



## **The changing needs of people with sight loss**

**This publication presents findings from a research study by Clare Thetford, Jude Robinson, Paul Knox, Jignasa Mehta and David Wong from the University of Liverpool.**

### **Summary**

The research study identifies and explores the changing support needs of people with sight loss from the clinical, visual function and quality of life perspectives. Data were derived from biographical narrative interviews and a visual function questionnaire with people with sight loss, and semi-structured interviews with professionals involved in the delivery of specialist visual impairment services. Needs that are ongoing as well as changing are identified and the ways in which these needs can be more easily identified and assessed are explored. Referral routes and access pathways to services are examined, identifying gaps and weaknesses. The findings are considered with regard to informing future service provision and identifying future research priorities.

### **Background**

The impact of sight loss upon everyday life changes over time, according to deterioration of vision and other changes and key events in people's lives. In view of this, the support needs of people even with relatively stable visual impairment may also change over time. Existing literature indicates that service providers are not always aware of the changing needs of people experiencing gradual or untreatable sight loss, or are unable to respond to them. Further, people with deteriorating sight conditions themselves (or their family) may not be aware of the degree to which their sight has deteriorated and often do not have easy access to information on their condition and on what treatments and services might be available to them.

The aims of this research were to:

- Enable people with sight loss, and those working with them, to identify what they think is needed to change both the services offered to them, and the wider social, cultural and political environment that continues to impact on people with visual impairments.
- Explore the ways in which health and social services could be tailored to meet these needs better.

## Methods

The study had two key components:

- Interviews with 37 people with sight loss using biographical narrative interviews, the National Eye Institute Visual Function Questionnaire 25 (NEI VFQ-25), and a personal characteristics questionnaire.
- Semi-structured interviews with 18 professionals engaged in providing services and assessments of need for people with sight loss.

### Interviews with people with sight loss

Most of the interviews were conducted in participants' own homes; they ranged in length from 45 minutes to over three hours. Each interview consisted of the following:

#### Biographical narrative (BNIM)

In Biographical Narrative Interpretative Method (BNIM), an opening question is used to induce a narrative response (a personal story) from the participant with minimal subsequent intervention by the interviewer.<sup>1,2</sup> This method is based on the assumption that individual-told stories are closest to lived experience and so is well suited to capturing the realities of life with sight loss.<sup>3,4</sup> For participants who were unable to engage in telling their own story (approximately a third of the sample), a semi-structured style of interviewing was adopted using the information they had already provided as the basis for questions, with new issues and topics introduced by the interviewer later in the interview.

<sup>1</sup> Wengraf T (2001) *Qualitative research interviewing*. London: Sage Publications.

<sup>2</sup> Wengraf T (2005) *The Biographic-Narrative Interpretive Method (BNIM) shortguide version 3.1*. Unpublished.

<sup>3</sup> Ainlay SC (1989) *Day brought back my night: Aging and new vision loss*. London: Routledge.

<sup>4</sup> Papadopoulos I, Scanlon K, Lees S (2002) *Reporting and validating research findings through reconstructed stories*. *Disability & Society*, 17(3): 269-281.

## Characteristics questionnaire

A brief questionnaire was administered to each participant to capture basic demographic data such as age, sex, income, cause of visual impairment, duration since onset of visual impairment, area of residence and ethnicity.

## National Eye Institute Visual Function Questionnaire (NEI-VFQ-25)

The NEI VFQ-25 (National Eye Institute Visual Function Questionnaire 25)<sup>5, 6, 7</sup> is a validated short questionnaire used to assess visual function, social functioning and emotional wellbeing. Given that many people in the target sample may not have had a clinical assessment for a number of years, the NEI VFQ-25 was administered during the interview to establish the degree of self-reported sight loss for each participant.

## Sampling and recruitment of people with sight loss

A sampling strategy of maximum variation was adopted, facilitating examination of commonalities and variations within the sample.<sup>8,9</sup> The sampling strategy was based upon the following participant characteristics: age; gender; duration since diagnosis or onset of condition; cause of sight loss; degree of sight loss; geographical location; income/socioeconomic status; ethnicity.

