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“If you talk to somebody that is sighted they don’t understand”: the experiences of adults with visual impairment and sight loss of NHS Outpatient Eye Care services within Shropshire.

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Shropshire Rural Community Council

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FIGURES & TABLES

GLOSSARY

AMD – age related macular degeneration

DB – diabetic retinopathy

ECLO – Eye Clinic Liaison Officer

JSNA –Joint Strategic Needs Assessment

Lucentis – registered name for ranibizumab injection for AMD

NICE – National Institute for Health and Care Excellence

PRH – Princess Royal Hospital

RCC – Rural Community Council

RNIB – Royal National Institute for the Blind

RSH – Royal Shrewsbury Hospital

SLOG – Sight Loss Opportunities Group

NOTES ON THE TEXT

The quotes from participants are verbatim, and do not have punctuation. Occasionally, they have been edited to avoid repetition or give explanation, and where this is the case brackets have been used to insert a comment, e.g. (laughs), or three full stops, i.e. …, are used to show where some text has been edited. (…) denotes a pause in speech.

Pseudonyms have been used, and initials in the transcripts. "I" refers to the Interviewer and in section 2 'M' refers to the Moderator..

Numbers in brackets i.e. (1), refer to references; smaller numbers, i.e. [1], are footnotes. The numbers at the end of quotations denote the line numbers in the original transcript.

1. ABSTRACT

Although sight loss affects people of all ages, one in five people aged 75 or over will have some visual impairment, rising to one in two over 90. 21% of Shropshire's population is over 65, and the county has an above average number of people with visual impairment. Anecdotal evidence suggests that visually impaired adults within Shropshire have some difficulties in their experiences of hospital outpatient services. This small scale qualitative study aimed to discover to what extent service users felt disadvantaged and disabled by those experiences.

DESIGN

A small-scale qualitative experiential design was adopted. In Stage 1, Interpretative Phenomenological Analysis (IPA) was used to explore how people make sense of their experiences, and which allowed individual voices to be heard. In Stage 2, Thematic Analysis was used to explore the themes and issues found in Stage 1. Stage 2 not only reported service users' experiences and found themes within the way service users described how they felt disadvantaged, but also explored suggestions for improvements.

METHOD

Stage 1 consisted of five individual interviews with people with long-term visual impairment. They participated in semi-structured interviews, and the resulting transcripts were analysed according to the guidelines for IPA. In Stage 2, seven people (six with sight loss and one carer) took part in a focus group, which was then transcribed and analysed according to Thematic Analysis guidelines. Participants came from all over Shropshire.

RESULTS

Stage 1 highlighted the general nature of the everyday problems people with sight loss encounter, including the nature of sight loss as a hidden disability. With reference to hospital services, themes around the timing of appointments, the physical environment and communication, highlighted the way people struggled. There was an additional theme around support and the various sources of support. Stage 2 considered these themes and found that there were two areas where people felt disadvantaged – communication and the environment.

CONCLUSIONS

Whilst it is acknowledged that measures are being taken to improve communication and support for visually impaired patients, there are issues and concerns highlighted by participants which Shropshire RCC hopes the NHS will seek to address. In particular, patients need to be supported appropriately by hospital staff, and this should happen from arrival at the hospital front door. Particular problems around the timing of appointments and the hospital environment in Shrewsbury also need to be addressed. Implementation of the RNIB's Low Vision Assessment framework is recommended.

2. EXECUTIVE SUMMARY

Background: Shropshire Rural Community Council (RCC) was funded by a Healthwatch Shropshire Research Grant to explore patient experiences of NHS hospital eye care services in Shropshire. Shropshire RCC provides information and support for adults with sight loss in Shropshire, and through this work has gathered anecdotal evidence of difficulties for patients of NHS outpatient eye care services in Shropshire.

Nationally, there are almost two million people living with sight loss (1). This figure is set to increase dramatically and it is predicted that by 2020, the number of people with sight loss will rise to over 2,250,000. Furthermore, by 2050 that number will have risen to nearly four million, as a result of both an ageing population and a growing incidence of key health problems, such as obesity and diabetes which can cause sight loss. (2). One in five people aged 75 will have some sight loss and this rises to one in two aged 90 and over (1). Within Shropshire there are an estimated 10,940 people living with sight loss and of this total 1,330 are living with severe sight loss. This is an estimated prevalence of 3.6% which is above the national average of 2.95%. In Telford & Wrekin, it is estimated that 4,240 people have sight loss, with 480 having severe sight loss.

People with visual impairments or sight loss can often experience a rapid loss of independence and become socially isolated, often suffering depression (11). Consequently social withdrawal makes them a hard-to-reach group, until they come into contact with professionals who help with their rehabilitation. Shropshire RCC provides a service to adults with visual and/or hearing impairment or loss by running support groups across the county. The charity targets the growing numbers of older people who are experiencing age related sight loss, to enable them to remain as active and independent as possible, and to avoid social withdrawal, loss of independence and rapid decline in health and well-being which can often result from loss of vision.

Aims: Anecdotal evidence gathered through Shropshire RCC's contact with visually impaired adults within Shropshire suggests that they have some difficulties in their experiences of hospital outpatient eye care services.

The project aims to provide an insight into the barriers and challenges that visually impaired people face in accessing services. It aims to inform the ways in which the patient experience could be improved by demonstrating in which ways patients feel both disadvantaged and disabled by current practices. Finally, it makes recommendations on how the issues raised may be addressed.

Method: In line with the NHS goal of patient-centred care, it was felt that a small scale qualitative research project would best identify the users' views, and give them the opportunity to share their experiences.

The project was devised in two stages: in the first stage, participants took part in individual interviews, discussing outpatient services in order to identify areas of concern as well as good practice. Interpretative Phenomenological Analysis (20) was used to explore the participants' lived experiences and their interpretation of those experiences, and to identify themes across the dataset.

The second stage then considered in more detail themes that arose in Stage 1. A focus group considered areas of concern and asked participants for suggestions on how services might be improved. Thematic Analysis (32) was employed to answer the question in what ways people felt disabled and disadvantaged by their experiences.

In total there were 12 participants, three men, nine women, who had a variety of eye conditions and were widely distributed across the county. They were recruited through personal contacts and support groups.

Results:

Stage 1 highlighted the general nature of the everyday problems people with sight loss encounter, including the nature of sight loss as a hidden disability. With reference to hospital services, themes around the timing of appointments, the physical environment and communication highlighted the way people struggled. Consultants were generally held in high esteem. There was an additional theme around support and the various sources of support, such as official, unofficial and family. The everyday experiences of this group are in line with published literature and highlighted the limitations that sight loss imposes on an individual.

Stage 2 considered the themes from Stage 1, particularly: sight loss as a hidden disability, the physical environment, communication with the hospital and accessing support. It was found that there were two areas where people felt disadvantaged – communication and the environment. Whilst the environment theme concentrated on particular situations that were problematic, communication was a wider theme, encompassing appointment letters, access to information about certification and registration, links between the NHS and support groups.

Discussion:

The Environment: At RSH the corridor on Clinic 10, where patients have to wait for their appointments, was of particular concern for service users. It raised the question of the suitability for purpose and also the emotional impact the environment has on the patients. Being visually impaired in a restricted space frequented by both staff and other patients made the participants feel physically vulnerable and disadvantaged, particularly when there were hygiene concerns. The environment at PRH and Wrekin Community Clinic (35) were considered more favourably, because there was more space which alleviated the feelings of physical vulnerability. Particularly, at Wrekin Community Clinic, the walk-in patients are separated from the patients who are there for injections or cataract operations, which made participants feel as though their condition mattered. The reference to Clinic 10 being a "*cattlemarket*" reflects not just the numbers of patients, but that those patients feel devalued and that care feels impersonal.

The issue which was raised in respect of the Princess Royal Hospital was the signage. It was acknowledged by participants that it is difficult to find 'a one solution fits all', due to the variety of eye conditions and the differing levels of sight. Given the problems that signs present to the visually impaired, alternatives such as guides, trained volunteers or audio guides and colour coding, were suggested.

The everyday problems of getting around affected how people travelled to the hospital, although there was evidence that even those with the most sight loss retained some independence, because hospital visits were part of their routine. More broadly, travelling to any hospital presented a variety of challenges for the visually impaired, in terms of transport, whether that was by train (Hereford), bus, hospital transport, car or even on foot. This is particularly true in rural communities within Shropshire, where in some rural areas, buses are infrequent and taxis may be prohibitively expensive.

Communication:

Stage 1 participants discussed that the format of appointment information and requests for patient information was often inappropriate, being sent out in letters in regular font sizes, and therefore illegible for those with visual impairments. There was limited evidence of more user friendly formats, such as text-messaging being used. However, it is understood that this issue of notification format is being addressed now by the NHS central appointment system within Shropshire, and, during the time this research was undertaken, systems were undergoing change. The issue of third parties, such as family members, being able to be informed of appointments is particularly important for this service user group, who may struggle regardless of the alternatives offered, or for those with memory loss. It is important that the preferred format, and the existence of a third party, is noted on health records, so that there is consistency of approach. However, the preferred format should be reviewed as needs change. (23)

The discussion around preferred formats drew attention to the access to appointments, particularly in terms of waiting times. Whilst the issue of waiting times is beyond the scope of this report in terms of making recommendations, it is nonetheless a matter of huge concern to patients, since they experienced delays and cancellations which meant the preferred intervals between appointments were not being adhered to. For those with age-related macular degeneration, these delays were of particular concern, as they believed their Lucentis injections were not being administered within the timeframe suggested by NICE guidelines. Patients believed these delays were due to the pressure of numbers within the ophthalmic clinics.

The participants also felt that there was a lack of joined up services, with poor communication between those services they accessed. For example GPs were seen as stepping stones to consultants, and as such were portals to care, but they were considered to be ill-informed about the roles of specific consultants and the certification and registration processes at times.

Secondly, the participants felt there was inadequate provision of information relating to support available post diagnosis. Although individuals were happy with the communication with the consultant when they saw him or her in person, and also with the support groups they accessed, the lack of joined-up services impacted on them and others they came into contact with. It was acknowledged that the consultant's time was precious, and that was spent explaining their condition rather than sign posting to further support.

The role of an ECLO (Eye Clinic Liaison Officer) was discussed: the importance of an ECLO's role is that it is patient focussed and looks beyond the disability per se to offer support to the individual. The impact of the support an ECLO can offer positively affects quality of life, by providing emotional support, signposting the patient to groups or helping with certification and registration processes. Whilst it was acknowledged that a previous trial of employing an ECLO at RSH was unsuccessful, it was also highlighted that that ECLO was not well supported in their role, having no allocated space to work in. This study also acknowledged that two members of the nursing team in the

Ophthalmology Department have undergone ECLO training, which was applauded by the participants. A study, published in 2013, has demonstrated that an ECLO provides a cost-effective alternative to nursing staff or consultants meeting the additional support needs of the visually impaired (38).

Participants were not always dealt with appropriately within the hospital setting and sight loss awareness training is considered to be vital. The ‘My Guide’ programme, from the Guide Dogs for the Blind, is being introduced into Princess Royal Hospital, and needs to be rolled out across Shropshire. In particular, patients need to be made aware if sighted guides are available, and that they may request them on arrival at the hospital; thus patients may avoid the indignity of being put in a wheelchair when they are capable of walking.

Throughout the accounts there is an acceptance of how things are, and there is little mention of complaints. However, patients do have a right to express their concerns and should know how to complain if they feel that is appropriate. Finally, Healthwatch Shropshire should continue contact with sight loss groups in order to fully understand these issues and to ensure the rights of those with sight loss and visual impairment are championed.

Recommendations:

ENVIRONMENT

1. The emotional impact of the environment needs to be understood and acknowledged by hospital staff and commissioners.
2. Royal Shrewsbury Hospital Clinic 10 corridor needs to be addressed by either
   a. Improving the environment , i.e. moving the clinic to a new location
   b. Allowing people to sit in the main waiting area, and improving communication to call them in to see the consultant (by intercoms, nurses, or volunteer staff)
3. Access around Princess Royal hospital needs to be addressed – by methods other than signage – audio, internet, or even by volunteer sighted guides.
4. Comparison with other eye hospitals may bring forward some suggestions for good practice, such as locally at Wrekin Community Clinic, and further afield, such as Manchester.

COMMUNICATION

1. All staff should be trained how to address the patients appropriately, from the moment they enter the hospital, not just within the eye clinics.
   The My Guide programme should be rolled out further in PRH, and within RSH.
2. The visual awareness training should be extended to those working in GP surgeries, including GPs, who also need to be aware of up-to-date information about consultants and their specific roles, and made aware of the certification and registration processes, and wider community based support.
3. Formats for communication between hospital and patients should be discussed at the first appointment, and recorded on notes. The format of communication should also be reassessed according to changing needs.
4. Information links between hospital and support groups need to be built and maintained.
5. Information provided by support groups needs to be disseminated in an effective and timely manner. Information should be available when a patient needs it, not just when a volunteer group is available to hand it out.
6. The timely distribution of information and support may be facilitated by the employment of an Eye Clinic Liaison Officer (ECLO).
7. Patients need to understand the pathway their care is taking, and should be informed of both health and social care processes involved if appropriate.
8. Patients should be informed of their rights, and processes by which they could complain if they wish to.

KEY RECOMMENDATION:

Many of the issues raised here are covered in the RNIB's Low Vision Services Assessment Framework. It is therefore recommended that an audit according to that tool would enable services to be evaluated and reviewed, and identify potential gaps
(see Appendix 4).

3. INTRODUCTION

3.1. Project Aims

This report aims to improve the understanding of patient experiences of NHS hospital eye care services in Shropshire. Additionally, it aims to provide an insight into the barriers and challenges that visually impaired people face in accessing services. It aims to inform the ways in which the patient experience could be improved by demonstrating in which ways patients feel both disadvantaged and disabled by current practices. Finally, it makes recommendations on how the issues raised may be addressed.

This research project has been supported by Healthwatch Shropshire Research Grant funding, and was directed towards exploring the experiences of hard to reach groups based in Shropshire in health and/or social care. People with visual impairments or sight loss can often experience a rapid loss of independence and become socially isolated, often suffering depression. Consequently social withdrawal makes them a hard-to-reach group, until they come into contact with professionals who help with their rehabilitation. However, cuts in local statutory Sensory Impairment services have impacted on this group meaning fewer services and long waiting times for them.

3.2 The role of Shropshire RCC with relation to visual impairment

Shropshire Rural Community Council's (RCC) core purpose is to work with individuals and groups to improve quality of life for Shropshire people, and contribute to thriving and sustainable communities. In particular, the charity aims to help hard-to-reach communities, and is concerned to alleviate the disadvantage that can result from living in a rural area, which can reduce access to services and support and increase vulnerability to isolation, poverty and poor health.

Shropshire RCC provides a service to adults with visual and/or hearing impairment or loss in Shropshire. The charity particularly seeks to target the growing numbers of older people who are experiencing age related sight loss, to enable them to remain as active and independent as possible, and to avoid social withdrawal, loss of independence and rapid decline in health and well-being which can often result from loss of vision. These people within Shropshire are hard to reach not only because of their geographical location but also because of the nature of their disability.

At present Shropshire RCC coordinates four small-scale Sight Loss Opportunity Groups (SLOG) in Shropshire; in the North, South and central areas of the county. Each group has between 12 and 15 members. These groups enable adults with sight loss to meet together and enjoy social and recreational activities.

The main purpose of these groups is to:-

- Reduce social isolation and loneliness
- Improve mental health and well being
- Improve physical health through physical activity
- Improve confidence
- Promote and enable independence
- Create networks of peer support
- Provide information about sources of help and support
- Signpost to wider sources of support and information

Anecdotal evidence suggests that visually impaired individuals have had some difficulties in their experience of NHS hospital outpatient eye care services in Shropshire. Consequently, it was decided to interview a small sample of patients to find out about their experiences of these services; what was helpful and what was not helpful, in order to make some practical recommendations about how that experience could be improved.

3.3 Background

Nationally, there are almost two million people living with sight loss (1). This figure is set to increase dramatically and it is predicted that by 2020, the number of people with sight loss will rise to over 2,250,000.[1] Furthermore, by 2050 that number will have risen to nearly four million, as a result of both an ageing population and a growing incidence of key health problems, such as obesity and diabetes which can cause sight loss. (2).

Although sight loss affects people of all ages, one in five aged 75 will have some sight loss and this rises to one in two aged 90 and over (1). Against these numbers only 360,000 are registered blind or partially sighted, and recent research by the Health and Social Care information Centre(HSCIC) report (3) showed that in March 2014 compared with 2011 there was fall of 3% in the **overall**

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[1] Definition of blind and partially sighted: the US definitions, which are adopted for international comparison are: Blindness is the best corrected visual acuity of less than 6/60 – that is being able to see at 6 metres what someone with normal vision can see 60 metres away. Partial sight is visual acuity of less than 6/12 to 6/60 (2). In the UK blindness is defined as 3/60 and partial sight as being 6/60, but having a reduced field of vision is also taken into account.

number of people registered blind, and a fall of 2% in those registered partially sighted[2]. Although there was a fall in **new** registrations of blind people, there was an increase in new registrations of partially sighted people. Overall, these statistics compared with the trend of a rising number of people with sight loss implies that fewer people are accessing help.

Many individual surveys have reported slightly higher rates of blindness in women, and a meta-analysis of population-based prevalence surveys in 2001 (4) found that overall women account for 64.5% of blind people. There were many different reasons for this finding, varying according to whether the countries were under-developed or industrialised, and although the finding was marked in the elderly population, it was not purely due to a longer-life expectancy.

According to research undertaken for the RNIB in 2009, the main causes of severe sight loss in adults are age-related macular degeneration (50%), cataracts (12%), glaucoma (17%), diabetic retinopathy (9%), refractive error (2%) and other eye diseases (10%). Age related macular degeneration (AMD) alone accounts for 1% of the prescription charges (5) of the total NHS budget. Economic impact of sight loss was estimated to have totalled £22 billion in 2008 (1).

