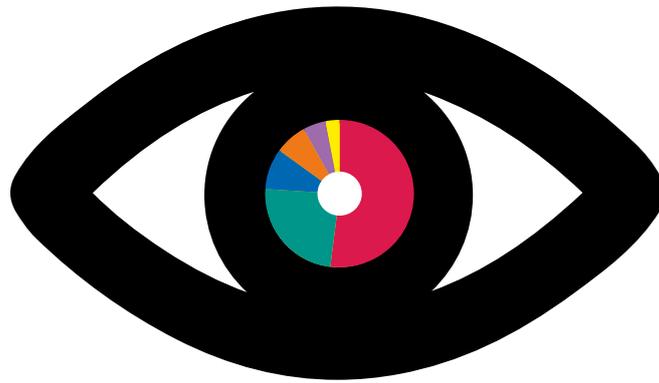


# Macular Society

Beating Macular Disease



## Understanding patients' perceptions of wet AMD treatment in 2020

September 2020

**Thank you to all those who took time to complete this survey.**  
Thanks to you we are better able to understand the effect anti-VEGF injections have on patients. Thank you also to Professor Clare Bradley and Professor Sobha Sivaprasad for their comments on the survey and report.

## **Introduction**

From March-June 2020 the Macular Society conducted a survey into the impact of anti-vascular endothelial growth factor (anti-VEGF) treatments for those with wet age-related macular degeneration (AMD). Anti-VEGF injections in the eye are the only treatment recommended by the National Institute for Health and Care Excellence (NICE) [1] for those with wet AMD, a condition where the over growth of blood vessels in the macula and leakage of fluid causes central vision loss.

AMD is the leading cause of vision loss in the developed world, and can cause permanent sight loss. There are two main types of AMD - wet and dry, and currently only wet AMD can be treated.

Those with wet AMD are recommended to undergo regular intravitreal (eye) injections every 1-2 months. Due to the large number of those with wet AMD, this can leave hospital ophthalmology clinics overcrowded, overworked and overbooked.

A new treatment for wet AMD, Beovu (brolucizumab), is currently being assessed by NICE for its clinical and cost effectiveness and it is hoped that it will be available to NHS patients in England soon. The Scottish Medicines Consortium have recently announced they have approved it to be used by NHS in Scotland. Patients receiving Beovu may only require injections every 3 months. This will help reduce the burden of injections for both patients and clinics.

The recent survey described in this report aims to improve understanding of patients' perceptions and experiences with the current wet AMD treatment and frequent intravitreal injections.

## **Methods**

The survey was largely conducted online using surveymonkey.com. However, we also used our network of regional managers based all over the UK to capture the views of those without internet access. This enabled some surveys to be completed over the phone and helped ensure results were representative of the population of people with wet AMD.

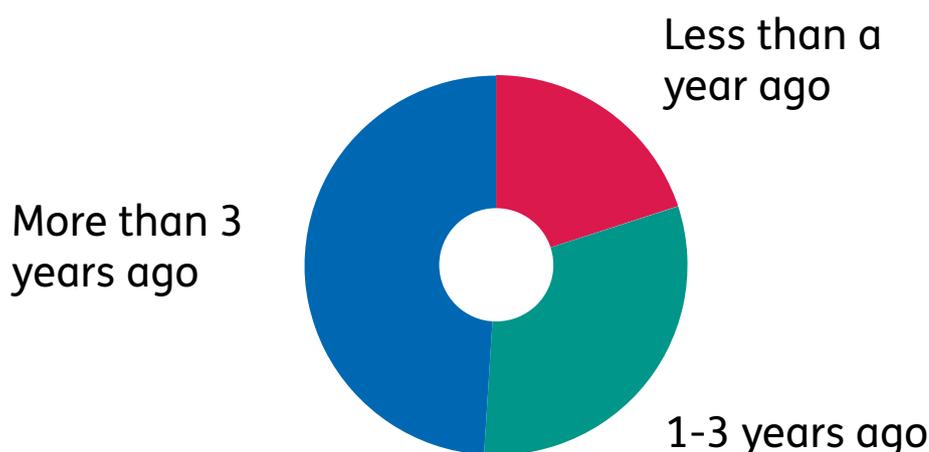
The survey was promoted online through the Macular Society's social media accounts and through the regular Macular Society e-newsletter, which has around 30,000 subscribers. Regional Managers also helped promote the survey through group teleconferences. The survey was designed in order to be as accessible as possible to those with macular conditions or sight impairment. The survey was tested with the help of colleagues to ensure its compatibility with screen readers and magnifying software. Contact information was also provided to allow patients to call the Macular Society to complete the survey over the phone and to answer any questions.

## Results

496 people took part in the survey, of those 456 were currently receiving treatment for wet AMD. 40 were not currently receiving treatment for wet AMD and their results were not included in the analysis.

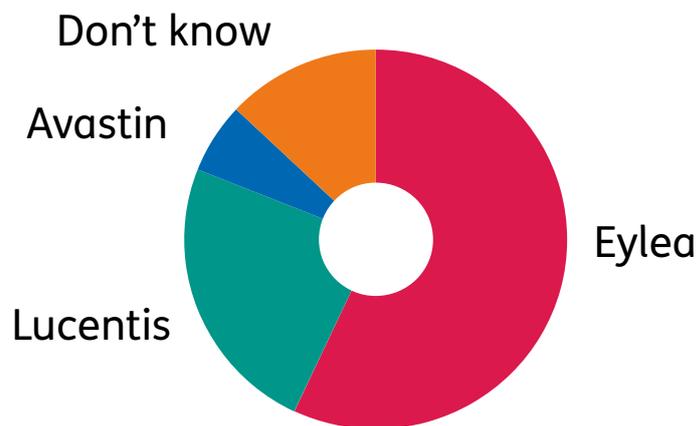
Of the 456 responses, 425 were from the online survey, which was promoted widely on the Macular Society e-newsletter and social media. The remaining 31 were from telephone interviews conducted by our team of regional managers.

