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**EVALUATING LOW VISION SERVICES IN THE
UNITED KINGDOM**

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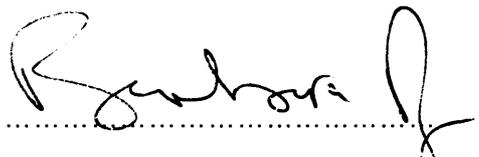
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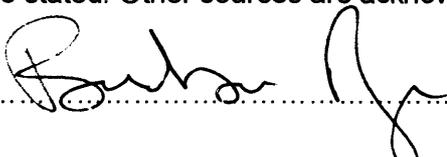
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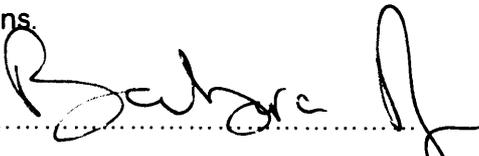
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Summary

This thesis describes a body of research undertaken over a period of 12 years into the characteristics of UK based low vision services.

Chapter 1 provides the reader with relevant background information on the nature and extent of low vision services in the United Kingdom and the methods used to evaluate them.

Chapter 2 describes a focus group study which found that people with a visual impairment reported mixed experiences of low vision rehabilitation services in terms of: information; getting an appointment; accessing services; the low vision assessment; equipment and personnel.

In **Chapter 3**, a survey to determine the nature of low vision services across the United Kingdom in 1997/1998 is reported. Of all respondents, 33% (n = 638) provided low vision services and the bulk of appointments were in hospitals. There were apparent inadequacies in low vision service provision in terms of distribution, magnitude, and coordination.

Chapter 4 reports the development of an outcome measure to evaluate the effectiveness of low vision services. Seven items from the National Eye Institute Visual Function Questionnaire (NEI VFQ) were incorporated into a questionnaire and Rasch analysis of 490 responses showed that all seven questions worked together to form a unidimensional scale. Category utilization and targeting were improved by combining two response categories.

In **Chapter 5** a study which found that the Welsh Low Vision Service (WLVS) improved access to low vision services throughout Wales is described. The

Summary

number of low vision assessments increased, the waiting times for low vision services reduced and the journey time to the nearest service provider reduced for most people.

Chapter 6 outlines an initial analysis of a database that was set up to enable clinical audit of the WLVS. The characteristics of those who used the service for the first time and how this changed as the service developed were investigated.

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Abstract

Chapter 1 provides the relevant background information on the nature and extent of low vision services and the methods used to evaluate them. It starts by providing an overview of what is meant by low vision and the epidemiology of visual impairment in the UK and ends by outlining the aims of the thesis.

Chapter 2 describes a study which used focus groups (n = 12) from all over the UK to find out the range of perceived needs from people with low vision. This involved asking different groups of users to discuss three main topics: good aspects; bad aspects; and aspects needed from low vision services. Six main themes emerged from the focus groups with people with a visual impairment reporting mixed experiences of low vision rehabilitation services in terms of: information; getting an appointment; accessing services; the low vision assessment; equipment and personnel. The results from the study show that people with sight impairment can participate in the process of suggesting solutions that could overcome problems with the way that low vision services are provided. The study gives a general indication of the type of problems experienced and the type of solutions that people find acceptable.

The purpose of the study in **Chapter 3** was to determine the type and location of low vision services within the UK. In 1997/8 a 29 point postal questionnaire, followed when necessary by a five point telephone questionnaire, was administered to all known potential providers of low vision services (n = 2539) including hospitals (n = 277), optician/optometry practices (n = 1683), social services (n= 177), voluntary groups (n =190), specialist teachers (n = 205), and universities (n = 6). For each service provider, the type, magnitude, and geographical location were determined. The distribution of services across the UK and the ratio of providers to population density of people with a visual

impairment were mapped using the Geographic Information System (GIS). Data were obtained on 1945 (77%) service providers. Of all respondents, 59% (n = 1135) offer some form of help to people with a visual disability, of which 26% (n = 497) only sell magnifiers and 33% (n = 638) provide low vision services. It was estimated that in total just under 155 000 low vision consultations were offered annually, the bulk of which were provided by hospital eye departments. The distribution was geographically uneven and there appeared to be scarcity in some areas. When compared to the probable number of people with a visual impairment in the UK there were apparent inadequacies in service provision in terms of distribution, magnitude, and coordination.

The purpose of **Chapter 4** was to describe a short, functional visual disability instrument capable of measuring the outcomes of a government funded country-wide multi-centre low vision service in Wales. Seven items from the NEI-VFQ, which had previously been shown to be responsive to low vision service intervention, were incorporated into a postal questionnaire which was given to patients before they attended the all Wales Low Vision Service. Rasch analysis was used to describe the instrument's psychometric properties. Rasch analysis of 490 completed questionnaires showed that all 7 questions worked together to form a unidimensional scale. By combining the first two response categories, category utilisation and targeting was improved. The 7 item NEI VFQ was an appropriate and precise outcome measure that was acceptable to patients and easy to administer. It measured aspects of near, reading and distance visual disability that had been shown to be amenable to low vision service provision and therefore, it should be highly responsive. The instrument was an appropriate measure with which to evaluate the patient based outcomes in a large-scale, multi-centre low vision service.

In **Chapter 5** the aim of the study was to determine whether the new, primary care based, Welsh Low Vision Service (WLVS) improved access to low vision

services in Wales. The impact of the WLVS was determined by measuring the number of low vision appointments; travel time to the nearest service provider; and waiting times to low vision services for one year before, and for one year after, its establishment. Following instigation of the WLVS, the number of low vision assessments increased by 51.7%, the waiting time decreased from more than six months to less than two months for the majority of people and journey time to the nearest service provider reduced for 80% of people. The extension of low vision rehabilitation services into primary care identified a considerable unmet burden of need as evidenced by the substantial increase in the number of low vision assessments provided in Wales and the new service exhibits improved access.

In **Chapter 6**, from an initial analysis of the data from the WLVS database, the characteristics of those who used the service for the first time over a number of years was investigated. Data collected on adults were analysed for four, one month time periods in September 2004, 2005, 2006 and 2007. The characteristics of the 904 'new' low vision patients were described. The median age of adults was 83 years (range 18 to 101) and 594 (65.7%) were women. Over 73% had visual acuity better than 6/60 and 37.3% (n= 313) reported that they were registered as sight impaired. Age was found to a significant barrier to registration; the older the person the less likely they were to be registered. Over the first four years, there was a significant increase in the number of people using the service (Chi^2 18.705 $p < 0.001$) and there was also a significant ageing of new patients between 2004 (median 81 years) and 2007 (median 84 years) (Mann-Whitney U 17243.0 $p = 0.007$).

In **Chapter 7** there is a discussion of the comparative strengths and weaknesses of the research techniques employed in this thesis. The potential influence of changes in the future are outlined suggestions for future research are provided.

Background

1.1 AN OVERVIEW OF LOW VISION

This chapter provides the reader with relevant background information on the nature and extent of low vision services and the methods used to evaluate them. It starts by providing an overview of what is meant by low vision and the epidemiology of visual impairment in the United Kingdom.

1.1.1 Definitions of low vision

The World Health Organisation defines 'low vision' as a visual acuity less than 6/18 to light perception or a visual field less than 20 degrees in the better eye with best possible correction (WHO 2002).

This definition excludes some people who are disabled by their visual impairment but who have a visual acuity better than 6/18. Several United Kingdom (UK) based epidemiological studies have defined low vision as a visual acuity less than 6/12 (Evans et al., 2002; Reidy et al., 1998; Wormald et al., 1992) possibly because in the UK, people with visual acuity less than 6/12 would be outside legal limits for driving (Drasdo and Haggerty, 1981).

Using clinical measures to define low vision is essential for epidemiological studies. However, this approach could exclude people who are disabled because of other visual factors, such as contrast sensitivity (Hazel et al., 2000), which if reduced can impact on a person's functioning. In addition, clinical measures of visual function alone are not able to account for the

variance in ability to function. Other factors about the person such as their emotional status (Brody et al., 2001) or the environment they are in, for example lighting levels (Brunnström et al., 2004) have been shown to play a part in the disability experienced by a person with low vision.

In the UK 'low vision' has not been defined in legislation. However, a definition was adopted by the Low Vision Services Consensus Group (1999):

“A person with low vision is one who has an impairment of visual function for whom full remediation is not possible by conventional spectacles, contact lenses or medical intervention and which causes restriction in that persons everyday life.”

This definition uses the person's functional ability rather than any specific level of acuity or other clinical measurements of function to define low vision. It goes on to say:

“This definition includes but is not limited to those who are registered as blind and partially sighted.”

For the purpose of this thesis this more inclusive definition of low vision has been adopted.

1.1.2 Registration as Sight Impaired

Different definitions of visual impairment are used for the purpose of legislation and certification throughout the World. In the UK, many people with low vision are registered as sight impaired. The statutory definition for the purposes of registration as a “blind” person under the National Assistance Act (1948) is that the person is “so blind as to be unable to perform any work for which eyesight is essential”. “Partial sight” is not defined in the act but a

guideline for functional definition is given as: “substantially and permanently handicapped by defective vision caused by congenital, illness or injury”.

Recently new forms have been adopted in most parts of the UK. In these the term blind has been replaced by “severely sight impaired” and “sight impaired” has replaced partial sight.

Guidelines are given on the forms about the level of impairment (including visual acuity and visual field) which help make the registration process more objective. The criteria for Severely Sight Impaired (previously Blind) registration are:

- Visual Acuity (VA) < 3/60
- VA > 3/60 but < 6/60 with a very contracted field of vision (unless this has been long standing)
- VA > 6/60 with a very constricted visual field especially in the lower part of the field (excluding people who suffer from homonymous hemianopia or bi-temporal hemianopia with VA > 6/18)

The criteria for Sight Impaired (previously Partial Sight) registration are:

- VA of 3/60 to 6/60 with a full visual field
- VA < 6/24 with a moderate restriction of visual field, media opacities or aphakia
- VA \geq 6/18 or better with a gross field defect (e.g. hemianopia) or a marked constriction of the field

It should be noted that the levels of visual function listed above are only guidelines. Decisions about who can be certified are made by a Consultant Ophthalmologist who is advised to take other circumstances (such as whether the person lives alone or if they also have a hearing impairment) into account.

1.1.3 The number of people with low vision in the UK

There have not been any large population- based surveys in the UK that provide all the information needed about the number of people with low vision.

There are, however, some figures available that allow useful estimates to be made.

In 1988, OPCS found that there were 1.7 million people in the UK who had a 'seeing difficulty' (OPCS, 1989). This was measured by self reported visual ability and it is not known how many of these people had uncorrected refractive error or treatable eye disease, of which there is known to be a significant number (Evans et al., 2002; Reidy et al., 1998; Wormald et al., 1992).

Ophthalmologists in the UK certify people as severely sight impaired and sighted impaired. This data has been collected nationally and is available over long periods of time. Currently, there are about 370,000 people registered as having a sight problem in England, Wales and Scotland (Local Government Data Unit Wales, 2008, The Information Centre, 2006, The Scottish Government, 2009). The registers potentially provide an opportunity to monitor the prevalence of the most important causes of low vision. It is, however, widely acknowledged that registration figures do not represent the true extent of low vision in the population because:

1. registration is voluntary and some people choose not to be registered;
2. it is known that about half of people attending eye hospitals who would be eligible for registration are not registered (Barry and Murray, 2005, Robinson et al., 1994);
3. the register is known to be inaccurate as people who die are not routinely removed; and
4. many people with low vision do not meet the 6/60 registration criteria (Evans et al., 2002; Reidy et al., 1998; Wormald et al., 1992).

About 80% of people certified as sight impaired are over the age of 65 years and the prevalence increases dramatically with age (Table 1.1) (Bunce and Wormald, 2007). A community based UK-wide Medical Research Council

(MRC) trial found that one in 5 people over the age of 75 and one in 2 over the age of 90 had a binocular visual acuity less than 6/12 (Evans et al., 2002).

Age	0 to 4	5 to 17	18 to 49	50 to 64	65 to 75	75+	Total
Registered Blind	710	3150	16450	13360	15780	108360	157810
Registered PS	620	3650	14030	11500	16160	102710	148670
Total Registered	1330	6800	30480	24860	31940	211070	306480
%Total Registered	0.44	2.22	9.95	8.11	10.42	68.87	100.00

Table 1.1 People certified as blind and partially sighted (PS) by age in England 2000 (Bunce and Wormald, 2007)

Most of the available epidemiological evidence on the prevalence of visual impairment in the UK is for older people. For people over 75 years living in the community, studies have found that between 12% and 15% have a visual acuity less than 6/18 (Charles, 2007; Evans et al., 2002; Van der Pols et al., 2000; Wormald et al., 1992); 8% to 13% at ages 75-84 and 27% to 32% at ages 85+ (Evans et al., 2002; Tate et al., 2005; Van der Pols et al., 2000). It should, however, be noted that these studies included people with treatable eye conditions. Indeed about half had cataracts or refractive error, much of which might have been amenable to treatment or correction (Evans et al., 2002). It does therefore seem that only about 6 to 8% of these 75 year olds are likely to have had a visual impairment that might have required rehabilitation services.

For people over 65 to 74 years studies have found a prevalence of 6% (Van der Pols et al., 2000, Tate et al., 2005). Unfortunately we don't know how many of these had a visual impairment that was amenable to treatment. Estimates for the nursing home population by Van der Pols et al (2000) show higher levels of vision impairment (VA <6/18): 12.1% at ages 65-74, 30.0% of those aged 75-84 and 46.9% of those aged 85+.

There is a scarcity of epidemiological evidence available about the prevalence of visual impairment in people of working age for the UK.

Serious visual loss in childhood is uncommon, with 6 of every 10,000 children born in the UK each year becoming blind by their 16th birthday and probably a further 12 becoming visually impaired (< 6/18) (Rahi and Cable, 2003). Thus there are at least 4 newly visually impaired children each day in the UK (Rahi and Dezateux, 2001). Less than 10% of visually impaired children acquire their sight loss after their first month of life (Blohme and Tornqvist, 1997), over 75% have additional non- ophthalmic disorders or impairments (Rahi and Cable, 2003) (Flanagan et al., 2003) and about 10% die within 1 year of diagnosis (Rahi and Cable, 2003). There has been a decrease in the number of children with an isolated visual problem and an increase in the numbers with VI and coexisting neurological disability.

Tate et al (2005) concluded that for the prevalence of vision impairment (VA < 6/18) that was not amenable to treatment, registration data provided reasonably accurate estimates in age groups up to 75 years and the MRC study (Evans et al., 2002) for people aged 75 and over. In Table 1.2 these recommendations are used to provide an estimate of the number of people in each of the countries of the UK who have a visual impairment (VA < 6/18) that is not amenable to treatment. This is likely to be an underestimation of the number of people who have low vision that may require rehabilitation because Evans et al (2002) found that the same number again of over 75 year olds had a visual acuity 6/12 to 6/18.

Country	Age (years)	0- 4	5-17	18-49	50-64	65-74	75+	All ages
	% with low vision <6/18*	0.045% ^a	0.083% ^a	0.141% ^a	0.29% ^a	0.78% ^a	6.4 % (5.6,7.2) ^{#b}	
England (2007)	Population	3,038,400	7,9564,400	22,818,300	9,119,600	4,192,400	3,966,900	51,092,000
	Low vision <6/18*	1,367	6,604	32,174	26,447	32,701	253,882 (222,146;285,617) [#]	353,174 (328,883;392,353) [#]
Wales (2007)	Population	163,700	473,300	1,237,000	575,100	276,100	254,700	2,980,000
	Low vision <6/18*	74	393	1,744	1,668	2,154	16,301 (14,263;18,338) [#]	22,333 (20,295;24,370) [#]
Scotland (2007)	Population	275,200.0	772,200.0	2,275,900	975,300.0	457,400	388,300	5,144,200
	Low vision <6/18*	124	641	3,209	2,828	3,568	24,851 (21,745;27,958) [#]	35,221 (32,115;38,327) [#]
N.I. (2007)	Population	115,300	316,600	792,900	291,100	131,900	111,500	1,759,100
	Low vision <6/18*	52	263	1,118	844	1,029	7,136 (6,244;8,028) [#]	10,442 (9,550;11,334) [#]
UK (2007)	Low vision <6/18*	1,617	7,901	38,245	31,787	39,452	295,750 (264,398;339,941) [#]	414,792 (390,843;466385) [#]
Wales (2031) ^c	Population	167,400	472,900	1,240,100	569,800	394,400	451,600	2,941,200
	Low vision <6/18*	75	393	1,749	1,652	3,076	28,902 (25,290; 32,515)	35,847 (32,235; 39,460)

Table 1.2 Estimated prevalence of people with low vision (Binocular VA < 6/18) requiring rehabilitation services in England, Wales, Scotland and Northern Ireland (N.I.) (using 2007 population census data) and projected prevalence in Wales in 2031.

^a based on 2000/2001 registration data (Tate et al 2005)

^b based on MRC trial (Evans et al 2002)

^c based on 2006 Census- based Wales population projections(<http://www.statswales.wales.gov.uk>)

*excluding those with treatable conditions

95% C

1.1.4 Future projections of the prevalence of low vision.

The number of people with low vision in the UK will undoubtedly increase in future as age is known to be a significant risk factor for vision loss (Evans et al., 2002) and the number of older people in the UK will increase. This potential change is evident by looking at the change in the predicted number of people with low vision in Wales for each age group in 2031 based on 2006 Census based government projections for the population (Table 1.2). Although 2006 Census based projections predict that the number of people in Wales will be fairly constant over the next 20 years, the number of people with low vision could increase by about 60% as the number of people over 60 years is projected to increase dramatically (Table 1.2).

Only the development of effective treatments for dry age-related macular degeneration (AMD) is likely to change this projection, and while there have been positive experimental breakthroughs (da Cruz et al., 2007), a treatment is not yet in sight. Advances in the treatment for Wet AMD, namely the use of Lucentis, may reduce the number of people with severe sight impairment. However, it is unlikely to change the number of people with low vision as few people regain 'normal sight' following treatment.

1.1.5 Causes of low vision in all age groups and older people

The registration process provides a considerable body of data on the causes of visual impairment. Figure 1.1 shows the causes of certifications for blindness in England and Wales for the year ended March 2000 (Bunce 2007). Data on partial sight registrations and the causes of visual impairment in older people for the same year shows very similar percentages.

The most common cause of blind (58%) and partial sight (56%) certification was 'degeneration of the macula and posterior pole' – largely age-related

macular degeneration (AMD). Glaucoma (11%) and diabetic retinopathy (6%) were the next most commonly recorded causes of blind certification.

1.1.6 Causes of low vision in children

The major causes of blindness in the 0 to 15 year old age group are distinctly different from those in the adult population (Figure1.2) (Bunce and Wormald, 2007).

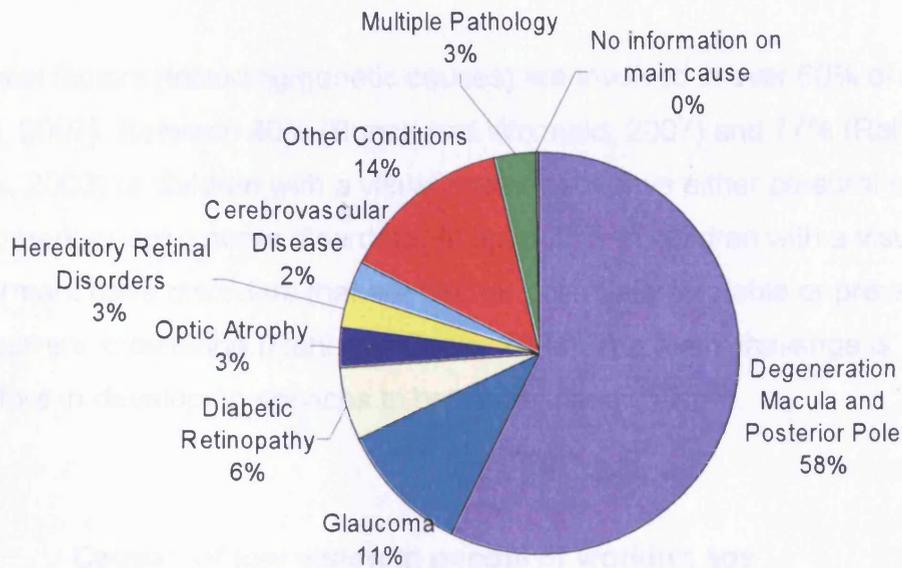


Figure 1.1 Causes of blind certifications (all ages) in England and Wales 1999–2000 (Bunce and Wormald, 2007)

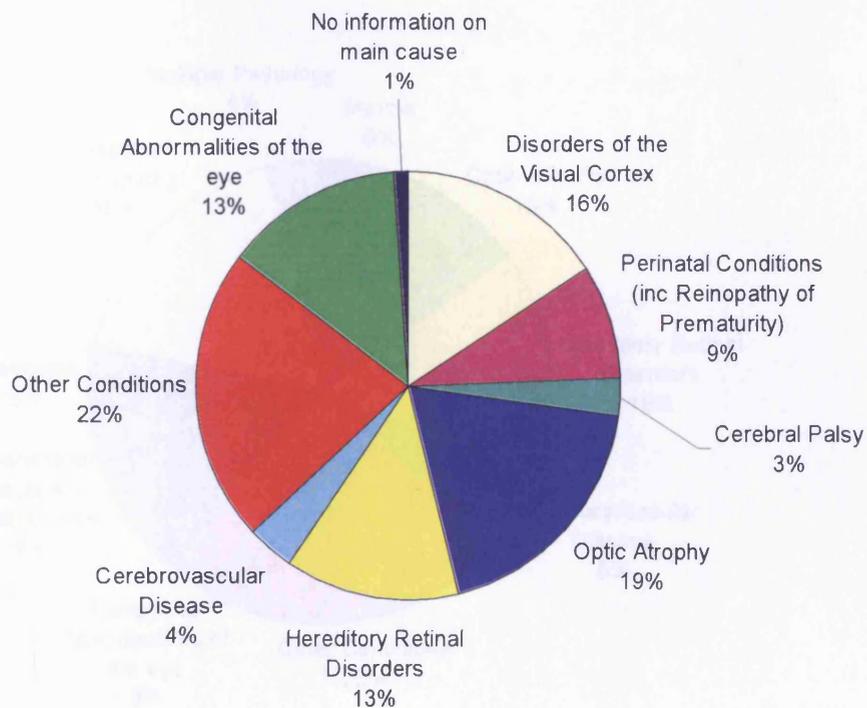


Figure 1.2 Causes of blind certifications (ages 0 to 15) in England and Wales 1999–2000 (Bunce and Wormald, 2007)

Prenatal factors (including genetic causes) are involved in over 60% of cases (Rahi, 2007). Between 40% (Bunce and Wormald, 2007) and 77% (Rahi and Cable, 2003) of children with a visual impairment have either cerebral visual impairment or optic nerve disorders. At least 75% of children with a visual impairment have disorders that are neither potentially treatable or preventable with current knowledge (Rahi and Cable, 2003). The main challenge is therefore in developing services to habilitate these children.

1.1.7 Causes of low vision in people of working age

In the population of working age people, the ocular complications of diabetes are the most common causes of blindness (18%) (Figure 1.3) (Bunce and Wormald, 2007). The hereditary retinal disorders are also a significant cause of blindness in this group, the most common being retinitis pigmentosa.

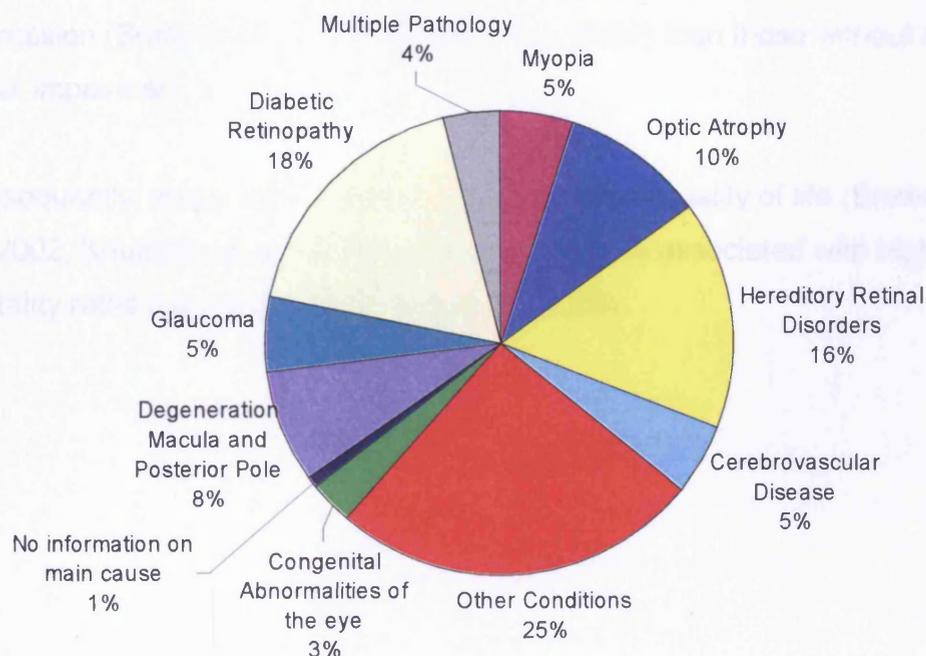


Figure 1.3 Causes of blind certifications (ages 16 to 64) in England and Wales 1999– 2000 (Bunce and Wormald, 2007)

1.1.8 How does low vision affect people?

Visual Impairment impacts on every part of a person's life. Individuals with low vision are less able to perform activities of daily living (Brabyn et al., 2001, Crews and Campbell, 2001, Haymes et al., 2002, Haymes et al., 2007, Lamoureux et al., 2004, West et al., 2002). This can include their ability to perform tasks such as reading, driving, preparing meals, taking prescription medications, and managing personal finances. They may no longer be able to pursue their hobbies, recognise their friends or deal with correspondence. Some lose the ability to care for themselves and others (Stevenson et al., 2004). Therefore, it is not surprising that people with low vision are more likely to reside in residential care than those of the same age who do not have low vision (Brezin et al., 2004).

People with a visual impairment are less mobile (Crews and Campbell, 2001, Sumi et al., 2003) and are more prone to falling (Lord and Dayhew, 2001, Legood et al., 2002, Ivers et al., 2000). They also suffer higher rates of depression (Brody et al., 2001; Rovner et al., 2002) than those without a visual impairment.

Consequently, visual impairment impacts to reduce quality of life (Brown et al., 2002, Knudtson et al., 2005) and, in addition, is associated with higher mortality rates (Lee et al., 2002, Lee et al., 2003).

1.2 LOW VISION SERVICES

1.2.1 What is a low vision service?

In 1999, in the UK, the Low Vision Services Consensus Group (1999) which was made up of professional and user groups defined a low vision service:

“A low vision service is a rehabilitative or habilitative process, which provides a range of services for people with low vision to enable them to make use of their eyesight to achieve maximum potential.”

In the UK there are two statutory funding streams for rehabilitation services for people with a visual impairment; NHS funded services and local authority funded services. These should work together to provide seamless support for people losing their sight. Although both services have elements which would fall into the definition of the Low Vision Consensus Group it is the NHS funded services that are commonly referred to as ‘low vision services’, the local authority funded services based in social services being known as ‘rehabilitation services’.

1.2.2 Low Vision Services

1.2.2.1 *The development of low vision service provision*

In the 1950’s low vision clinics first appeared in the United States and Denmark (Goodrich and Bailey, 2000, Mogk and Goodrich, 2004) and Keeler opticians started visiting Moorfields Eye Hospital (Keeler, 1956).

Over the next twenty years low vision service delivery developed rapidly throughout the UK. By 1977, when Silver and Thomsitt conducted a survey of low vision services, it was reported that there were 104 low vision service

delivery points in the UK; 77 private services in optometry practices and 27 NHS services in the Hospital Eye Service (Silver and Thomsitt, 1977). Invariably low vision consultations were carried out by optometrists and dispensing opticians. At that time, it was estimated that 35 000 low vision consultations took place annually of which the majority were in hospitals.

The next 25 years saw a considerable change in the assessment of the visual status of low vision patients in the UK (Jackson and Ryan, 2002). By the mid 1990's concerns were expressed about the lack of robust evidence to support the unstructured way in which services were developing (Dickinson, 1995).

1.2.2.2 Optometric hospital based low vision services

Hospital low vision services evolved in optometry departments in the UK (Silver and Thomsitt, 1977) and New Zealand (Sanderson et al., 1986) but not to a great extent in the United States (Owsley et al., 2009). Early assessments focused largely on the provision of optical low vision aids which provided the patient with access to conventional sized print (Bier, 1960). More recently they have encompassed a more holistic rehabilitative approach including: assessment of a patient's understanding of their ocular condition and its prognosis; discussion of needs and initial goal setting; assessment of vision; provision of low vision aids, on loan and free of charge; advice about lighting and other methods of enhancing vision; provision of information about the ocular condition and other rehabilitative services; referral to such services, where necessary; re-appraisal of goals; and arrangement for follow up (Reeves et al., 2004)

In response to increasing demands and resultant waiting lists some hospital services have established out-reach services in smaller community hospitals (Lindsay et al., 2004).

1.2.2.3 *Out-sourced low vision services*

Some hospitals contracted low vision services to community based optometrists and dispensing opticians. Once an Ophthalmologist had seen a patient whom they thought would benefit from a low vision service they completed a Hospital Eye Service Prescription (HESP) form. The HESP was given to the patient, together with a list of local optometrists/opticians who provided a low vision service (Landers et al., 1999). The optometrist/optician assessed patients, dispensed appropriate aids and invited them to return if they had problems.

1.2.2.4 *Services incorporating 'low vision therapists'*

In the early 1990's, reports on the effectiveness of optometric low vision services in the UK were not encouraging (McIlwaine et al., 1991, Humphrey and Thompson, 1986). At that time services in Scandinavia were reporting improved effectiveness by incorporating a 'low vision therapist' to teach people to use their low vision aids (Nillson and Nillson, 1986, Virtanen and Laatikainen, 1991). This influenced some UK services to swap to a low vision therapy model of provision (Shuttleworth et al., 1995).

The Partially Sighted Society championed this approach in the UK. It incorporated a specially trained orthoptist known as 'a low vision therapist' sometimes working alone (Shuttleworth et al., 1995) and sometimes alongside optometrists (Landers et al., 1999). The provision was very similar to the enhanced optometric approach but included the low vision therapist training the person how to use their low vision aids; including eccentric fixation techniques, steady eye strategies and focusing, tracking and scanning skills (Shuttleworth et al., 1995).

1.2.2.5 *Multi-disciplinary/ inter- disciplinary services*

Also in the 1990s, some UK services were influenced by multi-disciplinary approaches adopted in America (Jose, 1983) and Australia (Lawrence, 1985).

commissioning power to develop primary care based NHS low vision services (Rumney, 1992, Vineall, 1997). They utilised existing optometric practices and staff and were integrated with social services (Vineall, 1997). Some of these services also linked with hospital low vision services (Low Vision Services Implementation Group, 2002).

In Wales in 2004, because of long waiting times and poor access to existing hospital low vision services, the Welsh Assembly Government chose to develop primary care based low vision services throughout Wales (Margrain et al., 2005).

1.3 MEASURING THE PERFORMANCE OF LOW VISION REHABILITATION SERVICES.

This thesis concentrates on measuring the quality of care provided by low vision rehabilitation services in the UK. Hence this section reviews how the outcomes of healthcare and low vision service have been measured.

When evaluating a healthcare service the boundary between clinical audit and research is often difficult to distinguish. Research tends to be one-off projects, using rigorously defined experiments that collect complex data and discover the right thing to do. Audit is a cyclical series of reviews of what clinicians actually do using routinely collected data. It is often possible to generalise from the findings of research but not audit.

1.3.1 Quality in healthcare

Historically, monitoring the performance of healthcare was generally left to individual clinicians. However, with patients and purchasers wanting to know more about the quality of care available to them, and the increasing pressures on funding, the need to be able to measure the outcomes of interventions increased in importance in the 1980's and 1990's in the UK (Rao et al., 2006).

Measuring the quality of health care is complex and multidimensional (Campbell et al., 2000; Maxwell, 1984; Rao et al., 2006). Maxwell (1984) suggested six dimensions of quality of care:

- access to services;
- relevance to need;
- effectiveness;
- equity;
- acceptability; and
- efficiency.

Therefore, in order to assess the quality of care being offered a range of different measures and different assessment techniques need to be employed. Determining how to measure the effectiveness of a low vision service has proved as difficult as determining what a low vision service should be. Using a wide range of measures is particularly important in low vision rehabilitation services (Harper et al., 1999) because the interventions are complex.

1.3.2 Measuring access to services

The broad term 'access to services' has been described as a dimension of quality in health care by many (Campbell et al., 2000, Maxwell, 1984). Optimal

access in health care can very simply be described as: 'providing the right service, in the right place at the right time' (Rogers et al., 1999). Barriers that limit the use of a service will impede its effectiveness. However, measuring 'access to health care' is complex.

Five dimensions of access, into which the factors that influence access can be placed, have been identified (Penchansky and Thomas, 1981).

- Availability – are the capacity and types of services adequate to meet needs?
- Accessibility – describes geographical barriers, including distance, transportation, travel time, and cost. It highlights the geographical location of services in relation to population.
- Accommodation – identifies the degree to which services are organised to meet clients' needs, including hours of operation, referral procedures and waiting times.
- Affordability – refers to the price of services in regard to people's ability to pay.
- Acceptability – clients views on particular services and how service providers interact with clients.

Many of these factors are service attributes which can be defined and/ or measured as part of the delivery of care e.g. waiting times, capacity, the hours of operation or referral procedures. Others can be determined by consulting with patients (as described previously) e.g. whether services are organised to meet their need or how services interact with them.

Geographic Information Systems (GIS) are 'integrated systems which contain tools for managing, querying, analysing and displaying spatially referenced

data' (Higgs and Gould, 2001). They have been embraced by those approaching the geography of health from a 'spatial analysis' tradition i.e. when measuring the geographical location of services in relation to the population and resultant distance and travel times (Gatrell and Senior, 1999). One of the principle applications of GIS in terms of geography of health research has been concerned with the delivery of, and access to, healthcare services.

Accessibility to health services can be distributed unevenly over space because most health services are provided at fixed sites, serving a dispersed population. GIS can produce maps and statistics of accessibility by using: post code locations of healthcare facilities and/ or patients; ordnance survey information of environmental features such as mountains or road networks and census or other information about the people the facilities serve. This can enable differences in accessibility to be viewed and measured so that it is possible to determine if they stem from obvious gaps in service coverage or are structured along social or demographic variations (Cromley and McLafferty, 2002). Such a system may incorporate a variety of accessibility measures, including average travel distance and population coverage (Lovett et al., 2002).

1.3.3 Measuring clinical effectiveness

Early studies used improvements in the clinical measurements of distance visual acuity, reading speed and/ or near visual acuity (Margrain, 2000; Nillson and Nillson, 1986; Temel, 1989) to measure the effectiveness of low vision rehabilitation interventions or services.

In 1994, Leat found there was a large discrepancy between those who had good near visual acuity in the clinic (75%) and those who had good near visual acuity at home (39%) (Leat et al., 1994) perhaps because of

differences in lighting levels (Cullinan et al., 1979). However, in 2000, Hazel et al found that clinical reading performance (including near visual acuity and reading speed) was strongly associated with vision-related quality of life (Hazel et al., 2000). Therefore, more recently, when near visual acuity and/ or reading speed has been used; it has been as one of a number of outcome measures of the effectiveness of low vision rehabilitation service, rather than the sole measure (Shuttleworth et al., 1995, Scanlan and Cuddeford, 2004).

Instead of clinical measures of reading performance, Reeves and Harper used 'real life' tasks of reading such as 'use-by' dates on grocery items and instructions on a medicine bottle (Reeves et al., 2004) as one of their outcome measures. A good review of this type of battery testing approach is given by Dougherty et al. (2009) who found that low vision services are most effective at improving a person's ability to read a medicine bottle and/ or cooking instructions.

1.3.4 User based measures of effectiveness

Since the early 1990s, government policy has dictated that patients have a greater say in how statutory health and social care services are provided (Executive, 1992, Hanley et al., 2003). Ensuring services are responsive to the needs of patients has continued to be at the centre of the NHS strategy in the UK (Department of Health, 2006, Welsh Assembly Government, 2005). Hence, an essential part of assessing services is seeking the views of the people who use them and utilising user based outcome measures.

1.3.4.1 Qualitative research

Health services research traditionally relied upon the use of quantitative methods. However, once the importance of consulting with patients was realised, qualitative research also found a place in health care research (Kitzinger, 1995, Pope and Mays, 1995).

Qualitative research techniques are used '*when there is a need to identify or understand new or complex issues, rather than to enumerate their prevalence*' (Powell and Single, 1996b). In very simple terms, qualitative research helps to investigate 'What is X?' whereas quantitative methods are used to determine 'How many Xs?' Therefore, qualitative research is an essential part of any research that tries to determine patients' views on a given subject. A range of qualitative research techniques are available:

- An *in-depth interview* is a one-to-one research technique in which a respondent answers a researcher's questions which are directed by a loosely structured or unstructured interview guide. As they are likely to produce more in-depth information they are more useful when the subject to be discussed requires disclosure of very personal information (Powell and Single, 1996b).
- In the *nominal group, expert panel or group interview* technique respondents are required to express opinions on a subject without interaction (Powell and Single, 1996b). In a much more structured way, they write their responses to each question in turn. When requested participants declare their responses and they are recorded on a flip-chart.
- *Focus groups* are a qualitative research technique that has been used for just over a decade in health care research (Powell and Single, 1996b, Kitzinger, 1995). They have, however, been used for much longer in market and social science research to seek public opinion (Morgan, 1997). A focus group is a group of individuals selected and assembled by researchers to discuss, comment on, from personal experience, the topic that is the subject of the research (Powell and Single, 1996a). Focus groups are generally conducted in a semi-structured interview format. The interviewer has a short list of open-

ended questions to ask, and the group discusses each question, in sequence.

