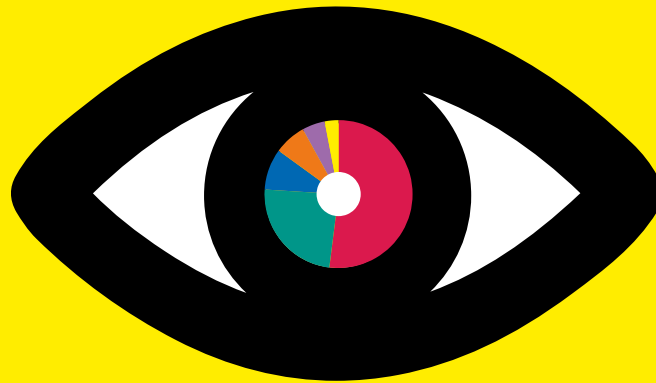


Macular Society

Beating Macular Disease



Understanding patient perceptions of diabetic macular oedema (DMO) management and support

June 2021

Thank you to all those who took time to complete this survey. Thanks to you we are better able to understand the effect DMO treatment and management has on patients. Thank you also to Professor Tunde Peto and Professor Sobha Sivaprasad for their comments on the survey and report.

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



Executive summary

This survey was conducted to better understand the experiences and needs of those living with diabetic macular oedema. The responses show a lack of information provided about the condition and support available when living with DMO and visual impairment. More than three in five responders (63 per cent) said they felt anxious about their condition and the sight loss it can cause, and four in five (80 per cent) said DMO impacts their life. Responders also found managing their DMO to be quite difficult, with only around a third (37 per cent) believing they were managing their DMO well.

The lack of information for those newly diagnosed with DMO can lead to higher levels of anxiety, as patients aren't sure of what their diagnosis means for their future. This anxiety can be worsened when patients aren't aware of the support available to help them. Diabetes management is vital for maintaining a healthy life and reducing the risk of developing or accelerating complications such as DMO. However, tasks needed to help manage diabetes, such as reading blood glucose levels and injecting insulin, can become much more difficult after losing central vision.

This report finds that better connections between diabetic clinics, eye clinics and low vision support are needed, so clinicians can signpost those with diabetes and/or DMO to information about the condition and support. When discussing diabetes management, clinicians also need to ensure patients are aware of the risk of sight loss, and the importance of attending diabetic eye screening.

The Macular Society can provide information and support for those newly diagnosed with, or at risk of, diabetic macular oedema. We look forward to working across the diabetic and eye sector to improve the lives of those with DMO.

Introduction

Diabetic macular oedema (DMO) is a complication of diabetes that can lead to irreversible sight loss. It is a build-up of fluid in the macula due to leaky blood vessels damaged by high blood sugar due to diabetes. It is one of the most common causes of sight loss in the working age group. There are currently around 300,000 people living with the condition in the UK. However, the effects of DMO are still not well known, with recent research from Australia showing only a quarter (26 per cent) of people aged 50-70 are aware of DMO [1]. Less is known about the levels of understanding in the UK.

Several treatments are available for DMO. Earlier treatment usually means better outcomes for the patient, including maintaining better sight or stable sight for longer. To address early diagnosis and referral for timely treatment, the UK has set up the Diabetic Eye Screening Programme, where those who have been diagnosed with diabetes aged 12 and over are invited to get an eye screen every year. This programme has been very successful in getting patients diagnosed earlier and referring patients to treatment if needed.

Altogether, 41 patients with DMO were surveyed about their perceptions of the management and support they have received for their diabetes and DMO. This work aimed to understand how the information and support for diabetes compares to that for DMO.

Methods

The survey was conducted online using surveymonkey.com, a platform we had previously used and found to be successful and accessible to those with visual impairment. The survey was tested with the help of colleagues to ensure its compatibility with magnifying software and screenreaders. Macular Society contact information was also provided to allow responders to complete the survey over the phone and to ask any questions.

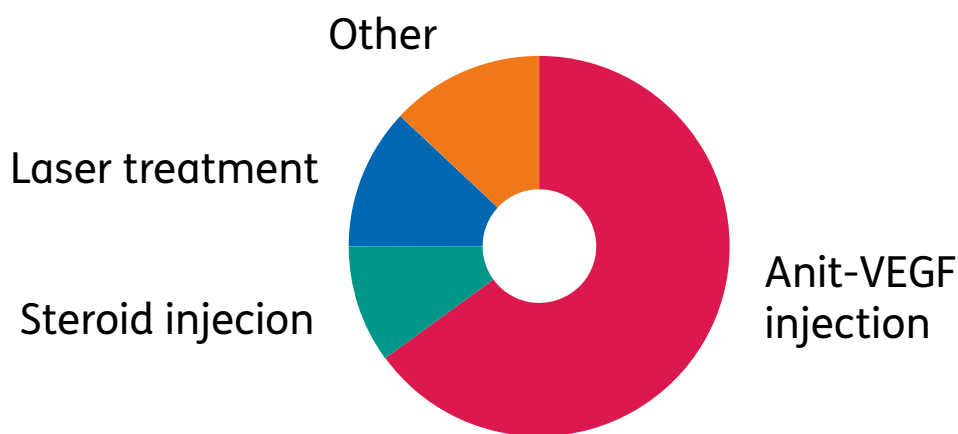
The survey was promoted online through the Macular Society's social media accounts and through the monthly Macular Society e-newsletter,

which has around 30,000 subscribers. The release of the survey also coincided with our Working Age and Young People Virtual Clinic on DMO and was promoted on the Zoom webinar to 52 attendees. Some of our members, and other charities including the Diabetes UK Research Team and Diabetes UK NI helped promote the survey wider.

