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A cross border comparative study of the vision related quality of life of urban and rural dwelling people aged 60 years and older who are registrable as vision impaired in Ireland

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A cross border comparative study of the vision related quality of life of urban and rural dwelling people aged 60 years and older who are registrable as vision impaired in Ireland.

A thesis submitted for the degree of Doctor of Philosophy

School of Medicine, Dentistry and Biomedical Sciences
Queen's University Belfast

by

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Abstract

This research seeks to evaluate the effects of visual impairment on people aged 60 and over on the island of Ireland, so that service providers can prepare appropriate and effective health care strategies in light of changing demographics. Participants for this study were selected from the registers of vision impaired persons in the Republic and North of Ireland. A total of 343 people who met the inclusion criteria were recruited to the study. Interviews, averaging 1.75 hour's duration, were conducted with 222 consenting participants. In addition, 121 vision impaired individuals agreed to participate in 14 focus groups. This allowed the researcher to explore further issues raised during individual interviews. A focus group was held with frontline professionals.

QOL scores are better in the Republic of Ireland than in Northern Ireland. Those living in Republic of Ireland (Dublin/urban) scored highest while those living in Northern Ireland (Belfast/urban) scored worst in every domain for QOL. Over 50% were living alone and 73% reported difficulty in getting around. Fear of falling was experienced by 73%, 64% had fallen and over 60% had received injuries as a result of their fall. Only 12.6% had received full formal mobility training. Dependency on family support was high, particularly for transport. The majority found public transport very difficult to use even where it was frequently available. Service providers & peer support groups were singled out for special praise. A public information and awareness campaign about sight loss is essential. Although over 75% reported at least one additional disability or illnesses, when asked what they might do to change their lives, the majority responded that they would like to have their eyesight restored. The implications of these findings highlight the challenges ahead for service providers and policy makers in meeting the needs of this growing population.

*The only thing worse than being blind
is having sight but no vision.*

Helen Keller

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I dedicate this work to my children

Fiachra and Caoimhe

You are my sunshine, my flowers, my reason for being.

Don't be afraid of the space between your dreams and reality.

If you can dream it, you can make it so.

-- Belva Davis.

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Chapter 1

1.0 Introduction

Vision impairment¹ not only has a serious personal, social and psychological impact on the individual (i.e. loss of functional ability and self-esteem), it also has a significant effect on society. In particular, it has a sizeable economic impact, through loss of productivity and income. Costs associated with the delivery of the necessary rehabilitative support required to minimize the effect on the individual can be high. "Blindness, with its social and economic consequences, therefore represents a significant public health problem in many parts of the world" (Thylefors, 1999: 453).

In light of the fact that our population is ageing it is likely that there will be an increased need and demand for eye care services. Vision loss leading to irreversible vision difficulties is common among the older population. The difficulties caused by low vision and blindness can have a major impact on the daily functioning of this cohort (Swagarty, 1995). Most research conducted on the topic of quality of life (QOL) and vision impairment has been mainly disease or intervention specific. There is however, very little information available on the implications and consequences of visual impairment in Ireland. As far as the author can ascertain, there is no other study available in Ireland, which has undertaken comparisons of the QOL of urban and rural dwelling people with vision impairment living in both jurisdictions.

¹ Blindness and vision impairment are used both together and interchangeably within this document. This terminology is inclusive of all people who are registrable as blind in both jurisdictions in Ireland.

1.1 Demographics

1.1.1 Global demographics²

The current world population stands at 6.7 billion. Demographic trends indicate that the global population will increase to an estimated 7.65 billion by 2020 (US Census Bureau, 2008). It is expected that this figure will rise to 9.2 billion by 2050 (UN Population Division 2007). There are currently 1 billion people aged 55 and older in the world today. This constitutes approximately 15% of the global population (US Census Bureau, 2008).

1.1.2 European Union demographics

The population of the European Union (EU 27) in 2007 was 495 million people (Eurostat, 2008). This is an increase of 3.4% over the last decade. Currently the proportion of people aged 50 and over in the EU is 35.2%. Those aged between 65 and 79 comprise 12.6% of the population while those aged 80 and over make up 4.3% of the population (Eurostat, 2008).

1.1.3 UK Population/Northern Ireland population

The total population of the UK according to the last census in 2001 was 60,512,390. The median age of the population was 39 with 18% under the age of 15 while 22% were aged over 60 (ONS, 2008).

UK life expectancy at birth in 2006 was 77 years for males with a healthy life expectancy at birth (HALE) of 69 years. Life expectancy at birth for females in 2006 was 82 years with a HALE of 72. Combined life expectancy at birth

². There is no harmony in the reporting of these figures. Please note that data is not available for some age bands

was 79 in 2006 with a HALE of 71. HALE is the "average number of years that a person can expect to live in "full health" by taking into account years lived in less than full health due to disease and/or injury" (WHO, 2008).

Northern Ireland is home to approximately 3% of the UK population. The mid year population estimates for Northern Ireland in June 2006 gave a total population of 1,741,619 comprising 853,404 males and 888,215 females (NISRA 2008). The population aged over 60 was 326,311, (18.7 %) of the population, with 143,136 males and 183,175 females. Population growth for the UK in 2005 was greatest in Northern Ireland at 0.8% (NISRA 2006). The population of Northern Ireland has proportionally more younger people than the UK population in total with 20.86% of its population aged under 15 in 2004 compared to 18.6% for the UK population (ONS, 2008).

1.1.4 Republic of Ireland population

The total population of the Republic of Ireland according to the last census in 2006 was 4,239,848 with a gender breakdown of males 2,121,171 and females 2,118,677. The median age of the population was 34. Twenty one percent were under the age of 15 while 15% were aged over 60 (CSO, 2007). The population aged over 60 was 649,653, with 298,656 males and 350,997 females (CSO, 2007).

Ireland had the fastest growing population in the EU at 18% growth since 1997 (Eurostat, 2008). It is predicted that the population of Ireland will rise to over 6 million by 2050 (Eurostat 2008).

Ireland's life expectancy at birth in 2006 was 77 years for males with a healthy life expectancy at birth (HALE) of 68 years. Life expectancy at birth for females in 2006 was 81 years with a HALE of 72. Combined life expectancy at birth was 80 in 2006 with a HALE of 70 (WHO, 2008).

1.2 Ageing

1.2.1 Global

The population is increasing worldwide. The population of older people is increasing at least twice as fast as the population as a whole. The global population of people aged 60 years and over almost trebled over the last 50 years increasing from 205 million in 1950 to 606 million in 2000. During the same period life expectancy increased by 20 years from 46 years in 1950 to 66 years in 2000. The population of older people (60+) is expected to increase from 673 million in 2005 to 1.2 billion by 2025 and to reach 2 billion by 2050 (Johnson et al., 2005; UN Population Division, 2007). These projections indicate that the global population of people aged over 60 will rise from 15.3% of the population in 2005 to 29.3% of the population by 2050 (UN Population Division, 2007).

The greatest growth in the older population is taking place in the most developed countries in the world where the proportion of the oldest old (80+) is increasing significantly. This population is expected to increase from 2.7% of the population in 2005 to 6.7% of the population by 2050, i.e. from 88 million in 2005 to 402 million in 2050 (UN Population Division, 2007). Those aged 80+ currently comprise 13% of the 60+ population and this figure is expected to rise to 20% by 2050. The population of centenarians, i.e. those people aged 100+, is expected to increase fourteen-fold by 2050 to 3.7 million from 265,000 in 2005 (UN Population Division, 2007).

1.2.2 European

Over the next quarter-century, Europe is projected to retain its title of "oldest" region in the world. This phenomenon is referred to as "population ageing". The median age of the EU 27 population is expected to rise from its current

figure in 2008 of 40.4 years to 47.9 years by 2060. The proportion of the EU27 population aged 65+ is currently 17.1% (84.6 million) in 2008 and is predicted to increase to 30% (151.5 million) by 2060 (Giannakouris, 2008). In 2003 3.8% of the population of the EU 25 was aged 80 or over. This percentage has increased from 1.6% in 1963 (Eurostat 2005). This population (80+) will triple from the current figure of 21.8 million to 61.4 million by 2060 (Giannakouris, 2008). The tripling of the population of older people means that the elderly dependency ratio in the EU member states will grow from 24.5% in 2004 to a predicted figure of 52.8% by 2050. Elderly dependency ratio is the ratio of the number of older people of an age when they are, in the main, economically inactive to the number of persons of working age. This demographic transition is occurring as the birth and death rates lower simultaneously. As a result of this growth in the older population and the reduction in the birth rates, there will be three dependent people to every four of working age (Eurostat, 2008).

1.2.3 Ageing UK/NI & ROI

In the UK people aged over 50 comprised 14.7% of the population in 1901. By 2003 they made up 33.3% of the population and it is predicted that by 2031 this figure will increase by 36% (ONS, 2005). The greatest increase in population has been in the oldest old (i.e. those aged 85+). To demonstrate this increase one can look at the number of centenarians (people who reach the age of 100) in the population of England and Wales. This figure has increased from 100 centenarians in 1961 to 8600 in 2001. By 2031 it is expected that this figure will increase to 48,000 centenarians (ONS, 2005). People aged 85+ as a proportion of the population increased from 0.7 in 1960 to 1.9 in 2004 in the UK while in Ireland it changed from 0.6 to 1.1. This age cohort (85+) is the fastest growing group (McGee, 2005). In fact Ireland was the only country in the EU where the proportion of people age 65+ did not change during this time and remained at 11.1% over the period,

while in the UK the proportion of the population in this age group rose from 11.7% in 1960 to 15.6% in 2004 (ONS, 2008). Due to the higher fertility rates in Ireland, both Northern Ireland and the Republic of Ireland have a younger population than Great Britain (NISRA 2008; CSO, 2008). Population projections for Northern Ireland predict that by 2051 the population will be 2,070,000. The population aged over 60 will comprise 32% of the population, 662,000, with 6000 of these aged 100 or more (NISRA, 2008).

UN population projections predict that the global population of people aged over 60 in the UK will rise from 21.2% of the population in 2005 to 30.1% of the population by 2050. The largest growth will be in those aged 80 and over. This population is expected to increase from 4.5% of the population in 2005 to 9.2% of the population by 2050 (UN Population Division, 2008).

1.3 Urban and rural residence

1.3.1 Republic of Ireland

Urban dwellers comprised 61% of the population (Census 2006). The rural population is made up of 12.2% people aged 65 and older while the urban population contains 10.3% older people.

There has been a major shift in urban-rural population allocation in the last century. In 1926 urban dwellers comprised 32% of the population of the Irish Free State. By 2002 they made up 60% of the population of the Irish Republic (CSO, 2007).

1.3.2 Northern Ireland

Urban dwellers comprised 90% of the population of the UK. However, the rural population of Northern Ireland is much more like that of the Republic of Ireland, comprising approximately 35% of the population (NISRA, 2008). It is expected that the rural population in Northern Ireland will grow by 9.8% over the next decade while the urban population is expected to grow at a much lower rate of 1.3% (ONS, 2008).

1.4 Global Population of blind and low Vision

An absence of epidemiological data means that the exact number of blind persons in the world is not known. The estimated worldwide prevalence of blindness is 0.7%, ranging from 0.3% in the Established Market Economies and Former Socialist Economies of Europe to 0.6% in China, 1% in India and 1.4% in Sub-Saharan Africa (WHO, 1997). (Definitions of blindness and low vision are given in the next section of this chapter.)

According to WHO there are 161 million people with vision impairment worldwide (WHO, 2003). Of these, 124 million have low vision and 37 million are blind. However, an additional 153 million suffer from vision impairment due to uncorrected refractive error (WHO, 2003).

Visual impairment and vision loss increase dramatically with age. WHO states that worldwide, approximately 4% of those aged over 60 are thought to be blind (WHO, 1999). The World Blind Union (WBU) state that between 50 and 75% of all known cases of blindness occur in persons 65 years of age or older. "With the predicted increase in the number of older people worldwide...it is estimated that 80% of new cases of blindness will be ageing related" (WHO, 1999). A study by Robinson et al. found that those least likely to be registered included the elderly, ethnic minorities, and patients undergoing treatment for chronic ophthalmic problems (1994). Under-registration "may be accounted

for by either under-recognition of eye disease or under-utilisation of services by elderly visually impaired people. The majority of those in this group will be female, suffer from age related macular degeneration and other forms of disability" (Jackson, 2007).

World Health Organisation (WHO) estimates of visual impairment derived from predicted elderly population increases indicate that the number of visually impaired people will have virtually doubled by 2021. In light of predicted demographic trends and the consequent likelihood of increased need and demand for eye care services, "the challenge for governments and health care providers will be to meet this demand" (WHO, 1997; Part V).

1.4.1 European figures of blindness

According to WHO approximately 2.7 million blind people live in Europe, this constitutes seven percent of the global blind population. There are, in addition, about 12.8 million people with low vision in Europe, giving a total population of people with vision impairment in Europe of 15.5 million (WHO, 2005).

Conservative estimates put the number of people who are blind or severely vision impaired because of macular degeneration at around 8 million worldwide. The absence of epidemiological data among many populations means that the true figure is probably much higher (WHO, 1997b). A study in Northern Ireland revealed that the number of individuals newly registered as blind or partially sighted as a result of Age Related Macular Degeneration (AMD) has increased by a factor of three over a twelve year period between 1984 and 1996 (Canavan et al., 1997). A more recent study in the Irish Republic shows a significant increase in the numbers of people who are registered as blind due to Age Related Macular Degeneration. Twenty five percent of the Irish register of blind people consists of people with ARMD. In 2003, of the 751 new cases added to the Irish register, 42% were due to ARMD (Kelliher et al., 2006). According to WHO this condition is seen in

around 25% of persons aged 80 years and older. As it progresses, it usually causes reading difficulties, followed by a loss of central vision, and leads finally to a dense central scotoma and severe visual disability. The increase in age related ophthalmic disease is consistent with increased longevity and changing demographic characteristics of the overall population.

1.5 Definitions of blindness

The WHO definitions of blindness and low vision, as included in the International Statistical Classification of Diseases, and Related Health Problems, tenth revision (ICD-10), include both quantifiable measures of vision (visual acuity and visual field) and reference to everyday visual functionality (WHO, 1992).

1.5.1 WHO definition of blindness

Blindness is defined as visual acuity of less than 3/60 (0.05 decimal/1.3 logMAR) or corresponding visual field loss in the better eye, with best possible correction (visual impairment categories 3, 4 and 5 in ICD-10). This corresponds to loss of walk-about vision.

Low vision corresponds to visual acuity of less than 6/18 (0.3 decimal/0.5 logMAR approx) but equal to or better than 3/60 in the better eye, with the best possible correction (visual impairment categories 1 and 2 in ICD-10).

1.5.2 Definition of blindness in Republic of Ireland

There is only one category of blindness in the Republic of Ireland. The statutory definition of blindness is visual acuity (VA) corrected with glasses of less than 6/60 (0.1 decimal/1.0 logMAR) in the better eye, or a field of vision

limited to a widest diameter of vision subtending an angle of not more than 20 degrees (NCBI 2008).

1.5.3 Definition of blindness in UK

There are two categories of blindness in the UK (including Northern Ireland), one for blindness, and one for partial sight.

1.5.3a Blindness

The definition of blindness is, as stated in the 1920 Blind Persons Act, "so blind as to be unable to perform work for which eyesight is essential" (BPA, 1920). Explanatory notes included with the original English BD8 Registration Form specify eligibility criteria for Blind Registration. Guidelines indicate that those with a Visual Acuity of $<3/60$ or $<1/18$) are eligible to be registered as blind. Extensive visual field loss can also entitle someone to be registered, at a better level of VA, than that required for full fields. This is particularly the case if the field loss is most marked in the inferior quadrants, a recognition that mobility is impacted most heavily by inferior loss.

1.5.3b Partial sight

A subsidiary register known as the "Partially Sighted Register" was established subsequent to the 1948 National Assistance Act, (NAA 1948). The definition of partial sight was such as to include "those who were substantially and permanently handicapped by congenitally defective vision or in whose case illness or injury had caused defective vision of a substantial and permanently handicapping character". Those with a VA of between $6/60$ and $3/60$ are eligible for partial sighted registration (Canavan et al., 1997). As with blind

registration visual field loss can also entitle someone to be registered, at a better level of VA, than that required for full fields. The proportion of those registered on the basis of field loss is, however, known to be small (Robinson et al., 1994).

Despite changes to the registration process in the UK, introduced in 2003, no changes have been made to the definitions.

1.5.4 Definitions of blindness in the EU

The differing definitions of blindness between the two jurisdictions on the island of Ireland inspired a research paper on definitions of blindness in Europe. For this research an investigation of the existing definitions relating to vision impairment in the various member states of the EU was undertaken to see if different definitions existed within the EU. Results show that throughout the EU many varying definitions of blindness and low vision exist and different terminology is often used to describe similar things. In the UK, for example as shown above, the terminology used is blindness and partial sight. The latter term is almost exclusive to the UK and refers to those registered whose level of vision impairment is less severe than that for classification as "blind". Just as terminology differs from country to country so too do the quantifiable definitions linked to the terminology. Some countries use different visual acuity categories whereas others categorise visual field loss differently to blindness relating to visual acuity.

A number of countries use WHO definitions or close derivatives of the WHO definitions while others use individual definitions. Some countries, including Austria & Sweden, have no legal definition of blindness. In these cases individual service providers determine the extent of the visual disability they will work with. Eight countries, Cyprus, Greece, Ireland, Italy, Luxembourg, The Netherlands, Portugal and Spain, recognise only one category of blindness although Italy and the Netherlands have "generally accepted" definitions of

low vision. Ten countries, Cyprus, Denmark, France, Germany, Greece, Hungary, Italy, Malta, The Netherlands, and Portugal, do not refer to visual field as pertaining to the registration process in their legal definition of blindness.

1.5.4a Low vision

The term "low vision" is used frequently now both among service providers and in the literature. So what is low vision? The Lighthouse organisation, a major service provider and research organisation in the field of vision impairment based in New York, defines low vision as follows: "Partial vision loss that cannot be corrected causes a vision impairment known as 'low vision'. A person with low vision has severely reduced visual acuity or contrast sensitivity, a significantly obstructed field of vision -- or all three". Categories 1 & 2 of the WHO definition are also referred to as low vision.

1.6 Registration UK/NI & ROI

Within the UK and Republic of Ireland data on vision impairment is normally drawn from official registration databases. The definitions of blindness used for inclusion on these registers not only differ from WHO definitions of blindness and low vision, they differ between jurisdictions. Registration as blind or partially sighted is voluntary in both jurisdictions but is linked to certain benefits such as the blind persons' pension (ROI), a travel pass (NI & ROI), a companion free travel pass (ROI) and tax credits (ROI) for blind people.

1.6.1 Northern Ireland

(Source: Department of Health, Social Services, and Public Safety, Community Statistics, Community Information Branch)

As in the UK there are two registers for people with sight loss in Northern Ireland, a blind register and a partially sighted register. These registers are also accessible via the SOSKARE register, a database of everyone who has used social services. This database also contains the names of all those who are known to have serious sight loss whether or not they have chosen to register. SOSKARE is an acronym for Social Services Client Administration and Retrieval Environment.

It was not possible to get a breakdown on the Northern Ireland register for those aged 60 and over. The age breakdowns for older people were those aged between 65 and 74 and those aged 75+. There were 2102 people registered as blind on the SOSKARE register in Northern Ireland on 31 March 2007. Of these 1272 people were aged over 65, 272 were aged 65 to 74 and 998 were aged over 75. Exact age data was missing for two people but they were included on the register as aged over 65.

The partially sighted register contains 3274 individuals of which 2274 are aged over 65. Of these, 400 people were aged between 65 and 74 while the remaining 1,864 are aged over 75. Exact age data was missing for 10 people but they were included on the register as aged over 65.

1.6.2 Republic of Ireland

(Source: NCBI 2008)

One category of blindness is used in the Republic of Ireland. The register of blindness is maintained by NCBI, on behalf of the Department of Health & Children in the Republic of Ireland. Registration is linked to certain benefits such as the blind persons' pension, companion free travel pass and tax credits

for blind people. The total number of people using NCBI services in 2007 was 12,639. However, not all of these people are registrable as blind although the majority have significant sight loss. The total blind register in Ireland contains 9758 people. There are a total of 5846 people aged 60+ who are registered as blind in Ireland. The number of people registered as blind in the six border counties of the Republic of Ireland total 702. In Dublin, postal districts 1 to 24, 2266 people are registered as blind. Of this figure, 1398 are aged over 60.

1.7 Service provision

1.7.1 Republic of Ireland (ROI)

In the Republic of Ireland NCBI (formerly known as the National Council for the Blind of Ireland) is the primary service provider to people who are blind or vision impaired. It is a not-for-profit charitable organisation that is funded through a cocktail of statutory funding, private fundraising, donations and legacies as well as through grants, financial awards and income raised by providing some fee generating services.

In April 2008 the Vision Impaired Service Providers Alliance (VISPA) was launched which formed an alliance between four voluntary sector organisations: NCBI, Irish Guide Dogs for the Blind, St. Joseph's Centre for the Visually Impaired and Fighting Blindness who all provide services to people who are vision impaired in Ireland. VISPA's stated purpose is to "be a cohesive voice advocating for increased understanding and awareness of needs and services" for people with vision impairment (VISPA 2008).

Services available for and on behalf of people with sight loss in the Republic of Ireland through the various organisations include

- Advice & support, advocacy

- Access & awareness issues
- Education & vocational training
- Employment support
- Independent living skills
- Orientation & mobility
- Information technology & assistive technology
- Library & information services including Braille, audio and large print
- Counselling
- Low vision service including aids & appliances
- Social activities & day centre
- Research
- Guide dogs

1.7.2 Northern Ireland (NI)

In Northern Ireland a number of organisations provide various services to people with sight loss. Social services employ both social workers and rehabilitation workers in their sensory support units. These are located in each of the relevant trusts in Northern Ireland. They provide a comprehensive range of services and resources tailored to individual needs with the aim of improving the independence of service users to enable them to live a fuller life

Services provided are similar to those in the Republic of Ireland and include

- Assessment of need, advice and assistance
- Awareness
- Aids and appliances
- Counselling and support for individuals, families & carers
- Orientation and mobility training
- Liaison with voluntary, private and statutory organisations and education services

- Social work services
- Social activities

A number of not-for-profit organisations also exist in Northern Ireland. Guide Dogs for the Blind Association (GDBA) provide rehabilitation training and guide dogs to people with sight loss in Northern Ireland. RNIB (Royal National Institute for the Blind) incorporating the Blind Centre of Northern Ireland (BCNI) a large advocacy organisation, which also provides some direct training and services to people with sight loss. These services include employment support, IT training, library services, home visits, etc.

1.8 The eye

The eye is an organ that facilitates one of five senses, that of sight. Light entering the eye via the pupil is focused by the cornea and lens and stimulates the photosensitive retina at the back of the eye. The photosensitive retinal cells convert the impulses to a neural message which is sent to the brain via the optic nerve for storage and analysis. The light sensitive cells in the retina are called cones (which interpret colour and fine detail) and rods (which interpret brightness and provide peripheral vision). The human eye shape is essentially spherical and is filled with both aqueous and vitreous humour. The front of the eye contains the lens which is directly behind the iris. It is the relaxing and contracting of the iris muscles that alters the size of the pupil, thus determining how much light enters the eye. The lens is supple and is able to change shape in order to focus light on the retina.

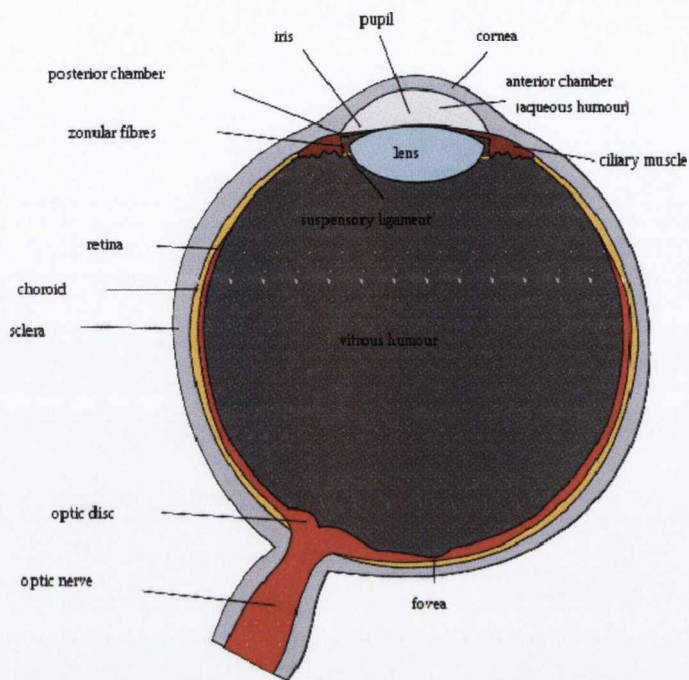


Figure 1 Diagram of a human eye³

The human eye is comprised of three layers. The outer layer consists of the cornea and sclera. The middle layer contains the iris, the ciliary body and the choroid. The choroid contains the blood vessels that supply the retina with oxygen. The inner layer of the eye includes the retina, which contains the fovea (colour vision and fine detail) and the optic disc (blindspot) where the optic nerve leaves the eye. There are no sensory neurons at the optic disc.

³ Free via Wikipedia. Permission is granted to copy, distribute and/or modify this image under the terms of the GNU Free Documentation License, Version 1.2 or any later version published by the Free Software Foundation; with no Invariant Sections, no Front-Cover Texts, and no Back-Cover Texts

1.9 Main Causes of Blindness in the developed world

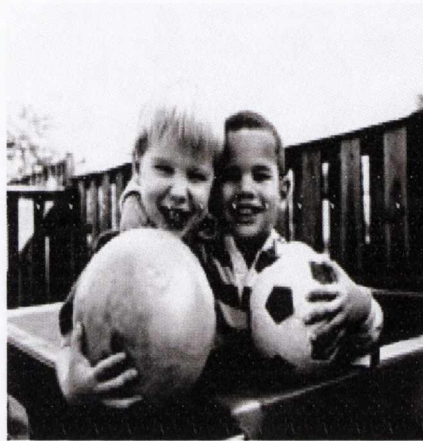


Figure 2a & b Images normal vision⁴⁵

The images above are as seen with 'normal vision'. These images will be used to demonstrate simulations of how a person's vision is affected by the differing eye diseases.

1.9.1 Ageing and the eye

The ageing process causes changes to occur within the eye, which may lead to a decline in vision and a change in refractive error. Changes that occur within the normal healthy eye include a reduction in the size of the pupil and a corresponding reduction in retinal luminance, and a reduction in the ability of the lens to vary its focus, presbyopia. This means that it is more difficult for an older person to undertake near work with uncorrected vision, particularly in conditions of reduced lighting. A separate reading correction will be required to carry out tasks of fine detail in these circumstances.

⁴ The images of the door and steps are provided courtesy of NCBI

⁵ The images of the children with ball are provided by, [National Institutes of Health](#), part of the [United States Department of Health and Human Services](#). As a [work](#) of the [U.S. federal government](#), the image is in the [public domain](#). The images of the door and steps are provided courtesy of NCBI.

Ocular pathology leading to serious sight loss and blindness increases with age. The main causes of age related sight loss in the developed world are Age Related Macular Degeneration (AMD), Glaucoma, Cataracts and Diabetic Retinopathy (DR). Age related eye disease is the leading cause of blind and partially sighted registration in both Northern Ireland and the Republic of Ireland. In Republic of Ireland 40% of those newly registered are aged 80 or over (Jackson & O'Brien et al., 2008).

1.9.2 Macular degeneration

Macular degeneration occurs when the central area of the retina, known as the macula, deteriorates. This leads to a reduction in central vision, the vision used for reading, driving, face recognition etc. As peripheral vision is not affected, MD does not result in total blindness. The onset of AMD usually occurs after the age of 50 (Hogg, 2006).

1.9.2a Two types of macular degeneration: dry and wet.

The dry form of macular degeneration is the most common type occurring in approximately 90% of cases. Vision loss generally progresses over a long period of time. The wet form of macular degeneration can cause a rapid deterioration in sight. The term "wet" is used because tiny fragile blood vessels grow behind the retina. The blood vessels leak causing fluid to accumulate beneath the photo receptor layer. This causes distortion of vision (metamorphopsia). The end result is often scarring and total disruption of the macular photo sensitive layer which in turn results in the formulation of a central scotoma (black hole).



Figure 3 a & b Simulation of AMD

The images above are the same images as shown earlier but simulated to represent how the image could appear to someone with AMD. Note the impact on the central area of vision and the distortion of the focal scenes in the right hand image. This is the area most likely to be of interest to the viewer and thus the point selected for fixation. The blur or defocus of the peripheral vision is entirely consistent with the design of the eye as the peripheral photoreceptive layer, consisting predominantly of rods, was never meant for the resolution of detail.

In both jurisdictions AMD is the leading cause of blindness. In Northern Ireland it accounts for 40% of all those on the registers of blind and partial sight (Canavan et al., 1997) while in the Republic of Ireland people with AMD comprise 25% of the Irish blind register (Kelliher et al., 2006). People with AMD usually benefit greatly from the provision of low vision aids. Recent research has found correlations between smoking and AMD. Smokers are 3-4 times more likely to develop macular disease compared to non-smokers. Family history will also increase the risk of developing the disease. Some current research is showing that risk factors can be reduced through improvements in diet (Coleman & Chew, 2007) and ceasing smoking (Smith et al., 2001; Thornton et al., 2005). Research confirms the increase in AMD worldwide. Prevalence of AMD was found to triple for each decade of age over 70 in Australia (Weih et al., 2000), while a study in the UK attributed 53% of

sight loss in people with vision impairments aged over 75 to AMD (Evans et al., 2004).

1.9.3 Diabetic related sight loss

Vision loss as a consequence of diabetes is the leading cause of blindness amongst those of working age in the developed world. Diabetes is on the increase in both the developed and the developing world (Wild et al., 2004). In the Republic of Ireland 5% of the total register consists of people with vision loss resulting from diabetic retinopathy (Kelliher et al., 2006). In Northern Ireland it ranks higher, as the third leading cause of registration as blind or partially sighted (Canavan et al., 1997). With the large increase in diabetes among the population an increase in sight loss related to diabetes is to be expected. Diabetic Retinopathy occurs when the blood vessels, which feed the retina, weaken and rupture. The retina is then irreparably damaged. Although the macula can be affected as in AMD, the damage is not confined to the macula thus the view for the person with vision impairment can appear patchy. With the increase in diabetes in the western world screening programmes are essential to identify & provide treatment for those at risk. Many people who are unscreened are going on to develop unnecessary sight loss (Jackson & O'Brien et al., 2008). Diabetic eye disease is progressive and therefore rehabilitation training and ancillary support services are important to those with the condition.



Figure 4 Simulation of diabetic retinopathy

Fig 4 shows the same image as in Fig 1a but simulated to represent how the image could appear to someone with diabetic retinopathy. In this case the damage has been diffuse, resulting in overall blur and isolated scotoma.

1.9.4 Cataracts

Cataracts are a leading cause of blindness among adults, however with surgery they can be removed. Nowadays cataract surgery usually includes the implantation of replacement (plastic) lenses known as an intraocular lens. With cataracts the lens of the eye becomes cloudy and opaque blocking the light that is needed for normal vision. Vision becomes blurred and glare can become a major problem.

As the disease can progress quite slowly often patients don't realise that there is a problem until it is advanced. The risk of cataract increases exponentially with age (Taylor & Keefe, 2001). As the population is ageing predictions are that the necessity for cataract surgery will place a significant demand on hospitals in the near future (Keenan et al., 2007).

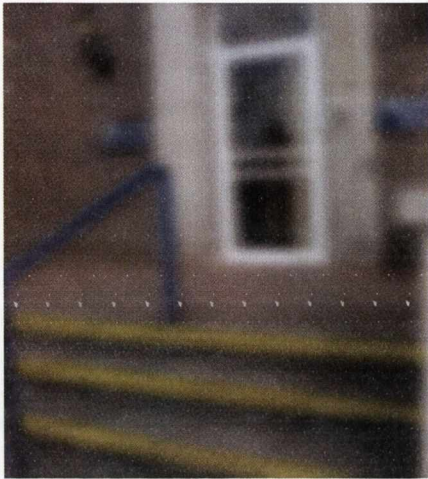


Figure 5 Simulation of cataract

This is the same image as fig 1a but simulated to represent how the image could appear to someone with cataract. Particular problems can be encountered when viewing targets which are low in contrast.

1.9.5 Glaucoma

Glaucoma usually starts after the mid thirties and if left untreated causes total blindness. Sight cannot be restored; intervention simply retains existing visual capacity. This condition involves a disruption to the delicate fluid balance within the eye with the result that the intraocular pressure is higher than that for optic nerve head competence within that individual eye. The damage caused to the retinal nerve fibre layer causes progressive loss of peripheral vision. Glaucoma that is not treated and managed will eventually cause total blindness as visual fields become progressively constricted. Glaucoma can present as either acute or chronic. Acute glaucoma causes severe ocular pain, nausea, blurred vision and photophobia. Chronic glaucoma has a much slower onset. A study in County Roscommon (n=2186) in the west of Ireland in the early 1990's found that the prevalence of primary open angle glaucoma

increases from 0.72% in those aged between 50 and 59 to 3.05% in those aged over 80 years of age (Coffey et al., 1993). Overall adult prevalence of glaucoma in the Blue Mountains study was found to be 3% (Mitchell et al., 1996). As with many conditions the ageing population will lead to an increase in glaucoma with predictions of 1 in 10 people developing the disease (Wensor et al., 1998).



Figure 6 Simulation of glaucoma

This is the same image as above but simulated to represent how the image could appear to someone with glaucoma. Glaucoma also reduces contrast sensitivity thereby diminishing one's ability to see low contrast targets.

1.10 Visual function and functional vision

Visual function is about how the eye sees. There are a number of methods of measuring visual function. For the purposes of this study four measures of visual function were chosen. Distance vision - Visual Acuity- High and Low Contrast, Near Vision and Visual fields. More information about the vision assessment used for this study can be found in the chapter on methods.

1.10.1 Visual function assessment

Irrespective of the cause of damage to the visual system the impact on function can be measured by assessing the eyes ability: to resolve fine detail (visual acuity); to detect peripheral targets (visual fields); to interpret details within a low contrast environment (contrast sensitivity); and to identify and discriminate colour (colour vision). More complex assessments of visual function involve search and find strategies, timed visual task analysis, and the simultaneous or sequential completion of visual tasks. Within a clinical environment the tests used to assess each of these functions can be grouped under the following headings:-visual acuity; near acuity; contrast sensitivity; visual fields; and colour vision.

1.10.2 Visual acuity

This involves assessing the eyes ability to resolve and indeed recognise the significance of detail using letter, symbol, or number (Optotypes) charts. A wide range of charts are available from the simple and universally understood 'Snellen chart' (Snellen, 1864) to the more complex scientifically designed LogMAR charts (Bailey & Lovie, 1976) (See Fig. 7)

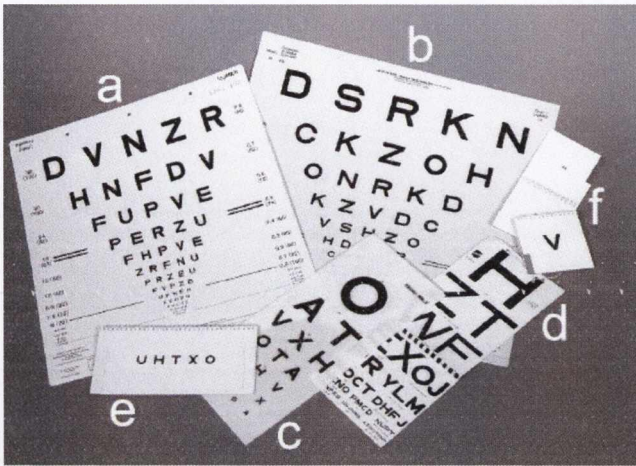


Figure 7 Selection of visual acuity charts (see footnote for names of charts)⁶

Results are expressed either in the form of a fraction 6/6 (UK), 20/20 (US), as a decimal 1.0 or in a logarithmic series (0.0). In the fraction form the numerator represents the test distance whereas the denominator represents the distance at which the smallest letter detectable, subtends an angle of 5 min of arc at the eye. When expressed in decimal or logarithmic form it is important to note the test distance. Practically, repeatable results can be assured if testing is undertaken using standardised lighting conditions in a controlled environment. Outcome measures need to be adjusted for working distance and it is important to record the refractive state, (unaided, with habitual corrections, best corrected, pinhole corrected).

1.10.3 Near acuity

Unlike distance acuity, near acuity is almost always measured using text as opposed to letter charts. Text may however be in the form of meaningful sentences, which are generally constructed using words appropriate for the

⁶ a. Bailey-Lovie LogMAR; b. Early Treatment of Diabetic Retinopathy Study (ETDRS); c. Modified Snellen; d. Keeler A series; e. Sonksen Silver; f. Sheridan-Gardner

category of individual being tested (Adults/Children/Individuals with learning disabilities).

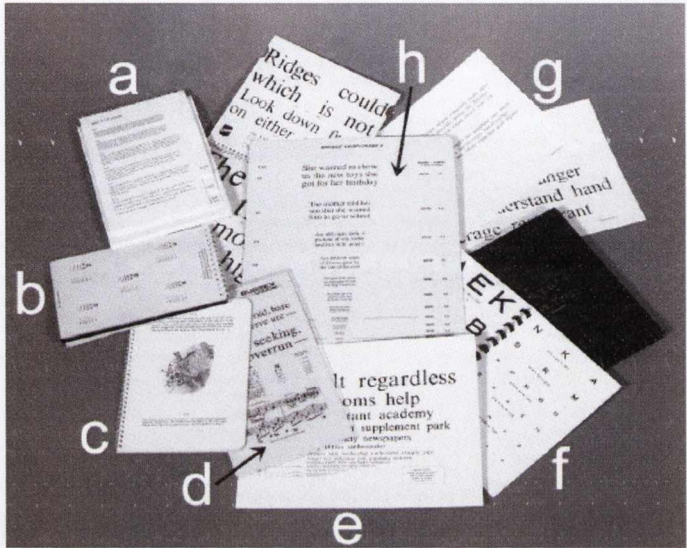


Figure 8 Selection of near vision charts (See footnotes for titles⁷)

Alternatively, near charts may consist of lines of unrelated words. In addition to assessing the minimum size of text that can be read at a specified working distance, note can be taken of both reading speed and fluency. Reductions in both reading speed and fluency can be an indication of early macular disease (Crossland et al., 2005). In patients with vision impairment, visual acuity, at both distance and near, may be assessed following the provision of low vision aids or the introduction of alternative reading strategies. Further information on the detail and theory of visual acuity testing can be found in a review of the subject by Jackson & Bailey (2004).

⁷ Maclure reading chart; b. Moorfields bar reading chart; c. Peter Rabbit reading chart; d. Sussex near test type chart; e. Bailey-Lovie word reading chart; f. Keeler A series near chart; g. Belfast ARMD reading speed chart; h. pepper chart.

1.10.4 Contrast sensitivity

Contrast Sensitivity testing was first introduced to clinical testing in the 1960's (Campbell & Green, 1965). Only recently has it achieved more widespread recognition. It can be assessed using a variety of charts from those incorporating gratings of various sizes (spatial frequencies) of different contrast settings, to those using optotypes of diminishing contrast. Examples of charts that can be used to assess the ability of the eye to identify low contrast detail are the (95% & 10%) Bailey Lovie letter charts, (Bailey & Lovie, 1982) the Lea 25%/10%, 5%, 2.5% and 1.25% letter, number and symbol charts (Hyvarinen, 2000).

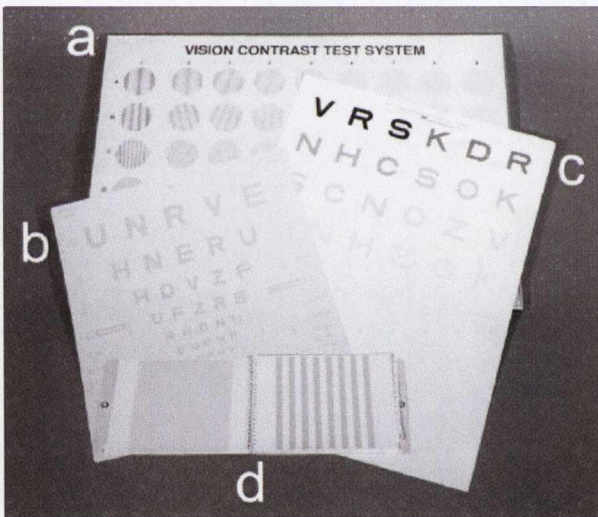


Figure 9 Selection of low contrast vision charts (see footnote for titles)⁸

Alternative chart designs include charts which use letters of only one size but of decreasing contrast. These charts include the gold standard Pelli-Robson chart which tests at the peak of the contrast sensitivity function curve, using letter triplets ranging in contrast from 89% to 0.5 % (Pelli et al., 1988).

⁸ . a. Ginsberg vision contrast system; b. Bailey-Lovie 10% contrast chart; c. Pelli-Robson chart; d. Cambridge low contrast gratings.

1.10.5 Visual fields

Diagnostic visual field tests, used predominantly to detect peripheral loss in early glaucoma and neurological disease, assess retinal sensitivity using tiny flashing (static) targets presented randomly in the peripheral field, as the patient fixates a central target. Central fields (within 10 degrees of fixation) can be assessed using similar strategies on patients with macular disease. Instruments used to assess fields to this degree of specificity include the gold standard Humphrey visual field analyzer. They are rarely of any use within the context of low vision functional evaluation. Testing is much more effective if larger diameter moving (kinetic) targets are used and in this case the gold standards are the Goldman bowl perimeter and the Bjerrum screen (Marowitz, 2006).

When attempting to equate field loss to functional mobility visual field integrity can be assessed using confrontation testing, in which the extent of the patient field loss is grossly compared with the field size of the examiner.

1.10.6 Colour vision

The colour vision system is essentially a three channel system, the respective channels detecting light which equates to the primary colours. Our colour spectrum thus consists of different combinations of colours detected by the three channels and the relative stimulation of the three channels provides us with colour. Most colour vision tests are designed to detect congenital colour vision defects, the most common of which involves red/green loss (protonopia / deuteranopia) in males. Patients with vision impairment, and in particular those with macular disease, may also have acquired colour vision loss and in these cases the extent of the loss is likely to be different in the two eyes. In these circumstances patients will most likely be aware of the fact that their colour vision is no longer normal whereas those with a congenital colour vision defect, which is stable, have never known normal colour vision. Conventional

tests including the Ishihara & City Vision tests can be difficult for the patient with vision impairment to do, as the coloured targets consist of small dots. More appropriate in the field of low vision are the jumbo type tests including the D15 large button test, which can be carried out by individuals with a visual acuity as low as 3/60. As with all tests of visual function, repeatability and accuracy of outcome data is best when tests are carried out under standardised conditions.

The result of all these tests can be affected by other factors including light and dark adaptation and the presence and location of glare in the immediate environment. Details on the methods used to assess visual function in this study can be found in the methodology section.

Chapter 2

2.0 Literature review

2.1 Background

Over the past fifteen years much discussion and debate has taken place about the prospect of an increasing burden on eye care services in light of the ageing population and how best this need should be met (Dickinson, 1995, Culham et al 2002). The World Health Organisation (WHO) highlights the need to establish the ramifications of vision impairment on everyday life so that interventions can be targeted at high-risk sub-populations (WHO, 1997b). WHO adds further that "It is well known that the burden of visual disability is greatest in economically deprived populations; women and the elderly are generally in the most disadvantaged positions" (WHO, 1997b:Part V). It is imperative that we study the full extent of vision impairment on the older population on the island of Ireland, and the impact that the predicted increases in the vision impaired population is likely to have on the population as a whole. Only by so doing can service providers prepare appropriate and effective health care strategies in response to this growing need.

This study explores the quality of life (QOL) of people who are aged 60 and over and are registrable as blind or partially sighted in Ireland. As far as we can ascertain, a comparison between people aged 60 and older with a vision impairment north and south of the Irish border has not been undertaken in Ireland prior to this study. It aims to explore the experience of vision impairment in two jurisdictions: Northern Ireland, which is governed by UK legislation; and the Republic of Ireland and in particular compares the QOL of urban and rural dwelling members of the target group in both areas.

The literature review for this study aimed to explore recent research on the topic of QOL and older people with serious sight loss and to examine which factors have been found in the literature to influence QOL. Comparisons between urban and rural dwelling were also explored. The literature search strategy is reported in the methodology chapter.

2.2 Influences on QOL

Self-reported function and quality of life are well documented in the literature as central to the development and delivery of successful care (Fitzpatrick et al., 1992; Read et al., 1987; Patrick & Deyo, 1989). QOL measures have been shown to uncover more information about the effects of sight loss on the individual than could be exposed by clinical evaluation alone (Dandona et al., 2000). Self reported visual ability can be of more importance to the person with vision impairment than the results of clinical measurement (Burmedi et al., 2003; du Feu & Ferguson, 2003). Some of the studies to date have produced conflicting results on the relationship between QOL and sight loss. Williams et al state that AMD is linked to worse QOL scores and increased emotional distress than the norms (1998).

Mangione et al., found poor correlation between the presence of age related macular disease and poor quality of life. It should be noted however, that 75% of their study population rated their own vision as 'good' or 'fair' (Mangione et al., 1999). Most studies have used questions designed to evaluate the functional impact of a narrowly defined condition or treatment. They appear to have concentrated on patients undergoing ophthalmic care, within hospital based clinics, and with a wide range of visual functions and pathology (Parrish et al., 1997; Gutierrez et al., 1997; Sherwood, 1998). Although it is known that visual impairment is associated with a loss of independence (Berndtsson, 2000; Old, 1996; Kosnik et al., 1988 and Oppegard et al., 1984), and that loss

of independence and poor quality of life are correlated, the dynamics of these interactions have not been explored.

Sight loss has been linked to increased risk of depression, with some studies focusing in particular on correlating depression, or psychological distress and vision impairment in an older cohort (O'Donnell et al., 2005; Travis et al., 2004; Horowitz, 2004; Hinds et al., 2003; Bermudi et al., 2002 Wahl et al., 1999). Vision loss has a higher association with depression than many other disorders (Mogk, 2000). While depression has been found to be highly correlated with vision loss, the delivery of rehabilitation services has been shown to cause a decline in depressive symptoms (Horowitz et al., 2005). However, vision rehabilitation is likely to be less effective where depression exists (Tolman et al., 2005; Horowitz et al., 2005).

A review of the literature revealed some conflicting results as regards depression and vision impairment (Karlson, 1998; Kleinschmidt, 1995 and 1999; Lindo & Nordholm, 1999; Horowitz & Reinhardt, 2000; Reinhardt & Benn, 2000 and Schainholz, 2000). The prevalence of depression can be twice as high in those with vision impairment when compared with their sighted peers (Bermudi, 2002). Depression is not linked to the extent of the sight loss. The belief that depression is inexorably linked to ageing is challenged by Kleinschmidt (1995). Horowitz & Reinhardt in their paper state that depression is not inevitably linked to sight loss (2006). Decreased functional status has been linked to psychological distress (Stelmack et al., 2003). Psychological distress is linked to reduced quality of life and increased difficulty in carrying out daily living activities leading to greater disability (Sloan et al., 2005; Williams et al., 1998). A small number of studies have suggested a negative association between the degree of social support available (statutory and family) and depression (Hersen et al., 1995 and Teitelbaum et al., 1994). Societal attitudes towards blindness can also impact on quality of life for people with vision impairment (du Feu & Ferguson, 2003, Vale & Smyth, 2002).

2.3 Urban rural comparisons

In the first European QOL study by Shucksmith et al. in 2006, on urban rural differences, no essential differences were found between urban and rural. Any differences that do occur in income and deprivation are more likely to occur in poorer countries. Education was found to be higher in urban areas while unemployment was higher in rural areas. There were no discernible differences in access to healthcare found in the wealthiest EU countries (EU 12). Life satisfaction and happiness were very slightly higher in the rural areas of the EU12 than in urban areas, while those living in urban areas are more optimistic about their futures. When times are strained economically the study suggested that some of this strain may be absorbed within the rural community "so that under conditions of adversity, reciprocity emerges as an important part of the social fabric" (Shucksmith et al 2006:27). This study found that there was "no substantial evidence of social isolation among the elderly population across Europe" (Shucksmith et al 2006:45).

Despite rural populations being generally older than urban counterparts, Wenger (2001) has noted that studies of older rural inhabitants are sparse in the UK. Wengers' study of ageing in rural Britain found while there were no disadvantages or advantages to make rural residence better or worse than urban dwelling, significant attention needed to be given to the method of delivery of services to rural areas (Wenger 2001). Older rural dwellers can be at an increased health risk due to their geographic isolation, and therefore the distance they may have to travel to access healthcare (Hinck, 2004). A separate study in 2006 reported that "Research is beginning to show that there are rural-urban differences in health outcomes, and challenges the belief that rural patients have a health advantage over their urban counterparts" (British Medical Association, 2005:44). This study goes on to say that rural dwellers have difficulty accessing healthcare services and that these difficulties will be further compounded for people with disabilities (British Medical Association, 2005). These results mirror a study from the USA that had similar findings about difficulties in access to healthcare for rural residents. These

difficulties were worse for people with disabilities (Lishner et al., 1996). However, a later study from the USA on QOL and rural residence of older people found no significant difference from norms (Cleary & Howell, 2006). Manthorpe et al.'s study of life in villages in the UK found that the main concerns expressed covered fears about poor health, having to move home, inability to drive and loss of independence (2004).

A recent study noted that there is very little research on rurality and ocular health (Saliba, 2008). As age is a predictor of vision impairment and the population of rural areas tends to be older than its urban counterparts, more attention should be given to the ocular health of rural dwellers (Saliba, 2008).

2.4 Quality of Life (QOL)

2.4.1 QOL and elderly

The older population is not homogenous. It includes very able bodied people together with those who are less able and those whose health difficulties disable them completely. In this study the common bond between subjects is that they are aged 60 or more and they all have sight loss significant enough to render them registrable as blind or partially sighted in both jurisdictions.

Current government social and health policies seek to promote independence and thus support people who wish to live in the community for longer (Department of An Taoiseach, 2006). This will be achieved through the provision of access to more local support e.g. carers, home help etc. This makes more economic sense, as the cost of maintaining a person in a nursing home is very expensive and rising all the time.

There is renewed interest world-wide in successful ageing, partly due to the policy concern of how to maintain people in the community for as long as

possible, and also due to higher expectations of old age as standards of living, health and health-care increase (Bowling & Dieppe, 2005).

