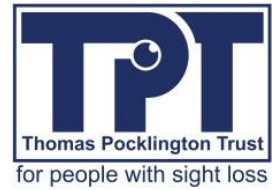




South West London  
**Academic, Health and Social Care**  
System



# **Visual Impairment, Depression and Access to Psychological Therapies**

**A review conducted for Thomas Pocklington Trust**

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A collaboration between South West London & St George's Mental Health NHS Trust, the Thomas Pocklington Trust, and the South West London Academic, Health and Social Care System.

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## **Executive Summary**

This summary reports the findings of a review of the literature on depression and visual impairment including access to psychological therapies for people with visual impairment and common mental health problems, and a preliminary test of brief training in recognising depression for professional and lay individuals who support people with visual impairment. The review is commissioned by Thomas Pocklington Trust, in collaboration with the South West London Academic, Health and Social Care System and was conducted by Ian Petch and Samyukta Mukhopadhyay at South West London and St George's NHS Mental Health Trust.

## **Aims**

The review aims were to

- understand the links between visual impairment and depression and the relevance of psychological treatments
- identify and describe data illustrating the utilisation of psychological therapy services by people with a visual impairment
- identify opportunities to improve access to psychological therapies for people with visual impairment experiencing depression
- test the impact of brief training in recognising depression for lay and professional staff

## **Methods**

The review took place between January and November 2015 and involved three main elements:

- a review of the published literature on vision impairment and depression and examination of national data regarding access to psychological therapies
- scoping meetings and workshops with people with visual impairment and key professionals and lay individuals supporting people with visual impairment
- the testing of introductory training workshops to improve confidence in recognising depression in people with visual impairment and supporting them to access treatment

## **Findings**

### **Prevalence**

The published literature referring to the prevalence of depression in people with visual impairment is characterised by studies adopting varying methodologies although the majority of published studies point to a clear association between visual impairment and increased risk of depression. The strength of association reported appears greater in those studies using convenience samples and those studies reporting rates of depression in visual impairment compared with population norms (rather than control groups). The association between visual impairment and emotional dysregulation occurs at the level of the syndrome (depression) and at the syndrome sub-threshold level (changes that are like those in depression without meeting diagnostic criteria).

### **Pathways to emotional dysregulation**

In examining the literature regarding the links between visual impairment and emotional dysregulation, the association between visual impairment and depression appears to be particularly connected with reported visual functioning rather than visual impairment per se. Visual functioning refers to the extent to which an individual with sight loss is able to carry out activities of daily living. This is a contributory factor that is specific to visual impairment. Further examination of contributory factors to the risk of depression in visual impairment suggests there may be a range of non-specific types. These factors arise in association with the circumstances under which visual impairment is more likely to occur e.g., with increased age and / or in the context of multiple disabilities or illness, or those factors that may arise as a result of visual impairment e.g., social isolation, reduced access to healthcare and reduced access to valued activities. Understanding the link between visual impairment and depression is therefore likely to require a multifactorial formulation of the link between visual impairment and emotional dysregulation. Such an approach is common within the provision of psychological therapies for conditions such as depression.



## **Impact of depression on visual ability and rehabilitation outcomes**

In addition to the personal, psychological and health costs of depression, the published literature suggests that depression adversely affects the rehabilitation outcomes of people with visual impairment. This is explained to some extent by the reduced use of rehabilitation services by people with visual impairment who are depressed (Horowitz et al, 2003). When outcomes are measured in relation to visual ability (a person's overall ability to perform activities that depend upon vision), depression has been identified as one of the strongest independent contributing factors (Goldstein et al, 2014). Additional evidence suggests that, for those in receipt of vision rehabilitation interventions, instrumental interventions aimed at improved adaptation results in limited improvement in depression. This might indicate that vision rehabilitation programmes require depression-specific interventions to address issues such as lost sources of pleasure and confidence (Reeves et al, 2004; Nyman, Gosney and Victor, 2012). The extent of this area of unmet need is illustrated by recent findings reported by Nollett et al (2016) that 43% of attendees at low vision rehabilitation clinics in the UK had depressive symptoms and around three quarters of these people were not receiving help with these symptoms.

## **Access to support and psychological treatments**

Some studies suggest that access to any form of health or social care support for people with visual impairment can be problematic e.g., Hodge et al (2015) and may depend largely upon the initiative and determination of the person with visual impairment to locate support services often with the guidance and support provided by peers. Depression experienced by people with visual impairment, particularly in older people, is often unrecognised (Fenwick et al, 2009; Renaud and Bédard, 2013) with no standard screening procedures in place currently within low vision support or vision rehabilitation services.

National initiatives to address the underutilisation of effective psychological treatments for depression include the Improving Access to Psychological Therapies (IAPT) programme with thirty-five IAPT services established by 2008. National data available from these sites suggests that on average IAPT services are recruiting very small numbers of people with visual impairment for the treatment of common mental health problems. It is not possible to determine from the available data

whether this is the result of not identifying and/or not recording visual impairment as a disability by some services or is the result of a genuine lack of recruitment into treatment of people with visual impairment who have common mental health problems.

Available data suggests there has been a slight increase in the proportion of people aged 65 years and over accessing IAPT services between 2013 and 2015 (5.4% to 6.27%). However, this contrasts with the percentage of this age group expected to access IAPT (12%) given the population age profile and prevalence of depression. As visual impairment increases significantly for people aged over 65 the under representation of older people in IAPT services is of concern as it suggests that people more likely to experience visual impairment are also less likely to access IAPT services.

The review found that there has been limited progress across IAPT services nationally over the preceding five years in the consistency of identifying and recording disability. This means there are significant limitations in the extent to which data available from IAPT services can be analysed. What the data is able to illustrate is that some services are identifying and recording visual impairment as a disability in much greater numbers than other services. This suggests that some IAPT services are being identified as an appropriate source of potential support and treatment for people with visual impairment who have common mental health problems.

The data suggests that where people with visual impairment have accessed an IAPT service, on average, they are equally as likely to remain in treatment, equally likely to engage in routine measurement of progress and appear to present with similar levels of severity of depression and anxiety as those without a visual impairment. Accepting the limitations on drawing firm conclusions from the national data set, this may suggest that, once accessed, IAPT services are proving to be just as appropriate for people with visual impairment as they are for people without visual impairment. This is consistent with one of a small number of studies directly testing the impact of treatments utilised in IAPT services on the management of depression in people with visual impairment (van der Aa et al, 2015 c). A more conclusive evaluation of the effectiveness of IAPT in helping people with visual impairment is only possible where there are substantial increases in the number of people with visual impairment referred to IAPT services.

## **Stakeholder views**

As part of the review a range of stakeholders provided views on the issues of access to treatment and support for people with visual impairment who may have mental health or emotional wellbeing needs. People with a lived experience of visual impairment suggested that initiatives to improve recognition of depression and access to services could make better use of the important roles played by support staff, family and carers in enabling a pathway to mental health services where the person with visual impairment is less likely to be in contact with a GP or other professional.

Stakeholders suggested also that a focus on identifying depression will need to be in the context of establishing rapport and trust, recognise mental health needs against a background of adjustment to sight loss and involve multiple opportunities for support as depression can emerge at different stages of a person's response to sight loss and in recognition of different states of readiness to acknowledge depression.

Both formal and volunteer support staff suggested that they need to be equipped with the necessary knowledge and skills to identify the possibility of depression and support access to appropriate services.

## **Evaluation of a brief service-related training**

The review of the literature, national IAPT data sets and stakeholder feedback suggested that one of the key challenges to improving access to psychological therapies for people with visual impairment and depression lies in the sensitive identification of depression in people with visual impairment. This will need to operate across a pathway that is broader than a traditional healthcare system as people with visual impairment are often receiving support from non-statutory or non-healthcare providers and may have limited routine contact with health services. The final phase of this review therefore focussed on the piloting of a brief training package for volunteer participants aimed at improving knowledge and confidence to identify depression and support a person with visual impairment to access local forms of support and treatment. Participants for the training who volunteered to take part were drawn from a network of formal and volunteer contacts that people with visual impairment might encounter linked with, or external to, the formal healthcare services. Evaluation of the training suggests that this fairly

brief intervention can promote confidence among a broad range of support staff in identifying depression among people with visual impairment and in supporting them to access treatment.

## **Recommendations for further developments**

Brief training provided by IAPT services can improve confidence in identifying possible signs of depression of a broad range of support staff who have regular contact with people with visual impairment. Further evaluation of this training across a larger sample, multiple sites and with a control comparison will help establish the generalisability of the current findings. It will also help establish the key elements of training that are required to achieve the required improvements in detection and referral of people with visual impairment and common mental health problems to support services.

In order to more robustly test the effect of this brief training on referral and access rates to local psychological therapy services further direct measurement of referral and access rates is required. This includes the need for IAPT services to improve their recording of disability data *per se* and more specifically data regarding visual impairment as a disability.

In addition, further studies might assess the impact of such training on improving engagement with visual impairment service led provision of psychological therapies for common mental health needs, such as depression. The findings from this provisional evaluation suggest that people from a broad range of backgrounds, working in a range of visual impairment support settings, felt more confident to identify possible signs of depression. This type of brief training may have the impact of increasing confidence to integrate mental health support interventions into a setting providing support for visual impairment that does not currently do so. The result of this may be to improve access to psychological therapies for people with visual impairment through their provision in visual impairment settings. This has yet to be formally tested and would be a logical next step in the progression of this area of work.

## **1.0 Introduction**

Loss of vision and vision impairment is a significant health issue in the UK with around two million people living with sight loss (Access Economics, 2009). Fear of sight loss may be the most common fear related to loss of sense (Baker and Winyard, 1998; De Leo et al., 1999) and it appears commonplace that being diagnosed with an eye condition can lead to anxiety, worry and uncertainty about the future (Norowzian, 2006; Royal National Institute for the Blind, 2007; Thurston, Thurston and McCleod, 2010). This report focuses on one element of this type of response to sight loss - the association between sight loss and depression.

The first part of this report reviews the literature regarding vision impairment and depression and examines issues related to the recognition of depression and access to appropriate forms of support. In the second part an evaluation of a brief training programme for people involved in supporting those with vision impairment is reported. The training aims to increase the recognition of depression in people with sight loss and improve support for people to access appropriate help. The intervention is provided from within a local service offering support and treatment to people with depression. This service evaluation is considered in relation to the implications for local health, social care, non-statutory and voluntary agencies supporting people with visual impairment.

### **1.1 A note on terminology**

#### **Visual Impairment**

'Visual impairment' is a term commonly used to refer to poor vision and associated disruption of usual activities. 'Vision impairment' may be used in the literature interchangeably with visual impairment, except in instances where it is intended to specifically refer to loss of visual acuity. Visual function is the term used to describe the extent to which everyday activities can be carried out in relation to the person's level of vision.

Unless otherwise stated, this report uses the term visual impairment, acknowledging that some studies to which the report refers have used the term visual impairment, without specifying a definition of this term.

## **Depression**

Depression refers to a wide range of experiences characterised by the absence of a positive affect (a loss of interest and enjoyment in ordinary things and experiences), low mood and a range of associated emotional, cognitive, physical and behavioural symptoms. Distinguishing the mood changes between clinically significant degrees of depression and normal variations in mood can be problematic and it has become accepted that the symptoms of depression are best considered as occurring on a continuum of severity (Lewinsohn *et al.*, 2000).

Mental health problems are experienced by at least one in four people in the course of a lifetime. There is considerable cost as a result of these problems, at a personal and family level, to the health and social care systems and to the wider economy. Anxiety and depression are considered common mental health problems and in addition to those who meet diagnostic criteria for these conditions, there are many people who will experience sub-threshold disorders (not reaching the threshold for diagnosis). Common mental health problems and sub-threshold problems affect large proportions of the population, with disorders such as depression increasing in the last decade in the relative contribution it makes to quality of life impairments (Murray *et al.*, 2012).

