# Understanding how the onset of sight loss affects employment

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## 1. Executive summary

### Purpose of this report

The purpose of this report is to increase our understanding of what happens to the employment status of people newly registered as blind or partially sighted. Specifically, why is it that some people feel able to stay in employment, and others don’t?

The report presents evidence about the factors that support individuals to stay in work, as well as explaining why others are unable to remain in work. It provides detail about the enablers and barriers to staying in work after experiencing sight loss, which go beyond individual employers or support from employment professionals.

The report will be useful for employers and employment professionals (for example, eye care liaison officers, vocational rehabilitation workers, occupational health providers and employment advisers) in considering how to assist people experiencing the onset of sight loss to remain in employment.

The research focused on a discrete group of blind and partially sighted people of working age, residing in the county of Kent in England. The study design provides a small amount of survey information on employment outcomes, and qualitative findings from individuals about the experiences of sight loss whilst in employment. The research concentrated on the relationship between the onset of sight loss, and its effect on employment.

### Overview

There is evidence to suggest a link between sight loss and job loss. Over a quarter of non-working registered blind and partially sighted people said the main reason for leaving their last job was the onset of sight loss or deterioration of their sight. Yet almost a third of registered people who were not in work but who had worked in the past said that they maybe, or definitely, could have continued in their job given the right support.

Evidence indicates that practical and emotional support, access to timely information and the provision of assistive technologies can aid job retention for blind and partially sighted employees. In contrast however, many employees who lose their sight take early retirement when they are at an age to do so, and many others are pressurised to resign.

### 1.3 Key findings

Three over-arching themes emerged from this study, irrespective of whether participants were still employed, or had left their last employment. These themes were; discussing sight loss with employers, adjustments at work, and support in the workplace.

Positive attitudes from employers made a significant difference in people being able to stay in work.

Some participants found that by disclosing their sight loss, they received timely and welcome support to remain in work. There were also examples of employers being comfortable recruiting someone with sight loss.

Practical support from employers helped people to adjust to working with sight loss.

Sight loss awareness training, support from disabled colleagues in senior management, occupational health advice, a commitment to uphold their legal obligations; these were all ways in which employers demonstrated a belief in their blind and partially sighted employees.

Flexible and empathic support from line managers helped people to stay in work.

Reduced hours, fewer face to face meetings, working from home, less travel, a phased return to work; these and other examples all helped ease the pressure on employees as they adjusted to sight loss.

Changes in expectations, especially productivity levels, caused conflicting emotions.

Whilst some accommodation was found to be helpful, in other cases a reduction in workload was experienced as a personal slight; and as a sign that the participant’s contribution was no longer as valued.

“I am paid for what I know rather than what I do, but this will diminish”

People in work articulated a strong personal desire to remain in employment and not to be defined by sight loss.

There was a strong emphasis on remaining as independent as possible.

“I’ve always worked. It’s important to who I am”

Larger organisations had a better awareness of the needs of blind and partially sighted people than smaller organisations.

Larger organisations had better resources and systems in place to support people with specialist needs. Smaller organisations lacked a clear policy on recruiting people with disabilities, and were more reluctant to hire individuals who would require some form of investment. This perception continues to stop some participants from applying to smaller organisations.

Support from colleagues and peers was important in adjusting to the workplace after experiencing sight loss.

Awareness training in sight loss helped this process, but this was rare. Poor understanding in the workplace led to participants feeling inadequate. This was particularly prevalent in smaller organisations, which lacked processes and policies around providing adjustments; leaving participants feeling a nuisance and leading some to give up and leave voluntarily.

Most participants no longer in work did not want to leave their employment.

A lack of understanding from management played an important role in some people leaving their jobs. Some felt they had little choice due to a lack of support from their employer, or due to health and safety reasons. Others agreed to leave, because they could see no way of being able to stay in their job, in some cases accepting redundancy.

People can be reluctant to tell their employer about losing their sight out of fear of losing their jobs.

People reported concealing their sight loss from their employer for long periods of time after it started to affect their working. There was a perception that employers would view their sight loss negatively and force them to leave.

“As long as I have been able to I’ve been hiding it, so that people underestimate its impact”

The majority of participants who were no longer in work felt this was a direct result of losing some or all of their sight.

For example, participants described difficulty travelling to work, being made redundant as a result of their sight loss, other health problems related to their sight loss, and simply losing their sight, as the main reason for leaving.

Specialist equipment made an important contribution to being able to stay in work.

Some of this equipment arrived as a result of an occupational health assessment, but in many cases specialist equipment was provided on an ad-hoc basis.

Participants’ experiences of using Access to Work were mixed.

People who used the Access to Work scheme were concerned about the length of time it took for equipment to reach them, with some left waiting for several months. Some felt that ATW assessors lacked the right skills and experience when dealing with blind and partially sighted people. In particular, there was a clear skills gap in providing advice on aids and adaptations. Despite receiving a formal assessment, blind and partially sighted people still felt that they themselves had to do much of the work in finding the right products and adaptations to help them in the workplace.

Knowledge of Access to Work was generally low.

People no longer in work had not been made aware of Access to Work. Some felt they would have secured employment again if they had known about the benefits of the scheme, such as help with travel to work.

“How would you know how to ask for something like that?”

External agencies showed a lack of awareness of schemes and initiatives to support blind and partially sighted people with retaining employment or getting back into work.

Awareness of government schemes was low, which suggests that external agencies, including local societies, have work to do in helping to inform people about schemes that can help them maintain their current employment or to seek employment.

Most participants felt that their sight loss was a significant hurdle to future employment.

The majority of participants no longer in work felt this was a direct result of losing some or all of their sight. However, support to find work, educating employers, support with travel, and building confidence, were all suggested as ways in which barriers to employment might be overcome.

Negative attitudes from employers adversely affected participants’ experiences of finding work.

Sight loss was considered by our participants as a barrier to all types of employment, and poor experiences with applying and failing to secure employment embedded a sense of despondency towards securing employment in the future.

These experiences echo those described by participants still in work. There was a clear sense of frustration and unfairness in the selection process for jobs as employers struggled to look beyond their sight loss.

“I’ve never obtained a job where I’ve had to fill out an equal opportunities form. Only ever when I have submitted a CV [have I got a job]. This is beyond a coincidence”

Participants no longer in work were unsure about what they could still do after losing their sight.

For those who were currently applying for positions, it remained challenging to judge whether they could meet the job description with their level of sight loss without “trying it out first”.

“I just don’t know what I could do, that’s the issue”

Participants in receipt of welfare benefits described a lack of understanding from Jobcentre Plus staff about work capabilities with sight loss.

They revealed complicated, time consuming and demeaning processes to accessing entitlements. Poor experiences and delays in payments have, for some, resulted in a reluctance to disrupt these processes by risking trying to work again.

### 1.4 Methods

RNIB conducted the research, in partnership with Kent Association for the Blind (KAB). There were two distinct phases:

* Phase 1: A survey of people residing in the Kent area of the UK who are registered as severely sight impaired (blind) or sight impaired (partially sighted) in the last two years.
* Phase 2: Qualitative interviews and focus groups with people identified as in employment now, or at the time they registered as blind or partially sighted. The survey in phase 1 underpinned the qualitative work in phase 2, by providing evidence of the issues people were facing. This in turn underpinned the development of discussion guides for this phase.

Participants were identified through the Kent Local Authority register of visual impairment, which is held by KAB. The study complied with the Research Governance Framework set out by Kent Social Services and authorised by Kent County Council.

#### 1.4.1 Phase 1 – survey analysis

The research team wrote to 186 people of working age (defined as between the age of 18 and 64) who had registered as blind or partially sighted in the last two years. Nineteen people took part in a telephone interview, using a structured questionnaire as part of phase 1 of the research. This represents a take-up of approximately 10 per cent, which is a standard response rate for opt in participation requests by post.

#### 1.4.2 Phase 2 – qualitative analysis

The qualitative sample was developed from the short survey completed with a range of blind and partially sighted people who had been registered within the last two years. Based on a review of answers, two typologies were created; those who have retained employment, and those who have left employment, since the onset of sight loss.

Depth interviews took place with those that had retained employment, whilst a mixture of depth interviews and a focus group were considered appropriate for those who had left employment. A total of 10 people took part in the qualitative work; 7 depth interviews and one focus group of 3 people.

#### 1.4.3 Analysis

Data was managed using a framework method, developed by the National Centre for Social Research. Both thematic and explanatory analyses were completed, which enabled researchers to produce a thematic narrative of the findings.

#### 1.4.4 Limitations of the research design

The work status of blind and partially sighted people is not routinely collected as part of the registration process, and so it was not possible to generate any meaningful quantitative data from this study. The sample size was very small, whilst participants were limited to a specific geographical area, and restricted to those who agreed to take part in the survey. The sample is therefore not representative of the wider UK working age population. The research is intended as a pilot study, to guide future work at a national level.

The qualitative work in this study has however raised some interesting questions about the enablers and barriers to employment, which echo findings from the Network 1000 research. Network 1000, which draws from a representative sample of people who are registered as blind or partially sighted, found that participants currently in work typically received some type of support from their employer; whilst a larger proportion of people no longer in work reported that they had received “no support” compared to those in work.

