

National Ophthalmology Database Age-related Macular Degeneration Audit

Patient Information



Why we collect information about Age-related Macular Degeneration (AMD) treatment and how your information is used

What is the National Ophthalmology Database Audit?

The Royal College of Ophthalmologists (RCOphth) runs the National Ophthalmology Database (NOD) Audit in England and Wales, Scotland, Northern Ireland, and Guernsey. The RCOphth NOD Audit collects data on AMD treatment. Estimates presently indicate that around 39,800 people develop AMD in the UK each year. The audit supports improvement in quality of care and is an important quality assurance measure.

What is Age-related Macular Degeneration (AMD)?

Age-related Macular Degeneration affects the part of the retina we use for our central vision, called the macula. There are two forms of AMD – wet and dry. The wet form is due to abnormal blood vessels growing within the macula, which leak fluid, and this can lead to rapid sight loss. Treatment involves regular injections of a drug into the eye. The drug stops new blood vessels growing and reduces the amount of fluid, thereby preventing further damage and maintaining vision. Treatment can be required for many years. Dry AMD is a slow deterioration of the cells of the macula, often over many years, as the retinal cells die off and are not renewed. The term ‘dry’ does not mean the person has dry eyes, just that the condition is not wet AMD.

For more information on AMD please go to:

- <https://www.nhs.uk/conditions/age-related-macular-degeneration-amd/>
- <https://www.macularsociety.org/macular-disease/macular-conditions/wet-age-related-macular-degeneration/>

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Why are we carrying out the NOD Audit?

The NOD audit aims to improve the care that patients undergoing AMD treatment receive. To achieve this, information will be collected on how your hospital is providing care to you to help identify areas that may need improvement.

What information is collected for the AMD audit?

Information can be submitted to the audit by your hospital if you had AMD treatment in England, Wales, Scotland, Northern Ireland, or Guernsey. We cannot identify any individual patient from this information. The information collected, as part of your patient record for AMD treatment, and used by NOD includes:

- Visual acuity (your ability to discern the shapes and details of the things you see)
- The change in visual acuity over time (adjusted for other variables which might affect this)
- Treatment within 14 days of diagnosis, as recommended in the National Institute for Health and Care Excellence (NICE) AMD clinical guidelines: www.nice.org.uk/guidance/ng82

Anonymised data submitted to the NOD shows us if you have had AMD treatment on one or both eyes. The hospital responsible for your AMD treatment can identify an individual patient from this information as it is part of your care record. However, we do not see any information which identifies individual patients. Information submitted into the audit will be retained for the duration of the audit.

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How is the information used?

The information is analysed, and the audit report will help hospitals and consultants to benchmark, improve and balance care across the UK. Although the risk of AMD treatment is on average quite low, the NOD AMD audit aims to further improve the quality of care and patient outcomes. The report is made available to the public, and surgeon and centre reports are published on the NOD website, www.nodaudit.org.uk. We emphasise that no individual patient can be identified from any audit report.

How will your information be kept safe?

There are strict rules about what happens to your data. Information collected is available to a very small number of specially restricted staff on the audit team. The data analyst uses a secure dedicated computer to analyse the information.

The RCOphth and its subcontractors undertake analysis of the data for the purposes of the audit. However, anonymized and / or aggregated information may be requested for research, service evaluation and commissioning purposes, and information will only be released following approval from the data controller. [The Royal College of Ophthalmologists](http://www.rcophth.co.uk) is the data controller and has overall authority over the data and all aspects of its use.

Legal basis for processing your data

The audit is covered under General Data Protection Regulation (GDPR) by the following legal basis for processing your data:

- processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller {Article 6 (1) (e)}
- processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy. {Article 9 (2) (i)}

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Further information

If you have any questions about patient information relevant to the audit, please contact the RCOphth Data Protection Officer, Kathy Evans at noa.project@rcophth.ac.uk.

Telephone: 020 7935 0702 (Monday to Friday, 9am – 5pm)

Website: www.nodaudit.org.uk

Your right to access data may be limited as the information submitted by participating hospitals is anonymous to the audit team. However, you can contact the hospital that provided your AMD treatment if you wish to access your information.

If you have concerns about the way your information is being handled, you have the right to make a complaint with the Information Commissioner's Office (ICO), the independent authority in the UK responsible for upholding information rights in the public interest via telephone on 0303 123 1113 or their website: <https://ico.org.uk/make-a-complaint/>