

## Understanding patients' perception of anti-VEGF treatment

Thank you to all those who took time to complete this survey.

With thanks to Bayer for supporting this research. As per our policy, they have no influence over the report's content.



## Background

Ophthalmology is now the busiest department in the NHS, with 8,898,379 attendances in 2023-2024<sup>1</sup>. This is in part due to the large number of patients requiring regular anti-VEGF injections. Anti-VEGF (Vascular Endothelial Growth Factor) injections can help maintain the vision of patients with wet age-related macular degeneration (AMD), diabetic macular oedema (DMO), retinal vein occlusion (RVO), myopic macular degeneration (MMD) and more. For these conditions, anti-VEGF therapy alleviates symptoms through the prevention of new vessel formation and associated fluid leakage into the retina. These injections, into the eye, are typically required for many months or years on a regular basis.

From 23rd September to 23rd December 2024 the Macular Society conducted a survey to better understand perceptions of anti-VEGF treatment. The survey eligibility criteria were any person currently receiving a form of anti-VEGF treatment, or who had received treatment in the last 5 years in the UK. Exclusion criteria were those outside of the UK or who have never received anti-VEGF injections.

In the last few years there have been several new anti-VEGF drugs approved as well as the introduction of biosimilars as a result of off-patent biologics. In addition, the range of treatment regimes that patients may be on have also expanded. We aimed to better understand these regimes and how they are communicated to patients.

## Methodology

The survey was developed through discussions with the team at the Macular Society and a consultant ophthalmologist. The Macular Society have previously produced surveys relating to treatments for wet AMD, and DMO patients, in 2020 and 2021 respectively. Therefore, the intention was not to reproduce the same survey, but learn more about other aspects of patient's care.

The survey was conducted through [surveymonkey.com](https://www.surveymonkey.com), a survey platform used due to compliance with accessibility standards and screen reader compatibility. The survey was open from 23 September to 23

<sup>1</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-outpatient-activity/2023-24> accessed 25/03/2025

December 2024. The survey was publicised on the Macular Society's website and November e-newsletter which is subscribed to by many people who have experience living with macular disease or those supporting them.

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. The survey was not condition specific, as there are many macular conditions that may require anti-VEGF injections.

## Results

896 participants responded to the survey, with a 91% completion rate. 64 responses were from outside of the UK and were excluded from analysis. 6 responses were also excluded as they had never received anti-VEGF treatment. Therefore, a total of 827 responses were analysed in the report.

## Demographics

	<b>Number</b>	<b>Percentage</b>
<b>Age</b>		
Under 45	18	2.2
45-54	71	8.6
55-64	225	27.3
65-74	415	50.3
75-84	90	10.9
Over 85	6	0.7
<b>Condition</b>		
Wet Age-related Macular Degeneration	684	82.7
Myopic Macular Degeneration	30	3.6
Retinal Vein Occlusion	38	4.6
Diabetic Macular Oedema	29	3.5
Other	46	5.6
Currently receiving injections	678	82
Received injections in last 5 years	149	18

## Condition

The majority (83%) of participants had wet AMD, 3.6% had MMD, 4.6% had RVO, 3.5% DMO and remaining 5.6% had another condition.

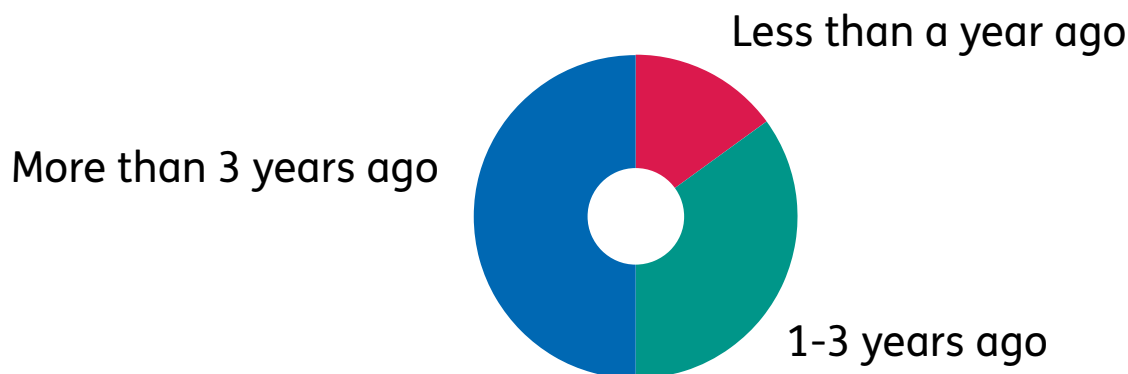
50% of participants were aged 75-85, 27% were aged 65- 74, 11% over 85 and 0.7% were under 45.

82% of responders are currently receiving treatment and 18% have received treatment in the last 5 years.

## Currently Receiving Treatment

Almost half (49.8) of participants who currently receive injections have been receiving injections for more than 3 years. 24.6% for 1-3 years and 15.6% for less than a year.