### When did you start receiving injections for your AMD?



Nearly half (49.5%) the responders had been having injections for more than three years, and therefore had had many experiences at the eye clinic and many injections. 30.8% of the participants had been having injections for 1-3 years, the remaining 19.8% had been having injections for less than a year.

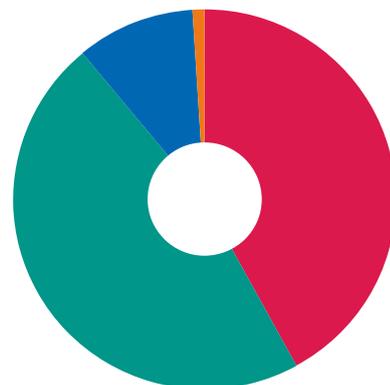
### What drug are you currently receiving?



There are two main drugs used to treat wet AMD in the UK, these are Eylea (aflibercept) and Lucentis (ranibizumab). Avastin (bevacizumab) may also be used however, it is currently unlicensed for use to treat wet AMD. It has been shown to be equally as safe and effective as Eylea and Lucentis [2]. 61.3% said that they were currently being treated with Eylea, 21.5% were receiving Lucentis, 12% did not know what drug they were receiving and 5.3% were receiving Avastin.

### How often do you currently go to the hospital for either your injections or a checkup related to your AMD?

-  About every month
-  About every 2 months
-  About every 3 months
-  Less often than every 3 months

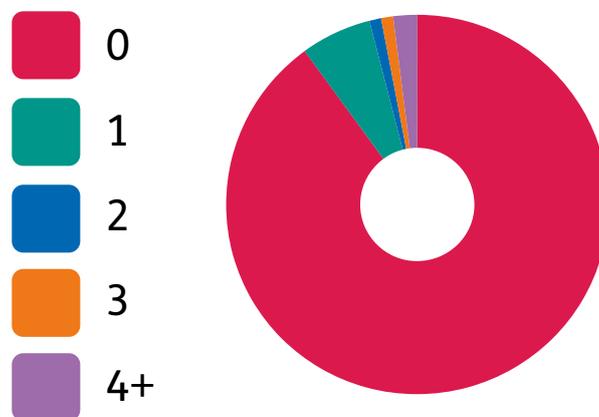


The majority of those who took part in the survey were receiving injections every 1-2 months, with 41.2% receiving injections every month and 46.5% every 2 months. This is similar to the current guidance for Eylea and Lucentis, which states that they should be given every 4-8 weeks. Although with treat and extend regimes, this can be extended for some patients. More than 10% of those who took part in the survey were receiving injections every 3 months or more, however this may not be frequent enough to maintain vision.

***“Constant worry to get appointments doctor requires, I have to telephone every time as no appointments come and then usually go a week or more longer than should be because all appointments are gone.”***

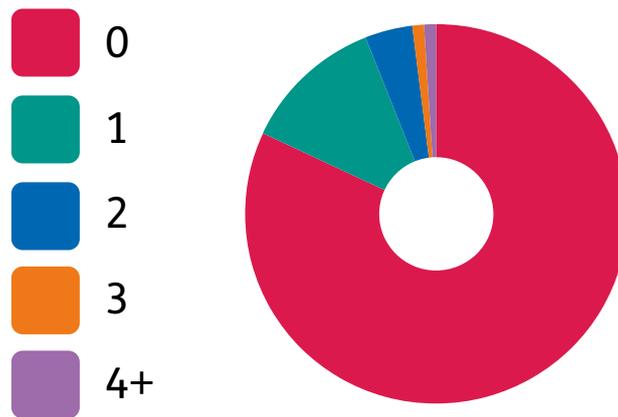
***“I worry when the expected appointments do not come on time, maybe as much as 4 months’ gap.”***

**In the last year how many eye clinic appointments were you unable to attend?**



90.4% of responders attended every eye clinic appointment. Of the 9.6% who missed appointments 51.2% said it was due to health issues, which may have affected their ability to attend the clinic, or meant that they were unable to receive an injection. Other reasons included having a spouse in hospital, confusion with dates in the diary and one person saying they had a fear of going to hospital due to COVID-19.

## In the last year how many eye clinic appointments have been cancelled by the hospital?

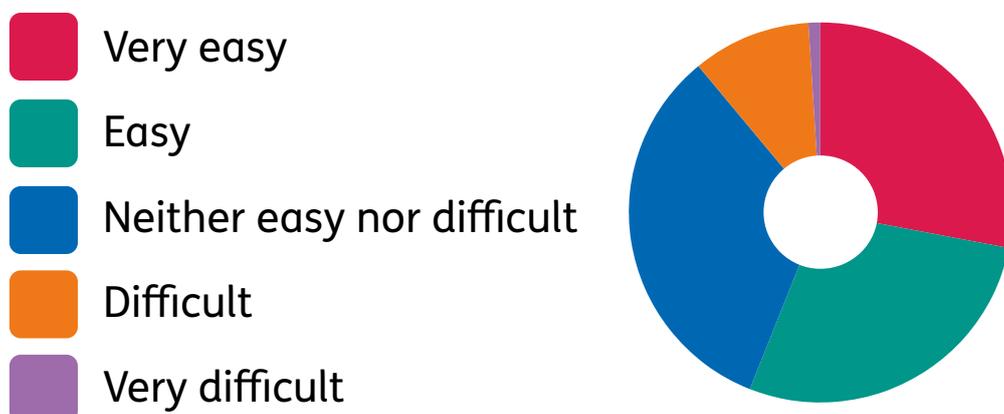


17.5% had at least one appointment cancelled by the hospital within the last year, with 5.8% having multiple appointments cancelled by the hospital. When these appointments are cancelled, some have a difficult time getting a new appointment and this can lead to patients waiting longer than advised for an injection.

