



A plain language summary of research and evidence relating to people with visual impairment and mental health in the United Kingdom

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1 Summary

This Insight provides an overview of current data and knowledge relating to mental health among people with visual impairment (V I) in the United Kingdom (UK). [Research](#) has demonstrated a significant association between V I and depression and/or anxiety in adults with V I, yet while the mental health impact of V I is well documented, in practice it is often [under- diagnosed and treated](#).

Barriers to diagnosis and timely treatment identified in this report include: a focus on the functional impacts of V I; eye/health care professionals' confidence, knowledge and skills; inconsistent and fragmented provision of mental health support across the eye care pathway; and a lack of health literacy for adults with V I about their increased risk of mental health problems.

The time of sight loss diagnosis, and initial transition period, thereafter, is a highly emotional and life-changing experience when people need information, support and signposting to appropriate services. Sources of support, such as Eye Care Liaison Officers (ECLOs), are beneficial to many, however, [recent studies](#) have revealed that there remains insufficient information and guidance at diagnosis.

The biggest facilitator to better identification, treatment and mental health support across the eye care pathway is greater awareness and knowledge, among eye care professionals, of the risk factors for depression and anxiety among people with V I, combined with the integration of depression screening into regular practice and clear referral pathways to mental health and social care services.

As the prevalence of V I continues to rise due to population growth and demographic aging, it becomes increasingly important to understand the wide-ranging impact of these impairments on an individual's mental health and to ensure that emotional and mental health support is embedded in the eye care pathway from the point of diagnosis onwards, as part of a holistic and integrated care system.

Several topics would benefit from greater research, notably: longitudinal and qualitative studies of the impact of sight loss diagnosis and the evolution of patients' psychological reactions; the appropriateness and effectiveness of psychological interventions from a clinical and patient perspective; and the mental health effects of V I across all age ranges.

2 About this report

2.1 About Insights

Insights are designed to aid understanding of issues relating to people with V I in the UK, and to inform and support decision-making processes by bridging gaps between research, government and charitable policy, service provision and public opinion. Insights are produced by the research charity [BRAVO VICTOR](#) and supported by the [V I Charity Sector Partnership](#). Insights are aimed primarily at readers from within the sight loss sector, local authorities, the wider health and social care sectors and employment professionals but are also of relevance to others seeking facts, figures, and academic comment on V I and sight loss. This includes, but is not limited to policy makers, academia, the media, retailers, transport providers, and technology companies.

Insights review and interpret research and current data (where available) to set out brief, plain language summaries. This is the second Insight produced by [BRAVO VICTOR](#), with upcoming Insights to cover many themes and topics relating to V I, the experiences of those living with V I and sight loss, and the services and care provided to them. Insights will be updated to reflect ongoing knowledge development and policy changes to remain relevant.

These summaries are written for a lay audience and reference academic and grey (unpublished or non-commercial) literature. Searches have been conducted by reviewing electronic databases and references from relevant articles and reports, as well as websites provided by government and other appropriate organisations. Data has also been directly submitted to [BRAVO VICTOR](#) by stakeholders. [Contributions and comment](#) are welcome via the [V I Insight Hub](#), where the Insights are hosted.

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2.3 Language and abbreviations

2.3.1 Definitions

Visual impairment:

In these reports, visual impairment/vision impairment (V I) is used as an umbrella term, encompassing severe sight impaired (blindness) and sight impairment (partial sight), defined individually below. Where referenced documents use different categorisations of, for example, 'V I', 'blindness', or 'sight loss', we provide a description of how the authors have defined the term.

Severe sight impairment or blindness:

Generally, people who are severely sight-impaired/blind are:

- People whose eyesight is below 3/60 [Snellen](#)
- People who are 3/60 but below 6/60 Snellen (very contracted field of vision).
- People who are 6/60 Snellen or above (reduced field of vision especially if the reduction is in the lower part of the field).

The terms severely sight impaired, and blind may be used interchangeably. An individual may be formally certified as severely sight impaired with a [Certificate of Vision Impairment](#).

Sight impairment or partial sight:

Generally, people who are sight-impaired are:

- People whose eyesight is 3/60 to 6/60 Snellen with a full field of vision
- People whose eyesight is up to 6/24 Snellen with a moderate reduction of field of vision or with a central part of vision that is cloudy or blurry
- People whose eyesight is 6/18, or better if a large part of their field of vision is missing or a lot of their peripheral vision is missing

Sight impairment will impact substantially on daily life and does not include impairments which are correctable (e.g., with glasses). An individual may be formally certified as sight impaired with a Certificate of Vision Impairment.

Age-related macular degeneration:

There are two [forms of age-related macular degeneration](#) (AMD) - dry and wet. Dry AMD is a gradual deterioration of the macula and causes gradual central vision loss. Wet AMD develops when abnormal blood vessels grow into the macula; these leak blood or fluid which leads to scarring of the macula and rapid loss of central vision.

Glaucoma:

Glaucoma is the name given to a group of eye conditions where there is damage to the optic nerve. It is usually [caused by fluid building up](#) in the front part of the eye, which increases pressure inside the eye.

Primary open angle glaucoma:

In cases of [primary open angle glaucoma](#), the eye cannot get rid of the fluid outflow fast enough and the build-up results in increased eye pressure. Damage to the optic nerve and changes to sight happen very slowly over time.

Primary angle closure glaucoma:

In [primary angle closure glaucoma](#), the outer edge of the iris blocks fluid from draining out of the front of the eye. The fluid builds up quickly, causing a sudden increase in eye pressure. If not treated, it can cause blindness.

Retinitis pigmentosa:

An inherited, progressive eye disease that is associated with degeneration of the photoreceptors and is the leading cause of inherited blindness in people under the age of 60. Age of onset varies from early childhood to middle-age.

Functional ability:

A wide concept that encompasses all body functions, activities and participation. [Functional ability](#) covers physical and social aspects of how a person lives his or her daily life.

Mental health:

In this report, mental health is used in line with the [World Health Organisation's](#) definition - a state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.

Mental health disorder / condition:

In this report, mental health disorder/condition is used in line with the [World Health Organisation's](#) definition as a disorder characterised by a clinically significant disturbance in an individual's cognition, emotional regulation or behaviour. It is usually associated with distress or impairment in important areas of functioning. Mental disorders may also be referred to as mental health conditions.

Depression / depressive symptoms:

According to the [Diagnostic and Statistical Manual of Mental Disorders \(DSM-5\)](#), 'depression' is characterised by a low mood (feeling sad, irritable, empty) or loss of pleasure or interest in activities for long periods of time. Other symptoms also present, may include:

- poor concentration
- feelings of excessive guilt or low self-worth
- disrupted sleep
- hopelessness about the future
- feeling very tired or low in energy

Subthreshold depression:

In the academic literature, 'subthreshold depression' is defined as the presence of clinically significant depressive symptoms which fall short of the criteria for major depressive disorder. Fewer than 5 symptoms of depression, as defined in the DSM-5, are present.

Anxiety:

The [DSM-5](#) diagnostic criteria defines 'anxiety' as characterised by excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities. The anxiety and worry are associated with three or more of the following symptoms:

- restlessness or feeling keyed up or on edge
- being easily fatigued
- difficulty concentrating or mind going blank
- irritability
- muscle tension
- sleep disturbance

Older adults:

Defined by the [Department of Health and Social Care](#) as those who are aged 60 or over. In this report, definitions of older adults vary between studies; the age to which older adults refers is stated.

Children and young people:

Defined by the [Department of Health and Social care](#) as those between the age of 0 and 25. In this report, definitions of CYP vary between studies; the age to which CYP refers is stated.

Cross-sectional study:

Cross-sectional refers to a study where researchers observe and analyse data from a sample population at a single point in time.

Population-based cohort study:

[Population-based cohort studies](#) are defined as a group of individuals taken from the general population who share common characteristics, such as age, sex, or health conditions. These types of studies are observational and seek to provide answers to a specific research question for defined populations.

Odds ratio:

The odds of an outcome occurring in a sample group versus the odds of the outcome occurring in a control group.

Hazard ratio:

An estimate of the relative risk of developing a disease/condition in one group compared to another; a ratio of greater than 1 suggests an increased risk.

Intrapersonal factors:

Constructs that occur within the individual person, such as self-esteem, coping responses, intrinsic motivation and resilience, that can play a significant role in the psychological outcomes of visual impairment.

Psychosocial:

Defined by the [American Psychological Association](#) as the intersection and interaction of social, cultural, and environmental influences on the mind and behaviour.

2.3.2 Abbreviations

N =: The total number of people in a sample population (e.g., the total number of participants in a research study)

n =: The number of people in a sub-sample (e.g., the number of people in one group within the total sample of participants in a research study)

VI: Visual impairment

ECLO: Eye Care Liaison Officer

CYP: Children and young people

AMD: Age-related macular degeneration

POAG: Primary open angle glaucoma

PACG: Primary angle closure glaucoma

RP: Retinitis pigmentosa

HADS: Hospital Anxiety and Depression Scale

PHQ-2: Patient Health Questionnaire 2-item

PHQ-4: Patient Health Questionnaire 4-item

GADS-2: Generalised Anxiety Disorder 2-item

2.4 Methods

A review was undertaken of available UK evidence relating to individuals living with V I between September - October 2023. Standard reviewing techniques such as searching electronic databases, hand searching of references from relevant articles and reports, and a review of websites from government and relevant organisations were used.

A comprehensive search of the Google Scholar database was conducted using a combination of the following keywords: visual/vision impairment, sight loss, blind/ness, mental health/disorder, depression and anxiety. The search strategy was developed to identify peer-reviewed articles that focused on mental health and diagnosable mental health conditions in the context of children, young people and adults living with V I in the UK. Mental health and [well-being](#) are independent

dimensions and, as such, studies focused on well-being and holistic support were excluded from this review.

Stakeholders and charities within the sight loss sector were consulted and asked to provide relevant information, data, or reports that might not be publicly available for inclusion in the review process. The search for academic literature (i.e., peer-reviewed publications or published books or chapters) was limited to publication since 2018 and works relating to the UK. Given the limited research and data available on some topics of relevance, the report includes other data and information reported prior to 2018 and from international sources as follows: where no more recent data is available, where UK-equivalent information is unavailable, or where this data is felt to provide useful context to the report.

Visual impairment is a broad 'umbrella' term, which covers many different experiences and encompasses both severe sight impaired (blindness) and sight impairment (partial sight). The main category discussed in this report, and the academic literature, is late onset sight loss in the older adult population (60 years and above) and its impact on mental health. Where referenced studies focus on a different V I population, for example, children and young people, or working-age adults, this is stated.

3 Introduction

The [Care Act 2014](#) acknowledged, for the first time, rehabilitation services for people with V I in statutory guidance. The Act requires Local Authorities to provide services and resources that maximise independence and promote well-being, yet there continues to be considerable variation in the level of V I service provision across the UK, which often results in a confusing and complex experience for people as they navigate the eye care pathway.

V I has a significant impact on activities of daily living and is associated with reduced quality of life, and feelings of social isolation and loneliness ([Jones et al. 2018](#)). Moreover, people with V I may be at greater risk of developing mental health conditions ([Demmin and Silverstein, 2020](#); [Ulhaq et al. 2022](#)). There is a sizeable body of cross-sectional and population-based studies providing robust evidence of an association between V I and depression ([Nollett et al. 2019](#); [Zhang et al. 2022](#)). However, because V I is conceptualised as a physical disability, primarily impacting functional mobility, the psychological impact of sight loss tends to be [under-diagnosed and treated](#) in practice.

In 2022, over [2 million people in the UK](#) were estimated to be living with varying degrees of sight loss. The largest number of adults living with sight loss were in the age range 85 years and above (713,000), whilst the total number of people aged 65 and above was estimated to be 1,781,000. The [Royal National Institute of Blind People](#) (RNIB) estimates that the number of people living with sight loss will increase to a total of 2,690,000 by 2032 ([RNIB Sight Loss Data Tool](#)). Age-related sight loss is a leading cause of disability among aging adults, principally resulting from eye conditions such as macular degeneration and glaucoma. Consequently, as demographic ageing in the UK continues to lead to a significant year-on-year increase in the prevalence of age-related sight loss, the demand on both eye care and mental health care for older adults with V I is expected to increase.

In the UK, provision of mental health support across the eye care pathway is largely unknown, especially amongst referring optometrists and ECLOs to whom patients look to for advice and support ([Trott, et al. 2023](#)). Furthermore, there is no national eye health strategy currently in place for England and, whilst the other UK nations have some form of eye care plan, policy progress has often been fragmented. This has created inequities in access to eye care services and support and,

perpetuated a focus on the physical impacts of sight loss diagnosis ([National Eye Health Strategy Debate, 2022](#)).