## When did you start receiving anti-VEGF injections for your macular disease?



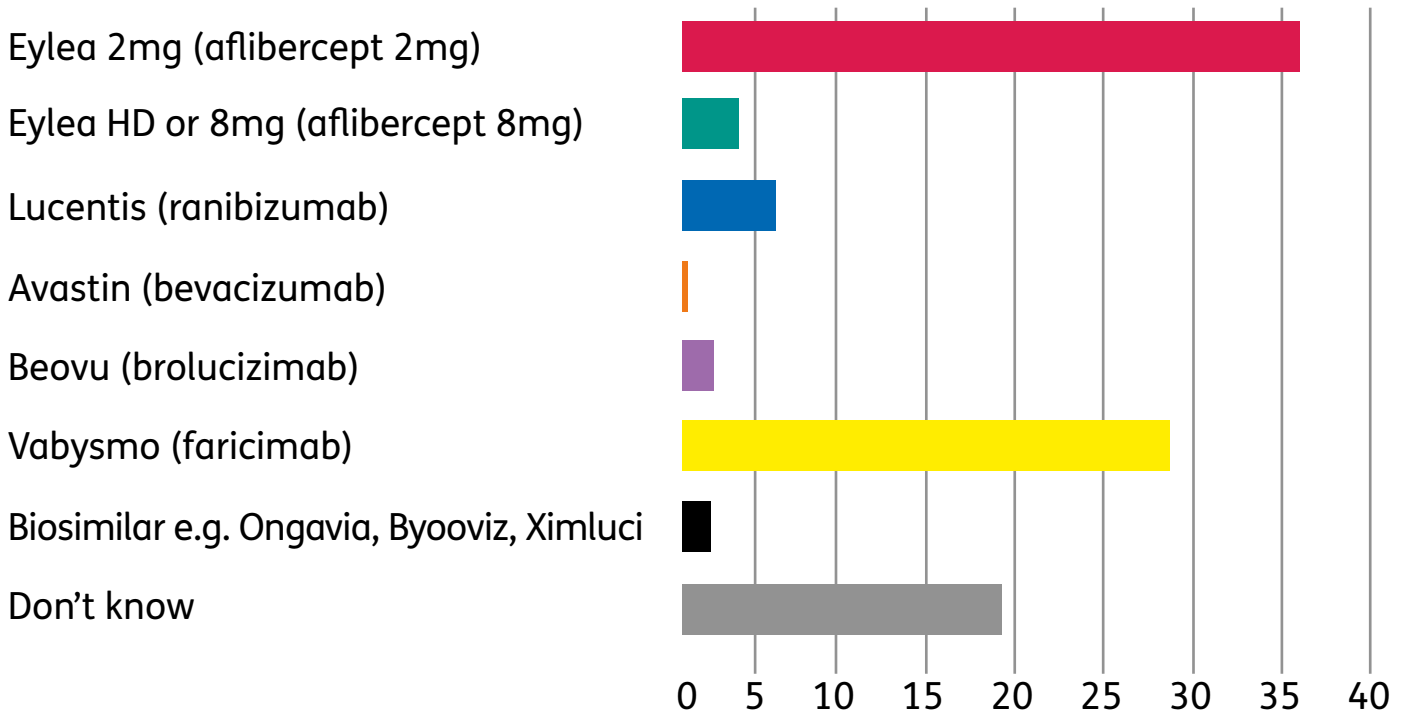
## What drug are you currently receiving?

The most reported treatments were Eylea (37%) and Vabysmo (27.8%). 19% do not know what drug they are receiving.

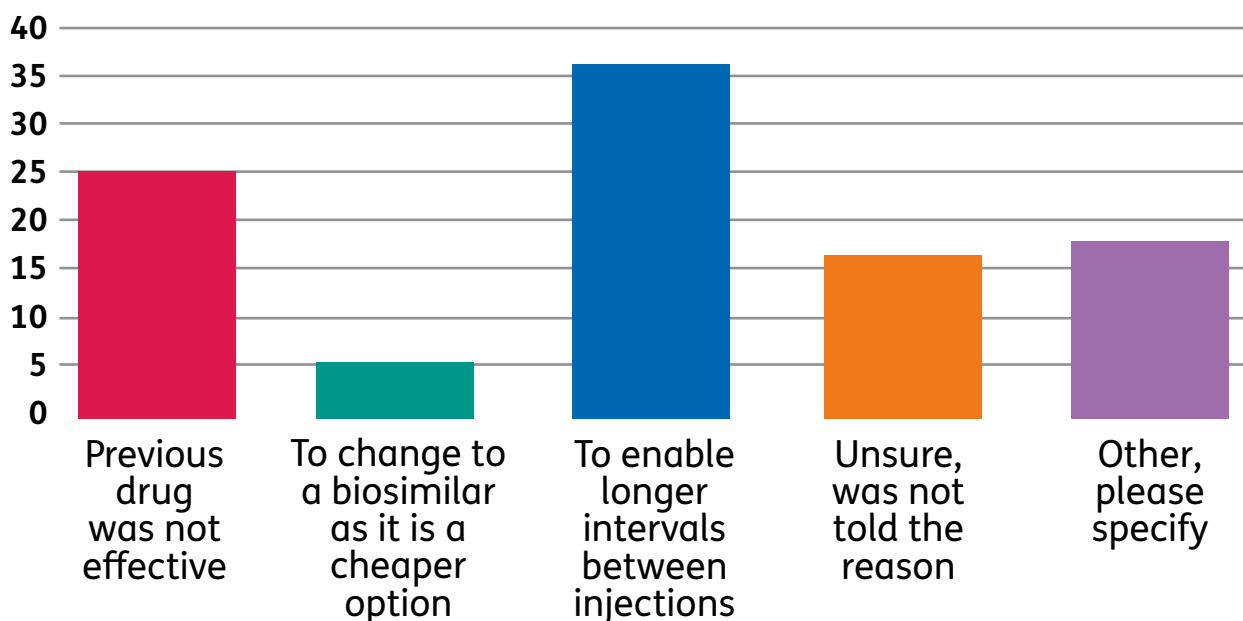
Nearly 50% of participants had been on more than one anti-VEGF therapy.

The most common reason for switching was to allow longer time between injections (36%) and as the previous drug was not effective (25%). 16% were not told the reason.

