Torres Strait Islander eye health in Australia such as the NIEHS requires exploration of the guidelines outlined above in order for it to be carried out in an effective and feasible manner.

A vision-related quality of life questionnaire has been developed in Australia to measure the impact of vision impairment on restriction of participation in daily activates in three domains of functioning. This study modified this questionnaire for use amongst Aboriginal and Torres Strait Islander populations and evaluated its validity so that the impact of vision impairment amongst Aboriginal and Torres Strait Islander people could be further understood and compared with mainstream Australians. It also allows assessment of real changes in the Impact of Vision Impairment on visual and other functions in the future.

The IVI_I was adapted from the Australian IVI (IVI_A), developed by the Centre for Eye Research Australia (CERA) to measure the impact of vision impairment on restriction of participation in daily activities. Validity testing of IVI_A has been conducted in Australia where it has demonstrated good discriminative ability, reliability, and relevance.[10-13, 15, 194-195] The IVI_A has also demonstrated responsiveness to cataract surgery and low vision rehabilitation.[198, 225] Permission was obtained from CERA (personal correspondence) to develop and validate the IVI_A for use in Australian and Torres Strait Islander populations.

3.2.1 Aim

- To develop a toolkit to assess the prevalence and impact of vision impairment in Aboriginal and Torres Strait Islander peoples

3.2.2 Objectives

- To conduct a pilot study to test protocols and procedures, all aspects of the questionnaire design, community acceptability, burden on both the participating individuals and the survey staff for the National Indigenous Eye Health Survey.
- To compare a rapid assessment with a comprehensive eye examination
- To develop, validate and test a vision-related quality of life instrument for use in Aboriginal and Torres Strait Islander populations.
- Assess the vision-specific health-related quality of life instrument in a representative sample of Aboriginal and Torres Strait Islander peoples.

3.2.3 Hypotheses

- That protocols and procedures as developed and modified in this study for the National Indigenous Eye Health Survey (NIEHS) will reliably detect the common causes of Vision Impairment and Blindness in Aboriginal and Torres Strait Islander adults and children in Australia with adequate sensitivity, specificity and examiner agreement.
- That adaptation of an existing quality of life questionnaire will result in an instrument with acceptable psychometric properties and determine the impact of vision impairment on quality of life in Aboriginal and Torres Strait Islander populations.

3.3 Ethical considerations

3.3.1 Researcher Accountability

The guidelines prepared by the NHMRC [226] on ethical matters in Aboriginal research were consulted throughout the development of the survey and clinical assessment phases of the project.

There have been instances in the past where research has been conducted in Aboriginal and Torres Strait Islander communities without any discernable benefit to the community or knowledge gained. Therefore it was important to ensure that this research study was to be advantageous to the community and the participants. Sunglasses (previously donated to ICEE) were provided to all those who participated in the RABVIIC Pilot Study. Ready-made reading glasses were provided free of charge to all adult participants of the RABVIIC Pilot Study if they were required and custom made spectacles were ordered through the VisionCare NSW spectacle subsidy scheme for any participant who needed them.

The vision and eye health data obtained by the research team were immediately provided to the AMS for their records and any follow-up referrals were coordinated with the relevant Aboriginal Eye Health Coordinator, AMS and the research team. All local staff were paid for their time contributions.

This research was conducted in accordance with the tenets of the Declaration of Helsinki as revised in 2000.

3.3.2 Ethics Applications

Approval was firstly obtained from the Board of Directors of the relevant Aboriginal Medical Services (AMS) prior to the commencement of any data collection.

Ethics applications were made to the Aboriginal Health and Medical Research Council (AHMRC) prior to the commencement of the survey. The AHMRC made suggestions to strengthen the research design and appropriateness of the research instruments to Aboriginal and Torres Strait Islander research participants. Ethical approval was obtained in August 2007. The AHMRC approval was then ratified by the University of New South Wales Human Research Ethics Committee, and the Vision CRC and Institute for Eye Research Human Ethics Committee (VIHEC). Ethical approval and consent letters can be found in Appendix A. The primary ethical approval for the NIEHS was obtained from the Royal Victorian Eye and Ear Hospital.[227] The survey protocol was also formally approved by the following Human Research Ethics Committees: Aboriginal Health and Medical Research Council of NSW, Aboriginal

Health Council of South Australia, Menzies School of Health Research, Central Australia HREC, Western Australian Aboriginal Health Information and Ethics Committee, ACT Health, and Tasmania Health and Medical HREC.

These clearances ensure that the survey protocol conforms to the requirements for health research with Aboriginal and Torres Strait Islander peoples and that it adheres to the National Health and Medical Research Council (NHMRC) ethical standards and guidelines for research with human subjects.

3.3.3 Informed Consent

Potential participants were given an information sheet describing the purpose of the study, methods and information dissemination (Appendix D). Potential participants were also given a verbal summary of the nature and purpose of the study and the procedures involved. If potential participants were happy to proceed, written consent was obtained from all participants prior to their participating in any aspect of the study. Participants were advised that they could withdraw from the study at anytime without penalty.

For children, informed consent was obtained from the parent or guardian of the participating child according to the process outlined above.

3.3.4 Confidentiality

Confidentiality was maintained in all aspects of the study by using identification codes. No patient identifying data were required for the study and participants were assured that no personal information of any persons would be disclosed in any report.

3.3.5 Definition of Aboriginality

Aboriginality was determined according to the currently accepted definition used by the Australian Commonwealth Government:

> *"An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she is associated."*[228]

3.4 The Rapid Assessment of Blindness and Vision Impairment in Indigenous Communities (RABVIIC) Protocol

3.4.1 The ICEE RABVIIC Pilot Study

3.4.1.1 Study Site

The RABVIIC Pilot Study was carried out in a northwest NSW town with nearly 14, 000 residents. At the time of the 2006 Census 2700 residents (19%) reported being of Indigenous origin.[229] The Northern NSW town study site has an AMS managed by a Board of Directors through which the study was conducted. A Census Collection District (CCD) was selected as the study site from which participants of the RABVIIC pilot were recruited.

3.4.1.2 Sample Population

In order to test the sampling strategy of the NIEHS, a single Australian Bureau of Statistics (ABS) designated Census Collection District (CCD) with an Aboriginal and Torres Strait Islander population of approximately 300 persons was selected. The target population consisted of Aboriginal persons of all ages who were residents or visitors of the selected CCD who had spent the previous night in the selected area.

The population of the target CCD (Table 3.1) was estimated using ABS census data collected in the 2006 census.[230] These are considered estimations only as problems with enumeration of Aboriginal and Torres Strait Islander persons are common in Australia.[34]

Table 3.1: Aboriginal and Torres Strait Islander status in the selected CCD by sex[230]

	Male	**Female**	**Persons**
Indigenous	113	135	248
Non-Indigenous	97	125	222
Total	210	260	470

3.4.1.3 Participants

Eligible participants were all Aboriginal and Torres Strait Islander peoples who were residents or visitors of the selected area during the survey period. Individuals who were not of Aboriginal and Torres Strait Islander descent were not eligible to participate. Efforts were made to recruit all eligible 248 participants from the target area.

Prior to the survey, local AMS staff delivered flyers (Appendix B) throughout the target area. During the study period potential participants were contacted directly either by phone or were visited at their homes by a staff member of the AMS and were asked if they would like to participate.

Many difficulties were experienced in recruiting sufficient participants from the specified area. In order to be able to meet the objectives of the study, it was decided to extend recruitment to other nearby areas in an attempt to recruit as many participants as possible to add statistical power to the Pilot Study. We did not select specific areas to concentrate our recruitment efforts, so in effect our sample became a convenience sample.

Efforts were made to ensure that the gender distribution was representative and that persons with low and normal vision were both recruited.

3.4.1.4 RABVIIC Pilot Study Logistics

3.4.1.4.1 Survey team

The survey team consisted of 5 individuals (Table 3.2) who were trained by the survey coordinator. Where possible, efforts were made to recruit local staff, particularly Aboriginal and Torres Strait Islander staff.

AHW study staff underwent one day of training prior to commencing the study and were assessed in their proficiency to measure VA, visual fields and retinal imaging. Trachoma grading was undertaken by an AHW who had prior training in primary eye health care.

Table 3.2: RABVIIC Pilot Study Team	
Staff Member	**Role**
Team Leader	Coordinate RABVIIC Pilot Study
Aboriginal health worker	Informed consent/ questionnaire
Aboriginal health worker	RABVIIC Examination
Optometrist	Conduct definitive examination
Optometrist	Conduct definitive examination

3.4.1.4.2 Examination equipment

The following examination equipment was used:

- CERA VISION screening chart to test near and distance visual acuity which includes a pinhole occluder
- Topcon TRC-NWS6s Non-mydriatic Retinal Camera (Paramus, NJ)
- Nikon D200 digital camera (Melville, NY) for capturing retinal images
- Righton Remtinomax Hand Held Auto Refractor (Tokyo, Japan)
- Trial lens set and frame
- Frequency Doubling Technology (FDT), (Welch Allyn/Humphrey Zeiss, San Leandro, California, USA)
- 2.5x magnification binocular loupes
- Nikon D40X Digital Camera and flash with Nikon AF Nikkor 85mm 1:1.8D lens (Tokyo, Japan) for capturing upper tarsal plate images
- WHO Simplified Trachoma Grading Classification card

3.4.1.5 The Health Services Questionnaire

The Health Services Questionnaire (HSQX, Appendix C) was used to obtain demographic details, relevant medical history and family eye health history. It is anticipated that in the NIEHS the HSQx will be used to evaluate the knowledge, attitudes and health care practices of Aboriginal and Torres Strait Islander people that can be compared across Australia and with results from previous surveys conducted in Australia. It was largely based on The Vision Initiative (TVI)[141] but was modified to better reflect relevant characteristics of contemporary Aboriginal and Torres Strait

Islander life and allow assessment of real change in knowledge, attitudes and health care practice in the future as well as plan appropriate interventions and services and health promotion initiatives.

Permission was obtained from CERA (personal correspondence) to adapt TVI questionnaires and to assess the HSQx for its appropriateness of use in Australian and Torres Strait Islander populations.

Domains investigated in the questionnaire (Appendix C) were:

- General information
- Languages spoken
- Education
- Eye health history
- Four questions from the Impact of Vision Impairment (IVI) questionnaire
- General health history

A Children's Health Services Questionnaire (CHSQx), also based on the TVI questionnaire was modified and reduced to a 6 item questionnaire for applicability to child participants.

3.4.1.5.1 Questionnaire modification

Semi-structured interviews with Aboriginal health workers and the members of the Aboriginal and Torres Strait Islander community were undertaken in order to determine if the questionnaire:

- items were meaningful and relevant;
- response categories were appropriate for Aboriginal and Torres Strait Islander cultures.

Modifications were:

- addition of responses that were considered relevant (e.g. including "service not culturally appropriate" and "discrimination" as available responses to the question "Why didn't you go somewhere for treatment"),
- inclusion of eye condition descriptions (e.g. including "high pressure in the eye" to describe glaucoma,
- Inclusion of information relating to where participants were most likely to seek eye health treatment (e.g. Community Health Centre).

Further detail on these modifications is provided in the respective results sections.

3.4.1.5.2 Questionnaire administration

The questionnaire was administered to all participants following their written informed consent (Appendix D). Each participant was given the opportunity to ask any questions about the survey before participating.

Questionnaires were self-administered apart from when the participant had reading difficulties due to vision impairment or illiteracy. In these instances the questionnaires were administered by AHWs or a member of the study team.

A subset of participants (n=8) were administered the HSQx for a second time after a period of between four and 24 hours to test reliability. The second questionnaire was administered before any treatment, correction or rehabilitation to ensure consistency in circumstances.

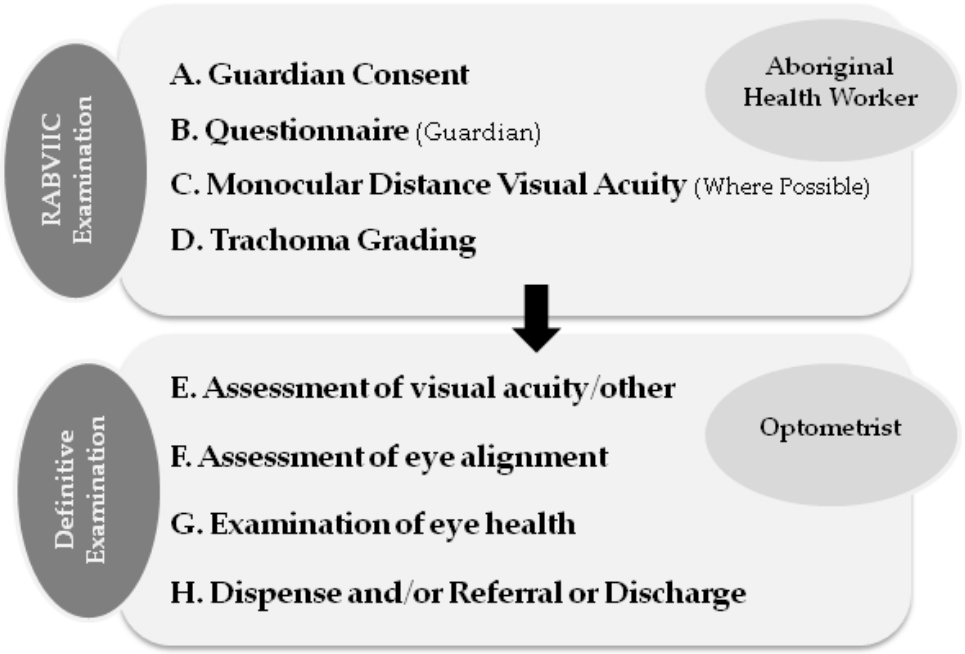
3.4.2 RABVIIC Pilot Study: Examination

The RABVIIC Pilot Study was conducted during the period from July 2007 to November 2008; data were collected on two occasions over a total of two weeks. Study participants were assessed with the RABVIIC examination procedure. The RABVIIC examination was followed by a standardized optometric examination conducted by optometrists for comparison and validation purposes.

3.4.2.1 RABVIIC Examination – Children aged 0 to 4 years

A flow diagram depicting the procedures administered to each child participant aged 0 to 4 years, and the responsibilities for each, is shown in Figure 3.1. As E charts are not suitable for children <5 years, a Lea Chart was use where possible with the younger children.

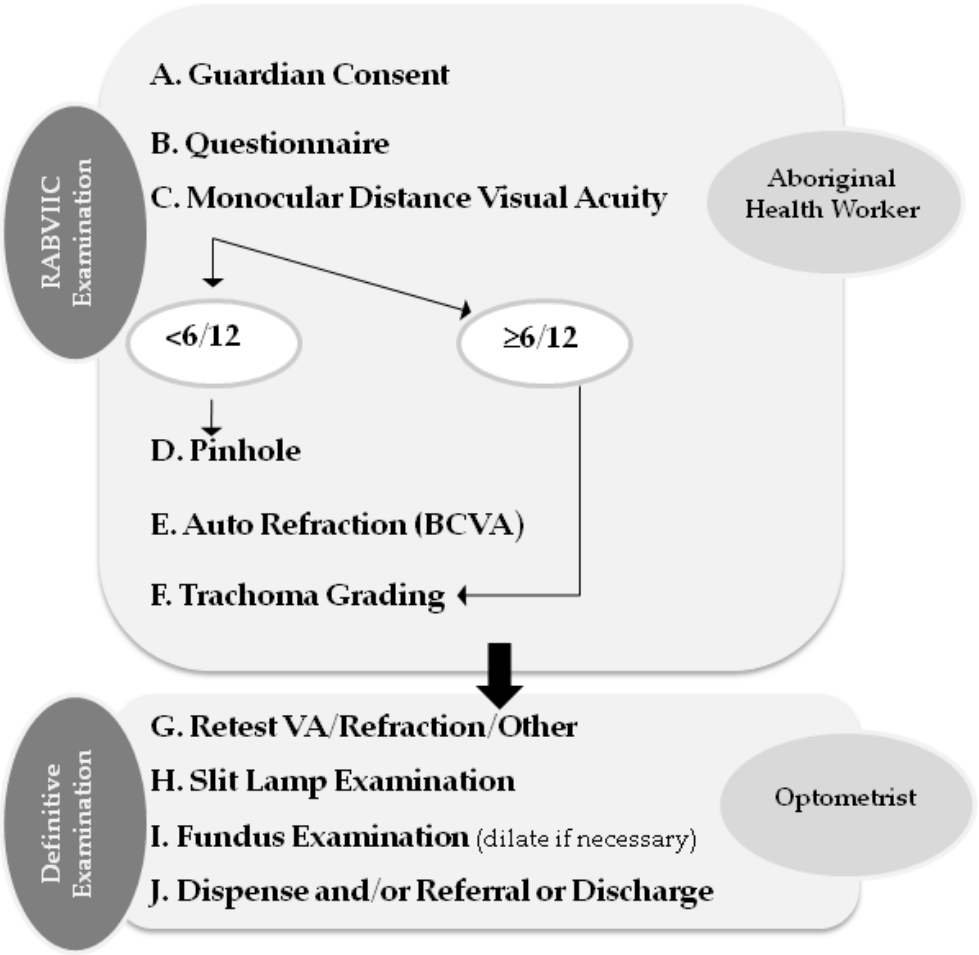
Figure 3.1: RABVIIC flow diagram (Children aged 0 to 4 years)



3.4.2.2 RABVIIC Examination – Children aged 5 to 15 years

A flow diagram depicting the procedures administered to each child participant aged 5 to 15 years, and the responsibilities for each, is shown in Figure 3.2.

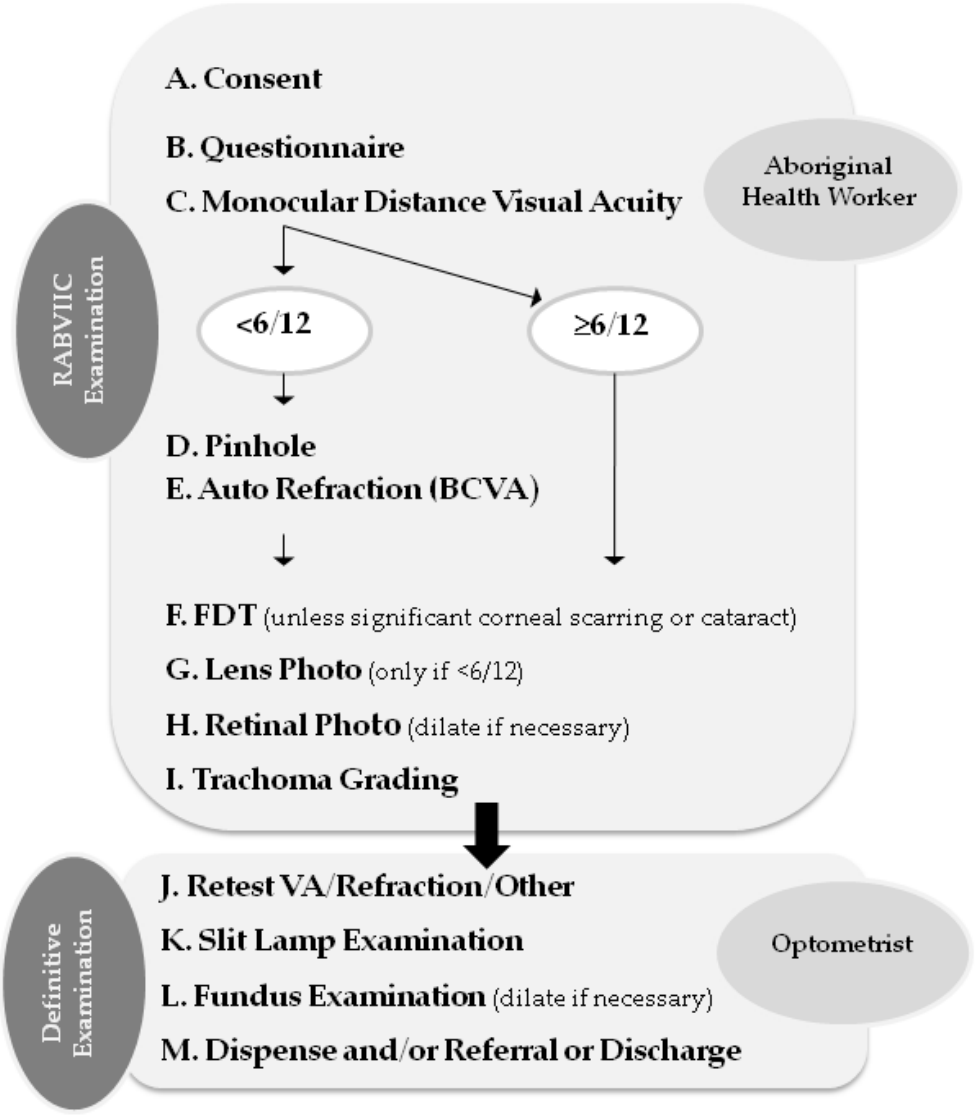
Figure 3.2: RABVIIC flow diagram (Children aged 5 to 15 years)



3.4.2.3 RABVIIC Examination – Adults aged 16 to 39 years

A flow diagram depicting the procedures administered to each adult participant aged 16 to 39 years, and the responsibilities for each, is shown in Figure 3.3.

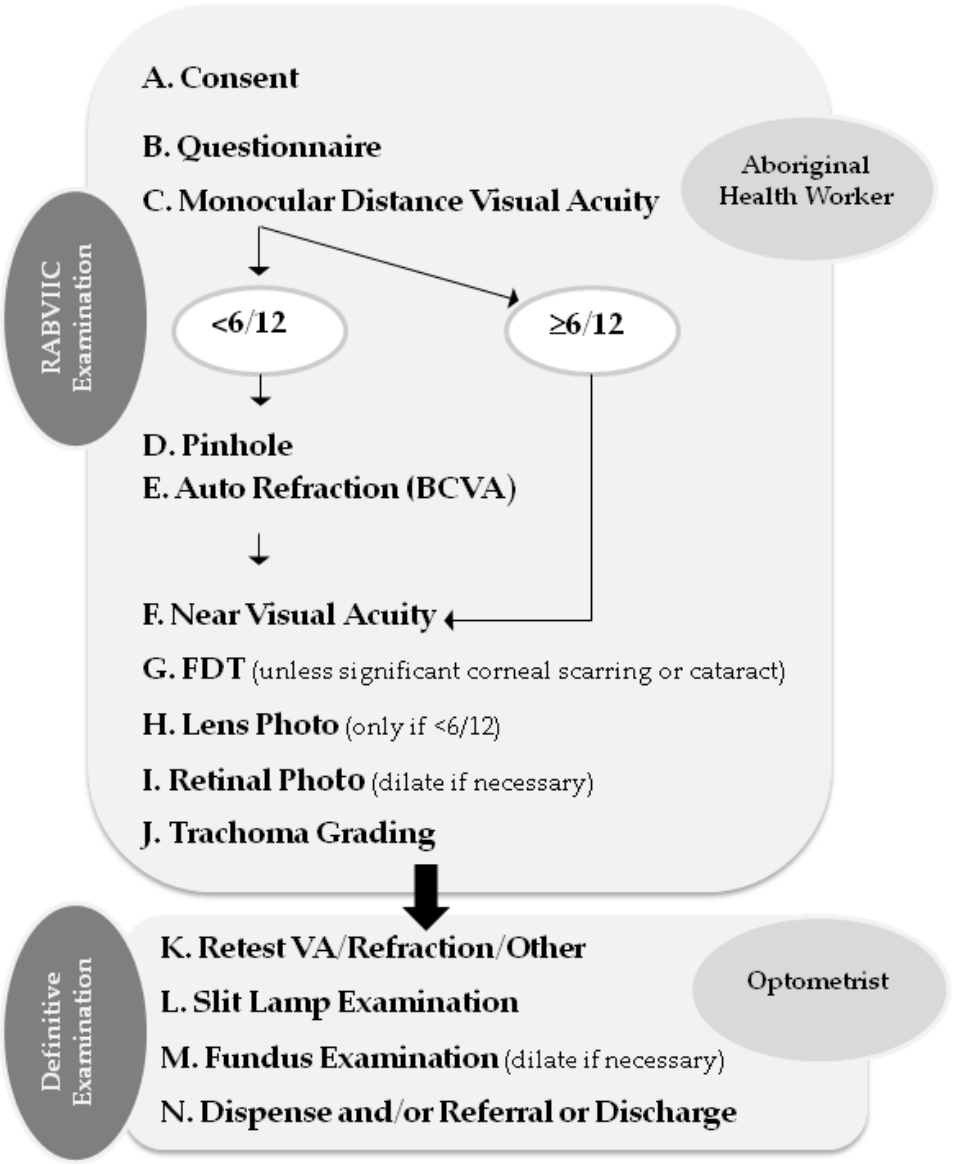
Figure 3.3: RABVIIC flow diagram (Adults aged 16 - 39 years)



3.4.2.4 RABVIIC Examination – Adults aged 40 years and over

A flow diagram depicting the procedures administered to each adult participant aged 40 years and over, and the responsibilities for each, is shown in Figure 3.4

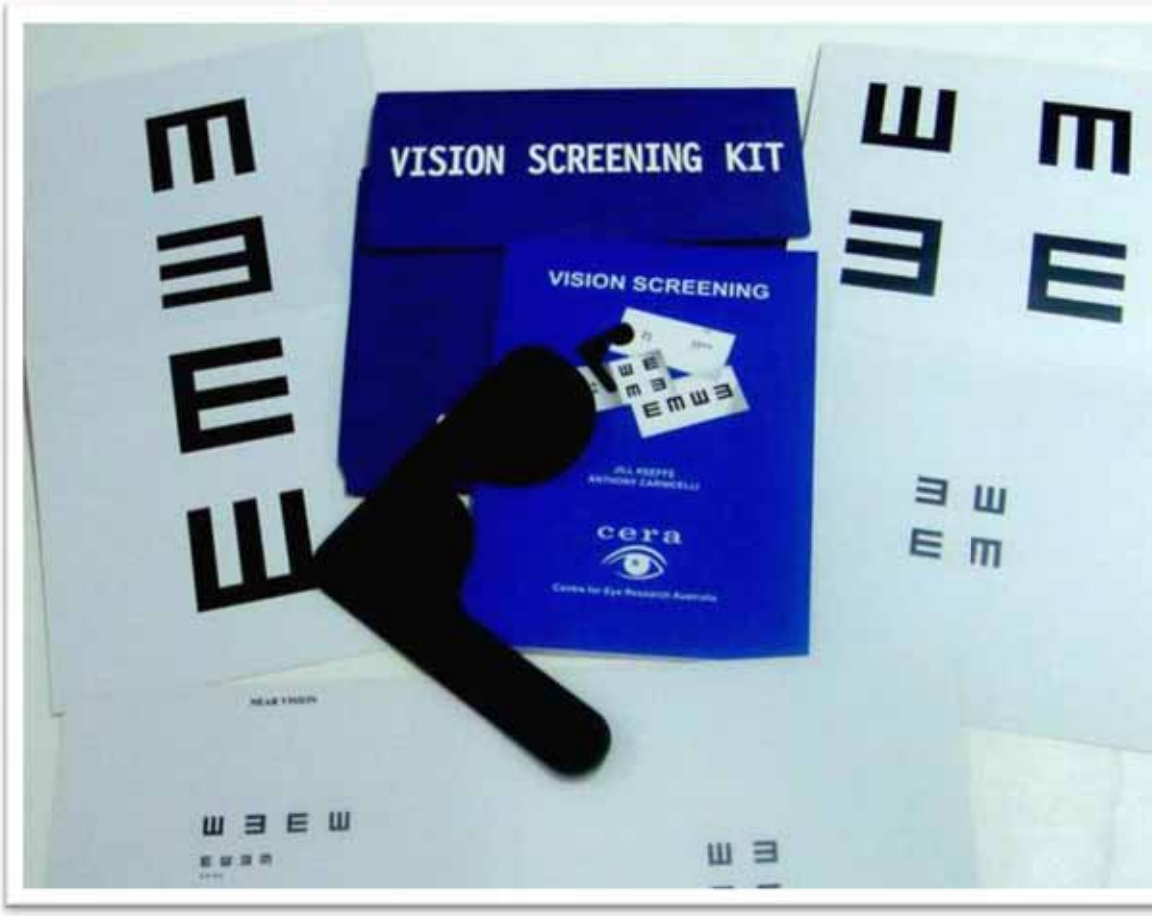
Figure 3.4: RABVIIC flow diagram (Adults aged 40 years and over)



3.4.2.5 Distance VA Using the E Chart

Visual Acuity (VA) was measured using a simplified E test (Figure 3.5), developed by CERA.[231] This test was used as it is appropriate for both illiterate participants and those who do not know the Latin alphabet. It was chosen because it provides a simple and inexpensive tool for rapid population screening. It has demonstrated high sensitivity (85% and 100%) and specificity (96% and 84%) as a screening tool for distance vision, and near vision respectively.[231]

Figure 3.5. CERA vision screening kit



The test uses the Snellen E-optotypes and measures visual acuity at the level of 6/12, 6/18 and 6/60. Four E optotypes with fingers in different orientations are presented to the participant, held at eye level and 3 metres from where the participant was standing or sitting. We made sure no window light or overhead light was reflecting on the chart

by trialling different testing layouts, and selecting the best areas. VA testing was only conducted in those areas.

Participants were tested with their normal distance vision correction if they usually wore any. The left eye was occluded with the participant's hand, and then the visual acuity was recorded as the line at which the participant successfully identified the direction of 3 Es correctly (Figure 3.6). Study staff ensured the participant used a 'cupped hand' over the eye, in order to avoid unnecessary pressure on the occluded eye. Staff also made sure the participant did not 'peek' through gaps in fingers or misalign and spectacles, potentially result in blurred vision if the participant was using bifocals or progressives.

If the participant was unable to identify 3 Es on the 6/12 card, VA was tested at 6/18. If the participant was unable to identify 3 Es on the 6/18 card, VA was tested at 6/60.

If the participant was unable to identify 3 Es on the 6/60 card, their ability to perceive light was determined using a pen torch. The above procedure was then repeated for the left eye.

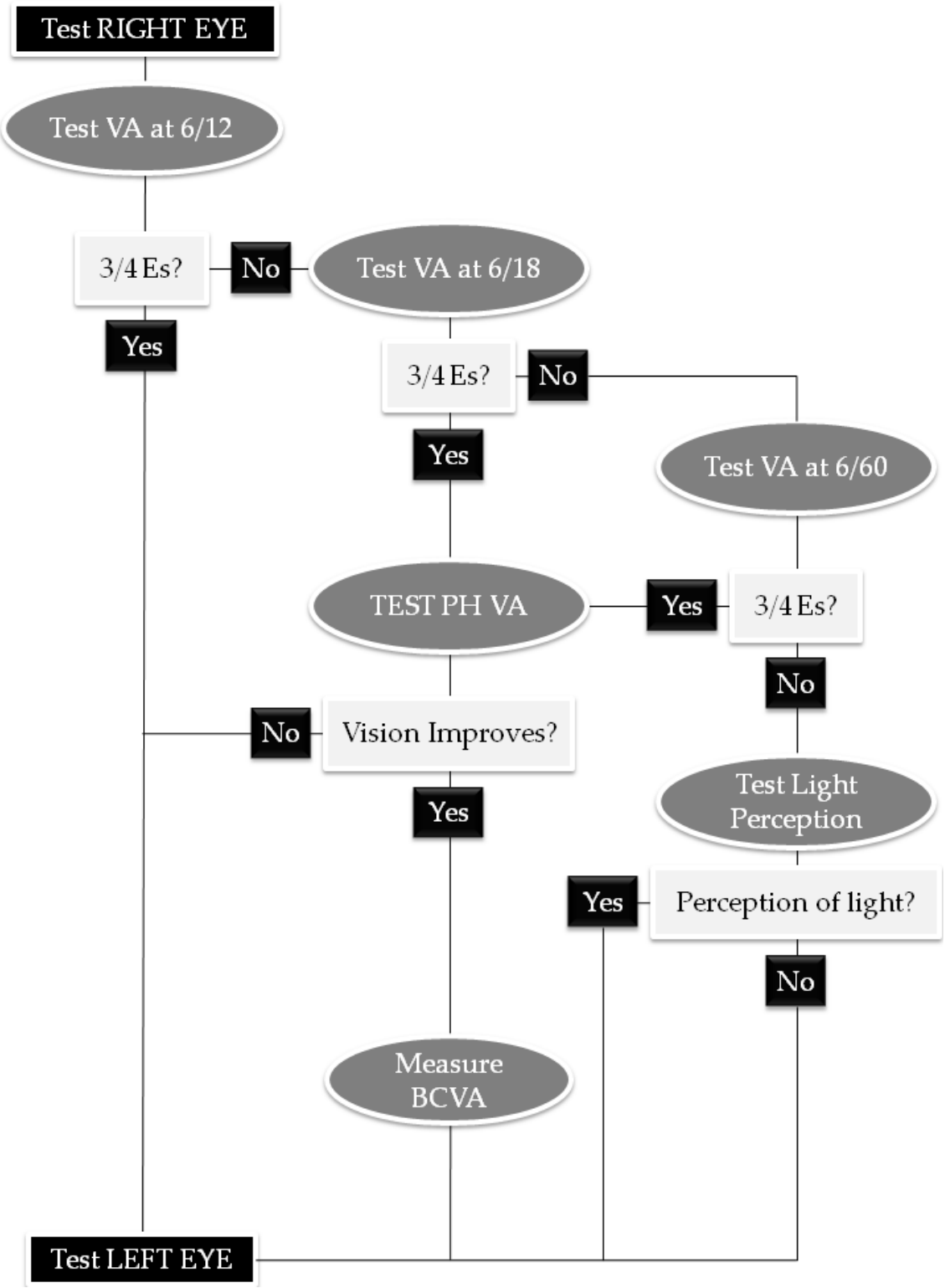
3.4.2.6 Pinhole VA

In order to determine if vision impairment is a result of refractive error or pathology, Pinhole VA was tested if the participant was unable to see 3 Es at 6/12, 6/18 or 6/60. In these instances the participant was asked to look through a pinhole occluder to determine their pinhole VA using the standard VA procedure as outlined in section 3.4.2.5.

3.4.2.7 Best Corrected Visual Acuity

If VA improved with pinhole the Best Corrected Visual Acuity (BCVA) was determined using a hand-held automatic refractor (Retinomax K plus 2, Nikon Corp, Japan). The auto-refraction result was corrected using trial lenses and BCVA was determined using the VA protocol as outlined in section 3.4.2.5.

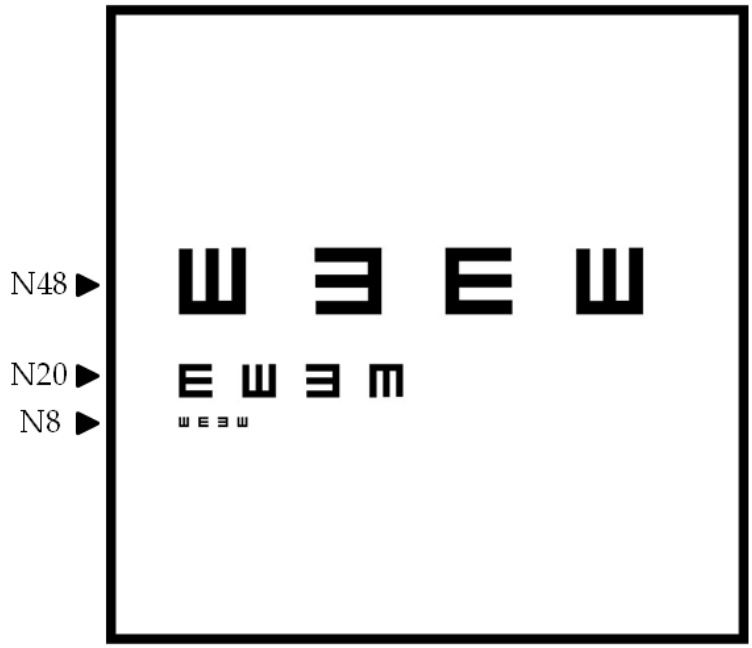
Figure 3.6: Distance Visual Acuity Protocol



3.4.2.8 Near VA

Near VA was measured using a tumbling near E chart, held at the participant's standard reading distance (Figure 3.7).

Figure 3.7. Near VA E test card



Again, VA testing was only conducted in specified areas, where no window light or overhead light reflected on the chart.

Participants were tested with their normal near vision correction, if they usually wore any using both eyes. Participants were asked to identify the direction of the Es on each line starting at the N20 line, and a pass was recorded if the participant was able to correctly identify the direction of three out of the four Es on the respective lines.