***“Chaos, where you never know if you will be cancelled or treated. It’s a lottery.”***

***“I continually struggle with being accepted for an injection on each occasion due to ongoing and persistent blepharitis”*** (inflammation of the eyelid).

## How easy or difficult do you find it to attend all your appointments?

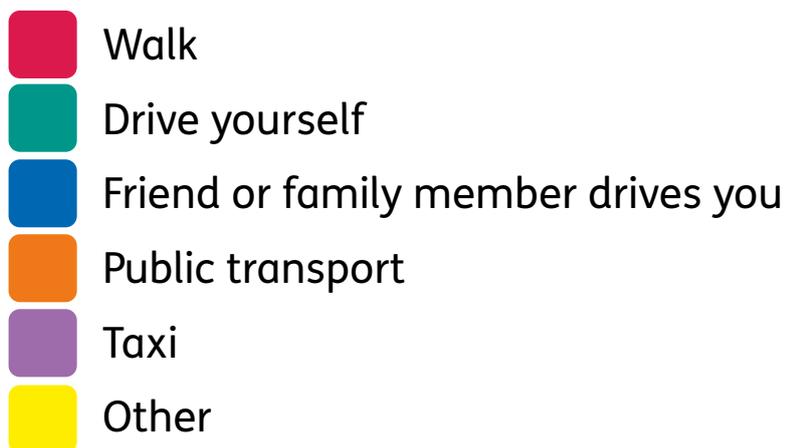


56.6% find it easy or very easy to attend all the appointments needed for their AMD, with only 10.7% finding it hard or very hard to attend all appointments. Responses from patients often indicated that the benefit to their eyesight and the reassurance they get from having injections and check-ups mean that they find these appointments worth any difficulty attending the clinic.

***“One stop shop is brilliantly run and a lot more efficient than previously. Attended this morning and in and out in 30 minutes.”***

***“I find the clinic I attend excellent. Sometimes they are short staffed but they work very hard to keep everything under control.”***

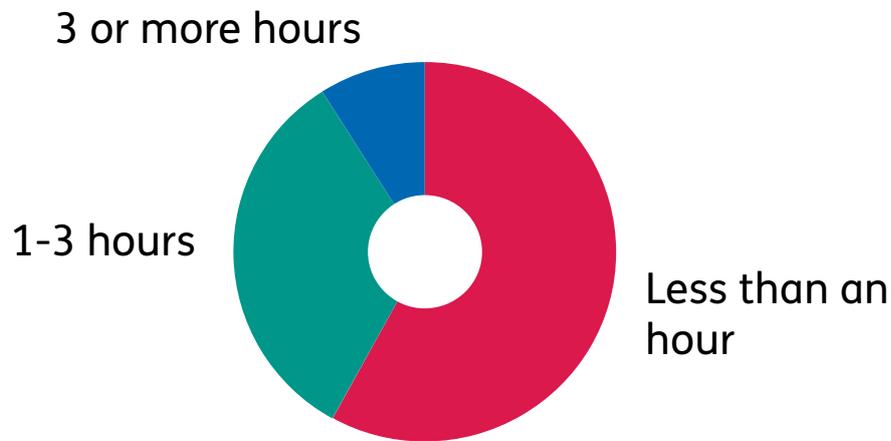
### How do you usually travel to your appointments?



61.6% of patients rely on friends or family to take them to and from eye clinic appointments. This can mean that their loved ones have to take time out of work or cancel commitments to ensure that they can help. This can cause strain when eye clinics are far away or waiting times in the clinic are particularly long.

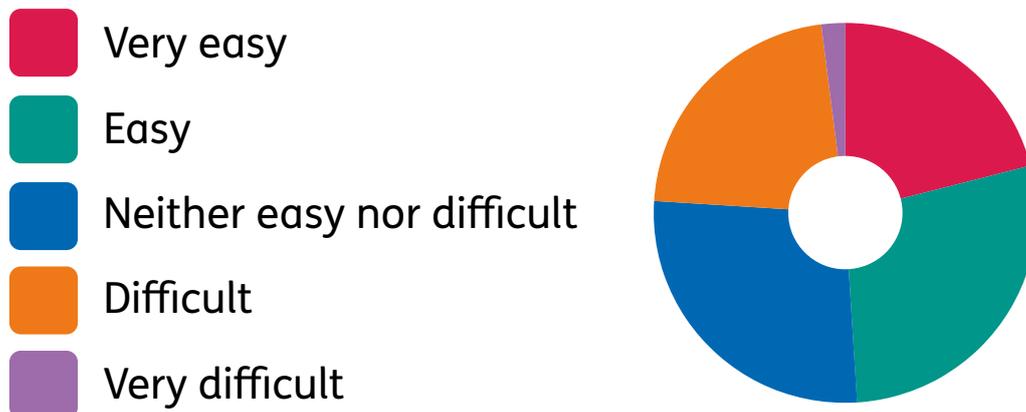
***“Every month my husband has an unpaid day off from work to take me to the eye clinic for injections.”***

**If you receive assistance from a friend or family member to attend the eye clinic, how many hours of the day of the appointment do they spend helping you?**



58.0% of responders said they require their friends or family to spend 1-3 hours helping them attend the clinic. 32.5% spend 3 or more hours helping attend eye clinics.