### **2.0 Visual impairment and depression**

Epidemiological studies indicate that the prevalence of depression in visually impaired older adults living in the UK is 13.5% compared to just 7.4% for those without a visual impairment (Evans, Fletcher & Wormald, 2007). However, depression is not an inevitable consequence of visual impairment e.g., DeLeo *et al.* (1999). While vision impairment does appear to be a significant risk factor for depression e.g., Brody *et al.* (2001), Rovner *et al.* (2002), Horowitz, Reinhardt, & Kennedy, (2005) Evans *et al.* (2007), many of the studies reporting this increased risk have examined rates of depression in older adults with vision impairment.

Older adults without vision impairment also have an increased risk of depression, often associated with multiple physical health morbidities (Barnett *et al.*, 2012). Therefore, while rates of depression in older adults with vision impairment are found to be higher in some studies when compared with rates among the general population of community-

dwelling older adults, some studies suggest that they are similar to those for older adults who are medically ill.

There is evidence that the prevalence of mental health problems may be higher in young and middle-aged adults with vision loss, with 40-45% having clinically significant depressive symptomatology, and 20% exhibiting moderate to severe anxiety symptoms (Brennan & Cardinali, 2000). In addition to the increased risk of depression in adults with vision impairment, the negative impact of sight loss on psychosocial wellbeing and sub-threshold symptoms of depression is also evident (Branch et al., 1989; Williams et al., 1998). As for the findings in relation to depression, studies examining sub-threshold depression (symptoms not meeting diagnostic criteria) vary in methodology and not all provide evidence for this relationship when controlling for age and physical illness e.g., (Upton et al., 1998).

Turning to meta-analytic studies, the meta-analytic review by Piquart & Pfeiffer (2011) examined 198 studies that compared emotional wellbeing in individuals with and without vision impairment and that included control group comparisons and population norms. Psychological wellbeing related to vision-specific problems showed a strong decline among those with vision impairment. The decline in wellbeing related to measures that were not linked to vision was found to be relatively small. While this supports the hypothesis that impaired psychological wellbeing results from vision-related impairments the meta-analysis could not control for possible confounding variables including variation in study methodology across time. Importantly, the Piquart & Pfeiffer (2011) review found that decreases in psychological wellbeing were stronger, in part, in older studies and in studies with convenience samples (rather than probability samples), in studies that used population norms as the standard for comparison (rather than control groups), in individuals with greater vision loss, and in patients with age-related macular degeneration as compared to glaucoma.

The systematic review by Burmedi, et al (2002) suggests that vision loss is associated with depression, poorer quality of life, and reduced social activity and Nyman, Gosney & Victor (2010) update this review (using the same search terms adopted by Burmedi et al) confirming that there is a clear tendency for older people with sight loss to have an increased probability of reporting symptoms of depression and being diagnosed with clinical depression than sighted matched controls. This review did not find evidence for an increased prevalence of anxiety among older people with sight loss or greater impairment of quality of life.

In contrast, the more recent cross-sectional study of Van der Aa et al (2015) did find evidence of an increased prevalence of anxiety. The study compared visually impaired older adults aged 60 years or older with a community control sample of sighted peers controlling for sex and age. Logistic regression analyses were used to compare the populations and to correct for confounding variables. The study reports a prevalence of major depressive disorder of 5.4% and of anxiety disorders of 7.5%. In addition, they report a prevalence of subthreshold depression of 32.2%. All prevalence rates were significantly higher in those with a visual impairment compared to peers without a visual impairment .

While some of the published studies referring to visual impairment and common mental health problems use convenience samples and samples of people aged 65 years and over, there is significant additional data from meta-analyses, controlling for some potential confounding variables, that suggests visual impairment is a clear risk factor for depression across all age groups. A recent finding from a study that attempted to control for the impact of small sample size and volunteer status of study participants looked at over one thousand consecutive attendees at low vision rehabilitation clinics in the UK (Nollett et al, 2016). The study reports that 43% of people attending the clinic with visual impairment had significant depressive symptoms and that around 75% of these were not being treated for that depression.

## **2.1 Possible pathways to emotional dysregulation in visual impairment**

In order to consider possible contributory factors and mechanisms for an association between sight loss and depression a brief overview of some of the characteristics of people living with vision impairment is provided.

### **2.1.2 Economic status**

73% of people who are registered blind or partially sighted are not in employment (Slade and Edwards, My Voice, RNIB 2015). These individuals are nearly five times more likely than the general population to have had no paid work for five years (Douglas et al, Network 1000: Access to employment, 2009). For those with a vision impairment who are in employment, Clements and Douglas (2009) found no difference in levels of overall job satisfaction between those with and those without visual impairment (around 80% in both groups reported being satisfied



with their current employment). As might be expected this confirms the assumption that whether one experiences visual impairment or not, employment can be a significant source of positive meaning in a person's life. Consequently, lack of employment can be experienced as an important loss or absence in an individual's life.

The impact of this higher rate of unemployment and restricted access to options for paid work may help explain why people with sight loss of working age are more likely than those in the general population to live in a household with low income levels. For the age group 45 to 64 years, this increased likelihood of low income (an income of less than £300 a week) is around twice that of the general working population (43% for those with vision impairment compared with 22% for those without).

### **2.1.3 Physical health co-morbidities**

It is common for those with a vision impairment to also have additional healthcare needs. The prevalence of visual impairment is higher among those with multiple disability and older people (van den Broek et al 2006). Slade (2014) in the UK Vision Strategy eye health data summary illustrates how, of those in the UK registered as blind and partially sighted, a significant number have additional health problems including physical disability (66-68%), hearing impairment (22%), and learning disability (5%).

### **2.1.4 Access to health care services**

People with visual impairment may encounter difficulties at any point in their interaction with healthcare services, from identification of a potential problem to the ongoing management of diagnosed illness (Cupples et al 2012). Using a focus group methodology O'Day, Killeen and Lezzoni (2004) describe problems in accessing healthcare identified by people with vision impairment, including receiving information in formats that are not accessible, difficulties communicating with practitioners and staff, doctors failing to respect a person's ability to participate in their own care, and access difficulties related to the spatially navigating healthcare facilities. Cupples et al (2012) provide useful guidance regarding the practicalities of improving access to appropriate healthcare for people with sight loss and identify three key areas - improving delivery of information about appointments and treatment, helping patients to navigate unfamiliar environments, and communication and consultation

skills. The following extract is taken directly from the Cupples et al (2012) report, and is an account from a study participant of the onset of poor mental health following loss of her sight and problems accessing healthcare services.

*A 37 year old woman describes her experience with her general practitioner after suddenly losing her vision: “After being registered blind and sent home from hospital without any information I went to see my GP for advice. I was aged 37, had lost my job, my [driving] licence, and most of all my confidence. Even though I was really upset, rather than listening to me, the GP opened a copy of the yellow pages. She told me she was looking for the address of a local sensory support team but that she had no idea what they could offer me, nor how long it would take them to contact me. When they did phone me months later it emerged that the GP had not considered the referral urgent. However, my mental health had deteriorated so much that I was referred urgently to the mental health team – I blame my GP and her lack of awareness for this.” (from Cupples et al, 2012)*

### **2.1.5 Social connectedness**

A number of studies have reported decreased levels of social functioning as visual impairment progresses. In a sample of 1191 people (mean age 50 years), with visual acuity less than 20/100, increased levels of visual impairment were associated with diminished social relationships, as reported on a Self Evaluation of Life Function Scale (Carabellese et al., 1993). Similar findings were reported in a sample of 84 registered blind participants (mean age 62) where social activity, as measured on a Personal Assessment of Role Skills Instrument, decreased with the duration of sight loss (Evans, 1983).

Hodge and Eccles (2013) summarise research in this area suggesting that the evidence of increased risk of isolation amongst people with visual impairment is modest. In particular, they point to the research of Focall et al, 1994, Foxall et al, 1993, and Wahl et al, 2013 utilising the UCLA ‘Loneliness Scale’, suggesting that there is no significant difference in the prevalence of loneliness in older people with and without sight loss. This is mirrored in the review of Nyman, Gosney & Victor (2010) who found that the literature in this area suggests that while social functioning is likely to be reduced in individuals with vision loss, social network size and social activity is not impaired.



### **2.1.6 Access to valued activities**

The impact on wellbeing of restricted access to meaningful social and leisure activities is described in a series of first-person narrative accounts given by people with sight loss in a study by Spendlove (2011). The report proposes that, for some people with sight loss, difficulty in engaging in valued activities is associated with isolation and depression. While the nature of the study (first-person narrative accounts of subjective experience) make it difficult to generalise findings the description is one commonly encountered in people experiencing depression where loss of valued goals is a key factor in promoting low mood.

Douglas, Corcoran, and Pavey (2006) conducted a similar study with a large sample of people with sight loss and report findings from 960 individual interviews. The report describes how 43% of visually impaired people indicated that they would like to, but felt unable to, leave the house more often rising to 55% for those of working age. Barriers reported more often by working-age participants include lack of confidence and issues relating to the cost and availability of transport. Those reported more frequently by people of retirement age included poor general health and mobility. Perceived barriers reported across age groups included the perception of not being able to go out alone or unaccompanied (around one third of respondents reporting this).

### **2.1.7 Visual acuity, visual functioning and perceived low vision**

The distinction made between visual acuity and visual functioning is important in understanding the potential for increased risk of depression in people with visual impairment and the possible pathways to this type of emotional dysregulation. Visual acuity is the ability to resolve detail and is a basic measure of how the visual system functions. Visual functioning (sometimes referred to as visual ability) is a person's overall ability to carry out activities of daily living that depend on vision.

Nyman, Gosney & Victor (2010) found that visual functioning (the extent to which an individual with sight loss is able to carry out activities of daily living) is a stronger predictor of depression than visual acuity (a measurement of residual visual capacity in those with sight loss). Impaired visual functioning increased the risk of depression with an average odds ratio of 4.25 (range 1.91-8.3), while severity of vision loss

was not consistently correlated with greater prevalence of symptoms of depression or impaired mental health more broadly.

The causal status of visual functioning in relation to depression is not established by cross-sectional studies such as this. A prospective cohort study of fifty-one older patients with recent-onset bilateral age-related macular degeneration by Rovner, Casten and Tasman (2002) provides useful data regarding the possible direction of causality. This study describes substantial disabling effects of depression on rehabilitation outcomes over a six month period. The study suggests that an increase in depressive symptoms over time predicted a decline in self-reported vision function independent of changes in visual acuity or medical status.

Studies such as these suggest a possible bi-directional relationship between visual functioning and depression. Further studies illustrating the relationship between these two variables is summarised in Table 1.

