

1 A qualitative exploration of eyecare professional perspectives on Age-Related Macular Degeneration  
2 (AMD) care

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## 17 Abstract

18 Despite the existence of evidence-based recommendations to decrease risk and progression of Age-  
19 Related Macular Degeneration (AMD) for some time, self-reported practices suggest that eyecare  
20 professionals' advice and people with AMD's adherence to these recommendations can be very  
21 poor. This study uses qualitative methods to explore Australian eyecare professionals' perspective  
22 on barriers to effective AMD care. Seven focus groups involving 65 optometrists were conducted by  
23 an experienced facilitator. A nominal group technique was used to identify, prioritize and semi-  
24 quantify barriers and enablers to AMD care. Participants individually ranked their perceived top five  
25 barriers and enablers with the most important granted a score of 5 and the least important a score  
26 of 1. For each barrier or enabler, the number of votes it received and its total score were recorded.  
27 Barriers and enablers selected by at least one participant in their top 5 were then qualitatively  
28 analysed, grouped using thematic analysis and total score calculated for each consolidated barrier or  
29 enabler. In-depth individual interviews were conducted with 10 ophthalmologists and 2  
30 optometrists. Contributions were audio-recorded, transcribed verbatim and analysed with NVivo  
31 software. One hundred and sixty-nine barriers and 51 enablers to AMD care were identified in the  
32 focus groups. Of these, 102 barriers and 42 enablers were selected as one of their top 5 by at least  
33 one participant and further consolidated into 16 barriers and 10 enablers after thematic analysis.  
34 Factors impacting AMD care identified through analysis of the transcripts were coded to three  
35 categories of influence: patient-centered, practitioner-centered, and structural factors. Eyecare  
36 professionals considered poor care pathways, people with AMD's poor disease understanding /  
37 denial, and cost of care / lack of funding, as the most significant barriers to AMD care; they  
38 considered shared care model, access, and communication as the most significant enablers to good  
39 AMD care. These findings suggest that Australian eyecare professionals perceive that there is a need  
40 for improved patient support systems and appropriately funded, clearer care pathway to benefit  
41 people with AMD.

## 42 Introduction

43 In 2015-2016, one in six Australians over the age of 50 had age-related macular degeneration (AMD)  
44 [1]. The impact of this common disease of the aging on people with AMD is significant. Contributing  
45 to approximately 70% of cases of bilateral blindness in non-indigenous Australians, AMD is the most  
46 common cause of blindness [1]. Having AMD (any stage of disease severity) has been shown to  
47 significantly impair activities of daily living [2]. Several modifiable risk factors have been shown to  
48 increase the risk of developing AMD and/or the speed at which the disease progresses [3, 4]. These  
49 include smoking and lifestyle risk factors such as dietary intake of antioxidants, low glycemic index  
50 diets, dark leafy green vegetables, fish and dairy product consumption [5-7]. Optimal AMD care can  
51 best be defined as appropriate and timely advice on uptake of dietary supplements and the  
52 importance of following a healthy diet and lifestyle (including refraining from smoking). Clear,  
53 evidence-based recommendations on appropriate modifications to recommend for people with  
54 and/or at risk of AMD have existed for some years, yet self-reported practices suggest that eyecare  
55 professionals' advice to their patients on smoking cessation and dietary supplementation are often  
56 lacking [8-10]. In a survey of eyecare professionals in the UK, only one in three optometrists  
57 reported regularly assessing the smoking status of their new or existing patients and advising them  
58 on smoking cessation [8]. Although 93% of eyecare professionals appropriately recommended  
59 dietary supplementation to at-risk people, the type of supplements recommended often did not  
60 comply with current best research evidence, as suggested by the Age-related Eye Disease Study  
61 (AREDS) [8]; and there was a greater likelihood that ophthalmologists would recommend the AREDS  
62 formula than optometrists [8]. Similarly, a recent Australian survey indicated that fewer than half  
63 (47%) of optometrists routinely assess the smoking status of their patients [9]; factors such as  
64 optometrist's age and gender were associated with self-reported clinical practice behaviors,  
65 although no consistent pattern could be detected [9]. Comparative data on Australian  
66 ophthalmologists was unfortunately not collected.

67

68 Even when advice is appropriate, adherence to smoking cessation and dietary modification is often  
69 very poor among adults with AMD [11, 12]. Hospital based series have shown that people with AMD  
70 who have been recommended dietary supplementation are often not using them or are using an  
71 incorrect dose [12-14]. Conversely, one study showed that 20% of people with AMD who were using  
72 dietary supplementation did not have a level of AMD severity anticipated to benefit from that usage  
73 [13].

74

75 Barriers to the delivery of optimal eyecare result from a complex interaction of social, organisational,  
76 political, economic and cultural factors [15]. Little is known on what barriers specific to AMD may  
77 underpin the findings summarised above. Previous research has identified key barriers to the  
78 delivery of best practice eyecare. These include lack of time, lack of knowledge or skills, poor access  
79 to evidence, and inefficient care pathways [16-19]. In the setting of AMD, barriers such as  
80 socioeconomic disadvantage, cost, workforce supply, compliance and adherence issues have been  
81 postulated to exist [5, 20]. The current study aimed to explore the perspectives of eyecare  
82 professionals (optometrists, ophthalmologists) on AMD care in Australia, with a view to identify and  
83 describe some of the possible reasons for under or over detection and inappropriate management.

84

## 85 **Materials and Methods**

86 The study received ethics approval from UNSW's Human Research Ethics Advisory Panel in  
87 December 2015, in advance of the study start date. The study adhered to the tenants of the  
88 Declaration of Helsinki. A qualitative research approach was adopted to explore professional  
89 perspectives of eyecare for AMD. The study endeavoured to comply with the COnsolidated Criteria  
90 for REporting Qualitative Research (COREQ) [21]. A combination of focus groups (with the nominal

91 group technique) [22] and semi-structured face to face or phone interviews were used to collect  
92 data from eyecare professionals. Purposive, snowball, and maximum variation (e.g. urban versus  
93 rural location) sampling were used to recruit eyecare professionals registered for practice as an  
94 ophthalmologist or an optometrist in Australia. Optometrists and ophthalmologists were recruited  
95 primarily from seven sites in three Australian states (New South Wales, Victoria, Queensland). In line  
96 with maximum variation sampling, these sites were selected to ensure the recruitment of eyecare  
97 professionals living in rural, urban and city locations. Recruitment continued until no new themes  
98 were emerging and data saturation had been achieved. Purposive sampling was applied to identify  
99 individuals across the age range, of both sexes, and those who were identified as specialising in the  
100 management of AMD as well as those from other specialty areas. To encourage participation of  
101 eyecare professionals, focus groups were held in the same location and at the same time as major  
102 national or state-based continuing education conferences (e.g. Australian Vision Convention 2016,  
103 Super Sunday 2016, Royal Australian and New Zealand College of Ophthalmologist Annual Scientific  
104 Congress 2016). All optometrists and ophthalmologists attending these conferences were invited to  
105 participate. Optometrists and ophthalmologists were also recruited by advertising in professional  
106 newsletters and email lists, through announcements at continuing education conferences, and by  
107 word of mouth. Early pilot work suggested probable difficulties in recruiting ophthalmologists to  
108 attend focus groups. Indeed, it was not possible to arrange enough participants (minimum of four)  
109 to conduct any ophthalmology focus groups. For that reason, the primary method of data collection  
110 used for optometrists was focus groups and for ophthalmologists was individual interviews. Formal  
111 consent was obtained prior to or on the day of the focus group session or the interview, prior to  
112 commencing data collection.