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[2] Registration: A Certification of Vision Impairment (CVI) formally certifies a person as either sight impaired (partially sighted) or severely impaired (blind). Each CVI is completed by a consultant ophthalmologist in an eye clinic, with a copy sent to social services, who will then offer Registration. As not everyone opts for registration, these figures only represent those who access social care, such as Disability Living Allowance (6).

3.3 (i) Local statistics

The following data is taken from the RNIB sight loss data tool (6) (See Appendix 1)

The county of Shropshire falls into two local authorities, Shropshire, and Telford and Wrekin, and while there is some variance in the sight loss statistics within the two areas, it should be noted that while Telford and Wrekin is ranked 70th, Shropshire is ranked the 113th (out of 149) most deprived local authority in England. The higher ranking is the most deprived, therefore, Telford and Wrekin is more deprived than Shropshire, which aligns with the national trend for urban areas to be generally more deprived. However, rural areas also have pockets of deprivation, and this is true of Shropshire. RNIB Sight Loss tool defines the “extent of deprivation” as “a measure of the proportion of people in a local authority who are living in the most deprived Lower Layer Super Output Areas (LSOAs) in the country”. The figures are drawn from the Government’s English Indices of Deprivation 2010, which look at a number of domains including health, income deprivation, employment deprivation, disability, education, skills and training deprivation, barriers to housing and services, living environment and crime.

According to the 2011 census, there are 306,129 people living within Shropshire, compared with 166, 641 in Telford and Wrekin. Within Shropshire there are an estimated 10,940 people living with sight loss and of this total 1,330 are living with severe sight loss. This is an estimated prevalence of 3.6% which is above the national average of 2.95%. In Telford, it is estimated that 4,240 people have sight loss, with 480 having severe sight loss. The prevalence is estimated at 2.6% which is below the national average. Given that age is a major factor in sight loss, (1) and that Shropshire’s over 65 population accounts for 21% of the total population, and Telford’s is proportionally a third less at 14%, this may account for the higher prevalence within Shropshire(See Appendix 1).

The figures are set to rise: by 2020 the RNIB predict that the number of people living with sight loss in Shropshire will have risen to 13,800, and in Telford to 5,600 (6). However, local authorities within the West Midlands area are not engaging with the issue. In 2013, the RNIB surveyed all the local authorities’ most recent Joint Strategic Needs Assessments (JSNA) and ranked them according to the quality of the information relating to visually impaired people and those at risk of developing sight loss (7). They found only 40% of those JSNAs in England contain information on sight loss and eye health, and 93% of the JSNAs in the West Midlands have little or no information. Furthermore, both Shropshire and Telford and Wrekin fell into the “Red” category, which indicated that the JSNA contains no information on sight loss or sensory impairment. As the RNIB point out, this is “problematic” as local authorities are asked to demonstrate improvements in public health outcomes against issues outlined in the JSNA, and if an issue, such as sight loss, is not listed it need not be addressed. Both the Joint Strategic Needs Assessments (JSNA) and the Health & Wellbeing strategies are integrated health and social care strategic planning mechanisms and vital for recognising problems areas, and planning adequate services for those recognised needs.

The Shropshire Health & Wellbeing Strategy laid out in February 2013 (8) outlined the council's desired outcomes and priorities, which were based on the Joint Strategic Needs Assessment (JSNA). This document was "informed by feedback from a series of engagement events with patients and service user groups, service providers, elected members, advocacy groups and service commissioners, together with public consultation". Amongst the five Outcomes listed in the Health and Wellbeing Strategy, three in particular are relevant to this service user group.

- Outcome 1: "Health inequalities are reduced, specifically to work with partners to address the root causes of inequalities, such as …access to services".
- Outcome 4: "Older people and those with long term conditions will remain independent for longer.
- Outcome 5: "Health, social care and wellbeing services are accessible, good quality and 'seamless'" (8).

The anecdotal evidence from those patients with visual impairments, known to Shropshire RCC, also suggests that the Health & Wellbeing Strategy outcomes are not being addressed in ways that might support this service-user group. In order to meet these outcomes, the Health & Wellbeing Board need to engage with the experiences and opinions of service users.

3.4 Other research

Dr Aeesha Malik, who was clinical advisor to the NHS Medical Director 2010-11 and a specialist registrar at Moorfields Eye Hospital has stated:

> *"there is a real move for the health service to be driven by the knowledge gathered from research, clinical and service data analysis and patient experience"* (5) .

Patient-led health care became a target under the government's NHS reform plan (2000), and previous research carried out by the Guide Dogs for the Blind Association states

> *"patient satisfaction is now an integral part of measuring health care quality…The Disability Discrimination Act now requires providers of services to make reasonable adjustments in their provision of services in order to facilitate access for all users of these facilities*" (9).

Their survey of over 800 blind and partially sighted people found that, whilst acknowledging the "excellent standard" of technical aspects of care, the NHS was not seen as "patient-centred" and consequently lacked sensitivity in meeting the needs and concerns of the patients, particularly in areas of communication and emotional support.

However, last year NHS England have opened a dialogue around issues of improving eye health and reducing sight loss, as part of their "Call to Action" (41). NHS England acknowledged the impact of sight loss on the general wellbeing of the individual, and set this in the context of the issues around an ageing population, health inequalities and the constrained financial outlook that the health service faces. The consultation document, which was open from June to September 2014, called for responses from all stakeholders including patient groups, local Eye Health Networks, local authorities and providers of healthcare services. At the time of writing this report, their results were unpublished.

The consultation document particularly focussed on prevention and early detection of sight loss, but one issue relevant to those already suffering long-term visual impairment was outlined:

> *"many people with sight problems will have multi-morbidities and will have particular needs around quality of life issues including independent living, managing their own health, social support, education and employment and we want to stimulate debate about promotion an integrated approach to care across health, social and education services, and the potential expertise that resides in community and voluntary groups".*

Secondary analysis of more general data gathered in two key large national surveys, found that subjective wellbeing is lower among people with sight loss; they are less likely to have a job and recession is likely to have a disproportionate impact on this group; and that people with sight loss were three times more likely than people without any impairment to have difficulty in accessing health and other services (10). The link with mental health and sight loss is well established; in a study of 13,900 people, depression and anxiety were found to have a higher prevalence within the visually impaired older population (11). A small scale study of people with recent onset age-related macular degeneration (AMD) were found that those with depression were likely to self-report worse vision function, independent of the changes to their vision (12).

Whilst quantitative research provides statistical evidence, qualitative research has value in providing insights into the lived experiences of those with sight loss. Recent research into the experience of AMD and diabetic retinopathy (DR) illuminate themes of loss of independence, and adaptation, engagement with health services and the emotional impact of sight loss (13)(14)(15). In particular, a systematic review of research into AMD showed that a "holistic approach to service provision and support for AMD is needed which takes into account individuals' needs and experiences" (13). Understanding the impact of sight loss on individuals, and the need for a holistic approach was also found in sufferers of diabetic retinopathy, who are more likely to become depressed and neglect their diabetic medication regimes (15). However, it is not all negative: recent changes in the treatment of AMD have led to an increase in optimism in those patients whose treatment was successful (14).

It is important for any patient to understand their diagnosis, as a part of accepting an illness (16). For these patients understanding why sight loss has occurred is not only important for their own wellbeing, but also for practitioners and care-providers to understand how best to educate and support them (17) (18). In particular, exploring the patients' experiences may lead to recommendations for practice – Burton, Shaw and Gibson (18) state that health care professionals "need to do more to understand the perspectives of individual patients in order to help them assimilate information and make sense of the progressive condition". Patients who were ill informed were unable to self-advocate and therefore unable to recognise what support they needed and how to access appropriate support.

Finally, supporting people with sight loss often falls back on family members. Research has shown that the diagnosis of sight loss may have "an immediate and lasting impact on family members" (19). Themes of readjustment, similar to the process of grieving, as well as an impact on family finances and relationships are all reported in the literature.

3.5 Project Outline

In line with the NHS goal of patient-centred care, it was felt that a small scale qualitative research project would best identify the users' views, and give them the opportunity to share their experiences.

The project was devised in the first stage to collect views through individual interviews around the hospital outpatient service and identify areas of good practice and also of concern. The second stage then considered in more detail those areas of concern, and asked participants for suggestions on how services might be improved.

4. STAGE 1 – Individual Interviews/IPA

4.1 METHOD

4.1 (i) Design

An exploratory design, using the qualitative method of Interpretative Phenomenological Analysis, was used in Stage 1 of the project to explore the patients' experiences of sight loss. In particular, this method was considered appropriate because the research aimed to gain an understanding of the patients' experiences of their eye care treatment, within the NHS, and the support they receive.

Interpretative Phenomenological Analysis (IPA) is a method of conducting qualitative research, which has its foundation in the philosophical beliefs of Heidegger and Husserl, and follows a detailed procedure as laid out by Smith, Flowers & Larkin (20). Whilst an in-depth explanation of the philosophical roots of the method are beyond the scope of this report, it essentially relies on phenomenology, which can be defined in the broadest sense as the lived experience of the individual in the here and now. Particularly, in this case the patient is not a passive perceiver of an objective reality (21), but rather constructs their own reality through interpreting the events that happen to them. The method therefore concentrates on the participants' experiences, understandings and views, and their interpretations of those experiences.

IPA relies on a small number of participants to explore individual experiences. The method does not aim to produce findings with large numbers of statistical significance, such as a trial of injections for AMD might produce, but rather concentrates on the individual experience of what having AMD and those injections might be like. The majority of published IPA reports have been in the field of health psychology, because its relevance to understanding how people construct and perceive their illnesses. The dependence on a small number of individual accounts is also considered appropriate for health psychology research because it is in line with current NHS efforts to acknowledge the voices of service-users (21). The methodology is therefore considered appropriate in helping explore and understand the individual's experiences around sight loss and consequent eye-care. In light of the aim of the NHS to deliver patient-centred care (9), exploring these experiences should help to inform service design and delivery, and highlight areas that may require improvement and help to implement those improvements.

The researcher in turn interprets the data in a staged analysis, outlined below. Central to the interpretation is the process of "bracketing", where the researcher must lay aside any preconceived ideas about society, disability, in this case sight loss, and the system that gives support in order to fully explore the participants' experiences. Throughout the process of IPA, the interpretation must arise from the text generated through interviews, not be imposed from the outside, in order to be considered valid (20). As part of the interpretation the researcher moves from single case studies to general themes, in an attempt to understand the interaction of the part and the whole, so a single episode in a person's eye care might reflect a universal experience. In this way a wider understanding may be gained.

4.1 (ii) Participants

The participants were five people living in Shropshire, who had long-term sight loss. They were recruited through personal contacts of the researcher and Shropshire RCC. Four out of five attended the Sight Loss Opportunities Groups organised by the RCC, and were informed of the research at group meetings; they then volunteered to take part. The fifth participant was approached directly by the researcher and given the information about the project and asked if they would like to participate .The volunteers were recruited selectively because they were considered to have insight into the experiences relevant to the research question. Although they were a homogenous group, required for IPA, there were several differences between them, see Table 1 below. Four out of the five participants were women, which is not representative of the sight loss male:female ration of 2:3 mentioned above, but was led by those who volunteered. In general however, it reflects the majority of women who suffer sight loss. More noticeably four out of the five volunteers were pensioners, although only one was diagnosed with age related macular degeneration.

Table 1 – participant profile (patients' conditions have been generalised to protect anonymity)

Participant (pseudonym)	Gender and Age	Registered blind	Level of sight/ condition
Roco	Male, 67	Yes, within last 12 months	Blind in one eye, since childhood; corneal graft and poor vision in other eye
Dilys	Female, 75	Yes, circa 7 years ago	Blind in one eye, very limited sight in other eye. Glaucoma
Judith	Female, 55	Yes, circa 15 years ago	Blind in one eye, very limited sight in other eye. Glaucoma
Vera	Female, 88	Yes, within last two years	Blind in one eye, very limited sight in other eye. AMD
Imogen	Female, 67	No	Limited vision in one eye. Glaucoma/ Macular Degeneration

Prior to the interviews, participants were read a sheet outlining what was expected. Particular care was taken to stress that participation was voluntary and that the participants were under no obligation to take part, when the researcher rang to arrange interview times.

4.1 (iii) Procedure

a) Data Collection

Each participant was read a consent form because of their difficulties of reading print; a recording was made of the consent form being read and then the participant signed the form. Each participant was given the opportunity to ask questions. They undertook an audio-taped, semi-structured interview, according to a schedule of open questions (Appendix 2) drawn up to generate data. Participants were asked to describe their condition, their experiences around attending hospital appointments, including referral, notification of appointments, transport, waiting and interaction with staff, and further sources of support. They were asked to describe both positive and negative experiences and to reflect on those. This process gave them the opportunity to express in their own words their experiences. Each interview took between 44 minutes and 1 hour and 4 minutes. Participants were allowed to tell their stories and the researcher followed some unexpected lines of enquiry, eliciting narratives which illustrated their experiences and their interpretations of events. Afterwards, the researcher read a debriefing sheet to the participant and the participant was given another opportunity to ask questions. At this stage, pseudonyms to protect the participants' identity were agreed.

Each interview was transcribed.

b) Analysis

The recorded interviews were listened to several times for familiarity before transcription. The transcripts were then repeatedly read and reviewed, and a summary of each participant's story was written in the 'audit trail' (which serves to show how conclusions were reached as part of the ongoing process of transparency). These summaries help the researcher to gain familiarity with and start to understand the participant's experiences.

When analysing the data, first-order descriptive themes are written in the right hand margin, which summarise small chunks of text, and serve to draw out what is important to the participant. At this stage, notes are sometimes made of any underlying concepts or questions, as pointers for further investigation.

In the second stage of the analysis, the descriptive summaries, and conceptual notes were examined in conjunction with the text, to draw out second-stage emergent themes. At this point, the researcher aimed to distil the essence of description into underlying concepts.

In the third stage of analysis, the identified emergent themes were separated from the text, typed up, studied and sorted into groups defined by common threads, where themes hung together, and where opposites of the same idea or experience were sometimes expressed. The themes were then regrouped under superordinate themes for each individual participant, and charts produced to summarise the data. Throughout the process, notes about each individual narrative were kept. Each transcript was analysed in turn before moving onto the next, when the process was repeated. Only when they had all been analysed in this way were they all brought together, although notes about common themes were made during the analysis process.

In the fourth stage, the superordinate and emergent themes across the whole data set were examined for common themes and patterns. Superordinate themes are identified by cross-checking. Tables were drawn up to illustrate these themes, and quotes relevant to each theme were extracted (See Appendix 3). The final stage of the analysis took place in the writing of the results.

c) Ethical issues

Although the project was not subject to the approval of an ethics committee, the researcher is a member of the British Psychological Society, and as such is bound by their code of ethics. Participants were informed of what participation would entail, of their right to withdraw during and after the interview, and were given the opportunity to ask questions. Additionally, a timescale was agreed for withdrawing data, anonymity was assured and discussed with relation to pseudonyms and withholding identifying data. Whilst written consent was obtained, because of the difficulties this participant group have in reading, all forms were read to them. Time was allocated to the participants' questions both before and during the debriefing process. The researcher also gave careful consideration to sensitivity and vulnerability during the interview process. Where appropriate, the participant was pointed to sources of further information, such as support groups.

4.2 RESULTS

The original research proposal stated that the Rural Community Council of Shropshire was interested in exploring the extent to which people feel disadvantaged and disabled by their experiences, with relation to NHS eye care services in Shropshire, and this aim was central to the research. However, the nature of IPA is exploratory and so the open-ended questions elicited both positive and negative responses, and did not just concentrate on their criticisms of services. Furthermore, during both the interviewing process and the analysis of the data, it became apparent that the participants' experiences of the eye care that they received needed to be seen in the wider context of what being visually-impaired meant to them as people. One participant commented

> *"if you talk to somebody that is sighted they don't understand"* (Dilys, l.552);

the following results aim to address this problem, and to this end, context setting is important to gain an understanding of the significance of their experiences.

Three themes were discovered: *Personal Responses to Sight Loss*, *Accessing and Barriers to Care* and *Supporting the Visually Impaired.*

Personal Responses to Sight Loss explores the practical impact on the individual of sight loss; the impact sight loss has on the individual in relation to other people; and finally the emotional impact of sight loss. This theme aims to set the context for the following two themes. *Accessing and Barriers to Care* looks specifically at the eye care people receive, exploring the physical environment as well as timeframes, and communication. Finally, *Supporting the Visually Impaired* explores practical aids, types of support such as official and unofficial, including emotional support such as empathy versus a lack of understanding, and the importance of family support.

4.2 (i) Theme 1 – *Personal Responses to Sight Loss*

a) *Impact of sight loss*

The participants had come to sight loss at different stages of their lives and so their experiences varied. This finding alone highlights the fact that there is no such thing as a universal experience of being blind. With sight loss, everyday life changed. Imogen, who still has the sight in one eye, discussed exploring total sight loss:

> *… I sometimes walk around with one eye closed just to see what what it's like and you realise how*
> *I: limiting*
> *Imo: yeah yeah and how I sometimes walk home from the town not all the way home along this road with one eye closed and not to cross the road (laughs) but just to sort of see what I can see …and it's er and I'm thinking "gosh this is how" if you've got it in both eyes "this is what you are seeing" you can't read you can't… the change is is so completely different*
> *Imogen, l.903-914*

Throughout the interviews, the participants moved through their experiences, describing what they had before they lost their sight, in terms of work, life experiences and independence, to how they managed currently, whether that was due to partial or severe impairment.