Testing the findings from this study with a larger, representative sample of the UK working age population such as Network 1000, or the forthcoming MyVoice research from RNIB, would enhance its validity.

### 1.5 Recommendations

Evidence generated from this research strongly suggests there is work to do to improve the employment experience of blind and partially sighted people working across a range of different organisations in the UK today. RNIB therefore makes the following recommendations:

* At the point of diagnosis, blind and partially sighted employees should receive clear and practical advice on their right to receive reasonable adjustments at work.
* Every blind and partially sighted person in work should be offered regular work-based assessments that are holistic and person-centred.
* More should be done to promote the Access to Work scheme. Awareness of Access to Work was shockingly low amongst participants in this research.
* There is a need for greater awareness among employers to understand the business benefit of employing and/or retaining disabled employees.
* A flexible approach to working hours and location should be adopted by employers, where possible.
* Sight loss awareness training should be well-publicised and readily available to all employers.
* Local societies have a role to play in making people aware of national schemes that support working age blind and partially sighted people to gain and retain employment.

This research has demonstrated a range of different experiences of people facing the onset of sight loss whilst in, or seeking, employment. A deep rooted motivation by those of working age to continue in meaningful employment reaffirms the important role that statutory services and the voluntary sector must play in improving outcomes for blind and partially sighted people.

“You have to find a way of making employers see you as a rounded person. I’m not just blind”

## 2. Introduction to the main report

The purpose of this report is to increase our understanding of what happens to the employment status of people newly registered as blind or partially sighted. Specifically, why is it that some people feel able to stay in employment, and others don’t?

The report presents evidence about the factors that support individuals to stay in work, as well as explaining why others are unable to remain in work. It provides detail about the enablers and barriers to staying in work after experiencing sight loss, which go beyond individual employers or support from employment professionals.

The report will be useful for employers and employment professionals (for example, eye care liaison officers, vocational rehabilitation workers, occupational health providers and employment advisers) in considering how to assist people experiencing the onset of sight loss to remain in employment.

There is evidence to suggest a link between sight loss and job loss. Twenty seven per cent of non-working registered blind and partially sighted people said the main reason for leaving their last job was the onset of sight loss or deterioration of their sight. However, 30 per cent of participants who were not in work but who had worked in the past said that they maybe, or definitely, could have continued in their job given the right support (Clements and Douglas, 2009).

Evidence indicates that practical and emotional support, access to timely information and the provision of assistive technologies can aid job retention for blind and partially sighted employees. In contrast however, many employees who lose their sight take early retirement when they are at an age to do so, and many others are pressurised to resign (Bruce and Baker, 2003).

For those people losing their sight who are not in work, research reveals that blind and partially sighted job seekers have specific needs related to their sight loss. They require specialist support on their journey towards employment. Research indicates that those furthest from the labour market require a more resource-intensive model of support to those who are actively seeking work. Many blind and partially sighted job seekers fall into this category (Saunders et al, 2013).

## 3. Employment statistics

### 3.1 UK working age population

There are approximately 84,000 registered blind and partially sighted people of working age in the UK (RNIB 2014). However, according to the Labour Force Survey (LFS), around 113,000 people of working age in the UK self-report that they are “long-term disabled with a seeing difficulty”. Included in this population are people with the most severe sight loss (ie people on the register), and in addition, those who may not be eligible for registration but whose sight loss still impacts on their ability to work or the job they can do (Hewett with Keil, 2015).

### 3.2 UK working age employment figures

There are two main research studies that focus on the employment status of people with sight loss. The Network 1000 reports (Douglas et al, 2006; 2009), which draw from a representative sample of people who are registered as blind or partially sighted; and RNIB's secondary analysis of the LFS (Hewett with Keil, 2015).

#### 3.2.1 Network 1000

Registered blind and partially sighted people are significantly less likely to be in paid employment than the general population or other disabled people. Looking at people of working age in 2006/07, 33 per cent of registered blind and partially sighted people were in paid employment, compared to 77 per cent of the general population (Clements and Douglas, 2009).

#### 3.2.2 Labour Force Survey

The LFS found that employment rates were approximately 45 per cent for people “long-term disabled with a seeing difficulty”, compared to almost 73 per cent of all working age people. At all ages, and all levels of education, people “long term disabled with a seeing difficulty” were less likely than the rest of the working age population to be in employment and more likely to be unemployed (Hewett with Keil, 2015).

## 4. Aims of the research

The research focused on a discrete group of blind and partially sighted people of working age, residing in the Kent region of England. The study design provides a small amount of information on employment outcomes, and qualitative findings from individuals residing in this area about their experiences of sight loss whilst in employment. The research concentrated on the relationship between the onset of sight loss, and its effect on employment.

The research is intended as a pilot study, to guide future work at a national level. It is hoped that this study could be replicated with a greater number of organisations who hold the register of visual impairment, which would significantly increase the number of participants. This study provides evidence of issues faced by newly registered working age people. A larger sample across a wider geographical spread would allow RNIB researchers to confirm the validity of these findings.

The overall aims of the research project were to:

* examine what happens to the employment status of people experiencing the onset of sight loss
* examine whether people experiencing the onset of sight loss receive adequate, employment-related support, whether they are in work or not
* understand the enablers and barriers to job retention, paying particular attention to employee's access to external sources of support.

## 5. Terminology

This report uses the term **blind and partially sighted people** to describe people who are registered **severely sight impaired** (blind) or **sight impaired** (partially sighted), or eligible for registration. The terms severely sight impaired, and sight impaired, are only used when referring to information taken directly from the Kent Local Authority register of visual impairment.

**Access to Work** is a government funded scheme that provides practical support for people with a disability, health or mental health condition. The grant is intended to help people, including people with sight loss, to:

* start work
* stay in work
* move into self-employment or start a business.

In 2010, the **Equality Act** replaced the 1995 Disability Discrimination Act, as the main piece of legislation covering the employment of blind and partially sighted people. It protects against unfair dismissal on the grounds of disability, and covers issues such as recruitment, retention, terms of employment, reasonable adjustments, and provision of accessible information.

## 6. Methodology

RNIB conducted the research, in partnership with Kent Association for the Blind (KAB).

There were two distinct phases to the research:

* Phase 1: A survey of people residing in the Kent area of the UK who are registered as severely sight impaired (blind) or sight impaired (partially sighted) in the last two years.
* Phase 2: Qualitative interviews and focus groups with people identified as in employment now, or at the time they registered as blind or partially sighted. The survey in phase 1 underpinned the qualitative work in phase 2, by providing evidence of the issues people were facing. This in turn underpinned the development of discussion guides for this phase.

We chose people who had registered as severely sight impaired or sight impaired in the last two years for two reasons:

* This is a probable indicator of someone who had recently lost their sight.
* We were likely to engage with people who had more recently dealt with the processes, systems and emotional factors related to employment that are relevant today.

Participants were identified through the Kent Local Authority register of visual impairment, which is held by KAB.

### 6.1 Ethical considerations

As the registration list is held by KAB on behalf of the local authority, authorisation was required from Kent County Council. The study complied with the Research Governance Framework set out by Kent Social Services and was approved by the Operational Research Manager, Families and Social Care at Kent County Council before commencing. Kent Social Services approved the consent forms, information sent to participants and the interview schedules for both phases of the research.

Interviewers for both phases of work were given guidance notes on how to deal with any emotional or practical issues for participants as a result of taking part in the study; including how to refer to RNIB’s emotional support line if necessary.

### 6.2 Phase 1 – survey analysis

Phase 1 used a structured questionnaire to obtain details relating to; people's current employment status, their employment status at the time of registration, and their employment status when they started to lose their sight. Information was also collected on the type of support they received and the impact it had (see Appendix 1). This survey was conducted over the telephone by Viewpoint, an award-winning social enterprise that provides a telephone research service to public and third sectors. Viewpoint's understanding of sight loss and wider disability issues is uniquely informed by interviewers’ direct experiences. Viewpoint employs people removed from the job market such as the long term unemployed or those with a disability, and includes a team of blind and partially sighted research assistants.

This exercise was undertaken to develop a sample for the qualitative work, and helped to give the researchers an overview of key issues which underpinned the development of discussion guides for the qualitative work that followed.

Through KAB, an opt in process was deployed; the research team wrote to 186 people of working age (defined as between the age of 18 and 64) who had registered as blind or partially sighted in the last two years. People were sent an information sheet explaining the research (see Appendix 2) and a consent form asking participants to confirm they were willing to take part in a 25 minute telephone interview (see Appendix 3). Both documents were provided in participants’ preferred format; and were available on audio tape, CD, DAISY format, Braille and large print. The response was low, and so a follow-up letter was sent to 175 people.

In total, 19 people agreed to take part in a telephone interview as part of phase 1 of the research. This represents a take-up of approximately 10 per cent, which is a standard response rate for opt in participation requests by post.