**If you travel to your eye clinic appointments by public transport, how do you find your journey?**



28.1% rely on public transport to get to and from appointments. However, during the injection process eye drops are given which dilate the iris and can lead to blurred vision. This may cause difficulty for patients who have to rely on seeing the bus number and gesturing to the bus driver to stop.

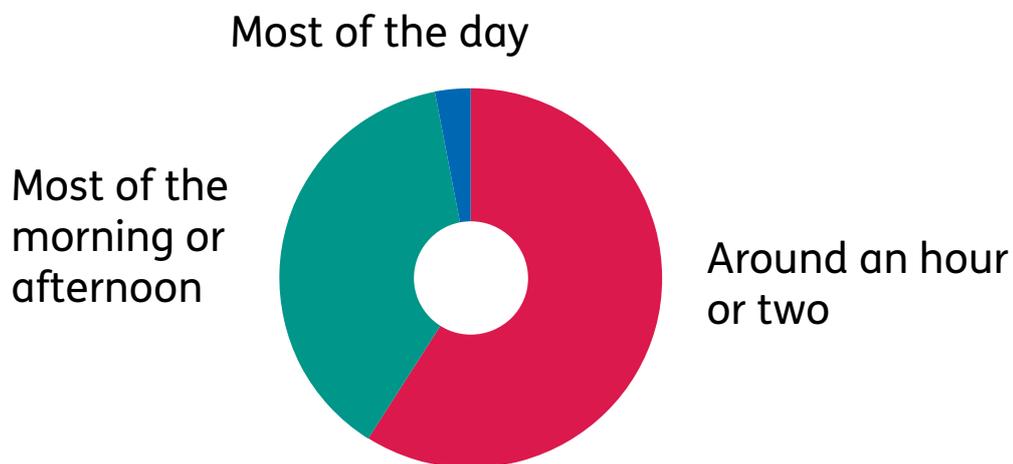
**“I can no longer drive and this has made a huge difference to my life as I have no family in the country. I live in a semi-rural area some distance from friends, local transport is not very good and taxis are being expensive and not very convenient.”**

**“My poor vision means we are likely to need to sell our house in the country and move to one closer to public transport and other amenities.”**

49.0% of those who travelled by public transport to their eye clinic appointments found their journey to be easy or very easy, while 23.8% found it to be difficult or very difficult. Some participants talked about having to spend hours on the bus, or having to make multiple changes due to no direct routes to the hospital.

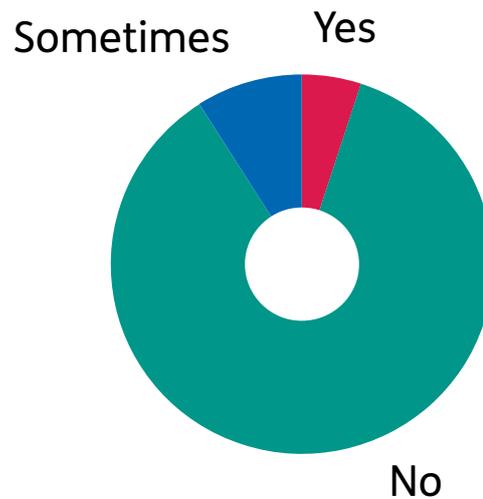
**“I can end up waiting 3 hours for a bus”**

### **On the day of the eye clinic appointment how much time does the hospital visit take?**



59.3% responders said that the hospital visit only takes an hour or two out of their day, while 27.7% said it can take most of the morning or afternoon. This may not include the time taken to get to and from the appointments, which can often be very time consuming for patients.

## Before the eye clinic appointments do you worry about the financial cost of attending?



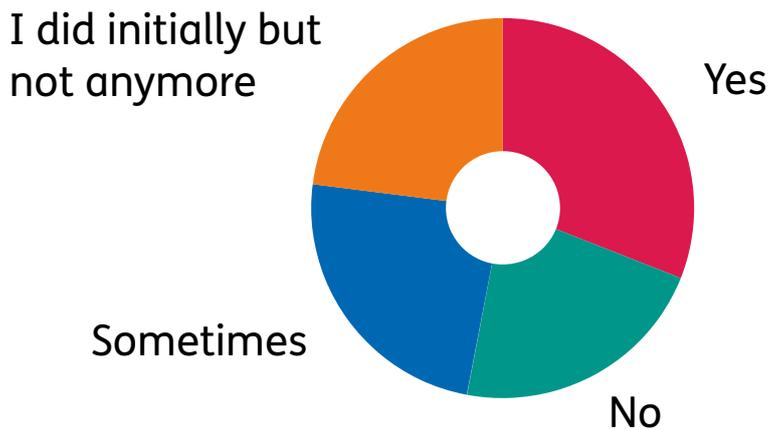
Some responses referred to having to pay privately due to needing urgent appointments or having eyesight outside the NICE guidelines for treatment [1]. In these cases, costs can be very high, however, for the majority of respondents (86.2%), due to being treated through the NHS, the financial costs were small with notable exceptions.