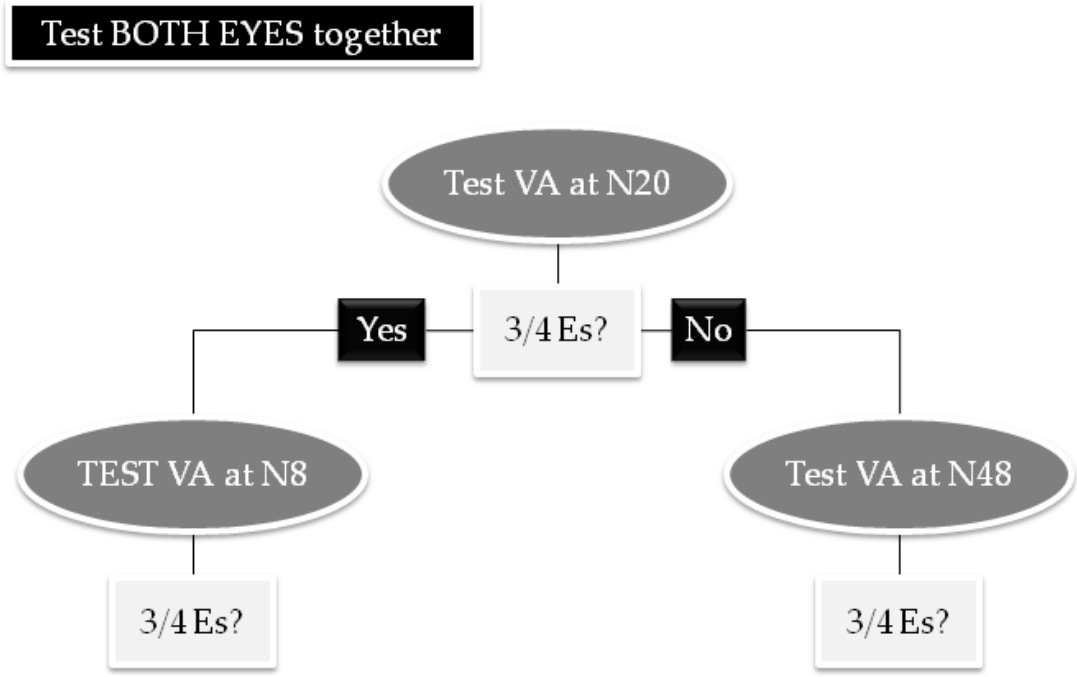
3.4.2.9 Visual Field assessment - FDT

Frequency Doubling Technology (FDT) was used to specifically test for visual field loss due to certain types of cell death that typically occur from glaucoma. FDT was used in preference to Humphrey Field Analyser (HFA) as the FDT is portable self-contained unit that weighs less than 10kg. The FDT used in screening mode has previously been described,[232-233] and can accurately determine the location and depth of scotomas when

compared with full threshold Humphrey 24-2 with adequate sensitivity and specificity. Criteria for a reliable test were no more than two fixation errors (33%), and no more than two false-positives (33%). Participants with any miss of any severity repeated the test. Participants missing more than one point of any severity after repeating the test were considered abnormal.[234-236] The right eye was tested first. The test was not repeated if the participant was not able to respond reliably to the instructions necessary for the completion of the test or if the participant could not see the fixation target.

The FDT test was administered using the participant's normal distance correction (including Bifocals). FDT was not performed if the participant was observed to have corneal scarring or significant cataract.

Figure 3.8: Near Visual Acuity Protocol



3.4.2.10 Trachoma grading

The WHO Simplified Grading System (Appendix E) developed for non-specialist health personnel,[237] shown in Table 3.3, was used to record trachoma using 2.5x magnification loupes and good lighting.

Facial cleanliness was observed (i.e. 'sleep' or dirt crusting around the eyes) and the cornea was examined for opacities. The upper eyelid was then pushed upwards slightly to expose the lid margins so that it was possible to examine for trichiasis (in-turned lashes or evidence of previously removed lashes.) The eyelids were then everted and examined for signs of trachoma. Photographs of the tarsal plate were captured with a digital camera and macro lens for grading validation purposes.

Table 3.3: The World Health Organization (WHO) Simplified Grading System for trachoma[237]

Stage	Description
Follicular Inflammation (TF)	Five or more follicles (whitish round spots, paler than the surrounding conjunctiva) of at least 0.5 mm in diameter on the upper tarsal conjunctiva Community Antibiotic Programs Facial cleanliness
Intense Inflammation (TI)	Inflammatory thickening of the tarsal conjunctiva that obscures 50% or more of the deep tarsal vessels. In TI, the tarsal conjunctiva often appears red, roughened and thickened. This should not be confused with thickening caused by scarring
Trachomatous Scarring (TS)	Scarring in the tarsal conjunctiva. This is visible as white lines or bands on the tarsal conjunctiva. Scarring may also obscure tarsal blood vessels but should not be confused with diffuse inflammatory thickening
Trachomatous Trichiasis (TT)	At least one eyelash rubs on the eyeball. Evidence of recent in turned eyelash removal should also be graded as trichiasis
Corneal Opacity (CO)	Easily visible corneal opacity over the pupil. Central corneal scarring must be sufficiently dense to blur at least part of the pupil margin

3.4.2.11 Retinal and lens assessment

The Topcon TRC-NW6S camera is a non-mydriatic digital retinal camera which allows 45° retinal colour photographs to be taken of the posterior pole and mid-peripheral retina without pupillary dilation (it is connected to a colour digital camera and is used to acquire images of the retina).[238] The software used for the digital camera was Nikon Capture Camera Control.

The camera was located in a darkened room and participants spent a 3-5 minutes in the dark room prior to imaging to induce pupil dilation.

The right eye was always photographed first (after up to 5 min of adaptation to the dark). Two photographs were taken with one centred on the macula, the other centred on the optic nerve head. Patients were asked to close their eyes for a few seconds between each photograph. After an interval of 2–3 min the left eye was photographed. The whole session lasted about 10 min for each patient. The photographer viewed each digital image immediately and repeated the image acquisition process if the original

image was unsatisfactory. If it was not possible to take an adequate image due to small pupils, dilating drops were used to induce pupil dilation. Digital photography of the fundus was performed without correction (distance or near).

If fundus photography showed disease or an eye condition that required attention participants were referred to an ophthalmologist.

If adult participants had distance visual acuity of less than 6/12 in either eye, images of the anterior segment of the eye were taken and assessed for the presence or absence of cataract or corneal opacity. This method of using a fundus camera to document lens opacities has been described previously[239] and has good sensitivity and specificity to detect visually significant cataracts compared with slit-lamp biomicroscopy. In this method the plus ten dioptre lens in the camera is used so that the focal point can be adjusted to focus on the lens.

3.4.3 Definitive Examination

After the 'rapid assessment' all participants also received a comprehensive eye examination to ensure that the RABVIIC is sensitive and specific in detecting common causes of vision impairment in Aboriginal and Torres Strait Islander populations. The definitive examination was conducted by a qualified optometrist and consisted of 1) an assessment of the visual acuity in each eye; 2) an assessment of the visual acuity with pinhole in each eye; 3) an examination of the lens in each eye; and 4) an assessment of the main cause of VA<6/12 in each eye and in person using a slit lamp and ocular fundus examination. Dilation drops were used when the examiner was unable to get a clear view of the fundus. Refractive error was measured on all those who presented with distance VA worse than 6/12 in either eye and near VA worse than N8. For subjects who could see 6/12 or better or N8 or better with their presenting refractive correction they were not considered to have any under or uncorrected refractive error.

3.4.4 Data Management, Grading and Analysis

3.4.4.1 Diabetic Retinopathy

Lens and retinal photos were graded at the Retinal Vascular Imaging Centre (RetVIC).The grader was masked to any other information about the participants' vision and examination results.

Grading of all digital photographs took place after the data collection phase of the survey was complete. Photos were graded for diabetic retinopathy, age-related macular degeneration, possible glaucoma, cataract and other abnormalities using images of the retina, lens and disc.

Diabetic retinopathy was classified according to Clinical Practice Guidelines published by the NHMRC and criteria established by the Early Treatment Diabetic Retinopathy Study.[109, 240] These guidelines broadly group retinopathy into Non-Proliferative Diabetic Retinopathy (NPDR), proliferative diabetic retinopathy (PDR) and clinically significant macula oedema (CSMO), according to the following criteria:

- Mild/moderate NPDR includes at least one definite haemorrhage or micro aneurysm.
- Severe NPDR includes any: haemorrhages or micro aneurysms in all four quadrants, severe Intra-Retinal Micro vascular Abnormalities (IRMAs) in one or more quadrants, venous beading in two or more quadrants.
- PDR includes any: New Vessels on the Disc (NVD) or New Vessels Elsewhere (NVE), vitreous/pre-retinal haemorrhages and NVE <1/2 disc area without NVD.

Macular oedema was recorded separately. The criterion for the diagnosis of macular oedema was retinal thickening within 2 disc diameters of the macula centre and definite hard exudate (due to or associated to DR) within 1 disc diameter from centre of the macula on digital photos.

The clinical examiners used the same grading criteria.

3.4.4.2 Age-related Macular Degeneration

Age-related macular degeneration was graded using the International Classification of Grading System for Age-related Maculopathy and Age-related Macular Degeneration, [241] using images taken with the non-mydriatic fundus camera.

Retinal photos were assessed for absence or presence of AMD according to the following criteria:

- Early AMD includes drusen >125 microns and /or pigment changes within 1500 microns of macular centre.
- Late AMD includes geographic atrophy or evidence of neovascular AMD.
- Other ocular abnormalities are also recorded using the Wisconsin Age-related Maculopathy grading system.

The clinical examiners used the same grading criteria.

3.4.4.3 Glaucoma

Optic photos were assessed for absence or presence of glaucoma. Vertical cup to disc ratio on retinal images was classified into two groups: less than 0.6 and greater than or equal to 0.6. An overlay transparency sheet was used to determine whether the vertical cup to disc ratio on the retinal images was greater than 0.6. The overlay transparency sheet consisted of 4 dividing lines spaced so that the upper and lower lines could be placed on the upper and lower edges of the optic disc and the two inner lines defined a 60% cup.

A glaucoma diagnosis was made if a participant had a CDR > 0.6 and missed ≥ 2 points on the FDT.

The clinical examiners were asked to specify whether glaucoma was suspected or not, based on optic nerve head appearance.

3.4.4.4 Cataract

Lens photos (for participants with VA <6/12) were assessed for absence or presence of cataract and categorised into the following three groups:

- No cataract,
- Probable cataract, and
- Definite cataract.

A pilot study during The Vision Initiative demonstrated good sensitivity, specificity and inter-observer reliability in assessing the presence and absence of cataract causing vision impairment using a non-mydriatic camera in comparison to dilated biomicroscopy examination. The study also showed that when VA was <6/12 or in the presence of sever cataract, perfect agreement was reported between examiners.[239]

The clinical examiners used the same groupings.

3.4.4.5 Data Analysis

Data were entered into a Microsoft Access database (Microsoft Corporation, Redmond, WA). Statistical analyses were performed using SPSS 16.0 software (SPSS Inc, Chicago, IL, USA). The prevalence of each condition was determined for each age group, and the degree of agreement between examination methods was calculated with the weighted kappa statistic for categorical judgment.[242] Analysis were conducted 'by eye' in order to increase power. Positive likelihood ratio (PLR) and negative likelihood ratio (NLR), sensitivities and specificities, positive predictive value (PPV) and negative predictive value (NPV) were also calculated. The visual status and any causes of vision impairment as determined by the RABVIIC and the comprehensive examination were compared for each patient and the sensitivity and specificity of the screening protocol in detecting the common causes of vision impairment were determined.

Completed questionnaires were double entered into a Microsoft Access database. Two research assistants entered the data into separate databases, which were compared for data entry consistency. A detailed analysis revealed conflicting responses and necessary corrections were made before the analysis was performed.

The visual status of the participants that constituted the sample frame of the NIEHS (individuals aged between 5 to 15 years and ≥ 40 years) were used to predict the prevalence of vision impairment for the full study population by extrapolating linearly

between persons aged 15 to persons aged 40, and from persons aged 5 to zero in order to determine whether the age groups selected by the national survey are appropriate.

3.4.5 NIEHS: Study Design

The NIEHS study methodology was based on the RABVIIC Pilot Study Protocol presented in this thesis.

The NIEHS was designed to collect vision and eye health data from a representative population of 3,000 Aboriginal and Torres Strait Islander Australians aged 5-15 years and 40 years and above. As the majority of vision impairment is associated with aging, a sample size of 1,500 was chosen for adults 40 years and older to detect a 10 percent minimum difference in presenting vision impairment from that reported elsewhere for Australians aged 40 years and older (4.2%), with an alpha of 0.05 and a beta of 0.20.[243] Similarly, a sample size of 1,500 was chosen for children to detect a 10 percent minimum difference in the rates of presenting vision impairment in the better eye. The number of approximately 50 children per cluster accorded with the World Health Organization recommended sample size for the assessment of trachoma and enabled the results to be included in the NTSRU Trachoma Surveillance Report.[243-244] A minimum cluster size was set at 200 people per site in order to yield approximately 54 children aged 5 to 15 years (27% of the population) and 44 adults aged 40 years and older (22%). The target cluster population of 300 was chosen as it was expected to contain approximately 82 children and 67 adults.[34, 243]

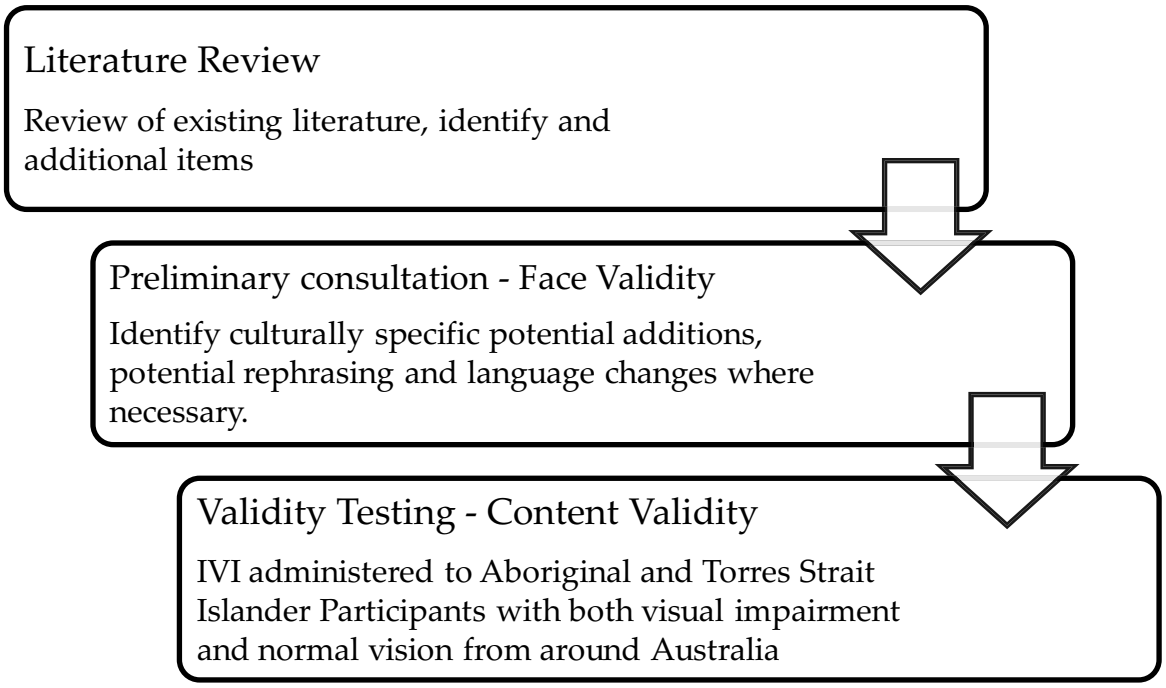
Participants were randomly selected using a multi-stage, random cluster sampling methodology, stratified by Remoteness Area according to the Accessibility and Remoteness Index of Australia (ARIA). This sampling frame consists of 50 adults over 40 and 50 children aged five to 15, selected from 30 Aboriginal and Torres Strait Islander communities, each containing approximately 300 Aboriginal and Torres Strait Islander peoples.

3.5 IVI_I Questionnaire

3.5.1 Development Overview

Development of the IVI_I was undertaken through three main phases (Figure 3.9).

Figure 3.9: Development and Validation of the Aboriginal and Torres Strait Islander IVI (IVI_I)



3.5.2 Literature Review

A search was undertaken to review the existing literature and identify any potential additional items to add to the existing IVI_A. Key areas of investigation were Aboriginal and Torres Strait Islander concepts of health and wellbeing, particularly those related to vision impairment and participation, functioning and quality of life.

3.5.3 Preliminary consultation

As outlined in section 3.3.1, due to difficulties in conducting research in Aboriginal and Torres Strait Islander communities, it was deemed that a full scale pilot study of the instrument would not be conducted. Instead, the face validity of the questionnaire was tested by consulting with Aboriginal and Torres Strait Islander peoples, Aboriginal health workers, Aboriginal eye health coordinators, optometrists who provide eye care

to Aboriginal and Torres Strait Islander peoples, and other eye health professionals and experts.

Semi-formal interviews were conducted with participants who were asked to provide feedback at the time of interview. Participants were asked the open-ended question "how do you believe poor vision affects Aboriginal and Torres Strait Islander peoples living in Australia?" Further questions were based upon the responses and prompts were used where necessary. Respondents were also asked to identify items or responses scales that were not appropriate, identify any language changes that may be necessary and to identify any additional items that may be relevant.

As a result of the vast number of Aboriginal and Torres Strait Islander languages and the relatively high level of English proficiency[34] the IVI questionnaire was not translated into any Indigenous languages.

3.5.4 Recruitment

Eligible participants were recruited through three mechanisms; (1) the RABVIIC study in Northern NSW, (2) the NIEHS, and (3) Aboriginal and Torres Strait Islander peoples presenting with vision impairment or blindness to regular ICEE clinics around NSW were also invited to participate. Individuals who were not of Aboriginal and Torres Strait Islander descent were not eligible to participate. Efforts were made to ensure that the gender distribution was representative and that persons with low and normal vision were both recruited using purposeful sampling.

Remoteness was classified according to the ARIA index.[245]

3.5.5 Questionnaire Administration

Every participant had the nature and purpose of the study explained to them and gave written informed consent.

Data were also collected on whether a language other than English was spoken at home, highest level of education, presenting distance and near visual acuity. For the participants attending ICEE clinics, the main cause of vision impairment was recorded

with VA testing results. For the remaining participants, the cause of vision impairment was abstracted from their eye examination results. Habitual vision was recorded at the time the data were collected.

The IVI was either self-administered according to the guidelines for IVI administration[15] or administered face-to-face to adult participants with responses recorded by a trained interviewer. An AHW, other community member or member of the study team was available to assist when needed. Answers were recorded on a four point Likert scale (0-3). Responses regarded difficulty experienced "in the past month" and were recorded as "not at all" (3), "a little" (2), "a fair amount" (1), "a lot" (0) or "don't do this for other reasons" (8). Items recorded as an "8" were excluded from data analysis.

Total scores were recorded as the arithmetic average of the item responses (range of 0-3) not including missing or excluded data. One of the primary criticisms of using Likert scales is that there is no standard distance between response options (i.e. the difference between "a fair amount" and "a lot" can vary considerably from participant to participant). Additionally, there can be variability between items, as the response "a lot" on one item may not be representative of the same amount of time for another item. As a result taking the arithmetic mean of the scores assumes that scale has interval scale properties, when none might exist. However, there is a general implication in the IVI that the Likert values are monotonic with the underlying trait that they are endeavouring to assess, and previous Rasch analysis has resulted in an instrument with interval like scales.[13]

3.5.6 Analysis

3.5.6.1 Data management

The questionnaire data were entered into a Microsoft Access database (2007; Microsoft Corporation, Redmond, WA). Double data entry was performed to identify data entry errors; discrepancies were examined by the author and corrected as necessary.

Statistical analyses were performed with Microsoft Office Excel (2007; Microsoft Corporation, Redmond, WA) and SPSS (version 17; SPSS science Chicago, IL).

3.5.6.2 Descriptive statistics

Descriptive statistics were obtained for all variables. Items were analysed to give percentage responses, means, standard deviations and skew. Correlations were calculated among items, and the proposed scales, and between the proposed domains.

The number of missing values for each item was determined as an indicator for item comprehension and relevance.

Total instrument scores were evaluated for normality using the Kolmogorov-Smirnov test for normality of a distribution.

3.5.6.3 Construct validity

The distribution and range of responses across each item was assessed as an indicator of relevancy. Items were also examined for the 'don't do this for other reasons' response as a high response rate would indicate irrelevancy of the item.

Floor and ceiling effects, which indicate irrelevancy and the inability to discriminate between participants, were examined. Items where ≥70% of the participants with vision impairment responded that they had no difficulty doing the task were identified as displaying a floor effect. Similarly, items where ≥70% of the participants with vision impairment reported that they experienced difficulty all the time were identified as displaying a ceiling effect. In order to investigate the floor or ceiling effect further, items displaying floor or ceiling effects were examined on the basis of the participants' remoteness or degree of vision impairment.

The correlation between items was assessed with Spearman's rank correlation. Consistent with prior IVI validation studies, items that correlated too closely (>0.70) were considered for removal.

The ability of the items to discriminate between vision categories was also examined with the Kruskal-Wallis test, taking into account the concept of the item and which

component of vision it theoretically measures (i.e. distance or near vision). Statistical significance was set at $p<0.05$.

As there were a high proportion of participants with normal vision, the majority of these investigations were conducted with all participants and again with vision impaired participants for comparison purposes. It was expected that participants with normal vision would frequently report no vision-related task difficulty (0) and may falsely skew results towards floor effects of low overall score and falsely increase the correlation of items with each other. Only data from participants with vision impairment were considered in floor and ceiling effects, instrument score and Spearmans's correlation coefficients.

3.5.6.4 Item Reduction

A set of psychometric criteria were developed in order to identify items suitable for removal.

- 80% of responses from vision impaired participants loading onto one response category;
- > 10% of participants indicating that they "did not do this for other reasons";
- >70% vision impaired participants reporting they had no difficulty with an item;
- >80% vision impaired participants reporting that they had difficulty "A lot";
- Absolute skewness >1.5
- SD<0.5, and
- Significant inter item correlation (>0.70).

Items that met at least one of these criteria were taken into consideration for removal.

3.5.6.5 Principal Components Analysis

Exploratory and confirmatory principal components analysis was used to identify the relationship of items to each other.

3.5.6.5.1 Exploratory factor analysis

The underlying internal factor structure of the questionnaire was examined using exploratory factor analysis. Factor analysis assesses which items group together and assists with the identification of underlying factors, domains or subscales that may be present.

Factor analysis extracts the greatest amount of variance for each of the concepts or items that are being factored, and in so doing links the variable with a specific factor. Each item has a specific factor loading or eigenvalue which represents the correlation between the factor and the item. The higher the factor loading, the greater the impact the factor has on the concept, or the more meaningful it is. The square of the factor loading (R^2) indicates the proportion of variance of a given indicator accounted for by the factor.[246] Each additional factor is uncorrelated with the first, maximizing the amount of variance extracted. This leaves the fewest factors to account for the most variance. Such analysis also produces a correlation matrix which provides communality estimates between the extracted factors.

Factors are then rotated to improve interpretability and provide a clear and simple method of associating the original items to the factors. If there is a theoretical reason to suppose that the factors should be related, the oblique rotation, rather than orthogonal should be used.[246] In this instance we expect that correlations will exist between the factors related to restriction of participation as a result of vision impairment. This hypothesis was confirmed by the correlated factor structure in the component correlation matrix. A value of 0.40 was established as the cut-off point for significant factor loading, even though it has been argued that loadings as low as 0.32 are appropriate.[247]

The Kaiser criterion, which suggests including all factors with an eigenvalue greater than 1 in the final model, was used to determine which factors to retain., The Cattell scree test was then used to discern the optimal number of factors by plotting components on the X axis and the corresponding eigenvalues as the Y axis to extract the most substantive factors.[210] With this method the "elbow" or the last substantial

drop in the magnitude of eigenvalues can be used to indicate the number of factors to retain.

Factor solutions were re-examined to determine whether they were theoretically consistent and repeated until a solution was attained in which all items included in the analysis met all criteria.

3.5.6.5.2 Confirmatory factor analysis

Once a hypothesized model has been developed through item reduction and exploratory factor analysis, this model is tested using confirmatory factor analysis (CFA). CFA is a particular type of structural equation modelling technique used to determine the goodness-of-fit index (GFI) between a model already obtained by another researcher and the sample data.

The sample size required for CFA is not clearly established in the literature and current conventions range between participant ratios of 3:1 to as high as 12:1. Simulation studies indicate that stable factor models can be found with samples as small as 100[248] and with samples as small as 150 if 10 or more items load at 0·4 or higher.[249] The hypothesized IVI_I model consisted of 25 items, and all items loaded at 0.4 or higher. Accordingly it was determined our sample size of 172 participants was adequate.

CFA was also undertaken to assess the hypothesized model with the findings of previous models.[14-15, 195] Previous solutions are comprised of either a three factor model (mobility and independence, emotional well-being and reading and access to information) or a four-factor model (mobility and safety, emotional well-being, independence, and reading and near-vision activities).

3.5.6.6 Internal Reliability

The internal reliability for the total instrument and the final domains identified in the CFA was estimated with the Guttman split-half correlation, which was used to assess the correlation between two halves of each scale.

The unidimensionality of the instrument as a whole was assessed using Cronbach's alpha, an average of corrected item-to-total correlations of the instrument.[206] This

approach determines the correlation of every item in the instrument with every other item. The Internal reliability of each of the domains was also assessed with Cronbach's α coefficient.

3.5.6.7 Discriminant Validity

Convergent construct validity was investigated using mean item score and presence and severity of vision impairment. The addition of participants with normal VA allowed for group construct validity testing. Discriminant construct validity was investigated using the variables remoteness, gender, age, cause of vision impairment, language and education compared with mean item score. Differences were tested with the Kruskal Wallis and Wilcoxon–Mann–Whitney tests. Statistical significance was set at $p<0.05$.

3.5.6.8 Multiple Linear Regression

We conducted Univariate linear regression to estimate the effect of clinical variables, sociodemographic variables and location on IVI_I scores for the instrument and each domain. $P<0.1$ was the critical value for significance in this analysis. Factors significant at $P<0.1$ were considered for the multivariate analysis.

Hierarchical multivariate analysis (multiple linear regression) was then used to examine the associations between IVI_I scores and visual acuity (distance and near), after adjusting for potentially confounding variables. Hierarchical multiple regression was used as we wanted to control for the possible effects of age and gender, and evaluate the ability of the model to still predict a significant amount of the variance in IVI_I scores. Four models were created to determine the most robust predictors for the IVI_I total score and each of the three domains. Preliminary analyses were conducted to confirm that the models did not violate the assumptions of normality, linearity, multicollinearity and homoscedasticity. The critical value of significance in the regression models was set at $p<.05$.

Chapter 4 Results

4.1 Purpose

As discussed in previous chapters, the purpose of this study was to develop a toolkit to assess the prevalence and impact of vision impairment in Aboriginal and Torres Strait Islander peoples. This chapter outlines the results obtained from the RABVIIC Pilot Study conducted in Northern NSW by non-specialist study staff and makes comparisons with a comprehensive examination conducted by an eye care practitioner. The intent is to provide a methodology to assess the prevalence of common causes of vision impairment in Aboriginal and Torres Strait Islander Communities in the NIEHS. Such a rapid examination also has applicability in other contexts as an extension of the RAAB methodology that includes more assessment of posterior-segment conditions. Subsequently, this chapter presents the results from the adaptation and validity testing of the IVI_I which can ultimately be used to gain a greater understanding of the impact of vision impairment in Aboriginal and Torres Strait Islander peoples in Australia.

4.2 RABVIIC Pilot Study

4.2.1 Refining the Health Services Questionnaire

The Health Services Questionnaire was based on the questionnaire used by The Vision Initiative (TVI) but modified for cultural appropriateness and relevancy. The Adult Health Services Questionnaire (AHSQx) modifications were based on advice from the Centre for Eye Research Australia, International Centre for Eyecare Education (ICEE) optometrists who provide eye health services to Aboriginal and Torres Strait Islander peoples, Office of Aboriginal and Torres Strait Islander Health (OATSIH), and Aboriginal Health Workers (AHWs), particularly the Aboriginal Eye Health Coordinator (AEHC). The original TVI questionnaire contained 15 questions (62 individual items). 14 items were deemed irrelevant or not appropriate and were removed (Table 4.1) to create a 14 question (48 items) questionnaire.

Table 4.1: Questions in TVI questionnaire that were not included in the HSQx
f) Daytime Telephone Number
1 ii) Are you of Aboriginal or Torres Strait Islander origin
3 iii) How old were you when you FIRST started wearing glasses or contact lenses?
4 i) Year of diagnosis (Cataract)
4 ii) Year of operation (Cataract)
7) Have you noticed a change in your vision over the last 5 years?
7 i) Who did you visit about this change?
7 ii) What is the reason for not visiting anyone?
8 ii) Have you ever had an eye examination where drops to dilated the eye were used?
8 iii) What year did you last have one of these examinations?
9 i) What year were you first diagnosed with this condition? (Stroke)
9 ii) Did if affect your vision? (Stroke)
9 iii) Does it still affect your vision? (Stroke)
13 i) In the past 12 months, have you noticed any of the following health messages about eyesight on TV, radio, newspapers or in any other sources?

Three items were modified from the original TVI questionnaire (Table 4.2) in order to match standard ABS classification, or for ease of questionnaire completion/data entry.

Table 4.2: Modifications to TVI questionnaire in HSQx	
Original Question	**New Question**
1 i) What is your main language spoken at home	2 a) Do you speak a language other than English at home
1 iii) What is the highest level of education you have completed?	2 b) What is the highest level of education you have completed?
-Primary School	-Did not go to school
-Some Secondary School	-Year 8 or below
-Completed Secondary School	-Year 9 to Year 12
-Completed a trade	-Certificate or Diploma (including trade certificate)
-Some university or college of advanced education or training	-Bachelor degree (from college or university)
-Degree from university, college or advanced education or higher degree	-Graduate Certificate/ Postgraduate Degree
2) Have you EVER seen someone who specialises in eyes?	3 a) Have you EVER had a problem with your eyes or vision?

Five additional questions were added to the HSQx (Table 4.3) in order to obtain further information about the levels of vision and eye health service utilisation and to explore potential barriers for seeking treatment. The additional questions were generated as a result of discussions with AHWs, OATSIH, ophthalmologists, ICEE optometrists and experts in low vision and Indigenous eye health.

Table 4.3: Additional questions in HSQx	
Questions Added	***Justification/ Sources***
Where did you go for treatment?	Included to examine levels and types of health service utilization for eye health problems.
Is the problem ok now?	Also included to assess follow-up care for eye health problems.
Why didn't you go somewhere for treatment? [Options: Cost, Discrimination, Language problems, Transport/ distance, Service not culturally appropriate, Not available in area, Felt it would be inadequate, Decided not to seek care, Waiting time too long or not available at time required, It is normal for eyesight to get worse, It was not severe enough, Too expensive, Too busy/ haven't gotten around to it, Other (please state)]	Discussions with AHWs, and reviews of the literature resulted in the list of potential reasons why Aboriginal and Torres Strait Islander people may not access eye health services.
What is the reason that you don't wear them (your glasses) all the time? [Additional option: Embarrassed}	Discussions with AHWs indicated that people may not wear glasses as a result of being embarrassed, so this was included as a potential response.
Do you normally wear glasses for near work (i.e. reading)?	Included to assess the levels of uncorrected presbyopia in the community

The final HSQx was a three and a half page (A4) document printed on A3 paper and folded in half. The remaining half page was used for recording the eye examination details.

4.2.2 Reliability

Test-retest reliability was performed with 8 participants who completed a second questionnaire after one day. 56 out of 69 items (81.2%) had 100% agreement; with 65 (94.2%) having greater than 85% agreement. Lowest agreement was found for items relating to family history, satisfaction with reading glasses, wearing of hats and whether previous eye or vision problems are "ok now" (Table 4.4).

4.2.3 Timing

The RABVIIC Pilot Study took place on the 18th and 19th of August, and 5th till the 9th of November 2007.

Table 4.4: Reliability (test-retest) of the AHSQx		
Item	**Agreement %**	**Kappa (95% CI)**
Do you speak another Language?	87.5	NC*
Is it ok now (problem with eyes or vision)?	75	0.80 (0.46-1)
Satisfaction with vision (if no spectacles)	87.5	0.81(0.5-1)
Satisfaction with vision (with spectacles)	87.5	0.81 (0.5-1)
Do you wear glasses all the time?	87.5	0.69 (0.28-1)
Satisfaction with reading glasses	75	0.84 (0.64-1)
Do you have a cataract?	87.5	0.071 (0-1)
Do you have AMD?	87.5	NC*
Family history Cataract	87.5	0.8 (0.46-1)
Family history Glaucoma	87.5	0.81 (0.46-1)
Family history Diabetic Retinopathy	87.5	0.81 (0.48-1)
Family history AMD	75	0.61 (1.43-1)
How often to do wear a hat?	62.5	0.5 (0-1)

*NC: Agreement not calculable

4.2.4 Recruitment

Recruiting sufficient participants was a significant challenge for the study team. Recruitment also had two specific goals to meet simultaneously:

1. Goal A - Recruit sufficient numbers to compare agreement between examination methods and assess validity of the questionnaire
2. Goal B - Recruit all eligible participants from the specified target area.

While the ideal recruitment outcome would have met both goals, it was very difficult to recruit sufficient numbers from the target area (Goal B). As a result participants who lived outside the specific target area were still included as their involvement will still provide the information required to meet the objectives of Goal A.

4.2.4.1 Recruitment Strategies

Various methods were used to recruit participants (Table 4.5) and all methods were successful in part in recruiting participants.

Table 4.5: Recruitment strategies
Flyers: AMS Staff delivered flyers to all residents of the target area prior to the commencement of the study
Direct contact (phone): AMS staff called AMS clients and invited them to participate
Direct contact (door knock): AMS staff drove around the community, approached residents directly and asked them if they would like to participate
Clients of the AMS who were visiting for other reasons were asked if they would like to participate
Participant Recommendation: Participants were asked if they had any family/ friends who would like to participate

4.2.4.2 Response Rates

The most recent national census conducted in June 2006 by the Australian Bureau of Statistics Census estimated that there were 248 Indigenous persons residing in the CCD selected for the study (Table 4.6).[230]

Table 4.6: 2006 Census count of Indigenous Persons in the target CCD			
	Males	**Females**	**Persons**
0-4 years	12	11	23
5-14 years	32	41	73
15-39	45	55	100
40 plus	24	28	52
Total	113	135	248

In order to increase recruitment from the target area additional recruitment staff were employed, other AMS program staff were engaged to help recruit participants through their networks, additional transport was made available and the study was further publicised on local radio. Despite these efforts the study population consisted of 19.3% from the target CCD area and 80.7% from surrounding areas of the target CCD (Table 4.7).

Table 4.7: RABVIIC Study Recruitment rates from Target Area			
Age Group	**Inside Target**	**Outside Target**	**Total**
Children - 0 to 4	3 (33.3%)	6 (66.7%)	9
Children - 5 to 15	6 (35.3%)	11 (64.7%)	17
Adults - 16 to 39	5 (12.5%)	35 (87.5%)	40
Adults - 40 plus	12(17.4%)	57 (82.6%)	69
Total	26 (19.3%)	109 (80.7%)	135

There were a higher proportion of females (63%) and the older age groups i.e. those over 16 years of age, as compared to the expected population. This occurred despite

efforts to increase sampling of children and men. The women in the older age groups appeared to be more motivated to participate in a study that would test their eyes. They were also generally more available to participate in the study during the day. Working directly with schools may have improved recruitment rates for children.

Commonly stated reasons for refusal were:

- Very recently had an eye examination
- Not interested
- Unavailable during work hours

There were 86 participants aged 5 to 15 years or 40 years and above (63.7% of the participant population).

4.2.5 Participants

4.2.5.1 Age and Gender

Vision and eye health data were obtained from 135 persons. The participants ranged in age from 0 years of age to 78 years of age, with a mean of 36.9 years and a median of 40.0 years (Table 4.8).

Table 4.8: Age and gender distribution of participants

Age Group	Male	Female	Total
Children 0-4	2 (1.48%)	7 (5.19%)	9 (6.67%)
Children 5-15	4 (2.96%)	13 (9.63%)	17 (12.59%)
Adults 16-39	11 (8.15%)	29 (21.48%)	40 (29.63%)
Adults 40 plus	33 (24.44%)	36 (26.67%)	69 (51.11%)
Total	50 (37.04%)	85 (62.96%)	135 (100%)

4.2.5.2 Education Profile (Adults)

The majority of adult participants (64%) had completed at least 9 years of schooling (Table 4.9). Education data were not collected from child participants.

Table 4.9: Adult participants' highest level of education completed			
Highest level of education completed	**16 to 39**	**40 plus**	**All Adults**
Missing	1 (2.5%)	1 (1.4%)	2 (1.8%)
Did not go to school	0 (0%)	5 (7.2%)	5 (4.6%)
Year 8 or below	3 (7.5%)	13 (18.8%)	16 (14.7%)
Year 9 to Year 12	35 (87.5%)	35 (50.7%)	70 (64.2%)
Certificate/ Diploma (including trade certificate)	0 (0%)	6 (8.7%)	6 (5.5%)
Bachelor degree (from college or university)	1 (2.5%)	9 (13%)	10 (9.2%)
Graduate Certificate/ Postgraduate Degree	0 (0%)	0 (0%)	0 (0%)
Total	40 (100%)	69 (100%)	109 (100%)

4.2.5.3 Languages

Five out of 127 participants reported that they spoke a language other than English at home (Table 4.10).

Table 4.10: Proportion of participants who speak a language other than English at home			
Age Group	**English**	**Other**	**Missing Data**
Children - 0 to 4	9 (100%)	0 (0%)	0 (0%)
Children - 5 to 15	16 (94.1%)	1 (5.9%)	0 (0%)
Adults - 16 to 39	35 (87.5%)	3 (7.5%)	2 (5%)
Adults - 40 plus	62 (89.9%)	1 (1.4%)	6 (8.7%)
Total	122 (90.4%)	5 (3.7%)	8 (5.9%)

4.2.5.4 Self-reported Diabetes

Twenty per cent of the study population reported having been told by a health care practitioner that they had diabetes (Table 4.11). Three females under 40 years of age reported that they had previously been diagnosed with diabetes. Retinopathy was not present in any of these individuals nor was it present in any other individuals under 40 years of age. There were 24 individuals (34.8%) over the age of 40 with self-reported diabetes. Of these, 5 individuals were found to have mild to moderate diabetic retinopathy and none had any vision impairment.