113  
114 Individual interviews were conducted with all ophthalmologists and two optometrists who wished to  
115 participate but could not attend the focus group sessions. An experienced eyecare professional,

116 educator, and qualitative researcher (IJ) conducted all interviews. The length of interviews varied  
117 from 15 minutes to 60 minutes. The topic guide used during eyecare professional interviews was  
118 informed by a review of the literature and by issues raised during the focus groups. The topic guide  
119 covered the following key areas: experiences of AMD referral pathways, effectiveness of  
120 communication, compliance to evidence-based care, sources of information, and opinions on  
121 barriers to appropriate care and how eyecare delivery for AMD could be improved. Follow-up probe  
122 questions were asked on an as-needed basis to facilitate the depth of the discussions. There was  
123 scope for participants to explore other relevant issues.

124

125 Focus groups lasted approximately 1.5 hours to 2 hours. The optometry focus groups were granted  
126 Continuing Professional Development (CPD) approval for 3 points in accordance with the guidelines  
127 from the Optometry Board of Australia. The focus groups were advertised under the Course Name  
128 “Breaking down barriers: What can be done to improve AMD care?” Participants received  
129 appropriate monetary compensation and light refreshments. One of two optometrists with public  
130 health training and experience in qualitative research (DR, Dr Nina Tahhan) co-facilitated the focus  
131 groups alongside an experienced optometrist, educator, and qualitative researcher (IJ) [16, 17]. The  
132 focus groups specifically aimed to identify and describe the possible reasons for under or over  
133 detection and inappropriate AMD management. The focus groups opened with a brief (5 minutes)  
134 presentation by the expert facilitator, summarising the current evidence-based classification,  
135 established risk factors, and management recommendations for AMD care. This included an  
136 overview of recent published evidence of eyecare professionals’ advice and people with AMD’s  
137 adherence to these recommendations being less than adequate. Seven focus groups were  
138 conducted in total. Background demographic information were collected on the participants prior to  
139 the commencement of each focus group. The nominal group technique was then used to elicit,  
140 prioritise and semi-quantify the participants’ perspectives on the barriers and/or enablers to

141 appropriate AMD care. The nominal group technique is a qualitative method of data collection that  
142 enables a group to generate and prioritise a large number of issues using a structure that gives  
143 everyone an equal voice [22]. It has been used in varying health contexts to generate ideas and allow  
144 groups to reach consensus on barriers and facilitators to health practices [23, 24] and was used for  
145 this research as previously described [17]. Briefly, participants in all focus groups were given an  
146 individual card and asked to record silently their responses to the question “From your perspective,  
147 what are some of the factors preventing people at risk of or with AMD from accessing and/or  
148 receiving good care and/or from following advice given to them?” In a subset of three focus groups  
149 (Gold Coast, Melbourne, Toowoomba), participants were also asked to record responses to the  
150 following second question “In your opinion, what more could be done to help people at risk of or  
151 with AMD to access and/or receive good care and/or to follow advice given to them?” Seating in the  
152 rooms in which the focus groups were held was configured in a U-shape. Participants took turns to  
153 read aloud a single response from their card with each response recorded on a flip chart at the front  
154 of the room. This continued in a round robin fashion until all responses were exhausted. A facilitated  
155 discussion occurred throughout this process to ensure that responses were reviewed and clarified,  
156 and a group consensus reached on the meaning of each individual contribution. This was followed by  
157 a group discussion where similar items were amalgamated. Participants were then asked to  
158 individually choose, rank, and record five responses they personally considered most important with  
159 the most important granted a score of 5 and the least important granted a score of 1. The rankings  
160 were summed for each item and the findings subsequently (after workshop) emailed back to  
161 participants for their information. For each barrier or enabler, the number of votes it received  
162 (maximum possible number is equal to the number of participants at each focus group) and its total  
163 (maximum possible score is equal to the number if a top rank of 5 was given by all participants in the  
164 focus group) and the number of individuals who ranked it first, second, third, fourth and fifth were  
165 recorded. All barriers and enablers were then reviewed independently by two researchers (DR, IJ) to  
166 identify and come to a consensus on common category themes generated across the different focus

167 groups. The two researchers met to review participants' responses, and this continued until a  
168 consensus had been reached. This iterative process allowed the category themes to emerge. The  
169 number of votes (total and by rank) and the total score for the barriers and enablers consolidated  
170 into a category theme were summed.

171

172 Focus group and interview contributions were audio-recorded, transcribed verbatim by a  
173 professional transcriptionist, and transcripts were checked by one of the researchers (IJ, DR) in  
174 preparation for qualitative data analysis. Analysis was conducted on transcribed interview data, by  
175 an experienced qualitative researcher (AY) using inductive thematic coding techniques and software  
176 NVivo 11 (QSR International, Melbourne, Australia) geared towards identifying patterns and  
177 discovering theoretical properties in the data. Interviews were coded 'openly' line by line drawing on  
178 grounded theory methods [25] which allowed a thematic structure to emerge organically from the  
179 data. This approach allows theory to evolve during actual research, and it does this through  
180 continuous interplay between analysis and data collection [26]. Thematic coding was conducted in a  
181 detailed manner, resulting in a large number of descriptive themes or 'codes'. This approach was  
182 taken so as not to lose context and enhance rigour in identifying saturation points. In addition to  
183 coding thematically, where applicable themes were also coded as a 'barrier' or 'enabler' to  
184 distinguish prevalence of these within eyecare professional perspectives.

185

186 The constant comparative method, a facet of grounded theory [25], was used to perform deeper  
187 analysis. The constant comparative method is described as a continuous growth process, where each  
188 stage after a time transforms itself into the next, and previous stages remain in operation  
189 throughout the analysis and provide continuous development to the following stage until the  
190 analysis is terminated [27]. In applying this method emergent themes were sorted by 'barrier' and  
191 'enabler' and triangulated with the barriers and enablers identified during the nominal group

192 process. Themes, including barriers and enablers, were discussed by two researchers (IJ, AY), merged  
193 and restructured, eventually resulting in three categories of influence (Table 1).

194 **Table 1. Categories of influence within qualitative data.**

Category of influence	Description
Structural	Factors related to health system or the processes within it such as referral pathways, human resources, equipment, funding.
Clinician-centered	Factors related to clinician's knowledge, experience, perspectives and practices.
Patient-centered	Factors related to patient's knowledge, experience, perspectives and practices.

195

196

197 **Results**

198 **Population**

199 Seventy-seven eyecare professionals provided their perspectives of AMD care in Australia. Individual  
200 interviews were held with 10 ophthalmologists (7 face to face and 3 phone interviews) and two  
201 optometrists (face to face only). Sixty-five optometrists from across Australia also participated in  
202 seven focus groups (Table 2).

