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National Ophthalmology Database Audit

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

Patient Summary 2024

Roche Products Limited have provided funding to support the conduct of this study. Roche Products Limited has had no further involvement in the project. The project has been supported by an unrestricted, hands-off grant provided by Bayer plc. Bayer plc has no involvement whatsoever in the development or implementation of the project. We are grateful for the funding received from these organisations. We also receive ongoing support through subscription fees from participating hospitals.

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, which can 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.

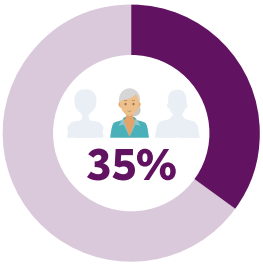
The AMD Audit looks at how treatment of wet AMD is provided across the UK. The audit aims to provide benchmarks and standards for the way that treatment is given and to improve the outcomes of treatment. By allowing treatment providers to compare their local performance with other units, the audit will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

What data is included in the 2024 Second Annual report?

The focus of the second annual report is on patients starting treatment for wet AMD in one or both eyes in the 2021 NHS year (01 April 2021 to 31 March 2022). 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 66 centres in England, Northern Ireland, Scotland, Wales and Guernsey. For clinical audits, the data is anonymous and individual patients cannot be identified.

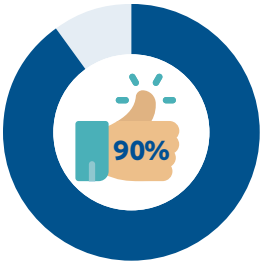
Key findings

The analysis includes data from more than 26,000 eyes and 24,000 patients starting NHS-funded treatment in 2021/22. Most people starting treatment were more than 80 years old and 60% (6 in 10) were women.



More than 35% (1 in 3) of patients started treatment within a month of referral from an optician or GP and the initial phase of treatment with 3 injections at monthly intervals was completed within 10 weeks in 66% of eyes.

The most frequent number of injections per eye in the first year of treatment was 6 and at least **68% (7 in every 10)** of injections were administered by trained staff who were not doctors, such as nurses or optometrists.



90% (9 in every 10) of eyes retained stable vision at the end of the first year of treatment and avoided a "significant" further decrease in vision. Without any treatment, **only 50% (1 in every 2)** of eyes would be expected to keep stable vision (see explanatory note).

Over 16% of eyes (1 in 6) experienced a "significant" improvement in vision and **more than 41% (4 in 10)** had "good" vision (close to driving standard) after the first year of treatment (see explanatory note).

"Good" vision 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.

Visual acuity gains after the first year of treatment were maintained during the second year. The most frequent number of injections per eye during the second year was 5.

Treatment appeared to be safe, with a low number of serious side-effects. For example, the risk of serious infection after each injection was around **1 in 6,500**.

The best outcomes were seen in younger patients, in eyes with better vision when treatment was started and when the initial 3 monthly injections were not delayed. This highlights the importance of prompt referral, initial assessment, diagnosis and treatment and making sure that ongoing treatment is not delayed.

Data for the audit was collected in electronic records as part of routine clinical care. Data quality, 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. One year follow-up data was not available for almost 25% (1 in every 4) of the eyes starting treatment. Follow-up also varied between centres. A goal of the AMD Audit is to reduce this variation so that patients receive the same care and similar outcomes wherever they go for 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.

Recommendations for patients

- Treatment for wet AMD is more likely to stabilise vision than to improve vision. Patients should seek advice promptly in the event of new difficulties with reading, distortion or a central blurred patch in one or both eyes. Use of an Amsler grid may help to identify changes in vision at an early stage.
- Patients and carers should ask staff in their treatment centre about the duration and frequency of treatment for wet AMD and the expected benefits, particularly in eyes with similar levels of vision to their own at the start of treatment.
- During treatment for the "first" eye, patients and their carers 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 it can become active again in the treated eye and know how to contact their treatment centre quickly in the event of new symptoms.
- 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.
- Patients and carers should ask clinical staff if their treatment centre is participating in the AMD Audit and, if not, encourage participation.
- More information and support for patients with AMD and their carers is available from the Macular Society or telephone 0300 3030 111 and the Royal National Institute of Blind People or telephone 0303 123 9999.

Future of the NOD AMD audit

- Results from the audit will be made available on the National Ophthalmology Database website, so that it is possible to compare the care pathway and treatment outcomes at different centres.
- The NOD AMD Audit will continue to work with NHS Trusts and independent sector treatment providers to improve the data quality for future audits.
- The third audit, planned for 2024, is expected to include data from a greater number of participating centres. Data extracted for the third audit will be used to report 12-month outcomes for eyes starting treatment in the 2022 NHS year, and 24-month outcomes for eyes starting treatment in 2021 NHS year.
- 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.

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.

Funding

In the three years since the formal launch in April 2021, the audit has received funding from industry partners. The audit is currently part-funded by Roche Products Limited Ltd and Bayer plc who have funded the AMD Audit since its commencement.

Roche Products Limited have provided a grant to support the development of the audit tool as a non-interventional study. Other than certification of the protocol, Roche Products Limited have had no involvement in the development of the tool or any audit outputs. The project has been supported by an unrestricted, hands-off grant provided by Bayer plc. Bayer plc has no involvement whatsoever in the development or implementation of the project. We are grateful for the donations received from these organisations. We also receive ongoing support through subscription fees from participating hospitals.

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