The impact of sight loss on work in some cases was considerable and affected not just the person, but also their family, such as in the case of Dilys:

> *… we were in the pub trade and we had to pack up because we'd just bought our own pub when it started getting really bad (*eyesight*) and erm we were out at XXX then and erm you know we had to pack up because I just couldn't do the cooking anymore*
> *I: mmh*
> *D: and I was I was doing the cooking*
> *Dilys l.53-58*

Vera's voluntary work was cut short, not only in contributing to a local museum's embroidery project but also working at a National Trust property:

> *then they said Health and Safety said I couldn't work there anymore and that was it this was when I could still see they said "you won't be able to get people down the stairs" I said "rubbish I can get them down those stairs quicker than anybody else here" "well" they said "health and safety say you can't"*
> *Vera l.412-416.*

The sight loss dictated what she was able to do in terms of work, but sometimes the decision-making about when to stop working was out of her hands, which she felt unable to challenge. For Judith, who has been visually-impaired her whole life, she felt that her disability had excluded her from "*a paid job*", continuing "*but nobody will give you the chance*". Roco's wife had given up her part-time job to become his carer, and both Judith and Imogen commented on how their husbands took time off work to accompany them to the hospital for appointments.

The impact of not being able to read was felt strongly by the participants. Although there are Talking Books, this format does not always suit everyone, for example Vera says she finds it hard to concentrate. Reading, however, is not just a leisure activity that has been taken away, but rather it is the loss of a cognitive skill, and so represents a regression, which then becomes a barrier to information. Roco explains

> *although I've been partially sighted it's not to this extent so it it still comes as a bit of a shock and you can't you don't realise how much you rely upon visual information if it's the number on the bus or or a sign telling you which direction to travel in you don't have that*
> *I: yeah*
> *R: and you've always had it so it's it's a bit of a a surprise and not to be able to read means you can't get day-to-day information you know*
> *Roco, l.45-52*

The inability to read and take in visual information then impacts on other areas. Problems with shopping were highlighted by Dilys, who said she couldn't "*find whether I've got a tin of peas or a tin of beans in my hands*", because she was unable to read the labels, and when paying was no longer able to see the numbers on the pad to put in her PIN. Vera discussed handing her purse over to the shop assistant to take money out for her purchases, revealing the need for trust. Both are heavily reliant on people to help them, and for Dilys in particular there is a sense of a lack of dignity when she described scrambling around on the floor trying to look at the labels on tins.

Getting around, in particular, was difficult; from losing the ability to drive, which Dilys described as "*just horrendous*" having been driving since she was 18, or never being able to drive, as in Judith's case. Roco, who had suffered from fluctuating eyesight, described

> *on another occasion I couldn't find my way you know you get a ticket at the ticket office … and I'll say "well where where is this train" "it's on platform 9" so "which way is that?" and then it's a big station with a lot of employees I had trouble finding platform 9 which I wouldn't have had before or if I had <u>had that problem</u> when I started the journey I wouldn't have undertaken the journey*
> *I: right so it went very quickly (*sight loss)

> *R: it goes quickly to to to foggy*
> *Roco, l.165-172*

Vera also described how crossing the road and finding her way home from town was problematic, and how on one occasion, when she missed her stop on the bus, the driver turned the bus round and took her back. Her stories of flagging down cyclists to help her, and near misses with cars, are commonplace occurrences in the visually-impaired world and echoed by Dilys, but are also symbolic of the difficulties that the visually impaired face, and in particular their loss of independence. As Imogen explains, when she discusses travelling to hospital appointments on her own:

> *I <u>like</u> to go on my own now because otherwise you just get so dependent and…I can go on my own if I couldn't manage it's just another one of your (sighs) <u>taking away</u> from you your independence*
> *I: yeah yeah yeah*
> *Imo: <u>if you're always being taken</u> to somewhere then you well your independence goes and that's part of being a person that you can do things independently*
> *Imogen, l.232-240*

So these changes to the participants' mobility, often as a result on an inability to read signs, do not just signify a physical disability but also challenge their own sense of independence and therefore their identity, as they moved from being a sighted person to someone with partial sight or registered blind, who is dependent on others.

Additionally, sight loss was at times considered to be a hidden disability. Both Judith and Roco had congenital sight problems as well as developing other problems later on. Roco lost sight in one eye in an accident when he was nine, but as a child he had chosen to hide his disability:

> *no I wasn't a <u>declared</u> erm partially sighted I always used to sit at the front of the class in school but I think you are a lot more self-conscious about identifying yourself as being different … when when you're young and you want to conform with the rest of them ...you know you want to play football you want to do whatever…*
> *R erm and so you <u>hide</u> it…*
> *I: yeah*
> *R: a lot of the time I think now socially it's a lot more erm permissible to declare that you are partially sighted or you have a disability of whatever sort*
> *Roco, l.57-68*

Vera mentions how some visually impaired people she knows will not carry white sticks for fear of being identified as blind and therefore more likely to be attacked. She also comments that some people "*try to hide it*" as they are embarrassed. For Dilys, however, the hidden nature of her disability causes social difficulties:

> D: *it's the worst thing not being able to see people (.)*

> *I: yeah*
> *D: cos you can't make friends the same cos you don't know if you've seen the person before or not like*
> *I: yes but … if you … explain your disability … you know if you can say you can't see and that you don't recognise people do they*
> *D: some are okay and then others are just they just don't understand*
> *I: mmh*
> *D: you know you've got two eyes and they work if you look at them aren't they a lot of people eyes who are blind don't move*
> *I: yeah*
> *D: but mine move so they don't they just think oh you know …and they don't understand it's hard to explain to people*
> *Dilys, l.798-813*

While for Roco, the apparent hidden nature of his sight loss caused problems when he went to hospital for a knee operation, and the anaesthetist had to read the consent form to him. This hidden nature of the disability often puts people at a disadvantage, whereas others chose to hide it in an attempt to maintain some control of their situations.

b) *Individual in relation to others*

The effect of sight loss had significant but often varied impact, in terms of the individual's interaction with other people. For Dilys, the effects of the hidden nature of her disability were far-reaching in her interaction with those with normal vision. The outward appearance of normal eyes led people to assume she had good eyesight, and this in turn affected their treatment of her, as she felt they didn't understand she couldn't recognise them; ultimately, this problem impaired her ability "*to make friends*". Vera, on the other hand, found strangers "*marvellous*" and particularly helpful, citing an occasion when someone offered help when she was waiting for a friend in town. Difficulty in recognising familiar faces, however, puts her at a disadvantage:

> *V: I keep saying it is embarrassing I never know who I'm talking to their <u>clothes</u> are always different*
> *I: yes*
> *V: they say "what are you <u>worrying</u> about we know who you are that's what's important"*
> *Vera, l.467-470*

Whilst Judith found that people's attitudes to her as a blind person varied according to whether she had her white stick or her guide dog:

> *if I go out with my cane I am treated so <u>different</u> to when I go out with <u>Rex</u>*
> *I: mmh*
> *J: you go out with Rex and they chat with you normal you go out with your cane and it it's like you're <u>alien</u> almost people don't want to speak to you you know*
> *Judith, l.246-248*

This sense of being treated like an alien, and people not understanding the condition, leads to a sense of 'them and us'.

However, there is also some disparity in attitude amongst the participants towards other people with visual impairment. Whilst the support and empathy aspect of this will be explored under Theme 3, it is important to understand that just because people share a disability, they do not necessarily see things in the same light. For example, Judith explains differing attitudes to Disability Living Allowance saying it makes her "*cross*" that other people think they are entitled to aids for free, when she believes that is what the DLA is there to help people pay for things. This is echoed by Vera. However, with Vera the alignment with other visually-impaired people fluctuates throughout the account as she sometimes aligns herself with them, referring to "we", when referring to sufferers of Age Related Macular Degeneration, and at other times "them", such as participants on a specially arranged theatre trip, which included people with guide dogs and wheelchairs; her identity as a visually impaired person is, therefore, very situation specific.

Vera also finds her independence challenged, and she didn't always agree with the people who knew her, who may have thought she was taking risks:

> *everybody keeps saying "you shouldn't go out you shouldn't do this you shouldn't do that" I said "what am I going to do sit here for the rest of my life doing nothing looking at the wall?" (angry) I said "No"*
> *Vera, l.432-434*

However, her stories of getting lost in the dark whilst walking home, and trouble crossing the roads, reveals a vulnerability which she refuses to accept.

c) *Emotional Impact on the Individual*

This participant group all had long-standing eye conditions (Vera was the most recently diagnosed four years ago) so they had largely come to some sort of acceptance, and their attitudes reflected that. (There is also possibly a bias in that the people who volunteer to discuss their visual impairments are likely to have come to some sort of acceptance, and are therefore happy to share their opinions). As Dilys explains

> *you know you see people doing things and you think "oh I wish I could do that" and then you know now I realise I just can't do them sort of thing*
> *Dilys, l.612*

The emotional impact is combined with coping in a positive manner. Judith's attitude is matter-of-fact:

> *you can either look at it you can feel sorry for yourself and expect everybody to run round after you and live in a 'can't do' world which would probably make you miserable and everybody else around you would get cheesed off with you or you can just get on with it*
>
> *Judith, l.223-226*

This approach is also echoed by Vera, when she discussed her registration:

> *they registered me and that time you were slightly impaired so nobody pays much attention to slightly impaired and then I got worse and they put me up to severely impaired/blind*
> *I: yup*
> *V: and that's when you get you get a lot more help then*
> *I: right so how did you feel about that you know did*
> *V: I I I mean it's just progression isn't it?*
> *I: yeah*

> *V: I mean they tell you right at the start there's no cure what what what do you want to feel? you've got to get on and do the best*
> *Vera, l.819-828*

but in other parts of her account, the emotional response to her situation breaks through:

> *I get so frustrated and so angry at such a waste cos I am so fit it seems*
> *I: yeah*
> *V: ridiculous to be so fit and so helpless*
> *Vera, l.209-211.*

Roco touches on the shock of not being able to access visual information, despite having had sight problems his whole life, and how this current change in his sight has affected his self-confidence, and his proximity to people and objects. At times, he too reveals a sense of feeling vulnerable.

> *erm I'm I'm careful everyday out and about erm it's the self-confidence that I did have I don't have when it comes to crossing roads and I don't like crowded places because I bump into people and things like that I'm*
> *I: right*
> *R: a lot more self-conscious about my awareness of where I am relative to anyone and anything else*
> *Roco, l.31-40*

It is not just the physical effects of the condition, but the knock-on effects that cause emotional reactions: Dilys finds the difficulty she has shopping "*embarrassing*", and there is a sense of loss of dignity in her description:

> *I had to go in one day Marie wasn't well or something and I needed something I have to take that magnifying glass with me and I was on my hands and knees on the floor trying to look what the things on the…it gets a bit embarrassing really*
> *Dilys, 137-141*

And ultimately, coping with sight loss is a challenge, not just physically but socially and emotionally as well, summed up by Dilys:

> *"we get there you struggle on but we get there". (l.73)*

4.2 (ii) THEME 2 – *Access and Barriers to Care*

This theme explores the specific reactions the participants had to their eye care, and the themes may be considered against the context of their visual impairments.

a) *Accessing Care*

The participants went through similar routes when accessing expert care. Sight problems may have been picked up by the ophthalmologist, who referred them to the GP, who in turn was the stepping stone for referral to the consultant. Opinions varied from participant to participant about the care they received from both the GPs they saw and their ophthalmologist, and depended largely on the relationships that had been developed with those professionals. In general, the longer they had known the professionals, the happier the participant was with their care, largely because they felt their condition was understood, because of a continuity in care.

When referring to the experts within the hospital settings, the participants mainly had respect for the consultants, referring to them as "*the boss*" (Roco), "*the chief*" (Dilys) and the "*top man*" (Vera). Whilst in Shrewsbury and Telford hospitals, participants are happy that they see the same consultants, for those who live in south Shropshire and are referred to Hereford this is not always the case:

> *er I'm just well on the conveyor belt and they have to read the notes anyway they're not going to remember that I've got whatever is wrong you know particularly wrong with my eyes they've still got to read the notes and sort of check them through*
> *I: yeah*
> *Imo: so in that regard it's not really doesn't really make any difference if you don't see the same one but it would be quite nice to sometime sort of know the face*
> *Imogen, l.352-358.*

Her use of the expression "*conveyor belt*" coupled with the fact that she rarely sees the same consultant twice implies that her treatment is somewhat impersonal. Roco, on the other hand, has a working relationship/partnership with his consultant with regard to his corneal graft; from the early discussions about when would be an appropriate time to tackle the operation, and subsequently discussing the removal of his stitches. At times he tries to take control of his eye care:

> *right now I'm pressurizing him as much as it's practical to take the stitches out so I know what I've got…but he's told me in no uncertain terms he wouldn't dare take them out*
> *Roco. l.201-205*

This sense of the patient being in control, and even the expert in their own care, is promoted further by Judith, when she met her new consultant several years ago:

> *he introduced himself and I just told him how it was going be I basically told him "right there is no experimenting no operations nothing I'm coming to see you I shall have my pressures checked and I expect you to look at the health of my eyes just to make sure" I said "but don't even think about putting me in for any operations not happening"*
> *I: mmh*
> *J: and he just sat there and he goes "oh right " and I said I said "just cos" (.) cos I'm unusual they it's like they wanna try things?*
> *Judith, l.66-73.*

She knows how she wants her care to be handled, and is happy to direct the consultant in that way. Her confidence is not always shared by other participants and may arise from the long term nature of her disability. However, it is clear that well-established relationships with the consultants increase patient confidence in their expression of their own wishes.

There was a difference of opinions about the other staff at the hospital. Largely, the nursing staff were praised; "*the staff are good I find them very good I can't complain about the staff at all*" (Dilys), "*they are all wonderful*" (Vera). However Roco expresses amusement but also frustration at the fact that he is asked to do an eye-test with his blind, plastic eye, because the nurses are "*doing a sea of people they don't read the notes*", and therefore are not aware of his total sight loss in one eye.

> *I: and how do you feel about that*
> *R: erm (.) not overly annoyed because it doesn't make much difference in my particular case erm I think they should maybe look pay attention to the notes before they ask questions of some people who might get concerned about them or they might miss something*
> *Roco, l.355-359*

This description echoes Imogen's "*conveyor belt*" metaphor, and points to a lack of attention to the individual's needs. His frustration is also echoed by Imogen and Judith, who also felt the tests they are asked to do sometimes were inappropriate, but these problems vary from individual nurses, and visits, rather than being a universal experience.

Roco saw the administrative staff as being gatekeepers, who may need to be approached in a certain way in order to get appointment.

> *I: you said the bit about the secretaries being the sort of gatekeepers*
> *R: yes they are*
> *I: erm*
> *R: I think that's very true*
> *I: so so you feel confident you'd be able to get a*

> *R: I feel confident erm but it's I don't know it sounds conceited of me but I think I stand as good a better chance than the most of the patients of doing it because I'm quite good at expressing my wishes strongly without being*
> *I: yeah*
> *R: angry or aggressive about it erm and I'm used to dealing with professional people*
> *I: yeah*
> *R: erm which I think makes a difference"*
> *Roco, l.283-296*

He continues that he believes it is "*within their gift to bring something higher up the pile*" and that to some extent the system can be worked to an individual's advantage, whilst acknowledging that the system would not work if everyone did this. Dilys also mentions an occasion when a secretary moved her appointment forward by changing the time on her letter when she arrived at the clinic, although not at Dilys's request.

Judith commented that when she requested to see the consultant with a particular problem, she was given access to him promptly, and this theme of self-monitoring and self-advocacy is echoed by Roco, who explains he has to ask to see the consultant if he is concerned his eye may be rejecting its new cornea.

b) *Communication*

A universal complaint about communication is that appointment letters are sent out in a regular font size, rather than large print. Participants recognise their appointment letters but need their reading aids, such as magnifying glasses in order to see the time and date. Roco plainly states "*the letters don't come in large font so I can't read them"* but does get an "*NHS reminder by text*" and as he can alter the font size on his phone he can read that. Imogen mentioned reminder letters for appointments, which again were in regular font size, and nothing highlighting a change in time of her appointment.

> *I said to my husband I said "given that it's a sight clinic you'd have thought (laughs) they would have had a big 'change of date'(sic)"*
> *I: yes yes*
> *Imo: and then they write the letter saying "Missed appointments cost us X number of pounds" well I thought to myself "well yes (laughs) it's not surprising if that's the way" it's just little nitty gritty thing but those little nitty gritty things it makes you think "oh well they're not on the ball"*
> *Imogen, l.427-433*

So while she feels responsible for turning up on time for her appointment, she also feels that if the service provided is inappropriate, the blame should also lie with the service providers, and this blame should extend to the bearing the cost of missed appointments. Judith also felt that services should cater for the needs of the patient,

> *J: I mean it wasn't until the day I was going that I saw there was stuff on the back that I was supposed to fill in or check and I thought "sod it" if they can't do it large print I'll say "you send it large print and I'll fill it in otherwise forget it" they've got all my information so I don't need to give them again*
> *Judith, l.387-390*

What Imogen calls "*nitty gritty*" is, for these visually impaired people, an understanding of their disability and acknowledgement of those limitations, by responding appropriately to them.

Spoken communication, and in particular the language used by the consultants was also a concern. As already explored, the patients have respect for the consultants, but also negotiate their care with them, which is a negotiation between the lay person and the expert. However, when it comes to the language the consultants use, the participants sometimes felt they were at a disadvantage: Dilys confronts the problem,

> *yeah if I don't understand it I just ask some of them…you know if you don't ask you don't get do you…and I think some people are just afraid of asking*
> *I: mmh*
> *D: but no no I say "what does that mean" you know if they say come out with a word you know that big sort of thing…and they will explain to you what it means*
> *I: yeah*
> *D: but you do have to <u>ask</u> …cos they just presume you know I suppose it's they it's their job isn't it*
> *Dilys, l.278-291*

Imogen also finds the language difficult, although consultants have explained things:

> *I think it when you do see a consultant you've got to be very alert as to what they are saying and I I've never had when you ask them a question I've never been told just some gabbled on as though as I am expected to know then if you do ask I've always found that erm they'll explain things*
> *I: yeah*
> *Imo: but erm some of the things they're so complicated anyway even if they are explained to you (laugh) you're not going to still know what's going on*
> *I: and erm (..) how does that make you feel … you still might not understand*
> *Imo: erm (..) I I feel that they're the professional*
> *I: mmh*
> *Imo: erm and I'm just the patient but I do sometimes would like a bit more … detail about it but I accept that it's time*

Both participants understand that the consultants use the language of their trade, but that at times that language might be inappropriate to them as lay people; the use of language then also impacts on their sense of identity. Roco, however, felt that his consultant gave clear explanations:

> *it wasn't an overly technical explanation it was one that I could understand and he's obviously very good at it because whatever level your competence is to understand the matter he can he can talk to you at that level*
> *Roco, l.188-191*

The language used may also have an emotional impact: Vera was left with a sense of regret when the consultant had said "*what a great shame you didn't come back to me straightaway*" when her eyesight deteriorated rapidly.