Focus groups can be employed either prior to, concurrently with, or after a quantitative study or they can be used separately (Powell and Single, 1996a).

In a focus group people are encouraged to talk to one another and this interaction can help foster a range of opinion and provide a more complete understanding of the issues (Kitzinger, 1995, Vaughan et al., 1996). A focus group enables the researcher to examine people's different perspectives, to explore how their thoughts are constructed, expressed, censured, opposed and changed through social interaction. Vaughan et al (1996) identified five advantages of the focus group:

1. Synergism (when a wider bank of data emerges through the group interaction).
2. Snowballing (when the statements of one respondent initiate a chain reaction of additional comments).
3. Stimulation (when the group discussion generates excitement about the topic).
4. Security (when the group provides a comfort and encourages candid responses).
5. Spontaneity (because participants are not required to answer every question, their responses are more spontaneous and genuine).

Unlike nominal groups, the focus group captures spontaneous rather than carefully considered responses. It follows that focus groups are much better for developing a hypothesis but nominal groups are better at determining consensus (Powell and Single, 1996b). The unique ability of focus groups to explore dissent and consensus (Morgan, 1996) means they are useful in determining cross cultural variables

e.g. why services are used by some groups and not others (Kitzinger, 1995).

Fern et al (Fern, 1982) found that despite the social interaction, focus groups generate 60 to 70% as many ideas as an in-depth interview. Focus groups, however, are more efficient (Morgan, 1996). For example, 2 focus groups with 8 people in each would produce as many ideas as 10 in-depth interviews and the resources used (time, venue, travel etc.) are less.

In vision research, as in other healthcare fields such as dermatology (McNally et al., 1998), focus groups have been used to:

- 1) develop (Dahlin-Ivanoff et al., 1996) and evaluate (Dahlin-Ivanoff et al., 1998) health education programs;
- 2) examine patient's experiences of health services or interventions (Hartnett et al., 2005b; Lewis et al., 2007; Owsley et al., 2006b) and
- 3) aid the development of patient centred outcome measures (Mangione et al., 1998b, Owsley et al., 2006a, Walsh et al., 2008).

All qualitative techniques can be influenced by the moderator and the people in the group. However, careful planning can minimise this to make them a useful and robust research technique. Care should be taken in interpreting qualitative research findings because although they can help to define peoples' views they do not provide any indication of how commonly held those views are.

1.3.4.2 Patient satisfaction surveys

NHS reforms increased pressure on health care providers and purchasers to monitor patient satisfaction. Early studies that asked patients about their satisfaction with low vision services in the UK (Leat et al., 1994; McIlwaine et al., 1991; Shuttleworth et al., 1995) found an enormous variation in the

proportions who were satisfied; from 50% (McIlwaine et al., 1991) to 92% (Humphrey and Thompson, 1986). However, these used questionnaires that were not validated. In 1999, Aspinall et al cautioned that care in interpreting patient satisfaction with low vision services should be exercised as, in line with more general findings, patient satisfaction is a multi-faceted concept which may easily be misinterpreted (Aspinall et al., 1999). For example, it has been found to be easier to frame reliable questions on respect for patients' privacy, dignity, and feelings than questions concerning communication of information and over-reliance on negative statements may provide a misleading picture (Cohen et al., 1996).

In 1999 a team from Manchester (Harper et al., 1999) reported the development of a questionnaire specific to low vision rehabilitation (the Manchester low vision questionnaire MLVQ). The MLVQ is a validated questionnaire that incorporates questions about a person's satisfaction with low vision services (Harper et al 1999).

In conclusion patient satisfaction surveys are an important means for anyone who provides a service to gain patient views. In research, care should be taken to use validated questionnaires that use positive rather than negative statements. Patient satisfaction should not be relied on as a primary measure, rather measure of a patient reaction to a service as one of a number of outcome measures.

1.3.4.3 Use of low vision appliances

The first report of an attempt to measure the effectiveness of low vision services in the literature was in 1956 (Fonda, 1956). Fonda interviewed patients who had been "examined for low vision lenses at the Lighthouse (the New York Association for the Blind)". Of the 500 patients assessed 240 (48%) had been prescribed low vision devices and were interviewed two months later to determine whether or not the lenses were beneficial. To

determine success a questionnaire was used with questions about how often, for how long and for what purpose the low vision aids were used. He concluded that 173 (72%) of those prescribed devices were successful and hence, 34.6% of the 500 people assessed were thought to have benefited from the intervention.

Since then people's use of low vision aids (Hiatt et al., 1963; Hinds et al., 2003; Humphrey and Thompson, 1986; McIlwaine et al., 1991; Nilsson and Nilsson, 1986; Reeves et al., 2004; Shuttleworth et al., 1995) and frequency of use (Leat et al., 1994; McIlwaine et al., 1991; Shuttleworth et al., 1995) have continued to be important outcome measures in studies of the effectiveness of low vision services. Nilsson and Nilsson argued that low vision therapy was effective because patients found their low vision aid to be more useful following low vision therapy than without (Nilsson and Nilsson, 1986). In Glasgow, the fact that only 67% (95%CI= 57-77%) of patients used the LVAs they had been prescribed led McIlwaine to argue that the service was not cost effective (McIlwaine et al., 1991). The 91% (95% CI= 86-96%) use of prescribed LVAs in a service in Devon which provided better follow-up of all patients and addition of low vision therapy, was used to argue better effectiveness of the service (Shuttleworth et al., 1995). However, none of the questionnaires used in these early studies were validated.

The only validated measure, the MLVQ, (Harper et al., 1999) has been used in several studies of the effectiveness of low vision services (Hinds et al., 2003; Reeves et al., 2004). In a randomised controlled trial comparing a traditional low vision service with one that incorporated a low vision therapist no difference in low vision aid use was found when using the MLVQ (Reeves et al., 2004).

1.3.4.4 Quality of life and visual function

Measuring a person's ability to perform specific tasks in a clinic (e.g. reading) may not be important to the individual or address their particular needs. Consequently, it may not improve the well being of the individual. Therefore, with a shift towards broader health perspectives and the emphasis on patients' preferences, like other areas of ophthalmology, 'quality-of-life' (QoL) is now an important measure when trying to determine the effectiveness of a low vision service (de Boer et al., 2006; Hinds et al., 2003; Scott et al., 1999; Stelmack, 2001; Stelmack et al., 2006; Stelmack et al., 2004; Wolffsohn et al., 2000) or intervention (Reeves et al., 2004, Smith et al., 2005). Initially most of the visual function assessment and QoL questionnaires were developed using Likert (ordinal) scales (Massof and Rubin, 2001) but latterly Rasch analysis has been generally used (Pesudovs, 2006).

In the area of health care assessment, QoL is a concept about which there is little agreement (Fitzpatrick et al., 1998, Garratt et al., 2002). However, within the area of vision rehabilitation, the notion that it was a multidimensional concept (which includes a functional, a physical, a social and a psychological dimension) is popular. Changes in an individual's ability (Fielder et al., 1999), would in theory be reflected in the individual's QoL.

The next section describes some of the most widely used outcome questionnaires used to evaluate low vision services.

1.3.4.5 Low vision service outcome questionnaires

A large number of vision related quality of life instruments exist. A descriptive review (Massof and Rubin, 2001) and a review of the psychometric properties (de Boer et al., 2004) of these are available. A number have been used, or have been developed to be used, as an outcome measure for low vision services:

- NEI VFQ

The National Eye Institute (NEI) saw the need for a more general health related QoL instrument which could be used to assess patients with a broad spectrum of eye diseases and visual impairments. The original version consisted of 51 items. The items were selected from focus groups of 248 people with a variety of eye conditions and levels of vision (Mangione et al., 1998b). Based on the judgement of the developers the items were assigned into one of 13 domains.

The scale included 5 response categories. Domain scores were the average of the difficulty ratings for the items in that domain. Validation and reliability studies were performed (Mangione et al., 1998b). In 2001 the NEI VFQ 25 was developed from NEI VFQ 51 (Mangione et al., 2001). Items of the NEI-VFQ25 were examined with Rasch analysis and items with difficulty ratings seemed to fit the Rasch model (Massof and Fletcher, 2001). In a review of vision-related QoL questionnaires it was identified as one of 3 showing the highest psychometric quality (de Boer et al., 2004).

Outside low vision services, in other areas of vision research the NEI-VFQ has been extremely widely used including: in specific eye diseases (Vincent et al 2005; Cahill 2005); in treatment trials (Submacular Surgery Trials Research, 2004); comparative clinical measures (Suner et al., 2009) in populations in the UK (Owen et al., 2006); and in Wales (Williams et al., 2006). The impact on the score of other factors such as depression and general health has also been investigated (Miskala et al., 2004, Rovner et al., 2006).

Stelmack et al (2004) suggested that the NEI-VFQ was not useful in low vision rehabilitation because it was developed for clinical research, did not have enough items to evaluate the range of activities required and it had not been developed using Rasch analysis.

- LVQOL

The Low Vision QoL Questionnaire (LVQOL) was developed specifically to measure the outcomes of low vision services. The 25-items were graded on an ordinal scale from 1 to 5 (1 greatest difficulty, 5 no problem). Higher scores represented lower disability. The results were added to give a score between 0 (a low quality of life) and 125 (a high quality of life) (Wolffsohn and Cochrane, 2000). De Boer et al used exploratory factor analysis and suggested that the factor structure of the LVQOL required modification (de Boer et al., 2005). Rasch Analysis has not been used on the LVQOL.

- IVI

Hassel et al argued that all the previously described tools measured the symptoms and functioning (i.e. impairment and disability) of the person with low vision and are thus not useful in assessing the impact of rehabilitation services (Hassell et al., 2000). The Impact of Visual Impairment (IVI) scale was therefore developed to measure the impact of rehabilitation services by determining a person's ability to participate in their society, a principle outlined in the World Health Organisation's universal model of human functioning and disablement (WHO, 2002).

The initial questionnaire contained 32 items that query level of restriction in everyday life which are sub divided into 5 domains of functioning (Weih et al., 2002). The final questionnaire had 28-items with a 4-category response scale for 26 items- "*not at all*" (0), "*a little*"(1), "*a fair amount*" (2), "*a lot*" (3) and a 3-category response scale for 2 items- "*not at all*" (0), "*a fair amount*" (1), "*a lot*" (2) (Lamoureux et al., 2007). It's 3-domain structure (emotional well being, reading and accessing information and mobility and independence) was confirmed using Factor and Rasch analyses (Lamoureux et al., 2007). In a review of vision-related QoL questionnaires

it was identified as one of 3 showing the highest psychometric quality (de Boer et al., 2004).

Outside low vision rehabilitation it has been used in cataract (Pesudovs et al., 2008) and AMD patients (Lamoureux et al., 2008) but it has not been used in the UK.

- LV VFQ 48

In response to shortcomings with the NEI- VFQ 25, Stelmack et al developed the LV VFQ to measure the effectiveness of vision rehabilitation (Stelmack et al., 2004). There were 48 items and 4 response categories for each question (not difficult, slightly/moderately difficult, extremely difficult, and impossible). It had 4 domains: reading; mobility; visual information processing; and visual guided motor behaviour (Stelmack et al., 2008). It's psychometric properties were confirmed using Rasch analysis (Stelmack et al., 2004) and it has been implemented by telephone (Stelmack et al., 2006, Stelmack et al., 2008). It's use has not been reported outside the low vision rehabilitation services of the Veteran's Affairs.

- VCM1

In 1998 Frost et al developed a 10 item vision- related QoL questionnaire (Frost et al., 1998). The items covered anger, depression, loneliness, fear of deterioration in vision, safety at home, safety outside the home, coping with everyday life, inability to do preferred activities, and life interference (Massof and Rubin, 2001). Each item is scored on a 6-point ordinal scale (0= no problem, 5= extreme problem). Low score= higher quality of life. It has been validated for postal and telephone administration (Frost et al., 2001). In a review of vision-related quality of life questionnaires it was identified as one of 3 showing the highest psychometric quality (de Boer et al., 2004).

- MacDQOL

The MacDQOL was developed as a condition specific QoL instrument for people with macular disease (Mitchell and Bradley, 2004). It had 22 items and two parts, the impact rating and the importance rating. The impact questions had 5 response categories scored -3 (high negative impact) to +1 (positive impact) and the importance questions had 5 response categories from 0 (not important at all) to 3 (very important) (Mitchell et al., 2005). A weighted impact score was obtained for each item by multiplying the impact score by the importance score. It was designed to be self completed. The MacDQOL hasn't been used to assess the effectiveness of low vision services.

Most of the visual function assessment and QoL questionnaires were developed using 'classical test theory' and incorporated Likert (ordinal) scales (Massof and Rubin, 2001). Typically, the category labels used (e.g. "agree", "disagree") were assigned numerical values (e.g. 1 to 5) which were treated as if they were quantities and added together to provide a domain and/or instrument scores. In 2001 the use of Likert scales was discouraged (Massof and Rubin, 2001). It was argued that it was not appropriate to perform mathematical operations (such as addition and averaging) on values which originate from ordinal scales because the true relationship between response categories was unknown. In addition, this method of analysis assumed that items within each sub-scale are of equal difficulty; each sub-scale was of equal difficulty; and patients' responses to one item corresponded to patients' responses to another item. To overcome this Massof and Rubin (2001) recommended using Rasch models because this could be used to overcome many of the limitations associated with Likert scales (Pesudovs, 2006, Stelmack et al., 2002, Massof, 2002) by providing estimates of the weights of the different items that corresponded to the difficulty of the activity described by the item (Bond and Fox, 2001).

The need for sensitive instruments has meant that Rasch analysis has been used to improve the design, sensitivity and validity of the outcome measures for low vision services (Babcock-Parziale et al., 2005; Lamoureux et al., 2007; Lamoureux et al., 2008; Massof and Fletcher, 2001; Stelmack, 2001; Stelmack et al., 2006). The exception is the LVQOL (Wolffsohn and Cochrane, 2000) which has not been validated using Rasch analysis.

Many of those who developed the questionnaires perceived them to measure different things and there has been considerable debate about whether they measured QoL, visual function or handicap (Hassell et al., 2000; Stelmack, 2001; Stelmack et al., 2002; Wolffsohn and Cochrane, 2000). However, with the exception of the VCM1, there is a lot of overlap between them. In particular, with regard to the specific tasks mentioned such as reading, figuring out bills, watching television or getting about. The VCM1 is different because it does not have any items relating to an individual's ability to do specific tasks that rehabilitation aims to address. Rather, the questions investigate higher constructs such as loneliness, safety, coping and fear.

The studies which have incorporated QoL/ visual function questionnaires to measure the effectiveness of a low vision service or intervention are summarised in Appendix 1.

Early studies found that low vision services made no significant difference (La Grow, 2004) or significant but modest changes in QoL / visual function (Hinds et al., 2003; Lamoureux et al., 2007; Scott et al., 1999; Stelmack, 2001; Wolffsohn et al., 2000). Rasch analysis was found to improve the sensitivity of the NEI- VFQ slightly (Stelmack et al., 2002). However, extremely intensive, multi-dimensional in-patient programmes still only induced changes in the scores of a small number of items, and mainly only in the domain of reading (Stelmack et al., 2002).

Some of the problems associated with measuring low vision service outcomes are exemplified by those studies that used the VCM1. For example, Reeves et al (2004) found there was no significant improvement when low vision therapy was added to a traditional low vision service. Hinds et al (2003) had found only a very modest change after a multi- disciplinary multi- intervention service and de Boer et al (2006) found no difference in effectiveness using the same measure (VCM1). These results raise a number of interesting questions: Were the interventions ineffective? Or was the outcome measure insensitive?

In 2008, a breakthrough came with the publication of the first randomised controlled trial in a peer reviewed journal, using Rasch analysis (Stelmack et al., 2008). Comparing a low vision service to a waiting list control, Stelmack et al found a substantial change in overall score of the LV VFQ-48 and also a significant change in all aspects of visual function (Stelmack et al., 2008). However, the low vision service in the trial reported by Stelmack et al. had more contact time than most NHS low vision services and the patient group were restricted to men with AMD. Therefore, it is not yet clear if these results can be expected in current NHS funded low vision services.

Another paper published just a few months earlier (Kuyk et al., 2008) added an interesting twist to the debate about the sensitivity of the different measures. Failure to detect substantial changes in NEI-VFQ 25 scores following services offered to veterans in the United States of America (USA) led to doubts about whether the NEI-VFQ 25 was sensitive to low vision rehabilitation (Szlyk et al., 2004), in particular whether it contained redundant items. This had led Stelmack et al (2004) to develop the LV VFQ-48. However, in 2008, Kuyk et al found a substantial and significant change in a number of the domains of the NEI VFQ 25 following an intensive low vision service (without using Rasch analysis) (Kuyk et al., 2008).

1.3.5 Cost Effectiveness

The National Institute of Clinical Excellence (NICE) which considers independently-verified evidence uses a standard method to assess the cost effectiveness of an intervention: the quality-adjusted life years measurement (QALY) (NICE, 2004). A QALY gives an idea of how many extra months or years of life of a reasonable quality a person might gain as a result of treatment or intervention. Cost effectiveness is expressed as '£ per QALY'.

In order to calculate the QALY for an intervention a measure of QoL is required. The QoL questionnaires discussed previously (e.g. the NEI-VFQ and similar instruments) are function-based measures that determine a person's perception of their ability to perform specific tasks considered to be relevant to "quality of life". In calculating the QALY for an intervention, only preference-based measures of QoL, which measure the meaning of the limitation to the patient, rather than the limitation, are used.

NICE has suggested that only three such preference based measures of quality of life should be used: standard gamble, time trade-off or discrete choice methods (NICE, 2004). All these methods are characterised by patients making a choice between alternative situations from which relative importance or value can be derived. A number of studies have looked at preference based quality of life measures in vision impairment (Kymes and Lee, 2007) but none has used them to determine the cost effectiveness of low vision services. The current opinion is that this is a young field in vision science which requires further work (Kymes and Lee, 2007, Aspinall et al., 2007) and caution is required in interpreting data obtained using these methodologies.

1.3.6 Aims and objectives of this thesis

The aim of this thesis was to employ a range of research techniques to:

- 1) determine user- defined needs for low vision services in the UK;
- 2) determine the nature, extent and geographical distribution of low vision services in the UK and compare this with the low vision prevalence;
- 3) develop a user centred outcome questionnaire to measure the effectiveness of a large-scale multi-centre low vision service in the UK;
- 4) determine if a new primary care low vision service had changed access to low vision services in Wales; and
- 5) determine who used the primary care low vision service and whether the characteristics of people using it changed as it developed.

Listening to people with low vision

2.1 INTRODUCTION

In 1992, the 'Needs Survey' conducted by the Royal National Institute for the Blind (RNIB) (Bruce et al., 1991) showed that a large proportion of people with a visual impairment were older and required rehabilitation services that encouraged sight enhancement rather than sight substitution techniques. Therefore, the charity sought to ensure that low vision services in the UK were developed in a way that ensured they were available for everyone who needed them and met the needs of those that used them.

RNIB as an organisation representing visually impaired people had anecdotal evidence that low vision services were difficult to access. As well as this, the institution was being consulted by professional bodies, healthcare commissioners and government about how low vision services should be developed to meet patient needs. Therefore, it commissioned a research project to find out what people with low vision felt they needed from low vision services. In 1999 the findings were disseminated widely to service providers and commissioners throughout the UK in a report 'Our better Vision' (Ryan and McCloughan, 1999). This Chapter describes a focus group study which was carried out in 1997/1998 by the author and Dr Lucy McCloughlan. The author directed the project, jointly planned its implementation and wrote the report with Dr McCloughlan. Dr McCloughlan implemented the project and part of the analysis was conducted solely by Dr McCloughlan.

2.1.1 Organising focus groups

Section 1.3.4 has already provided background information on focus groups. The following paragraphs provide the reader with a more in-depth understanding of implementing focus group research.

There are no rules for organising focus groups for research purposes. Rather, the design should reflect the purpose of the research (Morgan, 1996). That is, rather than simply asserting that focus groups should consist of 8 homogenous strangers in a formal setting for 2 hours, the implications of each part of the design should be considered. The organisation should be individually tailored so that it best applies for the question and population being investigated to encourage the full range of possible observations.

2.1.2 Group membership and recruitment

2.1.2.1 Number of participants

The usual lower and upper limits of successful focus groups are 4 to 10 people (Kitzinger, 1995b; Krueger and Casey, 2000; Morgan, 1996; Morgan, 1997). Larger groups encourage a wider range of responses. Smaller groups are easier to manage and are more appropriate with emotionally charged topics.

Much of the regulation and synchronisation of “turn taking” in focus groups relies on non-verbal communication. Fern (Fern, 2001) outlined 3 forms of non-verbal cues used in focus groups; eye contact and looking, facial expression and body movements and gestures. These cues are also used by a facilitator to encourage all participants to get involved. Most focus group studies relating to vision and vision rehabilitation services (Dahlin-Ivanoff et al., 1998, Hartnett et al., 2005, Lewis et al., 2007) have used groups of 3 to 6 people probably because of the difficulty of managing the discussion limited non-verbal communication. However, one study used 19 people with a visual impairment in 2 groups (O'Day et al., 2004).

2.1.2.2 Number and duration of sessions

Some studies meet once with several focus groups (Burgess, 1996), others meet the same group several times (Powell and Single, 1996b). Most projects consist of four to six groups but diversity in the study population increases the number required (Morgan, 1996). Focus group sessions usually last from one to two hours (Kitzinger, 1995, Powell and Single, 1996a).

2.1.2.3 Group Homogeneity

If a group is too heterogeneous the differences between participants can impact on their contributions (Powell and Single, 1996a). Discussion may flow better and people are usually more willing to talk about their experiences in a homogenous group because participants feel greater affinity with each other (Morgan, 1996). Women disclose more than men do (Dindia and Allen, 1992) and having a mixed group may reduce the amount women will disclose. In a study on family planning, it was found that the views of men were more wide ranging than those of mixed groups of women and men and also between groups in rural and groups in urban areas (Folchlyon and Trost, 1981).

2.1.2.4 The level of acquaintanceship between participants

When people within a focus group know each other, "friendship pairs" tend to assimilate which inhibit responses from those not in one of these pairs. Therefore, most studies try to recruit strangers (Krueger and Casey, 2000). In some circumstances, however, researchers have planned to use acquaintances. For example people who lived, worked or socialised together were used to explore how people might talk about AIDS (Kitzinger, 1994).

2.1.3 Conducting focus groups

2.1.3.1 Meeting place

The setting of a focus group affects the way people interact (Fern, 2001). Focus groups should be conducted in a relaxed environment to encourage

discussion (Kitzinger, 1995, Krueger and Casey, 2000). The spacing between chairs affects a person's interactions so Fern (2001) recommended allowing participants to arrange the chairs themselves. A venue that is considered neutral should be sought e.g. if the subject is a healthcare service the setting should be non- health service (Powell and Single, 1996b).

2.1.3.2 Moderator

In some circumstances it will be important for the moderator to have attributes in common with the group. For example, moderators with the same ethnic background are preferable to establish greater participation (Fern, 2001).

Groups in which the moderator exercises a higher degree of control are termed 'more structured'. In this a moderator imposes the researchers' interests by using pre-prepared open questions. A 'less structured' group can pursue its own interests and will have few if any structured questions. In general, market researchers prefer more structure (Morgan, 1997). Whereas in healthcare the moderator role should be minimal (Kitzinger, 1995).

2.1.3.3 Writing up

The results of focus groups are generally presented as ethnographic reports plus quotes (McNally et al., 1998). In general, it is not appropriate to give percentages in reports of focus group data (Kitzinger, 1995). When numerical summaries are used, care should be taken to include minority opinions and examples that do not fit the overall theory (Kitzinger, 1995).

2.1.4 Aim

The aim of this study was to determine user-defined needs for low vision services in the UK.

2.2 METHODOLOGY

2.2.1 Advisory Group

Knowledge of the literature and a brainstorming session with an Advisory Group was used to determine the composition and number of the focus groups. The advisory group (and titles at that time) comprised:

- Dr Nigel Charles, Head of Research, RNIB.
- Dr Christine Dickinson, School of Optometry, UMIST Manchester.
- Mr Carl Freeman, Social Services Team, RNIB.
- Dr Adrian Hill, Optometry Department, Oxford Eye Hospital.
- Mr Brian Jones, a low vision service user.

2.2.2 The composition and number of focus groups.

2.2.2.1 The homogeneity of the groups

It was known that different groups of people had different requirements from services. For example, people in education or employment may have a greater need for low vision aids for sustained activities. Therefore, focus group participants were chosen to have a homogeneous rather than heterogeneous composition e.g. including the over 65s, people of working age, pre-16s etc.

2.2.2.2 The level of acquaintanceship between participants

Attempts were made to compose the groups of strangers. To offset the initial shyness a time was set aside for introductions over refreshments.

2.2.2.3 The size of groups

Although the focus groups were planned to be less structured, the groups in this study were designed to be small (six or less people). This was to enable the moderator to manage turn taking without the use of visual cues with

participants who were visually impaired.

2.2.2.4 The number of groups

As an attempt was being made to explore the needs of as full a range of different types of users as possible (with in the constraints of time and cost) a total of twelve focus groups was used.

Stratified samples were used as this helps to improve the representation of people consulted and gives a voice to minority groups (Fern, 2001). Seven principal differences between people were identified for consideration: age; gender; onset of visual impairment; ethnic origin; the presence of a hearing impairment and education status. It was also felt that friends and family or carers should participate. Potential problems associated with finding participants and the characteristics of the five facilitators (e.g. gender and ethnicity) also influenced the selection. It was not the intention of the focus groups to explore needs in depth, rather explore the fullest range of needs.

2.2.2.5 Description of the groups

The stratification for recruitment to the focus groups is outlined in Table 2.1. Matching moderators with participants is thought to be important to encourage open discussion and reduce language barriers (Fern, 2001). Therefore, single gender groups were facilitated by a person of the same gender. In addition, for the ethnic minorities, two sub categories were targeted because of the characteristics of the researchers involved: people of Punjabi origin and people of Afro-Caribbean origin. In ideal circumstances, many other ethnic origins would be included, but this was not possible due to resource constraints.

Punjabi speakers may prefer to be involved in same gender rather than mixed gender groups so a female group only was used because the facilitator was female. A Punjabi speaking optometrist was consulted to ensure that all

technical terms were adequately covered.

<i>Grp</i>	<i>Age (yrs)</i>	<i>Gender</i>	<i>Ethnic Origin</i>	<i>Onset of visual loss</i>	<i>Other disabilities</i>	<i>Individual/ not</i>	<i>Education/ Employment status</i>
A	>60	-	-	≤ 18 months	-	I	-
B	>60	M	-	-	-	I	-
C	>60	F	-	-	-	I	-
D	>60	M	-	Later in life	-	FF	-
E	>75	M	-	-	-	I	-
F	>60	F	Punjabi	-	-	I	-
G	>60	M	Caribbean	-	-	I	-
H	>60	M	-	-	HI	I	-
I	18- 59	-	-	-	-	I	In/ out of work
J	18-21	-	-	-	-	I	Tertiary
K	11-17	-	-	-	-	I	Secondary
L	4 -11	-	-	-	-	I	Primary

Table 2.1 Stratification for recruitment to focus groups

M- mixed; F- female; M- male; HI- Hearing Impairment; I- Individual; FF- Family or friend

2.2.3 Recruitment of Focus Groups

Participants were recruited from different parts of the UK. In addition, it was expected that people would have had different experiences of services in rural and non-rural areas (Fern, 2001). Therefore, attempts were made to ensure some of the groups were recruited in rural areas.

All recruitment was carried out by local contacts. Voluntary organisations, social services or schools were given specifications for the group they were to

recruit and an information sheet and consent form to give to each participant. The organisations were paid a small administration fee for carrying out the recruitment. The organisation/ agency who helped recruit focus group participants and the location where they are based is shown in Table 2.2.

Once the person had signed to give consent to take part they were contacted by one of the research team who checked the details provided and confirmed the persons understanding of the project and process.

Organisation	Location
Birmingham Royal Institute for the Blind	Birmingham.
Organisation of Blind Afro-Caribbeans	London.
Ulster Community and Hospital Trust	Newtownards.
Barrow and Districts Society for the Blind Ltd	Cumbria.
Fife Society for the Blind	Kirkcaldy.
Norfolk and Norwich Association for the Blind	Norwich.
Grampian Society for the Blind	Aberdeen.
RNIB Education Centre: Wales	Cardiff.
Surrey Voluntary Society for the Blind	Fetcham near Leatherhead
RNIB Employment and Student Support Network	Bristol
Northumbria Sight Service	Newcastle.
Cornwall County Association for the Blind	Cornwall.

Table 2.2 Local organisations providing access to participants for the focus groups

2.2.4 Moderators

Five moderators were used in total. Four were experienced social science researchers and one was a former teacher. All had experience of conducting qualitative research and they all attended a one day session on focus groups at the College of Health, London. The moderators were male and female. One of the moderators spoke Punjabi and one was afro-caribbean.

2.2.5 Questioning protocol

To formulate appropriate questions, a definition of low vision services was agreed “professionals who help you with any aspect of your life affected by low vision”. This was a broad interpretation as it included teachers, general practitioners etc. because, from the users’ perspective, it may be found that people attribute solutions in “peripheral” domains that the experts have not yet encountered.

To this end, a Focus Group Schedule (Appendix 2) was designed to set broadly the scene about the topic under discussion. This incorporated very little direct questioning so that the participants could fully express their needs without being led by questions. This unstructured method was therefore capable of eliciting information previously untapped in this context.

Occasionally, participants in a focus group have difficulty in initiating or maintaining a discussion. For this reason, an “emergency” prompt list was developed as part of the schedule. This was the only structured material in the focus group and was developed in consultation with the Advisory Group.

The wording changed for children and carers of people with visual impairments. Between the four section areas the facilitators were directed to encourage the participants to speak, to probe for in-depth information and to make sure that the boundaries of inquiry were being adhered to.

2.2.6 Conducting the Focus Groups

Focus groups were arranged in neutral settings such as community centres or schools. People were invited to arrive half an hour before the focus group was due to start and taxis were arranged for participants to get to and from the venue. When they arrived they were given name badges and offered refreshments to encourage them to relax and talk informally.

Participants were then invited to sit around a table and everyone introduced themselves. The introduction from the Schedule (Appendix 2) was then read and the two tape recorders were turned on. One of the moderators facilitated each group and one took notes, checked the tape recorders and made sure the facilitator was reading all the non-verbal clues of the group. The focus groups lasted from between an hour and an hour and a half.

In the focus group with people with a hearing impairment care was taken to arrange a venue with a loupe system, all participants were offered interpreters and the facilitator used a personal microphone system.

2.2.7 Data analysis

The audio tapes were transcribed verbatim. The transcript for each group was analysed using the method described by Krueger and Casey (2000) and was similar to that used by Owsely et al (2006b). Dr Lucy McCloughan (the primary coder) first read the transcripts to get a general impression of the type of comments made by participants and identified all the sections relevant to the research questions. In the second read through she identified themes from the transcripts, highlighted them and coded them as to whether they related to negative comments, positive comments or ways to make the services better.

The highlighted transcripts were then read independently by the second coder (the author) to ensure no themes had been missed and to check the coding. A

2.3.2 Key themes

Six main themes emerged from the focus groups which were applicable to the three topics covered during the discussions (good aspects, bad aspects and aspects needed from low vision services). These themes were not necessarily representative of the views of all potential low vision service users: they reflected the main issues expressed during the focus groups. Quotations from the focus groups were intended to illustrate the themes but were not intended to summarise the diverse views of all the participants.

2.3.2.1 *Information about low vision services*

This theme dominated most of the focus groups. A small number of people mentioned that the information received about services and gadgets was good. However, most of the people provided numerous examples of situations where information was poor. Many people felt that they received no information at all regarding what help was available. In all focus groups, many of those who were in possession of information were unhappy that they had to ask for it themselves. For example, a participant who cared for an older person with serious sight loss felt that information about the existence of low vision services should come automatically:

'From my point of view it is information. I feel it shouldn't be so hard to find things out...I shouldn't be having to phone around hundreds of people'

Regarding the quality of information given, two main issues were discussed: the use of technical terminology and the fact that the differences between the different professionals (ophthalmologist, optician, optometrist, rehabilitation worker) involved were not explained. The group of people with Punjabi as a first language felt that there was an inequality between the information they received and the information that English speakers received.

People felt they needed information on the existence of low vision services and different types of equipment. To overcome the problem of getting information, a variety of solutions were suggested, the most common being the presence of someone at the eye hospital to give out information on relevant issues when a serious sight problem was diagnosed. Other suggestions regarding methods of information dissemination included: advertising low vision services in the local and national media, sending information to people's homes in non-print formats and having more information available at family doctors' surgeries.

2.3.2.2 *Getting an appointment*

Focus group discussions about getting an appointment were dominated by comments of dissatisfaction with waiting times for referral, which ranged from three months to a year. Other negative comments regarding appointments included the cancellation of appointments at short notice, being 'taken off' low vision service lists after a certain period of time and long delays between follow-up appointments. One person felt that these delays led to a worsening of his condition:

'I would like early appointments for people like me, don't leave us for six months ... you have to wait too long to see the optician at the hospital, and you deteriorate in the mean time.'

There were no positive comments about getting an appointment for low vision services. When asked what they needed in terms of getting appointments, most people felt that any help should be given as soon as possible after the time of diagnosis. Many people stated that they would like to be seen again after an initial assessment and some expressed a need to re-refer themselves for a low vision assessment when the need arose. Where self-referral was not possible, a few participants thought that follow up appointments should be made every 6 months or 12 months.

2.3.2.3 Access to services

Many difficulties relating to access (getting to the low vision service) were described. Problem areas regarding transport included: waiting for ambulance services, long ambulance journeys and a lack of parking for those using private transport. Problems with access did not stop on arrival at the service base and there were criticisms of architectural barriers such as steps and difficulty finding the low vision service. This was a particular problem in large hospitals:

'It's at the back of the hospital, in the bowels of nowhere ... you'd never find your way from where you entered'.

Two positive comments regarding access were recorded from two of the groups. The first was about a 'shuttle' system that transferred people from a pick-up point to different departments within the hospital grounds. The second concerned the accessibility of a local optician's (optometrist's) practice for low vision care which was very important to one of the younger participants.

When focusing on what they felt they 'needed' from low vision services in terms of access, many of the younger participants suggested that this could be achieved through architectural changes to the building where the low vision service was located, such as easy-to-see signs. Most of the older participants did not entertain the idea of visiting the low vision service on their own, so it was difficult to get ideas from them about how to improve building access to the service.

In terms of the geographical location of the low vision service, there appeared to be a polarisation in views between those who thought that the service should be in the 'centre of town', and those who thought it should be 'more

local'. The idea of low vision services being provided by a community optometrist did not seem to appeal to some of the older groups. People in several groups felt that a 'high street' optometrist was a commercial enterprise and not a health-care provider and consequently was concerned about charges for services and lenses. However, the people who were receiving low vision services from high street optometrists appeared to be satisfied with their treatment.

2.3.2.4 *The low vision assessment*

The most positive comments were about the low vision assessment itself. Mostly the comments related to different procedures carried out during the participants' visits. These included getting an eye health check, having the chance to 'talk things over' and getting help with tasks which were important to the participants. Many people felt that the overall help from the practitioner was very good:

'I got the magnifying glasses, I got television glasses, everything. They were really nice and kind and they did everything that they could'.

Negative comments about the low vision assessment related mostly to the way that 'vision tests' are conducted. Some people did not like having to do the letter reading tests when the chart was too high or when they could not see any letters on the chart at all. Being made to comply with forced choice testing and being encouraged to 'guess' at answers to vision tests also caused distress to some participants.

The only comments regarding solutions relating to low vision assessments concerned the way that vision was tested. For example, many people felt that the lighting conditions in the clinics were unrealistic and would like to be tested under domestic lighting conditions. Some people felt that the test

should be made easier, or that they should be allowed to sit closer to the test stimulus. For example, one person described how upsetting the process of sight testing in this context could be:

'It is devastating when you find out that you can't even read the top line. And you come out and you find that you're drained and you feel a lump in your throat'.

2.3.2.5 Equipment (optical and non-optical low vision aids)

Experiences with optical low vision aids (such as magnifiers) were polarised, with people finding them either very good or very poor. When asked about the reasons for not liking their magnifier, most comments related to the reduction in field of vision, as well as eye-strain which was attributed to using magnifiers. Regarding the way in which magnifiers are issued, many participants felt that the range of magnifiers on offer was too limited.

Most of the comments regarding non-optical devices were positive – 'bump-ons' were particularly liked. Localised lighting and black felt-tip pens were described favourably in most focus group sessions, as were sight-substitution devices such as talking books.

When discussing what they needed in terms of equipment from low vision services, comments mostly fell into three categories:

- The need to be able to get a wide variety of different types of equipment. These ranged from thick black marker pens and 'a better magnifier' to a closed circuit television (CCTV), the chance to learn Braille and 'getting a guide dog'.

