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Alcohol, other Drugs and Sight Loss: A Scoping Study

Final report

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Report Format

This report comes in two parts. The first part is this final research report which has been prepared to be as accessible as possible to screen readers. The second part is a collection of supplementary appendices. Appendix 7 is a summary of clinical case studies found in the literature and is screen reader accessible. The majority of the other appendices contain either forms or tables as well as text. Where possible these have been described in this main report and cross referenced to the relevant table in the appendices.

Acknowledgments

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Project Advisory Group

To guide and support our research the team brought together a number of experts to form a Project Advisory Group. It was a tremendously helpful and very committed group of people. We met physically on three occasions and we are grateful for their encouragement, passion and guidance. This group comprised:

- Catherine Dennison, Head of Research: Health and Wellbeing, Thomas Pocklington Trust.

- James Nicholls, Research Manager, ALR UK
- Shaun Leamon, Principle Research Officer, RNIB
- Susie Balderston, Policy and Training Director, VisionSense
- Pete Hoey, Planning Development Officer, Personalisation and Commissioning, Wellbeing and Communities, Kirklees Council
- Eva Cyhlarova, Head of Research, Mental Health Foundation
- Will Thornton, Head of Care and Support (Midlands), Thomas Pocklington Trust
- Mike McCabe, Company Secretary/Advocacy and Project Manager, VisionSense

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Terminology

- **Substance use** - this term refers to alcohol, illicit drug and prescribed drug use. Individual substances will be identified where reference is made to a particular drug by a research participant or within the literature reviewed.
- **Sight loss** - this term refers to someone who has no sight or whose sight is impaired beyond the use of correctional glasses or lenses. It is the term used throughout this report in line with the practice of Thomas Pocklington Trust.
- **Disability –** this research adopts a social model understanding of the distinction between disability and impairment. **Impairment** refers to the condition or diagnosis such as sight loss whereas disability refers to the disadvantage and discrimination experienced by people with impairments (disablism). Hence we use disabled people rather than people with disabilities.

When quoting individual respondents or citing literature sources we will use the terms they have chosen for accuracy of representation.

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Executive Summary

Introduction

This is an exploratory study of the relationship between substance use, that is, alcohol, illicit and prescribed drugs, and sight loss. Its origins lie in practice-based concerns about the extent to which service provision met the needs of people with sight loss who were experiencing problematic substance use. A preliminary review of the literature found limited evidence relating to medical or clinical associations[1] between sight loss and substance use but no literature that explored the experiences of those living, or working with, sight loss and substance use. Therefore, this study sought to answer three key research questions:

- What does current evidence reveal about the nature and extent of the relationship between substance use and sight loss?
- What is the role substance use plays in the lives of people with sight loss?
- What are the experiences of professionals working with people who have sight loss and substance problems?

Methodology

In order to answer the research questions, more detailed objectives were developed. These were:

- To explore what existing data can tell us about the extent of substance use among people with sight loss
- To review any clinical and medical evidence of an association between substance use and sight loss

1 'Clinical' in this context refers to the treatment and support of people by a range of health professionals; 'medical' is a broader term and in this context refers to evidence that focuses on medical associations between sight loss and substance use including laboratory-based evidence.

- To explore the meaning and function of substance use in the lives of people with sight loss.
- To explore how professionals in a) substance use and b) sight loss services are currently working with these overlapping issues.

Three forms of data were collected and analysed. The first was a statistical exploration of existing large scale surveys which were analysed for prevalence data relating to both substance use and sight loss; the second was a comprehensive review of international research evidence to explore what is already known about the medical, clinical and social relationship between substance use and sight loss; the third sought the views of people living with sight loss and substance use and the views of people working with, and supporting, individuals with sight loss and substance use.

This study focused on permanent and acute levels of visual impairment, rather than temporary or mild impairment. It focused primarily on problematic use of substances rather than any, or social, use. Finally, the focus of this study was initially on alcohol but given the dearth of research on other drugs and the fact that poly substance use is common, we also included problematic use of prescribed or illicit drugs.

Key findings

Existing data set analysis

The following three datasets were identified from the UK Data Service database as meeting the search criteria most closely (see chapter 3 of the full report for details):

- The General Lifestyle Survey (GLS) 2009 and 2010
- The Health Survey for England 2000
- The Primary Care Trusts Patient Survey 2008

The findings are based on smaller sub samples from each survey of people with sight loss. Analysis of the GLS found that people with sight loss (n=261) were significantly more likely than sighted peers to abstain from alcohol and to consume fewer units of alcohol per week than those

without sight loss. There was no statistically significant difference between those with sight loss compared to those without sight loss in relation to a) drinking every day of the week or b) binge drinking once adjustments were made for age and sex.

Analysis of the Health Survey for England dataset also found that people with sight loss (n=894) were significantly more likely to abstain from alcohol and, of those who drank, they were more likely to consume fewer units of alcohol per week. There was no statistically significant difference among people with sight loss compared to those without sight loss once adjustments were made for age and sex on the following variables: a) exceeding the recommended alcohol limits, b) feeling a need to reduce their drinking, or c) having been drunk in last three months.

In the Primary Care Trusts Patient Health Survey, patients of GP practices were questioned about a) whether or not they had been asked about how much alcohol they drank in the last 12 months and b) whether they had been given advice or help re "sensible alcohol intake". People with sight loss (n=1485) were no more or less likely than people without sight loss to say that they had been asked about how much alcohol they drank by someone at their GP practice in the last 12 months. However, after adjustment for age and sex, people with sight problems were significantly more likely to say that they had been given advice or help about sensible alcohol intake by someone at their GP practice in the last year. Of those who didn’t receive it, people with sight problems were more likely than those without sight problems to say that they would have appreciated it.

It is worthy of note that the first two databases exploring prevalence are based on relatively small sample sizes. There are currently 1.87 million people in the UK for whom sight loss has a "significant impact" in their daily lives (RNIB 2013). Thus, while there are clear messages from the analysis of small samples from these databases, there is a need for further research to fully determine the scale of relationship between sight loss and substance use.

International literature review

In total 31 searches were conducted generating 670 pieces of literature with date parameters set between 1990 and 2013. Following the

application of inclusion and exclusion criteria at different stages of the screening process, a total of 49 articles formed the basis of the findings.

There is a wide and varied range of evidence on this topic. Most of it suggests there is no causal association between substance use and different sight loss conditions but some of it does imply a connection between the two. In other words, while no evidence was found for substances causing sight loss directly, there was evidence that substance use may have a role to play as a coping mechanism for individuals with sight loss and also as a contributing factor in risks for sight loss. This is particularly the case when substance use occurs in combination with other individual characteristics or lifestyle choices, for example, smoking or poor nutrition.

The clinical case study material suggested that early intervention is vital in maximising a person's chances of sight improvement and recovery when someone has substance-involved sight loss.

There is also a body of work that highlights some of the challenges that may expose people with sight loss to a higher risk of substance use, for example, living with chronic pain, stigma, social isolation and boredom that may accompany sight loss. This has to be balanced with the potential advantages of social integration through alcohol-related activities, such as going to the pub.

Finally, the call for training for all professionals involved in assessing, identifying and responding to both sight loss and substance use in a range of contexts was highlighted in much of the literature. So too is the need for services to provide information about these overlapping issues in accessible formats.

Note: While this study focused on alcohol and other drug use, it is important to note that the literature consistently identifies **smoking** as posing a very significant risk in the development of a range of visual impairments. The list of ophthalmologic disorders associated with cigarette smoking continues to grow.

Individuals living with sight loss and substance use

Seventeen individuals with experiences of living with sight loss and substance use were recruited through contacts with a wide range of

organisations, adverts in relevant publications, social media and by word of mouth or 'snowball' sampling. Thirteen were male, the average age was 53 years old and most were outside of paid employment.

There was a broad range of experiences of sight loss and substance misuse. For some people alcohol or other drugs were a way of seeking comfort and temporary escape from the physical and emotional challenges they faced as a result of their sight loss; for others they lived with being told that their use of substances caused, or contributed significantly to, their sight loss through diagnoses such as 'tobacco-alcohol amblyopia' or 'toxic amblyopia'.

Some people had continued their substance use following their sight loss diagnosis, while others had long since changed their substance use behaviour. For those who chose to continue to their substance use there was far more planning and deliberation about how to do it, including who else was involved and where to go. Daytime pub visits replaced night time visits due to noise, levels of drunkenness, and the darkness when going home. The familiarity of venue and patrons was an important feature and made it a more pleasant experience although some people chose to socialise away from the pub with friends or at home.

For the majority of people who had, or have, experienced problematic substance use as well as their sight loss, it offered a double dose of challenges for relationships with families and friends. Primarily as a result of the substance use, family and friends had walked away. This often compounded the sense of isolation they already felt as a result of their sight loss and the subsequent barriers they faced to participation in everyday activities.

Many of our small sample of participants knew of other people with both substance problems and sight loss; so too did many of the professionals. It is possible that this project is only scratching the surface of a larger group of people or it could be that the scale of the problem remains small but there needs to be improvement in relation to identification of people affected.

Perhaps unsurprisingly, the resources and information people with sight loss and substance use required included information about the links between substance use and sight loss. People's need for information

and communication about the risks and the potential prognosis was clear; so too was the need for specialist services - be they substance use or sight loss - to have accessible information about the 'other' issue available to staff and service users alike.

In sum, the people we spoke to had very different journeys and experiences relating to sight loss and substance use. The commonality was they sought ways to adapt to a society that provides little by way of knowledgeable support about sight loss and substance use.

Professionals supporting people with sight loss and substance use

Eighteen professionals took part in the research. They were also recruited through the routes described above for accessing individuals with sight loss and substance use. Thirteen professionals worked in the sight loss sector, three in substance use and two in other related professions.

The professionals reported that only a small percentage of the people they worked with experienced sight loss and substance use, reflecting the findings of our existing dataset analysis and the wider literature review. Nevertheless, this smaller number of people took up a great deal of staff time and energy. There was no routine assessment of substance use among the sight loss professionals and vice versa; a significant number did not, and would not, ask about the person's substance use or sight loss unless it was obvious or disclosed.

While alcohol remained the dominant substance of choice for the individuals supported by the professional we consulted, there were clearly concerns about other types of drugs including prescribed medications. This raises interesting questions for future research.

There was a clear understanding among the professionals about how substance use could be a coping mechanism for people with sight loss. This was particularly apparent when substance use had been part of the person’s socialisation linked to their work culture, for example, veterans of the armed forces. Similarly, professionals acknowledged substance use as a coping mechanism as part of a person's response to a combination of losses and stresses in their lives. In general, the

professionals were unsure about whether or not there was a causal link between substance use and sight loss.

Almost without fail the professionals we interviewed were committed to doing their best in their role for people with sight loss and substance use even though they found this challenging at times. Some professionals went outside their employer's usual procedures to offer what they felt was appropriate support and were often creative in doing so. This was in spite of a frustrating lack of time to provide the service they wanted to provide. In substance use services the professionals faced particular challenges working with people with sight loss because some elements of their practice models involve written tasks and recording.

Partnership working was identified as key to providing the necessary support to people with sight loss and substance use and to stopping people falling through the gaps in services. This was particularly so when practitioners doubted the 'truthfulness' of the people they supported but lacked adequate knowledge of sight loss or substance use to challenge or respond appropriately.

Finally, the professionals made a number of suggestions for resources to support them in their learning and also as information for service users directly. Some commented on the demise of sensory specialist staff and services. Within the current climate of public health and local authority cuts, this is unlikely to improve and may heighten the demand for partnership practice and free training exchanges.

Implications for practice

1. Education and training on the relationship between sight loss and substance use is needed for professionals in sight loss and substance use services.
2. Practice guidance is also needed on how to adapt their current models of practice for work with someone who presents with the 'other' issue and will need tailoring to different roles and different areas of practice.
3. Resources and materials that focus on early intervention and harm reduction are needed to support staff in substance use and sight loss services.

4. Routine monitoring and screening within sight loss and substance use services are needed so that substance use services screen for sight loss and vice versa.
5. Resources and material about the relationship between substance use and sight loss are needed for people who use sight loss or substance use services. Services are likely to need guidance on how to meet this need appropriately.

The need for the development of a range of resources and materials for both individuals and professionals provides an ideal opportunity for joint training and resource development through locally formed partnerships.

Implications for future research

1. The perspectives of people who use services are absent from the majority of the research. More qualitative research is needed to fill this gap and to fully understand the social relationship between substance use and sight loss.
2. Carer and partner perspectives are absent from the research. Given the impact of sight loss and substance use on relationships, carers' and partners' perspectives and needs should be identified alongside research into how those needs may be met.
3. More comprehensive UK-wide prevalence data is needed. A survey of people with sight loss via sight loss and substance use services would be a start. This would fill a large gap in the research evidence.
4. Longitudinal research is needed to assess the impact of substance use on sight loss over time and vice versa, taking into account other lifestyle choices and circumstances.
5. A systematic review of evidence relating to the relationships between prescription medication and sight loss is needed.
6. Given the existing research focuses primarily on people in older age, the needs of people under 50 years old is a gap in the evidence base. Research with this group will establish the potentially different impact of sight loss and substance use on a younger group. It could also

provide a cohort of younger people to follow through longitudinal research on sight loss and substance use.

Conclusion

This is the first study of its kind to combine the evidence about sight loss and substance use from four sources:

1. existing datasets
2. the international research literature
3. the views of people living with sight loss and problematic substance use, now or in the past, and
4. the views of people working with, and supporting, individuals with sight loss and substance use.

The findings present a number of clear messages. First, conclusions from the existing dataset analysis are that people with sight loss are more likely to abstain from alcohol and consume fewer units of alcohol per week. Second, the existing literature found no consistent evidence for substance use causing sight loss, but there was evidence that substance use may have a role to play as a coping mechanism for individuals with sight loss and also as a contributing risk factor through conditions such as 'tobacco-alcohol amblyopia' or 'toxic amblyopia'. Third, there is a relationship between sight loss and substance use for the majority of people we interviewed who are living with sight loss and substance use. Some people had been told by professionals that this was a causal relationship, while for others their substance use was a way of coping with their sight loss. Fourth, for professionals, the number of people they worked with who had sight loss and substance use was small but they posed considerable professional challenges. The professionals felt ill-equipped to respond appropriately.

It is important to note that the existing evidence on sight loss and substance use is limited. Sample sizes are often small and taken from data collected primarily for other purposes in different countries and cultures around the world. While research in this area is in its infancy, it repeatedly reflects clinical concerns about the links between problematic substance use and various forms of sight loss.

The evidence also shows that sight loss and substance use services are often not set up well to work with these overlapping issues. However, the professionals we spoke to were not averse to change although they are often operating within systems and structures that do not, as yet, consider the 'other' issue as part of their remit, on whatever level. This study has begun the important conversation about what needs to improve in research, policy and practice.

Chapter 1 - Introduction

This project is an exploratory study of the relationship between sight loss, alcohol and other drug use (hereafter 'substance use'). It developed from practice concerns that people living with sight loss and substance use were not adequately supported and that the professionals who sought to support them were not equipped to do so. It is the first of its kind in that it seeks to combine the existing evidence with the lived perspectives of individuals living with sight loss and current or previous substance use and professionals working with them.

This research was jointly funded by sight loss charity, Thomas Pocklington Trust, and alcohol research charity, Alcohol Research UK. As subsequent chapters will show, this is an under-researched area with the majority of previous research focussing on medical or clinical connections between a particular substance and a particular form of sight loss. Importantly, our reviews of existing literature found people's voices and subjective experiences largely absent from the research evidence - an ongoing concern in sight loss research (Duckett and Pratt 2001).

There is a dearth of evidence about substance use among disabled people more generally including the extent of their substance use. Currently national alcohol and drug treatment monitoring systems in England do not routinely collect data on disability among people attending drug treatment services (National Treatment Agency 2009) even though some of the limited empirical evidence available suggests that substance use is higher among physically disabled people (Hoare and Moon 2010, Smith and Flatley 2011). Research from North America suggests rates of problematic substance use are more than twice those of the non-disabled population (Krahn et al. 2006). A review of the UK literature identified particular substances, primarily alcohol and cannabis, as higher among people with physical impairments and chronic illness due to their pain relieving qualities (Beddoes et al. 2010).

The sight loss data offer few further insights. The UK-wide survey 'Understanding Society' currently asks about ‘disabilities’, including sight loss, as well as recent alcohol use and age of first alcoholic drink. It also asks about the consumption of other drugs including illicit drugs and

prescription medication. Published findings are not available, however, preliminary analysis by researchers at Royal National Institute of Blind People (RNIB) found that people with sight loss were more likely to have abstained from alcohol in the previous seven days than people with other impairments or people with no impairment (Slade, personal communication, 17th July 2014). However, Slade reports that people with sight loss were also more likely than people with other impairments and no impairments to have had an alcoholic drink on each day of the preceding week. The data do not, however, establish problematic use and focus on alcohol only. Further, the daily use reported may not be significantly different from other groups once factors such as age are taken into account. Existing data on alcohol consumption has long since shown that older people are likely to drink more frequently than younger people but in lesser quantities (Office for National Statistics 2013, Robinson and Harris 2011). Older people are also the age group most likely to experience sight loss as part of the ageing process.

However, what evidence there is generally indicates that substance use is far lower among people with sight loss than their sighted peers (see chapters 3 and 4) possibly as a result of more limited independence to socialise with peers or more limited opportunities to buy or access alcohol (Pinquart and Pfeiffer 2010).

In terms of the nature of the relationship between sight loss and substance use, a number of attempts have been made to categorise the relationship between sight loss or other impairments and substance use (Crome et al. 2009, Galvani 2012, Koch et al. 2002). Koch et al., in their paper for "counselors" of people with sight loss proposed three main relationships:

1. Pre-existing problematic substance use which has already depleted the person's internal resources and may impede their ability to adjust to sight loss.
2. Substance use following the onset of sight loss where the person has previously adjusted to sight loss but who is now drinking problematically for the same reasons as non-disabled peers. This drinking may, in turn, damage the life skills they have used so far to help them adjust to their sight loss.

3. Substance use and sight loss occurring concurrently where substance use may be a coping device for the acquisition of sight loss.

However, the literature shows this has not been adequately explored with people living and working with sight loss and substance use. What it does show is that practitioners supporting disabled people identify substance use education as very important to their practice and identify their current knowledge as lacking (Dance and Galvani 2014).

Thus, in addition to exploring the experiences of people living with sight loss and substance use or working with people with sight loss and substance use, this project also set out to comprehensively review what is known from the existing research evidence about sight loss and substance use.

In sum, the research questions were:

- What does current evidence reveal about the nature and extent of the relationship between substance use and sight loss?
- What is the role substance use plays in the lives of people with sight loss?
- What are the experiences of professionals working with people who have sight loss and substance problems?

Before providing a summary of the methodology in chapter 2 we will provide background data on the nature and extent of sight loss and substance use in the general population.