It is also apparent that, sometimes, the problem for the patient was not what the consultant had said, but what had been left unsaid. In the case of Imogen it was requiring more information, but for Roco it was "*not knowing what the surgeon's opinion would be*" around the outcome of his corneal graft.

c) *Physical access and barriers*

The participants came from different areas of Shropshire and therefore accessed not only Royal Shrewsbury Hospital and the Princess Royal Hospital, but also Hereford County Hospital. As Imogen explained, living in the south of the county, she is given the choice of RSH or Hereford County Hospital and chose Hereford because it was within walking distance of the station. For patients throughout such a large county access to hospital is an issue, as one participant said living in Oswestry meant that an appointment in Telford meant changing buses at least twice and travelling could "*take hours*". She was concerned that services might be moved to Telford from RSH, which she felt would be "*very wrong*". Although transport was offered to some participants, it was rarely taken up. Although Vera has no one to take her to hospital, she doesn't request transport saying:

> *They would if I asked but I don't think that's fair I'm quite capable of walking*
> *Vera, l.754-5*

Dilys, has accepted help to get to Telford, which was a good service being guided to the clinic by the driver, but she does not request help to get to Shrewsbury. She supposed

> *If I'd got off my legs or something like that they'd have to come and fetch me.*

In this sense then, the participants cope with the challenges of attending hospital, and don’t see their disability as a barrier to getting about (although it does affect their mobility), in the same way that a mobility-specific disability would.

Once at the hospital however, the participants do feel disabled by some of their experiences. Roco explains:

> *… in general the system doesn’t work for … me as a partially sighted person to find clinics that used to be er twelve months ago they kept moving the clinic at Telford the Princess Royal erm so you had to find your way to a room upstairs erm so you’ve got to walk down a big main corridor and then along another main corridor that would erm with signs that er are maybe ten foot above your head so you can’t walk up to them you’d have to jump up to them to be able to read them*
>
> *I: yeah*
>
> *R: the ones on the wall you can read because you get close enough you can’t get close enough to the ones that are above your head*
>
> *Roco, L.399-408*

Signage is therefore an issue. In RSH the common complaint is the seating area, which essentially is a corridor.

> *the biggest complaint I have got is where you sit*
>
> *I: yeah*
>
> *D: that is absolutely disgusting you sit you sit here like that and all you are looking it’s about oh not even that far away as this wall*
>
> *I: yes no I’ve been up there and seen it*
>
> *D: it’s just horrible if they left you in that other room you’ve got plenty of people to talk to and things going on that the time whiles away quicker doesn’t it*
>
> *I: yeah*
>
> *D: but when you’re looking at a brick wall sort of thing it’s just horrible*
>
> *I: yes*
>
> *D: and people coming through with zimmer frames and guide dogs and*
>
> *I: wheelchairs?*
>
> *D: wheelchairs and everything you know we’re doing this sort of thing almost putting your feet up on your chair that is… that really is terrible*
>
> *Dilys, l.214-229*

The issue is not only that it is a corridor, which should be an area for movement rather than sitting, but also there is the risk that people, who are visually impaired will trip over the people sitting. Another comment was that seating is limited and by the nature of their complaint most people will have a carer with them, so twice as much seating as patients is required. Furthermore, for those with guide dogs there is no space at the side of the seats, except doorways, for the dogs to sit in.

Judith's comment that she "can't understand how they are allowed to do it" points towards the Health & Safety issues that are encountered by blind people in other areas of their lives. Furthermore, sitting in a corridor in a straight line is difficult for visually impaired people, who may find it difficult to see other people to chat to. Judith compared RSH with the old Eye, Ear and Throat hospital in town:

> *it was a dump and that but (.) you had waiting rooms and the consultants rooms were right by the waiting rooms and they'd call you and you'd go in you'd be there there was not all this looking for their patients it it's (.) it's it's it's demoralising going there …it's you feel like it's like a cattlemarket*
> *Judith, l.313-318*

The experience is impersonal and adds to the levels of anxiety which participants reported. Interestingly, sitting in a corridor is not unique to RSH; Imogen recounted how she had visited Moorfields Eye Hospital in London with her sister, where she witnessed someone having their eyes tested by reading the letters chart in the corridor, which she felt was potentially humiliating:

> *And I thought "oh no at least we only have to sit in our corridor"*
> *Imogen, l.599-600*

She continues that the corridor in Hereford is "not comfortable", from an emotional point of view, rather than physical one. The fact that participants see these areas as corridors, rather than as seating areas, suggests not just the inadequate provision of seating, but also that patients' wellbeing is not being holistically addressed. Judith explains how she feels about visiting the hospital for check-ups even though she has had life-long sight problems, and even her daughter questioned her reaction:

> *people that <u>go</u> to these places are <u>very anxious</u> I mean it's just for a pressure check for me but I still don't like <u>going</u> you feel a bit het up about it*
> *I: mmh*
> *J: and whatnot I suppose cos like N was saying "what is that you don't like cos you they're not going to do anything that you don't know what they are going to do" and all this and I said "<u>because it's in my face</u>"*
> *I: yeah*
> *J: "that I've got sight problem"*
> *Judith l.321-329*

However, not everyone sees waiting in the corridor as problematic

> *V: … they don't like sitting at a blank wall I mean why do you it's it's not a first class hotel I mean*

> *I: (laughs)*
> *V: what can you do? and if they sat in there (*the entrance hall*) it means the doctors will have to come out go into that area call out the names whereas all they do is open the door and call your name out and you're in*
> *Vera, l.627-633*

Vera believed that there may be the space and cost limitations placed on the hospital and time limitations placed on the consultants, who call the patients into their rooms in person.

d) *Timing*

Waiting times for any treatment are always subject to scrutiny. These participants do not express their waits for appointments in comparison to any NHS targets, but against their expectations which are set by the consultant.

For Vera, however, she felt her eyesight was at risk when she had to wait three weeks for an emergency appointment.

> *and when the first time they do this looking behind your eye thing they give you an injection*
> *I: right*
> *V: and apparently my blood pressure was too high and he said "It's too high we can't do it" so I was sent home (laughs) for another <u>week</u> and went back the following <u>week</u> only to be told that the man that did the x-rays wasn't there so I went home again by that time I was <u>panicking</u> because I thought if I'd lost one with within <u>a month</u>?*
> *Vera, l.45-52*

In order to take control over the situation, and because she was "*panicking*" she decided to go privately. The consultant told her she was "*wasting*" her money, but there is a sense that she feels her condition was not taken seriously: the consultant says

> *"I'll chivvy them up at the hospital"*

and it is only when she takes this extreme measure of paying thousands of pounds for her treatment that she gets the appointment she was hoping for:

> *so the third time which was <u>three weeks</u> after I'd been diagnosed as an emergency I eventually got onto the National Health one*
> *Vera, l.58-59*

Waiting times are quantifiable. For example, Roco discussed his follow-up treatment for his corneal graft in terms of months, and how those treatments have fallen behind the suggested schedule.

> *erm I have three month reviews now it went from sort of just a few weeks to two months to three months erm at the moment and for the last … six months the three months have been four months because they are behind (.) they are always behind so what should have been er three three months was four months two weeks ago when I rang*
> *I: right*
> *R: and he said "I'll see you again in another three months" erm so that three months which will work out at if it goes to four months which it is at the moment erm will will make that seventeen months since the surgery when it should have only been <u>twelve</u> months since the surgery*
> *Roco, l.253-263*

His complicated equation reveals concern that it has taken seventeen months to have the appointments he should have had in a twelve month period. The consultants are also seen to be complicit in this rescheduling although they too have to work the system. Imogen explained:

> *I've got an appointment in erm 5th December and I had that given to me when I was in in <u>May</u> I went and he said "oh I'd like to see you in six months" and he said "oh no I'll put four months cos it's gonna probably be six months by the time the actual appointment comes erm by you've sort of got a place*
> *Imogen, l.389-393*

These accounts reflect not just the patients' sense of time-keeping, but also a recognition that they are not getting their appointments when they should. Additionally, Imogen's account reveals that the consultants also recognise the problem and try to compensate for delays within the system. The participants seem to accept these problems; Vera, in particular, argues that there are so many patients and not enough doctors, the delays are understandable, and there is a sense of resignation in her account. What these participants found more difficult was the change in appointment dates, because of the inconvenience it causes, in Judith's case not just for herself but also for her husband, who has to take time off work to accompany her to the hospital. She expressed scepticism at the reasons for cancellation:

> *This last one was cancelled the morning of my appointment? Because er Mr X was apparently ill… erm whether he was or not I won't question*
> *Judith, l.359-362*

Once at the hospital, the participants have long waits to go through all the procedures , especially those with AMD:

> *V: you do have a long wait*
> *I: yes*
> *V: you know it's your morning gone if your appointment your morning's gone*

> *…it all takes so long*
>
> *I: does it?*
>
> *V: I mean you've got to go through all this session you get your eyes tested twice to begin with by the nurses…and then you've got to wait to go in to have the er (.) the photo of the back of your eyes … and then you wait for the doctor to do it and once that's done you go home but by that time most of the morning has gone (laughs)*
>
> *I: yeah*
>
> *V: I always get an early morning one eight eight forty-five something like that hopefully I'll be gone by twelve (laughs)*
>
> *Vera, L.658-677*

Again there is resignation to this experience. Although Vera is stoical about waiting, for others the problems with having to sit in the corridor, mentioned above, seem to exacerbate the emotional impact of waiting to be seen.

4.2 (iii) Theme 3 – *Supporting the visually impaired -Empathy v lack of understanding*

With their varying levels of sight loss, experiences and approaches in dealing with their disability, the participants discuss different kinds of support, from aids and physical support to emotional and social support. Again it is important to see the 'big picture' in order to understand how well the NHS performs in pointing people towards support. The theme of empathy versus lack of understanding runs throughout the dataset.

Although there are elements of praise for the service within the accounts, participants spoke of lack of understanding from people who are not visually impaired, which extends from poor signage, to failure to read the patients' notes or using inappropriate language, as mentioned above. Occasionally, individual examples help to illuminate the issues:

> *I find the reception staff quite officious you know they I don't know they just never they're always in there's they're always in such as rush because so many people there I suppose they haven't got time for any sort of small talk it was I mean I gave my letter in er "Oh go and take a seat" there's no erm (.) I could imagine that if you were on your own and you were it would be quite scary you know "go and and take a seat" they don't sort of say to you where to take a seat (laughs)*
> *Judith, l.526-532*

Judith is not only expressing her annoyance at the apparent lack of awareness from hospital staff, in failing to direct people who cannot see towards seating, but also reflects her own level of empathy with other visually-impaired people; it is this empathy that would help the sighted person to understand the issues the visually impaired encounter.

a) *Official support*

As outlined above, these participants have long-term visual impairments, so their experiences of diagnosis are not recent. Judith's experience of her diagnosis of glaucoma may have been fifteen years ago, but she believes her experiences are not uncommon with those diagnosed today.

> *J: …and I suppose that if you've always had normal sight and then you lose your sight and … that would be very difficult I can imagine for somebody in that position to have to deal with*
> *I: yeah*
> *J: and having to rely on somebody else because when you first lose your sight you don't get everything straightaway like you wouldn't you know get your long cane training and you'd lose your confidence and everything I mean it was bad enough when I was diagnosed with glaucoma cos basically they said erm "right you've glaucoma have these drops" erm they gave you a leaflet which basically told*

> *you if the pressures weren't controlled you'd damage your optic nerve and you'd go totally blind and <u>that was it</u> they didn't there was nobody saying you know anything else to you they didn't sort of sit down with you and say you know "it it's very <u>unlikely</u> that you'll lose your sight and all this"*
> *Judith, l.253-266*

The passage explores the change from being a sighted independent person, to someone who has to rely on others for physical support (getting about), and the emotional impact that might have in terms of loss of confidence, and a comparison with the lack of support she felt when she was diagnosed, in terms of explaining the condition fully to her.

The problems outlined in Theme 1, around reading and the lack of access to information through a visual channel, persist into accessing support. Judith describes the packs that were given out when there was an ECLO (Eye Clinic Liaison Officer) at the hospital, which she felt contained too much information

> *and it's no good giving somebody who is losing their sight a flipping <u>written pack</u> really*
> *Judith, l.454-455*

The approach then is to consider what appropriate support is.

Some of the participants were involved with producing the packs given out by Sight Loss Shropshire

> *when you've been diagnosed our feeling was you need to go home and have some time with your family and get your <u>head round it</u> and <u>then</u> start thinking about the practicalities*
> *I: yup*
> *J: with the help of your family*
> *I: mmh*
> *J: you know so that was the idea of the packs and as you need more stuff these numbers that were in there were of people who could sort of forward you on and stuff so (..) that that now but the van's only there on the first Wednesday of the month and the third Thursday of the month so if you go any other time there's nothing there… but whether they are being given out by anybodyI don't know…what we were trying to do was to signpost people but only in a small way because you don't erm as I say you don't want them this great big pack of <u>loads and loads of information</u> and stuff because it's <u>too much</u>*

There is a recognised need to come to terms with a diagnosis, but also to be pointed to some sources of support post diagnosis.

Judith's experiences of being given a leaflet, which outlined the worst case scenario with little emotional support and no-one to explain this to her are in contrast with a more desirable person-centred approach of guided support.

Once diagnosed the patient may be pointed towards other forms of support, such as registration and the low vision clinic within the hospital. The experiences of the participants were limited around these services. Roco had been recently registered severely visually impaired, and met with the person responsible for registration. As someone who is proactive in his eye care having had lifelong problems, Roco was somewhat critical of the service provided:

> *but I think the things that he could suggest or talk about were at least twenty years behind the time if not more you know he gave me free of charge a pair of over glasses which that you can put because I have trouble with bright lights and things like that you know*
> *I: oh yes*
> *R: erm but I got from the opticians something ten times better*
>
> *Roco, l.562-568*

Only Vera mentioned the Low Vision Clinic at the hospital:

> *the low vision clinic down the bottom which is always shut I don't know what they do in there if you go and knock on the door they might find find a magnifying glass for you*
> *Vera, l.304-309*

The opinion of the participants was that advice about aids and what is available were more likely to have come from support groups: Judith talked about a fellow sufferer of sight loss saying that he had learnt more about his condition from the low vision support group *"than he has from any professional you know at the hospital", Judith, l.282-3.*

Vera mentioned the See Hear exhibition (held annually in Shrewsbury) as a good source of help and support, particularly for her in terms of gaining access to and service for visual aids, such as a magnifier.

b) *Mutual support*

Three of the five are actively involved in supporting other visually impaired people, and four of the five attend support groups. The accounts are full of instances of mutual support, as being part of a community of visually impaired people.

Roco does not attend a support group at present, but is contemplating joining one. His expectations of a group are both for information and mutual support

> *I: if you went to a support group what sort of things would you hope to gain out of it do you think*
> *R: erm the honest answer is I don't know at least erm they would be kindred spirits so you wouldn't feel alone in being partially sighted a*
> *I: mmh*
> *R: there's probably some value in that because other people (.) erm would feel exactly the same about some things as you do you know… you wouldn't have to explain the difficulties you have…in some ordinary tasks of life you know…*
> *I: yeah*
> *R: erm and……….. if other people had been going through it a lot longer er yeah there would be a lot of information I'm sure you would share*
> *I: yes*
> *R: because if you pool information the the erm the sum is going to be greater than the parts isn't it?*
> *Roco, l.625-642*

The support groups are also a way for people to contribute as well as benefit. Imogen explains that for her it is not a social event, as she has lots of friends but as a way of giving something.

> *I go along to it because it's (.) hopefully to be sort of you know <u>helpful</u> me to be helpful to somebody and for somebody to be helpful to me*
> *I: yeah*
> *Imo: in this sight thing but as far as wanting somewhere to go out I don't need that I've got that I've got erm a big social life erm (.) I chose to (.) if I want to go out I can go out quite a lot and I've got lots of people I can meet for coffee or go out for a drink with erm but it's the people who are on their own they're going to benefit perhaps from things like that*
> *Imogen, l.797-805*

Imogen also does telephone befriending:

> *Francis took me we went to Nottingham stayed overnight there and had quite a nice time erm then we went to the befriending meeting the next day which I thoroughly enjoyed and now I'm a befriender of two elderly ladies*
> *I: oh that's good that's lovely*
> *Imo: which I really I enjoy for myself and I enjoy for them as well and you phone them every two or three weeks just to have a <u>chat</u>*
> *I: yeah*
> *Imo: it's erm to be honest we don't talk about eye they've both got macular we don't really talk about eyesight*
>
> *Imogen, l.834-843*

She wants to help others, but in order to do that has to attend training, and in order to access that she is supported by her husband. The support that she gives these "*elderly ladies*" is less about practical help – she comments they don't need information about support groups – but more about social and emotional support. They swap stories about their grandchildren.

However, there are other people who do not want to access support groups. Dilys talks about an encounter with a severely visually impaired man and his wife:

> *erm I said "well why don't you come to SLOG" [Sight Loss Opportunity Group] "oh no he won't join any groups like that" well I said "it's nothing it's all people all the same you know you can talk to people about things and they understand better than people who are not visually impaired"*
> Dilys. l.773-776

Not everyone responds in the same way; an encounter between Vera and a visually impaired friend highlight not just differing emotions but also differing approaches to dealing with disability, and even differing levels of empathy.

