The National Eye Survey of Trinidad and Tobago:

Prevalence, causes, risk factors, and impact of vision impairment

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The National Eye Survey of Trinidad and Tobago: Prevalence, causes, risk factors, and impact of vision impairment

Submitted by Dr. Tasanee Braithwaite of Merton College to the University of Oxford as a thesis for the degree of Doctor of Medicine, Trinity Term 2018.

I certify that all material in this thesis which is my own work has been identified and that no unchanged or acknowledged material has been previously submitted and approved for the award of a degree by this or any other university.

Abstract

Background: Avoidable vision impairment (VI, Snellen acuity <6/12) is a global public health concern. There were no data on the prevalence, causes, or risk factors associated with VI in Trinidad and Tobago, and only limited data within the Caribbean region. The societal cost of VI and the impact on quality of life was unknown.

Study design: A national, population-based, cross-sectional survey of the non-institutionalized population aged 40 years and above in Trinidad and Tobago in 2013/2014, used random multistage cluster sampling with probability proportional to size methods.

Methods: In each of 120 clusters, 35 eligible adults were enumerated. In community screening, the presenting uniocular distance and binocular near visual acuity was measured and basic demographic, socioeconomic and health data collected. All participants were invited to regional clinics for more detailed interview and comprehensive ocular and medical examination with imaging. Interviews included assessment of health service utilization, costs, and health-related quality of life, using the EQ-5D instrument.

Results: From 3556 households, 4263 eligible adults were identified, of whom 84.2% (n=3589) participated in community screening, and 65.4% (n=2790) in regional clinics. After adjustment for the multilevel, clustered study design and non-response rate, and weighting by the age, sex and municipality of participants, the prevalence of presenting VI was 11.88 % (95% confidence interval (CI) 10.88-12.97, n = 468 / 3580), including blindness in 0.73% (95% CI 0.48 to 0.97, n = 31). The leading causes of blindness were glaucoma (31.7% 95% CI 18.7 to 44.8), cataract (28.8%, 95 % CI 12.6 to 45.1), and diabetic retinopathy (19.1%, 95 % CI 4.2 to 34.0). The leading cause of presenting distance VI was uncorrected refractive error (47.4%, 95% CI 43.4 to 51.3), and 86.1% (95% CI 82.88-88.81) of distance VI was potentially avoidable. A further 22.3% (95% CI 20.7 to 23.8) had uncorrected near VI resulting from presbyopia. In total, within Trinidad and Tobago there were an estimated 185,273 (95% CI 167,337 to 203,048) people aged 40 years and above with near or distance VI, and 176,323 cases were potentially avoidable. Significant independent associations with presenting distance VI included increasing age (p<0.0001), diagnosed diabetes (p=0.0004), and employment status (p=0.0002). Significant independent associations with presenting near VI

included male sex (p<0.0001), no health insurance (p<0.0001) and employment status (p<0.0001). Presenting distance VI was significantly associated with the odds of reporting reduced health-related quality of life (p=0.004), after adjustment for independent predictors including older age, female sex, multiple co-morbidities, lack of health insurance, education level and marital status. An estimated 762 quality adjusted life years were lost from VI per 100,000 population in 2014. VI was associated with a total economic cost to society of TT$3,842,324,655 (UK£365,650,241), of which 73.3% resulted from loss of wellbeing. Excluding intangible effects, indirect costs accounted for 70.5% (TT$722,379,355) of the remaining total cost, direct medical costs for 17.9% (TT$183,303,734) and direct non-medical costs for 11.6% (TT$19,362,310)

Conclusions: The National Eye Survey of Trinidad and Tobago obtained original population-based data on the magnitude, causes and risk factors for avoidable VI in Trinidad and Tobago, and identified significant associated economic and quality of life impact. This evidence-base provides the foundation for the development of a national eye care strategy.

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A survey of this size is a significant undertaking, and would not have been possible without the hard work and commitment of the colleagues who joined me in the different aspects of the fieldwork over a 13-month period. In the regional eye clinic and community vision screening, I was joined by Mrs. Kala Dowlath, Dr. Debra Bartholomew, Mr. Frank Deomansingh, Mrs. Petra Bridgemohan, Miss Amandi Fraser, Miss Vedatta Maharaj, Mrs. Miner Persad, Mrs. Alicia Pascall, Mrs. Hema Pulchan, Mrs. Kathleen Carter, Mr. Mark Narine, Miss Najeebah Lynch, and Mr. Marlon Bruce. Mr. Christopher Applewhite supervised the team of enumerators. Particular thanks are due to Miss Diane Williams, of Medilex Ltd, and Mr. Avi Bhagan, for their invaluable logistical and technical support.

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Finally, I am most grateful to the participants, and to the Government of the Republic of Trinidad and Tobago for supporting the project. I hope that the data reported by the National Eye Survey of Trinidad and Tobago (NESTT) Study Group comes to play its part in the important work of addressing the burden of avoidable vision loss in Trinidad and Tobago.

Contributions

The National Eye Survey of Trinidad and Tobago was conceived by Professor Rupert Bourne and Mrs. Petra Bridgemohan. I devised inclusion of economic and quality of life outcome measures, and more extensive risk factor analysis.

Professor Rupert Bourne designed the initial study protocol and obtained a funding commitment from the Ministry of Health of the Government of the Republic of Trinidad and Tobago in 2012. He secured ethics committee approvals for the study from The Ministry of Health, the University of the West Indies, and Anglia Ruskin University in 2013. I secured additional funding from Fight for Sight, in collaboration with Professor Rupert Bourne, Professor Samuel Ramsewak, and Professor Konrad Pesudovs.

I designed the final study protocol for the epidemiological survey and selected the sample size and enumeration strategy, wrote the manual of operations and standard operating procedures, and the training manuals. Dr. Vrijesh Tripathi (University of the West Indies, St. Augustine) assisted me in creating the survey instruments using the Epi Info™ software platform. Mr. Neville Verlander (Biostatistician, Public Health England) reviewed the sample size calculation, sampling strategy and cluster selections.

I trained and supervised the clinical, vision screening and enumeration teams during a 13-month period of fieldwork in Trinidad and Tobago, and worked as the lead survey ophthalmologist examining all participants who attended the regional eye clinic. 18 local enumerators, under the supervision of Mr. Christopher Applewhite, gathered household enumeration data. Community vision screening data and informed written consent was gathered by the NESTT survey clinical team, which included Dr. Debra Bartholomew, Mr. Frank Deomangsingh, Miss Amandi Fraser, Miss Vedatta Maharaj, Mrs. Miner Persad, Mrs. Alicia Pascall, Mrs. Kathleen Carter, Mrs. Hema Pulchan and myself. Mrs. Petra Bridgemohan, Mrs. Lisa Robinson, Mr. Marlon Bruce, and Mr. Robert Ballah provided additional vision screening support. The NESTT survey clinical team gathered regional eye clinic data. The NESTT survey clinical team undertook data entry prospectively, with additional support from Mr. Mark Narine and Miss Najeebah Lynch.

Professor Tunde Peto and the Moorfields Eye Hospital Reading Centre, London, graded the retinal images and provided data on the grading process and outcomes.

I performed all data cleaning and biostatistical analyses, with guidance from Mr. Neville Verlander and Dr. Ayoub Saei (Biostatisticians, Public Health England) who reviewed my STATA code files. I performed all quality of life and economic analyses, with guidance from Professor Alastair Gray and comments from Dr. Henry Bailey.

I have written the thesis independently. I received limited feedback from co-investigators on some of the content of chapters 1, 3, 4, 5, 6 and 7, during preparation for submission to medical journals. All co-authors read and approved the final draft of submitted manuscripts relating to the work contained within these chapters.

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Table 1: Abbreviations used in thesis

Abbreviation	Full text
AMD	Age-related macular degeneration
ARM	Age-related maculopathy
BCVA	Best-corrected visual acuity
BMI	Body mass index
CDAP	Chronic Disease Assistance Plan
CI	Confidence interval
CLAD	Censored least absolute deviation
CSO	Central Statistical Office
DR	Diabetic retinopathy
DVI	Distance vision impairment
ED	Enumeration district
EQ-5D	Euroqol 5 dimension health-related quality of life instrument
ETDRS	Early treatment of diabetic retinopathy study
FFA	Fundus fluorescein angiography
GBD	Global Burden of Disease
GNI	Gross national income
HRQoL	Health-related quality of life
IOP	Intraocular pressure
IQR	Interquartile range
ISGEO	International Society of Geographical and Epidemiological Ophthalmology
LogMAR	Logarithm of the minimum angle of resolution
LRT	Likelihood ratio test
MAU	Multiattribute utility
MEHRC	Moorfields Eye Hospital Reading Centre
MSVI	Moderate or severe vision impairment
MVA	Multivariable analysis
MVI	Moderate vision impairment
NESTT	National Eye Survey of Trinidad and Tobago
NVI	Near vision impairment
OCT	Optical coherence tomography
OLS	Ordinary least squares
OOPE	Out of pocket expenditure
OR	Odds ratio
PAHO	Pan American Health Organization
PPP	Purchasing power parities
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
RAAB	Rapid Assessment of Avoidable Blindness survey protocol
RACSS	Rapid Assessment of Cataract Surgical Services survey protocol
RESC	Refractive Error in School Children survey protocol
RSE	Robust standard errors
sd	Standard deviation
SVA	Single variable analysis
SVI	Severe vision impairment
TT	Trinidad and Tobago
URE	Uncorrected refractive error
VAS	Visual analogue scale
VEGF	Vascular endothelial growth factor
VI	Vision impairment
WHO	World Health Organization
YLD	Years Lived with Disability
YLL	Years of Life Lost

Peer-reviewed academic outputs

Publications

Braithwaite, T., Winford, B., Bailey, H., Bridgemohan, P., Bartholomew, D., Singh, D., et al. (2016). Health system dynamics analysis of eye care services in Trinidad and Tobago and progress towards Vision 2020 Goals. *Health Policy and Planning, 33*(1), 70-84 (See Appendix A.1).

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Bartholomew, D., Winford, B., Bridgemohan, P., Singh, D., Sharma, S., … **Braithwaite, T**. (2017). Health system dynamics analysis of eye care services in Trinidad and Tobago and progress towards Vision 2020 Goals. Association for Research in Vision and Ophthalmology. Baltimore, USA.

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Ramsewak, S., Verlander, N., Deomansingh, F., Fraser, A., Maharaj, V., Sharma, S., … **Braithwaite, T**. (2016). National eye survey of Trinidad and Tobago: the prevalence and risk factors for refractive error. Association for Research in Vision and Ophthalmology. Seattle, USA.

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1

INTRODUCTION

This chapter is divided into two sections: Part 1 outlines the aims and structure of this thesis. Part 2 introduces the context of the thesis.

Part 1: Structure and aims of thesis

This thesis has multiple objectives:

- To report on the design, implementation and analysis of a study to estimate the prevalence and causes of presenting vision impairment (VI) in the adult population aged over 40 years in Trinidad and Tobago in 2013-2014, and the proportion that was potentially avoidable;
- To explore risk factors associated with presenting distance and near VI;
- To explore the impact of VI on health-related quality of life (HRQoL);
- To explore the economic impact of VI.

In this chapter, I outline the rationale that informed these objectives, and review the existing literature on VI in Trinidad and Tobago.

In Chapter 2, I present a narrative literature review exploring the objectives of this thesis. This informed the a priori expectations relating to each thesis objective.

In Chapter 3, I present a review of methodological approaches used in previous eye and vision surveys, which informed the study design.

In Chapter 4, I present the materials and methods of the NESTT, limiting my presentation to those aspects of the design directly addressing the objectives of this thesis.

In Chapter 5, I present results from the survey, concentrating on the prevalence and causes of presenting distance and near VI in adults over 40 years, and the proportion that was potentially avoidable. I also explore associated risk factors. The size of the population-based sample enabled estimation of the national burden.

In Chapter 6, I explore whether presenting VI impacted HRQoL, measured using the Euroqol 5 dimension health-related quality of life instrument (EQ-5D). Raw scores were transformed to utility values, in order to explore the odds of utility decrement by degree of VI, and to estimate associated loss of quality-adjusted life years.

In Chapter 7, I explore the societal cost of VI in adults aged 40 years and above, supplementing cost and utilization data from survey participants with additional data available in the public domain, and collected in a contemporaneous study of the eye care system (Braithwaite et al., 2018)(See Appendix A.1). I explore the proportion of total costs relating to direct medical, direct non-medical, indirect costs, and intangible effects, estimated from the disability-adjusted life years lost.

In Chapter 8, I summarize the key findings, and discuss the study limitations, implications, and future research questions arising from each chapter.

In the Appendix I include the First Author manuscripts published to date (Appendix A.1 to A.6), summaries of studies identified in the literature review, and search strategies (Appendix B), Ethics Committee approval letters, survey forms, consent

forms, and tables relating to the materials and methods (Appendix C), and additional data tables and key multivariable models (Appendix D).

Part 2: The context for this thesis

1.1 Avoidable vision loss – a global public health concern

The ability to see, both in the distance and at near, is considered by many people to be fundamental to their wellbeing, quality of life, educational, social, and employment opportunities. Avoidable vision loss presents a global public health challenge. Nearly two decades after the launch of a global initiative to reduce avoidable vision loss, 'Vision 2020: The Right to Sight' (World Health Organization [WHO], 1997), in 2015 an estimated 36.0 million people globally were blind (visual acuity, VA < 3/60 in better seeing eye), 216.6 million people had moderate or severe presenting distance vision impairment (MSVI, VA < 6/18 but $\geq$ 3/60), and 188.5 million had mild presenting distance VI (VA < 6/12 but $\geq$ 6/18) (Bourne et al., 2017). A majority of VI was attributed to potentially avoidable causes, such as uncorrected refractive error (URE), cataract and diabetic retinopathy (DR) (Flaxman et al., 2017). The populations of lower and middle-income economies, including those in the Caribbean region, were particularly affected, but in high-income regions too, as much as 10 % of the population were estimated to have distance vision too poor for safe driving (Bourne et al., 2017). Furthermore, functional near vision impairment (NVI) from presbyopia affected a further 1.1 billion people aged 35 years and older (Bourne et al., 2017). Frequently overlooked by earlier eye surveys, presbyopia is now recognized to impact economic productivity and quality of life (Frick, Joy, Wilson, Naidoo, & Holden, 2015; Tahhan, Papas, Fricke, Frick, & Holden, 2013).

1.2 The paucity of vision loss data in the Caribbean

The World Health Organization (WHO) Global Action Plan advocated gathering evidence on the magnitude, causes and risk factors associated with VI, to inform policy and track progress (WHO, 2013). In 2000, the Pan American Health Organization (PAHO) launched, 'Vision 2020 Caribbean Strategic Plan of Action on the Prevention of Avoidable Vision Impairment and Blindness' (Pan American Health Organization [PAHO], 2010). Since then, PAHO, Member States, and other stakeholders, have worked to develop objectives and set priorities to reduce avoidable blindness. However, progress to implement these has been slow. Multiple

possible reasons include inadequate resources, competing health care demands, lack of awareness of effective interventions, and a paucity of evidence on the prevalence, causes and risk factors for blindness (PAHO, 2010).

The need for population-based VI data from this region was highlighted by two systematic reviews (Bourne, Price et al., 2013; Munoz & West, 2002). Whilst over 288 population-based surveys had been conducted globally prior to 2014, only four had been done in the Caribbean (Bourne et al., 2017). The Barbados Eye Survey, undertaken between 1987 and 1992, took a simple random sample of 4631 adults aged over 40 years from the national population, and performed a comprehensive examination, achieving a response rate of 82.1 % (Hyman et al., 2001; Leske & Connell, 1988). The St Lucia National Glaucoma Prevalence survey of 1986-1987 took a cluster sample of 1963 adults over 30 years of age, and performed a comprehensive examination directed at detecting glaucoma, achieving a response rate of 82.1 % (Mason et al., 1989). A Rapid Assessment of Cataract Surgical Services (RACSS protocol) in Havana, Cuba, sampled 2716 adults aged 50 years and above and achieved a response rate of 98.4 % (Hernandez Silva, 2006). Finally, a national Rapid Assessment of Avoidable Blindness (RAAB protocol) sampled 3873 adults aged over 50 years in the Dominican Republic in 2008, but has not been published in the peer-reviewed literature. These studies are summarized in Appendix B.1.

The paucity of data from a region as heterogeneous as the Caribbean was problematic. The region was home to ethnically and socioeconomically diverse populations, dispersed over more than 700 islands, within 30 territories. In 2014, the World Bank classified two-thirds of the countries as high-income economies, whilst approximately 60 % of the total Caribbean population resided in seven countries with upper middle-income economies, and a further 24 % lived in Haiti, which had a low-income economy (World Bank, 2017c).

1.3 Trinidad and Tobago

Trinidad and Tobago is a twin-island country situated 11 km from Venezuela in the West Indies. Within the Caribbean, it is the fifth largest country, with a landmass of 5,128 km^2 (Central Intelligence Agency, 2015). In 2014, it was the sixth most populous (3.2 % of the total Caribbean population), with 95 % of the population of 1.3 million living on the larger island of Trinidad (Ministry of Planning and Sustainable Development, 2012). Approximately 71 % of the population lived in urban areas,

defined as those with a population density ≥ 200 people/km^{-2} (Central Statistical Office (CSO), 2008). The greatest population density aligned to the two major highways running east to west and north to south. Large areas of the northern and central hills and the southern and eastern swamp areas in Trinidad, and the central hills in Tobago, were sparsely populated, with limited transport infrastructure.

Trinidad and Tobago is a democratic republic, and former British colony, which has been independent since 1962. It progressed from being an upper middle-income to a high-income economy in 2005 (World Bank, 2017d), but is not in the Organisation for Economic Cooperation and Development. Large reserves of oil and natural gas contributed 40 % to Gross Domestic Product. The Gross National Income per capita is $US18,380 (GNI at Atlas Method, 2014) (WorldBank, 2014). However, a previous population-based household survey reported a mean annual household income lower than GNI, of TT$41,873 (US$6541, 2014 exchange rate) (Ministry of Health, 2012). This discrepancy may reflect a bias in self-reported income, but also a skewed distribution, with substantial income inequality. The Human Development Index (HDI) gauges a country's level of human development, taking into account how income is turned into education and health opportunities. Trinidad and Tobago had an HDI of 0.760 in 2012, ranking 67th out of 187 countries, approaching the threshold for designation as an "advanced economy" by the International Monetary Fund (≥ 0.788) (United Nations Development Programme [UNDP], 2015). Unemployment was very low, at 3.2 %, and literacy very high (99 %) (Central Bank Trinidad and Tobago, 2015).

1.4 A population at risk for sight threatening eye disease?

The only previous insight into the prevalence and causes of blindness in Trinidad and Tobago was provided by a brief report, published in the British Journal of Ophthalmology in 1933, in which a Mr. Metevier was reported to have made, "*A valuable attempt, admittedly incomplete*," to estimate the prevalence of blindness in the population (Anonymous, 1933). Defining blindness according to the 1920 Blind Persons' Act, he estimated that in 1931 there were 823 blind individuals in Trinidad (population 412,783) and 56 in Tobago (population 25,352), yielding an approximate prevalence of 199 and 221 per 100,000 population in the respective islands. He reviewed 194 cases and reported the most frequent causes of blindness to be syphilis (45), primary glaucoma (38), and primary senile cataract (20), followed by leprosy (14), adult purulent ophthalmia (11), congenital causes (5), and ophthalmia

neonatorum (4). The cause was not reported in 57 cases, but he noted that there was no blindness from trachoma, myopia or occupational injury. He reported that blindness had increased by 46 per 100,000 compared to a similar census in 1921. At that time, Trinidad and Tobago was a middle-income country under British colonial rule. Historic public health concerns, including infectious diseases, malnutrition, poor sanitation, and associated maternal and child mortality subsequently reduced, as Trinidad and Tobago transitioned, first to an independent democratic Republic in 1962, and then to a high-income economy in 2005. Between 1953 and 1992, epidemiological transition in mortality by cause was observed (Gulliford, 1996). For example, infant mortality declined from 180 to 10 per 1000, but age-standardized mortality from diabetes increased over the same period from 60 to 278 per 1000 in men, and from 89 to 303 per 1000 in women.

Several factors indicated that the adult population in 2012 were at higher risk of sight threatening eye disease than might be expected for a high-income country. Firstly, for several decades, Trinidad and Tobago had a high, and rising, burden of chronic non-communicable diseases (NCDs), which were associated with premature mortality (Molokhia, Nitsch, Patrick, & McKeigue, 2011; Poon-King, 1968). The World Health Organisation estimated that the prevalence of diabetes in Trinidad and Tobago will more than double between 2000 and 2030, from an estimated 60,000 cases to 125,000 cases (WHO, 2017). An estimated 55.7 % of the adult population were overweight or obese (body mass index (BMI) $\geq$ 25 kgm^{-2}); 26.3 % were hypertensive, and 20.5 % had diabetes mellitus (Ministry of Health, 2012). Chronic diseases, especially diabetes mellitus, may increase the risk of sight loss from retinal vascular disease. NCDs are associated with nutrition and lifestyle transition, and accounted for over 60 % of premature loss of life (Ministry of Health, 2012). A majority of diabetic patients attending the public clinics were reported to have poor glycaemic control, which increases the risk of retinopathy (Apparico et al., 2007). Furthermore, 28 % of men and 19 % of women had elevated cholesterol, and 21.1 % were current smokers (Ministry of Health, 2012).

Secondly, the population were ethnically heterogeneous, with 35.4 % of South Asian ancestry, 34.2 % of African ancestry, and 0.1 % of indigenous Amerindian ancestry (Ministry of Planning and Sustainable Development, 2012). Ethnic differences in the risk of cardiovascular death were identified in this population over 30 years ago (Beckles et al., 1986; G. J. Miller et al., 1989). This was of interest because some diseases, such as glaucoma (Tham et al., 2014) and diabetes (Spanakis & Golden,

2013) are more prevalent in certain ethnic groups. Previous studies indicated that these groups may have increased genetic risk of some eye diseases (Sivaprasad, Gupta, Crosby-Nwaobi, & Evans, 2012; Wadhwa & Higginbotham, 2005; W. L. Wong et al., 2014).

Thirdly, it was anticipated that there might be vulnerable subgroups within the population at greater risk of avoidable VI (Lane et al., 2018). An estimated 1.7 % of the population of Trinidad and Tobago were estimated to be poor, based on the multidimensional poverty index, with an additional 0.5 % living near poverty (UNDP, 2015). Equity in health outcomes may be influenced by social determinants including poverty, education, and various aspects of social structure (Koh, Piotrowski, Kumanyika, & Fielding, 2011). There were no previous studies on the association between socioeconomic status and VI in the Caribbean region, but a higher prevalence of hypertension and its complications has been reported in lower socioeconomic status groups of Caribbean origin (Bidulescu et al., 2015).

Finally, in common with most other countries, there was an ageing population. Advancing age is a risk factor for many eye diseases, including glaucoma, macular degeneration and cataract (Bourne, Stevens et al., 2013). The population growth rate in 2012 was -0.1 % and transitioning rapidly towards a more aged population, with 9.8 % of the population aged over 65 years (Ministry of Planning and Sustainable Development, 2012).

1.5 The eye care system in 2013-2014

Comprehensive, accessible, equitable eye care systems are necessary to address avoidable VI (WHO, 2013). However, there is a paucity of relevant health systems research to understand barriers to achieving the Vision 2020 objectives (Blanchet, Gilbert, & de Savigny, 2014) (Bozzani, Griffiths, Blanchet, & Schmidt, 2014; Katibeh et al., 2015).

To address this, in parallel with the NESTT, we undertook a comprehensive situation analysis of the eye care system in 2013-2014 (Braithwaite et al., 2018) (See Appendix A.1). In this study, we obtained feedback from six key stakeholder groups, including patients, the public, and eye care professionals, and in addition, reviewed policy documents and reports. This study identified that Trinidad and Tobago spends approximately 4.8 % of gross domestic product on healthcare (World Bank, 2017a),

and public and private sector expenditure contributed equally to total health expenditure (PAHO, 2012). The eye care system was pluralistic, with a single payer in the public sector (the Government) providing universal basic eye care through 112 general health centres and five hospital eye departments, and many private providers providing both basic and sub-specialized surgical care (See Figure 1.1).

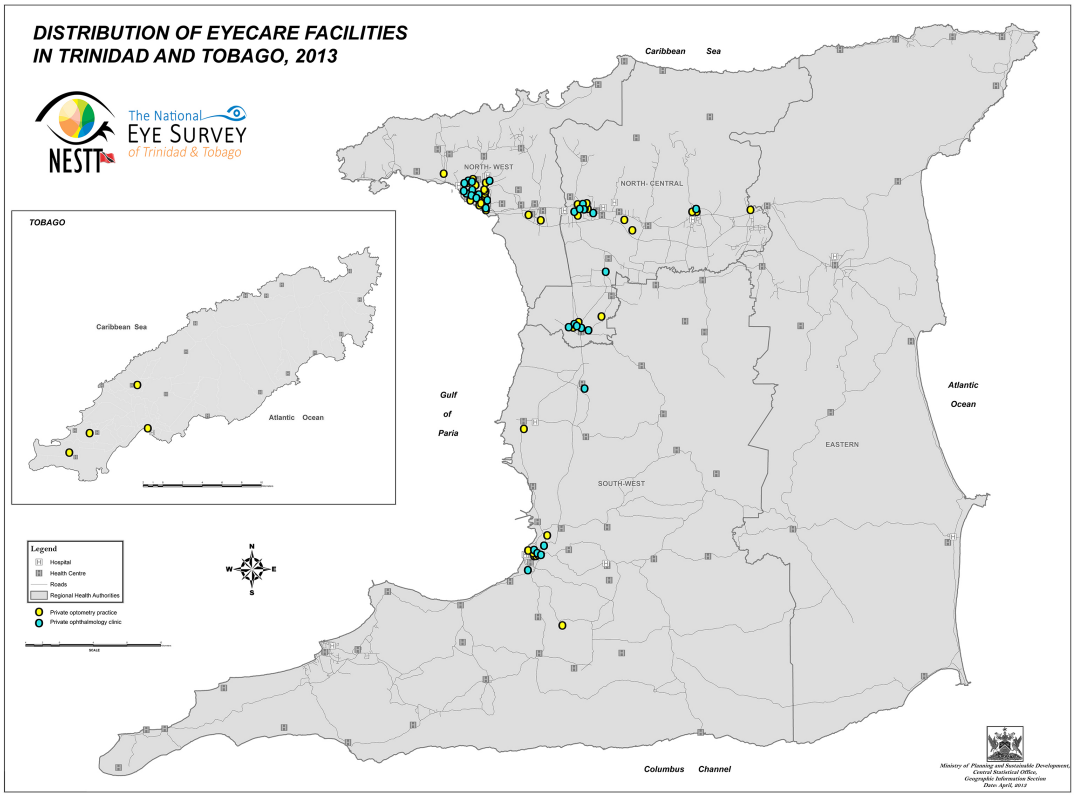

Figure 1.1: A map of Trinidad and Tobago showing the location of private and public eye care facilities

The eye care workforce included 115 private sector and 1 public sector optometrists; 90 optometrists-in-training; 54 dispensing opticians; 34 active ophthalmologists, 23 of whom worked in the private sector, 10 in both, and one in the public sector only; and 35 ophthalmologists-in-training in the public sector. We identified a number of health system weaknesses with potential to exacerbate avoidable VI at a population level. Firstly, there was no nationwide screening programme for DR, retinopathy of prematurity, or congenital cataract. Secondly, cataract surgical waiting times were long in the public sector (Haims, Duber, & Chang, 2014; Pinto Pereira et al., 2009). Thirdly, a few of the five hospital eye departments lack essential equipment: Specifically, two lacked visual field analysers, four lacked fundus fluorescein angiography (FFA), and two reported maintenance issues resulting in unavailability of

laser therapy for months at a time in the past year. Fourthly, some subspecialised surgery was unavailable in the public sector, including surgery for urgent or blinding conditions including retinal detachment and corneal scarring. Finally, the referral, medical records, and appointment systems were paper-based, with limited capacity for information gathering, integration or audit and accountability between levels and sectors. This study highlighted the importance of central governance of the eye care system and coordination with the private sector to avoid sight-threatening gaps in access to timely diagnosis and treatment.

1.6 Moving beyond the burden of disease

Societies and health systems are seeking to better understand the impact of disease states on health, and to adapt to the changing healthcare needs of their populations. Alternative population and individual health measures have been sought, to supplement traditional disease burden metrics. Population health outcome metrics include summary measures of population health, such as the quality-adjusted life year (QALY) and disability adjusted life year (DALY). QALYs measure individual preferences for time spent in different health states, and have been used since the late 1970s (Gold, Stevenson, & Fryback, 2002; Sassi, 2006). DALYs were introduced in the 1990s and aim to capture an explicit societal assessment of the burden of disease resulting from premature mortality and the non-fatal consequences of disease and injury (Murray, 1994). Their concern is for social justice and the association between the health states resulting from disease, and lost welfare, subjective wellbeing, and quality of life. In comparison to QALYs, DALYs facilitate more explicit comparison of health outcomes from different diseases for health sector planning and evaluation. These metrics help policy makers, and those responsible for the allocation of limited resources, target and prioritize healthcare investments. For example, the Global Burden of Disease (GBD) Study estimated that globally, in 2010, there were 2.49 billion, or 361 per 1000 population, DALYs associated with 291 diseases and injuries (Murray et al., 2013). Vision disorders accounted for 18.8 million DALYs, or 2.47 per 1000 population, and this number had increased 47 % since 1990, which was attributed to population ageing. The DALYs associated with VI were similar to the DALYs associated with colorectal cancer (2.1 per 1000) and epilepsy (2.5 per 1000), but less than those associated with diabetes mellitus (6.8 per 1000), low back pain (12.1 per 1000), ischaemic heart disease (18.8 per 1000) and stroke (14.8 per 1000).

Another useful approach for exploring the relative importance of VI in relation to other health problems, and the potential value of addressing it at a population-level, is the associated cost to both individuals and society. Over a decade ago, it was conservatively estimated that global, successful implementation of "Vision 2020: the right to sight", leading to the elimination of avoidable VI, could save US$102 billion in lost productivity alone, every year (Frick & Foster, 2003). Vision loss has previously been reported to be 5th costliest health problem in the USA, and 7th costliest health condition in Australia (Taylor, Pezzullo, & Keeffe, 2006). Whilst determining the prevalence of VI is important, such additional metrics offer the possibility of a more nuanced understanding of its impact at both individual and population level.

1.7 The National Eye Survey of Trinidad and Tobago (NESTT)

In 2011, local eye care professionals in Trinidad, in collaboration with academics at Anglia Ruskin University (Principal Investigator Professor Rupert Bourne) and the University of the West Indies in Trinidad (Chair of Steering Committee, Professor Samuel Ramsewak) proposed a nationwide eye survey. In 2012, The Government of the Republic of Trinidad and Tobago gave provisional funding approval for the National Eye Survey of Trinidad and Tobago. Following a visit to Trinidad in May 2012, I was appointed by both universities to contribute to the methodological development, fieldwork and analysis of this study. In April 2013, I moved to Port of Spain, Trinidad, with my husband and 5-month old son, for a period of 21 months, to lead these activities.

This thesis presents the design of the National Eye Survey of Trinidad, and selected findings from the NESTT dataset. In the next two chapters I explore the literature pertaining to the aims of this thesis, and key study design considerations.

2

LITERATURE REVIEW

The questions I aim to address in this thesis are multiple, and it is not possible to present a full systematic review of published and unpublished studies addressing each. In this chapter I therefore present a narrative synthesis of a structured review of the most relevant published literature. To explore the prevalence and causes of VI, and associated risk factors, and methodological considerations, I reviewed all population-based eye surveys undertaken between 1980 and 2014 identified in a systematic review and meta-analysis by the Vision Loss Expert Group for the GBD Study, to which I contributed as a co-author (Bourne, Price et al., 2013; Bourne et al., 2017; Flaxman et al., 2017). To explore the quality of life and economic impact of VI, I performed a systematic search of published studies indexed in the PubMed and EMBASE databases, with cited reference searching of relevant studies, and present a narrative review. Together these informed the study design and my prior expectations around the thesis objectives. I used a Literature Review Scoring Rubric to inform this evidence synthesis (Boote & Beile, 2005).

2.1 Literature review search questions

- What was the prevalence of VI globally, in the Caribbean, and in other high-income countries at the time of this study?
- What were the leading causes of VI in high-income and upper-middle income countries? To what extent were these potentially avoidable (preventable or treatable)?
- What risk factors for presenting VI have been identified in previous surveys in high-income countries?
- Which instruments can be used to measure HRQoL? Have other population-based surveys determined the impact of VI on HRQoL? Have confounding variables been identified? Was VI an independent predictor of reduced utility in other populations?
- What was the prevalent cost of VI in other high-income countries? Have previous population-based eye surveys estimated economic impact? What cost instruments and guidelines have been used?
- How should the NESTT be designed to obtain reliable estimates that answer these questions?

2.2 Literature review methodology

2.2.1 Identification and review of previous eye surveys

A published systematic review commissioned for the GBD Vision Loss Study identified all major population-based eye surveys reporting the prevalence of VI or blindness, undertaken between 1980 and February 2012 (Bourne, Price et al., 2013). The search included Ovid MEDLINE, Ovid EMBASE, the WHOLIS library and unpublished sources. Included studies recruited a population-based sample, used a clear definition of VI and blindness, and a clearly defined measurement protocol for visual acuity. Excluded studies were not population-representative (e.g. blindness registries, clinic case series), had a response rate lower than 60 %, or included only self-reported vision. This systematic review identified 21,716 records through database searching, and 48 unpublished datasets. After removal of duplicates, 2 independent expert reviewers screened 14,909 records (title and abstract), then 1,334 full text articles, and identified 243 unique data sets. Of these, 40 studis were nationally representative, and 45 included children. The systematic review and meta-

analysis was subsequently updated to July 2014, to include a total of 288 unique datasets from 98 countries (Bourne et al., 2017).

To explore the different methodological approaches used in previous eye surveys, I screened these 288 citations to identify all surveys published in peer-reviewed journals, and included these in my review (See Appendix B.2 and B.3). I excluded unpublished studies, because the methodology and results were not available for scrutiny. I also excluded individual surveys that used a standardized study design (i.e. RAAB, RACSS and RESC protocol studies) because my purpose was to explore variation in study design and methodological approach; I reviewed the standardized protocol for these studies instead. For each unique, published survey, in a high or middle-income economy setting, I performed a search in PubMed using key terms, “eye”, “vision”, “visual” and the name of the survey, region and/or country, and reviewed all citations associated with that survey to identify any analyses of risk factors, quality of life or economic cost.

For each included survey, I extracted the gross national income per capita (Atlas method) for the country in the year in which the survey commenced, using trend data published by the World Bank, and entered this in a database of the included studies (World Bank, 2017b) (See Appendix B.2 and B.3). I appliied the World Bank historical classification of income thresholds by year, based on Gross National Income per capita in dollars and calculated using the Atlas Method, to categorize each survey as being undertaken in a high-income, upper middle-income, lower middle-income or low-income economy setting (World Bank, 2017a, 2017d)

2.2.2 Identification and review of cost and health-related quality of life studies

I anticipated that the identification of all studies including multi-attribute utility and cost instruments would be challenging for multiple reasons. Specifically, there was incomplete and unpredictable indexing of such studies by the National Library of Medicine because the instruments and scales used are not a consistent part of indexing methodology. Furthermore, studies used variable terminology and may not have reported the specific instrument used in the abstract or title (Terwee, Jansma, Riphagen, & de Vet, 2009). I therefore followed recommendations on the construction of a systematic search for health state utility values from the literature, aiming to achieve a search with high sensitivity (Papaioannou, Brazier, & Paisley, 2013). I combined general, instrument-specific and method-specific terms, with terms for

vision loss and six leading eye diseases causing blindness (cataract, refractive error, age-related macular degeneration (AMD), glaucoma, DR and uveitis). I searched all fields in PubMed and EMBASE, with filters including ten study types, and a date range from 01/01/1980 to 27/04/2017 (See Appendix B.4 and B.5 for search strategy). I limited the search to English language publications. I only included quality of life studies that measured visual acuity directly, and used at least one of three multiattribute utility (MAU) instruments, EQ-5D, SF-6D or HUI3, in participants with VI or eye disorders. For each of the 165 studies included in my GBD population-based survey review, I also searched PubMed to identify associated papers reporting HRQoL.

For the HRQoL literature review, I screened the search results, and the citations of included studies, to identify systematic reviews or individual studies reporting the association between measured visual acuity or vision category and utility value, in population-based studies in high-income countries. I excluded studies reporting valuation studies using vignettes and selected samples, as these do not measure HRQoL using generic health state classification with values from the general public. I excluded studies on specific eye diseases or interventions. I excluded studies reporting only raw total or subscale scores obtained from HRQoL instruments. I excluded studies reporting only vision-related quality of life and other ophthalmic patient reported outcome measures, because these instruments are scaled differently from HRQoL, from 0 (blind) to 1 (perfect vision), and do not directly yield utilities. Whilst there have been attempts to devise formulae to map between vision and health related quality of life scales, including between MacDQoL and EQ-5D (Dixon, Dakin, & Wordsworth, 2016), and NEIVFQ and EQ-5D (Kay & Ferreira, 2014; Payakachat et al., 2009), these approaches do not appear to have been widely adopted. There have been previous systematic reviews of these instruments, and a review was beyond the scope of this thesis (de Boer et al., 2004; Khadka, McAlinden, & Pesudovs, 2013; Prem Senthil, Khadka, & Pesudovs, 2017).

For the cost review, I screened the search results, and the citations of the included studies, to identify best practice guidelines for the measurement of costs relating to VI, and systematic reviews or individual population-based cost of vision loss studies reporting a monetary estimate of costs by vision category in high-income country settings. I excluded studies of small patient cohorts, as these were unlikely to be representative of individuals with VI in the general population. I excluded cost and cost-effectiveness studies of specific eye diseases or treatments. I excluded studies

using only self-reported VI, with no measurement of visual acuity. I excluded studies from middle-income and low-income countries because these were not relevant comparators to Trinidad and Tobago. I also excluded studies that did not take a prevalence approach to cost estimation.

2.2.3 Previous relevant studies in Trinidad and Tobago

I performed a PubMed literature search in May 2013 and re-ran the search to 27th April 2017 to identify titles and abstracts of previous HRQoL and cost studies published in Trinidad and Tobago, to identify whether there was any prior in-country experience with these instruments (See Appendix B.6). I also searched the grey literature for Trinidad and Tobago technical reports and working papers relating to policies or recommendations in relation to health economics and quality of life.

2.3 Literature search outcome

2.3.1 Identified population-based eye surveys

Figure 2.1 presents a 'preferred reporting items for systematic reviews and meta-analyses' (PRISMA) chart, adapted for this narrative review (Moher, Liberati, Tetzlaff, & Altman, 2009). I screened 288 studies included in the GBD 2014 systematic review and meta-analysis (Bourne et al., 2017). I identified that three standardized study protocols were used by approximately one third of all studies, and excluded the individual studies. Specifically, eighty-seven published studies used the 'Rapid Assessment of Avoidable Blindness' (RAAB) protocol (Limburg, Meester, Kuper, & Polack, 2007), or the Rapid Assessment of Cataract Surgical Services (RACSS) (Limburg, 2001). In addition, three studies used, 'The assessment of the prevalence of visual impairment attributable to refractive error and other causes in school children' (RESC), which was first developed in 2000 (Negrel, Maul, Pokharel, Zhao, & Ellwein, 2000), and subsequently updated by the WHO (Resnikoff, 2007).

A key word search in PubMed for each of the remaining 165 studies, including study name, study location, principal investigator, and "vision", identified 1460 associated articles, ranging from one publication per study, to 318 articles associated with the Australian Blue Mountains Eye Study. The characteristics of these 165 published surveys are summarized in Appendix B.2. Only 25 (15 %) were nationally representative, and only 43 (26 %) were undertaken in high-income country settings.

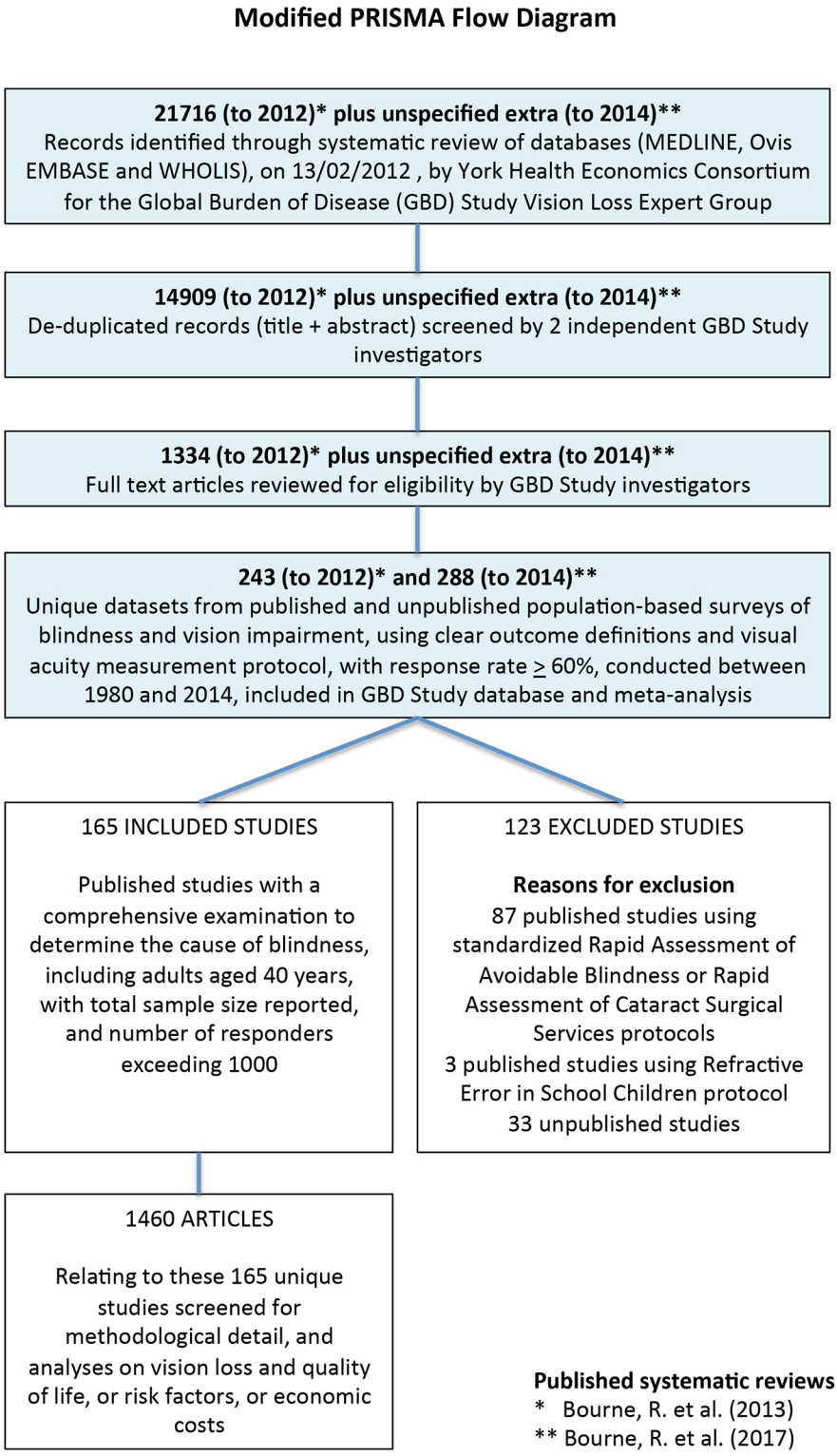

Figure 2.1 Modified PRISMA flow diagram summarizing the outcome of a search for population-based vision surveys

All age groups were included in 25 (15 %) studies, and adults aged 40 years and above were included in 38 (23 %) studies. The response rate was reported, or determinable, in 138/165 (83.6 %) surveys, and was on average 83.4 % (standard deviation (sd) 13.5). The response rate ranged from 29.1 % to 100 %, in spite of the GBD systematic review aim to exclude surveys with a response rate of < 60 % (Bourne, Price, et al., 2013). Inadvertent inclusion in the database of studies meeting the exclusion criteria probably resulted from the failure of some authors to explicitly report their response rate. A summary table, and table of the characteristics of each study are included in Appendix B.2 and B.3.

2.3.2 Identified quality of life and cost studies

Figure 2.2 presents a modified PRISMA chart summarizing the outcome of the HRQoL and economic costs search in PubMed and EMBASE (Moher et al., 2009). After screening abstracts and papers, 8 studies reported the population-based impact of VI on HRQoL in high-income countries, and 12 studies reported on costs associated with all-cause VI categories in high-income countries. Other studies provided additional context for the narrative review. The majority of excluded studies related to some aspect of cost or quality of life, including vision-related quality of life and vision related functioning, in small patient cohorts with specific diseases, or receiving specific interventions.

2.4 Narrative literature review findings

2.4.1 Prevalence and causes of vision impairment

There was variability between studies in the category definitions for VI as an outcome measure, with various definitions of VI, low vision, and blindness. Most studies used the current WHO definitions of blindness (<3/60) and VI (<6/18), but some studies defined blindness at a lower threshold of <6/60, and VI at <6/12, and in-vogue category definitions had changed over time. Some studies reported best-corrected visual acuity following refraction, some an approximation of BCVA obtained using a pinhole, and others presenting visual acuity. Most reported visual acuity in the better-seeing eye, but some reported visual acuity in the worse-seeing eye.

The meta-analysis on the prevalence of blindness and VI, undertaken by the Vision Loss Expert Group for the GBD Study, adjusted for these differences between raw datasets, and reported that, in 2010, amongst adults aged 50 years and older, the age-standardized prevalence of presenting blindness in the better-seeing eye was ten

times higher, at over 4.0 %, in Western and Eastern Sub-Saharan Africa, South Asia, North Africa and the Middle East, as compared to high-income regions, where it was less than 0.4 % (G. A. Stevens et al., 2013). In the same age group, the prevalence of MSVI ranged from 23.6 % in South Asia to less than 5 % in all four high-income regions. The ten-fold difference in the burden of blindness between low and high-income countries has multiple potential explanations. Poor sanitation, crowded living conditions, poverty, malnutrition, environmental pollution, infectious diseases (including trachoma), poor transport infrastructure, poor access to healthcare services, low educational attainment and illiteracy might all contribute to differential risk of VI.

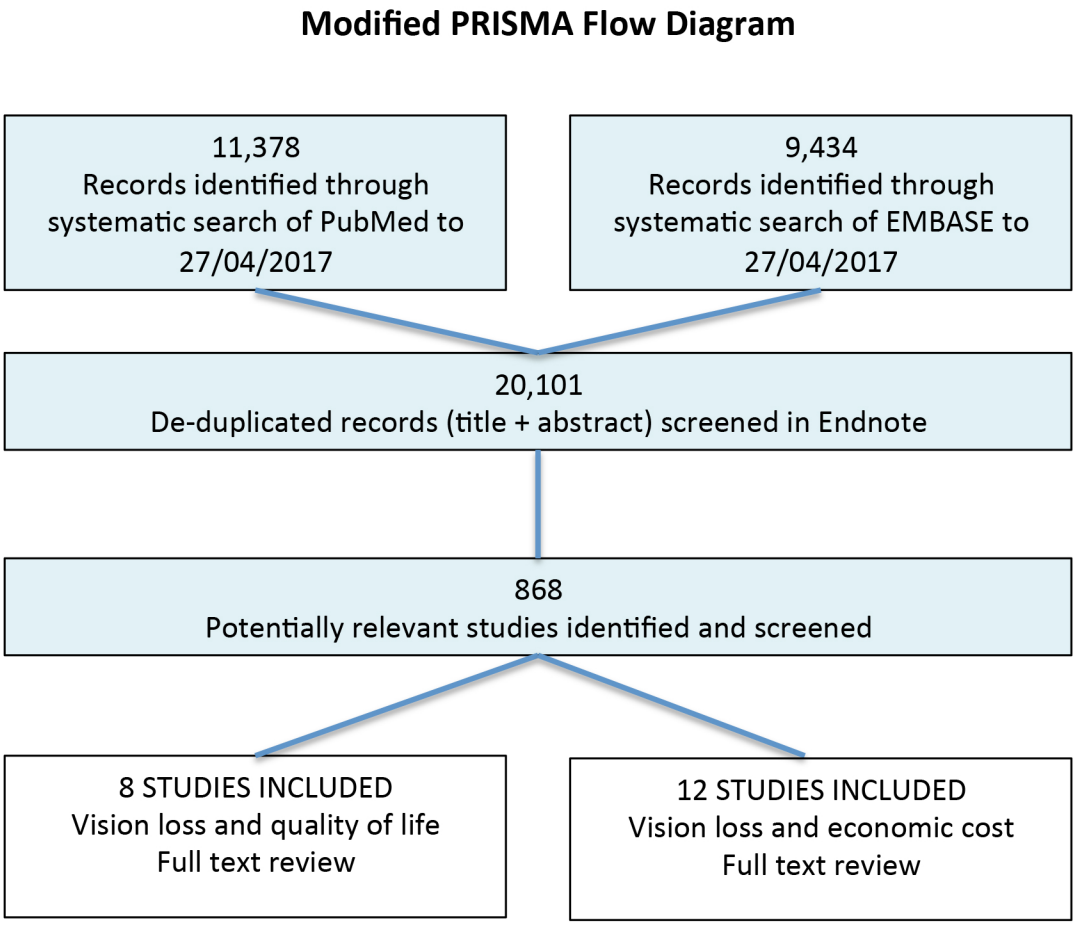

Figure 2.2 Modified PRISMA flow diagram summarizing the literature search for studies reporting the impact of vision impairment on health-related quality of life or economic cost

In the Caribbean region, the GBD model for the 2010 all-age population estimated that 0.5 % (95 % confidence interval (CI) 0.4-0.6) of the population were blind, and an additional 2.9 % (95 % CI 1.8-3.8) had MSVI (Leasher et al., 2014). Amongst adults aged 50 years and above this increased to 1.9 % (95 % CI 1.4-2.4) and 11.0 % (7.1-

13.9). The leading causes of blindness in all ages were cataract (30.2 %, 95 % CI 23.8-37.1), glaucoma (11.2 %, 95 % CI 8.0-15.1), URE (13.5 %, 95 % CI 8.1-17.8), DR (2.3 %, 95 % CI 1.7-3.4) and macular degeneration (6.1 %, 95 % 4.3-8.9). The leading causes of MSVI in all ages were URE (44.6 %, 95 % CI 36.3-51.2), cataract (15.9 %, 95% CI 11.4-21.3), glaucoma (4.3 %, 95 % CI 3.1-6.4), DR (2.0 %, 95 % CI 1.5-3.2), and macular degeneration (1.2 %, 95 % CI 0.90-1.9). However, the wide confidence intervals around these parameter estimates reflected considerable uncertainty, arising from the paucity of data available from this region for inclusion in the model. The four population-based eye surveys conducted in the Caribbean region between 1980 and 2010 are summarized in Appendix B.1, and include surveys from St Lucia (Mason et al., 1989), Barbados (Hyman et al., 2001), Havana, Cuba (Hernandez Silva, 2006), and the Dominican Republic (Limburg, Espinoza, Lansingh, & Silva, 2015).

2.4.2 Risk factors for presenting vision impairment

Approximately half of the comprehensive eye surveys conducted previously in high and upper-middle income countries explored associations between risk factors and the prevalence of specific eye diseases, whilst fewer explored risk factors for VI, either presenting or best-corrected (See Appendix B.7). All studies identified increasing age as an independent risk factor. The association with gender was more variable, with some studies, in Australia, America and Japan, reporting female sex to be a risk factor (Attebo, Mitchell, & Smith, 1996; Foreman, Xie, Keel, van Wijngaarden, Sandhu, et al., 2017; R. Klein, Klein, Linton, & De Mets, 1991; Nakamura et al., 2010). Rural dwelling was identified as a risk factor in some studies, for example in Australia and South Korea (Foreman, Xie, Keel, van Wijngaarden, Sandhu, et al., 2017; Rim, Nam, Choi, Lee, & Lee, 2014). However, there was lack of consensus on how categories such as ‘urban’, ‘rural’ and ‘remote’ were defined, with studies taking different approaches. Some studies identified groups defined by race or ethnicity to be at greater risk, including African American participants in the Baltimore Eye Survey and Salisbury Eye Evaluation Project (Munoz et al., 2000; Tielsch, Sommer, Katz, Quigley, & Ezrine, 1991), and indigenous people in The Australian National Eye Health Survey (Foreman, Xie, Keel, van Wijngaarden, Sandhu, et al., 2017). Various indicators of socioeconomic status, including income level and health insurance, were identified as risk factors in some studies (Rim et al., 2014; Tielsch et al., 1991), but not in others (Attebo et al., 1996; Livingston, McCarty,

& Taylor, 1997; Zheng et al., 2011). Lower education level and illiteracy were associated with VI in some studies, for example in Singapore, South Korea and Baltimore (Rim et al., 2014; Tielsch et al., 1991; Zheng et al., 2011). Only one previous eye survey has used causal inference techniques to explore associations with VI more fully. In the Salisbury Eye Evaluation Project, which included 8-year prospective follow-up of a population-based cohort of older adults in the USA, the investigators explored whether there was a causal effect of VI on emotional distress (Egleston, Scharfstein, Freeman, & West, 2007), or on the risk of dying (Freeman, Egleston, West, Bandeen-Roche, & Rubin, 2005).

The odds of NVI similarly increased with age on account of presbyopia. A meta-analysis from seven studies, including 14,805 people aged $\geq$ 35 years, with an overall response rate of 83.5 %, reported that older age (odds ratio (OR) 1.14, $p < 0.001$) and female sex (OR 1.12, $p = 0.027$), were significantly associated with uncorrected NVI (He et al., 2012). In these studies, lack of formal education ranged from over 60 % in Nepal and Niger, to less than 4% in urban China and Los Angeles, but was not independently associated with uncorrected NVI.

2.4.3 Impact of vision impairment on health-related quality of life

VI is expected to increase DALYs, and to decrease QALYs. In order to calculate these metrics for different vision states, it is necessary to apply a disability weight, or a utility value, respectively. Disability weights, on a scale from 0 (minimal health impact) to 1.0 (severe health impact, comparable to death), are obtained from ordinal measurement of preferences (paired health state comparisons). Advanced modeling is required to transform these data into weights. Eight studies since 1994 used a variety of approaches to estimate the disability weight associated with blindness and other levels of VI. The blindness disability weight ranged from 0.173 to 0.600 (Baltussen, Sanon, Sommerfeld, & Wurthwein, 2002; Haagsma et al., 2015; Lai, Habicht, & Kiivet, 2009; Murray, 1994, 1996; Salomon et al., 2015; Salomon et al., 2013; Stouthard, 2000) (See Appendix B.8). Controversy persists over which disability weights to use (Taylor et al., 2013). Possible reasons for the variation in disability weights are explored elsewhere (Braithwaite, Taylor, Bourne, Keeffe, & Pesudovs, 2017) (See Appendix A.3). The WHO's current preference is for prevalent DALYs, which represent one lost year of 'healthy' life (Department of Health Statistics and Information Systems, 2013; G. Stevens, personal communication, April 28,

2018). These are calculated by summing prevalent years lived with disability (YLD) and years of life lost (YLL) on account of premature cause-specific death, and use the latest WHO disability weights for categories of VI.

To explore quality of life, generic (not disease-specific), multi-attribute, health-related utility instruments have been used for over three decades. In these instruments, answers to a series of questions yield raw health state scores that can be transformed, by applying societal preference weights obtained from the general public, into a utility value, where a value of 1 represents perfect health, and states worse than death are accorded a negative value. Utility values are needed to calculate quality-adjusted life years lost or gained as a result of a disease state or health care intervention. The health state weights are obtained using cardinal preference measurement approaches, such as the time trade-off or the standard gamble.

The EQ-5D instrument was developed by the EuroQol Group almost 30 years ago (EuroQol, 1990). It has been translated into over 100 official languages and is widely used. It includes five questions on mobility, self-care, usual activities, anxiety/depression and pain/discomfort. The original EQ-5D included three levels (3L) for each question, resulting in 243 possible health states. A five level (5L) instrument has been introduced, yielding 3125 health states (Herdman et al., 2011). A further three bolt-on items have been developed for EQ-5D more recently, including a vision bolt on (Yang et al., 2015). The preference weights for the EQ-5D-3L were originally obtained from a UK population sample using time-trade off, with regression analysis to estimate a value for each of the health states (Dolan, 1997). Valuation sets have since been obtained through various approaches in many other countries, and differences between valuation sets are generally small (Bernert et al., 2009). The original EQ-5D scale using the UK valuations extended from -0.59 to 1.00 (Dolan, 1997), and a more recent UK value set for the EQ-5D-5L extends from -0.28 to 0.95 (Devlin, 2016). The mean minimally important difference reported in a review of eight studies in different conditions was 0.074 (range -0.011 to -0.140) (Walters & Brazier, 2005). A visual analogue scale (VAS) is recommended for use alongside the five EQ-5D questions. This consists of “thermometer” scale from 0 to 100, on which the respondent is asked to indicate the point that best represents their own health on that day.

The Short Form (SF-6D) includes 11 items in 6-domains, including physical functioning, role limitations, social functioning, pain, vitality and mental health (Kharroubi, Brazier, Roberts, & O'Hagan, 2007). This instrument yields 18,000 health states. Items were extracted from a larger, 36-item instrument, which was developed for the Medical Outcomes Study (Brazier, Roberts, & Deverill, 2002; Ware & Sherbourne, 1992). Preference weights were obtained from a UK population-representative sample and models derived to provide utility values for each health state. The SF-6D scale extends from 0.29 to 1.00, and a review of eight studies in different conditions estimated the mean minimally important difference to be 0.041 (range from 0.011 to 0.097) (Walters & Brazier, 2005).

The Health Utilities Index was developed in the early 1980s in Canada to assess outcomes in low birth weight infants (Torrance, 1986). Six domains were captured by HUI version two (HUI-2) including sensation, mobility, emotion, cognition, self-care, pain and fertility (Horsman, Furlong, Feeny, & Torrance, 2003). Each has between three and five levels, resulting in 24,000 possible health states. Valuations were originally obtained from Canadian parents using standard gamble and a visual analogue scale. Version three (HUI-3) expands the sensation domain into vision, hearing and speech, and yields 972,000 health states (Furlong et al., 1998). Valuations were elicited from the general public in Canada and a utility function estimated for each of the domains, and for the overall instrument.

Three decades of experience with these instruments highlights that they yield differing utility values in head-to-head comparisons. In seven health conditions, not including vision disorders, SF-6D was found to have a smaller range and lower variance in values than EQ-5D (Brazier, Roberts, Tsuchiya, & Busschbach, 2004). Differences resulted in estimation of different quality-adjusted life year savings for the same intervention and thus differing conclusions in relation to cost-effectiveness. As a result, some funding bodies are explicit about which instrument and valuation method they prefer. In England, the National Institute for Health and Care Excellence (NICE) prefers EQ-5D, but even amongst NICE Technology Appraisals, there is considerable variation in the methods used to select and incorporate utility values in economic models (Tosh, Longworth, & George, 2011). Population valuations obtained from the general public, rather than patients, or experts, are also generally preferred.

My search for the use of these generic preference-based measures of HRQoL in previous population-based studies of vision disorders identified two systematic

reviews and six population-based studies in high-income countries. The first systematic review explored the psychometric properties of HUI-3, SF-6D and EQ-5D in VI and three other conditions (Longworth et al., 2014). This study included an exploratory validation study and proposed three 'bolt-on' items for hearing, tiredness and vision, valued using time trade-off. The authors reported that the psychometric performance of EQ-5D in VI varied according to cause, whilst HUI-3 performed well in all causes of vision disorders. There was limited data with which to assess the performance of SF-6D. The second systematic review, which searched six databases for published studies and the Euroqol website in August 2010, identified 31 published studies, but none from population-representative samples (Tosh, Brazier, Evans, & Longworth, 2012). This study reported that the EQ-5D was used most frequently, and that many, but not all, studies reported reduced utility values with increasing severity of VI. The included studies were a mixture of case-control, prospective cohort, and cross-sectional studies, mostly in specific eye disease patient groups. Only one study reported utility by vision category, which ranged in diabetic patients from 0.83, in those with 6/6 to 6/9 vision, to 0.53 in those with 6/60 to 3/60 vision, and 0.34 in those with counting fingers vision (Lloyd et al., 2008). Tosh et al. (2012) also reported that the magnitude and statistical significance of the association between utility loss and VI varied between instruments. Meta-analysis was not possible on account of study heterogeneity, and the authors observed that many studies failed to control for age and other conditions, which may be important confounding factors.

My search of the published articles associated with 165 population-based eye and vision surveys confirmed that only six included assessment of HRQoL (See Appendix B.9). EQ-5D-3L was used in the Singapore Epidemiology of Eye Disease Survey (X. Wang et al., 2014) and EQ-5D-5L was used in the Korean NHANES (Park et al., 2015). SF-36 was used in the Blue Mountains Eye Study (Swamy, Chia, Wang, Rochtchina, & Mitchell, 2009), and the Shihpai survey in Taiwan (Tsai et al., 2004). SF-12 was used in the Los Angeles Latino Eye Survey (Varma, Wu, Chong, Azen, & Hays, 2006) and a survey of older adults in Cuenca, Spain (Esteban et al., 2008). I did not identify any population-based eye surveys utilizing HUI-3. To date, only the Singapore Eye Survey directly explored the association between VI and EQ-5D utility value (X. Wang et al., 2014). Wang et al. (2014) reported the marginal disutility of VI to range between 0.0239 and 0.0297 in different ethnic groups, after adjustment for important covariates, and calculated the QALYs lost.

To investigate the association between vision level and HRQoL at the population-level, it is important to gather data on numerous other potential causal or confounding variables. Multiple population-based studies, for example, in South Australia (McCaffrey, Kaambwa, Currow, & Ratcliffe, 2016), Spain (Garcia-Gordillo, Adsuar, & Olivares, 2016), Japan (Shiroiwa et al., 2016), Germany (Hinz, Kohlmann, Stobel-Richter, Zenger, & Brahler, 2014), and the UK (Feng, Devlin, & Herdman, 2015), have established normative values for the EQ-5D-5L instrument, and identified risk factors for reduced quality of life. Response rates ranged from 59 % to 64 %. The mean utility values ranged from 0.900 in Spain to 0.913 in Germany, whilst the mean VAS scores ranged from 75.7 in Spain to 91.5 in Germany. Full health was reported by 62.4 % in Spain, but by 42.8 % in South Australia. These studies are summarized in Appendix B.10.

The most consistent risk factor for reduced HRQoL was older age (Feng et al., 2015; Garcia-Gordillo et al., 2016; Hinz et al., 2014; McCaffrey et al., 2016; Shiroiwa et al., 2016). Other factors in some studies included female sex (Feng et al., 2015; Garcia-Gordillo et al., 2016; Hinz et al., 2014), lower education level (Feng et al., 2015; Shiroiwa et al., 2016), lower income (Shiroiwa et al., 2016), and unemployment (McCaffrey et al., 2016). Previous population-based studies using the EQ-5D-3L identified significant disutility associated with various chronic diseases (Sullivan, Lawrence, & Ghushchyan, 2005). Some of these factors, including older age, female sex, lower education level, socioeconomic status and comorbid disease, have also been found to be independent predictors of VI in previous population-based surveys.

Utility data from population-representative samples were not expected to have a normal distribution, because a majority of people will have a utility value of 1.0 or close to 1.0. Currently, there is no consensus on the best analysis approach to use. Some advocate the use of one and two-part beta regression models (Basu & Manca, 2012). Others advocate use of an adjusted limited dependent variable mixture model (Hernandez Alava, Wailoo, & Ara, 2012). Ordinary least squares (OLS) regression analysis, with robust standard error estimation, has also been recommended for EQ-5D utility analysis, in preference to alternative approaches such as Tobit, censored least absolute deviation (CLAD) and two-part models (Pullenayegum et al., 2010). Following a simulation of the alternatives, Pullenayegum et al. (2010) argue that OLS with robust standard errors (RSE) produces asymptotically unbiased estimation of regression parameters and valid confidence intervals, regardless of distributional

assumptions (including non-normality and heteroscedasticity), because OLS fits a model for mean utility and not the whole distribution.

2.4.4 Impact of vision impairment on economic cost

Economic impact is another metric of potential interest to policy makers. From the 1970s, new approaches to support resource-allocation decision making have been developed, guided by consideration of cost in relation to anticipated benefits, and grounded in utility theory (Weinstein & Stason, 1977). The economic costs of treating and preventing avoidable VI, and of managing untreatable VI merit exploration in different unique population contexts, because the economic impact may be complex and difficult to predict. For example, a person with myopia in a low-income country may present with blindness and amblyopia, having never incurred any direct costs for vision correction, but with significant indirect costs associated with lost education and employment opportunities, direct costs associated with falls, and informal care costs impacting on the wider family. In contrast, a person with myopia in a high-income country might present with normal vision and no indirect costs, but high direct costs associated with purchase of contact lenses, spectacles or laser refractive surgery. In both settings, there may be intangible costs associated with the vision state, its treatments, or its sequelae, which are difficult to predict. For example, spectacles might increase HRQoL, by correcting avoidable VI. Or wearing spectacles might be associated with a decrement in HRQoL, resulting from perceived loss of social status or attractiveness. Programmes to support and enable those with VI in their daily lives might be funded and sophisticated in some countries, or rudimentary in others, and these political and health system factors may also influence the intangible effects of VI in different contexts.

An important decision in costing is whether to use a top-down or a bottom-up approach. Simply put, in a top-down analysis, population size, disease prevalence, and overall cost and utilization data associated with each item at the national level are used to estimate unit costs. In a bottom-up analysis, detailed individual-level data on disease status, service utilization, and health care costs permits direct estimation of unit costs associated with a particular health state. Previous research suggests that when these approaches are compared, comprehensive bottom-up costing is likely to be more accurate (Hendriks et al., 2014). However, gathering this data is time demanding, expensive and context-specific (Wordsworth, Ludbrook, Caskey, &

Macleod, 2005). Where items to include in the costing are missing, a mixed approach can be used, and this has been done in previous cost of vision loss studies (Gordon, Cruess, Bellan, Mitchell, & Pezzullo, 2011). However, care needs to be taken in mixing these fundamentally different types of cost (Cunnama et al., 2016). Many previous cost of vision loss studies have used top-down modeling (Green et al., 2016). More bottom-up cost of vision loss analysis have been recommended (Frick, 2012). Comparatively few cost studies use country-specific, population-based data to work up cost estimates in both the visually impaired and normally sighted population (Taylor et al., 2006). Given the variability in approach, cost of illness studies vary significantly in total cost estimates, even for the same diagnosis in the same country, raising questions about their comparability, accuracy, usefulness and validity (Bloom, Bruno, Maman, & Jayadevappa, 2001).

Prevalent costs relate to the costs associated with prevalent cases over a defined period, as compared to incidence-based cost analysis, which describes the longitudinal or lifetime costs to individuals or cohorts. Prevalence-based costs provide a snapshot with which to assess the impact of VI on a population, potentially in comparison to the impact of other diseases (Frick et al., 2010). Prevalence-based cost of illness studies identify potential savings that might result from eliminating avoidable problems such as VI at a population-level at a specific time. They may also help in service planning, in monitoring the impact of policies, and in making decisions about the allocation of research funds between disease areas. The societal perspective is most consistent with economic public welfare theory, and includes all costs regardless of who bears them. Other, less comprehensive, perspectives include that of the Government, health care system, or patients. An economic evaluation, such as a cost-benefit analysis or cost-effectiveness analysis, was beyond the scope of this thesis, but the NESTT dataset aimed to provide a foundation for future modeling studies.

My literature search identified one paper highlighting the need for empirical research on best practices for economic evaluation in ophthalmic outcomes research (Frick, Clark, Martin, & Grover, 2006). My search identified subsequent consensus guidelines developed by the Vancouver Economic Burden of Vision Loss Group, resulting from an expert workshop convened under the auspices of the Association for Research in Vision and Ophthalmology and the International Agency for the Prevention of Blindness in 2007 (Frick et al., 2010). The guidelines recommended that cost of vision loss studies include a comprehensive list of cost items under each

category, with transparency and justification around any discount rates applied, sensitivity analysis, and a clear specification of the perspective of the analysis (Frick et al., 2010). The categories included direct monetary expenditure on health care (medical and other), monetary expenditure on non-health care items (such as low vision devices, refractive correction and travel costs), loss of family member productivity, loss of patient productivity, loss of patient wellbeing, transfer payments and deadweight losses. Transfer payments are defined as payments between economic agents, and include social welfare payments made for distributional purposes rather than as payment for goods or services. Deadweight losses are the cost to society that results from inefficient allocation of resources, which arise when markets are not in equilibrium. Examples include the cost of administering certain transfer payments, the lost utility for the customer resulting from raising taxation revenue, or the cost to society of introducing a price ceiling or floor, such as the minimum wage (Koberlein, Beifus, Schaffert, & Finger, 2013).

The Consensus guidelines on cost of vision loss studies have three key limitations. Firstly, they did not propose standardization of question formats or survey instruments under different categories. Secondly they did not consider the relative merits and limitations of bottom-up and top-down approaches. Thirdly, they did not make a clear case for whether, or how, to place a monetary valuation on welfare losses such as QALYs lost or DALYs. This latter issue results in considerable variation in total cost estimates from studies between, and even within, countries (Hirth, Chernew, Miller, Fendrick, & Weissert, 2000). Cost of illness studies typically do not attach monetary values to the QALY or DALY impact of a disease, although some do attach monetary valuations to productivity losses arising from morbidity and premature mortality (Koberlein et al., 2013). When economists do attempt to place a value on life, for example in cost-benefit analyses, they typically use revealed or stated willingness-to-pay preference studies to estimate the value of statistical life (VSL), which is the amount that groups of individuals are willing to pay for a marginal change in their likelihood of death (T. R. Miller, 2000). In a literature review including 69 studies from 13 countries, Miller found significant variation in estimates of the VSL (T. R. Miller, 2000). Specifically, the VSL in 1995 US dollars ranged from $620,000 in South Korea, to $8,280,000 in Japan, with a mean VSL in the USA of $3,472,000, and in the UK of $2,281,000. A more recent study estimated the 2015 VSL for 189 countries including Trinidad and Tobago, which had a VSL estimate of $3,035,000 (Viscusi, 2017). In the UK, the Department of Transport has for many years placed a value on the prevention of a road fatality, currently £1.8m (2016 UK £s), and this has become the

de facto value used across many government departments when valuing the benefits of safety measures that reduce fatalities (Department for Transport, 2007). An alternative approach, used by the National Institute of Health and Care Excellence in England and Wales, is to set an explicit value on what it is willing to pay for the health benefits yielded by health interventions. At present, standard interventions costing less than £20k per QALY gained are generally considered good value for money, and interventions costing above £30k per QALY gained poor value for money (Paulden, 2017). Higher thresholds have been introduced for end-of-life technologies (£50,000 per QALY) and very rare diseases (£100,000 to £300,000 per QALY) (Paulden, 2017). The methodology behind these figures is not clear, but the figures are interpreted as the opportunity cost to the NHS (health gains foregone from existing activities) of committing current funding to newly approved interventions (National Institue of Health and Care Excellence, 2013). In the USA, public financing thresholds ranging from US$50,000/QALY to US$200,000/QALY (R. Braithwaite, Meltzer, King, Leslie, & Roberts, 2008) have been proposed.

My search identified two systematic reviews by the same research group. One followed the PRISMA statement to identify studies on the economic burden of visual impairment and blindness in high-income country settings (Koberlein et al., 2013). This review was developed from an earlier systematic review (Koberlein, Beifus, & Finger, 2012). The authors reported that PubMed and Ovid databases were searched between May and June 2012 (without reporting the search start and end dates) using terms relating to cost and vision loss. They also searched the references of included studies. To allow comparison between studies, the authors transformed cost data to 2011 values, using a country-specific GDP deflator, and converted to US dollars using purchasing power parities (PPP). In the later review, the authors identified 22 interventional, non-interventional and cost of illness studies reporting direct, indirect and intangible costs associated with VI and blindness. Some studies were retrospective and others prospective. Some gathered self-reported cost and utilization data in small patient series or case-control groups, whilst others used large population-based surveys. Others modeled cost using national data sources such as medical expenditure data, or private insurance and Medicare claims data. Overall, this review reported that VI and blindness had considerable cost impact. Studies including intangible effects found that these had the greatest economic impact, as a result of loss of independence, quality of life, and excess morbidity, but the impact was hard to quantify in monetary terms, and only six studies attempted this. Otherwise, the highest costs related to productivity loss, both for the affected

individuals and their carers, followed by formal caregiving costs, recurrent hospitalization, and the use of medical and supportive services. Some studies reported QALY loss (Frick, Gower, Kempen, & Wolff, 2007), others reported DALYs (Cruess, Gordon, Bellan, Mitchell, & Pezzullo, 2011; Roberts et al., 2010), others reported increased 5-year mortality (McCarty, Nanjan, & Taylor, 2001), and increased risk of falls and injury (Bramley, Peeples, Walt, Juhasz, & Hansen, 2008; Wood et al., 2011). Only a few studies explicitly reported the cost perspective adopted. No studies adhered to the consensus guidelines (Frick et al., 2010). Meta-analysis was not possible on account of study heterogeneity, and the authors stated that, "*No two studies used the same methodology or reported exactly the same outcomes*". A limitation of this review was that the search methodology was not truly systematic, identified only 390 articles, and was insufficiently specified to permit replication.

My search identified ten national, prevalent cost of vision loss studies in high-income countries. These studies estimated costs in Canada (Gordon et al., 2011), the UK (Pezzullo, Streatfeild, Simkiss, & Shickle, 2018), the USA (Frick et al., 2007; Javitt, Zhou, & Willke, 2007; Rein et al., 2006; Wittenborn et al., 2013), Australia (Taylor et al., 2006), France (Lafuma, Brezin, Fagnani, et al., 2006), Taiwan (M. T. Wang et al., 2011), and Japan (Roberts et al., 2010). One study reported on the cost perspective of individuals and their carers (Lafuma, Brezin, Fagnani, et al., 2006), three adopted a health care system perspective (Gordon et al., 2011; Javitt et al., 2007; M. T. Wang et al., 2011), and six adopted a societal perspective. One used primary data collected by interview from a large, population representative sample of both the institutionalized and non-institutionalized population (Lafuma, Brezin, Fagnani, et al., 2006), and the remainder used secondary or mixed data sources. Six studies placed a monetary value on intangible losses (Cruess et al., 2011; Frick et al., 2007; Pezzullo et al., 2018; Roberts et al., 2010; Taylor et al., 2006; Wittenborn et al., 2013) (See Appendix B.11).

My review of 165 previous population-based eye and vision surveys found that very few included an economic analysis. A study linked to the Melbourne Visual Impairment Project (VIP) explored the reliability of monthly vision-related personal cost diaries completed by 104 visually impaired people prospectively over 12 months (Lamoureux, Chou, Larizza, & Keeffe, 2006). These included four categories of expense, namely a) medicines, products and equipment, b) health and community services, c) informal care and support and d) other expenses. This study reported no significant difference between 12-month data and estimates extrapolated from 1-

month, 3-months and 6-months. However, the authors recommended a minimum 3-month diary collection to minimize variance.

In summary, the literature suggested no consensus on the items to include in the NESTT cost and eye care service utilization survey.

2.4.5 Previous studies in Trinidad and Tobago

A PubMed search in February 2013, updated to 27 April 2017, of all terms relating to quality of life and cost, combined with Trinidad or Tobago, and limited to humans, yielded 1064 hits. After screening titles and abstracts, only a few were directly relevant. This search revealed that published health economics research from Trinidad and Tobago was limited, in spite of health economics postgraduate training at the University of the West Indies in Trinidad, which commenced before 1996 (James & Waddington, 1996). One study, published in 2008, asserted that cost-effectiveness analysis instruments with the potential to assist in resource allocation decision-making, have not been tested in Caribbean countries (Hector et al., 2008). This study assessed the validity of the Quality of Well-being scale on a sample of the non-institutionalized population, and advocated use of this instrument by health decision makers for comparison between different health interventions and health conditions. In a subsequent study, preference weights were derived in Trinidad and Tobago for the 65 health states in the Quality of Well-being scale, in a probability sample of 119 adults (51% response rate), and close similarity to US preference weights was reported (Hector et al., 2010). One study reported pilot data on the development of an EQ-5D-3L value set for Trinidad and Tobago (Bailey, 2013), and this was subsequently completed (Bailey, Stolk, & Kind, 2016). An earlier study by the same authors reported preliminary findings of an investigation into the relationship between Hofstede's dimensions of national culture and EQ-5D value sets (Bailey & Kind, 2010). There were no prior studies relating to quality of life or economic costs associated with vision disorders in Trinidad and Tobago.

2.5 Discussion

2.5.1 Literature review summary

This narrative review synthesized the key literature on the prevalence and causes of VI globally and within the Caribbean region, and identified a paucity of relevant,

contemporary VI prevalence data. This supported the rationale for the NESTT to be undertaken in 2013-2014. Consideration of the risk factors associated with VI in previous population-based eye surveys revealed key variables to include in the data collection instruments and analyses, seeking to identify any groups within the population who were, on average, at greater risk. Few previous population-based eye surveys included measurement of the association between VI and HRQoL. Whilst various MAU instruments were available, only the EQ-5D had been used to obtain utility values associated with vision loss in previous population-based surveys (X Wang et al., 2014; Park et al., 2015), thereby permitting potential comparison of QALY loss resulting from vision loss between countries. Furthermore, the recent availability of a more sensitive 5-level version of EQ-5D, and the development of a Trinidad and Tobago value set by local academics, coincident with the planning phase of the NESTT project, made EQ-5D the preferred MAU instrument for this study. Inclusion of this outcome variable in NESTT offered a novel opportunity to advance understanding of the association between presenting VI and HRQoL, and the potential confounding factors important to any association at a population-level. Such insights from large population-based eye surveys aimed to bring greater clarity to the largely clinic-based, heterogeneous, ophthalmic HRQoL literature. Very few prior population-based surveys had included cost and utilization data to permit bottom-up national estimation of the economic impact of VI, and inclusion of this element in NESTT presented a further opportunity to add value above the traditional remit of a prevalence survey.

2.5.2 Limitations

Whilst this review was comprehensive and structured, it did not aim to be a systematic review, and therefore did not include a search of unpublished studies, conference abstracts, or additional databases. Specifically, the other two major bibliographic databases, Scopus and Web of Science, were not included, as these require a subscription, and a more comprehensive search for studies was not essential for my purpose. PubMed remains an optimal tool in biomedical electronic research (Falagas, Pitsouni, Malietzis, & Pappas, 2008).

The GBD Study systematic review, which informed my *a priori* expectations around prevalence and causes of VI, had a number of potential limitations. The most important limitation was the lack of detailed appraisal of the quality of included

studies, and the resulting inclusion in meta-analysis of heterogeneous studies, some of which may be of poor methodological quality and at high risk of bias. In addition, summation of results from surveys is challenging when these use different definitions of VI and cause, different measurement protocols and equipment, variable analysis approaches, and take variable account of potential sources of bias, such as non-response. Such factors might undermine the reliability of the prevalence estimates. Whilst evidence-synthesis and meta-analysis can be valuable, especially in providing guidance to address major gaps in the literature, it does not lessen the value of obtaining good quality primary epidemiological data.

This chapter provided a narrative review of the key literature pertinent to the aims of this thesis. In the next chapter, I review the various methodological approaches used in previous population-based eye surveys to inform the NESTT study design.

3

METHODOLOGY REVIEW

This chapter considers the key epidemiological and statistical concepts pertinent to cross-sectional observational surveys, and explores methodological issues specific to surveys of vision and eye disease. A full methodological review of 165 published studies contained in the Global Vision Database (GVD) (Bourne et al., 2017), excluding individual standardized RAAB, RESC and RACSS studies, and unpublished studies, was beyond the scope of this chapter. Instead, a narrative summary of the key methodological approaches and issues identified in a selection of surveys (See Appendix B.12) is presented.

3.1 Sampling approaches

3.1.1 A census

A census attempts to include all individuals in the target population. This sampling approach was used in the Beaver Dam Survey of a township of approximately 6000

inhabitants in Wisconsin, USA (R. Klein, Klein, et al., 1991), and the Blue Mountains Eye Survey of two postcode districts in Sydney, Australia (Attebo et al., 1996).

3.1.2 Probability sampling – simple and systematic random sampling

When a population is too large or dispersed for a census to be feasible, a probability sample can be drawn from a target population, using various techniques. Probability sampling techniques, which have been commonplace in survey methodology since 1953, ensure that each person in the population has a known, non-zero, chance of selection (Hansen, 1953). In simple random sampling, n individuals or dwelling units are selected at random from a sampling frame including all individuals in the target population. Sampling frames might include Government lists of social security or national insurance numbers, or comprehensive landline telephone or address lists. This sampling approach was used in the Singapore Malay Eye Survey, which covered a survey area of 110km^2 (Foong et al., 2007), and the national Barbados Eye Survey, which covered a survey area of 430km^2 (Leske, Connell, Schachat, & Hyman, 1994). Since the n selected individuals are dispersed at random within the geographic territory of the target population, simple random sampling is not usually feasible when the territory is large.

In a related approach, systematic random sampling, a sampling interval, *k*, is calculated to ensure selection of an adequate sample size, a random start between 1 and k is chosen, and the constant *k*th interval is applied from that start to the sampling frame to select units, which could be individuals or units within which further sampling is necessary. The sampling interval is defined as N/n, where N is the total population size, and n is the desired sample size. Some surveys chose a systematic random sample of households in the penultimate stage of multi-level sampling, and such geographical dispersion is statistically preferred to a compact segment of geographically contiguous households and individuals. A rigorous approach is needed to select a single person within a selected household, and one approach to maintain random selection was devised by Kish (Kish, 1949). However, this approach is more logistically complicated, time-consuming and expensive than selecting a compact segment of contiguous households, which is the preferred approach in the final sampling stage of the Rapid Assessment of Avoidable Blindness survey protocol (Limburg et al., 2007). When the sampling frame includes a cumulative total of individuals grouped into units, systematic selection with probability proportional to

size (PPS) reduces variance of survey estimates relative to equal probability sampling schemes, and yields a 'self-weighting sample' for analysis. PPS sampling is useful when the units, such as administrative districts or postcode areas, are unequal in population size, and avoids the need to stratify by unit size. Many previous eye surveys used PPS sampling, for example the Aravind Eye Survey, India (Thulasiraj et al., 2003), the National Blindness and Low Vision Survey of Bangladesh (Bourne, Dineen, Modasser Ali, Mohammed Noorul Huq, & Johnson, 2002), the Nigerian National Blindness and Visual Impairment Survey (Dineen et al., 2008) and the Pakistan National Blindness and Visual Impairment Survey (Bourne et al., 2005).

In probability sampling interviewers are generally required to make at least three callbacks to selected households where members may be temporarily unavailable. Moreover, interviewers are usually trained to make extra efforts to convince reluctant households to agree to be interviewed, since these households should not be substituted, and each eligible 'no contact' impacts the response rate.

Sampling without replacement means that each individual has only once chance of being selected, and their selection probability will broadly be defined by n/N, where n is the sample size and N is the total population size from which the sample is drawn. Sampling with replacement means that a person can be selected more than once: N^n-tuples of people have equal selection probability.

3.1.3 Multi-stage, stratified and cluster sampling

In multi-stage sampling, sampling is done sequentially across two or more hierarchical levels, for example, at the district level, then the village level, then the household level, and finally within the household. It is important to maintain probability sampling at each stage to facilitate straightforward analysis.

In stratified sampling, available information in the sampling frame is used to partition the target population into mutually exclusive and exhaustive strata within which sampling units are selected. Stratification by geographic unit, by age, by certain characteristics of census tracts, such as socioeconomic status or race, or by multiple factors, is common. Many previous eye surveys, especially those covering large geographic regions in which access to eye services may vary considerably, have stratified by urban-rural residence, including the National Blindness and Low Vision

Survey of Bangladesh (Bourne et al., 2002), the Pakistan National Blindness and Visual Impairment Survey (Bourne et al., 2005), The Andhra Pradesh Comprehensive Eye Survey (Dandona, Dandona, Naduvilath, Nanda, & McCarty, 1997), and the Nigerian National Blindness and Visual Impairment Survey (Dineen et al., 2008). Others have stratified by age, including the Singapore Malay Eye Survey (Foong et al., 2007), and Salisbury Eye Evaluation Survey (Rubin et al., 1997). Others have stratified by geographic district, including the Aravind Eye Survey (Thulasiraj et al., 2003). Others have stratified by the racial characteristics of census tracts, including the Baltimore Eye Survey (Tielsch, Sommer, Witt, Katz, & Royall, 1990), and Salisbury Eye Evaluation Survey (Rubin et al., 1997), or by the indigenous versus non-indigenous population (Foreman, Keel, Dunn, et al., 2017). Disproportionate allocation to strata permits the sampling of a greater number from one stratum of interest who might form a minority of the target population, relative to others.

Cluster random sampling is another commonly used sampling strategy, in which clusters of houses or individuals are selected in one sampling stage. Single stage cluster sampling was used in the Baltimore Eye Survey (Tielsch et al., 1990), and within a multi-stage design in many other eye surveys. This approach is resource-efficient because it reduces geographic dispersion of the sample, making it easier and faster for survey staff to visit. Efforts to sensitize the population to the survey, and engage with community leaders, might also be more effective. However, since individuals living in close proximity are more likely to share certain characteristics with each other, than randomly selected individuals would, the sample size has to be increased by a factor to account for the reduced variability. This factor, the '*design effect'* (DEFF), describes how much precision is lost through the use of a more complex sampling strategy than simple random sampling, and is calculated as the ratio of the variability in the parameter estimate resulting from the sampling design, and the variability in the estimate that would be obtained from a simple random sample of the same size (Vandenbroucke et al., 2007). DEFF can only be calculated from survey data, and investigators unfortunately often fail to report it in the results publication. The design effect from surveys of the same outcome, using similar cluster size, in similar populations, can be used to plan the sample size of a new survey. If blindness, as the outcome variable, is evenly distributed amongst clusters then DEFF will be close to 1.0, but if it varies strongly between clusters then it can be much higher (> 5). Selecting clusters of constant size, which are as small as possible, minimizes the design effect.

3.1.4 Non-probability sampling

Some previous surveys have used approaches in the final sampling stage that may result in a non-probability sample. In non-probability sampling, the chance of an individual in the population being selected is not known, and could be zero, because subjective methods are used to decide which individuals are included in the sample. For example, quota and convenience sampling approaches could result from the spin-the-bottle-line-of-random walk recruitment if all recruitment occurs in a single visit, as reported in the National Blindness and Low Vision Survey of Bangladesh (Bourne et al., 2002), the Pakistan National Blindness and Visual Impairment Survey (Bourne et al., 2005) and the Nigerian National Blindness and Visual Impairment Survey (Dineen et al., 2008). Non-probability sampling is susceptible to significant bias from interviewer behavior. Enumerators are more likely to bypass 'difficult' houses – for example those with locked gates, threatening dogs, or hostile residents - leading to substitutions of non-responding households with responding households whose residents may differ in important, but unknown ways.

3.2 Selecting a sample size

The median target sample size reported by 127 studies (out of 165 studies) selected for review from the Global Vision Data base (Bourne et al., 2017), was 4800 (interquartile range (IQR) 2481 to 7272), and ranged from 278 to 72,044 (See Appendix B.2 and B.3).

The sample size for simple random sampling is given by:

$$N = (z)^2 \, p \, (1.0-p) \, / \, [(b)(p)]^2$$

Where p is the anticipated prevalence, b is the desired level of relative precision, and z is 1.96 for the 95 % confidence interval. For household demographic surveys, the United Nations recommend a level of relative precision of 5-10 %, if budget allows, or else 12-15 %, whilst RAAB suggest 20 % (Department of Economic and Social Affairs, 2005; Limburg et al., 2007). The optimal cluster size for vision loss surveys, based on estimation of the design effect, has previously been explored (Limburg, Kumar, Indrayan, & Sundaram, 1997). Based on extensive survey experience, the RAAB survey protocol recommends a DEFF of 1.4 for a cluster size of 40, 1.5 for 50 and 1.6 for 60 (Limburg et al., 2007). The National Blindness and Low Vision Survey

of Bangladesh assumed a DEFF of 1.5 for cluster sizes of 100 (rural) and 50 (urban) (Bourne et al., 2002). The Pakistan National Blindness and Visual Impairment Survey assumed a DEFF of 2.0 for cluster sizes of 100 (rural) and 50 (urban) (Bourne et al., 2005). The Nigerian National Blindness and Visual Impairment Survey assumed a design effect of 2.0 for clusters of 50.

This formula, combined with the design effect, and adjustment for anticipated non-response, has been used by the majority of previous single and multi-stage eye surveys. Table 3.1 compares the sample size needed in simple versus cluster sampling, for three different levels of prevalence and relative precision.

Table 3.1 Comparison of the sample size (n) required for various degrees or precision (b) around estimates of the prevalence (p) of blindness in simple random sampling (SRS) versus cluster sampling (with design effect 1.5)

SRS design

p blindness	n if b +/- 10%	n if b +/- 20 %	n if b +/- 30%
0.5 %	76,448	19,112	8,494
1.0 %	38,032	9,508	4,226
1.5 %	25,227	6,307	2,803

Cluster design

p blindness	n if b +/- 10%	n if b +/- 20 %	n if b +/- 30%
0.5 %	114,672	28,668	12,741
1.0 %	57,047	14,261	6,339
1.5 %	37,839	9,460	4,204

3.3 Potential sources of bias

There are many potential sources of sampling bias in observational research (Sackett, 1979). Non-response bias, selection bias and measurement bias are of particular concern in an epidemiological survey.

3.3.1 Non-response bias

"The effect of non-respondent bias upon relative odds is obvious and serves as the basis for repeated admonitions both to achieve response rates of at least 80% and to compare responders and non-responders" (Sackett, 1979).