Table 1: The role of visual functioning in depression

Study	N Sample Design	Mean Age (Range)	Vision Impairment	Depression Assessment Instrument	Prevalence of depression/ emotional dysregulation	Comments
Zhang et al (2013)	10 480 NCS  Survey	46.7 (20-65+)	Self-reported visual function loss (VFL)  Visual acuity impairment < 20/40 (VAI)	PHQ-9	VFL : 11.3% (9.7%-13.2%) No VFL : 4.8% (4.0%-5.7%)  VAI : 10.7% (8.0%-14.3%) No VAI: 6.8% (5.8%- 7.5%)	Self-reported VFL is significantly associated with depression (VAI is not)
Gall, Brosel & Sabel (2013)	108 CS	57.58 (not available)	Visual field loss due to optic neuropathies  Vision –related quality of life (Vr QoL)	SF-12	Mean SF12 of 66.2 “low ered in a clinically relevant extent w hen compared to healthy control”	Subjective visual functioning but not visual field parameters predicted mental-health symptoms due to visual problems  Maintenance of vrQOL may reduce / prevent mental distress due to visual problems
Gall et al (2011)	24 CS	56.17 (not available)	Visual field loss (various pathologies)	SCLR-90 R	40% met criteria for “psychiatric caseness”	Self-rated psychological distress is result of diminished vision-related quality of life ; extent of visual field loss itself did not influence rating of psychological distress
Loprinzi, Smit & Pariser (2013)	567 With diabetes NCS Survey	(18–85)	Self-reported vision ‘excellent, good, fair, poor, or very poor’	PHQ-9	9.7% total sample 23.3% ‘poor vision’ 41.1% ‘dual sensory impairment’ 20.6% ‘unable to do activities’	Both dual sensory impairment and physical functioning w ere independently associated with depression
Brown & Barrett (2011)	1,221 NCS	(60-96)	Self-reported visual impairment (The Americans’ Changing Lives Study - two items)	11-item Centre for Epidemiological Studies– Depression scale	Greater (self-reported) visual impairment significantly predicts an increase in depressive symptoms	64% of the effect of visual impairment on depressive symptoms accounted for by activity limitations, economic, social, and psychological resources  35% of the effect of visual impairment on depressive symptoms accounted for by self-efficacy  Activity limitations account for the effects of visual impairment on depressive symptoms and life satisfaction.
Court et al (2015)	291,169 Primary care registered patients aged 65+ Cross-sectional analysis health records	77.9 (n/a)	Primary Care Read codes referring to vision impairment	Recorded diagnosis	18.2 % visual impairment vs. 12% Non visual impairment OR 1.53 (CI 1.43 to 1.65)	After standardisation, those with visual impairment w ere twice as likely to have 5 or more physical/mental health comorbidities

NCS: National Community Sample CS: convenience sample VFL: Visual function loss

However, the relationship between depression, visual acuity and visual functioning might occur at other levels in addition to that described above. Bookwala and Lawson, (2011), report that depressive symptoms are predicted by self-reported poor vision but not by poor vision that is defined by level of functional impairment. This may suggest that *appraisal* of visual acuity or functional impairment may not always correlate with measured impairment. Similarly, Zimdars et al.( 2012) report that only about one third of participants in their study who self-reported having a visual impairment actually met the criteria for severely impaired vision as defined by a healthcare assessment. As may occur across all contexts in which people experience depression, negative mood-related appraisals may determine subjective experience that does not correspond to objective measures of the experience in question.

In addition, consideration should be given to the experience of dulled perception. Dulled perception can refer to a person's experience in the visual, olfactory or auditory senses. In the visual domain this is a form of subjective experience in which the individual reports that the appearance of objects seems dull, flat or colourless. Subjectively reported reduced sensory perception is a recognised symptom of depression for some people.

In addition to the impact of mood on subjective perception, there is also some evidence that mood can impact on objectively measured visual perception. One particular area of investigation in relation to impaired visual perception in depression refers to changes in contrast sensitivity. This is the ability of the visual system to distinguish between an object and its background. Performance in relation to this contrast discrimination has been found to be reduced in people with depression, and it is hypothesised that this may be mediated by altered functioning of the dopaminergic system (Bubl et al , 2009). Altered functioning of the dopamine neurotransmitter has also been implicated in depression e.g., Hasler et al (2008), suggesting that depression and impaired visual contrast sensitivity may share a common alteration in neurotransmission.

Bubl et al (2010) and Fam et al (2013) found that the strength of association between impaired visual contrast sensitivity and depression increased with severity of depression. It has also been found that visual contrast sensitivity returns to normal when depression is successfully treated (Bubl et al, 2012). These studies strongly suggest that the impairment of visual contrast sensitivity in depression is state-dependent. Therefore, while it has been recognised for some time that

subjective reports of dulled perceptions can occur in depression, these studies indicate that there are objective measures of this in the form of reduced visual contrast sensitivity.

Reduced contrast sensitivity is found in a number of conditions causing visual impairment including cataracts, macular degeneration, glaucoma and diabetic eye disease. Where depression occurs with visual impairment it would therefore seem that this may operate as an additional factor impairing contrast sensitivity. This is of importance as impaired contrast sensitivity can make it difficult for people with visual impairment to navigate kerbs and stairs and can be a significant risk factor for falls (Lord, Dayhew and Howland, 2002). This might suggest that, in addition to the personal and emotional costs of depression, in the context of visual impairment, depression may further impair visual acuity and visual functioning.

The bi-directional relationship between depression and visual functioning may in some instances therefore be underpinned by the impact depression has on visual acuity in the form of contrast sensitivity. This impairment of the visual system under conditions of depression may reduce confidence in carrying out activities dependent on residual vision and serve to maintain depressed mood as a result of impaired functioning.

## **2.2 Visual impairment and depression – comorbidities and non-specific factors**

The prevalence of visual impairment increases with age and therefore much of the data that is available concerning the impact of sight loss on mental health and wellbeing concerns the effect of visual impairment in older adults (age 60 years and over). In developing an understanding of the factors that might promote an increased risk of depression in older people with vision impairment it is necessary to consider the potential independent contribution of age-related factors and their possible interactive effects with sight loss.

The systematic review by Gjernes (2006) suggests that older adults may be at no greater risk of depression than younger adults and where apparent age-related effects on depression are found these are due to the physical health problems and related functional impairments associated with ageing.



In relation to visual impairment, Gjernes (2006) suggests that the increased association (odds ratio) between visual impairment and depression in older adults varies across studies from 2.6 to 4.9 (around a two-and-a half to five times stronger association with sight loss). In addition, a range of other factors in older age were identified as increasing the risk of depression. These include dissatisfaction with social support, living alone, lack of social activities, and low income, in addition to physical health problems and related impairments.

These factors also operate to increase the risk of depression across all age groups. For example, the large population based cohort study of Patten (2001) found that, in a non-depressed sample, those who developed a range of long-term physical health problems (hypertension, asthma, arthritis and rheumatism, back pain, diabetes, heart disease or chronic bronchitis) within two years had an increased risk of developing depression (odds ratio of 2.5). Similarly, Egede (2007) found that patients with chronic physical illnesses were around three times more likely to be depressed than healthy controls (odds ratio 2.6).

Regarding socioeconomic factors there is wide recognition that factors such as unemployment, socio-economic status, housing circumstances and lack of formal educational qualifications significantly increase the prevalence rates of depression (Singleton et al., 2001). Social isolation is an additional factor associated with poor outcome and chronicity in depression and there is evidence that the provision of social support might improve recovery from depression e.g., Cox et al, 1991.

In section 2.1 evidence was presented that suggests these risk factors for depression are more common among people with sight loss. This might suggest that sight loss *per se* may not be the key, or the only variable, increasing the prevalence of depression among people with visual impairment. Instead, the social, economic and additional health factors that tend to be associated with the circumstances of people with a visual impairment are responsible in part for the increased risk.

Considering the possible pathways to depression at population level among people with a visual impairment therefore requires inclusion of the non-specific factors that increase the prevalence of depression, factors which are not exclusive to people with sight loss but which tend to occur more frequently among people with sight loss. In combination with these non-specific factors, the role of visual functioning can be added, describing the degree to which a person with sight loss is able to

maintain activities of daily living. The literature does not appear to indicate a role for visual acuity as a risk factor for depression.

At an individual level, considering adaptive processes that might moderate risk of depression Wahl (2013) emphasises the importance of considering the losses and gains that can occur in ageing and visual impairment. For example, reference is made to 'the wellbeing paradox in old age' (Kunzmann, Little and Smith, 2000) in which it appears that, for some older adults, a diminishing social network results in greater effort and investment in remaining social relationships resulting in an enhanced sense of wellbeing (referred to by Carstensen et al, 1999 as the socioemotional selectivity theory). This may be relevant to the findings that loneliness is not inevitable among older people with visual impairment (Wahl & Tesch-Römer, 2001; Burmedi, et al, 2002; Hodge and Eccles, 2013).

In addition to socioemotional selectivity, Wahl et al (2013) consider the role that self-regulation skills play in determining successful progression through old age. 'Flexible goal adjustment' is an example of a self-regulation skill which refers to an individual's ability to flexibly adjust their approach to working towards goal attainment. This skill has been identified as a possible moderating variable in determining wellbeing outcomes in older people. Wahl et al, 2005 also provide some evidence that this variable may moderate mental health outcomes in people with sight loss.

Such perspectives on visual impairment in older people suggest that impaired wellbeing is not inevitable and that interventions which promote the adaptive behaviours that moderate the risk of depression might be a useful therapeutic approach.

## **2.4 Depression, visual functioning and rehabilitation outcomes**

Low vision rehabilitation services aim to enable participants to learn how to perform tasks with reduced visual acuity. These services are positioned to both enhance confidence in a person's functional abilities through the provision of instrumental support and to facilitate access to health and social care interventions to meet the wider needs of the individual.

In relation to depression in visual impairment, it is possible that depression diminishes the impact of vision rehabilitation programmes.

Grant, Seiple, and Szlyk, (2011) report on the impact of a reading rehabilitation programme suggesting that those who reported greater depressive symptoms did not respond as well functionally to the rehabilitation programme. In a prospective cohort study of fifty-one older patients with recent-onset bilateral age-related macular degeneration Rovner, Casten and Tasman (2002) describe substantial disabling effects of depression on rehabilitation outcomes over a six month period. The study suggests that an increase in depressive symptoms over time predicted a decline in self-reported vision function independent of changes in visual acuity or medical status.

Evidence for the impact of vision rehabilitation on depression is mixed. Horowitz et al (2003) in a two-year follow-up study of visually impaired older adults report that use of rehabilitation services predicted decline in depression over time. Although all forms of rehabilitation examined in the study contributed to reduced depression, independent effects were found for counselling, low vision clinical services and provision of optical aids. It was also found that skills training and the use of adaptive aids did not have such independent effects. The RNIB systematic review of low vision rehabilitation services (Binns et al 2009) found that these services were very much valued by people with a vision impairment and that available studies suggest there is a large effect size for improvements in clinical reading ability, and evidence that the different approaches to low vision rehabilitation have a medium to very large effect on self-reported functional ability. However, the review highlights that there is limited evidence to support improvements in 'vision related quality of life' and no evidence that an intensive rehabilitation programme can reduce depressive symptoms.

This appears consistent with the findings that suggest that *perceived* functional loss and not visual acuity is a key determinant of response to visual impairment. Trillo and Dickinson (2012) in a cross-sectional study of 448 patients attending a low vision clinic in the UK found that nonvisual factors including mental health were stronger predictors of quality of life in people with low vision than visual factors such as contrast sensitivity and visual acuity.

Similarly, among 194 participants with a median age of 82 years completing a trial to evaluate different types of rehabilitation programmes, Reeves et al. (2004) found no evidence for the effectiveness of a model of enhanced low vision rehabilitation on wellbeing. One explanation they consider for this finding is that quality of life for people with age-related macular degeneration may be primarily

determined by lost sources of pleasure and confidence and may not be strongly linked to restriction in everyday activities.

These findings raise two important issues. Firstly, where depression is part of an individual's experience, vision rehabilitation programmes may make more limited impact on vision-related outcomes. Secondly, where rehabilitation programmes for people with sight loss do not specifically address psychosocial factors, and where those who attend such programmes are depressed, people are likely to make limited improvements in depression. This draws attention to the importance of identifying depression in people with visual impairment and specifically addressing depression as part of a comprehensive rehabilitation and treatment programme.

### **3.0 Access to support – the Improving Access to Psychological Therapies (IAPT) services**

In the cross-sectional study of 871 older people (mean age 73 years) with visual impairment, van der Aa et al (2015a) report that more than half of the sample reported a need for mental health services while only around one third had been offered such support. The study suggested that the key reason for this unmet need was lack of knowledge regarding mental health problems and treatment options among older people with visual impairment. Similar challenges faced by people with visual impairment in accessing health and social support services are described in the review by Hodge et al (2015). In their interviews with twenty-one participants the authors describe the difficulties some people have in accessing timely treatment and support across a range of services providing physical health and psychosocial interventions. The UK Vision Strategy 2013-2018 recognises such problems and sets out the challenge of ensuring that all people with an eye condition receive the treatment and support they require including emotional support.