> *V: … and I said to her I said "how on earth can you be as calm as you … are because I get so <u>angry</u>" and she and this really amazed me because I wouldn't have answered like that " well… there is one thing you must remember I don't know what it's like to see"*
> *I: yeah*
> *V: but if someone had asked that to me my question I'd say "well get up and get on with it a lot of people worse than you are"*
> *Vera, l.211-217*

Vera tries not only to understand someone else's acceptance of their disability, but also shows her impatience when confronting her own sight loss . Furthermore she attempts to put herself in her friend's shoes and in so doing she reveals what seems to be an unsympathetic approach ("*a lot of people worse than you are*") but in reality that response is directed at herself. Her friend in explaining her position – she doesn't know what it is to have full vision – implies that she therefore doesn't know what she has lost, unlike Vera. So either of them may feel the other has lost more. These small, but significant, examples of understanding each others' sight loss and the limitations it imposes, reflect the mutual support that people can bring each other, and refer back to Dilys's comment that no sighted person understands what it is like to be visually impaired. The need then for support groups is apparent.

Beyond empathy and emotional support, groups give access to activities that people with visual impairments struggle with on a daily basis, but which are beneficial for health and wellbeing. For example, Dilys and Vera enjoy cycling, which is run by one of the SLOG groups.

> *it's really really good cos you feel normal….you know you are doing normal things that normal people do I know you've got someone in front of you you've still got handlebars you're still peddling*

Other group activities give access to physical exercise, such as walking

> *D: I think everybody enjoyed the walks as well*
> *I: yeah*
> *D: because if you can't see you've gotta you've either got somebody on your arm or you've got your stick or you've got a guide dog and and erm that again makes you feel normal because you are doing things you know like going up little hills and then taking a packed lunch with us or whatever*
> *I: yeah yeah*
> *D: it's er and getting you out and and doing physical things*
> *Dilys, l.908-915*

But ultimately, the irony of support groups is that for the visually impaired they need support in order to access them. Whether that is information in the right format given to them at an appropriate time, as discussed above,

> *but you need … a sighted person to find out what where and when…*
> *I: yeah yeah*
> *R: you can't do it yourself*
> *Roco, l.649-652*

or whether it is physical help in getting to them:

> *Imo: by virtue of the fact that it's a sight group you're not necessarily you can't just sort of say "Oh yeah I'll get the car out"*
> *I: you need someone to take you sometimes*
> *Imo: yeah yeah and if you're going if if you've got to pay for the taxi there's it it makes it well not necessarily expensive but you may sort of think twice about it*
> *Imogen, l.774-778.*

c) *Family support*

Throughout the accounts, the participants reveal their dependency on family members for support. For Imogen, whose sight loss is the least within this group, she still maintains a high level of independence, as mentioned in Theme 1, and sees that as a vital part of her personality. Family support came in the form of information sharing: her husband points out newspaper articles relevant to her condition, and her sister, who also has glaucoma, shared leaflets which she picked up on her hospital visits.

Roco also talks about how his wife helps him to access to information, whether it is finding out train times and pre-booking tickets for their travels, or more specifically looking up information about support groups. His dependency on his wife has increased as his sight deteriorated prior to the corneal graft, and that has meant a shift in family relationships, especially when dealing with his disabled son:

> *R: yes the day to day stuff you know my wife helps me with everything I said I've got a carer erm poor woman really erm because I don't go many places on my own …and I <u>certainly now</u> er can't take my son out on my own*
> *I: no well*
> *R: cos he's so much more aware than I am you know by the time he's decided he's going to grab something I'm I'm he does it before I'm even aware of cos he' so quick…I can't be responsible for him anymore*
> *I: no*
> *R: I <u>help</u> but he's just far too quick for me at the moment*
> *Roco, l.77-788*

As a father he can no longer look after his son on his own, and his role is diminished to that of a helper, his wife bearing the lion's share of the physical care.

The husband-wife relationship is an important one in providing support. Judith talks about her husband taking time off work to accompany her to appointments, both for eye care and other medical conditions. The repercussions when an appointment is cancelled at the last minute are revealed:

> *so they rang me up in the morning and my appointment was for the afternoon well Glen had booked a half day off to take me but he said I rang him and he said "well I'll cancel my half day today" and he rebooked it but not everybody would be able to do that*
> *Judith, l.332-336*

He also participates in those appointments, for example when a nurse went beyond Judith's range of vision with a sight test card:

> *she walked right down the end and Glen said "you'd be bloody lucky if she can see you never mind (the card)"*
> *Judith, l.554-555*

But despite having him by her side, she maintains control of her encounters with hospital staff:

> *I’ve never really experienced the ‘does she take sugar’ they always speak to me they don’t speak to Glen you know…cos that annoys me if anyone does that I go “Excuse me I’m the patient not him”*
> *Judith, l.745-748.*

So despite saying she hasn’t really experienced being ignored by staff, there is a suggestion that it has happened but she has taken control of the situation. The family member, therefore, needs to support in a way that is appropriate and not too controlling.

As well as social support, family members provide much needed practical support; for Dilys support provided by her daughter includes going shopping, filling in forms and doing paperwork.

> *D: she became a carer so*
> *I: right*
> *D: she comes like three days a week now so that she does paperwork for me one day and perhaps we go just mouching up the town or something on another day and then on a Friday she takes me to do the week’s shopping*
> *I: mmh*
> *D: so that all helps and then she comes back here and we have lunch together so that breaks the day up as well doesn’t it*
> *Dilys, l.867-874*

For Dilys, as with Roco, there is an element of handing responsibility over to someone else, in this case paperwork and financial matters, as she needs her daughter when she is shopping to put the PIN number in.

Also for the visually impaired elderly, there is the loss of support when a partner dies.
Dilys reveals how much her husband supported her in getting around, when she talks about getting a white stick

> *no it’d be after hubby died because I mean I didn’t <u>need</u> a help when I’d got him you see did I*
> *I: no*
> *D: I was okay*
> *I: yes*
> *D: I was always on his arms so I didn’t think about you know you just you get used to doing the same thing all the time don’t you*
> *I: yeah yeah*
> *D: no it must have been after he died that I had that er other stick*
> *Dilys, l.502-510*

The fact she was “*always on his arms*” reveals not only physical proximity needed for guidance, but also suggests emotional support, which is not replaced by a white stick.

The emotional impact on the carers, however, is not discussed in these accounts. Their time and support is given and received almost unquestioningly. It is only in Roco's account that there is a glimpse of the understanding between spouses, when he described her as his "*carer…poor woman really*". As with the impact of sight loss, discussed above, there is a sense of avoidance coping by not discussing the emotional impact of being cared for, and consequently limiting the self-identity as someone with a disability. For Vera, who has no immediate family nearby to care for her, she carries on regardless of risk taking in going out alone or handing her purse to shop assistants. It can therefore be seen that family support not only provides practical help but also, acts as a buffer between the vulnerable visually impaired and the world around them.

4.3 STAGE 1 - DISCUSSION

The aim of the report is to discover in what ways visually impaired people feel disabled and disadvantaged by their experiences with relation to NHS outpatient eye care services. Stage 1 results focussed on hospital outpatient services as these were points of the most regular contact for these participants, and were seen to have the most impact on the patients. Within the dataset, participants mentioned their GPs and ophthalmologists, who may have referred them to the consultant, and individual experiences differed around those services. However, they were seen as stepping stones to hospital services.

4.3.(i) Theme 1 – Personal responses to sight loss

Sight loss impacts on all aspects of the participants' lives, whether that is in daily life affecting the ability to read, getting about, shopping or work. Although this is a small scale project, with a few participants, their experiences in this aspect are universal. Research has shown the impact sight loss has in the over 65s: those with visual impairments, when compared with those with good eye sight in an age matched group, encountered increased difficulties in 'activities of daily living', such as shopping, food preparation, paying bills, as well a social and emotional problems (22). Problems with getting around, impact on all aspects of the participants lives, and demonstrate the importance of maintaining independence for this group. However, sight loss also brings an increasing dependence on others, particularly family members.

Increased social isolation, which is also partially attributable to the difficulties getting around, and the accompanying loss of self-confidence found in these accounts is also well documented in the visually impaired population (23). For example, the lack of being able to drive has been shown to impact on self-esteem in students with visual impairments (24), and the accessibility of public transport has been scrutinised (25). However, sociability is also limited by not being able to recognise people, which can make the visually impaired person feel disadvantaged and excluded, and occasionally discriminated against. Social isolation has an emotional impact (26), and whilst depression is common in the visually impaired, this study did not consider depression as a label, but rather explored the individual accounts of the impact, which related to themes of helplessness, resignation, embarrassment, frustration and anger.

The participants align themselves with other people with sight loss, but at times stress differences in attitude and levels of ability – in this way they manage their own identities as visually impaired people whether accepting their disability or at times rejecting it. It has been suggested that AMD sufferers themselves, such as Vera, do not consider themselves ‘blind’ because they retain peripheral vision. However, rejection of disability may be seen as an avoidance coping strategy (16).

The issue around sight loss being a hidden disability highlights not just the practical problems, but also the social and emotional problems the participants face. In particular, the lack of recognition and understanding by others of physical limitations brings additional emotional distress to the patients.

The survey for Guide Dogs for the Blind Association (9) stated that

> *“the presence …of staff who understand how their actions or non- actions could assist or hinder the mental and physical well-being of blind and partially sighted users of their service is obviously of paramount importance.”*

It should be explored more to discover if this lack of recognition of the extent of their sight loss affects the way patients are treated by healthcare professionals within the hospital environment.

The general alignment of these participants’ experiences within this theme with those reported in the literature suggests that they are typical of people with sight loss. It is therefore possible to take these experiences forward, and use them as a basis for further research.

4.3 (ii) Theme 2 – Access and Barriers to care

This theme around access and barriers to care addresses three key areas, which the participants have raised as problematic.

- Communication with the hospital
- The timing of appointments
- The physical built environment

The issues raised by the participants around the occasional lack of understanding from overworked hospital staff and the lack of accessibility in the hospital environment are not particular to Shropshire, and have been reported in the research literature (9) (10).

The issues suggest a lack of understanding of the impact of sight loss and a lack of the person-centred approach which is a goal of NHS care. Guidelines that staff should know the patient as an individual have been issued by NICE (27), who state

- *"ensure that factors such as physical or learning disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English are addressed so that the patient is able to participate as fully as possible in consultations and care".*

Additionally:

- *"take into account the requirement of the Equality Act 2010 and make sure services are equally accessible to, and support of, all people using adult NHS services".*

Communication divided into two areas: communication between hospital staff and the patients, and communication from the hospital for appointments.

Whilst the language used by the consultant was sometimes difficult to understand, the participants did not feel it was a major concern, although it may have impacted on their relationship, the consultant being seen as in a position of power. Previous research has suggested that this difference in communication affects the patient's understanding of the condition, and may in turn lead to an inability to self-advocate when their condition changes (13). It can be seen by the difference in attitude between the participants who regularly saw the same consultant, and Imogen who did not, that knowing who was dealing with their care was empowering, and they were more likely to express their wishes.

On a practical level, the format of the communication from the hospital in appointment letters was felt to be unacceptable. Participants need visual aids, such as magnifiers, or other people to help read the letters. The group believed the NHS is not taking modern technology into account: while one patient received reminders by text, which was more accessible because he could adjust the font size, no-one received e-mails or reminder phone calls. It would be empowering for patients to discuss and suggest formats which work for them. Whilst it is important for all patients to have their appointment times in accessible formats, for those who have additional problems, such as memory loss the format should be accessible at all times, not just when there is someone there to help read the letter. Many elderly people live alone and do not have someone there to read the letters for them.

Waiting for follow-up appointments to come through, the time lapses that occurred, and the cancellation of appointments were all concerns. The RNIB have commented that “long waiting times are forcing some patients to opt for private treatment” (28), but, more alarmingly, discovered in surveying eye health professionals that “*patients are going blind due to sizeable capacity problems in ophthalmology units across England*”. Certainly for Vera who has AMD, delays in her referral for emergency treatment, caused her considerable distress as she worried she was going to lose her remaining sight, and caused her to go privately. The sense of frustration at the system, but at the same time acceptance of the delays in her account, reflects that of other AMD sufferers across Shropshire reported by the Macular Society (personal correspondence). These patients are not only struggling to come to terms with the onset of sight loss, both emotionally, socially and physically (as Vera’s account demonstrates) but are also fighting a system which struggles to give appointments within the desired framework.

The issue of appointment times are beyond the scope of this research in terms of making recommendations, as changes to the system would need to be driven from the top-down within the health service. Positive outcomes are possible: such changes were demonstrated by the reduction of avoidable glaucoma by addressing waiting times, which was trialled in three eye hospital trusts (29). However, the voice of the AMD population within Shropshire needs to be heard as patient numbers are ever increasing with the ageing population.

Specifically, within the physical environment, the participants raised three issues, which they felt could be addressed:

- the location and accessibility of the hospital based services, within Shropshire
- the poor waiting facilities at Royal Shrewsbury Hospital
- the inaccessible signage at Princess Royal Hospital, Telford.

Whilst not all the participants shared all the concerns, there is sufficient evidence to suggest that these would be topics to take forward for further discussion. Shropshire is the second largest county but one of the least populated, so patients have to travel to access care, which is both time consuming and can be costly.

Concerns around seating while waiting for appointments are specific to RSH within this first stage of research, but it would be interesting to discover whether this is applicable to the Princess Royal, and how patients feel their experience could be improved.

For one participant, the signage at Princess Royal was inappropriate, although this was not the case at RSH because Clinic 10 is near the hospital entrance. In particular, the signage at PRH does not seem to meet with the NICE guidelines mentioned above in terms of taking into account sight loss which helps in making services accessible.

4.3 (iii) Theme 3 – Support

The semi-structured interviews threw light on the importance of support to these individuals, both official support such as the care received at the hospital, and unofficial support such as peer support from fellow sufferers of sight loss at organised support groups and finally family support, whether in an informal or paid capacity. What was absent from the accounts was any meaningful discussion of rehabilitation services or support from other sources within the hospital, such as the Low Vision Clinic.

The importance of support networks for general wellbeing are documented, not just for those with disabilities, but also for people who are undergoing life changes, for example the bereaved (30). For the visually impaired there is a journey which leads from independence to dependency on others for daily tasks, which has practical, social and emotional implications. There is discussion in the research literature about rehabilitation and support from social services (26) (30) to help in this transition, but in Shropshire at the current time, the participants believe that there is little offered to patients. This is not a parochial problem but also borne out in research into AMD (13). Support comes from the various societies (for example, Macular Society, Sight Loss Shropshire, the SLOG groups and Guide

Dogs for the Blind) for both information and social support. However, finding out about such support groups is a hit and miss affair.

Research into AMD states:

> *“these third sector support services are well placed to play a key role in the provision of information and support in order to relieve the pressure on ophthalmologists. At present patients need to be proactive in seeking this support and a more structured care pathway should be developed to ensure patients access third sector support following consultation”. (17)*

It was also acknowledged, by one participant, that with the time restrictions placed on consultants, who are dealing with medical issues, they are not necessarily the right person to give out advice on where to access support. This finding is also supported in the literature considering how the Royal College of Ophthalmologists guidelines for a consultation met with the patients’ reality (17) (32).

Theoretical models, such as Thurston et al (26) around the transition to blindness work through the stages from diagnosis to acceptance (see Figure 1), explain the issues around accepting sight loss, and suggest that by understanding processes, the patients can be better supported. For example, Roco resisted being identified as visually impaired as a child, because he did not want to be different from his peers (Stage 2). However, now his sight loss is such that he has accepted registration (Stages 3&4) and has had to accept the limitations his sight loss has had on his role as a father (Stage 5). His move through the model has, therefore, been a lifetime’s journey, whereas for Vera the diagnosis of her eye condition (Stage 1) came at the point of impact, when she was forced to change her lifestyle (Stage 3). Her resistance to changing her lifestyle (she continues to walk everywhere) is defined by Stage 2, although she has accepted a white stick (Stage 4). Imogen, on the other hand, has only some visual impairment and so might be defined as being in Stage 2.

The importance of the model is that by recognising where patients may be within the framework, service providers may be able to support, whether that is information or emotional support at the point of diagnosis, or practical support in the form of rehabilitation when sight loss becomes severe. While one size may not fit all, using a framework such as this model is at least a springboard to support.