Most of the people with sight loss were recruited through two voluntary organisations that provide a range of vision-related services in the geographical areas included in the study: Liverpool Voluntary Society for the Blind (LVSb) identified eligible people from their database and contacted them on behalf of the research team and 11 people were recruited in this way. Secondly the lead researcher (CT) attended the annual open day of another voluntary organisation, Vision Support, and approached individuals in person, recruiting 18 people. Vision Support Home Visitors recruited two participants to the study. Six participants were recruited through word of mouth.

<sup>5</sup> Mangione CM et al. (2001) *Development of the 25-item National Eye Institute Visual Function Questionnaire*. Archives of Ophthalmology, 119: 1050-1058.

<sup>6</sup> Mangione CM et al. (1998) *Psychometric Properties of the National Eye Institute Visual Function Questionnaire (NEI-VFQ)*. Archives of Ophthalmology, 116: 1496-1504.

<sup>7</sup> National Eye Institute (2000) *National Eye Institute Visual Functioning Questionnaire - 25 (VFQ-25): Version 2000*, in Interviewer administered format.

<sup>8</sup> Hudelson PM (1994) 'Introduction to qualitative research', in *Qualitative research for health programmes*. Division of Mental Health: Geneva.

<sup>9</sup> Morse JM (1998) 'Designing funded qualitative research', in *Strategies of qualitative inquiry*, NK Denzin, YS Lincoln (eds), Thousand Oaks, CA: Sage Publications.

## Interviews with service providers

Semi-structured interviews<sup>10,11</sup> were completed with 18 people engaged in providing services and assessments of need for people with sight loss. These interviews used open-ended questions that focused on how service providers currently identify and meet the changing needs of people with sight loss. Senior staff at the identified services and organisations were contacted by telephone or email and invited to participate, and/or to nominate appropriate members of staff within their service.

## Data recording and research ethics

The study followed principles of informed consent, and potential participants were provided with research documents in their preferred format, which included standard print, large print, audio CD and audio tape. All participants were assured of confidentiality. Ethical approval was gained from the Liverpool Adult Research Ethics Committee. NHS honorary contracts and study approval were obtained from two NHS Trusts where members of staff were interviewed. All interviews were recorded on a digital recorder, and then transcribed verbatim and stored as password-protected MS Word files.

## Data analysis

### Qualitative data analysis

Qualitative interview data were analysed thematically.<sup>12, 13</sup> Transcripts were read several times and coded; firstly using an inductive free-coding strategy based upon emergent themes, and secondly using key themes within the data which related to specific research questions. Comparisons were made within and across the samples of people with sight loss and with service providers throughout the process.

<sup>10</sup> Morse (1998) op cit.

<sup>11</sup> Holloway I (2005) (ed) *Qualitative research in health care*. Open University Press: Maidenhead.

<sup>12</sup> Miles MB and Huberman AM (1994) *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, CA: Sage Publications.

<sup>13</sup> Gifford SM (1998) 'Analysis of non-numerical data', in *A handbook of public health methods*, C Kerr, R Taylor, G Heard (eds), McGraw-Hill, pp.543-554.

## VFQ data analysis

The VFQ-25 is a questionnaire based on 25 vision-related questions. The questions were assimilated into 11 vision-related subscales and one overall general health rating question. Participants were asked to rate themselves from 1-5 (1-Excellent, 5-poor) in response to the questions. The data were recoded according to standard procedures. Each item was converted to a 0-100 scale, with a high score representing better functioning. Items were averaged to create 12 subscale scores. A composite score was calculated for each individual which was an average of the 11-vision related subscales, i.e. excluding the general health and driving scores.

