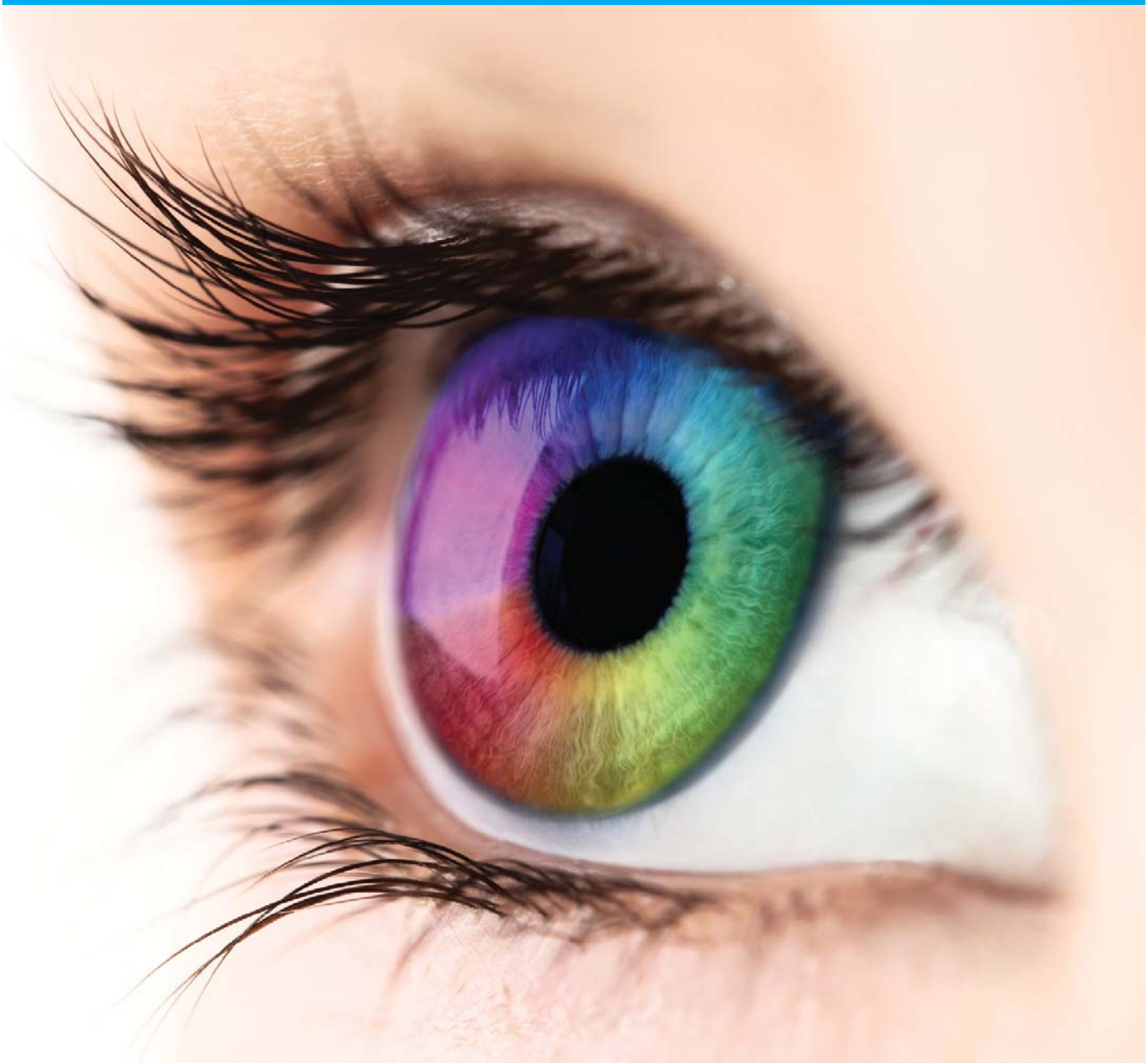
Macular Society

Executive Summary: A systematic review of literature evaluating eccentric viewing and steady eye training