As the prevalence of V I continues to rise, so does the need to better understand the wide-ranging impact of sight loss on an individual's mental health. The available research calls for greater recognition of the emotional impact of sight loss and for mental health support to be available as a matter of course, from the point of diagnosis and throughout the eye care pathway ([Boagey et al. 2022](#); [RNIB 2023](#)). This would ensure that the right support can be accessed at the right time for each person. There is a need for increased understanding, amongst eye health professionals and the wider sight loss sector, of the mechanisms that contribute to the onset and continuation of mental health problems in the V I population.

To date, research has indicated that to improve patient experiences and outcomes, it will be essential to create an integrated eye care pathway, improve the detection of mental health conditions in the V I population and develop more effective interventions for depression and anxiety ([Nollett et al. 2019](#); [Demmin and Silverstein, 2022](#)).

4 The association between V I and mental health in adults

4.1 Emotional trauma

A survey of 1,156 UK adults, conducted in 2019 and commissioned by [Fight for Sight](#), found that over 80% of people surveyed felt losing their sight would be worse than losing any other sense. Conditions that affect sight can yield a wide range of visual outcomes, from partial sight loss to blindness, with differing rates of progression and severity. There is a consensus in the [academic](#) and [grey literature](#) that V I is a highly emotional experience and people living with V I may be at greater risk of developing mental health conditions for a variety of reasons.

V I is known to impact functional ability and activities of daily living, which can result in feelings of frustration and isolation, and can require significant emotional adaptation, a complex process open to the emergence of mental health problems. The [2022 V I Lives](#) report indicated that 40% of blind and partially sighted people were struggling to come to terms with their sight loss and/or changes in their eye health and 65% said they frequently thought about the impact of V I on their lives. An [RNIB report \(2023\)](#), based on analysis of the 2019 Understanding Society dataset, reported that blind and partially sighted people are more than twice as likely to experience difficulties with unhappiness or depression compared to the UK average. This was associated with frustration at the changes respondents were having to make to their everyday lives and anxiety about the future.

The relationship between V I and mental health conditions, most commonly depression and anxiety, is multi-faceted. Research by [Heesterbeek *et al.* \(2017\)](#) from a longitudinal cohort study of patients attending three low vision rehabilitation organisations in the Netherlands and Belgium, demonstrated that multiple factors may influence the incidence of subthreshold depression and anxiety in older adults with V I. The study explored predictors such as age, gender, living situation, visual acuity, type of sight loss and time of onset, and found that better adaptation to sight loss was a strong predictor for lower levels of depressive symptoms. The study findings are discussed in more depth in section 5.

4.2 Functional limitation

The direct effect V I may have on functional ability in daily life is highlighted throughout the literature. Moreover, several studies have established a link between a change in functional ability and the onset of depression and/or anxiety. In 2019, [Nollett et al.](#) observed that a common perception amongst practitioners in the Low Vision Service Wales was that depression resulted from the activity limitations and loss of independence caused by failing sight, which in turn could lead to loneliness and isolation. This led practitioners to perceive that their core role of enhancing visual function and promoting independence would have a direct positive impact on patients' mood.

A systematic review by [Demmin and Silverstein \(2020\)](#), of recent articles on mental health outcomes and current treatments in people with V I, found that the distress and functional impairment that are associated with sight loss may elicit a variety of psychological problems, and in particular, affect one's mood. Findings indicated that while both vision impairment and depression are independently associated with functional decline, together these conditions may lead to even greater disability than either condition alone.

Looking to explain the increased risk of depressive symptoms and disorder in those with low vision, [Nollett et al. \(2019\)](#) pointed to the influence of the Activity Restriction Model of Depressed Affect. The model hypothesises that depression results from the restriction of routine and valued activities by a major life stressor, such as illness and disability. Depression is not directly attributable to the chronic medical condition (i.e., V I), or its symptoms, but rather to the restriction that patients experience in their everyday activities.

4.3 Other stressors

There is limited academic research exploring post-traumatic stress reactions among individuals with V I ([Brunes et al. 2019](#); [van der Ham et al. 2021](#)). However, a systematic review, conducted by [Brunes et al. 2019](#), indicated that people with a V I are more susceptible to some types of potentially traumatic events, such as falls and accidents. These traumatic events may lead to a variety of stress reactions and mental health problems. Findings from four quantitative studies, included in the review, showed that the prevalence of post-traumatic mental disorders

was 4-21.2% for depression, suggesting that traumatic experiences can have a significant impact on mental health among people with V I. Similarly, [van der Ham et al. \(2021\)](#) reported, from a review of five publications on the experience of traumatic events, that V I appeared to affect the experience of potentially traumatic events in two different ways: 1) it acted as a barrier for obtaining situational information, and 2) as a barrier to responding during and after the serious event. In each of the studies, the perceived barriers were shown to be accompanied by feelings of helplessness, lack of control and loss of security, which added to the stressfulness of the experience.

A [Netherlands-based Delphi study \(2023\)](#), conducted with 37 experts, including professionals, persons with V I, and relatives of people with V I, found that 'stressors' were an important factor in the experience and treatment of mental health problems. People with a V I generally experienced more stress compared to people without a V I. Causes of higher stress levels were found to include feelings of powerlessness, fatigue, travelling, dependence and coping with loss. On fatigue, findings suggested that persons with a V I are more likely to suffer from fatigue and limited energy, which can affect their ability to cope with various aspects of daily life ([Braakman et al. 2023](#)).

4.3.1 Vision-specific distress

Research suggests that vision-specific distress (i.e., emotional reactions to V I) is an important contributor to depression and a robust predictor of depressive symptom severity, independent of degree and duration of V I. Whilst no UK studies have been carried out on the mediating effect of vision-specific distress on depressive symptoms, an [Australian-based survey study](#) assessed vision-specific distress as part of an Impact of Vision Impairment Questionnaire in a randomised controlled trial of low vision clients.

The vision-specific distress domain of the questionnaire comprised 8-items that assessed the extent to which a person's level of vision had caused them to feel: embarrassed, frustrated, lonely/isolated, sad/low, worried about sight loss getting worse, concerned about coping with everyday life, or a nuisance/burden and the extent to which their eyesight interfered with life in general. The study observed a significant improvement in vision-specific distress in the intervention group, who received problem-solving treatment, compared to controls, up until the 6-

month follow-up. Whilst the findings reinforced an association between depressive symptoms and vision-specific distress, it was acknowledged that further research is needed to explore what factors are associated with distress outcomes and how problem-solving treatment can be adapted to better target these in the longer-term.

4.4 Eye condition progression trajectory and mental health

Across the literature it is acknowledged that the prospect of slow progressive sight loss may take its toll on patients' mental health, predisposing them to depression and/or anxiety. A [systematic review](#) of qualitative papers on experiences and coping strategies of adults living with Retinitis Pigmentosa (RP), that included 3 UK studies, showed that loss of confidence related to progressive sight loss was a common experience following diagnosis. For patients diagnosed with RP, progressive sight loss signified a loss of independence and freedom and, for some, loss of future plans.

A thread running through all the themes identified in a UK-based [qualitative study](#), into the experience of living with dry age-related macular disease (AMD), was its uniqueness as a chronic, untreatable and slowly progressive condition. Twenty-seven participants, recruited from [Moorfields Eye Hospital Trust](#), aged ≥ 60 years, described hopelessness and despair following diagnosis and their knowledge that the condition would only get worse and not better, even at the stages when their vision was not yet significantly affected.

The association between V I and mental health may also be mediated by the progression trajectory of common mental health conditions.

Depression and anxiety are well known transient conditions. [World Health Organisation \(2022\)](#) information about mental health highlights that mental health and mental disorders exist on a complex continuum, which is experienced differently from one person to the next, with varying degrees of difficulty, distress and potentially very different social and clinical outcomes.

A [2015 study](#) of 265 older adults, attending outpatient low-vision rehabilitation services in the Netherlands, with subthreshold depression and/or anxiety, showed that after a three-month watchful waiting period, in which no psychological treatment was given, 34% of participants recovered from these symptoms and 18% developed a depressive

and/or anxiety disorder. The study findings indicated that depression and anxiety symptoms tended to fluctuate over time in older adults, which is akin to trends in the general population.

4.5 Increased understanding of the association between V I and mental health

The literature provides consistent evidence, from cross-sectional studies, of a strong association between V I and depression and/or anxiety. However, evidence from longitudinal studies is more limited. A 2019 study undertaken in the [United States \(US\)](#) found a significant longitudinal association between V I and clinically significant symptoms of depression and anxiety in a cohort of 7,584 participants aged 65 years and older, with self-reported V I status. The prevalence of depression and anxiety symptoms were found to be twice as high among participants with self-reported V I than those who did not report V I. The study recommended that additional longitudinal research would be useful to clarify the nature of the causal relationship between V I and clinically significant symptoms of mental disorder. Based on a systematic review of mental health outcomes for people with V I, [Demmin and Silverstein \(2020\)](#) also highlighted a need to increase understanding of the range of psychological and psychosocial effects associated with V I (and anticipation of it) and the risk factors that contribute to the onset and continuation of mental health problems.

5 Common mental health conditions in adults with V I

V I and mental health are common coexistent morbidities in adults and older people in the general population. Studies ([van Nispen et al. 2016](#); [Nollett et al. 2016](#)) have shown that one-third of older adults with V I in general, and age-related macular degeneration and glaucoma, experience symptoms of depression and/or anxiety.

5.1 V I and depression

5.1.2 Prevalence rates

Cross-sectional and meta-analysis studies (see Table 1) have shown that the prevalence estimates of depression and depressive symptoms range from 12.4% to 43% amongst adult populations with V I. Whilst the academic literature provides substantive evidence for the association between V I and depression or depressive symptoms, it remains unclear if, and how, specific factors related to V I act as predictors and risk factors for depression. Yet, factors such as age, severity and duration of sight loss may influence an individual's risk of depression ([Heesterbeek et al. 2017](#)).

There is variability in the reported prevalence estimates across different studies from 2016 onwards; this is due to disparity in sample size, cohort, study method, inclusion criteria and symptom rating scales in screening for depression.

Nature of impairment	Source	Year	Actual or pooled prevalence	Depression or depressive symptoms	Rate	Sample
	Nollett et al.	2016	Actual	Depressive symptoms	43%	1,008 participants. Mean age 74.4 years. UK study.
	Heesterbeek et al.	2017	Actual	Depression	21.2%	235 participants. Mean age 74.8 years. Dutch study.
All visual impairment	Zheng et al.	2017	Pooled	Depression or depressive symptoms	25%	Total sample size 6,589 cases. Meta-analysis of 28 studies, including 2 UK studies.
	Frank et al.	2019	Actual	Depression	31.2%	7,584 participants aged 65 and above. US study.
	Zhang et al.	2022	Actual	Depression	12.4%	114,583 participants. Mean age 56.8 years. UK study.
Age-related macular degeneration	Zheng et al.	2017	Pooled	Depression or depressive symptoms	24%	Total sample size 6,589 cases. Meta-analysis of 28 studies, including 2 UK studies.
	Olson et al.	2019	Actual	Depression	25%	11,681 participants aged 50 years and above. US study.
	Demmin and Silverstein	2020	Pooled	Depression	32.5%	Meta-analysis.
Glaucoma	Groff et al.	2022	Pooled	Depression	19%	Total sample size 135,565 cases. Meta-analysis of 45 studies - 0 UK studies.

Table 1. Overview of the prevalence of depression and depressive symptoms in adults with V I from recent sources.

Whilst the literature on depression in people with V I is quite extensive, most studies have focused on determining the prevalence of depression in older adult populations. As estimates of depression differ across different age groups in the general population ([WHO, 2017](#)), it is important to establish whether the same applies to adults with V I. A [study in Norway](#) yielded specific estimates of depression for young and middle-aged adults with V I. The study population (736 adults) was divided into four age groups: 18-35 years, 36-50 years, 51-65 years and ≥ 66 years. Depression was measured with the nine-item [Patient Health Questionnaire \(PHQ-9\)](#), a validated diagnostic tool used in primary care settings. The prevalence of depressive disorders varied in different age groups between 4.2% and 15.6% for major depression and 10.3% and 19.9% for any depression (see Table 2). Overall, the estimates were highest in the age group 36-50 years and lowest in the age group 66 years or above.