Results

Forty-one people took part in the survey. All had DMO and were included in the analysis. Around three in five (60 per cent) were female, and the mean age was 60 years. Due to the small sample size of the responses, we were unable to get full reach of the whole of the UK.

What treatment are you currently on for your DMO?

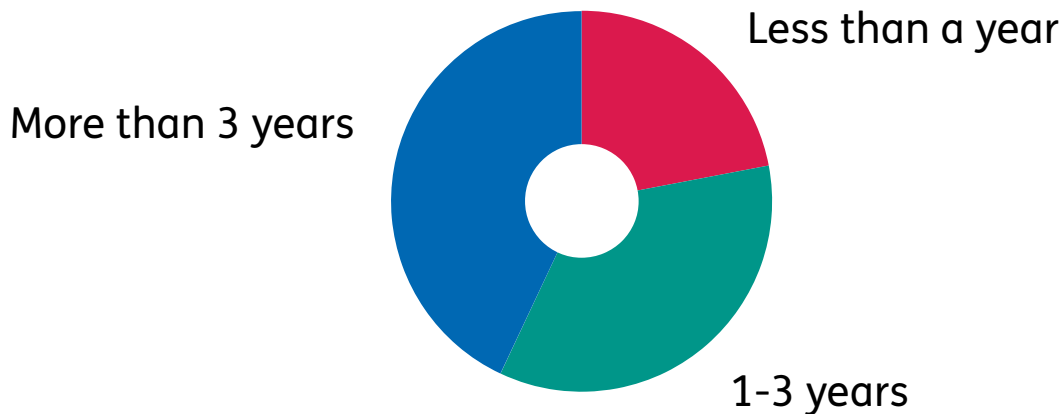


Two-thirds of responders (65 per cent) were receiving anti-VEGF injections to treat their DMO. Another 7.5 per cent (those who responded “other”) had stable DMO and were under observation, receiving injections when needed. One in ten (10 per cent) were receiving steroid injection as treatment and one in eight (12.5 per cent) had laser treatment. One responder was not receiving any treatment due to their sight loss being ‘too bad to treat’.

Anti-vascular endothelial growth factor (anti-VEGF) injections are the first line of treatment for DMO, and involve injecting these drugs into the eye at repeated intervals. These drugs work to stop the growth and leaking of blood vessels which leads to the damage and vision loss seen in DMO.

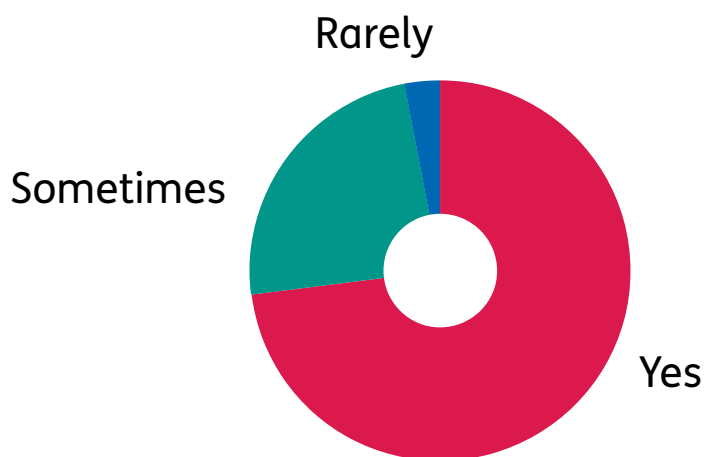
Some patients do not respond well to these anti-VEGF drugs, or respond better to steroid injections. However, currently there are more restrictions on the use of steroids for DMO due to the increased risk of developing cataracts after steroid use in the eye.

How long have you been receiving treatment?



More than four in ten responders (42.5 per cent) had been receiving treatment for their DMO for more than three years, so have had many years of living with the condition and the fear, or fact, of sight loss. A third of participants (35 per cent) had been having treatment for between one and three years and around a quarter (22.5 per cent) had been having treatment for less than a year.

Do you feel anxious about your DMO and the sight loss it may cause?



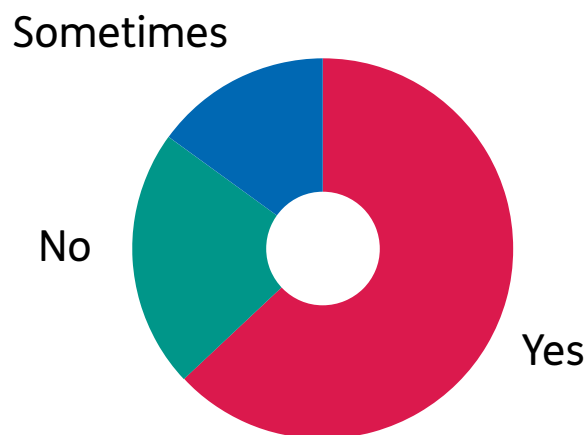
Nearly three-quarters of responders said they felt anxious about their DMO and the sight loss it might cause, compared to only one person who said they rarely felt anxious. No responders said they never felt anxious about their DMO and possible sight loss.

In many cases receiving a diagnosis of a sight-threatening condition can be overwhelming and scary. Often, people do not know what losing sight would mean for their future.

“It makes me worry what my future may look like. I also would love children and I worry about the impact this would have on my eyes.”

“Straight lines look wavy and blurry. It feels very scary and I’m frightened of losing more of my vision in both eyes.”

Do you feel anxious about your DMO treatments?