- The need to get more information and instruction on how to use magnifiers and non-optical devices.
- The need to be more informed about what low vision aids were available. Many participants suggested that some type of 'open display' of magnifiers was needed, so that the full range of magnifiers could be seen and tried out by the user on their own, either before or after seeing the practitioner.

One of the participants described this solution to the small range of LVAs on offer as follows:

'There should be a big range of all the visual aids on the market for people like us to try ... because everybody is different'.

2.3.2.6 Personnel involved in low vision services

Most of the negative comments regarding encounters with professionals related to experiences which had occurred before getting low vision help. In almost every focus group, people had been told that nothing could be done for them – this was described as being particularly upsetting or misleading.

Other negative comments included: not seeing the same person each time the low vision service was visited, and poor communication from staff, poor inter-professional communication, encountering negative attitudes towards older people and nurses not being 'eye trained'.

When discussing the type of personnel needed, many people mentioned needing someone to talk to about negative feelings or coping with sight loss. For example, one person felt that he would have been helped by an additional staff member:

'I think the most important thing would be to have somebody ... a social worker of sorts, with some knowledge of eye sight at the clinic. That to me would be most useful. And to be told what is the matter with you, you could go and sit quietly somewhere, have a chat and maybe given some advice'.

The term 'social worker' was mentioned in relation to training in magnifier use; although others felt that a rehabilitation worker should do this. Finally, in many of the focus groups there was some confusion about the label 'optometrist' and how this person is similar to or different from an ophthalmologist or an optician. Quite often, part of the focus group discussion was devoted to discussing the meaning of these terms.

2.4 DISCUSSION

The results from this study showed that people with a visual impairment were able to participate in focus group research to express their experiences of low vision rehabilitation services. They reported mixed experiences of services and suggested solutions to overcome some of the problems with the way that low vision rehabilitation services were provided. Therefore, this study served to give a general indication of the type of problems experienced and the type of solutions that people found acceptable for overcoming them. The six types of need which emerged are discussed here in further detail, both in terms of how they fit within the broader framework of improving low vision services, and the ways in which they could be implemented in regions where they are found to be relevant.

2.4.1 Information

The results of this study emphasise the need to improve the provision of information and communication to patients about their eye condition and the services to help them. This is supported by the findings of a number of other focus group studies related to sight loss and eye care services (Lewis et al., 2007; Owsley et al., 2006b).

Information provision has been described as a way to empower people using the services, helping them to take greater responsibility for their own welfare (Brading and Yerassimou, 1998) by giving them access to a range of services, reducing stress and helping positive adjustment to sight loss (Department of Health, 1989). When people with a visual impairment are given information about their vision and services available they value the information and being made aware of the possibilities and can choose to use them as they wish (Dahlin-Ivanoff et al., 1998).

An option for information dissemination, which was particularly popular, was to have someone available to give information about sight loss and low vision services. This reflects calls made in two other reports (Department of Health, 1989, Lomas, 1997) that workers providing information are necessary at the point of diagnosis and at the point of registration. The results from this study indicate that such an information officer would also have a useful role in low vision rehabilitation.

In the focus group discussions, one solution suggested for information dissemination was the advertising of low vision services through local and national media. This might raise the profile of low vision services in general and reduce the expectation that 'nothing can be done'. At a local level it might be more cost effective specifically to target information at those in need of services.

One of the suggestions made during the focus groups was for people to be contacted directly at home. Difficulties are that lists of people with a serious sight problem often do not exist or are inadequate and that medical confidentiality and the provisions of the Data Protection Act (1998) mean that lists that do exist may not be available to organisations, even for the purposes of circulating information.

Although a number of professional bodies and voluntary organisations provide information leaflets in places which might be attended by those with serious sight problems, such as eye hospitals, GPs surgeries and optometry/optician practices, information about topics highlighted in these studies as important, such as low vision help and magnifiers, is not generally available. Inclusion of information relating to low vision services in the range currently offered would seem a useful first step in providing information to people who need it.

Many people expressed wanting more information from the ophthalmologist. This is consistent with other focus groups of people with a visual impairment (Dahlin-Ivanoff et al., 1998). The provision of information by the ophthalmologist who first informs about the seriousness of the problem would be particularly helpful.

One study, which used focus groups of eye care professionals and of service users, found that professionals did not perceive problems with communication or the provision of information even though it was a dominant theme in groups of people using the service (Owsley et al., 2006c). This may be because while they are providing information it is not being done in a way that is effective. Older people in particular are known to require special strategies in health education. There is a need to involve friends and relatives and to reinforce with oral and written information in a format that can be understood (simple and large enough), an increased response time for questions and the reduction of environmental distraction would be helpful (Carter et al., 1989).

Greater inter-disciplinary working, and making people aware of other services has been suggested (Keeffe et al., 2002) as an important part of improving information. Self help groups have been found to be effective in health education for older people (Carter et al., 1989). In one such group education programme, people with low vision found it particularly helpful to understand that they were not going completely blind (Dahlin-Ivanoff et al., 1998).

In a number of the focus groups it was suggested that information should be available in different formats (large print/Braille/Audio tapes) and in a range of languages. The importance of providing information that people can read themselves needs to be considered in the context of the cost benefit of this when producing leaflets in different formats and languages is expensive. It is hoped that the rise in use of the internet and electronic formats will make the

dissemination of information to people with a visual impairment in different languages and formats much easier and cheaper in future.

2.4.2 Getting an appointment

The need to get low vision help as soon as possible after diagnosis was highlighted during the focus groups. While the problem of waiting times is an issue for every field within health care, the negative impact of serious sight loss upon all aspects of the individual's wellbeing means the initiation of low vision rehabilitation at the earliest possible stage, is needed by many people (Stelmack et al., 2008). Also, once a person has been identified as having a sight problem he or she may have to wait a considerable time for an appointment with an ophthalmologist before being referred to a low vision service. Such long waits can result in people losing essential life skills and therefore their autonomy.

The vast majority of people with serious sight problems will need to continue to re-visit low vision services because of changes in their eye condition or circumstances. Some people need to re-refer themselves for a low vision assessment as their condition changes. This method was favoured when it was introduced in a low vision service in Sweden (Dahlin-Ivanoff et al., 1998). To ensure that people who were not assertive and who would tend not to re-refer themselves would also have access to services, it might be useful to establish a 'safety-net' follow-up procedure. Staff in social care and voluntary sectors with contacts in the community might have a useful role in such a follow-up procedure.

2.4.3 Access to services

The issue of access is particularly important for people with serious sight problems who in many cases do not have access to private transport, do not go out alone and who encounter difficulties in using public transport (Baker

and Winyard, 1998). Difficulties with access to eyecare services have been expressed in focus group studies in other countries (Owsley et al., 2006c) and in the UK (Lewis et al., 2007). Providing access is one reason for offering services in city-centre based services in the local high street.

While there is an increasing move towards providing low vision services in the community some of those participating in the focus groups were concerned about the commercial aspects of high street optometrists. If the need for the extension of low vision service provision into high street optometrists and opticians can be demonstrated, a supporting public awareness campaign might be useful. Professional bodies could assist at a national level, in order to ensure users understand the role of community optometrists in providing a service.

During the focus groups, several people mentioned that they would like to receive their sight loss-related care 'all in one place'. This result may lend some support to the suggestions that services should be provided through 'one door' in an attempt to reduce the gap between the health, social and voluntary agencies involved in serious sight loss (Lomas, 1993). The implications of this would need to be weighed against the need for 'local' services and the results of studies of the effectiveness of different models (Reeves et al., 2004). An improvement in communication between services for people with serious sight problems (Ryan et al., 1999) might increase the likelihood that a person received all of the appropriate services.

Other issues relating to access problems concerned entering and moving around buildings. Older participants in the focus groups did not offer solutions to these problems. Where services were provided in hospitals, the responsibility for architectural access formally resides with estate managers and facility managers. It is suggested that in this connection there might be a role for low vision practitioners to use their knowledge about overcoming

problems with visibility (by the use of lighting, size and contrast) in advising those responsible for universal physical access to health service facilities.

2.4.4 The low vision assessment

Low vision assessments received the most positive comments from the focus groups and, for those who receive services, assessments are perceived as very useful.

Some people felt that the procedures for sight testing caused some distress. Where problems like this are found, they might be overcome by the use of a number of techniques. Firstly, charts which are especially developed for use with people with low vision such as LogMar charts (Bailey and Lovie, 1976) could be used. Secondly, it might be explained to patients why tests are difficult (i.e. to find the threshold at which the test stimulus can no longer be seen). Finally, ensuring the tests are carried out at a distance where the individual being tested can see the test stimulus is a technique well described in texts of low vision practice (Bailey and Lovie, 1976; Dickinson, 1998; Jackson and Wolffsohn, 2007; Macnaughton, 2005).

2.4.5 Equipment

Participants felt that they required training in the use of LVAs, as suggested by some in the UK (Shuttleworth et al., 1995) and in other countries (Nillson and Nillson, 1986). Furthermore, focus group participants suggested that social workers or rehabilitation workers were the appropriate professionals to provide this service. Rehabilitation workers were usually employed by social services departments to provide practical assistance to people with a serious sight problem in the areas of lighting, communication, daily living and mobility skills in their own environment. An extension of their role to provide training

with low vision aids would seem appropriate. The finding that they were part of many low vision teams may indicate that this is happening already.

Many people expressed a need to see all LVAs available at the same time and some suggested an open display of devices. This may not only inform how LVAs are presented, but may also have implications for how overall services are provided. Such a display may need to be manned as many people going through the trauma of losing their sight may be drawn to devices that they think look useful rather than the ones that would work for them. The cost and effectiveness of this over and above the current assessment system would need to be determined.

2.4.6 Personnel

During the focus groups, the main criticism of staff involved with aspects of help for people with serious sight problems was the perceived misinformation given by ophthalmologists about further care possibilities, that is by being told that 'nothing can be done'. This suggests a need for greater awareness amongst ophthalmologists about training in the rehabilitative strategies available to those dealing with people with serious sight problems – and their importance.

Other problems raised included poor communication skills and negative attitudes towards older people. This suggests the requirement for training in the needs of older people for staff involved with people with serious sight problems including optometrists (Rumney, 1992).

One need which was expressed during the focus groups involved the inclusion of 'someone to talk to about negative feelings'. While many practitioners may be aware of the emotional impact of serious sight loss, they are not trained to deal with it. There appears to be a real gap in the staffing

provision for these issues indicating the need for workers to be available for 'reassurance' and counselling at the point of diagnosis or certification of blindness and partial sight.

Other needs relating to personnel concerned the way that the staff-patient interaction is organised. Increasingly, low vision services are being provided by groups of professionals and agencies (Ryan and Culham, 1999). This need brings a new challenge to low vision service providers organising an integrated service involving numerous professional groups and agencies while, at the same time, satisfying the desire of people using the service to see the same person at each consultation. In Sweden when people were always seen by the same practitioner they reported this as a positive attribute of the service (Dahlin-Ivanoff et al., 1998).

The other issue concerning organisation was the need to be visited at home. The fact that many older visually impaired people have to rely on other people for transport means that implementation of home visits may make the difference between receiving services, or receiving none at all.

2.4.7 Strengths and weaknesses of the research

The real strength of this study was that it has enabled people to express their opinions in their own words to give guidance about the issues upon which low vision service providers and commissioners should focus. It also canvassed opinions throughout the UK so that the themes could be assumed to have relevance in many areas. The diversity of people included in the groups in terms of age, gender, ethnicity, other abilities, onset of visual loss and education/ employment status meant that the opinions expressed have resonance for many of those who attend low vision services (Fern, 2001).

The main weakness was that the study highlighted the range of issues people expressed but could draw no conclusions about how commonly held opinions were. The results highlighted the issues but provided no guidance as to their relative importance and how approaching them might be prioritised.

It is possible that some of the views of minority groups may have been lost. For example, there were no specific needs or comments identified to children or people with a hearing impairment. This study was designed to try to capture the needs of all low vision service users rather than the specific needs of some groups. Another study is needed to determine the specific needs of minority groups.

The fact that participants were recruited by local services is a weakness as those using services were aware / able to access local services and may miss those who can't access services. Local services may also recruit their 'best' users as they know they would participate. However, despite this there were a surprising number of people who did not know about or had not used low vision services.

The original data was not available for the write up of this work as the study was completed over 10 years ago. The study was conducted at a time when the use of focus groups in health care was in its infancy and a re-analysis of the transcripts using current techniques could have given further insights.

Survey of Low Vision Services

3.1 INTRODUCTION

By the mid 1990's concerns had been expressed about the way in which low vision services were developing in the UK (Dickinson, 1995). Organisations and professionals concerned with the rehabilitation of people with a visual impairment knew very little about the number, type and distribution of low vision services available as the basis for future service development. To this end, in September 1997, Moorfields Eye Hospital and RNIB established a joint research project to survey low vision services in the UK. In 1999 the findings were disseminated widely to service providers and commissioners throughout the UK. This Chapter describes the study carried out in 1997/1998 by the author and Dr Louise Culham with the support of research assistants and an active advisory group. The author was the grant holder, methodologist, supervisor of data collectors and advisory group co-ordinator. Statistical analysis was undertaken by Catey Bunce and Jimmy Young.

3.1.1 The increasing demand for low vision services in the UK.

In the UK in the 1990s, over 90% of people with a visual impairment were over the age of 60 years (Evans et al., 1996) and it was predicted that the number of older people in the population would rise dramatically (Shaw, 2004). Unfortunately, medical intervention was unlikely to offer much help to reduce the numbers of people developing low vision as no treatment existed for dry age related maculopathy, the primary cause of visual impairment in the United Kingdom. In the absence of a cure for blindness, the importance of rehabilitation was being realised (Margrain, 1999).

3.1.2 Changes in low vision service delivery

A low vision service is a rehabilitative process which provides a range of services for people with a visual impairment to make maximum use of their eyesight to achieve maximum potential (Low Vision Services Consensus Group, 1999). This adaptive process may involve the acquisition of optical and non-optical aids and appliances, the development of novel handling and viewing strategies, and modifications to the visual environment including the use of new lighting and contrast enhancement techniques.

Keeler opticians started visiting Moorfields Eye Hospital in the 1950s to provide low vision services (Keeler, 1956). Early assessments focused largely on the provision of optical low vision aids which provided the patient with access to conventional sized print (Bier, 1960).

Over the next twenty years low vision service delivery developed rapidly throughout the UK. By 1977, when Silver and Thomsitt conducted a survey of low vision services, it was reported that there were 104 low vision service delivery points in the UK; 77 private services in optometry practices and 27 NHS services in the Hospital Eye Service (Silver and Thomsitt, 1977). Invariably low vision consultations were carried out by optometrists and/ or dispensing opticians. At that time, it was estimated that 35 000 low vision consultations took place annually principally in hospitals but a potential 75,000 could have benefited.

In 1991, McIllwaine et al reported that the Hospital Eye Service (HES) typically provided low vision aids (magnifiers) in a single visit to an outpatient clinic. Consequently, in the late 1980s and early 1990s this traditional low vision service delivery model was being challenged.

Reports from Scandinavian countries suggested there were benefits in providing additional training to encourage the optimum use of devices and

residual vision. Therefore, a role for low vision therapists or trainers, in addition to the traditional prescribing of low vision aids, emerged in some services (Landers et al., 1999; Shuttleworth et al., 1995).

Multidisciplinary clinics, involving a range of professionals working together, were also being developed (Giltrow-Tyler, 1988, Moore, 1994). These followed examples from America (Jose, 1983) and Australia (Lawrence, 1985).

With the development of shared care initiatives for community based optometrists, NHS funded low vision services in primary care also started to emerge (Rumney, 1992, Vineall, 1997).

3.1.3 The need to survey low vision service provision

Organisations and professionals concerned with the rehabilitation of people with a visual impairment knew very little about the number, type and distribution of low vision services available. Despite developments in the field, by the mid 1990's, concerns were expressed about the "fragmented and patchy" nature of low vision services in the UK (Dickinson, 1995). Although there were concerns that provision was inadequate, there were also fears that unstructured growth could lead to intra-professional competition and a severe weakening of service provision. It was therefore determined that a comprehensive survey of services was needed as the basis for future service development.

3.1.4 The aim

The aim of this study was to determine the nature, extent and geographical distribution of low vision services in the UK and to compare this with the low vision prevalence rates.

3.2 METHODS

3.2.1 The Advisory Group

Knowledge of the literature and a brainstorming session with an Advisory Group were used to develop the design of a retrospective survey of low vision services in the UK.

The advisory group (and titles at that time) comprised:

- Dr A J Jackson, Optometry Department, Royal Victoria Hospital Belfast.
- Christine Miles, Manager, Moorfields Eye Hospital.
- Dr Adrian Hill, Optometry Department, Oxford Eye Hospital.
- Mr Brian Jones, a low vision service user and RNIB Trustee.
- Prof Alan Bird, Clinical Director and Consultant Ophthalmologist, Moorfields Eye Hospital.

The basic assumptions, founded on existing professional knowledge of services, were that:

- there was no set pattern of provision;
- services were being provided in many types of location;
- services were using a variety of professional and voluntary practitioners who in turn were providing a variety service models and
- there was a need for comprehensive data about service availability.

Based on these assumptions, the project was designed to ensure that information was collected from as many low vision services in the UK as possible. The intention was to obtain a response rate as close to 100% as possible from a retrospective survey so that data about low vision services, and the population they served, could be mapped thus revealing regional and national trends.

3.2.2 Identification of potential providers of services

Six groups of potential providers of low vision services were identified and their details sought. These included:

- hospitals with eye departments or eye clinics (HED);
- optician/ optometry practices (OP);
- local authority social services (SSD);
- local societies/voluntary organisations for people with visual impairment (VO);
- specialist teachers (ST); and
- universities/colleges with optometry/optical dispensing courses (UC).

Helen Mason, a research assistant, compiled a database of potential service providers, guided by the knowledge and contacts of the Advisory Group. Service providers were identified using existing published directories. Comprehensive lists of local societies, social services, universities with optometry/ dispensing courses and specialist teachers were easily obtained. A single list of all hospitals was less easy to obtain and databases from a range of sources such as the AOP and the NHS Executive were amalgamated.

At that time, it was difficult to access a list of optometry/ optician practices. Every effort was made to obtain details from as many sources as possible. Health Authorities were contacted up to three times. GOC lists were used to identify practices but, as they only contained information about practitioners and not practices, only a proportion could be clearly identified as practice addresses. Practices listed in Yellow Pages were added.

3.2.3 Survey Questionnaire Design

The only survey that had previously been conducted on low vision services in the UK used a postal questionnaire (Silver and Thomsitt, 1977) and it was decided to follow this methodology.

3.2.3.1 *Postal Questionnaire*

A postal questionnaire was designed to establish the nature and extent of low vision services in the UK in 1997/8. The advisory group drafted an initial questionnaire which incorporated questions designed to investigate a broad range of key aspects about low vision services:

- the location of services;
- where the service was based (e.g. hospital, community);
- who was involved in providing the service;
- access to the services (referral and waiting times);
- the number of appointments;
- the funding; and
- the type of equipment provided.

While the questions were primarily closed in format, using tick box responses, there were a number of open ended questions that aimed to ensure that the diversity within services became apparent.

Fifty service providers from all sectors involved in low vision service provision vetted the questionnaire to ensure it was clear, appropriate and as easy to complete as possible. An academic psychologist reviewed the phrasing of questions and questionnaire design and it was piloted with 20 service providers.

The questionnaire was revised in light of feedback and the pilot and the final postal 29 item questionnaire used is shown in Appendix 3.

A carefully worded covering letter was written which incorporated both Moorfields Eye Hospital and RNIBs logo to encourage responses from as wide a group of respondents as possible (Appendix 4) and to this end a stamped addressed return envelope was provided.

3.2.4 Questionnaire Administration

The survey was conducted in six main phases between October 1997 and June 1998.

3.2.4.1 Postal Questionnaire

Postal questionnaires were sent to all potential providers of low vision services. The first questionnaires were dispatched in October 1997 and in small waves thereafter as new sources of contacts for these groups were found and contact lists were updated.

Three to five weeks after the initial questionnaire postal follow-ups, including a second copy of the postal questionnaire, were sent to all those who had not responded to the survey. These follow-ups were sent in consecutive groups to reflect the fact that some of the original postal questionnaires were dispatched later than others.

Six to eight weeks after the initial questionnaire those who had not yet responded were contacted by telephone and where a further copy of the questionnaire was needed this was sent.

In March 1998 an additional list of optometrists became available which included 672 practices not previously identified. Due to the number of practices involved it was decided that a second wave of questionnaires should be sent out. This was done in April 1998.

3.2.4.2 Telephone Questionnaire

Six months after the initial postal questionnaire was distributed, consultation with the advisory committee led to development of a telephone questionnaire.

The telephone questionnaire (Appendix 5) consisted of just 5 of the original 29 point questions covering: where they were based; whether a low vision service was provided; access to the services (waiting times); the number of appointments and funding. The questionnaire was piloted on a random sample of 20 optometrists and revised.

The shorter telephone survey was designed to be administered when providers failed to respond to the initial questionnaire, the follow up postal correspondence and the follow-up telephone communication.

With the exception of optometry practices, in May and June 1998, all those who had not responded to the postal survey were contacted and the telephone survey was administered.

Optician/optometry practices represented the largest potential provider group (n = 1683) and a notable proportion (n = 723; 43%) did not respond to the two postal questionnaires. The telephone questionnaire, administered to an 18% (n = 130) random sample of OPs that did not initially respond, found that only a small percentage (n = 22; 17 %) offered low vision services. This sample suggested that OPs accounted for only a very small proportion of the total providers, and the decision was made not to complete the telephone questionnaire with this group.

3.2.5 Analysis

Data entry onto an Access 97 database was undertaken by two individuals working to a protocol to ensure consistency. For purposes of validation, data

were double entered; a low error rate (0.9%) was recorded and data amended accordingly.

Analysis of the type and extent of services were performed using STATA software (Stata Statistical Software: Release 5.0 College Station, TX, USA: Stata Corporation).

Plotting the location of service providers across the UK was achieved using Geographic Information Systems (GIS) technology (Burrough and McDonnell, 1998) together with population (Census, 1991) and boundary data (BORDERS, 1991).

Postcodes were checked against the Post Office's postcode address file, which is the definitive listing of all postal delivery addresses in the UK. In order to relate service provision with the demands of the population, the numbers of people with a visual impairment based on RNIB prevalence rates (RNIB, 1999) were mapped according to local authority.

RNIB estimates of registerable visual impairment (RNIB, 1999) were calculated using percentages derived for different age groups from the survey of the needs of blind and partially sighted adults (Bruce et al., 1991). The percentage for each age group was multiplied by the estimates of the population by age within each local authority.

3.2.6 Availability of services

Services were categorised into one of three groups: 1, no service; 2, sell magnifiers only—that is, without assessment or professional support; 3, low vision services, including the prescribing of low vision aids (LVAs) and/or support, such as counseling or training.

No assessment was made of the completeness or quality of services, although inferences could be drawn from the information provided.

In order to determine the magnitude of services, the total number of consultations offered annually across the UK was estimated. This calculation was achieved by adding together the number of consultations each service provider reported they had undertaken. All appointments, for the purpose of prescribing LVAs, training, or counseling were included in this calculation.

3.3 RESULTS

3.3.1 Response rate

In total, 2539 potential low vision service providers were identified and, of these, 1679 (66%) completed questionnaires. With the additional data collected from 266 (11%) telephone questionnaires, the overall response rate was 77% (n = 1945) (Table 3.1).

This represents a 100% response from all provider groups other than the OPs that recorded a response rate of only 65% (n = 1090).

Type of provider	Number of postal questionnaires sent	Postal response	Telephone response	Overall responses
HED	277	223 (81%)	54 (19%)	277 (100%)
SSD	177	146 (82%)	31 (18%)	177 (100%)
VO	190	148 (78%)	42 (22%)	190 (100%)
OP	1683	960 (57%)	130 (8%)	1090 (65%)
ST	205	196 (96%)	9 (4%)	205 (100%)
UC	6	6 (100%)	0 (0%)	6 (100%)
Not specified	1	0 (0%)	0 (0%)	0 (0%)
Total	2539	1679 (66%)	266 (11%)	1945 (77%)

Table 3.1 Response rates HED = hospitals with eye departments; SSD = social services/social work departments; VO = local societies/voluntary organisations for people with visual impairment; OP = opticians/optometry practices; ST = specialist teachers, UC = universities/colleges with optometry courses.

3.3.2 An overview of low vision services

Of the respondents to the postal and telephone questionnaires, 41% (n = 803/1938) offered no service, 26% (n = 497/1938) only sold magnifying devices, and 33% (n = 638/1938) provided low vision services. The type of provision is summarised in Table 3.2. Of the 638 respondents that provided a low vision service 566 (89 %) responded to the postal questionnaire.

Type of provider	No service provided	Providers that only sell low vision aids	Providers of low vision services	Total providing some form of help	Total respondents to that question
HED	97 (35%)	0 (0%)	180 (65%)	180 (65%)	277
SSD	82 (46%)	5 (3%)	90 (51%)	95 (54%)	177
VO	98 (52%)	44 (23%)	47 (25%)	91 (48%)	189 [#]
OP	390 (36%)	448 (41%)	246 (23%)	694 (64%)	1084 [#]
ST	135 (66%)	0 (0%)	70 (34%)	70 (34%)	205
UC	1 (17%)	0 (0%)	5 (83%)	5 (83%)	6

Table 3.2 Overview of the low vision services provided by the 1945 respondents to the postal and telephone questionnaire. # = 1 voluntary organization and 6 optometry practices that returned a questionnaire but did not answer that question. HED = hospitals with eye departments; SSD = social services/social work departments; VO = local societies/voluntary organisations for people with visual impairment; OP = opticians/optometry practices; ST = specialist teachers, UC = universities/colleges with optometry courses.

3.3.3 The magnitude of low vision service provision

Responses indicated that just under 155 000 appointments for low vision services were offered annually. This figure excluded any projection from the

non-respondents, which was found to be small. HEDs (that is, 180 service points) were the largest provider of services with 65% of the total annual appointments. Although other provider groups accounted for a larger number of service delivery points (that is, 458) they undertook less low vision work (Table 3.2 and Fig 3.1).

There was wide variation in the number of appointments offered annually by service providers, from 2 to 4000. Many low vision services were small--163 (32%) of the 515 services that provided information about appointments offered less than 50 appointments per year. The median number of annual appointments for all services was 120; the modal value was 10 and was quoted by 42 respondents.

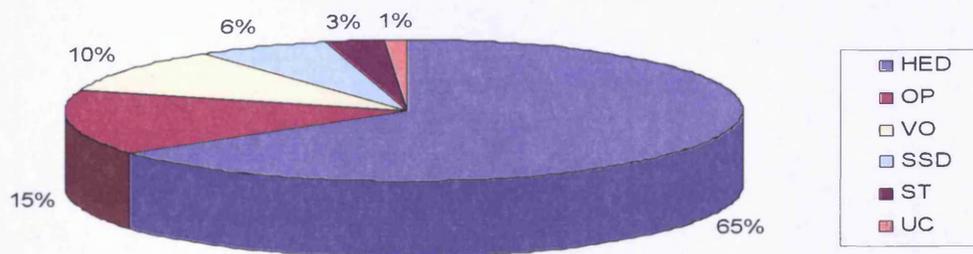


Figure 3.1 Percentage of the total number of appointments offered by provider type (n = 155 000). HED, hospitals with eye departments; SSD, social services/social work departments; VO, local societies/voluntary organisations for people with visual impairment; OP, opticians/optometry practices; ST, specialist teachers, UC, universities/colleges with optometry/optical dispensing courses.

3.3.4 Geographical location of service providers

The distribution of service delivery points, classified according to service provider, throughout the UK is illustrated in Figure 3.2. As expected, service providers were clustered in urban areas where population densities were highest, while rural regions were less well served.

Figure 3.3 shows the providers' location against the estimated visually impaired population mapped according to local authority boundaries. Where prevalence of visual impairment was highest but the general population was smaller, the number of service providers was relatively low. Conversely, in cities prevalence was moderate but the general population was larger and services were more available.

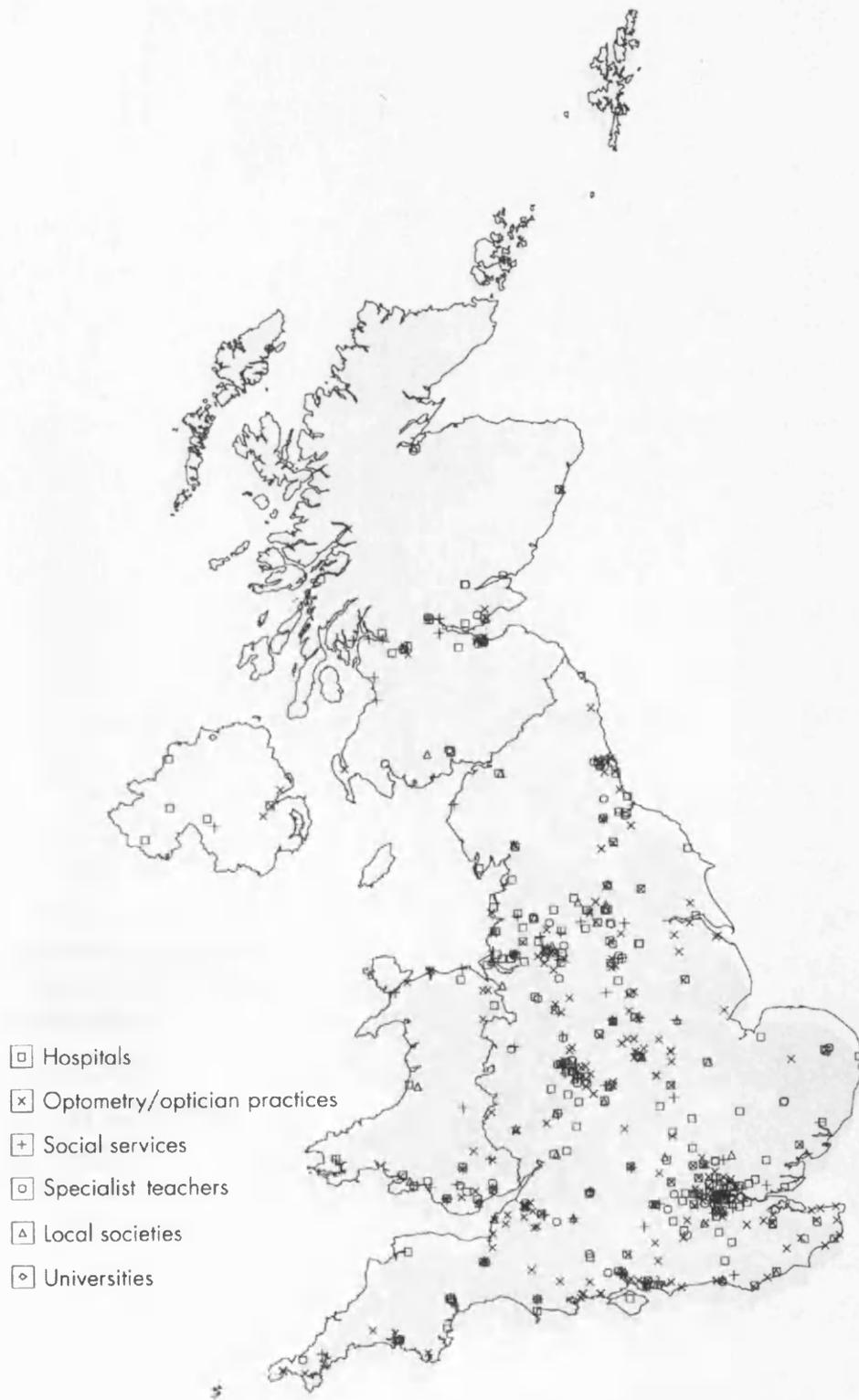


Figure 3.2 Location of low vision services in the UK.

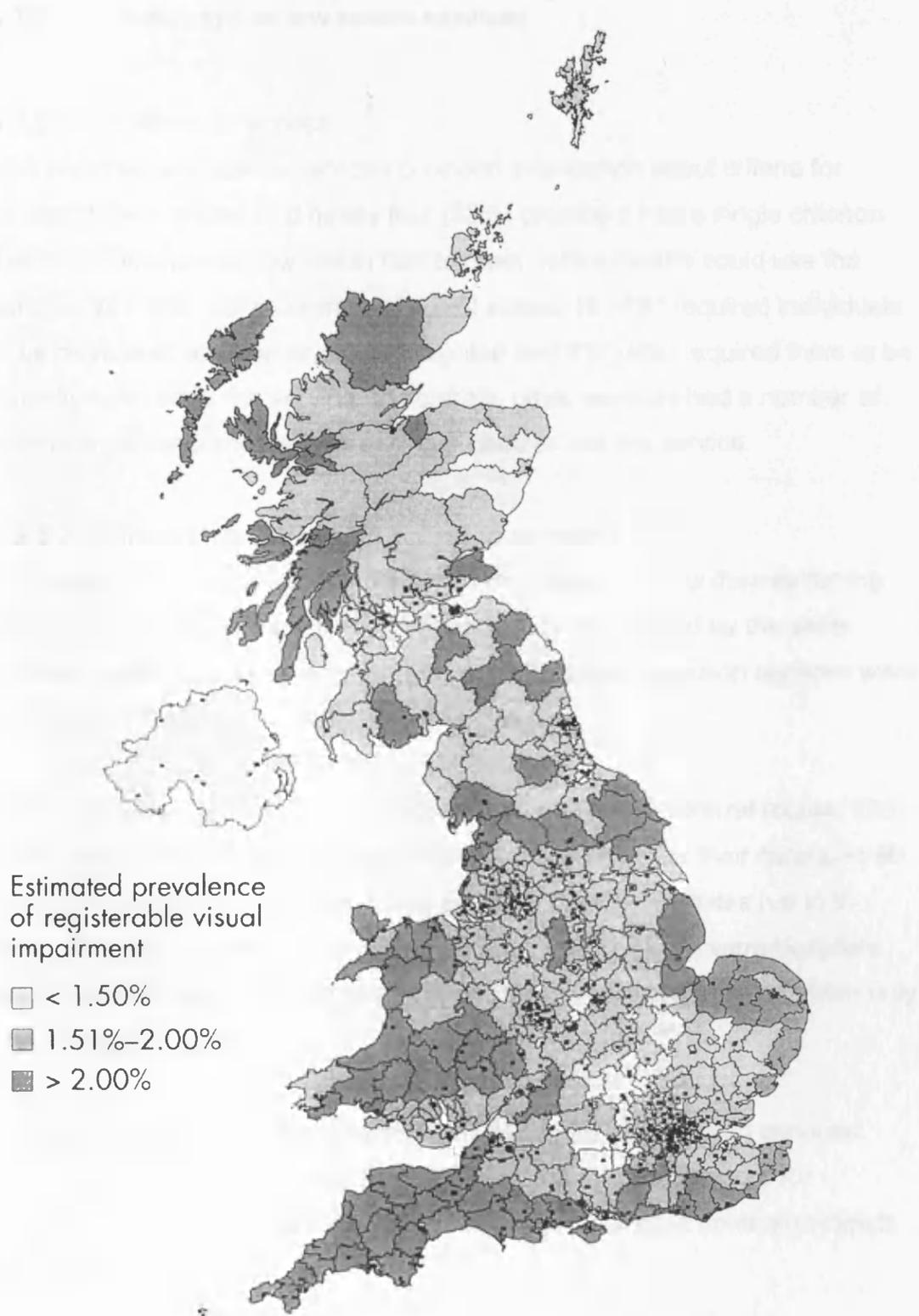


Figure 3.3 Location of low vision service providers against the visually impaired population according to local authority boundaries.

3.3.5 Gateways to low vision services

3.3.5.1 Criteria for access.

Five hundred and twelve services provided information about criteria for access. One hundred and ninety four (38%) providers had a single criterion that an individual with low vision had to meet before he/she could use the service: 92 (18%) set a criterion of visual status, 19 (4%) required individuals to be registered as blind or partially sighted and 83 (16%) required them to be formally referred to the service. In contrast, other services had a number of criteria or allowed anyone expressing a need to use the service.

3.3.5.2 Referral routes to gain access to services.

People access low vision services by different means. No uniformity for the referral routes was apparent even between services offered by the same provider types (for example referral routes to hospital low vision services were not always the same).

Of the 506 services that provided information about their referral routes: 233 (46%) services accepted referrals from the client/patient or their carers, in 98 (19 %) services there were 6 or more possible means of access (up to 9 maximum). One hundred and five (21%) (of which 32 (30%) were hospitals and 55 (52 %) were optometry/optician practices) accepted referrals from only one professional group.

Ophthalmologists were most often the gatekeepers of low vision services. This was either because of referral routes or due to a requirement for registration as blind or partially sighted that only consultant ophthalmologists can initiate.

3.3.5.3 *Waiting times for low vision appointments.*

People waited anything from under two weeks to one year for a low vision assessment appointment. Of the 574 services that provided information about waiting times for assessment appointments, 484 (84%) had waiting times of less than two months and 15 (3%) services reported waiting times over 6 months. The longest waiting times (> 6 months) were principally reported by hospitals or social work departments but one optician/optometry practice reported the same.

Some services from all provider types that supplied information had waiting times of less than two weeks: 3 Universities (40%), 5 social work departments (6%), 19 specialist teachers (33%), 20 local societies (48%), 21 hospitals (12%) and 168 optometry/optician practices (80%).

3.3.6 **Professionals and agencies involved**

Thirty-one different professions were reported to be involved in providing low vision services, some in isolation, others in teams. Low vision teams consisted of up to eight different professional groups. Generally, the more professions involved in a team, the broader the range of services provided.