In England in recent years there have been concerted efforts to improve the treatment of common mental health problems such as depression through improved access to psychological therapies (*Talking therapies: A four-year plan of action*, 2011). An analysis of this programme (Impact on Equality of Talking Therapies: a four year plan of action, Department of Health, February 2011) evaluated whether the programme has advanced equality and eliminated discrimination in access to talking therapies. Of the 35 Improving Access to Psychological Therapies (IAPT) services established in 2008, 91% (n=32) participated in the data

review with equalities data collated by age, disability, ethnicity and gender. From the data review the two categories that are of particular relevance to supporting people with visual impairment are 'disability' and 'age' (as the proportion of people with visual impairment rises significantly in older age groups). The data review revealed that only 2% of people using IAPT services had data indicating they had a disability and only 4% of the sample was in the age group 65 years and above. This suggests that people with any form of disability and older people are either significantly under-utilising IAPT services or that services are not reliably recording these details.

Data regarding the types of disability of people using IAPT services is available via the reports published by the Health and Social Care Information Centre (HSCIC). The most recent report refers to all IAPT services in England in 2014-15. Some of the data from this report is summarised below (Table 2), describing the number and percentage of referrals received by all IAPT services by recorded disability.

Over the period April 2014 to March 2015, around 1.27 million people were referred to IAPT service in England. Of these, the majority (83.54%) had no recorded code indicating the presence or absence of a disability, with only 7% given a coding of 'no disability'. This suggests that compared with the audit of 2011 noted above, the consistency of identifying and recording disability status has not improved. Drawing conclusions from this data set therefore requires some caution. With this in mind, the data illustrates that across the IAPT sites the average percentage of people referred and allocated the coding 'sight' as a disability label was 0.45%. The average percentage of referrals across all services accounted for by people with a recorded disability other than 'sight' (ten categories) was 8.3% (an average of 0.83% for each of the ten non-sight categories).

Of the eleven disability codes used by services this places 'sight' as the seventh most frequent type of disability in people seen by IAPT services. With a prevalence rate of visual impairment at around one in thirty of the UK population, even if it is assumed that common mental health problems such as depression are no more common in people with sight loss than in the general population, if people with sight loss were equally represented in IAPT services, the expected referral rate would be closer to 3%.

Extracting data for referrals received by each of the 216 Clinical Commissioning Groups (CCG) (all figures rounded to the nearest 5 in

the data reported by HSCIC) reveals that the average number of referrals of people with 'sight' as a disability per CCG over this period was 25.94 (range 0-160; median = 20; mode = 10). Whether this large range in the number of referrals is simply the product of differences in recording is not known. However, the data suggests that some IAPT services are clearly able to recruit into treatment people with problems related to 'sight' and to recognise and record these as disabilities while others do not appear to do this. The modal referral number of 10 people across 216 CCGs suggests that most IAPT services are recruiting very small numbers of people with a visual disability or failing to recognise or record this when receiving referrals of people with sight loss. More detailed data regarding the clinical and demographic characteristics of these referrals of people with a visual disability is not reported in the national data set.

Recognition that accurate and reliable recording of disability is limited in IAPT services (Impact on Equality of Talking Therapies: a four year plan of action, DH February 2011), and that the disability codes recorded by the reporting IAPT services have not been applied in a mutually exclusive manner, means formal analyses of these data will be of limited value.

In order to consider how helpful IAPT services have been to people with vision impairment and common mental health problems, a number of process and outcome measures can be considered. The progression from referral through the service can be mapped in terms of the number and proportion of people within each 'disability' coding group who move from referral to the service to entering treatment and then to completing treatment. The proportion of people with each type of disability label who progress through these stages is summarised in Table 3. Visual inspection of the data suggests that when people with sight loss are referred to IAPT services:

Table 2: People referred to IAPT finishing a course of treatment by recovery status and disability

Recorded Disability Type	Referrals Received	% of total referrals	Entered Treatment	% of referrals	Completed Treatment	% of referrals	Initially at caseness & completed treatment	% of referrals
Behaviour and Emotional	13,243	1.03%	10,013	75.6%	5,720	43.19%	5,284	39.90%
Hearing	9,549	0.74%	7,531	78.9%	4,507	47.20%	4,038	42.29%
Manual Dexterity	3,229	0.25%	2,764	85.6%	1,609	49.83%	1,507	46.67%
Learning Disability	12,409	0.96%	9,551	77.0%	5,358	43.18%	4,976	40.10%
Mobility & Gross Motor	34,836	2.71%	28,170	80.9%	16,852	48.38%	15,733	45.16%
Perception of Physical Danger	827	0.06%	539	65.2%	319	38.57%	304	36.76%
Personal, Self Care and Continence	2,126	0.17%	1,485	69.8%	813	38.24%	761	35.79%
Progressive Conditions & Physical Health	8,548	0.66%	6,579	77.0%	4,025	47.09%	3,714	43.45%
Sight	5,737	0.45%	4,553	79.4%	2,693	46.94%	2,435	42.44%
Speech	1,794	0.14%	1,443	80.4%	847	47.21%	766	42.70%
Other	21,068	1.64%	16,575	78.7%	9,610	45.61%	8,853	42.02%
No disability	90,049	7.00%	73,366	81.5%	59,908	66.53%	53,225	59.11%
Not stated	8,178	0.64%	4,772	58.4%	3,858	47.18%	3,405	41.64%
No code recorded	1,074,491	83.54%	663,216	61.7%	361,575	33.65%	321,534	29.92%
Invalid code	153	0.01%	117	76.5%	61	39.87%	57	37.25%

Multiple disabilities can be recorded against a referral and therefore the categories are not mutually exclusive for those with an identified disability

- the proportion who enter treatment (79.36%) is no lower than for people allocated to some of the other disability codes or coded as having no disability, and may be higher than the largest category 'no code recorded' (61.70%)
- the proportion who complete treatment (59.15%) appears similar to that reported for other disability categories, appears a little lower than for those coded as 'no disability' but is higher than the largest group 'no code recorded' (55.65%)
- the proportion of people entering and completing treatment who met the criteria for 'caseness' is similar across the disability groups, lower than the 'no disability' group and higher than the 'no code' group

In addition, there is little difference in the proportions of people in each category who were able to provide paired scores for the determination of change. This is achieved when people participating in treatment in IAPT provide standard measures of the severity of anxiety and / or depression at the beginning and completion of treatment.

Table 3: Proportion of people within 'disability' groups at each stage of the care pathway and outcome

Measure	Disability Code			
	'Sight' (%)	All other disabilities (%)	No disability (%)	No code recorded (%)
Entering Treatment	79.36	76.90	81.50	61.70
Completing Treatment	59.15	58.29	66.53	55.65
Caseness & Complete	42.44	41.48	59.11	29.92
Reliable Improvement	59.12	54.82	59.78	61.45
No Reliable Change	28.82	33.38	30.85	28.94
Reliable Deterioration	7.72	7.63	7.0	6.05
Recovery	41.80	34.51	43.66	46.36
Reliable Recovery	40.12	33.08	41.00	44.21
Paired Scores	95.66	95.78	97.63	96.44



The data suggests that there is little difference in the services' ability to achieve this across the 'sight', all other disability and non-disabled groups. This is an important finding as the measurement of progress and sharing this with the person is a fundamental element of treatment in evidence-based interventions in IAPT and therefore problems in participating in this part of the process would disadvantage those with visual impairment.

Therefore, considering the appropriateness of service offered, it would appear that, once referred to IAPT, people with a disability related to sight are just as likely to enter into treatment and complete it, as people with other types of disability and may be more likely to complete treatment than some others whose disability status is unknown ('no code recorded'). The large proportion of people with no code for disability recorded makes it difficult to draw firm conclusions regarding accessibility and acceptability of IAPT services for people with a visual impairment. It is clear however, that equity of access is an issue with the significant under-representation of people with sight loss.

Regarding outcomes, IAPT service data can be used to determine reliable improvement when the person shows a reliable decrease in anxiety or depression score between the first and last measurement, and the other clinical state (depression or anxiety) either also reliably decreases or shows no reliable change. A reliable decrease is identified when scores on the standard outcome measures used decrease by more than the standard error of measurement of the instrument. Reliable improvement is similar across the groups except for 'all other disabilities' which appears lower. Rates of reliable deterioration (an *increase* in scores on standard measures which is greater than the standard error of measurement) are similar across the groups.

Recovery is calculated for those who enter treatment at 'caseness' and complete treatment with scores that fall below this threshold. Reliable recovery is similarly calculated but requires the fall in score to be greater than the standard error of measurement of the assessment tool used. For both recovery and reliable recovery, those with sight loss appear to have slightly higher rates than those with other disabilities but a little lower than for those with no code recorded or 'no disability'.

A less direct review of whether IAPT services are providing support for people with visual impairment is to examine the use of the services according to age. As the rate of visual impairment increases with age,

particularly over the age of 65 years, access to IAPT for this age group is an indirect indicator of accessibility for people with visual impairment. Data regarding access by age group was extracted from the data available via HSCIC and is summarised in Table 4.

Table 4: Referrals to all IAPT services by age

Year	Referrals to all IAPT services		Referral rate per 100,000 population	
	Age 15-64 N	Age 65 and over N (%)	Age 18-64	Age 65 and over
2012-13	719,985	41,562 (5.45%)	1,789	408
2013-14	890,281	56,971 (6.01%)	2,204	545
2014-15	1,187,034	79,477 (6.27%)	NA	NA

The data extract above shows that while referrals to IAPT across all age groups increased between 2012 and 2015, the proportion of referrals of people aged 65 years and over has changed little. A review of IAPT services in the first year of commissioning found that on average older people represented four per cent of those accessing these services. While later figures show some improvement, based on the age profile of the general population and prevalence of depression and anxiety in the general population, the proportion of older people expected to use IAPT would be 12 per cent (Connelly and Perera, 2013).

The Department of Health have issued guidance regarding improving access to IAPT services for older people (How to make IAPT more accessible to Older People A Compendium - Department of Health, March 2013). While there is practical guidance such as offering home visits to those who may not be able to attend clinics due to mobility problems or visual impairments, the guidance also recognises the larger challenges of promoting age-related equality, tackling the stigma attached to depression or anxiety in later life and identifying and dismantling discriminatory practices that act as a barrier to older people's referral or self-referral to IAPT. The IAPT programme also plans to work in partnership with organisations representing the interests of older adults. Such recognition will be equally applicable to older people who also have a visual impairment and some of the identified challenges may be applicable to all people with visual impairment who experience depression irrespective of age.

### **3.7 Access to support for depression – the key points**

Available data regarding the use of IAPT services provides some understanding of rates of access for people with disabilities and older people and more limited understanding of accessibility for people with visual impairment. The low percentage of disabled users means limited conclusions can be drawn about equality experienced by those with any form of sensory impairment. Evidence about the experience of people with sensory impairments in IAPT services is insufficient to draw clear conclusions. With this in mind the following observations are made.

#### **3.7.1 Are the interventions offered by IAPT suitable for people with visual impairment?**

Data from the HSCIC regarding the activity and outcomes of people using IAPT services suggests that once in treatment people with sight loss may gain just as much from IAPT services as those without visual impairment.

Additional indirect evidence does give some reason for optimism regarding the efficacy of IAPT services for people with visual impairment. The recent randomised controlled trial of van der Aa et al (2015) suggests that the IAPT model of treatment would be effective with larger numbers of people with sight loss. This multicentre trial utilised interventions typical of IAPT services (including guided self-help and problem solving treatments) with people with visual impairment and found a significantly reduced incidence of depression (relative risk 0.63) in the intervention groups compared to the standard treatment controls. The trial included the management of people with vision impairment who had sub-threshold symptoms of depression which are common, especially among older people, with visual impairment (Lotery, Zlatava and Loftust, 2007; Evans, Fletcher, and Wormald, 2007; Van der Aa et al, 2015). Interventions are routinely offered in standard IAPT services for people with these sub-threshold presentations. It is also of significance that the interventions were delivered from within low vision support services in combination with usual low vision rehabilitation care. The integration of psychological interventions in non-mental health settings is an approach that some IAPT services adopt in attempting to improve access and acceptability.

The IAPT programme has issued guidance (Improving Access to Psychological Therapies Equality and Diversity Toolkit, 2008) suggesting that for people with sight impairment, IAPT services should ensure that

information is available in formats that can be accessed, that service venues are suitably adapted and that people may need to be visited in their homes or in community group settings. The guidance also suggests that IAPT services should seek advice from 'local associations for the blind'. Similarly, in the *Good practice guidance on the use of self-help materials within IAPT services* - (Department of Health, March 2010) also recommends that materials are adapted for sensory impairments.