	Age group	Cases/ total	Total rate (N= 736)	Rate for Women (n= 403)	Rate for Men (n= 333)
Major depression	18-35	18/157	11.5%	12.5%	10.1%
	36-50	29/186	15.6%	17.8%	12.9%
	51-65	14/200	7.0%	7.6%	6.4%
	≥ 66	8/193	4.2%	5.6%	2.4%
Any depression	18-35	25/157	15.9%	17.1%	14.5%
	36-50	37/186	19.9%	22.8%	16.5%
	51-65	22/200	11.0%	11.3%	10.6%
	≥ 66	20/193	10.3%	11.1%	9.4%

Table 2. The point of prevalence of depressive disorders in the V I population by age and gender. Source: [Brunes et al. \(2020\)](#).

Evidence from a longitudinal study in [Korea](#) also found an increased risk of depression in participants with V I in all adult age groups. Individuals registered with a V I ($n= 5,846$) were compared with controls ($n= 23,838$) for age, gender, income and region of residence. The hazard ratio (an estimate of the relative risk of developing a disease/condition; a ratio of greater than 1 suggests an increased risk) for the development of depression in participants with a V I was 1.22.

Following stratification by age at enrolment to the study (3 groups: 0-29 years, 30-59 years and ≥ 60 years), the adjusted hazard ratio was significantly increased only in the middle-aged population (30-59 years); the hazard ratio was 1.26 (see Table 3). A decreased hazard ratio was found in the elderly population (≥ 60 years) which [may be explained by the increased percentage of elderly subjects who developed depression in both the control and visually impaired groups](#) (7.3% in the control group vs. 8% in the V I group).

Characteristic	Crude hazard ratio	Adjusted hazard ratio
Young (0-29 years)		
Visual impairment	1.39	1.30
Control	1.00	1.00
Middle-aged (30-59 years)		
Visual impairment	1.31	1.26
Control	1.00	1.00
Elderly (≥ 60 years)		
Visual impairment	1.11	1.11
Control	1.00	1.00

Table 3. Crude and adjusted hazard ratio of V I for depression for age. Source: [Choi et al. \(2018\)](#).

There remains a lack of large-scale, longitudinal research exploring the risk and impact of depressive disorders on younger and middle-aged adults with V I, both in the UK and internationally, despite indications that there is a high risk among adults aged 20 years and older. As [estimates of depression vary across age groups in the general population](#), it would be helpful to examine whether the same applies to adults with V I.

5.1.3 Depression risk factors

Depression is a multifactorial condition, and its onset and progression are linked to a number of biological, environmental, psychological and social factors. [The National Institute for Health and Care Excellence \(NICE\)](#) states that risk factors for depression include:

- Female sex.
- Older age.
- Personal, social, or environmental factors such as stress, social isolation or bereavement.
- Other chronic physical health conditions associated with functional impairment.

Generic predictors of depression among older adults in the general population have also been reported in adults with V I ([Nollett et al. 2019](#); [Demmin and Silverstein, 2020](#)). The causes of depression in people with V I are likely to involve multiple contributory factors some of which are specific to V I and some which may be non-specific such as age-related risk factors for depression.

A UK, cross-sectional study of adults with V I (median age 79.0 years) by [Nollett et al. \(2019\)](#) sought to identify the risk factors for significant depressive symptoms. The study recorded age, gender, ethnicity, physical illness and ocular diagnosis, with these being the potential risk factors considered easily identifiable in primary care and general hospital clinics. Self-reported general health was also measured since this has been consistently shown to be a risk factor for depression.

Results found that the prevalence of depression was 29.8% in participants with no physical illness, and higher (54.3%) in those with three or more physical illnesses. A higher prevalence of depression was also seen in those who had one eye condition, worse visual acuity or

less time since the onset of sight loss. Analysis of self-report measures showed that significant depressive symptoms were highest in those with poor self-rated health and visual function (81.5%) and lowest in those with excellent health and visual function (4.3%). Overall, findings showed that among older adults, those of relatively younger age, with an ethnicity other than white and poorer self-reported health and visual function, had higher odds of having significant depressive symptoms. In line with [previous studies](#), [Nollet et al](#) identified that time since the sight loss was first identified was not a predictor of depression, indicating that patients may develop depressive symptoms at any point in their sight loss journey.

A [longitudinal cohort study](#) (24 months follow-up), conducted in the Netherlands, gives more insight into the risk factors for developing depression and/or anxiety in older adults with V I. The study calculated the cumulative incidences of subthreshold depression and anxiety in 540 older adults, with a mean age of 75 years, from outpatient low-vision rehabilitation organisations. All data were collected at baseline and after 6, 12, 18 and 24 months follow up, using the [Centre for Epidemiological Studies Depression Scale](#) and the [Hospital Anxiety and Depression Scale \(HADS\)](#). Risk factors for developing depression were living alone, having macular degeneration, having problems with adaptation to sight loss, reduced health related quality of life, and experiencing symptoms of anxiety. For developing anxiety symptoms, a relatively younger age, not living alone, experiencing symptoms of depression and experiencing challenges at work proved to be risk factors. The study suggested that a possible explanation for macular degeneration acting as a risk factor could be the high impact on daily life activities and the different stages and severity of the disease. Further, it was hypothesised that relatively younger older adults with V I might be more anxious due to the fact that they will live longer with the V I and have a more responsible social role, and are still able to work, and may, therefore, face more potential challenges than older adults.

For some individuals with V I, the risk of depression may be closely linked to changes in functional capacity caused by sight loss. A variety of functional limitations stem from sight loss such as difficulty walking, reading and being unable to drive. [Qualitative research](#), involving interviews with 18 patients at the [Oxford Eye Hospital](#), found that changes in functional ability as the eye disease progressed led to feelings of frustration and low mood, which were often linked to no

longer feeling as competent and confident. Being forced to rely on others more was also cited as frustrating. Overall, it was found that changes in functional ability had a negative impact on patients' self-identity as a capable and independent person.

5.1.4 Depression in adults with age-related macular degeneration

There are [two forms of AMD](#) – dry and wet. Dry AMD is a gradual deterioration of the macula and causes gradual central vision loss. Wet AMD develops when abnormal blood vessels grow into the macula; these leak blood or fluid which leads to scarring of the macula and rapid loss of central vision.

[NICE guidelines](#) (2018) for AMD highlight that people with the condition are at an increased risk of depression. Across the academic literature, studies have established a significant relationship between depression and AMD. A [US study](#) found 25% of patients with AMD ($n= 2,752$) suffered from depression and the estimated [odds ratio](#) (i.e. the odds of an outcome occurring in a sample group versus the odds of the outcome occurring in a control group) for AMD and depression was 1.3, across all patients ≥ 50 years or above. A systemic review by [Demmin and Silverstein](#) (2020) found that, in studies of AMD, 10.5-44.4% of participants reported moderate-to-severe symptoms of depression and up to 32.5% met major depressive disorder criteria.

The most common negative consequence of the V I caused by AMD is increased functional disability, which puts AMD patients at increased risk of mental health problems such as depression. One possible explanation for this could be that ADM affects central vision, thereby having a high impact on daily life activities. A population-based cohort study in [Korea \(2023\)](#) found that a diagnosis of AMD and related visual disability (i.e. decreased mobility and reduced social functioning) further increased the risk of depression. The hazard ratio for depression in the AMD with visual disability group was 1.23, compared with 1.14 for the AMD without visual disability group.

[Cimarolli et al. \(2016\)](#) identified a basic deficit in problem solving skills as a further potential mechanism for the development of depression in AMD. Most people diagnosed with AMD are 60 years and older and have developed a well-tested repertoire of skills to approach common problems in life. Sight loss, however, is a unique problem for which such

skills have not been developed and existing skills may not be sufficient to effectively manage the practical and psychological adjustment. The authors pointed to the results of several clinical trials testing mental health interventions to treat depression among older adults with AMD, which have shown promising short-term benefits, especially those incorporating problem solving techniques to remove barriers to activity engagement.

Recent studies ([Olsen et al. 2019](#); [Demmin and Silverstein, 2020](#)) have also suggested that AMD is particularly difficult for individuals to cope with because sight loss is progressive and involves a poor future outlook. Dry AMD is a progressive and untreatable disease whose advancement is slow, whilst wet AMD can be rapidly progressive. The prospect of either sudden, unpredictable loss in vision or gradual vision loss over years may take its toll on patients' mental health, predisposing them to depression.

5.1.5 Depression in adults with retinitis pigmentosa

At present there is no available treatment to stop RP disease progression or restore vision; the condition is incurable. Studies ([Garip et al. 2019](#); [Cross et al. 2022](#)) have shown that people with RP experience a lower quality of life, associated with reduced mobility and challenges with activities of daily living, reduced independence, increased financial burden due to difficulties retaining employment and often social isolation. As such, the overall impact of RP on patients is high and adults living with RP are more likely to experience higher levels of distress and depression.

The earlier onset of RP can cause [greater emotional and psychological impact](#) compared to people with conditions such as AMD and diabetic retinopathy. A [qualitative study conducted in Australia](#) found that participants with RP (mean age 55.6 years; range from 28 to 81 years) commonly experienced frustration, depression and worry which resulted from them having to depend on people, learn different ways of doing things and an inability to participate in social activities. They worried about their future, their employability, their eye condition and their coping skills.

There is a lack of recent academic research exploring the risk factors and prevalence of depression in adults with RP. Looking to determine

the relationship between visual function and mental health among young adults with RP, [a study in France](#) found depression in 15.5% of participants ($N= 148$); the HADS was used to measure mental health. A [2018 cross-sectional study](#), conducted in Japan, found that 26% ($N= 11$) of patients with RP had depression, as identified by the HADS. Further research is needed to focus on the association between RP and mental health.

5.2 V I and anxiety

Fewer studies have investigated rates of anxiety among V I populations, compared with depression, and only a small number in the UK ([Richards et al. 2014](#); [Senra et al. 2017](#)). Nonetheless, there is some evidence of an association between anxiety symptoms/disorders and eye diseases.

A longitudinal study ([Frank et al. 2019](#)) that involved 7,584 participants, in the US, found that the prevalence of anxiety symptoms was 27.2% in those with self-reported V I, compared with 11.1% in those without self-reported V I. [Ulhaq et al. \(2022\)](#) reviewed 95 studies (inclusive of 3 UK studies from 2007, 2014 and 2017), among which 81 evaluated anxiety symptoms while 14 evaluated anxiety disorders. Meta-analysis revealed an overall pooled prevalence of anxiety symptoms and disorders among patients with V I to be 31.2% (6,507/23,415 subjects) and 19.0% (6,502/60,174 subjects) respectively. When the study results were classified based on age, the pooled prevalence of anxiety symptoms in adult and paediatric patients were 29% (7,726/33,981 patients) and 58.6% (649/695 patients), respectively. Overall, the risk of developing anxiety disorders among ophthalmic disease patients was found to be two times higher than in healthy controls.

The reported prevalence of anxiety symptoms and disorders in people with V I that exists in the literature remains varied. A small number of studies have identified the estimated prevalence of anxiety associated with specific eye conditions (See Table 4).

Nature of impairment	Source	Year	Actual or pooled prevalence	Anxiety or anxiety symptoms	Rate	Sample
	Heesterbeek et al.	2017	Actual	Anxiety	9.5%	235 participants. Mean 74.8 years. Dutch study.
All visual impairment	Frank et al.	2019	Actual	Anxiety Symptoms	27.2%	7,584 participants aged 65 years and above. US study.
	Ulhaq et al.	2022	Pooled	Anxiety symptoms	31.2%	Meta-analysis of 95 studies, including 3 UK studies.
	Olson et al.	2019	Actual	Anxiety	19.0%	51,019 participants aged 50 years and above. US study.
Age-related macular degeneration	Ulhaq et al.	2022	Pooled	Anxiety symptoms	21.6%	Meta-analysis of 95 studies - 0 UK studies.
	Groff et al.	2022	Pooled	Anxiety	25.0%	4,995,538 subjects. Meta-analysis of 45 studies - 0 UK studies.
	Ulhaq et al.	2022	Pooled	Anxiety symptoms	30.7%	Meta-analysis of 95 studies - 0 UK studies.
Glaucoma				Anxiety	22.2%	
	Groff et al.	2022	Pooled	Anxiety	25.0%	4,995,538 subjects. Meta-analysis of 45 studies - 0 UK studies.

	Chaumet-Riffaud <i>et al.</i>	2017	Actual	Anxiety	36.5%	148 participants. Mean age 38.2 years. French study.
Retinitis pigmentosa	Sainohira <i>et al.</i>	2018	Actual	Anxiety	37.0%	112 participants. Mean age 60.7 years. Japanese study.
	Ulhaq <i>et al.</i>	2022	Pooled	Anxiety symptoms	36.5%	Meta-analysis of 95 studies, including 3 UK studies.
	Retina UK	2022	Actual	Anxiety*	78.0%	673 participants aged 18 years and above.

