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24 **Introduction**

25 Age-related macular degeneration (AMD) is the leading cause of visual impairment in older adults (> 50 years)
26 in the UK (RNIB, 2010). Currently, there are several AMD classification schemes which have been developed to
27 try to standardise research and clinical practice. Ferris et al. (2013), proposed a five stage classification scale
28 which has achieved some consensus among AMD specialists: Stage 1) No apparent aging changes, 2) Normal
29 aging changes, known as 'druselets' (small drusen $\leq 63 \mu\text{m}$) 3) Early AMD – medium sized drusen $\leq 125 \mu\text{m}$ 4)
30 Intermediate AMD - large drusen and pigmentary (hyper or hypo) anomalies and 5) Late AMD – geographic
31 atrophy and/or neovascularisation (Ferris et al., 2013). AMD can cause a gradual loss of central visual function
32 occurring within months, or over many years, and late AMD can cause central visual loss and metamorphopsia
33 within days or even hours. Many AMD patients have been given a simplified classification using the terms 'dry'
34 to describe geographic atrophy and 'wet' to describe neovascularisation or exudation. Visual loss is strongly
35 associated with a reduction in quality of life as it will limit the ability to perform daily activities. Subsequently,
36 depression often occurs in these patients (Mathew et al., 2011). It has been predicted that the prevalence of
37 AMD will increase significantly by 2020 due to the generalised aging of the population (Owen et al., 2012;
38 Shaw, 2006), but also due to socio-economic factors such as poor nutrition and increased smoking in some
39 areas (Huffman et al., 2012; Wennergren et al., 2013). Therefore it can be expected that there will be a
40 growing need for support services for people with this condition.

41 Diagnosis for AMD in the UK occurs via an ophthalmologist (RNIB, 2010). Often, after the initial diagnosis, the
42 patient will receive written material regarding the disease from the ophthalmology department. The decision
43 then rests with the ophthalmologist as to whether the patient requires any treatment. This might take the
44 form of anti-vascular endothelial growth factor medications (e.g. Lucentis®) or surgery/laser work to wet AMD
45 conditions, low vision services or placement upon a sight impairment register. If the AMD is of an early or
46 intermediate stage, the patient will have very little contact with any hospital services for some years – if at all –
47 unless the AMD changes to a late stage. Patients are advised to have a yearly eye examination with an
48 optometrist who will monitor the condition, but is often unable to provide physical or psychological help
49 without referral (AOP, 2001).

50 Whilst specialists agree that smoking has a big impact on AMD and that cessation will halt progression of the
51 disease (Caban-Martinez et al., 2011), there are conflicting research findings and therefore conflicting
52 information provided by eye care practitioners regarding the impact of nutrition on AMD (Kent, 2007).

53 The Age-Related Eye Disease Study (AREDS) reported that nutritional supplementation in people with
54 intermediate AMD can reduce their risk of progression to advanced AMD by 25 % (Kassoff et al., 2001). While
55 the AREDS was in progress, evidence emerged to suggest that the dietary nutrients lutein and zeaxanthin may
56 be more effective than other nutrients in reducing AMD risk or progression due to their antioxidant and photo
57 protective properties (Beatty, Koh, Phil, Henson, & Boulton, 2000). The plausibility for this hypothesis is due to
58 the high concentration of lutein, zeaxanthin, and a related compound meso-zeaxanthin, in the macula,
59 particularly in the fovea, which form the macular pigment (Khachik, Bernstein, & Garland, 1997). The
60 protective properties of the macular pigment are now well established and include the ability to interact with
61 free radicals, prevent lipid peroxidation and filter out incoming, high energy blue light (Alves-Rodrigues &
62 Shao, 2004; Ham, 1983; Junghans, Sies, & Stahl, 2001; RNIB, 2010) . Some studies also show a link between
63 increased intake of lutein and zeaxanthin, and higher macular pigment levels (Bhosale, Zhao, & Bernstein,
64 2007; Vishwanathan, Goodrow-Kotyla, Wooten, Wilson, & Nicolosi, 2009; Wenzel, Sheehan, Burke, Lefsrud, &
65 Curran-Celentano, 2007). Supplementation studies report increases in macular pigment of between 21 and
66 57% following lutein and zeaxanthin supplementation in people with healthy eyes. Increases in macular
67 pigment of between 24% and 36% have been reported in people with retinal disease. One randomized
68 controlled trial reported an improvement in several measures of visual function in a group of veterans who
69 supplemented with 10 mg of lutein for one year (Richer et al., 2004; Ziemssen, Warga, Bartz-Schmidt, &
70 Wilhelm, 2005). A recent study by Loughman et al. (2012) suggests that supplementation with all three
71 macular carotenoids may offer advantages both in terms of macular pigment optical density (MPOD) response
72 and visual performance enhancement (Loughman et al., 2012). The AREDS team recently released the results
73 for their follow-up study (AREDS 2) which encompassed lutein and zeaxanthin to the original AREDS
74 supplement formulation (Chew et al., 2013). The study found that adding lutein and zeaxanthin did not further
75 reduce the risk of progression to advanced AMD. However, investigators report that lutein and zeaxanthin may
76 be useful substitutes for beta-carotene in the original formulation (Cangemi, 2007). Despite the conflicts,