#### 6.2.1 Phase 1 participant characteristics

Table 1 below, is a basic sample characteristics table for phase 1 participants. There are 10 male and 7 female participants. The age range of participants is as follows: one person is aged between 18 and 25; 1 person is aged between 26 and 35; 7 people are aged between 36 and 49; and 10 people are aged 50 and over. Seventeen people describe their ethnicity as white, and 2 people describe their ethnicity as non-white. Nine people are registered as severely sight impaired (blind) and 10 people are registered as sight impaired (partially sighted). Six people were in employment at the time of registration, and 13 people were not in employment at the time they registered.

**Table 1: A basic sample characteristics table for phase 1 participants**

|  |  |
| --- | --- |
| **Characteristics** | **Number of participants** |
| Male | 10 |
| Female | 9 |
| Age: 18-25 | 1 |
| Age: 26-35 | 1 |
| Age: 36-49 | 7 |
| Age: 50 + | 10 |
| Ethnicity: White | 17 |
| Ethnicity: Non-white | 2 |
| Severely sight impaired (blind) | 9 |
| Sight impaired (partially sighted) | 10 |
| Employed | 6 |
| Not in employment | 13 |

### 6.3 Phase 2 – qualitative analysis

The qualitative element of this study had three main aims:

* To describe the experience of retaining and also seeking employment as a blind and partially sighted person.
* To understand the key issues and barriers facing blind and partially sighted people and employment.
* To describe the extent to which statutory programmes have made a difference to retaining and finding employment.

Qualitative research is ideally placed to elicit rich descriptions of people’s experiences, attitudes and behaviours. Data collection techniques enable researchers to be responsive and uncover depth and detail that may be hidden from purely quantitative analysis.

Our decision to include a qualitative element reflects the complexity of issues that blind and partially sighted people are faced with when trying to gain or retain employment. We aimed to conduct up to ten depth interviews with blind and partially sighted people who have retained employment, and conduct one focus group with blind and partially sighted people who have left employment since the onset of sight loss.

#### 6.3.1 Sample

In qualitative research, a sample should ensure as much range and diversity across key characteristics as is possible within the resource constraints of the project. Qualitative samples are not required to be representative of the wider population in terms of the proportion of people with certain key characteristics; instead they are purposely selected to ensure that the full range and diversity of the key characteristics is represented.

For example, if a key sampling criterion for a study is the number of people still in employment and now out of employment, a qualitative sample should not reflect the normal distribution of this in the population, but cut across that distribution ensuring both the employed and unemployed are considered equally.

For this particular study, the qualitative sample was developed from the short survey completed with a range of blind and partially sighted people who had been registered within the last two years. Based on a review of answers, two typologies were created; those who have retained employment since sight loss and those who have left employment since sight loss. It was decided that depth interviews with those that had retained employment would elicit a deeper understanding, which would allow the researcher to draw on specific examples of what works well. For those who had left employment, a mixture of depth interviews and a focus group were considered appropriate. A group setting would facilitate discussion of wider issues that blind and partially sighted people think important for employers, government and other decision makers to consider when employing someone with sight loss.

#### 6.3.2 Recruitment

To recruit participants, the lead researcher telephoned people who had taken part in the short, phase 1, telephone survey, and had opted in to being re-contacted. The next phase of the research was explained, and further consent was sought at the end of the telephone conversation. A final layer of verbal consent was obtained at the beginning of the depth interviews and focus group discussions. Obtaining additional verbal consent in this way was agreed with the ethics team at Kent Social Services.

Participants were informed of the nature of the study and that taking part was completely voluntary. Those attending focus groups were refunded for travel expenses. A total of 7 depth interviews and one focus group took place.

#### 6.3.3 Phase 2 participant characteristics

Table 2 below, is a basic sample characteristics table for phase 2 participants. There are 7 male and 3 female participants. The age range of participants is as follows: one person is aged between 18 and 25; 5 people are aged between 36 and 49; and 4 people are aged 50 and over. Nine people describe their ethnicity as white, and 1 person describes their ethnicity as non-white. Five people are registered as severely sight impaired (blind) and 5 people are registered as sight impaired (partially sighted). Six people were in employment, and 4 people were no longer in employment.

**Table 2: A basic sample characteristics table for phase 2 participants**

|  |  |
| --- | --- |
| **Characteristics** | **Number of participants** |
| Male | 7 |
| Female | 3 |
| Age: 18-25 | 1 |
| Age: 26-35 | 0 |
| Age: 36-49 | 5 |
| Age: 50 + | 4 |
| Ethnicity: White | 9 |
| Ethnicity: Non-white | 1 |
| Severely sight impaired (blind) | 5 |
| Sight impaired (partially sighted) | 5 |
| Employed | 6 |
| Not in employment | 4 |

#### 6.3.4 Data collection

Depth interviews were conducted over the telephone by researchers. The focus group took place at KAB, which is an environment participants are familiar and comfortable with. A topic guide was used to ensure consistency of coverage across the interviews and focus group. The guides are appended to this report (see Appendices 4-6), but included sections on employers, work colleagues, agency support, and value placed on employment and how these factors worked together.

It was important for the participant to lead the discussion on what factors most affected their ability to retain or leave employment. The role of the researcher and the topic guide was to facilitate this cognitive process for people. While participants led the discussion, researchers ensured, as far as possible, that time was given to discussion of each of the key factors affecting their employment.

#### 6.3.5 Analysis

Data was managed using a framework method, developed by the National Centre for Social Research (Ritchie et al., 2014). This first involves creating a descriptive framework comprising a series of headings and sub-headings that are relevant to the research objectives. The second stage of the process involves generating summaries of each piece of data and attaching each summary to the relevant sub-heading in the framework. Based on this organised data, both thematic and explanatory analyses were completed which enabled researchers to produce a thematic narrative of the findings.

### 6.4 Limitations of the research design

It was not possible to generate any meaningful quantitative data from this study. The work status of blind and partially sighted people is not routinely collected as part of the registration process, and so we were unable to determine, for example, the number of working age people with sight loss who were still in work, compared with the entire working age population included on the Kent register. Nor could we establish how many people had left employment in the two years since they had registered with the local authority.

The sample size was very small, whilst participants were limited to a specific geographical area, and restricted to those who agreed to take part in the survey. The sample is therefore not representative of the wider UK working age population. The research is intended as a pilot study, to guide future work at a national level.

The qualitative work in this study has however raised some interesting questions about the enablers and barriers to employment, which echo findings from the Network 1000 research. Network 1000 (Douglas et al, 2009) draws from a representative sample of people who are registered as blind or partially sighted. They found that participants currently in work typically received some type of support from their employer; 89% compared to 11% who received no support. A larger proportion of people no longer in work reported that they had received no support compared to those in work (38% and 11% respectively). The differences were particularly high in relation to special aids or equipment to do the job, and in relation to support from other staff.

Testing the findings from this study with a larger, representative sample of the UK working age population such as Network 1000, or the forthcoming MyVoice research from RNIB, would enhance its validity.

## 7. Phase 1: A survey of people residing in the Kent area of the UK who registered as blind or partially sighted in the last two years

### 7.1 Overview

The data generated from the telephone survey is indicative only of potential patterns (eg in occupations and qualification levels), and the types of issues facing newly registered working age people in respect of employment. The main purpose of this process was to develop a sample for the qualitative work, and to help give researchers an overview of key issues which underpinned the development of discussion guides for the qualitative work that followed.

### 7.2 Survey topics

The telephone survey covered a range of topics (see Appendix 1), including:

* basic sample characteristics
* occupational group
* employment sector
* qualifications
* employer support
* the Access to Work scheme
* rehabilitation services
* reasons for leaving work
* government employment support services
* reasons for not being in work now
* support required to find employment in the future.

Specific areas were discussed or excluded during the one-to-one telephone interviews as appropriate, depending on the employment status of each participant.

Table 3 below offers a breakdown of the employment status of the 19 participants in phase 1, based on four scenarios. Scenario 1 describes 6 people who were in work at the time they registered as blind or partially sighted, and are still in work now; scenario 2 describes 10 people who were in work at the time when they registered, but who are not in work now; scenario 3 describes people who were not in work at the time they registered, but are in work now (there is no-one in this scenario); and scenario 4 describes 3 people who were not in work at the time they registered, are who are not in work now.

**Table 3: A breakdown of employment status in relation to sight loss for phase 1 participants**

|  |  |  |
| --- | --- | --- |
| **Scenario** | **Employment situation** | **Number**  |
| Scenario 1 | In work at the time of sight loss / in work now | 6  |
| Scenario 2 | In work at the time of sight loss / not in work now | 10  |
| Scenario 3 | Not in work at the time of sight loss / in work now | 0 |
| Scenario 4 | Not in work at the time of sight loss / not in work now | 3  |

### 7.3 Employment situation

Participants were employed in a range of different occupations. Those still in work tended to be employed in more senior positions; for example, managers, directors or professional occupations as defined by the Standard Occupational Classifications, produced by the UK Office of National Statistics (ONS 2010). Those who were no longer in employment had typically been employed in administrative, secretarial, caring and leisure roles.

Participants were employed in public, private and not for profit organisations. Most of the participants who are no longer in work (9/10) were previously employed in the public sector.

