

Many GPs are ill-informed and unsupportive when tackling age-related macular degeneration, new research reveals

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Credit: Royal Holloway, University of London

New research published today in the *BMJ Open* has found that patients experiencing degenerative eye disease are not receiving the information and support needed to manage, understand and treat their condition. It found the quality of GP's support in this area has declined, and lack of timely information from optometrists and eye specialists may be leading to more patients being registered sight impaired or severely sight impaired.

Researchers from Royal Holloway, University of London working in conjunction with the Macular Society surveyed more than 1,000 patients diagnosed with [age-related macular degeneration](#) (AMD) about their experiences of [diagnosis](#) and the support offered thereafter. Of those patients who discussed AMD with their GP around the time of diagnosis, nearly 40 per cent felt their GP was 'not at all well-informed' about AMD and almost half reported that they were 'not at all helpful/supportive'.

Information is key to treating leading cause of blindness

AMD is a progressive chronic eye condition affecting people aged 50 and over, and is the leading cause of blindness in the developed world. Emily Boxell, PhD student at Royal Holloway's Health Psychology Research Unit and Department of Psychology, lead author of the study explained:

"There are over 500,000 people living with AMD in the UK, with this figure expected to grow by a third by 2020. While there are treatments available for some forms of the condition, it is still the leading cause of blindness – an outcome that in many cases may be avoided if the right information and support is given early."

The study noted, in particular the association between registration as sight impaired or severely sight impaired and a lack of information at diagnosis on what patients should do if they experience sudden deterioration in vision.

Ms Boxell commented, "Patient experiences are an important indicator of quality of healthcare and our study has shown that despite some improvements, GPs are not adequately informed or equipped to support

patients receiving this distressing diagnosis. The fact that ill-informed patients are more likely to go on to be registered severely sight impaired suggests that they do not know how to report deterioration or change to allow for urgent treatment when required. This means steps aren't taken at the right time to halt further degeneration."

Call for front-line staff equipped to support

Cathy Yelf, Chief Executive of the Macular Society, the national charity for those affected by central vision loss said:

"Around one in every 2,000 people has AMD at 60. However, by the age of 90 it affects one person in five. We are all living longer so the number of people affected is increasing. There are however, quite simple steps to take to lessen the impact of macular conditions. These include changes to diet, lighting levels, UV-blocking glasses, and stopping smoking. Without the right information at the right time, this debilitating condition can cause much more profound problems than necessary."

Cathy continued, "For example, visual hallucinations are a frequent side effect of AMD, and patients may worry unnecessarily that such visions are caused by other conditions such as dementia. Being able to provide them with reassurance in the early stages of diagnosis can make the condition much easier to cope with."

In 2009 the Royal College of Ophthalmologists introduced guidelines to help ensure patients were receiving timely facts and the support needed. The research published today found that since this time, patients have reported an increase in overall satisfaction with the diagnostic consultation, but not with receiving specific aspects of important information and support.

Cathy added: "Those on the front line, such as GPs, optometrists and

ophthalmologists still need support to ensure they are providing vital information to their patients newly diagnosed with AMD about the need for same- or next-day attendance at a hospital eye clinic if they experience changes in their second eye. This is particularly important for [patients](#) who are not being seen regularly for hospital treatment and are left to self-monitor their sight."

As a result of the study the Macular Society is campaigning for better signposting at diagnosis, with medical practitioners able to supply literature such as its [Guide to AMD](#) on diagnosis. The public can contact the Macular Society's helpline directly on 0300 3030 111 or help@macularsociety.org.

More information: Emily M Boxell et al. Healthcare experiences of patients with age-related macular degeneration: have things improved? Cross-sectional survey responses of Macular Society members in 2013 compared with 1999, *BMJ Open* (2017). [DOI: 10.1136/bmjopen-2016-012790](#)

Provided by Royal Holloway, University of London

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