2.4.2 What is QOL?

Individuals self reported QOL is today recognised as very important in the health setting, particularly in relation to service delivery (Fitzpatrick et al., 1992; Patrick & Deyo, 1989). Quality of life (QOL) is a multifaceted concept, both dynamic and subjective. There is no consensus as to what constitutes QOL. Its significance will vary according to the individual. The World Health Organization (WHO) defines quality of life as

An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment (WHO, 1998:3).

In this study, we are targeting health related quality of life (HRQOL). Many instruments exist to measure HRQOL, both generic and disease specific. HRQOL is usually linked to a pathology model focussing on difficulties within domains such as physical, mental, social etc. Bowling argues that this has led to such instruments having a negative focus on "dis-ability" rather than ability (Bowling 2001).

It has been argued that most QOL measures using individual domains may not "tap the most pertinent domains of people's perceptions of quality of life" (Brown et al., 2004:42). It has been questioned whether or not, the domains selected as important by many QOL measures, actually reflect what is important to the public as regards HRQOL (Bowling 2001). Therefore,

including open ended items may help the measure reflect what is important to the individual. Quality of life is also influenced by experience and expectations. Expectations are "closely related to people's relationship with their environment" (Carr et al., 2001; 1241). Such expectations are not allowed for in current HRQOL instruments. For example, a person who is profoundly blind from birth, has attended a specialised school, established a network of friends and colleagues, and has adapted accordingly may evaluate their quality of life as excellent. On the other hand, someone who has recently acquired a much lesser degree of vision loss may be devastated by this loss, however mild, and score much lower on a QOL scale. Their personal experience and expectations will have a major impact on QOL scores. Carr goes on to comment that raising expectations of health during health promotion exercises might actually reduce the quality of life of people already in poor health (Carr et al., 2001). In this study the inclusion of a variety of questions in addition to the generic and vision specific HRQOL instruments may address these concerns.

2.5 Qualitative and quantitative research

Quantitative research is primarily concerned with numbers and has the aim of generalising the results of data collected from a sample to the population under review. It provides the breadth in a study whereby it has the ability to generalise its results from a sample across a large population, i.e. from the specific to the general (Dereshiwsky, 1999). Qualitative Research is primarily concerned with words. It aims to gain a deeper understanding of the population of interest. It explores opinions, rationale, and motivations. It provides depth in research. Using this methodology one can explore a particular population in a more concentrated way (Dereshiwsky, 1999). Qualitative research can be considered a perspective as much as a method (Radcliff 2004). While quantitative results can be extended to wider populations, qualitative research is more focussed on the sample under study. It is hoped that by incorporating qualitative research methods within this study

a deeper exploration and a wider understanding of some of the pertinent issues affecting this population will be attained.

2.5.1 Strengths of qualitative research

Qualitative research has many strengths. It deals in depth and detail and its openness can generate new theories. It gives an opportunity for thorough exploration. It can discover an alternative world view. This research method endeavours to avoid pre judgements and accept people on their merits. As a methodology it is holistic, inductive and dynamic (Cook & Reichardt, 1979).

2.5.2 Limitations of qualitative research

Qualitative research is dependent upon the researcher's personal attributes and skills and one must be aware that the researchers' participation can influence outcome. The sample populations are usually much smaller. It is not generalisable and cannot be used for cause and effect. It is also difficult to aggregate data and make systematic comparisons.

2.6 Health

The definition of health according to WHO is as a "state of complete 'physical, mental and social wellbeing', and not merely as the absence of disease or infirmity" (Ellwein et al., 1995). Therefore, health related QOL measures should include all of the above. Health status can be partly measured by a person's self-rated health (Idler & Benyamini 1997).

HRQOL is affected by an individual's experience and expectations, as well as their self-rated health status and how they relate to their environment, physically, mentally and socially. In a study on sensory impairment and older

people in the US, people with vision impairment reported higher incidence of comorbid and secondary conditions, were more likely to have fallen and to report a fractured hip than people with hearing loss only or no sensory loss. They were also more likely to report mobility difficulties and difficulties with other ADL activities. People with vision impairments were also more likely to report being depressed or anxious (Crews & Campbell 2004).

2.7 QOL Instruments

QOL tools are used to measure generic quality of life, health related quality of life and functional status. They can be generic or disease specific. Some instruments are uni-dimensional, i.e. exploring one aspect of health, or multidimensional, exploring one or more aspects of how health may impact on lifestyle. They can be self reporting, administered by service provider or proxy using face to face interviews or telephone interviews. The chosen methodology will be specific to the instrument being used. In face to face interviews, the interviewer can be a professional involved in service delivery or independent people. All of these variables need to be factored into the data analysis. For the purposes of this study a number of the more prominent generic and vision specific QOL instruments were reviewed with a view to using one for this study. Quality of Life instruments must be validated for content and construct to be certain that they measure what they purport to measure. This study chose to use the SF36 generic HRQOL instrument and the DLTV vision specific instrument. Some information about other well known QOL tools is included below. Many generic QOL instruments have been developed. It must be noted that many of the questionnaires such as the ones described below, both health related and vision specific, are often referred to as QOL measures. However, while they measure different aspects of life that may influence QOL such as health status, physical functioning, vision functioning, well being, etc., they are not QOL measures (Mitchell & Bradley, 2006).

Questionnaires including QOL instruments are tested for psychometric properties. Does the instrument have content and construct validity, i.e. how well does it measure what it is supposed to measure when matched against other tools? It is checked for concurrent validity that is how well it correlates with other measures, and discriminant validity, i.e. its ability to discriminate between different subjects or different eye diseases. Responsiveness, i.e. how well it detects change in subjects, is also measured. Test–retest reliability is a measure of how reproducible the instrument is (Jackson, 2007b; De Boer, 2004; Margolis, 2002).

2.7.1 Generic Quality of Life instruments

2.7.1a WHOQOL (WHOQOL Group)

The WHOQOL-100 was developed as an instrument which would have cross cultural application and could be used across diseases. It contains 100 items within 25 facets across six domains: physical health; psychological; level of independence; social relations; environment; and spirituality/religion/personal beliefs. It is also used to collect socio-demographic and health information. A short form called WHOQOL-Bref has been developed more recently and contains 26 items across 25 domains. The WHOQOL instruments have good properties of reliability and validity, however, sensitivity to change is still being fully investigated. This WHOQOL-100 was too long for use within this study.

2.7.1b EURQOL (EuroQOL Group)

The EQ-5D, developed by the EuroQOL Group was originally developed to complement other instruments but it is now frequently used as a stand alone instrument. It is a short instrument covering five domains. Originally designed

for self-report it can also be interview administered with guidelines for this approach available from the EuroQOL group. It is however usually incorporated into studies which have a significant health economics component.

2.7.1c Sickness Impact Profile (SIP)

This HRQOL instrument is multidimensional and includes 136 items over 12 domains. These domains include ambulation, mobility, body care and movement, communication, alertness behaviour, emotional behaviour, social interaction, sleep and rest, eating, work, home management, and recreation. It was developed in the USA and has been found to discriminate between sick and healthy respondents. It can take up to 40 minutes to complete and so was considered too long for inclusion in this study.

2.7.1d Nottingham Health Profile (NHP)

The NHP covers six domains, pain; physical mobility; emotional reactions; energy; social isolation; and sleep. It includes 38 items. It has been widely used in the UK. This instrument was designed to assess perceived health in the chronically ill and is used to examine how effective medical interventions are on subjective health. It takes just 10 minutes to complete and includes a number of dichotomous responses. It has been successfully validated but there are some questions about the robustness of the scales used (Wann-Hansson et al., 2004). Our population were not chosen as chronically ill people but rather they were chosen as they were people who were registrable as blind or partially sighted.

2.7.1e SF36

The SF36 was developed in the USA as part of the Medical Outcomes Study (MOS) by Ware & Sherbourne. This tool was designed to measure basic health concepts regardless of age or disease. It is widely used in the evaluation of health status and has been used successfully (Ware & Sherbourne, 1992; McHorney & Ware, 1994; Jenkinson et al., 1999). The SF36 ver2 was used in this study and has been validated with a UK audience. It has also been shown to work with an elderly cohort and is suited to interviewer administration with this group (Brazier et al 1996, Walters et al., 2001). It is a good instrument to use with older people with limited morbidity who are living in the community (Haywood et al., 2005). The SF36 is a 36 item instrument with eight domains. It is one of the most widely used generic health-related QOL instruments. The eight domains are: limitations in physical ability; social activity; role limitations caused by physical health; role limitations caused by emotional problems; bodily pain; mental health; vitality; and general health perceptions.

2.7.2 Vision-Specific QOL (VSQOL)

2.7.2a Functional Impact

The loss of vision, whether central or peripheral, is associated with the impairment of functional ability. Often this has a severe impact on one's capacity to undertake daily living tasks and on one's ability to move around and to use all forms of transport. Low vision has been found to have a profound effect on activities of daily living and functional independence (Swagerty, 1995; Stelmack, 2004). As stated earlier many studies have associated vision impairment with a loss of independence (Berndtsson I, 2000; Old H, 1996; Kosnik W et al., 1988 and Oppegard K et al., 1984). This loss of

independence can also lead to social isolation among people with vision impairments (Long et al., 1996; Baker & Winyard, 1998).

AMD, the leading cause of blindness in the developed world, has been found to have a significant impact on QOL, reduce the ability to undertake ADL tasks and cause emotional distress (Williams et al., 1998). Those with vision loss are also at an increased risk of depression and worse QOL (Stelmack, 2002), and this loss has been shown to have an effect on the psychosocial functioning of the patient (Heine & Browning, 2002).

A holistic approach to the delivery of services has been recommended in the management of low vision patients (Wolffsohn & Cochrane, 1998). Clinicians should be aware not just of the eye disease but also its effects on the person including the psychological effects and the functional impacts (Wolffsohn & Cochrane, 1998). Functional assessment and rehabilitative support, particularly training in utilising residual vision and low vision aids and appliances is crucial to facilitate coping strategies of those with vision loss (Watson, 2003).

Interdisciplinary support services post diagnosis have been found to positively impact on functional ability (Peters, 1992; Hinds et al., 2003) and are associated with high patient satisfaction (Scott et al., 1999). Evaluation of the outcomes of low vision services is recommended (Raasch et al., 1997). One method of evaluation would include the use of QOL measures. Scott et al found that vision specific QOL instruments are more sensitive than generic HRQOL measures (Scott et al., 1999).

2.7.3 Vision specific QOL instruments

There are numerous vision specific QOL instruments and many of these are disease specific. These tools have been developed to measure the effects of vision loss on various tasks. Results from these questionnaires have been shown to be influenced by health and co-morbidities (Miskala et al., 2004).

This study planned to include both profoundly blind people and people with varying degrees of sight loss sufficient to render them registrable as blind or partially sighted. It was expected that we would recruit participants with a range of ocular pathologies resulting in various degrees of vision loss and there would be a wide experience in the duration of vision loss including those with congenital loss. As such we needed an instrument which would be suitable for a broad cohort of subjects. De Boer et al carried out a review of existing vision specific QOL measures (2004).

Some of the vision specific instruments that were reviewed in preparation for this research included: Activities of Daily Living Scale (ADVS); Low Vision Quality of Life Questionnaire (LVQOL); Visual Function Related Quality of Life Questionnaire (VFQOL); National Eye Institute Visual Function Questionnaire (NEI-VFQ); Impact of Vision Impairment (IVI); and the Daily Living Tasks of Vision (DLTV). There are a multitude of vision specific quality of life instruments (VSQOL), which have been developed over the years. Two major reviews of VSQOL instruments have been conducted by Margolis et al. (2002), and De Boer et al. (2004), and provide information on a host of VSQOL tools. De Boer recommends that the development of new instruments should cease and the refinement of existing measures should instead be the focus of development work (2004).

2.7.3a Activities of Daily Vision Scale (ADVS) (Mangione et al., 1992)

This instrument has been reviewed by De Boer et al., 2004 and Margolis et al., 2002. The ADVS instrument has 22 items and covers five domains: night driving; day driving; distance vision; near vision; and glare vision. Primarily a functional questionnaire it can be administered via interview. It has been found to have internal consistency, concurrent validity, discriminant validity, responsiveness and test-retest reliability. It was developed by clinicians. As none of our respondents were likely to be drivers, this instrument was not

deemed suitable (De Boer et al., 2004; Margolis et al., 2002, Mangione et al., 1992).

2.7.3b Low Vision Quality of Life (LVQOL) (Wolffsohn & Cochrane, 2000)

The LVQOL was developed in Australia for people with low vision across various eye diseases. It contains 25 items and is scored from 0 (low quality of life) to 125 (high quality of life) (De Boer et al., 2004). It can be administered either through postal implementation, telephone, or face to face interviews. Postal implementation was found to be most cost effective. When compared across the three administrative methodologies, QOL scores were lowest in the postal responses (Wolffsohn et al., 2000). It was found to have high internal consistency, and test-retest reliability (Wolffsohn & Cochrane, 2000). It covers both a psychological and functional aspect of QOL (De Boer et al 2004).

2.7.3d Visual Related Quality of Life Questionnaire (VCM1) (Frost et al., 1998).

The VFQOL instrument examines visual function and QOL in two separate sections. It was developed in the UK and is suitable for use in patients with various ocular pathologies. People with vision impairment were included in the development of this tool as well as the professionals who work in the field. This tool has been validated and has been shown to discriminate between various degrees of vision loss. It contains 10 items across six domains. It has measures of both psychological and social functioning. It has shown reliability and internal consistency. This measure can be completed through self-report, or interview administered via face to face or via the telephone.

2.7.3e National Eye Institute – Visual Function Questionnaire (NEI-VFQ) (Mangione et al., 1998).

This instrument is one of the most widely used vision specific QOL tools. Focus groups with people with vision impairment were used to develop the questionnaire and identify content area (Mangione et al., 1998). It contains 51 items across 13 domains: general health; general vision; visual pain; near activities; distance activities; vision-specific social functioning; vision specific mental health; vision-specific expectations; vision-specific role difficulties; vision-specific dependency; driving; colour vision; and peripheral vision. It is suitable for use across a wide variety of ocular pathologies. The NEI VFQ can be done via self report or administered by an interviewer. It has been shown to have internal consistency; test-retest reliability; discriminant validity and responsiveness (Margolis et al 2002). It has been widely validated but its use with non-US populations has been limited. Published vision function data is not readily available or published for the UK (RNIB, 2005).

2.7.3f Impact of Vision Impairment (IVI) (Hassel et al., 2001).

This questionnaire was derived from focus groups with people with vision impairments. It can be used in a variety of eye conditions including Cataract, Glaucoma, AMD and Diabetic Retinopathy. It has 32 items across five domains, which include: Work and leisure; household and personal care; mobility; consumer and social interaction; and emotional reaction to vision loss. It has been shown to have internal consistency; test-retest reliability and concurrent validity. It can be self administered or completed with an interviewer.

2.7.3g Daily Living Tasks Dependent on Vision (DLTV)

The Daily Living Tasks Dependent on Vision questionnaire (DLTV) was developed in 1995 specifically for use in older people with age related macular degeneration (AMD). Developed in Northern Ireland by Hart et al., it was designed to assess visual functioning in older people with vision impairment (Stevenson et al., 2004). The DLTV has been shown to provide information over and above that obtained from the measurement of VA (Visual Acuity) and has been shown to demonstrate discriminant validity between eye diseases, i.e. cataract and AMD (Hart et al., 1997, 1999 & 2005).

This instrument has been used successfully a number of times within Northern Ireland. Dr Hart, one of those involved in the development and design of the DLTV, was an advisor to this study. This was the vision specific instrument chosen for this study. More information on the DLTV is given in Chapter 3.

2.8 Visual function and functional vision

Visual function describes how the eye sees while functional vision describes how the person functions using their vision (Colenbrander, 2003). Many studies have exclusively used distance VA as the indicator of visual impairment. It has, however, long been recognised that distance VA does not adequately explain the impairment reported by visually disadvantaged people (Elliot et al., 1990; Cheng & Vingrys, 1995; McClure et al., 2000). Distance VA measures resolution at 95% contrast whereas adequate visual functioning involves resolution at both near and far distances, contrast sensitivity, and visual searching within the appropriate field of vision. Therefore visual function must be measured by examining visual acuity and contrast sensitivity, depth of field, field of vision, near vision, etc. In this study we chose to select simple screening instruments which were capable of detecting the extent of visual function in a domiciliary environment.

Functional vision is measured by exploring how well the individual functions within their environment using their vision, i.e. how well they get about or perform daily living activities. Previous research has shown that vision impairment is linked to reduced function and therefore impacts on independence (Rubin et al., 1994).

2.9 Low vision aids (LVA) Usage

The QOL of a person with a vision impairment can be enhanced by improving their functional vision (Jackson, 2007b). One method of improving functional vision is through the provision of low vision aids. Various studies of patients attending low vision clinics show that low vision aids are found to be very useful (Lindsay et al., 2004; Harper et al., 1999; Shuttleworth et al., 1995; Howe, 1995; Leat et al., 1994). Attending Low Vision Clinics (LVC's) encouraged the regular use of low vision aids (Leat & Rumney 1994). In a recent audit of low vision services 68.6% of respondents maintained that they used their low vision aids regularly (Lindsay et al 2004). Simple hand held & stand magnifiers of various descriptions including illuminated magnifiers were the most popular.

A study exploring the effects of the use of sensory aids by those with sensory impairment found that those using low vision aids performed better in activities of daily living, had better social interactions and a higher mood level than those subjects with vision impairment who were not using low vision aids (Apollonio et al., 1996).

2.10 Impact of sight loss on QOL and independent living

2.10.1 Mobility

People with vision impairment are also known to experience mobility problems, which can lead to social isolation (Long et al., 1996). In a report by the Royal National Institute for the Blind (RNIB) on older vision impaired people in the UK, mobility (both the ability to move around their environment safely and get out and about), has been cited as a major area of concern, and widespread social isolation and exclusion have also been highlighted as problem areas (Baker & Winyard, 1998). Mokg et al., suggest that vision loss and the resulting social isolation provide ideal conditions for depression (2000).

2.10.2 Access to services

It is generally accepted that registration does not capture the total population of people who are registrable as blind or partially sighted (Jackson & O'Brien et al., 2008; Bunce et al., 1998; Munier et al., 1998; Canavan et al., 1997; Robinson et al., 1994; Coffey et al., 1993). Discussions with professionals working in the field of vision impairment would suggest that there is a significant population with undiagnosed sight loss in both jurisdictions. A community survey in the UK confirmed that substantial vision impairment exists in the older population (van der Pols et al., 2000). "It is vital that all persons with a visual impairment are able to access services so that residual vision is maximised, independence maintained and quality of life improved" (Lindsay et al., 2004:361). Lindsay et al.'s study also revealed that the number of patients attending clinics who were registered as blind had decreased in the most recent audit for their study (2004). In the initial audit, many of the patients who were first time attendees at a low vision clinic had their eye sight

difficulties for more than five years. This may indicate that eye services are reaching people at an earlier stage in their disease (Lindsay et al., 2004).

2.11 Falls

Older people are at a greater risk of falling and falls are common in this group, leading to serious morbidity, extra strain on health services, and mortality (Rubenstein, 2006). WHO define a fall as "unintentionally coming to rest on the ground, floor, or other lower level" (WHO, 2008b). Vision impairment is associated with a greater risk of falls (De Boer et al., 2004; Lord & Dayhew, 2001; Tinetti et al., 1994). Older people with vision impairment are therefore at a greater risk of falling (Stevenson et al., 2004, Vu et al., 2005, Lord & Menz, 2000, Ivers et al., 1998; Jack et al., 1996; De Boer et al., 2004; Lord & Dayhew, 2001; Tinetti et al., 1994). Falls often result in injuries (Masud & Morris, 2001). Many papers have recommended that vision should be measured as part of any fall prevention strategy (Abdelhafiz & Austin, 2003; Campbell et al., 1999). Various studies have explored the relationship between different aspects of vision impairment and their influence on falls. De Boer et al., (2004) & Lord & Dayhew (2001) found a relationship between contrast sensitivity and falls while Lord & Dayhew (2001) found a relationship between depth perception and falls.

As vision decreases, the risk of falling increases (Harwood 2001). Reduced vision diminishes the ability to detect obstacles or hazards in the environment and therefore the chances of falling are much greater than for someone with normal vision. It is important that people are assessed on various aspects of their vision as it is not just visual acuity that is associated with risk of falling. Contrast sensitivity has been highlighted as an independent risk factor for falls, as was self reported vision impairment (De Boer et al., 2004). Visual acuity, contrast sensitivity, and depth perception were all found to play a role in increasing the likelihood of falling (Harwood 2001). A number of studies have

shown that cataract surgery may help reduce the risk of falling in elderly people (Brannan et al., 2003, Harwood et al., 2005). Falls lead to increased hospital admissions and are the leading cause of hospital admissions in people aged over 65.

In the Republic of Ireland, a strategy document to reduce the incidence of falls recognizes that a vision assessment should be included as part of a multifactorial assessment for fall prevention in at risk groups (Health Service Executive et al., 2008).

2.11.1 Fear of falling

Falls are strongly correlated with increased morbidity and mortality (Rubenstein, 2006). As well as the physical injuries falls have associated psychological trauma which can lead to a fear of falling, which in itself can reduce mobility and cause social isolation.

2.11.2 Consequences of reduced mobility

The Baker & Winyard report for the RNIB (1998) highlighted social isolation and exclusion as problem areas related to mobility difficulties. With declining vision and the subsequent reduction in mobility, physical activity is restricted and therefore reduced (Lamoureux, Hassell, & Keeffe, 2004). This reduction in physical activity can lead to a loss of physical fitness (Capella-McDonnall, 2007; West et al., 2002). A reduction in physical fitness can have a knock on effect on one's health. People with vision impairment who experience problems with mobility are at greater risk of social isolation (Long et al., 1996).

2.12 Transport difficulties

A study in the UK on sight loss and older people found that participants had significantly reduced social contact as a result of a combination of declining health, deteriorating mobility and most crucially impaired vision which left many unable to use public transport or able to use it with great difficulty (Hanson et al., 2001). A paper on social exclusion and transport in the UK stated "Lack of adequate mobility can have a dual impact, actively enforcing and reinforcing exclusion – that is, social exclusion can be a direct result of lack of mobility, or lack of mobility can exacerbate existing experiences of exclusion" (Kenyon et al., 2003:319). In a conference report on older people and people with disabilities in Ireland it was stated "Many older people with disabilities do not have access to transportation, either public or private. Almost one half of households with an elderly disabled person have no car, and two thirds of adults with a disability are unable to access public transport, so the potential for social isolation is great" (McDaid, 2006:13).

2.13 Social isolation and depression

Mokg et al. suggest that social isolation is a "perfect set up for depression" (2000). Historically, those living in these rural areas have been shown to be both geographically and economically isolated and disadvantaged (Robson, 1996). In addition, the WHO has suggested that with increasing urbanisation, a marginalised elderly population may still remain in rural areas with their needs, visual and others, unmet (WHO, 1997b). Sight loss in older adults has been linked to social isolation in many studies (Sloan et al., 2005; Conrod & Overbury, 1998; Fletcher et al., 1991). Social isolation has been shown to affect people with vision loss (Hinds et al. 2003; Smeeth & Iliffe, 1998; Kassa, 1998). After undertaking research on the effect of low vision services on vision related QOL, Hinds et al. stated "our study would indicate that social isolation must now, more than ever, be tackled by services for people with low vision"

(2003:1395). A study in Northern Ireland revealed that older partially sighted males were most likely to be isolated, not attending day centres or meeting others with vision loss (Caul, 2003).

2.14 Loneliness

In the literature people with vision impairment have been shown to be affected by loneliness (Hinds et al., 2003; Smeeth & Iliffe, 1998; Kassa, 1998). In a recent study on loneliness in Ireland, the overall rate of loneliness was low (Drennan et al., 2008). However, predictors of loneliness included age, that is being older, rural dwelling, poorer health in a rural setting, poorer health together with a lack of contact with friends (Drennan et al., 2008). These conditions all had a significant impact on loneliness. In the study over one in ten respondents reported that they had no access to transport either public or private and 60% of respondents were urban dwelling. In their conclusions Drennan et al., recommend that as part of a strategy to tackle issues of loneliness the provision of a transport system is necessary particularly in the rural areas (2008).

2.15 Need for research

WHO highlight the need to establish the ramifications of visual impairment for everyday life so that interventions can be targeted to high-risk subpopulations (WHO, 1997b). This study aims to commence that journey in exploring the effects of visual impairment on the older population of people registrable as blind or partially sighted on the island of Ireland. It is hoped that the results of this study will help service providers prepare a suitable response.

Chapter 3

3.0 Methodology

3.1 Aims & objectives

3.1.1 Aim

The primary aim of this study is to assess the quality of life (QOL) in people aged 60 years and older, registrable as having a vision impairment, living on the island of Ireland. The secondary aim is to examine the functional and demographic factors, which may influence this QOL.

3.1.2 Objectives

Having explored both the generic and vision specific QOL scores of the vision impaired respondents in this study, comparisons will be made between those respondents who are residents of Northern Ireland and those who are residents of the Republic of Ireland. Comparison will also be made between urban and rural dwellers, between and within both jurisdictions. These comparisons will examine the influence of functional and demographic factors.

Given the current recognition of the right of full participation of people with disabilities in all areas of social, economic and cultural life, the study seeks to provide a benchmark on the current situation of this particular group of people with a vision impairment. The findings of this study will furnish service providers with information which they can use to review their policies with a view to adjusting service provision, where necessary, to meet the

needs of the growing population of people aged 60 years and over who are registrable as vision impaired.

3.1.3 Null hypothesis

Rural or Urban Habitation does not influence the quality of life in the older vision impaired population living on the island of Ireland.

3.2 Literature review

An extensive literature search and review was carried out on the following topics: QOL and vision impairment; ageing and vision impairment; focus groups; QOL instruments; questionnaire design; QOL and urban and rural living (See Appendix for Search Strategy). A review of the various QOL instruments was carried out with a view to selecting an appropriate validated generic and complementary vision specific tool for use in this study. The generic SF36 and the vision specific DLTV instruments were subsequently selected as those deemed most appropriate for use in this study. However, none of the instruments that were reviewed covered all of the elements that this research wanted to explore, i.e. the demographic and functional factors.

The author developed a comprehensive complementary questionnaire. This allowed the collation of supplementary information, which could then be correlated with some of the many factors that have been shown, in the literature, to influence QOL, but which are not available currently for examination together in one instrument.

3.3 Individual interviews

3.3.1 Sample

The sampling framework chosen for this study was a probability sampling design. Designs for sampling from this geographically dispersed population (i.e. the population of people registered as having a vision impairment) involved the division of this population into groups of similar units and then the selection of a separate simple random sample in each of these units or stratum. In this way it was envisaged that the sample would reflect the general urban-rural distribution of people registrable as vision impaired in Ireland.

There were a number of ways this population could have been sought. One way would have been to identify those registrable as vision impaired via Low Vision Clinics (LVC's). The benefit of this would be that the availability of accurate data on visual status would ensure that only those registrable would be approached for recruitment. This would however, have left out all those people who were profoundly blind and not making use of low vision aids (LVA's) and also those people whose sight loss had stabilised and were no longer attending low vision clinics. It would also have missed those vision impaired people who felt that they lacked the motivation or ability to utilise the aids and appliances available through the Low vision Clinic and those who were unaware of these services. Those in current receipt of social services could also have been used as the sampling frame, however this too would have omitted many who had adapted to their sight loss and were no longer accessing social services. Accurate and detailed information on current visual status is also often not available from this source. The study chose to recruit from the blind (NI & ROI) and partially sighted (NI) registers and those people who are registrable as blind or partially sighted and currently resident but not necessarily registered in both jurisdictions. Using these

databases and registers ensured that the study would target a good mix of the blind and partially sighted populations who may or may not be in receipt of services currently – those with both long term sight loss and those who had more recently acquired their vision impairment. The downside is that supplementary assessment or confirmation of visual status is absent.

This study planned to use a probability sampling design and the initial sample was selected and recruited via a stratified random sample selected from the databases and registers of blind and partially sighted in both jurisdictions. By using probability sampling one is increasing the representativeness of the group by giving each member an equal chance of being selected. However for true representativeness via probability sampling one must be sure that all of the members of the population are identifiable via an accurate sampling frame. For the purposes of this study the sampling frame was the blind and partially sighted registers in both jurisdictions. It would generally be agreed that there are factors that contribute to accuracy issues with these registers. For example, sometimes people who die are not removed immediately from the registers. Others may have moved address but this fact has not been entered onto the register. Reasons for such inaccuracies are usually because the individual has not required services recently and accordingly their details have not been updated. Therefore, even using probability sampling it is unlikely that the sample selected will truly be reflective of the population being surveyed (Wilson I, 2006 cited in Nzegwu; 2006; Trochim, 2006).

As a result of the difficulties in recruitment via the probability sample a non-probability sampling methodology was adopted in order to increase the number of participants. Purposive, non-proportional quota sampling was then employed to contact potential participants who met the inclusion criteria for the study and invite them to take part. According to Trochim the difference between probability sampling and non-probability sampling is the lack of a random selection in the latter (Trochim, 2006). This means that non-probability sampling “cannot depend on the rationale of probability theory”; therefore the researcher will not know the probability that the population has

been represented well or be able to "estimate the confidence intervals for the statistic" (Trochim, 2006). Trochim goes on to state "however, in applied social research there may be circumstances where it is not feasible, practical or theoretically sensible to do random sampling" (2006). The representativeness of the resulting sample in non-probability sampling then depends on the researchers knowledge of population being surveyed (Trochim, 2006). Having worked in the field of vision impairment for twenty years and having undertaken many cross border projects involving people with vision impairments since 1995, the author would argue that she knows the population under survey rather well. The advisors for this study: Professor A Jonathan Jackson; Dr Patricia Hart; Miss Julie Silvestri, and Professor Colm O'Brien are also very familiar with this population in both jurisdictions.

The registers of vision impairment in Northern Ireland and the Republic of Ireland provided the initial sampling frames for the study. Each register was divided into rural dwellers and urban dwellers. "In consultation with the Spatial Planning Unit, rural areas were generally defined as District Electoral Divisions (DEDs) which did not have a population centre of 1,500 people or above in the 1996 Census." (National Spatial Strategy, 2000: 1) This was the definition of rurality used for the purposes of this study and rural dwellers in the Republic of Ireland were classified as those persons residing in the border corridor in areas with population clusters of 1500 or less inhabitants. The border corridor consists of the six border counties in the Republic of Ireland: Louth; Monaghan; Cavan; Leitrim; Sligo; and Donegal. In Northern Ireland the border corridor included the geographical area of the following Trusts: Newry-Mourne, Craigavon-Banbridge; Armagh-Dungannon; Sperrin-Lakeland and Foyle.

3.3.2 Inclusion criteria

Inclusion criteria were broad. Participants were urban or rural dwellers residing in both jurisdictions, Northern Ireland or the Republic of Ireland, aged 60 years or over and registered or registrable as blind or partially sighted.

Participants also needed adequate cognitive functioning to participate in a face to face interview and an ability to converse in English.

3.4 Sampling frame

The study planned to extract a random sample of approximately 1 in 5 to provide a total of 250 people in each subgroup – Northern Ireland: Urban (NIU), Northern Ireland: Rural (NIR), Republic of Ireland: Urban (ROIU), Republic of Ireland: Rural (ROIR). This research wanted to ensure that the influences of rural and urban dwelling, and the two service delivery systems in both jurisdictions (ROI & NI) were assessed.

Assuming a 2-tailed independent t test (with confidence level $\alpha = 0.05$ and power $1 - \beta = 0.80$) and also assuming a standard deviation of 25 points on a single dimension of the SF36, the study will have sufficient power to detect a major factor (e.g. NI/ROI or urban/rural) of size 6. It is the opinion of the researcher that true difference in sub groups at or approaching 10 should be considered noteworthy. Should attention focus on any two sub-groups then the study has sufficient power to detect such differences of size 8. The SF36 provides information on the impact of disease on QOL as a whole within eight domains, including physical functioning, social functioning, and emotional functioning. A population of 526 is sufficient to provide meaningful information on overall QOL as assessed by the SF36 and to identify which domains are maximally affected.

Due to the difficulties with recruitment, the sampling methodology had to be changed to an opportunistic method and so it was no longer subject to a

formal sample size calculation. Two hundred and twenty two people were recruited to the study for individual interviews. These interviews are much more in-depth than the original plan, which was to look at SF36 and DLTV QOL scores and compare across cohorts with some basic demographic information. One must remember too, that power statements are about populations not samples. This study was sampling four small populations of people with vision impairments in four areas of Ireland. In the end with 222 respondents it is capable of achieving a statistically significant difference between two major groups of size 9 or between sub groups of size 13.

The study fell below power. It would have been preferable to have been able to achieve a statistically significant difference of 10 in order to detect a statistically significant difference the four sub groups. Despite this, the research managed to pick up a sizeable number of statistically significant differences because the true differences between sub groups exceeded expectations.

3.4.1 Sample for focus groups

Fourteen focus groups were held with people with vision impairment and one focus group was held with professionals working with people with vision impairment. More information on focus group methodology is provided later in this chapter.

Purposive sampling was used to recruit participants to these focus groups. Frontline professionals working with people with vision impairment, from urban and rural areas in both jurisdictions, were given detailed information about the proposed study and were asked to select and invite participants to the focus group sessions. They were given guidelines for the selection of participants and every effort was made to ensure that the group reflected the make up of the blind and partially sighted community. Inclusion criteria issued was the same as that for the recruitment of participants for individual

interviews. The study aimed to include a good mix of age, disability, gender, rurality, duration of vision impairment, cause of vision impairment and socioeconomic status. However, in a number of focus groups people outside the age criteria were included by the focus group hosts as these individuals were particularly interested in the subject and had requested to attend. As the hosts were facilitating the PI she did not think it wise to exclude those few people outside the age brackets. Participants for the focus group with professionals were recruited via personal contact made by the Principal Investigator (PI) with service centres in both jurisdictions, including both urban and rural areas. Information about the focus group was distributed, including an invitation to participate and contact details for responses.

3.4.2a Accessing the register in Northern Ireland

There are two registration levels for people with serious sight loss in Northern Ireland – blind and partially sighted (See definitions of blindness in chapter 1). The names of people who are on these registers or who are known to have serious sight loss, i.e. registrable as blind or partially sighted, are contained on the SOS CARE register. SOS CARE is an acronym for Social Services Client Administration and Retrieval Environment. This is a database which holds information about those who use Trust services. This information includes basic demographics on each individual as well as details of illnesses, disability and what services they are using or have used.

In order to access a sample of people who are registrable as blind or partially sighted in Northern Ireland it was first necessary to contact the individual Trusts within Northern Ireland. An initial meeting took place with Mr David Bickerstaff (Principal Social Worker) who informed the relevant managers of the individual Trusts about the study and its requirements for accessing the sample. Contact details of all relevant staff were then forwarded to the PI and information about the study was forwarded to them.

The sampling frame was to include people registrable as vision impaired, both blind and partially sighted, who were residing in Belfast (urban) and along the border corridor (rural). This meant the involvement of seven Trusts, two in Belfast, South & Eastern Belfast Trust (SEBT) and North & Western Belfast Trust (NWBT) and five along the border corridor, Newry Mourne Trust (NMT), Craigavon Banbridge Trust (CBT), Armagh Dungannon Trust (ADT), Sperrin Lakeland Trust (SLT), and Foyle Trust (FT).

Letters were sent to the Senior Sensory Support Managers in each of the above mentioned Trusts in Northern Ireland. The mail gave a brief outline of the study and a summary information sheet was attached. An initial meeting was requested with the relevant manager in the Trust. Following on from this meeting, a further meeting was requested and permission granted to attend a team meeting in each Trust. The purpose of meeting the team was to meet the frontline staff, explain the study in more detail and answer any questions. The front line staff were most likely to be the first port of call for further information or explanations about the study by those who were invited to participate. It was very important to the study that these staff were familiar with the study. At least one meeting took place in each Trust with the sensory support frontline staff. Where requested other one to one meetings took place with staff.

In order to collate samples it was agreed by all relevant Trusts that they would forward a list of people who met the study's inclusion criteria from each Trust. The study team would not receive the identity of any individual. This list would not contain any information that could identify any individual. Instead each individual was represented by a unique identification number. Information on age or date of birth, gender and postcode was also received for potential participants. This process took until the end of April 2004 to finalise and agree. In order to comply with data protection legislation an information request form or data access request form had to be completed for some Trusts. Obtaining postcode information for the Trusts outside Belfast also proved problematic initially but after negotiations, discussions and reassurances about how such

data would be protected, this information was also received. The postcode information was crucial for the separation of people into urban and rural dwellers. Only rural dwellers were required for recruitment outside Belfast. There was a worry that people could be identified via post code information, particularly those residing in remote rural areas.

3.4.2b Accessing the register in Republic of Ireland

In the Republic of Ireland, NCBI (formally known as National Council for the Blind of Ireland) maintain the register of blind people on behalf of the Department of Health & Children of the government of Ireland. There is only one category of blindness in the Republic of Ireland (See definitions of blindness in chapter 1). While registration as blind is voluntary, NCBI maintains a database of all service users. Registration is linked to certain benefits such as the blind persons' pension, companion free travel pass and tax credits for blind people. The author was on sabbatical from NCBI to undertake this study and NCBI had given prior approval for the study as part of the ethical approval procedure in Republic of Ireland. As the author is well known to NCBI she did not experience similar problems obtaining a sampling frame from the register in the Republic of Ireland. In the Republic of Ireland a similar procedure to that of Northern Ireland took place. The sample selection for the urban cohort was obtained from the register of those residing in the Dublin postcode 1-24 areas and the rural cohort was selected from those people on the register who resided in the six border counties of Louth, Monaghan, Cavan, Leitrim, Sligo, and Donegal.

3.4.3 Identifying urban and rural dwellers

Once information for the sampling frames from both jurisdictions was received the next step was to separate the sampling frames into urban and rural

dwellers for those living along the border corridor in both Northern Ireland and the Republic of Ireland.

3.4.3a Northern Ireland

There is no universally agreed definition of what constitutes an 'urban' or 'rural' area (Carr-Hill & Chalmers-Dixon, 2005). Some researchers have used indicators which incorporate access to services and the proportion of population employed in agriculture (Cloke, 1977) but population density is more frequently used, as the data are readily available, though with this there is the theoretical possibility of misclassifying sparsely populated inner city areas. Population density, defined as the number of persons per square kilometre, was calculated for each of the 890 Super Output Areas (SOA) in Northern Ireland based on the number of people enumerated at the time of the 2001 census. Output areas (OAs), the smallest geographical area used in the release of Census data were built from adjacent post code areas and were merged to form Super Output Area using a mixture of common characteristics; population size, mutual proximity and social similarity (ONS, 2008b). The postcoded study data was entered into an EXCEL spreadsheet and assigned a density score using the Central Postcode Directory (a package that provides a lookup between postcodes and different administrative boundaries such as electoral wards and Super Output Areas (SOA)). Urban and rural areas are part of a continuum and any division to separate these areas is therefore arbitrary and open to challenge though a cut-off of four persons per square kilometre was chosen to represent rural areas. In this study, all those who lived within postcode areas with population densities below this figure were then eligible for inclusion as rural dwellers for the purposes of the sampling frame. This population density was based on local knowledge and previous experience in researching these populations (O'Reilly, 2001) and on the basis of visual inspection of small area maps of Northern Ireland. In retrospect, this

classification is based on a similar notion to that of rural maps from the Republic of Ireland.

A recent development in Northern Ireland which uses the same concepts as settlement size took place too late for this project. The Northern Ireland population band structure that now exists is compatible with that of the Republic of Ireland. Under this new eight band structure in Northern Ireland Band G includes villages with a population of 1000 or more but under 2,250 while Band H includes small settlements of less than 1000 people (NISRA, 2005). The Inter-Departmental Urban Rural Definition Group state that in the absence of any specific definition of urban and rural, Bands A to E can be defined as urban while Bands F to H can be defined as rural.

Because of irregularity in the manner by which post codes were recorded within the Trusts there were errors in the data extracted by the software. The author then manually matched the postcode information for each unique id on the list received from the Trusts to the population density for that post code provided by Dr. O'Reilly and then extracted all those rural dwellers for the sampling frame.

The study team received a total of 1795 unique identification numbers for the five rural Trusts in Northern Ireland. After cleaning, removing duplicates and those unique identification numbers where age, date of birth or postcode was absent from the data the sampling frame contained 778 items. On extracting the urban dwellers from this list, the remaining sampling frame consisted of 441 rural dwellers for the NIR sampling frame.

A total of 3010 items were received for the Northern Ireland urban sampling frame. After cleaning, removing duplicates and those unique identification numbers where age or date of birth was absent the sampling frame contained a total of 1051 unique identification numbers.

3.4.3b Republic of Ireland

The rural sampling frame for the Republic of Ireland was obtained by the PI manually going through each individual address from the NCBI database for the six border counties and hand matching it to the Central Statistics Office (CSO) published District Electoral Division (DED) population figures from the Republic of Ireland 2002 census. Those addresses within population clusters of 1500 or under were then included as rural dwellers. If an address did not match the CSO breakdown of townlands then the frontline NCBI worker was called and asked if the location of the individual matching the unique id was rural dwelling. If there was any doubt about the location of the individual they were left out of the sampling frame.

A total of 598 unique identification numbers were received for the Republic of Ireland Rural (ROIR) sampling frame. After extracting those residing in urban areas from this group the sampling frame then contained 424 rural dwellers.

A total of 1251 items were received for the Republic of Ireland Urban (ROIU) sampling frame. After cleaning, removing duplicates and those unique identification numbers where age or date of birth was absent the sampling frame then contained a total of 858 unique identification numbers.

3.4.4 Sample selection

Once the sampling frames were completed, Mr Mike Stevenson, Statistician & Senior Lecturer Medical Statistics, Department of Epidemiology and Public Health, QUB, generated a random sample from the sampling frame using several random sorting procedures via Excel. The details of the first 250 unique identification numbers from the random samples were selected from each of the urban and rural sampling frames from both jurisdictions. In the rural cohorts, these were further broken down into the Trust areas (NI) and sent to the Sensory Support Managers in Northern Ireland, and county areas

(ROI), and sent to the Regional Managers in the Republic of Ireland with instructions of what should be sent to the selected participants. Follow up phone calls were made to ensure that the instructions were understood and to see if any further information was required. Where required, further face to face meetings took place.

Information about the study was photocopied and sent to the individual who had been allocated a unique id by the Regional Manager or Sensory Support Manager responsible for the geographic area where the selected individual lived. The information sent to the selected participants included the following:

- Letter of invitation to potential participants;
- Information sheet about the study;
- Consent form for participation;
- Stamped addressed envelope for return of consent forms.

Copies of the documentation prepared for potential participants can be found in appendix 1. All information relevant to the study was produced in large print for distribution and all of this material was made available in alternative accessible formats, i.e. it was recorded onto audio tape, translated to ASCII code for printing into Braille format and made available as an electronic document for those who requested it. Unfortunately, as the identity of those selected for inclusion in the sample was unknown to the study team it was not possible to determine in advance the preferred method of access to the written word for selected individuals and so all material was initially dispatched in large print only. While there were a number of subsequent requests for the material to be sent out in audio format, there were no requests for either Braille or electronic format.

The study team had no control over when the letters containing the study information were dispatched and were relying on the goodwill of the staff in the Trusts and NCBI to make the time to identify those selected and send out

the information. The letters were sent out between June 2004 and the end of September 2004.

Individuals who agreed to participate in the research were invited to return a signed consent form or phone the researcher or her supervisor for further details. They were then contacted by telephone to arrange a time and venue of their choice for the interview. It was not until the respondent contacted the research team or gave their consent for contact via the Trust, Voluntary Organisation, or Low Vision Clinic personnel that the research team became aware of their identity.

3.4.5 Response

The response was extremely poor in all cohorts with the result that it was necessary to employ alternative recruitment methodologies.

3.4.5a Northern Ireland

To give an example of the difficulties encountered in the recruitment process the following information will demonstrate what happened in the Northern Ireland urban (NIU) situation. In the NIU cohort a total sample of 250 unique identification numbers were sent to the Trusts. The Trusts were asked to dispatch the approved information to the people represented by the first 200 unique identification numbers from the list. The 50 extra unique identification numbers were included to replace individuals who may have been deceased or unsuitable for inclusion due to dementia. When the Trusts examined their lists, they found that out of the 250 unique identification numbers they were only in a position to dispatch a total of 106 letters as the register was not up to date. The rest of the unique identification numbers were ineligible either because the individuals were deceased or recorded as either having dementia or being profoundly deaf. The information received from the SOS CARE register was

thus not up to date. The study team then requested that letters of invitation and accompanying documentation was sent to the next 150 unique identification numbers selected from the random sample but due to staff shortages and changes no feedback was received on how many of these were dispatched. A total of 23 eligible letters of consent were returned for this cohort. Six letters were returned where the addressee had died. The PI then approached the Trusts and asked if they could phone a sample of individuals from the list of the unique identification numbers within the selected sample. The purpose of the phone call was to explain verbally about the study and enquire if the individual would be interested in participating. The staff at the Trusts agreed to call some of those on the list but did not have time to call everyone. A further 21 individuals agreed for the study team to contact them in person and seek informed consent. Out of these 44 responses (postal and telephone) a total of 39 participated in the study. The study team are not certain how many were contacted by telephone, as it was not possible to ascertain this information from the Trusts. The Trusts found the process very time consuming and due to staffing difficulties were unable to provide further assistance in contacting people in this manner.

In NIR cohort 35 letters of consent were returned. Of these, six of the letters of consent had only an illegible signature with no address or contact details included and so it was not possible to identify these people. Twelve of the 29 letters of consent returned had postcodes from urban areas and these were excluded from the study. Reasons for the inclusion of urban respondents in the NIR sample have been given elsewhere. However, other reasons included the fact that respondents had moved address and their mail was forwarded. It is also possible that there was an error with addresses when sent out by the Trust or an error in original postcode in the sampling frame. Seventeen eligible letters of consent were returned via the postal request. Thirteen letters were returned stating that the addressee was deceased. Two letters were returned stating that the selected individual was unable to participate due to health reasons.

Some of the rural Trusts were unable to provide information on how many letters were sent out or how many follow up telephone calls were made.

3.4.5b Republic of Ireland

In the Republic of Ireland 21 letters of consent were received from the urban selection. Ten letters were returned due to the addressee being deceased. Four letters were returned stating that the addressee was unable to participate due to health reasons.

Letters of consent were returned from 32 of those selected in the Republic of Ireland rural cohort. Five letters were returned due to the addressee being deceased. Thirty letters were returned stating that the addressee was unable to participate due to health reasons.

Soon after the invitation letters were dispatched, a number of those selected in the Republic of Ireland (from both urban and rural areas) contacted the PI by telephone to find out more information about the purpose of the study. Further follow up telephone calls with selected participants alerted the PI to a possible reason for the poor response. The majority of people contacted almost immediately agreed to participate when asked on the telephone. Reasons given for non-response and non return of the letters of consent to the postal request included "too much print information", "if it is that important someone will contact me again", "Not able to read print" etc.

3.4.6 Alternative recruitment methodologies

As a result of these extensive recruitment difficulties the study moved from a probability sampling methodology to a non-probability sampling methodology.

The PI recorded an interview for the Northern Ireland audio magazine *SoundVision*, produced by Blind Centre of Northern Ireland (BCNI) and forwarded information to *Focus*, the audio magazine published by NCBI. In this interview she gave details about the purpose of the study and invited those who had already received information about the study, and were interested in finding out more, to contact the study team. Subsequent to these broadcasts a number of people responded by telephone and agreed to participate in the study.

Armed with the information gathered from the telephone calls in the Republic of Ireland, the PI approached the Trusts and asked if it was possible to follow up those selected from the sampling frame with telephone calls. This was not possible in some Trusts due to staffing problems, but where it was done the participation level increased.

Staff at Low Vision Clinics at the Royal Victoria Hospital were asked to inform review patients who met the inclusion criteria about the study and invite them to take part. BCNI and Guide Dogs for the Blind Association (GDBA) Northern Ireland were also contacted and asked to inform their service users who met the inclusion criteria about the study and invite them to take part.

3.4.7 Response rate via alternative recruitment methodologies

3.4.7a Northern Ireland urban (NIU)

Through this recruitment methodology an extra 20 urban participants were recruited from NIU, nine of whom consented via GDBA; seven of whom consented via the Low Vision Clinic at the Royal Victoria Hospital and four who contacted the research team directly. Four people refused to participate post consent.

3.4.7b Northern Ireland rural (NIR)

In the Northern Ireland Rural cohort an extra 27 participants were recruited, 21 of whom consented via BCNI, three through GDBA and three via outreach low Vision Clinics of the Royal Victoria Hospital. Two people refused to participate. No reason was given.

3.4.7c Republic of Ireland urban (ROIR)

Thirty five extra participants were recruited via phone calls through NCBI. Four people contacted refused to participate, reasons included: "Of no benefit to me"; "Couldn't be bothered"; and the other two just did not want to, primarily for health reasons.

3.4.7d Republic of Ireland rural (ROIR)

In the rural area of Republic of Ireland 27 extra participants were recruited via phone calls through NCBI. Two people refused to participate, due to health reasons.

It should be noted that many more from Republic of Ireland could have been recruited via this recruitment methodology. However, as all methods for recruiting from Northern Ireland had been exhausted, recruitment to the study stopped at these figures to ensure the cohort numbers were balanced.

Table 1 below summarises the recruitment figures for the study.

	NIU	NIR	ROIU	ROI R
Eligible letters of consent returned	23	17	21	32
Phone/Verbal consent	21	8	35	27
BCNI	0	21	0	0
GDBA	9	3	0	0
LVC	7	3	0	0
TOTAL Respondents (n=222)	55	52	56	59
Unable to participate post consent(n=13)	5	2	4	2

Table 1 Recruitment

3.5 Data collection

The QOL instruments chosen for use in this study were the SF36, which is a generic QOL tool and the DLTV, which is a vision specific QOL tool. A separate questionnaire was developed for data collection and a vision assessment was conducted.

3.5.1 QOL instruments

3.5.1a SF36

The SF36, a generic health related QOL tool, contains 36 items, which assess 8 multi-item domains including: physical functioning (10 items); social functioning (two items); limitations in usual role activities because of physical problems (four items); role limitations due to emotional problems (three items); bodily pain (two items); general mental health (psychological distress and well being) (five items); vitality (energy and fatigue) (four items) and general health perceptions (five items) (Parrish et al, 1997). One unscaled item asks respondents about changes in their health over the past year. This study is using the SF36 to provide information on the impact of disease on

QOL as a whole. The SF36 was developed in the first instance in the USA but the version used for this study (SF36v2) has been adapted and validated in a UK population.