The average response rate of 138 out of 165 published studies included in the GVD, excluding RAAB and RESC studies, was 83.4 % (sd 13.5), and ranged from 29.1 to 100 % (See Appendix B.2 and B.3). Analysis of this data raised concern at both ends

of the spectrum. In total, 27 studies did not publish their response rate explicitly, and on closer examination, some of these had a very low response rate. As a result, a number of studies were included in the GVD, which ought to have been excluded for a response rate <60 %. Furthermore, six studies had an apparent response rate of 100 %, which might indicate convenience sampling, and therefore questionable external validity (the extent to which the sampled population are representative of the target population). Significant variation in the response rate was apparent by income group (likelihood-ratio test (LRT) $Chi^2 = 27.38$, $p<0.001$) (See Figure 3.1) and by world region (LRT Chi^2 36.7, $p<0.001$) in simple ordinal and nominal logistic regression models, respectively (See Figure 3.2). The mean response rate in high-income countries (n = 41) was 74.4 % (sd 18.4), compared to 84.1 % (sd 7.9) in upper-middle income countries, 86.9 % (sd 8.9) in lower-middle income countries and 88.3 % (sd 8.2) in low-income countries.

Collecting key data on non-responders does not reduce bias, but may offer some reassurance, if responders and non-responders do not differ in key characteristics. Alternatively, this data might offer insight into the size or direction of the potential effect of non-response bias on parameter estimates. The Melbourne VIP study collected information from non-responders on age, sex, socioeconomic status, education level, first language, and reason for non-response (Livingston, Lee, McCarty, & Taylor, 1997). The Salisbury Eye Evaluation Survey collected information on age, gender, race, education level, marital status, living arrangement and self-reported vision status (Rubin et al., 1997).

3.3.2 Sampling bias

In addition to non-response, other errors of non-observation include sampling error (commission and omission) and coverage error. Errors of commission arise from the erroneous inclusion of a non-eligible person. Friends and family visiting an enumerated household might erroneously report being an eligible household member if they want to be included in the survey. Errors of omission arise from erroneously excluding an eligible participant from consideration. This source of bias is more likely in surveys that use non-probability sampling approaches, where there is greater risk that whole households who are not at home at the time of enumeration, or who do not open the door, are excluded in error. Door-to-door surveys depend on the honest answers of household members about eligibility. The person answering the door on behalf of the household may neglect to report an eligible person whom they do not think would want to participate.

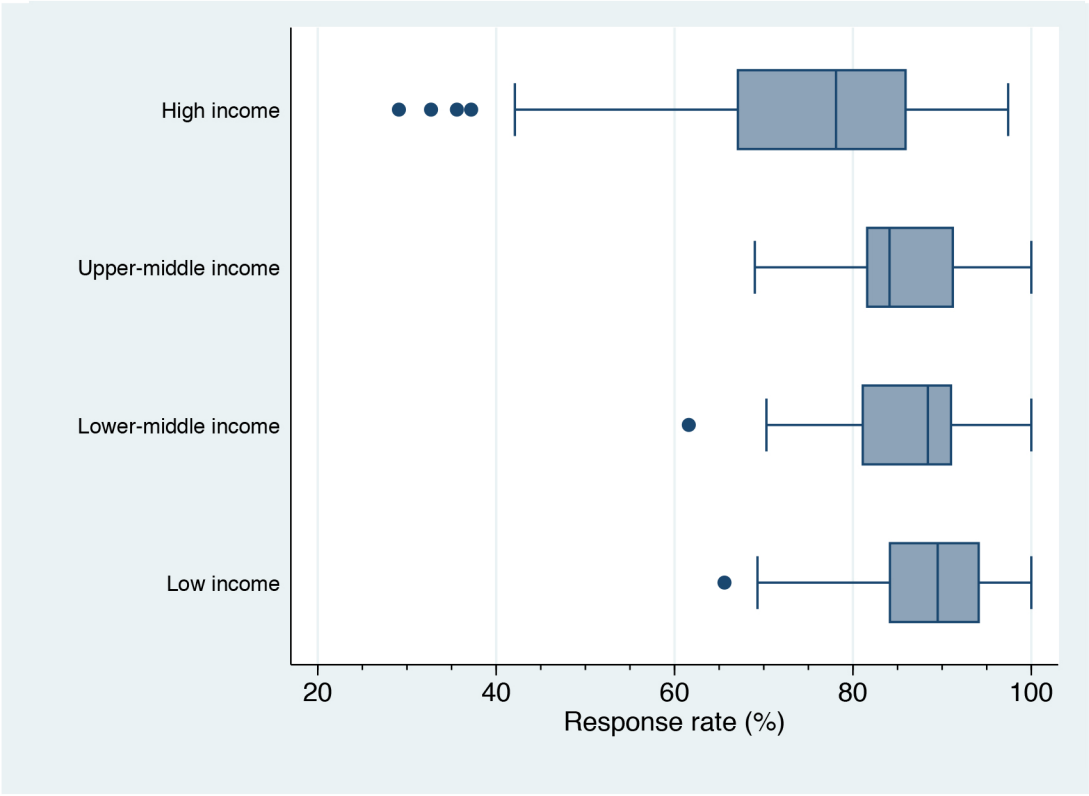

Figure 3.1: Box plots showing response rate in 138 eye surveys, compared to GNI per capita in the country for the epoch start year

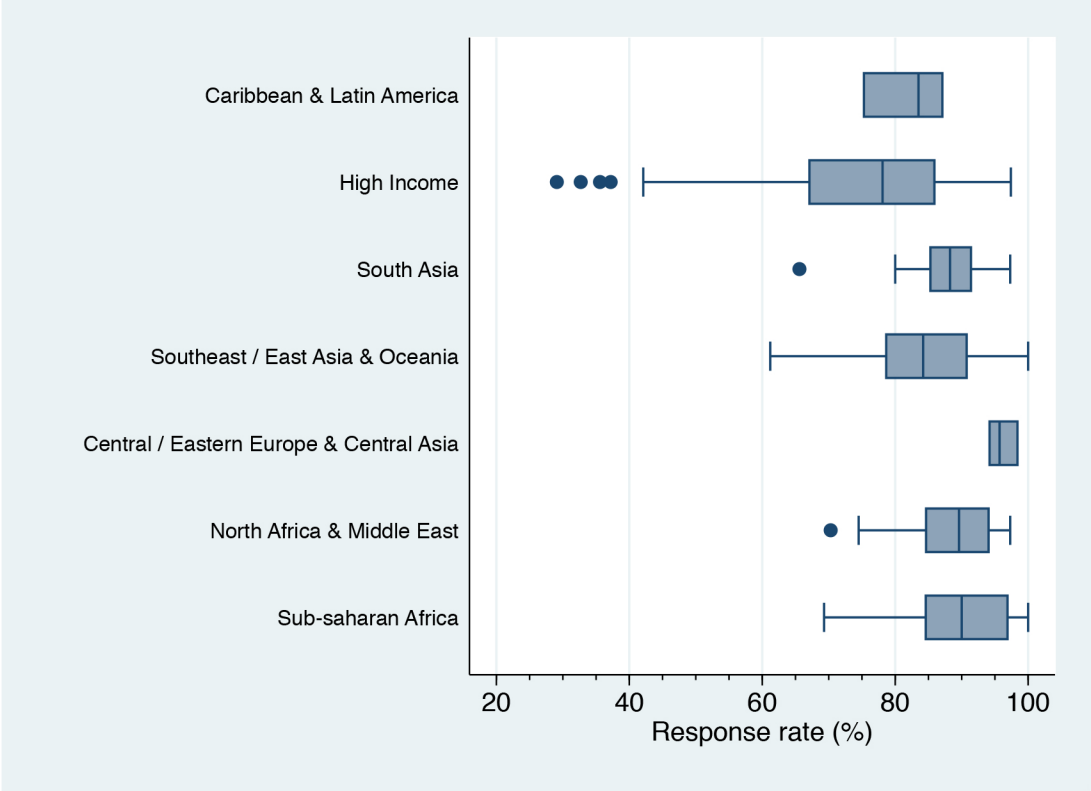

Figure 3.2: Box plots showing response rate in 138 eye surveys, by world region

Coverage error is a source of bias resulting from the population actually sampled not coinciding with the target population. Coverage indicates how well the sampling units included in the sampling frame account for the survey's target population. If the sampling frame does not contain all the units in the target population, because, for example, it is out of date, or if units, which are selected from the frame, are not included in the fieldwork stage, then there could be under coverage of the population. If the frame contains duplicate units, and if the same individuals are sampled more than once, or if extra individuals are included erroneously, then there could be over-coverage. If members of the target population are excluded erroneously from the sampling frame then there is non-coverage. For example, if the survey explicitly aims to sample the whole population, rather than the non-institutionalized population, but excludes those who reside in nursing homes. These errors impact the external validity of the survey – the extent to which the parameter estimates can be generalized to the target population or to other populations who are similar. Gathering basic data to permit comparison of the characteristics of study participants and non-responders, and comparison of the former to the latest census characteristics, has been recommended in consensus guidelines to improve reporting quality of observational studies (von Elm et al., 2007).

3.3.3 Measurement bias

Errors of observation, including measurement error, impact the internal validity of the survey. The risk of this type of bias can be reduced by specifying the protocol for all elements of the study in a manual of operations and standard operating procedures. Training, staff supervision, and quality assurance exercises are important to ensure all survey staff are adhering to measurement protocols.

3.4 Analysis considerations

3.4.1 Prevalence estimation

The prevalence is the proportion of people in the population who have VI or eye disease at a specified point or period in time. If a sample of n is selected with equal probability from a universe of N then the sampling fraction, F, is given by n/N, and is equal to the selection probability. In a systematic random sample, the sampling fraction F, is given by 1/i, where i is the sampling interval. F in stratified and multi-stage designs can also be calculated if selection is random and the selection probabilities are known. In this situation, it is possible to use design-based estimation

of population proportions, totals, means and ratios, and standard errors can be calculated.

Most statistical theory assumes that the population from which a sample is drawn is infinite. Survey sampling theory assumes finite population sampling, which has multiple ramifications. Variance is estimated from the sample, and a finite population correction (fpc) factor is used to assess the error in estimating a mean or a total, as a result of the fact that not all data in the finite population are observed. This fpc results in an adjustment to the variance estimate.

Post-stratification is an analysis tool to group similar elements for analysis, thereby reducing the variance of the survey estimates. If the sampling approach specified in the study design results in individuals having unequal probabilities of selection, then this needs to be corrected in the analysis. If there was substantial non-response, or under-representation amongst certain groups, then weighting is used to try to help compensate for this.

There does not appear to be consensus around appropriate analysis approaches, or application of consistent standards during the journal peer review process. For example, some surveys, including the Barbados Eye Survey (response rate 84 %) do not adjust for non-response, whilst others with comparable response rates do. There is no discussion in the ophthalmic epidemiology literature on how much non-response is too much, which leaves unanswered two key questions. When does it become inappropriate to report un-weighted data? And at what level of non-response is survey data so potentially biased as to be without publication merit? Studies selected for inclusion in the GVD had a response rate $\geq$ 60 %, but this threshold has not been justified explicitly (Bourne et al., 2017).

Age or sex-specific estimates are crude estimates presented in age and sex subgroupings, whereas age or sex-standardized estimates adjust the crude estimates from the sampled population to the age or sex structure of another population, using direct or indirect approaches. The reference population could be the national census population of the same country, or a standard WHO world population. Standardization to an international reference population facilitates cross-country comparison, by adjusting for differing age structures between countries.

3.4.2 Risk factor analysis

Causal inference is based on assumptions that cannot be derived from observations alone (Greenland, Pearl, & Robins, 1999). Comparing earlier and more recent studies, the complexity and sophistication of statistical analyses performed has increased over time. Earlier studies typically explore crude, or age and sex-specific prevalence estimates, and adjust for a few variables at most. More recent surveys, such as the Korean National Health and Nutrition Survey (Rim et al., 2014), Singapore Malay Eye Survey (Zheng et al., 2011), Los Angeles Latino Eye Survey (Varma, Ying-Lai, Klein, & Azen, 2004), and Australia National Eye Health Survey (Foreman, Xie, Keel, van Wijngaarden, Sandhu, et al., 2017), use multivariable logistic regression analysis to model the association between VI and larger numbers of independent variables, whilst controlling for potential confounders. Confounders are variables that are associated with the variable of interest, independently associated with the outcome, and are not on the causal pathway. Care is needed not to adjust for too many confounders in regression models estimated by maximum likelihood, as this can result in bias, especially in small samples or samples with a low prevalence of the outcome of interest.

Monte-Carlo simulation has been used to evaluate the effect of the number of events per variable (EPV) which are analysed in logistic regression analysis, and it has been found that when the EPV is less than ten, regression coefficients are biased in both positive and negative directions, the sample variance of the regression coefficients is both under and over estimated, and paradoxical associations (significance in the wrong direction) are increased (Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996). To illustrate this, a study of 4000 people would have an EPV per variable of 4 (40/10) if the prevalence of blindness is 1 %, but an EPV per variable of 40 (400/10) if the outcome of interest has a prevalence of 10 %. Blindness risk factor analysis including many co-variables may therefore be inappropriate in all but the largest population-based surveys, whilst smaller surveys can support analysis of risk factors for presenting VI.

The correlation of aggregated population-based data is not equal to the correlation of individual data, because the former takes into account both covariance within an individual and covariance between individuals, with respect to multiple variables. Extreme caution is needed in deducing conclusions about the risk of VI at an individual level from population-level data. It is important to avoid the ecological

fallacy; a term coined by Selvin to conceptualize the faulty reasoning that can arise from the interpretation of population-level data at the individual level (Selvin, 1957). Observation of such associations with VI at a population-level is interesting, but does not infer causation. Variable x will be marginally associated with VI if, ignoring chance, either x causes VI, or VI causes x, or they share a common cause. Even if there is no marginal association between x and VI, i.e. if the variables are independent in the population, they may be conditionally associated within strata of some other variable, y, if y is an effect of both x and VI. There are various, complementary approaches to modeling causal inference from observational data (Greenland & Brumback, 2002; Hernan, 2004). Regression models can deliver estimates of expectations of observed outcomes and these can be used to derive estimates of conditional causal effects, providing certain assumptions are met. The assumptions are of conditional exchangeability (within strata of x the mean potential outcome is the same in exposed and non exposed individuals), consistency of the exposure, and the absence of interference (the exposure of one individual does not affect the potential outcome of another). In observational studies, consistency and exchangeability are not guaranteed.

There are numerous approaches to iterative selection of regression models, including forward, backward and stepwise approaches in linear regression, and model fitting using maximum likelihood in logistic regression (Hamilton, 2007). Judgment is needed to select the optimal model, informed by prior knowledge, exploratory data analysis, and the purpose of the analysis (explanatory or confirmatory). The aim of model selection is to select a model sufficiently complex to explain the observed data well, whilst being simple enough to interpret, without over-fitting the data.

Linear regression analysis aims to minimize the sum of squares (the distance between the observed data and the fitted regression line (squared to avoid negative differences). The backward step-down approach starts with a complex full model and sequentially removes variables that have the least damaging effect on the model (e.g. the largest p-value) until no non-significant variables remain. The forward selection approach starts with no variables in the model and sequentially adds variables with the highest R-squared, until further additions do not improve model fit. The stepwise approach is a modification of the forward approach, which retests, after addition of each variable meeting a pre-specified level of significance (e.g. $p<0.10$), the significance of all variables in the model, removing those with a p-value above a second specified tolerance (e.g. $p<0.05$). Statistical significance in single variable

analysis is one reason for inclusion and assessment of a variable in the multivariable model, but other important considerations include a priori knowledge from review of the literature about established independent risk factors and confounding variables for the variables under consideration, and the extent of missing data for each variable.

3.5 Considerations specific to eye and vision surveys

3.5.1 Visual acuity measurement

International, standardized methods and conditions for the measurement of visual acuity with high contrast optotypes at photopic levels, in both clinical and epidemiological settings, have been defined since 1984 (Visual Functions Committee of the International Council of Ophthalmology, 1984). There are numerous visual acuity charts, but the Early Treatment of Diabetic Retinopathy Study (ETDRS) chart, using Snellen letter optotypes with logarithmic progression and constant crowding, is the gold standard, and is well suited to statistical analysis. Tumbling E optotype charts have been used in many population-based surveys in low literacy settings. Some population-based surveys, including the standardized RAAB and RACCS surveys, have used single letter 'E' optotypes to screen for those unable to see 6/18 and those unable to see 6/60. This is time-efficient, and permits task shifting to staff with limited training, with low risk of error. However, single optotypes yield a different measure of acuity on account of the absence of crowding. With a tumbling E optotype, which has four orientations, the chance of guessing correctly is 25 %, which is much higher than for the ETDRS letters. A further weakness of obtaining a non-continuous measure of visual acuity is that the accuracy of categorization for those with visual acuity close to the category threshold may be suboptimal, and more detailed categorization, or revision of categories for different comparisons over time or between studies is not possible. Measurement protocols, including approaches to measuring and controlling test distance and illumination, and stopping rules, vary between studies, and are not always fully reported.

Measurement of near visual acuity has not been standardized. Few population-based eye surveys have previously included near visual acuity measurement, with only 4 studies identified in the first GBD study review (Bourne, Price, et al., 2013). In clinic settings, there has traditionally been a focus on reading speed and reading acuity, but these yield inconsistent measures. Research tools such as the MNRead are very slow to administer and require a skilled staff member and optimal test conditions.

3.5.2 Definition of vision categories

Definitions of VI vary over time and between countries and surveys. Most surveys define vision according to visual acuity in the better-seeing eye for the purpose of prevalence reporting. A widely used definition is presented in Table 3.2, but in some surveys, blindness is defined as acuity < 6/60 rather than < 3/60.

Table 3.2: Categories of vision impairment used in the Global Burden of Disease Study

Category of vision	LogMAR visual acuity	Snellen visual acuity
Normal vision	≤ 0.30	≥ 6/12
Distance mild vision impairment	0.32 to 0.48	< 6/12 but ≥ 6/18
Distance moderate vision impairment (MVI)	0.50 to 1.00	< 6/18 but ≥ 6/60
Distance severe vision impairment (SVI)	1.02 to 1.30	< 6/60 but ≥ 3/60
Distance blindness	≥1.32	< 3/60
Near vision impairment	0.32 to 1.30 at 40 cm (plus ≤ 0.30 for distance)	< 6/12 but ≥ 3/60 at 40 cm (plus ≥ 6/12 for distance)

KEY: LogMAR Logarithm of the minimum angle of resolution

3.5.3 Definition of cases of eye disease

There are multiple approaches to defining cases of the most frequent eye diseases in epidemiological surveys, and for the most part, a lack of international consensus or standardization. The following sections summarize the more commonly used definitions and the equipment required to gather survey data.

3.5.3.1 Cataract

A diversity of lens grading systems exist, requiring use of direct ophthalmoscopy, slit lamp biomicroscopy, or lens photography, which have been used in previous surveys (See Appendix B.13) (Age-Related Eye Disease Study (AREDS) Research Group, 2001; Chylack et al., 1989; Chylack et al., 1993; B. E. Klein, Klein, Linton, Magli, & Neider, 1990; Mehra & Minassian, 1988; Sparrow, Bron, Brown, Ayliffe, & Hill, 1986; Taylor & West, 1989; Thylefors et al., 2002). Wong and colleagues have highlighted

the lack of consensus on how to define a cataract, both within and between different lens grading systems (W. L. Wong et al., 2013). Direct comparison of cataract prevalence between studies is therefore challenging. A few studies have developed conversion scores between cataract classification systems, for example, between LOCSIII and Wisconsin (W. L. Wong et al., 2013), and between LOCSIII and the Oxford Clinical Cataract Classification System (Hall, Thompson, Deane, & Rosenthal, 1997).

3.5.3.2 Uncorrected refractive error

Uncorrected or under-corrected refractive error (URE) exists if there is a discrepancy between the visual acuity measured in the presenting state, and that measured after refraction, with best correction in place. Earlier studies typically measured best-corrected visual acuity, but not presenting acuity, and as a result the importance of URE as a leading global cause of avoidable VI has only been appreciated in recent years. There is a lack of consensus and standardization around the threshold to define a case of URE. Some studies, including the Singapore Eye Survey (T. Y. Wong et al., 2008), define URE as having a 2-line improvement, of at least 0.2 logarithm of the minimum angle of resolution (logMAR). Other surveys, including the Timor-Leste survey (Ramke, du Toit, Palagyi, Brian, & Naduvilath, 2007), define URE as visual acuity worse than 6/18, improving to at least 6/18 with pinhole.

3.5.3.3 Age-related macular degeneration

Four grading systems for AMD have been used in many previous eye surveys (See Appendix B.14) (Bird et al., 1995; Davis et al., 2005; R. Klein, Davis, et al., 1991; Seddon, Sharma, & Adelman, 2006). A recent expert panel report that there is no universally agreed, precise definition of the AMD phenotype, for either clinical or research purposes (Ferris et al., 2013), and propose a new classification system. All classification systems require fundus photography, and none have yet included optical coherence tomography (OCT) imaging in the case definition.

3.5.3.4 Glaucoma

Most surveys designed to ascertain the prevalence of glaucoma include automated visual field assessment, grading of fundus photographs of the optic disc, with measurement of the cup-to-disc ratio, measurement of intraocular pressure, and

medical or treatment history in the case definition. The 1988 WHO Prevention of Blindness protocol defines glaucoma as a horizontal cup-disc ratio > 0.5, and intraocular pressure (IOP) ≥ 30 mmHg, or the eye being 'stone hard on digital palpation' (WHO/Prevention of Blindness, 1988). The Rotterdam study investigators highlight that different definitions of probable glaucoma yield 12-fold differences in prevalence estimates (Wolfs et al., 2000). The vertical cup-to-disc ratio alone is felt to be "probably insufficient" to define glaucoma cases in epidemiological surveys (Crowston, Hopley, Healey, Lee, & Mitchell, 2004). The International Society of Geographical & Epidemiological Ophthalmology (ISGEO) consensus definition was proposed for use in epidemiological research to define glaucoma damage (Foster, Buhrmann, Quigley, & Johnson, 2002). This combines assessment of structural features exceeding specified limits, with a 'gold standard' definition of glaucomatous field loss. A systematic review of population-based primary angle closure glaucoma (PACG) surveys in Asian adults reveals that a majority (25 out of 29 studies) use the ISGEO definition (Cheng, Zong, Zeng, & Wei, 2014). Another systematic review of PACG in Europeans reports a similar finding (Day et al., 2012). However, the ISGEO classification system requires formal perimetry and intraocular pressure measurement on all participants in the population, which are time consuming and resource intensive tests, in order to determine normal population parameters. An index for staging glaucomatous damage using both field and OCT data may emerge in the future (Medeiros et al., 2012).

3.5.3.5 Diabetic retinopathy

There are numerous DR grading systems, and some of the more frequently used in previous eye surveys are summarized in Appendix B.15 (Diabetic retinopathy study, 1981; Early Treatment of Diabetic Retinopathy Study [ETDRS], 1991). With feature-based DR screening being commonplace in clinical practice internationally, there is greater understanding of the similarities and differences between different grading systems, which permits more ready comparison. Whilst OCT imaging is used in clinical practice to define intervention thresholds for diabetic macular oedema, it is not yet included in any epidemiological case definition.

3.5.3.6 Other eye diseases

Less frequent eye diseases are typically defined by the International Classification of Disease codes, and clinical judgment, where the survey team includes an

ophthalmologist (WHO, 2010). One important issue with surveys that have a simple examination protocol, or survey teams that do not include an ophthalmologist, or which use basic equipment that does not permit detailed examination of the dilated fundus, is that the category of 'other' causes of VI is typically large.

3.5.3.7 Avoidable vision loss

The concept of avoidable vision loss in population-based eye surveys became well-established through the WHO Programme for the Prevention of Blindness (PBL) and Deafness program, and its associated field examination protocol (WHO, 1988). The definitions in this protocol (see Table 3.3) have been adopted in countless surveys. The WHO/PBL definition for the primary cause of vision loss focuses on the prioritization of eye diseases that were most curable, preventable or treatable in 1988, with a particular focus on low-income settings. Treatments have evolved significantly since then, for example, intravitreal anti-VEGF agents for wet AMD, diabetic macular oedema and cystoid macular oedema. There is now greater access to, and improved long term vision outcomes from, corneal, glaucoma and vitreoretinal surgery. These definitions may require review, especially in relation to their application within upper-middle and high-income economy settings.

Table 3.3: World Health Organisation Prevention of Blindness definitions (1988)

Category	Definition
Primary ocular disorder contributing to vision loss in eye	That disorder which resulted in other disorders, or 2) that which was the more significant cause of vision loss, or 3) that causing vision loss which was most amenable to treatment or prevention
Principal ocular disorder responsible for vision loss in person	The primary disorder affecting one or both eyes, when this is the same. When the primary ocular disorder differs between the eyes, it is defined as 1) that most amenable to treatment, or 2) that most amenable to prevention, or 3) that which was responsible for vision loss in the better seeing eye. The following ranking is recommended: 1) uncorrected aphakia, 2) refractive errors/amblyopia, 3) cataract, 4) preventable corneal opacities and phthisis, 5) primary glaucoma, 6) anterior uveitis, 7) posterior segment disorders
Principal cause of vision loss in the person	The principal ocular disorder, and underlying cause where applicable, are selected

3.6 Logistical considerations

Investigators of some previous comprehensive eye surveys published detail on their fieldwork logistics, which offer helpful insight for planning a new survey. For example, in the Blue Mountains Survey (sample n = 4433), at least five separate calls were made to houses at different times of day, on different days of the week, at least three letters were sent to non-responding households (Attebo et al., 1996), and the fieldwork took 23 months. The 1985-1988 Baltimore Eye Survey (n = 7104) planned a minimum of ten contacts at varying times of day, and days of the week, before declaring a dwelling unit non-responsive (Tielsch et al., 1990). This survey achieved a household enrollment response rate of 99.2 %, and 95.8 % to a short enumeration interview at the doorstep. The comprehensive medical and ocular examination, including perimetry and imaging, was conducted in neighbourhood enrollment centres, and achieved a response rate of 79.2%, over 3.5 years of fieldwork. The 1993-1995 Salisbury Eye Evaluation Survey (n = 3821) allowed 2-hours for an in-home interview, and a further 4 to 5 hours for comprehensive clinic examination (Rubin et al., 1997), and the fieldwork took 24 months.

Few epidemiological eye surveys have evaluated the effectiveness of their recruitment methods. The cost-effectiveness of different recruitment strategies is reported for the Melbourne VIP (Livingston, Guest, Bateman, Woodcock, & Taylor, 1994). Their pilot study found that doorstep interviews were more costly, but significantly more effective (76 % participation) than telephone interviews (47 %) ($p < 0.001$). A second phase of recruitment targeting initial non-responders was necessary to raise the response rate from 61 % to 89 %. Involvement of more senior field staff in phase 2 recruitment, at the doorstep and via telephone, was cheaper and more effective than repeat doorstep visits by the initial enumeration staff. Financial incentives were not cost-effective, but increased the response rate a little, and resulted in inclusion of people who would otherwise not have participated. The disadvantages of doorstep recruitment were reported to be the cost of salaries and travel. The advantage was the personal contact, which provided motivation, reassurance, and validity to the study. The disadvantages of a telephone recruitment approach were silent lines, no contact with those lacking phones, a risk of incorrect numbers, and more limited opportunity for the survey staff to develop rapport with potential participants. The advantages were that it was cheaper and more time-efficient. Not offering home visits to reluctant or frail participants was noted to reduce

response rates. The Melbourne VIP survey also reported that a short distance between households and survey examination centres was an important factor enhancing the response rate. The 1973-1975 Framingham Eye Study in the USA reported that too great a travel distance between households and screening centres was a factor in the low response rate, of 66.2 % (Leibowitz et al., 1980).

3.7 Summary of considerations for NESTT study design

This methodological overview provided insight into the rationale for the different sampling designs and sample size choices used in previous eye surveys. Factors related to the availability of a sampling frame, the geographic dispersion of the target population, and the resources available for the survey (time, staff, equipment). Consideration of different potential sources of bias highlighted important considerations for the study design, logistical planning, manual of operations, standard operating procedures, and training. In all studies, it was necessary to balance the desired data, with the finite resources and time available to the project. Previous comprehensive eye surveys in high-income settings indicated that substantial resource investment was necessary in the enumeration phase to achieve a reasonable response rate. My review identified considerable variability in the quality of reporting of previous surveys, and the importance of adhering to guidelines for the Strengthening of the Reporting of Observational studies in Epidemiology (STROBE) (von Elm et al., 2007).

Based on careful consideration of previous population-based eye survey methodology, weighing up the pros and cons of different approaches in the specific context of Trinidad and Tobago, and balancing the desire to answer as many questions as possible about the population's vision status, risk factors and ocular health, with the need to achieve a study within a fixed financial budget and time limit, I developed the study design for the NESTT.

The key factors driving the sampling strategy included the best available sampling frame, the large geographic area to be covered by the survey, and the limited staff and financial resources available to the study. The most informative sampling frame available to NESTT was the visitation record from the most recent 2011 Population Census. This partitioned the total non-institutional population into enumeration districts (EDs), and detailed the number of buildings and households in each ED, but did not include individual level data (e.g. name, social security number, address,

telephone number). Given the geographic territory to cover, of over 5000km^2, a simple random sample of individuals was not feasible, whereas a systematic random sample of clusters defined by enumeration district was resource-efficient. Furthermore, the unequal population size within each ED made probability proportional to size methods ideal, to yield self-weighting data for analysis. A multi-stage cluster design was selected to obtain a probability sample of individuals from the two islands.

Those elements of the study design pertinent to answering the objectives of this thesis are outlined in the next chapter.

4

MATERIALS and METHODS

This chapter reports the design and implementation of the NESTT, limiting the description of materials and methods to those aspects of the study that directly address the aims of this thesis.

4.1 Study design

The NESTT was a population-based, cross-sectional, national survey of the non-institutionalized population aged 5 years and above, and this thesis focuses on participants aged 40 years and above only.

4. 2 Study Objectives

4.2.1 Primary objectives

The primary objectives were:

- To estimate the prevalence and causes of presenting blindness and VI amongst adults aged 40 years and above in Trinidad and Tobago in 2014. In addition, to estimate the proportion of potentially avoidable VI.

4.2.2 Secondary objectives

1) To explore risk factors associated with presenting DVI and NVI
2) To explore the impact of presenting VI on HRQoL, adjusting for other independent predictors, and to estimate the quality adjusted life year loss attributable to VI in adults 40 years and above in 2014
3) To explore the economic cost of blindness and VI at a societal level in adults 40 years and above in 2014

4.3 Participants

The total population of Trinidad and Tobago was 1,328,019 in the latest Population and Household Census in 2011, and the non-institutionalized population was 1,322,546 (Ministry of Planning and Sustainable Development, 2012). An eligible person was defined as someone resident in Trinidad or Tobago for more than 6 months, who was aged 40 years or above at their last birthday, and who was a usual resident of the selected household. The latter was defined as sleeping in the household most nights of the week and sharing at least one daily meal with other household members (Ministry of Planning and Sustainable Development, 2012). People currently abroad or in an institution (e.g. hospital, prison) and not anticipated to return within one month were excluded.

4.4 Sample size

The Barbados Eye Survey suggested an expected prevalence (p) of best-corrected blindness of 1.7 % (Hyman et al., 2001). The sample size was chosen to achieve a desired level of absolute precision (d) of 0.5 % in the width of the 95 % confidence interval, and a design effect (DEFF) of 1.4.

$$n = \frac{1.96^2\, p\,(1 - p)(DEFF)}{d^2}$$

The sample was adjusted for a potential non-response of 20 %, based on the Barbados Eye Survey (Leske et al., 1994), to generate a target sample of 4147 people aged 40 years and above.

4.5 Sampling frame

The visitation record of the 2011 Population and Household Census was used as the sampling frame. This was stratified into two islands containing five regions (one in

Tobago, four in Trinidad), 21 municipalities, and 2820 mutually exclusive enumeration districts, of which 2671 were in Trinidad and 149 were in Tobago. An enumeration district (ED) was defined as a geographical area comprising approximately 150 to 200 households (Ministry of Planning and Sustainable Development, 2012). For each ED, the population size, gender distribution, age distribution, and number of buildings and households were known. There were 442,928 households in Trinidad and 24,454 households in Tobago. A sample of 120 ED clusters, each containing 35 eligible people, achieved the target sample size (n = 4200).

4.6 Sampling strategy: multi-stage randomized cluster

4.6.1 Primary sampling unit: the enumeration district

Random cluster sampling selected 120 EDs as the primary sampling units, by probability proportional to size (PPS) methods (Bierrenbach, 2008). PPS sampling was chosen to reduce bias in survey estimates, because the EDs differed in population size. The mean population size was 472 people (SD, 189) ranging from 1 to 1655 people. Each person in the population had an equal probability of being selected. The distribution of the 120 clusters is shown in Figure 4.1, and reflected the geospatial population density.

4.6.2 Secondary sampling unit: compact segment of households

A detailed field map of each ED was obtained from the Central Statistical Office (CSO). Consecutive buildings were numbered, and the ED was divided into a number of segments determined by the population size of the ED, with each segment containing approximately 100 people. One segment was selected at random using Microsoft Excel. The segment's buildings were marked clearly on the map and given to the enumerator, who was instructed to proceed from the first marked building to consecutively numbered buildings.

4.6.3 Tertiary sampling unit: eligible individuals

The enumerator attempted to contact everyone aged 40 years and above living in selected households to ascertain eligibility. If residents were not home on the first visit, a leaflet detailing the study was left, including a contact telephone number for the lead survey ophthalmologist. Enumeration continued until 35 people, aged 40 years and above, living in consecutive households were enumerated. If residents were not at home or refused, information on eligibility was sought from neighbours or

relatives. Sampling was with non-replacement. The sample therefore included eligible people who couldn't be contacted, despite at least three attempts by both enumeration and screening teams, and those who refused participation. This strategy was chosen to minimize selection bias.

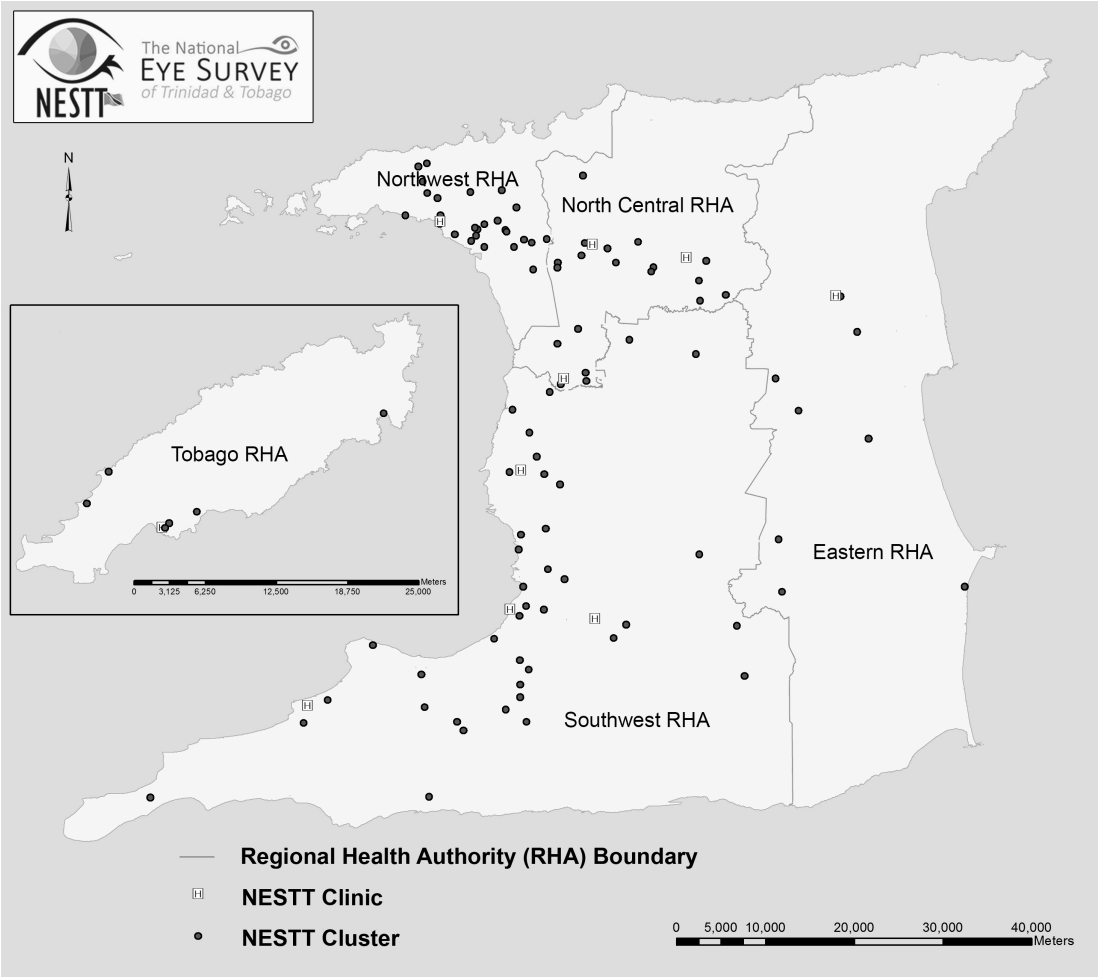

Figure 4.1: Map of Trinidad and Tobago illustrating the location of the 120 NESTT clusters and the 11 regional NESTT clinics

4.7 Recruitment strategy

Recruitment of participants followed a detailed strategy, refined following a series of pilot studies in the field. Eligible people who agreed to participate were given a full verbal and written description of the study. Both enumeration and screening teams visited each cluster on multiple occasions, at differing times and on different days, including weekends. If eligible for clinic, a written appointment date and time was given, and participants were telephoned or sent a mobile phone message with a reminder the preceding day. Non-attenders were re-contacted by telephone up to

three times to offer another appointment. Telephone scripts were developed to ensure consistent delivery of key information. People who refused enumeration were contacted by the clinical team in a further attempt to recruit them, and if still not interested were documented as 'refused'. In addition to an individualized communication strategy, various additional measures were taken to increase participation. These included information releases on national television, in the newspaper, on the radio, on websites and via social media (Facebook), sensitization of eye and primary care professionals to the study, and engagement with community leaders, where these could be identified.

4.8 Staff, training and logistics

The enumeration team included a field supervisor, and 18 local Central Statistics Office-trained enumerators who had each completed at least one National Census. The clinical team included me and a local ophthalmologist-in-training, three optometrists, two nurses, two enrolled nursing assistants, and two data entry staff. Clinic appointments were offered to participants five days a week from 7am to 3pm, including Saturdays. Pairs of the clinical team were released from clinic to participate in a rota to screen vision in the community, typically working from 11am to 7pm (dusk), including Saturdays and Sundays, with assistance from six part-time vision screeners. I oversaw the project delivery and managed the clinical and vision screening teams, with the assistance of a part-time administrator, and managerial oversight from the Principal Investigator and Chair of the Steering Committee.

Staff completed training, which was led by the Principal Investigator, the Field Supervisor, a Low vision specialist and me. The CSO-trained enumerators were given detailed enumeration manuals, and underwent one day of NESTT-specific training followed by supervised fieldwork in all clusters. The clinical and screening teams had dedicated training for one month. Technicians from Topcon (Topcon Corporation, Tokyo, Japan) and Medilex (Medilex LLC, 8253 NW 56th St.Doral, FL 33166, USA) also trained the team in the operation of the ophthalmic equipment. I wrote a detailed manual of operations and standard operating procedures, which was given to all team members.

The NESTT survey clinic was situated in eleven locations sequentially, within all five regions in Trinidad and Tobago. Three locations were in Regional Health Authority (RHA) facilities; 1 was within the University of the West Indies in St Augustine; and 7

were on a specially equipped NESTT mobile unit parked at RHA facilities (See Figure 4.2). The distance between the 120 clusters and the clinic ranged from 50 meters to 43 km, but was generally within 10 km. Poor road quality in some rural areas, and the sensitivity of the ophthalmic equipment, prevented the mobile unit from visiting additional rural locations.

Figure 4.2: Panel of images illustrating the NESTT clinic bus and one of the regional clinics, in St James, Port of Spain

4.9 Survey pathway

4.9.1 Stage 1: Enumeration, consent and vision screening

The enumerators explained the purpose of the study, ascertained eligibility, and obtained verbal consent to participate. They collected individual contact information and core demographic and socioeconomic data from eligible household members, and completed a questionnaire on each household (See Table 4.1 and Appendix C.1.1 and C.1.2). This took approximately ten minutes per household.

The vision screening team obtained written informed consent to participate in the survey, completed a basic questionnaire, and screened vision in the community (see Figure 4.3), usually directly outside the household (See Appendix C.1.3 and C.1.4). This took approximately ten minutes per person. Eligible people with a disability potentially affecting understanding were identified at enumeration, and I spoke with the family or visited the home to undertake a mental capacity assessment. If they lacked capacity to give informed consent, on account of a persistent impairment in the functioning of the brain, the reason for this was documented. They were counted as a non-responder and are not recruited to participate in the study. They were offered an eye examination if this was felt to serve their best interests.

Monocular presenting distance visual acuity was measured at eye level at 3.0 m, and binocular presenting near visual acuity was measured at 40.0 cm, using logMAR letter optotype charts (Precision Vision, La Salle, USA) (See Appendix C.1.5). If the participant was not fully literate, PV Number charts, with matching cards if needed, were offered (Precision Vision, La Salle, USA). The participant was tested with their habitual optical correction (spectacles or contact lenses), if applicable (Ferris & Bailey, 1996). Vision screening was conducted in an outside but shaded location to achieve supra-threshold chart illumination of at least 160 cd/m^2, without incident glare (Ferris & Bailey, 1996). The ETDRS-Fast protocol was used for measurement of distance visual acuity on the Sloan letter acuity chart (See Appendix C.1.5) (Camparini, Cassinari, Ferrigno, & Macaluso, 2001; Williams, Moutray, & Jackson, 2008). In brief, beginning with the top row the screener invited the participant to identify only one letter per line by briefly pointing to a letter. To guarantee the same degree of difficulty for each row, only Sloan letters of intermediate difficulty coefficient were chosen (D, K, V, R, H). At the first letter read incorrectly the subject was required to read the whole preceding row. This step was repeated upward if the subject made two or more errors. The participant then read all rows downward, letter by letter, until the screener determined that no further meaningful readings could be made despite urging the subject to read or guess. The visual acuity score was specified in terms of the number of optotypes correctly identified. Laminated charts were used to assist the screener, and included the chart optotypes in order, the line totals (five optotypes per line), a recommended sequence of letters, and the equivalent logMAR acuity. The standard ETDRS protocol was used for measurement with the Precision Vision numbers chart, and for measurement of near visual acuity (Ferris, Kassoff, Bresnick, & Bailey, 1982), with the same stopping rules. The visual acuity score was specified in terms of the number of optotypes correctly identified, and converted back to the logMAR scale later for analysis. If the participant was unable to correctly identify the optotypes at 3.0 m they moved to 1.50 m and 0.75 m sequentially. If no optotypes could be identified at 0.75 m, visual acuity was documented as ‘counting fingers’, ‘hand movements’, ‘perception of light’ or ‘no perception of light.’

4.9.2 Stage 2: Survey clinic

All eligible people aged 40 years and above were invited to attend the regional NESTT survey clinic for free comprehensive assessment (See Figure 4.4). On arrival,

each participant was assigned a unique survey identification number. The clinic pathway is summarized in Figure 4.5, and took between 1.5 and 2 hours to complete.

4.9.3 Questionnaires

The Epi Info™ software package (version 3.5.4, Centers for Disease Control and Prevention) was used to prospectively administer a series of structured questionnaires (Appendix C.1.6 to C.1.9). The questionnaires were developed from question sets used in previous studies, and included demographic (Limburg et al., 2007; Ministry of Planning and Sustainable Development, 2012), socioeconomic (Clarke, Gray, Legood, Briggs, & Holman, 2003; Ministry of Planning and Sustainable Development, 2012; International Labour Office, 2012), medical and ophthalmic history variables (Limburg et al., 2007; Yusuf et al., 2004), and low vision assessment. The questionnaire variables are summarized in Table 4.1.

Figure 4.3: Panel of images illustrating community-based visual acuity screening

4.9.4 Measurement of health-related quality of life

To assess HRQoL, a member of the survey team administered the EQ-5D 5-level (EQ-5D-5L) instrument (EuroQol, 1990; Herdman et al., 2011) (Appendix C.1.10). Further detail on this instrument, and the analysis approach, is outlined in Chapter 6.

Table 4.1: Question variables included in structured questionnaires

Questionnaire	Variables
Household enumeration (See Appendix C.1.1 and C.1.2)	Wall and roof material, the main fuel used for cooking, household ownership status, and ownership of a set of preselected goods(Ministry of Planning and Sustainable Development, 2012)
Individual enumeration (See Appendix C.1.4)	Sex, age, date and place of birth, ethnicity, position in household, employment status, number of years resident in Trinidad and Tobago, basic medical and ophthalmic history, self-reported vision status, and if not able to attend clinic for full assessment, the reason for this
Demographic and Socioeconomic (See Appendix C.1.6)	Place of birth, marital status, main language, religion, education, employment, household income, driving history, communication access, and health insurance status. Usage and out of pocket expenditure on health care over past 12 months, usual transportation mode, informal care required on account of VI, number of eye care-related sick days, and lost income in the past 12 months (Clarke et al., 2003)
Medical and ophthalmic (See Appendix C.1.7)	Past medical and ocular history, medication history and compliance, family history, and exposure history (alcohol, tobacco, and illicit drugs)
Optometric assessment (See Appendix C.1.8)	Spectacle and contact lens history, habitual reading distance
Low vision (See Appendix C.1.9)	History and duration of sight loss, functional adaptations, use of low vision devices, previous low vision assessment and barriers to access
Health-related quality of life (See Appendix C.1.10)	5-level EQ-5D™

4.9.5 Measurement of cost

Participants were asked about utilization of eye care services, treatments and vision aids, and the associated direct and indirect costs, using a questionnaire adapted from the UK Prospective Diabetes Study (Clarke et al., 2003) (See Appendix C.1.6). Specifically, this questionnaire included questions on the frequency of utilization of

eye care services over the past 12 months, out of pocket expenditure (OOPE), health sector preference, health insurance status, use of prescription medicines for the treatment of eye disease, previous eye surgery, intravitreal injection or laser therapy, and transport mode to access eye care services. Those in employment were also asked about sick leave, part-time work, and lost earnings associated with eye care. Participants were also asked about informal care needed on account of impaired vision. Those with low vision were asked about previous low vision assessment, access to low vision aids and barriers to access. Further detail on the economic analysis approach is given in Chapter 7. Unit cost data was obtained in a parallel study on the eye care system in Trinidad and Tobago in 2013-2014 (Braithwaite et al., 2018) (See Appendix A.1).

4.9.6 Examination

The examination stations included a general medical examination, conducted by a nurse; an eye examination before and after dilation, including assessment of the anterior chamber depth (Van Herick, Shaffer, & Schwartz, 1969), lens status (Bourne et al., 2005; Karbassi, Khu, Singer, & Chylack, 1993), and optic disc (Foster et al., 2002), conducted by myself or the other survey ophthalmologist; and an assessment of vision and refractive status, conducted by an optometrist. Additional stations included detailed ocular imaging and measurement, with fundus photography and subsequent grading (ETDRS, 1991), OCT, ocular biometry and measurement of corneal hysteresis. The examination variables, equipment and measurement protocols are outlined in Appendix C.1.5. In addition, some participants underwent further examination based on predefined eligibility criteria. The additional variables obtained in a subset of participants are summarized in Appendix C.1.11 and included glycosylated hemoglobin (Alberti & Zimmet,1998), best-corrected distance acuity, gonioscopy (Foong et al., 2007; Foster et al., 2002), automated visual field testing and low vision assessment. Examination findings were entered both on a paper case report form (CRF) and electronically using Epi Info™.

After the first slit-lamp examination, tropicamide 1% (1 drop) and phenylephrine hydrochloride 2.5% (1 drop) were instilled into each eye. An additional drop of each was instilled after a fifteen-minute interval if inadequate mydriasis was apparent. All participants had their pupils dilated providing the iridocorneal angle was not occludable. A normal angle was defined as a Van Herick limbal chamber depth $\geq$ 25%, or following gonioscopy as visibility of the posterior third of the trabecular

meshwork for more than 270 degrees (Van Herick et al., 1969; Foster et al., 2002). Dilation was avoided in those with known allergy to mydriatic eye drops, those with potentially occludable angles, and those who declined dilation despite encouragement.

Figure 4.4: Panel of images illustrating the NESTT clinic and clinical survey team

4.9.7 Domiciliary visits

Eligible people who failed screening and were unable to attend clinic owing to poor mobility, frailty, illness or care of dependents were offered a home visit by the ophthalmologists. A limited questionnaire was administered to obtain key data. Assessment to determine the principal cause of vision loss included pupil reactivity, pinhole distance visual acuity, and dilated examination using a direct ophthalmoscope (Professional Ophthalmoscope 3.5v, Keeler, Windsor, UK).

4.9.8 Service component

At the conclusion of the clinic visit participants were given a full explanation of any findings, and a written summary for onward referral if any abnormalities were

identified. Participants chose public or private sector referral. Imaging results were emailed or transferred to external memory sticks on request. Topical eye drops were dispensed at no cost for those requiring urgent treatment.

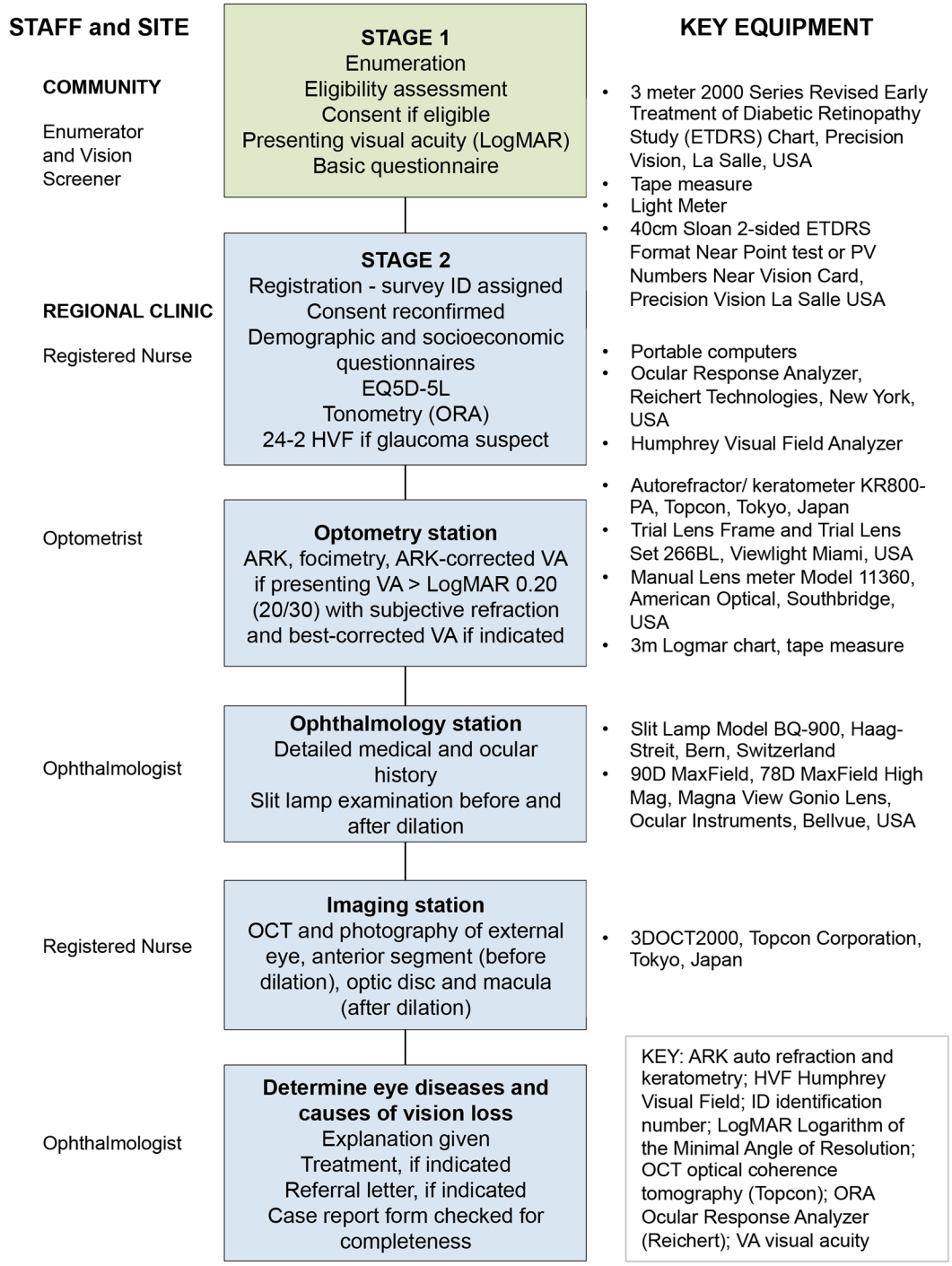

Figure 4.5: Flow diagram illustrating the participant pathway

4.10 Data management

Clinic data were identifiable by the survey ID number only. In-built consistency checks in Epi Info™, and validation through duplicate entry of key variables, was used to correct errors in data entry. The exported databases were copied to external hard drive daily, and the data from the ophthalmic equipment was exported weekly. A designated team member was responsible for the secure storage of the external hard drive at all times. The completed CRF and databases were crosschecked monthly to identify and correct any data entry errors. Forms were transported to a central medical records office at The University of The West Indies in St Augustine, Trinidad, with restricted access for secure storage.

4.11 Security considerations and deviation from the protocol

Trinidad and Tobago's homicide rate was 37.9 per 100,000 in 2012 (13th highest globally) (United Nations Office on Drugs and Crime, 2013). Criminal activity was particularly concentrated in certain areas east of the capital, Port of Spain, and escalated unpredictably. It was anticipated that some randomly selected EDs might be too dangerous to enumerate, even for experienced enumerators native to those districts. In this event, the selected ED was replaced by that closest in population size within the same municipality. In the case of an ED being too dangerous for door-to-door vision screening, we offered screening in a safer location (school, church, community center) within a few hundred meters of the selected households.

4.12 Quality assurance

The field supervisor coordinated the activities of the enumeration team. I coordinated the activities of the clinical and screening teams and audited enumeration in every cluster. If the number of 'no contact' households was greater than three, or if the initial refusal rate was high, I visited the cluster to review the enumeration and recruitment. Where additional enumeration of individuals who were skipped in error resulted in more than 35 people aged 40 years and above being included for a given cluster, this was accounted for in the statistical analysis. Supervisory visits were made to the survey clinic by co-investigators, to monitor practices and ensure adherence to protocols. Following the training period, inter-observer agreement in key examination variables was analysed using standard statistical software (StataCorp. 2013. Stata

Statistical Software: Release 13.1. College Station, TX: StataCorp LP). For the first six months of fieldwork each pair of vision screeners included either a supervising ophthalmologist or optometrist to provide ongoing training and quality assurance in the measurement of visual acuity.

4.12.1 Interobserver agreement for key examination variables

There was good agreement between the vision screeners in assigning volunteers to vision category in the better-seeing eye (Kappa coefficient > 0.75, p < 0.0001), and good agreement between the survey ophthalmologists in other binary and categorical variables, including lens grade using the LOCSIII grading scheme (Kappa coefficient $\geq$ 0.70, p < 0.0001) and abnormalities of the pupil, macula, retina, optic disc and iridocorneal angle (Kappa coefficient >0.78 for all, p < 0.0001) (See Table 4.2) (Cohen, 1960, 1968; Fleiss, 1979). There was also acceptable agreement in the continuous variables, visual acuity and intraocular pressure, which were analysed using Bland and Altman Limits of Agreement (See Table 4.3) (Barrio, Antona, & Puell, 2015; Bland & Altman, 1999; Cook et al., 2012).

Table 4.2: Kappa coefficient for the inter-observer agreement

Observers	Examination variable	Kappa (p-value)
All vision screeners	Monocular distance visual acuity	
	Visual acuity $\geq$ 6/6	0.81 (p<0.0001)
	Visual acuity < 6/6 and $\geq$ 6/18	0.76 (p<0.0001)
	Visual acuity < 6/18	0.85 (p<0.0001)
2 survey ophthalmologists	Lens opacity LOCSIII*	
	Nuclear	0.70 (p<0.0001)*
	Cortical	0.75 (p<0.0001)*
	Posterior subcapsular	0.86 (p<0.0001)*
2 survey ophthalmologists	Van Herick Limbal Chamber Depth	0.79 (p<0.0002)
2 survey ophthalmologists	Pupil normal or abnormal	1.00 (p<0.0001)
2 survey ophthalmologists	Macula normal or abnormal	1.00 (p<0.0001)
2 survey ophthalmologists	Retina normal or abnormal	1.00 (p<0.0001)
2 survey ophthalmologists	Optic disc normal or abnormal	0.87 (p<0.0001)

*Kappa weighting: 1, 0.6, 0.3, 0, 0, 0, and 0

20 eyes of 20 volunteers included in analysis

Table 4.3: Bland and Altman Limits of Agreement in the measurement of continuous examination variables

Variable (unit)	Observer	n	Mean (sd) and difference in mean (sd)	Bland-Altman Upper and Lower Limits of Agreement (95% CI)
Distance visual acuity (Number of letters correctly identified)	Trainer (ophthalmologist) *versus* Each vision screener	20 left eyes	Trainer: 56.4 letters (sd 9.0), range 33 to 66 Most dissimilar screener: 55.4 letters (sd 9.5), range 32 to 66. Mean difference: 1.1 letters (sd 3.1), range -6 to 9	Upper Limit: 7 letters (95% CI 5, 10) Lower limit: -5 letters (95% CI -3, -8) 100% within 10 letters (2 lines) of the trainer's measure; 85% within 5 letters (1 line)
Intraocular pressure (mmHg)	Manual Goldmann applanation tonometry (GAT) *versus* Automated Goldmann-correlated IOP measured by the ORA (g-IOP)	101 left eyes	GAT: 15.8mm Hg (sd 4.1), range 9 to 36 g-IOP: 16.0mm Hg (sd 4.8), range 7 to 39 Mean difference: 0.26 (sd 2.2) mm Hg (p=0.25)	Upper Limit: 4.2 mm Hg (95% CI 3.4, 4.9) Lower limit: -4.7 mm Hg (95% CI -5.4, -3.9) 83.2% of GAT IOP within 2mm Hg of g-IOP

4.12.2 Independent image grading

Retinal and optic disc photographs and OCT images were graded at the Moorfields Eye Hospital Reading Centre (MEHRC), London, UK. The grader was trained and certified for the existing protocol based on her experience grading other population-based studies (Bastawrous et al., 2014; Kyari et al., 2014), and on the satisfactory grading results of 100 sets of test images and OCT images, where no relevant pathology was misgraded. Grading was carried out under the supervision of the MEH Reading Centre Clinician. For initial (first pass) grading, the grader identified normal/abnormal images, both on OCT and colour imaging, and noted any abnormalities including age-related maculopathy (ARM) and AMD, DR, and suspicious optic disc. All eyes with ARM/AMD were classified using a modified version of the International Classification and Grading System for AMD (Bird et al., 1995). The following AMD features were evaluated: the presence of more than 10 hard drusen (< 63μm); soft drusen (>125 μm); atrophic AMD; and signs of

neovascular AMD (choroidal neovascularization, retinal pigment epithelium detachment, and disciform scar). Early AMD was defined as the presence of more than 10 hard drusen (< 63μm) and/or the presence of soft drusen (>125 μm). Late AMD was defined as the presence of atrophic AMD and/or neovascular AMD. Mixed AMD was defined as the presence of atrophic AMD in one eye and neovascular AMD in the other eye (Bird et al., 1995). The MEH Reading Centre Clinician adjudicated all AMD patients and any with questionable grade. Diabetic retinopathy was graded using the Welsh DR grading system (ETDRS, 1991), with the same level of adjudication and verification as for AMD. Optic discs were deemed suspicious if the cup-disc ratio was above 0.6, or if there was an optic disc haemorrhage, notching or thinning. All definite and questionable features were adjudicated. The Reading Centre clinician evaluated all abnormal OCTs. The senior grader or the reading centre clinician graded ten percent of all normal images. Ten percent of all images were re-graded 14 days later by the same grader, and any clinically relevant differences prompted a clinician review of the images.

4.13 Case Definitions

4.13.1 Vision Categories

Table 4.4 summarizes the definitions of presenting LogMAR VA in the better-seeing eye using revised WHO vision categories (Snellen notation) (Bourne, Price et al., 2013).

Table 4.4: Definition of vision category

Variable	Definition *
Normal vision	LogMAR <=0.30 (Snellen >=6/12)
Distance mild vision impairment	LogMAR 0.32 to 0.48 (Snellen <6/12 but ≥ 6/18)
Distance moderate vision impairment	LogMAR 0.50 to 1.00 (Snellen <6/18 but ≥ 6/60)
Distance severe vision impairment	LogMAR 1.02 to 1.30 (Snellen <6/60 but ≥ 3/60)
Distance blindness	LogMAR ≥1.32 (Snellen <3/60)
Near vision impairment	LogMAR 0.32 to 1.30 at 40 cm (plus ≤ 0.30 distance) (Snellen < 6/12 but ≥ 3/60 for near, and ≥ 6/12 for distance)

* Bourne et al. 2013

4.13.2 Eye disease definitions

Case definitions for the most common eye diseases associated with VI are summarized in Table 4.5. These were informed by the literature review of case definitions used in previous surveys, and by the resources and equipment available for the NESTT.

Table 4.5: Definitions of the most common causes of vision impairment

Variable	Definition	Citation
Cataract	LOCSIII >=4 nuclear colour/opalescence, >=2 cortical or >=2 PSCO. Home visit with direct ophthalmoscope: Dilated fundus view obscured by lens changes and no evidence of fundal abnormality	Wong 2013
Uncorrected refractive error	Improvement of at least 0.20 LogMAR in BCVA compared to presenting VA, and BCVA better than or equal to 6/12	Wong 2008
Glaucoma	ISGEO classification 1, 2, 3, assuming normal 97.5th CDR = 0.70 and asymmetry = 0.20, and 99.5th CDR = 0.80 and asymmetry = 0.30.	Foster 2002
Diabetic Retinopathy	Retinal photograph grading using a modification of the Airlie House classification of DR. If no imaging possible then ophthalmologist assigns grade	ETDRS 1991
Age-related macular degeneration	Graded from retinal photographs using modified version of the International Classification and Grading System for AMD. Early AMD is defined as the presence of more than 10 hard drusen (< 63µm) and/or the presence of soft drusen (>125 µm). Late AMD is defined as the presence of atrophic AMD and/or neovascular AMD (choroidal neovascularization, retinal pigment epithelium detachment, disciform scar). Mixed AMD was defined as the presence of atrophic AMD in one eye and neovascular AMD in the other eye. If no imaging possible then ophthalmologist assigns grade	Bird et al. 1995
All other eye diseases	International Classification of Diseases Version 10	ICD-10 2013

KEY: VA visual acuity; BCVA best-corrected visual acuity; DR diabetic retinopathy; AMD age-related macular degeneration; URE uncorrected refractive error

4.13.3 Determination of attributable cause of vision loss and definition of 'avoidable' vision loss

Survey ophthalmologists noted all eye diseases potentially contributing to VI (WHO, 2010). In eyes with more than one disorder, one was selected as the primary disorder (Dineen et al., 2008; WHO, 1988). The principal ocular disorder (Dineen et al., 2008), and principal cause of vision loss in the person, were documented (Limburg et al., 2007) (See Table 4.6). The MEHRC (London, UK) independently graded fundus photographs and OCTs. The presence of AMD (Bird et al., 1995), diabetic retinopathy (DR) (ETDRS, 1991), suspicious optic discs, and other abnormalities was recorded. The Principal Investigator remotely reviewed the records of those with VI to confirm final cause attribution.

Table 4.6 Defining the principal cause of vision loss and avoidable vision loss

Outcome variable	Definition	Citation
Primary ocular disorder contributing to vision loss in eye	That disorder which resulted in other disorders, or 2) that which was the more significant cause of vision loss, or 3) that causing vision loss which was most amenable to treatment or prevention.	Dineen 2008,
Principal ocular disorder responsible for vision loss in person	The primary disorder affecting one or both eyes, when this was the same. When the primary ocular disorder differed between the eyes, it was defined as 1) that most amenable to treatment, or 2) that most amenable to prevention, or 3) that which was responsible for vision loss in the better seeing eye.	WHO 1988
Principal cause of vision loss in the person	The principal ocular disorder, and underlying cause where applicable, selected from a 18-item list: age-related cataract, uncorrected refractive error (URE), uncorrected aphakia, amblyopia, glaucoma, diabetic retinopathy, trauma, surgical complications, corneal abnormality, age-related macular degeneration (AMD), congenital or neonatal, hereditary retinal disorder, multiple pathology, optic neuropathy, intracranial pathology, other, and cause not determined	WHO 1988 ICEH 2007
Avoidable vision loss	Vision loss resulting from uncorrected refractive error, cataract, trachoma, glaucoma or diabetic retinopathy	Bourne, Price et al. 2013

The most treatable causes of VI, in decreasing order, were assumed to be URE, cataract, corneal pathology (treatable), uncorrected aphakia, DR, and AMD. Of the remaining causes, the most preventable causes of VI, in decreasing order, were assumed to be glaucomatous optic neuropathy, surgical complications, amblyopia, and injuries. The proportion 'potentially avoidable' was compared using alternative definitions, to explore the impact of definition on this important public health outcome (Bourne, Price et al., 2013).

4.14 Statistical methods

4.14.1 Population-based prevalence estimation

Statistical analyses were performed using standard statistical software (StataCorp. 2013. Stata Statistical Software: Release 13.1. College Station, TX: StataCorp LP). The crude prevalence of VI, by category, was adjusted to account for the multilevel survey design (by island and cluster), and weighted for the probability of selection and response rate in each cluster using the survey suite of commands ('svy'). A post-stratification adjustment was made using the latest national Census (2011) for the non-institutionalized population (stratified by 15 municipalities, gender and 5-year age categories). Finite population corrections were applied to the first and second sampling stages, including the total number of EDs by island, and the total number of households by island. The WHO world standard population was used to obtain age-standardized estimates, for international comparison (Ahmad et al., 2001). The same statistical approach was used to obtain crude and adjusted estimates, of prevalence, proportion, and mean, for the EQ-5D-5L, utility, utilization and cost data.

4.14.2 Risk factor analysis

In my analyses for this thesis, I limited potential explanatory variables to those gathered in the Stage 1 community visit and vision screening (See Table 4.1 and Appendix C.1.2 and C.1.4) where the response rate amongst those with vision impairment was highest. I included variables with available data for >80 % of the sampled population in the full models, to ensure sufficient events per outcome variable. I selected the variables to be included in the Stage 1 questionnaires, based on my literature review, to be those most likely to be of importance to presenting vision state (See Appendix B.7). In addition, I created a new variable for the urban intensity index (Chadee & Stoute, 2018).

Given that my set of potential independent variables from stage 1 was relatively modest (in comparison to the hundreds of variables gathered in the Stage 2 clinic), and my aim was to fine-tune those for inclusion in the final model of presenting VI, from a full list of available variables, I chose the backward model fitting approach for linear regression analysis. I sequentially removed variables with the highest p-value from the full multivariable model. I planned to retain established confounder variables (age and sex), identified from literature review, in the model regardless of their significance value.

For binary outcome variables, two-level mixed-effects single and multiple logistic regression analysis assessed the odds of being a responder versus a non-responder, the odds of presenting with distance VI, the odds of presenting with near VI, and the odds of reporting disutility compared to full HRQoL, according to multiple potential explanatory variables. These were excluded from a full model and nested models considered one at a time using the likelihood-ratio test. The STATA reference manual reported that, "*melogit performs optimization using the original metric of variance components*" and that, "*the conditional distribution of the response given the random effects is assumed to be Bernoulli, with success probability determined by the logistic cumulative distribution function*" (StataCorp, 2013). This statistical approach was chosen to fit nested models for NESTT's binary outcome variables, enabling both fixed effects and random effects for each of 120 community clusters, stratified by island.

The final model selected was that which was most parsimonious, and which had the smaller or more negative value of Akaike's and Schwarz's Bayesian information criterion (AIC and BIC). These measures combine the fit and complexity of two alternate models and help to identify which is more likely to have generated the observed data (Akaike, 1974; Schwarz, 1978; StataCorp, 2013). Assessment of model fit, using post-estimation commands, was considered to ensure each model satisfies the assumptions of logistic regression. Specifically, that the true conditional probabilities are a logistic function of the independent variables, that the observations are independent, that the independent variables are not linear combinations of each other, that the independent variable is measured without error, and that no extraneous variables are included, or important variables omitted (Stoltzfus, 2011). For parameter estimation by single and multivariable regression analysis, global p-values were obtained using the likelihood ratio test (LRT). A p-value of 0.05 or lower was taken to be statistically significant.

4.14.3 Health-related quality of life analysis

The analysis approach for estimating the impact of VI on HRQoL is outlined fully in the methods section of Chapter 6.

4.14.4 Cost analysis

The analysis approach for estimating the societal economic cost associated with VI in persons aged 40 years and above is outlined fully in the methods section of Chapter 7.

4.15 Ethical and Government approval

The study adhered to the tenets of the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committees of the University of the West Indies (See Appendix C.2.1), the Ministry of Health of Trinidad and Tobago (See Appendix C.2.2), and Anglia Ruskin University (See Appendix C.2.3).

This chapter summarized the materials and methods of the NESTT relating to the objectives of this thesis. In the next chapter I present data on the prevalence and causes of presenting VI and associated risk factors in adults 40 years and above.

5

PREVALENCE AND CAUSES OF VISION IMPAIRMENT AND ASSOCIATED RISK FACTORS

This chapter presents the prevalence and causes of presenting VI, and associated risk factors, in the NESTT. Data analysis for this thesis was limited to participants aged 40 years and above.

5.1 Results

5.1.1 Outcome of cluster sampling

One hundred and nineteen out of 120 randomly selected clusters (primary sampling units) were sampled as planned. One cluster in Port of Spain had to be excluded and replaced, after a multi-homicide gunfight in the selected apartment building in Nelson Street, Port of Spain, during enumeration. An alternative cluster was selected according to the method outlined previously. A further three clusters were categorized ‘very high security risk’ and ten were categorized ‘high security risk’. Enumeration and vision screening in those communities was undertaken in safer locations (e.g. the

local health centre or church), in some cases out of sequence, and with armed cover from the Police and Special Task Force, at times when criminal activity was lower.

5.1.2 Response rate

Data collection commenced in October 2013 and concluded in November 2014. In total, a sample of 3410 households, including 10,651 individuals, were selected, of whom 9913 people aged 5 years and above, including 4263 people aged 40 years and above, were eligible for recruitment (See Figure 5.1). The regional distribution of the eligible sample was very similar to the distribution of the population in the 2011 Population Census (see Figure 5.2). Out of all eligible adults 40 years and above, 93.2 % (3914) were enumerated, and 84.2 % (3589) consented to participate, with measurement of presenting visual acuity. Comprehensive ophthalmic examinations were performed in 65.4 % (2790) responders, mostly in the regional clinic (2540) with a minority in participants' homes (250). The cause of presenting VI in the better-seeing eye was ascertained in 96.3 % (237/246) with presenting blindness or MSVI (See Appendix D.1). Reasons given for non-response included being busy (331), preferring to see their own eye specialist (60), being too ill/frail to participate (29), lackinging capacity to consent (18), and travel cost/distance (6).

Fundus photographs were available for 97.0 % (2463) right eyes and 96.7 % (2455) left eyes of 2540 participants who attend clinic. Image quality was graded "good" in 40.3 % (1984), "fair" in 30.6 % (1505), "poor" in 18.1 % (889) and "ungradable" in 11.0 % (540). OCT images of the macula and disc were available for 78.9 % (2007) right eyes and 75.9 % (1930) left eyes. Images were missing in eyes with dense media opacity, or as a result of occasional OCT equipment failure. The proportion of ungradable images ranged from 32 % (67) of worse-seeing blind eyes, to 8.6 % (19) of better-seeing eyes with mild VI (see Appendix D.1). Grading identified a specific abnormality in between 16 % and 31 % of imaged eyes with VI or blindness.

5.1.3 Characteristics of responders versus non-responders

Responders (3589) and non-responders (674) aged 40 years and above were broadly similar (see Table 5.1). Responders had a mean age of 57.1 years (sd 11.8), ranging from 40 to 103 years, 54.3 % (1950) were female, 43.7 % (1530) were South Asian and 40.0 % (1401) were African, 17.7 % (616) had private health insurance, 50.3 % (1721) had been employed over the past 12 months, and 71.9 % (2594) resided in high urban intensity index areas (Levels 1-3 out of 8) (Chadee & Stoute, 2018). These

characteristics were very similar to the 2011 census data for the same age group (Ministry of Planning and Sustainable Development, 2012).

Non-responders and responders did not differ significantly, in multilevel single variable logistic regression analysis, with respect to age, nationality, region, ethnicity, health insurance status, community urban intensity index, household roof and wall materials, or cooking fuel. A multilevel multivariable logistic regression model containing 3433 observations was fit to identify significant predictors of response versus non-response (See Appendix D.2). This finds that responders were significantly more likely to be female (OR 1.54, 95 % confidence interval (CI) 1.24-1.90, $p < 0.0001$), less likely to be employed (OR 0.46, 95 % CI 0.32-0.67) or formally unemployed (OR 0.52, 95 % CI 0.28-0.97) than on home duties ($p = 0.0003$), and less likely to rent than to own (OR 0.62, 95 % CI 0.48-0.82). These differences were a potential source of bias in the estimates.

5.1.4 Prevalence of blindness and vision impairment (distance)

After adjustment for the multilevel clustered design, the non-response rate, and for the age, sex and municipality of participants, an estimated 11.88 % (95 % CI 10.88-12.97) of the population had presenting distance VI in the better-seeing eye (n = 468/3580). This included bilateral blindness in 0.73 % (95 % CI 0.48-0.97, n = 31), severe vision impairment (SVI) in 0.47 % (95 % CI 0.28-0.65, n = 19), moderate vision impairment (MVI) in 4.92 % (95 % CI 4.26-5.57, n = 196), and mild VI in 5.77 % (95 % CI 5.06-6.48, n = 222). The distance vision was normal ($\geq$ 6/12) in both eyes in 74.85 % (95 % CI 73.48-76.21, n = 2617). The crude and adjusted prevalence of each category of vision is presented for the better and worse seeing eyes in Table 5.2. Figure 5.3 illustrates the crude prevalence of each category of vision considering both eyes together. The design effect for the outcome of VI was 1.27, demonstrating that the study was adequately powered to address the NESTT primary objective.

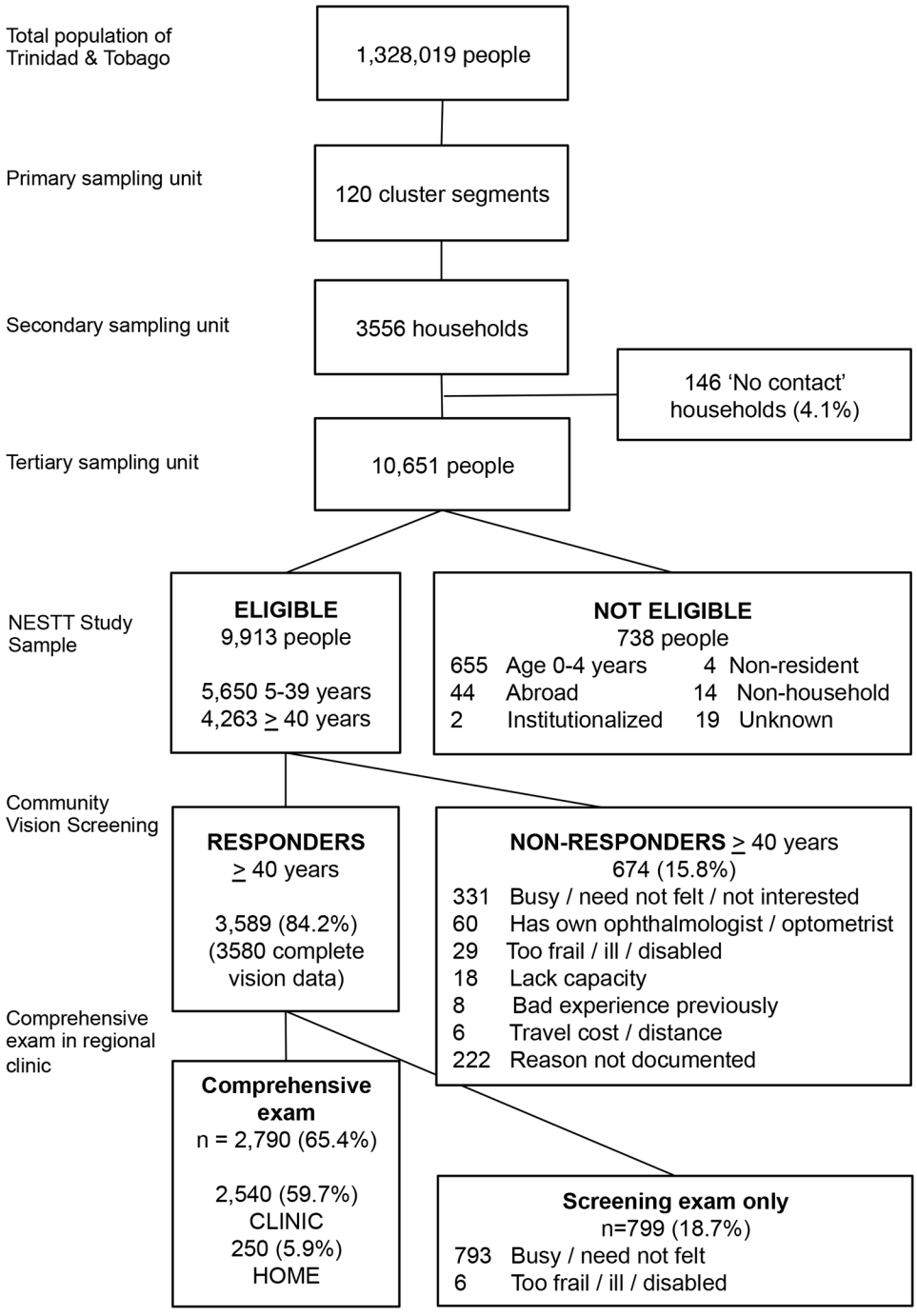

Figure 5.1: Flow diagram illustrating the outcome of enumeration and recruitment

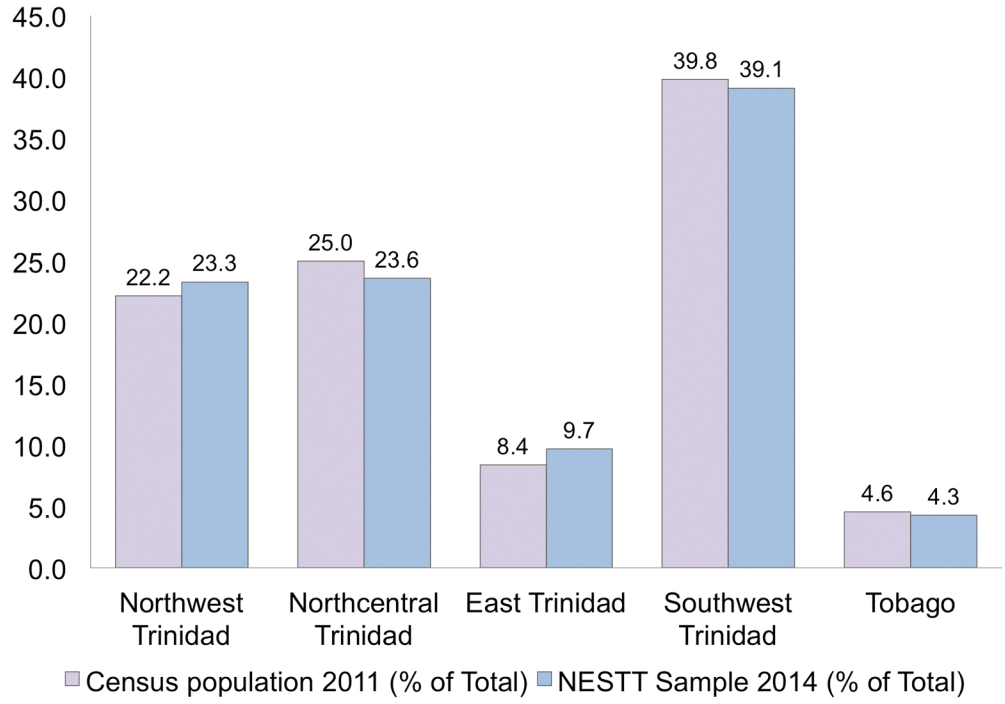

Figure 5.2: Bar chart showing the geographical distribution of the eligible NESTT sample (percent, %) by region, in comparison to the 2011 Census population

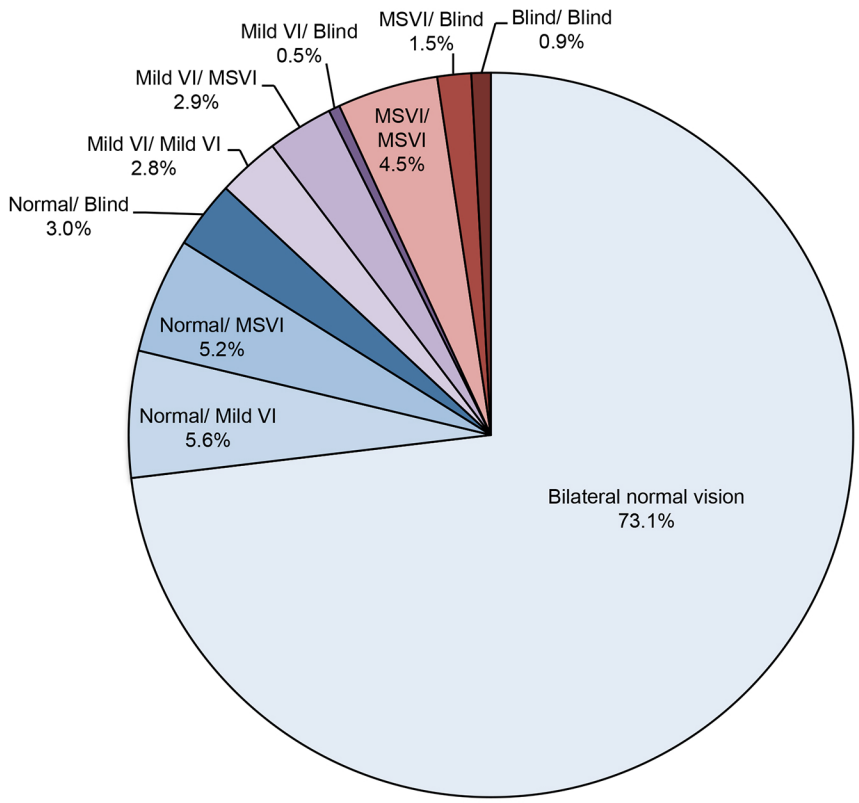

Figure 5.3: Crude prevalence of presenting distance vision category in the better and worse seeing eyes

Table 5.1: Characteristics of NESTT responders and non-responders

Variable	Category	Responders % (n)	Non-responders % (n)	Model OR (95% CI)	p-value	**Census** 2011%
Sample	n	84.2 (3589)	15.8 (674)			
Gender	Male	45.7 (1639)	56.7 (379)	1.00	<0.0001*	49.4
	Female	54.3 (1950)	43.4 (290)	1.54 (1.2-1.9)		50.6
Age (years)	Mean (sd)	57.1(sd11.8)	54.0 (11.8)	1.01 (1.00-1.02)	0.274*	
	Range	40 to 103	40 to 99			
Region	Northwest	22.6 (811)	22.1 (149)	1.00	0.384	22.2
	Northcentral	23.7 (849)	27.6 (186)	0.80 (0.5-1.2)		18.4
	Eastern	9.3 (332)	6.8 (46)	1.20 (0.7-2.1)		8.3
	South west	40.1 (1440)	39.3 (265)	0.95 (0.7-1.4)		46.6
	Tobago	4.4 (157)	4.2 (28)	1.00 (0.5-2.1)		4.6
Ethnicity	African	40.0 (1401)	41.0 (266)	1.00	0.080	34.2
	South Asian	43.7 (1530)	38.8 (252)	1.14 (0.9-1.4)		35.4
	Mixed	15.2 (533)	19.4 (126)	0.81 (0.6-1.1)		22.8
	Other	1.1 (38)	0.8 (5)	1.46 (0.6-3.9)		1.3
	Not stated	2.4 (87)	(25)			6.2
National	T & T	95.9 (3442)	96.7 (652)	1.00	0.307	96.3
	Caribbean	3.0 (108)	2.2 (15)	1.49 (0.8-2.6)		1.3
	Other	1.1 (39)	1.0 (7)	1.30 (0.6-3.0)		2.4
Relation to Head	Head	86.7 (3049)	77.0 (495)	1.00	<0.0001*	
	Child	6.4 (224)	11.8 (76)	0.54 (0.4-0.8)		
	Parent	1.8 (62)	3.0 (19)	0.36 (0.2-0.7)		
	Grandchild	0.6 (21)	0.2 (1)	2.63 (0.3-21.7)		
	Other	4.4 (154)	7.8 (50)	0.43 (0.3-0.6)		
	Domestic employee	0.1 (5)	0.3 (2)	0.77 (0.1-7.9)		
Home tenure	Owned	83.6 (2529)	76.6 (423)	1.00	0.002*	
	Rented	14.7 (446)	21.6 (119)	0.62 (0.5-0.8)		
	Squatted	1.7 (51)	1.8 (10)	0.64 (0.2-1.8)		
Home walls	Wood	9.4 (292)	9.2 (55)	1.00	0.745	
	Wood & brick	5.5 (170)	4.2 (25)	1.13 (0.7-2.0)		
	Wood & concrete	3.8 (119)	3.0 (18)	1.16 (0.6-2.1)		
	Wood & galvanize	0.1 (4)	0.3 (2)	0.33 (0.1-2.1)		
	Concrete	47.4 (1469)	45.8 (275)	1.03 (0.7-1.5)		
	Concrete & brick	33.4 (1036)	37.3 (224)	0.89 (0.6-1.3)		
	Wattle/Adobe/ Tapia	0.2 (6) 0.1 (4)	0.3 (2)	0.37 (0.1-2.2)		
Home roof	Sheet metal	96.5 (2998)	97.0 (582)	1.00	0.473	
	Asphalt	0.03 (1)	0.2 (1)	0.18 (0.01-3.24)		
	Concrete	2.8 (87)	2.0 (12)	1.07 (0.52-2.21)		
	Other	0.5 (14)	0.8 (5)	0.65 (0.21-2.03)		
Cooking fuel	None	0.5 (15)	0.9 (5)	1.00	0.758	
	LPG	90.0 (2688)	89.7 (496)	2.22(0.46-10.63)		
	Electricity	9.1 (272)	9.0 (50)	2.14(0.41-11.15)		
	Wood/coal	0.4 (13)	0.4 (2)	2.20(0.12-39.10)		
	Other	0.1 (4)				
Health insurance	Not insured	82.3 (2870)	82.0 (459)	1.00	0.828	
	Insured	17.7 (616)	18.0 (101)	1.07 (0.53-2.17)		
	Not stated	(103)	(114)			
Job status past 12 months	Home duties	18.3 (626)	9.2 (57)	1.00	0.0003*	
	Had a job	50.3 (1721)	69.2 (427)	0.46 (0.32-0.67)		
	Retired	26.2 (896)	15.6 (96)	0.91 (0.59-1.40)		
	Unemployed	3.4 (115)	3.7 (23)	0.52 (0.28-0.97)		
	Disabled	1.7 (59)	2.3 (14)	0.56 (0.26-1.18)		
	Student	0.2 (7)	0 (0)	-		
	Not reported	(165)	(57)			
Urbanicity	Mean index (Levels 1- 8)	2.76 (sd 1.9) range 1 to 8	2.76 (sd 1.9) range 1 to 8	1.00 (0.93-1.08)	0.545	

*Odds ratios (OR) from the multilevel multivariable logistic regression model (Model), adjusted for variables that were significant in the single variable analysis (SVA) (age (linear), sex, employment status, position in the family, and household tenure), with global p-values from likelihood-ratio test (LRT). All other OR and LRT p-values were taken from single variable analysis. KEY: LPG liquid propane gas

Table 5.2: Crude and adjusted prevalence of WHO category of presenting distance visual acuity (VA), in the better and worse seeing eyes

Vision category	BETTER EYE Presenting VA		WORSE EYE Presenting VA	
Distance VI category	Crude prevalence % (n)	Adjusted prevalence* % (95% CI)	Crude prevalence % (n)	Adjusted prevalence* % (95% CI)
Normal	86.93 (3112)	88.12 (87.09-89.14)	73.10 (2617)	74.85 (73.48-76.21)
Mild VI	6.20 (222)	5.77 (5.06-6.48)	8.41 (301)	7.91 (7.08-8.74)
Moderate VI	5.47 (196)	4.92 (4.26-5.57)	11.51 (412)	10.81 (9.89-11.82)
Severe VI	0.53 (19)	0.47 (0.28 – 0.65)	1.09 (39)	0.97 (0.69-1.23)
Blind	0.87 (31)	0.73 (0.48-0.97)	5.92 (212)	5.42 (4.75-6.10)

*Adjusted for multilevel design (island, cluster), weighted for response rate (by cluster), with post-stratification adjustment to 2011 Census population stratified by municipality (15), 5-year age groups and gender

5.1.5 Prevalence of near vision impairment

Binocular presenting near visual acuity was measured in 3560 participants, and NVI was present in 1050, giving an adjusted prevalence of 28.30 % (95 % CI 26.62-30.04). Amongst those with distance VI, 72.79 % (95 % CI 68.16-76.97, n = 352) also had binocular NVI, rising from 22.28 % (95 % CI 20.68-23.83) in those with normal distance visual acuity ($\geq$ 6/12), to 60.32 % (95 % CI 53.47-66.78) in those with mild distance VI, 81.77 % (95 % CI 75.64-86.63) in those with moderate VI, and to nearly 100 % in those with SVI or blindness (see Figure 5.4).

