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Investigating The Delivery and Impact of Lifestyle Modification Advice Given to Patients with Age Related Macular Degeneration

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A Thesis submitted for the degree of
Doctor of Philosophy



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Declaration

I, Sonali Dave, confirm that the work presented in this thesis is my own and has been completed under the supervision of Dr Tamsin Callaghan, Dr Alison Binns and Dr Valldeflors Vinuela-Navarro. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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List of abbreviations

AGEs- Advanced Glycation End products

AMD- Age related Macular Degeneration

AMED- Allied and Complementary Medicine Database

AREDS- Age Related Eye Disease Study

AREDS2- Age Related Eye Disease Study 2

ARMS2- Age-Related Maculopathy Susceptibility 2

CASP- Critical Appraisal Skills Programme

CFH- Complement Factor H

CINAHL- Cumulated Index in Nursing and Allied Health Literature

CRN- Clinical Research Network

CVD- Cardio Vascular Disease

DHA: Docosahexanoic acid

ECLO- Eye Care Liaison Officers

ECP- Eye Care Practitioner

EMBASE- Excerpta Medica Database

EPA- Eicosapentaenoic Acid

FRES- Flesch Reading Ease Score

GA- Geographic atrophy

HD- Healthy Diet

HL- Healthy lifestyle

HTRA1- High-Temperature Requirement Factor A1

JBI- Joanna Briggs Institute

LOC- Local Optometric Council

MEDLINE- Medical Literature Analysis and Retrieval System Online

nAMD- Neovascular Age related Macular Degeneration

NHLBI- National Heart, Lung and Blood Institute

NHS- National Health Service

NICE- National Institute for Health and Care Excellence

OCT- Ocular Coherence Tomography

PEMAT- Patient Education Materials Assessment Tool

PRISMA- Preferred Reporting Items for Systematic reviews and Meta-Analyses

RCOphth- Royal College of Ophthalmologists

RNIB- Royal National Institute of the Blind

RPE- Retinal Pigment Epithelium

SAM- Suitability Assessment of Materials

SC- Smoking cessation

SD- Standard Deviation

SDD- Subretinal Drusenoid Deposits

UV- Sunlight protection

UV- Ultra Violet

VEGF- Vascular Endothelial Growth Factor

VS- Vitamin Supplements

WI- Written information

COVID-19 Impact Statement

This statement is provided for the aid and benefit of future readers to summarise the impact of the COVID-19 pandemic on the scope, methodology, and research activity associated with this thesis. The academic standards for a research degree awarded by City, University of London and for which this thesis is submitted remain the same regardless of this context.

Title of the research project: *Investigating the delivery and impact of lifestyle modification advice given to patients with Age related Macular Degeneration.*

1. **Summary of how the research project, scope or methodology has been revised because of COVID-19 restrictions**

As this project began during the COVID-19 pandemic, the restrictions resulted in some delays to obtaining the ethical approvals and R&D activities from the hospitals where recruitment would be taking place. Additionally, the questions to be used in the studies were decided by co-design activities, but due to the restrictions, these groups were held virtually.

Due to the delays with approvals, there was limited time to recruit participants for the study. However, due to the helpful guidance from the supervisory team and Clinical Research Network, additional recruitment sites were added to the study to ensure the targets were met. This also allowed for a more diverse recruitment pool. Although this was not the original plan, the variation of hospitals has allowed the findings from this project to be more generalizable and working with multiple hospital sites was an excellent learning experience.

2. **Summary of how research activity and/or data collection was impacted because of COVID-19 restrictions, and how any initially planned activity would have fitted within the thesis narrative**

The initial plan for data collection was for me to go into the clinics to find patients that met the eligibility criteria for the study. However, after discussions with the hospital sites, it was determined that due to the COVID-19 restrictions, many participants were being seen virtually. Therefore, recruitment was modified to allow for phone calls to participants. As a result, for the main recruitment site (Moorfields Eye Hospital), I was given access to the patient database and list of patients seen recently. It was a valuable experience for me to learn how to use the database and I was able to screen for potential patients independently which helped to boost recruitment. Patients were then contacted via telephone to see if they were interested, if so, they were sent the information sheet, consent form and questionnaire. This allowed us to reach patients that also attended other clinics which widened the pool of patients.

3. **Summary of actions or decisions taken to mitigate for the impact of data collection or research activity that was prevented by COVID-19**

Under the supportive guidance of my supervisory team, it was decided that recruitment would be opened to other hospital sites across England. This was because the restrictions resulted in less patients attending clinics physically. We also decided to allow for telephone recruitment. Additionally, we applied for the recruitment end date to be pushed forward to allow us to meet the recruitment target as the uptake was slow during the first few months. As a result of these decisions, we were able to meet the targets.

4. **Summary of how any planned work might have changed the thesis narrative, including new research questions that have arisen from adjusting the scope of the research project**

Fortunately, the changes that were made to the study methodology improved the generalizability of the findings. Adding sites from less connected areas of England highlighted some key points that should be considered for improving patient outcomes, such as the importance of written information, particularly for those who are unable to attend appointments, or communicate with a health care professional regularly. New questions also arose as a result of the changes, such as how advice can be provided in an effective way while adhering to social distancing, masks and reduced staff in hospitals. Although

these questions were not investigated in this thesis, the work presented highlights the importance of standardized and revised guidelines for practitioners in these circumstances.

Date of statement: 15/07/2024

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Abstract

Age related Macular Degeneration (AMD) is progressive leading to irreversible blindness. The rate of progression can be reduced through lifestyle modifications such as stopping smoking, consumption of certain foods and vitamin supplementation. Eye Care Practitioners (ECPs) are recommended to provide lifestyle advice to patients, but studies show recommendations are not always followed, or patients cannot recall the advice. The aim of this PhD was to investigate the extent, nature and effectiveness of lifestyle modification advice given to patients with AMD, from a patient perspective.

Using themes from patient and practitioner co-design activities and literature, three surveys were created. The first survey was about patients' experiences, and lifestyle advice received previously or at their most recent appointment. Consenting participants were sent a second survey three months later, following up on any changes that they made since their last appointment. Survey three was given to practitioners to investigate what barriers they perceive to effective lifestyle advice. As this was an exploratory study, the quantitative analysis comprised summary descriptive statistics obtained using Excel version 2407 (Microsoft) and SPSS Statistics 25 (IBM). Thematic analysis of qualitative data was conducted using NVivo 12 (Lumivero).

In total, 404 participants responded to survey one. Participants were mainly female (n=244; 60.4%) and between 71 and 80 years old (n=172; 42.6%). Out of the 371 participants that answered the question, 246 (66.3%) reported not receiving any advice previously. Of the 125 participants that did, 63% (n=79) made lifestyle changes. Most participants did not receive written advice at their most recent appointment (n=345; 85.4%). For survey two, 153 participants responded (38% response rate). Only 16.3% (n=25) received lifestyle advice at their most recent appointment, and 9 (36%) reported making changes. The most common reason for not making changes was not being given advice (n=36; 46.2%). The importance of making changes was rated 6 out of 10 (IQR=5-9.5). The most common reason for the rating was 'uncertainty about whether changes are helpful'. For survey three, 54 ECPs responded. Most participants were nurses (n=22; 40.7%). In total, 47 (87%) participants

reported providing patients with AMD with lifestyle advice. Most participants asked about smoking (n=31; 57.4%). A 'lack of understanding/uncertainty' was the most mentioned barrier to patients implementing lifestyle changes.

Most patients cannot recall lifestyle advice after appointments and are not being provided with written information. The importance of making changes and detailed advice would help patients implement changes. Further research and written information are needed with patient involvement to optimise advice provision.

1. General Introduction

1.1 Background

Age related Macular Degeneration (AMD) is the leading cause of irreversible blindness globally in people over the age of 60 (Thomas et al., 2021). There is currently no cure for AMD. Treatment for the neovascular type of AMD involves regular intraocular injections of anti-vascular endothelial growth factor (anti-VEGF), and recently new treatments have been approved for advanced non-neovascular AMD (geographic atrophy, GA) in some countries, but these are only able to slow disease progression (Heier et al., 2023) There is no effective treatment for early or intermediate AMD.

However, research has shown that certain lifestyle modifications may slow down AMD progression such as stopping smoking (Smith et al., 1996, Velilla et al., 2013, Vingerling et al., 1996), adjusting diet (Seddon et al., 2003, Chapman et al., 2019a) and taking vitamin supplements (Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013). Therefore, the Royal College of Ophthalmologists recommend that Eye Care Practitioners (ECPs) advise patients with AMD, verbally and in writing, about the modifiable lifestyle changes that they can make (Royal College of Ophthalmologists, 2021). However, research has shown that these recommendations are not consistently followed (Lawrenson and Evans, 2013, Martin, 2017), but little research has been conducted to investigate the patient experience of advice provision, the barriers to effective advice, and what approaches may increase communication effectiveness.

1.2 AMD Epidemiology and Prevalence

Age related Macular Degeneration accounts for ~9% of all cases of blindness worldwide (Thomas et al., 2021, Wong et al., 2014). It is estimated that, worldwide, there are approximately 196 million people with AMD and this number is projected to increase by 2040 to 288 million (Wong et al., 2014). Globally, the number of cases of AMD increased between 1990 and 2019 (from approximately 21 cases per 100,000 to 45 cases per 100,000) (Jiang et al., 2023). Similarly, in Europe, it is estimated that there are 67 million cases

of AMD with this number projected to rise to 77 million by 2050. Late AMD diagnoses are also expected to rise from 400,000 a year to 700,000 per year (Li et al., 2020). AMD accounts for around half of the sight impairment and severe sight impairment certifications in England (Bunce et al., 2015).

Additionally, AMD has been found to be more common in men than women over the age of 85. More specifically, in the UK the prevalence of AMD in women is 60% higher than in men, with women having an overall higher incidence of late AMD (4.1 per 1000 women compared to 2.3 per 1000 men) (Lambert et al., 2016). Global estimates have also reported a significantly higher prevalence in women over the age of 80 compared to men (Jiang et al., 2023). Studies have also shown a higher prevalence of AMD in Northern Europe (UK and Norway) with approximately 17% of the population having early AMD and 4.2% of the population having late AMD compared to 12% having early AMD and 3.1 % having late AMD in Western Europe and 14% having early AMD and 3.1% having late AMD in Southern Europe (Colijn et al., 2017).

Age-related macular degeneration is significantly associated with increased rates of depression with a recent study highlighting that patients have a hazard ratio of 1.15 (95% CI, 1.13-1.17) compared with people without the condition. There was an even higher risk of depression in patients with related visual disability (hazard ratio of 1.23 (95% CI, 1.16-1.30) (Hwang et al., 2023). Further studies also highlight this association (Dawson et al., 2014), as well as an increased risk of falls (Wood et al., 2011, Szabo et al., 2008) and decreased quality of life in people with AMD (Sanabria et al., 2023, Taylor et al., 2016).

1.3 Pathophysiology of AMD

AMD is a progressive disease which affects the central part of the retina, known as the macula, and is characterised by the accumulation of deposits known as drusen (Thomas et al., 2021) that form between the Retinal Pigment Epithelium (RPE) and Bruch's membrane (see figure 1.1) (van Lookeren Campagne et al., 2014). Focal pigmentary abnormalities are also a feature of intermediate AMD (Ferris et al., 2013). Advanced AMD is characterised by the growth of new blood vessels from the choroidal circulation to proliferate

beneath the RPE and retina (neovascular AMD, nAMD), or by regional atrophy of the RPE and photoreceptors (geographic atrophy, GA) (Ferris et al., 2013).

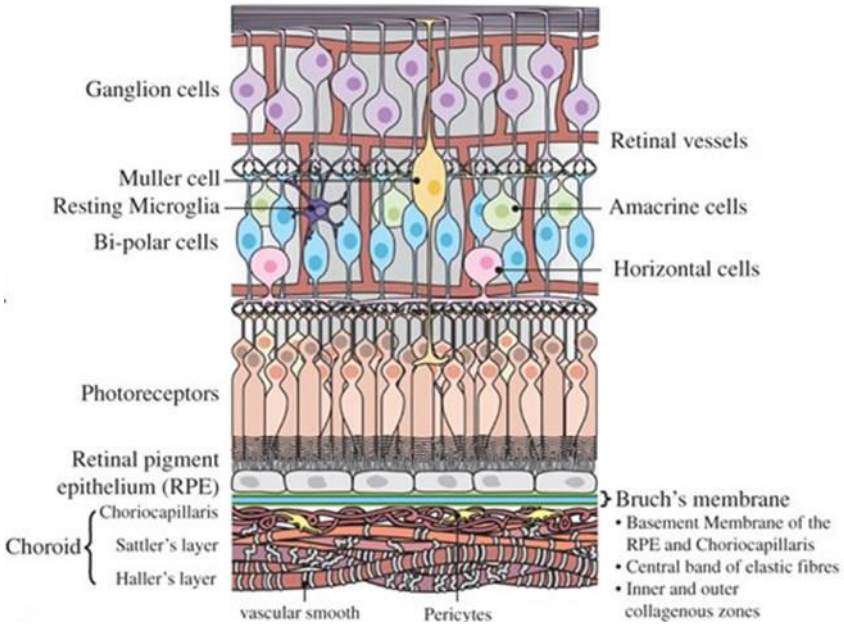


Figure 1.1- Structure of a normal retina and associated structures (van Lookeren Campagne et al., 2014)

It is valuable to the theme of this PhD to consider mechanisms of disease onset and progression as this gives insight into the potential mechanism of action of the lifestyle modifications suggested in AMD. The exact mechanisms and pathophysiology of AMD are still not known, however, in this chapter the main theories will be summarised. It is likely that multiple mechanisms play a role in the disease process (Ambati and Fowler, 2012). For more details, see the review by Fleckenstein et. al. (2021) and Ambati and Flower (2012).

1.3.1 Oxidation

One of the main candidate aetiologies of AMD is oxidative stress on the macula. The retina is prone to oxidative stress because it has a high concentration of polyunsaturated fatty acids, photo-oxidising agents, a high metabolic rate and is exposed to a high concentration of oxygen (Iizuka et al., 2015). The oxidation of materials in the photoreceptor outer segments leads to the formation of Advanced Glycation End products (AGEs). One of the functions of the RPE is to phagocytose the tips of the photoreceptor outer segments on a daily basis. They process this material and remove waste

products via the choroidal circulation (Beatty et al., 2000). When oxidative damage occurs to the photoreceptor outer segment prior to phagocytosis, the RPE cannot fully process these materials so unprocessed components accumulate in the RPE cells, leading to the formation of lipofuscin. Increased levels of oxidative stress (for example through environmental factors such as smoking or a high fat diet) (Fleckenstein et al., 2021) can increase lipofuscin formation by leading to the increased formation of abnormal oxidised materials in the photoreceptors. Lipofuscin itself contains photosensitive chemicals such as A2E which further increase the level of oxidative damage, it also causes inflammation, mechanical damage to RPE cells and reduced phagocytic capacity (Sparrow and Boulton, 2005). Lipofuscin formation can ultimately lead to RPE cell death. Lipofuscin deposition in the RPE is an inescapable part of the ageing process (Feeney-Burns et al., 1980). However, there is evidence to suggest that the distribution and quantity of lipofuscin may be associated with risk of AMD onset (Kennedy et al., 1995).

This build up of waste material leads to a loss of function of the RPE, and contributes to the formation of drusen and basal laminar and linear deposits at the level of Bruch's membrane (Beatty et al., 2000) and the progression of AMD (Datta et al., 2017). The dysfunction of the RPE impacts on the photoreceptor layer which in turn leads to a disruption of the signal transmission from the retina and ultimately vision loss (Thomas et al., 2021). Changes in the RPE (declining function) and Bruch's membrane (increased thickness and permeability) with increasing age also result in increased oxidative stress and the expression of oxidized proteins or lipids in the retina (Chen et al., 2015).

1.3.2 Inflammation

Immune dysfunction is also thought to be a key factor in the pathogenesis of AMD. The abnormal end products of oxidation, and the presence of damaged RPE cells may be a stimulus for the activation of the immune system in predisposed individuals. Hageman et al. (2001) identified the presence of multiple components (e.g. proteins) of the immune response in drusen, including classic acute phase reactants and complement cascade components (Hageman et al., 2001). Furthermore, immune cells

(macrophages and lymphocytes) have also been identified in choroidal neovascular membranes (Nagineni et al., 2012). The retinal immune system is a vital process for homeostasis in the visual system and overactivation of the immune cells can result in inflammation (Ambati et al., 2013). Altered expression levels of inflammatory factors, including C-reactive protein (commonly associated with cardiovascular diseases) have been revealed in AMD (Seddon et al., 2005). Inflammation results in a series of events leading to tissue damage, and accumulation of macrophages resulting in molecular damage at an ocular level. This process is described in further detail in a study by Chen and Xu, (2015).

1.3.3 Hypoxia

Some studies have also investigated the potential role of hypoxia in AMD (Inoue et al., 2007, Sheridan et al., 2009, Callaghan et al., 2020). This hypothesis is based on the fact that the choroidal circulation is only just sufficient to meet the needs of the outer retina in the healthy eye (Nickla and Wallman, 2010). In AMD, Bruch's membrane is thickened, which means that oxygen has further to travel to reach the retina from the choroidal circulation. This reduces available oxygen at the level of the outer retina (Feigl, 2009). There is also evidence suggesting changes to the choroidal circulation in AMD, where reduced vessel density leads to reduced blood flow rates. This leads to hypoxic regions in the choroid, resulting in the macular disciform response (Hayashi and de Laey, 1985, Mendrinos and Pournaras, 2009). This hypothesis is also supported by the presence of vascular endothelial growth factor (VEGF) upregulation in the pathogenesis neovascular AMD (Feigl, 2009). The exact mechanism of neovascular AMD is not known but the pathogenesis is linked to the upregulation of angiogenic VEGF by the RPE, which stimulates the growth of blood vessels. This VEGF upregulation may be linked to the presence of components of the immune response, or to outer retinal hypoxia, or both (Nagineni et al., 2012, Stefánsson et al., 2011). These fragile vessels leak fluid which damages the photoreceptors and impairs vision (Flores et al., 2021).

Research is still being conducted to complete the understanding of the disease pathophysiology. The complexity of the disease suggests that many

mechanisms may be involved in the manifestation of AMD and could inform how it can be managed.

1.4 Clinical features and classification of AMD

Typically, AMD is characterised by the presence of drusen. Drusen are yellow, hydrophobic extracellular sub-RPE deposits made of protein and lipids and are usually the first sign of AMD. Phenotypically, drusen can appear to be hard or soft. Small hard drusen are commonly seen in normal ageing and are not diagnostic for AMD (Klein et al., 1998, Klein et al., 1992, Bressler et al., 1989). However, the presence of a large number of small hard drusen does indicate an increased risk of AMD development (Klein et al., 2007). In contrast, soft drusen (≥63 microns in diameter) are pathognomonic for AMD (Heesterbeek et al., 2020). The size and number of drusen are used to identify the stage of AMD. This section will discuss the clinical features of each stage of AMD and the systems used to classify the stages.

1.4.1 Early AMD

According to the Beckman classification system (Ferris et al., 2013) described below, the early stage of AMD is characterised by the presence of small to medium drusen (more than 63-μm and less than 125-μm diameter) but no RPE abnormalities. Figure 1.2 displays a fundus image of an eye with early AMD. Drusen that are seen in early AMD can often be mistaken for normal ageing changes, particularly because the early stages of AMD are also asymptomatic, resulting in delayed diagnosis (Ridder et al., 2022).

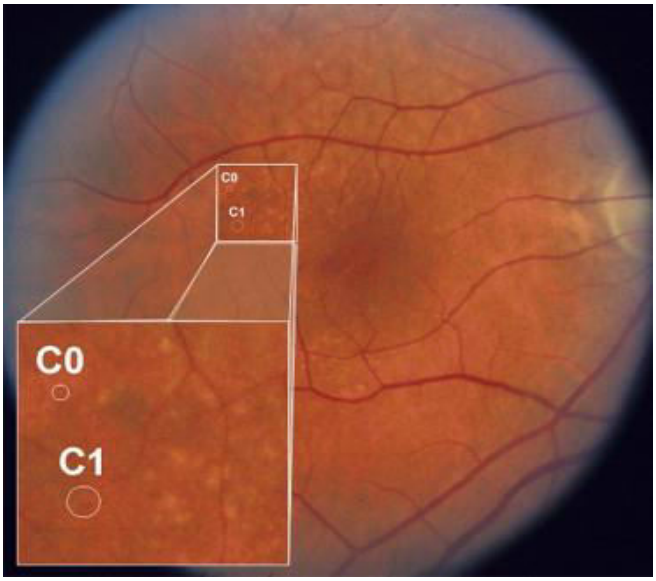


Figure 1.2- Fundus image displaying drusen deposits seen in early AMD. C0 represents drusen that are 63-µm diameter and C1 shows drusen 125-µm diameter. Image from Ferris et. al. (2013).

1.4.2 Intermediate AMD

As AMD progresses, the size and number of drusen increases, with large drusen (≥125 µm in diameter) being indicative of intermediate stage AMD, according to the Beckman classification (Abdelsalam et al., 1999, Ferris et al., 2013). Additionally, this stage of AMD is also characterised by changes in the RPE. Hyper or Hypo-pigmentary abnormalities may be seen in the RPE, independently or occurring alongside the drusen. Hyperpigmentation refers to increased pigmentation and appears darker on fundus images, whereas hypopigmentation is when pigmentation is decreased (García-Layana et al., 2017).

Although not considered in most classification systems (see section 1.4.4), another feature commonly seen in intermediate AMD is subretinal drusenoid deposits (SDD). SDD are also known as reticular pseudodrusen and are located between the RPE and the retina, unlike classic drusen which are found sub-RPE (see figure 1) (Keenan et al., 2021). SDD prevalence increases with disease severity. For example, one study reported SDD prevalence of 11.5% in early AMD, 25.1% in intermediate AMD, and 51.1% in late AMD (Cleland et al., 2021). The composition of the SDD are similar to soft drusen, but differ in lipid composition and strongly indicate a risk of AMD progression to advanced

AMD. Figure 1.3 shows a fundus image of intermediate AMD with hyperpigmentation and an OCT image showing the presence of SDD.

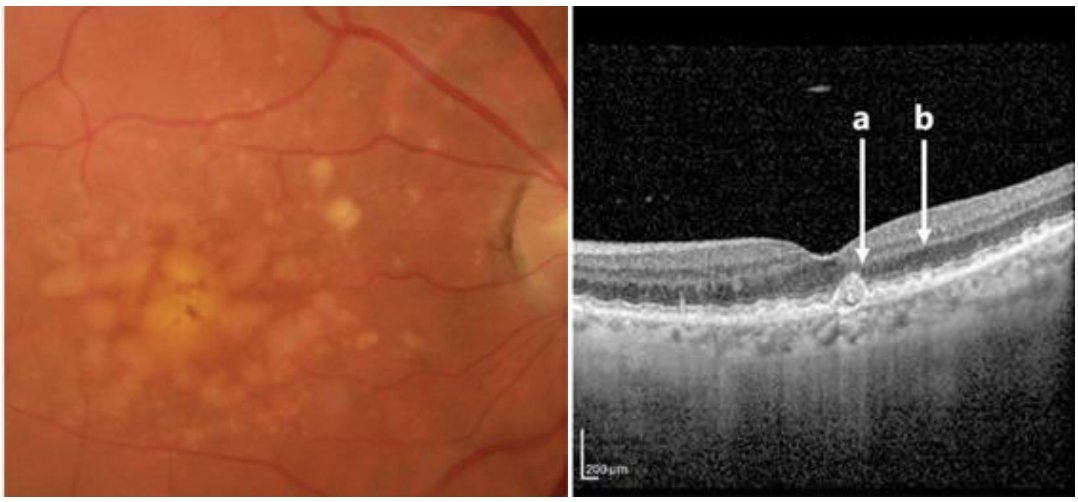


Figure 1.3- Fundus photograph of an eye with intermediate AMD (left) and OCT image of an eye with intermediate AMD and SDD above (a) and below (b) the RPE (Guymer and Campbell, 2023, Flores et al., 2021).

1.4.3 Advanced AMD

There are two subtypes of late AMD; nAMD and GA. GA, also known as 'dry' AMD, is characterised by the progressive loss of photoreceptors, RPE and choriocapillaris (a network of capillaries in the choroid underlying Bruch's membrane) (Fleckenstein et al., 2018). This results in atrophic lesions in the outer retina causing irreversible vision loss (figure 1.4). Neovascular AMD (figure 1.5) is also known as 'wet' AMD and results from the growth of a fibrovascular membrane from the choriocapillaris which extends through breaks in Bruch's membrane to proliferate beneath the RPE or retina (Spraul et al., 1999). These new vessels are fragile and are prone to the leakage of fluid and blood within and beneath the retina, as well as beneath the RPE. Initial symptoms of distortion are followed by sudden visual loss as vessels haemorrhage (Fine et al., 1986). See section 1.3 for further details about the pathophysiology of AMD. The Beckman classification categorises both types of AMD as 'Late AMD' (see section 1.4.4 for further information).

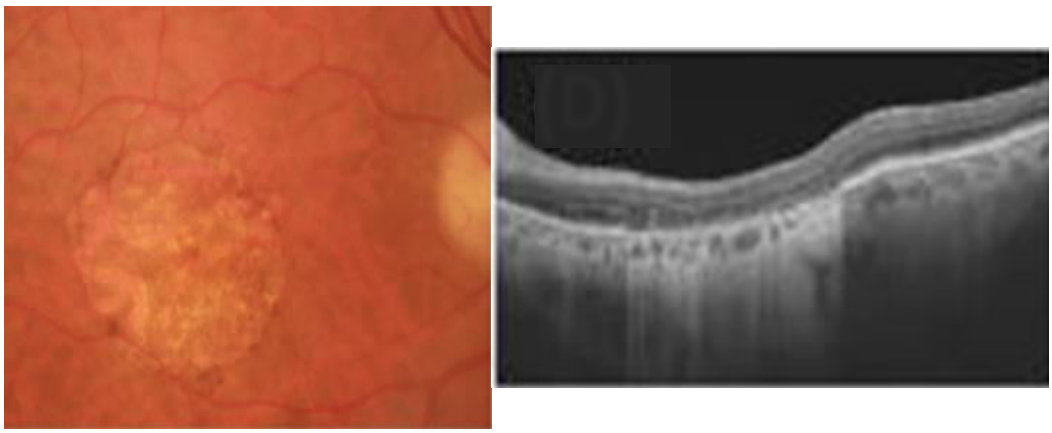


Figure 1.4- Fundus photograph showing geographic atrophy (left) and an OCT image portraying the effect of geographic atrophy in the RPE (Elsharkawy et al., 2021, Guymer and Campbell, 2023).



Figure 1.5- Fundus photograph showing neovascular AMD (left) and an OCT image showing changes in the retina seen in neovascular AMD (right) The white arrow shows the degeneration of photoreceptors seen in wet AMD (Metrangolo et al., 2021, Guymer and Campbell, 2023).

1.4.4 AMD classification systems

Various classification systems have been devised and evaluated for AMD (Bird et al., 1995, Klaver et al., 2001, Klein et al., 2014). The AREDS 9-step classification system, developed by the Age-related Eye Disease Study group, describes nine stages of AMD combining a six step drusen area scale with a five step pigmentary abnormality scale. The scale also describes the risk of developing advanced AMD progression at stage one as less than 1%, but the risk increases by step 9 (intermediate AMD) to 50%. Advanced AMD is described as neovascular changes such as RPE detachment or geographic atrophy. However, this scale excludes drusen size as a factor for determining

the stage of AMD which has been discussed as a limitation for the validity of the scale (Davis et al., 2005).

The Rotterdam Eye Study is a large prospective cohort study with over 10,000 participants based in the Netherlands (Vingerling et al., 1995). A smaller portion of the cohort (n=6418) were evaluated over two years to develop and understand how AMD progression can be classified. They concluded that a large number of small (more than 10), hard drusen or isolated pigmentary changes are indicative of early AMD. This would then be followed by the presence of multiple soft drusen and pigmentary changes (intermediate AMD). The end stages of AMD are characterised by subretinal neovascularisation or geographic atrophy (Klaver et al., 2001).

The Beckman initiative developed a grading scale which was linked to risk of progression i.e. a higher stage of AMD according to the scale was associated with an increased risk (Ferris et al., 2013). Using a Delphi process with AMD experts, literature and existing classification systems were evaluated followed by a survey containing 9 statements that the experts were asked to agree/degree with based on their evaluation. The results of the survey were then analysed and used to create the classification system (Ferris et al., 2013). According to this system, the maximum *size* of drusen and presence/absence of pigmentary abnormalities are used to classify the early/intermediate stages of AMD. Table 1.1 outlines the Beckman classification system.

Classification	**Clinical manifestation**
No AMD	No drusen and no RPE abnormalities
Normal ageing changes	Drusen ≤ 63μm and no RPE abnormalities
Early AMD	Drusen > 63μm and ≤ 125μm and no RPE abnormalities
Intermediate AMD	Drusen > 125μm and/or RPE abnormalities
Late AMD	GA and/or neovascular AMD

Table 1.1- Beckman clinical classification of AMD (Ferris et al., 2013)

Over the past several years, many severity scales have been created for classifying AMD, with several advantages and disadvantages. However, it is important that the appropriate scales are selected for studies and in healthcare

(Thee et al., 2020). See Thee et. al. (2020) for a full study comparing the most commonly used scales.

1.5 Non-modifiable risk factors for AMD progression

Certain risk factors strongly correlated with AMD progression including age, race and genetics are non-modifiable - they cannot be altered to decrease the chances of progression. For a full review and meta-analysis of the risk factors of AMD see Heesterbeek et. al. (2020) and Chakravarthy et. al. (2010).

1.5.1 Age

Age is the strongest non-modifiable risk factor for AMD (Tikellis et al., 2007, Jonasson et al., 2014). This is proposed to be due to age-related structural and functional changes, particularly in blood flow to the retina that can contribute to the development of AMD (Ehrlich et al., 2008, Heesterbeek et al., 2020). Some studies suggest that there is a stronger association between age and progression to geographic atrophy than neovascular AMD (Joachim et al., 2013, Chakravarthy et al., 2020).

1.5.2 Race and ethnicity

Studies have shown that white populations are at greater risk of incidence and progression to late AMD than black populations (Vanderbeek et al., 2011, Fisher et al., 2016, Friedman et al., 1999) with prevalence rates in Chinese and Hispanic populations the second and third highest after Caucasian populations (Heesterbeek et al., 2020, Wong et al., 2014). It has been proposed that this may be due to increased melanin in the RPE cells of black populations, which may be protective against UV radiation and as a result, reducing the risk of AMD progression (Age-Related Eye Disease Study Research, 2000). Interestingly, a more recent study found that race and ethnicity may not be as strong as other risk factors for AMD incidence such as smoking (Bucan et al., 2022), but this may be due to lower sample sizes of other ethnicities compared to white participants.

1.5.3 Genetics

There is strong evidence of genetic risk factors associated with AMD onset and progression, and having a first degree relative with AMD greatly increases

the risk of AMD incidence (OR= 27.8) (Shahid et al., 2012). Fifty-two genetic variants in 34 loci have been independently associated with increased risk of AMD incidence (Grassmann et al., 2015, Grassmann et al., 2019, Fritsche et al., 2016). A number of genetics studies have reported the common variants of the Complement Factor H (CFH) gene that are significantly associated with a risk of AMD incidence and progression (Desmettre, 2018, Liao et al., 2016, Cruz-González et al., 2014, Fritsche et al., 2016, Klein et al., 2005). In particular, variants such as rs570618 have been associated with an increased risk of developing nAMD and GA (Yu et al., 2012). Another important chromosome associated with AMD risk is Chr10, where the age-related maculopathy susceptibility 2/high-temperature requirement factor A1 (ARMS2/HTRA1) genes are located (Sobrin et al., 2011).

Together with the identified genotypes and variants, these studies suggest the strong link between family history and the risk of AMD incidence and progression. However, there have been a few studies demonstrating the benefits of lifestyle changes like diet modification on people with a genetic susceptibility of progression to geographic atrophy (Reynolds et al., 2013). Therefore, despite the link between genetics and AMD progression, the modification of certain lifestyle factors can still reduce the risk of disease advancement.

1.6 Modifiable risk factors for AMD progression

Certain lifestyle factors can influence AMD progression, regardless of age, race or genetics (Colijn et al., 2021). In the following sections, some of the lifestyle factors that show the most robust association will be presented and discussed.

1.6.1 Smoking

Smoking is the major modifiable risk factor for the advancement/development of AMD (Smith et al., 1996, Vingerling et al., 1996, Klein et al., 1998). Cigarettes contain over 4700 harmful chemicals of which many are oxidants which cause oxidative stress on the macula (Datta et al., 2017). Smoking has

been associated with an increased risk of AMD advancing and faster GA growth (Keenan et al., 2018).

Multiple epidemiological studies have reported a link between smoking and risk of AMD onset and progression (Tan et al., 2007, Klein et al., 1998, Vingerling et al., 1996, Willeford and Rapp, 2012, Smith et al., 1996, Chakravarthy et al., 2007, Delcourt et al., 1998, Mitta et al., 2013). For example, the Rotterdam study on 6174 participants found that smokers have a 4-fold increased risk of AMD progression compared to non-smokers, decreasing to a 3 fold increase if the patient is an ex-smoker, with the risk only decreasing to that of a non-smoker 20 years after a person stops smoking (Vingerling et al., 1996). Furthermore, smoking has also been associated with an approximately 10 year younger age of disease onset (Mitchell et al., 2002). Previous studies have also found that more than a quarter of all cases of advanced AMD in Europe are correlated with current or past smoking (Chakravarthy et al., 2007).

The Beaver Dam Eye Study also reported that current smoking and number of pack-years significantly increased the risk of AMD progression (Myers et al., 2014). Additionally, the EUREYE study reported an increased odds ratio of nAMD for current smokers (OR=2.6) and ex-smokers (OR=1.7) in people aged over 65 in European countries. The study also estimated that the attributable fraction of AMD due to smoking was 27% (Chakravarthy et al., 2007).

There are a number of physiological effects of smoking on the retina. A study by Moschos et. al. (2016) used OCT to examine the effects of more than 25 years of smoking on the retina and choroid. The findings from this study show that long term smokers appeared to have a thinner choroid and retina compared to non-smokers (Moschos et al., 2016). Additionally, despite the strong link between age and AMD, younger patients (between the ages of 35-55) who are either current or ex-smokers with a diagnosis of AMD have an increased risk of AMD progression (Brandl et al., 2022).

Due to this strong link, the Royal College of Ophthalmologists guidelines state that all patients with AMD should be advised by their eye care practitioner to

stop smoking (Royal College of Ophthalmologists, 2021). These guidelines are also recommended by other organisations such as the American Academy of Ophthalmology (Flaxel et al., 2020), Optometry Australia (Optometry Australia, 2019) and the Canadian Association of Optometrists (Canadian Association of Optometrists, 2023). However, there have been a number of studies demonstrating that there is a lack of smoking cessation recommendation by ECPs (Caban-Martinez et al., 2011, Lawrenson and Evans, 2013) and that knowledge amongst patients about the link between smoking and AMD is limited (Shah et al., 2015, Sanjay et al., 2009).

1.6.2 Diet and vitamins

Diet is also an important modifiable risk factor for AMD and observational studies have found that there are certain diets that can increase the risk of AMD progression (Rinninella et al., 2018). Additionally, foods with a high glycaemic index (carbohydrates that have a fast effect on blood glucose) have been identified as a significant risk factor for AMD incidence and oxidative stress (Kaushik et al., 2008). A diet high in fat has also been associated with the increased risk of late AMD due to a high fat diet causing oxidative stress (Chiu et al., 2014).

Recently, research has focused on the association between a diet high in nitrates and a reduced risk of AMD. Gopinath et. al. (2018) reported a 15% reduced risk of early incidence of AMD in people with a diet high in nitrates (Gopinath et al., 2018). Furthermore, a diet rich in nitrates can also be effective for reducing the risk of AMD progression. Broadhead et. al., (2023) analysed participant data from the AREDS and AREDS 2 studies to investigate this association. The study comprised 7788 participants, all of whom had a diagnosis of AMD, finding that patients with higher dietary nitrate intake had a decreased risk of AMD progression to late AMD (both GA and nAMD; (Broadhead et al., 2023). However, this effect disappeared after adjusting for other dietary patterns. It has been speculated that nitric oxide plays a role in the maintaining endothelial cell function and blood flow (Bondonno et al., 2016), and as discussed in section 1.3, endothelial dysfunction has been investigated in relation to AMD pathogenesis. Therefore, a diet high in nitrates could be protective against AMD progression.

Research shows that certain diets can potentially be protective against AMD progression, such as the Mediterranean diet (Keenan et al., 2020, Nunes et al., 2018). A recent systematic review analysed eight observational studies looking at adherence to the Mediterranean diet and AMD progression. All of the studies consistently concluded that people who followed the diet had a decreased risk of developing AMD and of progression to the late stages of AMD (Gastaldello et al., 2022). Specifically, a prospective cohort study found that people who followed the Mediterranean diet, rich in antioxidants, fruits, vegetables, legumes and a low consumption of meat and dairy products, had a 41% reduced risk of advanced AMD (Merle et al., 2019). On the other hand, another study found that although the Mediterranean diet was beneficial for protecting against onset of late AMD, after adjusting for confounding variables, there was no evidence of protection against early AMD associated with the consumption of a Mediterranean diet (Hogg et al., 2017). Importantly, these differing results could be due to the fact that the follow up periods for both studies were significantly different; the study by Hogg et. al. (2017) collected retrospective, self-reported dietary information from their participants for the previous 12 months whereas the study by Merle et. al., (2019) collected data from patients over an average of 9.9 years. This suggests that the Mediterranean diet may be effective, but over a longer period of time, so earlier interventions with this diet could be effective. More recent studies have shown that the Mediterranean diet is also effective in slowing down progression in the later stages of AMD, with one study reporting slower GA enlargement with adherence to the diet (Agrón et al., 2022).

Foods high in anti-oxidants, vitamins and carotenoids (fruits and green leafy vegetables) are also thought to be protective against AMD progression (Heesterbeek et al., 2020). Dietary carotenoids such as lutein and zeaxanthin are components of macular pigment. This is found principally in the cone axons in the Henle Fibre Layer, and in the interneurons of the inner plexiform layer (Nolan et al., 2008). It has been reported that these carotenoids have antioxidative qualities (Johra et al., 2020), as well as providing a blue light filter to help to protect the outer retina from excessive light exposure (Bernstein et al., 2010).

There is also evidence that increased dietary intake of lutein and zeaxanthin translates to increased plasma levels and is positively associated with an increase in macular pigment optical density (Ma et al., 2016, Wilson et al., 2021). There is also limited evidence that increased intake of these dietary xanthophylls may improve the visual function of people with AMD (Wolf-Schnurrbusch et al., 2015, Ma et al., 2009). Therefore, people with AMD should be advised to have dark green leafy vegetables (such as spinach or kale that are high in both carotenoids) to increase their consumption of lutein and zeaxanthin (Royal College of Ophthalmologists, 2021). For further details on how dietary carotenoids can aid in the management of AMD, see the review by (Lem et al., 2021).

Other dietary changes for AMD that have been investigated include the role of omega-3 long-chain polyunsaturated fatty acids. In particular, docosahexaenoic acid (DHA) and eicosapentaenoic acid (EPA) which are in high levels in the retina (Heesterbeek et al., 2020). DHA and EPA may affect the permeability, fluidity, lipid phase properties and thickness of the photoreceptor membrane (Querques and Souied, 2014, SanGiovanni and Chew, 2005). Additionally, EPA and DHA can also decrease T-cell activation associated with an inflammatory response (Heesterbeek et al., 2020). DHA and EPA are commonly found from dietary sources such as oily fish such as mackerel, tuna, salmon etc. or in the form of a supplement. Furthermore, oily fish are also a dietary source of omega-3 fatty acids. Research has shown that an increased intake of omega-3 fatty acids is associated with an overall reduced risk of neovascular AMD (SanGiovanni et al., 2007, Querques and Souied, 2014). Although other reviews have highlighted that the currently available evidence does not support increasing omega-3 for preventing or slowing AMD progression (Lawrenson and Evans, 2015).

Two large randomised controlled trials have been conducted to evaluate the effectiveness of vitamin supplementation at slowing progression of AMD. The Age related Eye Disease Study (Age related Eye Disease Study, 2001) was a large multi-centre randomised controlled trial which recruited 3,640 participants who had AMD and randomised them to receive one of four daily tablets [1. Antioxidants (vitamin C, vitamin E and beta carotene), 2. Zinc, zinc

oxide and copper, 3. Antioxidants plus zinc or 4. Placebo], and followed participants for 5 years. Results indicated that people with a high risk for developing advanced AMD (those with intermediate AMD, and those with advanced AMD in one eye only) had an approximately 25 percent reduced risk of progression and a 19% reduced risk of central visual loss during follow up when treated with the combination of antioxidants and zinc + copper (eventually becoming the final AREDS formula, which was created after the results of this study). The subsequent AREDS 2 trial found no additional benefit of adding lutein and zeaxanthin or omega-3 to the supplements but did report that effectiveness remained if beta carotene was exchanged for the less hazardous xanthophyll carotenoids, and if the zinc dose was reduced. Consequently, the so-called AREDS2 formula was developed incorporating these changes (De Luca and Ross, 1996, Tanvetyanon and Bepler, 2008, Alpha-Tocopherol, 1994). A sub analysis also revealed that participants taking the AREDS2 supplement, in the lowest quantiles of lutein and zeaxanthin intake showed significant benefits (Age related Eye Disease Study, 2013). Currently the AREDS based formulae are the only ones which are supported by robust randomised controlled trials. Therefore, the first AREDS formula, consisting of antioxidants, zinc and copper is recommended for patients in the early and intermediate stages of AMD. However, if they have a history of smoking, they should be recommended the AREDS2 formula, due to the link between beta-carotene and increased incidence of lung cancer in smokers (Alpha-Tocopherol, 1994, Tanvetyanon and Bepler, 2008, De Luca and Ross, 1996).

Since the AREDS trials, there have been a number of studies evaluating the effect of different types of nutritional supplements on AMD progression from various stages of the disease (Chew et al., 2022, Eggersdorfer and Wyss, 2018, Evans and Lawrenson, 2023). A systematic review assessed the effect of dietary supplements on AMD progression and the most researched carotenoids were lutein and zeaxanthin. The majority of the randomised controlled trials included in the review found that there was a significant difference in the rates of progression between those taking the AREDS2

supplement and those taking the placebo (Csader et al., 2022). However, the effectiveness of the supplements decreased significantly as AMD progressed.

Despite studies investigating the effects of vitamin supplements on AMD progression, it is important to note that the NICE guidelines do not recommend vitamin supplements (NICE, 2018b). This is because of the limited evidence for the effectiveness of vitamin supplements, including the AREDS formulas. Even though the risk of AMD progression for patients with intermediate AMD reduced by 25% when taking the AREDS formulation, the evidence on the effectiveness of supplements for people with early AMD is limited (Evans and Lawrenson, 2023). This is significant, as it can explain a lack of supplement recommendations from ECP's to patients with AMD if they are following the NICE guidelines. On the other hand, patient information from the RNIB (RNIB, 2023) and Macular Society (Macular Society, 2021) both include support and information on vitamin supplements, but do advise patients to exercise caution as the AREDS vitamins may not be suitable for everyone, and the evidence is still limited.

The role of diet and vitamins has been researched extensively, with the findings showing the importance of diet and vitamins in slowing down the progression of AMD. Additionally, the evidence also suggests that there are still some challenges such as the effect being reduced as AMD progresses and the importance of early interventions with these changes.

1.6.3 Sunlight exposure

Another risk factor that is associated with AMD incidence and progression is the cumulative exposure to short wavelength light (blue and UV light from the sun) (West et al., 1989) which has also been linked to oxidative stress (Tomany et al., 2004). The Beaver Dam Eye Study collected data from 3684 patients with AMD. When the participants were followed up after 5 years it was reported that the participants who spent a significant amount of time in the sunlight in their younger years were more likely to develop AMD (Darzins et al., 1997). A total of 2764 of these participants were followed up after 10 years and the people who had more sunlight exposure were also more likely to have increased RPE pigmentary changes (Tomany et al., 2004).

People with AMD are often told to wear sunglasses or some form of ocular protection due to this evidence of a cumulative effect of sunlight (College of Optometrists, 2021). However, due to the difficulties with measuring sunlight exposure accurately, studies evaluating the relationship between sunlight exposure and late AMD risk have limited reliability, and some studies have found no association (Klein et al., 2014, West et al., 1989). Currently, the research is still limited and epidemiological studies have shown that there is no significant association between sunlight exposure and macular pigment (Wolffsohn et al., 2022). This was also found to be the case in a meta-analysis conducted by Zhou et. al. (2018) who reported that out of fourteen studies including 43,934 participants worldwide, there was no association between sunlight exposure and risk of AMD incidence (Zhou et al., 2018).

Blue light exposure has also been investigated as a potential modifiable risk factor for AMD incidence due to the idea that the blue light enhances toxicity for the RPE cells (Marie et al., 2019). However, the evidence regarding the exact mechanism is unknown and the evidence supporting this is limited (Cougnard-Gregoire et al., 2023). Recent reviews have reported that there is currently no evidence supporting the idea that blue light filters have a protective effect on the macula (Margrain et al., 2004, Singh et al., 2023).

1.7 Lifestyle advice for people with AMD

The evidence regarding modifiable risk factors discussed in section 1.6 all forms the basis for advising patients to make lifestyle changes with the aim of reducing the risk of AMD progression. Based on the research showing the benefits of making these changes, lifestyle changes, such as smoking cessation and dietary modification, should be recommended to patients. The following sections will discuss the current guidelines for lifestyle advice recommendations and the present state of adherence to the guidelines for patients and practitioners. For a systematic review outlining what advice is currently given to patients with AMD see chapter 2.

1.7.1 Current guidelines for advice provision

In England, there are two main organisations that publish guidelines for advice provision to patients with AMD; The Royal College of Ophthalmologists and College of Optometrists. Both organisations recommend that ECPs provide lifestyle modification advice to patients with early and intermediate AMD (table 1).

Organisation	**Guidance**
The Royal College of Ophthalmologists (Royal College of Ophthalmologists, 2021)	• Advice on smoking cessation services must be made available. • A healthy diet rich in fresh fruit, vegetables, eggs and oily fish is recommended. • Patients should be made aware that they can choose to source over-the-counter supplements containing the AREDS2 formulation but further research is needed to evaluate its role in early AMD. • It is recommended that written information leaflets be provided to patients. • Patients with early AMD should self-monitor regularly with the Amsler grid.
College of Optometrists (College of Optometrists, 2021)	• Agreement with the guidance from the Royal College of Ophthalmologists. • An additional point referencing that the written information leaflets provided by the

	College of Optometrists should also be provided to patients.

Table 1.2- Table summarising the 2021 recommendations from the two main bodies for ophthalmologists and optometrists in the UK.

As well as the Royal College of Ophthalmologists and College of Optometrists, the National Institute for Health and Care Excellence (NICE) have also issued guidelines for practitioners, with information about lifestyle advice and how to discuss risk factors with patients. These guidelines outline the importance of informing patients about stopping smoking and maintaining a healthy diet. However, the main topics covered in the guidelines include providing patients with helpful information and resources for support, what to expect with AMD and key contact details (NICE, 2018b).

Current guidelines outline what patients should be told about lifestyle modification to reduce risk of AMD progression, depending on the stage of their disease. These guidelines are available for all ECPs, however, research shows that these guidelines are not consistently followed (Lawrenson and Evans, 2013, Martin, 2017). In this thesis, the 2021 guidelines are referred to as they were the guidelines that practitioners in this study would have had access to, However, there have since been updated guidelines published in 2024 (Royal College of Ophthalmologist, 2024). The updated guidelines continue to emphasize smoking cessation and dietary recommendations but includes more specific information about the Mediterranean diet.

1.7.2 What healthcare professionals are involved in advice provision?

The complexity of AMD means that there are normally a number of healthcare professionals involved in patient care such as optometrists, ophthalmologists, Eye Care Liaison Officers (ECLO), orthoptists, amongst others. However, the main source of lifestyle advice is expected to be from the primary and secondary healthcare services, i.e. optometrists, ophthalmologists and nurses.

Optometrists are the primary point of eye care provision for patients (Liu L, 2013). During an examination, optometrists perform a range of clinical tests and imaging, which are key for the detection of AMD (NHS, 2023). It is

recommended by NICE that patients should be referred to NHS eye services if they are in the later stages of AMD. However, if the patient has early AMD, the optometrist is recommended to provide the patient with verbal and written information about AMD, what to expect and key contact information (NICE, 2018b). Optometrists are also expected to provide guidance on smoking cessation services, nutrition counselling and (debatably) UV protection (Liu L, 2013). However, research shows that optometrists often do not feel like it is 'their place' to provide this advice (Martin, 2017).

Ophthalmologists are secondary care physicians that are normally involved in the care of patients with AMD when they are in the later stages and requiring anti-VEGF injections (neovascular AMD only). However, patients may be referred to ophthalmologists at any stage of their disease and therefore, ophthalmologists should provide patients with detailed information about lifestyle modifications they can make to reduce the risk of AMD progression shown in table 1. However, further research has shown that ophthalmologists do not always provide this advice, and optometrists are more likely to provide guidance on diet and nutritional supplements then ophthalmologists (Martin, 2017, Lawrenson and Evans, 2013). Although, a large proportion of ophthalmologists did provide smoking cessation advice (Lawrenson and Evans, 2013, Martin, 2017).

1.7.3 Current status of advice provision: overview of evidence regarding patient experience

In recent years there have been a number of studies exploring patients' knowledge of the risk factors associated with AMD, however, there is limited research into the patient experience of receiving lifestyle advice, particularly from the patient point of view. A full review of the literature surrounding the patient experience is presented in chapter 2.

Based on the guidelines for eye care practitioners discussed in section 1.7.1, practitioners should be making patients aware of the risk factors that make the progression of their AMD more likely. However, evidence shows that despite these guidelines, patients are still not aware of these factors. For example, a study by Burgmuller et. al. (2017) surveyed patients with AMD and found that 42% felt that their knowledge of AMD was not sufficient and 30% did not know

what form of AMD they had. 97% of the patients in this study got their information from their physician, but only 61.7% of patients mentioned a healthy lifestyle reducing the risk of AMD progression (Burgmüller et al., 2017). This highlights a gap in patients' knowledge of risk factors of AMD and the need for further education. Further evidence is provided by Cimarolli et. al. (2012) who conducted a survey on patients with AMD and found that one third did not know the risk factors associated with AMD (Cimarolli et al., 2012). One factor which may explain the patients' lack of knowledge of the risk factors may be the lack of adequate written materials given to them by ECPs (Boxell et al., 2017, Carlton et al., 2019). For example, researchers in another study administered a questionnaire to 158 participants with AMD and reported that only 55% were aware of the importance of diet to eye health, whilst 63% felt that the information they had received about AMD was inadequate. All of these patients obtained their information about nutrition from external sources i.e. charities (Stevens et al., 2014). Furthermore, in another study, even if patients were given written information, the information in current leaflets scored low on 'actionability' and 'understanding' (Wang et al., 2022). Therefore, patients' awareness of the risk factors for AMD progression is low, and there is a need for more education from ECPs in a practical and actionable way.

There are also a number of studies showing that there is a lack of awareness, particularly when it comes to vitamin supplements (Hochstetler et al., 2010, Ng and Goggin, 2006, Bott et al., 2018). For example, in a survey of patients attending an AMD outpatients' clinic, only 24% of the participants surveyed were advised to take dietary supplements resulting in 20% taking the supplements. The most common reason for not doing so was being unaware of how they would help (Bott et al., 2018). Another study found that 59% of the patients enrolled in the study were taking a vitamin supplement for AMD. Of those not taking any supplements, 75% met the criteria for advising supplements, but reported they were never recommended (Hochstetler et al., 2010). However, it is important to note that in this study, the researchers did not specify if the supplements that patients were taking were compliant with the AREDS/AREDS2 formulae. On the other hand, a study by Charkoudian et. al. (2008) found that more than one third of patients attending a clinic were not

taking AREDS supplements or were not taking the correct dosages despite meeting the criteria for the supplements (Charkoudian et al., 2008). Similarly, a more recent study by Alghamdi et. al. (2023) found that 40 out of 120 patients that met the criteria for the AREDS2 supplement were not taking the vitamins, with the most common reason being that they were never advised about the benefits. The research also highlights the importance of practitioners explaining the rationale for advice, as well as telling patients of the lifestyle changes recommended.

1.7.4 Current status of advice provision: overview of evidence regarding practitioner experience

As discussed in the previous section, the research on the patient experience of receiving lifestyle advice is limited, with the main focus of research being the patients' awareness of risk factors. However, there are a number of studies about the practitioner experience of giving lifestyle advice to patients, as well as research on what they perceive to be the main enablers and barriers to effective lifestyle advice provision. This is discussed in further detail in chapter 2, section 2.3.4.

Firstly, there have been a number of studies demonstrating that practitioners are not aware of the best practice guidelines (Sahli et al., 2020, Downie and Keller, 2015, Aslam et al., 2014). For example, a study by Zhang et. al. (2020) investigating the practice behaviours of optometrists in Australia found that 44 out of 206 practitioners were not recommending omega-3 fatty acid supplements because they felt they did not know enough about the supplements to make recommendations (Zhang et al., 2020). Additionally, a UK based study found that although ECPs were providing advice to patients about diet, including to eat more green leafy vegetables and oily fish, only one in three practitioners provided smoking cessation advice and 70% of the practitioners took smoking history into account when recommending vitamins supplements (Lawrenson and Evans, 2013). This demonstrates that practitioners require more education regarding the risk factors for AMD and the guidelines they should be following.

Secondly, the type of practitioner also has an impact on what advice is provided to patients. In the study by Lawrenson and Evans (2013), ophthalmologists were more likely to take a smoking history from patients than optometrists. In contrast, Martin (2017) found that optometrists were more likely to provide advice about nutritional supplements and diet to patients with AMD and at risk of AMD compared to ophthalmologists. However, In both studies, there were more optometrists than ophthalmologists. Although, in the study by Martin (2017) and consistent with the findings from the study by Lawrenson and Evans (2013), it was also reported that ophthalmologists were more likely to provide advice about smoking cessation than optometrists. A study looking at the clinical practice behaviour of optometrists in Australia found that younger practitioners were less likely to ask patients with AMD about smoking and diet (Downie and Keller, 2015). This demonstrates that there are a number of factors, such as a lack of awareness, type of practitioner and the location that practitioners are based in, that impact the practitioner experience of providing lifestyle advice.

Interestingly, despite this, one study reported that 78% of optometrists felt the information available on nutrition and eye health is adequate enough for them to give advice and 81% of optometrists made recommendations about lutein and zeaxanthin to patients, suggesting that practitioners felt confident recommending the supplements (Larson and Coker, 2009). However, this confidence is not necessarily reflected in the data regarding the appropriateness of actual recommendations made to patients (e.g. Lawrenson and Evans, 2013).

When it comes to recommendations regarding advice about the intake of vitamin supplements, the evidence is even less encouraging. A study investigating adherence to AREDS recommendations found that 90% of the practitioners in the study were aware of AREDS, but only 46% of practitioners were recommending the supplement when early/intermediate AMD was diagnosed and 18% on confirmation of neovascular AMD (Aslam et al., 2014). Furthermore, Lawrenson and Evans (2013), found that 93% of the practitioners surveyed were providing advice about vitamin supplementation but the recommended vitamins did not comply with the best practice guidelines

to recommend an AREDS based supplement for all stages of AMD if they are suitable (Lawrenson and Evans, 2013, Royal College of Ophthalmologists, 2021).

There have also been a few qualitative research studies investigating what practitioners believe to be the main enablers and barriers to lifestyle advice provision. Jalbert et. al. (2020) carried out focus groups with optometrists in Australia about what they think the main barriers are. Optometrists reported that the most important barriers were cost/funding and patient understanding/denial and the most commonly reported enablers were education, access and a 'shared care model' i.e. different practitioners working together to help the patients make the changes (Jalbert et al., 2020). The findings from these studies show that further work is needed to educate ECP's and that there are still significant barriers to the provision of lifestyle advice beyond practitioners experience and education.

1.8 Patient- practitioner communication

Patient-practitioner communication is a key aspect of effective advice provision. Studies have investigated the topic of communication in health care settings as well as theories on the best techniques for communicating lifestyle advice (Hair and Sripipatana, 2021, Noordman et al., 2012). In the UK, NICE guidelines outline the best ways to deliver health care advice to patients, and recommend that patients be given verbal and written advice as well as an opportunity to ask questions (NICE, 2018b). External factors can influence the impact of communication. For example, during the COVID-19 pandemic, effective communication between patients and practitioners was of utmost importance (Marler and Ditton, 2021) due to people reporting increased levels of depression and anxiety because of the loneliness of self-isolation (Alsawy et al., 2020). However, there is debate around the most effective form of communication when delivering lifestyle advice. For a detailed breakdown of communication theories in healthcare, see Bylund et. al. (2012).

In AMD specifically, there is limited research on the effects of communication between patients and practitioners and how this impacts health outcomes. Research on other health conditions show that co-ordination between different

healthcare systems (Huzzard et al., 2018), written education materials for patients (Shoemaker et al., 2014) and verbal communication (King and Hoppe, 2013) are highly recommended for the best health outcomes. With respect to AMD, verbal and written communication is recommended in the NICE guidelines (NICE, 2018b). However, a recent study by Wang, Kalloniatis and Ly (2023), investigated how health communication in AMD can be improved in the future via focus groups with patients and ECPs. They found that patients felt the quality and relevance of the written materials needed to be revised, with a lot of the information being inaccurate and challenging for patients having different cultural and digital literacy. Optometrists in the study also emphasised the importance of verbal communication and tailoring discussions to the individual, storytelling for relevance, and highlighting key points (Wang et al., 2023). This study emphasizes the importance of listening to the patient and practitioner, however, it only focused on optometrists and therefore it lacks information to consider the ophthalmologist point of view. Overall, effective communication between ECPs and patients with AMD should be studied further as there is limited evidence available and health outcomes may be significantly improved.

1.8.1 Verbal communication

As the research on verbal communication for AMD is limited, this section will focus on some general verbal communication theories. The current theories of effective patient practitioner verbal communication can be divided into three categories; Individually centred theories, interaction centred theories and relationship centred theories (Bylund et al., 2012).

Individually centred

Focuses on how practitioners in a health care setting plan and create goals and messages for their patients and how patients process and deal with the information they are given. This group of theories focuses on individual cognitive processes. For example, one of the theories within this category is the goals-plans-actions theory, creating goals or outcomes for patients, which plan with patients how they can achieve these goals and action them. This focuses on clear and effective communication with patients where

practitioners can talk about the plans and actions patients should take explicitly. This theory has been used in some healthcare settings to deliver genetic health information to patients (Bylund et al., 2012).

Interaction centred

Focuses on the interaction between the practitioner and the patient and how the way that they communicate can impact the interaction. For example, the speech codes theory states that individuals will encounter many speech codes which relate to people and culture (Philipsen, 2008). In a health care setting, a patient's speech code can influence how they process health information. The speech codes used can guide the communication experience and impact its effectiveness (Philipsen and Hart, 2015).

Relationship centred

These theories are about disclosure of information within relationships which can shape the patient practitioner relationship. This is important to consider when discussing confidential information. They emphasise establishing a trusting relationship with patients by ensuring privacy and open communication (Taylor, 1968).

Verbal communication theories can be applied to many healthcare settings and can help with effective conversations. However, it is also important to consider the individual and their experiences using a patient centred approach (McCabe, 2004).

1.8.2 Written communication

Written communication between practitioners and patients can be an impactful way of information delivery. Healthcare information for patients in the form of leaflets has been studied and found to be effective in helping patients to adhere to lifestyle advice and medication (Nicolson et al., 2009). Leaflets have also been reported to help with patients' mental health when it comes to health advice and preparing for appointments (Sustersic et al., 2017). Patients have been reported to look at written information for help on health related decision making (Raynor et al., 2007), and it can also reduce the number of visits to their doctor (de Bont et al., 2015). Weaver and Beaumont (2015) reported that

a clinic in which advice was provided according to AREDS guidelines verbally and in written format had a concordance rate of 81.6% compared to 44% in a clinic that had no policy about verbal or written advice (Weaver and Beaumont, 2015). This indicates that providing both, written and verbal advice, can have a substantial impact on the effectiveness of advice uptake.

It is important that the written materials for patients are designed to a high standard. In line with this objective, currently available written materials for patients with AMD have been evaluated. Using patient education materials from the UK, Australia, New Zealand, USA, Ireland and Canada, Wang Kalloniatis and Ly (2022) graded the materials for 'understandability' and 'actionability' using the Patient Education Materials Assessment Tool (PEMAT) (Shoemaker et al., 2014). Figure 1.6 displays the examples of materials that scored highly and materials that scored poorly in this assessment. The main negative 'understandability' points about the materials were that there was no summary of the main points, the visual aids had no titles or there was a lack of visual aids. The main negative 'actionability' points were the lack of visual aids, not breaking down actions into explicit steps and no tangible tools for the patients to use. However, the main limitation of this study is that the materials were rated by optometrists, not patients, and therefore, these findings are do not represent the patient view.

A recent review by Medina-Cordoba et. al. (2021) investigating the comprehensiveness of patient information leaflets, reported eight factors that may hinder a patient's understanding of written health information. These included too many medical/scientific terms, use of English for non-English speakers, and a lack of structure (Medina-Córdoba et al., 2021). The review also summarised factors that aide the comprehension of written communication such as use of pictograms and images, written information being provided in the user's native language, short highlights of the information and emphasis on the benefits of a drug/treatment. The current NHS guidelines also recommend that medical guidance is written at a 11-14 year old reading age (Health Education England, 2023).

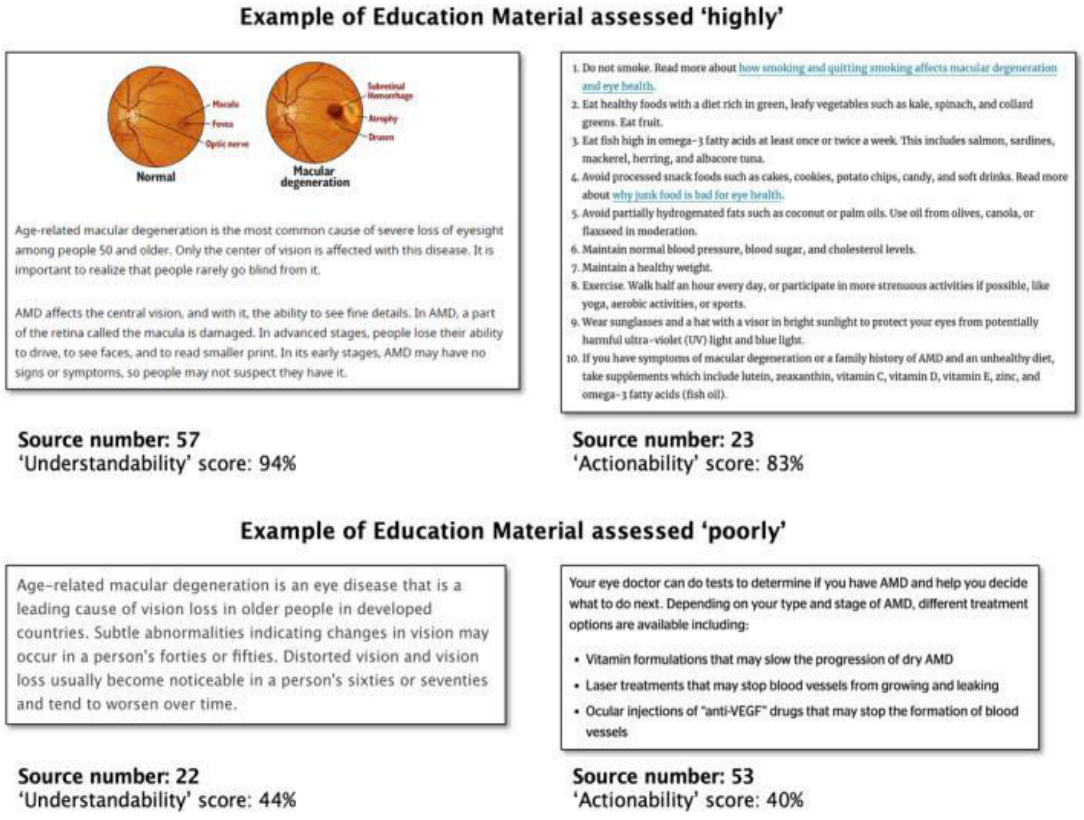


Figure 1.6- Examples of written patient information materials that were assessed by Wang et al (2022) for readability and actionability. Image from (Wang et al., 2022)

Written communication can be an effective tool for practitioners wanting to inform patients of their condition and to advise them about their treatment (Rajasundaram et al., 2006) or lifestyle changes. It is important to consider the patient's literacy level (Wynia and Osborn, 2010) and the comprehensiveness of the information in order for the leaflet to be effective. It is recommended in a number of studies that the best way of communicating information to patients is through both verbal and written communication as this increases the patient's knowledge and adherence with guidance as well as patient satisfaction (Johnson et al., 2003, Prip et al., 2019, Gasteiger et al., 2023).

The following sections provide an introduction to the methodological theories employed in the data analysis in this thesis. Section 1.9 discusses the philosophical paradigms which may be adopted when conducting

quantitative or qualitative research, and 1.10 discusses practical approaches to the analysis of qualitative data.

1.9 Research Paradigm

Epistemology is a philosophical concept that focuses on understanding the nature, origin and scope of knowledge. Additionally, this theory also focuses on the limits of knowledge and how beliefs about the research are justified. The philosophical framework or set of beliefs that guides the research and how it's conducted is known as the 'research paradigm' (Winit-Watjana, 2016). Generally, the paradigms that are used by researchers reflect the assumptions made by the researchers and what perspectives the research has been viewed from. There are four main paradigms of research; positivism, post-positivism, pragmatism and interpretivism (Mkansi and Acheampong, 2012).

Positivism involves focusing on creating explanatory relationships between an independent and a dependent variable with the ultimate goal of predicting, controlling and treating the problem. Although this paradigm is generally used in quantitative research, some qualitative research studies have used this paradigm to understand the effectiveness of an intervention (Park et al., 2020). The assumption of positivism about epistemology is that knowledge can be objectively observed or measured, and the main focus would be on causality. On the other hand, the research paradigm of post-positivism still focuses on objective and measurable data, but also includes a realist perspective i.e. perspectives and values of individuals (Clark, 1998). This paradigm assumes that knowledge about facts and numerical data can be observed and measured objectively but can also be interpreted and influenced. The focus is on causality but within a context.

Pragmatism is a paradigm that focuses on looking at 'actions' and utilizing multiple sources of data and knowledge to answer research questions (Brierley, 2017). Therefore, this paradigm is often used in mixed-methods research as it allows for the use of multiple types of data in a single study (Allemang et al., 2022). Pragmatism assumes that knowledge is objective,

subjective and what is practical. The focus of this paradigm is on actionable research that combines different perspectives and theories to interpret data.

Interpretivism opposes the positivist paradigm and states that there are several subjective realities that are created through individual interpretations. This paradigm involves looking for meanings through qualitative data and experiences (Ryan, 2018). Interpretive research is also theory based, i.e. data can be generalised through theories rather than hypotheses. Interpretivism assumes that knowledge is subjectively observed and relative. Research would involve an in depth look at data to reveal deep meanings (Winit-Watjana, 2016).

The research paradigm used in the qualitative research presented in this thesis is interpretivism. The methods used throughout the thesis focus on interpreting patient experiences to be applied to health care. Additionally, the research has been conducted with the lens of 'subjective patient experiences' i.e. everyone has different perspectives. Through these perspectives, different meanings and knowledge can be acquired. Additionally, this paradigm focuses on collecting data and extracting patterns from the data which are interpreted by researchers. However, an element of pragmatism is added to the study in the inclusion of quantitative analysis and statistical evaluation of factors influencing behaviour of individuals.

1.10 Analysis of qualitative data

A common criticism of qualitative data analysis has been the inconsistent methodology and labelling of codes and discussions (Sandelowski, 2010). Approaches to qualitative data analysis include narrative inquiry, grounded theory, content, framework and thematic analysis.

Narrative inquiry is a method of qualitative analysis that involves using patient's data from transcripts to create 'stories' out of the words and context to interpret patient experiences (O'Kane and Pamphilon, 2016). This can help understand the complexities of patients decision making and can ultimately lead to making meaningful policy changes. However, this approach is often seen as having issues with validity as the stories can often be misinterpreted (Polkinghorne, 2007). On the other hand, Grounded theory is a systematic

qualitative research methodology that involves generating theories from data (Connor et al., 2023). It was generated to highlight the importance of theory generation, rather than just theory testing (Glaser et al., 1968). The process involves constant comparison, theoretical sampling, memo-writing and parallel data collection and analysis (Berthelsen et al., 2018). However, this methodology can be time and resource consuming.

Framework and thematic analysis have similar methodologies as they all involve looking through data, looking for themes and interpreting/reporting the data (Vaismoradi et al., 2013). Whereas content analysis involves looking for codes, grouping them into categories and then reporting them (Elo and Kyngäs, 2008). Framework analysis involves using an existing framework and generating a codebook using the data that fits it (Ritchie et al., 2022). This can allow for comparisons across multiple studies using the same framework.

Thematic analysis is the most commonly used method in qualitative research, particularly in healthcare. Over the past several years, thematic analysis has been defined in various ways, which has led to inconsistencies in findings. More recently, in a review by Kiger and Varpio (2020), thematic analysis is defined as a method that involves searching data sets to 'identify, analyse and report repeated patterns'. As well as allowing for a more structured way of describing data, it also allows researchers to interpret the data through the selection of codes and themes (Braun and Clarke, 2006). Another advantage of thematic analysis is that it can be applied to several frameworks and study designs. The principles of thematic analysis have been applied to other methods such as grounded theory (Watling and Lingard, 2012). Nonetheless, the principles are applicable.

However, as the topic of this thesis is relatively new, it was decided that the thematic analysis methodology described by Braun and Clarke (2006) would be used. This methodology is a flexible and described in detail which allowed for the systematic analysis of the qualitative data in this thesis without being restricted to a particular framework (Braun and Clarke, 2006).The thematic analysis process they described involves six stages:

1. Familiarisation with the data- this involves the transcription and reading of the data and noting down ideas of any topics or trends.
2. Generation of initial codes- coding features of the data across the data set and collecting relevant data.
3. Searching of themes- Collecting the codes into potential themes and ensuring that all of the data that is relevant to the theme has been included.
4. Reviewing themes- checking to see if the themes make sense when looked at with the codes and the data set.
5. Defining and naming themes- Reviewing the themes to refine the specifics of each theme, the overall story and generating clear definitions of the themes.
6. Producing the report- Selection of vivid examples from the data, final analysis of the themes and extracts and relating it back to the research question. Finally producing a report of the data.

This approach was selected as it provides a clear and concise six step process for interpreting data and allows for several opportunities to review the themes and nodes in the analysis. For example, in steps 4 and 5 described above, another researcher can be involved to ensure the themes make sense and ensuring the validity of the data. However, there are some limitations with this process. For example, as thematic analysis does not have a fixed 'framework' or 'codebook' to follow, the themes may not always be relevant without following a systematic process. However, as this thesis followed an interpretivism paradigm, this 'exploratory' way of looking at the data allowed for interpretations to be made based on patient's experiences.

1.11 Rationale for thesis and aims

There are a number of studies investigating the advice ECPs deliver to patients with AMD that report that not all ECP's are giving consistent advice and are not always aware of the best practice guidelines (Lawrenson and Evans, 2013, Boxell et al., 2017). This suggests non uniformity in the provision of advice, and also raises barriers to effective provision.

Research conducted on people with AMD has reported that patients are not always informed about the lifestyle changes they can make to help their AMD. For example, one study investigating understanding and adherence to lifestyle advice of 92 patients found that 51% of the people with AMD recalled being told about dietary modification and only 5% recalled being told about smoking cessation. However, it is unclear if participants were actually told or not as these figures were dependent on patient recall. Importantly, only 62% of the people told about dietary modification felt that making dietary changes was necessary for their AMD (Shah et al., 2015). Additionally, another study found that 60% of the participants with AMD seen in a hospital setting did not recall being given any advice regarding diet from their practitioner and only 11% of the people who were given advice about diet made a change (Bott et al., 2018).

The current research on patients with AMD and the lifestyle advice they are given has limitations. For example, most surveys of patients have been conducted in a community setting and are not linked to a specific clinical experience. This introduces issues with separating lack of information provision by practitioners from the patients' ability to recall the advice provided. One study (Bott et al., 2018) was conducted in a hospital setting where it might be expected that lifestyle advice is provided at the first appointment, but not routinely thereafter. Again, this introduces the risk of recall bias. There is also no research from the patient's perspective on how advice provision can be improved and how the importance of the lifestyle changes can be communicated to patients. Previous studies (Shah et al., 2015, Hochstetler et al., 2010) have focused on the information that patients recall and adhere to, but there is a gap in the research regarding the patients' preferences on how they would like to receive information about their condition. Another area which is lacking in the current evidence base is the experience of clinicians, and the barriers they perceive in providing advice to patients with AMD.

Overall, there is a gap in the knowledge of the patients' experience of receiving lifestyle advice, and how this experience can be improved. Studying this would facilitate the development of a framework guiding healthcare professionals on the optimal mode of advice provision.

The overarching aim of this PhD is to investigate the extent, nature and effectiveness of lifestyle modification advice currently given to patients with AMD in hospital and optometric practice, from a patient perspective. Ultimately, the specific aim of this PhD is to answer the following research question:

- What is the patient experience of the current provision of lifestyle management in age-related macular degeneration (AMD)?

Secondary aims include:

- To investigate differences in the information delivered by different types of ECPs.
- To determine whether advice provided by ECPs impacts on self-reported patient behaviour.
- To determine whether there is a difference in the self-reported impact of the advice based on the mode of delivery.
- To identify factors, according to ECPs and patients, that impact on the effectiveness of advice provision.

The ultimate objective is to provide evidence to inform future guidance on optimising the effectiveness of communication between practitioners and patients with AMD. This guidance can help to inform an implementation science-based framework to increase the extent of the delivery of this information. By using practice-based evidence, this may in turn lead to improved patient satisfaction, management and prognosis.

The terms adherence and compliance are often used interchangeably in the field of health care. Adherence is defined as “the extent to which a person’s behaviour, taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.” (Chakrabarti, 2014) Conversely, compliance is defined as “the extent to which patients behaviours match health care providers recommendations” (Chakrabarti, 2014). An important distinction is that adherence refers to proactive behaviours, which result in a lifestyle change by

the patient (Mir, 2023). When patients are described as being compliant, it often refers to passive behaviours where the patient is following a list of instructions rather than making active changes (Mir, 2023). In this thesis, the proactive steps taken by patients following lifestyle advice receipt is being assessed, therefore, the term 'adherence' is used throughout.

1.12 Thesis overview

This thesis will cover the following topics:

- A systematic review covering the literature available on what advice is currently given to patients with AMD and how effective it is at changing lifestyles - chapter 2. **This review has been published (Dave et al., 2022) in the journal Nutrients.**
- A co-design activity conducted to create the questionnaires used in the main study. This section includes the basis of the questionnaire design, and the findings from the conversations - chapter 3
- The methodology used in this thesis - chapter 4
- The results of a study evaluating lifestyle advice provided by ECPs from a patient perspective, and feedback on how patients prefer to receive advice - chapter 5. **This chapter has been prepared as a manuscript for publication**
- The results of a study evaluating changes that patients may or may not have made to their lifestyle in the three months since first being surveyed - chapter 6
- The findings from a survey conducted with practitioners to explore their experience of providing advice and what they believe the barriers are to effective advice provision - chapter 7. **This chapter has been prepared as a manuscript for publication**
- A discussion of the findings of the thesis, how these relate to the aims of the PhD, and how these findings can impact lifestyle advice provision for patients with AMD- chapter 8

2. Systematic review: What advice is currently given to patients with Age-related Macular Degeneration (AMD) by eyecare practitioners, and how effective is it at bringing about a change in lifestyle?

This review has been published ((Dave et al., 2022), see Appendix M). Conceptualization, S.D., A.B., T.C. and V.V.-N.; Methodology, S.D., A.B., T.C. and V.V.-N.; Data Curation, S.D. and T.C.; Writing—Original Draft Preparation, S.D.; Writing—Review and Editing, S.D., A.B., T.C. and V.V.-N.; Visualization, S.D., A.B., T.C. and V.V.-N.; Supervision, A.B., T.C. and V.V.-N.; Project Administration, S.D. The CASP checklist for this review is provided in appendix B.

