

## **Emotional Support to People with Sight Loss**

**This publication summarises the findings from research conducted by the University of Reading, which was commissioned and funded by Thomas Pocklington Trust. Based at the Institute of Health Sciences, the principal investigators were Professors Margot A Gosney and Christina R Victor, and the post-doctoral research fellow was Dr Samuel R Nyman.**

The research team updated the evidence base for the psycho-social needs of individuals with sight loss and services available for them, including contemporary data on the emotional support needs of working age adults and older people by:

- systematically reviewing quantitative published and grey literature (literature not published in a peer-reviewed journal)
- carrying out a systematic review of qualitative studies with older people
- carrying out a new qualitative study, using interviews with adults with sight loss across a range of ages, about emotional support
- conducting a scoping survey of the provision and evidence of effectiveness of professional, formal counselling services in the UK for people with sight loss. Where possible, comparisons were made with services available for people with other long-term health conditions and for people who have been bereaved.

The research identified an absolute increased need for emotional support among people with acquired sight loss. Qualitative work showed that the diagnosis of sight loss is often a traumatic event. Social support and self-management/problem-solving interventions can potentially buffer against the negative impact of sight loss, e.g. in preventing the onset of depression. However, there is a lack of research on how best to support the emotional needs of people with sight loss. Further research may make the case for the provision of any of a range of emotional support services that at present are not available locally to everyone with sight loss in the UK.

## Background

It is estimated that 980,000 people in the UK are eligible for registration as blind or partially sighted, and of this figure 888,852 (90.7%) are aged 65 and older.<sup>1</sup> Age-related sight loss is projected to rise as the UK population becomes older.<sup>2</sup> Acquired low vision and blindness can be devastating for adults and older people, dramatically changing their whole way of life. Having a chronic medical condition has been identified as a risk factor for depression in older people,<sup>3</sup> with prevalence rates for major depression in adults with diabetes, coronary heart disease, HIV infection, stroke, Parkinson's disease and multiple sclerosis of between 12.5% and 25.33%.<sup>4</sup> The true prevalence of major depression in adults without a chronic condition is unknown, since most of these individuals are not known to healthcare services.

Thomas Pocklington Trust hosted a workshop with service providers and researchers in January 2007 to explore research questions relating to emotional needs and sight loss. One of the main conclusions of the workshop was that a firm evidence base was required with regard to the emotional aspect of sight loss. Hence, this project was commissioned and funded by Pocklington to update the evidence base, highlight areas for future research and indicate implications for policy and practice.

## Methods

The research team used three methods:

- systematic literature reviews to accumulate the evidence from previous research
- a scoping survey of services
- a qualitative study using interviews.

## Systematic literature reviews

Previous literature reviews on the psycho-social impact of sight loss are limited. They have generally been narrative and not systematic and have not used a transparent and thorough literature search with clear inclusion criteria for the papers reviewed. In addition, reviews have generally focused only on sight loss in older people due to age-related macular degeneration or glaucoma, and not on sight loss from any other cause or across a wider age range. One paper systematically reviewed quantitative studies that recruited

<sup>1</sup> Royal National Institute of Blind People (2008)

<sup>2</sup> Office for National Statistics (2007)

<sup>3</sup> Denihan et al. (2000)

<sup>4</sup> Katon (2003)

older people with any visual impairment and were published between the beginning of 1980 and the summer of 2001.<sup>5</sup> The research team therefore updated the evidence base in the existing publications up to July 2008. The review was also broadened to include studies that recruited working age adults and unpublished or 'grey' literature. Because no previous review of qualitative studies had been conducted, the research team also systematically reviewed the literature of qualitative studies that recruited older people and were published between the beginning of 1980 and the end of September 2008.

