

THE OXFORD VASCULAR STUDY (OXVASC) REC: 05/Q1604/70 PRIVACY NOTICE

What is the purpose of the Oxford Vascular Study (OxVasc)?

The Oxford Vascular Study (OxVasc) is a population-based study looking at:

- a) Frequency and outcome following a stroke
- b) Mini strokes known as transient ischaemic attacks (TIA)
- c) Heart attacks
- d) Acute peripheral vascular events (circulatory problems)

The aims of the study are to improve our understanding of these conditions and how better to treat patients.

How is my personal information collected for OxVasc?

Clinical data from the John Radcliffe Hospital is collected to confirm eligibility of participants for research purposes. Personal identifiable information is collected at the beginning of the study:

- a) To allow us to arrange follow-up visits in outpatients or at home
- b) Following any subsequent hospital admissions for up to 10 years by the study team

The legal basis for processing and storage of personal data for OxVasc is that:

- a) **It is a task in the public interest (article 6 (1)(e) UK General Data Protection Regulation (UK-GDPR))**
- b) **It is a required condition under UK-GDPR to process special category (sensitive) personal data:**
 - i) **In the public interest necessary for archiving purposes**
 - ii) **For scientific or historical research purposes**
 - iii) **For statistical purposes (Article 9 (2) (j) UK-GDPR)**

An important part of the follow-up is linking the information provided by participants at recruitment with NHS Digital and civil registration data (centrally held NHS health records) to report the survival rates and cause of death for all participants in the study and further healthcare use (Hospital Episode Statistics). This work will determine how long people live for following a diagnosis of vascular disease, whether they have further health problems and whether they die from problems relating to these or something else. The aim of this to help doctors and patients understand more about the condition, care, treatments and their consequences.

As part of the study a minimum amount of identifiable data (first and last name, date of birth, NHS number) from OxVasc participants will be shared with centrally held health records (NHS Digital) by the University of Oxford (data controller) to carry out linkage between the study data and civil registration healthcare data.

The common law duty of confidentiality is met by participants giving consent to participate in OxVasc. Mortality data (date and cause of death), from the Personal Demographics Service dataset, held by NHS Digital, will then be provided directly back to the study team. These data are provided by NHS Digital on behalf of ONS and is sourced from civil registration data. As soon as the date and cause of death have been linked with the participants study information, any data that could be used to directly identify individuals (name, date of birth, NHS number) will be removed and data will be stored within a highly secure data archive with limited access for designated OxVasc staff for the duration of the study.

Sharing the data

Any personal data that identifies you are collected and managed by the OxVasc team and will not be shared with anyone else, except to obtain health information about you from NHS Digital (see section above). Data obtained from NHS Digital will not be shared with anyone outside the OxVasc study team at the University of Oxford.

Fully anonymised data (not NHS data) collected as part of the study may be shared with other organisations outside the University of Oxford for research to improve healthcare delivery, subject to appropriate agreements being in place and approval by the Principal Investigator- Professor Peter Rothwell.

Who is responsible for the OxVasc data?

The 'data controller' is the University of Oxford and as such is responsible for processing and looking after all study data. Only named members of the OxVasc study team will have access to the data collected as part of the study that is regularly monitored by the Principal Investigator and senior OxVasc Coordinator.

How long will my data be held by OxVasc?

The University of Oxford will hold the minimal personal, identifiable data about you (first and last name, date of birth, NHS number) for up to 10 years after the study has finished as described in the OxVasc participant information sheet. This excludes any research documents with personal information, such as consent forms, which will be held securely at the University of Oxford for 25 years after the end of the study (date of last publication) following which annual reviews of data retention will be undertaken. Research data resulting from the study does not contain any personal data that could identify you.

The current end date for recruitment to OxVasc is March 31st 2022 but the study will extend beyond this date if further funding is secured.

What are my data rights?

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data under the UK General Data Protection Regulation is available on the University of Oxford's Compliance webpage at <https://compliance.admin.ox.ac.uk/individual-rights>

More information about OxVasc, the research team and how we use your data can be found at <https://www.ndcn.ox.ac.uk/research/oxvasc> or if you would like to contact us directly for more information about how we process and protect data collected for research please contact us at the address above.

What if I want to withdraw from the study?

If you are an OxVasc participant, you are free to withdraw your consent for data linkage with NHS Digital at any time by contacting the study team: Email orh-tr.oxvasc@nhs.net or telephone 01865 231601 or write to us at the address above.

Complaints:

If you have further questions or are not happy with the way your personal data has been handled please contact the study team using the contact details above. Alternatively, you can contact the study sponsor on 01865 616480 or email ctrq@admin.ox.ac.uk.

You also have the right to lodge a complaint with the Information Commissioner's Office (0303 123 1113 or <http://www.ico.org.uk>).