



## Heart Protection Study (HPS) 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 HPS 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 Oxford<sup>1</sup> (University Offices, Wellington Square, Oxford OX1 2JD). The data controller decides how to use your data and is responsible for looking after it in accordance with the GDPR.

The University of Oxford is a world-leader in developing systems to ensure that information is stored safely for studies like the Heart Protection Study. 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.

The University of Oxford's Data Protection Officer can be contacted via [data.protection@admin.ox.ac.uk](mailto:data.protection@admin.ox.ac.uk).

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

You may recall that HPS study clinics stopped in 2000-2001, and the last postal questionnaires were mailed out in 2007. We hold information that we collected directly from you at clinic visits and from questionnaires that you completed and returned to us. 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, NHS (NHS Digital in England, the Information Services Division in Scotland and the NHS Wales Informatics Service), and your General Practitioner (GP). This information includes special category sensitive data concerning your health, such as information on death and cancer registrations, hospital admissions (called Hospital Episode Statistics or HES) and mental health data sets.

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



As part of the HPS long-term follow-up, we will continue to collect data from these third parties.

We will use this information to learn more about the long-term benefits and safety of statins (and also anti-oxidant vitamins). Statins are one of the most widely prescribed drugs worldwide, and very long-term follow-up of a large randomised trial like HPS provides uniquely reliable evidence about the protection such drugs provide against heart attacks and strokes, and also allows detection of any delayed hazards associated with lowering cholesterol which may take many years to emerge.

We have taken the opinion of the South Central – Oxford B Research Ethics Service, who have granted approval for this legacy study.

Participants in HPS were recruited to the main trial using informed patient consent as a legal basis to process data. However, after advice from NHS Digital and the Confidentiality Advisory Board (CAG) we have section 251 support provided by the [HRA](#) which permits us to use confidential patient information for the purposes that we have described to carry-out long-term research on this cohort.

## 5. How does the University use your data?

The lawful basis for the processing and storage of personal data for HPS 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)).

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) and mental health datasets and will link this information to individual participants in the study. NHS Digital also provide 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 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 similar data from the equivalent registries in Northern Ireland for participants who reside there.

Using the trial ID number we will link to the original HPS database and also biological information collected during the trial (i.e. blood tests).

We will only process your personal data for the purposes for which we collected it as described in the HPS Protocol, 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://compliance.admin.ox.ac.uk/data-protection-policy>

## 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 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

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 HPS 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 and how to contact us.

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

For the long-term results of HPS 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.hpsinfo.org/>.

### 13. Your rights and who to contact for further information about data privacy

Under certain circumstances, by law you have certain rights with respect to your data. A summary of these rights is available here: <https://compliance.admin.ox.ac.uk/individual-rights>.

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](mailto: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](http://www.ico.org.uk).

If you would like to withdraw (opt out) or discuss your ongoing participation in this research please contact the HPS study team using the contact details below.

**Telephone:** 0800 585323

**Email:** [hpsinfo@ndph.ox.ac.uk](mailto:hpsinfo@ndph.ox.ac.uk)

**Address:** Dr Richard Bulbulia, Heart Protection Study (HPS), Clinical Trial Service Unit (CTSU), Nuffield Department of Population Health, Richard Doll Building, University of Oxford, Old Road Campus, Roosevelt Drive, Oxford OX3 7LF

You can also contact the study sponsor on 01865 616480 or [ctrng@admin.ox.ac.uk](mailto:ctrng@admin.ox.ac.uk).