Table 4.11: Self reported Diabetes		
Age Group	**n**	**Diabetes (Self reported)**
16-29	17	1 (5.9%) Current age 18, diagnosed with diabetes at 16
30-39	23	2 (8.7%) Current ages 31 and 38, diagnosed with diabetes at 13 and 38 years respectively
40 plus	69	24 (34.8%) Various ages

4.2.6 Performance of Health Services Questionnaire

4.2.6.1 AHSQx Performance

Most participants were able to complete the questionnaire successfully. However, it was the older participants, particularly when they did not have reading glasses, that had the most trouble completing the questionnaire. Participants who were visually impaired or had difficulty reading also struggled to complete the questionnaire. In these instances a study team member, ideally the AHW involved in the study helped the participant complete the form by reading the questions out to them.

It was found that participants who self-completed the AHSQx would routinely fail to answer all questions in the HSQx, so a study team member reviewed the questionnaire and assisted the participants with unanswered questions.

Despite the fact that the study team checked each participant's HSQx, there were still a number of unanswered questions (Table 4.12). The questions that were most often missed were also the questions that the participants had the most difficulty in answering. For instance, most participants had not heard of age-related macular degeneration and as a result often passed over this question particularly when it concerned family history.

The last five questions were on the last page of the questionnaire and in 4 instances participants failed to answer any question on the back page with one of these participants unable to complete any of the HSQx items due to time constraints.

While the RABVIIC study had a reasonable number of study staff there were times when all staff members were extremely busy. The reasonably high levels of HSQx

missing data indicated that it would've been advantageous to recruit more study staff specifically to ensure that more thorough data checks could have occurred.

Table 4.12: Unanswered Items AHSQx*

Question	n	Missing Data %
3 a) Ever Had Problem with eyes/vision	109	1%
3 b) See Somebody about eyes/vision	78	1%
3 c) Where did you go for treatment	78	1%
2 a) Speak other Language	109	2%
2b) Highest Level Education	109	2%
4 a) Wear spectacles for distance	109	2%
5 a) Wear spectacles for near	109	3%
6 a) History - cataract(s)	109	3%
7 d) History - other condition	109	3%
9 a) How often has your eyesight... falling or tripping	109	3%
9 d) How often has your eyesight stopped you doing...	109	3%
5 c) Where readers were obtained	57	4%
7 a) History – glaucoma	109	4%
10 b) History – diabetes	109	4%
7 b) History - diabetic retinopathy	109	5%
13 a) Smoked 100 cigarettes	109	5%
14 b) Wear Sunglasses	109	6%
7 c) History - AMD	109	6%
11) History – stroke	109	6%
4 b) How Satisfied (no specs)	70	6%
3 d) Last eye examination	70	6%
4 d) Where glasses obtained	36	6%
4 e) Age started wearing specs	36	6%
8 c) Family History DR	109	7%
12) Falls in last 12 months	109	7%
8 e) Family History - other condition	92	7%
9 b) How much has your eyesight interfered... reading	109	9%
8 a) Family History Cataract	108	9%
14 a) Wear a hat	109	10%
8 b) Family History Glaucoma	109	11%
4 c) Satisfaction with vision (with specs)	36	11%
8 d) Family History - AMD	109	14%

**Items with <1% missing data not shown.*

4.2.6.2 CHSQx Performance

Most child participants were able to respond confidently to the questions in the CHSQx, and the responses were confirmed with their parents, guardians or older siblings. There were four occasions when a CHSQx item was not answered by a

participant resulting in 4% rate of missing data for items 2a) 'Do you speak a language other than English at home? Please specify'; 3d) 'Is the problem ok now?' 4c) 'What is the reason that you don't wear them (glasses) all the time?' and 4d) 'How old were you when you first started wearing glasses or contact lenses?'

4.2.6.3 Overall Missing Data

The overall rate of missing data from the 135 questionnaires was 3.9%. This rate was calculated for numerical and categorical values in the questionnaire that participants or examiners were required to complete.

4.2.7 Testability and Repeatability of Examination Procedures

4.2.7.1 Examiner proficiency

The AHW study staff rapidly became proficient in measuring VA and visual fields. Trachoma grading was undertaken by an AHW who had prior training in primary eye health care. Proficiency in retinal imaging was achieved after one day of instruction and practice.

4.2.7.2 FDT

Visual field results from both eyes were obtained on 104 out of 109 adult participants (95.4%) with unilateral visual field results obtained from one participant with only one eye. Of the four remaining participants one could only see hand movements and two declined FDT testing.

Whenever participants failed the FDT screening test, by either missing a point, or having a significant fixation error or false positive result, the test was repeated. The results of the repeated test are shown in Table 4.13.

Table 4.13: Results of repeated FDT test

Result	**Missed Points**	**Fixation Errors**	**False Positive Error**
Improved and passed	5 (35.7%)	15 (83.3%)	1 (50%)
Improved but did not pass	3 (21.4%)	1 (5.6%)	0 (0%)
No Improvement	5 (35.7%)	2 (11.1%)	1 (50%)
Missed more points	1 (7.1%)	0 (0%)	0 (0%)
Total	14	18	2

4.2.7.3 Retinal Images

In 2 individuals (1.8%), the retina was not able to be examined by either examination method (complete corneal opacity n=1, participant left n=1) and in an additional 3 individuals (2.8%), the retinal camera was not available because of logistic constraints within the clinic.

A total of 6 persons (5.5%) had significant fundus pathology other than DR (such as chorioretinal lesion, nevus or epiretinal membrane / surface wrinkling retinopathy), and 12 (11%) had reduced VA (<6/12) in one or both eyes with no fundus abnormality.

On 18 occasions (8.3% of eyes) a mydriatic agent was required in order to obtain an acceptable image. There were 5 (2.3% of eyes) instances where the RABVIIC was unable to obtain a gradable retinal image due to cataract or lens changes and 6 (2.8% of eyes) instances where gradable images were not obtained due to operator error or other undocumented reasons (Table 4.14). A slitlamp examination was able to assess the fundus in all of these individuals and none had retinopathy.

Table 4.14. Reasons for failing to obtain a gradable retinal image

Parameter	Age Group	Number of Eyes (%)
Poor quality photo (cataract/ lens changes)	≥ 40	5 (2.3%)
Operator Errors	16-39	1 (0.5%)
	≥ 40	1 (0.5%)
Reason not documented	≥ 40	4 (1.8%)
Total		11 (5%)

4.2.7.4 All other procedures

Apart from the inability to test distance visual acuity with children under the age of 5 we were able to obtain reliable results from 85.5% of the examination procedures (Table 4.15). A minimum of 88 per cent was obtained from each examination component and fewer missing data were obtained from the definitive examination method.

Table 4.15. Missing Data			
	n	**RABVIIC**	**Definitive Examination**
Distance VA – Children (0-4)	9	66.7% (Unable n=2, Missing n=1)	66.7% (Unable n=2, Missing n=1)
Distance VA – Children (5-15)	17	0%	0%
Distance VA – Adults (16 - 39)	40	0%	0%
Distance VA – Adults (≥ 40)	69	0%	1.5% (Participant left n=1)
Near VA – Adults (≥ 40)	60	10% (Missing n=6)	Not tested
FDT - Adults (16 – 39)	40	0%	Not tested
FDT - Adults (≥ 40)	69	4.4% (Corneal opacity n=1, Declined n=2)	Not tested
Slit Lamp Adults - (16 - 39)	40	Not tested	2.5% (Refused n=1)
Slit Lamp Adults - (≥ 40)	69	Not tested	0%
Retinal Imaging/ Optical Fundus Examination – Adults (16 – 39)	40	6.3% (Image not obtained n=4 eyes, Not Gradable n=1 eye)	2.5% (Refused n=1
Retinal Imaging/ Optical Fundus Examination – Adults (≥ 40)	69	11.6% (Image not obtained n=6 eyes, Not Gradable n=10 eyes)	2.5% (Unable n=1)
Questionnaire	135	3.9% (179 questions missed out of a possible 7825)	

4.2.8 Visual Status

4.2.8.1 Visual Acuity

There was exact agreement in classification of distance visual acuity category in 238 (93%) of 256 participants' eyes and agreement within one step in 252 (99%, Table 4.16). Linearly weighted kappa was 0.79 (95% CI 0.71-0.89) and quadratic weighted kappa 0.89 (95% CI not calculable).

Table 4.16: Comparison of distance VA between methods by eye, all participants						
	Definitive Examination					
RABVIIC	**≥6/ 12**	**<6/ 12-6/ 18**	**<6/ 18-6/ 60**	**<6/ 60**	**LP**	**Total**
≥6/ 12 or better	216	4	0	0	0	220
6/ 12-6/ 18	7	15	0	0	0	22
6/ 18-6/ 60	2	1	4	3	0	10
Less than 6/ 60	0	0	0	0	0	0
LP	0	0	0	1	3	4
Total	225	20	4	4	3	256
κ_w= 0.79 (95% CI 0.71-0.89) – Substantial Agreement						
κ_{QW}= 0.89 (95% CI not calculable) – Almost Perfect Agreement						

In adults ≥ 40 there was exact agreement in classification of distance visual acuity category in 121 (90%) and agreement within one step of 134 (99%) of 135 participants' eyes (Table 4.17).

In adults between 16 and 39 years there was exact agreement in classification of distance visual acuity category in 77 (97%) of 79 participants' eyes, and agreement within one step in 100%. Unweighted kappa was 0.74 (95% CI 0.38-1, Table 4.18).

Table 4.17: Comparison of distance VA between methods by eye, Adults ≥40 years

	Definitive Examination					
RABVIIC	**≥6/ 12**	**<6/ 12-6/ 18**	**<6/ 18-6/ 60**	**<6/ 60**	**LP**	**Total**
≥6/ 12 or better	**102**	6	1	0	0	109
<6/ 12-6/ 18	3	**12**	1	0	0	16
<6/ 18-6/ 60	0	0	**3**	0	0	3
<6/ 60	0	0	3	**1**	0	4
LP	0	0	0	0	**3**	3
Total	105	18	8	1	3	**135**

κ_w= 0.81 (95% Confidence Interval 0.71 – 0.92)– Almost Perfect Agreement

κ_{QW}= 0.91 (95% Confidence Interval not calculable) – Almost Perfect Agreement

No vision impairment was observed in any children participants through either examination method, accordingly there was 100% rater agreement.

Table 4.18: Comparison of distance VA between methods by eye, Adults between 16 and 39 years

	Definitive Examination					
RABVIIC	**≥6/ 12 or better**	**<6/ 12-6/ 18**	**<6/ 18-6/ 60**	**<6/ 60**	**LP**	**Total**
≥6/ 12	**74**	1	0	0	0	75
<6/ 12-6/ 18	1	**3**	0	0	0	4
<6/ 18-6/ 60	0	0	**0**	0	0	0
<6/ 60	0	0	0	**0**	0	0
LP	0	0	0	0	**0**	0
Total	75	4	0	0	0	**79**

κ_w= 0.74 (95% Confidence Interval 0.39 – 1)– Substantial Agreement

4.2.8.2 Vision impairment

The lowest rate of agreement in detecting vision impairment in the individual eyes of all participants was 92% (Table 4.19).

Table 4.19: Agreement in detection of vision impairment (by eye)		
Age Group (years)	**Agreement (%)**	**κ (95% Confidence Interval)**
0 to 4	6/ 6 eyes (100%)	-
5 to 15	34/ 34 eyes (100%)	-
16 to 29	78/ 80 eyes (95%)	0.79 (0.49-1)
≥ 40	125/ 136 eyes (92%)	0.76 (0.60 – 0.84)
Total	243/ 256 eyes (95%)	0.78 (0.64-0.85)

The RABVIIC was shown to have 74% sensitivity and 97% specificity in detecting vision impairment (VA worse than 6/12) in the eyes of participants ≥ 40 years (Table 4.20). Higher sensitivities and specificities were observed in the adults aged 16 to 29.

Table 4.20: Vision Impairment sensitivity and specificity calculations (by eye)						
Age Group (years)	**Sensitivity (95% CI)**	**Specificity (95% CI)**	**Positive Predictive Value**	**Negative Predictive Value**	**Likelihood Ratio**	**Negative Likelihood Ratio**
0 to 4	-	1.0 (1.0–1.0)	-	1.0 (1.0–1.0)	-	-
5 to 15	-	1.0 (1.0–1.0)	-	1.0 (1.0–1.0)	-	-
16 to 29	0.80 (0.44-0.94)	0.99 (0.96-0.99)	0.80 (0.44-0.94)	0.99 (0.96-0.99)	60.0 (11.8-253.7)	0.20 (0.01-0.6)
≥ 40	0.74 (0.63-0.8)	0.97 (0.94-0.99)	0.89 (0.75-0.96)	0.93 (0.89-0.94)	25.9 (10.0-74.6)	0.27 (0.2-0.39)
Total	0.75 (0.64-0.81)	0.98 (0.96-0.99)	0.87 (0.75-0.94)	0.96 (0.94-0.97)	41.3 (17.9-102.2)	0.26 (0.19-0.37)

4.2.8.2.1 Prevalence of vision impairment

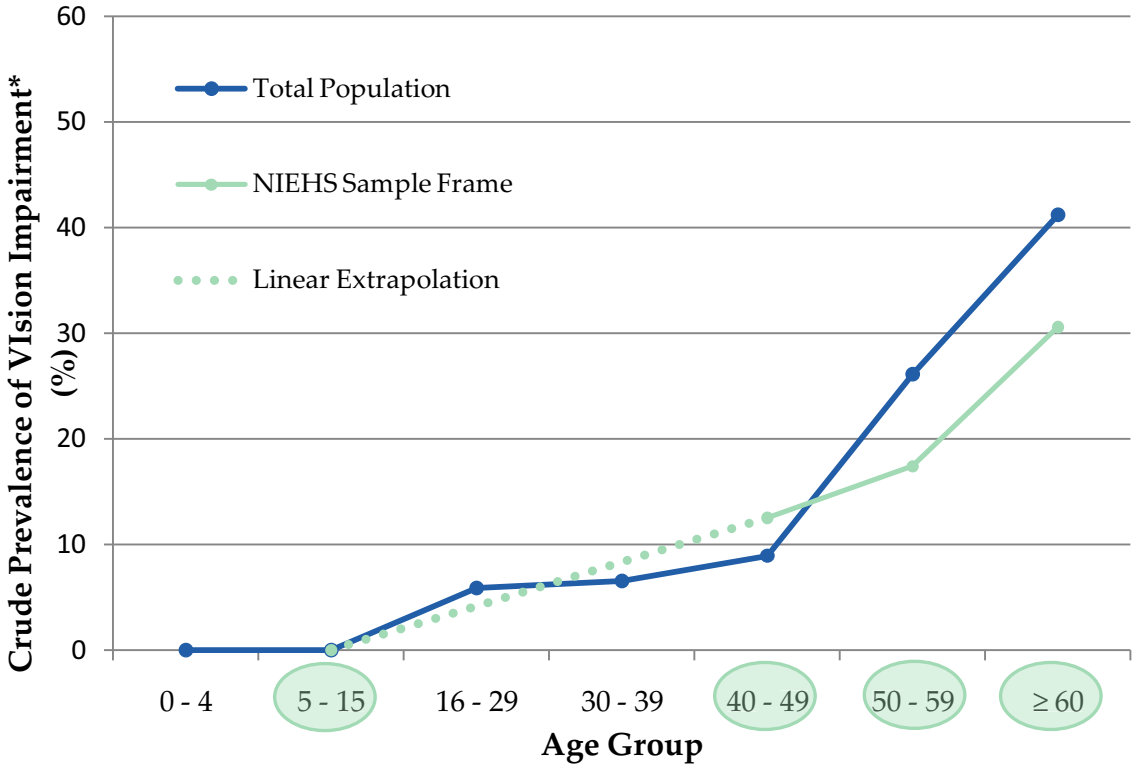
To assess the prevalence of vision impairment obtained by each examination method, calculations were conducted using the number of eyes with vision impairment (<6/12) rather than the occurrence of vision impairment in persons (better eye worse than 6/12) in order to increase the number of cases. According to this method, the prevalence of vision impairment in the study population as found by the definitive examination was 14.0% (95% CI 10.4%-17.5%). The RABVIIC method found 12.0% VI (95% CI 8.7%-15.4%), however these differences were not significantly different (z=0.52, p>.05).

4.2.8.2.2 Predicting vision impairment in an NIEHS sample frame

By using prevalence rates from the RABVIIC method and analysing only those participants who constituted the sample frame of the NIEHS (eyes of individuals aged

between 5 to 15 years and ≥ 40 years) we were able to predict the prevalence of VI in the eyes of the full study population (Figure 4.1).

Figure 4.1. Prevalence of vision impairment (by eye)



**Crude prevalence rates were calculated on the basis of vision impairment (<6/ 12) in individual eyes, rather than prevalence of VI in persons to increase the number of cases.*
Groups of participants in the NIEHS sample frame are circled.

By linearly extrapolating between ages 5 to 15 and age ≥40, we were able to estimate the prevalence in the total study population. Linear extrapolation was chosen as the crude prevalence of vision impairment in the total population appear to increase roughly linearly from age 5 to age 40. Using this method, the predicted prevalence of vision impairment in eyes in the full study populations was estimated to be 12.0% (95% CI 8.7%-15.3%). This estimated prevalence was the same as what was calculated by the RABVIIC method using the entire study population and was also not statistically different to the prevalence of vision impairment calculated by the definitive examination using the total population ($z=0.52$, $p>.05$). However this sample did not have enough participants to enable a study with sufficient power to show that there

was no difference, as failing to find evidence that there is a difference does not constitute evidence that there is no difference.

The distribution of the crude prevalence of vision impairment was similar in most age strata for each examination method and no statistically significant differences were observed with the Z-test for a significant difference between two proportions at the 95% level of confidence (Table 4.21).

Table 4.21. Expected prevalence of vision impairment (%, by eye)

Age Group	N (eyes)	RABVIIC Method: NIEHS Sample Frame	Definitive Method: Total Population	Z (*p*)
0-4	18	0.0 (0.0-0.0)	0.0 (0.0-0.0)	-
5-15	34	0.0 (0.0-0.0)	0.0(0.0-0.0)	-
16-29	34	5.9 (-0.8-12.5)	5.9 (-0.8-12.5)	-0.52 (>.05)
30-39	46	6.5 (0.5-12.5)	6.5 (0.5-12.5)	-0.42 (>.05)
40-49	56	12.5 (5.2-19.8)	8.9 (2.7-15.2)	0.38 (>.05)
50-59	46	17.4 (8.2-26.6)	26.1 (15.4-36.7)	0.79 (>.05)
60 plus	36	30.6 (17.9-43.2)	41.2 (27.3-55.1)	0.64 (>.05)
Total	270	12.0 (8.7-15.3)	14.0 (10.4-17.5)	-.005 (>.05)

4.2.8.2.3 Cause of vision impairment

The distribution by cause of VI was very similar for both examination methods (Table 4.22). However, the definitive examination detected 25 cases of vision impairment resulting from uncorrected refractive error whereas the RABVIIC detected 21 cases, which is discussed further in section 4.2.8.3. There were also 4 instances of uncorrected refractive error and 1 cataract in persons aged 16 to 39.

Table 4.22. Causes of VI in the total population and in persons aged 40 years and older and aged 5 to 15 years

	RABVIIC n (% in NIEHS Sample Frame)	RABVIIC n (% in total population)	Definitive n (% in total population)
URE	16 (10.4%)	21 (8.9%)	25 (10.8%)
Cataract	3 (1.8%)	3 (1.2%)	3 (1.2%)
Corneal Opacity	2 (1.2%)	2 (0.8%)	2 (0.8%)
Other cause/ Not identified/	5 (3.0%)	5 (2.0%)	6 (2.4%)
Total	**26 (18.1%)**	**31 (13.8%)**	**36 (16.4%)**

4.2.8.3 Uncorrected Refractive Error

Agreement in detection of vision impairment due to uncorrected refractive error (URE) was evaluated with both examination methods resulting in the same outcome in 260 out of 270 (96%) participants' eyes. Disagreements occurred in 10 (3.7%) instances (Table 4.23) resulting in 72% sensitivity (95% CI 0.58-0.79), 99% specificity (95% CI 0.97-0.99) and a kappa value of 0.76 (95% CI 0.60-0.85).

Table 4.23. Comparison of RABVIIC and definitive assessments of vision impairment due to uncorrected refractive error

	Definitive Examination		
RABVIIC	VI due to URE	No VI due to URE	Total
VI due to URE	18	3	21
No VI due to URE	7	242	249
Total	25	245	270

The RABVIIC detected 3 cases of vision impairment due to uncorrected refractive error in two individuals whereas the definitive examination detected 7 more cases of vision impairment due to uncorrected refractive error in 5 individuals. The details of the findings in the individuals from each of the methods is shown in Table 4.24.

Table 4.24. Disagreements in detection of vision impairment due to URE

Age	**Definitive Examination**		**RABVIIC Examination**	
	VA	**Other findings**	**VA**	**Other findings**
30-39	R/ L: ≥6/ 12	L: CDR >0.6	R: ≥6/ 12 L: <6/ 12-6/ 18	L: CDR >0.6
>40	R/ L: ≥6/ 12	None	R.L: <6/ 12-6/ 18	None
30-39	R: ≥6/ 12 L: <6/ 12-6/ 18	None	R/ L: ≥6/ 12	None
>40	R: <6/ 12-6/ 18 L: ≥6/ 12	None	R/ L: ≥6/ 12	None
>40	R: <6/ 18-6/ 60 L: ≥6/ 12	L: CDR >0.6, retinal pigment epithelial changes	R/ L: ≥6/ 12	None
>40	R: <6/ 12-6/ 18 L: <6/ 18-6/ 60		R/ L: ≥6/ 12	None
>40	R/ L: <6/ 12-6/ 18	R/ L: CDR >0.6, Mild nuclear sclerosis, early AMD	R/ L: ≥6/ 12	R: Epiretinal membrane surface wrinkling

4.2.8.4 Trachoma

Both the definitive and the RABVIIC examinations used the same WHO simplified grading system for active trachoma, trachomatous scarring or trichiasis.[237] There was exact agreement in 250 out of 257 eyes (97.3%, Table 4.25).

Table 4.25: Comparison of RABVIIC and definitive diagnoses of Trachoma

RABVIIC	**Definitive Examination**				
	No Trachoma	**Active Trachoma**	**Trachomatous Scarring**	**Trichiasis**	**Total**
No Trachoma	236	2	1	2	241
Active Trachoma	0	0	0	0	0
Trachomatous Scarring	0	0	14	0	14
Trichiasis	0	0	2	0	2
Total	236	2	17	2	257

κ= 0.79 (95% Confidence Interval 0.65 – 0.95) – Substantial agreement

4.2.8.5 Diabetic Retinopathy

There were no participants with vision impairment caused by diabetic retinopathy detected by either examination method. However, rater agreement was evaluated for non-vision impairing diabetic retinopathy and there was exact agreement in 192 (98%) of 197 participants' eyes and agreement within one step in 196 (99.5%) when retinal images or the direct fundus view was graded for retinopathy. Disagreements occurred in 5 (2.5%) instances (Table 4.26). Disagreements on the presence of mild or moderate diabetic retinopathy were equally divided between the RABVIIC and the definitive examination. The linear kappa and quadratic kappa values obtained were 0.74 (95% CI 0.5-0.98) and 0.85 (95% CI 0.81-0.89) respectively.

Table 4.26. Comparison of RABVIIC and definitive diagnoses of Diabetic Retinopathy

RABVIIC	**Definitive Examination**				
	No DR	NPDR	PDR	CSMO	Total
No DR	188	1	0	0	189
NPDR	3	2	0	0	5
PDR	0	0	0	0	0
CSMO	0	1	0	2	3
Total	191	4	0	2	197

When the criterion for referral was defined as mild proliferative retinopathy or worse, the sensitivity and specificity of the RABVIIC in detecting Diabetic Retinopathy

increased from 63% (95% CI 0.34 – 0.82) and 98% (95% CI 0.97 – 0.99) respectively to 100% (95% CI 0.39 – 1) and 99.5% (95% CI 0.98 – 0.99) respectively (Table 4.27).

No diabetic retinopathy was detected in any adult <40 years by either examination method.

Table 4.27: Agreement between RABVIIC and definitive examination diagnosis of diabetic retinopathy

Criterion for referral	Sensitivity (95% CI)	Specificity (95% CI)	Positive Predictive Value	Negative Predictive Value	Likelihood Ratio	Negative Likelihood Ratio	κ (95% CI)
No DR vs. NPDR/ PDR/ CSMO	0.63 (0.34-0.82)	0.98 (0.97-0.99)	0.63 (0.36-0.73)	0.98 (0.97-0.99)	39.4 (12.3-108.6)	0.38 (0.2-0.7)	0.61 (0.31-0.81)
No DR + NPDR vs. PDR + CSMO	1.0 (0.39-1.0)	0.99 (0.99-0.67)	0.67 (0.26-0.67)	1.0 (0.99-1.0)	195.0 (33.98-195.0)	0.0 (0.0-0.62)	0.79 (0.30-0.79)

4.2.8.6 Glaucoma

In the RABVIIC, glaucoma was assessed using Frequency Doubling Technology (FDT) and digital images of the optic nerve head. Optometrists were asked to specify whether glaucoma was suspected or not based on optic nerve head appearance, cup and disc ratio (CDR) and other clinical indicators such as intra ocular pressure.

In this population sample, glaucoma was not suspected to be the cause of vision impairment in any individuals. However, there were two individuals with normal vision with high cup:disc ratio (CDR), more than two points missed on repeated FDT (not caused by cataract or media opacity) and no history of stroke, although there was no known family history of glaucoma. The definitive examination resulted in a diagnosis of suspected glaucoma without VI in these same individuals. In the remainder of the study population there was agreement in CDR assessment in 185 out of 200 instances (93%), with 60% sensitivity (95% CI 0.45-0.7) and 97% specificity (95% CI 0.95-0.99, Table 4.28).

Table 4.28: Agreement in assessment of CDRs greater than 0.6		
Age Group	**Agreement (%)**	**κ (95% Confidence Interval)**
16 to 29	63/ 68 (92.6%)	0.63 (0.3-0.82)
≥40	97/ 106 (91.5%)	0.53 (0.26-0.71)
Total	160/ 174 (91.1%)	0.57 (0.39-0.72)

The RABVIIC was shown to have a minimum of 94% specificity and 50% sensitivity in the assessment of CDR with higher sensitivity (71%) observed for the younger adults (Table 4.29).

Table 4.29: Sensitivity and Specificity calculations for assessment of CDR						
Age Group	**Sensitivity (95% CI)**	**Specificity (95% CI)**	**Positive Predictive Value**	**Negative Predictive Value**	**Likelihood Ratio**	**Negative Likelihood Ratio**
16 to 29	0.71 (0.4-0.9)	0.95 (0.92-0.97)	0.63 (0.35-0.79)	0.97 (0.93-0.99)	14.52 (4.7-32.6)	0.3 (0.1-0.66)
≥40	0.5 (0.29-0.65)	0.97 (0.94-0.99)	0.67 (0.39-0.87)	0.94 (0.91-0.96)	15.6 (4.9-50.3)	0.62 (0.36-0.76)
Total	0.69 (0.48-0.84)	0.94 (0.92-0.96)	0.55 (0.38-0.67)	0.97 (0.95-0.98)	12.1 (6.1-20.4)	0.33 (0.17-0.57)

4.2.8.7 Cataract

Cataract was assessed using a method that has previously demonstrated good sensitivity (92%) and specificity (80%).[239, 250] In this study, there was 100% agreement in diagnosis of cataract as the primary cause of vision impairment.

4.2.8.8 Other Pathology

Both the definitive and RAABVIIC examination detected a range of other ocular conditions, but these were not causes of vision impairment nor were they conditions designed to be detected by the RABVIIC. Conditions detected were divided into 2 categories: potentially blinding or not potentially vision threatening. The definitive examination observed maculopathy in three participants (Table 4.30).

Table 4.30: Additional potentially vision threatening conditions detected by definitive examination

Age	N (eyes)	Examples
0-4	1	Unidentified dark lesion on optic nerve head*, infantile strabismus
16-29	2	Papilloedema* (participant already being managed for previously diagnosed benign intracranial hypertension)
≥ 40	5	Maculopathy, early maculopathy, very early macular changes.

**participant not in RABVIIC sample*

However, the majority of these conditions were categorised as requiring later review and were not current causes of vision impairment or conditions designed to be detected by the rapid assessment (Table 4.31).

Table 4.31: Additional conditions detected by definitive examination

Age	RABVIIC	Definitive	Examples
0-4	0	0	-
5-15	0	16	Papillae, Follicles, mild tortuosity, superficial punctate keratopathy
16-39	3	29	Corneal scar, Papillae, Follicles, meibomian gland dysfunction, anterior blepharitis, mild tortuosity, grade 1 allergy, grade 2 allergy, pingueculae, stye, myelinated nerves, macular defect, pterygium, slight disc pallor
30-39	3	8	Trachomatous scarring, early lens changes
≥ 40	5	33	Corneal scar, congenital optic nerve head abnormalities, loss of papillary frill, Corneal opacities, early lens changes, nuclear sclerosis, peripallary atrophy, sub epithelial deposits, mild nuclear sclerosis, RPE hypertrophy, chorioretinal lesion,

4.3 The IVI Questionnaire

4.3.1 Adapting the instrument

The Impact of Vision Impairment (IVI) questionnaire is a tool that has been developed to assess how vision impairment restricts participation in daily living and affects on QOL. Initial validity testing was performed in Australia and has demonstrated a valid range of vision-specific issues, discriminative ability, reliability and relevance.[10-15]

In order to assess its suitability for use in Aboriginal and Torres Strait Islander populations its face and content validity, reliability and responsiveness were determined.

4.3.1.1 Face and Content Validity

AHWs, AEHCs and optometrists who provide eye care to Aboriginal and Torres Strait Islander populations and Aboriginal and Torres Strait Islander participants in NSW were used to establish the face and content validity of the Indigenous IVI (IVI_I) questionnaire. Face validity was determined by the extent to which these experts agreed that the items and response scales were appropriate.

Table 4.32: Modifications to the IVI questionnaire

IVI_A Item	Original Question	Modified Question
2	Taking part in recreational activities such as bowling, walking or golf?	Taking part in recreational activities?
10	How much has your eyesight interfered with getting about outdoors? (on the pavement or crossing the street)	How much has your eyesight interfered with getting about outdoors?
12	In general, how much has your eyesight interfered with travelling or using transport? (bus & train)	In general, how much has your eyesight interfered with travelling or using transport?

Overall there was high acceptance of the instrument and agreement that it is comprehensive and representative to measure the impact of vision impairment. Modifications were made primarily by removing the examples provided in order to improve relevancy to participants from remote and very remote areas (Table 4.32).

4.3.2 Recruitment

The IVI questionnaire (Appendix F) was administered to Aboriginal and Torres Strait Islander adult participants across 31 locations around Australia. Participants were recruited via the Rapid Assessment of Avoidable Blindness and Vision Impairment in Indigenous Communities (RABVIIC) study in Northern NSW and the NIEHS. Participants presenting with vision impairment or blindness to regular ICEE clinics around NSW were also invited to participate. A recruitment schedule is shown in Table 4.33. The majority of participants were recruited from the NIEHS (52%, *n*=88).

Table 4.33: Participant recruitment methods

Recruitment method	Start date	End date	N (%)
RABVIIC	August 2007	November 2007	68 (39.5%)
NIEHS	February 2008	December 2008	88 (51.2%)
ICEE Clinics (NSW)	November 2008	June 2009	16 (9.3%)

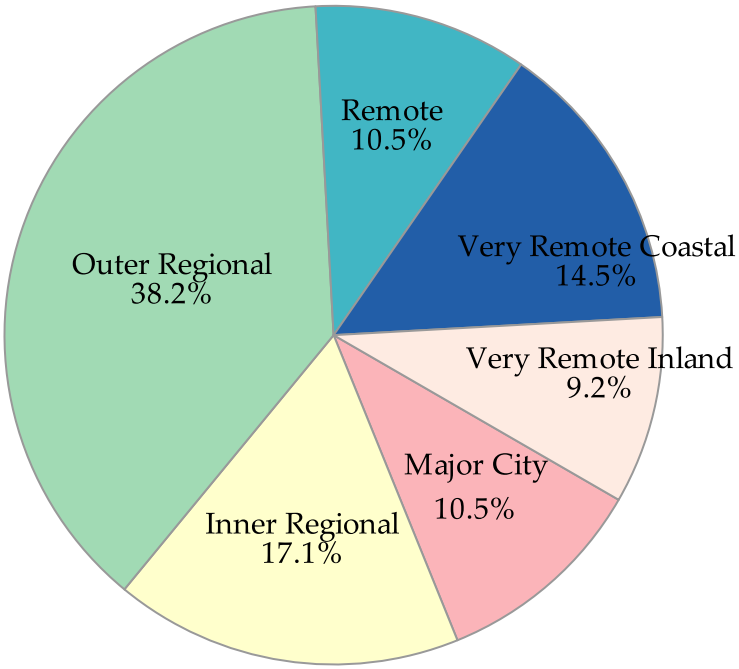
Participants were recruited from all states and territories in Australia. The majority of sites were from New South Wales (48%, *n*=15) followed by Western Australia (19%, *n*=6) and Queensland (10%, *n*=3), with at least one or two sites from the remaining states and territories (Table 4.34).

Table 4.34: Participant recruitment sites in each state/ territory

State	Sites	Percent
NSW	15	48.4
WA	6	19.4
QLD	3	9.7
NT	2	6.5
SA	2	6.5
ACT	1	3.2
TAS	1	3.2
VIC	1	3.2

Of the participants with vision impairment, similar numbers were recruited from each remoteness area (Figure 4.2), with the exception of the outer regional remoteness area. All the ICEE clinic and RABVIIC sites were in this region.

Figure 4.2: Remoteness status of vision impaired participants



4.3.3 Participants

Potential participants were given an information sheet describing the purpose of the study, methods and information dissemination (Appendix D). Potential participants were also given a verbal summary of the nature and purpose of the study. If potential participants were happy to proceed, written consent was obtained from all participants prior to their participating in any aspect of the study. Participants were advised that they could withdraw from the study at anytime without penalty. There were no refusals.

172 adults participated in this study, ranging in age from 16 to 83 years (Table 4.35). More females than males participated in the study (61%), and the majority of participants (83%) spoke English at home.

Table 4.35: Demographic characteristics of study participants	
	N (%)
Age (years)	
Range (median)	16 - 83
Mean ± SD	51.8 ± 15.8
Gender	
Male	68 (40%)
Female	104 (61%)
Language spoken at home	
English	142 (83%)
Other language	23 (13%)
Presenting Distance Visual Acuity	
Normal vision (≥6/ 12)	96 (56%)
Mild Impairment (<6/ 12 to 6/ 18)	45 (26%)
Moderate impairment (<6/ 18 to 6/ 60)	18 (11%)
Severe impairment (<6/ 60)	13 (8%)
Presenting Near Visual Acuity	
N8 or better	71 (44%)
<N8-N20	72 (45%)
<N20-N40	12 (7%)
<N48	6 (4%)
Urban/ Rural	
Major City	9 (5%)
Inner Regional	22 (13%)
Outer Regional	112 (65%)
Remote	11 (6%)
Very Remote Coastal	11 (6%)
Very Remote Inland	7 (4%)

Apart from a large group or participants with normal vision recruited as a comparison group, the largest vision category was those with mild vision impairment (26%, *n*=45).

Table 4.36: Education demographics				
Highest education level	**Normally sighted, n=96 (%)**	**Vision impaired, n=76 (%)**	**National Indigenous Education %** [251]	***p* value**
Did not go to school	4 (4.2%)	9 (11.8%)	2.2%	.01
Year 8 or below	19 (19.8%)	25 (32.9%)	14.1%	.02
Year 9 to Year 12	58 (60.4%)	28 (36.8%)	71.3%	<.01
Certificate or diploma	7 (7.3%)	7 (9.2%)	1.1%	.046
Bachelor Degree	5 (5.2%)	2 (2.6%)	8%	.25
Graduate Certificate/ Postgraduate	2 (2.1%)	0 (0%)	1.2%	.04
Unknown	1 (1%)	5 (6.6%)	-	-

The majority of participants (109/172) had completed at least year 9 or higher (Table 4.36).

4.3.4 Causes of Vision Impairment and Blindness

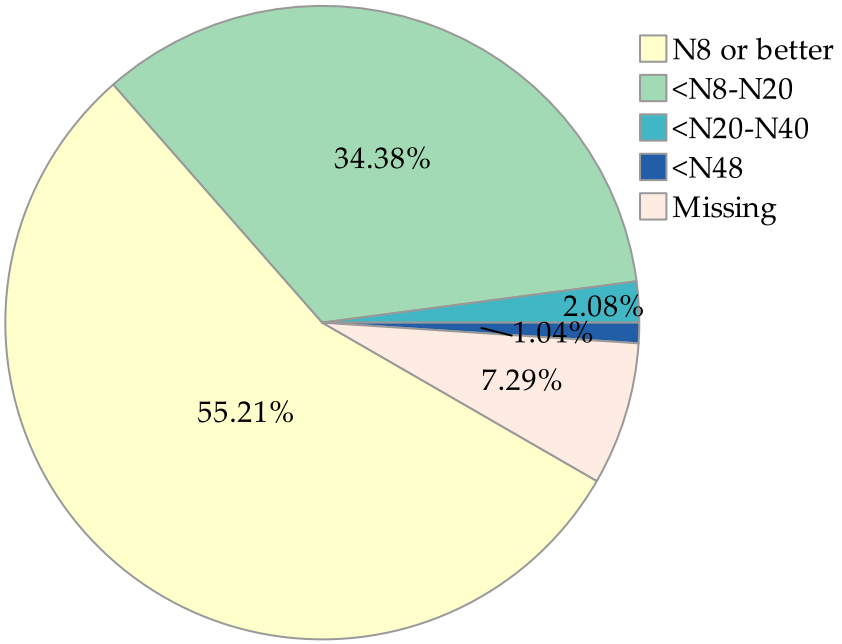
In the participants with vision impairment or blindness, the primary cause was refractive error (16%, *n*=28), followed by cataract (13%, *n*=23, Table 4.37).

