Alcohol and Sight Loss: A Scoping Study

Appendices

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Appendix 1 - Summary profile of people with sight loss and substance problems

- Barnaby - 60-65 years, Sudden sight loss; Macular Degeneration and Retina Vein Occlusion

Barnaby experienced very sudden sight loss in both eyes. This occurred within a matter of weeks while he was in his mid-50s. He was subsequently diagnosed with macular degeneration in one eye and the retina vein occlusion in the other. Prior to this he had successfully run his own business, been an active member of the local rugby community, a keen driver and well-known 'man about town'. He describes himself as having been a heavy social but non-problematic drinker. Following his sight loss, he had a number of years of heavy and problematic drinking, including some covert daily consumption of spirits. He attributes this level of drinking directly to coming to terms with his change in sight and the associated loss of the business, rugby and driving.

- Brandon - 40-45 years, Sudden sight loss following asthma attack; Anoxic Brain Damage including sight loss

At the age of 14 years, Brandon experienced a severe asthma attack that left him with anoxic brain damage, including significant loss of sight. Following this experience he stayed within mainstream schooling, went to university and became a trained psychotherapist. He takes a large amount of prescribed medication for 'a number of illnesses' but never drinks alcohol. At the age of 35 years he began taking illegal drugs for recreational purposes. He accounts for this as catching up with opportunities lost through teenage years and the onset of, and adaption to, sight loss.

- Charlie - 30-35 years, Sudden loss following alcohol-related hospital admission; Malnutrition Amblyopia

Charlie had an alcohol-related emergency hospital admission five years ago which resulted in him waking up with significant sight loss. Since his teenage years he had been a very heavy binge user of illegal drugs and a regular, heavy and excessive drinker. He was diagnosed with malnutrition amblyopia and it was suggested to him that his sight loss occurred through a combination of malnutrition and toxicity resulting from the drink and drug use. While he has more recently been abstinent from alcohol and drug use and has nearly completed his University degree, the preceding five years have seen him experience episodic heavy binge drinking,

which he accounts for as a direct coping mechanism for his emotional issues, including those of the sight loss.

- Chas - 60-65 years, Born with visual impairment and subsequent increased loss, including car accident; Retinal degeneration

Born with extra-large eyeballs and significant myopia, Chas became a successful entrepreneur until a car accident, aged 37, resulted in the total loss of vision in one eye. He has subsequently experienced significant cell deterioration in the right eye. He attributes the rapidity of that deterioration to his lifestyle, including smoking and drinking. He describes himself as being a heavy drinker from an early age, and rapidly becoming a 'functioning alcoholic'. With the exception of one 12 year period of abstinence, this heavy dependent drinking carried on until he was 57. With the reduction of his alcohol use, the cell deterioration has slowed down. Following recent cataract surgery, he regained a lot of vision, to the extent of being able to read although he notes some recent deterioration. Chas sees two relationships between his sight and alcohol and smoking; 1) the deterioration in health (including eye health) and 2) as a coping mechanism to nullify his experiences, including sight loss.

- Connor - 66-70 years, Rapid loss following use of prescribed medication; Optic Neuropathy

Six years ago Connor was prescribed Amioderone as part of treatment for a heart condition. He then began to experience a number of side effects, including complications with his vision. Subsequently both eyes 'went' within a couple of weeks of each other. Sight loss is a rare but known side effect of this prescribed drug. Prior to the sight loss he was a moderate alcohol drinker, and currently he does not drink at all.

- Graham - 50-55 years, Sudden loss; Optic Atrophy

Graham experienced a sudden loss of sight four years ago. He woke up totally blind, followed by a very limited return of vision and is now experiencing a further gradual deterioration. He has been diagnosed as having optic atrophy. Graham spent many previous years experiencing very heavy alcohol and illegal drug use, especially stimulants. It has been suggested to him that his sight loss is a consequence of his drug and alcohol use. He has rapidly established a very active voluntary role within visual impairment services and is currently at college. He does not use illegal drugs currently, but is a social drinker. His social drinking identity and having a guide dog comfortable with pub environments is important to him.

- James - 50-55 years, Sudden Loss; Optic Atrophy from Toxic Amblyopia

James experienced a sudden loss of sight, over a matter of weeks, three years ago. He was diagnosed with optic atrophy caused by toxic amblyopia, with a suggestion that his previous three years of very heavy and daily consumption of whisky had directly contributed to the sight loss. Initially following the sight loss James continued to drink whisky heavily, he ascribes this to coping with a number of life pressures like caring for his elderly mother as well as the experiences of sight loss. He went through a very depressed period and feelings of suicide. He says he wants to live now and has gained more control over his drinking (he refrains from spirits), as well as engaging with both alcohol and sight loss services.

- Jenny - 40-45 years, Sudden loss following overdose of prescribed medication; Diagnosis Unknown.

Jenny developed a problematic heavy binge drinking pattern during her 30's as her response to difficult familial and workplace relationships. Three years ago she took an overdose of her prescribed medication. She awoke in hospital virtually blind. Initially it was suggested she would recover her sight, but she has still lost 90% of her vision. It has been suggested to her that the sight loss is a direct result of the excessive amount of medication taken. Jenny continued to binge drink after her sight loss as a coping mechanism. However, over the last two years she has chosen abstinence and feels her life and family relationships are improving.

- Karen - 36-40 years, Accidental initial loss and subsequent gradual loss; Various Diagnoses

In her early teenage years Karen took up binge drinking and recreational drug use. This led directly to her being involved in a car accident aged 14, resulting in significant visual impairment. Her sight has deteriorated over the years, such that she now has lost the sight in one eye and acquired very limited sight in the other. Following the accident and initial loss, Karen describes herself as moving into a circle of 'broken people' doing a lot of 'numbing' with alcohol and drugs. Karen spent 18 years in a lifestyle of travel, in and out of education and jobs, with lots of drink and illegal drug use. She accounts for her drink and drug use impacting on her ability to take up some services and support. Since the loss of a number of friends who used substances and her young daughter's arrival Karen has made considerable changes in her substance using behaviour.

- Martin - 40-45 years, Sudden loss; Hereditary Eye Condition

Describing himself as an 'alcoholic', Martin describes very heavy alcohol and recreational drug use from his early years leading to relationship and employment

breakdown. Seven years ago he experienced a very dramatic and sudden loss of his sight, and after a three month period of many hospital visits was finally diagnosed with a hereditary eye condition. Martin rapidly engaged in sight loss rehabilitation programmes but continued to drink, if not more heavily, for a number of years following his sight loss. He describes this as a means of coping with his life experiences including the sight loss. He has more recently been abstinent from alcohol and enjoys part-time employment in the health service. He suggests the relationship between his drinking and sight loss is inextricably linked, calling them "two spinning balls, one egging on the other".

- Norman - 20-25 years, Gradual loss over time; Retinitis Pigmentosa

Norman became aware of his visual impairment in his teenage years and it has continued to worsen over time. He has been told that his condition is one he was born with. He indicates that his visual impairment first occurred following an epileptic seizure and has been made worse by subsequent seizures. Norman suggests that his epilepsy and related prescribed medications impact on his visual functioning, including experiences of dizziness and double vision, both of which are known common side-effects of anti-epileptic drugs. Norman was previously a moderate alcohol drinker, he is currently abstinent.

- Penny - 66-70 years, Gradual loss; Macular Degeneration.

Penny's sight loss is a recent medical condition. However, she says it has probably been present for a number of years. She describes the first 30 years of her adult life as one in which she was dependent on alcohol, and took other illegal drugs, in a very chaotic lifestyle. The latter 25 years she has been abstinent. Penny states it is unclear what is causing her sight loss although it is possibly related to a long standing lesion on her brain. Neither she nor the professionals had considered it might be related to her history of excessive alcohol use. There has been no overlap for Penny between her substance use and her visual impairment.

- Seb - 50-55 years, Gradual loss over time; artery and nerve damage

Seb was born with poor eye sight, but learned to adapt and enjoyed many years as a successful tradesman. Aged 40 yrs he experienced some specific deterioration of sight loss in one eye as a consequence of artery damage. While he continued to work this became increasing difficult as employers became hesitant due to perceived health and safety issues. He describes himself as having been a very heavy drinker for most of his adult life. More recently he lost most of the vision in his second eye following post-operative nerve damage. In much of the period since loss of employment and the deterioration of the second eye, he has combined heavy

drinking with periods of very intense cocaine use. Much of this use he attributes to a method of coping with his loss of lifestyle, including employment and sight. He is currently six months abstinent from alcohol but still has occasionally excessive periods of cocaine use. Seb believes that his illegal drug use, and the possibility that it has contributed to his sight loss, has had an impact on his willingness to take up visual impairment services.

- Sid - 30-35 years, Blind from birth

Sid was born without any vision. Although now drinking at more moderate levels, Sid describes the last twelve years as a period in which he has been a daily heavy or dependent drinker. He attributes this to a means of coping with difficult experiences; friendships, relationships, boredom, frustration, of which sight loss was another. He suggests his sight loss prevented him from getting involved in any illegal drug use.

- Stefan - 56-60 years, Gradual loss;"Macular Dystrophy" [Suspect he meant Macular Degeneration - ed]

Stefan has experienced the gradual onset of his visual impairment from the age of 35 yrs. Despite some really good support from his employer he felt increased levels of stress and anxiety resulting from the need to fulfil his work responsibilities and the impact his deteriorating sight loss was having on his ability to do so. Consequently he had a 15 year period of using alcohol and illicit Valium to help him cope and ‘feel better’. He is no longer working nor taking Valium although he continues to drink daily and heavily.

- Tommy - 66-70yrs, Loss over time; Macular Degeneration

Tommy was born with short sight but following complications from cataract surgery 12 years ago, and developing age-related macular degeneration, Tommy currently has no vision in one eye and two percent vision in the other. He describes himself as having coped well with the initial sight loss, although frustrated at the loss of driving, working with machinery and difficulties with cooking. Until two years ago he was a moderate and normative social drinker but is now a heavy and daily consumer of alcohol. He attributes this change in drinking as a means of coping with a range of increasing difficult life experiences; notably his wife’s very poor health as well as the increasing levels of sight loss and frustration. Tommy describes alcohol as ‘medication in a bottle’.