### Scoping survey

Professional counselling, other psychological therapies and/or informal peer support may be appropriate and beneficial for people with sight loss. A previous survey of members of Visionary (previously called NALSVI) estimated that 45 out of 113, or 40%, of Visionary members provided professional counselling (17) or 'informal support' (28) such as peer support groups, telephone helplines, befriending, etc.<sup>6</sup> However, little information was collected about evidence for the effectiveness of those services in mitigating the psycho-social impact of sight loss. The research team therefore conducted a scoping survey of service providers to assess the evidence base for the effect of professional counselling on the needs of people with sight loss for emotional support. During the spring/summer of 2008, the research team contacted the 17 professional counselling services identified in the previous survey of Visionary members and 11 more services (identified via Vision 2020UK, Visionary, the Visual Impairment Network for Counselling and Emotional Support, and specialist ophthalmic nurses via the Royal College of Nursing). In order to evaluate the evidence for the effect of the professional counselling services that were provided, the research team collected and reviewed documentation used to support their initiation and copies of any evaluation reports.

### Interviews

The research team also conducted a qualitative study to investigate the needs of adults and older people with sight loss for emotional support. The experiences of 17 people with sight loss, and their psycho-social wellbeing, were explored by means of an interview process. The research team endeavoured to identify similarities and

<sup>5</sup> Burmedi et al. (2002)

<sup>6</sup> Rees (2006)

differences in how people responded to their diagnosis of, and subsequent adjustment to, sight loss. To represent the range of individuals with sight loss, participants of different ages (between 19 and 92) and with different types of visual impairment were chosen, and included people with congenital sight loss as well as those who had acquired sight loss either in their childhood, or recently in adulthood/older age. Some participants had received emotional support (through counselling or a peer support group), and so the research team was able to collect comments about their experiences. The interviews were transcribed verbatim and analysed thematically.

## Findings

Findings from the project's three methods were grouped under themes identified as important markers of psycho-social well-being:

- depression
- mental health
- anxiety
- quality of life
- social functioning
- loneliness
- experience of complex visual hallucinations
- social support
- evaluation of interventions.

## Depression

In the systematic literature review of studies recruiting older people, 46 papers investigated the prevalence of both depression (clinical diagnosis) and depressive symptoms (indications of risk of depression but not a clinical diagnosis). Twenty-five of 28 studies suggested depressive symptoms to be on average almost twice as likely in those with sight loss than in controls, with approximately 23% reporting depressive symptoms. When using a clinical diagnosis of depression there was more variance in findings, but on average those with sight loss were found to be more likely than sighted peers to be diagnosed with depression, with a prevalence of 20.57% vs. 3.5% found previously in sighted peers in the USA. Higher levels of loss of visual functioning were more predictive of depressive symptoms than the type of visual impairment or its characteristics.

Nine studies using validated scales screened for depressive symptoms in working age adults. Four studies did not find a

significant relationship, or found only a minimal relationship, between sight loss and depressive symptoms. However, four studies suggested that depressive symptoms were three times more likely among people with more severe diabetic retinopathy in an African-American sample with Type 1 diabetes than among people without sight loss. Two studies found that depressive symptoms were associated with visual function but not degree of sight loss.

Studies in the grey literature reported that sight loss can result in feelings of depression and grief. Qualitative studies suggest that emotional adjustment to sight loss appears to follow a cycle and stages similar to those described in the context of bereavement. Participants reported initial feelings of panic and distress, followed by devastation and depression, and finally acceptance of sight loss. Low mood was felt in connection with the loss of independence, and in particular when participants were no longer able to drive. The qualitative study conducted by the research team similarly found that people reported feeling devastated and depressed, as illustrated by one interviewee's description of her reaction to the diagnosis of blindness:

*“Devastated, absolutely devastated. I locked myself up in my bedroom, um didn't talk to anybody ... I totally isolated myself, wouldn't drink wouldn't eat ... totally depressed totally went within myself ... I was that depressed I'd got, you know, you just ... you think what's out there? What use am I, what can I, you know, just self-pity really...”* (female, 30 years old).