Table 4.37: Causes of vision impairment and blindness

Cause	Frequency	% of Vision Impairment	% all participants
No vision impairment	96	-	55.8
Refractive Error	28	36.8	16.3
Cataract	23	30.3	13.4
Diabetic Retinopathy	4	5.2	2.4
Optic Atrophy	2	2.6	1.2
Corneal scarring	1	1.3	0.6
Glaucoma	1	1.3	0.6
Retinal detachment	1	1.3	0.6
Retinitis Pigmentosa	1	1.3	0.6
Trachoma	1	1.3	0.6
Unknown	14	18.4	8.1
Total	172	100.0	100.0

There were four instances of vision impairment or blindness as a result of diabetic retinopathy, and these cases ranged in severity from mild or moderate to severe.

Figure 4.3: Near vision status of participants with normal distance visual acuity



Out of 96 participants with normal distance vision, 36 (37%) had near vision impairment (Figure 4.3). There was missing data in seven instances.

4.3.5 Missing Responses

There were 3.0% missing values across all participants and all items. No items had missing values great than 4.9% (Table 4.38). When only vision impaired participants were examined the missing data rates were less (χ^2=44.9, p=.00).

Table 4.38: Missing Values (%)

	All Participants n=171	**Vision Impaired Participants n=75**
1 TV	1 (0.6)	0 (0.0)
2 Recreational Activities	3 (1.8)	1 (1.5)
3 Shopping	5 (3.0)	1 (1.4)
4 Visiting friends or family	4 (2.4)	1 (1.4)
5 Recognising people	1 (0.6)	0 (0.0)
6 Looking after appearance	4 (2.4)	0 (0.0)
7 Opening packaging	5 (3.0)	1 (1.4)
8 Reading medicine labels	2 (1.2)	0 (0.0)
9 Operating appliances	3 (1.8)	0 (0.0)
10 Getting about outdoors	2 (1.2)	0 (0.0)
11 Falling/ tripping	4 (2.4)	1 (1.4)
12 Interfered with travelling	1 (0.6)	0 (0.0)
13 Going down steps/ stairs	1 (0.6)	0 (0.0)
14 Reading ordinary print	7 (4.3)	0 (0.0)
15 Getting information	8 (4.9)	0 (0.0)
16 General safety at home	6 (3.6)	0 (0.0)
17 Spilling or breaking things	7 (4.3)	1 (1.3)
18 General safety when out	6 (3.6)	0 (0.0)
19 Stopped doing things	7 (4.3)	0 (0.0)
20 Needed help from others	7 (4.3)	1 (1.3)
21 Embarrassed	6 (3.6)	0 (0.0)
22 Frustrated/ annoyed	8 (4.9)	1 (1.3)
23 Lonely/ isolated	7 (4.3)	0 (0.0)
24 Sad/ low	6 (3.6)	0 (0.0)
25 Worried about eyesight	8 (4.9)	1 (1.3)
26 Concerned/ worried	7 (4.3)	0 (0.0)
27 Nuisance or burden	6 (3.6)	0 (0.0)
28 Interfered with life in general	6 (3.6)	0 (0.0)
Total	138 (3.0)	9 (0.4)

4.3.6 Distribution of Scores

The item score for each item ranked by vision status shows that lower scores, which indicate more difficulty with items of the IVI_I, were associated with poorer distance

visual acuity (Table 4.39). Overall, participants had greater difficulty with items related to reading and getting information.

Table 4.39: Mean (SD) scores for IVI_I items ranked by item response (sorted by mild distance vision impairment)

Item	N	Normal n=96	Mild n=45	Moderate n=17	Severe n=13
14 Reading ordinary print	157	1.3 (0.8)	0.9 (0.9)	1.2 (0.9)	0.7 (0.9)
15 Getting information	160	1.4 (0.8)	1.1 (0.8)	1.4 (0.8)	0.9 (1.1)
8 Reading medicine labels	163	2.0 (1.0)	1.4 (1.3)	1.4 (1.5)	0.4 (1.0)
25 Worried about eyesight	164	2.0 (1.0)	1.5 (1.1)	1.5 (1.3)	1.3 (1.1)
11 Falling/ tripping	166	2.6 (0.8)	1.7 (1.3)	1.8 (1.3)	1.8 (1.1)
3 Shopping	159	2.4 (0.9)	1.8 (1.2)	1.7 (1.2)	1.0 (1.1)
28 Interfered with life in general	166	2.4 (0.8)	1.9 (1.0)	2.0 (1.2)	1.3 (1.1)
19 Stopped doing things	166	2.6 (0.8)	1.9 (1.2)	2.1 (1.2)	1.5 (0.9)
1 TV	166	2.3 (0.9)	2.0 (1.0)	1.8 (1.1)	1.3 (1.1)
22 Frustrated/ annoyed	164	2.3 (0.9)	2.0 (1.0)	1.5 (1.4)	1.5 (1.3)
5 Recognising people	165	2.5 (0.8)	2.0 (1.0)	1.7 (1.3)	1.7 (1.2)
26 Concerned/ worried	169	2.6 (0.7)	2.0 (1.0)	1.8 (1.3)	1.3 (1.0)
13 Going down steps/ stairs	170	2.6 (0.8)	2.1 (1.1)	2.1 (1.2)	1.9 (1.1)
2 Recreational Activities	158	2.6 (0.8)	2.2 (1.1)	2.1 (1.0)	1.9 (1.1)
10 Getting about outdoors	166	2.7 (0.7)	2.2 (1.0)	2.4 (1.0)	1.8 (1.2)
27 Nuisance or burden	169	2.7 (0.7)	2.2 (1.1)	2.4 (1.0)	1.6 (1.4)
9 Operating appliances	160	2.6 (0.7)	2.3 (1.0)	2.4 (0.8)	1.4 (1.3)
20 Needed help from others	165	2.5 (0.7)	2.3 (0.9)	2.0 (1.1)	1.1 (1.1)
7 Opening packaging	164	2.6 (0.7)	2.3 (1.0)	2.0 (1.2)	1.5 (1.4)
12 Interfered with travelling	162	2.5 (0.8)	2.3 (1.0)	2.1 (1.1)	1.8 (1.3)
6 Looking after appearance	167	2.8 (0.6)	2.3 (1.0)	2.5 (0.9)	1.8 (1.1)
16 General safety at home	166	2.7 (0.7)	2.3 (0.9)	2.4 (0.8)	1.9 (1.0)
18 General safety when out	166	2.7 (0.7)	2.3 (0.9)	2.2 (0.9)	1.9 (0.9)
21 Embarrassed	166	2.7 (0.7)	2.4 (0.9)	2.1 (1.2)	2.0 (1.1)
4 Visiting friends or family	165	2.8 (0.5)	2.4 (1.0)	2.2 (1.0)	1.9 (1.2)
17 Spilling or breaking things	165	2.6 (0.8)	2.5 (0.8)	2.4 (1.0)	2.1 (1.1)
24 Sad/ low	166	2.6 (0.8)	2.6 (0.8)	2.5 (0.9)	2.0 (1.1)
23 Lonely/ isolated	165	2.7 (0.8)	2.8 (0.6)	2.6 (1.0)	2.2 (1.2)

Participants with normal distance vision ranked near vision items such as Item 14 (reading ordinary print) and Item 15 (getting information) lower than other items, which is likely be a result of participants with normal vision but uncorrected presbyopia experiencing greater difficulties with near vision tasks. The distribution of scores for participants with distance vision impairment is shown in Table 4.40.

Table 4.40: Distribution of Scores of participants with distance vision impairment (%)

Items 1-13	**Not at all**	**A Little**	**A fair amount**	**A Lot**	**Don't do this for other reasons**
1-TV	23 (30.3)	24 (31.6)	13 (17.1)	11 (14.5)	5 (6.6)
2-Rec Activities	35 (46.7)	15 (20.0)	8 (10.7)	8 (10.7)	9 (12.0)
3-Shopping	25 (33.3)	14 (18.7)	13 (17.3)	18 (24.0)	5 (6.7)
4-Visiting friends	44 (58.7)	14 (18.7)	8 (10.7)	8 (10.7)	1 (1.3)
5-Recognising people	27 (35.5)	19 (25.0)	17 (22.4)	12 (15.8)	1 (1.3)
6-Appearance	43 (56.6)	16 (21.1)	9 (11.8)	7 (9.2)	1 (1.3)
7-Packaging	38 (50.7)	14 (18.7)	8 (10.7)	12 (16.0)	3 (4.0)
8-Labels	20 (26.3)	10 (13.2)	9 (11.8)	30 (39.5)	7 (9.2)
9-Appliances	34 (44.7)	19 (25.0)	7 (9.2)	8 (10.5)	8 (10.5)
10-Outdoors	44 (57.9)	13 (17.1)	5 (6.6)	13 (17.1)	1 (1.3)
11-Falling/ tripping	31 (41.3)	15 (20.0)	9 (12.0)	19 (25.3)	1 (1.3)
12-Traveling/ transport	39 (51.3)	12 (15.8)	9 (11.8)	9 (11.8)	7 (9.2)
13-Steps	37 (48.7)	16 (21.1)	13 (17.1)	10 (13.2)	0 (0.0)
14-Ordinary size print	25 (32.9)		15 (19.7)	28 (36.8)	8 (10.5)
15-Getting info	31 (40.8)		19 (25.0)	21 (27.6)	5 (6.6)
Items 16-28	**Not at all**	**A little of the time**	**A fair amount of the time**	**A lot of the time**	
16-General safety home	37 (48.7)	25 (32.9)	8 (10.5)	6 (7.9)	
17-Spilling/ breaking	48 (64.0)	13 (17.3)	10 (13.3)	4 (5.3)	
18-General safety out	41 (53.9)	19 (25.0)	11 (14.5)	5 (6.6)	
19-Stopped doing things	31 (40.8)	17 (22.4)	15 (19.7)	13 (17.1)	
20-Needing help	34 (45.3)	16 (21.3)	16 (21.3)	9 (12.0)	
21-Embarrassed	44 (57.9)	14 (18.4)	11 (14.5)	7 (9.2)	
22-Frustrated/ annoyed	27 (36.0)	21 (28.0)	11 (14.7)	16 (21.3)	
23-Lonely/ Isolated	63 (82.9)	4 (5.3)	4 (5.3)	5 (6.6)	
24-Sad/ low	54 (71.1)	11 (14.5)	6 (7.9)	5 (6.6)	
25-Worried getting worse	17 (22.7)	21 (28.0)	16 (21.3)	21 (28.0)	
26-Coping with life	29 (38.2)	19 (25.0)	16 (21.1)	12 (15.8)	
27-Nuisance/ burden	42 (55.3)	16 (21.1)	10 (13.2)	8 (10.5)	
28-Interfered with life	27 (35.5)	19 (25.0)	18 (23.7)	12 (15.8)	

Shading indicates items where ≥70% of participants with distance vision impairment did not have any trouble with items.

Out of all IVI_I items, there were two items (highlighted) where over 70% of participants answered the question "In the past month, how much has your eyesight interfered with the following activity" with the response "not at all'. Over 80% of participants with distance vision impairment did not have any trouble with item 23, "have you felt lonely or isolated because of your eyesight".

The majority of participants (≥50%) with normal distance vision did not have any difficulty with any of the items, apart from items 8 (Labels) and 25 (worried about eyesight getting worse). In response to item 8, 34% of normally sighted participants reported that their eyesight interfered with their ability to read labels or instructions on medicines 'A little'. 16% reported 'A fair amount' and 13% reported 'A lot'. In response to item 25, 37% of normally sighted participants reported that have worried about their eyesight getting worse 'A little of the time'. 14% reported 'A fair amount of the time' and 14% reported 'A lot of the time'.

A high proportion of participants with vision impairment selecting the "Don't do this for other reasons" is one indicator that item is not relevant. There were no items where ≥10% of participants reported that they "Don't do this for other reasons".

4.3.7 Discriminant Validity: Vision Impairment

In order to test the discriminant validity of the IVI_I we investigated the ability of the IVI_I to discriminate between normal vision and vision impairment. We also investigated other demographic or vision-related factors such as gender and age.

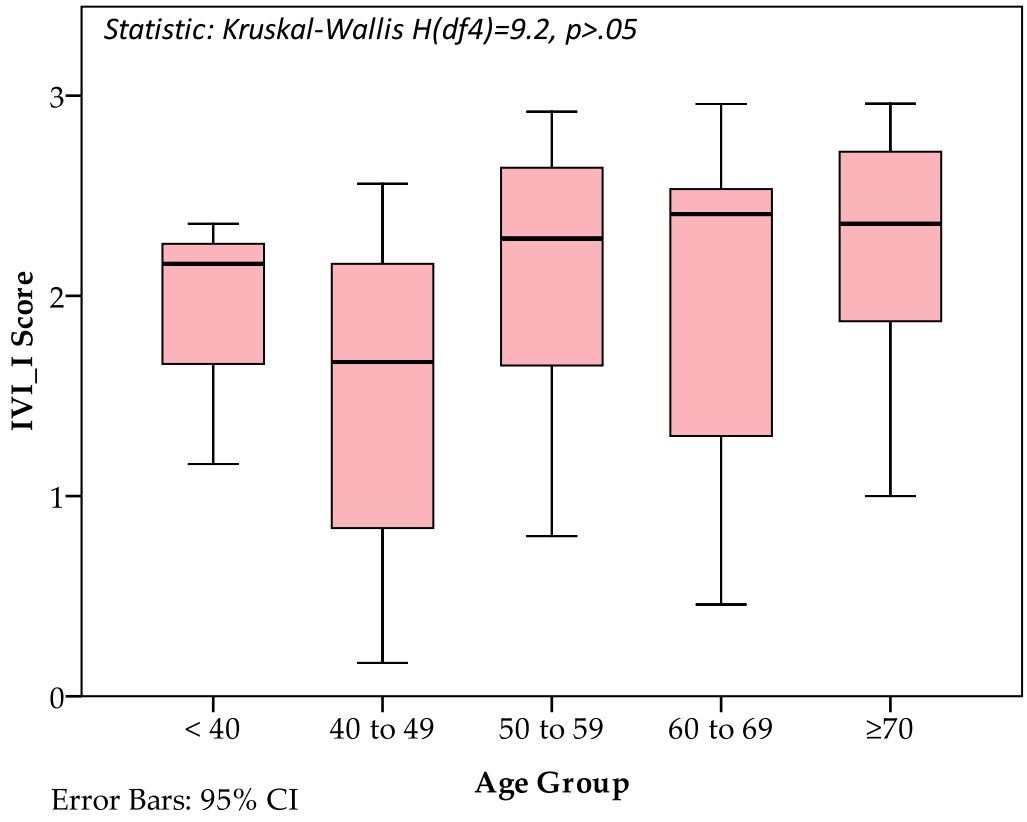
4.3.7.1 Age

Although mean item scores decreased slightly for the participants aged 40-49 (lower scores indicate more difficulty) there were no statistically significant differences between the total IVI_I score and the different age groups of vision impaired participants (Figure 4.4).

4.3.7.2 Gender

Females appeared to have slightly more difficulty with items (Figure 4.5) than males, however this difference was not statistically significant (Statistic: Mann-Whitney Test, U=553, p>.05). Although there were more female participants, the confidence interval for females appeared to be wider than the confidence interval calculated for males.

Figure 4.4: Age versus mean item score, participants with distance vision impairment



4.3.7.3 Language

No differences were observed in mean IVI_I total score between participants who spoke a language other than English at home (Figure 4.6, Statistic: Mann-Whitney Test, U=449, *p*>.05).

4.3.7.4 Remoteness

The degree of remoteness did appear to impact on difficulty with items, as participants in major cities appeared to have had the most difficulties with items (Figure 4.7) whereas participants in remote areas (but not very remote) had less difficulty with items. Areas of remoteness with more participants (Major City, Outer Regional and Very Remote Coastal) had wider confidence intervals than the other areas.

The differences in mean IVI_I total score was confirmed with the Kruskal-Wallis test for difference. However, post hoc analysis with Bonferroni correction failed to show

any significant differences between any of the remoteness groupings shown in Figure 4.7.

Figure 4.5: Gender differences in mean IVI_I total score, participants with vision impairment

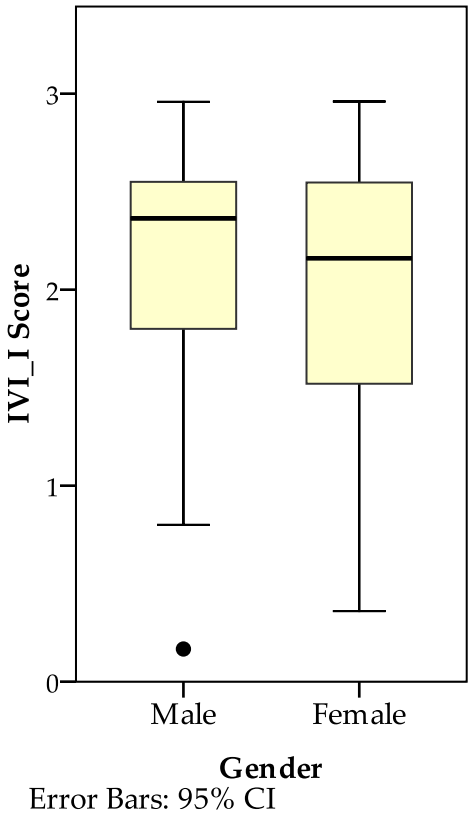
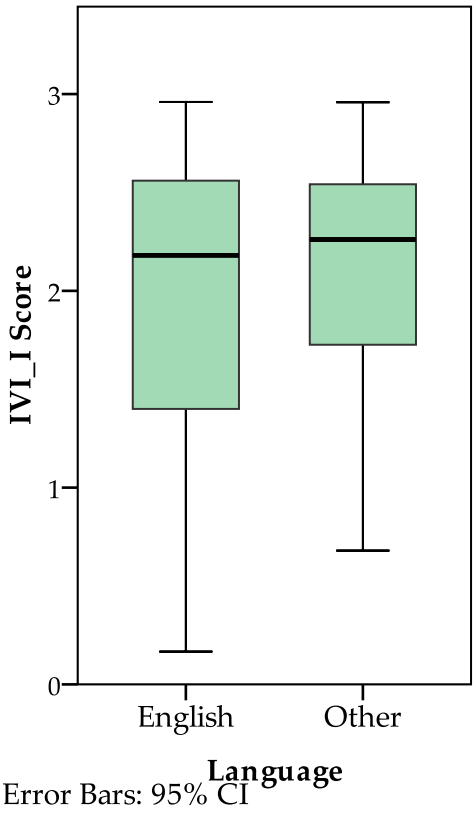
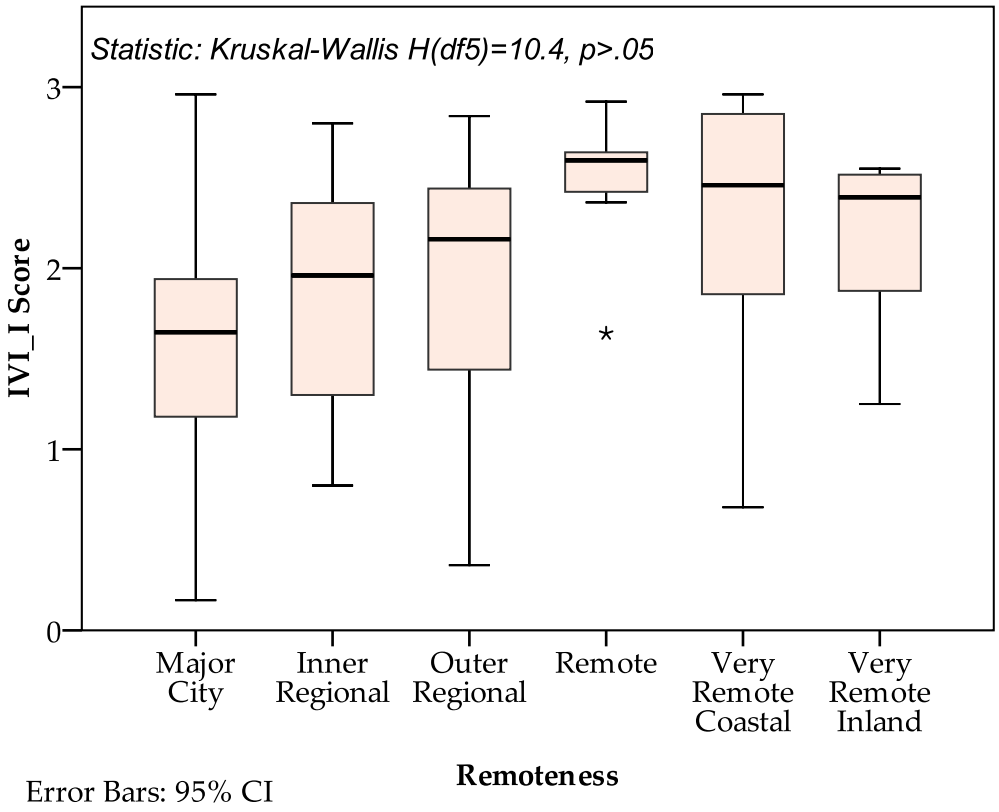


Figure 4.6: Mean IVI_I total score versus language spoken at home, participants with vision impairment



However, when locations were sub-categorised into either urban/regional or remote (Major City, Inner Regional and Outer Regional was classified as Urban, with the remaining categories of remoteness classified as Regional/Remote), there was a significant difference (Statistic: Mann-Whitney, U=391, p=.005). This indicates that participants with vision impairment in major cities, or regional areas had greater difficulty (lower scores) with IVI_I items than participants from other areas.

Figure 4.7: Mean score versus remoteness, participants with vision impairment



4.3.7.5 Education

The participants who appeared to have the most difficulty with items were those who had completed a certificate or diploma, however no statistically significant differences were observed. This lack of difference is an indicator that the instrument shows good comprehension to a variety of participants, regardless of their highest level of education reached, or literacy levels.

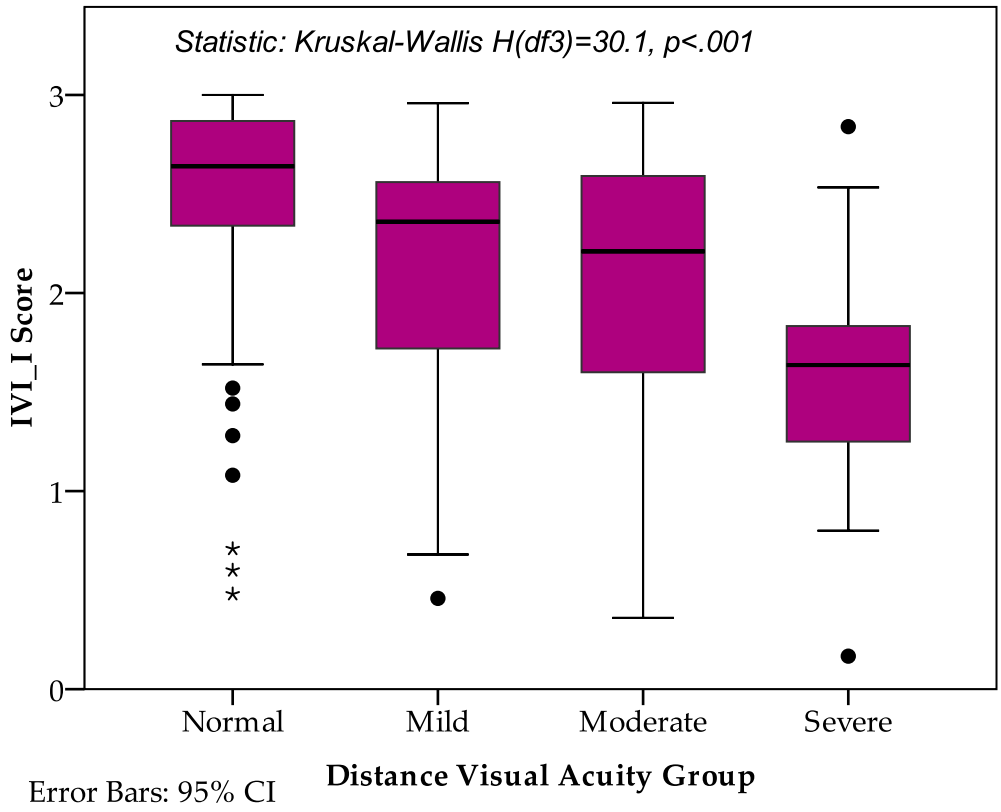
4.3.8 Visual Acuity

4.3.8.1 Distance Vision

The IVI_I demonstrated group construct validity as the group with normal distance visual acuity in the better eye demonstrated higher (better VRQOL) than the groups with vision impairment (Figure 4.8). Scores were similar for the participants with mild

or moderate vision impairment; however participants with severe vision impairment exhibited significantly greater difficulty with items than other participants.

Figure 4.8: Distance Vision Category by mean item score, all participants



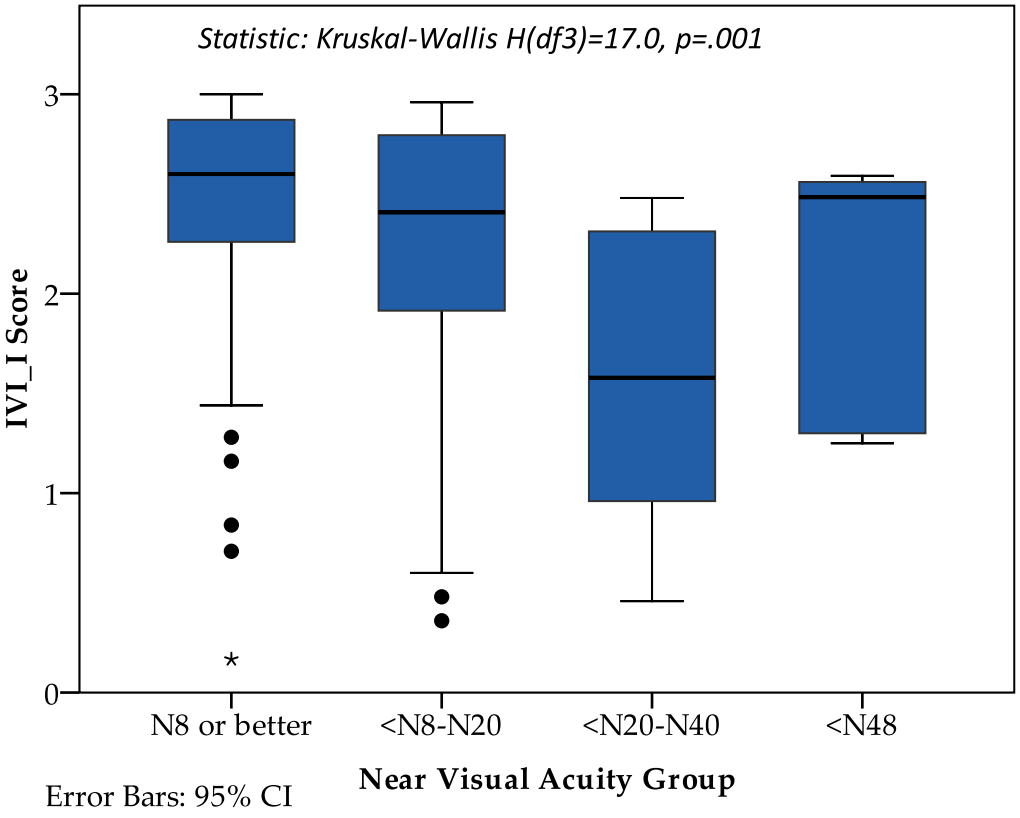
Post hoc analysis with a Bonferroni correction (level of significance =.0167) showed that there were significant differences in the total instrument score between normally sighted participants and all participants with vision impairment, even those with mild vision impairment (<6/12 to 6/18, Statistic: Mann-Whitney, *U*=1231.0, *p*<.001). The differences between the other categories of vision impairment were not significant at the Bonferroni corrected level of significance, although there was a difference between the mild and severe group at .05 level of significance (Statistic: Mann-Whitney, *U*=183.0, *p*<.05).

4.3.8.2 Near Vision

Of the participants with poor near visual acuity (i.e. uncorrected presbyopia), 41% had normal distance vision and the remaining 59% had distance vision impairment in their

better eye. There was an association with IVI_I total scores and presenting near vision (Figure 4.9).

Figure 4.9: Near Visual Acuity Category by mean item score, all participants



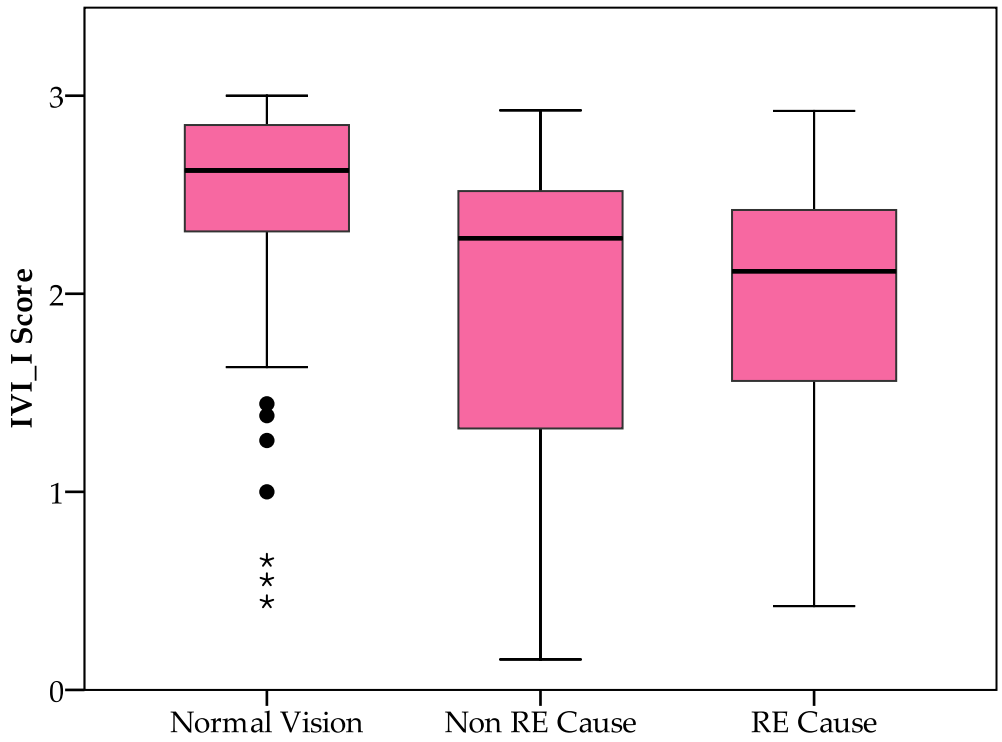
The normal group (N8 or better) had significantly better scores than the participants with moderate near visual acuity (<N20-N40, Statistic: Mann-Whitney with Bonferroni correction, U=132.0, p<.001). Differences were also detected between the mild and moderate groups (Statistic: Mann-Whitney with Bonferroni correction, U=200.0, p<.01). Although there were only six participants with near visual acuity <N48, there appeared to be a 'bounce back' effect, as these participants reported higher scores than the participants with moderate uncorrected presbyopia, although these differences were not significant (Statistic: Mann-Whitney with Bonferroni correction, U=16.0, p>.05).

4.3.8.3 Vision Impairment from Uncorrected Refractive Error

When participants were stratified by refractive error (RE) or non-refractive error causes (Figure 4.10), differences in IVI_I score were observed between participants with

normal vision and those with vision impairment as a result of uncorrected refractive error (Statistic: Mann-Whitney with Bonferroni correction, *U*=689.0, *p*<.001), as well as vision impairment from non-refractive error related causes (Statistic: Mann-Whitney with Bonferroni correction, *U*=1249.5, *p*<.001).

Figure 4.10: Cause of Vision Impairment (uncorrected refractive error versus other all other causes), all participants



Error Bars: 95% CI

There was no difference in IVI_I mean score between participants with vision impairment due to uncorrected refractive error and those with vision impairment as a result of other non-refractive error causes (Statistic: Mann-Whitney with Bonferroni correction U=635.0, p>.05).

4.3.9 Construct Validity

4.3.9.1 Distribution of Item Responses

All twenty-eight items had responses across the full 0-3 range. All items for which a "Don't do this for other reasons" response was available demonstrated relevancy to

participants, as this item was not selected more than 10% of the time for any item (i.e. 90% or more of the participants did not respond that they did not do the activity for reasons other than vision).

The mean score for the 28 items ranged from 0.96 to 2.6, and the Standard Deviation (SD) of the mean for the 28 items was between 0.9 and 1.3 (Table 4.41).

4.3.9.2 Floor and Ceiling Effects

Floor and ceiling effects were assessed by calculating the fraction of patients using the lowest or highest rating.

There is no consensus definition of significant ceiling or floor effect,[158, 252-253] strong floor and ceiling effects have been reported previously where 70% or more of the participants either had little or no problems with an item, or had a great deal or difficulty or were simply unable to do the task.[10]

Seven of the 28 items initially exhibited floor (greater than 70% of participants had no or little problems) or ceiling effects (greater than 20% of participants had a lot of difficulty). However, when the normally sighted participants were removed from analysis only 2 items still exhibited floor effects (Table 4.41).

When the items exhibiting floor effects were examined based on the 'remoteness' of the participants the floor effect was increased. 92% of vision impaired remote participants from Remote, Very Remote Coastal or Very Remote Inland regions (n=26) reported little or no problems with Item 23 'Lonely/Isolated', compared to 84% of all vision impaired participants. Similarly, 77% of vision impaired participants from remote regions reported little or no problems with Item 24 'Sad/Low', compared to 72% of all vision impaired participants

Conversely, when participants who were only from Major Cities and Inner or Outer Regional areas were included (n=50), the floor effect of Item 24 was reduced to 68%, but still remained at 78% for item 23.

Table 4.41: Floor and ceiling effects, participants with vision impairment

Item	N	Min	Max	Floor n (%)	Ceiling n (%)	Skew	Mean Score ± SD
1-TV	70	0	3	23 (32.9%)	11 (15.7%)	-0.5	1.83 ± 1.1
2-Rec Activities	65	0	3	35 (53.8%)	8 (12.3%)	-1.0	2.17 ± 1.1
3-Shopping	69	0	3	25 (36.2%)	18 (26.1%)	-0.2	1.66 ± 1.2
4-Visiting friends	73	0	3	44 (60.3%)	8 (11.0%)	-1.2	2.27 ± 1.0
5-Recognising people	74	0	3	27 (36.5%)	12 (16.2%)	-0.4	1.81 ± 1.1
6-Appearance	74	0	3	42 (56.8%)	7 (9.5%)	-1.1	2.27 ± 1.0
7-Packaging	71	0	3	37 (52.1%)	12 (16.9%)	-0.9	2.08 ± 1.2
8-Labels	68	0	3	20 (29.4%)	30 (44.1%)	0.3	1.29 ± 1.3
9-Appliances	67	0	3	34 (50.7%)	8 (11.9%)	-1.0	2.16 ± 1.0
10-Outdoors	74	0	3	44 (59.5%)	12 (16.2%)	-1.1	2.17 ± 1.2
11-Falling/ tripping	73	0	3	31 (42.5%)	18 (24.7%)	-0.4	1.78 ± 1.2
12-Traveling/ transport	68	0	3	39 (57.4%)	8 (11.8%)	-1.0	2.17 ± 1.1
13-Steps	75	0	3	37 (49.3%)	9 (12.0%)	-0.7	2.05 ± 1.1
14-Ordinary size print	67	0	2	25 (37.3%)	28 (41.8%)	0.1	0.96 ± 0.9
15-Getting info	70	0	2	31 (44.3%)	21 (30.0%)	-0.3	1.14 ± 0.9
16-General safety home	75	0	3	37 (49.3%)	6 (8.0%)	-1.1	2.22 ± 0.9
17-Spilling/ breaking	74	0	3	48 (64.9%)	4 (5.4%)	-1.3	2.40 ± 0.9
18-General safety out	75	0	3	41 (54.7%)	5 (6.7%)	-1.0	2.26 ± 0.9
19-Stopped doing things	75	0	3	31 (41.3%)	13 (17.3%)	-0.5	1.87 ± 1.1
20-Needing help	74	0	3	34 (45.9%)	9 (12.2%)	-0.6	2.00 ± 1.1
21-Embarrassed	75	0	3	44 (58.7%)	7 (9.3%)	-1.1	2.25 ± 1.0
22-Frustrated	74	0	3	27 (36.5%)	15 (20.3%)	-0.4	1.79 ± 1.2
23-Lonely/ Isolated	75	0	3	63 (84.0%)	4 (5.3%)	-2.3	2.64 ± 0.9
24-Sad/ low	75	0	3	54 (72.0%)	5 (6.7%)	-1.7	2.50 ± 0.9
25-Worried getting worse	74	0	3	17 (23.0%)	21 (28.4%)	0.0	1.45 ± 1.1
26-Coping with life	75	0	3	29 (38.7%)	12 (16.0%)	-0.4	1.86 ± 1.1
27-Nuisance/ burden	75	0	3	42 (56.0%)	7 (9.3%)	-1.0	2.21 ± 1.0
28-Interfered with life	75	0	3	27 (36.0%)	12 (16.0%)	-0.3	1.80 ± 1.1

Shading indicates items with significant floor effects (≥70% of participants with distance vision impairment did not have any trouble with items).

