

SEARCH Legacy Privacy Notice

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 collect and use your personal data during and after your participation in SEARCH 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.

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 data controller for this study is the University of Oxford¹ (University Offices, Wellington Square, Oxford OX1 2JD). The data controller decides how to use your personal data and is responsible for looking after it in accordance with the GDPR.

The University of Oxford's Data Protection Officer can be contacted via data.protection@admin.ox.ac.uk.

The University of Oxford is a world-leader in developing systems to ensure that information is stored safely for studies like the SEARCH. Information held about participants is only used for medical research purposes and for routine regulatory and audit purposes. The University of Oxford uses GDPR Articles 6(1)(e) and 9(2)(j) as the legal basis for processing personal and sensitive data. Where the University of Oxford is using information for medical research purposes, it will only process personal data as necessary for the performance of such research being carried out in the public interest.

4. How is information about me collected by the SEARCH study?

You may recall that SEARCH study clinics stopped in 2008. We hold information that we collected directly from you at clinic visits. This information includes name, address and date of birth, and special categories of more sensitive personal data including health-related data about medical history, hospital admissions, and factors such as height, weight, blood pressure. We hold information about blood samples that you may have provided us at clinic visits, which may include derived biochemical and genetic data.

We also hold data collected from third parties including the ONS and NHS Digital. This information includes special category sensitive data concerning your health, such as information on death and cancer registrations, and hospital admissions (called Hospital Episode Statistics or HES).

The major aim of the long term follow up of the SEARCH trial is to assess the effect of LDL-cholesterol lowering on dementia, major vascular diseases (such as heart attack and stroke) and death in people with previous vascular diseases.

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

For this long-term follow-up legacy study, we will link participants with the Office for National Statistics (ONS) mortality dataset, provided by NHS Digital on behalf of ONS, sourced from Civil Registration Data. We will obtain mortality data (date of death) held by NHS Digital and NHS Scotland.

We will use a new linkage to additionally link participants to hospital NHS electronic health records (hospital admissions, cancer registrations, hospital out-patient and mental health information) in Wales (NHS Wales Informatics Service), Scotland (Information Service Division, Public Health Scotland) and England (NHS Digital). This will allow us to compare rates of important health outcomes, including all cardiovascular events and dementia, experienced by participants in different randomised groups.

5. How does the University use your data?

The lawful basis for the processing and storage of personal data for SEARCH is that it is 'a task in the public interest' (article 6(1)(e) EU General Data Protection Regulation (GDPR)) and, that sensitive personal data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes (article 9(2)(j), based on Article 89(1) GDPR).

We send your identifiable data (name, date of birth, NHS number and postcode) to NHS Digital who have a record of all hospital admissions and outcomes data from the Hospital Episode Statistics (HES) dataset and will link this information to individual participants in the study. NHS Digital also provides us with information relating to cancer registrations on behalf of Public Health England (PHE). In addition NHS Digital provide us with information about participants who may have passed away, which includes date and cause of death and is sourced from civil registration data. The Information Services Division, Public Health Scotland will provide us with similar data for patients that live in Scotland and the NHS Wales Informatics Service will provide us with Patient Episode Data for patients that live in Wales. We may also request linkage to cancer registration data from Public Health Wales or the Secure Anonymised Information Linkage (SAIL) databank and equivalent registries in Northern Ireland for participants who reside there.

The data that we receive and analyse will be identified by a trial number only, and will not be identified by name, date of birth, NHS number or address. With the trial number, we will link to the original SEARCH database, and additional biological information collected during the trial (i.e. blood tests). This information received from NHS Digital and other registries will be imported into a database held securely by the University of Oxford and used solely for medical research purposes. Before analysing this complete dataset (including information already provided by trial participants with information from NHS Digital) personal identifiers will be removed. Importantly, whilst the information received is specific to each trial participant, no individual person will be identifiable in any publication arising from this work.

We will only process your personal data for the purposes for which we collected it as described in our SEARCH Legacy Study Protocol (<https://www.ctsu.ox.ac.uk/~search/>), 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.

Participants provided consent to take part in the main SEARCH trial. We have special permission from the Confidential Advisory Group to conduct the SEARCH Legacy study without reconsenting participants (i.e. to link, transfer, process and analyse the data). This permission is given under

Section 251 of the National Health Service Act 2006 and its current regulations, the Health Service (Control of Patient Information Regulations 2002) (CAG reference number: 19CAG0167).

This study has been reviewed and approved by the West of Scotland REC 3 Re Ethics Committee, reference number 19/WS/0115. To find out more about this long term follow up please see SEARCH Legacy Study Follow-up Protocol at <https://www.ctsu.ox.ac.uk/~search/>.

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 pseudonymised where possible.

7. Transfer of your data outside 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

The 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.

When there is no longer any requirement to keep the data it will be deleted.

9. Is the information about me collected by SEARCH secure?

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/>.

Access to the computer database is by unique combinations of usernames and passwords and only authorised study personnel can access information about participants. The building is secure with authorised swipe card access only. No individuals will be identified in any publications arising from this work.

The personal identifiers, including your NHS number, name, gender and date of birth, are removed from the data on receipt from NHS Digital and other data providers, and stored securely in an encrypted container within the Nuffield Department of Population Health (NDPH). Researchers at the NDPH will work with the "de-identified" data. De-identified means that health information are labelled with unique numbers linked inside a computer and not by name. It would be very difficult for anyone to re-identify participants after de-identification as we use special measures to protect data, but it remains theoretically possible.

10. How do I find out what data is held about me?

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, the study may be obliged by law to keep data to ensure consistency and reproducibility of the results and we cannot delete data that has already been used in analyses (note that 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, sometimes the data controller may not be able to (or have grounds not to) follow a request, for example, if we consider that deleting data would seriously harm the research.

See [Section 13](#) for full details of your rights.

11. What if I no longer wish for my information to be accessed or used in SEARCH?

For the long-term results of SEARCH Legacy Study to be as reliable as possible, the study team need to try to find out what has happened to everyone who initially agreed to enter the trial. If you do not wish to have information about you collected or recorded then you should inform the study team using the contact details below in [Section 13](#). You do not need to give a reason and this will not affect your usual medical care in any way.

12. 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 via our website <https://www.ctsu.ox.ac.uk/~search/>.

13. Your rights and who to contact for further information

If you decide you do not want your study data to be linked in this way you can withdraw from this follow-up, without affecting your current medical care, by contacting the SEARCH study team, who would require your identifiers to then inform NHS Digital that you no longer wish to be part of the cohort. NHS Digital will no longer provide us with data for anyone who has withdrawn consent.

Further information about your rights with respect to your personal data is available at <https://compliance.admin.ox.ac.uk/individual-rights> or by contacting the study team using the details below.

If you want to exercise any of your rights under the GDPR or are dissatisfied with the way we have used your information, you should contact the University's Information Compliance Team via data.protection@admin.ox.ac.uk.

You also have the right to lodge a complaint with the Information Commissioner's Office 0303 123 1113 or www.ico.org.uk.

If you have further questions please contact the SEARCH study team using the contact details below or alternatively you can contact the study sponsor on 01865 616480 or ctrg@admin.ox.ac.uk.

Email: search@ndph.ox.ac.uk

Address: SEARCH, CTSU, Nuffield Department of Population Health, Richard Doll Building, Old Road Campus, Oxford OX3 7LF, UK.