2.1 Introduction

Age related Macular Degeneration (AMD) is a progressive eye condition that leads to irreversible loss of central vision and it is the leading cause of visual impairment in developed countries (Gheorghe et al., 2015, Augood et al., 2006, Klein et al., 2011, Jonas et al., 2014, Friedman et al., 2004). The early and intermediate stages of AMD are associated with relatively modest changes in visual function, but can progress to GA or nAMD (Ferris et al., 2013). Both GA and nAMD are associated with significant visual disability (Taylor et al., 2018), inability to perform daily activities (Gopinath et al., 2014), an increased risk of depression (Mathew et al., 2011, Dawson et al., 2014, Casten and Rovner, 2013), reduced well-being, mood, quality of life (Taylor et al., 2016, Hassell et al., 2006) and social participation (Cimarolli et al., 2017), and increased risk of falls (Wood et al., 2011, van Landingham et al., 2014). Whilst nAMD can be treated with anti-vascular endothelial growth factor drugs, there are no currently licensed treatments for early-stage disease or geographic atrophy in the UK. However, observational studies have highlighted certain modifiable risk factors which may be addressed to slow the progression or reduce the risk of the disease (Chakravarthy et al., 2010a, Tan et al., 2007, Heesterbeek et al., 2020, Hogg et al., 2017). Whilst smoking is accepted to be the strongest modifiable risk factor for AMD (Smith et al., 1996, Tan et al., 2007, Bott et al., 2018), dietary changes such as increased intake of dietary xanthophylls (for example in green leafy vegetables) (Chapman et

al., 2019a), and dietary omega 3 fatty acids and oily fish (Chong et al., 2008) and adherence to a Mediterranean style diet (Hogg et al., 2017) have all been reported to help decrease the risk of AMD progression and incidence. With respect to nutritional supplements, robust data is available from the Age-Related Eye Disease Study (AREDS) and AREDS2, reporting that a formula (consisting of high dose vitamin C and E, zinc, and either beta carotene or lutein and zeaxanthin) can help to slow down AMD progression (by around 25% over 5 years) in people with intermediate AMD, or with unilateral nAMD in the fellow eye (Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013). Although evidence regarding dietary changes is less robust than the AREDS data regarding vitamin supplementation (Evans and Lawrenson, 2014), there is a general professional consensus that eating a healthy diet rich in vegetables (especially antioxidant rich green, leafy vegetables), with oily fish twice per week is likely to be beneficial and unlikely to cause harm (Royal College of Ophthlamologists, 2021).

On this basis, professional bodies advise Eye Care Practitioners (ECPs) to recommend lifestyle changes based on this evidence (smoking cessation, dietary changes and vitamin supplements where appropriate) to patients with AMD verbally and in written format and to recommend other services such as smoking cessation services to help patients make the changes.

However, studies have demonstrated that these recommendations are not consistently followed (Lawrenson and Evans, 2013, Martin, 2017) and not all patients recall receiving any advice (Bott et al., 2018, Shah et al., 2015). The aim of this systematic review was to investigate what advice is currently given to patients with AMD by ECPs and how effective this advice is at motivating patients to make lifestyle changes.

2.2 Methods

The review process was consistent with PRISMA guidelines (Page et al., 2021). The following databases were searched: CINAHL, MEDLINE, PsycINFO and PyscARTICLES (via EBSCO) and EMBASE and AMED (via OVID). The search was conducted in November 2020 for studies published since 2001 using the search terms displayed in table 2.1.

AND	AND	AND	AND	NOT
Age-related maculopathy	Advice	Specialist	lifestyle	diabetes
Age-related macular degeneration	guid*	eye care professional	diet	diabetic
Age related macular degeneration	Communication	eye care specialist	nutrition	genetic
Macular degeneration	Information	ophthalmologist	smoking	
Macular disease	Perception	optom*	risk factor	
	evidence based practice	clinic*	supplement	
	Counselling	health care professional		
	aware*	health care provider		
	attitude*	practi*		
	Behaviour	optic*		
	Behavior	physician		
	recommend*	Doctor		
	experience*	Ophthalmic		
		Nurse		
		Pharmacist		

Table 2.1- Search terms used in systematic review of electronic databases. Terms in a specific column were linked with the OR operator.

To be included in the review, the studies had to include people with any diagnosis of AMD and had to be an evaluation of the provision of lifestyle, smoking and nutritional advice by ECPs and/or the effectiveness of this advice in bringing about a change in behaviour.

Studies were excluded if they were not published in English language; they focused on people at risk of AMD (i.e. with no current diagnosis of AMD); the full manuscript was not available or was only a published protocol, they focused on AMD with other associated systemic and ocular conditions; they evaluated a medical treatment for AMD or advice following cataract surgery; or if they were published prior to 2001 – the year of publication of the original AREDS results paper (Age related Eye Disease Study, 2001). Reviews, letters to Editors and news articles were also excluded.

All of the records were assessed for eligibility by SD and supervisor TC and three disagreements were resolved by consulting with the other two supervisors (AB and VVN). The records were organised, and duplicates were removed using Mendeley software v1.19.8 (https://www.mendeley.com). The data from the included studies was extracted and recorded in a data extraction table (see appendix A). A quality appraisal assessment was also carried out for all of the records that met the eligibility criteria using quality appraisal tools including the Joanna Briggs Institute (JBI) checklist for cross sectional surveys (Moola S, 2020), The National Heart, Lung and Blood Institute (NHLBI) checklist for interventional audits (National Heart and Institute, 2019) and the Critical Appraisal Skills Programme (CASP) checklists for cohort studies (Critical Appraisal Skills Programme, 2023a) and qualitative studies (Critical Appraisal Skills Programme, 2023b). The findings from these tools and a summary of the included studies are shown in table 3. The JBI quality appraisal tools were used for the cross-sectional surveys (19/24) and case series (1/24). The CASP checklists were used for the cohort studies (2/24) and one qualitative study (1/24). There was also one interventional audit for which the NHLBI quality appraisal tool was used (see appendix A for quality appraisal checklists).

For the synthesis of the data, the descriptive-interpretive approach to the meta-analysis of qualitative data was used (Timulak, 2009). The review protocol was published on the PROSPERO site before commencing the literature search (PROSPERO registration number: CRD42020223724).

2.3 Results

Included studies

From the searches, 1370 records were identified, and 11 records were identified from other sources such as references and background reading. Before screening the records, 448 duplicates were removed, leaving 933 records to be screened. The records were screened independently by two members of the research team and 859 records were excluded. 73 reports were retrieved to be assessed for full text eligibility and 1 was not retrieved as it was an older version of a paper, already included, that had been reprinted. The 73 full texts were assessed for eligibility. Finally, 24 papers were included

in the review (see Figure 2.1 for PRISMA flowchart and Table 2.2 for list of included studies).

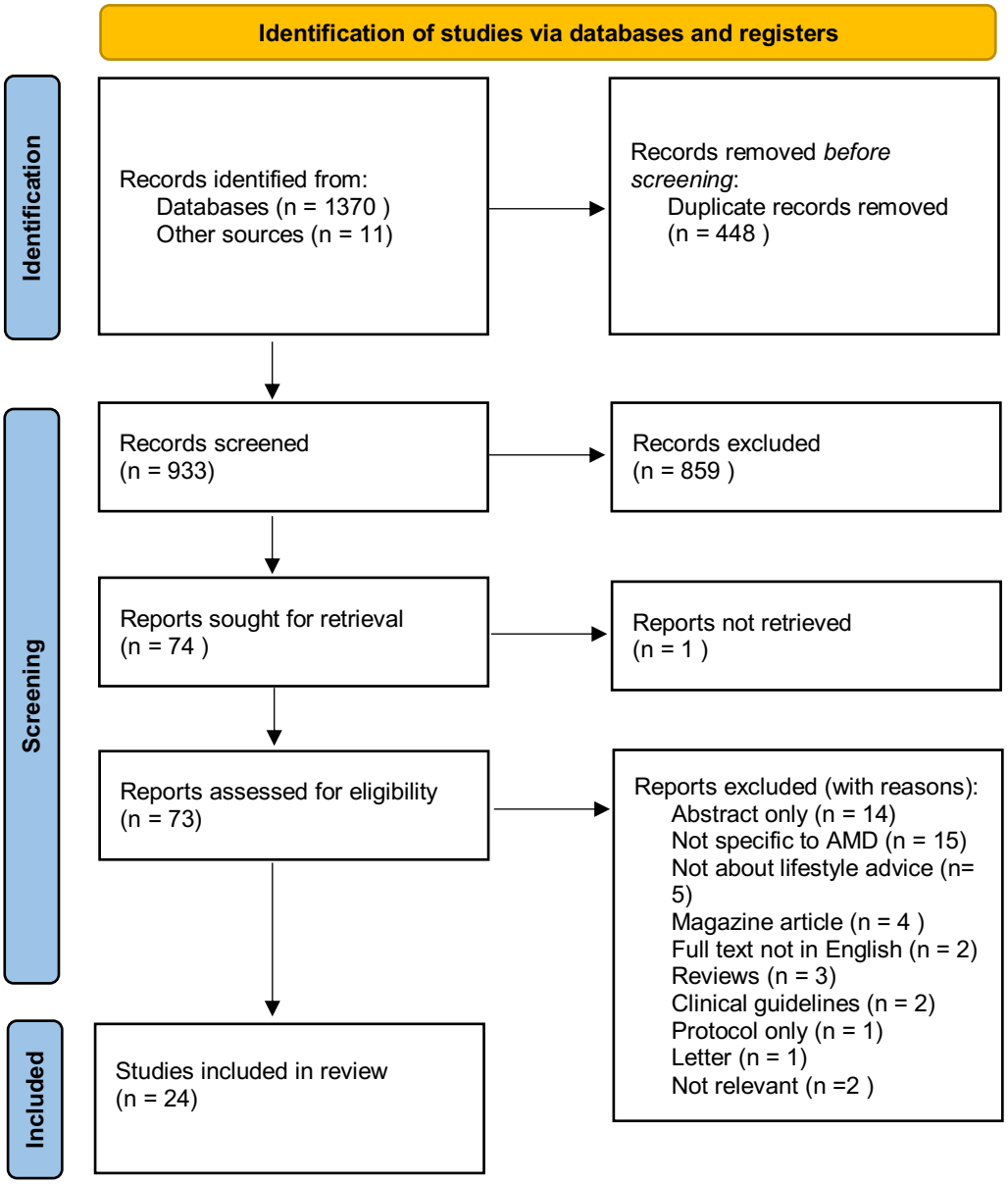


Figure 2.1- PRISMA flowchart for the selection of studies included in this review.

Study	Location (country)	Number of participants	Total study duration	Participant type	Study design	Quality appraisal checklist used	Risk of bias
Aslam et. al. (2014)	Belgium, France, Germany, Italy, Portugal, Spain and UK	216	Not specified	Practitioners	Survey	JBI	SA, OM
Bott, Huntjens and Binns (2017)	UK	248	6 months	Patients	Cross sectional survey	JBI	SS
Burgmuller et. al. (2016)	Germany	271	15 months	Patients	Cross sectional survey	JBI	SS
Caban-Martinez et. al (2011)	USA	98	One month	Both	Pilot cross sectional survey	JBI	IC*, CF, OM, SA, SS
Chang et. al. (2002)	Canada	108	2 months	Patients	Cross sectional descriptive study	JBI	IC, SA, SS
Charkoudian et. al (2008)	USA	332	2 months	Patients	Cross sectional clinical case series	JBI	SA, SS
Cimarolli et. al. (2012)	USA	99	Not specified	Patients	Descriptive study	JBI	EM, SA
Downie and Keller (2015)	Australia	379	2 weeks	Practitioners	Survey	JBI	IC, OM
Gocuk et. al. (2020)	Australia	20	17 months	Practitioners	Interventional audit	NHLBI	SAS, BL
Hochstetler et. al. (2010)	USA	64	One month	Patients	Cross sectional survey	JBI	IC, SS

Jalbert et. al. (2020)	Australia	77	Not specified	Practitioners	Qualitative research and focus groups	CASP	QD
Kandula et. al. (2010)	USA	83	Not specified	Patients	Prospective survey based study	CASP	CF, FU, SS
Larson and Coker (2009)	USA	127	One month	Practitioners	Descriptive and cross sectional survey	JBI	IC, CF, OM
Lawrenson and Evans (2013)	UK	1468	12 weeks	Practitioners	Cross sectional survey	JBI	IC
Lawrenson, Roberts and Offord (2014)	UK	26	One month	Practitioners	Survey	JBI	IC, EM, CF, OM, SA, SS
Martin (2017)	Sweden	393	Not specified	Practitioners	Cross sectional survey	JBI	SA
Parodi et. al (2016)	Italy	193	5 months	Patients	Cross sectional survey	JBI	EM, SS
Sahli et. al. (2020)	USA	42	Not specified	Practitioners	Survey	JBI	CF
Shah et. al (2015)	UK	92	29 months	Patients	Cross sectional survey	JBI	SS
Stevens et. al (2014)	UK	158	2 months	Patients	Survey	JBI	EM
Weaver and Beaumont (2015)	Australia	330	One month	Patients	Prospective controlled study	CASP	CF, FU, SS
Yu et. al. (2014)	Germany	65	Two months	Patients	Cross sectional questionnaire based study	JBI	SS
Yu et. al. (2014)	Germany	47	Not specified	Patients	Questionnaire	JBI	EM, OM

Zhang et. al. (2020)	Australia and New Zealand	206	5 months	Practitioners	Survey	JBI	IC

Table 2.2- Table of included studies- summary of key information about the studies included in the review in alphabetical order by first author. Quality assessment of studies included in the systematic review where SA= Statistical analysis unclear, OM= Measurement of outcome measures unclear, SS= Single site recruitment, IC= Inclusion criteria not clearly defined, EM= Exposure measurement not reliable or valid, SAS=Sample size sufficiency unclear, BL= Researchers not blinded to exposure, QD= Qualitative data only, CF= Unclear if confounding factors taken into account. FU= Follow up of subjects unclear. *= Patient questionnaire only. The full data extraction table and quality checklists can be found in Appendix A.

2.3.1 What is the patient reported experience of receiving advice from eyecare practitioners?

Of the 24 papers included in this review, 7 papers focused on the patient experience of lifestyle advice (Bott et al., 2018, Shah et al., 2015) and their knowledge of the risk factors of AMD (Caban-Martinez et al., 2011, Cimarolli et al., 2012, Kandula et al., 2010, Stevens et al., 2014, Burgmüller et al., 2017).

Two studies which surveyed patients with AMD at a hospital clinic, both reported that a high proportion of patients had no recollection of receiving advice regarding dietary modification from their ECP (Bott et al., 2018, Shah et al., 2015). Bott et al. (2017) surveyed 248 patients with nAMD attending a medical retina clinic in the UK regarding their recollection of lifestyle advice received and reported that, although more than half (53.1%) reported being advised to stop smoking, only 39.9% reported receiving advice regarding diet, and 24.2% recalled being recommended a nutritional supplement (Bott et al., 2018). Shah et al. (2015) carried out a similar retrospective cross sectional telephone survey of 92 patients with AMD who had attended a single UK vitreoretinal hospital unit to investigate the patients' recollection and understanding of lifestyle advice provided (Shah et al., 2015). They found that 47 (51%) recalled recommendations about dietary changes, 21 (23%) about exercise, 5 (5%) about smoking cessation and 90 (98%) about AREDS-based supplements. Of those who responded, based on the advice they were given, 62% felt that making dietary changes was necessary, 76% believed that exercise and weight reduction was necessary, 74% felt the AREDS supplement was a necessity, and 80% of the people who were told about smoking cessation felt it was necessary (Shah et al., 2015). Whilst these studies demonstrated significant gaps in the knowledge of patients, they did have limitations. For example, it was not possible to determine whether advice had been provided, and subsequently forgotten by patients, or whether the advice had not been given in the first place. Also, the generalisability of both of these studies was limited by participants being recruited from a single hospital site and both were conducted in the same country, thus, the results only focus on advice provided in the UK (Bott et al., 2018, Shah et al., 2015).

2.3.2 How much do people with AMD understand about the lifestyle risk factors for disease progression?

Five studies investigated patient awareness of risk factors of AMD (Caban-Martinez et al., 2011, Cimarolli et al., 2012, Kandula et al., 2010, Stevens et al., 2014, Burgmüller et al., 2017), and the source of their information. Kandula et al. (2010) and Cimarolli et. al. (2012) studied patient awareness of the risk factors for AMD in the United States of America (USA). Kandula et al. (2010) surveyed 83 patients from a retina practice in a suburban setting, while Cimarolli et al. (2012) conducted telephone interviews with 99 adults who were randomly selected from an Ipsos (a market research firm in the USA) database of people with AMD. Both survey-based studies reported a lack of awareness amongst patients with AMD about risk factors. Cimaroli and colleagues reported that out of the 99 patients with AMD surveyed, one third did not know the risk factors associated with AMD and the most common source of information for all patients was their eye care physician (Cimarolli et al., 2012). Similarly, in the study by Kandula and colleagues, 78% of the 83 patients in the study, received their AMD information from their physician, but 89% of patients would have preferred to receive more information. Furthermore, only 21%, 48%, 37%, 48%, and 36%, of patients respectively, correctly identified how diet, special vitamins, high blood pressure, family history, and smoking can affect AMD (Kandula et al., 2010). A strength of this study was that the random recruitment of individuals through the Ipsos database from across the country increased the external validity of the findings compared to the single site studies reported elsewhere in this report. Burgmuller et al. (2016) similarly reported that, of 271 patients with AMD visiting a hospital clinic in Germany over 9 months who were asked what factors have a positive influence on their disease, only 61.7% mentioned a healthy lifestyle, 53% said vitamins, and 42% of patients confessed that their knowledge of AMD was not sufficient (Burgmüller et al., 2017).

Stevens et al. (2014) aimed to characterise patients with AMD who seek the services of the Macular Society in the UK, and to determine the level and source of their knowledge about dietary recommendations for people with AMD (Stevens et al., 2014). The Macular Society is a voluntary organisation

which advocates for people with AMD, and provides services including provision of information and support (Macular Society, 2022). Stevens et al. (2014) conducted a telephone survey of 158 Macular Society members with AMD and found that just over half (55%) of the patients felt that diet was important for their eye health. Similarly to the study by Kandula et. al. (2010), the majority of patients (63%) did not feel that they had received enough information about AMD. Ninety-two percent of patients in this study got their information about AMD from the Macular Society, which most likely reflects the recruitment of participants from the membership of this society. However, it is interesting to note that awareness of the impact of diet on eye health remained low even in a group of individuals sufficiently motivated to join a patient advocate and support group such as the Macular Society.

Patient understanding of the risks associated with tobacco use and the potential benefit of smoking cessation was only investigated in one study (Caban-Martinez et al., 2011). Surveys were completed by 46 ECPs and 52 patients with AMD. 54% of the patients with AMD were not certain whether smoking caused macular degeneration and 90% of the people who smoked reported never being advised to quit by their ECP.

Overall, there is good evidence from these 5 studies (Caban-Martinez et al., 2011, Cimarolli et al., 2012, Kandula et al., 2010, Stevens et al., 2014, Burgmüller et al., 2017) that patients attending eye clinics in the UK, US and Germany do not receive sufficient lifestyle advice to ensure a high level of understanding of the possible risks and benefits associated with diet and smoking related factors. Given the patient reported survey design of these studies, it is not possible from this evidence to determine whether the deficit is in the provision of advice, or patient recall. However, this does indicate that advice which is provided is not necessarily in a format which facilitates ready recall. There is also evidence that a significant number of patients resort to voluntary organisations such as the Macular Society to plug gaps in their knowledge of their condition (Stevens et al., 2014). One area in which evidence was lacking was regarding patient preferences with regards to modes of advice provision. This is an area that has not been investigated for patients with AMD to date.

2.3.3 What is the practitioner reported experience of advice provision?

Twelve studies included in this review were based on practitioner reported experiences. Out of the 12 studies, seven papers related to diet, smoking and vitamin supplement advice, three focused solely on advice about vitamin supplements and 2 focused on smoking advice.

Lawrenson and Evans (2013) surveyed 1468 UK based ECPs (1414 optometrists and 54 ophthalmologists) about the lifestyle advice currently given to patients with AMD. Sixty-eight percent of the practitioners reported that they would always or usually provide dietary advice to patients with established AMD. Although 93% of practitioners recommended nutritional supplements to patients with AMD, for the majority the vitamins recommended did not comply with best evidence-based practice for nutritional supplementation in AMD i.e. not based on AREDS recommendations (Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013). With regards to smoking, only 32% of practitioners reported routinely taking a smoking history from patients, and 49% of the practitioners in the study reported informing patients about the link between smoking and AMD. However, 70% of practitioners took smoking history into account when recommending supplements, indicating an awareness of the possible risks of recommending certain vitamins to patient who smoke (Lawrenson and Evans, 2013).

Downie and Keller (2015) carried out an online survey of 379 optometrists in Australia and similarly found that only 47% reported routinely asking patients if they smoke, 62% reported counselling their patients with regards to diet and 91% of recommended nutritional supplements to patients with AMD (Downie and Keller, 2015). It was not clear whether the specific supplements recommended were informed by the best evidence-based guidelines, however the main supplement recommended was a high dose antioxidant which may be compliant with the AREDS formula (depending on the dosage of the specific product recommended). This is similar to the findings of Lawrenson and Evans (2013), with less than half of the ECP's in both studies taking a smoking history from patients but most ECP's recommending nutritional supplements (whether appropriately or otherwise). However, Downie and

Keller did report that most (88.5%) of respondents obtained their information and evidence base from peer reviewed journals, whilst non peer reviewed articles were used by 43.4% of respondents. This is in contrast to the finding of Lawrenson et al. (2013) that only 16.4% of respondents referred to scientific/research literature, and the majority were dependent on non-peer reviewed articles in professional journals (Lawrenson and Evans, 2013). This suggests the potential of some mismatch between the sources of information employed by optometrists in different countries.

In another study evaluating only optometrists, Sahli et al. (2020) administered postal surveys to 42 optometrists to examine the lifestyle advice that optometrists offer, to whom such advice is offered and reasons for not offering advice (Sahli et al., 2020). In contrast to the previous studies described above, this study found that 74% provided advice about smoking, 81% about the importance of a healthy diet and 79% regarding dietary supplements. The number of optometrists discussing smoking with patients with AMD was substantially higher in this study compared to others, but the percentage of practitioners offering dietary supplement advice was lower than previously reported (Sahli et al., 2020). However, the sample in this study was smaller than the other studies despite participants being contacted 3 times to encourage a response. The study had an overall low response rate (31% of 142 optometrists that were contacted) so the results may not be generalisable to the rest of the population.

Downie and Keller (2015) and Sahli et. al. (2020) only surveyed optometrists so the experience of lifestyle advice provision by ophthalmologists was not reported. This is significant as Martin (2017), looking at lifestyle advice given by optometrists (n=323) and ophthalmologists (n=48) in Sweden, reported that ophthalmologists were more likely to provide smoking cessation advice than optometrists. Lawrenson et al. (2013) also reported a higher rate of discussion about smoking cessation in their sub-analysis of ophthalmologists (as compared to optometrists, ~70% vs ~30%). Martin et al. (2017) reported that optometrists were more likely to provide advice about nutritional supplements and diet than ophthalmologists, and found that 75% of all of the optometrists and ophthalmologists surveyed would recommend nutritional supplements to

patients with late AMD in one eye and early in the other (Martin, 2017). However, Lawrenson and Evans (2013) reported that ophthalmologists were more likely than optometrists (70% vs. 26%) to offer an appropriate AREDS based formula in this situation, suggesting that the optometrists surveyed in the UK were less aware of the evidence base than their ophthalmologist counterparts. They also reported that ophthalmologists were more likely to ask about smoking history (~70%) compared to optometrists (~30%) (Lawrenson and Evans, 2013). Both studies highlighted the difference in lifestyle advice provision between optometrists and ophthalmologists, but it is worth noting that Lawrenson and Evans (2013) and Martin et al (2017) included a larger number of optometrists than ophthalmologists in their studies. However, in Europe, there are more optometrists than ophthalmologists so this may explain the difference (Statista, 2020). Furthermore, as in all such studies, the sample is self-selecting, meaning that those clinicians who choose to respond may be individuals with an increased interest in the topic, ophthalmologists who have specialised in AMD and therefore have a greater motivation to keep abreast of the relevant literature.

In a larger sample specifically targeting ophthalmologists, Aslam et al. (2014) evaluated ophthalmologists' opinion of, and use of, nutritional dietary supplements 10 years after the publication of the first Age-related Eye Disease Study (AREDS). This study surveyed 216 participants (112 general ophthalmologists and 104 retinal specialists) from 7 different European countries (Belgium, France, Germany, Italy, Portugal, Spain and UK) and found that, on average, information about the benefits of nutritional supplements was regularly given to patients with AMD by 67% of ophthalmologists (a figure comparable to the findings of both Martin and Lawrenson and Evans (Martin, 2017, Lawrenson and Evans, 2013)). Sixty-eight percent of ophthalmologists reported most commonly initiating primary prescriptions or providing advice on nutritional supplements (Aslam et al., 2014). However, no optometrists were involved in the study, and the ophthalmologists surveyed may have been unaware of advice previously provided by other healthcare professionals. A strength of this study was that ophthalmologists were asked specifically about their provision of AREDS

compliant supplements, removing any doubt about whether supplements provided were consistent with evidence-based guidelines. However, this could also be considered a limitation of this study as they did not include other variations of the AREDS supplements which may have caused this percentage to be higher.

Other studies have been more specific in the aspects of nutritional advice evaluated. For example, Larson and Cocker (2009) investigated the perceptions, recommendations and educational or informational materials of licenced Wisconsin optometrists on lutein and zeaxanthin and eye health. Although the AREDS2 findings did not support the recommendation of lutein and zeaxanthin supplements to well-nourished individuals (Larson and Coker, 2009), there is still evidence to suggest that a diet rich in xanthophylls is beneficial to slowing progression of AMD (Wolf-Schnurrbusch et al., 2015, Ma et al., 2016, Perry et al., 2009, Chong et al., 2008), and this forms part of the guidelines for patient advice of most optometric/ophthalmic bodies (Royal College of Ophthalmologists, 2021, College of Optometrists, 2021). Of the 127 practitioners in this study, 78% felt that the information available on lutein and zeaxanthin and eye health is adequate for them to make recommendations to patients. Eighty-one point one percent reported recommending lutein and zeaxanthin to patients diagnosed with AMD and 79.5% of optometrists distributed informational materials to patients (Larson and Coker, 2009).

Similarly, although AREDS2 did not find a benefit to the inclusion of omega 3 supplements in the AREDS formula, there is still evidence from observational studies (adopted by most practitioner guidelines) that inclusion of dietary omega-3, for example in oily fish, is beneficial to slowing AMD progression (Querques and Souied, 2014, SanGiovanni et al., 2007, Chong et al., 2008). Zhang et al. (2020) looked specifically at recommendations regarding omega-3 intake given to patients with AMD by 206 optometrists from Australia and New Zealand. Optometrists reported recommending omega-3 rich foods for AMD (68%) with 95% recommending fish or non-fish seafood as a source. But, in accordance with the lack of supporting evidence, only 29% recommended specific doses of omega-3 fatty acid supplements to patients (Zhang et al., 2020).

Two studies specifically assessed provision of advice on smoking cessation by practitioners (Caban-Martinez et al., 2011, Lawrenson et al., 2015). Caban-Martinez et al. surveyed practitioners (clinical faculty, fellows and residents) based in the United States about their experiences with providing smoking cessation recommendations to patients with AMD (Caban-Martinez et al., 2011). The 46 practitioners involved in the study were asked about their smoking cessation recommendation practices and said they asked about patients smoking status all the time (13%), periodically/seldom (80%) and never (7%). When asked if they advised patients to quit smoking, 28% said always, 65% said periodically/seldom and 7% said never. This is similar to the findings by Lawrenson and Evans (2013), Martin (2017) and Downie and Keller (2015) who reported that practitioners do not always ask about patients smoking status and history (Lawrenson and Evans, 2013, Martin, 2017, Downie and Keller, 2015), but this study only included ophthalmologists in a hospital setting and no optometrists. A pilot study by Lawrenson, Roberts and Offord (2015) surveying 26 UK optometrists reported that, while 77% were aware of the link between smoking and AMD, only 4% regularly took a smoking history from patients and 12% provided advice about stopping smoking to patients with AMD (Lawrenson and Evans, 2015). The most common barrier to providing smoking cessation advice was the potential effect on the practitioner-patient relationship (39%), being unsure how to raise the issue (31%) and time constraints (31%). Both studies demonstrate that practitioners are not regularly asking about smoking, despite knowing the link between smoking and AMD. The studies were also carried out in different countries, thus increasing the generalisability of the findings.

Having identified that there are limitations in the provision of lifestyle advice to people with AMD, there has been some effort to explore barriers to this advice provision. Jalbert et al. (2020) surveyed 77 eye care professionals and reported that cost/funding, patient understanding/denial, discipline silos, access/availability of services and willingness to make lifestyle changes were the most commonly reported barrier for practitioners to administer effective AMD care (Jalbert et al., 2020). As a potential solution to the issue, Gocuk et al. (2020) investigated whether performing clinical self-audit and receiving

analytical feedback improved clinical record documentation for patients with AMD and enhanced reported provision of advice to patients. To do this, they conducted an interventional audit on 50 eye care practitioners practicing and routinely managing patients with AMD. Practitioners audited their own records for patients with AMD for 3 months and were surveyed before and after the intervention. Post audit, average record documentation improved for asking about smoking status (21% to 58%), diet (11% to 29%) and nutritional supplementation (20% to 51%). Overall, optometrists' recording of having provided lifestyle advice improved. However, before the end of the study, 30/50 optometrists dropped out, with the main reason being due to the time commitment of having to audit records, suggesting that this may not be a sustainable intervention (Gocuk et al., 2021). It is also unclear from this study whether clinicians increased the frequency of advice provision, or merely became more thorough in their record keeping.

To summarise, practitioners seem to be more likely to give advice about diet and nutrition than smoking cessation advice, possibly in part because of concerns about a negative effect on the relationship between patient and practitioner of asking questions which might be perceived as being judgemental (Lawrenson and Evans, 2015, Schoenthaler et al., 2014). Between 62%-81% of ECPs reported providing advice regarding dietary change (although the upper limit of the larger studies i.e. >n=100 was 68%), while advice regarding nutritional supplements was given by between 67% and 93% (with the upper limit of larger studies i.e. >n=100 being 93%) of ECPs surveyed (Downie and Keller, 2015, Sahli et al., 2020, Lawrenson and Evans, 2015, Martin, 2017, Aslam et al., 2014). Evidence suggested that optometrists are possibly more likely than ophthalmologists to provide advice on nutritional supplements (Martin, 2017), although the advice given in this respect by ophthalmologists may be more compliant with evidence based guidelines (Lawrenson and Evans, 2013). Ophthalmologists may also be more likely to give advice about smoking cessation. However, comparison between practitioners is based on small sample sizes. Given the limitations in advice provided by ECPs with respect to lifestyle modification, further exploration of

the barriers limiting advice provision would be valuable to identify ways in which these barriers might be addressed.

2.3.4 How much of the lifestyle change advice is enacted?

Six studies included in this review examined the changes that patients with AMD made to their lifestyle following the receipt of lifestyle advice from their practitioners. Shah et al. (2015) asked the 92 patients with AMD surveyed in their study about their adherence to the lifestyle advice they were given. Adherence to diet modification advice was 81% of 47 participants who recalled advice about diet, 76% of 21 participants who recalled advice about exercise and weight reduction, and 88% of the 90 patients who recalled advice about AREDS supplementation. This suggested that advice provided by ECPs and recalled by patients did have the ability to effect a change in dietary behaviour. However, none of the 5 people who recalled being given smoking advice adhered to the recommendation.

Weaver and Beaumont (2015) aimed to understand lifestyle changes that patients make as a result of the way advice is given. They found after interviewing patients attending two different clinics (clinic 1 with a strict protocol driven regime about giving lifestyle advice and clinic 2 that had no policy), that 81.6% of patients attending clinic 1 made lifestyle changes consistent with the advice they were given compared to 44% of patients in clinic 2. However, the study did not specify what the changes were which is important as Shah et al. (2015) found that adherence differed between the type of lifestyle advice given.

Six survey-based studies specifically studied the initiation of vitamin supplement intake and dietary changes that patients with AMD made as a result of advice received. Chang et al. (2002) surveyed 108 patients with AMD recruited from a retinal specialist clinic in Canada (Chang et al., 2003). They found that 49/108 were using supplements specifically for their AMD (45%), although 85/108 (79%) were taking vitamin supplements for general health purposes. Of those taking nutritional supplements specifically for their eye health, 33/49 (67%) were using the supplements recommended by their ECP. Similar findings were reported in a study by Charkoudian et al. (2008) where

332 new and returning patients were recruited from the retina division in a hospital in the United States of America. Two hundred and forty one (72%) of the patients were taking any supplements and 70% of these patients were taking an AREDS compliant formula. However, they reported that many of the patients did not understand why they had to use the supplements (Charkoudian et al., 2008). Hochstetler et al. (2010) and Parodi et al. (2016) also both reported on the rates of adherence to vitamin supplement recommendations in patients with AMD (n=64 and n=193 respectively). In the Hochstetler et. al. (2010) study, participants were all recruited from the retina clinic of a single retinal specialist in the USA. Fifty-nine percent of the patients reported taking a vitamin supplement for AMD, with 71% of these being AREDS based. All of the participants taking supplements were recommended to do so by their retinal specialist. Seventy-five percent of the participants who did not take supplements said this was because it was never recommended to them (Hochstetler et al., 2010). Parodi et. al. (2016) also recruited patients from a single retinal clinic in a hospital based in Milan, Italy (Parodi et al., 2016). They reported that 40% of the patients were taking AREDS supplements and, similar to the Hochstetler et al. (2010) findings, 94% of the patients not taking supplements reported that this was because it was never recommended to them (Parodi et al., 2016).

The above studies (Chang et al., 2003, Charkoudian et al., 2008, Hochstetler et al., 2010, Parodi et al., 2016) all shared the limitation of recruiting participants from a single hospital site in the same country, thus reducing the generalisability of the findings. Also, the severity of AMD status of the participants was not categorised in two of these studies (Chang et al., 2003, Hochstetler et al., 2010), which is important as the AREDS trial results specifically recommended the formula for patients who have intermediate AMD or advanced AMD in the fellow eye (Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013).

Yu et al. (2014) also reported similar findings in a German cohort (Yu et al., 2014a, Yu et al., 2014b).The first study surveyed 47 patients with AMD attending eye clinics in Germany and found that 66% were recommended oral antioxidant supplements from their referring ophthalmologist, 68.1% of the

total cohort were taking oral supplements for AMD, and 21.3% had never received a recommendation for supplements (Yu et al., 2014b). The second study found that 36 out of 65 patients (55%) were taking oral anti-oxidant supplements for AMD with the most common source of recommendations being from an ophthalmologist (55.4%) and, as reported in previous studies, the main reason (69%) for not taking supplements was there being no recommendation (Yu et al., 2014a).

In summary, there was minimal evidence regarding adherence of patients to advice regarding general dietary changes, with the majority of studies focusing on adherence to vitamin supplement recommendations. The proportion of patients taking vitamin supplements for AMD in the included studies varied widely between around 40% and 68% (Yu et al., 2014a, Yu et al., 2014b, Parodi et al., 2016, Hochstetler et al., 2010, Chang et al., 2003, Charkoudian et al., 2008). It was not always clear whether these supplements conformed to AREDS guidelines. It also was not always apparent whether lifestyle changes of those surveyed were made directly as a result of ECP advice, but there was evidence from several studies to suggest that advice received from ECPs was impactful, particularly advice about nutritional supplements (Chang et al., 2003, Shah et al., 2015) and that the majority of people who were not making lifestyle changes were failing to do so because ECP advice had not been provided (Hochstetler et al., 2010, Parodi et al., 2016). There was also evidence from one study to suggest that the way in which advice is provided can have a significant impact on outcomes (Weaver and Beaumont, 2015).

2.4 Discussion

Overall, the studies included in this review have highlighted significant limitations in lifestyle modification advice provided by ECPs to patients with AMD.

2.4.1 The patient experience

This review highlights a number of key issues related to the patient experience or receiving life-style advice. Firstly, patient awareness of the risk factors for AMD in the included studies was poor. A review by Armstrong and Mousavi (2015) discussed the reported risk factors for AMD and highlighted that factors

including smoking cessation, dietary changes, and regular use of dietary supplements should all be considered to reduce the lifetime risk of AMD and that ECP's should work to increase patient knowledge of these risk factors (Armstrong and Mousavi, 2015). However, the reports in this review show that, despite the majority of patients citing their ECP as their main source of AMD information, they still believe they do not have enough information. This suggests that the information may not be provided to patients or they are not able to recall it (Bott et al., 2018, Shah et al., 2015). When advice was recalled and not acted on, patients reported that it was because they felt the change was not necessary or that they lacked understanding about how it would help, suggesting that further information about the benefit of the lifestyle change is required to enhance participant adherence to advice.

However, patient reported studies have some limitations. Firstly, patients may not want their clinician to know that they are not following advice, or may not want to make negative comments about their ECP, especially when they are surveyed in the clinics. Anonymising data may help with this, but patients may still have reservations. Secondly, there is a risk of selection bias, where participants who respond may be more motivated to take part. For example, Stevens et. al. (2014) recruited patients from a voluntary sector patient support group, which may have preferentially included people who were more inclined to engage with the management of their condition (Stevens et al., 2014). Thirdly, many of the studies (Bott et al., 2018, Parodi et al., 2016, Hochstetler et al., 2010, Burgmüller et al., 2017, Caban-Martinez et al., 2011, Chang et al., 2003, Charkoudian et al., 2008, Kandula et al., 2010, Lawrenson et al., 2015, Weaver and Beaumont, 2015, Yu et al., 2014a, Yu et al., 2014b) in this review recruited participants from single clinics. This decreases the generalisability of the results as the patients attending one clinic in one city may have different care experiences to patients in other places around the world. Finally, patient reported studies can be limited due to the incomplete patient recall of advice (Shah et al., 2015). Patients may not always remember the advice they were given so this would not have accurately represented advice provided by ECPs. However, this may also suggest that advice may not have been administered properly or in an effective enough way to help patient recall.

The overall experience of patients with AMD in the UK has been evaluated previously (Boxell et. al., 2017). The study compared patients' experiences of AMD care in 1999 compared to 2013 after the publication of commissioning guidance from the Royal College of Ophthalmologists (Royal College of Ophthalmologists, 2021). A higher proportion of patients surveyed in 2013 (n=1169) reported feeling satisfied overall with their diagnostic consultation (76% compared to 61% in 1999) (Boxell et al., 2017). Although this study did not investigate lifestyle advice specifically, studies have demonstrated that a positive health care experience can improve patient adherence (McMonnies, 2011, Rushforth et al., 2016).

2.4.2 The practitioner experience

The studies reporting practitioner experience in providing lifestyle advice for AMD found that practitioners tended to be more confident at providing advice about diet and nutrition, especially nutritional supplementation, than regarding smoking cessation. This was suggested to be at least partially attributable to concerns about a negative patient response to questions about smoking (Schoenthaler et al., 2014, Lawrenson et al., 2015). Advice on nutritional supplements was reported as being provided more frequently than advice about supplements. However, there was evidence that advice regarding nutritional supplements did not always follow the most robust evidence based guidelines (Lawrenson and Evans, 2013). There was some data to suggest that ophthalmologists might be more likely than optometrists to discuss smoking cessation (Martin, 2017, Lawrenson and Evans, 2013), and more inclined to follow AREDS (Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013) recommendations for nutritional supplement provision (Lawrenson and Evans, 2013). However, comparison between practitioners was limited by small sample sizes.

The evidence in this review suggests that (an upper limit of) around two thirds of ECPs regularly provide wider dietary advice to patients with AMD. Research in other healthcare disciplines (medical, dental and nursing professionals) indicates certain common barriers which may prevent implementation of advice regarding nutrition (Coxon et al., 2016). One factor raised (alongside the issues of insufficient time, education and resources) is that healthcare

practitioners feel that dietary advice guidelines can sometimes be unhelpfully vague. This may explain the finding in this review of increased confidence in providing advice regarding nutritional supplements, which is more specific and easily actioned, than advice regarding dietary change. It also emphasises the importance of a consistent and specific approach across eyecare regarding the best evidence-based approach to dietary modification advice in order to give confidence to practitioners in providing the advice as well as to patients in acting upon it.

All of the studies relating to practitioner experience were questionnaire based, self-reported studies about practitioners' opinions and practice behaviours. It can be argued that these studies can be biased by a desire for practitioners to appear in a positive light before their peers, and may not truly represent the views or behaviours of the ECP. Another potential issue is selection bias, whereby those individuals responding to a questionnaire may be those who are more engaged with research in this field and therefore more motivated with respect to providing patient lifestyle advice. However, these limitations mean that the self-reported lack of provision of dietary advice to people with AMD by one third of ECPs surveyed is likely to be a favourable representation of the true scale of advice provision.

An important point to consider is that the studies that were reported recently (2020 and later) (Jalbert et al., 2020, Gocuk et al., 2021, Sahli et al., 2020, Tang et al., 2020, Zhang et al., 2020) show that there are improved rates of advice provision amongst practitioners compared to earlier studies (Aslam et al., 2014, Caban-Martinez et al., 2011, Larson and Coker, 2009, Lawrenson and Evans, 2013, Downie and Keller, 2015, Lawrenson and Evans, 2015, Martin, 2017). However, this review highlights that there is still a need for further education for practitioners, specifically about the importance of smoking cessation advice. This is a key factor as the evidence regarding the increased risk of AMD onset and progression associated with smoking is irrefutable. One of the largest studies on the impact of smoking on AMD, The Blue Mountains Eye Study with 3654 patients with AMD, found a significant association between smoking and neovascular AMD (OR 3.20), geographic atrophy (OR 4.54) and early AMD (OR 1.75) compared to non-smokers (Smith

et al., 1996). There have also been a number of reviews demonstrating this link and highlighting the importance of informing patients about the risk of smoking on AMD (Thornton et al., 2005, Vingerling et al., 1996, Velilla et al., 2013). But, despite this, the 6 studies in this review that investigated smoking cessation advice given to patients, found that smoking advice was not regularly given (Shah et al., 2015, Lawrenson and Evans, 2013, Martin, 2017, Downie and Keller, 2015, Caban-Martinez et al., 2011, Sahli et al., 2020).

This finding is not unique to ECPs. A survey of 3167 general practitioners from four Scandinavian countries reported that, of the 67% who responded, the majority did not explicitly ask the patient about their smoking history unless they displayed smoking related symptoms, and few practitioners signposted smoking cessation services (Helgason and Lund, 2002). Similarly, of 149 dentists surveyed in South East England, whilst 75% recorded smoking status, only around a quarter took any kind of active role in assisting them to stop. In common with the ECPs included in this review, concern regarding negative patient response was one issue highlighted, alongside a general sense that smoking cessation advice is rarely heeded, and lack of understanding of the significance of smoking to dentistry, and organisational factors (such as limited time availability) (Watt et al., 2004). It is clear that across healthcare disciplines work is required to improve practitioner education and patient communication surrounding smoking cessation.

It is of particular concern that practitioners included in this review were also not asking about smoking history. This is crucial not just with respect to advising on smoking cessation, but also because as there is strong evidence that beta carotene supplementation increases the risk of lung cancer in smokers (Beta Carotene Cancer Prevention Study Group, 1994). This means that the original AREDS formula is not appropriate for people who smoke. The AREDS2 study group recommended giving patients lutein and zeaxanthin as a carotenoid substitute in the formula (Age related Eye Disease Study, 2013). This highlights the importance of taking a smoking history from patients, even with respect to recommending the appropriate vitamin supplement.

2.4.3 How effective is the advice at changing the lifestyles of patients with AMD?

In this review, the majority of studies reporting on adherence related to vitamin supplements. Overall, patients were taking the supplements they were recommended, but were unsure if they would help. Previous studies have shown that, when informing patients of new medication, it is important to inform them about what the medication is, how it will help and how long they should take it for as this improves adherence (Tarn et al., 2006, Brown et al., 2016). The importance of ECP advice is highlighted by the finding in this review that the main barrier to patients taking supplements was not having them recommended (Yu et al., 2014b, Bott et al., 2018, Hochstetler et al., 2010, Parodi et al., 2016).

Finally, despite the large amount of evidence showing the benefits of smoking cessation on AMD progression, with smokers having a 4-fold increased risk of progression and former smokers having a 3-fold increased risk (Tan et al., 2007), there was only one study that looked at adherence to smoking cessation advice and reported that none of the participants who recalled being told to stop smoking took the advice (0 out of 5 patients). The other studies in this review show that patients are not aware of the link between smoking and AMD and practitioners are not giving the advice to patients.

2.4.4 How can effectiveness of advice provision be improved?

There has been research into ways of improving effectiveness of advice provision to people with AMD. Stevens, Cooke and Bartlett (2018) carried out an interventional study to see if a novel educational intervention can promote healthy eating and nutritional supplementation in people with AMD (Stevens et al., 2018). The participants (n=100) allocated to the intervention group (n=49) were given a leaflet and prompt card containing advice on diet and supplements, whilst participants in the control group (n=51) were given a leaflet created by the UK College of Optometrists. All of the participants were followed up after 2 weeks, at which time there was evidence that participants in the intervention groups showed a larger increase in confidence that changing diet could slow progression of AMD, and were also more likely to make dietary changes. However, the follow up period of this study was short,

and participants were not randomly allocated to the intervention group. Another study assessed the effectiveness of a telephone delivered intervention designed for giving dietary recommendations to people with AMD (Tang et al., 2020). Participants in the intervention group (n=77) were given a 20-minute phone call every month for 4 months where they would provide advice to patients, assess their diet, help them with goal setting and arranging follow up support. The participants in the control group (n=78) were given general leaflets about AMD and were followed up briefly once a month. Participants were also given a follow up call 4 months after the study was completed. After the intervention, participants in the interventional group significantly improved their dietary intakes of green leafy vegetables compared to baseline, whilst the change in the control group was not statistically significant compared to baseline. Also, the intervention group made more overall dietary changes compared to the control group, with a significant difference being in the consumption of nuts (p=0.04) (Tang et al., 2020). Although the intervention was beneficial, the time commitment required from the ECP makes the approach challenging to instigate in routine clinical practice. However, these studies do indicate that enhanced advice provision may have an impact on adherence in this patient group.

2.5 Conclusion

In conclusion, this review shows that the lifestyle advice given to patients varies and is not consistent amongst all practitioners. Practitioners appeared to be most confident in providing advice about nutritional supplements, and least confident with respect to smoking, however nutritional supplements advised did not always comply with evidence-based guidelines. There was evidence that patients were inclined to follow advice regarding supplements provided by ECPs, and the main reason stated for not following lifestyle modification advice was that it had not been provided by the ECP and because patients were not sure if following the advice would be useful. This highlights the potential scope for ECPs to bring about a change in patient behaviour through effective advice provision. The review highlighted a need for more patient centred studies to understand the best ways of providing advice to patients as well as research regarding how to overcome the ECP perceived

barriers to effective lifestyle advice provision to facilitate the translation of research to positive outcomes.

3. The Experiences of Age-related Macular Degeneration (AMD) Patients Receiving Lifestyle Modification Advice: Co-design of the study questionnaire

3.1 Introduction

As discussed in chapter 1 and 2, there is currently no cure for AMD (Ricci et al., 2020, Hernández-Zimbrón et al., 2018, Brucker, 2009). The neovascular form of the disease may be managed with regular intravitreal injections of anti-vascular endothelial growth factor drugs, but there are no current UK licenced treatments for geographic atrophy or early/intermediate AMD. However, there is evidence that disease incidence and progression can be slowed down by making lifestyle modifications addressing the commonly known risk factors for AMD (Chakravarthy et al., 2010b), including smoking cessation, dietary changes and vitamin supplementation (Carneiro and Andrade, 2017, Mares et al., 2011, Meyers et al., 2015) .

This evidence has led to recommendations that Eye Care Practitioners (ECPs) should provide lifestyle advice to patients with AMD. The Royal College of Ophthalmologist guidelines state that patients should be informed verbally and through written information about smoking cessation services, a diet rich in fruit, vegetables, eggs and oily fish and licenced multivitamins containing the AREDS2 formula (Royal College of Ophthalmologists, 2021). These commissioning guidance and the guidance from NICE are also referenced by the College of Optometrists guidelines on AMD management t(College of Optometrists, 2021).

Despite this, research discussed in chapter 2 has shown that practitioners do not always comply with these recommendations (Lawrenson and Evans, 2013, Bott et al., 2018) and a large number of patients are not taking the recommended dosages or types of supplement (Waisbourd et al., 2007). Patients with AMD have been shown to have low awareness about the link between lifestyle modifications, such as smoking cessation (Caban-Martinez et al., 2011, Kandula et al., 2010), dietary changes (Kandula et al., 2010) and nutritional supplementation (Yu et al., 2014b, Chang et al., 2003, Parodi et al., 2016), and AMD progression (Bott et al., 2018, Burgmüller et al., 2017,

Cimarolli et al., 2012). This emphasises a need for effective communication between practitioners and patients regarding lifestyle changes in AMD (Boxell et al., 2017, Bott et al., 2018, Stevens et al., 2014).

There have been studies investigating the approach of practitioners to providing lifestyle advice to patients with AMD at medical retina clinics (Bott et al., 2018, Lawrenson and Evans, 2013, Suttle et al., 2012). However, there has not been, to our knowledge, an in-depth exploration of the experiences of people with AMD regarding the mode of delivery and type of lifestyle advice currently received. The objective of this study was to carry out a co-design activity with people with AMD to understand their experiences of receiving lifestyle advice and to help shape the questionnaires used in this thesis (see chapter 4 for details).

3.2 Methods

3.2.1 Participants

The co-design activity was reviewed and approved by City University of London, School of Health and Psychological Sciences Research Ethics Committee and in accordance with the Declaration of Helsinki. Participants self-recruited via the Macular Society research volunteer database. The Macular Society (https://www.macularsociety.org) is a charity which offers support, advice and information to people with macular disease. To be included in the co-design activity, participants self-reported a diagnosis of AMD in at least one eye. For pragmatic reasons, participants were not included in the study if they could not understand English. Due to the COVID-19 pandemic, the co-design activity took place via Zoom and therefore potential participants were excluded if they were unable to access the online platform for any reason. Potentially eligible patients were provided with the study information sheet and consent form via email. When the signed consent form had been received, participants were contacted via telephone to obtain demographic data before the co-design activity, including age, gender, date of diagnosis and diagnosing practitioner.

The co-design activity took place on the 16th and 19th of April 2021. Participants were sent a copy of the questions before the start of the session

(see Table 3.1). Verbal consent was confirmed for the co-design session to be video and audio recorded as well as verbal consent to take notes throughout the discussion. Participants were informed that the Chatham house rules would apply to maintain confidentiality.

The prompts/questions shown in table 3.1 were consistent for both groups and were read out by the female facilitator (SD). To ensure that everyone had a chance to participate in the discussion, each participant was asked in turn to relate their experience. Beyond this, to ensure minimal bias, the role of the facilitator during the co-design activity was minimal, as recommended in literature (Francis et al., 2010, Kiger and Varpio, 2020), with the main role of ensuring that all participants were given the opportunity to speak and to make sure the conversation stayed relevant to the research question (Francis et al., 2010).

1	Can any of you recall ever having been given advice by your optometrist, ophthalmologist, nurse, doctor or any healthcare practitioner about how you could change your lifestyle to reduce the chance of your AMD getting worse?
2	What does lifestyle mean to you?
3	When you were diagnosed or at subsequent appointments, what aspects of lifestyle do you remember being discussed with you?
4	How satisfactory did you find the information?
5	Did they give you any advice about how to modify these aspects of your lifestyle?
6	Did they tell you about the scientific evidence?
7	Who was it who gave you the advice? Was it when you were diagnosed, or later?
8	How was the advice delivered to you?
9	What else can you remember about how the advice was given?
10	Can you remember the actual advice given?
11	Have you ever been given any written information about your condition? How helpful was it? Do you remember what written information you were given?
12	What changes did you make as a result of the advice you were given?
13	If no, why? Could anything have been said that would have increased the likelihood of you making changes?
14	If yes, what made you do this?
15	To what extent do you think the method of delivery was important in your lifestyle change?
16	What do you think is the most effective way of delivering lifestyle advice?
17	Have you ever been given any other information about where to get additional support?

Table 3.1- Questions that were provided ahead of the co-design activity and asked to both sets of participants. The questions were read out but used as prompts for conversation.

3.2.2 Analysis

Conversations were audio recorded and transcribed verbatim. The transcripts were then analysed on a thematic coding software (Nvivo 12; QSR International). Thematic analysis was used to identify key themes and results from the co-design activity (Braun and Clarke, 2006). This technique involves six stages; familiarization; generating initial codes; searching for themes; reviewing themes; defining and naming themes and producing the report. After familiarization, key themes, issues or discussion points from the transcript were identified and put into different sections (nodes). Searching for themes involved grouping together nodes that were similar or covered similar issues. The nodes and themes were reviewed independently by the SD and supervisors (TC, AB, VVN), all of whom have experience in thematic analysis and focus group research (Taylor et al., 2020, Jones et al., 2021). Subsequently, the themes were logically ordered, and the results presented to reflect the co-design activity conversations. The full process of thematic analysis is discussed in chapter 1, section 1.10.

After the second group the research team reviewed the data and decided that additional co-design activities were not required as 'data saturation' had been reached (Francis et al., 2010). The initial sample analysis was based on the first set of data. The decision to stop after a second group was based on the stopping criterion employed that, when framework analysis was conducted of second groups data, additional relevant nodes and themes were not identified when compared to the first group analysis.

3.3 Results

A total of 6 participants took part in the co-design activity (3 participants per session). Each session lasted for 1-1.5 hours. The average age of participants was 66.3 years (SD +/- 7.5). There was an even number of males and females. Five participants were diagnosed by their ophthalmologist, whilst the sixth was diagnosed by an allied healthcare professional at the eye clinic. At the time of

the group, three out of six participants had unilateral or bilateral neovascular AMD and were regularly seeing their ophthalmologist for anti-VEGF injections, two participants had bilateral dry AMD and one participant currently had bilateral dry AMD and was being seen by their optometrist annually.

Ten key themes were identified. Figure 3.1 shows the themes in order of most to least discussed. The higher the number on the bar chart, the more commonly it was spoken about. Table 3.2 shows all of the nodes included in each theme. The sections below outline the key topics of discussion under each of these themes.

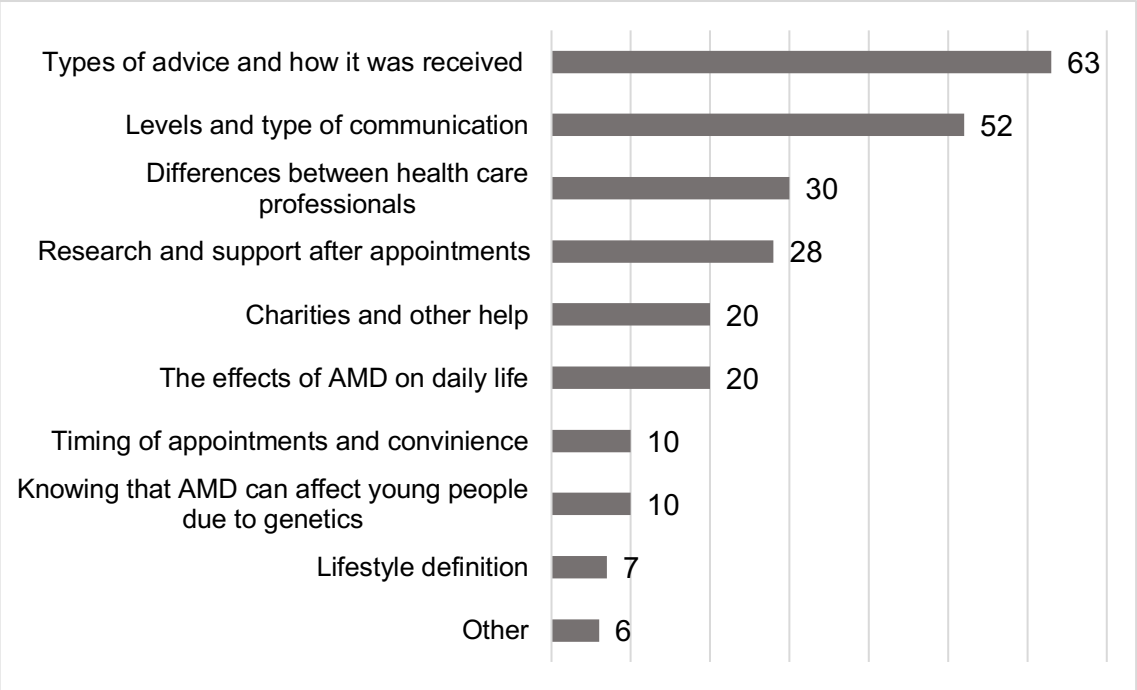


Figure 3.1- Bar graph displaying the themes that were spoken about during the co-design activity from most to least frequently spoken about. The length of each bar and the associated number represents the number of quotes in each theme, regardless of the duration of that discussion.

Nodes	Themes
Whether or not lifestyle advice was given	Types of advice and how it was received
Whether reasons for making changes were provided	
Difficulties taking in information	
Vitamins	
Whether written advice was provided	

Communication between health services	Levels and type of communication
How lifestyle advice can apply to other co-morbidities	
Setting goals	
Importance of taking an accurate patient history	
How the diagnosis was communicated	
Consultants	Differences between Health care professionals
GP	
Low vision clinic	
Opticians	
Discussion groups	Research and support after appointments
Google	
Improvement after making changes	
Aspects of lifestyle changed	
Apps	Charities and other help
Macular Society	
RNIB	
Social care	
Daily living	The effects of AMD on daily life
Public awareness	
Research participation	
Convenience	Timing of appointments and convenience
Time	
Genetics	Knowing that AMD can affect younger people due to genetics
Young people	
Lifestyle definition	Lifestyle definition

Table 3.2- Nodes included within each key theme.

3.3.1 Advice Provided

Figure 3.2 shows a word cloud of the most used terms during this part of the discussion generated using Nvivo 12 (https://lumivero.com/products/nvivo/). All of the statements that were coded under 'advice provided' were included in the word cloud generation. The word cloud generator was programmed to use

exact word matches i.e. not allowing stemmed words such as ‘talk’ and ‘talking’. The generator was also programmed to include the top 100 most frequently used words with a minimum length of 5 letters (to omit words such as ‘the’ and ‘they’). As all of the participants were a part of the Macular Society, they had all been advised previously to contact them. All participants had received some form of advice from their practitioners, with the most common advice being about a healthy diet, vitamin supplementation, smoking and sunglasses. The most common dietary advice was to eat green leafy vegetables and being told to eat ‘healthy’ or ‘sensibly’ with no specific recommendations.



Figure 3.2- Word cloud representation of the most frequently used words in the ‘types of advice and how it was received’ theme.

In some cases, no advice was provided at all at the time of diagnosis and participants were left feeling completely disempowered with respect to managing their condition. One participant reported that *‘he basically said “there is nothing we can do for you so if there are any changes, there is an open line, come back to us” but basically they didn’t want to see me again.’*

In most cases, some lifestyle advice was given, but participants largely felt that they were not informed how to implement it. For example:

“The lifestyle advice was because of my previous lifestyle which involved a lot of exposure to bright sunlight it was recommended that I wear glasses,

sunglasses, particularly with the aim to eliminating, reducing blue light. At [the hospital] itself there was no significant input on lifestyle or diet it was very much self-help. [They] did, for a period, have on the wall, leaflets, a brochure form, both on explaining what macular degeneration is and on things like diet but nothing was specifically discussed, like [P3] it was very much self-help."

"I wasn't told anything other than eat sensibly, well my sensible is probably not the same as [P1]."

"There was a strong emphasis on joining the Macular Society by the consultant, he said you'll find it a useful resource, start with that and then he advised me to go out and research it more and to stay in touch with the local Macular Society if I could."

For almost all of the participants in the co-design activity, there was a conversation with their ECP around recommended lifestyle change, however, there was a lack of explanation for the advice. Participants felt that knowing why they should make the recommended changes would motivate them more. One participant said:

'Rather than just saying you need to do "X", I would need to know why do I need to do "X", what's the benefit of doing "X"? Not in a super scientific way…'

Four out of six participants said they received written advice from their practitioners. This was either in the form of a letter or leaflet and was usually given to them following their appointment by their practitioner. However, participants did not always feel that the written advice was appropriate. A participant in the group mentioned they were given a leaflet at their eye clinic that they felt '*was actually written for children'* and described the leaflet as being one for a general healthy diet, rather than specifically for AMD. One participant also said that they were only given one minor leaflet but said *'it didn't impact me at all…the advice wasn't very specific'.*

In a more practical sense, participants discussed the logistical issues with leaflets, particularly with respect to the accessibility. One person said:

"When you do get a leaflet it's often in that smaller print, you can't read it, so it just highlights you have got an eye condition doesn't it?"

Another participant agreed with this and described reading leaflets as being a '*hassle*' so they '*try to read as little as possible*'.

Additionally, following their appointments, some of the participants were given a written letter describing the conversation they had with their practitioner during their appointment. However, in some cases, participants felt the letter did not reflect the advice they were given and described the letter as being 'cut and paste' and 'general'. The participant described what was in the letter:

"It just rambled on and said she, that's me, she was informed regarding age related maculopathy and information booklet given about two types, dry and wet and I had the dry type and there is nothing we could do about it. Was told to retain routine activity and quitting smoking and increasing antioxidant rich leafy green vegetables helps prevent further visual deterioration."

This participant thought the letter was something "*that goes out to everyone*" so it did not reflect the appointment. Finally, participants also discussed the written information available through the Macular Society. One participant, who received written information from their practitioner and the Macular Society said they had picked up some general leaflets from the hospital but said "*they were good but did not go to the extent that [I] was able to research myself through Macular Society resources"*.

3.3.2 Levels and types of communication

Another theme referenced communication between the practitioner and patient and between the different health care practitioners. An overview of the most commonly used terms with respect to communication can be seen in figure 3.3 (generated in the same way as described in section 3.3.1). Overall, all of the participants felt that there was room for improvement with regards to communication in general.



Figure 3.3- A word cloud showing the commonly used terms in the co-design activity when discussing the topic of 'levels and types of communication.'

One of the most discussed topics in the communication theme was 'time'. This was an issue for the majority of patients who described feeling as if "*they are talking at you and they don't have time. You have all these questions that you might have even written down before you get there, still they don't have time to talk to you about it"*. One participant also described their experience of going to a hospital eye clinic as being as if it were "*run like a factory*" and being '*always conscious of the queue of people"*.

When discussing how lifestyle advice fits into their appointments, it was described as having *"no facility or provision for telling people about the associated things like diet and other lifestyle issues…it wasn't part of the ethos to give that sort of information"*.

The appointment experience was described as *"bringing people in to be checked and possibly injected"*. So, because of this, participants believed it was more difficult to take in any information or advice because they know that at the end of their appointment, they will be given an injection. Similarly, participants described "*finding it hard to take anything else in"* when first diagnosed.

Participants also discussed their experiences with practitioners asking them about their current lifestyle and medical history. Overall, the participants spoke

about not feeling listened to, specifically when it came to discussing smoking cessation. One participant said:

"There was an optometrist there who was just doing a check because I noticed a change and it was him that sent a letter which just had a sentence on it 'don't smoke' or 'I talked to the patient and said not to be smoking.' I got really angry at that. I didn't say anything to him but I thought, I have never smoked a day in my life why would you even say that? He didn't even explain why you had to stop smoking if you did smoke."

Additionally, participants mostly felt as though other conditions they had were not being acknowledged or that there was a lack of communication between practitioners. One participant said they have "*not just got macular or arthritis…none of them seem to make any effort to make it all work together*". Another participant felt as though their general practitioner was not communicating with their optometrist, and emphasised that this might present a problem for people with multiple conditions requiring interdisciplinary communication.

3.3.3 Difference between health care professionals

When discussing the health care professionals involved in their care, two participants spoke about their experiences visiting their Optometrist and feeling like they did not get enough information. For example:

"The opticians didn't do anything or say anything. I found them to be absolutely useless. All my optician did was give me a peripheral vision test and tell me I've failed it."

When discussing the experience of being diagnosed, one participant said that they were not informed of their diagnosis by their optician*: "I just said to myself "why did you not tell me that? That's why I am going to your optician to tell me there is something wrong or right with my eyes." So that annoyed me."*

On the other hand, one participant felt that their experience at their optometrist was very positive*: "I have always had regular checks with my optician who was the first one to talk to me about macular and I think she does quite a lot of research herself, I think she's associated with [a university] so I was quite lucky to have her as an optician."*

Additionally, when discussing the role of a consultant or ophthalmologist, one participant said that receiving advice from a consultant *"can carry a lot of weight"* but also found that there was always a lack of time when seeing a consultant so there is not enough time to establish a personal connection.

3.3.4 Research and support after appointments

Another common theme was what participants generally do after appointments. One participant said "*I have this sort of little spell where I think I maybe need to do something a bit more without having a clue what it would be and then I go and talk to google which is probably about the worst thing you could do because by the time I have finished that I've got every disease in the land!"* This was common amongst two other participants who said their families would search the internet for answers and advice about changes they should make to their lifestyles when they were first diagnosed.

Additionally, when participants were asked what changes they made to their lifestyles after their appointments one participant said: "*I was eating green leafy vegetables anyway and I still am, eating a varied diet but I did wear sunglasses more. It's not working."* Another said, "*I feel I cope very well with the lifestyle changes I have made with regard to diet and taking the vitamins and as I said earlier I am still driving."*

After their appointments, four participants started taking vitamin supplements "*on the basis it's not going to do me any harm*".

Overall, all of the participants in the co-design activity made at least one change to their lifestyle after their appointments.

3.3.5 Charities and other help

As all of the participants were recruited from the Macular Society membership, all had previously been referred to the Macular Society for help and further guidance. The written information and leaflets from the Macular Society were described as *"helpful"* and more in depth compared those that they received from hospitals. A participant who had the Macular Society booklet said it was good as it also has an Amsler grid that they can use to monitor any changes in their vision and one participant said *"I found the self-help through the*

Macular Society fairly useful" when referring to the written information on the website.

Other help that participants received were from social care services. For example:

"I was assessed by a social worker for sensory support services who then allocated me a support worker who can come out and do stuff in the home with me and she told me everything about the Macular Society, she told me about the bus pass she told me about the low vision clinic at the hospital. She was the one who actually told me about everything. She sorted loads of things out in my house so she was my absolute saviour."

Another participant was referred to the Royal National Institute of the Blind (RNIB):

"They helped me with zoom on my mobile phone which I didn't even know was on the iphone and the ipad as well."

Overall, all of the participants in the co-design activity expressed gratitude towards the charities and social care services, particularly when it came to making lifestyle changes. All of the participants also felt that speaking to others with AMD was very helpful and would help them keep to the lifestyle changes that they are recommended.

3.3.6 Other themes

Another theme was 'daily life' where participants spoke about the daily struggles of living with AMD. One participant described the experience of AMD as having a *"loss of independence"* and thinking *"this is going to get worse"*. Another participant described their experience of lifestyle changes and AMD as being *"self help"*. The other issue participants described with AMD is a "*lack of awareness in the general public"*. One participant said *"It's almost like if you haven't got a dog or tapping the floor in front of you with a stick you're actually not got an eye condition that needs any extra care and I think, like you said, we all deal with it differently and it impacts us all differently".*

The other theme that was discussed was the convenience of appointments. One participant said that it was so difficult for them to get to the hospital for

their appointment that they would not be able to attend. They said *"I can't get there, unless they pay for a taxi. We don't do that anymore. So they are not doing themselves any favours".*

3.4 Discussion

This study highlighted a number of possible issues and gaps in the provision and efficacy of lifestyle advice currently given to patients with AMD. Firstly, the advice was not consistent for all of the participants and did not uniformly follow best evidence-based practice. Most participants were given advice about diet and vitamin supplements but not all of them were told about smoking or asked about their smoking history. The limited provision of smoking cessation advice has been reported previously (Lawrenson and Evans, 2013, Bott et al., 2018, Shah et al., 2015, Caban-Martinez et al., 2011, Downie and Keller, 2015). For example, a study looking at lifestyle advice given by optometrists (n=323) and ophthalmologists (n=48) in Sweden reported that 63% of ophthalmologists recommended smoking cessation to people with AMD, but only 12% of optometrists (Martin, 2017). A survey of patients at a medical retina clinic suggested that the provision of advice about diet and nutritional supplements was not as widespread as the co-design group suggested (Bott et al., 2018). Of 248 patients with nAMD surveyed, only 40% reported receiving advice regarding diet, and 24% recalled being recommended a nutritional supplement.

Although the importance of changing diets was mentioned to the majority of participants, the advice was often considered too generic. Also, whilst two participants were recommended AREDS supplements, two other participants were recommended different supplements not supported by the evidence base. This is consistent with the findings of Lawrenson and Evans (2013) who found that, although 93% of 1468 UK eyecare practitioners interviewed recommended nutritional supplements to patients with AMD, for the majority, the vitamins recommended did not comply with best evidence-based practice for nutritional supplementation in AMD i.e. based on AREDS guidelines (Lawrenson and Evans, 2013).

A second issue highlighted was that the participants all reported dissatisfaction with the written materials they were given by their practitioners. The advice was described as being too generalised with nothing specific for people with AMD. Furthermore, leaflets were often not presented in an accessible format i.e. with a font size appropriate for patients with reduced visual acuity. Despite this, many of the participants still believed that written information was helpful in reducing anxiety that may be caused by searching of unfiltered and unregulated information found on the internet. Effective written information can increase patients' knowledge of their health condition (Kay et al., 2016) and rate of adherence to the health advice (Chocron et al., 2021). Participants also described another advantage of written advice being that they would be able to refer back to it later which was particularly helpful when attending for an injection, when anxiety can prevent information absorption.

Another important point raised during the co-design activity was the appointment structure and feeling like there was not enough time to discuss their concerns. A UK based study, Action on AMD, found that a clinic focused on NHS patients with neovascular AMD had five key issues: clinic space, staffing, equipment, support and quality and funding (Amoaku et al., 2012). These issues were all highlighted in the co-design activity. Participants spoke about the queues, meaning they felt like they could not ask the questions they wanted because they were conscious of the number of people waiting. Reduced clinic space could mean that waiting rooms look busier, making participants feel guilty about asking questions or taking too much time. Staff shortages may also result in shorter appointment times, and tired or anxious staff and ultimately, a lower quality of care for patients (Bridges et al., 2019).

Given the association between AMD and older age, comorbidities are common in this patient group but participants in the co-design activity all believed that their other conditions were not acknowledged by their practitioner and there was a lack of communication between their eye care providers and their other health care providers. The impact of different health services not working together can be that patients are less compliant with medical advice because of having to manage different medications (Katon et al., 2004). Previous research has reported that the main issues with communication between the

different health disciplines was corporate culture, geographical distance, the multitude of processes, and formal paths of communication (Karam et al., 2018). This can result in further stress for a patient and potential missed information between services. However, when health services work together there is increased satisfaction from the patients and practitioners reporting feeling more satisfied with their interactions (Boult et al., 2008).

The co-design activity topics focused on risk factors which have been incorporated into professional guidelines for patient management (College of Optometrists, 2021, Royal College of Ophthalmologists, 2021, NICE, 2018b). For instance, although many of the participants mentioned that wearing sunglasses or UV protection was recommended to them by their practitioners, we did not include specific questions about this due to the lack of robust evidence supporting the role of light exposure on AMD incidence (Zhou et al., 2018, Tomany et al., 2004, Margrain et al., 2004).

The co-design activities conducted virtually via Zoom. Online group discussions confer many advantages including increased accessibility and lack of restriction in participation due to geographic location (Reisner et al., 2018). The use of a video platform enabled non-verbal cues to be visible during the discussion, the lack of which can be a limitation of other virtual platforms (Mann, 2000).

One limitation of the study was the small sample size of the groups. However, this was not intended to be an exhaustive survey of the advice provided across the wider healthcare system, but rather an in-depth exploration of the experiences of a group of people with AMD to identify potential issues which may be targeted in future research on a larger, more diverse sample. Another limitation was the potential lack of generalisability of the data. Sampling was a combination of convenience and purposive in this study (Shaheen et al., 2019). Participants with AMD were recruited through the convenient route of research volunteers registered with a charity (the Macular Society). Involvement with the charity may mean that the co-design activity participants were more motivated to be inquisitive regarding lifestyle risk factors compared to the general population. However, the main research question addressed in this study revolved around experiences with respect to the information

received from ECPs, especially at diagnosis, rather than around the opinions and attitudes of participants which may have been shaped by subsequent membership of the Macular Society.

3.5 Conclusion

In conclusion, the co-design activity highlighted the possible presence of considerable limitations in the mode and content of lifestyle advice provided to people with AMD. Despite the recommendations from professional bodies that advice should be provided encompassing dietary changes and smoking cessation, the co-design activity suggested that the guidelines may not be consistently followed, that advice is not always provided in a suitable format, and that some patients feel like they are not being listened to. The questionnaire studies in the following chapters aimed to further explore these themes.

4. Questionnaire Development and Recruitment Methods

4.1 Introduction

The questionnaire co-design activity described in chapter 3 were designed to aid in the questionnaire development for the main study, as it was important that this was developed based on evidence provided by patients and their experiences with lifestyle modification advice. It was also vital that the questionnaires covered topics described in previously published research on what advice eye care professionals provide to patients and how patients perceive the whole appointment experience (Lawrenson and Evans, 2013, Bott et al., 2018, Boxell et al., 2017). Thus, three questionnaires were developed, two were aimed at patients with AMD and another aimed at practitioners.

- Questionnaire one- Given to the patient at the time of their appointment was designed to investigate the experiences of patients with AMD regarding lifestyle modification advice that they may or may not have been given, as well as questions about their preferred mode of advice provision.
- Questionnaire two - Following up with patients three months after they completed questionnaire one, to investigate what factors influenced the likelihood of patients making lifestyle changes and what could motivate them to make lifestyle changes. This second questionnaire also allowed the exploration of whether the lifestyle modification advice that was given was implemented.
- Questionnaire three - For eye care practitioners (ECP's) to explore their practice behaviours and experiences with regards to the provision of lifestyle modification advice, and barriers to effective advice provision.

This chapter describes the process by which the questionnaires were developed using co-design activity data and the findings of the systematic review (chapter 2) and then outlines the recruitment process for patients and ECPs to the study.

4.2 Development of questionnaires one and two: the experiences of patients with AMD

The conversations from the co-design activity were analysed using the 'thematic analysis' technique described previously (chapter 1.10 and 3.2.2). The comments from the group were used to identify key themes around lifestyle advice and AMD. These themes were then used to create the questions for the two questionnaires. This process is highlighted in figure 4.1.

For example, one of the key parts of the conversations related to the participants' experiences related to AMD at the opticians, with the GPs and with their consultants. These points were grouped together to create the theme 'health care professionals'. This went on to form the basis of the question: 'From what source did you receive the advice?' in questionnaire 1. This process of grouping discussed topics together helped to create questionnaire one and supported the identification of any missing areas that may not have been discussed in the literature.

