**General Data Protection Regulation (GDPR)**

**Information for close relative/friend**

**Rates, Risks and Routes to Reduce Vascular Dementia (R4VaD)**

The EU General Data Protection Regulation (GDPR), along with the new UK Data Protection Act, will govern the processing (holding or use) of personal data in the UK.

You are receiving this as your close relative/friend is a participant on this clinical research study. The information below details what data is held about the participant and who holds or stores this.

The University of Edinburgh and NHS Lothian are the co-sponsors for this study based at several sites across the United Kingdom. We will use information from the participant and/or their medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after their information and using it properly. The co-sponsors will keep identifiable information about the participant for a minimum of 5 years.

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

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| **Providing personal data directly e.g. verbally, in a questionnaire or from their care provider** |

The University of Edinburgh and/or relevant study coordinating centre will use the participants’ name, Community Health Index (CHI) number and contact details (address, telephone number, email address) to contact them about the research study, and make sure that relevant information about the study is recorded for their 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 their 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 the participant and/or their medical records. The only people in The University of Edinburgh/ACCORD/relevant study coordinating centre who will have access to information that identifies the participant will be people who need to contact them 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 the participant and will not be able to find out their name, CHI number or contact details.

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

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| **Providing personal data indirectly e.g. from medical records** |

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

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| **Use of data for future research** |

When you agree for your close relative/friend to take part in a research study, the information about their health and care 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. The participants’ 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](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/)**.**

This information will not identify the participant and will not be combined with other information in a way that could identify them. The information will only be used for the purpose of health and care research, and cannot be used to contact the participant or to affect their care. It will not be used to make decisions about future services available to them, such as insurance.

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| **Contact for further information** |

You can find out more about how we use your information and our legal basis for doing so in our Privacy Notice at [www.accord.scot](http://www.accord.scot).

For further information on the use of personal data by NHS sites, please link to the Health Research Authority (HRA) website; <https://www.hra.nhs.uk/information-about-patients/>.

If you wish to raise a complaint on how we have handled personal data, you/the participant can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing their personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO) at <https://ico.org.uk/>.

Data Protection Officer contact information:

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| **University of Edinburgh**  Data Protection Officer  Governance and Strategic Planning  University of Edinburgh  Old College  Edinburgh  EH8 9YL  Tel: 0131 651 4114  [dpo@ed.ac.uk](mailto:dpo@ed.ac.uk) | **NHS Lothian**  Data Protection Officer  NHS Lothian  Waverley Gate  2-4 Waterloo Place  Edinburgh  EH1 3EG  Tel: 0131 465 5444  [Lothian.DPO@nhs.net](mailto:Lothian.DPO@nhs.net) |