Nine professional groups were cited by more than 1% of respondents:

- optometrists (293; 57%);
- dispensing opticians (152; 30%);
- rehabilitation workers (117; 23%);
- ophthalmologists (78; 15%);
- specialist teachers (77; 15%);
- social workers (48; 9%);
- orthoptists (32; 6%);
- counsellors (21; 4%) and
- nurses (20; 4%).



Many other professions, not widely recognised in the UK for their work in this field, were also reported. For example, disability advice officers, low vision therapists, technical officers, unqualified social workers, sensory impairment workers, support workers and low vision services officers. Six services mentioned the involvement of volunteers in their service.

Of the 515 service providers who responded with information about the different professions represented in their low vision teams, 57% (291) indicated that their team consisted of just one professional type.

3.3.7 Communication between agencies and professionals

Three hundred and thirty-four services provided information about the number of links that they had with other professionals and agencies. Service teams had links with between 0 to 10 agencies and professionals (Table 3.3). Low vision teams who completed the postal questionnaire (566) referred people to one or more of 31 different types of agency or professionals (Table 3.4).

There appeared to be no uniformity in the number or nature of links that a low vision service provider had and in general the provider type did not predict the links a provider had.

Voluntary organisations mentioned by less than 50 services included:

Citizens' advice bureaux, carers' organisations, organisations for older people and organisations for people with hearing impairment. Other professionals/agencies cited by less than 50 of the teams included (but were not limited to): optometrists, orthoptists, employment services, other low vision services, child development teams, talking book services and paediatricians.

Fifty-six of the 566 services that responded to the postal questionnaire (10%) reported not having any links at all with any other professionals or agencies.

Forty-six of these were based in optometry/optician practices.

Number of links	0	1	2	3	4	5	6	7	8	9	10
Provider Type (n)											
HED (57)	5	3	7	9	8	6	9	6	0	3	1
OP (162)	46	16	41	19	22	11	6	1	0	0	0
SSD (19)	0	1	1	2	5	2	3	2	2	1	0
VO (29)	3	8	4	3	2	2	0	4	3	0	0
ST (62)	2	2	3	8	5	14	15	11	2	0	0
UC (5)	0	1	0	1	1	1	0	1	0	0	0

Table 3.3 The number of links with agencies and professionals. HED, hospitals with eye departments; SSD, social services/social work departments; VO, local societies/voluntary organisations for people with visual impairment; OP, opticians/optometry practices; ST, specialist teachers, UC, universities/colleges with optometry/optical dispensing courses.

Agency/professionals	Total number of links
Ophthalmologists	333 (59%)
Local societies	296 (52%)
GPs	277 (49%)
Social workers	237 (42%)
Specialist teachers	177 (31%)
Rehabilitation workers	173 (31%)
Hospital-based social workers	114 (20%).
Other professionals or agencies mentioned by less than 50 services	88 (16%)
Counsellors	66 (12%)
National V I voluntary organisations	55 (10%)
Other voluntary organisations mentioned by less than 50 services	52 (9%)

Table 3.4 The agencies and professionals that the 566 low vision service providers that responded to the postal questionnaire linked with. NB some services linked with more than one agency or professional.

3.3.8 Funding of low vision services

A variety of sources of funding for low vision services exist (Table 3.5). The most frequently mentioned was the National Health Service (NHS). Of the 390 services that received NHS funding, 240 were through hospital contracts, 120 through the General Optical Services (GOS) and 30 through other NHS sources of funding. For example, primary care pilot studies.

Source of funding	Number of services (% of services)
National Health Service	390 (69%)
Private	221 (39%)
Social services	103 (18%)
Education	78 (14%)
Voluntary sector	65 (11%)
Employment	10 (2%)
Others	40 (7%)
No answer	4 (<1%)

Table 3.5 Funding of the 566 low vision services who responded to the postal questionnaire. NB Some services received funding from more than one source.

3.4 DISCUSSION

3.4.1 Response rates

The 100% response rate from the service providers responsible for offering most low vision services (HO, SSD, VO, ST, OC), means it is likely that the survey provided an good indication of provision of low vision services in the UK at that time. The overall response rate of 77% compares favourably with similar postal surveys—that is, 49.5% for a national survey in America (Owsley et al., 2009), 53% for a regional survey in Wisconsin, America (Nelipovich et al., 1991) and 75% for a national survey in America (Kirchner and Phillips, 1980).

3.4.2 Access to low vision services

Information about access to low vision services in terms of the geographic location of services, waiting times, criteria for access and referral routes was provided by this survey. Overall, it appeared there were many potential barriers encountered by a person with low vision trying to access a low vision service in the UK. It appeared that it was easier to access low vision services in some parts of the country compared to others and that people may have been able to use a low vision service in one area but not in another. Clearly there was inequality of access to low vision care.

3.4.2.1 Geographic location of services

This study has shown that services were unevenly distributed across the country (Figure 3.2) which supports the description of them as being "patchy" (Dickinson, 1995). Particularly notable was the scarcity of services in many areas where the prevalence of visual impairment was high (Figure 3.3), for example coastal and rural areas where, because of the migration of the elderly, the proportion of the population with visual impairment was often high. Difficulties getting to low vision services was found to be one of the greatest barriers to people receiving low vision care (Pollard et al., 2003). Lack of local

services in some areas meant that people had to travel long distances to get help and reaching a service was difficult for a group of people who often did not have access to private transport, did not go out alone, who encountered difficulties in using public transport (Baker and Winyard, 1998) and typically had other problems such as poor mobility (Klein et al., 2003).

3.4.2.2 *Waiting times*

There was variation in the length of time people had to wait to access a low vision service, ranging from less than two weeks to one year. It was, however, commendable that 84% of low vision providers reported waiting times of less than two months. This was contrary to the finding in focus groups with users of services who reported waits of between three and twelve months (Chapter 2 and (Ryan and McCloughan, 1999).

Once a person had been identified as having a sight problem he/she often had to wait a considerable time for an appointment with an ophthalmologist before being referred to a low vision service. Such waits could result in an extended period in which people could lose essential life skills and hence autonomy.

The problem of waiting times is important in every field of health and social care. Given the negative impact of serious sight problems on all aspects of life, from being able to make a hot meal to emotional well-being, many would argue that the initiation of low vision services at the earliest possible stage is essential. In a randomised controlled trial comparing low vision rehabilitation intervention with those on a waiting list for low vision rehabilitation (no intervention) it was found that the abilities of those waiting declined (Stelmack et al., 2008). Accordingly, the authors recommended that low vision rehabilitation commence as soon as possible (Stelmack et al., 2008). Less than two weeks was found to be the time period in which the majority of people felt they needed support the most (Ryan and McCloughan, 1999).

3.4.2.3 Criteria for defining who can use low vision services.

Variability in accessibility was also apparent in the differing criteria used to determine eligibility for and referral to low vision services. It has been shown that individual clinical measurements of vision alone do not predict the level of disability (and hence need for rehabilitation) that people experience as a result of their visual impairment (Legge et al., 1992). Despite this, whereas in some areas there were numerous routes for referral or people could refer themselves, in many areas, there was only one route or criterion.

Access into many low vision services in the UK was restricted by registration status and/ or visual status. This meant that a person could be eligible to use low vision services in one area but not another.

3.4.2.4 Referral routes to low vision services.

There appeared to be no uniformity in referral routes to low vision services; some services accepted referrals from numerous sources, whereas others limited themselves to a single one. People who used low vision services highlighted the need for local information about accessing them (Ryan and McCloughan, 1999). This finding strengthened the need to ensure professionals working with people with a visual impairment were aware of the routes by which services could be accessed especially because this survey demonstrated that low vision facilities were found in a large number of different types of base.

3.4.3 The availability of low vision assessments

One of the main questions facing those planning and commissioning low vision services relates to the demand for services. Age is a risk factor for vision loss (Evans et al., 1996) and the population is ageing (Shaw, 2004). The number of appointments had increased, as shown by a survey undertaken 20 years ago, when only 35 000 consultations took place annually (Silver and Thomsitt, 1977) compared to 150,000 in 1998.

Government statistics showed that in 1994 in the UK, 315 782 people were on the blind or partially sighted registers, and over 35 000 individuals were newly registered each year (Department of Health, Scottish Social Work Services Group, Welsh Office and Northern Ireland Health and Social Services Board 1994). It was widely acknowledged that this figure underestimated the true extent of registerable visual impairment in the population (Bruce et al., 1991, Evans et al., 1996, Reidy et al., 1998, Wormald et al., 1992, Evans et al., 2004). Furthermore, there were many who did not warrant registration but who could have been helped by low vision services. Thus, up to one million people in the UK at that time may have benefited from low vision support (70,000 of whom were newly impaired) but the system offered no more than 155,000 appointments per annum.

This study identified a means by which the potential increased demand for the service could be achieved. Hospital eye departments undertook the greatest amount of low vision work (that is, 65%). However, only one third of potential providers made an active contribution to low vision services, the majority either did not provide this service or simply sold magnifiers without professional support. Of particular note was the large number of OPs, which were staffed by professionals with appropriate training and expertise (Rumney, 1992), who did not offer a service.

Whilst this survey described services in 1997/1998, services now may be significantly different. In 1999, recommendations about the future of low vision service provision were made (Low Vision Services Consensus Group, 1999). In addition, in some areas significant expansion of hospital (Lindsay et al., 2004) and primary care low vision services (Margrain et al., 2005) have been reported. A follow-up survey to determine the impact of these initiatives would be useful.

3.4.4 Professionals working in low vision services

Low vision impacts on all areas of an individual's life including social, psychological, educational, employment and leisure aspects. In order to meet the arising needs, a broad range of rehabilitative measures is required and it would seem appropriate to involve a range of agencies and professionals. At the time of the study, the Government was just starting to promote this joint working as an approach to rehabilitation (Department of Health, 1998a) and the benefits of this approach to visual rehabilitation in the UK had been suggested (Shuttleworth et al., 1995).

The results of this survey show that someone going through a low vision service might have encountered one or more of 31 different professionals. In some services different professional groups worked together in multi-disciplinary teams.

The finding that professionals who have an optical training worked in low vision services (optometrists 52%, dispensing 27%) is consistent with the only other survey of low vision services in the UK (Silver and Thomsitt, 1977). There appeared however, to be other professionals involved with service provision. Of particular note was the involvement of rehabilitation workers. This was a relatively new professional group that was not established when the survey of low vision services by Silver and Thomsitt was undertaken in 1977. Rehabilitation workers are not optically trained but have low vision modules in their education (Jackson and Wolffsohn, 2007). They were usually employed by social services departments to provide practical assistance in the home environment in areas of: lighting, communication, daily living and mobility. The dramatic increase in their involvement suggests that they brought useful skills to the low vision team.

Although a broad range of rehabilitative measures is required and this would necessitate involvement of a range of agencies and professionals, the finding

that so many of the 31 'professionals' were from non-established professional groups is concerning. This indicated the need for an examination of the roles played by different professions to ensure the best use of skills and resources. A review of the training required to achieve suitable levels of expertise was also required particularly because many professionals appeared to be working in isolation. It would be impossible for someone working in a low vision service to be able to remember what 31 different professionals did. It is hard to imagine how someone using the services could determine or remember who did what.

3.4.5 Co-ordination of services

Collaboration with professions outside the immediate team is an important aspect of holistic low vision care and it was impressive that professionals may have passed a person on to one or more of 31 different types of agency or profession. However it appeared that, all too often, professionals and agencies involved in the provision of visual rehabilitation were acting alone or with only weak links with others. This poor communication may have exacerbated problems of efficiency of care and at the very least caused confusion for those working within the field and those using the services.

The wide variation in the extent and nature of collaboration found in this study indicated that this was an important area that deserved attention. It is hoped that the recommendations of the Low Vision Consensus Group (Low Vision Services Consensus Group, 1999) have helped to remedy this problem by encouraging agencies to work together and triggering an evaluation of models of care. To date, only one comparison of different models of care in the UK (Reeves et al., 2004) has been published.

3.4.6 Funding of low vision services

The majority of low vision services received some NHS funding. In contrast, only 18 per cent received funding from social services. Rehabilitation services

for older people required joint working between health and social services (Department of Health, 1998a). Low vision services are not an exception to this because skills gained in low vision "clinics" needed to be transferred to the person's own environment. An inspection of social services for people with a visual impairment showed that low vision services were variously provided by social services departments and voluntary organisations and it was suggested they would benefit from greater co-ordination with NHS low vision services (Department of Health, 1998b).

3.4.7 Shortcomings of the research

It is worth noting that the data collection was particularly challenging due to a lack of published databases of potential service providers, inadequacies in prevalence data and problems defining authority boundaries. An effort was made to use the best information available and address inadequacies whenever possible.

A subsequent study highlighted problems with the survey because of the use of the postal administration. In particular, possible misinterpretation of questions and the problems associated with whoever completed the postal questionnaire (Owen et al., 2003). Another study in Wales also reported difficulties obtaining information from low vision services in Wales (Furze et al., 2001) using postal administration. Therefore, in future surveys of service providers, resources should be sought to carry out telephone surveys rather than postal surveys.

The survey relied on the self reporting of waiting times and number of appointments. Many of the services did not collect this information routinely and so relied on estimates which may not have been accurate.

The development of an outcome measure for a community- based low vision service.

4.1 INTRODUCTION

In 2004 the Welsh Assembly Government commissioned the establishment of a community based low vision service throughout Wales. As this was the first attempt at a large-scale, national, government funded, multi-centre low vision service in the UK it was vital that the effectiveness of the service was evaluated. This chapter describes the development of an outcome measure used to evaluate the effectiveness of the service.

4.1.1 The establishment of a community based low vision service

The growing number of people with a visual impairment (Bunce and Wormald, 2006) and fragmented nature of low vision services (Culham et al., 2002, Ryan and Culham, 1999) prompted the Welsh Assembly Government to establish an all Wales Low Vision Service (WLVS) (Margrain et al., 2005). The service, which opened its doors in the summer of 2004, was based on the conventional hospital eye service model but was located in community based optometric practices and existed alongside established services in secondary care. It was staffed by accredited optometrists and a limited number of dispensing opticians, who successfully passed a theoretical and practical course in low vision, administered by Cardiff University.

The service responded to the views of patients (Ryan and McCloughan, 1999) and enshrined many of the features recommended by the UK Low Vision Services Consensus Group (Low Vision Services Consensus Group, 1999).

That is, the service had good links with other services (secondary health care, social services, education professionals and voluntary organisations), it was provided close to where it was needed, waiting times were expected to be less than 2 weeks and people with low vision could be referred to the service via a number of routes including self referral (Margrain et al., 2005). Low vision aids were provided on a loan basis and home visits were made where necessary. Anyone with a visual acuity of 6/12 or less, N6 or less, or whose field was significantly restricted, could access the service.

4.1.2 Measuring the effectiveness of the Welsh Low Vision Service (WLVS)

Although the WLVS was designed to be more 'user friendly' than traditional UK hospital based services it was not clear whether it was effective. All of the practitioners (over 170) providing the service, were trained and accredited, but there were differences in prior experience and the number of patients seen by them (some assessed less than 20 people a year). Consequently, there could have been variations in the effectiveness of the service in different locations. How then could the performance of a large-scale, multi centre, low vision service be evaluated?

4.1.3 Early attempts to measure the effectiveness of low vision services

The first attempt to measure the effectiveness of low vision services was reported in the literature in 1956 (Fonda, 1956). Fonda (1956) interviewed patients who had been "examined for low vision lenses at the Lighthouse (the New York Association for the Blind)". A questionnaire was used to determine how often, for how long and for what purpose low vision aids were used. It was reported that 34.6% of the 500 people assessed benefited from the intervention.

In the years that followed studies attempted to assess the effect of low vision interventions on objective task measures such as reading speed, patient satisfaction with low vision services and frequency and type of low vision aids used (McIlwaine et al., 1991, Temel, 1989, Shuttleworth et al., 1995, Nillson and Nillson, 1986, Leat et al., 1994). However, this emphasis on performance-based outcomes in a clinical setting was later thought to be too 'simplistic' (Dickinson, 1995). For example, in a survey by Leat et al (1994), 75% of patients could read newsprint equivalent in the clinic, but only 35% admitted to reading normal print at home.

All the early studies that tried to determine the effectiveness of low vision services in the UK (McIlwaine et al., 1991, Humphrey and Thompson, 1986, Shuttleworth et al., 1995) used LVA use as the primary indicator of success. McIlwaine et al and Humphrey et al found that a large proportion of people were not using the LVAs prescribed and argued, therefore, that the low vision services were not cost effective. In 1995, Shuttleworth et al found much better use of LVAs and explained this by their better service with follow-up of all patients and addition of therapy (training in the use of low vision devices and vision). However, the validity and reliability of the questionnaires used in all three studies were not established.

In 1999 a team from Manchester (Harper et al., 1999) reported the development of a questionnaire specific to low vision rehabilitation, the Manchester Low Vision Questionnaire (MLVQ). This contained sections that addressed the use of LVAs, importance of LVA's and satisfaction with the service. The validity and reliability of the MLVQ were reported.

4.1.4 Quality of life and visual function questionnaires

As outlined in the Chapter 1, like other areas of ophthalmology, (Fielder et al., 1999) QoL became an important measure when trying to determine the effectiveness of a low vision service (Mangione et al., 1998b, Hinds et al.,

2003, Scott et al., 1999, Stelmack et al., 2002, Wolffsohn and Cochrane, 2000) or intervention (Smith et al., 2005, Reeves et al., 2004). However, despite over 95% of people attending modern UK low vision services reporting that they used the devices loaned (Hinds et al., 2003, Reeves et al., 2004), improvements demonstrated in QoL following low vision intervention at the time the WLVS was established had been very modest (Wolffsohn and Cochrane, 2000, Stelmack et al., 2002, Hinds et al., 2003, Scott et al., 1999). Such modest findings could have been attributed to insensitive outcome measures and/ or could have reflected the fact that current forms of low vision service provision had little effect on overall QoL. What ever the reason, the use of patient based outcome measures that are unresponsive to the intervention is inappropriate (Fitzpatrick et al., 1998). From a service evaluation perspective the use of unresponsive outcome measures is highly problematic because they cannot differentiate between services that are offering a high standard of care from those that are not.

While in the area of health care assessment, QoL is a concept about which there is little agreement (Fitzpatrick et al., 1998, Garratt et al., 2002), within the area of vision rehabilitation, the notion that it was a multidimensional concept (which includes a functional, a physical, a social and a psychological dimension) was popular (Aaronson, 1988). Evidence suggested that, low vision services had their greatest effect on the 'functional' dimension (Stelmack et al., 2002, Wolffsohn and Cochrane, 2000). More specifically, low vision service provision had repeatedly been shown to help people with particular near, reading and distance vision tasks (Stelmack et al., 2002, Stelmack et al., 2006, Wolffsohn and Cochrane, 2000) i.e. it reduced disability for some near, reading and distance tasks. This is not surprising because one of the primary aims of low vision service provision is to help people overcome the disabling effects of visual impairment.

4.1.5 The use of Rasch analysis

The need for sensitive instruments to evaluate low vision service outcomes has meant that the development of questionnaires in the low vision field was possibly one of the most advanced in any area of ophthalmology. Of particular note was the use of Rasch analysis to improve the design, sensitivity and validity of questionnaires (Babcock-Parziale et al., 2005, Massof and Fletcher, 2001, Massof and Rubin, 2001, Massof, 2002, Pesudovs, 2006, Smith et al., 2005, Stelmack et al., 2004, Stelmack et al., 2002, Stelmack et al., 2006).

Most of the visual function assessment and QoL questionnaires used in ophthalmology used Likert scales (Massof and Rubin, 2001). Typically, the category labels used (e.g. "agree", "disagree") were assigned numerical values which added together to provide a domain and/or instrument scores. However, it is not appropriate to perform mathematical operations on values which originate from ordinal scales because the true relationship between response categories is unknown. In addition, this assumes that items within each sub-scale are of equal difficulty, each sub-scale is of equal difficulty and patients' responses to one item correspond to patients' responses to another item. Rasch analysis can be used to overcome many of the limitations associated with Likert scales (Massof, 2002, Pesudovs, 2006) by providing estimates of the weights of the different items that correspond to the difficulty of the activity described by the item (Bond and Fox, 2001).

4.1.6 Aims

The aim of this study was to develop and validate a short, sensitive, user centred, outcome measure and to describe its psychometric properties using Rasch analysis. In accordance with government funded National Health Service (NHS) Health Technology recommendations the measure should be: appropriate, responsive, valid, precise, easy to interpret, reliable, acceptable to patients and feasible in terms of the burden associated with its administration (Fitzpatrick et al., 1998).

4.2 METHODS

4.2.1 Questionnaire selection

Development of an entirely new instrument was outside the scope of this study there being many good examples already available (de Boer et al., 2004, Massof and Rubin, 2001, Raasch et al., 1997, Stelmack et al., 2006).

In March 2004, all questionnaires that had been used to evaluate low vision service outcomes were reviewed. Questionnaires were considered if:

- 1) published information regarding their development and psychometric properties was available;
- 2) they measured one or more dimensions of QoL as defined by Aaranson (1988); and
- 3) they had been reported to be sensitive to at least one low vision intervention.

At that time, only 3 questionnaires met the criteria: the VCM1; the National Eye Institute Visual Function Questionnaire (NEI VFQ); and the Low Vision Quality of Life questionnaire (LVQoL).

Of the three questionnaires reviewed, the NEI VFQ was considered to be the most suitable for several reasons:

- a change in QoL had been demonstrated in three low vision services by two independent research teams (Scott et al., 1999, Stelmack et al., 2002);
- it had been used to study populations in the UK (Smeeth et al., 2003);
- single item Rasch scores had been published which facilitated the evaluation of individual questions and
- the impact on the score of other factors such as depression and general health had been investigated (Miskala et al., 2004, Rovner et al., 2006).

The LVQoL was designed to evaluate low vision services (Wolffsohn and Cochrane, 2000) and it had been recommended for this purpose (de Boer et

al., 2004). However, single item scores had not been published and so there was no evidence upon which to base decisions of item reduction. The full instrument (25 questions) was deemed too long for the purpose intended. Additionally, it had not been used on a UK population. Three of the 10 items in the VCM1 (Frost et al., 1998) were found to be sensitive to low vision intervention in Fife (Hinds et al., 2003). The VCM1 was short enough to be used in its entirety, but it had no items in the functional dimension of QoL and Rasch analysis had not been performed on responses.

4.2.2 Questionnaire design

The original NEI-VFQ consisted of 51 items (Mangione et al., 1998a, Mangione et al., 1998b) but a shorter 25 item version, with 14 additional optional items, was later developed (Mangione et al., 2001). Given the scale of the WLVS, and the desire to evaluate the service continuously on a centre by centre basis, there was concern that the 25 item version of the NEI-VFQ was too long.

Scott et al (1999) had reported a change in the NEI VFQ (51) raw score following attendance at the low vision clinic in Bascom Palmer Eye Institute. Single item scores were not published. Evaluation of single item Rasch scores following attendance at two particularly comprehensive low vision services for veterans in America suggested that only 7 items were sensitive to low vision service intervention (Stelmack et al., 2002). Four activities were significantly less difficult after both of the services; and three additional activities were found to be significantly less difficult after one of the services. These questions were relevant to service users and they fitted Aaranson's definition of the functional dimension of QoL. It was also noted that the face validity of these questions was very similar to those on other outcome measures (Stelmack et al., 2004, Stelmack et al., 2006, Weih et al., 2002, Wolffsohn and Cochrane, 2000) (Table 4.1)

Item	Question	Original item		Comparable items on		
		number	number	other questionnaires		
		NEI	NEI	LV	LV	IVI
	Because of your eyesight, how much difficulty do you have....	VFQ	VFQ	QoL	VFQ	
			25		48	
1	reading ordinary print in newspapers?	15	5	18	34	7
2	doing work or hobbies that require you to see well close up, such as cooking, sewing, fixing things around the house, or using hand tools?	17	6	21	42	2
3	reading street signs or names of shops?	20	8	6	48	15
4	going out to see films, plays or sports events?	34	14	-	44	5
5	reading small print in a telephone book, or on a medicine bottle, or on legal forms?	16	A3	19	36	13
6	figuring out whether bills you receive are accurate?	26	A4	20	35	-
7	seeing and enjoying programmes on television? (changed to 'watching television')	32	A8	7	39	3

Table 4.1 The 7-items from the NEI-VFQ used to develop the outcome questionnaire and item numbers of comparable questions on other low vision questionnaires.

The WLVS focused on providing magnifiers, lighting, tints and advice. The seven items included aspects of functioning on which one would reasonably expect the new NHS funded WLVS to have an impact. They did not include items such as mobility and daily living skills which were covered by the local authority funded social services rehabilitation programmes in Wales, with which the NHS links, but which are not the focus of this evaluation. Accordingly a choice was made to base the outcome measure on these 7 items.

The information sheet for the NEI VFQ was revised to Anglicise the language, include the use of low vision aids in the instructions as recommended by Stelmack et al (2002) and incorporated a consent form.

It has been shown that people with a visual impairment can self-complete questionnaires if they are provided in large bold print (Wolffsohn and Cochrane, 2000). A version with 16 point bold print was piloted with two groups of people with low vision who attended Cardiff Institute for the Blind. They were asked to indicate whether they understood the questions, thought them to be relevant and the ease with which they themselves were able to complete them. Both groups reported that they found the questionnaire relevant and easy to complete. On their recommendation the wording of the question about television was changed. They didn't understand 'seeing and enjoying programmes on television' and asked for it to be changed to 'watching television'.

The questions were rated on a 1 to 6 scale, with response choices including no difficulty, a little difficulty, moderate difficulty, extreme difficulty, stopped doing this because of my eyesight, and stopped doing this for other reasons / not interested.

4.2.3 Administration of the 7-item NEI VFQ and record card.

During the establishment of the WLVS practitioners were informed of the study during their training and a copy of the protocol was included in the Service Manual.

Accredited practitioners were asked to distribute questionnaires along with a stamped addressed envelope to adults (>17 years of age) who booked an appointment for a low vision assessment. Patients who were prepared to take part in the study were asked to complete the questionnaire at home, before their appointment, and to return it completed, in a stamped addressed envelope to a central NHS administration team in Carmarthenshire LHB where the information was transferred to a centralised database.

In order to compare the biographical characteristics of those who did and those who did not complete or return the postal questionnaire, practitioners were also supplied with standard record cards (Appendix 7). Both biographical and clinical information was recorded and the record cards were faxed (via a secure fax) to the central NHS administration team following the low vision assessment. Data from patients who provided informed consent was incorporated into the database.

All procedures adhered to the tenets of the Declaration of Helsinki and ethical approval was obtained from the all Wales Research Ethical Committee (Appendix 8).

4.2.4 Statistical analysis

Biographical and clinical information and questionnaire data of those seen in the first year of the service (1 July 2004 to 1 July 2005), were transferred from the centralised database to SPSS 12.0.1 for analysis. Data from record cards

were matched with returned questionnaires on the basis of date of birth and name.

People without full biographical information (age, gender, binocular visual acuity, eye condition, registration status and living situation) were removed from the sample. Questionnaires that were dated after the assessment date on the record card were also removed.

Response categories 1 to 6 on the questionnaire response were recoded in SPSS as 0 to 5. In accordance with previous studies of the NEI VFQ, the last category "Stopped doing this for other reasons other than eyesight or not interested in doing this" was treated as missing data (Stelmack et al., 2002).

Patients with missing data for 3 or more of the 7 questions (i.e. more than 33% of questions) were removed from the sample because they were deemed unreliable.

To look for response bias, the demographic and visual function characteristics of patients who returned completed questionnaires was compared with those who did not return completed questionnaires. Following evaluation of the distributional characteristics of the data set (Shapiro-Wilks test) the Mann-Whitney U test was used to evaluate age and visual acuity data. Chi square tests were used to determine differences in gender, prevalence of AMD and living situation.

Rasch analysis was performed by Dr Helen Court using the Andrich Rating Scale model which was implemented using Winsteps Ver. 3.58.1 (Linacre, 2005). Rasch analysis assumes that only one underlying variable is being measured by the questionnaire i.e. that the scale is unidimensional. The analysis applies a probabilistic logistic model to the data set to produce logit values which provided estimates of the visual ability of each person, the

inherent difficulty of each item and the threshold for each response category on an interval logit scale. Summary fit statistics (Infit and Outfit mean square) described how well both item scores and person responses fit the Rasch model. Infit statistics are weighted to give more importance to those people who were closer to the item mean. Outfit statistics are not weighted and so, are more sensitive to outlying scores. Items which fit perfectly to the unidimensional scale have an expected Infit and Outfit mean square statistic of 1. Therefore, when examining the properties of a questionnaire, these statistics provide information about which items do not appear to be measuring the same underlying concept.

Dr Court also assessed the quality of the data using traditional statistical tests i.e. testing the normality of the data, calculating the percentage of missing data and assessing ceiling effect. The reliability of the data was also calculated with Cronbach's alpha.

4.3 RESULTS

4.3.1 Responses

In the first year of the service, 2255 adults were seen in 112 practices for a low vision assessment. During this initial period compliance with filling in the standard record card, recruiting people and giving out questionnaires improved. Reliable questionnaire responses were available for 490 adults who consented to take part in the study for whom full biographical information was available. Full biographical information was available for a further 664 people who attended for an assessment and consented for information from their record to be used.

The demographic and visual functioning characteristics of the sample (n=1154) are presented in Table 2. There were no significant differences in the age (Mann-Whitney U, p=0.291), gender (Chi square, p=0.750), distance binocular VA (Mann-Whitney U, p=0.862), living situation (Chi square, p=0.336) or prevalence of macular degeneration (Chi square, p=0.311) between those who returned a completed questionnaire and those who did not.

	questionnaire returned n = 490	questionnaire not returned n = 664
Mean age (range; SD)	80.2 (18-101;11.8)	80.6 (21-103; 12.3)
Binocular VA (range; SD)	0.75 (-0.1- 1.78; 0.36)	0.75 (-0.1-1.90; 0.36)
Men , women	166 (34%), 324 (66%)	219 (33%), 445 (67%)
AMD , no AMD	373 (76%), 117(24%)	488 (73%), 176 (27%)
Living alone	222 (45%)	325 (49%)
Living with partner / spouse	179 (36%)	213 (32%)
Living with relative / friend	60 (12%)	82 (12%)
Sheltered accommodation	18 (4%)	20 (3%)
Residential care	11 (2%)	24 (4%)

Table 4.2 Demographic and visual functioning characteristics of adults who did and did not return a completed questionnaire.

4.3.2 Initial questionnaire description

The Winsteps programme (Linacre, 2005) enables item difficulty and person ability to be visualised along a linear scale known as a 'person-item map' (Figure 4.1).

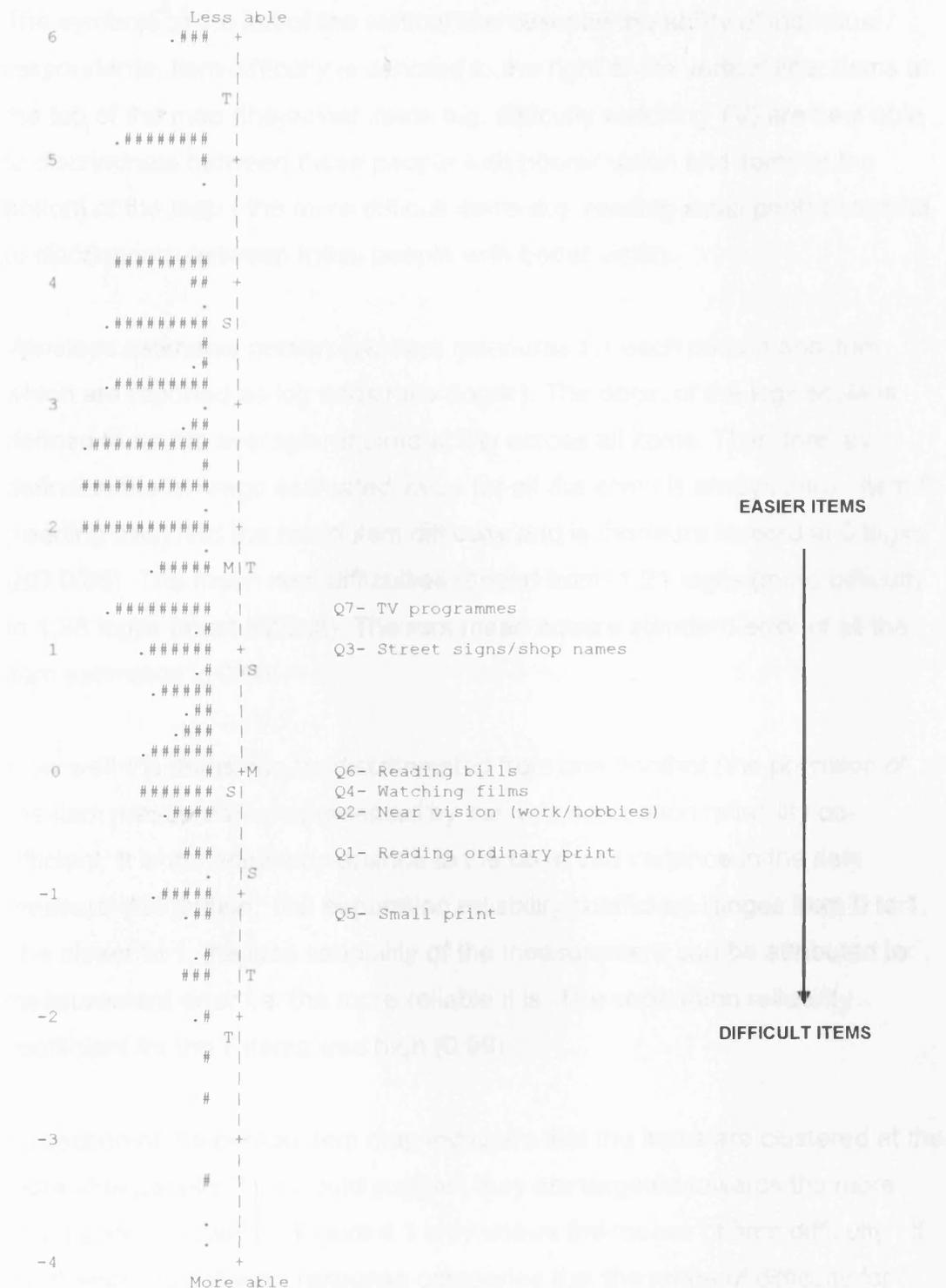


Figure 4.1 Rasch person-item map for the 7-item NEI-VFQ with 5 response categories.

Patients are represented on the left of the line: '#' is equal to 3 people and '.' is equal to 1 person. Items are represented by Q followed by item number on the right of the line. More visually able subjects and difficult items are placed near the bottom of the map. M = means, S = 1 standard deviation from the mean, T = 2 standard deviations from the mean.

The symbols to the left of the vertical line describe the ability of individual respondents. Item difficulty is denoted to the right of the vertical line. Items at the top of the map (the easier items e.g. difficulty watching TV) are best able to discriminate between those people with poorer vision and items at the bottom of the map (the more difficult items e.g. reading small print) best able to discriminate between those people with better vision.

Winsteps estimates person and item measures for each person and item which are reported as log odds ratio (logits). The origin of the logit scale is defined to be the average required ability across all items. Therefore, by definition the average estimated value for all the items is always zero. Item 6 (reading bills) had the mean item difficulty and is therefore located at 0 logits (SD 0.86). The mean item difficulties ranged from -1.21 logits (more difficult) to 1.38 logits (least difficult). The root mean square standard error of all the item estimates is 0.08.

How well the items can be discriminated from one another (the precision of the item measures) is represented by the item separation reliability coefficient. It is the adjusted variance to the observed variance in the item measure distribution. The separation reliability coefficient ranges from 0 to 1. The closer to 1, the less variability of the measurement can be attributed to measurement error i.e. the more reliable it is. The separation reliability coefficient for the 7 items was high (0.99).

Inspection of the person-item map indicates that the items are clustered at the more able people. This would suggest they are targeted towards the more able people. However, Figure 4.1 only shows the means of item difficulty. If the thresholds between response categories (i.e. the range of difficulty for each item) were presented on the map then the questions would cover more people.

The mean (SD) of the person estimates is 1.70, ranging from -3.90 to 6.48 logits. The root mean square standard error of the person estimates was 0.74.

The person separation reliability coefficient describes the reliability of person ordering and is similar to the conventional Cronbach's alpha coefficient. Like the item separation reliability coefficient, the person separation reliability coefficient ranges from 0 to 1 (1 being most reliable). For this sample it was 0.85.

The person separation ratio expresses the reliability of the scale to discriminate between people of different abilities. It was 2.39 for this sample, which exceeds the minimum recommended value of two (Pesudovs et al., 2003). Therefore, inspection of Figure 4.1 shows a substantial range in person ability, a relatively limited range in item difficulty and a mismatch between person and item means.

4.3.2.1 Response scale analysis

In order to see if the category structure worked, the response categories were analysed (Figure 4.2). Initial inspection of category usage data showed that all categories had been used, but category 0 (no difficulty at all) far less so than the others (0-8%). Therefore, it was decided to combine category 0 (no difficulty at all) with category 1 (a little difficulty) in the analysis.