103 The objectives of this study were firstly to find out who pursues the help of a non-professional charity, and
104 secondly, to determine the beliefs and understanding that these AMD patients have about the impact of
105 nutrition on the condition, and where patients have obtained information about nutrition.

106 **Methods**

107 *Participants*

108 A total of 158 participants were recruited between January 2012 and March 2012. Recruitment was via the
109 Macular Society helpline volunteer worker. Patients aged over 55 years of age who contacted the Macular
110 Society helpline between January 2012 and March 2012 were asked if they would like to take part in a
111 telephone survey (once they had received all the assistance they needed from the Macular Society). Pre-
112 requisites for potential participants were that they should be aged over 55 years and have been diagnosed
113 with a form of AMD; exclusion criteria were the inability to hear and reply to questions in English over the
114 telephone. No attempt was made to define and categorise the amount of visual loss the participant had, as
115 the objective was to assess typical patients seeking the Macular Society services.

116 *Ethics*

117 The procedures followed were in accordance with the ethical standards of the Aston University Ethics
118 Committee on human experimentation that conform to the Declaration of Helsinki 1975, revised Hong Kong
119 1989.

120

121 *Survey Design*

122 A systematic literature review of research on AMD patient's perceptions of nutrition and AMD was conducted
123 of the following databases: Web of Knowledge, The Cochrane Library, Optics Infobase, Ovid Journals,
124 PsycArticles, NCBI databases and Wiley Online Library. The following key-terms were used: "Age-related
125 macular degeneration", "Nutrition", "Survey", "Attitudes", "Behaviours" and "Diet". This review did not
126 identify any existing measure of patient's perceptions of nutrition, but found most surveys looked at
127 nutritional behaviours (Montgomery et al., 2010). As a result, a 36 question cross sectional survey was
128 designed to explore nutritional habits, supplement usage, physical abilities in food preparation and cooking,

129 and sources of knowledge in order to ascertain the beliefs AMD patients have, and compare their beliefs with
130 their behaviours. Not all the results of the 36 questions are covered in this paper. Because the survey was
131 exploratory, it was designed mainly with open ended questions in order to ensure responses reflected
132 participants' true beliefs. In addition, some closed ended questions were included with response scales to
133 grade participants' feelings.

134 The survey was then piloted on eight AMD participants, from the Macular Society, to test the reliability,
135 comprehensibility, and understanding among an informed population. This 'face validity' (i.e., does the
136 questionnaire appear correct at face value) was the only means of validation that it was possible to perform,
137 due to a lack of other instruments to compare the results with. Initially, the eight patients completed the
138 survey via a telephone interview. Three weeks later, the patients attended a focus group that had two parts:
139 firstly, the participants completed the survey once more. Next, the participants had a recorded, guided
140 informal discussion structured by a moderator – the volunteers were asked to comment on how easy the
141 questions were to understand and opinions on the topics covered. The results of this meeting were analysed
142 to further refine the survey, which was altered accordingly (e.g. the terms 'wet' and 'dry' were employed to
143 coincide with many patient's understanding of AMD classification, extra options were added to some
144 questions, some questions were removed or re-worded and additional instructions were added). The final
145 survey (see **Appendix 1.**) was then administered to the cohort.