203 **Table 2. Characteristics and output of optometry focus groups.**

Focus Group Location (Code)	No. of participants	No. of barriers	Barriers selected in top 5	No. of enablers	Enablers selected in top 5
--------------------------------	------------------------	--------------------	-------------------------------	--------------------	-------------------------------

Melbourne (FG1)	15	20	17	21	17
Gold Coast (FG2)	11	19	10	14	13
Sydney (FG3)	15	38	23		
Sydney (FG4)	4	27	14		
Sydney (FG5)	10	28	14		
Toowoomba (FG6)	5	19	13	16	12
Orange (FG7)	5	18	11		
<b>Total</b>	<b>65</b>	<b>169</b>	<b>102</b>	<b>51</b>	<b>42</b>

204 \* One participant ranked 2 items as 3 in importance.

205 Three focus groups were held in Sydney (NSW) and one each in the Gold Coast (QLD), Melbourne  
206 (VIC), Toowoomba (QLD), and Orange (NSW). The number of optometrists participating in the focus  
207 groups ranged from 4 to 15. Two non-optometry AMD stakeholders (one low vision rehabilitation  
208 provider and one corporate communications representative of a professional eyecare journal and  
209 relative of a person with AMD) attended one workshop each. One provided no contributions to the  
210 focus group discussions. The low vision rehabilitation provider contributed to the Toowoomba focus  
211 group discussion, thereby providing additional data that is included in the sample and analysis.

212

213 The demographic characteristics of the participants are shown in Table 3. The Modified Monash  
214 Model (MMM) was used to classify eyecare professionals' geographical location, based on the  
215 postcode on their primary practice location [28]. All ophthalmologists practiced primarily in  
216 metropolitan regions (MM1-3). Five of 69 optometrists practiced primarily in a regional setting  
217 (MM4-5). No eyecare professionals participating in this study reported a primary place of practice  
218 located in rural or remote settings (MM6-7). Nine of 10 participating ophthalmologists worked in  
219 private practice in combination with other settings. Three ophthalmologists practiced in public  
220 hospitals and five in private day surgeries. Ophthalmologists reported providing a range of sub-

221 specialty services including medical retina and AMD care (n=8), cataract and anterior segment (n=8),  
222 general ophthalmology (n=6), vitreoretinal surgery (n=3), glaucoma (n=1), corneal and external  
223 diseases (n=1), neuro-ophthalmology (n=1), and paediatric ophthalmology (n=1). Optometrists  
224 participating in the study practiced in a broad range of types of optometry practices. Fifteen worked  
225 primarily in an independent standalone private practice, 15 worked in educational facilities, 11 were  
226 part of a private practice buying group such as EyecarePlus or ProVision, nine worked in private  
227 practice franchises such as EyeQ or Specsavers, five locumed in private practices, four worked in  
228 private practice corporations such as OPSM or Bupa, three in community health services, three in  
229 other settings, and one each in hospital and in commercial / business services.

230 **Table 3. Demographic characteristics of the eyecare professionals participating in the study.**

	Optometrists	Ophthalmologists
n	67	10
Age (years)	41.4 ± 13.2	45.3 ± 7.2
Gender (F:M)	41:26	3:7

231

232 Eyecare professionals' perspective on factors impacting AMD care identified through analysis of the  
233 transcripts were coded into barriers and enablers and to patient-centered, structural, and clinician-  
234 centered factors, primarily.

235

## 236 **Overview**

237 An overview of the semi-quantitative analysis conducted on the barriers and enablers generated  
238 during the optometry focus groups is presented initially before major factors generated from both  
239 this analysis and the qualitative analysis of the transcripts are developed. One hundred and sixty-  
240 nine barriers to AMD care were identified by the nominal group process in the seven focus groups

241 attended by 65 optometrists. The characteristics and output in terms of number of barriers  
242 generated within each focus group are detailed in Table 2 above. Of these 169 barriers, 102 were  
243 selected as one of their top 5 by at least one optometrist. These 102 barriers were further  
244 segregated into 16 category themes after iterative analysis. Fig 1 illustrates the 10 most frequently  
245 cited themes that attracted the highest scores.

246

247 **Fig 1. Optometrists' perspectives on barriers to AMD care.** The most frequently cited (primary y-  
248 axis) and highest scoring (secondary y-axis) top 10 themes (representing barriers to AMD care)  
249 generated by the 7 optometry focus groups. The y-axis on the left is associated with the bars and  
250 represents the number of optometrists that identified these themes in their top five barriers and  
251 includes the detail of how many participants ranked each theme first (white), second (black), third  
252 (vertical lines), fourth (dots), and fifth (diagonal lines). The y-axis on the right is associated with the  
253 line and represents the top 10 total score given by focus group participants, based on how important  
254 optometrists felt these were (high score = high importance).

255

256 These represent the greatest impediments to AMD care as perceived by Australian optometrists.  
257 Although a substantial number of barriers were identified, the frequency at which the top two  
258 themes *cost/funding* and *understanding/denial* were cited was much greater than for all other  
259 themes or barriers. *Understanding/denial* was selected in the top five barriers by almost all  
260 participants (64 out of 65) and *cost/funding* was selected by 54 out of 65 participants. These two  
261 themes attracted the highest total score of 184 and 185, respectively, well above the next highest  
262 scoring theme *access/availability of services* at 103 (Fig 1). *Cost/funding* and *understanding/denial*  
263 were ranked as the top barrier (attracting a score of 5) by 15 and 14 optometrists, respectively.

264

265 Although well behind, other important themes consisted of *access/availability of services* (31 votes;  
266 total score 103), *discipline silos* (33 votes; total score 72), and *lifestyle changes* (25 votes; total score  
267 68). S1 Table presents the AMD care category themes and barriers to AMD care that were selected  
268 in the top five by at least one optometrist in at least one focus group. S2 Table presents the list of 67  
269 barriers that were identified by optometrists during any one of the focus groups but were not  
270 selected during “top five barriers” ranking process for that group (note that a number of these  
271 barriers may have been ranked by alternate focus groups). Most of these 67 barriers could be  
272 segregated in the 16 category themes identified in the iterative analysis (S2 Table). Two additional  
273 category themes were identified, those being *Amsler grid* and *supplements*. Two barriers could not  
274 be categorised in any of the 18 category themes and are listed in S2 Table as miscellaneous.

275

276 Fifty-one enablers of AMD care were identified by the nominal group process in the subset of three  
277 focus groups attended by 31 optometrists. The characteristics and output in terms of number of  
278 enablers generated within each focus group are detailed in Table 2 above. Of these 51 enablers, 42  
279 were selected as one of their top 5 by at least one optometrist. These 42 enablers were further  
280 segregated into 10 category themes after iterative analysis and these are illustrated in Fig 2.