*self-reported anxiety.

Table 4. Estimated prevalence of anxiety associated with specific eye conditions taken from recent sources.

[Ulhaq et al. \(2022\)](#) further differentiated rates of anxiety symptoms among glaucoma patients by the two main types of glaucoma: 1) [Primary-open angle glaucoma](#) (POAG) occurs due to a fluid build-up that causes pressure within the eye to slowly increase over time, leading to damage of the optic nerve and permanent sight loss; and 2) [Primary-angle closure glaucoma](#) (PACG) is caused by a narrowing of the drainage angle in the eye that reduces the effectiveness of fluid escaping the eye and causes fluid pressure inside the eye to rise very quickly.

Meta-data analysis revealed that patients with PACG had a higher prevalence of anxiety symptoms (52.5%) than those with POAG (33.1%) or any type of glaucoma (25.6%). For the first time, [Ulhaq et al. \(2022\)](#) showed a higher prevalence of anxiety symptoms in PACG than POAG subjects; this is possibly because relative to POAG, PACG carries a [threefold increased risk of severe bilateral V I](#). On the other hand, it was observed that the lives of people with glaucoma are largely unaffected while the disease progresses slowly and silently, which may have a long-term negative impact on their quality of life. The study concluded that it remains possible to hypothesise that the chronicity of glaucoma may be closely associated with the development of anxiety symptoms and disorders.

V I is likely associated with higher rates of anxiety compared to the general population. Further research to explore the causality of this association and to understand the characteristics of anxiety in people with V I would be valuable. Research exploring the association between anxiety and V I within the UK remains lacking.

6 Children and young people with V I and mental health

CYP with V I may present with more emotional and mental health difficulties than their sighted peers, namely anxiety and/or depression. Research indicates that these problems may stem from various factors, such as the neurological impairments associated with their vision, limited participation in social activities, loneliness, increased dependency on others, and increased parental intervention ([Augestad, 2017](#); [Jessup et al. 2017](#)).

A sizeable body of literature exists on CYP with V I, yet there remains limited coverage of mental health specifically, especially in a UK context. Research has tended to focus on, for example, the effect of V I on the well-being and quality of life of CYP, developmental and educational outcomes, and habilitation provision. An internal RNIB scoping review by Thurston *et al.* (2022) that evaluated 36 academic papers also observed this paucity of research, both in the UK and internationally, and the predominance of cross-sectional studies; this limits understanding of the relationship between V I and mental health on a longitudinal basis.

6.1 Mental health statistics for CYP with and without V I

6.1.2 How many CYP (general population) have mental health conditions?

A 2022 survey by [NHS Digital](#), which sampled 2,866 CYP aged 7 to 24 years living in England, found that 18% of children aged 7 to 16 years had a probable mental disorder, up from 12.1% in 2017 (see Figure 1). Among young people aged 17 to 24 years, the rates of probable mental disorder increased from 10.1% in 2017 to 22.0% in 2022. The [Strengths and Difficulties Questionnaire](#), which assesses aspects of mental health including problems with emotions, behaviour, relationships and concentration, was used as the main measure of mental health.

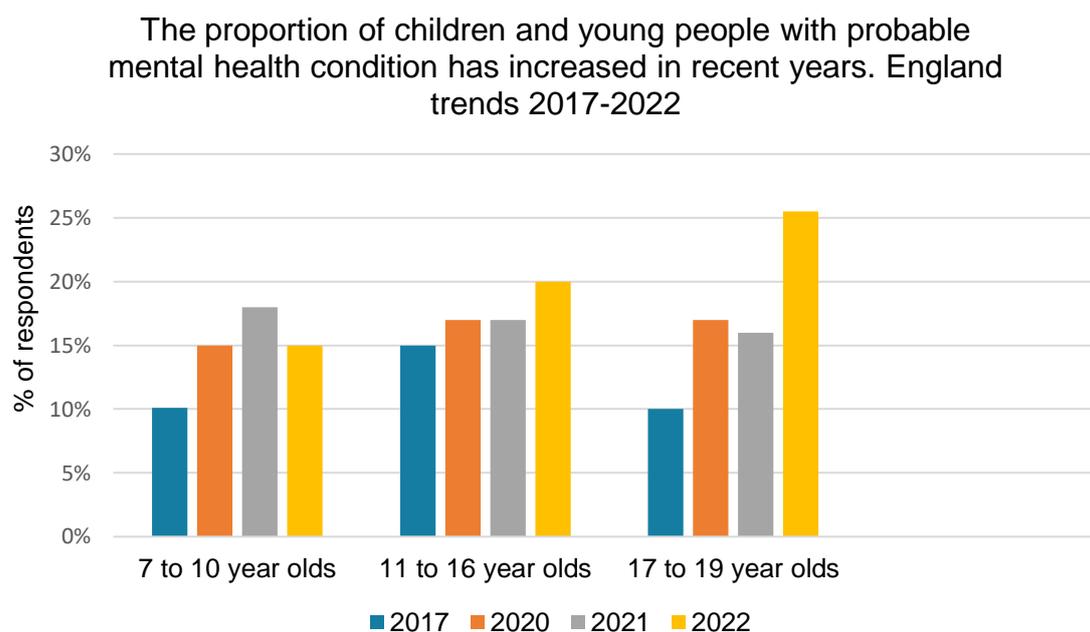


Figure 1. Trends in children and young people’s mental health in England 2017-2022. Source: [NHS Digital \(2022\)](#)

Data from [NHS Digital’s earlier 2021](#) survey included subgroup variation analysis and showed that more than half of children with special educational need or disability (SEND) had a probable mental disorder (56.7%), compared with 12.5% of those without SEND; this was an increase from 43.9% and 8.2% in 2017 for the respective groups, which may reflect the impact of the pandemic as a contributing factor. Whilst the analysis does not provide a further breakdown of disability, it is reasonable to assume the inclusion of V I within this category.

6.1.3 How many CYP with V I have mental health conditions?

In 2022, [RNIB](#) published findings from a secondary analysis of Wave 7 data from the [Millennium Cohort Study](#) – a longitudinal research project at the University of London, following the lives of children born in the UK in 2000/1. RNIB analysed interviews with 17 year olds, and their parents, conducted in 2017. From questions asked in the parent interviews RNIB split respondents into three groups: V I ($n= 124$); other disabled ($n= 315$); and non-disabled ($n= 9,532$).

The parents’ perspective indicated that young people with V I are significantly more likely to be unhappy, have many fears, and be easily

scared and nervous in new situations, compared to children without a disability (see Table 5).

Survey Question	% of young people with V I	% of young people without a disability
Whether young person is often unhappy, downhearted or tearful.	41.0%	21.0%
Whether young person is nervous or clingy in new situations.	78.0%	36.0%
Has many worries or often seems worried.	75.0%	45.0%
Has many fears or is easily scared.	74.0%	24.0%

Table 5. Parent perspective of young person wellbeing (age 17 years) from the Millennium Cohort Study, conducted in 2017. Source: [RNIB 2022](#)).

At age 17, young people with V I appeared to have a significant gap in wellbeing across multiple areas of life when compared to other disabled and non-disabled young people. They were much more likely to be depressed, feel worthless, feel hopeless, and have no optimism about the future (see Table 6). This contrasts with the views given at age 11 and 14, where self-reported wellbeing by children with V I did not show a significant difference and was similar to their peers.

Survey Question	% of young people with V I	% of young people without a disability
Whether often unhappy, downhearted or tearful.	45.0%	8.0%
Whether usually on my own or keep to myself.	49.0%	11.0%
Whether worries a lot.	58.0%	31.0%

Whether nervous in new situations or easily lose confidence.	62.0%	30.0%
Whether felt depressed all of the time in the last 30 days.	39.0%	30.0%
Whether felt depressed most of the time in the last 30 days.	50.0%	9.0%
How often felt worthless in the last 30 days (all or most of the time).	47.0%	10.0%

Table 6: Young person's perspective of their own wellbeing (age 17 years) from the Millennium Cohort Study, conducted in 2017. Source: [RNIB \(2022\)](#).

6.2 Impact of V I on CYP mental health

6.2.1 Prevalence of mental health conditions

Limited research on the prevalence of mental health conditions among CYP with V I in the UK means that the evidence presented in this section comes principally from a systematic review of academic papers pre-dating 2018.

[Augestad \(2017\)](#), conducted a systematic review of academic papers, published between 1990 and 2016, relating to the occurrence of mood disorders among children with V I. The majority of studies ($N= 17$) reported that CYP with V I had more emotional problems than did their sighted peers. Three studies showed that children with V I had levels of depression similar to their sighted peers, whilst the results of four studies showed a higher prevalence of depression than that among sighted peers. The impact of gender was examined, and results showed that girls with V I might experience serious symptoms of depression more often than might boys with V I, which is in line with the general population.

In a [2016 UK study](#), Harris and Lord identified an increased risk of psychiatric disorders among children aged 11 years with V I compared with sighted children of the same age. Based on parental scores, using the Strengths and Difficulties Questionnaire, 21% to 30% of children with V I were rated as high risk of a diagnosis of psychiatric disorder. An important variable was the presence or absence of an additional SEND. The presence of an additional SEND resulted in higher scores and more

children being identified as being at risk of psychiatric disorder compared to sighted peers.

Similar findings were reported by [Guide Dogs UK](#) (internal report, 2020), based on mixed methods research with 170 parents and guardians from across the UK. The study found that for children diagnosed with sight loss later in childhood the stress of diagnosis can lead to mental health conditions. However, the study highlighted that the impact of a childhood V I on wellbeing and mental health is difficult to measure at a younger age; this was attributed to young children appearing unaware of the potential impact of their condition.

6.2.2 Mental health support

[Harris and Lord \(2016\)](#) found that V I is associated with children's psychosocial adjustment by the age of 11 years and that 20% to 30% of children with V I may need professional support and advice at this critical time. Further, they suggested that child and adolescent mental health services should consider how those children with V I at high risk of mental health problems can be identified and what forms of treatment are most likely to be effective. [Augestad \(2017\)](#) also proposed that early detection of mental health problems among children with V I may contribute to their mental well-being if appropriate interventions are put in place.

Information empowers parents and children with V I. However, access to trustworthy information to aid understanding and manage the impact of a child's V I is mixed and often not timely (Guide Dogs internal report, 2020). Guide Dogs UK (2020) research on the lived experience of children with sight loss and their families found that 68% of parents and guardians agreed that there was not enough support available to them at the point of diagnosis. Over half (59%) of parents and guardians surveyed also agreed that access to emotional support to help them and their child come to terms with V I was extremely important. More research on what helps to support CYP in relation to their sight loss and mental health compared to research that explores prevalence and causal associations would be particularly helpful.

7 Impact of V I diagnosis on mental health in adults

7.1 Receiving a diagnosis

Receiving a diagnosis of a long-term illness is a profound event in peoples' lives, with consequences for daily living, mental health, and self-identity. Being diagnosed with an eye condition leading to sight loss, in particular, is life-changing and can be experienced as an emotional and traumatic event.

Reactions to a diagnosis of sight loss can vary based on prognosis, personality, perceived impact on daily life, and the emotional/social support available. A review by [Garip et al. \(2019\)](#), of qualitative papers on experiences of adults living with RP, observed that fear, shock, disbelief, devastation and loss were common upon diagnosis. Papers also reported that people with RP often search for meaning to understand why RP has happened to them, including genetic or non-genetic explanations.

A [qualitative study](#) into the experience of living with dry AMD in the UK found that the chronic, untreatable and slow progressive nature of the condition generated feelings of hopelessness and despair in participants, following diagnosis. This contrasted with other age-related conditions, for example glaucoma, that may cause significant emotional and physical burden to the patient but are treatable, which gives patient's confidence that they can manage their condition. These findings suggest that prognosis can have a mediating effect on the relationship between sight loss diagnosis and mental health.

[RNIB's 2023](#) assessment of pain points along the eye care support pathway highlighted how treatment pathways for eye conditions can be complex and slow. Waiting happens at every stage of the pathway but, the wait to see a specialist for a diagnosis was identified as particularly stressful and an inevitable time of worry. Similar findings were reported by interviewees in a UK study by [Ferrey et al. \(2022\)](#), with almost all participants ($N= 18$) referencing the long, often convoluted process of being diagnosed. For many patients, the gap between initial identification, through a visit to an optometrist for a routine eye test, and the final diagnosis triggered feelings of frustration, panic, anxiety, uncertainty and worry. Patients described a prolonged and emotional

period, characterised by long waits, multiple tests and sometimes no definitive diagnosis.