146 The initial questions covered demographic topics such as gender, age, employment, social history, type and
147 length of time with AMD and visual impairment registration. Opinions on diet and supplementation were
148 obtained, with particular interest in whether participants could identify lutein and zeaxanthin rich foods (e.g.
149 kale) amongst other vegetables. Participants were also asked where they had acquired any information about
150 the condition from (for instance, an ophthalmologist, optician, Macular Society etc). The questions
151 subsequently focused on perceived state of vision and health, and ability to perform preparation and cooking
152 of food. Participants also provided a food diary for 24 hours, as studies have shown there is less measurement
153 error in food recording than in food frequency questionnaires, and the ability to study associations between
154 diet and chronic diseases is slightly easier with food diaries (Bartlett & Eperjesi, 2004; Block, Hartman, &
155 Dresser, 1986). The results of the questions relating to cooking abilities, perceived health and vision states and
156 the food diary is beyond the scope of this paper and will be discussed in a future paper.

157 *Procedure*

158 If a patient agreed to take part, their name and contact details were taken by the helpline worker. The
159 potential participants were read an information factsheet informing them what the survey would involve, how
160 long it would take and how the information would be stored. If the patient decided to participate, an oral
161 informed consent was obtained over the telephone and they were advised that they could withdraw at any
162 time. Usually an appointment was scheduled for a future telephone interview or the interview began
163 immediately if the patient wished.

164

165 They were then contacted at a convenient time by one of four Macular Society employees who would
166 administer the telephone interview and fill in the survey online at the same time (Bristol Online Surveys). The
167 telephone interview lasted approximately 25 minutes, and was not recorded. Each volunteer was trained (by
168 RS) to ask the questions only, without bias, and if the participant had any questions regarding the survey, they
169 were given the author's contact details, although no participant made any contact.

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171

172 *Data Analysis*

173 The results were analysed to find the mean, median and standard deviation using the software Microsoft
174 Excel. Data from Excel was then used to create charts, and used in statistical software IBM SPSS (version 20) to
175 draw comparisons between supplement cost and usage using chi-square statistics. Qualitative data was
176 grouped into categories and general themes were extracted to then use in SPSS.

177

178 **Results**

179 *Sample Characteristics*

180 **Table 1** shows the demographic characteristics of the sample. The gender distribution of the 158 participants
181 showed that there were significantly more females (61%) in the sample than males (39%) (chi-square $p= 0.05$).
182 The participants ranged in age from 56 to 95 years; the median age was 80 years. There was a nearly even split
183 between 'wet' (47%) and 'dry' types of AMD (49%), with a small percentage of participants who were unsure
184 of their AMD classification. The median duration of having the condition was 5 years, ranging from 1 to 25

185 years. The majority of participants lived in their own home – either rented, mortgaged or owned outright, and
 186 participants mainly either lived with their partner or alone. The majority of participants were not registered
 187 partially sighted or blind, although there was a trend for those participants that had the condition for longer to
 188 be on a register (Kruskal Wallis H p= 0.09).

Characteristic		Percentage of Participants
<i>Living Arrangements</i>	Own home	88%
	With family/friends	3%
	Sheltered accommodation	7%
	Other	2%
<i>With</i>	Partner	50%
	Alone	47%
	Other family members	4%
<i>Registration</i>	Blind	16%
	Partially sighted	21%
	None	63%
<i>Supplement price willing to pay</i>	No cost	17%
	£1-5	10%
	£6-10	21%
	£11-15	24%
	£16-20	12%
	£20+	17%

189

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Table 1. Demographic characteristics of participants.

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Patient’s perceptions of diet and eye health

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When asked their overall opinions on diet and health, 87% of participants believe that diet affects general health, and 68% believe that diet affects eye health.