## What drug are you currently receiving?

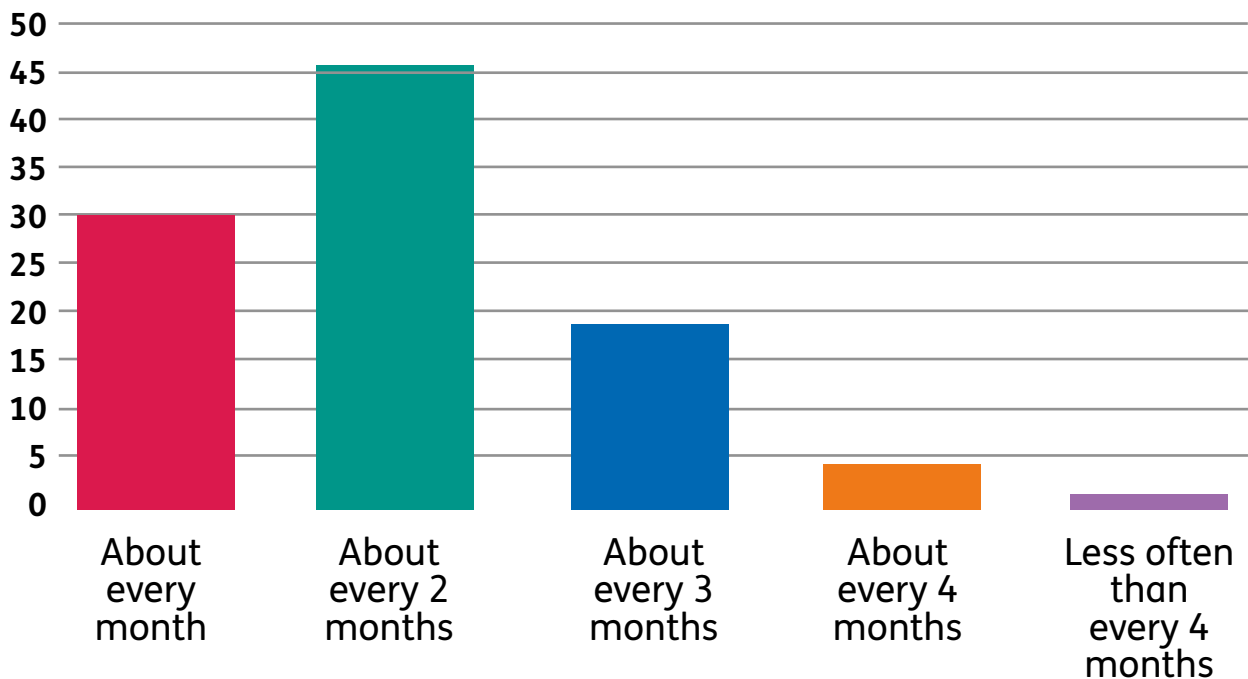


## If you have been on different drugs, do you know the reason why you were switched?

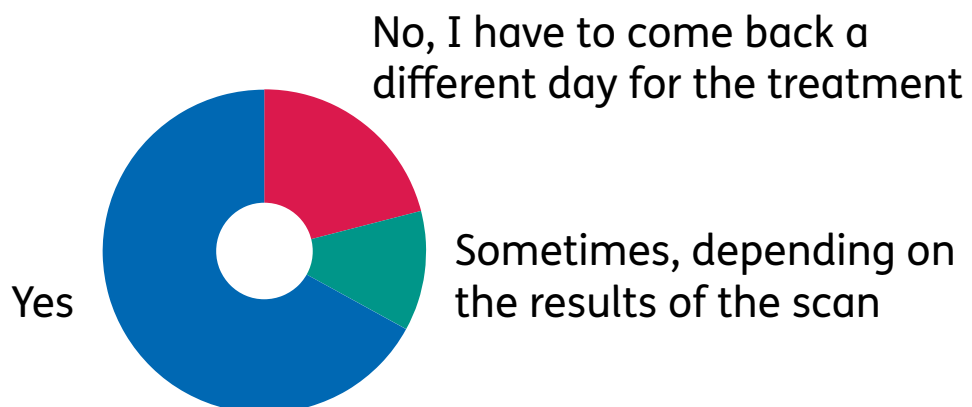


45% attend the eye clinic every 2 months. Two thirds of participants have injection and assessment on the same day. The majority (73%) of those who have injections in both eyes, have treatment in both eyes at the same appointment.

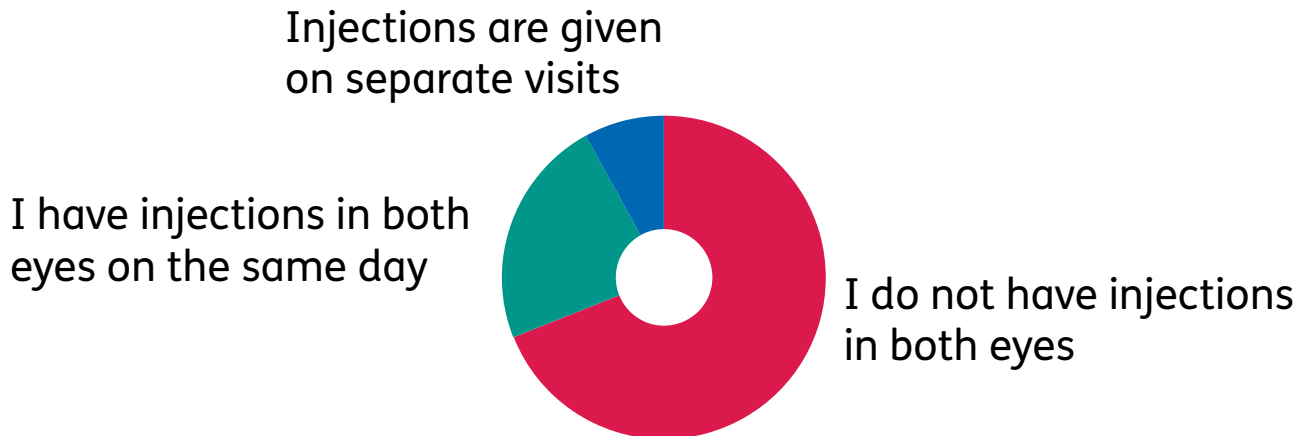
## How often do you currently go to the eye clinic for either your injections or a check-up related to your injections?