3.5.1b Administration

This questionnaire was included in its complete form as part of the overall interview protocol. (See appendix 11). It was administered after conducting the vision assessment. All relevant extraneous responses to individual items were recorded verbatim on the questionnaire.

The SF36v2 uses a likert type response scale varying from three level likert items to six level likert items throughout the questionnaire. The resulting scores for each domain are summated and transformed to a scale ranging from 0 to 100. The lowest end of the scale, 0 indicates a poor health related quality of life while a score of 100 represents an excellent health related quality of life (Ware & Sherbourne, 1992).

	Domain	Item	
Physical health	Physical Function (PF)	3a. Vigorous activities	
		3b. Moderate activities	
		3c. Lift or carry groceries	
		3d. Climb several flights	
		3e. Climb one flight	
		3f. Bend knee	
		3g. Walk mile	
		3h. Walk several blocks	
		3i. Walk one block	
		3j. Bathe dress	
	Role Physical (RP)	4a. Cut down time	
		4b. Accomplished less	
	Bodily Pain (BP)	4c. Limited in kind	
		4d. Had difficulty	
General Health (GH)	7. Pain magnitude		
	8. Pain interfere		
		1. EVGFP rating	
		11a. Sick easier	
		11b. As healthy	
		11c. Health to get worse	
Mental Health	Energy & Vitality (EV)	11d. Health excellent	
		9a. Pep/life	
		9e. Energy	
		9g. Worn out	
	Social functioning (SF)	9i. Tired	
		6. Social extent	
	Role emotional (RE)	10. Social time	
		5a. Cut down time	
	Mental health (MH)	5b. Accomplished less	
		5c. Not careful	
		9a. Nervous	
		9c. Down in dumps	
			9d. Peaceful
			9f. Blue/sad
9h. Happy			

Table 2 SF36 Domains

3.5.1c DLTV Daily Living Tasks Dependent on Vision

The DLTV (Daily Living Tasks Dependent on Vision), a visual function index previously known as a vision specific QOL tool, was applied. This instrument was designed for use with older people with unilateral or bilateral irreversible vision impairment (Stevenson et al., 2004).

The DLTV contains 25 items and uses a four point ordinal scale on which respondents can select their answers. The scale responses are designed to reflect how much difficulty the respondent believes he or she has with a particular activity. Each activity question is preceded by "How much difficulty do you have" and the responses include: Can't see to do; A lot of difficulty; A little difficulty; or No difficulty. Two of the questions included on the DLTV ask respondents to self-rate their overall visual distance and near vision. These questions are not included in the overall DLTV score.

The authors of the DLTV decided not to name the individual domains of the instrument, based on the activities within the domain e.g. 'near activities' as they felt this was a subjective judgement by the investigator. Rather the domains are numbered DLTV Domain 1, DLTV Domain 2, DLTV Domain 3 and DLTV Domain 4. (See appendix 11 for interview protocol which contains the DLTV).

DLTV Domain 1 (8 items)	DLTV Domain 2 (8 items)
Reading normal size newsprint	Distinguishing a person's features at arm's length
Reading correspondence, e.g. letters and bills	Reading newspaper headlines
Signing documents, e.g. cheques	Pouring yourself a drink
Identifying money from a wallet	Using kitchen appliances
Reading road signs/street names	Recognising seasonal changes in the garden
Watching TV programmes	Cutting up food on your plate
Distinguishing a person's features across the street	Enjoying the scenery if out for a drive
Distinguishing a person's features across the room	Cutting fingernails
DLTV Domain 3 (7 items)	DLTV Domain 4 (2 items)
How would you rate overall near vision?	Adjusting to brightness after being in the dark
How would you rate overall distance vision?	Adjusting to darkness after being in the light
Confidence in ability to walk around one's own neighbourhood	
Confidence in an ability to walk around an unfamiliar neighbourhood	
Do you agree? I feel I have to be more careful because of my eye condition	
Noticing objects off to either side	
Seeing steps and using them	

Table 3 Items in the daily living tasks dependent on vision by dimension (Stevenson et al., 2004)

3.5.2 Administration

This questionnaire was included in its complete form as part of the overall interview protocol. It was administered prior to conducting the vision assessment. All relevant extraneous responses to individual items were recorded verbatim on the questionnaire. This instrument had a dual purpose in this study. In the first instance it was being used to measure vision specific

quality of life of the cohort. Secondly, responses to individual items would be used to correlate difficulty with various activities of daily living with other functional and demographic variables.

Responses are scored on a scale of 1 to 4 where 1 represents the most difficulty in completing the task and 4 represents no difficulty in completing the task. Items within the different subscales are then summed. The resulting scores are transformed to a scale ranging from 0 to 100. The lowest end of the scale, 0 indicates an inability to complete an activity of daily living while a score of 100 represents perfect capacity to carry out a task (Stevenson et al, 2004).

3.6 Vision assessment

The vision assessment instruments included Bailey Lovie distance, LogMAR Visual Acuity charts, both high and low contrast, Bailey Lovie near single word reading charts and gross confrontational visual field testing in all four quadrants.

Vision tests were conducted under habitual lighting conditions in the respondent's home or place of interview. When testing in the home, participants were informed that best results would be achieved under those circumstances when their room was in best lighting. These lighting conditions were those they would choose if undertaking any tasks that involved getting the best out of their vision, i.e. room lights on and or curtains open. For the distance visual acuity tests respondents were encouraged to use their spectacles, those which they normally used for doing distance visual tasks. For the near vision tests, they were encouraged to use their reading glasses and or their magnification aids. Individuals who used multifocal spectacles were encouraged to use them for both distance and near vision testing.

Visual Acuity high and low contrast tests were conducted initially at 3m, if the respondent was unable to read at least 3 letters from the top line at this distance the chart was moved to 1.5m from the respondent. The respondent could view the chart monocularly or binocularly, whichever they preferred. If the respondent was unable to read any of the letters on the Bailey Lovie Chart at 1.5m their vision was then checked to see if they could count fingers, see hand movements, identify the location of light or see light at all.

Near Vision was assessed using Bailey Lovie Near Vision Reading charts. Respondents were given as much time as they needed and were encouraged to use their usual reading glasses or magnification aids. The test was thus of habitual reading ability. Results were quantified using the Faculty of Ophthalmology approved "N point" system. Respondents were grouped according to the score achieved ranging from a score of 1 which indicated the respondent was unable to read anything on the chart to a score of 6 where the respondent achieved a score of N8 or better. The intermediary scores were as follows: a score of 2 denoted that the respondent achieved N80; a score of 3 signified that the respondent read better than N80 but less than N40; a score of 4 indicated that the respondent achieved better than N40 but less than N20; and a score of 5 signalled that the respondent achieved better than N20 but less than N10.

Visual fields were measured using confrontation testing in all four quadrants. Where peripheral field loss was identified, arbitrary scales were allocated according to whether the loss extended into 1, 2, 3 or 4 quadrants. The magnitude of central loss was not quantified because for the purposes of this study central loss was deemed to equate with a loss of visual acuity.

3.7 Questionnaire development

A data collection instrument was devised to gather both demographic data and data on the many factors that have been shown to affect the lives of people with vision impairments.

The questionnaire development was informed by the literature review and the fact that as far as could be ascertained, no similar comparative study has been conducted with this group in Ireland. A draft questionnaire was developed. Two focus groups, one consisting of urban dwellers and one consisting of rural dwellers, were conducted at the beginning of the study to explore issues of relevance to this cohort and to aid in the design and refining of the questionnaire. As a result of the focus groups the questionnaire was further refined. The developed questionnaire was then piloted with 33 people from the four cohorts. The questionnaire was also distributed to various staff working in the field with people with vision impairment in all four cohorts to get their feedback. Pre-coded questions on the issues of the current health and social circumstances and the usage of existing services were included in the questionnaire as were a number of open ended questions. The open ended questions would give respondents an opportunity to articulate their needs.

As a result of the feedback gained from the pilot, the frontline staff, and the focus groups, a number of minor changes were made to the questionnaire and it was finalised.

Prior to the interviews with recruits to the study the PI met with all the Regional Managers responsible for service delivery to people with a vision impairment in the Republic of Ireland and all of the Community Resource Workers, Social Workers and Rehabilitation staff in the sample areas to discuss the study in detail. Interview materials were circulated to this group and meetings were organised at regional level to discuss the study. During the course of this exercise valuable feedback on the study design and the newly

developed questionnaire was obtained from both professionals and people with vision impairments. All of the managers in the field of sensory impairment in Northern Ireland had information about the study including the questionnaires, distributed to them, and were invited to provide feedback to the PI. Meetings took place between the PI and many of the frontline professionals in the field both on an individual basis and at team meetings. Feedback on the study design was received and through this contact the PI was reassured that the frontline professionals had obtained a thorough knowledge of all relevant areas of the study. These frontline professionals in both jurisdictions were also informed that a focus group would take place at a later stage of the study to explore services provision and the professionals' opinions on the unmet needs of the people with vision impairment.

3.8 Interviews

Domiciliary interviews, of approximately 1.75 hours duration, took place with consenting participants in their homes, or, alternatively, at a venue of their choice. In order to maximise participation rates, respondents were informed that the interview would take place at a time and venue that suited them. The selection of a convenient venue has been shown to encourage the participation of rural dwellers in particular (Morgan et al, 2005). Interviews consisted of the administration of generic (SF36) and vision specific (DLTV) QOL tools, demographic and needs assessment questionnaire together with a vision assessment. Interviewers were recruited and trained to carry out the interviews together with the PI in all cohorts. All interviewers, except one, were experienced in the field of health care and working with people with vision impairment. The one interviewer who was not experienced in the field of sight loss had experience in caring for an elderly person. Extra training was given to the interviewers with least experience in the field of vision impairment. All interviewers had to carry out pilot questionnaires with either the PI or her supervisor who assumed the role of a vision impaired older

person. Quality control of the interview process was maintained by the PI with regular meetings and phone calls to follow up after interviews were completed

The questionnaire in the appendix is ordered to follow the format of the interviews. The order of the interview protocol was decided in response to the pilot study. Using this structure the interview appeared to run as a logical sequence. In particular, it was important to complete the vision assessment after completing the SF36 and DLTV. In the pilot where the vision assessment was carried out very early in the interview process the respondents tended to respond to the questions on the DLTV in particular, and to some extent the SF36 with comments like "Don't use know my eyesight is bad...why are you asking me these questions." This scenario mainly applied to those people with severely reduced vision. When the QOL instruments were administered before the vision assessment, respondents were more likely to answer them without commenting on the fact that the interviewee should know the answer already.

3.9 Inclusion criteria

As inclusion criteria required that respondents had adequate cognitive abilities, a Cognitive Assessment Tool was administered at the beginning of every interview. Participants had to score a minimum of 8 out of 12 on this instrument to proceed with the interview. If a participant did not achieve a score of eight they were asked some basic questions demographic questions and this was followed by a vision assessment where appropriate. Finally the participant was asked if they had anything they would like to add. This process was carried out to ensure that the participant did not feel that they had failed, or were unworthy of participating. The study conducted 222 individual interviews with participants who met the inclusion criteria.

3.10 Data entry and data analysis

All data entry and analysis of the in-depth interviews was conducted using SPSS version 15. Data was entered by the author. Verification of correct data entry was conducted whereby the 10% of the respondents' questionnaires were randomly selected by chief advisor to the study and double entry checked against inputted data. Minimal errors were found. The author then double checked all questionnaires against inputted data and made corrections where necessary before analysis.

3.11 Triangulation

Methods triangulation is the use of a combination of methodologies to examine a fact or event and establish the accuracy of the information retrieved by comparing the different results (Patton, 2001). Using methodological triangulation it is hoped that the study will overcome the weaknesses associated with a single methodology, maximise the research results by combining the methods and provide confirmation of the findings via a convergence of the results. By using this process the study hopes to explore and explain in more depth some of the issues that arose during the individual interviews. While quantitative research gives the "breadth" to the research i.e. the statistics and confidence intervals, qualitative research can give the "depth" i.e. allow the study to explore in more depth the issues that arose during the quantitative interviews and thereby giving a deeper understanding of the issues. According to Mouton & Marais using a combination of quantitative and qualitative methodologies can capture more fully the entirety and complexity of human life (Mouton & Marais 1990).

Given the difficulties experienced with recruitment it was felt that triangulation was a particularly advantageous approach to use in this study.

"Triangulation of methods will most often revolve around comparing data collected through some kind of qualitative methods with data collected through some kind of quantitative methods" (Patton 1990, 465). Some researchers have discussed the conflicts between using these two methodologies and suggested that the researcher should not expect that the "findings generated by those different methods will automatically come together to produce some nicely integrated whole" (Patton 1990, 466). Patton goes on to state that the "triangulation of qualitative and quantitative data is a form of comparative analysis". He cites Fielding & Fielding who state "Comparative research often involves different operational measurements of the 'same' concept, and it is an acknowledgement of the numerous problems of 'translation', that it is conventional to treat each such measure as a separate variable. This does not defeat comparison but can strengthen its reliability" (1986; 130 cited in Patton 1990; 467).

3.12 Qualitative research

This study engaged both quantitative and qualitative methods. Qualitative research allows the investigation of respondents' attitudes, beliefs, and preferences and gets answers to questions that do not immediately appear as a result of quantitative explorations (Green & Britten, 1998).

The qualitative data was collected in a number of ways.

There were a number of open ended questions included on the questionnaire developed for this study. These gave respondents an opportunity to express their opinions if they so desired. Each trained interviewer was asked to record in writing any extraneous comments made by the respondent in response to each of the quantitative questions. All of these comments were then entered as string variables as part of the data entry process in SPSS. Using a mixture of quantitative and qualitative methods allowed the study to record and interpret issues of importance for each respondent.

Analysis of the qualitative data generated in this study was undertaken by the author using a combination of SPSS Text Analysis for Surveys™ 2.0 and conducting a manual examination and exploration of the data. SPSS Text Analysis for Surveys™ 2.0 is a survey text coding application used to undertake a text analysis of the qualitative data generated by the research. After importing the qualitative data, SPSS Text Analysis for Surveys™ 2.0 can be used to extract and categorise the key concepts that arise in the data. The extraction of data in this manner is a form of qualitative analysis called text analysis. For the purposes of this study text analysis was used to extract and explore the key concepts generated by the qualitative data and then content analysis was used to analyse data. Content analysis is a method of exploring and coding the information received via a focus group into themes.

The text analysis software was used in combination with a manual exploration of the data. The author was not interested in quantifying the number of responses on a particular theme rather she wanted to get an understanding of the main messages that were generated by the qualitative data, understanding quite clearly the limitations of such responses. Manual content analysis is quite time consuming but immerses the researcher in the data and is quite accurate. Using the SPSS text analysis software was further triangulation of the data as it allowed a different more in depth exploration of the data on a phrase by phrase basis thereby ensuring that the researcher could pick up any minute details that may have been missed.

3.12.1 Focus groups

Focus groups were used as part of the data collection methodology

3.12.2 What is a focus group?

A focus group is an organised gathering of people to discuss a subject, which will help a researcher assess the group's opinions on the topic. "The aim of focus group research is to learn and understand what people have to say about a topic and understand their arguments" (Proctor 2005). They provide a method of data collection that can help to assess opinions and were used in this study to gain insights into issues that arose during the individual interviews.

3.12.3 Number of participants

While Macintosh recommends from 6 to 10 participants (1981), Goss & Leinbach have been successful with greater numbers, up to 15 people (1996) or as few as four (Kitzinger 1995). What is important is that the group is small enough to facilitate intimate discussion but large enough to ensure enough people to provide a variety of opinions. Participants need to feel comfortable with each other. "Meeting with others whom they think of as possessing similar characteristics or levels of understanding about a given topic, will be more appealing than meeting with those who are perceived to be different" (Morgan 1988).

This study chose to use focus group sessions with people with vision impairments from both urban and rural areas in Northern Ireland and the Republic of Ireland in addition to the individual interviews that were carried out. This was done with the objective of exploring further some of the topics that arose during the individual interviews. Purposive sampling was used to

recruit participants to the focus groups. Frontline professionals working with people with vision impairment were asked to select and invite participants to the focus group sessions. They were given guidelines for the selection of participants and every effort was made to ensure that the group reflected the make up of the blind and partially sighted community. Inclusion criteria were the same as for the individual interviews in the quantitative part of the study. Guidelines requested that people who participated in the individual interviews did not participate in the focus groups. The study aimed to include a good mix of age, disability, gender, rurality, duration of vision impairment, cause of vision impairment and socioeconomic status.

Two focus groups, one consisting of urban dwellers and one consisting of rural dwellers, were conducted at the beginning of the study to aid in the design and refining of the questionnaire.

Subsequently, 14 groups of people were invited to take part; six focus groups took place in Northern Ireland and eight in the Republic of Ireland. One hundred and twenty one individuals attended 14 different groups in the four cohort areas.

3.12.3a Urban focus groups

In total seven focus groups were held with respondents who were urban dwellers. Three focus groups were held with participants from Belfast with total of 21 participants and four took place in Dublin with a total of 39 participants.

3.12.3b Rural focus groups

Seven focus groups were held with rural dwelling participants from the border corridor area in both jurisdictions. Three focus groups were held in Northern

Ireland with a total of 27 participants and four focus groups took place in the Republic of Ireland with a total of 34 participants.

Altogether there were 121 participants, 48 in Northern Ireland, and 73 from the Republic of Ireland

3.12.4 Focus group facilitation

The author facilitated 12 of the 14 sessions; two of the sessions were facilitated by a trained facilitator. All of the sessions included both a notetaker and a facilitator. The length of the sessions did not vary too much with an average of 90 minutes duration.

At the start of each session participants were asked to introduce themselves. First names only were used during the groups. The facilitator then introduced herself and gave a brief overview of the session including the purpose of the focus group, details of how the session would proceed, and what will happen to the information gathered. Issues regarding confidentiality and the recording of the session were explained and the participants were given time to ask questions. Ground rules were explained. In particular, participants were advised that there were no right or wrong opinions and that everyone's opinion was of great value to the research. Finally participants were asked if they were still happy to continue to participate. The session then began.

3.12.5 Focus group with professionals

A focus group was also held with frontline professionals in both jurisdictions to ascertain their views on actual service delivery and their perception of unmet needs in the field. Frontline professionals included those people whose primary role is the delivery of direct services on a day to day basis to people with

serious sight loss. The principal investigator facilitated this focus group and a notetaker was also present.

3.12.6 Focus groups analysis

After a number of readings of each of the transcripts of the focus groups, themes that were common to each group were noted and coded to categories. A list of words attributed to each category was then created. Following on from here a search was made of each transcript to locate any and all of the words related to each category. Examples of categories established included transport, public awareness, mobility, etc.

An Excel workbook was created and a work sheet for each focus group was established. Each participant in the focus group was assigned a unique id. Each worksheet had a section labelled with the title of the individual categories. Every time a word from the list arose in a transcript from a focus group the section of text related to the category was copied from the transcript and pasted into the relevant section of the Excel workbook together with its unique identification number. These workbooks were also imported into SPSS Text Analysis for Surveys™ 2.0 and analysed using the data extraction facility of this software.

3.12.7 Limitations of focus groups

The author is fully aware of the limitations of focus groups and was careful to avoid unduly influencing participants but recognises that this can happen in any case. All participants were encouraged to be forthcoming with their opinions to avoid responses as a result of peer pressure. It is understood that the results of the focus groups cannot be generalised but that they do indicate a range of views and opinions.

3.13 Ethical approval

Ethical approval was obtained in both jurisdictions before embarking on the recruitment procedure. In Northern Ireland ethical approval was granted by the Queen's University Research Ethics Committee Ethical Approval Reference Number 195/02 and the Republic of Ireland, Mater Misericordiae Hospital Research Ethics Committee: Ethical Approval Reference Number: 1-378-739.

In the Republic of Ireland the Research Ethics Committee applicants are required to attend interview with the research ethics committee. In the North of Ireland at the time of application for ethical approval, no attendance at interview was required.

During the study, normal ethical procedures were observed. Individuals' confidentiality was assured and maintained. Extensive consultation took place with the people with vision impairment and the professionals who work closely with them. The study was carried out in accordance with the tenets of the Declaration of Helsinki on research with human volunteers. Fully informed consent was obtained from participants.

Accessible and understandable letters of invitation, comprehensive information sheets, and consent forms were developed and supplied to potential participants prior to recruitment. It was made clear that participation or non-participation would bear no relevance or consequence on current or future receipt of services. Potential participants were also informed that they were free to withdraw from the study at any time.

Chapter 4

4.0 Results section 1

Individual interviews

4.1 Population

Participants for this study were selected from the population of people who were registrable as blind or partially sighted in the Republic of Ireland and Northern Ireland. The study consisted of four cohorts: rural dwellers (in the border corridor) and urban dwellers (Belfast and Dublin) in both jurisdictions.

4.1.1 Why these populations?

This study wanted to compare populations of people aged 60 and older who were vision impaired and either urban or rural dwelling from north and south of the Irish border. Dublin and Belfast are most representative of urban areas in both jurisdictions. Those living in these two large cities should have access to the wide range of services and amenities relating to health and social support that one would expect in any European city. Individuals resident in the rural areas chosen for this study are likely to have a greatly restricted access to the wide range of health and social facilities which are easier to locate in urban areas. The rural sample was chosen from the vision impaired population along the border corridor as these areas can be reasonably matched as rural and were likely to have certain deprivation factors in common (O'Reilly, 2001).

Domiciliary, one to one interviews averaging 1.75 hour's duration were conducted with consenting participants from the four cohort areas. The primary aim of this study was to examine and compare the quality of life (QOL) in urban and rural dwelling people over the age of 60, registrable as blind or partially sighted, on the island of Ireland. A secondary aim was to

examine the functional and demographic factors that possibly influence this QOL.

While the questionnaire primarily consisted of closed questions, there were a number of open ended questions included. In addition, relevant extraneous remarks in response to the quantitative questions were recorded for further analysis.

4.2 Demographics

The study recruited 235 participants in total for individual interviews. However, only responses from 222 participants were included in the final analysis, Northern Ireland (n=107) and the Republic of Ireland (n=115). Reasons for the exclusion of the 13 extra recruits were as follows: 6 refusals on reconfirming consent on arrival to their home for the interviews (3 Northern Ireland Urban (NIU), 1 Republic of Ireland Urban (ROIU) & 2 Northern Ireland Rural (NIR) with reasons given including fatigue, illness, and forgetting that they had made the arrangement and deciding not to rearrange). Two participants (ROIU) became tired during the course of the interview and decided they did not want to arrange a time to continue the interview. One participant (ROIR) called the principal investigator (PI) and asked that her interview be removed from the study, and four participants did not demonstrate sufficient cognitive skills for the interview to be completed (2 NIU, 1 NIR & 1 ROIU). Participants in both jurisdictions were selected from urban (n=111) and rural (n=111) populations. Urban participants in Northern Ireland (NIU) were resident in Belfast (n=55) while urban participants in the Republic of Ireland (ROIU) were resident in Dublin (n=56). Rural dwellers were selected from those dwelling along the border corridor in both jurisdictions, Northern Ireland Rural (NIR) (n=52) and the Republic of Ireland Rural (ROIR) (n=59).

4.3 Participant profile

4.3.1 Gender breakdown

As one would expect with an ageing population irrespective of whether the group are subdivided according to residency or otherwise the majority of individuals were female 72% (n=160) and 28% (n=62) males.

Cohort	ROIR	ROIU	NIR	NIU	TOTAL
Numbers	59	56	52	55	222
%	(26.6%)	(25.2%)	(23.4%)	(24.8%)	(100%)
Females	38	37	40	45	160
Males	21	19	12	10	62

Table 4 Gender Breakdown

There was no statistically significance to the minor difference in gender breakdown for the four areas, (Pearsons chi sq. (χ^2) = 5.92, df 3 p= .0.115).

The overall female: male ratio increased with increasing age from 1:1.62 in the 60 to 69 age band to 1:3 in the 90 to 99 age group, $\chi^2 = 8.10$, df 3, p < 0.05.

The gender breakdown and ratio for each of the four age bands are as indicated in Table 5 below

Age	60-69	70-79	80-89	90-99	Total
Females	34	47	73	6	160
Males	21	23	16	2	62
Ratio	1:1.6	1:2.0	1:4.6	1:3.0	1:2.6

Table 5 Age breakdown with ratio

4.3.2 Age

The age of participants ranged from 60 – 99. The mean age was 76.5 ± SD 8.6. The largest percentage, 40.4% of all people, was in the 80 to 89 age band.

Cohort	ROIR	ROIU	NIR	NIU	TOTAL
Mean Age ± SD	75.4 ± 8.5	78.6 ± 7.8	76.4 ± 9.7	75.8 ± 8.0	76.5 ± 8.6
Range	60 – 89	63 – 92	60-90	60-99	60-99
Median	76	79	76.5	80	77.5
IQR	68-82	72-85	67-86	70-82	70-83

Table 6 Age Profile

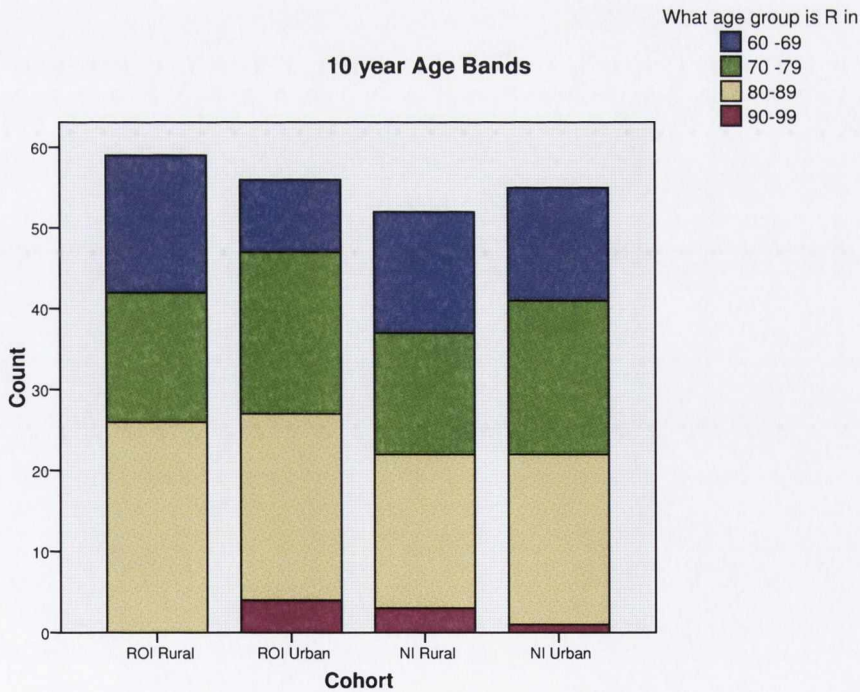


Figure 10 Age breakdown 10 year bands

There was no statistically significant difference between the ages of participants from any of the four geographic areas of interest, ($\chi^2= 9.11$, df 9, $p = 0.427$).

4.3.3 Additional disabilities or illnesses

The majority of respondents, 76.6 %, said they had at least one additional illness or disability (n=170). These additional illnesses or disabilities included: diabetes 13.1% (n=29), hypertension 14.9% (n=33), arthritis 35.1% (n=78), respiratory problems 7.7% (n=17), coronary problems 21.2% (n=47), hearing impairment 11.7% (n=26) and other 47.3% (n=105). The majority of respondents had multiple co-morbidities. ROIU was a little less disabled but this did not achieve statistical significance, ($\chi^2= 0.299$, df 1, $p = 0.632$).

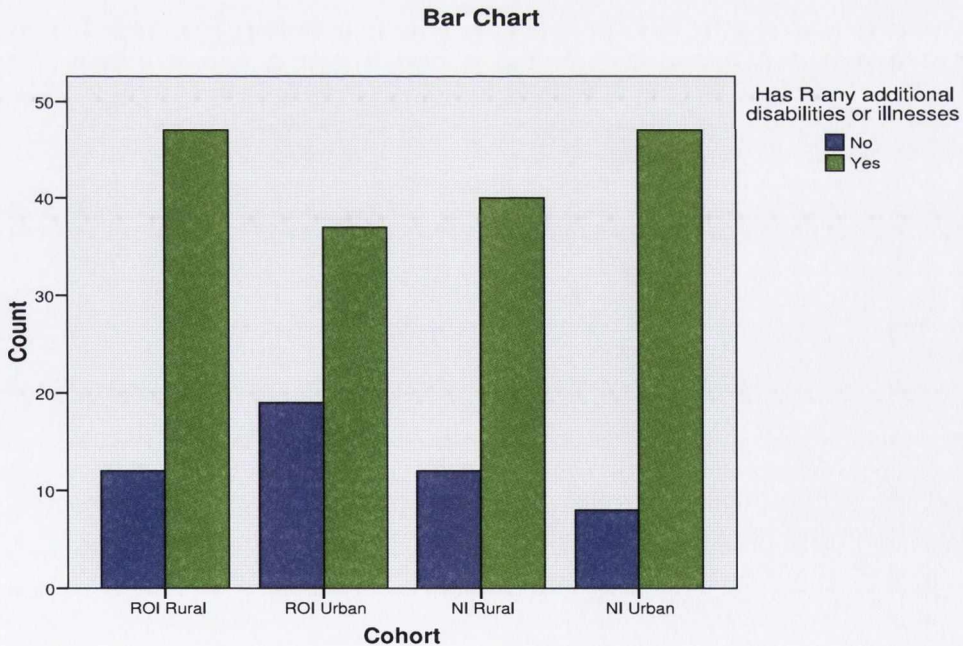


Figure 11 Additional illness or disability

4.3.4 Education

The majority of respondents 63% (n=138) completed their education after primary level. Second level was completed by 25.6% (n=56) of respondents. Vocational training or an apprenticeship was completed by 7.8% (n=17) while 3.7% (n=8) stated that they had completed third level education. Data was missing for three respondents. There was no difference in education achievement between urban and rural cohorts, ($\chi^2 = 0.66$, df 3, $p = 0.884$).

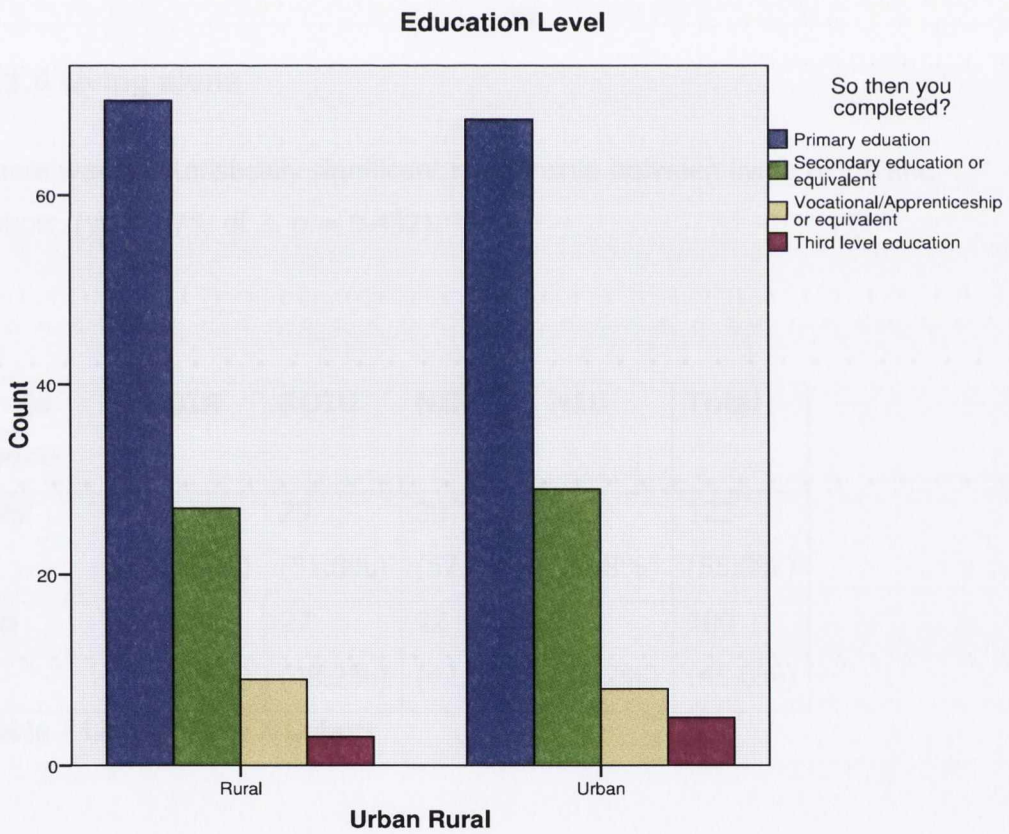


Figure 12 Education level

4.3.5 Urban rural residence

The participant numbers were divided evenly between urban (n=111) and rural dwellers (n=111). Republic of Ireland rural dwellers (ROIR) made up 53.2% of the rural participants and 26.6% of the total numbers in the study while Northern Irish rural dwellers (NIR) comprised 46.8% of the rural participants and 23.4% of the total numbers. Republic of Ireland urban dwellers (ROIU) made up 50.4% of the urban participants and 25.2% of the total study population while Northern Irish urban dwellers (NIU) encompassed 49.6% of the urban participants and 24.8% of all respondents.

4.3.6 Living alone

There was no statistically significant relationship between living alone and cohort, ($\chi^2 = 2.75$, df 3, $p = 0.432$).

Lives Alone	ROIR	ROIU	NIR	NIU	Total
Yes	28 (49.2%)	29 (51.8%)	30 (57.7%)	34 (61.8%)	122 (55.0%)
No	30 (50.8%)	27 (48.2%)	22 (42.3%)	21 (38.2%)	100 (45.0%)

Table 7 Living Alone X Cohort

4.3.7 Making ends meet

Respondents were asked how often they found it difficult to make ends meet. Here there was a statistically significant relationship between cohort and responses to this question. When analysed further it revealed a rural urban divide with those from rural areas more likely to say they found it difficult a

little of the time or sometimes to make ends meet, compared to urban dwellers who were more likely to say none of the time or a little of the time. $\chi^2 = 27.67$, $df\ 4$, $p < 0.001$. The relationship was moderately strong although still significant, with a gamma value of 0.441, $ASE\ \times 2\ 0.184$, $CI\ of\ 0.257 - 0.625$, $p < 0.001$.



Figure 13 Urban Rural x Ability to make ends meet

4.4 Eyesight & vision

4.4.1 Vision assessment

A vision assessment was carried out with each respondent in the manner described in the methodology chapter. All participants in the study had sight loss at a level which would allow them to register as legally blind or partially sighted in their respective jurisdiction.

4.4.2 Self reported category of sight loss

When asked to describe their category of sight loss 32.4% described themselves as blind (n=72) while the remainder, 67.5% described themselves as partially sighted (n=150).

There was no statistically significant difference between individuals from the four geographic areas in terms of self reported sight loss, ($\chi^2 = 7.62$, df 3, $p = 0.06$). There was however a tendency for those from urban areas to consider themselves partially sighted rather than blind, $\chi^2 4.029$, df 1, $p < 0.05$.

4.4.3 Duration of eye disease

There was no statistically significant difference between the four cohorts on duration of sight loss. Table 8 below gives the mean duration across cohorts. There are a number of missing values here as some (n=7) could not remember how long they had the eye disease.

Duration	ROIR	ROIU	NIR	NIU	TOTAL
Valid	58	54	49	54	215
Missing	1	2	3	1	7
Mean Duration	28.5	14.8	24.1	30.25	24.5
± SD	±26.7	±15.2	±23.9	±12.0	±23.8
Range	1 – 80	1-65	1-81	2-83	1-83
Median	26.7	15.2	23.9	12.0	13.0
IQR	7- 58	4 – 19.3	7.5- 35	10.8-50	7-37

Table 8 Duration of sight loss

Table 9 below details the duration of registration across cohorts. There are a number of missing values here as some (n=35) either did not know how long since they registered, or whether or not they were registered.

Duration	ROIR	ROIU	NIR	NIU	TOTAL
Valid	51	50	42	44	187
Missing	8	6	10	11	35
Mean Duration	15.2	8.8	15.9	20.5	14.9
± SD	±17.3	±11.6	±18.5	±21.1	±17.7
Range	0-73	0-65	1-81	1-70	0-81
Median	8.0	4.0	9.0	10.5	8.0
IQR	3-22	2-10.3	6.8-15.8	2.3-33.3	3-18

Table 9 Duration of time since registration

There was no statistically significant difference between the four cohorts on duration of time from onset of eye disease to registration (n=185). Thirty seven responses were missing. Table 10 below gives details of duration of time from onset of eye disease to registration.

Duration	ROIR	ROIU	NIR	NIU	TOTAL
Valid	51	49	41	44	185
Missing	8	7	11	11	37
Mean Age ± SD	11.4 ±17.2	6.8 ±12.3	8.7 ±17.1	10.45 ±12.9	9.33 ±15.0
Range	0-68	0-63	0-67	0-53	0-68
Median	3.0	2.0	1.0	5.0	2.0
IQR	1-14	0-7.5	0-8	1 – 15.8	1-10

Table 10 Duration from eye disease to registration

4.4.4 Eye condition

The principle cause of vision impairment as reported by respondents was Macular degeneration 38.3% (n=85), followed by Glaucoma 8.5% (n=19), RP 5.9% (n=13), Diabetic Retinopathy 5.9% (n=13), Cataract 5.0% (n=11) and Other including unknown 28.4% (n=64). Nine percent of respondents (n=20) did not know the cause of their eyesight difficulty. The results, broadly speaking, reflect our understanding of vision impairment in the developed world. The respondents in this study were less likely to list correctable visual difficulties, as the selected population is known to service providers and so are more likely to be referred into the system to manage medical and optical problems.

Table 11 below presents the results according to geographical regions of AMD as the principal cause of vision impaired against all other cases of vision impairment.

% with AMD	ROIR	ROIU	NIR	NIU
% within cohort	23.7%	46.4%	53.8%	30.9%
% of total AMD	16.5%	30.6%	32.9%	20%

Table 11 Eye Condition AMD x Cohort

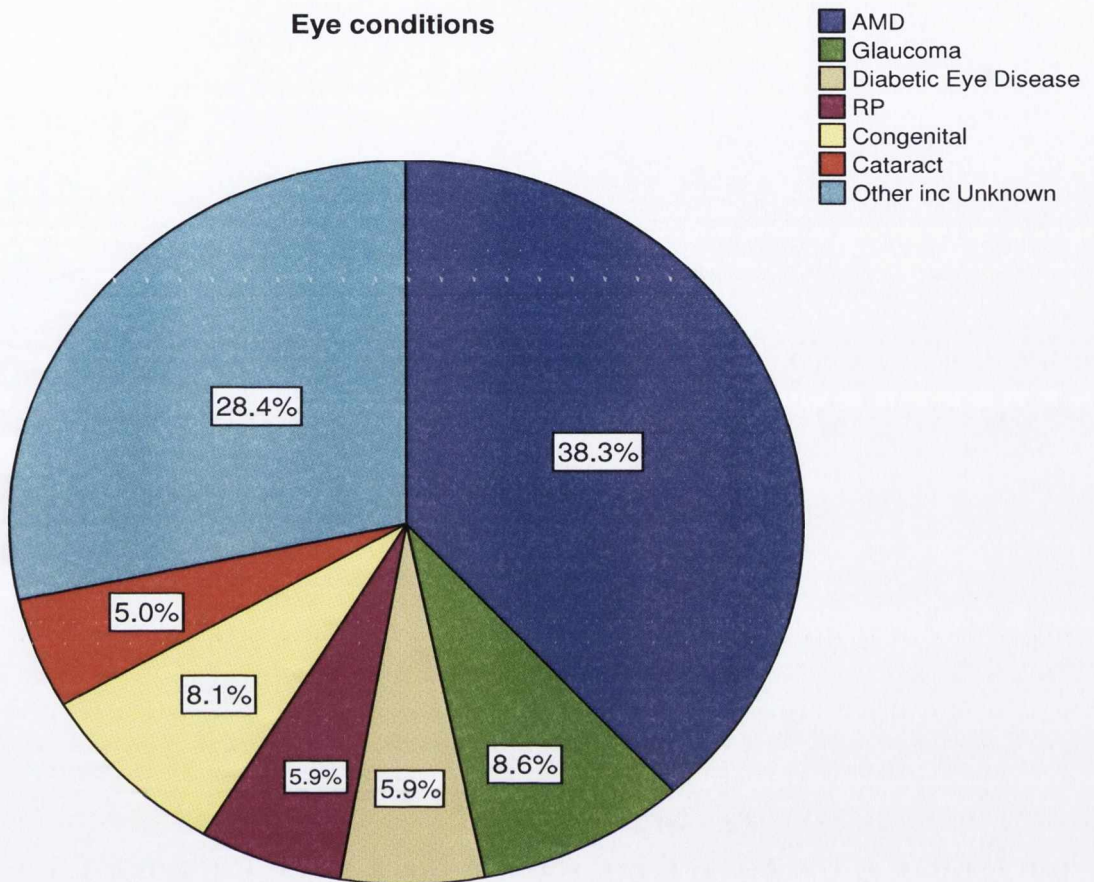


Figure 14 Eye conditions

4.4.5 Expectation of eyesight change

When asked about the changes they expected in their eyesight over the coming years 2.7% (n=6) said that they expected it to improve, 31.1% (n=69) said they expected it to remain stable, 42.8% (n=95) expected a slow deterioration while 3.6% (n=8) said they thought there would be a fast deterioration in their sight. Those who said they didn't know comprised 19.4% (n=43). There was one missing response. Some of the comments generated by this question included:

- ◇ "I live in hope of my eyesight improving. I want to wake up one morning and have sight even in one eye. It's very frightening you know, very frightening. I can't go out on my own, I live alone." ROIUIONA08
- ◇ "Really I have no expectation about my eyesight change but I am clinging on to hope that it won't get worse". ROIRLM10

4.4.6 Visual acuity

LogMAR scores for visual acuity of 1.6 or better were scored by 64.9% (n=144) respondents. A logMAR score of 1.7 was given to those respondents who were unable to read at least three letters from the top line of the Bailey Lovie chart at a distance of 1.5m. Of the 78 respondents in this category six were able to read one or two letters from the top line. The remainder (n=72) were unable to read any letters on the chart. Their vision was classified as follows: Count fingers 8.1% (n=18); Hand movements 9.0% (n=20); Light perception 8.1% (n=18); No light perception 7.2% (n=16).

The mean LogMAR score for visual acuity was 1.28 ± 0.44 SD. The median score for logMAR VA was 1.4 and the mode was 1.7. More than 50% of Respondents had a LogMAR score of 1.4 or worse.

This study then compared logMAR score with respondents self reported category of sight loss as blind or partially sighted. The graph below shows that with the exception of a few outliers, self description was close to LogMAR VA scores.

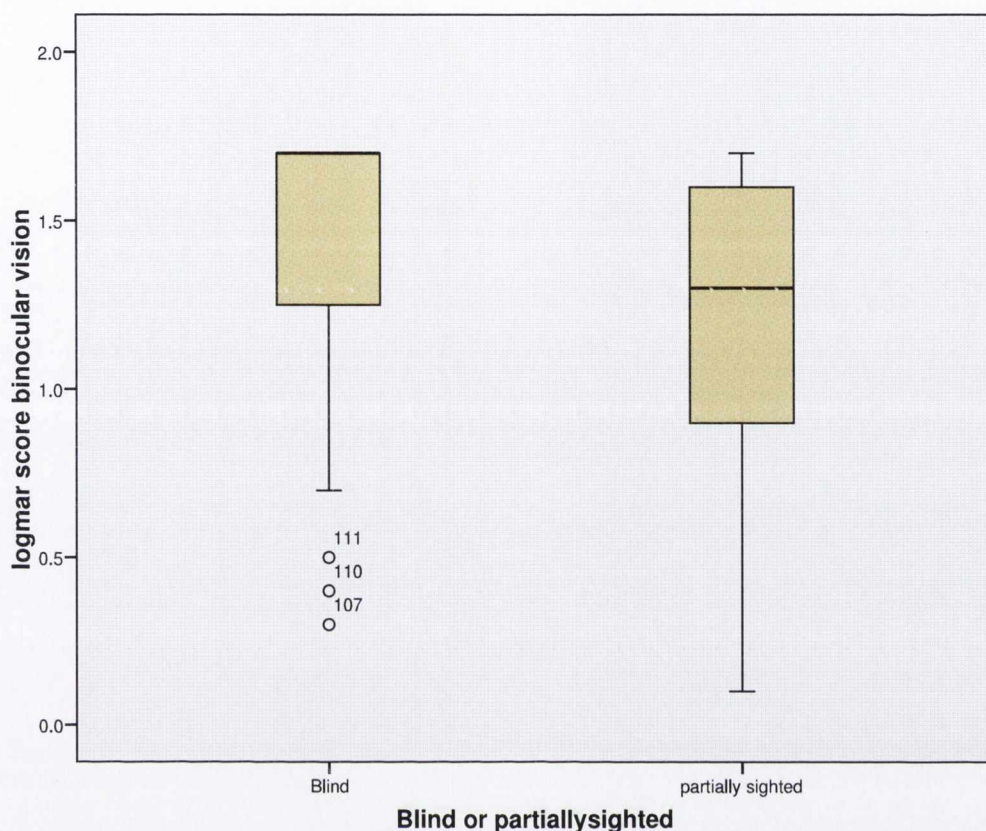


Figure 15 logMAR Visual Acuity X Self Description of sight loss

The shaded box represents the interquartile range. The black horizontal line in the shaded box represents the median. The whiskers represent the minimum and maximum. The circles represent data points that the software package has decided are outliers.

Visual Function	Mean	Median	Range	IQR
Visual Acuity	1.28±0.44	1.4	.1 – 1.7	.9 - 1.7

Table 12 Visual Acuity Mean Score

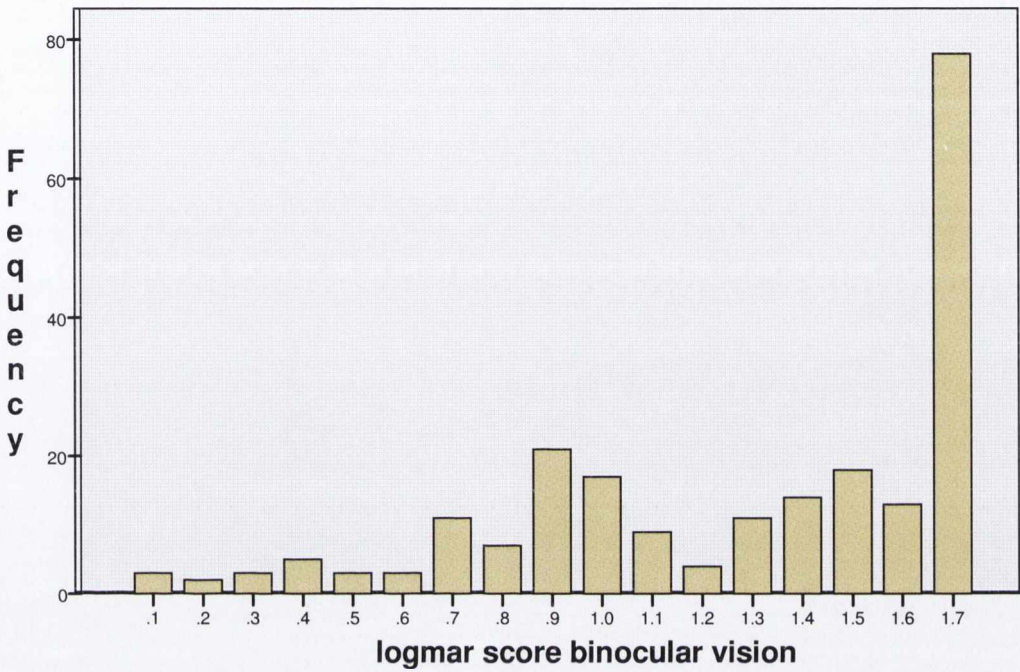


Figure 16 logMAR score binocular vision

4.4.7 Low contrast vision

LogMAR scores for low contrast vision of 1.6 or better were scored by 41.4% (n=91) respondents. The remainder 58.6% (n=129) were allocated a score of 1.7 LogMAR for low contrast vision. Data was missing on low contrast vision for two respondents. LogMAR score for low contrast vision of 1.7 was given to those respondents who were unable to read at least three letters from the top line of the Bailey Lovie chart at a distance of 1.5m.

The mean LogMAR score for low contrast vision was $1.51 \pm$ SD 0.31. More than 78% of respondents had a LogMAR score for low contrast vision of 1.4 or worse. Note the dramatic differences between the VA & low contrast graphs.

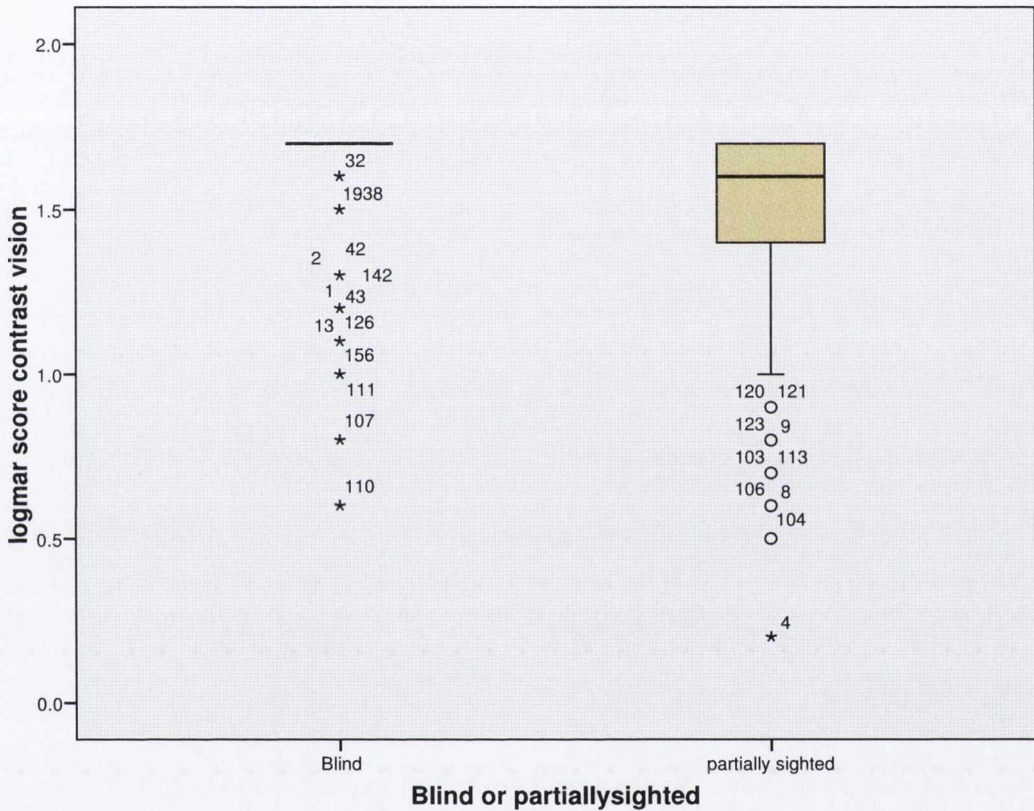


Figure 17 logMAR score low contrast vision X self description of vision loss

The shaded box represents the interquartile range. The black horizontal line in the shaded box represents the median. The whiskers represent the minimum and maximum. The circles/stars represent data points that the software package has decided are outliers. (In this chart those who described themselves as blind did not score on the logMAR charts therefore the interquartile range is non-existent).