## **Mental health**

Fifty-two studies measured mental health in older people. When measured with the vision-specific National Eye Institute-Visual Function Questionnaire (NEI-VFQ), older people with sight loss had significantly worse scores for mental health than their sighted peers. A much weaker relationship was identified when the 12-item (SF-12) and 36-item (SF-36) short form survey for mental health composite scores and mental health subscale scores were used. However, eight studies did not identify significantly reduced levels of mental health in older people with sight loss.

Eleven studies investigated mental health in working age adults. Ten of these studies used the NEI-VFQ and found moderately lower scores in those with sight loss than in controls. Again, the SF-36 was less sensitive and therefore less useful than the NEI-VFQ for identifying mental health issues in this population.

During the qualitative study conducted by the research team, participants spoke of their emotional reaction to the initial diagnosis

of visual impairment with terms that may be interpreted as reflecting reduced mental health. They talked of feeling shocked, as illustrated by a participant's reaction to a diagnosis of blindness:

*"I was probably in a state of shock. Actually the optometrist told me that I wasn't good to drive and I made the decision ... I don't break rules, I made the decision to drive home because I was actually terror stricken and I needed to get home as quickly as I could"* (female, 48 years old).

Similarly, with regard to longer-term emotional response to acquired sight loss, participants spoke of frustration, worry, sadness, and becoming more emotionally vulnerable.

## Anxiety

Sixteen studies measured symptoms of anxiety in older people and found mixed results. Whilst the prevalence of symptoms of anxiety in people with sight loss was on average 19.32%, the prevalence rates were similar to those found in previous studies with sighted peers, which ranged from 15% to 52.3%. Similarly, eight studies investigated the prevalence of symptoms of anxiety in working age adults with sight loss and found mixed results. A study using a clinical diagnosis of anxiety and a validated scale for symptoms of anxiety did not find elevated levels in those with glaucoma. It may be that anxiety is more acutely felt soon after diagnosis. Some participants spoke of anxiety/worry about the implications of their recent sight loss on their way of life:

*"I knew that as soon as they said that, unless it could be repaired, that everything was on the line in that moment so I was already worried about losing the car, I gave the keys to him ... um, so I knew immediately that there was a threat to independence ... there were huge implications for ... relationships and work ... that I was married to an artist, I was the main earner, so the implications in terms of what would happen if I could no longer work were immense"* (female, 48 years old).

## Quality of life

Quality of life in older people with sight loss was measured in 62 studies using a variety of scales. Twenty-one used a utility measure, most frequently with a time trade-off (TTO) score that measures the number of years that a person with sight loss would be willing to trade for either perfect vision (vision-specific) or perfect health including perfect vision (generic). Generic measures are more useful for comparison with other health conditions but only eight of the

21 studies used a generic measure of the TTO. Whilst the validity of the TTO score has been questioned,<sup>7</sup> they found either an absence of, or only a weak relationship with, sight loss. Eleven studies measured role limitations, as measured by the Short Form survey (either SF-12 or SF-36), related to emotional needs in people with sight loss. On average, using this scale, only a small difference was found on this scale between older people with and without visual impairment.

Three papers investigated quality of life in working age adults. Across a range of measures, lower scores of quality of life were found among people with sight loss, including being over four times more likely to report 'not feeling full of life'. Studies identified in the grey literature also reported that sight loss can result in feelings of reduced well-being, negative attitudes to life, vulnerability, and lack of control.

### Social functioning

Fifty-four studies measured social functioning in older people, most of which used the NEI-VFQ and found heterogeneity in the relationship between reduced social functioning and sight loss. Again, when measured with either the generic (and not vision-specific) SF-12 or with SF-36, the relationship between social functioning and sight loss was small.