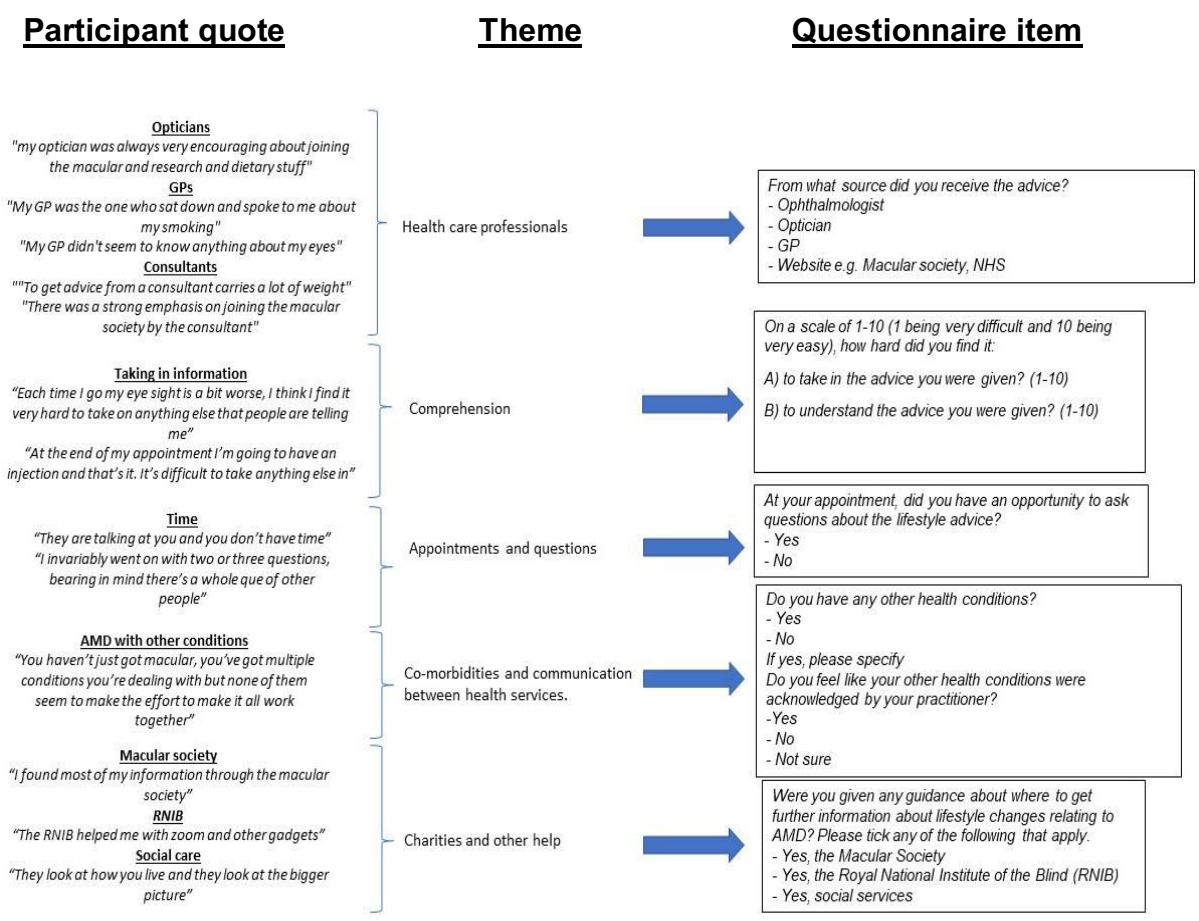


Figure 4.1- Co-design activity analysis highlighting the identification of key themes around lifestyle advice and AMD.

As described in chapter 3, ten key themes were identified from the co-design activity. These covered themes including advice, health care professionals and appointments and convenience. The conversations revealed a number of issues with the current system of lifestyle advice provision and highlighted the importance of the patient point of view. Therefore, most of the questions used in the main study were based on these discussions.

Based on the systematic review presented in Chapter 2 and key literature, gaps and themes that were not discussed in the co-design activity were also considered for the development of the questionnaires. For example, Lawrenson and Evans (2013) highlighted that only 32.3% of patients were asked about their smoking history. This was not covered in great detail during the co-design activity, but still included as a question on patient history in questionnaire one as the importance of taking a patient history has been highlighted in the AREDS study (Age related Eye Disease Study, 2001). Additionally, Boxell et al (2017) found that the overall appointment experience had improved from 1999 to 2013 leading to increased satisfaction amongst patients (Boxell et al., 2017). Therefore, the questionnaire also included a question on the patients' overall experience at their appointments. Finally, Bott et al. (2018) found that the most common reason that participants did not take vitamin supplements that they were recommended was because they did not understand how it would help (Bott et al., 2018). Therefore, in questionnaire one, two items were added regarding:

• whether or not patients felt like they understood the advice they were given.

• whether they were given reasons for why the advice is being given.

Although the reasons for lifestyle advice were covered in the co-design activity , these were not discussed in great detail. However, significant findings from the literature and the advice from governmental bodies such as NICE highlighted the importance to include this (Shah et al., 2015, Chang et al., 2003, NICE, 2018b). Figure 4.2 shows an example of how key findings from

the papers shown were used to inform some of the items in the questionnaire. For a full breakdown of how the questionnaires were created, see appendix F.

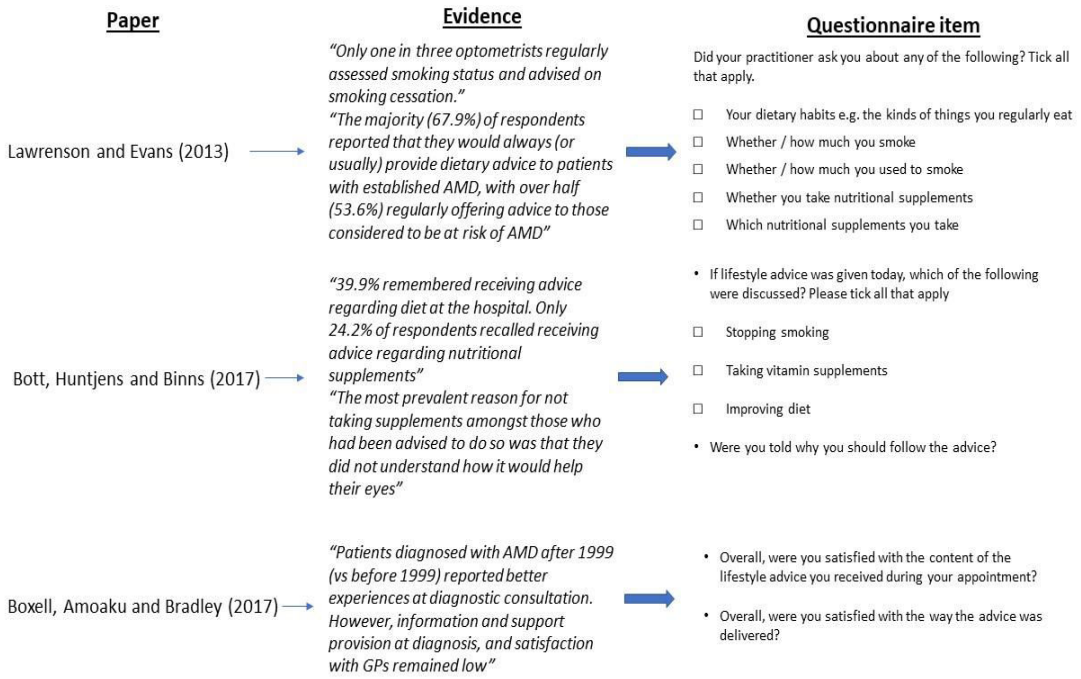


Figure 4.2- How key literature helped form questions.

4.3 Questionnaire feedback from co-design activity group

Once the patient focused questionnaires had been created, a group was conducted. The aim of this co-design activity was to gain feedback on the clarity, length and comprehensiveness of the questionnaire by inviting back the participants who also took part in the first co-design activity. The first three participants that responded to the invitation email were sent the questionnaires and were asked to complete them before meeting to discuss these. During this second group, participants were able to make any comments or suggestions that they felt would improve the questionnaires. Similar to the co-design activity process described in chapter 3.2, this group lasted one hour and took place via Zoom. The conversation was audio recorded and transcribed retrospectively.

In the second co-design activity group, the participants indicated that the questionnaires took them less than 30 minutes to complete and that were easy to read and understand. All participants felt the aim of the questionnaires was clear. Participants also believed that the formatting of the questionnaire was

clear but suggested that in some cases, responding on paper can be challenging due to difficulties staying within lines, and online formats were preferred. This would also be the case for people who use screen readers or enlarge print. Therefore, participants thought it would be beneficial to have an online version of the questionnaire and online versions of all questionnaires were created following this feedback.

Some of the questions were also changed as a result of the co-design activity group feedback. One was the question on vitamins. The initial questionnaire read 'do you regularly take any vitamins/minerals?' One of the participants indicated that the terminology in the question should be made clearer as vitamins and minerals are two different things. Another participant agreed and suggested the term 'dietary supplements'. This showed the range of terms used for vitamin supplements so the question was changed to read 'Do you regularly take any vitamins/minerals or dietary supplements?'

Another question that was discussed during the co-design activity was 'How many portions of oily fish do you eat each week?'. One participant recommended adding examples of oily fish as not everyone would be familiar with this concept. Following the feedback, the question was modified to 'How many portions of oily fish (such as sardines, mackerel, trout etc.) do you eat each week?'. In line with this feedback, another similar question asking about green leafy vegetables was also changed to include examples.

Additionally, participants felt that the question about when they were given advice was difficult to answer. This was because they had been given advice at multiple points so there was not a specific time point, they could say. This question was modified to include the option of 'On more than one occasion' to overcome this and would also allow participants to select multiple time points, if applicable. The final point from the co-design activity was related to the free text boxes provided in the questionnaires. Participants felt that there were not enough free text boxes in both questionnaires and further suggested that these should remain optional. Both questionnaires were amended accordingly to include more optional and larger free text boxes.

Participants also suggested adding more specific questions about sunglasses, family history of AMD and second-hand smoke however, it was decided that these questions would not be included as they are not directly related to the main aims of the study which were based around practice guidelines from governmental bodies such as NICE and professionals bodies such as the College of Optometrists (NICE, 2018b, College of Optometrists, 2021).

To discuss the progress of the study and to allow participants to be involved in the conduct of the research, a study steering committee was formed. This committee consisted of the study team, three patient representatives, a chair and a project advisor. During the first of these meetings, the committee were asked if they had any comments about the questionnaire. The only comment that was made was about potentially offering the participants an option to complete the study on the phone with the study team, to increase inclusivity for patients with more severe visual impairment, no access to the internet or who were house bound. The team agreed and an ethical amendment approval was approved to allow this. The study protocol, ethical approvals and amendments and final questionnaires are presented in appendix C, D, E and G.

Finally, it was decided that ECP's would be asked to complete a 'practitioner form' for each patient that is recruited onto the study. The practitioner form, presented in appendix H, consisted of a tick box for the patients diagnosis in each eye (based on the Beckmann classification discussed in chapter 1) and a free text space at the bottom for ECP's to write down any other health conditions that the patient had. By asking for these details on AMD diagnosis, and any co-morbidities it was possible to determine which advice was appropriate for that patient e.g. do they fall into the bracket of patients suitable for AREDS supplements, and are there any contraindications? The full questionnaires can be found in appendix G.

4.4 Questionnaire three: experiences from ECPs

Questionnaire three for ECPs was created using the relevant literature, the study aims, and the feedback from the co-design activity. For example, a study by Lawrenson and Evans in 2013 found that despite practitioners

providing some advice about vitamin supplements, the advice was not evidence based or based on best practice guidelines. Therefore, a question was created to find out about the sources of information currently used by ECP's.

Studies have also shown that practitioners do not always provide reasons on the importance of making these lifestyle changes (Shah et al., 2015, Bott et al., 2018). This was also highlighted as being an important factor for patients in the co-design activity (chapter 3.3). The participants in the co-design activity indicated that they would want to know the reason for the changes advised and how these would help them. In order to investigate if this approach is taken by ECP's, the following question was added: 'When delivering advice to patients, do you tell them why they should take the advice/make lifestyle changes?'.

The co-design activity group raised a concern regarding the lack of time at appointments, specifically to discuss lifestyle advice and to ask questions, (chapter 3.3). Therefore, a question about time spent discussing lifestyle factors was added to the ECP questionnaire to investigate this matter. Lastly, a question about written materials was also added as a lack of written resources was an issue heavily discussed.

Three ECPs and clinical lecturers from City, University of London were invited to attend a questionnaire co-design meeting on Zoom to discuss the questionnaire. The participants were all optometrists that were involved in teaching and research. All participants were sent a copy of the questionnaire, and a consent form a week before the meeting. The activity lasted one hour. Conversations were audio recorded and transcribed verbatim.

The ECP's agreed that the questionnaire was a good length and did not take very long to complete, they also felt that the questionnaire was easy to understand and followed a logical order. However, they suggested modifying a few questions to reflect the realistic nature of an appointment. For example, one question that was written as: 'Do you have flexibility to extend the appointment if necessary for a patient with additional needs?'. The feedback from the ECP's was that this was not realistic because in practice there are

usually several patients booked in one after the other, so extending was not an option. However, in this case, they ECP's indicated that they could usually re-book the patient for a longer appointment to discuss their co-morbidities in further detail. Following this discussion, the question was changed to 'Do you have flexibility to extend the appointment, or re-book your patient, if they have additional needs?'

Another point raised was related to the use of free text questions asking practitioners to describe the general structure of an appointment with a patient. The ECPs all said they would describe the appointment structure in the same way as it usually remains unchanged; this was discussed with the rest of the study team who agreed that this question would be difficult for ECP's to answer and may not be relevant for the study. Following this discussion, the question was omitted.

Finally, the ECP's all thought that the free text questions, or options to add free text should be worded to encourage people to write, regardless of their answer. For example, in the question 'do you ask the patient about their smoking history' one of the options was 'if no, please specify'. The ECP's suggested changing this option to 'Please explain your answer'. This would allow people to expand, whether they say yes or no and can help us understand what would motivate ECP's to ask or not ask.

All of the suggested changes were made to create the final version of questionnaire three that was used for the ECP's in the study. Table 4.1 displays the questions and the response options or free text. A fully formatted version of the questionnaire is available in appendix G and a full breakdown of how survey one and three were formed is in appendix F.

Question	**Response options**	**Free text**
1. What is your profession	• Ophthalmologist	
	• Optometrist	
	• GP	
	• Nurse	
	• Other (please specify)	
	• Independent practice	

2. In what setting do you perform eye examinations? (tick all that apply)	• Multiple practice (Specsavers, boots opticians etc.)	
	• Domiciliary	
	• Hospital	
	• University clinic	
	• Other (please specify)	
3. Please provide the first three digits of your practice postcode (if you work in multiple locations, please provide the postcode of your principle place of employment)		Free text question
4. How many years have you been practicing?	• Less than a year	
	• 1-3 years	
	• 4-6 years	
	• 7-10 years	
	• More than 10 years	
5. What gender do you identify as?	• Male	
	• Female	
	• Other (please specify)	
	• Prefer not to say	
6. Approximately, how many patients on average do you see per week?	• Less than 20	
	• 21-40	
	• 41-60	
	• More than 60	
	• Don't know	
7. How long is your average appointment duration for an older adult (aged 60+ years)?	• Less than 20 minutes	
	• 25 minutes	
	• 30 minutes	
	• 35 minutes or more	
8. Are visual fields screening, tonometry and any imaging performed within your appointment time, or are these tests carried out in a pre- or post-screening window?	• I do these tests myself within the appointment	
	• These tests are usually carried out separately	
9. Do you have flexibility to extend the appointment, or re-book your patient, I they have	• Yes	Free text option
	• No	
	• Comments	

additional needs e.g. pathology?		
10. Do you feel that you have sufficient time to spend with each patient?	• Yes always • Usually • Sometimes • Rarely • Never • Comments	Free text option
11. Do you ask the patient about their current and history of smoking?	• Yes • No • Sometimes	
12. Please explain your answer		Free text question
13. Do you ask patients about their current dietary habits?	• Yes • No • Sometimes	
14. If no, specify why not		Free text question
15. If yes, what questions do you ask?		Free text question
16. Do you ask any other questions about the patients current lifestyle?	• Yes • No	
17. If yes, please specify what questions you ask.		Free text question
18. Do you advise your patients to make lifestyle changes when they are diagnosed with AMD?	• Yes • No	
19. Please explain your answer		Free text question
20. If yes, approximately how many minutes, on average, do you spend discussing lifestyle factors?		Free text question
21. Please explain your answer		Free text question
22. If yes, how do you deliver the advice? Please tick all that apply.	• Face to face discussion • I give them written information (letter or leaflet) • I refer them to voluntary sector	Free text option

	groups (e.g. The Macular Society)	
	• I refer then to appropriate websites e.g. NHS	
	• I refer them to their GP practice for help	
	• I refer them to NHS quitting smoking services	
	• Other (please specify)	
23. What written material do you provide your patients?	• A personalised letter describing the conversation that we have in clinic	Free text option
	• A leaflet to provide some overall guidance	
	• Contact information for charities and other help	
	• Links to different apps and web pages	
	• I don't provide written advice	
	• Other (please specify)	
24. When delivering advice to patients, do you tell them why they should take the advice/make lifestyle changes?	• Yes	
	• No	
25. Please specify why not.		Free text question
26. What sources of evidence do you use to inform your views on the benefits of lifestyle changes in AMD?	• Prior knowledge from undergraduate degree	Free text option
	• Knowledge from continuing education resources i.e. CPD/CET training	
	• Articles from professional journals	
	• NICE/RCOpth guidelines	
	• Expert opinions	

	• Conference presentations	
	• Systematic reviews	
	• Discussion with peers	
	• None of the above	
	• Other (please specify)	
27. When providing lifestyle modification advice, do you consider other aspects of the patient's general health. For example, the number of tablets they may currently be taking when suggesting vitamin supplements?	• Yes	
	• No	
28. Please provide further details.		Free text question
29. Do you follow up at subsequent appointments by asking the patient about any changes they have made to their lifestyle?	• Yes	
	• No	
30. If no, please specify why		Free text question
31. What do you perceive as being the main barriers to patients adhering to advice provided?		Free text question
32. Can you think of anything that would make it easier for you to provide the best advice?	• Better access to training updates	Free text option
	• More written resources to provide the patient	
	• Longer appointments	
	• A specialist advisor in the practice who could have lifestyle advice discussions with the patients after each appointment	
	• Websites/Apps	
	• Other (please specify)	

Table 4.1- Table showing the questions from survey three along with the response options and which questions included the option for free text.

4.5 Recruitment methods

Participants were approached by the eye care practitioners and/or recruitment co-ordinators at each site. To be included in the study, participants had to be over the age of 40 with a confirmed diagnosis of AMD in at least one eye (based on the Beckman Classification). The study exclusion criteria included a diagnosis of late-stage AMD in both eyes or more than 3 anti-VEGF injections in their first diagnosed eye. Participants were also excluded if they had any other conditions such as diabetic retinopathy or glaucoma and if they could not read or understand English.

Professionals (ECPs) and research teams from hospital eye clinics and high street optometry practices were recruited to distribute questionnaire one to eligible patients. ECPs were instructed to provide questionnaire one, an information sheet, a consent form, and a pre-stamped envelope. Meetings were scheduled with ECP's from each site which included a short presentation to provide them with training and information on how to approach patients and explain the study to them. Furthermore, ECPs were also trained on the specific inclusion and exclusion criteria of the study and provided with the opportunity to ask any questions they may have. Participants could then take the questionnaire home with them to complete in their own time. For each patient that was recruited, practitioners were asked to complete a short form about the patient's diagnosis, stage of AMD in each eye and if they had any non-ocular co-morbidities (see appendix J).

The questionnaire was also offered as an online version if participants wished. In this case, participants were given the information sheet as well as step-by-step instructions of how to access and complete the questionnaire online. Their participant number was highlighted as well as contact details for the study team if they had any issues with the questionnaire. Participants were also offered the option to complete the questionnaire via telephone.

For both versions of the questionnaire, participants were given the option to consent and provide their contact details if they wished to be a part of the

follow up questionnaire. They were also given the option to opt in to receive a summary of the results at the end of the study. This was given as a separate page to ensure that all data was kept anonymous.

4.5.1 Recruitment of hospital eye clinics and optometry practices

When applying for the NHS ethical approval, we were offered the option for our study to be CRN portfolio adopted. This meant that our study would be offered support from the NIHR CRN portfolio team by providing us with funding for accruals, advertising our study to a network of hospitals and providing us with staff to support the conduct of the study to optimise recruitment. The study was advertised via the North Thames CRN and interested hospital sites were invited to submit an expression of interest if they could help with study recruitment. Upon receipt of the expressions of interest, local information packs were sent as per the Research Ethics Committee regulatory processes. The packs contained all of the essential study documentation, including the study protocol and ethical approvals (see appendix C and D). The hospitals sites were given the green light to start recruitment once a virtual site initiation meeting was held to ensure that the study was ready to begin, confirm the understanding of the participant eligibility criteria in the site, and to discuss any potential logistical issues.

The study recruitment at each hospital began, once an approval from the relevant hospital research and development department was received in the form of a letter confirming that the site had the capacity and capability to recruit participants for this study.

In total, 10 hospital sites in England participated; Moorfields Eye Hospital, University Hospitals Birmingham NHS trust, Huddersfield Hospital, Sheffield Hospital, Princess Alexandra Hospital, James Paget Hospital, Barking Hospital, Leicester Hospital, Rotherham Hospital and Coventry and Warwickshire Hospital). Another hospital (Barts NHS trust) also expressed interest but were unable to issue a confirmation of capacity and capability for their site due to staff changes and time restrictions. Therefore, the 10 sites were included to represent a range of geographical locations across England.

High street optometry practices were also recruited to help distribute questionnaires for this study. This was more challenging, as the financial benefits afforded to participating hospitals by the CRN portfolio adoption was not available to community optometrists. Optometrists were recruited via Local Optometric Committees (LOC), university clinic supervisors and social media e.g. Twitter and Facebook. For example, to increase the recruitment of optometrists who could support the study, this was advertised on the twitter pages of the College of Optometrists and also those of some local LOCs (See figure 4.3 for examples). Seventy-five LOCs in England were contacted, about presenting at their events or if they were able to advertise the study to their members via email or in their newsletter. As a result, a short summary of the study was presented at six LOC meetings about the study and all optometrists were invited to get in touch if they were interested. Ten of the LOCs contacted agreed to advertise the study to their members. Finally, optometrists working at City, University of London's eye clinic as visiting clinical tutors were also approached in person and during their beginning of year induction event. The study was presented during the induction, and the optometrists were provided with contact details for expressions of interest. Once optometrists got in touch and confirmed that they would like to help with the study, they were posted the study packs (described in section 4.4.2) and provided with any other assistance they required. In total, 24 community optometrists took part.

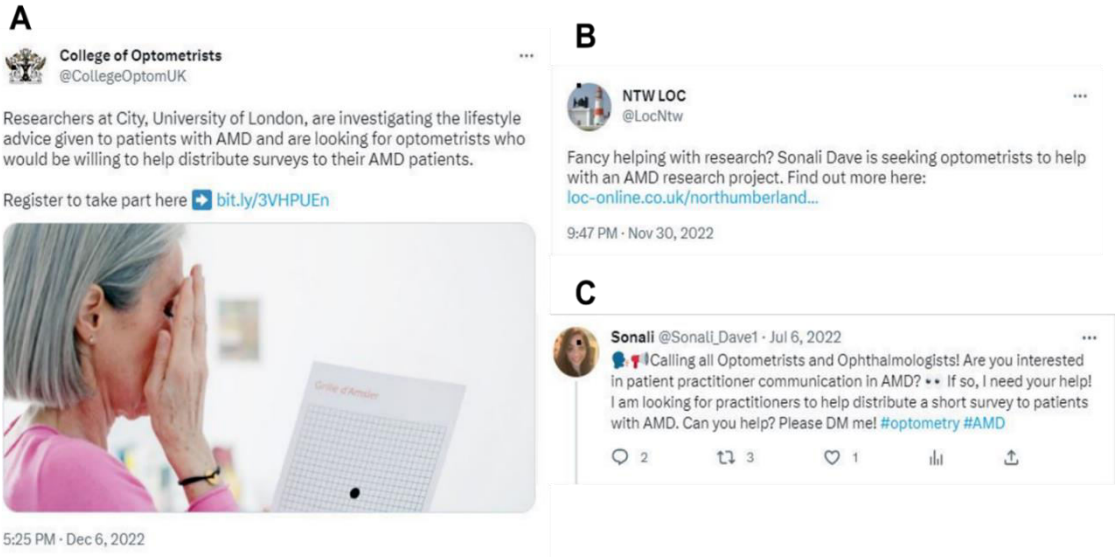


Figure 4.3: Examples of social media adverts. A. Tweet from College of Optometrists, B. Example tweet from one of the LOCs (Northumberland) and C. A tweet from SD's social media account.

Sample size calculations were conducted using a prevalence estimate for AMD and a confidence level of 95% (p=0.05) and allowing for a 5% margin of error in responses. A total of 384 participants were required for any findings to be generalisable to the population of patients with AMD (Minassian et al., 2011). An additional 10% of patients recruited will allow for uncompleted surveys.

4.5.2. Participant recruitment

Study packs for the participants were assembled to assist the staff at the sites. These contained a questionnaire, consent form, practitioner form and pre-stamped envelope. This meant that when handing it over to eligible patients when they attended for their appointments, all staff would need to do is remove and complete the practitioner form. Patients were also given the option to complete the study via telephone with a member of the study team.

For the portfolio adopted sites, when a questionnaire was received from a participant, SD counter-signed, scanned and sent the forms to the sites for recruitment numbers to be recorded.

Logistically, the recruitment of participants from the hospital sites was the same, except for Moorfields Eye Hospital. As this hospital site was intended to be a main source of recruitment for the study, and due to the hospitals research logistics, the procedure for identifying and recruiting participants was different. In this hospital, potential participants were obtained via the hospital databases and clinic lists provided by the research team. Using the hospitals electronic patient information system (OpenEyes), lists were screened for potentially eligible patients based on their hospital notes and previous clinic letters to ensure they met the inclusion criteria. Then, eligible patients were contacted by SD via telephone and/or post, or (for the patients due to attend the hospital clinics), SD approached them in person. Importantly, participants were informed that they do not have to take part and could withdraw at any time without giving a reason.

ECPs were recruited to take part in questionnaire three. All practitioners who took part in the recruitment of participants for questionnaire one were invited to complete the online questionnaire via email. Additionally, ECPs who did not take part in the first part of the study were also recruited via social media, the university clinics and the LOCs, who were provided with an email to send to their members containing the online link for survey three. The hospitals sites were also asked to email their staff with the questionnaire link and study information to encourage recruitment. For the ECPs to take part, the only requirement was that they should see patients with AMD on a regular basis.

Recruitment was encouraged by enrolling all of the participating optometrists into a monthly prize for the most number of participants recruited. Optometrists were informed if they had won each month and were also give reminders to recruit. Furthermore, regular newsletters were also sent to participating optometrists to keep them updated on the progress of the study.

For the hospital sites, regular meetings were arranged with the research team for each site to discuss ways in which recruitment could be improved. The recruitment techniques from the best performing sites were also shared with all of the participating sites so that the ideas could be implemented. The hospital sites were required to upload recruitment figures to EDGE (the NHS clinical research management system) and were also able to see how other sites were performing.

Finally, once participants were recruited and their completed questionnaires were received, a copy of the consent form was sent to the sites to ensure that the recruitment numbers were consistent.

5. The Patient Experience of receiving lifestyle advice regarding AMD

An abridged version of this chapter is under review for publication (Dave, S., Binns, A., Vinuela-Navarro, V., Callaghan, T. (2024) The Patient Experience of receiving lifestyle advice regarding AMD in primary care. See Appendix L). Author SD was responsible for contributing to the study design, collecting the data, analysing the data, and writing the manuscript. The other authors also contributed to study design and reviewed the manuscript draft. The STROBE checklist for this chapter is provided in appendix I.

5.1 Introduction

The progressive nature of AMD, and the evidence that lifestyle risk factors may have an impact on the rate of progression (see chapter 1, section 1.6), highlights the importance of early detection and modification of lifestyle. Therefore, as discussed in chapter 1 (section 1.7.1), practice guidelines are clear in emphasizing the importance of practitioners recommending these lifestyle changes to patients. The guidelines are also clear in the nature of the advice and how it should be presented to patients. For example, the guidelines from NICE emphasise the importance of providing information to patients that is 'available on an ongoing basis' and 'tailored to the person's needs'. Additionally, patients should also be provided with information in an 'accessible format' for them to take away at their first appointment (NICE, 2018b).

There are a number of studies on non-ocular conditions that demonstrate the positive impact of lifestyle advice/interventions on disease progression (Burch et al., 2023, Gemine et al., 2023, Wagnew et al., 2023, Barmentloo et al., 2021). Stead et al (2013) conducted a review of the effectiveness of physician provided smoking cessation advice in a variety of diseases and found that, across 42 trials mainly in a primary care setting, simple advice provision had a small but significant effect on the likelihood of stopping smoking. The quit rate increased from 2-3% (unassisted) by an additional 1-3%. There was little increase in the effect provided by additional components or more intensive interventions (Stead et al., 2013). Another systematic review considered the

effectiveness of a brief intervention in a primary care setting on lifestyle in diabetes patients. They reported that there was no strong evidence regarding the effectiveness of brief interventions, however cited studies demonstrating health benefits associated with such interventions, and indicating that these may be nearly as effective as more intensive intervention programmes (Price, 2012). Brief interventions are also recommended by NICE as an effective evidence based intervention (NICE, 2023).There is limited research on the impact of lifestyle advice on ocular conditions, however there is evidence that certain patients are more likely to respond to the advice. For example, Tan et. al., (2018) reported that visually impaired people that received advice and support were more likely to be compliant with eye care appointment attendance. Alhujaili et. al. (2024) reported that patients with diabetic retinopathy that had frequent eye exams had a greater adherence to lifestyle advice and long-term diabetics who were aware of the risk of developing diabetic retinopathy were also more likely to follow advice (Alhujaili et al., 2024).

The evidence points to greater success rates in changing behaviours of patients if they are provided with education, advice and support (Wagnew et al., 2023, Lindström et al., 2003). There is also evidence that brief intervention may be as effective as a more intensive strategy (Price, 2012, Stead et al., 2013). Yet, despite the research showing the positive impact of even brief lifestyle modification advice on people with various health conditions, the evidence from research on different ocular conditions suggests a lack of advice provision (Yu et al., 2022, Sahli et al., 2020, Boxell et al., 2017). As discussed in chapter 1 (section 1.7) and chapter 2 (section 2.3), there is evidence to suggest that patients with AMD are not consistently being given sufficient information and advice. The systematic review presented in chapter 2 highlighted a need for more patient centred studies to understand the best ways of providing advice to patients.

The aim of this study was to investigate the experience of patients with AMD of receiving lifestyle advice and to understand their perspective on their experiences and preferred mode of advice provision.

5.2 Methods

5.2.1. Participants

Four-hundred and sixty-five people with AMD were recruited to complete the first survey of this PhD study between April 2022 and August 2023. Participants were recruited via ten hospital sites and twenty-four optometry practices in England (for a full description of how these sites were recruited, see chapter 4.5.2). To be included in the study, participants had to have a diagnosis of AMD in at least one eye. Information regarding diagnosis was provided by the ECP that recruited the participant. Participants were excluded if they had a diagnosis of end-stage AMD in both eyes or had received more than 3 anti-VEGF injections in their first diagnosed eye, if they had any other conditions such as glaucoma and diabetic retinopathy and if they could not read or understand English. All of the participants were provided with an information sheet and contact information for the study team if they had any questions. Participants all provided written informed consent to participate in this study.

5.2.2 Questionnaire

As discussed in chapter 4, the patient informed survey was distributed to eligible patients via the hospital eye clinics and optometry practices. Based on the methodology described earlier (chapter 4 section 4.2) and the aims of the study, survey one was created and split into three sections.

The first section included questions about the participants' demographic information (i.e. age, gender, ethnicity), smoking status (i.e. current smokers, ex-smokers) and information about participants' current lifestyle practices. These questions included how many portions of oily fish and green leafy vegetables patients consume per week and whether or not they wear sunglasses. These questions helped establish the participants current habits and to investigate predictors of changes in lifestyle reported in the follow up survey.

The second section was focused on the participants' experiences of receiving their diagnosis and any lifestyle advice they may have received before their most recent appointment. This section focused on who participants were

diagnosed by, how long ago they were diagnosed, and whether or not they had ever received any lifestyle advice since their diagnosis. This section also explored the source of advice and whether or not they had made any changes to their lifestyle as a result of the previous advice they were given.

Finally, the third section explored the patients' experience of their most recent appointment. Participants were asked what questions practitioners had posed about their lifestyle habits and whether or not they received any lifestyle advice. Additionally, this section included questions about whether or not patients were recommended vitamin supplements (as well as which one they were recommended if they could recall), or if they were given any written advice. Additionally, to further understand the patient experience, this section included questions exploring whether participants were told why they should make lifestyle changes, how difficult they found it to understand and take the advice in and if they were told where they could get further guidance on AMD. Lastly, participants were asked about their preferred mode of advice provision as well as reasons for their choice.

Participants were all given the option to complete the survey online or by telephone as well as on paper. See appendix G for the full questionnaire.

5.2.3 Data analysis

The quantitative data collected from this survey was analysed using Microsoft Excel for frequencies and percentages and IBM SPSS 25 was used for in-depth descriptive analysis. Standard deviations and histograms were used to determine if the continuous data was normally distributed. Cross-tabulations were used to display contingency tables and describe associations between groups, and chi-square tests of independence were used to test for the statistical significance of the associations. For certain questions that were based on lifestyle changes made as a result of advice given (section B), logistic regression models were used to analyse the relationship between the observed count (i.e. whether changes were made) and the explanatory variables such as demographic information, source of advice and when the advice was provided. Finally, for the questions that used likert scales (rating understanding and ease of taking in advice), Kruskal-Wallis H tests were used

to compare differences between groups (written advice vs. no written advice and reasons for lifestyle changes given vs. no reasons given). A p-value of <0.05 was considered to be statistically significant. For the free text question responses, the frequency of words and phrases used to describe the patient experience were thematically analysed using Microsoft Excel and NVivo12. For the familiarisations stage, the data was transcribed from the questionnaires into Microsoft Excel and imported onto NVivo 12 for coding. The initial codes were generated e.g. mentions of eating more fruit and vegetables was entered into the code 'Fruit and veg'. The nodes were then reviewed to search for themes in the data, for example, the node 'fruit and veg' was grouped into the theme of 'diet'. The themes were reviewed again to ensure they were well defined. These nodes and themes were independently reviewed by supervisor TC and any disagreements were taken to supervisors AB and FVN for final decisions. For a full description of the thematic analysis methods used see chapter 1, section 1.10, and section 3.2.2.

5.3 Results

5.3.1. Participants and demographic information

Sixty-one participants were excluded due to no/incomplete consent forms (n=55), incorrect diagnosis (n=5) and incomplete questionnaires (n=1). In total, 404 participants were included in the survey. The majority of participants were recruited via hospital eye clinics (n=398) and six participants were recruited via high street optometry practices. Figure 5.1 shows the distribution of participants across recruitment sites. The site that recruited the highest number of participants was Moorfields Eye Hospital, including their 'hub' sites that are based in smaller areas outside of central London. The site with the second highest recruitment was Huddersfield Hospital.

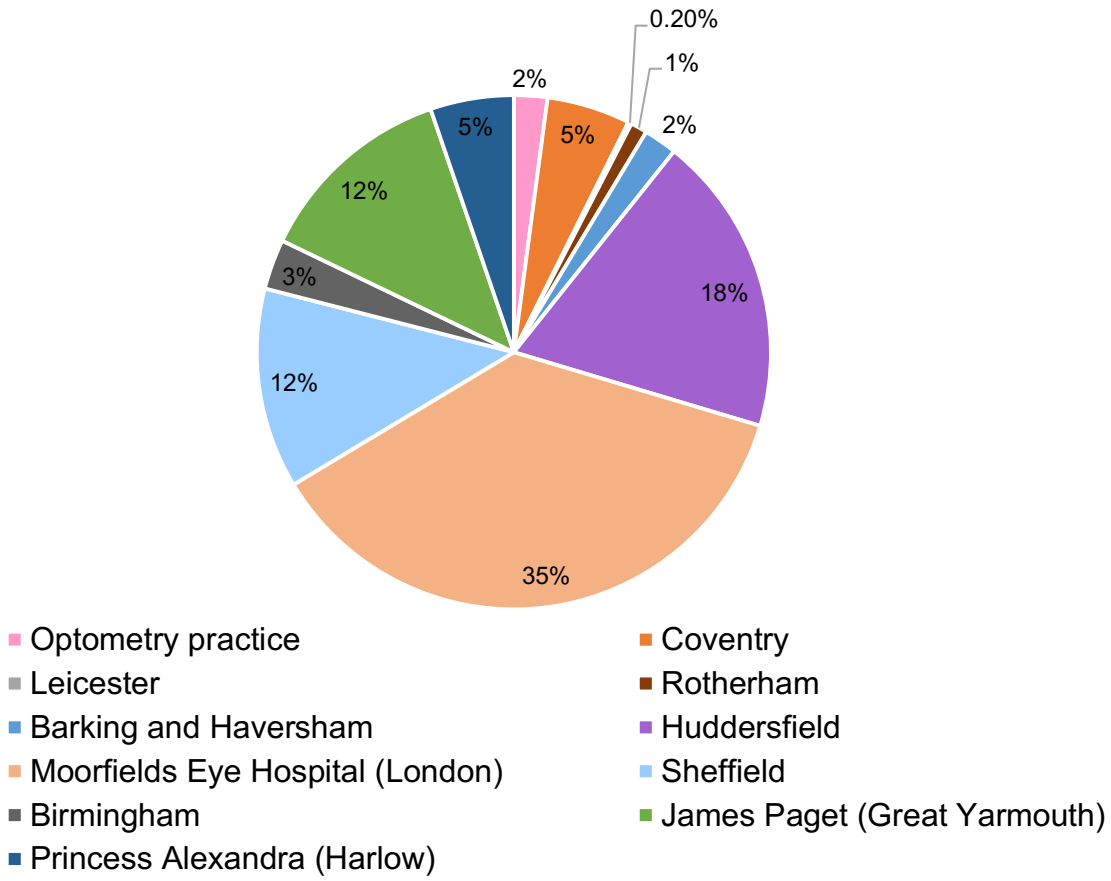


Figure 5.1 - Pie chart showing recruitment percentage distributions between the hospital sites and optometry practices.

Table 5.1 shows the participants' diagnosis. The majority of participants had bilateral late AMD, however all of these were within the first three rounds of

injections in their first diagnosed eye. The second most frequent diagnosis was one eye intermediate, one eye late AMD. Thirty-eight participants had other ocular conditions, with the most common being cataracts and pseudophakia. A full list of conditions can be found in Appendix J. In terms of demographics, the majority of participants were female (n=244; 60.4%) and were in the 71–80-year age bracket (n=172; 42.6%). English, Welsh, Scottish, Northern Irish or British was the most commonly reported ethnicity (n=359; 88.9%) and roughly half of participants reported that they lived with a partner, carer or friend (n=205; 50.7%). Table 5.2 shows a summary of participant demographic information.

Diagnosis	**Frequency (%)**
Bilateral late AMD	89 (22%)
One eye intermediate, one eye late	83 (20.5%)
Bilateral intermediate AMD	77 (19.1%)
One eye early, one eye late	68 (16.8%)
Unilateral late AMD*	33 (8.2%)
Bilateral early AMD	28 (6.9%)
One eye intermediate, one eye early	12 (2.9%)
Missing diagnosis	6 (1.5%)
Unilateral intermediate AMD*	4 (1%)
Unilateral early AMD*	4 (1%)

Table 5.1- Table displaying the participants diagnosis information. *- Indicates participants with AMD in one eye but no AMD in the other.

On the subject of lifestyle habits, 54.2% (n=219) of participants were already taking vitamin supplements, 55.9% (n=226) ate 1-2 portions of oily fish per week and 36.1% (n=146) consumed green leafy vegetables 1-2 times per week or 3-5 times per week (n=154; 38.1%). Finally, participants were asked if they wore sunglasses and the majority of participants responded 'yes-always when I go outside and it's bright' (n=159; 39.4%). Age was significantly associated with whether or not participants were taking vitamins (X^2 [df=16, n=401]=28.99 p=0.03) and whether or not they wear sunglasses (X^2 [df=16,

n=401]=34.14 p=0.005). Older participants (71-80 years old and over 80 years old) were more likely to take vitamin supplements and wear sunglasses than the younger age groups.

	Frequency (%)
Gender	
Female	244 (60.4%)
Male	157 (38.9%)
Prefer not to say	3 (0.7%)
Age	
Under 50	1 (0.2%)
51-60	5 (1.2%)
61-70	53 (13.9%)
71-80	172 (42.6%)
Over 80	170 (42.1%)
Prefer not to say	3 (0.7%)
Living situation	
Live with partner/carer/friend	205 (50.7%)
Live alone	150 (37.1%)
Live with family	39 (9.7%)
Live in supported accommodation	4 (1%)
Prefer not to say	3 (0.7%)
Ethnicity	
English, Welsh, Scottish, Northern Irish or British	359 (88.9%)
Irish	8 (2%)
Any other white background	9 (2.2%)
White and Black Caribbean	1 (0.2%)
White and Asian	2 (0.5%)
Any other mixed or Multiple ethnic background	1 (0.2%)
Indian	10 (2.5%)
Pakistani	2 (0.5%)
Chinese	2 (0.5%)
Any other Asian background	3 (0.7%)
African	1 (0.2%)
Caribbean	2 (0.5%)
Any other ethnic group	1 (0.2%)
Not specified	3 (0.7%)

Table 5.2- Prevalence of participant demographic factors

5.3.2. Participant experience of advice provision prior to the most recent appointment

The second section of the survey focused on the participants' diagnosis and lifestyle advice experience prior to their most recent appointment. Out of the 398 participants that responded to the question, the majority were diagnosed

by their ophthalmologist (n=130; 32.7%) or optometrist (n= 244; 26.3%). The remaining participants were diagnosed by their GP (n=3; 0.8%), both their optometrist and ophthalmologist at the same time (n=3; 0.8%) or another source (n=18; 4.5%) such as during a diabetic eye screening or private health screening. Figure 5.2 shows when participants were diagnosed. Most of the participants were diagnosed in the last year (n=152; 37.9%).

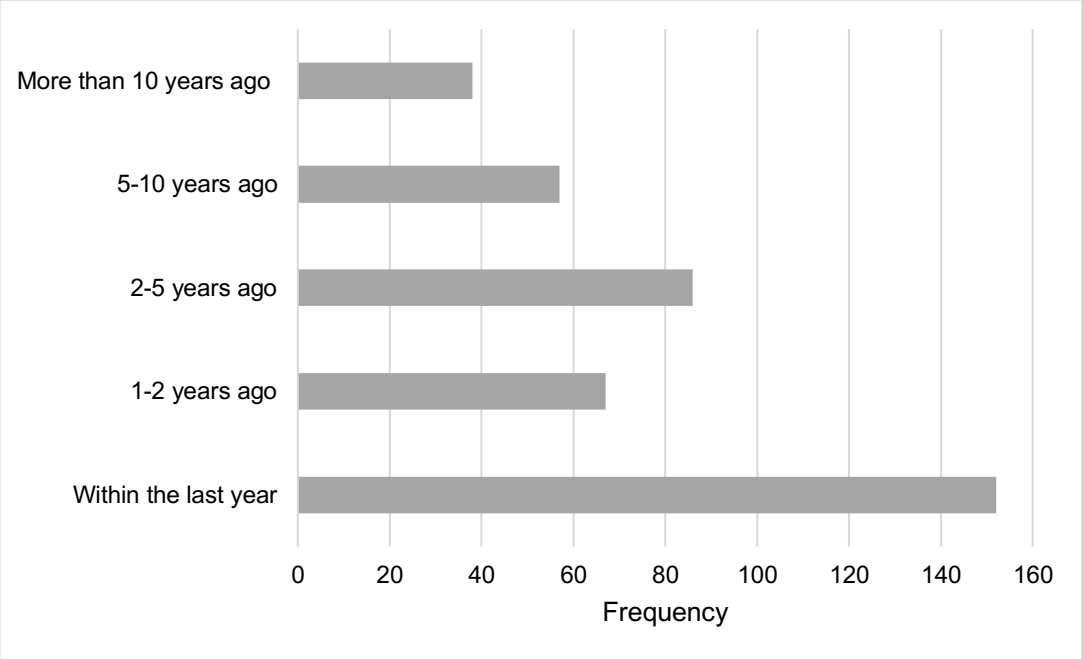


Figure 5.2- Bar chart showing the distribution of responses to the question 'How long ago were you diagnosed?'

A total of 371 participants answered the question about whether they had received any lifestyle advice before their most recent appointment. Out of these participants 66.3% (n=246) reported that they had not previously received any lifestyle advice regarding their AMD and 33.7% (n=125) reported that they had received advice. Higher age was significantly associated with whether participants recalled having received any advice previously (X^2 [df=5, n=371] =19.3 p=0.002) but there was no association with any other demographic factors. There was a significant association between when participants were diagnosed and whether they had received any lifestyle advice before their most recent appointment (more recent diagnosis was associated with a higher likelihood of recalling receiving advice) (X^2 [df=4,

n=215] = 130.5 p= <0.001). The model explained 6.5% of the variance (Cox & Snell R^2 = 0.065) and correctly classified 59.9% of cases.

Participants that reported receiving lifestyle advice before their most recent appointment (n=125) were asked if they made any lifestyle changes according to such advice provided (see figure 5.3). 63% (n=79) reported that they did make changes on the basis of the advice received. There was a significant association between when the advice was given and whether lifestyle changes were made, with advice provision around the time of diagnosis being associated with a greater likelihood of making changes (X^2 [df=5, n=116]= 11.6 p=0.04). However, there was no significant association between the source of the advice and whether any changes were made X^2 [df=15, n=116]= 16.3 p=0.361. None of the participants' demographic information (age (X^2 [df=5, n=187]= 8.60 p=0.13), gender (X^2 [df=2, n=187]= 3.42 p=0.18), diagnosis (X^2 [df=9, n=187]= 6.65 p= 0.67), ethnicity (X^2 [df=10, n=187]= 11.34 p=0.33) or living arrangements (X^2 [df=4, n=187]= 3.06 p=0.55)) were significantly associated with likelihood of making lifestyle changes. The model explained 18% (Cox & Snell R^2 = 0.18) of the variance in likelihood of making lifestyle changes and correctly classified 70.7% of cases.

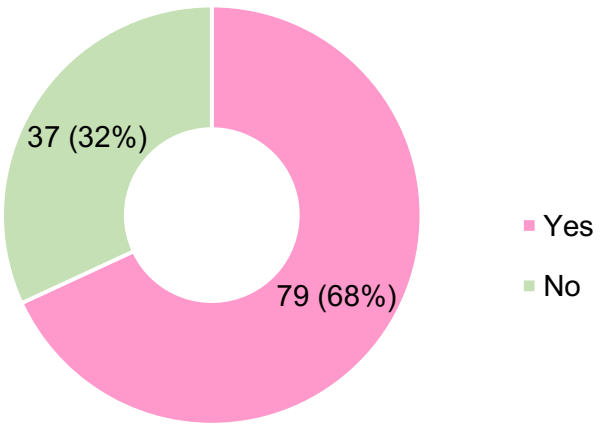


Figure 5.3- Pie chart displaying the percentage of participants that did or did not make lifestyle changes if they reported receiving lifestyle advice before their most recent appointment.

Participants that reported being given lifestyle advice before their most recent appointment were also given the opportunity to report what advice they were given as a free-text response. Table 5.3 shows the nodes and themes derived from the thematic analysis on these responses. The most commonly referred to type of advice given was 'dietary' and 'vitamins and medication'. Figure 5.4 shows the frequency of nodes and references within each theme. Key quotes from these themes are shown in table 5.4.

Theme	Node
Diet	Fruit and Veg
	Green leafy veg
	Healthy diet/eating
	Nuts
	Oily fish or omega 3
	Reduce red meat
	Vegetables
Vitamins and unspecified medication	Eye vitamins
	Non- eye related vitamins
	Eye drops
	Vitamins
	Other unspecified medication
UV protection	Sunglasses
	UV filter/coating
Smoking	Stop smoking
Healthy lifestyle and weight loss	Weight loss
	Exercise
	Visual aids
	Reduce alcohol intake
	Healthy lifestyle
	Lifestyle changes
Written information	Booklet
	Diet sheet

Amsler chart	Amsler chart
Charity	Macular Society

Table 5.3- Table displaying the themes and nodes from the question regarding what advice participants were given before their most recent appointment in order of most to least commonly referred to.

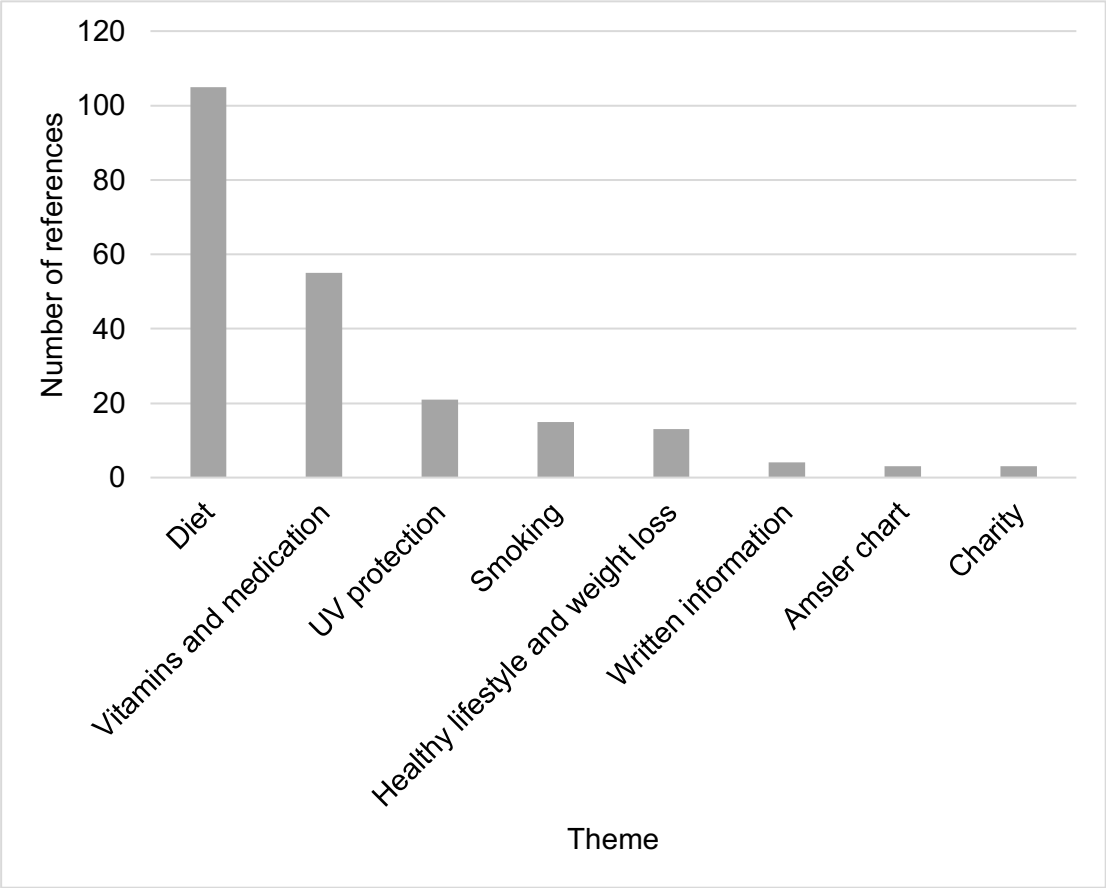


Figure 5.4- Bar graph displaying the themes from the question about what advice participants were given before their most recent appointment. The larger the bar, the more references that were made to this theme.

Theme	Quote
Diet	"Only to eat green vegetables- no advice on why, how much, how often"
	"Eat a healthy diet"
	"Eat oily fish or take omega 3"
Vitamins and medication	"[take] some vitamin supplements available specifically for eyes"

	"Take multivitamins"
	"Advised to take lutein"
UV protection	"Sunglasses of a special type which I have never been able to find"
	"Wear sunglasses outdoors whether sunny or not"
	"To have anti-UV coating on my prescription spectacles"
Smoking	"No smoking- never had"
	"Stopping smoking "
Healthy lifestyle and weight loss	"Told to get weight and diabetes under control"
	"Avoid alcoholic spirits"
	"General lifestyle change, healthy eating, exercise etc. "
Written information	"A diet sheet was given to me"
	"Copy of macular Society's booklet "your guide to AMD" no direct verbal advice"
Amsler chart	"Given Amsler grid, not told what to do with it"
	"Given Amsler chart to check eyes regularly"
Charity	"I joined the macular Society which I found on information given at the hospital and they sent info"

Table 5.4- Table displaying key quotes from each theme in the question about what advice participants were given before their most recent appointment.

The next free text question was about what changes participants made to their lifestyles based on the advice they were given before their most recent appointment. This question was answered by 105 participants. Table 5.5 shows the themes and nodes from this question and figure 5.5 shows the frequency of themes with the number of references made to each theme. Interestingly, even though it was not the most referenced theme in the previous question regarding advice provided (table 5.3), vitamins and supplements was the most referenced theme when participants were asked about what changes they made. Table 5.6 displays the key quotes from each theme.

Theme	Node
Vitamins and medication	Eye vitamins
	Non eye related vitamins
	Non specific vitamins
Diet	Fruit and veg
	Green veg
	Dietary change
	More water
	Reducing meat
	Oily fish
UV protection	Wearing sunglasses
	Caps
	Avoid bright light
Healthy lifestyle and weight loss	Healthy diet
	Alcohol
	Exercise
No change	Already doing
	No advice
Smoking	Stopped smoking
Other support	Visual aids
	Other support

Table 5.5- Table displaying the themes and nodes from the question regarding what changes participants made to their lifestyle following the advice they were given in order of most to least referred to.

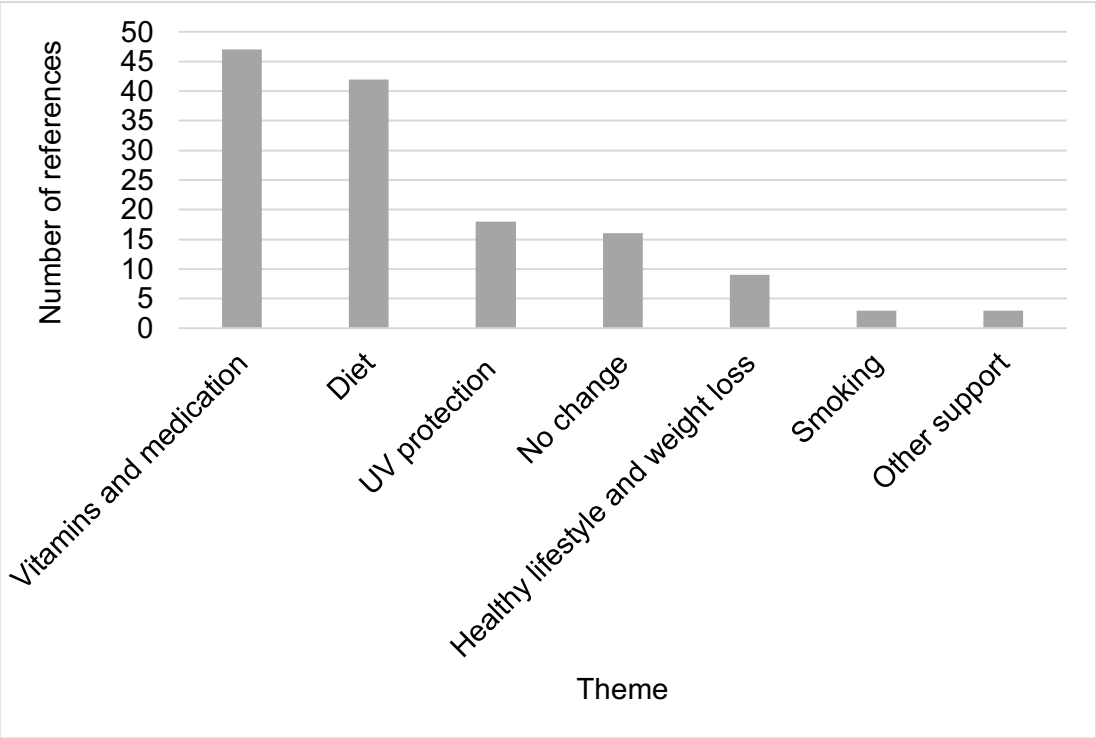


Figure 5.5- Bar graph displaying the themes from the question about what changes participants made to their lifestyle as a result of the advice they were given before their most recent appointment.

Theme	Quote
Vitamins and unspecified medication	"I immediately started AREDS2 vitamins"
	"I started taking multivitamin"
	"Took some supplements, not very accurately"
Diet	"Introduced more fruit and veg (especially red peppers and kale) to my diet."
	"My wife is a vegetable fanatic and insists on greens"
	"More aware of eating right foods"
UV protection	"Took more care to protect eyes by wearing a peak cap on strong sunny days"
	"More careful about wearing sunglasses and a hat when outdoors in bright light"
	"I have worn sunglasses more often"
No change	"No advice received therefore no changes made"
	"I already didn't smoke, drink excess, have a balanced diet, enjoy fibrous vegetables"

Healthy lifestyle and weight loss	"I already didn't smoke, drink excess, have a balanced diet, enjoy fibrous vegetables"
	“Tried to exercise more”
	“Stopped drinking alcohol”
Stopped smoking	"I quit smoking immediately"
Other support	"Brought magnifying equipment to help with reading"
	"Moved chair"

Table 5.6- Table displaying key quotes from each theme in the question about what changes participants made to their lifestyle following the advice they were given before their most recent appointment.

5.3.3 – Participants’ experience of dietary and nutritional supplement advice at the most recent appointment

The third section of the survey explored participants’ experiences of receiving specific types of lifestyle advice at their most recent appointment. When asked about their experience of receiving lifestyle advice at their most recent appointment, out of the 357 participants that responded to the question, 16% (n=57) answered that they had received advice and 84% (n=300) answered that they had not. None of the demographic factors predicted whether or not participants recalled receiving any advice at their most recent appointment.

Out of 404 participants, 15.1% (n=61) reported that their practitioner asked them about their current dietary habits at their appointment. Of the 57 participants that reported receiving lifestyle advice at their most recent appointment, 66.7% (n=38) reported that the advice was regarding their diet. Table 5.7 shows the specific dietary recommendations that were reportedly made to participants.

Type of dietary advice	Frequency (%)
Eat plenty of green leafy vegetables	33 (86.8)
Eat more oily fish	18 (47.4)
Eat lots of different coloured fruits and veg	17 (44.7)
Cut down on saturated fats	5 (13.2)
Eat a balanced diet	14 (36.8)
Reduce alcohol intake	1 (2.6)
Don't remember	1 (2.6)

Table 5.7- Table showing the types of dietary advice participants were given and the frequency for each type, expressed as a percentage of the number of people who reported receiving advice on diet. Participants were able to pick more than one option.

The most common dietary advice was regarding green leafy vegetables (n=33; 86.8% of those receiving dietary advice) followed by oily fish (n=18; 47.4%) and eating lots of different coloured fruits and vegetables (n=17; 44.7%). It is worth noting that 40 respondents (9.9% of the total cohort) reported that they never eat green leafy vegetables and 141 (34.9%) reported that they never eat oily fish, both foods that are recommended for slowing the progression of AMD.

In terms of recommendations of nutritional supplements, 341 out of 404 participants responded to the question. The majority of participants reported that they had not been recommended a supplement (n=293; 85.9% of those answering the question). Of the participants that responded that such a recommendation had been made, table 5.8 shows a breakdown of the types of supplements that they were offered.

Type of supplement recommended	Frequency (%)
AREDS compliant supplement*	26 (54.2)
Non AREDS compliant supplement*	9 (18.8)
Do not remember	5 (10.4)
Non eye related supplement	4 (8.3)
Not specified by practitioner	4 (8.3)

Table 5.8- Table showing the types of nutritional supplement participants were given and the frequency and percentages for each type. As a proportion of those (n=63; 15.6%) that received advice to take nutritional supplements. *= Participants were asked to name the supplements they were recommended and the formulae for these were looked up to investigate whether they were AREDS compliant.

5.3.4- Participants' experience of smoking cessation advice at the most recent appointment

Out of 404 participants, 390 responded to the question about their smoking status. The majority were non-smokers (n=252; 64.6%), followed by ex-smokers (n=114; 29.2%), and current smokers made up the lowest proportion (n=24; 6.2%). The ex-smokers reported smoking a mean of 14.5 cigarettes per day (n=114, SD 12.87-16.14) for an average of 28 years (n=112, SD 25.48-30.67). The current smokers reported smoking 12.4 cigarettes per day (n=24, SD 9.90-14.89) for an average of 50.2 years (n=24 SD 42.87-57.46).

Smoking status	Frequency (%)	Asked about current smoking (%)	Asked about smoking history (%)
Non smoker	252 (64.6)	58 (23)	24 (9.5)
Ex smoker	114 (29.2)	32 (28.1)	22 (19.3)
Current smoker	24 (6.2)	11 (45.8)	2 (8.3)

Table 5.9- Table displaying participants smoking status and proportions of participants asked about current smoking habits and smoking history.

Participants were asked if their practitioner asked them about their smoking status. Table 5.9 shows the proportion of smokers, ex-smokers and non-smokers and whether or not they were asked about their smoking status by their practitioner. In total, 11 (45.8%) out of the 24 participants that reported being current smokers were asked about their smoking habits, however, only 2 (8.3%) of the 24 participants recalled being given advice to stop smoking.

5.3.5- Participants' general experience of advice provision at the most recent appointment

To understand what the participants' experience was of receiving general support and guidance regarding lifestyle changes, they were asked if they were given any information about where to get further support. The majority of the 363 (89.9%) of participants that responded to the question said they were not given any information about this (n=278; 76.6% of respondents to the question). Of the 85 participants that were given information, the majority were directed to the Macular Society (n=62; 72.9%) followed by their local low vision clinic (n=18; 21.2%%), other services (n=12; 14.1%), RNIB (n=11; 12.9%) and finally social services (n=4; 4.7%). Eleven participants were offered multiple sources of where to get further guidance and eleven were recommended other sources of guidance such as pharmaceutical brochures and booklets.

In terms of written advice, out of the 381 participants that answered the question, 9.4% (n=36) were offered written advice at their most recent appointment. There was no significant difference between those who received written advice and those that did not in the reported difficultly in taking in the advice (H (2)= 4.39 p= 0.11) and in the understanding of lifestyle advice (H (2)=2.81 p=0.25). However, chi-squared tests on the yes/no question on satisfaction (see appendix G) showed there was a significant positive association between written advice given and feeling satisfaction with the way advice was delivered (X^2 [df=2, n=381]= 47.75 p <0.001).

With regards to other aspects of the participants' experience, out of 365 participants that answered the question, 31.5% (n=115) reported that they had an opportunity to ask questions during their appointment. This was significantly associated with participants' satisfaction with the content of the lifestyle advice they were given (X^2 [df=2, n=365]= 99.65 p <0.001) and satisfaction with the

way advice was delivered (X^2 [df=2, n=365]= 93.14 p <0.01). Participants that did not have the opportunity to ask questions were 1.5 times less likely to be satisfied with the way advice was delivered ($X^2(4)$ = 102.29, p= 0.05). The model explained 22% of variance in satisfaction with the way advice was given (Cox & Snell R^2 = 0.22), and correctly classified 72.2% of cases. However, there was no significant association between being given the opportunity to ask questions and the reported difficultly taking in advice and understanding advice.

Amongst the participants that recalled being given advice at the most recent appointment (n=57), forty-seven participants rated the difficulty of taking in and understanding advice. Difficulty of taking in advice was, on average, rated low (median=2.0 IQR=1.0-6.0) and difficulty understanding advice was also rated low (median=1.0 IQR=1.0-5.8). Histograms revealed that the responses were not normally distributed. Perceived difficulty was not associated with age (H (3)=3.52 p=0.32), gender (H(1)=1.23 p=0.268), ethnicity (H(3)=4.87 p=0.18) or living arrangements (H(2)=0.37 p=0.83). Out of the participants that were given advice at their most recent appointment, only 7 (12.3%) participants were told why they should make lifestyle changes. Being told why to make changes was not associated with a reduced difficulty taking in advice (H(1)=0.77 p=0.38) or improved self-reported understanding of advice (H(1)=0.001 p=0.98), however the sample size was small for this analysis (n=7).

The majority of participants reported that they had other health conditions (n=296; 76.7%). Of these participants, 92 (31.1%) believed that their other health conditions were not acknowledged by their practitioner during their most recent appointment, whilst 115 (39%) were unsure if this was the case.

At the end of the questionnaire, there was a free text box where participants were asked if they had any further comments in general about their experiences of lifestyle advice provision. Table 5.10 displays the themes and nodes from this question and figure 5.6 displays a bar graph with the themes and how commonly they were referenced. Out of all of the participants, 207 (51.2%) wrote comments for this question. Example quotes for each theme

are displayed in table 5.11. It can be seen from figure 5.6 that the most prevalent theme related to the lack of lifestyle advice which had been provided to the participants, a point the respondents were clearly displeased about (as exemplified by the sample quotes in table 5.11).

Theme	Node
No/minimal advice given	No advice given
	Minimal advice
	No recent advice
	Told nothing could be done
Further information needed	Questions about lifestyle/AMD
	Would like advice
	Unaware of the importance of lifestyle
	Would like to discuss/know more
	Unsure if advice was sufficient
	Need scientific proof of advice
Positives- hospital staff	Helpful practitioner
	Helpful staff/experience
	Happy with advice
	Questions answered
	Made lifestyle changes due to previous advice
No need for advice	Already aware of advice
	Already living a healthy lifestyle
	Did not want advice
	Advice not needed
	Lifestyle advice given not applicable
Negatives- hospital staff	Busy staff
	Rushed appointment
	Did not see a practitioner
	No personal approach
Discussion on future and treatment	Advice about further treatment

	Treatment was a priority
Written information	Referred to written materials
Independent research	Independent research
	Internet
	Advice from family and friends
	Joined Macular Society
	Private care for more information
	Visual aids
	Advice given at low vision clinic
Relation to other health conditions	Connection with co-morbidities
Contacts	Information on who to contact

Table 5.10- Table displaying the themes and nodes for participants that wrote 'further comments'.

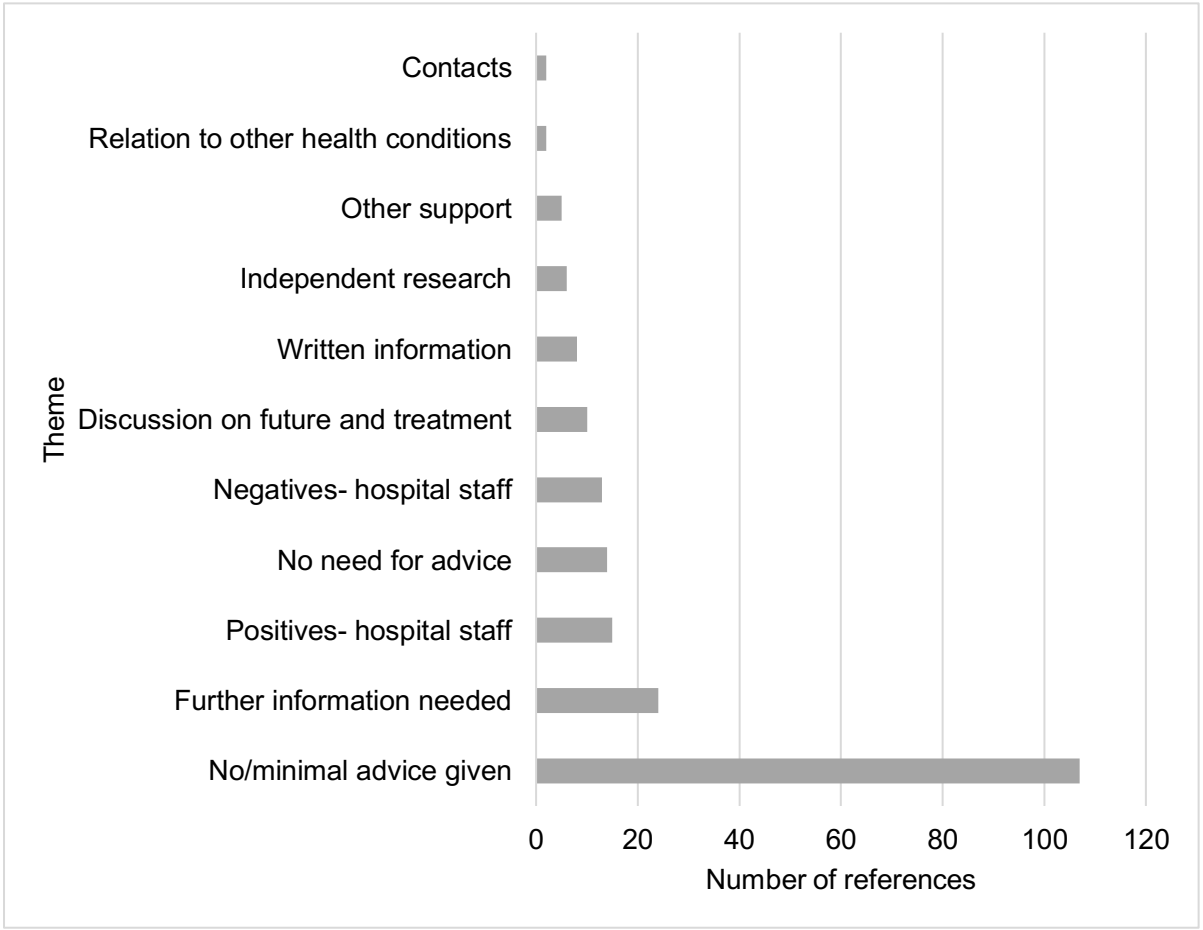


Figure 5.6- Bar graph displaying the themes based on participant responses to 'any further comments'.

Theme	Quote
No/minimal advice given	"Advice minimal, could have been signposted to websites"
	"The advice was brief and quite cursory. I don't recall anything about dietary advice or alcohol. Need written info to take home"
	"I haven't been given any lifestyle advice at any appointment regarding my vision"
Further information needed	"Forgot to ask what exactly is in the green plants that would help me"
	"Would have liked some emotional help and advice"
	"This questionnaire reveals to me that lifestyle is, or is thought to be, an important factor in the development of AMD. I have been educated!"
	"when I mentioned it to my GP he asked if I was tired of living. Reassured him that I am not"
Positives- hospital staff	"I am impressed with the treatment received and as such not much time for lifestyle advice"
	"I've only just found out that I have this condition. I thought I was just going for a scan no one said about injections until I got to apt, it was a shock but everyone was so kind and talked me through it"
No need for advice	"The trouble about acting on the lifestyle info 'take this' 'do that' is one never sees the benefit so you easily do not carry on the advice. Where can one find hard scientifically proved advice that is not commercially biased. How many times has the advice change?"
	"Didn't know about any help. Was told I'm losing my sight and there's no cure- in other words, get on with it."
	"Already aware of most advice"
Negatives- Hospital staff	"The clinic I attend is so busy they don't have time for discussions. So I went private to discuss the matter in more detail."
	"Unless I persist I do not receive comments on the reviews undertaken by technicians at XXX. It feels like I am only an NHS number and not a person"
Discussion on future and treatment	"With the realisation that the right eye how progression from dry to wet AMD, that took priority over other discussions"

Written information	"There was no advice or discussion on a face to face basis. All information was in booklet or leaflet form"
	"Received feedback via letter after appointment. Some changes were detailed in the letter and I had to ask my optician what the technical terms in the letter meant. Not a good way to receive information about changes"
Independent research	"In the first instance advice was given by local optician and I researched for myself regarding eye supplement"
	"I have never received any advice about AMD other than 'you have AMD'. Most information I have received was from a friend and my sister-in-law"
Other support	"My wife has joined the Macular Society online for advice regarding diet"
	"Only talked about light and magnification being helpful"
Relation to other health conditions	"Similar lifestyle changes made following advice given/received following coronary problems 25 years ago"
Contacts	"I did understand the advice at that time, and knew how and who to contact if needed"

Table 5.11- Table displaying key quotes from each theme under 'any further comments'

5.3.6- Participants' preferred method of advice provision

The final question was based on participants' preferred mode of advice provision. Figure 5.7 shows how participants responded to this question. The most frequently selected option for this question was 'a verbal discussion' (n=223; 55.4%) closely followed by 'written information in a letter' (n=213; 52.7%).

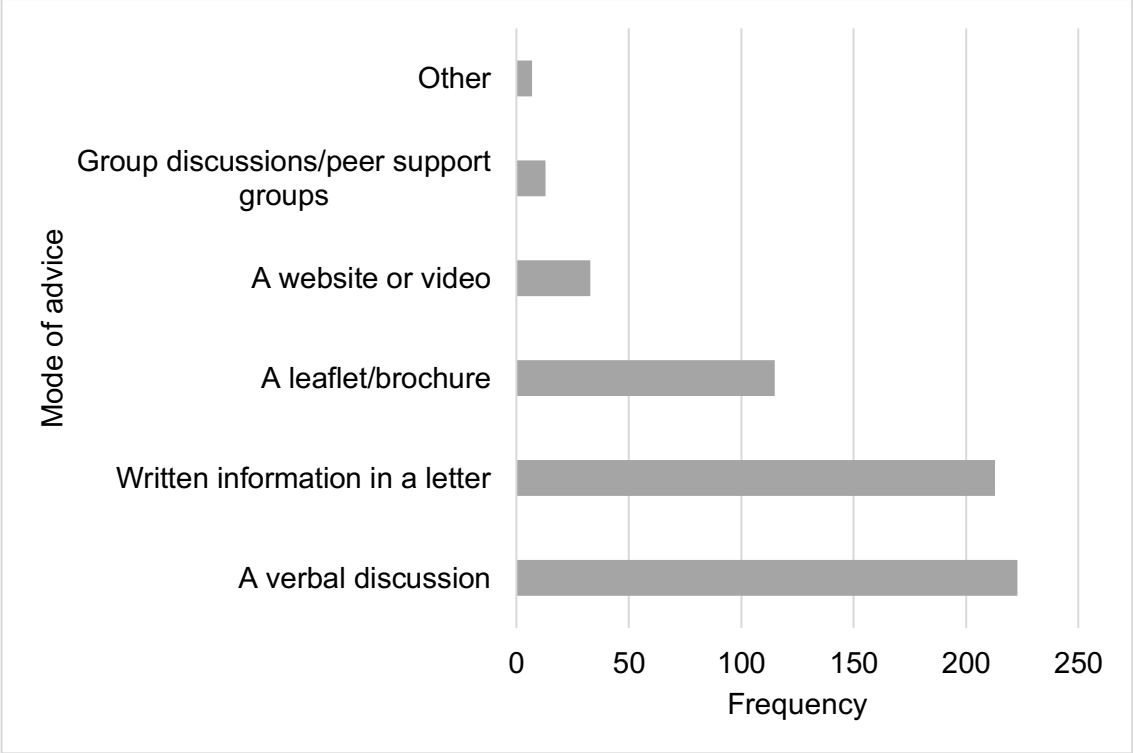


Figure 5.7- Participants responses to their preferred mode of advice provision. The larger the bar, the more frequently selected. Participants could select more than one option.

Table 5.12 shows the themes and nodes for the reasons that participants provided for their preferred modes of advice. Importantly, the most common theme in the overall question was 'Ability to refer to/review information'. This was particularly highlighted as a reason for participants choosing a verbal discussion and written information in a letter as their preferred modes of advice provision. Table 5.13 displays key quotes from each option as participants were asked to provide reasons for choosing the options they did.

Mode of advice provision	**Themes**	**Nodes**
A verbal discussion	Opportunities for discussion	Can talk more
		Can ask questions
		Can learn more
	Understandable	Understandability
	Preference	Prefer face to face
		Satisfaction

		The best way
	Issues with vision	Tired eyes
		Difficulty reading
	Technology	No internet/technology
	Personalised care	Personalised information
		Relevance
	Access	Ease
		Physical issues
	Back up written information	Verbal followed by written information
	Time to consider/take in information	Listening
		Easier to absorb/retain information
	Research	Information about research
		Independent research
	More details	Immediate information
Written information in a letter	Ability to refer/review information	Can refer back
		Remembering advice
		Easier to remember
		Can keep
	Time to consider/take in information	More time for consideration
		Easier to absorb/retain information
	Access	Ease
	Understandable	Understandability
	Back up verbal information	Verbal followed by written information
	Preference	Prefer writing
	Assistance from family	Can show/discuss with family
	Issues with hearing	Hearing loss/difficulty

	Personalised care	Personalised information
A leaflet/brochure	Ability to refer/review information	Can refer back
		Can keep
	Time to consider/take in information	Time to do further research
		More time for consideration
		Easier to absorb/retain information
	Access	Ease
	Back up verbal information	Verbal followed by written information
	Preference	Good idea
		Prefer writing
	Technology	No internet/technology
	Research	Information about research
		Independent research
	Assistance from family	Can show/discuss with family
	More information	Can get more information
A website/video	Ability to refer/review information	Can refer back
		Remembering advice
	Access	Ease
		No physical demands
	Time to consider/take in information	More time for consideration
	More information	Can get more information
	Understandable	Language barrier
Group discussions/peer support groups	Opportunities for discussion	Can discuss/learn more
	Support from others	Discussion with others

Other	Research	Information from research

Table 5.12- Nodes and themes from the reasons that participants provided for each mode of advice provision. Themes are displayed in order of most references to least references for each mode.