How effective such recommendations will be for people with visual impairment when implemented can only be reliably tested when there are more representative samples of people with visual impairment entering IAPT services. The following section considers possible obstacles to the recruitment of people with visual impairment into IAPT services.

### **3.7.2 Issues of accessibility**

#### *Problems accessing healthcare in general*

Cupples et al (2012) review a range of issues relevant to improving access to good healthcare for people with visual impairment. These include the need to identify the presence of visual impairment and to be aware of the specific needs related to this, improving accessible information about facilities and treatments, adapting communication styles, and considering the broader resources available to a person with visual impairment in order to facilitate engagement with treatments. Such issues relevant to accessibility of healthcare would equally apply to people with visual impairment who also have depression.

#### *Identifying depression*

The potential benefits of improving identification of comorbid conditions and services available to support with these is described by the Royal National Institute of Blind People (RNIB Group response to the Department of Health Consultation *Liberating the NHS: Greater Choice and Control*, 2011). The RNIB highlight in this document the role that can be played by voluntary organisations in providing information, services and training to health and social care professionals about the needs and requirements of the groups they represent.

At the level of primary care services Crawford et al (1998) report that nearly 50% of instances of depression in elderly patients were missed by GPs in routine practice. They found that those least likely to have their

depression recognised included, among other groups, those with visual impairment.

Regarding the identification of depression in eye healthcare settings, Fenwick et al (2009) suggest that eye care specialists may rely on observational cues of patients' behaviour or other indirect methods to identify depression. While this appeared to be associated with widespread awareness of depression among people with visual impairment they found that few staff in their study directly discussed depression with patients. Reasons given for this included lack of knowledge of resources or referral options, confusion over roles and responsibilities, and unclear communication pathways between staff. Similarly, routine screening for depression within low vision services is reported as being extremely limited (Nollett et al, 2016).

Examining the expressed need for psychological support among people with visual impairment, Sturrock et al (2014) interviewed 161 adults with sight loss in a cross-sectional study, reporting that 63% of participants indicated that they wanted psychological help while only 20% had ever received such help. The authors suggest that such low access rates might be improved if services supporting those with low vision emphasise education for patients and their families about the emotional impact of vision impairment and the symptoms of depression, its causes and treatment and that early screening and referral pathways to psychological support could be put in place. The authors also provide some evidence that people with sight loss would find depression screening an acceptable part of a support process.

Therefore, improving access to treatments for people with visual impairment and depression will require improved processes for identifying mental health needs and enabling a productive referral to services. This is in addition to any adaptations required to ensure people can benefit from IAPT services once referred and engaged in treatment. In order to further understand current levels of uptake and barriers to accessing support services for people with visual impairment and mental health needs a range of stakeholder views were gained.

#### **4.0 Stakeholder interviews**

The review and analyses described in preceding sections highlight the role played by a range of factors in promoting an increased risk of depression in people with vision impairment and some of the factors that might influence access to health care and mental health care

specifically. In order to further explore the role played by the factors described in preceding sections a range of stakeholders were engaged in a series of semi-structured interviews and small focus groups.

The following stakeholder feedback describes the comments made by 30 people with visual impairment recruited through local vision support services, 14 vision support staff, a desktop review with clinicians in a local IAPT service of the last consecutive six people with visual impairment recently treated, and two local GPs specialising in support of people with visual impairment. Vision support staff included two eye care liaison officers, two optometrists working in local low vision rehabilitation services, a member of staff from a local agency supporting older people and volunteers from local organisations supporting people with visual impairment. People with visual impairment and staff were interviewed using a semi-structured interview aimed at eliciting information regarding each step in a care pathway to mental health support services for common mental health problems. While the interviews were conducted flexibly to allow participants to focus on issues they felt were important, the interviewer followed a series of pre-specified questions aimed at eliciting information about the process of:

- disclosing mental health needs and having this disclosure recognised as a mental health need;
- being referred to a mental health service and finding the service accessible;
- being engaged in the treatment offered and remaining in treatment.

The purpose of this section of the review was to describe the participant's self-identified issues related to access to support for common mental health problems. Some of the issues reported may be specific to the experience of people with visual impairment, others might be equally applicable to any individual considering disclosure of mental health needs and seeking appropriate treatment.

The following categories were used to summarise the feedback obtained:

- disclosure of mental health needs
- recognition of mental health needs by professionals and support staff
- accessibility of appropriate services
- engaging and retaining people in appropriate treatment

For each category, some of the verbatim responses to questions are provided to illustrate the key themes emerging from those interviewed.

#### **4.1 Disclosure and recognition of mental health needs**

##### **(a) Feedback from people with visual impairment**

Trust and confidence: some people with visual impairment reported that they were not confident that healthcare professionals would respond sensitively to a disclosure of mental health needs

- “I’ve had some bad experiences with professionals; some people have been tactless”
- “Can sense I’m being treated differently because of my visual impairment (e.g., GP not looking at me when talking to me)”

Timing and process issues in disclosure and identification: some people with visual impairment talked about the importance of being able to discuss any mental health needs at different times in their contact with health and support staff and the need for this to be acted on effectively, taking into account the personal feelings of the individual

- “Too many people involved in the process of identification - repeating my story acts as disincentive to disclose wellbeing needs”
- “It takes too long for health service staff involved in the care of a patient to come to an agreement that there is an underlying mental health condition that needs to be addressed”
- “What is personally meaningful – may want to talk about how I feel, while staff want to talk about the treatment I need”
- “Coming to terms with sight loss involves going through phases. A person may be too distressed to engage with help at one point in time”
- “I may not feel like talking about these problems”

Care and support pathways for people with visual impairment may not be typical of those without visual impairment: some people with visual impairment talked about their preference for turning to informal sources of support or non-healthcare sources of support.

- “The support I need most is provided in my own community, my family, the support staff, my keyworker”
- “I rarely go to my GP – it has to be a really drastic physical health problem for me to go -any mental health needs don’t really get on the agenda”
- “Where self-referral is required , I might not feel well enough , might not be in the right frame of mind”

Uncertainty about entitlement to support: Some people with visual impairment talked about feeling uncertain about whether it was legitimate for them to talk to professionals about emotional or wellbeing needs.

- “I don’t want to be a burden – I don’t want to make a fuss”
- “I’m happy with *any* care I get”
- “My GP tends to focus on physical health issues and isn’t really interested in other things”

(b) Feedback from professional staff and volunteers supporting people with visual impairment

The themes emerging from this group included consideration of wider influences on wellbeing and therefore conceptualising wellbeing needs without recourse to identifying these as depression. Accordingly, interventions felt to be helpful were not necessarily about supporting access to treatment. Some participants identified issues of stigma in relation to identifying mental health needs while others focused on lack of familiarity with working definitions of common mental health problems.

- “what supports people with their mental health does not always have to be clinical in nature... quite a few people benefit from volunteering, befriending, meeting new people, getting more involved with their community etc. there’s a place for treatments but often what is also needed is friendship and a widening of interests and social circles”
- “I try and be empathic and listen well when making my own contacts with that person. The stigma of being referred to a mental health specific service (even an IAPT service) is noticeable when these services are mentioned to people”



- “I tend to refer or signpost them to a local vision support service (rather than to a mental health specific service) even if I have noticed that they may seem a bit down or isolated, thinking that practical support may help them”
- “I’m not sure I’m familiar enough with the clinical terms and classifications ...but we do see people who appear to be depressed. It shows as being poorly motivated in using low vision aids, giving up easily and being disinterested”

For some the issue of timing a discussion about mental health needs was a critical issue

- “...the process of coming to terms with visual impairment is difficult and a process that differs for everyone... a lot of people go into shock, denial and are less likely to process all the information handed to them at this particular moment. We need information that can be passed on to be utilised at a later stage when the patient is more able to address their changing needs”

Others referred to a circumscribed and time-limited role in relation to their role with people with visual impairment

- “...this is a time limited role in supporting people with visual impairment - so the access and contact they do make has to be quick, concise and effective; therefore, it is crucial to have the right information on hand to pass on to patients”

Some professional and volunteer support staff said they did not feel equipped to identify mental health needs

- “...we need to feel equipped in identifying and then approaching members (people with sight loss) about what would best support their needs. There is a lot of pressure on support staff already but if there is a way for them to identify and then refer on to the right services which are flexible and open on evenings and weekends then that would be very helpful in supporting members”

### (c) GP Feedback

The emerging themes from the GP interviews focused on identification of mental health needs among people with visual impairment and the implications this had for training.

Identification of mental health needs: feedback focused on challenges in identifying mental health needs against a background of complex physical and psychological presentations, sometimes with limited opportunity to achieve differential diagnosis due to infrequent/intermittent contact with patients:

- May be limited opportunities to follow people over time – makes identification more difficult against a background of multiple needs and changing presentation;
- Presenting with poor sleep and lack of energy may be misleading;
- Some diagnoses might reduce focus on monitoring for mental health needs: for example, Charles Bonnet syndrome (1) – symptoms of this might exclude consideration of alternative mental health diagnoses;
- Managing expectations important for patients with unrealistic beliefs regarding sight recovery – identifying mental health needs against this background can be complex;
- For some clinical staff specialising in support of people with visual impairment it may be that most exposure is to people with congenital conditions rather than to patients with acquired sight loss – the issues concerning identification of mental health needs might be quite different;
- It may be more effective if healthcare staff are open in their communication about possible mental health problems and their prognosis – open the dialogue with patients;
- Some people present with somatic complaints that are likely to be a manifestation of mental health needs – we need good models for differential diagnoses;
- Physicians can be aided by being aware of simple screening measures such as PHQ9 and GAD7 (2);

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1) Charles Bonnet Syndrome: a condition in which people with sight loss experience visual hallucinations

2) PHQ-9: Patient Health Questionnaire (9 item version); GAD-7: Generalised Anxiety Disorder (7-item version). Standard screening measures for depression and anxiety respectively.

- Timing of consultations means that you may see a patient at a low or good point – this may not be representative of their typical functioning – measures taken at one point in time may provide only a limited picture of patient’s mental state and functioning;
- (and related to previous point) Patients need to be enabled to complete their own measures (PHQ9 and GAD 7 – standard screening measures for depression and anxiety) – they need the autonomy to monitor themselves;
- For patients who frequently move, disengage from treatment, are not able to access service information (for example, can’t read letters) or who have long term history of mental health needs, identification of mental health needs can prove problematic for specialist mental health services – there is a loss of focus on current need.

## **Implications for GP Training**

The GP feedback also focused on the following implications for training of GPs in improving identification of common mental health problems in people with visual impairment:

- Formal training required in types of visual impairment and their manifestations and around common mental health problems and their presentation in people with visual impairment;
- Training at practice level regarding local care pathways, local formal and informal service availability, and development of special interest groups;
- Decision support software (already available) – can be updated to support identification of common conditions, support with referral procedures , guidelines for management of conditions and local non-statutory support services.

## **4.2 Accessibility**

### **(a) Feedback from people with visual impairment**

Some people with visual impairment talked about how they recognised they needed help with emotional or wellbeing needs but found that additional barriers restrict access to services – specifically being a speaker of another language, having a learning difficulty, or having a dual sensory impairment (in this instance hearing and vision impaired). Interviewees talked about feeling frustrated and disempowered, a lack of

advocacy and lack of access to services that seemed able to address their additional needs.

- “When dependent on support worker to access a service, it can be difficult, I feel like a burden – particularly because they have to help me with hearing problems and my sight”
- “My experience of using the local service was that it felt like a lot of red tape – by the time you are seen you are either better or worse”
- “Waiting times are too long”
- “Unrealistic expectations about when I would be seen”
- “Want options to be flexible – talking treatments not pills; counselling not cognitive behaviour therapy”
- “Consideration needs to be given to how information about services is provided: for example, phone, email or text rather than written letter.”