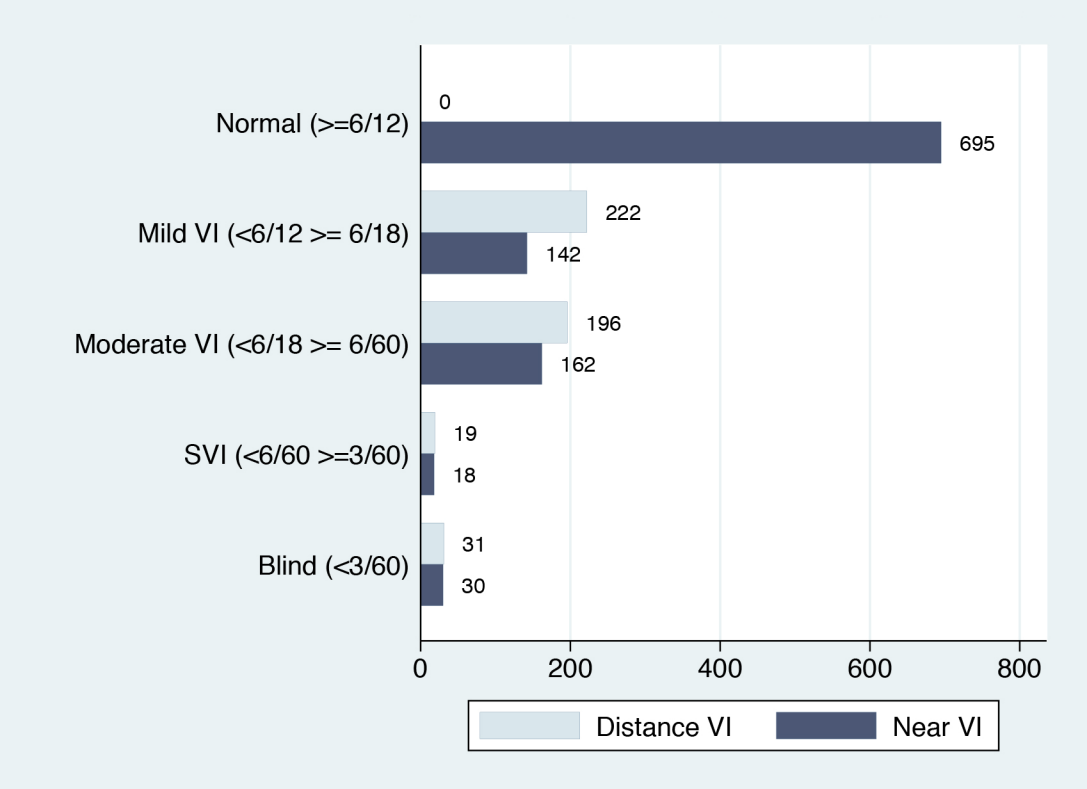

Figure 5.4 Bar chart showing the number of people with presenting distance vision impairment in each vision category, and the number who also had presenting binocular near vision impairment

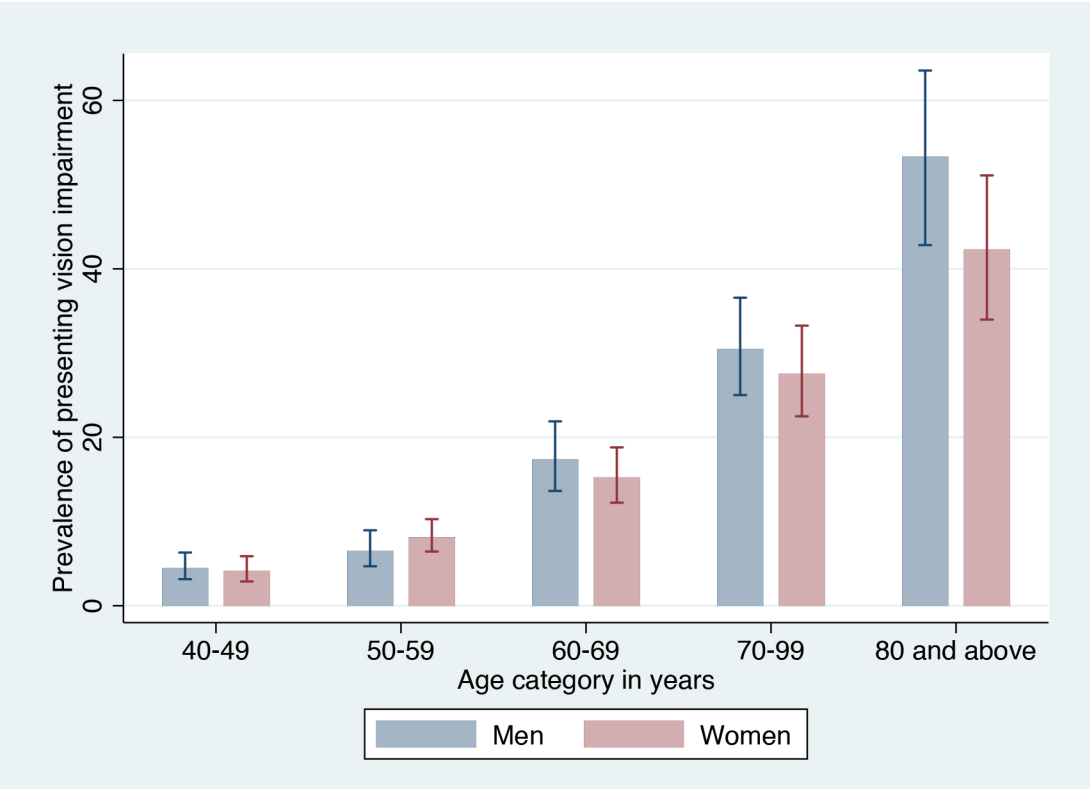

Figure 5.5: Prevalence of adjusted, age-standardized presenting vision impairment in the better-seeing eye, by age category and sex, with 95 % confidence intervals

5.1.6 Association between age and distance vision impairment

Table 5.3 presents the age-specific adjusted prevalence in each distance vision category. The adjusted, age-standardized prevalence of VI was slightly higher in men than in women, and increased markedly with age in both sexes (See Figure 5.5).

Table 5.3: Age-specific prevalence* of vision impairment categories in the better-seeing eye

		Adjusted prevalence				
Age	**Total n**	**Mild VI**	**MVI**	**SVI**	**Blind**	**NVI only****
		% (95% CI)	**% (95% CI)**	**% (95% CI)**	**% (95% CI)**	**% (95% CI)**
40-44	550	2.60 (1.4 to 3.8)	1.7 (0.7 to 2.6)	1.7 (0 to 0.5)	0	25.0 (21.9 to 28.4)
45-49	547	2.9 (1.7 to 4.2)	1.0 (0.3 to 1.7)	0.2 (0 to 0.4)	0.1 (0 to 0.4)	38.6 (34.6 to 42.8)
50-54	601	3.8 (2.6 to 5.1)	2.0 (1.0 to 3.1)	3.2 (0 to 0.8)	0.1 (0 to 0.4)	37.9 (33.8 to 42.4)
55-59	549	4.3 (2.6 to 6.0)	4.0 (2.4 to 5.6)	0	0.2 (0 to 0.5)	36.4 (32.2 to 40.8)
60-64	403	7.0 (4.7 to 9.2)	4.8 (2.4 to 7.2)	1.8 (0 to 5.4)	0.7 (0 to 1.6)	33.8 (28.9 to 39.0)
65-69	341	8.4 (5.7 to 11.1)	12.0 (8.3 to 15.7)	0.5 (0 to 1.1)	0.2 (0 to 0.6)	31.1 (26.4 to 36.1)
70-74	268	13.8 (9.9 to 17.6)	12.7 (9.1 to 16.3)	1.1 (0 to 2.3)	2.7 (0.7 to 4.7)	43.3 (36.9 to 49.9)
75-79	157	12.6 (8.7 to 16.4)	8.2 (4.7 to 11.8)	3.7 (1.8 to 5.5)	2.4 (0.4 to 4.5)	36.1 (28.4 to 44.6)
80+	164	16.3 (11.1 to 21.6)	21.3 (16.0 to 26.6)	2.0 (0.0 to 3.9)	7.3 (3.6 to 11.0)	52.3 (43.9 to 60.6)
All ≥ 40	3580	5.77 (5.06-6.48)	4.92 (4.26-5.57)	0.47 (0.28 – 0.65)	0.73 (0.48-0.97)	22.3 (20.8 to 23.8)

*Adjusted for multilevel design (island, cluster), weighted for response rate (by cluster), with post-stratification adjustment to 2011 Census population stratified by municipality (15), 5-year age groups and gender. **Cases of NVI with normal distance vision, to prevent double counting of cases of vision impairment

5.1.7 National estimate of cases of vision impairment in 2014

To estimate the burden of VI involving the better-seeing eye in the national population of Trinidad and Tobago in 2014, the adjusted prevalence of each vision category was applied to the 2014 mid-year population estimate for the non-institutionalized population aged 40 years and above (Ministry of Planning and Sustainable Development, 2014). In total there were an estimated 185,273 (95 % CI 167,337-203,048) people with distance or near VI. This included 64,431 (95 % CI 54,623-74,077) people with presenting distance VI, of whom 3,956 people were blind, 2,547

had SVI, 26,661 had MVI, and 31,267 had mild VI, and 120,842 (95 % CI 112,714-128,971) had presenting binocular NVI and normal distance visual acuity (see Table 5.4).

Table 5.4 Estimated cases of presenting distance and near vision impairment in the better-seeing eye

WHO category	Adjusted* prevalence (95% CI)	Estimated cases	Lower bound 95% CI	Upper bound 95% CI
Mild VI	5.77 (5.06 to 6.48)	31,267	27,420	35,115
Moderate VI	4.92 (4.26 to 5.57)	26,661	23,085	30,183
Severe VI	0.47 (0.28 to 0.65)	2,547	1,517	3,522
Blind	0.73 (0.48 to 0.97)	3,956	2,601	5,256
NVI*	22.3 (20.7 to 23.8)	120,842	112,714	128,971
Total distance VI		**64,431**	**54,623**	**74,077**
All VI		**185,273**	**167,337**	**203,048**

*Adjusted for multilevel design (island, cluster), weighted for response rate (by cluster), with post-stratification adjustment to 2011 Census population stratified by municipality (15), 5-year age groups and gender

5.1.8 Causes of vision impairment

Amongst NESTT participants, the principal causes of presenting blindness in the person (n=31) were cataract (32.3 %, n = 10) and glaucoma (29.0 %, n = 9), followed by DR (16.1 %, n = 5) (See Figure 5.6). The principal causes of MSVI (n = 215) were URE (42.5 %, n = 91), followed by cataract (34.6%, n = 74), DR (6.1 %, n = 13), glaucoma (3.7 %, n = 8), and AMD (2.3%, n=5). The principal causes of mild VI (n = 222) were URE (53.6 %, n = 119), cataract (22.2 %, n = 49), DR (10.4 %, n = 23), and AMD (3.2 %, n = 7). Less common causes of VI included surgical complications (including simple capsule opacification), amblyopia, other maculopathies, optic nerve or central nervous system pathology, corneal pathology (frequently on-axis pterygium), trauma, and multiple pathologies. Much less common were congenital and hereditary causes, retinal detachment, retinal vascular occlusion, and macular hole. The cause of VI could not be not established in 4.1 % (n = 19). A detailed breakdown of the primary ocular disorder responsible for VI in both the better and worse seeing eyes, and the MEHRC retinal grading outcomes, is presented in Appendix D.1.

5.1.9 Population-based estimation of cause-specific vision impairment

The adjusted prevalence of distance VI attributable to each cause in the person is presented in Table 5.5 and Figure 5.6. In 2014 there were an estimated 30,528 cases of VI attributed to URE (95 % CI 27977-33078), 16,924 cases of VI attributed to cataract (95 % CI 14653-19194), 5,406 cases of VI attributed to DR (95 % CI 3792-7019), 2819 cases of VI attributed to glaucoma (95 % CI 1703-3936) and 1824 cases of VI attributed to AMD (95% CI 966-2681).

Table 5.5 Prevalence of vision impairment attributed to each cause, and estimated cases in 2014

Cause in person	Mild VI %	MSVI	Blind	All distance VI	Estimated Cases of VI in 2014
URE	56.7 (51.2 to 62.1)	43.9 (37.8 to 50.1)	0	47.4 (43.4 to 51.3)	30528 (27977 to 33078)
Cataract	20.2 (15.7 to 24.7)	32.4 (26.9 to 37.9)	28.8 (12.6 to 45.1)	26.3 (22.7 to 29.8)	16924 (14653 to 19194)
Corneal pathology	0	0.9 (0 to 2.1)	0	0.4 (0 to 0.9)	262 (-81 to 606)
Aphakia	0	0	0	0	0
DR	9.5 (5.8 to 13.2)	5.7 (2.6 to 8.8)	19.1 (4.2 to 34.0)	8.4 (5.9 to 10.9)	5406 (3792 to 7019)
AMD	3.3 (1.2 to 5.4)	2.7 (0.8 to 4.6)	0	2.8 (1.5 to 4.2)	1824 (966 to 2681)
Glaucoma	1.6 (0 to 3.3)	3.6 (1.4 to 5.8)	31.7 (18.7 to 44.8)	4.4 (2.6 to 6.1)	2819 (1703 to 3936)
Surgical complication	0.6 (0 to 1.5)	1.5 (0 to 3.5)	0	1.0 (0 to 2.0)	639 (0 to 1277)
Amblyopia	0	1.5 (0 to 3.1)	3.2 (0 to 9.1)	0.9 (0 to 1.7)	560 (44 to 1077)
Trauma	0.5 (0 to 1.2)	0	3.2 (0 to 8.9)	0.4 (0 to 0.9)	267 (-65 to 600)
Congenital	0	0.5 (0 to 1.5)	0	0.2 (0 to 0.7)	155 (-130 to 440)
Hereditary retinal	0	0	2.5 (0 to 6.6)	0.2 (0 to 0.4)	100 (-62 to 262)
Optic nerve pathology	0	1.1 (0 to 2.2)	2.2 (0 to 6.7)	0.6 (0 to 1.2)	409 (35 to 782)
CNS pathology	0.3 (0 to 0.9)	0.5 (0 to 1.4)	0	0.4 (0 to 0.9)	239 (-78 to 556)
Multiple	0.4 (0 to 1.2)	0.4 (0 to 1.0)	2.7 (0 to 7.3)	0.5 (0 to 1.1)	332 (-24 to 689)
Other	1.7 (0 to 3.4)	1.1 (0 to 2.2)	6.6 (0 to 13.1)	1.8 (0.8 to 2.7)	1131 (496 to 1765)
Not established	5.2 (2.5 to 7.9)	4.1 (1.1 to 7.2)	0	4.4 (2.5 to 6.3)	2837 (1643 to 4032)

*Adjusted for multilevel design (island, cluster), weighted for response rate (by cluster), with post-stratification adjustment to 2011 Census population stratified by municipality (15), 5-year age groups and gender

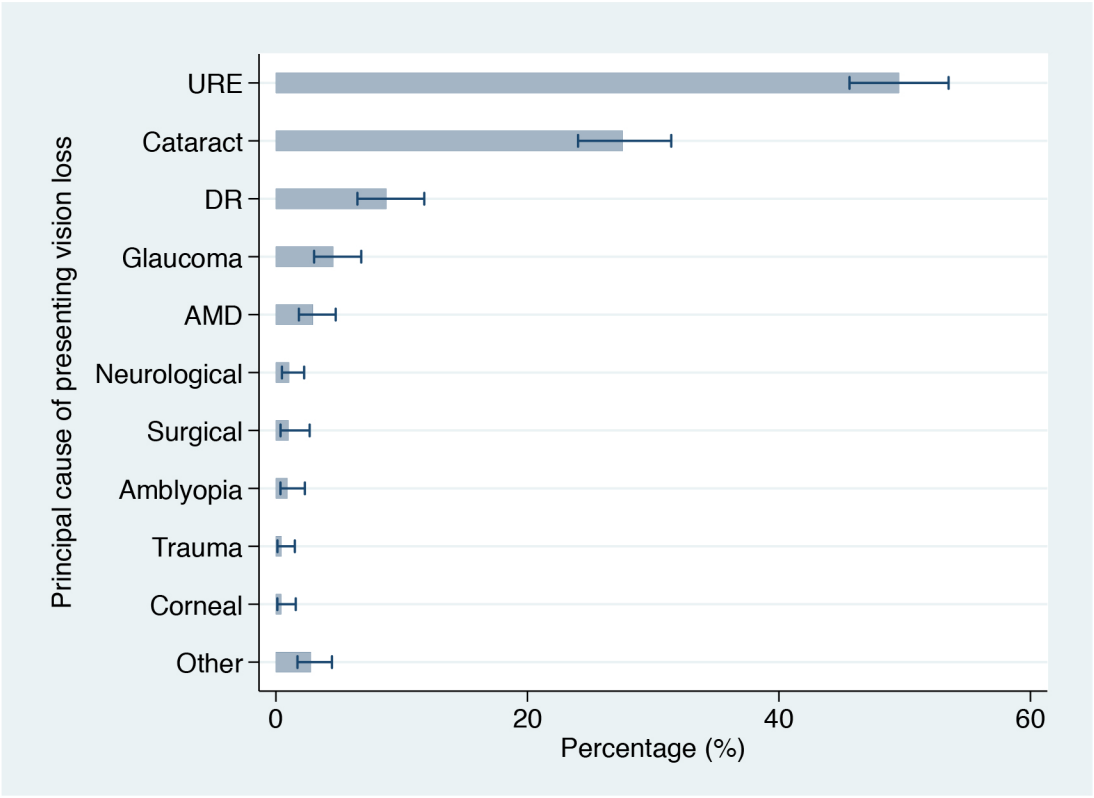

Figure 5.6 The principal causes of vision impairment (<6/12) in the better-seeing eye, based on the adjusted cause-specific prevalence, with 95% confidence intervals

5.1.10 Potentially avoidable vision loss

The vast majority of cases of presenting VI, 86.3 % (404/468), were potentially avoidable, when VI was defined to include URE, cataract, DR and glaucoma (Bourne, Stevens, et al., 2013). The adjusted population-based prevalence of potentially avoidable VI amongst those with VI was 86.11 % (95% CI 82.88-88.81). This indicated that amongst the 64,431 with distance VI in Trinidad and Tobago in 2014, there were 55,481 (95% CI 53,401 to 57,221) people with potentially avoidable distance VI. All 120,842 cases of NVI in those with normal distance vision were also readily correctable with reading spectacles.

5.1.11 Risk factors for presenting distance VI

Out of 3580 adult responders there were 468 with presenting distance vision impairment (DVI) (Snellen <6/12 in better-seeing eye). Those with DVI were significantly older than those with normal vision, with a mean age of 67.1 (sd 12.8) years, compared to 55.6 (sd 10.9) years (p<0.001). Those with and without DVI did not differ significantly in many factors, explored through multilevel single variable multiple logistic regression analysis. These non-significant factors included sex,

ethnicity, urbanicity index, history of other eye disease, or characteristics of the house (tenure, roof material, dwelling type, cooking fuel). Other variables ceased to be significant in the full multivariable model when nested model fit was explored using likelihood ratio testing. These included history of hypertension, household position, and household wall material. These factors may have been associated with a constellation of other factors associated with VI, rather than directly increasing the risk of VI. Region and municipality were not included in the model on account of overlap in content with the variable 'island'. Significant independent predictors of presenting DVI were included in a parsimonious multilevel multivariable logistic regression model containing 3325 observations (See Appendix D.3). These included age category, employment status, health insurance status, history of diagnosed diabetes, glaucoma, cataract and ownership of distance spectacles. Sex was also included in the model, as a potential confounding variable, and health insurance status and history of glaucoma were included because they improved model fit, whilst failing to achieve significance as independent predictors. The model identified that the risk of presenting DVI increased significantly with age, with those over 80 years being at ten times higher risk of DVI than those aged 40-49 years (OR 10.70, 95 % CI 6.17-18.57) (See Table 5.6). Compared to those in employment, those who were retired (OR 1.87, 95% CI 1.26-2.78), on home duties (OR 2.06, 95 % CI 1.38-3.07), unemployed (OR 2.20, 95 % CI 1.17-4.12) and disabled (OR 5.33, 95 % CI 2.74-10.39) were at between two and five times higher risk ($p < 0.001$). A past history of diabetes (OR 1.87, 95 % CI 1.46-2.39) or cataract (OR 2.09, 95 % 1.49-2.94) roughly doubled the strength of association, as did not owning distance spectacles (OR 2.06, 95 % 1.59-2.67) ($p < 0.001$ for each variable).

Ownership of different household goods was explored, as a proxy for socioeconomic status. These items were not included in the final multivariable model on account of incomplete data (n = 2930). In single variable analysis (SVA), ownership of certain household goods was associated with a lower likelihood of DVI, including air conditioning (OR 0.62, $p = 0.0009$), a computer (OR 0.52, $p < 0.001$), internet access (OR 0.62, $p<0.001$), cable TV (0.56, $p < 0.001$), a washer (0.45, $p = 0.0002$), a dryer (OR 0.67, $p = 0.013$), a microwave (OR 0.6, $p = 0.0092$), and a vehicle (OR 0.55, $p < 0.0001$). Ownership of a fridge/freezer, radio, swimming pool, TV or boat was not associated with DVI. When the significant household goods were included in the final multivariable analysis (MVA) model through stepwise addition, reducing the number of observations in the model to 1977, only internet access remained significant, associated with reduced likelihood of DVI (OR 0.83, 95 % CI 0.71-0.96, $p = 0.014$).

Table 5.6: Significant predictors of presenting distance vision impairment (DVI) versus normal vision in the multivariable logistic regression model

Characteristic		Normal vision % (n)	DVI (<6/12) % (n)	Odds Ratio (95% CI)	p-value
Responders		86.9 (3112)	13.1 (468)		
Age	40-49	33.6 (1046)	10.7 (50)	1.00	<0.001
	50-59	34.2 (1065)	18.2 (85)	1.35 (0.91-1.99)	
	60-69	20.1 (626)	25.3 (118)	2.48 (1.60-3.83)	
	70-79	9.3 (289)	29.1 (136)	5.18 (3.24-8.31)	
	80+	2.8 (86)	16.7 (78)	10.39 (6.00-17.98)	
Job status	Employed	55.1 (1640)	18.8 (83)	1.00	<0.001
	Home duties	17.3 (516)	23.6 (104)	2.06 (1.38-3.07)	
	Student	0.2 (7)	0.0 (0)	-	
	Un-employed	3.4 (100)	3.2 (14)	2.20 (1.17-4.12)	
	Retired	22.7 (675)	49.7 (219)	1.87 (1.26-2.78)	
	Disabled	1.2 (37)	4.8 (21)	5.33 (2.74-10.39)	
Health insurance	Yes	19.4 (586)	6.3 (29)	1.00	0.097
	No	80.6 (2435)	93.7 (431)	1.45 (0.93-2.25)	
Diabetes	No			1.00	<0.001
	Yes	18.6 (576)	37.2 (173)	1.87 (1.46-2.39)	
Glaucoma	No			1.00	0.089
	Yes	3.4 (104)	9.7 (45)	1.46 (0.95-2.25)	
Cataract	No			1.00	<0.001
	Yes	5.4 (168)	18.5 (86)	2.09 (1.49-2.94)	
Owns glasses	Yes			1.00	<0.001
	No			2.06 (1.59-2.67)	

Multivariable model adjusted for age category, sex, employment status, health insurance status, hypertension, diabetes, glaucoma, cataract and ownership of distance spectacles

5.1.12 Risk factors for presenting near vision impairment

Out of 3112 adults with normal presenting distance visual acuity (≤ 6/12) there were 695 with presenting NVI, attributed to uncorrected or under-corrected presbyopia. Those with NVI were on average significantly older, at 57.0 (sd 11.3) years, compared to 55.2 (sd 10.7) years (p = 0.003), but the association with age was not linear (See Table 5.7). Those with and without NVI did not differ significantly in many aspects, explored through multilevel single variable multiple logistic regression analysis. Specifically, there was no significant difference in the proportion reporting a prior diagnosis of hypertension, diabetes, glaucoma, cataract, or any other eye disease, nor a difference in the frequency of previous cataract surgery, nor any differences in participants' household tenure, household roof material, cooking fuel, or

type of dwelling unit. Further variables, which ceased to independently predict NVI once included in a full multivariable model included ethnicity, position in the household, region of inhabitance, municipality, urbanicity index of the community cluster, and household wall material. This suggested that, rather than directly increasing the risk of NVI, these variables were associated with a constellation of other factors that were associated with NVI. The significant independent predictors of presenting NVI were included in a parsimonious multilevel multivariable logistic regression model containing 2896 observations (See Appendix D.4). These included age, sex, employment status, health insurance status, and ownership of spectacles. Those at greatest risk of presenting NVI were men (OR 1.68, 95 % CI 1.35-2.09), who lacked health insurance (OR 2.47 95 % CI, 1.80-3.38), did not own spectacles (OR 3.60, 95 % CI 2.81-4.59), and were on home duties (OR 1.84, 95 % CI 1.36-2.48), or unemployed (OR 1.64, 95 % CI 1.03-2.61), or disabled (OR 3.76, 95 % CI 1.80-7.84) rather than being employed in the past 12 months (See Table 5.7).

Table 5.7: Significant predictors of presenting near vision impairment (NVI) versus normal vision in the multivariable logistic regression model

Characteristic		Normal near vision % (n)	NVI (<6/12) % (n)	Odds Ratio (95% CI)	p-value
Responders		77.7 (2417)	22.3 (695)		
Age (years)	40-49	34.6 (835)	30.4 (211)	1.00	0.003
	50-59	33.8 (817)	35.7 (248)	1.28 (1.01-1.62)	
	60-69	20.7 (499)	18.3 (127)	1.04 (0.74-1.45)	
	70-79	8.8 (212)	11.1 (77)	1.49 (0.98-2.27)	
	80+	2.2 (54)	4.6 (32)	2.60 (1.44-4.67)	
Gender	Female	57.3 (1386)	44.2 (307)	1.00	<0.001
	Male	42.7 (1031)	55.8 (388)	1.68 (1.35-2.09)	
Employment status	Employed	57.3 (1327)	47.6 (313)	1.00	<0.001
	Home duties	16.3 (378)	21.0 (138)	1.84 (1.36-2.48)	
	Student	0.3 (6)	0.2 (1)	0.65 (0.07-5.84)	
	Un-employed	2.8 (65)	5.3 (35)	1.64 (1.03-2.61)	
	Retired	22.5 (522)	23.3 (153)	1.24 (0.87-1.75)	
	Disabled	0.8 (19)	2.7 (18)	3.76 (1.80-7.84)	
Health insurance	Insured	22.5 (528)	8.7 (58)	1.00	<0.001
	Not insured	77.5 (1823)	91.3 (612)	2.47 (1.80-3.38)	
Own glasses	Yes	41.0 (988)	16.4 (113)	1.0	<0.001
	No	59.0 (1422)	83.6 (575)	3.60 (2.81-4.59)	

Multivariable model adjusted for age category, sex, employment status, health insurance status, and ownership of spectacles

5.2 Discussion

This survey provided the first estimates of the prevalence, causes and risk factors for distance and NVI in adults over 40 years in Trinidad and Tobago. In 2014 an estimated 120,842 people had NVI resulting from uncorrected presbyopia, and 64,431 people had distance VI in their better-seeing eye, of which 86.11 % resulted from URE, cataract, DR and glaucoma, and was thus potentially avoidable. Twice as many, 25.15 % of the population 40 years and above, had distance VI (< 6/12) in at least one eye.

These new estimates addressed the lack of epidemiological data on VI in the Caribbean region, highlighted by a systematic review of population-based vision and eye surveys for the GBD study (Bourne, Price et al., 2013). The adjusted prevalence of distance MSVI and blindness in Trinidad and Tobago in 2014, of 6.12 %, was almost half that reported in the Barbados Eye Survey conducted nearly 30 years ago (Hyman et al., 2001). This finding aligns with a modeled decline in the prevalence of VI in recent decades, both globally and within the Caribbean region (Leasher et al., 2014). However, the adjusted prevalence of blindness, at 0.73 % was still almost double that of other high-income regions, where the prevalence of presenting blindness is $\leq$ 0.4 % in those aged 50 years and above. This was not surprising, given the reported discrepancy between the official GNI per capita ($US18,380 in 2014) and mean household income (US$6,541) discussed in Chapter Section 1.3 (Ministry of Health, 2012; World Bank, 2014), which suggested marked income inequality. To place this in context, The World Bank thresholds for income designation in 2014 were US$4,126-12,745 for an upper middle income country, and US$1,046-4,125 for a lower middle income country (World Bank, 2017d). To close the observed blindness prevalence gap, further public health and health service development investment is likely to be needed in Trinidad and Tobago (G. A. Stevens et al., 2013).

URE was the leading cause of VI in the population, causing 47.4% of all distance VI, but no presenting blindness. There was negligible public sector provision of refractive services in 2014, with only one community optometry outreach program operating in the eastern Regional Health Authority. Whilst the cost of a sight test, at around £11, was affordable to a majority of the population, the cost of spectacles (£200-£300) was prohibitive for many. Furthermore, dispensing optometry practices were mostly located in urban areas, with some rural communities located more than 30 km by road from the nearest practice (Braithwaite et al., 2018).

Cataract was a leading cause of VI in the population (26.3 %), and a leading cause of blindness (28.8 %). Trinidad and Tobago had a pluralistic eye care system, but basic, free eye care, including cataract surgery, was universally available in the public system (Braithwaite et al., 2018). However, the backlog of public sector cataract patients waiting for surgery was identified to be a critical public health issue in 2014, and external partnerships were required intermittently to address this (Haims et al., 2014; Sonron, Tripathi, Bridgemohan, & Sharma, 2015). Ongoing oversight and investment by the Ministry of Health and its devolved partners will be necessary to facilitate access to timely and affordable cataract surgery (Silva, Bateman, & Contreras, 2002).

Whilst accounting for only 4.4 % of all VI in the population, glaucoma was the leading cause of blindness (31.7 %). From an international perspective, this is unusual. However, the Barbados Eye Survey, which predominantly included people of African ancestry, also reported that glaucoma accounted for 28.0 % of blindness (Hyman et al., 2001). Similarly, a nationally-representative study of adults aged 30 years and above in St Lucia found that 8.8 % had glaucoma (Mason et al., 1989). In addition to possible ethnic or genetic susceptibility to glaucoma in Caribbean populations of West African ancestry (Tham et al., 2014), several health system factors in Trinidad and Tobago may have been contributory. Whilst several glaucoma drops were freely available in the public sector in 2014, prostaglandin analogues, which are frequently the first line agent chosen to manage intraocular pressure internationally, were not included in the Chronic Disease Avoidance Program formulary. In addition, the 280 pharmacies in the country were predominantly located in urban centres, creating potential medicine access issues for more rural inhabitants (Maharaj et al., 2011). Furthermore, two out of the five public hospitals did not have a visual field analyser, which is essential for the diagnosis and management of glaucoma (Braithwaite et al., 2018).

Diabetic retinopathy accounted for 8.4 % of all VI, but 19.1 % of all blindness. The population's burden of diabetes had been high for several decades, relating in part to nutrition transformation and changing lifestyles in the second half of the 20th Century (Gulliford, 1996; Molokhia et al., 2011; Poon-King, 1968). The Barbados Eye Survey also found that 28.5 % of the population had evidence of DR on fundus photographs (Leske et al., 1999). The risk of sight-threatening DR was greater in those of South Asian, African, Latin American and indigenous tribal descent compared to white

populations (Sivaprasad, Gupta, Crosby-Nwaobi, et al., 2012; Sivaprasad, Gupta, Gulliford, et al., 2012). Ethnic-specific risk factors may include differential susceptibility to the conventional DR risk factors, differences in metabolic and anthropometric phenotypes, and genetic susceptibility (Sivaprasad, Gupta, Crosby-Nwaobi, et al., 2012). Furthermore, health system factors may have contributed to avoidable vision loss from DR. In 2014 there was no national DR screening program, and issues with timely access to diabetic laser treatment, and surgery for retinal detachment, were reported in the public sector (Braithwaite et al., 2018). The World Health Organisation estimated that the prevalence of diabetes in Trinidad and Tobago will more than double between 2000 and 2030, from an estimated 60,000 cases to 125,000 cases (WHO, 2017), making investment in screening and managing DR a very high priority.

Age was the strongest independent predictor of presenting distance VI, with the risk increasing ten fold in those over 80 years of age compared to those aged 40 to 49 years. With an ageing population, this finding has important implications for current and future demand on eye care services. Other independent associations with distance VI, which approximately double the risk, included having a diagnosis of diabetes, or cataract, not owning spectacles, and not being employed. Interestingly, sex, urban or rural inhabitance, and ethnicity were not associated with presenting distance VI in this study. Men who lacked health insurance and who were unemployed, on home duties or disabled were identified to be at greatest risk of presenting NVI resulting from presbyopia. Whilst the direction of any causal inference regarding the association between these independent variables and distance or near VI presents a challenge, the data help to identify subgroups at greatest risk.

The study had several limitations. Firstly, it lacked power to obtain precise prevalence estimates by subgroup (e.g. cause, age group), and this should be considered when interpreting the findings. Secondly, visual field constriction was not included in the blindness definition, and so glaucoma-related VI may be underestimated (Foster et al., 2002).

Thirdly, the high frequency of media opacity, especially cataract in this population, resulted in a relatively high proportion (11.0 %) of ungradable images. This was more than double the proportion of ungradable images reported in the recent Australian National Eye Health Survey, which used a Diabetic Retinopathy Screening nonmydriatic fundus camera, and reported that 1.3 % (59/4692) participants had

ungradable images in both eyes, and 4.3 % (202/4692) had ungradable images in one eye (Keel, Xie, Foreman, van Wingaarden, Taylor et al, 2018). A recent study in Australia directly compared the Topcon 3D OCT-1 Maestro and a DRS non-mydriatic camera amongst 222 diabetic patients and reported that the proportion of ungradable images was more than double using the combined OCT/fundus photos device, at 31.1% versus 13.8%, respectively (O'Halloran & Turner 2017). This indicates that the use of the Topcon 3D2000 combined OCT and fundus camera in NESTT may have been a contributory factor. Further work is needed to systematically review the gradability of images obtained in population-based surveys from different imaging devices. The effect ungradable images on cause attribution was mitigated by including a full history and examination by an ophthalmologist in the survey pathway, rather than task shifting to non-ophthalmologists within the survey team and relying solely on image grading, which was the preferred approach in the Australia National Eye Health Survey (Foreman, Keel, van Wijngaarden, Taylor, & Dirani, 2017).

Fourthly, 58.8 % (n = 18/31) blind, and 25.5 % (n = 55/215) MSVI, participants were examined at home by the ophthalmologist because they could not attend the regional clinic on account of poor health or limited mobility. Resources did not extend to purchasing portable imaging equipment. Finally, there was some missing data for certain variables, and this limited which variables were considered for inclusion in the multilevel multivariable risk factor models. Missing data arose for several reasons in the community screening questionnaires. Firstly, in some instances, the data collected by the enumerator was incomplete, either on account of participants preferring not to answer certain questions, such as those relating to ownership of household goods, or on account of enumerator error or omission. In other instances, data was collected but there was incomplete data entry. On further investigation, this typically occured if participants completed community screening and attended the regional clinic before the folder containing their completed hard copy enumeration form was returned from the field to the regional clinic for electronic data entry. When designing the participant pathway and survey logistics I did not anticipate that as many as eight visits would be needed to some communities, over more than one month, to achieve an acceptable response rate. Unfortunately, the project resources did not extend to duplicating the entry of over 13,500 community screening forms at the conclusion of the fieldwork, when the missing data was identified.

The study had a number of strengths. The rigorous sampling strategy, with up to eight repeat visits to each community cluster, minimized the risk of selection bias. By

sampling nearly 1 % of the total population, in 120 clusters, and selecting a small cluster size of 35, the findings are generalizable to the national non-institutionalized population. The comprehensive examination by an ophthalmologist, and independent retinal image grading, permitted robust assessment of the causes of VI, including identification of less frequent causes not captured by simpler survey designs. The response rate of 84 % compared very favorably with other high-income country surveys (Foreman, Xie, Keel, van Wijngaarden, Sandhu, et al., 2017; Varma, Paz, et al., 2004; T. Y. Wong et al., 2008). Weighting the prevalence estimates for non-response in each cluster, and adjusting for age, sex and municipality using the latest Census data mitigated the effect of non-response bias. Finally, the presentation of these findings, along with the methodological detail provided in Chapter 4 (Braithwaite, Verlander, et al., 2017) adhered to the 'Strengthening the Reporting of Observational Studies in Epidemiology' statement guidelines (von Elm et al., 2007).

5.3 Conclusions

This study provided the first population-based estimates for the prevalence of VI, the causes and risk factors in Trinidad and Tobago, and revealed a high proportion of potentially avoidable vision loss in persons over 40 years, with risk rising substantially with age. To address this, priorities for public sector resource investment include access to affordable spectacles, timely cataract surgery, investment to get visual field analysers for all hospital eye departments, and population-level health interventions to reduce incident diabetes, and to screen for, and treat, DR. This study provided the Government and stakeholders with an evidence-base to inform a national eye care strategy. The data provided a baseline for impact evaluation of future programs aiming to reduce avoidable vision loss in Trinidad and Tobago.

This chapter reported the prevalence of presenting VI, the causes and associated risk factors. The next chapter explores the impact of VI and blindness on HRQoL.

6

THE IMPACT OF VISION IMPAIRMENT ON HEALTH-RELATED QUALITY OF LIFE

6.1 Introduction

The last chapter presented the prevalence, causes and risk factors associated with presenting distance VI and NVI, and identified that 86.1 % of vision loss was potentially avoidable. Despite this compelling figure, the prevalence of avoidable vision loss internationally has reduced only slowly over the past few decades, even after adjustment for demographic changes and longer life expectancy. As societies and health systems seek to better understand the impact of disease states on health, and to adapt to the changing healthcare needs of their populations, alternative population and individual health measures have been sought, to supplement traditional disease burden metrics. Such complementary approaches may serve as advocacy tools, and assist policy makers and those responsible for the allocation of

limited resources, to target and prioritize healthcare and research investments effectively.

Very little was known about the factors associated with HRQoL in Trinidad and Tobago, or the wider Caribbean region. This chapter explores independent associations with HRQoL in the adult population of Trinidad and Tobago, assessed using the EQ-5D-5L instrument (Herdman et al., 2011). Of particular interest was whether the severity of presenting distance or NVI was independently associated with loss of HRQoL, and how many quality adjusted life years were lost at a national population level in 2014 on account of VI.

6.2 Methods

6.2.1 EQ-5D-5L instrument scoring

NESTT participants attending the regional clinic, and those who were visited at home by the survey ophthalmologist, were invited to complete the EQ-5D-5L instrument with an interviewer. This instrument was validated for use in the population of Trinidad and Tobago prior to the start of the study (Bailey, 2013; Bailey & Kind, 2010). EQ-5D-5L contains five questions relating to mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. Each question asked the participant to indicate whether they have no (score 1), slight (score 2), moderate (score 3), severe (score 4) or extreme (score 5) effects or problems. These answers resulted in 3125 (5^5) possible health states ranging from 11111 (best health) to 55555 (worst health, as bad as death) (Herdman et al., 2011). In addition, participants were invited to select a number on the visual analogue scale (EQ-VAS), which provided a single rating of self-perceived overall health, ranging from 0 to 100.

6.2.2 Transformation of raw values

The composite raw health states defined by the EQ-5D responses were transformed into a 'utility' score for each participant, using a scoring algorithm derived from public (societal) preferences. We used a Trinidad and Tobago value set and scoring algorithm developed for the 3-level EQ-5D, with cross walk to obtain utility values relating to the 5-level instrument, following a standard approach (Bailey et al., 2016; van Hout et al., 2012). The 3-level Trinidad and Tobago algorithm was estimated

using preference data collected using a discrete-choice experiment for bulk valuation with a time trade-off component for rescaling on a scale anchored at 0 (dead) and 1 (full health), with a resulting utility value set ranging from 1.000 for health state 11111, to -0.163 for health state 33333 (Bailey et al., 2016)..

6.2.3 Statistical analysis: prevalence estimation

Statistical analyses were performed using standard statistical software (StataCorp. 2013. Stata Statistical Software: Release 13.1. College Station, TX: StataCorp LP). Crude mean values and proportions were adjusted to account for the multilevel survey design (by island and cluster), and weighted for the probability of selection and response rate in each cluster using the survey suite of commands. A post-stratification adjustment was made using the latest national Census (2011) for the non-institutionalized population (stratified by 15 municipalities, gender and 5-year age categories). Finite population corrections were applied to the first and second sampling stages, including the total number of EDs by island, and the total number of households by island. Categories of vision were defined previously (See Table 4.4) (Bourne, Price, et al., 2013). The prevalence estimates for each category of presenting vision were applied to the 2014 mid-year population estimates (Ministry of Planning and Sustainable Development, 2014), to estimate the number of cases.

6.2.4 Independent predictors of less than full health

Section 4.14.2 outlined my approach to model selection following linear and logistic regression analysis. Potential explanatory variables for HRQoL were limited to those included in the survey in Stage 1, with additional variables from Stage 2 identified as potentially relevant in previous population-based surveys of vision loss or HRQoL, (See Table 2.4 and Appendix B.7, B.9 and B.10). Older respondents and women were expected to report greater utility loss (poorer health), and other anticipated risk factors included employment status, marital status, literacy or educational attainment, BMI and medical co-morbidities (Park et al., 2015; Swamy et al., 2009; Tsai et al., 2004; X. Wang et al., 2014). Additional variables, included for exploratory purposes, included religion, binge alcohol consumption, previous use of illicit drugs, and current smoking status.

A binary variable defined full health (utility value = 1.000) versus less than full health (utility < 1.000), in order to explore the relationship between the odds of less than full

health in relation to different categories of vision, with adjustment for significant independent predictors. These were explored in SVA. Where two binary or categorical variables contained exactly the same subcategory, only one was included in the analysis (e.g. Region of residence and Island both contained Tobago). All variables were then included in a full multivariable model, and model fit was assessed by comparing full and nested (reduced) models, estimated by maximum likelihood. The final model was that which was most parsimonious, and which had the smaller or more negative value of Akaike's and Schwarz's Bayesian information criterion (AIC and BIC). For parameter estimation by single- and multivariable multi-level mixed effects logistic regression analysis, global p-values were obtained using the LRT. A p-value of 0.05 or lower was taken to be statistically significant.

6.2.5 Estimation of health utility coefficients

To estimate the health utility coefficient associated with different types and levels of VI, for the purpose of QALY calculation, the survey parameters were set using the survey suite of commands, and then explored through single and multiple variable OLS regression analysis, with robust standard error estimation (RSE). Based on extensive simulation of alternative methods, Pullenayegum and colleagues advocated this approach for EQ-5D utility analysis in preference to alternative approaches such as Tobit censored regression, CLAD, and two-part models (Pullenayegum et al., 2010). They argued that OLS with RSE produced asymptotically unbiased estimation of regression parameters and valid confidence intervals, regardless of distributional assumptions (including non-normality and heteroscedasticity), because OLS fits a model for mean utility and not the whole distribution (Pullenayegum et al., 2010). Alternative statistical approaches were included in a sensitivity analysis to explore the effect on utility coefficients.

I used a backward model fitting approach, removing those with the highest p-value at each stage to identify the most parsimonious model. Wald p values were reported for linear regression analysis following the 'svy' command because LRT was not possible. Outliers were examined, and continuous variables explored to ensure no collinearity (indicated by a variance inflation factor exceeding ten) using the 'collin' command. The relationships between EQ-VAS scores and vision category were similarly explored, to provide a direct non-preference-based measure of patient reported outcomes (Parkin, Rice, & Devlin, 2010).

6.2.6 Estimation of QALY loss

The adjusted prevalence of each category of presenting vision in the better-seeing eye was used to estimate the cases in the national population in 2014. To estimate prevalent QALY loss per 100,000 population aged 40 years and above per year, the cases per 100,000 in each category of VI were multiplied by the utility coefficient for that vision category. To estimate the lifetime QALY loss experienced by one individual with incident VI at age 40 years, it was assumed that, in the absence of intervention, the vision level would persist to death, and a remaining life expectancy at 40 years of 36.1 years was assumed, which is the mean of the remaining life expectancy of women (38.3 years) and men (33.9 years) in 2014 (WHO, 2014). No discount was applied. The effect of uncertainty, both in the number of cases of VI, and in the utility coefficients associated with each vision category, on the QALY estimate, was explored in a sensitivity analysis.

6.3 Results

6.3.1 Response rate and summary quality of life outcomes

In total, 62.3 % (2658) eligible adults aged 40 years and above who were selected for inclusion in the survey participated in EQ-5D-5L assessment, yielding a design effect for this outcome of 1.43. The crude and adjusted vision and EQ-5D-5L outcomes in the NESTT sample are shown in Table 6.1. An estimated 52.8 % (95 % CI 50.6-54.8) of the population reported ‘no problem’ (score 1 out of 5) in any of the five domains on the instrument, and were considered to have full health (utility value 1.000). Considering each of the five domains, less than full health (i.e. a raw score > 1) was reported by 17.6 % (95 % CI 16.1-19.2) in relation to mobility, 5.5 % (95 % CI 4.8-6.3) in relation to self-care, and 10.6 % (95 % CI 9.6-11.8) in relation to usual activities. Some level of pain or discomfort was reported by 35.2 % (95 % CI 33.3-37.1), and some level of anxiety or depression was reported by 15.8 % (95 % CI 14.4-17.4). Overall, the adjusted mean EQ-VAS was 80.2 (95 % CI 79.6-80.8) and the adjusted mean utility was 0.920 (95 % CI 0.916-0.924).

Table 6.1: Summary EQ-5D-5L outcomes in the NESTT sample

Outcome	CRUDE % (n)	ADJUSTED (95% CI)*	Total n
Full health (raw score 11111)	49.8 (1312)	52.8 (50.6-54.9)	2634
EQ-5D-5L domain Problem with mobility	20.1 (535)	17.6 (16.1 to 19.2)	2658
Problem with self care	6.7 (177)	5.5 (4.8 to 6.3)	2657
Problem with usual activities	12.2 (323)	10.6 (9.6 to 11.8)	2657
Pain or discomfort	37.7 (998)	35.2 (33.3 to 37.1)	2649
Anxiety or depression	16.3 (432)	15.8 (14.4 to 17.4)	2644
Utility Mean (sd), range	0.913 (0.115), -0.098 to 1.000	0.920 (0.916 to 0.925)	2634
VAS Mean (sd), range	79.6 (14.7), 1 to 100	80.2 (79.6 to 80.8)	2626

*Adjusted for multistage cluster sampling (by island and cluster), weighted by the inverse of the respondent's probability for selection and the outcome response rate in each cluster, with post-stratification adjustment using the Census (2011) data (stratified by 15 municipalities, gender and 5-year age categories)

6.3.2 Association between vision category, age, sex and utility

The mean utility values by vision category are displayed in Table 6.2. The median utility value reduced with increasing severity of VI (See Figure 6.1). Mean utility also declined with age, was generally lower in women than in men, and was lower in those with presenting DVI than those without (See Figure 6.2).

6.3.3 Association between vision category, age, sex and EQ-VAS

The mean EQ-VAS values by vision category are displayed in Table 6.2. The median EQ-VAS scores also generally reduced with increasing severity of VI (See Figure 6.3). Similarly, the mean EQ-VAS scores declined with age, and women with DVI tended to report the lowest values (See Figure 6.4).

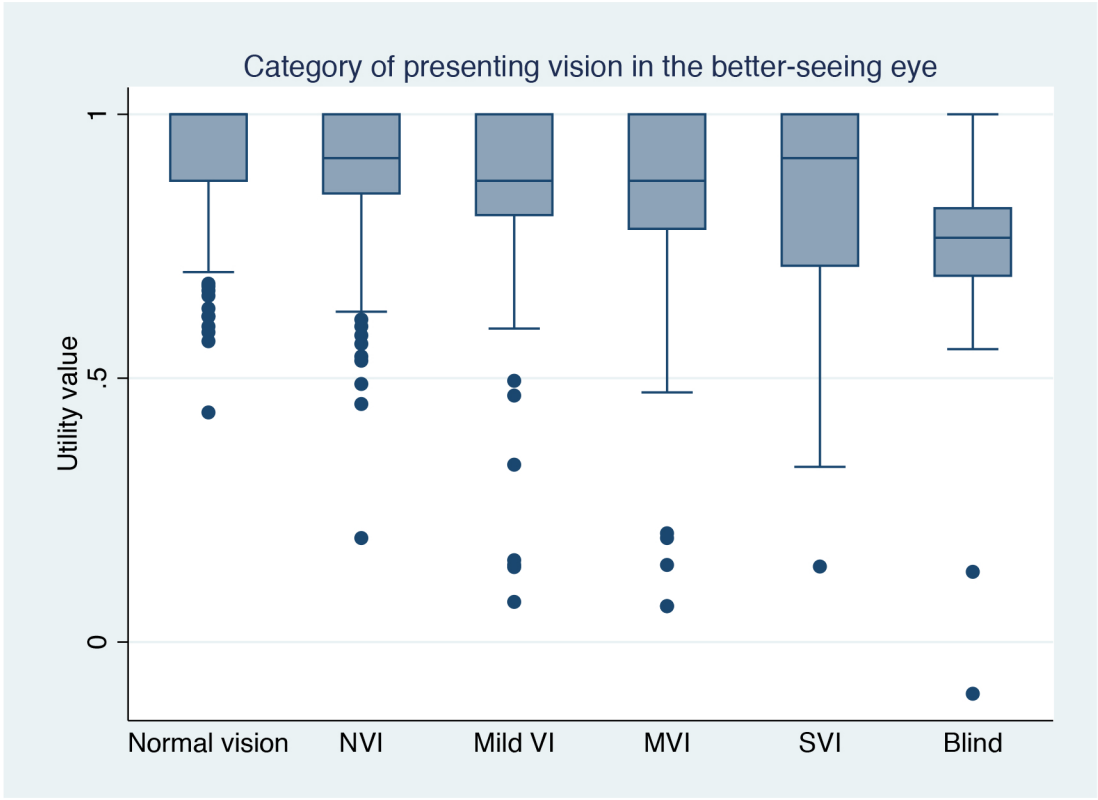

Figure 6.1: Box plot illustrating the median utility value with 25th and 75th percentiles (box), upper and lower adjacent values (whiskers), and outside values, by vision category in the better-seeing eye

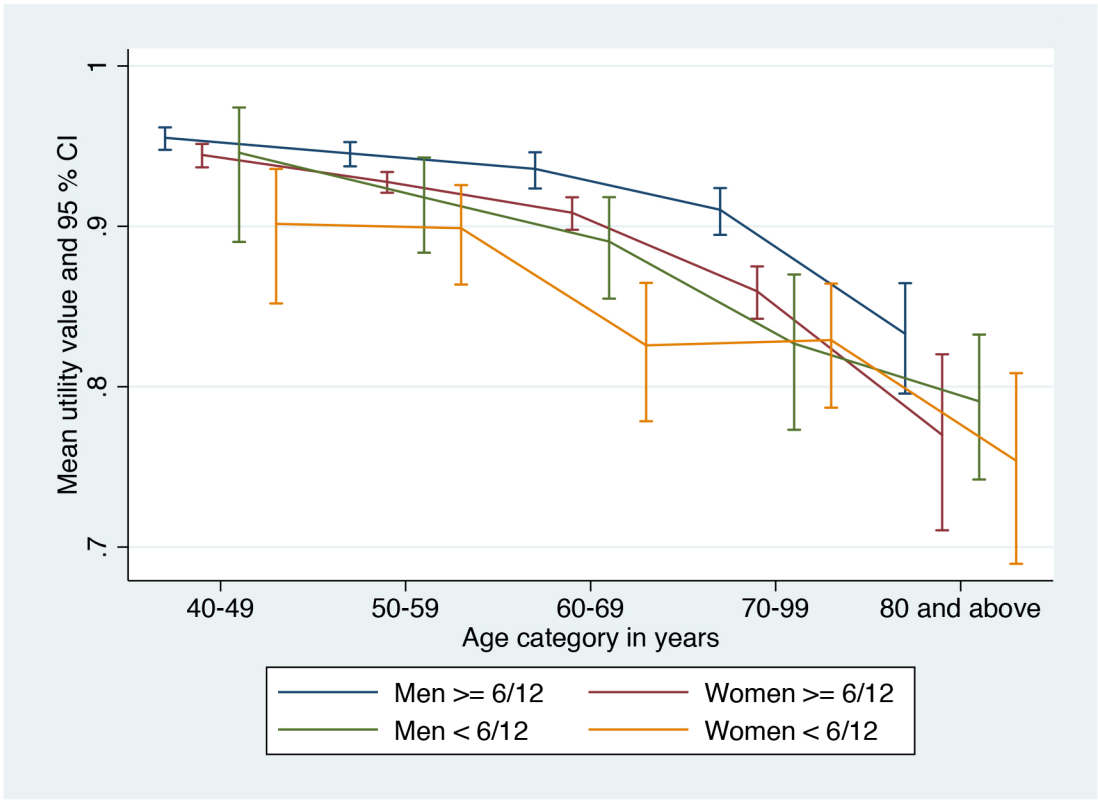

Figure 6.2: Line graph illustrating the relationship between the mean (and 95 % CI) utility value and age, in men and women with normal distance vision, versus distance vision impairment in the better-seeing eye

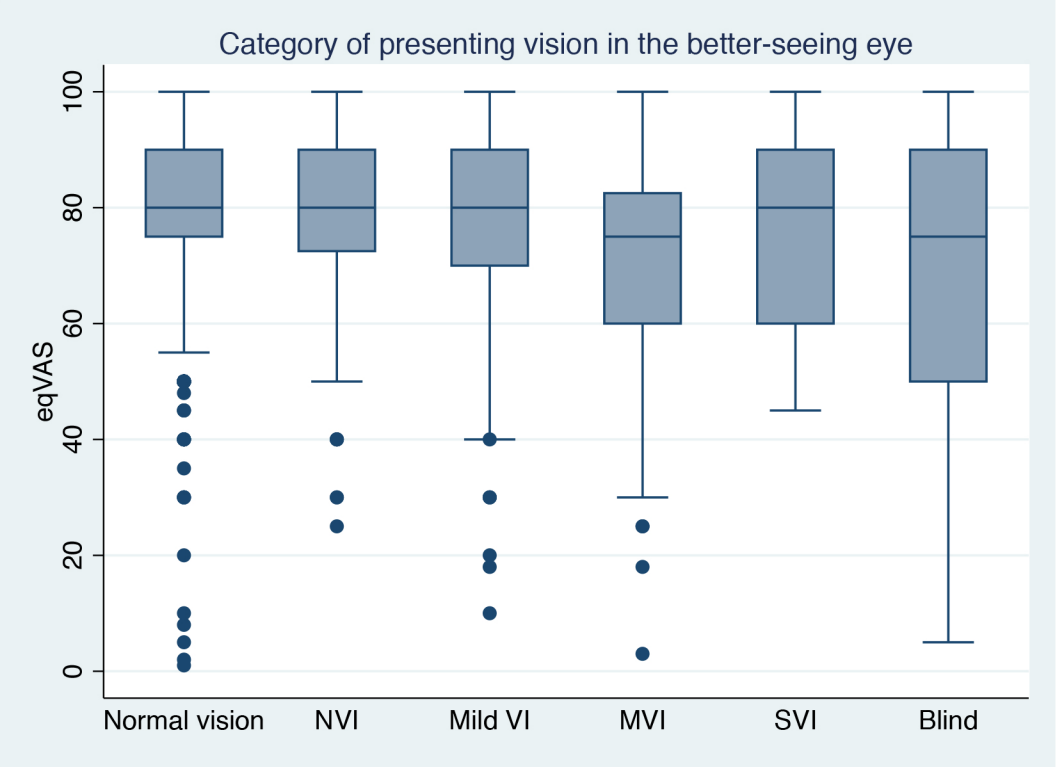

Figure 6.3: Box plot illustrating the median EQ-VAS value with 25th and 75th percentiles (box), upper and lower adjacent values (whiskers), and outside values, by vision category in the better-seeing eye

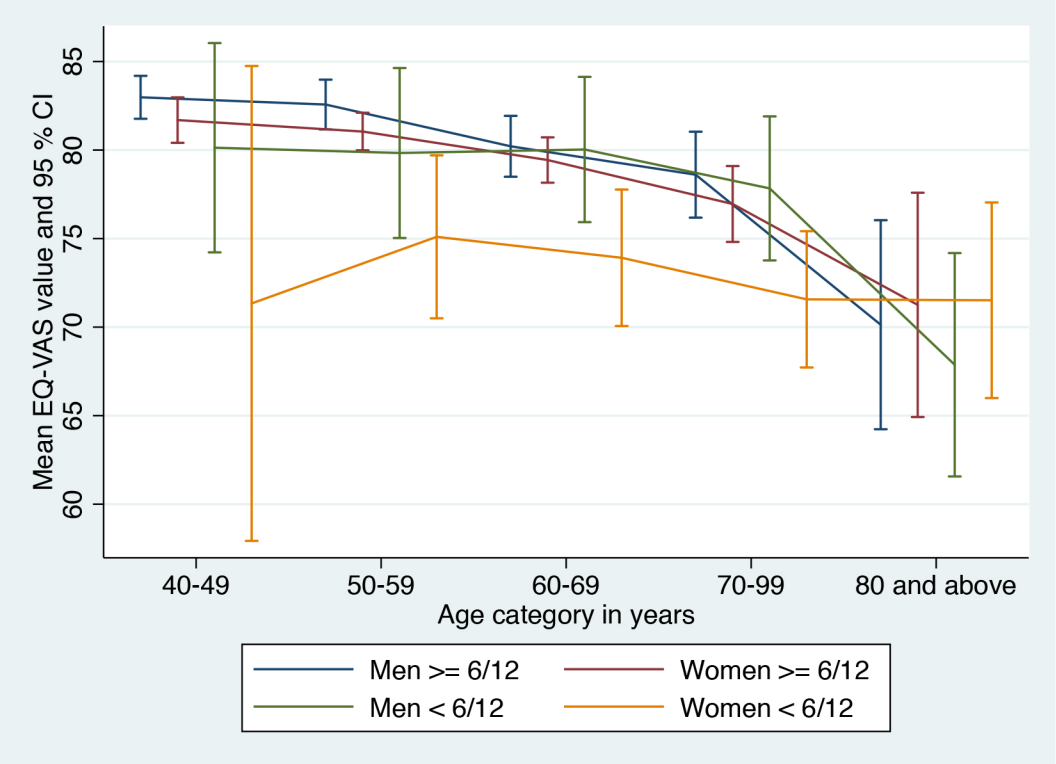

Figure 6.4: Line graph illustrating the relationship between the mean EQ-VAS value and age, in men and women with normal distance vision, versus distance vision impairment in the better-seeing eye

Table 6.2 Mean utility values and EQ-VAS scores by category of presenting vision in the better-seeing eye

Vision category	Mean utility value	95% CI	Mean EQ-VAS score	95% CI
Normal	0.938	0.934 to 0.942	81.6	81.0 to 82.2
NVI	0.917	0.909 to 0.925	80.2	79.0 to 81.4
Mild VI	0.878	0.858 to 0.899	77.4	74.3 to 80.5
Moderate VI	0.856	0.834 to 0.878	73.1	70.5 to 75.8
Severe VI	0.818	0.746 to 0.889	73.1	65.0 to 81.1
Blind	0.727	0.671 to 0.784	69.9	62.0 to 77.8
ALL	0.920	0.916 to 0.925	80.2	79.6 to 80.8

6.3.4 Characteristics of those reporting full health versus less than full health

Table 6.3 summarizes the characteristics of those reporting full health (utility 1.000) versus those reporting less than full health (utility < 1.000). The odds of reporting less than full health were explored in mixed effect multi-level logistic regression analysis. SVA identified the characteristics in which those reporting full health versus less than full health did not differ significantly. These included region of residence, ethnicity, religion, previous history of cancer or thyroid disease, smoking history, and household socioeconomic indicators. More specifically, the regional distribution of participants reflected the Census population, with 35.8 % (942) residing in southwest Trinidad, 25.7 % (678) residing in northwest Trinidad, 23.6 % (622) residing in north central Trinidad, 9.2 % (243) residing in eastern Trinidad, and 5.7 % (149) residing in Tobago (Ministry of Planning and Sustainable Development, 2012). Most participants identified as African (45.4 %, n = 1177) or South Asian (41.4 %, n = 1074) ethnicity. The most frequent religion was Christianity (73.5%, n = 1795) followed by Hinduism (21.2 %, n = 515). Most NESTT participants lived in a home that they owned (82.5 %, n = 1797), and the majority of homes were separate houses (77.7 %, n = 1722) with a sheet metal roof (96.3 %), and walls made of either concrete (49.8 %, n = 1109) or brick and concrete (32.6 %, n = 725). The most frequent cooking fuel in the home was gas (88.7 %, n = 1918) followed by electricity (10.4 %, n = 224).

All 25 potential explanatory variables were included in a full model containing 2138 observations. However, there was significant missing data for some variables included in Stage 2, especially amongst blind participants, many of whom had an abbreviated household assessment. The initial full model was not adequate to explore the association between VI and HRQoL, and a revised full model (including 19 variables) excluded marital status, BMI and household variables. Of these, only BMI was significant in SVA, with a linear association with the log odds of reporting less than full health (OR 1.02, 95 % CI 1.01-1.03).

After backward iterative assessment of model fit, the most parsimonious model, adjusted for 11 variables, included 2411 observations (See Appendix D.5). The odds of less than full health generally increased linearly with age (OR 1.03, 95% CI 1.02-1.04), and were greater in women than men (OR 1.59, 95 % CI 1.32-1.91). Less than full health was also significantly associated with vision category: compared to those with normal vision, those with blindness were 10 times more likely to report less than full health (OR 9.58, 95% CI 1.18-78.16) and those with NVI were 1.3 times more likely to report less than full health (OR 1.31 (1.03-1.66) (p = 0.009). Various medical co-morbidities also increased the likelihood of reporting less than full health, including having depression (OR 5.40, 95 % CI 1.95-14.99), previous stroke (OR 1.94, 95 % CI 1.11-3.51), arthritis (OR 2.69, 95 % CI 1.93-3.77), hypertension (OR 1.31, 95 % CI 1.07-1.60), and diabetes (OR 1.26, 95 % CI 1.08-1.58). Lacking health insurance was also a significant predictor (OR 1.37, 95 % CI 1.07-1.60). Higher educational attainment had a protective effect: in comparison to those who had only completed primary school, the odds of reporting less than full health were lower amongst those who had completed secondary school (OR 0.86, 95% CI 0.69-1.05), post-secondary school training (OR 0.75, 95 % CI 0.53-1.05), and university (OR 0.56, 95 % CI 0.38-0.84). Whilst not reaching statistical significance, inclusion of ethnicity improved model fit (p = 0.094). Variables which were significant in SVA, but ceased to be significant in the full multivariable model included job status in the past 12 months, household monthly income, hearing loss, previous myocardial infarction, being on prescription medication, and reporting consumption of alcohol in binges, and current or previous illicit drug use. These variables are summarized in Appendix D.6.

Table 6.3: Characteristics of NESTT participants, comparing those reporting full health (utility 1.000) to those reporting less than full health (utility < 1.000), with results from multilevel logistic regression analysis

Variable (n complete data)	Categories	Full health % (n)	Less than full health % (n)	Odds ratio (95% CI) Wald p value	p-value
Responder (2634)	**%** (n)	49.8 (1312)	50.2 (1322)		
Island (2634)	Trinidad Tobago	93.5 (1227) 6.5 (85)	95.2 (1258) 4.8 (64)		
11 variables included in final multivariable model*					
Vision category (2626)	Normal Normal unilateral NVI Mild VI MSVI Blind	54.9 (719) 14.3 (187) 20.2 (265) 5.3 (70) 5.1 (67) 0.2 (2)	41.9 (551) 17.9 (236) 19.6 (258) 9.4 (124) 9.3 (122) 1.9 (25)	1.0 1.14 (0.88-1.49) 1.31 (1.03-1.66) 1.53 (1.05-2.25) 1.39 (0.94-2.07) 9.58 (1.18-78.16)	0.009
Age category, years (2634)	40-49 50-59 60-69 70-79 80 and above	33.0 (432) 35.8 (469) 20.3 (266) 9.0 (118) 2.0 (26)	18.2 (241) 30.2 (399) 25.6 (338) 17.1 (226) 8.9 (118)	1.0 1.34 (1.06-1.70) 1.58 (1.21-2.08) 1.83 (1.29-2.60) 2.96 (1.65-5.30)	<0.001
Gender (2634)	Male Female	49.3 (647) 50.7 (665)	38.1 (504) 61.9 (818)	1.0 1.59 (1.32-1.91)	<0.001
Ethnicity (2594)	African South Asian Other Mixed	44.0 (571) 41.7 (541) 0.9 (11) 13.4 (174)	46.7 (606) 41.1 (533) 1.2 (15) 11.0 (143)	1.0 0.81 (0.66-1.00) 1.22 (0.49-3.00) 0.76 (0.57-1.02)	0.094
Health insurance (2599)	Yes No	23.9 (310) 76.2 (990)	12.2 (158) 87.8 (1141)	1.0 1.37 (1.07-1.77)	0.016
Hypertension (2634)	No Yes	72.6 (949) 54.4 (714)	56.2 (741) 67.4 (891)	1.0 1.31 (1.07-1.60)	0.011
Diabetes (2634)	No Yes	81.9 (1071) 26.6 (349)	71.2 (938) 35.6 (470)	1.0 1.26 (1.08-1.58)	0.044
Stroke (2634)	No Yes	98.5 (1292) 1.5 (20)	93.7 (1238) 6.4 (84)	1.0 1.94 (1.11-3.51)	0.022
Depression (2634)	No Yes	99.5 (1306) 0.5 (6)	98.2 (1298) 1.8 (24)	1.0 5.40 (1.95-14.99)	0.005
Arthritis (2634)	No Yes	95.2 (1249) 4.8 (63)	84.3 (1115) 15.7 (207)	1.0 2.69 (1.93-3.77)	<0.001
Highest level of education completed (2403)	Primary Secondary Post secondary University	41.0 (516) 39.8 (501) 10.1 (127) 9.06 (114)	55.5 (635) 32.8 (375) 7.4 (85) 4.4 (50)	1.0 0.86 (0.69-1.05) 0.75 (0.53-1.05) 0.56 (0.38-0.84)	0.026

p-value from multilevel multivariable logistic regression model adjusted for 11 variables (n=2411)

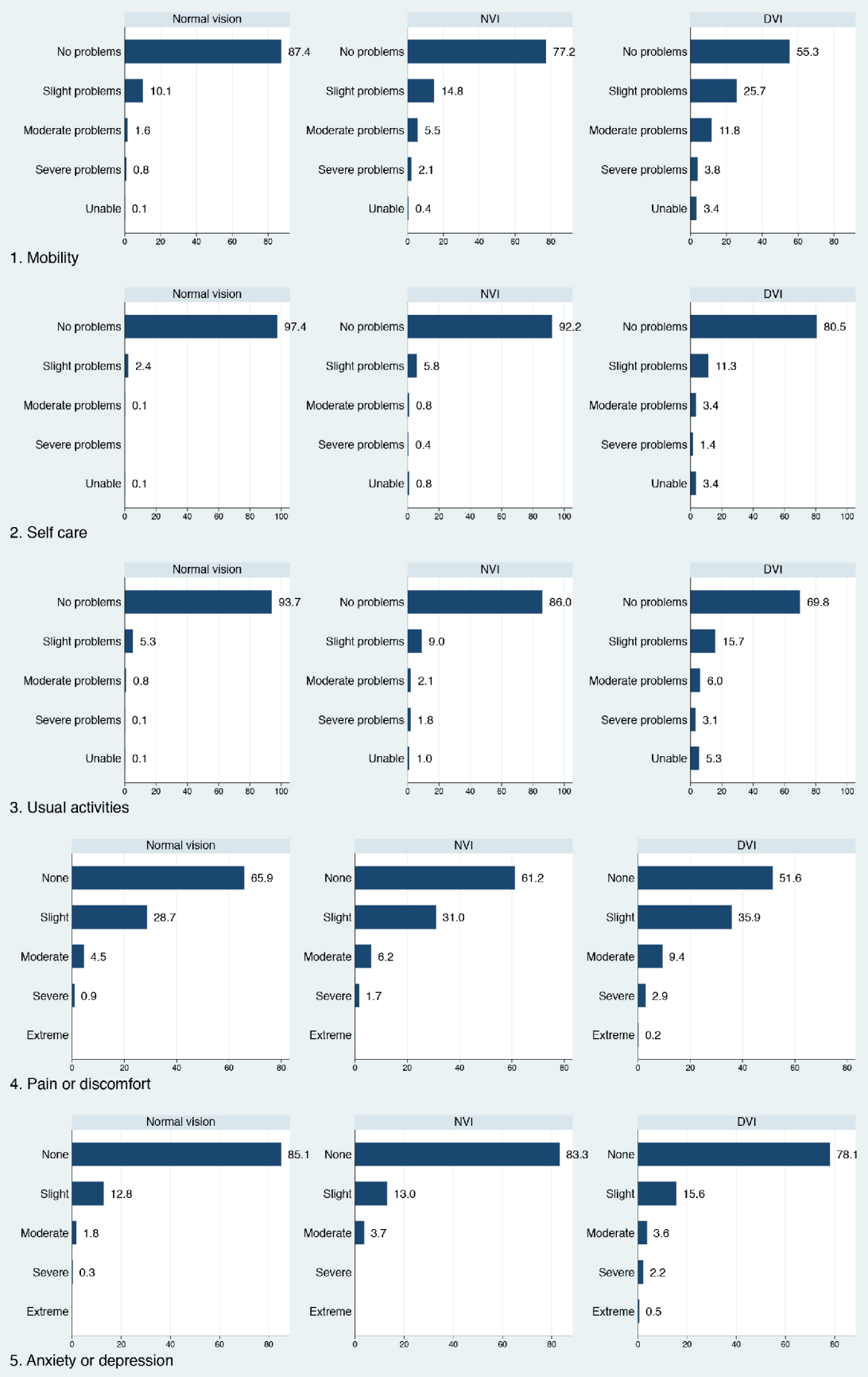

Figure 6.5 Comparison of EQ-5D-5L responses amongst those with normal vision, near vision impairment (NVI) and distance vision impairment (DVI)

6.3.5 Impact of vision impairment on individual EQ-5D-5L domains

Figure 6.5 illustrates the percentage of participants with normal vision, NVI and DVI who responded to each level of the five EQ-5D-5L domains. Amongst those with DVI, difficulty was experienced in three domains in particular, with 3.4 % reporting being unable to walk, 3.4 % reporting being unable to bathe or dress themselves, and 5.3 % reporting being unable to do their usual activities, in comparison to 0.1 % of those with normal vision. The odds of having no reduction (score 1), versus some reduction (score $\geq$ 2) in each domain were also explored in a series of multi-level multivariable models adjusted for age, sex, health insurance status and five significant co-morbidities (hypertension, diabetes, stroke, depression and arthritis). NVI significantly increased the odds of reporting some difficulty with mobility (OR 1.84, 95 % CI 1.35-2.50, p<0.001), self-care (OR 2.24, 95 % CI 1.33 to 3.76, p = 0.002), and usual activities (OR 1.89, 95 % CI 1.29-2.77, p = 0.001), but did not significantly increase the likelihood of reporting pain or depression. DVI significantly increased the odds of reporting some difficulty in all five domains. Specifically, those with DVI reported increased difficulty with mobility (OR 3.09, 95 % CI 2.29-4.16, p < 0.001), self-care (OR 4.11, 95 % CI 2.60-6.48, p < 0.001), and usual activities (OR 3.12, 95 % CI 2.21-4.40, p < 0.001), and were also more likely to report pain or discomfort (OR 1.39, 95 % CI 1.08-1.79, p = 0.012) and depression or anxiety (OR 1.43, 95 % CI 1.04-1.96, p = 0.025).

6.3.6 Impact of vision impairment on utility score

All variables without missing data (<20%) in those with vision impairment were included in a full multivariable OLS regression analysis with backward exclusion of variables. The final most parsimonious model was adjusted for sex, age category, significant comorbidities (stroke, renal impairment, depression, arthritis, diabetes and hypertension), lack of health insurance, being on prescription medications, employment status and literacy level (See Appendix D.7). The adjusted utility coefficients associated with different categories of vision were -0.012 (95 % CI -0.004 to -0.021) for NVI, -0.020 (95 % CI -0.004 to 0.013) for mild VI, -0.045 (95 % CI -0.024 to -0.067) for MVI, -0.091 (95 % CI -0.031 to -0.151) for SVI, and -0.140 (95 % CI -0.092 to -0.192) for blindness (See Figure 6.6). Blindness had the largest independent effect on utility value of any variable explored in this analysis.

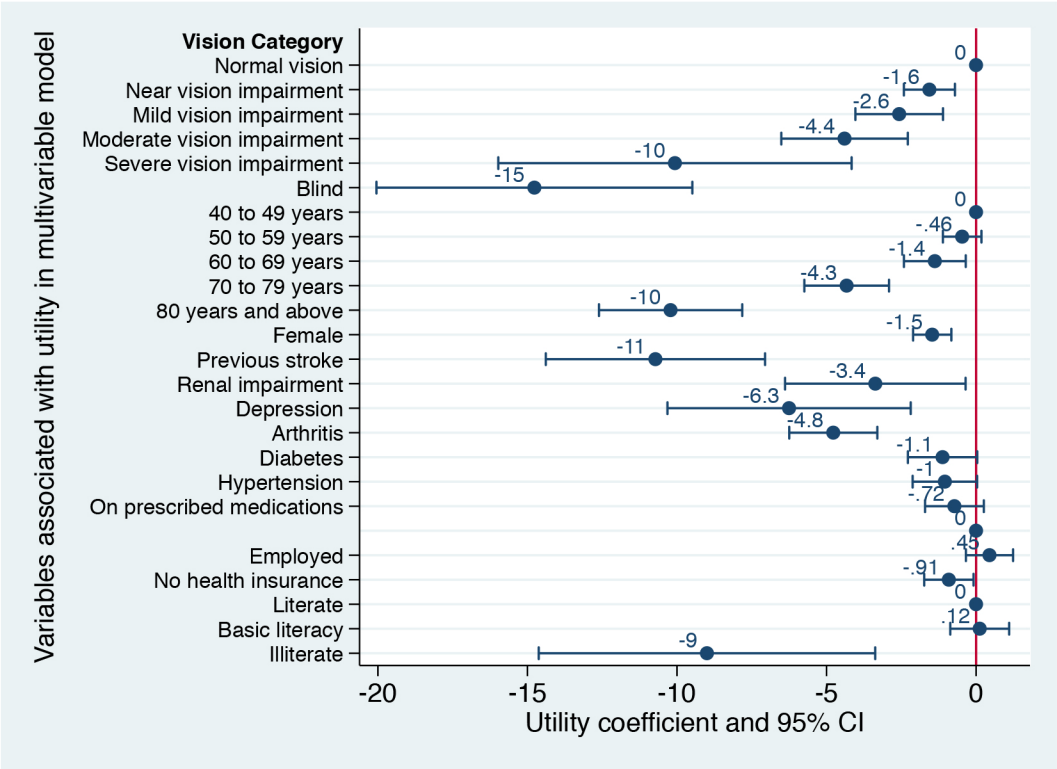

Figure 6.6 Utility coefficients (with 95 % CI) generated by the multilevel multivariable model adjusted for 13 independent predictors

6.3.7 Impact of vision impairment on EQ-VAS score

The same analysis approach was used to explore the association between vision and EQ-VAS score after adjustment for significant variables. The final OLS multivariable model was adjusted for sex, age category, significant comorbidities (stroke, depression, arthritis, diabetes and hypertension), ethnicity, being on prescription medications, and previous or current use of illicit drugs (See Appendix D.8). The adjusted EQ-VAS score coefficients associated with different categories of vision included -1.6 (95 % CI -0.2 to -3.0) for NVI, -2.5 (95 % CI 0.7 to -5.7) for mild VI, -6.2 (95 % CI -3.1 to -9.2) for MVI, -6.0 (95 % CI 1.9 to -13.9) for SVI, and -7.8 95 % CI -0.2 to -15.3) for blindness (See Figure 6.7). Blindness had the largest independent effect on EQ-VAS score of any variable explored in this analysis.

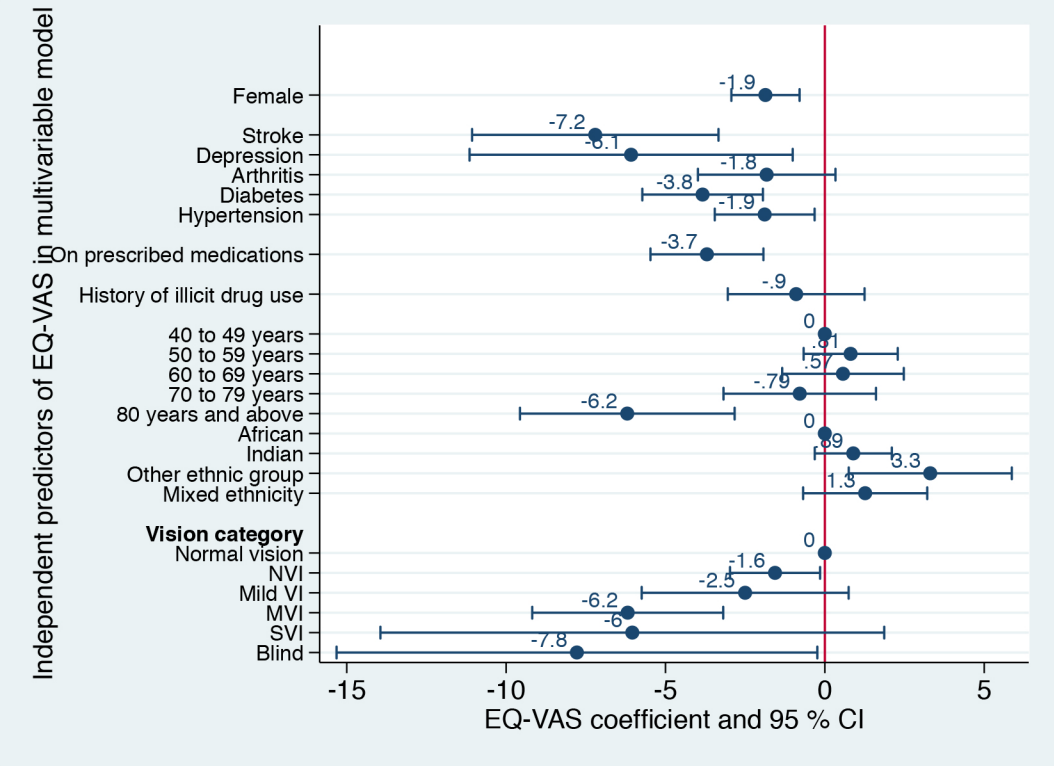

Figure 6.7 EQ-VAS score coefficients (with 95 % CI) generated by the multilevel multivariable model adjusted for 11 independent predictors

6.3.8 Quality adjusted life years lost

There were an estimated 4,131 QALYs lost in the population of Trinidad and Tobago aged 40 years and above on account of VI in 2014, including 1502 QALYs (36.4 %) resulting from NVI, 621 QALYs (15.0 %) resulting from mild VI, 1213 QALYs (29.4 %) resulting from mild VI, 233 QALYs (5.6 %) resulting from SVI and 562 QALYs (13.6 %) resulting from blindness. The QALY loss associated with all VI in 2014 was 762 QALYs per 100,000 people aged 40 years and above per year, of which 695 QALYs were potentially avoidable (see Table 6.4).

Considering one person aged 40 years with a remaining life expectancy of 36.1 years, applying no discount rate, and assuming a stable vision state from age 40 years until death, the lifetime QALY loss was 0.45 QALYs for NVI, 0.72 QALYs for mild VI, 1.64 QALYs for MVI, 3.30 QALYs for SVI and 5.13 QALYs for blindness. This gives an indication of the potential value of intervening to treat curable causes of presenting VI, such as uncorrected distance and near refractive error, or cataract.

Table 6.4 Quality adjusted life year loss per 100,000 population aged 40 years and above per year (2014)

Vision category	Adjusted prevalence	Utility	QALY loss per 100,000 per year	% QALY	Avoidable
NVI	0.2230	-0.012	-277.2	36.4	-277.2
Mild	0.0577	-0.020	-114.6	15.0	-98.7
MVI	0.0492	-0.045	-223.8	29.4	-192.8
SVI	0.0047	-0.091	-42.9	5.6	-37.0
Blind	0.0073	-0.142	-103.8	13.6	-89.4
TOTAL			-762.3	100.0	-694.9

6.3.9 Sensitivity analysis

The effect on total QALY loss of uncertainty around the true number of cases of VI in 2014, and the true utility value, was considered by varying these estimates around their 95 % CI and recalculating the QALY loss. Uncertainty in total cases of VI resulted in a range in total QALY loss from 3504 to 4743 QALYs. Uncertainty in the true utility coefficient for each vision category, resulted in a range of total QALY loss from 1655 to 6608 QALYs.

The effect of alternative statistical analysis approaches (Tobit, CLAD, and generalized linear model (GLM) with Poisson distribution) on the utility coefficient for blindness, was explored in comparison to OLS with RSE, with adjustment for age and sex only. For this analysis disutility (1-utility) was the dependent variable, to enable GLM to be included in the comparison, as this requires positive values. This revealed similar blindness disutility coefficients for OLS with robust standard error estimation (0.138), Tobit (0.135), robust linear regression with M-estimator and Tukey biweight function (0.110) and CLAD (0.090). The GLM with a Poisson distribution and log link yielded a markedly different coefficient for blindness disutility, of 0.670, which was not statistically significant ($p = 0.071$), and which seemed implausibly high.

The choice of vision category definitions was explored, compared to an alternative, which took account of the vision state in both eyes rather than the distance visual acuity in the better-seeing eye only. This model was adjusted for the same covariates that were included in the multivariable model to determine the utility coefficients (See section 6.4). The utility coefficient for blindness remained similar, at -0.145 (95% CI -

0.097 to -0.194, p < 0.001), as did that for binocular normal distance visual acuity with NVI, at -0.016 (95 % CI -0.007 to -0.024, p < 0.001). Importantly, uniocular blindness was associated with significant reduction in the utility coefficients, of -0.019 (95 % CI -0.002 to -0.037, p = 0.029) when the other eye had normal vision, of -0.092 (95% CI -0.0169 to -0.166, p = 0.017) when the other eye had mild VI, and of -0.101 (95 % CI -0.063 to -0.138, p < 0.001) when the other eye had MSVI.

Lower and upper limits of the 95 % CI for the Trinidad and Tobago utility value set were not available. The effect on the utility coefficient, by vision level, of using an alternative EQ-5D-5L value set obtained from a UK population was explored (Devlin, 2016). The coefficients demonstrated very close agreement. Specifically, the adjusted utility coefficients associated with different categories of vision were -0.011 (95 % CI -0.003 to -0.019) for NVI, -0.022 (95 % CI -0.002 to 0.041) for mild VI, -0.062 (95 % CI -0.033 to -0.090) for MVI, -0.064 (95 % CI -0.016 to -0.112) for SVI, and -0.159 (95 % CI -0.098 to -0.220) for blindness. This confirmed that the findings of this study were not overly sensitive to the choice of the Trinidad and Tobago value set.

6.4 Discussion

To our knowledge, this study was the first to explore the association between VI and HRQoL in a Caribbean country. Both DVI and NVI were significant predictors of HRQoL loss, after adjustment for other independent predictors. Overall, VI was associated with a 762 QALYs lost per 100,000 population aged 40 years and above in 2014. The difference in mean utility associated with different levels of VI, after adjustment for significant explanatory variables, ranged from -0.012 for NVI to -0.140 for blindness. A 40-year-old with blindness could expect to lose 5.13 QALYs over the course of his or her lifetime, whilst someone with NVI only could expect to lose 0.45 QALYs, in the absence of effective intervention. Whilst the latter reflects only a small decrement in HRQoL to a single individual, NVI resulted in significant population burden, affecting an estimated 120,842 people. This highlights the importance of including measurement of near visual acuity in future population-based vision surveys, which has historically been neglected (Bourne et al., 2017). The identified burden of VI affecting adults over 40 years in 2014 was associated with 695 potentially avoidable lost QALYs.

This study also provided the first insight into normative values for the EQ-5D-5L in Trinidad and Tobago, and identified independent predictors of HRQoL. The mean utility value, of 0.920 (95 % CI 0.916 to 0.925), and proportion reporting full health (52.8 %, 95 % CI 50.6-54.9) were similar to normative values from other high-income countries, which report mean utilities around 0.91, and full health in 42.8 % to 62.4 % of the population (See Appendix B.10) (Feng et al., 2015; Garcia-Gordillo et al., 2016; Hinz et al., 2014; McCaffrey et al., 2016; Shiroiwa et al., 2016). However, the proportion of the general population reporting some pain or discomfort was surprisingly high, at 35.2 % (95 % CI 33.3 to 37.1), and this was unrelated to VI. As in other studies, older age, female sex, lower education attainment, marital status and medical comorbidities were significant predictors of reporting less than full health, but ethnic and religious group were not (See Appendix B.9 and B.10).

A previous systematic review of generic preference-based measures of HRQoL in visual disorders identified no population-based surveys including levels of VI from all causes (Tosh et al., 2012). Two more recent epidemiological eye surveys included EQ-5D (Park et al., 2015; X. Wang et al., 2014). The Singapore Epidemiology of Eye Disease study (n = 10,009) modeled index scores derived from EQ-5D-3L, using ordinary OLS with RSE estimation, and reported an association between utility loss and severity of VI, with differences between ethnic groups. Considering the reduction EQ-5D-3L index score in those with binocular SVI compared to normal vision, Indian participants had a -0.127 (95% CI -0.237 to -0.017) difference, Malay participants had a -0.085 (95% CI 0.148 to -0.022) difference, and Chinese participants had a -0.044 (95 % CI 0.001 to -0.089) difference, after adjustment for socio-demographic characteristics. This study reported that bilateral SVI was associated with problems with mobility (OR 3.7) and usual activities (OR 6.5) in Chinese participants, whilst Indian participants were more likely to experience depression or anxiety (OR 2.7). The annual QALY loss per 100,000 was 512 QALYs in the Chinese population, 609 QALYs in the Indian population and 707 QALYs in the Malay population, and exceeded that associated with other health conditions.

The Korean National Health and Nutrition Examination Survey (n = 28,825) used the EQ-5D-5L and ordinal logistic regression, and reported that those with a utility value in the lowest quintile had significantly greater odds (OR 3.39, 95 % CI 1.46-7.84, p = 0.004) of having SVI than normal vision (Park et al., 2015). An earlier population-based normative value study in the USA modeled EQ-5D-3L utility values with CLAD analysis, and reported no marginal disutility with VI, but this study included only self-

reported vision status (Sullivan et al., 2005), which is not a reliable alternative to measuring visual acuity (Foreman, Xie, Keel, van Wijngaarden, Taylor, et al., 2017). Some of the observed differences between these studies may have resulted from use of the 3-level rather than EQ-5D-5L instrument, which may have less sensitivity to detect differences in health status between people. Other differences arise from the inclusion of different variables in multivariable models. Furthermore, there is a lack of consensus about the optimal statistical techniques to use to analyse EQ-5D utility data, and use of different statistical analysis approaches may have influenced findings (Basu & Manca, 2012; Hernandez Alava et al., 2012; Pullenayegum et al., 2010).

This study had a number of limitations. Firstly, the response rate was suboptimal, at 62.3 %, because HRQoL was a secondary outcome measure, and EQ-5D-5L was included in the regional clinic but not in the first stage questionnaire administered at the doorstep. To mitigate against potential non-response bias, the EQ-5D-5L results were adjusted by the response rate in each cluster. Secondly, the EQ-5D-5L questions were administered in the same order to all participants, which could have introduced bias resulting from fatigue or carry-over effects in answering later questions. However, the instrument is short, and previous studies have identified no clinically significant effect of the order of EQ-5D administration (McColl et al., 2003). Thirdly, since blind participants cannot see the EQ-VAS scale, they were asked to visualize it, which may have been a source of bias. However, telephone administration of EQ-5D and EQ-VAS has previously been found to have similar results to self-administration in normally sighted individuals (McPhail et al., 2009; Wu et al., 1997). Fourthly, the application of the Trinidad and Tobago value set, like any value set, introduced exogenous variance to the health profile data. To explore the sensitivity of our QALY estimates to the use of this value set, the model was rerun using the UK EQ-5D-5L value set (Devlin, 2016), and close agreement was found. In addition, the analysis was complemented by modeling the association between vision category and EQ-VAS score with adjustment for significant predictor variables, because EQ-VAS is not weighted by current societal preferences (Parkin et al., 2010). Finally, there was missing data for certain variables of interest, including BMI and marital status, amongst blind individuals, a disproportionate number of whom were examined at home rather than in clinic, with an abbreviated questionnaire.

The study had a number of strengths. The robust sampling methodology yielded a nationally representative population-based sample of adults aged 40 years and

above, providing the first normative values for EQ-5D-5L in Trinidad and Tobago. The comprehensive assessment protocol, which included an extensive range of important potential explanatory variables, facilitated exploration of the independent association between severity of distance VI and HRQoL. To our knowledge, this study was also the first population-based eye survey to observe the small but significant impact of binocular NVI on HRQoL.