- Wilma - 76-80 years, Born with 1/6th vision and now totally blind

Wilma spent a busy and rewarding life through her employment and her marriage to her husband whom she met as teenager when they were both students at the Royal

National College for the Blind. She lost the sight in one eye through a detached retina when pregnant and the second as a result of cataracts aged 70 years. Her husband died following a terminal illness and Wilma has lived alone, eventually experiencing total sight loss. She remains a current moderate drinker of alcohol. From the age of 40 onwards, she has experienced increasing levels of insomnia, which became acute during the period of total sight loss. She has experienced problems associated with prescribed medication for the sleep loss and in particular a period of sustained Benzodiazepine use.

Appendix 2 - Consent Form

Information sheet and consent form (Adults)

This research is seeking your views on the relationship between alcohol and other drug use and sight loss or visual impairment. We want to hear your views and personal experiences. There are no right or wrong answers.

The research is being conducted by the Universities of Bedfordshire and Lancaster. It is funded by the Thomas Pocklington Trust and Alcohol Research UK.

Before we start we would like to emphasise that:

- You don't have to take part
- You can refuse to answer any question
- You can stop the interview at any time and/or withdraw from it

The interview is expected to last an hour. Anything you tell us will remain confidential. Confidentiality will only be broken if anything you tell us suggests you are at risk of harm from yourself or others or that you have harmed, or were intending to harm, yourself, children or vulnerable adults.

In our research reports we may want to use something you have told us. If we do this we will not use your name or any other identifying information about you. All quotations will be anonymised. The findings of the research may also be used in articles and conference presentations but again no identifying information will be used.

With your permission we would like to record the interview. If not, we will take written notes as you talk. Recordings and any notes taken during the interview will be destroyed once the final report and related outputs are complete. This will be no more than 12 months following the end of the research. Data will be stored securely on password protected computers and encrypted memory sticks. Written data will be stored in locked filing cabinets.

If you wish to withdraw from the interview you are free to do so. All notes and recordings we have collected from you will be destroyed within two working days of your request to withdraw. You will not be able to withdraw once the research has been written up.

If you have any further questions about the research please feel free to contact the research lead for this project, Dr Sarah Galvani on 07884 007222 or sarah.galvani@beds.ac.uk. If you are unhappy with any element of the research

process you are also entitled to contact an independent person at the University of Bedfordshire. The contact is Giannandrea Poesio - Giannandrea.Poesio@beds.ac.uk on 01234 793289 or 09127 3367746.

Please sign this form to show you that you have read, or I have read to you, the contents of this information sheet and consent form and that you agree to take part in the research. Alternatively you can return this form electronically with an email stating you consent to take part.

_____ (signed by participant or by researcher on participant's behalf)

_____(printed)

_____ (date)

Return by email to: Sarah.Galvani@beds.ac.uk Return by hand or by post to: Sarah Galvani, Tilda Goldberg Centre, University of Bedfordshire, Park Square, Luton LU1 3JU

Appendix 3 - Information sheet

The Tilda Goldberg Centre in Social Work and Social Care at the University of Bedfordshire: Sight Loss, Alcohol and other Drugs Research Project.

Further Information and Support Sheet

Sight Loss

- RNIB - supporting blind and partially sighted people – Helpline 0303 123 9999, email helpline@rnib.org.uk and website www.rnib.org.uk
- National Federation of the Blind – supporting the voice of blind people - 01924 291313, www.nfbuk.org
- Blind Veterans UK – life beyond sight loss - 020 7723 5021, www.blindveterans.org.uk
- Thomas Pocklington Trust - Housing and support for people with sight loss - 020 8995 0880, www.pocklington-trust.org.uk

Alcohol and Drugs

The following national organisations provide general information and guidance about alcohol and drugs. Each local community also has a range of organisations that provide alcohol and drug support services to individuals and families; further information on local services is available from these organisations below.

- Alcohol Concern - 0207 566 9800, www.alcoholconcern.org.uk
- Alcohol Focus Scotland - 0141 572 6700, www.alcohol-focus-scotland.org.uk
- Alcohol Concern Wales - 029 2022 6746, www.drinkwisewales.org.uk
- Alcohol Action Ireland - 00353 1 878 0610, http://alcoholireland.ie/
- Alcohol Learning Centre - www.alcohollearningcentre.org.uk
- DrugScope - 0207 234 9730, www.drugscope.org.uk
- Scottish Drugs Forum - 0141 221 1175, www.sdf.org.uk
- Drugs Ireland - 1800 459 459, www.drugs.ie
- Wales Drug and Alcohol Helpline – 0808 808 2234, text 81066, www.dan247.org.uk
- Release – drugs, the law and human rights -www.release.org.uk

Families and Carers

- ADFAM – An agency specialising in support and information for families and carers on alcohol and drug issues - 020 7553 7640, www.adfam.org.uk
- Carers UK – The voice of carers - Advice Line 0808 808 7777, www.carersuk.org

Young People -Specific

- Drinkaware – good information for parents about talking to their children about alcohol, 0207 766 9900, www.drinkaware.co.uk
- FRANK - national telephone help line -0800 776600, www.talktofrank.com
- Daisy (Northern Ireland) – 028 9043 5815 or 028 7137 1162 or text DAISY to 81025 for a call back.
- Child and adolescent mental health services information - www.camh.org.uk

Older People Specific

- Age UK – 0800 169 6565, www.ageuk.org.uk
- Older People and Alcohol – information leaflet http://www.rcpsych.ac.uk/expertadvice/problemsdisorders/alcoholandolderpeople.aspx

Other

- Mental Health Foundation - 08457 90 90 90, www.mentalhealth.org.uk

Appendix 4 - Details of datasets considered

Table 1 - Datasets Containing Variables on Alcohol Misuse and Sight Loss

The table has five columns labelled as follows - name of study, study description, type of alcohol questions asked, type of eyesight questions asked, other comments. It has nine rows to represent nine studies or datasets.

Name of study	Study description	Type of alcohol questions asked	Type of eyesight questions asked	Other comments
1970 British Cohort Study	8170 members of a birth cohort from Great Britain born in 1970. Questions on alcohol only asked in 1999 to 2000 (when aged 30).	• How frequently had alcoholic drink. • Alcohol intake in last 7 days. • 4 items from CAGE.	• If have problems with eyesight (including wearing glasses). • What is wrong with vision (open). • Seen optician in last 12 months.	Questions on eyesight not specific enough to identify those with longstanding visual impairment that limits activities.
English Longitudinal Study of Ageing (ELSA)	People in England aged 50+.	Alcohol consumption in previous week.	• Ever diagnosed with four specific ocular conditions: glaucoma, diabetic eye disease, macular degeneration and cataracts. • Respondents asked to rate overall quality of own eyesight using corrective lenses if appropriate (excellent, very good, fair or poor).	Questions on eyesight not specific enough to identify those with longstanding visual impairment that limits activities.
British Household Panel Survey	5,500 households recruited in 1991, containing a total of approximately 10,000 interviewed individuals.	• Have “alcohol or drug-related problems”. • How many times in last 4 weeks had an alcoholic drink.	Have difficulty in seeing (other than needing glasses to read normal size print).	Questions on eyesight not specific enough to identify those with longstanding visual impairment that limits activities.

Name of study	Study description	Type of alcohol questions asked	Type of eyesight questions asked	Other comments
Understanding Society	A longitudinal UK household study of approximately 50,000 adults	• Age first had alcoholic drink • How often had alcohol drink in last 12 months • How often had alcoholic drink in last 7 days • Maximum number of different types of drinks on heaviest drinking day	Whether have long-standing physical or mental impairment, illness or disability (defined as anything that has troubled them over a period of at least 12 months or that is likely to trouble them over a period of at least 12 months) which causes substantial difficulties with sight (apart from wearing standard glasses).	Questions on alcohol do not provide information on average daily or weekly consumption or other measure of alcohol problems.
Primary Care Trust Patients Survey 2008. This database was selected for analysis.	**Postal survey conducted in every Primary Care Trust in England during January-April 2008 using a random sample of people registered with a GP. 69,470patients responded.**	• **Last 12 months been asked by someone at GP practice about how much alcohol drink.** • **Last 12 months been given advice/help from GP practice on sensible alcohol intake (yes definitely, yes to some extent, no but would have liked help/advice, no but didn't want any help advice, don't drink alcohol).**	**Longstanding condition involving blindness or partially sighted.**	**1485 (2%) of the sample reported that they had a longstanding condition involving blindness or being partially sighted. This provides an excellent opportunity to investigate whether healthcare professionals are less likely to ask people with visual impairment about their alcohol use or offer them advice/help on sensible alcohol intake and the extent to which people with visual impairment want advice/help on sensible alcohol intake. The response rate for the survey was relatively low at 38%. As it was a self-complete postal survey, those with visual impairment may have been less likely to take part.**

Name of study	Study description	Type of alcohol questions asked	Type of eyesight questions asked	Other comments
ONS Omnibus Survey 2007	Monthly, multi-purpose interview survey, circa 1,000 interviews per month.	• Amount of alcohol drunk on heaviest drinking day. • Average weekly consumption.	What prevented from reading more (eye sight or blind)	Questions on eyesight not specific enough to identify those with longstanding visual impairment that limits activities.
Adult Psychiatric Morbidity Survey 2007	Occasional face-to-face and interview cross-sectional study of adults living in private households in England. Achieved a sample of 7,403 in 2007.	• Frequency. • Average daily consumption. • Hazardous and harmful drinking (AUDIT). • Dependent drinking.	• Ever had cataracts or eyesight problems since age 16. • When first had cataracts or eyesight problems since age 16. • Doctor diagnosed cataracts or eyesight problems in last 12 months. • Doctor diagnosed cataracts or eyesight problems in last 12 months.	Questions on eyesight not specific enough to identify those with longstanding visual impairment that limits activities.