The problem around accessing information for services within Shropshire is not just restricted to sight loss. Outcome 5 of the Health & Wellbeing Strategy (8) states its second priority as

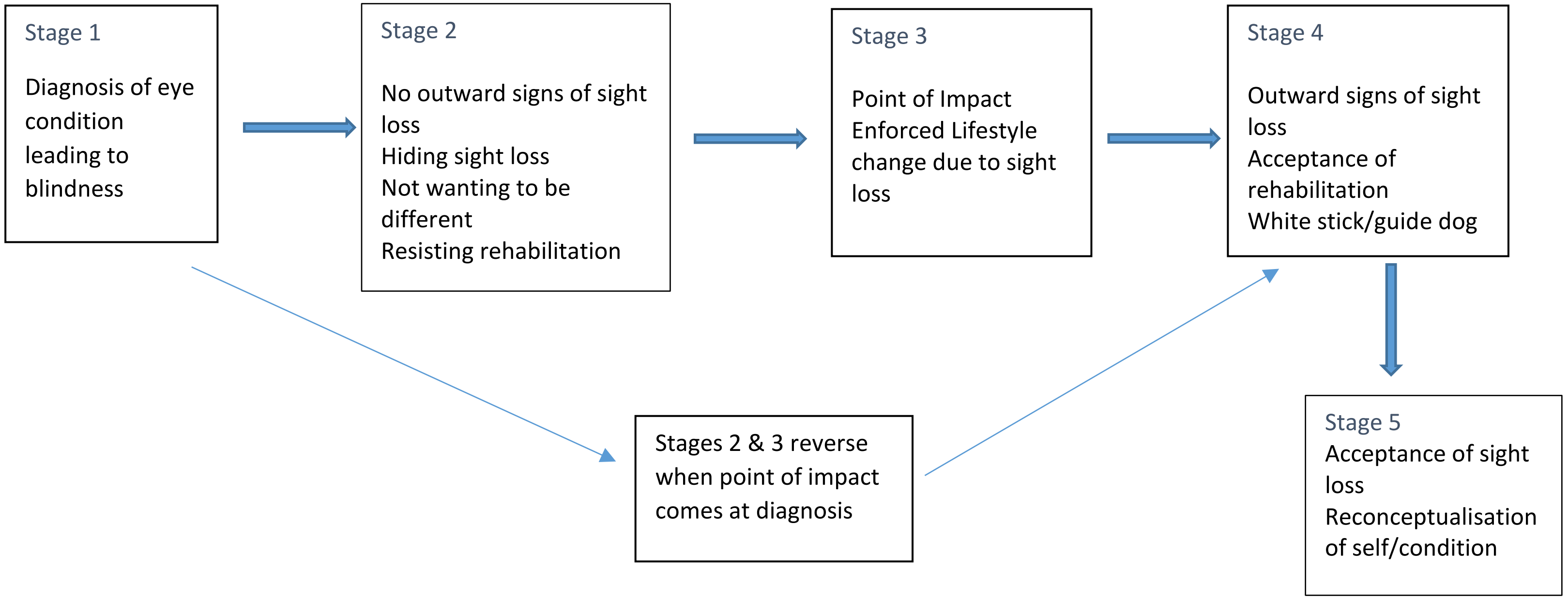
> “*Make it easier for the public and professional to access information, advice and support*”,

and continues that this is important because “*service users and carers often find it hard to access the advice and support they need*”, and acknowledging the “*onus*” is on the service user to “*understand and navigate the system*”. Furthermore it acknowledges that “*clinicians and other professionals sometimes do not know what support for service users is available and where to go for it”*.

In this respect, the support groups themselves have a role to play in identifying how they can reach patients and work with the healthcare professionals to give the right advice at the right time.

Finally, this theme reveals the reliance of the visually impaired on family members, who as carers will have their own needs. There is extensive literature on the experiences of carers and the effects caring has on them (both negative and positive) (34), but to date little research has been carried out on the particular difficulties the carers of the visually impaired face (23). Carers’ needs should be considered in supporting this group, as they are often the interpreter for the visually impaired person as well as the carer, and should therefore be able to be well-informed and confident in that role. There has been a call for further research into family members’ views on healthcare services, as a tool to assist shaping services, as well as considering their own emotional wellbeing (19), and that would seem appropriate for the carers of this service user group, who have to navigate the system both in terms of communication and physical environment.

Figure 1: Theoretical model of the transition to blindness (Thurlston et al, 2010)



5. STAGE 2

5.1 INTRODUCTION

Following on from the qualitative, individual approach of the first stage of the research, it was decided to explore some themes further through a focus group, with the aim of exploring opinions and identifying potential solutions.

A focus group approach was adopted because it was felt the topics leant themselves to discussion, as opposed to a questionnaire which would have been more directed and therefore less flexible, not allowing for any new concerns to arise or be discussed. Additionally, it was decided that paper-based questionnaires would be problematic for many of the potential respondents, who might not be able to see to read, and there were time constraints which prohibited the researcher exploring alternative formats, such as e-mail or telephone calls. Consequently, the limited number of people who could answer a paper-based questionnaire would not necessarily be representative of the general experiences of those with sight loss, and a lack of numbers would not give meaningful statistical power to any quantitative data retrieved. On these grounds, it was decided to proceed with a qualitative methodology.

The topics identified for further research stem from the themes of Stage One. In particular:

1. Sight loss as a hidden disability – the impact on the individual
2. Appointment letters/information. The format currently used and the participants' preferred format
3. The physical environment – with particular reference to RSH Clinic 10 and signage at PRH, Telford.
4. Receiving support – and information and communication between the individual, the hospital and support groups.

The aim of this stage of the research was to listen to the participants' experiences and suggestions, in order to make some small scale, practical recommendations that would improve the patient experience, and which could be feasibly implemented.

5.2 METHOD

5.2 (i) Design

An exploratory design, using the qualitative method of Thematic Analysis, as discussed by Braun and Clarke, 2006 (32) was used to explore the participants' experiences and opinions of, and suggestions for, NHS eye care services within Shropshire.

"Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data" (32) and is a flexible qualitative method of analysis, which has been widely used within health psychology in different formats. It is important, therefore, for clarity, to outline the approach adopted within this research. For the purposes of this report an 'essentialist' approach was adopted which "reports experiences, meaning and the reality of participants", as opposed to a 'constructionist' approach which explores those reports as a result of discourses within society.

The research set out to answer specific questions which had arisen in Stage 1, and is considered to be 'theoretical', as it is explicitly driven by the researcher looking for answers, as opposed to an 'inductive' approach where the themes are not fitted into a pre-existing coding frame. On a more refined level, the researcher adopted a 'semantic' approach, where the themes identified are "within the explicit or surface meaning of the data" as opposed to a 'latent' level which explores assumptions and conceptualisations (32).

Braun & Clarke (2006) describe a theme as capturing "something important about the data in relation to the research question, and represents some level of *patterned* response or meaning within the data set". The researcher is actively involved in identifying these themes, and throughout the process keeps notes, and reflects upon the data. In writing up the results, there is a move from description to interpretation of the findings.

5.2 (ii) Participants

The focus group of seven participants (who differed from those interviewed in Stage 1) was moderated by two people, since it was felt that this group might need extra support in signing forms, accessing drinks, or comfort breaks for themselves or guide dogs.

They were recruited through Sight Loss Shropshire, Shrewsbury Macular group and West Telford VIP group, who disseminated the recruitment form and asked people if they would like to participate. Seven people came forward, six with sight loss and a further participant (female) was included on the day who was a carer, but also actively involved in supporting people with sight loss. Four women and two men with differing conditions participated (see Table 2). Mostly they had long-term conditions, none had been diagnosed within the previous 24 months.

Table 2 showing the participant profile of the Focus Group

Name	**Gender**	**Registered blind**	**Age**	**Level of sight/ condition**
P1	Male	Yes	67	Severely visually impaired – No light sensitivity Glaucoma and complications of surgery
P2	Female	No	76	Partially visually impaired – wet AMD in both eyes, still able to drive
P3	Male	Yes	72	Severely visually impaired – Detached retinas in youth led to partial sight loss; more recently, AMD
P4	Female,	No	68	Partially visually impaired – diabetic retinopathy and diabetic oedema
P5	Female,	Yes	64	Severely visually impaired – Coreo retinal and macular degeneration
P6	Female,	Yes	n/a	Severely visually impaired – Diabetes retinopathy, macular oedema, macular degeneration
P7	Female	No - carer	69	No visual impairment

(1) It was considered appropriate to include P7 as she is instrumental in supporting other people with sight loss in an official capacity. Her contribution to the focus group related mainly around the topic of support.

5.2.(iii) Procedure

a) Data Collection

Participants were invited to introduce themselves, giving basic information about their eye condition. They were informed of the findings of the project so far, and reminded of the aims of the research. They were then read the consent form, and given assistance, where necessary, with signing the forms. Opportunity was given to ask questions before the focus group began. The discussion was recorded on two digital audio recorders and an iPhone app, to ensure all voices were picked up.

The focus group was based loosely around four topics (outlined above, see Appendix 2) and questions were asked by both moderators. Participants were asked to discuss difficulties within NHS environments with regard to their sight loss not being recognised; problems with the physical environment; communication with the hospital; and asked to make suggestions about improving the dissemination of information around support. Both positive and negative comments were encouraged. The focus group took an hour and a half. At the end, participants were asked if they had any further questions and were reminded of their rights.

The focus group was transcribed verbatim.

b) Analysis

The recording was repeatedly listened to before and during the transcription process and the transcript was read and re-read for accuracy. In this way the researcher immersed herself in the data, and began to think about the content. Initial ideas were listed (codes) and sections of the transcript were highlighted and annotated.

From these codes, themes were identified, and then reviewed and refined. Note making is an important part of the process, where the researcher outlines ideas of themes, paying attention to the prevalence of certain codes. The themes were named and defined, and further defined within the writing up process.

Particular notice was given to the assumptions made both by the moderators (and researcher in particular) and the implications of the comments of the participants within the analysis. In particular, as a sighted person it was important for the researcher not to make assumptions about the participants’ varying levels of ability, and their emotional reactions to their disability.

c) Ethical issues

As with Stage 1, the researcher is a member of the British Psychological Society, and as such is bound by their code of ethics. Participants were informed of what participation would entail, of their right to withdraw during and after the focus group, and were given the opportunity to ask questions. Additionally, a timescale was agreed for withdrawing data, anonymity was assured and discussed with relation to pseudonyms and withholding identifying data. Participants were asked not to discuss the focus group and personal information arising from that outside the focus group. Whilst written consent was obtained, because of the difficulties this participant group have in reading, all forms were read to them. Time was allocated to the participants' questions both before and during the debriefing process. The researcher also gave careful consideration to sensitivity and vulnerability during the focus group process.

5.3 RESULTS

From the outset of the research, there was an assumption on the part of the research team that sight loss is a disability. However, it was apparent in the focus group that some people resist the label of being "disabled" and this in turn may affect how they access support for their condition:

> *P3: cos I've just realised that probably erm although I am aware that I have a disability I don't actually think of myself on the whole as being disabled*
> *M2: yeah*
> *P4: no*
> *M2: that's interesting*
> *P1: I know what you mean by that*
> *P3: I think rather of people with severe physical disabilities needing these facilities*
> *ALL: yes yes*
> *P1: I'm with you I think of it as an impairment not a disability*
> (l.353-362)

As demonstrated in the findings of Stage 1, visually impaired people need considerable support in coming to terms with both the practical and emotional effects of sight loss, and may be resistant to the idea of disability. P3's comments that he is still adapting reflects the complexity of that adjustment:

> *P3: I went through quite a lot 1965 '66 '67 when I lost sight in one eye and I did a lot of adjusting myself you know but it took me to think it through and I'm aware that I'm still actually in that process myself …the psychological adjustment process…and I'm capable of sorting things out I think.*
> (P3. l.868-875)

Two broad themes were identified in Stage 2 of the research which best summarise the areas in which visually impaired people feel they are disadvantaged, and these themes are embedded in the patients' own understanding of what their disability means to them. *Communication* covers the themes of face-to-face communication, information dissemination and signposting, and self-advocacy. The theme of *Environment* is a more practically based theme and considers access, in particular signage and communication, within the environment, and the impact of environment. However, how an individual reacts to either communication with others or their environment may be dictated by their individual stance towards their sight loss.

As the discussions were semi-structured, and the participants had a variety of conditions and experiences, a variety of suggestions for change and comparisons were made.

5.3 (i) Theme 1 – *Communication*

One participant commented "*information is king*" (P7, l.373) in terms of what access that information gave the individual to services, but information is only part of the communication process which enables those with sight loss to manage their lives.

a) Face-to-face communication

Communication is a "two way" process; the visually impaired may take control by indicating their limitations, as well as expecting some recognition of their difficulties by the people they come into contact with.

One participant, who was less visually impaired, found managing at the hospital relatively easy because she was "*well known in the eye clinic*" (P4, l.54), and so did not need to explain her limitations, but found that out in the community, where people might not recognise her sight loss, everyday tasks were harder to manage. It is also possible that as she still had a good level of eyesight she was able to recognise the staff who were dealing with her, which facilitated good communication.

The lack of recognition of sight loss was also echoed by P3,

> *P3: … I still don't obviously show up in certain circumstances that I am quite severely visually impaired*
> *M2: yeah*
> *P3: and I'm aware that possibly people are a little bit confused both in hospitals and in other situations I've had one of these symbol canes for years but rarely use it until the last two years I do find it using that prominently is very useful I also find that I go to a reception desk and likewise in a shop I need to put it on my shoulder because people don't often always notice it*
> (P3, l.100-107)

Sometimes indicating to others the level of sight loss may not always be straightforward:

> *P1: I had a problem shall we say with stairs on one occasion my wife turned round and said "there are stairs ahead" now because of the light conditions and the way the shadows fell I could see them says "it's alright I can see them" so next time we're going along there my wife didn't bother to tell me about the stairs now the light conditions had changed*
> *P3: I know what you mean*
> *P1: and I couldn't see the darn things so I learnt very quickly keep your mouth shut say thank you*
> (P1, l.140-146)

The visual aids of sight loss, i.e. cane, dark glasses and guide dog, therefore, all help the visually impaired to indicate their disability, as well as having other practical benefits. However, even then the visually impaired might not be treated appropriately:

> *P5: I went to Shrewsbury two weeks ago and erm the hospital transport took me to the initial reception and then they called a volunteer to push me in a wheelchair actually to the …I know I'm perfectly capable to walking but…like P1 said I just accepted the wheelchair as an easy…option erm and it just got over the problem then*
> (P5. l.317-325)

P5's acceptance of being treated as a person with a physical disability which required a wheelchair, reflects the acceptance amongst this service-user group that staff do not always know how to respond to their sight loss. P1 was aware of a programme being introduced at Princess Royal Hospital to address this issue:

> *P1: there is a programme at the moment being run at the hospital under the My Guide programme run by Guide Dogs and this is part of My Guide programme is er sight awareness whereby they're training staff to be aware of those with sight loss and how to guide a person properly how to er address them properly so they don't cause offence in terms of how they would wish to be guided and so on and so forth and that programme is running at the moment*
> (P1, l.253-259)

It was explained by P6 that this programme was being introduced with volunteer staff, who might meet patients off transport, and there were plans to roll the training out to hospital staff later this year. P1's explanation that staff would be trained "*how to address them properly so they don't cause offence*" is a critical point, in that the expectation should be patients are treated with respect. In this way, addressing problems around fundamental communication skills meets Outcome 1 of the Health and Wellbeing strategy, which aims "specifically to work with partners to address the root causes of inequalities".

As a caveat, however, it was suggested that recognition of sight loss was not always a welcome approach:

> *P3: I'd make one comment there though as a person who was a long standing partially sighted person it could be very (.) annoying actually if I was thought of as really in need of assistance do you understand what I mean*
> *M1: yup*
> *P3: from the psychological point of view it's sensitivity I feel that I now have to indicate sometimes in a polite and definite way that I can't see certain things*
> (P3, l.129-135)

P3 suggests that it is important that he remains in control of the interaction.

b) Information dissemination

i. Appointments

The participants were asked about how they received information about their appointments, and what their preferred method of communication would be, as this topic was a concern amongst those interviewed in Stage 1. There was a brief discussion about formats, for example *"I've had text reminders of appointments"* (P4, l.650*),* and P3 asks his wife to read the letters for him.

There was an understanding, expressed by one participant, that the communication about appointments was subject to review at the hospital at the time of the focus group:

> *P1: the hospital is presently going through the list of all the people who are listed visually impaired or blind erm and the end result will be and this was started two months ago the end result will be people will be given the option of having letters sent out in font size 18 Ariel they will have the option of having third party recipient so if it's a person living alone a brother or a sister or uncle or aunt or daughter or son can have the letter sent to them because they won't be able to read them er the next is telephone reminders erm text is also in place*
> *M1: yes*
> *P1: and e mail is in place*
> *M1: and this at Telford or Shrewsbury*
> *P1: no this is central to all appointments*
> (P1. L.626-633)

This statement acknowledges the efforts of the NHS to address some of the issues faced by the visually impaired in terms of discrimination, and offers practical, patient-centred solutions. However, the real issue for this group was not primarily the format but what the communication indicated in terms of access to and waiting times for appointments.

P5 felt very strongly that she should have regular check-ups but did not get them so the question of format was almost irrelevant to her; however, she did have access to the clinic by phone, but at her instigation.

> *P5: I don't ever get a routine erm appointment to see a consultant I only go to see a consultant when I've got a major problem so*
> *M1: right*
> *P5: I never get to a point of having letters cos it's always done by the phone*
> *M1: right*
> *P5: and erm*
> *M1: and you have to ring them do you to have to chase that up or do*
> *P5: yes I just have to keep ringing*
> (P.5. l.653-662)

Access to clinic appointments could be achieved by persistent phoning and requesting, as P4 described:

> *P4: I mean when you've got to ring up four or five times to request an appointment and the last visit I've had they'd the consultant requested two appointments for me and I only got one and he said "you should have had two"*
> (P4, l.667-670)

The apparent difficulty experienced by these participants gave rise to concern for others:

> *P4: the people in their shall we say 80s and 90s they are of the generation where you didn't ask*
> *M2: mmh*
> *P4: you just accepted the help you were given but to suddenly to say now "if you want an appointment you have to ring up"*
> *P7: you've got to be active about*
> *P4: yes and that's who I like I share P1's view that's who the people I do feel sorry for*
> *M1: the vulnerable?*
> *P1: oh yes*
> *P4: the very vulnerable people that haven't got anybody to speak up for them*
> (P4. l.779-790)

There is a perceived need to be proactive, and a sympathy for those more vulnerable people who may not be able to request attention. This point emphasises that these participants were confident people, who were happy to express their opinions, and may not be representative of the less confident patient group who accept their care without questioning, but who nevertheless have a right to expect care to be delivered in an appropriate and timely manner.