The majority of participants still in work held higher level qualifications (ie degree or above), whilst the majority of participants no longer in work were not qualified to this level.

### 7.4 Types of support

The majority of people still in work received strong support from their employer. In contrast, those participants no longer in employment typically had received little or no support from their previous employer.

There was a range of responses in relation to Access to Work. Very few people who are no longer in employment received any information about, or support from Access to Work. The number of people who received information about, and then support from, Access to Work was greater for those still in employment; but overall the level of knowledge and subsequent support was still low.

No-one in the survey received any rehabilitation support directly connected to their employment. Having registered, the majority of people were contacted by, and received support from KAB. However, this rehabilitation work focused on supporting people to develop independent living skills; for example, through practical adaptations in the home, or training in how to use a mobility cane. One person received advice about lighting, which, since they sometimes worked from home, did have a positive impact on their employment situation.

### 7.5 Participants no longer in employment

The majority of participants who were no longer in work felt this was a direct result of losing some or all of their sight. For example, participants described difficulty travelling to work, being made redundant as a result of their sight loss, other health problems related to their sight loss, and simply losing their sight, as the main reason for leaving.

A small minority (2/10) of people chose to leave their job voluntarily, but a more common response was that participants did not want to leave their employment. Some felt they had little choice due to a lack of support from their employer, or due to health and safety reasons. Others agreed to leave, because they could see no way of being able to stay in their job, including accepting redundancy.

Participants described a range of issues for not working now, including their sight loss, health-related reasons, health and safety concerns, and simply out of choice. This variation was reflected in participants’ responses to whether they were seeking employment now. Several participants had decided that work was no longer an option, and so were not actively seeking work, and did not want it. However, some people were still keen to find new employment.

Most participants felt that their sight loss was a significant hurdle to future employment. However, support to find work, educating employers, support with travel, and building confidence, were all suggested as ways in which barriers to employment might be overcome.

## 8. Phase 2: Qualitative interviews and focus groups with people identified as in employment now, or at the time they registered as blind or partially sighted

### 8.1 Introduction

Two typologies were created for the qualitative work in this study, based on a review of answers from the telephone survey. These were:

* participants who have retained employment since the onset of sight loss
* participants who have left employment since the onset of sight loss.

Participants were treated as two distinct groups, with separate discussions about the issues they faced. However, three over-arching themes in particular cut across both narratives, irrespective of whether participants were still employed, or had left their last employment. These themes are as follows:

* Discussing sight loss with employers.
* Adjustments at work.
* Support in the workplace.

### 8.2 Discussing sight loss with employers

Apparent from the qualitative work is that talking to employers about the onset of sight loss, whether in work or not, is a vexed issue. In the next section there are several examples of organisations and staff acting in helpful and supportive ways when faced with an employee experiencing the onset of sight loss, which has enabled participants to remain in work. Yet many participants, whether still in work or not, spoke candidly about “not letting on” to their employer that they were losing their sight out of fear of losing their jobs.

A range of participants reported concealing their sight loss from their employer for long periods of time after it started to affect their working. There was a perception that employers would view their sight loss negatively and force them to leave. Participants described this process as two fold; at the point their sight was deteriorating such that it was affecting their work, this was also the point they realised the impact of their deteriorating sight on the everyday. Some participants found this difficult to deal with emotionally and did not tell employers in fear of being viewed differently. When sight loss is known, one participant explained how colleagues have consistently underestimated the difficulties they have faced:

“As long as I have been able to I’ve been hiding it, so that people underestimate its impact”

For those seeking work, the situation is equally nuanced. While participants largely agreed they would like to work again, they felt far away from achieving meaningful employment. Sight loss was considered a barrier to all types of employment, and poor experiences with applying and failing to secure employment embedded a sense of despondency towards securing employment in the future.

Some participants had been actively looking for work for several years, having relatively good success getting through to the second round of recruitment processes. The interview stage raised a number of issues for participants. Having disclosed their sight loss on an application form, one participant described an interview consisting entirely of questions about their sight loss. Another described how they sometimes did not tick the disability box in equal opportunities forms in applications, thinking this had negatively affected their chances in the past.

These experiences echo those described by some participants still in work. There was a clear sense of frustration and unfairness in the selection process for jobs as employers struggled to look beyond their sight loss. One participant, still in work, made the following observation:

“I’ve never obtained a job where I’ve had to fill out an equal opportunities form. Only ever when I have submitted a CV [have I got a job]. This is beyond a coincidence”

There were however examples of employers being comfortable recruiting someone with sight loss, and indeed one employer promoting one of the participants at interview; such was their belief in this person’s abilities.

Fear of discrimination in this study has often been based on the reality of experience, but equally, the reality of experience for others is that by disclosing their sight loss, they have received timely and welcome support.

### 8.3 Adjustments at work

Practical adjustments, as well as more subtle psychological ones, played a key role in participants being able to stay in work. There were a number of different aspects to this.

#### 8.3.1 Specialist equipment

Participants explained how specialist equipment made an important contribution to being able to stay in work. They described a number of items to help with everyday tasks, including:

* large screen mobile phones
* large computer screen and keyboard
* a signal cane to help navigate the journey to and from work
* video magnifier
* text reading and voice recognition software
* changes in lighting such as up lifter lamps
* large print copies of documents
* Windows accessibility options, such as using black text with white writing.

Some of this equipment arrived as a result of an occupational health assessment, but in many cases specialist equipment was provided on an ad-hoc basis. Few people were aware of, or benefitted from, Access to Work (discussed further below). Others spoke about simple changes to the working environment, for example by re-positioning desks to make the best use of light and access. A common theme however was that participants were often left to sort things out for themselves.

#### 8.3.2 Changes in working practices

Participants spoke about changes in their working practices, underpinned by flexible and empathic support from line managers. Several participants explained that they had been able to reduce their office presence, such that they could work from home on one or more days a week. This helped to reduce the strain of travel for some, and in one particular case reduced exposure to damaging fluorescent lighting. Occasionally these changes were the result of Occupational Health Adviser recommendations, or from a specialist support worker, who were able to suggest practical ways to reduce stress and to manage workload.

“As long as the work gets done, he [managing director] doesn’t mind how it’s done”

Others were able to reduce the number of hours they worked, and to attend fewer meetings. This helped ease the pressure on employees as they adjusted to their sight loss. One person explained how they had been able to establish a comfortable office at home, where they would complete all computer-based work.

#### 8.3.3 Changes in expectations

Participants felt that employers’ expectations often changed with regard to their productivity levels. Several spoke about how managers were “managing expectations” amongst their team; advising colleagues to adjust to a reduced output. This particular intervention caused some conflicting emotions. Whilst some accommodation was described as helpful, in most cases a reduction in workload felt like a personal slight; and as a sign that the participant’s contribution was no longer as highly valued.

Several people struggled with the combination of a change in personal capability and reduced expectations from management and colleagues. Two described suffering from depression, despite being able to remain in employment, and receiving cognitive-behavioural therapy as a consequence.

For some, these changes in expectations were the result of changing working practices, which participants were not able to keep up with due to their sight loss. One participant described their frustration at being able to do only a third of what they were once capable of, which now mostly comprised of telephone-based support to others in the field.

“I am paid for what I know rather than what I do, but this will diminish”

But there were also examples of participants adapting their role to suit their level of vision, with positive results. Overall, adjustments at work were underpinned by good management understanding throughout, even if this did not always result in practical solutions.

#### 8.3.4 Larger versus smaller organisations

Larger organisations were considered to have a better awareness of the needs of blind and partially sighted people, and able to better accommodate adjustments to the working environment. Participants considered them to have better resources and systems in place to support people with specialist needs. Human resources teams and Equality Officers were viewed as positive advocates of equality in the workplace.

Smaller organisations lacked a clear policy on recruiting people with disabilities. Based on previous experiences, participants felt small businesses were more reluctant to hire individuals who would require some form of investment; whether that was investment of time or money, in making adjustments to the workplace. This perception continues to stop some participants from applying to smaller organisations.

It was felt that all types of organisations had work to do in being able to see beyond the disability of the person applying for a job. Participants felt strongly that with the right kind of adjustments to the working environment they could make a positive contribution to the workplace.

#### 8.3.5 Outside agency support

There was a range of views related to statutory and outside agency support available to working age blind and partially sighted people. A prominent theme across both the in-work and out-of-work groups was a lack of awareness of schemes and initiatives in place to support blind and partially sighted people with retaining employment or getting back into work.

##### 8.3.5.1 Access to Work

Awareness of specialist schemes to help people retain work was low. The group who had left employment since losing their sight had not been made aware of Access to Work, for example. One person suggested that they would have secured employment again if they had known about the benefits of the scheme, as they had indicated they could not afford expensive taxis to the workplace: something Access to Work could have helped with.

“How would you know how to ask for something like that?”

Awareness of Access to Work and similar schemes was somewhat higher in the employed group. While participants recognised the benefits of the scheme; namely, providing accessible products at no cost to the employer, there had been a mixture of experiences with the scheme. There was a level of concern about the length of time it took for equipment to reach participants with some left waiting several months for equipment to arrive.