Sight loss in the general population

The most recent report from the Royal National Institute for Blind People (RNIB) suggests that 1.87 million people in the UK are living with sight loss that has a significant impact on their daily lives (RNIB 2013). This figure is likely to increase over the coming decades as the improvements in healthcare results in a growing older population (Access Economics 2009, Minassian and Reidy 2009, RNIB 2013). People with visual impairment tend to be older (McManus and Lord 2012) and people are more likely to experience sight loss as they get older (Access Economics

2009). It is suggested that 77% of those with a sight loss are over the age of 65 (RNIB 2013).

Using a wide definition, Charles (2007) estimates that there are between about 1.6m and 2.2m people aged 65 years and over in the UK with visual acuity ranging from mild to serious levels of impairment. Visual acuity measures a person's central vision including their ability to distinguish details and shapes. In contrast, the number of people registered as blind or partially-sighted is 358,000 and declining (Health and Social Care Information Centre (HSCIC) 2011, Liew et al. 2014, RNIB 2013).

Age is only one risk factor for sight loss. The RNIB also identifies people with low income, people who smoke, people who have diabetes, people with learning disabilities and those who belong to minority ethnic groups (RNIB 2013) as being at greater risk.

The main causes of blindness certifications in the working population (16-64 years) are hereditary retinal disorders, diabetic retinopathy or maculopathy and optic atrophy; together, these three causes account for almost 50% of all blindness certifications (Liew et al. 2014). The leading causes of wider visual impairment in the UK are uncorrected refractive error, age-related macular degeneration, cataract, glaucoma and diabetic retinopathy (RNIB 2013).

Smoking is consistently identified as a significant risk in the development of a range of visual impairments, with the list of associated ophthalmologic conditions growing (Kelly et al. 2004, Solberg et al. 1998). It is worth noting, therefore, that 20% of the adult population in the UK are current smokers (HSCIC 2013).

Experiences of living with sight loss involve a range of significant consequences for individuals and their families (McManus and Lord 2012, Nyman et al. 2010, RNIB 2013). A social model of disability clearly articulates how many of our systems and structures take little account of people who are not fully able bodied (Barnes 1991, Huber and Miller 2006). Employment, and therefore income generation, alongside practical access to transport and a range of services and agencies outside the home are among the many difficulties presented to people

with sight loss. Add to this the use of one or more substances and the discriminatory attitudes people with sight loss face are compounded.

Substance use in the general population

The mapping of volumes, patterns and changes of substance use in the general population is well established (Davies, A. et al. 2012, Department of Health 2007, Robinson and Harris 2011). These data illustrate a long term, historical use of substances, which has become engrained in the fabric of modern society (Gossop 2013, Plant and Plant 2006).

National prevalence data indicate that significant numbers of people in the UK drink at increasing or higher risk levels to their health. The annual General Lifestyle Survey reports that 34% of men and 26% of women consumed alcohol above recommended levels on at least one day in the previous seven, with a substantial number (19% of men, 11% of women) drinking ‘heavily’ on more than one of the previous seven days (Office for National Statistics (ONS), 2013).

Since 2004 the UK has seen a decline in per capital alcohol consumption per year from 9.5 litres to 7.99 litres in the adult population (The British Beer and Pub Association 2013), although concern remains about levels of consumption within particular age and gender groups, for example, older people and young women.

Recent statistics of illicit drug use in the general population show that 36.5% of people aged 16-59 years reported ever having taken an illicit drug with 8.9% reporting use within the past year (Home Office 2012b). Among these people will be individuals who have sight loss. The most widely used drug remains cannabis which is associated with a range of individual, familial and societal problems (Department of Health2007), including the negative impact on the individual’s wider networks of family and friends, work and community (Centre for Social Justice2013). It is estimated the current financial cost to society of substance use is £36 billion (Centre for Social Justice 2013). Within this bigger picture is more limited evidence that shows heightened levels of substance use among particular groups of people, including those identified as at higher risk of sight loss (Galvani 2012; Livingston and Galvani 2014, Paylor et al., 2012).

The associated harms and costs of substance use are well reflected in a succession of alcohol and drug related policies (Home Office 2012a, 2010, Scottish Government 2009, 2008, Welsh Assembly Government 2008). These policies have common objectives of: improving prevention, increasing treatment service provision, controlling supply, protecting vulnerable individuals and communities and, more recently, preoccupations with promoting 'recovery' models. Within this context treatment interventions have been extensively reviewed through meta and systematic analysis, (Drummond et al. 2005, Gossop 2006, Rastricket al. 2006). However, within all of this volume of policy, research and intervention activity, very little attention has been given to the issue of where substance use overlaps with sight loss.

Chapter 2 will now provide a summary of how we conducted the research before presenting the findings from each of the three strands - existing data set analysis, literature review, qualitative research - within chapters 3-7.

Chapter 2 - Methodology: the research approach

Aims and objectives

The overarching aim of this study was to explore the nature and extent of the relationship between substance use and sight loss from four perspectives:

1. analysis of existing datasets
2. existing research evidence
3. the views of people living with sight loss and substance use and
4. the views of people working with and supporting individuals with sight loss and substance use.

In order to achieve this aim and answer the research questions, more detailed objectives were established. These were to:

- explore what existing data can tell us about the extent of substance use among people with sight loss
- review any clinical and medical evidence of an association between substance use and sight loss
- explore the meaning and function of substance use in the lives of people with sight loss.
- explore how professionals in a) substance use and b) sight loss services are currently working with these overlapping issues.

Further, given sight loss and substance use are huge areas of study, a number of criteria were established at the start of the research to ensure a clear focus within the time and resources available. First, this study focused on permanent and acute levels of sight loss, rather than temporary or mild impairment. Second, it focused primarily on problematic use of substances rather than any use or social use. Third, the focus of this study was initially on alcohol. However, given the dearth of research on other substances and sight loss, and the fact that poly substance use is common, problematic use of prescribed or illicit drugs was included. While cigarette and tobacco smoking are risk factors for

sight loss, they were not a focus of this study due to the research that has already been conducted in this area.

Data collection

Three core strands of activity were needed to meet our aims and objectives:

1. Secondary analysis of existing datasets – these datasets were analysed to determine whether there were any existing data available on the prevalence of problematic alcohol use among people with sight loss (see note below).
2. International literature search – a wide search of English language literature was conducted to explore existing evidence of medical correlations between substance use and sight loss and indications of any role substance use plays in the social and emotional lives of those with a sight loss.
3. Qualitative data collection through interviews with service users, carers, and professionals who had experience of living and working with sight loss and substance use.

Note: the initial focus of the research was alcohol and sight loss and this is the focus of the existing dataset analysis. As the literature search progressed it became evident that the inclusion of other drugs in the international literature search and the qualitative data collection might offer some wider insights and understanding. Thus all substances were included in these subsequent strands.

Data analysis

Each research strand required different forms of data analysis including multivariate statistical analysis of quantitative data, descriptive narrative analysis of the existing research literature, and thematic analysis of the qualitative data. These analytic approaches will be detailed within chapters 3-7 alongside the results of each strand of the project.

Ethics

Ethical approval for the research was sought from the two tier research governance structure at the University of Bedfordshire, namely Institute and University level committees. It was further approved by Lancaster University.

Informed consent was required from all research respondents prior to each interview and usually via a written and signed consent form (see appendix 1). Where this was not possible as a result of accessibility issues, the consent form was read out and verbal consent was audio recorded and noted by the researcher.

High street gift vouchers were available to all participants living with sight loss and substance use and the volunteer worker who also took part. These were offered as gratuity payments at the end of completed interviews rather than incentive payments at the start of the interview. The key difference is that with gratuity payments participants are unaware of the vouchers until the end of the interview.

An information sheet on local and national support services for people with sight loss and substance use was created and offered to people at the end of each interview (see appendix 2).

Limitations

This study is an exploratory study with limited resources. It makes no claims to representativeness or generalisability of its findings. Its review of the evidence is not systematic nor is the analysis of existing data sets exhaustive. The numbers recruited for the empirical work are necessarily small. It is, however, the first study of its kind and provides an important insight into the overlapping issues of sight loss and substance use from three different sources of data. Further, it points to gaps in knowledge and evidence as well as highlighting the complexity and challenges of living, and working, with these overlapping issues. This, in turn, allows for consideration of supportive service responses.

Chapter 3 - Existing data set analysis

Introduction

There are currently no figures in the UK on the prevalence of alcohol use and sight loss. The first aim of the research, therefore, was to determine whether data existed that could reliably provide some evidence of the extent of the overlap between sight loss and alcohol in particular. To this end an online search was carried out of the UK Data Service database. This provides a single point of access to a wide range of secondary data including large-scale government surveys. The following section details how the datasets were identified and analysed.

Methodology

Identification of Datasets

The search for datasets within the UK Data Service database included the following terms:

- Alcohol + sight
- Alcohol + see
- Alcohol + vision
- Alcohol + visual
- Alcohol + visually
- Alcohol + blind

To ensure the data was recent and UK wide, datasets were excluded if:

- data were collected prior to the year 2000.
- the study was conducted in Scotland, Wales or Ireland only.
- it was a special population (e.g. International Passenger Survey).
- it was limited to young people or children.

Where datasets contained suitable questions on eyesight and alcohol use, the number of people with sight loss was determined to ensure an

adequate sample size. If there was the potential to combine data from repeat studies to increase the sample size, questions from previous years were examined to ensure comparability.

The following three datasets were identified from the UK Data Service database as meeting the criteria most closely:

- The General Lifestyle Survey 2009 and 2010
- The Health Survey for England 2000
- The Primary Care Trusts Patient Survey 2008

Details of these datasets and the rationale for selecting them are shown in table 1 (go to appendix 3). This table includes five columns providing the name of the study, a brief study description, the type of alcohol questions asked, the type of eyesight questions asked and any other comments about the suitability of the study for this research.

Data Analysis

Once the datasets had been identified the data were analysed in a number of ways:

1. Pearson's chi-squared tests were applied to examine the relationship between key demographic variables and sight loss in the six months prior to interview (see tables 2 and 4);
2. A univariate and multiple (logistic) regression analysis was conducted to determine whether sight loss was associated with various drinking behaviours (see tables 3 and 5).
3. A univariate and multiple (logistic) regression analysis was conducted to determine whether sight loss was associated with various alcohol interventions (see table 6).

The five tables to accompany this analysis can be found in appendix 4.

Results: Prevalence

General Lifestyle Survey

Combining 2009 and 2010 General Lifestyle Survey (GLS) datasets provided a sample of 261 people aged 16 years and over who had sight loss. This was defined as cataract, blindness or poor sight which had troubled the respondent over a period of time or that was likely to affect them over a period of time. Of this number 68% were aged 65 years and over.

The GLS contains a number of questions on drinking behaviour which allow the prevalence of risky drinking behaviour to be determined for those with sight loss and comparisons made with those who do not have sight loss. The key questions which were analysed in this study related to whether the individual:

- Abstains from alcohol.
- Exceeds the weekly drink limits
- Drinks every day of the week
- Has had a 'binge'[2] in the last 7 days

Data on the estimated number of alcohol units consumed per week were also analysed.

The analysis showed that:

1. People with sight loss were significantly more likely to abstain from alcohol and less likely to exceed the weekly recommended limits having adjusted for age and sex (table 3, appendix 4).
2. Among those who drink, people with sight loss consume fewer alcohol units per week on average than those without sight loss (10 vs. 15, p=0.002)

2 Binge is defined as drinking more than 8 units for men and 6 units for women on heaviest drinking day in last week.

3. 14% of those with sight loss exceeded the recommended weekly drink limits and 23% consumed alcohol every day in the past week (table 3, appendix 4).
4. There was no statistically significant difference in drinking every day of the week or binge drinking in those with sight loss compared to those without sight loss once adjustments were made for age and sex (table 3, appendix 4).

Health Survey for England

The Health Survey for England 2000 provided a sample of 894 people aged 16 and over who had a "sight disability". Respondents could select whether they had no sight disability or whether it was "moderate" or "severe". Of these 89% were aged 65 years and over.

The key questions which were analysed were whether the individual:

- Abstained from alcohol.
- Exceeded the weekly drink limits
- Reported that they felt they needed to cut own drinking
- Had been drunk in the last 3 months.

Data on the estimated number of alcohol units consumed per week were also analysed.

The analysis showed that:

1. People with a sight disability were significantly more likely to abstain from alcohol having adjusted for age and sex (table 5, appendix 4).
2. There was no statistically significant difference in exceeding the weekly drink limits, reporting feeling a need to cut down or having been drunk in the last 3 months in those with sight loss compared to those without sight loss once adjustments were made for age and sex (table 5, appendix 4).

3. Almost a quarter (24%) of people with a sight disability felt a need to cut down their drinking, 28% had been drunk in the last 3 months and 8% exceeded the weekly drink limits.
4. Among those who drink, people with sight disability consume fewer alcohol units per week on average than those without sight loss (9 vs. 13, $p<0.0001$)

Primary Care Trusts Patients Survey

Finally, the Primary Care Trust Patients Survey 2008 provided a sample of 1485 people aged 16 and over who had a longstanding condition involving "blindness" or were "partially sighted".

The survey asked two questions in relation to the extent to which participants were asked about their alcohol use and given advice/help about their alcohol use by someone at their GP practice. These questions were:

- whether they had been asked by someone at their GP practice about how much alcohol they drank in the last 12 months
- whether, in the last 12 months, they had been given advice or help from a GP practice on sensible alcohol intake (yes definitely, yes to some extent, no but would have liked help or advice, no but didn't want any help advice, don't drink alcohol).

The analysis showed that:

1. After adjustment for age and sex, there was no statistically significant difference between the extent to which people with and without sight loss were asked about alcohol by someone at their GP practice.
2. After adjustment for age and sex, people with sight loss were significantly more likely to say that they had been given advice or help about alcohol by someone at their GP practice in the last 12 months.
3. Of those who didn't receive help/advice, people with sight loss were more likely than those without sight problems to say that they would have liked it.

4. 68% of people with sight loss had not been asked about their alcohol use in the last 12 months and 10% of those who didn't receive help or advice about alcohol, would have liked it.

These findings are presented in table 6 in appendix 4.

Discussion

There are a number of important findings resulting from this analysis. The first is that people with sight loss, on average, appear to engage in less risky drinking behaviour than those without sight loss and this association remains significant following adjustment for age (a confounding factor). This could be because people with sight loss find it more difficult to access alcohol or are less likely to socialise in settings where alcohol is consumed (e.g. pubs, clubs and restaurants). It is also possible that there is an unidentified confounding factor which we have not been able to adjust for. For example, diabetes is associated with sight loss and people with diabetes may be advised to reduce their alcohol intake following their diagnosis. Due to the relatively small sample size, it has not been possible to carry out analysis to explore whether there is an association between diabetes and alcohol consumption in this study.

It is important to note that whilst levels of risky drinking may be lower among people with sight loss, they remain significant and almost a quarter of people with sight loss felt a need to cut down their drinking. Furthermore, 10% of people with sight loss would have liked advice/help about alcohol but did not receive it. This suggests that every opportunity should be taken to ask people with sight loss about their alcohol use and provide advice or help where it is needed.

It is not clear why people with sight loss were more likely to report that they have been given advice/help about alcohol by someone at their GP practice than people without sight loss, particularly as data from the General Lifestyle Survey and Health Survey for England suggest that they are, on average, less likely to engage in risky drinking behaviour. It may be that people with sight loss are more likely have visited their GP in the last 12 months providing more opportunities for GP to give advice/help. It may also be that there is a perceived 'vulnerability' from GP/health professionals or assumptions about coping strategies. People

with sight loss were also more likely to report being asked about their alcohol use by someone at their GP practice, although this difference was not statistically significant.

It is also interesting that among those who did not receive advice or help, people with sight loss were more likely to report that they would have liked it. Therefore it may be that those people with sight loss who do experience alcohol problems are more likely to be overlooked by healthcare professionals than people without sight loss for reasons that remain unclear.

Limitations

There was a relatively small number of people with sight loss interviewed in the General Lifestyle Survey which reduced the power of the analysis to detect differences in drinking behaviour between those with and without sight loss. While the number surveyed in the Health Survey for England was higher, this is still only a small proportion of the people in the UK with sight loss.

Summary of findings: existing dataset analysis

The evidence of the analysis from the datasets suggests that people with sight loss are more likely to abstain from alcohol and consume fewer alcohol units each week compared to their sighted peers. The Patients Survey 2008 found that of those who did not receive advice or help about alcohol from their GP, people with sight loss were significantly more likely than their sighted peers to have wanted it. They were also more likely to have been given advice or help relating to alcohol in the last 12 months.

Chapter 4 - International Literature Review

One of the key research questions for this exploratory study was to determine what is already known about the relationships between sight loss and substance use. Objectives 1-3 break this down more clearly into three particular foci: first, what is known about the extent of substance use among people with sight loss; second, whether there is medical or clinical evidence of an association between the two; third, the meaning and function of substance for people with sight loss.

The following section describes the approach to searching the literature before presenting a summary of findings.

Methodology

The literature search was designed to be a comprehensive and transparent review process. Appendix 5 provides full details of the four phase process of the literature review including search terms, databases accessed, and inclusion and exclusion criteria. To summarise:

- phase 1 involved a broad search of bibliographic databases and specific journals; relevant abstracts were identified.
- phase 2 involved a preliminary screening of all the abstracts against inclusion or exclusion criteria; abstracts were categorised thematically at this stage.
- phase 3 involved in-depth reading of full abstracts in their themed categories. Further exclusions were made at this phase for focus and relevance.
- phase 4 involved accessing and reading the full texts of all relevant abstracts; a data extraction template was used to record key findings and methodological data (see appendix 6 for the completed data extraction template). Several further exclusions were made at this stage for relevance, those not in English language, or duplicates of other articles.

In total 31 searches were conducted generating 670 pieces of literature with date parameters set between 1990 and 2013. Following the application of inclusion and exclusion criteria, this left 147 abstracts for secondary full abstract reading. On closer reading a further 90 were excluded leaving a final number of 57 abstracts for full text reading. At this point a further eight were excluded for reasons of relevance or because the full article was not available in the English language. This left 49 articles which form the basis of the findings below.

The following section provides a narrative synthesis of the literature review's findings.

Findings: what the research evidence tells us

The research on this topic is diverse in its form, content, the media through which it is disseminated, and in its geographical origins. It quickly became apparent that this is an international concern and not just one located in Europe and North America. While there is not a particularly large body of evidence, what is there is spread across Europe to Australia, from South America to Japan, as well as within the African nations. It is safe to conclude that this is not an anomaly of a particular ethnic culture or substance use culture within it.

The types of evidence presented and the methodologies used also vary tremendously. Common were clinical case studies presented in full in peer reviewed papers or, by contrast, in brief letters to editors (see appendix 7). They offered powerful descriptions of the type of issues these overlapping issues present in practice and the different type of sight loss and eye damage that can occur. They also offered a range of clinical treatment options.