6.5 Conclusion

This study identified a significant independent association between VI and reduced HRQoL, demonstrating the importance of addressing the burden of avoidable vision loss in this population. The EQ-5D-5L was simple to administer and acceptable to the participants surveyed and can be recommended as a useful HRQoL tool for use in Trinidad and Tobago and elsewhere in the Caribbean in the future. The generation of utility scores associated with different levels of VI permits future cost-effectiveness analysis relating to alternative intervention strategies, to support development of an evidence-based National Eye care Strategy in Trinidad and Tobago.

This chapter explored the impact of VI on HRQoL. The next chapter explores the societal cost of vision loss.

7

THE SOCIETAL COST OF VISION LOSS

7.1 Introduction

The global cost of vision loss was estimated at US$3 trillion in 2010, and projected to rise 20 % by 2020 (Gordois et al., 2012). Considered from a societal perspective, economic cost encompasses not only the direct costs resulting from eye care services, treatments and non-medical costs, and the indirect costs resulting from lost income, but also less tangible impacts on affected individuals and their family and friends. The DALY was developed to try and capture such intangible effects of disease (Murray, 1994). Globally, there were an estimated 18,837,000 DALYs associated with vision disorders in 2010 (Murray et al., 2013).

Despite the apparent importance of this problem, there has been relatively little primary observational research on the societal economic impact of VI. Cost of illness studies estimate the economic burden associated with a disease or health state, through describing, itemizing, valuing and summing the associated costs (D.P. Rice, 1967). However, their usefulness to policy makers has been debated since their

inception more than 50 years ago, with arguments advanced by proponents (Behrens & Henke, 1988; D. P. Rice, 1994), and critics (Koopmanschap, 1998). Arguably, cost of illness studies provide the most valuable insight for policy makers when designed as descriptive, bottom-up studies that capture "the true cost to society", "envisage the different subjects who bear the costs" and explain sources of cost variability (Tarricone, 2006). Every country has a unique population, and unique political, social welfare and health care systems, and these are likely to influence the economic impact of VI. A recent systematic review of 31 cost of vision loss studies from high-income countries revealed very few based on primary observational research from population-based surveys (Koberlein et al., 2013), and concluded that study heterogeneity precluded formal meta-analysis.

This chapter presents an estimate of the societal economic cost in 2014 resulting from VI involving the better-seeing eye of adults aged 40 years and above in the non-institutionalized population of Trinidad and Tobago. The analysis adhered to cost categories outlined by cost of vision loss consensus guidelines developed in 2010, under the auspices of the Association for Research in Vision and Ophthalmology (Frick et al., 2010). Additional descriptive data are provided to give additional insight into the economic impact of VI in Trinidad and Tobago in 2014.

7.2 Methods

7.2.1 Statistical methods

Statistical analyses used standard statistical software (StataCorp. 2013. Stata Statistical Software: Release 13.1. College Station, TX: StataCorp LP).
Crude estimates were reported when estimating means or proportions in a subgroup of NESTT participants. 'Adjusted' estimates were reported when estimating means or proportions in the full study group, who were selected to be population-representative. Adjusted estimates were obtained using the 'svy' suite of commands in STATA as outlined previously (Section 4.14.1). In brief, to obtain the adjusted estimates, crude estimates for each outcome variable were adjusted for the multi-level survey design (by island and cluster), weighted for the probability of selection, and the response rate to the outcome variable in each cluster (weight = 1 /response rate), and a post-stratification adjustment was made using the latest national Census (2011) for the non-institutionalized population (stratified by 15 municipalities, gender and 5-year age categories). Finite population corrections were applied to the first and second

sampling stages, including the total number of EDs by island, and the total number of households by island.

7.2.2 Cases of vision impairment and blindness

For the cost analysis, the same categories of vision defined previously were used (See Table 4.4) (Bourne, Price, et al., 2013). The adjusted prevalence estimates were applied to the 2014 mid-year population aged 40 years and above, of 541,894 people (Ministry of Planning and Sustainable Development, 2014), to estimate cases (Table 5.4).

7.2.3 Classification of economic impact

Costs were estimated in each category recommended by Consensus guidelines, and these are outlined below (Frick et al., 2010). The societal perspective was chosen to estimate all prevalent costs associated with VI in persons aged 40 years and above in Trinidad and Tobago in 2014, regardless of who incurred them. This approach included costs to individuals, family and friends providing informal care, the Government, health care system, and employers (in the form of productivity losses) (Gray, Clarke, Wolstenholme & Wordsworth, 2011).

Participants were asked to detail any OOPE over the past 12 months on each of these services, and on laser therapy, eye operations, eye medications and spectacles or contact lenses. They were asked which sector was used for eye care (public, private, both), and if they had health insurance. The usual mode of transport to eye care services was explored, along with OOPE on eye care-related travel. The number of hours of informal nursing, or other care or transportation provided by family or friends over the past month on account of eye and vision problems, was also explored. Those currently in paid employment were asked how many sick days had been taken over the past 12 months, and if so the quantity of earnings lost as a result of visits to eye care services, or ill health from eyes/vision, if any. In the ophthalmic and optometric interviews, spectacle ownership was reviewed. The questionnaire assessed prescription eye drop use over the past 3 months, and whether eye drops were provided for free by the public system, purchased privately, or a mixture. Participants with best-corrected visual acuity worse than 6/18 were asked about access to low vision services and use of low vision devices.

7.2.4 Definition and estimation of direct costs

Direct costs were defined as the expenses related to optimizing vision, including medical costs, non-medical costs and other direct costs.

7.2.4.1 Medical direct costs

Medical costs were defined as the resources used to treat an eye disease, on an inpatient or outpatient basis, and included pharmaceuticals, laser therapy, eye surgery, and eye care services provided by ophthalmologists, optometrists, health centres, general practitioners and the emergency department.

To estimate the direct medical cost of eye care service utilization, survey participants were asked how many times in the past year they have visited each group of eye care provider, and if more than once, how many times they have visited. From the prevalence of utilization, and mean number of episodes of utilization amongst those reporting any, both of which were adjusted (see section 7.2.1), the episodes of eye care service utilization per annum were estimated for each group of providers in 2014. These were multiplied by the mean unit cost for each eye care service.

Eye care service unit costs were estimated in a contemporaneous study on the eye care system in Trinidad and Tobago in 2014 (Braithwaite et al., 2018) (See Appendix A.1). In this study, all registered eye care providers in Trinidad and Tobago were contacted and invited to complete questionnaires, which included the public sector and private sector tariffs for outpatient, inpatient and emergency eye services and eye treatments. Provider groups included ophthalmologists, optometrists, public hospital eye department administrators, health centres, and public sector GPs. Questionnaires were also administered to 450 consecutive patients attending eye out-patient clinics in the five public hospitals. Further information sources included personal communication with officers within the Ministry of Health, three local pharmaceutical companies, and the Government supplier of medicines on the Chronic Disease Assistance Plan (CDAP). Unit costs were not available for public hospital day case and overnight admission, and public sector laser, and the cost of these was assumed to be the same as in the private sector.

The number of prescription eye drops was ascertained for each eye in the past 3 months, and was assumed to apply to the past 12 months. Private sector unit costs for 13 commonly used eye drops in 2014 were obtained from three private

companies, invited to submit competitive tender to supply drugs to the NESTT study, and averaged to produce a mean unit price per drug. Public sector unit costs were identified from the CDAP price list for the same year. Public sector unit costs were applied if participants reported free eye drops, private sector unit costs were applied if participants reported paying for all eye drops, and an average unit cost was applied if participants reported using a mixture of free and paid prescriptions. In 2014, four eye drops for the management of glaucoma (pilocarpine 2 or 4 %, betaxolol hydrochloride, and timolol maleate) were available at no cost to the patient in the public sector, via the CDAP (Braithwaite et al., 2018). Other agents available via the CDAP included antimicrobial agents moxifloxacin and oxytetracycline/polymixin B, and olopatadine hydrochloride for allergy. All other eye drops required over-the-counter purchase, or private prescription.

7.2.4.2 Non-medical direct costs

Non-medical direct costs included refractive correction, low vision aids, and transportation to attend eye care services. Survey participants were asked whether they had purchased spectacles or contact lenses in the past 12 months, and if so, how much they had spent. The adjusted prevalence was used to estimate the number of pairs of spectacles purchased in 2014. Unit costs of basic distance and reading spectacles, and of bifocal, trifocal or varifocal spectacles were obtained from 48 optometrists who respond to the eye care system study (Braithwaite et al., 2018). The base case assumed that 70 % of spectacles purchased were basic distance or near spectacles, and 30 % were bi, tri or varifocal spectacles.

Those with low vision (best-corrected visual acuity in the better seeing eye worse than 6/18) were invited to complete an additional questionnaire (See Appendix C.1.9), in which they were asked whether they had received a low vision assessment in the past year, and whether they owned any low vision aids. The list of low vision aids included devices to assist the individual in their personal, home and work environments, and was developed in consultation with the Low Vision Clinic at the University of the West Indies in St Augustine, Trinidad, and the Blind Welfare Association in Port of Spain, Trinidad, in 2013 (Braithwaite, Verlander, et al., 2017). The adjusted prevalence of low vision was used to estimate the number of cases in Trinidad and Tobago in 2014, and the crude proportion using each type of low vision aid was used to estimate low vision aid purchases in 2014. The unit cost of low vision

assessment was ascertained directly from optometrists in the eye care system study (Braithwaite et al., 2018), but the unit price of individual low vision aids in Trinidad and Tobago in 2014 was not determined. A literature review identified a study on the cost of low vision aids in four European countries in 2004 (Lafuma, Brezin, Lopatriello, et al., 2006), which has been used in other cost of vision loss studies in the USA and UK (Pezzullo et al., 2018; Wittenborn et al., 2013). Additional unit costs were obtained from the Royal National Institute of Blind People online shop (Royal National Institute of Blind People, 2018).

Survey participants who reported attending an eye care provider in the past 12-months were asked what their usual mode of transportation is (e.g. private car, taxi, water taxi, bus), and the crude proportion was applied to the total estimated episodes of eye care to estimate the number of return journeys of each type. Mean unit costs associated with return journeys using different modes of transportation were obtained from 450 outpatients attending regional hospital eye clinics in the eye care system study (Braithwaite et al., 2018).

7.2.5 Definition and estimation of indirect costs

Indirect costs to patients and caregivers were defined as the value of lost labour output caused by reduced economic productivity resulting from VI. Excluded from this analysis were the cost of allowances (benefits, financial support for income, residence) and consideration of the time that visually impaired people spend in prevention activities or self-help groups.

7.2.5.1 Productivity loss associated with vision impairment

Survey participants were invited to specify the category into which their household monthly income fell, but individual income was not ascertained, as the latter was felt to be too sensitive a question for inclusion in the survey. It was therefore not possible to directly determine the mean reduction in income associated with different categories of VI.

Instead, a simple human capital approach was used to estimate productivity loss. The employment rate (ER) was defined as the percentage of the population of working age in this study (40 years to 64 years, inclusive) who reported being employed over the past 12 months. The adjusted ER was determined for each vision category. To

estimate lost productivity, it was assumed that in the absence of VI, individuals would have been employed at the same rate as the average person aged 40 to 64 years in Trinidad and Tobago in 2014. The employment 'gap' was calculated as 1 minus the ER in that vision category divided by the overall ER in the population aged 40 to 64 years. Productivity loss for individuals in each vision category was calculated as the product of the employment gap, median annual income in 2014, and overall ER (Larg & Moss, 2011; Lofland, Pizzi, & Frick, 2004). For the base cost case, a median annual income for all occupations in 2014 of TT$54,000 was chosen (CSO, 2014). Sensitivity analysis explored two alternatives from the same Central Statistics Office data, namely the average annual income for all occupations in 2014 of TT$66,960, and the average annual income for elementary occupations of TT$40,704. The productivity loss for individuals in each vision category was multiplied by the estimated number of cases in the 2014 population aged 40 to 64 years, using adjusted prevalence estimates for this age group, and summed to obtain total productivity loss.

To calculate the productivity loss associated with part-time work, the same analysis approach was used, assuming a 50 % reduction in working hours. This approach was felt to be conservative, because it does not account for the possibility that those with VI might experience slower promotion or restricted choice over employment type and associated lower earning potential than those with normal vision (Taylor et al., 2006).

7.2.5.2 Productivity loss associated with sick leave

Participants who reported employment were asked how many sick days they had taken in the past 12 months in total, and specifically whether they had taken any days off to attend health care services for their eyes or vision. They were also asked to specify the total value of any lost earnings over this period. Workers who were absent on account of illness for a protracted period are likely to be replaced at some point. This period, the 'friction period' (e.g. 90 days), can be used to make an adjustment to the productivity loss to avoid overestimating the actual loss (Koopmanschap & van Ineveld, 1992). A friction period adjustment was not applied in this study because the number of days of sickness taken on account of incapacity from eye disease or VI was not directly ascertained, and was anticipated to be few days on average.

7.2.5.3. Informal care

Participants were asked if any friends or family members had provided them with informal care on account of their eyes or vision state in the past month, and if so, they were asked to specify how many hours. To estimate the value of productivity loss associated with informal care, the opportunity cost method was used (van den Berg, Brouwer, & Koopmanschap, 2004). Specifically, the proportion reporting need for informal care was used to estimate the number of people, multiplied by the mean hours of informal care per person needing any, and by the hourly wage rate for an individual in an elementary occupation, of TT$21.20. The latter was calculated from the mean annual income of an elementary occupation in 2014 of TT$40,704, assuming 40 working hours per week and paid annual vacation of 4 weeks per year (CSO, 2014).

7.2.6 Transfer payments and dead-weight losses

Transfer payments were defined as payments between economic agents, and include social welfare payments made for distributional purposes rather than as payment for goods or services. Pertinent transfer payments were considered, but not included in the total cost estimate, in line with the Consensus Guidelines (Frick, 2010). The real economic resource cost of transfer payments relates to the associated dead-weight loss, defined as the excess allocative inefficiency on society associated with administering transfer payments and raising additional taxation revenue (Koberlein et al., 2013). Examples of dead-weight loss include welfare payments resulting in reduced labour force participation, and taxation levels disincentivizing people from working. Dead-weight losses are challenging to estimate reliably, and have not been estimated in this analysis, in line with most other cost studies.

To explore transfer costs associated with VI, participants were asked about their employment status over the past 12 months, to estimate the prevalence of formal 'disabled' status. It was assumed that these individuals were in receipt of disability allowance if they were aged between 40 and 64 years. The means-tested disability allowance was TT$1500 per month in 2014 and was available up to the age of 64 years, after which it was replaced by the senior citizens pension of TT$3000 per month. There was no specific carers allowance in Trinidad and Tobago. The budget cost of Government-funded programs providing services for the blind, identified from documents in the public domain, was also reviewed, but fiscal flows resulting from reduced income tax revenue were not.

7.2.7 Definition and estimation of intangible effects

The suffering associated with VI greatly extends beyond financial costs. Intangible effects are defined as the loss of wellbeing experienced by individuals with VI, and are estimated using the DALY (Murray, 1994). To calculate DALYs in this analysis, the approach adopted by the WHO and Institute of Health Metrics for the GBD Study was used, in which prevalent YLDs are estimated, and YLL are assigned a value of zero to reflect an assumption that VI is not directly associated with premature mortality (Department of Health Statistics and Information Systems, 2013; G. Stevens, personal communication, April 28, 2018). To calculate prevalence YLD, prevalent cases were multiplied by the disability weight, with no discounting for time or unequal age weights. In this cost analysis the latest WHO disability weights were chosen, of 0.047 for NVI (with normal distance vision), 0.005 for mild distance VI, 0.089 for moderate distance VI, 0.314 for severe distance VI, and 0.338 for blindness (Department of Health Statistics and Information Systems, 2013), but alternatives at the high (Murray, 1994) and low (Salomon et al., 2015) extremes were explored in sensitivity analysis.

Previous cost of illness, and cost of vision loss studies specifically, have seldom assigned a monetary value to loss of welfare (Koberlein et al., 2013), but Consensus Guidelines recommend this (Frick et al., 2010). Previous cost of vision loss studies which have assigned a value to one DALY or QALY are summarized in Appendix B.11, with conversion to 2014 US$ for comparison. Trinidad and Tobago was a high-income non-OECD country, with no published in-country estimation of the value of a statistical life (VSL). Therefore, taking the 2015 life expectancy at birth to be 70.52 (PAHO, 2014), and using a VSL derived for Trinidad and Tobago in 2015, of US$3,035,000, the value of one VSL was estimated to be US$43,037 with no discounting (Viscusi, 2017). Using the World Bank GDP deflator the VSL for one year in 2014 was $42,483 (World Bank, 2018a), equivalent to TT$272,316.

7.2.8 Sensitivity analysis

In a sensitivity analysis multiple parameter estimates were varied within the bounds of the 95 % confidence interval of each parameter value. Where primary data was not available, or was available for only a subgroup of NESTT participants, the parameter was varied by +/- 50 %. The impact on total cost of various assumptions, and use of different disability weights was also explored.

7.2.9 Allocation of costs

Some costs were easier to attribute than others. For direct costs, public or private sector unit costs were applied depending on which sector participants reported preference for using for eye care. If participants reported using both sectors, an average of the public and private sector unit costs was applied. It was assumed that the Government, via the regional health authorities, bear the cost of public sector eye care and treatments made available via the CDAP. It was assumed that individuals bear the cost of transportation, all refractive correction, and private eye care services and treatments. Insured individuals were assumed to have a 30 % copayment. Participants were asked about OOPE on eye care services and treatments over the past 12 months and OOPE on eye care related travel.

7.2.10 Conversion of unit costs

All unit costs used in this analysis were inflated where necessary to 2014 values using the World Bank Gross Domestic Product deflator (World Bank, 2018a), which takes into account fluctuating exchange rates, different purchasing power of different currencies and inflation rates, and then converted into TT$ using The World Bank Official Exchange Rate (LCU per US$ period average) in 2014, which was TT$1 = UK£0.0952)(World Bank, 2018b).

7.3 Results

In total, 2,516 (59.0 %) responders ≥40 years completed the health economic questionnaire in the regional survey clinic, including 72.5 % (161/222) with mild VI, 73.5 % (158/215) with MSVI and 41.9 % (13/31) with blindness. Additional variables of relevance to this analysis were collected in additional questionnaires administered in the community vision screening stage and in the regional clinic.

7.3.1 Total economic cost of vision loss and eye care

The total societal cost of vision loss amongst adults 40 years and above in Trinidad and Tobago in 2014 was TT$3,842,324,655 (UK£365,650,241), with loss of wellbeing accounting for 73.3 % of the total cost. Excluding intangible effects, the economic cost was TT$1,025,045,399 (Table 7.1), of which indirect costs account for 70.5 %, followed by direct medical cost (17.9 %), and direct non-medical cost (11.6 %). These societal cost estimates equated to a per capita cost in the population aged 40 years

and above of £674.76 including intangible effects, and £180.01 excluding intangible effects. The following sections detail the cost calculations in more detail.

7.3.2 Estimation of number of cases with vision impairment in 2014

The total number of people aged 40 years and above with VI in Trinidad and Tobago in 2014 was estimated in Table 5.4. Out of 64,431 cases of distance VI, an estimated 86.11 % (95 % CI 82.88 to 88.81), or 55,481 (95 % CI 53,401-57,221) people, had potentially avoidable vision loss. In addition all 120,842 cases of NVI but normal distance vision, resulting from uncorrected presbyopia, were readily avoidable.

Table 7.1 Cost of vision loss in Trinidad and Tobago in 2014 in adults ≥40 years, subdivided into cost categories (TT$s 2014 (TT$1 = UK£0.0952 ())

Cost group	Cost item (sector, if applicable)	COST, TT$
Direct medical	Optometrist (private)	10,487,167
	Ophthalmologist (both)	53,339,693
	GP (private)	691,531
	Health centre (public)	3,148,044
	Emergency department (both)	1,017,023
	Overnight admission (both)	14,203,343
	Eye drop prescriptions (both)	66,612,229
	Laser therapy (both)	7,963,698
	Day case cataract surgery (both)	25,841,007
Direct medical subtotal (%)		183,303,734 (17.9)
Direct non-medical	Transportation to access eye care	11,394,239
	Spectacles (private)	70,391,870
	Low vision aids (private)	37,576,201
Direct non-medical subtotal (%)		119,362,310 (11.6)
Indirect	Productivity loss from VI	630,859,320
	Productivity loss - part time work	80,276,228
	Productivity loss - sick leave	6,211,776
	Productivity loss - informal care	5,032,032
Indirect subtotal (%)		722,379,355 (70.5)
TOTAL COST excluding intangible effects (%)		1,025,045,399 (100)
Intangible effects	Prevalence DALYs in 2014	2,817,279,256
TOTAL COST including intangible effects		3,842,324,655

7.3.3 Direct Costs

7.3.3.1 Medical direct costs

Direct medical costs for services and treatments were responsible for TT$183,303,734. The greatest costs resulted from prescription eye drops (36.3 %), visits to ophthalmologists in the public and private sectors (29.1 %), and day case cataract surgery (7.7 %), whereas the lowest cost resulted from visits to the GP (0.4 %).

7.3.3.1.1 Utilization and cost of eye care services in past 12 months

Out of 2516 responders, 701 reported 1028 eye care utilization episodes over the past 12 months, with the number of episodes per person ranging from 0 to 13. The crude and adjusted frequency of utilization of different eye care services is summarized in Table 7.2. Specifically, private optometrists were consulted by an estimated 16.8 % (95 % CI 15.3-18.4%) of the population and ophthalmologists by 12.1% (95 % CI 11.1-13.2), and a small number of people reported multiple visits in 12 months. The survey revealed that only a small percentage (<0.6 %) of the population seek eye or vision care from their private general practitioner (GP), public health clinics, or the public hospital accident and emergency departments. Day case eye surgery and overnight admission for an eye or vision problem or operation was similarly infrequent. Unit costs of eye care services are summarized in Table 7.3.

7.3.3.1.2 Utilization and cost of eye treatments in past 12 months

Use of prescribed eye drops in the past 3 months was ascertained in 2792 people, of whom 186 reported right eye use (adjusted prevalence 5.4%, 95 % CI 4.8-6.2), and 181 reported left eye use (adjusted prevalence 5.4 % (95% CI 4.7-6.1). The majority of prescribed eye drops were for the management of glaucoma, which was the leading cause of blindness, and some people were receiving four different pharmacological agents. In total, 367 eyes were receiving 509 agents, and the adjusted mean eye drop prescriptions per eye per month amongst those prescribed any was 1.7 (95 % CI 1.6-1.8) in the right eye and 1.6 (95 % CI 1.5-1.7) in the left eye. Thus, in the population aged 40 years and above in 2014, 58,516 eyes were prescribed 1,152,803 bottles of eye drops. Participants were asked if they ever forget to insert their eye drops, and 86 (46.2 %) reported that they do. The frequency of non-compliance was reported by 76 of these participants to be: less than once per month (17, 22.4 %), several times per month (21, 27.6 %), several times per week (15, 19.7

%), most days (5, 6.6 %), and 18 (23.7 %) reported that they are not using them at all. The reasons for non-compliance (given by 75 participants) included forgetting (49, 65.3 %), running out and not being able to afford to buy more (8, 10.7 %), running out and having difficulties getting more on account of transport issues (8, 10.8 %), believing that the eye drops were not effective (6, 8.0 %), running out and finding it difficult to get more on account of stock issues (3, 4.0 %), and disliking the drops on account of side effects (1, 1.3 %). These estimates did not include over-the-counter eye drops (e.g. ocular lubricants and anti-allergy drops), and were therefore a conservative estimate of total eye drop utilization by the national population in this age group.

Table 7.2: Population-based estimation of eye care service utilization amongst the population aged 40 years and above in 2014

Eye care provider	Crude prevalence	Adjusted prevalence	Adjusted mean episodes per person (95% CI)	2014 Population	2014 Episodes
	% (n)	% (95% CI)		n	
Optometrist	17.7 (444)	16.8 (15.3- 18.4)	1.02 (1.00-1.04)	90,871	92,807
Ophthalmol-ogist	13.0 (328)	12.1 (11.1- 13.2)	1.52 (1.37-1.66)	65,828	99,871
GP	0.40 (10)	0.33 (0.17- 0.62)	1.36 (1.00-1.72)	1,794	2,444
Health centre	0.52 (13)	0.57 (0.36- 0.89)	2.75 (2.03-3.48)	3,065	8,440
Emergency department	0.24 (6)	0.23 (0.11- 0.52)	1	1,269	1,269
Day case surgery	0.40 (10)	0.31 (0.17- 0.52)	1.23 (0.99-1.47)	1,678	2,062
Overnight admission	0.43 (11)	0.42 (0.25- 0.68)	3.15 (1.44-4.86)	2,253	7,102
TOTAL				166,758	213,995

The average cost of 4 IOP lowering agents was TT$50.34 from the government supplier, and the average cost of the same agents in the private sector was TT$100.52. The average unit cost to the health system of other commonly prescribed drugs (anti-inflammatory, anti-allergy, anti-microbial and lubricants) was TT$49.39 from the government supplier, and TT$111.09 from private pharmaceutical

companies. The estimates of the cost to the patient of the latter were conservative, because it was likely that individual retail pharmacies added profit margin to the cost price of the drug from the pharmaceutical company. Since the majority of eye drops prescribed to NESTT participants were for glaucoma, the cost of glaucoma drops was used for cost estimation in this analysis. The estimated total cost of prescription eye drops, of TT$87,303,053, was reduced by 23.7% to account for the reported non-compliance, to TT$66,612,229, and explored in sensitivity analysis (ranging from 52.6 to 100% compliance).

7.3.3.1.3 Utilization of laser in the past 12 months

Laser history was ascertained in 2792 people (5584 eyes). Six people (0.21%) reported laser therapy in the past 12 months in the private sector. The number of laser procedures performed in the past 12 months in the public sector was not ascertained from NESTT participants directly. However, the concurrent eye care system study found that 1433 laser procedures were performed in four out of five of the public hospitals in 2013-2014, serving 81.6 % of the national population (Braithwaite et al., 2018). Two assumptions, namely that all laser-treated patients were 40 years and above, and that each person had only one laser, yielded an estimate that 0.32 % of the population served by these four hospitals had received laser treatment. Extrapolating to the national population, an estimated 1165 people received laser in the private sector and 1756 in the public sector in 2014. The associated cost was TT$7,963,698. Previous laser at any time in the past was reported for 82 right eyes and 78 left eyes (2.9 %). The indications included DR (88 eyes), retinal tears (13 eyes), posterior capsule opacification following cataract surgery (33 eyes), and glaucoma (21 eyes). No one aged 40 years and over reported laser refractive correction, and the remainder of laser indications were not specified, generally because of recall difficulty. Unit costs for 2014 were calculated assuming that approximately 65.2 % lasers in 2014 were to the retina, 21.3 % were to the anterior segment, and 13.5 % were for glaucoma treatment.

Table 7.3 Unit costs of direct medical eye care services and treatments in 2013-2014 (TT$s 2014 (TT$1 = UK£0.0952))

Eye services and treatments	Mean Unit Cost TT$	SD	Range	n (RR)
PRIVATE SERVICES				
Optometrist	113	27.8	60 to 200	48
Ophthalmologist New	450	70.7	350 to 500	3
Ophthalmologist Follow-up	283	23.6	250 to 300	3
GP (Private)	283	40		2
A&E (Private hospital)	500			1
PUBLIC SERVICES				
Health Centre	373			1
A&E	1100			1
Eye Out-patient clinic	700			1
TREATMENTS				
Basic spectacles	805.6	313	400 to 1500	48
Bi/tri/varifocal spectacles	1370.4	554.7	575 to 2500	48
Cataract with IOL	11,333	942.8	2500 to 4000	1
Day case admission	1200			1
Overnight admission	2000			1
Anterior segment laser	1683.3	131.2	1500 to 1800	3
Glaucoma laser	2250	250	2000 to 2500	3
Macula/retina laser	3166.7	623.6	2500 to 4000	3
Eye drops public (CDAP)	50.34			1
Eye drops private	100.52			3

KEY: n number of survey responders; RR survey response rate

7.3.3.1.4 Utilization of other eye therapies

Intravitreal injections of anti-vascular endothelial growth factor (VEGF) were not available in the public health sector in 2014, and no NESTT participants reported receiving these in the private sector. More specialized ophthalmic surgery than cataract extraction was also not available in the public sector (e.g. vitreoretinal surgery, corneal transplant surgery). No participants reported use of oral medications for their eyes in the past 3 months.

7.3.3.2 Direct non-medical costs

7.3.3.2.1 Refractive correction

Spectacles or contact lenses were purchased by 353 out of 2524 participants in the past 12 months, yielding an adjusted population-based estimate of 13.3 % (95 % CI 11.9-14.8), or 72,194 people aged 40 years and above in 2014. Spectacles and contact lenses were exclusively available in the private sector, and in addition, basic reading spectacles could be purchased over-the-counter in some supermarkets. The cost of basic distance and near spectacles, and of bifocal, trifocal and varifocal spectacles and contact lenses was determined in the eye care system study, from registered optometrists who responded to the questionnaire (see Table 7.3) (Braithwaite et al., 2018). The total annual expenditure on spectacles was estimated to be TT$70,391,870, or £6,698,758, equivalent to £12.36 per capita.

7.3.3.2.2 Transport costs

Preferred transportation mode to attend eye care services was reported by 645 participants who attended eye care services in the past year. Modes of transport included private car (58.8 %, n = 379), maxi-taxi or bus (21.6 %, n = 139), taxi (17.7 %, n = 114), walking (1.1 %, n = 7) and taking the water taxi (0.9 %, n = 6). The unit cost of a return journey in 2014, assuming attendance at an eye care facility located within the same region as the home address, was estimated to be TT$20 for a maxi, TT$60 for a private car, TT$80 for a taxi, and TT$80 for a water taxi. Using the proportions reporting different modes of transport and the unit cost for each, the mean travel cost was TT$54.48 for each return journey. The total episodes of eye care in 2014 were summed, including visits to optometrists, ophthalmologists, GPs, health centres, emergency departments, day case admissions and overnight admissions, and the latter were divided by the adjusted mean length of each admission (3.15 days). The total estimated expenditure on transport associated with 209,145 episodes of eye care was TT$11,394,239. Travel costs incurred by family or friends accompanying an individual to their eye care service appointments were not included, so this estimate was conservative.

7.3.3.2.3 Low vision devices and support services

There were an estimated 16,535 (95 % CI 13,882-19,675) people aged 40 years and above in need of low vision assessment and aids in 2014. This was determined from the adjusted prevalence of best-corrected VI worse than 6/18 in the better seeing eye

of 3.05 % (95 % CI 2.56-3.63, n = 120 / 3578). The direct cost of LVA devices and assessment was estimated to be TT$37,576,201. However, the NESTT survey did not ask participants about home or workplace adaptations such as stair lifts, door-opening devices, and ramps, so this was a conservative estimate.

Importantly, the NESTT low vision questionnaire, which was completed by 80.8 % (97/120), revealed that only one person had received a low vision assessment, and very few were using low vision aids, indicating substantial unmet need for low vision support in Trinidad and Tobago in 2014. This group ranged in age from 41 to 99 years (mean age 74.1, sd 12.8) and 51.6 % (50) were female. Use of the following low vision aids was reported: 9.6 % (10) used a white stick or cane; 3.9 % (4) used a visor; 6.7 % (7) used tints or shields; 1 % (1) used a typoscope; 1 % (1) used closed circuit television; 1.0 % (1) used audio or DVDs, 3.9 % (4) used talking electronic devices; 1.0 % (1) used Braille; 1.0 % (1) used a hand held magnifier; 1.0 % (1) used a stand magnifier; 2.9 % (3) used spectacle magnification; 2.9 % (3) used magnification software; 1.9 % (2) used speech software; and 1.0 % (1) used a braille keyboard. No visually impaired participants reported use of a guide dog, GPS, liquid level indicators, mounted telescopes, speech input software, or contrast enhancing software. Participants were asked if they felt they would benefit from a low vision assessment: 26.0 % replied “yes”; 44 % were “unsure”, and 28.6 % replied “no”. Barriers included lack of access to this service (11), transport problems (2), cost of low vision aids (1), and the lack of availability of low vision aids in Trinidad and Tobago (2). In the contemporaneous eye care system study, 35.4 % (17 / 48) of responding optometrists reported offering low vision services; 7 offered assessment at no cost to clients (via the University of the West Indies Department of Optometry Low Vision Clinic), and the remaining 10 offered assessment for a mean fee of TT$196 (sd 93.95, range 60 to 400).

7.3.3.3. Health insurance and out of pocket expenditure (OOPE)

Health insurance was held by 617 (17.6 %) people out of 3506 surveyed in community screening, with an adjusted prevalence of 18.6 % (95 % CI 16.7-20.7). In close agreement with this, 17.8 % (463/2603) participants in the regional clinic reported they would choose exclusive use of the private sector for eye and vision services (adjusted prevalence 18.6 %, 95 % CI 16.7 to 20.8), whereas 20.5 % (535/2603) participants reported a preference for exclusive use of the public sector (adjusted prevalence 19.1 %, 95 % CI 17.4-20.9), and 61.7 % (1605/2603) reported

preference to use a mixture of public and private sectors (adjusted prevalence 62.3 %, 95 % CI 59.9-64.6). Compared to normally sighted individuals, blind people were less likely to have health insurance, after adjustment for age and sex (See section 7.3.8).

OOPE on any eye care services over the past 12m was reported by 20.5 % (513/2508), giving an adjusted population-based prevalence of 19.3 % (95 % CI 17.6-21.1). The adjusted mean annual OOPE per person was TT$157 (95 % CI 94.9-219.7), but the adjusted mean annual OOPE amongst those with any OOPE was TT$ 960.9 (95 % CI 822.7-1099.1). Table 7.4 summarizes the median OOPE on different services and treatments, highlighting close agreement with unit costs reported by eye care service providers in the eye care system study (Braithwaite et al., 2018).

Table 7.4: The crude proportion of NESTT participants reporting any out of pocket expenditure (OOPE) on eye care services, refractive correction and eye drops over the past 12 months, and the median OOPE in each category amongst those reporting any (TT$s 2014 (TT$1 = UK£0.0952))

Eye care	Crude % with any OOPE	Crude OOPE (TT$) amongst those with any OOPE, median (IQR), range
Optometry	16.0 (402)	100 (100 to 150), 50 to 2500
Ophthalmology	6.74 (170)	400 (300 to 550), 100 to 12000
GP	0.12 (3)	400 (100 to 2000), 100 to 2000
Day case	0.72 (18)	10000 (1600 to 13000), 200 to 100000
Laser therapy	0.24 (6)	4500 (3000 to 5000), 1000 to 10000
Any eye care services	20.5 (513)	150 (100 to 350), 50 to 101500
Refractive correction	14.0 (353)	2400 (1700 to 3000), 20 to 10000
Eye drops (any)	4.29 (108)	800 (220 to 2450), 35 to 12000

KEY: IQR Interquartile range; OOPE Out of pocket expenditure; TT Trinidad & Tobago

Amongst those NESTT participants who reported eye drop use, 42.1 % (74/176) reported paying for all their own private prescriptions, 40.9% (72/176) reported receiving all their eye drops free from the hospital via the CDAP, 13.6 % (24/176) reported having to pay sometimes on account of CDAP pharmacy supply problems, and 3.4 % (6 /176) reported receiving those available from CDAP free but routinely paying for additional eye drops not available from the CDAP (e.g. prostaglandin analogues).

7.3.4 Indirect costs

The total indirect costs associated with VI and blindness were TT$722,379,355, or 68.2 % of the total cost excluding intangible effects.

7.3.4.1 Lost productivity to individuals

Whilst productivity loss was not determined directly from individual participants, data from 2663 responders revealed an association between greater levels of presenting VI and lower household income (See Table 7.5).

Table 7.5: Category of household monthly income by level of presenting vision (TT$s 2014 (TT$1 = UK£0.0952))

Household monthly income	Normal vision % (n)	NVI, normal distance	Mild VI % (n)	MSVI % (n)	Blind % (n)
<TT$1000	0.6 (9)	0.9 (7)	1.0 (2)	0.5 (1)	0
TT$1000-4999	30.8 (454)	46.8 (360)	48.7 (96)	52.7 (98)	55.6 (15)
TT$5000-9999	43.3 (637)	38.4 (295)	41.6 (82)	40.3 (75)	40.7 (11)
TT$10,000-30,000	22.7 (334)	13.4 (103)	8.1 (16)	6.5 (12)	3.7 (1)
TT$ >30,000	2.7 (39)	0.5 (4)	0.5 (1)	0	0
Total	100 (1473)	100 (769)	100 (197)	100 (186)	100 (27)

The crude and adjusted employment rate amongst community screening respondents aged 40 to 64 years (inclusive) was 66.3 % (1684/2542), and 68.3 % (95% CI 66.5-70.0), respectively. However, the employment rate varied by category of presenting vision. Specifically, the adjusted rate ranged from 73.2 % (95 % CI 70.9-75.4) in those with both normal distance and near vision (1110/1561), to 63.9 % (95 % CI 61.0-66.9) in those with NVI only (491/795), 54.5 % (95 % CI 44.3-64.7) in those with mild distance VI (48/94), 41.4 % (95 % CI 30.6-52.2) in those with MSVI (28/69), and 0 % in those who are blind (0/5) in this age group. A table detailing the estimated annual productivity loss associated with each level of VI, assuming a median annual income for all occupations combined of TT$54000 and 421,316 people aged 40 to 64 years in Trinidad and Tobago in 2014, is included in Appendix D.9. The individual productivity loss ranged from TT$2366.9 in those with NVI only, to TT$36,868.7 in those who

were blind. The total annual productivity loss associated with all DVI and NVI in people aged 40 to 64 years was TT$630,859,319.9

Amongst the subgroup who completed the economic survey and were employed (1147), part-time work was reported by 12.5 % (143/1147), ranging from 11.1 % (84/760) in those with normal vision, 15.2 % (49/323) with NVI, 17.9 % (7/39) with mild VI, to 12.0 % (3/25) with MSVI. The additional productivity loss associated with part time work in those with VI was TT$80,276,227.7, and a breakdown by vision category is detailed in Appendix D.10.

Absenteeism was frequently reported. Amongst those aged 40 and above who were employed in the past 12 months, 37.2 % (438/1178) reported taking one or more days off sick, and amongst these people the mean number of sick days was 7.9 (sd 20.6) (median 4 (IQR 3-7), ranging from 1 to 365 days). Lost earnings specifically on account of healthcare visits for eye or vision care over the past 12 months were reported by 0.9 % (11/1248). Eight responders estimated the median value of lost income associated with these visits to be TT$ 2450 (IQR 700-8938, range 300-25000). An additional 1.5 % (18/1239) reported missing workdays on account of poor eye health, but no lost income is associated with these days. Extrapolated to the population aged 40 to 64 years (421316), there were approximately 2535 people who lost earnings on account of eye care visits, with an estimated median income loss of TT$6,211,776 (IQR 1,774,793-22,661,571).

Aside from the employment rate, employment type and education history were explored, but not included in the total cost estimate. The Information Commissioner's Office employment category was collected for all 68.2 % (1143) people who reported being employed in the past 12 months. Overall, the three most frequent occupations in Trinidad and Tobago in 2014, for those with VI and for those with normal vision were professionals (37.6 %), elementary occupations (20.6 %), and service workers or market sales people (18.2 %). Detail on worker status was available for 1231 participants, and revealed that overall 32.7 % (n = 402) were employed in a private establishment, 25.4 % (313) were self-employed with no paid employees, 22.5 % (277) worked in central or local government, and 8.1 % (100) were employed in a state owned enterprise (See Appendix D.11). In the employed group there were 63 people with presenting vision < 6/12, of whom only 2 had best-corrected visual acuity <6/18, suggesting that the majority of these people had mild VI, or VI from URE. In a multivariable model adjusted for age and sex, the odds of having presenting VI

(<6/12) were significantly higher amongst people employed in the service industry (OR 2.7, 95 % CI 1.3-5.4) and people employed in elementary jobs (OR 2.9, 95 % CI 1.5-5.8), as compared to professionals (p = 0.011). Other variables potentially associated with the occupational opportunities of those with VI included internet access and private car ownership within the family. An active email address was reported by 31.4 % (56) with normal vision, 9.5 % (17) with mild VI, 4.4 % (8) with MSVI and no one with blindness. Access to a family car was reported by 75.5 % (1712) with normal vision, 64.3% (128) with mild VI, 61.9 % (122) with MSVI, and 50.0 % (14) who are blind.

Table 7.6 Highest education level completed by category of presenting vision

Highest education completed	Normal vision % (n)	NVI % (n)	Mild VI % (n)	MSVI % (n)	Blind % (n)	Total % (n)
Primary	37.4 (538)	57.4 (413)	69.6 (112)	76.9 (120)	84.6 (11)	48.0 (1194)
Secondary	40.6 (584)	36.2 (260)	22.4 (36)	16.7 (26)	7.7 (1)	36.5 (907)
Post-secondary	12.7 (182)	3.1 (22)	6.2 (10)	2.6 (4)	7.7 (1)	8.8 (219)
University	9.3 (134)	3.3 (24)	1.9 (3)	3.9 (6)	0	6.7 (167)
Total	100 (1438)	100 (719)	100 (161)	100 (156)	100 (13)	100 (2487)

Individuals with normal vision had significantly higher educational attainment than those with VI (See Table 7.6). In a multivariable model adjusted for age, sex and the study design (cluster and island), the odds of presenting with vision <6/12 in the better seeing eye were significantly lower amongst those who had completed secondary school (OR 0.43, 95 % CI 0.31-0.59), post-secondary (OR 0.44, 95 % CI 0.25-0.77) or university (OR 0.30, 95 % CI 0.15-0.62), as compared to those who had completed only primary school (p < 0.0001).

Similarly, 2684 participants were asked about literacy, and this varied by vision level. Illiteracy was reported by 0.74 % (11/1483) of people with normal distance vision, compared to over 2.5 % of those with mild VI (5/199), MSVI (5/196) and blindness (1/30). Basic literacy and numeracy showed a similar association, and were reported by 10.3 % (152/1483) of people with normal vision, but over 26 % of those with NVI (210/776), mild VI (61/199), MSVI (65/196) or blindness (8/30). In a multivariable

model adjusted for age, island and cluster, the odds of presenting with vision <6/12 were significantly reduced in those who were literate (OR 0.26, 95 % CI 0.12-0.58), compared to those who were illiterate (p < 0.001).

7.3.4.2 Informal care

Use of informal care was reported by 23.1% (3/13) of people who were blind and attended the regional clinic. The mean hours of care per month reported by blind individuals needing care was 260 (sd 209) hours, with a median of 360 and range from 20 to 400. Those with NVI, mild VI, and MSVI reported less than one hour of care per month. The estimated number of blind people aged 40 years and above in Trinidad and Tobago in 2014 was 3956 (95% CI 2601- 5256). Assuming that 23.1 % of blind people need an average of 260 hours of care (95 % CI 23 to 497), the total cost of informal care for blind people was estimated to be TT$5,032032.

7.3.5 Transfer payments

Transfer payments were not included in the total cost estimate, but were explored for interest. Out of 3416 people aged 40 years and above, 1.7 % (58) reported disabled status, with an adjusted prevalence of 1.7 % (95 % CI 1.2-2.1). This varied by severity of presenting VI, from 0.9 % (95 % CI 0.4-1.5) in those with normal vision, to 27.3 % in those who were blind (95 % CI 23.8-30.8). Out of an estimated 3956 people who were blind in Trinidad and Tobago, 363 were aged 40 to 59 years (prevalence estimates presented in Table 5.3 applied to census data in each 5-year age group). The estimated annual cost of the disability allowance awarded to 27.3 % (99) of these individuals was TT$1,784,958, or £169,863.

The 2013/2014 budget of the Blind Welfare Association was TT$10,800,000, with the Government providing $7,922,000 and the remaining balance received from fundraising campaigns (sales, private contributions, donations), and rental income (Government of the Republic of Trinidad and Tobago, 2015). This non-profit, voluntary rehabilitation organization provided services for the blind, and reported serving about 1400 clients (Parliament of the Republic of Trinidad and Tobago, 2014). The 2014 budget allocated to Persons Associated with the Visually Impaired (PAVI), was $520,500 in 2014 (Government of the Republic of Trinidad and Tobago, 2015).

7.3.6 Intangible effects - Loss of wellbeing measured in DALYs

There were 10,346 (95% CI 8845 to 11806) disability adjusted life years lost in 2014 amongst the population aged 40 years and above on account of VI (Appendix D.11). Assuming the value of one year of statistical life to be US$42,483 in 2014, the monetary value of this wellbeing loss was TT$2,817,279,256.

7.3.7 Sensitivity analyses

The outcome of a 1-way deterministic sensitivity analysis to explore the impact of parameter uncertainty on the base cost estimate, excluding intangible loss, is illustrated in the form of a Tornado chart in Figure 7.1.

Applying the GBD 2013 Study disability weights for VI of 0.003 for mild VI, 0.031 for MVI, 0.184 for SVI, 0.187 for blindness and 0.011 for NVI, rather than the WHO 2013 disability weights, resulted in a substantial reduction in intangible loss, to just 3485 DALYs, equivalent to TT$941,661,752 (Department of Health Statistics and Information Systems, 2013). In contrast, applying the original GBD Study disability weights, of 0.096 for mild VI, 0.22 for MVI, 0.4 for SVI, and 0.6 for blindness, with no weight for NVI, increased the DALY loss to 12,259, equivalent to TT$3,338,445,299 (Murray, 1994).

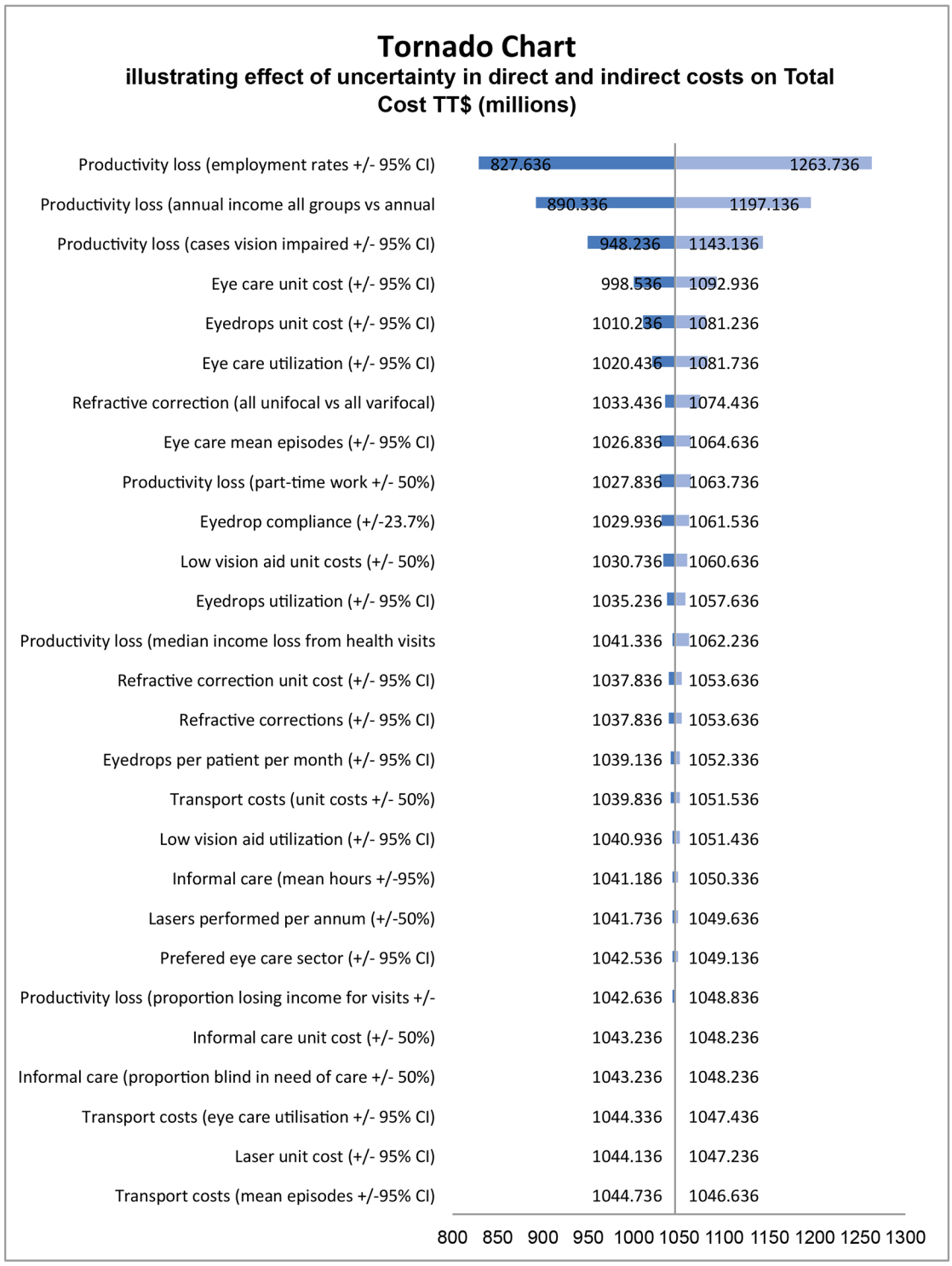

Figure 7.1 Tornado chart illustrating 1-way sensitivity analysis of parameter uncertainty in direct and indirect costs

7.3.8 Differential economic cost by vision level

Multi-level multivariable logistic regression models, adjusted for age and sex, explored the odds of utilizing any eye care services, of having health insurance, and of using the public sector exclusively for eye care, by vision category (See Appendix D.13). Eye care service utilization in the past 12 months varied from around 30 % in those with normal vision, mild VI and MSVI, to 18 % in those with NVI and 7 % in those who were blind. The model revealed that use of eye services was significantly more likely in women (OR 1.36, 95 % CI 1.13-1.64), and those in age groups greater than 60 years, whereas those with NVI (OR 0.49, 95 % CI 0.39-0.61), or blindness (OR 0.11, 95 % CI 0.01-0.85), were significantly less likely to report utilizing any eye care. Health insurance coverage also varied significantly by vision level, ranging from 24.6 % (95 % CI 21.8-27.6) in those with normal distance and near vision, to 0 % in those who were blind ($p<0.001$). Preference for exclusive public sector eye care was also significantly associated with vision level, but in the opposite direction, with the odds of using the private sector being more than seven times greater in those who were blind (OR 7.12, 95 % CI 2.92-17.37) compared to those with normal sight ($p<0.001$). Some OOPE on eye care services was reported by 25.3 % (95 % CI 22.9-27.8) of those with normal vision, and by no one who was blind, whereas 19.3 % (95 % CI 9.9-34.1) of blind people incurred OOPE on eye drops, compared to 4.7 % (95 % CI 3.7-6.0) with normal vision. Table 7.7 explores OOPE by vision category.

Table 7.7: Proportion with out of pocket expenditure (OOPE) on direct medical costs, by presenting vision level

Outcome variable	Normal vision	NVI	Mild VI	MSVI	Blind
Any OOPE on eye care % (95% CI)	25.3 (22.9-27.8)	10.5 (8.8-12.4)	15.1 (10.8-20.9)	12.7 (8.2-18.9)	0
Annual OOPE, all Mean (95% CI)	117 (74.4-159.8)	228 (41.5-414.4)	262.6 (-11.7-537)	79.5 (6.7-152.3)	0
Annual OOPE, in subgroup reporting any, Mean (95% CI)	511.2 (406.1-616.4)	2540.0 (2066-3014)	2589.0 (45.2-5132.9)	998.3 (449.7-1547.0)	0
OOPE on refractive correction % (95% CI)	20.3 (18.1-22.7)	4.9 (3.7-6.5)	4.0 (2.1-7.6)	1.3 (0.3-5.1)	0

Outcome variable	Normal vision	NVI	Mild VI	MSVI	Blind
OOPE on refractive correction, all Mean (95% CI)	492.9 (429.6-556.1)	117.4 (73.9-160.8)	76.4 (22.8-130.1)	38.6 (-23.5-100.7)	0
OOPE on refractive correction, if any Mean (95% CI)	2405.5 (2321.3-2489.7)	2472.2 (2131.4-2813.0)	1964.5 (1664.2-2264.7)	2935.0 (1965.3-3904.7)	0
OOPE on eye drops % (95% CI)	4.7 (3.7-6.0)	2.7 (1.8-4.0)	5.4 (2.9-10.0)	4.6 (2.2-8.9)	19.3 (9.9-34.1)
OOPE on eye drops, all Mean (95% CI)	77.4 (43.8 to 111.0)	57.2 (9.5 to 104.9)	57.7 (17.8 to 97.6)	190.0 (-46.8 to 426.8)	808.8 (419.5 to 1198.0)
OOPE on eye drops, in subgroup with any Mean (95% CI)	1462.4 (1348.6-1576.2)	2967.1 (2482.7-3451.4)	1068.8 (586.5-1551.1)	3142.0 (1560.4-4723.5)	2754.3 (1800.1-3708.5)

7.4 Discussion

The societal cost of presenting VI in adults 40 years and above in Trinidad and Tobago in 2014 was TT$3,842,324,655, with loss of wellbeing accounting for 73.3 % of the total cost, followed by indirect costs, and thus individuals and their families bore the major share of total cost (97.6 %). This study provides the first estimate of the economic burden of vision loss in any Caribbean country, and is the first eye survey to explore the economic impact of vision loss in a national population-representative sample.

The findings of this predominantly bottom-up, observational cost of vision loss study broadly agreed with other cost of vision loss studies in high-income countries. These similarly reported that intangible effects make the greatest contribution to the overall economic impact of VI and blindness (Koberlein et al., 2013). Excluding intangible losses, the next highest costs resulted from productivity losses, followed by caregiving, recurrent hospitalizations and use of medical and supportive devices, with drug costs not typically adding significantly (Koberlein et al., 2013). In Trinidad and Tobago in 2014, direct expenditure on eye drop medication made a significant contribution to total direct costs, perhaps reflecting that glaucoma was more prevalent

in Trinidad and Tobago than elsewhere. This is an interesting finding and indicates that, given the large volumes involved, there would be considerable benefit to the Ministry of Health intervening to reduce the acquisition cost of eye drops. The importance of vision level on economic productivity was supported by the finding that those with normal distance and near vision had a modest productivity gain compared to the population average, of TT$2638.8. The cost of reading spectacles varied from TT$50 for 'off the peg' reading spectacles to TT$3000 for bespoke reading / bifocal or trifocal spectacles (Braithwaite et al., 2018). Nevertheless, these figures indicate that addressing the unmet population need for reading glasses could result in a significant productivity gain, far exceeding the cost of refractive correction. Direct cross-study comparison of absolute costs is challenging because there was no consensus on what to include in cost of vision loss studies prior to 2010 (Frick et al., 2010), and there is still no standardization in cost tools, with investigators frequently devising their own, un-validated tools (Lofland et al., 2004).

Costs in other domains were lower than might be expected for a high-income country, indicating a possible gap in eye care service provision relative to the needs of the population. In support of this, no NESTT participant had received anti-VEGF therapy, which is standard care for multiple eye diseases internationally. The contemporaneous eye care system study confirmed that anti-VEGF was only available in the private sector (Braithwaite et al., 2018). However, the survey was not powered to reliably determine the prevalence of uncommon eye diseases, and may have failed to capture individuals who had received these treatments, by chance. The relatively low unit cost of ophthalmology outpatient services may reflect a historic underinvestment in public sector ophthalmic equipment. Specifically, only three out of five public hospital eye departments had visual field analysers, none had OCT imaging devices, and whilst two had FFA devices, they did not have sufficient staff to use them routinely (Braithwaite et al., 2018). There was also relative underinvestment by the Government in prevention programmes, with no national screening programme for DR, congenital cataract or retinopathy of prematurity, responsible for some cases of adult VI. A pilot screening programme for DR was completed in 2013, and a school vision screening programme was in the process of being implemented in 2014 (Braithwaite et al., 2018). Services for those with low vision were also relatively underdeveloped for a high-income country, with very few NESTT participants with low vision reporting previous assessment or access to low vision aids, such as guide dogs or assistive technologies. No blind people were employed, indicating that there may be an opportunity to strengthen workplace-based enablement policies. This

study found that improving access to the internet and to transport for those with VI might reduce barriers to work force participation. No NESTT participants reported laser refractive surgery. In summary, societal direct costs are anticipated to rise significantly in the near future, through a combination of increase in demand for eye care services from an aging population, and catch-up in ophthalmic management practices relative to other high-income country eye care systems driving a need for investment in equipment and newer medicines.

The study had a number of limitations. In common with many previous studies, this cost study was limited to costs incurred by those aged 40 years and above (Frick et al., 2007; Javitt et al., 2007; Rein et al., 2006). Secondly, the survey did not include the institutionalized population, or consider costs associated with long-term care placement resulting from VI. Thirdly, the cost and utilization estimates were subject to non-response bias (response rate 59%). Blind people were less likely to attend the regional clinic than normally sighted people, on account of transport difficulty, lack of someone to accompany them, frailty, or lack of perceived value to participating in the eye survey, and those blind people who attended clinic may have differed significantly from those who were housebound. This may account for the conservative estimate of informal care needs identified in this study (23 % blind people require a mean 8.4 hours per day), which is generally lower than that identified in other studies (Koberlein et al., 2013). A systematic review reported that average informal care hours range from 5.8 hours per week for persons with vision >6/9 to 94.1 hours per week for persons with vision <6/60 (Koberlein et al., 2013). Fourthly, the data were at risk of recall bias, because participants were asked to recall episodes and costs occurring over the past 12 months. Some may have forgotten an entire episode of eye care, or incorrectly recalled whether it occurred within or prior to the 12-month period in question (Clarke, Fiebig, & Gerdtham, 2008; Gray, Clarke, Wolstenholme & Wordsworth, 2011). Fifthly, in common with many other cost studies, this analysis did not include estimation of dead-weight losses. Furthermore, this analysis did not include consideration of the possible impact on quality of life or the opportunity cost of being a carer for someone with VI. Finally, direct health costs arising from falls, fractures, motor vehicle accidents and depression relating to VI were not explicitly measured in this survey. A systematic review reported that some studies identified a large proportion of direct costs relating to falls, accidents secondary to VI, and exacerbation of diabetic complications due to difficulty self-managing (Koberlein et al., 2013). This study was also subject to a number of assumptions. The market price for labour was assumed to be a reasonable approximation of the opportunity cost of the

employment gap resulting from VI (Gray et al., 2011). Furthermore, it was assumed that market prices that include an element of profit, such as private sector service and drug costs, were based on a fair rate of return on investment, such that they reflected societal opportunity costs (Gold, Franks, McCoy, & Fryback, 1998).

This study had multiple strengths. The majority of unit costs were estimated in a parallel, contemporaneous eye care system study in Trinidad and Tobago in 2014 (Braithwaite et al., 2018), and data on utilization of eye care services and therapies was ascertained from a population-representative national sample. Additional data relating to education and employment history provided additional valuable insight into the experience of those with VI in Trinidad and Tobago in 2014.

These cost estimates provide an important benchmark and baseline data for cost-effectiveness analyses in Trinidad and Tobago, for example to explore the potential value of introducing national DR screening, or a programme to widen access to affordable spectacles, or a cataract programme to reduce surgical waiting times. Further research will be needed to assess the impact of policies and programmes, and the rate of return on those investments. Future research is also needed to explore which individual-level cost and utilization variables should be captured in population-based surveys to permit comparison between countries. This would help to address concerns raised previously about the variability in cost estimates resulting from cost of illness studies, and contribute to the need for further research to standardize outcome measures, design approaches, and cost tools (Bloom et al., 2001; Frick et al., 2010; Koberlein et al., 2013).

7.5 Conclusion

This cost of vision loss study identified that VI in Trinidad and Tobago in 2014 had a significant societal economic impact. The findings highlight the extent to which affected individuals and their families were bearing the majority of economic costs associated with VI, including loss of wellbeing, informal care costs, productivity losses and other opportunity costs. Decisions based on direct costs to the health sector alone fail to apportion appropriate societal resources to addressing VI – at least 86 % of which is believed to be potentially avoidable through interventions to prevent and treat eye disease. In combination with the contemporaneous eye care system study (Braithwaite et al., 2018), the findings of this study help to identify priority areas for

investment, and the elements that may drive rising future eye care costs, which include the aging demographic, and the international evidence-base for best practice in eye care. Given the high proportion of indirect costs and intangible effects associated with VI, and Trinidad and Tobago's pluralistic eye care system, policy makers may need to consider intervening more proactively to correct market failures that limit timely access to sight-saving interventions in the public sector.

8

DISCUSSION

This chapter gives an overview of the main findings of the thesis and discusses conclusions, limitations, implications, and areas for further research arising from each chapter.

8.1 Chapter 1 – Thesis objectives, and rationale for NESTT

Chapter 1 specified the objectives of this thesis, which were to determine the prevalence and causes of presenting VI and blindness in the population aged 40 years and above, the proportion potentially avoidable, the associated risk factors, the impact on HRQoL, and the societal economic cost. This chapter provided an overview of the context in which the NESTT was conceived, and outlined the rationale for the study. In brief, the persisting global burden of avoidable vision loss highlighted a need for epidemiological data with which to develop evidence-based policy (Bourne et al., 2017; WHO, 1997). There was no population-representative data on the prevalence and causes of VI in Trinidad and Tobago, and a paucity of epidemiological data within

the Caribbean region in general (Anonymous, 1933; Bourne, Price, et al., 2013; Munoz & West, 2002). Although Trinidad and Tobago was a high-income economy country, the population's characteristics placed it at excess risk for certain diseases associated with VI. Specifically, the population had a very high burden of chronic non-communicable diseases (Molokhia et al., 2011; WHO, 2017), was ethnically diverse, and ageing (Beckles et al., 1986; G. J. Miller et al., 1989; Ministry of Planning and Sustainable Development, 2012), and there were pockets of socioeconomic disadvantage (Lane et al., 2018; UNDP, 2015). Trinidad and Tobago also had a highly pluralistic eye health care system, and issues around timely access to, and affordability of, eye treatments were identified in a contemporaneous eye care system study (Braithwaite et al., 2018) (See Appendix A.1).

There was demonstrable need for contemporary epidemiological data on VI and eye disease in this unique Caribbean population. The survey also created the opportunity to explore alternative population health metrics, which provide more nuanced understanding of the societal impact of vision loss. The Pan American Health Organization's, "Vision 2020 Caribbean Strategic Plan of Action on the Prevention of Avoidable Vision Impairment and Blindness" (PAHO, 2010) urged Member States to each develop an evidence-based national eye care strategy, thereby encouraging political engagement in epidemiological research.

8.2 Chapter 2 – Literature review identifies important gaps and informs study design

Chapter 2 defined literature search questions and outlined a narrative review of the published literature pertinent to the main aims of this thesis. A previous systematic review to July 2014 identified 288 population-based surveys of vision and eye diseases from 98 countries (Bourne et al., 2017). A more detailed appraisal of 165 of these studies, and 1460 associated published articles, revealed that only 15 % of studies were nationally representative, 26 % were undertaken in high-income country settings, 38 % included adults aged 40 years and above, and the average survey response rate was 83.4 %. A meta-analysis estimated that the global prevalence of blindness in people 50 years and older in high-income regions was < 0.4 %, which was ten times lower than in low-income regions (G. A. Stevens et al., 2013). A meta-analysis for the Caribbean region in 2010, estimated a prevalence of blindness and MSVI in all ages of 0.5 % and 2.9 %, respectively, but much higher in those aged 50 years and above, of 1.9 % and 11.1 %, respectively (Leasher et al., 2014). This meta-

analysis reported that the leading causes of blindness in all ages were cataract (30.2 %), URE (13.5 %), glaucoma (11.2 %), AMD (6.1 %), and DR (2.3%). The leading causes of MSVI were similarly URE (44.6 %) cataract (15.9 %), glaucoma (4.3 %), DR (2.0 %) and AMD (1.2 %) (Leasher et al., 2014). However, only four previous population-based studies from the Caribbean region, conducted in St. Lucia, Barbados, Havana, and the Dominican Republic, contributed data to the model, resulting in considerable uncertainty in parameter estimates (Hernandez Silva, 2006; Hyman et al., 2001; Limburg et al., 2015; Mason et al., 1989). These findings supported the need for more epidemiological data in the Caribbean region generally, and Trinidad and Tobago specifically.

Relatively few of the 165 studies explored independent risk factors associated with DVI and blindness. Increasing age was an independent predictor in all studies, whilst more variable associations included female sex, rural inhabitance, and subgroups defined by race, ethnicity, lower socioeconomic status, lower literacy or lower educational attainment (See Table 2.3). A systematic review of uncorrected NVI, including seven population-based studies, identified only age and female sex to be independent predictors (He et al., 2012). There had been no systematic review and meta-analysis of the risk factors associated with presenting DVI. This revealed an important gap in the literature, which future research should address. Such research would provide better understanding of the potential explanatory variables differing between individuals in a given population, but also those differing between populations, countries and health systems. This could help to identify why some countries are making faster progress than others towards reducing the burden of avoidable vision loss.

The narrative literature review of generic, multi-attribute, health-related utility instruments identified three in most frequent use over the past three decades, and the latest versions available for the NESTT in 2013. These were the EQ-5D-5L (Herdman et al., 2011), Short Form-6D (Kharroubi et al., 2007), and Health Utilities Index-3 (Furlong et al., 1998). A previous systematic review exploring the association between HRQoL and VI identified no population-based studies, and meta-analysis of included studies was not possible on account of study heterogeneity (Tosh et al., 2012). This review noted that many studies, especially those conducted in hospital clinic settings, fail to control for significant independent co-variables. My extended search identified six population-based eye surveys in high-income countries that had included assessment of HRQoL, including four using the SF-36 or SF-12, and two

using the EQ-5D (Park et al., 2015; X. Wang et al., 2014). Population-based normative value studies for the EQ-5D-5L in different countries identified key variables associated with reduced HRQoL, including older age, female sex, not being married, lower socioeconomic status and lower educational attainment, and informed key covariates to include in the NESTT survey questionnaire. The literature search revealed lack of consensus on the optimal analysis approach for utility data, which requires a non-parametric approach on account of substantial skew (Basu & Manca, 2012; Hernandez Alava et al., 2012; Pullenayegum et al., 2010). Further research is needed to advance a standardized approach to the design and analysis of studies exploring the association between HRQoL and VI.

A previous systematic review of interventional, non-interventional and cost of vision loss studies identified 22 studies, but the extent of methodological heterogeneity prevented direct comparison or meta-analysis (Koberlein et al., 2013). Consensus guidelines for estimating the cost of vision loss provided broad guidance on cost categories and the specification of a cost analysis perspective (Frick et al., 2010), but lacked the degree of detail needed to standardize study designs. The literature search revealed multiple different disability weights for the estimation of the disability adjusted life year loss associated with different levels of vision loss, but controversy over which weights to use, and these issues were outlined more fully in an Editorial (Braithwaite, Taylor, et al., 2017)(See Appendix A.3). There was also lack of agreement on whether to include a monetized estimation of DALY loss in cost of vision loss studies, and if so, what value to assign to one statistical life year, and whether to discount this. Ten national, prevalent cost of vision loss studies in high-income countries were identified, which revealed that the top-down approach is most frequently adopted, with very few studies using primary epidemiological or cost and utilization data.

A review of published studies from Trinidad and Tobago confirmed the need for data on the prevalence and causes of VI, with only one epidemiological report providing historic context (Anonymous, 1933). The association between VI and quality of life or economic cost was also unexplored, but there was recent local experience in Trinidad with the EQ-5D instrument (Bailey, 2013; Bailey et al., 2016).

This narrative literature review included only published literature, because a systematic review including unpublished literature pertinent to each aim was beyond

the scope of this thesis. It is therefore possible that some relevant studies were not identified.

8.3 Chapter 3 - Methodological review identifies need for international consensus

Chapter 3 provided a narrative review of aspects of the design, implementation and reporting of a large sample of 165 previously published population-based eye surveys included in the Global Vision Database (Bourne et al., 2017). The relative merits of different probability sampling approaches were considered, including simple and systematic random sampling, with probability-proportionate-to-size approaches, and additional approaches including multi-level sampling, cluster sampling and stratified sampling. The sample size calculation revealed the different components that must be selected and justified, including the design effect for surveys using a clustered design. Potential sources of bias were also considered, including non-response, selection and measurement bias. My evidence synthesis of 165 studies found that survey response rates were significantly lower in high-income countries (74.4 %, sd 18.4) than in low-income countries (88.3 %, sd 8.2). The many different sources of selection bias provided helpful instruction for the study design and training of enumerators. The risk of measurement bias highlighted the importance of standard operating procedures, staff training and supervision, and quality assurance exercises, and these considerations informed the logistical planning of the survey. Prevalence estimation and risk factor analysis approaches were outlined, with definition of related terms.

Reviewing the design of many previous surveys highlighted marked variability in protocols for the measurement of visual acuity, definition of cases, and analyses. International consensus on best practice is needed, along with standardization of measurement approaches, risk of bias reporting, and case definitions for eye disease and that vision loss which can be considered avoidable. Given substantial study heterogeneity, meaningful meta-analysis of eye and vision surveys is problematic. A system for grading the quality of included observational studies is urgently needed, similar to that used in Cochrane systematic reviews. This would permit sensitivity analysis in meta-analyses, to exclude studies of lower methodological quality, or at higher risk of bias, in order to explore the impact on prevalence estimates. Whilst consensus guidelines have been developed to strengthen the reporting of observational studies in epidemiology, these generic guidelines do not cover the

many issues particular to ophthalmic epidemiological surveys, and give limited consideration to detailing potential sources of bias (von Elm et al., 2007).

A limitation that hinders review of the methodological approach of previous studies is that full descriptions are not always available in published articles. Journal word count limits necessitate brevity, which may come at the expense of important scientific detail. Publication of methodology papers or additional online supplements helps to address this. Identifying all published articles associated with a survey was challenging, and use of a unique survey name in all articles greatly assisted database searching.

8.4 Chapter 4 – Strengths and limitations of the NESTT study design

Chapter 4 presented the materials and methods of the NESTT pertaining to the aims of this thesis. These were published as a detailed methodology paper (Braithwaite, Verlander, et al., 2017) (See Appendix A.2), which adhered to the STROBE checklist for Strengthening the Reporting of Observational studies in Epidemiology (von Elm et al., 2007).

The NESTT study had a number of strengths. Firstly, the rigorous sampling methodology ensured that a representative sample of the general population was selected. This representative sample was achieved through the selection of 120 clusters, chosen to reduce the design effect, and with careful oversight of enumeration to ensure sampling without replacement and minimization of selection bias. Secondly, the sample size was sufficient to give reasonable power and precision in estimates of the prevalence and causes of VI in those aged 40 years and over. Thirdly, the comprehensive examination procedures permitted detection of asymptomatic anterior and posterior segment disease, and estimation of the population-based prevalence of common ocular diseases, which are likely to impact on the future burden of VI in the population. Accurate data on refractive error as a cause of presenting VI will facilitate planning refractive error services, which are identified as a priority in the global initiative to eliminate avoidable blindness (WHO, 2013).

There were several limiting factors in the study design. Firstly, the January 2011 Population Census was the latest available sampling frame, and was 29 months out

of date at the time of cluster selection in mid-2013. Deaths, births, migration in and out of the country and between areas may have occurred during that interval, leading to population size change within different EDs. Probability proportionate to estimated size methods would be preferred. However, this approach requires full remapping of all households per ED, which was beyond the project's resources, and has seldom been achieved in previous epidemiological surveys of eye disease. Secondly, for logistical reasons, visual fields were not tested on all participants, but only on the subsample of suspected glaucoma cases, and therefore field loss was not included in the definition of blindness. Thirdly, the inclusion of OCT in the mobile clinic equipment list limited NESTT survey locations to those that could be readily accessed by well-surfaced roads, and even then, this sensitive equipment occasionally developed faults during the survey resulting in non-capture of data. A further limitation of the NESTT study was the exclusion of people with cognitive impairment, and the inclusion of only the non-institutionalized population. A future study is needed to systematically sample the residents of the nine residential elderly care homes in Trinidad and Tobago, who may be at higher risk of VI than the general population.

8.5 Chapter 5 - A burden of vision loss suboptimal for a high-income country and priorities for intervention

Chapter 5 reported the main findings of the NESTT, relating to the prevalence and causes of VI in the population aged 40 years and above in 2014, and the risk factors for presenting DVI and NVI. In brief, 25.2 % of the population presented with DVI (Snellen < 6/12) in at least one eye, and 11.9 % presented with DVI in the better-seeing eye. NVI affected 28.3%, and 22.3% of those with normal distance visual acuity. In total, an estimated 185,273 people had distance or near VI, and bilateral blindness affected 0.7 %, or 3956 people. The adjusted, age-standardized prevalence of VI was slightly higher in men than in women, and increased markedly with age in both sexes. The leading causes of DVI in the population were URE (30,528 cases), cataract (16,924 cases), DR (5,406 cases), glaucoma (2,819 cases) and AMD (1,824 cases), and 86.1% of all distance VI was potentially avoidable. In addition, there were 120,842 cases of uncorrected presbyopia. In multilevel multivariable logistic regression analysis, the risk of presenting DVI rose significantly with age, and other independent associations included not being in employment, having diagnosed diabetes or cataract, and not owning distance spectacles ($p < 0.001$ for each variable). Risk factors for presenting NVI but normal distance vision included male sex, not having health insurance, not owning distance spectacles, and not being in

employment in the past 12 months ($p < 0.001$ for each variable). The discussion considered whether the individual level associations with VI and eye disease in 2014 were also impacted by population-level and health system factors particular to this country. Whilst these were not measured directly by a prevalence survey, a contemporaneous analysis of the eye care system in Trinidad and Tobago in 2014 provided helpful context and insight into relevant eye care system weaknesses (Braithwaite et al., 2018) (See Appendix A.1).

The combination of the prevalence data from the NESTT presented in Chapter 5, and the health system data presented elsewhere (Braithwaite et al., 2018), identified key areas in which population-level health system intervention might be expected to have greatest impact on avoidable vision loss affecting the population aged 40 years and above. Successful intervention to address URE and the three eye diseases associated with the most severe VI, in particular, would eliminate the majority of avoidable vision loss in Trinidad and Tobago. Such population interventions and health system strengthening would be expected to make a significant contribution to closing the gap seen in the prevalence of blindness and VI in Trinidad and Tobago compared to other high-income countries (Bourne et al., 2017).

Addressing URE, accounting for nearly half of all distance VI and a further 120, 842 cases of uncorrected presbyopia, would have the greatest population-level impact on avoidable VI. Whilst this study identified some of the individual level factors predicting who is at greatest risk, and excluded other factors which might, a priori, have been anticipated to be important, further research is needed to understand why so many people who need spectacles are not wearing them, and which strategies would have greatest impact. Unanswered questions include whether people in Trinidad and Tobago attach stigma to wearing spectacles, whether the cost of sight tests, and spectacles obtained from private optometry services exceed the willingness or ability of the population to pay, whether there is demand or need for a public system or more rural outreach optometry services to be developed, and whether the current distribution of optometry practices in the country is adequately accessible, in terms of geography, to the population.

Cataract was the most curable cause of blindness, and the survey identified many people with VI and already diagnosed cataract. Further health system investment is likely to be needed to ensure sustainable, equitable access to timely and affordable

surgery. Strategies might include increased public-private partnerships, or investment in the equipment, facilities and number of trained staff working in the public sector.

Diabetic retinopathy was a preventable, and to some degree, treatable, cause of blindness and VI. There are many different approaches to population-level screening, and in combination with laser treatment, these are generally cost-effective (Pasquel et al., 2015). Given that the prevalence of diabetes was high in Trinidad and Tobago, and that it is anticipated to more than double between 2000 and 2030 (WHO, 2017), and that DR was the third most frequent cause of blindness, the introduction of a national screening program merits prioritization.

A final priority is improved treatment and management of glaucoma, which was the leading cause of blindness in Trinidad and Tobago. Possible strategies include adding more glaucoma medications to the CDAP, which provides access to essential medicines to patients in the public sector at no cost, investing in visual field analysers and devices for imaging and monitoring the optic nerve head (e.g. OCT) in all five public hospitals, and investing in a greater number of ophthalmologists trained to perform glaucoma surgery. Another issue identified by this survey was undiagnosed, asymptomatic, advanced suspected glaucoma, and further research is needed to explore the optimal strategies for public health education to address this.

The key limitation of the NESTT study findings was the possibility of non-response bias. The study had 15.8 % non-response to vision screening, and 34.5 % non-response to comprehensive assessment. Non-response is problematic because in addition to reducing statistical power, it increases the standard error due to random error, and has the potential to introduce bias in the estimates (if non-responders and responders differ in the outcomes of interest). Participation in epidemiological surveys has declined in recent decades (Galea & Tracy, 2007), and is frequently lower in communities with greater levels of deprivation and lower levels of education (Goodman & Gatward, 2008). In addition to these factors, which are noted to affect surveys internationally, additional factors may have impacted on the participation rate in this study, which was government funded and generally delivered in public sector venues loaned by the Regional Health Authorities. Interpersonal trust in Trinidad and Tobago has been ranked amongst the lowest in the world (Morrone, 2009); only 3.8 % of the population feel that most people can be trusted, and a majority of people have little or no trust in people they meet for the first time (75.0 %), little or no confidence in the government (71.3 %) and little or no confidence in the public service

(64.5 %) (Worcester R., 2014). Furthermore, no incentive was given to participate, aside from the opportunity to have a free comprehensive eye and health assessment. To mitigate against non-response, considerable human resources were deployed to sensitize communities and encourage participation, with an average of more than three visits to each of 120 communities by the enumerators, plus an additional three or more visits by the clinical survey team, and rebooking missed clinic appointments up to three times. Some key data was collected on non-respondents to permit assessment of potential bias. The key prevalence estimates were also adjusted, to account for the non-response rate in each cluster, with weighting by region, sex and age.

The most common reason given for non-response, by 74.5 % (331), was that they were too busy to attend. Only 1.4 % (6) non-responders stated that travel distance or cost were the reason for non-participation. With the benefit of hindsight, a higher response rate to many secondary outcome variables could have been achieved by collecting more questionnaire and examination variables at the first household visit. This would have required additional investment in technology, portable equipment, and mobile teams of staff. This approach is recommended to those designing future population-based vision surveys, particularly in high-income country settings, where a lower proportion of participants may be willing or able to take time to visit a regional clinic for a second, more detailed assessment.

8.6 Chapter 6 - Vision impairment significantly impacts health-related quality of life

Chapter 6 reported that both near VI and distance VI were independently associated with reduced HRQoL, after adjustment for significant explanatory variables. An estimated 762 QALYs were lost per 100,000 population aged 40 years and above in 2014 on account of VI, of which 695 were potentially avoidable. Without effective intervention, a 40-year-old who was blind could expect to lose 5.13 QALYs over the course of his or her lifetime, whilst someone with NVI could expect to lose 0.45 QALYs. Whilst the individual impact of presenting NVI was small, with a reduction in utility value of only -0.02, the societal impact was considerable, on account of the high prevalence of presenting NVI in this population. In this study, blindness had a greater independent effect on the difference in mean utility index than other co-morbidities in the medical history, including stroke and arthritis. This finding raises the question of whether measurement of visual acuity, but not self-reported vision state, should be

considered in future normative HRQoL studies. Limitations particular to this HRQoL study were considered in the discussion (Section 6.4), including potential non-response bias, and bias from the mode of instrument administration.

The main limitation of adding a HRQoL study into the NESTT study was that only prevalent HRQoL and VI could be explored. A preferable study design to better understand the impact of VI on HRQoL, and the other causal and confounding risk factors, would be a prospective cohort study in a population-representative sample, or in a case-control study. Sufficient follow-up duration would be needed to capture the trajectory of incident change in HRQoL in relation to the process of diagnosis and management of eye disease and the resulting vision states. HRQoL is dynamic, and is likely to be impacted in complex ways, which differ between individuals, and between eye care systems in different countries.

Secondly, the number of participants with MSVI or blindness was relatively low in this study (31 blind, 19 SVI, and 196 MVI in the better-seeing eye). Future studies with larger sample sizes, or different study design, to capture HRQoL outcomes in more participants with MSVI and blindness, would have greater power for risk factor analysis. Further research is needed to establish whether VI is a consistent independent predictor of reduced HRQoL, and the range in the effect size. To date, only the Singapore Eye Survey and Korean National Health and Nutrition Epidemiological Survey have included EQ-5D (Park et al., 2015; X. Wang et al., 2014). Different individual, cultural, societal, political and health system factors might be expected to lead to observed differences between populations. Further research is also needed to resolve issues around the preferred statistical analysis approach for HRQoL data resulting from the various MAU instruments (Basu & Manca, 2012; Hernandez Alava et al., 2012; Pullenayegum et al., 2010). Future international consensus around a standardized approach will be needed to permit meaningful meta-analysis of the association between HRQoL and VI.

Inclusion of EQ-5D-5L, a short and simple tool, in this population-based survey has advanced understanding of the individual impact of VI, for a small increase in the assessment time, and no additional equipment cost. EQ-5D-5L has been validated for use in Trinidad and Tobago (Bailey, 2013; Bailey & Kind, 2010; Bailey et al., 2016), and is likely to be suitable for future HRQoL research elsewhere in the English-speaking Caribbean. The more recent 3-item bolt-on for vision, hearing, and fatigue may further improve the psychometric performance of the instrument (Yang et al.,

2015), but further research will be needed to understand how to compare the data from these two instruments.

8.7 Chapter 7 - Vision loss has a substantial economic impact

Chapter 7 estimated that the societal economic cost of vision loss in adults 40 years and over was TT$3,842,324,655 in 2014, with loss of wellbeing accounting for 73.3 %. Individuals and their families or carers bore 97.6 % of costs. Excluding intangible effects, the second most important contributor to total cost was indirect cost (70.5 %), followed by direct medical cost (17.9 %), and direct non-medical cost (11.6 %). These are the first estimates of the economic burden of vision loss in a Caribbean country. This study demonstrated that in the case of vision loss, studies which estimate only direct costs, or costs incurred by the health service provider, will produce estimates substantially lower than studies taking a societal perspective. Nesting an observational, bottom-up, cost of vision loss study within a population-based epidemiological eye survey, yielded multiple insights, both into to the individual-level impact of maintaining vision health or living and working with VI, and into gaps in the current provision of hospital eye care, optometry and low vision services, relative to what might be expected for a high-income country.

The discussion (Section 7.4) reported multiple limitations of the cost of vision loss study, including possible non-response bias, missing data from participants who were housebound, recall bias, and non-coverage of the institutionalized population. It would have been preferable to prospectively gather cost data for 3 months in those identified by the survey to have low vision, using cost diaries, but time and resource constraint precluded this (Lamoureux et al., 2006). Furthermore, the cost instrument, which was modified for use in this survey, omitted certain key topics (Gray, Clarke, Farmer, & Holman, 2002). A future cost of vision loss study should add questions on utilization of imaging (e.g. OCT, CT, MRI), lab tests, and the frequency and type of laser therapy and surgery received in the public sector. This would avoid the need to use data from published sources, and the necessary assumption that the data are applicable in a different context.

A key challenge is that it is presently very difficult to make direct comparison between cost of vision loss studies, and they are too heterogeneous in both design and reporting to permit meaningful meta-analysis (Koberlein et al., 2013). Future work is needed to further develop the first consensus guidelines for cost of vision loss studies

(Frick et al., 2010), to include more specific detail on bottom-up approaches to study design and reporting. Development of a standardized cost tool for use in cost of vision loss studies is also needed.

8.8 Overall conclusions of thesis

The findings reported in this thesis, and additional work by other members of the NESTT Study Group, address the demonstrable need for contemporary, reliable epidemiological data on the prevalence and severity of VI, and associated causes and risk factors in the population of Trinidad and Tobago. Studies elsewhere in the region in the past four decades were few in number, and of questionable relevance to this population in 2014, on account of its heterogeneous ethnic composition, older population, and exceptionally high burden of non-communicable disease. The NESTT study data provides important population-based estimates to support the rational development of an evidence-based National Eye Care Strategy by the Ministry of Health of the Government of the Republic of Trinidad and Tobago. The aim of this strategy should be to address the unmet eye care needs in the population, and reduce the burden of avoidable vision loss. This will help Trinidad and Tobago to take a lead within the Caribbean region in delivering on the targets outlined by the Pan American Health Care Organization Strategic Framework for Vision 2020 (PAHO, 2010).

It is unclear whether the identified population burden of VI, in and of itself, is a sufficient metric to persuade decision makers of the importance of investment in eye health, when so many important public health problems compete for limited resources. To better understand the impact of VI, this thesis explored the association between VI and HRQoL, and the societal economic impact. Further research is needed internationally, to understand the cost-effectiveness of population-based epidemiological research, and different additional study design components, on resource allocation, policy-making, and actual population-level impact to improve eye health.

8.9 Future work by the NESTT Study Group

Further work is in progress by the NESTT Study Group. Specifically, we are currently exploring the prevalence, risk factors, and impact on HRQoL, of common eye diseases, including glaucoma, DR, and refractive error, and common medical

conditions, including diabetes mellitus, obesity, and hypertension. We are also investigating the impact of VI on daily functioning, and on vision-related quality of life. The use of various items of specialized ophthalmic equipment captured population-representative data on some relatively novel variables (e.g. corneal resistance factor, choroidal thickness, optic disc area, and other biometric parameters). In common with numerous recent epidemiological surveys of eye disease, the NESTT study collected and stored DNA samples from fully phenotyped, consenting adult participants (Roach, 2016). The DNA has been stored in the Duke University Biobank in the USA, and it is hoped that next generation sequencing techniques will be used for future genome-wide association studies to explore novel genetic risk factors for common, complex ocular and cardiovascular disease.

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APPENDIX

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Health system dynamics analysis of eyecare services in Trinidad and Tobago and progress towards Vision 2020 Goals

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Abstract

Avoidable blindness is an important global public health concern. This study aimed to assess Trinidad and Tobago's progress towards achieving the Pan American Health Organisation, "Strategic Framework for Vision 2020: The Right to Sight – Caribbean Region," indicators through comprehensive review of the eyecare system, in order to facilitate health system priority setting. We administered structured surveys to six stakeholder groups, including eyecare providers, patients, and older adult participants in the National Eye Survey of Trinidad and Tobago. We reviewed reports, registers and policy documents, and used a health system dynamics framework to synthesise data. In 2014, the population of 1.35 million were served by a pluralistic eyecare system, which had achieved 14 out of 27 Strategic Framework indicators. The Government provided free primary, secondary and emergency eyecare services, through 108 health centres and 5 hospitals (0.26 ophthalmologists and 1.32 ophthalmologists-in-training per 50,000 population). Private sector optometrists (4.37 per 50,000 population), and ophthalmologists (0.93 per 50,000 population) provided 80% of all eyecare. Only 19.3% of the adult population had private health insurance, revealing significant out-of-pocket expenditure. We identified potential weaknesses in the eyecare system where investment might reduce avoidable blindness. These included a need for more ophthalmic equipment and maintenance in the public sector, national screening programmes for diabetic retinopathy, retinopathy of prematurity, and neonatal eye defects, and pathways to ensure timely and equitable access to subspecialised surgery. Eyecare for older adults was responsible for an estimated 9.5% (US$ 22.6 million) of annual health expenditure. This study used the health system dynamics framework and new data to identify priorities for eyecare system strengthening. We recommend this approach for exploring potential health system barriers to addressing avoidable blindness, and other important public health problems.

Introduction

Blindness and vision impairment affect an estimated 223.4 million people globally (Stevens et al., 2013). Vision loss is an important public health issue, because over 65% is potentially avoidable through cost-effective interventions to prevent, treat or cure eye disorders (Bourne et al., 2013b). Populations of lower

and middle-income countries are particularly affected. Approximately 0.5% of the Caribbean population are blind, and an additional 2.9% have moderate or severe vision impairment (MSVI), resulting predominantly from cataract, glaucoma, uncorrected refractive error, diabetic retinopathy and macular degeneration (Leasher et al., 2014). The World Health Organization and partners launched a global initiative to eliminate avoidable blindness in 1997 (WHO, 1997). A Caribbean Region specific "Strategic Framework for Vision 2020: The Right to Sight', was developed by the Pan American Health Organisation with multiple partners and Member States in 2002, and updated in 2010 (PAHO, 2010). This strategic framework proposed 80 actions for Member States and stakeholders, and 27 progress indicators, to support individualised priority setting and objective development within each country.
Comprehensive, accessible, equitable systems are necessary to address avoidable vision loss (WHO, 2013). Whilst over 243 surveys have estimated the prevalence of blindness (Bourne et al., 2013a), a paucity of relevant health systems research limits understand of contributing factors (Blanchet et al., 2014). Such research is especially important in highly pluralistic health care systems in which public stewardship may be under-developed (WHO, 2000).
In 2013-2014, a National Eye Survey of Trinidad and Tobago (NESTT) was completed, to estimate the prevalence of vision loss and eye disease in the population aged 5 years and above (*citation in press, masked*). The current study aimed to address the absence of published literature on the health care system relating to eyecare in Trinidad and Tobago, and to identify potential areas for health system strengthening to reduce avoidable blindness.