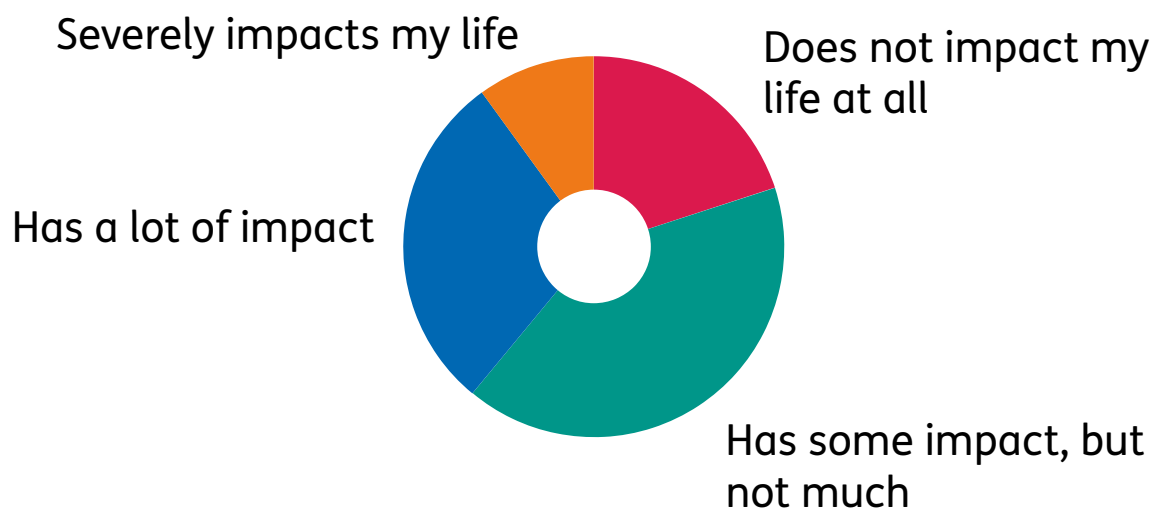
Almost four in five participants (78 per cent) feel anxious at least sometimes about their DMO treatment. Often this anxiety is due to having injections, which can be painful. Planning their life around injections can also be stressful, including taking time off work or finding someone to take them to the clinic.

“Regular trips to the hospital for check ups, having to arrange holidays etc around treatment. Painful treatment.”

The remaining 22 per cent do not feel anxious about their treatment, and see injections as a positive step to maintaining their vision.

“Only positively. It has given me reassurance that my sight is being preserved as well as it can be for as long as possible.”

To what extent do you believe your DMO treatment affects your life?



Less than one in five responders (20 per cent) said that their current DMO treatment did not impact their life at all. Almost twice as many said it has a lot of impact, or severely impacts their life.

The majority of responders were receiving anti-VEGF injections, which require injections every one to two months to maintain sight. This can often be burdensome to patients, especially those with jobs or who require family or friends to take them to clinics.

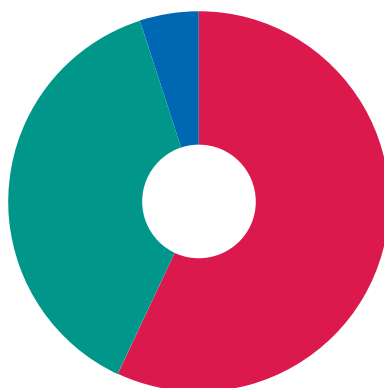
“Very difficult to carry out my office work for the small business that I run and also driving issues.”

“Travel to clinic is difficult my daughter has to take time off work for me.”

Do you feel that you are able to manage your diabetes?

I do not feel that I am managing it well

Managing it is difficult, but I feel I am doing OK

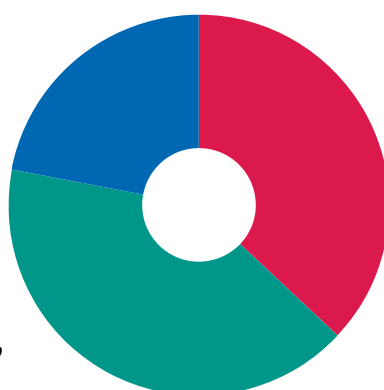


Yes, I am managing it well

Do you feel that you are able to manage your eye health (including DMO)?

I do not feel that I am managing it well

Managing it is difficult, but I feel I am doing OK



Yes, I am managing it well

Around one in five (22 per cent) responded that they feel like they weren't managing their eye health well, compared to only one in 20 (5 per cent) who felt they weren't managing their diabetes well.

Overall responders felt less able to manage their eye health and DMO compared to their diabetes. This lack of control may be a reason why responders felt anxious about their eye condition and the sight loss

it can cause. It is important that patients feel that they are able to manage their condition and have all the necessary information and support.

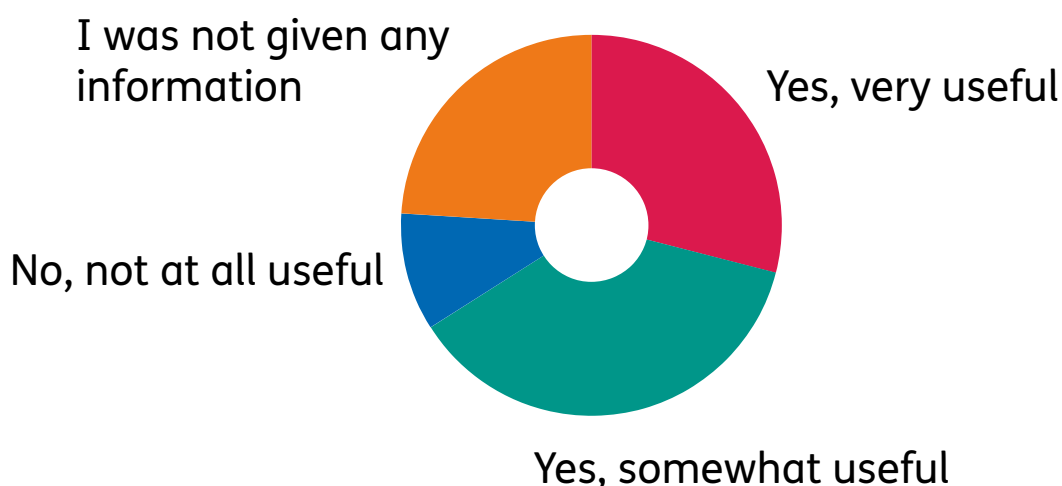
“I think it’s hard to manage how unpredictable sugar levels can be. Also to calculate the amount of insulin and correction doses are required takes a lot of hard work and concentration.”