In contrast, one participant was especially grateful for the assistance of a Progression Adviser, organised through Access to Work. They described the adviser as “absolutely crucial” in ensuring all of the recommendations made through Access to Work were implemented. When asked to reflect on why he was still in employment, he declared:

“The presence of an external Progression Adviser, who galvanises and glues together the coordination of work-based adaptations; who brings together managers and health and safety officers, and successfully implements Access to Work recommendations”

There was also mixed experiences with the people carrying out Access to Work assessments. Some felt that assessors lacked the right skills and experience when dealing with blind and partially sighted people. In particular, there was a clear skills gap in providing advice on aids and adaptations. Despite receiving a formal assessment, blind and partially sighted people still felt that they themselves had to do much of the work in finding the right products and adaptations to help them in the workplace.

##### 8.3.5.2 Local societies

Support from local societies was viewed as the gateway for practical services for blind and partially sighted people. Participants spoke highly of the local society support; which helped with equipment like white canes, liquid level indicators and BumpOn stickers. There was no expectation that local societies and groups should provide support in the workplace and participants felt this was the job of employers or the government to take responsibility.

In terms of charitable organisations, participants reported little contact with national charities like RNIB. Awareness of government schemes was low, which suggests that external agencies, including local societies, have work to do in helping to inform people about schemes that can help them maintain their current employment or to seek employment.

### 8.4 Support in the workplace

Support in the workplace had three aspects; organisational, managerial and colleague support.

#### 8.4.1 Employer support

The previous section offered contrasting examples of larger and smaller employers supporting participants at work. Participants felt larger organisations were better equipped to deal with sight loss related issues. Two reasons were given for this; the first being that larger organisations have a greater awareness of their legal obligations, for example under the Equality Act; and secondly, because they had organisational departments, such as occupational health, already set up to offer support.

This did not, however, entirely exclude support issues for larger organisations. Participants spoke about senior managers withholding details of the participants’ sight loss from business partners and external agencies. On the one hand, this allowed participants to operate on an equal footing, ie without the fear of discrimination, but it also left some participants exposed, when they found themselves in situations when disclosure became inevitable.

In contrast, one participant described how his organisation encouraged him to give a presentation to his colleagues, explaining the issues he was facing, and how they might support him. Another described a manager with disabilities elsewhere in the company, who helped a great deal when this participant faced negative comments from colleagues. And as discussed earlier, one participant has recently been promoted (via interview), which they felt demonstrated the organisation's faith in their ability.

#### 8.4.2 Line management support

Equally important was flexible and empathic support from line managers. This did not always translate into practical support, but when it did, participants gave examples of line managers signing off hospital appointments as disability leave, visiting the participant in their own time in order to set up a phased return to work, and in general terms, by thinking through issues a participant might face in any given work situation. Sometimes this was emotional, rather than practical support, but it was welcome nevertheless. A lack of understanding from management played an important role in some people leaving their jobs.

#### 8.4.3 Colleague support

In the main, participants were appreciative of, and encouraged by, the support they received from work colleagues. Colleague and peer support was viewed as vital for participants as some level of understanding and empathy was said to go a long way in adjusting to the workplace after sight loss. Poor understanding in the workplace led to participants feeling inadequate and “not pulling their weight”; this was particularly prevalent in much smaller organisations that were viewed as coping less well with making basic adjustments to the workplace or working conditions. They lacked processes and policies around providing adjustments, which left participants feeling a nuisance to the employer and eventually leading many to give up and leave voluntarily.

With one exception (mentioned above) participants’ work colleagues did not receive any awareness training in sight loss issues. One participant felt that this lack of training had an adverse effect on the team, who reacted negatively to their return to work. They described colleagues as unsure as to what was expected of them; expressed as a fear from staff that they would be caring for the participant, rather than getting on with their own work.

Some people felt ambiguous about this support. Whilst it was appreciated, there was also resentment at having to rely on others to do work that, until recently they were able to do without assistance.

### 8.5 Issues faced by only one group of participants

There were several issues pertinent to only one of the sample groups.

#### 8.5.1 Participants in employment now

##### 8.5.1.1 What about the future?

Depth interviews explored why people had felt motivated to continue working, despite the advent of sight loss. All of the participants articulated a strong personal desire to remain in work and not to be defined by sight loss. There was a strong emphasis on remaining as independent as possible.

“I’ve always worked. It’s important to who I am”

For some, there was a financial imperative to remain in work, which dovetailed with a responsibility to keep working in order to provide for the family.

However, the majority of participants expressed some degree of anxiety when contemplating future employment. Those without manual jobs were more optimistic about continuing their employment, but any further deterioration in their sight left a level of uncertainty about longer-term employment opportunities. Participants felt a moral obligation not to carry on working in a job they are no longer able to do well.

#### 8.5.2 Participants seeking employment only

A number of key issues were raised when considering future employment with those who are no longer in employment.

##### 8.5.2.1 Future employment

Participants were unsure about what they could still do in work after losing their sight. Those who had left the workplace voluntarily felt this was their only option, as their occupation meant they had to have useful vision to complete their work. This was common with people who had a trade or had been in the same role for most of their working life. Unless they could continue doing the job in the same way, it was not worth keeping it.

This “all or nothing” approach was, for some, a barrier to considering other types of work. For those who were currently applying for positions, it remained challenging to judge whether they could meet the job description with their level of sight loss without “trying it out first”.

“I just don’t know what I could do, that’s the issue”

##### 8.5.2.2 Quality of jobs

It was widely perceived that jobs on offer to blind and partially sighted people can be low paid, temporary and below the skill level people have been accustomed to. Views were divided on why this was the case. While some participants blamed the current economy for creating more temporary jobs, others felt that it was only entry level jobs that they would have any chance of securing. This further compounded the feeling that they were taking a “step down” in their careers.

##### 8.5.2.3 Welfare entitlements

There was also some level of concern related to employment and welfare entitlements. Poor experiences with Jobcentre Plus and DWP, with delays in payments have, for some, resulted in a reluctance to disrupt these processes by declaring a desire to work again, or by taking a job they were not confident of retaining.

Those in receipt of either Employment Support Allowance or Job Seekers Allowance described complicated, time consuming and demeaning processes to accessing entitlements. There was a lack of understanding from Job Centre staff about people’s work capabilities after the onset of sight loss. Another participant had refused to claim anything, explaining they did not want to be viewed as a “sponger” or someone taking [money] from the state.

## 9. Suggestions for future research

There are a number of suggestions for future research in the UK.

* Quantitative analysis of a representative sample of the UK working age population who had registered within the last two years, in order to establish: the number of people still in work, compared with the entire working age population; and the number of people who were in work at the time of registration, but who are no longer in work. Choosing people registered in the last two years is a probable indicator of someone who had recently lost their sight. It also means we are likely to engage with people who have more recently dealt with the processes, systems, and emotional factors related to employment that are relevant today.
* Qualitative research of the UK working age population who had registered within the last two years, in order to unpick the enablers and barriers to employment, and to compare the findings with this study. Depending on the sample size, this could even include a focus on specific job roles.
* Test the findings from this study with an existing, larger, representative sample of the UK working age population; for example Network 1000 or the forthcoming MyVoice research from RNIB.
* Employer knowledge of, and attitudes toward, applicants and employees who are blind and partially sighted; and the effect this has on the types of jobs available to people with sight loss.

## 10. Conclusion and recommendations

Evidence generated from this research strongly suggests there is work to do to improve the employment experience of blind and partially sighted people working across a range of different organisations in the UK today. RNIB would recommend:

* At the point of diagnosis, blind and partially sighted employees should receive clear and practical advice on their right to receive reasonable adjustments at work.
* Every blind and partially sighted person in work should be offered regular work-based assessments that are holistic and person-centred.
* More should be done to promote the Access to Work scheme. Awareness of Access to Work was shockingly low amongst participants in this research.
* There is a need for greater awareness among employers to understand the business benefit of employing and/or retaining disabled employees.
* A flexible approach to working hours and location should be adopted by employers, where possible.
* Sight loss awareness training should be well-publicised and readily available to all employers.
* Local societies have a role to play in making people aware of national schemes that support working age blind and partially sighted people to gain and retain employment.

This research has demonstrated a range of different experiences of people facing sight loss in or seeking employment. A deep rooted motivation by those of working age to continue in meaningful employment reaffirms the important role that statutory services and the voluntary sector must play in improving outcomes for blind and partially sighted people.