7.2 Transition period after diagnosis

7.2.1 Process of emotional adjustment

Although each person who lives with sight loss will have a different experience, there will inevitably be a period and process of coming to terms with their diagnosis and prognosis. The emotional impact of sight loss may not occur immediately and can arise months or years after initial diagnosis (Guide Dogs UK internal report, 2021).

The [experience of adjusting to sight loss is often likened to that of grief](#), with similar feelings of immense loss and the slow process of accepting a new way of living and a potentially changed identity. A UK study by [Boagey et al. \(2022\)](#) provides qualitative exploration of the psychological impact of sight loss, including coming to terms with diagnosis, and the effects on mental health and on identity. Themes related to the psychological impact of sight loss in the study centred around aspects of loss, denial and acceptance. Patients described stages of coping with the psychological impact of their diagnosis, similar to the five stages of grief identified in the [Kubler-Ross model](#). Many participants ($N= 18$) referenced the concept of denial in relation to their vision loss, either in terms of refusing to accept current constraints on their vision or denying that the eventual outcome might be complete sight loss.

A profound sense of loss, of abilities, interests, identity, social support and role in society was also evident in a 2019 [systematic review](#) of coping with RP, which included 3 UK studies. Moreover, the authors suggested that a person's subjective perception of the impact of RP on their physical, psychological, social functioning and wellbeing, and how they adjust to a diagnosis, are likely influenced by several intrapersonal factors, for example, coping skills and self-identity.

The wider academic literature indicates that intrapersonal factors play a significant role in the psychological outcomes of sight loss, regardless of the condition diagnosed ([Sturrock et al. 2016](#); [Masswinkel et al. 2020](#)). For example, problem solving skills, adaptive coping strategies and greater acceptance of sight loss seem to influence mental health outcomes in people with V I ([Holloway, 2017](#); [Garip et al. 2019](#)). However, there is a paucity of research exploring this topic in the UK.

Looking to understand the role of intrapersonal factors in determining psychological outcomes of low vision, research in [Australia](#) explored the mediating role of coping self-efficacy between two types of illness cognitions (i.e., acceptance and helplessness) and depressive symptoms in people with low vision. Illness cognitions occur in response to chronic disease/disability when an individual has evaluated how much his/her condition could impede daily and goal-oriented actions. The authors describe helplessness illness cognitions as a preoccupation with the adverse effects of low vision, its permanence and unmanageability with regard to everyday functioning. In contrast, acceptance illness cognitions involve acknowledgement of low vision and confidence in living with, and adapting to, the limitations.

The study comprised 163 patients (mean age 62 years), most with AMD (26%, $n= 43$) and moderate V I. Results found that lower levels of acceptance and higher levels of helplessness illness cognitions were associated with lower self-efficacy in problem-focused coping, which in turn was associated with greater depressive symptom severity. The authors suggested that psychological interventions that promote adaptive illness cognitions and increased problem-focused coping self-efficacy may be successful in reducing depressive symptoms in people with low vision.

Similar findings were reported in a Dutch study by [Maaswinkel et al. \(2020\)](#), who explored the influence of mastery and self-esteem on the relationship between visual acuity and mental health. Mastery is defined as the extent to which someone feels in control over his/her life and environment while self-esteem is the way someone evaluates their own self-worth, which is influenced by interactions with others. The longitudinal cohort study ($N= 2,599$) found that the association of V I and depression is mediated by an individual's sense of mastery and self-esteem. When self-esteem was included as a potential mediating factor, the effect of visual acuity on the development of depression reduced by 25%, and with mastery included as a potential mediating factor, the effect of visual acuity on the development of depression reduced by 79%. This indicates that a greater sense of mastery and self-esteem can have a positive effect on the relationship between V I and depression.

Identification of intrapersonal factors is important to better understand the psychological impact of V I and how best to treat individuals with appropriate interventions that promote adaptive coping strategies.

[Masswinkel et al. \(2020\)](#) proposed that recognising these factors, may help to identify those who are at risk of developing depression and enable interventions at an earlier stage. Research to elucidate the mediating effect of intrapersonal factors on visual acuity and depressive symptoms in the UK may be of value.

7.2.2 Clinicians' delivery of diagnosis

RNIB's 2023 report on the [eye care support pathway](#) highlighted a lack of empathy at the diagnosis stage and a focus solely on the eye condition and not the person as a whole. This confirms earlier findings by [Garip et al. \(2019\)](#) about experiences with healthcare professionals in the diagnosis of RP. A review of 12 papers found that physicians and clinicians' language use with people newly diagnosed with RP could be broadly categorised into three groups: blunt, vague, and mild. This in turn generated feelings of devastation, anxiety and hopefulness among patients.

[Qualitative research](#) in the UK, which explored the effect of clinicians' delivery of a diagnosis of eye disease on the patient experience, found that the words, tone of voice and demeanour of optometrists, ophthalmologists, nurses and other professionals had a significant impact on patients, especially in terms of the way they were informed of their diagnosis. Patients in the study stated that they remembered the clinician's words for years after diagnosis. Findings indicated that the way a diagnosis is presented can affect how a person feels about their condition and their ability to come to terms with their diagnosis. The time around diagnosis is a vital part of the patient journey and the manner with which bad news is delivered can have a lasting impact on patients. The importance of empathic communication and the need for communication skills training in ophthalmology training is discussed further in section 9.

7.2.3 Lack of information and guidance

The importance of appropriate and timely information and support at the point of diagnosis has been highlighted throughout the literature. The [2022 V I Lives](#) report confirmed that there remains insufficient information, guidance, empathy or support at diagnosis. The initial transition after diagnosis is the most difficult and people expected there

to be more practical and emotional support from medical professionals, alongside more signposting and quicker referrals to social care and V I organisations. The report suggested that a lack of information and understanding about the impact of their condition, what support is available, and how to access it, led to an initial sense of denial for many people.

Participants in a study by [Ferrey et al. \(2021\)](#) also reported a lack of information at diagnosis. They felt lost and unsupported, prompting many to search for information on their own from potentially less reliable sources online. Most were clear that they wanted to know about their condition and prognosis and to understand why particular tests were being done. However, participants worried about coming across untrustworthy information online and were sometimes confused about the terminology. [Trott et al. \(2023\)](#) highlighted similar findings in their qualitative study of mental health support across the eye care pathway. Participants reported that they had not proactively received support at the point of diagnosis, and the majority stated they did not know where to go for support should they need it. The study suggested that any gap in receiving information and support has the potential to directly affect a patient's adjustment to diagnosis, quality of life and mental health.

8 Eye care services for adults: barriers to, and facilitators of, mental health support

The complex and fragmented nature of eye care service provision in the UK has been frequently reported across the [academic](#) and [grey literature](#). [RNIB's](#) 2023 eye care support pathway report reiterated that demand for eye care is at an all-time high and is increasing. Based on data from [NHS Digital](#), the report estimated that across the UK nearly 850,000 people are waiting for eye care treatments, one of the largest waiting lists of all NHS specialities. Furthermore, there are more people entering the eye care clinical pathway than being treated, and there is an inability to meet the increased demand due to workforce gaps. The report suggested that problems accessing eye care services and delays to diagnosis and treatment can lead to poorer quality of life and high levels of stress and anxiety for people while they wait. Thus, it was observed that a transformation of eye care services is required to make the system fit for purpose and to improve outcomes for people with sight loss.

8.1 Barriers to mental health support

The considerable variation in the level of eye care service provision across the UK has been well documented ([Menon et al. 2020](#); [Trott et al. 2023](#)). Patients with V I require access to a range of support services for help with all aspects of their impairment, daily living and well-being; this includes rehabilitation, mobility training, access to low vision aids and emotional support. However, it is commonly reported that most patients receive inadequate information about the options available to them and most find it difficult to navigate the various agencies independently. For adults from minority ethnic communities living with V I there may be additional cultural barriers, such as language and accessible formats, that impact service use and support needs along the eye care pathway. A review by [Heinze et al. \(2023\)](#), to explore current knowledge of the experiences of adults from minority ethnic communities with V I in the UK, found that people from minority ethnic communities may experience V I at different life stages to those from majority white communities, resulting in different support needs. Moreover, the review highlighted the need to further explore the experiences and support needs of different ethnic communities and the extent to which these needs are met by service providers.

The V I sector in the UK is expansive and complex, overlapping with different aspects of the healthcare system, social care, and third-sector organisations. Currently, there is no national strategy for eye care in England. A [think tank review \(2023\)](#) of the V I sector noted that around 200 Care and Commissioning Groups and many local authorities have different guidelines and recommendations, which leads to patchy local provision and some parts of the country where there is no specialist provision.

Although mental health support, including counselling, patient support groups and primary care, has been shown to be beneficial to patients with V I, [Trott et al. \(2023\)](#) observed that current provision of mental health support to patients across the UK's eye care pathway is largely unknown. Further, it is not known how much mental health signposting referring practitioners offer. The study involved semi-structured interviews with 28 participants of which 18 were patients with varying eye conditions, 5 were referring optometrists and 5 were ECLOs. Findings showed that the processes of mental health referral and signposting to support services remain unclear, both to patients and practitioners. The study provides preliminary evidence that the provision of mental health support across the eye care pathway is likely to be poor throughout the UK and is unlikely to be delivered as standard practice in most areas. The authors noted limitations within the study, with the sample drawn from as wide a range of geographical locations in England as the scope and scale of the project permitted. Future research is warranted to examine the provision of mental health support in more granularity across the UK.

8.2 Facilitators to mental health support

In November 2022, a motion was put forward to bring in a Bill for a [national eye health strategy for England](#). The motion called for the strategy to include:

- An eye health and sight loss pathway to require care and support for those with sight loss. The pathway must focus on the physical and emotional impacts of being diagnosed with sight loss. It should address geographical and minority population eye health inequalities.
- Improved connections between primary and secondary care, with an emphasis on integrated care systems and improving the collaboration

across the two services to improve patient experience and health outcomes.

- Workforce expansion, placing emphasis on the recruitment, training and upskilling of medical and non-medical eye health professionals.
- Raising awareness of eye health, along with improved signposting on where to go for help, by creating better public health messaging.

For such a strategy to be successful and of value, the motion stressed the importance of designing it in collaboration with stakeholders, including blind and partially sighted people, civil society groups, care providers and the industry. Further details are provided in Appendix A.

The Welsh government published its [eye health care strategy](#) for NHS Wales in 2021, produced in collaboration with key stakeholders including the Welsh government, Optometry Wales and the Royal College of Ophthalmologists in Wales. The strategy set out several objectives ranging from early detection, diagnosis, and treatment of eye conditions in primary care optometry and a fully integrated eye care pathway where care is transferred seamlessly to a patient experience that is based upon effective communication and active involvement in decisions (see Appendix A).

The need for an integrated eye care pathway is similarly echoed in the academic literature. [Trott et al. \(2023\)](#) noted that shared standards of care and close cooperation between primary care optometrists and GPs, secondary care optometrists and ECLOs, and secondary care psychiatry and community mental health and social care professionals and service providers is an important facilitator in ensuring that a patient's need for mental health services is ascertained across the whole eye care pathway. Further large-scale studies and routine mapping of the availability and nature of mental health support services for people with V I, across all four nations of the UK, would be beneficial.

9 The role of eye care practitioners

Within the literature there is a consensus that eye care practitioners should be alert to the risk factors for mental health problems in people with V I. [Braakman et al. \(2023\)](#) highlighted that for patients it is essential that practitioners understand V I as well as the impact it has on the patient's quality of life and mental health. Qualitative research conducted in the [Netherlands](#) revealed similar insights from patients receiving support from three low vision service organisations.

Participants stated that practitioners should have a constant focus on possible mental health problems in people with V I, from the point of diagnosis until the end of rehabilitation. In the UK, [Nollett et al. \(2019\)](#) demonstrated that for patients with V I there are several risk factors for depression which can easily be identified, for example, the presence of a chronic physical health problem. As such, the authors recommended that all clinicians working with people with sight loss are alert to these factors and if a patient is identified as having likely depression, they should be referred to an appropriate professional/service.

9.1 Provision of information, signposting and support

[NICE guidelines](#) for depression in adults recommend that practitioners working with people with depression build a trusting relationship and work in an open and engaging manner. In addition, people with depression should be made aware of peer support groups and other local resources and be provided with up-to-date and evidence-based verbal and written information about depression and its treatment, appropriate to their communication needs. In line with NICE principles of care, an [RNIB report \(2022\)](#) called for a patient-centred approach to accessibility and provision of emotional support for people with V I. The report recommended that information should be tailored according to the patient's needs and level of competency because some patients may prefer all information at diagnosis, whilst others may want it incrementally through all stages of the eye care pathway.