281

282 **Fig 2. Optometrists’ perspectives on enablers of AMD care.** The most frequently cited (primary y-  
283 axis) and highest scoring (secondary y-axis) top 10 themes (representing enablers of AMD care)  
284 generated by the 3 optometry focus groups. The y-axis on the left is associated with the bars and  
285 represents the number of optometrists that identified these themes in their top five enablers and  
286 includes the detail of how many participants ranked each theme first (white), second (black), third  
287 (vertical lines), fourth (dots), and fifth (diagonal lines). The y-axis on the right is associated with the  
288 line and represents the top 10 total score given by focus group participants, based on how important  
289 optometrists felt these were (high score = high importance).

290

291 These represent the greatest enablers of good AMD care as perceived by Australian optometrists.  
292 *Education* was the most frequently cited enabler, being cited by 24 of 31 participants and it  
293 attracted the highest score of 94, more than 20 points above the next highest scoring enabler.  
294 *Access* (23 votes; total score 74), *shared care model* (23 votes; total score 69), and *communication*  
295 (21 votes; total score 21) were also considered important themes. S3 Table presents the AMD care  
296 category themes and enablers to AMD care that were selected in the top five by at least one  
297 optometrist in at least one focus group. S4 Table presents the list of nine enablers that were  
298 identified by optometrists during any one of the focus groups but were not selected during “top five  
299 enablers” ranking process for that group.

300

301 Qualitative analysis allowed coding of the transcripts from the optometry focus group and individual  
302 interviews into themes as well as into barriers and enablers that were then categorised into one or  
303 more of three categories of influence: structural, clinician-centered and patient-centered (Table 1,  
304 Fig. 3). Individual themes could be coded as barrier or enabler or both. Key themes are developed  
305 and described below, with emphasis on those themes that overlapped more than one category of  
306 influence. Supporting example quotes are provided.

307

308 **Fig 3. Overview of three categories of influence in a Venn diagram: structural, patient-centered,**  
309 **and clinician-centered themes generated by the qualitative analysis and their overlap and**  
310 **relationships.** Themes were categorised into structural (yellow circle), patient-centered (blue circle),  
311 and clinician-centered (green circle) categories of influence. Those themes that overlapped more  
312 than one category of influence such as for example trust and communication were placed at the  
313 appropriate intersection of the Venn diagram. Significant relationships between themes are

314 highlighted with dotted lines. Note that any theme could be classified as a barrier, enabler, or both,  
315 depending on the eyecare professional's individual context.

316

317 **Communication and trust**

318 The themes of trust and communication sat at the intersection between the patient-centered and  
319 the clinician-centered categories of influence. Communication was considered an important enabler  
320 by eyecare professionals (Fig 2). Lack of trust was often associated with people with AMD's lack of  
321 understanding and this was perceived to be related to the complexity of the information that is  
322 given to them.

323 *"My father in law, he's suffering now, he can't be bothered going, [...] doesn't understand  
324 why he's getting his injections and he's [...] to go and see a local ophthalmology."*

325 Optometrist, FG2

326 *"I think telling people, eat more fruit and vegetables, low GI food and some nuts, it just  
327 sounds like every bit of dietary advice, and it doesn't sound special, and they've got a special  
328 eye threatening disease, and that just sounds so generic, like how can that possibly work."*

329 *There's distrust of it working and there's a feeling that they've heard it all before and it  
330 doesn't do anything."* Optometrist, FG3

331 Optometrists and ophthalmologists felt that poor communication with people with AMD could  
332 represent a significant barrier to appropriate care and that this could occur both at the primary  
333 (optometry) and secondary (ophthalmology) AMD care stage.

334 *[...] it's only going to be possible for us to manage what we're doing in public hospitals by  
335 having optometrists dealing with early stages of macular degeneration and being able to  
336 explain to the patients well and not cause them worry. I think I deal often with people who*

337           *are unnecessarily worried just because [of] the words [that] have been used [by the*  
338           *optometrist].” Ophthalmologist P54*

339           *“He [the ophthalmologist] never explained anything.” Optometrist, FG7*

340   A lack of shared decision making and communication in AMD care and poor involvement of the  
341   people with AMD in decisions regarding their care plans by eyecare professionals was also identified  
342   as a problem.

343           *“I get a lot of clients who come and say, they told me I have to do this, I don’t know why, I*  
344           *just, they told me I have to, but I don’t want to, ‘cos he said I have to! So it’s involving the*  
345           *person in that decision making for their own health and wellbeing maybe.” Optometrist, FG6*

346

## 347   **Referral pathways and models of care, perception and awareness**

### 348   **of clinical roles**

349   At the intersection of structural, clinician- and patient-centered categories of influence sits the  
350   themes related to referral pathways for AMD care and the understanding and perception of the  
351   various eyecare professionals’ roles in the care model for AMD. These were perceived by eyecare  
352   professionals as significant barriers but at the same time as key enablers to AMD care. This is  
353   perhaps a reflection of the significance of these factors, whether they are well or poorly articulated  
354   and implemented in the Australian healthcare system. A number of the themes considered distinct  
355   by optometrists participating in the focus group sessions (see Fig 1) are encompassed in this factor  
356   including *discipline silos, care pathway, and underutilisation of optometry*.

357

358 Optometrists observed that they were often underutilised and recounted incidences of missed  
359 opportunities where their profession could have helped to provide care for people with AMD, but  
360 these people with AMD were instead directed to secondary or tertiary care by their general  
361 practitioner or relatives and friends. This factor overlapped with that of the perception of the role of  
362 optometry, from the perspective of people with AMD and other healthcare professionals.

363 *“One of the things [...] is practitioner cognition of the optometry’s role which comes down to*  
364 *professional understanding issues, people are seeing their GP [general practitioner] and the*  
365 *GPs are referring to ophthalmology.”* Optometrist, FG2

366 Poor patient awareness of services and clinical roles was cited, as well as poorly developed referral  
367 pathways and models of care.

368 *“For instance, we have diabetic patients, for diabetic patients we have a diabetic plan and*  
369 *the person has control of it, and that GP goes, you need to see your optometrist or*  
370 *ophthalmologist, you need to see a nutritionist, you need to see a podiatrist, I need to see*  
371 *you back in three months, and every three months he goes over it again, and goes over it*  
372 *again, and makes sure [...] And for people with macular degeneration it is kind of like, [...]*  
373 *there is a lot of information but there is nothing that puts it all together in a proper flow*  
374 *chart for anybody to find and it’s confusing for patients.”* Optometrist, FG2

375 *“Along the side of the barriers, is, for example, if optometrists actually refer to dieticians and*  
376 *are they allowed to or do they have to go through a GP to get a referral?”* Optometrist, FG4

377 Some optometrists also felt that the scope of services offered may vary between practices and that  
378 this may impact the effectiveness of the care for people with AMD and their care pathway.