***“If we use a taxi it costs £100 each way.”***

***“I go to a private clinic and the cost is about £6,000 a year. At present I can afford this but will have problems if the cost or frequency of injections increases.”***

***“Had to pay privately for first three injections after a bleed, needed urgent injections and the NHS could only offer appointment in 4-5 weeks.”***

## Do you feel anxious about your injection treatment?



54.9% of patients say they do, or sometimes do feel anxious about the injections. With another 22.6% saying that they initially felt anxious but do not anymore. It is common for people starting intravitreal injections to be anxious or scared of pain or discomfort. However, in many cases this will diminish over time and after a few injections. Some respondents referred to an increase in anxiety and fear after complications due to the injections, and in some cases they experienced increased pain or light sensitivity.

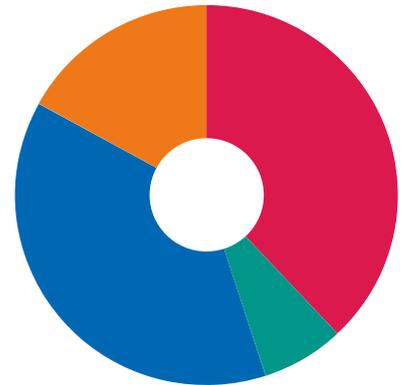
***“I have just been for my injection, had a scan and told the injections aren’t working. I’m going to have another appointment in 3 months before they sign me off. I am a bit worried what will happen then. Who I could get help off to cope.”***

***“I worry about the future and each visit I worry about losing more of my vision.”***

***“Blinded in right eye with infection due to injections. Now all injections are terrifying.”***

## Which of these following statements is most important to you?

- Keeping the same level of vision with fewer injections
- Keeping the same level of vision with fewer appointments
- Having the injection and monitoring (check-up) in the same appointment
- Having a confirmed date for your next appointment before you leave the clinic



38.4% would rather have fewer injections while keeping the same level of vision. 37.7% would prefer to have the injection and check up in the same appointment.

***“I have a round trip of over 50 miles, so it is important that we have treatment and monitoring at the same appointment – it is also only one lot of worry!”***

***“I would like a one stop shop. Have the scan, see the consultant, if needed have the injections. Not have the scan, see the consultant and wait for an appointment for the injections.”***

There are currently two different injection regimes clinicians use to treat wet AMD, pro re nata (PRN or ‘as needed’) and treat and extend (T&E). With the PRN regime, patients go in for the check-ups and clinicians then decide whether they need another injection. This can mean some patients have separate monitoring and injection appointments as it can take time to assess scans and decide whether injections are needed. With treat and extend, at every appointment there are check-ups and injections, so patients are receiving an injection at each appointment. At the end of the appointment, the clinician may decide whether to maintain the time between injections, extend it or reduce it depending on the scans and test results.

The final question in the survey “Is there anything you would like to add about how your AMD treatment has impacted you or those who help you?” gave respondents the opportunity to mention anything about their condition or treatment that they would like to add or to go into further detail about their answers to previous questions.

The responses fell into the main categories of:

Grateful and thankful for there being a treatment and the NHS

***“I have nothing but profound gratitude for my treatment and the NHS ... they’re wonderful!”***

***“Very thankful for excellent ongoing untiring service of the NHS of 9½ years of injections in both eyes.”***

Loss of independence due to vision loss

***“I have had to give up my career due to not being able to promise to meet deadlines. I have had to give up driving and as I live in a rural area this poses problems.”***

Anxiety and stress of injections, and hospital services

***“A great deal of stress is caused to us by the hospital’s inability to fix appointments for when the consultant requires the injections to be carried out.”***

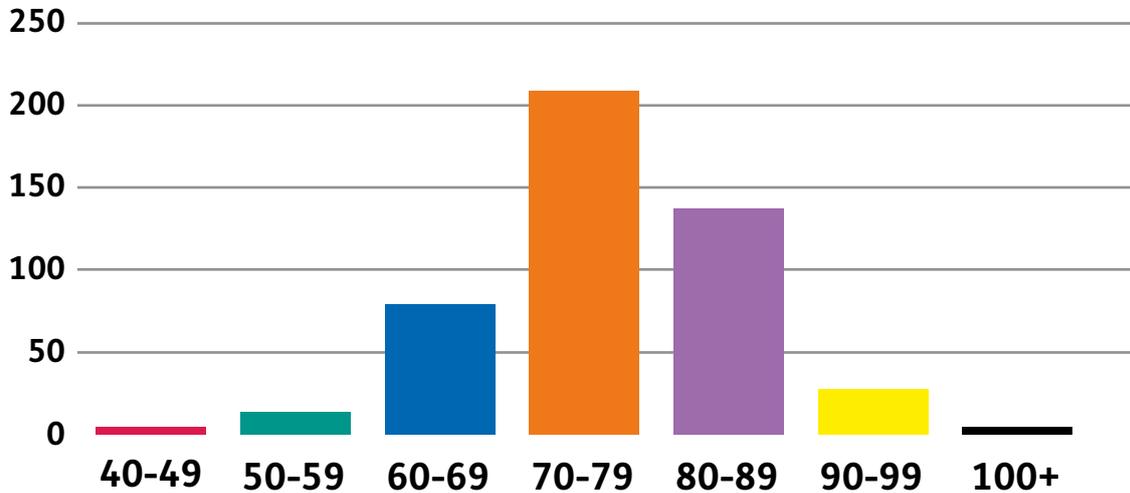
***“Being unable to see clearly following the injection which makes me feel vulnerable”***