“[It can be hard] keeping it [blood sugar] under control some difficulty reading syringes.”

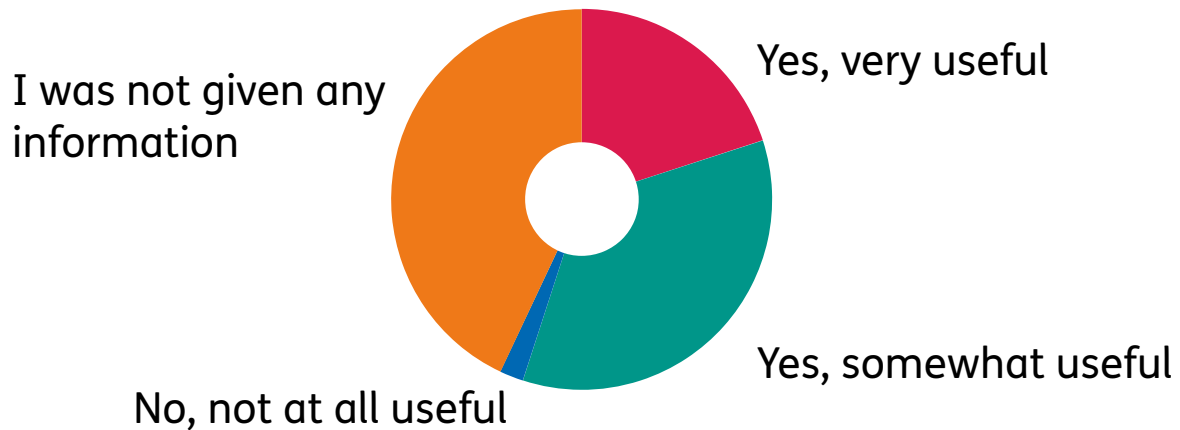
“Fear of the unknown is difficult with my eye condition. I have been given great care once it was discovered DMO but there did not appear to be anybody on hand to explain things properly or talk from experience.”

“Just struggling with understanding it all re HBA1C time in target blood pressure exercise etc.”

Was the information given to you on managing your diabetes useful to you?



Was the information given to you on managing your DMO useful to you?



More than two in five responders (42.5 per cent) were not given any information about managing their DMO, while only a quarter (24 per cent) were not given any information about managing their diabetes.

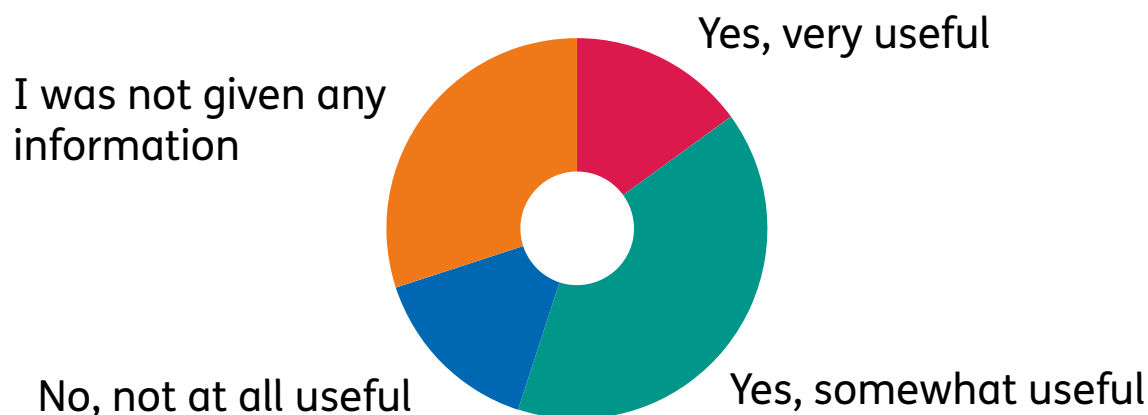
The importance of managing diabetes is well established, with poor blood sugar management being a major risk factor for developing complications such as diabetic macular oedema. Better management of diabetes through lifestyle changes and monitoring blood sugar levels help maintain good vision.

“I was told blood sugar too high and to bring it down quickly. I did bring it down within three months from 116 to 58. Shortly after this I started a range of treatments for retinopathy and DMO.”