## Findings

### Sample characteristics

#### People with sight loss

- *Gender*: 19 women and 18 men.
- *Age*: Average 67 (range 24 to 92: 4 people aged under 50 years, 12 aged 51-65 years, 8 aged 66-75 years and 13 aged over 75)
- *Ethnicity*: 34 white British, one white non-British, two people from minority ethnic backgrounds.
- *Locality*: 14 people lived within the city of Liverpool; 10 from the predominantly rural areas and small towns of Cheshire; seven from the urban areas of Ellesmere Port and Widnes; and six from the rural areas and small towns of North Wales.
- *Duration of sight loss*: The average duration of living with sight loss was almost 20 years, ranging from 18 months to 79 years, with 14 people having lived with sight loss for more than 16 years.
- *Primary cause of sight loss*: Age related macular degeneration (AMD) 15; retinitis pigmentosa (RP) 6; detached/torn retina 5; diabetes 4; stroke 2; multiple sclerosis 2; trauma 2; glaucoma 1.
- *Registration*: Registered blind/severely sight impaired 17; registered partially sighted/sight impaired 12; not registered 6; unsure 2.
- *Employment*: Retired 28; disability/sickness 8; working full time 1.
- *Home ownership*: Own home 25; rent/housing association 10; own with parent 2.
- *Living arrangements*: With partner 20; alone 12; with other family 5.

NB: Given that there was a great deal of variation in the duration of sight loss and time since last seen by a consultant ophthalmologist, reports of experiences of diagnosis and other service encounters some time ago may not reflect current practice.

### **Service providers**

The sample of service providers included: senior/middle managers (4); rehabilitation officers/managers (2); consultant ophthalmologists (2); low vision clinic optometrists (2); senior nurse specialists (2); eye clinic liaison officer (ECLO) (1); social worker (1); home visitor (1); day/activity centre manager (1); voluntary service worker (1); GP (1).

### **Findings from the NEI-VFQ (National Eye Institute Visual Function Questionnaire)**

This sample reported their general health to be poor and this impacted on their perception of other vision-dependent activities. The general, near and distance vision scores were amongst the lowest of the subscales, highlighting that this sample had high levels of visual impairment. The scores for mental health, dependency and social functioning are below average.<sup>14,15</sup> This provides further evidence of the general impact of visual dysfunction on all aspects of life and therefore the importance of meeting low vision needs. It also suggests that meeting low vision needs successfully may have a general effect on health (including mental health) and function (including social functioning).

### **Diagnosis, prognosis and treatment**

Most of the people in this sample had conditions which were untreatable or for which treatment has a low success rate; at least at the time they were seen by a consultant ophthalmologist, which varied from over a few weeks to several decades previously. Recent advances in treatments for conditions such as AMD mean that this scenario is becoming less common. If no suitable treatment is available, patients are typically discharged from the eye clinic, with no further follow-up. The nature of the condition appears to influence access to different forms of support and services because of the different points at which individuals come into contact with services and how frequently they are deemed to need such contact. For example, patients with diabetes continue to have regular review appointments but AMD patients are more often discharged.

<sup>14</sup> Mangione *et al.* (2001) *op. cit.*

<sup>15</sup> Mangione *et al.* (1998) *op. cit.*

### **'There's nothing we can do'**

Eye clinic patients for whom there was no (further) treatment available commonly retained a single message from the ophthalmologist: their sight was going to deteriorate and there was nothing that could be done about it. A lack of information and understanding surrounding diagnosis meant that many people in this study had not had further sight tests since their initial diagnosis as it was commonly assumed that there was no reason to have such tests. Eleven of the 37 participants reported having a secondary eye condition which had developed after the primary cause of sight loss, which complicated and contributed to their loss of vision. Some of these secondary eye conditions were treatable. It is possible that more of the sample had also developed further eye conditions but were unaware of this because they did not have regular sight tests. This lack of follow-up effectively prevents secondary causes of visual impairment from being detected and treated. Many participants had low levels of awareness of the degree of their declining visual function, which further masked the need for ongoing review.

### **Changing social and cultural lives of people with sight loss**

Participants who had been living with sight loss for several decades were able to reflect on how their needs had changed over their life course. This revealed that different types or amounts of support were required at times of rapid vision deterioration, but also often coincided with major life transitions and events. Such life transitions included their children growing up and their role within the household and family changing, ageing, illness or death of a partner (or other family), retirement and debilitating illness.