## Do you currently receive assessment and treatment on the same visit?



## Do you have injections in both eyes, and if so, how are you treated?



## Chance to discuss with consultant

37% of patients see an ophthalmologist at every appointment.

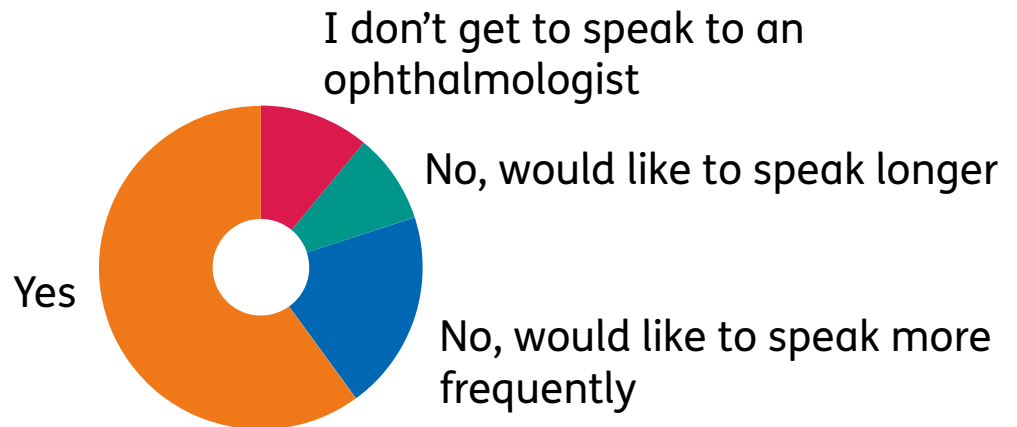
60% are happy with the frequency and duration of conversations with their ophthalmologist about their condition. 20% would like to speak more often to their consultant. While 12% said they do not get a chance to speak to an ophthalmologist at all.

When asked, less than 50% said their ophthalmologist engages with them in making decisions about treatment.

## How often are you able to speak to an ophthalmologist to discuss your treatment?



## Are you happy with how often you get to speak to an ophthalmologist and how long you get to speak to them?



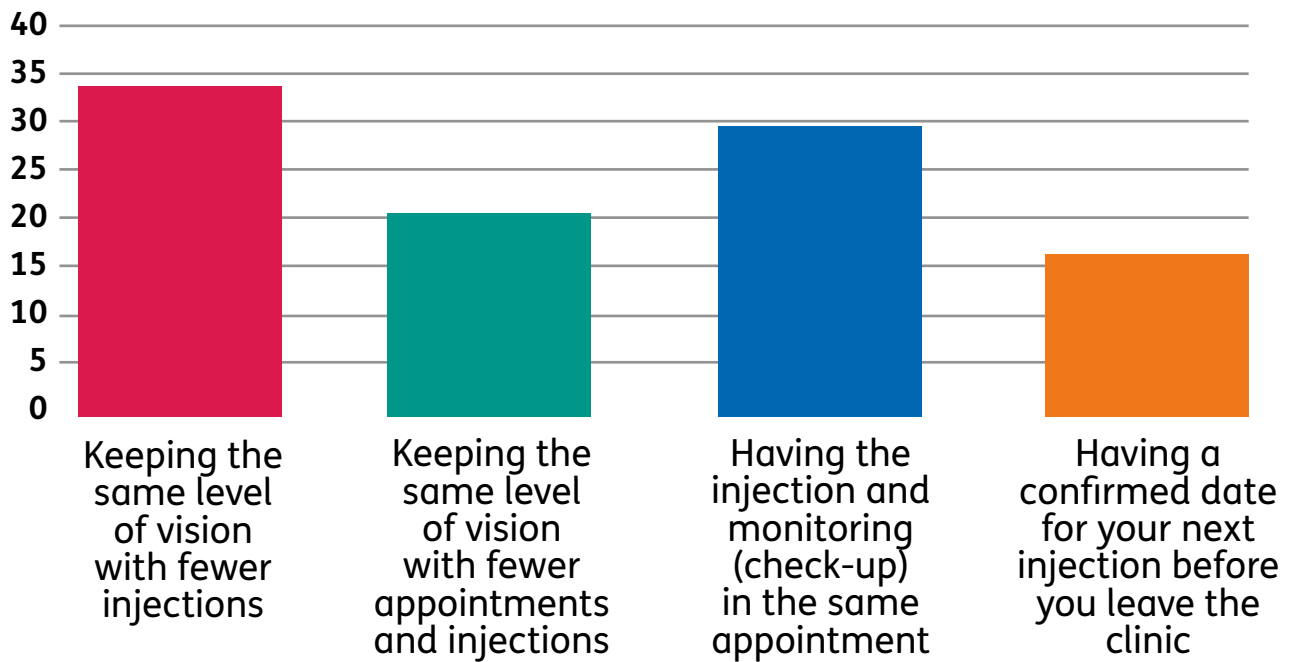
## Does your ophthalmologist actively engage you in making decisions about treatment?



