

Living with macular conditions

**Macular Society
funded project**

Understanding the experiences of people with macular conditions

Emily Boxell, PhD student and **Clare Bradley**, Professor of Health Psychology, Royal Holloway University of London

In 1999, a survey was sent to 2,000 randomly selected members of the Macular Disease Society (now the Macular Society). This survey was inspired by the experiences of members of the Macular Society Leicester support group. Together with Dr Mitchell and Professor Bradley, the group members designed a survey that revealed the experience of patients at diagnostic consultations.

From this survey, Mitchell and colleagues (2002, *Br J Ophthalmol*, 86, 777-781) reported a nationwide problem of poor support and information provision to patients with macular conditions. Fourteen years on, a follow-up survey is needed to find out how things have changed.

After the 1999 survey, the Royal College of Ophthalmologists published guidelines aiming to promote good clinical practice and improve patients' experience. New treatment became available for some kinds of wet age-related macular degeneration (AMD) in the form of anti-vascular endothelial growth factor (anti-VEGF) injections. Unfortunately there is no treatment currently available for dry AMD. However, it is important that all patients are referred to low-vision rehabilitation so that they can make the most of the vision they have.

The Macular Society has funded the researchers to lead on the design, analysis and

dissemination of a follow-up survey. This survey replicated key questions from the original survey to enable direct comparison over time. New questions were based on the Royal College of Ophthalmologist guidelines, including questions about information and support provision at, and after, diagnosis.

Additionally there are new questions about delays in the diagnosis of macular conditions, satisfaction levels with treatment, recommendations made (e.g. regularly taking vitamin and mineral supplements) and experiences of low-vision rehabilitation.

This postal survey was sent out to 4,000 members in November. We have received 1,800 replies at the time of writing. All members were given the telephone number of the lead researcher with whom they can arrange a time to complete the survey by phone if preferred.

Member experiences will be compared using data from the 1999 and 2013 surveys. The results will be used to identify

any improvements in service provision as well as any continuing or new concerns. Outcomes will inform subsequent research, update guidelines and inform Macular Society campaigns for improved services for people with macular conditions.

We would like to thank everyone who has completed the Macular Society 2013 Survey.

The Macular Society Survey 2013

Macular Society

This survey is designed to find out about the experiences and views of people with any type of macular condition. If you do not have a macular condition, please return this uncompleted survey in the envelope provided. Please tick the relevant boxes or write in the reply boxes. There are two blank pages at the end if you run out of space.

Your macular condition

1. Do you have age-related macular degeneration (AMD)?
 Yes → If 'yes' please go to Q2) No

If 'no' write the name of your macular condition in the box below and go to Q3.

2a) If you have AMD, which form do you have?
 • Left eye: Wet Dry Don't know None
 • Right eye: Wet Dry Don't know None

2b) If you have AMD, do you know what stage it is at now?
 • Left eye: Early Advanced Don't know None
 • Right eye: Early Advanced Don't know None

2. Date (approximate) of diagnosis of your macular condition:
 a) Left eye: ___/___/___ b) Right eye: ___/___/___

© 2013 Macular Society, 11-13, Southcombe Road, London, SE16 2NR
 Macular Society, 11-13, Southcombe Road, London, SE16 2NR, UK

3