Thirteen studies investigated social functioning in working age adults. Nine studies that employed the NEI-VFQ found those with sight loss reported modest but significantly lower scores than sighted peers. Studies identified in the grey literature reported that people with sight loss may have fewer face-to-face interactions with family and friends, but were more likely to be in contact by telephone. The studies only measured social contact and not satisfaction with social support or social networks and so the value of telephone contact is unknown.

The interviews conducted by the research team found that in the context of social functioning, members of the public may provide unwanted attention, and that a guide dog may facilitate conversations and be a companion. Voluntary organisations provided opportunities for social contact and peer support from others with sight loss, which was appreciated by some, and particularly by those who are depressed and/or socially isolated, as illustrated by one participant:

*"I go to the blind club in [place] they're very good they come and pick you up that's once a month ... but it's ... a couple of*

<sup>7</sup> Mitchell & Bradley (2005)

*hours out ... because you do, there's no doubt about it, you do get bored" (female, 85 years old).*

## Loneliness

Only five papers measured loneliness in older people. One study used a loneliness scale and found the prevalence of loneliness to be at 54%. This was 10% higher than had been found previously in the older general population. Severity of sight loss was not reported and the relationship between social functioning and loneliness was complex and unclear. In the remaining studies, a small but positive relationship between sight loss and loneliness was found.

Loneliness was not investigated in the published studies of working age adults with sight loss that were reviewed. Studies identified in the grey literature reported that working age adults with sight loss can feel less engaged with their community, excluded, isolated and lonely. In the qualitative interviews conducted by the research team, some participants spoke of feelings of loneliness and social exclusion. Some had difficulty relating to friends or had lost contact because their friends could not cope with them becoming blind, as illustrated by one participant:

*"I had a really good social life before I went blind, I had lots of friends, I was out all the time, I had a good job. ... I'd be travelling all over the country to see my friends and things so that was a massive change for me. My life suddenly became, um, being the whole world was my oyster, travelling and doing all sorts of things, to suddenly, my world shrinking to my everyday life, literally being [location name] – between here and the precinct basically ... so I became very isolated and very ... quite lonely really" (female, 35 years old).*

## Experience of complex visual hallucinations

Seven published studies investigated the experience of complex visual hallucinations in older people, two of which investigated their emotional consequences. One study found that half of those reporting hallucinations were concerned and a quarter frightened by their experience, a third feared insanity, and two thirds feared others thinking they were insane. Another study showed hallucinations to be linked with slightly reduced quality of life and heightened distress. The experience of complex visual hallucinations was not investigated in the grey literature and, because such hallucinations mainly occur in older people,<sup>8</sup> they were not investigated in working age adults with sight loss.

<sup>8</sup> Menon et al. (2003)

## Social support

Twenty-three studies investigated the dynamic and influence of social support from family and friends on older people with sight loss. Those with sight loss who perceived that their social network provided quality support reported better adaptation to sight loss and improved psychological well-being. Perceived adequacy of social support from family and friends was associated with a reduced risk of being diagnosed with mild (23% lower) and major (32% lower) depression.

Five studies investigated social support in working age adults with and without sight loss. There was only a minimal difference in the receipt of social support between these two groups. Individuals with low levels of perceived social support from family and friends and high levels of perceived over-protection had higher levels of depressive symptoms. Perceived over-protection was also correlated with reports of symptoms of anxiety.

From the qualitative study conducted by the research team, social support from family, friends, neighbours and cleaners was appreciated, particularly in the form of encouragement to accept and adjust to sight loss and in practical assistance. Social support was described as follows by one participant:

*“They often say that visually impaired people become isolated because they believe they can’t do it and there is no one telling them they can either, and that emotional support is what pulls you through” (female, 32 years old).*

## Evaluation of interventions

Of 30 studies reviewed, 16 investigated the efficacy of rehabilitation and 14 the efficacy of different psycho-social interventions in providing ‘emotional support’ for older people with sight loss. Whilst practical support from rehabilitation may be extremely useful in meeting other needs, it appears to be minimally effective in providing ‘emotional support’ and was only associated with at best a 12% reduction in depressive symptoms. However, different packages of rehabilitation were provided, and some studies found that rehabilitation had a positive effect on social functioning and emotional well-being.