Name of study	Study description	Type of alcohol questions asked	Type of eyesight questions asked	Other comments
General Lifestyle Survey 2010. This database was selected for analysis.	Multi-purpose cross-sectional survey that collected information on a range of topics from people living in private households in Great Britain. A sample of 18,637 was achieved.	• Ever drink. • Main reason non-drinker (religious reasons, don't like it, parents advice or influence, health reasons, can't afford it, other). • Perceived amount of alcohol respondent drinks (hardly drink at all, drink a little, drink a moderate amount, drink quite a lot, drink heavily). • Drinking days in last week. • How often drank in last 12 months (almost every day, 5 or 6 days a week, 3 or 4 days a week, once or twice a week, once or twice a month, once every couple of months, once or twice a year, not at all). • How much drink now compared to 5 years ago (more, about the same, less). • Average weekly consumption. • Amount alcohol drunk on heaviest drinking day in previous week.	Longstanding illness, disability or infirmity - cataract/blindness, poor sight. Definition for 'longstanding is "anything that has troubled him/her over a period of time or that is likely to affect him/her over a period of time".	129 (0.7%) respondents report cataract or blindness or poor sight. It is possible to combine the 2010 data with data from 2009 to boost the sample size but changes to alcohol and sight loss questions in 2008 mean that data from earlier studies cannot be used.

Name of study	Study description	Type of alcohol questions asked	Type of eyesight questions asked	Other comments
Health Survey for England 2011	Annual interviewer-administered survey of people living in private households in England. Sample of 10,617 was achieved in 2011.	• Drinking diary. • Frequency. • Average weekly consumption. • Amount alcohol drunk on heaviest drinking day in previous week. • Reasons for drinking.	Longstanding illness cataract or poor eyesight or blindness.	86 (0.8%) of respondents report cataract or poor eyesight or blindness. Can be combined with data from 2008, 2009 and 2010 but not previous years. Drinking diary and reasons for drinking was first introduced in 2011.
Health Survey for England 2000. This database was selected for analysis.	**Annual interviewer-administered survey of people living in private households in England. In year 2000 focused on health of older adults and included a sample of care home residents. Therefore 29% of 12,414 interviewees were aged 75 and over.**	• **Frequency.** • **CAGE questionnaire.** • **Average weekly consumption.** • **Amount alcohol drunk on heaviest drinking day in previous week**	**Sight disability (none, moderate, severe).**	**510 (5%) reported moderate sight disability and 388 (3%) reported severe sight disability. However, only 83 (16%) of those who reported moderate sight disability and 23 (6%) of those who reported severe sight disability were aged less than 65 years. Can't be merged with data from previous years.**

Appendix 5 - Tables to accompany data analysis of existing datasets

Table 2 Comparison of key characteristics of individuals with and without sight problems who were interviewed in the 2009 and 2010 General Lifestyle Survey

			Sight Problem[1]		
Characteristics		Total	Yes	No	p^2
Study group[3]		30169 (100%)	261 (0.9%)	29328 (99%)	-
Gender[4]	Male	14315(47%)	111(0.8%)	13875(99 %)	NS
	Female	15854 (53%)	150 (1%)	15453 (99%)	
Age (years)[5]	16-24	3486 (12%)	7 (0.2%)	3272 (99%)	<0.0001
	25-44	8756 (29%)	14 (0.2%)	8554 (99%)	
	45-64	10324 (34%)	65 (0.6%)	10119 (99%)	
	65+	7603 (25%)	175 (2%)	7383 (98%)	
Ethnic grouping[6]	White	27534 (93%)	253 (0.9%)	27259 (99%)	0.01
	Non-white	2049 (7%)	8 (0.4%)	2033 (99%)	
Socioeconomic group[7]	Managerial & professional Intermediate occupations Routine and manual	12561 (44%) 5296(19%) 10689 (37%)	102 (0.8%) 47(0.9%) 97 (0.9%)	12247 (99%) 5167 (99%) 10421 (99%)	NS

[1] Sight problem is cataract, blindness or poor sight which has troubled respondent over a period of time or that is likely to affect them over a period of time
[2] χ^2test: NS, non-significant at the *P*= 0.05 level.
[3] 580 not known
[4] 580 not known
[5] 580 not known
[6] 616 not known
[7] 2088 not known

Table 3 Univariate and multivariate analysis of drinking behaviours in people with and without sight problems who were interviewed in 2009 and 2010 General Lifestyle Survey

		Sight Problem[8]		Odds Ratio (95% CI)	
Drinking behaviour		Yes	No	Univariate	Multivariate[9]
Abstain from alcohol	Yes No	33% 67%	20% 80%	**1.97 (1.50-2.58)** 1.00 (Baseline)	**1.49 (1.13-1.96)** 1.00 (Baseline)
Exceeds weekly recommended drink limits	Yes No	14% 86%	25% 75%	**0.47 (0.31-0.72)** 1.00 (Baseline)	**0.56 (0.36-0.85)** 1.00 (Baseline)
Drinking every day of week	Yes No	23% 77%	14% 86%	**1.84 (1.20-2.84)** 1.00 (Baseline)	0.84 (0.53-1.30) 1.00 (Baseline)
Had a binge in last 7 days[10]	Yes No	8% 92%	24% 76%	**0.26 (0.13-0.52)** 1.00 (Baseline)	0.57 (0.28-1.16) 1.00 (Baseline)

[8] Sight problem is cataract, blindness or poor sight which has troubled respondent over a period of time or that is likely to affect them over a period of time.

[9] Results of four separate multivariate models, each adjusted for gender and age. Bold text indicates significant at the $p = 0.05$ level.

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

Table 4 Comparison of key characteristics of individuals with and without sight disability who were interviewed in the 2000 Health Survey for England

			Sight Disability[11]		
Characteristics		Total	Yes	No	*p*[12]
Study group[13]		10,251 (100%)	894 (9%)	9350 (91%)	-
Gender[14]	Male	4135 (40%)	217 (5%)	3916 (95%)	<0.0001
	Female	6116 (60%)	677 (11%)	5434 (89%)	
Age (years)[15]	16-24	625 (6%)	10 (2%)	615 (98%)	<0.0001
	25-34	1438 (14%)	19 (1%)	1416 (99%)	
	35-44	1590 (16%)	14 (1%)	1576 (99%)	
	45-54	1313 (13%)	26 (2%)	1287 (98%)	
	55-64	1115 (11%)	35 (3%)	1079 (97%)	
	65-74	1168 (11%)	75 (6%)	1091 (94%)	
	75+	3002 (29%)	715 (24%)	2286 (76%)	
Ethnic grouping[16]	White	8385 (82%)	412 (5%)	7969 (95%)	NS
	Non-white	554 (5%)	18 (3%)	536 (97%)	
Household Income[17]	≤ £7,186 £7,187 - £10,834 £10,835-£17,890 £17,891-£27,705 >£27,705	855 (8%) 1089 (11%) 1450 (14%) 1438 (14%) 1741 (17%)	41 (5%) 56 (5%) 46 (3%) 17 (1%) 19 (1%)	814 (95%) 1030 (95%) 1403 (97%) 1421 (99%) 1722 (99%)	<0.0001

[11] Interviewer recorded whether participant has a "disability" (none, moderate or severe)
[12] χ^2 test: NS, non-significant at the *P*= 0.05 level.
[13] 7 not known
[14] 7 not known
[15] 7 not known
[16] 1316 not known
[17] 3682 not known

Table 5 Univariate and multivariate analysis of drinking behaviours in people with and without sight disability who were interviewed in 2000 Health Survey for England

		Sight Disability[18]		Odds Ratio (95% CI)	
Drinking behaviour		Yes	No	Univariate	Multivariate[19]
Abstain from alcohol	Yes No	53% 47%	23% 77%	**3.84 (3.34-4.42)** 1.00 (Baseline)	**1.57 (1.35-1.84)** 1.00 (Baseline)
Exceeds weekly recommended drink limits	Yes No	8% 92%	20% 80%	**0.35 (0.25-0.49)** 1.00 (Baseline)	0.7 (0.49-1.02) 1.00 (Baseline)
Felt need to cut down drinking	Yes No	24% 76%	21% 80%	1.22 (0.72-2.09) 1.00 (Baseline)	1.33 (0.78-2.28) 1.00 (Baseline)
Been drunk in last 3 months	Yes No	28% 72%	38% 62%	0.63 (0.34-1.10) 1.00 (Baseline)	0.73 (0.39-1.36) 1.00 (Baseline)

Table 6 Univariate and multivariate analysis of alcohol interventions with people with and without sight problems who were interviewed in 2008 Primary Care Trust Patient Survey

		Sight Problem[20]		Odds Ratio (95% CI)	
Intervention		Yes	No	Univariate	Multivariate[21]
Asked about alcohol by someone at GP practice in last 12 months	Yes No	32% 68%	29% 71%	1.12 (1.00-1.26) 1.00 (Baseline)	1.08 (0.96-1.21) 1.00 (Baseline)
Given advice/help about alcohol by someone at GP practice in last 12 months	Yes No	29% 71%	19% 82%	**1.82 (1.57-2.12)** 1.00 (Baseline)	**1.61 (1.38-1.88)** 1.00 (Baseline)
Didn't receive advice but would have liked it	Yes No	10% 90%	6% 94%	**1.68 (1.29-2.20)** 1.00 (Baseline)	**1.89 (1.44-2.48)** 1.00 (Baseline)

[18] Interviewer recorded whether participant has a "disability" (none, moderate or severe)
[19] Results of four separate multivariate models, each adjusted for gender and age. Bold text indicates significant at the $p = 0.05$ level.
[20] Sight problem is a "longstanding condition involving blindness or being partially sighted".
[21] Results of two separate multivariate models, each adjusted for gender and age. Bold text indicates significant at the $p = 0.05$ level.