### **The emotional impact of sight loss**

A majority of the sample described the initial impact of their diagnosis as devastating, to varying degrees. For participants who lacked emotional support from family and friends, the only emotional support available to them came under the guise of more practical support, rather than from a service designed specifically to address emotional needs. As a result, participants described how some emotional issues were not fully addressed. For some, this led to the breakdown of close relationships and was linked to their rejection of offers of support, including rehabilitation. Sight loss was also reported to have considerable emotional impact for those close to the person with sight loss, yet there is very little support available to these people.

## **Wider impacts of sight loss**

Sight loss often had far-reaching consequences extending into almost every aspect of life, including work, family and relationships. For some, it was only when their visual function began to decline seriously and impact upon their lives significantly that they felt the need to access support. For others, a diagnosis and the threat of future sight loss had a similar impact. A lack of emotional support over time added to a sense of growing isolation and abandonment, with some reporting withdrawal from many aspects of life (such as social events or activities as well as everyday activities such as shopping) as they became depressed.

Many people, particularly older people, related their declining visual function to a decline in their confidence. This impacted upon their willingness to seek and/or accept help (such as rehabilitation) to enable them to continue to maintain their quality of life. Inevitably, this loss of confidence also affected other areas of their lives, such as social contact with friends, family and other people outside their home environment. Some people described how, for them, support had come too late and they had endured long periods without the help they had needed. In some cases they felt that the damage to their quality of life or ability to live independently was irreparable. More positively, when some participants accessed support, things began to improve, and they described how the impact of sight loss on their lives became more manageable.

## **The impact of declining visual function**

People with sight loss usually described declining visual function in terms of what they were no longer able to do and the impact of this on their lives. Examples include struggling to read, cook, or drive. The ability to perform such tasks had a direct impact on their ability to live independently and their quality of life.

Sight loss is often concurrent with other health/mobility problems and social changes associated with ageing.<sup>16</sup> Where there are so many changes, difficulties and losses around the same time or which build up over time, the support needs of these people can be incredibly complex and require a multi-disciplinary, well coordinated response. The data indicate that such a service response is not currently the norm and service user experiences reflected disjointed services that each focused upon specific issues (e.g. social services focus on care packages). This further emphasises the need for regular review, as well as close coordination and improved communication between a range of services and agencies.

<sup>16</sup> Campbell S (2004) *The identification project: Improving access to specialist services for people who are visually impaired*. Visibility: Glasgow.

## Accessing help and support

Accessing the appropriate support made a remarkable difference to people's quality of life. Those who were diagnosed many years ago often reported that very little or no support was available to them at the time. Many of these people later accessed some form of support which had a positive impact upon their quality of life. Often they had developed strategies and learned to cope to varying degrees with sight loss themselves and/or with the help of family/friends. For some this had meant avoidance strategies rather than development of coping skills, which had meant they missed out on some areas of life.

Most people felt that on the whole the information and support available to them had improved over time. Nevertheless, they experienced considerable difficulties in accessing the support they needed at their time of need, which was made more difficult by the sight loss itself; for example not being able to read leaflets, or struggling to use the telephone. Some service providers drew attention to improvements to their services, particularly concerning the provision of information and offers of support around the time of diagnosis, but highlighted that other areas had worsened.

### Registration remains central to accessing support

Excluding financial support, most services and support for visually impaired people are available regardless of registration status. However, data from this study indicated that the process of registration remains central to accessing support and those who are not registered, or who experience delays in registration, are effectively excluded from support services. A new registration system was introduced between 2003 and 2005 with the aim of improving access to support at different stages of sight loss via other professionals. The impacts of these changes to the new registration system have yet to be explored.

Several people with sight loss highlighted the problems associated with delays in registration. This delay can be months or sometimes a number of years, during which time the person with sight loss has restricted access to support. For people of working age in particular, any delay in registration caused considerable stress and hardship. They reported not knowing whom to approach for information and support [also reported by Pollard *et al.*<sup>17</sup>] and experienced serious financial problems and pressures until they were registered and became eligible for benefits and exemptions. Several people

<sup>17</sup> Pollard TL *et al.* (2003) *Barriers to accessing low vision services*. *Ophthalmic Physiol. Opt.*, 23: 321-327.

indicated that they expected that registration would lead to service providers contacting them with offers of a range of different types of support. Whilst for some this was the case, others reported feeling very disappointed and misled by the professional who had encouraged them to register.