Finally, there was a broad range of journals within which the evidence was found. With the exception of the journal Eye, which contained a number of relevant articles, the evidence was spread across a breadth of journals in different languages and in the spheres of public health, various specialist branches of medicine, ophthalmology, addiction, psychology, and psychiatry.

The key findings from the literature will now be presented within four categories, 1. Prevalence, 2.Cause or association, 3.Use of substances by people with sight loss and 4.Foetal Alcohol Spectrum Disorder (FASD).

1. Prevalence of problematic substance use among sight loss populations

Eleven pieces of literature were more directly focussed on prevalence from the initial screening process. These were based primarily on large population cohort studies, with some additional survey and secondary data analysis material. Methodologically the dominant (n=8) approach was that of cohort population eye studies that involved the use of medical and optometrist examinations with additional survey questionnaire data. Six of the articles were specific outputs from the two biggest international longitudinal studies; The Beaver Dam Study (U.S.A.) and the Blue Mountain Eye Study (Australia), which have been extensively published over the last 10 years. The outputs used here, are those which specifically pick up on alcohol, tobacco and caffeine use in relation to eye conditions. The other two population studies came from China and Kenya. The remaining three represent secondary statistical analysis of existing datasets, one from a large American lifestyle survey and two from diabetes-related surveys in the U.K. and U.S.A. respectively.

Ten of 11 studies concern themselves with an older sample group, with minimum ages between 40 and 49. The three secondary analysis studies are predominantly concerned with degrees of visual functioning and impairment, rather than acute sight loss or specific eye conditions.

None of the studies reviewed had the prevalence of alcohol and drug use among those with sight loss, or vice versa, as the primary focus of the research. However, the 11 studies reviewed focussed on sight loss and then considered alcohol and other drug use as one of a number of aetiological, contextual and risk considerations.

Key messages relating to prevalence of problematic substance use among people with sight loss

- There is a distinct population of people who live with or experience both sight loss and problematic substance use.
- Within this population it is possible to identify a small percentage of individuals whose use of alcohol or drugs is at the higher levels associated with risks to health.
- Consistent with wider literature findings on alcohol there is some argument for possible beneficial impact of small levels of alcohol consumption in the prevention of eye health deterioration (Kanthan et al. 2010). Kanthan et al. found that, compared with abstinence or more than 2 "standard [alcoholic] drinks" per day, 1-2 drinks were a protective factor against cataract surgery.
- Sustained alcohol and drug use is considered to be a consistent and significant risk factor for the development of sight loss conditions.

The studies suggest that excessive alcohol use among people with sight loss or visual impairment is lower than for the general population (Mukamal 2007). Given the ages of the populations studied here, this is perhaps not surprising, as older age is considered a protective factor for drink and drug use, with lower levels of consumption than in the general population (Wadd and Galvani 2014). However, potentially problematic consumption can still be identified; one secondary analysis of a large dataset from North America found that 5% of those with diabetes and eye disease could be categorised as binge drinkers (Mukamal 2007).

Ploudibis et al. (2013), in their Kenya-based study, found that increased wealth was only weakly associated with healthy lifestyle choices, including alcohol consumption and smoking, and was not necessarily a protective factor against sight loss. Alcohol and drug use is considered as one of a number of high risk behaviours for developing sight loss. However, these studies are often cautious and contradictory in the extent to which they will support the existence of significantly positive correlations between sight loss and substance use. For example, in the Beaver Dam study, Knudstan et al. (2007) suggest that earlier correlations between heavy drinking and the increased risk of developing exudative macular degeneration after 10 years were not sustained at 15 years. In the same study, Moss et al. (1998) established there was no

significant correlation between alcohol consumption as a risk factor for incidence of age-related maculopathy after five years, except for an association of beer drinking with retinal drusen in men. Where positive correlations are identified they are often very specific in respect of the population, eye condition and time frame. In one study drinking patterns were significantly associated with the subjective self-reports of difficulties in recognising friends or reading newspapers (Fan et al. 2012). In another alcohol use was identified as a significant risk factor for eye injuries which in turn leads to a correlation for sight loss(Wang et al. 2012).

2. The relationship between sight loss and substance use: cause or association?

This narrative summarises 20 pieces of literature based primarily on clinical studies or empirical research within a wide range of international research contexts. Methodologically, 10 pieces of literature presented single or multiple case study examples, two were reviews of eye injuries presenting at clinical settings, one was a literature review, and one study involved rats only while the remainder used various data collection methods involving human participants from particular populations, for example, people attending schools for blind people in Cameroon.

This is a vast topic area and the research and associated literature reflect this through their focus on different aetiologies, stages and aspects of sight loss. There is little evidence for a causal relationship between substance use and sight loss but there is a wide and varied range of evidence with much of it suggesting some connection between the two. The most consistent connection between substance use and sight loss was presented in the clinical case studies. However, the particular form of visual impairment or sight loss varied as did the substance that appeared to contribute to it. The case studies also demonstrated the geographical reach of the clinical presentations; they came from around Europe, south-east Asia, and north America. They involved primarily men aged from 21 to 68 years old (Anyfantakis et al. 2012, Bhatnagar and Sullivan 2008, Davies, C. et al. 2012, Kee and Hwang 2008,Shinya et al. 2003- abstract only available – Japanese article, Shwe-Tin et al. 2007, Sivilotti et al. 2001, Steel et al. 1993, Syed and Lioutas 2013, Zoccolella et al. 2010). Five of the ten studies

reported that early intervention and speedy, appropriate treatment reversed or at least improved the sight loss to some degree. This included cessation from the substance use. A sixth showed this was only the case for those who had been using substances for a shorter period of time, while a seventh found only minimal improvement. Three authors did not comment on the visual impairment treatment or its outcomes, describing instead the medical or neurological condition that they had encountered.

An additional three studies focussed on whether there was an association between alcohol consumption and particular forms of sight loss, for example, age-related macular degeneration (ARMD) (Ajani et al. 1999, Venza et al. 2011) or two particular forms of cataracts (Durant et al. 2006). Two of these studies, while focussing on very different sample populations, found no evidence of a significant negative relationship between alcohol intake and those particular forms of visual impairment in their particular samples (Ajani et al. 1999, Durant et al. 2006). Indeed, the Durant study found alcohol to be a significant protective factor for one type of cataract – retrodots – but cautioned that its study sample included few heavy drinkers.

Venza et al. (2011) found that the combination of alcohol and smoking contributed to oxidative imbalance and subsequent DNA damage in people with ARMD. This focus on the impact of alcohol on oxygen levels was also a focus of two further studies. The first used a sample of rats to explore oxidative stress and subsequent damage to rat retina (Sancho-Tello et al. 2008). It concluded that 'ethanol' had a toxic effect on rat retina. The second study, with eight people, found that alcohol had an impact on the blood oxygen levels using magnetic resonance imaging which led to an increased "idle" visual function in the resting brain (Esposito et al. 2010).

Firth's (2005) editorial in the journal Eye, on Class A drugs and their impact on substance use, highlights a range of sight loss conditions relating to different substances. He notes that users of cocaine and crack cocaine report the highest rates of ocular problems although there is similar evidence relating to other drugs such as heroin and to rapid detoxification. Firth refers to other studies that suggest use has lead to sight loss but states 'substantiated studies are not available' suggesting

they are limited single cases. His key recommendation is that clinicians need to be aware of the potential ocular outcomes of class A drug use as this may help to identify the aetiology of presenting conditions.

In two cases the research article was not available or not available in English and therefore limited information could be established from it. For example, one French language study from Cameroon (Noche and Bella 2010) reported that alcohol was responsible for sight loss in 1.8% of the sample but it is not possible to discern if this was a result of, for example, toxic amblyopia, parental substance use in utero, or external injuries to the eye/s under the influence of alcohol.

By way of complete contrast, moderate drinking was identified in one study as a possible protective factor against eye health deterioration (Fan et al. 2012). In the Blue Mountain study, the authors argue for the establishment of a U-shaped correlation between alcohol consumption and cigarette smoking and long-term incidences of cataract or cataract surgery (Kanthan et al. 2010, Cumming and Mitchell 1997). Kanthan et al. (2010) suggest that moderate consumption was associated with 50% lower cataract surgery incidence, compared either to abstinence or heavy alcohol consumption. Thus, at lower levels, alcohol and nicotine use is protective and only becomes a risk at higher levels of consumption. It should be noted, however, that for this study the overall number of heavy drinkers was a small part of the sample and heavy drinking is measured as self-reported consumption of more than 2 drinks a day - arguably a low threshold for heavy drinking.

Substance-related external factors causing sight loss

The literature search criteria identified two studies about eye injuries caused by external factors relating to substance use. Parver et al. (1993) reviewed the characteristics and causes of penetrating eye injuries reported to the US National Eye Trauma System Registry between 1985 and 1991. There was evidence of definite or possible alcohol use by the injured party in 24% of cases [n=2,939] and of ‘illicit drug use’ in 8%. The involvement of substances was most commonly found among those with transport- and assault-related eye injury as opposed to workplace injury for example. The second study was an Italian study which reported on the clinical outcomes in 34 cases of bottle cork and cap injury to the eye

over an eight year period (Cavallini et al. 2009). Such injuries constituted 11% of all eye injuries presenting to the Ophthalmological Unit. They found a correlation with areas of large scale production and the sale of sparkling wine and higher incidences of eye injuries over holiday and bottling periods. There was no discussion of whether alcohol consumption had affected the likelihood of injury. There is clearly a larger body of work on eye injuries which was not identified using our search criteria and could be explored in future. These studies relate to eye injuries caused by different types of violent behaviour or road traffic accidents, for example, where alcohol or other drug use by the perpetrator or victim is a feature. There are also particular research populations, for example, people attending Accident and Emergency Departments in hospitals, where this type of injury or other accidental eye injury while intoxicated will be more easily identified.

3. Use of substances by people with sight loss

This narrative summarises seven pieces of literature which primarily addressed the use of substances by people with sight loss based on clinical studies or empirical research. Interestingly the studies suggest quite different findings compared to the UK prevalence data highlighting how different studies can reach different conclusions based on methodology and focus. It also highlights the need for more research in this area.

Methodologically three of the papers were reviews of the literature, four reported on empirical studies including interviews and self-reporting questionnaires with people with sight loss and, in two studies, with their peers without sight loss.

The three literature reviews were concerned with alcohol and substance use of disabled people in Canada and the USA. Watson et al. (1998) sought to identify the prevalence of alcohol and substance use among certain impairment groups including sight loss while Koch et al. (2002) were specifically focused on those with sight loss. Csiernik and Brideau reviewed the literature around the intersection of ‘addiction and issues of ability’ in Canada and so considered disabled people generally as well as a focus on particular impairment groups including ‘sensory disabilities’

such as visual impairment. The paper is a review of 40 peer reviewed journal articles on disability and addiction published between 1990-2011.

Watson et al. (1998) highlighted the way in which the ‘characteristics of the life styles’ of some disabled people may place them at higher risk for developing substance problems, for example, they may be required to use (addictive) prescribed medication for long periods. Csiernik and Brideau also highlight this as an issue where total abstinence is a requirement of treatment. Watson et al. cite living with chronic pain, experiencing ‘peer group difficulties’, feeling isolated, having excess free time, and being unemployed as specific risk factors for substance problems. They also highlighted people's minimal access to substance use prevention and support including a lack of relevant literature and other support materials in accessible formats.

Koch et al. (2002) sought to identify the potential impact of substance use on sight loss, the barriers to providing effective substance use services to people with sight loss, and strategies that improve services for this group. Drawing on a north American report by the National Association on Alcohol, Drugs and Disability (NAADD 1999), they suggest disabled people experience substance use at ‘rates equal or in excess’ of the general population. NAADD estimates that the true figure of people with sight loss who require treatment for alcohol and drug 'disabilities' could be as high as 50%. This was supported by a number of other north American studies that suggested similar levels of substance use leading to the conclusion that people with visual impairment ‘are significantly at risk' for problematic substance use. This is supported by Moore and Li’s (1994) survey of alcohol use and consequences among disabled people who were found to use alcohol as much or more than the general population. They identified higher levels of problematic substance use among those with acquired impairments and those undertaking rehabilitation.

Buss and Cramer's study (1989 cited in Moore and Li 1994) of alcohol use among users of vocational rehabilitation or independent living services in Wisconsin, U.S.A., concluded that those with certain types of impairment (including visual impairment) ‘can be classified as heavy or moderate consumers of alcohol in approximately 40-50% of reported cases’ (n = 3,216). Moore and Li’s survey suggested 57.5% of people

with visual impairment currently drink alcohol (compared to 71.5% with spinal cord injuries, 60.9 % hearing impaired, and 57.5% with a learning disability).

As outlined in chapter 1, Koch et al. (2002) identified three categories of relationship between substance use and disability which they applied to sight loss:

1. Pre-existing substance use where the consequence of this is likely to ‘exacerbate the psychosocial consequences’ of sight loss and may impede rehabilitation. It may also mean a range of other ‘risk’ factors such as limited work history or a lack of interpersonal skills or positive social supports.

2. Substance use following the onset of visual impairment where it may damage the life skills that have helped them to adjust to their sight loss.

3. Substance use and sight loss occurring concurrently where substance use may be a coping device. This has the potential to ‘sabotage’ the rehabilitation process.

Koch et al. also noted that substance use can be a strategy for gaining 'social acceptance/easing social discomfort’ and therefore may be ‘justified’ by professionals, that is, it is seen as a ‘natural’ response and thus overlooked. Unfortunately Koch et al.'s paper does not provide detail of their methodology making it difficult to establish the quality and rigour of the literature review on which they based their typology. Nevertheless, it highlights the stigma associated with substance use as compounding disability stigma and suggests rehabilitation professionals demonstrate negative attitudes towards what they term ‘people with substance use disabilities’ as they are perceived as less likely to benefit from vocational rehabilitation. Wider societal fear and discomfort about substance use, and users of substance use services, can lead to isolation and segregation within communities and in disability, sight loss or rehabilitation services. Koch et al. highlighted a lack of specialist knowledge about substance use in sight loss services and vice versa and a lack of integration or co-ordination between these services. They point out that this can result in people being ‘lost in the system’ with neither service seeing someone with sight loss and substance use as

their primary responsibility. This finding was echoed in Csiernik and Brideau (2013), and Moore and Li (1994).

Csiernik and Brideau's (2013) review cites articles that suggest the ‘average' amount of substance use among people with sight loss is higher than the general population although they do not provide figures. They suggest that while professionals recognise the impact of stereotyping and discrimination resulting from substance use and sight loss, this understanding does not extend to the psychosocial effects experienced by people with sight loss and using substances. This may be the result of negative public and professional attitudes to their substance use and this additional stigma can result in people being resistant to working with these professionals. There was also concern that disclosing substance use may endanger their eligibility for, or access to, services. Again the review highlighted a lack of knowledge about sight loss or substance use and about the cross-cutting issues. There was also a tendency for professionals to ‘compartmentalise thinking’ and to be confused about which issue is the ‘primary’ issue or symptom.

Moore and Li (1994) found that disabled people were less likely to be confronted about their substance use. Csiernik and Brideau (2013) identified barriers to people with sight loss accessing substance use services. These included a lack of policies and procedures which took account of their access and wider needs, a lack of consideration regarding their inclusion in group therapy and other activities suggesting a need for greater disability equality training for staff and other users. There is a "vicious cycle of unmet needs and unsuccessful treatment strategies, which only serves to further perpetuate the isolation and oppression that is already experienced by members of this [sight loss] population" (Csiernik and Brideau 2013: 174).

Pinquart and Pfeiffer (2010) compared alcohol use among young people under the age of 20 with and without visual impairment in Germany. They found that young people with visual impairment were less likely to consume alcohol, become drunk or binge drink and tended to experience their first episode of drunkenness in later life than their peers without visual impairment. The authors suggest the lower level of alcohol use are the result of young people with visual impairment spending less time with their peers and more time alone and thus they may have fewer

opportunities to buy alcohol. They also speculate that sight loss ‘sensitizes individuals to health risks and may promote positive health behaviours’. Pinquart and Pfeiffer question where the balance should be struck between promoting social integration which may increase social drinking and the health hazards of alcohol use. They also point to the importance of highlighting socialisation strategies and techniques for young people with sight loss that do not involve alcohol.

4. Foetal Alcohol Spectrum Disorder (FASD)

The search of the literature identified a body of work that focussed on FASD and the impact of alcohol consumption on sight loss as one of the physical manifestations of FASD. FASD was not a specific focus of this literature review; it emerged as a result of our search criteria. It should be noted that there is a large body of work on FASD and the FASD literature which emerged adds a different dimension to the focus of the study. This section therefore summarises the findings briefly. The 11 studies were located within the international research community and comprised experimental trials primarily with human and animal-based subjects. The studies involving samples of children (n=3) explored the comparative testing of visual functioning and impairment for children born to mothers who used alcohol and drugs during pregnancy and those who did not. The animal experimentation research involves exposing the non-control group to alcohol during pregnancy and measuring the impact on cognitive and nerve development of the foetus.

The literature identifies that visual impairment and sight loss is one of a number of conditions that children may experience when exposed to heavy maternal alcohol and other drug use in utero. Bruce et al. (2009: 153) in their literature review identify a wide variety of ocular and neuro-ophthalmic conditions relating to FAS (Fetal Alcohol Syndrome) resulting in lifelong visual impairment. This is further supported by Strömland (2004) who states;

> "All parts of the eye may be affected and anomalies such as microphthalmus, microcornea, Peters' anomaly, cataract, persistent hyperplastic primary hyaloid vitreous body, coloboma of the iris and choroid, retinal dysplasia and, most commonly,

optic nerve hypoplasia and tortuosity of the retinal vessels, have been reported."

However, Elliot et al. (2008) found that a relatively small number of respondents in a general epidemiological population study of FASD children had visual impairment (4.3%). The other studies identified more specific VI conditions among children born to substance using mothers:

1. Impairment is more pronounced in the peripheral vision (Coffman et al. 2012).
2. Hamilton et al. (2010) provided a description of 20 case studies and found the following proportion of ophthalmic abnormalities in his sample of children: reduced acuity (95%), nystagmus (70%), delayed visual maturation (50%), strabismus (30%), refractive errors (30%), and cerebral visual impairment (25%). Visual electrophysiology was abnormal in 60% (Hamilton et al. 2010)..
3. In the visual attention in pre-school children (14-60 months) exposed to cocaine in pregnancy, FAS children show slower reaction times(Heffelfinger et al. 2002).

Flannigan et al. (2008) conducted a quasi-experimental, long term, follow up study with 98 children in Chile who were exposed to heavy neo-natal alcohol use. They identified that the development of visual impairment was confined to those who developed Foetal Alcohol Syndrome (FAS) only. Flannigan et al. (2008) caution that despite the high prevalence of visual impairment among children with FAS, ophthalmologic examinations are not likely to help diagnose FAS.