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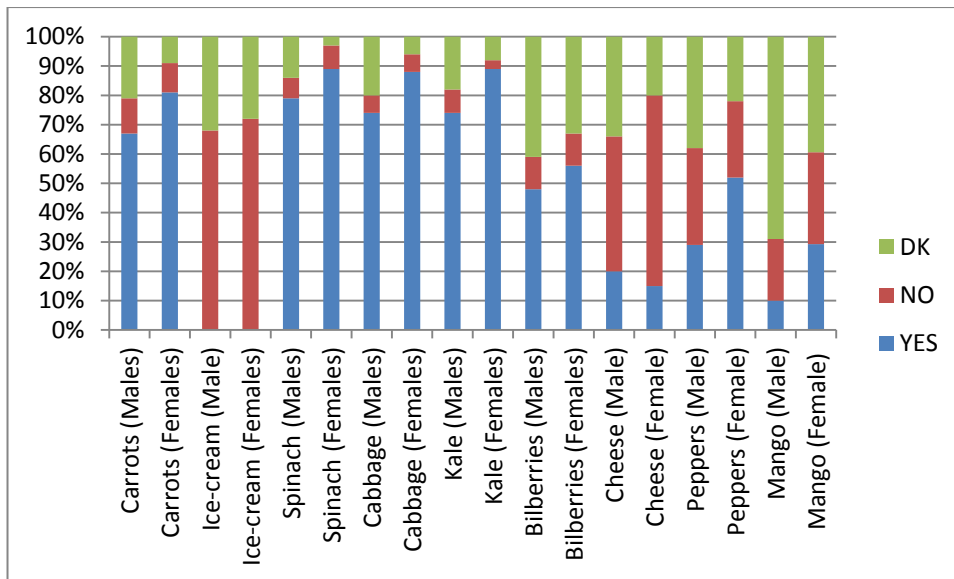
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Figure 1 shows the beliefs that participants held about specific foods:- leafy green vegetables, which are good sources of lutein and zeaxanthin, other fruit and vegetables, and dairy products . Participants were asked if they believed each food was beneficial for eye health, and if they answered ‘Yes’, they were asked why they thought so.

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199 **Figure 1.** Participant’s beliefs about the eye health benefits of several foods. ‘Yes’ indicates the participant believed the
 200 food was beneficial, ‘No’ indicates the participant did not believe that the food was beneficial, and ‘DK’ indicates the
 201 participant didn’t know.

202 As shown, the majority of participants were accurate in their perceptions of the food which would be
 203 beneficial for eye health. Leafy green vegetables such as spinach, cabbage and kale were identified as being
 204 beneficial by over 80% of participants. Ice-cream was identified as not beneficial for eye health by 72% of
 205 participants. For mango, bilberries and peppers, 25% or more participants answered ‘don’t know’, and
 206 responses were more mixed. Males responded with ‘Don’t know’ on average 10% more than females.

207 When asked why they felt a particular food was valuable for eye health, the majority of participants (81%)
 208 struggled to verbalise why they held that belief. Of those that did express the reasoning behind their beliefs,
 209 the majority of the responses had nothing to do with nutrients. Only 2% of those that felt spinach and kale are
 210 beneficial for eye health knew that they contain lutein. Some participants responded that leafy green
 211 vegetables were known to be good for eyes (spinach 5%, kale 3%, and cabbage, 6%), while others merely
 212 responded that coloured foods were good for eyes (carrots 2%, peppers 5%, and mango 1%). Some
 213 participants (1%) responded that spinach and kale contained iron, which was why they felt it would be
 214 beneficial for eye health. One percent of participants felt that carrots were beneficial because they contained
 215 carotene, and that peppers were beneficial because they contained vitamin C. Participants also included the
 216 following reasons for carrots: “They help you see in the dark” (6%), “war propaganda” (6%), “We were told to

282 This sample may not represent all patients seeking services from organisations like the Macular Society. Access
283 to other organisations would provide a more rounded view. It would be important to find out the opinions of
284 those with AMD who have not sought support from non-professional organisations, and this will form the next
285 step to the overall project.

286 *Patient's perceptions*

287 This study provides a clear picture of the perceptions of diet and eye health among a sample of AMD patients.
288 The majority of participants agreed that specific foods can affect general health, and participants also agreed
289 that specific foods affect eye health. The results of the specific food questions show that the majority of
290 participants felt that the vegetables and fruit were beneficial for eye health, and these perceptions were
291 generally accurate. However, apart from a few individuals who mentioned specific nutrients in regard to
292 specific foods (e.g., lutein in kale), most participants were not able to identify why these foods helped promote
293 eye health, or gave vague responses such as "I read it somewhere". This suggests that participants, who would
294 be expected to be well-informed, were not clear about the links between diet and eye health.