A verbal discussion
"I like to know immediately if I need to make changes and be told directly to ensure I understand"
"A verbal discussion gives an opportunity to seek clarification when needed"
"A verbal discussion gives the opportunity to ask questions, but it needs to be backed by information that can be taken away"
"Allows me to leave feeling satisfied after a verbal conversation"
"Found the diagnosis quite upsetting and difficult to and would have liked someone to talk to"
Written information in a letter
"Written information would give me time to consider changes."
"Can be referred to at any time"
"Email information is easier to 'go back to' and can be more sequented for 'early diagnosis, what to expect, injections etc. what looks good, bad etc.'"
"Verbal is pleasant, written backs up what has been said and what you may forget or not have understood properly"
"I'm not happy with receiving information "electronically"- easier to read brochure or letter"
A leaflet/brochure
"Provides a permanent record of advice, not dependent on memory of patient or thoroughness of clinician"
"So my wife can read it to me"
"Ability to easily consult information from time to time"
"Leaflets back up verbal advice given and can be used for future reference"
"It would be good to be able to refer to leaflet as reminder of key points"
A website or video
"I usually prefer to read info on computer rather than have to physically attend meetings"

"Prefer to take in the advice in my own time and watch/refer to more than once"
"Don't understand English, can ask for interpretation can watch when I wanted"
Group discussions/peer support groups
"It would be very helpful to be with a group of people who also suffer with ARMD"
"You can pick up useful everyday tips to manage AMD"
"I don't mind how I receive valid information [so] I would like to join a support group "
"Macular is initially 'scary' word and it covers a multitude of symptoms/treatments. Someone to offer written information or a peer group would be useful"
Other
"I am interested in AMD trials and results and treatment and changes"
"Names contact at clinic if needed"
"For all members of the family to visualize advice given if they were not at initial appointment"

Table 5.13- Table displaying key quotes from the free text question about why participant preferred particular modes of advice provision.

5.4 Discussion

The findings from this study highlight that there are a number of inconsistencies and gaps in the current state of lifestyle advice provision from the patient perspective. Despite all of the participants included in the study meeting the criteria to be provided with lifestyle advice, the results from this study support the previous research that states patients are not consistently being provided with lifestyle advice from their practitioners, or patients are not able to recall the advice they are given. Demographic factors do not seem to influence the likelihood of advice being received or remembered. Additionally, the results of this study indicate that a proportion of participants are given lifestyle advice around the time they are diagnosed, however, this advice is rarely repeated which may account for the low proportion of participants that made subsequent lifestyle changes. This backs up the findings from previous research (Bott et al., 2018, Lawrenson and Evans, 2013, Shah et al., 2015)

that report a lack of advice provision to patients, low rates of recall and low perceived importance of making lifestyle changes. The results of the current study indicate that being provided with written information and opportunities to ask questions does predict patient satisfaction. This highlights the importance of providing patients with adequate information and enough time to discuss lifestyle changes with their practitioner. The guidelines for practitioners recommend provision of advice regarding diet and smoking (NICE, 2018b, Royal College of Ophthalmologists, 2021, College of Optometrists, 2021), however, our results show these guidelines are not being consistently followed.

5.4.1 Dietary and nutritional supplementation advice

Dietary changes are recommended for patients with AMD to help reduce the rate of disease progression. The findings from this study show that dietary advice was the most commonly offered advice before participants most recent appointment (84% of n=125 who gave details of prior advice), however 66% of participants who responded said that have had received no lifestyle advice of any nature before previous appointments. Again, at the most recent appointment, out of the participants that were given lifestyle advice, dietary advice was offered most commonly. However, as the proportion of patients that were offered advice was low, the number of participants offered dietary advice made up only 9.4% of the total study population. Moreover, although most of the participants were given dietary advice before their most recent appointment, it was not the advice that was most commonly taken on. The most commonly reported lifestyle change was vitamin supplementation.

The importance of making dietary changes has been emphasised in recent research (Gorusupudi et al., 2017). In particular, as discussed in chapter 1 (section 1.6.2), research has shown that specific nutrients such as lutein and zeaxanthin are associated with a decreased rate of progression to intermediate and late AMD (SanGiovanni et al., 2007). There is also strong evidence to suggest that the Mediterranean diet is associated with lower risk of incidence or progression to late AMD (Merle et al., 2019, Nunes et al., 2018, Hogg et al., 2017). Given the research, guidelines highlight the importance of informing participants about modifying their dietary habits. For example, the

Royal College of Ophthalmologists advise that practitioners should recommend that patients follow a 'healthy diet, rich in fresh fruit, vegetables, eggs and oily fish' (Royal College of Ophthalmologists, 2021). This advice is reflected on an international level, for example Australian practice guidelines recommend that patients with AMD are encouraged to adopt a diet rich in green leafy vegetables, fish and antioxidants (Optometry Australia, 2019).

Crucially, the findings from this study show that these recommendations are not necessarily being made consistently, or the importance of making these changes is not being emphasised. Of the 57 participants that reported receiving lifestyle advice at their most recent appointment, 66.7% (n=38) were given dietary advice. Reassuringly, the most common types of dietary advice was to increase consumption of green leafy vegetables (n=35; 61.4%), oily fish (n=18; 31.6%) and fruits and vegetables (n=18; 31.6%) which are all consistent with the Royal College of Ophthalmologists and College of Optometrists guidelines (Royal College of Ophthalmologists, 2021, College of Optometrists, 2021). However, some participants were given advice regarding alcohol consumption, which is not specified in the guidelines and is not supported by the limited evidence base about the association between alcohol consumption and AMD progression (Zhang et al., 2021).

There are currently no guidelines available for how to provide dietary advice specifically for eye diseases. However, research on general nutritional guidance for an elderly population shows that providing personalised advice and using food diaries can help to increase consumption of macronutrients such as protein (Grasso et al., 2022). Additionally, providing patients with specific dietary advice such as how to increase nutrient intake and during what meals can be effective in helping patients make dietary changes (Reinders et al., 2020). In this study, this approach appears to have been adopted to a certain extent, as participants that were given dietary advice at their most recent appointment were commonly given specific advice such as to eat 'green leafy vegetables' and 'oily fish'. However, it can be argued that the information should be more specific and personalised, based on previous research (Reinders et al., 2020, Anderson and Nguyen, 2018).

The most commonly reported lifestyle change made on the basis of previously received advice was nutritional supplementation despite dietary advice being the most common advice provided. Indeed, over half of those surveyed reported taking nutritional supplements. Evidence suggests that the population of Europe is very familiar with the concept of nutritional supplements, with around 36% of adults sampled in the UK reporting supplement use (Skeie et al., 2009). It may be that people perceive this as being an easier lifestyle change to comply with than a more comprehensive change in dietary intake. However, in our study, participants that reported taking nutritional supplements were not asked whether they were taking them daily as required, so adherence to treatment may have been poor. The issue of adherence has been investigated previously (Hochstetler et al., 2010), where in a sample of sixty-four participants, less than half (43%) were taking the supplements at the correct dosage. Therefore, adherence to nutritional supplements for AMD should be investigated further.

The AREDS trial demonstrated that a supplement containing high dose anti-oxidants plus zinc could reduce risk of progression of intermediate AMD by around 25% (Age related Eye Disease Study, 2001). The follow up AREDS2 trial showed that potentially harmful beta-carotene in the supplement could be replaced by carotenoids lutein and zeaxanthin without reducing the effectiveness (Age related Eye Disease Study, 2013). Hence, there is strong evidence from large randomised controlled trials to support the recommendation of vitamin supplements to patients with intermediate AMD based on these formulae. A recent Cochrane review and meta-analysis of the evidence regarding the impact of antioxidant vitamins and minerals on risk of progression of AMD concluded that there was moderate-certainty evidence supporting the hypothesis that a formulation based on the original AREDS formula slows down progression to late AMD (Evans and Lawrenson, 2023). However, the review highlighted that people with early AMD were less likely to benefit from supplements, given their reduced risk of progression compared to people with intermediate stage AMD. The review also concluded that studies on other vitamins and minerals have been small and evidence from the studies have been mixed, so further research is needed, although it

recognised the assertion of the AREDS2 trial that lutein/zeaxanthin may be an appropriate replacement for beta carotene in the original AREDS formula. Practice guidelines specifically mention the AREDS/AREDS2 formulations due to the large clinical trials (Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013) (chapter 1; section 1.6.2) and extensive research supporting their effectiveness. However, according to our results, not all of the nutritional supplementation advice adhered to the formulae used in the AREDS trials. Just over half of the participants that were recommended nutritional supplements were specifically recommended AREDS compliant vitamins (n=26/48; 54.2%). This suggests that practitioners may be unaware of or not compliant with current best evidence-based practice in their advice provision.

As discussed in chapter 2, there have been a number of studies exploring patients' adherence to the AREDS vitamins. For example, Alghamdi et. al. (2023) found that out of 120 patients that met the AREDS criteria for supplementation, only 60% were taking the supplements. Of the patients that were not taking the supplements 83% reported that they could not recall being advised of their benefit (Alghamdi et al., 2023). Similarly, another study investigating patients with AMD's' adherence to nutritional supplements found that out of 193 patients surveyed, only 40% were taking AREDS-type vitamin supplements. Furthermore, 65% of patients were not informed by their ophthalmologist about the potential benefits of nutritional supplementation (Parodi et al., 2016). It has been reported that cost of the supplements and a lack of understanding from practitioner and patients for why they can be beneficial present a barrier to adherence to supplement use (Yu et al., 2014a). The findings from our study and previous research highlight that the importance of nutritional supplements is not being advertised, despite the extensive research demonstrating the effectiveness of these particular formulations (Chew et al., 2022, Age related Eye Disease Study, 2013, Evans and Lawrenson, 2017, Age related Eye Disease Study, 2001). However, it is also important to note that over half of the participants in this study were already taking vitamin supplements at the time of the survey, so it may not have been recommended for that reason.

Even though there have been a number of studies demonstrating the benefits of adherence to specific diets and nutritional supplements, the findings from our study show that only some people are being provided with the advice, and adherence to the recommendations is limited. Therefore, it is important for practitioners to emphasise the importance of these lifestyle changes.

5.4.2 Smoking advice

In our study, only around a quarter of participants were asked if they currently smoke and ~13% were asked about their smoking history. In addition to the well-established association between smoking and risk of AMD incidence and progression and other ocular conditions (Tan et al., 2007, Mitchell et al., 2002, Willeford and Rapp, 2012, Asfar et al., 2015), previous research, particularly on the AREDS formulation, has emphasized the importance of asking about smoking habits and history with respect to the contraindications of smoking when recommending beta-carotene containing supplements (Age related Eye Disease Study, 2013). In our cohort, of the 390 participants that answered the question about their smoking status, only 24 (6%) were current smokers, with a larger proportion of our participants being ex-smokers (29%). However, it should be noted that of the 14 participants that did not answer the question, it is possible that some may have been current or ex-smokers who did not wish to disclose the information, as has been reported previously (Poland et al., 2000). Of the ex-smokers, only 2 reported that they had stopped smoking due to their eye condition. Furthermore, only 3 of the participants that reported being current smokers were offered smoking cessation advice. Unfortunately, this supports previous research which reports low rates of smoking cessation advice offered by eye care practitioners (Lawrenson and Evans, 2013, Bott et al., 2018, Shah et al., 2015). However, these studies all also reported low numbers of current smokers in the included cohort of participants.

Smoking is a well-known, prominent risk factor for AMD progression (Heesterbeek et al., 2020). In fact, a commonly reported statistic in a number of AMD practice guidelines (College of Optometrists, 2021, Royal College of Ophthalmologists, 2021) is the fact that smokers have a 4 fold increased risk of developing AMD compared to non-smokers (Tan et al., 2007). However, the findings from our study and previous research show a lack of adherence with

the guidelines of recommending smoking cessation. Martin (2017) reported that although smoking cessation advice was low, ophthalmologists were more likely to provide smoking cessation advice than optometrists (Martin, 2017). The majority of the participants in our study were recruited via hospital eye clinics, and 32.7% were diagnosed by an ophthalmologist, suggesting that rates of advice provision may have been even lower had we recruited a higher proportion from optometric practice. Smoking cessation advice was not commonly mentioned when participants described what advice they were given and some participants mentioned being given smoking advice, having never smoked. This reflects the finding that ECPs did not routinely ask about current or previous smoking status (only 48 i.e. 12%, of participants reported being asked at their most recent appointment). This was also echoed during the co-design activity described in chapter 3.

There are many guidelines for how smoking cessation advice should be provided to patients, including offering support to stop and referring patients to nicotine patches, gum and support groups (NICE, 2023). However, these guidelines do not mention the effects of smoking on vision and how advice should be provided to patients with AMD. A pilot study by Caban-Martinez et. al. (2011) on smoking cessation advice offered by eye care providers reported that two thirds of the practitioners wanted additional training and resources to help patients quit (Caban-Martinez et al., 2011). The findings from our study back up this finding as smoking cessation advice was rarely offered so more education may help practitioners provide patients with adequate information and support to quit. Although, the College of Optometrists do offer training courses on how to provide effective advice to patients regarding the treatment and management of AMD (College of Optometrists, 2023b), but practitioners may not be aware of these courses or they are not accessing it.

5.4.3 Perceived barriers to effective lifestyle advice provision

The findings from our study highlighted a number of patient perceived barriers to effective lifestyle advice provision. Firstly, at the most recent appointment, the majority of patients were not given any guidance on where they could get additional support. The NICE guidelines recommend that patients should be provided with resources for additional support (NICE, 2018b), particularly to

help with making lifestyle changes. Importantly, the participants in our study were most commonly referred to the Macular Society for additional help. This reflects recent studies reporting a gradual increase in referrals to the Macular Society in recent years (Boxell et al., 2017, Macular Society, 2023). However, this was only still a small portion of our participants (n=62; 15.3% of the total cohort). Previous research has highlighted the importance of offering patients additional support when recommending lifestyle changes as this has the greatest impact (Cowan et al., 2023, Lindström et al., 2003). However, this is also impacted by the patients' willingness to contact the sources for additional support and their levels of engagement (Bae et al., 2021). Nonetheless, it is still important to offer patients the option.

Secondly, despite guidelines for practice, the majority of participants (n=345, 90.6% of the 381 participants that answered the question) were not offered any written information. This is a significant finding. Despite participants also expressing a desire for verbal discussions, almost half of the participants also expressed a preference for written information for lifestyle advice. A common reason for the preference was having the ability to refer back to the information at their convenience. This is a vital part of offering lifestyle changes as the patients' ability to recall the information will strongly impact the changes made (Bardach et al., 2017, Booth and Nowson, 2010). Furthermore, being given written advice was associated with increased patient satisfaction with their experience. However, it is important to consider that some of the patients may have been visually impaired. Difficulty with accessing written materials due to reduced vision was one of the main reasons why participants reported a preference for a verbal discussion as their mode of receiving advice. This illustrates the importance of providing written materials in a high contrast, large print, or electronic format where possible. It is also important to consider patient education and health literacy, as advice provided using too much medical jargon could prevent patient engagement (Wittink and Oosterhaven, 2018).

5.4.4 Limitations

There were a few important limitations to this study. Firstly, the majority of the participants included in the study were recruited from hospital eye clinics.

Previous research has shown there are differences in the information given in primary and tertiary care (Pak et al., 2020, Lo et al., 2016) and therefore, these differences were not able to be captured in this study. Secondly, even though participants were sent the questionnaire within 3 weeks of their appointments, their responses to the questions may have been affected by an inability to recall the advice. This is especially the case with respect to advice received at previous appointments (part one of the questionnaire). Evidence suggests patients' recall of information is affected by their participation in discussions and repetition of information (Richard et al., 2017, Visser et al., 2017). Advice that is forgotten by patients is not useful, so our assessment of patients ability to recall advice is vital in emphasising the need for more effective communication techniques such as repetition and two-way discussions between patients and practitioners. As there were multiple centres in the study, for logistic reasons it was not always possible to provide the participants with the questionnaire on the day of their appointment, when they may have been more likely to recall advice. Finally, some of the questions did not provide a free text option. In some cases, participants may have wanted to provide additional information, and were unable to at this point. However, participants were given the option to write further details at the end of the questionnaire.

5.5 Conclusion

In conclusion, the findings from this study highlight that, as per the patients' experience, there is limited adherence to practice guidelines by the eye care practitioners and patients are not being provided with lifestyle advice consistently. The findings highlight a number of barriers such as a lack of information for further guidance and no written information which should be considered by practitioners and commissioning bodies. Further research is required to understand if these findings are replicated in primary care practice. The mismatch between patient preferences and the advice they receive indicates the need for more patient input when creating guidelines for lifestyle management advice provision.

6. Factors affecting patient reported adherence to lifestyle advice regarding AMD

The STROBE checklist for this chapter is provided in appendix I.

6.1 Introduction

Previous chapters highlight that the guidelines from the College of Optometrists and the Royal College of Ophthalmologists recommend that patients with AMD should be provided with information about lifestyle changes they can make to help reduce their risk of AMD progression (Royal College of Ophthalmologists, 2021, College of Optometrists, 2021). However, as well as providing the advice, it is important to understand whether or not patients act on the advice they are given, and what factors influence their adherence. The positive impact of adhering to lifestyle modification advice in AMD has been reported by a number of studies (Raimundo et al., 2018, Sin et al., 2013). Despite this, there is limited research on whether patients with AMD make lifestyle changes once they receive the advice.

As discussed in chapter 2, findings from the systematic review show that research on the patient experience of receiving lifestyle advice is limited, as is the research on the factors affecting lifestyle change, and the majority of these studies focus on factors affecting adherence to taking vitamin supplements (Dave et al., 2022). However, the vitamin adherence studies do show that one of the main factors which can make patients less likely to make lifestyle changes is when lifestyle advice is not provided by their ECP (Parodi et al., 2016, Hochstetler et al., 2010). For example, Hochstetler et. al. (2010), reported that of 64 patients surveyed that met the criteria for AREDS supplements, only 43% (n=28) were taking the AREDS supplements at the correct dosage. However, 75% of the participants that were not taking AREDS2 supplements reported not doing so because the supplements were not recommended to them. Similarly, Alghamdi et al (2023) reported that 40% of 120 patients who met AREDS criteria were not taking supplements and, of these, 83% of patients did not recall being advised of their benefit. This emphasises the importance of effective advice provision. However, other factors are likely to be at play. For example, the number of other medications

patients are taking (Parodi et al., 2016), and the cost of the supplements (Alghamdi et al., 2023) have also been reported to impact on adherence.

Adherence to other types of lifestyle advice was investigated in a study with 92 participants with AMD (Shah et al., 2015). Out of these patients, 51% recalled being given dietary modification advice with 81% of these individuals adhering to this advice. However, importantly, only 5% of the patients recalled being given smoking cessation advice, although it is not clear how many of these were current smokers. Notably, none of these patients adhered to the advice they were given. Considering the strong link between smoking and risk of AMD progression, this is a cause for concern. All of the studies that reported on the impact of lifestyle advice on behaviour modification took place at single sites and the majority of these studies only captured information from a single time period (Chang et al., 2003, Charkoudian et al., 2008, Parodi et al., 2016, Hochstetler et al., 2010). This limits the generalisability of the findings (for a full review of these studies, see chapter 2).

Given the limited evidence in the field of ophthalmology, it may be informative to consider research into patient adherence to lifestyle advice in other areas of healthcare (e.g. Hair and Sripopatana, 2021, Alfulayw et. al., 2022, Neuvonen et. al., 2022). For instance, Hair and Sripopatana (2021) investigated patient adherence to lifestyle advice given at a cholesterol management service. On average, patients were two times more likely to adhere to lifestyle advice if they believed their practitioner had an adequate knowledge of their medical history, spent enough time with them and provided information that was easily understandable. Neuvonen et. al. (2022) investigated the psychosocial determinants of adherence to a healthy lifestyle recommendation, reporting that a lower health related quality of life and depressive symptoms predicted a lower likelihood of lifestyle change (Neuvonen et al., 2022). Additionally, Alfulayw et. al. (2022) reported that forgetfulness and lack of knowledge about the importance of making lifestyle changes were two of the main factors for non-adherence to lifestyle modification advice in a diabetic population.

Following the study described in the chapter 5, which evaluated the patient experience of receiving lifestyle advice, the aim of this follow up study (three months after the first questionnaire was administered) was to investigate what factors influenced the likelihood of patients making lifestyle changes and what could motivate them to make lifestyle changes and to understand whether patients had made lifestyle changes based on the advice that they were given.

6.2 Methods

6.2.1 Participants

Participants that took part in survey one were given the option to consent to receiving a follow up survey 3 months later. The inclusion and exclusion criteria were the same as outlined in chapter 5 section 5.2.1. Participants were only contacted if they consented by completing the contact form at the end of survey one. In total, 336 participants (83.17% of the participants that returned survey one) consented to receiving the survey as a part of survey one and provided their preferred mode of contact (email or post) to receive the follow up survey. However, despite participants consenting to the second survey a total of 77 participants did not provide or provided incorrect contact details. Therefore, a total of 259 (64.11% of the survey one respondents) follow up surveys were sent.

6.2.2 Survey design

The three- month follow up survey (survey 2) was designed using the methodology described in chapter 4 and was given to the patient groups to review before it was finalised (see appendix G). Similar to survey one, the questions were split into sections.

Section A, titled ‘after your last appointment’ consisted of questions about the specific advice that patients may or may not have been given at their last appointment. The questions focused on whether or not they were given any advice, what advice they were given and what specific changes they made to each lifestyle factor, depending on the advice they were given. Although the participants provided information about the advice that they had received at their recent appointment contemporaneously in survey 1, repeating this question 3 months later enabled the level of patient recall of advice to be

evaluated. Additionally, following information from the co-design activity group, this section also consisted of questions about how easy participants found making the changes, reasons for not making lifestyle changes (if appropriate), whether they searched the internet for further information and which online resources they found to be the most helpful.

The second section focused on the participants' general thoughts and opinions around lifestyle advice and AMD. The questions included a scale-based question that asked participants to rate the importance of lifestyle changes for AMD progression, whether or not participants were likely to keep the changes they made and what would motivate them to do so. Finally, participants were given the opportunity to write in free text boxes about which sources of information they found to be the most effective in informing their choices about lifestyle and AMD followed by another free-text box for participants to add any other comments or feedback they had (see appendix G for the full survey).

Participants were all given the option to complete the survey online,on paper (font: Arial, size 16pt) or via telephone. Following advice from the study steering committee, participants were also provided with contact information for the study team if they wished to provide any further comments or feedback.

6.2.3 Analysis

In this mixed methods study the quantitative data was all analysed using IBM SPSS Statistics v28 0.1.0 (Available at: https://www.ibm.com/products/spss-statistics). Pearson's X^2 tests were used to evaluate differences in proportions, for example the difference in the proportion of people making self-reported changes in lifestyle between those who received lifestyle advice from their ECP and those who did not. Graphical representations of the frequencies and percentages of the responses given by patients were evaluated using bar charts and contingency tables. Standard deviations and histograms were used to determine if the continuous data was normally distributed. The continuous data was not normally distributed so Mann-Whitney U tests were used to compare variables with two groups and Kruskall-wallis H tests were used to compare variables with more than two groups. Binomial logistic regression analyses were conducted to examine the relationship between predictor

variables (i.e. demographic factors) and the outcome variable (whether or not lifestyle changes were made).

To analyse the qualitative data, NVivo 12 (https://lumivero.com/products/nvivo/) was used. Similar to the process described in chapter 5, thematic analysis was used to evaluate free text sections of the survey to determine types of lifestyle modification made, reasons for adherence/non-adherence and to analyse the optional free-text boxes included in the multiple choice questions. See chapter 1, section 1.10 and 3.2.2 for a full description of the process.

6.3. Results

Out of the 259 surveys sent to the participants that consented and were able to be contacted, 163 surveys were returned and 153 were included in the analysis. The recruitment process and number of participants included at each stage is shown in figure 6.1. Nine surveys were excluded from the analysis because they were incomplete i.e. contained insufficient data to allow analysis. One participant was excluded as they chose to withdraw.

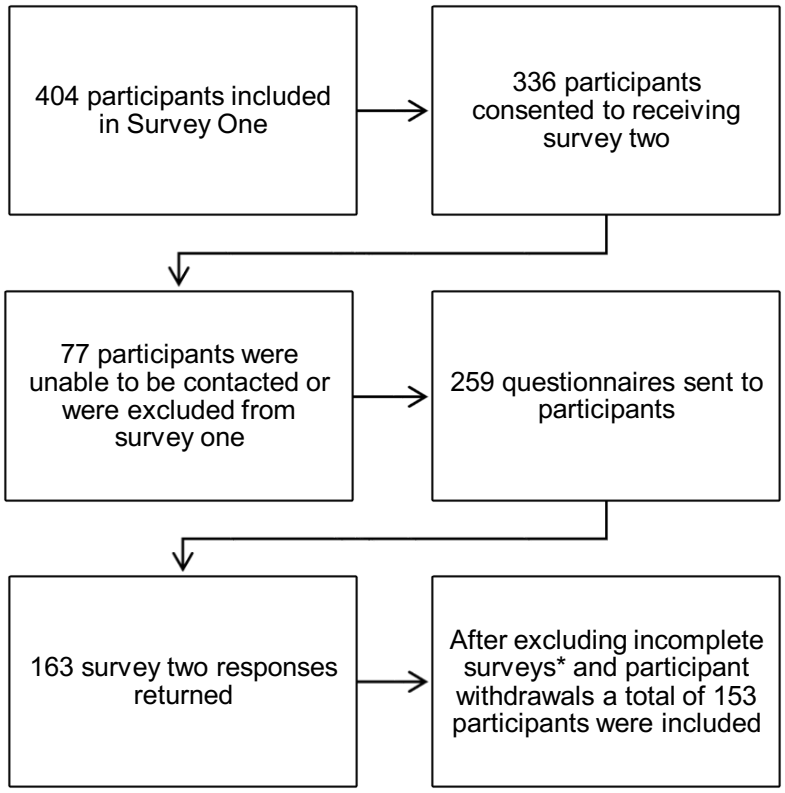


Figure 6.1- Flow chart displaying how many participants were included at each stage. Reasons for participants not being sent survey two include participants not providing contact information details or providing incorrect details. Participants were followed up for their contact details and those that responded were sent the questionnaire. *- Surveys were considered incomplete if they answered less than 5 questions as the questions that were answered were following on from previous questions that were not answered and therefore were not valid when looked at independently. One participant was excluded as they chose to withdraw.

Amongst the participants that were included in the study, the majority were female (n=88; 57.5%) and in the 71-80 year age bracket (n=75; 49%). The vast majority classed themselves as White British with respect to ethnicity (n=141; 92%). Table 6.1 displays the full demographic details for the participants. The most common diagnosis was unilateral intermediate AMD with unilateral late AMD (n=38; 24.8%) and the second most common diagnosis was bilateral intermediate AMD (n=29; 19%). Table 6.2 displays how many participants were recruited from each hospital or optometry site.

	Frequency (%)
Gender	
Female	88 (57.5%)
Male	65 (42.5%)
Age	
51-60 years	2 (1.3%)
61-70 years	21 (13.7%)
71-80 years	75 (49.0%)
Over 80 years	55 (35.9%)
Ethnicity	
White English, Welsh, Scottish, Northern Irish or British	141 (92.2%)
Irish	3 (2.0%)
Any other white background	3 (2.0%)
Any other mixed or multiple ethnic background	1 (0.6%)
Indian	4 (2.6%)
Chinese	1 (0.6%)
Living arrangement	
Live alone	54 (35.3%)

Live with partner/carer/friend	88 (57.5%)
Live with family	10 (6.5%)
Prefer not to say	1 (0.7%)
Diagnosis	
Unilateral early AMD*	1 (0.7%)
Unilateral intermediate AMD*	3 (2.0%)
Unilateral late AMD*	13 (8.5%)
Bilateral early AMD	9 (5.9%)
Bilateral intermediate AMD	29 (19%)
Bilateral late AMD	27 (17.6%)
One eye early, one eye late	28 (18.3%)
One eye intermediate, one eye early	4 (2.6%)
One eye intermediate, one eye late	38 (24.8%)
Diagnosis missing	1 (0.6%)
Smoking status	
Current smoker	3 (2.0%)
Non smoker	100 (65.4%)
Ex smoker	47 (30.6%)
Prefer not to say	3 (2.0%)

Table 6.1- Demographic information for participants in survey two. Demographic information was obtained from survey one responses as this information was not collected again. *- participants with AMD in one eye but no AMD in the other.

Hospital site	Number of participants
Moorfields Eye Hospital	52
Huddersfield	29
Princess Alexandra	19
James Paget	18
Sheffield	14
Coventry	8
Barking	4
Birmingham	3
Optometrists	3
Rotherham	2
Leicester	1

Table 6.2- Table displaying the recruitment sites and how many participants were included from each site.

6.3.1 Lifestyle advice and factors affecting lifestyle change

Information from survey one and survey two were linked using participant ID numbers to ensure anonymity was ensured at all times. Out of the 153 participants included in this study, 16.3% (n=25) had previously reported in survey one that they had received lifestyle advice at their most recent appointment, 73.2% (n=112) said they did not receive any lifestyle advice, and 10.5% (n=16) participants could not recall if they had or had not received any advice (see chapter 5, section 5.3). Interestingly, participants were asked the same question in survey two, in which 24.2% (n=37) reported that they had received lifestyle advice at their most recent appointment, 67.3% (n=103) said they had not received any advice and 8.5% (n=13) did not answer the question. This change is likely to reflect recall bias or could indicate that participants had another appointment between surveys, therefore responses from survey one were used in this part of the analysis. Out of the participants that reported receiving lifestyle advice in survey one, the most frequently reported type of advice was 'wearing sunglasses' (n=13, 52%). Figure 6.2 shows the frequencies of the types of lifestyle advice participants reported being given.

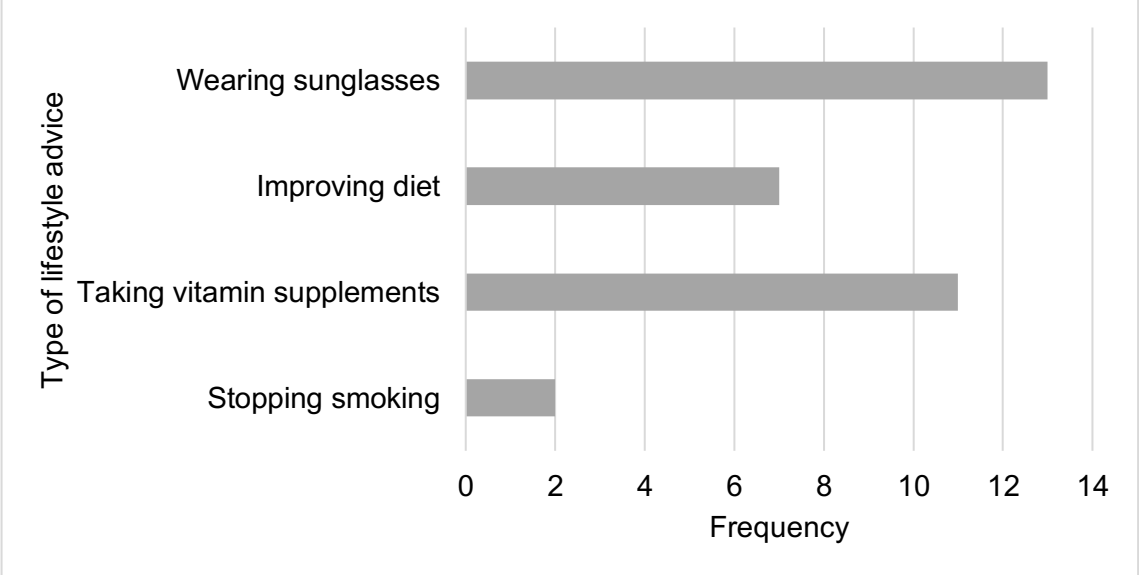


Figure 6.2- Bar chart displaying the types of lifestyle advice participants were given at their last appointment (based on survey one data from participants in follow-up survey two). Longer bars represent higher frequency of the

administration of this type of lifestyle advice. Participants were able to select more than one option.

However, only around one third of the participants who recalled receiving advice (n=9; 36.0%) reported that they had made lifestyle changes based on the advice they received. Of the remaining participants (those who reported no advice given or those who could not recall), 13.3% (n=17) reported that they had made lifestyle changes despite the lack of advice provision. Eight participants of the 17 reported that they had received lifestyle advice in survey two, but not survey one, suggesting they may have received advice from another source in the time between the two surveys. Out of these 17 participants, eight (47.1%) searched the internet for more information and seven (41.2%) contacted the Macular Society for further information. Overall, 104 participants responded to the question about whether they made lifestyle changes and, of these, 26 reported making lifestyle changes (17% of the total cohort, and 25% of those who answered the question). The proportion of patients who made a change to lifestyle after receiving advice from their ECP was higher than the proportion making a change having not received the advice, however this difference was not significant (X^2 [df=1, n=92] 3.97; p=0.05). Although, out of the 127 participants that reported not making lifestyle changes or did not answer the question, 46 (36.2%) reported already taking vitamin supplements in survey one, 89 (70.1%) were already eating oily fish at least once a week and 117 (92.1%) were eating green leafy vegetables at least once a week.

With respect to the specific changes made, out of the three current smokers, one participant reported that they had stopped smoking with the other two reporting that they had not made any changes. However none of these three participants reported receiving lifestyle advice in survey one. Thirteen (50%) of the twenty-six participants who made lifestyle changes reported that they had started to wear sunglasses more often. Finally, participants were asked about the specific dietary and vitamin supplement changes they had made. Forty-three participants answered this question and the most common changes were an increased intake of green leafy vegetables (n=10; 38.5%) and oily fish (n=9; 34.6%). Figure 6.3 shows the changes reported by

participants. Twenty-two out of the twenty-six (84.6%) participants that made lifestyle changes made at least one dietary change.

Ten out of the 26 participants that reported making changes to their lifestyle responded to say that they started taking vitamin supplements after their last appointment. Half of these respondents reported they had started taking a vitamin supplement that was AREDS/AREDS2 compliant. Of the other 143 respondents 88 (61.5%) reported in survey one that they were already taking vitamin supplements, 43 of which were AREDS compliant.

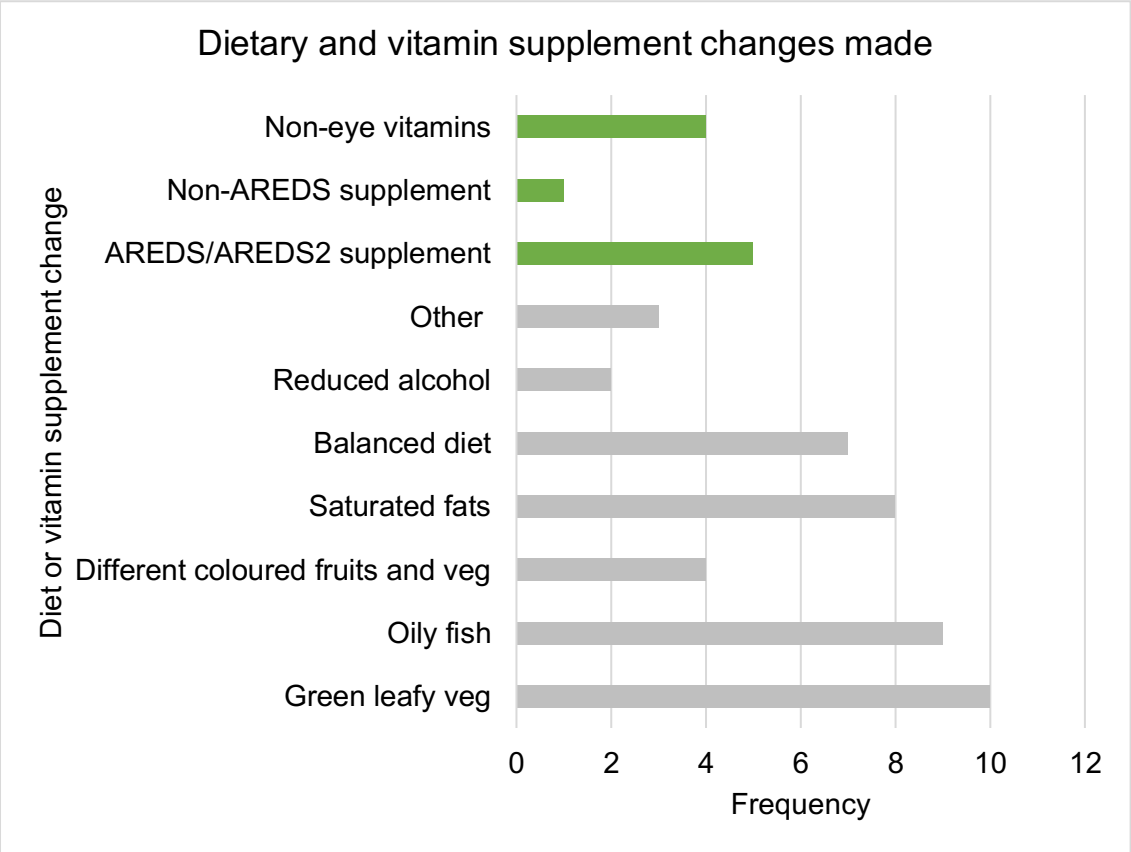


Figure 6.3- Bar graph representing the reported changes that participants made to their diet and vitamin supplements they started taking. The green bars represent the vitamin supplements participants reported taking. However, only 10 participants responded to the question. The grey bars represent the dietary changes participants made. Participants were able to select more than one option.

Participants that did not make lifestyle changes since completing survey one were asked to provide reasons for not making changes (see Figure 6.4). Out of the 78 participants that said they had not made any changes since their last appointment, the most common reason was that participants were not given any advice (n=36; 46.2%), followed by believing that they were already doing everything they were advised to (n=32; 41.0%). Of the 32 who thought that they were already following best advice, 22 reported in survey 1 regularly (at least 1-2 times per week) eating oily fish and green leafy vegetables, and 10 reported taking AREDS/AREDS2 compliant supplements. The participants that selected 'other' were asked to specify their reasons. These included quotes such as '*[I have a] very sensitive stomach and reluctance in taking any form of medication'* and '*no advice given, scans taken by a technician'*.

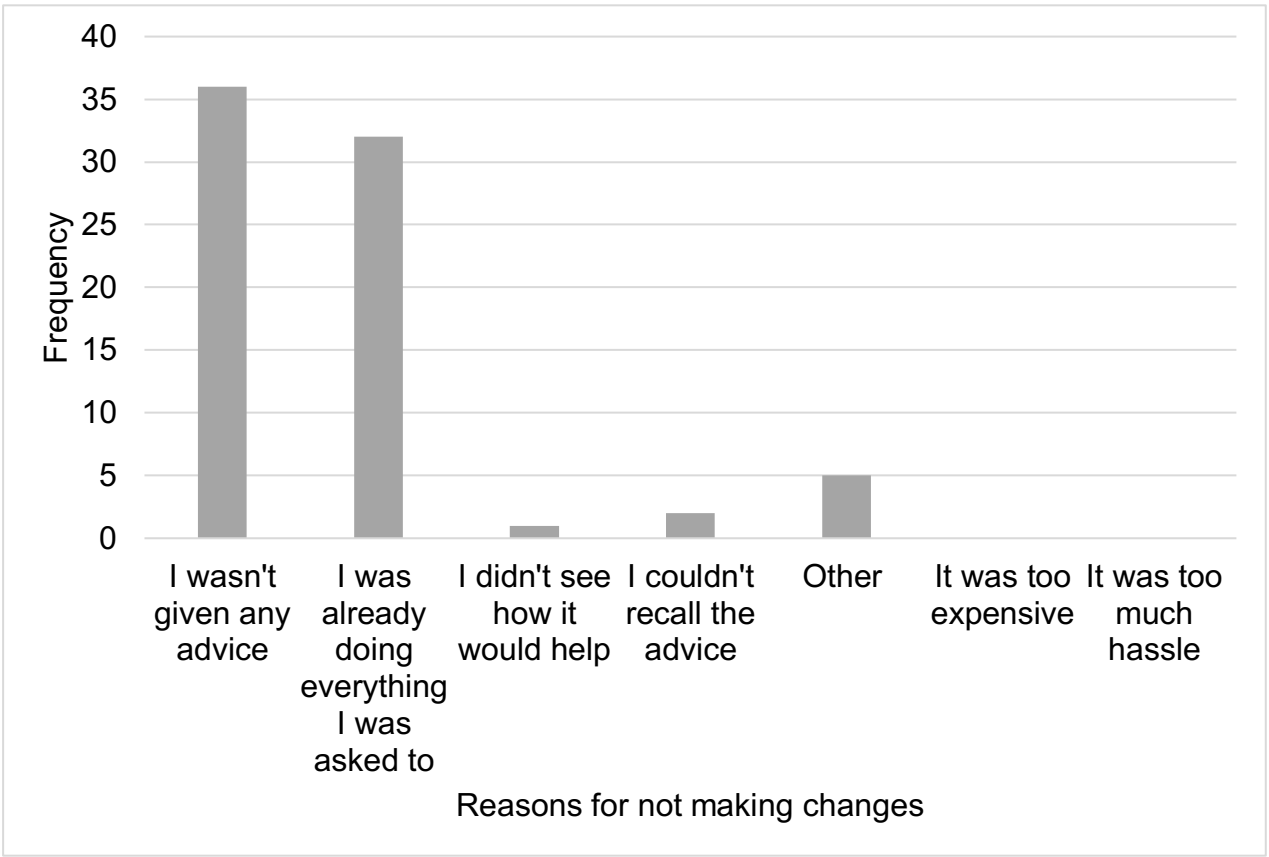


Figure 6.4- Bar graph displaying the reasons that participants selected for not making lifestyle changes. Participants were able to select more than one option. None of the participants responded to say the changes were too expensive or that it was too much hassle.

Table 6.3 displays the specific dietary advice that the 153 participants in survey two reported being offered in survey one. It also shows the proportion of those that did and did not receive a certain piece of advice (e.g. to eat more green, leafy vegetables) that reported making that specific change in survey two. There was a significant association between receiving specific dietary recommendations and making concordant dietary changes. For example, the proportion of participants that increased their consumption of green leafy vegetables was 3.99 times higher in those that received specific advice to do so, compared to all respondents to survey two that did not receive specific advice (X^2 [df=1, n=153] 5.08; p=0.02). This was also the case for participants that were given specific advice to increase their consumption of oily fish. These participants were 4.66 times more likely to have increased oily fish consumption than participants who were not given this specific advice (X^2 [df=1, n=153] 4.49; p=0.02). However, it is important to note the small number of participants.

Type of dietary advice	**Number of participants given advice**	**Number of participants given advice that made changes (%)**	**Number of participants <u>not</u> given specific advice**	**Number of participants not given advice who made changes**	**X^2 (df)**
Eat plenty of green leafy vegetables	**28**	**6 (21.4%)**	**125**	**8 (6.4%)**	**5.08 (1)***
Eat more oily fish	**15**	**4 (26.7%)**	**138**	**10 (7.3%)**	**4.49 (1)***
Eat lots of different coloured fruits and veg	11	1 (9.1%)	142	11 (7.7%)	0.24 (1)
Cut down on saturated fats	5	0 (0%)	148	9 (6.1%)	0.62 (1)
Eat a balanced diet	13	2 (15.4%)	140	7 (5%)	1.71 (1)
Reduce alcohol intake	3	0 (0%)	150	6 (4%)	0.24 (1)

Table 6.3- Table displaying the proportion of participants that were offered specific dietary advice and the proportion of participants that made the changes. * - Indicates statistically significant association.

Participants who had made lifestyle changes were asked to reflect on the difficulty of doing so, on a scale of 1 to 10, with 1 being very difficult and 10 being very easy. Overall, 50 participants responded to the question and, on average, they rated making changes to be towards the 'easy' end of the scale (median= 9.25; IQR==7.75-10). Interestingly, the number that responded to the ease of making changes was almost double the number that reported actually *making changes* (n=26). Out of the participants that responded to the question but reported not making changes (n=24), twelve participants (50%) reported that they did not make changes because they were already doing everything they were advised to do which supports the hypothesis that these participants may have made changes, but not in the three-month study period. Mann-Whitney U tests revealed there was no association between the perceived difficulty of making changes and whether or not changes were made (U=1.892; p=0.989).

In survey one, participants were asked if they were satisfied with the content of the lifestyle advice they were given and the way the advice was given (see chapter 5, section 5.3.2). A significantly higher proportion of participants who were satisfied with the content of the advice they were given (X^2 [df=2, n=104] 10.52; p =0.005), and were satisfied with the way advice was delivered (X^2 [df=2, n=104] 10.52; p =0.005) made lifestyle changes compared to those who were not satisfied. Binomial logistic regression analysis revealed that none of the demographic factors (age, gender, diagnosis, ethnicity or living arrangements) predicted the odds of making lifestyle changes (X^2 (9)= 12.89; p=0.168). Before running the analysis, the assumptions of regression analysis were tested for. The observations were independent of one another. Multicollinearity for the variables was assessed using Variance Inflation Factors (VIFs), which ranged from 1.030 to 1.352 indicating low multilinearity. The model fit was assessed using pseudo R2 measures (Cox & Snell R2 = 0.215). This indicates that the predictors in the model explain approximately 21.5% of the variability in the binary outcome variable. There was also no

association between the proportion of participants that made lifestyle changes and whether or not participants were given any written advice (X^2 [df=1, n=103] 0.095; p =0.76), or whether they had the opportunity to ask questions (X^2 [df=4, n=152] 7.07; p =0.13). The question was followed by another question to ask if there was anything that would have made it easier for participants to make lifestyle changes. Out of the 76 participants that answered the question, the most commonly selected answer was more detailed advice (n=39, 51.3%) followed by 'written advice' (n=33 43.4%), 'signposting to services that can help (n=16 21.1%). Thirteen participants selected the option 'other' and included suggestions such as '*being given vitamins/supplements as a part of being over a certain age, as a part of the NHS prevention programmes*' and '*more detailed information on diet*' and finally '*signposting to mental support and social support*'.

6.3.2 Resources contacted after appointments

Based on the co-design activity discussions described in chapter 3, a question was included in this survey to ask if participants had searched the internet for further information regarding lifestyle changes. Out of the 144 participants that answered the question, the majority (n=103; 71.5%) had not searched the internet. However, 41 participants (28.5%) reported that they had. These participants rated the helpfulness of the websites they explored on a scale of 1 to 10 (10 being the most helpful). Overall, the websites were rated as being helpful (median= 7; IQR= 2-10) and the website that participants said they would recommend to a friend was the Macular Society website (n=20; 48.8%).

Participants were also asked if they contacted any other services for more information regarding lifestyle advice. The 17 (11.1%) participants that responded only reported contacting two services, the Macular Society (n=14; 82.4%) and low vision clinics (n=4; 23.5%) (one participant contacted both). The Macular Society was rated the most helpful (median= 9; IQR=7-10) out of 10 for helpfulness. There was also no association between whether or not participants reported being given guidance on where to get further information and whether or not they contacted the services (X^2 [df=36, n=41] 46.18; p=0.119). Participants were also given an opportunity to say why the services

they contacted were helpful or unhelpful. Table 6.4 shows the themes and key quotes from this answer.

Theme	Key quotes
A lot of helpful information	"Broad range of information in one place"
	"Lots of information and counselling services"
Information not needed	"I have all the information I need at the moment"
	"I do not wish to change my lifestyle"
Written information was helpful	"[The Macular Society] have a good newsletter"
	"I consulted reliable [written] sources to give the mechanisms of wet AMD"
Never told about websites	"I was not directed towards any of the organisations"
	"I was only given a magnifier and told to crack on!"
Help with referrals and help to other services	"The low vision clinic were particularly helpful"
	"They put me in touch with the appropriate department of my local council"
The services were positive/personable	"Very confident and friendly advice given"
	"I felt understood"
Uncertainty about whether the sources are helpful	"They felt quite removed"
Difficult website to navigate	"They just kept asking me for donations, and not providing any useful information"

Table 6.4- Key themes and quotes from the answer to the question asking why certain websites were helpful or unhelpful. The themes are in order from most references to least references.

Finally, participants were asked which sources of information they found to be the most effective in informing their choices about their lifestyle with respect to their AMD. One hundred and forty-three participants answered the questions and Figure 6.6 shows the frequency of each source of information selected. Additionally, as this was a free text response, participants were able to specify which aspects of the sources they found to be the most effective. These quotes from each option are displayed in table 6.5.

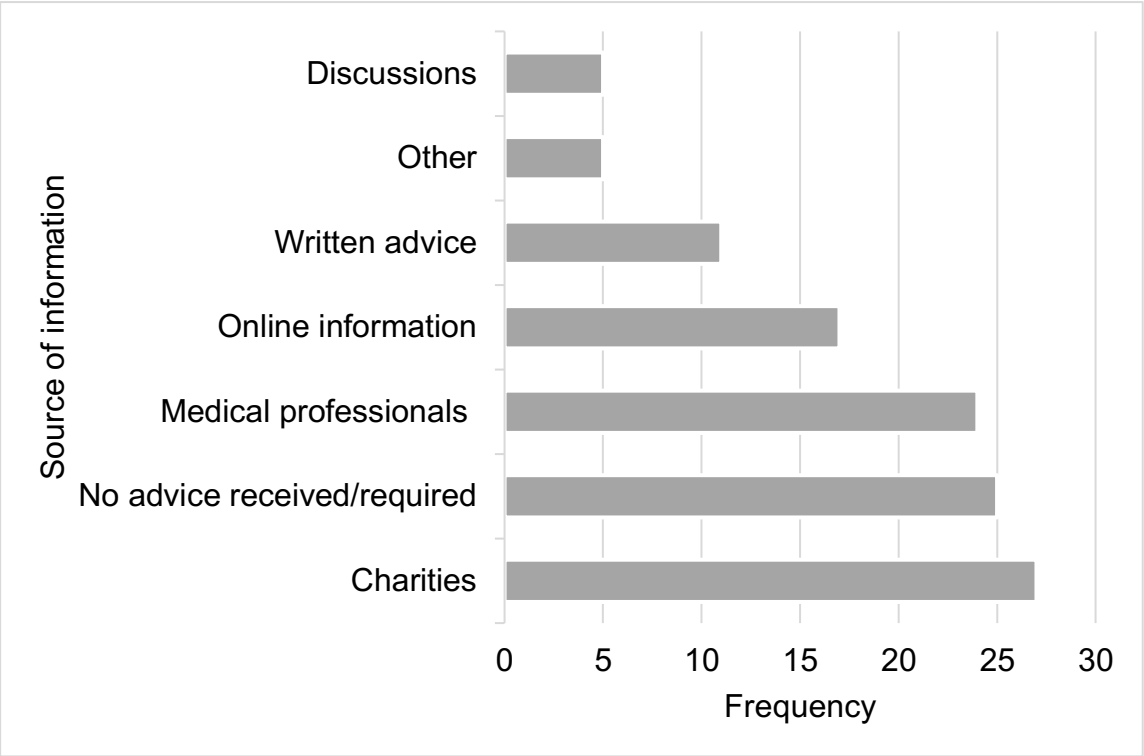


Figure 6.5- Bar chart displaying the sources of options that were specified by the participants as being the most effective. Participants were able to write more than one option.

Themes	**Key quotes**
Charities	The Macular Society keeps me up to date with recent research and with helpful articles.
	RNIB- very helpful and sent information to read
	A local charity 'Support4Sight' helped me to cope in my daily life
No advice received/required	None. I haven't looked as I am not aware of things being a matter of choice in relation to AMD.
	I have had no contact with anyone except my monthly appointments at the hospital, where lifestyle has not been mentioned
Medical professionals	Advice from practitioners and other professionals on a one-to-one basis. Explanations and analysis as to what is happening and the changes occurring help most.

	My optician has advised me for the last 3 years
Online information	I use NHS website through my local GP webpage.
	Some online information and information from hospital
Written advice	The information leaflet from The College of Optometrists.
	Booklets supplied by the clinic and advice given by them.
Other	Your contact about this survey
	The injections have most certainly improved my left eye condition and vision
Discussions	Speak to friends who also have AMD
	I am aware of what could happen because it happened to my mother

Table 6.5- Table displaying the sources of information selected by participants and key quotes from each source.

6.3.3 Perceived importance and the future of lifestyle advice

In the last section of the questionnaire, participants were asked to rate on a scale of 1 to 10 (1 being not at all important and 10 being very important) how important they thought lifestyle change is to slowing the progression of AMD. Out of the 106 participants that responded, importance of lifestyle changes was rated at a median of 6 (IQR=5-9.5) and the distribution of responses is shown in figure 6.6. Interestingly, there was no significant difference in ratings of perceived importance between those that were given the opportunity to ask questions at their most recent appointment and those who were not, determined by the Mann-Whitney U test (U= 1069, p =0.19). There was also no significant difference in importance ratings between different demographic groups.

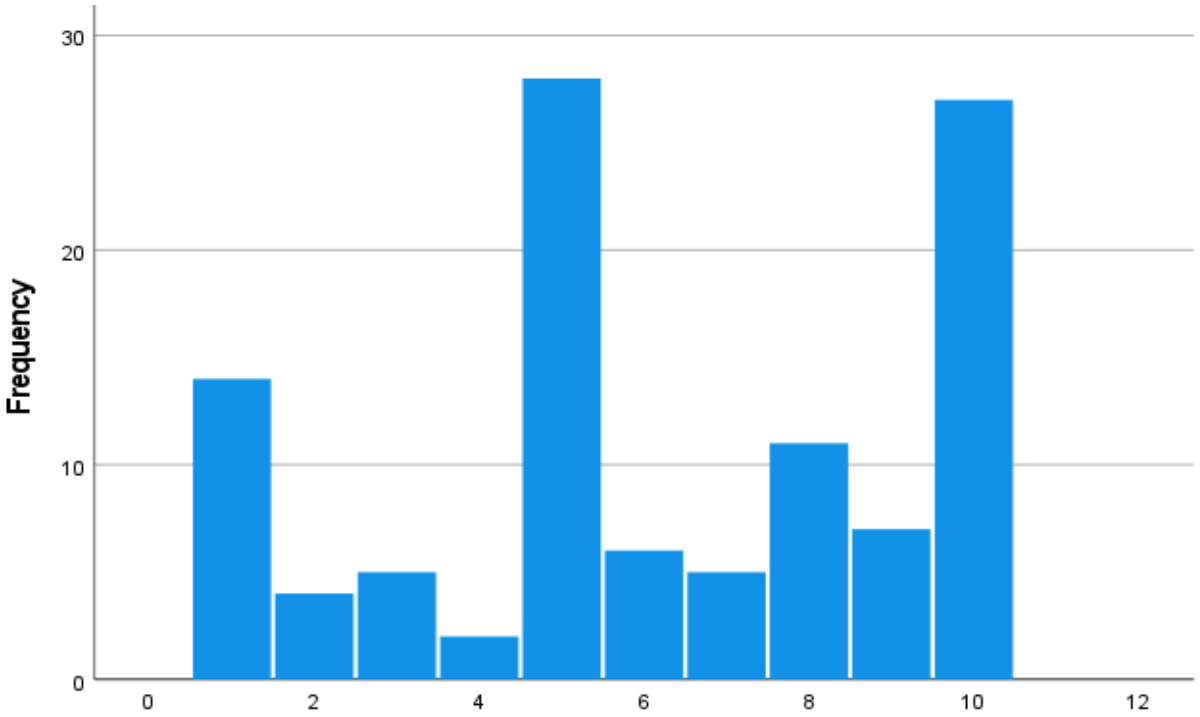


Figure 6.6- Histogram displaying the distribution of responses to the question 'on a scale of 1-10 how important do you think lifestyle change is to slowing the progression of your AMD?'. The data was not normally distributed.

Participants were also asked to specify reasons for the ratings they gave to the importance of making lifestyle changes to slowing the progression of AMD. The thematic analysis of the responses revealed that the most commonly referred to theme was 'Uncertainty about whether changes are helpful' and 'changes not required'. Table 6.6 shows the themes and key quotes from this question.

Theme	Key quotes
Already following advice and changes have helped	"Over 20 years taking supplements and eating lots of leafy green vegetables, plus eggs and certain fruits etc, have helped slow down progress. "
	"The help and advice has I feel, enabled and helped to preserve my vision , and continues to do so"
Knowing the importance of making changes	"If you are given advice it is very important to listen and make changes for your health"
	"Although it is not easy to measure whether, or to what extent, lifestyle change really does slow the progression of AMD, I think it is important to be proactive."

Making the lifestyle changes can help with other conditions	"Reducing fat in diet and overall nutritional improvement is known to help many age related diseases"
	"Lifestyle change for slowing progression of AMD is very important, as these lifestyle changes also help with other health problems."
Knowing changes can be made provides hope/motivation	"Every little helps. I have seen the devastation in my family"
	"Hopefully all changes will help with the condition of my sight"
Importance of the source of the information	"Advice given by ophthalmologist therefore 'expert' advice"
	"Always assume advice from places like [hospitals] to be beneficial"
Knowing that lifestyle changes can help with preserving sight	"Very important if lifestyle changes can slow the progression because no one wants to lose their sight and independence"
Changes made so far have been unhelpful	"Optician recommended lifestyle changes when I was first diagnosed with dry AMD which I have followed but this does not seem to have halted progression."
	"In spite of all lifestyle changes that I made, my AMD has still progressed but slowly"
Uncertainty around whether changes are helpful	"Once you have AMD there's nothing to stop it"
	"Regardless of following a good diet and taking the relevant supplements, the disease, sadly, is progressing"
	"I am unsure if lifestyle changes make any difference, feel the condition is more genetic"
Belief that the changes are not required	"My lifestyle is good, so there's nothing to change"
	"I believe the injections play a much larger part in my treatment"
No information/advice received	"As I have received no information I would not make changes"
	"I have no information on the effects of lifestyle changes but if they can make a difference then they are [very] important"
Further information/evidence needed	"Overall impression is that it is age related and there is little definitive evidence that it would improve the condition"

	"More research [will reveal] more information"

Table 6.6- Table displaying the themes and key quotes from the answers to the question about why changes were perceived to be important or unimportant. Themes are in order of most references to least references. Sections in blue are the comments that support lower ratings of importance and sections in black are the comments that support higher ratings of importance.

In terms of the future, the majority of participants that made lifestyle changes reported that they plan to keep the changes they made (n=23; 88.5% of 26 who reported making changes since their last appointment). Participants were also asked to specify reasons for anticipating keeping or not keeping the lifestyle changes. Thematic analysis showed that the most commonly referred to theme was “Positives and benefits” followed by “Preserving vision and delaying progression” (see Table 6.7).

Theme	**Key quotes**
Changes not made or required	"There was nothing to change"
Advice not given or understood	"I have made very few changes but they are healthy and will become a regular part of my life"
No evidence	"To be honest I have no way to prove or measure how much they help"
	"Need to see if any of it works."
Personalised information needed	"Have no alternative, but would have liked more tailored advice"
Positives and benefits	"As with any condition it is up to the individual to help themselves as much as possible - even small changes can make a difference"
	"The lifestyle changes I have made have been easy to implement. Knowing that these changes may help slow progression of AMD contributes to feeling more positive about living with the condition."
Preserving vision and delaying progression	"I hope my AMD will proceed as slowly as possible, so I retain as much sight as possible in both eyes"

	"Having established a routine based on this information, and I believe this to have assisted in preserving my vision, I can see no reasoning to stop"
Benefits to other health conditions	"I believe they are good for my general health, and I want to stay active for as long as possible "
UV protection	"Wearing dark glasses certainly help with glare and brightness"
	"Sunglasses cut glare"
Financial/lifestyle help	"Positive experience of supplements and alcohol reduction is at least saving money."
Research	"I am committed to the research I'm involved with"
Medical reasons	"I am still getting injection every 10 to12 weeks"

Table 6.7- Table displaying the key themes and quotes answering the question 'Will you keep the changes you made? Please provide reasons for your answers' The themes are in order of most to least references. Comments in blue support a negative expectation of keeping to changes, comments in black support a positive expectation.

Participants were also asked to specify what would motivate them to keep to the lifestyle changes. In total, 113 participants answered the question out of which, the majority selected that 'knowing it was making a difference' would motivate them the most (n=60; 53.1%). Figure 6.7 displays the other options and how the selections were distributed. For the participants that selected

'other', motivations included '*I am self-motivated*', '*Using health checker applications*' and '*Viewing images of the retina'*.

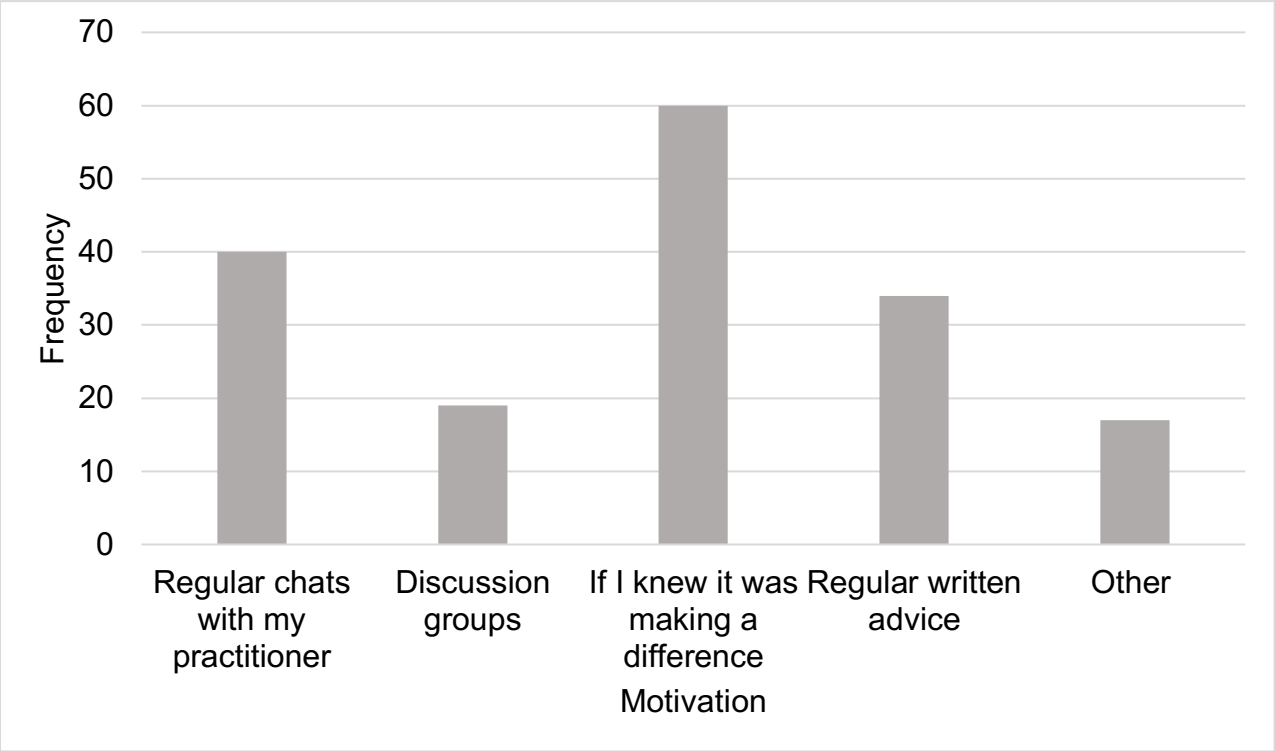


Figure 6.7- Bar chart displaying the frequency of options selected for the question about what would motivate participants to keep lifestyle changes. Participants were able to select more than one option.

Finally, similar to survey one, participants were given the option to add any further comments they may have had. The responses were thematically analysed and the key themes and quotes are displayed in table 6.8.

Theme	**Key Quotes**
Structure and timings of appointments and health discussions with HCPs	"Being talked through the findings, with images and analysis of the changes seem the only way forward in helping me to go forward."
	"No time given for questions or answers"
Injections and treatment are helpful	"I am fortunate at the present time as the injections have stabilised and I think improved my condition. My optician diagnosed it at early stage."
	"The injections are expertly given it is worth a little discomfort to preserve my sight."

Would like or already following advice	“Lifestyle choices are already built into my general health pattern of behaviour.”
	“Have never been given any lifestyle advice but would have been happy to follow lifestyle changes to preserve eyesight”
No changes made and no advice provided	“Not a lot to say, once you have AMD nothing can stop it not even a good lifestyle”
	“I have been told that vitamins etc. are a waste of money and its not going to make any difference”
Awareness that lifestyle changes can help in other areas of life	“I am nearing 75 and most people think I look young for my age; I put that down to a healthy and active life and enjoy pushing myself on my long walks.”
	“I am a recovering diabetic. I have lost a lot of weight from 175kg to 112kg.”
Understanding the value of participation in research	“I'm very interested in learning about all the research taking place”
	“By being part of a research programme and having 3 monthly appointments has helped me accept my diagnosis and changes”
More information required before making changes	“I would have appreciated more information about the condition itself, I still do not know much about the causes, how the treatment actually helps, will it get worse, will I have to have monthly appts for the rest of my life”
	“I would like to know more about taking supplements to help eye health.”
More written information and support is needed to read between appointments and to help adherence	“The macular degeneration appointments and associated tests and injections take up to 3 hours or so. Much of this time is sitting and waiting. If there was such a leaflet available to advise any do's or don'ts I feel that many people/patients would read, possibly take home and maybe adhere to good advice from NHS”

Table 6.8- Table displaying the key themes and quotes from the question asking if participants had any further comments. The themes are displayed from most to least references.

6.4 Discussion

An important finding from this study was the fact that the majority of patients (around three quarters) did not make lifestyle modifications in the three months following their last appointment. A major reason for this was the fact that many

of the participants were not given any lifestyle advice - only 16% of respondents to survey 2 reported in survey 1 being given lifestyle advice at their most recent appointment. However, other reasons included feeling like participants were already doing everything they were advised to, an inability to recall the advice, and the belief that the advice was not practical due to other health conditions. In this study we were able to tease apart some of the factors which influenced the likelihood of people with AMD making the choice to adjust their lifestyle risk factors.

6.4.1 Factors influencing likelihood of making changes to lifestyle

One unexpected finding of this study was the fact that the number of patients who reported having received advice at their most recent appointment increased from 16% of the survey 2 respondents when asked around the time of their appointment in survey one, to 24% when asked the same question 3 months later. It is possible that some of these individuals had attended further appointments in the interim period at which additional advice was provided. It does, however, also emphasise the possibility of a recall bias existing. For example, it is possible that patients received advice or information from other sources (such as the internet), other appointments or from engagements with charities like the Macular Society and mistakenly attributed this to their ECP. Recall bias is an important issue in self-report studies (Althubaiti, 2016), and represents an error introduced by inaccurate or incomplete recollection and reporting of past events. It is also possible that taking part in survey 1 and signing up to do survey 2 may have positively impacted adherence with lifestyle modifications.

Interestingly, the advice remembered by most participants was to wear sunglasses, when this is not currently a part of evidence based guidelines (Singh et al., 2023). This is due to the lack of evidence regarding the impact of UV light on macular health (Wolffsohn et al., 2022, Amari et al., 2024, West et al., 1989) and the difficulties with measuring UV light (Klein et al., 2014). However, some studies have validated the importance of protection against UV light (Tomany et al., 2004, Cruickshanks et al., 2001, Sui et al., 2013), but this evidence is limited (Zhou et al., 2018). Therefore, these findings illustrate a lack of clarity and standardized protocols and guidelines in the ECP

community about the role of light exposure in AMD progression, and emphasises that best evidence-based practice is not always followed. This was investigated in survey three (see chapter 7 for further information).

Overall, 26 participants (17%) reported having made changes to their lifestyle in the past 3 months. However, 103 participants (67.3% of the total cohort) had already reported in questionnaire 1 that they were following recommendations to some degree regarding vitamin supplements, diet (green leafy vegetables and oily fish at least once a week), and smoking, and so might not be expected to make further changes based on recent advice. This leaves 24 participants (15.7% of the total cohort) who could benefit from making changes and yet have not done so. Previous research has mainly focused on adherence to vitamin supplements and patients recollection of advice, however, the proportion of patients that comply with/recall advice in these previous studies is higher than the proportion of participants from our study (Shah et al., 2015, Chang et al., 2003, Charkoudian et al., 2008, Hochstetler et al., 2010). For example, one study reported 47 out of 92 participants recalled dietary advice and 81% of these participants adhered to the advice they were given (Shah et al., 2015). A possible explanation for the difference in our study could be that many participants were already compliant with advice and felt no further change was necessary. It could be argued that practitioners should provide more specific advice and ask more specific questions to fully gauge the patients' current lifestyle.

The main reason participants gave for not having made lifestyle changes was not having been advised to do so, which is supported by the low rate of patient reported advice provision detailed above. Analysis showed that a higher proportion of those that received advice reported making changes than the proportion of those who were not advised, supporting the importance of advice provision. Being given lifestyle advice has previously been reported as being one of the main determinants of patients with AMD changing their lifestyle (Alghamdi et al., 2023, Hochstetler et al., 2010, Shah et al., 2015). For example, in a study investigating patient adherence to AREDS supplements, one of the main reasons for patients not taking the vitamin supplements was that the advice was never provided to them (Hochstetler et al., 2010). Another

study also investigated adherence to AREDS supplements and reported that 83% of the participants that were not taking supplements could not recall being advised to take them (Alghamdi et al., 2023). This highlights the importance of training ECPs in the importance of advice provision.

Another important reason that participants reported for not making changes was that they felt that they already had all of the appropriate lifestyle behaviours in place. Of the 43 individuals (in the whole cohort) who stated this, 11 (25.6%) participants responded to questions about their lifestyle in survey 1 in a way that suggested that further changes would be beneficial in at least one aspect of their lifestyle (i.e. reported that they never consumed any green leafy vegetables or oily fish). The existence of this group highlights the risks of patients who are unaware of further changes that they could make to reduce the risk of disease progression, which emphasises the importance of checking the understanding of risk factors for progression of patients who believe that they are currently following all guidelines.

Satisfaction with the content of the advice given and the way the advice was provided were both significantly associated with the likelihood of patients making changes to their lifestyle based on the advice. Interestingly, this has been found in other areas of healthcare such as cardiovascular health and hypertension (Singh et al., 2021, Sargent et al., 2012). This research has shown that as patient satisfaction with their care increases, adherence to their medication also increases (Söylemez and Aşılar, 2023). Similarly, a systematic review from the field of dermatology noted that patient satisfaction was associated with adherence to treatments (Snyder et al., 2014). The findings from this study and previous research are significant in highlighting the importance of making a good relationship between practitioners and patients.

It was interesting to note that none of the demographic factors were significantly associated with the likelihood of respondents making lifestyle changes in the three month follow up period. Previous research on health related behaviours has shown that patients that are married and older than 50 years of age have a greater likelihood of having better health behaviours

(Chumbler et al., 2000, Deeks et al., 2009). Ethnicity has also been associated with likelihood of making lifestyle changes due to the specific challenges faced by ethnic minorities such as language barriers and cultural norms (Patel et al., 2017). However, this effect may not have been seen in our population due to the lack of ethnic diversity. Additionally, previous literature has also highlighted other factors that influence the decreased likelihood of making changes such as sociodemographic status (Kelaher et al., 2008), but this was not evaluated in this study.

With respect to written advice, although ~40% of respondents reported that provision of written advice would have made it easier for them to make lifestyle changes, there was actually no association between the likelihood of making lifestyle changes and having received advice in a written format. Research on written materials for the self-management of AMD have shown that the materials are effective in helping patients make lifestyle changes and has also shown to help with mood (Brody et al., 2002). However, this was not seen in our study findings, this could be due to the small sample size of participants that made changes (n=26; 17% of the total cohort). Another possible explanation for this finding could be that some participants may have obtained written information from other sources such as the Macular Society or the internet. Yet the freely available written information online regarding lifestyle changes for AMD have been evaluated previously and were found to be 'low quality' and consisting of 'unproven' information (Kloosterboer et al., 2021, Stone and Jumper, 2001).

Whilst research in the field of eyecare is limited, there are a number of studies in other areas of healthcare evaluating the barriers and facilitators of lifestyle modification and in many cases, one of the main barriers includes the varying beliefs about the lifestyle changes required and the benefits of doing so (Murray et al., 2012, Brummel et al., 2023). In one study, patients with prostate cancer were interviewed about their perceptions of lifestyle advice. The participants specified that one of the most important barriers to the enactment of lifestyle advice is the lack of evidence regarding the effectivity of lifestyle changes (Er et al., 2017). This finding was also supported by the results of this study, where participants specified that knowing the changes were making a

difference would make them more likely to keep to the lifestyle changes they made. However, it is important to note that in many cases, this would require further imaging, tests and hospital appointments which may result in greater burdens on patients and healthcare providers. Additionally, participants did not specify the specific type of evidence they expected to see to convince them to make changes.

More than one third of participants who reported making changes to their lifestyle since the last appointment reported starting supplement intake, and 69% responded that they had started wearing sunglasses more frequently and 84.6% of those who reported making lifestyle changes changed some aspect of their diet. In other studies on lifestyle advice and AMD, dietary advice was adhered to and recalled by patients more often than the other forms of lifestyle advice (Shah et al., 2015, Bott et al., 2018). It might be argued that making dietary changes is less financially demanding and requires less support than other lifestyle changes. However, in other ways, additional wearing of sunglasses or taking a vitamin supplement once daily may be perceived by patients as a simpler change to make than a dietary modification which permeates daily activity on a much wider basis.

The most commonly made dietary changes were increased intake of green vegetables and oily fish. This is in accordance with the current guidelines that specify patients with AMD should increase their intake of green leafy vegetables and oily fish (College of Optometrists, 2021, Royal College of Ophthalmologists, 2021), and with research evidencing the benefits of these dietary changes (Eisenhauer et al., 2017, Mozaffarieh et al., 2003, Rondanelli et al., 2023). On the other hand, the Mediterranean diet has been supported more recently with strong evidence for its benefits in early/intermediate AMD (Gourgouli et al., 2023, Hogg et al., 2017) and geographic atrophy (Angelia et al., 2024, Keenan, 2023), but this was not mentioned by the participants in this study.

Only a quarter of the patients who reported making changes started taking AREDS compliant vitamin supplements. This is only 3% of the total cohort surveyed. However, an additional 43 (28.1% of those who completed survey

2) were already taking AREDS/AREDS2 compliant supplements when first surveyed. This means that 71.9% of total respondents were not, at the time of survey 2, taking AREDS/AREDS2 compliant formulations, despite meeting criteria suggesting that they would be of benefit. Upon referring back to questionnaire 1, only 13.1% of the participants taking part in survey 2 reported being advised to take AREDS compliant supplements. This suggests that a key reason that patients were not taking the supplements was because they simply had not been advised to do so. This is consistent with previous research that demonstrated recommendations for AREDS/AREDS2 compliant supplements are not consistently given (Broadhead et al., 2015, Lawrenson and Evans, 2013). Previous studies show that despite participants meeting the eligibility criteria for the AREDS/AREDS2 formulation, a large majority of patients are not recommended vitamins (Hochstetler et al., 2010, Charkoudian et al., 2008). Our study showed that of 20 respondents in survey two who had been recommended vitamins, 30% were compliant with that advice. In other words, even when recommendations are given, adherence to taking the vitamins is low. However, an additional 30% of the participants given vitamin supplement recommendations were already taking AREDS compliant supplements. Parodi et. al. (2016) reported that in a sample of 193 patients, 52% were given appropriate vitamin supplementation advice and approximately 85% were taking supplements based on this advice (Parodi et al., 2016). The willingness of patients to take vitamins when recommended to do so may reflect a general cultural willingness in European populations to take nutritional supplements. For example, evidence suggests that between 30-40% of adults of retirement age in the UK take some form of supplement (Lentjes, 2019, NatCen SR, 2017). However, even among those who do take supplements, awareness for why they are doing so is reportedly limited. For example, in a recent study by Tsou et. al., (2021), out of 91 patients with AMD, 60.4% of patients were taking AREDS or AREDS2 supplements. However, 42.2% of these participants were unable to correctly identify why they were taking the supplements (Tsou et al., 2021). This evidence highlights the need for practitioner and patient education with regards to the benefits of vitamin supplements, and effective communication of advice to all patients who may benefit from supplementation.

The findings from this study show that specific advice was more effective than generic advice in bringing about behavioural change. For example, those patients that received advice to eat more leafy greens were more likely to have made that change than people who had not received this specific advice. When asked, half of patients who responded said that receiving more detailed advice would have made it easier to make lifestyle changes, suggesting that patients also placed importance on advice which went beyond generic statements about dietary change and healthy living.

Previous research has also shown that giving specific targeted dietary advice helps ensure that patients adhere to the advice (Deslippe et al., 2023). For example, Astbury et al., (2020) held semi-structured interviews with adults on a weight management programme. Their data suggested that one to one dietary counselling and conversations with a specific interventionist were the main facilitators to effective implementation of the dietary advice (Astbury et al., 2020). In a review discussing management of health behaviours associated with progression of arthritis, including weight management and smoking, (Knittle et al., 2012) similarly reported that specific information provision is more effective at facilitating lifestyle changes than generic advice.