Limitations

This was not a systematic literature review. There are likely to be articles we did not find alongside those in foreign languages that we were unable to access. It was also limited by the quality and extent of the literature available including those who provided no information on their research methodology thus not allowing a determination of the quality, rigour and reliability of their findings.

Research gaps

A more extensive literature review may reveal more research in this area. However, there are clearly notable gaps in the evidence base which have also been highlighted by the authors whose work we reviewed. Completely absent from the literature were participants' perspectives; qualitative research that reflects their life histories and experiences of substance use and sight loss are clearly needed to accurately construct a social as well as medical context that can inform practice and clinical responses. None of the literature reviewed contained direct quotations or reports on the experiences of disabled people. This may be due to the predominance of literature found in medical or clinical journals where qualitative data is limited at best. It may also reflect a lack of funding for research in disabled peoples' experiences. Csiernik and Brideau (2013) highlighted how it is rare to hear the voices of disabled people experiencing addiction. There was a clear gap in the literature on the illicit use of prescribed medication among people with sight loss and the non-compliance with sight loss medication regimes resulting from substance use.

Another gap is substantive research on younger people with the majority of the studies reviewed focussing on people aged 40 years and older. Similarly one of the FASD research groups highlighted the need for research on older children given the focus on younger children and infants.

A number of studies identify the need for longitudinal approaches to research as the means by which to establish whether sustained substance use over time correlates with eye health deterioration. Consistent with this is an expressed need to focus on chronic eye conditions and alcohol use, rather than just acute episodes and presentations.

As is often the case, authors highlight the implications for future research within the limitations of their own studies or papers. In a review of interactions between non-steroidal medication and glaucoma, Razeghinejad et al. (2011) concluded that while there are many reports of drug-induced glaucoma, there is an absence of controlled, comparison trials. The case for experimental and longitudinal research on the associations between alcohol, other drugs and sight loss, is undoubtedly a strong one given the gaps in the evidence base. As the

authors conclude, drug-induced glaucoma is also preventable in many cases. Ajani et al. (1999) felt different levels of alcohol consumption needed further exploration in relation to ARMD.

Practice implications

The clear message from the body of literature reviewed was the need to ensure services - be they sight loss or substance use - are aware of the overlapping issues of sight loss and substance use and that the professionals within them were prepared for identifying, assessing and responding in an appropriate way. This was not only because of the need to identify these overlapping issues but because other health conditions that may co-exist and could worsen or effect sight loss need to be considered in services for substance use, for example, diabetes or glaucoma.

The call from many papers reviewed was for better training for all those involved in the diagnosis and care of people with sight loss, for example, physicians and ophthalmologists. The need to ask about recreational substance use as well as regular substance use was highlighted by clinicians as well as their need to be prepared to consider rare cases and environmental factors. With evidence suggesting that early intervention had a positive impact on improving sight loss in many cases, such assessment was viewed as a necessity for practice.

Given the mutual lack of expertise in the two broad areas of specialist practice, some authors highlighted the necessity of cross-service training and the need to strengthen relationships between the two areas of practice. They also highlighted the importance of developing accessible materials for each service about the 'other' issue including information on medication and substance use.

In addition to the above implications the FASD literature drew attention to the need to support pregnant mothers to be aware of substance use during pregnancy [Flannigan et al. 2008], and the likelihood of ophthalmologic examinations being important in the assessment or evaluation of a child who has FASD.

Summary of findings: what the research evidence tells us

This is a vast topic area and the research and associated literature reflect this through their focus on different aetiologies, stages and aspects of visual impairment. The literature reviewed here, in general, demonstrates a lack of evidence for a causal association between sight loss and substance use and low prevalence rates. Some of the literature, particularly the north American data presents a different picture and the FASD evidence also indicates a connection between substance use and visual impairment in FAS-affected children. It was unclear in many studies what level of drinkers are included with some identifying a lack of 'heavier' drinkers in their studies and this needs to be considered in the interpretation of some of the evidence.

The clinical case study material suggests links between substance use and sight loss and identifies that early intervention is vital in maximising people's chances of sight improvement and recovery.

There is also a body of work that highlights some of the challenges that may expose people with sight loss to higher risk of substance use, for example, living with chronic pain, stigma, social isolation and boredom that may accompany sight loss. This has to be balanced with the potential advantages of social integration through alcohol-related activities, for example, going to the pub. This will be explored further in Chapter 5.

Finally, the call for training for all professionals involved in assessing, identifying and responding to both sight loss and substance use in a range of contexts is clear. So too is the need for services to provide information about these overlapping issues in accessible formats.

Smoking: an addendum to the literature review

While this study focused on alcohol and other drug use, it is important to note that the literature consistently identifies smoking as a posing a very significant risk in the development of a range of visual impairments. The list of ophthalmologic disorders associated with cigarette smoking continues to grow.

A literature review by Solberg et al. (1998) identified that both cataract development and age-related macular degeneration, key causes of severe visual impairment, are directly accelerated by smoking. Kelly et

al. (2005) in their review of 27 studies found evidence that suggests that smoking has a three-fold increase on the risk for incident nuclear cataract development. Thornton et al. (2005) in a review of 17 studies confirmed a strong association between current smoking and age-related macular degeneration, concluding that cigarette smoking is likely to have toxic effects on the retina. Chakravarthy et al. (2010) in a systematic review and meta-analysis also demonstrated that current cigarette smoking has strong and consistent associations with late age-related macular degeneration. In addition to confirming the role of smoking in cataracts and age related macular degeneration, Rowe et al.'s (2004) review also highlighted smoking as a significant risk factor in diabetic retinopathy and thyroid eye disease.

These review findings can be further illustrated by numerous other studies, for example McCarty (2002) and Tsai et el. (2003) who identified smoking as a significant risk factor associated with the onset of cataracts; and Lim et al. (2012) and Venza et al. (2011) who illustrate the aggravation caused by smoking contributing to age-related macular degeneration. In the Blue Mountain Eye Study, both Kanthan et al. (2010), and Cumming and Mitchell (1997) identify the links between smoking and cataracts. Zhang et al. (2011) study illustrates that smoking is linked to self-reported visual impairment among older adults with age-related eye diseases, particularly cataract and age-related macular degeneration. Kelly et al. (2004) estimate that approximately 53,900 United Kingdom residents older than 69 years may have age-related macular degeneration attributable to smoking. Bhatnagar and Sullivan (2008) and Solberg et al. (1998) highlight that smoking is a cause of tobacco–alcohol amblyopia (TAA); visual impairment as a consequence of toxic optic nerve damage.

Further, smoking is often correlated with other health and dietary lifestyle choices that also impact on the likelihood of developing visual impairment.

The key messages from these findings are the importance of clear health promotion messages, early eye health screening and support for smoking cessation programmes.

The following chapters 5-7 will now report on the interviews conducted with people with sight loss and substance use and professionals involved in service provision.

Chapter 5 - Interview methodology

This aspect of the study sought to collect primary data on individuals' experiences of living or working with sight loss and substance use and their related accounts of support and service provision. The intention was to collect data from service users, carers, and professionals across a range of sight loss and substance use contexts. This section explores; a) the recruitment and sampling strategy, b) data collection tools and c) data analysis methods.

Recruitment and Sampling Strategy

The exploratory nature of the study allowed an element of creativity in our recruitment approach that mixed, and went beyond, formal recruitment strategies. This was particularly important given the potentially sensitive nature of the research for some participants. The team adopted a number of sampling strategies that mixed purposive sampling (Davies and Hughes 2014) with snowball sampling techniques (Browne 2005) and personal and professional channels of contact.

The recruitment for all three groups of people - individuals with sight loss and substance use, professionals, and carers - can be summarised in three distinct phases:

1. initial and general circulation of project flyer (see appendix 8),
2. more targeted dissemination and follow up on initial dissemination routes,
3. purposeful and opportunistic recruitment of very specific individuals.

The first stage of the recruitment involved the dissemination of project information to a large group of individuals and organisations within sight loss, substance use and other health and social care fields (see appendix 8 for the project information). Given this approach it is not possible for the research team to confirm how many individuals received the information or read it. However, between June-August 2013, the information was disseminated to 52 organisations or sources. This included 21 sight loss organisations, 20 substance use organisations and 11 others. People were invited to contact the research team via

telephone, LinkedIn, Facebook or Twitter. An informal telephone conversation followed explaining the nature of the research, clarifying criteria for involvement and, where appropriate, arranging an interview date.

Response to the initial recruitment phase was limited resulting in a second phase of recruitment from September-December 2013 including an additional 16 organisations, 14 from the sight loss sector. This phase also involved sustained follow up on a number of the initial contacts, including seeking confirmation of original dissemination; and for some methods, notably the social media routes, repeated dissemination was required. This proved important, as in some instances, individuals who had agreed to disseminate the work had either left organisations or simply forgotten their commitment and needed a reminder. In addition to this follow up, the second phase included some first time dissemination requests to other specific organisations, often those suggested by PAG members in a direct response to a) the initial slower uptake and b) obvious omissions from the original dissemination list. Significantly during this phase a number of individuals and organisations became pivotal in their enthusiasm for dissemination and ensuring that recruitment built up a good degree of momentum. A sufficient number of individuals had volunteered to participate by mid-October, such that the first interviews could commence in November.

Phase 3 from January to March 2014 looked to recruit people in particular roles or attributes who had not previously come forward (or had not received the information) but whose perspectives were important to capture. This recruitment was therefore much more purposive and opportunistic and did not involve blanket invitations to respond.

The methods of dissemination for the recruitment phases were diverse. These included direct mail and email shots, information printed off and displayed in buildings, and inclusions in specialist magazines and newsletters. It additionally included the use of social media; Facebook, Linked In and Twitter. Information was disseminated in a range of formats: print, large print and braille.

Data Collection Tools

All data for this strand was collected using semi-structured interviews. This approach to interviewing allows for a greater degree of flexibility in the administration of the interview schedule while at the same time allowing exploration of people's views and experiences in some depth. People are less constrained by a particular order of question and the interview can adopt a more conversational tone. It also enables the researcher to ask supplementary questions to clarify responses as well as respond to questions posed by the participant.

Interview schedules were designed for each of the three groups: individuals, carers, professionals(see appendix 9). All but one of the respondents gave consent for the interviews to be digitally audio recorded- extensive hand written notes were taken instead.

Interviews lasted between 38 and 167 minutes. The average length of interviews with individuals living with sight loss and substance use was 78 minutes and with professionals it was 52 minutes.

Individuals living with sight loss and substance use were asked if they preferred to be interviewed in person or on the telephone. Many expressed a strong preference to have face-to-face interviews. Professional interviews were predominantly conducted by telephone. Face-to-face interviews took place in individual homes, community centres and places of work.

Data Analysis Methods

The audio digital files were transcribed in full and uploaded into computer-based qualitative data analysis software, NVivo 10. This software allows for detailed coding and analysis in line with approaches to thematic analysis (Bryman and Cramer 1990, Gibbs 2002) by reading and assigning each word or group of words a particular concept or theme. Once this initial coding (level 1) is complete, the resulting themes are grouped into categories (level 2) and synthesised within thematic domains (level 3).

The process originates from grounded theory analysis (Strauss and Corbin 1997) in that it ensures the findings are grounded in the data and are constantly compared across all sources as the coding progresses in order to develop themes that accurately reflect the source material.

The initial coding was divided between the researchers by the two main groups of respondents: individuals living with sight loss and substance use and professionals working with them. The first two interviews of each of these cohorts, was then double coded to ensure that the coding and theme identification were broadly identified and agreed by more than one researcher.

When all the data had been coded at least once and, in some instances, two or three times, the research team met to reflect on the common, dominant and important themes emerging from the data. This session then informed the beginning of the substantive write up process.

Interview sample responses

Fifty-five individuals responded positively to the recruitment requests. The respondent group comprised:

- 26 individuals with sight loss and substance use
- 3 carers
- 26 professionals

Not all of these initial expressions of willingness to be involved were translated into interviews. The reasons for those not subsequently interviewed were as follows:

- Individuals - nine people in total did not take part: five were excluded as their experience was not relevant to both sight loss and problematic substance use; four could not be contacted despite numerous follow up calls.
- Carers - one declined further involvement and another was not appropriate as they only offered a friend's story via Facebook.
- Professionals - eight people in total did not take part: two initial scoping interviews were conducted to inform the development of data collection and were ruled out of the full data collection phase; one declined, three could not be contacted again, one was only an enquiry about the project and the other was only offering to put us in contact with other professionals.

In total 36 individuals were interviewed, comprising 17 individuals with sight loss and substance use, 18 professionals and one carer who, following interview completion, is more accurately described as a volunteer from this point on.

Of the people experiencing sight loss and substance use, the majority came through contact with two sight loss organisations they had contact with. It is therefore possible that the research included people who had accessed some support and may have been more adjusted to, or accepting of, their sight loss experiences.

It is worth noting that whilst the participants have been grouped in these categories, there was some degree of overlap for a small number of the participants. Several people with sight loss and substance use were actively involved in volunteering within sight loss or substance use services and the volunteer and several of the professionals had a significant degree of visual impairment.

Chapter 6: Findings - individuals with sight loss and substance use

"For me they’re two spinning balls, one egging on the other."

"Every time I take a drink, the one thing I worry about the most is the fact that I'm going to affect my eyesight even more from it."

This chapter presents the findings of the interviews with people who have, or had, experiences with substance use in addition to living with sight loss.

The questions began by asking how people had heard about the research and their motivation for involvement in it. Five participants found out through contact from Action for Blind People, and five through RNIB - some recalling Vision magazine as their source. Three people were approached by a sight loss worker while two others were contacted via email but could not remember who had sent it. One person saw the research Facebook page, one the Linked-In post and the final one was approached by a colleague of one of the research team members. It is notable than none of our participants were recruited from substance use services.

The majority of people took part in the hope that it would help others by sharing their own experience, or to give something back to the agencies they saw as supporting them. One person was motivated as part of their own recovery process, one was interested in research generally and finally one person felt the research was relevant to their own situation.

Key characteristics

The following lists the key characteristics of the 17 people we interviewed who live with, or have lived with, sight loss and substance use.

- Thirteen were male, four were female
- The average age was 53 years old; seven participants were under 50.

- The dominant ethnicity of the group, as self-defined, was white English and/or British. Within this context four individuals provided more specific descriptors based on their regional or national identity. Only one participant identified themselves as having another ethnic origin and he was Asian.
- Seven respondents identified as having a religious faith including five Christian, two of these specified Church of England and one Methodist, one person was a Quaker and one a Pagan.
- None of the respondents were in full-time paid employment, four were in part-time paid employment, four in unpaid employment or voluntary roles, two were students, two were retired and one was a ‘full-time mum’.
- Five respondents identified themselves as current smokers, six were previous smokers and six had never smoked.

Our 18th participant, the volunteer who took part, was male, white English, in his late 50s, no current religious affiliation, has sight loss and had no known history of substance use.

Substance use and sight loss status

Among our 18 participants there was a broad range of experience in relation to sight loss and substance use (see appendix 10). Four people had lost their sight for between 1-5 years, three between 5-10 years, three between 10-20 years and one 20-30 years ago. The remaining seven had sight loss since birth or for more than 30 years. The sight loss history of our volunteer participant was not established.

In terms of the timing of their sight loss in relation to their substance use three people had lost their sight prior to their substance use, seven after their substance use and seven had sight problems pre and post use.

Substances of choice also varied. Seven people, currently or previously, primarily consumed alcohol, one illegal drugs, three prescribed medication and six were poly drug users.

Appendix 11 provides a summary of the participants' self reported sight loss diagnosis and their current or previous substance use. The table

has six columns listing as follows: pseudonym, age, smoker, sight loss, alcohol or drug use, relationship between the two. Reported sight loss status included macular or retinal degeneration, toxic or malnutrition amblyopia, optic atrophy and anoxic brain damage including sight loss. The relationship between people's substance use and sight loss varied and will be explored further below.

Key themes

Among the core aims of this research was a desire to explore the meaning and function of substance use in the lives of people with sight loss. This section provides a summary of the responses we received. It begins with a brief summary of the impact of sight loss on aspects of people's lives before focussing on the themes relating to substance use and sight loss in particular.

Impact of sight loss

The route to sight loss was hugely varied in this small sample. So too was the response people had when they found out they were losing their sight. All perceived it as having a negative impact on their lives initially at least. People described the shock, stress, and subsequent depression of finding out:

Charlie stated: “I was a bit shocked, you know a bit taken back thinking... I think my first question was, "can it be cured?" I think once I found that out, that it wasn't going to happen, I was a bit, sinking into quite a big depression”.

Karen talked of the denial in addition to the shock: “I went into shock and that stayed for quite a long time and a massive amount of denial. …I felt very vulnerable I think, [that] would be the overall feeling of that time and a sense of not knowing what was going to happen, what would go on”.

Connor had recently lost his sight and he and his wife were finding it hard to adjust: “We’ve got to try and continue the best way we can and try and get on with life but basically it’s terrible. It’s the only sense that you really, if you was deaf or you couldn't speak but if you can see, you can participate, you can see what’s going on in the world.”

Martin described feeling useless: “When I lost my sight, I’m sorry for repeating myself, I felt useless, I felt that my life had ended, I couldn’t read, I couldn't drive, I couldn't work”.

Even for Wilma who gradually lost her sight she still felt shocked by it: “…until you come to the very last point, the very last bit where you stop seeing anything and you see nothing, that I think is as much of a shock as it probably is to somebody losing all their sight at once”.

People also disclosed a range of emotions from anger and frustration to fear. Karen illustrated her frustration and anger with an example: “It has been extremely frustrating and I think it’s probably why I’ve got such a bad temper. I can remember getting –and this was so pathetic – I couldn't get the top off a new bottle of mouthwash because it had clear, shrink wrapping over the lid and I couldn't get it off because I couldn't see the end of it to do it and I thought “somebody with normal eyesight could do this because they could see the minuscule red tag that says open here” and I remember hurling it across the landing, going “I won’t bloody use it”. It’s frustrating, when you know that normal people who do things and you would be able to do that thing too, it’s just that little bloody bit of cellophane that won’t come off and it’s really frustrating.”

Penny and others spoke of the difficulties the dark presented and the fear this engendered: “Since they told me about my loss of peripheral vision, I’ve actually become really quite scared, it’s in the dark, I can’t see ... you only have to decrease the light a bit and I tend to start panicking.”

The sense of loss more generally was a very common and heartfelt response. In particular, people described the loss of independence resulting from losing their job, being unable to drive, unable to take part in regular family activities, socialising and hobbies:

Charlie spoke of the difference it made to his time with the children: “playing around with my children at the park, kicking a football around and all that, all become difficult. And being able to keep an eye on them all the time…”

Barnaby spoke of missing the social aspect of his previous job and subsequent difficulties socialising: “I missed it tremendously and with the

problem, everybody got to know I had a problem, it's not recognising people, that was one of the big problems, walking down the street, someone would walk past you and you don't recognise them".

