



# National Ophthalmology Database Audit

First Annual Report of the Age-related Macular Degeneration (AMD) Audit

**Patient Summary 2023** 

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#### What is AMD and how is it treated?

The macula is the central part of the retina, the lining of the back of the eye. The macula is responsible for our central vision and gives fine detail and colour vision, enabling us to read, watch TV and recognise faces. Macular disease can affect people of any age, and the risk of getting the most common form, known as age-related macular degeneration or AMD, increases with age. At age 60 around one in every 200 people has AMD. However, by the age of 90 it affects one person in five.

AMD is the biggest cause of sight loss in the UK, affecting more than 700,000 people. The wet or neovascular form of AMD develops when new blood vessels grow into the macula. These blood vessels leak fluid and blood into the macula and cause scarring. Common problems include difficulty reading, dark spots in the vision, distortion or bending of straight lines and difficulty adapting when moving from dark to light environments.

The wet form of AMD can be treated if caught early. Medicines used to stop the growth of the abnormal blood vessels help to stabilise vision in most people and many find that their sight improves. The best results are achieved with early treatment. This involves a course of injections into the eye and often continues over several years.

#### What are the aims of the NOD AMD Audit?

Clinical audit is a way to find out if healthcare is being provided effectively and in line with agreed targets and standards. It lets treatment providers and patients know when their service is doing well and if any improvements are needed. The aim of clinical audit is to improve both the way that care is delivered and the treatment outcomes for patients.

The AMD Audit looks at the way that treatment of wet AMD is provided across the UK. The audit aims to provide standards or benchmarks for the way that treatment is given and to improve the results of treatment. By allowing treatment providers to compare their local performance with other units, the audit will encourage all providers to adopt practices in the "best" centres.

# What data is included in the 2022 First Annual report?

The focus of this first annual report is on patients starting treatment for wet AMD in one or both eyes in the 2020 NHS year (01 April 2020 to 31 March 2021). All providers of NHS-funded AMD treatment were invited to take part and to submit routinely collected healthcare data for analysis. Results are available from 63 centres in England, Northern Ireland, Scotland, Wales and Guernsey. For clinical audits, the data is anonymous and individual patients cannot be identified.

## Key findings

# The analysis includes data from more than 20,000 eyes and 18,000 patients starting treatment in 2020/21.



**More than 90% of eyes** retained stable vision at the end of the first year of treatment and avoided a "significant" further decrease in vision. **Almost 20% of eyes (1 in 5)** experienced a "significant" improvement in vision and **more than 40% (4 in 10)** had "good" vision (close to driving standard) after the first year of treatment.

**"Good"** vision acuity was retained in most eyes with this level of vision at the start of treatment but eyes with "poor" vision at the start of treatment rarely achieved "good" vision. This highlights the importance of prompt referral, initial assessment diagnosis and treatment.



**More than 50% (1 in 2) of patients** started treatment within a month of referral and the initial phase of treatment with 3 injections at monthly intervals was completed within 10 weeks in 65% of eyes.

The most frequent number of injections per eye in the first year of treatment was 7 and **almost 70%** (7 in every 10) of injections were administered by trained staff who were not doctors, such as nurses or optometrists.



**Treatment appeared to be safe, with a low number of serious side-effects**. For example, the risk of serious infection after an injection was around **1 in 6,800**.

Levels of vision at the start and end of the first year of treatment, key care processes and the proportion of injections given by non-medical staff varied between centres.

**Almost 12% of patients** did not complete the first year of treatment.

The treatment outcomes from this audit can help patients and their carers make informed decisions around starting treatment when wet AMD is first diagnosed, especially in eyes with "poor" vision at the start of treatment.



Recording of routine healthcare data was generally **above the quality target of 75%** for most items but varied between centres.

The impact of the COVID-19 pandemic on initial referral, the care pathway, data quality and the treatment outcomes for eyes starting treatment in 2020 is not known but comparison with patients starting treatment in earlier years suggests that outcomes were similar.

#### **Recommendations for patients**

- Patients and carers with an interest in wet AMD treatment are encouraged to access information about care pathways and treatment outcomes, either from their local provider or through the full audit report, available on the <u>National Ophthalmology Database Audit</u> website
- Patients and carers whose local AMD treatment provider is not participating in the AMD Audit should encourage the clinical staff to participate. Staff can contact the NOD AMD Audit team directly by email: noa.project@rcophth.ac.uk

- Treatment for wet AMD is more likely to stabilise vision than to improve vision. This re-enforces the need to seek advice promptly in the event of new difficulties with reading, distortion or a central blurred patch in one or both eyes
- Patients and carers should ask staff in their local provider about the expected benefits and the duration of treatment for wet AMD, particularly in eyes with specific levels of vision at the start of treatment
- During treatment for the "first" eye, patients should ask clinical staff at regular intervals if there are any signs of wet AMD in their second eye
- If treatment for wet AMD is ever paused, patients and their carers should be aware that wet AMD can become active again in the treated eye and know how to contact their local provider quickly in the event of new symptoms
- Similarly, if treatment in the first eye is stopped or was not appropriate and no further follow-up is planned, patients and their carers should be aware that more than a third (33%) of people develop wet AMD in their second eye. In the event of new symptoms in the second eye, help should be sought promptly and usually from a local optometrist
- More information and support for patients with AMD and their carers is available from the <u>Macular Society</u> or telephone 0300 3030 111 and the <u>Royal National Institute of Blind People</u> or telephone 0303 123 9999

### Future of the NOD AMD audit

- The NOD AMD Audit will continue to work with NHS Trusts and independent sector treatment providers to improve the data quality for future audits
- Results from the audit will be made available on the National Ophthalmology Database website, allowing elements of the care pathway and treatment outcomes to be compared between centres
- The second audit, planned for 2023, is expected to include data from a greater number of participating centres. This data analysis aims to report 12-month outcomes for eyes starting treatment in the 2021 NHS year, and 24-month outcomes for eyes starting treatment in 2020 NHS year

- With better quality data, the NOD AMD Audit aims to develop a statistical model to improve the comparison of treatment outcomes between different providers. The model will make an adjustment for differences in starting vision and age and help to identify the parts of the care pathway that are the most important to achieve the best treatment outcomes
- The project delivery team for the audit will continue to engage with electronic medical record providers to improve data quality, especially at centres where data quality is poor
- Patient surveys to look at patient-reported outcomes and experiences are being considered as a future option for the NOD AMD Audit

#### **Explanatory notes**



A **"significant"** change in vision is one that most people would be expected to notice and is equivalent to a change of 15 or more letters on an EDTRS vision chart.

In this summary report, **"Good"** vision is equivalent to reading 70 or more letters on an EDTRS chart and **"Poor"** vision is equivalent to reading 35 letters or fewer.

Dry macular degeneration is not included in the audit as there are currently no licensed or approved treatments for this form of macular degeneration.

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