

## H.8 Information

### H.8.1 Barriers and facilitators to appointment attendance and update of treatment for people with age-related macular degeneration

RQ17: What are the barriers and facilitators to appointment attendance and uptake of treatment for people with AMD?

Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Sample size	% (n) reported (95%CI)	Quality
<b>Barriers to appointment attendance and uptake of treatment</b>								
<b>Burden of periodic follow-up visits (3 studies)</b>								
1 (Boulanger-Scemama 2015)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	20 lost to follow-up and no longer receiving care	15% (n=3) (5%, 36%)	VERY LOW
1 (Varano Monic 2015)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Not serious	910 treated for wet AMD	8.6% (n=78) (7%, 10.7%)	LOW
1 (Vaze 2014)	Observational study	Very serious <sup>1</sup>	N/A	Serious <sup>3</sup>	Not serious	248 began anti-VEGF treatment	0.8% (n=2) (0.2%, 2.9%)	VERY LOW
<b>Travel problem (4 studies)</b>								
1 (Boulanger-Scemama 2015)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	58 lost to follow-up	51.7% (n=30) (39.2%, 64.1%)	VERY LOW
1 (Droege 2013)	Observational study	Very serious <sup>1</sup>	N/A	Serious <sup>3</sup>	Serious <sup>2</sup>	19 stopped visits and interviewed	26.3% (n=5) (11.8%, 48.8%)	VERY LOW
1 (Nunes 2010)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	19 answered phone questionnaire	5.3% (n=1) (0.9%, 24.6%)	VERY LOW
1 (Vaze 2014)	Observational study	Very serious <sup>1</sup>	N/A	Serious <sup>3</sup>	Not serious	248 began anti-VEGF treatment	10.9%(n=27) (7.6%, 15.2%)	VERY LOW
<b>Comorbidities (5 studies)</b>								
1 (Boulanger-	Observational	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	58 lost to follow-	1.7% (n=1)	VERY LOW

Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Sample size	% (n) reported (95%CI)	Quality
Scemama 2015)	study					up	(0.3%, 9.1%)	
1 (Droege 2013)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	19 stopped visits and interviewed	15.8% (n=3) (5.5%, 37.6%)	VERY LOW
1 (Nunes 2010)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	19 answered phone questionnaire	15.8% (n=3) (5.5%, 37.6%)	VERY LOW
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	102 failed to reschedule a missed or patient-cancelled appointment within 1 month of the desired follow-up date	23.5% (n=24) (16.3%, 32.6%)	LOW
1 (Vaze A 2014)	Observational study	Very serious <sup>1</sup>	Not serious	Serious <sup>3</sup>	Not serious	248 began anti-VEGF	4.4% (n=11) (2.5%, 7.8%)	VERY LOW
<b>Treatment related emotion (pain/discomfort/fear/dissatisfaction with treatment benefit) (4 studies)</b>								
1 (Boulanger-Scemama 2015)	Observational study	Very serious <sup>1</sup>	Not serious	Not serious	Serious <sup>2</sup>	20 lost to follow-up and no longer receiving care	50% (n=10) (29.9%, 70.1%)	VERY LOW
1 (Droege 2013)	Observational study	Very serious <sup>1</sup>	Not serious	Not serious	Serious <sup>2</sup>	19 stopped visits and interviewed	36.8% (n=7) (19.1%, 59.0%)	VERY LOW
1 (Varano 2015)	Observational study	Very serious <sup>1</sup>	Not serious	Not serious	Not serious	910 treated for wet AMD	3.0% (n=27) (2.0%, 4.3%)	LOW
1 (Vaze A 2014)	Observational study	Very serious <sup>1</sup>	Not serious	Serious <sup>3</sup>	Not serious	248 began anti-VEGF	1.2% (n=3) (0.4%, 3.5%)	VERY LOW
<b>Lack of information (2 studies)</b>								
1 (Mitchell 2002)	Observational study	Serious <sup>1</sup>	Not serious	Serious <sup>5</sup>	Not serious	604 completed and answered	43.4% (n=262) (39.5%, 47.4%)	LOW

Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Sample size	% (n) reported (95%CI)	Quality
1 (Nunes 2010)	Observational study	Very serious <sup>1</sup>	Not Serious	Not serious	Serious <sup>2</sup>	the question 19 answered phone questionnaire	26.3% (n=5) (11.8%, 48.8%)	VERY LOW
<b>Specialist's attitudes (dismissive, patronising, brusque, unfeeling, uninterested in patients, using jargon) (1 study)</b>								
1 (Mitchell 2002)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>5</sup>	Not serious	604 completed and answered the question	43.5%(n=263) (39.6%, 47.5%)	LOW
<b>Poor visual results (2 studies)</b>								
1 (Nunes 2010)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	19 answered phone questionnaire	42.1%(n=8) (23.1%, 63.7%)	VERY LOW
1 (Vaze 2014)	Observational study	Very serious <sup>1</sup>	N/A	Serious <sup>3</sup>	Not serious	248 began anti-VEGF	2.4% (n=6) (1.1%, 5.2%)	VERY LOW
<b>Difficulty in re-scheduling (2 studies)</b>								
1 (Nunes 2010)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	19 answered phone questionnaire	10.5% (n=2) (2.9%, 31.3%)	VERY LOW
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	102 failed to reschedule a missed or patient-cancelled appointment within 1 month of the desired follow-up date	37.3% (n=38) (28.5%, 46.9%)	LOW
<b>Carer cannot take the patient to the appointment (2 studies)</b>								
1 (Varano 2015)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Not serious	910 treated for wet AMD	23.5% (n=214) (20.9%, 26.4%)	LOW

Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Sample size	% (n) reported (95%CI)	Quality
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	102 failed to reschedule a missed or patient-cancelled appointment within 1 month of the desired follow-up date	21.6% (n=22) (14.7%, 30.5%)	LOW
<b>Financial burden (4 studies)</b>								
1 (Boulanger-Scemama 2015)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Serious <sup>2</sup>	58 lost to follow-up	8.6% (n=5) (3.7%, 18.6%)	VERY LOW
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	102 failed to reschedule a missed or patient-cancelled appointment within 1 month of the desired follow-up date	25.5% (n=26) (18.0%, 34.7%)	LOW
1 (Varano 2015)	Observational study	Very serious <sup>1</sup>	N/A	Not serious	Not serious	910 treated for wet AMD	5.0% (n=45) (3.7%, 6.5%)	LOW
1 (Vaze 2014)	Observational study	Very serious <sup>1</sup>	N/A	Serious <sup>3</sup>	Not serious	248 began anti-VEGF	0.8% (n=2) (0.2%, 2.9%)	VERY LOW
<b>Long wait time (1 study)</b>								
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	102 failed to reschedule a missed or patient-cancelled appointment within 1 month of the desired	52.0% (n=53) (42.3%, 61.4%)	LOW

Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Sample size	% (n) reported (95%CI)	Quality
						follow-up date		
<b>Facilitators to appointment attendance and uptake of treatment (1 study)</b>								
<b>Pre-appointment reminder (by phone, text, email)</b>								
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	240 participants answered the question	81.7% (n=153) (70.6%, 93.9%)	LOW
<b>Parking vouchers</b>								
1 study (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	240 participants answered the question	47.9% (n=115) (41.7%, 54.2%)	LOW
<b>Transportation service to and from the clinic</b>								
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	240 participants answered the question	44.6% (n=107) (38.4%, 50.9%)	LOW
<b>Mobile eye care van</b>								
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	240 participants answered the question	32.1% (n=77) (26.5%, 38.2%)	LOW
<b>Networking with other patients with the same eye diseases</b>								
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	240 participants answered the question	41.3% (n=99) (35.2%, 47.5%)	LOW
<b>More education on eye disease/the importance of follow-up</b>								
1 (Thompson 2015)	Observational study	Serious <sup>1</sup>	N/A	Serious <sup>4</sup>	Not serious	240 participants answered the question	70.8% (n=170) (64.8, 76.2%)	LOW
1. Downgraded one level for study design; downgraded two levels for retrospective design; 2. Downgraded one level for wide 95%CI; 3. Downgraded one level for patients were from a single institute (i.e. practice, clinic) ;								

## Macular Degeneration

### Appendix H: Grade tables and meta-analysis results

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Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Sample size	% (n) reported (95%CI)	Quality
4. Downgraded one level for 86 of a total of 240 participants had AMD;								
5. Downgraded one level for participants were member of macular society and not all had AMD								