“You have to find a way of making employers see you as a rounded person. I’m not just blind”

## 11. References

Further information and links to all the references listed in this section can be found at our Knowledge and Research hub: rnib.org.uk/research

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## 12. Appendices

### Appendix 1: Phase 1 survey questions

#### Section 1: Demographics

1. Age

Record year

1. Gender

Male / Female

1. Ethnicity

Refer to ONS list (provided)

1. Registered blind or partially sighted

Please state which

1. Eye condition

Please explain

1. What is the highest qualification or education level you have achieved?

Refer to Network 1000 categories (provided)

1. When did you start losing your sight?

Month / Year

1. What was the length of time between your first hospital appt and certification / registration?

Months / Years

1. How long ago were you registered?

Months / Years

#### Section 2: Level of vision

1. Which of the following best applies to you?
* I can see well enough to recognise a friend who is across the road

Yes / no

**If yes, go to Question 11**

* I can see well enough to recognise a friend who is across the room

Yes / no

**If yes, go to Question 11**

* I can see well enough to recognise a friend who is at arm’s length away

Yes / no

**If yes, go to Question 11**

* I can see well enough to recognise a friend if I get close to his or her face

Yes / no

1. Which of the following best applies to you?
* I can see well enough to read ordinary newspaper print

Yes / no

**IF yes, go to Question 12**

* I can see well enough to read a large print book

Yes / no

**IF yes, go to Question 12**

* I can see well enough to read a newspaper headline
1. Please describe briefly any useful vision you have?
2. Which of the following best applies to you?
* I can see more than I could a year ago
* I can see less than I could a year ago
* I can see about the same as I could a year ago
* I’m not sure
1. What additional methods do you use to access information?

Record all that apply

#### Section 3: Employment status

1. Were you in paid employment at the time of sight loss OR your first hospital appt?

Yes / no

1. Are you in paid employment at the moment?

Yes / no

1. Were you in paid employment at time of registration?

Yes / no

This provides four possible scenarios:

* Scenario 1: In employment at the time of sight loss – and working now (Q15 = yes; Q16 = yes)

Questions 18 – 49

* Scenario 2: In employment at the time of sight loss – but not working now (Q15 = yes; Q16 = no)

Questions 50 – 91

* Scenario 3: Not in employment at the time of sight loss – and still not working (Q15 = no; Q16 = no)

Questions 92 – 113

* Scenario 4: Not in employment at the time of sight loss – but working now (Q15 = no; Q16 = yes)

Questions 114 – 147

#### Scenario 1: in employment at the time of sight loss – and working now

From Section 3: Employment Status – Q15 = yes; Q16 = yes

##### Present employer

1. What is your current job title?
2. Could you give a brief description of your role and responsibilities?
3. Is it a permanent or temporary job?
4. If the job is temporary, is it?
* Seasonal work
* Done under contract for a fixed period or for a fixed task
* Agency temping
* Casual type of work
* Some other way that it is not permanent? (please explain)
1. Is your job full-time or part-time?

Record the number of hours

1. Do you work in the public, private or voluntary/charity sector?
2. Approximately how many people work for your employer?
* Less than 10
* Between 10 and 50
* Between 50 and 250
* More than 250
1. Salary (£):
2. Are you the main income provider in your household?

Yes / no

1. Are you in the same job as when you started losing your sight?

Yes / no

**If yes, go to Question 41**

**If no, continue to Question 28**

**“I would like to find out about your employer at the time you started to lose you sight.”**

1. When did you change jobs?

Record month / year

1. What was the job title of the job you were in when you started to lose your sight?
2. Could you give a brief description of your role and responsibilities at that time?
3. Salary (£):
4. Did you receive any support from this employer as a result of your sight loss?

Please explain

1. What was the reaction of your work colleagues to your sight loss?

Please explain

1. What was the main reason for changing jobs?

Please explain

1. Was it your choice to change jobs?

Please explain

1. Please describe what happened with your employer?
2. Have you had any other jobs between the job you were in when you started to lose your sight, and your current job?

Yes / no

**If no, go to Question 41**

Please record job title and a brief description of roles and responsibilities

1. What was the main reason for changing jobs?

Please explain for each job

1. Was it your choice to change jobs?

Please explain

1. Have you had any periods of unemployment between changing jobs?

Please explain

##### Present employer (continued)

1. **Have you received any support from your present employer as a result of your sight loss?**

Please explain

1. What was the reaction of your work colleagues to your sight loss?

Please explain

1. Have you received any information about Access to Work?

Yes / no

**If no, skip Questions 44-45**

1. Who provided you with this information?

For example, employer, rehabilitation worker, RNIB, Action for Blind People

1. Have you received any support from Access to Work?

Please explain

1. Can you describe any rehabilitation training you have received whilst in work? For example, mobility or independent living skills training?

Record which organisation provided the rehabilitation training and brief description

1. Can you describe any employed-related support from a specialist organisation you have received whilst in work, such as RNIB or Action for Blind People?

Record which organisation provided the support and brief description

1. What difference, if any, has being registered made to your employment prospects?

Please explain

1. **If we need to, are you happy for us to contact you again to talk about your experiences in more detail?**

Yes / no

#### Scenario 2: in employment at the time of sight loss – but not working now

From Section 3: Employment Status – Q15 = yes; Q16 = no

##### Employer at the time of sight loss

1. What was your job title at the time you started to lose your sight?
2. Could you give a brief description of your role and responsibilities?
3. Was it a permanent or temporary job?
4. If the job was temporary, was it?
* Seasonal work
* Done under contract for a fixed period or for a fixed task
* Agency temping
* Casual type of work
* Some other way that it is not permanent? (please explain)
1. Was your job full-time or part-time?

Record the number of hours

1. Did you work in the public, private or voluntary/charity sector?
2. Approximately how many people worked for your employer?
* Less than 10
* Between 10 and 50
* Between 50 and 250
* More than 250
1. Salary (£):
2. Were you the main income provider in your household?

Yes / no

1. When did you leave the job?

Record month / year

1. Have you had any other jobs between the job you were in when you started to lose your sight, and now?

Yes / no

**If no, go to Question 63**

Please record job title and a brief description of roles and responsibilities for each job

1. What was the main reason for changing jobs?

Please explain for each job

1. Was it your choice to change jobs?

Please explain for each job

##### Employer at the time of sight loss (continued)

1. Did you receive any support from your employer as a result of your sight loss?

Please explain

1. What was the reaction of your work colleagues to your sight loss?

Please explain

1. What was the main reason for leaving your job?

Please explain

1. Was it your choice to leave your job?

Please explain

1. **Please describe what happened with your employer?**
2. Did you receive any information about Access to Work?

Yes / no

**If no, skip Questions 69-70**

1. Who provided you with this information?

For example, employer, rehabilitation worker, RNIB, Action for Blind People

1. Did you receive any support from Access to Work?

Please explain

1. Can you describe any rehabilitation training you received whilst in work? For example, mobility or independent living skills training?

Record which organisation provided the rehabilitation training and brief description

1. Can you describe any employed-related support from a specialist organisation you received whilst in work, such as RNIB or Action for Blind People?

Record which organisation provided the support and brief description

##### Since leaving work

1. What do you feel are the main reasons for you no longer being in work?

Please explain

1. Which of the following best describes your situation now?
* I am seeking paid work
* I am not seeking paid work but would like it
* I am not seeking paid work and do not want it
* Something else (please explain)
1. Are you in receipt of any state benefits?

For example, Job Seekers Allowance, Employment Support Allowance, Disability Living Allowance. Please list all benefits.

1. Have you undergone a Work Capability Assessment?

Yes / no

**If no, skip Questions 77-81**

1. If so, what was the outcome?
2. Were you satisfied with this outcome?

Yes / no

Please explain

1. If not, did you appeal?

Yes / no

1. If so, what was the outcome of the appeal?
2. Were you satisfied with this outcome?

Yes / no

Please explain

1. Have you been enrolled onto a government scheme such as 'The Work Programme' or 'Work Choice'?

If yes, please record which programme

**If no, please skip Questions 83-85**

1. What kind of support has been provided?

Record the name of the provider and a brief description of the support offered

1. Is the support time limited?

Please explain

1. **How do you feel about the support they have given you?**

Please explain

1. Please describe any rehabilitation training you have received since becoming unemployed? For example, mobility or independent living skills training?

Record which organisation provided the rehabilitation training and brief description

1. Please describe any employment-related support from a specialist organisation, such as RNIB or Action for Blind People, you have received since becoming unemployed?

Record which organisation provided the support and brief description

1. What do you think would help you to get a job?
2. Put another way, what prevents you from getting a job?
3. What difference, if any, has been registered made to your employment prospects?

Please explain

1. **If we need to, are you happy for us to contact you again to talk about your experiences in more detail?**

Yes / no

#### Scenario 3: Not in employment at the time of sight loss – and still not working now

From Section 3: Employment Status – Q15 = no; Q16 = no

1. Have you ever had a paid job?

Yes / no

**If no, ask why that is**

**If no, skip Questions 93-95**

What was the job title of your last paid employment?

1. Could you give a brief description of your role and responsibilities?
2. When did you leave the job?

Record month / year

1. What was the reason for leaving this job?

Please explain

1. Which of the following best describes your situation now?
* I am seeking paid work
* I am not seeking paid work but would like it
* I am not seeking paid work and do not want it
* Something else (please explain)
1. Are you in receipt of any state benefits?

For example, Job Seekers Allowance, Employment Support Allowance, Disability Living Allowance. Please list all benefits.