Appendix 6 - Literature Review Methodology

The following appendix details the four phases of the literature review.

Phase 1

Three primary sources underpinned the search:

1. Ebscohost - this is an academic search facility that allows searching across bibliographic databases, hundreds of thousands of journals as well as e-books. To make the search manageable our search included the following four key databases: CINHAL, Medline, PsychInfo and Sage.
2. Social Care Online - this is one of the UK's largest databases for information and research for social work and social care
3. Journal specific searches.

In total 31 searches were conducted with date parameters set between 1990 and 2013.

Twenty five of the searches of Ebscohost and Social Care Online used combinations of the following search terms: Alcohol*, Addict, Drug*, Medication, Medicine, Substance, Blind*, Coping, Glaucoma, Macular Degeneration, Pigmentosa, Sight Loss or Visual Impair*. The use of an asterisk allows the database to use the identified expression as a stem and search all words containing this stem, i.e. alcohol* would also locate articles using terms such as alcoholic, alcoholism.

The remaining six searches were made in three specific journals: Alcohol and Alcoholism, Addiction, and Eye. These were chosen, following the initial searching, as the journals most likely to include relevant articles to the study. Alcohol journals were searched with terms of sight loss and visual impair* and the Eye journal was searched with the terms alcohol* and drugs*. This identified only a small amount of additional abstracts, thus providing some confirmation of the appropriateness and accuracy of the other 25 searches and search terms used.

In total, 670 pieces of literature were generated across the 31 searches breaking down as follows: Ebscohost, n=551; Social Care On-Line, n=66; Journal specific searches, n=53).

Phase 2

All abstracts were then initially screened for their relevance, with the following exclusion or screening codes applied:

Table 7: Exclusion and inclusion criteria

Code	Criteria
A	No reference to sight loss or visual impairment
B	No reference to problematic alcohol or drug use
C	No reference to either or both included but not used in any related matter.
Q	This was used to retain literature that was not directly related to the criteria above but offered some other potentially relevant interest.

This initial coding included double coding by the research team to ensure consistency of application of the coding frame. The few differences that emerged were discussed and rejected or accepted as a result or coded Q where full text reading would allow a clearer decision to be made.

The results of the first screening can be found in table 8 below. The table has eight columns including the name of the database, the number of hits, the number of duplicates, four columns representing exclusion or inclusion codes A, B, C, Q, and a final column that reports the number of articles that were retained following screening.

Table 8: Results of first screening by database

Name of the Database	Total no. of hits	No. of duplicates	Exclusion/inclusion criteria				Retained
			A	B	C	Q - temporary exclusion	
Ebsco	551	19	126	120	142	19	**125**
Social Care On-Line	66	1	7	13	29	15	**1**
Journal Specific	53	4	5	18	2	3	**21**
Totals	670	24	138	151	173	37	**147**

As can be seen from the table, the exclusions were spread relatively equally across exclusion criteria A,B, and C.

Many of the exclusions under code A were accounted for by the use of terms like ‘lose sight of’, ‘blind spot’, impairment and visual, as grammatical expressions or in other contexts rather than any specific reference to the issues of sight loss or visual impairment. Additionally a number of articles referred to alcohol, but as a substance used in eye related operations or as a surgical cleaning agent. Some of the exclusions under A were also visual performance related and in particular associated with issues of ability to drive or impaired driving skills under the

influence. Finally, many of those excluded here were associated with the sight of alcohol acting as a cue or trigger to alcohol use and were not connected with sight loss.

Many of the abstracts excluded under B made no reference to social or problematic drug use and instead referred to drugs for the treatment of sight loss. Also excluded in this group were a number of studies examining the impact on visual performance following consumption of alcohol or mild intoxication; some of these studies explicitly used tasks that required sight. A smaller number of studies of this type were retained especially where the test was on those with established drink or drug problems.

Those excluded under the C criteria either had no reference to sight loss or visual impairment and alcohol or drug use or they contained a reference to both but were not explored in any related matter. There was also a group of exclusions made for experiments involving metals and animals, with only a smaller specific number of animal studies retained.

This left a retained number of 147 abstracts for secondary full abstract reading plus the 37 category Q's which were set aside for further consideration later in the review process. These were initially divided into the following seven categories for further analysis:

- Prevalence data - this category comprised predominantly epidemiological data.
- Cause (Medical) - this category included articles suggesting a direct correlation between sight loss and alcohol or other drug use.
- Cognitive Functioning–Visual Memory - these studies primarily conducted experiments with drinkers and drug users and a range of cognitive functions.
- Consequence (Short term-cause) - this category included studies showing sight loss through intoxication. This could be temporary and extended but not permanent loss.
- Consequence (Long Term) - studies identifying physical, psychological and social consequences of long term substance use on sight loss.
- Core studies - these clearly exploredsight loss and substance use in a combined and integrated manner across physical, psychological and social considerations.
- Foetal Alcohol Syndrome/FASD - this group contained specific literature linking childhood or adult sight loss with parental, neonatal use of drink and drugs.

Phase 3

The second, in-depth reading of the abstracts was split between the research team by category. On closer reading a further 90 were excluded from the 147 as follows:

- No sight loss focus - exclusion criteria A; n=62.

  This included 33 abstracts focussing on visual memory/cognitive functioning.

- No substance use focus - exclusion criteria B; n=13
- No sight loss and no substance use - exclusion criteria C; n=14

An additional criteria had to be added at this stage:

- Exclusion criteria D – both sight loss and substance included in the abstract but not related to each other; n=1

With these exclusions 57 abstracts remained.

Phase 4

This phase involved accessing, or attempting to access, full texts for the 57 abstracts. A further eight were excluded at this stage for reasons of relevance or because the full article was not available in the English language. This left 49 articles.

A data extraction template was applied to all the articles. The data extraction process rapidly identified that the initial seven thematic groupings were unsustainable, as many of our initial themes were found within each article. They were subsequently reduced to four categories for the purposes of the narrative below. A summary of the key texts identified are provided in the data extraction format in appendix 7.

At this stage, 11 of the 37 category Q articles were also accessed for information and evidence relating to smoking, labelling on prescribed medication, and wider issues around sight loss and coping.

Appendix 7 - Total data extraction summary

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Ajani et al.	1999	USA	To examine the relationship between alcohol intake and AMD	Randomized trial of aspirin and beta-carotene among 22,071 U.S. male physicians age 40 to 84 years at entry. Proportional hazards models were used to estimate relative risks (RR) and 95% confidence interval (CI). Follow up data gathered over 12 year period.	These prospective data from the PHS suggest that there is no appreciable association between reported alcohol use and subsequent risk of age-related macular degeneration during 12 years of follow-up.	Research - Due to wide confidence intervals possible negative or positive effect that needs further exploration in relation to diff levels of drinking.
Anyfantakis et al.	2012	Greece	N/A	Case study of 23 year old man presenting with sudden sight loss who was regular alcohol user.	Initial diagnosis of methanol poisoning confirmed by gas chromatographic determination. Speedy treatment led to discharge after four days and normal visual acuity at one month follow up.	Practice –the necessity for physicians tobe alert for entities provoked by rare environmental factors at assessment/ diagnosis
Bhatnagar and Sullivan	2008	UK	N/A	Case study [included in letter to Editors of *Eye*] of 68 yr old man presented with number of visual impairment problems	Regular drinker of 30 years and smoked a pipe. Stopped drinking and smoking and with vitamin supplements, showed a tremendous improvement in visual acuity and increased peripapillary RNFL thickness.	Practice -In patients with Tobacco–alcohol amblyopia , RNFL thickness measured by OCT may be useful to predict the visual prognosis.

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Bruce et al.	2009		Litt Review	Review of neuro-ophthalmic literature on Foetal Alcohol Syndrome (FAS)	A wide variety of ocular and neuro-ophthalmic conditions occur in FAS and result in lifelong visual impairment	Practice Timely ophthalmic referral and early intervention for treatable ophthalmic conditions – can improve long-term functioning
Cavallini et al.	2009	Italy	Multiple case studies descriptions of bottle cork and cap injuries to the eye in order to report the VI and clinical outcomes	Retrospective review of database of Opthalmology Institute of Modena 1999-2007. All cases caused by sparkling wine.	11% of eye injuries admitted to dept during the study period. Correlation with areas of large-scale wine production and sale of sparkling wine. Higher incidences over holiday [festive] period and bottling. Can cause very serious visual impairment.	
Coffman et al.	2012	Mexico	Testing whether FASD adolescents had poorer visual responses Testing visual response and identification to visual stimuli	Experiment (RCT) of 41 teenagers – use of recording rain responses (MEG)	Some detail in Litt search of other studies FASD patients' visual systems are impaired in general, this impairment is more pronounced in the periphery vision. *Very technical paper*	Part of new wave of brain scan research Notes less research done on older children/adults with FASD. More claims for screening.
Colzato et al.	2004	Nether-lands	Investigating 'whether suppressing chloingergic activity through moderate alcohol consumption in affects behavioural measure of feature binding in visual perception	Subjects were 17 right handed 'social drinkers'	Exclude? Short term moderate alcohol use – no mention of longer term VI or participation of people with VI.	

