



Detecting Dementia From a Scan of the Retina Privacy Notice

Who we are

UCL and Moorfields Eye Hospital (“we” “us”, or “our”) are joint controllers for the purposes of data protection legislation.

The Institute of Ophthalmology, which is co-organising this study, is part of the University College London (UCL). UCL, a company incorporated by Royal Charter (number RC 000631), is the entity that determines how and why your personal data is processed. This means that UCL is the ‘controller’ of your personal data for the purposes of data protection law.

Moorfields Eye Hospital NHS Foundation Trust (Moorfields), which is co-organising this study, is an NHS Foundation Trust, authorised under the National Health Service Act 2006. Moorfields is the entity that determines how and why your personal data is processed. This means that Moorfields is the ‘controller’ of your personal data for the purposes of data protection law.

This Privacy Notice

Please read this Privacy Notice carefully – it describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us, both by individuals themselves or by third parties and supplements the following wider UCL privacy notice(s):

[Research participants for health and care purposes privacy notice](#)

Available at: <https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice>

What will the study involve?

By 2025, it is estimated that approximately 1 million people in the United Kingdom will suffer from dementia. Research has shown that people with dementia have changes in the retina, the layer of light-sensitive cells at the back of the eye. The purpose of this study is to link

retinal scans taken between 2008 and 2018 in patients over 40 years of age from Moorfields Eye Hospital with national data on dementia from NHS Digital to see if there are patterns of change, which can help us diagnose and grade the condition. Additional information on risk factors for dementia, such as diabetes mellitus and high blood pressure, will also be received from NHS Digital. In order to link the scans with data on dementia, confidential patient information from Moorfields Eye Hospital will be disclosed to NHS Digital. However, the resulting data will not contain any personally sensitive information and therefore it would not be possible to identify any individual patient from this study.

How long will the study last?

The study is likely to run from 2019 until 2020. Depending on the results found, analysis of the data may continue for a longer period. The data will be securely stored within UCL for 10 years.

What are the data protection measures in place for this project?

Confidential patient information will only be used to facilitate linkage and not be included in any of the analysis. Both Moorfields and NHS Digital will ensure that no personally identifiable data is included in this study. The data will only be accessible to members of the research team.

UCL's lawful bases for processing of the personal data will be:

GDPR Article 6(1)(e) - 'Processing is necessary for the performance of a task carried out in the public interest'.

UCL's lawful bases for processing special category personal data will be:

GDPR Article 9(2)(j) - "the processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes... which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject"

Personal data that we collect about you

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

We may collect, use, store and transfer different kinds of personal data about you. This may include:

- 'Special category data' about you (this may include details about your race or ethnicity, religious or philosophical beliefs, sexual orientation, political opinions, trade union membership, information about your health etc.);

Will any patient information be shared with third parties or commercial organisations?

Beyond the sharing of patient information with NHS Digital for linkage, your patient information will not be shared **with third parties**.

Moorfields Eye Hospital NHS Foundation Trust and University College London are conducting the study. At no point will the data be shared with commercial organisations.

Your rights

Your rights are set out in the Research participants for health and care purposes privacy notice.

International transfers

We do not transfer your personal data outside the European Economic Area.

Information security

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. We have established procedures to deal with any suspected personal data breach and will notify you and any applicable regulator of a breach where we are legally required to do so.

Rights to withdraw consent

Your identifying details have been removed from the data at the first available opportunity and cannot be back tracked to identify you. Therefore, we would be unable to remove you from the study. However, if you have previously registered for the national data opt-out, your data will not be included in this study.

Automated decision-making

There is no automated decision-making in this study. Moreover, the data cannot be back tracked to any individual.

Contact details

You can contact UCL by telephoning +44 (0)20 7679 2000 or by writing to: Data Protection & Freedom of Information Officer, University College London, Gower Street, London WC1E 6BT or data-protection@ucl.ac.uk

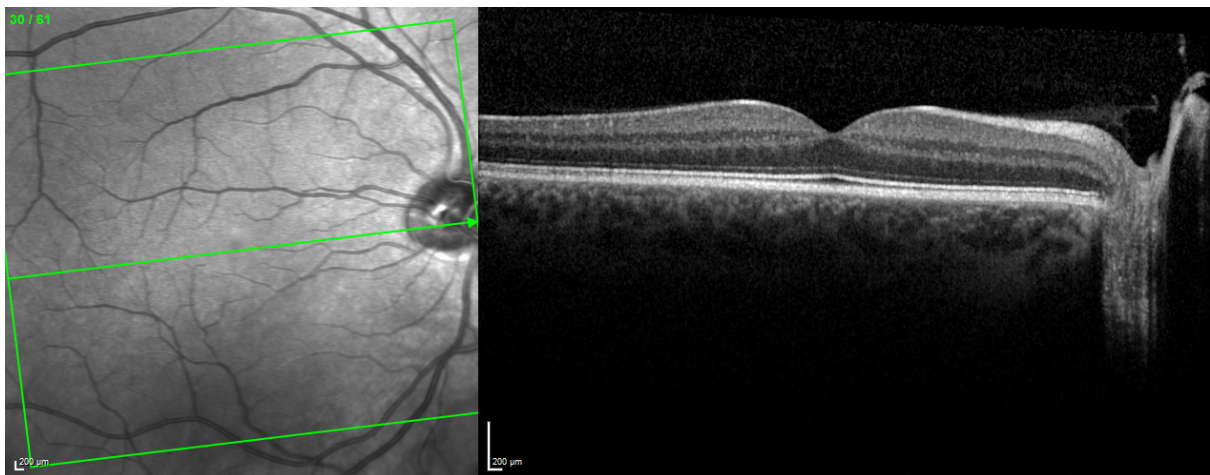
You can contact Moorfields by writing to Research and Development Office, Moorfields Eye Hospital NHS Foundation Trust, 162 City Road, EC1V 2PD or emailing Moorfields.resadmin@nhs.net

How do I complain?

If you wish to complain about any aspect of the study, you may contact the Moorfields Research and Development team or the Patient Advice and Liaison Service (PALS) at Moorfields Eye Hospital.

PALS Office, Moorfields Eye Hospital NHS Foundation Trust, 162 City Road, EC1V 2PD
Telephone: 020 7566 2325
Email: Moorfields.pals@nhs.net

If you prefer to direct your complaint to an independent body, you may contact the Information Commissioner's Office on 0303 123 1113.



Caption: An optical coherence tomography scan (OCT). OCTs are high resolution retinal scans, which take seconds to capture and contain a wealth of information. This study will explore whether we can find signs of dementia in the retina.