## Future treatments

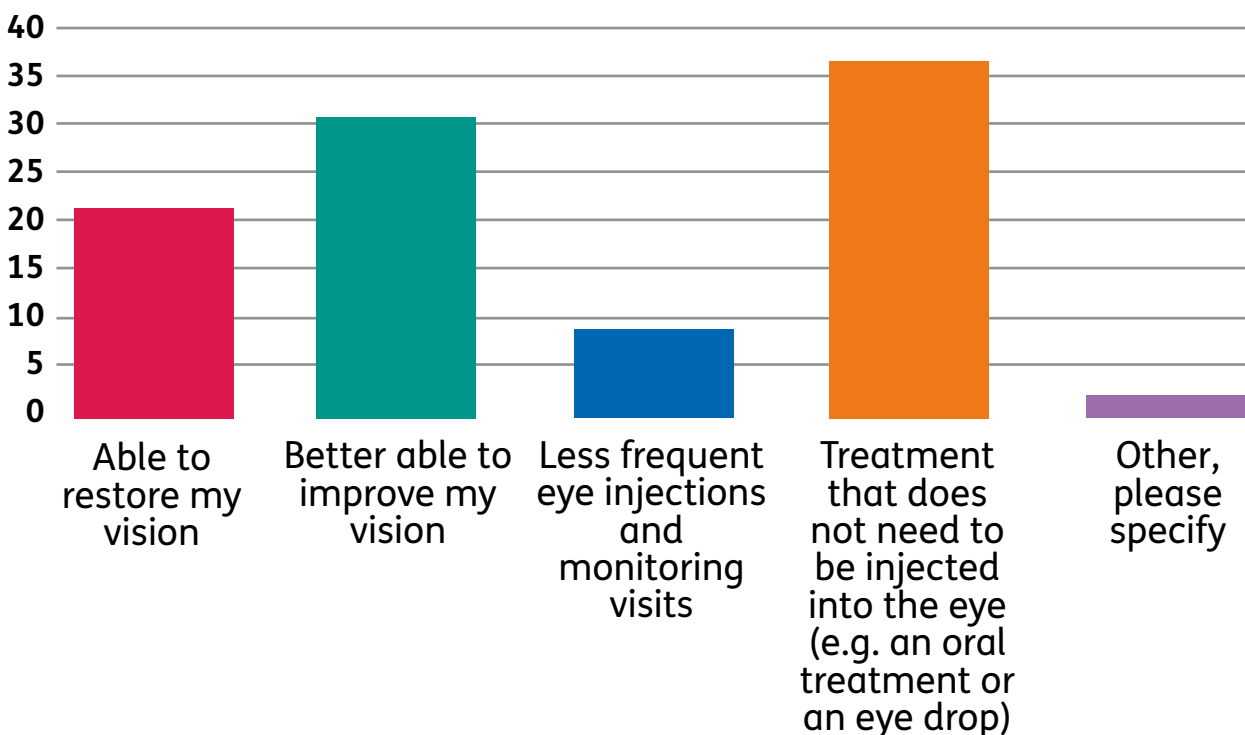
When asked to choose what statement is most important, 34% said to keep same level of vision with fewer injections. 29% said to have injection and monitoring at same appointment. The order of responses is similar to the responses when this question was asked to wet AMD patients in 2020. Where 38.4% would rather have fewer injections while keeping the same level of vision, and 37.7% would prefer to have the injection and check up in the same appointment. The reduction in numbers asking for injection and monitoring at the same appointment, may highlight that this happens more often than in 2020.

## Which of these following statements about your current treatment is most important to you?



Looking at future treatments, 36% participants said having a non-injectable treatment is most important to them. 31% chose treatment that improves vision, and 21% chose a treatment to restore vision as most important to them.

## Which one of the following would be most important to you in a future treatment?

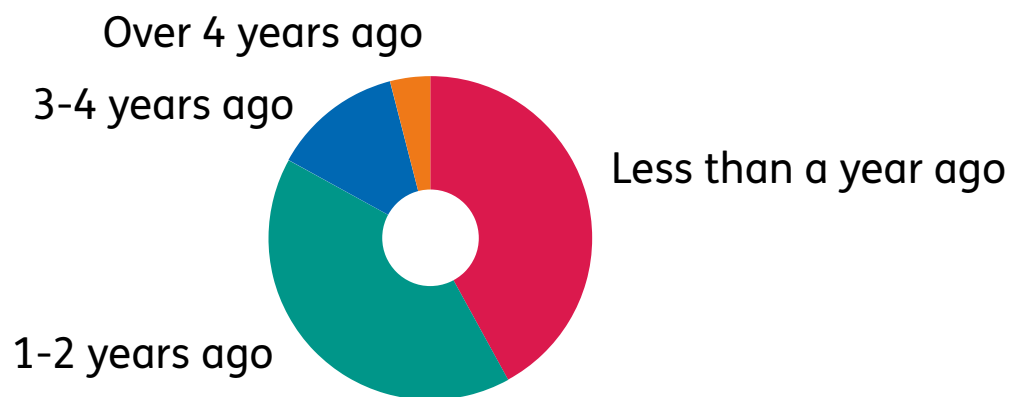


## No longer receiving injections

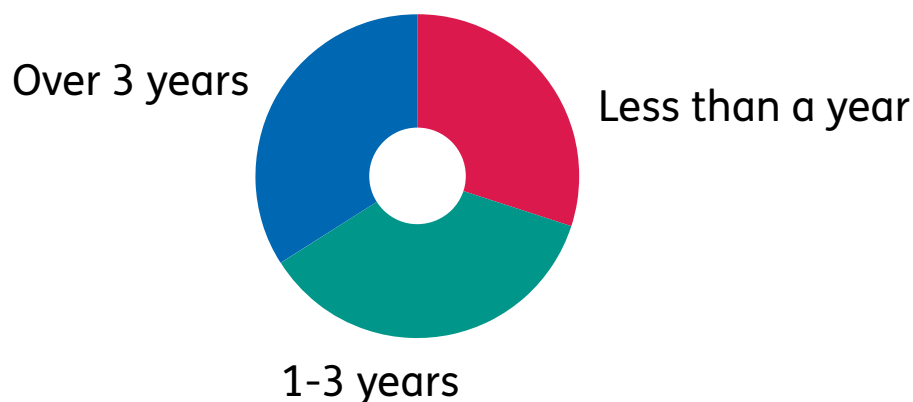
80% responders stopped injections less than 2 years ago. 30% stopped injections after less than one year. Another 36% after 1-3 years.