Visual Function	Mean	Median	Range	IQR
Low Contrast	1.5±0.31	1.7	.2 – 1.7	1.4- 1.7

Table 13 Low Contrast Mean Score

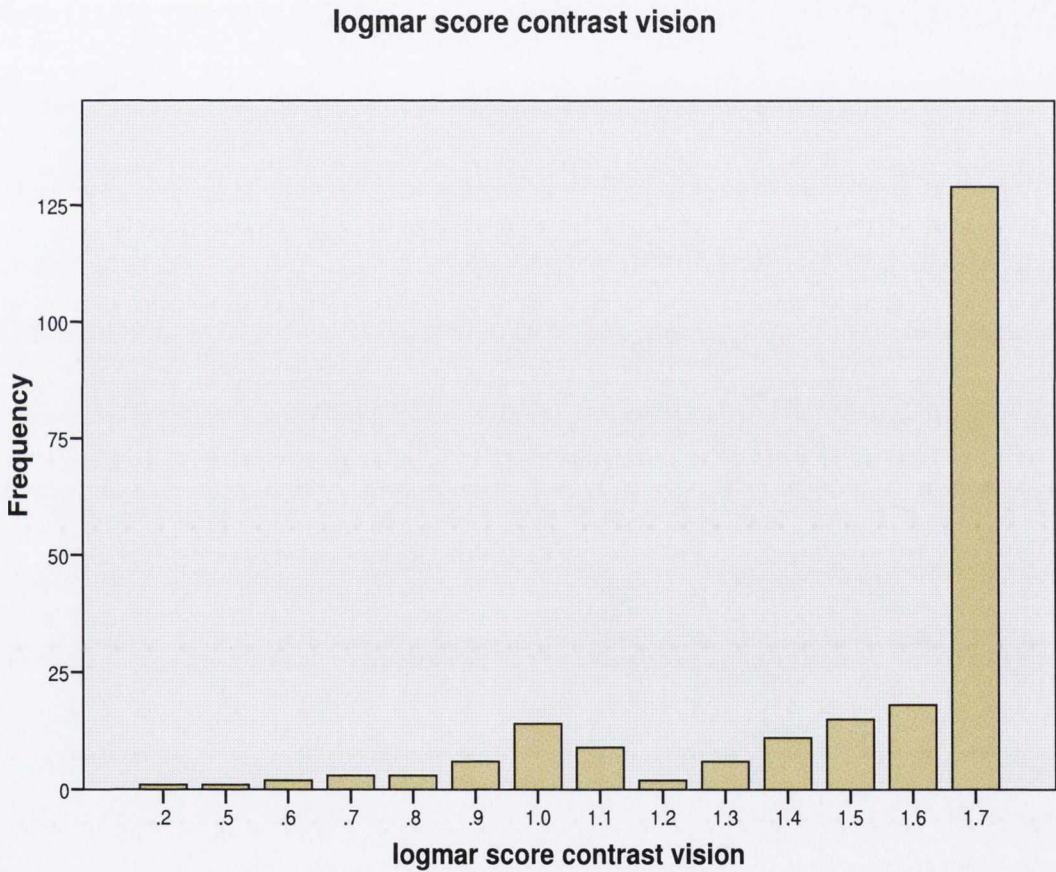


Figure 18 logMAR score low contrast vision

4.4.8 Near vision

Respondents were asked to read words from a Bailey Lovie Near Vision Reading chart. They were given as much time as they needed and were encouraged to use their usual magnification aids. This was done to measure habitual reading ability.

Only 62.2% (n=138) of respondents were able to read any words on the near vision charts. Scores (Font size N) for those able to read any words on the chart ranged from N3 to N80 with a score of N3 being an excellent near vision score and a score of N80 meaning only the top line of words could be read. Of the group who were able to read the charts the mean score was 29.6 ± 24.1 SD. The median was 20 and the mode was 63.

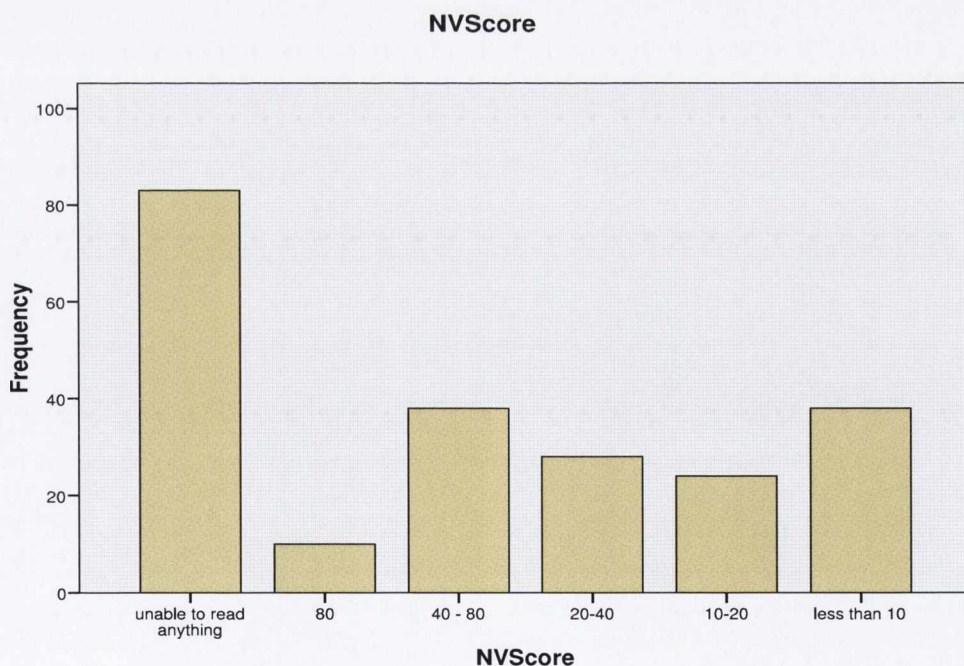


Figure 19 Near vision

The near vision scores had a highly statistically significant relationship with LogMAR VA scores with a $p < 0.001$. Those unable to read anything on the near vision charts 84.3% (n=70) were allocated a LogMAR visual acuity vision score of 1.7. A similar relationship existed between Near Vision scores and LogMAR low contrast scores with 96.4% (n=80) of those who were unable to read anything on the near vision charts having logMAR low contrast vision score of 1.7.

Near vision scores also had a highly statistically significant relationship with field of vision measurement with a $p < 0.001$. Those who had no field of vision comprised the majority of respondents who were unable to read anything on the near vision charts.

A very statistically significant relationship existed between use of magnifiers and near vision scores, $p < 0.001$. Those who used their magnifiers to read the near vision chart had the highest near vision scores. One respondent who had very recent cataract surgery scored very highly on the near vision chart.

Bar Chart

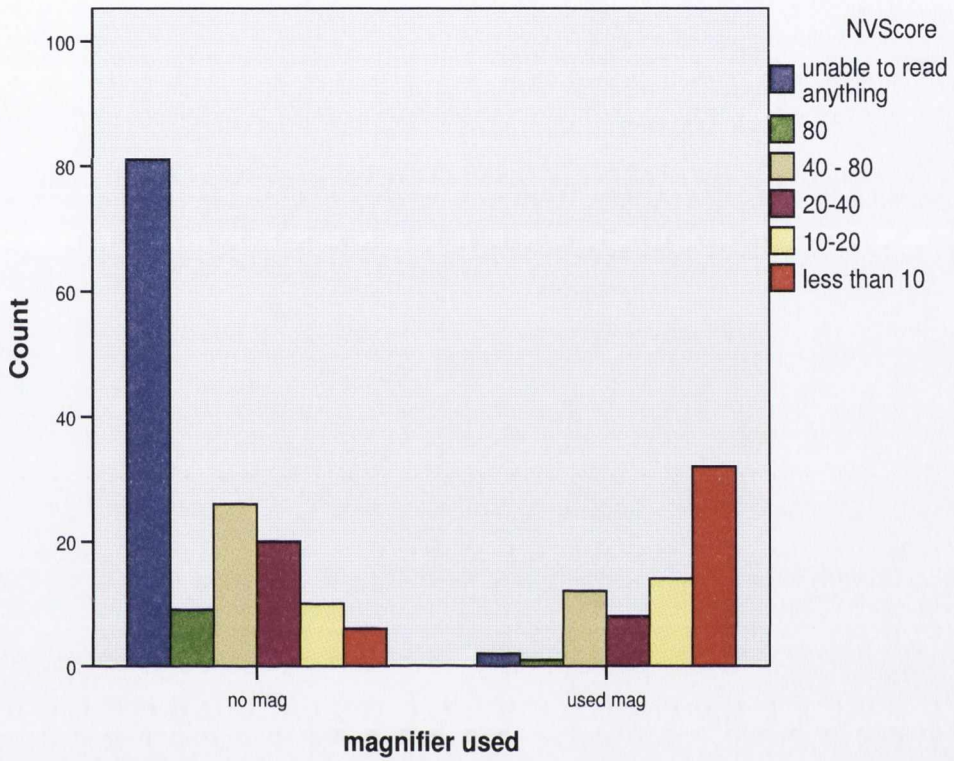


Figure 20 Magnification used X NV score

4.4.9 Visual fields

Visual fields were assessed to gross confrontation in all four quadrants. Full peripheral fields existed in 41.4% (n=92) of respondents and 36.5% (n=81) had no useful peripheral field of vision. The remainder 22.1% (n=49) had varying degrees of limitation in their field of vision.

Number of quadrants by full peripheral field by gross confrontation?

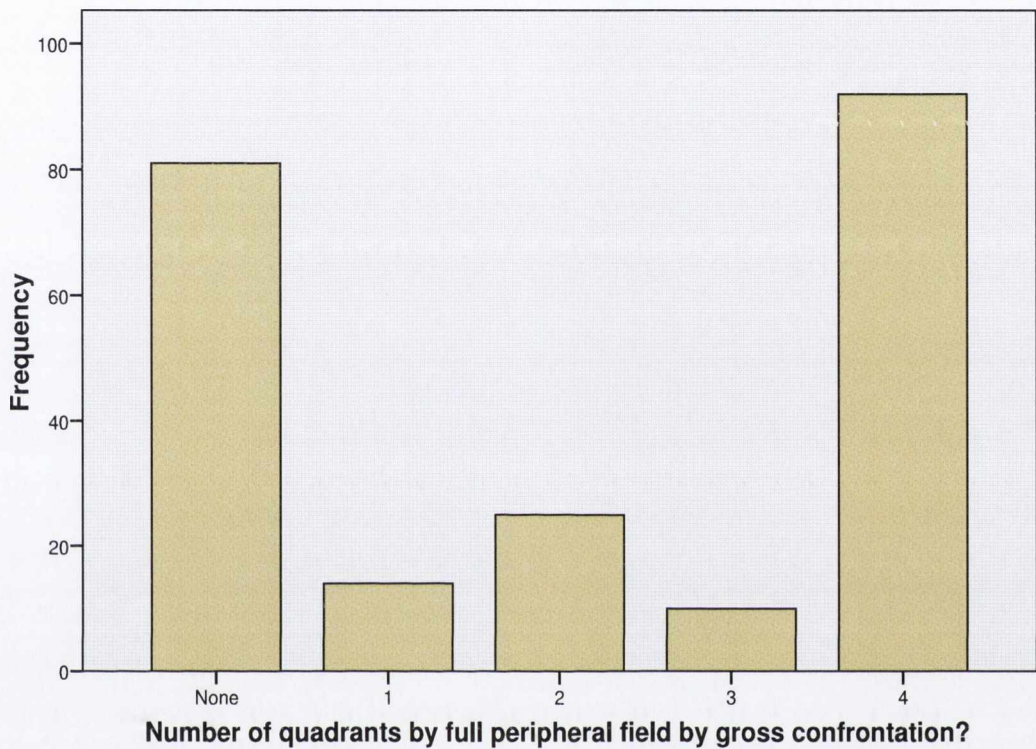


Figure 21 Visual fields

4.5 Low vision aids (LVA's)

4.5.1 Magnifiers

Magnifiers were owned by 62.6% (n=139) of respondents. This figure closely corresponds with the numbers of respondents who had some useful residual vision. Of those who owned magnifiers, a simple handheld magnifier (HM 1) was owned by 69.8 % (n=97). An illuminated magnifier (HILM 2) was owned

by 65.4% (n=91). A monocular or binocular device (Mono/Binoc 3) was owned by 19.4% (n=27). Of those who owned a low tech vision aid, 43.8% had more than one type of low vision aid. There was a statistically significant relationship between logMAR VA score and ownership of low tech vision aids, $\chi^2 = 94.24$, df 14 p < 0.001. The relationship was moderately strong with a gamma value of 0.501, $ASE_{\chi^2} = 0.138$, CI = 0.363 – 0.639, p < 0.001. There was no statistically significant relationship between cohort and LVA ownership.

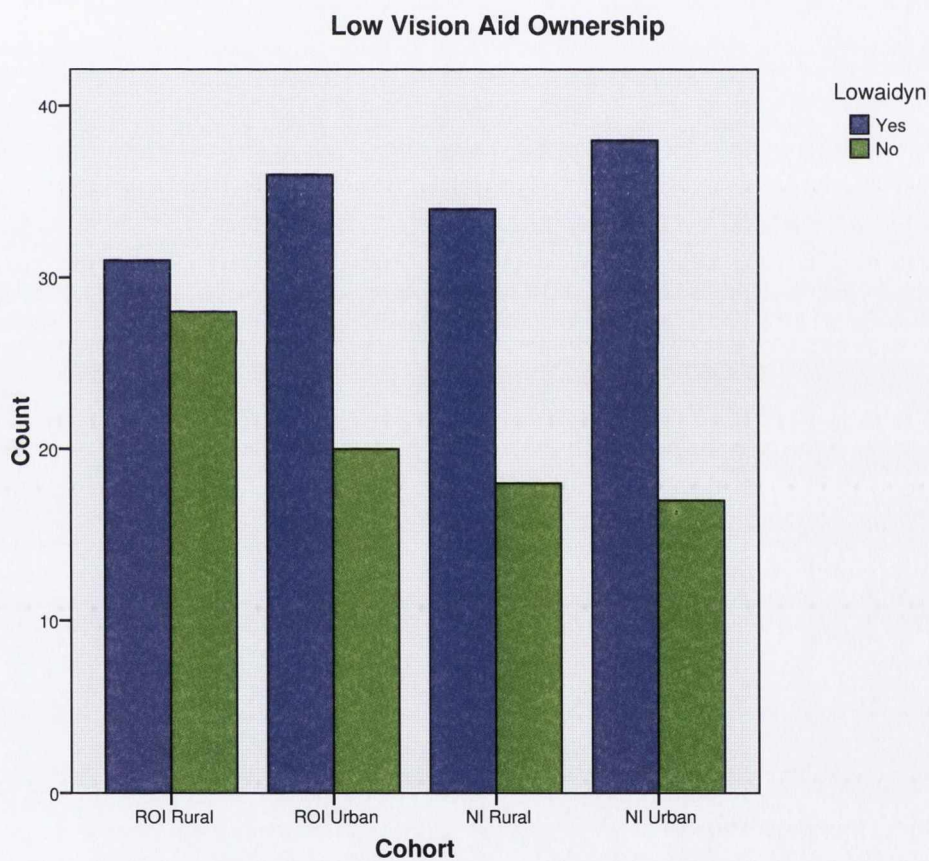


Figure 22 Low vision aid ownership

4.5.1a High tech devices

Fourteen percent of respondents (n=31) said they had a high tech device, or a combination of high tech devices. A CCTV or TV reader was owned by 7.7% (n=17). Screen magnification software for use with a PC was used by 3.6% (n=8) while 5% (n=11) used a screen reader software for a PC.

4.5.2 Other vision aids and appliances

Writing aids were owned by 13.1% (n=29). A liquid level indicator was owned by 28.8% (n=64). 'Bump ons' were used by 37.4% (n=83) and 51.8% (n=115) had a talking watch or clock. A special reading light was used by 13.5% (n=30). There was no statistically significant relationship between LVA ownership and cohort ($\chi^2 = 3.78$, df 3, p = 0.286).

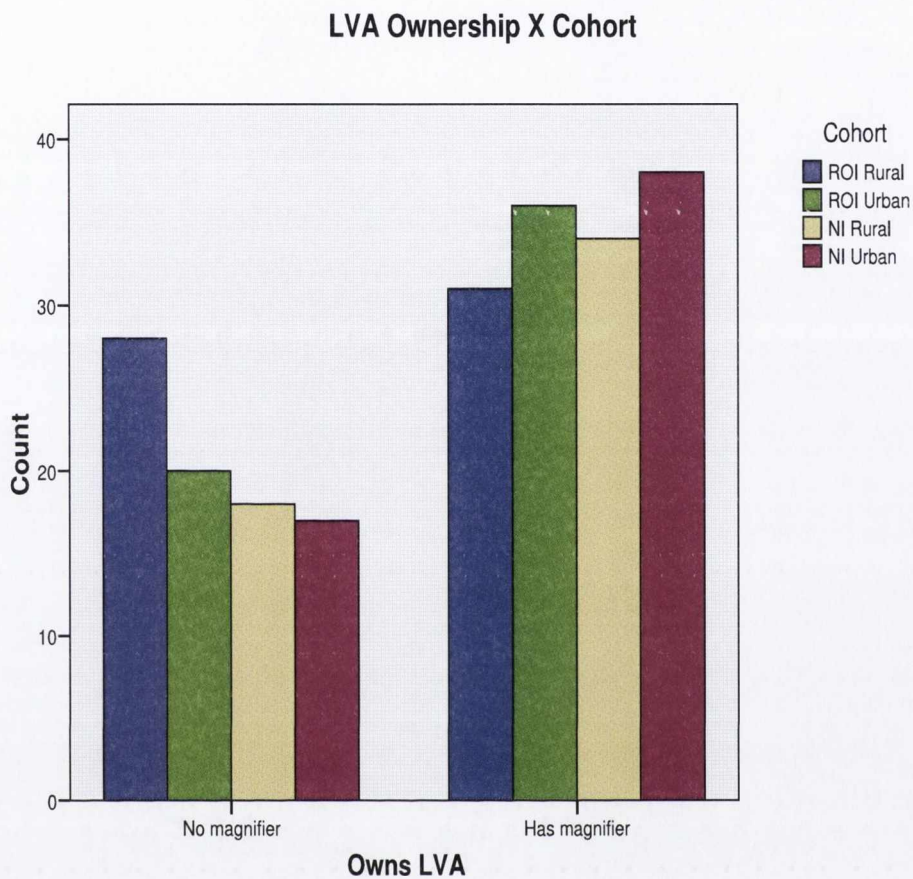


Figure 23 LVA ownership X cohort

4.5.3 Aids & appliances provider

A low vision clinic or similar service had been attended at some time by 70.7% (n=157) of all respondents. The majority, 55.4% of respondents, received their LVA's via a low vision clinic or hospital (n=123). Social services was the source of aids for 18.5% (n=41), while 16.2% of respondents obtained their aids and appliances via a private source such as high street optometrists,

other retail outlet or via family or a friend. No vision aids or appliances were owned by 7.7% (n=17) respondents. Respondents were full of praise for low vision services via the low vision clinics in all areas. The following quotes are representative of some of the comments generated during the quantitative interviews, in response to the question on low vision service:

- ◇ "Low vision clinic at the Royal Victoria hospital, this service made a big improvement in my quality of life. Low vision clinic staff and services are excellent". NIR31

Those who were using their aids and appliances were very happy with them and extremely grateful for the difference they made to their lives.

- ◇ "I love the aids I have. I'd love to get a liquid level indicator". ROIRSOJG02

Others expressed hopes of being able to get something to help restore vision.

- ◇ "I would like to get a magnifier that fits on my glasses". ROIUIONA02

The questionnaire included an open ended question where participants were asked to name any service they felt had made a difference in their lives. A number of respondents singled out the low vision service and magnifiers as being very important to them and that this service had changed their lives. While respondents from all cohorts expressed satisfaction with their low vision aids those from rural areas, particularly the Republic of Ireland were more vociferous on this subject.

- ◇ "Being given magnifiers & training in how to use them made a big difference". NIR53DY
- ◇ "Being given a scanner that reads my post and training at Omagh College for VI computing made all the difference." NIR53LK
- ◇ "Low vision aids have been a great help, "terrific". ROIR23/150
- ◇ "Getting a CCTV - I read a book on my relations who went to Australia many years ago". ROIRLM01

- ◇ "Aids & appliances in particular magnifier and signature guide". ROIRLM09
- ◇ "Magnifier made all the difference but magnifier is no good now".
ROIRLM11
- ◇ "Magnifier is my life couldn't read without it". ROIRLM14

These statements are just a sample from the responses. They indicate the importance of magnifiers and low vision aids in general in the lives of people with low vision. Respondents showed genuine appreciation of such items in the way they talked about them during the interview.

4.6 QOL results

Scores for the two QOL measures, the SF36 & DLTV were ascertained by domain and compared among the four cohorts. Results can be seen in table 14 below.

QOL Results: Mean scores by domain	ROIR	ROIU	NIR	NIU	Total
SF36 Physical functioning (PF)	42.5	53.1	37.5	37.1	42.7
SF36 Role Physical (RP)	61.8	72.8	49.8	45.1	57.6
SF36 Role Emotional (RE)	81.9	78.6	68.1	61.4	72.7
Social Functioning (SF)	70.8	85	67.1	61.1	71.1
Pain (P)	64.2	74.7	52.8	45.2	59.5
SF36 Mental health (MH)	69.9	62.7	70.5	60.2	65.8
Vitality (VT)	50.3	53.8	49.3	42.8	49.1
General Health (GH)	56.6	73.2	61.3	55	61.5
DLTV domain 1 scores	21.9	25.5	20.2	27.7	23.9
DLTV domain 2 scores	47.8	45.3	38.6	48	45.1

Table 14 QOL Results

Figures in bold indicate the highest mean score by domain. Figures in bold and italics indicate the lowest mean score by domain, the higher the score the

better the result. Please note that scores from DLTV domains 3 and 4 were not cumulated for the purposes of this research. Current advice from the designers of the DLTV is that results from Domains 3 & 4 are not useful in the overall Vision Specific QOL Scores (Personal communication, Hart, P & Stevenson, M 2008).

4.6.1 SF36 – generic HRQOL

Results from the research show that generic HRQOL scores are better in the Republic of Ireland than in Northern Ireland. Those living in urban Republic of Ireland Urban (ROIU), Dublin, scored highest in six out of the eight domains of the SF36. NIU scored lowest on all eight domains of the SF36. ROIR scored highest on the role emotional domain while NIR scored highest on the mental health domain. Mean scores \pm standard deviation (SD) across cohorts and totals per domain and the 95% confidence interval for the mean can be found in table 15 below.

SF36 Domain	Cohort	Mean ± SD	95% Confidence Interval for Mean	
Pf	ROI Rural	42.5 ± 26.3	35.7	49.4
	ROI Urban	53.2 ± 25.9	46.2	60.1
	NI Rural	37.5 ± 31.1	28.9	46.2
	NI Urban	37.1 ± 29.3	29.2	45.0
	Total	42.7 ± 28.7	38.9	46.5
Rp	ROI Rural	61.8 ± 39.1	51.6	71.9
	ROI Urban	72.8 ± 25.4	66.0	79.6
	NI Rural	49.8 ± 37.4	39.3	60.2
	NI Urban	45.1 ± 36.2	35.3	54.9
	Total	57.6 ± 36.4	52.8	62.4
Re	ROI Rural	81.9 ± 30.8	73.9	89.9
	ROI Urban	78.6 ± 28.6	70.9	86.2
	NI Rural	68.1 ± 34.9	58.4	77.8
	NI Urban	61.4 ± 38.5	50.9	71.8
	Total	72.7 ± 34.1	68.2	77.3
Sf	ROI Rural	70.8 ± 36.1	61.4	80.2
	ROI Urban	85.1 ± 22.4	79.0	91.0
	NI Rural	67.1 ± 29.3	58.9	75.2
	NI Urban	61.1 ± 34.4	51.8	70.4
	Total	71.1 ± 32.1	66.9	75.4
Bp	ROI Rural	64.2 ± 31.2	56.1	72.3
	ROI Urban	74.7 ± 27.2	67.4	82.0
	NI Rural	52.8 ± 31.4	44.0	61.5
	NI Urban	45.2 ± 33.7	36.1	54.3
	Total	59.5 ± 32.7	55.1	63.8
Mh	ROI Rural	69.9 ± 25.0	63.4	76.4
	ROI Urban	62.7 ± 17.2	58.1	67.3
	NI Rural	70.5 ± 21.6	64.5	76.5
	NI Urban	60.2 ± 18.4	55.2	65.2
	Total	65.8 ± 21.1	63.0	68.6
Ev	ROI Rural	50.3 ± 26.2	43.5	57.2
	ROI Urban	53.8 ± 13.7	50.1	57.5
	NI Rural	49.3 ± 23.5	42.7	55.8
	NI Urban	42.8 ± 19.1	37.7	48.0
	Total	49.1 ± 21.5	46.3	51.9
Gh	ROI Rural	56.6 ± 28.0	49.3	63.9
	ROI Urban	73.2 ± 18.5	68.3	78.2
	NI Rural	61.3 ± 23.0	54.9	67.8
	NI Urban	55.0 ± 26.6	47.8	62.2
	Total	61.5 ± 225.3	58.2	64.9

Table 15 DLTV Mean Scores X Cohort

4.6.2 Analysis of variance (ANOVA)

Using ANOVA the data was then checked to see if any of the scores were significant and to explore if there were any differences between the four cohorts. Where there was significance we applied Duncan's post hoc tests (alpha = 0.05) to see why such significance occurred. The scores from 7 of the 8 domains of the SF36 were significant. Vitality was the only domain that did not have significance.

ANOVA		
SF36 Domain	F	P-value.
Pf	(3, 218) = 3.88	0.01
Rp	(3, 218) = 7.02	0.001
Re	(3, 218) = 4.54	0.01
Sf	(3, 218) = 5.93	0.001
Bp	(3, 218) = 9.71	0.001
Mh	(3, 218) = 3.40	0.05
Ev	(3, 218) = 2.57	0.06
Gh	(3, 218) = 6.38	0.001

Table 16 Analysis of variance SF36 domains

4.6.3 Post hoc tests

Duncan's post hoc tests (alpha = 0.05) revealed that the main reason for significance in the ANOVA tables was due to ROIU scores being higher than the other three cohort areas. The only other difference detected revealed a dichotomy between NI & ROI populations because Republic of Ireland SF36 scores were higher in the urban than the rural population while the reverse occurred in Northern Ireland where the rural population scored higher than their urban counterparts (See appendix VI for output).

4.6.3a Post hoc test result details

- **PF:** Republic of Ireland urban score was much higher than other three cohort areas.
- **RP:** Under role physical there was a Northern Ireland: Republic of Ireland divide. Both groups in the Republic of Ireland scored higher.
- **RE:** For role emotional again we had a Northern Ireland Republic of Ireland divide with both Republic of Ireland groups scoring higher.
- **SF:** For social function ROIU scored higher than other three groups.
- **P:** For pain we had a Republic of Ireland Northern Ireland divide with Republic of Ireland scoring higher in this domain.
- **MH:** For mental health we had an urban rural divide with both rural cohorts scoring higher in the mental health domain than their urban counterparts. In fact, a dichotomy occurs on the mental health domain showing a very definite urban-rural divide with the rural cohort in both jurisdictions scoring higher than their urban counterparts in the area of mental health, which was statistically significant.
- **Ght1:** ROIU scored higher than the other three cohorts in the General Health area

Regression analysis was used to identify and quantify factors associated with poor quality of life including age, additional disability, fear of falling, living alone, and logMAR VA. A general linear model (GLM) was applied which allows for the mix of factors (e.g. cohort) and covariates (e.g. VA (continuous)) or fear of falling (ordinal)) together and then a linear trend was modelled across it. This analysis showed that the one of the factors having an influence on the SF36 QOL scores was having an additional disability. ROIU was a little less disabled but this was not statistically significant.

4.6.4 SF36 Normal scores for 65+ population

The SF36 scores achieved in this study were then compared and correlated against the population norms for the SF36 in populations aged 65+. The study which produced the SF36 normative values that we used for comparative purposes was conducted on an older population of community dwelling adults in the UK. According to the study authors the characteristics of the respondents were broadly similar to the UK population of those aged over 65. It included 8117 respondents aged 65 to 104 from two randomly selected practices in Sheffield. As 27 of the participants in our study were aged under 65 years we had to adjust our sample for age matching purposes and this left us with 195 participants for the comparisons with the SF36 norms in this age group. We then obtained an age and gender based weighted norm based on an age and gender weighted distribution in the Walters study. Next we tested our study means against the normative values gained using a one sample t test. All of the resulting scores when matched against the SF36 norms from the Walters study fell within the confidence intervals (Walters et al, 2001). Results for four of the domains ran close to expectation and were not statistically significant when matched against the norms. These included Physical Functioning (PF), Bodily pain (BP), Mental Health (MH), and Energy and Vitality (EV). Four of the domains produced values which exceeded our expectations and were highly statistically significant in a positive direction. These included Role Physical (RP), Role Emotional (RE), Social Functioning (SF) and General Health (GH).

Weighted means are used as the norms against which one sample t-tests were run, p-values and confidence limits for difference against norm were then calculated and are summarised in table 17 below.

Performance of overall sample against SF-36 Norms

Domain	Age/Gender Weighted Norm	Study Mean	P-value	Difference + 95% CIs
PF	44.9	42.4	0.20	-2.5 (-6.2, 1.3)
RP	35.0	57.2	<0.001	22.2 (17.4, 27.1)
RE	48.8	72.6	<0.001	23.8 (19.3, 28.3)
SF	62.4	71.1	<0.001	8.7 (4.4, 12.9)
BP	57.4	59.1	0.43	1.7 (-2.6, 6.1)
MH	67.8	65.9	0.18	-1.9 (-4.7, 0.9)
EV	46.8	49.1	0.12	2.3 (-0.6, 5.1)
GH	51.3	61.3	<0.001	10.0 (6.7, 13.4)

Table 17 Performance of overall sample against SF36 norms

Note: Positive values of a difference represent better than Norm performance

4.6.5 Daily Living Task Analysis - DLTV

There were very little differences between the cohorts in the vision specific QOL DLTV domain 1 scores. The two urban cohorts scored slightly higher than their rural counterparts, while the NIR cohort scored the lowest but this did not achieve statistical significance. In the DLTV domain 2, ROIR scored a little higher than other three cohorts but this was not statistically significant. DLTV scores adjusted for eyesight and age still showed no significant difference in the four cohorts. ROIU is a little less disabled but this is not statistically significant. Having an additional disability has an influence on QOL scores. DLTV scores were consistent with level of vision. There was no statistically significant difference between vision impairment and locations.

DLTV Domain	Cohort	Mean ± SD	95% Confidence Interval for Mean	
Dltv1	ROI Rural	21.9 ± 19.1	17.0	26.9
	ROI Urban	25.5 ± 20.2	20.1	31.0
	NI Rural	20.2 ± 18.7	15.0	25.4
	NI Urban	27.7 ± 22.1	21.8	33.7
	Total	23.9 ± 20.1	21.2	26.5
Dltv2	ROI Rural	48.2 ± 23.8	41.6	54.0
	ROI Urban	45.3 ± 25.5	38.5	52.1
	NI Rural	38.6 ± 25.8	31.5	45.8
	NI Urban	48.0 ± 26.6	40.8	55.2
	Total	45.1 ± 25.5	41.7	48.5

Table 18 DLTV Mean Scores X Cohort

4.6.6 Cross tabulations

Activities of daily living, in the form of the items within the DLTV were cross tabulated with logMAR Visual Acuity scores, logMAR low contrast scores and near vision scores in order to explore the relationship between these variables and activities of daily living.

In the tables below items are ranked in terms of reducing gamma. The higher the gamma score the stronger the relationship between the items. The tables include the confidence interval and the relevant domain number from the DLTV.

Gamma measures association between ordinal scales. By looking at the following tables, one can view the strength of the relationship between visual acuity, low contrast, near vision and self reported mobility skills and the various activities of daily living which are included in the DLTV. This will demonstrate the relationship between visual function and the use of functional vision. DLTV has been shown previously in the literature to be sensitive to clinical measures of vision (Hart et al, 1999, McClure et al 2000).

The DLTV has previously been shown to correlate well with distance acuity, near acuity and contrast sensitivity (McClure et al 2000). The cross tabulations carried out on the DLTV with LogMAR VA, low contrast acuity and near vision

scores reflect this fact, as can be seen in the following tables 19, 20 and 21. Here we can see that the items with the higher gamma values across the three levels of vision are those tasks requiring better levels of vision. In table 22, which cross tabulates the DLTV with self reported mobility skills, the gamma values for vision related tasks are reduced.

4.6.6a DLTV x LogMAR VA

In the table below DLTV activities of daily living are cross tabulated with logMAR scores of visual acuity as divided into three levels: Good (.01 to .99); Fair (1.0 – 1.6); Poor (1.7 or worse). Items related to reading show the highest correlation with VA. There was a moderate to high relationship with tasks requiring vision and logMAR VA.

Descriptor	Gamma	2 x ASE	Confidence	DLTV
	Value		Interval	Domains
Reading normal size newsprint	0.753 ^{***}	0.118	0.635 to 0.871	1
Reading road signs / street names	0.729 ^{***}	0.116	0.613 to 0.845	1
Reading newspaper headlines	0.726 ^{***}	0.092	0.634 to 0.818	2
Reading correspondence	0.726 ^{***}	0.112	0.614 to 0.838	1
Enjoying the scenery if out for a drive	0.697 ^{***}	0.108	0.589 to 0.805	2
Distinguish person's features arms length	0.665 ^{***}	0.108	0.557 to 0.773	2
Watching TV programmes	0.652 ^{***}	0.112	0.540 to 0.764	1
Distinguish person's features across room	0.640 ^{***}	0.120	0.520 to 0.760	1
Rate your overall near vision	0.605 ^{***}	0.132	0.473 to 0.737	3
Distinguish person's features across street	0.600 ^{***}	0.168	0.432 to 0.768	1
Recognising seasonal changes in garden	0.580 ^{***}	0.118	0.462 to 0.698	2
Rate your overall distance vision	0.512 ^{***}	0.154	0.358 to 0.666	3
Noticing objects off to either side	0.481 ^{***}	0.136	0.345 to 0.617	3
Seeing steps and using them	0.466 ^{***}	0.132	0.334 to 0.598	3
Signing documents e.g. cheques	0.464 ^{***}	0.128	0.336 to 0.592	1
Identifying money from a wallet	0.458 ^{***}	0.144	0.314 to 0.602	1
Cutting up food on your plate	0.416 ^{***}	0.138	0.278 to 0.554	2
Walk around unfamiliar neighbourhood	0.303 ^{***}	0.186	0.117 to 0.489	3
Cutting fingernails	0.297 ^{***}	0.158	0.139 to 0.455	2
Using kitchen appliances	0.293 ^{***}	0.146	0.147 to 0.439	2
Pouring yourself a drink	0.288 ^{***}	0.150	0.138 to 0.426	2
Adjusting to brightness after in dark	0.204 ^{**}	0.166	0.038to 0.370	4
Adjusting to darkness after in light	0.172 ^{**}	0.156	0.016 to 0.328	4
Walk around own neighbourhood/Area	0.113	0.158	-0.045to 0.271	3
Need to be careful due to condition	0.095	0.294	-0.199to 0.389	3

Table 19 DLTV X logMAR VA * p<0.001 ** p<0.01**

4.6.6b DLTV x low contrast acuity

In the table below DLTV activities of daily living are cross tabulated with logMAR scores of low contrast as divided into three levels: Good (.01 to .99); Fair (1.0 – 1.6); Poor (1.7 or worse). As with logMAR VA, items related to reading and highly visual tasks show the highest correlation with low contrast acuity.

Descriptor	Gamma Value	2 x ASE	Confidence Interval	DLTV Domain
Reading newspaper headlines	-0.757***	0.090	0.667 to 0.847	2
Reading normal size newsprint	-0.738***	0.130	0.508 to 0.738	1
Reading correspondence	-0.673***	0.130	0.543 to 0.803	1
Enjoying the scenery if out for a drive	-0.634***	0.130	0.504 to 0.764	2
Reading road signs / street names	-0.621***	0.152	0.469 to 0.773	1
Distinguish person's features arms length	-0.606***	0.126	0.480 to 0.733	2
Distinguish person's features across street	-0.553***	0.186	0.367 to 0.739	1
Rate Your overall near vision	-0.550**	0.152	0.398 to 0.702	3
Rate Your overall distance vision	-0.534***	0.160	0.364 to 0.694	3
Watching TV programmes	-0.523***	0.140	0.383 to 0.663	1
Signing documents e.g. cheques	-0.504***	0.140	0.364 to 0.640	1
Distinguish person's features across room	-0.502***	0.156	0.346 to 0.658	1
Recognising seasonal changes in the garden	-0.478***	.146	0.332 to 0.624	2
Seeing steps and using them	-0.464***	0.146	0.318 to 0.610	3
Identifying money from a wallet	-0.457***	0.148	0.309 to 0.606	1
Cutting up food on your plate	-0.406***	0.160	0.246 to 0.566	2
Noticing objects off to either side	-0.404***	0.148	0.256 to 0.552	3
Using kitchen appliances	-0.403***	0.152	0.251 to 0.555	2
Walk around unfamiliar neighbourhood/ Area	-0.394***	0.188	0.206 to 0.582	3
Cutting fingernails	-0.341***	0.166	0.175 to 0.577	2
Need to be careful due to eye condition	-0.336**	0.280	0.056 to 0.616	3
Pouring yourself a drink	-0.312***	0.164	0.148 to 0.476	2
Adjusting to brightness after being in dark	-0.225**	0.178	0.047 to 0.497	4
Adjusting to darkness after being in light	-0.187**	0.172	0.015 to 0.359	4
Walk around own neighbourhood/Area a	-0.183**	0.184	-0.001 to 0.367	3

Table 20 DLTV X Low Contrast Acuity * p<0.001 ** p<0.01**

4.6.6c DLTV X near vision

In the table below DLTV activities of daily living are cross tabulated with Near Vision to explore the relationship between individual items of the DLTV and near vision scores. The scores for near vision are divided into six levels, 1: Unable to read anything on the chart; 2: Score of N80; 3: Score of N40 to N80; 4: Score of N20 to N40; 5: Score of N10 to N20; and 6: Score of N10 or better. Items related to reading show the highest correlation with near vision.

Descriptor	Gamma Value	2 x ASE	Confidence Interval	DLTV Domain
Reading newspaper headlines	0.716***	0.080	0.572 to 0.796	2
Reading correspondence	0.693***	0.092	0.601 to 0.785	1
Reading normal size newsprint	0.681***	0.112	0.569 to 0.793	1
Distinguish person's features at arms length	0.637***	0.140	0.480 to 0.777	2
Reading road signs / street names	0.620***	0.108	0.512 to 0.728	1
Enjoying the scenery if out for a drive	0.609***	0.102	0.507 to 0.711	2
Watching TV programmes	0.590***	0.098	0.492 to 0.688	1
Distinguish person's features across the room	0.571***	0.112	0.459 to 0.683	1
Rate Your overall near vision	0.567***	0.114	0.453 to 0.681	3
Recognising seasonal changes in the garden	0.563	0.106	0.457 to 0.669	2
Signing documents e.g. cheques	0.536***	0.110	0.426 to 0.646	1
Distinguish person's features across the street	0.533***	0.148	0.367 to 0.739	1
Rate Your overall distance vision	0.512***	0.132	0.380 to 0.644	3
Noticing objects off to either side	0.490***	.116	0.374 to 0.606	3
Seeing steps and using them	0.477***	0.120	0.357 to 0.597	3
Cutting up food on your plate	0.466***	0.126	0.340 to 0.592	2
Identifying money from a wallet	0.431***	0.126	0.305 to 0.557	1
Using kitchen appliances	0.352***	0.126	0.226 to 0.478	2
Cutting fingernails	0.335***	0.138	0.197 to 0.473	2
Pouring yourself a drink	0.312***	0.164	0.148 to 0.476	2
Walk around unfamiliar neighbourhood / Area	0.307***	0.150	0.157 to 0.457	3
Adjusting to brightness after being in the dark	0.301**	0.138	0.163 to 0.439	4
Need to be careful due to eye condition	0.251**	0.234	0.017 to 0.485	3
Adjusting to darkness after being in the light	0.225**	0.138	0.087 to 0.363	4
Walk around own neighbourhood / Area	0.202**	0.134	-0.068 to 0.336	3

Table 21 DLTV X Near Vision * p<0.001 ** p<0.01**

4.6.6d DLTV x self reported mobility skills

DLTV was then crosstabulated with self reported mobility skills to examine the relationship between the various items on the DLTV and mobility. The results are reported in the table below. Self reported mobility skills are divided into four levels, 1: No difficulty; 2: Some difficulty; 3: Great difficulty and 4: Can't get around at all. The correlations are highest here with tasks that are not as highly visual as reading. DLTV1 have tended to move further down the scale.

Descriptor	Gamma Value	2 x ASE	Confidence Interval	DLTV Domain
Walk around your own neighbourhood / Area	-0.596***	0.130	0.466 to 0.726	1
Seeing steps and using them	-0.522***	0.126	0.396 to 0.648	3
Identifying money from a wallet	-0.465***	0.138	0.327 to 0.603	1
Reading normal size newsprint	-0.439***	0.208	0.231 to 0.647	3
Using kitchen appliances	-0.428***	0.130	0.298 to 0.558	2
Watching TV programmes	-0.412***	0.146	0.266 to 0.558	1
Rate your overall near vision	-0.406***	0.168	0.238 to 0.574	1
Need to be careful due to eye condition	-0.402**	0.282	0.120 to 0.684	2
Walk around unfamiliar neighbourhood/Area	-0.400***	0.174	0.226 to 0.574	2
Recognising seasonal changes in the garden	-0.385***	0.146	0.239 to 0.531	2
Pouring yourself a drink	-0.380***	0.148	0.232 to 0.528	2
Cutting up food on your plate	-0.380***	0.146	0.234 to 0.526	2
Signing documents e.g. cheques	-0.348***	0.158	0.190 to 0.506	2
Rate Your overall distance vision	-0.343***	0.178	0.165 to 0.521	1
Reading newspaper headlines	-0.332***	0.158	0.174 to 0.490	2
Distinguish a person's features across street	-0.320***	0.230	0.090 to 0.550	1
Reading correspondence e.g. letters, bills	-0.318***	0.186	0.132 to 0.504	1
Adjust to brightness after being in the dark	-0.308***	0.154	0.154 to 0.462	1
Noticing objects off to either side	-0.306***	0.150	0.156 to 0.456	4
Enjoying the scenery if out for a drive	-0.305***	0.160	0.145 to 0.465	4
Reading road signs / street names	-0.304***	0.196	0.108 to 0.500	3
Cutting fingernails	-0.290***	0.172	0.118 to 0.462	3
Adjusting to darkness after being in the light	-0.290***	0.144	0.146 to 0.434	3
Distinguish a person's features arms length	-0.280***	0.152	0.128 to 0.432	3
Distinguish a person's features across room	-0.243**	0.164	0.079 to 0.407	3

Table 22 DLTV x Self reported mobility skills * p <0.001, ** p <0.01**

4.4.6e LogMAR VA & ability to recognize facial features

As expected, there was a highly statistically significant relationship, $p < 0.001$, between logMAR scores and ability to complete visual tasks. LogMAR VA scores were consistent with scores for individual relevant items on the DLTV. i.e. as VA scores worsened so the difficulty in achieving or completing visual tasks worsened. The tasks which appeared to cause the most distress for respondents were those that involved distinguishing peoples' faces.

Distance→	Across street			Across room			Arm's length		
LogMAR Score→	0-0.9	1.0-1.6	1.7	0-0.9	1.0-1.6	1.7	0-0.9	1.0-1.6	1.7
Difficulty↓									
Can't do	30	66	71	10	35	60	2	18	48
Severe diff	13	14	6	19	30	12	9	27	18
Quite diff	9	5	0	8	15	5	10	17	4
A little diff	5	0	1	14	6	0	19	19	4
No diff	1	1	0	7	0	1	18	5	4
Total	58	86	78	58	86	78	58	86	78

Table 23 LogMAR VA & ability to recognise facial feature x 3 distances

The inability to recognise people when out and about was "upsetting", "embarrassing" for many respondents and in some cases, prevented respondents from socialising (This subject was raised in each of the focus groups as well, which will be reported on later). Respondents were upset that people (friends, neighbours, and the general public) did not understand their sight loss and so had no idea that recognising others was a difficulty.

Some of the comments from those interviewed included:

- ◇ "It 's upsetting because I can't recognise people". ROIUIONA21
- ◇ "I have not been able to recognise when people say hello, especially not able to see my friends...The neighbours think I'm being snobby".

ROIUIONA13

- ◇ "It's upsetting because I can't recognise people, nervous about going out and about". ROIUIONA21

4.7 Independent variables

Other independent variables were explored including:- duration of vision impairment; time from registration; access to services; satisfaction with services; living arrangements; help available; perceived social support; mobility; fear of falling; social activities; access to transport; use of optical aids and appliances; education and finances; additional disabilities and or illnesses; public awareness of visual disability & helpfulness; eye disease and understanding; distant and near visual acuities, low contrast acuity and visual fields; and other demographic data.

4.7.1 Living status

Fifty five percent of respondents lived alone (n=121). While the geographical spread of those who lived alone was quite even, the highest number of those who lived alone were based in Northern Ireland with NIU (n=34) at 61.8% of cohort, followed by NIR (n=30) at 57.7% of cohort. In the Republic of Ireland ROIU (n=29), had 51.8% of the cohort living alone while 47.5% of the ROIR (n=28) cohort were living alone.

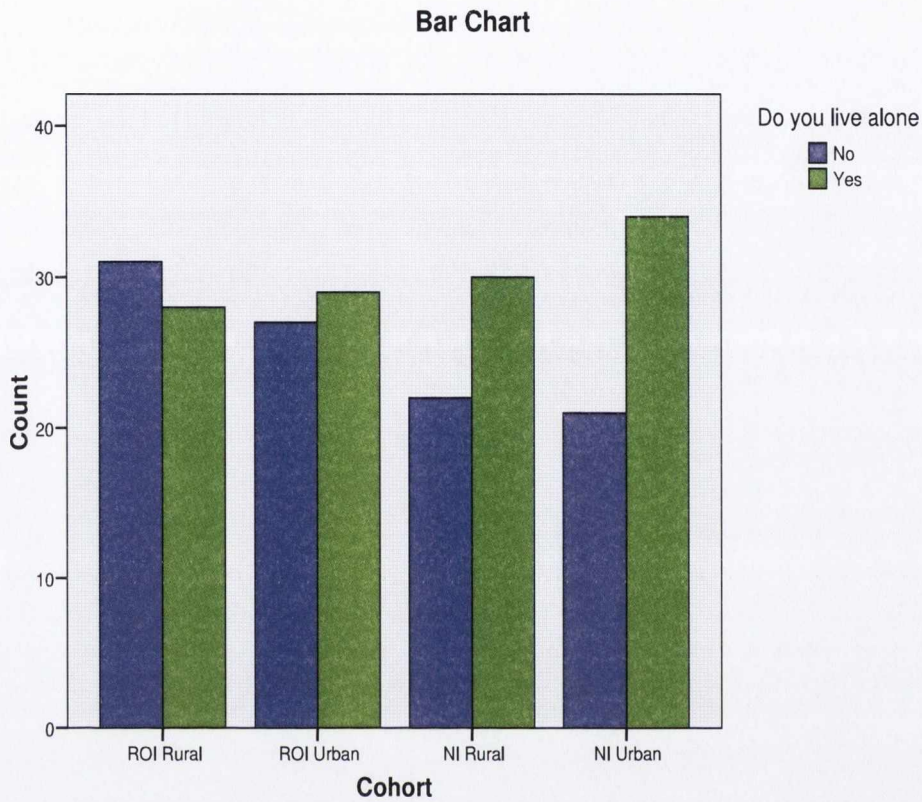


Figure 24 Living arrangements

4.7.2 Distance from neighbours

Over 97% of all respondents live within walking distance of their nearest neighbours with the majority (80.5%, n=78) living next door to their neighbours.

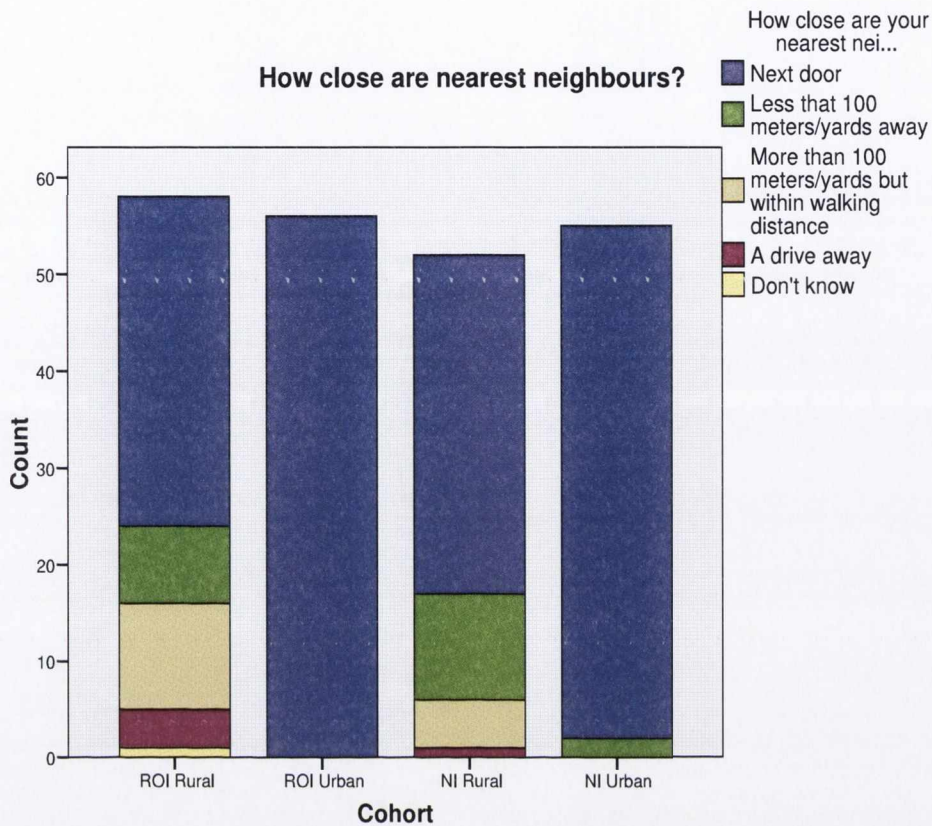


Figure 25 Proximity to neighbours

Of those who live alone, 83.5% have neighbours next door. Of the remainder 14.9% are within walking distance. Just two of the participants who lived alone were a drive from their nearest neighbours. Of those who did not live alone, 19 lived within walking distance of their nearest neighbours while three lived a drive away from their nearest neighbours. There was no statistically significant difference between living alone or not and distance from neighbours, $\chi^2 = 3.147$, $df\ 4$, $p = 0.533$.