### **'They can contact us if they need us'**

Following initial assessments and offers of services soon after registration or referral, most service providers operate on the basis that if an individual has further needs they will contact the provider to ask for help. However, the people with sight loss in this sample made it clear that very often they do not know what is available and do not know what to ask for. Some indicated that they did not know who they could call to access services or that they could re-contact those who had provided services or assessed them previously. In some cases, they may not articulate their needs or problem clearly enough for service providers to identify their needs easily in the very limited contact time they have with individuals. Both service user and service provider accounts suggest that awareness of the types of support available and how to access them is low among service users and – perhaps of greater concern – among service providers as well. 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.

### **Needs that are ongoing rather than changing**

In addition to needs that are changing and emerging over time, some people have needs for support that are ongoing. Older people, and those who are socially marginalised in particular, have greatest need for ongoing support because their needs are more complex and also because they are least able and likely actively to seek formal support.<sup>18</sup> Needs that are ongoing for most of the people in this sample included eye health and vision checks after hospital discharge, skills development and rehabilitation, particularly when sight loss was gradual. Examples of needs that are ongoing for some of the people in this sample include social and activity groups to maintain social contact and create opportunities for needs to be identified and responded to, assistance with transport, and a home visitor or telephone befriending service.

<sup>18</sup> Howse K, Ebrahim S, Goberman-Hill R (2004) *Help-avoidance: why older people do not always seek help*. *Reviews in Clinical Gerontology*, 14: 63-70.

### **The complex configuration of support services**

Service users and providers reported many complicated issues regarding access to a wide range of support and services. Adding to this complexity was the large variation in availability and access pathways, depending on which NHS trust, local authority and voluntary organisation(s) an individual received services from. Navigating these very different systems and pathways proved challenging for many.

### **Urban and rural differences in access**

Service users in Liverpool generally reported easier physical access to services than those in Cheshire and Wales. Those in rural areas and some towns reported considerable difficulty in getting to the location where services were provided because of limited public transport, longer distances to travel, high costs, and inflexible community transport services. In particular, people with mobility problems or other physical health problems had much greater difficulty as they were often unable to take advantage of community buses, even if picked up at home. This was reported to make a huge difference to accessing information, support and services.

Most referrals to the eye clinics came through GPs. The process of GP referral can take a number of weeks, and this delay is added to any time spent on a waiting list for the eye clinic. When advised that there was no further follow-up required or that nothing further could be done at the eye clinic, many of the people in this sample were discharged and told to return to the eye clinic only if they noticed any major changes in their vision. However, it was not always made clear to them how they should do this and several people reported considerable difficulties and delays re-accessing the eye clinic on this basis. In a small number of cases this delay meant opportunities for treatment to save or restore vision were lost.

### **Accessing low vision clinics**

Service users experienced problems accessing low vision clinics in both the short and long term because of a lack of awareness/information, referral, waiting lists and transport. Further problems were reported to be associated with a lack of follow-up or being discharged, particularly in the long term.

### **Accessing support from voluntary organisations and statutory services**

The data indicated that it is often more acceptable to agree to offers of support from voluntary organisations contracted by local authorities because statutory social services remain stigmatised,

particularly amongst older people. Service users and providers reported that it was usually much easier to access support from voluntary organisations than statutory services. However, obtaining information about voluntary organisations was difficult in many cases. Whilst a small number of people in this sample spoke highly of statutory social services they received, overall the people in the sample expressed a great deal of dissatisfaction regarding the accessibility of statutory social services. Some local authorities appeared to have greater problems in the provision of services than others due to different models of service provision and geographical accessibility.