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Csiernik and Brideau	2013	Canada	Lit review	Between 1990-2011 40 peer reviewed journals on disability/addiction. Specific focus is on brain/spinal cord injury, sensory and mobility impairments based on the disciplines that had taken a 'leadership role' in investigating the intersection.	Range of description of findings – across both research and practice implications – that generally account for complex and diverse interactions, not necessarily met or supported by existing provision	Research - significant gaps' remain in research and treatment continuum where the two intersect Practice – assessment and training
Cumming and Mitchell	1997	Australia	Specific report from within a bigger whole population study	Blue Mountain Eye Study – long term population study To investigate the associations between alcohol consumption, tobacco smoking, and cataract.	Existing of U shape curve for alcohol and some protective considerations at moderate consumption and harm with heavy consumption Reinforces smoking as a greater risk factor/statistically significant than alcohol	

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Davies et al.	2012	UK	N/A	A case series of seven patients presenting to four hospitals with visual impairment and maculopathy associated with inhalation of poppers.	All patients experienced visual symptoms associated with poppers use. The majority had impaired visual acuity, central scotomata, distortion, or phosphenes May be dose related effects or cumulative toxicity as two longer term cases showed no signs of improvement *isopropyl nitrite has largely replaced isobutyl nitrite in poppers since the change in legislation. Cases 1 and 2 were 'long-term' users who only developed symptoms after this change.*	Practice – need for VI workers to ask about recreational drug use Policy - there may be a role for change in legislation to prohibit supply of isopropyl nitrite to the general public. Public Health - messages
Durant et al.	2006	UK	To investigate risk factors for two human lens cataract subtypes: waterclefts and retrodots.	Two nested case–control studies: Detailed ophthalmic and potential risk factor data were collected,	Univariate analysis identified alcohol as risk factor for both but with multi-variate analysis higher number of alcohol units consumed per month remained significant in terms of a protective factor for retrodots! However authors report few heavy drinkers in their sample.	

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Eilliot et al.	2008	Australia	Prospective National Survey	General epidemiology of FASD over 3 year period as reported by Paediatricians Exposure to alcohol and drugs	4.3% had visual impairment VI as one amongst a number of complexities	
Esposito et al.	2010	Italy	To assess if acute alcohol administration changed the baseline neural activity as measured by RS-fMRI.	Eight healthy volunteer subjects (5 males and 3 females, age 28± 3.2) participated in two fMRI sessions on two separate days. Scanning took place on day 1 following alcohol consumption and day 2 without any alcohol – results compared.	Findings demonstrate that alcohol increases spontaneous BOLD signal fluctuations in the visual network and this phenomenon suggests that alcohol abnormally promotes the “idle” state of the visual function in the resting human brain. The visual cortex, and preferentially the perceptual occipital regions, may thus be considered a primary target of alcohol-induced inhibition of neural processing.	Research –use of scanning.
Fan et al.	2012	America	To examine whether alcohol drinking status and drinking pattern are associated with self-reported visual impairment.	Secondary Analysis of existing data set from general state health and lifestyle survey. Self-reporting on vision functioning and alcohol consumption. Quantitative study.	Explores literature suggesting moderate drinking as protective and heavy drinking .Among current drinkers, drinking patterns were significantly associated with near and distance vision impairment.	Research – need for longitudinal studies. Research - need to focus on chronic and not just acute relationship between alcohol and visual impairment.

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Firth	2005	UK	Links between Class A drug abuse and *ocular sequlae*.	Literature Review	Cocaine/crack cocaine – highest number of reported ocular problems including visual loss (can be transient). Heroin withdrawal can lead to *estropia* (squint/lazy eye), rapid detox to *diplopia* (double vision). Also 'sight-threatening conditions' i.e. toxic amblyopia from quinine as cutting agent. LSD – 'sun-gazing' can lead to solar retinopathy, perceptual changes more significant problem. MDMA – visual perception disorder.	Practice – need for VI professionals to be alert to and ask about drug use.
Flanigan et al.	2008	Chile	To determine whether children who do not develop fetal alcohol syndrome (FAS) despite heavy alcohol exposure are at risk for eye abnormalities	Quasi-experimental, with 98 children followed up to 11 years, and using a range of examinations by ophthalmologist.	Ophthalmologic abnormalities are an important finding in FAS. That development of VI confined to FAS and not others exposed to heavy neo-natal alcohol use offers a big list of limitations to work. Ophthalmologic examinations are not likely to help diagnose FASD, but they may be important in the assessment/ evaluation of a child who has FAS	Practice -Eye examinations are unlikely to clarify the diagnosis in children suspected of having alcohol-related damage. Research -Value of actual eye examinations in research

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Hamilton et al.	2010		Investigate VI in children exposed to opiates (methadone) and other drugs during pregnancy	Descriptive case studies -20	Range of ophthalmic abnormalities identified in majority of cases	
Heffelfinger, et al.	2002		Test visual attention in pre-school children (14-60 months) exposed to cocaine in pregnancy	Experiment (RCT)	FAS did show slower reaction times	
Kanthan et al.	2010	Australia	To assess whether alcohol consumption is associated with the long-term incidence of cataract or cataract surgery.	Specific report from - Blue Mountain Eye Study – long term population study Statistical analysis	A U-shaped association of alcohol consumption with the long-term risk of cataract surgery was found in this older cohort: moderate consumption was associated with 50% lower cataract surgery incidence, compared either to abstinence or heavy alcohol consumption.	Research – population even for 'heavy' drinkers does not compare to those of addiction or treatment seeking populations.
Kee and Hwang	2007	Korea	N/A	Case study – 45 year old man with tobacco-alcohol amblyopia.	During the acute phase of visual loss in a patient with tobacco-alcohol amblyopia, visual loss may precede optic disc changes as detected by fundoscopic examinations or by OCT.	
Knudtson et al.	2007	US	To investigate alcohol consumption as a risk factor for the 15-year cumulative incidence and progression of age-related macular degeneration	Specific report form larger whole population study - Beaver Dam Study. Utilises - Questionnaires and eye examinations	There were no consistent associations with the amount of beer, wine, or liquor consumption and the incidence or progression of AMD. Alcohol consumption is unlikely to strongly increase (or decrease) the risk of AMD .	Research – value of using both questions and examinations Research – where are the studies on younger people?

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Klein et al.	1999	US	To examine the relationships of cigarette smoking, alcohol, and caffeine intakes to incidence of age-related cataracts five years later	Specific report form larger whole population study - Beaver Dam Study. Statistical analysis of the project data – a 5 year incidence follow up	Cigarette smoking and alcohol consumption were associated with modestly increased risks of incident nuclear cataract over a five-year interval.	
Koch et al.	2002	USA	Identify potential effect of, barriers to providing effective services and strategies for improving services for those with coexisting VI and alcohol and other drug abuse	Literature review	Reports on a range of findings in respect of prevalence, barriers to services, service provision and recommendations for improvements to services	Need for greater knowledge and understanding of lived experience. Practice -Need for greater cross-training and professional dialogue. Suggests 'local heroes'
McCann et al.	2012	UK	To compare issues relating to medication self-management between older people with and without VI	Case control study. 156 VI patients (65+). 2 q'aires to 'assess medical adherence' and question re 'medical self-management, beliefs and support'. Random 10% sample – prescribing data collected from GP/ dispensing pharmacists to verify self-reported adherence.	Similar levels of medication adherence. Almost 30% of older people with VI need help in managing their medication. (13% non VI). 97% had difficulty reading labels (despite optical aids). 24% had difficulty distinguishing medication. More than twice as likely as non-VI to receive help from friends/ statutory services.	Practice - Importance of appropriate support to take medication as prescribed. Policy/Practice - pharmaceutical packing – lack of standardisation, need for user-involvement

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
McGlone et al.	2013		Test flash visual evoked potentials (VEPs) in neonates exposed to methadone in utero	Large prospective cohort study –with quasi-experiment (control group) n =150	Positive affect for FASD	Practice - infants may warrant early clinical visual assessment
Medina et al.	2003			Experimental (animal based – ferrets)	alcohol exposure during a brief period of development impairs ocular dominance plasticity at a later age	
Moore and Li	1994	USA	Report patterns of alcohol use and consequences of amongst disabled adults.	Self-reporting questionnaire (SARDI project see Koch et al.). Mentions those unable to complete written questionnaire (i.e. because of VI) could complete via a collect phone number.	57.5% alcohol use amongst VI group – authors suggest this 'high' level compared with other groups is 'surprising' given previous research suggesting trauma-related or mental illness report heavier patterns of use. Highlights higher levels of medication use and potential for adverse reactions between disability related health care and alcohol use.	Rehab counsellors need greater training/awareness of substance issues.

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Moore and Polsgrove	1991	USA			Limited attention on developmental disabilities and on adolescent and young people. Suggest an 8% chemical dependency prevalence 'may be conservative'. Access can be easier in residential settings but these settings can influence drug use in ways that cannot be generalised. Shared risk factors for disabled people (across impairment groups) Hypothesis – path to misuse may be 'reciprocally reinforcing and spiral in nature' i.e. impact of discrimination, low self-esteem, isolation etc.	
Moss et al.	1998	US	Evaluated alcohol consumption as a risk factor for incidence of age-related maculopathy at 5 years	Specific report form larger whole population study - Beaver Dam Study.	No significant correlation Except for an association of beer drinking with retinal drusen in men,	

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Mukamal.	2007	US	To estimate the prevalence of problem drinking and related risk behaviours among adults with diabetes and eye disease in the United States.	Secondary analysis of specific data set within a large population-based, cross-sectional telephone survey.	Binge drinking exists amongst 5% of those with diabetes and eye disease (lower than general population but significant numbers). Also prepared to engage in risky behaviour (drink driving and gun ownership). Drinking may contribute to cardio-vascular issues/death – a concern amongst diabetes	Public Health – prevention messages Practice – screening and assessment/awareness Research -accuracy of self-reporting and assessment (and definitions of binge drinking)
Nabarro	1991		Examination of diabetes		Alcohol as an aetiological factor in diabetes. Alcohol use leads to diagnosis of diabetes being made. Prevalence of sight loss and blindness amongst diabetes group	Practice -alcohol complicates the treatment for diabetes. Collective/combined risk factors
Noche and Bella	2010	Came-roon	To determine the causes of blindness and visual impairment in students attending schools for the blind and to estimate their frequencies.	This study examined 56 students at three schools for the blind. Demographic data and eye examinations. Statistical analysis..	Alcohol accounted for blindness/visual impairment in 1.8% of sample.	Practice -Need access to better quality specialist ocular care. Local authorities should create more centres specialised in the rehabilitation of the visually handicapped.