6.4.2 Additional Support

Around a quarter of the participants in the study sought extra support after their last appointment via the internet. Eleven percent reported having approached support services such as the Macular Society or Low Vision Services. The importance of adequate extra support services for patients has been highlighted in a number of interventional studies (van der Laag et al., 2023, Verheijden et al., 2005), with research showing that extra support leads to an increase in adherence to changes (Cohen Rodrigues et al., 2022). It has been reported that, as far back as 2013, there was an improvement in the number of patients being given information on the Macular Society and other support (Boxell et al., 2017). However, in our first survey only 31.2% of participants reported being signposted to such services. It is possible that more participants in survey two would have contacted these services had they been given advice to do so (see chapter 5). However, many of the participants in this study highlighted, during the qualitative portions of the questionnaire,

that they did not have access to the internet which may have limited their access to these services regardless of information given. Signposting of supportive services and provision of written advice were also identified by respondents as factors which would have helped them to make changes. These findings emphasise the need to ensure that participants are given help in a range of formats, including written information, which is a recommendation also specified in the NICE guidelines (NICE, 2018b), as well as signposting to other resources such as websites, support groups and low vision clinics.

6.4.3 Patient perceptions of the importance of lifestyle modification

Participants were also asked to rate how important they perceived lifestyle modification to be to their risk of AMD progression. Participants overall did not rate the importance of making lifestyle changes to the progression of AMD very highly (the average rating was ~6, where 1 indicated a score of not at all important, and 10 of very important). Furthermore, perceived importance was not associated with whether or not lifestyle changes were made. Reasons for why participants believed that lifestyle changes were not important included the uncertainty around whether changes are helpful and the need for further information and evidence. There were still many participants that believed there were more important factors for slowing AMD progression, including injections.

Research on the importance people with AMD ascribe to making lifestyle changes is limited, but one study investigated patients' opinions on the necessity of making specific lifestyle changes (Shah et al., 2015). They reported that smoking cessation was perceived to be important by the highest proportion of participants (80%) and the lowest proportion of participants perceived dietary modifications as being necessary (62%). However, despite the relatively low importance ascribed to dietary modification, 81% of participants adhered to the dietary advice they were given but none of the participants adhered to the smoking cessation advice (Shah et al., 2015). The findings from this study and our study therefore show not only the need for ECPs to provide further information on the importance of lifestyle changes, but also that perceived importance alone may be insufficient to bring about a

change without other supportive measures being in place e.g. access to smoking cessation services.

6.4.4 Limitations and future work

It is important to note that there are some limitations in this study. Firstly, although the response rate for the survey was relatively good, with 38% of respondents to survey 1 competing survey 2, approximately 62% of the study population in survey one were unrepresented in this study. This means that the findings may not be generalisable to the cohort that was included in survey one, or to the wider population. This could be because many of the participants in survey one reported not have been given any advice (n=300; 84%), and therefore would not have anything to contribute to survey two. Therefore, this survey may have been limited by there being too much emphasis on one appointment. It is also likely to have been the more motivated individuals, or those with particularly strong opinions, who were inclined to return the follow up survey. Another potential source of bias is that taking in the survey itself may have impacted on the behaviour of participants by drawing their attention to the importance of the advice (a phenomenon known as the Hawthorne effect (Nossaman and Nossaman, 2022)). For all patient reported studies, a common limitation is and that they may be restricted by how much of the advice patients recall. However, it may be argued that advice presented in a way that is readily forgotten by patients has not been effectively delivered.

There was a particularly low response rate for certain questions, which reduced the generalisability of the findings. Moreover, unilateral nAMD was the most common diagnosis. This was likely to reflect the recruitment of the majority of patients through hospital AMD clinics, which routinely only see and treat patients with nAMD, also reducing the generalisability of the sample. However, despite the attrition in sample size, the distribution of where the responses were from reflects a similar distribution across the sites compared to survey one (e.g. in survey one 35.14% were participants from Moorfields and in survey two 33.99% participants were from Moorfields).

The low response rate to some items also impacted on the power of the statistical analysis. This was particularly problematic when evaluating the

association between different factors and the likelihood of individuals having made lifestyle changes, as only 26 individuals reported having amended their behaviour since the last appointment. An additional limitation in exploring the factors impacting on behavioural change was that the participants that made lifestyle changes were not asked what made them make these modifications. If asked, participants would have been able to provide valuable insight into what was working, and how this could be implemented into other appointments.

Finally, as this is a self-reported study, individual factors based on recall or comprehension of the survey may have influenced how participants answered each question. For example, there may have been cases where participants misunderstood questions or may have been unclear in describing the advice received. We attempted to mitigate this by testing our survey on co-design activity group participants (see chapter 3), however, this could have been further avoided by using structured interviews rather than a survey based approach which may have provided a more in-depth exploration of the patient experience (Moss et al., 2012). This would have allowed a greater opportunity for participants to explain their answers, and for the interviewer to clarify their questions. Although logistically, carrying out interviews with such a large sample would have been challenging and the response rate for this approach may have been lower. For all patient reported studies, a common limitation is that they may be restricted by how much of the advice patients recall. However, it may be argued that advice presented in a way that is readily forgotten by patients has not been effectively delivered. There is also always a risk of response bias in self-report studies, with patients self-reporting more positively than is actually true, but this risk was minimised by anonymity, by the survey not being conducted by the patient's eye care provider but by researchers, and by the questionnaire not being conducted in person (Althubaiti, 2016).

Future research using structured interventions and interviews with participants over longer periods of time following diagnosis would be informative. Furthermore, it would be interesting to see if there is a disparity between participants' perceptions of their lifestyle habits and advice received and the

perception of health care professionals. Survey three was designed to investigate this practitioner perspective (see chapter 7).

6.5 Conclusion

In conclusion, this study highlights some key issues with the current state of advice provision to patients with AMD and also provides insight into patient perspectives of what information is important, and what methods of advice provision can ensure that patients adhere to the changes that are recommended. The factors which were identified by patients as being the biggest barriers to making lifestyle changes were lack of advice provision and the perception that they were already following all appropriate advice, despite the fact that our data has shown this not to be the case. It was also found that satisfaction with the content of lifestyle advice and provision of specific information (found in survey one) are vital to a patient's decision to make lifestyle changes. Additionally, participants that were given specific advice such as green leafy vegetables and oily fish were more likely to make changes consistent with that advice than those that were given non-specific advice such as 'eat a balanced diet'.

An important finding from this study is that only around one quarter contacted other support services via the internet. In conjunction with the limited written information provided by ECPs, this results in a majority of patients lacking access to written materials which can be perused at a later date. Participant perceived importance of making lifestyle changes was influenced by whether or not they were given the opportunity to ask questions and the key reasons for not perceiving lifestyle changes to be important included the uncertainty of whether the changes are helpful and the belief that changes are not required if other treatments are being given or if participants are already living a healthy lifestyle.

Overall, this study shows that there are still a number of gaps in the provision of lifestyle advice and the adherence to the changes that should be addressed by health care professionals and governing bodies.

7. What is the practitioner experience of lifestyle advice provision for patients with Age related Macular Degeneration (AMD)?

An abridged version of this chapter is under review for publication (Dave, S., Binns, A., Vinuela-Navarro, V., Callaghan, T. (2024). British Journal of Ophthalmology. *Under review.* See Appendix L). Author SD was responsible for contributing to the study design, collecting the data, analysing the data, and writing the manuscript. The other authors also contributed to study design and reviewed the manuscript draft. The STROBE checklist for this chapter is provided in appendix I.

7.1 Introduction

Previous work (chapter 5) has focused on the patient experience of receiving lifestyle advice, and has explored the factors which influence people making lifestyle changes based on the provision of advice (chapter 6). Patients in surveys one and two recommended how lifestyle advice provision can be more effective from their perspective. To facilitate these recommendations being accepted we investigated the practitioner barriers to effective lifestyle provision.

Previous literature on GP practice behaviours has highlighted several barriers to lifestyle advice provision. A study in Poland found that over 50% of the GP's in their cohort (n=161) provided lifestyle advice, but this was more commonly given to patients with a chronic health condition (Znyk and Kaleta, 2023). The main barrier to lifestyle advice provision in this study was a lack of time. Similarly, a UK based study exploring GP attitudes and experiences of providing lifestyle advice to patients with depression found that the most significant barriers were a lack of time and inadequate training (Astaire et al., 2024). However, they also highlighted that advice provision would only be effective if there was a good rapport between patients and practitioners which can take time to build.

There is currently limited evidence regarding the barriers to the effective provision of lifestyle advice for AMD or, indeed, for other eye conditions. One

study by involved focus groups with 65 Australian optometrists that were asked about what they perceived to be the main barriers to AMD care. The main barriers included poor eye care pathways, poor disease understanding and cost of care or funding (Jalbert et al., 2020). With relation to provision of lifestyle advice, Jalbert et al. reported that some practitioners felt that they lacked the requisite knowledge of current evidence-based guidelines for AMD management. This is consistent with other studies which have reported that lack of knowledge and limited access to evidence present barriers to effective eyecare advice provision (Alnahedh et al., 2015, Suttle et al., 2015, Suttle et al., 2012). However, these studies were all based in Australia, where care pathways and guidelines vary from the UK. Despite this, the lifestyle advice that practitioners are recommended to provide to patients is consistent throughout global guidelines (see chapter 1, section 1.8). In other aspects of healthcare, the following factors have been highlighted as barriers to provision of effective healthcare advice; lack of practitioner knowledge (Crowley et al., 2019, Macaninch et al., 2020, Chatterjee et al., 2017), lack of practitioner self-confidence and lack of confidence in the effectiveness of lifestyle interventions (Brotons et al., 2005) and a lack of time (Douglas et al., 2006, Lambe and Collins, 2010, Geense et al., 2013). Further evidence also states that practitioners are also influenced by their own lifestyle. For example, practitioners who smoke are less likely to provide smoking cessation advice and those that exercised felt more confidence advising physical activity (Brotons et al., 2005).

Hence, even though there are studies exploring practitioners' experience of AMD management, there is very little information on practitioners perspectives of barriers to providing effective lifestyle modification advice to patients with AMD. Additionally, the research has mainly been with optometrists and there is limited information on other eye care professionals such as ophthalmologists and practice nurses. The aim of this study was to investigate the experience and opinions of different types of ECP in England when it comes to the provision of lifestyle advice for AMD. We also aimed to understand what practitioners perceive to be the main barriers to effectiveness of lifestyle advice provision for AMD and how these might be overcome.

7.2 Methods

7.2.1 Participants

Based on the recruitment methods described in chapter 4 section 4.4, practitioners from all of the sites that took place in survey 1 (see chapter 5, section 5.2) along with practitioners from across England were invited to take part in this study between November 2022 and June 2023. Practitioners were only included in the survey if they were currently practicing as eye care professionals in England. There were no other inclusion or exclusion criteria.

7.2.2 Practitioner survey

The third survey in this project was created based on the patient discussions described in chapter 3 and literature surrounding the practitioner experience of providing lifestyle modification advice to patients with AMD. Once the survey was created, meetings were held with three Optometrists that were asked to review the questions and provide feedback. This process is described in further detail in chapter 4, section 4.4, and the final survey can be found in Appendix G.

Prior to beginning the questionnaire, participants were all asked to read the consent form and provide their electronic signature confirming informed consent. The final survey consisted of three main sections; the first section collected optional demographic information. Specifically, the participants' gender, profession, setting in which they practiced and number of years that they have been practicing.

The second section of the questionnaire was mainly focused on participants' practice behaviours. Based on the co-design activity group conversations (see chapter 3) regarding the patients feeling like there was not enough time during appointments to discuss lifestyle, and evidence from other fields of healthcare that time limitations are a key factor preventing lifestyle advice provision (Douglas et al., 2006, Lambe and Collins, 2010, Geense et al., 2013), the first half of this section mainly consisted of questions regarding the amount of time spent with patients in the clinics. Participants were asked how many patients they saw per week on average and how long each appointment was for an older patient. Additionally, they were asked if they had flexibility to extend

appointments and if they felt they had enough time to spend with each patient. The second half of the section was focused on the information that practitioners would usually collect from older patients that have AMD or are at risk of AMD progression. This included questions about whether or not the participants asked patients about their current dietary habits, smoking and other lifestyle-based questions.

The final section was focused on the participants' practice behaviours when it comes to providing lifestyle modification advice to patients with AMD. Following on from section two, they were asked how long they spent discussing lifestyle with patients, whether or not they provide lifestyle advice and how that advice is delivered. Additionally, participants were asked to explain their answers to fully understand their reasons for their practice behaviours. Participants were then asked specific questions about what written material they provide to patients, whether or not they inform patients about why they should make lifestyle changes and what sources of evidence they use to inform their views on the benefits of lifestyle change for AMD. Participants were also asked if the patients' other health conditions are considered when providing advice, and whether they follow up any advised changes with patients at subsequent appointments. Finally, participants were asked to provide their opinion on what they perceived to be the main barriers to effectiveness of lifestyle advice provision and if anything would facilitate providing impactful lifestyle advice.

7.2.3 Analysis

The quantitative data collected from this survey was analysed using Microsoft Excel version 2407 for frequencies and percentages and IBM SPSS 25 for in-depth descriptive analysis. Standard deviations and histograms were used to establish if the continuous data was normally distributed. Only one question in this survey collected data that was continuous and was not normally distributed, therefore Mann-Whitney-U tests were used to compare differences between groups (e.g. differences in time spent with patients discussing lifestyle factors between those who did or did not provide written advice). Kruskal-Wallis H tests were used to compare differences between variables with 3 or more groups (e.g. differences in time spent with patients discussing

lifestyle factors between professions). Cross-tabulations were used to display contingency tables and describe associations between groups and chi-square tests of independence were used to test for the statistical significance of the associations or differences. A p-value of <0.05 was considered to be statistically significant. For the free text question responses, the frequency of words and phrases used to describe the patient experience were thematically analysed using Microsoft Excel and NVivo12. Based on the responses, each point was coded into a different section (node) and then grouped to form the themes for each question. These nodes and themes were independently reviewed by supervisor TC and any disagreements were taken to supervisors AB and VVN for final decisions (see chapter 1, section 1.10 and 3.2.2 for a full description of the process). For free-text questions with 10 or less responses, a thematic analysis was not conducted as the was inadequate data to create the nodes and themes for a thematic analysis (Vasileiou et al., 2018).

7.3 Results

Out of the 10 hospital sites, 20 high street optometry practices, and arising from social media advertising, 55 practitioners opened the survey link to complete the questionnaire. In total, fifty-four practitioners completed the questionnaire and were included in the study analysis, one participant entered their name and only answered the first question, so they were not included in the study. All questionnaires were completed online. Table 7.1 shows the demographic and practice types of the participants. The majority of participants were female (n=42; 77.8%) and there was a fairly even distribution between ophthalmic nurses (n=22; 40.7%), optometrists (n=17; 31.5%) and ophthalmologists (n=14; 25.9%). Most of the participants worked in hospital settings (n=44; 81.5%), with a smaller number in independent practices (n=10; 18.5%), and multiple practices (n=6; 11.1%). Participants working in more than one setting were able to select multiple options. Importantly, the majority of the participants in the study had been practicing for more than 10 years (n=33; 61.1%), with only around 10% having qualified within the last 3 years.

Similar to the patient surveys, participants were also recruited from multiple locations around England. Figure 7.1 shows the locations that participants

reported practicing in. The majority of participants practiced in the same locations that patients in survey one and two were located (n=49; 90.7%), however, five participants (9.3%) were recruited from new places (Newcastle, Peterborough, Manchester, Wolverhampton and Bolton).

	Frequency (%)
Gender	
Female	42 (77.8%)
Male	12 (22.2%)
Profession	
Nurse	22 (40.7%)
Optometrist	17 (31.5%)
Ophthalmologist	14 (25.9%)
Other	1 (1.9%)
Practice setting*	
Hospital	44 (81.5%)
Independent practice	10 (18.5%)
University Clinic	7 (13.0%)
Multiple practices (Boots, Specsavers etc.)	6 (11.1%)
Number of years practicing	
More than 10 years	33 (61.1%)
4 to 6 years	8 (14.8%)
7 to 10 years	8 (14.8%)
1 to 3 years	4 (7.4%)
Less than a year	1 (1.9%)

Table 7.1- Table outlining the participants demographic factors and practice experience and location in order to most to least prevalent. *- indicates a question where participants could pick more than one option.

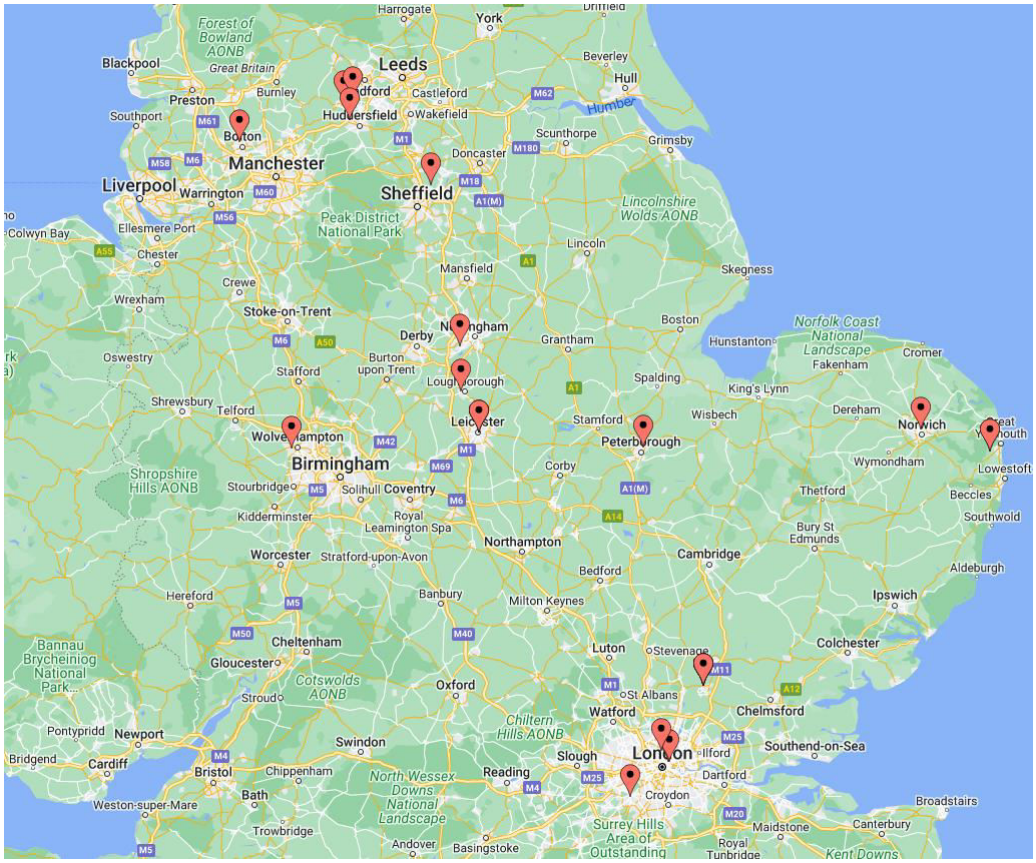


Figure 7.1- Figure displaying a map of England with red pinpoints showing the locations that the practitioners included in this study reported practicing.

7.3.1 Practice behaviours and discussion of risk factors

Although most participants in this study reported working in a hospital setting, participants were also asked about their individual practice behaviours. The majority of participants reported that they saw more than 60 patients per week (n=19; 35.2%) and reported that on average, an appointment for an older adult would be less than 20 minutes (n=18; 33.3%). However, these times differed between the participants of different professions. Table 7.2 displays the average number of patients seen by each profession and length of appointment.

Profession	Number of patients seen per week				Average appointment duration			
	< 20	**21 to 40**	**41 to 60**	**> 60**	**< 20 minutes**	**25 minutes**	**30 minutes**	**35 minutes or more**
Ophthalmologist	3	3	1	7	7	5	1	1
Optometrist	1	4	7	5	2	4	4	7
Nurse	5	6	5	6	8	6	6	2
Other	0	0	0	1	1	0	0	0

Table 7.2- Table displaying the frequencies of how many patients are seen each week and duration of the appointments by each professional.

There was no significant relationship between profession and average appointment duration (X^2 (9)= 9.02, p= 0.436). Although, most of the participants (n=18; 33.3%) reported that they spent less than 20 minutes with patients, most of these participants felt that this was 'usually' a sufficient amount of time (n=14; 77.8%). The remaining four participants felt it was sometimes sufficient (n=2; 11.1%), rarely sufficient (5.6%) and always sufficient (n=1; 5.6%). Three of the participants who had less than 20 minutes per patient commented, *'Insufficient time for those that are older or more complex'* or '*patients are booked at 10 minute intervals some require much more than this and I feel we do not have enough time to spend with each patient*'. The last participant that commented said this would be sufficient time '*provided all the investigations are done beforehand'*. When asked about the investigations such as visual fields, tonometry and imaging, the majority of participants said the tests were carried out separately to the appointment (n=46; 85.2%). Additionally, considering the importance of time to discuss lifestyle modification, participants were asked if they had the flexibility to extend appointments if they felt it was necessary. Most of the participants said they were able to extend or rebook appointments if needed (n=42; 77.8%),

although it was not clear whether patients would be given another appointment only for advice provision.

Figure 7.2 shows the lifestyle factors and that were asked about by each type of professional. There was no significant difference between the professions with respect to asking about smoking (X^2 (9)= 8.84, p= 0.453), diet (X^2 (9)= 10.86, p= 0.285) or any other questions (X^2 (6)= 5.09, p= 0.532). In general, practitioners reported asking about smoking more than dietary habits (n=31 (57.4%) reported regularly asking their patients about smoking, and n=13 (24.1%) about diet).

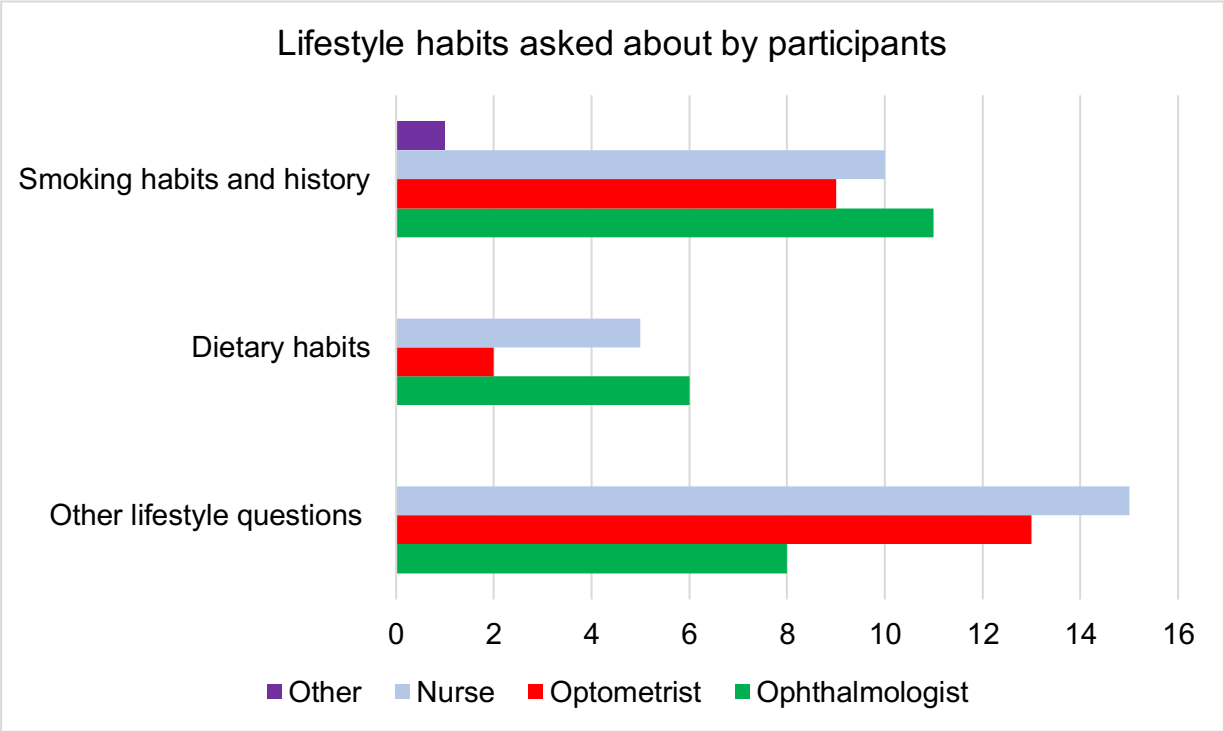


Figure 7.2- Bar chart displaying the lifestyle factors and the proportion of practitioners that asked about each factor.

Participants were asked to report the factors they ask about with respect to lifestyle. For the question about smoking, 27 out of 54 participants wrote comments detailing the specific questions they ask patients with AMD and what factors determine whether or not smoking is asked about. Out of the seven themes that emerged, the most commonly discussed themes were 'lack of time and clinic roles and clinic set up' and 'depends on the individual patient characteristics'. Table 7.3 shows the themes and key quotes from each theme.

Theme	**Key quotes**

Lack of time and clinic roles and set up	"Time restraints"
	"Presume already asked at referral"
Depends on individual patient characteristics	"Tend to ask if family history or signs of Cardio Vascular Disease (CVD)"
	"If a patient has a family history of AMD or has early signs of AMD. Or if they smell smoky"
Mentioning that lifestyle changes can help with general health and other conditions	"discuss smoking cessation If appropriate in relation to general health and eye condition- explain about further risks"
	"to advise on health promotion"
Asking about smoking details	"how many/would you like to stop"
	"document if current or ex smoker and how many per day and how many years etc"
Knowing lifestyle factors are a risk associated with AMD	"Important risk factor"
	"relevant to AMD risk"
Dependent on condition or on casual basis only	"If I think it's relevant to their condition or prompted for health advise I will usually ask re smoking"
	"Casual, not mandatory"
Always asking about smoking	"I always ask about current status of smoking"

Table 7.3- Table showing the comments written under the question 'do you ask patients about their current/history of smoking?'. The themes are listed in order of number of references from most to least.

Most of the participants reported asking patients about their diet 'sometimes' (n=26; 48.1%) whereas only thirteen out of fifty-four participants (24.1%) reported that they always asked. The participants that said they did not ask were asked to comment on why. Ten participants wrote responses to this such as '*information taken on initial referral*' or '*I inform them of the dietary additions that can slow progression of AMD but do not try to explore their dietary habits*' or '*Because I suggest patients eat a diet rich in leafy green vegetables, but it does not change my management for me to know if patients eat green vegetables or not.*'. However, two participants felt that diet was not relevant to

the issue, for example, '*no time, mostly irrelevant to presenting problem*' and *'[dietary information] does not change my management of patients'*.

Participants were also asked to specify what dietary advice they give and the thematic analysis of these responses showed that there were 7 themes. The most commonly discussed theme was 'fruits and vegetables' followed by 'general dietary advice'. Table 7.4 shows the themes and key quotes from each theme.

Theme	**Key quotes**
Fruits and vegetables	"5 a day fruit and veg"
	"How frequently do you eat vegetables?"
	"Intake of leafy greens / supplements"
General dietary advice	"Diet relevant to AMD"
	"Do you consider your diet to be healthy and varied"
Recommendations of dietary supplements	"Discuss diet and supplements"
	"Do they take any additional supplements"
Oily fish/omega 3	"Healthy diet including omega 3"
	"Leafy greens, oily fish, water intake"
Other sources of help/health conditions	"Make suggestions using the macula society diet booklet to give to them"
	"Health conditions/hobbies and interests"
Providing advice as a part of routine in clinic or a part of research	"Part of conversation"
	"As part of research I may need to ask about how they manage their condition"
Understanding if patients have access to meals	"Are you able to have regular meals or access a well balanced diet"

Table 7.4- Table showing the comments written under the question 'do you ask patients about their dietary habits?'. The themes are listed in order of number of references from most to least.

Finally, the majority of participants reported that they asked about lifestyle factors other than smoking and diet (n=36; 66.7%). Out of these participants,

25 wrote specific comments about the other lifestyle factors. The most commonly discussed theme was ‘exercise’ and ‘hobbies’. The themes and number of references in each theme are displayed in figure 7.3.



Figure 7.3- Bar chart displaying the number of references made to each theme under the question ‘do you ask any other questions about the patients’ current lifestyle?’ The length of the bar represents the number of references in each theme. *- this theme referred to 3 references, one about recent falls, one about computer screen time and one about general vision problems.

7.3.2 Lifestyle advice provision

Out of the 54 participants included in this study, 47 (87%) of participants said that they provide patients with lifestyle modification advice. Six participants (11.1%) said they did not provide patients with advice and one participant did not answer the question. However, there was no association between whether or not lifestyle advice is given and any of the demographic factors such as gender (X^2 (2)= 2.29 p=0.32) or profession (X^2 (6)= 11.69 p=0.07) and the likelihood of providing advice was not associated with number of years practicing (X^2 (4)= 4.03 p=0.40) or type of practice worked at (X^2 (10)= 5.37

p=0.87). Amongst the participants that said they did not provide advice, three participants provided explanations such as *'not routinely'*, *'find it not necessary'* or '*Not within my remit of research nurse, but I may have a general conversation about their overall health*'.

Participants were also asked how many minutes they spend on average discussing lifestyle advice with patients. On average, participants reported spending a median of 3 minutes (IQR 3-5) discussing lifestyle modification with patients. Kruskal-Wallis tests showed that there was no significant association between the time spent discussing lifestyle modification and profession ($H(3)= 3.861$, $p= 0.277$), type of practice ($H(9)= 5.61$ $p=0.78$) and number of years practicing ($H(4)= 1.23$ $p=0.87$). Participants were also given the opportunity to explain their reasons for their responses. The most common themes were 'diet and exercise' and 'patient questions'. The themes and key quotes for this question are shown in table 7.5.

Theme	**Key quotes**
Providing standard advice on diet and exercise	"A quick, eat healthy, more greens, reduced UV exposure, no smoking and give them a leaflet"
	"tell them dietary inclusion of green leafy vegetables and coloured fruits and vegetables help. Tell them central obesity is a risk factor for progression of AMD and addressing that may help."
Only providing advice if the patient asks questions	"Only if asked by patient"
	"I feel that is sufficient given that there the other anxieties that the patient will have other worries about their vision."
	"Enough time to cover AMD risk factors and answer questions if necessary. Time taken will be longer if patient has more questions"
Smoking cessation advice	"I suggest they stop smoking"
Difficulties providing advice due to time restraints	"it's the time the appointment allows depending on how busy clinic is."
	"Don't have a lot of time to spend any more."
	"Mainly mention benefits of well balanced diet full of leafy greens and vits"

Taking time to explain the benefits	"I go through the main lifestyle changes that reduce the risk of AMD"
Standard advice on UV protection	"A quick [comment that said] reduce UV exposure"
	"Good UV protection"
Providing patients with written information	"Include a leaflet for them to take away"
	"I go through the main lifestyle changes that reduce the risk of AMD, then I provide then with a leaflet that includes everything in detail "
Recommendation of vitamin supplements	"If have drusen recommend lutein vitamins"
	"Consider AREDS2 supplementation and a Mediterranean diet"
Explainign the importance of injections and monitoring	"I inject diagnosed and prescribed patients"
	"[I suggest] self-monitoring"

Table 7.5- Table showing the comments written under the question 'How many minutes on average do you spend discussing lifestyle factors? Please explain your answer.' The themes are listed in order of number of references from most to least.

Participants were also asked how they provide the lifestyle advice to patients and these findings are shown in figure 7.4. The most common mode of advice provision was a 'face to face discussion' followed by 'written information'. Participants that selected 'other' were asked to specify. Responses included *'supplement samples'* , '*I offer and explain how to access these services*', *'Macular society leaflets and websites'* and *'We have leaflets informing on wet and dry AMD'*. Interestingly, participants that provided written information to patients spent longer discussing lifestyle factors during appointments than those that did not (*U= 235.5, p=0.03)*. Participants that had face to face discussions also spent longer discussing lifestyle compared to those who did not have a face to face discussion (*U= 27.0, p<0.001*). Additionally, participants that referred patients to voluntary sector groups also spent longer discussing lifestyle compared to those who did not (*U= 117.5, p=0.03)*.

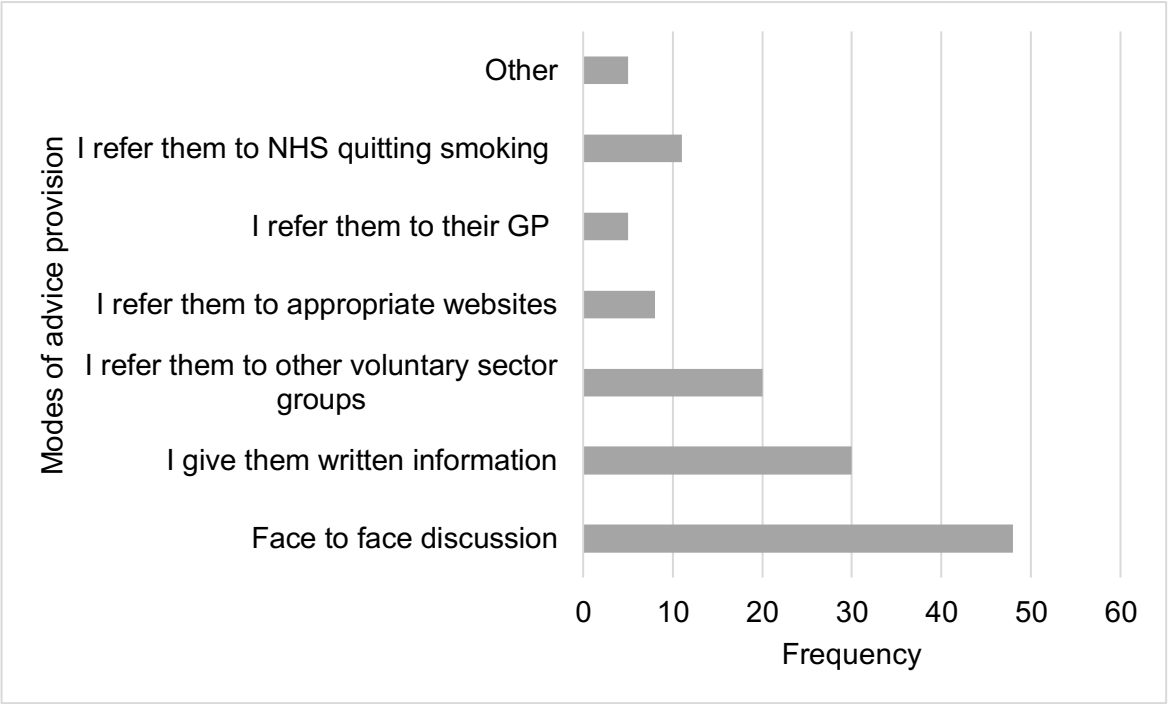


Figure 7.4- Bar chart displaying the frequencies for each mode of advice provision reported by practitioners. Participants were able to select more than one option.

Participants that reported providing written information (n=30, 55.6%) to patients regarding lifestyle modification advice were also asked what specific written materials they provide. The majority of participants reported providing leaflets (n=25, 83%) and providing contact information for charities (n=13, 43.3%). Although preferred by patients (see chapter 5, section 5.3), a personalised letter was only provided by 5 participants (16.7%). Participants were also able to select 'other' and were asked to specify. Responses included *'[I] don't tend to use apps as when I mention to many patients they say they can't use them'*, *'Diaries'*, *'An Amsler grid'* and *'supplement leaflets'.*

An important point from the co-design activity discussions (chapter 3, section 3.3) and the patient survey (chapter 5, section 5.3) was the patients' desire to understand why they should make the lifestyle changes. Participants in this survey were asked if they provide patients with reasons for why they should make changes and the majority of participants said they did tell patients why (n=47, 87%) and only 4 participants said they did not (7.4%), but did not provide their reasons for not doing so.

Finally, participants were asked what sources of evidence they used to inform their views on the benefits of lifestyle changes in AMD. These findings are shown in figure 7.5. The most commonly used source of evidence was 'knowledge from CPD' (n=38, 70.4%) and 'NICE/RCOpth guidelines' (n=32, 59.3%).

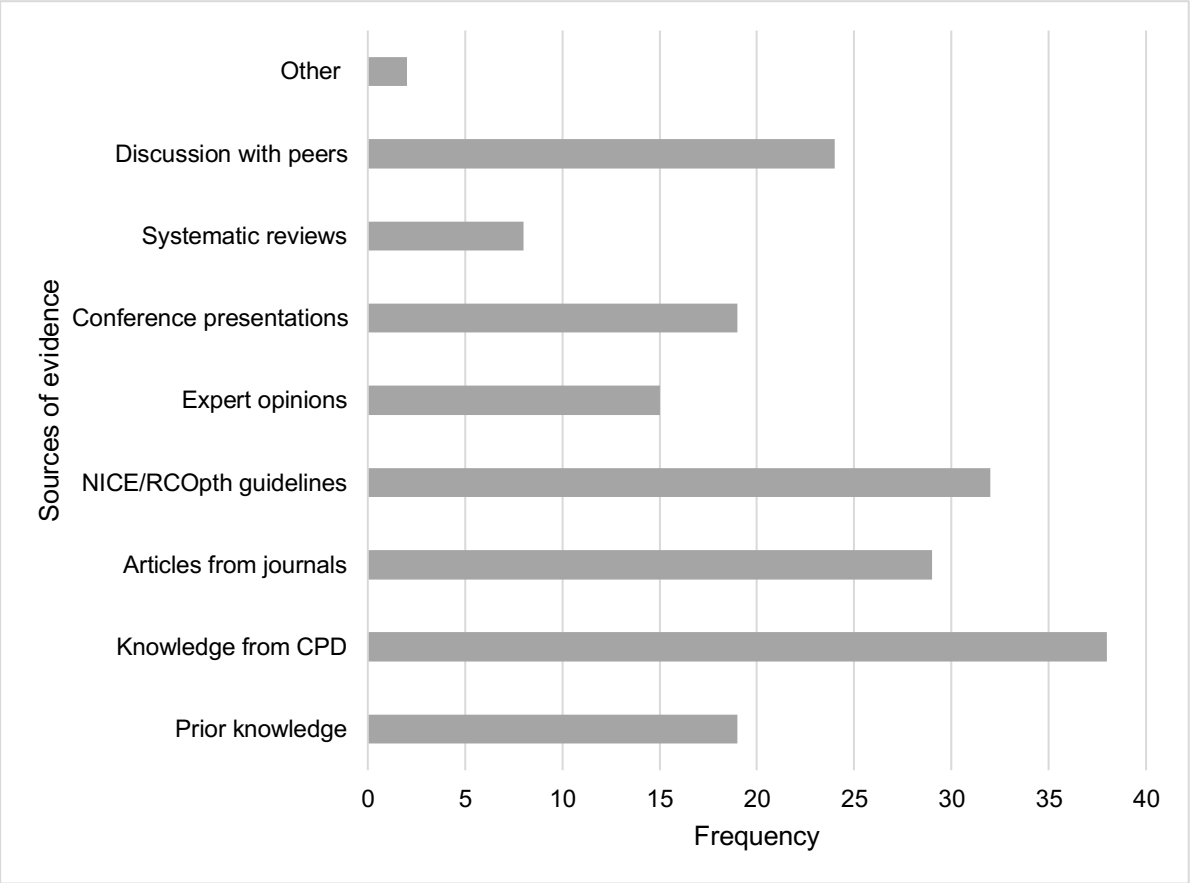


Figure 7.5- Bar chart displaying participants responses to the question 'What sources of evidence do you use to inform your views on the benefits of lifestyle changes in AMD?'. Participants were able to select more than one option.

7.3.3 Barriers to lifestyle advice provision

Participants were asked if they were able to follow up with patients at subsequent appointments to gauge if they have followed the lifestyle advice. More than half of the participants said they did not follow up with patients (n=28; 51.9%), 22 participants said they did (40.7%) and 4 participants did not answer the question (7.4%). Participants that said 'no' were asked to explain their answer and the themes and key quotes are displayed in table 7.6. Out of the 17 participants that responded to the question, the most commonly

discussed themes were ‘not seeing the same patients more than once’ and ‘lack of time/opportunities’.

Theme	Key quotes
Not seeing the same patients more than once	"I do not see the same set of patients at each visit. So I discuss life style modification with everyone"
	"Generally, don't see same person twice"
Lack of time/opportunities	"No time to do so- clinics are fully booked from when I get in to when I leave, and I have referrals on top"
	"No capacity for this in hospital setting"
Belief that it is someone else's responsibility	"Not in my scope of responsibilities"
	"Not currently in my duties, usually these patients are discharged to community with dry AMD so we don't have to have a follow up unless there is a change or progression to wet AMD"
Lifestyle advice is not required/won't make a difference	"Because I told them once. Telling them again is not going to change my management. "
	"Not essential"
Forgetting to ask	"Hard to remember everything"
	"Tend to either forget or not enough time"
Do not want to pressure patients	"Don't want them to feel pressured - often nervous enough"

Table 7.6- Participant responses to the question ‘Do you follow up at subsequent appointments by asking the patient about any changes they have made to their lifestyle? If no, please specify why’. Themes are displayed in order of most to least references.

Additionally, participants were given a free text option to describe what they perceived to the be main barriers to effective lifestyle advice provision to patients with AMD. Forty participants responded to the question and the most commonly discussed themes with respect to effective advice i.e. achieving the desired outcome were 'lack of understanding/uncertainty' and 'individual patient reasons'. With respect to the barriers to advice provision, the key theme was 'not enough time to discuss'. Figure 7.6 shows all of the themes and the number of references in each theme. Individual quotes are shown in table 7.7. Key quotes relate to the patients' inability to understand why they need to make the changes, and how to begin to make the changes. These problems are likely to be exacerbated by another frequently referenced barrier that there is insufficient time in clinic to address these issues in depth.

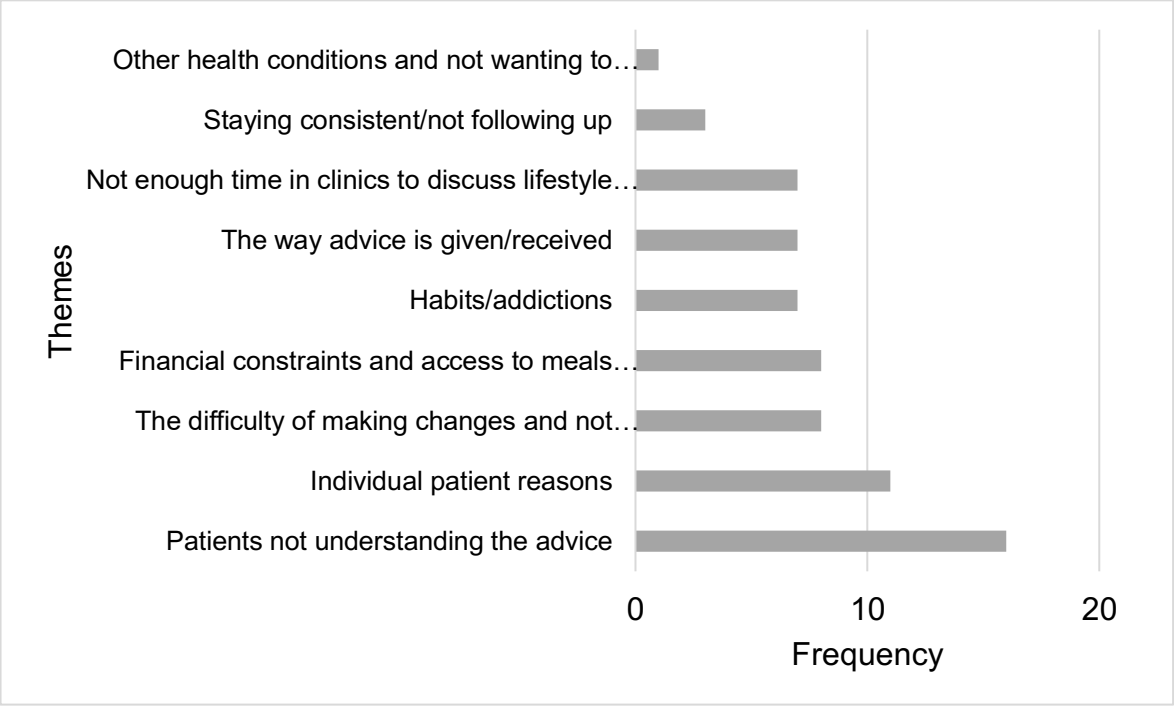


Figure 7.6- Bar chart displaying the themes from 'what do you perceive as being the main barriers to the provision of lifestyle modification advice?'

Theme	Key quotes
Patients not understanding the advice	"not fully understanding why they need to change, not discussed fully with them"
	"Overwhelmed or unsure where to start/ where to access help from"
	"[patients] culture"

Individual patient reasons	"Older patients quite often set in their ways "
The difficulty of making changes and not wanting to change	"Unwillingness to change habits"
	"Lifestyle changes are difficult to get used to"
Financial constraints and /access to meals and supplements	"Cost of vitamins, not prescribed, burden of additional medication"
	"Access to GP"
Habits/addictions	"Probably the addictiveness of smoking."
	"Old habits; friends/family members who may also have the same habits"
The way advice is given/received	"Quality of advice given + available time"
	"Patients can also be anxious but clearly overwhelmed at the time receiving news about their condition, so it is hard to listen to further loads of info as well as comprehend that at the time."
Not enough time in clinics to discuss lifestyle changes in detail	"Sometimes appointment time is not enough to explore all possible barriers for patient to understand or implement any changes. "
	"Lack of time in clinic to explain"
Staying consistent/not following up	"Their understanding, being able to stick to lifestyle changes"
	"Advice given is not followed up to see if there has been a change"
Other health conditions and not wanting to take on extra medication	"Burden of additional medication"

Table 7.7- Participant responses to the question 'What do you perceive as being the main barriers to provision of lifestyle modification advice for AMD?'. Themes are displayed in order of most to least references.

Finally, looking to the future, participants were asked if they could think of anything that would make it easier for them to provide the best advice. Participants were able to choose more than one option and the most commonly selected option amongst all of the participants was 'more written resources' (n=32; 59.3%). The frequencies for the other options are shown in figure 7.7. Additionally, participants that selected 'other' were asked to specify and all six participants wrote responses such as

'Greater public and other health care professional awareness'

'Definitely time. There is no incentive for multiple practices to provide time for follow ups as it doesn't generate money for the practice…hence you have to do it in your own time – there's only so many patients you can follow up so AMD and lifestyle advice would normally just be reiterated at the next appointment.'

'ECLO referral very helpful'

'Better websites with easy access. Keep them simple and not too long'

'More access to specialist nurses'

'Tailored advice with better management of expectations'

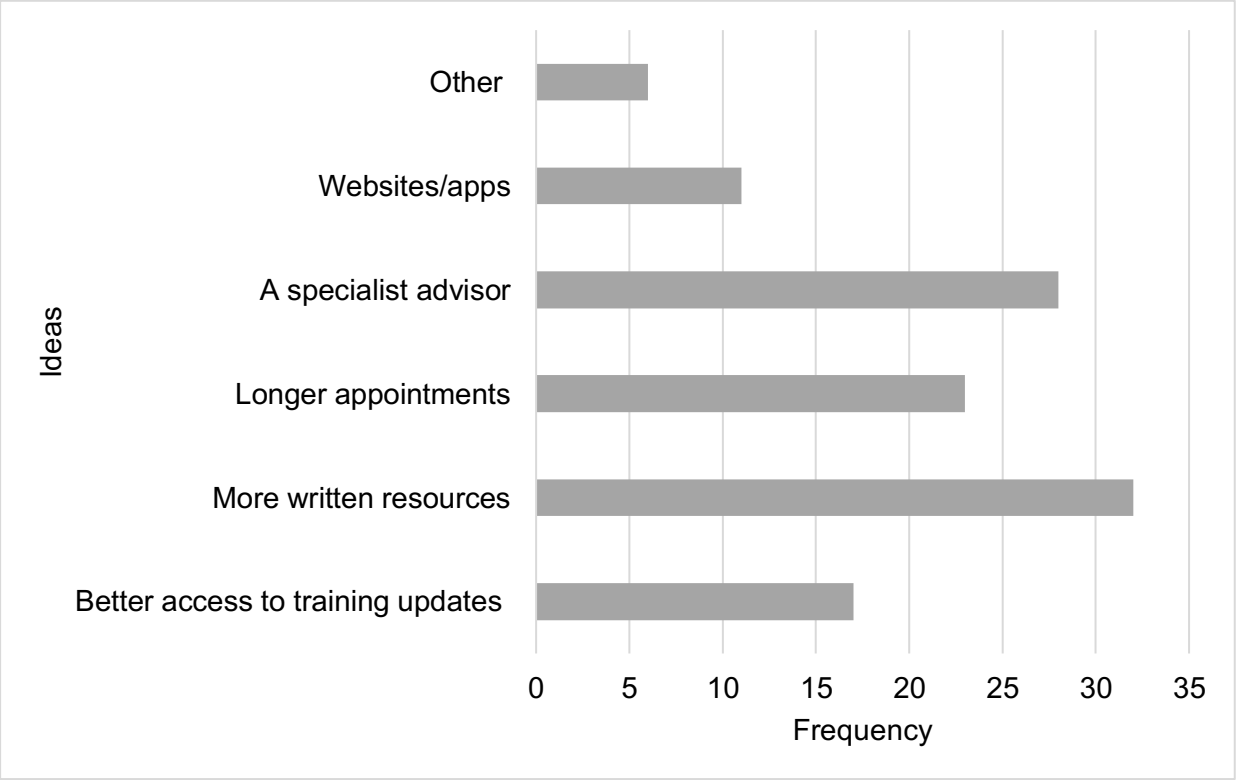


Figure 7.7- Bar chart displaying the themes from 'Can you think of anything that would make it easier for you to provide the best advice?'

7.4 Discussion

The findings from this study showed that there are a number of factors that affect lifestyle advice provision from the practitioner perspective. The amount of time available for discussing lifestyle with the patient is often low, and in many cases, participants felt it was insufficient for the purposes of providing lifestyle modification advice. Additionally, despite the majority of participants saying they provide lifestyle advice to patients, the number of participants that ask patients questions about their lifestyle habits is still limited.

The findings showed that lifestyle factors were not being asked about consistently, with 'other lifestyle questions' being the most frequently asked across all professions (n=38; 70.3%) followed by smoking habits and history (n=31; 57.4%). Practitioners in this survey reported asking about smoking (n=31; 57.4%) more frequently than about diet (n=13; 24.1%) with no significant difference between the practitioners regarding what was asked.

Interestingly, this differs from previous research, where optometrists were more likely to provide dietary advice than ophthalmologists regarding diet and ophthalmologists were more likely to provide smoking cessation advice than optometrists (Martin, 2017). However, there were more optometrists than ophthalmologists included in this study, which could explain this finding. It was also uncommon for smoking cessation advice to be more frequently provided than dietary advice in previous research (Shah et al., 2015). Nonetheless, smoking was only discussed by just over half of the practitioners and in many cases, according to the practitioners comments, it was only asked about in specific cases. Previous research on smoking cessation have reported that practitioners hesitate to ask about smoking if the practitioners are smokers (Brotons et al., 2005), or if they fear about resistance from patients (Wheat et al., 2022). This was a common finding in this study, where many of the reasons for not providing advice were based on assumptions that patients did not want advice, would not be able to understand the advice and the burden of making changes on the lives of patients. However, our findings from survey one and two highlight that patients want advice (see chapters 5 and 6).

A much smaller proportion of participants reported asking about dietary habits (n=13; 24.1%). This contradicts the findings from the patient surveys (chapters 5 and 6), where dietary advice was most commonly recalled by patients. However, the type of dietary advice that practitioners provided was similar to the advice that patients recalled being given such as ‘eating more green leafy vegetables’ and ‘eating oily fish’. Previous research on general practitioners’ experiences of providing dietary advice shows that practitioners generally felt minimally effective or ineffective at providing dietary advice, however, practitioners believed that working with nurses and utilising written information can be more effective in helping patients make lifestyle changes (Brotons et al., 2003). This was also corroborated by the practitioners in this survey, where there were common references to advice provision being someone else’s job and highlighting the need for better written resources. Several previous studies from other health conditions have highlighted that the most effective and preferred way of providing advice is when verbal advice is accompanied by

written information (Eze et al., 2005, Wilcock and Harding, 2011, Fylan and Grunfeld, 2002, Wongtaweepkij et al., 2021, Cronin, 2012)

Importantly, for the 'other lifestyle questions' the most commonly asked about factor was 'exercise', despite there being some evidence for the association between AMD and exercise (McGuinness et al., 2017), there is no or limited mention of exercise as a modifiable risk factor for AMD in any of the practice guidelines (Royal College of Ophthalmologists, 2021, NICE, 2018b, College of Optometrists, 2021). Exercise and weight loss advice was also recalled by the patients in survey one (chapter 5). This brings into question the sources of evidence used by practitioners to inform their practice behaviours. However, the findings regarding whether or not practitioners were using evidence based practice in clinics were consistent with previous studies (Lawrenson and Evans, 2013) and showed that the majority of practitioners were using effective and reliable sources of evidence to practice, most commonly CPD training (n=38; 70.3%) and RCOphth guidelines (n=32 59.3%). However, in some cases practitioners made recommendations that are not in the guidelines or have no evidence base in relation to AMD. This could be because general advice such as 'exercise more' can be recommended for most health conditions. It was interesting to note that systematic reviews were not widely accessed by practitioners, despite the free accessibility of Cochrane reviews of effectiveness of nutritional supplementation and dietary modification in managing risk of AMD progression (Lawrenson and Evans, 2015, Evans and Lawrenson, 2023).

7.4.1 Barriers to lifestyle advice provision

Throughout the questionnaire that the participants completed in this study, there were a number of factors that emerged that were seen as barriers to effective lifestyle advice provision for patients with AMD. These included not being able to follow up with patients, a lack of patients' understanding and the difficulties of making lifestyle changes.

Time restraints

In this study, the majority (n=47; 87%) of participants said that they offered lifestyle modification advice to patients. However, the time taken to discuss

lifestyle factors was low, with the time taken averaging to be just over 3 minutes. However, many practitioners also reported that the test time was around 10 minutes, and the most common duration of appointments was less than 20 minutes, so three minutes is likely to reflect the maximum time available for this purpose. Studies have previously shown that a lack of time has been one of the main reasons for why eye care practitioners feel as though sufficient lifestyle advice cannot be provided (Brûlé et al., 2012, Downie and Keller, 2015, Suttle et al., 2015). For example, one study by Suttle et. al. (2015) investigated optometrists perceived barriers to implementing evidence-based practice into clinics. Although practitioners believed that evidence based practice was essential, the key barrier to this was a lack of time in clinics (Suttle et al., 2015). This was also found in a study by Downie and Keller (2015), where practitioners reported that there was a lack of time during appointments to provide advice to patients and that the responsibility of providing patients with lifestyle advice was with the patients general practitioner (Downie and Keller, 2015). However, both studies only interviewed optometrists in hospital settings, where it can be assumed that clinic times in hospitals are more limited than in primary care (Lee and Bunting, 2013). Nevertheless, this is consistent with the findings from our study, where a number of the practitioners reported that there was not enough time during appointments to discuss lifestyle changes. Several studies investigating barriers to effective lifestyle advice provision amongst GPs have also highlighted that lack of time to provide advice is the most significant barrier (Astaire et al., 2024, Znyk and Kaleta, 2023, Wolker Manta et al., 2022, Hamilton et al., 2019). Retrospective studies have also shown that, in primary care, there is a relationship between appointment duration and quality of care (Chen et al., 2009) and improved education about disease prevention (León-García et al., 2023). Therefore, this suggests that perhaps clinic set up and appointment duration should be re-visited to ensure higher quality of care and information provision. However, the financial implications of this need to be considered.

Scope of practice and clinic set up

The way that clinics are set up and the roles of individuals were factors that were consistently mentioned in the study questionnaire. For example, when

discussing reasons for not providing lifestyle advice or asking about the risk factors for AMD, participants used phrases such as ‘assume asked at referral’ or ‘not in my scope of responsibilities’. These responses were from nurses, but it can be argued that discussion of lifestyle advice should be a collaborative responsibility. The idea of collaborative care for patients has been explored in vision research. For example, O’Connor et al. (2012) investigated the impact of sharing care of chronic eye diseases between ophthalmologists and optometrists. They reported that the practitioners were generally accepting of the collaborations and patients reported many positive outcomes such as saved time and increased satisfaction with their care (O'Connor et al., 2012). Additionally, a scoping review on the barriers and facilitators perceived by GP’s for implementing lifestyle interventions for patients with osteoarthritis reported similar findings. The most significant facilitators were related to good interdisciplinary collaboration and a positive perception of their role in implementing lifestyle change (Bouma et al., 2022). The researchers highlighted that there is a need for interprofessional trust and communication but did not discuss if this would work for advice provision. Nonetheless, the previous research and our findings highlight a need for more clarity on staff responsibilities and opportunities to follow up with patients to ensure that information is being provided consistently and correctly.

Patient understanding and written information

The perceived ability for patients to understand and implement complex healthcare changes is a factor that has been discussed throughout this study and is consistently mentioned as one of the main barriers to effective lifestyle advice provision in AMD studies (Sahli et al., 2020, Jalbert et al., 2020). In this study, practitioners reported that a barrier to effective lifestyle advice provision was the lack of patient understanding, or uncertainty. To overcome this issue, advice needs to be presented in a way which can resolve these uncertainties. When participants were asked how they deliver advice to patients, the most common method was a ‘face to face discussion’ (n=48; 88.9%), followed by written advice (n=30; 55.6%). This is encouraging as studies have consistently shown that verbal discussions, when accompanied by written information are the most preferred by patients and improve health outcomes (Wongtaweepkij

et al., 2021, Andersson et al., 2015, Fylan and Grunfeld, 2002). Information provided to patients should be clear and concise, even in a written format, so that patients can comprehend and understand the information more effectively (Fylan and Grunfeld, 2002). This point was also highlighted in survey one (chapter 5) where patients described a preference for clear and simple information with little 'medical jargon' and something to refer back to/discuss with friends and family.

There have also been a number of studies that show patients understanding of the modifiable lifestyle risk factors for AMD is low (Burgmüller et al., 2017, Caban-Martinez et al., 2011, Kandula et al., 2010). However, in all of these studies, the main reasons for patient knowledge being low was the fact that they were never informed about the lifestyle factors (discussed in detail in chapter 5 section 5.4). In this study, some participants reported that they only provided lifestyle advice to patients that asked questions as practitioners perceived this to be a sign of a lack of understanding from the patients. However, in previous studies when practice in optometry clinics have been evaluated, the importance of practitioners asking if patients have any questions has been highlighted (Burgmüller et al., 2017). This was also discussed in chapter 3 during the co-design activity discussion, where patients reported having questions written down for their appointment but factors such as queues of patients, shock and fear of injections meant that these questions were not asked (see chapter 3, section 3.3).

As per the NICE guidelines for AMD management, information should be provided to patients in written format for them to take away and refer back to at any time (NICE, 2018b) as this would increase patient understanding. Crucially, in this study, when practitioners were asked how lifestyle advice provision could be improved, the most commonly selected option was for 'more written resources'. This highlights that practitioners understand the importance of written advice, but that the existing resources are not clear enough, which has also been demonstrated in previous research (Fortuna et al., 2020, Wang et al., 2022). Although, The College of Optometrists and the Royal College of Ophthalmologists have written information available (College of Optometrists, 2023a, Royal College of Ophthalmologist, 2023), so it is

possible that practitioners may not be aware or may not be looking for these resources. However, it is important that written advice does not replace verbal advice, as research has consistently shown that both are required for the most effective advice provision (Cronin, 2012, Eze et al., 2005).

When discussing barriers to effective lifestyle advice provision and implementation of lifestyle changes, the participants discussed various factors such as “older patients are set in their ways” and “lifestyle changes are difficult to get used to”. Interestingly, this is similar to what was discussed in survey two by the patients (see chapter 6) where participants reported feeling like the advice was not required (i.e. non-smokers being advised to stop smoking) or they were unable to implement the changes due to a lack of specific information. Both reasons can be due to poor advice provision and a lack of understanding of what patients need. For example, the practitioners in survey three reported that the cost of vitamins may be a barrier to patients implementing lifestyle changes, but this was not discussed by the patients themselves.

7.4.2 Limitations and future directions

One limitation of this study was the sample size. The main aim of this study was an exploratory analysis of the experience of eyecare practitioners with respect to provision of lifestyle advice, and it should be noted that no formal sample size calculation was carried out to determine the power of the statistical analysis in this chapter. Furthermore, the generalisability of the findings is limited by the fact that the majority of participants were practicing within hospital settings, although there was a good balance of different types of practitioners included. The structure of the clinics and the types of patients that are seen differ significantly from high street optometry practices where there may be more opportunities to provide patients with lifestyle advice. Secondly, participants were recruited from large hospital sites and urban cities around England. The ethos to provide lifestyle advice may differ in smaller clinics and rural towns and outside of England. Further research is needed on a larger scale with practitioners on a global scale and in different settings. Thirdly, there was no specific question in the survey that addressed vitamin

supplementation, so practitioners were not asked about whether they provide advice regarding supplementation, and whether the advice is adherent to current healthcare recommendations. Finally, although participants were asked to explain their responses at the end of each question, there was no opportunity for participants to add further comments at the end or provide specific information such as what specific leaflets they provide to patients or how often they attend CPD training on the importance of lifestyle advice provision. Therefore, there may have been some details that were missed and could help understand more details about where the gaps are for effective lifestyle advice provision.

In terms of future work, having identified these barriers it would interesting to evaluate potential measures to address these. For example, to assess whether having a specific programme in place for lifestyle advice, with written materials, would be accepted by practitioners and whether it would help with communication between practitioners and patients.

7.5 Conclusion

In summary, lifestyle modification advice is being provided to patients by practitioners, however, there are still issues regarding the consistency of the advice given. However, the findings from this study show that this may be a larger, structural issues with how clinics are set up and the time allocated for patients to be seen in. There are also gaps in the consistency of which sources of information practitioners use to gain knowledge as there are still uncertainties around the benefits of making lifestyle changes, especially in relation to diet. Practitioners should use the reliable sources of information and training courses that are available and there should be more patient-based resources for practitioners to refer to. This would enable practitioners to provide more detailed advice to patients to ensure they are getting sufficient information and support.

8. Discussion

8.1 Novelty and importance of this research

The overall aim of this thesis was to investigate the extent, nature and effectiveness of lifestyle modification advice currently given to patients with AMD in hospital and optometric practice from a patient perspective. In addition, this study also aimed to investigate and present the viewpoint of the eyecare practitioner. As discussed in chapter 2, there have been several global studies investigating the practitioners' perspective of lifestyle advice provision (Lawrenson and Evans, 2013, Downie and Keller, 2015, Sahli et al., 2020, Martin, 2017). However, the patient and practitioner experiences have rarely been compared and sample sizes are usually small (Dave et al., 2022). This is important as evaluating the situation from both patient and practitioner viewpoints is essential to ensure the best patient outcomes and healthcare practices (Saini et al., 2021). One study which did incorporate both patient and practitioner experience focused solely on the provision of smoking cessation advice and only incorporated 52 patients (Caban-Martinez et al., 2011). Another study investigated factors impacting on healthcare communication in AMD and also included a small sample of 17 patients with AMD and 17 optometrists (Wang et al., 2023), recruited from one centre. The current study included a larger sample (n=404) recruited from sites across England and investigated multiple aspects of the advice given with the aim of providing a more generalizable overview of the experience of patients and practitioners.

This was also one of the first studies to look at the impact of lifestyle modification advice on AMD by collecting data from two different time points. The findings of these studies are important, as they enable analysis of the factors which impact on likelihood of behavioural change in the months following advice provision. Further information was also gained into patients' motivation for making and keeping lifestyle changes, which can be used to inform guidelines for practitioners to refer to when providing lifestyle advice to patients.

8.2 Key findings from Survey One - The Patient Experience

The first survey (chapter 5) from this study was conducted to understand the patient experience of receiving lifestyle advice at previous appointments and their most recent appointments. The results from the 404 participants surveyed show several inconsistencies in the lifestyle advice provided to patients. For example, although around one third of participants reported receiving lifestyle advice at some time in the past before their most recent appointment (n=125; 33.7%), there was a much smaller proportion of participants that reported receiving advice at their most recent appointment (n=57; 16%). NICE guidelines state that information on AMD should be 'available on an ongoing basis' (NICE, 2018b), however, this finding suggests that, contrary to this recommendation, the information is not provided routinely at follow up appointments. Evidence from other areas of healthcare suggests that repetition of advice can improve effectiveness (Mahdad et al., 2014, Jimison et al., 2008, Ley, 1979, World Health Organization, 2014). For example, a systematic review by Jimison et. al. (2008) reported that the repetition of information and regular conversations with a health care professional increased the likelihood of patients engaging with health information technology. Outcomes were also shown to be improved in people with type II diabetes when a nutritionist followed up patients for 3-6 months after a preliminary appointment to reinforce advice (Mahdad et al., 2014). The WHO suggests a model for encouraging smoking cessation which is based on the '5 Rs' – the last of which stands for 'repetition' i.e. for patients to have their readiness to quit repeatedly assessed. Similarly, research on smoking cessation advice has found that patients may benefit from repeatedly addressing the question of lifestyle on the basis that patient attitude and receptiveness to change may alter over time (World Health Organization, 2014).

The content of advice participants were given was also an important finding. Dietary advice was the most common advice provided before the most recent appointment (n=105; 84% of the 125 participants that were given advice) and at the most recent appointment (n=38; 66.7% of the 61 participants that were given advice). This was followed by advice regarding vitamin supplements

(n=55; 44% before and n=48; 14.1% after the most recent appointment) and then smoking cessation advice (n=15; 12% before and n=2; 8.3% after the most recent appointment). Participants reported receiving some specific advice such as eating green leafy vegetables (n=33; 63.5%), but others reported more generic advice such as 'eat a balanced diet' (n=14; 26.9%). This advice is consistent with the guidelines from the Royal College of Ophthalmologists to an extent, but the guidelines recommend other specific dietary changes be recommended to patients which was not as commonly reported such as eating oily fish (n=18, 47.4% of 38 participants that received dietary advice at their most recent appointment). Advice regarding vitamin supplements was also limited, with only 48 participants reporting receiving supplement advice at their most recent appointment, and only just over half of these being given advice consistent with the AREDS/AREDS2 formulae (n=26; 54.2% of those receiving vitamin supplementation advice). Finally, smoking is the biggest risk factor for AMD, resulting in a 4-fold increased risk of disease progression (Tan et al., 2007). However, only 101 participants (25% of the whole cohort) were asked about their current smoking habits at the most recent appointment, and 48 (11.9%) were asked about their smoking history. Crucially, of the current smokers in the study population, only 8.3% (n=2 out of 24) recalled being advised to stop smoking. This shows that smoking advice is not always being given to patients, despite the strong evidence about its importance as one of the main risk factors for AMD incidence and progression (Tan et al., 2007, Smith et al., 1996, Velilla et al., 2013, Willeford and Rapp, 2012).

Another key finding from survey one was the low number of participants that were given written advice at their appointment. The NICE guidelines state that patients should be provided with lifestyle advice 'in accessible formats for people with AMD to take away at their first appointment, and then whenever they ask for it'. Previous research also states that patients find written advice helpful (Jallow et al., 2022, Haji, 2019) and helps to improve adherence to lifestyle advice (Smith et al., 2000, Bull and Jamrozik, 1998). However, participants in survey one preferred a combination of written and verbal advice, with free text responses suggesting that a face-to-face conversation can allow

patients to get more information whilst the written advice can give them something to refer back to or show friends/family members (see chapter 5, section 5.3.6). This was also a finding in previous studies (Gremeaux et al., 2013, Hind et al., 2020, Watson and McKinstry, 2009) but only a small percentage of the participants from survey one received verbal advice (n=57; 16% at the most recent appointment) and an even smaller percentage received written advice (n=36; 9.4% at the most recent appointment).

This survey highlighted significant gaps between the types of advice that participants are given and what the guidelines recommend. It can be argued that these findings were limited by patient recall of advice, however it is also the case that advice that is not recalled by patients is unlikely to be effective. Survey two was important in determining how much advice is recalled by patients over a longer period of 3 months, and how much of the advice was acted upon.

8.3 Key findings from Survey Two - The impact of lifestyle advice

The purpose of survey two (chapter 6) was to investigate the impact of the advice that participants were given in survey one, how much of the advice was recalled and enacted and what participants believed to be the main barriers to advice provision.

Firstly, an important finding from survey two was the limited recall of lifestyle advice by patients, and the disparity between the content of advice that was reported close to the time of the appointment, and when surveyed three months later. For example, twenty participants reported receiving vitamin supplementation advice in survey one, but this was only recalled by nine participants (45%) in survey two. This was also the case for dietary advice which was recalled by five (20%) out of twenty-four patients given advice in survey one. The most commonly recalled advice after 3 months was regarding sunglasses or UV protection, even though dietary change was reportedly the most commonly provided advice in survey one. Furthermore, half of the participants who had made lifestyle changes since completing their first survey reported that they had started to wear sunglasses more often. Interestingly, there was also a lot of emphasis on the importance of sunglasses recalled in

chapter 3 during the co-design activity group conversations. Current evidence suggests that there is not enough evidence to say that sunlight is a risk factor for AMD incidence or progression (Zhou et al., 2018, Cruickshanks et al., 1993, Wolffsohn et al., 2022). This lack of definite association is also mentioned in the RCOphth guidelines, with an associated lack of recommendation to advise UV protection for AMD management (Royal College of Ophthalmologists, 2021). This suggests that the evidence-based guidelines may not be necessarily referred to by practitioners. However, patients may be recalling advice regarding UV protection from other sources like unregulated websites rather than from their practitioner. It may also be that patients recalled the sunglasses advice specifically due to the fact that wearing sunglasses is a simple lifestyle change to understand and implement. In contrast, smoking cessation is commonly known to be among the most difficult lifestyle changes to effect, especially when appropriate support is not provided (such as referral to smoking cessation services, provision of smoking cessation aids) (Wei et al., 2022). Without detailed guidance (Burns et al., 2018), dietary changes and vitamin supplementation can also be complicated to implement due to the variable nature of implementing the advice i.e. patients are not always clear on exactly what dietary changes might be most effective, or how to introduce these changes into their diet (Hilger et al., 2017, Alghamdi et al., 2023). This suggests a need for more detailed advice and guidance for patients to ensure that the lifestyle advice is implemented by patients successfully. This detailed guidance would also increase patients' motivation to make smoking and dietary changes.

The potential importance of clear and specific recommendations is supported by the finding that participants that were given specific advice such as 'eat more green leafy vegetables' and 'eat more oily fish' were significantly more likely to act on the advice than those who were given more generic dietary advice. When participants were asked about factors that would influence the likelihood of making lifestyle changes in this study reasons included: feeling like changes were not required, a lack of understanding/personalisation of advice and not enough evidence that the changes work. Provision of specific advice and details about why lifestyle changes can be beneficial could address

these reasons as patients would be more aware of the changes that need to be made and would feel more motivated to do so. Several studies from other health conditions have previously commented on the importance of providing detailed advice to patients to increase satisfaction, understanding and decrease anxiety (Holmes et al., 2009, Friedemann Smith et al., 2022, Zhang et al., 2024). For example, Yannitsos et. al. (2020) found that specific lifestyle advice improved patient outcomes and adherence to advice in men with prostate cancer (Yannitsos et al., 2020).

The majority of participants in survey two reported not making any lifestyle changes since their most recent appointment (n=78, 75% of those who responded) mainly because they were not given lifestyle advice (n=56; 71.8%) also because they were unsure if the changes would make a difference. Participants also did not rate the importance of making lifestyle changes highly (mean=6.2 out of 10, SD=3.11) however, it is unclear if different types of advice would have been rated at differently, as this was not asked in the survey. Continuous support and regularly seeing a health care professional have previously been reported as being effective in helping participants make and keep lifestyle changes (Schmidt et al., 2020). This was also the case for the participants in survey two, where 'knowing the changes were making a difference' (n=60 out of 113 participants that responded; 53.1%) and 'regular chats with my practitioner' (n=40 out of 113 participants that responded; 35.4%) were selected to be the main motivators for lifestyle change. Not only does this highlight the need for regular appointments, but it also shows that there needs to be more research, particularly using patient and public involvement groups, regarding the benefits of making lifestyle changes that can be presented to patients to further emphasise its importance. A protocol for a randomised controlled trial investigating the benefits of lifestyle changes for AMD has recently been published (de Koning-Backus et al., 2023), so the findings may be helpful in highlighting the impact of lifestyle changes to patients in future appointments. The findings from survey one and two also highlight that practitioners should ensure their practice is evidence-based by disseminating advice in the most effective ways.

8.4 Key findings from chapter 3 - The practitioner perspective

The aim of survey three (chapter 7) was to investigate the eye care practitioner perspectives when it comes to the provision of lifestyle advice for AMD. The practitioners in survey three provided some valuable insights into the barriers for effectiveness of lifestyle advice provision to patients with AMD. For example, practitioners mentioned a lack of time as an important barrier; more time was necessary to discuss lifestyle change in detail to ensure that patients were well informed. This is supported by findings in patient-based studies. Wang et al (2023) in their exploratory qualitative study reported that patients feel longer appointment times could improve health communication in AMD (Wang et al., 2023). This aligned with the responses to survey two presented in chapter 6 which highlighted the patient perceived importance of detailed and specific advice and guidance, with explanations of how the changes could help – all factors which practitioners suggested were detrimentally impacted by a lack of time. Previous research has shown that factors such as increasing practical assistance for practitioners, alteration of clinic schedules and assigning follow up clinics to trainees can increase efficiency in clinics, decrease waiting times and ensure patients are getting sufficient information (Kagedan et al., 2021). However, the practitioners in this study highlighted that there are a lot of factors to consider in clinic timings which may prevent longer appointment times from being implemented, such as insufficient staff and difficulty in accounting for the varying time needs of different types of patients.

As discussed in section 8.2, there is evidence to suggest that repetition of advice can increase the likelihood of patient adherence. In survey two when patients were asked if there was anything that would motivate them to keep the changes they made to their lifestyle, the second most commonly selected option was ‘regular chats with my practitioner’. This would allow for the repetition of information and reassurance that they are on the right track, however, the responses from the practitioners to survey three highlighted that patients are not normally seen by the same practitioner. This limits the ability of an individual practitioner to follow up on the information provided and to reiterate the message through repeated discussions. The practitioners surveyed in the current study felt that this could prove a significant barrier to

effective advice provision. Lack of continuity of care has been associated in many areas of healthcare with poorer outcomes (Hofer and McDonald, 2019). It emphasises the need for detailed records to be kept to enable different practitioners to reinforce the message on subsequent visits and where possible, for this to be considered in clinic timetabling.

The practitioners in survey three reported a need for more, clear written material to provide to patients. Although some written material is available in clinics, they have previously been described by patients as being 'too generic' (see chapter 3). They also comment that the NICE guidelines recommend that patients should be given written information 'in accessible formats to take away' (NICE, 2018b), and queried whether available resources met these criteria. The available written materials specifically for AMD have been evaluated recently, and the researchers reported that the majority of the materials were above the readability level of a significant proportion of the population and therefore not suitable/understandable for all patients (Fortuna et al., 2020). This was also the case for other eye conditions such as glaucoma (Crabtree and Lee, 2022) and for paediatric populations (John et al., 2015). It is therefore apparent from both the patient and practitioner perspective that a wider availability of written materials is required, which are personalised to patients and accessible, and that outline specific lifestyle advice.

8.5 Overview of findings and significance of research

This research aimed to understand the patient and practitioner experience of receiving and giving lifestyle advice, and what barriers there are to effective lifestyle advice provision. Overall, the majority of patients did not recall being given lifestyle advice, despite the current guidelines (College of Optometrists, 2021, NICE, 2018b, Royal College of Ophthalmologists, 2021). Less than a quarter reported being asked about their dietary habits or smoking status at the most recent appointment, suggesting that not only is advice not being routinely provided, but also practitioners are not determining the current lifestyle risk factors of their patients and considering if the progress of their AMD can be slowed down.

There were significant improvements suggested by both patients and practitioners that should be implemented to ensure the best patient outcomes. A key element highlighted by patients was the need for more detailed advice with rationale for implementation. This was echoed by the practitioner report that lack of time to discuss lifestyle during appointments was a key barrier to effective advice provision. However, their responses also show that clinic set up is a key factor that needs to be considered to ensure that lifestyle advice provision becomes a part of the appointment process. This was also a factor for why advice was not repeated, as patients are rarely seen more than once by the same practitioner and in many cases, it is assumed that advice has already been discussed, so repetition is not required. There was a strong patient preference for a mixture of verbal and written advice, which is not currently being regularly provided. Practitioners also reported a need for more written materials to provide to patients, in an accessible format.