60% stopped receiving injections due to no longer needing injections. 13% due to the injections no longer working.

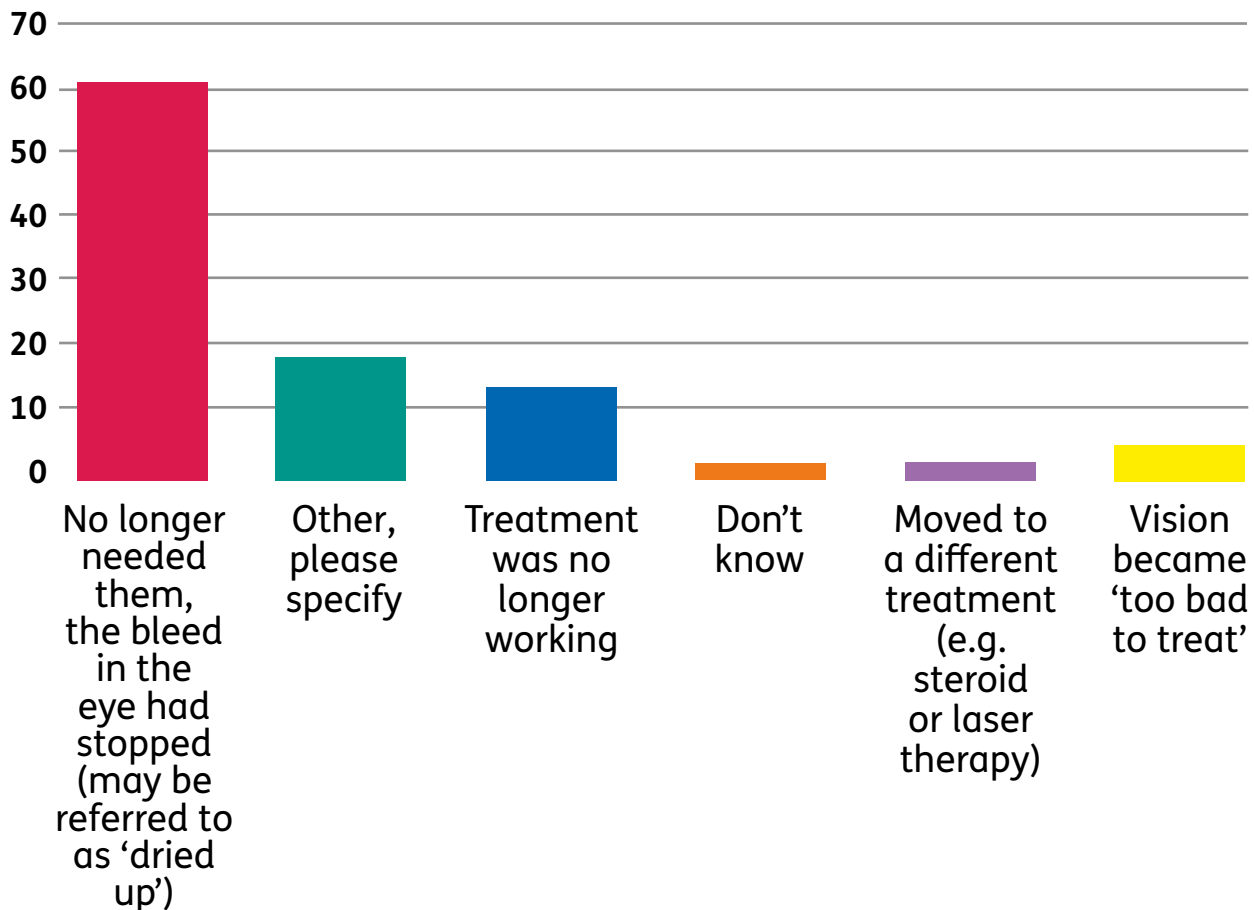
## When did you stop receiving injections?



## How long were you receiving injections, before you stopped?



## Do you know the reason you stopped receiving injections?

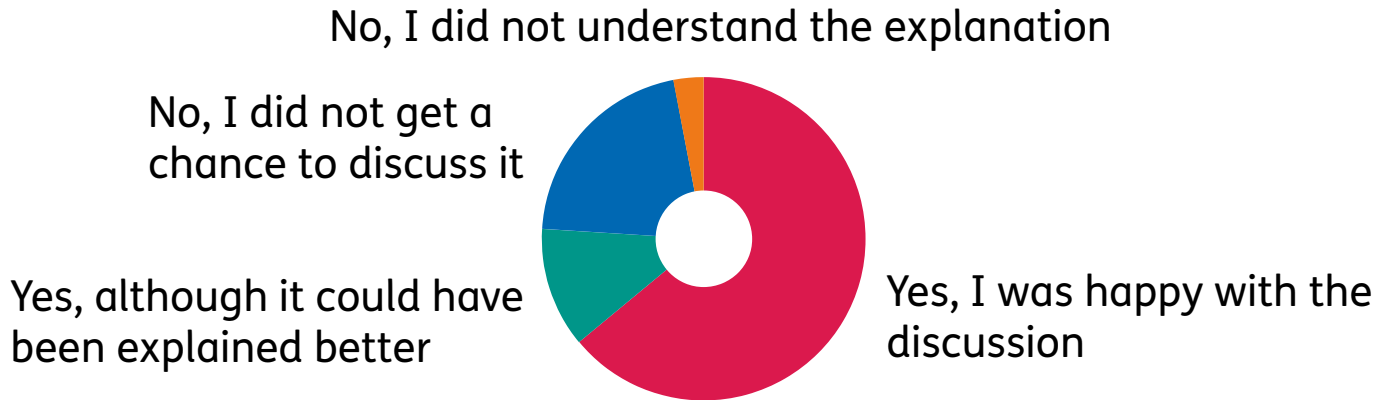


Two thirds were happy with the discussion about stopping injections. 14% either thought the explanation could be better or did not understand the explanation. However, 20% did not get a chance to discuss it. This can lead to confusion, uncertainty and anxiety about their future vision.