Two randomised control trials (RCTs) of interventions with older people were identified, both of which were conducted in the USA. Neither study presented detailed descriptions of the content of the interventions. One RCT tested a self-management intervention in which participants with macular degeneration were placed in

groups that received six two-hour information/advice sessions. The intervention was found to reduce emotional distress and prevent clinical diagnoses of depression for up to six months, with half the rate of depression in the intervention group compared to the control group.<sup>9</sup> One RCT trialled a problem-solving intervention provided through a psychological treatment addressing negative thinking that may impede finding practical solutions to problems. This was manual-driven, with a therapist making six 45-60 minute home visits to individual participants. The intervention was found to prevent depression and reduce the number of relinquished activities at two months, with half the number of those in the intervention group depressed compared to the control group. However, the effect of the intervention disappeared after six months.<sup>10</sup>

Three studies investigated psycho-social outcomes of rehabilitation and other interventions in working age adults. Rehabilitation showed promise for helping people meet their family relationship goals. Achievement of such goals was linked with greater satisfaction with life and lower levels of depressive symptoms. Employment programmes may also be effective in increasing quality of life; a study found that those with eight or more years' experience in an employment programme reported greater life satisfaction and empowerment/independence.

Within the grey literature, 11 studies had collected data to evaluate various interventions. Studies indicated that after counselling, participants reported feelings of empowerment and a reduction in feelings of isolation. Participants who received telephone counselling reported a decrease in depressive symptoms and feelings of isolation. Other studies suggested that tele-befriending increased confidence and decreased feelings of isolation and loneliness, and that workshops helped individuals 'cope with everyday life'. However, the results of all of these studies from the grey literature need to be interpreted with caution as the studies did not use a validated outcome measure and reports lacked information about control groups, concurrent use of medication, type of therapy delivered, timing, length and format of delivery of the intervention.

Of the qualitative studies reviewed, one study evaluated a group-based programme that provided education about visual impairment and the opportunity for exchange of peer support. This intervention received favourable comments on the information provided and social support from both the low vision clinic and peers on the course.

<sup>9</sup> Brody et al. (2005)

<sup>10</sup> Rovner & Casten (2008)

The qualitative study conducted by the research team demonstrated that the various forms of support received from voluntary organisations were appreciated, including help to continue working or return to work, provision of low vision aids, and social contact/peer support. Counselling and an information/peer support group were both perceived to be very helpful.

The scoping survey of 28 formal counselling services for people with sight loss in the UK identified little evidence as to whether counselling improves emotional well-being in adults and older people.

## **Discussion**

### **Limitations**

Studies published about the psycho-social needs of working age and older people with sight loss are poor. Studies are of variable size and quality, and in some cases use poorly validated outcome measures. We have analysed publicly available data and have attempted to take account of both peer-reviewed and grey literature. Where data are lacking, no inferences can be made. Where detail about specific interventions is poorly reported it is difficult to comment on the true efficacy of certain interventions. It is possible that some papers were not identified due to poor indexing; however, a number of articles were identified from cross-referencing.

With regard to the grey literature of studies of working age adults with sight loss and qualitative papers, our review is unique and updates the systematic review of quantitative studies that recruited older people and was published between 1980 and 2001.<sup>5</sup> The scoping survey collected data on professional formal counselling that was identifiable to us. There may be informal 'counselling services' of which we were unaware. It is unlikely that formal evaluation of these services, which could have enhanced our study, had been undertaken. In the interview study, themes were identified across a heterogeneous group of participants that had been recruited to reflect different characteristics. It is unlikely that recruiting a larger sample would have identified further themes.

