**Retina Outcomes Group (ROG)**

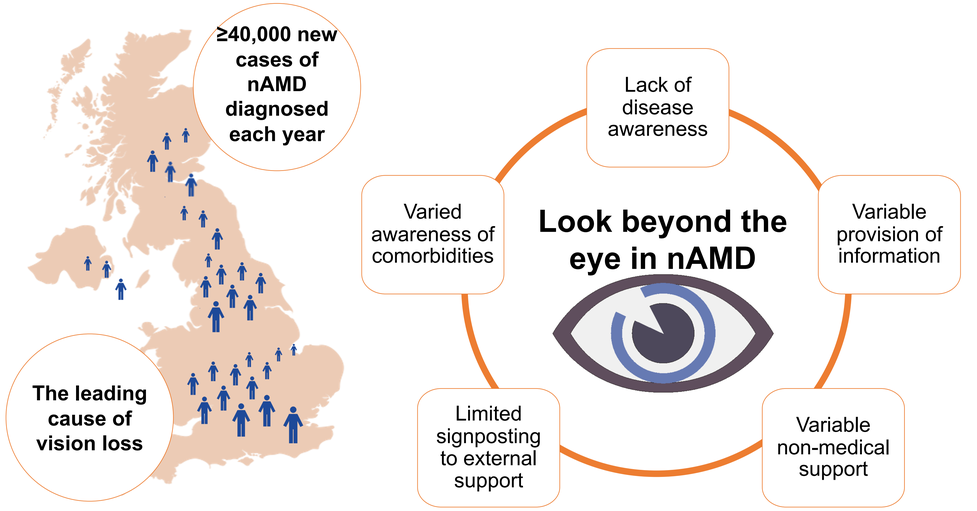
Macular Society

# Treating beyond the eye: Guidance for healthcare professionals on how to improve health literacy for patients living with neovascular age-related macular degeneration (nAMD)


Sajjad Mahmood,[1] Winfried Amoaku,[2] Konstantinos Balaskas;[3] Tomas Cudrnak,[4] Louise Downey,[5] Markus Groppe,[6] Hemal Mehta,[7] Quresh Mohamed,[8] Bushra Mushtaq,[9] Philip Severn,[10] Athanasios Vardarinos,[11] Yit Yang,[12] Cathy Yelf,[13]

[1](Presenting author) University of Manchester, Manchester, UK; [2]Academic Ophthalmology, University of Nottingham, Nottingham, UK; [3]Moorfields Eye Hospital NHS Foundation Trust; [4]University Hospitals Plymouth NHS Trust, Plymouth, UK; [5]Hull University Teaching Hospital, UK; [6]Ophthalmology, Stoke Mandeville, Buckinghamshire Healthcare NHS Trust, Aylesbury, UK; [7]Royal Free London NHS Foundation Trust, London, UK; [8]Gloucestershire Hospitals NHS Foundation Trust, Gloucester, UK; [9]Birmingham and Midland Eye Centre, Sandwell and West Birmingham NHS Trust, Birmingham, UK; [10]South Tees Hospitals NHS Foundation Trust, Middlesbrough, UK; [11]Eye Treatment Centre, West Suffolk NHS Foundation Trust, Bury St Edmunds, UK; [12]Wolverhampton Eye Infirmary, The Royal Wolverhampton NHS Trust, Wolverhampton, UK; [13]Macular Society, Andover, Hampshire.


## Challenge: The UK patient experience varies widely




**Deficiencies in patient support "beyond the eye" can lead to psychological distress, loss of independence and reduced adherence to treatment regimens, leading to poorer outcomes for patients with nAMD**

## Availability, accessibility, acceptability and quality of information

Simple steps to provide crucial information for your patients at key stages of the treatment journey with the aim to standardise across the UK

### HCP support

- Provide verbal and written information to patients, including eye clinic liaison officer (ECLO) contact
- Clinician and/or ECLO: reiterate the typical patient journey and long-term nature of disease
- Tailor support to individual patient needs
- Ensure MDT is appropriately trained and has the available patient resources

### Patient information materials

- Give clear written information, tailored to patients' needs, avoiding medical jargon
- Offer different information at different visits regarding nutrition, comorbidities, cataract surgery
- In the waiting room, provide information posters, leaflets, videos
- Find existing resources, adapt as necessary
- Use clear terminology to avoid confusion

### Signposting

- Signpost patients and HCPs to online information, apps, and charities that provide a wide range of support
  www.macularsociety.org
  www.rnib.org.uk
- With patient permission, consider patients' family, friends and carer when signposting to external support

### The patient journey: Repeated opportunities for information sharing

**Diagnosis** → **1st treatment** → **Aftercare (e.g. ECLO)** → **Regular intervals during the first year of care** → **Beyond 1 year: continue to provide information and support**

**Make every interaction count**

## Methods

- **The Retina Outcomes Group (ROG)** is a forum group consisting of retinal specialists from a variety of NHS hospital ophthalmology departments, who aim to review contemporary issues in retinal disease therapy
- Roundtable meetings between the ROG and Macular Society (facilitated by Novartis UK) explored guidance for HCPs on how to improve health literacy for patients with nAMD

## Conclusion

Taking a holistic "beyond the eye" approach when treating nAMD patients is essential.

These recommendations are designed to help promote best practice, and improve patient experiences and understanding, regardless of where they are being treated.

Every interaction with your patient is essential, and it is important to make every interaction count.


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