An important difference between the patients and practitioners was regarding whether or not advice regarding where to get further information and support was provided. The majority of practitioners reported providing patients with the available leaflets (83%) and information for charities (43.3%) whereas 68.8% of the patients in survey one reported that they were not given information about other services they could contact for further support. However, it is also possible that this is due to the patients' recollection of information. Although participants completed the survey soon after their appointment, they may not remember being given the information. This was discussed in the co-design activity (chapter 3) where participants described the process of going in to hospital clinics for appointments and being so worried about injections, that it was difficult for them to take anything else in. Previous research on general healthcare advice has highlighted that written and recorded advice improved patients' recollection of information (Watson and McKinstry, 2009). This again, emphasizes the importance of written information and repetition of information to aid patient recall of advice.

Referring back to the communication theories discussed in chapter 1 section 1.8.1, the findings from all three of the surveys support the need for implementing these theories into practice. For example, the finding from

surveys 1 and 2 that additional detail was required regarding the lifestyle changes which should be made, and the potential benefit of these changes would be consistent with implementation of the individually centred theory of verbal communication (which focuses on changing cognitive processes by setting clear goals for patients). Adopting a strategy based on this approach could encourage practitioners to set specific goals with patients, along with a plan for implementing the change and to discuss clear actions that patients can take to do this successfully. In other health conditions, such as Parkinson's disease, a study on the communication strategies used by nurse specialists reported several techniques that aided healthcare communication. These involved establishing a therapeutic relationship with the patients (i.e. using a gentle voice, building a good rapport), adapting communication to reduce cognitive load (using visual tools, closed questions, allowing additional time and paraphrasing when needed) and working through recommendations practically (Pitts et al., 2022). Although Parkinson's disease recommendations are different to AMD, some of these strategies could be applied to AMD advice provision. This could be done by discussing lifestyle changes calmly, allowing plenty of time for discussions and working through practical changes that participants can make. However, this may also require further training for practitioners to improve the communication abilities of practitioners who work with patients with AMD.

Overall, there are some differences between the patient and practitioner experience, but both groups show that there are some larger, systematic issues such as how appointments are booked for patients, clearer and more specific guidelines for what advice should be provided to patients and a need for more structure during appointments so that advice provision, referrals for further support and time for questions becomes a regular part of appointments. These are the issues that need to be addressed to make the provision of lifestyle advice more common and efficient.

8.6 Practical applications of the findings

The findings from this thesis provide several valuable insights into the patients' and practitioner's perspectives. However, it is important to understand how these findings can be implemented into health care. Implementation science

consists of theories for how research findings can be implemented into healthcare by allowing for the selection of appropriate approaches to practice (Nilsen, 2015). These theories aim to help describe or guide the process of translating research into practice (process models), understand or explain what influences the outcomes of implementation (determinant frameworks, classic theories and implementation theories) and evaluate it (evaluation frameworks). For the aims of this thesis and the findings, the implementation focus is on understanding what influences the outcomes of implementation, so this section will describe these theories and how they can be used to implement the findings from this thesis. See review by Nilsen (2015) for a full review of the theories.

Determinant frameworks focus on the factors that influence how change is implemented. Typically, this is in the form of barriers and enablers (Nilsen, 2015). A commonly applied framework is the theoretical domains framework (TDF) (Cane et al., 2012). This framework was created through the synthesis of 33 theories of behaviour and behaviour change and consolidated into 14 theoretical domains that determine behaviour change (knowledge, skills, intentions, goals, social influence, beliefs about capabilities, social/professional role and identity, optimism, beliefs about consequences, reinforcement, memory and attention, environmental context, emotion and behavioural regulation). The TDF is a conceptual framework for examining how thoughts, emotions, social interactions, and environmental factors shape human behaviour. Due to the structure of the TDF, it can provide a strong theoretical basis for implementation studies and also highlight potential problems for implementation. The TDF can also be used to guide data collection using interviews, focus groups, and questionnaires designed to identify barriers and facilitators to change (Atkins et al., 2017). This framework has been used previously to determine behaviour change in young people's uptake of diabetic eye screening (Prothero et al., 2022). For the findings from this study, the patients and practitioners all discussed aspects of these domains e.g. a lack of written information which can fit under a number of the domains e.g. knowledge, memory and attention and reinforcement. Therefore, these areas can be targeted for effective implementation of change in health

care. Having explored in this research the patient and practitioner perspectives on communication regarding lifestyle changes, it would be valuable in future to conduct a theoretical domains framework type analysis to further explore the wider factors which influence the behavioural changes of people with AMD with regard to behavioural change. Factors identified can then be mapped onto the COM-B model discussed below for implementation.

Classic theories are considered to be more 'passive' theories for behaviour change as they describe the mechanisms for how change can take place but do not focus on practical applications. For example, one branch of classic theories are known as 'habit theories'. The fundamental idea of these theories is that change can be brought about if habits are formed with a change in cognition i.e. creating a 'habitual mindset' (Verplanken and Aarts, 1999). These theories have also been applied in organisational settings. For example, situated change theory suggests that if behaviour change actors or particular members in an organisation change their behaviour over time and implement change, the rest of the organisation will follow (Orlikowski, 1996). Relating back to the findings of this thesis, these theories can be used particularly for the health care professionals as in survey three, practitioners discussed not always providing lifestyle advice, or believing it was someone else's responsibility to do so. Implementation of these theories may allow for lifestyle provision to become a habit and part of the ethos of healthcare. However, there are several practical considerations that should be made such as clinic times and how the cognitive mind-set of practitioners can be changed.

Implementation theories have been adapted from existing behaviour change models to develop a greater understanding of behaviour change. One of the most popular implementation theories is known as the COM-B model (Capability, Opportunity, Motivation and Behaviour). The focus of this theory is to identify the motivators for behaviour change and then understanding ones capability and opportunity to implement the change and change behaviour. The theory highlights that capability and opportunity influence a person's motivation, but changing behaviour can alter capability, motivation and opportunities (Michie et al., 2014). Participants in all three questionnaires described issues that can be summarised into the COM-B model. The model

has been applied to understand behaviour change in a systematic way through the 'behaviour change wheel'. At the centre of the wheel is the COM-B model which is surrounded by nine intervention functions which address the areas of the COM-B model that are in deficit. The final outer circle of the wheel is seven categories of policy change that can help implement the interventions (Michie et al., 2011). Therefore, before change can happen, these findings must first be applied to understand how patients and practitioners can be motivated, provided with enough opportunity to make change and increase their capability to do so.

8.7 Limitations

Despite the importance of the findings from all three surveys, it is important to note that there are several limitations to all of the studies. Firstly, the participants in our study may not be representative of the general AMD population as the majority of the participants in our study had a diagnosis of neovascular AMD. As discussed in chapter 1 (section 1.2), this is not the most common form of AMD, and treatment usually involves injections. However, as most of our participants were recruited from hospital eye clinics, these are the patients that would be most likely to attend. However, it can be argued that lifestyle advice should still be provided to these patients as they did not have end stage AMD in both eyes.

Secondly, the proportion of participants that responded to survey two was significantly lower than those that responded to survey one, although all geographical areas were still represented. This may have introduced a source of bias (non response bias) (Elston, 2021). The participants who responded to the second survey might have been more engaged with the management of their condition, and better informed about lifestyle related factors. This means that, if anything, the rates of adherence to advice reported here are likely to be an overestimate of behavioural changes. This could have been exacerbated by the potential effects of participants responding more positively to questions about lifestyle changes made than may have actually been the case, in an effort to please healthcare providers. The latter issue was minimised by the

researcher collecting the data being completely uninvolved with healthcare provision to the patient, and by assurances that data would be anonymised.

Another important limitation with respect to the generalisability of this study is the types of participants who participated. All of the participants were self-selecting, which means they might have been more motivated and proactive than the general populace i.e. a self-selection bias may have existed (Elston, 2021). This was the case for both patients and practitioners, therefore, our sample would not be representative of the average AMD patient or practitioner (perhaps not for practitioners in hospital settings, as their say in research would be limited). With respect to patients, they may have been more likely to seek out assistance and advice than less motivated individuals, whilst practitioners who respond to surveys may be more likely to be proactive in advice provision. This could imply that the actual situation may be worse than what was reported by participants in this study. However, this was mitigated for by ensuring that all participants that met the eligibility criteria were contacted regarding the study and not picked by researchers. Additionally, participants were offered a variety of participation methods to ensure inclusivity and generalisability.

Another potential source of bias in any survey type study is recall bias (Althubaiti, 2016). In this case, participants were being asked to recall advice provided both historically, and at their most recent appointment, as well as their response to said advice. This might lead to an underestimation of the level of lifestyle advice provided by practitioners. However, given that advice can only be acted upon if patients recall it, one might say that advice provided in a format whereby it is not remembered by the patients is not effective advice.

For the practitioner survey (chapter 7), most of the practitioners were practicing in hospital settings. Considering the most common types of AMD are early, intermediate or non-neovascular AMD, these patients would typically not attend hospital clinics, therefore we are unable to assume that practitioners in other settings are not providing this advice, so these findings would not be generalisable to primary care practitioners. The findings from our

study definitely highlight the need to revised guidelines and systemic change in hospital settings.

This research followed the paradigm of interpretivism with the aim of understanding the patient perspective, interpreting their experiences and using this to generate knowledge that is helpful for healthcare and practice. Although this theoretical lens allowed us to gain a deeper understanding of the patient experience, the approach is still limited. The approach relied on patient and practitioner descriptions and recall, which can be unreliable due to 'recall bias' (discussed above), but also because the interpretation of the data relies on the researcher and the context which can lead to 'researcher bias' (Simundić, 2013). However, for all of the qualitative data, the nodes and themes were checked by SD and supervisors AB, TC and FVN which reduces the potential of bias. Additionally, once the quantitative data was analysed, the findings were presented to the supervisors and reviewed throughout the writing process.

Finally, the scope of this research was restricted to the impact of communication elements on effectiveness of advice provision. In future, a theoretical domains framework type analysis evaluating the wider determinants of adherence to behavioural change recommendations would provide additional depth to the evidence base to determine the best package of measures to affect a behavioural change.

8.7 Recommendations for the future

The patient and practitioner perspectives in this study provided some key insights into where the current issues lie. Based on the findings and participants views, the following recommendations are made:

- At the time of diagnosis, patients should be made aware of the specific modifiable risk factors for AMD and given guidance on how to address these. Reasons for making the changes should be emphasised and advice should be repeated at subsequent appointments (chapters 5 and 6).

- Lifestyle changes should be recommended to patients in a verbal conversation, but also as a written and personalised letter (chapters 5 and 6).
- Patients should be provided with contact information and leaflets for where to find other support such as the Macular Society or RNIB (chapters 5 and 6).
- Written information and leaflets should be reviewed to ensure that the advice is easy to understand, specific and detailed for patients to refer back to (chapter 5). For example, written materials should be evaluated for readability using validated assessment tools such as the Suitability Assessment of Materials (SAM) (Williams et al., 2016) or the Flesch Reading Ease Score (FRES) (Kasabwala et al., 2013) (see appendix K for details).
- Time to discuss lifestyle changes should be included in clinic appointments. Extending the length of an appointment can provide enough time for practitioners to communicate advice and for patients to ask questions (chapter 7).
- Where possible, all practitioners should be provided with information and support for what advice they should be providing to patients. Training for current and future optometrists should emphasise the importance of providing lifestyle advice consistently. There should also be specific training about communication and delivering information to patients to all health care practitioners (chapter 7).

8.8 Ideas for future research

The findings from this study can be used for future work to further understand the impact of lifestyle advice. For example, it would be interesting to observe if various interventions such as patient informed written materials, the presence of a nutritional specialist or increased appointment times have an impact on patients' adherence to lifestyle advice. This could be done by measuring changes in patients lifestyle habits using diaries and self-reported measures such as interviews with patients to understand the specific details of what they found to be the most difficult aspect of making lifestyle changes.

It would also be interesting to see if these findings back up previous research about which aspects of lifestyle change are the most difficult.

It would also be important to see if these findings could be replicated in a larger, global study. Worldwide guidelines are similar to the UK (see chapter 1) in describing what advice should be given to patients with AMD. However, as practice behaviours and health seeking behaviours differ between countries, it would be interesting to understand whether lifestyle advice is adhered to differently. Using the protocol from this study as a basis, a version of survey one has already been created in collaboration with the University of Western Australia. The aim of this study is to investigate the differences between the recommendations provided by practitioners in the UK and Australia and what aspects of the practice make patients more or less likely to adhere to the advice.

Finally, the participants in these studies specified that it was important for them to have evidence that the lifestyle changes are actually effective. Despite recent studies showing the positive impact of a Mediterranean diet (Wu et al., 2023, Agrón et al., 2022), there is a lack of larger, randomised controlled trials. Further evidence and increased awareness of the impacts of the lifestyle changes, (especially with respect to dietary changes) would be beneficial for patients to see that these changes are effective. This has been demonstrated with several studies on the negative implications of smoking (Chakravarthy et al., 2007, Klein et al., 1998, Mitchell et al., 2002, Moschos et al., 2016, Smith et al., 1996, Tan et al., 2007, Velilla et al., 2013). Since these studies, smoking cessation has increased and led to various health benefits. Thus, more studies on the benefits of making these lifestyle changes could motivate patients to make changes when they are provided with the advice.

8.9 Conclusions

In conclusion, from the patients perspective, there are still a number of gaps and issues with the current state of lifestyle advice provision to patients with AMD. In the majority of cases, even when patients meet the criteria for lifestyle changes, they are not being provided or cannot recall any advice from their practitioners. Additionally, written advice is also not being provided to patients,

despite the evidence that written advice is effective in motivating patients to make changes. When specific advice was given, patients were more likely to follow the advice. Moreover, from the practitioner's perspective, the issues went beyond the way advice is communicated. There are larger issues with the way clinics are set up, confusion about whose responsibility it is to provide advice and a lack of time to do so. Importantly, many patients were unaware that there was any lifestyle advice, but highlighted that it would be welcomed.

8.10 Peer reviewed manuscripts

- Dave S, Binns A, Vinuela-Navarro V, Callaghan T. (2022). What Advice Is Currently Given to Patients with Age-Related Macular Degeneration (AMD) by Eyecare Practitioners, and How Effective Is It at Bringing about a Change in Lifestyle? A Systematic Review. *Nutrients.* Nov 3;14(21):4652.
- Dave S, Binns A, Vinuela-Navarro, V, Callaghan, T. (2024). The Patient Experience of Recieveing Lifestyle Advice Regarding AMD in Primary and Secondary Eye Care: A Mixed Methods Study. *BMC Public Health- Under review*
- Dave S, Binns A, Vinuela-Navarro, V, Callaghan, T. (2024). What do Practitioners Percieve to be the Main Barriers to Effective Lifestyle Advice Provision for Patients with Age related Macular Degeneration (AMD)? *British Journal of Ophthalmology- Under review*

8.11 Conference presentations

- Poster presentation- Women In Vision (2022)- Dave, S., Binns, A., Vinuela-Navarro, V., & Callaghan, T. The Experiences of Age Related Macular Degeneration (AMD) Patients Receiving Lifestyle Modification Advice: A Focus Group Study.
- Oral presentation- Vision and Eye research Institute (VERI) & Crabb Lab symposium (2022)- Dave, S., Binns, A., Vinuela-Navarro, V., & Callaghan, T. The Experiences of Age Related Macular Degeneration (AMD) Patients Receiving Lifestyle Modification Advice: A Focus Group Study.

- Oral presentation- British Congress of Optometry and Vision Sciences (BCOVS) (2022)- Dave, S., Rathore, M., Campbell, P., Edgar, D, E., Crabb, D, P., Callaghan, T., & Jones, P, J.- Patient Views on Vision Home Monitoring: Opportunities and Challenges
- Macular Society and Crabb Lab meeting (2023)- Dave, S., Binns, A., Vinuela-Navarro, V., & Callaghan, T., Rathore, M., Campbell, P., Edgar, D, E., Crabb, D, P., & Jones, P, J. Understanding Patient Perspectives: Communication and Home Monitoring in AMD and Glaucoma.
- Oral presentation- University of Western Australia (2023)- Dave, S., Binns, A., Vinuela-Navarro, V., & Callaghan, T. Patient practitioner communication in AMD.
- Macular Society webinar (2024)- Dave, S., Binns, A., Vinuela-Navarro, V., & Callaghan, T. Patient practitioner communication in AMD.
- Association for Research in Vision and Ophthalmology (2024)- Dave, S., Binns, A., Vinuela-Navarro, V., & Callaghan, T. Patient experience of receiving lifestyle modification advice regarding Age related Macular Degeneration in hospital and optometric practices.

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Appendix A- Data extraction table and quality checklists

Study		Methods/Participants								Outcomes (definition; unit of measurement)		Results		
	Aim	Study design	Total study duration	Total number participants	Exclusion criteria	Inclusion criteria	Age (mean in years)	Setting	Details of intervention e.g. hours of patient contact	Primary outcome measure	Secondary outcome measure	Sample size	Key results	Key conclusions study authors
Lawrenson and Evans (2013)	To survey the current practice of UK eye care professionals in relation to the advice given on diet and other lifestyle modifications for patients with or at risk of AMD.	Cross sectional survey	12 weeks	1468 UK based eye care professionals				UK	An online survey consisting of 18 forced choice questions and one free text question about dietary advice, recommendations on the use of nutritional supplements, smoking and the evidence base for nutrtional supplement interventions.	Investigation of current practice in relation to targetting modifiable risk factors in AMD.	Identification of sources of evidence used by practirioners to inform recommendations .	1468 (1414 optometrists and 54 ophthalmologists)	67.9% of all participants reported that they would always or usually provide dietary advice to patients with established AMD. 53.6% regularly offered advice to those at risk of AMD. 34% of paritcipants reported recommending nutrtitional supplements to patients with a family history of AMD and 93% for patients with advanced AMD. AREDS formula was the most commonly recommended supplement. For smoking 32.3% of participants reported taking a smoking history in new patients and 49.4% frequently informed smokers of the link between smoking and eye disease. 70.3% said they took smoking history into account when recommending supplements.	Supplement recommendations do not comply with current available evidence. Assessment of smoking status and the provision of targetting support to quit can also be improved. There is a need for profession specific guidance for supporting lifestyle interventions for AMD.
Bott, Huntjens and Binns (2017)	To investigate lifestyle advice recalled by patients with neovascular AMD.	Cross sectional survey	6 months	248 patients with neovascular AMD	Inability to read or understand the study survery	Patients disgnosed with unilateral nAMD.	80	UK	An anonymous self-report survey consisting of 20 closed questions with spaces to elaborate on answers.	The lifestyle advice that patients recalled recieveing from their eye care provider.	The self reported compliance to the advice given and reasons for non-compliance (if any).	248	60.1% of survey respondents reported receiving no advice regarding diet from their hospital eye care practitioner. 11% of participants made a change to their diet as a result of their eyes. The most prevelant reason for not making a change was not being given any advice to do so. 24.2% were recommended nutritional supplements and 19.8% started taking supplements for their eyes. The most common reason for not taking the supplements was not understanding how it would help (13.4%). 53.1% of the current smokers were advised to stop smoking and the most common reason for not stopping smoking was because they enjoyed it too much (40.6%).	The majority of patients attending an outpatient clinic had no recollection of dietary advice, nutritional supplements and only half of the smokers were advised to stop. The findings show that the provision of lifestyle advice should be reviewed and consider whether advice is being delivered in optimal format.
Shah et. Al (2013)	To evaluate the patient's understanding of the importance and adherence to the various lifestyle and Age-Related Eye Disease Study (AREDS) supplement recommendations for age-related macular degeneration (AMD).	Cross sectional survey	29 months	157	Participants who do not have AMD, hearing loss, dementia, other debilitating comorbidities.	Participants with AMD in at least one eye	79 years	UK	Telephone questionnaire survey was administered to assess knowledge and adherence to various recommendations made to patients with AMD about lifestyle and AREDS supplements.	The patient's perspective the necessity to follow these recommendations	The patient adherence, and the financial difficulty faced by the patients in following various recommendations	92	Out of the 92 patients in the study, 47 (51%) recalled recommendations about dietary changes, 21 (23%) about exercise, 5 (5%) about smoking cessation and 90 (98%) about AREDS supplements. 62% of people felt that making dietary changes was necessary, 76% believed that exercise and weight reduction was necessary, 80% of the people who were told about smoking cessation felt it was necessary and 74% of patients felt the AREDS supplement was a necessity. Adherance to diet modification was 81%, exercise and weight reduction was 76%, smoking cessation was 0% and AREDS supplementation was 88%. In terms of finances, overall, patients experienced an increase in expenditure as a result of making dietary changes but felt that it was justified.	Overall the most recalled recommendation was for the AREDS supplement compared to the other lifestyle changes. Patients also felt that the recommendations were necessary and affordable. However, adherence to smoking cessation was the worst.
Aslam et. al. (2014)	To evaluate ophthalmologists opinion of, and use of, mictronutritional dietary supplements 10 years after publication of the first Age-related Eye Disease Study (AREDS)	Survey		216 ophthalmologists and retinal specialists	Ophthalologists who are involved in rumunerated work for pharmaceutical companies or other health care related companies, ophthalmologists seeing less than 40 AMD patients a month or giving less than 4 prescriptions or advice about nutritional supplements per month.	Ophthalologists who are not involved in rumunerated work for pharmaceutical companies or other health care related companies, ophthalmologists seeing a minimum of 40 AMD patients a month or giving at least 4 prescriptions or advice about nutritional supplements per month.	30-40 years	Belgium, France, Germany, Italy, Portugal, Spain and UK	Internet based questionnaire	The opinions of European ophthalmologists involved in the prescription of nutritional supplements or in providing advice for nutritional supplements to their AMD patients.	The clinical practice of ophthalmologists and their attitudes to dietary supplements, the extent of their knowledge of scientific developments and their expectations of this field from the future.	216 participants (112 general ophthalmologists and 104 retinal specialists)	In a typical month, 89 nutritional supplements were prescribed or oral advice provided (37 written prescriptions and 52 oral advice. Greatest number of prescriptions were observed in France and Spain (69.2). 65% of patients with AMD were receiving nutritional supplements (69% ophthalmologists and 60% retinal specialists). Ophthalmologists were the most common people to initiate primary prescription or provide advice on nutritional supplements (68%). Nutritional supplementation was most frequently initiated when a disgnosis of early or intermediate AMD was confirmed (46% of patients, 49% general ophthalmologists, 42% retinal specialists). Ophthalmologists state that more than half their patients (58%) taking nutritional supplements were not aware of them before recieving first prescription or advice. Information about the benefits of nutritional supplements was given by 67% of ophthalmologists (lowest in the UK at 53.3%). Ophthalmologists suspected 40% of their patients had poor complicance. 21.8% of ophthalmologists considered nutritional supplements to have no symptomatic benefit.	Overall, presecription of nutritional supplements is a part of routine management of AMD for many ophthalmologists. Those that choose the nutritional supplements are well informed. There are some differences in the knowledge and practice of general ophthalologists and retinal specialist.

Burgmuller et. al. (2016)	To evaluate the level of knowledge patients have about AMD and whether there is a need for more information.	Cross sectional survey	15 months	271	Patients who did not want to answer the questionnaire, patients with dementia, patients who were not able to read the questions.	Patients with a diagnosis of AMD with an explanation from a physician at the clinic and patients with proper vision in at least one eye to be able to read the questionnaire.	>70	Germany	During their visit to the clinic, AMD patients were given a questionnaire consisting on 17 questions. One group was interviewed by a physician and the other group filled out the questionnaire independently.	The patients knowledge of AMD	The need for more information to be given to patients with AMD.	271 patients (121 in the questionnaire group and 150 in the interview group)	97.3% of patients got their knowledge of AMD from their physicians. When asked about lifestyle factors that patients believe have a positive impact on their disease, 61.7% of patients mentioned having a healthy lifestyle, 93.9% mentioned visiting a physician, 53% said vitamins , 27.3% mentioned getting new informations and 1.5% believed lifestyle factors had no influence on the disease. There was no significant difference between the patients in the questionnaire and interview groups. 30.4% of patients didn't know what form of AMD they suffered from and 42% of patients confessed that their knowledge of AMD was not sufficient.	In conclusion, although patients have some knowledge of their disease, there is still some room for improvement. Participants don't seem to have specific knowledge of lifestyle factors such as smoking or diet, but are aware of the benefits of a healthy lifestyle.
Caban-Martinez et. al (2011)	To assess tobacco use and smoking cessation preferences of AMD patients and level and preference of smoking cessasion services offered by their eye care providers.	Pilot cross sectional survey	One month	98	Participants who do not have AMD, younger than 18 years old and are not fluent in English or spanish	Participants with AMD in at least one eye, over the age of 18 and who are fluent in English or Spanish	For practitioners the most common age group was 30-39 and for the participants the mean age was 81 years	USA	A 16 item online survey was given to the practitioners via email. Patients were approached when visiting a retinal clinic and were interviewed using a 43 item paper questionnaire.	The tobacco use and smoking cessastion preferences of patients with AMD	The level and smoking cessation preferences of eye care providers.	46 eye care providers and 52 patients with AMD	Eye care providers asked about patients smoking status all the time (13%), periodically/seldom (80%) and never (7%). They assessed patients willingness to quit always (7%), periodically/seldom (76%) and never (17%). Finally when asked if they advised patients to quit smoking, 28% said always, 65% said periodically/seldom and 7% said never. 94% of practitioners were aware of local smoking cessastion services. 50%, 94% 94%, 85% and 59% of practitioners never recommend nicotine replacement therapy, prescribe other medication, provide brouchures/self-help materials, arrange follow up visits with patients to address smoking and monitor patients progress in attempting to quit respectively. 54% of patients with AMD were not certain whether smoking causes macular degeneration. 90% of smokers reported never being advised to quit by their eye care provider.	Clinicians and patients with AMD who smoke expressed a desire to facilitate smoking cessation but there is a lack of knowledge on how to stop smoking and smoking cessation services amogst patients and eye care providers.
Chang et. al. (2002)	To characterize the current use of dietary supplementation in patients with AMD in order to determine whether AREDS recommended doses were being achieved.	Cross sectional descriptive study	2 months	108	Patients who did not have a diagnosis of AMD	Patients with a diagnosis of AMD.	77.3	Canada	Patients with AMD given a survey during a visit ro a retinal speciality clinic. Patients were given a follow up phone call to confirm medication dosages.	Supplement use in patients with AMD in accordance to AREDS recommendations.	The easiest and most cost effective method to reach recommended dosages using currently available supplements.	108 patients (69 women and 39 men)	49 patients used dietary supplements for their AMD and 33 of the 49 were using the supplements recommended by their eye care providers. 68% of the 108 participants were using supplements containing at least one AREDS ingredient. 21 out of 108 participants were smokers and 10 were using dietary supplementation.	Although there is agreat awareness of dietary supplementation amongst patients with AMD, the exact recommendations of AREDS are not being followed.
Charkoudian et. al (2008)	To understand micronutrient supplement usage among patients with AMD in a tertiary ophthalmic center.	Cross sectional clinical case series	2 months	332	Participants without a diagnosis of	Patients with either a previous confirmed diagnosis of AMD from the Retinal division or patients with a referral diagnosis of AMD.	79	USA	Patients with AMD given a survey to be completed individually or read out by a researcher.	Responses to the study questionnaire about the use of micronutrient supplement usage in patients with AMD and level of AMD severity.	Supplement usage in comparison to the AREDS results.	332	52% of the cohort were confirmed to be using an AREDS like supplement at the recommended dose. 79% of the total cohort said they were taking the supplements for their AMD. Most patients were recommended the supplements by their eye care provider, but irrespective of this, many of them did not comprehend the rationale for using the supplements. The most common reason for non compliance was adverse side effects.	In the cohort of patients in this study, one third that were deemed candidates for AREDS supplements were not taking them or were taking the incorrect doses.
Cimarolli et. al. (2012)	To assess awareness, knowledge and concern about AMD and health-information seeking patterns among the general population, patients at risk of AMD due to race and age, patients at high risk of AMD and those diagnosed with AMD.	Descriptive study		894	General population: Participants under the age of 18. At risk group: Under 60, non caucasian, smokers. High risk group: Under 60, non caucasian, non smoker. AMD group: those without a diagnosis of AMD by an eye care professional.	population group: adults over the age of 18, at risk group: adults over the age of 60, caucasian and do not smoke, high risk group: adults over the age of 60, caucasian, who smoke AMD group: those diagnosed with AMD by an eye care professional	General population: 45-59, At risk: 65-74, High risk: 65-74, AMD: 65-74	USA	Telephone interviews conducted using a computer assisted telephone interview (CATI) method about awareness, knowledge and concern about AMD.	Responses to questions about awareness, knowledge and concern about AMD	Health information seeking patterns in the USA.	AMD group: 99	1/3 of the participants in the AMD group did not know the risk factors associated with AMD. The most commonly reported source of AMD information for the diagnosed group was eye care physicians, the internet, newspapers and magazines. All of the groups were aware of AMD.	Although the patients diagnosed with AMD were aware of the disease, not all of them were aware of the risk factors This shows a need for futher information from the eye care physicians.

Downie and Keller (2015)	To examine the self-reported, routine clinical practice behaviors of Australian optometrists with respect to advice regarding smoking, diet and nutritional supplementation.	Survey	2 weeks	379	Practitioners not registered with Optometry Australia.	Registered optometry practitioners.	40-49	Australia	An online 45 item survey about patient management	Practice behaviors of Australian optometrists with respect to advice regarding smoking, diet and nutritional supplementation	The potential influence(s) of practitioners' age, gender, practice location, therapeuticendorsement status and personal habits for nutritional supplementation	379 optometrists	Less than half of respondents (47.4%) indicated routinely asking their patients whether they smoke(d). Less than two-thirds of optometrists (62.2%, n = 176) indicated routinely counseling their patients with regard to diet. 91.2% of respondents recommended nutritional supplements to patients with AMD.	There is still room for improvement when it comes to practitioners speaking to their patients about smoking, diet and nutritional supplements, but the majority of practitioners are recommending supplements to patients with AMD.
Gocuk et. al. (2020)	To investigate whether performing clinical self audit and receiving analytical feedback improved clinical record documentation as a proxy for AMD care.	Interventional audit	17 months	50	Optometrists not currently practicing, routinely managing patients with or at risk of AMD and do not have access to their own clinical or written records.	Optometrists currently practicing in Australia, routinely managing patient with or at risk of developing AMD and who have access to their own written or clinical records.		Australia	A survey about practitioners confidence in AMD care followed by a three month audit of their practice records, after they receive analytical feedback, re-audit of clinical records.	Improvement in clinical record documentation of the care provided by optometrists.	Improvement in clinical care	20 optometrists	Post audit, average record documentation improved for asking about smoking status (21% to 58%), diet (11% to 29%) and nutritional supplementation (20% to 51%). Optometrists more consistently documented lifestyle modification advice to patients at earlier stages of AMD.	Clinical documentation improved overall after audit when asking about smoking, diet and nutritional supplement but there is still room for improvement, particularly in these three areas.
Hochstetler et. al. (2010)	To investigate the rate of adherence to the AREDS recommendations for vitamin supplementation in patients with AMD and to investigate factors associated with the use/non use of supplements.	Cross sectional survey	One month	70	Participants without a diagnosis of AMD	Participants who have a reported diagnosis of AMD		USA	A survey administered by one of the study investigators before ophthalmic examination by a retina specialist.	Rate of adherance to AREDS recommendations.	Factors associated with adherence to AREDS recommendations	64	59% of patients reported taking a vitamin supplement for AMD (71% of these was AREDS based). All the patients taking AREDS supplements were recommended to do so by a retinal specialist. Other sources of information were family members or friends and primary care providers. 75% of the participants who met the criteria for supplements reported not taking them because it was never recommended to them. Other reasons include thinking it would not benefit them, taking another vitamin, or recommended not to do so by another practitioner.	Patients still show low adherence rates to AREDS supplements with the main reasons being that it was never recommended to them.
Jalbert et. al. (2020)	To explore Australian eyecare professionals perspective on barriers to effective AMD care.	Qualitative research and focus groups		77	Non registered optometrists and ophthalmologists	Ophthalmologists and optometrists registered in Australia.	Optometrists: 41.4 Ophthalmologists: 45.3	Australia	Interviews with 10 ophthalmologists and two optometrists (14 minutes to 33 minutes) and seven focus groups (1.5 to 2 hours)	Barriers to effective AMD care	Enablers of effective AMD care	77	Cost/funding, understanding/denial, dicipline slios, access/availability of services and lifestyle changes were the most commonly reported barrier to AMD care. Education, access, shared care models, communication and funding were considered to be the top five enablers of AMD care. Lack of trust was often associted with people with AMD's lack of understanding and this was percieved to be the complexity of the information given to them.	There are clear barriers to the information regarding lifestyle advice given to patients with AMD, including a lack of trust in how simple/complex the advice is.
Kandula et. al. (2010)	To identify areas in which ARMD patients may be uninformed about their disease	Prospective survey based study		83	Patients who did not have the wet form of macular degeneration, or patients with wet macular degeneration who had not yet received an injection.	Any patient diagnosed with wet macular degeneration who had already received a minimum of one anti-VEGF injection	82	USA	An anonymous 32-item questionnaire	Areas in which AMD patients may not be informed.	Fears and expectations patients have about anti-VEGF injections.	83	78% of patients received their AMD knowledge from their physician. And 89% prefered if they could receive more information. 21%, 48%, 37%, 48%, and 36%, of patients respectively, correctly identified how diet, special vitamins, high blood pressure, family history, and smoking can affect AMD. 89% of patients preferred to recieve information from their physician.	Knowledge of risk factors and modification of risk factors is low amongst AMD patients. This demonstrates a need for further education.
Larson and Coker (2009)	To describe the perceptions, recommendations and educational or informational materials of licenced Wisconsin optometrists on lutein and zeaxanthin and eye health.	Descriptive and cross sectional survey	One month	300	Optometrists who are not registered	Optometrists registered in Wisconsin	43.6	USA	A 20 item survey sent to the optometrists	The questionnaire responses on the perceptions, recommendations and educational materials of optometrists.	The nutritional recommendations of optometrists and the percieved availability and importance of educational materials	127	78% of the optometrists in the study felt that the information available on lutein and zeaxathin and eye health is adequate for them to make recommendations to patients. 81.1% of optometrists reported recommending lutein and zeaxathin to patients diagnosed with AMD. 75.6% recommended spinach or other foods rich in lutein and zeaxathin. 79.5% recommended a zinc supplement and 66.9% recommended a multivitamin. 26.3% of optometrists recommended vitamin a or beta carotene supplements to patients who smoked. 79.5% of optometrists distributed informational materials to patients.	Optoemtrists felt informed about lutein, zeaxathin and eye health and are recommending supplements to patients with AMD. There needs to be further education surrounding smoking and supplements.

Lawrenson, Roberts and Offord (2014)	To explore the practices and attitudes of a representative sample of community optometrists regarding smoking and eye health and to evaluate the impact of an educational intervention which was designed to facilitate referral to a specialist stop smoking services.	Survey	One month	26	Non community optometrists	Optometrists practicing in community settings in Shropshire	N/A	UK	An online questionnaire featuring 10 forced choice questions	Responses of optmetrists to questions about their attitudes towards smoking and AMD. Knowledge of the link between smoking and AMD and the frequency at which smoking history is taken.	Barriers to delivering advice about smoking cessation and knowledge of local stop smoking services.	26	77% of the optometrists were aware of the link between smoking and AMD, 4% of optometrists reported that they regularly took a smoking history and 12% provided regular advice on stopping smoking. 88% of the optometrists were not aware of the mechanism for referring patients to smoking services. The most common barriers to providing smoking cessation advice was the potential effect on the practitioner relationship (39%), being unsure how to raise the issue (31%) and time constraints (31%).	Although there is a lot of awareness of the link between smoking and AMD, many practitioners do not taking a smoking history regularly and do not provide advice on how to stop smoking.
Martin (2017)	To investigate the extent to which ophthalmologists and optometrists in Sweden recommend the use of nutritional supplements, changes in diet or smoking cessation to patients at risk of or with signs of AMD.	Cross sectional survey		393	None	All Ophthalmologists and optometrists practicing in Sweden.	N/A	Sweden	A survey featuring 18 forced choice questions and one free text question	The reported extent to which optometrists and ophthalmologists recommend the use of nutritional supplements, dietary changes and smoking cessastion to paitnet at risk of or with AMD.	The rated strength of evidence for nutritional supplementation in AMD.	393 (323 optometrists and 48 ophthalmologists)	Optometrists were more likely to recommend micronutrient supplements than ophthalmologists. 75% of all respondents said they would recommend nutritional supplements to a patient with advanced AMD in one eye and early AMD in the other eye. Ophthalmologists were more reluctant to provide dietary advice compared to optometrists. The most common advice was to increase consumption of green vegetables and oily fish to two times a week. Ophthalmologists were more likely to provide smoking cessation advice compare to optometrists. 61% of optometrists never recommend smoking cessation.	Optometrists are more likely than ophthalmologists to provide advice about nutritional supplements and dietary changes and ophthalmologists are more likely to provide smoking cessastion advice. Ophthalmologists are also more likely to rely on findings from the AREDS study.
Parodi et. al (2016)	To evaluate the rate of adherance to prescribed nutritional supplementation in patients affected by age-related macular degeneration in an Italian tertiary center.	Cross sectional survey	5 months	283	Refusal to participate in the study, identification of ocular discorders other than AMD and any debilitating comorbidities impeding verbal interaction such as dementia and hearing loss.	Patients aged over 50, diagnosed with AREDS category 3 and 4 AMD.	50-95	Italy	A dialated fundus exam was performed to categorise patients into the correct AREDS category and an interview featuring 11 items administered by retinal specialists.	The assessment of the frequency of the at which AREDS supplementation was taken, evaluating any differences in supplementation between AREDS categories.	The assessment of both the frequency of AREDS-like nutritional prescription by the retinal specialist and information received by patients, adherence to AREDS recommendations and reasons for non-adherence.	193	40% of patients were taking an AREDS type oral supplement. 37% of the smokers were taking vitamin supplements. In 44% of the cases, oral supplementation was recommended by the patients ophthalmologist (all the patients taking vitamin supplements and 8 who were recommended the supplement but decided not to take it). 49% of the patients claimed they recieved no information from their ophthalmologist on why they should be taking oral supplementation. 94% of the patients meeting the criteria for supplements and not taking oral supplements were not taking them because it was never recommended to them. 56% were not aware they were even available.	Patients in AREDS category 3 and 4 have low adherence to nutritional supplements but in the majority of cases (65%) patients were not adequately informed by their ophthalmologist of the potential benefits of oral supplementation for AMD.
Sahli et. al. (2020)	To examine the lifestyle advice that optometrists offer, to whom such advice is offered and reasons for not offering advice.	Survey		42	None	Optometrists in the state of New York	47.5	USA	A self-reported mail in survey	The self-reported advice optometrists give to patients regarding lifestyle.	Who the advice is given to and why advice isn't given to others.	42	74% of optometrists provided advice on smoking to patients with AMD. 81% gave advice on a healthy diet, 79% on dietary supplements and 79% on specific foods and supplements.	Optometrists are giving advice on smoking cessation and diet but there is still some room for improvement. General reasons for not giving advice include lack of time, training and knowledge and a lack of belief that the advice would encorage a patient to change their behaviour.
Stevens et. al (2014)	To characterise AMD patients who seek the services of the Macular Society, and determine the level and source of their dietary knowledge.	Survey	2 months	158	The inability to hear and reply to questions in English on the phone	Participants aged 55, diagnosed with a form of AMD.	79	UK	A telephone survey administered by the researchers lasting approximately 25 minutes.	The beliefs and understanding of patients with AMD about the impact of nutrition on their condition.	Where the patients obtain their information about nutrition.	158	55% of participants felt that diet was important for their eye health, 63% felt they didn't have enough information about AMD. 40% received information about AMD from their ophthalmologist and 92% from the Macular Society.	Patients are aware of the effect of diet and nutritional supplementation on their eye health but there is still not enough information and room for more education.

Stevens, Cooke and Bartlett (2018)	To develop a novel educational intervention to promote healthy eating and nutritional supplementation among AMD patients.	Interventiona l	6 months	100	Participants who did not have AMD	Participants with AMD in the Macular Society	76.47	UK	Baseline measures of participants opinions on how diet effects AMD, motivation to engage in health protective behaviours and knowledge about the nutritients that are helpful as well as intake of kale, spinach and eggs. Participants allocated to the intervention condition were given a leaflet and prompt card containing advice on diet and supplements. Participanrs in the control group were given a leaflet created by the Royal College of Optometrists. Finally, a follow up phone call after two weeks asking the same things as the baseline measures.	An individuals confidence (self-efficacy) that changing their diet can slow progression of their AMD.	Motivation to engage in health protective behaviours, knowledge about AMD and intake of three foods high in Lutein and Zexathin (kale, spinach and eggs)	100	70 participants got their information about AMD from the Macular Society, 36 participants stated they got their information from their ophthalmologists, 19 said optometrists, 16 said friends, 8 said RNIB, 4 said they had received no information and 2 people said their GP. A total of 63 participants were taking nutritional supplements for their AMD. Participants in the intervention condition showed a large increase in self efficacy over time (61.3 at baseline compared to 74.7 at follow up). Participants in the control group showed a smaller change (61.9 at baseline compared to 65.5 at follow up). Motivation to talk to an eye care professional was significantly higher in the intervention group than the control group by the end of the study. Overall, participants rated the Royal College of Ophthalmologists leaflet at 5.77 out of 10 and the interventional leaflet and prompt cards at 7.54 out of 10.	Overall, all participants increased their motivation to eat kale, take nutritional supplements and improved their knowledge. However the study shows that the educational intervention is beneficial compared to the leaflets currently given to patients with AMD.
Tang et. al. (2020)	To assess the effectiveness of a telephone delivered intervention to impart and dissemate evidence based dietary advice for people with AMD.	Randomised controlled trial	13 months	155	A lack of sufficient english fluency, unwillingness to participate in the 4 month intervention programme, inability to provide informed consent.	A physician diagnosis of any form of AMD in either eye and aged over 50	78.1 (intervention group) and 77.9 (control group)	Australia	A baseline questionnaire and dietary questionnaire, participants in the intervention group were given a 20 minute phone call each month for 4 months. The phone calls were about assessment of the patients diet, advice on dietary behaviours, assistance with goal setting and arranging follow up support. Participants in the control group recieved freely available leaflets and brochures about AMD and nutrition and were also breifly followed up once a month. All participants were given the questionnaires again after 4 months.	0.5 serving per day increase in total vegetable intake.	Appreciable improvements in the dietary intakes of dark green leafy vegetables, fruit, low GI foods, fish and nuts.	155(78 controls, 77 interventions)	Immediately after the intervention, there was a significant improvement in the dietary intakes of the participants in the intervention group compared to baseline, including weekely intakes of green leafy vegetables (1.95 compared to 1.01 p=0.001). 3 months after the intervention, there was a significant difference between the intervention group and the control group in the weekly intake of nuts (p=0.04). Overall, patients reported finding the phone calls in the intervention group very helpful (72%).	Overall, the study showed some improvements in dietary habits of the people in the intervention group with most patients reporting finding the phone calls helpful.
Weaver and Beaumont (2015)	To investigate the effect of an intensive strict protocol-driven education versus a non proscriptive verbal education on the concordance rate.	Pospective controlled study	One month	330	Participants not aged over 55 years, not aware of their AMD diagnosis, could not comprehend the survey or could not rememeber the number of tablets they were taking.	Participants over the age of 55 with a diagnosis of AREDS catergory 3 or 4 AMD.	79	Australia	Survey administered face to face and read aloud to the patients attending the clinic before they see their consulting physician.	Concordance of taking the full AREDS dose of 2 tablets per day.		330	Clinic 1 had a formal policy of administering verbal and written information and a verbal repetition of these instructions from each staff member on each patient visit and clinic 2 had no specific education policy. Clinic 1 had a concordance rate of 81.6% compared to clinic 2 who had a rate of 44.1%. The most common reason that patients gave for not taking the AREDS supplements was that they were not aware of the supplement (43%).	The study shows that a high rate of concordance can be achieved through intensive patient education inculing repetition of intructions and advice.
Yu et. al. (2014)	To evaluate the current use of oral antioxidant supplements in AMD patients who are at increased risk for progression to advanced AMD.	Cross sectional questionnaire based study	Two months	65	Participants who refused to take part, patients with dementia or patients with language barriers.	Participants with AMD of AREDS category 3 or 4.	74.5	Germany	A questionnaire designed to evaluate potential factors influencing the use or non-use of oral antioxidant supplements for AMD.	The use of oral anti-oxidant supplements for AMD	Factors influencing the use or non use of oral anti-oxidants.	65	36 out of 65 patients were taking oral anti-oxidant supplements for AMD. The main source of recommendations for most patients was their ophthalmologist (55.4%) and 30.8% of the participants received no recommendations. 30 patients could name the supplement they were taking but 56.7% were taking the correct doses. 69% of the patients not taking supplements reported the main reason being no recommendation or a lack of awareness.	In conclusion, one third of the patients in the study were not taking AREDS supplementation despite being eligible. The main reason for this is the lack of awareness of the supplements being an option for AMD management.

Yu et. al. (2014)	To assess the use of oral antioxidant supplements by patients with late AMD and to identify factors that may affect their use or nonuse.	Questionnaire		47	Refusal to participate, dementia, language barriers.	Patients with late (bilateral advanced) AMD.	78	Germany	A questionnaire about oral anti oxidant supplement use for AMD given to patients attending an eye clinic.	The use of oral anti-oxidant supplements for AMD	Factors influencing the use or non use of oral anti-oxidants.	47	68.1% of the participants were taking oral supplements for AMD and 31.9% were not. 31/47 of the patients were recommended to take oral antioxidant supplements by their ophthalmologist (66%) and 21.3% of patients reported not recieveing any recommendations. Half of the patients taking the supplements did not believe in the benefits of the supplements but were still using them. The most common reson for non-use was was a lack of belief that the supplements would help.	In conclusion, most patients with late AMD are taking oral anti-oxidants despite not believeing in the benefits. There is still a number of patients nto receiving any advice about supplements.
Zhang et. al. (2020)	To investigate the current attitudes and self-reported practice behaviors of optometrists towards omega-3 fatty acid recommendations for eye health, and to assess their opinions and understanding of the potential benefits and risks associated with oral omega-3 fatty acid intake	Survey	5 months	206	Participants who did not complete the survey until section 3 and optometrists practicing outside Australia and New Zealand.	Optometrists practicing in Australia and New Zealand.	<30	Australia and New Zealand	An anonymous web based survey distributed to optometrists electronically.	Self-reported practices and recommendations relating to diet, nutritional supplements, and omega-3 fatty acids for age-related macular degeneration (AMD) and dry eye disease (DED)	Practitioner knowledge about omega-3 fatty acids	206	Optometrists reported recommending omgega 3 rich foods for AMD (68%) with 95% recommending fish or non fish seafood as a source. 29% provided specific dosages in their recommendations and 12%did not make specific recommendations relating to the brand or dosage of omega 3 supplement. 11% said they would advise patients to see a pharmacist or GP for specific recommendations about dosage and products. 40% of optometrists indicated using published primary reseach papers or systematic reviews to guide their clinical decision making.	Most optometrists are making recommendations about omega 3 and AMD. Many optometrists recommended diet based omega 3 sources for AMD over the supplements.

Study	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of the condition?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the outcomes measured in a valid and reliable way?	Was appropriate statistical analysis used?
Lawrenson and Evans (2013)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bott, Huntjens and Binns (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Shah et. Al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Aslam et. Al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear
Burgmuller et. al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Caban-Martinez et. Al. (2011)	Yes- for patient questionnaire only.	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear
Chang et. Al. (2002)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear
Cimarolli et. Al. (2012)	Yes	Yes	No	Yes	Yes	Yes	Yes	Unclear
Downie and Keller (2015)	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear- Outcomes measured in a reliable way	Yes
Hochstetler et. Al. (2010)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Larson and Coker (2009)	No	Yes	Yes	Yes	Yes	Unclear	No	Yes
Lawrenson, Roberts and Offord (2014)	No	Yes	Yes	Unclear	No	No	Unclear	Unclear
Martin (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Parodi et.al. (2016)	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes
Sahli et.al. (2020)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Stevens et.al. (2014)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes
Yu et.al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Yu et.al. (2014)	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes
Zhang et.al (2020)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table (appendix B)- JBI quality appraisal checklist for cross sectional surveys (https://jbi.global/critical-appraisal-tools).

Study	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?
Jalbert et. Al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table- CASP checklist for qualitative studies (https://casp-uk.net/casp-tools-checklists/)

Study	Did the study address a clearly focused research question?	Was the assignment of participants to interventions randomised?	Were all participants who entered the study accounted for at its conclusion?	Were the participants 'blind' to intervention they were given?	Were the investigators 'blind' to the intervention they were giving to participants?	Were the people assessing/analysing outcome/s 'blinded'?	Were the study groups similar at the start of the randomised controlled trial?	Apart from the experimental intervention, did each study group receive the same level of care (that is, were they treated equally)?	Were the effects of intervention reported comprehensively?	Was the precision of the estimate of the intervention or treatment effect reported?	Do the benefits of the experimental intervention outweigh the harms and costs?
Tang et.al. (2020)	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes

Table- CASP checklist for randomised controlled trials (https://casp-uk.net/casp-tools-checklists/)

Study	Did the study address a clearly focused issue?	Was the cohort recruited in an acceptable way?	Was the exposure accurately measured to minimise bias?	Have the authors identified all important confounding factors?	Have they taken account of the confounding factors in the design and/or analysis?	Was the follow up of subjects complete enough?	Was the follow up of subjects long enough?	Can the results be applied to the local population?	Do the results of this study fit with other available evidence?
Kandula et. Al. (2010)	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Yes
Weaver and Beaumont (2014)	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes

Table- CASP checklist for cohort studies (https://casp-uk.net/casp-tools-checklists/)

Study	Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Were the participants included in any comparisons similar?	Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Was there a control group?	Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Were the outcomes of participants included in any comparisons measured in the same way?	Were outcomes measured in a reliable way?	Was appropriate statistical analysis used?
Stevens, Cooke and Bartlett (2018)	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	Yes	Yes

Table- JBI checklist for Quasi-experimental studies (https://jbi.global/critical-appraisal-tools)

Study	Were there clear criteria for inclusion in the case series?	Was the condition measured in a standard, reliable way for all participants included in the case series?	Were valid methods used for identification of the condition for all participants included in the case series?	Did the case series have consecutive inclusion of participants?	Did the case series have complete inclusion of participants?	Was there clear reporting of the demographics of the participants in the study?	Was there clear reporting of clinical information of the participants?	Were the outcomes or follow up results of cases clearly reported?	Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	Was statistical analysis appropriate?
Charkoudian et. Al. (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear

Table- JBI checklist for Case Series studies (https://jbi.global/critical-appraisal-tools)

Study	Was the study question or objective clearly stated?	Were eligibility/selection criteria for the study population prespecified and clearly described?	Were the participants in the study representative of those who would be eligible for the test/service/intervention in the general or clinical population of interest?	Were all eligible participants that met the prespecified entry criteria enrolled?	Was the sample size sufficiently large to provide confidence in the findings?	Was the test/service/intervention clearly described and delivered consistently across the study population?	Were the outcome measures prespecified, clearly defined, valid, reliable, and assessed consistently across all study participants?	Were the people assessing the outcomes blinded to the participants' exposures/interventions?	Was the loss to follow-up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis?	Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided p values for the pre-to-post changes?	Were outcome measures of interest taken multiple times before the intervention and multiple times after the intervention (i.e., did they use an interrupted time-series design)?	If the intervention was conducted at a group level (e.g., a whole hospital, a community, etc.) did the statistical analysis take into account the use of individual-level data to determine effects at the group level?
Gocuk et. Al. (2020)	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	No	Yes	Yes	Yes

Table- NHLBI checklist for interventional audit studies (https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools)

Appendix B- CASP checklist

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?	Yes Can't Tell No	X 	HINT: An issue can be 'focused' In terms of • the population studied • the intervention given • the outcome considered

Comments:

2. Did the authors look for the right type of papers?	Yes Can't Tell No	X 	HINT: 'The best sort of studies' would • address the review's question • have an appropriate study design (usually RCTs for papers evaluating interventions)

Comments:

Is it worth continuing?

3. Do you think all the important, relevant studies were included?	Yes Can't Tell No	X 	HINT: Look for • which bibliographic databases were used • follow up from reference lists • personal contact with experts • unpublished as well as published studies • non-English language studies

Comments:

4. Did the review's authors do enough to assess quality of the included studies?	Yes Can't Tell	X 	HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies'

No		results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)

Comments:

5. If the results of the review have been combined, was it reasonable to do so?

Yes	X
Can't Tell	
No	

HINT: Consider whether
- results were similar from study to study
- results of all the included studies are clearly displayed
- results of different studies are similar
- reasons for any variations in results are discussed

Comments:

Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider
- If you are clear about the review's 'bottom line' results
- what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments:
There are significant limitations in the lifestyle modification advice given to patients with AMD. There is also a lack of papers from the patient perspective and even less papers discussing the current state of advice provision and patient recall of the advice.

7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments: N.A

Section C: Will the results help locally?

8. Can the results be applied to the local population?

Yes	
Can't Tell	X
No	

HINT: Consider whether
- the patients covered by the review could be sufficiently different to your population to cause concern
- your local setting is likely to differ much from that of the review

Comments: As the study includes populations from different regions in the world, it may not be applicable to one local population.

9. Were all important outcomes considered?

Yes	X
Can't Tell	
No	

HINT: Consider whether
- there is other information you would like to have seen

Comments:

10. Are the benefits worth the harms and costs?

Yes	X
Can't Tell	
No	

HINT: Consider
- even if this is not addressed by the review, what do **you** think?

Comments: The benefits are that this review addresses the gaps in the current state of advice provision that can be researched.

Appendix C- Study protocol

Project Overview

1.1 Project short title

Patient-practitioner communication in AMD

1.2 Co-investigators/collaborators

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1.3 Project Summary

Age related macular degeneration is the leading cause of visual impairment and severe visual loss. The only management strategy that is supported by robust evidence for people with non-neovascular AMD is the modification of lifestyle risk factors, such as smoking cessation and dietary changes. However. there is strong evidence suggesting that many optometrists are not routinely providing the most appropriate advice (Lawrenson and Evans, 2013), and that patients are often unable to recall the advice they were given (Bott et al., 2018). This finding is of utmost importance to the field of optometry and shows the need to evaluate the provision and effectiveness of lifestyle advice.

Therefore, the overall objective of this research is to investigate the extent, nature and effectiveness of lifestyle modification advice currently given to patients with AMD in hospital and optometric practice, from a patient perspective. The ultimate objectives are i) to provide an implementation science based framework to increase the extent of the delivery of this information and ii) to provide guidance on optimising the effectiveness of communication between practitioners and patients with AMD. By using practice based evidence, important in developing translational research, this may in turn lead to improved patient satisfaction, management and prognosis.

Surveys (developed following best practice guidelines and through a co-design activity with patient representatives) will be used to collect self-reported outcome data, reflecting the patient experience. Survey 1, at the time of the consultation, will collect data about communication during the visit, patient understanding and preferred mode of advice provision. After three months, survey 2 will be sent to consenting participants gathering information on any self-reported lifestyle changes made since the advice. A final survey will be provided to Eye Care Practitioners (ECPs) exploring factors that may have affected the provision of information (e.g. appointment duration). These data will be used to develop informed recommendations for overcoming barriers to the incorporation of lifestyle advice into eye examinations.

Introduction

2.1 Background and rationale

Age related Macular Degeneration (AMD) is the leading cause of irreversible blindness in developed countries, particularly in people 60 years and over. Given the projected shift in the demographic of the population towards older age, the number of people affected is also projected to rise (Wong et al., 2014). In 2020, there were approximately 200 million cases of AMD worldwide (Stahl, 2020). The early stages of AMD are usually asymptomatic (Boxell et al., 2017) and the later stages of AMD (neovascular) are symptomatic and impact vision permanently (Stahl, 2020). There are no current treatments for patients with non-neovascular AMD, however, modification of lifestyle risk factors may reduce the risk of progression. For example, smokers have a 4-fold increased risk of developing AMD compared to non-smokers (Bott et al., 2018) and this decreases to 3-fold if they are a past smoker. Other lifestyle factors such as a healthy diet have also been found to reduce the risk of AMD (Tan et al., 2008). For example, observational studies have shown that diets with a low glycaemic index containing zinc, omega-3 fatty acids, antioxidants, vitamins, minerals and carotenoids lutein and zeaxanthin may be protective against AMD progression (Mares and Moeller, 2006). So it is recommended that people with AMD consume a diet rich in green leafy vegetables, oily fish and vitamin supplements (Royal College of Ophthalmologists, 2021).

Eye Care Professionals (ECPs) are therefore recommended to provide lifestyle advice to patients with AMD. Recommendations from the Royal College of Ophthalmologists state that patients should be informed through both written and verbal communication of the modifiable risk factors and patient actions which can reduce the risk of disease progression such as smoking cessation, consumption of a diet rich in fruit vegetables and oily fish, and for certain patient groups, the addition of an AREDS based supplement (Royal College of Ophthalmologists, 2021). Similarly, although the College of Optometrists has not released AMD management guidelines, patient information leaflets are available providing practical advice and guidance with similar recommendations.

However, recent studies surveying both ECP's and patients have suggested that the recommendations are not consistently followed in primary or tertiary eye care settings (Boxell et al., 2017). Furthermore, studies have also found that optometrists are more likely to give advice regarding nutrition compared to ophthalmologists (Martin, 2017) but a study also found that when giving nutritional advice, the majority of eye care professionals did not recommend the supplement that complies with the best evidence (Lawrenson and Evans, 2013). However, little research has been conducted within the AMD population to see what approaches may increase coverage and effectiveness of communication. One study conducted in the AMD population found that although patients recalled some of the advice, particularly advice regarding AREDS supplements, many of them felt it was not affordable. Additionally, only 5% of patients recalled smoking cessation advice and none of the patients adhered to the advice they were given (Shah et al., 2015). This shows the importance of understanding the perception of advice that is currently being given to patients with AMD from their own perspective. Therefore, the overarching aim of this study is to investigate the nature of the lifestyle advice currently being given to patients, as related from the viewpoint of the patient and the practitioner, and to ultimately create the basis of a future framework to increase the effectiveness of communication between patients and practitioners.

2.2 Aims

The objectives are to investigate the extent, nature and effectiveness of lifestyle modification advice currently given to patients with AMD to provide a framework to increase the provision of delivery and optimise communication effectiveness.

Specific aims:

1) To investigate the patient experience of receiving lifestyle modification advice from their ECP.
2) To investigate differences in the information delivered by different types of ECPs.
3) To determine whether advice provided by ECPs impacts on self-reported patient behaviour.
4) To determine whether there is a difference in the self-reported impact of the advice based on the mode of delivery.
5) To investigate barriers which prevent ECPs from providing advice.

2.3 Outcome measures

The outcome measures for this study are:
1) Synthesised description of the patient experience of lifestyle advice currently provided by ECPs.
2) Evidence of impact of advice on self-reported patient lifestyle changes.
3) Identification of factors that predict self-reported adherence.
4) Identification of factors that facilitate provision of lifestyle advice by practitioners, and barriers to effective advice provision.

Participants and Study Design

3.1 Inclusion criteria

To be eligible for this study participants must:

- Have a diagnosis of AMD in at least one eye.

3.2 Exclusion criteria

Participants will not be included in the study if they:

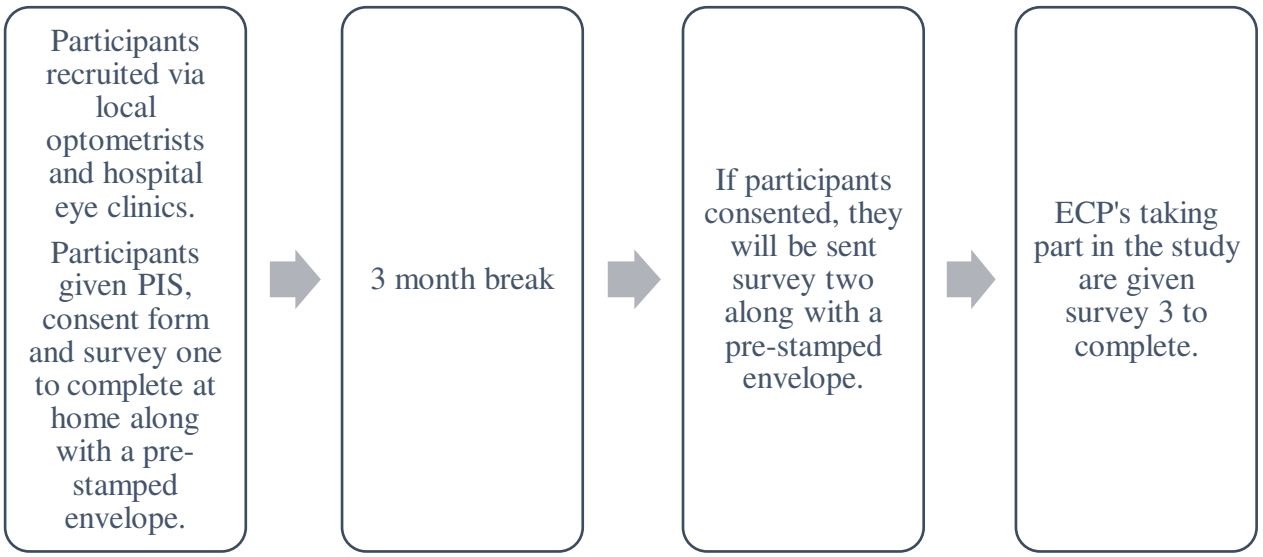
- Do not have a confirmed diagnosis of AMD.
- Have end stage AMD in both eyes (i.e. fovea involving geographic atrophy or scarring secondary to neovascular AMD
- Have any other ocular conditions affecting the retina or optic nerve, including inherited retinal dystrophies, glaucoma, diabetic retinopathy.
- Are not able to read or understand English

3.3 Recruitment and sample size

Participants will be recruited through ophthalmologist collaborators at the AMD clinics of Moorfields Eye Hospital London and University Hospital Birmingham, and from high street optometrists recruited from different UK locations. To meet the first two aims we aim to recruit a total of 426 patients with AMD. They will be invited to complete a survey via local optometrists (n=213) and Hospital Eye Services (n=213). Using a sample size calculation with a prevalence

estimate for AMD, a confidence level of 95% (p=0.05) and allowing for a 5% margin of error in responses (deviation amongst patients) a total of 384 participants are required for any findings to be generalisable to the population of patients with AMD. The additional 10% of patients recruited will allow for uncompleted surveys.

3.4 Participant pathway



Survey design

Prior to beginning the study, we obtained consent from City, University of London to carry out some focus groups comprising patients with various stages of AMD. The aim of the focus groups was to support the development of patient-centred surveys for the study by exploring the experiences of patients with AMD and their views and opinions on the mode of advice provision. The surveys were created based on the analysis of the focus group conversations, relevant literature and the aims of this study. Survey three was created and validated using relevant literature and conversations with optometrists. All of the surveys were evaluated by patient/practitioner focus groups for usability, applicability, and comprehensiveness before finalisation.

Study design

Participants will be recruited via local optometrists and hospital eye clinics. The ECP (or the researcher, if present) will discuss the aims of the study with all eligible patients after their eye examination. Following a discussion, participants will be given the option to complete the survey on paper or online and an opportunity to ask any questions before they are given the appropriate paperwork. This comprises of either an information sheet and instructions on how to complete the online survey (should they opt for the online option) or an

information sheet, a paper version of the survey and a stamped, addressed envelope (should they choose to complete the paper survey). The patient will not be asked to provide consent at this time, but will be given chance to leave with the survey/online survey instructions and to consider whether they wish to take part after reading the participant information sheet. The patient will complete the consent form at the time of completing the survey, and post it back in a pre-stamped addressed envelope (if seen at optometric practice, or if the participant prefers to complete in their own time). The participant will be encouraged to keep the participant information sheet for their own records. The practitioner will complete the patient diagnosis, their unique ECP ID, and the date of the examination on the practitioner form, but no identifying information regarding the patient will be added. The participant ID code will also be present on this form. The practitioner form will be retained and returned to the research team. If the patient wishes to take part in the second survey, or if they wish to be provided with a summary of the results of the study, they will be invited to fill in an additional detachable form (or a separate section of the online survey) detailing their name and contact details. This will be removed and stored separately from the main survey before analysis of results.

Survey one will consist of topics relevant to communication and information given during patient visits including patient demographic information, the type of ECP providing the advice, delivery method (verbal vs. written), location (practice vs. HES) and the patient understanding of the information given. Feedback, using raked answers questions, regarding the individual's preferred mode of advice provision will also be collected. There will be a free text section where the patient can describe their experience of the advice provided and the delivery manner, as well as their preferred form of delivery of advice. The data obtained from this survey will enable aims 1 and 2 to be met.

After 3 months, participants who provided consent to be contacted will be sent survey 2. This survey will gather information on any self-reported changes to their lifestyle patients have made since the advice was given. This survey will enable aims 3 and 4 to be met. Participants will be asked to return their completed surveys via email or using a pre-paid envelope. The survey will have a participant code on the cover page, enabling it to be analysed alongside the first survey for that individual without using patient identifiable data. The second survey will also have a Participant Information Sheet and patient consent item attached.

Finally, to meet aim 5, ECP's taking part in the study will be given a survey to complete at the end of recruitment. This survey will explore factors that may have affected or restricted the provision of .lifestyle advice to patients. Factors investigated will include average appointment time, motivation and evidence base understanding. These data will be used to develop informed

recommendations for overcoming barriers of implementing lifestyle advice into eye examinations.

Statistical analysis

To meet aim 1, graphical representations of the frequencies and percentages of the responses to survey 1 given by patients with AMD will be evaluated using diverging stacked charts and contingency tables. A thematic evaluation of free text sections of the survey will be conducted through analysis of the frequency of words and phrases used to describe the patient experience (Braun and Clarke, 2006). To meet aim 2, the responses to survey 1 given by patients seen by optometrists and ophthalmologists (in practice and hospital) will be analysed using descriptive statistics in order to investigate communication and lifestyle management advice differences between types of ECP. Independent samples t-tests (or Mann Whitney U test for non-normally distributed data) will be used to look for significant differences in continuous factors between different types of ECP (e.g difference in average time taken per patient to provide advice). To compare proportions between different types of ECP (e.g. proportions of individuals providing advice about diet), the Pearson's X^2 test will be used. To meet aim 3, Pearson's X^2 tests will be used to evaluate differences in proportion of patients making self-reported changes in lifestyle (survey 2) between those who received lifestyle advice and those who did not. Thematic evaluation will be used to evaluate free text sections of the survey to determine types of lifestyle modification made. For aim 4, any difference in impact by communication method will be analysed by mode of delivery (e.g. verbal, written) using Pearson's X^2. The same methods will be used to determine whether there are differences in patient adherence when advice is provided by different types of ECP (i.e. optometrists and ophthalmologists). Logistic regression analysis will be carried out to determine which factors contribute most to a patient's likelihood of making lifestyle changes, including demographic factors, whether advice is provided by the ECP, and the format of the advice. In order to meet aim 5, independent samples t-tests will determine whether there are significant differences in factors such as mean appointment time between those practitioners who provide information and lifestyle advice and those who do not. We will also carry out a thematic evaluation of the factors reported by ECPs to provide the greatest barriers to advice provision (survey 3).

Dissemination

The findings of the study will be presented at national and international conferences, and published in peer reviewed journals. It will also be presented to patient user groups, for example through the Macular Society magazine, Sideview.

The results of the analysis above will be synthesised into a report broken down into themes. This report will be used to form the basis of the future development of a framework for enhancing advice provision.

Appendix D- Ethics approval letters

NHS ethics approval letters





Dr Tamsin Callaghan

Division of Optometry Email: approvals@hra.nhs.uk

HCRW.approvals@wales.nhs.uk
City, University of London

Northampton Square

EC1V 0HBN/A

11 November 2021

Dear Dr Callaghan

HRA and Health and Care

Study title:	**Investigating the delivery and impact of patient practitioner communication in modifying lifestyle of people with Age-Related Macular Degeneration (AMD).**
IRAS project ID:	**298625**
Protocol number:	**ETH2021-1769**
REC reference:	**21/YH/0259**
Sponsor	**City, University of London**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the

basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **298625**. Please quote this on all correspondence.

Yours sincerely,
Hayley Henderson
Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Alison Welton, Sponsor Contact* **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster Recruitment]	3	07 October 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
HRA Schedule of Events		
IRAS Application Form [IRAS_Form_22092021]		22 September 2021
Letter from statistician [Statistician email]	1	21 July 2021
Organisation Information Document		
Other [Practitioner form]	1	26 October 2021
Other [Survey 1]	5	20 October 2021
Other [Survey 2]	4	20 October 2021
Other [Survey 3]	4	20 October 2021
Participant consent form [Survey 1]	2.1	07 October 2021
Participant consent form [Survey 3]	2	07 October 2021
Participant information sheet (PIS) [ECP Online Survey]	2.1	02 November 2021
Participant information sheet (PIS) [Online Survey]	2.1	02 November 2021
Protocol	3	20 October 2021
Referee's report or other scientific critique report [Comments to scientific review by Macular Society]		17 September 2021
Referee's report or other scientific critique report [Response to statistician's comments]		17 September 2021
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		20 September 2021
Summary CV for student		

Summary CV for supervisor (student research)		
Summary CV for supervisor (student research)		

Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 02071048083

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

11 November 2021

Dr Tamsin Callaghan

Division of Optometry

City, University of London

Northampton Square

EC1V 0HB

Dear Dr Callaghan

Study title:	**Investigating the delivery and impact of patient-practitioner communication in modifying lifestyle of people with Age-Related Macular Degeneration (AMD).**
REC reference:	**21/YH/0259**
Protocol number:	**ETH2021-1769**
IRAS project ID:	**298625**

Thank you for your letter of 2nd November, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registratio n-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-sum maries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:

https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster Recruitment]	3	07 October 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Initial Assessment for REC		
IRAS Application Form [IRAS_Form_22092021]		22 September 2021
Letter from statistician [Statistician email]	1	21 July 2021
Other [Practitioner form]	1	26 October 2021

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Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		20 September 2021
Summary CV for student		
Summary CV for supervisor (student research)		
Summary CV for supervisor (student research)		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

https://www.hra.nhs.uk/planning-and-improving-research/learning/

With the Committee's best wishes for the success of this project.

Yours sincerely

pp

H Hendr

Kirstie Melish

Chair

Email: bradfordleeds.rec@hra.nhs.uk

Copy to: Alison Welton, Sponsor Contact

Appendix E- List of ethics amendments

Date of amendment	Summary of requested amendment	Date of approval
02/12/2021	After the first steering committee meeting for the study, there were some survey changes recommended by the members which we have now made. The changes we made are as follows: We have expanded the question on vitamin supplements in survey one to include more detail. We have also added a sentence at the end of all of the questionnaires to give people the option to provide feedback on the surveys.	09/12/2021
07/03/2022	1) After discussing recruitment strategies and changes to patient pathways due to the COVID-19 pandemic, we would like to obtain consent from eligible patients who would like to complete the paper version of the survey via telephone. Patients will only be contacted if they have previously given consent to be contacted. A member of the research team will talk to them about the study on the phone and will go through the consent form with them. This will also provide the participant with an opportunity to ask any questions. For	17/03/2022

	the patients that we see in the clinics, we will still complete the consent process face to face. 2) Seeing as we will be speaking to some patients a few days after their appointments, we have changed the wording of some of the questions in the survey. Instead of the question asking 'about your appointment today' this has been changed to 'about your most recent appointment'. 3) We would like to open the study to involve other hospital-based clinics around England. We have received an expression of interest from other sites (Rotherham hospital, James Paget hospital, Sheffield Hospital, Princess Alexandra Hospital) in England who all believe they have the capacity to help us reach the recruitment goal for this study.	
29/06/2022	Following the approval of our previous amendment on the 17th of March 2022 about adding more NHS sites as a result of the expressions of interest we received. We would like to add Calderdale & Huddersfield NHS Foundation Trust as a site for the study. This site will distribute	26/07/2022

	surveys to eligible patients and discuss the study with them. The practitioners at this site will also complete a practitioner form for each patient they recruit about their diagnosis.	
05/08/2022	As we have received a range of interest from other NHS sites to be a part of the study. Therefore we would like to include the following NHS trusts to the study as recruitment sites: 1) Barking, Havering and Redbridge University Hospitals NHS trust 2) University Hospitals of Leicester 3) Barts Health NHS trust. These sites will distribute surveys to eligible patients and discuss the study with them. The practitioners at this site will also complete a practitioner form for each patient they recruit about their diagnosis.	05/08/2022
27/10/2022	Following the approval of our previous amendment on the 17th of March 2022 about adding more NHS sites as a result of the expressions of interest we received. We would like to add University Hospitals Coventry and Warwickshire NHS trust as a site for the study. This site will distribute surveys to eligible patients and discuss the study with them. The practitioners at this site will also complete a practitioner form for	27/10/2022

	each patient they recruit about their diagnosis.	
12/12/2022	We have made a few minor changes to the consent form for survey one. We have included a statement at the end of the consent form offering participants the option to hear about other research. We have made it clear that this is completely optional. We have also added 'optional' to the statements on the consent form that participants do not need to agree to.	12/12/2022
23/05/2023	1) We would like to amend our exclusion criteria to exclude people that have had more than three injections. This is due to the fact that after this point they are less likely to receive advice as the AMD is too advanced for lifestyle change to have any effect. 2) We would like to amend our protocol to say that survey three can be completed at anytime throughout the study by practitioners. This would give us the best chance to achieve our target for practitioners given the time frame remaining. 3) We would like to apply for a three month extention of our ethics to allow for follow up questionnaires to come in. The active recruitment will still end on 01/08/2023, but the extra three months will be for the follow up	23/05/2023

	questionnaires to be sent out (three months after patients have completed the first one).	
14/07/2023	We would like to extend our recruitment period by one week to allow for any extra questionnaires to come in. This would enable us to reach our recruitment target.	14/07/2023

Appendix F- Table showing how the survey questions were formed

Survey one

Participant quote or paper	**Theme or evidence**	**Questionnaire Item**
"My optician was always very encouraging about joining the macular society and research and dietary stuff" *"My GP was the one who sat down and spoke to me about my smoking"* *"My GP didn't seem to know anything about my eyes"* *"To get advice from a consultant carries a lot of weight"* *"There was a strong emphasis on joining the macular society by the consultant"*	Health care professionals	From what source did you receive the advice? ☐ Ophthalmologist ☐ Optician ☐ GP ☐ Website e.g. Macular society, NHS
Lawrenson and Evans (2013)	*"Only one in three optometrists regularly assessed smoking status and advised on smoking cessation"* *"The majority (67.9%) of respondents reported that they would always (or usually) provide dietary advice to patients with*	Did your practitioner ask you about any of the following? Tick all that apply. ☐ Your dietary habits e.g. the kinds of things you regularly eat ☐ Whether / how much you smoke

	established AMD, with over half (53.6%) regularly offering advice to those considered to be at risk of AMD."	☐ Whether / how much you used to smoke ☐ Whether you take nutritional supplements ☐ Which nutritional supplements you take ☐ How much alcohol you consume ☐ How much exercise you get ☐ Whether you wear sunglasses
Bott, Huntjens and Binns (2017)	*"39.9% remembered receiving advice regarding diet at the hospital. Only 24.2% of respondets recalled receiving advice regarding nutritional supplements."* *"The most prevalent reason for not taking supplements amongst those who had been advised to do so was that they did not understand how it would help their eyes"*	If lifestyle advice was given today, which of the following were discussed? Please tick all that apply ☐ Stopping smoking ☐ Taking vitamin supplements ☐ Improving diet ☐ Wearing sunglasses
"*they are talking at you and they don't have time. You have all these questions that you might have even written down before you get there, still*	Communication	Approximately how long did your practitioner spend today discussing lifestyle advice related to slowing the progression of your AMD?

they don't have time to talk to you about it".		
"I have never smoked a day in my life why would you even say that? He didn't even explain why you had to stop smoking if you did smoke." *'Rather than just saying you need to do "X", I would need to know why do I need to do "X", what's the benefit of doing "X"? Not in a super scientific way…'*	Communication	Were you told why you should follow the advice?
"Each time I go, my eyesight is a bit worse, I think I find it very hard to take on anything else that people are telling me" *"At the end of my appointment I'm going to have an injection and that's it. It's difficult to take anything else in."*	Communication	On a scale of 1-10 (1 being very easy and 10 being very difficult), how hard did you find it: to take in the advice you were given? to understand the advice you were given?
"[The letter seemed like it] was actually written for children" "*it didn't impact me at all…the advice wasn't very specific."*	Written advice	Were you given any written advice at your appointment today about changing your lifestyle to slow the progression of your AMD?
"*they are talking at you and they don't have time. You have all these questions that you might*	Communication	At your appointment, did you have an opportunity to ask questions about the lifestyle advice?

have even written down before you get there, still they don't have time to talk to you about it". *"I invariably went in with two or three questions, bearing in mind there's a whole queue of other people"*		
"You haven't just got macular, you've got multiple conditions you're dealing with but none of them seem to make the effort to make it all work together"	Comorbidities and communication between health services	Do you feel like your other health conditions were acknowledged by your practitioner?
"I found most of my information through the macular society" *"The RNIB helped me with zoom and other gadgets"* *"They look at how you live and they look at the bigger picture"*	Charities and other help	Were you given any guidance about where to get further information about lifestyle changes relating to AMD?
Boxell, Amoaku and Bradley (2017)	*"Patients diagnosed with AMD after 1999 (vs before 1999) reported better experiences at diagnostic consultation. However, information and support provision at diagnosis, and satisfaction with GPs remained low"*	Overall, were you satisfied with the content of the lifestyle advice you received during your appointment? Overall, were you satisfied with the way the advice was delivered?