### **Reflections on policy, practice, and directions for future research**

There is evidence to suggest that psycho-social distress occurs at different stages following the diagnosis of sight loss. Similar psycho-social distress occurs during adjustment to, and while living with, sight loss. Although different services are available, not everyone will

be aware of their availability, their own individual needs, or what they may find useful at different times.

The provision of a range of emotional support services is patchy across the UK. Professional, formal face-to-face counselling for people with sight loss in the UK demonstrates a significant inequality. There is evidence that suggests that 'counselling' in its broadest sense may be beneficial. Many services have good intentions but few have been evaluated and quality and impact are not clear. In addition, the problems experienced at different ages are sometimes similar and sometimes very different. In order to support individuals at varying stages of sight loss, different approaches may be required.

From the wider literature, guidance from the National Institute of Clinical Excellence (NICE) states that patients at high risk of depression – such as those with a significant physical illness causing disability – should be screened for depression. For those diagnosed with mild depression, healthcare professionals are advised to consider recommending to patients a guided self-help programme that is based on cognitive behavioural therapy (CBT). For those with mild or moderate depression, psychological treatment of 6-8 sessions is to be considered, and for those with severe depression this is to be considered in combination with prescribed anti-depressants.

Although NICE guidelines state that there should be provision of appropriate services for all people who have emotional support needs, the services contacted in our scoping survey did not mention these guidelines.

It is important to ascertain whether people diagnosed with low vision or blindness are receiving care as per the NICE guidelines, i.e. whether they are screened for depression at the point of diagnosis and at different times following diagnosis, and whether those found to be at risk of depression are offered treatment that is appropriate and accessible to them. The UK's *Improving Access to Psychological Therapies* (IAPT) initiative aims to ensure depression is treated by adding another 10,000 cognitive behavioural therapists in the UK by 2013. It is not known whether CBT is appropriate for people with sight loss. Concerns have been expressed over the sensitivity to sight loss of exercises in some CBT approaches that involve writing and in computerised versions of CBT (cCBT). An audit could ascertain how accessible CBT is in general for people with sight loss, and whether other or more specialist approaches are required for those adjusting to sight loss.

A number of suggestions for future research arose from this project, in particular from the systematic literature reviews:

- gaps in research were clear in the context of mixed evidence to support the notion that anxiety is more prevalent in working age adults and older people with sight loss, and that depression is more prevalent in working age adults with sight loss
- loneliness was under-researched in older people and not studied in working age adults
- for older people, the emotional consequences of experiencing complex visual hallucinations were under-researched
- most of the studies reviewed only measured emotional well-being at one point in time
- more longitudinal research is required to investigate the emotional support needs of people with sight loss over time<sup>11</sup>
- the qualitative studies reviewed suggested that older people adjusting to sight loss progress through a cycle that resembles grief. The relevance of the grief cycle to providing support for people with sight loss could be researched.

The main gap in knowledge identified by research reported here and an area for future research is in systematic evaluation of services that aim to meet the needs of people with sight loss for emotional support. The recent literature suggests that only relatively few studies have been conducted to evaluate the psycho-social effect of services. Most of those evaluated were pilots and only two were RCTs. Further research could investigate the long-term effectiveness of different psycho-social interventions.

## Conclusions

From reviews of a wide range of studies and new research this project suggests that working age adults and older people with sight loss are at an increased risk of reduced psycho-social well-being that suggests a need for emotional support. Research attention now needs to be given to how people with sight loss want and need emotional support to be provided, and what is the efficacy and cost-effectiveness of different models of support. It is possible that evidence could lend support to the development and expansion of services throughout the UK.