(b) Feedback from professional staff and volunteers supporting people with visual impairment

Themes related to issues of access to services for wellbeing needs from this group referred to the need to follow familiar referral or signposting routes through agencies linked with, or known to, the particular service the individual worked in; lack of awareness of local mental health services; and lack of knowledge and skills to know when to refer.

- “...in my role I liaise with the local authority services and signpost to local charities - not mental health services”
- “I was only aware of a referral to the GP in order to help with mental health”
- “I am not aware of an organisation specifically for common mental health problems”
- “Signposting can be easily done in the clinic but we need good quality, accessible information”
- “I don’t have the training to know when I should be trying to access mental health services for the person I support”

### (c) GP Feedback

GP feedback focussed on methods for improving access to treatments for depression, specifically psychological treatments

- Referral by GPs to local treatment services may be enhanced by
  - clarification of what happens to patient once referred
  - feedback following referral reinforces the referral behaviour
  - confirmation of types of presentation service will see
  - website resource for patients to access
  - alternative methods for informing patients about service
  - podcasts / audio material as a therapeutic intervention for patients
- (related to point above) – clarifying the pathway for patients during triage may improve engagement
- GPs may be more likely to refer if they have ready access to consultation with specialist mental health professional regarding referral
- Patient more likely to opt-in to treatment if called by service – validates patients' concerns and needs
- Self-referral can be less stigmatising – might improve engagement with treatment offered
- Patient needs to be given a picture of realistic goals – an idea of the things that treatment can help with
- Option of home visits needs to be available

## 4.3 Engagement and retention in treatment

### (a) Feedback from people with visual impairment

Themes emerging from discussion about issues of acceptability of treatment covered a range of topics, some specific to living with a visual impairment, others which may be applicable to anyone embarking on psychological therapy

- Therapy didn't make sense – need clear explanation of tasks to be undertaken and why;
- Too painful to talk about issues – got half-way through – found it too difficult;
- Need to be helped in considering what happens after therapy - what's next;

- Carers are key source of support – their expertise and contact with us needs to be factored in to treatment;
- Forms can be difficult to work with – don't like them – need formats enabling screen readers, or MP3 interactive material;
- Would be better if there is no use of standard materials like diaries in therapy.

(b) Feedback from professional staff and volunteers supporting people with visual impairment

For this group of interviewees most respondents indicated that they were not in a position to comment on how people with visual impairment experienced services supporting mental health needs, in the main because they were not in a role in which reviewing these issues with an individual was appropriate. The limited feedback available included that from a small number of clinical staff who had experience of supporting people with visual impairment who had mental health needs.

- No disability information was recorded about the individual – this means it's not possible to plan in advance to adapt the session when first meeting the person
- As is typical of psychological therapy, work was goal-focused and included vocational support – only this time it was adapted to consider the issues faced by the person adjusting to deteriorating sight
- Often the person's problems were not directly linked to visual impairment – the treatment was the same as it would be for someone without visual impairment – except some adaptations might be needed

Some examples of adaptations required to ensure people with visual impairment were able to engage with and remain in treatment were provided, including:

- check each group session that person with visual impairment is able to participate and benefit from group format;
- ensure person is following individual sessions;
- standard materials usually in written form are presented orally;
- written materials provided in large font;

- person escorted to bus stop as light diminishes in late afternoon.

### (c) GP Feedback

- Treatment needs to be individualised – reflecting varying backgrounds and circumstances in which a person’s mental health problems arise.

## **5.0 Improving access to psychological therapies for people with visual impairment and depression**

### **5.1 Synthesis of literature review and stakeholder feedback**

The review of existing literature regarding visual impairment and common mental health problems highlights a number of key issues relevant to improving access to psychological therapies:

- depression is common in people with visual impairment and may be particularly prevalent among people who attend low vision support services;
- depression is commonly not recognised or identified among people with visual impairment at the level of general practice, and visual impairment support services;
- depression in people with visual impairment can be associated with reduced benefits derived from vision rehabilitation programmes;
- the causes of depression in visual impairment are likely to involve multiple possible contributory factors some of which are specific to visual impairment and some which may be non-specific and are associated with factors that increase the risk of visual impairment, such as age-related risk factors for depression;
- low vision rehabilitation programmes that do not specifically address psychosocial variables associate with risk of depression tend to have limited impact on the experience of depression in visual impairment;
- improving recognition of depression and support to access psychological therapies may need to take account of the tendency for some people with visual impairment to find access to all forms of health and social care more difficult;
- the tendency for some individuals to find peer networks and sources of support in less formal non-health care settings more accessible than formally offered health services might suggest that greater access to treatment for depression might be achieved by utilising these settings.

## **5.2 Implications for training to support improved access to psychological therapies for people with visual impairment**

The stakeholder feedback and selective review of the literature suggests that training to support improved access to mental health services for people with visual impairment should consider:

### Care pathway development

- Participants pointed to the critical roles that can be played by support staff, family and carers. These resources to the person with visual impairment can be utilised in enabling a pathway to mental health services where the person is less likely to be in contact with a GP or other professional.

### Disclosure and identification

- The need to establish rapport and trust, recognising the specific needs of people with visual impairment and recognising that detection of mental health needs against background of adjustment;
- The need to maximise opportunities to assess for depression at different points in time and different points across a care pathway in order to allow identification of depression which can emerge at different stages of a person's response to sight loss and in recognition of an individual's different states of readiness to acknowledge depression;
- The need to equip individuals working with people with visual impairment with the necessary knowledge and skills to identify the possibility of depression and support access to appropriate support;
- The need to acknowledge the sense of burden some people with visual impairment can feel and to formulate the experience of depression as a common experience which warrants treatment;
- The use of simple tools to screen for possible common mental health problems expediting the identification process in context of the above factors;
- The need to ensure availability of self-monitoring tools to enable people with visual impairment to self identify possible mental health needs.



The review also highlights the difficulties in drawing clear conclusions about the acceptability of services commonly used by people with depression, the IAPT services. With limited data referring to people with visual impairment clear conclusions regarding the acceptability and impact of IAPT interventions cannot be drawn. The data that is available from all IAPT services across England does suggest however, that upon entering treatment, people with visual impairment may be gaining just as much benefit from IAPT interventions. It is possible that those entering IAPT treatments are not representative of most people with visual impairment and depression. Instead they may represent a highly motivated group of individuals, able to overcome obstacles to access and who therefore may be predisposed towards gaining from the interventions offered.

In the absence of larger numbers of people with visual impairment entering IAPT services these interpretations remain speculative. The limited review of work undertaken with people with visual impairment by a local IAPT service suggested that adjustments to standard treatment procedures were feasible and appropriate to the needs of the people with visual impairment. These provisional conclusions suggest that the most important next step in improving access to support for depression in people with visual impairment may be to focus on improving referral rates to IAPT.

In order to assess the feasibility of delivering training to promote increased access to IAPT the final stage of this review focused on incorporating the implications for training identified above into a brief training package aimed at improving identification of depression in people with visual impairment and improving confidence to support access to local IAPT services.

## **6.0 Feasibility study – evaluating a local training initiative**

In order to assess the feasibility of adopting the identified training initiatives developed from the literature review and stakeholder meetings the third part of the review focused on testing the feasibility of utilising these methods within services supporting people with visual impairment. The aim of this part of the review was to determine how feasible it would be for an IAPT service to offer brief, accessible training to a broad range of individuals involved in supporting people with visual impairment to improve knowledge and confidence in talking to people with visual

impairment about the possibility of depression and about local support services.

## 6.1 Recruiting local staff for the evaluation

The program was offered on a voluntary basis to a range of employed professionals and volunteer staff working with people with vision impairment across two London boroughs. Fifty volunteers from a range of backgrounds related to supporting people with vision impairment participated in this evaluation. Table 5 outlines the participant's sociodemographic and role characteristics.

Table: 5 Characteristics of training participants (n=50)

Sex, n (%)	
Female	41 (82%)
Age (years)	
Mean (range)	50.48 (23-74)
Ethnicity, n (%)	
White	39 (78%)
Black/Black British	6 (12%)
Other	5 (10%)
Vision impairment, n (%)	14 (28%)
Had previous training specifically related to depression, n (%)	44 (88%)
Current role, n (%)	
Volunteer	8 (16%)
Befriender	6 (12%)
Rehabilitation Worker	18 (36%)
Local Authority Social Care Staff	5 (10%)
Low vision clinic support workers	6 (12%)
Information, employment volunteer coordinator	7 (14%)
Experience working in services for people with vision impairment (years), mean (range)	11.16 (3.16-16.33)
Average number of people with visual impairment participant is in contact with each week, mean (range)	9.82 (1-52)
Average number of minutes spent with each person with vision impairment each week, mean (range)	26.1(2-45)

## **6.2 Measures**

Those measures used by Rees et al (2010) were adopted, with permission from the author, as primary outcome measures for assessing the impact of training. The present authors would like to thank Dr Gwynn Rees for her support and permission to use these measures. Two of these measures were adapted by Rees et al (2010) from existing measures developed to assess confidence in and perceived barriers to working with elderly people with depression. Two additional items were adopted from the Rees et al (2010) study and are described below. Higher scores represent higher levels of confidence, higher levels of perceived barriers to recognition, assessment and management of depression and greater action taken in response to depression.

### **Views on depression**

This is a measure adopted from the work of Rees et al (2010) and consists of 16 items referring to knowledge about depression, depression in people with vision impairment and knowledge about detection and treatment of depression in people with vision impairment. Participants respond on a four-point scale (“strongly agree” to “strongly disagree”).

### **Confidence in Recognizing and Responding to Depression in People with Vision Impairment**

This is a measure to assess confidence in working with people with vision impairment and is based on a measure used to assess confidence in working with older people with depression. The measure was adapted by Rees et al (2012) on the basis of data derived from focus groups with eye health professionals described in Fenwick et al (2009) and McCabe et al (2008). Participants responded to 11 items on a four-point scale (“not confident” to “very confident”) with a higher score representing greater confidence. For example, “In being able to recognize that a patient with vision impairment might be depressed, I feel...”

### **Barriers to Recognition, Assessment, and Management of Depression**

This scale includes 15 items that are rated on a four-point scale (“strongly disagree” to “strongly agree”) with higher scores representing greater perceived barriers. This scale is also based on an adaptation of

a scale previously developed to measure perceived barriers to recognising depression in older adults (McCabe et al, 2008). Item content refers a range of factors that may be considered barriers including personal factors: for example, “The possibility of depression is not explored because I need to protect myself from being involved in people’s emotional problems”, organisational factors: for example, “The absence of standard procedures to follow in my role when I suspect a person is depressed means that they may not always receive the best management of depression”, and role or work demand issues: for example, “My high workload makes it difficult to know if a person might be depressed”.

## **Responding to Depression**

Participants were asked to rate the frequency of undertaking 8 actions if they suspect a patient to be depressed (for example, “Discuss referral options with the patient”) using a four-point scale (“never” to “often”). These items were derived from the original 14 item version with redundant items removed to improve validity of the measure. All items in the revised version were positively worded with a high score representing more frequent action.

## **Depression vignette**

A brief vignette (82 words) of a person (Mary) who has major depression is presented to participants who are asked “From the information given, what, if anything, is wrong with Mary?” (open-ended question) and “Do you think Mary needs professional help? (yes/no). This item is derived from the evaluation method utilised in the mental health first aid training developed and evaluated across a range of public settings and across a number of countries (Kitchener and Jorm, 2002).

Participants were also asked whether they thought that the subject of the vignette seeking help from each of twelve different people would be helpful, harmful or neither. Participants therefore received a score of 0 to 4 according to the number of interventions endorsed as helpful based on the professional consensus regarding helpful interventions for depression (Kitchener and Jorm, 2002).

## **Training evaluation**

In order to make comparisons with the results of the depression training program evaluated by Rees et al (2010), this review adopted the

measures for training evaluation. Questionnaire items refer to the structural and procedural elements of the training, the relevance of the content of the training, perceived benefits and reported intention to implement the recommended actions.

### **6.3 Assessing the feasibility of recruiting people to the training**

Local support organisations, local authority services and local healthcare services working with people with vision impairment were contacted and provided with written information regarding the training and asked to participate.