## CERQual tables

Review finding	Contributing studies	Confidence in the evidence	Explanation of confidence in the evidence assessment
<b>Barriers to appointment attendance and uptake of treatment</b>			
<b>Patients' psychological issues (anxiety, fear and distressing)</b>			
Patients may decline treatment due to emotion such as anxiety, fear and distressing. Patients described these emotions, when they prepared for treatment, or were relative newness of the treatment, or experienced disease progression.	Burton Amy E, Shaw Rachel, and Gibson Jonathan. 2013. British Journal of Visual Impairment 31:178-188 McCloud C, et al. 2014	Moderate confidence	This review finding is rated as moderate, because there are two studies with minor to moderate methodological limitations (one only had 7 participants who were volunteers; one recruited participants through a nonprobability, convenience sampling). Minor concern about coherence. Fairly adequate and relevant data from one UK and Australian study.
<b>Communication with healthcare professionals</b>			
Patients described a sense of confusion when having to interact with a variety of healthcare professionals during their treatments and commented on problems with hospital appointment letters which gave little information about what each appointment was for and what the participant should expect plus many struggled to read letters. A wide variety of information deficits after diagnosis was evident. A lack of knowledge about the purpose of medical processes and procedures was highlighted. Patients were unsure about when their treatment cycle and there were examples of patients attempting to make their own judgement about the need for treatment.	Burton Amy E, Shaw Rachel, and Gibson Jonathan. 2013. British Journal of Visual Impairment 31:178-188 Burton A E, Shaw R L, and Gibson J M. 2013. BMJ Open	Moderate confidence	This review finding is rated as moderate, because there are two studies with minor to moderate methodological limitations (one only had 7 participants who were volunteers; one recruited participants through a nonprobability, convenience sampling). Minor concern about coherence. Fairly adequate and relevant data from one UK and Australian study.
<b>The nature of treatment/treatment regimen</b>			
The invasiveness of the treatment and often painful recovery were significant issues for patients. The physical difficulties participants experienced with frequent and on-going treatment were often	McCloud C, et al. 2014	Low confidence	This review finding is rated as low, because there is one study with minor to moderate methodological limitations (participants were recruited through a nonprobability,

Review finding	Contributing studies	Confidence in the evidence	Explanation of confidence in the evidence assessment
compounded by anxiety and fear.			convenience sampling). Coherence could not be assessed as only 1 study. Adequate data with minor concern about relevance.
<b>Facilitators to appointment attendance and uptake of treatment</b>			
<b>Knowledge and treatment experience</b>			
Patients felt treatments were not as distressing as originally feared at their later appointments. They shared their treatment experiences with others, helping to ease concerns and reduce unnecessary distress.	Burton Amy E, Shaw Rachel, and Gibson Jonathan. 2013. British Journal of Visual Impairment 31:178-188	Moderate confidence	This review finding is rated as moderate, because there is a study with moderate methodological limitations (only had 7 participants who were volunteers). Coherence could not be assessed as only 1 study. High relevance with fairly adequate data from the study in the UK.
<b>Regular monitoring</b>			
Patients expressed a desire for regular monitoring by healthcare professionals. It seemed that traditional view of healthcare professionals prevailed and therefore knowing that they were under the care of the hospital gave a sense of security.  Patients highlighted the need to self-advocate; they were expected to identify advancing vision loss and seek appropriate support as and when it was necessary.	Burton A E, Shaw R L, and Gibson J M. 2013. BMJ Open	Moderate confidence	This review finding is rated as moderate, because there is one study with minor methodological limitations (13 participants). Coherence could not be assessed as only 1 study. High relevance with fairly adequate data from the study in the UK
<b>Relationship with healthcare providers</b>			
Some patients described building relationship with healthcare professionals (i.e. nurses) as a way to manage the distress treatment caused.  Patients preferred appointments that exemplified balanced relationships, mutual respect, and professional friendship and that left them feeling empowered about decisions they could make regarding treatment and management of their	Burton Amy E, Shaw Rachel, and Gibson Jonathan. 2013. British Journal of Visual Impairment 31:178-188	Moderate confidence	This review finding is rated as moderate, because there is a study with moderate methodological limitations (only had 7 participants who were volunteers). Coherence could not be assessed as only 1 study. High relevance with fairly adequate data from the study in the UK.

Review finding	Contributing studies	Confidence in the evidence	Explanation of confidence in the evidence assessment
condition.			
<b>Treatment outcome (vision acuity)</b>			
Patients expressed a clear willingness to endure their treatments if they continued to gain or maintain their vision.	McCloud C, et al. 2014	Low confidence	This review finding is rated as low, because there is one study with minor to moderate methodological limitations (participants were recruited through a nonprobability, convenience sampling). Coherence could not be assessed as only 1 study. Adequate data with minor concern about relevance.