Survey three

Participant quote or paper	Theme or evidence	Questionnaire item
"I invariably went in with two or three questions, bearing in mind there's a whole queue of other people"	Appointments	Approximately, how many patients on average do you see per week? ☐ Less than 20 ☐ 21-40 ☐ 41-60 ☐ More than 60 ☐ Don't know
"*they are talking at you and they don't have time. You have all these questions that you might have even written down before you get there, still they don't have time to talk to you about it*".	Communication	How long is your average appointment duration for an older adult (aged 60+ years)? ☐ Less than twenty minutes ☐ 25 minutes ☐ 30 minutes ☐ 35 minutes or more
"*they are talking at you and they don't have time. You have all these questions that you might have even written down before you get there, still they don't have time to talk to you about it*".	Communication	Do you have flexibility to extend the appointment, or re-book your patient, if they have additional needs e.g. pathology?
Lawrenson and Evans (2013)	*"Only one in three optometrists regularly assessed smoking status and advised on smoking cessation"*	Do you ask the patient about their current and history of smoking?

	"The majority (67.9%) of respondents reported that they would always (or usually) provide dietary advice to patients with established AMD, with over half (53.6%) regularly offering advice to those considered to be at risk of AMD."	Do you ask your patient about their current dietary habits? Do you ask any other questions about the patient's current lifestyle?
Bott, Huntjens and Binns (2017)	*"39.9% remembered receiving advice regarding diet at the hospital. Only 24.2% of respondents recalled receiving advice regarding nutritional supplements."*	Do you advise your patients to make lifestyle changes when they are diagnosed with AMD?
"*they are talking at you and they don't have time. You have all these questions that you might have even written down before you get there, still they don't have time to talk to you about it*".	Communication	If yes, approximately how many minutes, on average, do you spend discussing lifestyle factors?
"[The letter seemed like it] was actually written for children" "*it didn't impact me at all…the advice wasn't very specific."*	Written advice	What written material do you provide your patients? ☐ A personalised letter describing the conversation that we have in the clinic. ☐ A leaflet to provide some overall guidance.

		☐ Contact information for charities and other help. ☐ Links to different apps and web pages
"I have never smoked a day in my life why would you even say that? He didn't even explain why you had to stop smoking if you did smoke." *'Rather than just saying you need to do "X", I would need to know why do I need to do "X", what's the benefit of doing "X"? Not in a super scientific way…'*	Communication	When delivering advice to patients, do you tell them why they should take the advice/make lifestyle changes?
Lawrenson and Evans (2013)	*"Articles in professional journals and conference presentations were the most frequently cited sources that have informed practitioner views on the role of nutritional supplements in AMD."*	What sources of evidence do you use to inform your views on the benefits of lifestyle changes in AMD?
"You haven't just got macular, you've got multiple conditions you're dealing with but none of them seem to make the effort to make it all work together"	Comorbidities and communication between health services	When providing lifestyle modification advice, do you consider other aspects of the patient's general health. For example, the number of tablets they may currently be taking when suggesting vitamin supplements?
"he basically said "there is nothing we can do for you so if there are any changes, there is an open line, come back to us" but	Communication	Do you follow up at subsequent appointments by asking the patient about

basically they didn't want to see me again."		any changes they have made to their lifestyle?
Jalbert et. al. (2020)	*"Eyecare professionals considered poor care pathways, people with AMD's poor disease understanding / denial, and cost of care / lack of funding, as the most significant barriers to AMD care"*	What do you perceive as being the main barriers to patients adhering to advice provided?
Jalbert et. al. (2020)	*"[practitioners] considered shared care model, access, and communication as the most significant enablers to good AMD care"*	Can you think of anything that would make it easier for you to provide the best advice?

Appendix G- Full questionnaires

Survey One

Section A: Questions about you

1) What is your age?

- □ Under 50 years old
- □ 51-60 years old
- □ 61-70 years old
- □ 71-80 years old
- □ Over 80 years old

2) What gender do you identify as?

- □ Male
- □ Female
- □ Other _____ (please specify)
- □ Prefer not to say

3) How would you describe your ethnicity? (please tick)

White

- ☐ English, Welsh, Scottish, Northern Irish or British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background

Mixed or Multiple ethnic groups

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed or Multiple ethnic background

Asian or Asian British

- ☐ Indian
- ☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

Black, African, Caribbean or Black British

☐ African

☐ Caribbean

☐ Any other Black, African or Caribbean background

Other ethnic group

☐ Arab

☐ Any other ethnic group (please specify)

4) What are the first three digits of your postcode?

_____

---

5) What are your current living arrangements?

☐ Live alone

☐ Live with partner/carer/friend

☐ Live with family

☐ Live in supported accommodation

☐ Prefer not to say

6) Do you smoke cigarettes?

☐ Yes (Please go to question 7)

☐ No (Please go directly to question 9)

☐ Not now, but I used to (Please go directly to question 8)

7) If you are a current smoker, please could you answer the following:

How many cigarettes do you smoke, on average, per day? _____

For how many years have you smoked?

_____

8) If you used to smoke cigarettes but have given up, please could you answer the following:

How many cigarettes did you used to smoke, on average, per day? _____

For how many years did you smoke? _____ Did you stop smoking because of your eye condition?

☐ Yes

☐ No

9) Do you regularly take any vitamins/minerals or dietary supplements?

☐ Yes

☐ No

☐ If yes, please specify

_____

_____

_____

9) How many portions of oily fish (such as sardines, mackerel, trout etc.) do you eat each week?

☐ None

☐ 1-2

☐ More than 2

10) How often do you eat green, leafy vegetables (such as kale, spinach, broccoli) each week?

☐ Never

☐ 1-2 times per week

☐ 3-5 times per week

☐ Every day

11) Do you wear sunglasses?

☐ Yes – always when I go outside and it's bright

☐ Sometimes

☐ Occasionally

☐ Never

Section B : About your diagnosis and experience before today

1) Who first diagnosed you with AMD?

- □ Ophthalmologist
- □ Optician
- □ GP
- □ Other _____ (please specify)
- □ Do not know/do not remember

2) How long ago were you diagnosed with AMD?

- □ Within the last year
- □ 1-2 years ago
- □ 2-5 years ago
- □ 5-10 years ago
- □ More than 10 years ago

3) Do you recall being given any advice **before today** about changing your lifestyle to help to slow down the progression of your AMD (e.g. dietary changes, stopping smoking, taking vitamins etc.)? If yes, please answer questions 4, 5, 6 and 7. If no, please move onto the next section.

- □ Yes
- □ No
- □ Don't remember

4) What lifestyle advice were you given?

_____

_____

_____

5) When were you given the advice?

- □ Around the time I was diagnosed
- □ Within 1 year of being diagnosed
- □ More than 1 year after I was diagnosed
- □ On more than one occasion (tick all that apply)

- ☐ I was never given any advice

6) From what source did you receive the advice?

- ☐ Ophthalmologist
- ☐ Optician
- ☐ GP
- ☐ Website e.g. Macular society, NHS
- ☐ Newspaper article
- ☐ Discussion groups/ Peer support groups
- ☐ Other _____ (please specify)
- ☐ Don't remember

7) Did you make lifestyle changes based on that advice?

- ☐ Yes
- ☐ No

If yes, please specify

_____

_____

_____

Section C: About your most recent appointment

1) Did your practitioner ask you about any of the following? Tick all that apply.

- ☐ Your dietary habits e.g. the kinds of things you regularly eat
- ☐ Whether / how much you smoke
- ☐ Whether / how much you used to smoke
- ☐ Whether you take nutritional supplements
- ☐ Which nutritional supplements you take
- ☐ How much alcohol you consume
- ☐ How much exercise you get
- ☐ Whether you wear sunglasses

2) Do you recall being given any advice **at your most recent appointment** about changing your lifestyle to help to slow the progression of your AMD (e.g. dietary changes, stopping smoking, taking vitamins etc.)?

- ☐ Yes
- ☐ No
- ☐ Don't remember

3) Approximately how long did your practitioner spend at your most recent appointment discussing lifestyle advice related to slowing the progression of your AMD?

- ☐ No time
- ☐ Less than 2 minutes
- ☐ 2-5 minutes
- ☐ More than 5 minutes

4) If lifestyle advice was given at your most recent appointment, which of the following were discussed? Please tick all that apply

- ☐ Stopping smoking
- ☐ Taking vitamin supplements
- ☐ Improving diet
- ☐ Wearing sunglasses
- ☐ Other (please specify)

_____

_____

_____

5) What dietary recommendations were made to you at your most recent appointment by eyecare practitioner with respect to your AMD? (tick all that apply)

- ☐ None
- ☐ Eat plenty of green leafy vegetables
- ☐ Eat more oily fish

□ Eat lots of different coloured fruits and vegetables

□ Cut down on saturated fats

□ Eat a balanced diet

□ Reduce alcohol intake

□ Don't remember

□ Other (please specify)_____

6) Did your clinician recommend that you take a daily nutritional supplement? (e.g. vitamins, minerals etc)

□ Yes, the type of supplement was

_____

□ Yes, but I don't remember which supplement was recommended

□ Yes, but they didn't specify which supplement to take

□ I don't know

□ No

7) Were you told why you should follow the advice?

□ Yes

□ No

□ Don't remember

8) On a scale of 1-10 (1 being very easy and 10 being very difficult), how hard did you find it:

to take in the advice you were given?

_____

to understand the advice you were given?

_____

9) Were you given any written advice at your most recent appointment about changing your lifestyle to slow the progression of your AMD?

□ Yes

□ No

□ Don’t remember

10) At your most recent appointment, did you have an opportunity to ask questions about the lifestyle advice?

□ Yes

□ No

11) Do you have any other health conditions?

□ Yes

□ No

□ If yes, please specify

_____

_____

12) Do you feel like your other health conditions were acknowledged by your practitioner?

□ Yes

□ No

□ Not sure

13) Were you given any guidance about where to get further information about lifestyle changes relating to AMD? Please tick any of the following that apply.

□ Yes, the Macular Society

□ Yes, the Royal National Institute of the Blind (RNIB)

□ Yes, social services

□ Yes, a low vision clinic

□ Yes other (please specify) _____

_____

□ No

14) Overall, were you satisfied with the content of the lifestyle advice you received during your most recent appointment?

□ Yes

□ No

15) Overall, were you satisfied with the way the advice was delivered?

- ☐ Yes
- ☐ No

16) Do you have any further comments to make on your experience of receiving lifestyle advice at your most recent appointment?

_____

_____

_____

17) What is your preferred method of receiving advice?

- ☐ A verbal discussion
- ☐ Written information in a letter
- ☐ A leaflet/brochure
- ☐ A website or video
- ☐ Group discussions/peer support groups
- ☐ Other (please specify) _____

  _____

18) Please provide reasons for your answer to the previous question.

_____

_____

_____

Survey two

Section A- After your last eye appointment

1)Did you receive any lifestyle advice at your appointment?

- □ Yes
- □ No
- □ I don't remember

2)What advice were you given?

- □ Stopping smoking
- □ Taking vitamin supplements
- □ Improving diet
- □ Wearing sunglasses
- □ Other (please specify)_____

3)Based on this advice, have you made any changes to your lifestyle since your last appointment?

- □ Yes (Please answer the questions that apply below)
- □ No (Please go directly to question 9)
- □ Don't know (Please go directly to question 9)

4)**Answer this question if you reported smoking cigarettes at the time of your last appointment.**

What changes did you make to your smoking habits?

- □ I stopped smoking.
- □ I cut down on the number of cigarettes I smoke.
- □ I started using nicotine patches/gum to help me cut down.
- □ I did not make any changes.
- □ Other (please specify)_____

5)**Answer this question if you have started taking a regular vitamin supplement since your last appointment.**

What vitamin supplement did you start taking?

_____

6)What changes have you made to your diet since your last appointment?

- ☐ I started eating more green leafy vegetables
- ☐ I started eating more oily fish
- ☐ I started eating more different coloured fruits and vegetables
- ☐ I cut down on saturated fats
- ☐ I started to eat a more balanced diet
- ☐ I reduced my alcohol intake
- ☐ None
- ☐ Other (please specify)_____

  _____

7)Did you start wearing sunglasses more often?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

8)Did you make any **other** changes to your lifestyle based on the advice you were given? If yes, please specify.

_____

_____

_____

9)On a scale from 1 to 10 (1 being very difficult to 10 being very easy) how difficult did you find it to make the lifestyle changes?

_____

10)Please provide a reason for your answer.

_____

_____

_____

11)If you did not make any changes to your lifestyle, please could you explain why you chose not to.

- ☐ I wasn't given any advice.
- ☐ I was already doing everything I was advised to do.
- ☐ I didn't see how it would help.
- ☐ I couldn't recall what the advice was.
- ☐ It was too expensive.
- ☐ It was too much hassle.
- ☐ Other (please specify)_____

12)Can you think of anything which would have made it easier for you to make lifestyle changes after your last eye appointment?

- ☐ More detailed advice provision at the eye examination
- ☐ Written advice provision
- ☐ Signposting to services which could help with making lifestyle changes
- ☐ Other (please specify):

_____
_____
_____
_____
_____
_____
_____

13)After your last eye appointment, did you search the internet for further information about lifestyle changes in AMD?

- ☐ Yes
- ☐ No
- ☐ I don't remember

14)On a scale of 1-10 (1 being not at all helpful to 10 being very helpful), how helpful were the websites you explored?

_____

15)Were there any websites in particular which you would recommend to a friend with AMD?

_____

_____

16)Did you contact any of the following to get further information about lifestyle changes relating to AMD?

□ Yes, the Macular Society

□ Yes, the Royal National Institute of the Blind (RNIB)

□ Yes, social services

□ Yes, a low vision clinic

□ Yes other _____ (please specify)

□ I didn't contact anyone (please go directly to section B)

17)On a scale of 1-10 (1 being not at all helpful to 10 being very helpful), how helpful were the services/charities you contacted?

_____

18)Please provide a reason for your answer.

_____

_____

Section B- Lifestyle advice and AMD

1) On a scale from 1-10 (1 being not at all important to 10 being very important), how important do you think lifestyle change is to slowing the progression of your AMD?

_____

2) Please provide a reason for the answer you have given.

_____
_____

3) Will you keep to the changes you made to your lifestyle?

□ Yes

□ No

□ I don't know

4) Please give your reasons below.

_____
_____
_____
_____

5) Would any of the following motivate you to keep to the changes you made?

□ Regular chats with my practitioner.

□ Discussion groups with other people who have AMD.

□ I would feel motivated if I knew it was making a difference.

□ Regular written advice.

□ Other (please specify)_____

6) Since your diagnosis, which sources of information have you found to be the most effective in informing your choices about your lifestyle with respect to your AMD?

_____
_____
_____

7) Please add any other comments here.

_____
_____
_____

Survey three

Section A- About you

1) Please provide your ECP code for this study

_____

2) What is your profession?
   - ☐ Ophthalmologist
   - ☐ Optometrist
   - ☐ GP
   - ☐ Other (please specify) _____

3) In what setting to do perform eye examinations (tick all that apply)?
   - ☐ Independent practice
   - ☐ Multiple practice (e.g. Specsavers, Boots Opticians, Vision Express)
   - ☐ Domiciliary
   - ☐ Hospital
   - ☐ University Clinic
   - ☐ Other (please specify) _____

4) Please provide the first three digits of your practice postcode (if you work in multiple locations, please provide the postcode of your principle place of employment).

_____

5) How many years have you been practicing?
   - ☐ Less than a year
   - ☐ 1-3 years
   - ☐ 4-6 years
   - ☐ 7-10 years
   - ☐ More than 10 years

6) What gender do you identify as?

- ☐ Male
- ☐ Female
- ☐ Other (please specify) _____
- ☐ Prefer not to say

Section B- Your practice

1) Approximately, how many patients on average do you see per week?

- ☐ Less than 20
- ☐ 21-40
- ☐ 41-60
- ☐ More than 60
- ☐ Don't know

2) How long is your average appointment duration for an older adult (aged 60+ years)?

- ☐ Less than twenty minutes
- ☐ 25 minutes
- ☐ 30 minutes
- ☐ 35 minutes or more

3) Are visual fields screening, tonometry and any imaging performed within your appointment time, or are these tests carried out in a pre- or post-screening window?

☐ I do these tests myself within the appointment

☐ These tests are usually carried out separately

4) Do you have flexibility to extend the appointment, or re-book your patient, if they have additional needs e.g. pathology?

- ☐ Yes
- ☐ No
- ☐ Comments_____

_____

5) Do you feel that you have sufficient time to spend with each patient?

☐ Yes always
☐ Usually
☐ Sometimes
☐ Rarely
☐ Never
☐ Comments_____
_____

The following questions relate to the information you routinely collect from older patients (aged 60+) who you consider to be at risk of AMD.

6) Do you ask the patient about their current and history of smoking?
   ☐ Yes
   ☐ No
   ☐ Sometimes
7) Please explain your answer.

_____
_____

8) Do you ask your patient about their current dietary habits?
   ☐ Yes (please go to question 10)
   ☐ No (please go to question 9)
   ☐ Sometimes (please go to question 10)
9) If no, please specify why not.

_____
_____

10) If yes, what questions do you ask?

_____

_____

_____

11) Do you ask any other questions about the patient's current lifestyle?

□ Yes (Please go to question 12)

□ No

12) If yes, please specify what questions you ask.

_____

_____

Section C- Advice provision

1) Do you advise your patients to make lifestyle changes when they are diagnosed with AMD?

□ Yes (please go to question 3)

□ No (please go to question 2)

2) Please explain your answer.

_____

_____

_____

3) If yes, approximately how many minutes, on average, do you spend discussing lifestyle factors? (please write your answer on the line below).

_____

4) Please explain your answer.

_____

_____

_____

5) If yes, how do you deliver the advice? Please tick all that apply

□ Face to face discussion

- ☐ I give them written information (letter or leaflet) Please provide details in question 4 below.
- ☐ I refer them to other voluntary sector groups (e.g. The Macular Society)
- ☐ I refer them to appropriate websites e.g. NHS
- ☐ I refer them to their GP practice for help
- ☐ I refer them to NHS quitting smoking services
- ☐ Other (please specify)

  _____

  _____

  _____

6) What written material do you provide your patients?

☐ A personalised letter describing the conversation that we have in the clinic.

☐ A leaflet to provide some overall guidance.

☐ Contact information for charities and other help.

☐ Links to different apps and web pages

☐ I don't provide written advice.

☐ Other (please specify)

_____

_____

_____

7) When delivering advice to patients, do you tell them why they should take the advice/make lifestyle changes?

- ☐ Yes
- ☐ No

8) If no, please specify why not.

_____

_____

9) What sources of evidence do you use to inform your views on the benefits of lifestyle changes in AMD?

- □ Prior knowledge from undergraduate degree
- □ Knowledge from continuing education resources i.e. CPD/CET training
- □ Articles from professional journals
- □ NICE/RCOpth guidelines
- □ Expert opinions
- □ Conference presentations
- □ Systematic reviews
- □ Discussions with peers
- □ None of the above
- □ Other (please specify)

_____

_____

_____

10) When providing lifestyle modification advice, do you consider other aspects of the patient's general health. For example, the number of tablets they may currently be taking when suggesting vitamin supplements?

- □ Yes
- □ No

11) If yes please provide further details.

_____

_____

_____

12) Do you follow up at subsequent appointments by asking the patient about any changes they have made to their lifestyle?

- □ Yes
- □ No

If no, please specify why.

_____

_____

_____

13) What do you perceive as being the main barriers to patients adhering to advice provided?

_____

_____

_____

14) Can you think of anything that would make it easier for you to provide the best advice?

- ☐ Better access to training updates
- ☐ More written resources to provide the patient
- ☐ Longer appointments
- ☐ A specialist advisor in the practice who could have lifestyle advice discussions with the patients after each appointment
- ☐ Websites/Apps
- ☐ Other (please specify)

  _____

Appendix H- Practitioner form

To be completed by practitioner

ECP Number: _____

Practice name: _____

Date: _____

Patient diagnosis:

Right eye

- ☐ No AMD/normal ageing changes
- ☐ Early AMD (medium sized drusen (> 63µm and ≤ 125µm) and no AMD related pigmentary abnormalities)
- ☐ Intermediate AMD (large sized drusen (>125µm) +/- AMD related pigmentary abnormalities)
- ☐ Late AMD (neovascular or geographic atrophy

Left eye

- ☐ No AMD/normal ageing changes
- ☐ Early AMD (medium sized drusen (> 63µm and ≤ 125µm) and no AMD related pigmentary abnormalities)
- ☐ Intermediate AMD (large sized drusen (>125µm) +/- AMD related pigmentary abnormalities)
- ☐ Late AMD (neovascular or geographic atrophy

Non-AMD ocular co-morbidities- please specify

_____

_____

Appendix I- STROBE checklists

STROBE Statement—Chapter 5

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	N/A
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	N/A
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	130-131
Objectives	3	State specific objectives, including any prespecified hypotheses	131
Methods			
Study design	4	Present key elements of study design early in the paper	132
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	132
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	132
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	133
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	132-133
Bias	9	Describe any efforts to address potential sources of bias	134
Study size	10	Explain how the study size was arrived at	135
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	133
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	133

		(*b*) Describe any methods used to examine subgroups and interactions	133
		(*c*) Explain how missing data were addressed	135
		(*d*) If applicable, explain how loss to follow-up was addressed	135
		(*e*) Describe any sensitivity analyses	139
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	135
		(b) Give reasons for non-participation at each stage	135
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	136-137
		(b) Indicate number of participants with missing data for each variable of interest	137
		(c) Summarise follow-up time (eg, average and total amount)	N/A
Outcome data	15*	Report numbers of outcome events or summary measures over time	137-158
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	137-158
		(*b*) Report category boundaries when continuous variables were categorized	148-149
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	149
Discussion			
Key results	18	Summarise key results with reference to study objectives	158-159

Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	166
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	166
Generalisability	21	Discuss the generalisability (external validity) of the study results	158-166
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	N/A

STROBE Statement—Chapter 6

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	N/A
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	N/A
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	168-170
Objectives	3	State specific objectives, including any prespecified hypotheses	170
Methods			
Study design	4	Present key elements of study design early in the paper	170
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	132 and 170
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	132 and 170
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	170-171
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	170-171
Bias	9	Describe any efforts to address potential sources of bias	172
Study size	10	Explain how the study size was arrived at	172
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	171-172
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	171-172
		(*b*) Describe any methods used to examine subgroups and interactions	171-172

		(*c*) Explain how missing data were addressed	173
		(*d*) If applicable, explain how loss to follow-up was addressed	173
		(*e*) Describe any sensitivity analyses	172
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	173
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	173
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	173-174
		(b) Indicate number of participants with missing data for each variable of interest	173
		(c) Summarise follow-up time (eg, average and total amount)	N/A
Outcome data	15*	Report numbers of outcome events or summary measures over time	173-191
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	173-191
		(*b*) Report category boundaries when continuous variables were categorized	181
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	181
Discussion			
Key results	18	Summarise key results with reference to study objectives	191-192
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	200

Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	202
Generalisability	21	Discuss the generalisability (external validity) of the study results	191-202
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	N/A

STROBE Statement—Chapter 7

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	N/A
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	N/A
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	204-205
Objectives	3	State specific objectives, including any prespecified hypotheses	205-206
Methods			
Study design	4	Present key elements of study design early in the paper	206
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	206
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	206
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	206-207
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	206-207
Bias	9	Describe any efforts to address potential sources of bias	208
Study size	10	Explain how the study size was arrived at	208
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	207-208
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	207-208
		(*b*) Describe any methods used to examine subgroups and interactions	207-208

		(*c*) Explain how missing data were addressed	208
		(*d*) If applicable, explain how loss to follow-up was addressed	N/A
		(*e*) Describe any sensitivity analyses	208
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	208
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	208-209
		(b) Indicate number of participants with missing data for each variable of interest	209
		(c) Summarise follow-up time (eg, average and total amount)	N/A
Outcome data	15*	Report numbers of outcome events or summary measures over time	208-223
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	208-223
		(*b*) Report category boundaries when continuous variables were categorized	N/A
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	208-223
Discussion			
Key results	18	Summarise key results with reference to study objectives	224
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	230
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of	231

		analyses, results from similar studies, and other relevant evidence	
Generalisability	21	Discuss the generalisability (external validity) of the study results	224-231
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	N/A

Appendix J- List of other eye conditions

- Cataract
- Pseudophakia
- Disciform scar
- Peripapillary choroidal neovascular membrane
- Lamella hole
- Asteroid hyalosis
- Ocular Hypertension
- Dominant basal laminar drusen
- Subretinal haemorrhage
- Cortical cataract*
- Eyelid lesion
- Right angle narrow -10 degree closure grade 1
- Episcleral membrane
- Left sixth cranial nerve palsy
- Choroidal naevus
- Myopia
- Pars Plana Vitrectomy*
- Internal Limiting Membrane peel for Epiretinal membrane*
- Dry Eye

*- Prior surgeries

Appendix K- Written materials assessment tools

Factors to be rated	Score	Comments
1. Content (a) Purpose is evident **2** Purpose is explicitly stated in title, or cover illustration, or introduction **1** Purpose is not explicitly. It is implied, or multiple purposes are stated **0** No purpose is stated in the title cover illustration, or introduction		
(b) Content about behaviors **2** Thrust of the material is application of knowledge/skills aimed at **1** Desirable reader behavior rather than non-behavior facts **0** Nearly all topics are focused on non-behavior facts		
(c) Scope is limited **2** Scope is limited to essential information directly related to the purpose. Experience shows it can be learned in time allowed. **1** Scope is expanded beyond the purpose; no more than 40 percent is non-essential information. Key reports can be learned in time allowed **0** Scope is far out of proportion to the purpose and time allowed		
(d) Summary or review included **2** A summary is included and retells the key messages in different words and examples **1** Some key ideas are reviewed. **0** No summary or review is included		

2. Literacy demand (a) Reading grade level **2** 5th-grade level or lower (5 years of schooling level) **1** 6th-, 7th-, or 8th-grade level (6-8 years of schooling level) **0** 9th-grade level and above (9 years or more of schooling level)		
(b) Writing style, active voice **2** Both factors: (1) Mostly conversational style and active voice (2) Simple sentences are used extensively; few sentences contain embedded information **1** Both factors: (1) About 50 percent of the text uses conversational style and active voice (2) Less than half the sentences have embedded information **0** Both factors: (1) Passive voice throughout (2) Over half the sentences have extensive embedded information		
(c) Vocabulary uses common words **2** All three factors: (1) Common words are used nearly all of the time (2) Technical, concept, category, value judgment (CCVJ) words are explained by examples (3) Imagery words are used as appropriate for content **1** (1) Common words are frequently used (2) Technical and CCVJ words are sometimes explained by examples **0** Two or more factors: (1) Uncommon words are frequently used in lieu of common words (2) No examples are given for technical and CCVJ		

words (3) Extensive jargon		
(d) Context is given first **2** Consistently provides context before presenting new information **1** Provides context before new information about 50 percent of the time **0** Context is provided last or no context is provided		
(e) Learning aids via “road signs,” subtitles and captions **2** Nearly all topics are preceded by an advance organizer (a statement that tells what is coming next) **1** About 50 percent of the topics are preceded by advance organizers **0** Few or no advance organizers are used		
3. Graphics (a) Cover graphic shows purpose **2** The cover graphic is: (1) friendly (2) attracts attention (3) clearly portrays the purpose of the material to the intended audience **1** The cover graphic has one or two of the superior criteria **0** The cover graphic has none of the superior criteria		
(b) Type of graphics **2** Both factors: (1) Simple, adult-appropriate, line drawings/sketches are used (2) Illustrations are likely to be familiar to the viewers **1** One of the superior factors is missing **0** None of the superior factors are present		

(c) Relevance of illustrations **2** Illustrations present key messages visually so the reader/viewer can grasp the key ideas from illustrations alone. No distractions **1** (1) Illustrations include some distractions (2) Insufficient use of illustrations **0** One factor: (1) Confusing or technical illustrations (non-behavior related) (2) No illustrations, or an overload of illustrations		
(d) Lists and tables explained **2** Step-by-step directions, with an example, are provided that will build comprehension and self-efficacy **1** "How-to" directions are too brief for reader to understand and use the graphic without additional counseling **0** Graphics are presented without explanation		
(e) Captions used for graphics **2** Explanatory captions with all or nearly all illustrations and graphics **1** Brief captions used for some illustrations and graphics **0** No captions		
4. Layout and typography (a) Layout factors **2** At least 5 of the following 8 factors are present: Illustrations are on the same page adjacent to the related text Layout and sequence of information are consistent, making it easy for the patient to predict the flow of information Visual cuing devices (shading, boxes, and arrows) are used to direct attention to specific points or key		

content Adequate white space is used to reduce appearance of clutter Use of color supports and is not distracting to the message. Viewers need not learn color codes to understand and use the message Line length is 30-50 characters and spaces There is high contrast between type and paper Paper has non-gloss or low-gloss surface **1** At least three of the superior factors are present **0** (1) Two (or less) of the superior factors are present (2) Looks uninviting or discouragingly hard to read		
(b) Typography **2** The following 4 factors are present: Text type is in uppercase and lowercase serif (best) or sans-serif Type size is at least 12 point Typographic cues (bold, size, color) emphasize key points No ALL CAPS for long headers or text **1** Two of the superior factors are present **0** One or none of the superior factors are present or six or more type styles and sizes are used on a page		
(c) Subheads (“chunking’) used **2** (1) Lists are grouped under descriptive subheadings or “chunks” (2) No more than five items are presented without a subheading **1** No more than seven items are presented without a subheading **0** More than seven items are presented without a subheading		
5. Learning stimulation, motivation (a) Interaction used **2** Problems or questions presented for reader		

responses **1** Question-and-answer format used to discuss problems and solutions (passive interaction) **0** No interactive learning stimulation provided		
(b) Behaviors are modeled and specific **2** Instruction models specific behaviors or skills (for example, for nutrition instruction, emphasis is given to changes in eating patterns or shopping or food preparation/cooking tips; tips to read labels) **1** Information is a mix of technical and common language that the reader may not easily interpret (e.g., technical: starches – 80 calories per serving; high fiber – 1 to 4 grams of fiber in a serving) **0** Information is presented in nonspecific or category terms such as the food groups		
(c) Motivation, self-efficacy **2** Complex topics are subdivided into small parts so that readers may experience small successes In understanding or problem-solving, leading to self-efficacy **1** Some topics are subdivided to improve the readers' self-efficacy **0** No partitioning is provided to create opportunities for small successes		
6. Cultural appropriateness (a) Match in logic, language, experience (LLE) **2** Central concepts/ideas of the material appear to be culturally similar to the LLE of the target culture **1** Significant match in LLE for 50 percent of the central concepts **0** Clearly a cultural mismatch in LLE		
(b) Cultural image and examples **2** Images and examples present the culture in positive ways		

1 Neutral presentation of cultural images or foods **0** Negative image such as exaggerated or caricatured cultural characteristics, actions, or examples		
Total SAM score: The maximum possible total score is 44 points – 100% **44** (maximum possible score) Minus #N/A____4___ × 2 _36___ (revised maximum score) Total SAM score ___21____ / revised maximum score ___36____% score: _58 adequate_____ Interpretation of SAM percentage ratings: 70-100 percent= superior material 40-69 percent= adequate material 0-39 percent= not suitable material		

Flesch Reading Ease Test

This test rates text on a 100-point scale. The higher the score, the easier it is to understand the document. For most standard files, you want the score to be between 60 and 70.

The formula for the Flesch Reading Ease score is:

206.835 – (1.015 x ASL) – (84.6 x ASW)

Where:

ASL = average sentence length (the number of words divided by the number of sentences)

ASW = average number of syllables per word (the number of syllables divided by the number of words)

Appendix L- Manuscripts under review

Title: The patient experience of receiving lifestyle advice regarding AMD in primary and secondary eye care: a mixed-methods study

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Author Contributions: Conceptualization, S.D., A.B., T.C. and F.V.N..; Methodology, S.D., A.B., T.C. and F.V.N..; Data Curation, S.D. and T.C..; Formal analysis, S.D., A.B., T.C. and F.V.N..; Writing – Original Draft Preparation, S.D..; Writing – Review & Editing, S.D., A.B., T.C. and F.V.N.; Visualization, S.D., A.B., T.C. and F.V.N..; Supervision, A.B., T.C. and F.V.N.; Project Administration, S.D.

Abstract

Background: Age related Macular Degeneration (AMD) is a progressive condition which can lead to irreversible sight impairment. While there is no cure, modification of lifestyle risk factors (smoking, dietary changes, vitamin supplementation) can slow down disease progression. Although professional guidelines recommend that clinicians provide lifestyle advice to patients, evidence suggests that this may not be provided consistently.

Methods: This mixed methods study aimed to investigate the experiences of people with AMD receiving lifestyle modification advice in primary and secondary eye care, to determine the current status of advice provision and to explore patient opinions regarding the optimal mode of communication. Participants were recruited via ten hospital clinics and twenty-four optometry practices. Participants were excluded if they had bilateral end stage AMD, more than three rounds of anti-VEGF injections or other ocular conditions. Eligible patients were sent a questionnaire to complete online or on paper, including three sections; demographic, historical experiences of lifestyle advice and experiences at the most recent appointment. Exploratory descriptive analysis was conducted of quantitative data. Qualitative data was thematically analysed using NVivo 12.

Results: Four-hundred-and-four participants were included in the study. Most were female (n=244; 60.4%), recruited via hospital clinics (n=398; 98.5%) and diagnosed within the last year (n=152; 37.6%). The majority reported never having received lifestyle modification advice from an eyecare practitioner (n= 209, 51.7%). Of those that reported receiving advice prior to their most recent appointment (n=125), 63% reported making subsequent changes. Three-hundred participants (84% of respondents) reported not receiving advice at their most recent appointment. Only 25% were asked about their current smoking habits and only 2 (8.3%) of current smokers recalled being given advice to stop smoking. The most common type of advice received was regarding diet. A combination of verbal and written

information was the preferred mode of advice provision, yet only 9.4% were given written advice.

Conclusions: Despite the guidelines, the findings from this study show that advice is not consistently being provided to patients in their preferred formats. A clearer framework of patient informed guidelines is needed to improve lifestyle advice provision by eye care practitioners.

Keywords: Age related macular degeneration, lifestyle, smoking, diet, vitamins, advice

Introduction

Age-related macular degeneration (AMD) is the most common cause of blindness in the UK and industrialized countries, affecting more than 200 million people globally (Wong et al., 2014). While the late AMD stages (neovascular [nAMD] and geographic atrophy [GA]) are causal for visual impairment and blindness due to AMD, people with earlier AMD stages carry a considerable risk of future visual impairment (Bunce et al., 2015), inability to perform daily activities (Gopinath et al., 2014), depression (Mathew et al., 2011, Dawson et al., 2014, Casten and Rovner, 2013), reduced well-being, mood, quality of life (Taylor et al., 2016, Hassell et al., 2006) and falls (Wood et al., 2011, van Landingham et al., 2014). Currently there is no medical treatment available for early or intermediate AMD, and management is limited to addressing modifiable risk factors for progression. These include smoking cessation (Tan et al., 2007, Smith et al., 1996, Velilla et al., 2013), dietary changes such as increased intake of dietary xanthophylls (Chapman et al., 2019b), and dietary omega 3 fatty acids and oily fish (Chong et al., 2008) and adherence to a Mediterranean style diet (Hogg et al., 2017). Evidence regarding the effect of light exposure on disease progression is less defined (Klein et al., 2014, West et al., 1989). With respect to nutritional supplements, the robust Age-Related Eye Disease Studies (AREDS1 and AREDS2) demonstrated that the antioxidant formulae evaluated (comprising high dose vitamin C and E, zinc, and either beta carotene or lutein and zeaxanthin) can reduce progression by around 25% in people with intermediate AMD or unilaterial nAMD in the fellow eye over 5 years (Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013).

The progressive nature of AMD, and the evidence that lifestyle risk factors may have an impact on the rate of progression, leads to professional guidelines which emphasise the importance of eyecare practitioners (ECPs) recommending these lifestyle changes to patients (College of Optometrists, 2021, Royal College of Ophthalmologists, 2021, Ophthalmology, 2022, Hart

et al., 2020, International Agency for the Prevention of Blindness, 2021). NICE guidelines also indicate that advice should be provided to patients 'on an ongoing basis', 'tailored to the person's needs', and in an in an 'accessible format' for them to take away at their first appointment (NICE, 2018a).

However, there is evidence that ECPs are not necessarily following the best evidence based guidelines with respect to advice provision. For example. Lawrenson et al. reported in their survey of 1468 UK based practitioners that, whilst the majority provided dietary advice to people with AMD, advice regarding nutritional supplements was not compliant with the AREDS1 and 2 findings, and only a third of optometrists regularly asked about smoking status or provided advice about smoking cessation (Lawrenson and Evans, 2013). In a survey of 248 patients with AMD attending a hospital clinic in the UK, Bott et al (2017) reported that only 40% of patients recalled receiving dietary advice, and 24% advice about nutritional supplements, although this may also reflect limitations in patient recall.

The aim of this study was to investigate in greater depth the experience of receiving lifestyle advice in primary and secondary care for patients with AMD. Specifically, we aimed to explore the nature and comprehensiveness of advice received, and patient opinions regarding the optimal mode of advice provision.

Materials and Methods

People with AMD were recruited via ten hospital sites and twenty-four optometry practices in England. To be included in the study, participants had to have a diagnosis of AMD in at least one eye. Participants were excluded if they had bilateral end stage AMD, had received more than 3 anti-VEGF injections in their first diagnosed eye, if they had any other ocular conditions affecting the retina or optic nerve, including inherited retinal dystrophies, glaucoma and diabetic retinopathy or if they could not read or understand

English. All of the participants were provided with an information sheet and contact information for the study team if they had any questions. Participants all provided written informed consent to participate in this study.

In order to develop the survey, a PPIE group was held with people with AMD. Framework analysis was used to identify ten key themes around lifestyle advice and AMD, which formed the basis of questions in the survey. A systematic literature review (Dave et al., 2022) identified additional areas requiring exploration. A second focus group was held to trial the survey draft, to evaluate readability and to ensure that it captured patient opinions and experiences. The final survey was divided into three sections, relating to demographic information and current lifestyle (section 1), participant experience of receiving lifestyle advice prior to their most recent appointment (section 2), and the experience at their most recent appointment, and opinions about the best mode of advice provision (section 3).

Surveys were eligible distributed to patients when they attended their eyecare appointments. Participants were given the option to complete the survey online, by telephone or on paper (16 point Arial font). Eligible surveys had to be completed within three weeks of the appointment to facilitate recall. The full survey can be seen in supplementary material.

Data analysis

The primary analysis of the quantitative data was exploratory descriptive (IBM SPSS 25). Normally distributed data was described by mean/standard deviation, whilst median/interquartile range (IQR) was used as a non-parametric equivalent. Cross-tabulations were used to display contingency tables exploring the association between participant characteristics and advice preferences/experiences, with chi-square tests of independence used to test statistical significance of associations (Microsoft Excel). For items that used Likert scales, Kruskal-Wallis tests were used to identify significant differences between groups. For the qualitative analysis of free text question

responses, the frequency of words and phrases used to describe the patient experience were thematically analysed using Microsoft Excel and NVivo12. Based on the responses, each point was coded into a different section (node) and then grouped to form the themes for each question. These nodes and themes were independently reviewed by two authors (SD and TC).

Results

Participants and demographic information

Four-hundred and sixty-five participants were recruited, of which 61 were excluded due to no/incomplete consent forms (n=55), incorrect diagnosis (n=5) or incomplete questionnaires (n=1). In total, 404 participants were included in the survey analysis. Table 1 shows a summary of participant demographic and clinical information. The majority of participants were recruited via 10 hospital sites (n=398) and six participants were recruited via high street optometry practices. Figure 1 shows the geographic distribution of recruitment sites. The site that recruited the highest number of participants was Moorfields Eye Hospital in London, including their 'hub' sites that are based in smaller areas outside of central London. The site with the second highest recruitment was Huddersfield hospital.

	Frequency (% of whole cohort)
Gender	
Female	244 (60.4%)
Male	157 (38.9%)
Prefer not to say	3 (0.7%)
Age	
Under 50	1 (0.2%)
51-60	5 (1.2%)
61-70	53 (13.9%)
71-80	172 (42.6%)
Over 80	170 (42.1%)
Prefer not to say	3 (0.7%)
Living situation	
Live with partner/carer/friend	205 (50.7%)
Live alone	150 (37.1%)

Live with family	39 (9.7%)
Live in supported accommodation	4 (1%)
Prefer not to say	3 (0.7%)
Ethnicity	
English, Welsh, Scottish, Northern Irish or British	359 (88.9%)
Irish	8 (2%)
Any other white background	9 (2.2%)
White and Black Caribbean	1 (0.2%)
White and Asian	2 (0.5%)
Any other mixed or Multiple ethnic background	1 (0.2%)
Indian	10 (2.5%)
Pakistani	2 (0.5%)
Chinese	2 (0.5%)
Any other Asian background	3 (0.7%)
African	1 (0.2%)
Caribbean	2 (0.5%)
Any other ethnic group	1 (0.2%)
Not specified	3 (0.7%)
Diagnosed by	
Optometrist	244 (60.4%)
Ophthalmologist	130 (32.1%)
GP	3 (0.7%)
Other	21 (5.3%)
Not specified	6 (1.5%)
Time since diagnosis	
Within past year	152 (37.6%)
1-2 years ago	67 (16.6%)
2-5 years ago	86 (21.3%)
5-10 years ago	57 (14.1%)
>10 years ago	38 (9.4%)
Not specified	4 (1.0%)

Table 1- Summary of participant demographic and clinical factors

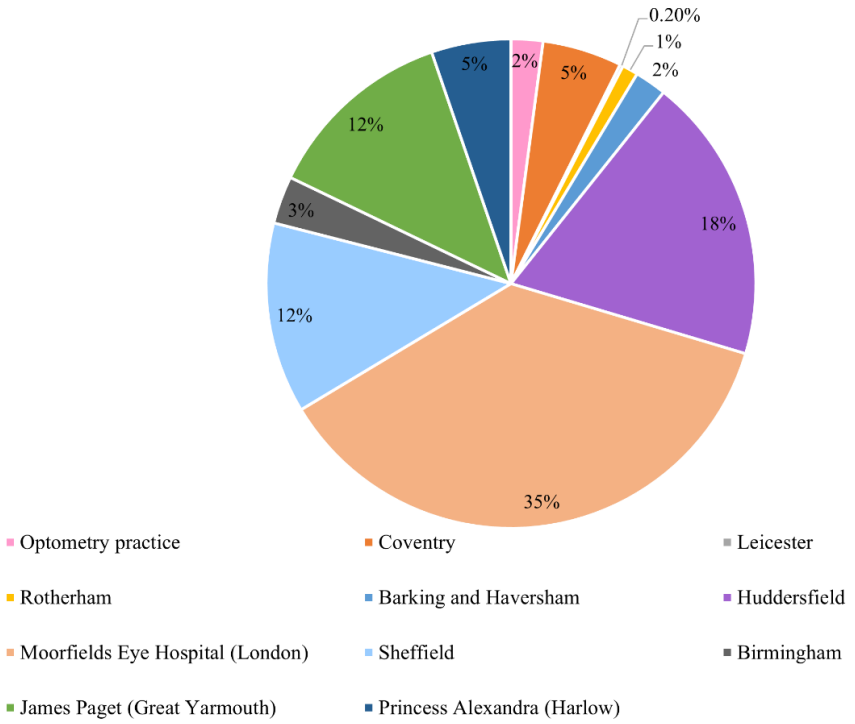


Figure 1- Pie chart showing geographic distribution of recruitment and proportion of participants recruited.

With respect to current lifestyle habits, 54.2% (n=219) of participants were already taking vitamin supplements, 55.9% (n=226) ate 1-2 portions of oily fish per week and 36.1% (n=146) consumed green leafy vegetables 1-2 times per week or 3-5 times per week (n=154; 38.1%). Finally, participants were asked if they wore sunglasses and the majority of participants responded 'yes- always when I go outside and it's bright' (n=159; 39.4%). Older participants (71-80 years old and over 80 years old groups) were more likely to take vitamin supplements (X^2 [df=16, n=401]=28.99 p=0.03) and wear sunglasses (X^2 [df=16, n=401]=34.14 p=0.005) than the younger age groups (Under 50 to 61-70 years old groups).

<u>Participant experience of advice provision prior to the most recent appointment</u>

Three hundred and seventy-one participants answered the question about whether they had received any lifestyle advice before their most recent appointment. Of these 246 (66.3%) reported not having received any prior advice. There was a significant association between being more recently diagnosed and recalling having received lifestyle advice prior to the most recent appointment ([X^2 [df=4, n=215]=130.5 p<0.001]). When asked in free text to report on the nature of the advice received prior to the most recent appointment, the most frequently referenced theme was diet (n=105 references), followed by vitamins and medication (n=55), UV/light protection (n=21), smoking (n=15) and healthy lifestyle/weight loss (n=13).

Those individuals that did report having received lifestyle advice before their most recent appointment (n=125) were asked if they had accordingly made any lifestyle changes. Seventy-nine (63%) reported that they did make changes on the basis of the advice received. There was a significant association between when the advice was given and whether lifestyle changes were made, with advice provision around the time of diagnosis associated with a greater likelihood of making changes than advice provided at a later stage (X^2 [df=5, n=116]= 11.6 p=0.04). However, there was no significant association between whether any changes were made and the source of the advice (X^2 [df=15, n=116]=16.3 p=0.361) or any demographic factors (p>0.05).

One hundred and five participants responded to a follow up free text question asking about the changes they had made to their lifestyles based on historical advice received. Interestingly, even though it was not the most referenced theme with respect to advice provided, vitamins and supplements was the most referenced theme when participants were asked about what changes they made as a result of advice received (n=47; 85% of those that reported receiving advice regarding vitamins), followed by diet (n=42; 40% of those receiving advice), UV protection (n=18; 86% of those receiving advice),

healthy lifestyle and weight loss (n=9; 69% of those receiving advice) and smoking (n=3; 20% of those receiving advice).

Participants' experience of advice at the most recent appointment

When asked about their experience of receiving lifestyle advice at their most recent appointment, of the 357 participants that responded to the question, 57 (16.0%) answered that they had received advice. The most prevalent lifestyle advice received was regarding diet (n=38 i.e. 66.7% of those receiving advice). This is despite the fact that, of 404 participants, only 61 (15.1%) reported that their practitioner actually asked them about their current dietary habits. Table 2 shows the specific dietary recommendations that were reportedly made to participants. The most common dietary advice was regarding green leafy vegetables, followed by oily fish, and eating lots of different coloured fruits and vegetables. However, each of these only amounted to between 4-8% of the total cohort (n=404) of which 40 respondents (9.9%) reported that they never eat green leafy vegetables and 141 (34.9%) reported that they never eat oily fish.

Type of dietary advice	Frequency (% of those reporting receiving advice about diet/% of whole cohort)
Eat plenty of green leafy vegetables	33 (86.8/8.2)
Eat more oily fish	18 (47.4/4.5)
Eat lots of different coloured fruits and veg	17 (44.7/4.2)
Cut down on saturated fats	5 (13.2/1.2)
Eat a balanced diet	14 (36.8/3.5)
Reduce alcohol intake	1 (2.6/0.2)
Don't remember	1 (2.6/0.2)

Table 2- Table showing the types of dietary advice participants were given at their most recent appointment and the frequency for each type. Participants were able to pick more than one option.

The majority of participants reported that they had not been recommended a nutritional supplement at their most recent appointment (n=293; 85.9% of 341 who answered the question). Of the participants that responded that such a recommendation had been made, table 3 shows a breakdown of the types of supplements that they were recommended.

Type of supplement recommended	Frequency (% of those recommended supplement/% of whole cohort)
AREDS1/AREDS2 compliant supplement*	26 (54.2/6.4)
Non AREDS compliant supplement*	9 (18.8/2.2)
Do not remember	5 (10.4/2.6)

Non eye related supplement	4 (8.3/1.0)
Not specified by practitioner	4 (8.3/1.0)

Table 3- Table showing the types of nutritional supplement participants were recommended and the frequency and percentages for each type. *= Participants were asked to name the supplements they were recommended and the formulae for these were looked up to investigate whether they were AREDS compliant.

Out of 404 participants, 390 responded to the question about their smoking status. The majority were non-smokers (n=252; 64.6%), followed by ex-smokers (n=114; 29.2%), and current smokers (n=24; 6.2%). The ex-smokers had smoked an average of 20.37 pack years (SD=9.59), current smokers 31.08 pack years (SD=26.71). In total, 101 participants (25% of the whole cohort) were asked about their current smoking habits, and 48 (11.9%) were asked about their smoking history. Crucially, only 2 (8.3%) of current smokers recalled being given advice to stop smoking.

Participants' general experience of advice provision at the most recent appointment

Amongst the participants that recalled being given advice at the most recent appointment (n=57), forty-seven participants rated the difficulty of taking in and understanding advice, on a scale of 1-10 where 1 indicated very difficult and 10 indicated very easy. Difficulty of taking in advice was, on average, rated low (median=2.0, IQR=1.0-6.0) as was difficulty understanding advice (median=1.0, IQR=1.0-5.8). Perceived difficulty was not associated with demographic factors ($p>0.05$). Out of the participants that were given advice at their most recent appointment, only 7 (12.3%) participants were told why they should make lifestyle changes. 48.8% (n=139 out of 285 participants that answered the question), reported feeling satisfied with the content of the advice and 54.4% (n=149 out of 274) were satisfied with the way the advice was delivered.

Out of the 381 participants that answered the question, 9.4% (n=36) were offered written advice at their most recent appointment. There was no significant difference between those who received written advice and those that did not in the reported difficultly in taking in the advice ($H(2)=4.39;p=0.11$) and in the understanding of lifestyle advice ($H(2)=2.81;p=0.25$). However, there was a significant positive association between written advice being given and feeling satisfaction with the way advice was delivered ($X^2[df=2,n=381]= 47.75;p<0.001$).

The majority (n=278; 76.6%) of the 363 participants that responded to the question said they were not given any information about where to get further support on lifestyle modification. Of the 85 participants that were given information, the majority were directed to the UK charity, the Macular Society (n=62; 72.9%), followed by a local low vision clinic (n=18; 21.2%), other services (n=12; 14.1%), UK charity the Royal National Institute for Blind people (RNIB; n=11; 12.9%) and finally social services (n=4; 4.7%).

Out of 365 participants that answered the question, 31.5% (n=115) reported that they had an opportunity to ask questions during their appointment. This was significantly associated with participants' satisfaction with the content of the lifestyle advice they were given ($X^2[df=2,n=365]= 99.65;p<0.001$) and satisfaction with the way advice was delivered ($X^2[df=2,n=365]=93.14;p<0.01$). However, there was no significant association between being given the opportunity to ask questions and the reported difficultly taking in and understanding advice. The majority of participants reported that they had other health conditions (n=296; 76.7%). Of these participants, 92 (31.1%) believed that their other health conditions were not acknowledged by their practitioner during their most recent appointment, whilst 115 (39%) were unsure if this was the case. The final question was based on participants' preferred mode of advice provision. The most frequently selected options for this question were 'a verbal discussion' (n=223; 55.4%) and 'written information in a letter' (n=213; 52.7%), followed

by ‘a written leaflet/brochure’ (n=115; 28.5%), ‘a website or video’ (n=33; 8.2%) and a group discussion/peer support group (n=13; 3.2%).

At the end of the questionnaire, there was a free text box where participants were asked if they had any further comments in general about their experiences of lifestyle advice provision. Table 4 displays the themes and nodes from this question with the frequency of reference in the text, with sample quotes. Two hundred and seven individuals (51.2% of the cohort) wrote comments for this question. Over half of those who made comments in this section were dissatisfied with the quantity of advice provided.

Theme (frequency of reference)	Node	Sample quotes
No/minimal advice given (n=107)	No advice given	*"Advice minimal, could have been signposted to websites"* *"The advice was brief and quite cursory. I don't recall anything about dietary advice or alcohol. Need written info to take home"* *"I haven't been given any lifestyle advice at any appointment regarding my vision"*
	Minimal advice	
	No recent advice	
	Told nothing could be done	
Further information needed (n=24)	Questions about lifestyle/AMD	*"Forgot to ask what exactly is in the green plants that would help me"* *"Would have liked some emotional help and advice"* *"This questionnaire reveals to me that lifestyle is, or is thought to be, an important factor in the development of AMD. I have been educated!"*
	Would like advice	
	Unaware of the importance of lifestyle	
	Would like to discuss/know more	
	Unsure if advice was sufficient	

	Need scientific proof of advice	*"when I mentioned it to my GP he asked if I was tired of living. Reassured him that I am not"*
Positives- hospital staff (n=15)	Helpful practitioner	*"I am impressed with the treatment received and as such not much time for lifestyle advice"* *"I've only just found out that I have this condition. I thought I was just going for a scan no one said about injections until I got to apt, it was a shock but everyone was so kind and talked me through it"*
	Helpful staff/experience	
	Happy with advice	
	Questions answered	
	Made lifestyle changes due to previous advice	
No need for advice (n=14)	Already aware of advice	*"The trouble about acting on the lifestyle info 'take this' 'do that' is one never sees the benefit so you easily do not carry on the advice. Where can one find hard scientifically proved advice that is not commercially biased. How many times has the advice changed?"* *"Didn't know about any help. Was told I'm losing my sight and there's no cure- in other words, get on with it."* *"Already aware of most advice"*
	Already living a healthy lifestyle	
	Did not want advice	
	Advice not needed	
	Lifestyle advice given not applicable	
Negatives- hospital staff (n=13)	Busy staff	*"The clinic I attend is so busy they don't have time for discussions. So I went private to discuss the matter in more detail."*
	Rushed appointment	
	Did not see a practitioner	

	No personal approach	*"Unless I persist I do not receive comments on the reviews undertaken by technicians at XXX. It feels like I am only an NHS number and not a person"*
Discussion on future and treatment (n=10)	Advice about further treatment	*"With the realisation that the right eye how progression from dry to wet AMD, that took priority over other discussions"*
	Treatment was a priority	*"There was no advice or discussion on a face to face basis. All information was in booklet or leaflet form"*
Written information (n=8)	Referred to written materials	*"There was no advice or discussion on a face to face basis. All information was in booklet or leaflet form"* *"Received feedback via letter after appointment. Some changes were detailed in the letter and I had to ask my optician what the technical terms in the letter meant. Not a good way to receive information about changes"*
Independent research (n=6)	Independent research	*"In the first instance advice was given by local optician and I researched for myself regarding eye supplement"* *"I have never received any advice about AMD other than 'you have AMD'. Most information I have received was from a friend and my sister in law"*
	Internet	
	Advice from family and friends	
	Joined Macular Society	
	Private care for more information	
	Visual aids	

	Advice given at low vision clinic	
Relation to other health conditions (n=5)	Connection with co-morbidities	*"Similar lifestyle changes made following advice given/received following coronary problems 25 years ago"*
Contacts (n=2)	Information on who to contact	*"I did understand the advice at that time, and knew how and who to contact if needed"*

Table 4- Table displaying the themes and nodes with the frequency of reference for participants that wrote 'further comments'

Table 5 shows the themes and nodes for the reasons that participants provided for their preferred modes of advice, as well as key quotes. Participants appreciated the personalised element of face to face discussion, and the ability to ask questions, as well as commenting on their difficulty with reading due to eyesight. Those that preferred written material highlighted the benefits of being able to review information and to take time to consider and absorb the advice. A number of individuals commented on the advantages of receiving advice in both verbal and written format.

Mode of advice provision	**Themes**	**Nodes**	Sample Quotes
A verbal discussion	Opportunities for discussion	Can talk more	*"I like to know immediately if I need to make changes and be told directly to ensure I understand"* *"A verbal discussion gives an*
		Can ask questions	
		Can learn more	
	Understandable	Understandability	
	Preference	Prefer face to face	
		Satisfaction	
		The best way	

	Issues with vision	Tired eyes	*opportunity to seek clarification when needed"*
		Difficulty reading	
	Technology	No internet/technology	*"A verbal discussion gives the opportunity to ask questions, but it needs to be backed by information that can be taken away"*
	Personalised care	Personalised information	
		Relevance	
	Access	Ease	*"Allows me to leave feeling satisfied after a verbal conversation"*
		Physical issues	
	Back up written information	Verbal followed by written information	
	Time to consider/take in information	Listening	*"Found the diagnosis quite upsetting and difficult to and would have liked someone to talk to"*
		Easier to absorb/retain information	
	Research	Information about research	
		Independent research	
	More details	Immediate information	
Written information in a letter	Ability to refer/review information	Can refer back	*"Written information would give me time to consider changes."*
		Remembering advice	
		Easier to remember	*"Can be referred to at any time"*
		Can keep	
	Time to consider/take in information	More time for consideration	*"Email information is easier to 'go back to' and can be more sequenced for 'early diagnosis, what to expect, injections etc. what*
		Easier to absorb/retain information	
	Access	Ease	

	Understandable	Understandability	*looks good, bad etc.'"*
	Back up verbal information	Verbal followed by written information	*"Verbal is pleasant, written backs up what has been said and what you may forget or not have understood properly"*
	Preference	Prefer writing	
	Assistance from family	Can show/discuss with family	
	Issues with hearing	Hearing loss/difficulty	*"I'm not happy with receiving information "electronically"- easier to read brochure or letter"*
	Personalised care	Personalised information	
A leaflet/brochure	Ability to refer/review information	Can refer back	*"Provides a permanent record of advice, not dependent on memory of patient or thoroughness of clinician"*
		Can keep	
	Time to consider/take in information	Time to do further research	*"So my wife can read it to me"*
		More time for consideration	*"Ability to easily consult information from time to time"*
		Easier to absorb/retain information	*"Leaflets back up verbal advice given and can be used for future reference"*
	Access	Ease	
	Back up verbal information	Verbal followed by written information	*"It would be good to be able to refer to leaflet as reminder of key points*"
	Preference	Good idea	
		Prefer writing	
	Technology	No internet/technology	
	Research	Information about research	
		Independent research	

	Assistance from family	Can show/discuss with family	
	More information	Can get more information	
A website/video	Ability to refer/review information	Can refer back	*"I usually prefer to read info on computer rather than have to physically attend meetings"* *"Prefer to take in the advice in my own time and watch/refer to more than once"* *"Don't understand English, can ask for interpretation can watch when I wanted"*
		Remembering advice	
	Access	Ease	
		No physical demands	
	Time to consider/take in information	More time for consideration	
	More information	Can get more information	
	Understandable	Language barrier	
Group discussions/peer support groups	Opportunities for discussion	Can discuss/learn more	*"It would be very helpful to be with a group of people who also suffer with ARMD"* *"You can pick up useful everyday tips to manage AMD"* *"I don't mind how I receive valid information [so] I would like to join a support group "* *"Macular is initially 'scary' word and it covers a multitude of symptoms/treatme*
	Support from others	Discussion with others	

			nts. Someone to offer written information or a peer group would be useful"
Other	Research	Information from research	*"I am interested in AMD trials and results and treatment and changes"* *"Names contact at clinic if needed"* *"For all members of the family to visualize advice given if they were not at initial appointment"*

Table 5- Nodes, themes and key quotes from the reasons that participants provided for preferring each mode of advice provision. Themes are displayed in order of most references to least references for each mode.

Discussion

The findings from this study highlight a number of inconsistencies and gaps in the current state of lifestyle advice provision from the patient perspective. Only 45% of respondents had received any type of lifestyle advice from an ECP for their condition at any time (3.3% of the total population did not answer the question), and only 16% at the most recent appointment. Despite all of the participants included in the study meeting the criteria to be provided with lifestyle advice, results suggest that patients are not consistently being provided with lifestyle advice from their practitioners, or that they are not able to recall the advice they are given.

Dietary and nutritional supplementation advice

The importance of making dietary changes has been emphasised in recent research (Gorusupudi et al., 2017, Chapman et al., 2019b, SanGiovanni et

al., 2007, Merle et al., 2019, Nunes et al., 2018, Hogg et al., 2017, Wu et al., 2023, Chong et al., 2008, Eisenhauer et al., 2017). A recent systematic review including 18 high quality studies reported that adherence to a Mediterranean, Oriental or low glycaemic index (GI) diet was associated with reduced risk of AMD progression (Chapman et al., 2019b). High intake of omega 3 fatty acids/oily fish, and carotenoids lutein and zeaxanthin (abundant in green, leafy vegetables such as kale) was also associated with reduced risk of progression to advanced AMD. Aoki et al. (2016) demonstrated that high intake of a combination of antioxidant macro and micronutrients in the diet, including vitamins D, C, zinc, alpha-tocopherol, beta carotene and omega 3 fatty acids reduced the odds of developing neovascular AMD by 60-90% (Aoki et al., 2016). Accordingly, clinical guidelines highlight the importance of informing participants about modifying their dietary habits. For example, the Royal College of Ophthalmologists (UK) advise that practitioners recommend a 'healthy diet, rich in fresh fruit, vegetables, eggs and oily fish' (Royal College of Ophthalmologists, 2021). This advice is reflected on an international level, for example Australian practice guidelines recommend that patients with AMD are encouraged to adopt a diet rich in green leafy vegetables, fish and antioxidants (Optometry Australia, 2019).

Crucially, the findings from this study show that these recommendations are not necessarily being made consistently, or the importance of making these changes is not being emphasised. Patients reported that the most commonly offered advice at past appointments was about dietary changes (n=125, 84% who gave details of prior advice), which was also the case at the most recent appointment (n=38, 67% of those receiving advice). However, when considered as a proportion of the whole cohort, this only amounted to 9.4% receiving dietary advice at the most recent appointment and 33.2% receiving advice at either the most recent or a previous appointment. There was also a mismatch between advice offered and behaviour change, whereby the most

frequently offered advice in the past (regarding diet) did not match the most frequently made behavioural change (vitamin supplementation).

Reassuringly, the dietary advice most frequently given was to increase consumption of green leafy vegetables (n=35; 61.4%), oily fish (n=18; 31.6%) and fruits and vegetables (n=18; 31.6%) which are consistent with evidence based guidelines (e.g. (Royal College of Ophthalmologists, 2021, College of Optometrists, 2021). However, some participants were given advice which was less well supported by the evidence base, such as regarding alcohol consumption (Zhang et al., 2021).

There are currently no guidelines available for how to provide dietary advice specifically for eye diseases. However, research on general nutritional guidance for an elderly population shows that providing personalised advice and using food diaries can help to increase consumption of macronutrients such as protein (Grasso et al., 2022). Additionally, providing patients with specific dietary advice such as how to increase nutrient intake and during what meals can be effective in helping patients make dietary changes (Reinders et al., 2020). In this study, this approach appears to have been adopted to a certain extent, as participants that were given dietary advice at their most recent appointment were commonly given specific advice such as to eat ‘green leafy vegetables’ and ‘oily fish’. However, a more personalised approach may have been beneficial (Reinders et al., 2020, Anderson and Nguyen, 2018). The fact that most patients were not asked about their current dietary habits at the most recent appointment means that the advice given was unlikely to have been customised to their current lifestyle.

Only 48 participants (11.9% of the total cohort) reported being given advice about nutritional supplements at their most recent appointment and 97 (24% of the total cohort) had received this advice either at the most recent appointment or previously. This is in line with the findings of a previous study of 158 people with AMD conducted through the Macular Society helpline in the UK, in which 30% of respondents said that they had discussed nutritional

supplements with their Ophthalmologist (Stevens et al., 2014). The AREDS trial demonstrated that a supplement containing high dose anti-oxidants plus zinc could reduce risk of progression of intermediate AMD by around 25% (Age related Eye Disease Study, 2001). The follow up AREDS2 trial showed that potentially harmful beta-carotene in the supplement could be replaced by carotenoids lutein and zeaxanthin without reducing the effectiveness (Age related Eye Disease Study, 2013). Hence, there is strong evidence from large randomised controlled trials to support the recommendation of vitamin supplements based on these formulae. Other vitamin supplements do not have the same compelling evidence base. Hence, practice guidelines specifically recommend the AREDS formulations. However, according to our results, only ~50% of the advice provided about nutritional supplements adhered to the formulations used in the AREDS trials. This meant that only ~6% of the total cohort were specifically recommended AREDS compliant vitamins at the most recent appointment. This supports the findings of other studies that practitioners may be unaware of or not compliant with current evidence based practice in their advice provision (Lawrenson and Evans, 2013). The lack of awareness in people with intermediate stage AMD of the potential benefits of AREDS/AREDS2 type supplements has also been reported elsewhere. For example, Alghamdi et. al. (2023) found that out of 120 patients that met the AREDS criteria for supplementation, only 60% were taking the supplements. Of the patients that were not taking the supplements 83% reported that they could not recall being advised of their benefit. Similarly, the main reason given in another study by the ~80% of 248 respondents with AMD who had not started nutritional supplementation was that they lacked understanding of how it would help their eyes (Bott et al., 2018). Parodi et al. (2016), reported that, of 193 patients with AMD surveyed, only 40% were taking AREDS-type vitamin supplements. Furthermore, 65% of patients were not informed by their ophthalmologist about the potential benefits of nutritional supplementation (Parodi et al., 2016).

It was of interest that, despite dietary advice being the most common advice provided, starting to take nutritional supplements was the most commonly reported lifestyle change made on the basis of previously received advice. Indeed, over half of those surveyed reported taking nutritional supplements of some form. Evidence suggests that the population of Europe is very familiar with the concept of nutritional supplements, with around 36% of adults sampled in the UK reporting supplement use (Skeie et al., 2009). It may be that people perceive this as being a more straightforward lifestyle change to comply with than a more comprehensive change in dietary habits.

One area which we did not explore in our study was how compliant participants were in taking nutritional supplements daily as recommended. There have been a number of studies exploring patients' adherence to the AREDS vitamins (Hochstetler et al., 2010, Alghamdi et al., 2023, Parodi et al., 2016, Chang et al., 2003, Charkoudian et al., 2008). In one study. In a sample of 64 participants, it was reported that less than half were taking the supplements at the correct dosage (Hochstetler et al., 2010). It has been reported that cost of the supplements and a lack of understanding from practitioner and patients for why they can be beneficial present a barrier to adherence to supplement use (Yu et al., 2014a).

The findings from our study suggest that, even though there have been a number of studies demonstrating the benefits of adherence to specific diets and nutritional supplements (Charkoudian et al., 2008, Chang et al., 2003, Hochstetler et al., 2010, Yu et al., 2014a, Agrón et al., 2022, Alghamdi et al., 2023, Keenan et al., 2020, Nunes et al., 2018, Parodi et al., 2016), only some people are being provided with the advice, and adherence to the recommendations is limited. Therefore, it is important for practitioners to emphasise the importance of these lifestyle changes. However, it is also important to note that over half of the participants in this study were already taking some form vitamin supplements at the time of the survey, so it may not have been recommended to some individuals for that reason.

Nonetheless, this study and previous research particularly highlight that the importance of nutritional supplements is not being advertised (Bott et al., 2018, Lawrenson and Evans, 2013, Stevens et al., 2014, Alghamdi et al., 2023, Parodi et al., 2016), despite the extensive research demonstrating the effectiveness of these particular formulations in certain patients (Chew et al., 2022, Age related Eye Disease Study, 2013, Evans and Lawrenson, 2017, Age related Eye Disease Study, 2001).

Smoking advice

In our study, only around a quarter of participants were asked if they currently smoke and ~12% were asked about their smoking history. In addition to the well-established association between smoking and risk of AMD progression and other ocular conditions (Tan et al., 2007, Mitchell et al., 2002, Willeford and Rapp, 2012, Asfar et al., 2015), previous research has emphasized the importance of asking about smoking habits and history with respect to the contraindications of smoking when recommending beta-carotene containing supplements (Age related Eye Disease Study, 2013, Alpha-Tocopherol, 1994). In our cohort, of the 390 participants that answered the question about their smoking status, only 24 (6%) were current smokers and 113 (29%) were ex-smokers. However, it should be noted that of the 14 participants that did not answer the question, it is possible that there may have been current or ex-smokers who did not wish to disclose the information, which has been reported in studies investigating attitudes and behaviours regarding smoking (Poland et al., 2000). Of the ex-smokers, only 2 reported that they had stopped smoking due to their eye condition which may align with the finding that only 2 out of the 24 current smokers were offered smoking cessation advice. In contrast, some participants mentioned being given smoking advice, having never smoked. Unfortunately, this supports previous research which reports low rates of smoking cessation advice offered by eye care practitioners (Lawrenson and Evans, 2013, Bott et al., 2018, Shah et al., 2015).

Smoking is a well-known, prominent risk factor for AMD progression (Heesterbeek et al., 2020, Tan et al., 2007, Smith et al., 1996, Velilla et al., 2013). In fact, a commonly reported statistic in a number of AMD practice guidelines (College of Optometrists, 2021, Royal College of Ophthalmologists, 2021) is that smokers have a 4 fold increased risk of AMD progression compared to non-smokers (Tan et al., 2007). However, the findings from our study and previous research show a lack of adherence with the guidelines of recommending smoking cessation. Martin (2017) reported that although smoking cessation advice was low, ophthalmologists were more likely to provide smoking cessation advice than optometrists. The majority of the participants in our study were recruited via hospital eye clinics, and 32.7% were diagnosed by an ophthalmologist, suggesting that rates of advice provision may have been even lower had we recruited a higher proportion from optometric practice.

Although in this study, the number of people who were current or past smokers was low, a key point to note is that only 25% of respondents were asked about current smoking habits. Hence, the lack of advice provision cannot be justified by the low proportion of smokers in the cohort, as the practitioners were not in a position to know whether or not their patient was a current smoker. The proportion of patients who reported being asked about their smoking history was much lower than the 70% of practitioners surveyed by Lawrenson et al (2013) who reported that they regularly check on smoking history. It is possible that this reflects either a response bias in the self-reported behaviours of the optometrists and ophthalmologists surveyed in the previous study, or a recall bias in the patients surveyed in the current study. However, our findings are more in line with a previous report in which 35% of ophthalmologists stated that they ask about smoking status every time or most times for new patients (Sahu et al., 2008).

There are many guidelines for how smoking cessation advice should be provided to patients, including offering support to stop and referring patients

to nicotine patches, gum and support groups (NICE, 2023). However, these guidelines do not mention the effects of smoking on vision and how advice should be provided to patients with AMD. A pilot study by Caban-Martinez et. al. (2011) on smoking cessation advice offered by eye care providers reported that two thirds of the practitioners wanted additional training and resources to help patients quit (Caban-Martinez et al., 2011). The low levels of smoking cessation advice provision in the current study may similarly reflect a lack of practitioner confidence in advice provision. However, the College of Optometrists do offer training modules on how to provide effective advice on AMD management and treatments (College of Optometrists, 2023b). The limited smoking cessation advice that patients were offered may reflect that practitioners are not aware of the training or they are not accessing it.

Perceived limitations in lifestyle advice provision

The findings from our study highlighted a number of patient perceived limitations in the lifestyle advice received. Indeed, 48.3% (n=131 of the 271 participants that responded) reported not feeling satisfied with lifestyle advice received at their most recent appointment.

Firstly, at the most recent appointment, the majority of patients (around two thirds) were not given any guidance on where they could get additional support. The NICE guidelines recommend that patients should be provided with resources for additional support (NICE, 2018b), particularly to help with making lifestyle changes. The participants in our study who did receive guidance on additional support were most commonly referred to the Macular Society, a UK based charity, for additional help. This reflects recent studies reporting a gradual increase in referrals to the Macular Society in recent years (Boxell et al., 2017, Macular Society, 2023). Previous research has highlighted the importance of offering patients additional support when recommending lifestyle changes as this has the greatest impact (Cowan et al., 2023, Lindström et al., 2003). However, effectiveness is also impacted by

the patients' willingness to contact the sources for additional support and their levels of engagement (Bae et al., 2021).

Secondly, despite guidelines for practice, the majority of participants were not offered any written information. This is a significant finding, and contrary to evidence which suggests that well written patient information leaflets (PILs) are an effective tool in improving outcomes in healthcare (Watson and McKinstry, 2009, Lampert et al., 2016). These materials are also freely available from the College of Optometrists and the Royal College of Ophthalmologists (College of Optometrists, 2023a, Royal College of Ophthalmologist, 2023). Despite participants in this study also expressing a desire for verbal discussions, almost half of the participants expressed a preference for receiving written information for lifestyle advice in parallel. A common reason for the preference was having the ability to refer back to the information at their convenience. This is a vital part of offering lifestyle changes as the patients' ability to recall the information will strongly impact the changes made (Bardach et al., 2017, Booth and Nowson, 2010). Furthermore, being given written advice was associated with increased patient satisfaction with their experience. It has also been suggested that provision of written information helps older patients who may be hearing impaired (Watson and McKinstry, 2009). However, it is important to consider that some patients with visual impairment caused by AMD may have difficulty with accessing written materials. This was highlighted by the participants in this study for whom reduced vision was a key reported reason for why they preferred a verbal discussion as their mode of receiving advice. This illustrates the importance of providing written materials in a high contrast, large print, or electronic format where possible. It is also important to consider how easily patients are able to understand the written information. Other factors may also impact on accessibility of written advice. For example, PILs provided using too much medical jargon could reduce patient engagement (Wittink and Oosterhaven, 2018), whilst complex syntax could impact on understanding by patients with literacy problems (Kessels, 2003) –

a significant proportion of the population (Department of Education and Skills, 2003). The potential problem posed by this issue is highlighted by an observational study of the content of PILs in 17 GP practices in England which reported that of 345 PILs assessed, 75% were too complex in readability for at least 15% of the English population (Protheroe et al., 2015).

Limitations

There were a few important limitations to this study. Firstly, the majority of the participants included in the study were recruited from hospital eye clinics. Previous research has shown there are differences in the information given in primary and tertiary care (Pak et al., 2020, Lo et al., 2016, Lawrenson and Evans, 2013). We were unable to capture these differences in this study. Secondly, even though participants were sent the questionnaire within 3 weeks of their most recent appointments, their responses to the questions may have been affected by an inability to recall the advice. This is especially the case with respect to advice received at previous appointments. Advice that is forgotten by patients is not useful, so our finding that 55% of participants did not recall receiving lifestyle advice either in the past or at the most recent appointment is concerning regardless of whether the advice was not provided in the first place, or whether it was provided in a format which was not readily retained by the patients. Evidence from other areas of healthcare suggests patients' recall of information is affected by their participation in discussions and repetition of information (Richard et al., 2017, Visser et al., 2017), and the provision of written or recorded advice (Watson and McKinstry, 2009). It would be valuable in future to fully explore the factors which impact on the recall of advice in the sphere of lifestyle management in AMD.

Finally, some of the questions limited the participants' responses to selecting options only. However, participants were given the option to write further details at the end of the questionnaire.

5.5 Conclusion

In conclusion, the findings from this study highlight that, as per the patients' experience, there is limited adherence to practice guidelines by the eye care practitioners, and patients are not being provided with lifestyle advice consistently. The findings highlight a number of limitations in current advice provision such as a lack of information for further guidance, and no written information provided. These limitations should be addressed in future by practitioners and commissioning bodies. Further research is required to understand if these findings are replicated in primary care practice. The results of the current study indicate that being provided with written information and opportunities to ask questions does predict patient satisfaction. This highlights the importance of providing patients with adequate information and enough time to discuss lifestyle changes with their practitioner. The mismatch between patient preferences and the advice they receive indicates the need for more patient input when creating guidelines for lifestyle management advice provision.

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What do practitioners perceive to be the main barriers to effective lifestyle advice provision for patients with Age related Macular Degeneration (AMD)?