### **Access to rehabilitation services**

Most people with sight loss in this sample had received some kind of rehabilitation service, but for a majority this was limited to a visit by a rehabilitation officer or specialist social worker who provided a small number of very basic aids (such as a liquid level indicator, a talking watch and some bump-stickers for kitchen appliances). Only a small minority (eight) had undertaken a full programme of rehabilitation and mobility training. It was notable that those most likely to have done so were younger people of working age. There appeared to be variability in access to rehabilitation services based on geographical location, model of service delivery, service provider, age and health of service user. There was also considerable variability in the duration and content of a rehabilitation programme based upon the service provider and individual local authority policy.

A number of people reported that offers of rehabilitation services (along with other support) had been made at a stage in their life/visual impairment when they did not feel the need for it (or it was not offered at that stage as there was no apparent need for it). Several people in this sample who had completed at least some rehabilitation reported that they had initially declined any offers of these services. At a later stage, however, they were persuaded (by a service provider) to try and did complete the programme. This was only possible, however, through follow-up or ongoing contact with a service provider with whom they developed a positive relationship.

### **The timing of offers of help**

Those people who did recall being offered support reported that this was usually soon after diagnosis and registration. However, this was often not the point at which they needed or wanted it. Some people described how they were 'unwilling' or 'not ready' to accept support at the time when they were still coming to terms with their

diagnosis and so they had declined offers of help at this point. As their situation changed over time, they developed needs but experienced difficulties in trying to access support they required, largely because they were not in contact with specialist organisations. Generally, there was little or no follow-up or review, particularly from statutory services. The data indicate that flexibility is required to accommodate individual needs and there should be multiple opportunities to access services. As visual ability and other aspects of life change over time, it becomes necessary to access these services more than once but the current configuration of services did not appear to support this.

### **Lack of awareness among other professionals and lack of inter-agency cooperation**

The data indicate that opportunities for other professionals (such as social workers, occupational therapists, physiotherapists, domiciliary carers) to identify needs for vision-related support are not being seized. In many instances, these other service providers do not have sufficient awareness of appropriate services to refer to, even where they were able to identify vision-related needs. Many of the people in this sample had considerable health and social problems which meant they were in contact with other professionals on a regular basis. There is enormous potential for these professionals to have a larger role in identifying vision-related needs and facilitating access to support, but this would require far greater awareness of issues surrounding sight loss and of the services available and the access pathways to these.

## **Discussion**

*Recognition of the point of diagnosis as a critical point of intervention:* The eye clinic appointment represents an opportunity to provide information to people who lose sight and to enable them to establish regular contact and build relationships with both statutory and voluntary organisations. Where this opportunity is not seized, either during an eye clinic appointment or through the registration process, the ability of someone who loses sight to access the support they need is severely compromised in both the long and short term.

*Understanding changing needs and help-seeking behaviour:* The overall system of clinical, statutory and voluntary services for people with sight loss is based on the premise that those who have needs (or whose needs have changed) will identify those needs, identify a suitable service provider, contact the service provider, articulate their needs and requests, and in the case of state funded services,

resources and equipment, effectively demonstrate their need for support. Such a system further marginalises and disadvantages those who have greatest need, who are less able to do any of these things and who are least likely to have someone do them on their behalf.

*The timely identification of changing needs and appropriate interventions:* There is a requirement for clinical and non-clinical follow-up and review as declining visual function can have enormous impacts on the ability to live independently and may be an indicator of a need for further or changed social care support and/or rehabilitation. When information and support are offered, this is usually around the time of diagnosis or registration, although this is not always done routinely. While this presents a clear strategic opportunity, it may not be the right time for many. There is a need for multiple opportunities to access services, as well as greater follow-up and review from a range of different service providers.

*The provision of rehabilitative services for people with sight loss:* There is substantial value in rehabilitation which, in addition to improving the lives of people with sight loss and those close to them, may also reduce the costs of providing other services, such as care packages and care homes. The benefits of rehabilitation for people with sight loss are currently far from being maximised.