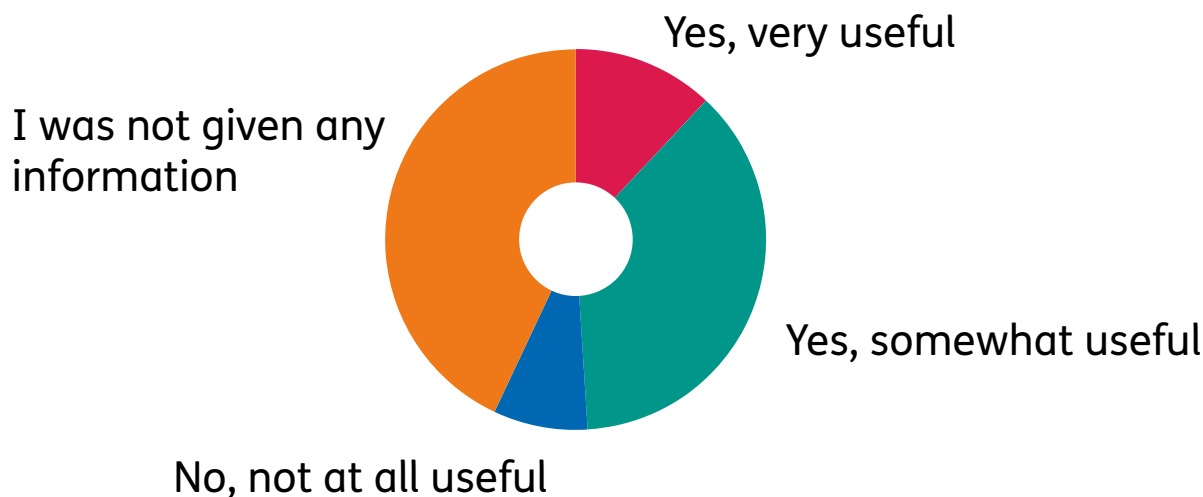
“I wasn’t really given any advice [about managing diabetes]. I had to research it all.”

“I do have a ROVI [Rehabilitation Officer for the Visually Impaired] who has helped.”

How useful were the support resources you received for your diabetes (e.g. leaflets, contacts for charities or support groups)



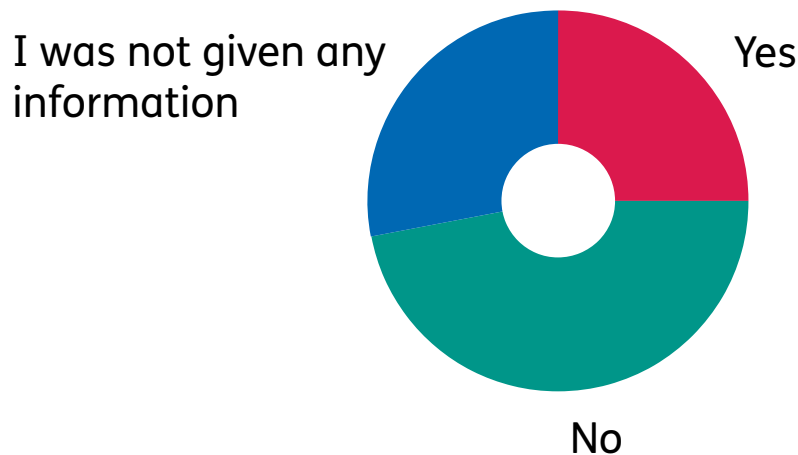
How useful were the support resources you received for your sight loss and DMO? (e.g. leaflets, contacts for charities or support groups)



Only around half of responders were given useful support resources for their sight loss and DMO. This leaves 45 per cent not having received useful support resources for the diabetes, and 50 per cent not receiving useful resources for their DMO.

It is important that our patients get the right support resources, so they can manage the change in daily life that diabetes and DMO may cause.

Do you feel you were given all the information you needed about DMO when you were diagnosed?

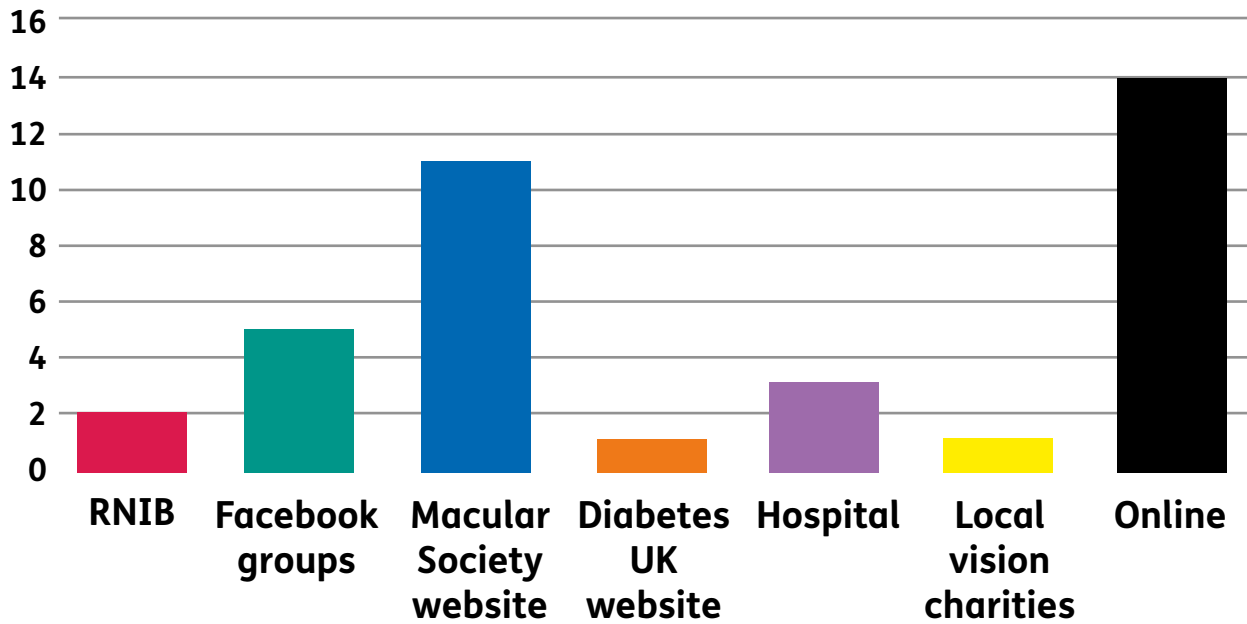


Only one in four (25 per cent) of those who took the survey felt they were given all the information about DMO that they needed when they were diagnosed. On the other hand, a similar proportion (28 per cent) were given no information at all.