Methods

We sought structured feedback from six stakeholder groups in Trinidad and Tobago: all optometrists, all ophthalmologists and ophthalmologists-in-training, all public hospital eye department administrators, all public health centres, all public sector primary care physicians (PCPs), and a sample of out-patients attending the public hospital eye clinics. The content of the surveys was based on several pre-existing tools including the Vision 2020 situation analysis (WHO, 2002), essential equipment for a functional eye unit (IAPB, 2011, Hornby, 2013, Bailey, 2011), healthcare costs (Clarke et al., 2003), with modifications to better suit the local context following stakeholder focus group feedback. The surveys included information about services, human resources, training, equipment, referral pathways, access to guidelines and protocols, administrative support, types and volume of services, fees, patient satisfaction, and feedback on the eyecare system. Trainee ophthalmologists were invited to complete a survey on their clinical learning environment (Boor et al., 2007). (See Table 1).
We collected details of all eyecare professionals and practices in mid-2013 from various sources. These included: lists published by newspapers and the telephone directory; lists held by professional registration bodies including the Medical Board of Trinidad and Tobago (MBTT) (MBTT, 2013) and Trinidad and Tobago Optometry Registration Council (TTORC) (TTORC, 2013); lists of active practitioners held by professional societies including the Ophthalmological Society of Trinidad and Tobago (OSTT) and the Trinidad and Tobago Optometry Association (TTOA); and lists of professionals-in-training held by University and Hospital departments. Twelve ophthalmologists on the MBTT register were excluded; 2 were deceased, 1 was retired, and 9 were working in the UK. The MoH supplied details of all health centres and public hospitals containing eye departments.
We circulated electronic surveys to eyecare providers and PCPs using an online platform (Smart Survey©). The Chief Nursing Officer distributed hard copies to the Head Nurse in every health centre. Interviewers visited each hospital eye clinic to meet administrators, review equipment, and survey a convenience sample of out-patients attending over a ten-day period, aiming for a quota of 100 in each clinic in Trinidad, and 50 in Tobago. We utilised survey methods known to improve response rates, including pre-notification about the study, university sponsorship, use of a white background, and reminders with notification that others had responded (Edwards et al., 2009).

In addition, we obtained new data on eye care utilisation over the preceding 12 months, and unit costs for eyecare services, collected from older adults (aged 40 years and above) who participated in the National Eye Survey of Trinidad and Tobago (NESTT, 2013-2014). The study rationale and methods are detailed elsewhere (*citation masked*). In brief, randomised multistage cluster sampling, with probability-proportionate-to-size methods, was used to select 9913 eligible people from the population aged 5 years and above. 4263 older adults were invited to attend a regional clinic for comprehensive assessment and structured interview. Finally, we reviewed reports and policy documents offering insight into the health and eye care system in Trinidad and Tobago.

Ethics Committee Approvals

The authors obtained ethical approval from their institutions (*masked)* and from the Ministry of Health of the Government of Trinidad and Tobago.

Statistical analysis

We used standard statistical software for descriptive data analysis (StataCorp. 2013. Stata Statistical Software: Release 13.1. College Station, TX: StataCorp LP).

Analytic frameworks

We used the Health System Dynamics Framework to synthesise data (Russell et al., 2013, van Olmen et al., 2012). This systems model promotes consideration of the broader social determinants of health (Russell et al., 2013), and has been used previously to review eye care services in Zambia (Bozzani et al., 2014). The framework incorporates eight components and their interactions to facilitate a comprehensive analytical overview of the system, its constituent parts and functioning at national, regional and individual levels (See Figure 1). In addition, we integrated the 27 Vision 2020 Strategic Framework Indicators for the Caribbean (PAHO, 2010), to review Trinidad and Tobago's progress.

Results

We collected data between May 2013 and November 2014. Amongst providers, response rates ranged from 83% of health centres (n = 90), to 15% of ophthalmologists (n = 5) and 14% (n=5) of ophthalmologists-in-training. Amongst the general population aged > 40, who were sampled as part of the National Eye Survey of Trinidad and Tobago, 59% (n = 2520) responded to the demographic and socioeconomic questionnaires (See Table 2). The characteristics of the latter were broadly similar to the 2011 population census (Citation masked). We also surveyed 454 patients attending eye clinics in all 5 hospitals. Responder characteristics are summarised in Table 3.

Health System Dynamics Analytical Framework

The Context

Trinidad and Tobago is a twin-island democratic state, and former British colony that has been independent since 1962. It is the fifth largest Caribbean country, with a landmass of 5,128 km^2 (CIA, 2015). It became a high-income nation in 2005, on account of large reserves of oil and natural gas, which contribute 40% to Gross Domestic Product (GDP). The Gross National Income per capita is $US 18,380 (GNI at Atlas Method) (World Bank, 2014). However, monthly household income was reported as less than TT$ 9999 (US$ 1562) by 79.7% (n = 1985) at an exchange rate of 6.4086 TT$ = 1 US$ in 2014

(Central Bank of Trinidad and Tobago, 2017) (See Table 2). This discrepancy may reflect a bias in self-reported income, but also a skewed income distribution, with substantial inequality. 1.7% of the population are considered poor, based on the multidimensional poverty index, and an additional 0.5% are living near poverty (UNDP, 2015). The Human Development Index (HDI) gauges a country's level of human development, taking into account how income is turned into education and health opportunities. Trinidad and Tobago had an HDI of 0.760 in 2012, ranking 67th out of 187 countries, approaching the threshold for designation as an "advanced economy" by the International Monetary Fund (>=0.788) (UNDP, 2015). Unemployment is low, at 3.2% (Central Bank of Trinidad and Tobago, 2015). Literacy is very high (99%) (CIA, 2015), but 19% (n=475) of older adults report only basic literacy (See Table 3). The eyecare system, like the general health system, faces multiple challenges. Internationally, there have been significant advances in imaging technology and treatments. These facilitate improved screening, diagnosis and management of eye disease, but at significant cost. Health care expectations are also changing, with potential impact on health-seeking behaviour. Factors driving these changes include improved education and computer literacy; 61% of adults over 40 years (n = 1537) report internet use.

The Population

Trinidad and Tobago had a population of 1.35 million people in 2014 (6th largest in the Caribbean), with life expectancy at birth of 70 years for men and 76 years for women (Central Statistical Office, 2014). The maternal mortality rate was 63 deaths per 100,000 live births (112th in world), and the infant mortality rate was 24 deaths per 1000 live births (72nd in the world) (CIA, 2015). These metrics indicate a good level of development of the population, its health system and its interaction with the social determinants of health. The population was ethnically diverse, with 34% of African origin, 35% of South Asian origin, 23% of mixed ethnicity and 1% of other ancestral origins (CSO, 2011). This is of interest because some diseases, such as glaucoma (Tham et al., 2014) and diabetes (Spanakis and Golden, 2013) are more prevalent in these ethnic groups. The population size was static but demographically transitioning rapidly towards a more aged population, with 9.8% of the population aged over 65 years (CSO, 2011). Advancing age is a risk factor for many eye diseases, including glaucoma, macular degeneration and cataract (Bourne et al., 2013b). The larger island of Trinidad was residence to 95% (CSO, 2011), with the greatest population density along two major highways. Large areas of rainforest and swamp were sparsely populated, with limited transport infrastructure.

The Global Burden of Disease Study estimated that in 2010, 6727 people in Trinidad and Tobago were blind and 39,014 had moderate or severe vision impairment, a burden more typical for a middle-income country (Leasher et al., 2014). The burden of chronic non-communicable diseases (NCDs), associated with nutrition and lifestyle transition, is the highest of any Caribbean nation (Ministry of Health, 2012a). NCDs may cause vision loss, and account for over 60% of premature loss of life (Ministry of Health, 2012a). Approximately 55.7% of adults are overweight or obese, 26.3% are hypertensive, 5.1% are diabetic and 20.5% have pre-diabetes (Ministry of Health, 2012a), and poor glycaemic control is common (Apparico et al., 2007). Childhood obesity affects 23% and 25% of primary and secondary school children, respectively (Traboulay and Hoyte, 2015), but the prevalence of childhood type 2 diabetes is currently only 10 per 100,000 children (Batson et al., 2013).

THE EYECARE SYSTEM

Leadership and Governance

The MoH in Trinidad and Tobago devolved responsibility and funding for health care provision to six autonomous Regional Health Authorities (RHAs) in 1994 (Rutten et al., 2002). These were subsequently

reduced to five. The MoH sets regional policies, goals and targets based on needs assessment, and indirectly governs the health system (Ministry of Health, 2015). Facilities are operated by the Northwest, Northcentral, Southwest, and Eastern RHAs in Trinidad, and by the Tobago RHA. Regulatory bodies include the MBTT and the TTORC. Key professional societies include the OSTT, the TTOA, and the Opticians Association of Trinidad and Tobago, who set professional and ethical standards.
Analysis of the effectiveness of the leadership and governance of the health and eye care sector in Trinidad and Tobago was beyond the scope of this study. However, Van Olmen and colleagues (Van Olmen et al., 2012) have observed that strong capacity and strategic oversight are needed within a Ministry of Health and its decentralised structures to steer pluralistic health care systems into satisfactory balance. Governance is also important, to engage all stakeholders and ensure their interests are made explicit. Furthermore, mechanisms of population accountability are needed, with fair and transparent decision-making processes, to prioritise short, medium and long-term goals. Governments have an important role in monitoring health systems, intervening to correct market failures, and redistributing resources among the population where necessary, to ensure that health care is accessible to all according to need (Van Olmen et al, 2012). Mills and Ranson (Mills and Ranson, 2006) caution that a lack of monitoring, insufficient knowledge of the health system, insufficient resources, diverging priorities or insufficient political commitment may cause gaps between rules and their enforcement.

Values and Principles: Review of key stakeholder mission statements

The MoH's (Ministry of Health, 2015) vision was to be a, "*people-centred, caring, proactive institution that assures standards of excellence are achieved by all stakeholders that promote, protect and improve the health status of the people of Trinidad and Tobago*". Its mission was, "*to provide effective leadership for the health sector by focusing on evidence-based policy making, planning, monitoring, evaluation, collaboration and regulation*," and, "*to establish national priorities for health and ensure an enabling environment for the delivery of a broad range of high quality, people-centred services from a mix of public and private providers*". The MoH explicitly recognised the importance of the social determinants of health and their effect on individuals and the population, and fully endorsed the WHO Charter of Patients' Rights and Obligations (Ministry of Health, 2011). Mission statements were readily available online for the TTOA, the Trinidad and Tobago Blind Welfare Association (BWA), and The Caribbean Council for the Blind's member agency in Trinidad and Tobago, Persons Associated with Visual Impairment (PAVI).

Infrastructure for the delivery of health and eyecare services

Over the ten-year period leading up to 2013/4, substantial investments were made in the public and private health sectors. There were no published data on health system capacity, but direct contact with every healthcare facility in 2014 revealed that there were 20 hospitals, including 406 beds and 27 operating theatres in 11 private hospitals, and 2,862 beds (including 1093 mental health patient beds) and 31 operating theatres in 9 public hospitals. There were 146 outpatient facilities, of which 32 were private. The health system also included four cardiac catheterisation facilities, 9 magnetic resonance imaging (MRI) facilities and 10 computerised tomography (CT) imaging facilities. The public infrastructure for primary eyecare, offering basic universal access, included 112 health centres, 84 in Trinidad and 18 in Tobago, and the accident and emergency (A&E) departments of the regional hospitals (See Figure 2). Diabetic eyecare was provided on an ad hoc basis in 2014, without systematic integration into primary care. However, diabetic retinopathy screening, modelled on the service in Wales, had been piloted in the southwest RHA in 2012-2013, and plans to continue and extend this nationwide were being considered. Secondary eyecare was provided in 5 regional public hospitals. Port of Spain General (PoSG) hospital served northwest Trinidad (22.1% population), Mount Hope (MH) hospital served northcentral Trinidad (18.4% population), Sangre Grande (SG) hospital served eastern Trinidad (8.3% population), San

Fernando General (SFG) hospital served southwest Trinidad (46.6% population), and Scarborough hospital served Tobago (4.6% population) (See Figure 2). Hospital records from 4 hospitals identified that 2010 cataract operations were performed in 2013-2014, giving a public sector cataract surgical rate of at least 1489 per year per million population (Table 4). Subspecialised ophthalmic services, such as vitreoretinal surgery and corneal surgery, were generally unavailable. There were 3 neonatal high dependency units (PoSG, MH and SFG; none in the private sector), but no screening programme for retinopathy of prematurity, and only one private vitreoretinal surgeon offering laser therapy for identified cases. Eye examination for congenital cataract was not routinely included in neonatal health checks. Public hospitals were fairly accessible to the population (See Figure 2). Patients attending the five eye clinics (n=453) reported a median travel time from home of 30 minutes (IQR 20-60), ranging from 1 to 240 minutes, and a median cost for the return journey of TT$16 (IQR $8 to $22, range $0 to $300) (US$2.50). Median travel times were shortest in Tobago (15 minutes, IQR 15-30), and longest in southwest Trinidad (60 minutes, IQR 30-90). The majority of patients travelled using public transport (58.2%, n=262), or private car (33.8%, n=152). Referrals between health centres and eye clinics were mostly paper based, requiring hand delivery by the patient (98%, n=88 health centres), with referral by phone in the remainder. Feedback from the eye clinics to the referring professional was infrequent, with 75% of health centres, and 80% of optometrists reporting 'never' receiving it. By comparison, only 2.6% optometrists reported 'never' receiving feedback from private ophthalmologists.

In the private sector, primary eyecare was provided by optometrists located in 44 practices and by PCPs. Spectacles were available from 20 dispensing optician practices. 31 private ophthalmology clinics, located in the larger cities and towns, offered services, including subspecialised surgery (See Figure 2). The number of cataract operations undertaken in the private sector in 2013-2014 could not be reliably ascertained on account of a low response rate to the ophthalmologist survey.

Within the public system, the population could self-refer to health centres to see a nurse or PCP, or to A&E, who in turn referred to the regional eye department. The insured population were able to self-refer to private optometrists or PCPs, who referred to private ophthalmologists. The population also had the option to pay out-of-pocket to access private care directly.

Data on eyecare service utilisation in a 12-month period was collected from the population-representative sample of adults over 40 years in the NESTT survey (n=2520) (Citation masked). This revealed that 18.2% (n=454) used the public sector, 63.7% (n=1586) used both sectors (paying out-of-pocket), and 18.1% (n=451) were insured for private eyecare. Out of 1020 eyecare episodes reported in one year in this sample, 19.8% (n=202) were public sector, and 80.2% (n = 818) were private sector, indicating a preference for the latter, and a willingness by the uninsured population to pay out-of-pocket for eyecare. Private optometrists provided 44.3% (n=452) of episodes, private ophthalmologists provided 34.7% (n=354) and private PCPs provided 1.2% (n=12). Within the public sector, health centres provided 2.8% (n=29) of episodes, A&E departments provided 0.6% (n=6), and hospital clinics provided 13.6% (n=139). An additional 1.5% (n=15) involved overnight admission, and 1.3% (n=13) involved day case surgery (See Figure 3).

This infrastructure was supplemented by a low vision clinic offering limited free refractions at the University Optometry Department during term time. The BWA offered services to clients on the blind register, including general and vocational counselling, rehabilitation, leisure activities, library services, social welfare assistance, and courses on daily living skills, mobility, social and communication skills (BWA, 2015). PAVI offered additional rehabilitation services in mobility, communication skills, social adjustment, daily living skills, and vocational guidance (CCB, 2014).

Organisation of health and eyecare resources

Financing

Trinidad and Tobago's GDP in 2014 was US$ 27.8 billion (Central Bank of Trinidad and Tobago, 2015) and 5.5% was spent on health (world rank 131st) (CIA, 2015). Public and private sector expenditure contributed equally to total health expenditure (PAHO, 2012). Government spending on pharmaceuticals and medical supplies was stable in 2012-2014, and totalled US$ 83 million ($69M was for pharmaceuticals and $14M for medical supplies). There was no data on eyecare expenditure. The surveys for optometrists, ophthalmologists, and hospital administrators estimated typical unit costs associated with eyecare services (See Table 5). Public sector unit costs were provided by the MoH (Personal Communication, 2016). The total cost, from a health service perspective, associated with 1020 eyecare episodes utilised over 12 months by the NESTT population sample, was TT$ 691,413 (Figure 3). Extrapolating to all adults over 40 years (39.2% of the total population) suggested an eyecare service expenditure of TT$ 144.7 million (US$ 22.6 million), equivalent to 9.5% of total healthcare expenditure. The NESTT survey found that 18.9% (n = 471) of the population had health insurance, which was provided by approximately 20 companies. Most private sector employees had insurance cover including healthcare. Government employees received a medical plan, 'Unimed', valued at TTD$300 per month. Co-payments were typically 80/20 or 70/30 for vision needs. Policies did not include subsidised sight tests (TTD$120), but covered some or all the cost of spectacles (typically TTD$1000 to 3000).
The MoH had a permanent External Patient Program to reduce waiting times for surgery in the public sector, and sporadically entered public-private partnerships for subspecialised surgery on a case-by-case basis (Ministry of Health, 2012b).

Human resources

The Ministry of Health estimated that there were 20 physicians per 10,000 people (16.2 PCPs and 3.8 specialists) in 2012/13. This compares favourably with the unweighted average for the Latin America Region of 16.1 (in 2012), and the USA of 26 (in 2011) (PAHO, 2014).

The 2013-2014 eyecare workforce included: 115 private optometrists, and 1 in the public sector (TTORC, 2013), with 90 optometrists-in-training; 54 dispensing opticians; 34 active ophthalmologists (eye surgeons), of whom 23 worked in the private sector, 10 in both, and one in the public sector; and 35 ophthalmologists-in-training in the public sector. The ophthalmologists had mostly obtained postgraduate qualification in the UK (n=31/34) (MBTT, 2013). The optometrists (n=50) had obtained qualification in the UK (41%) or USA (30%), and had been in practice for between 2 and 65 years, with an average time since qualification of 17 years. The optometrists reported an average 36-hour week (sd 15, range 1 to 70), spending 77.2% of their time refracting, 9.0% on management/business, 8.3% teaching, and the remainder doing research (1.5%), fulfilling a role in a professional organisation (1.8%), or undertaking charity work locally (2.2%) or abroad (0.02%). Optometry capacity was not fully utilised; only 54% reported having over 75% of their available appointments filled on a typical day.

Trinidad and Tobago's eyecare workforce comfortably exceeded the Vision 2020 Goal to have at least one ophthalmic surgeon, one optometrist able to refract, and one ophthalmic-trained nurse or ophthalmic medical assistant per 50,000 population (WHO, 2007). Overall, per 50,000 population, there were 4.37 optometrists, 2.03 dispensing opticians, 0.93 private sector ophthalmologists, 0.26 public sector ophthalmologists, and 1.32 public sector ophthalmologists-in-training (See Table 6). These estimates reveal an unequal distribution of independent ophthalmologists between the public and private sectors, and highlight a significant dependence within the public sector on service provision by trainee eye

surgeons. Furthermore, the workforce distribution was not evenly matched to the population distribution, with a higher concentration of eyecare providers in northwest Trinidad, and a paucity in eastern Trinidad (see Table 6 and Figure 2). Low income countries typically have 0.45 ophthalmologists per 50,000 population, compared to 4.0 per 50,000 in high income countries (Resnikoff, et al. 2012). Significant geographic variability in ophthalmologist distribution has also been reported in the USA (Gibson, 2015), and in France, where it ranges from 5.5 to 13.5 per 100,000 population (Lafuma et al., 2006). The eyecare workforce in Trinidad and Tobago was significantly underestimated previously, at 16 (Resnikoff et al., 2012), illustrating the value of health system studies undertaken within country.

Technical support and maintenance of specialised ophthalmic equipment in the hospitals was provided by supply companies, whose technicians were located abroad but sporadically visited.
The public health centres made a small contribution to the eyecare workforce. Health centres (n=90) included a median 1.9 district health visitors, 0.6 district nurses, 0.9 registered nurses, 2.2 enrolled nursing assistants, 1.8 PCPs and 0.9 school health screeners. However, competence in the measurement of visual acuity was estimated to range from 25.0% amongst district nurses to 76.5% amongst PCPs. Only 20.5% (n=17) of health centres had protocols for the triage and management of eye or vision problems. A School Health Project, including hearing and vision screening for all 1st year primary school children, was in the process of being implemented nationwide in 2014. This resulted from collaboration between the Ministries of Health, Education, and Social Development, and NGOs including PAHO, and the United Nations Children's Fund. A scheme to enable free access to spectacles was in the process of being extended to meet demand.

Infrastructure

Equipment and supply of pharmaceuticals

The optometry survey confirmed that the majority of private practices were appropriately equipped for primary eyecare (IAPB, 2011, Hornby, 2013). The following services were included by at least 80% of optometrists in a standard sight test with a mean cost of TT$113 (sd 28): distance visual acuity (100%, n=50), near acuity or reading assessment (98.0%, n=49), refraction (98.0%, n=49), direct ophthalmoscopy (92.0%, n=46), slit lamp examination of the anterior segment (80.0%, n=40), and air puff tonometry (86.0%, n=43). Less frequently included components were slit lamp examination of the fundus (58.0%, n=29) and Goldman Tonometry to measure intraocular pressure (20.0%, n=10). Visual field testing, essential for the diagnosis and monitoring of glaucoma and other conditions, was offered by 76%, but for a mean additional fee of TT$178 (sd 30). However, optometry practices were concentrated in more affluent areas, leaving large rural areas without geographically proximate access (Figure 2). Optometrists reported a desire to increase the scope of their practice by dilating eyes to enable more thorough examination, and this became legal in December 2014, although professional indemnity cover exclusions still limited its application.

In contrast, health centres were within easy reach of all communities nationwide, but they were often not adequately equipped to offer primary eyecare. Only 58% had a distance visual acuity chart, 19% had a near acuity or reading chart, and whilst 85% had a direct ophthalmoscope, only 5% had dilating eye drops to facilitate fundus examination. None had a visual field analyser. In the preceding 3-month period, 2% had offered ophthalmology outreach clinics, and 1% (all in the ERHA) had offered optometry outreach clinics for patients with chronic disease, via the Shared Community Ophthalmology Primary Eyecare (SCOPE) program.

The equipment available for ophthalmic service delivery in the 5 public hospital eye departments did not meet minimum requirements (Bailey, 2011) in some cases (see Table 4), but Scarborough was in the process of ordering new equipment. Scarborough and MH Hospital did not have a visual field analyser. This equipment, considered essential for even a primary care eye service (Hornby, 2013), is needed for the safe management of glaucoma patients. Scarborough, PoSG, and MH hospitals did not have a fundus camera to facilitate monitoring of retinal disease. Only SG hospital had fluorescein angiography, but reported seldom using it on account of inadequate availability of trained staff. 4 hospitals had corneal topography and 3 had advanced biometry devices, considered desirable but not essential for secondary eyecare (Bailey, 2011). Laser treatment was available in all hospitals. However, maintenance problems were reported by three hospitals, leading to periods of unavailability lasting weeks or months. Delayed laser treatment, for example in patients with proliferative diabetic retinopathy, may result in irreversible vision loss. All five were equipped for a modern cataract surgical service, with biometry and phacoemulsification machines. Vitrectomy equipment, which is used most frequently to repair retinal detachments, was available in two hospitals, but expertise to use it in only one. Availability of other investigations was reasonable. Four hospitals had access to CT imaging and two to MR imaging, which are valuable for the investigation of certain ophthalmic emergencies and complex cases. All hospitals had access to serological investigations.

Access to essential medicines is a crucial commodity in any health system (IAPB, 2011). From 2005, a Chronic Disease Assistance Programme provided 47 prescription medicines for 11 chronic conditions, including diabetes, hypertension, and glaucoma, in all public health facilities. These drugs were dispensed through over 250 public and private pharmacies (PAHO, 2012).

Training of eyecare providers

A 4-year BSc degree in optometry commenced at the University of the West Indies in Trinidad in 2009, and had 90 students enrolled. Training of ophthalmologists occurred under each autonomous RHA. A postgraduate ophthalmology training program commenced in 2009 at UWI, but had been suspended in 2013. There was no rotation of ophthalmology trainees between RHAs and no national organisational structure to oversee training standards and competency progression, or to issue postgraduate qualifications. Ophthalmology trainees reported self-funding postgraduate qualifications abroad, via examination systems in the UK, USA and Jamaica.

Public Education in eyecare

The eyecare community hosted annual events for World Sight Day, and intermittent Glaucoma community awareness programs. The MoH led intermittent public education initiatives on eyecare, and general healthcare, for example, a “Fight the Fat” initiative, promoting healthy lifestyles (Ministry of Health, 2012a). PAVI organised fund-raising events, and an International Day for Persons with Disabilities (CCB, 2014).

Information and knowledge

There was no existing literature on the prevalence, causes and risk factors for avoidable blindness in Trinidad and Tobago, and NESTT (*citation masked*) was designed to address this. Health systems also need data for monitoring, evaluation and quality assurance, and to support clinical decision-making. In many countries, but not currently in Trinidad and Tobago, routine administrative and clinical data, including data on cataract surgical outcomes, hospital episodes statistics including diagnostic

classification codes, and patient safety incidents, are collated nationally by computer-based information systems.

Outcomes

Eye clinic outpatients (n = 453) were generally satisfied (55.8%, n = 250) or very satisfied (21.7%, n = 97) with the quality of care received in the 5 public hospitals. The median waiting time for a new patient appointment was 2.8 months (IQR 0.5-9, range 0 to 36). Suggestions for improvement included reducing clinic waiting time (n = 148), improving staff communication skills (n = 26) and the quality of explanations given to patients about their condition and management (n = 9), more physical space (n = 28), improved wheelchair access (n = 12, in POSG hospital), more eye doctors (n = 26), more nurses (n = 14), improving the referral, appointments and medical records systems (n = 14), reducing the waiting time for appointments (n = 14), reducing the waiting time for operations (n = 6), improving availability of drugs in pharmacy (frequently out of stock) (n = 8), investment in more equipment (n = 5), and government support for the cost of transport to clinic (n = 4), and spectacles (n = 2).

Eyecare providers also provided feedback on current eyecare services. Optometrists (n = 50) highlighted the lack of availability in the public hospitals of key investigations (e.g. visual field analysis in 2 hospitals) and services (e.g. low vision assessment, refraction, contact lens fitting, keratoconic assessment and orthoptics). They also reported that government financial assistance for the cost of eye tests and spectacles was only available to parents of children with visual impairment who were in receipt of welfare grants, leaving many families unable to afford spectacles. They highlighted the need for orthoptists and more paediatric ophthalmologists in Trinidad and Tobago. Some suggested that, "*more union and harmony between all levels of eye care professionals is needed*." There were also reports of a lack of enforcement of professional standards in optometry, and a risk of missed diagnoses in some optometry practices lacking a slit lamp. PCPs (n = 22) suggested systematic screening for diabetic retinopathy, training and employing more ophthalmologists in the public sector, developing public sector optometry services, and offering ophthalmology outreach services in health centres. Ophthalmologists (n=5) working in public and private sectors provided feedback on access to consumables and specialised equipment in clinic and theatre, and availability of supporting administrative and allied health professionals.

Ophthalmologists-in-training (n=5) provided feedback on their training environment. Whilst these provided interesting insights into the eyecare system, we have not reported this data on account of the risk of bias from such small samples.

Eyecare Goals

In 2014, Trinidad and Tobago had made good progress towards the prevention of avoidable blindness, with the achievement of 14/27 (51.9%) indicators in the Caribbean region's, ""Strategic Framework for Vision 2020: The Right to Sight' (PAHO, 2010) (Table 7). In addition, a further three were imminently achievable. Specifically, a diabetic retinopathy screening and treatment program, integrated into primary care, was piloted in southwest Trinidad in 2013, and there was political commitment in 2014 to introduce this nationally. The Ministry of Health had also invested in a National Eye Survey to generate an evidence-base on the magnitude and causes of avoidable blindness. This would support the development of a National Vision-2020 plan and also provide baseline data against which progress towards the ultimate goal of eliminating avoidable blindness can be measured in future.

Linkages between health system elements

Linkage between different elements in a highly pluralistic system is important to ensure integration and coordination between public and private sectors, and primary, secondary and tertiary levels, to prevent gaps in access and care. Ideally, the tiers should operate in a complementary way to ensure the optimal flow of patients and the optimal management for each individual at the most appropriate level, rather than competition (van Olmen et al., 2012). This study identified a dominant role of the private sector in the provision of eyecare services in Trinidad and Tobago, but uneven geographic distribution of private optometry and ophthalmology services, and high costs for some services relative to household income. In contrast, the geographic distribution of public sector primary care facilities was good, but staffing and equipment were inadequate for a primary eyecare service, and utilisation data identified that the population seldom seek eyecare via that route. Relationships between different tiers of the eyecare system were governed by some formal arrangements, but predominantly by market forces.

Discussion

This study provides the first comprehensive overview of the health system in Trinidad and Tobago, and focuses specifically on its capacity to deliver eyecare. The strengths of this study include its inclusivity, and obtaining qualitative feedback from providers, users and the general public, on aspects of the quality, affordability, and acceptability of eyecare in 2014. Investigators included senior local ophthalmologists, optometrists, health economists and academics, who were able to provide important external validation of the study findings. Direct engagement to understand different stakeholders' perspectives is essential, because intervening in health systems may change power dynamics, and sustainable development is likely to depend on the alignment of goals and interests (van Olmen et al., 2012). In addition, we present quantitative data on the public and private eyecare system infrastructure, human resources, equipment, referral pathways, unit costs, and utilisation in a 12-month period, which will be of value in future economic analyses. To our knowledge, this study is also the first in a Caribbean nation to report on progress towards the PAHO Vision 2020 Strategic Framework Indicators.

In common with many other countries, the major challenge facing the Trinidad and Tobago health system is rising health care demand linked to the rapid emergence of chronic diseases and an aging population, with associated rising health care expenditure. Health systems need to be prepared to respond to these challenges (Atun et al., 2013). We estimate that eyecare for older adults may be responsible for as much as 9.5% of all health care expenditure in Trinidad and Tobago, and this may increase in the future. This study identified several weaknesses in the eyecare system, which could result in avoidable blindness. Firstly, there were no national screening programmes to identify and treat sight-threatening conditions, including diabetic retinopathy, retinopathy of prematurity, and congenital cataract. Secondly, potential patient safety issues relating to equipment were identified. Specifically, two public hospitals lacked automated visual field equipment essential for the management of glaucoma, a leading cause of avoidable blindness, and three hospitals had laser equipment maintenance issues with delayed treatment of sight-threatening diabetic retinopathy. Thirdly, some subspecialised surgery was unavailable in the public sector, including surgery for urgent or blinding conditions including retinal detachment and corneal scarring. This highlights the importance of central governance of the eyecare system and on-going coordination with the private sector to avoid sight-threatening gaps in access to timely diagnosis and treatment. Similar public-private partnerships have been used effectively to strengthen eyecare systems in other countries (Blanchet and Patel, 2012). Finally, the referral, medical records, and appointment systems were paper-based, with limited capacity for information gathering, integration or audit, and accountability between levels and sectors.

An important limitation of this study was the suboptimal response rate to the ophthalmologist survey. Given the potential non-response bias, we only presented data that could be objectively verified from

other sources, including the Medical Board registration list, Ministry of Health reports, Newspaper and Directory listings. We have not reported qualitative feedback obtained from ophthalmologists or ophthalmologists-in-training, or estimated private sector ophthalmic equipment ownership, as these could not be corroborated. We presented private sector unit costs reported by ophthalmologists for different services and procedures because the fees reported by responding ophthalmologists were similar to the costs reported by patients selected to participate in the national eye survey. These data, allowing for uncertainty in the true mean values, will be important for future health economic modelling of cost-effective health system interventions. Seeking potentially sensitive financial information from ophthalmologists may have been one factor influencing non-response. In addition, low participation in this study may have been influenced by a contemporaneous national eye survey (citation masked), to which a minority (<10%) were publicly opposed.

Low response rates to health provider surveys have been reported elsewhere (McLeod et al., 2013), and may result in data from non-representative samples of different groups. In addition, most of the data in this study was based on self-report, which is subject to potential recall bias. We sought to mitigate bias by gathering information on key parameters, such as waiting times, human resources, infrastructure, and service fees, from multiple sources. This study did not include a survey of private patients, and a follow-up study should address this.

Conclusions

The most recent WHO global eye health strategy advocates research into, and strengthening of, health systems to address the existing burden of avoidable blindness (WHO, 2013). Countries have diverse, unique, and frequently pluralistic health service delivery models, and obtaining a detailed overview can be challenging. By undertaking a comprehensive in-country situation analysis, and describing the function and inter-relation of each element using the health system dynamics framework, we have taken a systematic approach to identify strengths and limitations of the eyecare system. However, there is little research on how eyecare systems should respond effectively and sustainably to the challenges identified, highlighting the need for more research in this area (Blanchet et al., 2012). Through exploring the context in which potentially avoidable blindness develops, we have sought to provide decision-makers with important insights with which to interpret the NESTT blindness prevalence estimates in due course. This evidence-base will support the development of a national eyecare strategy and the priorities for future resource allocation. We recommend the survey instruments developed for use in this study, and the health system dynamics analytic framework, as useful tools for country-level health systems research elsewhere in the Caribbean and beyond.

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The National Eye Survey of Trinidad and Tobago (NESTT): Rationale, Objectives and Methodology

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ABSTRACT

Purpose: This paper describes the rationale, study design and procedures of the National Eye Survey of Trinidad and Tobago (NESTT). The main objective of this survey is to obtain prevalence estimates of vision impairment and blindness for planning and policy development.

Methods: A population-based, cross-sectional survey was undertaken using random multistage cluster sampling, with probability-proportionate-to-size methods. Eligible participants aged 5 years and older were sampled from the non-institutional population in each of 120 cluster segments. Presenting distance and near visual acuity were screened in their communities. People aged 40 years and older, and selected younger people, were invited for comprehensive clinic assessment. The interview included information on potential risk factors for vision loss, associated costs and quality of life. The examination included measurement of anthropometrics, blood glucose, refraction, ocular biometry, corneal hysteresis, and detailed assessment of the anterior and posterior segments, with photography and optical coherence tomography imaging. Adult participants were invited to donate saliva samples for DNA extraction and storage.

Results: The fieldwork was conducted over 13 months in 2013–2014. A representative sample of 10,651 individuals in 3410 households within 120 cluster segments identified 9913 people who were eligible for recruitment.

Conclusion: The study methodology was robust and adequate to provide the first population-based estimates of the prevalence and causes of visual impairment and blindness in Trinidad and Tobago. Information was also gathered on risk factors, costs and quality of life associated with vision loss, and on normal ocular parameters for the population aged 40 years and older.

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Introduction

The Global Burden of Disease (GBD) Study estimated that, in 2010, 32.4 million people worldwide were blind and 191 million were moderately or severely visually impaired.[1] Around 80% of vision loss is avoidable, through cost-effective interventions to prevent, screen and treat sight-threatening eye disease.[2] Avoidable vision loss remains a key public health concern.[2] The GBD study also modeled vision loss prevalence by region and country, but highlighted the paucity of population-based data in the Caribbean region (Table 1).[3–12] In addition to knowing the prevalence of vision loss, epidemiological data on the risks, impacts and costs of vision loss on individuals and society are also important. Such country-specific data provides a robust foundation for the development of evidence-based policies and services which aim to reduce avoidable blindness and to support people with vision loss to achieve their full potential.[2]

There was no previous population-based data on vision loss in Trinidad and Tobago, a high-income, twin island republic in the Caribbean with a population of 1.3 million[13] and a total landmass of 5128 km^2. Expenditure on health-care accounts for 4.8% of gross domestic product and eye care services are available from both the private and public health sector.[14] Several factors suggested that the population was at particular risk of sight-threatening eye disease. First, the demographic profile is that of an aging population,[13] and with age the frequencies of cataract, glaucoma and other age-related eye diseases increase.[15] Second, the population has a unique and heterogeneous ethnic mix,[13] which may put it at increased genetic risk of certain eye diseases.[16–18] Furthermore, there is an emerging epidemic of chronic non-communicable diseases, which

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Table 1. Previous population-based surveys of vision impairment in the Caribbean.

Location	Population	Year	Age, years	Sample size, *n* (response rate, %)	Prevalence outcomes
Barbados	National	1987	40–84	4631 (82.1)	Visual impairment,[4] blindness, glaucoma,[5] cataract,[6] DR,[7] AMD,[9] refractive error[8]
Cuba	Local (urban)	2005	50–99	2716 (98.4)	Blindness, low vision[10]
Dominican Republic	National	2008	50–99	3873	Blindness, low vision[11]

DR, diabetic retinopathy; AMD, age-related macular degeneration.

are associated with ocular complications. An estimated 56% of the adult population is overweight or obese, 26–30% are hypertensive, and 19–21% have diabetes mellitus.[19,20] Recognizing the value of country-specific data to inform a national eye care strategy, the Ministry of Health of the Government of Trinidad and Tobago approved funding for a National Eye Survey in 2012. This paper outlines the rationale, study design and procedures of the National Eye Survey of Trinidad and Tobago (NESTT).

Materials and methods

Study design

The NESTT was a population-based, cross-sectional survey of the population aged 5 years and older. The study was conducted through a collaboration between Anglia Ruskin University (United Kingdom), and the University of the West Indies (Trinidad and Tobago). An ancillary genetic epidemiology study was conducted in collaboration with Duke University (United States of America).

Aims

Primary objective

To estimate the prevalence of presenting blindness and vision impairment among adults aged 40 years and older.

Secondary objectives in persons aged 40 years and older

(1) To determine the principal cause and risk factors associated with blindness and moderate or severe vision impairment (MSVI); (2) To estimate the prevalence of common eye conditions; (3) To establish a normative database of various biometric and ocular parameters; (4) To explore the cost and impact of vision impairment on quality of life; (5) To investigate the availability of low vision rehabilitation services and barriers to uptake; (6) To investigate the effectiveness of eye care services, including cataract surgical coverage and cataract surgical rate; (7) To establish a bio repository of saliva DNA samples to enable future genome-wide association studies of ocular and cardiovascular disease.

In addition, we aim to estimate the prevalence and causes of presenting blindness and MSVI in people aged 5–39 years.

Participants

The total population of Trinidad and Tobago was 1,328,019 in 2011, and the non-institutionalized population was 1,322,546.[13] An eligible person was defined as someone resident in Trinidad or Tobago for more than 6 months, who was aged 5 years or older at their last birthday, and who was a usual resident of the selected household. The last was defined as sleeping in the household most nights of the week and sharing at least one daily meal with other household members.[13] People currently abroad or in an institution (e.g. hospital, prison) and not anticipated to return within one month were excluded.

Sample size

The study population required to address the primary objective comprised individuals aged 40 years and older. The Barbados Eye Survey suggested an expected prevalence (p) of best-corrected blindness of 1.7%.[4] The sample size was chosen to achieve a desired level of absolute precision (d) of 0.5% in the width of the 95% confidence interval, and a design effect (DEFF) of 1.4;

$$n = \frac{1.96^2\, p(1 - p)(DEFF)}{d^2}$$

The sample was adjusted for a potential non-response of 20%, based on the Barbados Eye Survey,[5] to generate a target sample of 4147. A total of 35 persons aged 40 years and older were sampled in each of 120 enumeration districts (EDs) to achieve this target (n = 4200). This sample size was anticipated to give the study adequate power to estimate the prevalence of major eye conditions affecting older persons (Table 2). The population aged 5 years and older comprise 92.91% of the total population.[13] Within this, 57.83% are aged 5 to 39 years and 42.17% are aged 40 years and older. We therefore expected to find 5760 eligible people aged 5 to 39 years living alongside those aged 40 years and older, giving a total anticipated sample of 9886 people.

Table 2. Sample size required to give precise estimates of the prevalence of different ocular diseases, in the National Eye Survey of Trinidad and Tobago (NESTT).

Condition	Prevalence, %	Precision, 95% CI	Required sample, *n*
Blindness	1.70[4]	1.19–2.21	3455
Vision impairment	5.90[4]	4.90–6.90	2986
Myopia	21.9[8]	19.9–23.9	2300
Hyperopia	46.9[8]	44.4–49.4	2143
Cataract	41.0[6]	38.5–43.5	2082
Glaucoma	7.0[5]	5.8–8.2	2431
Diabetic retinopathy	1.0[7]	0.5–1.5	2130
Exudative AMD	0.50[9]	0.25 – 0.75	4281

Based on a 2-sided type 1 error, α, of 0.05 for different prevalence rates, and adjusted for the design effect due to clustering (1.4), but not including anticipated non-response (for which the sample was increased by 20%).
CI, confidence interval; AMD, age-related macular degeneration.

Sampling frame

The visitation record from the 2011 Population and Household Census was used as the sampling frame. This was stratified into the two islands containing five regions (one in Tobago, four in Trinidad), 21 municipalities, and 2827 mutually exclusive EDs. An ED was defined as a geographical area comprising approximately 150 to 200 households.[13] For each ED, the population size, sex distribution, age distribution, and number of buildings and households were known.

Sampling strategy: Multi-stage randomized cluster

Primary sampling unit: The enumeration district

Random cluster sampling selected 120 EDs as the primary sampling units, by probability-proportional-to-size (PPS) methods.[21] PPS sampling was chosen to reduce bias in survey estimates, because the EDs differed in population size. The mean population size was 472 people (standard deviation, SD, 189) ranging from 1 to 1655 people. Each person in the population had an equal probability of being selected. The distribution of the 120 clusters is shown in Figure 1, and reflects the geospatial population density.

Secondary sampling unit: Compact segment of households

A detailed field map of each ED was obtained from the Central Statistics Office (CSO). Consecutive buildings were numbered, and the ED was divided into a number of segments determined by the population size of the ED, with each segment containing approximately 100 people. One segment was selected at random using Microsoft Excel, by an investigator not directly involved in enumeration. The segment's buildings were marked clearly on the map and given to the enumerator, who was instructed to proceed from the first marked building to consecutively numbered buildings.

Tertiary sampling unit: Eligible individuals

The enumerator attempted to contact everyone aged 5 years and older living in selected households to ascertain eligibility. If residents were not home on the first visit, a leaflet detailing the study was left, including a contact telephone number for the lead survey ophthalmologist. Enumeration continued until 35 people aged

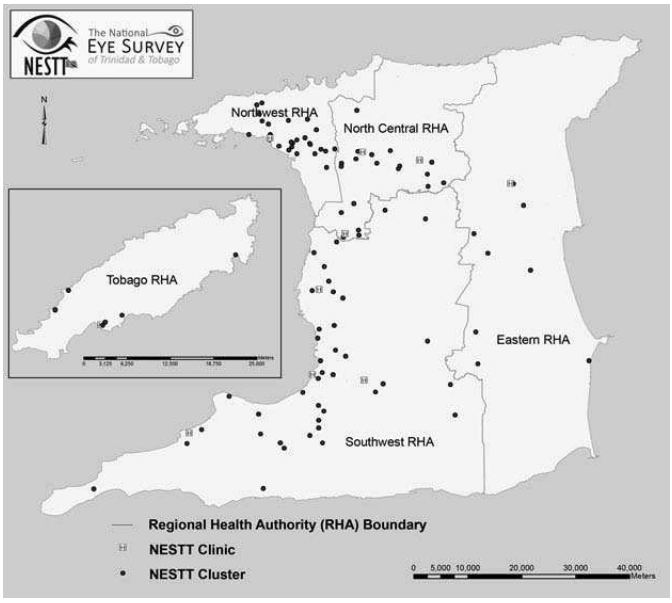

Figure 1. Map of Trinidad and Tobago showing distribution of the 120 National Eye Survey of Trinidad and Tobago (NESTT) clusters.

40 years and older in consecutive households were enumerated. If residents were not at home or refused, information on eligibility was sought from neighbors or relatives. Sampling was with non-replacement. The sample therefore included eligible people who could not be contacted, despite at least three attempts by both enumeration and screening teams, and those who refused participation. This strategy was chosen to minimize bias.

Recruitment strategy

Recruitment of participants followed a detailed strategy that was devised following a series of pilot studies. Eligible people who agreed to participate were given a full verbal and written description of the study. Both enumeration and screening teams visited each cluster on multiple occasions, at differing times and on different days, including weekends. If eligible for clinic, a written appointment date and time were given and participants were telephoned or sent an SMS message with a reminder the preceding day. Non-attenders were re-contacted by telephone up to three times to offer another appointment. Telephone scripts were developed to ensure consistent delivery of key information. People who refused enumeration were contacted by the clinical team in a further attempt to recruit them, and if still not interested were documented as "refused." In addition to an individualized communication strategy, various additional measures were taken to increase participation. These included information releases on national television, in the newspaper, on the radio, on websites and via social media (Facebook), sensitization of eye and primary care professionals to the study, and engagement with community leaders where these could be identified. A separate Community Engagement and Sensitization Strategy sensitized the general public and participants to the ancillary NESTT genetics study.[22]

Staff, training and logistics

The enumeration team included a Field Supervisor, and 18 CSO-trained enumerators who had each completed at least one national census. The clinical team included two survey ophthalmologists, three optometrists, two nurses, two enrolled nursing assistants, and two data entry staff. The clinic was offered 5 days a week from 7 am to 3 pm, including Saturdays. Pairs of the clinical team led community vision screening, during afternoons and weekends, with assistance from six part-time vision screeners. The genetic study sample team included three research assistants under the supervision of a human geneticist. The project was managed by the lead survey ophthalmologist, and by a part-time administrator, with oversight from the Principal Investigator and co-investigators.

Staff underwent training by the Principal Investigator, lead survey ophthalmologist, human geneticist, field supervisor and a low vision specialist. The CSO-trained enumerators were given detailed enumeration manuals, and underwent one day of NESTT-specific training followed by supervised fieldwork in all clusters. The clinical and screening teams had dedicated training for one month. Technicians from Topcon (Topcon Corporation, Tokyo, Japan) and Medilex (Medilex LLC, Doral, FL, USA) trained the team in the operation of the ophthalmic equipment. A detailed manual of operations and standard operating procedures were given to team members.

The NESTT survey clinic was situated in 11 locations sequentially, within all five regions. Three locations were in Regional Health Authority (RHA) facilities, one was within the University, and seven were on a specially equipped NESTT mobile unit parked at RHA facilities. The distance between the 120 clusters and the clinic ranged from 50 m to 43 km, but was generally within 10 km. Poor road quality in some rural areas, and the sensitivity of the ophthalmic equipment, precluded the mobile unit from visiting additional locations.

Survey pathway

Enumeration, consent and vision screening

The enumerators explained the purpose of the study, ascertained eligibility, and obtained verbal consent to participate. They collected individual contact information and core demographic and socioeconomic data from eligible household members, and completed a questionnaire on each household (Table 3). Written informed consent to participate in the survey was obtained by the vision screening team. Children aged 5–12 years and young people aged 13–17 years were asked to sign separate assent forms, and consent was obtained from a legal guardian. Eligible persons with a disability potentially affecting understanding were identified at enumeration and flagged to the survey ophthalmologist, who arranged to speak with the family or visit the home to undertake a mental capacity assessment. If they were considered to lack capacity to give informed consent on account of a persistent impairment in the functioning of the brain, the reason for this was documented. They were counted as a non-responder and were not recruited to participate in the study. They were offered an eye examination by the ophthalmologist if this was felt to serve their best interests.

Table 3. Variables included in structured questionnaires, National Eye Survey of Trinidad and Tobago (NESTT).

Questionnaire	Variables	Source of questions
Individual enumeration	Sex, age, date and place of birth, ethnicity, position in household, employment status, number of years resident in Trinidad and Tobago, basic medical and ophthalmic history, self-reported vision status, disabilities, and reason if not able to attend clinic for full assessment	Trinidad and Tobago Population and Housing Census,[13] RAAB instruction manual[27]
Household enumeration	Wall and roof material, main fuel used for cooking, household ownership status, and ownership of a set of preselected goods	Trinidad and Tobago Population and Housing Census[13]
Demographic	Place of birth, marital status, main language, religion, education, employment, household income, driving history, communication access, and health insurance status	Trinidad and Tobago Population and Housing Census,[13] International Standard Classification of Occupations[28]
Socioeconomic	Usage and out-of-pocket expenditure on health care over past 12 months, usual transportation mode, informal care required on account of vision loss, number of eye care-related sick days, and lost income in the past 12 months	UKPDS Study Healthcare Costs[29]
Medical and ophthalmic	Past medical and ocular history, medication history and compliance, family history, and exposure history (alcohol, tobacco, and illicit drugs)	The INTERHEART study,[30] RAAB instruction manual[27]
Patient-reported outcomes	Three standardized instruments: VisQoL, the IVI and the 5-level EuroQol questionnaires. These instruments were tested and validated in the pilot survey. The IVI was only administered to those with best-corrected vision worse than 6/18 in the better seeing eye, and to a randomly selected control group of people with normal vision	VisQoL instrument,[31] IVI,[32,33] EuroQol[34,35] questionnaires
Low vision	Age at onset, duration and rate of vision loss, eye care service use history, functional adaptations and use of low vision aids, access to low vision services and barriers, feedback on experience using eye care services, and potential to improve quality of life of visually impaired people	Developed through consultation with the Blind Welfare Association, Trinidad and Tobago
Cardiovascular	History of passive smoke exposure, activity level at work and during leisure time, dietary intake of fruit and vegetables, sleep and snoring history	The INTERHEART study[30]

RAAB, rapid assessment of avoidable blindness; UKPDS, United Kingdom Prospective Diabetes Study; VisQoL, Vision Quality of Life Index; IVI, Impact of Visual Impairment.

Monocular presenting distance visual acuity was measured at eye level at 3.0 m, and binocular presenting near visual acuity was measured at 40.0 cm, using logarithm of the minimum angle of resolution (LogMAR) letter optotype charts (Precision Vision, La Salle, IL, USA; Table 4). If the participant was not fully literate, PV Number charts, with matching cards if needed, were offered (Precision Vision). The participant was tested with their habitual optical correction (spectacles or contact lenses), if applicable.[23] Vision screening was conducted in an outside but shaded location to achieve supra-threshold chart illumination of at least 160 cd/m^2, without incident glare.[23] The Early Treatment Diabetic Retinopathy Study (ETDRS) fast protocol was used for measurement of distance visual acuity on the Sloan 3 metre 2000 Series Revised ETDRS Chart, Precision Vision, La Salle, IL, USA; Table 4).[24,25] The standard ETDRS protocol was used for measurement with the PV numbers chart, and for measurement of near visual acuity.[26] The visual acuity score was specified in terms of the number of optotypes correctly identified, and converted back to the LogMAR scale later for analysis. If the participant was unable to correctly identify the optotypes at 3.0 m they moved to 1.50 m and 0.75 m sequentially. If no optotypes could be identified at 0.75 m, visual acuity was documented as "counting fingers," "hand movements," "perception of light" or "no perception of light."

Survey clinic

All eligible people aged 40 years and older were invited to attend the regional NESTT survey clinic for free comprehensive assessment. People aged 5 to 39 years were invited if their presenting vision was worse than 6/12 or if they had diabetes or glaucoma. On arrival, each participant was assigned a unique survey identification number. The clinic pathway is summarized in Figure 2.

Questionnaires

The Epi Info software package (version 3.5.4, Centers for Disease Control and Prevention, Atlanta, GA, USA) was used to prospectively administer a series of structured questionnaires. The questionnaires were developed from question sets used in previous studies, and included demographic,[13,27,28] socioeconomic,[13,29] medical and ophthalmic history variables.[27,30] Three validated patient-reported outcome measure instruments were also included.[31–35] A supplementary questionnaire on low vision was developed following focus group feedback with clients registered with the Blind Welfare Association in Trinidad and Tobago. This was administered to those with a best-corrected visual acuity in the better-seeing eye worse than 6/18. A supplementary questionnaire on cardiovascular risk factors was administered to those who

Table 4. Variables included in the examination, with brief outline of equipment and measurement protocol, National Eye Survey of Trinidad and Tobago (NESTT).

Examination variable	Equipment	Measurement protocol
Vision screening		
Distance visual acuity	3 m 2000 Series Revised ETDRS Chart, or PV Numbers acuity vision test, Precision Vision, La Salle, IL, USA	If literate: ETDRS Fast Protocol;[24,25] Beginning with the top row the screener invited the participant to identify only one letter per line by briefly pointing. To guarantee the same degree of difficulty for each row, only Sloan letters of intermediate difficulty coefficient were chosen (D, K, V, R, H). At the first letter read incorrectly the subject was required to read the whole preceding row. This step was repeated upward if the subject made two or more errors. The participant then read all rows downward, letter by letter, until the screener determined that no further meaningful readings could be made despite urging the subject to read or guess. If not literate: Standard ETDRS Protocol:[26] participants asked to identify all PV numbers from the top, using a matching card if needed, with the same stopping rules as the ETDRS-Fast protocol
Near visual acuity	Sloan 2-sided ETDRS Format Near Point Test or PV Numbers Near Vision Card, both with 40 cm measuring cord, Precision Vision,; Reading lamp	Standard ETDRS Protocol:[26] participants asked to read all letters from the top, with the same stopping rules as the ETDRS-Fast protocol
Medical exam		
Weight	Analogue weighing scale	Nurse measured to nearest kilogram with shoes removed
Height	Wall-mounted tape measure with horizontal measuring level	Nurse measured after removal of shoes to nearest centimeter with participant standing against wall, and stretching their back with their head level and feet together
Waist circumference	Non-stretch fiberglass tape measure	Nurse measured at the smallest circumference between the ribs and iliac crest, to the nearest 1 cm, while standing with the abdomen relaxed at the end of a normal expiration. Where there was no natural waistline, measurement was taken at the level of the umbilicus
Blood pressure and pulse rate	HEM 907XL IntelliSense Professional Digital Blood Pressure Monitor, Omron Corporation, Kyoto, Japan	Nurse measured blood pressure and pulse rate with participant seated after 5 minutes of rest, using an appropriate cuff size for the left arm circumference
Capillary blood glucose	Accu Check, Roche, Basel, Switzerland	Nurse swabbed finger with alcohol wipe and used safety lancet used to obtain drop of blood. Glucose level recorded (mg/dL). Fasting defined as having had no food and no drink except water for 8 hours. If not fasted, recorded as random level.
Optometry exam		
Auto refraction, keratometry and corneal topography	KR8000-PA, Topcon, Tokyo, Japan	Auto refraction sphere, cylinder and axis, and corneal radius of curvature in the horizontal and vertical meridian. One measurement taken of each eye, and repeated if measurement error
Spectacle prescription	Model 11360 Manual Lens meter, American Optical, Southbridge, MA, USA	Manual focimetry
Habitual reading distance	Tape measure	Participant asked to hold the near chart at their usual preferred reading distance and this "habitual distance" was measured from the corneal surface to the chart with a tape measure
Optimal near add	Trial Lens Frame, Viewlight, Miami, FL, USA; Trial Lens Set 266BL, Viewlight	Trial frame fitted to the participant's face with the distance prescription mounted (that required to achieve at least 6/9 with auto-refraction correction, or the lens achieving best correction). Bracketing used to identify the plus DS lens prescription, ranging from 0.25DS to 3.00DS, required to achieve best near visual acuity in each eye, with the other occluded.
Contrast sensitivity	Mars Letter Contrast Sensitivity Test, Precision Vision	Binocular presenting contrast sensitivity at 50 cm measured using the Mars chart, with participants in their habitual near optical state
Ophthalmic exam		
Face, adnexa, ocular movements		Face, adnexa, globe, ocular alignment and ocular movements documented normal or abnormal with description if abnormal
Pupils	Pen torch	Appearance of the pupils, direct, indirect and relative pupil reactions documented as normal or abnormal with description if abnormal
Anterior segment	Slit lamp model BQ-900, Haag-Streit, Bern, Switzerland	Any abnormalities of the anterior segment documented. Van Herick anterior chamber depth graded: 4 (≥100%), 3 (>25–50%), 2 (25%) or 1 (<25%)[36]

(*Continued*)

Table 4. (Continued).

Examination variable	Equipment	Measurement protocol
Posterior segment (after dilation)	90D MaxField and 78D MaxField High Mag, Ocular Instruments, Bellevue, WA, USA; Slit lamp model BQ-900, Haag-Streit	Lens graded using the LOCS III grading system, with comparison to the standard photographic transparency.[37] Nuclear color and opalescence grades were amalgamated into a single grade.[38] Vitreous, macula, retina and optic disc[39] were documented as normal or abnormal, with description if abnormal
Ocular imaging and measurement		
Intraocular pressure and corneal hysteresis	Ocular Response Analyzer, Reichert Technologies, New York, NY, USA	Three measurements taken of each eye, aiming to optimize the signal to noise ratio, and the best-waveform values for two measures of IOP (corneal compensated IOP and Goldmann-correlated IOP) documented for each eye
Ocular biometry	Lenstar LS 900^{R}, Haag-Streit	Corneal thickness, axial length, white-to-white distance, lens thickness, anterior chamber depth, keratometry and pupillometry. Three measurements taken of each eye
Color photographs and optical coherence tomography	3DOCT2000, Topcon Corporation	B-scan of the temporal iridocorneal angle, radial B-scan of the cornea, and an external color photograph. After dilation, two 45° color photographs of ETDRS standard field 1 (centered on the optic disc) and ETDRS standard field 2 (centered on the fovea).[40] Spectral domain optical coherence tomography images including the "macula wide," "5-line cross" and "3D disc."

ETDRS, Early Treatment Diabetic Retinopathy Study; DS, diopter sphere; LOCS, Lens Opacities Classification System; IOP, intraocular pressure.

donated a saliva sample for the genetics substudy.[30] The questionnaire variables are summarized in Table 3.

Examination

The examination stations included a general medical examination, conducted by a nurse; an eye examination before and after dilation, including assessment of the anterior chamber depth,[36] lens status,[37,38] and optic disc,[39] conducted by an ophthalmologist; and an assessment of vision and refractive status, conducted by an optometrist. Additional stations included detailed ocular imaging and measurement, with fundus photography,[40] optical coherence tomography, ocular biometry, and measurement of corneal hysteresis. The examination variables, equipment and measurement protocols are outlined in Table 4. In addition, some participants underwent further examination based on predefined eligibility criteria. The additional variables obtained in a subset of participants are summarized in Table 5 and include glycosylated hemoglobin,[41] best-corrected distance acuity, gonioscopy,[39,42] automated visual field testing and low vision assessment. Examination findings were entered on a paper case report form (CRF) in addition to Epi Info. People aged 5 to 39 years who were eligible to attend the clinic had a slightly more limited examination (Figure 2).

After the first slit-lamp examination, tropicamide 1% (1 drop) and phenylephrine hydrochloride 2.5% (1 drop) were instilled into each eye. An additional drop of each was instilled after a 15-minute interval if inadequate mydriasis was apparent. All participants had their pupils dilated providing the iridocorneal angle was not occludable. A normal angle was defined as a van Herick limbal chamber depth ≥25%, or following gonioscopy as visibility of the posterior third of the trabecular meshwork for more than 270°.[39] Dilation was avoided in those with known allergy to mydriatic eye drops, those with potentially occludable angles, and those who declined dilation despite encouragement from the survey ophthalmologist.

DNA saliva sample

The survey ophthalmologist outlined the genetics substudy and ascertained whether adult participants were willing to discuss participation further. If they were, the genetics research assistant delivered comprehensive information in a semi-structured format. Participants were free to decide not to donate a saliva sample for extraction and storage of DNA, to donate a sample for future genetics studies relating to ocular and cardiovascular disease only, or to donate a sample for both this and for addition to the Duke University Biobank in the USA. The decision was documented on the case report form. Written consent was obtained, and participants were asked to fill an Oragene tube (DNA Genotek, Ontario, Canada) with saliva, according to the manufacturer's instructions. A unique barcode supplied by the Duke University Biobank was placed on the Oragene saliva tube, on the case report form, and on the genetics consent form. Samples (maintained at room temperature) were shipped

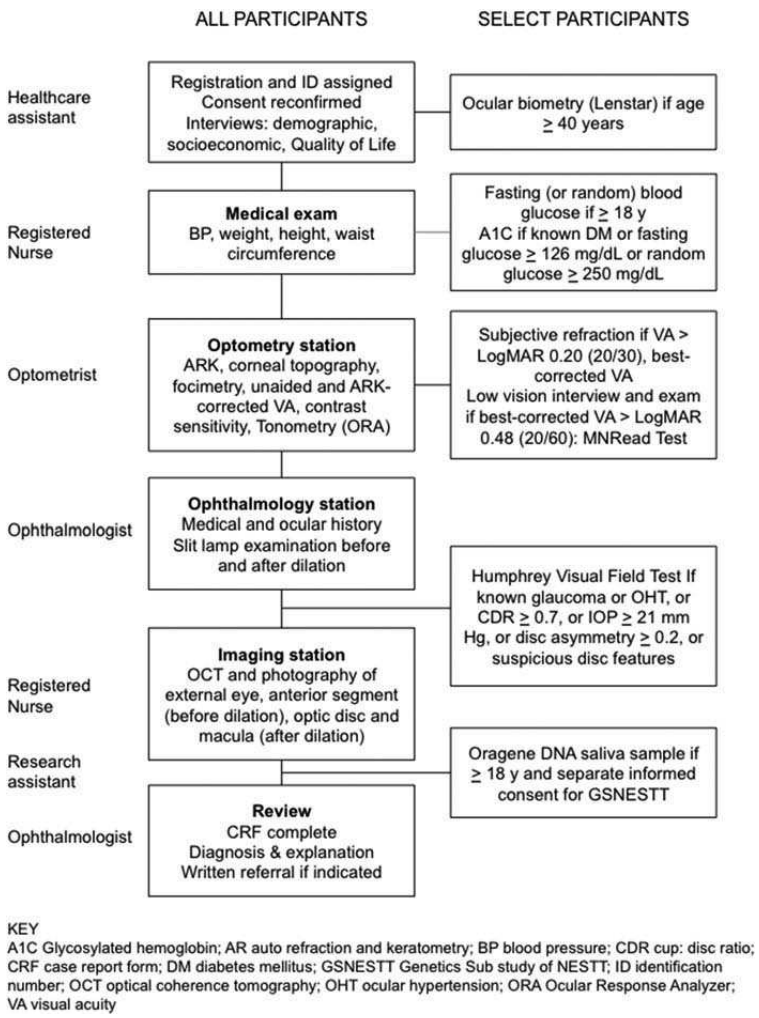

Figure 2. National Eye Survey of Trinidad and Tobago (NESTT) clinical pathway.

to Duke University for future DNA extraction, quantification and genetic analyses.

Domiciliary visits

Eligible people who failed screening and were unable to attend the clinic owing to mobility issues, frailty, illness or care of dependents were offered a home visit by one of the survey ophthalmologists. A limited questionnaire was administered to obtain key data. Assessment to determine the principal cause of vision loss included pupil reactivity, pinhole distance visual acuity, and dilated examination using a direct ophthalmoscope (Professional Ophthalmoscope 3.5v, Keeler, Windsor, UK).

Service component

At the conclusion of the clinic visit participants were given a full explanation of any findings, and a written summary for onward referral if any abnormalities were identified. Participants chose public or private sector referral. Imaging results were emailed or transferred to external memory sticks on request. Topical eye drops were dispensed at no cost for those requiring urgent treatment.

Quality assurance

The field supervisor coordinated the activities of the enumeration team. The lead survey ophthalmologist

Table 5. Examination procedures for a subset of participants according to specific indications, National Eye Survey of Trinidad and Tobago (NESTT).

Examination variable	Equipment	Measurement protocol	Indication
Glycosylated hemoglobin A1C	Rapid point-of-care assay machine (DCA Vantage Analyzer, Siemens, Berlin, Germany)	Droplet of capillary blood obtained with safety lancet. Rapid point-of-care assay performed according to manufacturer's instructions	Previous diagnosis of diabetes or a fasting blood glucose ≥126 mg/dl (7.0 mmol/l) or a random blood glucose >200 mg/dL (11.1 mmol/L)[41]
Best-corrected visual acuity	Trial Lens Frame, Viewlight, Miami, FL, USA; Trial Lens Set 266BL, Viewlight	Subjective refraction performed by optometrist	Presenting distance visual acuity worse than LogMar 0.20 (approximately 6/9) in either eye
IOP (manual)	AT900 Applanation Tonometer, Haag-Streit, Bern, Switzerland; proxymetacaine hydrochloride 0.5%; dry strip of fluorescein; Slit lamp model BQ-900, Haag-Streit	Care taken to use just enough fluorescein to obtain mires of standard thickness. IOP measured once in each eye using Goldmann applanation tonometer	Ocular Response Analyzer measurement of IOP not possible
Cup-to-disc ratio (manual)	78D MaxField High Mag, Ocular Instruments, Bellevue, WA, USA; Slit lamp model BQ-900, Haag-Streit	Optic disc examined at x10 magnification and vertical dimensions of the disc and cup measured using the eyepiece light, in 0.1 mm units, excluding areas of peripapillary atrophy and Elschnig's ring. The margins of the cup were defined by stereoscopic examination as the point of maximum inflexion of contour, and the height of the cup was measured as the vertical distance between the points of maximal centrifugal extension of the cup between 11 and 1 o'clock and 5 and 7 o'clock.[42] For small discs with no visible cup, the measurement was taken as the diameter of the emerging retinal vessels[39]	Automated cup-to-disc ratio measurement not possible owing to OCT machine malfunction or the presence of significant media opacity
Gonioscopy	Magna View Gonio Lens without flange, Ocular Instruments; proxymetacaine 0.5%; Gel tears, Bausch & Lomb Incorporated, Rochester, NY, USA	The visibility of the four key structures was documented	Van Herick limbal chamber depth grade 2 or less[36]
Visual field test	Humphrey Visual Field Analyzer II (model 740i), Carl Zeiss, Meditec AG, Jena, Germany	24-2 SITA static, threshold-related visual field test performed with near refractive correction in place, prior to dilation, in both eyes. Test reliability determined by the instrument's algorithm. Test repeated once if Glaucoma Hemifield Test abnormal, borderline, or reduced sensitivity	(1) Vertical cup-to-disc ratio ≥0.70 (2) IOP ≥21mmHg (3) Abnormal optic disc features suggestive of glaucoma (4) History of diagnosed glaucoma or ocular hypertension Not performed in eyes with a visual acuity worse than 0.48 Log MAR (6/18)
Low vision tests	Mars Letter Contrast Sensitivity Test, Precision Vision, La Salle, IL, USA; MN Read English Continuous text chart Black/White, Precision Vision	(1) Uniocular Mars contrast sensitivity in best-corrected state (2) Uniocular MN Read test in best-corrected state	Distance best-corrected visual acuity in the better seeing eye worse than 6/18 (Log MAR 0.48)

IOP, intraocular pressure; OCT, optical coherence tomography; SITA, Swedish Interactive Threshold Algorithm; LogMAR, logarithm of the minimum angle of resolution.

coordinated the activities of the clinical and screening teams and audited enumeration in every cluster. If the number of "no contact" households was >3, or if the initial refusal rate was high, the lead survey ophthalmologist visited the cluster to review the enumeration and recruitment. Where additional enumeration of individuals who were skipped in error resulted in more than 35 people aged 40 years and older being included for a given cluster, this was accounted for in the statistical analysis. Supervisory visits were made to the survey clinic by co-investigators to monitor practices and ensure protocols were being followed. Following the training period, inter-observer agreement in key examination variables was analyzed using standard statistical software (Stata release 13.1; StataCorp LP, College Station, TX, USA). For the first 6 months of fieldwork each pair of vision screeners included either a supervising ophthalmologist or optometrist to provide ongoing training and quality assurance in the measurement of visual acuity. The Moorfields Eye Hospital Reading Centre, London, UK, graded retinal photographs and optical coherence tomography scans to provide independent validation of the findings.

Data management

Clinic data were identifiable by survey ID number only. In-built consistency checks in Epi Info, and validation through duplicate entry of key variables, was used to correct errors in data entry. The exported databases were copied to an external hard drive daily, and the data from the ophthalmic equipment were exported weekly. A designated team member was responsible

for the secure storage of the external hard drive at all times. The completed CRF and databases were cross-checked monthly to check for and correct any data entry errors. Forms were transported to a central medical records office at the University of the West Indies with restricted access for secure storage.

Security considerations and deviation from the protocol

Trinidad and Tobago's homicide rate was 37.9 per 100,000 in 2012.[43] Criminal activity was particularly concentrated in certain areas east of the capital, Port of Spain, and escalated unpredictably. It was anticipated that some randomly selected EDs might be too dangerous to enumerate, even for experienced enumerators native to those districts. In this event, we planned to replace the ED with that closest in population size within the same municipality. In the case of EDs being too dangerous for door-to-door vision screening, screening was offered in safer locations (schools, churches, community centers) within a few 100 meters of the selected households.

Statistical methods

Statistical analyses will be performed using standard statistical software (StataStata release 13.1). We will explore the raw data, and the characteristics of responders and non-responders, with simple descriptive statistics. The health-related utility values (from the EuroQol 5-dimension questionnaire, EQ5D) and vision-related utility values (from the Vision Quality of Life index, VisQoL) will be calculated from transformation of raw scores. Crude estimates for key outcome measures, including the prevalence of visual impairment and common diseases, the proportion incurring eye care costs, and the proportion suffering decrements in utility, will be adjusted to account for the multilevel survey design (by island and cluster), and weighted for the response rate in each cluster. A post-stratification adjustment will be made using the 2011 Population and Household Census for the non-institutional population of Trinidad and Tobago (stratified by 15 municipalities, 5-year age categories and sex). Multilevel regression analysis, taking into account the cluster (primary sampling unit), building and household number (secondary sampling unit), and individual (tertiary sampling unit), will be performed for single potential explanatory variables, which will be considered one at a time. Multilevel multiple regression models will be estimated to control for the effects of potential explanatory and confounding variables on the outcomes of interest. Analyses will be done for the ≥40 years and 5–39 years age groups separately. Logistic regression will be used for binary outcomes including responder, vision impaired, blind and for eye disease groups. Ordinal logistic regression will be used for expenditure on eye care, and utility value. For parameter estimation by single and multiple regression analysis, global p-values will be obtained using the likelihood ratio test, except when this is not possible, when the Wald p-value will be used. A p-value ≤ 0.05 will be taken to be statistically significant.

Ethical and government approval

The study adhered to the tenets of the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committees of the University of the West Indies (May 2012), the Ministry of Health of Trinidad and Tobago (May 2013) and Anglia Ruskin University (July 2013). Approval for an ancillary genetic epidemiology study was obtained from the Ethics Committees of the University of the West Indies (May 2012), Anglia Ruskin University (July 2013) and the Ministry of Health of Trinidad and Tobago (July 2014). DNA samples were stored in the genetic repository at the Centre for genetics at Duke University Medical Center, with approval from the Duke University Institutional Review Board.

Results

The epidemiological survey commenced in October 2013 and concluded in November 2014. Sample collection for the genetics substudy commenced in August 2014 and concluded in June 2015. Overall, 119 of 120 randomly selected clusters (primary sampling units) were sampled as planned. One cluster in Port of Spain had to be excluded and replaced, according to the methodology outlined in the protocol, on account of unacceptably high security risk. Three clusters were categorized "very high risk" and 10 "high risk." Enumeration and vision screening in these communities was undertaken in safe locations and in some cases out of sequence, at times when criminal activity was lower. In total, a representative sample of 3410 households of 10,651 individuals were contacted, of whom 9913 people aged 5 years and older were eligible for recruitment (Figure 3). Figure 4 shows the geographical distribution of eligible persons, in comparison to the 2011 census population.

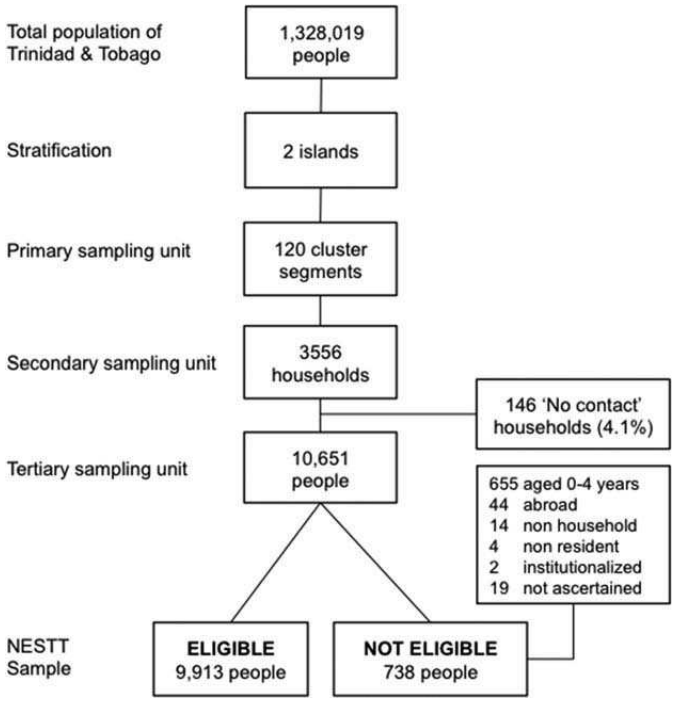

Figure 3. Multilevel selection of a nationally representative population-based sample for the National Eye Survey of Trinidad and Tobago (NESTT).

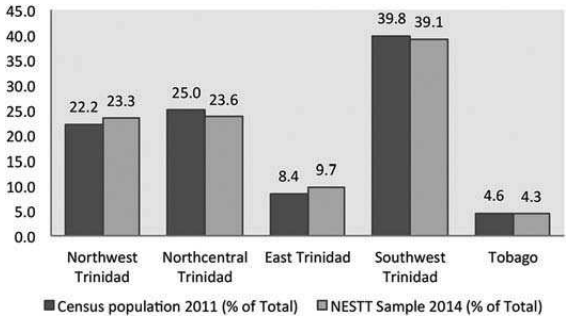

Figure 4. Geographic distribution of National Eye Survey of Trinidad and Tobago (NESTT) sample in comparison to the 2011 Population and Household Census population.

Inter-observer agreement for key examination variables

During training, there was good agreement between observers for binary and categorical variables, including vision category, lens grade and ocular abnormalities, which were analyzed using a kappa coefficient (range 0.70–1.00; Table 6).[44–46] There was also acceptable agreement in the continuous variables visual acuity and intraocular pressure, which were analyzed using Bland-Altman limits of agreement (Table 7).[47–49]

Discussion

The NESTT study design has a number of strengths. First, the rigorous sampling methodology ensured selection of a representative sample of the target

Table 6. Kappa coefficient for inter-observer agreement in binary and categorical examination variables, National Eye Survey of Trinidad and Tobago (NESTT).

Observers	Examination variable	Kappa (*p*-value)
All vision screeners	Monocular distance visual acuity	0.81 (<0.0001)
	Visual acuity ≥6/6	0.76 (<0.0001)
	Visual acuity <6/6 and ≥6/18	0.85 (<0.0001)
	Visual acuity <6/18	
Two survey ophthalmologists	Lens opacity LOCS III[a]	0.70 (<0.0001)[a]
	Nuclear	0.75 (<0.0001)[a]
	Cortical	0.86 (<0.0001)[a]
	Posterior subcapsular	
Two survey ophthalmologists	Van Herick limbal chamber depth	0.79 (<0.0002)
Two survey ophthalmologists	Pupil normal or abnormal	1.00 (<0.0001)
Two survey ophthalmologists	Macula normal or abnormal	1.00 (<0.0001)
Two survey ophthalmologists	Retina normal or abnormal	1.00 (<0.0001)
Two survey ophthalmologists	Optic disc normal or abnormal	0.87 (<0.0001)

[a]Kappa weighting: 1, 0.6, 0.3, 0, 0, 0, 0.
20 eyes of 20 volunteers included in analysis.
LOCS, Lens Opacities Classification System.

national population. The design effect was reduced by inclusion of 120 clusters of 35 people aged 40 years and older. Careful oversight of enumeration minimized the risk of selection bias. Second, the comprehensive examination procedures will enable estimation of the prevalence of common, asymptomatic eye diseases and refractive errors in people aged 40 years and older. Third, the specialized ophthalmic equipment generated data on several novel variables, whose significance in relation to other variables and outcomes will be explored. The NESTT data will provide the first normative database of ocular biometric parameters for a Caribbean population. Fourth, like numerous other recent epidemiological surveys of eye disease,[50–52] the NESTT included DNA sampling. Next generation sequencing techniques will be used for genome-wide association studies to explore novel genetic risk factors for some of the common, complex, chronic ocular and cardiovascular diseases, whose etiology remains elusive. Last, the study design and reporting of the NESTT cross-sectional survey adhere to the recommendations outlined in the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.[53]

There were several limiting factors in the study design. First, resource constraints precluded the examination of a sufficiently large sample of 5–39-year-olds to give statistical precision around estimates in this age group. Second, the January 2011 Population and Housing Census was the latest available sampling frame, and was 29 months out of date at the time of cluster selection. Deaths, births, migration in and out of the country and between areas may have occurred during that interval, leading to population size change within different EDs. Probability proportionate to estimated size methods would have been preferred. However, this approach requires a full remapping of all households per ED, which was beyond the project's resources, and has seldom been achieved in previous epidemiological surveys of eye disease. Last, for logistical reasons visual fields were not tested on all participants but on the subsample of suspected glaucoma cases, and therefore field loss will not be included in our definition of blindness.

The prevalence, causes, risk factors and impact of visual impairment and blindness in the population of Trinidad and Tobago were unknown. Regional data were sparse,[3] applicable only to persons aged 40 years and older, and of questionable relevance to this population,[4] which has a heterogeneous ethnic composition.[13] The NESTT will provide novel, robust, population-based data to inform the

Table 7. Bland-Altman limits of agreement in the measurement of continuous examination variables, National Eye Survey of Trinidad and Tobago (NESTT).

Variable (unit)	Observer	*N*	Mean (SD) and difference in mean (SD)	Bland-Altman upper and lower limits of agreement (95% CI)
Distance visual acuity (number of letters correctly identified)	Trainer (ophthalmologist) *versus* Each vision screener	20 left eyes	Trainer: 56.4 letters (9.0), range 33–66 Most dissimilar screener: 55.4 letters (9.5), range 32–66 Mean difference: 1.1 letters (3.1), range −6–9	Upper limit: 7 letters (95% CI 5, 10) Lower limit: −5 letters (95% CI −3, −8) 100% within 10 letters (2 lines) of the trainer's measure; 85% within 5 letters (1 line)
IOP (mmHg)	Manual GAT *versus* Automated Goldmann-correlated IOP measured by the Ocular Response Analyzer (g-IOP)	101 left eyes	GAT: 15.8 mmHg (4.1 mmHg), range 9–36 mmHg g-IOP: 16.0 mmHg (4.8 mmHg), range 7–39 mmHg Mean difference: 0.26 mmHg (2.2 mmHg) (p = 0.25)	Upper limit: 4.2 mmHg (95% CI 3.4, 4.9 mmHg) Lower limit: −4.7 mm Hg (95% CI −5.4, −3.9 mmHg) 83.2% of GAT IOP within 2 mmHg of g-IOP

SD, standard deviation; CI, confidence interval; IOP, intraocular pressure; GAT, Goldman applanation tonometry.

rational development of a national eye care strategy that aims to address the unmet needs of the population and reduce the burden of avoidable vision loss.

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Declaration of interest

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

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Editorial

Does blindness count? Disability weights for vision loss

How important is blindness? Is being blind 17%[1] or 60%[2,3] as bad as being dead? More importantly, why is there such disagreement?

These numbers are from disability weights. They were introduced by the Global Burden of Disease (GBD) Study (1990) to give a new population health measure, the disability adjusted life year (DALY).[2] DALYs aimed to capture a societal assessment of the burden of disease resulting from premature mortality and the non-fatal consequences of disease and injury.[2] Their concern was for social justice and the association between the health states resulting from disease, and lost welfare, subjective well-being and quality of life.[2] DALYs differed from quality-adjusted life years, which measure individual preferences for time spent in different health states.[4] DALYs aimed to facilitate a more explicit and consistent comparison of health outcomes for health sector evaluation and resource allocation.

DALYs are the sum of years of life lost due to premature mortality and years lived with disability. Calculation of the latter includes the disability weight – a number on a scale from 0 to 1.0. A weight close to 0 indicates a state of minimal impact, and a weight close to 1.0 indicates a state so severe its impact is almost as bad as death. Disability weights are obtained from ordinal measurement of preferences (paired health state comparisons). Advanced modelling transforms these data into weights. To date, eight studies have estimated disability weights for blindness (Table 1),[5] using different approaches.[1–3,6–10] These weights vary from 0.60 in the original GBD study to 0.19 in the 2010 GBD study. This threefold reduction in the recent GBD disability weight reduces the apparent importance of cataract blindness,[11,12] questioning the validity of the disability weights. Applying the weights from the original and 2010 GBD studies gives very different estimates of the effectiveness of cataract surgery: in one study, from 2599 DALYs averted (disability weight 0.60 for blindness) to just 156 DALYs averted (disability weight 0.033 for moderate distance vision impairment).[13]

There are a number of possible explanations for the discrepancy. In our opinion, the most significant is the change from rating 'disability' to rating 'health'. Health, as conceptualized by the World Health Organization, is a multidimensional construct, defined as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' In the original GBD Study, six weights captured 'loss of well-being', blindness was assigned a weight of 0.60.[2] These were defined in reference to limitations in ability to perform activities of procreation, occupation, education and recreation or needing assistance with activities of daily living. Fundamentally, this is the measurement of disability. In contrast, the recent GBD Studies[9,10] framed questions about 'loss of health'. Although this resulted in only small changes to the disability weights for most disease states, for disabling conditions, including vision and hearing loss, the reduction was dramatic, attributed by some to the change in construct.[14,15] This is not surprising; blind people often say, 'I am not sick, I just can't see!'

A second factor is variability in the description of different effects of the 'disease'. The original GBD Study (1990) defined blindness as, 'maximal visual acuity of less than 3/60 with the best possible correction', resulting in 'limited ability to perform most activities in all of the following areas: recreation, education, procreation or occupation'.[3] The recent GBD studies defined blindness as, 'completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance' (Table 2).[9,10] After criticism of some of the GBD 2010 disability weights, including those for vision loss,[14,15] the GBD 2013 study tested a revised lay definition for some conditions. For example, the revised definition for deafness included a more explicit description of social isolation. When retested, the weight changed dramatically from 0.09 to 0.32, leading to the conclusion that, 'in some cases, responses are evidently highly sensitive to particular details in these descriptions'.[10] The definition for blindness was not modified in the GBD

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Table 1. Summary of studies estimating a disability weight for blindness

First author	Year	Region	Panel	*n* panel	*n* health states	Valuation methods	DW (95% CI)	Construct in the question
Murray[2]	1994	Global	Independent experts	NS	6	Magnitude estimation	0.6	Disability
Murray GBD 1990[3]	1996	Global	Medical experts	10	483	PTO and VAS	0.6 (0.50–0.70)	Disability
Stouthard[6]	1997	Netherlands	Medical experts	38	175	PTO and VAS	0.43 (0.34–0.52)	Disability
Baltussen[7]	2002	Burkina Faso	Health professionals, population	39 lay people, 17 health workers	9	Culturally adapted VAS	0.36	Disability
Lai[8]	2009	Estonia	Medical experts	25	283	PTO and VAS	0.478	Disability
Salomon GBD 2010[9]	2012	Global	Population-based samples	30,230	220	PC and PHE	0.195 (0.132–0.272)	Health loss
Haagsma GBD Europe[1]	2015	Europe[4]: Sweden, Italy, Netherlands, Hungary	Population (quota sampling of internet panels, population representative, 18–65 years)	30,660	255	PC and PHE	0.173 (0.145–0.213)	Health loss
Salomon GBD 2013[10]	2015	Global	Population (combined data)[7,8]	60,890	183 or 235	PC	0.187 (0.124–0.260)	Health loss

GBD, Global Burden of Disease; NS, not specified; PC, paired comparison; PHE, population health equivalence; PTO, person trade-off, VAS, visual analog scale.

Table 2. Example of paired comparison question used in GBD 2013 Study[10] to determine a disability weight for two disease effects, distance vision blindness and severe neck pain

Example of GBD 2013 paired comparison question	GBD 2013 disease effect and disability weight (95% CI)
'Now, we want to learn how people compare different health problems. A person's health may limit how well parts of his body or his mind work. As a result, some people are not able to do all of the things in life that others may do, and some people are more severely limited than others. I am going to ask you a [series of] question[s] about different health problems. In each question, I will describe two different people to you. You should image that these two people have the same number of years left to live, and that they will experience the health problems that I describe for the rest of their lives. I will ask you to tell me which person you think is healthier overall, in terms of having fewer physical or mental limitations on what they can do in life. Some of the questions may be easy to answer, while others may be harder. There are no right or wrong answers to these questions. Instead we are interested in finding out your personal views.	
The first person is completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance	Distance vision blindness 0.187 (0.124–0.260)
The second person has constant neck pain and arm pain, and difficulty turning the head, holding arms up, and lifting things. The person gets headaches, sleeps poorly, and feels tired and worried	Severe neck pain 0.304 (0.202–0.415)
Who do you think is healthier overall, the first person or the second person?"	

2013 study, and the weight changed negligibly, from 0.195 to 0.187, in comparison with that reported in the GBD 2010 study.[9,10]

A third factor for the variability in disability weights may be the way questions were asked in different studies. Comparing two health problems with different limitations requires complex judgement about which characteristics are more important.[10,14] The recent GBD studies asked who, of two hypothetical people, was 'healthier' (Table 2).[9,10] A definition was given at the start, but not repeated for each of the 14 paired comparisons, so respondents may not have retained the intended definition of 'health' all the way through.[14]

A fourth factor may be differences in the respondents in different studies. The original GBD study used medical or health experts. Others, including the recent GBD studies, used members of the general public, with no expectation of understanding of health conditions, who may not have been population representative.

A fifth factor may be the different valuation methods used: paired comparison, population health equivalence, person trade-off or a visual analogue scale. The potential impact of these different approaches is unknown. To add further potential confusion, the DALY itself is not a single measure, but combines years of life lost and years lived with disability, which may vary with different combinations of data on prevalence, incidence, and life expectancy,[16] adding complexity when comparing conclusions from different studies.[16,17]

The downgrading of the disability weight for blindness has considerable consequences. Over the past two decades, both the disability weight and the DALY have gained credence as important advocacy tools to highlight the burden and impact of disease at a population level. DALYs and quality-adjusted life years have been used in 825 national studies to demonstrate that surgical interventions are cost-effective global priorities.[18] Disability weights have been used to estimate the potential global productivity loss associated with uncorrected refractive error,[19] and with uncorrected presbyopia.[20] Multiple organizations advocate 'DALYs averted' as bottom-line performance metrics for guiding strategic and resource prioritization decisions in relation to competing public health interventions.[21,22]

In the ranking of the global burden of DALYs by cause, the recent GBD Studies ranked cataract and other blinding eye diseases much lower than in the original GBD study,[23] sparking controversial debate, even between the GBD Core and Vision Loss Expert Groups.[15,24] The ophthalmic community has been left in a state of understandable confusion. Which summary outcome measure should be preferred for advocacy, benchmarking and resource allocation decisions at the population level? If the DALY is a useful metric, which disability weight should be used to calculate it?

The World Health Organization has not endorsed the recent GBD disability weight for blindness, given the significant and unexpected reduction in its value, and proposes an alternative weight of 0.338 obtained from modelling utility data.[25] Understanding the context of deriving disability weights is important, as is recognizing that the recent weight for blindness, 0.19, represents a valuation of health loss rather than disability.[26] Further empirical research is needed to better understand societal valuations of blindness, by isolating the impact of what questions are asked and how, and through ensuring conceptual clarity on the key construct under investigation (is it disability or is it health?).

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Patient Related Outcome Measures

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REVIEW

The use of patient-reported outcome research in modern ophthalmology: impact on clinical trials and routine clinical practice

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Abstract: This review article considers the rising demand for patient-reported outcome measures (PROMs) in modern ophthalmic research and clinical practice. We review what PROMs are, how they are developed and chosen for use, and how their quality can be critically appraised. We outline the progress made to develop PROMs in each clinical subspecialty. We highlight recent examples of the use of PROMs as secondary outcome measures in randomized controlled clinical trials and consider the impact they have had. With increasing interest in using PROMs as primary outcome measures, particularly where interventions have been found to be of equivalent efficacy by traditional outcome metrics, we highlight the importance of instrument precision in permitting smaller sample sizes to be recruited. Our review finds that while there has been considerable progress in PROM development, particularly in cataract, glaucoma, medical retina, and low vision, there is a paucity of useful tools for less common ophthalmic conditions. Development and validation of item banks, administered using computer adaptive testing, has been proposed as a solution to overcome many of the traditional limitations of PROMs, but further work will be needed to examine their acceptability to patients, clinicians, and investigators.

Keywords: patient-reported outcome measures, Rasch analysis, eye disease, randomized controlled trials

Introduction

Recent years have seen greater awareness of the importance of the patient voice in ophthalmology.[6] This paradigm shift influences our understanding of the impact of disease, and the efficacy of interventions, with implications for both clinical practice and clinical trials. There has been a move away from the sole use of traditional outcome metrics (eg, visual acuity, intraocular pressure [IOP]) toward inclusion of metrics that matter as much, or possibly more, to patients and providers (eg, symptoms, quality of life [QoL], convenience, and cost of treatment). Patient-reported outcome measures (PROMs) seek to comprehensively capture these important outcomes.

PROMs are increasingly used in clinical trials to assess the impact of treatment from the patient perspective. They offer particular value as the primary outcome measure where two interventions have been established to be equally efficacious in terms of a traditional outcome measure (eg, IOP lowering effect), but where differences are anticipated in terms of side effects, cost, and convenience. Multiple randomized controlled clinical trials (RCTs) have recently completed or are in progress using PROMs as the primary outcome measure.[7–10] PROM data from trials may be used to inform pharmaceutical labeling claims, clinical guideline development, reimbursement

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decisions, and health policy. In addition, PROMs have potential application in clinical governance and quality assurance, performance management of health care providers, and integration into routine clinical practice.[11,12] The international consortium for health outcome measurement (ICHOM) has proposed standard outcome sets including PROMs for clinical assessment of cataract (using Catquest-9SF) and age-related macular degeneration (AMD) (using the Impact of Vision Impairment, IVI) (http://www.ichom.org/medical-conditions/). Reporting of ICHOM outcome sets for ophthalmic conditions was recently mapped to current reporting practices in eight large eye centers internationally.[14] This exercise revealed wide variation in current reporting practice, and no reporting of vision or eye disease-related PROMs by any hospital. Potential barriers to extend the use of PROMS in routine clinical care include logistical, social, legal, technical, and cultural factors.[12]

This review outlines what PROMs are, explores PROMs development, and probes the extent to which they have had meaningful impact on clinical and research practice in modern ophthalmology.

What are PROMs?