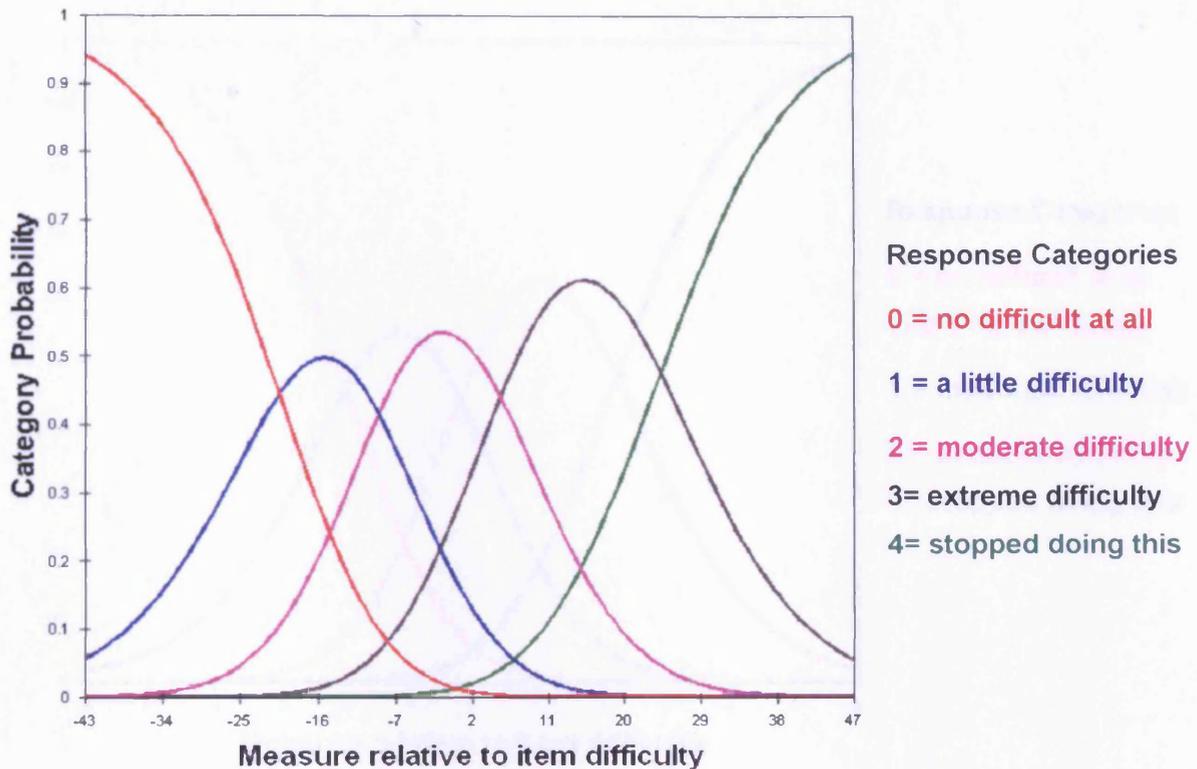


Figure 4.2 Graph of response category usage with 5 response categories

When category 0 and category 1 were combined this improved category utilisation of the end category (4-22%) (Figure 4.3) and had the added benefit of improving the targeting of questions to persons (Figure 4.4).

The mean of the person estimates reduced to 0.86 logits. The root mean square standard error of person ability and item difficulty estimates were 0.78 and 0.09 respectively. Regarding the ability of the scale to discriminate between patients of different visual ability, person separation reduced slightly from 2.39 to 2.32 after category combination, however, it still remained above the value 2 recommended as a minimum by Pesudovs (2003).

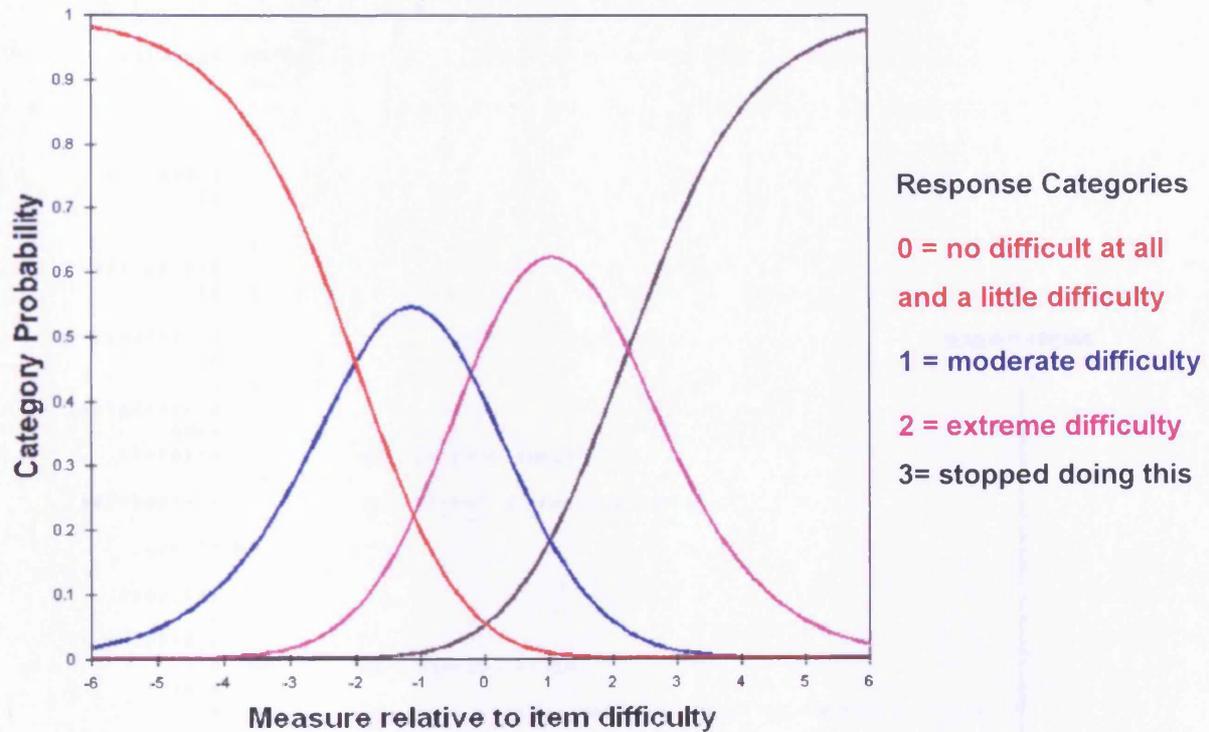


Figure 4.3 Graph of response category usage with 4 response categories

The reliability of the scale was not compromised by reducing the categories from five to four. Prior to reduction Cronbach alpha = 0.9034. After reduction Cronbach alpha = 0.9002.

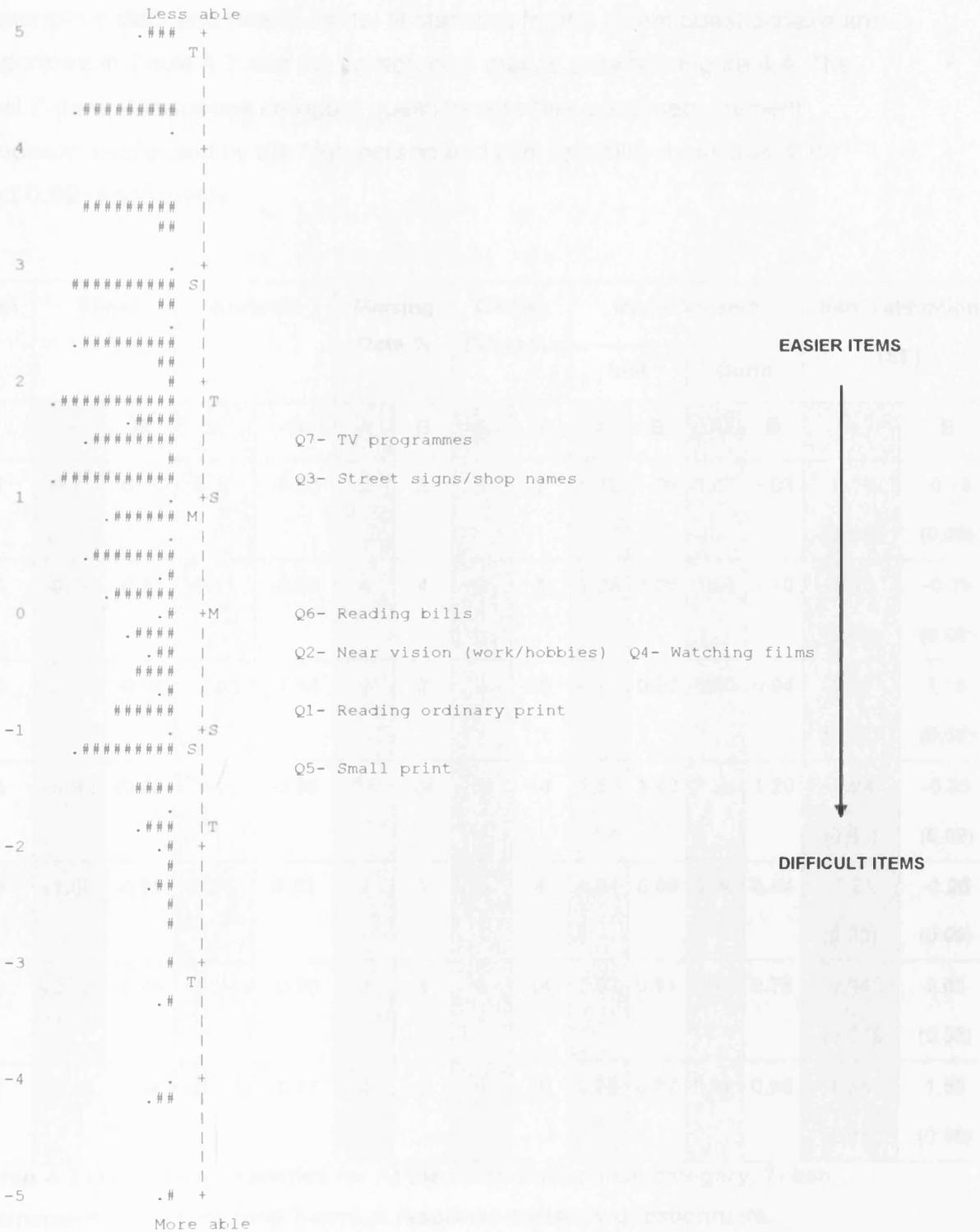


Figure 4.4 Rasch person-item map for the 7-item NEI-VFQ with 4 response categories. Patients are represented on the left of the line: '#' is equal to 3 people and '.' is equal to 1 person. Items are represented by Q followed by item number on the right of the line. The more visually able subjects and difficult items are placed near the bottom of the map. M=means, S=1 standard deviation from the mean, T=2 standard deviations from the mean.

Descriptive data and Rasch model fit statistics for the 7 item questionnaire are described in Table 4.3 and the person item map is shown in Figure 4.4. The final 7-item, 4 response category questionnaire has good measurement precision expressed by the high person and item reliability measures, 0.84 and 0.99 respectively.

Item	Skew		Kurtosis		Missing Data %		Ceiling Effect %*		Mean Square†				Item calibration (SE)	
	A	B	A	B	A	B	A	B	Infit		Outfit		A	B
1	-0.91	-0.76	0.22	-0.36	2	2	1	7	1.12	1.09	1.07	1.05	-0.75	-0.78
													(0.08)	(0.08)
2	-0.74	-0.51	0.11	-0.66	4	4	2	8	1.08	1.08	1.09	1.10	-0.29	-0.29
													(0.08)	(0.08)
3	-0.42	-0.04	-0.63	-1.14	2	2	8	20	0.96	0.97	0.93	0.94	1.06	1.10
													(0.07)	(0.08)
4	-0.99	-0.75	-0.16	-0.93	24	24	5	14	1.50	1.42	1.28	1.20	-0.24	-0.35
													(0.09)	(0.09)
5	-1.05	-0.98	1.15	0.82	1	1	0	4	0.84	0.89	0.80	0.84	-1.21	-1.26
													(0.08)	(0.09)
6	-0.73	-0.49	-0.24	-0.90	4	4	3	14	0.82	0.81	0.76	0.75	0.04	0.03
													(0.07)	(0.08)
7	-0.44	0.04	-0.13	-0.77	2	2	6	20	0.86	0.87	0.88	0.90	1.38	1.55
													(0.07)	(0.08)

Table 4.3 Descriptive statistics for A) the initial 5-response category, 7- item, instrument and B) the final 7-item, 4 response category questionnaire.

*percentage ceiling effect -percentage of answers on the most able end category of the response scale

†infit/outfit statistics provided by Rasch analysis

4.3.3 Item reduction

Descriptive data and Rasch fit statistics are shown in Table 4.3. Prior to inspecting the items, person fit was examined to check for rogue responses which may contribute to poorly fitting items. Questionnaires completed by people with poor fit statistics were examined but there were no apparent inconsistencies so all the questionnaire data were used. To ensure measurement validity, Rasch analysis was used to identify any items which misfitted the Rasch model.

A framework to assess the functioning of items has been proposed (Pesudovs et al., 2003). Items were considered for removal from the scale if they fulfilled any of the following criteria:

1. Infit mean square outside 0.80 to 1.20.
2. Outfit mean square outside 0.70 to 1.30.
3. Item furthest from the subject mean.
4. High proportion of missing data (>50%).
5. Ceiling effect (>50% in end category).
6. Skew and kurtosis outside -2.00 to $+2.00$.

This assessment suggested that all questions performed well. Only one aspect of the performance of question 4 (Infit mean square 1.42) was flagged.

Item 4 was removed. The person item map for the remaining 6-items (4 response category) is shown in Figure 4.5. All the items fitted the criteria outlined by Pseudovs. However, targeting was not improved. The person separation remained at 2.32. Therefore, given that all the other parameters for item 4 (including Outfit mean square) were within acceptable limits, and Linacre (2005) indicates that items with Infits of up to 1.5 are productive of measurement, it was decided to retain item 4.

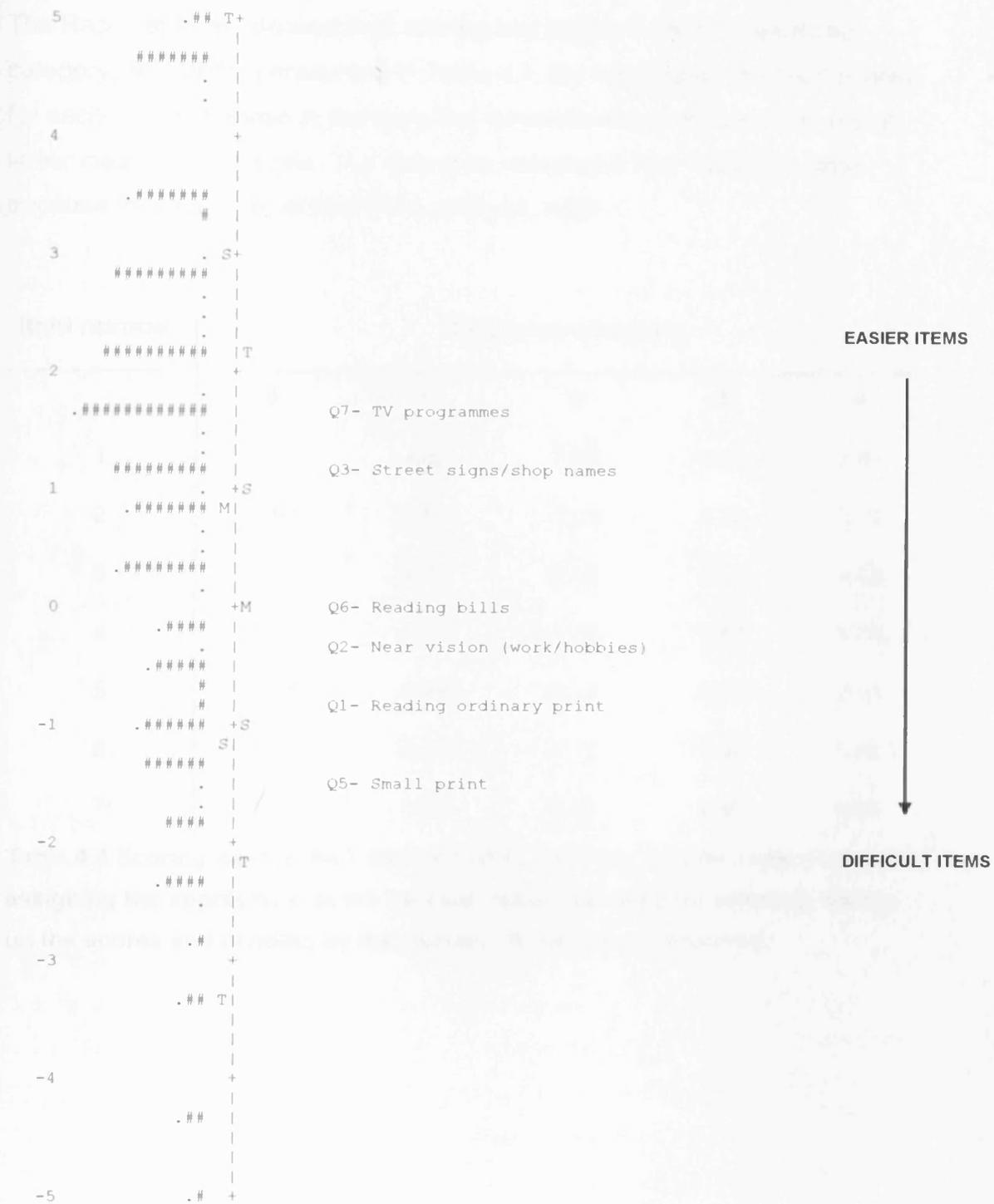


Figure 4.5 Rasch person-item map for the 6-item NEI-VFQ with 4 response categories.

Patients are represented on the left of the line: '#' is equal to 4 people and '.' is equal to 1 person. Items are represented by Q followed by item number on the right of the line. The more visually able subjects and difficult items are placed near the bottom of the map. M=means, S=1 standard deviation from the mean, T=2 standard deviations from the mean.

The Rasch analysis derived logit scoring key for the 7- item (4 response category) NEI VFQ is presented in Table 4.4. By substituting the likert scores for each item with those in the table the questionnaire is converted to a true linear measurement scale. The response category 0 and 1 are the same because these are combined in the analysis stage.

Item number	Response category				
	0	1	2	3	4
1	-4.00	-4.00	-1.93	0.27	2.61
2	-3.51	-3.51	-1.44	0.76	3.10
3	-2.12	-2.12	-0.05	2.15	4.49
4	-3.57	-3.57	-1.50	1.40	3.04
5	-4.48	-4.48	-2.41	-0.21	2.13
6	-3.19	-3.19	-1.12	1.08	3.42
7	-1.67	-1.67	0.40	2.60	4.94

Table 4.4 Scoring key for the 7 item NEI-VFQ. This key may be implemented by assigning the appropriate score for each response category selected, adding up the scores and dividing by the number of questions answered.

4.4 DISCUSSION

4.4.1 The 7 item NEI-VFQ

Although it is generally accepted that low vision service provision helps people with low vision, at the time this study was conducted, there was little evidence to support this notion (Scott et al., 1999, Stelmack et al., 2002, Stelmack et al., 2006, Wolffsohn and Cochrane, 2000) and even less was understood about what influences the success of a service (Stelmack et al., 2006, Reeves et al., 2004). Evaluation of the WLVS is complicated because there are over 170 practitioners and service delivery points and outcomes may vary from centre to centre. It was, therefore, thought essential to ascertain if all the services were having an impact and if there was variation in their effectiveness. This dictated that the initial service evaluation should include an outcome measure at each location and be pragmatic.

This approach to questionnaire design broke with tradition in as much as items were not selected on the basis of focus group discussions. Rather it was decided to build on the work of others and to use questions which had been field tested on people with low vision (Scott et al., 1999, Smeeth et al., 2003, Stelmack et al., 2002) and, which had also been shown to be responsive (Stelmack et al., 2002). Although the original NEI VFQ, from which the 7 items were drawn, was developed in response to issues raised by people with chronic eye diseases which could cause low vision (e.g. cataract, age-related macular degeneration, glaucoma and diabetic retinopathy) and not specifically from people with low vision, the overlap with items on other questionnaires, which had been developed in response to issues raised specifically by people with low vision, was striking (see Table 4.1) (Mangione et al., 1998a, Mangione et al., 1998b, Mangione et al., 2001, Stelmack et al., 2004, Weih et al., 2002, Wolffsohn and Cochrane, 2000). There is

accordingly, very strong evidence to suggest that the 7 items are relevant to people with low vision.

Low vision service provision does not seek to give people back the vision they have lost i.e. it is unlikely to improve their overall visual ability. Rather, it offers a range of interventions which aim to minimise disability by making specific tasks easier to perform. Three hundred and thirty seven tasks have been identified that are relevant to people with low vision and which could be included in a customised questionnaire (Massof et al., 2005a, Massof et al., 2005b). Tailor made questionnaires are arguably the ideal method of quantifying an individual's disability because they include only items that are relevant to the person concerned. However, tailor made questionnaires need to be administered by an interviewer, require the use of specialist software and are relatively time consuming to implement. It follows that such questionnaires are not well suited to the evaluation of a large-scale community based low vision service. Similarly the associated resources required to use any of the excellent validated instruments (19 items and above) which have been developed specifically to evaluate the outcome of visual rehabilitation programmes (IVI, VFQ 48 and LVQOL) would be prohibitive to evaluate the performance (for thousands of people within a couple of days of making an appointment all over the country) of each of the 170 practitioners that provide the WLVS.

The 7 items clearly do not cover all of the issues that may be relevant to an individual with low vision and so the questionnaire would not be well suited to the task of quantifying an individual's overall level of disability or exploring the holistic impact of a service on an individual. Rasch model fit statistics, however, suggest that they measure a single unidimensional construct i.e. it is more than the sum of its parts. This observation is consistent with previous reports which have shown that items in the NEI VFQ which use difficulty ratings work together to measure a single latent variable (Massof and

Fletcher, 2001). Although it could be argued that the questions are measuring one dimension of QoL (i.e. the functional dimension) it is more appropriate to describe the 7 items from the NEI VFQ as a visual disability scale. Even this description is not complete because the 7 questions were selected on the basis that they have previously been shown to be responsive to low vision service intervention. Therefore, the 7 items from the NEI VFQ only try to measure aspects of vision related disability that are addressed by low vision service intervention. Consequently, it is targeted toward measurement of low vision service outcomes and should allow differentiation between the performances of low vision service providers. Low vision service provision may have an effect on constructs such as QoL, vision related QoL or overall disability but at the very least, it should have an effect on the aspects of disability that it claims to be able to do something about. It is suggested this is the construct measured by the 7 item NEI VFQ and in that respect; it should be a highly responsive service evaluation tool.

This targeted approach of focusing the measure used on the goals of the intervention was used in the LOVIT trial (Stelmack et al., 2008). The primary outcome measure for the trial was the change in participant responses of the reading items of the LV VFQ 48 which overlap with the 7-items. To date the LOVIT trial has been the only study to show more than modest effects of low vision rehabilitation suggesting that the measure is highly sensitive.

Inspection of the person item map for the raw 7 item NEI-VFQ (Figure 4.1) indicated that whilst the questions were good at discriminating between people with relatively good vision they were less well suited to those with poorer vision. However, by combining the first and second response categories in the analysis ('no difficulty at all' and 'a little difficulty') both targeting and category usage were improved without compromising person separation (Figure 4.4). Hence, the response categories are collapsed in the analysis of the 7 item NEI-VFQ to a 4 point response scale. Although this

change improved targeting there is still a bias towards slightly more able people (0.86 logits). This is unlikely to be problematic because the 7 item NEI VFQ item difficulties range from -4.48 to 4.94 logits when the influence of category structure is accounted for i.e. it can reliably measure a whole range of person ability. There is no evidence to suggest that the presentation of the questionnaire should be changed.

Questionnaires with a reduced number of items are advantageous in as much that they reduce response burden and facilitate efficient implementation. Nevertheless, short form questionnaires run the risk of compromising measurement precision (Mallinson et al., 2004). The statistics used to describe the performance of the questionnaire are the 'real' not the 'model' summary statistics and hence describe the 'worst case' performance of the instrument. Even this conservative estimate indicates that the 7 item NEI VFQ is a fully functional questionnaire.

In the UK the NHS Health Technology Assessment Programme has established a set of criteria designed to aid the selection of appropriate patient based outcome measures (Fitzpatrick et al., 1998). That is, questionnaires should be: appropriate, responsive, valid, precise, easy to interpret, reliable, acceptable to patients and feasible in terms of the burden associated with its administration. Patient outcome measures differ in their ability to meet each of these criteria. Indeed, there are trade offs between criteria e.g. questionnaires containing a large number of items may be precise but they are less likely to be feasible. There is also a trade off between the concept being measured and responsiveness i.e. the more distal the concept is from the intervention the less likely it is to be responsive (Fitzpatrick et al., 1998). Whilst it might be expected low vision service provision would have a beneficial effect on QoL it is arguably a distal concept and hence is likely to be less responsive. Although the sensitivity of the 7 item NEI VFQ has not been determined, judged against the criteria listed above, it is believed it is an appropriate

instrument with which to measure the outcomes of this large scale multi-centre low vision service.

It is possible that changing the wording of the question about television from 'seeing and enjoying programmes on television' to 'watching television' made it less visually challenging. As the questionnaire is targeted towards the visually more able, the change that made it less visually challenging may actually have improved the questionnaire.

4.4.2 Limitations of the study

Although biographical information was available with consent to use it, from 1154 adults only 490 took part in the questionnaire study giving a recruitment rate of 42.5%. This figure must be treated with caution because it is not certain that everyone was asked to take part by being given the information, consent form and questionnaire e.g. from time to time optometrists may have forgotten to give the patient a questionnaire before their appointment. Hence, this recruitment rate is the minimum.

4.4.3 Future Research

To date, the only robust evidence that low vision rehabilitation is effective comes from a study of a very intense service for veterans (all men)(Stelmack et al., 2008). Therefore, it will be important to measure the effectiveness of an NHS service for a more heterogeneous group of people. By obtaining a measure of visual disability before and after low vision service intervention it should be possible to determine the effectiveness of the service and monitor the performance of service centres in the WLVS. In addition implementing the measure before and after other services should enable comparison of effectiveness to be made.

This study provided a baseline measure. It would be useful to follow a group of people over time enabling tracking of how their ability changes and understanding how parameters of service provision, such as follow-up appointments affected their ability.

The short nature and ease of implementation and scoring would make this a useful clinical audit tool for services that don't have resources for research projects to evaluate their service.

Does extending the provision of low vision services into primary care improve access?

5.1 INTRODUCTION

One of the key objectives of the National Assembly for Wales for the future operation of the NHS in Wales was to offer an extended range of services in locally accessible primary care settings (Welsh Assembly Government, 2005). As part of this move, the Welsh Assembly Government established a primary care based all Wales Low Vision Service (WLVS) as part of the Welsh Eye Care Initiative (Margrain et al., 2005). The motivation for this development was to improve the accessibility of a service which, as outlined in Chapters 2 and 3, was difficult to access. But what has been the effect on the accessibility of low vision services of placing them in the community? It is essential that the effect of such a significant shift in service delivery should be measured (Haines and Iliffe, 1995). This chapter describes a study which aims to determine the effect the change in provision has had on access to low vision services in Wales.

5.1.1 Access to healthcare

The concept of equity of access for all has been a cornerstone of the UK National Health Service since its inception in 1948 and improving access to healthcare remains a priority for our governments (Department of Health, 2006, Welsh Assembly Government, 2005). But, what is “accessibility” to healthcare and how can it be measured?

The broad term 'accessibility' has been described as a dimension in quality of healthcare by many (Maxwell, 1992, Campbell et al., 2000). Optimal access in health care can very simply be described as: 'providing the right service, in the right place at the right time' (Rogers et al., 1999). Barriers that limit the use of a service will impede its effectiveness. However, achieving and measuring 'access to health care' is complex.

Deville (2001) very aptly described access as "the facilitator or barrier between need and utilisation" (Figure 5.1). In other words, accessibility is the existence of many factors that influence the translation of need for a particular service into the *use* of the service.

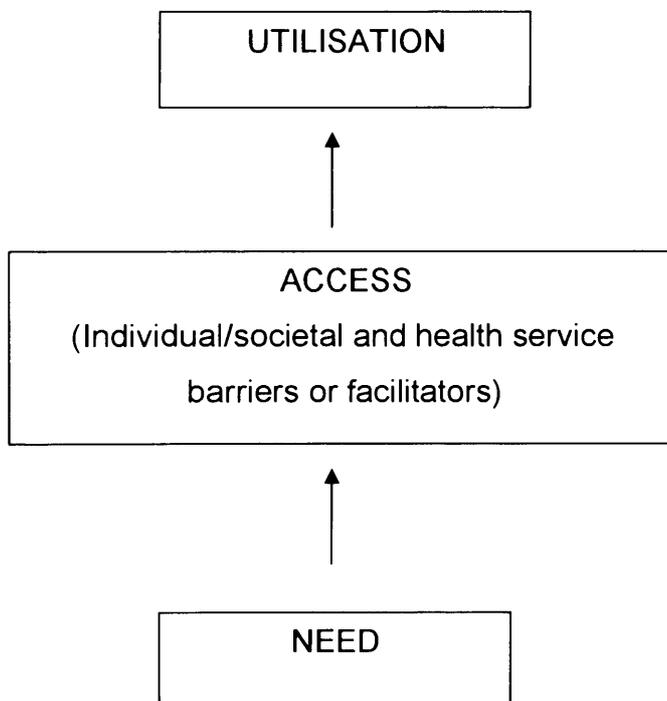


Figure 5.1 The relationship between Access, Utilisation and Need (Deville, 2001).

The number of available appointments, transport, waiting times, distance travelled, referral routes and physical access are all factors that are known to affect access to healthcare. Other factors that influence a person's access include acceptability, effectiveness (Gulliford et al., 2002), awareness, need (due to factors such as health, age and socio-economic variation), interfaces between services (Rogers et al., 1999) and quality and cost to the patient (Goddard and Smith, 2001). The inter-relation of many factors has led social scientists to develop a number of models to try to describe how to predict and measure access to health care (Joseph and Phillips, 1984) but no single measure has been generally accepted and implemented.

5.1.2 Determining access in the context of low vision services

Five dimensions have been identified into which the factors that influence access can be placed (Penchansky and Thomas, 1981):

- Availability – defines the supply of services in relation to needs.
- Accessibility – describes geographical barriers, including distance, transportation, travel time, and cost.
- Accommodation – identifies the degree to which services are organised to meet clients' needs, including hours of operation, referral procedures and waiting times.
- Affordability – refers to the price of services in regard to people's ability to pay.
- Acceptability – clients views on particular services and how service providers interact with clients.

These dimensions in relation to low vision services are discussed below.

5.1.2.1 Availability of low vision services- the supply in relation to need

There has been a rapid increase in the number of NHS low vision services provided in the UK in the last four decades; in 1956 practitioners started seeing low vision patients in a hospital (Keeler, 1956), in 1977 there were 104 services (Silver and Thomsitt, 1977) and in 1998 there were 638 low vision services (Ryan and Culham, 1999). Despite this, by 1998 there were just under 155, 000 appointments offered annually in the UK (Culham et al., 2002). This falls short of the conservative estimate of 414,792 (95% CI: 390,843; 466,385) (see Chapter 1) people who might benefit from low vision services. The high prevalence of visual impairment in older people (Evans et al., 2004) and ageing population (Shaw, 2004) mean the need is likely to increase.

5.1.2.2 Accessibility – geographic barriers

Increased distance between where people live and health care providers is commonly thought to decrease utilisation of health care (Bentham and Haynes, 1985, Bronstein and Morrissey, 1990, Roderick et al., 1999, Fortney et al., 1995, Haynes et al., 1999). This reduction in access is known as 'distance decay' (Cromley and McLafferty, 2002).

Even controlling for needs and provision, Bentham and Haynes (1985) found that the greater the distance to hospitals in Norfolk the less all types of services were used. There is, however, variation in the rate of decay. Greatest reductions in hospital outpatient attendances have been found for older people and people with long-standing illness (including people with a visual impairment) and those in remoter areas (Haynes et al., 1999). In the UK there is evidence of distance decay in inpatient episodes (Fortney et al., 1995) and outpatient treatments such as renal replacement therapy (Roderick et al., 1999). These effects have not been demonstrated by all services e.g. the distance travelled and age of the patient was not found to influence admittance for day case cataract surgery (Strong et al., 1991). Rurality, (Goddard and Smith, 2001) distance and transport (Pollard et al., 2003,

Owsley et al., 2006b) have been found to influence access to eyecare services.

The RNIB/ Moorfields Survey mapped the geographical accessibility of low vision services using GIS mapping software. This highlighted regional differences in availability and accessibility of services (Culham et al., 2002). Low vision services were unequally distributed throughout the country meaning that many people lived a considerable distance from the nearest service. In parts of the country where prevalence of low vision was high (greater than 2% of the population) there were no services at all (Ryan and Culham, 1999).

Issues about difficulty accessing low vision services were reported by service users (Ryan and McCloughan, 1999). They complained about travelling a long way to get to their nearest low vision service and problems regarding transport included: waiting for ambulance services, long ambulance journeys and a lack of parking for those using private transport. Accessing low vision services is not just difficult in the UK (Ilango and Krishna, 2005, Pollard et al., 2003). Transport difficulties and the distance to services were two of the main barriers to low vision services in Australia (Pollard et al., 2003).

The problems associated with travel due to reduced vision are compounded by the fact that older people also have an increased risk of conditions such as hearing loss and reduced mobility (Crews and Campbell, 2001, Sumi et al., 2003). The level of visual acuity at which the WHO defines a person as having Low Vision (6/18) (WHO, 1980) is just below that required to drive legally in the UK (Drasdo and Haggerty, 1981). Therefore, people with low vision are very unlikely to drive themselves. Car ownership is below average amongst older people (Office for National Statistics, 2002) so getting a lift may also be problematic. In addition, people with a visual impairment encounter difficulties using public transport (Baker and Winyard, 1998) and are less likely to be confident about getting about outside their home (Bruce et al., 1991).

One would therefore imagine that the geographic location of services is likely to be an important influence in service use by people with a visual impairment.

Primary care low vision services have been in operation for over a decade but the effects on access are unknown. A Cochrane Collaboration Review (Gruen et al., 2003) found that, although evidence is poor, in rural areas outreach services reduced the distance to the service, reduced the time getting to the service, reduced the cost to the consumer and improved patient satisfaction. Although very little health outcome gain was found. In ophthalmology, cataract surgery in a community hospital outreach clinic showed no difference in clinical outcome but reduced patients costs and increased patient satisfaction (Haynes et al., 2001).

5.1.2.3 Accommodation – organisation to meet patient' needs.

As outlined in Chapter 2, issues about difficulty accessing low vision services dominated focus groups of people with a visual impairment on low vision services (Ryan and McCloughan, 1999). Issues apart from geographic access and transport that were reported were:

- *Referral*
Many had not had a low vision assessment. Of those who had, many had not been referred automatically following diagnosis.
- *Waiting times*
The theme of "getting an appointment" was dominated by negative comments about waiting times for referral of 3 months to a year.
- *Physical Access*
Problems with access did not cease on arrival at the service base and there were criticisms of architectural barriers such as steps. This was a particular problem in large hospitals.

Many of these problems with the organisation of services were also highlighted by the RNIB/ Moorfields Eye Hospital survey (Culham et al.,

2002). Waiting times for some services were found to be long. Referral too was an issue; there were differing criteria used to determine eligibility for and referral to low vision services; in some areas there was only one referral route to the service.

5.1.2.4 Acceptability- user views

Little work has been done on the acceptability of low vision services to those that use them. The one study that touched on this found that people, on the whole, were positive about low vision services once they had actually got to the assessment but getting an appointment and getting to the appointment as problematic (Ryan and McCloughan, 1999).

5.1.3 Access to low vision service provision in Wales

A postal survey to determine the main problems with NHS funded low vision services in Wales (Furze et al., 2001) had poor responses from hospital trusts. However, they were able to report that the problem with low vision services in Wales was three dimensional:

1. Referral route

Access to low vision services was restricted by a convoluted referral route typically involving referral from an optometrist to a general practitioner to an ophthalmologist and to a low vision service.

2. Waiting times

Waiting times for a low vision assessment in some parts were 18 months.

3. Geographical Access

The geographical distribution of services was also of concern. The topography of Wales means that transport routes often entail long journeys and some patients were required to undertake round trips of over 100 miles (160 km) to reach their nearest service provider.

5.1.4 The establishment of the WLVS

In 1999, a Consensus Report was developed by all the professional groups and organisations who work with people with a visual impairment. This gave recommendations for future developments of low vision service provision in the UK and was launched by the then Secretary of State for Health (Low Vision Services Consensus Group, 1999).

The Welsh Assembly Government (WAG) considered that access to the services was unacceptable for those going through the trauma of sight loss and for whom the delays in access could lead to loss of independence. In 2004, to improve access and ensure provision for the increasing number of older people, WAG took the radical step of extending low vision services into the primary care setting throughout Wales (Margrain et al., 2005). This formed part of the Welsh Eye Care Initiative (WECI) (www.eyecarewales.nhs.uk).

5.1.5 Measuring change in access to low vision services in Wales

The WLVS was established to improve, and ensure equity of, access to low vision services throughout Wales. As described earlier in this chapter, the accessibility of any service is multi-factorial. Measuring all aspects of access would not be possible. When trying to achieve improved access WAG stipulated 4 key objectives for change for the WLVS:

- 1) to increase the availability of appointments i.e. to meet any unmet needs;
- 2) to provide services closer to people's homes;
- 3) to reduce waiting times to less than 2 weeks for most people; and
- 4) to open access by increasing the number of referral routes.

The aim of this study was to determine if the WLVS had changed these 4 aspects of access to low vision services.