Participants completed measures one to two weeks prior to the training intervention and at the end of the training workshop. Upon completion of the workshop participants were asked to identify small steps they could take in implementing in the coming weeks some of the ideas they had been asked to consider in the workshop. The aim was to begin the process of participants building confidence in the use of the ideas they had been exposed in routine practice of supporting people with vision impairment. These actions were reviewed four to six weeks later in an action learning set (one hour) for participants.

### **6.4 Training program**

The training program was delivered in one 3-hour workshop with one 1-hour action learning set 4 to 6 weeks later. It was designed to address the key issues identified in section 5.0 regarding the potential barriers to accessing mental health care in people with vision impairment and common mental health problems. This is summarised in Table 6.

#### **Training Groups**

Fifty participants attended one of five training groups delivered in local settings where participants usually worked in their support of people with vision impairment.

Table 6: Overview of the training program

Section	Focus	Content summary
1	Link between vision impairment and depression	Increased risk of depression in people with vision impairment Importance of loss of functional ability Impact of vision impairment on healthcare access A provisional model of depression and vision impairment
2	Recognising depression	Listening skills Key changes in mood and behaviour Signs and symptoms of depression
3	Responding to depression	Approaching someone who may be depressed Supporting someone who may be depressed The things that don't help  Recognising and responding to suicidal thoughts
4	Encouraging the person to seek professional help	When low mood becomes more than a temporary experience Information that might be helpful Using a simple screening tool Taking small steps

## 6.5 Training outcomes

Table 7 outlines the impact of training on self-reported confidence in recognising and responding to depression and perceived barriers to recognition and responding to depression. Following training, participants reported significantly higher levels of confidence in recognising and responding to depression in people with vision impairment (86% of the sample showed higher confidence scores, 6% no change and 8% lower confidence scores post-training). Changes related to each item of the confidence measure are illustrated in Table 8.

Participants also reported being significantly more likely to respond to depression (70% reported higher 'respond' scores, 6% no change and 24% lower scores).

Table 7: Impact of training on self-reported confidence, tendency to respond and perceived barriers

Measure	Pre-training	Post-training	
	Mean (SD)	Mean (SD)	
Confidence recognising & responding to depression	27.52 (10.65)	34.50 (5.30)	t = -9.106; p<0.001
Responding to depression	17.52 (6.54)	19.52 (2.94)	Z = 3.80; p<0.01
Barriers to recognition & responding	36.00 (6.73)	34.90 (8.25)	Z = -0.91; N.S.

There was no significant change in the extent to which training participants perceived *barriers* to the recognition, assessment and management of depression (48% of participants reported lower levels of perceived barriers, 12% no change and 40% reported higher levels of perceived barriers post-training). Further examination of the data revealed that the percentages of participants reporting an increase in perceived barriers was fairly evenly distributed across 'current role' type with the exception of 'rehabilitation worker' where 54% of participants post-training reported higher levels of perceived barriers.

From further inspection of the data collected, two of the items included in the measure referring to perceived barriers showed an increase in scores after training. Both items referred to participants' knowledge of depression. The first item referred to *My limited knowledge of depression means that people may not always receive the best management for depression* - pre-training mean (SD)= 2.1 (0.99); post-training means(SD) = 3.28(0.85); t= - 7.22, df=49; p< 0.01. The second item referred to *My poor knowledge of what to do if a person could be depressed means that they may not always receive the best care* - pre-training mean (SD)= 3.00 (0.60); post-training mean(SD) = 3.32(0.47); t= - 3.17, df=49; p< 0.05. These items may appear to respondents to refer to the same issue, although the second is intended to refer specifically to the person's self-rated knowledge of how to proceed with a course of action to support the individual who may be depressed. This apparent increase in perceived barriers for some respondents might be the result of exposure to more information about depression and its management during the training which served to prompt participants to become more aware of what they did not know in relation to this condition and its management. However, this would not appear consistent with the increased scores referring to confidence to take action in relation to managing depression.



**Table 8: Impact of training on specific items in the confidence scale**

Confidence in dealing with depression item	Pre-training Mean (SD)	Post-training Mean (SD)		
Asking people with vision impairment about their feelings or mood	2.74 (0.98)	3.26 (0.66)	t = -4.045	P<0.001
Listening to people with vision impairment talk about their feelings or mood	3.08 (0.75)	3.44 (0.64)	t = -3.674	P<0.005
Being able to recognise that a person with vision impairment might be depressed	2.50 (0.93)	3.18 (0.66)	t = -5.264	P<0.001
Knowing which signs to look for to tell if a person with vision impairment might be depressed	2.42 (0.92)	3.24 (0.65)	t = -6.824	P<0.001
Knowing if a person might have depression or is just dissatisfied with their current situation	2.24 (0.93)	2.98 (0.65)	t = -5.546	P<0.001
Discussing my concerns about possible depression with a person's family members	2.08 (0.98)	2.62 (0.98)	t = -4.556	P<0.001
Providing education on the link between vision impairment and depression	1.94 (1.01)	3.04 (0.72)	t = -8.352	P<0.001
Providing education on possible treatment strategies for depression	1.90 (0.97)	3.04 (0.69)	t = -8.920	P<0.001
Directing a person who might be depressed to appropriate services or agencies	2.66 (1.00)	3.34 (0.65)	t = -5.024	P<0.001
In passing on my concerns about possible depression to a person's GP	2.44 (1.09)	3.08 (0.87)	t = -3.855	P<0.001
Passing on my concerns about possible depression to vision rehabilitation agencies	2.72 (0.96)	3.28 (0.85)	t = -3.832	P<0.001

## Depression vignette

In response to the brief hypothetical case vignette, prior to training 84% of participants correctly identified the subject as being depressed and after training 96% of participants correctly identified depression (McNemar Related Samples Test,  $X^2 = 4.167$ ;  $p < 0.05$ ). No change was observed in the proportion of training participants correctly identifying that the person required professional help with performance on this item close to the ceiling at pre-training assessment (Table 9).

Table 9: Correct identification of depression, need for professional help and percent of interventions correctly endorsed as helpful

Depression vignette	Pre-training	Post-training	
Correctly identify depression, n (%)	42 (84%)	48 (96%)	$\chi^2 = 4.167; p < 0.05$
Correctly identify person needs professional help, n (%)	49 (98%)	49 (98%)	NS
All four interventions correctly endorsed as helpful, n (%)	37 (74%)	42 (84%)	NS

Changes in the number of correctly identified interventions is shown in table 10. Comparing the number of correctly identified interventions pre- and post-training revealed no significant difference. Although an additional 10% of participants correctly identified all four interventions as helpful this was not a statistically significant increase.

Table 10: Number of interventions correctly identified pre- and post-training

Number interventions correctly identified as helpful	Number participants (%)	
	Pre-training	Post-training
1	1 (2%)	0
2	5 (10%)	1 (2%)
3	7 (14%)	7 (14%)
4	37 (74%)	42 (84%)

## Training evaluation

The majority of participants reported that the structural elements of the workshop were appropriate to their needs (Table 11).

Table 11: Structure of workshop

Workshop structure	N (%)	
Session duration	Too short 6 (12%)	Just right 44 (88%)
Number of people in the group	Too many 1 (2%)	Just right 49 (98%)
Information presented	Too basic 1 (2%)	Just right 49 (98%)

The majority of participants 'agreed' or 'strongly agreed' with each element of the workshop they were asked to evaluate (the responses

'agree' and 'strongly agree' are collapsed to form one category 'agree', Table 12).

Table 12: Participant feedback on each element of the workshop

Element of the workshop (%)	N	
	Agree	Disagree
The program was well taught	50 (100%)	0
The training allowed enough discussion	49 (98%)	1 (2%)
The information taught was appropriate to my role	48 (96%)	2 (4%)
A one session training program was sufficient	42 (84%)	8 (16%)
The training made the signs and symptoms of depression clear	48 (96%)	2 (4%)
I feel more confident bringing up emotional issues with people I support	49 (98%)	1 (2%)
I know where and to whom I can refer people who I suspect to have depression	49 (98%)	1 (2%)
I feel the people I support will benefit from what I have learnt in this program	50 (100%)	0
I would recommend this training to others	49 (98%)	1 (2%)
The training materials provided were useful	50 (100%)	0
I intend to discuss the screening and referral system with my colleagues	48 (96%)	2 (4%)
I intend to use the screening tool with my clients	45 (90%)	5 (10%)
When I suspect clients are depressed I intend to suggest they consult their GP	45 (90%)	5 (10%)

## 6.6 Training evaluation - summary and discussion

This assessment of feasibility of a brief training package suggests that staff working across a broad range of roles, both paid and voluntary, are interested and motivated to improve support for people with visual impairment and depression. Those volunteering for the training were from a broad range of roles and nearly one-third had lived experience of visual impairment. A large majority of training participants rated the training very highly (Table 10 and Table 11) and would recommend it to others. Therefore, as a preliminary assessment of how feasible it would be for local IAPT services to work with partner agencies across the care pathway for people with visual impairment, this brief (one session) training package appears to be a practical method for beginning this work. The content of training had face validity for the participants (it was felt appropriate to their roles) and was rated as something that would be helpful to the people with visual impairment that they work with.

This form of training has been undertaken in other settings outside of the UK with staff supporting people with visual impairment (Rees et al, 2012). This is the first report the authors are aware of this type of training with visual impairment support staff in the UK where the training participants also included people with visual impairment and those in volunteer roles and of training of this brevity. Other examples of this type of training specifically designed to improve detection and management of depression in people with visual impairment, for example Rees et al, 2012, have been more extensive and integrated within larger programmes of professional development. The feedback from the stakeholders in this review suggests that it may be important to create multiple opportunities to identify depression and support someone with visual impairment to access help. The training reported here therefore focused on staff and volunteers who may have repeated contact with people with visual impairment. Perhaps of greater importance is the informal role some participants had with people with visual impairment, in the form of peer supporters creating the opportunity to support someone with visual impairment and depression while allowing them to recognise the complex background of adjustment to sight loss, and the multiple possible influences on emotional dysregulation. This may create a less stigmatising context in which to support a person with visual impairment to access help.

The training assessed in this review was limited to one workshop of four hours and one action learning set of 1.5 hours. The positive results from this brief training suggest it is feasible and effective in improving the knowledge and confidence of participants from a wide range of backgrounds and roles. Almost 90% of the group taking part reported that they had some previous experience of training that referred to depression and reported, on average, more than ten years' experience of working with people with visual impairment. The group therefore might have been expected to gain little additional benefit from the training. However, there were significant improvements in confidence in recognising depression and reported likelihood of responding to depression.

Improvements in confidence appeared across all items assessed including those referring to the process of directing an individual to further sources of support. This contrasts with the lack of improvement in relation to perceived barriers to access reported by some training participants. One preliminary interpretation of this is that lack of confidence in one's knowledge base among some individuals, prompted

by exposure to more information about depression as a condition and services to support people with depression, prompts a decrease in confidence in one's own knowledge. Importantly, this was not associated with a reduced likelihood to act when one suspected depression might be present. This is crucial as the aim of this preliminary assessment of the training was to establish whether participants would feel more able to take some action to facilitate access to appropriate assessment and treatment services. This is the critical change being sought, not improvement in knowledge regarding depression *per se*. However, the evaluation is not focused on the actual behaviour of participants. It is not possible to conclude that as a result of the training people will act on more instances of suspected depression and support individuals with visual impairment to access treatment.

While this evaluation of a pilot training programme designed to be accessible to a range of support staff working with people with visual impairment showed some positive outcomes, these outcomes must be considered in the context of the limitations of the current review. The volunteers who took part in this training worked in a range of roles in relation to supporting people with visual impairment. However, having volunteered for the training evaluation it is possible that they do not represent 'typical' staff in these roles but instead represent a more motivated group who are more likely to benefit from training than those who did not volunteer. There is no information regarding the number or characteristics of those who could have volunteered but refrained.