4.3.9.3 Inter-item Correlations

The inter-item correlation matrix is presented in Table 4.42. Correlations among individual items varied between 0.2 and 0.9.

Eight pairs of items had Spearman's correlations (ϱ) >0.7 and two pairs of items showing significant inter-item Spearman's correlations (r≥0.8).

Table 4.42: Inter Item Correlation Matrix, participants with vision impairment

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
1	1.00																											
2	0.44	1.00																										
3	0.48	0.58	1.00																									
4	0.36	0.45	0.67	1.00																								
5	0.45	0.50	0.55	0.52	1.00																							
6	0.28	0.57	0.50	0.45	0.51	1.00																						
7	0.41	0.49	0.60	0.47	0.40	0.56	1.00																					
8	0.35	0.55	0.58	0.45	0.45	0.45	0.74	1.00																				
9	0.24	0.42	0.56	0.50	0.29	0.38	0.69	0.62	1.00																			
10	0.30	0.49	0.59	0.67	0.53	0.49	0.45	0.43	0.53	1.00																		
11	0.23	0.37	0.23	0.24	0.21	0.34	0.22	0.30	0.27	0.47	1.00																	
12	0.33	0.47	0.55	0.46	0.39	0.55	0.31	0.36	0.40	0.61	0.59	1.00																
13	0.20	0.35	0.40	0.34	0.32	0.44	0.36	0.39	0.39	0.57	**0.83**	0.70	1.00															
14	0.33	0.45	0.49	0.41	0.40	0.49	0.60	0.72	0.52	0.35	0.22	0.32	0.26	1.00														
15	0.36	0.40	0.51	0.45	0.37	0.51	0.70	0.62	0.55	0.52	0.35	0.41	0.37	**0.83**	1.00													
16	0.30	0.44	0.37	0.36	0.31	0.50	0.33	0.31	0.31	0.50	0.52	0.56	0.51	0.33	0.41	1.00												
17	0.36	0.36	0.49	0.44	0.32	0.40	0.37	0.35	0.48	0.58	0.58	0.66	0.61	0.32	0.48	0.65	1.00											
18	0.39	0.41	0.44	0.54	0.37	0.52	0.39	0.35	0.36	0.56	0.69	0.64	0.69	0.43	0.50	0.78	0.68	1.00										
19	0.33	0.57	0.38	0.37	0.32	0.44	0.50	0.42	0.57	0.49	0.45	0.49	0.40	0.41	0.59	0.39	0.51	0.48	1.00									
20	0.44	0.48	0.42	0.35	0.40	0.32	0.29	0.32	0.36	0.34	0.44	0.54	0.42	0.27	0.39	0.48	0.47	0.53	0.57	1.00								
21	0.32	0.30	0.33	0.32	0.35	0.30	0.30	0.23	0.30	0.37	0.41	0.50	0.46	0.25	0.41	0.35	0.40	0.39	0.45	0.55	1.00							
22	0.41	0.27	0.35	0.20	0.22	0.26	0.43	0.35	0.43	0.34	0.47	0.53	0.47	0.29	0.55	0.38	0.49	0.44	0.57	0.58	0.70	1.00						
23	0.29	0.25	0.34	0.40	0.34	0.45	0.30	0.20	0.46	0.46	0.43	0.67	0.51	0.34	0.44	0.50	0.60	0.57	0.42	0.50	0.56	0.52	1.00					
24	0.18	0.09	0.31	0.22	0.21	0.30	0.19	0.25	0.39	0.39	0.38	0.54	0.43	0.22	0.31	0.43	0.59	0.43	0.38	0.44	0.48	0.54	0.71	1.00				
25	0.23	0.32	0.41	0.41	0.27	0.44	0.55	0.48	0.40	0.56	0.46	0.36	0.52	0.42	0.61	0.47	0.47	0.49	0.54	0.30	0.51	0.49	0.43	0.42	1.00			
26	0.30	0.21	0.32	0.48	0.29	0.32	0.39	0.36	0.36	0.50	0.43	0.36	0.43	0.31	0.43	0.39	0.46	0.49	0.50	0.33	0.35	0.51	0.50	0.44	0.77	1.00		
27	0.36	0.29	0.33	0.41	0.38	0.47	0.40	0.28	0.44	0.58	0.54	0.58	0.51	0.31	0.52	0.51	0.63	0.63	0.62	0.59	0.47	0.59	0.63	0.58	0.56	0.54	1.00	
28	0.33	0.33	0.44	0.36	0.41	0.39	0.49	0.41	0.49	0.52	0.35	0.49	0.34	0.42	0.61	0.35	0.47	0.45	0.67	0.54	0.50	0.65	0.55	0.55	0.57	0.53	0.74	1.00

Shading indicates items with inter-item correlations >0.70. Shading with bold indicates items with significant inter-item correlations >0.80.

4.3.9.4 Internal Consistency

When the IVI_I items were examined using the IVI_A domain structure, the total instrument had high internal consistency as demonstrated by a Cronbach α of 0.89 or greater (Table 4.43).

Table 4.43: Internal Consistency of Provisional Domains (Cronbach α)

IVI_A Domains	Number of Items	All Participants (n=172)	Vision Impaired Participants (n=75)
Reading and accessing information	9	0.90	0.89
Mobility and Independence	11	0.93	0.92
Emotional Wellbeing	8	0.93	0.91
Total	28	0.97	0.96

Eliminating one item at a time did not significantly alter the Cronbach α for each provisional domain or the total scores.

4.3.9.5 Item Reduction

The basic psychometric properties of items were examined and those failing to meet predetermined criteria are shown in Table 4.44.

Table 4.44: Items failing at least one psychometric criteria

Items	Criteria not met	Removed?
7-Opening packaging	Inter-item Correlation (Item 8)	Retained
8-Labels	Inter-item Correlation (Item 7)	Retained
11-Falling/ Tripping	Significant inter-item Correlation (Item 13)	Removed
13-Steps	Significant inter-item Correlation (Item 11)	Retained
14-Ordinary size print	Significant inter-item Correlation (Item 15)	Retained
15-Getting info	Significant inter-item Correlation (Item 14)	Removed
23-Lonely isolated	Significant floor effect	Removed
24-Sad/ low	Floor effect	Retained

The criteria for failure were: >80% of responses from vision impaired participants loading onto one response category; more than 10% of vision impaired participants indicating that they "Did not do this for other reasons"; >70% vision impaired participants reporting they had no difficulty with an item; >70% vision impaired participants reporting that they had difficulty "A lot"; significant inter-item Spearmans correlation (≥0.8); and SD<0.5. The ability of the item to discriminate between normal vision and vision impairment was also

examined, taking into account which component of vision it theoretically measures (i.e. distance or near vision).

It was determined that Item 23 did not meet psychometric criteria due to the floor effect and was therefore removed in further analysis. Items 11 and 15 exhibited significant inter-item correlations (≥0.8) with items exhibiting the similar theoretical construct and were therefore removed.

Inter-item correlations were assessed again after the three items identified were removed. There were no additional pairs of items displaying Spearman's correlations (ϱ) >0.7.

4.3.10 Principal Components Analysis

The remaining 25 items of the IVI_I were subjected to principal components analysis (PCA) using SPSS version 17. Prior to performing PCA, the suitability of data for factor analysis was assessed. The moderate correlation (>0.3) among factors (Table 4.45) indicates that these factors are likely to be correlated and confirms the appropriateness of an Oblimin (oblique) rotation solution. The Kaiser-Meyer-Olkin value was 0.81, exceeding the recommended value of .6,[254] and Bartlett's Test of Sphericity[255] reached statistical significance (<.001) supporting the factorability of the correlation matrix. Eigenvalues > 1.00 were used to determine the number of components.[256]

Table 4.45: Component Correlation Matrix

Component	1	2	3	4	5
1	1.000	.422	-.288	.407	.419
2	.422	1.000	-.423	.309	.292
3	-.288	-.423	1.000	-.202	-.085
4	.407	.309	-.202	1.000	.271
5	.419	.292	-.085	.271	1.000

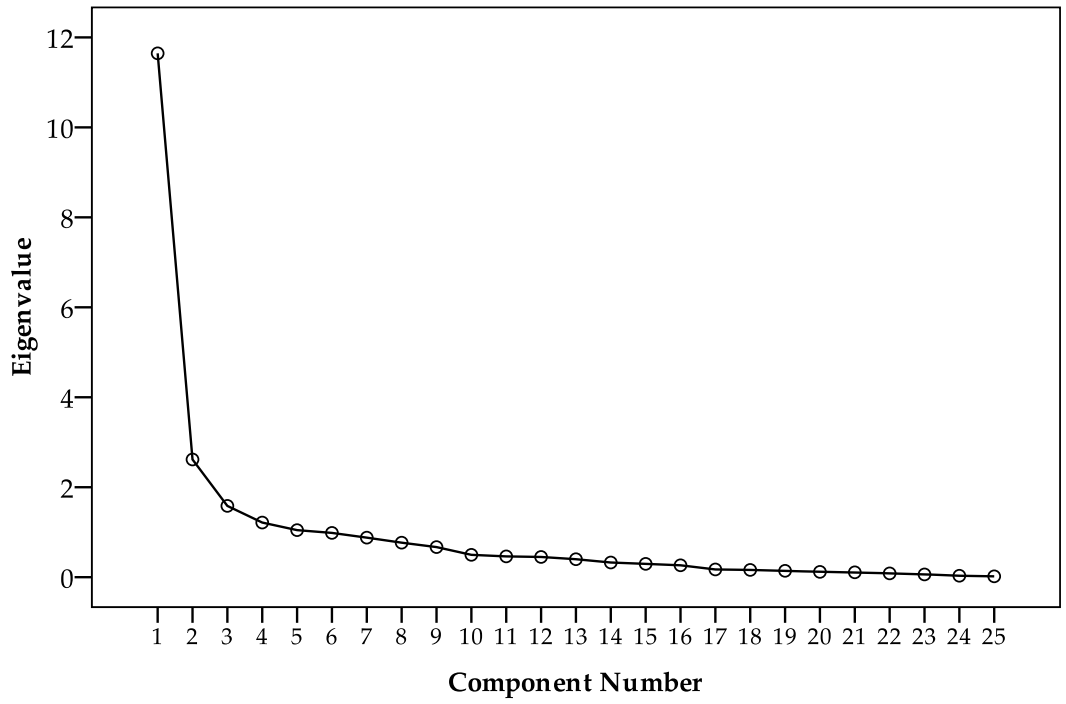
Extraction Method: Principal Component Analysis.
Rotation Method: Oblimin with Kaiser Normalization.

Principal components analysis with direct Oblimin rotation revealed the presence of five components with eigenvalues greater than 1 that satisfied Kaiser's criterion and explained

70.8% of the total variance. The solution was dominated by the first component, eigenvalue 11.5, which explained 45% of the variation in the data. Components two, three, four and five explained 9.7%, 5.9%, 5.3% and 4.2% of the variation respectively.

Catell's scree test[257] was then used to determine the number of components to retain (Figure 4.11). The x axis contains the Principal Components sorted by decreasing fraction of total variance explained. The y axis contains the fraction of total variance explained. The shape of the scree plot suggests a three component solution, as the 'elbow', where the plotted line starts to level out is used as the criterion for selection of how many components to extract. Previous research has confirmed a three-subscale structure of the IVI_A.[204]

Figure 4.11: EFA Initial Solution Scree Plot of Factors



The Pattern Matrix and Structure Matrix are shown in Table 4.46.

Table 4.46: Exploratory PCA Pattern/ Structure Matrix

	Pattern Matrix[a]					**Structure Matrix**				
	Component					Component				
Item	1	2	3	4	5	1	2	3	4	5
16 General safety at home	.891	.009	.009	-.091	-.032	.890	.396	-.313	.338	.389
18 General safety when out	.875	.004	-.065	-.040	.027	.841	.343	-.230	.263	.318
17 Spilling or breaking things	.724	.110	.043	.109	.073	.833	.453	-.241	.449	.434
13 Going down steps/ stairs	.724	.045	.022	.072	.011	.825	.391	-.364	.627	.348
12 Interfered with travelling	.680	-.045	-.118	.348	-.029	.770	.367	-.221	.379	.345
27 Nuisance or burden	.489	-.045	-.087	.228	.376	.745	.378	-.287	.533	.637
24 Sad/ low	.429	.009	.272	.287	.363	.691	.468	-.660	.275	.455
6 Looking after appearance	.395	.347	-.287	-.163	.006	.623	.269	.055	.507	.600
8 Reading medicine labels	-.067	.879	-.057	.004	.002	.323	.877	-.411	.261	.236
7 Opening packaging	-.146	.846	-.044	-.007	.180	.296	.853	-.374	.253	.367
14 Reading ordinary print	.058	.791	-.017	-.044	-.034	.481	.804	-.237	.304	.327
9 Operating appliances	.175	.779	.149	.012	.036	.365	.800	-.357	.219	.211
2 Recreational Activities	.134	.447	-.357	.299	-.320	.413	.654	-.618	.477	-.022
19 Stopped doing things	.132	.417	.020	.363	.214	.539	.639	-.287	.599	.487
4 Visiting friends or family	.093	.057	-.779	-.131	.219	.560	.586	-.515	.165	.253
5 Recognising people	-.033	.011	-.740	.250	.027	.380	.449	-.822	.141	.305
10 Getting about outdoors	.478	.008	-.517	-.090	.232	.298	.396	-.788	.397	.147
3 Shopping	.110	.350	-.512	.156	-.076	.436	.639	-.717	.391	.158
20 Needed help from others	.294	.078	-.021	.704	-.128	.566	.392	-.271	.817	.211
22 Frustrated/ annoyed	.079	.149	.203	.657	.359	.501	.404	-.046	.792	.596
21 Embarrassed	.110	-.085	-.102	.649	.251	.473	.279	-.251	.757	.457
1 TV	-.056	.087	-.376	.543	-.077	.278	.368	-.500	.602	.105
26 Concerned/ worried	.068	.058	-.170	.040	.777	.483	.398	-.288	.331	.848
25 Worried about eyesight	.082	.250	-.137	-.052	.702	.499	.531	-.315	.276	.806
28 Interfered with life in general	.039	.224	-.012	.410	.486	.508	.515	-.243	.630	.681

To test the data against previously reported factor analysis and the EFA results, the data were fitted to a three-factor solution (using confirmatory factor analysis) and interpreted with an oblique rotation solution (Table 4.47). Only loadings greater than .4 are shown. Three items loaded onto two components. All 25 retained items loaded with commonalities that ranged from 0.44 to 0.85.

Table 4.47: Pattern and Structure Matrix of Three Component Solution of IVI_A items

	Pattern Coefficients Components			**Structure Coefficients Components**		
	1	**2**	**3**	**1**	**2**	**3**
13 Going down steps/ stairs	.854			.859	.440	
17 Spilling or breaking things	.818			.823		
18 General safety when out	.811			.811		-.590
24 Sad/ low	.776			.809		
16 General safety at home	.750			.784	.402	-.459
12 Interfered with travelling	.702			.741		
27 Nuisance or burden	.701			.715		
26 Concerned/ worried	.619			.710	.548	-.438
22 Frustrated/ annoyed	.565		-.430	.698		-.621
25 Worried about eyesight	.547	.486		.682	.658	
10 Getting about outdoors	.537			.679	.513	
28 Interfered with life	.439			.673	.607	-.500
7 Opening packaging		.892			.844	
8 Reading medicine labels		.868			.843	
14 Reading ordinary print		.805			.775	
9 Operating appliances		.719		.410	.749	
6 Looking after appearance		.679		.462	.730	-.558
3 Shopping		.586		.410	.727	
4 Visiting friends or family		.544		.523	.685	-.581
19 Stopped doing things		.493		.440	.668	-.444
2 Recreational Activities		.506	-.490	.419	.671	-.659
1 TV			-.757	.571		-.816
20 Needed help from others			-.697			-.765
5 Recognising people			-.552	.439	.567	-.696
21 Embarrassed	.489		-.509	.642		-.665

Extraction Method: Principal Component Analysis. Rotation Method: Oblimin with Kaiser Normalization.

The three factor solution accounted for 63.4% of the common factor variance and all three factors had eigenvalues greater than 1 (Table 4.48).

Table 4.48: EFA - Explanation of Variance

Component	Eigenvalues	% of Variance	Cumulative %
1	11.6	46.6	46.6
2	2.6	10.5	57.1
3	1.6	6.3	63.4

Extraction Method: Principal Component Analysis.

Interpretation and description of the theoretical constructs underlying each of three components (Table 4.49) resulted in domains that differed from the original IVI_A in the way that the former 'emotional well-being' domain has been redistributed among the activities to which it is possibly associated.

The first factor consisted of items from the mobility and independence and emotional wellbeing domains of the IVI_A. Items with the highest and most closely related loadings in the second component consisted of 8 items from the reading and accessing information and mobility and independence domains of the IVI_A. The final third component consisted of items from all of the IVI_A's domains and were concerned with restrictions in social interactions both within and outside the home.

Table 4.49: Hypothesised IVI_I Domains

Domain	Description	Number of Items
1 – Mobility, Independence and Emotional Wellbeing	Restrictions in mobility and independence, and the emotional reaction to the loss of independence and mobility.	12
2 –Getting information	Restrictions in getting information through reading, symbols and personal interactions	8
3 – Social implications	Restrictions in social interactions both within and outside the home	5

A total of 13 items loaded on factors similar to those reported by Lamoureux.[14] The items that did not load on similar underlying factors included the mobility and independence and emotional wellbeing items. The predominant lack of fit with the proposed domain structure occurred with items related to emotional wellbeing, as they are now grouped

together with items related to independence. However, a new domain concerned with the social implications of vision impairment also emerged.

4.3.11 Reliability: Domains

4.3.11.1 Split-Half Correlation

The Guttman split-half correlation was used to assess the correlation between two halves of each scale (Table 4.50). The total instrument had a corrected reliability coefficient of 0.92. The domain indicating the least reliability with this method was the 'Getting Information' scale (0.86). Cronbach's α tests indicated that the subscales identified by the PCA were internally consistent.

Table 4.50: Guttman Split-Half Correlation

Domain	N	Spearman-Brown Coefficient (Range, 0-1)
1 – Mobility, Independence and Emotional Wellbeing	151	.88
2 –Getting information	137	.86
3 – Social implications	149	.80
Overall instrument	123	.92

4.3.11.2 Internal Consistency Reliability (uni-dimensionality)

Internal consistency was adequate for the total scale (Cronbach's $\alpha = 0.96$), with individual factors yielding alphas between 0.83 and 0.94.

The reliability of each domain was also assessed and is reported in Table 4.51. All domains demonstrate extremely high reliability, although some redundancy may be present. The 'Social Implications' subscale displayed the least internal consistency (0.83), however it still demonstrates high robustness.

Table 4.51: Domain Reliability

Domain	n	Cronbach α
1 – Mobility, Independence and Emotional Wellbeing	151	.94
2 –Getting information	137	.90
3 – Social implications	149	.83
Overall instrument	123	.96

We further assessed internal scale reliability by calculating scale reliabilities for each of the three subscales according to distance vision impairment and vision impairment as a result of refractive error (Table 4.52). The 'Mobility, Independence and Emotional Wellbeing' and 'Getting Information' subscales were highly robust, with reliabilities ranging from .86 to .9. The 'Social implications' demonstrated lower robustness for each level of vision impairment, particularly for the severely vision impaired. However, there were only 13 participants in this category. The total instrument demonstrated high robustness (≥.92) for each category of vision impairment.

Table 4.52: Internal Scale Reliability

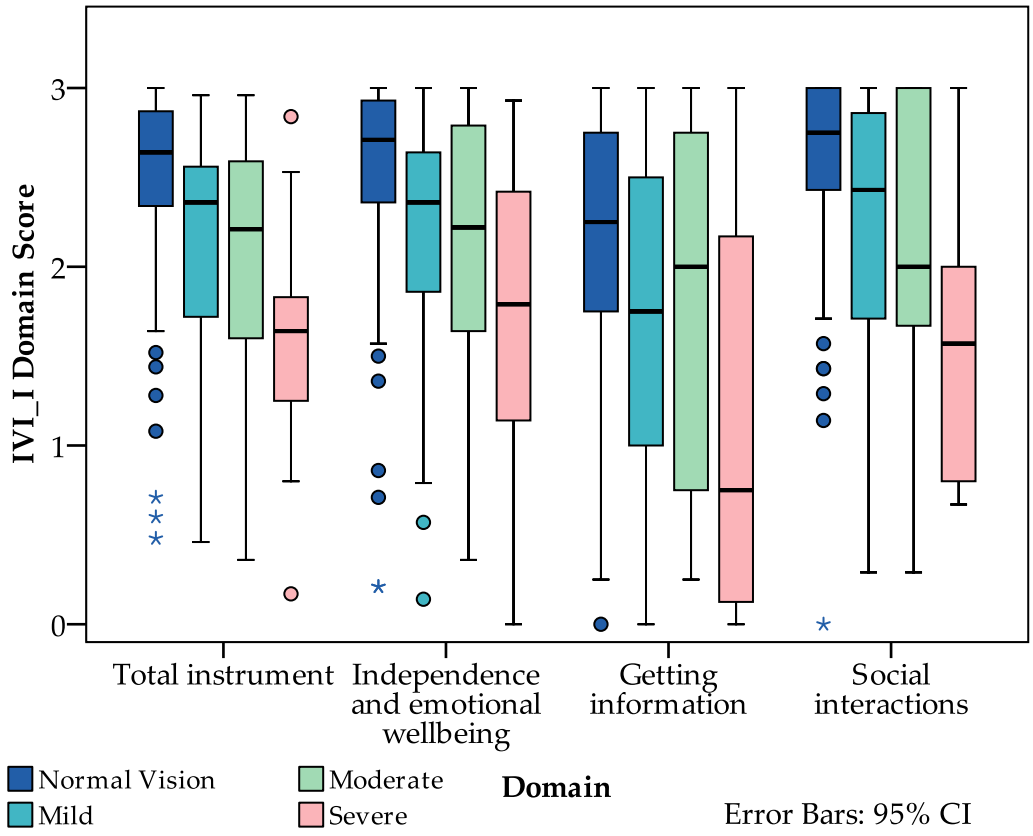
Level/ Cause of Vision Impairment	**N**	**Mobility, Independence and Emotional Wellbeing (α)**	**Getting information (α)**	**Social implications (α)**	**Three-factor total scale reliability (α)**
Normal	96	.93	.87	.81	.96
Mild	45	.93	.86	.81	.94
Moderate	18	.94	.94	.83	.97
Severe	13	.95	.87	.54	.94
Total		.94	.90	.83	.96
Refractive VI	30	.91	.86	.85	.92
Non-refractive VI	46	.95	.91	.78	.97

4.3.12 Discriminative Validity: Domains

4.3.12.1 Distance Visual Acuity

The construct validity of the proposed domain structure of the IVI_I was tested by assessing its ability to discriminate between participants of different levels of vision impairment for each of the three domains (Figure 4.12). Stratification by vision impairment by the three IVI_I domains demonstrated a significant association. This suggests that the scores generated for each domain are associated with distance visual acuity.

Figure 4.12: Distance visual acuity by domain score, all participants



Poorer vision was clearly associated with increased difficulty across all domains and in the total instrument score. When a comparison was made of the average score for each domain, participants with vision impairment had a greater range of responses, and had greater difficulty with items.

Figure 4.12 also demonstrates that the participants with normal vision have relatively smaller confidence intervals than the vision impaired participants across all domains, except in the accessing information domain, which is likely to be a result of participants with normal distance vision having uncorrected presbyopia.

A strong consistent relationship was found with distance visual acuity and IVI_I score for each domain using the Kruskal-Wallis test for difference. Median scores were lower for participants with poorer vision. Significant differences were found between each of the

vision categories for each of the three domains, as well as the total instrument score (Table 4.53).

Table 4.53: Median domain scores categorised by level of vision impairment (Kruskal-Wallis H Test)

IVI_I scores	Normal (N=96)	Mild (N=45)	Mod (N=18)	Severe (N=13)	$\chi 2$ (df=3)	p
1 – Mobility, Independence and Emotional Wellbeing	2.73	2.33	2.35	1.67	30.15	<.001
2 –Getting information	2.50	2.13	2.14	1.40	22.39	<.001
3 – Social implications	2.71	2.25	2.00	1.60	21.89	<.05
Overall instrument	2.64	2.36	2.21	1.64	33.37	<.001

Post hoc Mann-Whitney tests were used to examine these differences, with a Bonferroni correction applied so all effects are reported at a .017 level of significance. There were significant differences between normally sighted participants and those with mild vision impairment (<6/12 to 6/18), for each of the domains and for the total instrument (Table 4.54). A significant difference was also observed between the participants with mild vision impairment and those with severe vision impairment for the social interactions domain (statistic: Mann-Whitney with Bonferroni correction, U=121.5, ρ=.001). No other significant differences were observed.

Table 4.54: Differences in domain scores, those with normal vision, versus mild vision impairment

Domain	Mann-Whitney U	*z*	*p*
1 – Mobility, Independence and Emotional Wellbeing	1325	-3.64	$<.001^{\infty}$
2 –Getting information	1358	-3.56	$<.001^{\infty}$
3 – Social implications	1398	-3.42	$<.001^{\infty}$
Overall instrument	1231	-4.11	$.001^{\infty}$

$^{\infty}$ Significant differences when comparing the means of the two groups

Although Figure 4.12 demonstrates an apparent difference between participants with moderate vision impairment and those with severe vision impairment, this group had fewer participants than the other groups (n=13) and the confidence intervals were quite

wide. These differences were not statistically significant at the Bonferroni corrected significance value.

When the mild and moderate groups were grouped and then compared with either normal vision or severe vision impairment (Table 4.55), differences between mild/moderate and normal vision impairment were significant for all domains and the total instrument (level of significance p=.025). Differences between mild/moderate and severe vision impairment were significant for the 'Social implications' domain only (level of significance p=.025).

Table 4.55: Median scores for those with normal vision, mild/ moderate combined and severe vision impairment

Domain	Normal (n=96)	Mild/ Mod (n=63)	Severe (n=13)	Mann-Whitney U	*z*	*p*
1 – Mobility, Independence and Emotional Wellbeing	2.73	2.33	1.67	**1880.5***	**-3.97**	**.000**
				309$^{\infty}$	-1.39	.17
2 –Getting information	2.50	2.13	1.40	**2056***	**-3.42**	**.000**
				263$^{\infty}$	-2.02	.043
3 – Social implications	2.71	2.20	1.60	**1888***	**-4.05**	**.001**
				199$^{\infty}$	**-2.91**	**.004**
Overall instrument	2.64	2.29	1.64	**1770***	**-4.42**	**.000**
				257.5$^{\infty}$	-2.10	.036

*Post hoc comparison between Normal vision and Mild/ Moderate vision impairment combined

$^{\infty}$ Post hoc comparison between Mild/ Moderate vision impairment combined and Severe vision impairment

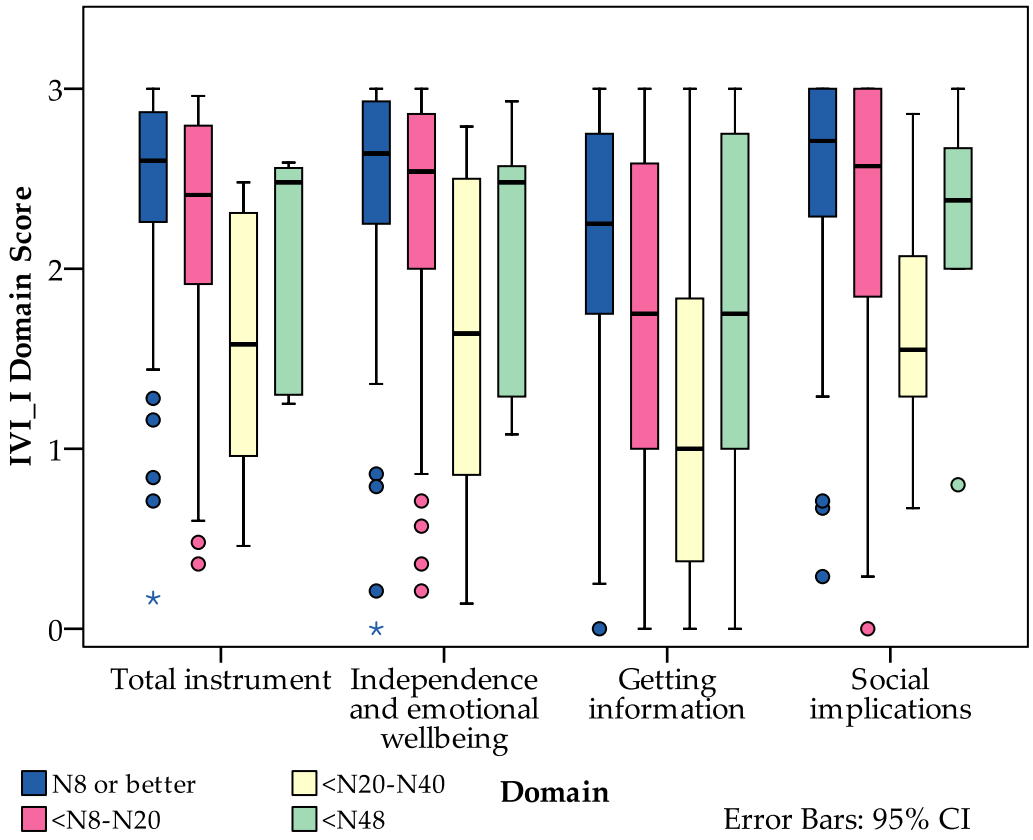
Bolded cells indicated significant differences at p=.025 level of significance.

4.3.12.2 Near Visual Acuity

The association between domain scores and levels of visual acuity was also observed for each of the three proposed domains (Figure 4.13).

Participants with reduced visual acuity also had lower median scores and experienced more difficulty with items for all domains and the total instrument (Table 4.56).

Figure 4.13: Near visual acuity by domain score, all participants



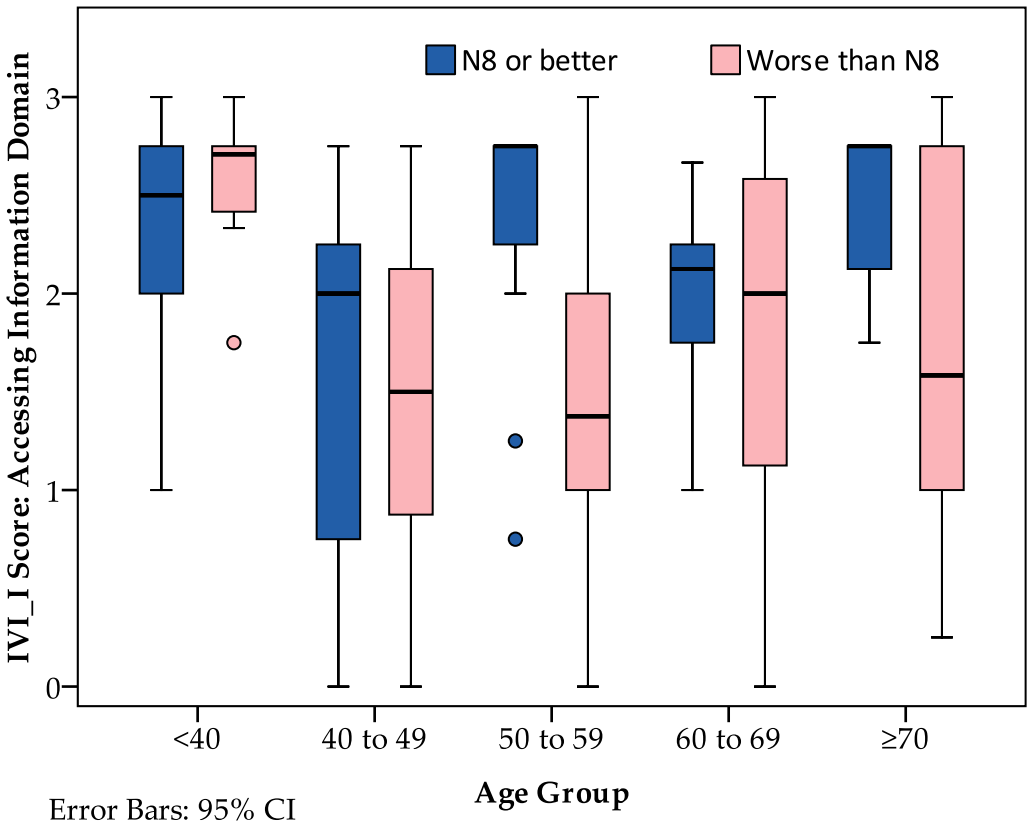
There was a 'bounce back' effect for participants with severe near vision impairment (<N48), however there were not enough participants in this group (n=8) to investigate reasons for these differences.

Table 4.56: Median domain scores categorised by level of near vision impairment (Kruskal-Wallis H Test)

IVI_I scores	**>N8 (N=71)**	**<N8-N20 (N=72)**	**<N20 (N=18)**	χ^2 ***(df=2)***	***p***
1 – Mobility, Independence and Emotional Wellbeing	2.46	2.32	1.84	9.9	.007
2 –Getting information	2.33	2.06	1.62	15.5	.000
3 – Social implications	2.42	2.33	1.72	14.9	.001
Overall instrument	2.41	2.24	1.75	15.5	.000

The 'Getting Information' domain is likely to be impacted by near vision impairment and uncorrected presbyopia. When the scores for this domain were examined by age significant differences were observed for both participants with (statistic: Kruskal-Wallis, H (4) =14.7, p=.005) and without (statistic: Kruskal-Wallis, H (4) =13.7, p=.008) near vision impairment (Figure 4.14). When participants unlikely to have presbyopia (i.e. those less than 40 years) were excluded, differences in the 'Getting Information' domain scores were only observed for participants with normal near vision (statistic: Kruskal-Wallis, H(4)=11.2 p=.011).

Figure 4.14: Getting Information domain score by age and presence of near vision impairment.



When differences in education were explored for each of the four near visual acuity groupings, no differences were observed (p<0.1) for either the total instrument score, or for any of the three subscales. Similarly, when differences in each of the domain scores were

examined by remoteness for participants by each category of near vision impairment, there were no differences in IVI_I score for any domain, or the total score (p<0.1).

When each domain was explored for differences in degree of remoteness, the overall instrument and the 'Social Implications' domain demonstrated differences in IVI_I scores (Table 4.57). Differences were not observed for the two other domains. The median scores for each level of remoteness indicated that the greatest differences occur between the Major Cities and the other areas. However, these differences were not significant (p >.01) after post hoc analysis with a Bonferroni correction (level of significance =.01)

Table 4.57: Median domain scores categorised by level of remoteness (Kruskal-Wallis H Test)

Level of Remoteness	**1 – Mobility, Independence and Emotional Wellbeing**	**2 –Getting information**	**3 – Social implications**	**Overall instrument**
Major City	1.83	1.57	1.60	1.65
Inner Regional	2.38	2.00	2.50	2.36
Outer Regional	2.67	2.46	2.60	2.58
Remote	2.58	2.38	2.40	2.59
Very Remote Coastal	2.41	2.57	2.40	2.46
Very Remote Inland	2.50	2.50	2.00	2.39
χ^2 $(df=3)$	11.0	9.5	18.2	13.8
p	>.05	>.05	.003	.012

4.3.13 Multiple Linear Regression

The association of demographic and vision impairment factors with reduced participation (IVI_I scores) was analysed using univariate linear regression (Table 4.58). The variables near vision, age, degree of remoteness and education were collapsed into two or three categories so that each category would have sufficient participants for subsequent multivariate analysis.

The variables significantly associated (p<.05) with total IVI_I score were distance visual acuity (mild, moderate and severe), near visual acuity (<N8) and age (≥40). Distance visual acuity was similarly associated with the three domain scores. Near visual acuity and age

were associated with the 'Mobility, Independence and Emotional Wellbeing' and 'Getting Information' domains, but not with 'Social Implications'.

A generalized linear model (Table 4.59) confirmed that increasingly severe distance vision impairment was significantly associated with IVI_I total scores.

Severe distance visual acuity was also significantly associated with poorer IVI scores for with the three domain scores. In this model, worsening near vision impairment was not significantly associated with either the poorer IVI_I scores or any of the domains.

Multiple regression was then used to assess the ability of distance and near visual acuity to predict IVI_I scores. Variables that were significantly associated with either the total IVI_I score or any of the domain scores were included in a multivariate model to determine which variables were the best predictors of IVI_I scores, after controlling for potential confounders. Variables that were associated with IVI_I scores at the p <0.1 level of significance were also included in the multivariate model. As gender was associated with the 'Social Implications' domain at the p <0.1 level of significance, it was also included in the multivariate model. After controlling for age, multivariate linear regression models showed that IVI_I instrument scores were related to distance visual acuity (Table 4.60).