Inconvenience of frequent injections

***“My daughters both live a distance from me so a whole day is needed ... for every appointment. So this impacts considerably on family life for them as well as me.”***

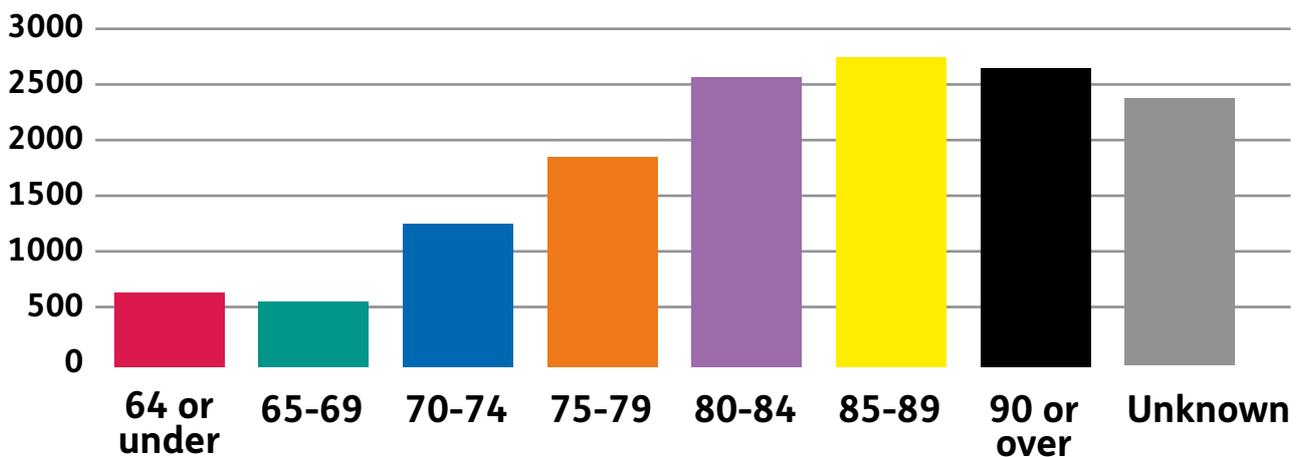
At the end of the survey we asked about age and location of the respondents, this was to ensure our results were representative of the wet AMD population.

### What is your age?



Of those who took part in the survey 46.3% were aged 70-79, 29.5% were 80-89 and 16.3% were 60-69. Very few respondents were 40-49 (0.4%), 50-59 (2.4%), 90-99 (4.9%) and over 100 (0.2%). This differs from the age distribution of the members of the Macular Society (below).

### Members by age



We believe the difference in age distribution between our survey respondents and the Society membership is due to the survey largely being conducted and promoted through online platforms, such as social media and the e-newsletter. As well as on-line, this survey was intended to be conducted through paper surveys distributed at local groups. However, on 10 March, due to the rise in cases of COVID-19, the Macular Society suspended all face-to-face local support groups to ensure the health and safety of our members and volunteers. Before this, we had planned to fully utilise the local groups and regional managers to ensure representation both in terms of age and location.

Despite the change in circumstances, we still believe that through the online survey we have adequate coverage of the whole of the UK as this data is similar and representative of the distribution of our members. There is a possibility that a small number of those who responded may have been from outside of the UK, despite stating in the introduction that it was a UK only survey. 48 responses did not include a postcode, with another 13 saying they lived abroad or providing a non-UK postcode. It is unlikely that such a few number of responses from non-UK residents would impact the results of the survey.

<b>Region</b>	<b>Number</b>	<b>Percentage of responses to the survey from each area (%)</b>	<b>Percentage of Members in each area (%)</b>
England	335	87.2	87.1
Scotland	25	6.5	7.2
Northern Ireland	6	1.6	1.4
Wales	18	4.7	4.3
<b>Total</b>	<b>384</b>		

## **Implications of COVID-19**

This survey was conducted during the coronavirus pandemic, but started before lockdown measures had begun, and hospitals brought in safety precautions to protect staff and patients. Results such as the number of hospital appointment cancellations and anxiety due to injection appointments may therefore have been affected by fears related to COVID-19. However, 79% (395) of the responses were received before full lockdown measures began on 23 March.

To investigate if there was any effect on the responses due to the pandemic we have analysed the data from responses before and after the Macular Society announced the suspension of all face-to-face local group meetings (11 March). We analysed questions relating to patients missing and the hospital cancelling appointments, as well as anxiety patients feel due to injections. We found no large differences in results before or after 11 March. Comparison of the results can be found in the Appendix.

COVID-19 has greatly affected the way ophthalmology clinics are now run. Anti-VEGF injections continued throughout lockdown as they were considered necessary to preserve sight but routine appointments were cancelled. Changes were needed to ensure the safety of those who attended clinics, who are largely considered to be in the 'clinically vulnerable' group due to their age, visual impairment, and possible other health conditions. In the UK, changes that were made to the eye clinics included patients waiting in cars or outside of the clinic to avoid crowding of the waiting room; only allowing one visitor to attend the appointment with them, and having to wait outside; increased PPE for the hospital staff and visitors and fewer tests before the injections.

