

SEARCH Legacy Privacy Notice

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.

For this follow-up 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, hospital out-patient and mental health information) in Wales, Scotland and England. This will allow us to compare rates of important health outcomes, including all cardiovascular events and dementia, experienced by participants in different randomised groups.

Research is a task that we perform in the public interest. The University of Oxford, as sponsor, is the data controller. This means that we, as University of Oxford researchers, are responsible for looking after your information and using it properly. We will use the minimum personally-identifiable information possible. The University's Data Protection Officer can be contacted at data.protection@admin.ox.ac.uk.

The legal 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 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 additionally biological information collected during the trial (i.e. blood tests). This information received from NHS Digital will be imported into a database held securely by the University of Oxford and used solely for academic 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. Your personal data will not be shared with any 3rd parties and will not be used for any automated decision making or profiling. If you would like to have this data withdrawn, please contact the study team using

the details given below. We will continue to store the data we already hold about you in accordance with your consent to the SEARCH study.

Although participants have already given consent for the trial to be supplied with information about serious illnesses, we have updated the arrangements so that they are compliant with current data regulation laws. Therefore, under Section 251 of the NHS Act 2006, we have obtained permission to conduct this study without further consent.

We have special permission to conduct the SEARCH study without study-specific consent (i.e. link, transfer, process and analyse the data) from the Confidential Advisory Group. 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: 19CAG0166).

Anonymous results of the study may be made available to collaborators and relevant bona fide researchers according to the Nuffield Department of Population Health (NDPH), University of Oxford data sharing policy: <https://www.ndph.ox.ac.uk/about/data-access-policy>.

This study has been reviewed and approved by the West of Scotland REC 3 Research Ethics Committee, reference number 19/WS/0116. To find out more about this long term follow up please see SEARCH Legacy Study Follow-up Protocol <http://www.ctsu.ox.ac.uk/~search/>.

How to withdraw your data, or get further information about your personal data rights

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 would like to discuss this further, or are not happy with the way the SEARCH study team have handled your data, please contact the SEARCH coordinating centre using the contact details below or alternatively you can contact the study sponsor on 01865 616480 or ctrg@admin.ox.ac.uk. You 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 at the following email address:-

Email: search@ndph.ox.ac.uk

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