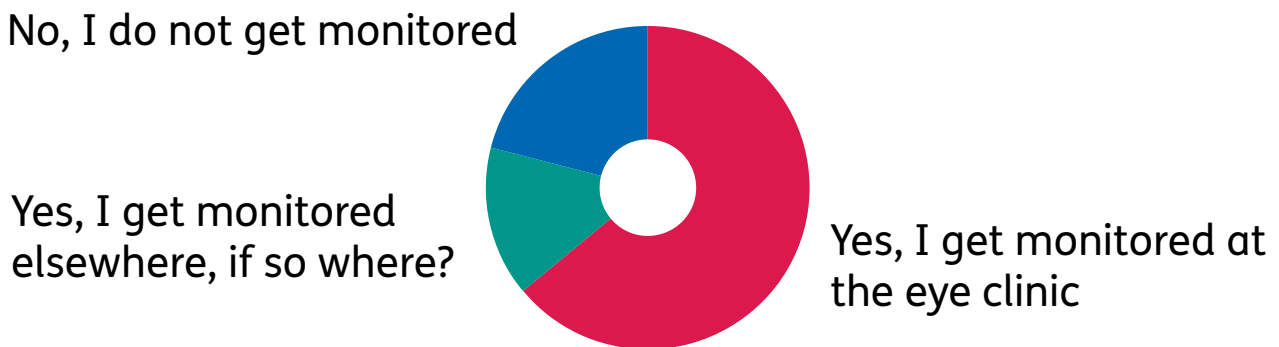
Depending on the reason for stopping injections, many will still need monitoring after stopping injections to pick up any re-activation. 65% still get monitored at the eye clinic.

24% were not told to monitor their vision at home. Monitoring vision at home can pick up any changes in vision and re-activation of disease, which can signal a need to visit the opticians or eye clinic.

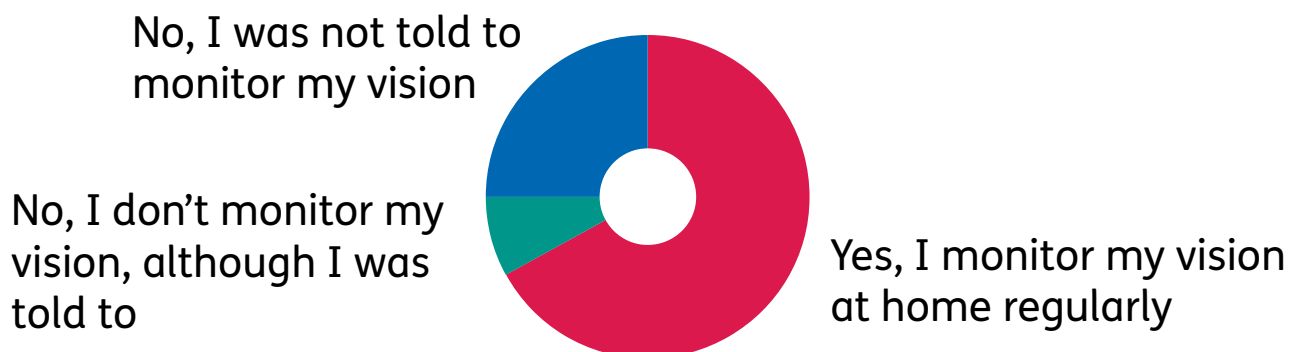
## Were you happy with the discussion about stopping injections?



## Do you receive regular monitoring (at the eye clinic or elsewhere such as at local opticians)? This does not include regular optician vision checks.



## Do you monitor your vision at home (e.g. using an Amsler grid, app)?



## Discussion

Many patients are very happy with the service provided to them for their anti-VEGF treatments and feel their care is discussed with them to a good level. Many responses from participants thanked the staff and treatment for stopping their vision loss. However, many participants did not feel involved in their care or discussions about their treatment.

Those receiving anti-VEGF treatment for AMD, DMO, RVO or any other condition may require injections for many years, on a regular basis, often every few months. Therefore, it is important that patients are involved in their care and understand why these injections are important. Having meaningful discussions with patients can answer any questions they may have and allow discussions related to switching to new treatments or stopping treatment.

## Comparing care in different conditions

When comparing those with AMD, DMO, MMD and RVO there were some differences in the care based on the condition. Those with AMD were most likely to be receiving injections currently, while MMD, RVO patients and DMO patients had a higher percentage of those who received treatment in the last 5 years. 85.8% of AMD patients were receiving treatment, while only 46.3% of RVO patients were receiving treatment and 48.8% of RVO patients received treatment in the last 5 years. When asked why patients switched or stopped treatment, many patients with RVO switched from anti-VEGF injections to steroid implants.

DMO patients had the highest proportion of patients who have received injections for more than 3 years. This may be due to the age of DMO patients being younger, therefore patients may need treatment for a longer period.

Most participants only have treatment in one eye (68%). However, when comparing different conditions, 80% of those with DMO have treatment in both eyes.

Of those who are no longer receiving treatment, there was a strong disparity between patients with wet AMD and MMD, versus those with DMO and RVO. Around 70% of those with wet AMD or MMD were told to monitor their vision at home, while less than 30% of those with DMO or RVO were told to monitor their vision at home. This may be due to wet AMD and MMD being more likely to re-occur, therefore there is a stronger need for self-monitoring or because there is little correlation between vision loss and recurrence of DMO or RVO.