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Papia et al.	2010			Experiment Primates		
Parver et al.	1993	USA		1985-1991 National Eye Trauma System Registry collated data on 2,939 case of penetrating eye injury from 48 eye trauma centres.	77% injuries unintentional, 22% assault, 1 self-inflicted. 'There was evidence of definite or possible alcohol use by at least 24% of the injured persons and illicit drug use by 8%'. 90% of eye injuries believed to be preventable	Public Health – prevention messages
Pinquart and Pfeiffer	2010	Germany	To establish differences between VI and non VI drinking, whether this varied by age and whether lower peer integration explains these differences.	Self-reported alcohol use – comparable sample VI and non –VI school children	Adolescents with VI less likely to consume alcohol, less likely to have episodes of drunkenness and binge drinking, experience first episode of drunkenness later. Provides explanations based on less time with peers and more time alone; may have fewer opportunities to buy alcohol and additional support provided by schools. Speculate that VI 'sensitizes individuals to health risks and may promote positive health behaviours'.	Practice - balancing social integration (which is likely to increase alcohol use) and health hazard. Importance of highlighting socialisation strategies/techniques that don't involve alcohol.
Pinazo-Duran et al.	1993		Test changes to optic nerve with alcohol consumption	Experimental (animal based –rats) Physical examination (dissection) of optic nerves	Alcohol exposure damages optic nerve	

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Ploubidis et al.	2013	Keyna	To examine the extent to which the association between socioeconomic position (SEP) and later life prevalence of hypertension, diabetes and visual impairment is mediated by health-related behaviour.	Survey (nurse led) using both interviews and medical tests Statistical analysis (modelling)	Alcohol and smoking less of a contributed factor in health outcomes (VI) -in (African) low-income countries (crude alcohol measures)	Research – not just asking about VI but testing Policy - Alcohol/VI in part a consequence over developed wealth?
Razeghinejad, and Katz	2011	USA and Iran	Interactions of non-steroidal medication and glaucoma and treatment	Lit review	There are numerous reports of drug-induced glaucoma which is an issue that is preventable in many cases.	Practice -. Prompt recognition and appropriate treatment may help protect the vision of these susceptible patients
Sanchez-Tello et al.	2008	Spain	To analyze the effect of long-term alcohol use on oxidative stress parameters of the retina, and its correlation to retinal function, as well as to the expression of the antiapoptotic protein Bcl-2. Also the protective effect of ebselen, a synthetic selenoorganic antioxidant.	Experimental (animal based –rats)	Ethanol has a toxic effect on rat retina associated with oxidative stress. Decreases in retina glutathione concentration and increases in malondialdehyde content in whole eye homogenate significantly correlate with ERG b-wave decrease and Bcl-2 overexpression. We also show how ebselen is able to prevent all the alterations observed.	Research -Authors propose an 'alcoholic retinopathy' in rat species.

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Shinya et al.	2003	Japan	N/A	Two case studies of lacquer thinner vapour sniffing in young men – “addicted” to thinner sniffing for “many years”	Started with slight visual disturbance and progressed to loss of vision after several more days of sniffing. Had steroid injections and vitamin B and recovered to some extent “but still had severe impairment of visual acuity”. Toluene is usually the main component of thinner however gas analysis found methanol to be main component and conclude methanol inhalation not toluene is responsible.	
Shwe-Tin et al.	2007	UK	N/A	Case report –of perfringens endophthalmitis progressing to panophthalmitis in IV drug user – 28 yr old male.	Treated for endogenous endophthalmitis, absconded, returned day 3 with panophthalmitis. Source of infection thought to be contaminated needle or the access sites for iv injection.	Practice - the importance of considering C. perfringens as a cause of endophthalmitis in an IVDA.
Smith and Mitchell	1996	Australia	To assess associations between alcohol intake and age-related maculopathy.	Specific report form larger Blue Mountain Eye Study – long term population study	These findings provide little evidence that alcohol is causally associated with age-related maculopathy	

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Sivilotti et al.	2001	USA	N/A	Case report -Adult male 'central blindness' after ingesting methanol	Complete recovery from VI following treatment (14 days, usually recovered after 6 days of treatment). Ocular toxicity following methanol ingestion 'well characterised'. Prompt treatment 'may resolve' signs and symptoms. Untreated can result in 'more ominous signs of blindness, absent pupillary response to light, and ultimately, permanent optic nerve atrophy'	
Steel et al.	1993	UK	N/A	Case report -27 year old man admitted to casualty Heavy drinker with past drug abuse diagnoses with acute pancreatitis. Complained he was 'completely blind' but some sight	Likely explanation was pancreatitis, vision minimally improved when seen in outpatients 1 month later. Discussion of cases of post-traumatic visual loss. Association between retinopathy and acute pancreatitis – aetiology remains 'uncertain'. 'The visual outcome depends on a number of factors including the pre-existing state of the retinal vasculature, the location of cotton wool spots and the duration and severity of vascular compromise'	

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Syed and Lioutas	2013	USA	N/A	Case study: 61 year old male with history of "altered mental state" (possible Wernicke-Korsakoff's) and vision loss in context of severe alcohol and tobacco use and poor nutrition.	Loss of central vision in left eye, blurring of vision in right eye and got worse by time of presentation. Discharged to rehab facility after 30 days after "a steady reversal of his symptoms in the setting of abstinence and nutritional supplementation". 3 month follow up stopped drinking but still smoking. Atypical presentation which reinforces need for biomarkers for this disease.	Practice - Nutritional fortification has made these cases rare Condition can be difficult to diagnosis due to lack of biomarkers and rare occurrence. Additionally, due to decreased incidence, which makes it less likely to be encountered on a regular basis, increased awareness among younger physicians in training is important, as early diagnosis and treatment is a good prognostic indicator.
Watson and Ingram	1998					
Wang et al.	2012	China	To determine the prevalence and incidence of ocular trauma and proportion of trauma-related visual impairment in the population.	Specific report from p Population based Eye Study interviews and eye examinations Statistical analysis.	Ocular trauma (eye injury) leads to a range of VT conditions. Positive association between alcohol consumption and ocular trauma. Alcohol as a significant risk factor for eye injuries (so drinking present prior to injury).	Research – use of both interviews and eye examinations

Author/s	Year	Country of origin	Aims/study focus	Study design and methods	Key findings	Implications for policy and/or practice and/or research
Weintraub et al.	1998		Neonatal withdrawal syndrome and behavioural effects produced by maternal drug use		General set of behavioural effects, includes some reference to VI Neonatal withdrawal syndrome and behavioral effects produced by maternal drug use	
Venza et al.	2011	Italy	To investigate the single and joint effects of smoking and alcohol on oxidative stress in AMD.	Range of tests measured in a total of 416 patients with early or late ARMD and controls (n=262).	The combination of alcohol and smoking appears to be an aggravating factor that contributes to serious oxidative imbalance and DNA damage in ARMD	
Zoccolella et al.	2010	Italy	N/A	Case report: 63 year old male with a 40 yr history of alcohol abuse who developed visual impairment, hearing loss and memory dysfunction – suggestive of Susac's syndrome.	It remains unclear if chronic alcohol abuse combined with the mitochondrial genetic background prompted an aged-related neurodegeneration or deferred the onset of the Leber hereditary optic neuropathy (LHON) disease.	

Appendix 8 - Individual clinical case studies from the literature search

1. A 23 year old man in Crete presenting with sudden slight loss and who was a “regular alcohol user” (Anyfantakis et al. 2012).
2. A 68 year old man in the UK who smoked a pipe and had been a “regular” drinker for 38 years with several visual impairment problems (tobacco-alcohol amblyopia) (Bhatnagar and Sullivan 2008).
3. A 45 year old man in Korea who smoked and drank high strength Korean gin for over 30 years with “a gradual decrease in vision” over four years (tobacco-alcohol amblyopia) (Kee and Hwang 2008).
4. A 61 year old man in the USA who was experiencing vision loss and who had “severe alcohol and tobacco use and poor nutrition” (Syed and Lioutas 2013).
5. A 63 year old male in Italy with a 40 year history of problematic alcohol use who developed visual impairment as well as hearing loss and memory problems (Zoccolella et al. 2010).
6. Seven people aged between 32 and 53 yrs (two women, five men) presenting to four UK hospitals with visual impairment and maculopathy related to popper inhalation (Davies, C. et al. 2012).
7. Two Japanese men aged 21 and 23 who had been sniffing vapours of lacquer thinner for “many years” and whose initial slight visual disturbance had escalated to vision loss (Shinya et al. 2003 – abstract only available – Japanese article).
8. A 28 year old male intravenous drug user in the UK presenting with C perfringensendophthalmitis progressing to panophthalmitis (Shwe-Tin et al. 2007).
9. A 29 year old man in the UK, a heavy drinker with a history of past drug use diagnosed with acute pancreatitis and reporting he was [newly] ‘completely blind’. This study considered an association between retinopathy and acute pancreatitis although the aetiology remains ‘uncertain’ (Steel et al. 1993).
10. A 42 year old North American man who presented with ‘progressive dyspnea and central blindness’ which was found to be the result of ingesting methanol (after a prolonged period of abstinence) (Sivilotti et al. 2001).

Appendix 9 - Project information disseminated at the start of the project

- Version 1 - For organisations

The Tilda Goldberg Centre in Social Work and Social Care at the University of Bedfordshire invite you to particpate in the research project below.

Sight Loss, Alcohol and other Drugs

We would like to hear from any practitioner or organisation that may have experience of working with sight loss and alcohol or other drugs. This could be current or previous experience. We would also like to hear from family members, friends, befrienders, helpers of people living with both issues. All information provided would be held in strictest confidence.

The research is exploring the relationships between sight loss or visual impairment and alcohol or other drug use (including prescription drugs). We want to understand more about the experiences of people living with both issues and also of those working or living with them. For example, we want to find out how both sight loss and alcohol or other drug services support people with both issues, what the challenges are and how they have been overcome? We hope the findings of the project will improve support for those living, and working, with sight loss and who use alcohol and other drugs.