Martin keenly felt the loss of employment: "I could no longer view anything that I'd done in the past, I felt useless. I couldn't put up scaffolding, drive trucks, work metal, sell t-shirts, work with the homeless, I could do none of these things".

For Tommy, and nine other people, the loss of driving or riding ability was a profound loss: "My first real pain was not being able to drive a car anymore, it's a total lack of independence. You become totally dependent on other people to take you here, take you there. That I found very difficult.

However, a number of people spoke about the fact that in spite of their initial reactions they had to cope or had learned to cope:

Jenny said: "It's like an obstacle, you just don't realise...I've never realised how blind people, how they coped but you do,…it's a hell of a loss to have".

Chas described a gradual process of coping: "I do a lot of things that you find difficult but you learn to adapt, there are ways round most things".

Graham stated: "You have to cope with it the best you can. … But no-one knows why they're here, just get on with it and do the best you can and if you help someone along the way, that's a good thing".

Brandon describes throwing himself into life in academia: "you pull up your socks and you march on, I went to university like everyone else did, …and I just persevered and my mum was great, she said "if you don't read, your brain will begin to say 'I can't be bothered'", … So yes, I just continued forcing my brain to continue".

Substance use as a cause of, or key contributor to, sight loss

Among the initial aims and objectives of this research was establishing whether people who experience sight loss and have used substances problematically felt there was any connection between the two. If so, we sought to establish the nature of that connection from their perspective.

A number of relationships became apparent including several people whose use, or over use, of alcohol, illicit drugs or prescription medication had led to, or significantly exacerbated, their sight loss:

James stated:"it was caused by [alcohol], they say, toxic amblyopia. I was told that ... I shouldn't drink or smoke because I'm an alcoholic so they said 'cut down as much as you can'. I thought because I was hitting the booze very heavily, so I thought if anything, it might get my liver…".

For Jenny the alcohol appeared to be a response to depression which in turn removed her lack of judgement in relation to prescription medication. She recalls "I was taking tablets when I was suicidal, I'd have drink first and then I wouldn't know what I was doing and then take the tablets,...I've damaged my nerves at the back of my eyes with these [prescribed] tablets". Ultimately it was the prescribed medication that damaged her sight but the alcohol appears to have facilitated the process.

The volunteer who took part recalled one of the people he befriended losing his sight after an attempt to take his own life by a medication overdose. Gregory recalled "He told me himself he'd had enough and he was on medication anyway for different things and he just thought, "I'm going to take the lot" and they found him, got him into the medical ... and he'd been in a semi coma for about two months... they brought him round after a while, ... he said to one of the nurses, ... "I can't see anything", they said "don't panic, sometimes this happens when there's been a drugs overdose and you've been in a coma, your sight will come back after, it's a shock to your system." Gregory stated that he regained a small amount of sight but remained visually impaired.

Some participants continued their substance use knowing the risks to their sight and often feeling scared about it. Charlie stated: "I know I shouldn't be drinking, that is a full blown conclusion that I shouldn't be drinking. Every time I take a drink, the one thing I worry about the most is the fact that I'm going to affect my eyesight even more from it. If I happen to be going on a very dangerous binge myself again, I could very well end up losing more vision. That sort of stuff should scare the shit out of me, pardon my French, it should really scare the crap out of

me. I shouldn’t be sitting there going, 'oh yeah, it will just be fine to have one drink,' because it's never fine to have one drink."

Chas was among the participants who were currently abstinent from substances despite heavy prior use. He stated: "I think it was the steroids kicked off cell deterioration which is the retinal degeneration, so basically over the years, the cells were dying off but obviously that was exacerbated by my drinking, drug and smoking habits. Since I’ve become a good boy, the cell deterioration has slowed down but it’s lots of things, could be diet as well, lifestyle, everything...well anything basically that you're putting into your body, any substance, if your body’s not well and your blood’s not well, it’s going to affect your eye-sight."

Two participants were slightly different from the rest of the participant group in that while their substance use was not excessive, they felt strongly that their normative use of prescribed medication was responsible for their sight loss. Given the seeming lack of evidence on this topic, their stories have been included here.

In Connor's case he was prescribed medication for a heart condition. He says: "It was a prescribed drug, I’ve got a heart arrhythmia ... they decided that what [I] needed to do was go on [amioderone]". Connor handed the researcher several pieces of literature and asked her to read the side effects which stated “If blurred or decreased vision occurs, complete ophthalmology examination including condoscopy should be promptly performed, appearance of optic neuropathy and/or optic neurotis requires amioderone withdrawal due to potential progression to blindness...”. Connor added "But they never once told me".

Norm felt that his epilepsy had led to his sight loss and that his epilepsy medication made it worse. He also felt his sight loss had led to his epileptic seizures. He said: " When I'm focusing with my vision, with my eye, I'm trying to see something, I'm focusing... focusing makes me stressed, and stress can turn into epilepsy. And then the same thing if I've got a seizure, it straight away affects my vision. So I realised that when I came home from hospital, when I was discharged, I realised I'd lost some vision after that". In addition to these two specific examples, Penny also found a temporal association between her hearing loss and

change of epilepsy medication but was told that might be one of the "unusual" side effects.

For Martin there was a clear relationship between his sight loss and substance use although he did not know the direction of it - whether it was causal, coping or both. He stated: "When I lost my sight, I'm sorry for repeating myself, I felt useless, I felt that my life had ended, I couldn't read, I couldn't drive, I couldn't work but by God I could drink.... I had an alcohol problem long before my sight loss. Did the sight loss aggravate the alcoholism or did the alcoholism aggravate the sight loss? For me they're two spinning balls, one egging on the other. "

Finally there were a few people who did not feel there was a direct association or simply did not know. Penny, who stopped problematic substance use 25 years ago recalled how different specialists had said her hearing loss and (more recent) sight loss were both neurological but had not related them directly to her substance use history. She stated: "we don't know if it's connected, I've no idea if this is connected with the alcohol. I can tell you about I drank exhaustively for 20 years ... . Sometimes I think I was extremely lucky to get away with it because I did used to drink a colossal amount, we're not talking about the odd bottle of cider, I used to get through over a bottle of spirits a day and I'm not very big. So it would be remarkable if no damage got done, it really would. I reckon I've destroyed a few bits up there. "

Using substances to cope

The second key relationship between sight loss and substance use further develops the issue raised by Martin above; the use of substances to cope with the sight loss and associated losses and emotional and psychological impact.

Barnaby stated: "It's all right if you're drinking beer but when I was going through, can I say my dark patch, it was spirits and it wasn't good. [I was] trying to work it all out in here, within that time. "Why me?". "What am I going to do with myself?", "Am I going to go blind?". This is where I think the consultants could help a lot more, say "with macular, you never go blind". One of the things I said just now, one was driving, that's the biggest thing you come across, anyone with a real sight problem, you miss driving".

Karen stated: "Yeah, I think the trauma of having the accident and all the horrible operations and stuff, drove me to drink and get high, to escape the reality of what was going on. ... I was thinking, “I know what my claim’s worth” and I got £200,000, £20,000 of which I just blew getting high and getting drunk, so that didn't do the confidence much good".

Sid's deteriorating sight led him to use valium to cope initially although currently his concerns are more about his alcohol use: "So I think actually I do sit down and worry about my sight, then I have a beer, and I don't [worry]. There's still a bit of that there, but whether it's just the alcohol that I'm more hooked on than the fact that it helps me with, I could say my sight loss, the worry because of my sight loss. I don't think I'll go completely blind, but it is it impacting, and if I wasn't married I would be in serious trouble. I wouldn't be able to manage very well on my own I don't think".

One person's use of substances occurred after almost a lifetime of sight loss and he described it as a way of recouping the experiences he did not have in his youth because of his sight loss. Brandon's reflections on his substance use infers a coping strategy but also simply a choice to use. He stated: "So I studied and studied and went to all these good universities and stuff and then about two years ago, I just said “fuck it” and I just kind of, I had never lived a teenage life, I’d never gone to parties and I’d never gone clubbing , ... I’d never been crazy so I thought 'you're 45 now and you've never been crazy, it’s time for you to...' and I’ve been married, I got married to a man, we had a nice white wedding and stuff, so I thought 'now the relationship is over, now it’s time for you to look after you and be crazy'. And just you know, you're disabled as well and fuck that as well, I just thought, you know, live a little."

The use of substances as a coping mechanism for the experience of sight loss itself also overlapped with the need to cope with issues it created. For example, on finding out about their sight loss many people spoke of shock and depression, feeling alone and without help, aware that their lives were never going to be the same and wondering if they could continue living in such circumstances. There were many discussions about the losses created by sight loss, in terms of relationships, independence - driving in particular, routine, employment, leisure interests, self-confidence and generally feeling frustrated and

angry. It is in this context that the use of substances to cope needs to be understood.

Challenges of negotiating substance use with sight loss

It was also apparent that for some people their choice, and their right, was to continue to use substances, be they licit or illicit, and that this continued use required planning and negotiation as a result of their sight loss.

Some continued to go to the pub for socialising although were reliant on support from others. For example, Barnaby talked of his partner driving him to the pub for a meal occasionally and meeting friends a couple of times a week: "I still go to the pub once or twice a week, just socialise. We call it early doors, there's about four or five of us meet, about quarter past 5 and we're gone by quarter past 6. ... It's nice to talk to somebody like that, then someone comes in, "did you hear about the rugby?" and it's just the social."

Connor also relied on support from his wife to allow him to continue with his DJ work: "I was in the entertainment, as a DJ, so I'm a DJ, I compere. I used to do disco's and everything, now it's all on computer so the wife can do it and I just front it as a DJ basically. We do it on a Thursday, Saturday and Sunday but at the same pub now because I can't see to carry the equipment and set it all out. I just cover for a friend of mine now and again and I'll go and see how he's set up, so you guide me in and put a tripod down and she'll guide me in on it and everything, so we do kind of get by." Using the same local pub because of the familiarity of where things were located and the familiarity of patrons was raised by several participants.

Stefan and Stuart (one of our interviewees from the professional's group who had sight loss) reported going to places either that they were familiar with or with other people. Stuart reported it was a far more pleasurable experience than having to work out "Number one where the hell are the loos going to be in this place? Number two, where's the bar? If I don't know for example, if you took me to [another town], and

you said, "there's the pub," and I walk in, I'd have a problem. I'd have to work out where the bar was, where the loos might be, is there anything between me and the bar. Unless somebody acknowledges me when I walk in, then I'm going to have to go straight to the bar, because I know where the bar is, I'm going to order a pint, and stand there and you can scan and see what's going on and people can see you. Going to a different place is a complete... nightmare is a slight exaggeration for it, because you could always work it out. But all of this stuff goes through my head."

Graham's pub support came in the form of his guide dog. Graham was given a guide dog that was used to a pub environment: "Yeah, they let him, all the pubs, everyone wants to pet him and everything but with the job he does, he does great for me and it's like when they asked me what dog would I like, I said "I don't mind the breed" because if you say a specific breed, it takes longer and I said "I don't mind what breed it is, as long as it likes cats, kids and is used to a pub environment", the puppy handlers were in a darts team so they was always in the pub, he was in the pub as a puppy, so I know he's good in a pub. It's like people say to me, "I never seen a guide dog in a pub", I went "well that's going to change"...why shouldn't we be allowed in pubs?".

However, the pub also offered challenges and potential areas of conflict. Bumping into people or perceived miscommunication relating to eye contact were mentioned on several occasions. Barnaby states "The best one I can use is if somebody's drinking and their partner's there, you're looking across, "what are you looking at my wife for?", I turn round and say "is that your wife, I can't see her?". He also described needing to be more careful in the pub environment because of the potential for trouble and found the presence of a visual aid such as a white cane helpful: "I think you've got to be more careful because this is where, going back to if you've got your cane, you bump into somebody and they see your cane, 99.9% of them are very understanding that it was a pure accident. But if you bump into somebody who's got a drink onboard and you haven't got the cane, that's when things can flare up."

The challenges of finding your way home from the pub when intoxicated prompted some people to drink at home. Chas recalls "I was more likely to drink at home than in social situations because you always had the

self preservation thing, you thought “I’ve got to get home” and if you can’t see very well to get home and you're drunk in charge of your body, I think some people I know, I think they’re more likely to do it within their own home and possibly be secretive about it. Yes, and that’s to do with eyesight more than any other reason."

Graham stated he only went to the pub in the daytime because of his guide dog and the higher volume of noise in the evening that might upset his dog: "...all these voices and everything else and you can’t even see them. It just freaks you out".

Karen had stopped going to the pub because of the negative responses from those around her as she tried to find people she was meeting. Instead she went to friends' houses. "I’d be out in a pub and they’d go “Karen’s horrible, giving everyone filthy looks”, I’m not, I’m trying to find my mate in the pub because I can’t see! That also affected me going out because one of my cousins, there’s only 9 days between us and he’s a Marine and he only comes back every now and again, he was going, “Karen, I’ll be in the White Bull at 9 o'clock”, “make sure you’re standing at the bar because I won’t see you otherwise and I will just stand at the bar until you come to me”, because I find it really confusing, looking at lots of different faces and trying to hone in on it, looking at you, “no that’s not my cousin”, honing on the next one, “no that’s not my cousin” and by the time I’ve done that, you feel paranoid, you feel very self conscious because you know that everyone else can see perfectly well and you can’t."

Medication labelling was another area where people needed support. Wilma required Braille labelling on her medication and a local Society for the Blind printed out instructions for her. She states that: "A lot of medication these days does come with Braille but it’s very faint and difficult to read, so they now label it for me."

Two participants recalled alcohol or drugs being delivered by taxi. Chas recalled the local taxi company delivering fellow students' takeaways, drugs and drink. Jenny called the taxis herself: "One time when I did have sight loss, when I first lost my sight, I’d never get out of bed, I’d get a taxi with drinks delivered here, got bottles of drink every day and I’d just sit here and I’d drink and drink and then I’d collapse." Jenny also

recalled giving her cash card and number to the taxi men when she was drinking heavily to help her withdraw cash.

Impact on others

In addition to the impact of sight loss on some participants' use of substances it was quickly apparent that both sight loss and or problematic substance use had a significant negative impact on some participants' relationships with family and friends. Martin stated: "There are four sets of people, my friends in [a city], they've known my alcoholism, they've known me, they know my sight loss. Prior to dealing with my alcoholism, prior to going into AA, they rightly wanted absolutely nothing to do with me."

Sid spoke about the fact his substance use was exacerbated by his previous living conditions which, in turn, had a negative impact on his relationships: "It was having a very big problem, that's why they got me this place. It was 'cause they could see how things were going and they could see it was only a matter of time before something just went and there might be real trouble. ...the way the frustration was affecting my temper, yeah and the way that both the frustration and the booze would sometimes really spark things off."

Charlie discussed the split from his partner and the separation from and of the children too: "The drinking was getting too heavy... I took [my son] from my first relationship and my daughter stayed with [my partner], and yes, we live on good terms you know. We're not in a bad way, it's just we couldn't live with each other at the time...Plus I think my drinking was a little bit too heavy, and it wasn't good for the... And I needed to sort all that out, so, not much has been done on sorting that bit out."

Gregory, the volunteer participant, stated there were times when he cried and felt drained by the difficulties people faced. After a text from someone he was supporting who was threatening suicide Gregory said "I laid there and I felt physically sick, for someone to put that onto your shoulders, that they're going to commit suicide, I laid there in bed and I was actually crying, I thought "what can I do?" and ended up ringing the police because I didn't have the number of the place where he was staying".

All participants spoke of the impact on them and those around them of either the sight loss or the substance use, ranging from hiding the extent of their sight loss or substance use from family and friends to keeping people at a distance for a variety of reasons. Wilma spoke of 'pretending' to see things as a child so her mother would not get upset even though she had been sent to a blind school as a child. Norm talked of his sight loss affecting "everything, like daily life [in] general, with relationships, family and friends". Jenny described her husband as having a "nervous breakdown because he couldn't cope with, you know with me drinking and then this [sight loss] came on top." Two participants felt badly about putting their mothers through the stress that resulted from their substance use and sight loss while others reported marital difficulties and separation as life changed for both partners.

Knowledge of others with sight loss and substance use

Given the sensitive and potentially hidden nature of this topic the team asked participants if they knew of other people with both sight loss and substance problems. Many of the participants had.

Barnaby stated he'd "met one or two" and gave examples of someone who attended the computer club with alcohol and was asked to leave and another who "hit the bottle when his guide dog died". Chas stated "since I've got to know people within the blind world, I see it all the time, the people who don't cope tend to drink far too much". He also gave an example of someone he drinks with who was "hiding his eyesight problems". Karen spoke of another woman she knew with sight loss and substance use: " There is another girl in town whose eyesight is far worse than mine, she has got a white stick and she's a few years younger than me...and I know my friends used to supply her with drugs, she would take a lot of speed and drink a lot of cider and you don't see her out." Martin spoke of two of his closest AA friends as suffering sight loss in addition to historic alcohol problems and Seb recalled an acquaintance who "didn't do drugs but he did drink and he slaughtered himself with drink and I didn't know that and I didn't know a high percentage of people who lost their sight late in life took their life as well." The topic of suicide was raised more than once alongside discussion of people who used substances. Tommy knew three people

who he said had committed suicide as a result of sight loss as well as "other guys" with similar issues albeit some years before.

Stefan had met one person through work who had both sight loss and substance problems. He stated: " I did have a colleague who... I say colleague he was a full time paid up member of [a charity]. He had sight loss but he also had ability and he liked a drink. I think he was playing with fire and he died ...". Wilma's response raised interesting questions about cause and effect and the ability to put on a brave face: "I do know of a few people who have had drink problems but I don't think it was necessarily connected with being blind, although you don't know, we can all put on a bit of a show to other people but you don't really know what they feel and what they think."

One other person did not give details but was clear he knew of others within his social circle who had substance problems in addition to sight loss. The volunteer who participated also said he had supported two people to date with sight loss and substance use.

Substance use services attended

A number of participants had previously attended substance use services in the form of rehabilitation services, peer support or mutual aid groups or other community services. One person was busy developing a substance use service for women in the local area. Their experiences of services overall did not seem to be influenced negatively or positively by their sight loss.

Chas described positive experiences attending a specialist substance use charity: "The staff there, they were very good because I had my guide dog then but no, you normally find people work in those services [supportive], ... they didn't specifically offer me anything particularly for my eyesight but like one time ... when it got dark in the winter, they offered me to pay because they didn't want me not to go, they offered to pay for me to travel by taxi because it was dark so yes, they were supportive in that way." Jenny also described a particular worker in her local specialist agency who was helpful and supportive to her.

Seb's experience was not so positive: "After a year I went into one of these agencies and they didn't finish up until, they wouldn't do anything

until you were on your arse and basically rock bottom, when you had nothing left and you were practically on the street, that’s what they did." Four had tried AA or another associated fellowship organisation and hadn't found it to their liking while one respondent rated it highly and had become very involved in the fellowship.