It can be difficult for patients to receive a diagnosis of DMO and learn that they could lose their vision. Understanding more about the condition and what treatments are available can be reassuring, and help patients feel more in control of the situation.

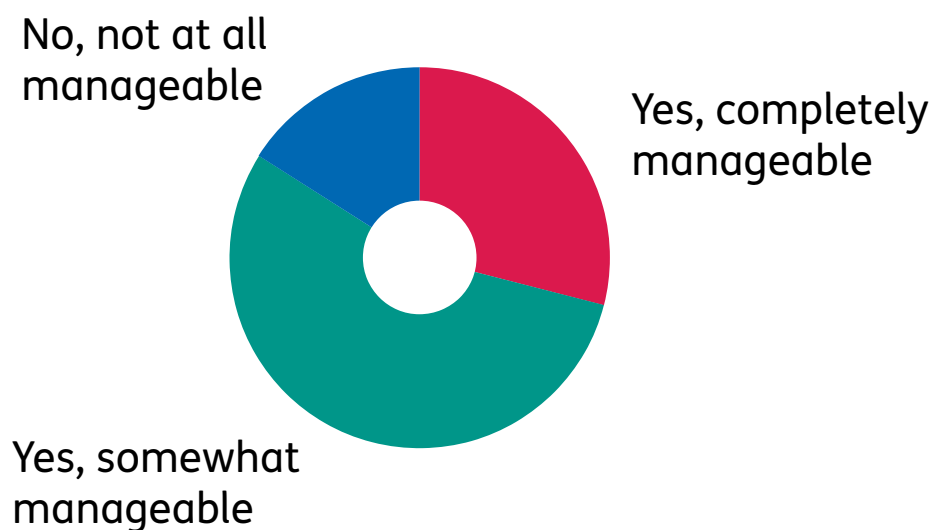
- **“I felt very alone and was unaware of my actual diagnosis.”**
- **“Given a booklet from the Macular Society when given an appointment for laser consultation.”**
- **“Speaking to me beyond lie down, keep still was absent.”**

Where do you usually look for resources relating to DMO?



Around half of those who responded said they looked for resources relating to DMO from charity websites, with 11 of those mentioning the Macular Society specifically. Half also said they search the internet. Only 3 per cent mention asking at the clinic or using hospital resources.

Do you think that the risk of DMO is manageable by lifestyle changes?

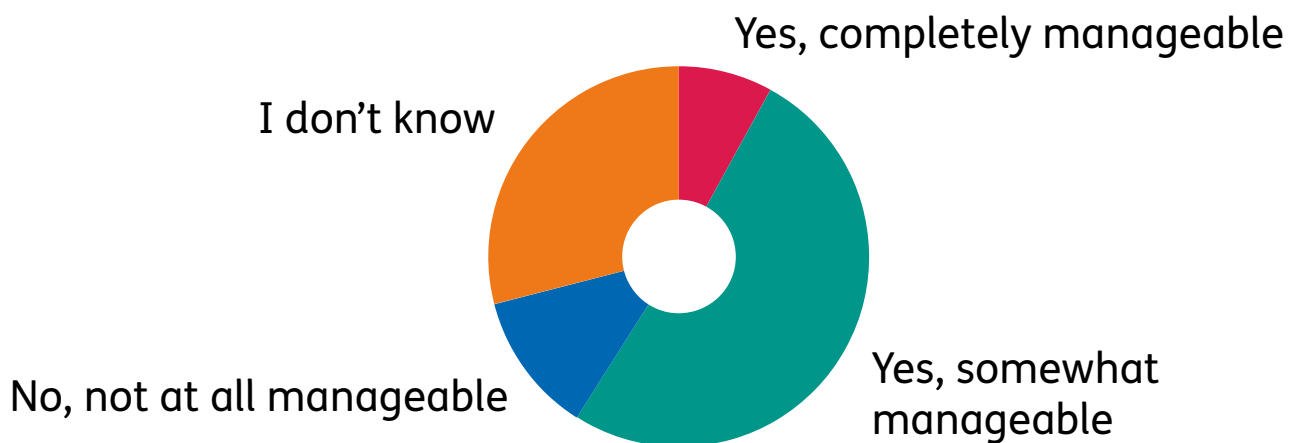


Two-thirds of people (65 per cent) were aware that the risk of developing DMO is manageable by lifestyle changes. Patients with better control of blood sugar and blood pressure are at lower risk of developing DMO. Other factors, such as age, genetics and time since developing diabetes also can play a role.

It is important that those with diabetes understand the importance of a healthy lifestyle and the risk of complications such as DMO.

“I think there needs to be better communication between Eye and Diabetes departments. Maybe shared training resources on how to enable diabetic patients to gradually lower their blood glucose in a safer time frame plus give them the resources to do so.”

Do you think that progression and severity of DMO are manageable by lifestyle changes?

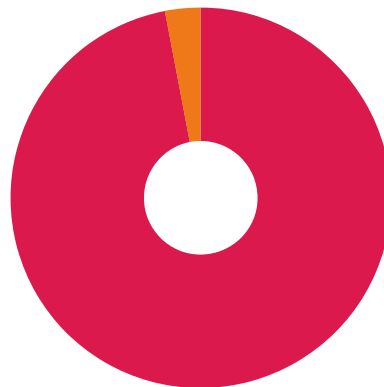


Three in five (59 per cent) were aware that DMO can be managed with lifestyle changes, and that careful monitoring and lowering of blood sugar levels can help slow the progression or reduce the severity of the condition. However, the remaining two in five (41 per cent) either did not believe DMO was manageable, or did not know, showing the need for better education of DMO patients about their condition.