We would also appreciate any support you could give us to access people living with both issues, or those involved in their care and support (e.g. paid-unpaid carers, family members). Please feel free to pass this information on to others you know who may be interested.

If you think you can help us please contact Wulf or Sarah:

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This research project is jointly funded by Thomas Pocklington Trust (www.pocklington-trust.org.uk/) and Alcohol Research UK (www.alcoholresearchuk.org/).

- Version 2 - For individuals

The Tilda Goldberg Centre in Social Work and Social Care at the University of Bedfordshire invites you to particpate in the research project below.

Sight Loss, Alcohol and other Drugs

We would like to hear from you if you have experience of sight loss or visual impairment and experience of using alcohol or other drugs. This could be now or in the past. We would like to hear your story and experiences and would welcome any information you may wish to share. All information would be held in strictest confidence.

We want to learn about the possible connections between sight loss or visual impairment and alcohol or other drug use. For some people this might be coping with sight loss for example, for others it may be that their use of alcohol/other drugs got out of hand at some point in their lives. There are no right or wrong answers. We just want to listen. At the end of this research we hope our findings will help to improve the support available for those living with both issues. There will be a £15 voucher payment for people who take part as a small thank you for your time.

We would also like to hear from family members, friends, health and social care professionals, and anyone who may be able to help us learn more about these issues. Please feel free to pass this information on to others you know who may be interested.

If you would like to take part or want to find out more, please contact Wulf or Sarah:

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This research project is jointly funded by Thomas Pocklington Trust (www.pocklington-trust.org.uk/) and Alcohol Research UK (www.alcoholresearchuk.org/).

Appendix 10 - Interview schedules

Schedule – Professionals – Substance use or Visual impairment

Warm Up	• We used a lot of different ways to reach people for this study. How did you find out about it? • We're really pleased you got in touch with us, what made you do that?
Demographics	• Would you mind if i just ask you a few questions about yourself o Age (use groupings?) o Gender o Ethnicity o Religious affiliation o Length of time in present post o Length of time in sector
Work Background	• Can you please tell me about your working history with [visual impairment/sight loss and/or alcohol and other drugs?] • Any formal training, professional qualifications
Current Role	• Please describe your current role • To what extent does your current role involve supporting people with a range of health and social care needs [if not already answered above] • To what extent is drug and alcohol/visual impairment an element within your current work [choose whichever one is NOT their specialist area of practice] [How are folk engaging, referred…] • Does your role contain a particular brief to support people with substance problems/visual impairment? • To what extent do your organisational policies and procedures address substance use or sight loss?
Alcohol/Drugs/Visual impairment in caseload	• To what extent do you think there is a link between sight loss and substance use? • In what way do you think they are related? • Have you noticed any particular trends or changes in relation to the number of people in your service with sight loss and substance problems? • Are you able to provide a rough estimate on how many people with both issues are in your service at any one time? Out of a total of how many? • Can you provide any anonymous examples where you have worked with both issues? • What were the particular challenges you/your colleagues faced? • What were some of the solutions you found? • Were other services involved in working with you and that particular service user? [if not already stated] • To what extent would/did people's sight loss/substance use affect the service they received from your organisation – positively or negatively? • Was there additional knowledge or resources you would have liked to support you working with the substance use/sight loss? • Have you previously attempted to work collaboratively with specialists from sight loss/substance use agencies? If so, how did that go?
Service Users	• From your experience, what do you think is the impact of these two issues together on a) the lives of services users and b) on those close to them?

	• How well do you think your agency and its staff are prepared for supporting people with substance use/sight loss? [Any issues of building and material accessibility] • What more do you think it could provide for service users with both issues? • What do you think it would take for that to happen? • What developments if any do you see are **required i**n services to support those experiencing both issues?
Miscellaneous	• Anything else you would like to tell me about the relationships between sight loss and substance use from your experience? • [If not answered] – any particular issues/experiences of stigma/discrimination? • Anything you'd like to ask me?

Remind about confidentiality and anonymity in writing up.

Ask if they'd like a copy of the research findings and in what format?

Ask if we can come back to them if, in the course of the research we think there may be something else they can help with or comment on?

Provide information/support agencies/contacts sheet.

Thank You

Schedule – Service users

Warm Up	• We used a lot of different ways to reach people for this study. How did you find out about it? • We're really pleased you got in touch with us, what made you do that?
Demographics	• Would you mind if I just ask you a few questions about yourself o Age (use groupings?) o Gender o Ethnicity o Religious affiliation o Live alone or with others o Current or previous employment/ o Smoker – now/past
Sight Loss History	• Do you have a preference for the use of sight loss, visual impairment or some other expression? • The following questions relate to your visual impairment/sight loss? o What kind of visual impairment is it? (type and extent of loss) o How and when did you [begin to] lose your sight? o What were your feelings at the time? (where appropriate) o How did you cope with it when you first found out? (where appropriate) o How/have your coping mechanisms changed since then? (where appropriate) o How has it impacted on your life? (relationships, work, daily living) o What have been the positive and negative aspects of these experiences? o What support do you currently receive in relation to your sight loss? (Generic and specialist e.g. RNIB, ECLO) o Do you belong to any support organisations for people with sight loss? If so, which ones?
Alcohol and Drug History	The next set of questions ask about your current and past alcohol and other drug use • Could you tell us about any current alcohol or drug use? (Where, when , who with etc) o If none, explore further o If some, what they are using, how often, how much, effects – physical and psychological • Could you tell us about your past alcohol or drug use? • What about prescription or over the counter drug use? For example sometimes people report using more than prescribed, or other peoples medication or black market drugs.
Connection between the two	• We're particularly keen to understand the links, short or long term, between your sight loss and your substance use. o To what extent do you feel there is a link between your sight loss and your current/past use of [substances]? o What do you think is/are the nature of the links? ▪ [Prompts to explore more will be tailored to each individual – "anything else?"] o [If not already answered] To what extent does your sight loss encourage or prevent your current/past substance use? o [If not already answered] To what extent has your sight loss had an

	impact on your ability to make safer choices about your current/past substance use? o [If not already answered] To what extent does your [substance use] support or restrict your other experiences?
Related Family History	• Do any of your family members have experiences of sight loss or alcohol or drug use? • To what extent does/did your combined substance use and sight loss impact your family members/friends?
Support Needs/Services	• Have you previously had support from substance use or sight loss services? If so, how involved were they in supporting you about both issues? • Have you talked about or received support from your GP/surgery in respect of these matters? • What [other] kind of support would be/would have been helpful to you in relation to your substance use and sight loss? • To what extent does your sight loss prevent you from accessing support or services for your substance use? • To what extent does your substance use prevent you from accessing support or services for your sight loss? • Were there any services that you used that were really helpful? If so, what was it that was helpful about them? • Are there any services you'd like to receive now relating to your sight loss and substance use? • What developments, if any, would you like to see in service provision
Community	• To what extent do are you aware of other people who experience both sight loss and substance use? • [If not answered] – any particular issues/experiences of stigma/discrimination?
Miscellaneous	• Anything else you would like to tell me about in relation to your sight loss and substance use? • Anything you'd like to ask me?

Remind about confidentiality and anonymity in writing up.

Ask if they'd like a copy of the research findings and in what format?

Ask if we can come back to them if, in the course of the research we think there may be something else they can help with or comment on?

Provide information/support agencies/contacts sheet.

Thank You

Schedule – Family member or informal carers

Warm Up	• We used a lot of different ways to reach people for this study. How did you find out about it? • We're really pleased you got in touch with us, what made you do that?
Demographics	• Would you mind if I just ask you a few questions about yourself o Age (use groupings?) o Gender o Ethnicity o Religious affiliation o Length of time supporting family member/friend
Experience of offering personal support.	• Can you please tell me a little about your friend/family member's substance use and sight loss issues? Anonymously of course. • Can you please tell me what you do in terms of supporting him/her with their sight loss and substance use? [separately and together], e.g. how long, nature of help provided etc • How does their substance use and sight loss impact on them from your experience? • How does it impact on you and your relationship with them? • To what extent do you think there is a link between their sight loss and substance use? • In what way do you think they are related? • What were/are the particular challenges you have faced in supporting your friend/family member? • What were/are some of the solutions you found?
Explorations of professional support.	• Were other services involved in supporting you and/or your family member/friend? [if not already stated] • Have you talked about or received support from your GP/surgery in respect of these matters? • To what extent would/did his/her sight loss/substance use affect the service they received from other organisations generally – positively or negatively? • Have you previously attempted to work collaboratively with specialists from sight loss/substance use agencies? If so, how did that go? • [If supported had] – what was the helpful positive elements and unhelpful/negative of …… • Are/were there additional knowledge or resources you would like/have liked to support you working with the substance use/sight loss? • Is there anything else that you would like to see that would support you to support your friend/family member? • What support or information would you like/have liked in your own right? • Do you have any particular messages for services who are thinking about how best to support people with both issues and their family members?
Miscellaneous	• Anything else you would like to tell me about in relation to your friend's/family member's sight loss and substance use? • [If not answered] – any particular issues/experiences of stigma/discrimination? • Anything you'd like to ask me?

Remind about confidentiality and anonymity in writing up.
Ask if they'd like a copy of the research findings and in what format?
Ask if we can come back to them if, in the course of the research we think there may be something else they can help with or comment on? Provide information/support agencies/contacts sheet.
Thank You.