379 *“So if we’re expecting people to refer to optometrists to diagnose and manage macular*  
380 *degeneration patients, how would anyone know which optometrist is appropriate to refer to*  
381 *when you could have anything from 10 minute refraction through to the whole gamut*

382 *bordering on the level of investigation of an ophthalmologist, there's a huge scope in the way*  
383 *we practice.” Optometrist, FG2*

384

## 385 **Cost, funding and resources**

386 This factor explored the extent to which cost impacted the ability for AMD care to be delivered and  
387 received in Australia. The structural barriers, cost and inadequate funding, were cited frequently by  
388 eyecare professionals as a significant barrier to good AMD care. This was consistently expressed  
389 across the various focus groups and included cost of transport, the out of pocket consultation costs  
390 faced by people with AMD when consulting various eyecare professionals (optometrists,  
391 ophthalmologists), optometry's access to equipment (Amsler grid, optical coherence tomography,  
392 autofluorescence), the cost of ancillary tests (e.g. fundus photos, optical coherence tomography  
393 scans), the cost of accessing other types of services (e.g. dietician, counselling), and the cost of  
394 various available management and treatment strategies including dietary supplements, healthy  
395 foods, anti-VEGF injections and low vision aids, and the inadequacy of government support provided  
396 through Medicare funding and the Pharmaceuticals Benefit Scheme, and the costs associated with  
397 publicly funded versus private health insurance care.

398 *“Lack of funding for various aspects of care (e.g. counselling); patients take up lots of chair*  
399 *time but not profitable – barrier to good care.” Optometrist, FG2*

400 *“And then finally with the health system I've also talked about the time consultation with*  
401 *Medicare, you've got a full book, it's all very well to say you should counsel that person on*  
402 *quitting smoking and you should counsel that person on the size type of fish they should eat,*  
403 *and the colour vegetables that are best for them, in a 15 minute consult time, which you*  
404 *need to be able to pay your bills, you can't do it. So there is that, I guess the reimbursement*

405 *for the time that you're spending with the patient, it's inadequate. We don't get paid*  
406 *enough. It should be \$120 a visit, it's as simple as that, it's garbage.*" Optometrist, FG3  
407 "We need subsidies for low vision aids." Optometrist, FG2  
408 "Not many ophthalmologists bulk bill, in fact, hardly anybody where I am." Optometrist, FG3  
409 "If you've got dry macular disease and you want just public care then I think that's something  
410 you're not going to get because the hospitals just don't have the capacity to see those  
411 patients every twelve or twenty-four months, if there is not additional need or intervention."  
412 Ophthalmologist P60  
413 "Still poor access to autofluorescence and OCT in primary care optometry." Optometrist, FG3  
414

## 415 **Clinician's knowledge and skills, misdiagnosis**

416 Participants listed eyecare professionals' knowledge and skills and their ability to properly diagnose  
417 and treat AMD as an important clinician-centered factor. As discussed above, ophthalmologists were  
418 generally supportive of optometry's role in the care pathway but there were occasional reservations  
419 expressed regarding optometry's skills in AMD care. This intersected with the availability of  
420 specialised equipment discussed above.

421 "*I get a lot of referrals from solo practitioners who've got no cameras or any, and they seem*  
422 *to have very little knowledge or understanding about or ability to distinguish pathology at*  
423 *the back of the eye. I mean, they're relatively a minority but there's quite a lot around.*"  
424 Ophthalmologist P62

425 For ophthalmology, it was felt that the potential earnings from AMD care, particularly in the context  
426 of government supported anti-VEGF injections, may attract ophthalmologists to expand their  
427 services into this area without perhaps the necessary expertise.

428        *“I do think the lure of AMD treatments attracts many people with varying degrees of*  
429        *expertise to participate in the care of AMD patients. So look through the community, there*  
430        *are a lot of people calling themselves retinal specialists who in fact have no particular*  
431        *training in retina. So I think that, whereas in the past they have had zero interest in having*  
432        *that patient under their care.”* Ophthalmologist P56

433        *“There’s a motivator for that patient to stay in that practice, ok, intravitreal injection, you*  
434        *don’t need to be that skilled to do it, in some ways, but you do need to be very skilled in*  
435        *making a diagnosis and monitoring the patient and getting the right balance between*  
436        *treating them appropriately and not treating them. So I would say that, and I do some*  
437        *regional work as well, cost can be a barrier in regional centres where there is limited public*  
438        *hospital access and there are, you know, potentially ophthalmologists in a limited number,*  
439        *who have significant fee structures that are perhaps even higher than what would be seen in*  
440        *the city.”* Ophthalmologist P55

441        A number of optometrists also expressed some uncertainty regarding their knowledge whilst at the  
442        same time expressing a desire for more targeted education.

443        *“We hear all these professionals at conferences and whatever, most of it’s all sort of on that*  
444        *really high level, but I don’t think most of us really understand, really what we should be*  
445        *telling people [at risk or with macular degeneration]. You said yourself that only half of us*  
446        *asked whether our patients are smoking, [referring to the talk prior to focus group] you*  
447        *know, why is that? So we need kind of this simple education, this is where we what, really,*  
448        *the science is saying about supplements, this is what the science is saying about diet, this is –*  
449        *I reckon we’re all a bit confused as well out there in working land.”* Optometrist, FG6

450

## 451        **Access (geographical, availability)**

452 The structural factor *access* intersects with the referral pathways above and was perceived by  
453 eyecare professionals as both a significant barrier and an important enabler to good AMD care.  
454 Eyecare professionals expressed the view that people with AMD were often highly dependent on  
455 having the appropriate support to enable them to access the care they required. This included  
456 people in the form of families and friends but also systems such as supportive nursing home staff  
457 and adequate transport systems (e.g. bus).

458 *“So mine was more about the lack of support because older people are more dependent on  
459 their family and friends and they don’t see a doctor independently. Like the older people have  
460 given up their licences because they feel they’re not safe enough to drive or anything like  
461 that so it’s hard for them to get to these places even if we refer them to, say, Vision Australia  
462 or you refer them to other health care providers. It’s hard for them to get around when they  
463 can get access to them.”* Optometrist, FG3

464 The need for more frequent visits associated with treatments requiring regular injections (e.g. every  
465 4 to 6 weeks) was frequently cited as a specific factor that significantly complicates access to AMD  
466 care.

467 *“I think, particularly in the country, transport’s a big issue, to actually try and get to see an  
468 ophthalmologist, they’re living probably on their own and maybe riding a scooter around and  
469 they can’t get into town. They might be able to come once or twice but then for treatment,  
470 for injections and things, it’s just difficult.”* Optometrist, FG6

471

## 472 **Discussion**

473 Our findings suggest that a combination of patient (e.g. trust), clinician (e.g. models of care) and  
474 structural (e.g. health care system cost) factors present significant barriers to AMD care. Australian

475 eyecare professionals perceive that patient support systems and appropriately funded, clearer  
476 models of care would benefit people with AMD.

477

## 478 **Models of care: a role for AMD case managers?**

479 Many optometrists and ophthalmologists commented on the lack of effective AMD care  
480 coordination in the current health system. Eyecare professionals' descriptions of a unidirectional,  
481 ineffective model of AMD care aligns with previous research findings [29-31]. Previous research has  
482 suggested that the role of the optometrist in the ophthalmic care pathway often goes unrecognised,  
483 with optometrists seen differently from other healthcare professionals [32]. Many people with AMD  
484 referred for ophthalmological care do not require specialised services or ongoing treatment in a  
485 secondary or tertiary setting [31] and could benefit from better recognition and usage of primary  
486 eyecare services. The reasons underpinning this are likely complex and may be related to the public  
487 perception of the optometry profession. For example, adults surveyed in the United Kingdom  
488 believe that spectacles are overpriced, they perceive sales tactics to be dubious and that  
489 optometrists cannot be trusted to give impartial advice [32].