Prepared for the Macular Society

August 2012



Allannah Gaffney, Tom Margrain,
Alison Binns, Cardiff University, Cardiff, Wales
Catey Bunce, Moorfields Eye Hospital, London, England

Contents

List of abbreviations

ADL	Activity of daily living
AMD	Age-related macular degeneration
CVL	Central vision loss
ESP	Elicited sequential presentation
EV	Eccentric viewing
ICER	Incremental cost effectiveness ratio
JMD	Juvenile macular degeneration
LVA	Low vision aid
LV QoL	Low vision Quality-of-Life Questionnaire
MacDQoL	Macular Disease-Dependent Quality of Life
MD	Macular degeneration
NEI-VFQ	National Eye Institute Visual Function Questionnaire
NICE	National Institute for Health and Clinical Excellence
PRL	Preferred retinal locus
QALY	Quality adjusted life year
QoL	Quality-of-life
RCT	Randomised controlled trial
RSVP	Rapid serial visual presentation
SES	Steady eye strategy
SLO	Scanning laser ophthalmoscope
TRL	Trained retinal locus
VA	Visual acuity
VR QoL	Vision-related Quality-of-life

1. Executive Summary

Macular degeneration (MD) is a term describing conditions of the central retina that cause a progressive loss of central vision. The most prevalent type of MD is age-related macular degeneration (AMD); advanced AMD is believed to affect 500,000 people in the UK alone (Owen et al., 2012). The end-stage of MD is the development of a central scotoma, which has a detrimental effect on a number of visual functions, and hinders activities of daily living (also known as ADLs, daily living activities or independent living skills) such as reading, mobility, visual search and face recognition.

Eccentric viewing (EV) is an adaptive strategy used to compensate for central vision loss (CVL), in which relatively healthy paracentral areas of the retina are used to fixate objects. Individuals often self-select an anomalous area of retina for this purpose, known as the preferred retinal locus (PRL). Alternatively, they may be taught to use a specific paracentral area of retina during EV training, known as the trained retinal locus (TRL). Eccentric viewing may be used in conjunction with a steady eye strategy (SES), in which the eyes are held in a steady position and text is moved from right to left, or

training in more accurate eye movements may be provided.

Different models of EV and SES training have developed to meet the rehabilitation needs of people with CVL. There is limited evidence regarding the prevalence of EV training, but in reviews of low vision service provision in the USA and Australia, around 40-50% of services claim to offer this type of therapy. Given the number of people across the world who could benefit from this training if it is successful, and setting this alongside the expense of providing such training on a universal basis, there is a need for a strong evidence base regarding the ability of the different training strategies to achieve positive outcomes in people with CVL. This report is a systematic review of the literature evaluating the effectiveness of EV and SES training in people with CVL.

Primary Objective:

The primary objective of the review is to provide a comprehensive overview of previous and current practice in EV and SES training.

Secondary Objectives:

1) To describe the value, impact and outcomes of EV and SES training, with respect to objective measures of

fixation and eye movements; basic clinical measures such as reading speeds, reading accuracy, and visual acuity; visual functioning and ability to perform ADLs; quality of life; and cost effectiveness.
2) To summarise the variety of models and approaches to EV and SES training, including those which are clinical and community based.
3) To assess the impact of the model of EV training on the outcomes of EV and SES training
4) To assess the impact of the characteristics of the participant on the outcomes of EV and SES training.
5) To identify any gaps in the literature which future research should address.

Literature was identified by searching the following databases: Web of Science, EMBASE, Medline, Cochrane CENTRAL, PsychINFO, and CRD. Additional literature was identified by hand searching of relevant reviews and by asking experts in the field for additional sources of information. Of the 2536 potential articles identified by the literature searching strategies, 32 were found to meet the inclusion criteria for the review.