There was a very statistically significant relationship between cohort and distance from neighbours, $\chi^2 = 55.109$, $df\ 12$, $p < 0.001$. Those living furthest from their neighbours were rural dwellers from both jurisdictions.

4.7.3 Social life

When asked how often they receive visitors 30.6% (n=68) said daily, 31.5% (n=70) said several times a week, 19.4 % (n=43) said weekly, 5.9 % (n=13) said several times a month while 11.7% (n=26) said monthly or less.

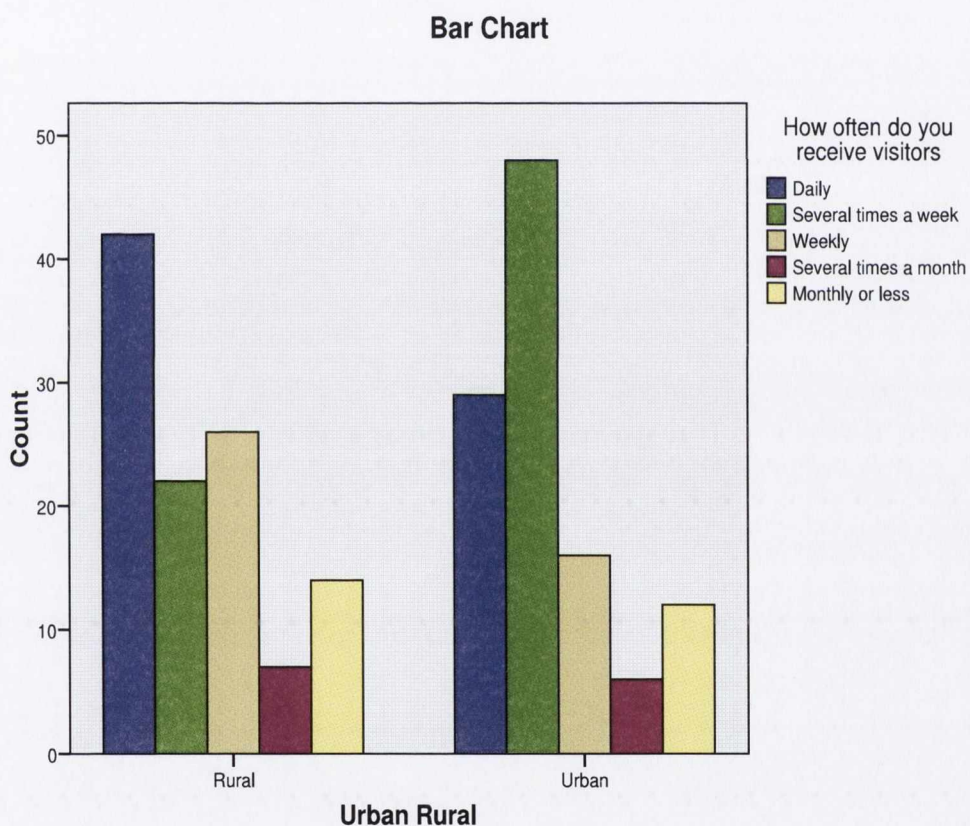


Figure 26 Number of times receiving visitors Urban & Rural

The majority of respondents said that they got out on a regular basis, 33.3% (n=74) said daily, 35.1% (n=78) said several times a week, 19.8% (n=44) said weekly and 2.7% (n=6) said several times a month. Just 10% said monthly or less (n=20). There was a statistically significant relationship between cohort and getting out and about, $\chi^2 = 28.191$, df 12, $p < 0.01$.

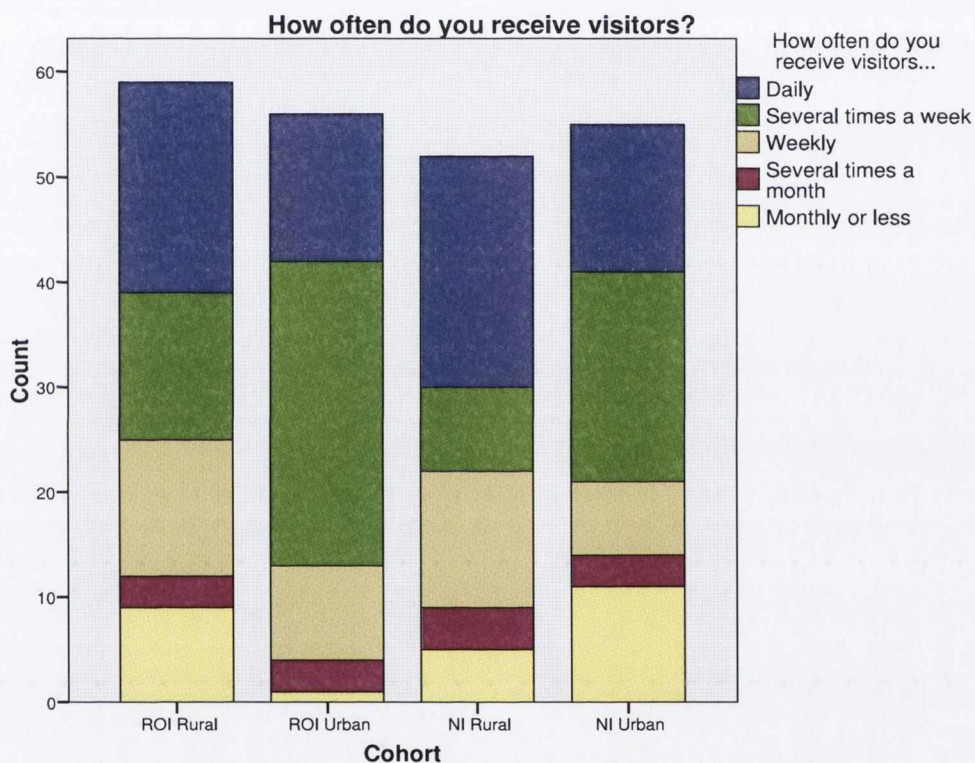


Figure 27 Receiving visitors X cohort

Of those who live alone 11.7% (n=14) do not get out on a regular basis, 5.0% (n=6) get out less than weekly but more than once a month, while 6.7% (n=8) get out monthly or less. There was a statistically significant relationship between cohort and receiving visitors, $\chi^2 = 25.788$, df 15, $p < 0.05$.

Although a statistically significant relationship existed between cohort and visitors and cohort and getting out and about, the strength of the relationship was weak as shown by the gamma values in Table 24.

Descriptor	Gamma Value	2 x ASE	Confidence Interval
How often receive visitors	0.038	0.158	0.120 to 0.196
How often get out & about	0.026**	0.154	0.613 to 0.845

Table 24 Cohort X visitors & getting out ** p<0.05

When asked if they would like to get out and about much more 80.6% (n=179) said they would with 13.1% saying sometimes and the remainder 67.6% saying mostly or always. There was no statistically significant difference between cohorts and responses to this question, $\chi^2 = 6.10$, df 9, p = 0.729.

4.7.4 Distance to essential services

Distance to essential services has been used previously as an indicator of rurality (O'Reilly et al, 2001). For the purposes of this study essential services included Post Office, GP, and A&E department in a hospital. In general, respondents from ROIR lived furthest from their nearest big town or city with 76% of them living more than 10 miles away. Almost 17% of ROIR lived more than 30 miles away from their nearest big town or city. The mean distance in this group was 17.1 miles \pm 10.2 SD. In NIR the mean distance was 8.7 with a \pm 7.4 SD.

Respondents were asked to give the approximate distance in miles to three services, their GP, their nearest post office and their nearest A&E hospital.

4.7.3a General Practitioner GP

The distance from respondents' home to their GP ranged from right next door to 10 miles away across all cohorts. The mean distance was 2.2 miles \pm 2.3 SD. Rural dwellers in both jurisdictions lived farthest from their GP's. In ROIR over 25% (n=15) lived more than five miles from their GP.

4.7.3b Post Office PO

The distance from respondents' home to their nearest Post Office ranged from 0.01 of a mile to 10 miles away across all cohorts. The mean distance was 1.2 miles \pm 1.6 SD.

4.7.3c A & E department in hospital

The distance from respondents' home to their nearest hospital with an A & E department ranged from 0.1 of a mile to 50 miles away across all cohorts. The mean distance was 9.2 miles \pm 10.0 SD. There was a very significant statistical relationship between cohort and distance to hospital, $p < 0.001$.

Table 25 below summarises these findings.

Service	Range (miles)	Mean (miles)	SD
GP	0 to 10	2.1	2.3
Post Office	0.1 to 10	1.2	1.6
A&E hospital	0.1 to 50	9.2	10.0

Table 25 Distance from essential services

4.7.3d Reasons for travelling to nearest big town or city

Rural dwellers were asked to give the main reason for travelling to their nearest big town or city. The response given by 82.93% (n=92) was to attend medical appointments.

4.8 Transport

Access to transport emerged as a major issue during this research. It was emphasised in all four cohorts that difficulties with transport were very problematic. It arose as a concern in both the qualitative commentary in the individual interviews and in the focus groups with people with vision impairment, as well as in the focus group with front line professionals. A major issue raised by the rural groups, both in Northern Ireland and the Republic of Ireland, is the fact that restricted access to transport dramatically reduces their access to a social life resulting in isolation. Many participants in the individual interviews suggested that social outings should be arranged for them.

4.8.1 Access to transport

The majority of respondents 64.9% (n=144) had access to public transport frequently during the day. A substantial minority, 23.9% of respondents (n=53) had no access to public transport within walking distance. Of the remainder 6.8% (n=15) have access to public transport at least once a day while 4.1% (n=9) have access to public transport once a week. There was a statistically significant relationship between cohort and access to transport, $\chi^2 = 117.674$, df 9, $p < 0.001$.

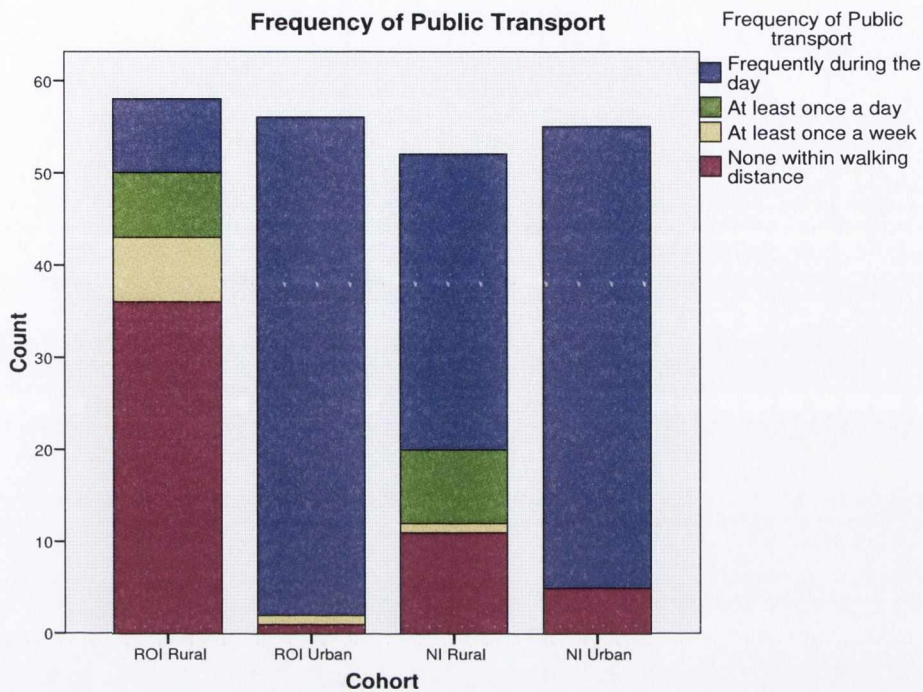


Figure 28 Frequency of public transport x cohort

Access to public transport was least available in ROIR, with 64.4% (n=38) of this cohort stating that there was no public transport available to them within walking distance. In NIR, 21.2% (n=11) of participants stated that they have no public transport within walking distance. The relationship between urban or rural dwelling and access to public transport is highly statistically significant, $\chi^2 = 117.674$, df 9, $p < 0.001$.

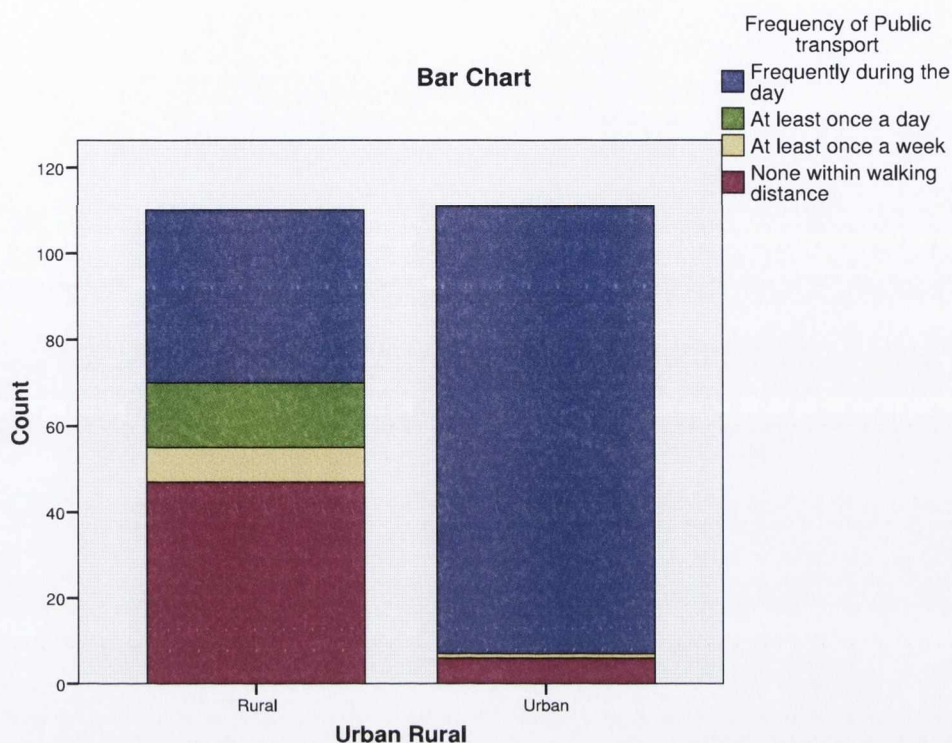


Figure 29 Frequency of public transport Urban Rural

The relationship between dwelling place and availability of transport was found to be highly statistically significant. When the strength of the relationship was explored further it was found to be a very strong relationship as shown by the gamma values in table 26 below. The graph above (figure 29) shows that more rural dwellers stated that they had no access to transport within walking distance.

Availability of transport x cohort	Gamma Value	2 x ASE	Confidence Interval (CI)
Urban , Rural dwelling	0.888	0.088	0.800 to 0.976
Cohort: ROIR, ROIU, NIR, NIU	0.609	0.142	0.467 to 0.751

Table 26 Availability of transport

4.8.2 Main transport used

When asked what was the main form of transport used the majority of respondents, 48.4%, depend on family or friends for transport (n=107). Taxis are used as the main form of transport by 18.6% of respondents (n=41). Public transport is used as the main form of transport by 14.5% of respondents (n=32). Other forms of transport are used by 18.6% (n=41) respondents. When asked to specify these other forms of transport the majority (80%) of those who specified other (n =33) stated that 'other' transport was that provided to attend day centres or support groups run by health boards, trusts and the voluntary sector (BCNI and NCBI). These organisations provide transport to their service users in some areas. There was a statistically significant relationship between form of transport used and cohort, $\chi^2= 34.40$, df 9, $p < 0.001$.

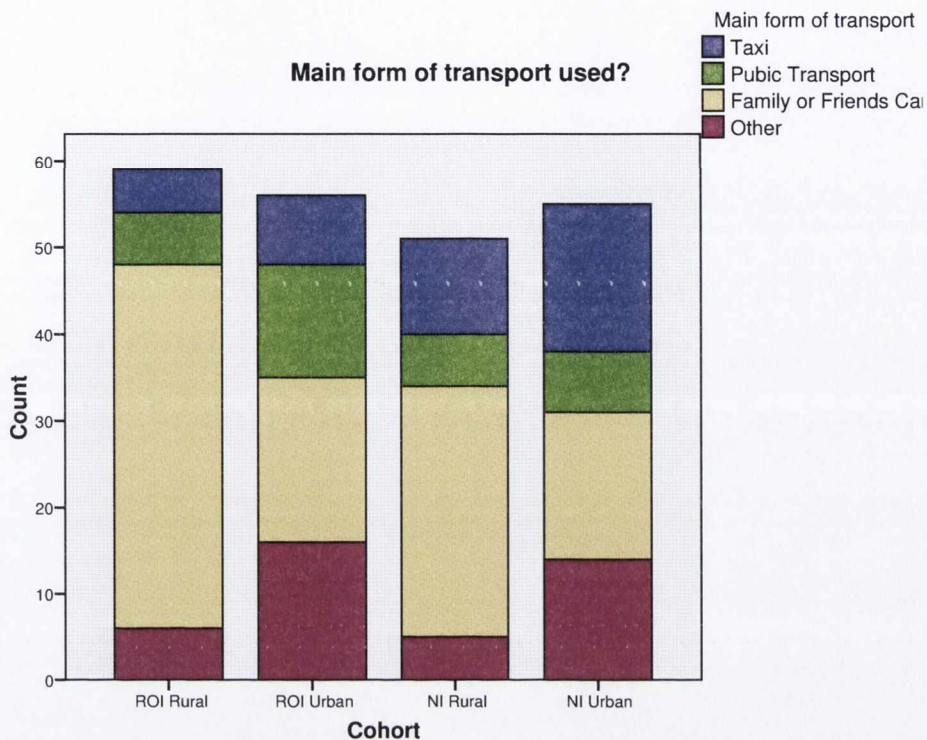


Figure 30 Transport mainly used x cohort

A highly statistically significant relationship existed between urban and rural dwelling and main form of transport used, $\chi^2 = 24.225$, $df = 3$, $p < 0.001$. From the graph below it can be seen that more rural dwellers were dependent on family or friends as their means of transport.

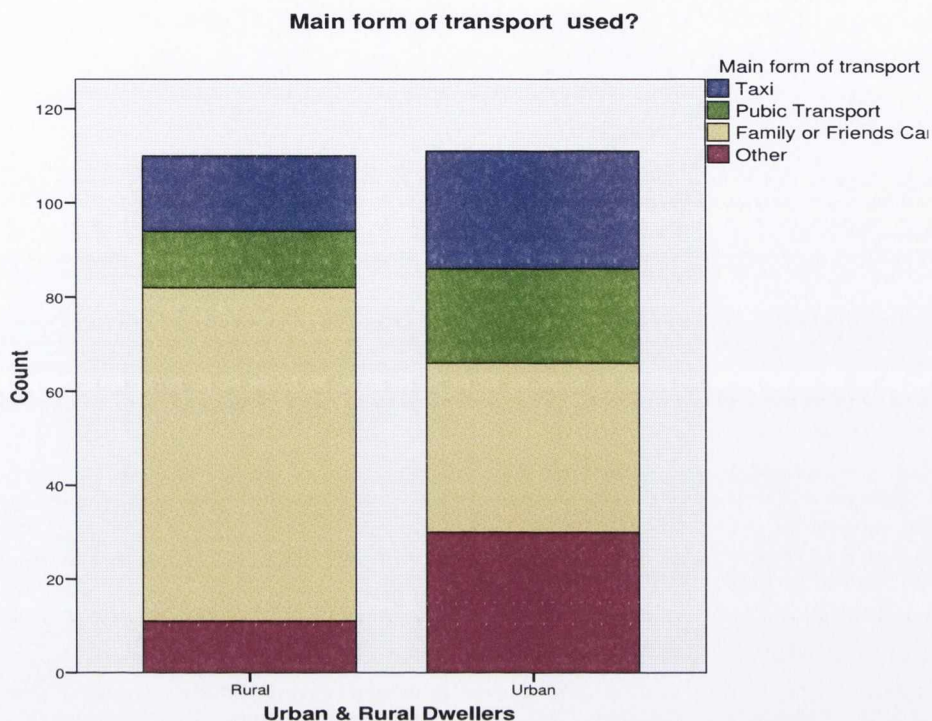


Figure 31 Transportation used X urban & rural dwellers

The relationship between dwelling place and form of transport used was highly significant. When the strength of the relationship was explored further it was found to be very weak as shown by the gamma values in table 27 below.

Descriptor	Gamma Value	2 x ASE	Confidence Interval (CI)
Availability of transport x Cohort: ROIR, ROIU, NIR, NIU	-0.125	-0.031	0.94 to 0.156
Urban , Rural dwelling	0.010	0.210	0.200 to 0.220

Table 27 Availability of transport X cohort & X urban rural dwelling

This weak relationship can be explained by the graph below (figure 32). This shows that even where transport was available frequently during the day, the majority of respondents 39.6 % (n=57) did not use the transport available to them, instead they depended on family or friends as their main method of getting about. Those living in ROIR had the greatest dependency on family and friends as their main form of transport. There was a statistically significant relationship between main form of transport and availability $\chi^2 = 22.561$, df 9, $p < 0.01$. However the strength of the relationship was weak with gamma value of 0.018, ASE $\times 2 = 0.202$ and CI -0.184 to 0.220.

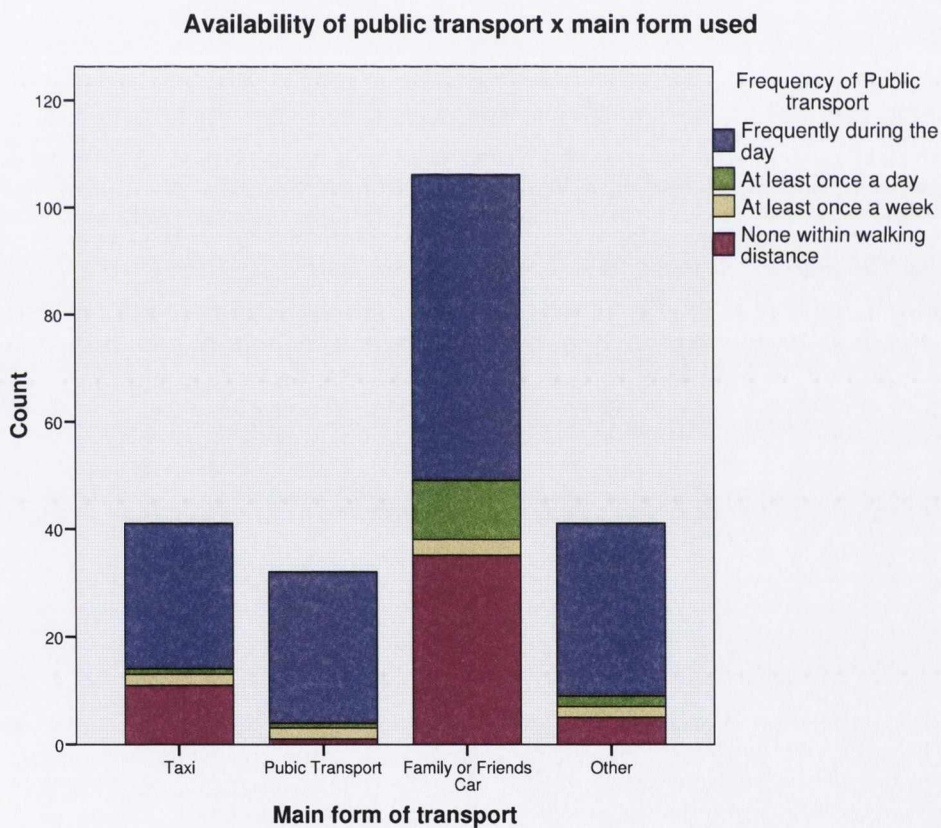


Figure 32 Availability of transport X main form used

4.9 Mobility

As well as transport issues mobility was a major issue for all study participants

4.9.1 Mobility Skills

When asked about their ability to get around 73.0% (n=162) of respondents stated that they had some difficulty getting around, ranging from 50.9% saying that they had some difficulty (n=113) to 17.6% stating that they had great difficulty (n=39). An inability to get around at all was expressed by 4.5% of respondents (n=10). The majority of respondents, 76.1%, stated that any mobility difficulties they had were caused primarily by their vision difficulties (n=169). There was no statistically significant difference between cohort and self reported mobility skills, $\chi^2 = 9.869$, df 9, p = 0.361. No statistically significant relationship existed between urban or rural dwelling and self reported mobility skills, $\chi^2 = 0.706$, df 3, p = 0.872.

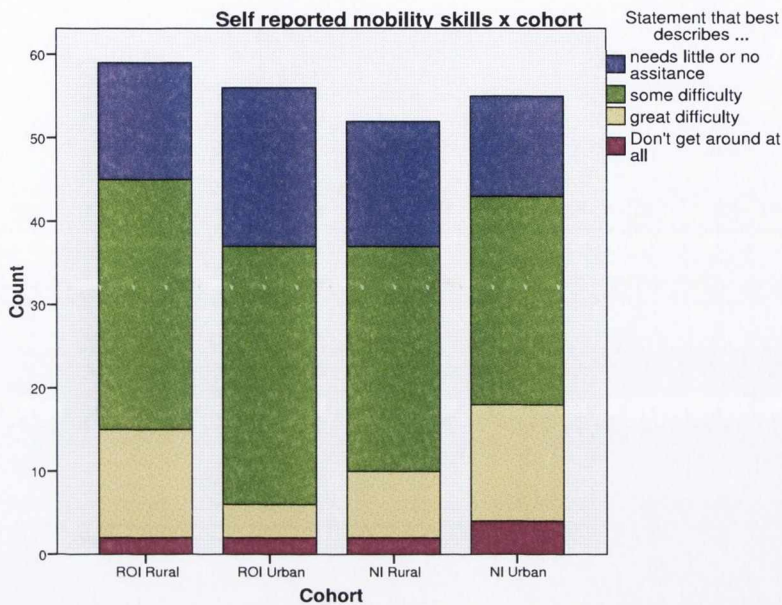


Figure 33 Self reported mobility & cohort

4.9.2 Mobility and vision

Self reported mobility skills when cross tabulated with various visual functions showed a statistically significant relationship with all functions as can be seen in table 28 below.

Descriptor	χ^2	Df	P-value
Visual Acuity (VA)	15.588	6	0.016**
Low Contrast Acuity (CV)	19.249	9	0.023**
Near Vision (NV)	32.719	15	0.005**
Visual Fields (VF)	33.842	12	0.001***

Table 28 Mobility X visual function *p<0.05 *p<0.001**

These statistically significant relationships were then explored for strength. The results can be seen in Table 28 below. There was a weak to moderate strength in the relationship between the four visual functions as measured in this study and self reported mobility skills. All of the relationships showed significance.

Mobility X Visual Function	Gamma Value	2 x ASE	Confidence Interval (CI)
Visual Fields (VF)	0.384***	0.162	0.223 to 0.546
Near Vision (NV)	0.365***	0.164	0.201 to 0.529
Low Contrast Acuity (CV)	0.352***	0.202	0.150 to 0.554
Visual Acuity (VA)	0.283***	0.164	0.119 to 0.283

Table 29 Self reported mobility X visual function * p<0.001**

4.9.3 Mobility aids

Walking aids were used by 34.7% of respondents. These included a Zimmer frame, walking stick or wheelchair (n=77). A symbol cane was owned by 13.5% (n=30) of respondents while 8.6% of respondents said they had a guide cane (n=19). Just 7.2% of respondents (n=16) used a long cane and 5.4% used a guide dog (n=12). Of those who used the long cane or guide dog, 12.6% (n=28) had received formal full mobility training. No mobility aids were used by 30.6% of respondents (n=68). There were no guide dog owners in ROIR. There was a statistically significant relationship between the use of mobility aids and visual function scores as seen in table 29 below. Table 30 demonstrates that there was a weak to moderate strength in the relationship between the four visual functions as measured in this study and use of mobility aids. All of the relationships were statistically significant.

Visual Function	χ^2	Df	P-value
Visual Acuity (VA)	31.149	10	0.001***
Low Contrast Acuity (CV)	33.837	15	0.01**
Near Vision (NV)	39.639	25	0.05**
Visual Fields (VF)	48.808	20	0.001***

Table 30 Mobility aid x visual function ** p<0.05 * p<0.001**

Visual Function	Gamma Value	2 x ASE	Confidence Interval (CI)
Low Contrast Acuity (CV)	0.438***	0.174	0.264 to 0.612
Visual Fields (VF)	0.328***	0.138	0.190 to 0.466
Visual Acuity (VA)	0.310***	0.154	0.156 to 0.464
Near Vision (NV)	0.260***	0.140	0.120 to 0.400

Table 31 Mobility aid X visual function (Gamma) * p<0.001**

4.9.4 Getting out & about

When asked about difficulty in walking around their own neighbourhood the responses are fairly evenly spread across LogMAR scores, with the highest number of those who state that they can't see to do this having a LogMAR score of 1.7 or worse. Responses to this question corresponded with the responses on the description of the mobility skills, i.e. those with poorer mobility skills stated that they had most difficulty in getting around a familiar neighbourhood.

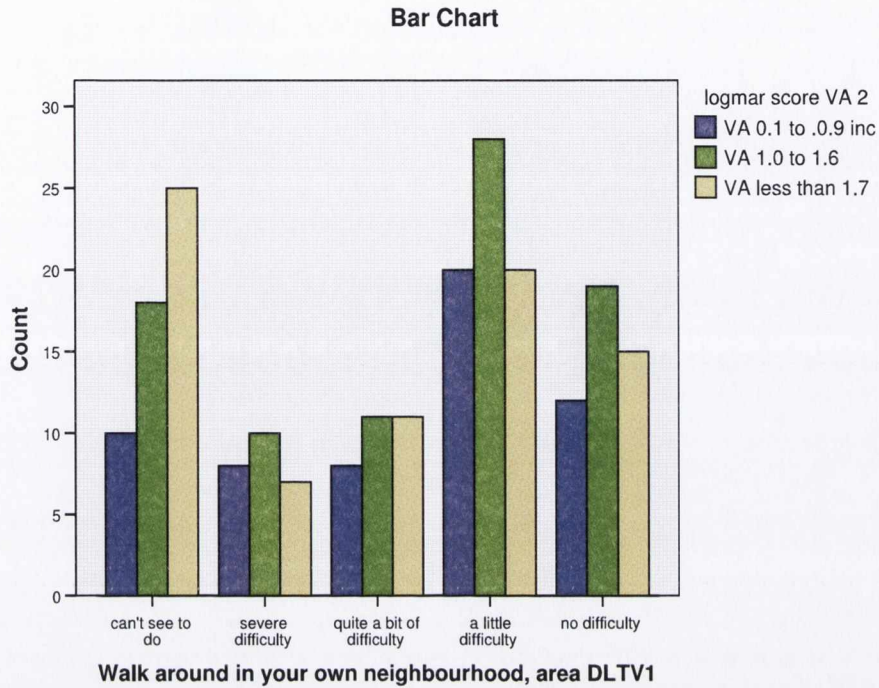


Figure 34 Difficulty walking in own neighbourhood X VA

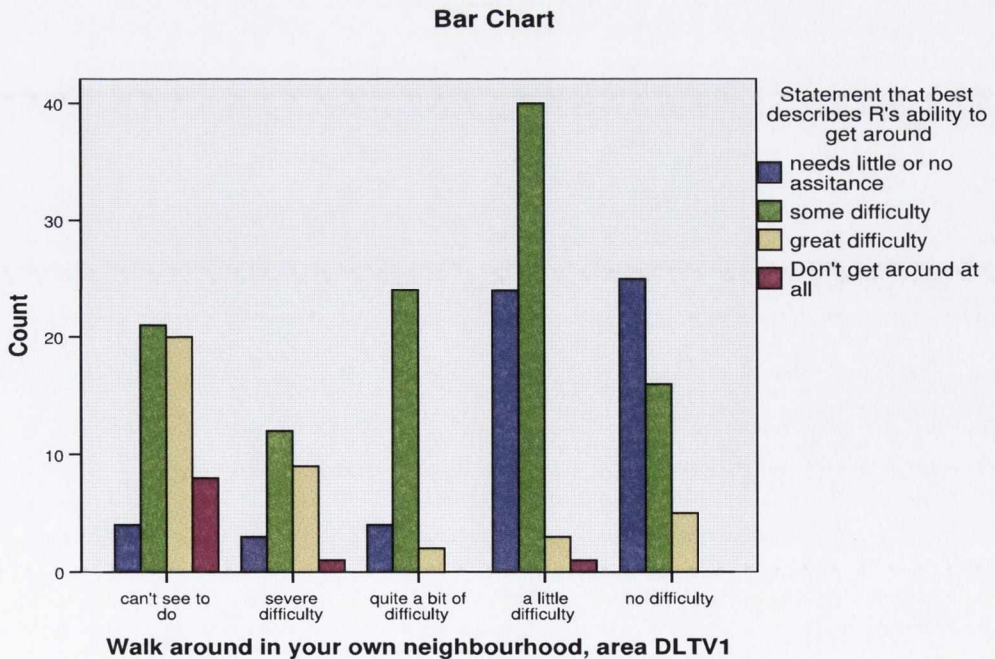


Figure 35 Difficulty walking in own neighbourhood X mobility

When asked about the extent of difficulty in walking around an unfamiliar neighbourhood, the majority of respondents 64.0% (n=142), irrespective of their LogMAR score or self reported mobility skills state that they "can't see to do".

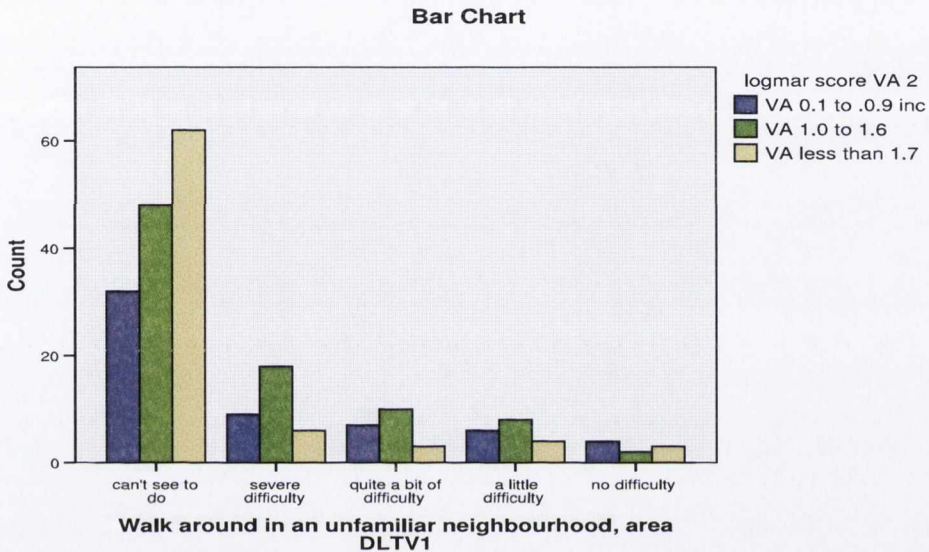


Figure 36 Difficulty walking in unfamiliar neighbourhood X VA

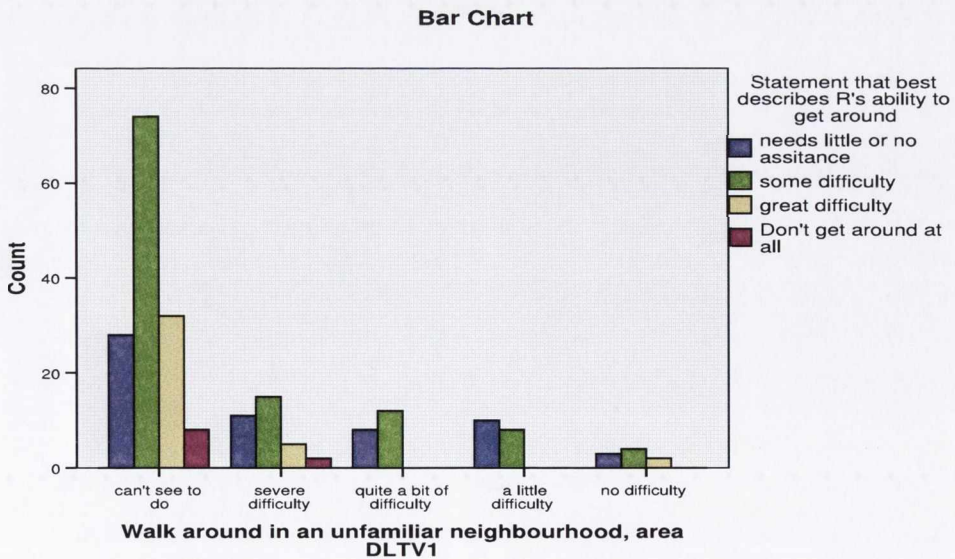


Figure 37 Difficulty walking in unfamiliar neighbourhood X mobility

When asked how much they agree with the statement "I feel I have to be more careful because of my eyesight" 84.7%, an overwhelming majority of respondents, irrespective of their level of vision, stated that they agreed strongly (n=188), while 13.2% stated that they agreed with the statement, (n=29).

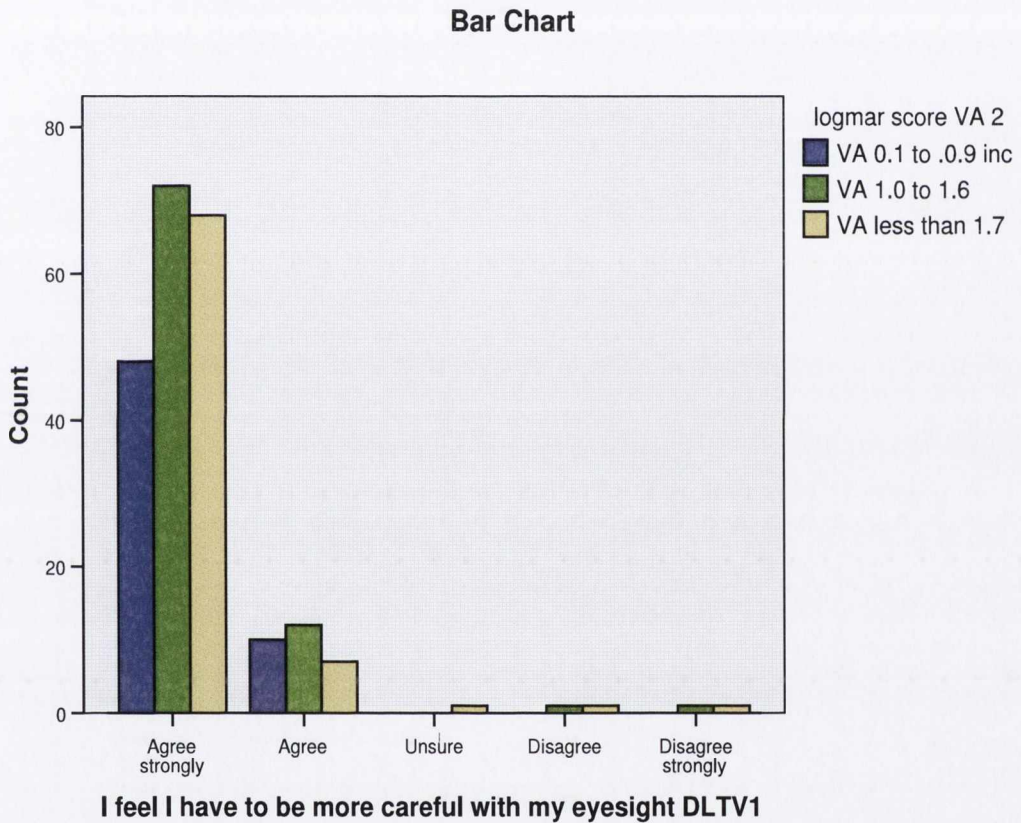


Figure 38 Need to be careful because of eyesight X VA

Levels of self reported mobility skills do not appear to influence the answer to this question as can be seen from Figure 39 below.

Bar Chart

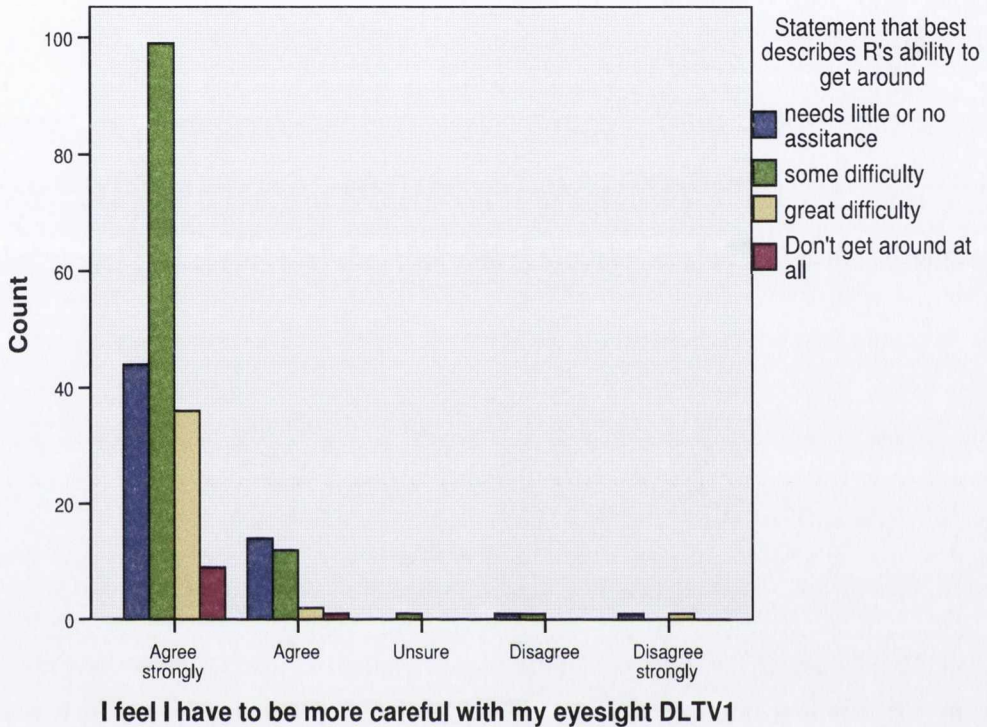


Figure 39 Need to be careful X mobility

When asked if they would like to be much more active 86.5% said they would with 46.4% stating always and 24.3% stating mostly. The question asking respondents if they would like to more independent had a similar response with 78.8% of respondents said they would like to be much more independent, with 46.8% saying always and 20.7% saying mostly. There was no statistical relationship between cohort and response to these questions.

4.10 Falls

4.10.1 Fear of falling

Some fear of falling existed for 73.6% of respondents (n=162). Just 26.1% stated that they were not at all afraid. Of the 73.6% who expressed a fear of falling 18% stated that they were so afraid of falling they would not go out alone (n=40), 13.5% said they were very afraid (n=30) while 41% said they were a little afraid (n=91).

4.10.2 Visual Function and fear of falling

Visual function scores were crosstabulated against fear of falling to see if there was a relationship between the variables. Two visual function results were significant, Visual Acuity $\chi^2 = 19.677$, df 8, $p \leq 0.05$ and Near Vision $\chi^2 = 21.313$, df 16, $p \leq 0.05$

Visual Function	χ^2	Df	P-value
Visual Acuity (VA)	19.677	8	0.05**
Low Contrast Acuity (CV)	16.851	12	0.155
Near Vision (NV)	36.44	20	0.05**
Visual Fields (VF)	21.313	16	0.167

Table 32 Visual function and fear of falling

4.10.3 Main cause of fear

Respondents were then asked what they were most afraid of in relation to falls. There were a variety of answers which included fear of steps and stairs,

obstacles, holes or uneven pavements, and roadworks. Many expressed a fear of breaking bones and seemed quite fearful of the consequences of a fall.

Comment generated to illustrate this fear included

- ◇ "I'm afraid of breaking my arm, hurting myself, getting an injury". NIU13
- ◇ "I'm afraid of getting a bad injury, of being left alone". ROIRJG09
- ◇ "Afraid of steps, everything, breaking something". ROIUIONA08
- ◇ "Steps, obstacles, just afraid of breaking bones & having to have someone come in who I'd have to depend on". NIREK3
- ◇ "I have a fear of falling & of nobody being around to help". ROIR29/R210
- ◇ "Getting hurt. I fell & broke my leg before, scared it will happen again". NIUMB05
- ◇ "I fell five weeks ago. I'm afraid of falling everywhere". ROIUAC03
- ◇ "Biggest problem when I fall is the panic, I just lie there and cry, Home help is in & out a couple of hours a week". NIR34
- ◇ "I fell down steps at house, broke wrist and ankle". NIU13
- ◇ "I go up & down the stairs on my hands & knees. Won't go to shop on my own because I can't see prices, I know I'm going to fall & don't recognise the money, transport would be fantastic if I could have a bus to collect me, my husband does everything for me". ROIRBGLM21

The above statements depict some of the real fear experienced by this group across all cohorts. The main themes were breaking bones, tripping on steps and previous injuries received. There was a highly statistically significant relationship between self reported mobility skills and fear of falling ($p < 0.001$). Those with better mobility skills were less afraid of falling.

Bar Chart

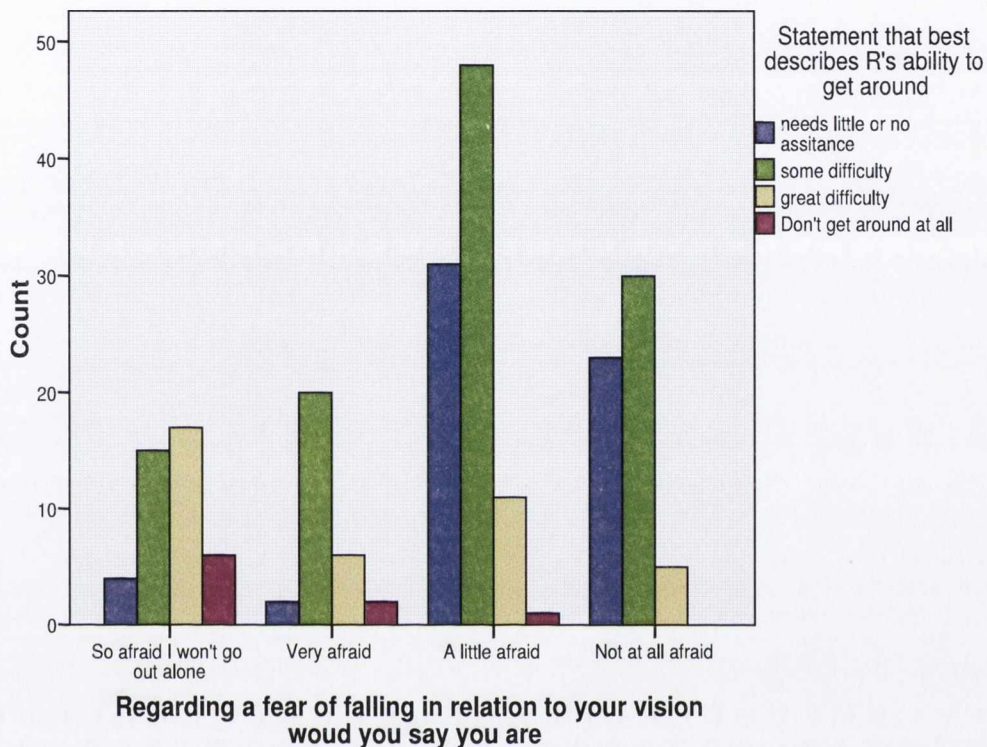


Figure 40 Fear of falling X mobility

4.10.4 Number of falls

A sizeable majority, 64.4%, of respondents had fallen as a result of their vision impairment (n=143), 15.3% had fallen once (n=34), 27.0% had fallen two or three times (n=60) while 21.6% had fallen four times or more (n=48). Of those who had fallen, (51.7%) had their most recent fall in the past year (n=74), 34.3% (n=49) had fallen between one & five years ago while 14.0% (n=20) had their last fall over five years ago. There was no statistical relationship between any of the vision function scores and number of falls.

4.10.5 Injuries

Of those who had fallen only 17.5% (n=25) said that they had received no injuries. Of the remainder 27.3% (n=39) stated that their injuries as a result of falling were very severe and required a visit to the hospital; 14.7% (n=21) stated that they had moderate injuries requiring a visit to their GP; and 40.5% (n=58) had minor injuries which were treated at home.

4.11 Exercise

Reduced mobility can lead to a restriction in ability to exercise. Respondents were asked how often they managed to take exercise. There was no correlation between cohort and response to this question. The majority of respondents, 74.3% (n=165) said that they get some exercise with 28.4% (n=63) stating that they exercised often and 45.9% (n=102) say they got exercise sometimes. No exercise was engaged in by 25.7% (n=57) respondents. Remarks in relation to this question were mainly related to an explanation by the participant of how they managed to achieve some exercise. This ranged from attending keep fit classes to playing ten pin bowling. Others had adapted their exercise regime to activities within the home.

- ◇ "I use an exercise bike & touch my knees, I'm afraid of people". NIR50LK
- ◇ "I walk up & down the back for exercise, I try". NIU20
- ◇ "I try to walk a little to stop arthritis getting me". ROIU20/150
- ◇ "I am very active. I do light gardening but I am 89". NIR04

One respondent presented a practical response from a participant whereby he liked to combine his exercise with his social life and commented:

- ◇ "My exercise takes place twice weekly when I walk 3 miles to and from the pub". NIR49LK

4.12 Help available

The majority of respondents 90.1% (n=200) have someone available to help them on a regular basis with tasks that they can not complete themselves, leaving 10.0% (n=22) without access to this help. When asked if they had someone they could call on for help if they need to, 5.0% said they did not have access to anyone who can help them (n=11).