A systematic review by [Garip et al. \(2019\)](#) reported similar findings about the importance of adopting a patient-centred approach to diagnosis and patient support. The review found that patients living with RP often turned to healthcare professionals to help make sense of their diagnosis at an intellectual, practical, and emotional level, though the need for, and importance of, each of these levels of information varied from patient to

patient. The review suggested that training eye care professionals to adopt a patient-centred approach could minimise some of the distress people with RP experience at the time of diagnosis.

Similar issues with insufficient information at the point of diagnosis were reported by [Ferrey et al. \(2022\)](#), who found that patients who had attended ophthalmic appointments in primary and secondary care and in opticians in the South of England would have appreciated more information about the potential course of their eye condition, including timelines and potential outcomes. Patients also expressed that an opportunity to speak to someone about living with a V I would have been particularly valuable. Moreover, patients felt it would have been helpful to them to have been signposted to services, such as charities or referral to counselling, when first diagnosed.

[Studies](#) carried out in the Netherlands have shown a need for practitioners to educate patients with V I about how their impairment impacts both activities of daily life and mental health. Participants in a study by [van Munster et al. \(2021\)](#) experienced difficulties in recognising their mental health problems and some indicated this was due to limited knowledge about the impact of V I on mental health and treatment possibilities. Thus, health literacy seems an important facilitator in helping adults with V I seek mental health support. The study also highlighted that people with V I can face barriers in obtaining health-related information because it is inaccessible. This emphasises the importance of eye care practitioners using accessible and tailored ways of informing people with V I about mental health problems and support services.

9.1.2 Communication skills and training

Most eye care practitioners break difficult news to patients in the course of their clinical practice; these discussions include diagnosing V I, explaining visual prognosis and proposing how to treat and/or manage an eye condition. Conducting such conversations requires empathy, clarity, and confidence since they can set the tone for how [a patient will view, respond to, and cope with a diagnosis of V I](#).

[Nollett et al. \(2019\)](#) interviewed 12 low vision practitioners and surveyed 122 to understand if/how community low vision practitioners identified and managed depression in patients. Results highlighted that

practitioners generally lacked confidence in their communication skills around depression and feared that by talking about possible depression, they could be perceived as being nosy or inappropriate or upset the patient, doing more harm than good. The study suggested that practitioners require training to improve their knowledge of depression and communications skills, including how to initiate and contain a conversation about depression and how to respond to emotion from the patient.

In the context of dry AMD diagnosis specifically, [Taylor et al. \(2020\)](#) concluded that those working in eye care settings should undergo regular training on communication skills related to breaking bad news. This may prove beneficial in reducing the negative psychological effect on patients of receiving bad news, if communicated in a more sensitive manner, while also minimising any associated negative effect on the practitioner delivering the news. However, research exploring communication skills training in ophthalmology, including pilot studies, remains limited within the UK.

Looking to address gaps in communication skills training in ophthalmology residency programmes (i.e., postgraduate education), a study in the [US](#) conducted a needs assessment and piloted a communication training workshop with post-graduate students. Ophthalmology programme directors ($n= 45$) across the US were questioned on their perception of resident communication skills training through an online survey, and a targeted needs assessment - in the form of a narrative exercise - captured resident perspectives ($n= 15$). A group of 8 residents participated in the pilot workshop and a pre- and post-survey assessed its effectiveness. Results from the pre-workshop questionnaire indicated that residents experienced anxiety, frustration, empathy, exhaustion and insecurity/sadness when having difficult conversations with patients. Seven of the 8 residents noted that the emotions they experienced affected the patient care they provided. Pre-workshop, the residents reported a median score of 3.0 on their abilities to manage their emotions during difficult conversations. Post-workshop, there was a significant improvement in their scores with a median score of 4.0. The study results showed that there is a need to further develop and implement formal training that teaches residents to lead difficult conversations with patients. A similar exercise in the UK may be of value.

9.1.3 Lack of confidence and knowledge

[Nollett et al. \(2019\)](#) interviewed 12 eye care practitioners working in the Low Vision Service Wales as part of a mixed methods study. Analysis identified practitioners' lack of confidence in their knowledge and skills to address depression as a recurrent theme. It was observed that, during the interviews, practitioners were often hesitant and used terms such as "I think" or "I assume" when expressing opinions about depression. Some practitioners cited a lack of knowledge as a barrier to their ability to correctly recognise depression and shared concerns about making an incorrect judgement about a patient, which might lead to unnecessary patient distress. Most practitioners expressed a need for formal training and protocols in order to feel confident about initiating a conversation about depression and referring cases of depression.

Similarly, a study by [Trott et al. \(2023\)](#) found limited evidence of referring optometrists effectively determining whether there was a need for mental health support. Some referring optometrists were not confident in their knowledge of what kind of support was available to patients at the time of referral, which then meant emotional support services were likely to be poorly signposted. The study recommended that further training may be required to support optometrists to do this more effectively.

9.2 Impact of the Eye Care Liaison Officer (ECLO)

9.2.1 Role of the ECLO

Evidence from across the literature indicates that ECLOs are an important source of emotional and practical support to patients - at the point of diagnosis and beyond through signposting and patient referral to eye care services and third sector and social support services ([Menon et al. 2020](#); [RNIB, 2023](#)).

[RNIB's ECLO Quality Framework and Practice Guidelines \(2019\)](#) identify the provision of emotional support to patients, their families and carers, information-giving and making quality referrals as core ECLO activities. Informal emotional support is described as:

'... a combination of listening to the individual, providing a space within which a patient can express themselves, talking through their worries or concerns and being understanding and empathic... At all times the ECLO is independent and non-judgemental and remains person centered.'

A qualitative study that gathered views of health and social care professionals across the UK ($N= 141$) found that the emotional support that ECLOs provide is not only hugely beneficial to patients, but also the work of clinical staff ([Llewellyn et al. \(2019\)](#)). Clinical staff reported that they simply did not have the time to provide emotional support and practical advice to patients about living with sight loss. ECLOs were found to streamline the certification of V I process and play an important role in referring and signposting appropriately and according to the needs of patients, in a timely manner. These findings suggest that the skills and time of ECLOs can enhance and add capacity within a clinic to make for a more efficient service that better meets the emotional and support requirements of patients.

The study also found that clinical staff felt the presence of ECLOs in clinical eye services helped to make them more of a 'complete' service, which in turn enabled continuity of patient engagement and care. Equally important was the ECLO acting as a bridge between information coming from the clinical team to the patient and ensuring that the voice of the patient was heard by the clinical team. ECLOs can, therefore, be considered as providing a link service for patients between healthcare, social care and the voluntary sector that enables patients to receive the holistic care and support that they require.

9.2.2 ECLO provision in the UK

ECLOs are not a mandatory part of the eye care pathway, despite a 2017 recommendation by the [Department of Health and Social Care](#) that it is good working practice to have ECLOs in hospitals, because they create a valuable link between health and social care and enable joined up support for the patient.

A retrospective observational study, by [Papastefanou et al. \(2019\)](#), analysed patient data collected using the RNIB database for ECLOs, which covered trusts and health boards across the UK, in the first quarter of 2015. A total of 4,139 patients were assessed by ECLOs (the most prevalent age range of patients was 80 to 90 years - 20.5%), and a total of 13,240 ECLO meetings for all the UK countries were recorded. In all ECLO meetings, eye condition and treatment was the most frequently discussed topic (21.2%), while emotional support was discussed in only 2% of ECLO meetings and local support services in 14% of meetings. The authors suggested that whilst patients find low vision services

largely very useful, some form of psychological evaluation in order to provide emotional support at an earlier stage may be of benefit.

RNIB's 2023 report on ECLO coverage in the UK (available upon request) found that 68.7% out of the top 150 ophthalmic footfall sites in England had ECLO provision, inclusive of both trained and untrained ECLOs (see Table 7). Moreover, it was observed that there are now a total of 32 private providers within the top 150 sites.

ECLO provision	<i>n</i>	%	<i>FTE Approx.</i>
Sites with trained ECLO*	91	60.7	110.4
Site with non-trained ECLO	17	11.3	19.3
Sites with any ECLO	103	68.7	129.7

*RNIB recognise an ECLO as someone who is qualified on the Eye Clinic Support Studies Course, is paid and working to the RNIB Quality Framework for ECLO Services.

Table 7: Statistics for the largest 150 sites in England by ophthalmic footfall. Source: RNIB (2023) UK ECLO Coverage.

All Health Boards in Northern Ireland, Scotland and Wales Ireland have a qualified ECLO service, with the exception of NHS Lanarkshire in Scotland (see Table 8).

UK nation	<i>Number of Health Boards covered</i>	%	<i>FTE Approx.</i>
Northern Ireland	5	100.0	10 (including locum)
Scotland	14	93.0	16.9 (including locum)
Wales	7	100.0	10.6

Table 8: Statistics for ophthalmic footfall sites in Northern Ireland, Scotland and Wales. Source: RNIB (2023) UK ECLO Coverage.

Research by [Menon *et al.* \(2023\)](#) found that 8% (105/1247) of patients attending [University Hospitals Birmingham NHS Trust](#), during the year 2019, received emotional support from the ECLO, while 45% (560/1247) were supported through the CVI registration process and 13% (156/1247) received low vision support. The study defined emotional support as 'encouraging patients to voice their concerns and providing focused information advice and guidance'. Furthermore, it was highlighted that the ECLO provides much needed continuity of care and ensures long-term access to support services for patients as their needs continue to change and evolve over time.

There is agreement across the literature that ECLOs are a core patient service within ophthalmology, and they have a beneficial impact on patients' emotional, practical and physical adjustment to sight loss. However, in the UK it remains that ECLOs are not fully integrated into NHS eye care pathways across all hospitals. [Llewellyn *et al.* \(2019\)](#) suggested that gaps in signposting and referral may persist unless the ECLO is formally incorporated as part of a patient-centred care pathway. The authors noted that further quantitative research to determine the optimum level of ECLO support needed in clinics, which would deliver the greatest benefit to the clinic and to patients, would be valuable. In addition, [Papastefanou *et al.* \(2019\)](#) recommended that the assessment of patient reported outcome measures and an understanding of the patients' physical and psychological adaptation process to sight loss are much needed to support the evidence-base for the expansion of appropriate ECLO services and funding.

10 Mental health interventions and support services

10.1 Holistic approach

As discussed in section 4, the mental health impact of sight loss is often under-diagnosed, and treatment may be lacking. [Demmin and Silverstein \(2020\)](#) identified the tendency of both patients and eye care practitioners to focus on the physical and/or functional aspects of sight loss, or the need to relearn practical skills, rather than the psychological and emotional impact as one reason for the lack of mental health support and treatment for people with V I. It is suggested that this is perhaps based on the misguided assumption that mood will necessarily improve after new skills are learned.

Across the literature, the integration of mental health interventions and support into the eye care pathway is highlighted as key to offering an effective, holistic support service for patients. [Garip et al. \(2019\)](#), for example, stated there is a need for a holistic and multidisciplinary approach to understand and support people with RP, that takes into consideration the psychological and psychosocial impacts of sight loss. This approach is applicable for all eye conditions.

The need for mental health support at several stages of the eye care pathway has been highlighted in the literature. Qualitative research, by [Trott et al. \(2023\)](#) found that ECLOs considered it necessary for mental health support to be available throughout the stages of someone's sight loss journey because each person goes through the grief and loss cycle in their own time. In the context of RP, [Garip et al. \(2019\)](#) suggested the importance of future research on longitudinal interviews with people with RP from diagnosis to advanced stages of RP to explore how transitions in identity are experienced and resolved, and to identify optimal points in the RP trajectory to provide relevant support. Similarly, for V I in general, [Boagey et al. \(2022\)](#), found that as vision changes, a person's identity and thought processes continually adapt, making it likely they will require intervention at multiple points on the sight loss journey.

10.2 Depression Screening

The [UK National Screening Committee](#) states that the purpose of screening for depression in adults is to detect undiagnosed cases of

depression, of any severity, with the aim of preventing progression to depression of greater severity. Moreover, it is suggested that screening could provide an opportunity for health professionals to begin a discussion on the underlying causes of depression symptoms.

[NICE](#) guidelines advise practitioners working in primary care and in general hospital settings to be aware that patients with a chronic physical health condition are a high-risk group, particularly where there is functional impairment, and they suggest practitioners consider asking patients two screening questions, with referral for assessment if the result is positive. Despite the high prevalence of depression in adults with V I and those using low vision services, screening for depression is not currently routine practice within the eye care pathway.

There is some debate in the literature about the pros and cons of routine screening for depression, both in the [general adult population](#) and the [adult V I population](#). However, evidence from recent [UK](#) and [Dutch](#) studies has suggested that screening for depression among adults with V I, in low vision settings and primary care, can lead to the identification of new cases and early intervention.