The findings of the report were as follows:

1.1. Quality of evidence

Although a number of publications have reported the outcomes of EV and SES/eye movement training, the quality of these reports has not always been good. Many of the studies included in the review failed to report in sufficient detail the study design, the characteristics of the participants, the nature of the intervention or the findings obtained. Only four of the studies included in the review presented the results of a randomised controlled trial, the recommended study design according to the Cochrane Collaboration. In addition, only two of these studies meet the criteria for well-designed RCTs given by the Collaboration, and these included moderately sized cohorts of around 25 participants per intervention (Vukicevic & Fitzmaurice, 2005; 2009). Instead, the majority of studies used a relatively weak ‘before and after’ comparison design. Few of the studies incorporated a control group of participants and there was a lack of longitudinal data.

In this review we use the terms: ‘very good evidence’ when referring to the results of well-designed randomised controlled trials that meet the criteria set out by the Cochrane Collaboration; ‘good evidence’ when referring to consistent results from at least two robust studies that are

not randomised controlled trials and ‘evidence’ when referring to the results from at least one robust study or a randomised controlled trial with substantial issues regarding the quality of the evidence obtained. Studies were judged to be robust on the basis of the risk of bias table.

1.2. Outcomes of EV & SES training

A diverse range of outcome measures have been used to quantify the effectiveness of EV training.

There is very good evidence that EV training incorporating SES or eye movement training improves near visual acuity (VA) and reading speed in participants with central vision loss (Nilsson & Nilsson 1990/94; Vukicevic & Fitzmaurice, 2005; 2009; Seiple et al., 2011). Moreover, with the exception of one study (Watson et al., 2006), all of the 19 studies in the review that used reading speed as an outcome measure reported increases in the reading speed of the participants after training. However, few studies have examined the effect of training on other clinical measures of vision such as distance VA.

There is also very good evidence that EV and SES/eye movement training improves the ability of participants with

CVL to perform ADLs (Vukicevic & Fitzmaurice 2005; 2009; Seiple et al., 2011). In contrast, there is no conclusive evidence regarding the effect of training on quality-of-life, as only one study included in the review assessed vision-related quality-of-life after training (Jeong & Moon, 2011) and this did not specify which ten items from the 25-item Low Vision Quality-of-Life Questionnaire (LVQOL) were chosen to assess quality-of-life. It is therefore possible that these items related to near visual functions only. No studies evaluated the effect of training on general health-related quality-of-life.

It is notable that only two of the studies included in the review stated that the outcome data were collected by a different individual to the one that provided the training (Jeong & Moon, 2011; Seiple et al., 2011). As there is a strong risk that participants will be inclined to respond more positively when outcomes are measured by the service provider, this may have exaggerated the effects of training, particularly on self-report outcome measures.

Although there is very good evidence that EV and SES training generate improvements in clinical measures of vision and performance of ADLs on completion of the training programme, only two of the studies re-assessed

outcomes after some time had elapsed following training (Vukicevic et al., 2005; Deruaz et al., 2006). Consequently, there are insufficient data to assess the long-term outcomes of training with EV and SES.

1.3. The effect of training model on training outcomes

A broad array of models for training EV and SES were described by the studies included in this review. These models comprised an eclectic range of aims, training strategies, technologies, training materials and settings. However, seven of the 32 studies included in the review did not provide any details of the model used for training EV and SES (Nilsson & Nilsson, 1986a; 1986b; Woo &; Nilsson & Nilsson, 1989; 1990/94; Feely et al., 2007; Jeong & Moon, 2011).