These comments regarding phoning to request appointments echo those made in Stage 1, where Vera, for example, laughed at the suggestion the hospital might ring her with an appointment, and explained it was always her that had to ring to request to be seen. So although the patients feel the communication should be coming from the hospital to the patient with appointment information, it seems that the patients are approaching the hospital for this information, because it is not forthcoming in the timescales they expect. This is of particular concern for those with age-related macular degeneration:

> *P2: I get regular follow up letters erm there was always an issue where I needed erm an injection*
> *M1: mmh*
> *P2: because each consultant I saw said I needed it in two weeks mmh it's one of the things with wet macular*
> *P3: yes*
> *P2: er and when I phoned up the erm Lucentis co-ordinator she would say "there is <u>no</u> chance you'll get an appointment in two weeks you'll be lucky to get one in four to six weeks"*

> *so I wrote to Mr X about this query about having injection within the two weeks and he said "that's mainly to do with erm initiation when you you have your very first injection when you're diagnosed" and he said "there's no clinic in the country would see you to have an injection in two weeks"*
> *M1: right*
> *P2: so I quoted NICE they recommend that that you should have*
> *M1: yes*
> *P2: but obviously NICE haven't budgeted for that delay*
> (P2, l.729-745)

P2's frustration at the delay of appointments reflects genuine concern amongst this patient group, also expressed by Vera in Stage 1, that the timing for the Lucentis injections is critical and that they (as patients at Royal Shrewsbury Hospital) are not always receiving them in the timescale as directed by NICE guidelines. P2's referral to the NICE guidelines reflects her knowledge and sense of entitlement, and she goes on to compare her experience to someone she knows who was treated more quickly at Wolverhampton. She tries to reconcile NICE guidelines with observed practice, ironically blaming NICE, but there is no mention that she took the complaint further. There was no mention of official complaints being lodged in either participant group despite considerable dissatisfaction with the timeframe aspect of their care.

ii. Patient - GP- Consultant hierarchy

Apart from medical support, patients also require access to consultants for registration, which in turn enables them to access social support. However, this process was not always straightforward for these participants. P3 had recently moved to Shropshire from another part of the country, and found that his GP was not aware of the processes involved.

> *P3: … I pointed out to him that I needed to be referred to a consultant ophthalmologist to be sorted out registered in this county yes? not a registrar*
> *P1: that's right*
> *P3: I don't think he was aware of that*
> *M1: oh that's interesting*
> *P3: I'm not saying he definitely wasn't aware but I don't think he was aware of the registration requirements*
> (P3, l.266-1273)

P5 had also recently moved to Shropshire and had a similar experience, and had been helped by P1 to sort out her registration. P1 also described how he had accompanied other patients to their appointments to request they were seen by a consultant (as opposed to a registrar) for this purpose. P1 also went on to say: *"some of the GPs are not aware of the specialities of the various consultants"* (l.1298-1299*)*, which echoes Roco's experience, mentioned in Stage 1, that he went to his GP, who was a locum to request a referral to a particular consultant for his corneal transplant, and had to tell the GP what to write in the letter. It would seem, therefore, that as a vital link in the chain of accessing medical support, GPs should be well informed of whom to contact, and for what purpose, within the eye care services at the hospital.

iii. Self-referral and access to received support

Stage 1 emphasised the importance of received support for the visually impaired. Increasingly, there is a reliance on support groups, as information and help from social services has been reduced, as P1 stated "*Sensory Loss teams.. quite frankly are decimated*" (l.836). The move away from support from social services was highlighted when P3 recounted how he had accessed a twelve week rehabilitation course in the 1960s when he had become partially sighted, which was in stark contrast with the provision of long-cane training available to patients within the Telford and Wrekin area; patients, known to P6, were reportedly restricted to receiving just eight sessions. Another participant commented that it was a "*postcode lottery*" and that she was aware that rehabilitation services were available to people living over the border in Powys. It is clear then that services within Shropshire at the current time have suffered, and people are being disadvantaged as a result of cutbacks.

As the focus group was made up of people who both attended and, in some cases, ran support groups there was an emphasis on the importance of that type of support (as opposed to family support mentioned as a theme in Stage 1). For the participants accessing that support has been a matter of self-referral, and sometimes chance:

> *P3: I've become a member of the VIP group in Market Drayton (name removed)*
> *P7: that's right*
> *P1: yes*
> *M2: how did you find out about it P3?*
> *P3: by looking in the town guide (laughs)*
> *M1: so yes so*
> *P3: I just got a town guide erm and looked through organisations*
> (P3, l.940-946)

P3 was not directed towards a support group by either his GP, his local medical centre or anyone at the hospital. The local Macular Society group was praised by the participants as providing good support and information, and was also felt to be a group that participants were happy to refer others to. Participants in Stage 1 referred to support being available through Sight Loss Shropshire only on certain days of the week at the hospital, and in the focus group it was clearly expressed that there were not strong enough links between the support groups and hospital services.

> *P6: it would be helpful if the staff were probably erm told erm about all these societies*
> *M2: yes*
> *P6: and obviously communicated with people like ourselves*
> (P.6, l.971-974)

Those running support groups recounted how they had handed information to the hospitals, in particular P7 discussed a CD produced by a support group, but saw little evidence of their information being disseminated. This finding echoes Vera's complaints that she had handed in leaflets, but had not seen them being available. The question was then posed how could those people who were newly diagnosed, and needed information, be reached. The suggestion of an ECLO was raised:

> *P3: what is an ECLO?*
> *P1: ECLO is Eye Care (sic)Liaison Officer who works between the consultant and the person who's (sighs) after the patient has just had had the tap on the shoulder and said "sorry me old cock there's bugger all we can do for you now (.) I'm afraid you've lost your sight and we can't do anything about bringing it back"*
> *P3: right*
> *P1: instead of allowing them to go and sit outside and wonder where their future was the idea is is the ECLO Eye Care Liaison Officer steps in*
> *P3: right*
> *P1: and they start helping and signposting immediately rather than waiting for the local authority services to step in through the Sensory Loss Teams that quite frankly are now decimated*
> (P1. l.824-836)

It was acknowledged (by Judith in Stage 1) that a previously employed ECLO had not worked out for a number of reasons, including lack of support within the hospital environment, and there is concern that anyone employed in such a role would have to "*prove the effectiveness of them within the er ophthalmic department*" (P1. l.854) . Nonetheless, it was felt the benefit would support for people who might otherwise

> *P1: suffer and then suffer from depression*
> *P3: oh yes*
> *P1: and all the other things that stem from sight loss er similarly if they are working to direct them to such as Access to Work erm to direct them to local help groups*
> (P1, l.856-860)

Critical to information dissemination is having the right person there at the right time, or a variety of sources of information available. However, a discussion around the possibility of volunteers handing out information to people at clinics was dismissed by of one of the participants who had witnessed such as scheme in a different county, which had failed, because their services were not accessed by patients.

The efforts of two auxiliaries within the Eye Clinic were also acknowledged:

> *P1: two auxiliaries at the Telford hospital and er the Royal Shrewsbury have gone through first stage ECLO training now it you're going to be dependent upon those two auxiliaries being around*
> *P2: being on duty at the right time…*
> *M2: that's right well it's the same with an ECLO isn't it*
> *P1: yeah well they've taken that initiative but they took it themselves it wasn't by the direction of the hospital…it was just they saw a need and decided to try to fulfil that need God bless them*
> (P1, l.993-1003)

But again the problem of being dependent on particular people was raised.

P6 suggested a mentoring system, which was similar to the befriending system run by the Macular Society, and might point people towards support groups. The variety of suggestions indicate more than one first point of contact might be appropriate for further information. In whatever format then, it was acknowledged that there is a missing link between health services and support, which previously would have been met by social services, but needs to be addressed by either an ECLO, a mentoring system and/or better communication between the NHS ophthalmology services to ensure that people have access to information about support at the appropriate time.

5.4 (ii) Environment

a) Access

For those whose sight loss is less severe (for example P4), attending hospital appointments may be easily managed, since they can find their way round and may be well known by staff. However, those with more severe sight loss are often dependent on help from others, or their own memories.

> *P3: I'd learned a lot of coping techniques and I was also for twenty years you see erm aware of certain hospital facilities in Kent (.) and I'm aware of memorising you know…locations and corridors since I've come here I came a year ago I found that the Market Drayton medical centre easy to handle although I had to think my way in erm you know where to go for this and that I also had to erm overcome the fact that I can't read signs now at all really*
> (P3, l.54-61)

P3's comments elucidate his coping techniques: familiarity with the environment, which in turn leads to the development of a mental map ("*I had to think my way in*") and memorising where he needs to go. This echoes Dilys's description of how she has memorised the bus routes to get to the hospital for appointments. P5, on the other hand, relies on hospital transport because it facilitates her access to the hospital, even if she is put in a wheelchair, as previously discussed:

> *P5: can I just say I use hospital transport always for all my eye for all my hospital appointments for this reason because it gets over the I ask them to take me to the reception desk*
> *P1: yes*
> *P5: for any clinic I've got to go to and I just always use it as a matter of course*
> (P5, l.298-302)

P3 was not aware of hospital transport and commented that his wife takes him to appointments, which suggests that the wider environment isn't always easy to access without support. So the issue of accessing the hospital environment is one that requires consideration by this user group, whether it is in transport, accompanied or even unaccompanied as is the case with a number of "*elderly ladies"* mentioned by P1.

Although the signage at the Princess Royal Telford was brought up by Roco in Stage 1 (the signs were inaccessible because they hung overhead), there was agreement within the focus group that it was difficult to provide signage that would suit everyone:

> *P3: I'm aware that there are so many sight conditions and I'm aware of the variation like you've mentioned that lighting levels I'm acutely aware now myself of changes in lighting change my ability to see things fantastically*
> *P7: and then you've got the colouring haven't you*
> *P4: oh yes*
> *P7: blue on white and all the rest of it black on yellow*
> *P1: cos some people want black on yellow*
> *P3: yeah I know*
> *P1: yellow on black you're never going to get it right*
> *P4: or black on white*
> *M1: right okay so it's quit] a complex problem?*
> *P3: very complex I'm aware*
> *P7: many people in actual fact go blind in later on in life very few of them I noticed you've got you've got disabled blind erm erm braille signs on things*
> *M2: mmh we have here*
> *P7: but unless I don't actually know what percentage of people are that actually read braille*
> *M2: mmh*
> *P7: but I don't think*
> *P1: I think it's more blind from birth than*
> (l. 450-470)

The provision of signs in braille was questioned by one participant because of the relatively small percentage of users of braille, and not relevant to this particular group of people.[3]

However, other suggestions were made, based on comparisons with other hospitals:

> *P6: I was it was a suggestion one would be to colour co-ordinate the erm clinics like putting colours on the walls*
> *P3: oh yes*
> *P6: cos they tend to do that in Manchester*
> *M2: mmh*
> *P6: and also having some sort audio er*
> *P3: guide yes*
> *P6: communication button or whatever as you're going along*
> *M2: mmh yes*
> *P6: you could go to which tells you where to go*
> (P6, l.496-504)

Websites and maps sent out with appointment letters were also suggested. With all aids there was a tendency for participants to refer to examples that might not work, such as the braille or internet-based solutions, because of the age or abilities of some of the service user group. This negativity itself is somewhat surprising, as it might be expected with a group who encounter barriers in their daily lives they would consider all options, and it is prejudicial to decide old people cannot access the internet, as was demonstrated by both Vera (88) and Dilys (75).

The question of long cane training was raised as a vital method of accessing the environment. The limitation of the training for this aid is, therefore, both a cause for real concern:

> *P6: I mean we've we know of people who have been offered eight sessions of mobility training and asked for more and been refused*
> *P3: really?*
> *P6: and yet when I did my white cane training I I had enough until I was you know*
> *M2:confident*
> *P6: confident*
> (P6, l.1179-l.1185)

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[3] According to RNIB research (2011), Braille is only used by 1% of the blind and partially sighted population, who have mainly been blind from childhood.

b) *The impact of the environment*

In Stage 1, the hospital environment itself came under scrutiny, and was found to have an emotional as well as physical impact on the participants. This finding was borne out by the focus group participants as well:

> *P3:	going into the toilets finding which is the hot and which is the cold tap there's no there isn't standardisation*
> *P6:	mmh*
> *P3:	whereas I used I am <u>aware</u> now that I used to be able to use a lot of peripheral and just glance down*
> *P6:	mmh*
> *P3:	and see if it's red or blue or hot I can't do it now and I fiddle around with that and also sometimes is it to be pressed? or is it to be turned?*
> *P6:	mmh*
> *P3:	so they do it varies immensely*
> *M1:	so*
> *P1:	why don't you use the disabled toilet*
> *M1:	erm*
> *P1:	they've got that lever that starts off with cold and goes to the hot*
> *P3:	yeah right (hesitantly) I might do (laughs)*

P3's comments demonstrate that he has to confront his own disability in the hospital environment (and presumably elsewhere) in that he finds the toilets and washing facilities difficult to use. P1's assumption that he should use the disabled toilet reflects their differing approaches to sight loss, so although P1 refers to it as an "impairment" rather than a disability, he still feels entitled to use disabled facilities, whereas P3 does not see himself as disabled, and therefore does not feel entitled. This exchange demonstrates that whatever facilities are provided there will always be some discrepancy in attitude towards using them, depending on the level of acceptance of the service user. However, the importance of choice, as with the Braille signs and website information, should not be discounted.

For those depending on memory and mental maps, change can be confusing; in the case of buildings and physical layout: P3 describes his confusion at PRH

> *P3:	because I was a little bit confused about the layout from my own visual perspective…I think we were in a part of the building that was temporary or under redevelopment being redeveloped*
> P3, l.73-78

or in the case of changing light conditions, as described by P1, and quoted earlier, when he tripped on the stairs.

It is important to recognise and acknowledge the issues that the visually impaired face (even if they not always easily remedied) in order to understand the underlying anxiety that the environment can cause. The waiting corridor on Clinic 10 is a case of particular concern.

> *P4: I feel that they've just moved the hospital from the erm Town Wall's hospital and they've just plonked it*
> *M1: yeah*
> *P4: in that tiny area and you sit in there you are waiting and it's a waiting area if you're going to the other clinics also if you go into the emergency referral clinic and erm it's just lack of space*
> *M1: yeah*
> *P1: it's dignity isn't it at the end of the day*
> *P4: yes*
> *P1: and the hospital … says it is about patient dignity*
> (P4, l.561-670)

There is a feeling of disregard on behalf of the hospital for their feelings, but also concern around hygiene:

> *M1: when the staff are walking up and down that corridor that they are sort of aware of the sight limitations of the people who are sitting the corridor do you do they give you enough respect really*
> *P4: no no no*
> *P2: no no they're not aware I don't think they are aware they are just going about their business cos on the days that they give injections you wonder if it's all hygienic enough as it should be*
> *M2: mmh*
> *P2: cos they walk on that corridor in their*
> *P3: yes*
> *P2: outfits that they give injections in*
> (l. 193-203)

Additionally there is no food or drink allowed, presumably because of "*spillage*" (P2, l.539) which raises the question of whether patients are being penalised and discriminated against because of their sight loss (given that visually impaired people may spill drinks). The participants' comments reflect an alleged double standard with patients not allowed drinks on hygiene grounds but staff walking around a non-sterile environment in clothes that they give injections in. However, the key issue which underlies these feelings of being disregarded and concerns is of the suitability to a purpose. The corridor in Clinic 10 is seen as an access corridor, whereas P4 pointed out that there was waiting in the corridor in Princess Royal Hospital but that was less problematic:

> *P4: I think it's an access corridor to the other rooms rather than a waiting corridor*
> *M2: yes*

> *P4: because I've*
> *P3: yes yes*
> *P4: been to the eye clinic at the Princess Royal Hospital a couple of times and you wait in the corridor there but the corridor is much wider*
> *P2: wider this is only six foot wide wide roughly*
> (l.214-221)

Again, the comparison with the former Ears, Eyes and Throat Hospital on the Town Walls was drawn (as in Stage 1 by Judith).

> *P4: I would say that they need to move the waiting area somewhere different because when the hospital was on Town Walls I never actually went there as a patient but I used to take a friend for appointments and you had a large area waiting area with all the rooms off it but I mean to sit as erm P2 said to sit in that little corridor*
> *M1: yeah*
> *P4: I mean I was sat there for an hour and a half with eye drops in my eye well about four lots of eye drops I couldn't see properly and all the time you're so you can't sit and relax you're worried that somebody's going to come along with the trolley with the patients' notes on it it is just ridiculous*
> (P4, l.243-252)

The concerns reflect a feeling of vulnerability; repeatedly participants express concerns about wheelchairs and trolleys and having to raise their feet up to avoid being knocked, which might be stressful for a sighted person, but as visually impaired people they are unable to assess the risk. The issue is not just about patient comfort but emotional and psychological wellbeing.

P6, on the other hand, had a positive experience of being allowed to wait in the main waiting area and being called in for her appointment

> *P6: when I last went to Shrewsbury for my appointment you actually went and sat erm as you went through the main door on the left hand side which is the main reception*
> *P2: mmh*
> *P6: area? And you could and then you were erm then the nurse would come to you? to say that that consultant was ready to see you*
> *P3: yes*
> *P6: and there was no reason why you couldn't go back to that place and therefore you could have a drink or what have you*
> *M1: yes*
> *P6: which is what I used to do instead of sitting in the corridor*
> (P6, l.543-551)

This experience, which differs from the rest, suggests a different approach to communication. It was previously expressed, in Stage 1,that it would be a nuisance for the consultants to have to walk out to the waiting area to call their patients, but, if the corridor could not be addressed in terms of environment, letting people wait in the main reception area could be addressed by improved communication.

This area of the hospital was compared unfavourably to other areas; a consultant reportedly said to one participant, his room was like "*a broom cupboard*" compared with the Hummingbird Centre. Participants did, however, acknowledge that the Hummingbird was supported by fundraising, and the comparison was therefore somewhat unfair. However, it was felt that at Wrekin Community Clinic in Telford (referred to as "*Euston House*") the environment is much better suited to its purpose:

> *P4: yeah I went there for an eye injection and it's completely different*
> *M2: mmh*
> *P4: because if you're going for eye treatment you sit in a separate area than the people who are just in the walk-in clinic and it's brilliant*
> *P1: yes and or and the er cataract surgery*
> (l.612-616)

It is obvious then that the hospital environment at Clinic 10, RSH, is unfavourably compared to other wards within the hospital and to the old hospitals in Shrewsbury, and also against Telford and further afield.