## Conclusions

This study explored the changing needs of people with sight loss and highlighted problems in accessing information and support at the time of need. Most services are configured to meet needs on an acute, short-term basis but this does not accommodate the continual changes in visual function and in people's lives [also reported in Malton and Norton<sup>19</sup>]. The accounts of people with sight loss clearly demonstrate that their needs for support are often continuing and repeated and hence time-limited service provision is often inappropriate and insufficient.

<sup>19</sup> Malton and Norton in Touch (1999) *Losing sight in Ryedale. Routes to rehabilitation: Systems and services and individual experiences.*

## Recommendations for service development

Improved doctor/nurse–patient communication in ophthalmic settings is essential so that patients have better levels of knowledge and understanding about their eye condition. There should also be increased promotion of and improved access to community sight tests for everyone, including those diagnosed with untreatable degenerative eye conditions.

The opportunity to provide information, support, signposting and referral at the eye clinic should be seized as a matter of routine on multiple occasions, regardless of registration status.

Efforts should be made to ensure that referral to a low vision clinic (either within the hospital or community) becomes an integral part of the eye clinic procedure to prevent people falling through gaps in service provision.

Greater follow-up and review is required in both clinical and community settings. In community settings, ongoing contact and relationship building between service user and provider should be facilitated. Improved pathways are required to facilitate both initial and repeated access to support.

Greater inter-agency communication and cooperation is required. The complex support needs of people with sight loss necessitate a well coordinated system of services.

## Further research

This study has taken a very broad exploratory approach. This has enabled the identification of a number of issues worthy of further research and/or service delivery improvements.

### *The new registration process*

Broad exploratory research is required to examine the operation and impact of the new registration process including awareness and understanding of the new process from service user and provider perspectives.

### *Emotional support needs*

The emotional support needs of people with sight loss and those close to them require further definition. Ways of providing appropriate emotional support should be investigated.

### *Caring responsibilities*

The caring responsibilities of those close to people with sight loss, as well as the caring responsibilities of people with sight loss, require closer examination in order to develop appropriate supports.

### *Help-seeking behaviour*

Further exploration of service user knowledge and understanding of eye conditions is required in order better to understand help-seeking behaviour regarding sight loss. This can then be used to improve access to services.

### *Communication in ophthalmic settings*

Medical professional communication with patients in ophthalmic settings requires exploration, including examination of the impacts of poor communication and what factors restrict and facilitate effective communication.

### *The dynamics of age and sight loss*

Given the close relationship between advanced age and sight loss in developed countries, research is required into age-related impacts of sight loss and access to appropriate support.

## **Authors**

### **Clare Thetford and Jude Robinson**

Health and Community Care Research Unit (HaCCRU)  
University of Liverpool

### **Paul Knox and Jignasa Mehta**

Orthoptics Division  
University of Liverpool

### **David Wong**

St Paul's Eye Unit  
Royal Liverpool Hospital

## **References**

Ainlay SC (1989) *Day brought back my night: Aging and new vision loss*. London: Routledge.

Campbell S (2004) *The identification project: Improving access to specialist services for people who are visually impaired*. Visibility: Glasgow.

Gifford SM (1998) 'Analysis of non-numerical data', in *A handbook of public health methods*, C Kerr, R Taylor, G Heard (eds), McGraw-Hill, pp.543-554.

Holloway I (2005) (ed) *Qualitative research in health care*. Open University Press: Maidenhead.

Howse K, Ebrahim S, Gooberman-Hill R (2004) *Help-avoidance: why older people do not always seek help*. *Reviews in Clinical Gerontology*, 14: 63-70.