PROMs are sets of questions, or "items," that capture information on health from the patients' perspective. Some PROMs provide rudimentary summary information, while others provide detailed measurement suited to statistical analysis. Measurement of PROMs began in the 1950s, and there has been rapid expansion in the past two decades in all fields of health care, including ophthalmology. A small survey in 1998 reveled that very few UK ophthalmologists were familiar with QoL outcome measures.[15] In 2001, Massof and Rubin reported that more than 12 PROMs had been developed since 1980.[16] Now there are more than 160 PROM instruments in ophthalmology and optometry.[17] Many have been developed for use in glaucoma, cataract, and low vision, but there are no validated PROMs for a large number of eye diseases and interventions.

There are many generic instruments (eg, EQ-5D, Short Form [SF]-36, Health Utilities Index-3 [HUI-3]), vision-related instruments (eg, IVI, National Eye Institute-Vision Function Questionnaire, NEI-VFQ-25), and ocular disease-specific PROM instruments (eg, Catquest-9SF). The plethora of available instruments presents a challenge – how should one be selected for use in clinical practice or a clinical trial?

Selecting a PROM

There is no "gold standard" PROM. In order to select a PROM, investigators and clinicians must choose the latent trait that they want to measure, in consultation with patients and their carers. This might be the impact of disease, or treatment, on symptoms, daily activities, emotional well-being, or side effects, measured at one time point or longitudinally. The choice of PROM will depend on the rationale for assessment. For example, if the data will be used to provide in-depth information to clinicians and patients on the impact of disease, then a disease-specific measure may be most appropriate. However, if data will be used for health economic evaluation, then a health utility measure, which seeks to take account of preferences for different health states, such as the EQ-5D, will be required. Impact on QoL is a frequently desired outcome measure, particularly by health policy makers. However, the challenge with measuring QoL is that it is a multidimensional construct. The latent traits encompassed within vision and eye disease-related QoL are proposed to include visual symptoms, ocular surface symptoms, general symptoms, emotional well-being, activity limitation, mobility, convenience, health concerns, social well-being, and economic well-being, but are not necessarily limited to these.[17] Each trait, or domain of interest, requires due consideration and measurement. Having chosen the latent trait or traits to be measured, a PROM can be selected from the pool of available instruments, and piloted for use to establish validity for use in a new patient or population context, or a new PROM may need to be developed. To better understand the multiple factors that should be considered, the next section explores what the ideal PROM might look like.

What does the ideal PROM look like?

Multiple approaches to evaluate PROMs have been proposed[18–22] and have informed the US Food and Drug Administration's guidance.[23] In brief, important considerations include 1) content development; 2) the psychometric properties of the instrument (judged using either Classical Test Theory, or Item Response Theory approaches, including Rasch analysis – see Boxes 1 and 2 for more details); 3) responsiveness; and 4) administration burden and resource implications.

The ideal PROM contains a necessary and sufficient set of questions (content) to measure a single underlying construct such as ocular surface symptoms (unidimensionality), or, for a multidimensional construct like QoL, a series of sets of questions, each demonstrating unidimensionality and together targeting each important element of the multidimensional construct. It has a logical order of evenly spaced response categories. It is reliably able to distinguish between patients with different abilities or degrees of severity for each

Box 1 Classical test theory and item response theory

Analysis of patient-reported outcome measures has been centered on two approaches, Classical Test Theory (CTT), and Item Response Theory (IRT).[2]

In CTT, each item is assumed to have equal difficulty, and each response score is assumed to have equal weight (eg, a score of 4 for "extreme difficulty" is assumed to have twice the value of a score of 2 for "mild difficulty"). Summary scores are assumed to represent measurement of the underlying trait (eg, quality of life). In IRT, both items and responders are scaled according to responses, which are assumed to reflect the different ability of responders and the different difficulty of items. Ordering of category responses is explicitly tested to ensure that "extreme difficulty" scores more highly across responders than "mild difficulty." Rasch analysis is a special case of IRT, where the data are fit to a simple measurement model. This creates valid measurement to which parametric statistics can be applied. Massof has discussed the theoretical constructs and methodology as applied to ophthalmology in detail.[13]

Box 2 The importance of Rasch analysis

The Rasch model provides interval-level scoring to enable examination of each unidimensional construct. Rasch analysis permits quantitative psychometric assessment of each latent trait and generates measurement data that are readily amenable to statistical analysis, whereas summary scoring does not. The classical test theory approach, which does not use Rasch analysis, is defined by the use of summary scoring (simple adding up of ordinal values assigned to response options) and a high-level reliance on simple reliability statistics like Cronbach's alpha. The latter statistic is calculated from pairwise correlations between items and provides rudimentary insight into an instrument's internal consistency. Gothwal et al have argued that Rasch scaling achieves smaller standard errors of the measures and further enhances precision by applying a logistic transformation to expand the range of measurement, thereby reducing ceiling and floor effects.[1] An important implication of this for clinical trials is that Rasch-validated instruments require a smaller sample size to detect significant differences in outcomes.

Rasch analysis has therefore been used to "re-engineer" some of the popular existing instruments, such as the Visual Function Index-14 (VF-14) and NEI-VFQ-25. For example, the VF-14 was used before and after cataract surgery, and re-engineered into a shorter instrument, achieving both reduced respondent burden and administration time, and precision 2.5 times greater than the original instrument.[1] Doubling the precision of the primary outcome measure halves the required sample size, with very important cost implications for clinical trials. Flaws in the psychometric properties of the, widely used, NEI-VFQ-25 have been identified by multiple investigators, and Rasch re-engineered instruments have been proposed.[3–5]

item, and between patients at each end of the range of the construct (measurement precision), with neither significant floor nor ceiling effects (targeting). The instrument score correlates with important clinical measures such as visual acuity (concurrent validity), and with any existing instruments purporting to measure the same construct (convergent validity), while not correlating highly with instruments purporting to measure a different construct (discriminant validity). It can discriminate between clinically distinct groups and is responsive to detecting clinically important changes over time. The instrument demonstrates test–retest reliability when repeated. Specific quality scoring criteria have been outlined in detail by Prem Senthil et al.[24] Further considerations include the cost of the instrument (some are not freely available), the availability of the PROM in different languages, the staffing administration requirements, and the patient response burden. One of the most frequent trade-offs that must be made is between selecting a short PROM that is readily applicable in a busy clinical or research context, and selecting a PROM that provides comprehensive insight, but takes much longer to administer. It is also important to note that a PROM developed for one target disease or patient population in one cultural context may have poor targeting of item difficulty to respondent ability in another disease or population, which is why validation is necessary.[17]

Generic PROMs

Generic, multi-attribute, health-related utility instruments have been used for over three decades, and the most widely used include the EQ-5D, SF-6D, and HUI. In these instruments, answers to a series of questions yield raw health state scores that can be transformed into a utility value, where 1 represents perfect health and 0 is death. Utility values are used to calculate quality-adjusted life years (QALY) lost or gained as a result of a disease state or health care intervention. The health state weights are obtained using cardinal preference measurement approaches, such as the time trade-off or the standard gamble.

The EQ-5D instrument was developed by the EuroQol Group almost 30 years ago.[25] It has been translated into

over 100 official languages and is widely used. It includes five questions on mobility, self-care, usual activities, anxiety/depression, and pain/discomfort. The original EQ-5D includes three levels (3L) for each question, resulting in 243 possible health states. A five-level (5L) instrument has been introduced more recently, yielding 3,125 health states.[26] A further three bolt-on items have been developed for EQ-5D, including a vision bolt on.[27] The preference weights for the EQ-5D-3L were originally obtained from a UK population sample using time-trade off, with regression analysis to estimate a value for each of the health states.[28] Valuation sets have since been obtained through various approaches in many other countries, and differences between valuation sets are generally small.[29] The original EQ-5D scale using the UK valuations extends from –0.59 to 1.00,[28] and a more recent UK value set for the EQ-5D-5L extends from –0.28 to 0.95.[30] The mean minimally important difference reported in a review of eight studies in different conditions was 0.074 (range –0.011 to –0.140).[31] A visual analog scale (VAS) is recommended for use alongside the EQ-5D. This consists of a "thermometer" scale from 0 to 100, on which the respondent is asked to indicate the point that best represents their own health on that day.

The Short Form (SF-6D) includes eleven items in six domains, including physical functioning, role limitations, social functioning, pain, vitality, and mental health.[32] This instrument yields 18,000 health states. Items were extracted from the larger, 36-item instrument (SF-36), which was developed for the Medical Outcomes Study.[33,34] Preference weights are obtained from a UK population-representative sample and models derived to provide utility values for each health state. The SF-6D scale extends from 0.29 to 1.00, and a review of eight studies in different conditions estimates the mean minimally important difference to be 0.041 (range from 0.011 to 0.097).[31] The SF-36, and a shorter version – the SF-12 – are also still frequently used in studies to assess aspects of QoL more fully, where obtaining a utility value is not the primary objective.

The Health Utilities Index was developed in the early 1980s in Canada to assess outcomes in low birth weight infants.[35] Six domains are captured by HUI version 2 (HUI-2) including sensation, mobility, emotion, cognition, self-care, pain, and fertility.[36] Each has between 3 and 5 levels, resulting in 24,000 possible health states. Valuations were originally obtained from Canadian parents using standard gamble and a VAS. Version 3 (HUI-3) expands the sensation domain into vision, hearing, and speech and yields 972,000 health states.[37] Valuations are elicited from the general public in Canada and a utility function estimates for each of the domains, and for the overall instrument.

Up to three decades of experience with these instruments highlights that they yield differing utility values in head-to-head comparisons. In seven health conditions, not including vision disorders, SF-6D is found to have a smaller range and lower variance in values than EQ-5D.[38] Differences result in the estimation of different estimates of quality-adjusted survival for the same intervention and thus differing conclusions in relation to cost-effectiveness. As a result, some funding bodies are explicit about which instrument and valuation method they prefer. In England, the National Institute for Health and Clinical Excellence (NICE) prefers EQ-5D, but even among NICE Technology Appraisals, there is considerable variation in the methods used to select and incorporate utility values in economic models.[39] Health state valuations obtained from the general public, rather than from patients or clinical experts, are also generally preferred.

The limitation of generic PROMs is that they may lack sensitivity for the impact of eye disease and its treatment. For example, a vision-related QoL instrument, the Vision Function (VF-14), identified significant benefit of cataract surgery at 3 months, but the SF-36 found no significant benefit.[40] While the very brief preference-based generic QoL instruments such as EQ-5D are unable to capture QoL outcomes comprehensively, their shortness and ease of administration face to face, or by telephone, postal questionnaire, SMS messaging, web or email usually results in higher response, and completion rates than longer questionnaires. Moreover, the ability to transform raw scores into utility values provides wide application across different populations and medical specialties, thereby securing their role as important PROMs in informing resource allocation and reimbursement decisions, which typically have to make comparisons across a wide range of different disease areas. Partly in consequence, they are also increasingly used in medical product development.[41]

Some investigators, seeking instruments more sensitive to vision-related preference, have recommended use of the Vision Preference Value Scale, first validated in 2004, in which a score of 0 is equivalent to an outcome as bad as death, and a score of 1.0 is equivalent to perfect vision.[42] However, caution is needed in interpreting the findings of studies using a "vision-truncated scale," and scales anchored by vision are not generally used in cost-effectiveness analysis.[43]

Vision-related PROMs

There are many instruments that focus on the impact of vision impairment and ocular symptoms and signs on different

domains of QoL, such as the NEI-VFQ-25, the IVI, and the VF-14. These are typically referred to as vision-related or ophthalmic PROM instruments, and for consistency we have used the former throughout. Khadka et al conducted a systematic review for vision-related PROM instruments demonstrating interval measurement properties and identified 48 (out of 121 instruments in total). They appraised the quality of each against criteria similar to those proposed by the "Consensus-based Standards for the selection of Measurement Instruments" group[44] and highlighted those of higher quality, by ophthalmic subspecialty.[45] Where no disease-specific PROM exists, the IVI has been proposed as being valuable for assessing domains including the ability to read and access information, mobility, and emotional well-being.[17] A shorter version, the (15-item) Brief IVI, has also been validated.[46]

Impact of PROMs by ophthalmic subspecialty

It is beyond the scope of this review to critique all vision-specific and eye disease-specific PROMs. The following sections highlight examples of the more frequently used, or better validated PROMs in ophthalmology, by subspecialty area, and illustrate examples of their impact.

Narrative review search methodology

We performed a PubMed search for "patient reported outcome" and terms relating to each subspecialty, dated January 1990 to September 30, 2018 with no field restrictions. This identified 4,114 hits (Table S1). We screened these to identify systematic reviews of PROMs, RCTs reporting PROMs, and examples of the use of PROMs in clinical practice. In addition, we reviewed the Cochrane Eyes and Vision database (https://eyes.cochrane.org/). This revealed that across all subspecialties, relatively few RCTs contained within systematic reviews of interventions have, to date, reported PROMs or economic outcome measures. Greatest progress in terms of developing PROMs and introducing them into RCTs have been made in low vision, medical retina and glaucoma.

Glaucoma

Vandenbroeck et al published a systematic review of PROM instruments in glaucoma in which the search, dated to December 2010, identified 27 instruments, 18 of which were disease specific.[47] The authors highlighted that the instruments mostly lacked a conceptual framework, had been tested using classical validation techniques, and that item generation strategies had not involved the patients' perspective adequately. Another systematic review by Che Hamzah et al, in which the search dated to January 2009, cataloged 33 instruments.[48] They highlighted the NEI-VFQ-25, IVI, and Treatment Satisfaction Survey-Intraocular Pressure (TSS-IOP) as having the highest content validity. Another review of PROM instruments by Khadka et al against quality criteria recommended the Modified Glaucoma Quality of Life questionnaire (GAL-9/10), as a higher quality instrument for assessing activity limitation and mobility.[17] These authors subsequently took a systematic approach to identify 737 unique content items for a Glaucoma-specific item bank and refined these into a minimally representative set containing 342 unique items in ten QoL domains.[49] The authors highlighted that the majority of items were identified de novo from patient focus groups, rather than existing PRO instruments in glaucoma.

A review of trials and clinical studies registered with Clinicaltrials.gov, assessing the efficacy of minimally invasive glaucoma surgical devices, identified that only one of 51 studies included health-related QoL as a secondary outcome measure.[50] The recently published RCT protocol for the Treatment of Advanced Glaucoma Study claims to be the first RCT to set patient perspectives as the primary outcome measure.[51] Table 1 summarizes RCTs in glaucoma that have included PROMs as primary outcome measures. This table highlights that the impact of PROMs has been relatively limited to date, with focus on anxiety levels between different treatments, but that RCTs are currently underway using PROMs as the key determinant of comparative efficacy.

Medical retina, uveitis, and vitreoretinal disease

A systematic review of retinal disease PROMs by Prem Senthil et al (search date not specified) identified 217 studies, most frequently on AMD (108 studies), diabetic retinopathy (DR) (31 studies), and hereditary retinal dystrophies (29 studies). In total, 110 different PROM instruments were reported, more than half of which were generic (62 studies, most frequently the SF-36, and the Hospital Anxiety and Depression Scale [HADS]), followed by disease-specific (29 studies) and vision-related (19 studies, most frequently the NEI-VFQ and VF-14) instruments.[24] Only three instruments had been rescaled and tested using Rasch analysis. They also critically appraised the psychometric performance of the instruments against criteria and identified numerous limitations. The authors reported that most instruments had limited content coverage, typically measuring only one or a few domains of QoL. In another study by Prem Senthil et al, semi-structured,

Table 1 Impact of PROMs in glaucoma RCTs, highlighting only trials in which PROMs were selected as primary outcome measures

Study name	N	Intervention	PRO outcome measures	Impact	Reference
Tube Versus Trabeculectomy Study	202 patients with previous trabeculectomy and/or cataract surgery	Tube shunt (350 mm^2 Baerveldt implant) vs trabeculectomy with MMC	NEI-VFQ composite score and minimally important difference	No significant difference at baseline or annual review for 5 years	Kotecha et al[110]
Glaucoma Australia Educational Impact	101 newly diagnosed glaucoma patients	Glaucoma education vs control	Auckland Glaucoma Knowledge Questionnaire	Significant reduction in anxiety in intervention group	Skalicky et al[111]
Glaucoma Intensive Treatment Study	242 glaucoma patients	Topical drug monotherapy vs topical triple therapy plus 360 degree laser trabeculoplasty	Eye-tem Bank Glaucoma module	Study Protocol Published	Lamoureux et al[7] Bengtsson et al[112]
Treatment of Advanced Glaucoma Study	440 patients presenting with advanced open angle glaucoma	Medical therapy vs augmented trabeculectomy	NEI-VFQ at 24 m. EQ-5D-5L, HUI-3 and Glaucoma Utility Index	Study protocol published	King et al[51]
Shared Care for Stable Glaucoma Patients	233 patients with stable glaucoma	Primary eye care vs specialist outpatient clinic	Patient satisfaction, cost	Comparable patient satisfaction, clinical care and management, but lower cost with PEC	Goh et al[113]
Laser in Glaucoma and OHT Trial	718 patients with glaucoma or OHT	Selective laser trabeculoplasty vs topical treatment	EQ-5D-5L, Glaucoma Utility Index, GSS, Glaucoma QoL	Study protocol	Gazzard et al[8]

Abbreviations: EDSQ, Eye Drop Satisfaction Questionnaire; GSS, Glaucoma Symptom Scale; HADS, Hospital Anxiety and Depression Scale; OHT, ocular hypertension; QoL, quality of life; MMC, mitomycin C; PRO, patient-related outcome; NEI-VFQ, National Eye Institute-Vision Function Questionnaire ; RCT, randomized controlled clinical trial; GITS, Glaucoma Intensive Treatment Study.

qualitative interview data from 79 patients with hereditary and acquired retinal diseases identified nine QoL domains relevant to both the groups, which were each explored and reported in detail. This paper provides a scientific basis for splitting vs lumping less common retinal diseases to develop a retina-specific PROM.[52] Further work has formed the basis for a hereditary retinal disease item bank.[53]

A systematic review of clinical trial registries to identify uveitis trials reported that none out of 104 registered by October 2013 used a PROM as a primary outcome measure.[54] The Core Outcome Set for Uveitic Macular Oedema (COSUMO) study aims to develop a core outcome set for trials, using systematic review, qualitative research with focus groups, and a Delphi process to reach consensus.[55] A core outcome set is also being developed by the Outcome Measures in Rheumatology (OMERACT) Vasculitis Working Group for Behcet's disease, which includes the ocular manifestations.[56] Another core outcome set has been proposed for JIA-associated uveitis.[57] The Multicenter Uveitis Steroid Treatment study (MUST) investigators reported that their trial, comparing systemic or implanted corticosteroid therapy in 255 patients, was underpowered to explore secondary outcomes of interest including QoL, highlighting the importance of considering sample size in future comparative effectiveness trials.[58] Table 2 provides examples of the inclusion of PROMs in uveitis RCTs. The examples illustrate that PROMs are making an important impact in this specialty, where identification of traditional outcome metrics (eg, cells in the vitreous) that correlate meaningfully with the patient-centered experience of disease and its treatment has been more challenging likely due to the reliance on non-disease-specific instruments.

Krezel et al systematically reviewed the frequency and type of PROMs used in RCTs for AMD published between 2010 and 2013.[59] They reported 177 RCTs including 858 outcomes, of which 38 outcomes were PROMs (4.4%), and these were included in 25 trials (14.1%). The NEI-VFQ was the most frequently used instrument. A minimum set of standardized outcome measures has been defined for macular degeneration and promoted internationally, recommending IVI be used due to its three measurable traits and valid interval scaling.[60] However, there are currently no PROMs that are clinically validated and acceptable to regulatory agencies for drug development in intermediate AMD, and development of another novel PROM has been proposed.[61] In a study reviewing health state utility values in AMD and

Table 2 Impact of PROMs in uveitis RCTs, illustrating inclusion of PROMs as secondary outcome measures (no RCTs found including PROMs as primary outcome measure)

Study name	N	Intervention	Outcome measures	Impact	Reference
VISUAL-1 and VISUAL-2	217 with active (VISUAL 1), 226 with inactive (VISUAL-2) uveitis	Subcutaneous adalimumab vs placebo	NEI VFQ-25 composite score	Significant improvement in QoL in both trials in the treatment group comparing baseline to final visit	Sheppard et al[114]
SAKURA	347 posterior noninfectious uveitis	Intravitreal sirolimus, 3 doses	NEI-VFQ-25	The composite score and mental health subscore are relevant visual function response measures	Lescrauwaet et al[115]
RCT on antimetabolites for noninfectious uveitis	80 with noninfectious intermediate, posterior, or panuveitis	Oral methotrexate 25 mg weekly or oral mycophenolate mofetil 1 g bd	Indian VFQ and SF-36 at 6 m	Both the treatments improved vision-related QoL (but not health-related) compared to baseline, but both also worsened mental health	Niemeyer et al[116]
HURON	244 with noninfectious intermediate or posterior uveitis	Ozurdex implant vs sham	NEI-VFQ, SF-36, SF-6D, EuroQol-5D	Significant differences were identified for uveitis participants vs general population, except with SF-36 physical component and EQ-5D	Naik et al[117]

Abbreviations: NEI-VFQ, National Eye Institute Visual Function Questionnaire, QoL, quality of life; RCT, randomized controlled clinical trial; SF, Short Form; VFQ, Vision Function Questionnaire; PROM, patient-reported outcome measures.

their use in health care decision-making, Butt et al highlight that generic health-related QoL instruments may lack sensitivity in AMD and that the choice of a utility value should be explicitly critiqued given the existing variability in utility values derived by different studies.[62]

PROMs have been used to assess diabetic eye disease for many years. In the landmark Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications, intensive diabetes therapy in this cohort modestly improved NEI-VFQ score at 30 years.[63] However, reviews in the past decade have highlighted the importance of capturing the patient perspective in diabetic retinopathy more comprehensively,[64] including the need to measure its social and emotional impact through further PROMs development.[65] A systematic and comprehensive approach to identify the content for inclusion in a DR item bank yield 1,165 unique items that were winnowed to a minimally representative set of 314 items across nine domains of QoL.[66,67] Initial evaluation of DR and DME item banks has been undertaken using computer adaptive testing (CAT).[68]

Table 3 provides examples of landmark RCTs in medical retina in which PROMs have had an impact. Many of these trials have used PROMs not only to demonstrate improvement in patient experience in comparison with sham interventions, but also, importantly, to demonstrate non-inferiority of QoL outcomes for interventions differing dramatically in cost. Such trial data have very important health policy implications. A very recent example is the NICE guideline (2018) to recommend the more cost-effective anti-VEGF therapy bevacizumab as an effective therapy for the treatment of AMD in the UK's NHS. PROM data (mostly using the NEI-VFQ-25 and SF-36) contributed to this policy decision.[69] No vitreoretinal PROMs were identified by our search.

Cataract

The first vision-related activity limitation instrument for cataract was introduced in 1992, and a review of questionnaires published since 1992 explored the relative merits and psychometric properties of each.[18] Another review compared 16 Rasch-scaled cataract questionnaires before, and 6 months after, cataract surgery.[70] This study found the Catquest-9SF to be the most responsive to cataract surgery and, being short, was advocated as the best tool for measuring visual functioning outcomes in trials and routine practice. A minimum standardized outcome set has been proposed internationally for cataract surgery, which includes administration of Catquest-9SF pre- and 3-months postoperatively.[71] This instrument has also been included as a secondary outcome measure in a recent RCT protocol (The FACT trial).[72] A newer PROM, Cat-PROM5, has been tested head-to-head against Catquest-9SF in 822 typical NHS cataract surgery patients and, as an even shorter instrument, advocated as

Table 3 Impact of PROMs in medical retina RCTs, highlighting two RCTs in which the PROM was the primary outcome measure

Study name	N	Intervention	Outcome measures	Impact	Reference
MARINA and ANCHOR	646 (MARINA) and 379 (ANCHOR) patients with wet AMD	Ranibizumab vs sham or photodynamic therapy	NEI-VFQ-25 at baseline, 12 and 24 months	Improvement in outcomes with intervention	Bressler et al[118]
SCORE2 Report 5	362 with CRVO or HRVO and macular edema	Intravitreal bevacizumab vs aflibercept	NEI-VFQ-25 composite and subscale scores	Non-inferiority of bevacizumab	Scott et al[119]
OZDRY	100 patients with refractory center involving DME	5-monthly fixed dosing vs OCT-guided pro-re-nata regimen of Ozurdex	Retinopathy-Dependent QOL, NEI VFQ-25, (RetTSQ) (primary outcome)	No significant difference at month 12	Ramu et al[120]
IVAN	610 with active wet AMD	Ranibizumab vs bevacizumab, continuous or discontinuous	EQ-5D	Similar efficacy of drugs in terms of visual acuity. Continuous ranibizumab cost £3.5 million per QALY compared with bevacizumab	Chakravarthy et al[121]
RIDE and RISE	382 RIDE and 377 RISE patients with center-involving DME	Ranibizumab vs sham	NEI-VFQ 25 at baseline, 12, and 24 months	Treatment improved vision-related function significantly more than sham	Bressler et al[122]
RESTORE Open-label extension	303 with DME	Ranibizumab 0.5 mg vs laser monotherapy	NEI-VFQ-25 (primary outcome)	Greater gain in ranibizumab group at 12 months, with similar gain in both the groups treated with open-label extension from 12 to 24 months	Mitchell et al[123]
BEVORDEX	61 patients with center-involving DME	Ozurdex implant every 16 weeks vs bevacizumab every 4 weeks	IVI	Both the groups had significant improvement in IVI scores	Gillies et al[124]
MACUGEN	260 with center-involving DME	Pegaptanib sodium vs sham, with focal/grid laser	NEI-VFQ-25, EQ-5D	Clinically and statistically significant differences between groups in composite and sub-scores, no difference in mean change in EQ-5D utility scores	Loftus et al[125]
BRAVO and CRUISE	397 with branch and 392 with central retinal vein occlusion and macular edema	Ranibizumab vs sham	NEI-VFQ-25	Treatment results in significant mean improvement in composite score compared to sham from month 1	Varma et al[126]

Abbreviations: AMD, age-related macular degeneration; BRVO, branch retinal vein occlusion; CRVO, central retinal vein occlusion; DME, diabetic macular edema; IVI, Impact of Vision Impairment; NEI-VFQ, National Eye Institute Visual Function Questionnaire; RetTSQ, Retinopathy Treatment Satisfaction Questionnaire; PROM, patient-reported outcome measures; RCT, randomized controlled clinical trial.

being preferred by patients, and better suited for use in high volume routine surgical practice.[73]

Amblyopia, strabismus, and pediatric ophthalmology

Kumaran et al conducted a systematic review of PROMs in amblyopia and strabismus published up to July 2016.[74] This identified 71 PROMs of which 32 were amblyopia and/or strabismus specific, but only four of these had been subjected to psychometric tests, and only the adult strabismus questionnaire (AS-20) demonstrated good measurement properties. The authors concluded that all instruments had gaps in their content and failed to assess QoL comprehensively and proposed the development of an item bank to address this. Another review recommended the Modified AS-20 instrument, which measures self-perception, interaction, reading, and general function, as one of the strongest of the existing instruments.[17,75] Incorporation of AS-20 QoL questionnaires into pre- and postoperative clinical practice has been proposed, on account of finding that many apparent surgical failures report subjective improvement.[76]

Tadić et al conducted a systematic review of PROMs for ophthalmic disorders in children, and identified 17 instruments, of which 11 were condition-specific and six were

for children and young people with visual impairment. The authors recommended the need for the development of new instruments.[77] Tadić and Rahi further elaborated on issues particular to the development of PROMs for use in children.[78] These include conflation between theoretically distinct vision-related constructs and outcomes, the importance of developmentally appropriate approaches to design and application, the feasibility of administering self-report standard questionnaire formats to visually impaired children, ethical issues, and statistical issues. More recently, Hatt et al have identified a comprehensive list of child- and parent-derived items from 180 children and 328 parents, which they grouped into 614 unique items identified by children in 36 subgroups, and 589 items identified by parents in 61 bins. The authors report that they intend to develop a formal set of pediatric PROMs from this pool.[79]

Cornea and external disease

A systematic review of PROMs for surgically amenable epiphora identified that 69% of 227 studies included a PROM as the primary outcome measure, although in 48% the PROM was a single-item symptom score.[80] The authors critically appraised each PROM and concluded that they lacked adequate content validity. In Primary Sjogren's Syndrome, qualitative work and PROM development have been done to identify 484 items covering 86 concepts in 3 dimensions impacting QoL.[81,82] In the TEARS trial (Tolerability and Efficacy of Rituximab in Primary Sjogren's Syndrome), SF-36 scores were found to be strongly associated with patient-reported symptoms.[83] A review of PROMS for use in RCTs of dry eye identified 18 instruments, some of which were generic, many of which focused on symptoms, and concluded that very few available PROMs satisfy FDA guidance on the requirements of a suitable PROM to be acceptable as support for a label claim in support of a drug or medical device.[84] The first RCT (n=16) to demonstrate the beneficial effects of autologous serum in patients with severe ocular surface disease used a daily subjective symptom scale, the Rasch-scored Faces scale, to demonstrate a significant effect of the intervention.[85]

While limited PROMs have been designed for use in corneal diseases, Catquest-9SF has been validated for use in patients who have had corneal transplant surgery.[86]

Refractive error

Kandel et al conducted a systematic review for studies using PROMs to assess refractive surgery outcomes.[87] They identified 27 instruments, 12 of which were specific to refractive error. The authors reported that while the NEI Refractive Error Quality of Life instrument (NEI-RQL) was the most frequently used, it did not provide valid measurement, whereas a number of other instruments, including the Quality of Vision, Near Activity Visual Questionnaire, and Quality of Life questionnaire (QIRC) had been constructed using Rasch analysis and were suited to measurement of visual symptoms, activity limitations, and QoL, respectively. They subsequently developed a pool of refractive error items from patient groups in Australia (n=337 items) and Nepal (n=308 items), spanning 12 QoL domains and are working to develop a CAT system suitable for use in both high- and low-income country settings.[88] An RCT using PROMs as the primary outcome measure to compare ready-made spectacles and custom-made spectacles for the correction of refractive error in adults in India found that both result in comparable patient satisfaction and large gains in visual function and QoL, with the custom-made spectacles achieving a small but statistically significant higher QoL outcome.[89]

Oculoplastics

A systematic review of PROMs for eyelid, orbit, and lacrimal disorders, conducted in 2013, identified ten generic and 32 disease-specific instruments and assessed their content domains and psychometric quality.[90] The SF-36 and NEI-VFQ-25 were the most frequently used generic instruments, and thyroid eye disease was the most studied condition. Of the 32 disease-specific instruments, 13 were developed for eyelid-related disease, ten for orbital disease, and nine for lacrimal disease. Physical function and self-image were the most frequently studied domains of QoL. The authors reported that the majority of instruments had very limited psychometric development and poorly defined content domains and concluded that efforts to develop PROMs in oculofacial surgery had been sparse, fragmented, and generally rudimentary, making assimilation into daily clinical practice challenging. More recently, the FACE-Q Eye Module has been developed for use in cosmetic eye treatments and contains four scales measuring appearance of the eyes, upper and lower eyelids and eyelashes,[91] and a module for children and young adults with diverse conditions causing facial appearance differences has also been developed.[92] While there have been a few further clinical studies reported since 2013, no RCTs utilizing PROMs as key outcome measures were identified by our search.

Neuro-ophthalmology

We identified one systematic review of PROMs for use in patients with vision impairment following stroke,

which identified 34 vision-specific PROMs, and critically appraised the quality of the identified instruments.[93] The authors highlighted four high-quality instruments, including NEI-VFQ, Activity Inventory (AI), Daily Living Tasks Dependent on Vision (DLTV), and the Veterans Affairs Low Visual Function Questionnaire (VA LV VFQ), but cautioned that these had each only been assessed in a limited number of patients.

There were no other systematic reviews of PROM instruments for neuro-ophthalmic conditions, and only scattered examples of PROMs that have been developed for specific conditions. A neuro-ophthalmic module was developed for the NEI-VFQ.[94] This was assessed for content and quality by Ramey et al and considered to perform reasonably well by classical test criteria.[90] Generic instruments including NEI-VFQ and SF-36 have been used in an RCT in idiopathic intracranial hypertension (IIH) patients,[95] and in a study of neurofibromatosis (NF) type 2.[96] The Children's Visual Function Questionnaire has been proposed as a secondary endpoint for clinical trials in children with NF1-associated optic pathway gliomas.[76] Disease-specific instruments have been developed for patients with neuromyelitis optica spectrum disorders.[97,98] The first use of a PROM information system utilizing CAT in patients with neurofibromatosis has also been reported.[99]

Low vision

A literature review of RCTs on low vision rehabilitation identified 15 trials, utilizing nine PROMs, and one hybrid PROM and performance-based outcome measure, the Melbourne Low-Vision ADL Index.[100] The other instruments included the AI, Canadian Occupational Performance Measure, Functional Assessment Questionnaire, Groningen Activity Restriction Scale, IVI, Katz' Index of Activities of Daily Living, Low Vision QOL, NEI-VFQ, and the VA LV VFQ. Most of these instruments (seven out of ten) have utilized Rasch or IRT modeling, have been validated for use in low-vision populations, and include items in a number of different domains. The Veterans Affairs Low Vision Intervention Trials (LOVIT I and II) used LV VFQ-48 as the primary outcome measure. Significant benefit on reading ability at 4 months was demonstrated for low-vision rehabilitation (n=126 patients with low vision from macular disease).[9] The LOVIT II trial randomized 323 patients to receive low vision devices with or without rehabilitation therapy and found that the latter group improved more in all visual function domains except mobility.[10]

The Impact of PROMs in routine clinical practice

Our search identified very few examples of the use of PROMs in routine clinical practice. Clinicians may be more likely to report such progress and real-life experience in the gray literature and unpublished sources, and we recognize that this is a limitation of this narrative, rather than systematic, review of the published literature indexed in PubMed.

The Swedish National Cataract Outcome Study (1995–1999) prospectively administered Catquest-9SF, before and after surgery, to 8,595 patient eyes and demonstrated greater impact on satisfaction, and surgical benefit to vision, of second-eye surgery.[101] A similar finding was reported when Catquest-9SF was administered to 870 patients in five Dutch hospitals.[102] Data for the Swedish National Outcome Study (2008–2011), on 9,707 patient eyes before and after surgery, further revealed large variation in PROMs, influenced by factors including the degree of anisometropia, indication for surgery, and postoperative problems.[103] These examples highlight the value of implementing PROMs in real-world clinical practice and Illustrate that they may reveal patient preferences unexpected by clinicians and policy makers.

Hee et al recently explored the feasibility of implementing glaucoma PROMs in daily clinical practice in Singapore.[104] They reported that while the majority of health care professionals and patients felt that the four glaucoma PROMs selected for use in this study were relevant to them, there were multiple barriers to their routine use. These included the need for brevity, yet the desire for a more comprehensive instrument able to capture patient concerns more fully, and the challenge for patients with vision impairment to self-administer the instrument on paper. Furthermore, responders highlighted the desire for inclusion of measurement of financial impact. The authors highlighted that participation in completing PROMs was much lower among patients from lower socioeconomic and education backgrounds, who tend to be those most severely affected by eye disease.

A single PROM for all ophthalmic situations?

The previous section outlines considerable achievements in recent years to develop PROMs for the most prevalent eye diseases globally. In some ophthalmic subspecialties, such as low vision, medical retina, and glaucoma, PROMs are frequently included as secondary, and increasingly as primary, outcome measures in clinical trials, and are being

explored for integration into routine clinical practice. Other subspecialties are still at an earlier stage of developing and assessing PROMs that target the impact of the key diseases and treatments. There is a dearth of PROMs for rarer diseases, especially in neuro-ophthalmology. The issues particular to PROM research in rare diseases have been explored by Slade et al.[105] A key challenge is the time it takes to develop a valid and reliable PROM. High-quality PROM development requires extensive qualitative work with patients and focus groups, pilot studies in which a long set of potential items are administered to patients, psychometric data analysis and winnowing of redundant items, before validation of the final instrument in clinical practice and trials, and PROMs are not necessarily directly applicable in differing cultural contexts.

One solution is to develop a very large bank of items and to validate subsets of questions from this bank in many different diseases and patient populations.[106] Methods to develop one such "Eye-tem bank" to measure vision and eye disease-related QoL have been outlined.[17] This bank is being developed across 13 disease groups, namely AMD, cataract, glaucoma, DR, retinal detachment, other vitreo-retinal, cornea, refractive error, uveitis, other inflammation, amblyopia and strabismus, lacrimal and ocular surface, and neuro-ophthalmology.[17] While CAT can be used to target items to the dynamic responses of each individual responder, further work will be needed to ascertain the time response burden and acceptability of such comprehensive tools in both research and clinical practice settings.

Another approach is to routinely include at least one generic PROM such as the EQ-5D alongside the wide range of vision and eye disease-related PROMs currently being used.

Future research priorities

Guidelines for the inclusion of patient-reported outcomes in clinical trial protocols and reporting guidelines have been developed: the SPIRIT-PRO and CONSORT-PRO Extensions, respectively.[107] Standardization of vision-related PROMs is needed, and progress toward achieving this has been made in other fields. For example, the SISAQOL consortium, "Setting International Standards in analyzing PRO and QOL endpoints for cancer clinical trials," is developing standardized approaches for the analysis of PROM data in cancer.[108]

A systematic review has identified methodological frameworks to measure the health care impact of research.[109] Beyond measuring PROMs more precisely, reliably, and comprehensively in the future, further research is needed to better understand and demonstrate the impact of measuring PROMs in ophthalmic research and clinical practice.

Conclusion

There is much improved awareness of PROMs among both researchers and clinicians over recent decades, but much work needs to be done to standardize the outcomes and the measures. PROMs provide a unique and exciting opportunity to capture what matters to patients and to inform understanding of all stakeholders. Through influencing the decisions of clinicians, regulators, and policy makers involved in the care of patients with ophthalmic diseases, PROMs have the potential to transform medical care.

Author contributions

All authors contributed to data analysis. TB drafted the manuscript in consultation with all co-authors, who provided critical revision. All authors gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

Disclosure

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National Eye Survey of Trinidad and Tobago (NESTT): prevalence, causes and risk factors for presenting vision impairment in adults over 40 years

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ABSTRACT

Aim To estimate the prevalence, causes and risk factors for presenting distance and near vision impairment (VI) in Trinidad and Tobago.

Methods This is a national, population-based survey using multistage, cluster random sampling in 120 clusters with probability-proportionate-to-size methods. Stage 1 included standardised, community-based measurement of visual acuity. Stage 2 invited all 4263 people aged ≥40 years for comprehensive clinic-based assessment. The Moorfields Eye Hospital Reading Centre graded fundus photographs and optical coherence tomography images independently.

Results The response rates were 84.2% (n=3589) (stage 1) and 65.4% (n=2790) (stage 2), including 97.1% with VI. The mean age was 57.2 (SD 11.9) years, 54.5% were female, 42.6% were of African descent and 39.0% were of South Asian descent. 11.88% (95% CI 10.88 to 12.97, n=468) had distance VI (logarithm of the minimum angle of resolution [logMAR] >0.30), including blindness (logMAR >1.30) in 0.73% (95% CI 0.48 to 0.97, n=31), after adjustment for study design, non-response, age, sex and municipality. The leading causes of blindness included glaucoma (31.7%, 95% CI 18.7 to 44.8), cataract (28.8%, 95% CI 12.6 to 45.1) and diabetic retinopathy (19.1%, 95% CI 4.2 to 34.0). The leading cause of distance VI was uncorrected refractive error (47.4%, 95% CI 43.4 to 51.3). Potentially avoidable VI accounted for 86.1% (95% CI 82.88 to 88.81), an estimated 176 323 cases in the national population aged ≥40 years. 22.3% (95% CI 20.7 to 23.8, n=695) had uncorrected near VI (logMAR >0.30 at 40 cm with distance acuity <0.30). Significant independent associations with distance VI included increasing age, diagnosed diabetes and unemployment. Significant independent associations with near VI included male sex, no health insurance and unemployment.

Conclusions Trinidad and Tobago's burden of avoidable VI exceeds that of other high-income countries. Population and health system priorities are identified to help close the gap.

INTRODUCTION

Avoidable vision impairment (VI) remains a global public health challenge. Even in high-income region populations, 10% have distance VI (DVI) too poor for driving, much of which is treatable or preventable.[1] The WHO Global Action Plan advocates gathering evidence on the magnitude, causes and risk factors associated with VI to inform policy and track progress.[2] Yet there have been only three previous Caribbean surveys[3]; the most comprehensive was over 20 years ago.[4] Furthermore, only 3 of 33 high-income countries have national-level data.[1] Few surveys have estimated the prevalence of uncorrected near VI (NVI) attributed to presbyopia, which significantly impacts economic productivity and quality of life.[5 6]

The Republic of Trinidad and Tobago is a twin-island nation of 1.3 million people, which became a high-income economy in 2005. Approximately 95% of the population live in Trinidad[7] and 71% live in urban areas (population density >200 people/km^2).[8] Several factors indicated a population at risk of sight-threatening disease. First, the burden of chronic non-communicable diseases had been high for decades[9]; 55.7% of adults were overweight or obese, 26.3% were hypertensive, and 20.5% had diabetes mellitus.[10] Second, the population demographic was ageing.[7] Third, the ethnic profile, of 35.4% South Asian ancestry, 34.2% African ancestry and 0.1% indigenous Amerindian ancestry,[7] increased cardiovascular mortality risk,[11 12] and potentially increased risk of glaucoma, age-related macular degeneration (AMD) and diabetic retinopathy (DR).[13–15] Fourth, the gross domestic product expenditure on healthcare was only 4.8%.[16] Finally, while 99% were literate and only 2.2% lived in poverty,[17] certain subgroups, such as those of lower socioeconomic status, were potentially vulnerable to poorer health.[18]

Here we present the prevalence, causes and risk factors associated with presenting DVI and blindness, and the prevalence of uncorrected NVI resulting from presbyopia, in participants aged ≥40 years in the National Eye Survey of Trinidad and Tobago (NESTT).

MATERIALS AND METHODS

Study design

We report the study design in detail elsewhere.[19] In brief, NESTT was a nationally representative, population-based, cross-sectional survey of 9913 people aged 5 years and above, selected from the non-institutional population between October 2013 and November 2014. Here we report the

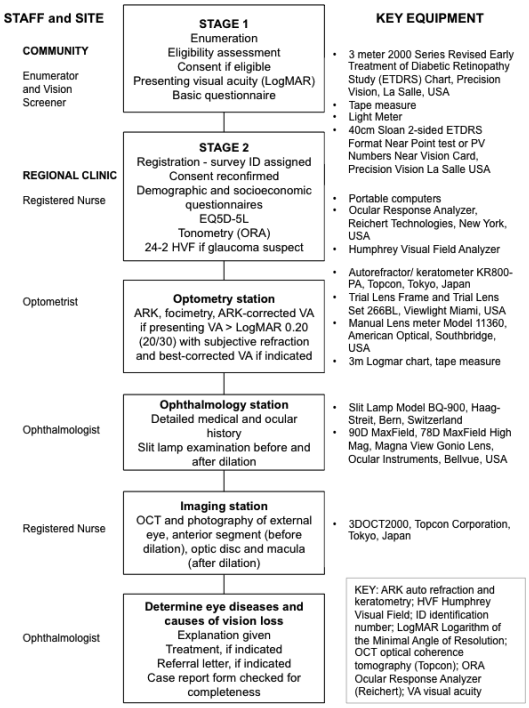

Figure 1 Flow diagram illustrating the participant pathway and survey equipment.

primary study objectives; secondary objectives will be reported elsewhere.[20 21]

Participants

We subdivided the latest Census visitation record by island, selected a random systematic sample of 120 clusters, then a random compact segment of contiguous households within each cluster. We screened consecutive households for eligible residents aged >=40 years to identify 35 people. Eligibility included usual household residence, residence in Trinidad and Tobago for ≥6 months, age ≥5 years at the last birthday, and excluded people abroad or institutionalised.[19] This yielded a self-weighting sample. If residents were repeatedly not home or declined participation, we ascertained eligibility from relatives or neighbours, and included all eligible people without replacement, to achieve high coverage and minimise bias. We documented reasons for non-response. We present further detail on staff training, quality assurance, survey logistics, public sensitisation, recruitment, security and data management elsewhere.[19]

Survey pathway

The two-stage pathway is summarised in figure 1. The first stage, conducted outside the household or community venue, included enumeration, informed written consent, a basic interview and measurement of visual acuity (VA) for everyone aged ≥5 years (approximately 15 min). The second stage, conducted at 1 of 11 regional, ophthalmologist-led clinics, included all persons aged ≥40 years (approximately 1.5 hours). Assessment included structured interviews, comprehensive examination and ocular imaging, with prospective data entry using Epi Info software (V.3.5.4, Centers for Disease Control and Prevention). Participants unable to attend, on account of illness, immobility or the care of dependents, were offered a home visit by the ophthalmologist, including dilated direct ophthalmoscopy.

Measurement of VA

We measured presenting distance monocular VA at 3.00 m, and near binocular VA at 40 cm, with the participant wearing habitual optical correction. We used logarithm of the minimum angle of resolution (logMAR) letter charts or number charts and matching cards. We screened vision outside in a shaded location to achieve suprathreshold chart illumination exceeding 160 cd/m^2, without incident glare.[22] We used the ETDRS-Fast measurement protocol.[23] If individuals had difficulty, and for all near VA measurements, we used the standard ETDRS protocol, with the same stopping rules.[24] The VA was recorded as optotypes correctly identified, and later converted to logMAR. If unable to identify optotypes at 3.00 m, we retested at 1.50 m and 0.75 m, sequentially. If no optotypes were identified, VA was documented as 'counting fingers', 'hand movements', 'perception of light' or 'no perception of light'. If presenting VA exceeded logMAR 0.20 in either eye, the optometrist mounted a spherical and cylindrical lens prescription, determined by autorefraction (AR) and retested VA in clinic. If the AR-corrected monocular distance VA still exceeded logMAR 0.20, the optometrist performed subjective refraction to determine best-corrected VA.

Vision categories

We categorised presenting logMAR VA in the better-seeing eye using revised WHO vision categories.[3] Categories included blindness (≥1.32), severe VI (1.02–1.30), moderate VI (0.50–1.00), mild VI (0.32–0.48) and normal vision (≤0.30). To prevent double-counting, we defined presenting NVI as 0.32–1.30 at 40 cm, with ≤0.30 for distance VA.

Determination of the cause of vision loss and whether avoidable

Survey ophthalmologists noted all eye diseases potentially contributing to VI, and in eyes with more than one disorder selected one as the primary disorder. They documented the principal ocular disorder[25] and the principal cause of vision loss in the person.[26] The Moorfields Eye Hospital Reading Centre (London, UK) independently graded the fundus photographs and optical coherence tomography (OCT) images and recorded the presence of AMD,[27] DR,[28] suspicious optic discs and other abnormalities. A senior investigator reviewed the case records and concordance between survey and Reading Centre outcomes to confirm final DVI cause attribution. We assumed that the most treatable causes of VI, in decreasing order, were uncorrected refractive error (URE), cataract, corneal pathology (treatable), uncorrected aphakia and DR. We assumed that the most preventable causes of vision loss, of the remaining causes, were glaucoma, surgical complications, amblyopia and injuries.

Statistical methods

Statistical analyses were performed using standard statistical software (Stata Statistical Software V.13.1). We adjusted crude prevalence estimates, by category, to account for the multilevel survey design (by island and cluster), and weighted for the probability of selection and cluster response rate using the survey suite. We made a poststratification adjustment using the latest Census (2011) for the non-institutional population (stratified by 15 municipalities, gender and 5-year age categories). We applied

finite population corrections to the first and second sampling stages, including total enumeration districts and total households, by island. We used the WHO World Standard Population to age-standardise estimates.[29]

We performed multilevel logistic regression analysis, enabling both fixed and random effects for 120 clusters, stratified by island (Stata 'melogit' commands). The conditional distribution of the response given the random effects was assumed to be Bernoulli, with success probability determined by the logistic cumulative distribution function. Outcome variables included being a non-responder and presenting with DVI or with NVI. We included potential explanatory variables from the stage 1 questionnaire, selected following review of previous population-based surveys in high-income and upper-middle-income countries, for potential relevance to presenting vision. Variables included age, sex, region, urbanicity,[8] nationality, ethnicity, health insurance status, employment status, household type and tenure, construction materials, cooking fuel, and household ownership of 12 goods (eg, computer, air conditioning, vehicle). In addition, for responders, we included past ocular and medical history variables. We estimated multilevel multivariable logistic regression models. Variables were considered one at a time using the likelihood ratio test (LRT). The final model was the most parsimonious, with smallest Akaike's information criterion and Schwarz's Bayesian information criterion. Global p values were obtained using the LRT. A p value of 0.05 or lower was taken for statistical significance.

RESULTS

Response rate

Of 4263 eligible adults aged ≥40 years, we enumerated 3914 (93.2%) and measured presenting VA in 3589 (84.2%). We examined 2790 (65.4%) in clinic (n=2540) or home visits (n=250) to determine DVI cause, including 97.1% with DVI. Reasons for non-response included being busy (n=331), preferring to see own eye specialist (n=60), feeling too ill/frail (n=29), lacking capacity to consent (n=18) and travel cost/distance (n=6).

Characteristics of responders versus non-responders

Responders (n=3589) had a mean age of 57.1 years (SD 11.8), 54.3% (n=1950) were female, 43.7% (n=1530) were South Asian and 40.0% (n=1401) were African. Of the responders, 17.7% (n=616) had private health insurance, 50.3% (n=1721) had been employed over the past 12 months and 71.9% (n=2594) resided in high urban intensity index areas (levels 1–3 of 8) (table 1).[8] These characteristics were similar to the 2011 Census data for the same age group.[7] Risk factors for non-response were explored, with a final model containing five variables plus age as a potential (non-significant) confounder (n=3232). In most characteristics, responders and non-responders (n=674) did not differ significantly (table 1). Men were more likely to be non-responders than women (OR 1.54, 95% CI 1.23 to 1.93, p<0.001). In comparison with those on home duties, those employed (OR 2.21, 95% CI 1.19 to 3.27), unemployed (OR 2.20, 95% CI 1.26 to 4.06) or disabled (OR 2.73, 95% CI 1.30 to 5.78) were more likely to be non-responders (p<0.001). In terms of potential socioeconomic indicators, non-responders were more likely to live in homes with air conditioning (OR 1.76, 95% CI 1.34 to 2.30, p<0.001), but they were less likely to have health insurance (OR 0.68, 95% CI 0.51 to 0.91, p=0.010) or a vehicle (OR 0.71, 95% CI 0.56 to 0.91, p=0.008). These differences are a potential source of bias.

Prevalence of blindness and VI

We identified presenting DVI in 11.88% (95% CI 10.88 to 12.97, n=468/3589). Table 2 presents crude and adjusted prevalence of presenting and best-corrected VI in the better-seeing eye, by severity. A further 22.28% (95% CI 20.68 to 23.83, n=695/3121) had presenting NVI. The age-standardised adjusted prevalence of DVI was similar in men and women, but increased markedly with age in both (figure 2). In 2014, 64 431 (95% CI 54 623 to 74 077) people had DVI, of whom 3956 were blind and 120 842 (95% CI 112 714 to 128 971) had presenting binocular NVI. The design effect was 1.27.

Image grading

Fundus photographs were available for 2463 (96.9%) right eyes and 2455 (96.5%) left eyes of 2543 stage 2 clinic participants. Image quality was graded 'good' in 40.3% (n=1984), 'fair' in 30.6% (n=1505), 'poor' in 18.1% (n=889) and 'ungradable' in 11.0% (n=540). OCT images were available for 2007 (78.9%) right and 1930 (75.9%) left eyes. Missing images resulted from a 3-week period of Topcon 3D OCT-2000 equipment failure, when we loaned a Topcon non-mydriatic retinal camera (TRC-NW8). There was no significant difference in the causes of DVI between groups with both OCT and photographs (n=340), photographs only (n=94) and no imaging (n=34) (Pearson's χ^2=26.2, p=0.666). Ungradable images ranged from 32% (n=67) in blind worse-seeing eyes to 8.6% (n=19) in better-seeing eyes with mild VI. Grading identified a specific abnormality in between 16% and 31% of imaged eyes with DVI.

Causes of vision loss

Figure 3 illustrates the leading causes of DVI (n=468), which were URE (47.4%, 95% CI 43.4 to 51.3), cataract (26.3%, 95% CI 22.7 to 29.8) and DR (8.4%, 95% CI 5.9 to 10.9), followed by glaucoma (4.4%, 95% CI 2.6 to 6.1) and AMD (2.8%, 95% CI 1.5 to 4.2). Less common causes (≤1.0%) included surgical complications (n=4), amblyopia (n=4), other maculopathy (n=4), multiple pathology (n=3), optic nerve pathology (n=3), central nervous system pathology (n=2), on-axis corneal pathology (n=2), trauma (n=2), and (n=1 each) of congenital, hereditary retinal, retinal detachment, retinal vein occlusion, macular hole and central retinal artery occlusion (online supplementary table 1). Cause was not established in 4.1% (n=19). The leading causes of blindness were glaucoma (31.7%, 95% CI 18.7 to 44.8, n=9), cataract (28.8%, 95% CI 12.6 to 45.1, n=10) and DR (19.1%, 95% CI 4.2 to 34.0, n=5).

The vast majority, 86.8% (406/468), of presenting DVI was potentially avoidable if defined to include URE, age-related cataract, DR and glaucoma. If glaucoma was excluded, 82.5% was potentially avoidable. With timely and successful treatment of pterygium, posterior capsule opacification, retinal detachment, macular hole and amblyopia, up to 88.9% was potentially avoidable.

Independent risk factors for presenting VI

In multivariable analysis, the risk of DVI increased tenfold, from <4% in those aged 40–49 years to >50% in those >80 years (OR 10.7, 95% CI 6.2 to 18.6). Compared with the employed, people who were retired (OR 1.9, 95% CI 1.3 to 2.8), on home duties (OR 2.1, 95% CI 1.4 to 3.1), unemployed (OR 2.2, 95% CI 1.2 to 4.1) or disabled (OR 5.3, 95% CI 2.7 to 10.4) were at between two and five times higher risk (p<0.001). A history of diabetes (OR 1.9, 95% CI 1.5 to 2.4) or cataract (OR 2.1, 95% CI 1.5 to 2.9) roughly doubled the risk, as did not owning

Table 1 Characteristics of NESTT responders and non-responders in comparison with the latest national Census, and risk factors for being a non-responder in multivariable logistic regression analysis

Variable	Subcategory	Responders n (%)	Non-responders n (%)	Model OR (95% CI)	P value	Census %
Sample	n	3589 (84.2)	674 (15.8)			520 351
Age (years)	Mean (SD)	57.1 (11.8)	54.0 (11.8)	0.99 (0.98 to 1.00)	0.13*	
	Range	40–103	40–99			
Gender	Male	1639 (45.7)	379 (56.7)	1.00	<0.001*	49.4
	Female	1950 (54.3)	290 (43.4)	1.54 (1.23 to 1.93)		50.6
Job status	Home duties	626 (18.3)	57 (9.2)	1.00	<0.001*	
	Had a job	1721 (50.3)	427 (69.2)	2.21 (1.50 to 3.27)		
	Retired	896 (26.2)	96 (15.6)	1.07 (0.69 to 1.67)		
	Unemployed	115 (3.4)	23 (3.7)	2.20 (1.19 to 4.06)		
	Disabled	59 (1.7)	14 (2.3)	2.73 (1.29 to 5.77)		
	Student	7 (0.2)	0			
Health insurance	None	2870 (82.3)	459 (82.0)	1.00	0.010*	
	Yes	616 (17.7)	101 (18.0)	0.68 (0.51 to 0.91)		
Ownership	Home AC	703 (23.7)	173 (31.8)	1.76 (1.34 to 2.30)	<0.001*	
	Family car	1755 (59.3)	314 (58.7)	0.71 (0.56 to 0.91)	0.008*	
Region	North-west	811 (22.6)	149 (22.1)	1.00	0.43	22.2
	North central	849 (23.7)	186 (27.6)	1.22 (0.76 to 1.95)		18.4
	Eastern	332 (9.3)	46 (6.8)	0.84 (0.41 to 1.70)		8.3
	South-west	1440 (40.1)	265 (39.3)	1.29 (0.81 to 2.07)		46.6
	Tobago	157 (4.4)	28 (4.2)	1.05 (0.37 to 2.94)		4.6
Ethnicity	African	1401 (40.0)	266 (41.0)	1.00	0.14	34.2
	South Asian	1530 (43.7)	252 (38.8)	0.83 (0.61 to 1.11)		35.4
	Mixed	533 (15.2)	126 (19.4)	1.20 (0.87 to 1.66)		22.8
	Other	38 (1.1)	5 (0.8)	0.55 (0.15 to 2.05)		1.3
	Not stated	87	25			6.2
Nationality	Trinidad and Tobago	3442 (95.9)	652 (96.7)	1.00	0.72	96.3
	Other (Caribbean)	108 (3.0)	15 (2.2)	0.78 (0.37 to 1.67)		1.3
	Other	39 (1.1)	7 (1.0)	0.89 (0.35 to 2.26)		2.4
Tenure	Owned	2529 (83.6)	423 (76.6)	1.00	0.08	
	Rented	446 (14.7)	119 (21.6)	1.48 (1.04 to 2.11)		
	Squatted	51 (1.7)	10 (1.8)	1.78 (0.60 to 5.29)		
Dwelling	Separate house	2458 (79.6)	468 (78.5)	1.0	0.59	
	Apartment	455 (14.7)	101 (17.0)	0.82 (0.56 to 1.22)		
	Other	174 (5.6)	27 (4.5)	0.88 (0.49 to 1.58)		
Home walls	Wood	292 (9.4)	55 (9.2)	1.00	0.56	
	Wood and brick/concrete/ metal	293 (9.5)	45 (7.5)	1.25 (0.73 to 2.14)		
	Concrete	1469 (47.4)	275 (45.8)	1.13 (0.72 to 1.46)		
	Brick and concrete/stone	1036 (33.5)	224 (37.3)	1.25 (0.78 to 2.02)		
	Other (wattle, adobe, tapia)	7 (0.2)	2 (0.3)	2.61 (0.39 to 17.7)		
House roof	Sheet metal	2998 (96.5)	582 (97.0)	1.00	0.63	
	Shingle (asphalt)	1 (0.03)	1 (0.2)	5.31 (0.26 to 110.65)		
	Concrete	87 (2.8)	12 (2.0)	0.62 (0.23 to 1.65)		
	Other	14 (0.5)	5 (0.8)	0.99 (0.24 to 4.25)		
Cooker fuel	None	15 (0.5)	5 (0.9)	1.00	0.92	
	LPG	2688 (90.0)	496 (89.7)	0.91 (0.23 to 3.52)		
	Electricity	272 (9.1)	50 (9.0)	0.85 (0.24 to 3.05)		
	Wood/Charcoal	13 (0.4)	2 (0.4)	0.48 (0.04 to 6.41)		

Continued

Table 1 Continued

Variable	Subcategory	Responders n (%)	Non-responders n (%)	Model OR (95% CI)	P value	Census %
Ownership of household goods	Cable	2033 (68.2)	354 (65.7)	0.79 (0.58 to 1.07)	0.08	
	Television	2949 (98.7)	525 (97.6)	1.05 (0.37 to 2.96)	0.36	
	Radio	2659 (89.4)	463 (87.0)	0.69 (0.48 to 0.99)	0.10	
	Washer	2792 (93.8)	486 (91.4)	0.87 (0.52 to 1.46)	0.60	
	Clothes dryer	543 (18.6)	113 (21.5)	0.98 (0.71 to 1.36)	0.81	
	Microwave	2540 (85.4)	457 (86.9)	1.36 (0.91 to 2.04)	0.11	
	Fridge freezer	2905 (97.7)	515 (97.0)	1.05 (0.47 to 2.38)	0.80	
	Swimming pool	20 (0.7)	5 (1.0)	1.92 (0.60 to 6.14)	0.26	
	Computer	1522 (51.4)	301 (57.0)	1.14 (0.71 to 1.85)	0.56	
	Internet	1400 (47.4)	277 (52.9)	1.27 (0.78 to 2.05)	0.31	
	Boat	19 (0.6)	1 (0.2)	0.32 (0.04 to 2.66)	0.22	
Urbanicity	Mean index (SD) (levels 1–8)	2.76 (1.9) Range 1–8	2.76 (1.9) Range 1–8	0.99 (0.89 to 1.09)	0.782	

All other OR and LRT p values from initial full multivariable model containing 26 variables (n=2969).
*ORs from the final multilevel multivariable logistic regression model (model, shaded grey), adjusted for six variables including age (linear), sex, employment status and three socioeconomic indicators (health insurance status, household AC and household ownership of a vehicle) (n=3232). Global p value from LRT.
AC, air conditioning; LPG, liquid propane gas; LRT, likelihood ratio test; NESTT, National Eye Survey of Trinidad and Tobago.

distance spectacles (OR 2.1, 95% CI 1.6 to 2.7) (p<0.001 for each variable) (online supplementary table 2).

Significant independent predictors of NVI in multivariable analysis included male sex (OR 1.7, 95% CI 1.4 to 2.1), lack of health insurance (OR 2.5, 95% CI 1.8 to 3.4), not owning distance spectacles (OR 3.6, 95% CI 2.8 to 4.6), and being on home duties (OR 1.8, 95% CI 1.4 to 2.5), unemployed (OR 1.6, 95% CI 1.0 to 2.6) or disabled (OR 3.8, 95% CI 1.8 to 7.8), as compared with having a job for the past 12 months (p<0.001 for each variable) (online supplementary table 3).

DISCUSSION

This study addresses the paucity of data on vision loss in the Caribbean, providing the first estimates of the prevalence, causes and risk factors for presenting DVI and NVI in adults >=40 years in Trinidad and Tobago in 2014. NVI resulting from uncorrected presbyopia affects more than a fifth of those with normal distance vision. The prevalence of blindness is half that reported in the Barbados Eye Survey over 20 years ago.[4] This aligns with a modelled decline in recent decades both globally and within Caribbean region.[30] However, the blindness prevalence is still almost double that of other high-income regions in 2012 (≤0.4%),[31] and the burden of potentially avoidable vision loss is substantial (87%). Public health awareness and education campaigns, and health service development investments, are urgently needed to close this gap.

URE was responsible for half of all presenting DVI (47.4%). Optometrists reported average costs in 2014 for sight tests (US$18, SD 4), reading or distance spectacles (US$126, SD 49), and bifocal, trifocal or varifocal spectacles (US$213, SD 86).[32] Given that 80% of the population report a monthly household income of <US$1559.9, spectacles were relatively unaffordable.[32] There was negligible public sector provision of refractive services in 2014.[32] Furthermore, dispensing optometry practices were located in urban areas, with some rural communities more than 30 km from the nearest practice.[32] Further research is needed to understand the factors contributing to the unmet need for refractive correction.

Glaucoma was a leading cause of blindness and the fourth most frequent cause of DVI. A previous diagnosis of glaucoma did not predict presenting VI (p=0.089), indicating the burden of undiagnosed glaucoma in this population. The 1992 Barbados Eye Survey and the 1986 St Lucia National Glaucoma Prevalence Survey similarly reported high glaucoma prevalence in their populations of predominantly West African ancestry.[4] In addition to possible ethnic or genetic susceptibility,[15] our contemporaneous eye care system study identified that two out of the five regional public hospitals lacked visual field analysers, and three

Table 2 Crude and adjusted prevalence of category of vision in the better-seeing eye

	Better eye Presenting VA		Better eye Best-corrected VA	
Vision category	Crude prevalence n (%)	Adjusted prevalence* % (95% CI)	Crude prevalence n (%)	Adjusted prevalence* % (95% CI)
Normal	3112 (86.93)	88.11 (87.07 to 89.17)	3357 (93.82)	94.64 (93.98 to 95.30)
Mild VI	222 (6.20)	5.77 (5.06 to 6.48)	101 (2.82)	2.32 (1.89 to 2.75)
Moderate VI	196 (5.47)	4.92 (4.26 to 5.57)	78 (2.18)	2.05 (1.63 to 2.48)
Severe VI	19 (0.53)	0.47 (0.28 to 0.65)	12 (0.34)	0.27 (0.13 to 0.42)
Blind	31 (0.87)	0.73 (0.48 to 0.97)	30 (0.84)	0.71 (0.48 to 0.95)

*Adjusted for multilevel design (island, cluster), weighted for response rate (by cluster), with poststratification adjustment to 2011 Census population stratified by municipality (15), 5-year age groups and gender.
VA, visual acuity; VI, vision impairment.

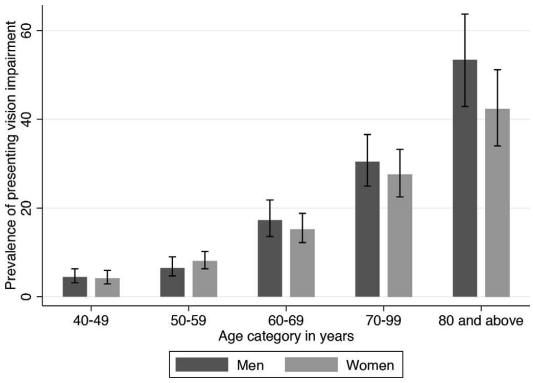

Figure 2 Prevalence (%) of adjusted, age-standardized presenting vision impairment in the better-seeing eye, by age category and sex, with 95 % confidence interval bars.

did not have devices to image the optic discs, to assist in the diagnosis and monitoring of disease.[32] While several glaucoma drops were freely available via the Chronic Disease Assistance Programme, prostaglandin analogues were not. Furthermore, the 280 dispensing pharmacies were predominantly located in urban centres, resulting in possible rural access issues.[33]

The second leading cause of both blindness and DVI was cataract. Trinidad and Tobago had a pluralistic eye care system, with basic, free eye care, including cataract surgery, universally available.[32] However, public sector waiting times were long and external partnerships had been required previously to address this.[32] Ongoing oversight and investment by the Ministry of Health and its devolved partners will be necessary to facilitate access to timely and affordable cataract surgery.

DR was the third leading cause of blindness and DVI. In 2014, there was no national DR screening programme, and some issues with timely access to laser treatment and vitreoretinal surgery were reported in the public sector.[32] The WHO estimates that the prevalence of diabetes in Trinidad and Tobago will more than double between 2000 and 2030, from an estimated 60 000 cases

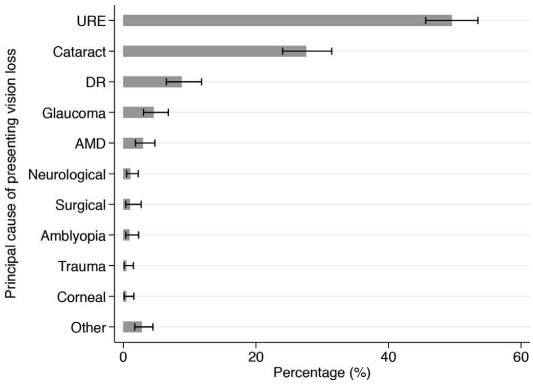

Figure 3 The principal causes of distance vision impairment (Logmar > 0.30) in the better-seeing eye,based on the adjusted cause-specific prevalence (%), with 95% confidence interval bars.

to 125 000 cases, making investment in screening and managing DR a high priority.[34]

DVI was most strongly predicted by age, with risk increasing tenfold comparing people 40–49 years with those over 80 years of age. With an ageing population, we anticipate increasing demand for healthcare, eye care and social services. For both DVI and NVI, risk varied by employment subgroup and was greater in those lacking spectacles. Lack of health insurance and male sex were also associated with NVI. Subgroups defined by these variables may benefit from more targeted interventions.

This study had several limitations. First, it lacked power to yield precise prevalence estimates by subgroup (eg, specific causes of blindness). Second, visual field constriction was not included in our blindness definition, potentially underestimating glaucoma-related vision loss. Third, 58.8% (n=18/31) blind participants required home examination, and resources did not extend to portable imaging equipment.

This study had multiple strengths. The rigorous sampling methodology minimised the risk of selection bias. Sampling 1% of the total population in 120 clusters ensured generalisability to the national non-institutionalised population. The comprehensive examination protocol permitted detailed cause determination. The 84% response rate compared favourably with other high-income country eye surveys. Weighting prevalence estimates and adjusting for age, sex and municipality minimised the effect of non-response bias. We adhered to the 'Strengthening the Reporting of Observational Studies in Epidemiology' guidelines.[35]

The NESTT provides the government and stakeholders with the evidence base to inform a national eye care strategy and a baseline to evaluate impact of future programmes. Combined with a contemporaneous eye care system study,[32] we identified priorities for intervention and investment. With 2020 rapidly approaching, this study highlights that even high-income countries face significant challenges in reducing the burden of avoidable vision loss. To better understand why, we advocate the inclusion of health systems research alongside future population-based prevalence surveys.

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Impact of Vision Loss on Health-Related Quality of Life in Trinidad and Tobago

Estimating quality-adjusted life years (QALYs) lost to vision impairment (VI) and the cost effectiveness of alternative interventions requires reliable measurement of health-related quality of life. Whether VI impacts health-related quality of life is uncertain,[1] but recent population-based surveys in Singapore and South Korea established an independent association between severe distance VI and utility loss. Here we report novel independent association between less severe categories of distance and near VI (NVI) in adult participants 40 years of age and older in the National Eye Survey of Trinidad and Tobago.

The 2013 through 2014 National Eye Survey of Trinidad and Tobago is the most comprehensive Caribbean eye survey undertaken in recent decades. Details are provided elsewhere.[2] Briefly, we sampled 9913 eligible people 5 years of age and older, including 4263 who were 40 years of age or older, residing in 3556 households (95.9% coverage) in 120 clusters, using multistage, random cluster sampling with probability-proportional-to-size methods. We measured presenting distance and near visual acuity outside households using logarithm of the minimum angle of resolution (logMAR) charts at 3 m and 40 cm, respectively, and standard measurement protocols (stage 1). We defined mild VI (0.32−0.48 logMAR), moderate VI (0.50−1.00 logMAR), severe VI (1.02−1.30 logMAR), and blindness ($\geq$1.32 logMAR) in the better-seeing eye, and binocular NVI (0.32−1.30 logMAR at 40 cm with $\leq$0.30 logMAR at 3 m). Avoidable VI included uncorrected refractive error, cataract, diabetic retinopathy, and glaucoma.

All participants 40 years of age or older were invited for clinic-based assessment (stage 2), including EQ-5D-5L.[3] EQ-5D-5L contains 5 questions on mobility, self-care, usual activities, pain and discomfort, and anxiety and depression, scored from 1 to 5, resulting in 3125 (5^5) possible health states. We transformed these into utility values using a Trinidad and Tobago value set and scoring algorithm for the EQ-5D-3L by so-called cross-walking.[4] In addition, participants selected 1 number on the visual analog scale (EQ-VAS), ranging from 0 to 100 (worst to best imaginable heath state). The University of the West Indies (Trinidad), Anglia Ruskin University (United Kingdom), and Ministry of Health (Trinidad and Tobago) provided ethics committee approvals. The study adhered to the tenets of the Declaration of Helsinki. All participants provided written consent.

Using standard statistical software (StataCorp. 2013, version 13.1; StataCorp LP, College Station, TX). we adjusted crude data for multilevel sampling (island, cluster) and weighted for selection probability and cluster response rate. Poststratification adjustment used census data (15 municipalities, gender, and 5-year age categories). We applied finite population corrections to first and second sampling stages. We applied VI prevalence to the 2014 midyear population to estimate cases.

We estimated utility coefficients and EQ-VAS scores using ordinary least squares regression analysis, with robust standard error estimation.[5] We explored odds of less than full health (utility, $<$1.000) and experiencing difficulty (raw score, $\geq$2) in each domain by vision category, using multilevel mixed-effects logistic regression analysis. Full models contained 25 variables, including age, gender, and ethnicity as potential confounders. We took a backward approach to select the most parsimonious model. After logistic regression, we assessed nested model fit using the classical likelihood ratio test to obtain P values and the smaller value of Akaike and Schwarz's Bayesian information criterion. After linear regression, we used Wald P values. We set significance at 5%.

We estimated prevalent QALY loss by multiplying cases of VI by utility coefficients. To illustrate individual lifetime QALY loss, we assumed VI states persisted from age 40 years to death 36.1 years later, applying no discount. In sensitivity analysis, we explored the effect of alternative statistical analysis approaches (adjusting for age and gender), a United Kingdom EQ-5D-5L value set, and binocular vision category definitions.

Three thousand five hundred eighty-nine of 4263 eligible adults (84.2%) completed stage 1 and 62.4% completed stage 2. Mean age was 58.4 years (standard deviation, 11.7 years; range, 40−103 years), 56.3% (n = 1496) were women, and most were African (45.4% [n = 1177]) or South Asian (41.4% [n = 1074]). After adjustment, full health (utility value, 1.000) was reported by 52.7% (95% confidence interval [CI], 50.6−54.9), mean utility was 0.920 (95% CI, 0.916−0.925), and EQ-VAS score was 80.2 (95% CI, 79.6−80.8); both reduced with severity of VI (Table S1, available at www.aaojournal.org).

Blindness showed the largest independent effect on EQ-VAS and utility value (Fig 1). Utility coefficients ranged from −0.140 (95% CI, −0.092 to −0.192) for blindness, −0.091 (95% CI, −0.031 to −0.151) for severe VI, −0.045 (95% CI, −0.024 to −0.067) for moderate VI, and −0.020 (95% CI, −0.004 to 0.013) for mild VI to −0.012 (95% CI, −0.004 to −0.021) for NVI. Visual analog scale score coefficients similarly ranged from −7.8 (95% CI, −0.2 to −15.3) for blindness to −2.5 (95% CI, 0.7 to −5.7) for mild VI and −1.6 (95% CI, −0.2 to −3.0) for NVI.

Reporting less than full health was 10 times more likely for blind persons (odds ratio [OR], 9.58; 95% CI, 1.18−78.16) and 1.3 times more likely for those with NVI (OR, 1.31; 95% CI, 1.03−1.66; $P = 0.009$) than for those with normal vision. Table S2 (available at www.aaojournal.org) details independent predictors. Near VI significantly increased reporting some difficulty with mobility (OR, 1.84; 95% CI, 1.35−2.50; $P < 0.001$), self-care (OR, 2.24; 95% CI, 1.33−3.76; $P = 0.002$), and usual activities (OR, 1.89; 95% CI, 1.29−2.77; $P = 0.001$), and distance VI significantly impacted all 5 domains.

A 40-year-old would experience a lifetime loss of 0.45 QALYs for NVI, 0.72 QALYs for mild VI, 1.64 QALYs for moderate VI, 3.30 QALYs for severe VI, and 5.13 QALYs for

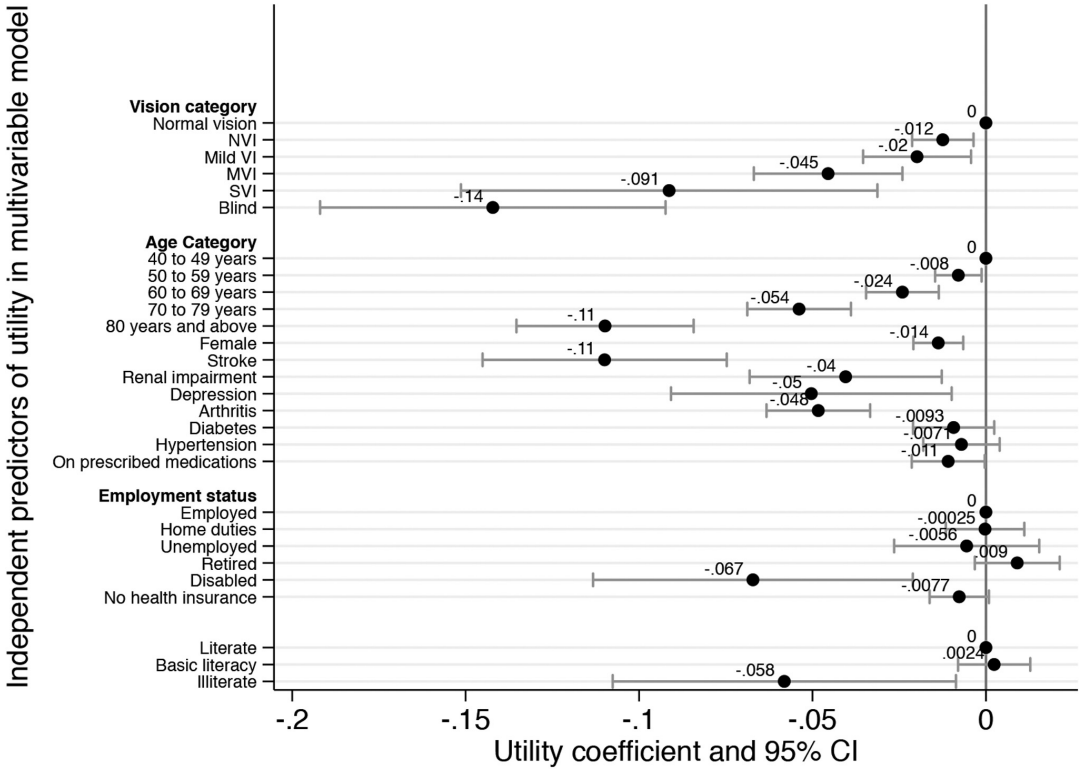

Figure 1. Graph showing utility coefficients (with 95% confidence intervals [CIs]) from the multilevel multivariate model showing the independent effect of vision impairment (VI) category. MVI = moderate vision impairment; NVI = near vision impairment; SVI = severe vision impairment.

blindness. Visual impairment was associated with 4131 lost QALYs in 2014, equivalent to 762.3 QALYs per 100 000 people per year, 694.9 of which were potentially avoidable.[2] This exceeded the equivalent rate of QALYs lost from stroke (307 QALYs), depression (284 QALYs), and arthritis (522 QALYs). One-fifth of adults 40 years of age or older (120 842 people) demonstrated NVI, accounting for 36.4% (1502 QALYs) of total QALYs lost.

Blindness disutility coefficients were similar for ordinary least squares with robust standard error estimation (0.138), Tobit (0.135), and censored least absolute deviation (CLAD) (0.090) analyses and closely agreed with the United Kingdom value set (−0.159; 95% CI, −0.098 to −0.220). Uniocular blindness utility loss ranged from −0.019 (95% CI, −0.002 to 0.037; $P = 0.029$) to −0.101 (95% CI, −0.060 to 0.138; $P < 0.001$), depending on the other eye having normal vision or moderate or severe VI, respectively. Uncertainty in the 95% CI around VI cases and utility coefficients resulted in ranges of 3504 to 4743 lost QALYs and 1655 to 6608 lost QALYs, respectively.

This national survey is the first to report that both distance VI and NVI independently predict health-related quality of life loss. This highlights the societal impact and importance of continued investment to address all degrees of avoidable VI.