490 Also lacking in the AMD care pathway is a recognition of the role of support services (e.g. mobility  
491 and orientation, dietician, counselling, etc.). A very low percentage (33%) of people with AMD with  
492 visual impairment have knowledge about low-vision services and only half of those with knowledge  
493 report actually using low-vision services [33]. Focus group and interview participants in this study  
494 frequently contrasted these known findings with the perceived effectiveness of the diabetes care  
495 model in Australia, where care is supported through appropriately funded diabetic care plans,  
496 managed by general practitioners acting as case managers. Participants felt that the diabetes care  
497 model ensured better continuity, access, and timeliness of eyecare in Australia. Case management  
498 provided by workers such as nurses or community health workers have been shown to improve

499 diabetic care outcomes [34]. To the best of our knowledge, the potential effectiveness of having  
500 case managers and/or community health workers provide intensive support to people with AMD has  
501 not been formally tested. A new “fast track” referral pathways where people with wet macular  
502 degeneration are referred from the optometrist or the general practitioner directly to a specialist  
503 AMD center for triage has been advocated in the United Kingdom [35]. Should similar  
504 recommendations be adopted in Australia as well as in the United Kingdom, AMD case managers  
505 could provide effective liaison between the people with AMD and the healthcare and aged care  
506 systems. In line with evidence and the findings from this study, AMD case managers could ensure  
507 adequate and timely access to services focusing on education delivery and smoking cessation,  
508 nutrition, physical activity, orientation and mobility, low vision rehabilitation, driving support and  
509 cessation, medication and dietary supplementation adherence, appointment adherence,  
510 psychological counselling, and socioeconomic issues. In an Australian context, the low population  
511 density and cost of case managers are factors to be considered.

512

## 513 **Clinician’s skill and knowledge: accuracy of diagnosis and treatment 514 advice**

515 Clinicians’ skills and knowledge and misdiagnosis were identified as significant barriers to good AMD  
516 care in this study. In support of this, a recent cross-sectional audit study of people examined in  
517 primary eyecare practices in the United States and deemed normal revealed that approximately 25%  
518 of eyes had AMD based on fundus photography assessment by trained raters [36]. In the same  
519 study, 30% of undiagnosed eyes had AMD with large drusen that would have benefited from a  
520 recommendation to use nutritional supplements [36]. Ophthalmologists and optometrists in these  
521 primary eyecare practices were equally likely to misdiagnose AMD [36]. Between country differences  
522 may complicate this issue. In an analysis of quality of 54 rapid access referrals to a neovascular AMD

523 clinic in the United Kingdom, optometrists' ability to accurately recognise common signs of macular  
524 degeneration such as drusen and sub-retinal fluid was low at 52% and 44%, respectively [37]. The  
525 overall accuracy of optometry diagnosis was low as 63% of referrals to this clinic did not have  
526 macular degeneration [37]. Conversely, in a retrospective review of patients records and referrals for  
527 macular disease at a diagnostic imaging centre in Australia, excellent diagnostic congruency between  
528 the optometric referral and the centre was observed with 47 of 50 or 94% of cases correctly  
529 diagnosed by the referring optometrist [38]. A lack of trust between optometrists and  
530 ophthalmologists in Australia was identified as a fundamental issue to address [31]. This issue sits at  
531 the intersection between clinician's skills and knowledge and models of care, with this lack of trust  
532 likely to hinder any possible progress in enacting any new proposed models of care. In a qualitative  
533 study of a shared care model in Australia, ophthalmologists expressed reservations about the skills  
534 of optometrists [31] and this was reflected at times by opinions expressed in this study. UK  
535 healthcare professionals when asked for their perspectives on care for wet or neovascular macular  
536 degeneration also spoke about optometry competency and models of care as important factors or  
537 concerns [39]. This issue remains an ongoing impediment to progress on shared care for AMD.  
538 This study also found that there remains confusion among eyecare professionals, most particularly  
539 optometrists, about what supplements and what foods should be recommended for people with  
540 AMD. Previous data from surveys of optometrists in the UK and Australia has highlighted deficiencies  
541 in eyecare delivery in the areas of risk factor assessment, dietary supplementation advice, and  
542 diagnostic techniques.[8, 9, 40]

543

## 544 **Education**

545 Education was ranked as the top strategy to improve AMD care delivery by optometrists in this study  
546 (Fig 2). This theme included education of eyecare providers, people with AMD and the general public

547 (S3 Table) but the focus groups did not provide any insights on the potential design, feasibility and  
548 effectiveness of these educational interventions. One such example might be a clinical decision-  
549 making tool in the form of a flowchart, which was recently shown to aid qualified and student  
550 optometrists in the UK match patients to the AREDS 2 eligibility criteria [41]. The “nutrition advice  
551 for people with, or at risk of AMD” clinical decision-making tool was shown to increase practitioner  
552 confidence and lead to improved student optometrist performance on five hypothetical clinical  
553 scenarios [41].

554 Group-based health education programmes for people with AMD has previously been shown to be  
555 beneficial, notably through the provision of social support and through meeting other people with  
556 AMD [42]. Unfortunately, problems with understanding the information provided by the eyecare  
557 professionals were still experienced and reported in attendees of these health education  
558 programmes [42]. Educational interventions based on focus group findings have in the past been  
559 unsuccessful in other fields when these failed to properly consider the complexity of the  
560 recommended management and when the intervention failed to include a combination of different  
561 approaches [43]. Shaw and colleagues have unfortunately shown that patient education by  
562 optometrists in the United Kingdom was likely to be underutilised and inconsistent: very few  
563 optometrists in their study discussed glaucoma risk factors with a patient of African racial decent,  
564 even when the standardised patient asked the optometrists if she was at greater risk of any eye  
565 conditions [44]. Sustained interventions are likely to be required in order to effect long-term  
566 behaviour changes in eyecare professionals and in people with AMD. This will require significant  
567 policy commitment and dedicated resources from the Australian government.

568

569 **Communication**

570 In a survey of Macular Disease Society members in the UK, 39.2% of people with AMD were  
571 dissatisfied with their consultation [45]. The most common reasons for dissatisfaction with  
572 diagnostic consultation were poor specialist's attitudes (described as dismissive, patronising,  
573 brusque, unfeeling, uninterested, etc. - 43.5%) and lack of information about macular disease  
574 (43.4%) [45]. Over half of people with AMD indicated that they do not receive enough information  
575 about nutrition and lifestyle choices [46]. Ninety percent of participants reported having been told  
576 "nothing can be done about your macular disease" by their specialist and reported feeling anxiety /  
577 depression, resignation, shock / sick/ panic, helplessness, anger, and suicidal as a result [45]. This  
578 highlights the importance of effective communication between eyecare professionals and people  
579 with AMD. In the current study, communication and trust were placed at the intersection of patient-  
580 centered and practitioner-centered factors. Public perception of optometrist as retail  
581 businesspersons with little to no healthcare role may affect the professions' credibility and the  
582 people's trust in the perceived utility of optometrist recommendations [47].