## **Discussions on stopping or switching treatment**

Stopping or switching treatments can be a significant change in patients care. It is important that these changes are thoroughly discussed with patients, so they understand why this is happening and what it might mean for their care.

Of those who switched, the most common treatments to be switched from were Eylea and Lucentis. These are the first-generation approved anti-VEGF treatments and have been available the longest, which may explain why they are often used as first line treatment.

Patients must sign new consent forms when switching anti-VEGF drugs. This provides a good time for a discussion on why they are switching drugs, and the differences in treatment. Most participants knew why they were switched and the different drugs they had taken, with only 15% of participants who have switched drugs not told the reason.

However, when asked if the ophthalmologist engaged them in decision making about treatment only half of the responders agreed.

- “Yes, partly - I get told what I should do and then I ask questions - but I feel I need to be quite ‘pushy’ to find out what I want to and then I research afterwards”
- “Option is given, but in a way that says, they know best”
- “The nurses that have administered the injection have usually provided an update on changes since the previous injection, but as

I attend a satellite hospital to the main Eye Clinic there is usually no ophthalmologist available to discuss any issues or potential changes to treatment.”

- “It has put a burden on my partner and I feel a high level of anxiety as I never see a consultant. The nurse led service is good but I would like a conversation with a consultant to discuss trials and new treatments”

Discussion with patients is also vital to help understand their disease and the goal of treatment. It is important that patients have all the facts, and are aware of how the disease may progress. As well as having the opportunity to ask questions and having these questions answered.

- “I managed well at first hoping to alter the progressive deterioration but now I realise this will never happen and it is affecting my emotional response”
- “Can’t seem to have the opportunity to have this query answered and then actioned.”

When it came to those who were no longer receiving injections, 20% said they did not have a discussion about why treatment was stopping. In some cases, patients simply never got an appointment, and when chased were told they were discharged.

- “I couldn’t have been happier about the treatment I received until I was discharged. I wasn’t even told. I kept waiting for my next appointment to arrive through the post and it never did. I eventually rang and told them I was concerned I hadn’t received an appointment. They looked on the computer and told me I had been discharged. That was how I found out. I’m not happy at all I really would like regular screening”

Previous work from the Macular Society has shown that there is a disconnect between what patient information eye care professionals say they provide to patients, and what those patients remember receiving. These results are also shown here:

- “When first diagnosed in 2016 I did not understand the implications of the diagnosis. I was given a leaflet but did not alter my lifestyle or diet in any way.”

## **Holistic care and supporting patients**

Many patients praised the care they had received from their eye care providers, highlighting the kindness and support they receive during injections.

- “I am grateful for the treatments I am given and the kindness shown to me when I visit the eye Department of my local hospital. The staff are reassuring, kind and helpful”

As shown in the 2020 wet AMD survey report from the Macular Society, anti-VEGF injections can cause a lot of anxiety to patients. Anxiety can be due to fear of blindness, fear of injections, and difficulty getting injections within the appropriate timeframe and fear of delays.

- “It impacts emotionally every time (anxiety, fear, lack of sleep). Sometimes is painful and vision gets more blurred. It is scary every time!”
- “I have to phone hospital to chase appointment, irregular timing makes me concerned about vision deteriorating, which it is.”
- “I realise it is hard for staff but they are so matter of fact and lacking in sympathy. For me it is major.”

Many responses also highlighted that doctors and nurses treated their macular condition, but didn't consider them as a whole person and how their disease and treatment may be affecting them in other aspects of their life. There can be assumptions that patients have support at home, or that patients can easily attend appointments.

- “I find at my clinic (as in many other situations) there's an assumption that I 'must have someone who can help me' & once was almost refused an injection because I didn't have anyone to take me home,

& the hospital couldn't risk me travelling home on public transport after an injection. I pretended to ring someone, & said I'd have a lift waiting, so they gave me an injection ... I continued to lie about having a lift home if I was asked again, & continued to travel home on 2 buses for over 2 hours after treatment & check ups.”

- “Impacts greatly as appointments are often provided with very little notice for injections and myself and husband then have great difficulty getting time off work”

## Conclusion

There is a strong need for patients to have the opportunity to receive information and ask questions to their eye care providers. Shared decision making is best practice and should be accepted by all as a key process to ensure treatments are suitable both for health care workers and patients. However, only around half of participants in this survey agreed that their clinicians involve them in decision making.

Part of shared decision making involves understanding the care options, risks, benefits and outcomes of treatments and creating a treatment plan based on strong medical and scientific evidence and guidelines, as well as patient preference. These treatment plans may change due to how the disease progresses and may be dependent on national or local guidelines. NHS England created a wet AMD decision making tool in 2022 which covers key information relating to anti-VEGF injections to provide patients with clear understanding before making the decision to start treatment: [www.england.nhs.uk/publication/decision-support-tool-making-a-decision-about-wet-age-related-macular-degeneration/](http://www.england.nhs.uk/publication/decision-support-tool-making-a-decision-about-wet-age-related-macular-degeneration/)

There are situations where guidelines determine treatment plans or decisions. However, discussion explaining what decisions were made and why, can provide clarity and help patients understand these changes. When surveyed those who no longer received injections, there were some who were not told why or in some cases, not even told their injections had been stopped.

Through discussions with patients and shared decision making, this provides time for patients to ask questions about their care, and discussions about other aspects of their life that may impact treatment. This holistic care can lead to insights about patients to ensure that their treatment regimen is manageable and sustainable. Hopefully leading to better patient outcomes and longer lasting vision.

This report highlights the need for shared decision making and discussions with patients about their care and changes to treatment, especially when stopping or pausing treatment.



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