6. DISCUSSION

The overall research aim of the project was to explore the extent to which people feel disadvantaged and disabled by their experiences, with relation to NHS eye care services in Shropshire. Stage 1 of the research set the scene and explored personal experiences within that context; Stage 2 aimed to take the findings of the Interpretative Phenomenological Analysis and explore them further, with a view to providing further detail of, and suggestions, for problem areas.

The two themes identified are broad and cover a range of concerns, some of which are quite specific (e.g. the corridor in Clinic 10), whilst others reflect more general concerns about how to access services if information about those services is lacking.

6.1 The Environment

For services users at RSH the corridor at Clinic 10 was of particular concern. It raised the question of the suitability of purpose and also the emotional impact the environment has on the patients. Being visually impaired in a restricted space frequented by both staff and other patients made the participants feel physically vulnerable and disadvantaged, particularly in the respect of hygiene concerns. The lack of space did not comfortably accommodate carers or guide dogs, and access to refreshment was restricted, which is particularly relevant when people have travelled long distances and have long waits for their appointments. The environment at PRH and Wrekin Community Clinic (35) were considered more favourably, because there was more space which alleviated the feelings of physical vulnerability. Particularly, at Wrekin Community Clinic, the walk-in patients are separated from the patients who are there for injections or cataract operations, which made participants feel as though their condition mattered.[4] The reference to Clinic 10 being a "*cattlemarket*" reflects not just the numbers of patients, but that those patients feel devalued and that care is impersonal.

The RNIB have produced a Low Vision Services Assessment framework (35), which is tool for service providers to refer to when reviewing their services. Section 1, 'Building and infrastructure' deems it essential that "the building has been designed or adapted for people with visual impairment" and it is apparent in this respect Royal Shrewsbury Hospital is failing its patients.

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[4] Wrekin Community Clinic is a joint initiative between Wrekin Commissioning Group and SATH Ophthalmology department. It opened in 2011 and looks to provide an alternative to hospital based treatment, especially for cataracts.

In relation to the signage at Princess Royal, it was considered difficult to find ‘a one solution fits all’, as the variety of eye conditions and levels of sight were acknowledged. In this respect the RNIB Assessment tool also considers it essential that the “service location is well signposted from entrance to site”. Given the problems that signs present to the visually impaired, alternatives such as guides, trained volunteers or audio guides, colour coding, were suggested.

More broadly, travelling to any hospital presented a variety of challenges for the visually impaired, in terms of transport, whether that was by train (Hereford), bus, hospital transport, car or even on foot. This is particularly true in rural communities within Shropshire, where buses are infrequent and taxis may be prohibitively expensive. (The participants came from as far as Whitchurch in the north, Ludlow in the south, Telford in the east and Oswestry in the West.) The everyday problems of getting around affected how people travelled to the hospital, although there was evidence that even those with the most sight loss retained some independence, because hospital visits were part of their routine. For those on the wrong side of the county, there was concern about accessing PRH, in terms of the number of buses needed to get there, and the time that would take. For this patient group, any changes to the location of their care caused considerable anxiety, because of the additional problems that they have in getting about. Other research confirms that people with sight loss living in rural areas are disadvantaged, and that it can impact on their ability to access not just hospital services but also information and social support (23).

Using hospital transport was closely identified with accepting sight loss as a disability, and was therefore a matter of individual choice. Even with this small participant group, there were a variety of attitudes from ignorance of the service, not considering themselves as entitled because they were physically fit enough, to using it occasionally to access an unfamiliar setting or people who used it regularly because it made life easier. Using the service is therefore dependent on firstly knowledge and an understanding of that service, and then a sense of entitlement, which is closely linked to their understanding of their sight loss.

Whilst these findings do not fall neatly into one of the desired outcomes of Shropshire’s Health and Wellbeing Strategy , they do fall under the cross cutting principles of “keeping people well” and “recognising the wider determinants of health”. Sight loss has a psychological impact, as previously discussed with depression being a common factor, and participants stressed that in particular at RSH the hospital environment increased anxiety. In response, hospital services should be looking at ways they can minimize the impact the hospital environment has on their patients.

6.2 Communication

Whilst examining the topic of appointment communication from the hospital, it emerged that the issue is much more complicated than just the format of letters, and reveals problems within the system.

It is understood that the issue of the format of appointment notification is being addressed now by the NHS central appointment system within Shropshire, and during the time this research was undertaken systems were undergoing change. The issue of third parties, such as family members, being able to be informed of appointments is particularly important for this service user group, who may struggle regardless of the alternatives offered, or for those with memory loss. It is important that the preferred format, and the existence of a third party, is noted on health records, so that there is consistency of approach. However, the preferred format should be reviewed as needs change. (23)

The discussion around preferred formats drew attention to the access to appointments, particularly in terms of waiting times. Whilst the issue of waiting times is beyond the scope of this report in terms of making recommendations, it is nonetheless a matter of huge concern to patients. Even within this small sample of the visually impaired population, there was concern amongst those with AMD that delays in their treatment would affect their sight; one patient quoted NICE guidelines, another resorted to private treatment. The issue of sight deterioration due to treatment delay is nationally recognised (28) (29), and within this participant group there was both resignation and, at times, scepticism at the way their appointments were delayed or deferred. There was also concern for people more vulnerable than themselves.

Additionally, some people feel entitled to more care, both in regular check-ups or receiving the right number of follow-up appointments. Again these complaints are borne out in the published literature (23). The Thomas Pocklington Trust goes further to highlight that secondary causes of visual impairment that were treatable were being missed, due to lack of follow up appointments or a misunderstanding on behalf of the patients, who were told nothing could be done, and so assumed further eye checks were not necessary. At times, the onus is placed on patients to self-refer, which the participants in this study felt was difficult. The Thomas Pocklington Trust report states

> *"for a majority, access to support on the basis that the service user must identify their need and contact an appropriate service provider for support appears inappropriate and creates a range of barriers to those most in need of support". (p.10)*

The participants also felt that there was a lack of joined up services, with poor communication between those services they accessed. For example GPs were seen as stepping stones to consultants, and as such were portals to care, but they were considered to be ill-informed at times. One participant stated GPs needed to know what the consultants specialised in, however, there is a good list on the Shrewsbury and Telford Hospital NHS Trust website. In particular it was felt that GPs lacked an understanding of the process for certification and registration, which is experienced beyond Shropshire (39), and is not just confined to GPs but also ophthalmologists. Although nationally the Royal College of General Practitioners (RCGP) chose eye health as one its four clinical priorities for 2013-2016, and therefore should be well-informed, the participants felt more support was needed at a local level. The role of GPs play within eye care was also a topic for debate within the NHS England's "A Call to Action" (41).

Secondly, the participants felt there was inadequate provision of information relating to support available post diagnosis. Although individuals were happy with the communication with their consultant when they saw him or her in person, and also with the support groups they accessed, the lack of joined-up services impacted on them and others they came into contact with. It was acknowledged that the consultant's time was precious, and that was spent explaining their condition rather than sign posting to further support.

There was little sense of multi-agency working: information about further sources of support was not readily available at the hospital, and there were long waits to access Sensory Impairment teams within social services, which were seen to be over-stretched and heavily cut back. On this latter point, Shropshire RCC approached both Telford and Shropshire Social Services to define the perceived loss of rehabilitation officers. Telford & Wrekin Prevention Team, Care and Support responded:

> *"Following a restructure in 2011, the Sensory Impairment workers were merged with the Occupational Therapy team to form a one Team approach, thus providing a holistic service in the area of Prevention. New ways of working have been implemented, mobile working to cut down on time spent office based. We retain a full time Rehabilitation Officer for Visual Impairment, who works exclusively within Telford and Wrekin and at present [April 2015] we*

> *are about to embark on a restructure, which will take into consideration the requirements of Visual impairment as outlined in the Care Act 2014."*

It is unclear whether this streamlining of services is being perceived as beneficial by service users; changes to the structure are seen as cut backs, with services, such as long cane training, allegedly being limited as well as long waiting lists for social support.

The RNIB Low Vision Services Assessment contains a section on Service Integration (36), an essential requirement being "*the low vision service is provided by a multidisciplinary team which works closely with other agencies, e.g. ophthalmology, social care, GPs, voluntary sector and emotional support*". Although changes in social care teams are a step towards this integration in working practice, the participants did not feel services between hospital and support services were integrated. These findings around communication are at odds with the Shropshire Health & Wellbeing Strategy's Outcome 5, which aims for "*health, social care and wellbeing services*" to be "*accessible, good quality and seamless*". In particular, the priority of "*making it easier for the public and professional to access information, advice and support*" is not being met.

The RNIB believe that the introduction of an Eye Clinic Liaison Officer, within each eye care unit can provide the vital link needed between patients and services. The role of an ECLO was developed by the RNIB with Action for Blind People and other voluntary and statutory bodies, and has been introduced into a number of hospitals across the country. The RNIB state

> *"Most importantly the ECLO roles is specifically designed to have time to spend with patients – enabling them to discuss in depth, their concerns about the impact their condition may have on their lives and those close to them".*

Eye Clinic Liaison Officers *"provide access to relevant support services at the point of need",* which essentially means that the care they provide is person centred, whether that is some emotional support at the point of diagnosis, or further information around support groups, or explaining the certification and registration process. In 2005 the RNIB stated that *"every hospital should have an eye clinic liaison officer and every social service department should be looking to joint fund one"* (37).

It is understood that part of the reason there has been limited development of ECLO services throughout the UK is due to limited research around their cost estimates and effectiveness (38). A study undertaken by Gillespie-Gallery, Subramanian & Conway in 2010 found that the "cost of an ECLO per patient per contact was £17.94 based on an average annual ECLO salary of "23,349.60 per year, reviewing on average 9.1 patients per day, in a 42 week year" (37). What is harder to quantify is the impact having someone to talk to at the relevant time has on the patients. The participants in this study recognised that consultants did not have the time to fulfil this role, and that patients needed information at other times than when they were in the hospital to attend appointments. Another study of AMD (18) stated

> ”*In order to improve practice healthcare professionals need to see patients as more than ‘diseased bodies’ and attempt to empathise and understand how being diagnosed with a long-term condition and dealing with the healthcare service feels from a patient’s perspective”* (Burton, p.7).

The importance of an ECLO’s role is that it is patient focussed and looks beyond the disability per se to offer support, and the impact of that support positively affects quality of life. Whilst it was acknowledged that a previous trial of employing an ECLO at RSH was unsuccessful, it was also highlighted that that ECLO was not well supported in their role, having no allocated space to work in. Gillespie-Gallery et al (37) also found that ECLOs were not always provided with facilities to carry out their role effectively. Not having a private space where the ECLO could talk to a potentially upset patient was identified as difficult, when client confidentiality might be compromised and made it difficult to provide emotional support. For an ECLO to provide appropriate support to those with sight loss, they must be appropriately supported themselves by their employers.

This study also understood that two members of the nursing team in the Ophthalmology Department have undergone ECLO training, which was applauded by the participants. However, RNIB research states that the practice of nurses undergoing ECLO training is

> *“admirable and will provide the information and knowledge to help patients facing sight loss, it will not provide the nurse with the time required to sit and listen to a patient presented with a life-changing eye condition”* (37).

Participants in the focus group suggested a number of ideas for sources of information and support, but the key point was that it was deemed “helpful” if hospital staff were informed of further sources of support. This is central to the role of the ECLO, but keeping all staff informed (which may be another part of the ECLO’s role) would be preferable. Other training such as sight loss awareness training is deemed essential by the RNIB (34), not just for those working in low-vision clinics but also for non-specialist staff, such as people on reception. Patients need to be made aware if sighted guides are available, and that they may request on arrival at the hospital and thus patients may avoid the indignity of being put in a wheelchair when they are capable of walking.

The RNIB also deem it essential that "*low vision practitioners have specific visual impairment accreditation, with communication skills training e.g. to work with clients who have problems hearing*". Although none of the participant group had substantial hearing loss, people who do have sight and hearing loss do attend Shropshire RCC's Sight Loss Opportunity Groups. The issue of the lack of Deafblind signing within Shropshire hospitals and the problems that caused was raised in the recruitment process of the project; it seems unacceptable that, in a society that appropriately meets the needs of people whose first language is not English by providing translators or written information in alternative languages, the needs of this vulnerable disabled population are ignored.

Throughout the accounts there is an acceptance of how things are, and there is little mention of complaints. It is possible that the esteem in which the consultants are held (demonstrated particularly in Stage 1) inhibits people from complaining, as the consultants are their main point of contact and they do not have issues with the individual treating them but with the system as a whole, (for example, P2's discussion of NICE guidelines). Alternatively, they may be concerned that complaining may affect their care (as demonstrated by Roco's description of how he approaches the administrative staff). Another explanation may be that not complaining is an avoidance coping strategy, when life is challenging enough dealing with the effects of sight loss.

However, patients do have a right to express their concerns and to need to be made aware of how to complain if they feel that is appropriate. This is particularly important when timescales for appointments, and therefore treatment, are not always met, and there is a strong possibility that eyesight might deteriorate as a result (28). The Patient Advice and Liaison Service (PALS) is available and information relating to it is accessible on the Shrewsbury & Telford Hospital website (41), but more could be done to raise patient awareness of the service, either by support groups or the hospital. Whilst unable to deal with particular complaints, Healthwatch Shropshire needs to continue contact with sight loss groups in order to fully understand these issues and to ensure the rights of those with sight loss and visual impairment are championed.

6.3 Strengths, limitations & further research:

This study was a small scale qualitative study, the nature of which allows the patients' voices and experiences to be heard, which is a strength of the design. The comparison of individual experiences with published literature demonstrates that many of the experiences and concerns are universal.

These participants had all been in the system for a number of years, and so they may have become accustomed to certain aspects of the eye care system. The strength of this group is that they were well versed in the workings of the NHS systems, and had strong opinions. It would be interesting to interview people who have been more recently diagnosed to ascertain what support they would like around diagnosis and during the early stages of their sight loss. Efforts were made to recruit such a group, particularly those with macular degeneration, as it is the largest cause of sight loss, but participants were not forthcoming.

Inevitably, however, with a sample of this size there may be issues that other members of the partially sighted community feel strongly about which were not raised here. Four out of the five participants in Stage 1 attended support groups, so the importance of providing support may have be emphasised as a result. The participants in Stage 2 were all recruited from support groups. It would be interesting to research the views of people who do not attend support groups to find out about their ideas around support; they are, however, a hard to reach group. If they were recruited through the hospital clinics, NHS Ethical Approval would be required.

Throughout Stage 1 and Stage 2 reference was made to family members who support the visually impaired. In other areas of disability, carers have been subject to research, and it would be interesting, in light of Shropshire RCC's carers' support service, to explore further the impact caring for someone with visual impairment in particular has on family members, and whether they have distinctive needs.

7. RECOMMENDATIONS:

ENVIRONMENT

1. The emotional impact of the environment needs to be understood and acknowledged by hospital staff and commissioners.
2. Royal Shrewsbury Hospital Clinic 10 corridor needs to be addressed by either
   a. Improving the environment , i.e. moving the clinic to a new location
   b. Allowing people to sit in the main waiting area, and improving communication to call them in to see the consultant (by intercoms, nurses, or volunteer staff)
3. Access around Princess Royal hospital needs to be addressed – by methods other than signage – audio, internet, or even by volunteer sighted guides.
4. Comparison with other eye hospitals may bring forward some suggestions for good practice, such as locally at Wrekin Community Clinic, and further afield, such as Manchester.

COMMUNICATION

1. All staff should be trained how to address the patients appropriately, from the moment they enter the hospital, not just within the eye clinics.
   The My Guide programme should be rolled out further in PRH, and within RSH.
2. The visual awareness training should be extended to those working in GP surgeries, including GPs, who also need to be aware of up-to-date information about consultants and their specific roles, and made aware of the certification and registration processes, and wider community based support.
3. Formats for communication between hospital and patients should be discussed at the first appointment, and recorded on notes. The format of communication should also be reassessed according to changing needs.
4. Information links between hospital and support groups need to be built and maintained.
5. Information provided by support groups needs to be disseminated in an effective and timely manner. Information should be available when a patient needs it, not just when a volunteer group is available to hand it out.
6. The timely distribution of information and support may be facilitated by the employment of an Eye Clinic Liaison Officer (ECLO).
7. Patients need to understand the pathway their care is taking, and should be informed of both health and social care processes involved if appropriate.
8. Patients should be informed of their rights, and processes by which they could complain if they wish to.

KEY RECOMMENDATION:

Many of the issues raised here are covered in the RNIB's Low Vision Services Assessment Framework. It is therefore recommended that an audit according to that tool would enable services to be evaluated and reviewed, and identify potential gaps (see Appendix 4).

8. CONCLUSIONS

This report reinforces that sight loss can be debilitating in a number of ways, and that people with sight loss are vulnerable, have genuine needs (both physical and emotional) and consequently need support. Currently, local ophthalmology services are operating at full capacity, which means patients are not always receiving the care, in terms of appointments, and access to support they require. There is a need for Clinical Commissioning Groups to acknowledge the emotional impact of sight loss and look at how they can alleviate that within the communication and environment settings of the NHS. However, the failure of Shropshire Council to include any information regarding sight loss in their Joint Strategic Needs Assessment means that these people are not considered when planning services, which in turn means that real needs are being ignored. A systematic audit of services according to RNIB guidelines, would begin the process to address these issues. It is worth noting that the participants’ experiences reflect general experiences in published literature, so it may be assumed also their experiences also reflect those of others within Shropshire.

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11. APPENDICES

Appendix 1	RNIB Sight Loss Data Tool retrieved data for Shropshire
Appendix 2	Questions
	Stage 1 – Individual interviews
	Stage 2 – Focus group
Appendix 3	Table of Superordinate Themes – Stage 1
Appendix 4	RNIB - Low Vision Assessment Tool

(also available on request as a separate file)