As those attending the service are predominantly older and all have a visual impairment it was assumed that, when considering equity of access, people would have equal need for low vision rehabilitation services (i.e. horizontal equity). Whether access varied appropriately in accordance with need was not considered (vertical equity) (Goddard and Smith, 2001)

Waiting times, referral routes and number of appointments are routinely monitored in most modern NHS services. However, quantifying the journey people are required to make to access the service is not. GIS are tools for analysing spatially referenced data, usually via postcode data. GIS has been embraced by those approaching the geography of health from a 'spatial analysis' tradition. One of the principal applications of GIS in terms of healthcare research has been concerned with geographical access to healthcare services (Gatrell and Senior, 1999).

5.2 METHODS

To establish how the arrival of the WLVS has changed low vision service provision it was necessary to define the characteristics of the service prior to its introduction.

5.2.1 Low vision service provision prior to the establishment of the WLVS (2003/4)

A retrospective survey of all potential NHS providers of low vision care was conducted to establish service provision just prior to the establishment of the new service in 2004. This first audit period was a year from 1 April 2003 to 31 March 2004.

5.2.1.1 Identification of potential providers of services

Three groups of potential providers of low vision services in Wales were identified and their details sought. These included: hospitals with eye departments or eye clinics (HED); optician/ optometry practices (OP); and a university with an undergraduate optometry clinic (UC).

A database of all potential providers was compiled using contact details obtained from the Health of Wales Information Services (HOWIS) website, databases of WECl and Low Vision accredited practitioners, yellow pages and the GOC Register 2004/5. Details of hospitals which had ophthalmologists attending were obtained from HOWIS.

5.2.1.2 Survey Questionnaire Selection

In April 2004, all questionnaires that had been used (or were being used) to survey low vision service provision in the UK and/ or Wales were reviewed. Four relevant questionnaires were found: 1977 Sliver and Thomsitt (Silver and Thomsitt, 1977); RNIB/ Moorfields Eye Hospital 1998 (Culham et al., 2002, Ryan and Culham, 1999); GOC 1999 (General Optical Committee, 1999); Cardiff University 1999 (Furze et al., 2001).

Three of the 4 questionnaires previously used had been directed to slightly different target audiences. The RNIB/ Moorfields Survey was directed at Health Care, Social Care, Voluntary Sector and Education providers (Ryan and Culham, 1999, Culham et al., 2002) and the GOC questionnaire at optometry practices only (General Optical Committee, 1999). Only the 1977 survey had targeted the same providers (Silver and Thomsitt, 1977) but this was over 30 years old and low vision service provision had changed considerably. Therefore, it was decided to design a new questionnaire based on earlier ones.

5.2.1.3 Survey Questionnaire Design

A baseline questionnaire was designed to establish the nature and extent of NHS funded low vision services in Wales in 2003/4. In order to ensure maximum response rates (VanGeest et al., 2007) the questionnaire was designed to be brief (just eight closed questions), personalized, and endorsed by Cardiff University and the Welsh Assembly Government.

The questions covered: where low vision services were provided; how people were referred; how long people had to wait for an initial assessment; how many people were seen each year; what proportion of people were referred to social services following assessment; and who funded the service. The postcode of the service was also recorded to allow GIS mapping of the results. See Appendix 6 for a copy of the questionnaire.

In order to allow comparisons with the previous studies and developments in other UK countries, when possible, wording overlapped with the 29 point RNIB/ Moorfields Eye Hospital Survey outlined in Chapter 3.

5.2.1.4 Questionnaire Administration

- Telephone administration

Three of the four previous surveys of low vision services in the UK had exclusively used postal administration (Silver and Thomsitt, 1977, General Optical Committee, 1999, Furze et al., 2001) and the Moorfields/ RNIB survey used postal and telephone administration combined (Culham et al., 2002). Difficulties obtaining information from low vision services in Wales (Furze et al., 2001) and throughout the UK using postal administration were expressed. Shortcomings with the RNIB/ Moorfields Eye Hospital Survey (Culham et al., 2002) due to the possible misinterpretation of questions and the problems associated with which personnel completed the postal survey questionnaire have also been raised (Fletcher et al., 2001). Telephone surveys have been found to give good response rates from physicians (VanGeest et al., 2007). Therefore, as Wales had just over 400 potential providers of low vision services, it was decided to administer the questionnaire over the telephone.

- Piloting the questionnaire

The baseline questionnaire was initially administered to 10 practices to find the best time of day to contact them and get an estimate of the length of time it took to administer. The introductory dialogue and response categories for 3 questions were changed following the pilot.

- Optometry practices and the university eye clinic

The questionnaire was administered by telephone to all optometry practices and the university eye clinic in Wales between July and October 2005. A research assistant was employed to do this part of the work. The first contact was generally made first thing in the morning or at lunch time as this was the best time to get a response. Those not able to respond straight away were contacted at a convenient time. All contacts were recorded on a log sheet. Providers were asked to consult appointment records rather than relying on recall. Occasionally practices asked for a paper copy

of the questionnaire which was provided. Practices were contacted up to five times to try to elicit a response.

- Hospitals

All hospitals with an eye department or outreach eye clinic were contacted by telephone by the author to ascertain if a low vision service was provided and who the best person to answer the questionnaire might be. Generally this was the service provider or the person responsible for the low vision service. No hospital service provider was able to complete the survey over the telephone and they all asked for a request in writing with a copy of the questionnaire. All hospital providers were asked to ensure they consulted with the appointment records for that period rather than relying on recall and a fee of £50 was offered for the administration cost of doing this. Up to 2 telephone reminders and 3 personalised postal reminders were sent to hospitals.

Information from all the questionnaires was entered into an SPSS Version 12.0 database.

5.2.2 Low vision service provision after the introduction of the WLVS

The second audit period was a year from 1 April 2005 to 31 March 2006 (9 to 21 months from the time the WLVS started). To determine low vision service provision in Wales after the low vision services was established, two methods were used in the second audit period:

- 1) Information from standard record cards was used for those OPs that had one or more practitioners accredited to provide the WLVS.
- 2) A follow-up questionnaire was used to gather information from HEDs, UC and OPs where there were no practitioners accredited to provide the WLVS.

5.2.2.1 *Record cards*

From the start of the service all practitioners providing the WLVS used a standard record card (Appendix 7). The record cards were designed alongside the survey questionnaires so that the information available from them included the same information as the questionnaires. This included: the postcode of the service; how people were referred to the service; how long people had to wait for an initial low vision assessment; how many people were seen each year at each practice; and what proportion of people were referred to social services following assessment.

Signed consent was sought from everyone using the service to use the information from the record cards for service evaluation purposes. Following a low vision assessment, practitioners faxed the record card to a secure fax in the central administration based in Carmarthenshire Local Health Board (LHB). An administration team then entered information from the record cards onto a Microsoft Access 2003 computer database and addresses were checked using a Royal Mail BPH Enhanced Postcode Address Checker (UK Street/Postcode Flat File). Practitioners who provided the WLVS were informed of the research/ audit protocol during their training and a copy was included in the service manual (Appendix 9). An audit of the record card was carried out at 6 months.

The information from the record cards (waiting times, postcodes and referral routes) for those adults who had given their consent (2453 of the 3932 people aged > 17 years who were seen in the second audit period) was transferred from the Access Database to SPSS.

5.2.2.2 *The follow-up questionnaire*

A follow-up questionnaire was designed to determine the nature and extent of NHS low vision service provision in Wales in 2005/6. This was identical to the baseline questionnaire except that wording was changed to reflect the fact this was a follow-up.

The details of all the 140 practices that had practitioners accredited and providing the WLVS on 31 March 2006 were removed to establish the follow-up contact database. The contact details of HEDs, UC and OPs on the database established for the baseline administration were updated. The follow-up questionnaire was administered over the telephone to UC and OPs by the same research assistant as before from July to October 2006. The author administered the follow-up questionnaire to hospitals by contacting the relevant person by phone initially and then sending a postal questionnaire if requested. All hospital providers were asked to ensure they consulted with the appointment records for that period rather than relying on recall and a fee of £50 was offered for the administration cost of doing this.

Information from all the questionnaires was entered into the SPSS Version 12 database.

5.2.3 GIS mapping of people with low vision

In order to determine if there was any change in travel distance or journey time to low vision services in Wales following commencement of the WLVS it was necessary to map the location of service providers and people with low vision. This was achieved using postcodes of service providers for both audit periods and postcodes of people with low vision who used the WLVS during the second audit period. In the second audit period (1 April 2005 to 31 March 2006) 3932 people accessed the WLVS. Of those who had an assessment in that time, 2453 adults (> 17 years) agreed for information from their records to be used for audit/ research purposes. Valid postcodes were available for 2451 people. These corresponded to 2273 discrete locations.

5.2.4 Data analysis

5.2.4.1 Geographical Information

In order to establish the geographical distribution of NHS Low Vision Services in Wales, and the distance and journey time patients were required to travel to attend services, a GIS analysis was undertaken. This analysis was implemented using ArcGIS version 9 and carried out by Dr Sean White in the School of Planning, Cardiff University.

Postcode data of services that existed in the first and second audit periods, and patients seen in the community based WLVS in the second audit period, were used to plot the location of services and patients using GIS.

Road network data was obtained for Wales and areas of England that border Wales using Ordnance information (Survey Strategi, 1:250000 from Digimap).

The actual distances that needed to be covered along the network in order to access the nearest service by road in the two different audit periods was calculated for each of the patients.

A drive time analysis, based on the work of Christie and Phone (2002), was then performed and a travel time along the network calculated for each service. Each road type was assigned a speed using the methodology adopted by the Scottish Executive in their Urban and Rural Classification study which was based upon access to particular services (Scottish Executive, 2004). These road speeds were further modified depending on whether the road was within an urban area – if this was the case then a congestion factor was added to the urban road speeds. Further modelling of the network data was undertaken in rural areas to indicate waiting time at junctions and distance to 'start points' or nodes on the network. Urban areas were denoted by employing the National Statistics Urban Area 2001 classification (National Statistics, 2004).

The Mann-Whitney U test was used to explore differences in distance travelled and journey times between the two audit periods.

5.2.4.2 Waiting times

If referral could only be instigated by following a consultation with an ophthalmologist, the waiting time for a routine ophthalmology outpatient appointment at the nearest hospital (<http://www.statswales.wales.gov.uk>) was added to the low vision service waiting time.

5.2.5 Ethical approval

All procedures adhered to the tenets of the Declaration of Helsinki and ethical approval was obtained from the all Wales Research Ethical Committee (Appendix 8).

5.3 RESULTS

Following a description of the data quality (response rate etc.) this section characterises low vision service provision in Wales in the first (2003/4, just prior to commencement of the WLVS) and second audit period (2005/6, 9 to 21 months from the time the WLVS started). The number and type of providers, the number and type of appointments, waiting times, distance and journey time to services and referral routes are described.

5.3.1 Data quality

Questionnaires were administered to 412 services in the first audit period and 263 services in the second audit period. Responses received are shown in Table 5.1.

Year	Type of provider	Number of services	Responses received
2003/4	Hospitals	33	33 (100%)
	Optometry Practices	378	354 (94%)
	University Eye Clinics	1	1 (100%)
	Total	412	388 (94%)
2005/6	Hospitals	33	33 (100%)
	Optometry Practices *	229	195 (85%)
	University Eye Clinics	1	1 (100%)
	Total	263	229 (87%)

Table 5.1 Questionnaire response rates from potential providers of low vision services in Wales in 2003/4 and 2005/6 *Information from 140 optometry practices providing the WLVS was taken from record cards in 2005/6 and therefore no questionnaire was sent to them.

In 2005/6, 168 optometry practices had accredited practitioners registered to provide the WLVS and 140 (83.33%) of these provided low vision assessments in the

second audit period. Of the practices that were not providing the WLVS, 19 had practitioners that were only accredited and equipped to provide the service in February 2006.

5.3.2 The characteristics of low vision services in Wales before and after the establishment of the WLVS

In the first audit period, low vision appointments were provided by 19 hospitals, 21 optometry practices and one university eye clinic. In the second audit period, following implementation of the WLVS, low vision services were provided by an additional 127 optometry practices. The location of NHS low vision services before and after the establishment of the WLVS is shown in Figure 5.2.

The principal source of funding of low vision services in Wales is shown in Table 5.2. The University Eye Clinic provided NHS low vision services through a secondary care contract and was also a primary care service provider.

Principal source of funding	Services 2003/4	Services 2005/6
NHS Hospital Trust	26 (22%)	21 (11%)
NHS Primary Care	16 (14%)	148 (77%)
Private	65 (57%)	20 (10%)
Voluntary / Charity	4 (4%)	0 (0%)
Free / Goodwill	3 (5%)	3 (2%)
Other	0 (0%)	0 (0%)
Total NHS	42	169
Total	114	192

Table 5.2 The principal source of funding of low vision services in Wales in 2003/4 and 2005/6

Before (2003/4)

After (2005/6)

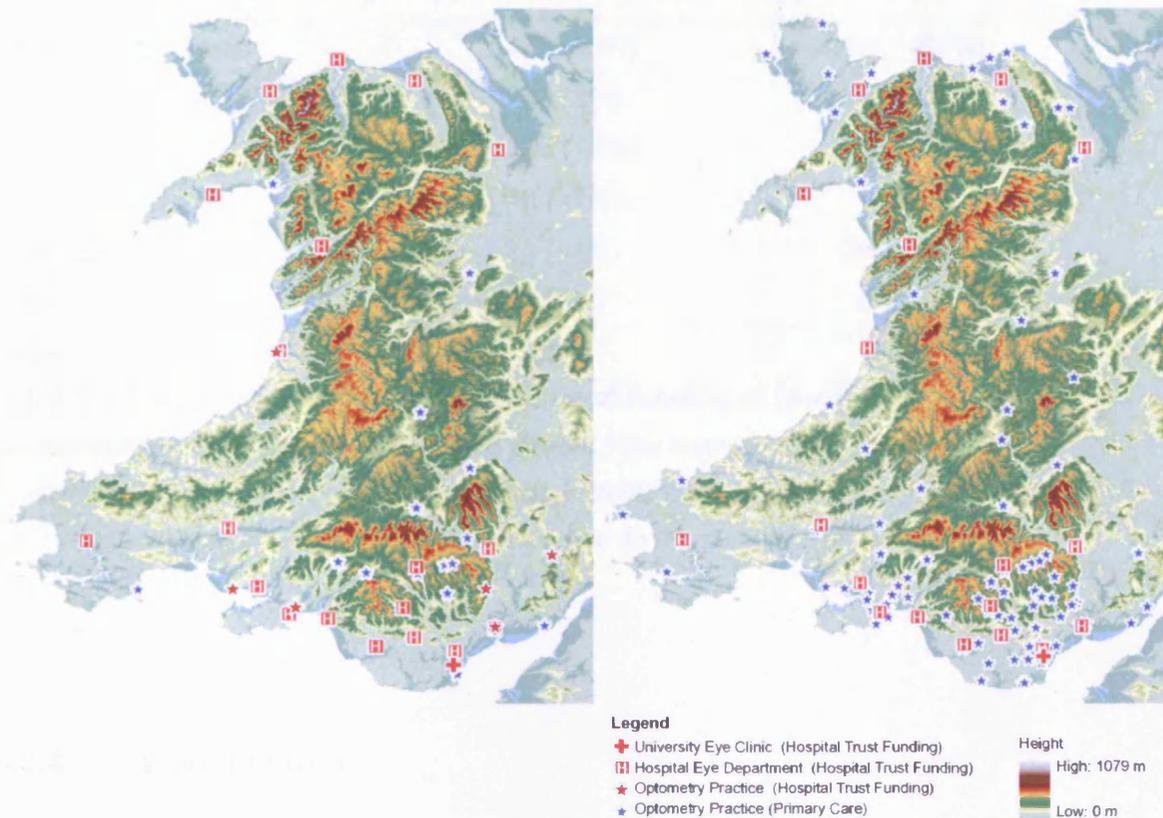


Figure 5.2 Location of low vision service providers in Wales before and after establishment of the WLVS. The location of services is influenced by regional differences in population density and geography.

5.3.3 Number of appointments

Responses indicate that in the first audit period, 5692 NHS funded low vision appointments (5472 secondary care; 220 primary care) were provided. This increased by 51.7% to 8,636 (4704 secondary care; 3932 primary care) in the second audit period, following implementation of the WLVS. The number and funding of low vision appointments in Wales in 2003/4 and 2005/6 is shown in Table 5.3.

Principal source of funding	Appointments 2003/4	Appointments 2005/6
NHS Hospital Trust	5472 (80%)	4704 * (52%)
NHS Primary Care	220 (3%)	3932 (43%)
Private	1122 (16%)	437 (5%)
Voluntary / Charity	46 (<1%)	0 (0%)
Free / Goodwill	21 (<1%)	26 (<1%)
Other	0 (0%)	0 (0%)
Total	6881	9099

Table 5.3 The number and principal source of funding of low vision appointments in Wales in 2003/4 and 2005/6

*One hospital was unable to provide exact information about low vision appointments in 2005/6. 3 members of staff reported that the numbers were unchanged from the previous year so this number (180) was used.

5.3.4 Waiting times

Waiting times for the two audit periods are shown in Figure 5.3

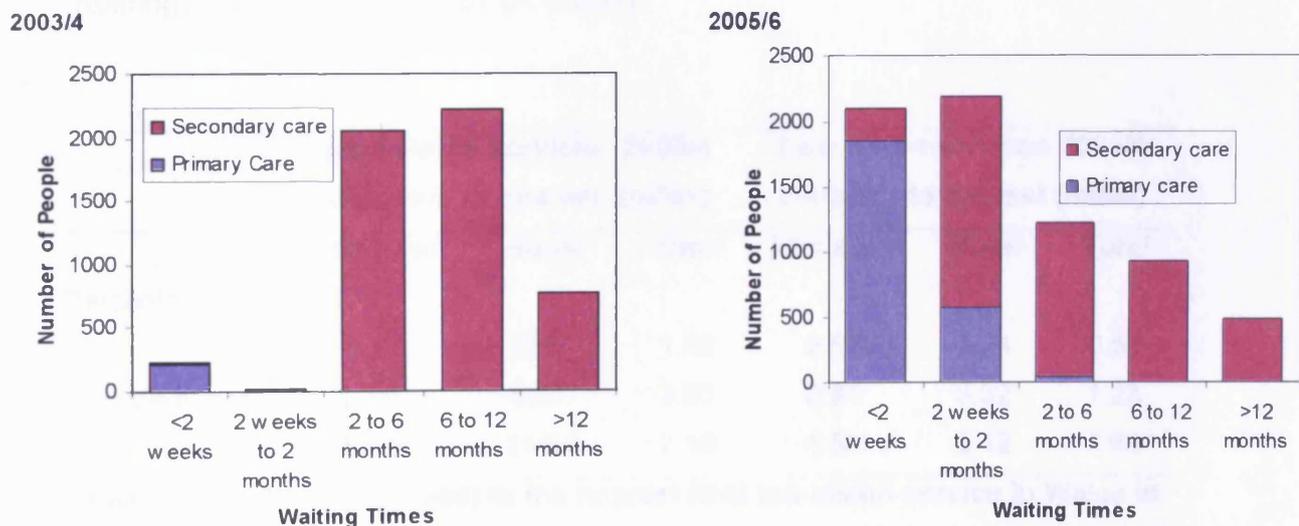


Figure 5.3 Waiting times for an NHS funded low vision appointment in Wales.

Prior to the introduction of the WLVS, over 50% of people waited 6 months or more for a low vision assessment and 11% waited for less than 2 months. Following the change in service delivery, waiting times reduced: approximately 60% of people waited less than 2 months for a low vision assessment and over 70% of those who attended the primary care WLVS waited less than 2 weeks. The modal response category for primary care remained the same in both audit periods (less than 2 weeks) but for secondary care it reduced from 6 to 12 months to 2 weeks to 2 months following the implementation of the WLVS. There was a significant increase in the proportion of people waiting less than 2 weeks from 4.4% to 30.37% ($\text{Chi}^2 = 36.18, p < 0.001$). The proportion of people waiting less than 2 months in the hospital increased significantly from 0.67% to 41.87% ($\text{Chi}^2 = 36.18, p < 0.001$).

5.3.5 Distance to services

The network distance to the nearest low vision service in the two audit periods is shown in Table 5.4 and Figure 5.4. The data was not distributed normally (Kolmogorov-Smirnov = 0.151 $p < 0.001$).

	Low vision services 2003/4			Low vision services 2005/6		
	Distance to nearest (miles)			Distance to nearest (miles)		
	<i>Non rural</i>	<i>Rural</i>	<i>Total</i>	<i>Non rural</i>	<i>Rural</i>	<i>Total</i>
Percentiles						
25	1.57	3.67	1.92	0.50	1.24	0.56
(Median) 50	2.96	6.97	3.93	0.94	3.32	1.23
75	5.52	11.64	7.18	1.56	6.12	2.68

Table 5.4 The distance (miles) to the nearest NHS low vision service in Wales in 2003/4 and 2005/6 for the 2274 locations (519 in a rural location and 1754 in a non rural location) where people used the low vision service in 2005/6.

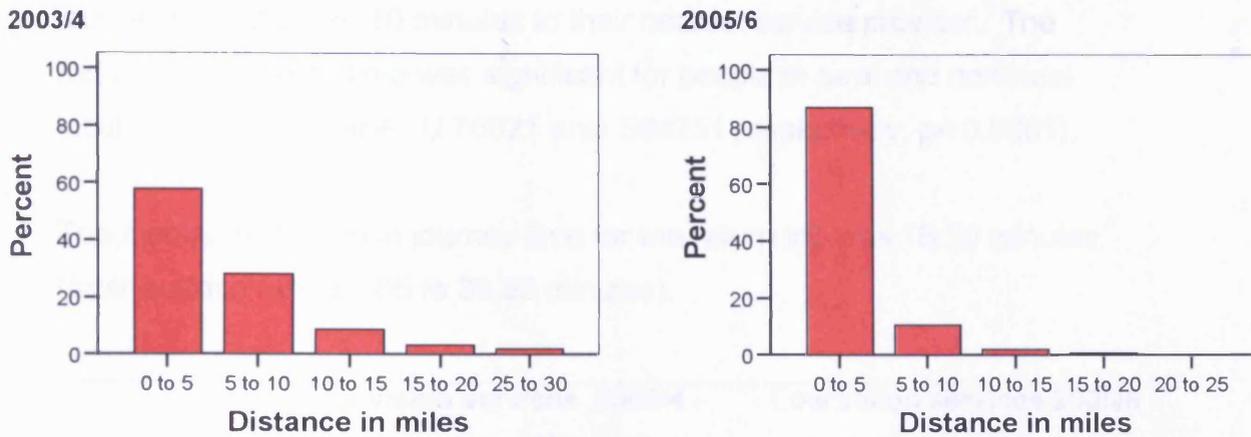


Figure 5.4 The distance (miles) that the people who used the WLVS in 2005/6 would have travelled to their nearest low vision service in 2003/4 and 2005/6.

There was a significant reduction ($p < 0.0001$) in the distance people had to travel to their nearest low vision service in the two audit periods for people in all locations (Mann-Whitney U 1256036) as well as those in rural and non-rural locations separately (Mann-Whitney U 177293 and 379925 respectively).

5.3.6 Journey times to services

Journey times to low vision services in 2003/4 and 2005/6 are shown in Table 5.5 and Figure 5.5. The data was not normally distributed (Kolmogorov-Smirnov = 0.17 $p < 0.001$).

The change in journey time for patients is shown in Figure 5.6. There was a significant reduction in journey time (Mann-Whitney U 1171608; $p < 0.0001$) and of the 2451 consenting people attending the WLVS, 1988 (81.1%) had shorter journey times than they would have had prior to the introduction of the WLVS: six times fewer people (from 611 to 101) had a journey of 30 minutes

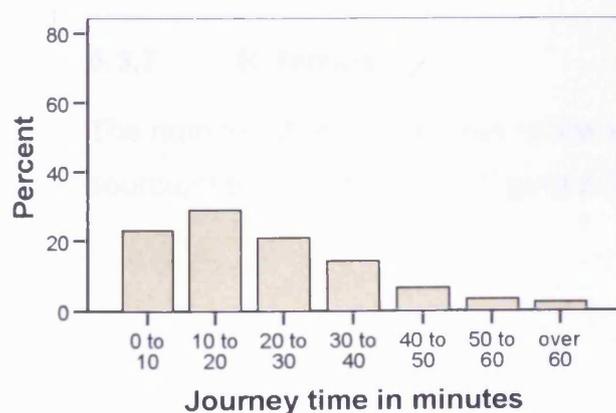
or more and three times as many people (from 525 to 1482) would have had a journey time of under 10 minutes to their nearest service provider. The reduction in journey time was significant for people in rural and non-rural locations (Mann-Whitney U 76921 and 564251 respectively; $p < 0.0001$).

The median reduction in journey time for the return trip was 16.50 minutes (Inter-quartile range 1.66 to 39.32 minutes).

	Low vision services 2003/4			Low vision services 2005/6		
	Journey time (Minutes)			Journey time (Minutes)		
	<i>Non rural</i>	<i>Rural</i>	<i>Total</i>	<i>Non rural</i>	<i>Rural</i>	<i>Total</i>
Percentiles						
25	10.17	14.42	10.46	3.37	5.13	3.51
(median) 50	17.78	30.33	19.30	6.49	16.21	7.17
75	26.52	47.98	30.94	10.38	25.55	12.99

Table 5.5 The journey time (minutes) to the nearest NHS low vision service in Wales in 2003/4 and 2005/6 for the 2274 locations (519 in a rural and 1754 non rural) where people used the low vision service in 2005/6.

2003/4



2005/6

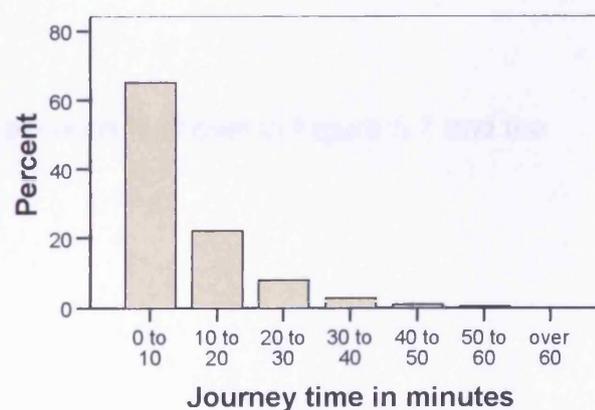


Figure 5.5 The time that the people who used the WLVS in 2005/6 would have taken to travel to their nearest low vision service in 2003/4 and in 2005/6.

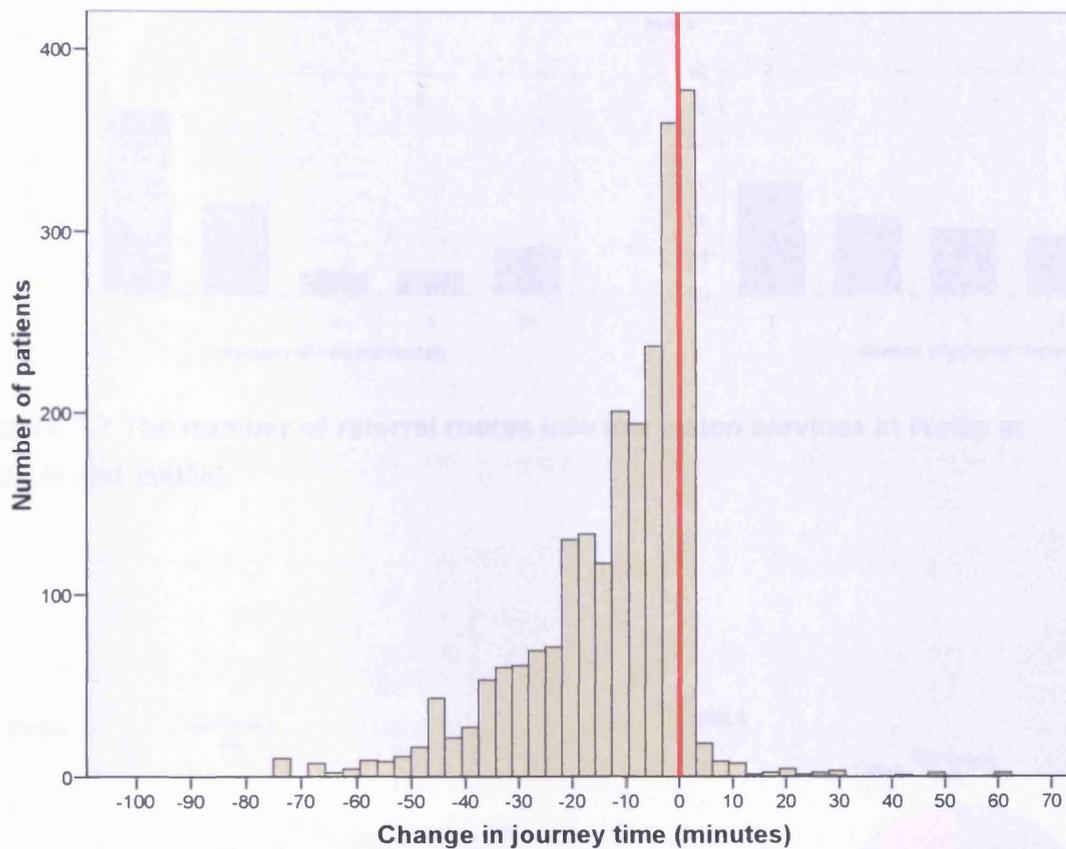


Figure 5.6 The change in journey time between 2003/4 and 2005/6 to the nearest low vision service (i.e. one-way).

5.3.7 Referrals

The number of referral routes to low vision services is shown in Figure 5.7 and the source of those referrals in Figure 5.8.

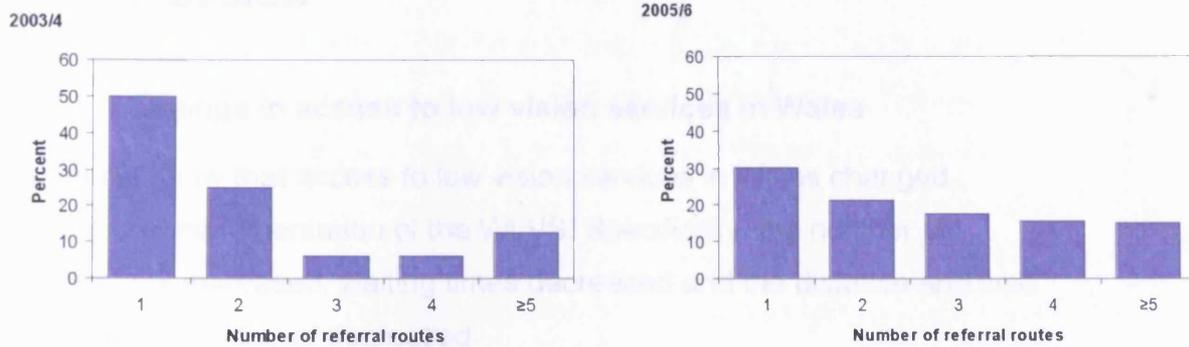


Figure 5.7 The number of referral routes into low vision services in Wales in 2003/4 and 2005/6.

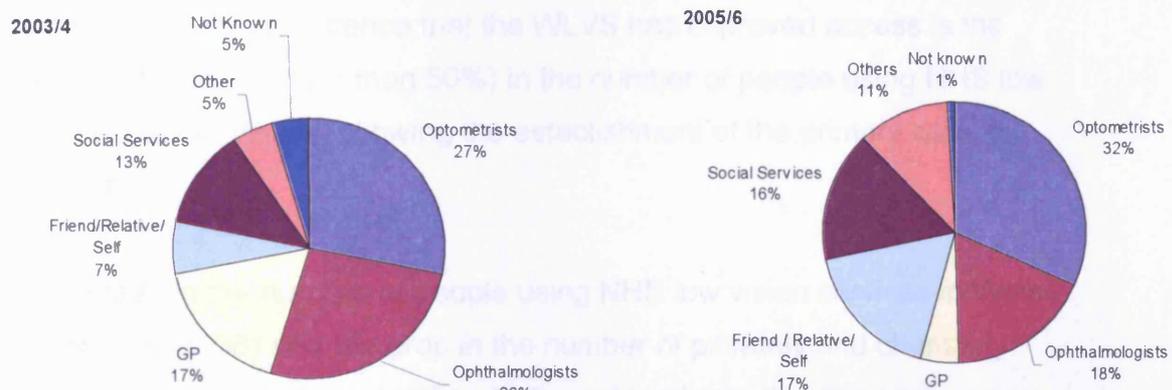


Figure 5.8 The source of referrals to low vision services in Wales in 2003/4 and 2005/6.

5.4 DISCUSSION

5.4.1 Change in access to low vision services in Wales

The results show that access to low vision services in Wales changed following the implementation of the WLVS. Specifically, the number of appointments increased, waiting times decreased and the distance and time people needed to travel decreased.

5.4.1.1 *Availability of low vision services- the supply in relation to needs*

“The proof of access [to services] is use of the service, not simply the presence of a facility” (Donabedian, 1973).

The most convincing evidence that the WLVS has improved access is the significant increase (more than 50%) in the number of people using NHS low vision services in Wales following the establishment of the primary care low vision service.

The increase in the number of people using NHS low vision services in Wales (from 5692 to 8636) and the drop in the number of privately and charitably funded appointments (from 1168 to 463) would indicate that the primary care service is enabling access for a considerable number of people for whom there was previously an unmet need for statutory provision of care. This increase would support the view that there is significant unmet need for low vision services throughout the UK (Culham et al., 2002) and other countries (Lovie-Kitchin, 1990, Pollard et al., 2003).

This study found that the number of hospital low vision appointments available fell by about 700 between the two audit periods. Therefore, it is possible that the number of hospital appointments has continued to decline as the community service has become established.

5.4.1.2 *Accessibility – geographic barriers*

One would imagine that since distance to services has been a significant barrier to those wishing to access them, the closer geographic location of services and resultant shorter journey times for over 80% of people found in this study is likely to be an important influence in increased service use (Ryan and McCloughan, 1999, Pollard et al., 2003). Increased distance between where people live and health care providers is commonly thought to decrease utilisation of health care (Haynes and Bentham, 1982, Haynes et al., 1999, Bentham and Haynes, 1985, Roderick et al., 1999, Fortney et al., 1995, Bronstein and Morrisey, 1990) particularly for older people and people with long-standing illness (Haynes et al., 1999). People who require low vision services find it particularly difficult to overcome distance. A similar dramatic increase in community service use has also been found for those with musculoskeletal disability who also experience difficulty overcoming distance (Maddison et al., 2004).

The problems faced by those without access to private transport are compounded by dwindling public transport services in rural Wales. An attempt was made to determine the change in journey time for those using public transport to get to low vision services. However, using a Wales public transport journey planner, it became apparent that it was impossible for the majority of people to get to a hospital appointment using public transport. Therefore, it was not possible to compare the journey times by public transport for the two audit periods.

A Cochrane Collaboration Review (Gruen et al., 2003) found that, although evidence is poor, in rural areas outreach services reduced the distance to the service and reduced the time getting to the service. This study found that extending services into primary care resulted in a significant reduction in the distance and journey times to low vision services for people living in Wales. Following establishment of the WLVS over 80% of people were closer to their nearest low vision service and the median reduction in journey time for the

return trip was 16.50 minutes (inter-quartile reduction range 1.66 to 39.32 minutes).

Although the new service arrangements may have brought the service closer to people's homes than traditional UK hospital based services, at this time it is not clear whether it is effective. While all the practitioners providing the service have been trained and accredited, the increased number of locations means that the service is spread more thinly and some will assess fewer than 20 people a year. Although evidence is currently lacking in this area, there may be advantages in having 'expert' centres in hospitals. For example, there may be variations in the effectiveness of the WLVS in different locations. There is continuing tension and debate about whether improved geographically accessible care is as safe, effective and efficient as larger more centralised provision (Rogers et al., 1999).

Nevertheless, contrary to common perception, a review of the literature found that there is no general relationship between volume and quality (NHS Centre for Reviews and Dissemination and Nuffield Institute for Health, 1996). In some specialities for some procedures there appear to be quality gains associated with increased hospital and/ or clinician volume but for many services no such gain has been found. For example, one study found that practitioners seeing more than 8 patients a year had better long term outcomes when fitting prism field expanders for patients with a hemianopia (Bowers et al., 2008) but no statistically significant association has been found in cataract surgery outcomes between volume and visual acuity (Schein et al., 1994). No studies have yet reported the influence of volume on the effectiveness of low vision care but a study is underway to look at this in the WLVS (Ryan et al., 2008). It is unlikely that no intervention is more effective than providing the service as improvements in VA (Margrain, 2000) have been found and the vast majority of people use and appreciate the devices prescribed from modern low vision (Reeves et al., 2004, Hinds et al., 2003).

Another problem with spreading the service so thinly is that the community care service only provides basic low vision aids such as hand and stand magnifiers because the capital cost of holding specialist fitting sets for infrequently prescribed devices in so many service bases is prohibitive. Near spectacle-mounted telescopes have traditionally been provided by hospital low vision services and although the number of these devices being prescribed is falling (Crossland and Silver, 2005), for a small number, they can enable some people to carry out tasks they would not normally perform. With the increasing reliance on primary care provision for low vision services in Wales it is important that the provision of very specialist equipment is not lost.

5.4.1.3 Accommodation – organisation to meet patient' needs.

The proportion of services receiving referrals from only one source dropped from 50% to 30% from 2003/4 to 2005/6. The proportion of referrals from social services, the person themselves, friends, relatives and others (other than healthcare professionals), rose from 25% to 44% from 2003/4 to 2005/6. This was the least impressive of all the changes in access as prior to the introduction of the WLVS it seems that referrals were accepted by a considerable number of routes. This might be a reflection of a poorly phrased question rather than small change in provision and will be discussed in the section about limitations of the study. The finding that 17% of services had referrals from service users, relatives and friends in 2005/6 compared to 7% previously suggests that public awareness of the service had improved.