A number of people said they had not attended any substance use service electing to try to make changes themselves sometimes helped by their relationships or a change in their circumstances, for example, a house move. Others identified support from other non-substance specialist agencies or individuals. For example, Brandon spoke about seeing a mental health nurse who, in turn, had recommended he attend a substance use service which he chose not to follow up. James' GP suggested he attend a local substance use service but "I didn't get on very well". Several people were quite ambivalent about doing anything. Tommy said: "it's something I have to look at myself I suppose. I don't know, if I don't have a few drinks then I don't sleep.", while Stefan seemed to have given it a little more consideration: "So no I haven’t done yet, but sitting here talking to you all serious, I haven’t actually done anything it, but I'm pretty adamant that I'm going to have to start winding down [the drinking], try and have two days off."

Service access and improvements

In terms of wider service access, some participants had very positive experiences of individual organisations and individuals working within sight loss and substance use services. Others had not and found either the organisation's approach or a particular worker's manner off putting or unsuited to their needs. Participants raised significant needs stemming primarily from their sight loss but also as a result of wider societal attitudes to their sight loss, for example, lack of accessible transport and so on. One participant described his experience of loneliness following his sight loss and how all he wanted was a hug. Another how he needed help with shopping and developing relationships, another how counselling would have been helpful to come to terms with the sight loss. What was apparent was the wide range of experiences and needs that people had - some of which appeared to relate to their stage of adjustment to their sight loss.

The research sought to establish participants' experiences and views on how services for supporting people with both substance problems and sight loss could be improved. One person spoke of feeling ashamed to access services at the time of the interview due to his substance use. Martin recalled how he went to Guide Dogs for the Blind and was turned down for a dog due to his "level of alcoholism" at that time. He agreed, with hindsight, that it was the right thing to do.

There were also a number or respondents who, because they had not accessed any services, did not know how services could improve, while a few made practical suggestions which included:

- substance use services having large print information
- national sight loss charities having information about the relationship between substance use and sight loss and being able to provide information on that from helplines
- greater awareness campaigns of the links between drink and drugs and sight loss
- front line sight loss service providers, e.g. medical staff, to tell service users about links between the two
- sight loss services to understand that the impact on sight may not be temporary
- more sight loss services for young people and service provision that catered to their interests.

Barnaby believed there were no services that addressed sight loss and substance use while Penny was setting up a holistic service for women to offer "something which is kind and friendly and supportive, which women can come back to and try again if they want to ... holding a big bank of up to date information about things, places they can go and things they can find out if they want to". She concludes "I suppose basically, we’re trying to supply the things that we would have liked ourselves".

Summary of findings - individuals with sight loss and substance use

This chapter has paid particular attention to the focus of this study, the overlapping issues of substance use and sight loss. It sought the perspectives of people who were living with sight loss and substance use or who had sight loss and had previously experienced problematic substance use. Because of this focus, what has not been presented is the experiences that people generously shared with us about their sight loss alone, their paths to diagnosis, the impact on themselves and their lives, and their struggles to adapt to a world that is geared towards sighted people. A little more of this will be discussed in chapter 8.

Given the challenges people endured, and were recounted in the interviews, it is difficult to imagine how people had coped with the challenges they faced. For some people alcohol or other drugs were a way of seeking comfort and temporary escape; for others they lived with knowing that their use of substances caused or contributed significantly to their sight loss; and some people fell into both groups. What was clear was that these were highly individual circumstances and experiences, requiring an individual, sensitive and skilled response from professional support and services.

Some people had continued their substance use following their sight loss diagnosis, while others had long since changed their substance use behaviour and taken on different challenges. For those who chose to continue to use substances there was far more planning and deliberation about how to do it, including who else was involved and where to go. Daytime pub visits replaced night time visits due to noise, levels of drunkenness, and the darkness when going home. The familiarity of venue and patrons was an important feature and made it a more pleasant experience although some people chose to socialise away from the pub with friends or at home.

For the majority of people who had, or have, problematic substance use as well as their sight loss, it offered a double dose of challenges for relationships with families and friends.

In spite of the findings from the existing dataset analysis and the existing literature, which conclude that people with sight loss are more likely to abstain from alcohol consumption, many of our small sample knew of

other people with both substance problems and sight loss. As the next chapter shows, so too did many of the professionals.

Perhaps unsurprisingly the resources and information people with sight loss and substance use wanted was information about the links between substance use and sight loss. People's need for information and communication about the risks and the potential prognosis was clear; so too was the need for specialist services - be they substance use or sight loss - to have accessible information about the 'other' issue available to staff and service users alike.

We asked everyone about whether they had experienced any positives as a result of their sight loss. Most struggled to find anything at all but we also heard tales of speedy responses from utility companies when informed that the caller was 'registered blind'. Some respondents said their sight loss had made them appreciate life more and concentrate on what was important.

In sum, the people we spoke to had very different journeys and experiences relating to sight loss and substance use. The commonality was that they all sought ways to adapt to a society that provides little by way of knowledgeable support about substance use and sight loss.

The next chapter presents findings from the interviews with people who provided support services to people with sight loss or problematic substance use.

Chapter 7: Findings - Professionals

This chapter sets out the key characteristics and key themes from the analysis of interviews with 18 participants who worked in substance use, sight loss or other relevant services.

Key characteristics - professionals

The professionals group comprised:

- Ten females and eight males
- The average age was 47 years old.
- The majority of the group described themselves as White British or British, with the exception of three individuals who described themselves as: Asian Other, Irish British and Welsh.
- Six of the group suggested they had no current religious affinity. Five said their religion was Church of England, two said Catholic and four said Christian. One participant was a Buddhist.

The professionals group was dominated by those working within the sight loss sector rather than in specialist alcohol and drug agencies.

- Thirteen participants worked in the sight loss sector, three in substance use and two in other related professions.
- In terms of time in their respective areas of specialism, five had worked less than 10 years, six between 10-20 years, and seven worked more than 20 years.
- Three participants worked in specialist sight loss veterans' services, two were optometrists, three were vision rehabilitation officers, one was a nurse practitioner in a substance use service, one a volunteer advocate in disability services, two were counsellors, (one in substance use, one in sight loss), one had their own sight loss consultancy, one was a social worker in a disability team, one an enablement officer in sight loss services, one a manager of a visual impairment support team, one an ophthalmic surgeon and finally one was an alcohol practitioner.

A number of professionals also had their own experiences of sight loss and substance use - some of which was problematic - which they drew on in the course of their interviews.

The professionals worked in a range of roles from an ophthalmic surgeon to a volunteer advocate and from a substance use counsellor to social workers. Their details including their pseudonym, age range, gender, ethnicity, religious affiliation, whether they work within sight loss or substance use specialist services, current job role and time in sector, can be found in appendix 12.

Two thirds (n=12) of the professional participants heard about the research via an email to their employing organisation which was passed on by a manager or mentioned to them by a colleague. Four were contacted directly by the research team following up leads given by other people, one person was recruited via LinkedIn, and one person attended a conference presentation about the research.

Professionals were primarily motivated to participate because they had experience of working with someone with sight loss and substance use and hoped they could contribute. Ten of the 18 participants took part for this reason. One took part because he was aware there was no research in this area and it was needed, another hoped it would improve service provision and a third said it was already an issue for the service in which he worked. Three people stated they were interested in the research area. The reasons for the final two participating remain unclear or unstated.

Key themes - professionals

The final core aim of this research was to explore how professionals in a) substance use and b) sight loss services are currently working with these overlapping issues. As mentioned above, only three professionals in our sample were currently working in substance use services. This section provides a summary of the responses we received.

Trends of overlapping issues on professionals' caseloads

Without exception, the professionals consulted reported very small numbers of people with sight loss and substance use on their caseloads. Perhaps as a consequence of this only two of our participants had or

knew of specific organisational policies; both worked or had worked in National Health Service (NHS) settings specialising in sight loss. No one had identified an increase in incidence of people with sight loss and substance use problems and the overwhelming sense was that they are dealing with only small numbers of people, typically "one or two". Some professionals volunteered percentages although without knowing caseload size their worth is somewhat limited; the most common percentage offered was 1% or 'less than 1%' with the highest being 5%.

Scott stated: "I think it’s less than 1%, over four years, I wouldn't be able to think how many people I’d worked with but it really is on the periphery. But again I’m getting aware that older people are drinking and this is why the alcohol question on care management assessments are relevant." Thus, in his role in a sensory service, he was increasingly aware of the ageing population and the evidence which shows an increase in alcohol and other drug use among this older group. Given that older people are the main group of people using sight loss services, this ageing demographic will result in higher levels of people presenting to sensory services with both sight loss and substance use issues.

A number of professionals pointed out that they do not routinely ask questions about substance use and therefore would not know the true prevalence within their services. As Alex said "We’re not actively looking for it either so Ida goes home and has two bottles of sherry in an evening, I don't know".

Similarly Alison felt she couldn't say either way: "If this was a discussion about HIV I would be saying to you yes there's definitely been a change. In relation to visually impaired people and addiction, I don't know if I can say either way. I don't know that I've noticed anything."

For Rachel, however, it was "not an uncommon issue for discussion". She also found it difficult to see trends but stated it was more likely to become apparent when she had started to "unpick their lifestyle" after she had worked with them for some time.

Seamus emphasised the importance of overstating the numbers of people with sight loss and substance use problems. He stated: "...whilst this is an issue and nobody is trivialising this, in the grand scheme of things, it's not the major issue. ... The number who've got alcohol who

have damaged their eyes is very small. ... So there are other issues such as eye injuries which are a big matter quite frankly, but that's not the focus of your work. But eye injuries are an important ocular public health matter ... I've seen a lady who took off her stiletto heel and she hit another woman into the eye with her stiletto heel, because of some altercation in the nightclub, things like that. So injuries associated with alcohol are significant, so don't leave that out right".

Sight loss and other substances

While alcohol is the dominant substance at the centre of this research, other substances associated with sight loss were mentioned by our participants. Alex had experience of working with patients with chloraquine toxicity. Chloraquine is an anti-malarial drug with side effects that can "damage the central zone of the back of the eye". To his knowledge they were taking the medication as prescribed.

Cannabis or 'weed' was mentioned but as drug of choice of some people rather than hinting at an association with sight loss. However, as cannabis is often smoked with tobacco it also has potential to damage vision. One participant had particular expertise around the use of poppers and sight loss and had researched the topic extensively and published on the topic. He highlighted the change in the composition of poppers from isobutyl to isopropyl nitrates as a notable landmark in the emergence of sight loss as well as finding evidence of a relationship with the quantity used.

Veronica and Gregory raised questions about the potential connection between the prescribed medication and sight loss. Veronica questioned whether the blood thinner Warfarin might impact on sight loss based on her own service users' experiences. She felt there were too many to be a coincidence. Some evidence suggests that Warfarin may cause severe intraocular haemorrhage and loss of vision in a minority of patients who have the neovascular form of age-related macular degeneration (Kowal and Harper 2002). Gregory also noticed that among the people he supported "the average age for people with sight loss is between 60 and 80 years old". He said "If they're on a medication or medications, has that helped towards their sight loss? ".

Seamus also reported the consumption of alcohol through eye absorption using vodka in egg cup sized glass and putting it on your eye, thus causing temporary damage to the eye's surface.

Substance use as a coping mechanism

More than half the professionals had experience of, or a view on, alcohol use in particular as a coping mechanism for people with sight loss. Three made particular reference to younger people losing their sight. Alison stated "I imagine that for younger people losing their sight and we know with that comes a lot of isolation and social issues, and relationship breakups. I can imagine that for some people alcohol or drugs may actually be the crutch they turn to. If they possibly had a predisposition towards that before they lost their sight, or not." Similarly Heather made reference to people in their 30s and 40s: "I'm talking about under 60, like the guy yesterday, about 40 but the other young man, well I think he's 30-ish that I saw at the cenotaph and some of them have horrific injuries, they're looking for oblivion, just to get out of it and not think about it, to get away from that situation."

Jonathan's experience led him to believe that all four of the service users he most recently worked with who had sight loss and problematic substance use had only developed those problems post sight loss: "I would say that in the small numbers that I have seen, all of them had lost their sight and then started, they were drinking alcohol prior to this but not in a problematic fashion, so they weren't dependent drinkers until this whole thing happened and then it almost became difficult for them to lead their lives, go to work, function in any sort of way ... so job loss was a major factor, family problems is another factor and another thing was almost like the grieving as well and I think the alcohol dependent drinking plays a part in blocking all of that out...".

Tracey highlighted how people drank to cope but often with a range of overlapping or interlinked support needs: "... obviously some people may end up with issues around mental health or drugs, alcohol because of their visual impairment, because you know coping strategies and so on. So for other people they may have those needs anyway regardless of the visual impairment, because a lot of the people do. I think people sort

of think they can only have one support need, and actually that's more complex than that."

The professionals from veterans' agencies in particular highlighted how "alcohol is a huge part of their life" and thus becomes "a prop" to cope with living with impairments including sight loss. Josie said "I know with the cases that I have worked on, they have said “I drink because it helps me to forget” ". She was unsure whether the drinking was just about coping with the sight loss or whether it was part of the bigger picture of losses that accompany it, for example, the inability to provide for themselves or their families. Heather also spoke of a loss of masculine identity associated with drinking and going to the pub.

In general the professionals were aware of the links between substance use and sight loss - alcohol primarily. Several professionals were unsure or cautious about the relationship being a direct causal link, however, given that people often had additional health problems such as diabetes, poor nutrition, and smoking, all of which could be key contributors. Others were more accepting that alcohol could play a causal role and that substances can be used to cope with the difficulties people have in terms of adjusting to sight loss. Sarah stated: "...that’s a really tough one for people to come to terms with, ... they may have caused it by drinking so [there's] that particularly sensitive issue to deal with and then of course, a lot of people use alcohol as a coping mechanism. That’s how I see it." Alex worked with someone who told him that given the other losses in his life, losing his sight was 'the least of his worries'.

Challenges of intervention, support and rehabilitation

Working with intoxicated people in sight loss services

There was a great deal of discussion about the challenges of providing support, rehabilitation or other services to people who were intoxicated or living with problematic substance use. The first of these related to undertaking rehabilitation work with people who drank problematically.

Alison raised a key dilemma for those working in rehabilitation roles which resulted in both practical and ethical issues: "what do we do faced with the alcoholic visually impaired person, who needs mobility training to get to the pub? He wants to be able to go to Iceland and get his ready

meals, and he wants to be able to do that safely, and he probably wants to go and get his booze as well, well I know he does, but we want him to do it safely. There's quite a difficult crossing where he lives, and if he's willing to commit and he wants to learn how to do that, then I'm really very willing to train him..... But then faced with that as a rehab officer there has to be some guidelines, and obviously the guidelines are... "I'm happy to do some cane training with you, but I won't do it with you if you're drunk, I'm not happy to do that." Clearly ethical issues relate to people's right to choose to consume alcohol but not at the risk of others which was Alison's concern: "My reasoning for that would be probably risk to others...he could do some damage with [the white cane] if you're not using it properly, that's why we train people. Especially in a busy suburb like [this], there's people everywhere. So risk to others, risk to himself, and also if I'm training someone, I want them to actually concentrate! "

Sarah concurred about safety concerns: "I have to think about, as you do with any client, about looking after myself and looking after the people on the frontline, this is when I use my supervisor to maximum effect, do I see people who are intoxicated or under the influence of substance misuse? So things like that, that I have to brush up on and be clear about, that's always a tricky one because often if they're taking so many units in, that probably there isn't maybe a time in the week where they are clean, if that's the word you'd use and do you turn them away because of it?".

Veronica appeared to have fewer concerns: "That's fine for me, that's absolutely fine for me, because otherwise how would you ever get them ever to come along the road with any degree of safety. Teaching somebody to use a long cane, even whilst having a dependency can save their life. It can certainly stop them from injuring themselves as much as well, it can actually get them to the local pub. People argue that, "hang on you can't be teaching them a route to the local pub," again going back to my example of someone that's overweight and wants to learn the route to the fast food restaurant, you can't make moral judgements there.... In actual fact you can probably say that that person now is actually not so isolated and is getting out. ...You're probably more

likely to find someone to talk to in a pub then what you would in a corner shop or something. "

Vinnie had adhered to the policy of not working with people who are intoxicated but, in a recent example, took the decision to 'keep an eye on' a particular service user anyway: "... the council's rehabilitation team wouldn't work with him because he would turn up drunk, would miss appointments and all sorts of things ...[The team] has said, "we can't do anything with this guy", I said "somebody needs to keep an eye on him", so he didn't receive a service from us, other than the fact that I was keeping an eye on him and going to see him once a week, making sure that everybody who was involved with him was doing their part...". However, further discussion found that he had also exhibited some worrying behaviour towards staff, one of whom he locked in his house and would not let out. Vinnie explained further: "Well, we couldn't do rehab with him because his ability to retain information, you could teach him something one day, go back the next, and he couldn't remember it, he could remember something but he couldn't remember what we'd done yesterday, that's even if he was sober."

Concerns about retaining the rehabilitation information were shared by others. Josie stated that there was no point "investing a lot of time in training if he's not going to retain any of the information". However, as with Vinnie, there was no sense that the professionals just stopped their support at that point. In Josie's example she said "we had a doctor to see him and he clearly was very low in B12, he had to have injections and things have improved since then but then there has been a change in his life as well, so there's so many variables aren't there?". She also recognised his wish to work and learn and the importance of getting the pace of that right so as not 'to make him feel worse about himself' by going too fast.

Scott's approach was direct from the start: "...what I'd done before [is] having ground rules before we started, with some difficult to reach groups it were about saying, "look, this is what I can do but we're only gonna do it ..." and then nothing came as a surprise. So I said "if you are under the influence, I'm not going to go out on the road crossings ... but because you're a binge drinker, I'll come Tuesday morning, we'll do mobility", but it were clear from the beginning, none of these techniques

are useful under the influence of alcohol so he were never under any impression that it would make him safe, if he carried a cane and went out drinking. So it was about clear boundaries or guidelines about how we would provide the rehabilitation. ".

Alison and Seamus shared the experience of people with substance problems not always engaging. For Alison she stated: "I just know I would do whatever I could do to try and give people that hope again. So the frustration for me as a rehab officer is, okay I get it that this person's sight isn't their biggest issue, or isn't their biggest concern. ... Possibly getting their next drink is their biggest issue or getting the drugs they need is their biggest issue.". For Seamus, two patients had not returned to see him in spite of his encouragement: "such people can be hard to get them to engage with healthcare and they may want to just continue doing what they're doing. They may want to continue their habit....among people who self neglect themselves. So the individual with heavy alcohol use is less likely to turn up to the clinic with their problems which can be things like diabetes and cataracts or whatever. They're less likely to turn up to the clinic, they're poor attenders, they're less likely to comply with treatment, the poor compliance that goes with the poor lifestyle.".