- Hudelson PM (1994) 'Introduction to qualitative research', in *Qualitative research for health programmes*. Division of Mental Health: Geneva.
- Malton and Norton in Touch (1999) *Losing sight in Ryedale. Routes to rehabilitation: Systems and services and individual experiences*.
- Mangione CM, Lee PP, Pitts J, Gutierrez P, Berry S, Hays RD. (1998) *Psychometric Properties of the National Eye Institute Visual Function Questionnaire (NEI-VFQ)*. Archives of Ophthalmology, 116: 1496-1504.
- Mangione CM, Lee PP, Gutierrez P, Spritzer K, Berry S, Hays RD. (2001) *Development of the 25-item National Eye Institute Visual Function Questionnaire*. Archives of Ophthalmology, 119: 1050-1058.
- Miles MB and Huberman AM (1994) *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, CA: Sage Publications.
- Morse JM (1998) *Designing funded qualitative research, in Strategies of qualitative inquiry*, NK Denzin, YS Lincoln (eds), Thousand Oaks, CA: Sage Publications.
- National Eye Institute (2000) *National Eye Institute Visual Functioning Questionnaire - 25 (VFQ-25): Version 2000*, in Interviewer administered format.
- Papadopoulos I, Scanlon K, Lees S (2002) *Reporting and validating research findings through reconstructed stories*. Disability & Society, 17(3): 269-281.
- Pollard TL, Simpson JA, Lamoureux EL, Keeffe JE. (2003) *Barriers to accessing low vision services*. Ophthalmic Physiol. Opt., 23: 321-327.
- Wengraf T (2001) *Qualitative research interviewing*. London: Sage Publications.
- Wengraf T (2005) *The Biographic-Narrative Interpretive Method (BNIM) shortguide version 3.1*. Unpublished.

## How to obtain further information

A summary report, in the form of 'Research Findings', entitled *The changing needs of people with sight loss*, by Clare Thetford, Jude Robinson, Paul Knox, Jignasa Mehta and David Wong is available from:

Thomas Pocklington Trust  
5 Castle Row  
Horticultural Place  
London W4 4JQ

Telephone: 020 8995 0880  
Email [info@pocklington-trust.org.uk](mailto:info@pocklington-trust.org.uk)  
Web [www.pocklington-trust.org.uk](http://www.pocklington-trust.org.uk)

Copies of the full report and executive summary are available to download from the University of Liverpool website:  
<http://www.liv.ac.uk/haccru/html/reports.html>

Copies of this report in large print, audio tape or CD, Braille and electronic format are available from Thomas Pocklington Trust.

## Acknowledgements

The authors would like to thank the following people for their invaluable help. The Research Advisory Group, Tracy Quillan and Lyn Hunter for administrative and technical assistance. LVSB and Vision Support provided a great deal of assistance with the entire project, but especially in the recruitment of participants with sight loss. Service providers gave up their valuable time to take part in interviews. Special thanks to the people with sight loss and their families who participated in interviews, sharing very personal experiences.

## Copyright ©

Note – All rights reserved: no part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means electronic, mechanical, photocopying, recorded or otherwise, without prior permission. The copyright of the research is held jointly by University of Liverpool and Thomas Pocklington Trust.

## Background on Pocklington

Thomas Pocklington Trust is the leading provider of housing, care and support services for people with sight loss in the UK. Each year we also commit around £700,000 to fund social and public health research and development projects.

Pocklington's operations offer a range of sheltered and supported housing, residential care, respite care, day services, home care services, resource centres and community based support services.

A Positive about Disability and an Investor in People organisation, we are adopting quality assurance systems for all our services to ensure we not only maintain our quality standards, but also seek continuous improvement in line with the changing needs and expectations of our current and future service users.

We are working in partnership with local authorities, registered social landlords and other voluntary organisations to expand our range of services.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss, by improving social inclusion, independence and quality of life, improving and developing service outcomes as well as focusing on public health issues.

We are also applying our research findings by way of pilot service developments to test new service models and develop best practice.

*In this publication, the terms 'visually impaired people', 'blind and partially sighted people' and 'people with sight loss' all refer to people who are blind or who have partial sight.*



5 Castle Row  
Horticultural Place  
Chiswick  
London W4 4JQ  
Tel 020 8995 0880

**Email** [info@pocklington-trust.org.uk](mailto:info@pocklington-trust.org.uk)  
**Website** [www.pocklington-trust.org.uk](http://www.pocklington-trust.org.uk)  
**Registered Charity No.** 1113729  
**Company Registered No.** 5359336

Published by Thomas Pocklington Trust

ISBN 978-1-906464-09-7