When asked who was available to provide help if needed (multiple answers were permitted), 59% had immediate family available to call on for help, 14.9% had other relatives, 51.4% said they could call on friends or neighbours. Twenty three percent said they had used professional help when needed e.g. medi alarm and, 2.7 said they had a voluntary visitor they could call on if needed. A number of respondents from NIR said that the BCNI field worker was a great help to them. Some respondents said that the BCNI worker is the only help they have, while others said that the BCNI workers does everything for them, even unofficially outside their working time.

- ◇ "My help is a medi call alarm". NIRBG150
- ◇ "I could not get on without my wife so 35 hours is the minimum help she gives me, she does everything, I walk very slowly". NIR52DY
- ◇ "My husband does everything that I need". NIRBB73
- ◇ "I stagger around and hold furniture. The only unpaid help is a nurse comes re insulin, for medication, once a week". NIREK4
- ◇ "Neighbours would help if I asked but I don't like to ask people". NIU01
- ◇ "I don't bother with the neighbours, I never have visitors". NIU03
- ◇ "The home help makes a cup of tea for me. I ring 999 if I need help. My only visitor is the home help". NIU23
- ◇ "Friends and neighbours help out, by setting the fire, helping with shopping etc." NIU38
- ◇ "The field officer from BCNI does it all for me". NIUMB04
- ◇ "The blind centre worker takes me to social activities and my son takes me shopping". NIUMB100

- ◇ "On Saturday & Sunday my family do everything; I pay €11 an hour for help other times. I get €145 BWA (Blind Welfare Assistance) a month".
ROIRBGLM10
- ◇ "My wife helps, there's no back up for her at all". ROIRSOJG01
- ◇ " I would not survive without my wife". ROIRSOJG07
- ◇ "It a very long walk to neighbours now, all my neighbours have died off or moved away, I've 2 neighbours and their brothers who help out".
ROIU2/133
- ◇ "The field officer (BCNI) from Everton helps; she comes 2 hours a week, does more unofficially if necessary" I get 5hrs a week help from my niece or a neighbour helps". NIUMB04
- ◇ "I fell on two occasions & needed surgery. My neighbour is never there, I've give a donation every month to home help overseer, €10".
ROIRBGLM15
- ◇ "The home help comes once a week otherwise I have no one to help me with anything". ROIRBGLM14
- ◇ "My wife is very elderly too. The home help comes twice a week, get meals on wheels 4 days but having difficulty with meals on other 3 days. Our daughters help out on those days". ROIUAC03
- ◇ "My neighbours are wonderful, I pay €17 for person to come and shower me". ROIUIONA06

As is evident from the above statements many people are depending on their families, friends, and neighbours to help them. There is recognition among some that their current living arrangements are dependent on the continuing availability of this help.

- ◇ "My wife is able to do all of this for me. I worry though if anything happens to her what would happen to me?" ROIU 24/77

4.13 Other activities

When asked about other areas of need, a number of respondents stated that they would like help to be able to engage in social activities or just have someone to keep them company from time to time.

- ◇ "I would love to have someone come in the evening to keep me company". ROIUIONA25
- ◇ "I'd like a voluntary visitor".NIU45
- ◇ "To have someone take me to pub or to take me to visit friends". ROIRBGLM12

Nevertheless, others cited more basic needs like getting meals, help with housework, shopping, gardening, home maintenance, and getting personal care for things like having a home visit from a chiropodist to take care of toenails and feet, and help to take a bath.

- ◇ "I need someone to cut my toes nails". NIU13
- ◇ "I could do with help with bath". ROIUIONA10
- ◇ "I need a cleaner, my son does it occasionally. I need someone to point out the shampoo and conditioner, etc. My husband manages my medication. It would be great to have company or help when my husband is at work, the day can be long". NIRLK04
- ◇ "I would like to get dinners everyday".ROIRSOJG12
- ◇ "I need help with heavy housework". NIU30

Requests for help with transport, in particular, to attend hospital appointments, and help with social activities were much more frequent from the respondents from rural Republic of Ireland, although some urban dwellers also made requests in these areas. Respondents from the North did not request help with these two areas under expressions of further needs.

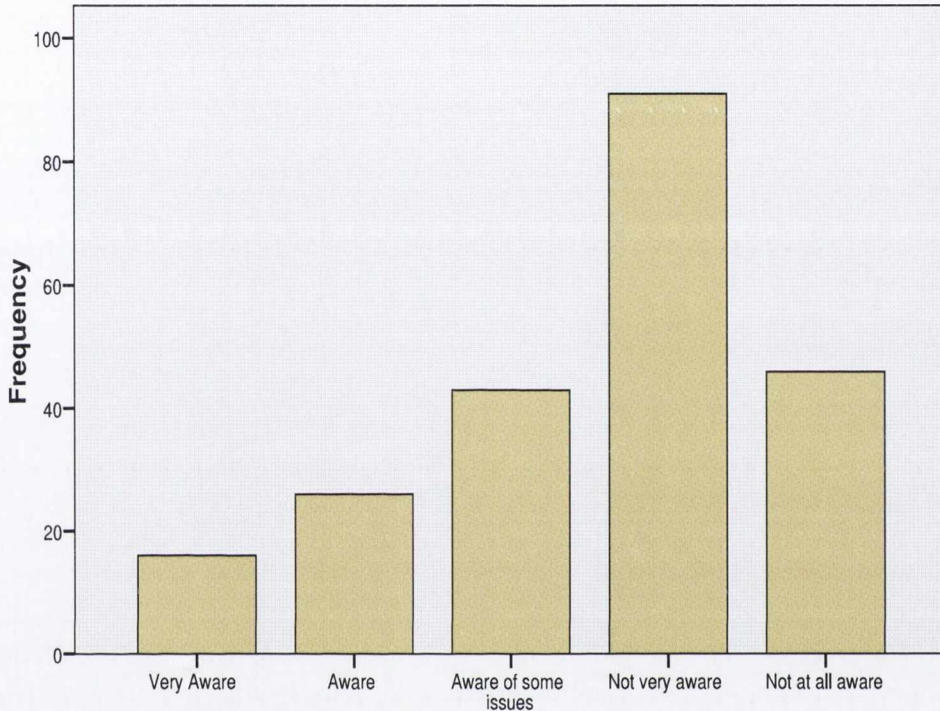
4.14 Awareness & helpfulness of public

When asked their opinion on how aware the public are of issues relating to vision impairment, the majority 61.7% (n=137) said that the public were not aware, and this ranged from not at all aware 20.7% (n=46) to not very aware 41.0% (n=91). When asked the same question in relation to friends and family the majority 74.8% (n=166) said friends and family were aware or very aware.

Respondents were asked how helpful they perceived the public to be in relation to their blindness. The majority stated that they found the public helpful 78.4% (n=174), ranging from sometimes helpful to always helpful. This result achieved statistical significance $\chi^2 = 36.69$, df 15, $p < 0.001$. Many of the respondents qualified their answers on this topic by saying that if and when the public know you have a sight problem they are helpful. However many participants felt that there was an absence of understanding about sight loss. A number of respondents were of the opinion that disability awareness training was needed by the public.

- ◇ "People just don't understand. They don't know about sight problems. If you had a walking problem they'd understand but not blindness, you feel different; I suppose things could be worse". ROIRBGLM01
- ◇ "The public...if you ask them to help they are nervous at the thought, they don't know what to do. I would like to be able to get about more independently; loosing the ability to drive was a major blow to me". ROIRBGLM04
- ◇ "People say 'You wouldn't think there was anything wrong with you; your eyes look ok' My eyesight interferes with my lifestyle big time, How could the public be helpful when they don't know anything". ROIRBGLM11
- ◇ "They public are aware & helpful when they see the symbol cane. Before I got the symbol cane the public did not understand. I get annoyed & upset by my circumstances". NIU10
- ◇ "Most do not understand partial sight". ROIUIONA11

How aware do you think the general public are of the issues relating ot vision impairment? Would you say they are



How aware do you think the general public are of the issues relating ot vision impairment? Would you say they are

Figure 41 Public Awareness of vision impairment

How are do you think your family and friends are of your needs relating to vision impairment? Would you say they are

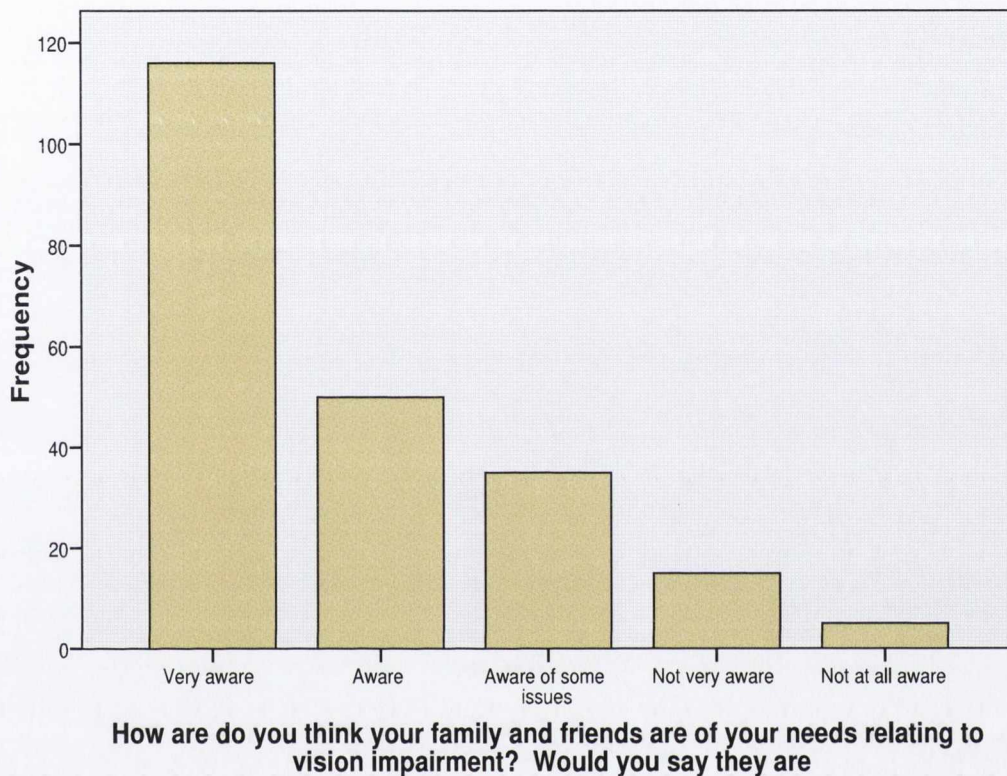


Figure 42 Family & friends awareness of vision impairment

4.15 Loneliness

Just over half of the participants said that they experience loneliness 51.0% (n=114), with 17.2% saying that they were mostly lonely or always lonely. There was no significance between cohort or urban rural dwelling and loneliness ($\chi^2 = 7.55$, df 9, $p = 0.580$). There was a statistically significant relationship between living alone or not, and loneliness, with those who were living alone more likely to state that they were lonely at least sometimes. $\chi^2 =$

13.30, $df\ 3$, $p < 0.01$. The relationship between loneliness and living alone or not was not very strong although it was still significant when subjected to further analysis with a gamma value of 0.377, CI 0.173 to 0.581, $p < 0.001$.

The subject of loneliness generated a number of responses from participants. The selection of comments below is an example of unprompted responses.

- ◇ "I'm lonely because I can't get out. Why can't I just put on a coat and just get out. I was always active, very active, up to a few years ago".
ROIUIONA22
- ◇ "I don't trouble my family with my problems. I don't complain about being lonely although I am, very. I don't tell people, I try not to be sad".
ROIUIONA09
- ◇ "Coming to terms with my sight loss was huge. I don't think the professionals realise. I'm lonely now. Sight loss comes and there's no way of getting anywhere. I think all the services are for younger people, not for us". ROIRBG10
- ◇ "I feel very lonely, especially at night". NIR08
- ◇ "I've no life at all now; it's a very lonely place". NIR21

4.16 Explanation of eye condition

Respondents were asked how well they felt that their eye condition had been explained to them by the ophthalmologist. Information was missing for five respondents. The majority of respondents, 66.8% ($n=145$) were satisfied with 30.6% ($n=68$) saying it was explained very well, and 34.7% ($n=77$) stated that the explanation had been satisfactory. Of the remainder 19.8% ($n=44$) said that the explanation had been done very poorly and 12.6% said that they had been given no explanation ($n=28$). This means that almost 32.5% of participants were not happy with the explanation they received. Applying a chi square statistical test showed a statistically significant relationship between cohort and scoring on how well respondents felt that the explanation of their

eye condition was given by their ophthalmologist, $\chi^2 = 19.3$, $df\ 9$, $p < 0.05$. Respondents from NIU were most satisfied with the explanation of their eye condition. However, the relationship was very weak although still significant when subjected to further analysis with a gamma value of -0.188 , $ASE\ x\ 0.154$, $p < 0.05$. Figure 43 below show the breakdown of the four possible responses to this question across the cohorts.

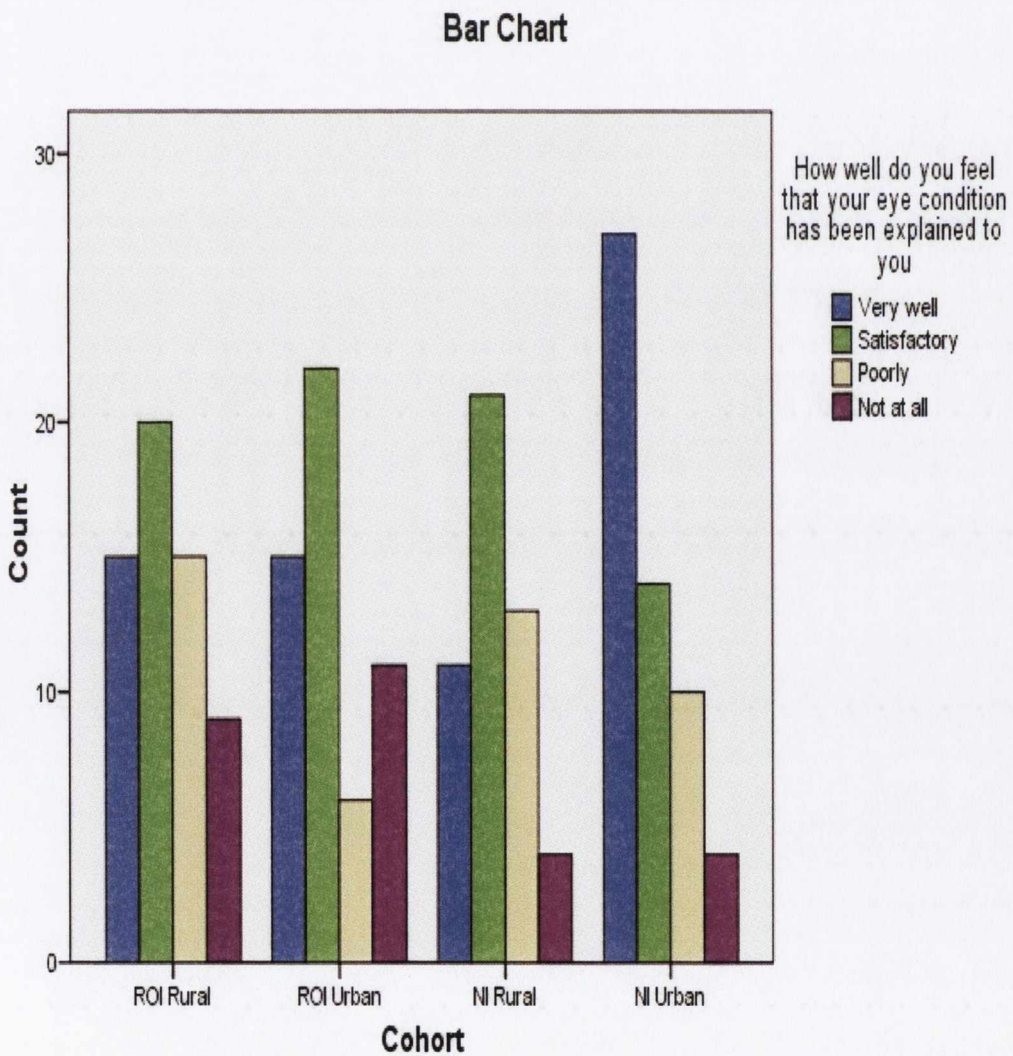


Figure 43 Explanation of eye disease X cohort

Comments are included below on this subject. They mainly came from respondents who were not very happy with the explanation that they received about their eye condition.

- ◇ "Eyesight loss not explained by the doctor in any way. Dr said "I can't do anything for you", I just went into shock and I don't think I ever came out". ROIUIONA05
- ◇ "At first explanation was very poor but when I went back I got a better explanation". NIR42
- ◇ "I was told that the deterioration was "old age" I'm insulted by this comment, I had no follow up from my last appointment, they don't give a hoot" (R aged 62). ROIRSOJG09
- ◇ "It took a long time from initial diagnosis to explain eye condition to me". NIR51LK
- ◇ "Doctor just told me that I had RP and that 100's of people have RP, and are blind and to contact NCBI". ROIUIONA25
- ◇ "In the beginning it was very poorly explained to me, terrible in fact". NIR53LK
- ◇ "The doctor did not explain macular degeneration to me; I overheard the doctor saying to the houseman that I needed to contact the National Council for the Blind. I got a real shock but didn't say anything to him. I really thought I must be going blind but he didn't tell me anymore, I knew the National Council for the Blind as I often donate to them. My biggest loss is not driving my car; I'm very isolated up here now". ROIRLM10
- ◇ "I feel eyesight was explained very poorly". NIU19

4.17 Services evaluation

The majority of respondents were satisfied (86%) with the services they were receiving but many commented that better information about services available would be very useful. Many respondents felt that they had gained a

lot of information about services available through the process of this research.

4.18 One wish

Respondents were asked if they could change one thing to improve their lives what would it be. This was an open ended question. There were 45 missing responses, which included 24 who said they didn't know or could not make a choice and 21 who chose not to answer this question. Of the remainder (n=177), 67% (n=119) said they would like to get their eyesight back. It must be noted that despite the fact that over 75% reported at least one additional disability or illnesses when asked what they might do to change their lives the majority of responses were concerned with the return of lost vision. This demonstrates the significance of sight loss in the lives of this cohort.

Chapter 5

5.0 Results: section 2 –

Focus groups with people with vision impairments

This study chose to use focus group sessions with people with vision impairment, from both urban and rural areas in Northern Ireland and the Republic of Ireland.

5.1 Methodology

Frontline professionals working with people with vision impairment were given detailed information about the proposed study and were asked to select and invite participants to the focus group sessions. They were given guidelines for the selection of participants and every effort was made to ensure that the group reflected the make up of the blind and partially sighted community. The study aimed to include a good mix of age, disability, gender, rurality, duration of vision impairment, cause of vision impairment and socio economic status.

5.1.1 Participants

Fourteen groups of people were invited to take part in focus groups on the subject of mobility and transport. Six focus groups took place in Northern Ireland, three consisting of people with vision impairment living in the urban area (Belfast, n=21) and three consisting of people with vision impairments living in rural North West Northern Ireland (n=27). In the Republic of Ireland, eight focus groups took place. Four of these groups consisted of people with vision impairment living in urban areas (Dublin, n=39), and four consisted of people with vision impairments living in rural North West Ireland (n=34)

Altogether there were 121 participants, 48 in Northern Ireland, and 73 from the Republic of Ireland.

5.1.2 Group facilitation

Each focus group session was chaired by a facilitator who explained the purpose of the group, reaffirmed that everyone was happy to be involved and obtained consent for the recording of the sessions, which lasted for between 90 to 120 minutes. A notetaker was also present. Group participants were told that the aim of the discussions was to determine the nature of unmet need in relation to vision difficulties. They were told that mobility had already been highlighted as an issue by many of those undertaking individual interviews. They were also informed that taking part in the study was absolutely voluntary and deciding not to take part would in no way affect their receipt of current or future services. All sessions were recorded with the consent of participants. Participants were then given an opportunity to ask any questions before the session began.

Focus groups in Northern Ireland were organized and hosted by the Blind Centre. In the Republic of Ireland focus groups were organized and hosted by the National Council for the Blind of Ireland.

5.2 Results

5.2.1 Demographic profile

Demographic data confirmed that the focus group population reflected what is known about people with vision impairment in Ireland, both Northern Ireland and the Republic of Ireland. The majority of individuals were female (n = 96, 79%). The ages ranged from 19 to 91 with a mean age of 64.7, the median being 70. All group members were registrable as blind or partially sighted. The

age range is outside the inclusion criteria here because in a number of focus groups people outside the age criteria were included by the focus group hosts, as these individuals expressed strong interest in the subject and had requested to attend. As the hosts were facilitating the PI she did not think it wise to exclude those few people outside the age brackets.

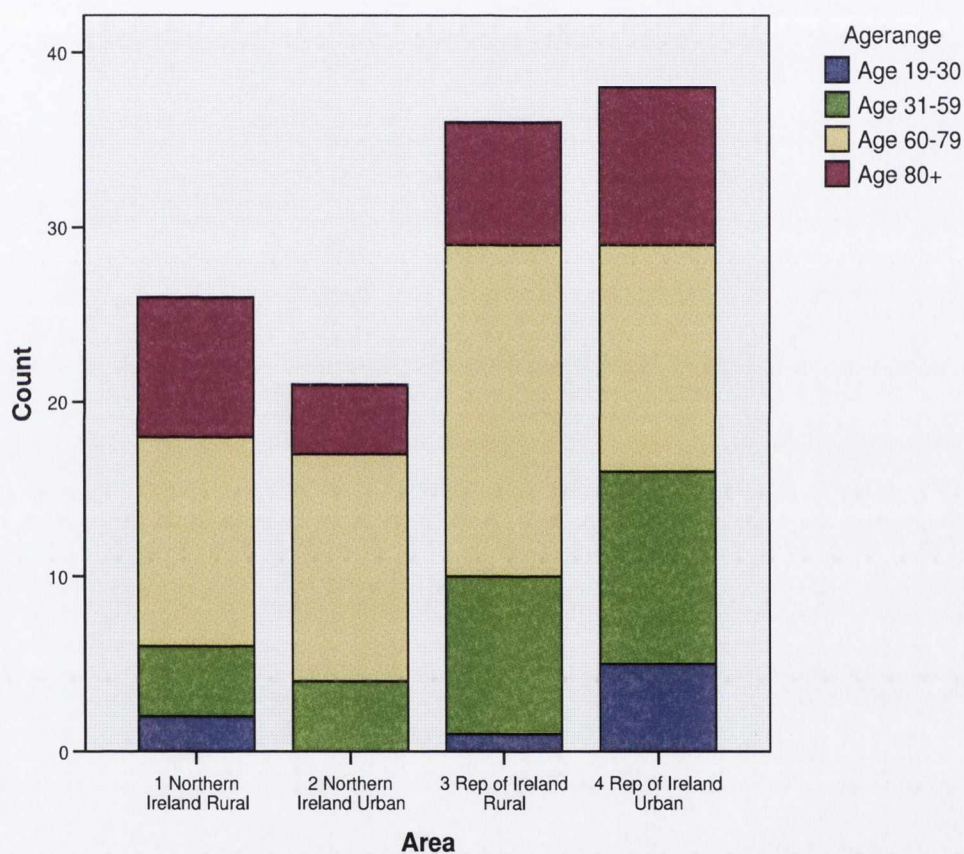


Figure 44 Focus group X age & cohort

Thirty eight (31.4%) participants received some formal mobility training. Of the participants who had received mobility training, six were described as dependent and two were described as having only good indoor mobility, i.e. independent in their own homes, and of the remainder 30 were independent. Current guide dog users comprised nine of the participants, three participants had recently retired their guide dogs, and one person was awaiting a guide dog.

Sixty three (51.2%) participants had not received mobility training. Twenty two of these resided in Northern Ireland and 41 resided in the Republic of Ireland. Forty two of these were rural dwellers, 24 from the Republic of Ireland and 18 from Northern Ireland. Twenty five (20.6%) participants were described as having no or very poor mobility skills. Eighteen of these were blind while the remaining seven were partially sighted.

Information on mobility was unavailable for 21 (17.4%) participants.

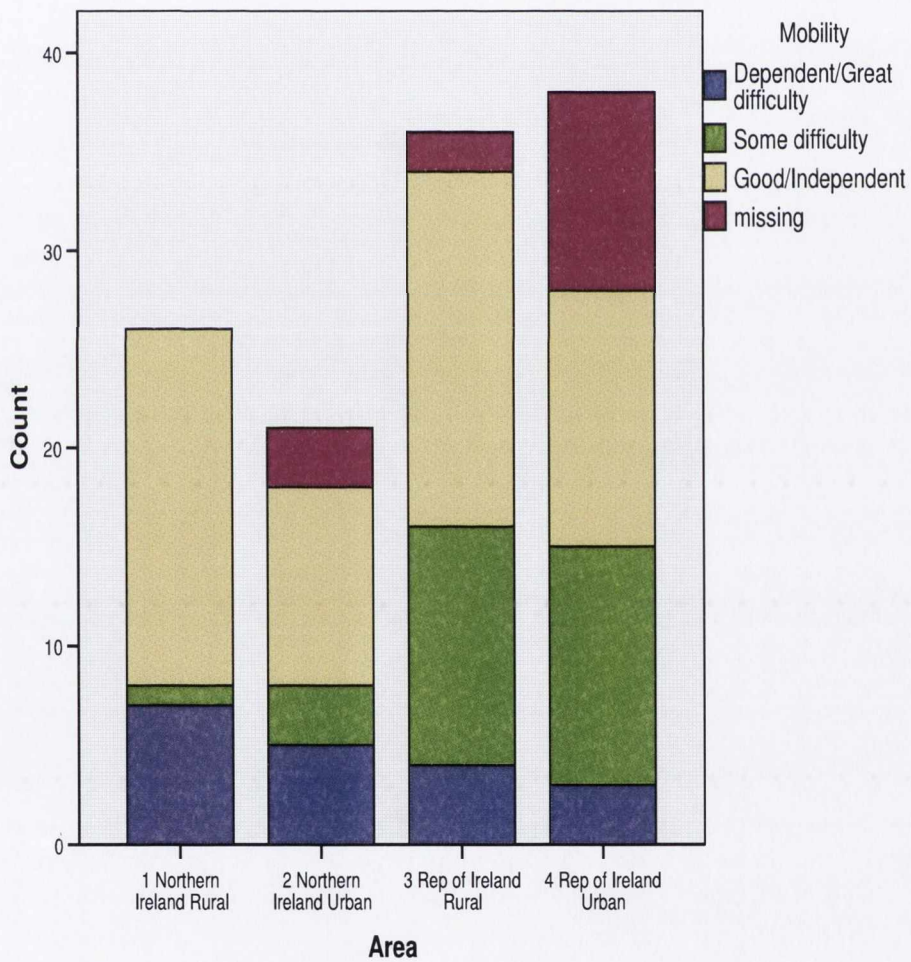


Figure 45 Information on mobility

The breakdown of eye disease by participant is as follows

Retinitis Pigmentosa	8
Albinism	8
Age Related Macular degeneration	30
Glaucoma	13
Not specified	18
Other	44

Pathologies causing total blindness included Diabetic Retinopathy, Optic Atrophy, and Retinopathy of Prematurity. Those resulting in only central visual loss included Age Related Macular degeneration and Diabetic Maculopathy whereas those resulting in peripheral visual field loss included Retinitis Pigmentosa and Glaucoma. Those resulting in diffuse visual loss included Cataracts, Albinism etc.

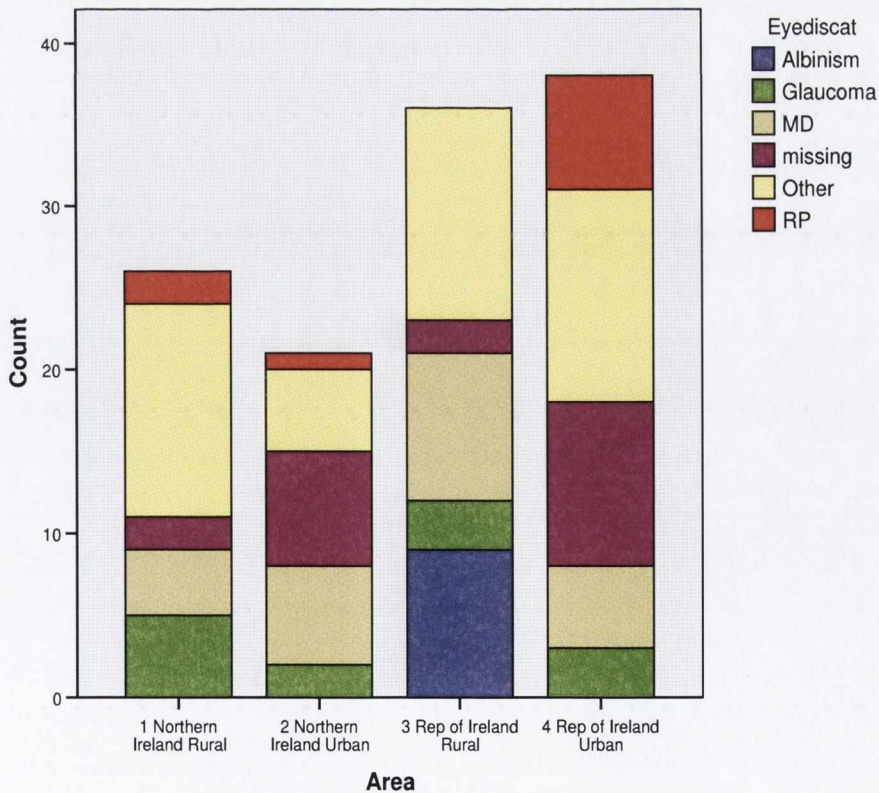


Figure 46 Breakdown of eye disease X cohort

Details of the duration of visual loss were missing for 39 participants. For the remainder of participants, 25 had congenitally defective visual loss, while for those with acquired visual loss, the duration of vision impairment ranged from two to 48 years. Sixteen (13.2%) participants had additional disabilities, three of whom were wheelchair users and three used walking aids.

5.3 Overview of issues

There was much data generated via the focus groups conducted as part of this study. Only those issues that were raised as key issues for discussion will be reported here. Under each heading some information about the discussion that took place will be reported and where appropriate this will be supplemented with direct quotes from the participants. The major issues raised during these focus groups centre on themes of loss of independence, loneliness, social isolation, coping strategies, mobility, transport, public attitudes and disability awareness.

5.3.1 Loss of independence:

Many participants voiced the sentiment that their "independence is gone". Family can become overprotective. The loss of the ability to drive was a major blow to independence. Participants who were drivers prior to their loss of sight expressed deep regret at the loss of their ability to drive and stated that such a loss equated with a massive loss of independence.

- ◇ "Giving up driving was the hardest thing that ever happened to me." NIR15
- ◇ "I'm now totally isolated cause of not being able to drive" ROIR26
- ◇ "The loss of driving was a big blow to my independence" ROIU36

All participants in the rural groups disliked the fact that they are always dependent on others to get anywhere.

- ◇ "...the little things I can't do anymore, when you put them all together they add up". NIR 9
- ◇ "It's the small wee things that add up to independence" ROIR 30
- ◇ "I used to be very independent, I miss my independence very much." NIR 29

In both Republic of Ireland & Northern Ireland, the minimum legally prescribed visual acuity for driving is approximately $6/12$. There is no facility, as for example in the USA, to use spectacle mounted telescopes as acuity enhancement devices in order to achieve the recommended standard. Those with acuities of less than 6/12 must thus be considered to have irreversible sight loss and the loss of independence resulting from having to give up their driving license has much greater psychological and social impact.

5.3.2 Loneliness and social isolation:

The loss of access to a social life was a repeated theme in all groups. Learning to cope with the loneliness and isolation that comes with sight loss is necessary, particularly for those living alone.

- ◇ "Loneliness can be overpowering" ROIR6
- ◇ "I think blindness is the worse thing that could happen to me". ROIR4
- ◇ "If only I could have someone calling to visit because I am very lonely." NIU10
- ◇ "It's embarrassing going out, not recognising faces, walking by those you know". ROIU8
- ◇ "Entertainments consist of radio, TV, talking books, gardening". ROIR39
- ◇ "There's no social life anymore for those living alone, I find sighted people (public) don't really want me as a friend". ROIU1
- ◇ "Parties, for older people would be great". ROIR23
- ◇ "I used to play bowls and darts. I do not do any of these things now". NIR27

- ◇ "Isolation is a big problem. There could be drivers designated for certain areas for elderly people". NIR24

5.3.3 Coping strategies

Participants stressed that one needed to develop new techniques to cope with everyday living. In each group the topic of coping strategies led on to the techniques one must learn to function as a person with sight loss. For some who have not yet developed those techniques, they said that they don't do anything.

- ◇ "I just sit there all day, my daughter comes to give me my meals". ROIR4
- ◇ "As a person with vision impairment you need to develop techniques to cope with every day things" .ROIR1
- ◇ "I stick my finger in the cup when making tea and when it gets hot I know to stop". NIR5
- ◇ "Services can make a difference". ROIR2
- ◇ "DLS was the best thing ever, particularly learning how to use a washing machine, crossing roads. Helped me to cope". ROIR3
- ◇ "But still have to carry on". ROIR34
- ◇ "I just accept what I have". NIR2
- ◇ "Low vision aids, they improve your independence". NIU1

5.3.4 Mobility

The majority of participants in the focus groups had not received mobility training. Those who have received training appear more confident in their ability to go out and about.

- ◇ "Long cane gives you great confidence...and independence" NIU1

- ◇ "My guide dog is a great asset". I depend on him for everything, once he learns a route. It's a big difference to mobility" ROIU8

The majority stated that their mobility is restricted or reduced and in some cases absent altogether. Participants in all focus groups spoke about obstacles on footpaths e.g. cars parked, street furniture, shop signs, overhanging branches, overgrown hedges, telephone boxes, bikes, narrow footpaths and steps on some footpaths. These obstacles posed particular problems for the groups from urban areas and those participants from rural areas who lived in towns and villages, as they make safe mobility and safe passage very difficult.

In all jurisdictions, both urban and rural, participants cited difficulty with crossing roads.

- ◇ It's too difficult to cross busy roads when getting on or off the bus." NIU8 "

Many fear crossings and also complain of the long walk around roundabouts. They believe that there are a minimal number of safe crossings. Participants stated that audio crossings are often placed too near each other. When two bleeps are going at the same time it is difficult to know which road you can cross. They feel that there is not enough time to cross roads, particularly on dual carriageways. At pedestrian crossings they also stated that the extended orange time should be extended green time to give people much more time to cross. It was agreed by all participants that the human voice is excellent at crossings. Many participants stated that where audio crossings do exist they are often broken. Many participants claimed that even when they are working, cars often ignore them.

Both the urban and rural groups from the Republic of Ireland highlighted problems with footpaths. They complained that there is no uniformity or consistency of design, some are high, some are low. In many areas, for example Dublin, O'Connell Street and Manorhamilton, Main Street, the kerbs have been removed so the footpath is now flush with the street. One doesn't know where the footpath stops and the road begins. Guide dogs are trained to

stop at kerbs. Without kerbs they can walk out onto the road without realising it. It was strongly requested that public authorities consult widely with both disabled and non disabled groups before making environmental changes. People with vision impairments need to adjust mobility in line with new design. In order to avoid stepping out onto the road the person with a vision impairment must keep to the inner shoreline of the footpath but it is in this area that one encounters most obstacles. Wheelchair users with vision impairment have more difficulties. There is a lack of accessible kerbs for wheelchair users. Some kerbs are as high as 18 inches.

Another issue raised in the Dublin focus groups was the fact that there seems to be ongoing roadworks by various departments. Participants felt that no consultation or cooperation exists between departments so road works last longer. The resulting uneven surfaces cause great difficulty for mobility.

Participants thought that tactile paving is very useful. However overuse, or lack of care in the use of tactile paving can also cause confusion. Colour contrast on the edge of footpaths would also be of great assistance to people with partial sight. It was remarked that street signs for the general public are too high up for easy access by people with low vision. Participants also suggested that all County Councils should have disability access officers.

5.3.5 Public attitudes

Participants from all groups stated that going out can be a very stressful experience. Comments made by low vision participants indicate that when out and about, it is difficult to recognise those who greet you, and this creates problems, as the general public don't understand about low vision. This can be very embarrassing. When the environment is very noisy it is very difficult for people with vision impairment to communicate with each other or their sighted peers. Some participants commented that when the public do realise that that they have a vision impairment they can "talk over your head as if you've got a

disease and they will not acknowledge that you're beside them." It was generally agreed in all groups that while there are many nice and kind people, in general the public are often discourteous and unhelpful. Participants stated that it is often difficult to get help in shops.

- ◇ "I feel we have to keep making excuses for example I'll say 'sorry I forgot my glasses' when asking for help in shops". ROIR13

It was agreed in all groups that having some sort of identification such as a lapel pin to show that you are disabled might be useful. However, much discussion ensued around issues of vulnerability and possible discrimination and pride.

- ◇ "The cane is so obvious that it makes you feel vulnerable". ROIU30
- ◇ "I was stopped from going to the aqua aerobics for insurance reasons". ROIU12
- ◇ "I feel using the cane (symbol cane) would mean losing my independence. My pride makes me not carry one". NIU10

One other issue that was raised in the rural groups in the Republic of Ireland was that in order to deal with the public, and venture out, as a person with a vision impairment, you must be assertive.

5.3.6 Public awareness

It was strongly felt by all groups, urban and rural, in both jurisdictions, that the provision of disability awareness training for both the general public and those in public service provision would ease the stress associated with going out & about. Awareness training for the public, about the needs of people with vision impairment, is very necessary according to participants from all focus groups.

- ◇ "Need a campaign to alert people about sight loss & helping people to ensure independence" NIR22

In particular, many of the low vision participants expressed frustration with the general lack of understanding of low vision.

- ◇ "Unless you walk roads with dark glasses and white stick the public have no understanding or recognition of vision problem". ROIR3
- ◇ "More information should be available to general public about sight loss & how partial sight works". ROIR13
- ◇ "Could do with awareness training for public. Even the family don't realise or understand sight loss". NIU17

While some people are very helpful, there are many who are not at all helpful. The general feeling within groups is that the lack of help is due to lack of awareness and understanding of the needs of people with vision impairments.

- ◇ NIR19 "Public are helpful but they're not aware of blindness, they don't understand partial sight"

Participants also stated that the public are often discourteous and do not offer seats on public transport. It was highlighted that sighted pedestrians need to be more aware of people with vision impairments, in particular those using a cane. Driver awareness is also necessary, according to comments from focus group participants.

5.4 Transport

Rural participants stated that they would love independent transport to be available from home. Two people from the rural groups stated that they had to move into a local town due to lack of transport.

- ◇ "I had to move to the town because there was no transport. " NIR10

Discussions in all groups centred on modes of transport, its availability, and problems encountered when seeking out and using the various types of transport available. Issues relating to private transport, taxis and the cost of same were also examined. Problems concerning transport were a major issue for all focus groups even those in urban areas.

5.4.1 Bus travel

In the discussion groups for urban areas, lack of uniformity and access issues were predominant, while in the rural areas, lack of available public transport and the uselessness of the free travel pass were identified as topics of great importance. Individuals had many comments concerning problems they had experienced with bus transport. Although some of the difficulties, and in particular a total lack of access to any form of transport, were specific to rural users, they were raised by participants, in all groups, in both jurisdictions.

5.4.2 Bus design

In the urban focus group sessions, north and south, participants stated that bus design should be uniform as the differing bus styles make it very difficult for a person with a vision impairment to find a seat. In the Dublin area participants remarked that the introduction of the luggage rack next to the driver's seat, on newer buses, means that a vision impaired person has no means of communication with the driver to find out where to get off.

In both the urban and rural focus group sessions in the Republic of Ireland participants stated that bus stops are not announced and often, despite requests, the driver forgets to announce the stop for the person with vision impairment. Participants state that they find this very distressing when travelling as one is usually at a loss to find the way back to the destination. In both jurisdictions the public providers have adopted appropriate colour coding

to differentiate between urban and rural services. Confusion does however arise in that private coach companies utilise a vast mishmash of colours and styles.

- ◇ "The buses I need to get all look different". This means it's difficult to identify them. It is important to be able to distinguish them. I never know which one to get". NIU21

5.4.3 Bus accessibility

Many issues arose concerning the accessibility of bus transport. Particular concern was expressed in all focus groups both north and south regarding access to buses for those people who are wheelchair users.

- ◇ "Old buses have too many steps and the seats are too close together. New buses, which kneel, are much better". NIU18

Participants stated that many buses do not have a low floor. In the Dublin focus groups participants said that where low floor buses do exist, the user usually has to request that the floor be lowered. Participants commented that this draws attention to the disability and can lead to embarrassment, as most people do not want attention drawn to the fact that they have a disability. It was suggested that the floor should be lowered automatically at every stop as this in turn would help all people including those with heavy luggage, parents with children in buggies and older people who find the steps on buses difficult to negotiate. Many participants expressed great difficulty negotiating the steps on buses and do not as a result, use the buses.

- ◇ "Getting on a bus is difficult I'm unsteady getting on and off so I do not use buses." NIR5

Participants stated that many stops are not equipped for people with disabilities. They recommended that all buses should pull right into the stop at

a fixed pick up area. They felt that there should be an announcement by the driver or by an electronic device, at each stop indicating the bus stop name, the bus number, and the bus destination. Participants stated that at present a blind person has to find their way to the point where the bus has stopped. This may involve stepping out onto the road itself, a practice that may be hazardous as the passenger with vision impairments is unlikely to be aware of impending danger such as an oncoming bicycle. A number of participants stated that they have received very short, sometimes rude, responses from drivers. "Are you blind or what?" Another difficulty highlighted by participants is that bus drivers often move off before they have found a seat. This is both distressing and dangerous for people with vision impairments as they have much more difficulty in finding seats, or a safe place to stand, than their sighted peers.

In the rural focus groups in the Republic of Ireland participants stated that bus timetables are not readily available in an accessible format. In rural groups in Northern Ireland participants stated that the Braille signs which are provided at bus stops, are too low. Only a small proportion of people with vision impairment are wheelchair users.

5.4.4 Bus service provision

The majority of participants from the rural focus groups in both jurisdictions stated that they do not have access to a regular bus service and as a result, they are dependent on friends, family, or a taxi service. Rural dwellers living in towns on main bus routes do have access to buses. Many participants stated that they do not use buses even where they are available as it is too difficult to cross busy roads when going to, or coming from, the bus. Participants from the rural focus groups in the Republic of Ireland had the perception that even where bus services do exist there seemed to be no co-ordination of services. For example, while one might get a bus into the nearest big town for shopping

once a week, there is no bus back home. Therefore, when only one-way bus travel is available, one must get family or friend to collect them or alternatively get a taxi home.

There are no night buses in rural areas and this mitigates against people with vision impairment having any evening social life.

- ◇ "There's no late buses so therefore it's a big problem to socialise. There's no coordination in services." ROIR19

In Northern Ireland, participants also said that there is little access to buses at the weekend. Lack of transport services in rural areas is highlighted in a report on accessible transport in Northern Ireland (DRD, 2004).

5.4.5 Travelling alone

Participants stated that travelling alone, as a person with vision impairment, is very stressful, particularly on long journeys.

- ◇ "You know travelling as a person with sight problems is very stressful, not knowing if you will be forgotten about". ROIR33
- ◇ "One needs to be alert at all times and implement a strategy for travelling, such as noting every stop". ROIR 13
- ◇ "I'm dependant on others to go places I don't know. I ended up in the wrong town when bus driver forgot to tell my stop. That's terrible for a blind person you know". ROIR18

When changing buses there is usually no automatic help for changing so the person has to keep asking for help and reminding the staff at the station that they are still there and need help.

- ◇ " Loss of conductor a big loss" ROIU16

Where buses don't keep to the timetable a blind person can never be sure whether or not they have missed their bus. In the era of satellite navigation technology public transport providers should be able to offer automatic stop announcements.

- ◇ "Sometime discourteous drivers can abandon you and you don't know where you are or where else to go for help." NIU17

5.4.6 Taxis

Participants stated that people with vision impairments, particularly those in the North West of the Republic of Ireland are often dependent on taxis to get around. They are required, not only for trips to the shops and social activities but also to attend doctor and hospital appointments etc. This creates a large expense.

- ◇ "I pay £25 taxi fare to hospital it is £12.40 one way to the Royal. A lot of blind people are paying for taxis and that's a lot of money for me". NIU3
- ◇ "I would love transport. I have to pay taxi €20 just to go to doctor". ROIR7

Some participants from the rural areas of the Republic of Ireland, who do not have access to a local taxi service, need to ask family members to take time off work to take them to appointments. In some remote rural areas, particularly in parts of Donegal, there is no access to a taxi service. Where taxis can be requested, the cost is prohibitive, as one has to pay the taxi fee for coming to collect them as well as the cost of the travel to their own destination.

- ◇ "I live very rural, am completely dependent on my husband. There's no taxi service here". ROIR 26

Bureaucracy in dealing with the Health Board in the Republic of Ireland in reclaiming partial refunds for taxi journeys to medical appointments is unnecessarily time consuming and complex.

- ◇ "To go to general hospital I have to keep my son home from work to take me to hospital. The Health Board will pay part of the taxi fare but only after much bureaucracy. But there are, however, no taxis in my area, I live too rural". ROIR28

The issue of taxi drivers refusing to take guide dogs arose in all sessions in the Republic, both urban and rural. Equality legislation has not changed this. Participants say that drivers now just say they are allergic to dogs, when queried.

- ◇ "Many taxi drivers still refuse to take guide dogs". ROIU4

Participants feel that the taxi driver should have to carry a medical cert to confirm this diagnosis. Mostly participants feel they are being discriminated against. Before legislation drivers would use the need to valet the car as an excuse.

- ◇ "The Taxi service often refuses me because of guide dog as he says he would have to valet the car and would cost 30 euro". ROIR3

Participants in all groups felt that taxi-drivers should be obliged to have disability awareness training.

5.4.7 Trains

Participants in the rural focus groups in Northern Ireland have no access to a train service and therefore no discussions about trains took place.

Focus group participants in the urban areas of Northern Ireland did not mention train usage. In both urban and rural focus group sessions in the

Republic of Ireland participants who had access to a train service stated that they found train staff generally helpful. Heuston Station in Dublin was singled out for special mention because of the helpfulness of staff. Difficulties cited by participants, for passengers with vision impairments, include getting stuck in automatic doors, falling from platforms, difficulty negotiating the gap between the train and the platform, and the occasional rudeness of staff. For example, when one totally blind participant asked for help at a train station the response she received indicated that she was not entitled to any help.

- ◇ “They said to me that since I was entitled to a companion pass I should use a companion instead of bothering transport staff”. ROIR19

Participants also stated that station announcements are not always made when travelling on trains. This is particularly the case toward the end of journeys when there are fewer people on the train.

5.4.8 Free travel pass

In the Republic of Ireland a person who is registered as blind is entitled to a free travel pass. In Northern Ireland a person who is registered as blind is entitled to a free travel pass while a person who is registered as partially sighted is eligible for a reduced fare, 50% of full price. This seems particularly unusual in that neither the blind or partially sighted person is eligible to hold a driving license, and both groups are dependent on the public transport system. Most participants in rural areas stated that they received little or no value from their free travel pass, as they could not use it. They stated that they were at a great disadvantage compared to their sighted peers whereby most sighted people in rural areas could at least drive to the bus or walk some distance on busy roads. People with vision impairments cannot do this.

Many proposals were made in relation to potential solutions to compensate for the lack of access and poor utilisation of public transportation. Practical

suggestions included the creation of a more flexible travel support system involving vouchers, grants, contracted taxis, and a volunteer driver network.

- ◇ "Since the pass is no good we should get access to a money grant for transport or an allowance". ROIR1
- ◇ "They should provide voluntary transport or maybe a driver system that got a grant". ROIR2
- ◇ "We should be able to use our pass for taxis". NIR5
- ◇ "What about a voucher or coupon system". NIR9

5.5 Peer support

In all of the focus groups the issue of peer support was raised. Those who were attending peer groups run by the voluntary sector found them invaluable and felt they would be lost without them. Participants felt that there was an acceptance and understanding among their blind and low vision peers that was impossible to get within the sighted community.

5.6 Miscellaneous

In the urban focus groups in the Republic of Ireland, participants with acquired sight loss commented that people who have been vision impaired from birth often expect the same of those who have only recently acquired their vision impairment. They also felt that there is a lack of information about services and rights. In both the urban and rural groups in the Republic of Ireland participants felt that the state was behind other countries as regards rights for people with disabilities.

"Ireland's behind as regards rights". ROIU 59

Chapter 6

6.0 Results: Section 3

Focus group with frontline professionals

This focus group session was organised to elicit the opinions of professionals working primarily and directly with people with vision impairment. It was anticipated that their opinions on current service provision, their perception of unmet need among their service users and their suggestions for change would be useful for informing this research and setting it within context.

6.1 Methodology

Fourteen professional staff from both jurisdictions were recruited to participate in a focus group as part of this study. For the purposes of this focus group the study chose to include as "front line professionals" those people whose primary role is the delivery of direct services on a day to day basis to people with serious sight loss. Clinicians and other medical professionals were not included as their primary focus is working with the general population. Frontline professionals include social workers, rehabilitation workers, community resource workers, assistive technology/information technology (AT/IT) trainers, service managers, etc.

6.1.1 Recruitment

Recruitment was conducted via personal contact made by the principal investigator (PI) with service centres in both jurisdictions in urban and rural areas. Information about the focus group was distributed, including an

invitation to participate and contact details for responses. Staff at all these service centres were already aware of the study, as participants with vision impairment for the main part of the study had been recruited via these centres. A mix of statutory and voluntary sector service centres were contacted. Participants came from a mix of organisations.

6.1.2 Participants

All of the participants were currently working in service provision to people with sight loss in Ireland, either within a statutory agency or within the not for profit sector. Nine came from the Republic of Ireland and five were from Northern Ireland. They served a mixture of urban and rural populations. Participants in this group included rehabilitation officers/orientation & mobility (O&M) officers (7), social workers (2, 1 dual qualified), community resource workers (8, 4 dual qualified), AT/IT trainers (2, both dual qualified), project co-ordinator (1), and area manager (1). Seven participants were dual qualified, i.e. a combination of community resource worker/social worker with a rehabilitation qualification or with an AT/IT training qualification. There were only two male participants in the group. This would reflect the fact that the overwhelming majority of staff in this field in both jurisdictions are female.