## **Discussion**

It has been documented that often the treatment regimen used in clinical trials differs from that which can be maintained in routine clinics [3]. This can mean that the benefit seen in clinical trials may not always be translated to the real world. Clinics may not be able to ensure 4-8 week injection appointments for patients, or patients may delay, miss

or stop treatment. It has also been shown that increased time between diagnosis and treatment due to busy clinics and long waiting lists can negatively affect patients' vision and visual improvement after anti-VEGF treatment [3].

Fear and anxiety due to intravitreal anti-VEGF injections is common, especially at the beginning of treatment. Research has looked into the reasons why patients have anxiety, and ways to reduce it. Studies have shown that initially the fear is largely due to the fear of the discomfort of the injection, and worries about becoming blind if the treatment does not work [4]. However, 54.9% of responders always or sometimes feel anxious before injections compared to 22.6% who initially felt anxious but no longer do. This goes against the belief that over time patients are likely to become less anxious after multiple injections once they know what to expect [4].

Many responses mentioned continued fear of injections, due to either discomfort or fear after complications, therefore, with less frequent injections these patients would experience less anxiety. However, it may be that although some respondents have less anxiety than at the start of treatment, they still have some level of anxiety and ticked the 'yes' or 'sometimes' response as they felt this was the most accurate response. It is difficult to state how much anxiety decreased from the beginning of treatment, instead only whether patients currently have anxiety due to injections.

While the survey shows an accurate representation of people with wet AMD in terms of age and wide range of location, the responses are likely to be limited to our members or those who sign up to our e-newsletter. It is likely that many wet AMD patients who may have not heard of the Macular Society and those who do not have access or who do not wish to engage with the charity are not represented. Our members largely have some form of macular condition and are very interested and eager for cures and treatments for macular disease. Our members and those who responded may also be more proactive with their treatment, thus ensuring that they get treatment within the 4-8 week time frame and meaning they may be less likely to miss appointments [5].

Our survey showed that 88% of the participants were able to attend hospital appointments every 1-2 months and 90% attended every appointment scheduled for them. In addition, 83% did not have any appointments cancelled, highlighting that on average, the AMD services are providing a satisfactory service and most patients with wet AMD are able to keep to the intensive monitoring and treatment schedule. However, approximately 62% of the participants are reliant on friends and families for assistance with attending their hospital appointment. Although duration of hospital appointments vary, on average, about 90% of them needed more than an hour of assistance and 41% had to spend at least half a day for their hospital visit. Therefore, even though patients and healthcare providers are trying their best, the associated burden of these treatments is high. Through new advances in wet AMD treatment allowing for longer intervals between treatments, we hope that some of the burden for both patients and clinicians will be reduced.

## References

- [1] National Institute for Health and Care Excellence, “Age-related macular degeneration: NICE guideline,” NICE, London, 2018.
- [2] L. Moja, E. Lucenteforte, K. H. Kwang, V. Bertele, A. Campomori, U. Chakravarthy, R. D’Amico, K. Dickersin, L. Kodjikian, K. Lindsley, Y. Loke, M. Maguire, D. F. Martin, A. Mugelli, B. Muhlbauer, I. Puntmann, B. Reeves, C. Rogers, C. Schmucker, M. L. Subramanian and G. Virgili, “Systemic safety of bevacizumab versus ranibizumab for neovascular age-related macular degeneration,” *Cochrane Database of Systematic Reviews*, 2014.
- [3] J. Monés, R. P. Singh, F. Bandello, E. Souied, X. Liu and R. Gale, “Undertreatment of Neovascular Age-Related Macular Degeneration after 10 Years of Anti-Vascular Endothelial Growth Factor Therapy in the Real World: The Need for A Change in Mindset,” *Ophthalmologica*, pp. 1-8, 2020.
- [4] J. Boyle, M. Vukicevic, K. Koklanis, C. Itsiopoulos and G. Rees, “Experiences of patients undergoing repeated intravitreal

anti-vascular endothelial growth factor injections for neovascular age-related macular degeneration,” *Psychology, Health & Medicine*, vol. 23, pp. 1-21, 2017.

- [5] A. Parfitt, E. Boxell, W. Amoaku and C. Bradley, “Patient-reported reasons for delay in diagnosis of age-related macular degeneration: a national survey,” *BMJ Ophthalmology*, London, 2019.

## **Appendix**

### **Survey**

**Q1: Are you currently receiving regular treatment injections for your wet age-related macular degeneration? (required)**

- Yes
- No

**Q2: When did you start receiving injections for your AMD?**

- Less than a year ago
- 1-3 years ago
- More than 3 years ago

**Q3: What drug are you currently receiving?**

- Eylea
- Lucentis
- Avastin
- Don't know

**Q4: How often do you currently go to the hospital for either your injections or a check-up related to your AMD?**

- About every month
- About every 2 months
- About every 3 months
- Less often than every 3 months

**Q5: In the last year how many eye clinic appointments were you unable to attend?**

- 1
- 2
- 3
- 4+

**Q6: If so, why were you unable to attend? (tick all that apply)**

- Health issues
- Travel issues
- Financial issues
- Lack of support or carer to help you attend
- Other (please specify)

**Q7: In the last year how many eye clinic appointments have been cancelled by the hospital?**

- 0
- 1
- 2
- 3
- 4+

**Q8: How easy or difficult do you find it to attend all the appointments required for your AMD?**

- Very easy
- Easy
- Neither easy nor difficult
- Difficult
- Very difficult

**Q9: How do you usually travel to your appointments (tick all that apply)**

- Walk
- Drive yourself
- Friend or family member drives you
- Public transport
- Taxi
- Other

**Q10: If you receive assistance from a friend or family member to attend the eye clinic, how many hours of the day of the appointment do they spend helping you?**