Table 4.58: Univariate associations with the IVI_I total and domain scores

	n	mean	SD	β	*p*	95% CI	R^2	mean	SD	β	*p*	95% CI	R^2
Poor Distance Vision			**Total Instrument**					**Mobility, Independence and Emotional Wellbeing**					
Normal (≥6/ 12)	96	2.49	0.54	*				2.54	0.59	*			
Mild (<6/ 12 to 6/ 18)	45	2.09	0.67	-0.40	**<.001**	-0.62, -0.18		2.16	0.73	-0.37	**0.003**	-0.62, -0.13	
Moderate (<6/ 18 to 6/ 60)	18	2.03	0.77	-0.45	**0.005**	-0.77, -0.14	.16	2.10	0.84	-0.43	**0.015**	-0.78, -0.09	.10
Severe (<6/ 60)	13	1.59	0.73	-0.89	**<.001**	-1.25, -0.54		1.75	0.91	-0.78	**<.001**	-1.18, -0.38	
Poor Near Vision													
Normal (≥N8)	71	2.41	0.60	*			.04	2.46	0.65	*			.01
Worse than N8	90	2.14	0.70	-0.27	**0.010**	-0.48, -0.07		2.22	0.76	-0.24	**0.038**	-0.46, -0.01	
Older Age													
≤39	34	2.64	0.39	*				2.68	0.49	*			
40 to 59	83	2.14	0.70	-.51	**<.001**	-0.69, -.14	.07	2.22	0.75	-.46	**.005**	-.75, -.16	.05
≥60	55	2.23	0.68	-.41	**.004**	-.77, -.25		2.30	0.75	-.38	**.015**	-.69, -.08	
Male Gender													
Female	104	2.21	0.69	*			.01	2.27	0.72	*			.01
Male	68	2.36	0.62	0.15	0.145	-0.05, 0.36		2.43	0.72	0.16	0.152	-0.06, 0.38	
Less Remote													
Remote/ Very Remote	29	2.23	0.66	*			.01	2.30	0.77	*			.01
City/ Regional	143	2.28	0.67	0.05	0.716	-0.22, 0.32		2.34	0.72	0.04	0.798	-0.25, 0.33	
Less Education													
Year 9 or greater	106	2.25	0.69	*			.01	2.31	0.74	*			.01
Year 8 or below	57	2.27	0.64	0.01	0.89	-0.20, 0.23		2.36	0.71	0.05	0.69	-0.19, 0.28	
English Language													
Other Language	23	2.18	0.66	*			.01	2.26	0.75	*			.01
English	142	2.28	0.67	0.09	0.53	-0.20, 0.39		2.34	0.72	0.08	0.62	-0.24, 0.4	

Table 4.58: Univariate associations with the IVI_I total and domain scores(continued)

	n	mean	SD	β*	*p*	95% CI	R^2	mean	SD	β	*p*	95% CI	R^2
Poor Distance Vision				**Getting information**						**Social Implications**			
Normal (≥6/ 12)	96	2.38	0.56	*				2.54	0.57	*			
Mild (<6/ 12 to 6/ 18)	45	1.93	0.77	-0.45	**<.001**	-0.69, -0.21	.15	2.16	0.75	-0.37	**0.002**	-0.61, -0.14	.17
Moderate (<6/ 18 to 6/ 60)	18	1.99	0.86	-0.39	**0.024**	-0.73, -0.05		1.95	0.83	-0.59	**0.001**	-0.92, -0.26	
Severe (<6/ 60)	13	1.42	0.82	-0.96	**<.001**	-1.35, -0.57		1.51	0.60	-1.03	**<.001**	-1.41, -0.65	
Poor Near Vision													
Normal (≥N8)	71	2.33	0.63	*			.05	2.42	0.67	**			.02
Worse than N8	90	1.97	0.78	-0.36	**0.002**	-0.59, -0.14		2.21	0.74	-0.21	*0.067*	-0.43, 0.02	
Older Age													
≤39	34	2.61	0.37	*				2.60	0.45				
40 to 59	83	1.96	0.77	-0.65	**<.001**	-.92, -.37	.10	2.24	0.79	-.36	0.13	-.65, -.08	.03
≥60	55	2.15	0.71	-0.46	**<.001**	-.76, -.16		2.22	0.70	-.38	0.14	-.69, -.08	
Male Gender													
Female	104	2.09	0.76	*			<.01	2.23	0.76	*			.01
Male	68	2.23	0.67	0.13	0.246	-0.09, 0.36		2.41	0.64	0.19	*0.094*	-0.03, 0.41	
Less Remote													
Remote/ Very Remote	29	2.17	0.73	*			-.01	2.14	0.60	*			<.01
City/ Regional	143	2.14	0.73	-0.03	0.822	-0.33, 0.26		2.33	0.74	0.19	0.195	-0.1, 0.48	
Less Education													
Year 9 or greater	107	2.13	0.75	*			-.01	2.32	0.72	*			-.01
Year 8 or below	57	2.14	0.69	0.01	0.914	-0.22, 0.25		2.26	0.71	-0.06	0.62	-0.29, 0.17	
English Language													
Other Language	23	2.09	0.76	*			<.01	2.15	0.60	*			<.01
English	142	2.14	0.73	0.05	0.749	-0.27, 0.38		2.33	0.73	0.18	0.27	-0.14, 0.49	

*β=standardised regression coefficient. Higher beta values indicate greater impact of the predictor variable on the criterion variable. Positive betas indicate a positive relationship between the predictor and criterion variable. Negative betas indicate the reverse.

Table 4.59: IVI_I total and domain scores general linear model

	β	*p*	95% CI	β	*p*	95% CI
	Total Instrument			**Mobility, Independence and Emotional Wellbeing**		
Distance Vision						
Normal (≥6/ 12)	*			*		
Mild (<6/ 12 to 6/ 18)	-0.26	**.038**	-0.5, -0.01	-0.25	.075	-0.52, 0.03
Moderate (<6/ 18 to 6/ 60)	-0.36	**.036**	-0.7, -0.02	-0.31	.105	-0.69, 0.07
Severe (<6/ 60)	-0.85	**<.001**	-1.22, -0.49	-0.75	**<.001**	-1.16, -0.34
Near Vision						
Normal (≥N8)	*			*		
Worse than N8	-0.13	.200	-0.34, 0.07	-0.11	.372	-0.34, 0.13
Age						
≤39	*			*		
40 to 59	-0.38	**.006**	-0.65, -0.11	-0.37	**.019**	-0.67, -0.06
≥60	-0.08	.604	-0.39, 0.23	-0.09	.615	-0.44, 0.26
Gender						
Female	*			*		
Male	0.23	**.022**	0.03, 0.43	0.24	**.033**	0.02, 0.47
Adjusted R^2		.208			.139	
	Getting information			**Social Implications**		
Distance Vision						
Normal (≥6/ 12)	*			*		
Mild (<6/ 12 to 6/ 18)	-0.27	**.043**	-0.54, -0.01	-0.24	.070	-0.51, 0.02
Moderate (<6/ 18 to 6/ 60)	-0.31	.096	-0.68, 0.06	-0.57	**.002**	-0.94, -0.2
Severe (<6/ 60)	-0.89	**<.001**	-1.28, -0.49	-1.03	**<.001**	-1.43, -0.64
Near Vision						
Normal (≥N8)	*			*		
Worse than N8	-0.22	.050	-0.44, 0	-0.06	.613	-0.28, 0.16
Age						
≤39	*			*		
40 to 59	-0.48	**.001**	-0.78, -0.19	-0.22	.144	-0.51, 0.07
≥60	-0.09	.587	-0.42, 0.24	-0.01	.967	-0.34, 0.32
Gender						
Female	*			*		
Male	0.22	**.048**	0, 0.43	0.25	**.024**	0.03, 0.46
Adjusted R^2		.229			.188	

*Referent group

Table 4.60: Multiple Linear Regression model

	β	*p*	95% CI	β	*p*	95% CI
Variables	**Total Instrument**			**Mobility, Independence and Emotional Wellbeing**		
Constant	1.44[1]			1.65		
Distance Visual Acuity	.34	**<.001**	.12, .36	.27	**.002**	.08, .34
Near Visual Acuity	.12	.133	-.03, .25	-.14	.180	-.05, .27
Gender	-.13	.072	-.38, .12	.11	.070	-.42, .02
Age	-.02	.842	-.17, .14	-.01	.876	-.18, .16
	Getting information			**Social Implications**		
Constant	1.16			1.47		
Distance Visual Acuity	.31	**<.001**	.11, .37	.41	**<.001**	.19, .43
Near Visual Acuity	.14	.082	-.02, .30	.07	.381	-.08, .22
Gender	-1.0	.172	-.37, .07	-.18	.058	-.41, .01
Age	-.02	.836	-.19, .15	-.04	.606	-.20, .12

B: standardised coefficients
[1]: Unstandardised Beta Coefficient

In the first model for the total IVI_I scores, age and gender were entered at Step 1, which explained 4% of the variance in IVI_I scores. After entry of distance and near visual acuity at Step 2 the total variance explained by the model as a whole was 17.5%, F (4,156) = 8.3, *p*<.001. The two control measures explained an additional 13.5% of the variance in IVI_I score, after controlling for age and gender, R squared change = .14, F change (2, 156) =12.80, *p*<.001. In the final model, only distance visual acuity was statistically significant (beta=.34, *p*<.001). Similarly, distance visual acuity was the only significant variable in the final model for the three domains. A summary of the R square change values for each domain is shown in Table 4.61.

Table 4.61: Multiple Regression Model Summary

Domain	**Variance explained: Step 1**	**Variance explained: Step 2**	***F* change**	***p***
1 – Mobility, Independence and Emotional Wellbeing	3.4%	12.6%	8.2%	**<.001**
2 –Getting information	3.2%	15.8%	11.8%	**<.001**
3 – Social implications	3.8%	20.3%	16.1%	**<.001**
Overall instrument	4.0%	17.5%	12.8%	**<.001**

Chapter 5 Discussion

5.1 Overview

This study addressed an important gap in previous work by being the first to present a toolkit to assess the prevalence and impact of vision impairment in Aboriginal and Torres Strait Islander communities. The ICEE Toolkit will allow future epidemiological studies of Aboriginal and Torres Strait Islander vision and eye health in Australia, and has already been utilised in the NIEHS conducted in 2008.[1, 258]

The first component of the ICEE Toolkit, the RABVIIC Pilot Study, validated and tested a methodology to rapidly assess the vision and eye health conditions in Aboriginal and Torres Strait Islander peoples in Australia. Most previous research of this nature has focused on individual conditions or data obtained from ad hoc service delivery. This rapid methodology required a minimum of equipment and training and can be performed by primary health care workers who have no specialised eye health training. Utilising health care workers as research personnel instead of optometrists or ophthalmologists reduces staffing costs and makes study staffing more practical in settings where tertiary care providers are limited. It is important, however, to have an appropriately qualified team member trained to make appropriate referral decisions correctly and grade for trachoma.

Results obtained from the RABVIIC Protocol, can then be compared to other similar vision and eye health assessments in Australia and elsewhere. Additionally, this study suggests a potential additional use of the RABVIIC Pilot Study as an extended RAAB methodology that may be successful in other settings where more detailed investigations of posterior-segment conditions such as diabetic retinopathy and glaucoma are required.

The second component of the ICEE Toolkit presented here is an instrument adapted from the Australian Impact of Vision Impairment (IVI_A) instrument in order to examine the impact of vision impairment in Aboriginal and Torres Strait Islander populations (IVI_I).

This has provided knowledge on: (a) how vision impairment affects Aboriginal and Torres Strait Islander peoples' participation in daily tasks of living; and (b) an understanding of social and cultural consequences of vision impairment. It is anticipated that the IVI_I will help enable planning of more culturally appropriate eye health services, as an understanding of how vision impairment affects Aboriginal and Torres Strait Islander peoples' independence and emotional wellbeing, participation in social networks, and their ability to obtain information will impact on strategies for health promotion and education activities. It will also assist in tailoring rehabilitation services to be more effective and relevant. It is also anticipated that the IVI_I will assist in assessing the effectiveness of eye health services.

This chapter will discuss these results and their implications as well as their scope, applicability and limitations.

5.2 Conducting Research with Aboriginal and Torres Strait Islander Research Participants

Conducting vision and eye health surveys in Aboriginal and Torres Strait Islander populations in urban, rural and remote regions of Australia presents many logistical challenges. The primary difficulty in this research was recruiting sufficient numbers of participants from targeted areas that are representative of the Aboriginal and Torres Strait Islander population.

Critical to the successful completion of this research was the approach taken to work with and within the Aboriginal and Torres Strait Islander community. The researcher was guided by the frameworks developed by the NHMRC and other bodies as well as previous literature outlining the ways in which previous research has been detrimental to Aboriginal and Torres Strait Islander research participants (discussed in section 2.10).

One of the primary enabling factors for the success of this research project was working with the AEHCs who are the key custodians for eye care in the regions where this research

was conducted. The relationship developed between ICEE and the AEHCs was absolutely critical in enabling the research staff to engage with communities, local staff and the AMS. During the RABVIIC Pilot Study the AEHC, in conjunction with the AMS, greatly assisted in coordinating appropriate follow up care and referrals for participants. Additionally, the AEHC was able to identify key community contacts that were able to garner interest and enthusiasm for the study within their networks. Recruitment would have been even more difficult if an AEHC was not present or available, or if we were not able to engage them in this study.

5.3 RABVIIC Pilot Study

5.3.1 Introduction

The RABVIIC Pilot Study was a novel population-based methodology to examine the eye health of Aboriginal and Torres Strait Islander peoples. Although all of the components of the RABVIIC Pilot Study Protocol have been widely used for different population groups, this study has built on RAAB strategies and incorporated additional assessment for posterior segment disease and trachoma in order to assess the prevalence of expected common causes of vision impairment in Aboriginal and Torres Strait Islander peoples. The research design was planned to establish the validity of a rapid examination method to detect a defined set of significant and prevalent vision disorders within Aboriginal and Torres Strait Islander populations. The rapid examination was designed to be non-invasive, quick, reliable, and highly sensitive, with the least possible sample size based on RAAB sampling strategies.[133] The RABVIIC Pilot Study Protocol presented here has since been used successfully to conduct the NIEHS.[1]

5.3.2 HSQx Development

The adapted questionnaire used to obtain demographic information and information about the utilisation of eye care services was well received by participants and demonstrated acceptable repeatability. Missing data were highest when the participants

were not familiar with the conditions used in the question (e.g. AMD), which highlights the importance of checking each questionnaire with the participant. There was also lower reliability for the question "Is it ok now" (referring to the eye problem the participant indicated that they had previously sought treatment for). It is anticipated that this question could be difficult for people with refractive error, as while spectacles assist with vision, it could be difficult for the participant to decide whether the eye problem is 'ok' or not now. Similar confusion may exist for eye problems that are intermittent, such as blepharitis.

The test-retest reliability procedure that was performed indicated that when the Health Services Questionnaire (HSQx) was administered at two time points there was high agreement, indicating the HSQx elicits the same responses in most instances each time it is used under the same conditions with the same participant. Although it would have been preferable to perform repeatability testing in a larger sample, the questionnaire demonstrated acceptable temporal stability in the eight participants of the test-retest study. We were unable to conduct the same test-retest with children participants due to difficulties with recruitment and because we did not have the resources to bring children and their guardians back to the clinic a second time. While these are potential limitations of the current study, both questionnaires were widely used in the NIEHS and have provided a great deal of information on the self-reported vision and eye health of Aboriginal and Torres Strait Islander Australians.[259]

Although the HSQx is similar to the questionnaire used in TVI, several questions were modified, omitted or added based on evaluation of the advice from AHWs, OATSIH, ophthalmologists, optometrists and experts on low vision and Indigenous eye health.

As a result of the performance of the HSQx in the RABVIIC Pilot Study, the HSQx underwent minor reformatting for the NIEHS to make it easier for study staff to check for missing data and to streamline data entry. The last five questions on the final page of both the adult and child questionnaires were moved forward due to the instances in the

RABVIIC where participants failed to answer any question on the back page. In the RABVIIC Pilot Study there were 18 questions with ≥ 5% missing data. However, in the NIEHS there were only three questions with ≥ 5% missing data, resulting in questionnaire data which was 96% complete.[258] Although there was greater staff vigilance and follow up of missing data in some cases in the NIEHS, questionnaire modifications as a result of the learning from the RABVIIC Pilot Study contributed to these low NIEHS missing data rates.

The adult and child versions of the HSQx have been able to provide valuable guidance to future planning of eye health prevention strategies for Aboriginal and Torres Strait Islander Australians. For instance, the results from the questionnaire have been able to demonstrate that only one fifth of children who had previously been prescribed glasses wore them appropriately and that people over-reported their history of eye disease.[259] It also showed that people with low vision due to eye diseases were often not aware of it.[259] Accordingly, there is a need for information about health promotion materials related to vision and eye health to be developed. There are a handful of vision health resources designed or adapted specifically for Aboriginal and Torres Strait Islander populations such as the "Turtle Chart"(Queensland University of Technology),[260] the Trachoma Eye Health Information flip chart (Kimberley Public Health Unit),[261] the Children's Eye Health Education Program (CERA),[262] and the "I See for Culture" eye health education resources (ICEE).[263] It is anticipate that some of these tools will assist in increasing knowledge of eye health among Aboriginal or Torres Strait Islander populations, however outcomes research and published evaluations of these resources is required.

5.3.3 Recruitment

The RABVIIC Pilot Study was performed in an outer regional area (Northern NSW) where 19% of the total population and 50% of residents in the target CCD reported being Indigenous.[230] Recruitment was a significant challenge and as a result a number of different strategies were used in order to try to increase the participation rate from the

targeted area. The study was supported by the AHMRC and the AMS. The study site was very close to the target area and advertising through flyers was conducted prior to and during the study period. The study also relied heavily on the local AHW's to approach community members and encourage potential participants. Free transport, spectacles (when relevant) and sunglasses were offered. We also worked with local networks and families to motivate potential participants. The study site was based in the local AMS, a very trusted location in this setting, to encourage trust and enthusiasm to participate. Encouragement from local health workers and AMS staff was also essential in encouraging participation.

Detailed enumeration lists could not be used as such lists did not exist with any degree of accuracy. Additionally, for privacy reasons we were not able to obtain a clinic client list of the target area so had to rely primarily on clinic contacts. As a result we may not have been able to access people who are not clients of the clinic.

Previous studies in Aboriginal and Torres Strait Islander communities in Victoria and Western Australia have described difficulties in obtaining reliable estimates of the community size and have reported a relatively low proportion of Indigenous peoples compared to ABS estimates.[264-265] The NIEHS reported similar difficulties to these studies and found that the population was highly mobile, contact details changed frequently and population enumeration was difficult.[243] Similarly, in the RABVIIC Pilot Study it was very difficult to establish a precise denominator for the study area. We also became aware that the target area had high levels of drug and alcohol abuse which contributed to non-participation levels.

The initial goal of recruiting all Aboriginal and Torres Strait Islander residents from the selected area quickly proved to be an extremely difficult objective without a door-to-door census approach which was not possible due to time, staffing and financial constraints. As a result participants from neighbouring CCDs were included in the study as we deemed that having a satisfactory participation rate was a higher priority than adhering to strict

location definition. This highlights the difficulties in recruiting Aboriginal and Torres Strait Islander participants from randomly selected target areas, and emphasises the need to understand the unique challenges and difficulties each particular location may provide when conducting national surveys, particularly in urban to semi-rural environments.

RAABs generally use census style recruitment approaches as outlined in section 2.7.2 and have been conducted successfully in a wide range of countries in both urban and remote areas.[134-135, 137-139] However, in all of these studies the study sample was selected from the entire population of the country, state or region of interest rather than just a subset of the population as was the case here. In the NIEHS a door-to-door style approach was used successfully in some areas, although this was only practical in the more remote areas where there was a significantly higher (approximately >80%) concentration of Aboriginal and Torres Strait Islander people. In these very remote areas over 87% of eligible adults and 92% of eligible children were examined.[258] However, in regional and urban areas difficulties in recruitment were similar to those experienced in this pilot RABVIIC study. In the outer regional areas of Dubbo (NSW) and Albany (WA), 24% and 44% of eligible adults were recruited respectively.[258] Subsequent analysis revealed that participation rates in the NIEHS decreased as the proportion of Indigenous people per total population in a community decreased.[243]

Recruiting children was particularly difficult in this study. Although the local AMS was deemed the most appropriate venue for the study to be conducted, restrictions in opening hours resulted in only a limited window of two to three hours each day for school children to attend. Working with the Department of Education and local Aboriginal School Liaison Officers would have allowed children to be recruited from within the schools. Consequently the NIEHS used these strategies and were able to recruit 83.4% of all eligible children across all six regions of remoteness.

5.3.4 Vision and Eye Health Examination

The rapid examination in this study was safely performed by health workers and study staff. All components of the RABVIIC Pilot Study provided valid results at least 88% of the time, with the exception of visual acuity testing in children under the age of 5, in whom it is known that testing can be relatively unreliable. Highest rates of missing data occurred with retinal imaging (discussed below).

5.3.5 Retinal Imaging

Many prior studies have assessed the sensitivity of non-mydriatic retinal imaging in detecting diabetic retinopathy. The National Health and Medical Research Council (NHMRC) states that tests should aim for a sensitivity of at least 60%, specificity levels of 90-95% and technical failure rates of 5-10%.[109] Technical failure is due to ungradable photographs caused by small pupils and media opacities and the NHRMC states that lower technical failure rates are common. The British Diabetic Association has proposed minimum levels of at least 80% sensitivity and 95% specificity.[266] Prior studies in Aboriginal and Torres Strait Islander have been able to obtain gradable retinal photos in at least 90% of eyes.[110]

In this study 90% of the retinal images obtained were gradable and pharmacological dilation was not necessary in 91% of eyes. Operator errors and undocumented reasons were the primary cause for non-gradable images. However, retinal images were not obtained in an additional 11 eyes (5% of participants). In three of these individuals, logistic constraints within the clinic prevented the study team from accessing the retinal camera. All but two of these individuals were examined by the definitive examiner, however, it is likely that retinal images could have been obtained in these individuals if additional training and experience was provided to the camera operator to reduce operator error. Additional training and experience has been shown elsewhere to improve the quality of retinal images despite the presence of small pupils, minor media opacities, distorted fundi

and people less able to comply with instructions.[267-268] Taking additional care to avoid scheduling conflicts within the clinic would have also resulted in more images.

The use of non-mydriatic retinal cameras in studies such as this have numerous benefits as they can be used by personnel who are not ophthalmologists or optometrists, and participants routinely do not require dilation. Non-specialist personnel have been shown to achieve acceptable sensitivity with non-mydriatic retinal imaging elsewhere[269] and these minimum standards were reached in the RABVIIC Pilot Study . Although, due to the fact that grading can often take place elsewhere, there can be additional logistical difficulties with follow-up care, particularly for highly mobile Aboriginal and Torres Strait Islander participants. However, this was avoided in both the RABVIIC Pilot Study as an ophthalmologist or optometrist was always available to assist with referral decisions. Follow up care was coordinated by the regional AEHC.

The NIEHS reported a similar rate of missing data, with completely gradable images in both eyes for 966 participants (81%) and either completely gradable in one or partially gradable in both in 1124 (94.5%).

5.3.6 Detection of Targeted Conditions

5.3.6.1 Vision Impairment

This study found that the rapid examination was highly specific in correctly identifying vision impairment, with higher examiner agreement when examining the older adults (kappa statistic 0.69 versus 0.57). The RABVIIC Pilot Study examination detected vision impairment in the entire study population with 71% sensitivity and 99% specificity and with 100% agreement between the two testing methods for participants below 40 years of age. There was 100% agreement between the two testing methods for children below 16 years of age, although sensitivity/specificity calculations were not possible as no children in the study had vision impairment.

The simplified E test was originally reported to detect vision impairment less than 6/18 with 85% and 95% specificity.[231] Using this categorization the RABVIIC Pilot Study was able to detect vision impairment less than 6/18 in our entire study population with 100% sensitivity and 100% specificity. However, the sensitivity of the RABVIIC to detect vision impairment of less than 6/12 in adults was lower and this may lead to some under-estimations of the prevalence of vision impairment.

The rates of vision impairment and blindness assessed by the RABVIIC Pilot Study and linearly extrapolated between age groups that were not examined in the NIEHS were similar to the rates measured by the definitive examination of the whole population. This suggests that by examining participants aged between 5-15 years and ≤40 years, the NIEHS will adequately assess the prevalence of vision impairment and blindness in Aboriginal and Torres Strait Islander people of all ages. However, this cannot be confirmed by these results as there were no children with vision impairment in this study.

Although agreement for the detection of vision impairment was better in the older adults (kappa statistic 0.69 versus 0.57), the sensitivities were similar and there was greater specificity (the ability of the test to identify participants who do not have vision impairment) when testing adults aged 16-39. There was 100% agreement between the two testing methods for children below 16 years of age, but sensitivity/specificity calculations were not possible as there were no instances of vision impairment.

5.3.6.2 Refractive Error

This study found that the rapid examination had moderate sensitivity (72%) but very high specificity (99%) in correctly identifying vision impairment due to uncorrected refractive error. However, the RABVIIC Pilot Study was only able to detect uncorrected refractive error if the participant moved from one visual acuity category to another with pinhole. For instance - if a participant presented with 6/60 and improved to 6/24 with pinhole during the RABVIIC examination, the improvement would not be recorded as the participant failed to improve to the next visual acuity category (in this case <6/12-6/18). Conversely,

during the definitive examination the participants' improvement with pinhole would be noted and uncorrected refractive error would have been recorded. If no other causes of vision impairment were recorded the participant was coded as having vision impairment due to uncorrected refractive error. This discrepancy is likely to be the cause of reduced sensitivity in detecting vision impairment due to uncorrected refractive error. Despite this, sensitivity was still reasonable with very high specificity.

5.3.6.3 Diabetic Retinopathy

In this study there was high rater agreement in detecting diabetic retinopathy even when it did not result in vision impairment. One individual <50 years was diagnosed with diabetic retinopathy bilaterally (without vision impairment) by the RABVIIC. The definitive examiner did not observe any retinopathy in this individual, however retinal imaging has been widely shown to have greater sensitivity in documenting the presence of very mild DR than direct ophthalmoscopy.[270] Although there was only this one instance of diabetic retinopathy, the relatively younger age of onset of diabetes in Aboriginal and Torres Strait Islander Australians[7-8] means that there is a real need to investigate the prevalence of vision impairment due to diabetic retinopathy in Indigenous populations.

Minimum standards of gradability were met. As a result we were able to demonstrate that the non-mydriatic camera is suitable for use in this Aboriginal and Torres Strait Islander population. There are many benefits to both the study team and the participant in using non-mydriatic cameras. The camera can be used by anyone as long as adequate training is provided. The images can be taken very quickly which improves efficiency and participant flow. One of the most significant advantages is that there is no need for mydriatic dilation drops. Dilation drops have a low acceptability among the general public as they can sting the eye, take a minimum of 15 minutes to cause effect and affect vision and sensitivity to glare for the hours following application. Non-mydriatic cameras avoid these difficulties. Some participants are not suitable for non-mydriatic retinal imaging (e.g. participants with very small pupils). In these instances dilation drops are required. In the RABVIIC Pilot

Study 8.3% of eyes required a mydriatic agent, although it is likely that this proportion could have been reduced with further training and experience in dealing with small pupils and minor media opacities.

5.3.6.4 Risk of Glaucoma

Glaucoma has rarely been observed in Aboriginal and Torres Strait Islander communities.[2] Glaucoma diagnosis also requires a judgment of multiple clinical findings. This study did not identify any instances of vision impairment suspected of being glaucomatous in origin. However, the combined FDT and CDR resulted in the successful identification of suspected glaucoma (non-vision impairing) as confirmed by the definitive examination which suggests that the RABVIIC will successfully identify instances of vision impairment due to glaucoma.

The rapid examination showed high sensitivity (>90%) in detecting cases of CDR greater than 0.6. Specificity ranged from 0.563 for adults over 40, to 0.667 for younger adults. Sensitivity, specificity and rater agreement were reduced when multiple diagnostic indicators were combined to indicate risk of glaucoma. Due to the relatively low prevalence of glaucomatous optic neuropathy in general, and the low numbers of participants suspected of having glaucoma by either examination (n=14), we propose that the rapid examination is still a useful tool for identifying functional risk factors of glaucoma.

In the NIEHS, glaucoma was originally assigned if a participant had a CDR > 0.6 and missed ≥2 points on the FDT. As it was found that many participants had generally larger disc sizes than the non-Indigenous population,[258] grading criteria for glaucoma was redefined to CDR >0.7 and ≥2 points missed on FDT or CDR > 0.8. Similar results had been confirmed in previous studies in Aboriginal and Torres Strait Islander peoples,[78] but, it was not possible to re-examine the results from the RABVIIC Pilot Study with these new criteria as the definitive examiner only recorded instances where CDR were >0.6.

5.3.6.5 Cataract

Previous studies have demonstrated adequate agreement, sensitivity and specificity in detecting cataract.[239, 250] In the RABVIIC Pilot Study there was 100% agreement between both methods for participants with vision impairment due to cataract. This further confirms the work of Lee and Ferraro in establishing the suitability of non-mydriatic fundus cameras in screening for visually significant cataract.[239, 250]

5.3.6.6 Other Conditions

While the rapid examination was designed to detect the five common causes of vision impairment and blindness (diabetic retinopathy, trachoma, glaucoma, refractive error and cataract) in Aboriginal and Torres Strait Islander peoples, any examination by an eye care professional will result in a number of additional conditions detected, as was the case in this study. The majority of these conditions were identified in adults and required follow up care but were not potentially blinding. There were also three participants showing early signs of age-related macular degeneration (AMD) in both eyes. Two of these individuals showed vision loss in one eye. Although the prevalence of AMD is expected to be lower in Aboriginal and Torres Strait Islander populations in Australia, primarily due to a lower life expectancy, screening for AMD would provide an indication of the need for rehabilitative services for Aboriginal and Torres Strait Islander peoples with AMD.

There were also multiple instances of meibomian gland dysfunction, papillae and non-trachomatous follicles that were of concern to participants. Although these are not the specified targeted conditions, they highlight the need and relevancy of making appropriate eye care services available to Aboriginal and Torres Strait Islander communities. Treating participants of this study and the NIEHS for these conditions is also an important component of providing 'service with survey'. As Aboriginal and Torres Strait Islander peoples access eye care services less often than non-Aboriginal and Torres Strait Islander peoples, and in some instances study participants had never before received

an eye examination it is vital to provide all clinically relevant eye health care to participants.

5.3.7 Target Age Groups

The NIEHS proposed to only examine adults over the age of 40 and children between the ages of 5 and 15. This study showed that while Aboriginal and Torres Strait Islander peoples outside of these age brackets do experience vision impairment, cataracts and diabetes, most of the burden of vision impairment and blindness was experienced by adults over the age of 40. This study found that more than 80% of vision impairment in this population was in adults over the age of 40. Including a cohort of younger adults would not increase the sensitivity of the NIEHS in detecting the overall burden of vision impairment in Aboriginal and Torres Strait Islander communities.

Although the only case of active trachoma was observed in a child under the age of 5, the prevalence of trachoma varies markedly in Aboriginal and Torres Strait Islander communities around Australia. It has also been established previously that the younger children carry most of the disease burden in endemic communities, particularly children under 10.[271] As a result, including these younger children plus a cohort of older school aged children gave the NIEHS a more comprehensive view of the eye health needs of Aboriginal and Torres Strait Islander children in communities around Australia.

Self reported rates of diabetes were much more prevalent in the adults over the age of 40, and of those who did report diabetes under the age of 40, no retinopathy was observed. These results further indicate that a national survey of Aboriginal and Torres Strait Islander eye health would not grossly underestimate the prevalence of key conditions by only examining adults over 40 and children between the ages of 5 to 15.

The causes of vision impairment in those ≤40 years were very similar to the total population, excepting refractive errors in younger adults. These results support the idea that examining adults over the age of 40 and children between the ages of 5 and 15 will be

a good indicator for the causes of vision impairment in the total Aboriginal and Torres Strait Islander population and will help establish a greater understanding of their overall eye heath needs.

5.3.8 Strengths and limitations

In the RABVIIC Pilot Study, participation rates from the specified target areas were low. However, this provided valuable information on the potential logistical difficulties in recruiting Aboriginal and Torres Strait Islander participants from semi-urban and rural areas. We were able to demonstrate reliable sensitivity and specificity calculations for detection of diabetic retinopathy, active trachoma, trichiasis, uncorrected refractive error, cataract and glaucoma risk. It is expected that the spectrum of vision and eye health disorders experienced in this study population is indicative of the spectrum of vision and eye health disorders of the broader Aboriginal and Torres Strait Islander community, apart from the trachoma, as it was not obvious in this community.

There is the possibility of selection bias if eligible participants that were not recruited or declined to participate were demographically different or exhibited significantly different eye health outcomes from those in this study. This should only affect the conclusions drawn about the appropriateness of the target age groups as we are more likely to have overestimated the prevalence of conditions because participants with concerns about their vision or eye health are more likely to be motivated to participate. However, the purpose of this study was not to conduct a population based study of eye health of the region, but to investigate the feasibility and validity of the RABVIIC Pilot Study Protocol.

The participants in this study were a relatively highly literate sample, so aspects of questionnaire administration may prove to be more difficult in other areas, particularly where English is not the primary language spoken at home. It is unlikely that the sensitivity or specificity of the examination will differ with level of education, literacy or primary language, but the likelihood of enrolling participants who had difficulties with

either written or spoken English reinforced the need to ensure that a local health worker or liaison officer was present to assist with explaining the study goals and procedures to participants.

Due to the difficulties in establishing a precise denominator, and the relatively small sample size, the prevalence data obtained from this study should not be considered representative of any other Aboriginal and Torres Strait Islander population. Notwithstanding this consideration, the condition specific prevalence data obtained for this study population are within expected ranges compared to other assessments of Aboriginal and Torres Strait Islander eye health.

5.4 Impact of Vision Impairment: Indigenous Peoples (IVI_I)

5.4.1 Introduction

It has been emphasized that eye care services need to be appropriately designed to achieve accessibility, service uptake and satisfactory treatment outcomes for vision problems.[272] *Appropriate* eye care service design requires an understanding of local community needs, perceptions, aspirations, and the real life burden of vision impairment. The importance of instruments that have been specifically developed for the setting in which they are intended has been further outlined in section 2.8.3.

Understanding how the effects of vision impairment impact the quality of life of Aboriginal and Torres Strait Islander peoples is a core component in the knowledge base needed to design appropriate services. While many quality of life measures have been designed and validated globally, none have shown to be ideal for use with Aboriginal and Torres Strait Islander peoples for the following reasons:

- Some quality of life tools are too general without sensitivity to vision impairment (e.g. SF-36);

- Some vision-specific quality of life tools are only suitable for measuring the effects of the vision impairment associated with eye disease; (e.g. VF-14 measures the impact of cataract surgery);
- Many questionnaires are specific for more developed regions (e.g. they are appropriate only in high income, well resourced settings and do not describe everyday life of individuals with limited education or living in low resource areas);
- No vision-related quality of life questionnaires have been specifically designed or culturally adapted for use with Aboriginal and Torres Strait Islander communities.

With the intention of developing a tool to better understand how vision impairment impacts Aboriginal and Torres Strait Islander peoples we were faced with two options. The first option was to develop an item pool from focus groups, administer the draft tool and evaluate the potential new quality of life tool to assess its appropriateness for the task, plus the culture, customs and environmental conditions of Aboriginal and Torres Strait Islander peoples. Relevant items from previously published tools such as the NEI_VFQ,[159] Indian Vision Function Questionnaire,[273] Aravind Comprehensive Eye Survey Questionnaire,[156] Timor-Leste vision-specific quality-of-life instrument[166] and Near Vision Related Quality of Life Questionnaire (Tanzania)[274] may have been useful in forming an initial pool of questions. The second option was to adapt a vision-related quality of life tool designed elsewhere and/or for other things, to make it appropriate for measuring the effect of vision impairment on quality of life in Aboriginal and Torres Strait Islander peoples.

The first option can take many years of development and testing. The WHO Quality of Life (WHOQOL) group special report has outlined the development of their quality of life assessment instrument.[275] The steps they used for development of the questionnaire were:

1. Development of study protocol and selection and definition of QOL facets.

2. Discussion groups on quality of life
3. Translation of facets into local language
4. Conduct of focus groups
5. Question generation work
6. Development of the pilot instrument
7. Administration of pilot questionnaire
8. Development of the core module
9. Testing of core module for reliability, validity and responsiveness

However, if the instrument does not meet minimum requirements for testing during stage 9, then further development and testing will need to take place. This whole process can takes years or even a decade or more to develop an instrument with acceptable psychometric properties. For instance, in the mid 1990s the National Eye Institute (NEI) funded the development of a vision-targeted measure of quality of life.[276] The NEI-VFQ, has been widely used to assess the treatment of ocular disease and describe the health related quality of life of patients with ocular disease.[277-279] The NEI-VFQ underwent a similar development process to that described by WHOQOL.[203, 280] In order to generate the pool of items for the NEI-VFQ 26 focus groups each containing 15 individuals were conducted.[203] The content generated from these focus groups was then field tested before its psychometric properties were assessed. The shorter 25-item NEI-VFQ was the result of extensive development.[280] This process has taken many years, has required many participants and has undoubtedly been very expensive. The IVI_A underwent a similar development and validation process.[15]

However, by using the second option, a vision-related quality of life instrument for Aboriginal and Torres Strait Islander peoples has been culturally adapted with only 172 participants with all field testing completed within 18 months. By taking an existing instrument and examining it from within the context of what was important, different or irrelevant to Aboriginal and Torres Strait Islander peoples, we were able to develop and

test the instrument with only one stage, rather than multiple stages that would be required if an instrument was newly developed.

5.4.2 The IVI_I Instrument

The IVI_A was designed to capture the individual's experience with restriction of participation in society as a result of vision impairment. The IVI_A also links into the WHO's holistic bio-psychosocial framework by evaluating health and participation rather than disability. The IVI_I was developed through modification and cultural adaptation of the IVI_A. The ability of the IVI_I to assess restriction of participation by people with vision impairment in Aboriginal and Torres Strait Islander communities was evaluated by examining descriptive and psychometric qualities based on content and construct validity, reliability and factor analysis.