“Knowing what affect the eyes HbA1c reduction blood pressure and cholesterol all affect DMO.”

Do you think that progression and severity of DMO are manageable by lifestyle changes?

I don't know

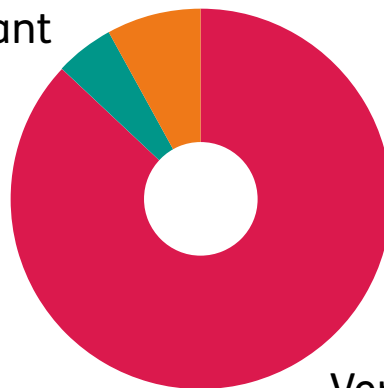


Very important

How important do you think controlling blood sugar and blood pressure levels is for your DMO?

I don't know

Somewhat important

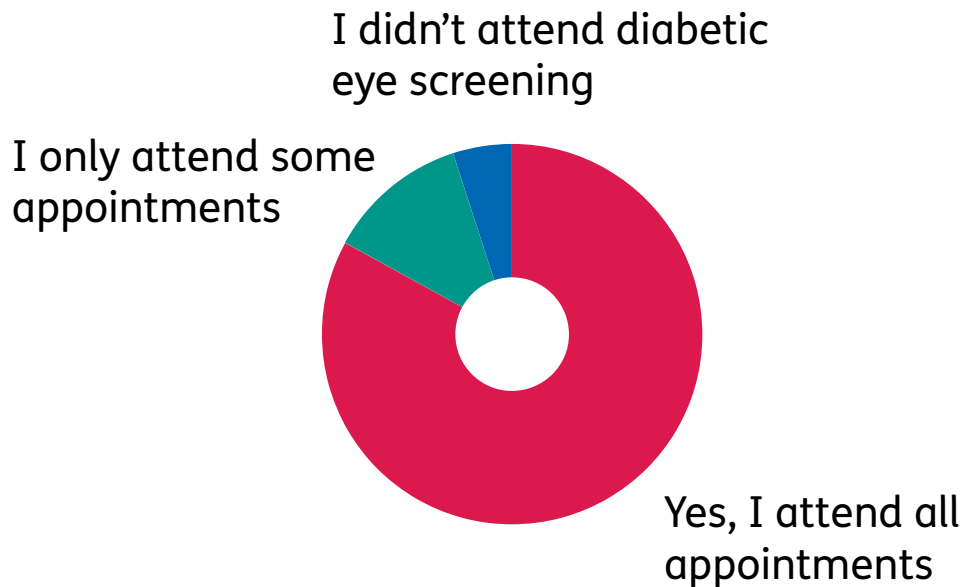


Very important

Almost all (39/40) responders believed that controlling blood sugar and blood pressure was very important for their diabetes, and almost nine in ten (88 per cent) believed it was very important for their DMO.

It's promising that such a high proportion of participants understand the need for managing their blood sugar levels and blood pressure, and that it can help not only their diabetes but also their DMO.

Did you attend all the Diabetic Eye Screening appointments?



The majority (84 per cent) of those who took part in the survey attended all their Diabetic Eye Screening appointments. These annual appointments are important to attend as it means relevant diabetic eye changes can be seen as early as possible, referral can be done and treatment can be given when it is needed.

Five per cent did not attend any of their appointments, and around one in eight (12 per cent) only attended some appointments. It can be hard attending appointments, as people with diabetes have to attend multiple check-ups for their condition and other complications. Difficulties might include taking time off work or arranging friends or family to take them to these clinics.

“Unable to get anyone to take me. I live alone and I am 82 years old.”

Some others find the idea of diabetic eye disease and DMO daunting or something that would not affect them, so might not see the need for attending. It is important for those people that the clinic can highlight the importance of these appointments for their vision.

“When I was younger between the ages of 16-26 I did not attend my screenings. I think part ignorance from being young and also

because I didn't fully understand the implications of diabetes on the eyes. Since having retinopathy diagnosed I have attended every appointment."

Some told us that they had stopped receiving invitations for appointments, which meant they could not attend every year. It is vital that clinics have correct and updated information about all those with diabetes who need to attend eye screening.

"I missed one appointment due to ill health. I was not sent another even though I requested it. Life took over I was a single mum working full time and I didn't even realise I'd missed 3 years of eye screening until I hit some problems time went so fast."

"Attended all I was invited to but slipped through the net and only invited after found to have DMO."

Discussion

Our survey found a significant number of those with DMO did not feel they received enough information about their condition, or how to access support for living with sight loss and DMO. Many also experienced anxiety about their DMO and the sight loss that it can cause. More needs to be done to ensure those with DMO feel informed and supported about their condition and are prepared to cope with changes in their vision.

Vision loss can make daily tasks more difficult, including tasks needed to monitor and manage diabetes. This can risk further vision loss as poor management of diabetes is a risk factor for DMO progression. This highlights the need for more support and guidance for those newly diagnosed with DMO.

Many patients experience anxiety on DMO diagnosis, and when thinking about the risk of losing their sight. This is often made worse as many did not know anything about DMO when they were diagnosed, and weren't provided with appropriate information or support. Treatment, especially

injections, can also cause anxiety for some patients, in particular for those who may experience pain after or during injections.