- Less than an hour
- 1-3 hours
- 3 or more hours

**Q11: If you travel to your eye clinic appointments by public transport, how do you find your journey?**

- Very easy
- Easy
- Neither easy nor difficult
- Difficult
- Very difficult
- I don't use public transport

**Q12: On the day of the eye clinic appointments how much time does the hospital visit take?**

- Around an hour or two
- Most of the morning or afternoon
- Most of the day

**Q13: Before the eye clinic appointments do you worry about the financial cost of attending?**

- Yes
- No
- Sometimes

**Q14: Do you feel anxious about your injection treatment?**

- Yes
- No
- Sometimes
- I did initially but not anymore

**Q15: Which of these statements is most important to you?**

- Keeping the same level of vision with fewer injections
- Keeping the same level of vision with fewer appointments
- Having the injection and monitoring (check-up) in the same appointment
- Having a confirmed date for your next injection before you leave the clinic

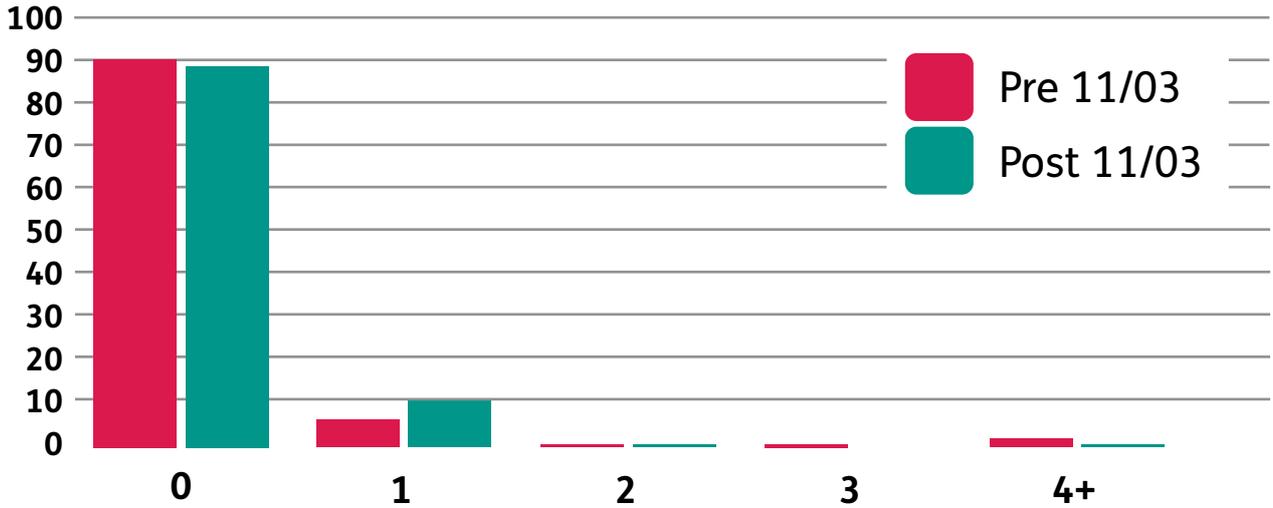
**Q16: What is the first half of your postcode (e.g. RG27)**

**Q17: What is your age?**

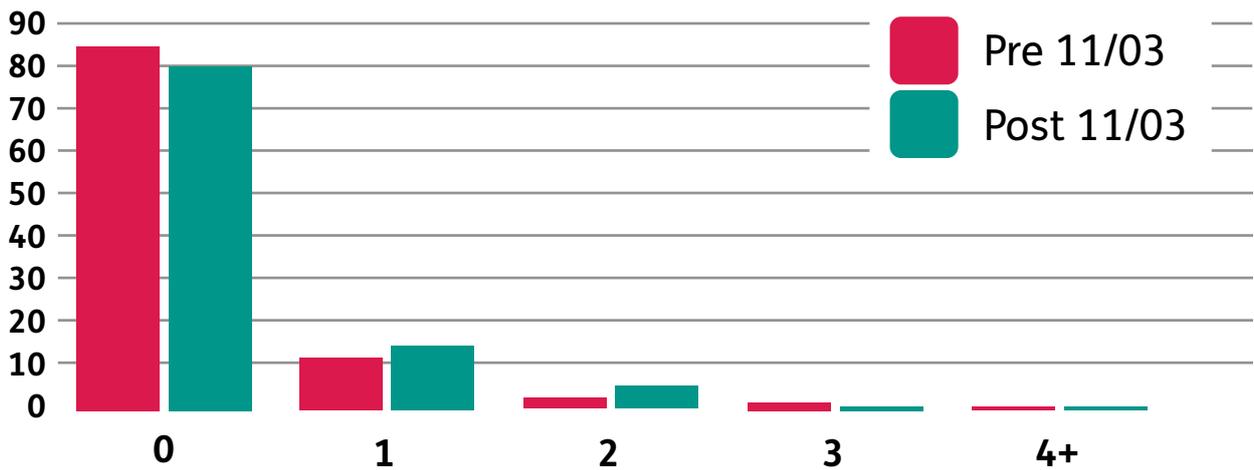
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90-99
- 100+

**Q18: Is there anything you would like to add about how your AMD treatment has impacted you or those who help you?**

### In the last year how many eye clinic appointments were you unable to attend? (%)



### In the last year how many eye clinic appointments have been cancelled by the hospital? (%)



### Do you feel anxious about your injection treatment? (%)