A study by [Nollett et al. \(2019\)](#) found that 87.7% (107/162) of practitioners working in the Low Vision Service Wales did not use a screening tool to identify depression. Only one third of practitioners who completed an online questionnaire reported that they aimed to identify depression in their patients. Qualitative data revealed that those who did try to identify depression relied on cues from, and conversation with, the patient to get a general feeling about whether someone may be depressed. Findings indicated that before implementing routine depression screening in low vision services, practitioners need training to improve their confidence, knowledge and communication skills. It was also suggested that clear referral pathways to a GP for further assessment, and accessible mental health services should be available to address the patient's needs in a timely manner and ultimately to improve patient outcomes.

To explore the potential for those who provide low vision services to perform depression screening, [Bartlett et al. \(2020\)](#) undertook a mixed methods study to assess the impact of a training programme on practitioners' confidence and behaviour in identifying depression in patients attending the Low Vision Service Wales. Prior to training, participants ($n= 180$) had no formal guidance on how to identify

depression. Post-training, risk of depression was determined using the two Whooley questions (see Figure 2).

1. During the last month, have you often been bothered by feeling down, depressed or hopeless?
2. During the past month, have you often been bothered by having little interest or pleasure in doing things?

Figure 2. The two Whooley questions as recommended by NICE for the consideration of depression in adults with a chronic health problem which impact on daily functioning. Source: [Bartlett et al. \(2020\)](#)

Of the 148 practitioners who completed low vision assessments pre- and post-training, 28 (18.9%) documented risk of depression in their patients pre-training, which increased substantially to 65 (43.9%) post-training. Practitioner confidence increased following training, with 92.3% feeling more confident to approach emotional and mental health issues with patients and 92.2% intending to use the recommended screening tool to identify depression. In the 6 months prior to training, a total of 3,569 patients were seen. Of these, 118 (3.3%) were identified as at risk of depression. In the 6 months following the training, a total of 239/4209 (5.7%) patients were identified as at risk of depression. Whilst the two Whooley questions appeared to have ease of application and validity, it was noted that they have not yet been validated for use within the primary eye care setting. Such a validation could, it was suggested, include comparison of patient screening scores to formal recognition by an appropriate professional.

A recent [Dutch study \(2022\)](#) investigated the process of implementing the Patient Health Questionnaire-4 (PHQ-4) in three nationwide low vision service organisations to improve the identification of anxiety and depression among adults with V I. PHQ-4 consists of 4 questions and is a combination of the validated PHQ-2 questionnaire for depression and the Generalized Anxiety Disorder (GAD)-2 questionnaire for anxiety (see Appendix C for more information). Participants included clients with V I (18 years and older), health care providers and managers.

In general, health care providers were positive about implementing the PHQ-4, because it provided them with the opportunity to detect mental health problems, offer appropriate care, and monitor clients. It was reported that some health care providers doubted their ability to administer the PHQ-4 due to lack of confidence, knowledge and self-efficacy, which indicates the importance of training prior to implementation. In line with [previous studies](#), health care providers indicated a preference for training to increase their knowledge on depression and anxiety and in administering the PHQ-4, resulting in higher confidence and greater likelihood of using the tool.

Overall, the study suggested that the PHQ-4 is an appropriate screening instrument for use in low vision service organisations because of its proven specificity for detecting depression and its adaptability for use in adults with V I. Furthermore, it was shown to provide opportunities to detect depression and anxiety early, provide appropriate care, and monitor mental health. To support implementation of the PHQ-4, the authors recommended training health care providers in how to ensure confidentiality; have an open, non-judgemental attitude; probe adequately to obtain more information; and listen to their clients while recording their responses accurately.

Research exploring the implementation and efficacy of the PHQ-4 in screening for depression and anxiety in UK-based low vision services and primary eye care settings could yield useful results and help to progress debates about the adoption of standardised screening, and the most appropriate screening tool for V I patients.

10.3 Counselling provision for adults with V I

[Research](#) suggests that counselling, delivered as part of rehabilitation services, can contribute to improved mental health among adults with sight loss. Results from the Macular Society's 2022 internal client questionnaire, completed at the start and end of 6 counselling sessions, to measure level of low mood, anxiety and hope for the future revealed a 41% positive increase among respondents ($n= 602$). A review by [Garip *et al.* \(2019\)](#) revealed similar findings among patients with RP. Patients who had participated in counselling reported finding it helpful to alleviate anxiety and to adopt a more helpful perspective around RP. Whilst there is some evidence of the beneficial impact of counselling for adults with V

I, there remains limited data on the provision and impact of counselling on mental health and patient outcomes in the UK.

Specialist accredited counselling for blind and partially sighted people is provided by organisations such as [RNIB](#) and the [Macular Society](#), while [Moorfields Eye Hospital](#) offers counselling via specialist nurse counsellors. The Macular Society has observed a year-on-year increase in referrals, from a total of 264 referrals in 2019 (pre-pandemic) to 602 referrals in 2022, and there is an expected further increase to 650 referrals by the end of 2023 (Internal reporting). Respondents of [Retina UK's 2022](#) sight loss survey were asked about their take-up of services, including counselling, and the extent to which these made a positive difference to their lives. 25% of respondents ($N= 673$) had accessed counselling and, of those, 65% reported that it made a positive difference to them. These findings point to a need for people with sight loss to access emotional support in the form of counselling.

[Pybis et al. \(2016\)](#) remains the largest UK study to explore the provision of emotional support and counselling for people with sight loss. Survey respondents included service providers from voluntary sector organisations (50%, $n= 91$) and the NHS (32%, $n= 58$), with the remaining respondents comprising a mix of providers (e.g., private, social care and other settings). Of those identifying as being part of the NHS, 91.4% ($n= 53$) were based within an eye clinic. Counselling was provided by 44.2% ($n= 68$) of respondents and was typically delivered by a person-centred (45.8%, $n= 27$) therapist; the majority were members of a professional body (74.1%, $n= 43$). Services were available to a wide range of clients, with the majority (70.5%, $n= 91$) being available to adults with V I (see Table 9).

Who are services available to	%	<i>n</i>
Friends of someone with a V I	33.3	43
Children (0-11 years) with a V I	37.2	48
Children (11-18 years) with a V I	45.7	59
Adults with a V I	70.5	91

Older people with a V I	56.6	73
Those registered with sight impaired (partially sighted)	55.0	71
Those registered severely sight impaired (blind)	55.0	71

Table 9: Who counselling services are available to (percentages add up to more than 100 as respondents could select multiple options. Source: [Pybis et al. \(2016\)](#)).

The survey found that most referrals to emotional support and counselling services were self-referrals, suggesting eye clinics and GPs may not be regularly referring people throughout the eye care pathway. As such, the study highlighted that counselling needs to be available at the point of patient need, which may not always be at the time of diagnosis. The authors also advocated for the introduction of a national framework of emotional support and counselling to ensure the provision of standardised support for all people affected by sight loss when needed.

In recognition of a real and urgent need to provide accessible and appropriate counselling to those affected with sight loss, a study by [Gray et al. \(2023\)](#) evaluated the efficacy of a volunteer-delivered counselling and emotional support service (CESS) in the UK, run over a 3-year period. Volunteer counsellors included those with and without sight loss, and all received a week of intensive training on the impacts of sight loss and were supported by a Senior Counsellor. The counselling was integrated into a comprehensive package of care and rehabilitative services and, where possible, clients were offered access to counsellors who had a V I themselves.

Clinical outcomes for 817 service users, assessed pre- and post-service use, showed a significant positive change in all clients. Post-counselling assessment showed a significant improvement in psychological distress for all clients, with the mean number of clients reporting severe problems with depression and anxiety decreasing from 18.952 to 11.011 (assessed using the Clinical Outcomes in Routine Evaluation system). Qualitative findings from counsellors emphasised the benefits of the specialist volunteer service for clients as a 'safe' space to discuss issues. Specialist training and access to V I counsellors was seen as a

key element of the success of the service, allowing clients with V I to feel understood by someone with the same/similar lived experience. Moreover, qualitative findings showed that volunteer counsellors who had sight loss considered themselves as having an important role in terms of modelling positive experiences of living with sight loss.

The study findings are limited by the lack of a control group, which means that the clinical change in clients cannot reliably be attributed solely to the provision of the CESS. However, additional research comparing different forms of counselling service provision with a V I and control group could help to inform future models of this type, as a means of widening access and facilitating specialist peer support.

10.4 Adaptations in mental health interventions and support for people with V I

A range of psychological interventions, for example cognitive therapy, are regarded as evidence-based treatment options for various mental health conditions in the general population ([Connolly-Gibbons et al. 2016](#); [van Agteren et al. 2021](#)). However, [recent studies](#) have highlighted that the provision of psychological support for people with V I should be evidence-based and designed specifically to address the concerns and needs of this population since general interventions have been suggested to be [less effective when applied to people with V I](#). Compared to the large body of research in the general population, research on the adaptation and efficacy of psychological interventions to improve mental health in people with V I is still in its infancy.

A review by [Demmin and Silverstein \(2020\)](#) found that among people with AMD, modified cognitive-behavioural interventions have been used to improve depression and anxiety symptoms, with some success. In one study, it was found that individuals with blindness receiving Rational Emotive Behaviour Therapy (REBT), a form of cognitive therapy, reported significant reductions in irrational beliefs, depression, anxiety, and stress and improvements in self-esteem, while these same changes were not observed in the control group. The review also highlighted that self-guided cognitive behavioural treatment has been shown to lead to a significantly greater reduction in depressive symptoms among patients with AMD relative to other interventions. [Demmin and Silverstein \(2020\)](#) suggest that, together, these study findings indicate that cognitive

behavioural interventions may be effective in improving psychological functioning of adults with V I.

Whilst no studies have been carried out in the UK on the adaptation of mental health interventions and support for adults with V I, a [Netherlands-based Delphi study](#) found that, in psychological treatment, clients require individual adaptations for their specific V I. The study identified seven factors (detailed in Appendix D) that should be addressed when adapting mental health treatments for adults with V I: the visual impairment, environment, stressors, emotions, treatment-setting, the professional's role and attitude, and accessibility of materials.

Results showed that the severity of the V I and the point in lifetime at which the client became visually impaired greatly influenced the extent to which adjustments should be made in psychological therapy. Findings also highlighted the importance of professionals being aware of the seven factors to help them understand the needs of clients with V I and mental health problems, and to adjust treatment accordingly. Finally, it was considered important to perform a continuous evaluation of patient treatment and to 'fine-tune' the method to the client's specific needs as they evolve. Developing tailored, targeted mental health interventions aligned to the specific lifestyle changes, thoughts, and feelings that commonly accompany sight loss, may increase the success and take-up of such interventions.

Findings from a meta-analysis by [Demmin and Silverstein \(2020\)](#) indicated that, overall, there is evidence of mild-to-moderate effects of existing approaches for treating mental health conditions in people with V I. Additionally, a shortage of knowledgeable mental health practitioners with training or practical experience in treating patients with V I may create a barrier to receiving effective assessment and treatment. The study reviewed current approaches to treatment and found that problem-solving interventions may be beneficial in the short-term; however, in one randomised control study, the effectiveness of the intervention was no longer significant after six months. Evidence from the meta-analysis indicated that further work is needed to develop new and specific interventions that can be applied to a wider range of people with V I.

11 Future research

The literature review undertaken in the production of this report has highlighted several areas in which data and knowledge is lacking:

- It is widely acknowledged that sight loss is likely to have a [significant impact on mental health](#) and that for each person diagnosed there is a process of coming to terms with their diagnosis and prognosis. Despite the research cited in this report, there is a relative paucity of longitudinal studies of the long-term impact for patients who receive a diagnosis leading to sight loss, particularly in reference to the evolution of patients' psychological reactions and the process of adjustment after diagnosis.
- Studies adopting qualitative methodologies to understand the experience of living with V I, with respect to diagnosis, the psychological impact of this and emotional/mental health support are underrepresented in the literature. There is valuable qualitative insight from two studies in England ([Taylor et al. 2020](#); [Ferrey et al. 2022](#)), and a growing number of studies emerging from the [Netherlands](#), but the voices of people with V I remain absent in the majority of studies related to mental health.
- Studies in [Australia](#) and the [Netherlands](#) have demonstrated that the relationship between V I and mental health conditions is mediated by intrapersonal factors, such as self-esteem, sense of mastery and coping skills. Yet, no such exploration has been undertaken in the UK. Research in this area would help to provide greater insight into the mediating role of intrapersonal factors and help to establish new possibilities to identify, support and treat those at risk of depression and/or anxiety by addressing these factors in patient assessment, referral and treatment.
- Research suggests that the provision of emotional and mental health support for people with V I varies greatly across the UK and the processes of mental health referral and signposting to support services remain unclear, both to patients and practitioners. Future research to examine the provision of mental health support in more granularity across the UK would help to identify the evidence-base for an integrated eye health and care pathway.