There was a drop in the proportion of services receiving referrals from GPs between the first and second audit periods. This might be because of poor awareness of the WLVS amongst this group of practitioners. Alternatively, individuals who might have previously sought referral from a GP may have self referred and bypassed the GP.

People with a visual impairment in Wales appear to be able to access low vision rehabilitation services in less than two months in most cases. Long

waiting times are common complaints about most NHS service. As visual impairment has ramifications in all aspects of a person's life someone experiencing serious sight problems can be at risk of losing their autonomy. In a randomised controlled trial, Stellmack et al (2008) found that low vision services improved the ability of people losing their sight and ability declined without intervention in the control arm. Therefore, they recommended early rehabilitation intervention. It is possible that the WLVS could improve outcomes because it can be accessed promptly.

5.4.2 Aspects of service delivery

In Wales in 2003/4, 19 (58%) hospitals which had ophthalmologists and 86 (24%) (21 NHS funded and 65 private) optometry practices provided low vision services. This is very similar to the findings of the RNIB/ Moorfields UK-wide Survey in 1999 which found that 65% of hospitals with eye clinics and 24% of optometry practices provided a low vision service (Culham et al., 2002). This suggests that, the pattern of health care provision of low vision services in Wales prior to the establishment of the WLVS was similar to the UK as a whole.

When training and NHS funding was offered to primary eye care professionals with the implementation of the WLVS the number of primary care optometry practices providing low vision services doubled from 86 (21 NHS and 65 private) to 168 (148 NHS and 20 private). This increase supports the findings of a survey of low vision work carried out by optometrists and dispensing opticians in 1999 by the General Optical Council (General Optical Committee, 1999) which found that only 11% of optometrists and dispensing opticians were involved in low vision work. Of those that were not, 72% said it was because it was not economical or that they did not feel competent or a mixture of the two.

It would appear that the extension of services into primary care has reduced waiting times in secondary care low vision services and that there was a reduction in the number of appointments provided. This evaluation was carried out shortly after the service was established, the second audit period commencing just 9 months after the first patient was seen, and so it will be important to monitor the long term effects of the WLVS on the secondary care provision of low vision services in Wales. As low vision services are the only NHS funded rehabilitation services for people losing sight in many parts of the UK they provide an important link between ophthalmological care and rehabilitation services in social services. The loss of low vision services from secondary care where ophthalmological care is based may have an effect on the longer term provision of rehabilitation services for people with a visual impairment in the UK.

5.4.3 Limitations of the study

The response rate to the questionnaire as a whole and most of the individual questions was very high. However, two of the questions had poor response rates. Very few of the services surveyed were able to provide retrospective information about what proportion of the patients seen in the low vision service were referred to social services. Hospitals and non WLVS providers were asked about the number of days each week that they provided the low vision service. However, providers of the WLVS were not asked to provide this information on the record card and so the information collected was not useful. These two questions should be deleted from any subsequent surveys.

Anecdotal evidence suggests that prior to the establishment of the service referral routes were convoluted and most people were referred to low vision services by ophthalmologists. In the survey, services were not asked what proportion of patients was referred by each route, just who was able to refer (Appendix 6). Therefore, the results obtained reflect the diversity but not the pattern of referral of patients. This question should be rephrased in any subsequent surveys.

Contact details for practices were obtained through a number of routes. Due to time limitations it was not possible to contact Business Service Centres to obtain definitive lists. Hence, only about 2/3 of practices in Wales (The Information Centre, 2007) were contacted. As very few optometry practices were providing services prior to the establishment of the WLVS and as all the information available from all the providers of the WLVS was known it is unlikely that this would have made a significant difference to the findings.

Service use in an open access low vision rehabilitation service.

In Wales the community based WLVS accepts referrals from numerous sources including 'self referral' i.e. it is an 'open access' service. Although there is a wealth of information about the prevalence of visual impairment and its causes we know relatively little about the characteristics of those accessing rehabilitation services. If access to rehabilitation services were not restricted, who might benefit? If open access low vision rehabilitation were established would the characteristics of those using it for the first time change as the service became established?

This chapter outlines how a database was set up to enable clinical audit of the WLVS. Through an initial analysis of the data, the characteristics of those who used the service for the first time over a number of years was investigated.

6.1 INTRODUCTION

Traditionally information about the characteristics of people with a visual impairment has been obtained in three ways. Firstly, via commissioned surveys e.g. The Needs Survey (Bruce et al., 1991), Network 1000 (Douglas et al., 2006), Functionality and the Needs of Blind and Partially-Sighted Adults in the UK (Pey et al., 2007) which have sought to assist with policy questions by describing the social characteristics of people with a visual impairment and their access to support services.

Secondly, epidemiological studies have described the distribution of disease, their risk factors and levels of visual impairment in the United Kingdom. For example; the MRC longitudinal study which was expanded to include vision related questions (Evans et al., 2004).

Thirdly, blind and partially sighted registers have provided information about the number of people with a visual impairment, their age and their eye condition (Bunce and Wormald, 2006, Evans et al., 1996, Bunce and Wormald, 2007).

Until now, routine data base information has not been used to report on the use of services or the social circumstances of persons with irremediable visual impairment. Such databases now exist in many services but in most cases within the UK, because of the structure of service delivery, they are of limited size.

6.1.1 Development of the WLVS database

In 2004, when the community based WLVS was set up (Margrain et al., 2005), an administrative database was established to enable ordering of low vision equipment, payment of practitioners and audit of the service. Since it was set up information about a large number of people with a visual impairment has accrued which, though used for administrative purposes, has become a research resource. This resource while not being a methodically derived sample or a total population included data from a large number of people in Wales who needed low vision services. While access to such a database within the NHS is rarely available, the opportunity was available to use this database to provide quantitative information about the characteristics of those accessing low vision services. Specifically, information about: age, registration status, social situation, visual acuity, pathology and support services received.

6.1.2 How does service use change over time?

It was known that the population of people using hospital low vision services in the UK had changed over the last 20 years (Crossland and Silver, 2005). But it was not known if service use changed in the first few years in a newly established low vision service. The number of people seen might be higher than the true demand initially due to a back log of people waiting. Conversely, there might have been less demand initially as not everyone would have been aware of the service.

The visual characteristics of those who used the service for the first time might have changed as the service became established. One would expect that initially, as there was a back log of people waiting for low vision care in Wales, people's vision would have declined while they were waiting. Therefore, it was expected that the visual acuity of people using the service would have improved as the backlog was cleared and people using their sight were picked up earlier and referred into the service.

Patterns of referral into the service might also have changed over time. In particular, as links with social services develop the number of referrals to and from social services might have increased.

Knowledge about the characteristics of those using the service and referral routes to and from it could help more appropriate services to be delivered in Wales. It might also act as an evidence base for commissioners and service providers wishing to shape low vision service provision elsewhere.

6.1.3 Characteristics of primary and secondary care low vision services users

In the last decade, biographical information about people using secondary care low vision services have been reported for a service in Wales (Margrain, 2000), one in Northern Ireland (Lindsay et al., 2004) and one in England (Crossland and Silver,

2005). There might have been biographical differences in those using secondary care services and those who used the WLVS. Knowledge about any differences in the characteristics between those using the primary care based WLVS and those reported as using secondary care services could be useful to commissioners of services.

6.1.4 Aims

The aim of this study was to:

- 1) determine who used the WLVS;
- 2) compare those who used the WLVS to people who used secondary care based low vision services in the UK; and
- 3) determine whether the characteristics of people who used the WLVS for the first time changed over the first 4 years.

6.2 METHOD

6.2.1 The record card

From the start of the service (July 2004), all practitioners providing the WLVS used a standard record card (Appendix 7). The record card used tick box lists in many sections to aid data entry and audit. A section at the end was used to obtain signed consent from everyone using the service to use the information for audit/ research.

Following a low vision assessment, practitioners were required to fax the record card (via a secure fax) to a central NHS administration team in Carmarthenshire Local Health Board (LHB). The administration team entered information from the record cards into a Microsoft Access computer database. All procedures adhered to the tenets of the Declaration of Helsinki and ethical approval was obtained from the All Wales Research Ethical Committee.

6.2.2 Data Extraction

In November 2008, data collected in the administration database for the WLVS until 1st November 2007 were extracted. The methodology employed in the longitudinal follow-up of a hospital low vision service by Crossland and Silver (2005) of using a one month period in each year was followed. The service started in April 2004 and in April, May and June practitioners from the first wave of training were just starting to provide the service. July and August, the summer holiday period, were quiet months for the service. The attendance in the months of September and October was average for the service. Therefore, September was chosen as the first month in which the service was established that was out of the holiday period. Data were extracted, prepared and analysed for four one month time periods in September 2004, 2005, 2006 and 2007.

6.2.2.1 Preliminary extraction of data for analysis

The data were held in a Microsoft Access database format. Every extracted record had to pass all of the following criteria:

- signed consent provided for information in the record to be used for audit/research;
- the visit had to be a first low vision assessment in the WLVS; and
- people had to be aged 18 or older.

Variables identified for analysis were:

- gender;
- date of birth;
- previous consultations (low vision, ophthalmology);
- ocular history (AMD, glaucoma, diabetic eye disease, cataract, nystagmus);
- referral to the service (ophthalmologist, GP, optometrist, social/ rehab worker, voluntary agency, friend/ relative/self, education, employment);
- living arrangement (alone, with partner/ spouse, with other relatives, sheltered accom, residential care);
- occupation (in education, employed, unemployed, retired);
- services received (social services, voluntary sector, education, employment, optometry);
- visual acuity (habitual near);
- visual acuity (with low vision aid near);
- type of low vision aid;
- number of low vision aids;
- visual acuity (best binocular distance); and
- report/referral (for registration, social services).

6.2.2.2 *Preparation of data for Analysis*

All variables were systematically checked for obvious or out-of-range errors, and corrected when possible. Missing value codes were assigned to fields that were blank or had nonsense entries. New variables were created for age groupings. The variable for distance visual acuity was re-coded so that the outputs would be in LogMAR notation.

Since much of the analysis would be by age and gender, those with unknown gender (n=15) were excluded from all analyses.

6.2.3 Data Analysis

Data were analysed using SPSS. In accord with the first aim of this study, most of the analysis involved simple cross-tabulations. Where necessary, to take into account the effect of other possible confounders, logistic regression was used.

At the outset it was hypothesised that over time:

- 1) the number of people using the service would increase;
- 2) the age of patients attending for first assessment would increase;
- 3) the visual acuity of people using the service for the first time would improve
- 4) the proportion of domiciliary visits would increase;
- 5) the proportion of people reporting a previous ophthalmology consultation would decrease; and
- 6) the links between social services and the WLVS would develop and hence the number of referrals to social services would increase;

The hypotheses were tested using significance tests based on Chi², Mann-Whitney U, Fisher's exact and t-tests, as appropriate.

6.2.4 Clinical Outcomes

The improvement in near visual acuity resulting from service provision was defined as the near acuity at the end of low vision service provision (including the use of low vision aids if prescribed) compared to the presenting habitual near visual acuity.

6.3 RESULTS

6.3.1 People using the WLVS in the month of September 2004 to 2007

Before looking at the changes over time, the characteristics of the 904 'new' low vision patients (seen for their first assessment in the WLVS) in the month of September from 2004 to 2007 are described.

6.3.1.1 Age and gender

The age and gender profile of adults attending the WLVS are shown in Figure 6.1. The median age of adults was 83 years (range was 18 to 101; Skew 1.823; Kurtosis 4.425); 310 (34.3%) were men and 594 (65.7%) were women.

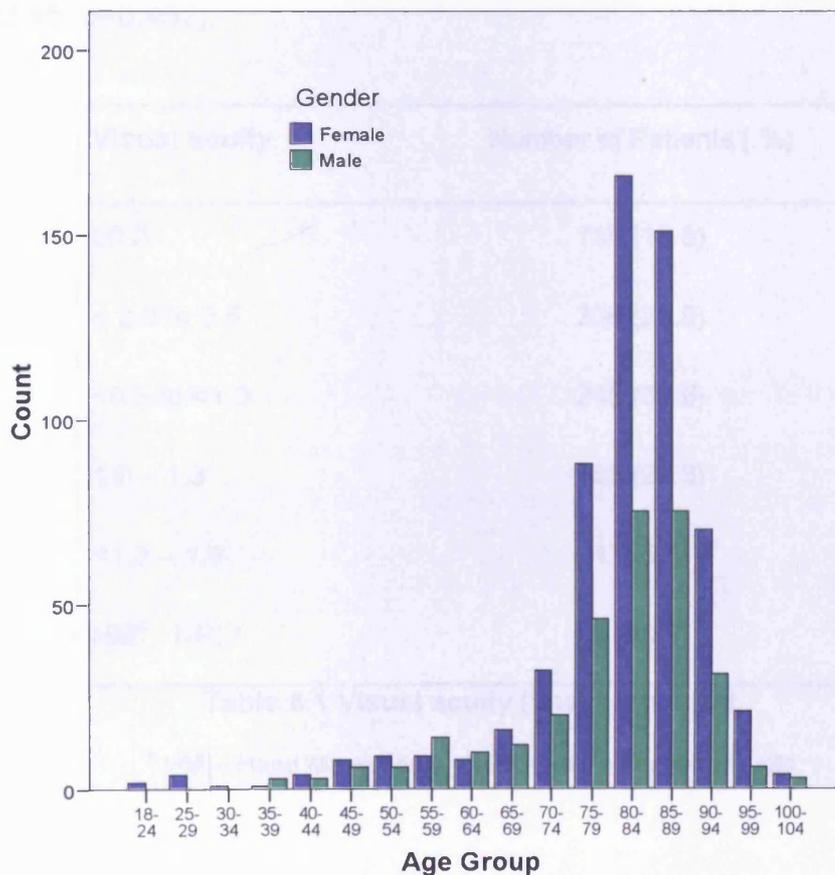


Figure 6.1. Age and gender distribution for 904 patients who had a first low vision assessment in the WLVS in September between 2004 and 2007.

Though there were fewer men overall, the percentage of men as a group who were under pensionable age (13.5%) was higher than for women (7.7%). However, the median ages of men and women were similar (82 and 83 respectively). There was no significant difference in age between men and women ($\text{Chi}^2 = 81.295$, $p = 0.97$).

6.3.1.2 Visual acuity

The visual acuity of patients presenting for a low vision assessment is summarized in Table 6.1. Binocular distance visual acuity was not normally distributed (Kolmogorov-Smirnov = 0.151 $p < 0.001$). Median LogMAR acuity was 0.6 (6/24) and the range was 0.0 to 1.6 (6/6 to 1/60). Of the 804 adults for whom binocular distance visual acuity was recorded, 73.1% had visual acuity better than 1.0 (6/60). There was no difference in VA between men and women (Mann-Whitney $U = 70822.55$, $p = 0.462$).

Visual acuity	Number of Patients (%)
≥ 0.3	135 (16.8)
< 0.3 to 0.5	208 (25.9)
<0.5 to <1.0	245 (30.5)
1.0 – 1.3	163 (20.3)
<1.3 – 1.6	47 (5.8)
HM [#] - NPL [*]	6 (<0.7)

Table 6.1 Visual acuity (best binocular).

[#] HM – Hand Movements ^{*}NPL- No Perception of Light

6.3.1.3 Eye condition

Age-related macular degeneration was the most prevalent of the diseases ($n = 635$, 70.2%) then cataract ($n = 284$, 31.4%) and glaucoma ($n = 135$, 14.9%). The percentages do not sum up to 100 because a patient may have had more than one

disease. There was no significant difference between the prevalence of AMD in women (72.1%) than men (66.8%) ($\text{Chi}^2 = 2.716$, $p = 0.099$).

6.3.1.4 Living situation

Of the persons attending for whom living situation was recorded ($n = 880$), 43.2% lived alone, 39.1% lived with a partner or spouse, 9.9% with a relative, 4.3% lived in sheltered accommodation and 3.3% in residential care.

Overall, women attendees were significantly more likely than men to live alone (Table 6.2) ($\text{Chi}^2 = 63.665$, $p < 0.001$).

Proportion Living Alone		
Male	$n = 92/300$	30.7%
Female	$n = 288/580$	49.7%

Table 6.2 Men and Women Living Alone.

6.3.1.5 Previous consultations

Of the total 904 patients, 467 (51.7%) reported a previous ophthalmology consultation, and 187 (20.7%) reported having a previous low vision consultation (Table 6.3). People under retirement age were significantly more likely to have had a low vision or ophthalmological appointment ($\text{Chi}^2 = 5.937$ $p = 0.015$; $\text{Chi}^2 = 23.389$ $p < 0.001$ respectively).

Age group	Previous consultation			
	Low Vision		Ophthalmology	
18-64	$n = 27/88$	30.7%	$n = 67/88$	76.1%
65+	$n = 160/816$	19.6%	$n = 400/816$	49.0%
Total	$n = 187/904$	20.7%	$n = 467/904$	51.7%

Table 6.3 Previous consultations with ophthalmology and low vision by age group

Men were no more likely to have had low vision (n = 70/310, 22.6%) and/ or ophthalmological consultation (n = 167/310, 53.9%) than women (low vision n = 117/594, 19.7%; ophthalmology n = 300/594, 50.5) ($\text{Chi}^2 = 1.032$ p= 0.310; $\text{Chi}^2 = 0.924$ p=0.336 respectively).

When giving information on non-NHS funded support and services received (i.e. other than low vision or ophthalmology consultations) prior to the low vision assessment, 370 (40.9%) reported receiving services from social services, 99 (11%) from the voluntary sector, 9 (1%) from employment services and 4 (0.4%) from education services.

Three hundred and eighteen people (35.2%) had not consulted with any other service (low vision, ophthalmology, social services, voluntary sector, education or employment) prior to using the WLVS.

Of the 527 people not registered, 25.2% (n = 133/527) had received support from social services prior to their first WLVS assessment.

6.3.1.6 *Registration status*

Of the 840 persons for whom information was available on registration, 37.3% (n= 313) reported that they were registered as either 'blind' or 'partially sighted' (Table 6.4). Of the 840, 142 people had VA < 6/60 and 81.0% of these were registered (n = 68, 47.9% Blind ; n = 47, 33.1% Partially Sighted).

Reported registration as Blind or Partially Sighted was found to have been significantly more likely if a person had VA ≥ 1.0 ($\text{Chi}^2 = 139.8$, p < 0.001), they had had a previous low vision consultation ($\text{Chi}^2 = 129.5$, p < 0.001) and/ or they were under 65 years old ($\text{Chi}^2 = 48.157$, p < 0.001). People who lived alone were significantly less likely to report being registered compared to those who didn't ($\text{Chi}^2 = 8.128$, p < 0.04). Gender and ocular disease were not found to affect registration.

Age group	Blind n (%)	Partial sight n (%)	Not registered n (%)	Total n(%)
18-65	32 (37.6)	29 (34.1)	24 (28.2)	85 (100)
66-75	14 (15.9)	28 (31.8)	46 (52.3)	88 (100)
76-85	49 (12.5)	78 (19.8)	266 (67.7)	393 (100)
Over 85	32 (11.7)	51 (18.6)	191 (69.7)	274 (100)
Total	127 (15.1)	186 (22.1)	527 (62.7)	840 (100)

Table 6.4 Registration status at the first low vision assessment by age.

Binary Logistic regression (entry method) was used to predict registration from visual acuity ≥ 1.0 , living alone, previous low vision consultation, and age under 65 (Table 6.5). By far the strongest predictor of registration was visual acuity ≥ 1.0 , but previous low vision consultation and age under 65 were also significant predictors. Visual acuity ≥ 1.0 , previous low vision assessment and age under 65 years together predicted 77.9% of the variance. When other factors were taken into account people living alone were not found to be a significantly more likely to be registered.

Variable	Chi ²	P value	Odds Ratio	95% CI Odds Ratio	
				Upper	Lower
*VA ≥ 1.0	86.07	<0.001	10.00	6.15	16.26
*Under 65 years	32.14	<0.001	0.19	0.11	0.34
*Previous low vision	83.382	<0.001	0.15	0.10	0.22
Lives alone	2.148	0.143	0.77	0.54	1.09

Table 6.5 Logistic Regression to predict registration as Blind or Partially Sighted. * significant predictors

6.3.1.7 Referral to social services

Following low vision assessment, 11.7% (n = 106/904) were referred to social services.

6.3.2 Clinical Outcomes

6.3.2.1 Low Vision Aids Prescribed

Figure 6.12 shows the number of low vision aids prescribed per person. This ranged from 0 to 8 (median 3).

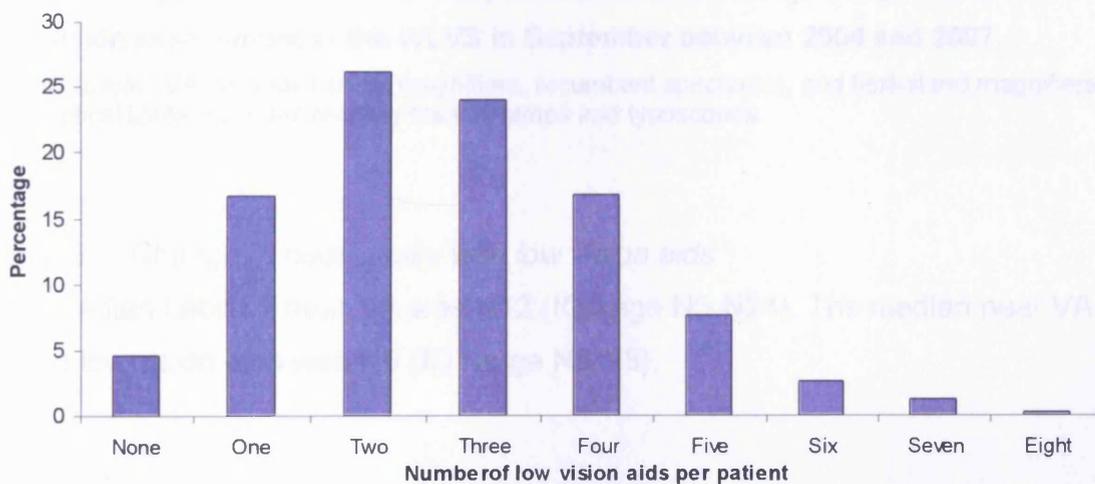


Figure 6.2. Number of low vision aids prescribed per patient for the 904 patients who had a first low vision assessment in the WLVS in September between 2004 and 2007.

The proportion of low vision aid types dispensed are identified in Figure 6.3.

Together, hand, folding pocket and illuminated hand magnifiers were the most commonly dispensed.

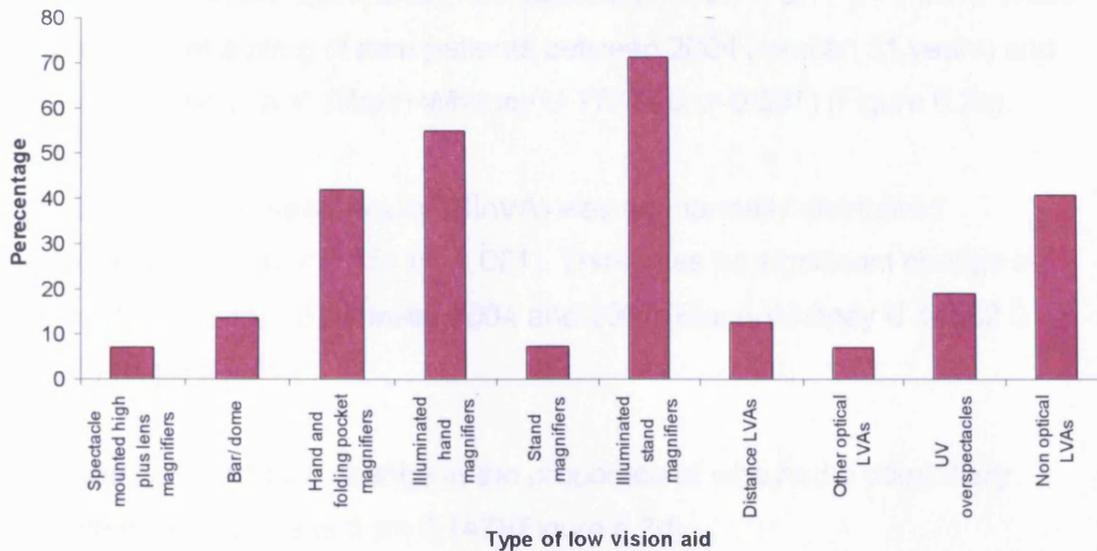


Figure 6.3. Types of low vision aids prescribed for the 904 patients who had a first low vision assessment in the WLVS in September between 2004 and 2007.

Other Optical LVAs includes chest magnifiers, recumbent spectacles, and flexi-stand magnifiers. Non-optical LVAs, includes reading stands, lamps and typoscopes.

6.3.2.3 Change in near acuity with low vision aids

The median habitual near VA was N12 (IQ range N6-N24). The median near VA with a low vision aids was N5 (IQ range N5-N8).

6.3.3 The change in characteristics of those using the WLVS from September 2004 to 2007

A summary of people using the WLVS in September for each year 2004 to 2007 is shown in Figure 6.2. The number of patients increased from 164 in the first year to between 240 and 251 in subsequent years. The number of new assessments in 2004 was significantly lower than that in 2007 (χ^2 18.705 $p < 0.001$).

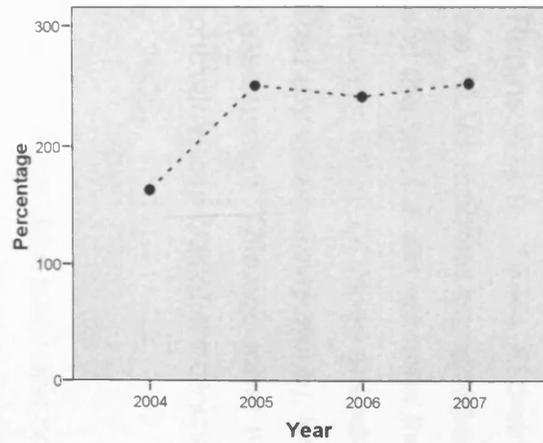
Age was not normally distributed (Kolmogorov-Smirnov = 0.17 $p < 0.001$). There was a significant ageing of new patients between 2004 (median 81 years) and 2007 (median 84 years) (Mann-Whitney U 17243.0 $p = 0.007$) (Figure 6.2b).

Binocular Distance Visual Acuity (BinVA) was not normally distributed (Kolmogorov-Smirnov = 0.151 $p < 0.001$). There was no significant change in binocular VA was found between 2004 and 2007 (Mann-Whitney U 14832.0 $p = 0.131$) (Figure 6.2c).

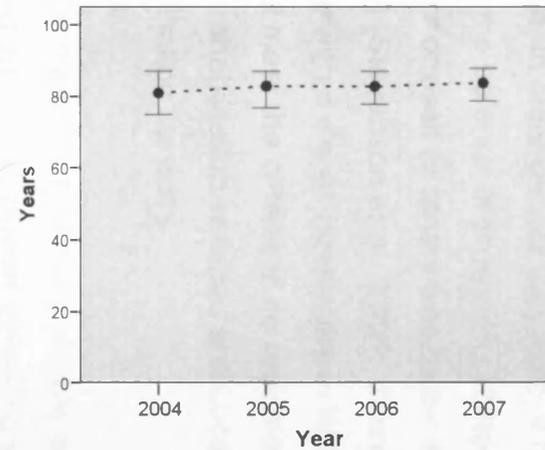
There was no significant change in the proportion of who had a domiciliary assessment (Fisher's exact $p = 0.147$) (Figure 6.2d)

There was a significant reduction in the proportion of people who had had a previous ophthalmology consultation (60.7%; CI 53.2% to 68.2% to 45.8%; CI 39.6% to 52.0%) (Fisher's exact $p = 0.003$) and those who were referred to social services (20.2%; CI 14.0% to 26.4% to 12.0%; CI 8.0% to 16.0%) (Fisher's exact $p = 0.025$) (Figure 6.2 e and f).

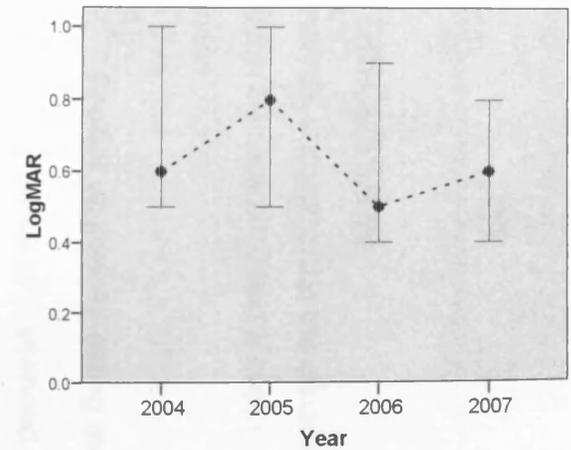
a) *Number of appointments



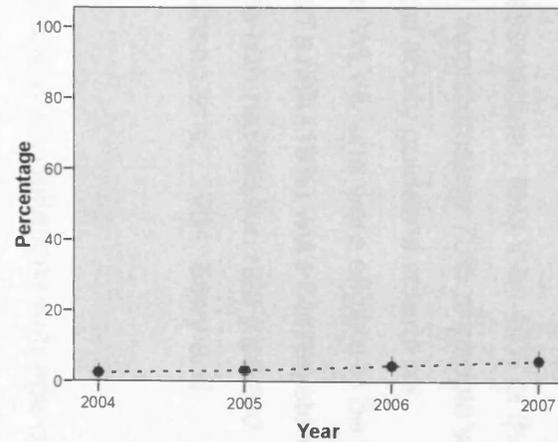
b) *Age (median and interquartile range)



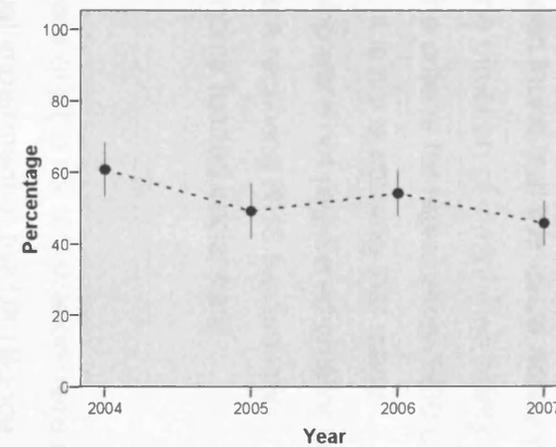
c) Binocular Distance VA (median and interquartile range)



d) Domiciliary visits (proportion and 95% CI)



e) *Previous ophthalmology (proportion and 95% CI)



f) *Referral to social services (proportion and 95% CI)

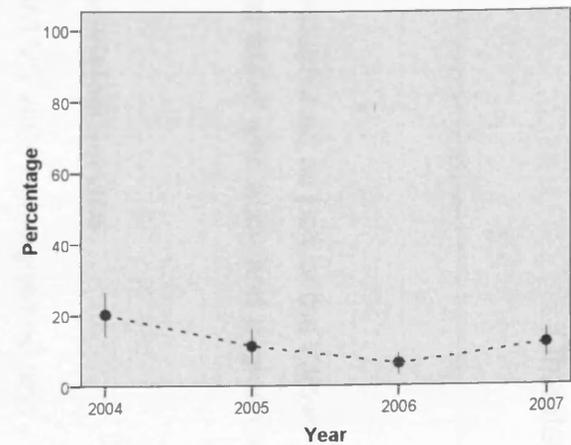


Figure 6.4 Plots describing the change in characteristics of those using the WLVS from September 2004 to 2007 a) number of patients, b) age, c) binocular distance visual acuity, d) proportion of domiciliary visits, e) proportion that had had a previous ophthalmology consultation, f) proportion referred to social services. * Significant differences. CI Confidence Interval.

6.4 DISCUSSION

This analysis suggests that the database established as part of the Welsh Low Vision Service provided a useful tool to assist with audit and evaluation of the service.

6.4.1 Profile of people using the low vision service

More than half of those who attended the WLVS were not registered and many of those not registered had received or were referred for social services support. In older people with AMD, it has been found that the visual acuity at which the balance of probability shifted in the direction of diminished ability to care for oneself or others was better than the criteria for registration (6/60 or worse) (Stevenson et al., 2004). Therefore, it is not surprising that many people with a visual impairment in Wales who were not registered and/ or who did not meet the criteria to be registered were receiving NHS funded low vision rehabilitation services and Local Authority funded social care rehabilitation services.

There is evidence that many people who were eligible for registration were not certified and/ or registered as having a visual impairment in the UK (Bunce and Wormald, 2007, Barry and Murray, 2005, Bruce et al., 1991, King et al., 2000, Robinson et al., 1994). At their first assessment, less than 40% of those using the WLVS reported being registered. Approximately 70% of people who accessed the service did not meet the visual acuity guideline criteria for registration (< 6/60). Of those attending the WLVS who were eligible to be registered (by visual acuity alone), less than a fifth (19%) were not registered at first assessment. This was lower than the non-registration rate reported from ophthalmology outpatient clinics (Robinson et al., 1994, Barry and Murray, 2005).

The reduced registration rates and ophthalmology consultations with age is concerning. There is evidence that older people with a visual impairment are

As the backlog of people waiting for low vision services was cleared and people losing their sight were picked up earlier in the community, it was anticipated that the entry visual acuity of people using the service would have improved over the first few years. However, there was no clear trend in this direction.

As hypothesised, the age of people using the service increased between 2004 and 2007. This increase may reflect easier access for older, less mobile, people. The increase (but not significant) in the proportion of domiciliary visits may have also been a factor. It is possible that aging within the population may also had an impact.

It was anticipated that as the WLVS developed, links with social services would develop and referrals to social services would increase. Instead there was a decrease in referrals. This finding and another audit have informed the development of a standardised referral system between the WLVS and social services and multi-disciplinary training days to encourage better links in future.

A significant drop (of about 15%) in the number of people having a previous ophthalmology consultation was found. This was anticipated as the WLVS became an early point of contact for people losing their sight in Wales.

6.4.3 Comparing the WLVS with other UK low vision services

Statistical comparison with other UK low vision services is difficult because reports are for much smaller numbers and variables are collected slightly differently. The gender; living situation, visual acuity; and incidence of AMD in those using the WLVS appear to be similar to those reported in secondary

care low vision services in Wales (Margrain, 2000) and Northern Ireland (Lindsay et al., 2004) in the last decade (Table 6.6).

People using the WLVS appear to be older than all other reported low vision service users in the UK (although this might not be significant). People with a visual impairment are known to become more restricted as they grow older (Klein et al., 2003). Domiciliary visits are not offered as part of a secondary care service. Hence, it may be that domiciliary visits explain in part why people using the community service are older than those in secondary care (Margrain, 2000, Crossland and Silver, 2005, Lindsay et al., 2004). The ability to self refer and reduced waiting times and reduced journey times of the WLVS (Margrain, 2000) may also be factors that helped older people with a visual impairment to access the service.

	Wales (Margrain, 2000)	Northern Ireland (Lindsay et al., 2004)	England (Crossland and Silver, 2005) (2003 data)	WLVS
Sample size	168	48	About 230	904
Age				
>65	83%			90.1%
>80	57.7%	56.3%		61.6%
Median			70	83
Gender Female	63%	58.3%	53%	64.15%
VA \leq 6/60	35.3%	30%		26.9%
Registered		54%		37.3%
AMD	58.3%	79.2%	25-40%	70.2%
Living Alone		37.5%		43.18%

Table 6.6 Comparison of people using the WLVS with reported users of secondary care low vision service users in the last decade.

The profile of people using the low vision service in Moorfields Eye Hospital (Crossland and Silver, 2005) appear to be different from those using all other

low vision services but in particular the WLVS. Those using Moorfields Eye hospital are in the main younger, more likely to be male and less likely to have AMD. This is likely, in part, to be due to the tertiary care nature of Moorfields Eye Hospital and the likelihood that it receives a great number of referrals of younger people with rare congenital eye conditions.

Reported registration status in the WLVS appears to have been lower than that reported by those using secondary care low vision services in Northern Ireland (Lindsay et al., 2004). This may be because everyone referred to secondary care low vision services would have seen an ophthalmologist, whereas half of those attending the WLVS had not and hence a low vision assessment would be the first opportunity to initiate the registration process.

6.4.4 Limitations of the study

6.4.4.1 Using self reported information

Some of the information in the database and presented in this report (registration status and previous consultations with ophthalmology and social services) is self reported. Therefore, caution should be used when interpreting the results as some people might have been registered or used a service but failed to remember doing so. Members of the public in general underestimate their contacts with services, both hospital and community (Bhandari and Wagner, 2006). It would be wise to check the reported status of a sample of people against hospital and social services records.

6.4.4.2 Using one month in each year

The methodology employed by Crossland and Silver (2005) of using a one month period in each year was followed. There may have been variations between months, hence, using information about everyone who used the service in each given year would have been more robust.

6.4.4.3 *Missing data*

The use of the record card and data entry was audited in December 2004. One hundred record cards were randomly selected and the information recorded on each of the selected record cards and data entry was checked. Overall the standard of record keeping and data entry was good. However, accredited practitioners were advised of the audit results and sent a template to remind them of fields which were mandatory for completion. Following the audit, the administration team at Carmarthenshire LHB was advised to return record cards which were not completed to practitioners without processing them. Therefore, it is likely that most of the data recorded as missing was from the September 2004 dataset. As the data collected in September 2004 was compared to that in September 2007 a greater amount of missing data in September 2004 might have introduced errors in the analyses to determine the change in characteristics of people using the WLVS between 2004 and 2007.