There is insufficient evidence to conclude that a particular model of EV training is superior to another, as there are only three studies that compare the effectiveness of different models alongside each other using the same outcome measures (Arditi, 1999; Nguyen et al. 2011; Seiple et al., 2011). There is very good evidence that the use of a TRL can improve reading ability and performance of ADLs in participants with CVL (Frennesson et al., 1995; Nilsson et al., 1998; 2000; 2003; Gustafsson & Inde, 2004;

Vukicevic & Fitzmaurice, 2005; 2009; Kasten et al., 2010). However, there were no robust studies that recorded outcomes of training that aimed to optimise the use of the currently adopted PRL, and no studies that directly compared the effect of retinal locus on training outcomes. Similarly, the studies that have trained SES outnumber those that have trained eye movements, making comparison of these training approaches difficult.

Many of the studies included in the review failed to report key information regarding the training model, such as the frequency and duration of training, the setting of the training and the person administering the training. However, based on the data available, this review demonstrated little clear evidence of an association between training outcomes and dose of training, setting of training, the person providing the training or the training materials provided.

In addition to directing individuals to an appropriate retinal locus for use during EV training, 28 of the included studies described how eye movements were integrated into the training. Twenty-one of these studies used SES training. These studies provide very good evidence that EV training incorporating a SES or training to optimise eye

movements improves reading ability and performance of ADLs in people with central vision loss. However, there is currently little evidence regarding outcomes of EV training in isolation, i.e. without SES or eye movement training.

Twenty-three of the studies included in this review delivered EV and SES training in conjunction with other services, such as the provision of LVAs. Positive training outcomes were reported when EV and SES training were delivered as part of a comprehensive low vision assessment, also including the prescription of LVAs and the provision of lighting advice (Nilsson & Nilsson, 1986a; 1986b; 1989; 1990/4; Palmer et al., 2010). These studies provide good evidence that EV and SES training is an important part of a low vision rehabilitation program for patients with CVL. However, it is unclear what proportion of the outcomes reported by these studies may be attributed to EV training alone, as it is likely that the provision of magnifiers would have markedly improved near VA, even in the absence of EV training.

1.4. The effect of participant characteristics on training outcomes

With the exception of one study, all of the studies reviewed reported the age of the participants that

underwent EV and/or SE training and a median of 74 years (interquartile range: 55.27-76.95 years) was calculated from these studies. However, there was no evidence of a relationship between age and training outcomes.

In general, the duration and characteristics of the participants' visual loss were poorly specified by the studies included in the review. However, there is evidence that EV and SES/eye movement training can lead to improvements in reading speed, near VA and performance of ADLs in individuals with established vision loss (greater than 6 months) (Gustafsson & Inde 2004; Deruaz et al., 2006; Feely et al., 2007; Vingolo et al., 2009; Kasten et al., 2010; Chung, 2011). None of the studies which specified the duration of the visual loss included people with newly diagnosed CVL. In addition, none of the studies specifically examined the relationship between the duration and characteristics of the vision loss and the outcomes of training.

Many of the studies included in the review reported a marked variation in the training gains between individual participants (Arditi, 1999; Palmer et al., 2010; Chung, 2011). However, the potential causes of this variation in

outcomes between participants were not explored by any of the studies.

1.5. Cost effectiveness of EV and SES training

The studies included in this review provide no information about the cost effectiveness of EV and SES/eye movement training. There were no studies that included an economic evaluation of EV provision and only two of the studies acknowledged the source of the funding for the training (Gustafsson & Inde, 2004; Palmer et al., 2010). Consequently, it is not possible to conclude whether the training programmes studied were cost effective. This lack of evidence regarding the cost-effectiveness of EV and SES training poses a significant problem to the development of an economic case for its use in the rehabilitation of individuals with CVL.

1.6. Grey literature

'Grey literature' is a term encompassing literature that has not been formally published in books or journals, and may include conference abstracts, unpublished reports and on-going clinical trials. Grey literature can provide important information to supplement published literature and consequently, this literature review also evaluated grey

literature that assessed outcomes of EV and SES training in participants with CVL.