<sup>11</sup> Thetford et al. (2009)

## Glossary

Cognitive behavioural therapy (CBT)	A form of therapy that uses cognitive and behavioural therapy techniques to challenge negative thinking.
Computerised cognitive behavioural therapy (cCBT)	A computerised version of CBT.
Counselling	A talking therapy that uses active listening and encourages clients to gain perspective on their problems and work out how best to resolve them. Such counselling is usually carried out formally by a trained professional.
Emotional support	A supportive intervention that seeks to comfort people emotionally, in contrast to medical care, which treats ophthalmic complications, or rehabilitation, which addresses difficulties with daily living and mobility.
Grey literature	Reports or papers that have not been peer-reviewed or published, e.g. a document available on the Internet. In contrast, most academic papers are published in journals that are peer-reviewed and widely distributed by a publisher.
Mental health composite score	The SF-12/SF-36 (see below) overall score can be divided into both a physical and mental health overall score. The mental health composite score is the overall score for mental health.
Mental health subscale score	This is the subscale score for mental health that is combined with others to generate the mental health composite score of the SF-12/SF-36.

NEI-VFQ	National Eye Institute-Visual Function Questionnaire; a questionnaire to assess visual functioning (how well people are able to do tasks that require vision to do them), that includes subscales relating to social functioning and mental health.
Prevalence	The proportion from a population, e.g. the proportion of participants with sight loss who report feeling lonely.
Qualitative	A research method that typically uses interviews and focus groups to generate people's views as data. The data are then typically transcribed into text and analysed to form a summary of people's views.
Quantitative	A research method that typically uses surveys or experiments to generate data in the form of numbers (e.g. overall score on a mental health scale). Such data are then typically subject to statistical analysis to determine whether there are patterns in the data (e.g. if mental health scores are lower in people with sight loss).
Randomised Control Trials (RCTs)	An experimental method of testing the effect of an intervention. This method is considered the gold standard for testing whether an intervention works, as it reduces the various forms of bias that can occur in research. Typically RCTs recruit large numbers of participants to make generalisable conclusions, but in doing so are usually more costly to conduct.
Scoping survey	An exploratory survey that provides preliminary data on a subject. Such a survey may be useful as a forerunner or in place of more rigorous research methods, particularly when participants are not easily located.

Social functioning	An individual's ability to engage in social activities and retain social relationships.
SF-12	The 12-item version of the Short-Form Survey that broadly measures health-related quality of life.
SF-36	The 36-item version of the Short-Form Survey that broadly measures health-related quality of life.
Systematic literature review	A literature review of previously published/grey papers that have investigated a certain topic, conducted in a manner that is transparent (and so can be replicated) and seeks to identify every paper within the timeframe that would contribute to answering the research question.
Time Trade Off (TTO)	Score that measures the number of years that a person with sight loss would be willing to trade for either perfect vision (vision specific) or perfect health including perfect vision (generic).
Utility measure	A measure of quality of life, which assesses the level of risk a person with acquired sight loss would be willing to accept in order to restore their vision. For example, would a person with sight loss be willing to undergo treatment to restore their vision even if the treatment has a high risk of death?
Visionary	A national association of local voluntary organisations for blind and partially sighted people. Members are registered charities, independent of major national charities for the blind, providing services locally and acting as a central focal point to provide information to service providers and users.

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The principal investigators for this research were Professors Margot A Gosney and Christina R Victor, of the Institute of Health Sciences, University of Reading. Thomas Pocklington Trust commissioned and funded the research, which funded the appointment of Dr Samuel R Nyman as postdoctoral research fellow.

## How to obtain further information

A research findings summary entitled *Emotional Support to People with Sight Loss* by the research team is available from:

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Telephone: 020 8995 0880  
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Copies of this report in large print, audio tape or CD, Braille and electronic format are available from Thomas Pocklington Trust.

## Background on Pocklington

Thomas Pocklington Trust is a leading provider of housing, care and support services for people with sight loss in the UK. Each year we also fund a programme of 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, resource centres and volunteer-based community support services.

We strive to improve continuously the quality standards in our operational centres to meet the changing needs and expectations of our current and future service users. We are proud to be an Investor in People and a Positive about Disability organisation.

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, and improving and developing service outcomes as well as focusing on public health issues.

*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.*



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