



ACST-2 Personal Data Privacy Notice

There are changing data protection regulations that researchers need to follow, and these laws require us to disclose your rights and how we will use your data.

The 'data controller' for ACST-2 is the University of Oxford, which is responsible for deciding how any personal data collected during ACST-2 are processed and will ensure data protection laws are followed. We will only process personal data as necessary for the performance of such research being carried out in the public interest. This is known under data protection law as our 'legal basis' for processing personal data.

During your participation in ACST-2, you provide(d) personal data about yourself, such as information on your medical condition and medical history to your doctors at your local hospital and also to the ACST office in Oxford when you complete the Annual Questionnaire. These data are entered into a computer system managed by the University of Oxford and stored securely. Only staff with appropriate training and permission can access this computer system.

What will happen to information about me?

In ACST-2, personal data that directly identifies you such as your name, address, or date of birth (so-called "personal identifiers"). Such 'personal identifiers' will be held securely in Oxford for up to 5 years after the scheduled end of the study (i.e. 2030) to enable long-term follow-up of all participants until 2025 and further contact with a smaller number of people (e.g. those who may have had a stroke) if considered necessary. We will not send these personal identifiers to anyone else. To help keep your information confidential, the information recorded about you in this study is 'de-identified', which means that your health information is labelled with an unique study ID number and not with your name.

Only this de-identified data will be used for the following purposes:

- analysis of the study results
- to help learn more about the best way to treat narrowed neck arteries to prevent stroke
- to do future research
- to write scientific articles on stroke prevention
- to help design and conduct future studies

It may be necessary for copies of the de-identified database to be shared with health regulators (such as the UK Medicines and Healthcare Regulatory Agency) and ethics committees, and it may be shared with other bona fide researchers.

The University of Oxford will keep all the study data and any research documents with personal information, such as consent forms, safely for at least 25 years after the end of the study, and perhaps longer if required by the law or other research needs.

What are my data protection rights?

If you decide that you do not want any new information about you to be collected and used for the study (known as 'withdrawal of consent'), please let the ACST-2 office know (see contact details below) and we will not collect any further information from you. All information that we have already collected will still be kept and used for the study.

You have the right to know what personal data the University of Oxford hold about you and to have a copy of that data. You also have the right to correct wrong or outdated personal data and request the deletion of your data. However, we may be obliged by law to keep your data to ensure consistency and reproducibility of the results and we cannot delete data that has already been used in analyses (please note that such analyses are run regularly throughout the study).

You also have the right to restrict or object to what we do with your data, or to request that your data be transferred elsewhere. However, your rights to access, change, or move your personal information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at <http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/>

If you would like to exercise any of these rights or have other concerns about the way we have handled your personal data, please contact us; acst@nds.ox.ac.uk or **+44 (0)1865 617979** and we will work with you to try to resolve matters. You may also contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on **01865 616480**, or the head of CTRG, email ctrq@admin.ox.ac.uk

If you remain unhappy, you may lodge a complaint with the Information Commissioner's Office (telephone **0303 123 1113** or www.ico.org.uk).