- Research and evaluations on the effectiveness of existing, and new, psychological interventions to improve mental health in people with V I is still limited. Future research may wish to consider the effectiveness of interventions in different age groups and to use longer follow-up measurements to investigate the maintenance effects of interventions. Qualitative studies would also help to shed light on the appropriateness and effectiveness of mental health interventions from the perspective of people with V I.
- The introduction of depression screening in low vision services has been advocated for in [several studies](#) because the prevalence of depression and anxiety is high in people with V I, but more research is needed to investigate the clinical effectiveness of depression screening and the impact on patient outcomes. Further research may also focus on the process from the patients' perspective to determine the desire for and acceptability of screening.
- The literature on the mental health impacts of V I is focused largely on the older adult population, meaning those aged 60 year and above. Consequently, there is a scarcity of research on the mental health effects of V I in younger and middle-aged adults. Research exploring the prevalence of depression and/or anxiety across the entire adult age range would help to increase understanding of the influence of age of onset on the risk of and psychological response to depression and/or anxiety.
- There is a shortage of literature on mental health among CYP with V I, both in the UK and internationally. Most studies are cross-sectional in nature and focus more on the impact of V I to CYPs quality of life, educational attainment, social development, and wellbeing. There is a need for more evidence-based knowledge of mental health problems among CYP with V I and for further longitudinal and randomized clinical trial studies to observe the relationship between V I and mental health and to determine appropriate interventions and support services for CYP.
- [Research outside the UK](#) has considered the importance of educating people with V I about their increased risk of mental health problems and symptoms to recognise depression and anxiety. Research in this area would help to establish how eye care practitioners might destigmatise discussion of mental health and better support patients.

- It is acknowledged that adults from [minority ethnic communities \(MEC\) may be at increased risk of V I](#) and may face cultural barriers to accessing services and support. Yet, research on the experiences of MEC adults with VI in the UK remains limited. Further work to explore barriers and facilitators to the use of eye care services, among MEC adults living with VI, would help to identify the impact of cultural perceptions and attitudes towards V I and mental health, and the different support needs of different ethnic communities.

Appendix A- Overview of eye health care government strategy

National Eye Health Strategy for England

In November 2022, a motion for leave to bring a Bill to require the Secretary of State to publish a [national eye health strategy for England](#) was debated in the House of Commons. The Bill called for the introduction of a strategy to include the following areas:

1. An eye health and sight loss pathway to require care and support for those with sight loss, focusing on the provision of non-clinical community support to complement the work of community optometrists, ophthalmologists in hospitals and rehab officers. The pathway must focus on the physical and emotional impacts of being diagnosed with sight loss, as research has shown that people affected are likely to experience poor mental health lifetime outcomes such as depression and anxiety. It should not only address geographical eye health inequalities but ensure more equity of access to eye care among communities and populations more at risk of being unable to access NHS sight tests, including people who are homeless and people with a learning disability.
2. Improved connections between primary and secondary care, with an emphasis on integrated care systems and on improving the relationships and collaboration across the two services so that they can work more effectively together while ensuring timely and accurate referrals.
3. Workforce expansion, placing an emphasis on the recruitment, training and upskilling of medical and non-medical eye health professionals.
4. Health intelligence and data, focusing on robust data collection to inform decisions and improve the delivery of the service. Advances in research and technology, from how people are diagnosed to how they receive treatment, must be incorporated.
5. Raising awareness of eye health by creating better public health messaging. We need campaigns to raise awareness of the importance of maintaining good eye health and to educate the

public on the differences between eye screening and eye tests, along with improved signposting on where to go for help, should one need it.

The motion also called for the Government to appoint a single Minister with responsibility for eye health rather than having the current situation where multiple Ministers are responsible.

A second reading of the National Health Strategy Bill is scheduled to sit on 24th November 2023.

NHS Wales Eye Health Care. Future Approach for Optometry Services

In 2021, the Welsh Government published a transformation paper, setting out its expectations for the delivery of eye care services over the next decade. The aim is to facilitate a national approach for eye health care services in Wales, a fully integrated workforce and eye care pathways without boundaries. Table 10 below outlines the core strategy objectives for patients, the Optometry profession and Hospital Eye Service.

Patient	Optometry Profession	Hospital Eye Service
Access to eye care services close to home.	Continuous professional development.	Closer working relationship with optometrists and eye care multidisciplinary teams.
Timely access to all eye care services.	IT data and digital tools to facilitate the care of patients along the eye care pathway.	Joint clinical governance arrangements embedded in all eye care pathways.
Supported self-care approach to eye care.	Enhanced working arrangements between optometrists and primary care clusters.	Appropriate health board structures at local, regional, and national levels to enable robust clinical leadership of eye care pathways.

Encourage preventative action to avoid permanent sight loss.	Ensure quality improvement throughout all eye services.	Patients only referred for specialist intervention when clinically necessary.
Early detection, diagnosis, treatment and management of eye conditions in primary care optometry.	Health board lead Optometric Advisers to work in co-production across the professions to ensure smooth integration of eye care pathways.	Increased capacity for specialist services to manage patients and work at the top of their license.
A fully integrated eye care pathway.	A closer working relationship with ophthalmologists and the multidisciplinary eye care team.	
Shared care follow-up between optometry and hospital eye departments when clinically appropriate.		
Patient experience that is based upon effective communication and active involvement in decisions.		

Table 10: Summary of NHS Wales Eye Health Care Strategy objectives.
Source: [Welsh Government, Health and Social Care 2021](#).

Appendix B- Depression and anxiety screening tools

Patient Health Questionnaire-2 (PHQ-2)

The PHQ-2 inquires about the frequency of mood, with a score ranging from 0 to 6. A PHQ-2 score is obtained by adding together the score for each question. Its purpose is not to establish final diagnosis or to monitor depression severity, but rather to screen for depression.

Patients who screen positive, with scores of 3 or more, should be further evaluated with the PHQ-9 to determine whether they meet criteria for a depressive disorder.

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3

Table 11: PHQ-2 screening tool. Source: [United States Government](#), National Library of Medicine.

Patient Health Questionnaire-4 (PHQ-4)

The PHQ-4 is a concise screening tool for anxiety and depression, which combines the PHQ-2 and the Generalised Anxiety Disorder-2 (GAD-2). It has four items, two each from the GAD-2 and PHQ-2, with responses given on a Likert scale. The total PHQ-4 score ranges from 0 to 12. On each subscale, a score of 3 or greater is considered positive for screening purposes.

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge.	0	1	2	3

2. Not being able to stop or control worrying.	0	1	2	3
3. Little interest or pleasure in doing things.	0	1	2	3
4. Feeling down, depressed or hopeless.	0	1	2	3

Table 12: PHQ-4 screening tool. Source: [Patient Health Questionnaire Screeners](#).

Geriatric Depression Scale-15 (GDS-15)

The GDS-15 is a screening tool used to identify symptoms of depression in elderly adults. It is a self-report instrument that uses a “yes/no” format as answers, and 1 point is given to each answer that suggests depression and 0 is given for the other answer. There are total of 15 questions (see Figure 3) and a score of ≥ 5 points suggests depression and should be followed by a comprehensive assessment.

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life? YES / NO
2. Have you dropped many of your activities and interests? YES / NO
3. Do you feel that your life is empty? YES / NO
4. Do you often get bored? YES / NO
5. Are you in good spirits most of the time? YES / NO
6. Are you afraid that something bad is going to happen to you? YES / NO
7. Do you feel happy most of the time? YES / NO
8. Do you often feel helpless? YES / NO
9. Do you prefer to stay at home, rather than going out and doing new things?
YES / NO
10. Do you feel you have more problems with memory than most? YES / NO
11. Do you think it is wonderful to be alive now? YES / NO
12. Do you feel pretty worthless the way you are now? YES / NO
13. Do you feel full of energy? YES / NO
14. Do you feel that your situation is hopeless? YES / NO

15. Do you think that most people are better off than you are? YES / NO

Figure 3: GDS-15 Scoring Questions. Source: Geriatric Depression Scale, [Stanford University](#).

Hospital Anxiety and Depression Scale (HADS)

The HADS was developed to help identify anxiety disorders and depression in people with physical illness and is used in both hospital and community settings. To avoid overlap with physical disorders, the HADS does not include somatic symptoms, such as insomnia, loss of appetite, or fatigue. It is a self-administered scale, with 14 questions in total (seven covering depression and seven covering anxiety). The maximum score is 21. Scores of 8-10, 11-14, and 15-21 represent cut-off points for mild, moderate, and severe depression respectively.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time		3	Nearly all of the time
	2	A lot of the time		2	Very often
	1	From time to time, occasionally		1	Sometimes
	0	Not at all		0	Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much	0		Not at all
1		Not quite so much	1		Occasionally
2		Only a little	2		Quite often
3		Hardly at all	3		Very often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever

		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or tv program:
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not often	2		Not often
	3	Not at all	3		Very seldom

Figure 4: Hospital Anxiety and Depression Scale (HADS) Assessment.
Source: HADS, [BMJ Open \(2018\)](#).

Strengths and Difficulties Questionnaire (SDQ)

The SDQ is a brief emotional and behavioural screening questionnaire for CYP. The tool can capture the perspective of CYP, their parents and teachers. There are three versions of the SDQ: a short form, a longer form which also assesses the impact of difficulties on the child's life) and a follow-up form. The 25 items in the SDQ comprise 5 scales of 5 items each. The scales include:

1. Emotional symptoms subscale
2. Conduct problems subscale
3. Hyperactivity/inattention subscale

4. Peer relationships problem subscale

5. Prosocial behaviour subscale

The SDQ can be completed by CYP aged 11-17 years old, and a separate version by those aged 18 and over. The parent and teacher SDQ can be completed for CYP between 2 and 17 years old.

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with others (food, games, pens etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am usually on my own. I generally play alone or keep to myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make other people do what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on me or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get on better with adults than with people of my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I'm doing. My attention is good.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 5: SDQ for 11-17 years old. Source: <https://www.sdqinfo.org/>

Appendix C- Further explanation of the seven categories identified as important in the treatment of mental health among adults with V I (Braakman et al. 2023)

Category 1: Visual Impairment

Several factors related to V I affect mental health treatment were identified. These include:

- The severity of the V I.
- Fatigue and limited energy.
- When the V I began in the client's lifespan.
- Having to cope with missing visual information, such as non-verbal signals.

Findings indicated that clients with late onset V I experience more loss processing than those who have V I from birth.

Category 2: Social environment

The study suggested that it is important to involve the social environment in the treatment of mental health among adults with V I. Persons with V I depend on relatives for practical help and social-emotional support. The relatives must also deal with grief and loss themselves when their partner is diagnosed with V I. Therefore, during treatment, it is crucial to pay attention to both the client and the client's support network. Psychoeducation for both the client and the people closest to them will support the client individually and their relationships.

Category 3: Stressors

V I clients generally experience more stress compared to people without a V I. Causes of higher stress levels may include feelings of powerlessness, fatigue, dependence and coping with loss. As part of treatment, it was considered important to identify the causes of stress. The study highlighted that many daily tasks require more energy for a person with V I, therefore, stress can quickly build up. Again, psychoeducation can be helpful.

Category 4: Emotions

The study found that the extent to which the client perceives and expresses emotions depends on several factors, such as the client's developmental stage, personality, and environment. The client's trust in the eye/health care professional is also important when discussing emotions during treatment. It was also observed that, during treatment, the professional should focus on clients' non-verbal signals.

Category 5: The professional's role and attitude

Findings revealed that, for clients, it is essential that professionals understand V I as well as the influence it has on their quality of life and psychological problems, and the extent to which the psychological problems can affect V I. This does not automatically mean that the professional will know or decide what the client can or cannot do. Rather, the professional and the client should agree on what the client likes and dislikes in terms of support, and what the client needs from the professional to feel comfortable.

Category 6: Treatment setting

The setting in which treatment is provided was identified as an important factor for clients with V I. The treatment location should be easily accessible for the client. In the case of any group treatments, it is important to consider group composition. For example, it is not preferable to put blind and partially sighted people in the same group because they encounter different types of problems.

Category 7: Accessibility of material

Materials used in the treatment must be accessible to the client and the materials that work best will vary depending on the client. To support this, it is important for the professional to ascertain what type of reading materials the client uses and what they can and cannot see.

[Full Mental Health Insight on the VI Insight Hub.](#)