1. Have you undergone a Work Capability Assessment?

Yes / no

**If no, skip Questions 99-103**

1. If so, what was the outcome?
2. Were you satisfied with this outcome?

Yes / no

Please explain

1. If not, did you appeal?

Yes / no

1. If so, what was the outcome of the appeal?
2. Were you satisfied with this outcome?

Yes / no

Please explain

1. Have you been enrolled onto a government scheme such as 'The Work Programme' or 'Work Choice'?

If yes, please record which programme

**If no, skip Questions 105-107**

1. What kind of support has been provided?

Record the name of the provider and a brief description of the support offered

1. Is the support time limited?

Please explain

1. **How do you feel about the support they have given you?**

Please explain

1. Please describe any rehabilitation training you have received since being unemployed? For example, mobility or independent living skills training?

Record which organisation provided the rehabilitation training and brief description

1. Please describe any employment-related support from a specialist organisation, such as RNIB or Action for Blind People, you have received since being unemployed?

Record which organisation provided the support and brief description

1. What do you think would help you to get a job?
2. Put another way, what prevents you from getting a job?
3. What difference, if any, has been registered made to your employment prospects?

Please explain

1. **If we need to, are you happy for us to contact you again to talk about your experiences in more detail?**

Yes / no

#### Scenario 4: Not in employment at the time of sight loss – but working now

From Section 3: Employment status – Q15 = no; Q16 = yes

##### Present employer

1. What is your current job title?
2. Could you give a brief description of your role and responsibilities?
3. Is it a permanent or temporary job?
4. If the job is temporary, is it?
* Seasonal work
* Done under contract for a fixed period or for a fixed task
* Agency temping
* Casual type of work
* Some other way that it is not permanent? (please explain)
1. Is your job full-time or part-time?

Record the number of hours

1. Do you work in the public, private or voluntary/charity sector?
2. Approximately how many people work for your employer?
* Less than 10
* Between 10 and 50
* Between 50 and 250
* More than 250
1. Salary (£):
2. Are you the main income provider in your household?

Yes / no

1. When did you get this job?

Record month / year

1. Have you received any support from your present employer as a result of your sight loss?

Please explain

1. What was the reaction of your work colleagues to your sight loss?

Please explain

1. Have you received any information about Access to Work in this job?

Yes / no

**If no, skip Questions 127-128**

1. Who provided you with this information?

For example, employer, rehabilitation worker, RNIB, Action for Blind People

1. Have you received any support from Access to Work in this job?

Please explain

1. Can you describe any rehabilitation training you have received whilst in work? For example, mobility or independent living skills training?

Record which organisation provided the rehabilitation training and brief description

1. Can you describe any employed-related support from a specialist organisation you have received whilst in work, such as RNIB or Action for Blind People?
2. What helped you to get back into work?

Please explain

1. What difference, if any, has been registered made to you finding work?

Please explain

##### Whilst out of work

1. Which of the following best described your situation then?
* I was seeking paid work
* I was not seeking paid work but would have liked it
* I was not seeking work and did not want it
* Something else (please explain)
1. Were you in receipt of any state benefits?

For example, Job Seekers Allowance, Employment Support Allowance, Disability Living Allowance. Please list all benefits.

1. Did you undergo a Work Capability Assessment?

Yes / no

**If no, skip Questions 136-140**

1. If so, what was the outcome?
2. Were you satisfied with this outcome?

Yes / no

Please explain

1. If not, did you appeal?

Yes / no

1. If so, what was the outcome of the appeal?
2. Were you satisfied with this outcome?

Yes / no

Please explain

1. Were you been enrolled onto a government scheme such as 'The Work Programme' or 'Work Choice'?

If yes, please record which programme

**If no, skip Questions 142-144**

1. What kind of support did they provide?

Please explain

1. Was the support time limited?

Please explain

1. **How do you feel about the support they have given you?**

Please explain

1. Please describe any rehabilitation training you received whilst unemployed? For example, mobility or independent living skills training?

Record which organisation provided the rehabilitation training and brief description

1. Please describe any employment-related support from a specialist organisation, such as RNIB or Action for Blind People, you received whilst unemployed?

Record which organisation provided the support and brief description

1. **If we need to, are you happy for us to contact you again to talk about your experiences in more detail?**

Yes / no

### Appendix 2: Phase 1 information leaflet about the research project sent to all working age people who had registered in the last two years

Name

Address 1

Address 2

Address 3

Postcode

Date

Dear xxxxxxxxxx,

#### Invitation to help with some research about working age people who start to lose their sight

We would like to invite you to take part in our research study, being carried out by RNIB and Kent Association for the Blind (KAB). Before you decide, we have set out below why the research is being done and what it would involve for you.

#### Purpose of the study

We do not know the number of people with sight loss who lose their jobs each year, but there is evidence to suggest a link between sight loss and people losing their jobs. This study seeks to understand the factors which help people to remain in their jobs, or which result in people leaving work. We will pay particular attention to the support people might have received, either from their employer or from other sources. At the same time, we also want to talk to people of working age who are not in work, to find out why that might be.

#### Who should take part?

We would like to speak to everyone between the age of 18 and 64 (ie of working age), who has registered as blind or partially sighted in the Kent area over the last two years. People have been identified through the Kent Local Authority register of visual impairment which is held by KAB. We will discuss your experiences of being in work and then losing your sight, or if you have not worked, your experiences of being out of work.

#### Do I have to take part?

It is up to you to decide to take part in the research. And if you decide to take part, you are free to withdraw at any time, without giving a reason. Any information we have collected will be destroyed. Taking part or deciding to withdraw will not affect any care or support you receive from RNIB, KAB or anyone else.

#### What will I have to do?

You will be asked to complete a 25 minute questionnaire over the phone. The research assistant who completes the questionnaire will also be blind or partially sighted. At the end of the call, we will ask if you are willing to talk about you experiences in more detail. This will be either as part of a focus group (ie a discussion with a small number of people who had similar experiences to you), or it might be through another one to one interview.

#### Will taking part in the study be kept confidential?

The research team will not tell anyone that you have taken part in the study. We may use comments from you in the final report, but these will be kept anonymous. We will not include any information that would make it possible to identify you. All data is kept secure and will only be seen by the research team. It will only be used for this study and will be destroyed after 5 years.

#### What will happen to the results of the research?

We plan to publish the results of the research, and to use the findings to influence government in how they support people in work who start to lose their sight. A summary of the research will be sent to you, and a copy of the full report will be sent to you on request.

#### What to do next

If you are happy to take part, please sign the consent form enclosed and return to Alex Saunders at RNIB.

If you would like to discuss the study first, please contact Alex Saunders, who will be happy to go through this letter with you. The address and contact details for Alex Saunders are below.

We look forward to hearing from you.

Further information and contact details:

Alex Saunders

Employment Impact Officer

RNIB

105 Judd Street

London WC1H 9NE

email: alex.saunders@rnib.org.uk

phone: 0207 391 2193

mobile: 07810 851552

Here are the contact details for Kent Association for the Blind:

Patricia Weeden

PA to Jonathan Ward

Kent Association for the Blind

72 College Road

Maidstone

Kent ME15 6SJ

Tel: 01622 691357

Direct Dial: 01622 358985

Fax: 01622 663999

Email: pat.weeden@kab.org.uk

[www.kab.org.uk](http://www.kab.org.uk)

This document is also available on audio tape, CD, DAISY format, Braille and large print

### Appendix 3: Phase 1 consent form sent to all working age people who had registered in the last two years

#### What happens to people in work once they start to lose their sight?

**Participant consent form**

Thank you for considering taking part in this research. If you have any questions please contact Alex Saunders (full details below). You will be given a copy of the consent form to refer to at any time.

Please answer yes or no to each of the following points:

I confirm that I have read and understood the letter explaining the research. I have had the opportunity to consider the information and to ask any questions.

**Yes / no**

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and that any care or support I receive will not be affected by this.

**Yes / no**

I understand that I will be interviewed by telephone for approximately 25 minutes.

**Yes / no**

I understand that I may be asked to take part in a focus group or more in-depth interview at a later stage.

**Yes / no**

I understand that the data from any interviews I take part in during the study will be looked at by members of the research team only, and will not be passed on to any other parties. It has been explained to me this information will be securely stored and any comments from me used in the final report will be kept anonymous.

**Yes / no**

I agree to take part in the study

**Yes / no**

Name:

Signature:

Contact telephone number:

When is it convenient to call you?

Date:

If you have any questions please contact Alex Saunders, Employment Impact Officer, RNIB at:

email: alex.saunders@rnib.org.uk

telephone: 0207 391 2193

mobile: 07810 851 552

This document is also available on audio tape, CD, DAISY format, Braille and large print

### Appendix 4: Phase 2 depth interview topic guide, for people in work at the time of registration and in work now

**Notes for interviewer**: We wish to encourage participants to discuss their views, perception and attitudes in an open way without excluding issues which may be of importance to the research. Therefore the questioning will be responsive to the issues raised in the course of the group discussion.

The following guide lists the key themes, sub-themes and questions to be explored during the discussion. It does not include many follow-up questions like “why”, “when”, “how”, as it is assumed that participant’s contributions will be fully explored throughout in order to understand how and why views are held.