5.4.2.1 Translation

When conducting cross-cultural adaptations of quality of life instruments it is important to demonstrate that there is conceptual, item and semantic equivalence in order to investigate different concepts of health.[173] Appropriate translation of questionnaires into the language normally spoken is a key element of this process. Although over half (56%) of Aboriginal and Torres Strait Islander peoples living in very remote areas speak an Indigenous language at home, only 1% do in major cities. Overall, 86% of Aboriginal and Torres Strait Islander peoples speak English at home, as did 83% of this study population. Nationally, the ABS reports that of those that do speak an Australian Indigenous language, the majority (79%) reported that they speak English well or very well.[129] However, a minority of Aboriginal and Torres Strait Islander peoples who speak an Indigenous language do not speak English at all, or not very well, or speak one of a wide variety (>20) of languages. The majority (11%) of non-English speakers use Torres Strait Islander languages, with the remainder speaking other less widely used Indigenous

languages, not all of which are in written form.[129] As a result the IVI_I was not translated into any Indigenous languages.

5.4.2.2 Content validity

Face and content validity were assessed by recording outcomes of semi-structured interviews with Aboriginal health workers, and eye health workers. Although examination of the validity of a questionnaire would normally take a number of rounds or cycles of development, testing and modification efforts were made to keep this to a minimum due to the relatively small number of Aboriginal and Torres Strait Islander peoples in Australia and the complexities in conducting Indigenous research. As there were sufficient participants in this study to examine the validity of the IVI_I, and it demonstrated high reliability, it was considered that conducting one round of validity testing was appropriate.

Items in the IVI_I demonstrated a full range of responses and low rates of missing data. The items exhibited high relevancy, indicated by the limited selection of 'Don't do this for other reasons' response. These results indicated that the instrument was plausible, relevant and intelligible.

Based on the feedback from experts and participants consulted when examining face validity, no items were initially removed. Overall there was good acceptance of the instrument with suggested changes to the language in three items to make them more relevant. The examples provided as a guide for the questions were removed as it was felt that these examples (i.e. golf) would not represent activities relevant to Aboriginal and Torres Strait Islander peoples around the country.

When the three items that were modified due to the information obtained during face validity testing were examined on the basis of their psychometric properties, Items 2 ("How much has your eyesight interfered with taking part in recreational activities"), 10 ("How much has your eyesight interfered with getting about outdoors"), and 12 ("How

much has your eyesight interfered with travelling or using transport") met all the predetermined criteria. All three items were included for all analyses.

5.4.3 Administration

5.4.3.1 Instrument Administration

The IVI_I was self administered to 172 adult Aboriginal and Torres Strait Islander persons around Australia. Some difficulties were experienced by participants who did not have high literacy or had trouble seeing the questionnaire. In these situations a member of the study team assisted the participant with completion. However, this should not impact on the reliability of the results obtained as the IVI has previously demonstrated consistency between forms of administration (self versus interviewer administration).[15]

A proportion of participants, particularly the elderly from more remote locations, were also not accustomed to survey style research and were more likely to 'tell a story' when asked about their vision loss, rather than choose an answer from one of options. In these situations the administration time was quite lengthy, as it was important to listen to the participants' experiences of vision loss before encouraging them to choose the appropriate response. Care was taken in these situations to ensure that the answer selected was that of the participant, and not how the researcher thought the participant would like to respond.

5.4.3.2 IVI_I Participants

Aboriginal and Torres Strait Islander participants were recruited from a wide range of locations around Australia. These participants had varying educational levels, came from different levels of remoteness and had a range of severity of vision impairment. As a result it is proposed that the participants of this study form a cohort that represents the Aboriginal and Torres Strait Islander population in Australia as a whole.

5.4.4 Construct Validity

5.4.4.1 Distribution of Data

Participants with distance vision impairment reported lower scores for most items. Participants with moderate vision impairment reported similar scores to those with mild vision impairment, but both groups generally reported lower scores than those with normal distance vision.

Lowest scores for all participants regardless of distance vision were recorded for items relating to reading ordinary sized print, getting information, and reading medicine labels. This was likely the result of uncorrected presbyopia interfering with participants' ability to conduct near vision activities. Similar results have been reported previously in Australia for the IVI_A in a group of patients with age related macular degeneration.[157] Hassell et al report that items concerned with reading ordinary size print and reading labels or instructions on medicines were among the items that participants had the most difficulty or concern. Conversely, in the IVI_Melanesian validation study, items related to reading and getting information were found to be redundant to the Melanesian context, which the authors conclude relates to the education and literacy differences between Vanuatu and Australia.[167]

Twenty six out of 28 items (92%) were considered relevant by participants with vision impairment, as the "Don't do this for other reasons" response was not selected more than 20% of the time. The two items that did exhibit irrelevancy were items 22 "Have you felt frustrated or annoyed because of your eyesight" and item 25 "Have you worried about your eyesight getting worse". For these two items "Don't do this for other reasons" was selected by 21% and 28% of vision impaired participants respectively. These items were consequently considered for removal but were retained as item scores reduced with poorer distance and near vision impairment.

5.4.4.2 Missing Data

Missing data were low (3.0%) and were reduced even further (0.4%) when only the vision impaired participants were included. A low rate of missing data is one indication that an instrument that is well understood and easy for participants to complete. A lower missing data rate among vision impaired participants may have occurred as the participants felt the instrument was more relevant to their situation, although it may also have occurred through chance, or improved checking by the study team.

5.4.4.3 Reliability

The internal consistency of the IVI_I was determined through Guttman Split-half reliability, which assesses the correlation between two halves of the questionnaire. If the instrument is reliable and free from random error we would expect the two halves to be positively correlated. The IVI_I demonstrated high correlations for the instrument overall (correlation 0.92), and for the Mobility, Independence and Emotional Wellbeing (0.88), Getting Information (0.86) and Social Implications domain (0.92). High split-half correlations indicated that the test halves are highly correlated and the questionnaire has high internal consistency and has low levels of random error.

A further assessment of instrument reliability was explored with Cronbach's alpha, which investigates unidimensionality, or how well the set of items measure a single, unidimensional latent construct. The alpha value for the total instrument was 0.96, which indicates very high instrument reliability and indicates that the items in the instrument are examining the same concept, or how vision impairment impacts participation. The alpha value obtained for the IVI_I is the same as what was obtained in original internal consistency testing of the IVI_A (alpha score of 0.96),[15] while reliability testing of the adapted IVI questionnaire for use in Pacific Island countries resulted in Cronbach alpha of 0.85.[167, 172] Such a high alpha score however does indicate potential correlations and removal of additional items may reduce any redundancy. High domain reliability was also

observed for the Mobility, Independence and Emotional Wellbeing (0.94), Getting Information (0.90) and Social Interaction (0.96) domains.

Additional standard tests of reliability were either not possible or feasible. For instance, test-retest methods to assess reliability were logistically impractical within the recruitment frame of this research. The parallel-forms method was also not possible as there are no measures that demonstrate true equivalence in this context and there is no 'gold-standard' for comparison.

5.4.4.4 Removed Items

One item (Item 23) failed to meet the predetermined psychometric criteria for item retention, which was concerned with whether the participant had felt lonely or isolated because of their eyesight in the past month. Over 80% of all participants, and participants with vision impairment answered 'Not at all' to this item. When only remote participants were examined, over 90% answered 'Not at all'. Though this indicates an important sociological conclusion, that stronger social and family linkages may exist which limit the impact of vision impairment on feelings of loneliness or isolation compared to other Australians, for the purposes of this questionnaire the item is irrelevant to participants. Item 24 which was concerned with whether participants felt 'sad or low' because of their eyesight also demonstrated lack of relevance to many participants (72%). However, less than 70% of non-remote participants selected 'Not at all', compared to 77% of remote participants. As a result we felt that the variable met the criterion for relevance for the urban and rural participants and decided that it should be retained.

Two items exhibited significant inter-item correlations with items exhibiting the same theoretical construct. Item 11: 'How often has your eyesight made you go carefully to avoid falling or tripping?' correlated highly with Item 13: 'How much has your eyesight interfered with going down steps, stairs, or curbs. Item 14: 'How much has your eyesight interfered with the reading ordinary size print?' correlated highly with Item 15: 'How much has your eyesight interfered with getting the information that you need'. These pairs

of items appear to be examining the same latent construct. When determining which items are to be removed and which items are to be retained both the statistical findings and the knowledge of how the items fit together both rationally and theoretically need to be considered.[281] As a result it was decided to retain the more specific items, and delete the more general items (Items 11 and 15).

5.4.5 Discriminant Validity

A relationship between visual acuity and the IVI_I scores indicates that the instrument discriminates between people with normal versus impaired vision. It was hypothesized that worse vision impairment would be correlated with reduced scores, i.e. more difficulty with items. This relationship was observed for all domains and the overall instrument, as visual acuity decreased, so did the IVI_I scores. Other studies have found a similar relationship between distance visual acuity and restriction of participation.[15, 194-195] The similarities in IVI scores between participants with mild and moderate visual acuity has also been observed previously.[157]

Visual acuity of <6/12 can result in loss of ability to drive, operate common applications and technology, and affect safety in general.[282-283] Our results suggest that restrictions in participation as a result of mild vision impairment may result in significant changes in quality of life in Aboriginal and Torres Strait Islander populations, although this would need to be confirmed with additional research. By contrast in Melanesia, the IVI_M found that <6/18 appeared to be the threshold at which vision impairment has significant implications of life in the Melanesian context.[167, 172]

Participants with normal near VA also reported higher (better QOL) scores than participants with moderate near vision impairment. Although, there was a 'bounce back' effect for participants with severe near vision impairment (<N48). Although there were not enough participants in this group (n=8) to investigate reasons for these differences, we speculate that this 'bounce back' effect may result from participants' adaptation to

uncorrected presbyopia. As the severity of near vision impairment worsens and reaches <N48, the participant may adapt to this experience and no longer participate in activities at near. Although, this hypothesis would need to be explored further with a larger sample.

Optometrists in Australia endeavour to improve the vision of their patients to >6/6 and Aboriginal and Torres Strait Islander should be able to expect the same vision outcomes from their eye health providers. Spectacles are one of the most cost-effective interventions in eye care[48] and it is not more difficult or expensive to correct vision to <6/6 in most instances. What remains unknown at this stage, however, is what associations are present between distance visual acuity and IVI_I score if different criteria for vision impairment are used (i.e. <6/6 or <6/9). Future studies will need to investigate whether differences are observed when the IVI_I is administered to participants with excellent vision and even milder forms of distance vision impairment than that which was investigated here.

Our findings confirm the need and value of treating and preventing vision impairment in Aboriginal and Torres Strait Islander peoples, even when it is mild. This has important implications for planning appropriate eye health programs. For instance, cataract surgery in Aboriginal and Torres Strait Islander populations is more likely to be performed at a more advanced stage compared with non-Indigenous Australians.[98] These results indicate that significant improvements in vision-related quality of life may occur when interventions are given to Aboriginal and Torres Strait Islander people with mild vision impairment due to cataract. Similarly, these results indicate that treatment of mild vision impairment due to uncorrected refractive error with spectacles will also result in significant improvements.

Our results also confirm that despite the relatively small sample size, the IVI_I questionnaire is a relevant and responsive instrument to assess participation in Aboriginal and Torres Strait Islander individuals with vision impairment with a range of visual acuity levels.

Investigating the effect of cause of vision impairment on IVI_I scores showed that both uncorrected refractive error and non-refractive error causes resulted in significant differences from those with normal vision. There were however no differences in the IVI_I scores between refractive error and non-refractive error causes of vision impairment. This again suggests that relatively simple intervention strategies, such as providing spectacles for Aboriginal and Torres Strait Islander peoples with mild vision impairment due to uncorrected refractive error will make significant differences in terms of an individual's ability to participate in society.

As expected, there were no relationships between vision-related quality of life scores and gender, age, and level of education. This supports the theory that the differences in scores obtained are a result of differences in vision experienced by the participants, rather than some other variable. It also illustrates that the IVI_I can be completed by participants with limited or no formal education. However, there were differences in the vision-related quality of life scores based on the participants' level of remoteness as the urban participants reported lower scores indicating greater difficulty with items. Although when these differences were explored further it became apparent that differences existed for only the 'Social Implications' domain but not the 'Mobility, Independence and Emotional Wellbeing' or 'Getting Information' domain. Although not significant, the participants from Major Cities appeared to report lower median scores than all other participants. Greater difficulty in the 'Social Implications' domain for urban and city dwellers makes some theoretical sense when considering how cities can be isolating and lead to reduced social networks.

5.4.6 Principal Components Analysis

The final proposed domain structure of the IVI_I consists of three domains, each exploring a different aspect of the restriction of participation as a result of vision impairment (Figure 5.1).

It could be argued from the scree test that the IVI_I items may also suit a four factor model, however preliminary investigations of a four factor model revealed a solution that only marginally increased the common factor variance.

Average IVI_I scores for the three domains were all significantly different between participants with normal vision and those with mild/moderate vision combined. Initial testing with the IVI_A found that emotional reactions to loss of vision were not significantly related to the degree of vision impairment,[12] however later versions of the IVI_A showed significant associations between distance visual acuity and average IVI_A scores for all domains, including emotional reactions to vision loss.[161, 194] Average IVI_I scores for the participants with mild and moderate vision impairment were similar for all domains.

A comparison of the IVI_I with the IVI_A is shown in Figure 5.2. The domain structure differed from the IVI_A, in that most of the items previously associated in the domain 'Emotional Wellbeing' loaded with all the items associated with Independence. In figure Figure 5.2 it can be seen that there is no longer a distinct domain identifying emotional reactions to vision loss and the impact of participation in daily living.

During initial IVI_A development and validity testing, items representing social interactions formed a 'social' or 'social and consumer interactions' domain.[12, 15] Subsequent assessment of its domain structures using confirmatory factor analysis and Rasch analysis resulted in the three factor solution shown in Figure 5.2.[14] In the IVI_I, a domain concerned with Social Interactions clearly emerged.

Figure 5.1: IVI_I Domains

Mobility, Independence and Emotional Wellbeing

In the PAST MONTH, how much has YOUR EYESIGHT INTERFERED with the following activities:

10. Getting about outdoors?
12. Traveling or using transport?
13. Going down steps, stairs, or curbs?

In the PAST MONTH, how often has YOUR EYESIGHT MADE YOU CONCERNED OR WORRIED about the following:

16. Your general safety at home?
17. Spilling or breaking things?
18. Your general safety when out of your home?
22. Have you felt frustrated or annoyed because of your eyesight?
24. Have you felt sad or low because of your eyesight?
25. Have you worried about your eyesight getting worse?
26. Has your eyesight made you worried about coping with everyday life?
27. Have you felt like a nuisance or a burden because of your eyesight?
28. Has your eyesight interfered with your life in general?

Getting Information

In the PAST MONTH, how much has your eyesight interfered with:

4. Visiting friends or family?
6. Generally looking after your appearance?
7. Opening packaging?
8. Reading labels or instructions on medicines?
9. Operating household appliances/phone?
14. Reading ordinary size print?

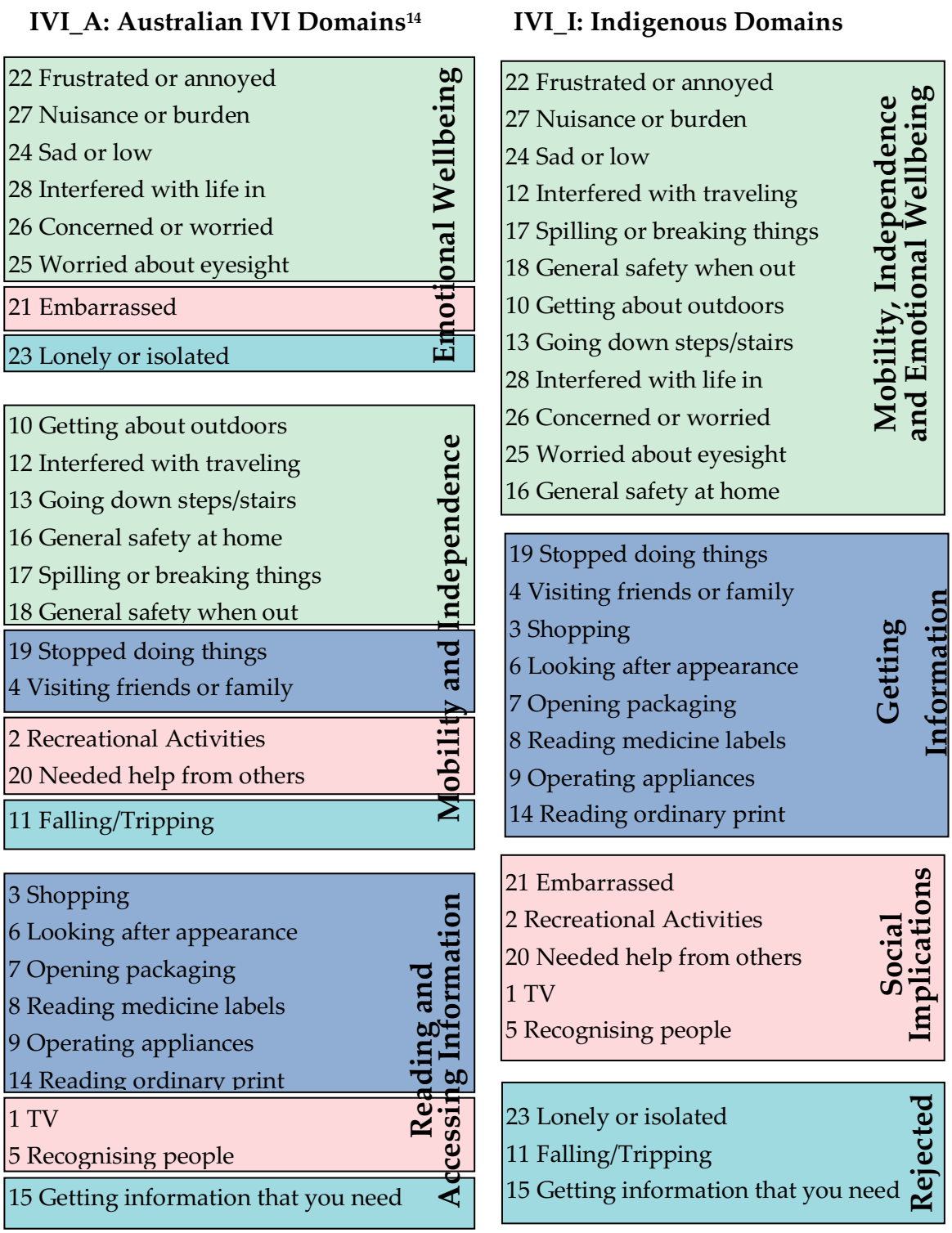
Social Implications

In the PAST MONTH, how much has your eyesight interfered with:

1. Your ability to see and enjoy TV?
2. Taking part in recreational activities?
5. Recognising or meeting people?
20. How often have you needed help from other people?

It was only the 'Social Implications' domain however that showed significant difference in IVI_I scores between participants with mild/moderate distance vision impairment compared to those with severe vision impairment. This indicates that Aboriginal and Torres Strait Islander peoples with severe distance impairment are significantly impacted by a restricted ability to carry out social interactions.

Figure 5.2: Domain structure changes



5.4.7 Multiple Linear Regression

In Univariate linear regression, distance and near visual acuity and age were shown to be associated with the IVI_I total instrument and domain scores. These variables were included in the multivariate model to assess independent associations. Age is likely to be a cofounder in the model as a result of the progression of presbyopia whereby near visual acuity declines with age due to the inability to accommodate. Although gender was not a significant predictor of IVI_I scores in the univariate analysis at the .05 level of significance, it was included in the multivariate model as it was a predictor of IVI_I score in the 'Social Implications' domain at the 0.1 level of significance.

In the multivariate model, after controlling for age and gender, distance visual acuity was shown to be an independent predictor in each domain and for the total instrument. This association strongly supports findings from discriminant validity testing. Near vision impairment was not shown to be a significant predictor of IVI_I scores. However, there appeared to be some interaction between near vision impairment and distance vision impairment, particularly in the 'getting information' domain, as the standardised correlation coefficient (β) reversed direction and approached significance (p=.08). This highlights the importance of future work with a larger sample of participants with near vision impairment to explore these potential interactions (discussed in more detail in the next section).

These results confirm that, of the variables included, distance visual acuity is the strongest independent predictor of IVI_I score which is consistent with the findings of previous IVI_A studies.[195, 204]

While there may be some interaction between

5.4.8 Further studies to be undertaken

As there was a relatively high proportion of items with Spearman Correlation Coefficients outside the desired <0.1 to >0.5 range, some item redundancy may exist. The high overall

Cronbach α confirms this potential redundancy. Reducing the number of IVI_I items even further would reduce respondent burden and likely improve practicality in clinical settings, however all remaining items have demonstrated relevancy and fit the proposed domain structures.

Further exploration of the relationship between IVI_I scores and uncorrected refractive error, both distance and near, would provide valuable information on the QOL improvements achievable through spectacle provision. Additionally, we propose to use discriminant function analysis to assess the ability of individual items to predict vision category group membership. We suggest that we will be able to identify specific items that form discrete 'distance' or 'near' vision impairment scales. This will also allow us to assess the appropriateness of using a single instrument to assess both distance and near vision impairment.

During the adaptation of the IVI_A for use in Melanesia, it was proposed that the other aspects of vision impairment, such as contrast sensitivity, dark adaptation, visual field loss and glare, may also be determinants of restriction of participation of activities of daily living.[172] Investigation of these may also provide greater understanding of how vision impairment and other factors restrict participation. Likewise, examination of other components of the ICF may provide new information on factors that influence the lives of Aboriginal and Torres Strait Islander peoples with vision impairment. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.[152] Accordingly, the IVI_I may become a more comprehensive instrument if the unique factors that influence the way Aboriginal and Torres Strait Islander peoples undertake activities and participate in society are investigated. For instance, if we were to consider participation in education and employment and living arrangements, such research may suggest how the absence or presence of a particular environmental factor affects participation in performing daily activities.

Investigating the relationship between IVI_I score and more refined categories of mild distance vision impairment (i.e. ≥6/6, <6/6 to 6/9 and <6/6 to 6/12) may provide insight on the thresholds at which vision impairment begins to impact negatively on quality of life.

5.4.8.1 Application of Rasch Analysis

Rasch analysis is now widely accepted as the most appropriate method for psychometric analysis due to the inherent weaknesses in ordinal Likert scales. The original IVI benefitted from Rasch analysis by generating an interval scale for participants' scores which has allowed parametric testing of the predictors on participation.[13-14, 284] The IVI_I uses the rating scale that was developed as a result of IVI Rasch analysis.

While there is some evidence that some IVI_I items have disordered thresholds as shown in Table 4.39, the same table displays important similarities to the person-item map of the original Rasch-scaled IVI questionnaire as reported by Lamoureux in 2006.[13] The relative difficulty levels of each of the original IVI items showing on the person-item map are very similar to those shown Table 4.39, as the five most difficult items in the original IVI are among the six most difficult items in the IVI_I. Similarly, the five least difficult items in the original IVI are among the six least difficult items of the IVI_I.

However, the purpose of this study was to assess whether the IVI, adapted for use in Aboriginal and Torres Strait Islander populations demonstrated adequate reliability and discriminant validity. We were also wanted to assess whether Aboriginal and Torres Strait Islander conceptualizations of health and quality of life result in differences in dimensionality using factor analysis. We found that an alternate three-factor solution was more appropriately suited to this population. Building on this knowledge, future studies using confirmatory factor analysis would be useful to corroborate the three-factor dimensional structure of the IVI_I presented here. Additionally, an examination of the psychometric properties of the three IVI_I subscales using Rasch analysis will be important in confirming that the interval measurement characteristics of the IVI_I subscales provide valid and reliable assessments of restriction of participation.

5.4.9 Conclusions

The IVI_I is the first vision-related quality of life questionnaire designed for use with Aboriginal and Torres Strait Islander peoples that has undergone psychometric validation. Construct validity, which relates to the extent to which the instrument is consistent with its theoretical foundation, supports the notion that the IVI_I is able to demonstrate the restriction in participation in daily life by Aboriginal and Torres Strait Islander participants with distance and near vision impairment, even when it is mild.

The extent of commonality between IVI_I and the Australian IVI highlights the instrument's potential to facilitate cross-cultural comparisons regarding the quality of life implications of vision impairment. There were, however, important differences that confirm the value and need for an instrument that has been specifically adapted to ensure cultural appropriateness. In contrast to IVI_A participants, the item concerned with feelings of loneliness or isolation due to eyesight was irrelevant to most IVI_I participants. This implies that differences in Indigenous family, community and social structures may result in reduced feelings of loneliness or isolation as a result of reduced vision.

Principal components analysis also highlighted that there are very important social implications to vision impairment. A subscale domain emerged that was quite clearly associated with social interactions and reduced vision. And in contrast to the IVI_A, the emotional reaction to vision loss items loaded with the mobility and independence items.

Our findings show that across all the domains of quality of life, the impact of vision impairment score was significantly different between people with normal vision and those with mild, moderate and severe vision loss. The significant decrease in participation scores from those with mild vision loss as compared to normal vision suggests that the majority of people with mild vision loss (≥6/12) experience difficulty or concern with many activities of daily life. These results in Aboriginal and Torres Strait Islander participants endorse the findings of broader population based studies that provide evidence of the significant morbidity and effects on quality of life of people with only mild vision loss.[285-287]

Chapter 6 Conclusions

6.1 Purpose

Aboriginal and Torres Strait Islander peoples experience a higher burden of chronic and preventable disease and disability compared to non-Indigenous Australians. Vision and eye conditions are similarly over represented in Aboriginal and Torres Strait Islander populations. Blindness occurs 6.2 times more commonly in Indigenous adults than in non-Indigenous adults and 94% of vision loss in Indigenous Australians is preventable or treatable.[1]

There is always a great need for reliable and current data, although care needs to be taken with regard to any research in Aboriginal and Torres Strait Islander communities to ensure that the research is respectful, appropriate and accompanied by on-site treatment of conditions if the methods allow for doing so. Aboriginal and Torres Strait Islander peoples are also very concerned with being 'over-researched' and not having control over information collection and analysis. As a result methodologies need to demonstrate cultural appropriateness in the research methodologies and instruments as well as in the overall process.

This thesis has described a culturally appropriate toolkit for assessing the prevalence and impact of vision impairment in Aboriginal and Torres Strait Islander peoples along with immediate treatment, amelioration or referral. This has been achieved by:

- Conducting the RABVIIC Pilot Study to test protocols, procedures, questionnaire design, community acceptability, and burden on both the participating individuals and the survey staff for the NIEHS;
- Adapting, validating, and testing a vision-related quality of life instrument for use in Aboriginal and Torres Strait Islander populations; and by

- Providing spectacles to all participants with uncorrected or under corrected refractive error as well as primary eye health care or an appropriate referral for further tertiary care for those who required it.

This research has been conducted in consultation with the AHMRC and with local AWHs and AEHCs.

6.2 Key Activities

In order to meet the aims outlined in Chapter 1, the following activities were undertaken:

- The RABVIIC Pilot Study was performed to test all aspects of the NIEHS questionnaire design, community acceptability, and burden on both the participating individuals and the survey staff;
- Aboriginal and Torres Strait Islander participants were recruited from a specified area to participate in the RABVIIC Pilot Study. Participants from surrounding areas were also included to increase sample size;
- A rapid assessment examination methodology was compared with a comprehensive eye examination;
- A vision-specific HRQOL instrument was adapted for use in Aboriginal and Torres Strait Islander populations with subsequent validity testing to ensure psychometric suitability; and
- The vision-specific HRQOL (IVI_I) was administered to Aboriginal and Torres Strait Islander peoples around the country to examine the impact of vision impairment.

6.3 Findings

RABVIIC, the rapid assessment method used in this study, with minimal staff training and equipment, resulted in a valid, rapid examination methodology which is able to detect

vision impairment, refractive error, diabetic retinopathy, glaucoma, and trachoma in Aboriginal and Torres Strait Islander populations in Australia and compares favourably with a definitive eye examination performed by optometrists in detecting these causes of vision impairment.

The development of the IVI_I from the IVI_A for use in Aboriginal and Torres Strait Islander populations was successful. The IVI_I demonstrates reliability, internal consistency and cultural appropriateness. It also demonstrates face, construct and content validity and discriminates participants with normal vision from those with vision impairment.

The findings from this research support the hypotheses that were presented in Chapter 1 section 1.6.3. The two key findings are:

- RABVIIC protocols and procedures that have been developed and modified in this study for the NIEHS reliably detect the common causes of Vision Impairment and Blindness in Aboriginal and Torres Strait Islander adults and children in Australia.
- Adaptation of the existing IVI_A questionnaire into the IVI_I resulted in an instrument that was administered to Aboriginal and Torres Strait Islander populations and successfully demonstrated the impact of vision impairment on the restriction of participation and quality of life in Aboriginal and Torres Strait Islander peoples.

Successful recruitment of Aboriginal and Torres Strait Islander participants was challenging in this research and required adaptation of key strategies. Recommendations based on this research for the successful completion of the NIEHS were:

- More time would be needed to work with local staff to ensure they understood the aim and scope of the survey (especially with respect to the need to recruit participants only from one specific area).

- It would be necessary to spend a great deal of time understanding the site specific issues in any selected area (e.g. high drug and alcohol abuse) as this could significantly impact recruitment.
- In order to recruit enough children, it may be necessary to conduct future surveys in school holidays or work with local schools.
- Spend more time working with the local Aboriginal personnel to recruit study staff.
- Ensure that there was an adequate supply of reading glasses and acceptable sunglasses to dispense to participants immediately.

6.4 Impact

The RABVIIC Pilot Study Protocol developed as part of this thesis was used in the NIEHS. The questionnaires, procedures and study materials (i.e. checklists and flow diagrams) initially modified from TVI for use in the RABVIIC Pilot Study were all used in the NIEHS, with only minor changes to the questionnaires to improve ease of administration.

The RABVIIC Pilot Study methodology was successfully used in 30 randomly selected sites each containing approximately 300 Aboriginal and Torres Strait Islander peoples (range 200-400), stratified by Remoteness Area according to the Accessibility and Remoteness Index of Australia (ARIA).

The NIEHS was completed during 2008 and the results have provided valuable information in order to plan and prioritise effective and appropriate Aboriginal and Torres Strait Islander eye health services.[1, 258]

The IVI_I has demonstrated that even mild vision impairment is associated with restrictions in societal participation in Aboriginal and Torres Strait Islander peoples. The IVI_I is a valuable tool in clinical practice or research for analysing the outcomes of intervention programs or rehabilitation strategies.

6.5 Implications

The RABVIIC rapid examination methodology can be performed efficiently and exhibited high sensitivity and specificity in diagnosing the most prevalent and significant vision and eye health conditions. Although recruitment was challenging, working within existing Aboriginal and Torres Strait Islander networks increased acceptance.

The RABVIIC Pilot Study methodology expands on aspects of the RAAB protocol as the inclusion of a non-mydriatic fundus camera allows for retinal imaging and fundus examination. Assessing the prevalence of vision impairment due to conditions such as diabetic retinopathy, glaucoma and age related maculopathy will be increasingly relevant among ageing populations and where the prevalence of diabetes is increasing such as the Asia-Pacific region.[288] However, the sensitivity and specificity of non-mydriatic cameras would need to be tested in regions where the prevalence lens opacities can be much higher. Importantly, the RABVIIC methodology allows for the study to be conducted mainly by non-specialist staff.

Investigations of the impact of vision impairment on Aboriginal and Torres Strait Islander peoples using the IVI_I suggest that significant improvements in vision-related quality of life may be achievable through the simple correction of refractive errors or low vision rehabilitation. Additionally, the IVI_I instrument will enable measuring change after treatments such as cataract surgery, low vision rehabilitation or correction of uncorrected refractive errors with spectacles.

The findings presented here demonstrate the relevance of the IVI_I instrument as an appropriate questionnaire to identify the nature and magnitude of participation in daily activities for Aboriginal and Torres Strait Islander persons with vision impairment.

6.6 Recommendations

Epidemiological studies of Aboriginal and Torres Strait Islander vision and eye health are much needed, but must take cultural and historical factors into account and be conducted

with full support and buy-in from representative community members. Conducting vision and eye health surveys in Aboriginal and Torres Strait Islander populations in urban and rural regions of Australia present many logistical challenges, the primary challenge being recruiting sufficient numbers of participants from targeted areas. Any such study must be accompanied by immediate treatment of any condition lending itself to such action.

There are several areas of interest for further research that have arisen from the present study. As stated in section 5.4.8, Rasch analysis of the IVI_I could be used to overcome many of the limitations associated with the Likert scale. This would provide a more robust instrument to assess vision-related quality of life in Aboriginal and Torres Strait Islander populations. Although the IVI has been shown to be sensitive to low vision rehabilitation and cataract surgery, its responsiveness to correction of vision impairment as a result of uncorrected refractive error had not previously been investigated. The results presented here suggest that correction of uncorrected refractive errors by the simple prescription of spectacles will significantly improve vision-related QOL scores for Aboriginal and Torres Strait Islander peoples. However, this will need to be confirmed with further research.

6.7 Final remarks

Conducting research within Aboriginal and Torres Strait Islander communities is an incredibly rewarding experience, but it requires sensitivity and foresight to overcome geographical obstacles and cultural differences. However, in situ research is the only way to design and monitor intervention strategies that will help alleviate the excess burden of blindness and vision impairment in Aboriginal and Torres Strait Islander peoples compared to non-Indigenous Australians. The ICEE Toolkit presented in this thesis will help with these strategies. Even so, more needs to be done. While knowledge is important, more important than knowledge is the will and commitment to actually eliminate the vision and eye health disparities that contribute to the broader health gaps experienced by Aboriginal and Torres Strait Islander peoples.

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Appendix A: Ethical Approvals

Aboriginal Health and Medical Research Council Ethics Committee Final Approval Letter (560/06)

University of New South Wales Human Research Ethics Committee Ratification Approval Letter (HREC 07248)

Vision CRC and Institute for Eye Research Human Ethics Committee Ratification Approval Letter (0727)

Aboriginal Health and Medical Research Council of NSW

AH&MRC ETHICS COMMITTEE

27 August 2007

Professor Brian Layland
Director of Aboriginal Programs
Vision CRC Ltd
Level 4 Rupert Myers Building
UNIVERSITY OF NSW 2052

Dear Professor Layland

Evaluation of selected vision and eye conditions in three Aboriginal communities (560/06)

At its meeting on 6 August 2007, the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee considered your application of 27 June 2007 seeking for approval for amendments to the above project previously approved by the Committee on 3 April 2007.

The Committee agreed to approve the application, subject to the conditions below.

Standard Conditions of Approval

1. The approval is for the period from 6 August 2007 until 31 August 2008, with extension subject to providing a report on the research by 31 August 2008.
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.
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 research must continue throughout to comply with the *National Statement on Ethical Conduct in Research Involving Humans* (April 2007).
6. A final draft report must be provided to the AH&MRC Ethics Committee to be vetted for compliance with ethical and cultural criteria prior to:
   - any submission for publication; and/or
   - any dissemination of the report.

Funded by NSW Health

Level 3, 66 Wentworth Ave, Surry Hills, NSW, 2010; POBox 1565 Strawberry Hills 2012
Ph: 02 9212 4777 Fax: 02 9212 7211; Email ahmrc@ahmrc.org.au
ABN66 085 654 397 ACN 085 654 397

7. A copy of the final published version of any publication is to be provided to the AH&MRC Ethics Committee.

Special Conditions of Approval

NIL

Can you please acknowledge receipt of this letter and your acceptance of the above conditions within fourteen (14) days?

We would also appreciate your agreement that the AH&MRC may, on request, obtain access to the data obtained from the research in order to assist the future development of policy and programs in Aboriginal health.

We take this opportunity to wish you well in your research.

Yours sincerely

Val Keed
Chairperson
AH&MRC Ethics Committee

THE UNIVERSITY OF
NEW SOUTH WALES

HUMAN RESEARCH ETHICS
COMMITTEE (HREC)

11 September 2007

Professor Brian Layland
Director of Aboriginal Programs
Vision CRC Ltd
Level 4 Rupert Myers Building

Dear Professor Layland

Evaluation of selected vision and eye conditions in three Aboriginal communities
(HREC 07248) (AH&MRC560/06)

We acknowledge with thanks receipt of the above application for ethics clearance.

At the Executive meeting held on 11 September 2007, the Committee accepted the approval given by the Aboriginal Health and Medical Research Council of NSW to Professor Brian Layland dated 3 April 2007 for the above project to proceed.

Please note that the UNSW HREC period of approval for this project is valid for the duration of the approval period given by the primary ethics committee.

Yours sincerely,

A/Professor Michael Grimm
Presiding Member
HREC

UNSW SYDNEY NSW 2052
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Location: Rupert Myers Building
C/o Research Office / Ethics,
Gate 14, Barker Street Kensington
ABN 57 195 873 179

26 September 2007

Prof. Brian Layland
Level 4, North Wing, RMB
Gate 14, Barker Street
UNSW SYDNEY NSW 2052

Dear Prof. Layland

RE: Evaluation of selected vision and eye conditions in Aboriginal communities.

VIHEC Application No: 07/27

Thank you for your correspondence dated 26th September 2007 requesting ratification of the above-titled study. In accordance with the Vision Cooperative Research Centre and Institute for Eye Research Human Ethics Committee (VIHEC) procedures for ratification, the study documentation has been reviewed by the VIHEC Executive Committee.

After consideration, and given that protocol for this study has received final approval from the AH&MRC, and ratification from the UNSW HREC, VIHEC have agreed to also ratify the above protocol.

Several recommendations/comments raised by the VIHEC executive in relation to this study protocol are noted below and will also be forwarded to the AH&MRC for their review.