Appendix 11 - Key demographics of individuals with both issues

Pseudonym	Age range	Gender	Ethnicity	Current Religion	Current Employment
Barnaby	61-65	Male	Cornish	Christian	None Paid
Brandon	41-45	Male	White English	Methodist	Psychotherapist – not working full-time
Charlie	31-35	Male	White British	None	Student
Chas	61-65	Male	White British	Pagan	Paid –Retired; Voluntary – Learning Disabilities
Connor	66-70	Male	English British	C of E	Part-time DJ
Graham	51-55	Male	White Caucasian	None	None Paid; Voluntary in VI
James	51-55	Male	White British	None	None
Jenny	41-45	Female	English more than Welsh	None	None
Karen	36-40	Female	Devonshire, White British	None	'Full time mum'
Martin	41-45	Male	White British	Christian	Receptionist, Part Time
Norm	21-25	Male	Asian	None	Part-time Student
Penny	66-70	Female	White British, well English	Friends-Quakers	Self Employed. Paid and Voluntary (Research, Alcohol and Women's groups)
Seb	51-55	Male	Irish –White British	None	None
Sid	31-35	Male	English	None	None
Stefan	56-60	Male	White	C of E –but not practicing	None
Tommy	66-70	Male	White	None	Retired
Wilma	76-80	Female	Welsh	None	Retired
Volunteer					
Gregory	56-60	Male	White English	None	Volunteer (VI)

Appendix 12 - Summary of participants' self-reported sight loss diagnosis and substance use status

Pseudonym	Age range	Smoker	Sight loss status	Alcohol and or drug use	Relationship between two
Barnaby	61-65	Occasional cigar smoker; Stopped cigarettes 37 yrs ago	Sudden loss in both eyes 5-10 years ago. Diagnosis - Macular Degeneration and Retina Vein Occlusion. Registered Blind	Currently a social and moderate drinker. Previously a heavy and problematic alcohol user following sight loss. History of heavy social drinking.	Coping with experiences of loss. Retention of a social identity associated with drinking after sight loss.
Brandon	41-45	Never	Loss as a teenager following a severe asthma attack. More than 30 years ago. Diagnosis – Anoxic Brain Damage (including sight loss). Registered Blind.	Currently not drinking. Takes lots of prescribed medication (mostly taken as prescribed). Recreational cocaine use.	Late onset recreational use, catching up with opportunities lost through teenage sight loss. Problematic financially.
Charlie	31-35	Two weeks stopped at time of interview	Sudden loss following alcohol- related hospital admission 1-5 years ago. Diagnosis - Malnutrition Amblyopia.	Abstinent from alcohol for last 3 months. Previously a heavy binge use of a range of illegal drugs as well as heavy and regular alcohol use.	Drinking was suggested cause for sight loss, through combination of malnutrition and toxicity. Drinking to cope with sight loss and other emotional issues. Had an impact on access to services.
Chas	61-65	Not in last 12 months	Born visually impaired, compounded by car accident injuries. Retinal degeneration. Registered blind.	Abstinent for last 6 years. Very long history of heavy and dependent drinking Describes himself as alcoholic. Some other illegal drug use.	Alcohol and drug use accelerating decline in sight. Subsequently alcohol as a coping or nullifier of experiences.

Pseudonym	Age range	Smoker	Sight loss status	Alcohol and or drug use	Relationship between two
Connor	66-70	Never	Sight loss following use of prescribed medication for heart condition. 5-10 years ago. Diagnosis - Optic Neuropathy.	Currently no substance use. Previously moderate alcohol use.	Side effect (known) of prescribed drug causing sight loss.
Graham	51-55	Current – Moderate. Past - Heavy.	Sudden loss. Limited return and now gradual deterioration. 1-5 years ago. Very limited. Diagnosis - Optic atrophy	Currently, occasional and moderate alcohol, no illicit drug use. Previously, heavy alcohol and illegal drug use (especially stimulants).	Suggested sight loss was a consequence of drug and alcohol use. Current drinking social and normative and reports specific experiences of this with sight loss.
Jenny	41-45	Never	Sudden and immediate loss following overdose of analgesic medication. 1-5 years ago Diagnosis – she can't remember. 90% sight loss – some shades. Registered Blind. Has guide dog.	Currently, no alcohol or Illicit drugs. Previously heavy alcohol use pre and post sight loss. Overdosing on prescribed medication. No illegal drug use.	Sight loss direct consequence of alcohol induced overdose of prescribed medication. Alcohol use continued post sight loss as a coping mechanism.
James	51-55	Current	Recent sight loss 1-5 years ago. Diagnosis - Optic Atrophy caused by Toxic Amblyopia. Registered severely sight impaired.	Currently a moderate non-spirit drinker. Previously a heavy and daily whisky drinker.	Substance use is suggested cause of sight loss. Drinking as a coping method with difficult experiences of which sight loss is one.
Karen	36-40	Currently 5-10 per day. Past heavy smoker.	Loss of sight as teenager in car accident 20-30 years ago. Cannot see out of one eye and limited vision in the other. Diagnosis – various over the years.	Currently drinking alcohol daily and moderate user of cannabis. Previously excessive and heavy drinking and illicit drug use (all types).	Alcohol led to trauma that resulted in sight loss. Coping and escape mechanism with loss of sight and her life.

Pseudonym	Age range	Smoker	Sight loss status	Alcohol and or drug use	Relationship between two
Martin	41-45	Been a smoker for the last 30 years.	Sudden loss within a week. 5-10 years ago. Hereditary Eye Condition	Currently abstinent. Previously a heavy and excessive use of alcohol and recreational cannabis use.	Describes himself as alcoholic before sight loss. Coping mechanism with loss of sight and life.
Norm	21-25	Never	Told genetic from birth – aware of loss in teenage years. Diagnosis -Retinitis Pigmentosa.	Currently prescribed medication (for epilepsy) only. Previously moderate alcohol use.	Suggest sight loss occurred following epileptic seizure and or made worse by seizures. Prescribed medications and epilepsy impact on visual functioning.
Penny	66-70	Not for 24 years	Recent medical discovery - but probably been present for a number of years. Within last 2 years. Diagnosis – Macular Degeneration. Certified partially sighted.	Currently abstinent. Not drunk for 25 years. Prior to this was a heavy drinker and dependent drug user .	Cause of sight loss was meningitis or alcohol, but no clear picture (for her or professionals). No overlap in experience.
Seb	51-55	Current – income dependent	Poor eye sight from birth. Specific deterioration in sight in one eye (artery damage) 10-15 years ago, second eye lost (nerve damage) following operation 1-5 years ago.	Current irregular but excessive crack cocaine use. Abstinent from alcohol last 6 months. Previously periods of very intense crack cocaine use. Heavy regular alcohol use.	Drug use impacts on take up of sight loss services. Drug use as a coping mechanism with life loss –including sight loss.
Sid	31-35	Never	Blind, without any vision, from birth.	Currently moderate alcohol use, since last year. Previously 12 years of very heavy, daily and dependent alcohol use. Never used illegal drugs.	Drinking as a coping method with difficult experiences of which sight loss is one.

Pseudonym	Age range	Smoker	Sight loss status	Alcohol and or drug use	Relationship between two
Stefan	56-60	Teenage years only	Sight loss was gradual from age 35. Diagnosis "Macular Dystrophy" [? Macular degeneration]	Currently no illicit valium use, but heavy and regular alcohol use. Previously 15 years of illicit use of valium, and heavy alcohol use.	Drug use to relieve anxiety of not coping at work due to sight loss. Alcohol to 'feel better' and cope with fear of further loss.
Tommy	66-70	Not in last 10 years	No vision in right eye and 2% in left eye. Complications 10-20 years ago following cataract surgery combined with macular degeneration.	Currently daily heavy levels of alcohol consumption (last 2 years). Previously normative social drinking.	Alcohol as a means of coping with increasing sight loss and complications in life.
Wilma	76-80	Never	Born with 1/6th vision. Lost sight in right eye aged 20. Lost sight in left eye aged 70. Currently has total blindness.	Currently moderate social alcohol use. Previously moderate social alcohol use. Problematic prescribed medication.	Increase in levels of insomnia when going totally blind, related to increase use of and associated problems with prescribed medication, in particular benzodiazapines.
Volunteer					
Gregory	56-60	Not asked	Has sight loss, previously and currently accesses services in own right. (His sight loss - not focus of interview)	N/A (is not or has not been a significant user himself)	N/A

Appendix 13 - Professionals' demographic profiles

Pseudonym	Age range	Gender	Ethnicity*	Current religious affiliation	Primary sight loss or substance use	Current job role	Time in sector
Abigail	51-55	F	British	No	Sight loss	Welfare manager specialising in sight loss	20 years
Alan	31-35	M	White British	Buddhist	Substance use	Alcohol practitioner	1 year
Alex	41-45	M	White British	Christian	Sight loss	Optometrist	23 years
Alison	51-55	F	White British	No	Sight loss	Rehabilitation Officer - Statutory	20 Years
Elisabeth	41-45	F	White British	No	Sight loss	Optometrist	21 years
Heather	56-60	F	White British	Christian	Sight loss	Social worker specialising in sight loss	10 years
Jonathan	46-50	M	Asian Other	No	Substance use	Nurse practitioner	20 years
Josie	> 50	F	White British	Church of England	Sight loss	Social worker specialising in sight loss	9 years
Mark	46- 50	M	White British	Catholic	Sight loss or disability	Volunteer advocate	13 years
Rachel	31-35	F	White British	Church of England	Sight loss	Own consultancy – "counselling" background	5 years
Sandy	36-40	F	White British	No	Substance use	Counsellor	13 years
Sarah	56-60	F	British	Church of England	Sight loss	Counsellor	11 years
Scott	51-55	M	White British	Church of England but not practicing	Sight loss	Rehabilitation Officer NHS Sensory Service	20 years

Seamus	51-55	M	Irish White	Christian	Sight loss	Consultant ophthalmic surgeon	31 years
Stuart	46-50	M	Welsh	No	Current learning disability and mental health. Previously substance use	Social Worker	15 years
Tracey	46-50	F	White British	Christian	Sight loss	Head of Support - Visual Impairment	4 Months
Veronica	36-40	F	White British	Church of England	Sight loss	(Vision) Rehabilitation Officer - Statutory	17-18 Years
Vinnie	46-50	M	White British	Lapsed Catholic	Sight loss	Enablement Officer	9.5 years

Document Ends