Discretion should be used regarding coverage of questioning as some participants may have limited knowledge of some topic areas and some areas may not be relevant to all interviewees.

#### 1. Introduction

* Introduce self and RNIB
* We would like to record the interview and data will be stored securely in accordance with the Data Protection Act. Recordings are only accessible to the research team at RNIB. Check with all participants they are happy for this to happen.
* Switch mobiles off / put silent
* Check if any questions and start recording
* Brief overview of research design and KAB involvement
* The discussion will last no longer than 1 hour
* Confidentiality and anonymity. Everything discussed is confidential and any raw data used in public outputs will not be attributable to them
* No right or wrong answers
* We do not expect people to share each other’s views, but respect differences and views
* Speak one at a time
* Confirm everyone is happy to continue (additional consent)

#### 2. Background

Notes for interviewer: Ask each member of the group to introduce themselves giving their name, job title and the key factor/most important element they believe helped them to retain employment through their sight loss.

Note down these key points in bullet point form, explaining what you’re doing to participants

#### 3. Sight loss and employment

* Concerns when losing sight

Family

Friends

Employment

Income/financial support

Quality of life

* Employment considerations

Leaving employment

Changing jobs

Early retirement

Level of reluctance to tell employer, disclosure issues

Knowledge/awareness of existing support at workplace for VI people

* Contact with outside support agencies
* Motivation to stay in employment

#### 4. Staying in employment

**Notes for interviewer**: Interviewer to fully explore the range of adjustments made to their working including level of satisfaction with adequacy of support received. Time should also be spent exploring social and psychological impact of these adjustments. Focus should be kept on the enablers and barriers to retaining employment.

##### Enablers and barriers to staying in employment

###### Social aspects

* Staff
	+ Disclosure issues
	+ Colleagues, HR
	+ Management
	+ External colleagues
	+ Staff training of VI issues
* Social impact of sight loss at work
	+ Ability to work independently
	+ Confidence in the workplace
	+ Dependency on colleagues
	+ Effect on wellbeing
* Equality Act – did this play a role?
* Perceptions of adequacy of support

###### Practical aspects

* Adjustments to the workplace
	+ VI assessment/toolkit use
	+ Equipment – mobility and technology aids
	+ Outside agency help or advice
	+ Work based assessments / Access to Work; process, who completes
* Adjustments / changes to role
	+ Travel to and from work
	+ Tasks given
	+ Outside agency help or advice
* Progression
	+ Opportunity for promotion, CPD
	+ Equality of opportunity
	+ Moving employer
* Sight loss deterioration and future employment
	+ Ongoing adjustments and considerations
		- How well is employer able to adjust to future changes in sight condition
		- How well they feel they are coping with sight loss deterioration at work
* Perceptions of adequacy of support
* Could more have been done
* Future adjustments
* Satisfaction with work now

#### 5. Reflections

* Expectations for future employment
* Importance of retaining employment
	+ Social impact
	+ Economic impact
	+ Effect on wellbeing generally
* Advice they would give to others in similar situation

### Appendix 5: Phase 2 focus group topic guide, for people in work at the time of registration but not in work now

**Notes for interviewer**: We wish to encourage participants to discuss their views, perception and attitudes in an open way without excluding issues which may be of importance to the research. Therefore the questioning will be responsive to the issues raised in the course of the group discussion.

The following guide lists the key themes, sub-themes and questions to be explored during the discussion. It does not include many follow-up questions like “why”, “when”, “how”, as it is assumed that participant’s contributions will be fully explored throughout in order to understand how and why views are held.

Discretion should be used regarding coverage of questioning as some participants may have limited knowledge of some topic areas and some areas may not be relevant to all interviewees.

#### 1. Introduction

* Introduce self and RNIB
* We would like to record the interview and data will be stored securely in accordance with the Data Protection Act. Recordings are only accessible to the research team at RNIB. Check with all participants they are happy for this to happen.
* Switch mobiles off / put silent
* Check if any questions and start recording
* Brief overview of research design and KAB involvement
* The discussion will last no longer than 1 hour
* Confidentiality and anonymity. Everything discussed is confidential and any raw data used in public outputs will not be attributable to them
* No right or wrong answers
* We do not expect people to share each other’s views, but respect differences and views
* Speak one at a time
* Confirm everyone is happy to continue (additional consent)

#### 2. Background

**Notes for interviewer**: Ask each member of the group to introduce themselves giving their name and the kind of work they did before losing their sight. Note down these key points in bullet point form, explaining what you’re doing to participants.

#### 3. Sight loss and employment

* Concerns when losing sight

Family

Friends

Employment

Income/financial support

Quality of life

Outside agency help or advice

**Note to interviewer**: If they did not use any agencies, why was that?

* Employment considerations

Leaving employment

Changing jobs

Early retirement

Level of reluctance to tell employer, disclosure issues

Knowledge/awareness of existing support at workplace for VI people

* Contact with outside support agencies
	+ Access to Work
* Motivation to stay in employment

#### 4. Decision to leave employment

**Note to interviewer**: Interviewer to fully explore why individuals could not retain / did not want to stay in employment.

Go round the group, asking each individual to explain reasons/considerations when not continuing with work. Facilitators should categorise these reasons under ‘practical’, ‘social’ and ‘economic’ on a flip chart, explaining to participants throughout. Use these headings as prompts when considering how the group may consider prioritizing these different factors/reasons and how they may have been overcome / resolved.

The below should be used as a loose guide to prompt discussion.

##### Barriers to staying in employment

###### Social aspects

* Staff
	+ Disclosure issues
	+ Colleagues, HR
	+ Management
	+ External colleagues
	+ Staff training of VI issues
* Social impact of sight loss at work
	+ Ability to work independently
	+ Confidence in the workplace
	+ Dependency on colleagues
	+ Effect on wellbeing
* Equality Act – did this play a role?
* Perceptions of adequacy of support

###### Practical aspects

* Adjustments to the workplace
	+ VI assessment/toolkit use
	+ Equipment – mobility and technology aids
	+ Outside agency help or advice
	+ Work based assessments / Access to Work; awareness, process, who completes
* Adjustments / changes to role
	+ Travel to and from work
	+ Tasks given
	+ Outside agency help or advice
* Progression
	+ Opportunity for promotion, CPD
	+ Equality of opportunity
	+ Moving employer
* Sight loss deterioration and future employment
* Perceptions of adequacy of support
* Could more have been done
* Future adjustments

#### 5. Reflections

* Life now without employment
	+ Social impact
	+ Economic impact
	+ Effect on wellbeing generally
	+ Outside agency help or advice

**Note to interviewer**: What support are they getting? If they are not engaged with anyone else, why not? And what support would they like to receive? What would good support and service look like for them?

* Expectations for future employment

Advice they would give to others in similar situation (possible use of vignettes?)

### Appendix 6: Phase 2 depth interview topic guide, for people in work at the time of registration and not in work now

#### 1. Introduction

* Introduce self and RNIB
* We would like to record the interview and data will be stored securely in accordance with the Data Protection Act. Recordings are only accessible to the research team at RNIB. Check with participant they are happy for this to happen.
* Switch mobiles off / put silent
* Check if any questions and start recording
* Brief overview of research design and KAB involvement
* The discussion will last no longer than 1 hour
* Confidentiality and anonymity. Everything discussed is confidential and any raw data used in public outputs will not be attributable to them
* No right or wrong answers
* Confirm participant is happy to continue (additional consent)

#### 2. Background

* Who they live with
* When they started losing their sight
* Employment history

#### 3. Sight loss and employment

* Concerns when losing sight

Family

Friends

Employment

Income/financial support

Quality of life

* Employment considerations

Leaving employment

Changing jobs

Early retirement

Level of reluctance to tell employer, disclosure issues

Knowledge/awareness of existing support at workplace for VI people

* Contact with outside support agencies
* Motivation to stay in employment

#### 4. Leaving employment

**Note to interviewer**: Interviewer to fully explore why individuals could not retain / did not want to stay in employment.

##### Barriers to staying in employment

###### Social aspects

* Staff
	+ Disclosure issues
	+ Colleagues, HR
	+ Management
	+ External colleagues
	+ Staff training of VI issues
* Social impact of sight loss at work
	+ Ability to work independently
	+ Confidence in the workplace
	+ Dependency on colleagues
	+ Effect on wellbeing
* Equality Act – did this play a role?
* Perceptions of adequacy of support

###### Practical aspects

* Adjustments to the workplace
	+ VI assessment/toolkit use
	+ Equipment – mobility and technology aids
	+ Work based assessments / Access to Work; awareness, process, who completes
* Adjustments / changes to role
	+ Travel to and from work
	+ Tasks given
	+ Outside agency help or advice
* Progression
	+ Opportunity for promotion, CPD
	+ Equality of opportunity
	+ Moving employer
* Sight loss deterioration and future employment
* Perceptions of adequacy of support
* Could more have been done
* Future adjustments

#### 5. Reflections

* Life now without employment
	+ Social impact
	+ Economic impact
	+ Effect on wellbeing generally
* Expectations for future employment
* Advice they would give to others in similar situation (possible use of vignettes?)

End of document.