1. We are concerned that the study protocol does not clearly indicate the community to be studied in WA or NT, and thus does not have local input for this part of the study. The other two communities are indicated as being in the Bega Valley and Moree Plains, with direct consultation of these local communities for the study protocol. The third community is listed as "..to be announced.." Could this be further clarified?

2. We cannot give approval for use of the AH&TSI logo, and the AH&MRC need to approve this request.

3. Proposed changes Section B, Point 4 of Informed consent form should read "We may also put a drop into your eyes that makes your pupils larger and help us to check the both the prescription and health of your eyes. By looking into your eyes with a light for a short time (retinoscopy and ophthalmoscopy). We may also take a photo of the back of your eye with a digital camera."

4. Could the investigators make it clear whether or not the spectacles are to be provided free of charge. Under benefits of the study it says "If you need glasses, you will be provided with a prescription". A lay person may interpret this to mean being provided with spectacles, despite later in that paragraph, a statement that additional costs will not be reimbursed by the study. This needs to be very clearly defined by the investigators.

Page 11 of the original application also states that 'we will be providing a prescription therefore alleviating low vision/blindness". This will only happen if people are able to fill the prescription and have access to glasses.

Should you have any queries about your project please contact the VIHEC Ethics Secretariat – Mary Restrepo phone 9385 7455, email ethicsvihec@onevision.org.au. The VIHEC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the IER intranet site: www.ier.org.auww

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Towassistwinwtrackingwsub-protocols,wtheywarewbeingwassignedwawuniquewVIHECwapprovalwnumber.w
PleasewquotewVIHECw07/27winwallwcorrespondence.ww

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Yourswfaithfullyw

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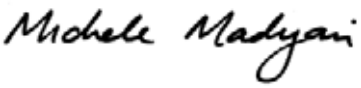

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DrwMichelewMadiganwPhDw
Chair,wVIHECw

Appendix B: Recruitment Flyer

Recruitment Flyer for RABVIIC Pilot Study

EYE EXAMINATIONS

Will be held at Pius X on the [?] till the [?] of [Month].

Would you like a free eye examination?

The International Centre for Eyecare Education (ICEE) has been working to improve eye and vision care for Aboriginal communities in NSW since the late 1990's.

To see whether strategies such as these are working, ICEE would like to know several things:

- How much eye disease is there in the community?
- How much do people already know about caring for their eyesight?
- What stops people getting the eye care they need?

A survey is being conducted in your area which has been designed to provide some important information about the major causes of blindness and visual impairment in Aboriginal and Torres Strait Islander communities in Australia and the influence that access to eyecare services has on the status of eye health.

ICEE is looking for volunteers of all ages to attend a vision screening and to answer some questions related to eye health. We need people with perfect eyesight, as well as people who know they have an eye problem.

Participation in the study is entirely voluntary and you are welcome to an eye examination even if you choose not to participate in the study. However if the examination shows you need further health care, the costs of that additional health care will not be reimbursed by the study.

For more information please phone the study team on 6752 8432.

Yours sincerely

ICEE

Appendix C: Health Services Questionnaires

Adults Health Services Questionnaire (AHSQx)

Child Health Services Questionnaire (CHSQx)

HEALTH SERVICES QUESTIONNAIRE (Adults)

ID:

Personal Details

Name: Given Family

Male ☐ Female ☐

Date of Birth: / /

Daytime Telephone Number:

Address:

Postcode:

Please answer ALL of the following 14 questions

1.a) What is your main language spoken at home?

b) What is the highest level of education you have completed? *(please tick ONE box that applies)*

- Primary school ☐
- Some secondary school, some technical or commercial ☐
- Completed secondary school ☐
- Completed a trade ☐
- Some university or college of advanced education or training ☐
- Degree from university, college of advanced education or higher degree ☐

Eye Health

2.a) Have you EVER had a problem with your eyes or vision? Yes ☐ No ☐ → If No, go to 3

b) Did you see somebody about your eye or vision problem? Yes ☐ No ☐ → If No, go to 2e

c) Where did you go for treatment? *(please tick ALL boxes that apply)*:

- Hospital ☐
- Community Health Centre/Aboriginal Medical Service ☐
- General Practitioner (GP) ☐
- Optometrist ☐
- Ophthalmologist ☐
- Other ☐ *(please state)*

d) How long ago did you last see someone about your eyes or vision? years ago

e) Is the problem look how? Yes ☐ No ☐

f) Why didn't you go somewhere for treatment? *(please tick ALL boxes that apply)*:

- It is normal for eyesight to get worse ☐
- It was not severe enough ☐
- Too expensive ☐
- Too busy/haven't gotten around to it ☐
- Other ☐ *(please state)*

3.a) Do you normally wear glasses or contact lenses (APART from reading)? Yes ☐ No ☐

If No,

b) How satisfied are you with the quality of your vision?

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied
☐	☐	☐	☐

If Yes,

c) How satisfied are you with the quality of your vision while wearing glasses or contact lenses? (APART from reading) your

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied
☐	☐	☐	☐

d) Where did you get your glasses or contact lenses from (APART from reading glasses)?

Local Optometrist ☐
Other ☐ *(please state)*

e) How old were you when you FIRST started wearing glasses or contact lenses (APART from reading glasses)?

Age

f) Do you wear your glasses or contact lenses ALL (or nearly all) of the time? Yes ☐ → go to 4a No ☐ → go to 3g

If No, g) What is the reason that you don't wear them all the time? (please tick ALL boxes that apply)

- - don't need to wear them all the time ☐
- - They are uncomfortable ☐
- - Can't see properly wearing them ☐
- - New pair too expensive ☐
- - Embarrassed ☐
- - Other ☐ *(please state)*

4.a) Do you normally wear glasses for near work (i.e. reading)? Yes ☐ No ☐ → go to 5a

If Yes,

b) How satisfied are you with the quality of your vision while wearing your glasses for near work (ie reading)

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied
☐	☐	☐	☐

c) Where did you get your glasses for near work?

Local Optometrist ☐
Other ☐ *(please state)*

5.a) Have you been told that you have cataract(s)? Yes ☐ Don't Know ☐ No ☐ → go to 6a

If Yes, b) Have you had cataracts surgery? Yes ☐ → go to 6a No ☐ → go to 5c

c) If you have NOT had an operation for your cataract, what is the reason

- - Cataract not advanced enough for operation yet ☐
- - On waiting list ☐
- - Could not get transport to hospital ☐
- - Does not bother me ☐
- - Not medically fit to have the operation ☐
- - Worried about the operation going wrong or not working ☐
- - Concerned it will cost too much ☐
- - Other ☐ *(please state)*

Eye Health continued

6. Have you been told that you have ANY of the following eye problems?

	Yes	No	Don't know
a) Glaucoma (high pressure in eye)	☐	☐	☐
b) Diabetic eye disease or diabetic retinopathy	☐	☐	☐
c) Age-related macular degeneration/AMD	☐	☐	☐
d) Other	☐		*(please state)*

7. Have ANY of your immediate family (parents, brothers or sisters) ever suffered from any of the following eye problems?

	Yes	No	Don't know
a) Cataract	☐	☐	☐
b) Glaucoma (high pressure in eye)	☐	☐	☐
c) Diabetic eye disease or diabetic retinopathy	☐	☐	☐
d) Age-related macular degeneration/AMD	☐	☐	☐
e) Other	☐		*(please state)*

8. a) Have you ever seen any health messages about looking after your eyes? Yes ☐ → If Yes go to 9 | No ☐

b) What have the messages been about? *(please describe)*

c) Did any of the messages change the way you look after your eyesight? Yes ☐ No ☐

9. Please answer about your eyesight with glasses, contact lenses or magnifiers, if you use them (please tick ONE box that applies in EACH row)

In the past month	Not at all	A little	A fair amount	A lot	Don't do this for other reasons
a) How much has your eyesight interfered taking part in recreational activities such as bowling, walking or golf?	☐	☐	☐	☐	☐
c) How often has your eyesight made you go carefully to avoid falling or tripping	☐	☐	☐	☐	☐

In the past month	Not at all	A fair amount	A lot	Don't do this for other reasons
b) How much has your eyesight interfered with reading ordinary size print? e.g. newspapers	☐	☐	☐	☐

In the past month	Not at all	A little of the time	A fair amount of the time	A lot of the time
b) How often have you worried about your eyesight getting worse?	☐	☐	☐	☐
e) How often has your eyesight stopped you doing the things you want to do?	☐	☐	☐	☐

General Health

10. a) Have you been told by a doctor you have diabetes? Yes ☐ No ☐ → If No, go to 11

b) What year were you first diagnosed with diabetes? _____ Year

11. Have you ever had a stroke? Yes ☐ No ☐

12. How many falls have you had in the last 12 months? _____ Number of falls

13. a) Over your lifetime, would you have smoked at least 100 cigarettes or a similar amount of tobacco? Yes ☐ No ☐ → If No, go to 14

b) Do you currently smoke? Yes ☐ No ☐

14. When you go out in the sun do you usually wear: Always ☐ Sometimes ☐ Never ☐

a) A Hat? ☐ ☐ ☐

b) Sunglasses? ☐ ☐ ☐

Office Use Only

1. Date of Examination: _____ / _____

2. Interviewer _____

3. Inclusion Criteria:

Community Resident (6 months or more)	☐
Aboriginal Person	☐
OR	
Torres Strait Islander Person	☐

Age in Years: _____

4. Presenting Correction:

No Correction	☐	☐
Spectacles	☐	☐
Contact Lenses	☐	☐

Other _____ (please state)

5. FDT:

	RE	LE	
0 Points Missed	☐	☐	☐
1 Point Missed	☐	☐	☐
≥2 Points Missed	☐	☐	☐

6. Visual Acuity (with Presenting Correction):

_____ VA: _____ PH: _____ BCVA:

	RE	LE		RE	LE		RE	LE	
≥6/12	☐	☐	☐	☐	☐	☐	☐	☐	☐
<6/12 6/18	☐	☐	☐	☐	☐	☐	☐	☐	☐
<6/18 6/60	☐	☐	☐	☐	☐	☐	☐	☐	☐
<6/60	☐	☐	☐	☐	☐	☐	☐	☐	☐
NPL	☐	☐	☐	☐	☐	☐	☐	☐	☐

7. Trachoma Grading:

	TT	CO	TF	TI	TS
RE	☐	☐	☐	☐	☐
LE	☐	☐	☐	☐	☐

8. Referral:

GP	☐
Optometrist	☐
Ophthalmologist	☐

9. Completion Check

	Yes	No	Comments
Consent Obtained	☐	☐	☐
Services Questionnaire	☐	☐	☐
Visual Acuity	☐	☐	☐
Auto Refraction	☐	☐	☐
FDT	☐	☐	☐
Retinal Photo	☐	☐	☐
Lens Photo	☐	☐	☐

10. Other Relevant Information

HEALTH SERVICES QUESTIONNAIRE (Children)

ID:

Personal Details

Name: Given Family Male Female

Date of Birth: / / Daytime Telephone Number:

Address: Postcode:

Please answer ALL of the following 5 questions

1. a) What is your main language spoken at home?

Eye Health

2. a) Have you EVER had a problem with your eyes or vision? Yes No → If No, go to 3

b) Did you see somebody about your eye or vision problem? Yes No → If No, go to 2d

If Yes c) Where did you go for treatment? *(tick ALL that apply)*

- Hospital
- Community Health Centre/Aboriginal Medical Service
- General Practitioner (GP)
- Optometrist
- Ophthalmologist
- Other *(please state)*

d) Is the problem ok now? Yes No

3. a) Have you ever been told that you should wear glasses or contact lenses? Yes No

b) How old were you when you FIRST started wearing glasses or contact lenses? Aged

c) Do you wear your glasses or contact lenses ALL (or nearly all) of the time? Yes No

If No d) What is the reason that you don't wear them all the time? (please tick ALL boxes that apply)

- I don't need to wear them all the time
- They are uncomfortable
- Can't see properly wearing them
- New pair too expensive
- Embarrassing
- Other *(please state)*

General Health

4. Have you been told by a doctor you have diabetes? Yes No

5. When you go out in the sun do you usually wear: **a)** A hat? Always Sometimes Never

b) Sunglasses? Always Sometimes Never

Office Use Only

1. Date of Examination: /

2. Interviewer:

3. Inclusion Criteria: Consent Obtained ☐
Community resident (6 months or more) ☐
Aboriginal person ☐
OR Torres Strait Islander person ☐
Age: years

4. Presenting Correction:
No Correction ☐
Spectacles ☐
Contact Lenses ☐
Other ☐ (please state)

5. Visual Acuity (with Presenting Correction):
VA: PH: BCVA:

	RE	LE	RE	LE	RE	LE
≥6/12						
<6/12–6/18						
<6/18–6/60						
<6/60						
NPL						

6. Trachoma Grading:

	TT	CO	TF	TI	TS
RE					
LE					

7. Referral:
GP ☐
Optometrist ☐
Ophthalmologist ☐
Thank You ☐

8. Completion Check: Yes ☐ No ☐ Comments

	Yes	No	Comments
Services Questionnaire			
Visual Acuity			
Auto Refraction			
FDT			

9. Other Relevant Information:

Appendix D: Participant Informed Consent Forms

VRRP2006-005 Adult Consent-V3

VRRP2006-005 Child Consent-V1

NATIONAL SURVEY OF ABORIGINAL & TORRES STRAIT ISLANDER EYE HEALTH

Participant Information Sheet/Informed Consent

Protocol Number: VRRP 2006-005-V2 HREC Approval Date/Number:

EXPLANATION OF STUDY

You are invited to participate in a study performed by the Vision CooperativeResearch Centre (Vision CRC) in collaboration with the International Centre for Eyecare Education (ICEE), the Centre for Eye Research Australia (CERA) and the Aboriginal Health and Medical Research Council (AH&MRC). The purpose of this study is to provide information on the major causes of blindness and visual impairment in Aboriginal and Torres Strait Islander communities in Australia and the influences that access to eyecare services has on the status of eye health. You were selected as a possible participant in this study because you identify as an Aboriginal or Torres Strait Islander person, are aged eighteen or over and live in this community.

STUDY PROCEDURES, DURATION OF PARTICIPATION AND VISITS SCHEDULE

If you decide to participate, you are consenting to our reviewing your medical records if necessary and we will take the following basic measurements of your eyes.

1. We will ask you about your eye health history and your knowledge and use of eye health services.
2. We will check how well you can see (visual acuity) by asking you to read letters on a chart.
3. We may place lenses in front of each of your eyes and ask you to tell us which lens gives you the clearest vision.
4. We may put a drop into your eyes that makes your pupils larger and helps us to check the health of your eyes by looking into the eyes with a light for a short time (retinoscopy). We may also take a photo of the back of your eye with a digital camera.
5. We will ask you how your eyesight affects your ability to go about your daily activities.
6. We may also ask you to comment on the appropriateness of the language and phrasing of the questions we ask, or if there are important questions that you think we need to ask in an interview or focus group so that we can make them more appropriate for Aboriginal and Torres Strait Islander people.

We may ask you to repeat some of the above procedures so that we can test the reliability of our testing procedures, which may take an additional hour of your time now, or on a separate day. You don't have to repeat any part of the examination or questionnaire if you don't want.

RISKS AND PRECAUTIONS

The above procedures are those used routinely by optometrics or ophthalmics practitioners for general eye examinations. The worst thing that could happen is extremely rare (happens in 1 in every 183,000 people) and causes a rise in the pressure in the eye after we place the drops in your eye. This can lead to pain, blurry vision, red eye, headaches, and feeling sick in the stomach. Other events that could happen are stinging, blur, sensitivity to light, redness and fainting. These are all short lasting, and will not cause permanent damage, and a trained optometrist will be close by at all times.

There are no known increased risks to pregnant or lactating mothers, foetus, or nursing child. If you are pregnant and have additional questions, please ask the a member of the study team.

ILLNESS AND INJURY RELATING TO THE STUDY

The Vision CRC has Public and Products Liability insurance to cover you in the event of any study related illness, injury or damage to any property. Compensation for injury will be in accordance with the Australian Pharmaceutical Manufacturers Associates Compensation Guidelines. The study team has a copy of these guidelines if you wish to see them.

BENEFITS OF THE STUDY, EXPENSES AND COMPENSATION

The eye examination will check your vision, whether or not you need glasses and will assess the health of your eyes. If you need glasses, you will be provided with a prescription. If you require other eyecare, as a referral to an eyes doctor will be made. There will be no costs for you to participate in this study. However, there is no guarantee or promise that you will receive any benefits to your health from the study. Also, if the study shows you need further health care, the costs of that additional health care will not be reimbursed by the study.

NATIONAL SURVEY OF ABORIGINAL & TORRES STRAIT ISLANDER EYE HEALTH

Participant Information Sheet/Informed Consent

CONFIDENTIALITY/ANONYMITY AND DATA SECURITY

You are assured that any information provided by you or relating to you or any personal details obtained in the course of this study will be kept confidential and that your name or any identifiable information will neither be used nor published without your written permission. Summary findings arising out of the project may be presented at scientific meetings and published in scientific journals once the participating Aboriginal Community Controlled Health Service (ACCHS) has been consulted. The data from this study will be stored securely for 15 years by the Vision CRC and then may be disposed of by shredding or erasure.

ABORIGINAL COMMUNITY CONSENT

You are assured that any information provided in the course of this study that identifies that Aboriginal community to which you belong, including de-identified data, will not be used nor published without the express written permission of the Community through the relevant ACCHS.
You are assured that the Aboriginal and Torres Strait Islander community has agreed that an adequate time-frame to consider the appropriateness of this project has been provided. You are also assured that the Aboriginal and Torres Strait Islander community, through the representative members of the relevant ACCHS has been duly consulted and that any required negotiation has occurred.

ETHICAL PROVISIONS

You are assured that the ethical provisions relating to the health of Aboriginal and Torres Strait Islander people, as stated in National Aboriginal Community Controlled Health Organisation, National Health and Medical Research Council and AH&MRC publications, have been complied with and that there are terms of reference for any variation from these protocols.

VOLUNTARY PARTICIPATION WITHDRAWAL

You don't have to participate in this study if you don't want to. If you do decide to participate in this study you may withdraw at any time. Refusal to participate and/or withdrawing from the study will involve no penalty or loss of benefits to which you are entitled.

QUESTIONS OR PROBLEMS

Enquiries about your rights as a research study participant or concerns about the conduct of this research project may be directed to the AH&MRC Ethics Committee, Level 3, 66 Wentworth Ave, Surry Hills NSW 2012, Australia (Phone [02] 9212 4777 or Fax [02] 9212 7211 or e-mail ethics@ahmrc.org.au). Any questions or concerns will be handled independently from all study staff.

Your signature indicates that you have read or been verbally informed about the study and understand the statements of the informed consent form. It indicates you have had a chance to ask questions, and consent to the procedures and treatment described above.

Signature of Participant	Signature of person explaining the study and informed consent	Signature of Witness
Please PRINT Name	Please PRINT Name	Please PRINT Name
Date and Time (am/pm)	Date and Time (am/pm)	Date and Time (am/pm)

NATIONAL SURVEY OF ABORIGINAL & TORRES STRAIT ISLANDER EYE HEALTH

Parent/Guardian Information Sheet/Informed Consent

Protocol Number: VRRP 2006-005-V2 HREC Approval Date/Number:

EXPLANATION OF STUDY

You are invited to permit your child to participate in a study performed by the Vision Cooperative Research Centre (Vision CRC) in collaboration with the International Centre for Eye care Education (ICEE), the Centre for Eye Research Australia (CERA) and the. The purpose of this study is to provide information on the major causes of blindness and visual impairment in Aboriginal and Torres Strait Islander communities in Australia and the influences that access to eye care services has on the status of eye health. Your child was selected as as possible participant in this study because he/she identifies as an Aboriginal or Torres Strait Islander person and lives in this community.

STUDY PROCEDURES, DURATION OF PARTICIPATION AND VISITS SCHEDULE

If you decide to permit your child to participate, you are consenting to our reviewing your child's medical records if necessary and we will take the following basic measurements of your child's eyes.

1. We will ask you about your child's eye health history and knowledge and use of eye health services.
2. We will check how well your child can see (visual acuity) by asking them to read letters or shapes on a chart.
3. We may place lenses in front of each of your child's eyes and ask them to tell us which lens gives the clearest vision.
4. We may put as drops into your child's eyes to make the pupils larger and help us to check the health of your child's eyes by looking into the eyes with a light for a short time (retinoscopy). We may also take a photo of the back of your child's eye with a digital camera.

We may ask your child to repeat some of the above procedures so that we can test the reliability of our testing procedures, which may take an additional hour of your child's time now, or on a separate day. You don't have to repeat any part of these examinations or questionnaires if you don't want.

RISKS AND PRECAUTIONS

The above procedures are those used routinely by optometrics or ophthalmics practitioners for eye examinations. The worst thing that could happen is extremely rare (happens in 1 in every 183,000 people) and causes a rise in the pressure in the eye after we place the drops in your child's eyes. This can lead to pain, blurry vision, red eye, headaches, and feeling sick in the stomach. Other events that could happen are stinging, blur, sensitivity to light, redness and fainting. These are all short lasting, and will not cause permanent damage, and a trained optometrist will be close by at all times.

There are no known increased risks to pregnant or lactating mothers, foetus, or nursing child. If you have additional questions, please ask any members of the study team.

ILLNESS AND INJURY RELATING TO THE STUDY

The Vision CRC has Public and Products Liability insurance to cover your child in the event of any study related illness, injury or damage to any property. Compensation for injury will be in accordance with the Australian Pharmaceutical Manufacturers Associates Compensation Guidelines. The study team has a copy of these guidelines if you wish to see them.

BENEFITS OF THE STUDY, EXPENSES AND COMPENSATION

The eye examination will check your child's vision, whether or not your child needs glasses and assess the health of your child's eyes. If your child needs glasses, she/he will be provided with a prescription. If your child requires other eye care, a referral to an eye doctor will be made. There will be no costs for you for your child to participate in this study. However, there is no guarantee or promise that you or your child will receive any benefits to your health from the study. Also, if the study shows your child needs further heath care, the costs of that additional health care will not be reimbursed by the study.

NATIONAL SURVEY OF ABORIGINAL & TORRES STRAIT ISLANDER EYE HEALTH

Parent/Guardian Information Sheet/Informed Consent

CONFIDENTIALITY/ANONYMITY AND DATA SECURITY

You are assured that any information provided relating to you or your child or any personal details obtained in the course of this study will be kept confidential and that you and your child's name or any identifiable information will neither be used nor published without your written permission. Summary findings arising out of the project may be presented at scientific meetings and published in scientific journals once the participating Aboriginal Community Controlled Health Service (ACCHS) has been consulted. The data from this study will be stored securely for 15 years by the Vision CRC and then may be disposed of by shredding or erasure.

ABORIGINAL COMMUNITY CONSENT

You and your child are assured that any information provided in the course of this study that identifies that Aboriginal community to which you and your child belong, including de-identified data, will not be used nor published without the express written permission of the Community through the relevant ACCHS.

You are assured that the Aboriginal and Torres Strait Islander community has agreed that an adequate time-frame to consider the appropriateness of this project has been provided. You are also assured that the Aboriginal and Torres Strait Islander community, through the representative members of the relevant ACCHS has been duly consulted and that any required negotiation has occurred.

ETHICAL PROVISIONS

You are assured that the ethical provisions relating to the health of Aboriginal and Torres Strait Islander people, as stated in National Aboriginal Community Controlled Health Organisation, National Health and Medical Research Council and AH&MRC publications, have been complied with and that there are terms of reference for any variation from these protocols.

VOLUNTARY PARTICIPATION/WITHDRAWAL

You don't have to allow your child to participate in this study if you don't want to. You may also withdraw your child from this study at any time. Refusal to participate and/or withdrawing your child from the study will involve no penalty or loss of benefits to which you or your child are entitled.

QUESTIONS OR PROBLEMS

Enquiries about your child's rights as a research study participant or concerns about the conduct of this research project may be directed to the AH&MRC Ethics Committee, Level 3, 66 Wentworth Ave, Surry Hills NSW 2012, Australia (Phone [02] 9212 4777 or Fax [02] 9212 7211 or e-mail ethics@ahmrc.org.au). Any questions or concerns will be handled independently from all study staff.

Your signature indicates that you have read or been verbally informed about the study and understand the statements of the informed consent form. It indicates you have had a chance to ask questions, and consent to the procedures and treatment described above.

Child's Name		
Signature of Parent/Guardian	Signature of person explaining the study and informed consent	Signature of Witness
Please PRINT Name	Please PRINT Name	Please PRINT Name
Date and Time (am/pm)	Date and Time (am/pm)	Date and Time (am/pm)

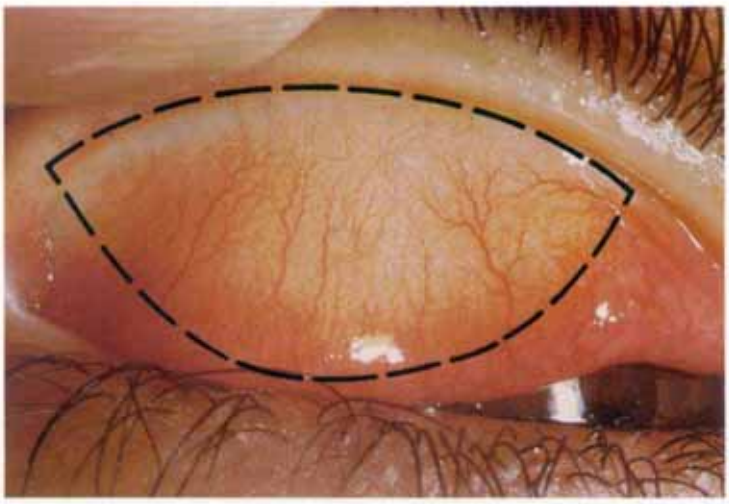
Appendix E: WHO Trachoma Grading Card

TRACHOMA GRADING CARD

– Each eye must be examined and assessed separately.
– Use binocular loupes (x 2.5) and adequate lighting (either daylight or a torch).
– Signs must be clearly seen in order to be considered present.

The eyelids and cornea are observed first for inturned eyelashes and any corneal opacity. The upper eyelid is then turned over (everted) to examine the conjunctiva over the stiffer part of the upper lid (tarsal conjunctiva).

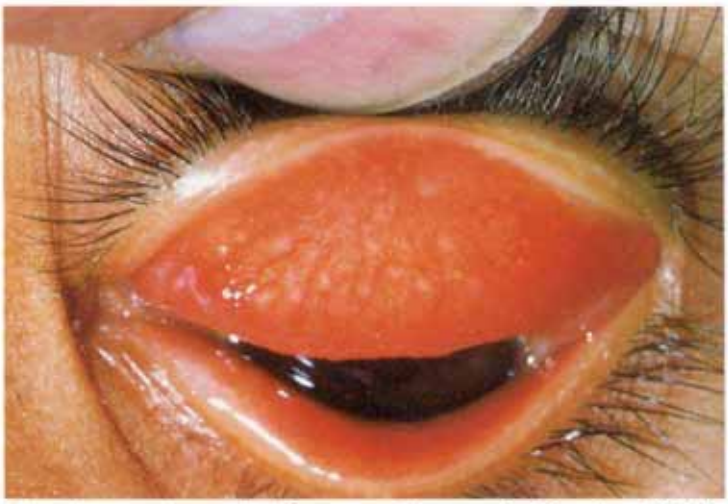
The normal conjunctiva is pink, smooth, thin and transparent. Over the whole area of the tarsal conjunctiva there are normally large deep-lying blood vessels that run vertically.



Normal tarsal conjunctiva (x 2 magnification). The dotted line shows the area to be examined.

***TRACHOMATOUS INFLAMMATION – FOLLICULAR (TF)**: the presence of five or more follicles in the upper tarsal conjunctiva.*

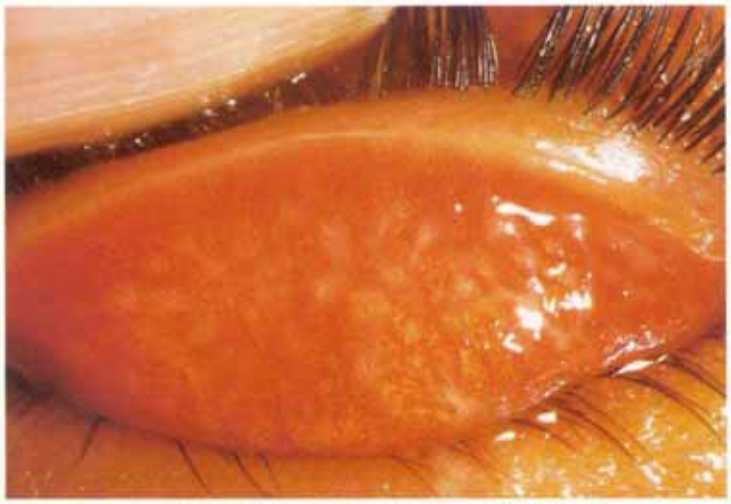
Follicles are round swellings that are paler than the surrounding conjunctiva, appearing white, grey or yellow. Follicles must be at least 0.5mm in diameter, i.e., at least as large as the dots shown below, to be considered.



Trachomatous inflammation – follicular (TF).

***TRACHOMATOUS INFLAMMATION – INTENSE (TI)**: pronounced inflammatory thickening of the tarsal conjunctiva that obscures more than half of the normal deep tarsal vessels.*

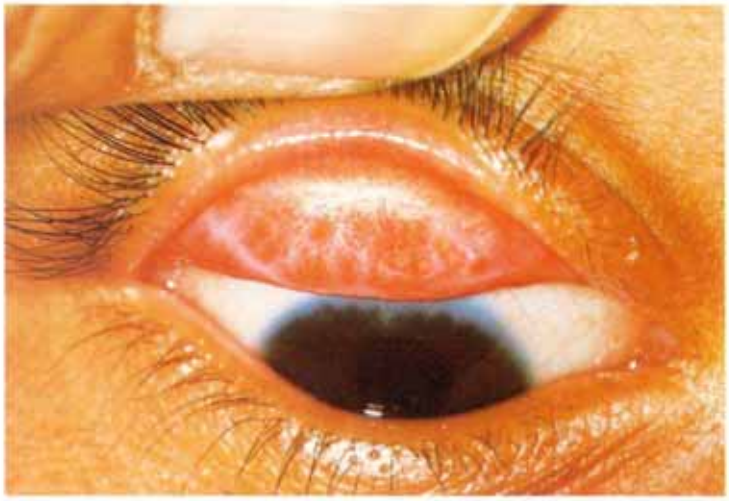
The tarsal conjunctiva appears red, rough and thickened. There are usually numerous follicles, which may be partially or totally covered by the thickened conjunctiva.



Trachomatous inflammation – follicular and intense (TF + TI).

***TRACHOMATOUS SCARRING (TS)**: the presence of scarring in the tarsal conjunctiva.*

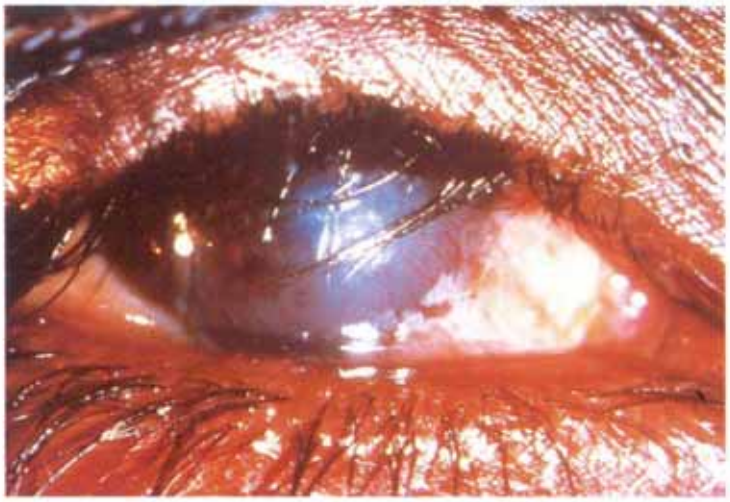
Scars are easily visible as white lines, bands, or sheets in the tarsal conjunctiva. They are glistening and fibrous in appearance. Scarring, especially diffuse fibrosis, may obscure the tarsal blood vessels.



Trachomatous scarring (TS)

***TRACHOMATOUS TRICHIASIS (TT)**: at least one eyelash rubs on the eyeball.*

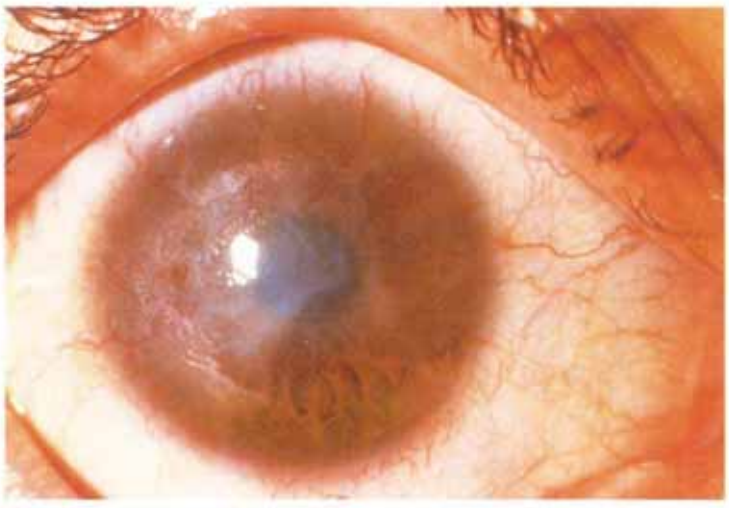
Evidence of recent removal of inturned eyelashes should also be graded as trichiasis.



Trachomatous trichiasis (TT)

***CORNEAL OPACITY (CO)**: easily visible corneal opacity over the pupil.*

The pupil margin is blurred viewed through the opacity. Such corneal opacities cause significant visual impairment (less than 6/18 or 0.3 vision), and therefore visual acuity should be measured if possible.



Corneal opacity (CO)

TF:– give topical treatment (e.g. tetracycline 1%).
TI:– give topical and consider systemic treatment.
TT:– refer for eyelid surgery.

WORLD HEALTH ORGANIZATION
PREVENTION OF BLINDNESS AND DEAFNESS

Support from the partners of the WHO Alliance for the Global Elimination of Trachoma is acknowledged.

Appendix F: Impact of Vision Impairment Questionnaire

Impact of Vision Impairment – Indigenous Communities (IVI_I)

Impact of Vision Impairment Profile (IVI)

Put a tick on each row. Please do not leave any rows blank.

ID

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES, or MAGNIFIERS, if you use them.

In the PAST MONTH, how much has YOUR EYESIGHT INTERFERED with the following activities:	Not at all	A little	A fair amount	A lot	Don't do this for other reasons
1. Your ability to see and enjoy T.V?	☐	☐	☐	☐	☐
2. Taking part in recreational activities?	☐	☐	☐	☐	☐
3. Shopping? (finding what you want and paying for it)	☐	☐	☐	☐	☐
4. Visiting friends or family?	☐	☐	☐	☐	☐
5. Recognising or meeting people?	☐	☐	☐	☐	☐
6. Generally looking after your appearance? (face, hair, clothing etc.)	☐	☐	☐	☐	☐
7. Opening packaging? (for example, around food, medicines)	☐	☐	☐	☐	☐
8. Reading labels or instructions on medicines?	☐	☐	☐	☐	☐
9. Operating household appliances and the telephone?	☐	☐	☐	☐	☐
10. How much has your eyesight interfered with getting about outdoors?	☐	☐	☐	☐	☐
11. In the past month, how often has your eyesight made you go carefully to avoid falling or tripping?	☐	☐	☐	☐	☐
12. In general, how much has your eyesight interfered with traveling or using transport?	☐	☐	☐	☐	☐
13. Going down steps, stairs, or curbs?	☐	☐	☐	☐	☐

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES, or MAGNIFIERS, if you use them.

In the PAST MONTH, how much has YOUR EYESIGHT INTERFERED with the following activities:	Not at all	A fair amount	A lot	Don't do this for other reasons
14. Reading ordinary size print? (for example newspapers)	☐	☐	☐	☐
15. Getting information that you need?	☐	☐	☐	☐

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES or MAGNIFIERS, if you use them.

In the PAST MONTH, how often has YOUR EYESIGHT MADE YOU CONCERNED OR WORRIED about the	Not at all	A little of the time	A fair amount of the time	A lot of the time
16. Your general safety at home?	☐	☐	☐	☐
17. Spilling or breaking things?	☐	☐	☐	☐
18. Your general safety when out of your home?	☐	☐	☐	☐
19. In the past month, how often has your eyesight stopped you doing the things you want to do?	☐	☐	☐	☐
20. In the past month, how often have you needed help from other people because of your eyesight?	☐	☐	☐	☐

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES or MAGNIFIERS, if you use them.

Think about how YOUR eyesight has made you FEEL in the PAST MONTH.	Not at all	A little of the time	A fair amount of the time	A lot of the time
21. Have you felt embarrassed because of your eyesight?	☐	☐	☐	☐
22. Have you felt frustrated or annoyed because of your eyesight?	☐	☐	☐	☐
23. Have you felt lonely or isolated because of your eyesight?	☐	☐	☐	☐
24. Have you felt sad or low because of your eyesight?	☐	☐	☐	☐
25. In the past month, how often have you worried about your eyesight getting worse?	☐	☐	☐	☐
26. In the past month how often has your eyesight made you concerned or worried about coping with everyday life?	☐	☐	☐	☐
27. Have you felt like a nuisance or a burden because of your eyesight?	☐	☐	☐	☐
28. In the past month, how much has your eyesight interfered with your life in general?	☐	☐	☐	☐

Please check that all the questions have been answered and Thank you!