Literature was identified from the following sources: the databases of the American Academy of Optometry and the Association for Vision in Research and Ophthalmology, OpenSIGLE, the Healthcare Management Information Consortium (HMIC) database, King's Information and Library Services, the websites of the Macular Disease Society, the Royal National Institute of Blind People and the Thomas Pocklington Trust, and *meta*register of controlled trials (*mRCT*). Of the 20 potential items identified by the literature searching strategies, 17 were found to meet the inclusion criteria for the review. These comprised 11 conference abstracts, two project reports and three ongoing RCTs.

Five of the conference abstracts identified by the search strategies reported all or some of the data that had appeared in peer-reviewed publications included in the review. Of the remaining six abstracts, four described studies in which all or part of the training was administered in the participant's home (Vital-Durand et al., 2003; Mitchell et al., 2009; Lui et al., 2010; 2011), including a novel approach in which in which the trainer delivered an

EV training programme remotely, via the internet (Lui et al., 2010; 2011). However, as a whole, the models of EV and SES training and the outcomes of training were poorly described by the conference abstracts included in the review. This complicates the analysis of the outcomes of EV and SES training when no full peer-reviewed publication is produced.

Of the two project reports identified by the literature search, one describes a training programme in which EV training was administered as part of a comprehensive low vision assessment (Palmer, 2009) and was subsequently published in a peer-reviewed journal included in the main section of the review (Palmer et al. 2010). The other project report identified by the search contains an evaluation of the Macular Disease Society's 'Train the Trainer' home-based EV training programme (Mitchell & Bradley, 2011). During this programme, individuals with CVL attended a 3-day course where they were taught about locating the PRL, using a SES, optimising lighting and using LVAs. These 'trainers' subsequently taught these skills to other people with CVL in a series of training sessions in their home. These 'trainees' usually underwent three or four one hour training sessions. After training, the

trainers and trainees both demonstrated a significant increase in mean reading speed and quality-of life.

There are three randomised controlled trials currently in the recruitment phase: one comparing EV training to CCTV for rehabilitation in AMD (Lawson Health Research Institute), one comparing EV training to the conventional hospital based low vision service (Moorfields Eye Hospital) and a multicentre study of reading rehabilitation in macular disease (Veterans' Affairs Institute). These trials propose to use a range of outcome measures including measures of reading speed and quality of life. This will generate new data regarding the effect of the location of training, the type of training and the duration of training on outcomes.

1.7. Summary

In summary, this review shows:

- There is very good evidence that EV training incorporating SES or eye movement training improves reading ability in participants with CVL.
- There is no evidence regarding the effect of training on measures of distance visual acuity.

- There is very good evidence that EV and SES/eye movement training improves the ability of participants with CVL to perform ADLs.
- There is no evidence regarding the effect of training on measures of quality-of-life from peer-reviewed literature. However, there is evidence from the grey literature that EV and SES training generates improvements in vision-related quality-of-life.
- There is very good evidence that the use of a TRL can improve reading ability and performance of ADLs in participants with CVL, but there are few robust studies that recorded outcomes of EV training at the PRL.
- There is evidence that EV and SES/eye movement training is beneficial to individuals with established vision loss, however no study has examined the relationship between the duration of the vision loss and outcomes of EV training.
- There is no evidence of a relationship between participant characteristics, such as age and severity of visual loss, and the outcomes of training.
- There is no evidence about the cost-effectiveness of EV training.
- There is currently little evidence regarding the outcomes of EV training in isolation (i.e. in the absence of SES/eye movement training).

- There is a paucity of longitudinal data regarding the long-term outcomes of EV and SES/eye movement training.
- There is a relative lack of high quality evidence (only two well-designed RCTs, incorporating a small number of participants) to support the effectiveness of EV and SES training in participants with CVL. Robust research methods and high quality reporting are needed to advance our understanding of how EV and SES/eye movement training can best help individuals with CVL.

Macular Society
PO Box 1870, Andover, Hampshire SP10 9AD
Helpline: 0300 3030 111 www.macularsociety.org