6.1.3 Logistics

The focus group took place in a hotel. The session was facilitated by the PI. A note taker was also present. The PI explained the purpose of the group and reaffirmed the consent of participants who were informed that all information received would be treated in the strictest confidence and maintained in a confidential manner. Participants were reassured that their identities would not be made known outside of the research team. Permission was obtained and granted for the recording of the session. Information about the background, purpose, and methodology of the research was given to the group. The aim and expectation for the focus group session in light of the ongoing research

project was clarified. It was anticipated that discussions during the session would determine participants opinions on service provision to the community of people with vision impairments in both Northern Ireland and the Republic of Ireland. The session lasted for two hours.

6.1.4 Analysis

Data gathered from the focus groups was transcribed into a Word document, entered into an Excel workbook and was then imported into SPSS Text Analysis for Surveys™ 2.0, a software programme used in the analysis of qualitative data. A textual analysis was undertaken for common words which were allocated to categories. The author then conducted a content analysis on the text and scanned it for common themes.

6.2 Results

The following themes emerged from the data:

6.2.1 Disability awareness

A great need exists for a disability awareness drive to highlight issues relating to people with sight loss, and inform the public and those who provide services to the public in both jurisdictions. A proper campaign needs to be orchestrated by the government in conjunction with the service providers. Such a campaign might also raise awareness among the public about ocular health in general and about services available in relation to sight loss. A parallel campaign should target medical and paramedical professionals working in primary and secondary care. According to participants, referrals of people with recent diagnosis of sight loss is still quite poor and many of the

primary and secondary care professionals are not sensitive to the needs of people with vision impairment.

Differences arose between participants from the two jurisdictions in relation to awareness about service provision. Participants from the Republic of Ireland felt very strongly that there needs to be a public awareness campaign highlighting the multiple services available for people with sight loss in the Republic. They also feel that RNIB in the North has a much higher profile. NCBI should place more focus on advocacy issues.

This topic generated a lot of discussion about the names of existing organisations. Strong feeling emerged about the using the term "blind" in the title name of the organisation. Participants felt that it could prejudice those with recently acquired sight loss against making contact with the organisation. This was felt to be especially important in Republic of Ireland where there was only one main service provider.

- ◇ "Having the term "blind" as in "National Council for the Blind of Ireland" is really off-putting for people thinking about coming to us". ROI4
- ◇ "If you've just been diagnosed with sight loss the last thing you want to hear is the word "blind". ROI7

6.2.2 Public awareness of vision impairment

The participants voiced concerns that many service users express concern about the apparent invisibility of their sight loss. This in turn generates worry about being perceived as fraudulent. Amputees, for example, may choose to use a wheelchair, making their disability apparent to all. Those with hearing loss may be seen to have a hearing aid etc. Even with profound sight loss of retinal origin the eye can look perfectly normal to the lay person. It was felt that an awareness campaign would help to alleviate such feelings from service

users as the public became more aware of the different dimensions of sight loss.

6.2.3 Transport

The lack of easily accessible transport was highlighted as being a particular difficulty in rural areas. Professionals from the Republic of Ireland said lack of transport is a major problem in the Republic of Ireland. While access to transport can pose a problem in certain rural areas of Northern Ireland, participants from this jurisdiction were not as vocal as their counterparts from the Republic of Ireland about the transport issue.

- ◇ "Some of my clients have to pay €50 for a one-way taxi trip just to visit the hospital". ROI2

This issues echoes the discussions within the focus groups held with people with vision impairment, where many of the participants, mostly from rural Republic of Ireland, but also some from urban areas complained about the cost of taxis to get to health services.

Republic of Ireland participants stated that lack of transport reduces access to services.

- ◇ "I know clients who just don't attend the medical appointments because they have no one to bring them". ROI8

The Health Boards in the Republic of Ireland have a scheme through which one can recoup the cost of a taxi ride for attending hospital appointments in special circumstances. However, little seems to be known about how the scheme works, and it seems that too much bureaucracy exists in the process of trying to recoup costs from the health board for most service users. Therefore, most don't bother to reclaim any costs.

6.2.4 Access to services

Republic of Ireland participants stated that there are some people who are registered with NCBI who have not yet seen a frontline worker. This is due a difficulty with the staff: service user ratio. This issue did not arise for participants from NI, where there are a number of different organisations serving the needs of people with sight loss. NCBI staff would be aware of all referrals, and therefore know whether someone has been seen by a frontline worker or not. Suggestions were made for stronger official linkages with Public Health Nurses (PHNs) in the Republic of Ireland, who have greater access to potential service users. Access to ophthalmologists is not as available as the professionals feel it should be in either jurisdiction but Republic of Ireland participants were more vocal about this topic and felt that access in the Republic of Ireland was quite limited. Professionals from both jurisdictions consider that responses from ophthalmologists in both jurisdictions are patchy and that waiting lists from first referral is too long. Not only is patient access to Ophthalmologists restricted but participants believed that ophthalmologists were quite slow to return the forms for registering their patient on the blind register.

There are waiting lists for rehabilitation training in all areas. However; participants thought that the waiting list for orientation and mobility training (O&M) was particularly long in the Dublin area. Participants commended the rehabilitation services available in both jurisdictions but stressed the need for more workers in this area.

6.2.5 Self referral

In the Republic of Ireland it appears that more and more people are self referring to NCBI as an alternative to paying for an optician. In light of this fact, the participants reason that it may be a good idea to set up a triage system to screen self referrals.

6.2.6 Home help service

Home help is very difficult to come by in Dublin. In other areas where it is available, it is generally considered very helpful. However, it is only available at a maximum of one hour per day Monday to Friday.

- ◇ "Sometimes the home help is the only person the service user gets to see on any regular basis. This can leave them feeling very lonely". NI3

There are also trust issues for people with vision impairment about having home help in the house.

- ◇ "Particularly in the beginning, as they cannot see what they (the home help) are doing. This can make them feel very vulnerable". ROI5

6.2.7 Personal assistants (PA's)

The issues of home help led to a short discussion on the need for personal assistants. These are apparently available in the Republic of Ireland but only for those aged under 65, and the provision of PA's is linked to the ability to access employment.

- ◇ "Sometimes people with vision impairment are provided with a home help when what they really need is a personal assistant". ROI3
- ◇ "Many PA's are provided to people under 65 who are not employed nor have any intention of going to work" ROI1

From the discussions it was clear that participants felt that the provision of a personal assistant to older people with vision impairment would improve their independence, their access to services and thereby improve the quality of their lives.

6.2.8 Peer support

All professionals felt that more interaction between services users should be facilitated, as peer support is invaluable in many ways. In attending peer support groups, people with vision impairment realise that they are not alone and can share and exchange experiences.

6.2.9 Rural urban divide

Professionals from Republic of Ireland believe that there are more services available for people with vision impairment in Dublin. This contributes to an urban-rural divide. The main service provided directly in the rural areas of the Republic of Ireland is that of the Community Resource Worker. The Community Resource Worker is usually the first point of contact and the key worker for the service user. Their role includes assessment, emotional support, advice on entitlements and benefits and sourcing or signposting to other services. Other services are provided either on a regional basis or are only available through the Head Office of NCBI, in Dublin. Services available on a regional basis include Rehabilitation services and AT/IT training. Most regions, but not all, have access to a central resource centre where aids and appliances are on display and where low vision clinics take place on a monthly basis. From time to time, peer support groups and other one off events such as short training courses may be organised. However, major service provision such as family therapy, rehabilitation training courses, Iona day centre, early learning services etc. are only available through Dublin. The NCBI Iona day centre has a very good programme for older people, which is very popular. As rural Ireland is not well served by public transport, this accentuates the divide with urban areas. The urban rural divide did not surface at all to the same extent between participants from Northern Ireland.

6.2.10 Northern Ireland vs. Republic of Ireland

In Northern Ireland, participants stated that although there are a number of different service providers, service provision is, in the main, complementary. A short discussion ensued about the differences between service provision strategies in both jurisdictions, i.e. "NCBI is a one stop shop" and that this might be better for service users. In Northern Ireland sometimes service users have to deal with a whole gamut of professionals from different agencies, based in different places "who often never speak to or see each other". The fact that in NCBI each service user has a named frontline worker who "keeps tabs on the services being offered and received" was thought of as a useful system within the group.

"The system in Northern Ireland can cause confusion as to where a person has been referred from." NI4

6.2.11 Staff

Staff shortages were vocalised by participants from both groups.

- ◇ "Not enough front line staff to cover the service requirements". NI5
- ◇ "More staff is needed and perhaps different levels or grades". NI3
- ◇ "More emphasis should be placed on partnership with other organisations and agencies to spread the workload". ROI 5

Participants from NI felt that more should be done to prevent the duplication of service provision. Staff from both jurisdictions stated that more administrative support should be provided to help with the paperwork that needs completion.

- ◇ "As time goes on we have more and more paperwork to complete" ROI4
- ◇ "This would free us for more hands on service delivery". NI1
- ◇ "A personal laptop would be very useful" ROI2

6.2.12 Aids and appliances

There was consensus within the group that much more funding is needed for aids and assistive technology. IT and AT provision should be regularly reviewed as without follow up participants believed that sometimes the equipment does not get used.

- ◇ "Some people just get the equipment for the sake of it". ROI4.

Participants from Republic of Ireland felt very strongly about the availability of free equipment.

- ◇ "Giving out free AT or IT to people with vision impairment is not a good idea". ROI2
- ◇ "If there was at least a nominal charge even 10%, it might mean it would be valued more". ROI8
- ◇ "Vision impaired people are the only ones to receive completely free IT". ROI3

Participants generally agreed that training in the use of equipment is vital and must be improved in order to improve use. Participants are certain that the level of use of IT & AT will continue to increase for people over 65.

6.2.13 Low vision clinics (LVC's)

There was much praise and admiration for the services provided by the LVC's in both areas. In Northern Ireland low vision clinics are attached to the Optometry and Ophthalmology departments of hospitals. In recent years more and more outreach clinics are being provided in Northern Ireland on a regular basis, which means less travel for people. In the Republic of Ireland until quite recently all referrals to the low vision clinic were seen at NCBI headquarters in Dublin, with the occasional clinic facilitated in rural areas. These outreach clinics were not guaranteed. There was only one optometrist funded through

NCBI to provide the low vision service. This is in the process of change and more and more monthly clinics are happening on a regional basis.

In both areas referrals from High Street optometrists have become more frequent and this is increasing uptake.

A discussion then took place between participants on the availability and provision of low tech equipment such as magnifiers and talking watches etc.

- ◇ "Magnifiers are given out free at LVC's to medical card holders". ROI7
- ◇ "Watches and liquid level indicators are given free in the north". NI2

Other aids and appliances are paid for by the individual as required.

- ◇ "If someone says they cannot afford it, and then it will be funded". NI1,

According to participants from NI, it is the rehabilitation worker from this jurisdiction who applies for funding for aids and appliances. Concern was voiced by participants from Republic of Ireland about lack of funding for aids and appliances in the Republic of Ireland.

- ◇ "Community Resource Workers can feel bad about showing low tech aids which service users cannot afford, or which may not be appropriate". ROI3
- ◇ "Community Resource Workers do not want to be a travelling salesman". (sic) ROI2

6.2.14 Overall service provision

Participants from Republic of Ireland stated that services there are tailored to the individual. Some concern was voiced by participants that services produced can be low quality, for example when counselling is needed and not available, the emotional support provided by the Community Resource Worker can appear close to the line between emotional support and counselling, but Community Resource Workers are not trained in counselling skills. Participants

feel that there should be more professional counsellors available in all areas in both jurisdictions. In the Republic of Ireland, a family therapy service is available but this is Dublin based. There were strong feelings that this service should be available on a nationwide basis. There is no specialised counselling service available outside Dublin.

Some participants felt that more specialisation is needed in some areas. This topic generated a heated discussion among the group. There was some disagreement on this topic across all participants from both jurisdictions.

- ◇ "A Generalist is more comfortable for service users". ROI6
- ◇ "Often they (service users) prefer to have one contact person". NI4
- ◇ "Service users can distract one person with other concerns when doing mobility". ROI8
- ◇ "O&M is a good example. Community Resource Worker's should do O&M only to gain experience". ROI5
- ◇ "Full time O&M workers are a good idea". ROI2
- ◇ "Needs professional training". ROI3

The last comment above led to a discussion about the training needs of front line staff. The background training of staff was found to be very varied, particularly in the Republic of Ireland. There was consensus that training in the area of bereavement counselling was essential for all front line staff.

- ◇ "One area that is absent in our training and service delivery is that of bereavement counselling re sight loss". ROI4
- ◇ "Service Users can still feel grief after many months". NI2

This generated discussion about ophthalmologists' manner with patients. Some ophthalmologists in both jurisdictions seemed to be unaware of the effect of their diagnosis on patients. Often they seemed indifferent to the feelings of their patients.

- ◇ "Ophthalmologists should be trained in how to inform people that they will go blind". ROI6

Further to these discussions, the issue of standards in service delivery arose. Participants from both jurisdictions commented that the standards varied from place to place and depended on what staff were employed. The discrepancy in standards was related to staff levels and not the quality of the staff employed. In some areas there was no rehabilitation officer employed, while in others the ratio of service users to staff was too high.

- ◇ "There is an element of post code lottery about service availability" (NI4)

6.2.15 Changes needed

Participants were then asked what changes they would make if they had access to unlimited funds. In general there was much agreement on the suggestions generated here. The first area that they would change was staffing levels, with a reduction in the distance workers needed to travel, and the ratio of staff to service users. Some participants from the Republic of Ireland said that they would change their job description. Participants from both areas felt that the value for money concept could jeopardise service delivery"

- ◇ "The business model can be taken too far". ROI7

Participants felt that a standardised strategic plan might alleviate the postcode lottery effect. All participants from both jurisdictions would welcome more staff consultation. However, this was on the proviso that the consultation would generate a response, and that change would be implemented where necessary. In particular, participants believed that much more communication is necessary both within and between organisations and both within and between jurisdictions. More staff consultation should take place particularly in relation to policy development.

- ◇ "Really we should be the first to know". ROI6

Staff consultation forums should be solutions focussed.

- ◇ "Otherwise they could turn into negative sessions where nothing is achieved". ROI 7

Participants from Northern Ireland stated that services should become more centred on the service user rather than being driven by the service providers.

- ◇ "We really need to focus our service development more on those who use our services". NI3

Participants from Northern Ireland also believed that there needed to be more action and awareness of the various service providers in the field of vision impairment in Northern Ireland. As far as they are concerned GDBA (Guide Dogs for the Blind Association) has the highest profile.

- ◇ "Perhaps because puppies are cute and attract attention" NI4

The interaction of different services is necessary and contacts between the various agencies should be promoted more.

- ◇ "This might prevent the duplication of services and save money in the long run". ROI8
- ◇ "Staff in NHS is not consulted too often". NI4
- ◇ "BCNI (Blind Centre of Northern Ireland) are good at consulting". NI2

This topic generated discussion about whether such consultation can promote change. Participants were in agreement that recommendations that come from the "ground up" must be listened to. It was generally felt that the lack of consultation with staff had affected service users. A forum for service users should also be provided. It was recognised that attempts to do this had been made in both jurisdictions but participants were unsure whether or not the consultation was genuine.

- ◇ "Was it a PR exercise?" ROI4

Another issue that participants considered important was the lack of peer support. This was felt especially strongly by the participants serving rural areas of the Republic of Ireland. It was believed that peer support could only benefit the service provision. More training courses should be available and participants in both jurisdictions thought that there needed to be more emphasis on professional development of staff on an ongoing basis.

6.2.16 Joint meetings of staff

The exchange of experience and expertise by meeting other professionals in the same field was very important. There should be more cross border meetings of staff serving the needs of people with vision impairment. The recent VICBAT training programme was singled out as a good example. (VICBAT was a cross border EU Intereg funded project managed by NCBI, which provided specialised training to professional staff working in the field of vision impairment from both the Republic of Ireland and Northern Ireland.)

- ◇ "There should be more training like that". ROI3
- ◇ "Some of us had never met our counterparts from the Republic before". NI2

6.2.17 Older service users

Many older service users can be very lonely. Participants stated that there is a paucity of services for this group in rural Republic of Ireland. Again, the Iona Centre in Dublin was singled out for mention as having a very good programme for older people in Dublin.

- ◇ "There are more services available overall in Dublin". ROI2

It was suggested that there should be a pilot programme to test the idea of a "Social PA", that is someone, a personal assistant, to help services users get out and about.

- ◇ "Look at the Cheshire Homes for an example". ROI5

A discussion followed about job descriptions and tasks associated with jobs. Many participants stated that they would like to lose the social activities associated with their job.

- ◇ "For example lose making tea and we could concentrate on more important tasks". ROI2

Many felt it would be useful to have an auxiliary staff member for tasks like that. This would be especially helpful when bringing people to centre based services and the staff member could get on with their own job. It was also commented in general that it can be difficult getting people to participate in activities. Participants from Dublin responded that they have difficulty getting people placed as there is a long waiting list for the Iona Centre in Dublin.

- ◇ "The Iona centre is known for its good service". ROI6
- ◇ "The Iona Centre has a good name among service users because Community Resource Workers publicise it". ROI4
- ◇ "Social skills deteriorate because of lack of confidence due to vision impairment". NI5
- ◇ "Service users do not like the 'day centre' label, example, prefer "active retirement club". ROI3

6.3.17 What is good about their role?

Participants were in general agreement that being an advocate for service users was a very worthwhile role. Visits to the homes of service users are also very important.

- ◇ "You get to see the true abilities of the person". ROI1
- ◇ "You can judge much better what is needed by the person". NI3
- ◇ "Starting to work as a disability advocate". (ROI16)

More staff are needed according to the group participants. The first step is to recruit extra staff, particularly Community Resource Workers (ROI), and Rehabilitation Officers (NI). It was suggested that different levels of Community Resource Workers were needed, ranging from junior auxiliaries to senior workers. More partnership working is needed with other agencies. Extra funding is needed for aids and assistive technology and the whole service and provision of aids, appliances and IT should undergo regular review.

- ◇ "If something increases the independence of a service user then it should be provided". (ROI3)

Participants were concerned about the lack of free IT for over 65's. Professionals feel that as this age cohort is growing, the whole area of IT provision for people with vision impairment in the age group will increase. Service providers and funders need to be aware and prepare for this fact.

- ◇ "Many of those under 65 are not in employment and still get it". ROI4
- ◇ "IT will increase in use by older people". ROI2

Overall providing rehabilitation and giving service users the skills to get over barriers is considered as an important and worthwhile part of the role of the professionals working in the frontline with people with vision impairment. Participants believe that there is a lot more that is needed to be done. The current system is not without flaws.

Chapter 7

7.0 Discussion

This study sought to compare the quality of life (QOL) of urban and rural dwelling people with vision impairment from the Republic of Ireland and Northern Ireland and to explore the demographic and functional factors that may influence the QOL. The null hypothesis was that urban and rural dwelling would have no influence on the QOL of older people with vision impairment.

Through conducting 222 in-depth individual interviews, 14 focus groups with 121 people with vision impairment, and one focus group with the frontline professionals who work with this population, a wealth of both quantitative and qualitative information has been collated on the issues of importance to the population under study. Very little information exists on this population here in Ireland in either jurisdiction.

The results of this research highlight a number of issues that need to be addressed by service providers. These findings also demonstrate the value of recording qualitative comments when administering QOL instruments for research purposes, in order to gain a fuller picture of the person's abilities and coping strategies, which may influence the results. Discussions in the focus groups concurred with the results from the individual interviews, particularly in the areas of transport and mobility. These two topics seem to be very important issues for this group.

The issues of importance to people with vision impairment in this study reflect the literature on similar issues concerning this population from other countries (Lamoureux, Hassell & Keefe, 2004; Kenyon et al 2003; Priestley & Rabiee, 2002; Hanson et al., 2001; Baker & Winyard, 1998). The primary issues for the population in this study were mobility, transport and public knowledge of and attitudes to vision impairment.

7.1 Overview

The study recruited 107 participants from Northern Ireland and 115 from the Republic of Ireland, urban (n=111) and rural (n=111) populations. The urban rural population breakdowns was as follows: Northern Ireland urban 55 (NIU); rural 52 (NIR); Republic of Ireland urban n=59 (ROIU). rural (n=56 (ROIR). The gender breakdown was 72% (n=160) females and 28% (n=62) males. The higher percentage of females may not only be related to the mean age of the population at 76.5 ± 8.6 SD but it may also reflect the anecdotal belief that that females are more likely to participate in such research. However this belief has not been substantiated in the literature. The majority of respondents, 40.4%, were in the 80 to 89 age band. The Hinds study in the UK had a similar female: male ratio with 69% females and 31% males (Hinds et al., 2003). The majority of respondents in this study also reported a high number of co-morbidities, 76.6 % (n=170). Over half of the respondents lived alone, 55%. An RNIB study in 2002 found that over 50% of people with vision impairment were living alone (Association of Directors of Social Services, 2002). In the Hinds et al. study, 54% of their participants were living alone (2003). Self-report of vision loss was 32.4% blind (n=72) and 67.5% partially sighted (n= 150). There was no statistically significant difference between individuals from the four geographic areas in terms of self-reported sight loss. The self description of blindness and partial sight reflected the vision function measurements achieved. The majority of respondents, 76.6 %, said they had at least one additional illness or disability (n=170). The literature has shown that people with vision impairment often have high levels of co-morbidities (Crews & Campbell, 2004).

7.2 Eye conditions

Eye conditions reflected those expected in the developed world. The principal cause of vision impairment as reported by respondents was Age related Macular Degeneration (AMD), 38.3% (n=85) followed by Glaucoma, 8.5% (n=19), Retinitis Pigmentosa (RP), 5.9% (n=13), Diabetic Retinopathy, 5.9% (n=13), Cataract, 5.0% (n=11) and Other including unknown 28.4% (n=64). This is in keeping with Kelliher's study which found that main causes of blindness on the Irish register in 2003 were Age related Macular Degeneration 25%, Glaucoma 12%, Retinitis Pigmentosa 7%, and Diabetic Retinopathy, 4.7%.

7.2.1 Age related macular degeneration (AMD)

In Munier et al.'s study of Irish blind registration, 16% of registrations were due to AMD (Munier et al 1998). Kelliher et al's findings of AMD at 25% in a more recent study marked a 113% increase in registrations due to AMD over a 7 year period (2006). Canavan et al found that AMD was the leading cause of blindness in Northern Ireland and that it had risen steadily over the previous 12 years (1997). In the UK, Evans et al's study showed that AMD was the main cause of vision loss in subjects at 36% of their population. In the international literature, AMD is also highlighted as the leading cause of blindness. Predictions are that it will grow exponentially in the ageing population with 25% of those in their 90's losing their sight as a result of AMD (van Newkirk et al., 2000). The Beaver Dam study has shown similar findings with a huge increase in AMD in those aged 74+ when compared with the younger cohort in this study (Klein et al., 1997). Age Related Maculopathy (ARM), a precursor to AMD was present in 36% of the study population aged 65+ in the EUREYE study (Augood et al 2004). The rise in AMD is a cause for concern amongst healthcare providers.

7.2.2 Glaucoma

Coffey's study in the West of Ireland found that for every one person blind due to glaucoma, four had low vision (Coffey et al., 1993). Coffey et al. also identified a prevalence of primary open angle glaucoma which increased from 0.72% in those age 50 to 59 to 3.05% in those aged over 80 (1993). The Blue Mountains study cited a prevalence rate of 3% in the adult population (Mitchell et al., 1996). The Beaver Dam study identified a similar prevalence rate of 2.1% in the adult population (45+) rising from 0.9% in the younger cohort (43 to 54 years) to 4.7% in the population aged over 75 years (Klein et al., 1992). Glaucoma numbers on the Irish register have not changed significantly over the years (Kelliher et al., 2006).

7.2.3 Diabetic eye disease

Diabetic eye disease is on the rise (Kohner, 2008). Figures from the UK show that diabetic eye disease accounted for 3.4% of those with vision loss aged over 75 years (Evans et al. 2004). Registration as blind or partially sighted as a result of diabetic eye disease has increased dramatically in recent years in the UK, where figures have doubled (Bunce 2006). In the Republic of Ireland the numbers on the blind register as a result of diabetic eye disease increased by 120% in the seven year period between Munier et al.'s study, which examined the 1996 registration figures and Kelliher's study on the 2003 registration figures (Munier et al., 1998; Kelliher et al., 2006). Vision loss as a result of diabetic retinopathy occurred in 5.9% of the respondents in this study. The Melbourne study showed a prevalence rate of 0.8% for diabetic disease related sight loss in those aged over 80 years (Weih et al., 2000).

7.2.4 Retinitis Pigmentosa (RP)

Retinitis Pigmentosa accounts as the third leading cause of blindness on the Irish blind register, with those registered due to this disease making up 7% of the total figures (Kelliher et al., 2006). Prevalence of RP varies from about 0.02% in the USA (Bunker et al., 1984) to approximately 0.03% in the UK (Bundley & Crews et al., 1984). In this study, 5.9% of participants had RP.

Uncorrected Refractive Error (URE) has been found to be a leading cause of bilateral vision impairment in a number of studies (Weih et al., 2000; Evans et al., 2000). As this study was dealing with people registered or registrable as blind or partially sighted, who had already had some contact with eye care services, uncorrected refractive error was not likely to be the main cause of vision impairment.

7.3 QOL & Urban & rural

There is an absence of literature on the influence of urban and rural dwelling on the QOL of people with vision impairment in the developed world. While urbanisation is increasing in both jurisdictions, the Republic of Ireland and Northern Ireland still have significant rural populations and are less urbanised than their European neighbours (NISRA, 2007; CSO, 2006; Leeson, 2002).

7.4 Generic HRQOL

Results from this study show that generic HRQOL scores are better in the Republic of Ireland than in Northern Ireland. NIU scored lowest on all eight domains of the SF36. ROIU scored highest on six of the SF36 domains. ROIR scored highest on the role emotional domain while NIR scored highest on the mental health domain. In fact, a dichotomy occurs on the mental health domain showing a very definite urban-rural divide with the rural cohort in both

jurisdictions scoring higher than their urban counterparts in the area of mental health, which is statistically significant. A study by Scott et al. investigating QOL, vision impairment and the effect of low vision services, used the SF36 as a generic measure of HRQOL before and after intervention. Scores on the SF36 did not change significantly between administrations in Scott's study however, the scores on the vision specific QOL instrument showed improvement after the intervention (Scott et al., 1999).

Urban and rural residence did not appear to influence QOL in this study when comparisons were made between the four cohorts, as QOL was highest in urban Republic of Ireland in six domains and lowest in urban Northern Ireland in all domains. Mental health was the only different domain here where the contrast is urban dwellers versus rural dwellers with rural residents getting higher scores than their urban counterparts in the area of mental health. There was however a North-South divide in 6 out of the 7 domains, which can be seen from the figures in table 32 below. In almost every case this is a Northern Ireland versus Republic of Ireland contrast. Scores for Northern Irish residents are lower than those of Republic of Ireland dwellers. Mental health may be the only different domain here where the contrast is urban dwellers versus rural dwellers with rural residents getting higher scores than their urban counterparts in the area of mental health.

QOL Results: Mean scores by domain	ROIR	ROIU	NIR	NIU	Total	Sig
SF36 Physical functioning (PF)	42.5	53.1	37.5	37.1	42.7	.009**
SF36 Role Physical (RP)	61.8	72.8	49.8	45.1	57.6	.001***
SF36 Role Emotional (RE)	81.9	78.6	68.1	61.4	72.7	.005**
Social Functioning (SF)	70.8	85	67.1	61.1	71.1	.001***
Pain (P)	64.2	74.7	52.8	45.2	59.5	.000***
SF36 Mental health (MH)	69.9	62.7	70.5	60.2	65.8	.017**
General Health (GH)	56.6	73.2	61.3	55	61.5	.000***

Table 33 SF36 QOL results - significant domains ** p<0.05 * p<0.001**

When regressed to explore the impact of other factors on the QOL scores none were significant. ROIU is a little less disabled but again not statistically significant. Having an additional disability has an influence on QOL scores. Living alone has no influence. QOL scores adjusted for vision and fear of falling still had no influence on SF36 scores. There was no significant difference between vision impairment and locations.

The SF36 scores in this study were compared with age and gender weighted norms for this age group in a community dwelling UK population (Walters et al., 2001). Four of our SF36 domains (PF, MH, BP & EV) were on a par with SF36 age and gender weighted UK norms. Four of the domains (RP, RE, SF, & GH) exceeded the norms for this population. While the Physical Functioning (PF) and Mental Health (MH) scores were slightly below the normative values, it appears that the population in this study were generally more optimistic as per their SF36 scores when compared with the age and gender weighted UK norms, suggesting that vision impairment is not negatively affecting the health related quality of life of this population.

Why should this be the case? It is possible that the majority of people interviewed for this research have adjusted to their vision impairment and now see it as a normal part of their lives. The average duration of sight loss in this sample was 24.5 years. The sample was not recruited from those who were newly diagnosed with eye disease. Neither was the study recruiting people from a hospital or medical setting. The research was thus not being conducted on patients, i.e. people who were attending for medical treatment, which in turn may allow them view themselves as sick people. Rather, the sample was of people selected from within the community who have sight loss. While it is obvious that vision impairment is impacting on the lives of this group in many negative ways, it does not appear to be impacting on their HRQOL.

The one critical factor may be that these individuals had to a large extent undergone response shift. Response shift is the name given to phenomenon whereby an individual and their circumstances change over time. A change in

their internal standards and in their values can lead to a change in their self evaluation (Sprangers & Schwartz et al 1999). QOL measures have been designed in the expectation that respondents will answer consistently on a scale and that these scores are directly comparable over individuals and over time (Ring et al 2005). However with response shift an individual's response may change because of the way they may have adapted to the change in their life or their environment. One could speculate that as the data collection period took place during 2005, 2006 and early 2007 changing environmental and political factors may have had a bearing on outcome. During this period, the economy in the Republic of Ireland was booming. As a result of the "Celtic Tiger" the Irish government had a number of very generous budgets, which favoured the older person. Pension payments increased significantly, the medical card scheme, which is normally means tested, whereby those on very low incomes can avail of free public health services, was awarded to all people aged 70 and older irrespective of their income. At the same time in Northern Ireland although the Peace Process was almost complete, the economy was not as vibrant, there was no assembly sitting, and the two main parties were not speaking to each other. This may have been creating uncertainty for the future, which may be reflected in our QOL results.

It is also possible that respondents in Northern Ireland have higher expectations of service delivery due to the fact that it is a statutory service provision whereas service provision in the Republic of Ireland is still through the voluntary sector. Perhaps respondents in the Republic of Ireland feel that there is a sort of benevolence in the service provision as it is coming from a charitable source and therefore have lower expectations and greater appreciation. In the open ended comments it was BCNI (voluntary sector in Northern Ireland) & NCBI that were singled out for mention.

7.5 Vision specific QOL

There has been much discussion in the literature on the issue of self-reported impairment and its relationship to visual function with a number of studies stating that it is more accurate than clinical measurement alone (Stevenson et al., 2004; Massof & Rubin, 2001; McClure et al., 2000; Hart et al., 1999). There were very little differences between the cohorts in the vision specific QOL DLTV Domain 1 scores. DLTV Domain 1 tasks are those tasks that generally require better vision, e.g. reading, recognising faces, than the tasks in the other domains. The two urban cohorts scored slightly higher than their rural counterparts while the NIR cohort scored the lowest but this did not achieve statistical significance. In the DLTV Domain 2 scores ROIR scored a little higher than the other three cohorts but this was not statistically significant. DLTV Domain 2 tasks include tasks that one may learn to do despite vision loss, e.g. pouring a drink, cutting up food on a plate, using kitchen appliances. DLTV scores were consistent with level of vision. There was no significant difference between vision impairment and locations. DLTV scores adjusted for eyesight and age still showed no significant difference in the four cohorts.

Massof et al. found that respondents with vision loss tended to undervalue tasks that were more difficult for them to do (2005a & 2005b). In this current study respondents often said certain activities caused them no difficulty. However this belied the fact that they had great difficulty initially. The answers to the closed questions, no matter how they were reconstructed, or how many different ways they were asked, would not tell the complete story or give a true understanding of why an answer was selected. For example, if we take the question on how much difficulty the respondent has in pouring a drink, quite a number of respondents stated that they had no difficulty. However, many qualified their score by adding that this was after much practice and adaptation to their new situation. Many stated that they have no difficulty pouring a drink because they "now only pour a drink over the sink where it doesn't matter if it spills". This information adds to the single response of the

question and fills in the picture. Without this additional information, one could assume that pouring a drink is just not a difficulty. Others stated that it now caused no difficulty because they had a liquid level indicator, while others said they had no difficulty because they no longer did a task. Therefore, in reality this qualitative part of this research project is broadening the picture and therefore our understanding of why we may get the answers we do to our quantitative questions (Dereshiwsky, 1999). It is the author's belief that such responses are more valuable than knowing only that the respondents have no difficulty. For example from the answers received here service providers can take note of this response and adapt their service delivery programmes where necessary to take into account a method of reducing the difficulty of various activities of daily living for their service users. The same can be said for access to transport, dependency on family or friends for various activities.

7.6 Rehabilitation

Those with acquired vision loss will take time to adjust and adapt to their new situation. There may be initial reluctance to accept assistance or rehabilitation. Some older people may just see their vision loss as an inevitable part of the ageing process; others may try to conceal the loss due to feelings of vulnerability. Therefore, they may not seek help or support (Thompson, 1989).

In acquiring vision loss and the resulting disability, one's relationship with the world and immediate environment is changed. Adaptation needs to take place and the timing of this adaptation will vary from person to person. However, service providers should be ready at the earliest appropriate opportunity to introduce the various adaptive techniques and technologies that will allow the person to function to their maximum ability in the new relationship with their environment. Loss of vision is associated with decreased self confidence (Tolman et al., 2005). The ultimate aim of such intervention will be to increase confidence and facilitate confident and safe travel outside the home. Such

training should be adapted to the individual's requirements and may include a range of training from making the best use of residual vision to developing techniques such as using hearing to augment knowledge of surroundings, to full long cane training, which enables a person to use a long cane to travel independently. A comprehensive vision rehabilitation programme has been shown to be beneficial to people with vision impairment and improve self reported QOL (Kuyk et al., 2008).

7.7 Mobility

Environmental design can play a large role in social exclusion (Percival & Hanson, 2007). Mobility training can teach people how to negotiate their way through their environment. There is no doubt that people with vision impairment benefit from rehabilitation intervention. Mobility training has been found to improve the self reported mobility of people with vision impairment (Kuyk et al., 2004). A recent study from the USA (Stelmack et al 2008) found that providing a low vision therapy programme, which included: domiciliary training and environmental adaptation; the provision of low vision aids; follow up support and training in making the best use of residual vision; and counseling, significantly improved the functional vision of people with macular disease. Due to the reduction in functional ability over time of the wait-listed control group, the investigators in the study recommended that low vision rehabilitation services should be offered as early as possible after visual impairment is diagnosed (Stelmack et al., 2008). Research in the UK showed reduced social activities for people with vision impairment (Bruce et al., 1991, Horowitz et al., 2005b).

Mobility training helps participants to develop techniques to avoid environmental hazards such as obstacles. Those who undergo mobility training will be able to travel outside with greater safety and independence. Providing such training could help reduce the incidence of social isolation. Vision loss

and its impact on the daily functioning of the individual have been linked to depression (Horowitz et al., 2005a). However, vision rehabilitation has been shown to have a positive effect on adaptation and adjustment to vision loss in those with age related ocular pathologies (Horowitz et al., 2006).

7.8 Aids and appliance

Although QOL instruments fail to go deep enough to highlight the specifics about what makes a difference to QOL, the literature has shown that QOL of people with vision impairment can be improved by the provision of low vision aids and appliances (Hinds et al., 2003; Scott et al 1999). The provision of low vision aids and follow up support has been recognised as increasing the independence of people with vision impairment (Vale and Smyth, 2002). Low vision aids, in particular magnifiers, were highly valued in our sample as evidenced via the many comments about them and how they impact on respondents' lives. Some studies have shown that a high percentage of those attending low vision clinics regularly use their low vision aids (Lindsay et al. 2004; Leat et al., 1994).

There are many low vision appliances that can be used to increase the independence of people with vision impairment including: large button phones; liquid level indicators; signature guides, talking watches, talking microwaves and talking weighing scales, just to name a few. Some of these devices are ordinary everyday pieces of equipment which have been adapted for someone with low vision without too much cost while others such as the talking devices are a little more expensive.

Minor low cost alterations can be made to the home environment, which will improve the ability of the person with vision impairment to function in the home (Lin et al., 2005). Such modifications could include improving the

lighting conditions within the home by a combination of task lighting and enhanced ambient lighting, together with a reduction of the incidence of glare. Providing good contrast within the home, for example, dark plates on a light surface; wall paint which contrasts with light switches, sockets, and door surrounds; or something as simple as ensuring that the colours of towels in the bathroom are in strong contrast with the walls, mats are non-slip and well fixed, etc., can all make life easier for the person with low vision. Having a professional in the field of vision rehabilitation visit a home in with a view to assessing and modifying the environment can result in a reduction in falls (La Grow et al., 2006)

7.9 Falls

Several studies have found that various visual functions are associated with the risk of falling (Freeman, 2007; Ivers et al., 1998; Nevitt, 1989). Age is also associated with falling (Vu et al 2005). People with vision loss are further handicapped by the external environment (La Grow et al., 2006). This difficulty was voiced strongly by respondents in this study who have a fear of the hazards that they are likely to encounter if they ventured out and about. Falls are caused by intrinsic (e.g. medical problems) and extrinsic (environmental hazards). For people with vision impairment the risk of falling due to extrinsic factors is increased (Tideiksaar, 1997). Falls are a frequent event in older adults (Tinetti et al., 1994). Visual field loss (Freeman et al., 2007) & contrast sensitivity (de Boer et al., 2004) have both been associated with increased risk of falling. Freemans' study also highlighted history of falling as an increased risk factor (2007).

7.9.1 Fear of falling

Fear of falling is associated with increased risk of falling (Freeman, 2007; Cumming et al., 2000). People with vision impairment can have a heightened fear of falling and therefore impose restrictions on themselves which leave them socially isolated (Crews & Campbell, 2001). Fear of falling featured as an issue for 73% of the respondents in this study with 18% of respondents stating that they were so afraid of falling that they would not leave home. This is in line with other studies that cite falling and fear of falling as important issues for older people. (Lawrence et al., 1998; Howland et al 1993). As well as the psychological implication of the social isolation, being confined to home can reduce the potential for exercise, which in itself can have a negative effect on physical health. Over half of the participants in a study on people with vision loss in Northern Ireland said that they were concerned that they did not get enough exercise (Caul, 2003).

7.10 Transport

The adequate provision of an integrated accessible public transport service is one of the significant services that impact on the quality of life for people with reduced mobility and sensory impairments.”

National Disability Authority, 2004

Access to transport has been recognised as a major issue for older people with disabilities. Almost 50% had no access to a car, and a greater number, two thirds are unable to access public transport (McDaid, 2006). Transport has proven problematic for people with vision impairment (Vale and Smyth, 2002). This paves the way for social isolation. As is shown in this study access to transport is a major issue, for all cohorts, but access to transport is nonexistent for many rural dwellers. This is reflected in the literature, which indicates that residents of rural areas are likely to be both geographically and economically isolated and disadvantaged. (Robson et al., 1996)

Government policy in Ireland is controversially focusing on developing a small number of centres of excellence in the various health specialties, starting with cancer treatment. This will result in a number of large tertiary centres. As a result, rural residents will have increased distance and travel time to access the specialised healthcare available. For people unable to drive and with no access to public transport this new healthcare approach will add to the stress of dealing with their healthcare issues.

7.11 Awareness

From this research one can deduce that it is often the respondents own fear of how they assume the public expects them to behave as a blind person that is a limiting factor on their social engagement. This reflects the literature about lack of awareness about people with disability (Hurree & Aro, 2000). The negativity surrounding the labelling of oneself as blind or partially sighted can also affect respondents' self perception (Dodds, 1991). The invisibility that is associated with many ocular pathologies means that the individual must draw attention to themselves and their difficulties in order to get support. Feelings of vulnerability or fear of discrimination may prohibit the individual from seeking assistance (Percival and Hanson, 2007). The strength of feeling about the necessity for an awareness raising campaign about sight loss was high. In particular, respondents expressed strong opinions about the necessity to expand the understanding amongst the public, both the general public and those in public service provision, about the fact that the majority of legally blind people have some retention of residual vision. Respondents believed that if there was some understanding among the public about sight loss and the various ways people see as a result of their sight loss, it would help as a confidence building exercise. Many respondents had themselves acquired their vision loss and therefore were fully aware of their own knowledge of "blindness" prior to their loss. Most of them thought sight loss was complete darkness. As one participant stated, "How can you expect the public to

understand that I can't see to tell what bus is coming but yet I can read the small print on a newspaper while on the bus. Sure, I couldn't believe that myself if it wasn't me!"

7.12 Recruitment difficulties

Recent research looking at reasons for refusal to participate in research has shown that many of those approached simply refuse due to lack of understanding and confusion. A study followed people who had refused to take part in a study to obtain their reasons for their original refusal. For the vast majority of people it was not due to an objection to participating in research but was more related to confusion and misunderstanding about the process or what was expected from them. Just 28% of those who refused initially said they were not interested in research (Williams et al., 2007). Considering the issues raised during the recruitment of participants to this study, the author suggests that there needs to be a rethink about the best approach to recruitment of respondents for similar research to increase the numbers of people with vision impairment participating in research, particularly when recruiting from the community as opposed to the clinical setting. With due regard for the requirements necessary to meet ethical guidelines perhaps a different approach to informed consent should be considered in the case of those with difficulties accessing the written word.

In light of the difficulties this study encountered with recruitment it is important that those responsible for ethical approval give extra consideration to the difficulties posed for the researcher when recruiting people who have difficulty with the written word such as people with sight loss or people with literacy difficulties.

When selecting people with severe sight loss on a random basis from a register that can include people with a variety of eye diseases, with visual acuities ranging from 6/6 (ability to read N5) with very restricted fields, to no

perception of light, they will use assorted methods to access the written word. Such methods will vary from clearly laid out, standard print on high contrast background, to large print, to Braille. Others may use an electronic format to read using a computer, or cassette audio tape or CD. Those providing print information to people with sight loss must take account of the fact that large print in itself may be of no use to many of these potential respondents whereas to others audio format might be of no value and the task of getting a recorder or CD player to listen to it a disincentive to participation. Braille is only useful to a very small minority, as less than 10% of people with sight loss read Braille. .Choosing an inaccessible format can act as a deterrent to potential participants.

With no knowledge of the preferred format of accessing written material by potential participants, researchers may experience problems in recruitment when following current guidelines of an ethics committee. The research team has to send reams of paper (Letter of Invitation, Information Sheet, Consent Form) in large print to demonstrate to the potential participant with sight loss that we have some knowledge of their access to print difficulties. This documentation will also inform the potential participant that this material is available in alternative formats on request. Our study encountered these problems when a number of those people selected for inclusion made contact with the research team to criticise the study for sending reams of print material to a person who was registered as blind. The study team did not know the identity of those selected to receive the information about the study and so could not choose the preferred format of the individual. We were not permitted to contact the people to ask what format was preferred and those who were sending on information on our behalf simply did not have time to sort this kind of thing out.

The PI translated all of the relevant material into the various formats however all initial material was dispatched to potential participants in large print and no further contact was made by the majority of potential participants to request alternative formats. As outlined earlier in the methodology chapter, the

response rate for this study was very poor. Therefore, it might be worth considering other methods of recruitment for people with sight loss. For example, recruitment via the telephone could be considered once the researchers ensure that there is no undue pressure and issues of confidentiality are given the highest priority. It may be necessary to liaise with those who are responsible for the database (blind register) and pay a staff member to telephone potential participants to inform them about the study using a prepared script. At the end of that call they can ask permission to pass on the telephone number of the potential respondent to the research team. A member of the research team would then go about fully informing the individual via the telephone about the study again using a prepared script, the information sheet and by answering any questions. Only when the potential participant is happy enough to proceed would they ask for contact details, address, and the preferred format of the individual in receiving the material. In particular, the issue of signing a printed consent form must be dealt with as it is unfair, and expecting a great deal of trust from the potential participant who cannot read print to ask them to sign a printed consent form. For all they know, without a witness, they could be signing anything and the potential for fraud is left wide open.

Chapter 8

8.0 Inferences & recommendations

Changing demographics means our population is ageing and as vision impairment is associated with ageing there is a growing need to provide services for the increased population of people with vision impairment. There are currently approximately 11,000 people in total registered as blind or partially sighted on the island of Ireland. However, indications from the voluntary sector suggest that this is a gross underestimation of the true figure and in line with changing demographics that this figure is rising.

Whereas this body of work set out to investigate whether the author could identify differences in the quality of life between the urban and rural populations of people with vision impairments, few differences were found. The only area where there was a statistically significant difference in the QOL scores showing a difference between urban and rural dwellers was in the area of mental health. Here a rural urban divide showed that rural dwellers had a higher score in the mental health area than their urban counterparts, indicating that rural dwellers had better mental health.

Using a combination of methodologies which resulted in both quantitative and qualitative findings has however enabled this research to explore in both breadth and depth those issues which are important to this community. From the results of this study it can be ascertained that the major issues for this population, the ones that come to the fore, include mobility, falling, transport and public attitudes to and awareness of blindness and partial sight.

Professionals concur with many of the findings, as similar topics arose in their focus group. While there may be a huge challenge ahead to adjust the service provision in line with the findings, it does not necessarily mean huge expenditure. There is a need to increase the staff: service user ratio and this

will incur a short term cost. However there is not a need to invest in massively expensive highly technical resources.

8.1 Recommendations

8.1.1 Mobility

The issue of mobility emerged as a major concern to the participants in this study. Lack of mobility skills reduces the independence of the person with vision impairment. Reducing independence by default increases dependency which has a personal, societal, and economic cost. A strong association exists between ageing, vision impairment and falling and these risks are greater for those who are older, with sight loss and poor mobility. Service providers must re-examine their policies on the provision of mobility skills and find a way of ensuring that every service user with sight loss is encouraged to gain, at the very least, basic skills to enable them to travel safely and independently in their immediate neighbourhood. The offer of this training should be tailored in line with the emotional needs of the service users and should be reoffered periodically. This would be one step towards increasing the confidence of the individual and perhaps reduce some social isolation.

8.1.2 Transport

People with vision impairments deserve equality within the world of transportation. This research clearly indicates that people with vision impairments experience very considerable mobility and transport problems, particularly in rural areas. Transport issues are a major concern to people with vision impairments irrespective of urban or rural residence. It is clear that issues relating to mobility of vision impaired rural dwellers, in particular, require review.

The majority of participants do not feel that public transport is accessible for many reasons. In many rural areas, particularly in the Republic of Ireland, public transport is not available. Other accessibility issues include lack of low floor buses, lack of disability awareness training among transport staff, lack of communication to passengers during travel about transport service, such as stops, bus number, announcements of stops etc.

It was agreed by all rural participants that the free travel pass is of little use to those who do not live adjacent to a public transport stop. Participants felt that free transport should be available when it is needed, and in an appropriate format. One should be able to avail of a free taxi to take the passenger with vision impairment to and from their nearest bus stop. It was strongly suggested that systems should be put in place which would allow taxi drivers to accept the free travel pass in rural areas or instead there should be a system of vouchers, grants, or transport allowances, which could be used for taxis in isolated areas. Alternatively, a voluntary transport or driver system should be set up in those areas with no access to transport or there could be regular trusted drivers designated for certain areas for elderly people or those people with restricted mobility. This service should be available for shopping or for social use. A nominal fee would be acceptable to participants.

8.1.3 Awareness

The first step in alleviating some of the issues raised during this research will involve mounting a high profile campaign to alert people with vision impairment about services available and how even very simple steps can increase their independence and reduce the impact of their vision loss on their every day living. This campaign could be run in parallel with a public awareness campaign to highlight the prevalence of the varying ocular pathologies and how they affect individuals. It should be explained to the public that many people who are legally blind can still have some useful residual vision. Such a campaign could also highlight possible environmental

hazards. This campaign should focus on ability and the handicapping effects of the environment. In light of the growing population of people with sight loss, this campaign could be used to remind the public of the importance of regular eye checks to maintain ocular health.

8.1.4 Need for epidemiological study

It is almost universally agreed that the true extent of vision impairment is not reflected by current registration figures and that current registration figures in the UK and Ireland considerably underestimate the true extent of vision impairment (Canavan et al., 1997, Coffey et al., 1993). The academic literature would suggest that registration underestimates the true extent of vision impairment by a factor of at least 2 (Robinson et al., 1994; Coffey et al., 1993; Bruce et al., 1991). Under registration is, in addition most pronounced amongst those who are disadvantaged, namely the elderly, the poor, the infirm and those with multiple disabilities including the neurologically impaired (Kleinschmidt, 1999; Baker et al., 1998; and Bruce et al., 1991).

In determining the need for service provision and support networks, governments require robust epidemiological data on the extent and nature of disability. Disability related data is however collected through a variety of channels while service provision is based on either medical, social or voluntary sector models. The result is that the methodology used to collect data and the definitions used to define impairments and disability are however often different resulting in various versions of studies which are difficult to compare. A major epidemiological study is needed in Ireland to determine the true extent of vision impairment in both Northern Ireland and the Republic of Ireland.

8.2 Conclusion

Clearly, if the true impact of visual impairment on the population is to be understood, and if adequate and appropriate service provision is to be made, data collected and used must be accurate. Accurate data will inform calculations on the economic burden of visual disability and will also serve to increase public awareness of the personal and societal costs of vision impairment. It will be of immense use to those who are charged with allocating adequate resources to meet the needs of the vision impaired community. Immediate scientific estimates of the number of blind and low vision people in the EU is critical if we are to plan future services, which will provide equality of care and service provision across the member states.

Within the EU there are currently no standardised legal definitions of vision impairment, 'blindness' or 'low vision'. Whether one is registered or recognised as being "legally" blind or as having low vision or partial sight depends on where you live in the EU. Blindness and low vision are defined by each individual member state within the EU. Criteria related to visual acuity or field of vision or both are often but not always used to categorise individuals as blind or low vision. Without a standard definition of vision impairment it will be difficult to make accurate estimates of the true extent of visual disability within the EU. The lack of a standard definition of vision impairment within the EU creates problems in terms of epidemiology, standardised treatment, and service delivery.