583

## 584 **Strengths and limitations**

585 Strengths of this study include the mixed methods approach that allowed the participants to express  
586 concerns in their own words, the involvement of primary and secondary eyecare professionals, and  
587 the use of nominal group technique which allowed quantification of barriers and enablers. These  
588 strategies are known to be helpful when trying to understand complex behaviours and characterise  
589 knowledge, attitudes, and barriers of diverse stakeholder groups [23, 48, 49].

590

591 There are some potential limitations to this study. The number of ophthalmologists interviewed for  
592 this study was small and they were all from New South Wales and thus, the findings on the  
593 ophthalmology perspective are based on fewer comments and may not be representative of the

594 whole of Australia. These should be interpreted with caution as state-based factors from other  
595 Australian states may have been missed. Participants were also relatively young, in their 40s and  
596 50s, and may not be reflective of views and perspectives of older eyecare professionals. The  
597 generalisability of these findings outside of Australia is also unknown. The findings of this research  
598 may not be unique to the setting of macular degeneration or the Australian context. Selection bias  
599 may have been present in this study. Eyecare professionals who volunteered to participate in the  
600 study may have been those who have better knowledge and familiarity and a more positive attitude  
601 towards AMD care. However, the effect of this would be to underplay the barriers to AMD care. This  
602 study's findings would also benefit from cross-tabulation with the perspective of people with AMD  
603 and their carers. This research is underway and will be reported separately.

604

## 605 **Recommendations**

606 The results of these focus groups and interviews provide guidance on the kinds of intervention that  
607 can improve the appropriateness of AMD healthcare delivery in Australia. On the basis of the  
608 findings from this study, the following recommendations are made:

- 609 • Clear, effective models of care should be developed collaboratively (with the involvement of  
610 all stakeholders), tested, and adequately incentivised
- 611 • Research into the potential benefits and cost-effectiveness of public funding support of case  
612 managers for people with AMD is warranted
- 613 • Affordable, accessible transportation services for people with AMD need to be broadly  
614 available
- 615 • Appropriately designed (e.g. group-based programs, decision aids, etc.) educational  
616 interventions directed at people with AMD, ophthalmologists, and optometrists could be  
617 beneficial

618 A comprehensive approach that encompasses clinical training, research into the most  
619 appropriate models of care, followed by the dissemination of clear evidence-based referral  
620 guidelines and pathways with appropriate associated remuneration (e.g. Medicare) is required.

621

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629

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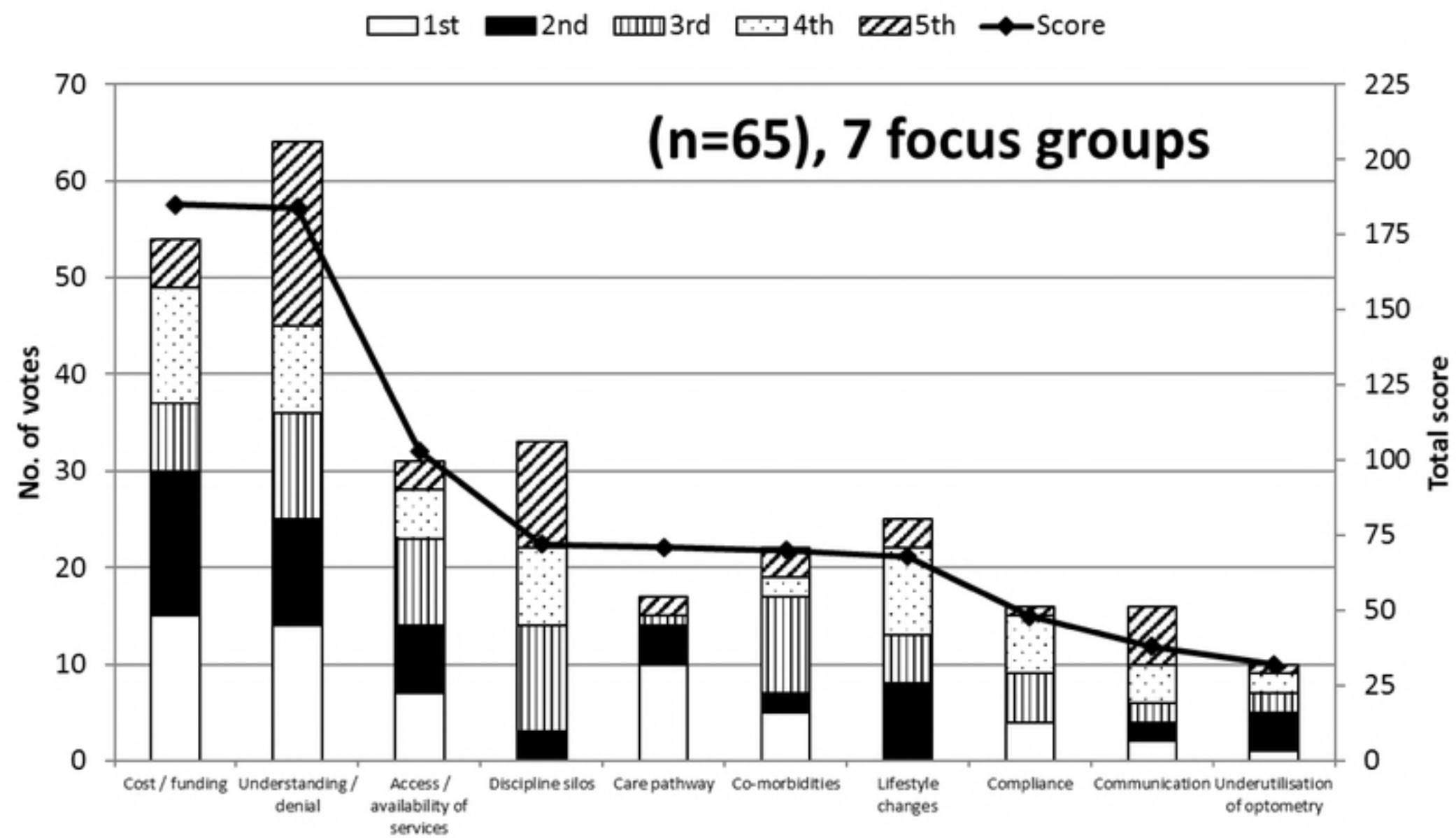


