

Data Privacy Notice

ISIS-2: Second International Study of Infarct Survival

1. What is the purpose of this document?

The University of Oxford is committed to protecting the privacy and security of your personal information ('personal data').

This privacy policy describes how we collected and used your personal data during your participation in the ISIS-2 Study in accordance with the General Data Protection Regulation (GDPR).

It is important that you read this policy so that you are aware of how and why we are using your information. We may update this policy at any time.

2. Glossary

Where we refer in this policy to your 'personal data', we mean any recorded information that is in relation to you and from which you can be identified.

Where we refer to the 'processing' of your personal data, we mean anything that we do with that information, including collection, use, storage, disclosure or retention.

3. Who is using your personal data?

The University of Oxford¹ is the "data controller" for the information that we obtained from you or others as part of the ISIS-2 study. This means that we decide how to use it and are responsible for looking after it in accordance with the GDPR.

Access to your data will be provided to designated members of our staff who need to view it as part of their work in carrying out the purposes set out in [Section 5](#). We also share it with the third parties described in [Section 6](#).

4. The types of data we hold about you and how we obtained it

We collected information directly from you, when you were recruited into the ISIS-2 study. This information includes the personal details provided by you on study questionnaires at recruitment between 1985 and 1987. This information includes name, address and date of birth, and special categories of more sensitive personal data including health-related data related to your hospitalisation and treatment around the time of randomisation.

We may also have collected blood samples from you, and derived biochemical and genetic data from these samples.

We also collected additional information from third parties including from the National Health Service (NHS Digital in England (previously information was received from the Office of National Statistics & the Health & Social Care Information Centre), and the National Records of Scotland (previously information was received from the General Register Office for Scotland)). This information includes special category sensitive data concerning your health, such as information about death and cancer registrations.

¹ The University's legal title is the Chancellor, Masters and Scholars of the University of Oxford

5. How the University uses your data

During the main trial and the 10-year follow-up we used data collected from you to investigate the effects of aspirin and streptokinase given to participants after having a heart attack. We combined the information you gave us with the information we collected from third parties. For example, to study the long-term survival of participants we used linked death data. Using this information the ISIS-2 trial demonstrated that the early survival advantages produced by fibrinolytic therapy (streptokinase) and one month of aspirin in acute myocardial infarction seemed to be maintained for at least 10-years.

While there is no specific research currently being conducted using this data, we are retaining data for the purposes of conducting future long-term follow-up over several decades.

The lawful basis for the processing and storage of your personal data for ISIS-2 is that it is 'a task in the public interest' - GDPR Article 6(1)(e) - and, that sensitive personal data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes - GDPR Article 9(2)(j).

We will only process your personal data for the purposes for which we collected it (i.e. medical research into the effects of aspirin and streptokinase given to participants after having a heart attack), unless we reasonably consider that we need to use it for another related reason and that reason is compatible with the original purpose. We will not use your data for any unrelated purposes. We do not use your personal data for any form of automated decision making or public profiling.

Please note that we may process your data without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

The University of Oxford Policy on Data Protection can be accessed via the following link <https://www.admin.ox.ac.uk/councilsec/compliance/gdpr/universitypolicyondataprotection/>

6. Who has access to your data?

Access to your data within the University will be provided to those who need to view it as part of their work in carrying out the purposes described above.

In addition, in order to perform our research and other legal responsibilities or purposes, we will, from time to time, need to share your information with the following:

- external organisations providing services to us, including those who provide us with data; and,
- external regulatory bodies.

Where information is shared with these third parties, we will share the minimum amount necessary, and it will be de-identified where possible.

7. Transfer of your data outside of the European Economic Area (EEA)

Your data is securely stored on our secure servers and/or at our premises within the UK. Your data will not be transferred outside of the EEA.

8. Retention Period

University of Oxford is required to keep information collected about you for at least 25 years after the "end of the study". Information may also be kept for longer if required by law or for research purposes.

9. Security

Your data will be held securely in accordance with the University's policies and procedures. Further information is available on the University's Information Security website:

<https://www.infosec.ox.ac.uk/>.

10. Your rights

Under certain circumstances, by law you have certain rights with respect to your data. A summary of these rights is available here:

<http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/>.

If you want to exercise any of the rights described or are dissatisfied with the way we have used your information, please contact the University's Information Compliance Team at

data.protection@admin.ox.ac.uk. The same address can be used to contact the University's Data Protection Officer.

You also have the right to lodge a complaint with the Information Commissioner's Office at

<https://ico.org.uk/concerns/> or 0303 123 1113.

11. Changes to this privacy notice

We reserve the right to update this privacy notice at any time, and will seek to inform you of substantial updates. We may also notify you in other ways from time to time about the processing of your personal data.

12. Contact

If you wish to raise any queries or concerns about this privacy notice please contact us at isis.ehr.comms@ndph.ox.ac.uk, or write to: ISIS Legacy Studies, Clinical Trial Service Unit, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Roosevelt Drive, Oxford OX3 7LF, UK.