295 *Information*

296 The majority of participants reported that they did not have enough information on nutrition and its
297 relationship to AMD. As expected, all participants reported that they had received information from
298 organisations such as the Macular Society. In contrast, not all the participants reported getting information
299 from their ophthalmologist, which is consistent with previous studies (Dahlin-Ivanoff, Sjöstrand, & Klepp, 1998;
300 RNIB, 2013). The data reported here shows that there are clear gaps in the knowledge patients have of AMD
301 risk factors (Sushma, Lamkin, Albanese, Edward, 2010). A lack of information might also explain why four
302 percent of the participants were not sure what type of AMD they were suffering from. Patients appear to be
303 actively seeking advice but not all are getting it from sources such as ophthalmologists or optometrists. These
304 findings are similar to results from the Royal College of Ophthalmologists audit of AMD services in March 2009
305 (Amoaku & Hubbard, 2009) which found that there was an insufficiency of resources to deliver adequate AMD
306 Services. Lawrenson and Evan's survey (2012) of eye professionals (Lawrenson & Evans, 2013) showed that
307 although over 60% of respondents reported that they frequently provide dietary and supplement advice to
308 patients with established AMD and those at risk of AMD, the nutritional advice given only consisted of leafy

309 green vegetables and oily fish recommendations, and type of supplement recommended did not comply with
310 current best research evidence, based on the findings of the Age-Related Eye Disease Study (AREDS). Only one
311 in three optometrists regularly assessed smoking status and advised on smoking cessation (Lawrenson &
312 Evans, 2013). The results reported in the present study reinforce those of the survey and the Royal College of
313 Ophthalmologists, and provide further evidence that greater support and information provision for AMD
314 patients is needed.

315

316 *Nutritional supplementation*

317 Over 75% of participants reported taking a nutritional supplement (mainly on a once-per-day basis) – this is a
318 larger number than other studies into supplement usage have found (Block et al., 2007) (Bartlett & Eperjesi,
319 2004; Denison et al., 2012). The majority of patients that were taking ocular supplements were not taking an
320 exact AREDS formulation, and were taking an incorrect dosage or combining it with one or two other brands
321 with the same formulation (maybe believing that more might be better). This pattern of supplementation
322 could reflect a lack of information from healthcare professionals, with only a third of patients having discussed
323 nutritional supplementation with their ophthalmologist, while some participants had not discussed
324 supplementation with anyone at all. Those participants in our study that reported not taking any supplements
325 listed the primary reason as not believing they would be effective, and hence were unwilling to spend much
326 money on an unproven supplement. The high number of nutritional supplements marketed towards people
327 with AMD makes it difficult for both patients and health professionals to navigate this issue for the prevention
328 or treatment of the condition (Kent, 2007). There are currently no clear supplement guidelines for health
329 professionals to use; The College of Optometrists advises that patients should eat a healthy diet and to stop
330 smoking, adding that there “is no definitive scientific evidence of the effectiveness of nutritional
331 supplements”, but patients should speak to their optometrist for supplement advice (The College of
332 Optometrists, 2011). Some institutions might have been waiting for the results of AREDS 2, but since the
333 AREDS 2 results have been released, there is a need for unified guidelines for all health professionals. When
334 asked how much participants would be willing to pay for an effective nutritional supplement, only one quarter
335 responded that they would pay more than £11 per month, and there was a significant correlation between
336 those who did not take supplements and those that were not willing to spend any money on supplements.

337 *In conclusion*

338 The development of this survey has created a new measure that can be used again. The study has identified
339 that AMD patients have a definite lack of information and understanding of the link between AMD and
340 nutrition, and this needs to be corrected. The results of this study will inform the design of more effective
341 education and dissemination methods, and help to outline guidelines for health professionals.

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348 **Declaration of Conflicting Interests**

349 The authors declare no conflict of interest and have no proprietary interest in any of the materials mentioned
350 in this article.

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Appendix 1. Survey Questions.