## **7.0 Discussion**

### **7.1 Key findings**

#### **In the aetiology of depression in visual impairment, are standard psychological therapies likely to be effective?**

In reviewing the literature on visual impairment and depression it was argued that there are likely to be multiple factors contributing to the increased risk of depression among people with visual impairment. These factors include those that are specific to sight loss, including visual functioning. In addition, there may be a range of non-specific factors that are more common among people with a visual impairment but which represent risk factors for depression for all groups of people. These factors refer to socio-economic variables, health status and restricted access to health care which may independently increase risk

of depression or which may interact with factors such as reduced visual functioning to increase the risk of depression.

It was also noted that depression appears to reduce the positive impact that rehabilitation programmes can have for people with a visual impairment. Where depression operates in this way to maintain reduced visual functioning (activities of daily living in the context of sight loss) this may serve to maintain the increased risk of depression. However, there are also encouraging reports of people who may navigate the challenges of sight loss, particularly in older age, where adaptive personal and psychological skills can moderate the risk of depression.

This combination of risk factors and moderators in the formulation of depression in relation to visual impairment suggests that interventions to reduce risk of depression or treat depression might target factors at a number of levels. At a social and economic level, interventions to improve disposable income and address issues of isolation are likely to be important. Similarly, ensuring people have fair and equitable access to health and social care services would seem to be a basic priority in any attempt to improve mental health outcomes.

The role of visual functioning in relation to depression may suggest that interventions should specifically target this as a way of moderating depression. In the comprehensive review by Rabiee, Parker and Baxter (2015) the authors provide convincing evidence of some value of low rehabilitation programmes to improved mental health outcomes while illustrating the limited conclusions that can be drawn from the existing published literature in this area of study. The current report has also highlighted the literature suggesting that interventions specifically aimed at mental health gains may be required in addition to standard vision rehabilitation interventions if reductions in depression are required.

The key issues related to the risk of depression in visual impairment suggest that there may be a number of pathways to depression and a number of opportunities to intervene to support recovery from depression. Many psychological models of depression are considered maintenance models in which those factors which appear responsible for maintaining depression are targeted, irrespective of causal aetiological factors. In this respect, common experiences in depression such as reduced activity, loss of pleasure, low mood and mood-congruent negative appraisals may be targeted in a psychological intervention in an attempt to diminish these experiences as maintaining factors. It would appear that such a model may be equally applicable in relation to

depression in visual impairment. The limited evidence available has suggested that psychological interventions of the kind offered by IAPT services (van der Aa et al, 2015) can be effective for people with visual impairment and depression.

### **Are IAPT services suitable for people with visual impairment and common mental health problems?**

Available data from the Health and Social Care Information Centre (HSCIC) suggests that when people with sight loss access IAPT services they are just as likely to engage with and benefit from the interventions offered. However, the data concerning outcomes in the national IAPT data set provides limited insight into the acceptability of, and outcomes from, IAPT interventions for people with visual impairment and common mental health problems. The limitations arise as a result of the restricted sample of people with visual impairment accessing IAPT services or being correctly identified and recorded as having accessed IAPT services.

A more convincing account of the experience of people with visual impairment referred to IAPT services will only be possible when services demonstrate they have seen (and recorded having seen) larger numbers of people with sight loss. This current report has highlighted the evidence suggesting that despite a high prevalence rate of depression among people with sight loss, there appears limited recognition and treatment offered. The studies of Rees (2010) and Rabiee et al (2015) recommend that staff in all services who have contact with people with visual impairment need to be skilled and confident enough to identify depression and to refer on to specialist services. This is a critical issue in improving access to services of any kind in the support of people with depression who have a visual impairment.

The national data set for IAPT, although limited in its inclusion of people who have visual impairment, does suggest that engagement and benefits derived do not differ significantly for people with visual impairment. Therefore, a focus on improving detection rates of depression in visual impairment and increasing referrals to IAPT would seem justified as the available evidence suggests that there will be clinical benefits for the individuals concerned.

In addition, the stakeholder review suggested that relatively small adjustments can be made in order to support people with visual

impairment to engage with and remain in treatment. The importance of these adjustments is supported by the findings of Wiles (2014) who describes some of the problems people with visual impairment encounter accessing routine healthcare (in this instance GP services) and the negative impact this has on the development of trust between the person with visual impairment and the health practitioner. Guidance on making such adjustments in health care settings and in relation to IAPT services specifically can be found in the following documents:

**Good practice guidance on the use of self-help materials within IAPT services, Department of Health March 2010.**

This guidance provides limited reference to people with visual impairment. It acknowledges the need to ensure materials used consider the needs of people with visual impairment but little detail regarding this process is provided.

**How to make IAPT more accessible to Older People: A Compendium Department of Health, March 2013**

This guidance concerns improving access to older people and is therefore relevant to issues of accessibility for some people with visual impairment as the incidence of visual impairment increases with age. The guidance provides a useful self-assessment framework for IAPT services in relation to accessibility for older people. This framework can be easily adapted to consider issues of access for people with visual impairment and an example of this is provided in Appendix 1.

**Can staff be helped to feel more skilled and confident in recognising depression?**

The current review carried out a preliminary investigation of the impact of delivering relatively brief training to a broad range of support staff working with people with a visual impairment. The training focused on improving identification of depression in people with visual impairment and on promoting confidence in talking to people with visual impairment about emotional wellbeing and the possibility of benefiting from support with this. In broad terms the training worked. Most participants reported feeling more skilled and confident in relation to the target outcomes.

This training was undertaken in settings in which people with visual impairment were currently being offered support services. It is possible that access to psychological interventions offered by IAPT and their



acceptability to people with visual impairment will be enhanced if the interventions are delivered in the locations in which people with visual impairment are currently being offered support. This may be especially relevant given some of the research concerning the sense of trust that some people with visual impairment feel in relation to healthcare professionals. Stoneman (2014) found an association with people with visual or hearing impairment and dissatisfaction with GPs in some of the behaviours, such as giving time and listening, that have been associated with relationships of trust between patients and GPs. By offering time to listen in the form of a broader range of support workers, including peers who live with a visual impairment, issues of trust may be more sensitively addressed and the probability of accessing support for depression improved.

## **7.2 Limitations**

This report pulls together sources of information from a broad range of published studies and reports with varying methodologies. The review is selective rather than systematic and any conclusions must be seen in light of this. The range of existing reviews of related areas of study make it apparent that there is limited availability of high quality research to draw on in making conclusions about the availability of, access to and effectiveness of psychological therapies for depression in visual impairment. The current report is therefore necessarily selective as it attempts to draw attention to the issues that need to be addressed.

Stakeholders in this review provided a rich source of ideas regarding changes needed to improve access to support for people with sight loss and depression. This self-selected group of participants, however, may not be representative of all staff working in this field. With this caveat, the participants provide a useful source of information for any local provider of mental health services to consider issues to be addressed in order to make their interventions more useful to people with sight loss.

In relation to the training intervention, the limitations of the sample of participants has already been noted as has the question of whether reported increases in self-confidence and knowledge necessarily leads to changes in target behaviours (identifying depression and supporting access to treatment). However, the findings of the report suggest the training is feasible and has face validity for participants from a wide range of backgrounds.

### **7.3 Implications for practice**

The findings from the current report build on the guidance to providers of IAPT services to work with local organisations supporting people with visual impairment by demonstrating the potential benefits of providing training for staff in such organisations. This may help resolve the under-representation of people with sight loss in IAPT services. It is recommended that local IAPT services consider offering the type of brief training described in this review with the aim of promoting referrals and access.

The report has also highlighted the multiple factors that might be implicated in the development of depression among people with sight loss. A comprehensive and personalised approach to the management of depression may therefore benefit from integration of interventions targeting factors at different levels. While psychological treatments aim to address psychological factors maintaining depression, local support services can target social factors that can promote recovery. This can be achieved by delivering psychological interventions in settings in which people with sight loss are receiving support with these broader issues. In addition, the frequency of contact and the development of trust with support services might improve the probability of people with sight loss engaging with psychological interventions if these are provided in support settings with which they are already familiar. In particular, training peers to support the delivery of interventions may have a critical impact on engagement.

### **7.4 Suggestions for further research**

It is not possible to determine in the current review whether the training described results in the increased detection of depression and an increase in referrals to services for treatment. An important extension of the current preliminary evaluation would be an assessment of the impact of the training on a wider and representative sample of support staff and of the impact on identification and referral rates.

There is encouraging but limited evidence regarding the effectiveness of psychological treatments for depression in people with visual impairment. Extending the knowledge base in this area could include the evaluation of standard psychological interventions compared with a combination of standard interventions plus rehabilitation interventions

aimed at improving visual functioning. The development of bespoke interventions such as this can be designed through collaboration of rehabilitation experts and mental health experts. In addition, it is suggested that people living with sight loss may prove to be important collaborators in the design and delivery of such interventions where issues of credibility and trust are crucial to engaging people with sight loss. This is an intended next step in the current practice development work described in this report.

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## Appendix 1

Is your service accessible to people with a visual impairment?

(Adapted from the original document designed by Steve Boddington)

<b>Aspect of service design:</b>	<b>Existing actions that already facilitate access for people with visual impairment:</b>	<b>Further actions that could be adopted to improve your service:</b>
<p><b>Equity of Access Targets:</b></p> <p>What proportion of your services referrals is currently of people with visual impairment?</p> <p>Does this reflect your local demographic?</p> <p>(on average there should be 3% referrals with visual impairment but will vary locally)</p>		
<p><b>Does your service undertake ongoing publicity to attract referrals of people with visual impairment?</b></p> <p>In general healthcare and social care professionals may find difficulties recognising common mental disorders in people with visual impairment. The 3rd sector, acute services and people with visual impairment themselves also need to be targeted. Consistent publicity can help to resolve this pattern.</p>		
<p><b>Modified engagement procedures for getting into your service.</b></p> <p>People with visual impairment may be reluctant to opt into psychological services due to:</p> <ul style="list-style-type: none"> <li>• Being unfamiliar with 'psychological treatments'</li> <li>• Mobility/health problems</li> <li>• Fear of being a burden to support staff and others</li> </ul>		

<p><b>Offer home visits if necessary</b></p> <p>A proportion of people with visual impairment will not be able to attend clinics.</p> <p>Sometimes an initial home visit may be all that is needed to break down reticence and encourage attendance at clinic/telephone appointments after that</p> <p><b>Offer help to complete IAPT forms where necessary:</b></p> <p>People may be requires support to complete paper work electronic materials that have not been adjusted to support a person with visual impairment.</p> <p>When working with older people with visual impairment consider</p> <ul style="list-style-type: none"> <li>• Psychological language may be unfamiliar</li> <li>• There is a higher level of literacy problems amongst older people as educational opportunities were less equally available 60+ years ago</li> <li>• Mild Cognitive Impairment may affect ability to concentrate/focus.</li> </ul>		
<p><b>Capacity to adjust the pace, length, frequency of sessions where necessary</b></p> <ul style="list-style-type: none"> <li>• Can your therapists offer longer or shorter appointments to accommodate the needs of the patient?</li> <li>• Can appointments be scheduled more/less frequently?</li> <li>• Can additional sessions be offered for patients when progress is slow?</li> </ul>		
<p><b>Do you have a resource for signposting to services which support people with visual impairment?</b></p> <p>Is this up to date?</p>		

<p><b>Have your staff had any training to work with people with visual impairment?</b></p> <p>Consider local visual impairment support services as sources of support in developing training resources</p>		
<p><b>Do some IAPT staff with a special interest undertake supervision of colleagues who are working with people with visual impairment?</b></p> <p>This ensures that people with visual impairment do not get overlooked and may be seen by therapists with an interest/ knowledge/ skill</p>		
<p><b>Referral to vocational/ educational/occupational services:</b></p> <p>These should be set up to meet the needs of people with visual impairment, making links with local visual impairment support organisations.</p>		
<p><b>Is there a person with visual impairment on your service user group?</b></p> <p>Active involvement of service users with visual impairment will help to ensure that the service attends to the needs of people with visual impairment.</p> <p>People with visual impairment may have knowledge and experience of local resources that can help IAPT to integrate with wider network of health and social care</p>		