6.4.5 **Future work**

The database and this initial analysis have provided a useful means to determine whether initiatives to improve service provision are effective. For example, whether the standardised referral system and multidisciplinary training currently being implemented for health and social care professionals in vision rehabilitation services in Wales improves the link and referral between health and social care professionals.

The reduced registration rates and ophthalmology consultations with age reported by people using the WLVS is concerning. This is an area that requires further investigation, starting with a check of the self reported registration status and hospital use amongst a sample of people in the WLVS database.

Discussion, conclusions and the future

7.1 DISCUSSION AND CONCLUSIONS

In vision research, scientists investigate the cellular changes that lead to an eye condition or measure the resultant changes in a person's eyesight. However, when trying to evaluate a rehabilitation service for a person losing their sight, a purely scientific approach would not be appropriate. There aren't quantitative research techniques that could encompass the measurement of the diverse influences on rehabilitation outcomes that we need. Hence, in this thesis an attempt was made to use a number of qualitative and quantitative research techniques to evaluate low vision services in the UK.

When evaluating a service, if you don't listen to service users you may fail to measure the outcomes that really matter to them. In the focus group study conducted in 1997/8 (Chapter 2), people with low vision were able to provide an insight into low vision services that had not previously been heard. As well as outlining what they found to be good and difficult, they suggested solutions that they found acceptable to overcome some of the problems they found with low vision rehabilitation services. Although focus groups can be influenced by the moderator and the people in the group, careful planning can minimise this to make them a useful and robust research technique.

The focus group study in this thesis was conducted at a time when focus group research was just emerging as a technique in health care evaluation. Despite being reported as an important technique in BMJ (Kitzinger, 1995), focus groups are rarely used in healthcare research except in the development of questionnaires. The author believes this is a great shame as there is little more powerful when determining service outcomes than the

views of service users. The fact that the results of the focus group study in this thesis were used as the foundation for setting the standards for low vision care in the UK (Low Vision Consensus Group, 1999) is an example of the impact this technique can have in changing practice and policy. More recently, the author has been part of a team that has used focus groups with children with low vision to understand their needs from low vision services and to develop a questionnaire (Khadka et al., 2010). This study has resulted in the Welsh Assembly Government providing electronic low vision aids through the Welsh Low Vision Service, again demonstrating the potential impact of focus group research.

GIS was used in two separate studies conducted about 10 years apart that are reported in this thesis (chapter 3 and chapter 5). Like focus groups, when first employed by the author, GIS was just emerging as a technique in health service research. However, unlike focus groups, the use of this technique has developed incredibly quickly in healthcare research. There are now a number of journals dedicated solely to GIS in healthcare, the data that is freely available has dramatically increased (e.g. postcodes; ordinance survey information of environmental features such as mountains or road networks and census or other information about the people) and the analysis options have changed beyond recognition in that time. There are now GIS specialists working in government departments, the NHS executive and University geography departments. User interfaces and software developments have also resulted in GIS being available on most University networks enabling basic analysis and mapping to be carried out by any researcher.

The revolution in GIS is in part due to the fact that the internet, computers and satellite technology have all developed at an exponential rate. However, the usefulness to healthcare planning of the maps and statistics that enable differences in accessibility to be viewed and measured along social or demographic variations is also likely to be an important driver. The author predicts that the use of GIS will continue to increase in healthcare evaluation

The dramatic increase in the number of people accessing low vision care in Wales following the implementation of the WLVS demonstrates that extending low vision services into the community is one option for providing services for the increasing number of people who will need them. However, improved access should not be aspired to in isolation. It was important to ensure that the WLVS was effective. A description of the psychometric properties of the 7 item NEI-VFQ, using Rasch analysis in a population of adults attending the WLVS (Ryan et al., 2008), showed that it provided a meaningful measure of the ability of a person with low vision to perform everyday tasks (Chapter 4). Hence, it is a valid tool with which to evaluate a large scale multi-centre low vision service. The questionnaire was made up of items that were important for people with low vision but, it did not include them all. The 7 item NEI VFQ only measured that aspect of visual disability that low vision service provision claimed to be able to do something about.

The 7 item NEI VFQ has been found to be a sensitive tool for measuring the effectiveness of the community WLVS (Ryan et al., 2010) and a hospital low vision service (Court et al., 2010) when used before and after low vision service intervention.

The development of visual disability, visual function and vision related quality of life measures is a strength in low vision research (see Appendix 1). It is therefore hard to see how there is room for another questionnaire. However, most questionnaires have 19 questions or more and many have not been found to be very sensitive to low vision intervention. The 7 item questionnaire may find a niche in research as a secondary measure, in studies using long questionnaires as the primary measure. Its ease of use and simple scoring may also mean it finds a place as a useful audit tool for low vision services.

The database established as part of the administration of the WLVS was originally developed to facilitate service audit. The initial analysis reported in Chapter 6 gave an interesting insight into those using the service and in the

longer term will enable changes to be monitored. It will be helpful to direct future effort in developing the service and in determining areas for future research. For example, the reduced registration rates with age is concerning and requires further investigation. It will also be useful to determine whether interventions have been successful. For example, a standardised referral system and multidisciplinary training has been implemented for health and social care professionals in Wales to try to improve the link and referral between health and social care professionals. The database will enable any change in referral and reporting rates to be evaluated.

Recruiting older people with a visual impairment to evaluate new interventions or provide opinions is always difficult. The WLVS now has over 16,000 users who are all asked to give signed consent if they would be prepared to take part in research. Therefore, the database may be a useful resource to obtain samples of people with low vision to use in future research.

7.2 THE FUTURE

The predicted increase in the number of people with low vision (by 60% in the next 20 years in Wales) alongside a decline in the working age population who can care for them, makes the development of accessible, effective rehabilitation services an important challenge for those providing, evaluating and commissioning eye care. It is possible that scientific breakthroughs will produce more effective treatments for sight threatening eye disease.

However, such advancements are unlikely to dramatically alter the picture. For example, whilst the exciting advancements in the treatment of Wet AMD will reduce the long term chances of severe sight impairment visual impairment (VA less than 6/60) they are unlikely to change the future projections for the overall number of people with low vision as they don't completely correct vision in most cases.

Although there have been some advancements in the provision of low vision care and an exponential increase in research in this field over the last 20 years, it is frustrating how little the rehabilitation services for those losing their sight in the UK have changed.

In low vision research over the last decade much effort has been concentrated on finding ways to measure the effectiveness of interventions in terms of improvements in ability and functioning. Now that there is evidence that the basic NHS clinical service reduces disability, it will be important to build on that to find how the rehabilitation process can be made more effective. This will involve improving current interventions, for example, finding out when we should follow up low vision patients or using randomized controlled trials to measure the effectiveness of local authority rehabilitation services. However, some attention should also be turned to developing interventions to combat the other affects of visual impairment such those that can reduce depression and/ or social isolation. For this we will need to look to other rehabilitation disciplines. Dr Tom Margrain at Cardiff University is hoping to determine the effectiveness of interventions for depression in people with a visual impairment.

It is hoped that advancements in technology, will provide new ways to help people with low vision. For example, portable electronic magnifiers or voice output scanners may be incorporated as apps into mobile phones. The advancements of computers and the internet have already had a very positive affect in terms of enabling people with a visual impairment to access information. However, as the IT literate population grows old the opportunities to improve the autonomy of people with a visual impairment will hopefully also be realised. For example, as the social networking adults of today become the low vision elders of tomorrow there may be new and novel opportunities to reduce social isolation and offer peer support.

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Appendices

APPENDIX 1: TABLE OF STUDIES INCORPORATING QOL/ VISUAL FUNCTION QUESTIONNAIRES

Study	Measures	Subjects	Design	Results	Comments
(Scott et al., 1999)	NEI-VFQ 51 Telephone	N=156 All low vision patients in a year	- 1 wk prior to low vision appointment - 3/12 after	NEI-VFQ 51 Absolute changes modest but statistically significant (p,0.001) in 4 domains.	Not RCT Not Rasch
(Wolffsohn and Cochrane, 2000)	LVQoL Self completion	N=278	Before LVA and 4 weeks after	Statistically significant change post rehabilitation (p=0.001)	Not RCT Not Rasch
(Scanlan and Cuddeford, 2004)	NEI-VFQ 25 Telephone	N=64 32 in each arm AMD only VA 20/60 to 20/400	RCT LVA + 5hrs teaching Control - LVA + 1hr teaching Outcomes measured before and 1 year after LVA	Didn't publish single item/ domain scores Used Monte Carlo exact test because small number Significantly better post 5hr teaching:	Person who did the teaching did the evaluation Not clear how it was administered Not peer reviewed

Appendices

(Stelmack et al., 2002)	NEI- VFQ 25 (34 items) Telephone	N=126 77 'blind' veterans from the Hines 51 'partially sighted' veterans from the Victors	Outcomes measured before and on discharge	Rasch Analysis NEI VFQ Modest but significant ($p < 0.001$) Only change in 7 items	Not RCT Follow up questionnaire on discharge 4 to 42 days later. Sample ' Magione's recommendation'
(Hinds et al., 2003)	VCM1 Face to face in persons home	N= 71 Patients attending one of two low vision services	Outcomes measured before and 6/12 after intervention	VCM Statistically significant reduction in concern in 3 areas: eyesight getting worse ($p=0.0004$); safety at home ($p=0.0005$); coping with everyday life ($p=0.0095$).	Not RCT Not Rasch
(Reeves et al., 2004)	VCM1 Face to face in persons home	N=196 AMD, community dwelling, VA 6/18 to 1/60	RCT – 3 arms 1) LVA 2) LVA + 3 therapy visits 3) LVA + 3 visits (control) Questionnaire before and 1 yr after	No statistically significant difference in any of the 3 arms	Not Rasch

Appendices

(La Grow, 2004)	NEI VFQ 25 Telephone	N=186 93 had a low vision service, 93 didn't.	Outcomes measured before, 6/12 and 12/12 after intervention	No statistically significant difference found between those who had a service and those that didn't. groups	Not RCT Not Rasch
(Stelmack et al., 2006)	LV VFQ 48 Telephone	N= 242 116 from 4 outpatient services (62% male) 136 from an in-patient service (93% male)	Outcomes measured before and 3/12 after intervention	Average change after in-patient 1.49 logits for inpatient groups and 0.33 logits for the outpatients	Not RCT Predominantly old white males.
(de Boer et al., 2006)	LV QOL VCM1 ? admin	N=215 116 to an optometric service 99 to a multi-disciplinary service	Outcomes measured before and 12/12 after intervention	Lower scores on the mobility subscale of the LVQOL (p=0.04) for patients in multidisciplinary low-vision. No other differences were observed	Not RCT Not Rasch
(Lamoureux et al., 2007)	IVI ? admin	N=192	Outcomes measured before and 3 to 6 months after intervention	Significant improvements in 2 of 3 subscales: reading and accessing information	Not RCT

(Stelmack et al., 2008)	LV VFQ 48 Telephone administration	N=126 Consecutive AMD 98% white male VA 20/100 - 20/500	RCT (2 arms) 1) LVA+counselling + teach (10hrs plus) 2) control- LVA + phonecalls Outcomes measured before and 4 months after intervention	Treatment group improved in all aspects of visual function compared to the control group. 2.43 logits overall (p<0.001)	Predominantly veterans (old white males).
(Kuyk et al., 2008)	NEI- VFQ 25 (39 items)	N=176 Veterans attending an in- patient service (11-109 days)	Outcomes measured before and 2 and 6 months after intervention	Statistically significant improvement in 9 of 11 NEI VFQ subscales and 9composite score at 2 and 6 month post-rehabilitation intervals.	Not RCT Not Rasch

Table 8.1 A Summary of studies which have incorporated quality of life/ visual function questionnaires to measure the effectiveness of a low vision service or intervention. LVA- Low Vision assessment

APPENDIX 2: FOCUS GROUP SCHEDULE

Introduction

Good [morning/afternoon], my name is [xx] and I am doing a study for RNIB. We are looking at the services that help you with any aspect of your life affected by low vision. In order to do this, we need to learn your views and experiences so that we know the good and bad aspects of the services and your opinions about things you might like to see changed.

All of the information that we collect during these sessions is confidential, and none you can be identified by name or address. The information will be summarized and used by the RNIB to help try to improve services, and none of the views or opinions expressed will be passed onto any body who helps you.

To make sure that we can record everybody's view, we usually like to tape record these discussions. Does any body mind if I tape what they say?

Focus group questions

Low vision services are those which help the user to adapt and accept his or her or her condition, and helps the user to achieve his or her full visual potential. To get the ball rolling, perhaps everybody in turn can tell the group if they have accessed these services, and if so, which professionals and services deal with any aspect of their low vision.

Can anybody think the good points and bad points of services that you receive now? [probe: why / who / where / how].

What do people feel they need from these services? [probe: why / who /

where / how].

If money was no constraint, what would be your idea of an ideal service?

[probe: why / who / where / how]

What do you feel are your most important needs/ if money was a constraint, what would think should be dealt with first? [probe: why / who / where / how]

Prompt Sheet

what is low vision? Have you heard of low vision, do you think you have low vision? Serious sight problems, visual impairment, fading sight, seeing difficulties, sight difficulties.

professionals optometrist, ophthalmologist, orthopedist, social worker, GP, rehabilitation officer, mobility officer, occupational therapist, counselor, teacher, voluntary worker.

services and locations hospital, low vision center, resource center, social services, school, voluntary center health center/ doctor's surgery.

referrals finding about services, length of time between having a sight problem and finding out about services.

specific to appointment waiting to be seen, was the time reasonable.

information about the assessment/ appointment. appointment card.

information and advice, your questions answered, training to use equipment.

follow up appointments, frequency of follow ups.

person dealing with you. adequate explanations of who they were or what they were going to do. information you would have liked at this stage, difficulties you were having.

general needs: ethos of organizations, VIP/ professional ratio, delays between certification & registration, delays between registration and help given, location and physical access to services, cultural access to organizations, frequency of help given, service centered - user centered, reactive - proactive, holistic approach, information about services, importance of registration.

training and special equipment specific skills training, mobility training, trying different LVAs, training to use LVAs, use of residual vision, vision substitution gadgets, making things bigger, making things closer, using colour, lighting and contrast.

mobility training for street, public transport, lifts, within buildings, reliance on motor car, white stick training, guide dogs, human escorts. Accessibility to the service itself: transport, near to home? accessibility around service buildings: signage etc.

people from ethnic minorities cultural access to services, language differences, cultural differences, access for people from ethnic minorities to work in health / social / voluntary sector, availability of bilingual and bicultural professionals

emotional self help groups, counseling, social isolation, family support

networks, counseling for parents and careers, low self image in teenagers and newly impaired.

communication embossed communication, talking books, help with mail related tasks, access and information about cassette recorders, talking newspapers.

domiciliary adequate housing, home needs, lighting at home, personal care around the house, obtaining practical help in the home, meals on wheels.

leisure leisure time and holidays.

carers emotional support for carers and parents, respite care, relief baby-sitting.

health information about medical diagnosis and prognosis, maintaining and enhancing physical functioning.

welfare rights and occupational residential placements, day care, employment, special equipment at work.

educational choosing a school, mainstream schools, bullying, abuse, language development at school.

APPENDIX 3: 1997/8 SURVEY OF LOW VISION SERVICES

Survey of Low Vision Services

Appendix A(1)



Affixed label

Please amend incorrect details and ensure there is a contact name, telephone number and postcode.

The following questions have been constructed to collect clear details about low vision services. To reply, tick the relevant boxes and add written comments where appropriate. We very much value your support in this survey.

If you are involved in more than one service, you may receive more than one questionnaire. If so, please complete one questionnaire for each different type of service. If all your services are the same, then please complete one questionnaire only and detach, complete and return the front covers of the remaining questionnaires.

Where are you based? Tick all that apply.

- | | | | |
|----------------------|--------------------------|----------------------------|--------------------------|
| Resource centre | <input type="checkbox"/> | Rehabilitation centre | <input type="checkbox"/> |
| Domiciliary only | <input type="checkbox"/> | Optician/Optomety practice | <input type="checkbox"/> |
| Hospital | <input type="checkbox"/> | School | <input type="checkbox"/> |
| University | <input type="checkbox"/> | | |
| Other (please state) | <input type="checkbox"/> | _____ | |

Do you provide any form of low vision service? N.B. This can include selling low vision aids. (Low vision aids are assumed to include magnifiers, lights, reading frames, CCTVs etc., not just optical low vision aids.)

- | | | |
|------------------------------|--------------------------|-----------------------------------|
| No | <input type="checkbox"/> | Please go to Section 3 on page 12 |
| Selling low vision aids only | <input type="checkbox"/> | Please go to Section 2 on page 11 |
| Other | <input type="checkbox"/> | Please go to Section 1 on page 3 |

Section 1. This section should be filled in by people who provide low vision services

1. Does your service consist of satellite unit(s) as well as a main base?

No

Yes please provide details of the main base _____

Yes – please provide details of the satellite(s) _____

Yes – are you completing this questionnaire on behalf of all these services?

Yes No

2. How do people gain access to your low vision service?

You can tick more than one box.

Referral by ophthalmologist

Referral by GP

Referral by optometrist

Registration as blind or partially sighted

Referral by school

Referral by Department of Education

Self/carer's referral

Referral by Social Services/Work Department

Other (please state) _____

3. What criteria do you use to determine who can access your low vision service?

You can tick more than one box.

Registered blind/partially sighted

Referral

Visual status

None

Other (briefly explain) _____

Appendices

4. How many people from each of the following groups are seen in a year in your low vision service?

Please tick all that apply.

	Less than 50 in a year	More than 50 in a year but less than 200	More than 200 in a year
Children (0-16)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People of working age (17-65)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People over retirement age (65+)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People with multiple disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. How long do people usually wait for their first low vision assessment after you receive the initial request?

Less than two weeks	<input type="checkbox"/>
Over two weeks but less than two months	<input type="checkbox"/>
Between two and six months	<input type="checkbox"/>
Over six months but less than a year	<input type="checkbox"/>
More than a year	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

6. Is refraction part of your low vision assessment? Yes No

If no, how do you determine refractive status?

7. Do you have access to medical/clinical information?

Yes No

Please explain:

Briefly describe their role

Counsellor(s)

Dispensing optician(s)

Medical social worker(s)

Nurse(s)

Ophthalmologist(s)

Optometrist(s)

Orthoptist(s)

Rehabilitation worker(s)

Social worker(s)

Specialist teacher(s)

Other (please state)

9. **Do you dispense low vision aids?** Yes

If no, how do people who use your service obtain low vision aids?

If yes, do people ever pay for the low vision aids? Yes

If yes, please explain:

Appendices

10. (a) Do people receive specialised low vision training in the use of their low vision aids (this should not include basic handling) and/or their residual vision?

Always Usually Rarely Never

- (b) If you provide this training, when is it undertaken?

At initial low vision assessment

At separate additional appointment(s)

Both

- (c) In total, how many appointments are given for training and how much time overall is allocated?

Number _____ Time _____

11. Following low vision assessment (and training where undertaken), when do you tend to offer follow-up appointments?

0 to 3 months 4 to 6 months 7 months to a year

More than a year On request On re-referral

Never Other (Please state) _____

12. How long do appointments normally last (excluding refraction)?

Initial low vision assessments _____ minutes

Follow ups _____ minutes

13. How many people do you normally see each year in your low vision service?

Initial low vision assessments _____

Follow ups _____

14. Does any part of your service occur outside your unit, e.g. in the person's own home? You can tick more than one box.

Home School Place of work
 None of these Other (please state) _____

15. Please indicate the agencies/professionals with whom your low vision team has links and indicate the nature of these links where applicable.

	Formal	Informal	More often than once a fortnight
Counsellor(s)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Local societies for visually impaired people	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical social worker(s)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ophthalmologist(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rehabilitation worker(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist teacher(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other voluntary organisations (please list)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>			
Other (please state)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendices

- 16. Please specify which of the following types of optical low vision aids you have available for demonstration and the highest approximate power (as indicated by the manufacturer) in your range.**
 Only tick one box for each low vision aid type.

	Up to x3	Up to x6	Up to x10	Over x10
Hand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Illuminated hand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Illuminated stand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Near telescopes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Distance telescopes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spectacle magnifiers/ high reading additions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 17. Do you assess people for CCTVs, Eezee Readers or Writers?**

Yes No

If yes, how many different makes do you have? _____

How do people obtain these, if they are thought to be appropriate?

18. Please indicate which types of non-optical low vision aids you have available for demonstration and explain how people obtain them.

		How do people obtain these?
Lighting	<input type="checkbox"/>	_____
Large print (reading material and daily living aids)	<input type="checkbox"/>	_____
Specialist tints (including UV/overshields)	<input type="checkbox"/>	_____
Typoscopes	<input type="checkbox"/>	_____
Tennis peaks/brimmed hats	<input type="checkbox"/>	_____
Reading stands	<input type="checkbox"/>	_____
Other (please state)	<input type="checkbox"/>	_____
None	<input type="checkbox"/>	

19. Who funds your low vision service? You can tick more than one box.

NHS - Hospital contract	
Separate contract for low vision	<input type="checkbox"/>
In the general ophthalmology contract	<input type="checkbox"/>
Don't know	<input type="checkbox"/>
NHS - GOS	<input type="checkbox"/>
NHS - Other (please state)	<input type="checkbox"/>
Social Services/Work Departments	<input type="checkbox"/>
Voluntary sector	<input type="checkbox"/>
Private (i.e. by the person using the service)	<input type="checkbox"/>
School	<input type="checkbox"/>
Department of Education	<input type="checkbox"/>
Department of Employment	<input type="checkbox"/>
Other (please state)	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

Appendices

20. Please state the **MAIN** authority/agency which funds your low vision service.

21. Please comment on any aspects of your low vision service, or low vision services in general, that could be improved.

(a)

(b)

22. What do you feel are the best aspects of your low vision service?

(a)

(b)

If you **SELL** low vision aids, please now proceed to **Section 2** on page 11.
Otherwise proceed to question 29, which is the very last question.

Section 2. This section should be filled in by people who sell low vision aids

23. Do you sell OPTICAL low vision aids?

Yes If yes, go to question 24.

No If no, go to question 26.

24. Please indicate which of the following types of optical low vision aids you sell and the highest approximate power (as indicated by the manufacturer) in your range.

Only tick one box for each low vision aid type.

	Up to x3	Up to x6	Up to x10	Over x10
Hand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Illuminated hand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Illuminated stand magnifiers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Near telescopes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Distance telescopes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spectacle magnifiers/ high reading additions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25. Approximately how many optical low vision aids do you sell in a year?

_____ Don't know

26. Do you sell CCTVs, Eezee Readers or Writers?

Yes No

If yes, how many different makes do you have available? _____

27. Please indicate which of the following non-optical low vision aid types you sell:

Lighting

Enlarged print
(reading material and daily living aids)

Specialist tints
(including UV/overshields)

Typoscopes

Tennis peaks/brimmed hats

Reading stands

Other (please state) _____

None

Section 3. Other information

28. If you do not provide a low vision service, what is the reason for this?

Lack of funding

Not sufficient need

Lack of trained staff

Lack of space

Other (please state) _____

29. Please help us to ensure that our contacts are complete by listing below any low vision services to which you refer people:

None

The questionnaire is now complete. Thank you for taking the time to complete it. Please put it in the envelope provided and return it as soon as possible.

APPENDIX 4: COVERING LETTERS FOR 1997/8 SURVEY



Appendix A(2)
Sample accompanying
letter



Dear Sir/Madam

Survey of Low Vision Services in the United Kingdom

In March you should have received a questionnaire about low vision services. To date we do not appear to have received a completed questionnaire from you. This is the most comprehensive survey ever undertaken and your response is vital, even if you do not provide such services.

The information you provide will be used to build a better picture of the extent and type of services available to people with low vision. If you do provide a low vision service, your contact details will be placed on a database that may be available to user groups and professionals. If you do not wish your details to be added to the database, you can specify this on the front page of the questionnaire. All other information that you provide will remain strictly confidential.

We enclose another copy of the questionnaire for your convenience. If it is appropriate that someone else should complete the survey, please pass it on to them or let us know whom we should approach. If you have any queries, please contact Helen Masey on 0118 969 3660.

With thanks in anticipation of your help.

Yours faithfully,

B. Ryan

Barbara Ryan
Low Vision Officer
RNIB

Louise Culham

Dr Louise Culham
Head of Optometry
Moorfields Eye Hospital



Appendix A(a)
Sample follow-up
letter



Dear Sir/Madam,

Survey of low vision services in the UK

RNIB and Moorfields Eye Hospital are undertaking a major survey of all low vision services in the UK. To ensure that the findings give an accurate picture of current provision, we need your help. Often, people with low vision tell us that they have difficulty accessing services that meet their needs, and some service providers often comment on the frustration of working within current limitations. We believe that this survey is the first step to helping both service providers and individuals with low vision.

Please fill in the enclosed questionnaire and return it in the envelope provided by Monday 27 October. A pilot study has shown that it takes about 10 minutes to complete. It is vital that you participate in the survey, even if you do not provide low vision services.

With the information you provide, a database of low vision services in the UK will be developed. This will allow people with low vision to locate services in their area and provide a national resource for those involved in the development and provision of low vision services. If you do not wish to be included in this database please complete the questionnaire but write a note on the front page asking to be excluded, and we will honour this.

Yours faithfully,

B. Ryan

Barbara Ryan
Low Vision Officer
RNIB

Louise Culham

Dr Louise Culham
Head of Optometry
Moorfields Eye Hospital

APPENDIX 6: SURVEY QUESTIONNAIRE 2003/4

ID.....

When possible the potential provider of low vision services (i.e. dispensing optician/ orthoptist/ optometrist) should answer the telephone questionnaire.

Contact Name.....

Address.....
.....
.....

Postcode.....

Tel

Notes

Telephone Log

Date	Time	Outcome
Introduction		

To be read to the potential provider

My name is I am phoning from Cardiff University.

You are probably aware that the Welsh Assembly Government has established a new All Wales Low Vision Service. The School of Optometry and Vision Sciences at Cardiff University are carrying out an evaluation to determine the impact the service is having. In order to do that we need to establish properly what was happening before the service was set up. To do this I need to ask you some questions about any low vision work carried out where you work.

This will take a maximum of 5 minutes. All your answers will be treated as confidential.

All the questions I am asking you relate to the year April 2003 to April 2004.

1) Where are you based?

Probe as necessary

- Domiciliary only 1
- Optician/ Optometry practice 2
- Hospital 3
- University 4
- Other 5

.....

2) Did anyone undertake any low vision work (i.e. assessment and prescribing/ selling LVAs) at that practice/ clinic in the year April 2003 to April 2004?

- Yes 1 Go to Q3
- No 2 Thank and close

3) What kind of service did you provide?

- | | | |
|----------------------------------------------|---|---------|
| Assessment and prescribing | 1 | Go to 4 |
| Sell only | 2 | Go to 7 |
| Assessment and prescribing and selling | 3 | Go to 4 |

4) How did people gain access to your low vision service in 2003/4?

You can tick more than one box. Please indicate the primary referral source if more than one.

- | | |
|--------------------------------------------------|---|
| Referral by ophthalmologist..... | 1 |
| Referral by GP | 2 |
| Referral by optometrist | 3 |
| Registration as blind or partially sighted | 4 |
| Referral by school | 5 |
| Referral by Department of Education | 6 |
| Self/ Carer's referral | 7 |
| Referral by social services | 8 |
| Other | 9 |

5) How long did people wait for their first low vision assessment after you received the initial request?

- | | |
|-----------------------------------------------|---|
| Less than two weeks | 1 |
| Over two weeks but less than two months | 2 |
| Between two and six months | 3 |
| Over six months | 4 |
| More than a year | 5 |
| Don't know | 6 |

6) Who funded the service in 2003/ 4?

Where more than one answer is given please indicate the main source

NHS Hospital contract.....	1
NHS Primary Care	2
Charity / voluntary	3
Private	4
Free bee / good will	5
Other	6

7) About how many people did you see between April 2003 and March 2004?

If exact number available

	7a1	7b1
	Assess and provide	Sell only
Exact number

*If the practitioner estimates that the total number is **more than 10** for both categories ask the practitioner to look through the records for an exact number. Otherwise prompt for an estimated number and code.*

	7a2	7b2
	Assess and provide	Sell only
Estimated number

8) What proportion of people with low vision was referred to social services in the year between April 2003 and March 2004?

If no exact number is available, try to establish an estimated percentage.

	8a		8b
Exact number	Estimated %%

Thank you for your help.

Is there anything else you would like to tell us about?

APPENDIX 7: WLVS RECCORD CARD

Outcomes

LVAs advised and ordered

Code	Magnification & description	Comments	VA

Spectacles/ tints

- IRX issued
- Tints issued/ prescribed
- No spectacles/ tint

Advice/ information given

- Lighting
- Registration
- Contrast
- Support groups
- Eye condition
- Television
- Talking books
- None

Report /Referral to other Agencies

- For Registration
- Ophthalmologist
- GP
- Other Low Vision Service
- Social Services
- Voluntary Agency
- Education services
- Employment services
- No referral
- Other
- Vision Passport issued

Next Appointment

Practitioner name GOC No:.....
 Practice address

Order Faxed Date Pt Collected
 LVAs Arrived & Checked Claim form sent for payment

I agree to the information in this record being used in referrals to other agencies.

I am happy for the information in this record to be used for audit and research purposes.

I am happy to be contacted at a later date for audit and research purposes.

Signed _____ Date _____

Low Vision Assessment Record Card

Date: ___ / ___ / ___

Patient Detail	DOB
Title	Patent Address
Surname	
First Names	
GP	Postcode
GP address	Telephone
	<input type="checkbox"/> Male <input type="checkbox"/> Female

Ocular History

- Previous Consultations
- Ophthalmology
 - Low Vision

- AMD
- Glaucoma
- Diab Eye Dis
- Cataract
- Nystagmus
- Other
- Not known

Registered: Blind Partially Sighted Not Registered

General Health Medication

Hearing Impairment

Accessing the service

How did they get there?	Who referred them?	How long did they wait?
<input type="checkbox"/> Public transport	<input type="checkbox"/> Ophthalmologist	<input type="checkbox"/> < 2 weeks
<input type="checkbox"/> Car	<input type="checkbox"/> GP	<input type="checkbox"/> 2 weeks to 2 months
<input type="checkbox"/> Taxi	<input type="checkbox"/> Optometrist	<input type="checkbox"/> 2 to 6 months
<input type="checkbox"/> Walked	<input type="checkbox"/> Social/ rehab worker	<input type="checkbox"/> 6 months to 1 year
<input type="checkbox"/> Ambulance	<input type="checkbox"/> Voluntary agency	<input type="checkbox"/> > 1 year
<input type="checkbox"/> Domiciliary	<input type="checkbox"/> Friend/ relative/ self	<input type="checkbox"/> Don't know
<input type="checkbox"/> Accompanied	Education	
<input type="checkbox"/> Alone	Employment	
	Other	

Social Situation

Lives

Alone

With partner/spouse

With other relative

Sheltered Accom

Residential Care

Other

Occupation

In education

Employed

Unemployed

Retired

Reported Difficulties

Reading post Telephone

Reading newspaper Mobility

Reading instructions Cooking

Reading books Telling time

Reading large print Television

Reading other Glare

Writing Lighting

Taking medication Other

Shopping None

Support and services received to date

Social Services

Voluntary Sector

Education

Employment services

Other

None

Help most needed with:

1.

2.

3.

PATIENTS NAME

Current Visual Status (Current Vision or VA with spectacles)

Rx	Sph	Cyl	Axis	Prism	VA	Sph	Cyl	Axis	Prism	VA
1										
2										
3										

Best Binocular Vision/ VA Distance Near

Current LVAs

Low Vision Aid	Obtained from	Used for	VA

Contrast Sensitivity

Severe Loss	VRS 80%	KDR63%
	NHC 44%	SOK 31%
Significant Loss	SCN 22%	OZV 15%
	CNH 11%	ZOK 7.8%
Noticeable Loss	NOD 5.6%	VHR 3.9%
	CDN 2.8%	ZSV 1.9%
OK	KCH 1.4%	ODK 1.0%
	RSV0 7%	HVR C 5%

Other relevant investigations e.g Refraction, Ophthalmoscopy.

LVAs tried today

Low Vision Aid	VA / reading ability	Comments

APPENDIX 8: ETHICAL APPROVAL

SLC4 Project not requiring REC review
Version 2, October 2004



Canolfan Gwasanaethau Busnes
Business Services Centre

**COPY FOR YOUR
INFORMATION**

South East Wales Local Research Ethics Committee Panel B

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Dr T H Margrain
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17 December 2004

Dear Dr Margrain

Full title of project: *Evaluating the effectiveness of the new Welsh Low Vision Service*
REC reference number: 04/WSE02/170

The Research Ethics Committee reviewed the above application at the meeting held on 15 December 2004.

The Committee was most grateful to you for taking the time to attend the meeting.

You provided the following documents for consideration:

Document Type:	Version:	Dated:	Date Received:
Application	Parts A,B and C - signed	25/11/2004	26/11/2004
Investigator CV			26/11/2004
Protocol	1	25/11/2004	26/11/2004
Copy of Questionnaire	1	25/11/2004	26/11/2004
Copy of Questionnaire	1 - Telephone Questionnaire	25/11/2004	26/11/2004
Sample Diary/Patient Card	no version		26/11/2004
Participant Information Sheet	1	25/11/2004	26/11/2004
Participant Consent Form	1	25/11/2004	26/11/2004

The Committee was unanimous in its view that the proposal should be considered as an Audit, and as such does not require ethical approval.

Although review by a Research Ethics Committee is not required, you should check with the R&D Department for Cardiff University whether management approval is required before the project starts.



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APPENDIX 9: RESEARCH PROTOCOL

The patient (Px) journey

- Px makes a low vision appointment in an optometric practice
- Receptionist advises px that the practice is participating in some research looking at how the low vision service helps people
- Receptionist hands/posts the information sheet, consent form and questionnaire. An envelope is also provided.
- At home the patient reads the information sheet and decides to take part in the research.
- If the px does not want to take part in the research they do not fill in the questionnaire or consent form and they will no longer be involved in this part of the study.
- If the px desires to participate, px signs the declaration sheet.
- Px or a representative then fills in the questionnaire.
- The consent sheet and questionnaire are then placed in the stamped addressed envelope and posted.
- A few days later the person attends the low vision consultation.
- When the consultation is complete the practitioner asks the px if:
 1. The person consents to the information on the record card being used for audit and/or research purposes.
 2. The person consents to being contacted again for audit and/or research purposes.
- The statements that the patient consents to are ticked on the record card and the patient signs and dates the consent on the record card.

The Practitioners Role

- When the low vision consultation is drawing to a close the practitioner reads the consent statements at the end of the record card to the patient and ticks the statements they agree to.
- The px then signs and dates the consent section.
- The record card is checked to ensure all the required information is there.
- The record card is then faxed to the secure fax at Carmarthen LHB.

The Receptionists Role

- The receptionist advises pxs when they make an appointment that the practice is participating in some research looking at the low vision service.
- Receptionists posts or give an information sheet, consent form, questionnaire and stamped addressed envelope.

APPENDIX 10: PUBLICATIONS RESULTING FROM THIS WORK

The following publications have resulted from this work:

- Ryan B, Margrain TH. 2010, Registration- fit for purpose? *British Journal of Ophthalmology* (accepted in press).
- Court, H., Ryan, B., Bunce, C., Margrain, T.H. 2010, How effective s the new community based Welsh Low Vision Service? *British Journal of Ophthalmology* (accepted in press).
- Ryan, B., Margrain, T.H., Reidy A., Minnasian, D. 2010, All Wales Visual Impairment Database (AWVID) Research Findings number 28 (Final draft signed off for printing) The Thomas Pocklington Trust.
- Ryan, B, Margrain, T.H., Reidy, A., Minnasian, D. 2010, All Wales Visual Impairment Database (AWVID) Occassional Paper number 24 (Final draft signed off for printing) The Thomas Pocklington Trust.
- Ryan, B., White, S. Wild, J.W., Margrain, T.H. 2010, The newly established primary based Welsh Low Vision Service is effective and has improved assess to low vision services in Wales. *Ophthalmic and Physiological Optics* In Press.
- Ryan, B., Court, H., Margrain, T. H. 2008, Measuring low vision service outcomes: Rasch analysis of the 7 item NEI VFQ. *Optometry and Vision Sciences* 2008; 85:112-121.
- Ryan, B., Margrain, T.H., White, S. 2007, Does extending the provision of low vision services into primary care improve access? A report commissioned by the Welsh Assembly Government, (Cardiff University, Cardiff).

- Culham, L. E., B. Ryan, A. J. Jackson, A. R. Hill, B. Jones, C. Miles, J. A. Young, C. Bunce and A. C. Bird, 2002, Low vision services for vision rehabilitation in the United Kingdom. *British Journal of Ophthalmology* 86, 743-747
- Ryan, B., L. E. Culham, A. R. Hill, A. J. Jackson, B. Jones, A. C. Bird and C. Bunce, 1999, Multi-disciplinary low vision services in the United Kingdom. *Visual Impairment Research* 1, 181 - 186.
- Ryan, B. and L. Culham, 1999, *Fragmented vision: Survey of low vision services in the UK*, (Royal National Institute for the Blind, London).
- Ryan, B. and L. McCloughan, 1999, *Our better vision: What people need from low vision services in the UK*, (Royal National Institute for the Blind, London).