Questions	Options
How old are you?	
Would you describe yourself as...	Male
	Female
Do you live...	Alone
	With partner
	With family
	With friends
	Other (please specify)
Do you live...	In own residence
	In family/ friend's residence
	In sheltered accommodation
	In nursing home
	Other (please specify)
What is, or was your main occupation	
How would you describe your general health today? How would you describe your vision today?	Extremely good

	Good
	Satisfactory
	Poor
	Extremely poor
Do you have the eye condition age-related macular degeneration	Yes
	No
	Have not heard of this condition
If Yes, how many years have you had it in total?	
What type of age-related macular degeneration do you have?	
Are you on any visually impaired register?	Sight impaired (partially sighted)
	Severely sight impaired (blind)
	Neither
Who MOSTLY prepares your food?	You
	Partner
	Family member
	Care giver
	Other (please specify)
Who MOSTLY cooks your food?	You
	Partner
	Family member
	Care giver
	Do not eat cooked food
	Other (please specify)
What prevents you from preparing food (select all that apply)	Visual impairment
	Physical impairment
	Nothing
	Other (please specify)
Are you able to cook a hot meal on your own?	Yes
	No
What prevents you from cooking food (select all that apply)	Visual impairment
	Physical impairment
	Nothing
	Other (please specify)
Who MOSTLY does your food shopping?	You
	Friend
	Family member
	Care giver
	Other (please specify)
Where do you get your food from? (select all that apply)	Supermarket
	Local grocers/ corner shop
	Internet
	Meals on wheels

	Market
	Grow own food
	Other (please specify)
What is the most important factor that dictates what you eat?	Cost
	Preference
	Habit
	Ability to cook or prepare it
	Ability to acquire it
	How it affects your health
	Other (please specify)
Would you like to change your diet in any way?	Yes
	No
What prevents you from changing your diet?	Visual impairment
	Physical impairment
	Nothing
	Other (please specify)
	Do not want to change diet
Please could you describe what you ate yesterday (Breakfast, Lunch, Dinner, Snacks - your interviewer will describe portions).	
Were the vegetables eaten yesterday (if any)...	Mostly cooked
	Mostly raw
	No vegetables eaten yesterday
Please state how strongly you agree or disagree with the following statement:	Strongly agree
There are specific foods that can affect your health.	Agree
	Neither
	Disagree
	Strongly disagree
Please state how strongly you agree or disagree with the following statement:	Strongly agree
There are specific foods that can affect your EYE health.	Agree
	Neither
	Disagree
	Strongly disagree
Do you think any of the following foods are beneficial for eye health... and why	Carrots
	Ice-cream
	Spinach
	Cabbage
	Kale
	Bilberries
	Cheese
	Peppers
	Mango
Which, if any, of the following vegetables did you eat last week? (select all that apply)	Carrots
	Peas

	Spinach
	Cabbage
	Broccoli
	Kale
	None of the above
Have you ever discussed taking a nutritional supplement with a health specialist or advisor?	Yes
	No
If yes, who?	Ophthalmologist
	GP
	Optician
	Specialist doctor
	Nurse
	Herbalist
	Pharmacist
	Dietician
	Helpline worker
	Other (please specify)
Do you Currently take any nutritional supplements?	Yes
	No
If yes, what supplements do you take?	
How often do you take the supplements listed above?	More than twice per day
	Twice per day
	Once per day
	Once per week
	Other (please specify)
If you answered No, Can you give a reason for not taking a nutritional supplement	Too expensive
	Not sure if effective
	Fear/ experience of side-effects
	worry about interaction with other drugs
	Too much trouble
	Other (please specify)
How much money would you be willing to spend on a monthly basis on a nutritional supplement which promised good results?	No money
	£1-5
	£6-10
	£11-15
	£16-20
	£20+
Please state how strongly you agree or disagree with the following statement:	Strongly agree
Age-related macular degeneration patients are given enough information on how nutrition affects their eye health.	Agree
	Neither
	Disagree

	Strongly disagree
Where have you received information on age-related macular degeneration from? (select all that apply)	Ophthalmologist
	Optician
	Internet
	Newspapers
	TV
	Organisations such as the Macular Society
	Other (please specify)
Do you believe that age-related macular degeneration can be prevented by lifestyle choices such as nutrition?	Strongly agree
	Agree
	Neither
	Disagree
	Strongly disagree
Which changes to the way that you live do you think could affect age-related macular generation?	

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