If we could improve transport availability and accessibility; ensure equality of access in the environment and provide disability awareness training for everyone including transport providers, drivers and the public we would go a long way towards improving the mobility and independence of people with vision impairments. Imaginative rethinking regarding transport provision in rural areas & continual consultation will improve the ability of people with vision impairments to access public services, reduce social isolation and gain some equality with their sighted peers.

In light of the findings from this study, it is important that we explore further the issues raised by respondents. Those of us who are active in service provision and research in relation to people with vision impairments have a duty to highlight these issues, bring them to the attention of the relevant authorities, and demand action. This gives an opportunity for the research community together with their colleagues both in the statutory and the voluntary sector to provide a collective voice and advocate on behalf of people with vision impairments.

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Appendix 1
Letter of Invitation
Information Sheet
Consent Form

The ROYAL
VICTORIA
HOSPITAL

Directorate of
OPHTHALMOLOGY

Dear

I am writing to invite you to participate in a study entitled

An assessment of the quality of life in elderly people of 60 years and older that are registered as vision impaired in Ireland.

Attached please find an information sheet, which will give you full details about the study, its purpose and what you will be asked about at interview. Taking part is absolutely voluntary. If you decide not to take part in the study this will in no way affect any services you receive currently or wish to receive in the future. We have also enclosed a consent form (on coloured paper), which we would like you to sign if you are happy to participate in this study.

Your name was chosen at random from the register of people with vision impairment in Northern Ireland. Participation in this study will involve a researcher meeting with you to conduct an interview. This interview can take place at your home or any other place of your choice. We expect that the interview will take about one and a half hours to complete.

Please feel free to ask any questions you have about the study.
You may contact Prof J Jackson at 028 90 63 4128 or Ms B
Gallagher at 00 353 87 23 68 302.

Yours faithfully,

Prof AJ Jackson
Principle
Optometrist

Ms B Gallagher
HRB Health Services
Research Fellow

Dr. Pat Hart
Consultant
Ophthalmologist

Information Sheet

Study Title

An assessment of the quality of life in people of 60 years and older who are registered as vision impaired in Ireland.

Research Team

Ms B Gallagher

Prof AJ Jackson

Dr PM Hart

Mr M Stevenson

Introduction

Today people are living longer. As people age, they frequently develop difficulties with their vision. Often the type of vision problems developed by older people cannot be easily corrected by glasses. So it is highly likely that as the population of older people increases, more and more people will need to access services that will help them cope better with their reduced vision. There is very little information available on how the lives of older people in Ireland are affected by this loss of vision. It is very important that proper services are put in place to ensure that the needs of people

who have experienced some loss of sight are met. However these services can only be properly provided once the true problems caused by vision impairment are fully understood and the related needs identified. We believe it is very important to talk to those people who are experiencing sight difficulties to find out what affect their vision loss is having on their lives.

Aim of The Study

This study will assess the Quality of Life (QOL) in people of 60 years and older who are registered as vision impaired (VI) in Ireland. The study will also record how vision impairment affects the practical aspects and daily living activities of each participant. We want to find out how impaired vision influences day to day living activities such as being able to get out and about, filling out forms, watching TV, etc. The study will also explore what services have been available to you since you lost your vision, which of these services you have used and how useful you found these services.

Who is responsible for the study?

This study is being conducted as a major study funded by the Health Research Board in the Republic of Ireland. It is supervised and supported by Prof. Jonathan Jackson, Principal Optometrist Royal Victoria Hospital (RVH) and Queen's University, (QUB), Belfast and Dr Pat Hart, Consultant Ophthalmologist RVH and QUB. AND Prof. Colm O'Brien, Consultant Ophthalmologist, Mater Hospital, Dublin. Mr Mike Stevenson of QUB will provide statistical advice. The researcher is Ms Bláithín Gallagher, HRB Health Services Research Fellow, Queen's University, Belfast in Northern

Ireland and of the National Council for the Blind in the Republic of Ireland.

Duration

It is expected that this study will take place over three years starting in September 2002 and finishing in September 2007.

Publication

It is intended that the results of the study will be published and distributed to funding bodies and service providers to people who are vision impaired.

Hospital Ethics Committee Approval

This study has been approved by the Queen's University Ethics Committee

How have you been selected??

In order to get a true assessment of the quality of life of vision impaired people in Ireland, we intend to interview at least 600 people. We have selected your name at random from the registers of blind and partially sighted people who are aged 60 and older and live in Northern Ireland

What will happen if you take part

In order to get all the information we need for this study we will be interviewing a selection of people with impaired vision. The interview process is expected to take approximately one to one and a half hours.

Each person will be asked a series of questions, under the following headings

- ⇒ physical functioning;
- ⇒ social functioning;
- ⇒ limitations in usual role activities because of physical problems;
- ⇒ role limitations due to emotional problems;
- ⇒ bodily pain;
- ⇒ general mental health (psychological distress and well being);
- ⇒ vitality (energy and fatigue)
- ⇒ and general health perceptions.

You will be asked some questions about how your vision difficulties affect your everyday activities, which will give us some idea about how your vision problem affects your daily life.

We will also be asking you some questions about yourself, which will include questions about your age, your eye sight difficulty, your general health, the tablets or medication that you are taking. We will enquire about any aids or appliances (glasses, magnifiers) you are using to help you since you developed your vision impairment, We will ask you about the services that have been available to you since you lost your vision, which of these services you have used and how useful you found the services.

If it is appropriate we will conduct some simple tests to find out how your vision is on the day of the interview. These tests may include

an assessment of your ability to see fine detail, (visual acuity) to see with your peripheral vision (visual fields) and to see objects with limited contrast (contrast sensitivity) and of different colours (colour vision).

GP notification

With your consent we will contact your General Practitioner to enquire about your general health and any medication that you may be taking.

Where will the interview take place

We will conduct the interview in your home if this is convenient for you or at any other location that you would prefer.

Benefits of taking part

Although you will not receive any direct benefit from taking part in this study, the interview will give you the opportunity to voice your opinion about the services currently available to older vision impaired people. Your answers will help us to understand the needs of older blind people living on the island of Ireland. The information we get from this study will then allow us to inform the funding authorities of the quality of life of older vision impaired people in Ireland.

There are no risks to your health from taking part in this study.

Blind Register

With your permission we will obtain a copy of your registration details from the blind/partially sighted register

Confidentiality

All information gained will be kept confidentially in a numerical database, which means your identity will only be known to the researcher and the supervisory research team.

Voluntary Participation

Taking part is absolutely voluntary. If you decide not to partake in the study, or if you wish to withdraw from the study at any time, this will in no way affect any services you receive currently or wish to receive in the future.

Further Information

If you wish to receive further information about this study please contact Ms B Gallagher, Prof Jonathan Jackson, Dr PM Hart or at 028 9063 4128 or Ms. B Gallagher 00 353 87 23 68 302.

Thank you very much for taking the time to read this document.

Survey No

M/F

DOB

Date

I/V Initials

Appendix II

Questionnaire Cover Sheet

Questionnaire

An assessment of the quality of life people aged 60 years and older who are registered as vision impaired in Ireland.

Notes to interviewer

Please ensure that you familiarise yourself thoroughly with this questionnaire prior to administration. Please note that all information in italics is for the guidance of the interviewer. . It is very important that the respondent (R) is relaxed and not in any way anxious about the interview. Try to establish a rapport with the respondent. Please circle appropriate answers where necessary and write in a detailed summary of R's response to open questions. Please make notes of any extra information given by interviewee even if it does not seem relevant to you.

There is space at the side of every page and at the back of each sheet. Please write question number beside each response. Before you start ensure you complete the following information on the questionnaire, Survey Number, Date of Birth, Interviewer Name and Initials, Date of Interview, Male or Female, Place of Interview. Complete requested information for the top of each sheet on the questionnaire.

Read the following to the Respondent (R) in a conversational style

Good day. My name is Thank you very much for granting me your time. I am here as part of a study. which will assess the Quality of Life in People aged 60 and older who are registered as vision impaired in Ireland. The study will record how vision impairment affects the practical aspects and daily living activities of each participant. We want to find out how impaired vision influences day to day living activities, such as being able to get out and about, filling out forms, watching TV, etc. The study will also explore what services have been available to you since you lost your vision, which of these services you have used and how useful you found these services. It is intended that the results of the study will be published and distributed to policy makers, funding bodies and service providers to help develop and improve services to people who are vision impaired.

Some time back you received information about this study and agreed to take part. Are you still happy to do so.?(If yes proceed with the interview, if no make certain that R understood you properly and probe gently for a reason for their refusal. Record reason and thank R for their time)

Thank you very much.

I want to reassure you that this interview is completely confidential. Your name does NOT appear anywhere on these interview forms. Each person who answers these questions is given a unique number and only the study team has access to these questionnaires. Secondly there are no **right or wrong** answers to these questions. It is by being as honest and forthright as possible you will give us the best answers.

Some of the questions in this questionnaire are quite personal, for example, we will ask you about your schooling and a little about your finances. As I said earlier all of this information is confidential and anonymous. It all goes into a database of information, which I will analyse to find out how individual differences of the people who answer this questionnaire affect their experience of vision impairment and their related needs. *(If R requires examples, give the following)* such as is there a difference in the needs of people with different educational backgrounds or different financial situations, or do additional disabilities affect a persons needs)

This process should take about 1 hour. If at any time you feel tired and would like a little break please be sure to let me know. Some of the questions may seem to repeat themselves but I can assure you every question has a purpose and all questions are actually different! Also some of the questions may not fit very well with your experience however we need to ask all the participants in the study the same questions. Please give the response that best fits your own experience. I repeat all information is treated in a strictly confidential manner

Have you any questions for me before we start? Are you ready then?

Start the interview

Survey No M/F DOB Date I/V Initials

Interviewers Name Date of I/V ___/___/___
Survey No _____ DD / MM / YY

1 Sex of the respondent: Male Female

1b Area of residence(City or County)_____ Rural Urban

1c Place of interview Home or Other Specify_____

CAS

(Please give a score of 1 for every correct answer and a score of 0 for every incorrect answer. Total scores before proceeding to the next section. **Do not** write answers except for age and date of birth.)

What is your name? Who is the Taoiseach/Prime minister?

How old are you? Who is the President of the U.S.A?
(Write age here _____)

What is your Date of Birth? What day is it?
(Write DOB here _____)

Where are you now? What month is it?

Name of the organisation What year is it?
that I have come from?

What is the name of this place? Colour of "STOP LIGHT AT Traffic lights

TOTAL SCORE I/O

Need to score minimum of 8/12

If score is less than 8 Conduct eye test only. Thank R and leave.

Location

2a How far are you from your GP? (Miles)_____

2b How far are you from the nearest accident and emergency main hospital? (Miles) _____

2c How far are you from the nearest post office? (Miles) _____

2d Please tell me which of the following statements is true for you (Tick one only)
The public transport system is within walking distance and is:-

- | | |
|--|---|
| Available frequently during the day | 1 |
| Available at least once a day | 2 |
| Available at least once a week | 3 |
| No public transport is available to me within walking distance | 4 |

(Urban dwellers Do DLTV and then return to Q3, Rural Dwellers ak 2e to 2i then Do DLTV and return to Q3)

Survey No

M/F

DOB

Date

I/V Initials

Ask Rural Dwellers Only

2e What is the name of the nearest city or large town to you

2f How far are you from this city/large town (Miles) _____

2g How long does it usually take you to get there from when you leave home?
(Minutes) _____

2h How do you normally travel there from home. (Circle one only)

Walk	Public Transport	Family/Friends Car	Taxi	Other specify_____
1	2	3	4	5

2i What are your main reasons for traveling to the city/town (Circle all that apply)

To attend medical appointments (Doctor, dentist, physiotherapist , chiropodist etc)

To access other services

To do shopping

For social activities

Other Specify_____

Do DLTV

DLTV Ask R about difficulty of each activity and the importance of the activity to R		NI No Importance SI Some Importance VI Very Important		How Important is it						
Survey Number	M/F Date	No difficulty	A little bit of difficulty	Quite a bit of difficulty	Severe Difficulty	Can't see to do at all	Not done (Nonocular)	NI	SI	VI
How much difficulty do you have										
1		5	4	3	2	1	0	0	1	2
2		5	4	3	2	1	0	0	1	2
3		5	4	3	2	1	0	0	1	2
4		5	4	3	2	1	0	0	1	2
5		5	4	3	2	1	0	0	1	2
6		5	4	3	2	1	0	0	1	2
7		5	4	3	2	1	0	0	1	2
8		5	4	3	2	1	0	0	1	2
9		5	4	3	2	1	0	0	1	2
10		5	4	3	2	1	0	0	1	2
11		5	4	3	2	1	0	0	1	2
12		5	4	3	2	1	0	0	1	2
13		5	4	3	2	1	0	0	1	2
14		5	4	3	2	1	0	0	1	2
15		5	4	3	2	1	0	0	1	2
16		5	4	3	2	1	0	0	1	2
17		5	4	3	2	1	0	0	1	2
18		5	4	3	2	1	0	0	1	2
19		5	4	3	2	1	0	0	1	2
20		5	4	3	2	1	0	0	1	2
		Extreme	Moderate	Somewhat	Barely	Not at all				
21		5	4	3	2	1	0	0	1	2
22		5	4	3	2	1	0	0	1	2
		Excellent	Very good	Reasonably Good	Poor	Very Poor				
23		5	4	3	2	1	0	0	1	2
23		5	4	3	2	1	0	0	1	2
		Disagree Strongly	Disagree	Unsure	Agree	Agree strongly				
24		5	4	3	2	1	0	0	1	2
		I feel I have to be more careful because of my eye condition								

Survey No

M/F

DOB

Date

I/V Initials

Ask All

Eyesight

3a Can you tell me what is the cause of your eyesight problems? [Ask R to provide the name of the disorder causing their blindness or visual impairment; or if not known to describe as fully as possible how it arose - that is, what the symptoms were and how fast it occurred]

3b What age were you when your visual impairment/blindness first occurred?

Age----- (convert to Year-----) Don't Know □

3c Do you consider yourself to be? (Tick one only)

Partially sighted 1 or Blind 2

3d When did you first registered as blind / partial sighted (Ask as appropriate)?

Age----- (Don't offer) Don't Know

3e Can you tell me which of the following best describes your current vision to me? (Circle one answer only)

- | | | | |
|--|---|------------------------------------|---|
| Poor Central Vision | 1 | Poor to one side (Rt/Lt) | 4 |
| Poor peripheral (side) vision | 2 | Poor central and peripheral vision | 5 |
| Generally Foggy/Blurry/Misty | 3 | | |
| Can see distance but can't make out detail | | | 6 |

Other 7 Specify_____

3f What is your expectation for your eyesight change over the coming years? (Circle one only.)

Your eyesight will:-

- | | | | | |
|---------|---------------|--------------------|--------------------|----------------|
| Improve | Remain stable | Slow Deterioration | Fast Deterioration | Don't offer |
| 1 | 2 | 3 | 4 | (Don't know) 9 |

3g How well do you feel that your eye condition has been explained to you by your eye doctor? (Circle one only)

- | | | | |
|-----------|--------------|--------|------------|
| Very well | Satisfactory | Poorly | Not at all |
| 1 | 2 | 3 | 4 |

Survey No

M/F

DOB

Date

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Use of Vision Aids

4a Can you please tell me which (if any) of the following aids you use *(Tick all the apply)* Write other devices specified by R in column 3

Device	Device	Device	Anything else?
Handheld Magnifier	CCTV / TV Reader		?
Illuminated Magnifier	Writing Aids		
Monocular/Binocular	Liquid level indicator		?
Screen Magnifier for PC	Bump ons		?
Screen Reader for PC	Talking watch		?

4b *(Ask only if R has ticked any item in 4a)* If you use low vision aids please tell me where do you usually source your low vision aids. *(Tick one only)*

Outlet

Describe

Low Vision Clinic /Hospital

High Street Optometrist

Other retail outlet

Family/Friend

Do Vision Assessment then Administer SF36 v2 Return to Q5

Vision Assessment

Visual Acuity Eye Chart Binocular

Allow R to use usual spectacles for test. Allow R to close or cover one eye if they wish to. Turn on room lights. Set chart up in brightest part of room (e.g. near a window) ensuring that there is no glare for reader.

Move the chart to 3m from R if possible. If room is too small then move the chart to 1.5 and record distance from R.

Circle each letter the respondent identifies correctly. Mark a slash through the letter Respondent gets wrong or misses. Write the total correct for each row in the column at the right. At 3m if R cannot read any of the letters then move to 1.5m.

Distance of chart from R		Distance of chart from R	
1.1	H E F P U	1.6	H E F P U
1.0	E P U R Z	1.5	E P U R Z
0.9	H N R Z D	1.4	H N R Z D
0.8	F N H V D	1.3	F N H V D
0.7	N D Z R U	1.2	N D Z R U
0.6	V D E H P	Total number correct	
0.5	N F V H D	.	
0.4	N R E H U	Count fingers	
0.3	R Z V D E	Hand movements	
0.2	D H E V P	Light perception	
0.1	E P N R Z	No light perception	
0.0	H P V D U		
-0.1	N U P F H		
-0.2	Z P E H R		
Total number correct			

Did R wear spectacles?

Yes

No

Notes

Low Contrast Test Binocular

Allow R to use usual spectacles for test. Allow R to close or cover one eye if they wish to. Turn on room lights. Set chart up in brightest part of room (e.g. near a window) ensuring that there is no glare for reader.

Move the chart to 3m from R if possible. If room is too small then move the chart to 1.5 and record distance from R.

Circle each letter the respondent identifies correctly. Mark a slash through the letter Respondent gets wrong or misses. Write the total correct for each row in the column at the right. At 3m if R cannot read any of the letters then move to 1.5m.

Distance of chart from R		Distance of chart from R		Distance of chart from R	
F H P Z D		F H P Z D		F H P Z D	
D F V P Z		D F V P Z		D F V P Z	
R N U P E		R N U P E		R N U P E	
N P H D V		N P H D V		N P H D V	
Z E F P V		Z E F P V		Z E F P V	
D V R Z N		D V R Z N		D V R Z N	
R E H Z D		R E H Z D		R E H Z D	
Z N R D V		Z N R D V		Z N R D V	
H D U N R		H D U N R		H D U N R	
F H Z E P		F H Z E P		F H Z E P	
U H D R N		U H D R N		U H D R N	
E F N V P		E F N V P		E F N V P	
Z U R V D		Z U R V D		Z U R V D	
H N E P F		H N E P F		H N E P F	
Total number correct		Total number correct		Total number correct	

Notes

Survey No

M/F

DOB

Date

I/V Initials

Near Vision Chart

Allow R to use usual spectacles and or usual magnifier for test. Allow R to close or cover one eye if they wish to. Turn on room lights. Ask R to look at chart and to tell you the smallest line they can read to you (with magnification aid if they are using one) Ask R to read the line they select. Circle each complete line R reads. When R is unable to read complete line circle individual words that R reads. Mark an X on words that R misses in a line.

Type of magnification aid used, if none write none. _____

(M) N. LogMAR (VAR)

(10) '80 1.6(20)	daytime loop
(8.0) 63	shut careful
(6.3) 50	hate settled
(5.0) 40 1.3(35)-	soft pronounced reached
(4.0) 32.	aggressive hall journey.
(3.2) 25	package especially deal
(2.5) 20 1.0(50)	kind accomplish roughly proceed sigh providence
(2.0) 16	tent importance trouble busy meaningful require
(1.6) 12	hearing traditions legs assumed puts structural
(1.2) 10 .0.7 (65)-	struggling noticed draw assignment easy obliged
(1.01) 8	automobile sheriff span remarkable pure lowered
(0.80) 6	classes compromise guys artificial monthly hill
(0.63) 5 0.4(70)-	quietly barn associates hope tremendous drawing
(0.50) 4	comparison reading fare dull equivalent exited
(0.40) 3	eventually concern talk laboratory crop periods
(0.32) 2.5	functional beat formula ends sixteen discussion
(0.25) 2 0.0(100)	beam represents project shop attack individual

While reading where did R hold reading card? (Circle one only)

Very close

Normal distance

Very distant

In regards to their vision how much difficulty did R display in reading words on card (Circle one only)

With little or no difficulty

With some obvious difficulty

With great difficulty

Notes

Survey No

M/F

DOB

Date

I/V Initials

Fields test

Sit directly in front of participant at about 1 metres distance.

High position Hold your hands out to your sides with your arms in the shape of right angles. Both hands should be parallel to your ears.

Low Position Bring your elbows down and close to your body with your hands parallel with your shoulders.

Ask participant to look directly at your face. Keep looking at their eyes. If you notice them wandering remind participant to keep looking at your face.

Ask participant to tell you when they see movement, by just saying "yes"

While participant is looking at you move your fingers on each hand at different times. Move from high to low position and back again. Try one in high and one hand in low and reverse hands all the time noting when the participant observes movement. Keep moving until you are sure participant has had the chance to observe all quadrants. Mark YES in the quadrants participant has observed, Mark NO in the quadrants R has missed.

Quad Scores

		TESTERS LEFT		TESTERS RIGHT	
High					High
			Low		Low

NOTES

Survey No

M/F

DOB

Date

I/V Initials

SF-36 v2 Health Survey

This survey asks for your views about your health. Answer every question by selecting one of the answers as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: [Circle one only]

Excellent Very Good Good Fair Poor

2. Compared to one year ago, how would you rate your health in general now? [Circle one only]

Much better now than one year ago
Somewhat better now than one year ago
About the same as one year ago
Somewhat worse now than one year ago
Much worse now than one year ago

3. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much? [Please tick one answer only on each line]

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	Vigorous Activities, such as running, lifting heavy objects, participating in strenuous sports			
b	Moderate Activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf			
c	. Lifting or carrying groceries			
d	. Climbing several flights of stairs			
e	Climbing one flight of stairs			
f	. Bending, kneeling, or stooping			
g	. Walking more than a mile			
h	. Walking several hundred yards			
i	. Walking one hundred yards			
j	Bathing or dressing. Yourself			

4. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? [Please tick one answer only on each line]

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	. Cut down on the amount of time you spent on work or other activities					
b	. Accomplished less than you would like					
c	Were limited in the kind of work or other activities					
d	Had difficulty performing the work or other activities (for example, it took extra effort)					

5. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any **emotional problems** (such as feeling depressed or anxious)? [Please tick one answer only on each line]

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
A	. Cut down on the amount of time you spent on work or other activities					
B	. Accomplished less than you would like					
C	Did work or activities less carefully than usual					

Survey No

M/F

DOB

Date

IV Initials

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? : [Circle one only]

Not at all Slightly Moderately Quite a bit Extremely

7. How much bodily pain have you had during the past 4 weeks? : [Circle one only]

None Very Mild Mild Moderate Severe Very Severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? : [Circle one only]

Not at all A little bit Moderately Quite a bit Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. Please give the one answer that comes is closest to the way you have been feeling for each item . [Tick one only in each row.] Please repeat "How much of the time during the past 4 weeks...?" before the statements in each row.

	How much of the time during the past 4 weeks...	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	Did you feel full of life?					
b	Have you been very nervous?					
c	Have you felt so down in the dumps that nothing could cheer you up?					
d	Have you felt calm and peaceful?					
e	Did you have a lot of energy?					
f	Have you felt downhearted and depressed?					
g	Did you feel worn out?					
h	Have you been happy					
i	. Did you feel tired?					

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)? : [Circle one only]

All of the time Most of the time Some of the time A little of the time None of the time

11. How TRUE or FALSE is each of the following statements for you? [Please tick one box on each row that best describes your answer.]

		Definitely true	Mostly true	Don't Know	Mostly false	Definitely false
a	I seem to get sick a little easier than other people					
b	I am as healthy as anybody I know					
c	I expect my health to get worse					
d	My health is excellent					

Survey No

M/F

DOB

Date

I/V Initials

Additional Illnesses/disabilities

5a Do you have any other disabilities/illnesses. (Tick one only)

Yes 1 No 0 (Go to 6a)

5b Would you mind telling me what these disabilities/illnesses are?

[i]----- [ii]----- [iii]-----

[iv]----- [v]----- [vi]-----

Mobility

6a Which of the following mobility aids do you use mainly to get around? (Tick one only)

Symbol Cane	1
Guide Cane	2
Long Cane	3
Guide dog	4
Walking Stick/Zimmer frame/Wheelchair	5
I don't use any aids	6

6b Including the use of any aids disclosed above, can you please tell me which of the following statements best describes your ability to get around:-

I need no assistance to get around	1
I get around with some difficulty	2
I get around with great difficulty	3
I don't get around at all	4

6c Are your mobility difficulties primarily caused by (Circle one only)

Your vision problems	1
Your other disabilities/illnesses	2 Specify
I have no difficulty with my mobility	3

6d Do you manage to exercise at all?

Often	Sometimes	Never
1	2	3

6e Regarding a fear of falling in relation to your vision problems would you say you are
So afraid I won't go out alone Very afraid A little afraid Not at all afraid

1	2	3	4
---	---	---	---

6f (Only ask if R answers 1to 3 in 6e others go to 6g) Please tell me of what you are most afraid.

6g Have you ever fallen as a result of your vision impairment

Never (Go to 7a)	Yes once	Yes 2 or 3 times,	Yes 4 times or more
0	1	2	3

6h (Only ask if R answered 1, 2 or 3 in 6f) How long ago was your more recent fall?

In the past year	1-5 years ago	More than 5 years ago
1	2	3

6i Would you describe your injuries when you fell as

Very severe injuries	Moderate injuries	Minor injuries	No injuries
Requiring hospitalization	Requiring GP visit	Treated at home	
1	2	3	4

Living Arrangements

7a Do you live alone? Yes 1 (Skip to 7d) No 0

7b How many adults are in your household including all children aged 16 and over? _____

7c How many children aged 15 or less are in your household? _____

7d How close are your nearest neighbours? (Tick one only)

- Next door 1
- Less than 100 meters/yards away 2
- More than 100 meters away but within walking distance 3
- A drive away 4
- Don't know 5

8a Have you someone who helps you on a regular basis with any tasks that you cannot accomplish yourself? (e.g. reading post, collecting pension, housework, cooking etc)

Yes 1 No 0 (Go to 8f)

8bc and d How many hours, on average, per week do you receive assistance from? (Write in all that apply)

b) a source e.g. home help provided by state _____

c) a source paid for privately by you _____

d) an unpaid source e.g. family member/volunteer _____

(If R says none write 0 and go to Q8e)

Survey No

M/F

DOB

Date

I/V Initials

8e Please indicate to me any areas of your life where you need assistance but don't currently receive it. *(Tick all that apply)*

Task <i>(Tick all that apply)</i>	Need help
Domestic chores e.g. cooking, cleaning, laundry etc	
Personal matters e.g. reading post, dealing with finances such as collecting pension. Paperwork, etc	
Personal care e.g. bathing, washing, dressing yourself	
Leisure/Social Activities Taking you out	
Shopping	
Transport -getting out and about e.g. to hospital, Doctor or out socially	
Managing Medication e.g. helping you sort out your tablets	
Keeping you company at home	
Anything else?	
?	
?	

Social Activities

9a Do you have someone nearby who you can call on for help if you need it?

Yes 1 No 2

9b Is it *(Tick all that apply)*

Immediate Family	1
Other Relative	2
Friend/Neighbour	3
Professional visitor (eg home help, social worker, etc)	4
Voluntary visitor	5

9c How often do you receive visitors? *(Tick one only)*

Daily	1
Several times a week	2
Weekly	3
Several times a month	4
Monthly or less	5

SOCIAL SUPPORT ALL Qs 1-7:

Now I'd like to ask you something about your family and friends, including those who live with you as well as those who don't. The following statements have been made by people about their family and friends; will you please listen to them and tell me how true they are for you.

1 There are people among my family or friends who do things to make me happy.

Is that: not true,
 partly true
 or certainly true?

2. There are people among my family or friends who make me feel loved.

Is that: not true,
 partly true
 or certainly true?

3. There are people among my family or friends who can be relied on no matter what happens.

Is that: not true,
 partly true
 or certainly true?

4. There are people among my family or friends who would see that I was taken care of if I needed to be.

Is that: not true,
 partly true
 or certainly true?

5. There are people among my family or friends who accept me just as I am.

Is that: not true,
 partly true
 or certainly true?

6. There are people among my family or friends who make me feel an important part of their lives.

Is that: not true,
 partly true
 or certainly true?

7. There are people among my family or friends who give me support and encouragement.

Is that: not true,
 partly true
 or certainly true?

Survey No

M/F

DOB

Date

IV Initials

Public Awareness

11a How aware do you think the general public are of the issues relating to vision impairment? Would you say they are: *(Circle one only)*

1	2	3	4	5
Very aware	Aware	Aware of Some issues	Not very aware	Not at all aware

11b Please rate on a scale of 1 –5, (where 1 is most helpful and 5 is least helpful) how helpful you perceive the general public in connection with your disability - would you say they are: *(Circle one only)*

1	2	3	4	5
Very Helpful	Helpful generally	Helpful for some things	Rarely Helpful	Never Helpful

11c How aware do you think your family and friends are of your needs relating to vision impairment? Would you say they are: *(Circle one only)*

1	2	3	4	5
Very aware	Aware	Aware of Some issues	Not very aware	Not at all aware

12 Can you tell me how accurately the following statements apply to you, where 1 is not at all true 2 is sometimes true 3 mostly true and 4 always true *(Please repeat possible responses to R after each statement and tick appropriate answers)*

		1Not at all true	2Sometimes True	3Mostly true	4Always true
12a	I would like to be much more active				
12b	I am usually a very happy person				
12c	I am often frustrated by my eyesight difficulty				
12d	I would like to get out & about more				
12e	I am often angry about my eyesight difficulty				
12f	I am often sad				
12g	I wish I was more independent				
12h	I am often lonely				
12i	My eyesight difficulty interferes with my life style				

Survey No

M/F

DOB

Date

I/V Initials

Education and Finances**13a** What age did you finish your education at? _____**13b** So then you completed... (Tick one only)

- | | |
|--|---|
| Primary Education | 1 |
| Secondary Education or equivalent | 2 |
| Vocational/Apprenticeship or equivalent) | 3 |
| Third level Education | 4 |

13c What is/was your main occupation? _____**14a** Who is/was the main income earner in your household? (Circle one only)

Respondent (Go to 14c) Partner/Spouse (Go to 14b) Other (specify) Go to 14b

1 2 3

14b So what was her/his occupation? _____**14c** What is your main source of income now? (Prompt R with list below & tick all that apply)

Blind Pension	Other state benefits	
Other State pension	Savings	
Private Pension	Employment	
Disability Living Allowance	My Family support me	
Attendance Allowance	Other specify?	
Other state allowances	?	

14d I want to get an idea of your weekly/monthly household income. The answers we get to this question will allow the study to compare quality of life with financial status. As I said earlier all of this information is confidential and your name does not appear anywhere on this form.

If you would not mind telling me, I would like to know how much money you have to spend in your household each week. Your **weekly household** income is how much? (Please specify currency and ensure amount written is weekly, if R gives monthly figure divide by 4, annual figure divide by 52 etc.) _____

14e (Only ask if R does NOT live alone Refer to Q7a, others go to Q14f)) How much money do you get personally each week? _____**14f** How would you describe your ability to make ends meet? (e.g. pay bills, buy groceries etc) (Circle one only)

Impossible	Very difficult	Some difficulty	No difficulty
1	2	3	4

14g Do you have private medical health insurance? Yes 1 No 0**14h** (Ask only in the republic of Ireland) Do you have a medical card? Yes 1 No 0

Survey No

M/F

DOB

Date

I/V Initials

Services for vision related problems

15a Can you please tell me what services you have received since losing your sight and how recently you received this service. (Please repeat the headings under each column to R and circle the appropriate responses for each service)

15 Service	Column 1 Received 1=Yes (Go to Col 2) 2=No (Go to Col 3) 3=Can't recall (Go to Col3)	Column 2 If yes in Col 1 When 1 in the past week 2 in the past month 3 in the past year 4 over a year ago	Column 3 If No or Can't recall in Col 1 Would like to receive 1 Yes 2 No
Visit from social worker/community resource worker/ other professional who gives advice on practical matters e.g. welfare benefits, home care appliances etc	15.1a 1 2 3	15.1b 1 2 3 4	15.1c 1 2
Home help for personal care eg washing, dressing etc	15.2a 1 2 3	15.2b 1 2 3 4	15.2c 1 2
Home help for domestic duties eg cleaning, laundry,etc.	15.3a 1 2 3	15.3b 1 2 3 4	15.3c 1 2
Training to help you cope better for domestic chores	15.5a 1 2 3	15.5b 1 2 3 4	15.5c 1 2
Training to help you get about more independently both at home and outside	15.6a 1 2 3	15.6b 1 2 3 4	15.6c 1 2
Access to Braille or audio books and other accessible reading materials	15.7a 1 2 3	15.7b 1 2 3 4	15.7c 1 2
Access to/Assistance with computers	15.8a 1 2 3	15.8b 1 2 3 4	15.8c 1 2
Low vision clinic e.g. to get advice on aids that may help you cope better with your vision loss	15.9a 1 2 3	15.9b 1 2 3 4	15.9c 1 2
Eye specialist /ophthalmologist, i.e. the doctor who can give you medical advise re your vision loss.	15.10a 1 2 3	15.10b 1 2 3 4	15.10c 1 2
Counseling	15.11a 1 2 3	15.11b 1 2 3 4	15.11c 1 2
Organised social activities e.g. craft class	15.12a 1 2 3	15.12b 1 2 3 4	15.12c 1 2
Other specify	15.13a 1 2 3	15.13b 1 2 3 4	15.13c 1 2

15b Overall, how would you rate the **quality** of the services you are receiving now or have received? Would you say overall that the quality is...(Circle one only)

Excellent Good Fair Poor

Survey No

M/F

DOB

Date

IV Initials

15c Which of the following statements best reflects how the services you are receiving **meet your needs**? (*Tick one only*)

- Almost all of my needs are being met 1
- Most of my needs are being met 2
- Only a few of my needs are being met 3
- None of my needs are being met 4

15d Overall, are the services you are receiving **helping** you deal with your problems. (*Circle one only*)

- No definitely not, 1
- No not really 2
- yes generally, 3
- yes definitely 4

15e Overall, how **satisfied** are you with the services you are receiving. (*Circle one only*)

- Very satisfied 1
- Generally Satisfied 2
- Mildly dissatisfied 3
- Very dissatisfied 4

15f Are you receiving the kind of services you **want**? (*Circle one only*)

- No definitely not, 1
- No not really 2
- yes generally, 3
- yes definitely 4

15g Please tell me how true the following statements are for you in relations to services for vision impairment. (*Please repeat possible responses to R after each statement and tick appropriate answers*)

		1Not at all true	2Sometimes True	3Mostly true	4Always true
15g	I do not have enough information about the services available to help me deal with my sight problems				
15h	I don't get the services I require because of problems with transport				
15i	I don't get the services I require because I can't afford them				
15j	I don't get the services I require because of long waiting lists				

15k When did you last attend your GP? (*Circle one only*)

- In the last week,
- In the last two weeks,
- In the last month
- In the last year
- Over a year ago

Appendix III
Focus Group Introduction

APPENDIX 111

An assessment of the quality of life people aged 60 years and older who are registered as vision impaired in Ireland.

Focus Group Introduction

Good afternoon every one. My name is Bláithín Gallagher and I am accompanied today by my colleague _____. Thank you very much for granting us your time. We are here as part of a study, which will explore the Quality of Life (QOL) in People with vision impairment who are 60 years and older in Ireland.

I will first tell you a little about the background to the study

Today people are living longer. As people age, they frequently develop difficulties with their vision. Often the type of vision problems developed by older people cannot be easily corrected by glasses. So it is highly likely that as the population of older people increases, more and more people will need to access services that will help them cope better with their reduced vision. There is very little information available on how the lives of older people in Ireland are affected by this loss of vision. It is very important that proper services are put in place to ensure that the needs of people who have experienced some loss of sight are met. However these services can only be properly provided once the true problems caused by vision impairment are fully understood and the related needs identified. We believe it is very important to talk to those people who are experiencing sight difficulties to find out what affect their vision loss is having on their lives.

The study aims to record how vision impairment affects the practical aspects and daily living activities of each participant. We want to find out how impaired vision influences day to day living activities such as being able to get out and about, filling out forms, watching TV, etc. The study will also explore what services have been available to participants since vision loss first occurred, which of these services you have used and how useful you found these services. We are talking to people on either on an individual basis or in a group setting.

This focus group is one such group setting. We want to explore your experience of vision impairment. How does vision impairment impact on your life. Some of the issues we may discuss today include

- Your understanding of eye disease and the explanation given by medical professionals
- Services received or needed for vision related problems
- Rating of services
- Availability & frequency of public transport
- Mobility in general
- Help available private, state or unpaid
- Help needed
- Social Activities
- Social support
- Public Awareness of VI issues

I would like you to think about the following items in particular:

- Any services you have received that really made a difference to your life;
- Any other services, which they would like to see in place that might improve your quality of life.
- And finally if you had a wish and could do one thing, anything at all, to improve your life, what would it be?

This session will last approximately 1 and a half to two hours duration.

I would like to remind you that taking part in the group is absolutely voluntary and deciding not to take part will in no way affect any of the services you currently receive, or may wish to receive in the future.

I want to reassure you all of the information I receive from you will be treated in the strictest confidence. Your name does NOT appear anywhere in the study rather each person is given a unique number and your identity is only known to the study team.

If it is okay with everyone here I will be recording our discussion. This is so that you don't have to wait whilst I write things down and it is normal practice during focus groups. Is everyone okay with this?

Okay thank you.

It is important that you all understand that there are no right or wrong opinions in this discussion. Everybody's views are very valuable. It is by being as honest and forthright as possible you will help us best.

I would like to hear everyone's opinion, so forgive me if I stop you and ask someone else for his or her view. Don't worry if you feel you don't know much about the topic. And if there are different viewpoints in the group, please voice them, as they are important to know about. As I said everyone's views are important and because I am tape-recording this session, I will ask that only one person talks at a time. Please no side discussions or important points will be missed.

I would also ask that you don't ask me questions about what I think. In this context what I know and think is not important

If at any time you feel tired and would like a little break please be sure to let me know.

Have you any questions for me before we start?

Are you ready then?

Appendix IV
Search Strategy

Appendix IV
Search Strategy (Medline)

Ovid MEDLINE(R) 1950 to November Week 3 2008

#	Searches	Results
1	elderly.mp. or Aged/	1827619
2	aged.mp. or "Aged, 80 and over"/ or Middle Aged/	3152034
3	Frail Elderly/	4672
4	older people.mp.	8829
5	1 or 2 or 3 or 4	3165508
6	blindness.mp. or Blindness/	23460
7	Vision Disorders/ or vision impairment.mp.	18830
8	visually impaired person\$.mp. or Visually Impaired Persons/	713
9	partially sighted.mp. or Vision, Low/	1560
10	6 or 7 or 8 or 9	42163
11	5 and 10	15782
12	loneliness.mp. or Loneliness/	2511
13	5 and 12	1355
14	11 and 12	18
15	social isolation.mp. or Social Isolation/	10328
16	5 and 15	3084
17	11 and 15	24
18	elderly.mp. or Aged/	1827619
19	aged.mp. or "Aged, 80 and over"/ or Middle Aged/	3152034
20	Frail Elderly/	4672
21	older people.mp.	8829
22	18 or 19 or 20 or 21	3165508
23	blindness.mp. or Blindness/	23460
24	Vision Disorders/ or vision impairment.mp.	18830
25	Visually impaired person\$.mp. or Visually Impaired Persons/	713
26	partially sighted.mp. or Vision, Low/	1560
27	23 or 24 or 25 or 26	42163
28	22 and 27	15782
29	loneliness.mp. or Loneliness/	2511
30	22 and 29	1355
31	28 and 29	18

Appendix V

SF36 SPSS outputs

Appendix V

ANOVA

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
pf	Between Groups	9292.802	3	3097.601	3.988	.009
	Within Groups	169320.5	218	776.700		
	Total	178613.3	221			
rp	Between Groups	25146.793	3	8382.264	6.855	.000
	Within Groups	266578.0	218	1222.835		
	Total	291724.8	221			
re	Between Groups	14513.036	3	4837.679	4.358	.005
	Within Groups	241983.5	218	1110.016		
	Total	256496.5	221			
sf	Between Groups	17212.511	3	5737.504	5.948	.001
	Within Groups	210276.2	218	964.570		
	Total	227488.7	221			
p	Between Groups	27252.815	3	9084.272	9.456	.000
	Within Groups	209437.1	218	960.721		
	Total	236689.9	221			
mh	Between Groups	4546.034	3	1515.345	3.484	.017
	Within Groups	94807.682	218	434.898		
	Total	99353.716	221			
vt	Between Groups	3463.328	3	1154.443	2.565	.056
	Within Groups	98102.867	218	450.013		
	Total	101566.2	221			
ght1	Between Groups	11850.252	3	3950.084	6.675	.000
	Within Groups	129014.0	218	591.808		
	Total	140864.3	221			

Post Hoc Tests

pf

Duncan^{a,b}

Cohort	N	Subset for alpha = .05	
		1	2
NI Urban	55	37.091	
NI Rural	52	37.532	
ROI Rural	59	41.525	
ROI Urban	56		53.145
Sig.		.435	1.000

Means for groups in homogeneous subsets are displayed.

- a. Uses Harmonic Mean Sample Size = 55.387.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

rp

Duncan^{a,b}

Cohort	N	Subset for alpha = .05		
		1	2	3
NI Urban	55	45.114		
NI Rural	52	49.760	49.760	
ROI Rural	59		60.381	60.381
ROI Urban	56			72.805
Sig.		.485	.111	.063

Means for groups in homogeneous subsets are displayed.

- a. Uses Harmonic Mean Sample Size = 55.387.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

re

Duncan^{a,b}

Cohort	N	Subset for alpha = .05		
		1	2	3
NI Urban	55	61.364		
NI Rural	52	68.109	68.109	
ROI Urban	56		78.571	78.571
ROI Rural	59			81.356
Sig.		.288	.100	.661

Means for groups in homogeneous subsets are displayed.

- Uses Harmonic Mean Sample Size = 55.387.
- The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

sf

Duncan^{a,b}

Cohort	N	Subset for alpha = .05	
		1	2
NI Urban	55	61.136	
NI Rural	52	67.067	
ROI Rural	59	70.551	
ROI Urban	56		85.045
Sig.		.134	1.000

Means for groups in homogeneous subsets are displayed.

- Uses Harmonic Mean Sample Size = 55.387.
- The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

p

Duncan^{a,b}

Cohort	N	Subset for alpha = .05		
		1	2	3
NI Urban	55	45.182		
NI Rural	52	52.788	52.788	
ROI Rural	59		62.949	
ROI Urban	56			74.714
Sig.		.198	.086	1.000

Means for groups in homogeneous subsets are displayed.

- a. Uses Harmonic Mean Sample Size = 55.387.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

mh

Duncan^{a,b}

Cohort	N	Subset for alpha = .05	
		1	2
NI Urban	55	60.182	
ROI Urban	56	62.679	62.679
ROI Rural	59		70.169
NI Rural	52		70.481
Sig.		.529	.063

Means for groups in homogeneous subsets are displayed.

- a. Uses Harmonic Mean Sample Size = 55.387.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

vt

Duncan^{a,b}

Cohort	N	Subset for alpha = .05	
		1	2
NI Urban	55	42.841	
NI Rural	52	49.279	49.279
ROI Rural	59	50.212	50.212
ROI Urban	56		53.795
Sig.		.085	.295

Means for groups in homogeneous subsets are displayed.

- a. Uses Harmonic Mean Sample Size = 55.387.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

ght1

Duncan^{a,b}

Cohort	N	Subset for alpha = .05	
		1	2
NI Urban	55	55.036	
ROI Rural	59	55.864	
NI Rural	52	61.346	
ROI Urban	56		73.214
Sig.		.201	1.000

Means for groups in homogeneous subsets are displayed.

- a. Uses Harmonic Mean Sample Size = 55.387.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Appendix VI
DLTV Means SPSS

Appendix VI
DLTV SPSS OUTPUTS 1/3

Statistics

	N		Mean	Median	Std. Deviation	Percentiles		
	Valid	Missing				25	50	75
Distinguish a persons features across a room DLTV T1	222	0	1.94	2.00	1.134	1.00	2.00	3.00
Noticing objects off to one side DLTV T1	222	0	2.66	3.00	1.335	1.00	3.00	4.00
Watching TV programmes DLTV T1	222	0	2.33	2.00	1.224	1.00	2.00	3.00
Seeing steps and using them DLTV T1	222	0	2.37	2.00	1.236	1.00	2.00	3.00
Enjoying the scenery if out for a drive DLTV1	222	0	2.28	2.00	1.310	1.00	2.00	3.00
Reading road signs and street names DLTV1	222	0	1.59	1.00	.960	1.00	1.00	2.00
Distinguishin g a persons features accross the street DLTV1	222	0	1.39	1.00	.798	1.00	1.00	1.25
Recognising seasonal changes in the garden DLTV1	221	1	2.86	3.00	1.723	1.00	3.00	4.00
Distinguishin g a persons features at arms length DLTV1	222	0	2.58	2.00	1.405	1.00	2.00	4.00

DLTV SPSS OUTPUTS 2/3

Statistics

	N		Mean	Median	Std. Deviation	Percentiles		
	Valid	Missing				25	50	75
Pouring yourself a drink DLTV1	222	0	3.41	3.50	1.251	3.00	3.50	4.00
Cutting up food on your plate DLTV1	222	0	3.32	4.00	1.459	2.00	4.00	5.00
Cutting fingernails DLTV1	222	0	2.50	2.00	1.533	1.00	2.00	4.00
Using kitchen appliances DLTV1	222	0	3.17	3.00	1.674	2.00	3.00	4.00
Reading normal size newsprint DLTV1	222	0	1.49	1.00	.945	1.00	1.00	2.00
Reading newspaper headlines DLTV1	222	0	2.35	2.00	1.505	1.00	2.00	4.00
Reading correspondence e.g. letters, bills, cards DLTV1	222	0	1.79	1.00	1.150	1.00	1.00	2.00
Signing documents e.g. cheques DLTV1	222	0	2.61	2.00	1.360	1.00	2.00	4.00
Identifying money in a wallet DLTV1	222	0	2.72	3.00	1.327	2.00	3.00	4.00

DLTV SPSS OUTPUTS 3/3

Statistics

	N		Mean	Median	Std. Deviation	Percentiles		
	Valid	Missing				25	50	75
Adjusting to brightness after being in the dark DLTV1	221	1	2.54	2.00	1.346	1.00	2.00	4.00
Adjusting to darkness after being in the light DLTV1	221	1	2.81	3.00	1.401	2.00	3.00	4.00
Walk around in your own neighbourhood, area DLTV1	222	0	3.13	4.00	1.482	2.00	4.00	4.00
Walk around in an unfamiliar neighbourhood, area DLTV1	222	0	1.73	1.00	1.164	1.00	1.00	2.00
Rate your overall near vision DLTV1	221	1	1.77	1.00	.988	1.00	1.00	2.00
Rate your overall distance vision DLTV1	221	1	1.68	1.00	.995	1.00	1.00	2.00
I feel I have to be more careful with my eyesight DLTV1	222	0	1.20	1.00	.578	1.00	1.00	1.00

Oneway

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
dltv1	Between Groups	1877.596	3	625.865	1.556	.201
	Within Groups	87698.925	218	402.289		
	Total	89576.521	221			
dltv2	Between Groups	3207.963	3	1069.321	1.649	.179
	Within Groups	141363.3	218	648.455		
	Total	144571.3	221			

Post Hoc Tests

Homogeneous Subsets

dltv1

Duncan^{a,b}

Cohort	N	Subset for alpha = .05
		1
NI Rural	52	20.1923
ROI Rural	59	22.0339
ROI Urban	56	25.5456
NI Urban	55	27.7273
Sig.		.072

- Uses Harmonic Mean Sample Size = 55.387.
- The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

dltv2

Duncan^{a,b}

Cohort	N	Subset for alpha = .05
		1
NI Rural	52	38.6418
ROI Urban	56	45.3125
NI Urban	55	48.0114
ROI Rural	59	48.2143
Sig.		.071

- Uses Harmonic Mean Sample Size = 55.387.
- The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Appendix VII Relevant Publications/Presentations

Chapman, J. (2001). *Globalization and the Environment*. London: Earthscan Publications Ltd.

Chapman, J. (2002). *Globalization and the Environment: A Report for the World Commission on Environment and Development*. London: Earthscan Publications Ltd.

Chapman, J. (2003). *Globalization and the Environment: A Report for the World Commission on Environment and Development*. London: Earthscan Publications Ltd.

Chapman, J., & Pridemore, M. (2001). *Globalization and the Environment: A Report for the World Commission on Environment and Development*. London: Earthscan Publications Ltd.

Chapman, J., & Pridemore, M. (2001). *Globalization and the Environment: A Report for the World Commission on Environment and Development*. London: Earthscan Publications Ltd.

Chapman, J., & Pridemore, M. (2001). *Globalization and the Environment: A Report for the World Commission on Environment and Development*. London: Earthscan Publications Ltd.

The above publication highlights the results of 12 research projects and their broader impact. These 12 projects emerged out of a total of 50 research organizations funded by the UNFCCC and completed in the second year. The UNFCCC study was carried out over the 12 reported months and published in the second year of the study.

Chapman, J., & Pridemore, M. (2001). *Globalization and the Environment: A Report for the World Commission on Environment and Development*. London: Earthscan Publications Ltd.

Appendix VII

Relevant Publications or Presentations

Gallagher B., Hart P., O'Brien C., Jackson A.J. WBU/RNIB November 2002 Conference "Frail Elderly Blind People" *Comparative Analysis of the legal definitions of blindness within the European Union.* , Eastbourne UK Oral Presentation

Gallagher B., Stevenson M., Jackson A.J. *An evaluation of mobility and transport needs of people with vision impairment in the North West of Ireland.* ISLRR The 8th International Conference on Low Vision, Vision 2005, London UK

Gallagher B., Stevenson M., Hart P., O'Brien C., Jackson A.J. Title: *Lack of mobility training and fear of falling in people with vision impairment aged 60 and older.* Abstract number A-071-0000-00204; Oral Presentation: ISLRR Vision 2005 The 8th International Conference on Low Vision, Montreal Canada

Jackson, AJ. O'Brien, C, Gallagher, B, Dardis, E, Sugrue, R, Codd, M; 2008, *Eyes on the Future*, VISPA, Ireland

Aldridge, S, 2008, *A Picture of Health. A Selection of outcomes from HRB funded research.* Health Research Board, HRB Dublin,

The above publication highlights the results of 17 recently completed research projects and their potential impacts. These 17 were chosen out of a total of 68 research programmes funded via the HRB and completed in last funding year. This QOL study was chosen as one of the 17 reported on in this publication and is reported on under the title "Life with Lower Vision", p42.