Another frustration was the lack of time some professionals felt they had to work as they would like with people. Rachel spoke of the need to take an holistic approach to supporting people including time allocated to working with people. She stated it was "very frustrating and upsetting to clinicians that they couldn’t do more" but they were just "not in a position to do more". As a result she reported it was a relief to pass it on to someone as opportunity for someone to support them and make a difference. She feels that many optometrists know about the link and may mention it to patients where appropriate but they won't have time to discuss it, treat it, take notes as well.

Scott was also aware of not having time to learn all the links "because rehab officers are asked to cover all areas of disability or conditions". He added "that makes it really difficult so you get a good knowledge of probably typical eye conditions but not the links between things, so like the sight loss and alcohol or substance misuse, that’s not so transparent, there’s not a lot of information about it". He felt that large sight loss

charities needed to have information about it on their website and that such information should be disseminated.

Working with people with sight loss in substance use services

Among the challenges for the substance use service professionals was the lack of fit between the needs of people with sight loss and their service models, questions about truthfulness regarding their sight loss, and the lack of appropriate resources for staff and service users. Resource issues and truthfulness will be discussed later in the chapter but the key challenge for one of the substance use professionals was that the agency's service models, while flexible, were not always appropriate for people with sight loss.

Sandy reported the key challenge as being getting her client to complete a drink diary. "We tried to find different ways of her being able to say "this is how much I drink", because it's really difficult to get an idea and I've needed to refer her for a detox twice and it's been very difficult...so we've tried to find different ways, even if it's a mark on a paper with a pen or pencil, or if she leaves all the bottles and then I go round and count them. But it's been impossible, we have not found a way that's worked ... even when I've given [her pen and paper], she's put them down somewhere and she hasn't done it because she couldn't find them. We've just tried various methods, we've tried phoning her to say "how much did you drink last night?", and often she goes to sleep on the sofa, she drinks till she blacks out and she can't remember and it's very difficult. Often she just makes it up! So it can be quite random and then when I go back and get her to confirm what she's drunk, it's changed, so just getting a pattern of what she's drinking is really difficult." Sandy explained that so much of the agency's approach was using materials that were written down "although I do it verbally with her and she goes home at the end of the day, she's not really got anything to take with her apart from what she remembers and she's got a very poor memory, so that's just getting her to retain information when it's not, she hasn't got that visual kind of back-up, that's been quite difficult". Because of the different types of sight loss for his service user, Alan had not yet encountered particular problems with the completion of drink diaries and Jonathan's work was more verbal than written.

What was clear from both Sandy's and Alan's responses were their views that even without the sight loss, their service users were challenging to work with. Alan raised the issue that with or without sight loss some people are simply harder to work with than others. He felt his service user fell more into this category than having different needs as a result of his sight loss: "I think the sight loss, even without that, he is an exceptionally complex individual who we've found very challenging, sadly." Sandy felt similarly to Alan and was aware that her service user suffered with anxiety before her sight loss: "I think she's one of my most hard work clients, I think that's partly because of her, she's got really high levels of anxiety and I think that's, they have definitely been made worse by her sight loss and then by her drinking so much. And then isolation and she's very anxious about not being able to come into the service so I think she takes up a lot of my time and I spend a lot of time on the phone to her and she cancels quite a lot…". Jonathan's four service users seemed more motivated to change their alcohol use and proceeded well through his interventions with them. However, Jonathan also felt that the sight loss per se was not more of a barrier than for example, a bereavement or other type of loss and that the speed of the adjustment period was key to their ability to avoid developing multiple problems: "the more people took time to adjust to that, the more they lost really, so things like if you were taking two, three years to adjust to losing your sight, then you would lose your job, your family, your home and in a way when they got to me, they'd got multiple problems – which were solvable – but just needed addressing, as compared to the person who I'd just see after a year, who was still able to function, had lost a job but still had their own house and could move on fairly quickly...they have the same sort of problems that I would say that most people who present to drug and alcohol services around bereavement have".

Both Sandy's and Alan's service users had little family or friend support. Given positive social support can be a key contributor to effective substance use treatment this also meant their service users relied heavily on them or other agencies they attended. Alan said "I don't know that he has many people around him, other than people who are professionally involved with him in some way and sometimes he associates with other service users". Sandy concurred stating her service user: "I think her daughter's really angry with her, they have

massive, massive arguments and when they have an argument, daughter stops Mum coming round for a couple of weeks or months … and with her two sons as well because again they work and then they come and see her in the evenings but by that time, often she's had quite a lot to drink so then they get angry with her and then they go away and then they don't visit, so then she's even more isolated."

Access to services

A number of the professionals referred to the challenges sight loss and substance use combinations posed for people accessing services. Sandy recalled the person she worked with having to get a taxi when the Ring and Ride service refused to bring her to the agency. The woman had cancelled over 500 bookings with the Ring and Ride service. However, taxis were too expensive and she had now stopped attending groups.

Stuart, in his previous substance use work, recalled two enquiries from men who had some sort of health needs one of whom was visually impaired. The agency would not accept them as they couldn't 'cover that sort of eventuality'. He also recalled people who arrived for initial visits only to find the building was "not suited to them because of their mobility".

Mark was also frustrated at the single lens focus of services: "It's just on-going really, trying to get that issue across that as well as a visual impairment he's got a learning disability and the two don't go together really because they can deal with one but they don't know how to deal with the other. " Mark felt that solutions such as 'easy read print' information and materials people need could begin to address the issues. As he said "a standard leaflet doesn't make any sense to him. So he needs it in his sort of format. But it's getting that message across".

Rachel also recalled a particular person with substance problems who was due to attend the sight loss clinic for a particular procedure but the person would fail to turn up at the last minute. She subsequently found out that if the procedure removed the sight loss the person would lose the services of the person who was supporting them with daily living.

System or structural change also hampered service access and availability. Some services had been cut resulting in a less frequent service. Heather recalled being able to visit people in the community more regularly but found it much harder to build relationships with the move to annual home visits only. Similarly, Josie reported how changes within social service departments made it difficult to provide and coordinate care because they "no longer develop long term relationships with their clients".

Solutions and strategies for working with people with sight loss and problematic substance use

It was clear that, in spite of the challenges, the professional participants were committed to their work and passionate about it. None of them had a specific remit to work with people with sight loss and substance use although one participant had a particular clinical and academic interest in certain forms of substance use and sight loss. However, in most cases the professionals stated they would refer on to specialist sight loss or substance use services as appropriate. It was also apparent that some professionals made a concerted effort to engage with the 'other' issue as best they could when it arose. This was particularly the case for the professionals in roles where a more holistic approach was taken to assessment and meeting people's needs. People often spoke about learning by experience or responding to whatever they're presented with at the time. The following section outlines some of the ways people found solutions and strategies to support people with sight loss and substance use.

Creative solutions within remit

Alison tried to schedule mobility lessons for a particular service user with substance problems at the beginning of the week when the person had run out of money and wouldn't be drinking as much. She was open with people about this strategy: " "So we won't do it from Wednesday onwards when you get your benefits because obviously then you'll be drunk for a few days." It feels like a very grown up conversation, because it's an accepting conversation."

Sandy said a range of exceptions were made for the person she worked with that would not be standard procedures within the substance use

service including home visits, swapping to downstairs rooms, sitting alongside the person in groups she attended, writing things out for her on large pieces of paper in large print, programming numbers, for example the Samaritans, into her mobile phone.

Stuart said that when he worked in a substance use service the staff "were quite aware of disabilities and any physical impairment or mobility issues. They were really sharp and clued up on that. If it turned out that somebody wasn't seeing so and so, it might be taken to the house meeting, "can we put fluorescent and sticky tape on the knife handles or something, so John gets the right end of it?" sort of thing."

Vinnie also identified practical strategies for shopping based on individual needs and the supportiveness of staff. He gave examples including supporting people with sight loss to access the internet to "get an idea of what you want and then have to go in and then, you know". He spoke of a colleague who is a volunteer with the charity who "likes nice wine and good wine and she's a member of a wine club or something, so she's overcome [her sight loss] by ordering everything through them. ...It's different things for different people, you'd mark it up in a different way. As strangely as putting an elastic band around the reds and no elastic bands round the whites, or you have the shapes of the bottles I suppose. It's that pattern where you are independent but still restricted, like this lady will only buy her food at Marks and Spencer's and Waitrose and that's because the staff in there are much better than the staff in other places, they know her, they understand what she needs...".

Scott's approach was to find tools that can help him in his work while being honest with people that he's not a substance misuse worker: "One of the things I've used in the past is the chart, I think they were from the Department of Health, which shows general impairment of alcohol with so many milligrams, of it affecting depth perception and things like that, so I always explain 'this is without a visual impairment, so if you're drinking, these sort of things are happening, regardless of that it makes it dangerous to cross a road!' ".

Partnership working with external agencies

The need for partnership working to meet people's holistic needs was another common topic. Abigail stated "what we're talking about here are people in a complex situation where they've got sight loss and possible addiction issues as well. Having been on both sides or having been working in a detox environment and working in a VI environment, ... I don't think that any agency could take all the problems and deal with them, I think it is about partnership and cooperation with the agencies... I suppose there's a general principle really about sharing information and having the same aims for the individual person".

Alan, an alcohol specialist, recounted the person he worked with as having contact with RNIB, social work, nurses, and a cleaner, all of whom were working to support this person. However, he was critical of communication between his employing agency and key sight loss charities. Sandy met up regularly with the wider team of staff supporting the person she worked with including her social worker, and staff from RNIB, Age Concern and MIND.

GPs were the first point of contact for some professionals when they met a service user with alcohol and other drug issues. Alex stated "I have no great speciality in alcohol or drug abuse, so when we come across issues with that, we typically would include it in the report for the GP to act on rather than referral direct from here....Just talking that through with you, it would be perhaps useful for us to get links with other agencies that may support people with drinking problems, to see if we can form better relationships in terms of what we can do and what we can offer people with that sort of problem, but that's for us to do, I'm sure there's agencies out there that we could be contacting and getting involved in, which up to this point we haven't, so perhaps something, a point of work for us to do rather than for other people to have to do."

Some professionals had more limited contact with other disciplines or professionals. Heather had no regular contact with alcohol professionals as part of her role but had contact with social workers and occupational therapists. Jonathan mainly worked alongside his GPs and a counsellor in the practice.

Scott highlighted how people with sight loss and substance use are often treated separately and may get lost in the service gaps without

partnership working: "I think it's treated as two very different things... it [would] have been better if they got together and had a joint approach". Scott felt that as one person he was limited in terms of what he could change but was "trying to make links with like the DAAT [Drug and Alcohol Action Team] team and things like that, so they're aware of the sensory team, they're aware of the work we do, what are the links? So then it makes, with the other teams we've worked, they know who to refer to and they also know who to turn to for advice."

The joint working was picked up by Tracey who stated it was "also about trying to make a plan, making sure they were referred in with a local alcohol agency, so that both of us could work together to support the person. I don't think it's something you should do alone if you're not a specialist agency, you need that support from someone else. So I think as I've said before it's about looking at the person as a whole and looking who can support them, who we can work with and just having some sort of plan in place to manage any risk. I wouldn't like to say never take anybody who has those problems, but you don't want to fail them".

Assessment issues

Assessment and the inclusion of questions about substance issue came up repeatedly for sight loss professionals. A number of sub themes arose including a lack of assessment of substance use, whether it was a legitimate part of an assessment and having a more holistic approach to assessment. Both sight loss and substance use colleagues also raised issues about the truthfulness of people they worked with who lived with sight loss and substance use and the difficulty they had in determining the reality when working from a position of ignorance. These are explored further below.

Lack of assessment of substance use

As someone with specialist knowledge of both substance use and sight loss, Seamus stated that little was being done by ophthalmologists, optometrists, and general practitioners in relation to wider questions about lifestyle issues affecting eye health. He said "we know that they're not doing much about it because our survey shows that actually a lot of the ophthalmologists don't even ask the questions about smoking.....I'm

fairly well tuned into this, but a lot of the doctors will not be because they don't necessarily think about it. And they don't necessarily ask the patient who they'll see in the eye clinic, they don't necessarily or routinely ask them enough about lifestyle issues such as drug abuse, smoking or alcohol. They don't necessarily ask that much".

Rachel also felt that professionals needed to discuss it with people: "If you can’t get change in your environment through your eyes, then change of internal state is understandable [through drinking]". She suggested the need to 'make it ok to talk about it' by having information in the clinic, or self assessment questionnaires, and to "at least broach the subject like ‘other people have reported that they have increased their alcohol use after losing their vision....etc’.

Four people who worked in different sight loss roles (see appendix 12) - Abigail, Alex, Alison, and Veronica - reported that substance use was not something they would assess for and that if people told them they were having problems or it was picked up in conversation then they would be referred on. Abigail said: "I wouldn't say it’s part of our work, I would say that it’s something that people sometimes share with us but like I say, we wouldn't, we’ve had people come and ask us to help them but we would signpost them, definitely". Alex described it as more "opportunistic" as opposed to formal assessment. Veronica said it was a matter of "waiting for someone to disclose rather than asking" even though she got "to work often and you can smell it quite often, and then you think, 'Well this person is a very heavy drinker, or they've got some sort of dependency'".

Alison was reflective on whether, having discussed it for the research interview, she should be considering questions on substance use within her assessment. "I don't ask in my assessments, I do not say to someone, "do you have any addictions?" it's not something I have ever asked.... So unless I picked that up from may be a case note or something that somebody else has written... I wouldn't ask the question. Maybe I should?.. I mean this will challenge me, I can ask whatever questions... I mean I don't feel uncomfortable asking anybody anything, but it's not something I currently ask. ... It's an interesting one, should that be part of our assessment? ...Yes and maybe the outcome possibly should be well maybe we should think about talking about it during our

assessments. I'm happy to talk about it, I've never thought about it before".

The final reflection from Alison above echoed other professionals' sentiments about the legitimacy of asking about substance use. Scott recalls experienced social workers asking him 'who am I to ask them about their substance use?' and felt local area training was required to support people to ask the right questions.

Abigail felt that in the sight loss sector "the Guide Dogs might be the only people that could be legitimately ask somebody about their drinking". Alex also felt unsure about asking questions: "Is it something that we raise, is it something that we refer on? Is it something that people want to discuss or is it too personal when we're dealing with another area so that if we start raising the alcohol question, "you do rather smell like you've had a couple of pints this morning, do you have a problem with booze?", that then puts up barriers and stops us getting involved in other areas." Such fears about invading privacy by asking about substance use and concerns potentially damaging therapeutic relationships is a frequent concern among professionals who have not had training or education in how to ask about substance use.

Finally a number of professionals felt that a more holistic or bigger picture view was required in terms of assessment and providing support. This was clearly easier for professionals in some roles than others. Rachel spoke of the Low Vision Service model being holistic and taking all factors in someone's life into account. She stressed the need to respond to people individually: "It is important to look at the person as a whole as the support you'd give to one person would be totally different from the next person – everybody's circumstances [are] different."

Tracey also felt that taking a "whole picture" perspective was important in relation to what someone's issues were, which other agencies they're working with and whether there was potential for partnership working. She also highlighted the need to manage risks to others "if something happens".

Issues around truthfulness

Two substance use professionals reported concerns about the truthfulness of their service users. Alan was concerned about it in relation to his person's sight loss and his substance use. However, while he was equipped to challenge the substance use issues he felt too ignorant about sight loss to do the same: " ...there's a kind of strategy that I would normally take would be to first of all accept what the client says, then if it becomes obvious that there's a discrepancy between what the client says and the reality, to kind of highlight that and show it to the client and say, "look, what about this". With the visual impairment, I suppose I feel like I just don't have the knowledge to do that and although everything I've told you about people saying "he can bend over and pick up £1 off the floor", it's very anecdotal and I just don't know whether it might be, I mean how does a visual impairment affect somebody basically? It could be that there's certain sorts of things that are very easy to pick up or if something's moving or I've got no idea, so it's hard for me...". He went on to give examples of how the person he worked with had lied about his drinking and a family bereavement while at the same time giving examples of how the service user in question had acted in a way that indicated a fair degree of sight. He said there was a lack of clarity about the effects of his sight loss, and whether or not he is exaggerating it.

This lack of knowledge appeared to interfere with Alan's ability to provide a service and was leading to distrust and scepticism. Sandy had similar experience: "I think they say it's worse than it is, to get the support that they need because especially for this client, she's very, very anxious; her blindness causes her huge anxiety and she's just terrified of being isolated and being left by herself, she's quite needy in that she'll want to phone me every day, sometimes two or three times a day and when she comes and sits in groups, she wants someone to come and sit and hold her hand, so she gets very anxious. But then she'll say she can't see things but then when she thinks she's by herself or when she forgets, she'll reach for something or she'll walk past a car and could identify the car, "oh you brought your car today?" and it's like "how do you know?".

Stuart, who has worked in substance use, health and social care and has sight loss, confirms this lack of knowledge and understanding from his personal experience: "... they're just not getting visual impairment,

[they think] you can either see or you can't. I explained my condition that I can't see anything in the middle, "yet if I throw you an apple, you catch it see," "yes because I can actually guess to make the trajectory." They wouldn't get it that there were various degrees of blindness, there was different types of it."

An optometrist participant also raised issues around truthfulness of people he saw in relation to their substance use: "We've had a lot of people who will talk to us about the fact that they used to be drinkers and will come in and "this is got me into this situation, I used to be a drinker" and it's quite obvious from appearance and smell and everything else, they are still quite heavy drinkers and so living in denial, in terms of their drinking as an issue." His concern was also whether there were safeguarding issues for staff if people attended inebriated given their practice was "in an isolated room with the door closed". It is interesting to note that this participant stated 'a lot of people' talked about drinking affecting their vision and it perhaps gives some indications for future directions for research.

Support and resources needed for professionals working with sight loss and substance use

A number of suggestions were made for resources or support that would enable professionals to work more effectively with sight loss and substance use. Some of these related to professionals' needs, others to resources that would better support the people who use their services. These included:

Substance use professionals	Sight loss professionals
• Large print materials and information in substance use services	• Audio recordings and appropriate adaptations of tools used within substance use services, for example, a drink diary.
• Basic training on the "do's and don'ts" of working with someone with sight loss.	• More information and posters on substance use and sight loss in eye clinics.
• Training on the links between substance use and sight loss. Shared training between substance use and sight loss services to establish closer working, pathways between services and information on referrals and different perspectives.	
• A system of job swaps between substance use and sight loss services.	

Some suggestions were for more information, for example, the request for more statistics on sight loss-related problematic alcohol use and also an economic analysis of the costs to NHS.

Education for people with sight loss about substance use before it is too late was also suggested. The issue of staffing levels and service cuts was also apparent. Professionals variously identified the need for:

- more staff needed in sensory teams within local authorities
- more optometry services - particularly for homeless people.
- more accessible substance use services
- specialist workers to deal with the "cross overs" between sight loss and substance use.