Figure 1

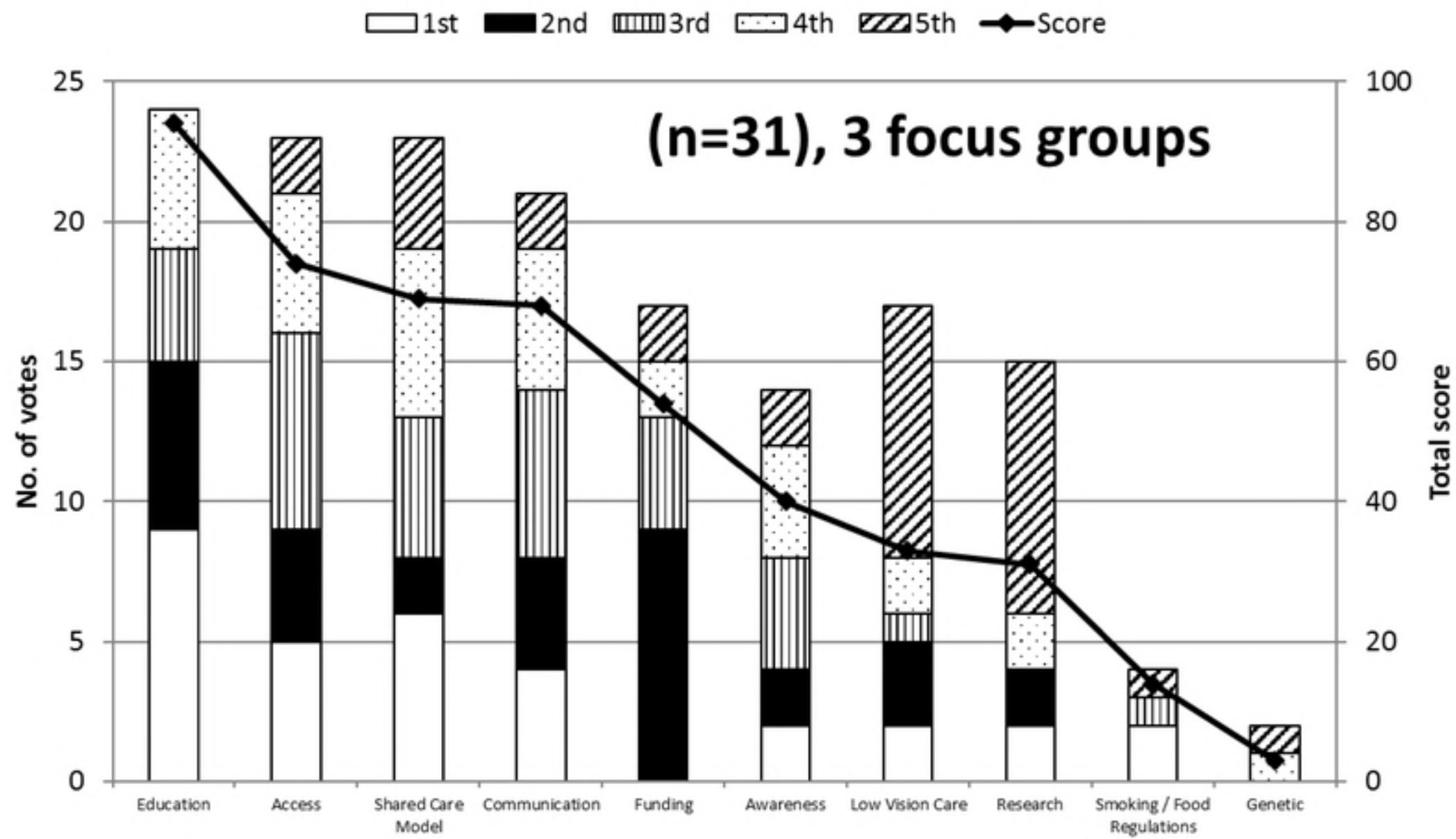


Figure 2

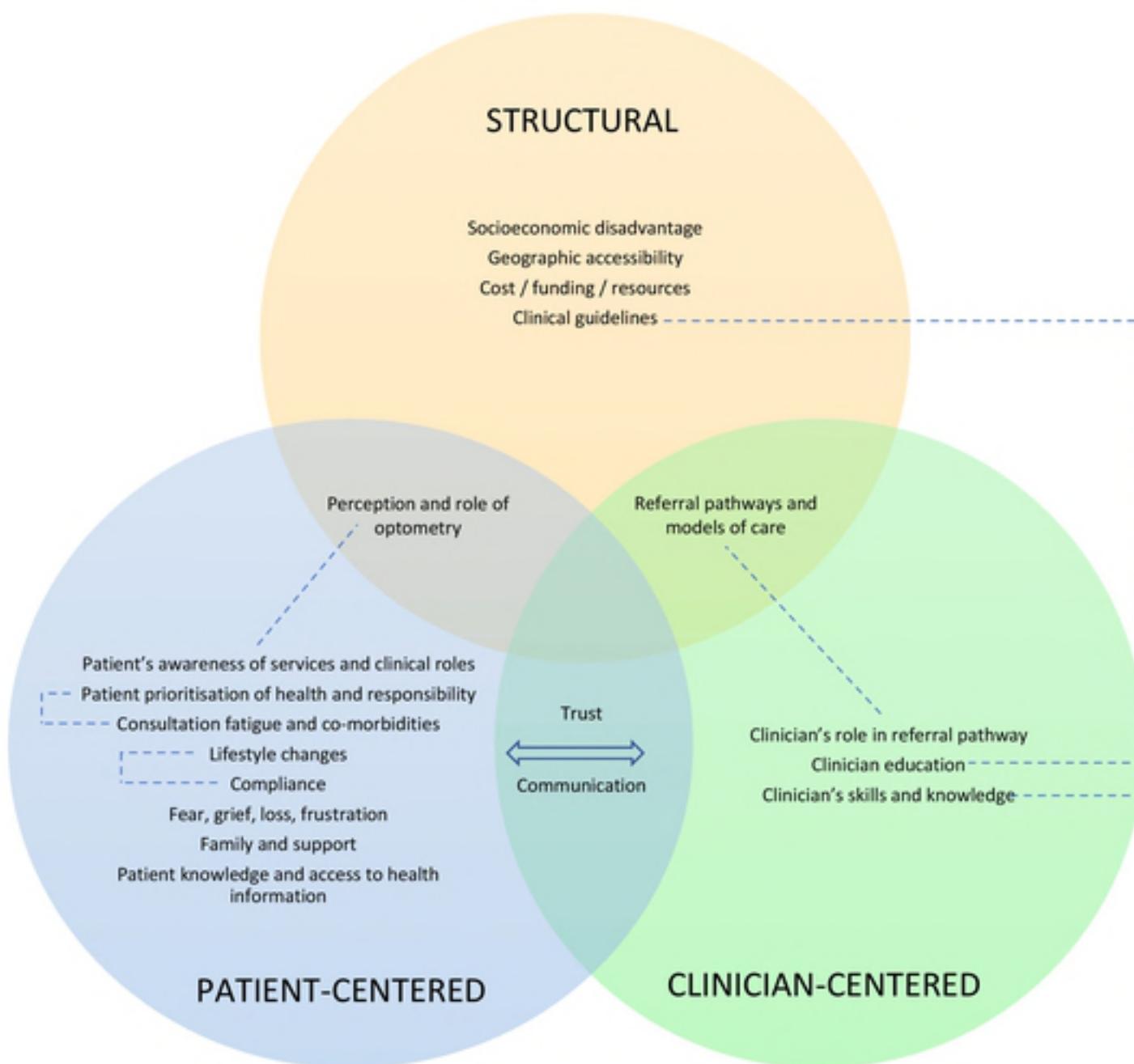


Figure 3