

# **Risks and Routes to Reduce Vascular Dementia (R4VaD) study Privacy Statement**

This information is for participants in the Risks and Routes to Reduce Vascular Dementia (R4VaD) clinical research study. The information below details what data is held about you and who holds or stores this.

## **About the study**

Stroke is a highly prevalent disease and is known to be a cause of cognitive impairment and vascular dementia. R4VaD is a UK-wide observational study of cognitive, physical and neuropsychiatric complications after stroke. Patients can experience memory, thinking or mood changes, or dementia, after a stroke but enough is not yet known about how to treat these conditions. R4VaD is looking at these conditions to help more people to make a better recovery.

The aim of R4VaD is to improve our understanding of the rates of and risk factors for post-stroke cognitive impairment (PSCI), while informing patient services, intervention targets and research into mechanisms. We will use information on pre-morbid and pre-stroke cognition, medical, lifestyle and socioeconomic factors collected in our main study and via data linkage to this end. The fundamental questions are: who will develop memory and thinking problems after stroke, why does this happen, how can we treat it?

## **Information about you: how we use it and with whom we share it**

### **The type of personal information we collect**

We currently collect and process your name, Date of Birth (DOB), NHS number and contact details (address, telephone number, email address) along with relevant medical details relating to your stroke.

### **How we get the personal information and why we have it**

The identifiable information you provide will be used by the University of Edinburgh solely for your participation in the R4VaD study.

The University of Edinburgh and/or relevant study coordinating centre will use your name, DOB, NHS number and contact details (address, telephone number, email address) to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the Academic and Clinical Central Office for Research and Development (ACCORD) and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The University of Edinburgh will pass these details to ACCORD along with the information collected from you and/or your medical records. The only people in The University of Edinburgh/ACCORD/relevant study coordinating centre who will have access to information that identifies you will be people who need to contact you to carry out the study (including arranging study appointments) or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

The University of Edinburgh/relevant study coordinating centre will collect information about you for this research study from your patient records. This information will include your name, NHS number, contact details and health information, which is regarded as a special category of information. We will use this information to contact you regarding the study, including arranging your study appointments.

So that we do not need to keep asking you questions and can find out about your health in the years to come (after the active part of Study has finished), with your permission, we will ask the NHS Central Health Records, Hospital Records, Drug prescribing records, NHS England in England and Wales and the Information Statistics Division in Scotland, to give us information about your future health problems or tell us if you have died and the cause. These processes involve sharing your personal identifiable data (including name, DOB, NHS/CHI number) with other organisations to obtain additional information and are closely guarded by data and privacy experts.

Holding and processing of personal data will be under jurisdiction of article 6(1)(e) as 'task carried out in the public interest' and article 9(2)(j) 'processing is necessary for archiving purposes in the public interest, scientific or historical research purposes' of Regulations (EU) 2016/679, April 27th 2016 (the General Data Protection Regulations) and as supported by regulations 8 and 10 and part 1 schedule 1 (4) of the UK GDPR and the Data Protection Act. All investigators and study site staff involved with this study comply with the requirements of the appropriate data protection legislation (including the General Data Protection Regulation and Data Protection Act) with regard to the collection, storage, processing and disclosure of personal information.

You are free to withdraw your consent at any time and without giving a reason. Deciding not to take part, or withdrawing from the study, will not affect your healthcare, or your legal rights. If you withdraw from the study, we will keep the information about you that we have already obtained.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible

When you agree to take part in a research study, the anonymised results of this study may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you. It will not be used to make decisions about future services available to you.

## **How we store your personal information**

Your information is securely stored. All information that we record about you will be kept in the strictest confidence. The data that we collect for the Study will be held in a special secure computer record at the University of Nottingham where we have lots of experience of records in stroke studies. The Study information is only identified by your Study number, not by any personal information such as your name. The paper questionnaires and consent forms will be stored at each hospital in special research areas in secure cabinets in case they need to be checked. So that we can contact you during the study, your name and contact details will be stored in a separate secure computer record also at the University of Nottingham, and will only be seen by approved study team members and by the computer programmer in charge.

The University of Edinburgh will keep identifiable information about you from this study for a period of 5 years after the study has finished.

## **Your data protection rights**

Under data protection law, you have rights including:

**Your right of access** - You have the right to ask us for copies of your personal information.

**Your right to rectification** - You have the right to ask us to rectify personal information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

**Your right to erasure** - You have the right to ask us to erase your personal information in certain circumstances.

**Your right to restriction of processing** - You have the right to ask us to restrict the processing of your personal information in certain circumstances.

**Your right to object to processing** - You have the the right to object to the processing of your personal information in certain circumstances.

**Your right to data portability** - You have the right to ask that we transfer the personal information you gave us to another organisation, or to you, in certain circumstances.

You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

Please contact us if you wish to make a request.

## **Our contact details**

If you have any questions, please contact the R4VaD study team at:

[R4vad@ed.ac.uk](mailto:R4vad@ed.ac.uk)

R4VaD study team,  
Centre for Clinical Brain Sciences, University of Edinburgh,  
49 Little France Crescent,  
Edinburgh, EH16 4SB  
0114 242 9599

## **How to complain**

If you have any concerns about our use of your personal information, you can make a complaint to the University of Edinburgh's Data Protection Officer at: [dpo@ed.ac.uk](mailto:dpo@ed.ac.uk)

You can also complain to the ICO if you are unhappy with how we have used your data.

The ICO's address:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

Helpline number: 0303 123 1113

ICO website: <https://www.ico.org.uk>