One participant stated that optometrists have "no specific training" on substance use and relied on experience and their "generic helping skills" to work with people experiencing substance use and sight loss. Abigail appeared to accept that this professional health or social care education was enough: "I think that the nub of the matter for us is that they are all professionally qualified, they all have an awareness of different things from safeguarding, which obviously affects all the cohorts, so I think that it is having skilled workers who are sensitive to what people are telling them and reacting appropriately. "

Summary of findings-professionals

The group of professionals that contributed to this research was diverse in terms of the roles they held and the time they had been in the sight loss and substance use fields. The group contained three substance use professionals and at least two others had previous experience in substance use work. For the majority their motivation to contribute to the research stemmed from their professional experiences of working with the overlapping issues of substance use and sight loss.

The reported number of people they worked with who experienced these dual issues was low, reflecting the findings of the existing dataset analysis and the wider literature. They suggested this was a very small part of their work. Yet we also found that there was no routine assessment about substance use among the sight loss professionals and vice versa, and that a significant number did not and would not ask

about the substance use or sight loss unless it was obvious or disclosed. Arguably the professionals need to ask the questions in order to more accurately determine the size of the problem. As some participants highlighted, this is likely to require education and training to facilitate assessment that is appropriate to the role and practice context.

While alcohol remained the dominant substance of choice for the people supported by the professionals, there were clearly concerns about other types of drug including a number of prescribed medications. This raises interesting questions for future research particularly given some of these, for example, Warfarin, are used predominantly by older people who are more likely to experience sight loss as part of the ageing process and for whom older age increases their risk of sight loss. Evidence also shows that in an ageing demographic increasing numbers of older people are suffering harm from substance use, primarily alcohol.

There was a clear understanding among the professionals that substance use could be a coping mechanism. This was particularly apparent when substance use had been part of the individual's socialisation with work colleagues, for example, people within the armed forces, or when people had a combination of losses and stresses in their lives. In general, the professionals were less likely to be sure about whether or not there was a causal link between sight loss and substance use.

Almost without fail the professionals we interviewed were committed to doing their best in their role for people with sight loss and substance use even though they found this challenging at times. Some professionals went outside their employer's usual procedures to offer what they felt was appropriate support and were often creative in doing so. This was in spite of a frustrating lack of time to provide the service they wanted to provide. In substance use services the professionals faced particular challenges working with people with sight loss because some elements of their practice models involve written tasks.

Partnership working was identified as key to providing the necessary support to people with sight loss and substance use and to stopping people falling through the gaps in services. This was particularly so when practitioners doubted the 'truthfulness' of the people they worked

to support but they lacked adequate knowledge of sight loss or substance use to challenge or respond appropriately.

Finally professionals made a number of suggestions for resources to support them in their learning and also as information for service users directly. Some also commented on the demise of specialist sensory staff and services. Within the current climate of public health and local authority cuts, this is unlikely to improve and may heighten the demand for partnership practice and free training exchanges.

Chapter 8 - Discussion

This study is the first of its kind. While it has been exploratory by nature and small in scope, it has served to bring together three sources of evidence on the nature and extent of the relationship between sight loss and substance use: existing research evidence, new analysis of existing datasets and empirical qualitative research.

The headline findings can be summarised as follows:

1. Conclusions from the existing dataset analysis are that people with sight loss are more likely to abstain from alcohol and consume fewer units of alcohol per week.

2. The existing literature found no consistent evidence for substances causing sight loss, but there was evidence that substance use may have a role to play as a coping mechanism for individuals with sight loss and also as a contributing risk factor through conditions such as 'tobacco-alcohol amblyopia' or 'toxic amblyopia'.

3. There is a connection between sight loss and substance use for people living with sight loss and substance use. Some people had been told by professionals that this was a causal relationship, while for others their substance use was a way of coping with their sight loss.

4. For professionals, the number of people they worked with who had sight loss and substance use was small but they posed considerable professional challenges.

5. In general, professionals in sight loss and substance use services are not adequately equipped with the knowledge, professional guidance, or organisational policy frameworks, to help them to identify and respond confidently when working with someone with sight loss and substance use.

While these are the headlines, they must be considered in context. In terms of the literature reviewed, there is not a large body of existing evidence from which to draw reliable conclusions. Not only are there large gaps in the evidence base, but for some studies the data was case study based only, for others the methodology was unclear, and for some

the studies had particularly narrow foci on particular cohorts, for example physicians, and particular conditions causing sight loss. While it is often the case that research needs to retain a narrow focus in a broad topic, the current evidence is simply too diverse or too limited to draw reliable conclusions about sight loss and problematic substance use.

Similarly, the two existing databases analysed to explore the question of prevalence are based on relatively small sample sizes. The number of people currently registered blind or partially sighted is 360,000 (RNIB 2014) increasing to 1.87 million when sight loss conditions which have a "significant impact" on people's daily lives are taken into account (RNIB 2013). Thus, while there are clear messages from the sight loss samples drawn from these larger surveys, there is a need for further research to fully determine the scale of relationship between sight loss and substance use.

The existing evidence focuses primarily on older people. This study included a number of younger people (seven of 17) and it is evident that the needs of this younger age group require more research. Given the ageing population, it is also important to determine their needs in order to accurately consider the implications of their substance use and sight loss for future practice.

Much more reliable and rigorous evidence is needed. The UK Vision Strategy (UK Vision Strategy Team 2013) concurs. In order to meet its first outcome, that is, for everyone in the UK to look after their eyes and sight, it sets out a number of priority actions. Priority 1.6 is:

"To promote investment in further research to reduce sight loss through development of interventions for conditions that are currently untreatable and also to build an evidence base for effective rehabilitation and support services."

Importantly it highlights the need for evidence to support effective rehabilitation and support services too. It is therefore not just about building the medical evidence base but also looking at the services people need.

The key findings from our research with individuals living with both substance use and sight loss support to some degree Koch et al.'s

(2002) three typologies of relationships between substance use and disability (highlighted in chapter 4). To recap Koch et al. identified three relationships in which i) the person's pre-existing substance use limits their abilities to adjust to sight loss, ii) having adjusted to sight loss, their subsequent substance use, as with sighted peers, negatively impacts their skills to continue their process of adjustment, and iii) there is co-occurring substance use and sight loss with the substance use as a coping mechanism but in doing so the person may develop problematic substance use. The experiences of the 18 people who participated in this study contain echoes of Koch et al.'s typologies but fell primarily into two main groups - the pre-existing substance use causing or contributing to sight loss, and the substance use as coping mechanism. These were not mutually exclusive and for some people they believed their continuing substance use further damaged their limited sight. Other relationships included the use and misuse of prescribed medication that led to the sight loss and some instances where the relationship between the substance used and the person's sight loss is possible but not identified or known.

The people we spoke to were at very different points in their sight loss journeys. Some people at or near the start of their sight loss journey resisted using 'gadgets' and aids, going to lengths to avoid or hide them. For others their reluctance was overcome and the aids became a helpful signal to their sighted peers.

The amount of ignorance people experienced from peers in relation to their sight loss was also apparent. The lack of understanding about sight loss led people to question the legitimacy of their impairment, mock them and abuse them. The development of the concept of ‘psycho-emotional disablism’ by Thomas (1999) and latterly Reeve (2014) highlights the impact of oppressive social relationships upon disabled people. This direct form of disablism through personal abuse and mockery from individuals is extended through the 'indirect' psycho-emotional disablism (Reeve 2014) where agencies or other services do not address the structural or other barriers that prevent access.

Direct psycho-emotional disablism can be a result of assumptions made by practitioners or others, for example, that excessive drinking is an appropriate response to what some might see as the tragedy of sight

loss. This could result in professionals overlooking or ignoring substance use.

These approaches rarely place the experience of impairment and disability in a wider context: for example, while loneliness and isolation can be triggers for problematic substance use this needs to be acknowledged in the context of a disabling society that devalues deviations from the supposed able-bodied norm and makes it difficult for people living with sight loss to actively participate in society.

In some circumstances, the stress of sight loss on people in this study, and the negative impact on many aspects of their lives, including loss of employment, independence and mental health, led to the breakdown of relationships and friendships. Some people attempted, or considered, suicide. It is important to consider the extent to which the negative impact on people's lives could be lessened through system or structural changes in society, for example, fewer barriers to employment. When first articulating the social model of disability in the early 1980s, Oliver (2004) highlighted the concept of ‘personal tragedy’ underpinning individualistic interpretations of disability. However, while the social model may allow for a recognition that it is not acceptable to discriminate against disabled people there frequently remains an implicit assumption that you would not want to be disabled. Therefore disabled lives remain undervalued and seen as inherently less or lacking.

While we did not search the existing literature for evidence of the impact of sight loss and substance use on wider social networks, the substance use literature has recently evidenced the need for support for family members of people with substance problems in their own right rather than as an adjunct to the individual with the substance use problem (Copello et al. 2000, 2006). It has also found that such approaches, while focussing on family members, have led to the individual making changes in their own substance use. Such approaches to supporting family members could be used within this context particularly given the increasing cuts to services and other austerity measures resulting in greater responsibility and expectations upon the family and community (Home Office 2010).

On occasions the communication skills of the professionals who were involved in the early stages of people's sight loss were also lacking. Some people reported having little to no information and support in relation to their sight loss diagnosis, its trajectory, and what to expect on a physical and practical level. This was often from the frontline medical consultants who, at the time, were their source of information and hope. These experiences are sadly not new. The 'Seeing it my way' outcomes drawn up by over 1000 people with sight loss, and embedded in the UK Vision Strategy, have 'understanding their eye condition' for themselves, family and carers, as the first of 10 outcomes. Its definition is "I will know what my eye condition is and what it means for me, my family and carers. Someone will talk me through the certification and registration processes, what they mean and the benefits they can offer" (UK Vision Strategy Team, 2013: 26).

Yet there were also positive reports of services and individual professionals that took pains to support people in whatever way they could. For one person their need for human touch and contact was met with an impromptu hug from a support worker on their first meeting following weeks of telephone contact. Undoubtedly this hugely important moment would be considered officially as flouting the rules. Such initiative and care was reflected in the practice of a number of the professional participants.

The professionals in our study appeared to be a dedicated and committed group of people. They recognised the overlapping issues of substance use and sight loss among the people who used the services in which they worked, albeit a small portion of the people they supported. However, the impact of that small number on their time and resources was often great. While they understood substance use as a coping mechanism, most, but not all, admitted ignorance about the 'other' issue. Overall they found working with the dual issues can be challenging and few felt that it was within their remit to do more than respond in the best way they can as and when it arose. The services they worked for appeared to have no policy of routine questioning about the other issue.

This failure to anticipate that 'the other' can be an issue for their service is a common and apparently enduring experience for disabled people particularly in relation to health and social care services. This tendency

is captured in the title of Jenny Morris' (2004) report 'One town for my body, another for my mind' which considered services for people with physical impairments and mental health support needs (including alcohol and drug services). Disabled people reported there was little recognition of mental health support needs and negative staff attitudes towards mental health in disability services and vice versa. In addition, there is considerable evidence that disabled people can become victims of diagnostic overshadowing where their 'primary' impairment obscures other impairments, health or social needs resulting in high levels of health inequalities and poor outcomes when compared to non-disabled people (Disability Rights Commission 2006, Mencap 2007; McManus and Lord 2012).

The social model of disability is formally adopted at policy and practice level in statutory, private voluntary and independent disability and social care sector. However, there are two significant issues of relevance here. First, is the extent to which a formal commitment to a social model understanding of disability has been embedded in a meaningful way within organisations and second, whether a focus on structural disabling barriers is sufficient to address the very significant psycho-emotional disablism experienced by people living with sight loss.

Drawing on an evaluation of a local authority's service provision Oliver (2004) noted that much current practice can be described as taking a 'compliance approach', that is it takes a procedural approach to meeting laws, regulations and rules. This can frequently result in a checklist approach that is focused on meeting minimum standards. For example, a service might provide information in Braille and assume it has thereby met the access needs of people living with sight loss. This type of approach remains service led and, while not intentionally seeking to be exclusionary, it provides an inadequate service which may fail either to meet the needs of service users or engage them meaningfully. Oliver contends that service provision needs to be based on a citizenship approach that recognises and values those using services as citizens. This requires services to see those who use services holistically and not as their 'presenting' label, diagnosis or issue.

One of the shared activities among the professionals in our study, regardless of role or remit, was an element of assessment, be it formal

assessment or informal on-going assessment. However, assessing the 'other' issue raised questions about whether it was a legitimate part of their role to ask about substance use in particular. This questioning is not untypical of front line professionals who do not specialise in substance use, nor of their attitudes towards substance use. Similar responses to people using substances have been found from social workers (Galvani et al. 2013, Loughran et al. 2010), and medical staff (McLaughlin et al. 2000, Lock et al. 2002) not working in a specialist substance use capacity. Evidence shows that even where some professionals felt it was a legitimate topic to raise, they did not feel equipped with the knowledge or confidence to do so (Galvani et al. 2013).

In the case of sight loss and substance use, sight loss is likely to be perceived far more sympathetically, once known, as a condition about which the person has no choice. This is set against substance use which some people still consider to be self-inflicted and showing a lack of determination or moral fibre among people unable to stop in spite of negative consequences to themselves or others.

To overcome ignorance and provide a better service, the literature and the interview data both identified education and training for professionals as an important part of enabling professionals to respond more effectively to the overlapping issues of sight loss and substance use. Again priority action 1.3 of the UK Vision Strategy is: "To increase the understanding of eye health among health and social care and education practitioners, through training and development programmes. Professionals working with groups at a higher risk of sight loss should be prioritised."

Education and training alone are unlikely to change attitudes to substance use that are embedded in professional or local cultures. However, awareness and education is needed to start that process within particular cultures where heavy alcohol consumption in particular remains strong, for example, veterans' services.

Similarly priority action 1.5 is "To identify and address potential sight loss for all individuals with health conditions where sight loss is a known correlate and increase awareness of these among healthcare practitioners, including eye health practitioners."

The commonality of assessment processes provides key opportunities for one or more relevant questions to be asked within sight loss and substance use services, supplemented by clear pathways to support staff and service users on what to do next. A sight loss pathway has been drawn up as part of the UK Vision Strategy (appendix C in the Strategy) and clarifies the importance of "seamless transition from NHS diagnosis and interventions, through emotional support, information, reablement (visual impairment rehabilitation), maximising residual vision, and other social care supports, to full autonomy, independence, health and wellbeing.” (UK Vision Strategy Team, 2013)

Chapter 9 - Implications

The key implications for practice and research have been set out below. These have been drawn from the different types of data accessed for this study.

Implications for practice

1. Education and training on the relationship between sight loss and substance use is needed for professionals in sight loss and substance use services.
2. Practice guidance is also needed on how to adapt their current models of practice for work with someone who presents with the 'other' issue and will need tailoring to different roles and different areas of practice.
3. Resources and materials that focus on early intervention and harm reduction are needed to support staff in substance use and sight loss services.
4. Routine monitoring and screening within sight loss and substance use services are needed so that substance use services screen for sight loss and vice versa.
5. Resources and material about the relationship between substance use and sight loss are needed for people who use sight loss or substance use services. Services are likely to need guidance on how to meet this need appropriately.

The need for the development of a range of resources and materials for both individuals and professionals provides an ideal opportunity for joint training and resource development through locally formed partnerships.

Implications for future research

1. The perspectives of people who use services are absent from the majority of the research. More qualitative research is needed to fill this gap and to fully understand the relationship between substance use and sight loss. As an exploratory study this research only scratched the surface. Other specialist sight loss organisations and

educational establishments, and NHS clinics and patients are all further sources for research of this kind.

2. Carer/partner perspectives are absent from the research. Given the impact on relationships of sight loss and substance use, even as separate issues, carers' and partners' perspectives and needs should be identified alongside research into how those may be addressed.
3. More comprehensive UK-wide prevalence data is needed. A survey of people with sight loss via sight loss and substance use services would be a start. This would fill a large gap in the research evidence.
4. Longitudinal research is needed to assess the impact of substance use on sight loss over time and vice versa, ideally taking into account other lifestyle choices.
5. A systematic review of evidence relating to the relationships between prescription medication and sight loss is needed.
6. Given the existing research focuses primarily on people in older age, the needs of people under 50 years is a gap in the evidence base. Research with this group will establish the potentially different impact of sight loss and substance use on a younger group. It could also provide a cohort of younger people to follow through longitudinal research on sight loss and substance use.

Chapter 10 - Conclusion

This exploratory study set out to answer three research questions:

- What does current evidence reveal about the nature and extent of the relationship between substance use and sight loss?
- What is the role substance use plays in the lives of people with sight loss?
- What are the experiences of professionals working with people who have sight loss and substance problems?

In seeking to answer these questions, it became the first study of its kind to harness the combined perspectives of individuals who experience, or have experienced, problematic substance use in addition to their sight loss, and professionals who provide sight loss or substance use services. Further, it has drawn together existing research evidence and new analysis of existing data sets.

The findings present a number of clear messages. First, conclusions from the existing dataset analysis are that people with sight loss are more likely to abstain from alcohol and consume fewer units of alcohol per week. Second, the existing literature found no consistent evidence for substance use causing sight loss, but there was evidence that substance use may have a role to play as a coping mechanism for individuals with sight loss and also as a contributing risk factor through conditions such as 'tobacco-alcohol amblyopia' or 'toxic amblyopia'. Third, there is a connection between sight loss and substance use for people living with sight loss and substance use. Some people had been told by professionals that this was a causal relationship, while for others their substance use was a way of coping with their sight loss. Fourth, for professionals, the number of people they worked with who had sight loss and substance use was small but they posed considerable professional challenges.

The existing evidence on sight loss and substance use is limited. Some of it is weak in its quality and quantity but its strength lies in its diversity and international origins. The evidence came from around the globe and, while this appears to be an area of research in its infancy, there are

shared clinical observations, in addition to the personal and professional experiences reported here, about the nature of the links between problematic substance use and various forms of sight loss.

The evidence also shows that services are rarely set up to work well with the overlapping issues of sight loss and substance use. However, the professionals we spoke to were not averse to change. One of the powers of qualitative research is that it can make people reflect on how they are practising and whether they can or should be doing it differently. There were instances in this study where participation in the research prompted people to think out loud on initiatives they could take to improve their individual or service responses.

While individual practitioners may strive to do their best they are operating with systems and structures that do not, as yet, consider the 'other' issue as part of their remit. This study has begun the important conversation about what needs to improve in research, policy and practice.

The following poem was written by one of our participants and reprinted here with permission:

Cocaine Rain

This is for the young ones of today, they’re no blame.

I took cocaine, now I can only feel pain in every day.

I fight my way through and try to tell young but they won’t listen, they still think it’s fun.

Losing sight, it might be losing my sight, doesn't mean I can’t see.

Now I can see what others can’t hear, they moan, groan and I have created my own hell that I can't tell, for I survive.

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