In a previous survey looking at those receiving anti-VEGF injections for wet AMD, more than half (54.9 per cent) said they felt anxious about their injections at least sometimes [2]. Anxiety can also be related to fear of not getting treatment as often as needed, and the risk that infrequent treatment may have on their sight.

Better partnership between eye clinics and diabetes clinics would help improve DMO awareness and highlight ways to reduce the risk of developing DMO, including the importance of attending diabetic eye screening. As poor management of blood sugar and blood pressure is linked to increased risk of developing DMO, and progression of DMO, such a joined-up, holistic approach may be beneficial.

Diabetic eye screening is an important resource in the UK for those with diabetes, and despite it being free, approximately one in seven people living with diabetes invited for screening (15 per cent) do not attend [3]. This is similar to our data suggesting that 84 per cent of those with DMO attended all their screening appointments. Often the blame is put onto the patients for not attending screening appointments, but many claimed that they did not receive the invitations.

This survey highlights a need for further support and more resources for those with DMO. To provide the most benefit, these should be available when needed for people at all stages of their DMO journey, including for diabetics at risk of DMO. Support and resources are out there from charities such as the Macular Society, RNIB and Diabetes UK. However, this survey shows that these resources aren't being provided and those with DMO are having to find them by themselves. Better communication between diabetic clinics, eye clinics and charities that support those with DMO is needed.

References

[1] <https://www.mdfoundation.com.au/news/macula-month-focus-on-diabetes/>

[2] Macular Society. Understanding Patients' Perceptions of Wet AMD Treatment in 2020, 2020. Available: https://www.macularsociety.org/sites/default/files/AMD_Research_Report_2020_FINAL_1.pdf

[3] Strutton R, Du Chemin A, Stratton IM, et al System-level and patient-level explanations for non-attendance at diabetic retinopathy screening in Sutton and Merton (London, UK): a qualitative analysis of a service evaluation *BMJ Open* 2016;6:e010952. doi: 10.1136/bmjopen-2015-010952

Appendix

Survey

Q1: What treatment are you currently on for your DMO?

- Anti-VEGF injection (e.g. Eylea, Lucentis etc. injection every 4-6 weeks)
- Steroid injection (e.g. Ozurdex, injection every 3-6 months or every 3 years)
- Laser treatment
- Other

Q2: How long have you been receiving treatment for DMO?

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

Q3: Do you feel anxious about your DMO and the sight loss it may cause?

- Yes
- Sometimes

- Rarely
- Never

Q4: Do you feel anxious about your DMO treatments (e.g. injections, laser therapy)?

- Yes
- No
- Sometimes

Q5: To what extent do you believe your current DMO treatment affects your life?

- Does not impact my life at all
- Has some impact, but not much
- Has a lot of impact
- Severely impacts my life

Q6: If so, in what way does it affect your life?

- FREE TEXT

Q7: Do you feel that you are able to manage your diabetes?

- Yes, I am managing it well
- Managing it is difficult but I feel I am doing ok
- I do not feel that I am managing it well

Q8: If you find managing your diabetes difficult, what aspects do you find the hardest?

- FREE TEXT

Q9: Do you feel that you are able to manage your eye health (including DMO)?

- Yes, I am managing it well
- Managing it is difficult but I feel I am doing ok

- I do not feel that I am managing it well

Q10: If you find managing your eye health (including DMO) difficult, what aspects do you find the hardest?

- FREE TEXT

Q11: Was the information given to you on managing your diabetes useful to you?

- Yes, very useful
- Yes, somewhat useful
- No, not at all useful
- I was not given any information
- FREE TEXT

Q12: Was the information given to you on managing your DMO useful to you?

- Very useful
- Somewhat useful
- Not at all useful
- I was not given any information

Q13: How useful were the support resources you received for your diabetes? (e.g. leaflets, contacts for charities or support groups)

- Very Useful
- Somewhat useful
- Not at all useful
- I was not given any information

Q14: How useful were the support resources you received for your sight loss and DMO? (e.g. leaflets, contacts for charities or support groups)

- Very Useful

- Somewhat useful
- Not at all useful
- I was not given any information

Q15: Do you feel you were given all the information you needed about DMO when you were diagnosed?

- Yes
- No
- I was not given any information
- FREE TEXT

Q16: Where do you usually look for resources relating to DMO?

- FREE TEXT

Q17: Do you think that the risk of DMO is manageable by lifestyle changes?

- Yes, completely manageable
- Yes, somewhat manageable
- No, not at all manageable
- I don't know
- FREE TEXT

Q18: Do you think that the progression and severity of DMO are manageable by lifestyle changes?

- Yes, completely manageable
- Yes, somewhat manageable
- No, not at all manageable
- I don't know
- FREE TEXT

Q19: How important do you think controlling blood sugar and blood pressure levels is for your Diabetes?

- Very important

- Somewhat important
- Not important at all
- I don't know

Q20: How important do you think controlling blood sugar and blood pressure levels is for your DMO?

- Very important
- Somewhat important
- Not important at all
- I don't know

Q21: Did you attend all the Diabetic Eye Screening Appointments?

- Yes, I attended all appointments
- I only attend some appointments
- I didn't attend Diabetic Eye Screening

Q22: If you didn't attend your Diabetic Eye Screening appointments, why?

- FREE TEXT

Q23: How did you hear about survey?

- Macular Society website/e-newsletter/social media
- Macular Society Working Age and Young People Facebook
- From another sight charity
- From another charity
- Your eye care professional
- From friend or family member
- Other _____

Q24: Age

- 20-29
- 30-39
- 40-49

-
- Prefer not to say

Q25: Gender

- Male
- Female
- Prefer not to say

Q25: Country

- England
- Scotland
- Wales
- Northern Ireland
- Outside of the UK