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Appendix B: Literature Search

B.1 Population-based surveys of vision impairment in the Caribbean

Location Level Year	Age, years	Total sample (RR, %)	VA measure & Definition	Prevalence	Causes of blindness
St Lucia National 1986	30+	1936 (87)	Presenting VA, Snellen chart, vision categories not reported	NR (glaucoma prevalence only)	NR
Barbados National 1987	40-84	4631 (82.1)	BCVA in better-eye, Ferris Bailey Chart, blind <3/60, low vision <6/18 >=3/60	B 1.7% (95% CI 1.3-2.1), Low vision 5.9% (95% CI 5.1 to 6.5)	Cataract (28%), POAG (28%), Retinal disease (15%), optic atrophy (11%), macular disease (5%), combined cataract & POAG (4%), other (8%)
Cuba Local 2005	50-99	2716 (98.4)	Presenting VA, better-eye, single Snellen optotype B <3/60, low vision <6/18 >=3/60	B 2.4%, low vision 5.1%	Cataract (50%), glaucoma (26%), DR (9%)
Dominican Republic, National, 2008	50-99	3873 (NR)	BCVA, better-eye, single Snellen optotype <6/18 +/- pinhole	Functional low vision 2.1%	NR

Key: B Blind; BCVA Best-corrected visual acuity; DR diabetic retinopathy; NR not reported; RR response rate; VA visual acuity

B.2. Summary table of the characteristics of 165 studies included in review

Survey Characteristic (Total n)	Categories	Value, n (%)
Age groups included (n = 165)	All ages	25 (15.2)
	All adults ≥18 years	13 (7.9)
	Children only < 18 years	35 (21.2)
	Children and young adults ≤ 40 years	10 (6.1)
	Adults ≥ 40 years	38 (23.0)
	Adults ≥ 50 years	23 (13.9)
	Adults ≥ 60 years	17 (10.3)
	Adults ≥ 70 years	4 (2.4)
Geographical Regions (n = 165)	Asia Pacific, High Income	8 (4.8)
	Asia, Central	2 (1.2)
	Asia, East	27 (16.4)
	Asia, South	24 (14.5)
	Asia, Southeast	10 (6.1)
	Australasia	6 (3.6)
	Caribbean	1 (0.6)
	Europe, Central	1 (0.6)
	Europe, West	19 (11.5)
	Latina America, Tropical	2 (1.2)
	North Africa/Middle East	15 (9.1)
	North America	4 (2.4)
	Oceania	5 (3.0)
	Sub-Saharan Africa, Central	1 (0.6)
	Sub-Saharan Africa, East	14 (8.5)
	Sub-Saharan Africa, South	6 (3.6)
	Sub-Saharan Africa, West	20 (12.1)
Epoch start year (n = 141)	1980-1989	19 (13.5)
	1990-1999	53 (37.6)
	2000-2009	61 (43.3)
	2010-2014	8 (5.7)
Status of economy at time of the survey (n = 164)	High income	43 (26.2)
	Upper middle income	17 (10.4)
	Lower middle income	42 (25.6)
	Low income	62 (37.8)
Level of survey (n = 165)	National	25 (15.2)
	Regional	31 (18.8)
	Local	109 (66.1)
Response rate (n = 138)	Mean (sd), range (%)	83.4 (13.5), 29.1 to 100

B.3 Table of 165 studies identified by the GBD Study

Global Burden of Disease 165 studies

Study identifier	Country	Epoch Start	Age Start	Age End	Coverage	Total n	Sample size	Response rate
Caribbean & Latin America								
Barbados Eye	Barbados	1988	40	49	national	4631	5546	0.835
Sao paulo Eye	Brazil	2004	50	99	local	3678	4224	0.871
Botucatu	Brazil	NR	0	99	local	2485	3300	0.753
High Income								
Japan Community	Japan	1997	40	49	Local	2263	7790	0.291
Tajimi ES	Japan	2000	40	49	Local	2977	3870	0.769
Kumejima	Japan	2005	40	99	local	3762	4632	0.812
Korean NHANES 08	Korea	2008	30	95	national	14924	NR	0.904
Korean NHANES 10/11	Korea	2010	40	99	national	7899	NR	NR
Singapore (SiMES)	Malaysia	2004	40	49	Local	3280	4168	0.787
Tanjng Pagar	Singapore	1997	40	49	Local	1152	1717	0.671
Singapore Preschool	Singapore	NS	3	6	subnational	3009	NR	0.723
Elderly Urban	Australia	1992	70	99	local	1446	3263	0.443
Blue Mountains	Australia	1992	49	99	local	3654	4433	0.824
Melbourn VIP	Australia	1992	40	99	local	4744	5520	0.859
robaei 6 years	Australia	2003	5	8	local	1738	2238	0.777
robaei 12 years	Australia	2004	12	12	local	2353	3144	0.748
Sydney Paeds Eye	Australia	2007	0	6	subnational	1188	3335	0.356
British Elderly	Britain	1994	65	74	National	1487	1526	0.974
Copenhagen City	Denmark	1986	60	64	Local	946	976	0.969
Elderly UK	England	1982	75	99	Local	529	677	0.781
UK elderly	England	NR	65	74	Local	207	288	0.719
Finland	Finland	2000	30	44	National	6663	7393	0.901
EUREYE	France, Nor	2003	65	99	local	4166	11200	0.372
Rejkjavik Eye	Iceland	1996	50	99	local	1045	1379	0.758
West Bank Gaza	Israel OPT	1982	20	60	local	9054	9548	0.948
Ponza ES	Italy	1988	40	51	Local	250	305	0.820
Rotterdam ES	Netherlands	1990	55	106	Local	6756	7983	0.846
Tromso ES	Norway	2007	38	87	subnational	6459	19762	0.327
Sergovia ES	Spain	2007	40	49	Local	510	569	0.896
Cuenca Spain	Spain	NR	65	74	Local	1144	1435	0.797
Swedish Children	Sweden	1982	0	11	Local	3126	3271	0.956
Leiden 85+ Study	The Netherl	1997	85	99	Local	459	691	0.664
National 10y olds	UK	1980	10	12	National	12853	13871	0.927
Elderly community	UK	1995	75	79	National	13900	33000	0.421
North London	UK	1995	65	99	Local	1547	1840	0.841
Working adults UK	UK	2002	44	45	National	9377	11971	0.783
Proyecto VER	Mexico	1999	40	99	local	4774	6658	0.717
Baltimore Eye	USA	1985	40	99	local	5308	7104	0.747
Beaver Dam	USA	1988	43	86	local	4926	NR	NR
Salisbury Eye	USA	1993	65	84	local	2520	3821	0.660

KEY: BCVA Best-corrected visual acuity; H high income; L low income; LM lower middle income; NR not reported; pVA presenting visual acuity; UM upper middle income

Global Burden of Disease 165 studies

Study	Country	Epoch Start	Age Start	Age End	Coverage	n	Sample size	Response rate
South Asia								
Bangladesh National	Bangladesh	1999	30	NR	national	11624	12782	0.909
Hyderabad Children	India	1993	3	18	local	3669	4029	0.911
Aravind	India	1995	6	99	local	16735	17200	0.973
Andhra Pradesh Eye	India	1996	0	15	local	10293	11786	0.873
Sivaganga eye survey	India	1999	50	99	local	4642	5081	0.914
India 15 states	India	1999	50	99	subnational	63337	72044	0.879
Tirunelveli	India	2000	50	99	local	5411	5795	0.934
Chennai Glaucoma	India	2001	40	99	local	3924	4800	0.818
Rajnandangaon Glaucoma	India	2001	35	99	local	7438	8397	0.886
Kariapatti Paediatric	India	2002	0	15	local	10605	11206	0.946
Karnataka	India	2002	50	99	local	1505	NR	NR
Maharashtra India	India	2009	50	99	local	2005	2300	0.872
Central India Eye	India	NR	30	99	subnational	4706	5885	0.800
Rural Rajasthan	India	NR	50	99	local	4284	4728	0.906
Southern India Hobli	India	NR	0	15	local	8684	13241	0.656
Nepal National Eye	Nepal	1979	0	4	national	39887	NR	NR
Gandaki Children	Nepal	2002	45	99	local	5002	5863	0.853
Dhulikhel Children	Nepal	2007	0	15	local	466	NR	NR
Kavrepalan-Chowk	Nepal	2007	3	22	local	1802	NR	NR
Bhaktapur Glacuoma	Nepal	2010	40	99	local	4003	4800	0.834
Mountain Children Myopia	Nepal	NR	4	18	local	140	NR	NR
Mechi children	Nepal	1997	5	15	subnational	4803	5526	0.869
Pakistan rural	Pakistan	1998	40	49	local	1106	NR	NR
Pakistan National Eye	Pakistan	2001	30	99	national	16507	17314	0.953
Asia (Southest, East) & Oceania								
China National	China	1987	0	99	national	1579316	NR	NR
Shunyi County	China	1996	50	99	Local	5052	5555	0.909
Doumen County	China	1997	50	99	Local	5342	6444	0.829
Tibet	China	1999	0	99	Subnationa	12644	15900	0.795
Bejing Eye	china	2001	40	99	Subnationa	4439	5324	0.834
Nantong	China	2003	60	69	local	3040	3352	0.907
Beijng preschool	China	2004	3	6	local	17699	28738	0.616
Handan Eye	China	2006	30	39	Local	6830	7557	0.904
Nine Province	China	2006	50	59	Local	45747	50395	0.908
Rural Southern Harbin	China	2006	50	59	Local	5057	5559	0.910
Sichuan	China	2006	0	99	subnational	125641	NR	0.990
Xichang Pediatric	China	2007	11	17	Subnationa	1892	2235	0.847
Bin county	China	2007	40	99	local	4956	5764	0.860
Nantong	China	2008	60	99	local	1305	1391	0.938
Heilongjiang	China	2008	1	99	local	10384	11787	0.881
Xiu'Shui county	China	2009	0	15	local	23675	NR	NR
Baoshan	China	2009	60	99	local	4545	NR	NR

Global Burden of Disease 165 studies

Study	Country	Epoch Start	Age Start	Age End	Coverage	n	Sample size	Response rate
Liwan	China	2009	50	99	local	1399	NR	0.753
Southern Jiangsu	China	2010	50	99	subnational	5632	6155	0.915
Northern China	China	2010	7	99	subnational	20298	24539	0.827
Shuimogou District	China	2010	40	99	local	4104	5032	0.816
Yunnan Minority Eye	China	NR	50	99	subnational	2133	2742	0.778
Beijing schoolchildren	China	NR	5	13	local	663	NR	NR
Hong Kong Elderly	HongKong,C	1998	60	69	Local	3441	4487	0.767
Elderly Taiwan	Taiwan	2002	65	99	National	3160	5000	0.632
Eastern Taiwan	Taiwan	NR	65	99	local	2316	NR	0.612
Taiwan precinct	Taiwan, Chi	1993	50	59	Local	2038	2700	0.755
Cambodia	Cambodia	1996	46	99	subnational	5803	6558	0.885
Rural Indonesia	Indonesia	2001	21	99	local	989	1043	0.948
Lao schoolchildren	Lao	2009	6	11	subnational	2899	3330	0.871
Selangor	Malaysia	1993	18	99	local	282	330	0.855
Malaysia National Eye	Malaysia	1996	0	9	national	18027	NR	0.690
Sepang district	Malaysia	2000	40	99	local	311	341	0.912
The Meiktila Eye Study	Myanmar	2005	40	99	local	2076	2481	0.837
Kandy Eye	Sri Lanka	2006	40	99	local	1375	1721	0.799
Bangkok Glaucoma	Thailand	1997	50	99	local	701	790	0.887
Elderly Thais	Thailand	1997	40	99	local	2092	NR	NR
Rarotonga	Cook Island	1980	20	99	local	1127	1412	0.798
Fiji National	Fiji	2006	0	15	national	NR	NR	NR
Fiji adults	Fiji	2009	40	99	subnational	1381	1892	0.730
Tonga	Tonga	1991	20	99	subnational	4056	5000	0.811
Vanuatu	Vanuatu	1989	6	19	national	3520	3520	1.000
Europe (Eastern, Central) & Central Asia								
Mongolia >40y	Mongolia	1991	40	49	Subnationa	4345	4542	0.957
Mongolia glaucoma	Mongolia	1995	40	87	Subnationa	942	1000	0.942
Sofia Bulgaria	W Bulgaria	1993	50	99	local	6173	6274	0.984
North Africa & Middle East								
Cairo School Children	Egypt	1994	7	15	Subnationa	5839	6000	0.973
Tehran	Iran	2002	1	99	local	4565	6497	0.703
Dezrul schoolchildren	Iran	2005	7	15	Local	5544	5726	0.968
Khuzestan	Iran	2006	5	87	subnational	6960	NR	0.745
Shahrud	Iran	2009	40	64	local	5188	6311	0.822
Lorestan	Iran	NR	0	15	local	123	NR	NR
Jordan children	Jordan	2010	6	14	local	3200	NR	NR
National Lebanon	Lebanon	1995	3	98	National	10148	11218	0.905
Morocco	Morroco	1992	50	54	National	8878	10198	0.871
Oman National Eye Study	Oman	1996	0	39	National	11417	12500	0.913
Eastern Saudi Arabia	Saudi Arabia	1989	0	4	subnational	4340	4819	0.901
Western Saudi Arabia	SW Saudi A	1991	0	99	Local	2882	2963	0.973
Tunisia	Tunisia	1993	0	14	National	3547	3981	0.891

Global Burden of Disease 165 studies

Study	Country	Epoch Start	Age Start	Age End	Coverage	n	Sample size	Response rate
SE Turkey 2 provinces	Turkey	1989	0	99	Subnationa	7497	8571	0.875
SE Turkey	Turkey	2008	6	14	local	21062	NR	NR
Sub-saharan Africa								
Congo	Congo	1988	0	99	national	6185	7044	0.878
Jimma Zone	Ethiopia	1994	0	9	local	7423	8215	0.904
Sekhoru district	Ethiopia	2009	0	16	subnational	58480	NR	0.940
Rural central children	Ethiopia	2010	7	18	local	4238	5470	0.775
Gurage Zone	Ethiopia		40	99	local	2693	2964	0.890
Ethiopia Seven Regions	Ethiopia		7	14	subnational	11441	15753	0.726
Nairobi Kibera Slums	Kenya	2002	18	89	local	1438	NR	NR
Nakuru	Kenya	2007	50	99	local	4381	5010	0.874
Kenyan rural	Kenya	1980	0	19	local	13803	NR	0.900
Kenya presbyopia	Kenya		50	59	local	130	NR	NR
Southern Malawi	Malawi	1983	0	70	local	5415	NR	NR
Southern Sudan	Sudan		5	29	local	2499	2954	0.846
Central Tanzania	Tanzania		7	20	local	1827	2510	0.728
Rural Tanzania	Tanzania	2004	40	99	local	1709	NR	NR
SW Uganda	Uganda		13	24	local	4076	NR	0.693
Botswana National	Botswana	1998	60	69	national	372	NR	NR
Western Cape, Mamre	South Africa	1992	40	99	local	987	1194	0.827
Zululand	South Africa	1998	40	99	local	1005	1115	0.901
Cape Town	South Africa	2010	50	99	local	2744	3100	0.885
Northen Kwazulu	South Africa		0	99	local	6090	6090	1.000
Zimbabwe regional	Zimbabwe		60	99	local	278	278	1.000
North Camaroon	Cameroon	1992	6	99	subnational	10647	NR	NR
National Cape Verde	Cape Verde	1998	0	9	subnational	3374	3800	0.888
Volta Ghana	Ghana	2001	40	99	local	2298	2400	0.958
Tema Eye	Ghana	2006	65	99	local	5603	6806	0.823
Segou Mali	Mali	1990	0	4	local	5871	6000	0.979
SW Nigeria	Nigeria	1991	0	99	local	2921	2921	1.000
Anamrba	Nigeria	1992	0	99	subnational	1752	1752	1.000
Kano State Nigeria	Nigeria	1995	0	99	local	3332	3596	0.927
Northern Nigeria	Nigeria	1999	40	99	Subnationa	1461	1924	0.759
Rural SW	Nigeria	2002	8	92	local	2201	NR	NR
SW Students	Nigeria	2002	4	24	local	1144	1144	1.000
Sokoto state, Nigeria	Nigeria	2005	0	99	local	4848	NR	0.910
Yobe Trachoma	Nigeria	2006	1	97	subnational	3357	3906	0.859
South Nigeria Farming	Nigeria	2007	0	99	local	1513	NR	NR
SW Nigeria	Nigeria	NS	60	99	subnational	630	640	0.984
Adeoti 2004	Nigeria		0	99	local	3204	NR	NR
Atakunmosa	Nigeria		0	10	local	1248	NR	NR
Nigeria National	Nigeria		40	49	national	13599	15122	0.899
Benin	Republic of	1990	0	59	national	7047	7272	0.969
Gambia National	the Gambia	1986	0	19	national	8174	8696	0.940

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Study	Visual acuity measure and chart	Dilated?	GNIpc mid-epoch	Income group
Caribbean & Latin America				
Barbados Eye	BCVA, Ferris-Bailey	If < 6/18	7400	H
Sao paulo Eye	BCVA. LogMAR Tumbling E	Yes	3280	LM
Botucatu	BCVA and pVA, LogMAR Tumbling E	Yes	6030	UM
High Income				
Japan Community	BCVA, Landolt C	NR	40040	H
Tajimi ES	BCVA, Landolt C	If < 6/12	36230	H
Kumejima	BCVA, Landolt C	Yes	40560	H
Korean NHANES 08	BCVA, Jin's vision chart	NR	21260	H
Korean NHANES 10/11	BCVA, Jin's vision chart	NR	22540	H
Singapore (SiMES)	BCVA and pVA. LogMAR number chart	Yes	25650	H
Tanjng Pagar	BCVA, LogMAR	No	27750	H
Singapore Preschool	BCVA, LogMAR	Yes	37080	H
Elderly Urban	pVA, Snellen chart	NR	18620	H
Blue Mountains	BCVA, LogMAR with ETDRS protocol	NR	18620	H
Melbourn VIP	BCVA and pVA, LogMAR	Yes	18620	H
robaei 6 years	pVA LogMAR chart; Near LogMAR HOTV	Yes	21110	H
robaei 12 years	pVA LogMAR	Yes	25490	H
Sydney Paeds Eye	pVA	NR	37340	H
British Elderly	pVA, 3m glasgow acuity card	No	21520	H
Copenhagen City	pVA	Yes	14140	H
Elderly UK	BCVA and pVA, Snellen	Yes	10470	H
UK elderly	pVA, binocular Snellen	Yes	19050	H
Finland	pVA	No	26420	H
EUREYE	BCVA and pVA, EDTRS LogMAR	Yes	36819	H
Rejkjavik Eye	BCVA	Yes	27320	H
West Bank Gaza	pVA, Tumbling E single optotypes x2	NR	6020	H
Ponza ES	BCVA and pVA, LogMAR	Yes	15900	H
Rotterdam ES	BCVA	Yes	20060	H
Tromso ES	BCVA, Snellen	NR	78400	H
Sergovia ES		NR	29920	H
Cuenca Spain	BCVA and pVA, LogMAR	Yes	29920	H
Swedish Children	pVA, HVOT chart or Line E chart	Yes	15760	H
Leiden 85+ Study	pVA, EDTRS Diabetic chart	Yes	29490	H
National 10y olds	pVA, Snellen or Stycar	No	9380	H
Elderly community	pVA, Glasgow acuity LogMAR	Yes	20990	H
North London	pVA, Log MAR	Yes	20990	H
Working adults UK	pVA, crowded LogMAR	NR	28900	H
Proyecto VER	BCVA and pVA, LogMAR ETDRS protocol	Yes	33780	H
Baltimore Eye	BCVA, Ferris and Tumbling E	Yes	17510	H
Beaver Dam	BCVA, LogMAR, modified ETDRS protoco	Yes	23580	H
Salisbury Eye	BCVA, ETDRS protocol	Yes	26480	H

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Study	Visual Acuity measure and chart	Dilated?	GNIpc mid-epoch	Income group
South Asia				
Bangladesh National	BCVA, LogMAR Tumbling E	Yes	410	L
Hyderabad Children	BCVA, Snellen	Subgroup	330	L
Aravind	BCVA, logMAR Tumbling E	Yes	380	L
Andhra Pradesh Eye	BCVA, logMAR	Yes	410	L
Sivaganga eye survey	BCVA, logMAR	If < 6/18	450	L
India 15 states	pVA, logMAR	Subgroup	450	L
Tirunelveli	BCVA, logMAR	Subgroup	450	L
Chennai Glaucoma	BCVA, logMAR	Yes	460	L
Rajnandangaon Glaucoma	BCVA, LogMAR EDTRS	Yes	460	L
Kariapatti Paediatric	pVA, Cambirgde crowding cards	Subgroup	470	L
Karnataka	pVA, Snellen Tumbling E optotype	Subgroup	470	L
Maharashtra India	BCVA	If VA <6/12	1110	LM
Central India Eye	BCVA and pVA	NR	1380	LM
Rural Rajasthan	pVA, LogMAR	Subgroup	450	L
Southern India Hobli	pVA, Snellen Tumbling E optotype	NR	930	L
Nepal National Eye	pVA, Tumbling E single optotype	If < 6/18	140	L
Gandaki Children	pVA, LogMAR	If < 6/19	240	L
Dhulikhel Children	BCVA	Subgroup	370	L
Kavrepalan-Chowk	BCVA, pVA	Yes	370	L
Bhaktapur Glacuoma	BCVA, pVA	NR	540	L
Mountain Children Myopia	pVA, Snellen	If VA < 6/9	540	L
Mechi children	BCVA, LogMAR	Yes	220	L
Pakistan rural	BCVA and pVA, Snellen Tumbling E	If VA < 6/18	470	L
Pakistan National Eye	BCVA, LogMAR Tumbling E	Yes	500	L
Asia (Southest, East) & Oceania				
China National	NR	No	320	L
Shunyi County	BCVA, ETDRS	If < 6/18	650	L
Doumen County	pVA, LogMAR Tumbling E	No	750	L
Tibet	pVA, Tumbling E	If < 6/18	860	LM
Bejing Eye	BCVA, pVA, Jaeger	Yes	1010	LM
Nantong	BCVA, LogMAR	If <6/18	1280	LM
Beijng preschool	pVA	If <6/18	2510	LM
Handan Eye	BCVA, LogMAR Tumbling E	Yes	2060	LM
Nine Province	BCVA and pVA, Snellen	if <6/12	2060	LM
Rural Southern Harbin	pVA, LogMar	No	2060	LM
Sichuan	BCVA	Yes	3100	LM
Xichang Pediatric	pVA, Snellen tumbling E	No	2538	LM
Bin county	BCVA and pVA	If <6/18	2510	LM
Nantong	BCVA and pVA	No	3100	LM
Heilongjiang	BCVA	No	3690	LM
Xiu'Shui county	pVA	NR	3690	LM
Baoshan	BCVA and pVA	Yes	3690	LM

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Study	Visual Acuity measure and chart	Dilated?	GNIpc mid-epoch	Income group
Liwan	BCVA and pVA, ETDRS	Yes	3690	LM
Southern Jiangsu	pVA	Yes	4340	UM
Northern China	BCVA and pVA	If VA <6/18	4340	UM
Shuimogou District	BCVA, Tumbling E	NR	4340	UM
Yunnan Minority Eye	BCVA and pVA, ETDRS	If VA <6/18	4340	UM
Beijing schoolchildren	BCVA and pVA	No	5060	UM
Hong Kong Elderly	pVA, logMAR	No	24800	H
Elderly Taiwan	BCVA, Snellen	If < 6/12		H
Eastern Taiwan	BCVA	NR	37000	H
Taiwan precinct	pVA, Snellen	No		L
Cambodia	pVA, Tumbling E	Yes	310	L
Rural Indonesia	pVA, Tumbling E logMAR	Yes	670	L
Lao schoolchildren	pVA	If VA < 6/12	890	L
Selangor	pVA, single letter or Tmbling E optotype	Yes	3200	UM
Malaysia National Eye	pVA, Snellen Tumbling E	If < 6/18	4450	UM
Sepang district	pVA, Snellen	Yes	3420	UM
The Meiktila Eye Study	pVA, Snellen Tumbling E	Subgroup	260	L
Kandy Eye	BCVA, LogMAR	Yes	1570	LM
Bangkok Glaucoma	pVA LogMAR tumbling E	Yes	2690	LM
Elderly Thais	BCVA, Snellen	Subgroup	2690	LM
Rarotonga	pVA, Snellen Tumbling E	Yes		NA
Fiji National	Review of hospital records	No	3630	UM
Fiji adults	pVA	If VA <6/18	3870	LM
Tonga	pVA, Snellen Tumbling E or letter	Yes	1350	LM
Vanuatu	pVA Tumbling E or letter single optotypes	Yes	1090	LM
Europe (Eastern, Central) & Central Asia				
Mongolia >40y	pVA, Landolt C or Cyrillic alphabet	Yes	1200	LM
Mongolia glaucoma	BCVA, Snellen	Subgroup	460	L
Sofia Bulgaria	pVA	No	1250	LM
North Africa & Middle East				
Cairo School Children	pVA, Landolt C	No	820	LM
Tehran	BCVA, pVA	Yes	1880	LM
Dezrul schoolchildren	pVA, BCVA, Snellen Tumbling E	NR	2910	LM
Khuzestan	BCVA	If VA <6/18	3370	LM
Shahrud	BCVA, pVA, LogMAR	NR	5350	UM
Lorestan	Not measured directly	NR	3370	LM
Jordan children	Not measured directly	NR	3680	LM
National Lebanon	pVA, Snellen E	NR	5710	LM
Morocco	NR	NR	1270	LM
Oman National Eye Study	pVA, Snellen Tumbling E	No	6520	UM
Eastern Saudi Arabia	pVA, Landolt C	No	6950	H
Western Saudi Arabia	pVA Landolt C single optotype	NR	8010	H
Tunisia	NR	NR	1700	LM

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Study	Visual Acuity measure and chart	Dilated?	GNIpc mid-epoch	Income group
SE Turkey 2 provinces	pVA	NR	1920	LM
SE Turkey	BCVA and pVA	Yes	9770	UM
Sub-saharan Africa				
Congo	NR	No	380	L
Jimma Zone		NR	160	L
Sekhoru district	No direct measurement - key informant	NR	340	L
Rural central children	BCVA, pVA	If VA < 6/12	380	L
Gurage Zone		If VA < 6/18	120	L
Ethiopia Seven Regions	Snellen	NR	210	L
Nairobi Kibera Slums		No	390	L
Nakuru	pVA, LogMAR Tumbling E	Yes	710	L
Kenyan rural	pVA, Landholt C	No	400	L
Kenya presbyopia	N type reading chart	NR	730	L
Southern Malawi	Landolt C	No	160	L
Southern Sudan		NR	560	L
Central Tanzania	Tumbling E	NR	200	L
Rural Tanzania	N type reading chart	NR	410	L
SW Uganda	pVA, Tumbling E single optotypes +/- char	If VA < 6/18	250	L
Botswana National	pVA, ability to count fingers	NR	3010	LM
Western Cape, Mamre	NR	Yes	3320	UM
Zululand	pVA, Tumbling E	NR	3370	UM
Cape Town	pVA	If VA < 6/18	6220	UM
Northen Kwazulu	pVA, Snellen E chart	No	3320	UM
Zimbabwe regional	pVA, Snellen chart	NR	670	L
North Camaroon	pVA Landolt C	Yes	870	LM
National Cape Verde	pVA, Tumbling E	If < 6/18	1300	LM
Volta Ghana	pVA, Snellen Tumbling E	If < 6/18	300	L
Tema Eye	BCVA, LogMAR Tumbling E	If < 6/12	600	L
Segou Mali	pVA, Snellen Tumbling E	Subgroup	290	L
SW Nigeria	pVA, Snellen Tumbling E optotype	If < 3/60	270	L
Anamrba	pVA, Snellen letter or Tumbling E	NR	270	L
Kano State Nigeria	pVA, Snellen letter or Tumbling E	NR	170	L
Northern Nigeria	pVA, Snellen	No	270	L
Rural SW	pVA, Tumbling E	Subgroup	350	L
SW Students	pVA, Snellen. Near- Sussex vision test	Subgroup	350	L
Sokoto state, Nigeria	pVA	No	670	L
Yobe Trachoma	pVA letter or Tumbling E	NR	840	L
South Nigeria Farming	pVA	No	1470	LM
SW Nigeria	BCVA, pVA, Tumbling E	No	1470	LM
Adeoti 2004	pVA, single Tumbling E optotype	Subgroup	410	L
Atakunmosa	pVA, Snellen's orTumbling E	No	840	L
Nigeria National	BCVA, pVA, LogMAR	Yes	1160	LM
Benin	NR	NR	360	L
Gambia National	pVA, Tumbling E single optotype	If < 6/18	310	L

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Study	Reference
Caribbean & Latin America	
Barbados Eye	Hyman, L., et al. (2001). Ophthalmology 108(10): 1751-6
Sao paulo Eye	Salomao, S. R., et al. (2008). Ophthalmic Epidemiology 15(3): 167-75
Botucatu	Schellini SA, et al. (2009). BMC Ophthalmol.;9:8
High Income	
Japan Community	Iwano, M., et al. (2004). Japanese Journal of Ophthalmology 48(1): 37-43
Tajimi ES	Iwase, A., et al. (2006). Ophthalmology 113(8): 1354-62
Kumejima	Nakamura Y, et al. (2010). Ophthalmology 117(12):2315-21
Korean NHANES 08	Rim THT, et al. (2014). Acta Ophthalmol. 2014;92(4):e317-25
Korean NHANES 10/11	Cho B, et al. (2014). Invest Ophthalmol Vis Sci;55:1101-1110
Singapore (SiMES)	Wong, T. Y., et al. (2008). Archives of Ophthalmology 126(8): 1091-9
Tanjng Pagar	Saw, S. M., et al. (2004). Ophthalmology 111(6): 1161-8
Singapore Preschool	Dirani, M., et al.(2010). Br J Ophthalmol.;94(12):1561-5
Elderly Urban	Casson, R., et al.(1996). Aust N Z J Ophthalmol.;24(3):239-43
Blue Mountains	Attebo, K., et al. (1996). Ophthalmology. 103(3): 357-64
Melbourn VIP	VanNewkirk, M.R., et al. (2001). Ophthalmology; 108(5): 960-7
robaei 6 years	Robaei, D., et al. (2005). Ophthalmology; 112(7): 1275-82
robaei 12 years	Robaei, D., et al. (2006). Opjhthalmology; 113(9): 1567-73
Sydney Paeds Eye	Pai A.S., et al. (2011). Ophthalmology;118(8):1495-500
British Elderly	van der Pols, J. C., et al. (2000). British Journal of Ophthalmology 84, 165-70
Copenhagen City	Buch, H., et al. (2001). Ophthalmology 108(12): 2347-57.
Elderly UK	Gibson, J. M., et al. (1986). British Journal of Ophthalmology 70, 700-5
UK elderly	Wormald, R. P., et al. (1992). BMJ 304, 1226-9
Finland	Laitinen, A., et al. (2005). Ophthalmology 112, 2227-2237
EUREYE	Seland, et al. (2011). Acta Ophthalmol;89(7):608-13
Rejkjavik Eye	Gunnlaugsdottir E, et al. (2008). Acta Ophthalmol;86(7):778-85
West Bank Gaza	Thomson, I. M., et al. (1984). Br J Ophthalmol;68:598-602
Ponza ES	Cedrone, C., et al. (2007). Ophthalmic Epidemiology 14(5): 320-326
Rotterdam ES	Klaver, C. C., et al. (1998). Archives of Ophthalmology 116(5): 653-8
Tromso ES	Bertelsen, G., et al. (2013) Acta Ophthalmol:91;635-642
Sergovia ES	Anton, A. et al. (2009) Ophth Epi:16(4);231-237
Cuenca Spain	Esteban, J. J., et al. (2008). Quality of Life Research 17, 37-45
Swedish Children	Kvarnstrom, G., P. et al. (2001). Acta Ophthalmologica Scandinavica 79, 240-4
Leiden 85+ Study	Gussekloo, J., et al. (2005). American Journal of Geriatric Psychiatry 13, 781-6
National 10y olds	Stewart-Brown, S. et al (1985). Journal of Epi & Comm Health 39(2): 107-12
Elderly community	Evans, J. R., A. E. Fletcher, et al. (2004). Ophthalmology 111(3): 513-7
North London	Reidy, A., et al. (1998). BMJ 316(7145): 1643-6.
Working adults UK	Rahi, J. S., et al. (2008). British Journal of Ophthalmology 92, 1190-4
Proyecto VER	Munoz, B., et al. (2002). IOVS;43(3):608-14
Baltimore Eye	Tielsch, J.M.,et al. (1990) Arch Ophthalmol;108(2):286-90
Beaver Dam	Klein, R. et al. (1991) Ophthalmology;98(8):1310-5
Salisbury Eye	Rubin, G.S., et al. (1997) Invest Ophthalmol Vis Sci.;38(3):557-68

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Study	Reference
South Asia	
Bangladesh National	Dineen, B.P., et al. (2003). Br J Ophthalmol. 2003;87(7):820-8
Hyderabad Children	Kalikivayi, V., et al. (1997). Indian Journal of Ophthalmology 45(2): 129-34
Aravind	Thulasiraj, R. D., et al. (2003).Ophthalmology 110(8): 1491-1498
Andhra Pradesh Eye	Dandona, R. et al. (2003). British Journal of Ophthalmology 87(3): 263-5
Sivaganga eye survey	Thulasiraj, R. D., et al. (2002). Ophthalmic Epidemiology 9(5): 299-352
India 15 states	Murthy, G. V., et al. (2005). British Journal of Ophthalmology 89(3): 257-60.
Tirunelveli	Nirmalan, P.K., et al. (2002). British Journal of Ophthalmology 86(5):505-12
Chennai Glaucoma	Vijaya, L., et al. (2006). British Journal of Ophthalmology 90(4): 407-10
Rajnandangaon Glaucoma	Palimkar, A., et al. (2008). Indian Journal of Ophthalmology 56(1): 57-62
Kariapatti Paediatric	Nirmalan, P. K., et al. (2003). Am Journal of Ophthalmology 136(4): 703-709
Karnataka	Chandrashekhar, T.S., et al. (2007). Tropical Doctor 37: 18-21
Maharashtra India	Dhake, P.V.,et al. (2011). Oman J Ophthalmol.;4(3):129-34
Central India Eye	Nangia, V., et al.(2013). Acta Ophthalmol.:91:483-488
Rural Rajasthan	Murthy, G. V. S.,et al. (2001). Ophthalmology 108(4): 679-685
Southern India Hobli	Dorairaj, S.K., et al. (2008). Ophthalmic Epidemiology. 15(3): 176-182
Nepal National Eye	Brilliant, L.B., et al. (1985). Bulletin of the WHO. 63(2): 375-386
Gandaki Children	Sapkota, Y. D., et al. (2006). British Journal of Ophthalmology 90(4): 411-6
Dhulikhel Children	Sherpa, D., et al. (2011). Nepal J Ophthalmology;3(2):172-176
Kavrepalan-Chowk	Marasini, S., et al. (2010). Kathmandu Univ Med J (KUMJ);8(32):362-6
Bhaktapur Glacuoma	Thapa, S.S., et al.(2011) BMC Ophthamol;11:2
Mountain Children Myopia	Adhikari, S. et al. (2013). Nepal J Ophthalmol;5(2):246-249
Mechi children	Pokharel, G.P., et al.(2000). Am Journal of Ophthalmology 129(4):436-444
Pakistan rural	Ahmad, K., et al. (2005). Ophthalmic Epidemiology. 12(1), 19-23
Pakistan National Eye	Dineen, B., et al. (2007). Br J Ophthamol.:91(8);1005-10
Asia (Southest, East) & Oceania	
China National	Zhang, et al. (1992). Chinese medical journal 1992;7:603-608
Shunyi County	Zhao, J., et al. (1998). American Journal of Ophthalmology; 126(4):506-514
Doumen County	Li, S., et al. (1999) Ophthalmology;106:1602–1608
Tibet	Dunzhu, S., et al. (2003). Br J Ophthalmol;87:1443–1449
Bejing Eye	Xu, L., et al. (2006) Am J Ophthalmol: 141;591-593
Nantong	Li, L., et al. (2008). Eye; 22:1069-75
Beijng preschool	Lu, Q., et al. (2009). Am J Ophthalmol. 2009;147(6):1075-81
Handan Eye	Liang, Y.B., et al.(2008). Ophthalmology 115(11):1965-72
Nine Province	Zhao, J., et al. (2010). Ophthalmology 117(3): 409-416
Rural Southern Harbin	Li, Z., et al. (2008) Ophthalmic Epidemiol.; 15:334-8
Sichuan	Wei, M., et al. (2010). Int J Ophthalmol: 3(1);83-89
Xichang Pediatric	Congdon, N., et al. (2008). Invest Ophthalmol Vis Sci.;49:2888–2894
Bin county	Song, W., et al. (2010). Acta Ophthalmol.;88(6):669-84
Nantong	Zhou, J., et al. (2012). Zhonghua Yan Ke Za Zhi.;48(10):908-14
Heilongjiang	Zhang, Y., et al. (2012) Clinical and Experimental Ophthalmology; 40:484-489
Xiu'Shui county	Xiao, B., et al. (2011) Ophthalmic Epidemiology;18(1):30-5
Baoshan	Zhu, M. et al. (2013) BMC Public Health 2013;13:311-324

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Study	Reference
Liwan	Huang, S., et al. (2009). Arch Ophthalmol.;127(10):1362-7
Southern Jiangsu	Yao, Y., et al. (2013). Pak J Med Sci.;29(5):1203-7
Northern China	Li, X., et al. (2012).Ophthalmic Epidemiology. 19(5);272-277
Shuimogou District	Mai Dina, N.B., et al. (2012) Zhonghua Yi Xue Za Zhi.;92(11):743-7
Yunnan Minority Eye	Li, J., et al. (2012) IOVS;53(8):4498-4508
Beijing schoolchildren	Guo, Y., et al. (2014) Eur J Ophthalmol; 24(2):258-265
Hong Kong Elderly	Michon et al. (2002). BJO;86:133-139
Elderly Taiwan	Tsai, C. Y.,et al. (2005). Japanese Journal of Ophthalmology 49(2): 166-172
Eastern Taiwan	Chen, N., et al. Japanese Journal of Ophthalmology. 2012;56:624-630
Taiwan precinct	Liu, J., et al. (2001). Ophthalmic epidemiology;8:339-350
Cambodia	Rutzen, A. R., et al. (2007). Ophthalmic Epidemiology 14(6): 360-6
Rural Indonesia	Saw, S. M., et al. (2003). British Journal of Ophthalmology 87(9): 1075-8
Lao schoolchildren	Casson, R.J., et al. (2012) Ophthalmology;119(10):2021-7
Selangor	Zainal, M., et al. (1998). Medical Journal of Malaysia 53(1): 46-50
Malaysia National Eye	Zainal, M., et al. (2002). British Journal of Ophthalmology 86(9): 951-6
Sepang district	Reddy, S. C., et al. (2004). Medical Journal of Malaysia 59(2): 212-7
The Meiktila Eye Study	Casson, R. J., et al. (2007). Ophthalmology 114(12): 2302-2308
Kandy Eye	Edussuriya, K., et al. (2009). Ophthalmology;116(1):52-6
Bangkok Glaucoma	Bourne, R. R., et al. (2003). British Journal of Ophthalmology 87(9): 1069-74
Elderly Thais	Singalavanija, A., et al. (2001). J Medical Association Thailand 84(10): 1383-8
Rarotonga	Heriot, W. J., et al. (1983). Australian Journal of Ophthalmology 11(2): 81-94
Fiji National	Cama, A.T., et al. (2010). 128(5):608-12
Fiji adults	Ramke, J., et al. (2012) Clin Experimental Ophthalmology;40(5):490-6
Tonga	Newland, H.S., et al. (1994). British Journal of Ophthalmology 78(5): 344-8
Vanuatu	Newland, H. S., et al. (1992). Bulletin of the WHO 70(3): 369-72
Europe (Eastern, Central) & Central Asia	
Mongolia >40y	Baasanhu, J. et al. (1994). Bulletin of the WHO. 72(5), 771-776
Mongolia glaucoma	Foster, P.J., et al. (1996). Arch Opthalmol. 114, 1235-1241
Sofia Bulgaria	Vassileva, P., et al. (1996). Ophthalmic Epidemiology 3, 143-9
North Africa & Middle East	
Cairo School Children	El-Bayoumy, B. M., et al (2007). Eastern Med Health Journal 13(3): 575-9
Tehran	Fotouhi, A.H., et al. (2004) Bristish Journal of Ophthalmology .88(6):740-5
Dezrul schoolchildren	Fotouhi, A., et al. (2007). British Journal of Ophthalmology 91(3): 287-292
Khuzestan	Feghh,i M., et al. Journal of Ophthalmic and vision research; 4(1):29-34
Shahrud	Hashemi, H., et al. (2012). Eye;26:1071-1077
Lorestan	Razavi, H. et al.(2010) Ophthalmic Epidemiol.;17(2):95-102
Jordan children	Mousa, A.M.V., et al. (2014) J Pak Med Assoc;64(1):13-5
National Lebanon	Mansour, A. M., et al. (1997).British Journal of Ophthalmology 81(10): 905-6
Morocco	Annon. (1994). Weekly Epidemiological Record 69(18): 129-161
Oman National Eye Study	Khandekar, R., et al. (2004). Ophthalmic Epidemiology 11(4): 291-9
Eastern Saudi Arabia	Badr, I., et al. (2004). Saudi Journal of Ophthalmology 18: 56
Western Saudi Arabia	al Faran, M. F., et al. (1993). International Ophthalmology 17(3): 161-165
Tunisia	Ayed, S., et al (1998) Cahiers Sante;8:275-282

Study	Reference
SE Turkey 2 provinces	Negrel, A. D., et al. (1996). Ophthalmic Epidemiology 3(3): 127-34
SE Turkey	Caca, I., et al. Journal of Paediatric Ophthalmology and strabismus;50(1):37-43
Sub-saharan Africa	
Congo	Annon. (1990). Weekly Epidemiological Record:65:249-256 (N°33)
Jimma Zone	Zerihun, et al. (2009) Ophthalmic Epidemiology, 4:1; 19-26
Sekhoru district	Demissie, B.S., et al. (2011). Trans R Soc Trop Med Hyg.;105(9):507-11
Rural central children	Mehari, Z., et al. (2013). Clin Exp Optom; 96: 65-74
Gurage Zone	Melese M., et al. (2003) Br J Ophth; 87(6):677-680
Ethiopia Seven Regions	Cerulli, L., et al. (1984). Revue Int Trachome et de Pathologie Oculaire(2-4): 127-
Nairobi Kibera Slums	Ndegwa,L.K., et al. (2006). East Afr Med J.;83(4):69-72
Nakuru	Mathenge, W., et al. (2013) PLoS Med 10(2):e10001397
Kenyan rural	Whitfield, et al. (1990) Br J Ophth.;74(6):333-340
Kenya presbyopia	Sherwin, J. C., et al. (2008). Clinical & Exp Ophthalmology 36(3): 245-51
Southern Malawi	Chirambo,M.C. et al. (1986) Bulletin of the WH);64(4): 567-572
Southern Sudan	Ngondi, J.et al. (2006). PLoS Medicine 3(12)e477: 2416-2424
Central Tanzania	Rapoza, P.A., et al. (1991) International Ophthalmology;15(2):123-9
Rural Tanzania	Burke, A. G., et al. (2006). Ophthalmology 113(5): 723-727
SW Uganda	Mbulaiteye, et al. (2002). Ophthalmic Epidemiology 2002;9(4):251-262
Botswana National	Clausen, T., et al. (2005).Journal of Nutrition, Health and Aging 9(6)455-461
Western Cape, Mamre	Salmon, J.F., et al.(1993). Arch Ophthalmol. 111(9): 1263-1269
Zululand	Rotchford, A.P., et al. (2002). Arch Ophthalmol. 120(4):471-478
Cape Town	Cockburn, N., et al. (2012) PLoS ONE 7(2):e30718
Northen Kwazulu	Cook, C.D.,et al. (1993). South Africa Medical Journal. 83 (8):590-593
Zimbabwe regional	Allain, T.J., et al. (1997). Age and Ageing;26:115-121
North Camaroon	Wilson, M. R., et al. (1996).Ophthalmic Epidemiology 3(1): 23-33
National Cape Verde	Schemann, J.F.,et al. (2006). Ophthalmic Epidemiology. 13(4), 219-226
Volta Ghana	Guzek, J.P., et al. (2005). Ghana Medical Journal. 39 (2) 55-62
Tema Eye	Budenz, D., et al. (2012) Ophthalmology 199 (9):1744-1753
Segou Mali	Kortlang, C., et al. (1996). Trop Medicine and International Health.1(3):314-319
SW Nigeria	Adeoye, A., et al. (1996). Trop Medicine and International Health.1(5):672-676
Anamrba	Ezepue, U.F., et al. (1997). Public Health. 111:305-309
Kano State Nigeria	Abdu, L., et al. (2002). Nigerian Journal of Medicine. 11(3):108-112
Northern Nigeria	Rabiu, M., et al. (2001). British Medical Journal 85(7): 776
Rural SW	Adegbehingbe, B.O., et al.(2007). Aust J Rural Health. 15: 269-272
SW Students	Ajaiyeoba, A.I., et al. (2007). Int Ophthalmol. 27:287-292
Sokoto state, Nigeria	Muhammad, N., et al. (2011) Middle East Afr J Ophthalmol. 18(2):123-8
Yobe Trachoma	Mpyet, C., et al. (2008). Ophthalmic Epidemiology. 15, 303-307
South Nigeria Farming	Ejimadu, C., et al. (2012) Nigerian J Community Medicine;21(2):218-222
SW Nigeria	Abegunde, K., et al. (2012). Annals African Medicine 12(2);90-97
Adeoti 2004	Adeoti, C.O., et al (2004. WAJM. 23 (3). 249-252
Atakunmosa	Onakpoya, O.H., et al. (2007). Tanzania Health Research Bulletin. 9(2):126-131
Nigeria National	Kyari, F., et al. (2009). IOVS;50(5): 2033
Benin	Negrel, A.D.,et al. (1995). Med Trop (Mars) 55(4): 409-414
Gambia National	Faal, H., et al. (1989). British Journal of Ophthalmology.73:82-87

KEY: BCVA Best-corrected visual acuity; H high income; L low income; LM lower middle income; NR not reported; pVA presenting visual acuity; UM upper middle income

B.7 Risk factors associated with vision loss in high-income and upper middle-income country population-based prevalence surveys

Study	Outcome variable	Independent variable	Confounders	NS	Citation
Blue Mountains Australia	≤ 6/12 in better eye	Age, sex	NR	SES. Nil else included in model.	(Attebo et al., 1996)
Melbourne VIP	< 6/18 or field <20°	Age OR 3.19	Retirement status, health insurance, household position	Retirement status, private health insurance, household arrangement	(Livingston, McCarty, et al., 1997)
Baltimore Eye Survey	< 6/18	Age, general health status, educational level, household income, employment status	Race	Use of health services	(Tielsch et al., 1991)
Beaver Dam	≤ 6/12 in better eye	Sex, age	NR	Nil else included in model	(R. Klein, Klein, et al., 1991)
Los Angeles Latino*	≤ 6/12 in better eye	Age 70-79y (OR 2.8), >80y (OR 8.7), history of ocular disease (OR 3.2), unemployed (OR 3.3), diabetes (IOR 2.2), separated/divorced (OR 1.8) or widowed (OR 2.8), ≥12y education (OR 0.5)	NR	NR	(Varma, Ying-Lai, et al., 2004)
Salisbury Eye Evaluation	< 6/12 in better eye	Increasing age, African American race (OR 1.7)	Sex and score on Mini-Mental state exam	NR	(Munoz et al., 2000)
Singapore Malay Eye Survey	logMAR > 0.30 in better eye	Age, sex, reading and writing literacy OR 2.66	Education level, income, marital status, occupation and housing type	NR	(Zheng et al., 2011)
Japan Kumejima	< 6/18	Increasing age, female sex (OR 7.4), lower BMI (OR 0.94)	NR	*"No other factors were significant"*	(Nakamura et al., 2010)

Study	Outcome variable	Independent variable	Confounder	NS	Citation
Korean NHANES	< 6/12	Older age, lower education level, rural area (OR 2.0), unemployed, no spouse (OR 2.1), no health insurance (OR 2.3), eye disease, lack of utilization of eye care	NR	NR	(Rim et al., 2014)
Australia NEHS*	Binoc pVA <6/12	Indigenous status (OR 2.4), age (OR 1.72 per decade), education level, remoteness (OR 2.02), male sex (OR 0.60), diabetic with no prior eye exam (OR 14.5)	Adjustment for all significant variables	Self-reported stroke, self-reported diabetes, speaking English at home	(Foreman, Xie, Keel, van Wijngaarden, Sandhu, et al., 2017)

Key: NS Not significant; OR odds ratio; SES socioeconomic status; pVA presenting visual acuity; Binoc Binocular; NR Not reported
* Published since GBD Review

B.8 Summary of studies estimating a disability weight for blindness

First author, Year	Region	Panel	Panel, n	Health states, n	Valuation methods	DW (95% CI)
Murray 1994	Global	Independent experts	NS	6	Magnitude estimation	0.6
Murray 1990, 1996	Global	Medical experts	10	483	PTO and VAS	0.6 (0.50 – 0.70)
Stouthard 1997	Netherland	Medical experts	38	175	PTO and VAS	0.43 (0.34 -0.52)
Baltussen 2002	Burkina Fasso	Health professionals, Population	39 lay, 17 health worker	9	Culturally adapted VAS	0.36
Lai 2009	Estonia	Medical experts	25	283	PTO and VAS	0.478
Salomon 2015	Global	Population-based samples	30,230	220	PC and PHE	0.195 (0.132-0.272)
Haagsma 2015	Sweden, Italy, Netherlands, Hungary	Population (quota sampling of internet panels, 18-65 years)	30,660	255	PC and PHE	0.173 (0.145 -0.213)
Salomon 2013	Global	Population (combined data)	60,890	183 or 235	PC	0.187 (0.124 - 0.260)

KEY: GBD Global Burden of Disease, PC = Paired comparison, NS= Not specified, PTO=person trade off, VAS=visual analog scale, PHE = Population Health Equivalence

B.9 Previous eye surveys including HRQoL as an outcome variable

Survey Sample, n, Authors & Year	Instrument and valuation set	Analysis, Outcome variable (y)	Adjustment factors	Association between vision category and utility
Singapore Eye n =10,009 Wang et al. 2014	EQ-5D-3L, UK valuation set	Multivariate linear regression with RSE estimator y = utility	Stratification by ethnicity. Obesity, hypertension, diabetes, hyperlipidaemia and socio-demographic characteristics	Indians with SVI (<6/60): -0.127 (95% CI -0.237 to -0.017) Malays with SVI (<6/60): -0.085 (95% CI 0.148 to -0.022)
Korean NHANES n = 28,825 Park et al. 2015	EQ-5D-5L, Korean valuation set	Ordinal logistic regression y = severe vision impairment	Sample design weights, age, sex, marital status, smoking status, alcohol intake, stress level, depressive symptoms, education level, household income, co-morbidity	Not directly reported. Those in lowest quintile of utility had greater odds of SVI: OR 3.39 (95% CI 1.5 to 7.8, p<0.004)
Blue Mountains n = 1436 Swamy et al. 2009	SF-36	Correlation coefficients	Age, sex, number of hospital admissions, co-morbidity and disability	Utility not determined. Correlation between subscales and NEI-VFQ subscales explored
Shipai, Taiwan n = 1361 Tsai et al. 2004	SF-36	Multiple linear regression of subscale scores	Sociodemographic characteristics, co-morbidities	Utility not determined. VI associated with significant reduction in physical functioning subscale (b = -3.26, p<0.001) and social functioning scale (b = -3.25, p=0.015)
Los Angeles Latino n = 5377 Varma et al. 2004	SF-12	Subscale scores	No analysis with adjustment for significant covariate	Utility not determined. No association found between vision impairment and SF-12 composite or subscale scores
Cuenca, Spain n = 1155 Esteban et al. 2008	SF-12	Composite score	No analysis with adjustment for significant covariates	Utility not determined. No association found between vision impairment and SF-12 composite score, but VI category was associated with significant differences in mean physical subscale score

B.10 Population-based studies reporting normative values for the EQ-5D-5L

Country (First author, year)	n	RR %	Mean utility	Mean VAS	Full health %	Risk factors for worse health status
South Australia (McCaffrey et al. 2016)	2908	63.4	0.91	78.6	42.8	VAS: older age, female, fewer years of education, lower annual household income, not in employment, not married
Spain (Garcia-Gordillo et al. 2016)	21007	NR	0.90	75.7	62.4	Older age, female, regional variation
Japan (Shiroiwa et al. 2016)	1143	NR	NR	NR	55.0	Older age, lower income, fewer years of education
Germany (Hinz et al. 2014)	2469	59.0	0.91	91.5	47.5	Female, older age
UK (Feng et al. 2015)	996	64.0	NR	NR	47.6	Older age, female, lower education level

KEY: NR Not reported

B.11 The monetary value of a disability-adjusted life year (DALY) or a quality adjusted life year (QALY) in a selection of previous cost of vision loss studies

Country	Year	Unit	Value of one statistical life year	Discount applied	US$ 2014*	Citation
UK	2013	DALY	£88,825	1.5%	63,237	(Pezzullo et al., 2018)
Australia	2004	DALY	A$162,561	3.3%	327,850	(Taylor et al., 2006)
USA	2004	QALY	US$50,000	None	61,795	(Frick et al., 2007)
USA	2012	QALY	US$50,000	None	50.805	(Wittenborn et al., 2013)
Canada	2007	DALY	C$151,347	None	210,667	(Cruess et al., 2011)
Japan	2007	DALY	US$234,552	3.0%	223,911	(Roberts et al., 2010)

*Adjustment using the World Bank Gross Domestic Product deflator, which takes into account fluctuating exchange rates, different purchasing power of different currencies and inflation rates, and then converted into US$ using The World Bank Official Exchange Rate (LCU per US$ period average) (World Bank, 2018a, 2018b)

B.12 Examples of sampling designs in a selection of previous surveys

Study ID First author Year	Sampling Frame	Levels	Strata	First sampling unit	Second sampling unit	Third sampling unit
RAAB protocol Limburg 2007	Latest census	Multi-stage	None	SRS of clusters	SRS of compact segment of households	Quota of 50 people
RACSS protocol Limburg 2001	Latest census	Multi-stage	None	SysRS of clusters with PPS	Spin the bottle from cluster centre then walk in line	Quota of 50 people
RESC protocol Resnikoff 2007	School class listing	Multi-stage	Optional, by age, or SES	SRS of clusters (classes)	Individual children	-
Barbados national Leske 1994	National registration number (name, DOB, sex, birthplace)	Single	None	SRS of individuals	-	-
Andhra Pradesh Dandona 1997	List of population units	Multi-stage	Urban-rural, then by SES (and religion in urban strata)	SRS of clusters	SysRS of households	All eligible people in each
Nigeria National Dineen 2008	Latest census	Multi-stage	Urban/ rural	SysRS of clusters with PPS	Spin the bottle from cluster centre then walk in line	Quota of 50 people
Bangladesh National Dineen 2002	Latest census	Multi-stage	Urban/ rural	SysRS of clusters with PPS	Spin the bottle from cluster centre then walk in line	Quota of 100 (rural) or 50 (urban) people
Aravind Thulasiraj 2003	Village listing from latest Census	Multi-stage	2 districts	SRS of 14 blocks then SysRS with PPS of 25 villages	Villages divided into segments of approx. 100 eligible people, one selected at random	All eligible people in segment
Pakistan National Bourne 2005	Latest census	Multi-stage	Urban/ rural	SysRS of clusters, with PPS	Spin the bottle from cluster centre then walk clockwise	Quota of 100 rural or 50 urban people, plus children

Study ID First author Year	Sampling Frame	Levels	Strata	First sampling unit	Second sampling unit	Third sampling unit
Singapore-Malay Foong 2007	National registration data (name, address, ID number, DOB)	Single	Age by decade	SRS of individuals (computer generated)	-	-
Tajimi Eye Iwase 2004	Register of city residents	Single	None	SRS of individuals	-	-
Baltimore Tielsch 1990	Latest census	Multi-stage	Race	SysRS of clusters with PPS	All eligible people in all residential units in cluster	-
Beaver Dam Klein 1991	Private census of individuals	Single	None	All eligible individuals in census area	-	-
Salisbury Rubin 1997	Medicare eligibility list	Single	Race, age	SRS individuals	-	-
Blue Mountains Attebo 1996	Private census of 2 postcode areas	Single	None	All eligible individuals in census area	-	-

KEY: DOB date of birth; ID identification; SES socioeconomic status; SRS simple random sample; SysRS systematic random sample; PPS probability-proportionate-to-size

B.13 Cataract grading systems used in previous eye surveys

Grading system and citation	Definition	Equipment needed	Survey ID
LOCS II (Chylack et al., 1989)	Nuclear opalescence and colour (4 levels), cortical (5 levels), subcapsular (4 levels)	Slit lamp, standard photograph image set, dilating drops	Barbados Eye, Los Angeles Latino, Andhra Pradesh
LOCS III (Chylack et al., 1993)	Nuclear opalescence and colour (6 levels), cortical (5 levels), subcapsular (5 levels)	Slit lamp, standard photograph image set, dilating drops	Aravind, Tanjong Pagar, Shihpai, Kandy Eye, Handan
Mehra-Minassian (Mehra & Minassian, 1988)	Area of lens opacity obscuring red reflex relative to area of clear red reflex, as visualized through undilated pupil (level 0, 1, 2a, 2b, 3, 4 and 5)	Direct ophthalmoscope, standard image set	Bangladesh
WHO simplified grading system (Thylefors et al., 2002)	Nuclear (3 levels), cortical (3 levels), subcapsular (3 levels)	Slit lamp, standard image set	Nakuru
Wisconsin Cataract Grading System (B. E. Klein et al., 1990)	Photographic grading scheme: nuclear sclerosis (5 levels), cortical area (out of 9 segments), posterior subcapsular (involvement of central circle)	Slit lamp with camera, standard image set	Beaver Dam, Blue Mountains
Wilmer (Taylor & West, 1989)	Cortical (involved segments), subcapsular	Slit lamp, standard image set	Salisbury Andhra Pradesh
AREDS (AREDS Research Group, 2001)	Nuclear opacity (7 levels), cortical area, subcapsular area	Specially modified camera, standard image set	Beijing
Oxford Clinical Cataract Classification System (Sparrow et al., 1986)	Grading of individual features	Slit lamp, standard image set	Melton Oxford

B.14 Age-related macular degeneration grading systems used in previous eye surveys

Classification system	Equipment required	Study ID
International classification and grading system (Bird et al., 1995)	Fundus camera	Rotterdam, Korean NHANES, Andhra Pradesh, Melbourne VIP
Clinical age-related maculopathy staging system, CARMS (Seddon et al., 2006)	Fundus camera	None identified
Age-related Eye Disease Study severity scale for age-related macular degeneration (Davis et al., 2005)	Fundus camera	Nakuru Kenya
Wisconsin age-related maculopathy grading system (R. Klein, Davis, et al., 1991)	Stereoscopic fundus camera	Beaver Dam, Blue Mountains, Singapore Eye, NHANES, Los Angeles Latino, EUREYE, Handan, Beijing, Reykjavik, Shihpai, Copenhagen, Salisbury Eye
Beckman Clinical Classification System (Ferris et al., 2013)	Fundus camera	Australia NEHS

B.15 Diabetic retinopathy grading systems used in previous eye surveys

Classification system	Equipment	Study ID
ETDRS (ETDRS, 1991)	Stereoscopic fundus camera	Nakuru, Kenya
Modified ETDRS	Stereoscopic fundus camera	Blue Mountains
Modified Airlie House (Diabetic Retinopathy Study 1981)	Stereoscopic fundus camera (7 fields)	Singapore Eye, Melbourne VIP, Los Angeles Latino, Korean NHANES, Beaver Dam
International Classification of Diabetic Retinopathy (Wilkinson	Stereoscopic 7-field photography using 30 degree field	

Appendix C: Materials and methods

C.1. Survey forms and questionnaires

C.1.1 Building listing form

NESTT HOUSEHOLD LISTING FORM
Page ____ of ____

Cluster number	Reg ID	Community code	ED number	Segment

SERIAL NUMBER OF STRUCTURE (on MAP) (1)	ADDRESS/ DESCRIPTION OF STRUCTURE (2)	RESIDENCE Y/N (3)	SERIAL NUMBER OF HOUSEHOLD IN STRUCTURE (4)	NAME OF HEAD OF HOUSEHOLD (5)	OBSERVATIONS (6)

C.1.2 Household enumeration form

NESTT Household Summary Form

Cluster number	Reg ID	Community code	ED number	Building number (on map)	Household number in building	Household FORM number	Enum ID
						of (total houses in cluster)	

Address of household and contact details for main respondent

TOTAL number of household members	

No. / Street name																					
Community																					
Region																					
NAME of RESPONDENT																					
Email																					
Landline and cell											C										

VISITS

Result code: 1 COMPLETED 2 PARTIALLY COMPLETED 3 NOT AT HOME 4 REFUSED 5 OTHER: Specify in notes

Visit	Date (DD)	Month (MM)	Year (YY)	Arrival time 00:00	Result Code	Visit NOTES
Weekday daytime						
Weekday evening						
Weekend						

ALL Household Members

If more than 6 household members, fill in a second page

Household members are persons who sleep here most nights of the week and share at least one daily meal

ELIGIBLE for NESTT if 1) AGE 5 years or above at last birthday AND 2) resident in T&T for the past 6 months or more AND 3) usual resident of this household . If not eligible note which of the above is not fulfilled, out of 1, 2 and 3.

If person is eligible but does NOT agree to attend community screening, reason code: 1) too unwell/immobile to leave home 2) transport difficulty 3) not available on date of community vision screening but available on other dates 4) not interested

Forename	Surname	Age	Sex (M or F)	Eligible? (Y or N)	If NO, which criteria not fulfilled? (1,2,3)	Eligible person number in household	Agrees to attend vision screening? (Y or N)	If No, reason code

Interviewer's Name: _____ Signature: _____ Date: _____

Field supervisor's name: _____ Signature: _____ Date: _____

NESTT Household Summary Form

Cluster number	Reg ID	Community code	ED number	Building number (on map)	Household number in building	Household FORM number	Enum ID
						of (total houses in cluster)	

Household members (continue if more than 6…)

Forename	Surname	Age	Sex (M or F)	Eligible? (Y or N)	If NO, which criteria not fulfilled? (1,2,3)	Eligible person number in household	Agrees to attend vision screening? (Y or N)	If No, reason code

Characteristics of household's building/dwelling

What are the main materials of the outer walls		01 Wood 02 Wood and brick 03 Wood and concrete 04 Wood and galvanize	05 Concrete 06 Concrete and brick 07 Stone 08 Stone and brick	09 Wattle/Adobe/Tapia 10 Other, specify:
What is the main material used for roofing?		01 Sheet metal 02 Shingle (Asphalt) 03 Shingle (wood) 04 Concrete	05 Tile 06 Thatch/Makeshift 07 Other, specify:	
How would you describe the type of dwelling unit that your household occupies?		01 Separate House 02 Flat/apartment/condo 03 Townhouse 04 Double house/duplex	05 Part of Commercial/Indust building 06 Barracks 07 Out-room 08 Other dwelling	09 WAFDA 10 Other: Specify
What type of tenure/ownership does the dwelling have?		01 Owned fully 02 Owned with mortgage/loan 03 Rent to own 04 Rented private	05 Rent free 06 Rented government 07 Leased private 08 Leased government	09 Squatted 10 Other: specify
What type of fuel does this household use most for cooking?		01 None 02 Electricity 03 LPG/cooking gas	04 Kerosene 05 Wood/charcoal 06 Solar energy	07 Other: specify

Does the household have any of the following (Y = Yes or N = No)

	Y or N		Y or N		Y or N		Y or N
Air Conditioner?		**Radio/Stereo?**		**Refrigerator/Freezer?**		**Computer?**	
Cable TV/Satellite?		**Washing machine?**		**Leisure boat/Yacht?**		**Internet access?**	
Television?		**Clothes dryer?**		**Swimming pool?**			
DVD/MP3?		**Microwave?**		**A vehicle for private use?**			

C.1.3 Adult Consent Form

Survey ID | | | | | |

THE UNIVERSITY OF THE WEST INDIES

ST AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
FACULTY OF MEDICAL SCIENCES
OFFICE OF THE DEAN
Telephone: (868) 645-3232 Ext. 5025 Fax: (868) 663-9836 e-mail: deanfms@sta.uwi.edu
Dean: Professor Samuel S. Ramsewak MB BS (UWI) DGO FRCOG FACOG MD CMT

THE ETHICS COMMITTEE
CONSENT TO PARTICIPATE IN RESEARCH

TITLE OF RESEARCH: THE NATIONAL EYE SURVEY OF TRINIDAD AND TOBAGO (NESTT): PARTICIPANTS OF THE NATIONAL SURVEY

CHIEF INVESTIGATOR: Professor Samuel Ramsewak (The University of the West Indies, Trinidad & Tobago)
CO-INVESTIGATORS: Professor Rupert Bourne (Anglia Ruskin University, Cambridge, UK)
STUDY COORDINATORS: Prof. Samuel Ramsewak (The University of the West Indies)
On behalf of the NESTT Steering Committee.
RESEARCH SITE (S): Trinidad and Tobago
SPONSORS: Ministry of Health, Government of Trinidad & Tobago

Why is this research being done?
This is a national study that aims to understand the pattern of eye disease in Trinidad and Tobago. There has not been a study like this for almost 80 years and there are no recent studies of eye disease like this in the Caribbean. There is an urgent need to better understand how many people are affected by eye disease in Trinidad and Tobago and how many people have eye disease that has not been detected. Many causes of eye disease can be prevented or cured and this study will help planners of eye care in the country direct resources to those who need it. Additionally, people with eye disease who are detected in this study will be given advice and directed to eye care.

How long is the study? There are two stages to participation. Stage one, the vision screening, will take approximately 10 minutes. Following this you will be advised whether or not you are eligible for further, more detailed assessment of your eyes and vision in the regional research clinic. If you are invited to this, your appointment with the study team will take a maximum of 3 hours.

What will happen to me? During the vision screening you will be asked some questions and then your distance and reading vision will be assessed. If you are invited to the clinic (based on specific eligibility criteria), you will be asked more questions about your eyes and general health and you will receive a thorough check of your eyes including special photographs and measurements. Our eye doctors/nurses will ask to put some eye drops in your eyes. These eye drops are not uncomfortable and they allow us to make measurements of your eyes to help us understand if you have an eye problem. One of the eye drops will make your pupils big with the result that your near eyesight will be blurred for at least 30 minutes. By the time your visit finishes, your near vision will probably have returned to normal, but we recommend that you should not drive a car until your vision is normal again (please allow 4 hours).

What should I do if I have a problem on the day of the examination? Please inform a member of the

Survey ID | | | | | |

research team, who will help you. If a problem develops after you have left the research clinic, please call this **emergency** number to speak to a member of the team: 3483520.

Are there any risks if I take part in the study? There are no significant risks. Your records will be kept confidential.
Will I get paid? No.
What are my rights? All your normal rights are protected.
What are my responsibilities if I take part? We would like you to answer the questions as accurately as you can.
Will my records be kept confidential? Yes. These records will be kept confidential under guidelines of University of the West Indies.
How does my participation in the study benefit the University of the West Indies and/or the study team? There is no financial gain for either.

CONSENT

I have read and understood this explanation. A trained member of the NESTT research team has also explained the study to me. I have had a chance to ask questions and have them answered to my satisfaction. I agree to take part in this study. I have not been forced or made to feel like I had to take part.

I have read the attached Experimental Subject's Rights, which contains some important information about research studies. I have also read the Authorisation to use my Private Health Information. **I must sign this Consent Form**, the **Experimental Subject's Rights** and the **Authorization to use my Private Health Information**. **I will be given a signed copy of each to keep.**

Printed Name of Subject	Signature/ thumbprint* of Subject	Date

Signature of person conducting informed consent discussion	Role in research	Date

Signature of Second Witness, if applicable*	Date

* If participant is illiterate, or if the participant is unable to read the form on account of visual impairment or blindness, a literate witness with reading vision must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate or significantly visually impaired should include their thumb-print as well. Witness statement: I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Survey ID | | | | | |

EXPERIMENTAL SUBJECT'S RIGHTS

If I am asked to consent to participate as a subject in a research study involving a medical experiment, or if I am asked to consent for someone else, I have the right to:

1. *Learn the nature and purpose of the experiment (also called "study" or "clinical trial").*
2. *Receive an explanation of the procedures to be followed in the study, and any drug or device used.*
3. *Receive a description of any discomforts and risks that I could experience from the study*
4. *Receive an explanation of any benefits I might expect from the study*
5. *Learn about the risks and benefits of any other available procedures, drugs or devices that might be helpful to me*
6. *Learn what medical treatment will be made available to me if I should be injured as a result of this study*
7. *Ask any questions about the study or the procedures involved*
8. *Quit the study at any time, and my decision will not be used as an excuse to withhold necessary medical treatment.*
9. *Receive a copy of the signed and dated consent form*
10. *Decide to consent or not to consent to a study without feeling forced or obligated*

If I have questions about a research study, I can call the contact person listed on the consent form. If I have concerns about the research staff, or need more information about my rights as a subject, I can contact the secretary of the University of the West Indies Research Ethics Committee, Mrs Evelyn Fereira, at 452640 ext 5021.

By signing this document, I agree that I have read and received a copy of this document.

_____ _____

Signature of Subject Date

Survey ID | | | | | |

REQUEST FOR PERMISSION TO USE AN INDIVIDUAL'S PRIVATE HEALTH INFORMATION

Name of Study: The National Eye Survey of Trinidad and Tobago

Investigators: Professor Samuel Ramsewak and Professor Rupert Bourne

What is private health information?
Private health information is any information that can be traced back to you. We need your permission to collect and use your private health information in this research study.
The type of private health information that we will use and share for this study includes:

- Your past and present physical and mental health information;
- Information that can be used to contact you;
- Results of your medical tests;
- Questionnaires on your quality of life and costs of eye care (if applicable);
- Information on risk factors (including drug/alcohol usage) and family medical history.

Who else will see my information?
Designated members of the research team will see your information at the time of data collection, however this information will then be pseudo-anonymised which means that the data relating to you will be given a code which removes any personal identifying information. Identifying personal data (name, address, etc.) will be kept in a locked cabinet with restricted access (held at University West Indies).

How long will the investigators use and share my information?
The information will be stored for a period of at least 15 years, and over this time the data will be available to the research team for their studies.

What if I change my mind about sharing my research information? At any time you have the right to request that your research information be withdrawn from the research archive.

Do I have the right to see and copy my research information? Yes.

If you agree to share your information, you should sign this form below. You will receive a copy of this form.

I agree to share my information as described in this form

_____	_____	_____
Print your name	Sign your name	Date

If you have questions or concerns about your privacy and the use of your personal medical information, please contact the investigator at the telephone number listed in the consent form.

C.1.4 Individual Enumeration Form

To be completed in clinic: CONSENTS? (Y or N) | SITE | SURVEY ID (allocated in clinic)

NESTT Eligible Person Enumeration Form

Cluster number	ED number	Building number	Household number in building	Eligible person number in household	AGE	ED enumerated person >40y number	Enum ID
						of 35	

NAME	
Ethnicity	
Place of Birth	
Landline and cell	C

Duration resident in T&T (years)	DOB (MM/ DD / YY)	Sex (M or F)	Health insurance (Y or N)

Relationship to Head of household	H	Head	CHS/P	Child of Head + Spouse/Partner	S/PC Spouse/Partner of child
	SH	Spouse of Head	CHO	Child Head only	G Grandchild of Head/Spouse/Partner
	PH	Partner of Head	CS/PO	Child of Spouse/Partner only	PH/S/P Parent of Head/Spouse/Partner
	OR	Other relative	DE	Domestic employee	
What did you do most during past 12 months?	HJW	Had a job and worked	HD	Home duties	
	HJNW	Had a job did not work	R	Retired	
	U	Unemployed	D	Disabled	
	S	School/student	NS	Not stated	

Do you have any of the following?	Y or N
Long standing disability?	
Glasses to see in the distance	
Glasses for reading/near	
Contact lenses	
High blood pressure	
Diabetes	
Laser for diabetic eye disease	
Glaucoma	
Cataract (untreated)	
Previous cataract surgery	
Other diagnosed eye disease	
Poor vision, reason unknown	

If you have a disability, does it prevent you from doing any of the following?	Y (Yes) or N (No)	If Y, How much difficulty does it cause you? 1 = some difficulty 2 = a lot of difficulty 3 = can not do at all
Seeing even if wearing glasses?		
Hearing even if using a hearing aid?		
Being mobile-walking and climbing steps		
Remembering, concentrating		
Gripping (strength in hands)		
Speaking and understanding?		

Date today (mm/dd/yy)

Informed:date of community vision screening (mm/dd/yy)

E. HISTORY, IF NOT EXAMINED
(From relative or neighbour)

Believed	Right eye	Left eye
not blind	O (1)	O (1)
blind due to cataract	O (2)	O (2)
blind due to other causes	O (3)	O (3)
operated for cataract	O (4)	O (4)

F. WHY CATARACT OPERATION WAS NOT DONE
(Mark up to 2 responses, if VA<6/18, not improving pinhole, with visually impairing lens opacity in one or both eyes)

Unaware that treatment is possible	O (1)
Believes it to be destiny / God's Will	O (2)
Told to wait for cataract to mature	O (3)
Surgical services not available or very far	O (4)
Don't know how to get surgery	O (5)
Cannot afford operation	O (6)
No one to accompany	O (7)
No time available / other priorities	O (8)
Old age and need not felt	O (9)
One eye adequate vision / need not felt	O (10)
Fear of operation	O (11)
Fear of loosing eye sight	O (12)
Other disease contra-indicating operation	O (13)

G. DETAILS ABOUT CATARACT OPERATION

	Right eye	Left eye
Age at operation (years)		
Place of operation		
Government hospital	O (1)	O (1)
Voluntary / charitable hospital	O (2)	O (2)
Private hospital	O (3)	O (3)
Eye camp / improvised setting	O (4)	O (4)
Traditional setting	O (5)	O (5)
Type of surgery		
Non IOL	O (1)	O (1)
IOL implant	O (2)	O (2)
Couching	O (3)	O (3)
Cost of surgery		
Totally free	O (1)	O (1)
Partially free	O (2)	O (2)
Fully paid	O (3)	O (3)
Cause of VA<6/18 after cataract surgery		
Ocular comorbidity (Selection)	O (1)	O (1)
Operative complications (Surgery)	O (2)	O (2)
Refractive error (Spectacles)	O (3)	O (3)
Longterm complications (Sequelae)	O (4)	O (4)
Does not apply - can see 6/18	O (5)	O (5)
Are you satisfied with results of cataract surgery?		
Very satisfied	O (1)	O (1)
Partially satisfied	O (2)	O (2)
Indifferent	O (3)	O (3)
Partially dissatisfied	O (4)	O (4)
Very dissatisfied	O (5)	O (5)

SITE ID ☐ SURVEY ID (allocated in clinic) ☐☐☐☐☐

NESTT Community Vision Screening

Cluster number	ED number	Building number	Household number in building	Eligible person number in household	AGE	ED Enumerated person >40y number	NESTT Screener ID
☐☐☐	☐☐☐☐☐	☐☐☐	☐☐☐	☐☐	☐☐	☐☐ of 35	☐☐

PRESENTING distance VISUAL ACUITY (DVA) at 3m
With usual distance specs or contacts if worn, else unaided

RIGHT 3m: Number of letters ☐☐☐ **Specs or CL?** ☐ **Y or N**

LEFT 3m: Number of letters ☐☐☐ **Specs or CL?** ☐ **Y or N**

Presenting BINOCULAR near VISUAL ACUITY at 40cm
With usual reading specs if worn, else in presenting state

Binocular near VA at 40cm: number of letters ☐☐☐ **Specs? Y or N** ☐
If unable enter 'U'

Date today (mm/dd/yy) ☐☐☐☐☐☐

ONLY COMPLETE NEXT BOX IF UNABLE TO SEE AT 3m

Test distance (cm)150 or 075 ☐☐☐
RIGHT chart number of letters (Chart or CF, HM, PL, NPL) ☐☐☐

Test distance (cm)150 or 075 ☐☐☐
LEFT chart number of letters (Chart or CF, HM, PL, NPL) ☐☐☐

ELIGIBILITY CODE?
1) ALL aged ≥40y
Age 5 - 39y with:
2) Distance VA ≤45 or near VA ≤ 50 letters
3) diabetes or glaucoma
4) NOT ELIGIBLE ☐

NESTT COMMUNITY SCREENING OUTCOME

AGREES TO ATTEND? (Y/N) _____
If NO, why? _____
CLINIC DATE: _____
CLINIC TIME: _____
ABLE TO GET THERE? (Y/N) _____

Remainder of form to be completed ONLY in those aged ≥50 years
Use E letters & ophthalmoscope, examine undilated, and check info over page complete

NESTT Screener ID ☐☐

B. VISION - presenting vision

Using distance glasses: No: O (1) Yes: O (2)

	Right eye	Left eye
Can see 6/18	O (1)	O (1)
Cannot see 6/18 but can see 6/60	O (2)	O (2)
Cannot see 6/60 but can see 3/60	O (3)	O (3)
Cannot see 3/60 but can see 1/60	O (4)	O (4)
Light perception (PL+)	O (5)	O (5)
No light perception (PL-)	O (6)	O (6)

VISION - with pinhole

	Right eye	Left eye
Can see 6/18	O (1)	O (1)
Cannot see 6/18 but can see 6/60	O (2)	O (2)
Cannot see 6/60 but can see 3/60	O (3)	O (3)
Cannot see 3/60 but can see 1/60	O (4)	O (4)
Light perception (PL+)	O (5)	O (5)
No light perception (PL-)	O (6)	O (6)

C. LENS EXAMINATION

	Right eye	Left eye
Normal lens / minimal lens opacity:	O (1)	O (1)
Obvious lens opacity:	O (2)	O (2)
Lens absent (aphakia):	O (3)	O (3)
Pseudophakia without PCO:	O (4)	O (4)
Pseudophakia with PCO:	O (5)	O (5)
No view of lens:	O (6)	O (6)

D. MAIN CAUSE OF PRESENTING VA<6/18

(Mark only one cause for each eye)

	Right eye	Left eye	Principal cause in person
Refractive error:	O (1)	O (1)	O (1)
Cataract, untreated	O (2)	O (2)	O (2) (F)
Aphakia, uncorrected:	O (3)	O (3)	O (3)
Surgical complications:	O (4)	O (4)	O (4)
Trachoma:	O (5)	O (5)	O (5)
Phthisis:	O (6)	O (6)	O (6)
Other corneal scar:	O (7)	O (7)	O (7)
Globe abnormality:	O (8)	O (8)	O (8)
Dilate pupil:			
Glaucoma:	O (9)	O (9)	O (9)
Diabetic retinopathy:	O (10)	O (10)	O (10)
ARMD:	O (11)	O (11)	O (11)
Onchocerciasis:	O (12)	O (12)	O (12)
Other post. segment / CNS:	O (13)	O (13)	O (13)
Not examined (can see 6/18)	O (14)	O (14)	O (14)

Regional NESTT clinic: complete dilated ophthalmoscopy main cause of presenting <6/18

Dilated ophthalmoscopy performed (Y or N)		Agreement with undilated main cause of presenting VA <6/18? Comments?		NESTT Screener ID
				☐☐

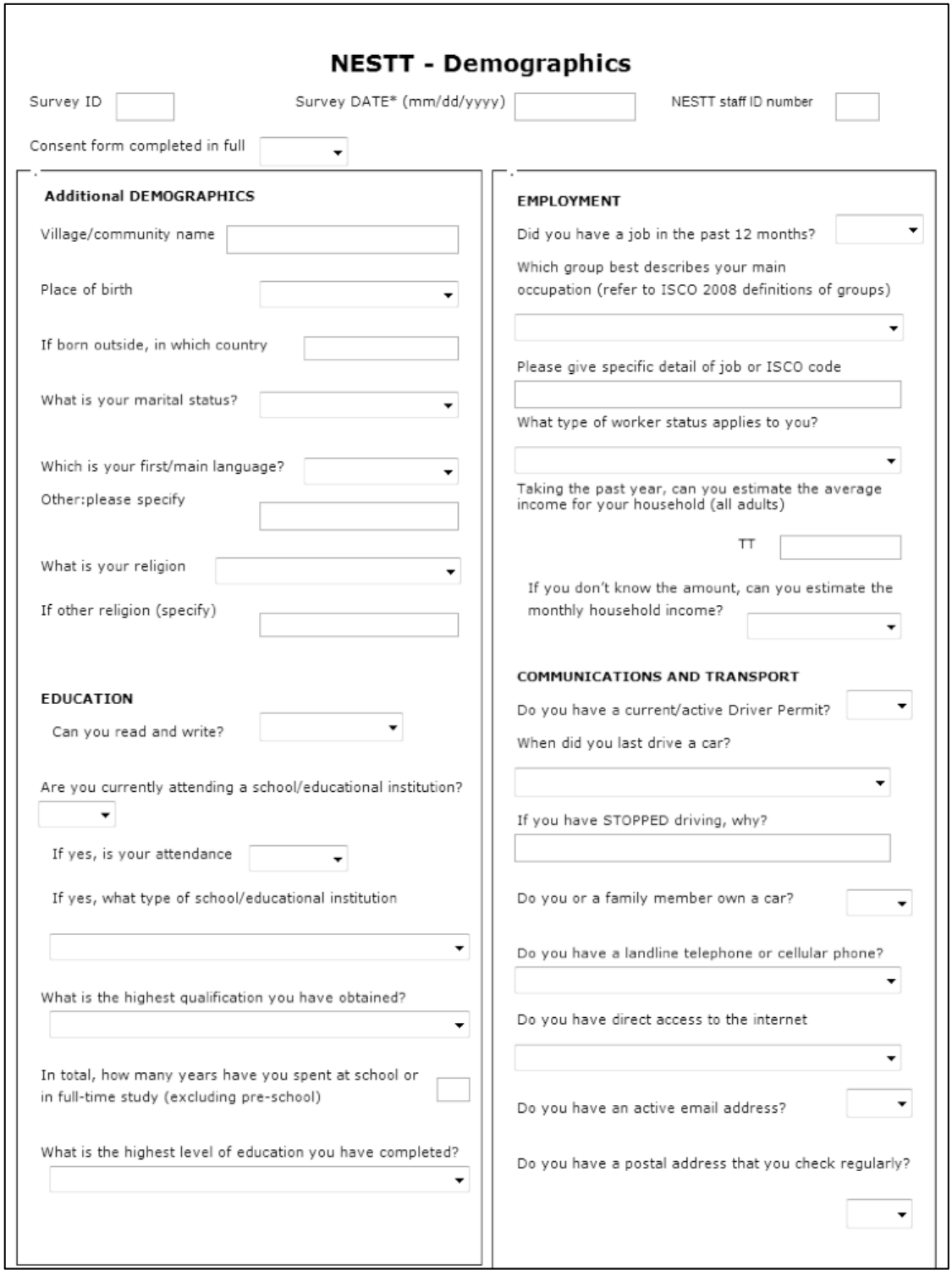
C.1.5 Examination variables, with brief outline of equipment and protocol

Examination variable	Equipment	Measurement protocol
Vision screening		
Distance visual acuity	3 Meter 2000 Series Revised ETDRS Chart, or PV Numbers acuity vision test, Precision Vision, La Salle, USA	If literate: ETDRS Fast Protocol: Beginning with the top row the screener invited the participant to identify only one letter per line by briefly pointing. To guarantee the same degree of difficulty for each row, only Sloan letters of intermediate difficulty coefficient were chosen (D, K, V, R, H). At the first letter read incorrectly the subject was required to read the whole preceding row. This step was repeated upward if the subject made two or more errors. The participant then read all rows downward, letter by letter, until the screener determined that no further meaningful readings could be made despite urging the subject to read or guess. If not literate: Standard ETDRS Protocol: participants asked to identify all PV numbers from the top, using a matching card if needed, with the same stopping rules as the ETDRS-Fast protocol
Near visual acuity	Sloan two-sided ETDRS Format Near Point Test or PV Numbers Near Vision Card, both with 40cm measuring cord, Precision Vision, La Salle, USA; Reading lamp	Standard ETDRS Protocol: participants asked to read all letters from the top, with the same stopping rules as the ETDRS-Fast protocol
Medical exam		
Weight	Analogue weighing scale	Nurse measured to nearest kilogram with shoes removed
Height	Wall-mounted tape measure with horizontal measuring level	Nurse measured after removal of shoes to nearest centimeter with participant standing against wall, and stretching their back with their head level and feet together
Waist circumference	Non-stretch fibreglass tape measure	Nurse measured at the smallest circumference between the ribs and iliac crest, to the nearest 1 cm, while standing with the abdomen relaxed at the end of a normal expiration. Where there was no natural waistline, measurement was taken at the level of the umbilicus
Blood pressure and pulse rate	HEM 907XL IntelliSense Professional Digital Blood Pressure Monitor, Omron Corporation, Kyoto, Japan	Nurse measured blood pressure and pulse rate with participant seated after 5 minutes of rest, using an appropriate cuff size for the left arm circumference
Capillary blood glucose	Accu Check, Roche, Basel, Switzerland	Nurse swabbed finger with alcohol wipe and used safety lancet used to obtain drop of blood. Glucose level recorded (mg/dL). Fasting defined as having had no food and no drink except water for 8 hours. If not fasted, recorded as random level.

Optometry exam		
Auto refraction, keratometry and corneal topography	KR8000-PA, Topcon, Tokyo, Japan	Auto refraction sphere, cylinder and axis, and corneal radius of curvature in the horizontal and vertical meridian. One measurement taken of each eye, and repeated if measurement error
Spectacle prescription	Model 11360 Manual Lens meter, American Optical, Southbridge, USA	Manual focimetry
Habitual reading distance	Tape measure	Participant asked to hold the near chart at their usual preferred reading distance and this 'habitual distance' was measured from the corneal surface to the chart with a tape measure
Optimal near add	Trial Lens Frame, Viewlight, Miami, USA; Trial Lens Set 266BL, Viewlight, Miami, USA	Trial frame fitted to the participant's face with the distance prescription mounted (that required to achieve at least 6/9 with auto-refraction correction, or the lens achieving best correction). Bracketing used to identify the plus diopter sphere (+DS) lens prescription, ranging from 0.25 DS and 3.00 DS, required to achieve best near visual acuity in each eye, with the other occluded.
Contrast sensitivity (CS)	Mars Letter Contrast Sensitivity Test, Precision Vision, La Salle, USA	Binocular presenting CS at 50 cm measured using the MARS chart, with participants in their habitual near optical state
Ophthalmic exam		
Face, adnexa, ocular movements		Face, adnexa, globe, ocular alignment and ocular movements documented normal or abnormal with description if abnormal
Pupils	Pen torch	Appearance of the pupils, direct, indirect and relative pupil reactions documented as normal or abnormal with description if abnormal
Anterior segment	Slit lamp model BQ-900, Haag-Streit, Bern, Switzerland	Any abnormalities of the anterior segment documented. Van Herick anterior chamber depth graded: 4 (≥100%), 3 (>25-50%), 2 (25%) or 1 (<25%)
Posterior segment (after dilation)	90D MaxField and 78D MaxField High Mag, Ocular Instruments, Bellevue, USA; Slit lamp model BQ-900, Haag-Streit, Bern, Switzerland	Lens graded using the LOCS III grading system, with comparison to the standard photographic transparency. The nuclear color and opalescence grades were amalgamated into a single grade. The vitreous, macula, retina and optic disc were documented as normal or abnormal, with description if abnormal
Ocular imaging and measurement		
Intraocular pressure and Corneal Hysteresis	Ocular Response Analyzer (ORA, Reichert Technologies, New York, USA	Three measurements taken of each eye, aiming to optimize the signal to noise ratio, and the best-waveform values for two measures of IOP (corneal compensated IOP and Goldmann correlated IOP) documented for each eye
Ocular biometry	Lenstar LS 900^{R}, Haag Streit, Bern, Switzerland	Corneal thickness, axial length, white-to-white distance, lens thickness, anterior chamber depth, keratometry and pupillometry. Three measurements taken of each eye

Color photographs and optical coherence tomography	3DOCT2000, Topcon Corporation, Tokyo, Japan	B-scan of the temporal iridocorneal angle, radial B-scan of the cornea, and an external color photograph. After dilation, two 45^{o} color photographs of Early Treatment for Diabetic Retinopathy Study (ETDRS) standard field 1 (centered on the optic disc) and ETDRS standard field 2 (centered on the fovea). Spectral domain optical coherence tomography images including the 'macula wide', '5-line cross' and '3D disc'.

C.1.6 Demographic and socioeconomic form



NESTT - Demographics

Survey ID | Survey DATE* (mm/dd/yyyy) | NESTT staff ID number

Consent form completed in full

Additional DEMOGRAPHICS

Village/community name

Place of birth

If born outside, in which country

What is your marital status?

Which is your first/main language?

Other:please specify

What is your religion

If other religion (specify)

EDUCATION

Can you read and write?

Are you currently attending a school/educational institution?

If yes, is your attendance

If yes, what type of school/educational institution

What is the highest qualification you have obtained?

In total, how many years have you spent at school or in full-time study (excluding pre-school)

What is the highest level of education you have completed?

EMPLOYMENT

Did you have a job in the past 12 months?

Which group best describes your main occupation (refer to ISCO 2008 definitions of groups)

Please give specific detail of job or ISCO code

What type of worker status applies to you?

Taking the past year, can you estimate the average income for your household (all adults)

TT

If you don't know the amount, can you estimate the monthly household income?

COMMUNICATIONS AND TRANSPORT

Do you have a current/active Driver Permit?

When did you last drive a car?

If you have STOPPED driving, why?

Do you or a family member own a car?

Do you have a landline telephone or cellular phone?

Do you have direct access to the internet

Do you have an active email address?

Do you have a postal address that you check regularly?

NESTT Health Economics

How long is it since your last eye test/exam

What was the reason for your last eye/vision test?

Health Insurance

Which sector do you use for vision and medical care?

Are you covered by Private Health insurance or by a Group Health Insurance Plan at work?

If NO, no further questions in this section

If yes, which is your insurance company?

Other (Please specify)

If yes, what is your co-insurance payment for the vision benefit?

What is your maximum coverage under the vision benefit? $TT

Who is the main policy holder?

Over the past 12 months how many times have you

Seen an eye doctor as an out-patient

Seen an optometrist

Seen a primary care doctor about your eyes/vision

Visited a health centre about your eyes/vision

Visited Emergency about your eyes/vision

Been admitted for one day for eye surgery

Spent the night in hospital on account of your eyes

ONLY ANSWER next 2 questions IF DIABETIC

Seen a diabetes specialist or physician about diabetes

Spent a night in hospital for a diabetes-related problem

ONLY answer if previous visits for eye care

How do you normally travel from your home to eye/health care facilities? If you normally use more than one form of transport please indicate the way you most usually travel for the main (longest in terms of distance) part of the journey

Over the last 12 months, please estimate how much you or a family member or friend have spent(in TT$) on the following for you

a. Health insurance that covers eye care

b. eye drops

c. consultations with the optician / vision tests

d. consultations with the eye doctor

e. consultations with your primary care doctor relating to eye or vision problems

f. spectacles and/or contact lenses

g. laser treatment for your eyes

h. eye surgery

l. Travel costs for all visits to clinics and hospitals relating to your eyes or vision

ONLY ANSWER next 4 if DIABETIC OR HYPERTENSIVE

i. medicine for diabetes

j. blood glucose monitoring equipment

m. Travel costs for all visits relating to diabetes (excluding eye/vision care)

k. Medicine/equipment for BP control

Informal care for vision loss

Over the last year, how many HOURS per MONTH have family or friends devoted to providing you with informal nursing or other care or transportation as a result of your eye or vision problems.

Are you in paid employment at the moment?

ONLY ANSWER IF CURRENTLY EMPLOYED

How many days off sick have you had in the last 12 months

Have you lost any earnings in the last 12 months as a result of:

a. visits to doctors or hospitals for eye/vision care:

Yes - please estimate $

b. ill health relating to your eyes/vision:

Yes –please estimate $

ONLY ANSWER IF CURRENTLY EMPLOYED AND DIABETIC

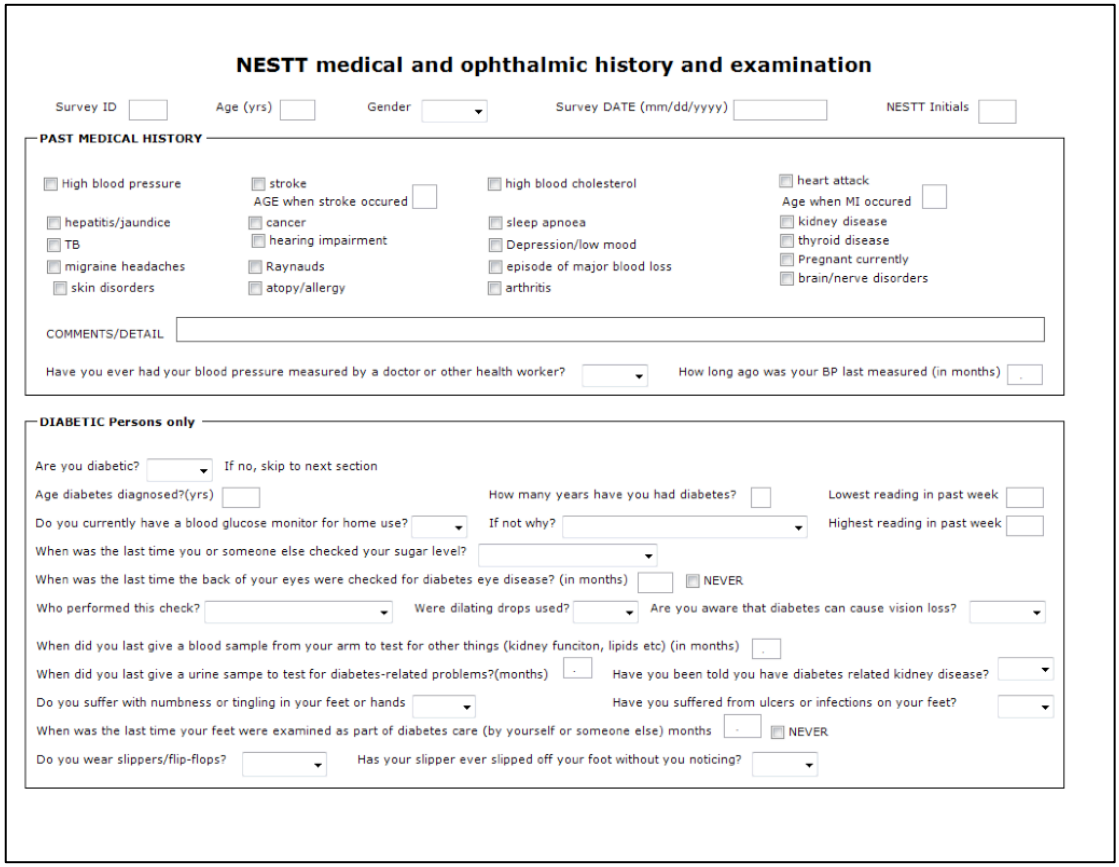
c. visits to doctor or hospitals for diabetes care

Yes – please estimate $

d. ill health relating to diabetes

Yes – please estimate $

C.1.7 Ophthalmology and medical assessment form



NESTT medical and ophthalmic history and examination

Survey ID | Age (yrs) | Gender | Survey DATE (mm/dd/yyyy) | NESTT Initials

PAST MEDICAL HISTORY

- High blood pressure
- stroke — AGE when stroke occured
- high blood cholesterol
- heart attack — Age when MI occured
- hepatitis/jaundice
- cancer
- sleep apnoea
- kidney disease
- TB
- hearing impairment
- Depression/low mood
- thyroid disease
- migraine headaches
- Raynauds
- episode of major blood loss
- Pregnant currently
- skin disorders
- atopy/allergy
- arthritis
- brain/nerve disorders

COMMENTS/DETAIL

Have you ever had your blood pressure measured by a doctor or other health worker? | How long ago was your BP last measured (in months)

DIABETIC Persons only

Are you diabetic? If no, skip to next section

Age diabetes diagnosed?(yrs) | How many years have you had diabetes? | Lowest reading in past week

Do you currently have a blood glucose monitor for home use? | If not why? | Highest reading in past week

When was the last time you or someone else checked your sugar level?

When was the last time the back of your eyes were checked for diabetes eye disease? (in months) NEVER

Who performed this check? | Were dilating drops used? | Are you aware that diabetes can cause vision loss?

When did you last give a blood sample from your arm to test for other things (kidney funciton, lipids etc) (in months)

When did you last give a urine sampe to test for diabetes-related problems?(months) | Have you been told you have diabetes related kidney disease?

Do you suffer with numbness or tingling in your feet or hands | Have you suffered from ulcers or infections on your feet?

When was the last time your feet were examined as part of diabetes care (by yourself or someone else) months NEVER

Do you wear slippers/flip-flops? | Has your slipper ever slipped off your foot without you noticing?

MEDICATION HISTORY

Have you been taking any medications regularly (ie at least once per week in the last month)? (If no, no further questions in this section)

Do you know the names of your medicines (or have you brought a list)? | What type of prescription do you receive?

Have you been prescribed any of the following in the last 3 months? If yes,which

Medicine to lower BP — Atenolol, bendrofluazide, enalapril, frusemide, lisinopril, methyldopa, nifedipine SR, I can't remember which, other — If other which

Medicine to lower cholesterol or triglycerides — simvastatin, fenofibrate, I can't recall, other — If other, which

Medicine for diabetes — insulin FAST, insulin SLOW, insulin MIX, metformin, gliclazide, glibenclamide, I can't recall, other — If other, which

Medicine for Stroke, ischaemic heart disease

ANY OTHER MEDICATIONS | How often do you remember to take the medicines you have been prescribed?

PAST OCULAR HISTORY

RIGHT EYE

- eye injury resulting in vision loss
- corneal problem (eg scar, degeneration, dystrophy)
- hereditary eye disease
- strabismus/squint
- congenital cause of vision loss
- vision loss resulting from premature birth
- refractive error
- lazy eye/amblyopia
- OTHER
- cataract
- uveitis
- glaucoma
- macular degeneration
- retinal vascular occlusion
- retinal detatchment
- diabetic retinopathy
- optic neuropathy

Additional details on right eye diagnoses

LEFT EYE

- eye injury resulting in vision loss
- corneal problem (eg scar, degeneration, dystrophy)
- hereditary eye disease
- strabismus/squint
- congenital cause of vision loss
- vision loss resulting from premature birth
- refractive error
- lazy eye/amblyopia
- OTHER
- cataract
- uveitis
- glaucoma
- macular degeneration
- retinal vascular occlusion
- retinal detatchment
- diabetic retinopathy
- optic neuropathy

Additional details on left eye diagnoses

Have you had surgery in the right eye?

If yes, what type of surgery in your RIGHT eye?