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Abstract

Background/Aims: Global guidelines recommend that practitioners advise patients with Age-related Macular Degeneration (AMD) to make lifestyle changes to help reduce the risk of disease progression. However, research shows that not all practitioners are providing this advice and there are still several barriers that impact advice effectiveness. The aims of this study were to investigate the experiences and perceptions of eye care professionals (ECPs) about the barriers to effective lifestyle advice provision.

Methods: Practitioners from ten hospital sites and twenty-four optometry practices in England were recruited to complete a questionnaire. The questionnaire consisted of questions about the ECP's experiences with lifestyle advice provision and their perceptions on how it can be improved. Quantitative data was analysed using Chi-squared and Mann-Whitney U tests in SPSS and the qualitative data was analysed using thematic analysis on NVivo12.

Results: Fifty-four practitioners were included in the study. Most participants were nurses (n=22; 40.7%) practicing primarily in hospitals (n=44; 81.5%). Most participants reported that they provide lifestyle modification advice to patients when they are diagnosed (n=47; 87%). However, this was not associated with profession (X^2 (6)= 11.69, p=0.07), number of years practicing (X^2 (4)= 4.03, p=0.40) or type of practice worked at (X^2 (10)=5.37, p=0.87). The most common advice was regarding 'diet and exercise'. Appointment duration was considered 'usually' enough (n=32; 59.3%), but not for older patients. A 'lack of understanding/uncertainty' was the most commonly discussed theme in the barriers to effective lifestyle advice provision. Participants reported 'more written resources' (n=32; 59.3%) would make it easier to provide lifestyle advice to patients.

Conclusion: Lifestyle modification advice is being provided to patients with AMD, but there are still several inconsistencies in the way advice is given.

Appointment duration and a lack of satisfactory written materials require further research to increase the efficacy of lifestyle modification advice.

Key Messages

What is already known on this topic- The modifiable risk factors for AMD progression are well known and practitioners are recommended to provide lifestyle advice to patients to reduce these risks. Previous research has shown that advice is either not being provided to patients, or patients are unable to recall the advice. There are also a number of inconsistencies in the content and mode of advice provision, which may be reducing the patients recall and effectiveness of the advice.

What this study adds- Importantly, research on lifestyle advice provision has mainly focused on the content of the advice provided and has not investigated what practitioners perceive to be the barriers to effective lifestyle advice for people with AMD in the UK. This study also provides valuable insight into the practitioners experience in recent years, as this has not been investigated since previous papers were published.

How this study might affect research, practice or policy- This study has highlighted that there is a need to modify current practice and clinic set ups to allow for lifestyle advice provision. Similarly, the study shows that effective written materials could be useful to improve patients' understanding and therefore increase advice effectiveness. Further research into these areas are needed to create effective written materials for patients as it can help with their understanding and can increase the effectiveness of the advice. Finally, the findings from this study can impact policies around collaborative care, and highlights the importance of practitioners working together to produce the best patient outcomes.

Introduction

Individuals with intermediate Age related Macular Degeneration (AMD) or unilateral advanced AMD are at significant risk of developing vision threatening advanced disease (Ferris et al., 2013), but there is good evidence that modification of lifestyle risk factors including dietary changes, high dose antioxidant vitamin supplementation and smoking abstinence can slow down disease progression (Tan et al., 2007, Chapman et al., 2019b, Age related Eye Disease Study, 2001, Age related Eye Disease Study, 2013). This advice has been incorporated into patient management guidelines in the UK (Royal College of Ophthalmologists, 2021, NICE, 2018b).

However, current evidence suggests that professional guidelines regarding smoking cessation (Kennedy et al., 2011, Downie and Keller, 2015), dietary change (Martin, 2017, Lawrenson and Evans, 2013) and vitamin supplementation (Aslam et al., 2014, Hochstetler et al., 2010) are not being followed consistently by eye care practitioners.

Few studies have specifically evaluated barriers to advice provision by clinicians to patients with AMD. Jalbert et al. (2020) in their focus groups with 65 Australian optometrists exploring barriers to AMD care reported that some felt that they lacked the requisite knowledge of current evidence-based guidelines for AMD management (Jalbert et al., 2020). In other aspects of healthcare, lack of practitioner knowledge (Crowley et al., 2019, Macaninch et al., 2020, Chatterjee et al., 2017), of self-confidence and confidence in the effectiveness of lifestyle interventions (Brotons et al., 2005) and of time (Douglas et al., 2006, Lambe and Collins, 2010, Geense et al., 2013) have been identified as limiting provision of effective healthcare advice.

The aim of this study was to investigate the experience and opinions of different types of Eye Care Professionals (ECPs) in England when it comes to the provision of lifestyle advice for AMD. The aim of this study was to

understand what practitioners perceive to be the main barriers to effectiveness of lifestyle advice provision for AMD and how these might be overcome.

7.2 Materials and Methods

Participants

Ten hospital sites from across England participated in recruitment for this study. All clinicians who were engaged in the care of medical retina patients at these sites were invited to participate. In addition, optometrists working in high street practices were also recruited (via the College of Optometrists, Association of Optometrists and social media). All of the participants completed the survey online via Qualtrics XM (https://www.qualtrics.com/strategy/research/survey-software/). To be eligible to take part practitioners had to be currently practicing as eye care professionals in England, with a role involving the examination or management of patients with AMD.

Prior to beginning the survey, participants were all asked to read the consent form and provide their electronic signature confirming informed consent.

Practitioner survey

The survey was created based on literature surrounding the practitioner experience of providing lifestyle modification advice to patients with AMD (Lawrenson and Evans, 2013, Martin, 2017), and on focus groups regarding the patient experience of lifestyle advice provision. Once the survey was created, a focus group was held with three Optometrists who were asked to review the questions and provide feedback on comprehensiveness and comprehensibility of items.

The final survey is available in supplementary materials. The survey consisted of three main sections; the first collected demographic information (gender, profession, practice setting and number of years of practice); the second focused on general practice behaviours (time spent with each patient, the

flexibility of appointment times for older adults, whether or not patients were asked about their current lifestyle); the third addressed provision of lifestyle modification advice (whether or not advice was regularly provided, mode of delivery, sources of evidence, follow up on advised changes at subsequent appointments). Finally, participants were asked to provide their opinion on the main barriers to lifestyle advice provision and how these could be addressed.

Analysis

Exploratory descriptive analysis of quantitative data was carried out in IBM SPSS 25. As data were not normally distributed, between group comparisons were made using Mann-Whitney U test or Kruskal-Wallis H tests (for variables with 3 or more groups). Cross-tabulations displayed contingency tables and described associations between groups, and chi-square tests of independence were conducted to find the statistical significance of the associations (p=0.05). For the free text question responses, the frequency of words and phrases used to describe the patient experience were thematically analysed using Microsoft excel and NVivo12. Based on the responses, each point was coded into a different section (node) and then grouped to form the themes for each question. For free-text questions with 10 or less responses, a thematic analysis was not conducted (Vasileiou et al., 2018).

Results

Participants

Fifty-four practitioners completed the questionnaire and were included in the study analysis. Table 1 shows the demographic and practice types of the participants.

	Frequency (%)
Gender	

Female	42 (77.8%)
Male	12 (22.2%)
Profession	
Eye care Nurse	22 (40.7%)
Optometrist	17 (31.5%)
Ophthalmologist	14 (25.9%)
Other	1 (1.9%)
Practice setting*	
Hospital	44 (81.5%)
Independent practice	10 (18.5%)
University Clinic	7 (13.0%)
Multiple practices (Boots, Specsavers etc.)	6 (11.1%)
Number of years practicing	
More than 10 years	33 (61.1%)
4 to 6 years	8 (14.8%)
7 to 10 years	8 (14.8%)
1 to 3 years	4 (7.4%)
Less than a year	1 (1.9%)

Table 1- Participants demographic factors, practice experience and location.
*- indicates a question where participants could pick more than one option.

Practice behaviours and discussion of risk factors

The majority of participants reported that they saw more than 60 patients per week (n=19; 35.2%) and that on average, an appointment for an older adult

Profession	Number of patients seen per week				Average appointment duration			
	< 20	**21 to 40**	**41 to 60**	**> 60**	**< 20 minutes**	**25 minutes**	**30 minutes**	**35 minutes or more**
Ophthalmologist	3	3	1	7	7 (50%)	5 (36%)	1 (7%)	1 (7%)
Optometrist	1	4	7	5	2 (12%)	4 (24%)	4 (24%)	7 (41%)
Nurse	5	6	5	6	8 (36%)	6 (27%)	6 (27%)	2 (9%)
Other	0	0	0	1	1 (100%)	0	0	0
Total	9	13	13	19	18 (33.3%)	15 (27.8%)	11 (10.7%)	10 (18.5%)

would be less than 20 minutes in duration (n=18; 33.3%; see Table 2). There was no significant relationship between profession and average appointment duration (X^2 (9)= 9.02, p= 0.436). Most participants felt that the appointment duration was 'usually' sufficient (n=14; 77.8%). Three participants who had less than 20 minutes per patient commented, *'Insufficient time for those that are older or more complex'* or '*patients are booked at 10 minute intervals, some require much more than this and I feel we do not have enough time to spend with each patient*'. Most participants said they were able to extend or rebook appointments if needed (n=42; 77.8%).

Table 2- Frequencies of how many patients are seen each week and duration of the appointments by practitioner type.

More practitioners reported always asking patients aged over 60 years about smoking behaviour (n=31; 57.4%) than dietary habits (n=13; 24.1%), and the majority (n=36; 66.7%) also reported asking other lifestyle factors, including 'exercise' and 'hobbies'. There was no significant difference between the professions with respect to asking about current lifestyle (X^2, p>0.05). Respondents reported that key decisions influencing their decision of whether or not to ask about current smoking habits included time availability, the assumption that this had already been covered at referral, and factors relating to the individual patients, such as whether they 'smell smoky' or have signs of an unhealthy lifestyle such as a history of cardiovascular disease.

Participants were asked to specify what questions were asked about diet and 7 themes were identified. The most commonly discussed was 'fruits and vegetables' followed by 'general diet', 'dietary supplements', and then 'Oily fish/omega 3'. Reasons given by those who did not obtain information about diet included '*information taken on initial referral*', '*I inform them of the dietary additions that can slow progression of AMD but do not try to explore their dietary habits*' and '*Because I suggest patients eat a diet rich in leafy green vegetables, but it does not change my management for me to know if patients*

eat green vegetables or not.'. Two participants felt that asking about diet was not relevant to the issue of AMD progression.

Lifestyle advice provision

Forty-seven participants (87%) said that they provide lifestyle modification advice when patients are diagnosed with AMD. There was no association between whether or not lifestyle advice is given and any demographic factors (X^2; $p>0.05$), with number of years practicing (X^2 (4)= 4.03 p=0.40), type of clinician (X^2 (6)= 11.70 p=0.07) or type of practice worked at (X^2 (10)= 5.37 p=0.87). On average, participants that gave advice reported spending a median of 3 minutes (IQR 3-5) discussing lifestyle modification with patients. The majority of participants said they tell patients why they should make changes (n=47, 87%). Table 3 provides the themes and key quotes obtained in the free text box provided for practitioners to expand on their advice provision behaviour.

Theme	**Key quotes**
Diet and exercise	"A quick, eat healthy, more greens, reduced UV exposure, no smoking and give them a leaflet"
	"tell them dietary inclusion of green leafy vegetables and coloured fruits and vegetables help. Tell them central obesity is a risk factor for progression of AMD and addressing that may help."
Patient questions	"Only if asked by patient"
	"I feel that is sufficient given that there the other anxieties that the patient will have other worries about their vision."
	"Enough time to cover AMD risk factors and answer questions if necessary. Time taken will be longer if patient has more questions"
Smoking advice	"I suggest they stop smoking"

Time restraints	"it's the time the appointment allows depending on how busy clinic is."
	"Don't have a lot of time to spend any more."
Explanation of benefits	"Mainly mention benefits of well balanced diet full of leafy greens and vits"
	"I go through the main lifestyle changes that reduce the risk of AMD"
UV protection	"A quick [comment that said] reduce UV exposure"
	"Good UV protection"
Written information	"include a leaflet for them to take away"
	"I go through the main lifestyle changes that reduce the risk of AMD, then I provide then with a leaflet that includes everything in detail "
Supplements	"If have drusen recommend lutein vitamins"
	"consider AREDS2 supplementation and a Mediterranean diet"
Injections and monitoring	"I inject diagnosed and prescribed patients"
	"[I suggest] self-monitoring"

Table 3- Themes and key quotes obtained in the free text box provided for practitioners to expand on their advice provision behaviour. The themes are listed in order of number of references from most to least.

Participants were also asked how they provide the lifestyle advice to patients (Figure 1). The most common mode of advice provision was a 'face to face discussion' (n=48, 88.9%) followed by 'written information' (n=30, 55.6%). Other responses included *'supplement samples'*, and*'Macular society leaflets and websites'*.

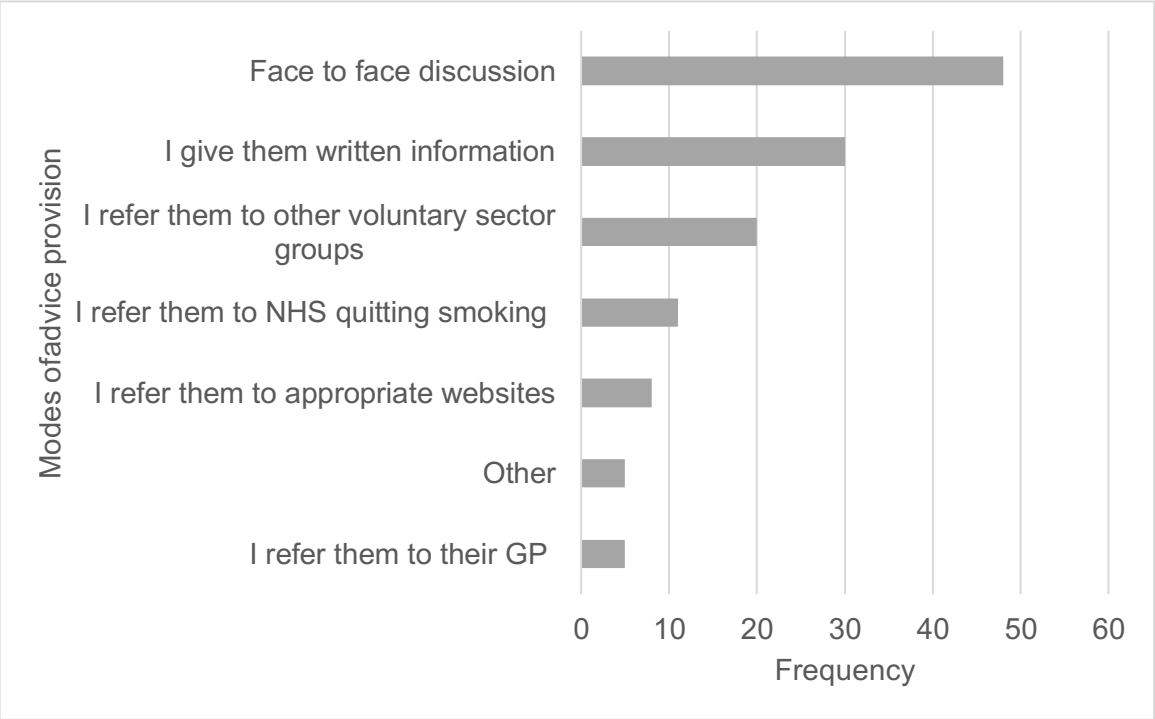


Figure 1- Bar chart displaying the frequencies for each mode of advice provision reported by practitioners. Participants were able to select more than one option.

The majority of those providing written information reported providing leaflets (n=25, 83%) or contact information for charities (n=13, 43.3%). A personalised letter was only provided by 5 participants (16.7%). Other responses included *'[I] don't tend to use apps as when I mention to many patients they say they can't use them'*, *'Diaries'*, and *'supplement leaflets'.* Interestingly, participants that provided written information to patients spent longer discussing lifestyle factors during appointments than those that did not (U= 235.5, p=0.03). Participants that had face to face discussions also spent longer discussing lifestyle compared to those who did not have a face to face discussion (U=

27.0, p<0.001). Additionally, participants that referred patients to voluntary sector groups also spent longer discussing lifestyle compared to those who did not (U= 117.5, p=0.03).

Finally, participants were asked what sources of evidence they used to inform their views on the benefits of lifestyle changes in AMD (Figure 2). The most commonly used source of evidence was ‘knowledge from CPD’ (n=38, 70.4%) and ‘NICE/RCOpth guidelines' (n=32, 59.3%). Many also relied on articles from journals (n=29, 53.7%), peer discussion (n=24, 44.4%), conference presentations or prior knowledge (both options n=19; 35.2%), or expert opinion (n=15; 27.8%). Only 8 reported consulting systematic reviews (n=8; 14.8%).

Participants were asked if they were able to follow up with patients at subsequent appointments to gauge if they have followed the lifestyle advice. Approximately half of the participants said they did not follow up with patients (n=28; 51.9%), and only 22 participants said they did (40.7%). The main reasons for not following up fell within the themes of ‘not seeing the same patients more than once’ and ‘lack of time/opportunities’. Other references suggests that it was someone else’s responsibility, was not required/would not make a difference, tended to be forgotten, or was omitted out of a desire to avoid pressurising the patient.

Barriers to effective lifestyle advice provision

Forty participants responded to describe what they perceived to be the main barriers to effectiveness of lifestyle advice provision to patients with AMD. The most commonly discussed themes with respect to *effective* advice i.e. achieving the desired outcome, were ‘lack of understanding/uncertainty’ and ‘individual patient reasons’ (see Table 4). With respect to the barriers to advice provision, the key theme was ‘not enough time to discuss’.

Theme	**Key quotes**
	"not fully understanding why they need to change, not discussed fully with them"

Lack of understanding/uncertainty	"Overwhelmed or unsure where to start/ where to access help from"
Individual patient reasons	"[patients] culture"
	"Older patients quite often set in their ways "
Difficulties/not wanting to change	"Unwillingness to change habits"
	"Lifestyle changes are difficult to get used to"
Finances/access	"cost of vitamins, not prescribed, burden of additional medication"
	"Access to GP"
Habits/addictions	"Probably the addictiveness of smoking."
	"old habits; friends/family members who may also have the same habits"
The way advice is given/received	"Quality of advice given + available time"
	"Patients can also be anxious but clearly overwhelmed at the time receiving news about their condition, so it is hard to listen to further loads of info as well as comprehend that at the time."
Not enough time to discuss	"sometimes appointment time is not enough to explore all possible barriers for patient to understand or implement any changes. "
	"Lack of time in clinic to explain"
Staying consistent/not following up	"Their understanding, being able to stick to lifestyle changes"
	"advice given is not followed up to see if there has been a change"
Other health conditions	"burden of additional medication"

Table 4- Participant responses to the question 'What do you perceive as being the main barriers to provision of lifestyle modification advice for AMD?'. Themes are displayed in order of most to least references.

Finally, participants were asked if they could think of anything that would make it easier for them to provide the best advice. The most commonly selected options chosen were 'more written resources' (n=32; 59.3%), a specialist advisor (n=28, 51.9%), longer appointments (n=23, 42.6%), better access to training updates (n=17, 31.5%), and websites/apps (n=11, 20.4%; multiple choices could be made). Free text responses also included *'Greater public and other health care professional awareness', 'Better websites with easy access. Keep them simple and not too long', and 'More access to specialist nurses'.*

Discussion

This survey collected data from eye care practitioners across England, in hospital and primary care practice. Whilst the majority of respondents reported providing advice, the clinicians surveyed reported significant barriers to effective advice provision.

Eliciting details about an individual's current lifestyle habits enables targeted lifestyle advice provision. However, only 57% of respondents asked regularly about smoking status, despite the strong association between smoking and AMD risk (Tan et al., 2007), whilst only 24% asked about current diet. Free text responses suggested that appointment duration limits the ability to take a detailed lifestyle history, and so practitioners often make judgements regarding the patient's lifestyle by their appearance, cigarette smell, or history of cardiovascular disease to determine whether such questions may be necessary. Some felt that they would provide the same dietary advice regardless of someone's current habits. The lack of questioning about an individual's current lifestyle is contrary to evidence that providing patients with specific customised dietary advice can be effective in helping patients make dietary changes (Reinders et al., 2020, Anderson and Nguyen, 2018).

Overall, the majority of respondents (87%) reported that they provided advice about lifestyle when patients are diagnosed with AMD. This compares favourably to the 68% of optometrists in a previous survey who reported providing dietary advice to people with AMD and 49% who advised upon smoking cessation (Lawrenson and Evans, 2013). However, given that only 57% of practitioners reported regularly asking older patients about their smoking habit, it is likely that targeted smoking cessation advice is not being widely offered. Caban-Martinez et. al. (2011) in their pilot study of smoking cessation advice offered by eye care providers reported that two thirds of the practitioners wanted additional training and resources to help patients quit (Caban-Martinez et al., 2011). Martin (2017) reported that although smoking cessation advice was low, ophthalmologists were more likely to provide smoking cessation advice than optometrists. In this study, we found no difference in behaviour between the different healthcare professions, however 81% were working in a hospital setting, which may have impacted behaviour.

As in previous studies (Lawrenson and Evans, 2013) advice regarding diet and exercise was more frequently provided than smoking cessation advice. The Royal College of Ophthalmologists (UK) advise that practitioners recommend a 'healthy diet, rich in fresh fruit, vegetables, eggs and oily fish' (Royal College of Ophthalmologists, 2021). However, the finding that practitioners frequently asked about exercise habits, and advised accordingly, belies the limited evidence for an association between AMD and exercise (McGuinness et al., 2017), and the lack of reference to exercise as a modifiable risk factor for AMD in clinical guidelines (Royal College of Ophthalmologists, 2021, NICE, 2018b). Despite this, the majority of practitioners reported using evidence based sources to guide their practice, most commonly CPD training and RCOphth guidelines. It was interesting to note that systematic reviews were not widely accessed by practitioners, despite the free accessibility of Cochrane reviews of effectiveness of nutritional supplementation and dietary modification in managing risk of AMD progression (Lawrenson and Evans, 2015, Evans and Lawrenson, 2023).

One common response in this survey was that practitioners would only provide lifestyle advice if asked specifically by patients, largely because of time limitations. This is in keeping with studies which have reported that patient question asking leads to improved provision of information (Street and Millay, 2001, Cegala et al., 2007). Other reasons for not providing advice were based on assumptions that patients did not want or would not understand the advice and would struggle with the burden of making changes. The perceived inability of patients to understand and implement complex healthcare changes is consistently mentioned as one of the main barriers to effective lifestyle advice provision in AMD studies (Sahli et al., 2020, Jalbert et al., 2020), although patient-centred studies suggest that the biggest barrier to patient knowledge and understanding regarding risk factors is lack of information provision rather than inability to comprehend advice provided (Caban-Martinez et al., 2011, Kandula et al., 2010).

Enhanced patient understanding of advice requires appropriate resources to be available to clinicians. Studies have consistently shown that verbal discussions accompanied by written information are preferred by patients and optimal for improving health outcomes (Andersson et al., 2015, Fylan and Grunfeld, 2002). Information provided to patients should be clear and concise, even in a written format so that patients can comprehend and understand the information more effectively (Fylan and Grunfeld, 2002). This is reflected in the NICE guidelines for AMD management, which state that information should be provided to patients in written format for them to take away and refer back to at any time (NICE, 2018b). More than half of respondents in this study reported providing written advice in addition to face to face discussion. This was mainly in the form of leaflets. When practitioners were asked how lifestyle advice provision could be improved, the most commonly selected option was for ‘more written resources’. This highlights that practitioners understand the importance of written advice, but that the existing resources are not clear enough.

Lack of time was perceived by practitioners as being another key barrier to effective advice provision. This is consistent with previous evidence that optometrists find lack of time to be an important barrier to advice provision in a hospital setting (Downie and Keller, 2015). Retrospective studies have shown that, in primary care, there is a relationship between appointment duration and improved education about disease prevention (León-García et al., 2023). Therefore, this suggests that perhaps clinic set up and appointment duration should be re-visited to ensure higher quality of care and information provision.

The main aim of this study was an exploratory analysis of the experience of eye care practitioners with respect to provision of lifestyle advice, and no formal sample size calculation was carried out. The survey was distributed to all willing clinicians at ten hospital sites, and to all optometrists who responded to adverts. This self-selection approach may have introduced a response bias to the results. The generalisability of the findings may also be limited by the fact that the majority of participants were practicing within hospital settings, although there was a good balance of different types of practitioners included.

In summary, although lifestyle modification advice is being provided to patients by practitioners, there are still issues regarding the consistency of the advice given. This report highlights insufficient appointment duration and inadequate written materials as key factors which may be addressed in future to help to improve advice provision.

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Appendix M- Published Systematic review

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MDPI

Systematic Review

What Advice Is Currently Given to Patients with Age-Related Macular Degeneration (AMD) by Eyecare Practitioners, and How Effective Is It at Bringing about a Change in Lifestyle? A Systematic Review

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Abstract: There is currently no treatment for early/intermediate Age-related Macular Degeneration (AMD) but Eye Care Professionals (ECPs) are recommended to advise patients about modifiable lifestyle factors, including dietary changes, that can slow disease progression. The aim of this review was to understand advice currently given to patients with AMD by ECPs and to evaluate evidence regarding patient compliance. A systematic review was conducted of literature published in electronic databases: CINAHL, MEDLINE, PsycINFO, PyscARTICLES, EMBASE, AMED. Methods followed PRISMA guidelines (PROSPERO registration number: CRD42020223724). Twenty-four reports were eligible for inclusion, 12 focused on ECP experience, 7 on patient experience, and 6 on impact of advice (one paper reported on the ECP and patient experience). Studies reported that a substantial proportion of patients did not recall receiving lifestyle modification advice from their ECP (57.95%, range 2–95% across patient based studies). Practitioners were most likely to provide advice about nutritional supplements (80%, range 67–93% across ECP studies), and least likely about smoking (44%, range 28–71% across ECP studies), however supplements advised did not always comply with evidence-based guidelines. The main reason for patients not following lifestyle advice was lack of provision by the ECP (54.5%, range 21–94% across studies on the impact of advice). The review highlighted a need for more studies to understand patient preferences for receiving advice and research on ECP perceived barriers to advice provision.

Keywords: age-related macular degeneration; lifestyle; nutrition; communication; advice

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1. Introduction

Age related Macular Degeneration (AMD) is a progressive eye condition that leads to irreversible loss of central vision and it is the leading cause of visual impairment in developed countries [1–5]. The early and intermediate stages of AMD are associated with relatively modest changes in visual function, but can progress to either geographic atrophy (GA) or neovascular Age related Macular Degeneration (nAMD) [6]. Both GA and nAMD are associated with significant visual disability [7], inability to perform daily activities [8], an increased risk of depression [9–11], reduced well-being, mood, quality of life [12,13] and social participation [14], and increased risk of falls [15,16]. Whilst nAMD can be treated with anti-vascular endothelial growth factor drugs, there are no currently licensed treatments for early stage disease or geographic atrophy. However, observational studies have highlighted certain modifiable risk factors which may be addressed to slow the progression of the disease [17–20]. Whilst smoking is accepted to be the strongest modifiable risk factor for AMD [18,21,22], dietary changes such as increased intake of

dietary xanthophylls (for example in green leafy vegetables) [23], and dietary omega 3 fatty acids and oily fish [24] and adherence to a Mediterranean style diet [20] have all been reported to help decrease the risk of AMD progression. With respect to nutritional supplements, robust data is available from the Age-Related Eye Disease Study (AREDS) and AREDS2, reporting that a formula (consisting of high dose vitamin C and E, zinc, and either beta carotene or lutein and zeaxanthin) can help to slow down AMD progression (by around 25% over 5 years) in people with intermediate AMD, or with unilateral nAMD in the fellow eye [25,26]. Although evidence regarding dietary changes is less robust than the AREDS data regarding vitamin supplementation [27], there is a general professional consensus that eating a healthy diet rich in vegetables (especially antioxidant rich green, leafy vegetables), with oily fish twice per week is likely to be beneficial and unlikely to cause harm [28].

On this basis, professional bodies advise Eye Care Practitioners (ECPs) to recommend lifestyle changes based on this evidence (smoking cessation, dietary changes and vitamin supplements where appropriate) to patients with AMD verbally and in written format and to recommend other services such as smoking cessation services to help patients make the changes. The recommendations for some professional bodies are shown in Table 1.

Table 1. Table showing a few of the professional optometry and ophthalmology associations and the lifestyle advice they are recommended to provide to patients with early AMD. *—Recommends that the RCOphth guidelines should also be followed.

Professional Body	Location	Recommendations for ECP's
Royal College of Ophthalmologists [29]	UK	Smoking Cessation, Healthy Diet, Vitamin Supplements, Written Information
College of Optometrists * [30]	UK	Healthy Diet, Smoking Cessation, Vitamin Supplements, Written Information
American Academy of Ophthalmology [31]	USA	Smoking Cessation, Vitamin Supplements
Optometry Australia [32]	Australia	Smoking Cessation, Healthy Lifestyle
Canadian Association of Optometrists [33]	Canada	Healthy Diet, Vitamin Supplements, Sunlight protection, Smoking Cessation
International Agency for the Prevention of Blindness Africa [34]	Africa	Vitamin Supplements, Smoking Cessation

However, studies have demonstrated that these recommendations are not consistently followed [35,36] and not all patients recall receiving any advice [22,37]. The aim of this systematic review was to investigate what advice is currently given to patients with AMD by ECPs and how effective this advice is at motivating patients to make lifestyle changes.

2. Methods

The review process was consistent with PRISMA guidelines [38,39]. The following databases were searched: CINAHL, MEDLINE, PsycINFO and PyscARTICLES (via EBSCO) and EMBASE and AMED (via OVID). The search was conducted in November 2020 for studies published since 2001 using the search terms displayed in Table 2.

To be included in the review, the studies had to include people with any diagnosis of AMD and had to be an evaluation of the provision of lifestyle, smoking and nutritional advice by ECPs and/or the effectiveness of this advice in bringing about a change in behaviour.

Table 2. Search terms used in systematic review of electronic databases.

And	And	And	And	Not
Age-related maculopathy	Advice	Specialist	lifestyle	diabetes
age-related macular degeneration	guid *	eye care professional	diet	diabetic
age related macular degeneration	communication	eye care specialist	nutrition	genetic
macular degeneration	information	ophthalmologist	smoking	
macular disease	perception	optom *	risk factor	
	evidence based practice	clinic *	supplement	
	counselling	health care professional		
	aware *	health care provider		
	attitude *	practi *		
	behaviour	optic *		
	behavior	physician		
	recommend *	Doctor		
	experience *	Ophthalmic		
		Nurse		
		Pharmacist		

Terms within a specific column were linked with the OR operator. Terms in different columns were linked with the term in the title (And or Not). *= shortened words to widen the searches.

Studies were excluded if they were not published in English language; they focused on people at risk of AMD (i.e., with no current diagnosis of AMD); the full manuscript was not available or was only a published protocol, review, letter to Editors or news article; they focused on AMD with other associated systemic and ocular conditions; they evaluated a medical treatment for AMD or advice following cataract surgery; or if they were published prior to 2001—the year of publication of the original AREDS results paper [25].

All of the records were assessed for eligibility by two authors (SD and TC) and any disagreements were resolved by consulting with the other two authors (AB and VVN). The records were organised, and duplicates were removed using Mendeley software v1.19.8 (https://www.mendeley.com accessed on 20 September 2022). The data from the included studies was extracted and recorded in a data extraction table (see Supplementary Material Table S1). A quality appraisal assessment was also carried out for all of the records that met the eligibility criteria using quality appraisal tools including the Joanna Briggs Institute (JBI) checklist for cross sectional surveys [40], The National Heart, Lung and Blood Institute (NHLBI) checklist for interventional audits [41] and the Critical Appraisal Skills Programme (CASP) checklists for cohort studies [42] and qualitative studies [42] the findings from these tools and a summary of the included studies are shown in Table 3. The JBI quality appraisal tools were used for the cross-sectional surveys (19/24) and case series (1/24). The CASP checklists were used for the cohort studies (2/24) and one qualitative study (1/24). There was also one interventional audit for which the NHLBI quality appraisal tool was used.

Table 3. Table of included studies- summary of key information about the studies included in the review in alphabetical order by first author including a summary of the quality assessment of studies included in the systematic review.

Study	Location (Country and Setting)	Number of Participants	Total Study Duration	Participant Type	Study Design	Quality Appraisal Checklist Used	Risk of Bias
Aslam et al. (2014) [43]	Belgium, France, Germany, Italy, Portugal, Spain and UK	216	Not specified	Practitioners	Survey	JBI	Statistical analysis unclear, Measurement of outcome measures unclear
Bott, Huntjens and Binns (2017) [22]	UK	248	6 months	Patients	Cross sectional survey	JBI	Single site recruitment
Burgmuller et al. (2016) [44]	Germany	271	15 months	Patients	Cross sectional survey	JBI	Single site recruitment
Caban-Martinez et al. (2011) [45]	USA	98	One month	Both	Pilot cross sectional survey	JBI	Inclusion criteria not clearly defined *, Unclear if confounding factors taken into account, Measurement of outcome measures unclear, Statistical analysis unclear, Single site recruitment
Chang et al. (2002) [46]	Canada	108	2 months	Patients	Cross sectional descriptive study	JBI	Inclusion criteria not clearly defined, Statistical analysis unclear, Single site recruitment
Charkoudian et al. (2008) [47]	USA	332	2 months	Patients	Cross sectional clinical case series	JBI	Statistical analysis unclear, Single Site recruitment
Cimarolli et al. (2012) [48]	USA	99	Not specified	Patients	Descriptive study	JBI	Exposure measurement not reliable or valid, Statistical analysis unclear
Downie and Keller (2015) [49]	Australia	379	2 weeks	Practitioners	Survey	JBI	Inclusion criteria not clearly defined, Measurement of outcome measures unclear
Gocuk et al. (2020) [50]	Australia	20	17 months	Practitioners	Interventional audit	NHLBI	Sample size sufficiency unclear, Researchers not blinded to exposure
Hochstetler et al. (2010) [51]	USA	64	One month	Patients	Cross sectional survey	JBI	Inclusion Criteria not clearly defined, Single Site recruitment
Jalbert et al. (2020) [52]	Australia	77	Not specified	Practitioners	Qualitative research and focus groups	CASP	Qualitative data only
Kandula et al. (2010) [53]	USA	83	Not specified	Patients	Prospective survey based study	CASP	Unclear if confounding factors taken into account, Follow up of subjects unclear, Single Site recruitment

Table 3. *Cont.*

Study	Location (Country and Setting)	Number of Participants	Total Study Duration	Participant Type	Study Design	Quality Appraisal Checklist Used	Risk of Bias
Larson and Coker (2009) [54]	USA	127	One month	Practitioners	Descriptive and cross sectional survey	JBI	Inclusion criteria not clearly defined, Unclear if confounding factors taken into account, Measurement of outcome measures unclear
Lawrenson and Evans (2013) [35]	UK	1468	12 weeks	Practitioners	Cross sectional survey	JBI	Inclusion criteria not clearly defined
Lawrenson, Roberts and Offord (2014) [55]	UK	26	One month	Practitioners	Survey	JBI	Inclusion Criteria not clearly defined, Exposure Measurement not reliable or valid, Unclear if confounding factors taken into account, Measurement of outcome measures unclear, Statistical analysis unclear, Single Site recruitment
Martin (2017) [36]	Sweden	393	Not specified	Practitioners	Cross sectional survey	JBI	Statistical Analysis unclear
Parodi et al. (2016) [56]	Italy	193	5 months	Patients	Cross sectional survey	JBI	Exposure measurement not reliable or valid, Single Site recruitment
Sahli et al. (2020) [57]	USA	42	Not specified	Practitioners	Survey	JBI	Unclear if confounding factors taken into account
Shah et al. (2013) [37]	UK	92	29 months	Patients	Cross sectional survey	JBI	Single site recruitment
Stevens et al. (2014) [58]	UK	158	2 months	Patients	Survey	JBI	Exposure measurement not reliable or valid
Weaver and Beaumont (2015) [59]	Australia	330	One month	Patients	Prospective controlled study	CASP	Unclear if confounding factors taken into account, Follow up of subjects unclear, Single Site recruitment
Yu et al. (2014) [60]	Germany	65	Two months	Patients	Cross sectional questionnaire based study	JBI	Single Site recruitment
Yu et al. (2014) [61]	Germany	47	Not specified	Patients	Questionnaire	JBI	Exposure Measurement not reliable or valid, Measurement of outcome measures unclear
Zhang et al. (2020) [62]	Australia and New Zealand	206	5 months	Practitioners	Survey	JBI	Inclusion Criteria not clearly defined

* = Patient questionnaire only. Quality appraisal checklists from the Joanna Briggs Institute (JBI), National Heart, Lung and Blood Institute (NHLBI) and Critical Appraisal Skills Programme (CASP) were used. The full data extraction table can be found in Supplementary Table S1 and the full quality assessment checklists can be found in Supplementary Tables S2–S6.

For the synthesis of the data, the descriptive-interpretive approach to the meta-analysis of qualitative data was used [63]. The review protocol was published on the PROSPERO site before commencing the literature search (PROSPERO registration number: CRD42020223724).

3. Results

3.1. Included Studies

From the searches, 1370 records were identified, and 11 records were identified from other sources such as references and background reading. Before screening the records, 448 duplicates were removed, leaving 933 records to be screened. The records were screened independently by two members of the research team (SD and TC) and 859 records were excluded. 73 reports were retrieved to be assessed for full text eligibility and 1 was not retrieved as it was an older version of a paper, already included, that had been reprinted. The 73 full texts were assessed by SD and TC. One study was taken to the other two authors (AB and FVN) who confirmed eligibility. Finally, 24 papers were included in the review. Figure 1 summarizes the distribution of the studies included in this review. Most of the studies focus on the practitioner reported experiences with one study looking at both patient and practitioner experience. (see Figure 2 for PRISMA flowchart and Table 3 for list of included studies).

3.2. What Is the Patient Reported Experience of Receiving Advice from Eyecare Practitioners?

Of the 24 papers included in this review, 7 papers focused on the patient experience of lifestyle advice [22,37] and their knowledge of the risk factors of AMD [44,45,48,53,58].

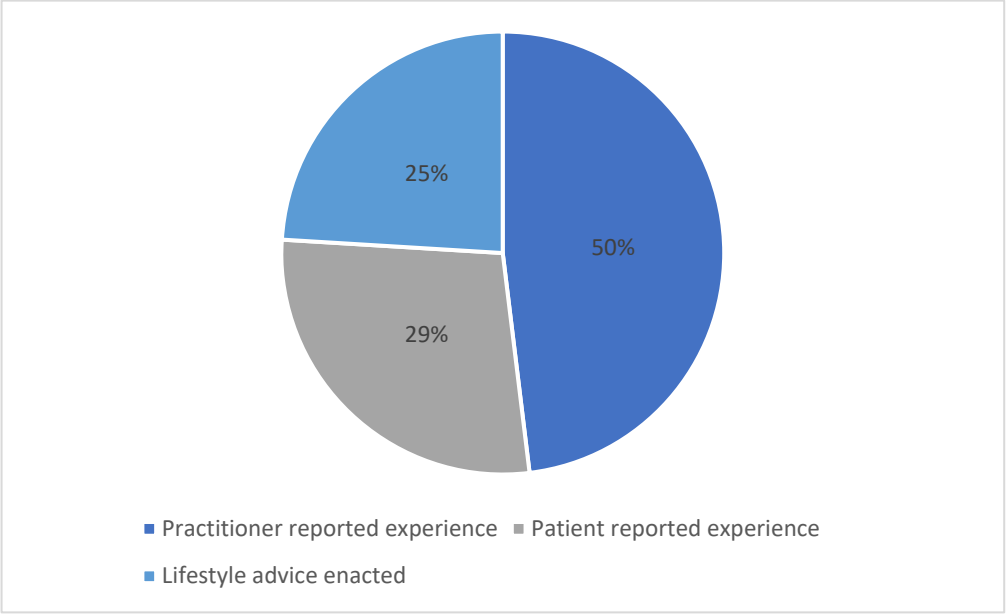


Figure 1. Pie chart showing how the focus of the included studies are distributed in this review. One of the papers in this review by Caban-Martinez et. al. (2011) reports on the patient experience and the practitioner experience [45]. Therefore, the percentages on this pie chart do not total 100%.

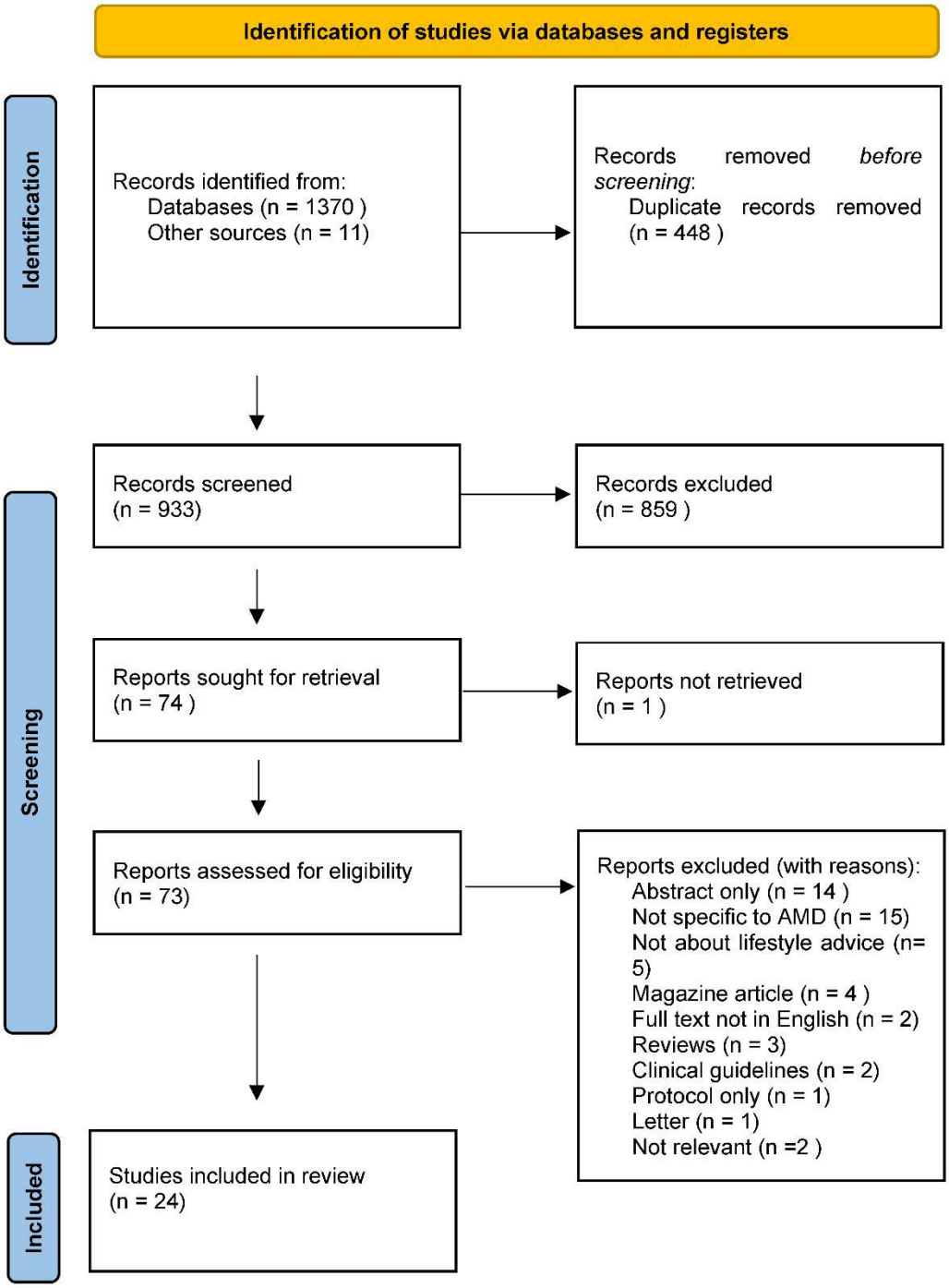


Figure 2. PRISMA flowchart for the selection of studies included in this review [38].

Two studies which surveyed patients with AMD at a hospital clinic, both reported that a high proportion of patients had no recollection of receiving advice regarding dietary modification from their ECP [22,37]. Bott et al. (2017) surveyed 248 patients with nAMD attending a medical retina clinic in the UK regarding their recollection of lifestyle advice received and reported that, although more than half (53.1%) reported being advised to stop smoking, only 39.9% reported receiving advice regarding diet, and 24.2% recalled being recommended a nutritional supplement [22]. Shah et al. (2013) carried out a similar retrospective cross sectional telephone survey of 92 patients with AMD who had attended a single UK vitreoretinal hospital unit to investigate the patients' recollection and understanding of lifestyle advice provided [37]. They found that 47 (51%) recalled recommendations

about dietary changes, 21 (23%) about exercise, 5 (5%) about smoking cessation and 90 (98%) about AREDS-based supplements. Of those who responded, based on the advice they were given, 62% felt that making dietary changes was necessary, 76% believed that exercise and weight reduction was necessary, 74% felt the AREDS supplement was a necessity, and 80% of the people who were told about smoking cessation felt it was necessary [37]. Whilst these studies demonstrated significant gaps in the knowledge of patients, they did have limitations. For example, it was not possible to determine whether advice had been provided, and subsequently forgotten by patients, or whether the advice had not been given in the first place. Additionally, the generalisability of both studies was limited by participants being recruited from a single hospital site and were conducted in the same country, thus, the results only focus on advice provided in the UK [22,37].

3.3. How Much Do People with AMD Understand about the Lifestyle Risk Factors for Disease Progression?

Five studies investigated patient awareness of risk factors of AMD [44,45,48,53,58], and the source of their information. Kandula et al. (2010) and Cimarolli et al. (2012) studied patient awareness of the risk factors for AMD in the United States of America (USA) [48,53]. Kandula et al. (2010) surveyed 83 patients from a retina practice in a suburban setting [53], while Cimarolli et al. (2012) conducted telephone interviews with 99 adults who were randomly selected from an Ipsos (a market research firm in the USA) database of people with AMD [48]. Both survey-based studies reported a lack of awareness amongst AMD patients about risk factors. Cimaroli and colleagues reported that out of the 99 AMD patients surveyed, one third did not know the risk factors associated with AMD and the most common source of information for all patients was their eye care physician [48]. Similarly, in the study by Kandula and colleagues 78% of the 83 patients in the study, received their AMD information from their physician, but 89% of patients would have preferred to receive more information. Furthermore, only 21%, 48%, 37%, 48%, and 36%, of patients, respectively, correctly identified how diet, special vitamins, high blood pressure, family history, and smoking can affect AMD [53]. A strength of this study was that the random recruitment of individuals through the Ipsos database from across the country increased the external validity of the findings compared to the single site studies reported elsewhere in this report. Burgmuller et al. (2016) similarly reported that, of 271 patients with AMD visiting a hospital clinic in Germany over 9 months who were asked what factors have a positive influence on their disease, only 61.7% of patients mentioned a healthy lifestyle, 53% said vitamins, and 42% of patients confessed that their knowledge of AMD was not sufficient [44].

Stevens et al. (2014) aimed to characterise AMD patients who seek the services of the Macular Society in the UK, and to determine the level and source of their knowledge about dietary recommendations for people with AMD [58]. The Macular Society is a voluntary organisation which advocates for people with AMD, and provides services including provision of information and support [64]. Stevens et al. (2014) conducted a telephone survey of 158 Macular Society members with AMD and found that just over half (55%) of the patients felt that diet was important for their eye health. Similar to the study by Kandula et al. (2010), the majority of patients (63%) did not feel that they had received enough information about AMD. Ninety-two percent of patients in this study got their information about AMD from the Macular Society, which most likely reflects the recruitment of participants from the membership of this society. However, it is interesting to note that awareness of the impact of diet on eye health remained low even in a group of individuals sufficiently motivated to join a patient advocate and support group such as the Macular Society.

Patient understanding of the risks associated with tobacco use and the potential benefit of smoking cessation was only investigated in one study [45]. Surveys were completed by 46 ECPs and 52 patients with AMD. 54% of the patients with AMD were not certain whether

smoking caused macular degeneration and 90% of the people who smoked reported never being advised to quit by their ECP.

Overall, there is good evidence from these 5 studies [44,45,48,53,58] that patients attending eye clinics in the UK, US and Germany do not receive sufficient lifestyle advice to ensure a high level of understanding of the possible risks and benefits associated with diet and smoking related factors. Given the patient reported survey design of these studies, it is not possible from this evidence to determine whether the deficit is in the provision of advice, or patient recall. However, this does indicate that advice which is provided is not necessarily in a format which facilitates ready recall. There is also evidence that a significant number of patients resort to voluntary organisations such as the Macular Society to plug gaps in their knowledge of their condition [58]. One area in which evidence was lacking was regarding patient preferences with regard to modes of advice provision. This is an area that has not been investigated for AMD patients to date.

3.4. What Is the Practitioner Reported Experience of Advice Provision?

Twelve studies included in this review were based on practitioner reported experiences. Out of the 12 studies, seven papers related to diet, smoking and vitamin supplement advice, three focused solely on advice about vitamin supplements and 2 focused on smoking advice.

Lawrenson and Evans (2013) surveyed 1468 UK based ECPs (1414 optometrists and 54 ophthalmologists) about the lifestyle advice currently given to patients with AMD. Sixty-eight percent of the practitioners reported that they would always or usually provide dietary advice to patients with established AMD. Although 93% of practitioners recommended nutritional supplements to patients with AMD, for the majority the vitamins recommended did not comply with best evidence-based practice for nutritional supplementation in AMD, i.e., not based on AREDS guidelines [25,26]. With regard to smoking, only 32% of practitioners reported routinely taking a smoking history from patients, and 49% of the practitioners in the study reported informing patients about the link between smoking and AMD. However, 70% of practitioners took smoking history into account when recommending supplements, indicating an awareness of the possible risks of recommending certain vitamins to patient who smoke [35].

Downie and Keller (2015) carried out an online survey of 379 optometrists in Australia and similarly found that only 47% of the optometrists reported routinely asking patients if they smoke, 62% reported counselling their patients with regard to diet and 91% of recommended nutritional supplements to patients with AMD [49]. It was not clear whether the specific supplements recommended were informed by the best evidence-based guidelines, however the main supplement recommended was a high dose antioxidant which may be compliant with the AREDS formula (depending on the dosage of the specific product recommended). This is similar to the findings of Lawrenson and Evans, with less than half of the ECP's in both studies taking a smoking history from patients but most ECP's recommending nutritional supplements (whether appropriately or otherwise). However, Downie and Keller did report that most (88.5%) of respondents obtained their information and evidence base from peer reviewed journals, whilst non peer reviewed articles were used by 43.4% of respondents. This is in contrast to the finding of Lawrenson et al. (2013) that only 16.4% of respondents referred to scientific/research literature, and the majority were dependent on non-peer reviewed articles in professional journals [35]. This suggests the potential of some mismatch between the sources of information employed by optometrists in different countries.

In another study evaluating only optometrists, Sahli et al. (2020) administered postal surveys to 42 optometrists to examine the lifestyle advice that optometrists offer, to whom such advice is offered and reasons for not offering advice [57]. In contrast to the previous studies described above, this study found that 74% provided advice about smoking, 81% about the importance of a healthy diet and 79% regarding dietary supplements. The number of optometrists discussing smoking with patients with AMD was substantially higher in this study compared to others, but the percentage of practitioners offering dietary

supplement advice was lower than previously reported [57]. However, the sample in this study was smaller than the other studies despite participants being contacted 3 times to encourage a response. The study had an overall low response rate (31% of 142 optometrists that were contacted) so the results may not be generalisable to the rest of the population.

Downie and Keller [49] and Sahli et al. [57] only surveyed optometrists so the experience of lifestyle advice provision by ophthalmologists was not reported. This is significant as Martin (2017), looking at lifestyle advice given by optometrists (n = 323) and ophthalmologists (n = 48) in Sweden, reported that ophthalmologists were more likely to provide smoking cessation advice than optometrists [36]. Lawrenson et al. (2013) also reported a higher rate of discussion about smoking cessation in their sub-analysis of ophthalmologists (as compared to optometrists, ~70% vs. ~30%). Martin et al. (2017) reported that optometrists were more likely to provide advice about nutritional supplements and diet than ophthalmologists, and found that 75% of all of the optometrists and ophthalmologists surveyed would recommend nutritional supplements to patients with late AMD in one eye and early in the other [36]. However, Lawrenson and Evans (2013) reported that ophthalmologists were more likely than optometrists (70% vs. 26%) to offer an appropriate AREDS based formula in this situation, suggesting that the optometrists surveyed in the UK were less aware of the evidence base than their ophthalmologist counterparts. They also reported that ophthalmologists were more likely to ask about smoking history (~70%) compared to optometrists (~30%) [35]. Both studies highlighted the difference in lifestyle advice provision between optometrists and ophthalmologists, but it is worth noting that Lawrenson and Evans (2013) and Martin et al. (2017) included a larger number of optometrists than ophthalmologists in this study. However, in Europe, there are more optometrists than ophthalmologists so this may explain the difference [65]. Furthermore, as in all such studies, the sample is self-selecting, meaning that those clinicians who choose to respond may be individuals with an increased interest in the topic, ophthalmologists who have specialised in AMD and therefore have a greater motivation to keep abreast of the relevant literature.

In a larger sample specifically targeting ophthalmologists, Aslam et al. (2014) evaluated ophthalmologists' opinion of, and use of, nutritional dietary supplements 10 years after the publication of the first Age-related Eye Disease Study (AREDS). This study surveyed 216 participants (112 general ophthalmologists and 104 retinal specialists) from 7 different European countries (Belgium, France, Germany, Italy, Portugal, Spain and UK) and found that, on average, information about the benefits of nutritional supplements was regularly given to patients with AMD by 67% of ophthalmologists (a figure comparable to the findings of both Martin and Lawrenson and Evans [35,36]). Sixty-eight percent of ophthalmologists reported most commonly initiating primary prescriptions or providing advice on nutritional supplements [43]. However, no optometrists were involved in the study, and the ophthalmologists surveyed may have been unaware of advice previously provided by other healthcare professionals. A strength of this study was that ophthalmologists were asked specifically about their provision of AREDS compliant supplements, removing any doubt about whether supplements provided were consistent with evidence-based guidelines. However, this could also be considered a limitation of this study as they did not include other variations of the AREDS supplements which may have caused this percentage to be higher.

Other studies have been more specific in the aspects of nutritional advice evaluated. For example, Larson and Cocker (2009) investigated the perceptions, recommendations and educational or informational materials of licensed Wisconsin optometrists on lutein and zeaxanthin and eye health. Although the AREDS2 findings did not support the recommendation of lutein and zeaxanthin supplements to well-nourished individuals [54], there is still evidence to suggest that a diet rich in xanthophylls is beneficial to slowing progression of AMD [24,66–68], and this forms part of the guidelines for patient advice of most optometric/ophthalmic bodies [28,30,69]. Of the 127 practitioners in this study, 78% felt that the information available on lutein and zeaxanthin and eye health is adequate

for them to make recommendations to patients. Eighty-one point one percent reported recommending lutein and zeaxanthin to patients diagnosed with AMD and 79.5% of optometrists distributed informational materials to patients [54].

Similarly, although AREDS2 did not find a benefit to the inclusion of omega 3 supplements in the AREDS formula, there is still evidence from observational studies (adopted by most practitioner guidelines) that inclusion of dietary omega-3, for example in oily fish, is beneficial to slowing AMD progression [24,70,71]. Zhang et al. (2020) looked specifically at recommendations regarding omega-3 intake given to patients with AMD by 206 optometrists from Australia and New Zealand. Optometrists reported recommending omega-3 rich foods for AMD (68%) with 95% recommending fish or non-fish seafood as a source. However, in accordance with the lack of supporting evidence, only 29% recommended specific doses of omega-3 fatty acid supplements to patients [62].

Two studies specifically assessed provision of advice on smoking cessation by practitioners [45,55]. Caban-Martinez et al. surveyed practitioners (clinical faculty, fellows and residents) based in the United States about their experiences with providing smoking cessation recommendations to patients with AMD [45]. The 46 practitioners involved in the study were asked about their smoking cessation recommendation practices and said they asked about patients smoking status all the time (13%), periodically/seldom (80%) and never (7%). When asked if they advised patients to quit smoking, 28% said always, 65% said periodically/seldom and 7% said never. This is similar to the findings by Lawrenson and Evans (2013), Martin (2017) and Downie and Keller (2015) who reported that practitioners do not always ask about patients smoking status and history [35,36,49], but this study only included ophthalmologists in a hospital setting and no optometrists. A pilot study by Lawrenson, Roberts and Offord (2014) surveying 26 UK optometrists reported that, while 77% were aware of the link between smoking and AMD, only 4% regularly took a smoking history from patients and 12% provided advice about stopping smoking to AMD patients [55]. The most common barriers to providing smoking cessation advice was the potential effect on the practitioner-patient relationship (39%), being unsure how to raise the issue (31%) and time constraints (31%). Both studies demonstrate that practitioners are not regularly asking about smoking, despite knowing the link between smoking and AMD. The studies were also carried out in different countries, thus increasing the generalisability of the findings.

Having identified that there are limitations in the provision of lifestyle advice to people with AMD, there has been some effort to explore barriers to this advice provision. Jalbert et al. (2020) surveyed 77 eye care professionals and reported that cost/funding, patient understanding/denial, discipline silos, access/availability of services and willingness to make lifestyle changes were the most commonly reported barrier for practitioners to administer effective AMD care [52]. As a potential solution to the issue, Gocuk et al. (2020) investigated whether performing clinical self-audit and receiving analytical feedback improved clinical record documentation for patients with AMD and enhanced reported provision of advice to patients. To do this, they conducted an interventional audit on 50 eye care practitioners (20 completed the study) practicing and routinely managing patients with AMD. Practitioners audited their own records for AMD patients for 3 months and were surveyed before and after the intervention. Post audit, average record documentation improved for asking about smoking status (21% to 58%), diet (11% to 29%) and nutritional supplementation (20% to 51%). Overall, optometrists' recording of having provided lifestyle advice improved. However, before the end of the study, 30/50 optometrists dropped out, with the main reason being due to the time commitment of having to audit records, suggesting that this may not be a sustainable intervention [50]. It is also unclear from this study whether clinicians increased the frequency of advice provision, or merely became more thorough in their record keeping.

To summarise, practitioners seem to be more likely to give advice about diet and nutrition than smoking cessation advice, possibly in part because of concerns about a negative effect on the relationship between patient and practitioner of asking questions

which might be perceived as being judgmental [55,72]. Figure 3 summarises the reported proportions of optometrists and ophthalmologists giving lifestyle advice. Evidence suggested that ophthalmologists are possibly more likely than optometrists to provide advice on nutritional supplements [36], and the advice given in this respect by ophthalmologists may be more compliant with evidence based guidelines [35]. Ophthalmologists may also be more likely to give advice about smoking cessation. However, comparison between practitioners is limited on small sample sizes.

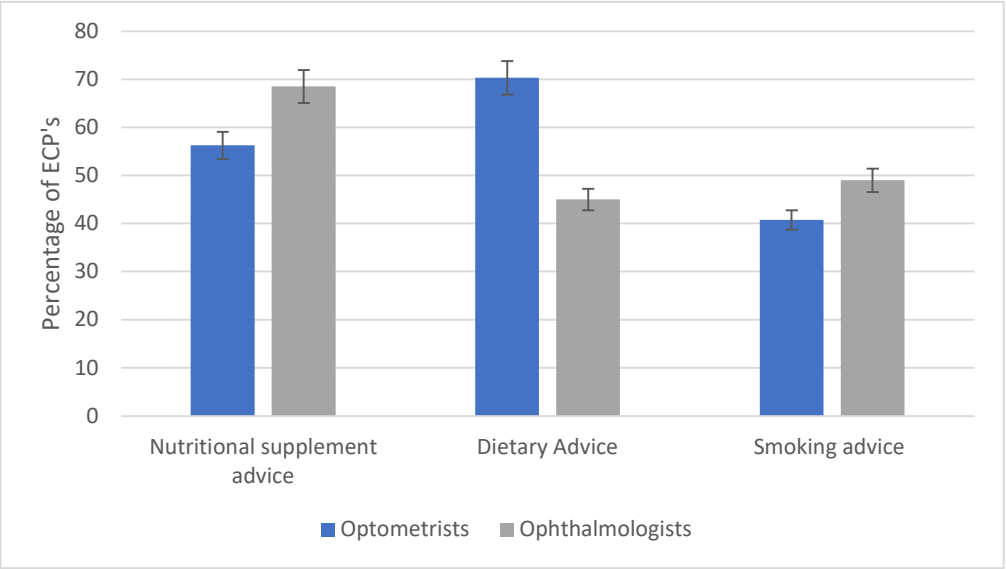


Figure 3. Bar chart representing the self-reported lifestyle advice given to patients about nutritional supplements, diet and smoking cessation by the two different types of ECP included in this review. Each bar represents the mean proportion of ECPs across studies who reported providing advice. Error bars denote the standard error of the mean reported value across studies. Studies contributing to these data were as follows, nutritional supplement advice optometrists [35,36,49,50,54,57], ophthalmologists [35,36,43], dietary advice optometrists [35,36,49,50,54,57,62]. ophthalmologists [35,36]. smoking advice optometrists [35,36,49,55,57] ophthalmologists [35,36,45].

3.5. How Much of the Lifestyle Change Advice Is Enacted?

Six studies included in this review examined the changes that patients with AMD made to their lifestyle following the receipt of lifestyle advice from their practitioners. Shah et al. (2013) asked the 92 AMD patients surveyed in their study about their compliance to the lifestyle advice they were given [37]. Adherence to diet modification advice was 81% of 47 participants who recalled advice about diet, 76% of 21 participants who recalled advice about exercise and weight reduction, and 88% of the 90 patients who recalled advice about AREDS supplementation. This suggested that advice provided by ECPs and recalled by patients did have the ability to effect a change in dietary behaviour. However, none of the 5 people who recalled being given smoking advice adhered to the recommendation.

Weaver and Beaumont (2015) aimed to understand lifestyle changes that patients make as a result of the way advice is given [59]. They found after interviewing patients attending two different clinics (clinic 1 with a strict protocol driven regime about giving lifestyle advice and clinic 2 that had no policy), that 81.6% of patients attending clinic 1 made lifestyle changes consistent with the advice they were given compared to 44% of patients in clinic 2. However, the study did not specify what the changes were which is important as the study by Shah et al. found that compliance differed between the type of lifestyle advice given [37].

Six survey-based studies specifically studied the initiation of vitamin supplement intake and dietary changes that patients with AMD made as a result of advice received. Chang et al. (2002) surveyed 108 patients with AMD recruited from a retinal specialist

clinic in Canada [46]. They found that 49/108 were using supplements specifically for their AMD (45%), although 85/108 (79%) were taking vitamin supplements for general health purposes. Of those taking nutritional supplements specifically for their eye health, 33/49 (67%) were using the supplements recommended by their ECP. Similar findings were reported in a study by Charkoudian et al. (2008) where 332 new and returning patients were recruited from the retina division in a hospital in the United States of America. Two hundred and forty one (72%) of the patients were taking any supplements and 70% of these patients were taking an AREDS compliant formula. However, they reported that many of the patients did not understand why they had to use the supplements [47]. Hochstetler et al. (2010) and Parodi et al. (2016) also both reported on the rates of adherence to vitamin supplement recommendations in patients with AMD (n = 64 and n = 193, respectively). In the Hochstetler et al. (2010) study, participants were all recruited from the retina clinic of a single retinal specialist in the USA. Fifty-nine percent of the patients reported taking a vitamin supplement for AMD, with 71% of these being AREDS based. All of the participants taking supplements were recommended to do so by their retinal specialist. Seventy-five percent of the participants who did not take supplements said this was because it was never recommended to them [51]. Parodi et al. (2016) also recruited patients from a single retinal clinic in a hospital based in Milan, Italy [56]. They reported that 40% of the patients were taking AREDS supplements and, similar to the Hochstetler et al. (2010) findings, 94% of the patients not taking supplements reported that this was because it was never recommended to them [56].

These studies [46,47,51,56] all shared the limitation of recruiting participants from a single hospital site in the same country, thus reducing the generalisability of the findings. Additionally, the severity of AMD status of the participants was not categorised in two of these studies [46,51], which is important as the AREDS trial results specifically recommended the formula for patients who have intermediate AMD or advanced AMD in the fellow eye [25].

Yu et al. (2014) also reported similar findings in a German cohort [60,61]. The first study surveyed 47 patients with AMD attending eye clinics in Germany and found that 66% were recommended oral antioxidant supplements from their referring ophthalmologist, 68.1% of the total cohort were taking oral supplements for AMD, and 21.3% had never received a recommendation for supplements [60]. The second study found that 36 out of 65 patients (55%) were taking oral anti-oxidant supplements for AMD with the most common source of recommendations being from an ophthalmologist (55.4%) and, as reported in previous studies, the main reason (69%) for not taking supplements was there being no recommendation [61].

In summary, there was minimal evidence regarding compliance of patients to advice regarding general dietary changes, with the majority of studies focusing on compliance to vitamin supplement recommendations. The proportion of patients taking vitamin supplements for AMD in the included studies varied widely between around 40% and 68% [46,47,51,56,60,61]. It was not always clear whether these supplements conformed to AREDS guidelines. It also was not always apparent whether lifestyle changes of those surveyed were made directly as a result of ECP advice, but there was evidence from several studies to suggest that advice received from ECPs was impactful, particularly advice about nutritional supplements [37,46] and that the majority of people who were not making lifestyle changes were failing to do so because ECP advice had not been provided [51,56]. There was also evidence from one study to suggest that the way in which advice is provided can have a significant impact on outcomes [59].

4. Discussion

Overall, the studies included in this review have highlighted significant limitations in lifestyle modification advice provided by ECPs to patients with AMD.

4.1. The Patient Experience

This review highlights a number of key issues related to the patient experience or receiving life-style advice. Firstly, patient awareness of the risk factors for AMD in the included studies was poor. A review by Armstrong and Mousavi (2015) discussed the reported risk factors for AMD and highlighted that factors including smoking cessation, dietary changes, and regular use of dietary supplements should all be considered to reduce the lifetime risk of AMD and that ECP's should work to increase patient knowledge of these risk factors [73]. However, the reports in this review show that despite the majority of patients citing their ECP as their main source of AMD information, they still believe they do not have enough information. This suggests that the information may not be provided to patients or they are not able to recall it [22,37]. When advice was recalled and not acted on, patients reported that it was because they felt the change was not necessary or that they lacked understanding about how it would help, suggesting that further information about the benefit of the lifestyle change is required to enhance participant adherence to advice.

However, patient reported studies have some limitations. Firstly, patients may not want their clinician to know that they are not following advice, or may not want to make negative comments about their ECP, especially when they are surveyed in the clinics. Anonymising data may help with this, but patients may still have reservations. Secondly, there is a risk of selection bias, where participants who respond may be more motivated to take part. For example, Stevens et al. (2014) recruited patients from a voluntary sector patient support group, which may have preferentially included people who were more inclined to engage with the management of their condition [58]. Thirdly, many of the studies [22,44–47,51,53,55,56,59–61] in this review recruited participants from single clinics. This decreases the generalisability of the results as the patients attending one clinic in one city may have different care experiences to patients in other places around the world. Finally, patient reported studies can be limited due to the incomplete patient recall of advice [37]. Patients may not always remember the advice they were given so this would not have accurately represented advice provided by ECPs. However, this may also suggest that advice may not have been administered properly or in an effective enough way to help patient recall.

The overall experience of patients with AMD in the UK has been evaluated previously (Boxell et. al., 2017). The study compared patients' experiences of AMD care in 1999 compared to 2013 after the publication of patient management guidelines from the Royal College of Ophthalmologists [28]. A higher proportion of patients surveyed in 2013 (n = 1169) reported feeling satisfied overall with their diagnostic consultation overall (76% compared to 61% in 1999) [74]. Although this study did not investigate lifestyle advice specifically, studies have demonstrated that a positive health care experience can improve patient compliance [75,76].

4.2. The Practitioner Experience

The studies reporting practitioner experience in providing lifestyle advice for AMD found that practitioners tended to be more confident at providing advice about diet and nutrition, especially nutritional supplementation, than regarding smoking cessation. This was suggested to be at least partially attributable to concerns about a negative patient response to questions about smoking [55,72]. Between 62–81% of ECPs reported providing advice regarding dietary change (although the upper limit of the larger studies, i.e., $>n$ = 100 was 68%), while advice regarding nutritional supplements was given by between 67% and 93% (with the upper limit of larger studies, i.e., $>n$ = 100 being 93%) of ECPs surveyed [36,43,49,55,57]. In other words, advice on nutritional supplements was reported as being provided more frequently than advice about diet. However, there was evidence that advice regarding nutritional supplements did not always follow the most robust evidence based guidelines [35]. There was some data to suggest that ophthalmologists might be more likely than optometrists to discuss smoking cessation [35,36], and more in-

clined to follow AREDS [25,26] recommendations for nutritional supplement provision [35]. However, comparison between practitioners was limited by small sample sizes.

Research in other healthcare disciplines (medical, dental and nursing professionals) indicates certain common barriers which may prevent implementation of advice regarding nutrition [77]. One factor raised (alongside the issues of insufficient time, education and resources) is that healthcare practitioners feel that dietary advice guidelines can sometimes be unhelpfully vague. This may explain the finding in this review of increased confidence in providing advice regarding nutritional supplements, which is more specific and easily actioned, than advice regarding dietary change. It also emphasises the importance of a consistent and specific approach across eyecare regarding the best evidence based approach to dietary modification advice in order to give confidence to practitioners in providing the advice as well as to patients in acting upon it.

All of the studies relating to practitioner experience were questionnaire based, self-reported studies about practitioners' opinions and practice behaviours. It can be argued that these studies can be biased by a desire for practitioners to appear in a positive light before their peers, and may not truly represent the views or behaviours of the ECP. Another potential issue is selection bias, whereby those individuals responding to a questionnaire may be those who are more engaged with research in this field and therefore more motivated with respect to providing patient lifestyle advice. However, these limitations mean that the self-reported lack of provision of dietary advice to people with AMD by one third of ECPs surveyed is likely to be a favourable representation of the true scale of advice provision.

An important point to consider is that the studies that were reported recently (2020 and later) [50,52,57,62,78] show that there are improved rates of advice provision amongst practitioners compared to earlier studies [35,36,43,45,49,54,55]. However, this review highlights that there is still a need for further education for practitioners, specifically about the importance of smoking cessation advice. This is a key factor as the evidence regarding the increased risk of AMD onset and progression associated with smoking is irrefutable. One of the largest studies on the impact of smoking on AMD, The Blue Mountains Eye Study with 3654 patients with AMD, found a significant association between smoking and neovascular AMD (OR 3.20), geographic atrophy (OR 4.54) and early AMD (OR 1.75) compared to non-smokers [21]. There have also been a number of reviews demonstrating this link and highlighting the importance of informing patients about the risk of smoking on AMD [79–81]. However, despite this, the 6 studies in this review that investigated smoking cessation advice given to patients, found that smoking advice was not regularly given [35–37,45,49,57].

This finding is not unique to ECPs. A survey of 3167 general practitioners from four Scandinavian countries reported that, of the 67% who responded, the majority did not explicitly ask the patient about their smoking history unless they displayed smoking related symptoms, and few practitioners signposted smoking cessation services [82]. Similarly, of 149 dentists surveyed in South East England, whilst 75% recorded smoking status, only around a quarter took any kind of active role in assisting them to stop. In common with the ECPs included in this review, concern regarding negative patient response was one issue highlighted, alongside a general sense that smoking cessation advice is rarely heeded, and lack of understanding of the significance of smoking to dentistry, and organisational factors (such as limited time availability) [83]. It is clear that across healthcare disciplines work is required to improve practitioner education and patient communication surrounding smoking cessation.

It is of particular concern that practitioners included in this review were also not asking about smoking history. This is crucial not just with respect to advising on smoking cessation, but also because as there is strong evidence that beta carotene supplementation increases the risk of lung cancer in smokers [84]. This means that the original AREDS formula is not appropriate for people who smoke. The AREDS2 study group recommended giving patients lutein and zeaxanthin as a carotenoid substitute in the formula [26]. This

highlights the importance of taking a smoking history from patients, even with respect to recommending the appropriate vitamin supplement.

Given the limitations in advice provided by ECPs with respect to lifestyle modification, further exploration of the barriers limiting advice provision would be valuable to identify ways in which these barriers might be addressed.

Additionally, this literature review has identified a significant limitation in the current published evidence base. The published studies do not cover the behaviour of practitioners in all countries. In fact, all of the studies which met our inclusion criteria were based in Europe, Australia and the USA, so there is a real need for research investigating the behaviour of practitioners in areas in Asia, Africa, South America.

4.3. How Effective Is the Advice at Changing the Lifestyles of Patients with AMD?

In this review, the majority of studies reporting on compliance related to vitamin supplements. Overall, patients were taking the supplements they were recommended, but were unsure if they would help. Previous studies have shown that, when informing patients of new medication, it is important to inform them about what the medication is, how it will help and how long they should take it for as this improves compliance [85,86]. The importance of ECP advice is highlighted by the finding in this review that the main barrier to patients taking supplements was not having them recommended [22,51,56,61].

Finally, despite the large amount of evidence showing the benefits of smoking cessation on AMD progression, with smokers having a 4-fold increased risk of progression and former smokers having a 3-fold risk [18], there was only one study that looked at adherence to smoking cessation advice and reported that none of the participants who recalled being told to stop smoking took the advice (0 out of 5 patients). The other studies in this review show that patients are not aware of the link between smoking and AMD and practitioners are not giving the advice to patients.

4.4. How Can Effectiveness of Advice Provision Be Improved?

There has been research into ways of improving effectiveness of advice provision to people with AMD. Stevens, Cooke and Bartlett (2018) carried out an interventional study to see if a novel educational intervention can promote healthy eating and nutritional supplementation in people with AMD [87]. The participants (n = 100) allocated to the intervention group (n = 49) were given a leaflet and prompt card containing advice on diet and supplements, whilst participants in the control group (n = 51) were given a leaflet created by the UK College of Optometrists. All of the participants were followed up after 2 weeks, at which time there was evidence that participants in the intervention groups showed a larger increase in confidence that changing diet could slow progression of AMD, and were also more likely to make dietary changes. However, the follow up period of this study was short, and participants were not randomly allocated to the intervention group. Another study assessed the effectiveness of a telephone delivered intervention designed for giving dietary recommendations to people with AMD [78]. Participants in the intervention group (n = 77) were given a 20 min phone call every month for 4 months where they would provide advice to patients, assess their diet, help them with goal setting and arranging follow up support. The participants in the control group (n = 78) were given general leaflets about AMD and were followed up briefly once a month. Participants were also given a follow up call 4 months after the study was completed. After the intervention, participants in the interventional group significantly improved their dietary intakes of green leafy vegetables compared to baseline, whilst the change in the control group was not statistically significant compared to baseline. Additionally, the intervention group made more overall dietary changes compared to the control group, with a significant difference being in the consumption of nuts (p = 0.04) [78]. Although the intervention was beneficial, the time commitment required from the ECP makes the approach challenging to instigate in routine clinical practice. However, these studies do indicate that enhanced advice provision may have an impact on compliance in this patient group.

5. Conclusions

In conclusion, this review shows that the lifestyle advice given to patients varies and is not consistent amongst all practitioners. Practitioners appeared to be most confident in providing advice about nutritional supplements, and least confident with respect to smoking, however nutritional supplements advised did not always comply with evidence-based guidelines. There was evidence that patients were inclined to follow advice regarding supplements provided by ECPs, and the main reason stated for not following lifestyle modification advice was that it had not been provided by the ECP and because patients were not sure if following the advice would be useful. This highlights the potential scope for ECPs to bring about a change in patient behaviour through effective advice provision. The review highlighted a need for more patient centred studies to understand the best ways of providing advice to patients as well as research regarding how to overcome the ECP perceived barriers to effective lifestyle advice provision to facilitate the translation of research to positive outcomes.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/nu14214652/s1, Table S1: Data extraction table describing studies included in this review. (.xlsx), Table S2: Joanna Briggs Institute (JBI) checklist for Qualitative studies. Table S3: Critical Appraisal Skills Programme (CASP) checklist for Cohort studies. Table S4: Joanna Briggs Institute (JBI) checklist for Case Series. Table S5: Joanna Briggs Institute (JBI) checklist for Cross Sectional Surveys. Table S6: National Heart, Lung and Blood Institute (NHLBI) checklist for Interventional Audit.

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