- catarct
- cornea
- retina
- squint
- glaucoma
- trauma
- other

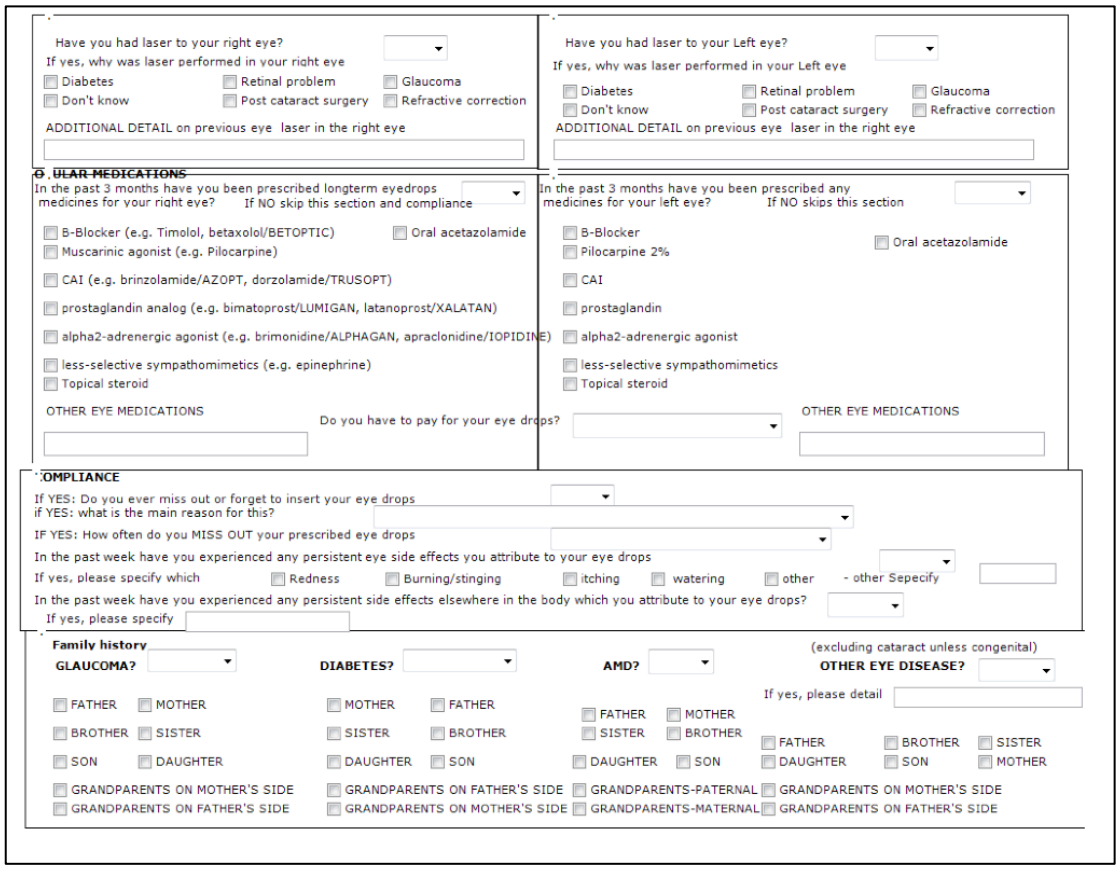
ADDITIONAL DETAILS on previous surgery in the right eye:

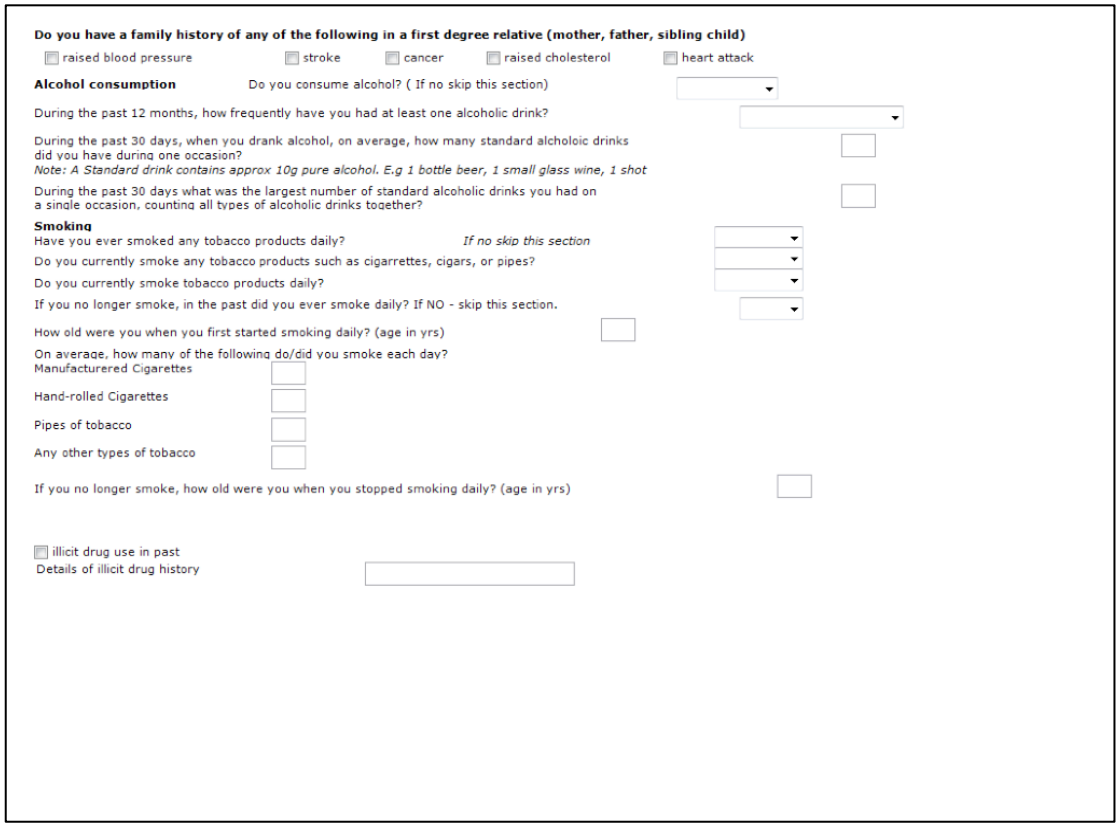
Have you had surgery in the Left eye?

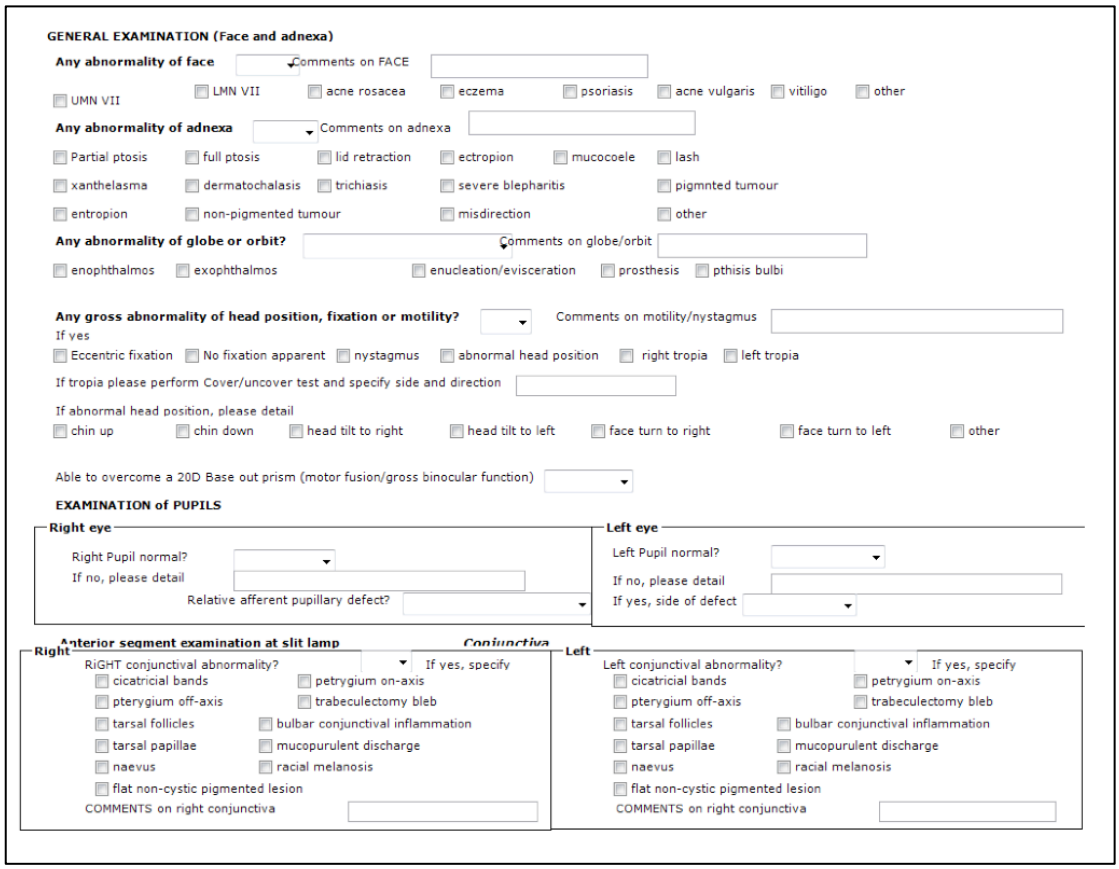
If yes, what type of surgery in your Left eye?

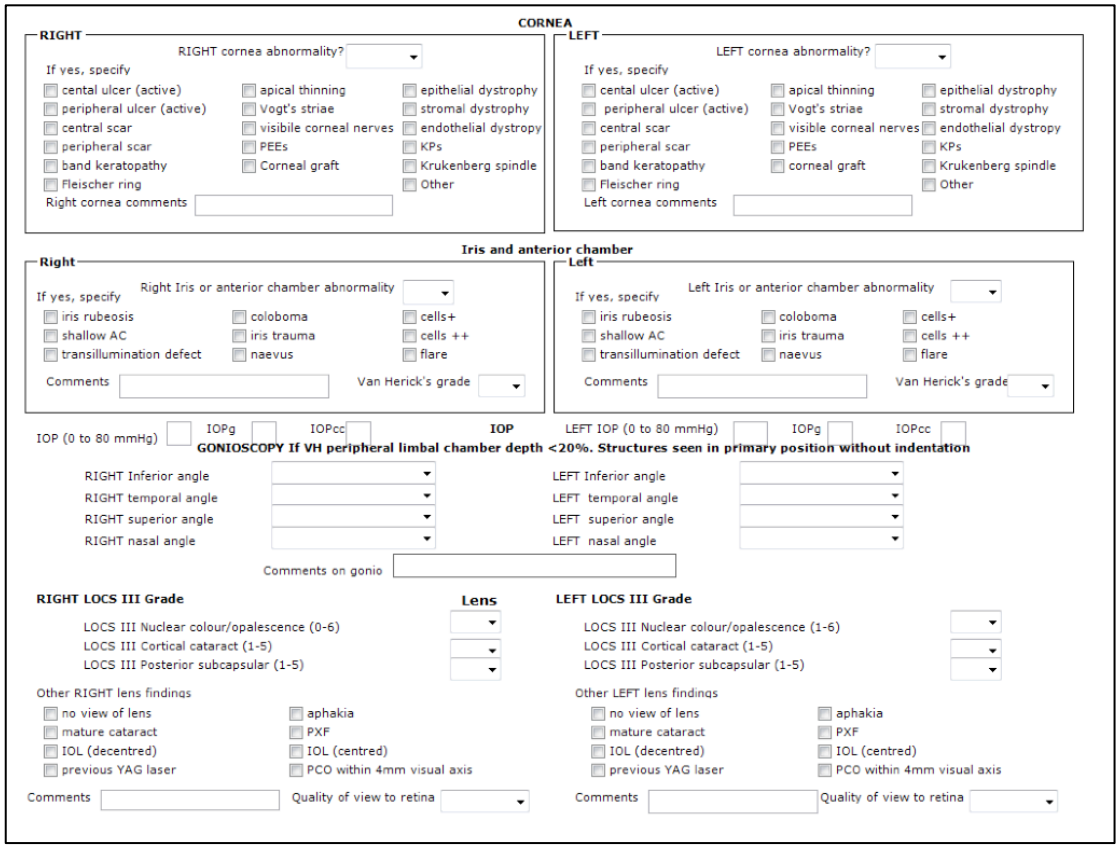
- catarct
- cornea
- retina
- squint
- glaucoma
- trauma
- other

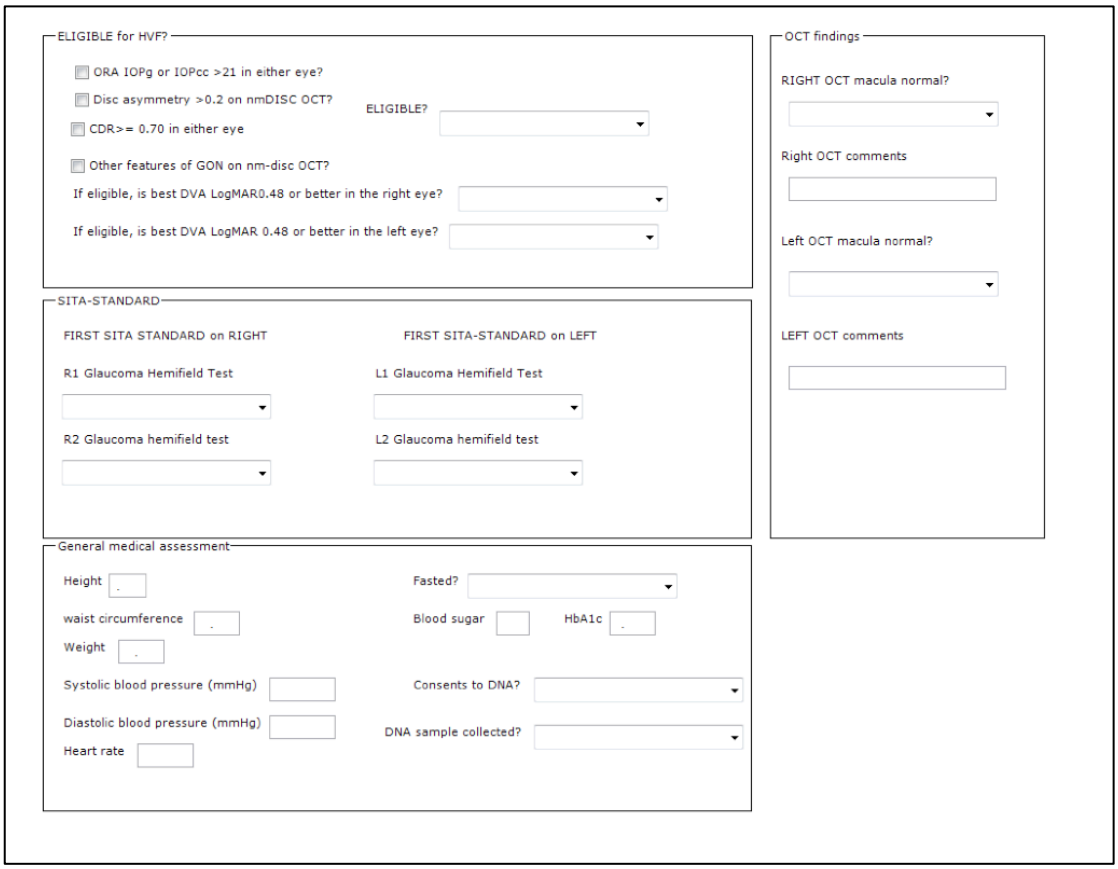
ADDITIONAL DETAILS on previous surgery in the Left eye:

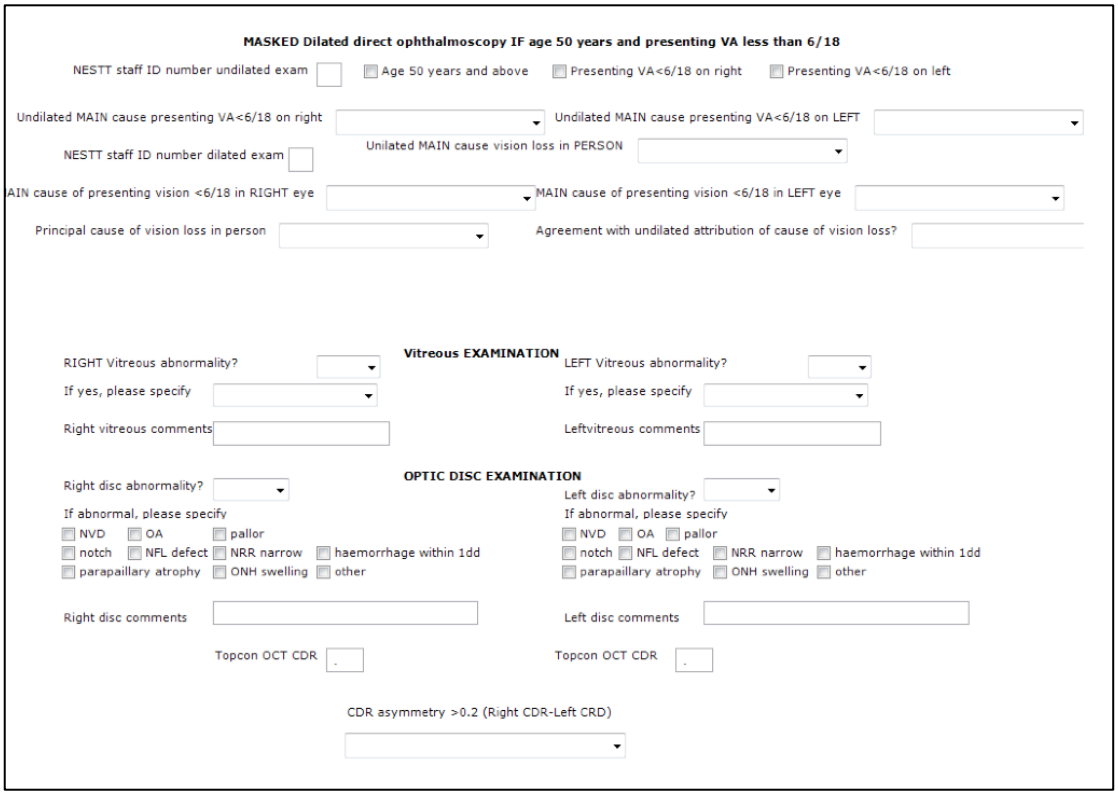

Have you had laser to your right eye?
If yes, why was laser performed in your right eye
Diabetes
Retinal problem
Glaucoma
Don't know
Post cataract surgery
Refractive correction
ADDITIONAL DETAIL on previous eye laser in the right eye
Have you had laser to your Left eye?
If yes, why was laser performed in your Left eye
Diabetes
Retinal problem
Glaucoma
Don't know
Post cataract surgery
Refractive correction
ADDITIONAL DETAIL on previous eye laser in the right eye
O ULAR MEDICATIONS
In the past 3 months have you been prescribed longterm eyedrops medicines for your right eye?
If NO skip this section and compliance
B-Blocker (e.g. Timolol, betaxolol/BETOPTIC)
Oral acetazolamide
Muscarinic agonist (e.g. Pilocarpine)
CAI (e.g. brinzolamide/AZOPT, dorzolamide/TRUSOPT)
prostaglandin analog (e.g. bimatoprost/LUMIGAN, latanoprost/XALATAN)
alpha2-adrenergic agonist (e.g. brimonidine/ALPHAGAN, apraclonidine/IOPIDINE)
less-selective sympathomimetics (e.g. epinephrine)
Topical steroid
OTHER EYE MEDICATIONS
Do you have to pay for your eye drops?
In the past 3 months have you been prescribed any medicines for your left eye?
If NO skips this section
B-Blocker
Pilocarpine 2%
Oral acetazolamide
CAI
prostaglandin
alpha2-adrenergic agonist
less-selective sympathomimetics
Topical steroid
OTHER EYE MEDICATIONS
OMPLIANCE
If YES: Do you ever miss out or forget to insert your eye drops
if YES: what is the main reason for this?
IF YES: How often do you MISS OUT your prescribed eye drops
In the past week have you experienced any persistent eye side effects you attribute to your eye drops
If yes, please specify which
Redness
Burning/stinging
itching
watering
other
- other Sepecify
In the past week have you experienced any persistent side effects elsewhere in the body which you attribute to your eye drops?
If yes, please specify
Family history
(excluding cataract unless congenital)
GLAUCOMA?
DIABETES?
AMD?
OTHER EYE DISEASE?
If yes, please detail
FATHER
MOTHER
BROTHER
SISTER
SON
DAUGHTER
GRANDPARENTS ON MOTHER'S SIDE
GRANDPARENTS ON FATHER'S SIDE
GRANDPARENTS-PATERNAL
GRANDPARENTS-MATERNAL

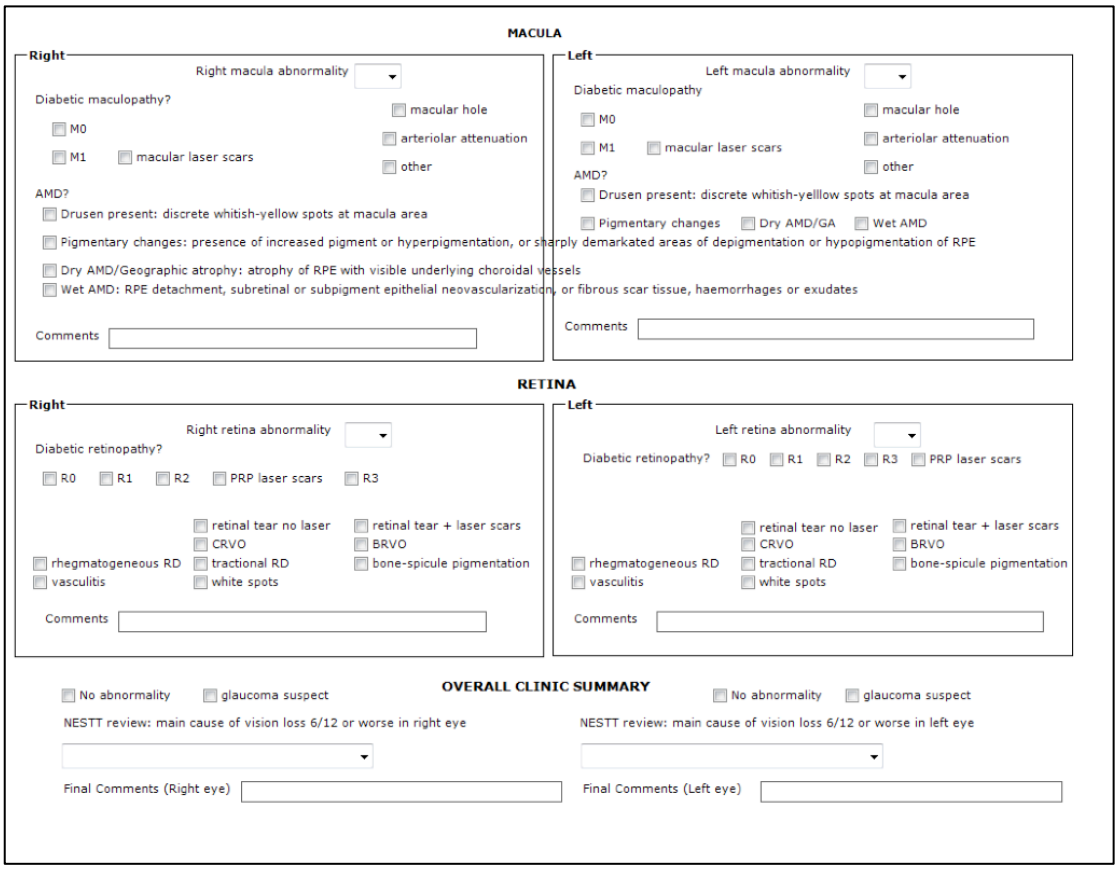

Do you have a family history of any of the following in a first degree relative (mother, father, sibling child)
raised blood pressure
stroke
cancer
raised cholesterol
heart attack
Alcohol consumption
Do you consume alcohol? (If no skip this section)
During the past 12 months, how frequently have you had at least one alcoholic drink?
During the past 30 days, when you drank alcohol, on average, how many standard alcholoic drinks did you have during one occasion?
Note: A Standard drink contains approx 10g pure alcohol. E.g 1 bottle beer, 1 small glass wine, 1 shot
During the past 30 days what was the largest number of standard alcoholic drinks you had on a single occasion, counting all types of alcoholic drinks together?
Smoking
Have you ever smoked any tobacco products daily?
If no skip this section
Do you currently smoke any tobacco products such as cigarrettes, cigars, or pipes?
Do you currently smoke tobacco products daily?
If you no longer smoke, in the past did you ever smoke daily? If NO - skip this section.
How old were you when you first started smoking daily? (age in yrs)
On average, how many of the following do/did you smoke each day?
Manufacturered Cigarettes
Hand-rolled Cigarettes
Pipes of tobacco
Any other types of tobacco
If you no longer smoke, how old were you when you stopped smoking daily? (age in yrs)
illicit drug use in past
Details of illicit drug history


GENERAL EXAMINATION (Face and adnexa)
Any abnormality of face
Comments on FACE
UMN VII
LMN VII
acne rosacea
eczema
psoriasis
acne vulgaris
vitiligo
other
Any abnormality of adnexa
Comments on adnexa
Partial ptosis
full ptosis
lid retraction
ectropion
mucocoele
lash
xanthelasma
dermatochalasis
trichiasis
severe blepharitis
pigmnted tumour
entropion
non-pigmented tumour
misdirection
other
Any abnormality of globe or orbit?
Comments on globe/orbit
enophthalmos
exophthalmos
enucleation/evisceration
prosthesis
pthisis bulbi
Any gross abnormality of head position, fixation or motility?
Comments on motility/nystagmus
If yes
Eccentric fixation
No fixation apparent
nystagmus
abnormal head position
right tropia
left tropia
If tropia please perform Cover/uncover test and specify side and direction
If abnormal head position, please detail
chin up
chin down
head tilt to right
head tilt to left
face turn to right
face turn to left
other
Able to overcome a 20D Base out prism (motor fusion/gross binocular function)
EXAMINATION of PUPILS
Right eye
Right Pupil normal?
If no, please detail
Relative afferent pupillary defect?
Left eye
Left Pupil normal?
If no, please detail
If yes, side of defect
Anterior segment examination at slit lamp
Conjunctiva
Right
RiGHT conjunctival abnormality?
If yes, specify
cicatricial bands
petrygium on-axis
pterygium off-axis
trabeculectomy bleb
tarsal follicles
bulbar conjunctival inflammation
tarsal papillae
mucopurulent discharge
naevus
racial melanosis
flat non-cystic pigmented lesion
COMMENTS on right conjunctiva
Left
Left conjunctival abnormality?
If yes, specify
cicatricial bands
petrygium on-axis
pterygium off-axis
trabeculectomy bleb
tarsal follicles
bulbar conjunctival inflammation
tarsal papillae
mucopurulent discharge
naevus
racial melanosis
flat non-cystic pigmented lesion
COMMENTS on right conjunctiva


CORNEA
RIGHT
RIGHT cornea abnormality?
If yes, specify
cental ulcer (active)
apical thinning
epithelial dystrophy
peripheral ulcer (active)
Vogt's striae
stromal dystrophy
central scar
visibile corneal nerves
endothelial dystropy
peripheral scar
PEEs
KPs
band keratopathy
Corneal graft
Krukenberg spindle
Fleischer ring
Other
Right cornea comments
LEFT
LEFT cornea abnormality?
If yes, specify
cental ulcer (active)
apical thinning
epithelial dystrophy
peripheral ulcer (active)
Vogt's striae
stromal dystrophy
central scar
visible corneal nerves
endothelial dystropy
peripheral scar
PEEs
KPs
band keratopathy
corneal graft
Krukenberg spindle
Fleischer ring
Other
Left cornea comments
Iris and anterior chamber
Right
If yes, specify
Right Iris or anterior chamber abnormality
iris rubeosis
coloboma
cells+
shallow AC
iris trauma
cells ++
transillumination defect
naevus
flare
Comments
Van Herick's grade
Left
If yes, specify
Left Iris or anterior chamber abnormality
iris rubeosis
coloboma
cells+
shallow AC
iris trauma
cells ++
transillumination defect
naevus
flare
Comments
Van Herick's grade
IOP (0 to 80 mmHg)
IOPg
IOPcc
IOP
LEFT IOP (0 to 80 mmHg)
IOPg
IOPcc
GONIOSCOPY If VH peripheral limbal chamber depth <20%. Structures seen in primary position without indentation
RIGHT Inferior angle
RIGHT temporal angle
RIGHT superior angle
RIGHT nasal angle
LEFT Inferior angle
LEFT temporal angle
LEFT superior angle
LEFT nasal angle
Comments on gonio
RIGHT LOCS III Grade
Lens
LEFT LOCS III Grade
LOCS III Nuclear colour/opalescence (0-6)
LOCS III Cortical cataract (1-5)
LOCS III Posterior subcapsular (1-5)
LOCS III Nuclear colour/opalescence (1-6)
LOCS III Cortical cataract (1-5)
LOCS III Posterior subcapsular (1-5)
Other RIGHT lens findings
no view of lens
aphakia
mature cataract
PXF
IOL (decentred)
IOL (centred)
previous YAG laser
PCO within 4mm visual axis
Other LEFT lens findings
no view of lens
aphakia
mature cataract
PXF
IOL (decentred)
IOL (centred)
previous YAG laser
PCO within 4mm visual axis
Comments
Quality of view to retina
Comments
Quality of view to retina

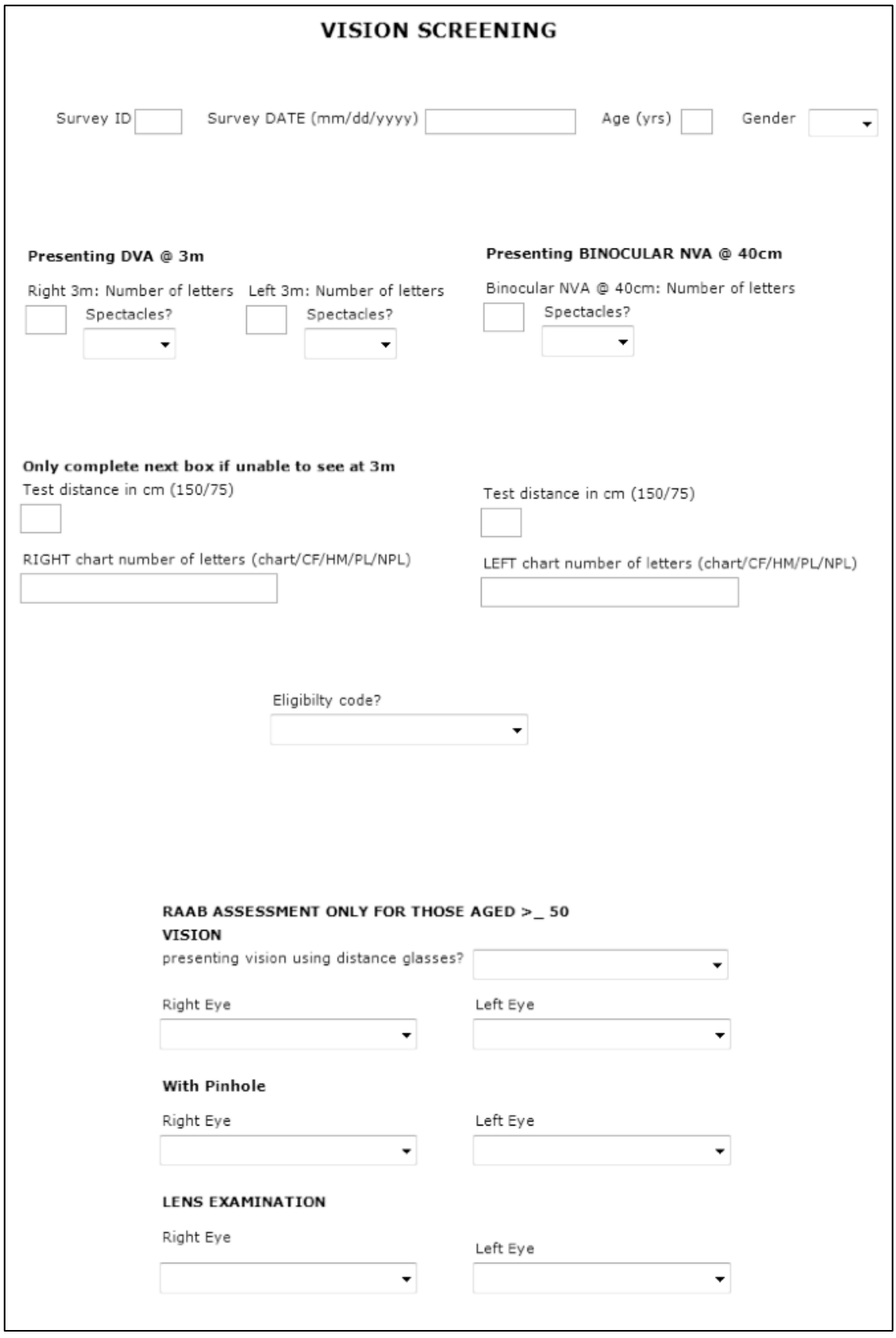

ELIGIBLE for HVF?
ORA IOPg or IOPcc >21 in either eye?
Disc asymmetry >0.2 on nmDISC OCT?
CDR>= 0.70 in either eye
ELIGIBLE?
Other features of GON on nm-disc OCT?
If eligible, is best DVA LogMAR0.48 or better in the right eye?
If eligible, is best DVA LogMAR 0.48 or better in the left eye?
SITA-STANDARD
FIRST SITA STANDARD on RIGHT
FIRST SITA-STANDARD on LEFT
R1 Glaucoma Hemifield Test
L1 Glaucoma Hemifield Test
R2 Glaucoma hemifield test
L2 Glaucoma hemifield test
General medical assessment
Height
Fasted?
waist circumference
Blood sugar
HbA1c
Weight
Systolic blood pressure (mmHg)
Consents to DNA?
Diastolic blood pressure (mmHg)
DNA sample collected?
Heart rate
OCT findings
RIGHT OCT macula normal?
Right OCT comments
Left OCT macula normal?
LEFT OCT comments


MASKED Dilated direct ophthalmoscopy IF age 50 years and presenting VA less than 6/18
NESTT staff ID number undilated exam
Age 50 years and above
Presenting VA<6/18 on right
Presenting VA<6/18 on left
Undilated MAIN cause presenting VA<6/18 on right
Undilated MAIN cause presenting VA<6/18 on LEFT
NESTT staff ID number dilated exam
Unilated MAIN cause vision loss in PERSON
AIN cause of presenting vision <6/18 in RIGHT eye
MAIN cause of presenting vision <6/18 in LEFT eye
Principal cause of vision loss in person
Agreement with undilated attribution of cause of vision loss?
Vitreous EXAMINATION
RIGHT Vitreous abnormality?
If yes, please specify
Right vitreous comments
LEFT Vitreous abnormality?
If yes, please specify
Leftvitreous comments
OPTIC DISC EXAMINATION
Right disc abnormality?
If abnormal, please specify
NVD OA pallor
notch NFL defect NRR narrow haemorrhage within 1dd
parapaillary atrophy ONH swelling other
Right disc comments
Topcon OCT CDR
Left disc abnormality?
If abnormal, please specify
NVD OA pallor
notch NFL defect NRR narrow haemorrhage within 1dd
parapaillary atrophy ONH swelling other
Left disc comments
Topcon OCT CDR
CDR asymmetry >0.2 (Right CDR-Left CRD)


MACULA
Right
Right macula abnormality
Diabetic maculopathy?
M0
M1
macular laser scars
macular hole
arteriolar attenuation
other
AMD?
Drusen present: discrete whitish-yellow spots at macula area
Pigmentary changes: presence of increased pigment or hyperpigmentation, or sharply demarkated areas of depigmentation or hypopigmentation of RPE
Dry AMD/Geographic atrophy: atrophy of RPE with visible underlying choroidal vessels
Wet AMD: RPE detachment, subretinal or subpigment epithelial neovascularization, or fibrous scar tissue, haemorrhages or exudates
Comments
Left
Left macula abnormality
Diabetic maculopathy
M0
M1
macular laser scars
macular hole
arteriolar attenuation
other
AMD?
Drusen present: discrete whitish-yelllow spots at macula area
Pigmentary changes
Dry AMD/GA
Wet AMD
Comments
RETINA
Right
Right retina abnormality
Diabetic retinopathy?
R0
R1
R2
PRP laser scars
R3
retinal tear no laser
retinal tear + laser scars
CRVO
BRVO
rhegmatogeneous RD
tractional RD
bone-spicule pigmentation
vasculitis
white spots
Comments
Left
Left retina abnormality
Diabetic retinopathy?
R0
R1
R2
R3
PRP laser scars
retinal tear no laser
retinal tear + laser scars
CRVO
BRVO
rhegmatogeneous RD
tractional RD
bone-spicule pigmentation
vasculitis
white spots
Comments
OVERALL CLINIC SUMMARY
No abnormality
glaucoma suspect
NESTT review: main cause of vision loss 6/12 or worse in right eye
Final Comments (Right eye)
No abnormality
glaucoma suspect
NESTT review: main cause of vision loss 6/12 or worse in left eye
Final Comments (Left eye)


Outcome if abnormality identified
Referral to
Presciption:
NKDA
OR allergic to:

C.1.8 Optometry assessment form



VISION SCREENING

Survey ID | Survey DATE (mm/dd/yyyy) | Age (yrs) | Gender

Presenting DVA @ 3m

Right 3m: Number of letters | Spectacles?

Left 3m: Number of letters | Spectacles?

Presenting BINOCULAR NVA @ 40cm

Binocular NVA @ 40cm: Number of letters | Spectacles?

Only complete next box if unable to see at 3m

Test distance in cm (150/75)

RIGHT chart number of letters (chart/CF/HM/PL/NPL)

Test distance in cm (150/75)

LEFT chart number of letters (chart/CF/HM/PL/NPL)

Eligibilty code?

RAAB ASSESSMENT ONLY FOR THOSE AGED >_ 50

VISION

presenting vision using distance glasses?

Right Eye | Left Eye

With Pinhole

Right Eye | Left Eye

LENS EXAMINATION

Right Eye | Left Eye

VISION ASSESSMENT

GENERAL:

Survey ID | Survey DATE (mm/dd/yyyy) | Age (yrs)

Gender | NESTT initials

IF 18y or above: AUTOREFRACTION UNDILATED

RIGHT EYE

Sphere sign

Sphere 'S' (2 d.p obligatory) in dioptres

Cylinder sign

Cylinder 'C' (2 dp obligatory) in dioptres

Axis 'A' (in degrees)

LEFT EYE

Sphere sign

Sphere 'S' (2 d.p obligatory) in dioptres

Cylinder sign

Cylinder 'C' (2 dp obligatory) in dioptres

Axis 'A' (in degrees)

Spectacles

Regarding distance spectacles? The patient:

☐ Brought these to clinic ☐ Currently wears, but forgot to bring to clinic ☐ Previously wore but they are lost/broken

☐ Previously wore and no longer needed ☐ Never wore

Regarding near/ reading spectacles? The patient:

☐ Brought these to clinic ☐ Currently wears, but forgot to bring to clinic ☐ Previously wore but they are lost/broken

☐ Previously wore and no longer needed ☐ Never wore

Regarding bi/tri/vari focal spectacles?

☐ Brought these to clinic ☐ Currently wears, but forgot to bring to clinic ☐ Previously wore but they are lost/broken

☐ Previously wore and no longer needed ☐ Never wore

Comments

PRESENTING Distance visual acuity

Test distance right (in m)

RIGHT Unaided Distance visual acuity (LogMAR)

RIGHT spectacle-corrected distance visual acuity (LogMAR to 2dp) (skip if no spectacles)

Chart used for Right eye

Presenting 3m equivalent logMAR

Test distance left (in m)

LEFT Unaided distance visual acuity (LogMAR)

LEFT spectacle-corrected distance visual acuity (LogMARto 2 dp) (skip if no spectacles)

Chart used for Left eye

Presenting 3m equivalent logMAR

NESTT optometrist initials:

FOCIMETRY IF spectacles brought to clinic

Right

right sphere sign

right sphere (in dioptres)

right cylinder sign

right cylinder (in dioptres)

right axis

right prism

right 'add' (in dioptres)

Left

left sphere sign

left sphere (in dioptres)

left cylinder sign

left cylinder (in dioptres)

left axis

left prism

left 'add' (in dioptres)

COMMENTS ON SPECTACLES (condition etc)

Undilated autorefraction-corrected VA (AR-VA)

NOTE: perform in adults 18 years and above if VA suboptomal. either without or with spectacles

Right

RIGHT test distance (in m)

RIGHT AR-VA(LogMAR)

AR 3m equivalent VA

If unable to see chart with AR in trial frame, best vision level at 1m RIGHT

- counting fingers
- hand movements
- light perception
- no light perception

Left

LEFT test distance (in m)

LEFT AR-VA(LogMAR)

AR 3m equivalent VA

If unable to see chart with AR in trial frame, best vision level at 1 m LEFT

- counting fingers
- hand movements
- light perception
- no light perception

Comments on autorefraction correction:

If visual acuity still LogMAR 0.20 in either eye then attempt subjective refinement to obtain best-corrected visual acuity

Subjective refraction

Right

right sphere sign

right sphere

right cylinder sign

right cylinder

right axis

right best-corrected VA

Subjective 3m equivalent VA

Left

left sphere sign

left sphere

left cylinder sign

left cylinder

left axis

left best-corrected VA

Subjective 3m equivalent

If subjective refraction not possible, why

if option is other (please specify in comments)

Comments on subjective refraction

NEAR Visual Acuity

Habitual distance: where you usually hold a newspaper/letter/book to read it?(cm)

How do you usually see to read (presenting near vision)?

Test distance (40cm or use habitual distance if unable to see at 40cm)

BINOCULAR presenting near visual acuity (in logMAR)

Were spectacles worn to test presenting near acuity today?

UNIOCULAR assessment of uncorrected and corrected near VA (with best distance prescription mounted in trial frame if applicable) at 40cm

RIGHT near VA (NO +DS) logMAR

LEFT near VA (NO +DS) logMAR

Right +DS required (with distance correction)

Left +DS required (with distance correction)

RIGHT best near-corrected near visual acuity logMAR

LEFT best near-corrected near visual acuity logM

COMMENTS on near acuity assessment

Pathway eligibility

Is BEST VA at 3m (or equivalent) worse than or equal to LogMAR 0.50 (<6/18) in the BETTER seeing eye and age 5-39 years?

Is BEST VA at 3m (or equivalent) worse than or equal to LogMAR 0.50 (<6/18) in BETTER seeing eye and age 40y or above?

If NO and age 40 years or above then FINISH. If NO and age 5 to 39 years then recall after dilating for dilated ARK only

If YES to either of the above then complete low vision assessment

LOW VISION ASSESSMENT

Fixation with a Freeman Cross?

Visual fields to confrontation (if able to fixate)

Right

Left

MNRead Test

MNRead Test: To be performed with best distance correction (AND +2.50DS if 40 years or above)

RIGHT: Chart number

LEFT: Chart number

RIGHT: test distance (cm) Note: aim 40cm

LEFT: test distance (cm) Note: aim 40cm

RIGHT: Reading Acuity logMAR

LEFT: Reading Acuity LogMAR

RIGHT: estimated max reading speed (in wpm)

LEFT: estimated max reading speed (in wpm)

RIGHT: CPS (at 40cm)

LEFT: CPS (at 40cm)

RIGHT Optimal magnification Add

LEFT Optimal magnification Add

RIGHT Reading acuity with magnification add

LEFT Reading acuity with magnification add

COMMENTS on MNRead test

MARS TEST

Test Binocular constrast sensitivity in the PRESENTING NEAR STATE

Binocular CS

Test uniocular CS with best distance prescription mounted in the trial frame. If 40 years or above then mount, in addition: +2.00 (for 50cm), or +2.50 (for 40cm), or +4.00 (for 25cm)

Right test distance (aim 50cm)

Left test distance (aim 50cm)

Right log CS

Left log CS

COMMENT on MARS

Cont...

ONLY PXS <40: AUTOREFRACTION DILATED (>30 mins after cycloplegia) Adequate cycloplegia?

Defintion: pupil non-responsive to light, dilated >6mm

IGHT		LEFT	
Sphere sign		Sphere sign	
Sphere 'S' (2 d.p obligatory) in dioptres	.	Sphere 'S' (2 d.p obligatory) in dioptres	.
Cylinder sign		Cylinder sign	
Cylinder 'C' in dioptres	.	Cylinder 'C' in dioptres	.
Axis 'A' (in degrees)		Axis 'A' (in degrees)	

SIGHT REGISTRATION CATEGORY

DOES PATIENT meet criteria for sight registration in the better seeing eye when wearing best-correction?

If yes, in which group does patient fall:

- ☐ BCVA of LogMAR 1.30 (Snellen 3 / 60) to 1.00 (6 / 60) with a full field of vision
- ☐ BCVA of LogMAR 0.60 (up to 6 / 24) or worse, with a moderate reduction of field of vision or with a central part of vision that is cloudy or blurry
- ☐ BCVA of LogMAR 0.48 or worse (up to 6 / 18), with a large part of field of vision missing, e.g.

Comments

C.1.9 Low vision assessment form

National Eye survey Trinidad and Tobago: Low Vision Assessment Form

Survey ID

Survey Date

Age Years

Gender

Initials of NESTT team member

HISTORY OF YOUR VISION LOSS and eye care:

The following questions are about your RIGHT EYE ONLY

At what age did vision loss develop in your right eye?

How long have you had reduced vision in your right eye?

How quickly did you lose your vision in the right eye

Which hospital or eye clinic did you attend at the time of your main diagnosis and treatment for the right eye?

Do you feel any of the following factors contributed to vision loss in your RIGHT eye?

Delay in correct diagnosis for the RIGHT eye?

If yes, please select the cause(s) of the delay

Delay or lack of treatment for the RIGHT eye ONCE the correct diagnosis was made

If yes, please select the cause(s) of the delay or lack of treatment

The following questions are about your LEFT EYE ONLY

At what age did vision loss develop in your left eye?

How long have you had reduced vision in your left eye?

How quickly did you lose your vision in the left eye

Which hospital/eye clinic did you attend at the time of your main diagnosis and treatment for the left eye?

Do you feel any of the following factors contributed to vision loss in your LEFT eye?

Delay in correct diagnosis for the LEFT eye?

If yes, please select the cause(s) of the delay

Delay or lack of treatment for the LEFT eye ONCE the correct diagnosis was made

If yes, please select the cause(s) of the delay or lack of treatment

FUNCTIONAL ADAPTATION

I would like to ask about adaptations you may have made to your daily living arrangements to overcome your low vision. Please select all that you can do, currently use or have in your home

Are you able to read large print?

If yes, how easy is it to obtain large print versions of the things you wish to read?

have you made any of the following adaptations to your daily living arrangements, or do you use any aids or devices, to overcome your low vision?

☐ Guide Dog ☐ White stick or cane ☐ telescopes ☐ extra lighting for specific tasks ☐ CCTV

☐ GPS ☐ Visors and shields (e.g. wearing a hat with a brim) ☐ Tints/sunglasses ☐ Braille Typewriter

☐ coloured tape or paint to highlight edges ☐ Audio books ☐ liquid level indicator ☐ Braille ☐ Stand magnifiers

☐ Talking microwaves, clocks, watches, thermometers or scales ☐ hand held magnifiers ☐ Illuminated Hand held magnifiers

Computers Are you computer literate? Do you own or have access to a computer

Do you use any of the following computer features:

☐ Magnification software ☐ Speech output software ☐ contrast or colour modification

☐ Large characters or braile keyboard ☐ speech input

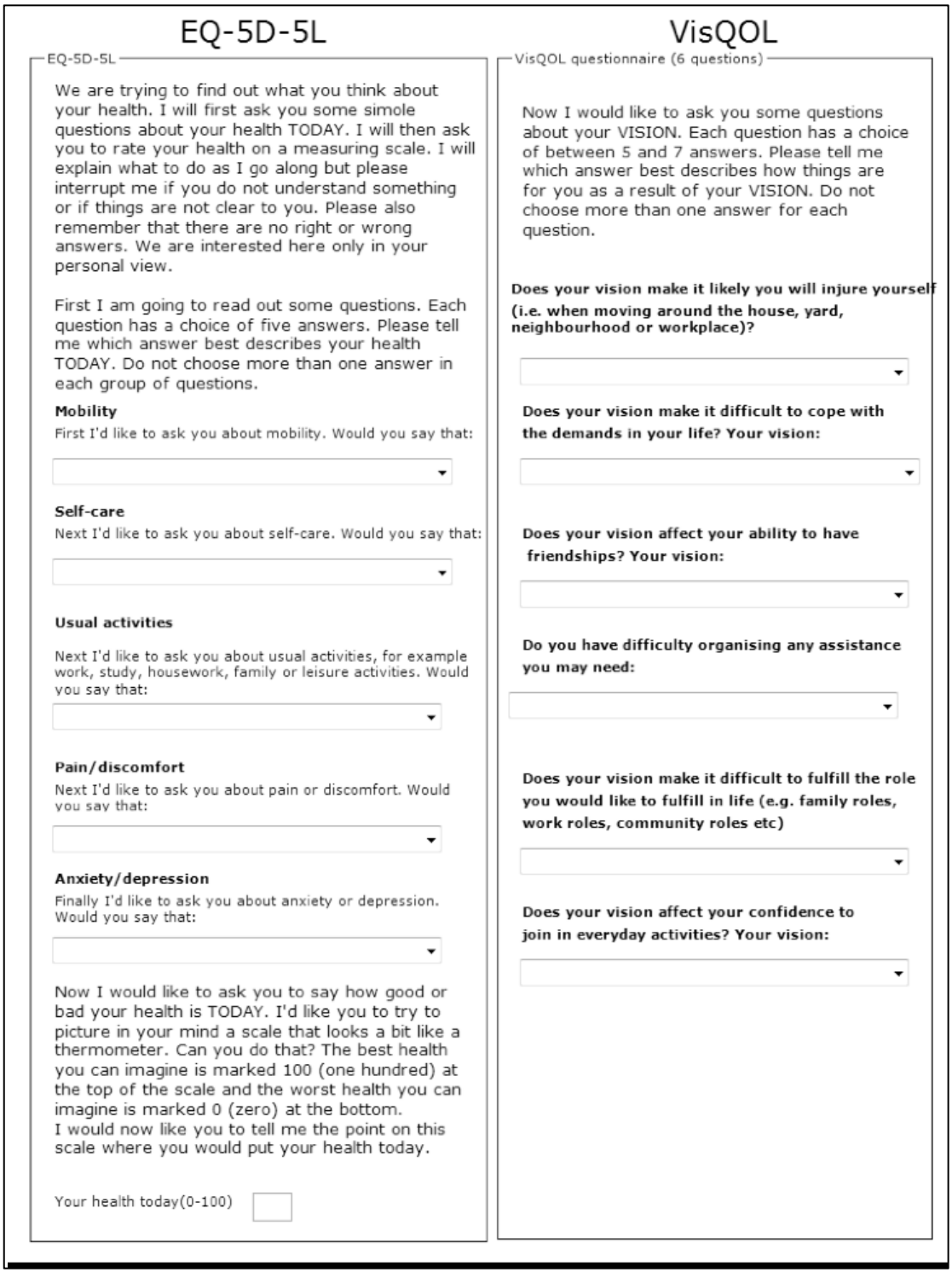
Do you feel you might benefit from a low vision aid assessment and trial of low vision aids?

If you feel you might benefit from low vision assessment or aids and devices, what are the obstacles to you obtaining and using these?

☐ Lack of access to low vision assessment to find out if appropriate ☐ transport diffculties for assessment

☐ cost of low vision aids ☐ availability of low vision aids in TT ☐ other

C.1.10 Quality of life form



EQ-5D-5L

EQ-5D-5L

We are trying to find out what you think about your health. I will first ask you some simole questions about your health TODAY. I will then ask you to rate your health on a measuring scale. I will explain what to do as I go along but please interrupt me if you do not understand something or if things are not clear to you. Please also remember that there are no right or wrong answers. We are interested here only in your personal view.

First I am going to read out some questions. Each question has a choice of five answers. Please tell me which answer best describes your health TODAY. Do not choose more than one answer in each group of questions.

Mobility

First I'd like to ask you about mobility. Would you say that:

Self-care

Next I'd like to ask you about self-care. Would you say that:

Usual activities

Next I'd like to ask you about usual activities, for example work, study, housework, family or leisure activities. Would you say that:

Pain/discomfort

Next I'd like to ask you about pain or discomfort. Would you say that:

Anxiety/depression

Finally I'd like to ask you about anxiety or depression. Would you say that:

Now I would like to ask you to say how good or bad your health is TODAY. I'd like you to try to picture in your mind a scale that looks a bit like a thermometer. Can you do that? The best health you can imagine is marked 100 (one hundred) at the top of the scale and the worst health you can imagine is marked 0 (zero) at the bottom.
I would now like you to tell me the point on this scale where you would put your health today.

Your health today(0-100)

VisQOL

VisQOL questionnaire (6 questions)

Now I would like to ask you some questions about your VISION. Each question has a choice of between 5 and 7 answers. Please tell me which answer best describes how things are for you as a result of your VISION. Do not choose more than one answer for each question.

Does your vision make it likely you will injure yourself (i.e. when moving around the house, yard, neighbourhood or workplace)?

Does your vision make it difficult to cope with the demands in your life? Your vision:

Does your vision affect your ability to have friendships? Your vision:

Do you have difficulty organising any assistance you may need:

Does your vision make it difficult to fulfill the role you would like to fulfill in life (e.g. family roles, work roles, community roles etc)

Does your vision affect your confidence to join in everyday activities? Your vision:

C.1.11 Examination procedures for a subset of participants according to specific indications

Examination variable	Equipment	Measurement Protocol	Indication
Glycosylated hemoglobin (A1C)	Rapid point-of-care assay machine (DCA Vantage Analyzer, Siemens, Berlin, Germany)	Droplet of capillary blood obtained with safety lancet. Rapid point-of-care assay performed according to manufacturer's instructions	Previous diagnosis of diabetes or a fasting blood glucose greater than or equal to 126 mg/dl (7.0mmol/l) or a random blood glucose greater than 200 mg/dL (11.1mmol/L) (Alberti & Zimmet, 1998)
Best-corrected visual acuity	Trial Lens Frame, Viewlight, Miami, USA; Trial Lens Set 266BL, Viewlight, Miami, USA	Subjective refraction performed by optometrist	Presenting distance visual acuity worse than LogMar 0.20 (approximately 6/9) in either eye
Intraocular pressure (manual)	AT900 Applanation Tonometer, Haag-Streit, Bern, Switzerland; proxymetacaine hydrochloride 0.5%; dry strip of fluorescein; Slit lamp model BQ-900, Haag-Streit, Bern, Switzerland	Care taken to use just enough fluorescein to obtain mires of standard thickness. IOP measured once in each eye using Goldmann applanation tonometer	ORA measurement of IOP not possible
Gonioscopy	Magna View Gonio Lens without flange, Ocular Instruments, Belleview, USA; proxymetacaine 0.5%; Gel tears, Bausch & Lomb Incorporated, Rochester, USA	The visibility of the four key structures was documented	Van Herick limbal chamber depth grade 2 or less (Van Herick et al., 1969)
Visual field test	Humphrey Visual Field Analyzer II (model 740i), Carl Zeiss, Meditec AG Jena Germany	24-2 SITA static, threshold-related visual field test performed with near refractive correction in place, prior to dilation, in both eyes. Test reliability determined by the instrument's algorithm. Test repeated once if Glaucoma Hemifield Test abnormal, borderline, or reduced sensitivity	1) Vertical CDR ≥ 0.70 2) IOP ≥ 21 mm Hg 3) Abnormal optic disc features suggestive of glaucoma 4) History of diagnosed glaucoma or ocular hypertension Not performed in eyes with a visual acuity worse than 0.48 Log MAR (6/18)

Low vision tests	Mars Letter Contrast Sensitivity Test, Precision Vision, La Salle, USA; MN Read English Continuous text chart Black/White, Precision Vision, La Salle, USA	1) Uniocular MARS contrast sensitivity in best-corrected state 2) Uniocular MNRead test in best-corrected state	Distance best-corrected visual acuity in the better seeing eye worse than 6/18 (Log MAR 0.48)
Cup: disc ratio (manual)	78D MaxField High Mag, Ocular Instruments, Bellevue, USA; Slit lamp model BQ-900, Haag-Streit, Bern, Switzerland	Optic disc examined at x10 magnification, vertical disc dimensions measured using eyepiece light, in 0.1mm units, excluding areas of peripapillary atrophy and Elschnig's ring. Margins of cup defined by stereoscopic examination as the point of maximum inflexion of contour, and height of the cup was measured as vertical distance between points of maximal centrifugal extension of cup between 11 and 1 o'clock and 5 and 7 o'clock (Foong et al., 2007) For small discs with no visible cup, the measurement is taken as the diameter of the emerging retinal vessels (Foster et al., 2002)	Automated CDR measurement not possible owing to OCT machine malfunction or the presence of significant media opacity

C.2 Ethics Committee Approvals

C.2.1 University of the West Indies

THE UNIVERSITY OF THE WEST INDIES
ST AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
FACULTY OF MEDICAL SCIENCES
ETHICS COMMITTEE
Telephone: (868) 645-2640 Ext. 5025 Fax: (868) 663-9836 e-mail: deanfms@sta.uwi.edu

May 31, 2012

Prof. Rupert Bourne
Faculty of Medical Sciences
The University of the West Indies
St. Augustine

Dear Prof. Bourne

The national eye survey of Trinidad and Tobago (NESTT)

I am pleased to advise that your application for research on the above captioned topic has been approved on behalf of Ethics Committee.

Yours sincerely

Haytham Al-Bayaty (Dr.)
Ag. Chairman, Ethics Committee
Faculty of Medical Sciences

/erf

C.2.2 Ministry of Health

MINISTRY OF HEALTH Government of the Republic of Trinidad and Tobago

OFFICE OF THE CHIEF MEDICAL OFFICER
O: (868)-627-0010/12/14 exts.1617/1616/1609 F: (868)-623-3755
e-mail: colin.furlonge@health.gov.tt

December 19th, 2013

Professor Samuel Ramsewak
Dean
Faculty of Medical Sciences
Eric Williams Medical Science Complex
Champ Fleurs

Dear Professor Ramsewak

Re: Submission of NESTT Study Proposal for Approval by the Ethics Committee Ministry of Health

The Ethics Committee of the Ministry of Health, Trinidad & Tobago has reviewed your revised proposal for the research study entitled '**National Eye Survey of Trinidad and Tobago (NESTT)**' to be conducted by principal investigator Professor Samuel Ramsewak and co-investigator Prof. Rupert Bourne.

I am pleased to inform you that approval has been granted for the research, excluding the DNA study, thus far.

You are requested to submit an annual progress report or a report at the end of the project, whichever comes first. You are also responsible for immediately informing the Committee of any changes to your research protocol, or of any previous unforeseen risks to the research participants or any unanticipated or serious adverse events.

Best wishes in the conduct of your research.

Regards

Dr. Colin Furlonge
Chief Medical Officer (Ag)

www.health.gov.tt
63, Park Street, Port of Spain, Trinidad. T: (868) 627-0010/12/14

C.2.3 Anglia Ruskin University

12 July 2013

Anglia Ruskin University
Cambridge & Chelmsford

Cambridge Campus
East Road
Cambridge
CB1 1PT

T: 0845 271 3333
Int: +44 (0)1223 363271
www.anglia.ac.uk

Professor Rupert Bourne
Vision and Eye Research Unit
Anglia Ruskin University
East Road
Cambridge
CB1 1PT

Dear Rupert

Re: Application for Ethical Approval

Project Number: 12/104
Project Title: National eye survey of Trinidad and Tobago (NESTT)
Principal Investigator: Professor Rupert Bourne

Thank you for resubmitting your documentation in respect of your application for ethical approval. This has been reviewed by the Chair of the Faculty (of Health, Social Care & Education) Research Ethics Panel (FREP) in advance of the next scheduled meeting in September.

I am pleased to inform you that your research proposal has been approved by the Faculty Research Ethics Panel under the terms of Anglia Ruskin University's *Policy and Code of Practice for the Conduct of Research with Human Participants*. Approval is for a period of three years from 12 July 2013.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Policy and Code of Practice for Research with Human Participants and specifically:

- The procedure for submitting substantial amendments to the Panel, should there be any changes to your research. You cannot implement these changes until you have received approval from FREP for them.
- The procedure for reporting adverse events and incidents.
- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP Secretary copies of this documentation.
- Any laws of the country where you are carrying the research out (if these conflict with any aspects of the ethical approval given, please notify FREP prior to starting the research).

- Any professional codes of conduct relating to research or research or requirements from your funding body (please note that for externally funded research, a project risk assessment must have been carried out prior to starting the research).

- Notifying the FREP Secretary when your study has ended.

Information about the above can be obtained on our website at:

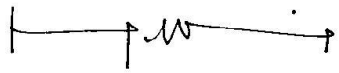
http://web.anglia.ac.uk/anet/rdcs/ethics/index.phtml/

Please also note that your research may be subject to random monitoring by the Panel.

Please be advised that, if your research has not been completed within three years you will need to apply to our Faculty Research Ethics Panel for an extension of ethics approval prior to the date your approval expires. The procedure for this can also be found on the above website.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely



Dr Leslie Gelling
For the Faculty (of Health, Social Care & Education) Research Ethics Panel

T: 0845 196 2529
E: leslie.gelling@anglia.ac.uk

cc:
Beverley Pascoe (RESC Secretary)

Appendix D: Analysis and Supplementary results

D.1 Table detailing the Primary ocular disorder in the better and worse seeing eyes at presentation, and Moorfields Eye Hospital Reading Centre retinal grading outcomes

	BLIND		MSVI		MILD VI	
	Better eye, n (%)	**Worse eye, n (%)**	**Better eye, n (%)**	**Worse eye, n (%)**	**Better eye, n (%)**	**Worse eye, n (%)**
EYES Screened	**31 (100)**	**212(100)**	**215(100)**	**450(100)**	**222(100)**	**301(100)**
Right %	14 (45.2)	98 (46.2)	83 (38.6)	225(50.0)	80 (36.0)	146(48.5)
Left %	7 (22.6)	104(49.1)	92 (42.8)	185(41.1)	103(46.4)	116(38.5)
Equal, %	10 (32.3)	10 (4.7)	40 (18.6)	40(8.9)	39 (17.6)	39(13.0)
Attended clinic exam	13 (41.9)	145(68.4)	161(74.9)	339(75.3)	165(74.3)	240(79.7)
CAUSES						
Uncorrected refractive error	0	2 (0.9)	89 (41.6)	161 (35.8)	117 (52.7)	152 (50.5)
Cataract	9 (29.0)	75 (35.4)	68 (31.8)	138 (30.7)	40 (18.0)	44 (14.6)
Corneal pathology	0	3 (1.4)	3 (1.4)	9 (2.0)	0	4 (1.3)
Aphakia	0	3 (1.4)	0	1 (0.2)	0	0
Diabetic retinopathy	5 (16.1)	16 (7.5)	17 (7.9)	39 (8.7)	21 (9.5)	23 (7.6)
Age-related macular degeneration	0	8 (3.8)	7 (3.3)	26 (5.8)	12 (5.4)	15 (5.0)
Glaucoma	10 (32.3)	34 (16.0)	7 (3.3)	8 (1.8)	4 (1.8)	6 (2.0)
Surgical complication	0	12 (5.7)	4 (1.9)	7 (1.6)	6 (2.7)	2 (0.7)
Amblyopia	1 (3.2)	1 (0.5)	2 (0.9)	8 (1.8)	1 (0.5)	4 (1.3)
Injury	1 (3.2)	24 (11.3)	0	2 (0.4)	0	0
Congenital	0	4 (1.9)	1 (0.5)	1 (0.2)	0	0
Optic nerve pathology	1 (3.2)	3 (1.4)	2 (0.9)	2 (0.4)	0	0
Central nervous system Pathology	0	0	1 (0.5)	4 (0.9)	1 (0.5)	1 (0.3)
Pigmentary retinopathy	1 (3.2)	1 (0.5)	0	1 (0.2)		0
Multiple pathology	1 (3.2)	3 (1.4)	1 (0.5)	3 (0.7) ERM/cat	1 (0.5)	1 (0.3)
Pthysis or prosthesis	0	4 (1.9)	0	0		0
Other cause	1 (3.2)	11 (5.7)	4 (1.9)	16 (3.6)	5 (2.3)	10 (3.3)
Retinal detachment	1	0	0	2	0	0
Macular hole	0	2	1	4	0	2
CRAO	0	3	0	1	0	0
RVO-ME	0	1	0	2	1	3
Exudative maculopathy	0	2	0	0	0	0
Endophthalmitis	0	1	0	0	0	0
Epiretinal membrane	0	0	1	0	0	1
Vitreomacular traction	0	0	0	1	0	0
Myopic MD	0	0	1	1	0	0
Melanoma associated R	0	0	1	1	0	0
Chorioretinal scar	0	0	0	2	0	1
Chronic CSR	0	0	0	1	0	0
Cystoid macular edema	0	0	0	1	0	1
Hypertensive	0	0	0	0	1	1
Retinopathy	0	0	0	0	0	1

Osmotic lens changes						
Cause not determined	1 (3.2)	8 (3.8)	8 (3.7)	22 (4.9)	18 (8.1)	32 (10.6)
Potentially avoidable	26 (83.9)	178 (84.0)	197 (92.1)	398 (88.4)	201 (90.5)	248 (82.4)
MEHRC Grading						
No abnormality	1 (3.2)	8 (3.8)	54 (25,2)	112 (24.9)	73(32.9)	111 (36.9)
Abnormality	5 (16.13)	62 (29.3)	66 (30.8)	146 (32.4)	66 (29.7)	89 (29.6)
Ungradable	6 (19.4)	67 (31.6)	32 (15.9)	66 (14.7)	19 (8.6)	33 (11.0)
No images	19 (61.3)	75 (35.4)	62 (29.0)	126 (28.0)	64 (28.8)	68(22.6)

KEY: CRAO central retinal artery occlusion, **RVO-ME** retinal vein occlusion with macular edema, **MD** macular degeneration, **R** retinopathy **CSR** central serous chorioretinopathy, **MEHRC** Moorfields Eye Hospital Reaching Centre (London, UK).

D.2 Model: Odds of being a responders versus a non-responder

Multilevel multivariable logistic regression model for the odds of responding to the survey

```
melogit responder age i.positioncat i.most12mB sex i.tenurecat2 island || cluster: island, or asis


Mixed-effects logistic regression               Number of obs      =      3433
Group variable:         cluster                 Number of groups   =       120

                                                Obs per group: min =        16
                                                               avg =      28.6
                                                               max =        37

Integration method: mvaghermite                 Integration points =         7

                                                Wald chi2(14)      =         .
Log likelihood = -1385.8809                     Prob > chi2        =         .
------------------------------------------------------------------------------
           responder | Odds Ratio   Std. Err.      z    P>|z|     [95% Conf. Interval]
---------------------+--------------------------------------------------------
                 age |   1.007255   .0066123     1.10   0.271     .9943786    1.020299
                     |
Position in Household |
        Child of Head |    .543715   .0947723    -3.50   0.000     .3863693    .7651384
       Parent of Head |   .3621399   .1268635    -2.90   0.004      .182258    .7195584
    Grandchild of Head |   2.632689   2.835068     0.90   0.369     .3189808    21.72874
      Other Relative   |   .4346115   .0862746    -4.20   0.000     .2945299    .6413174
   Domestic Employee   |   .7690126   .9157034    -0.22   0.825     .0745355    7.934206
                     |
Employment status 12m |
      School/Student   |   9.92e+16          .        .       .            .           .
Had a job and worked   |   .4597056   .0880943    -4.06   0.000     .3157639    .6692637
          Unemployed   |   .5248919   .1638213    -2.07   0.039     .2847119     .967685
             Retired   |   .9064222   .2006959    -0.44   0.657     .5873018    1.398942
            Disabled   |   .5560748   .2129037    -1.53   0.125     .2625637    1.177692
                     |
                 sex |    1.53646   .1669901     3.95   0.000     1.241676    1.901227
                     |
     Household tenure |
              Rented |   .6233572   .0853097    -3.45   0.001     .4767005    .8151327
            Squatted |   .6413566   .3282785    -0.87   0.386     .2351863     1.74899

              island |   1.126956   .4239226     0.32   0.751     .5391553    2.355592
               _cons |   6.951467   3.039369     4.43   0.000     2.950586    16.37739
---------------------+--------------------------------------------------------
cluster              |
          var(island)|   1.07e-30   3.47e-15                           .           .
           var(_cons)|   .4403605   .1062811                      .2743915    .7067179
------------------------------------------------------------------------------
LR test vs. logistic regression:     chi2(0) =    62.97   Prob > chi2 =
```

D.3 Model: Odds of DVI versus normal distance vision

Multilevel multivariable logistic regression model for the odds of DVI

```
melogit VI i.agecattable40 male i.job uninsured dm glaucoma1 cataract nodistspecs island ||
Cluster: island, allbaselevels or asis
```

```
Mixed-effects logistic regression               Number of obs      =      3325
Group variable:         Cluster                 Number of groups   =       120

                                                Obs per group: min =        17
                                                               avg =      27.7
                                                               max =        38

Integration method: mvaghermite                 Integration points =         7

                                                Wald chi2(16)      =    352.52
Log likelihood = -1062.5166                     Prob > chi2        =    0.0000
------------------------------------------------------------------------------
                  VI | Odds Ratio   Std. Err.      z    P>|z|     [95% Conf. Interval]
---------------------+--------------------------------------------------------------
        agecattable40 |
      40 to 49 years  |          1  (base)
      50 to 59 years  |   1.347609   .2690389     1.49   0.135     .9112315    1.992963
      60 to 69 years  |   2.479308   .5514545     4.08   0.000      1.60326    3.834044
      70 to 79 years  |   5.184307   1.247082     6.84   0.000      3.23545     8.30705
  80 years and above  |   10.38767   2.906871     8.36   0.000     6.002323      17.977
                      |
                male  |   1.150243   .1545746     1.04   0.298     .8838964    1.496848
                      |
                 job  |
            Employed  |          1  (base)
        Home duties   |   2.062414   .4192365     3.56   0.000     1.384676    3.071875
            Student   |   2.04e-07   .0008107    -0.00   0.997            0           .
         Unemployed   |   2.196675   .7060739     2.45   0.014     1.169945    4.124452
            Retired   |   1.872124   .3772362     3.11   0.002     1.261293    2.778774
           Disabled   |   5.334779   1.813265     4.93   0.000     2.740295     10.3857
                      |
            uninsured |   1.448318   .3246516     1.65   0.098     .9333845    2.247332
                   dm |   1.867962   .2332731     5.00   0.000      1.46241    2.385981
             cataract |   2.092429   .3616838     4.27   0.000     1.491137    2.936189
            glaucoma1 |   1.458822   .3213176     1.71   0.086     .9473664    2.246397
          nodistspecs |   2.062772   .2714367     5.50   0.000     1.593834    2.669682
               island |   .6727079   .2286845    -1.17   0.244     .3455125    1.309753
                _cons |   .0130081   .0035402   -15.96   0.000     .0076306    .0221753
---------------------+--------------------------------------------------------------
Cluster              |
           var(island)|   2.44e-37   5.60e-20                           .           .
            var(_cons)|   .1319181   .0678904                      .0481106    .3617157
------------------------------------------------------------------------------
LR test vs. logistic regression: chibar2(01) =     5.83 Prob>=chibar2 = 0.0079
```

D.4 Model: Odds of NVI versus normal binocular near vision

Multilevel multivariable logistic regression model for the odds of NVI

```
melogit NVI i.agecattable40 male i.job uninsured nospecs island || Cluster: island, or asis

Mixed-effects logistic regression               Number of obs      =      2896
Group variable:         Cluster                 Number of groups   =       120

                                                Obs per group: min =        13
                                                               avg =      24.1
                                                               max =        35

Integration method: mvaghermite                 Integration points =         7

                                                Wald chi2(13)      =    215.55
Log likelihood =   -1382.02                     Prob > chi2        =    0.0000
------------------------------------------------------------------------------
         NVI | Odds Ratio   Std. Err.      z    P>|z|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
             |
agecattable40 |
50 to 59 years |   1.279882   .1527799     2.07   0.039     1.012889    1.617254
60 to 69 years |   1.037172   .1773443     0.21   0.831     .7418315    1.450094
70 to 79 years |    1.49209    .319719     1.87   0.062     .9803992    2.270842
80 years and above |   2.595262   .7765815     3.19   0.001     1.443696    4.665376
             |
        male |    1.68005   .1867246     4.67   0.000     1.351194    2.088943
             |
         job |
Home duties |   1.839958   .2810193     3.99   0.000     1.363963    2.482064
    Student |   .6494268   .7277474    -0.39   0.700     .0722228    5.839642
 Unemployed |   1.641279   .3882036     2.09   0.036     1.032409    2.609233
    Retired |   1.235714     .21842     1.20   0.231     .8739027    1.747323
   Disabled |   3.760756   1.410783     3.53   0.000     1.802858    7.844924
             |
  uninsured |   2.465815   .3976247     5.60   0.000     1.797629    3.382368
    nospecs |     3.5952   .4493917    10.24   0.000     2.814004    4.593263
     island |   .5364266   .2055452    -1.63   0.104     .2531345    1.136761
      _cons |   .0276448   .0056176   -17.66   0.000     .0185629    .0411702
-------------+----------------------------------------------------------------
Cluster      |
   var(island)|   .3751875   .5103965                      .0260791    5.397635
    var(_cons)|   .0819673   .0485518                      .0256712    .2617186
------------------------------------------------------------------------------
LR test vs. logistic regression:     chi2(2) =     6.85   Prob > chi2 = 0.0326
```

D.5 Model: Odds of full health versus less than full health

Multilevel multivariable logistic regression model for the odds of disutility

```
melogit disutility01 i.highedu2 age sex i.ethcat insured i.vision6 htn dm stroke1
kidney1 depression1 arthritis1 island|| cluster: island, allbaselevels or
> asis
```

```
Mixed-effects logistic regression               Number of obs      =      2411
Group variable:         cluster                 Number of groups   =       120

                                                Obs per group: min =         5
                                                               avg =      20.1
                                                               max =        36

Integration method: mvaghermite                 Integration points =         7

                                                Wald chi2(21)      =    226.74
Log likelihood = -1524.2077                     Prob > chi2        =    0.0000
```

disutility01	Odds Ratio	Std. Err.	z	P>|z|	[95% Conf.	Interval]
highedu2						
Primary School	1	(base)				
Secondary School	.8575956	.0897427	-1.47	0.142	.6985683	1.052825
Post-secondary	.7175894	.1220418	-1.95	0.051	.5141745	1.001478
University	.6339975	.1246417	-2.32	0.020	.4312651	.932032
age	1.023665	.0046604	5.14	0.000	1.014571	1.03284
sex	1.619577	.148825	5.25	0.000	1.352645	1.939187
ethcat						
African	1	(base)				
Indian	.8164619	.0852557	-1.94	0.052	.6653539	1.001888
Other ethnic group	1.216725	.5608554	0.43	0.670	.492977	3.003019
Mixed ethnicity	.7530829	.1114663	-1.92	0.055	.5634477	1.006542
insured	.7379214	.0920953	-2.44	0.015	.5777993	.9424172
vision6						
Normal distance both and binocular near	1	(base)				
Normal distance but NVI	1.301949	.1561146	2.20	0.028	1.029266	1.646873
Better eye normal	1.097425	.1446886	0.71	0.481	.8475182	1.42102
Better eye Mild VI	1.478	.2826223	2.04	0.041	1.016034	2.150011
Better eye MSVI	1.370461	.2676826	1.61	0.107	.9345601	2.009675
Blind	12.63178	13.35446	2.40	0.016	1.590614	100.3146
htn	1.278458	.1304901	2.41	0.016	1.046661	1.561591
dm	1.240485	.1419402	1.88	0.060	.9912752	1.552346
stroke1	1.952605	.5870175	2.23	0.026	1.083216	3.519765
kidney1	1.611	.5552743	1.38	0.167	.8197969	3.165811
depression1	5.494223	2.840722	3.30	0.001	1.994356	15.13595
arthritis1	2.687788	.4558724	5.83	0.000	1.927631	3.747713
island	.7034161	.1579301	-1.57	0.117	.4530035	1.092252
_cons	.1669745	.0496707	-6.02	0.000	.0932051	.2991308
cluster						
var(island)	6.01e-33	7.35e-17			.	.
var(_cons)	.0765181	.0407353			.0269536	.2172255

```
LR test vs. logistic regression: chibar2(01) =     5.41 Prob>=chibar2 = 0.0100
```

D.6 Additional characteristics for variables non significant in multivariable analysis, comparing those reporting full health to those reporting less than full health

Variable (n)	Categories	Full health % (n)	Less than full health % (n)	Odds ratio (95% CI) Wald p value	p-value*
Job status (2507)	Employed Home duties Student Unemployed Retired Disabled	57.0 (705) 16.0 (198) 0.3 (4) 2.8 (35) 22.9 (284) 1.0 (12)	36.2 (459) 20.7 (263) 0.1 (1) 3.5 (44) 36.6 (465) 2.9 (37)	1.0 2.03 (1.62-2.54) 0.40 (0.04-3.66) 1.91 (1.19-3.04) 2.57 (2.12-3.12) 4.63 (2.37-9.04)	<0.001
Household monthly income, TT$ (2563)	< 1000 1000-4999 5000-9999 10,000-30,000 >30,000	0.5 (7) 34.1 (438) 40.6 (522) 22.6 (291) 2.2 (28)	0.9 (11) 42.9 (548) 42.1 (537) 12.9 (165) 1.3 (16)	1.00 0.77 (0.29-2.04) 0.64 (0.2501.69) 0.35 (0.13-0.93) 0.35 (0.11-1.12)	<0.001
Prescribed drugs (2594)	No Yes	57.8 (747) 42.2 (546)	42.3 (550) 57.7 (751)	1.00 1.91 (1.63-2.24)	<0.001
Marital status (2514)	Unmarried Married Cohabiting Divorced Separated Widowed	16.6 (212) 55.1 (706) 10.5 (135) 5.7 (73) 4.1 (53) 8.0 (102)	17.2 (212) 46.7 (576) 8.0 (99) 7.3 (90) 4.7 (58) 16.1 (198)	1.0 0.83 (0.66-1.04) 0.75 (0.54-1.04) 1.28 (0.88-1.85) 1.13 (0.74-1.74) 2.00 (1.47-2.74)	<0.001
Heart attack (2634)	No Yes	98.3 (1290) 1.7 (22)	96.1 (1271) 3.9 (51)	2.40 (1.44-4.01)	<0.001
Renal disease (2634)	No Yes	98.8 (1296) 1.2 (16)	97.1 (1284) 2.9 (38)	1.0 2.42 (1.33-4.39)	0.002
Hearing loss (2634)	No Yes	99.1(1,300) 0.9 (12)	97.7 (1293) 2.3 (30)	1.00 2.52 (1.27-4.99)	0.006
Use of illicit drugs (2634)	No Yes	91.5 (1201) 8.5 (111)	94.2 (1245) 5.8 (77)	1.00 0.66 (0.49-0.90)	0.009
Binge alcohol (2634)	No Yes	88.6 (1147) 11.4 (148)	91.4 (1187) 8.6 (112)	1.00 0.72 (0.55-0.93)	0.013
Cancer (2634)	No Yes	98.2 (1288) 1.8 (24)	97.1 (1284) 2.9 (38)	1.00 1.63 (0.96-2.76)	0.066
Religion (2441)	Christianity Hinduism Islam Other	74.4 (948) 20.9 (267) 3.5 (44) 1.3 (16)	72.6 (847) 21.5 (251) 5.1 (59) 0.8 (9)		0.214
Smoker (2634)	No Yes	88.6 (1162) 11.4 (150)	88.9 (1175) 11.1 (147)		0.694
Literacy (2586)	Literate Basic literacy Not literate	85.4 (1101) 14.1 (182) 0.5 (7)	76.2 (988) 22.0 (285) 1.8 (23)		0.784
Thyroid disease (2634)	No Yes	97.0 (1273) 3.0 (39)	97.1 (1283) 3.0 (39)		0.999

** p-values from single variable analysis with odds ratios presented for those variables reaching significance

D.7 Model: Association between utility value and vision level

```
svyset cluster [pweight = wgtu], poststrata(stratavar) postweight(popsizeutility) strata(island)
svy: regress utility i.WHOnear i.agecattable40 sex stroke1 kidney1 depression1 arthritis1 dm htn
regularmeds1 i.job uninsured i.illiterate

Survey: Linear regression

Number of strata   =         1                  Number of obs      =      2194
Number of PSUs     =       120                  Population size    =    513585
N. of poststrata   =       261                  Design df          =       119
                                                F(  24,     96)    =     27.89
                                                Prob > F           =    0.0000
                                                R-squared          =    0.2630

------------------------------------------------------------------------------
             |             Linearized
   utility2016 |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
     WHOnear |
         NVI |  -.0124303   .0044681    -2.78   0.006    -.0212776    -.003583
    Mild VI  |  -.0198588   .0078584    -2.53   0.013    -.0354193   -.0042983
         MVI |  -.0454978   .0108148    -4.21   0.000    -.0669122   -.0240834
         SVI |  -.0913218   .0303166    -3.01   0.003    -.1513516   -.0312919
       Blind |  -.1421648   .0251483    -5.65   0.000     -.191961   -.0923686
             |
  agecattable40 |
50 to 59 years |  -.0079533    .003383    -2.35   0.020    -.0146519   -.0012547
60 to 69 years |  -.0240774   .0052911    -4.55   0.000    -.0345543   -.0136005
70 to 79 years |  -.0538577   .0075465    -7.14   0.000    -.0688006   -.0389148
80 years and above |  -.1098088   .0129009    -8.51   0.000     -.135354   -.0842637
             |
           sex |  -.0137324   .0036293    -3.78   0.000    -.0209188    -.006546
       stroke1 |  -.1099235   .0177758    -6.18   0.000    -.1451212   -.0747257
       kidney1 |  -.0404358   .0139863    -2.89   0.005    -.0681301   -.0127415
   depression1 |  -.0503368   .0204304    -2.46   0.015     -.090791   -.0098826
     arthritis1 |  -.0483254   .0075491    -6.40   0.000    -.0632734   -.0333774
             dm |  -.0093142   .0059102    -1.58   0.118     -.021017    .0023886
            htn |  -.0070578   .0055624    -1.27   0.207    -.0180718    .0039562
   regularmeds1 |  -.0108772   .0053167    -2.05   0.043    -.0214048   -.0003496
             |
            job |
   Home duties |  -.0002482   .0057126    -0.04   0.965    -.0115597    .0110633
    Unemployed |  -.0055583   .0105617    -0.53   0.600    -.0264715    .0153549
       Retired |   .0090214   .0061782     1.46   0.147     -.003212    .0212548
      Disabled |  -.0671699   .0232792    -2.89   0.005    -.1132652   -.0210747
             |
      uninsured |  -.0076933   .0043209    -1.78   0.078    -.0162491    .0008625
             |
     illiterate |
 Basic literacy |   .0023704   .0052588     0.45   0.653    -.0080426    .0127833
    Illiterate |   -.058126   .0249904    -2.33   0.022    -.1076095   -.0086425
             |
           _cons |   .9786472   .0045942   213.02   0.000     .9695503    .9877441
------------------------------------------------------------------------------
```

D.8 Model: Association between EQ-VAS score and vision level

Multivariable linear regression model to explore the mean change in utility coefficient according to multiple predictor variables

```
. svy: regress eqvas sex i.agecattable40 i.ethcat i.WHOnear dm htn regularmeds1 drugs stroke1
depression1 arthritis1

Survey: Linear regression

Number of strata   =         1                  Number of obs      =      2332
Number of PSUs     =       120                  Population size    =    514296
N. of poststrata   =       261                  Design df          =       119
                                                F(  20,    100)    =     16.61
                                                Prob > F           =    0.0000
                                                R-squared          =    0.1242

------------------------------------------------------------------------------
             |             Linearized
       eqvas |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
         sex |  -1.863297   .5403031    -3.45   0.001    -2.933151   -.7934431
             |
agecattable40 |
50 to 59 years |   .8104338   .7456307     1.09   0.279    -.6659895    2.286857
60 to 69 years |   .5699576   .9635314     0.59   0.555    -1.337931    2.477846
70 to 79 years |  -.7872307    1.20806    -0.65   0.516     -3.17931    1.604848
80 years and above |  -6.197708   1.700436    -3.64   0.000    -9.564741   -2.830675
             |
      ethcat |
      Indian |   .8924092   .6105678     1.46   0.146     -.316576    2.101394
Other ethnic group |   3.308046   1.291762     2.56   0.012     .7502286    5.865864
Mixed ethnicity |   1.265709   .9832078     1.29   0.200    -.6811408    3.212558
             |
     WHOnear |
        NVI |  -1.561822   .7137677    -2.19   0.031    -2.975153   -.1484907
    Mild VI |    -2.4998   1.639868    -1.52   0.130    -5.746903    .7473026
        MVI |  -6.184839     1.5131    -4.09   0.000    -9.180928    -3.18875
        SVI |  -6.039664   3.991355    -1.51   0.133    -13.94295    1.863617
      Blind |   -7.77795   3.808814    -2.04   0.043    -15.31978   -.2361186
             |
         dm |  -3.834832   .9557524    -4.01   0.000    -5.727317   -1.942347
        htn |     -1.887   .7909514    -2.39   0.019    -3.453162   -.3208368
regularmeds1 |  -3.698916   .8947376    -4.13   0.000    -5.470586   -1.927247
      drugs |  -.8990841   1.083265    -0.83   0.408    -3.044056    1.245888
    stroke1 |   -7.20214    1.95218    -3.69   0.000    -11.06765   -3.336628
depression1 |   -6.07775   2.560142    -2.37   0.019    -11.14709   -1.008414
  arthritis1 |  -1.824227   1.089731    -1.67   0.097    -3.982003    .3335488
       _cons |   85.42441   .6855249   124.61   0.000       84.067    86.78182
------------------------------------------------------------------------------
```

D.9 Productivity loss in 40-64 year olds in 2014, by vision category, estimated from the employment rate gap resulting from vision impairment

Vision category	n	ER*	Gap	Median annual income TT$	PL	Cases in 2014	TOTAL PL
Normal	1561	73.2	-0.07	54000	-2638.8	258726	-682735706.6
NVI	795	63.9	0.06	54000	2366.9	134244	317737113.8
Mild VI	94	54.5	0.20	54000	7432.2	16431	122120496.6
MSVI	69	41.4	0.39	54000	14505.9	11103	161064270.2
Blind	5	0.0	1.00	54000	36868.7	812	29937439.33
TOTAL	2524	68.3				421316	630,859,319.9

ER* Adjusted employment rate; PL productivity loss

D.10 Productivity loss associated with part-time work (assuming 50% working hours)

Vision category	% PT	ER for PT	Gap PT	Median annual income TT$	PL	n	Additional PL for PT
Normal	11.1	69.1	-0.08	54000	-2936.9	258,726	-77,107,869.5
NVI	15.2	59.0	0.08	54000	2864.2	134,244	66,757,509.0
Mild VI	17.9	49.6	0.22	54000	8292.6	16,431	14,137,453.1
MSVI	12.0	38.9	0.39	54000	14450.2	11,103	-618,734.4
Blind	0.0	0.0	1.00	54000	36868.7	812	0.0
TOTAL	12.5	64.0					80,276,227.7

KEY: ER employment rate; PL productivity loss; PT part time (assumed to be 50% working hours); TT Trinidad and Tobago; VI vision impairment.

D.11 Information Commissioner's Office (ICO) employment group by category of presenting vision

ICO employment group	Normal	NVI	Mild VI	MSVI	Blind	Total
Professionals	43.6 (331)	26.5 (85)	10.8 (4)	38.5 (10)	0	37.6 (430)
Elementary occupation	18.4 (140)	24.3 (78)	32.4 (12)	23.1 (6)	0	20.6 (236)
Service workers	16.2 (123)	20.9 (67)	35.1 (13)	19.2 (5)	0	18.2 (208)
Clerical support work	5.4 (41)	2.2 (7)	0	0	0	4.2 (48)
Technicians	4.3 (33)	2.8 (9)	2.7 (1)	3.9 (1)	0	3.9 (44)
Machine operators	4.0 (30)	7.8 (25)	5.4 (2)	0	0	5.0 (57)
Craft	3.0 (23)	6.9 (22)	2.7 (1)	7.7 (2)	0	4.2 (48)
Armed forces	2.9 (22)	2.8 (9)	2.7 (1)	0	0	2.8 (32)
Skilled agricultural	2.1 (16)	5.9 (19)	8.1 (3)	7.7 (2)	0	3.5 (40)
Total	100 (759)	100 (321)	100 (37)	100 (26)	0	100 (1143)

D.12 Estimation of DALY loss in 2014

Vision category	2014 cases	DW	pYLD	YLL	DALY	95 % CI	95 % CI
Mild VI	31,267	0.005	156	0	156	137	176
MVI	26,661	0.089	2373	0	2373	2055	2686
SVI	2,547	0.314	800	0	800	476	1106
Blind	3,956	0.338	1337	0	1337	879	1777
NVI	120,842	0.047	5680	0	5680	5298	6062
TOTAL vision loss	185,273		10346		10346	8845	11806

KEY: pYLD prevalent years lived with disability; YLL Years of life lost; DALY disability adjusted life years; VI vision impairment; M moderate; S severe; N near; DW disability weight

D.13 Eye care episodes, health insurance status and preference for exclusive public sector use for eye care/vision, by category of vision

Prevalence		Vision category				
		Normal	**NVI**	**Mild VI**	**MSVI**	**Blind**
Any eye care episodes in past 12 months	**Crude % (n/N)**	32.2 (468/1452)	18.5 (135/728)	29.2 (47/161)	31.7 (50/158)	7.7 (1/13)
	Adjusted %,95% CI	30.7 (28.35-33.22)	18.15 (15.85-20.70)	26.42 (20.60-33.21)	32.11 (25.31-39.76)	4.60 (0.73-24.01)
	OR* 95% CI	1.0	0.49 (0.39-0.61)	0.72 (0.50-1.06)	0.75 (0.52-1.09)	0.11 (0.01-0.85)
Health insured	**Crude % (n/N)**	24.0 (473/1968)	10.7 (113/1053)	9.6 (21/218)	3.8 (8/212)	0 (0/30)
	Adjusted %,95% CI	24.6 (21.8 to 27.6)	12.0 (10.2 to 14.2)	9.9 (6.5 to 14.9)	5.1 (2.6 to 9.9)	0
	OR* 95% CI	1.0	0.42 (0.33-0.54)	0.69 (0.41-1.13)	0.25 (0.12-0.52)	0
Public sector use only	**Crude % (n/N)**	11.2 (165/1470)	29.0 (218/751)	30.3 (54/178)	47.2 (85/180)	54.2 (13/24)
	Adjusted % 95% CI	10.46 (8.84-12.34)	26.96 (23.86-30.31)	30.71 (24.13-38.17)	41.88 (34.96-49.13)	60.02 (45.10-73.29)
	OR* 95% CI	1.0	3.29 (2.58-4.18)	2.74 (1.86-4.04)	5.69 (3.94-8.19)	7.12 (2.92-17.37)

* Prevalence estimate adjusted for multilevel design (island, cluster), weighted for response rate (by cluster), with post-stratification adjustment to 2011 Census population stratified by municipality (15), 5-year age groups and gender
** Odds of outcome, by vision category, adjusted for age and sex in multivariable model.

Global Wald p< 0.001