

London School of Hygiene & Tropical Medicine – Privacy Notice for Research Participants

Thank you for agreeing to help us with one of our research studies. This privacy notice explains how we will keep your personal data safe, how and when we will use it, and what happens if you decide to stop being part of the study.

We are the London School of Hygiene & Tropical Medicine, or “LSHTM” for short. We are a university in the UK with registration number RC000330 and we have been around for over 100 years. Our main office is at Keppel Street, London, WC1E 7HT. When we talk about using your personal data in the research study, legally we are what is called the “data controller. We will treat your personal data safely and carefully, and we will obey all relevant data privacy laws.

If you want to know more, we have a [Data Protection Policy](#) which we will also follow. If you have any questions or concerns about how we use your personal data, please email dpo@lshtm.ac.uk.

Research data

You probably already share your data with people, for example your employer if you have a job, your doctor if you get sick, or retailers if you shop online. When you share your data as part of a research study, the rules about how your data can be used are slightly different.

An example of this is that once we have collected your data for this study, we will normally write it down next to a unique number. The people who do day-to-day work on the study, and who analyse the data, will not be able to see your name or other identifying information like your birth date or address. In some studies, we will keep your name and unique number in a separate list, in case we need to follow up with you for any reason, like arranging a further appointment, or for your safety. If so, we will keep the list separately from the study data. Only a very small number of people will be allowed to get access to the list and they will have to follow strict rules about what they can do with it.

For example, if you helped us with a study about eyesight, we might use your name and address to check who you are, and then we might take some measurements about how well you can see. We would write these measurements next to your unique number. If we needed to test you again, one of the small number of people on the study team who can access the list would use your unique number to find your name and contact details so that we could invite you back. Once we had taken your new measurements, we would write them down next to the same unique number as before. When we had enough measurements for the study, we would destroy the list which has your name and contact information. From that point, nobody would be able to tell which measurements were yours, but we would be able to use the results for our research.

If at that stage you decided you did not want to help with the study any more, we would not contact you any more. But we may need to keep your data if we were unable to tell which measurements were yours. Also, in some situations, we may be allowed to keep data we have already collected from you, if you decide not to help any more. For example, we may be allowed to keep your data if we need results from a certain number of people, and losing your data would take us below that number.

How we get data about you

We ask you questions, and we might measure or observe you. Please see the Participant Information Sheet for more details about how we get your data.

What data we will use

We will only collect the minimum of data that we need for the study. Please see the Participant Information Sheet for details about what data we will use.

Why we are using your data

We want to use your data for research purposes. We will use the results to see if the study could help others. We will not use your data for anything else. We will not share any data that could identify you with anyone who is not working on the study with us. Please see the Participant Information Sheet for more details.

How long we will use your data

Usually, we only keep your personal data for the minimum time necessary. If we can delete data such as your name and contact details, we will do that as soon as we can, and just use your unique number. If we need to keep data such as your name and contact details we will keep them very securely, and usually for ten (10) years after the end of the study. It is then securely destroyed.

We may also share data from the study with other researchers or add it to a public repository so that other scientists can conduct research with the full data set. Before we do so, we would always remove data that could identify you, like your name and contact details, and would only refer to the unique number. This means you would not be identified. Please see the Participant Information Sheet for more details.

Legal basis for using your personal data

The data protection laws in the UK changed in May 2018. Under these new laws we have to say how we are lawfully going to use your data. (If you are interested, you can find out more about the law by visiting the Information Commissioner's Office website at www.ico.org.uk.)

Research

Legally, we consider that our research is *"a task carried out in the public interest"*. We use your data because it is necessary for *"scientific or historical research purposes or statistical purposes"* and we use appropriate safeguards. Sometimes we will archive data, for example so that other research teams can check that we have not made any mistakes, but data that could identify you, like your name and contact details, will have been taken out of our records by then.

Your consent

We will ask you to consent to helping us with the study. This is an important way to be sure that you are helping us because you want to, not because you feel under any pressure to help. Importantly, though, we do not process your research data on the basis of consent. This is because we may sometimes need to keep people's data even if they decide not to help with the study any more.

Protecting your interests

The design of all of our studies is checked by a committee of people trained in ethical issues. Before the study team is even allowed to speak to you about the study, these people make sure that your privacy rights have been considered and protected.

Transferring personal data outside the European Economic Area (EEA)

Occasionally we work with organisations around the world. If we share your data with anyone outside the EEA, we will only do so once we have written agreement from them that they have the right systems in place to protect your information and your privacy rights.

Contact details for queries

If you want further information about how your personal information is used or want to correct, restrict or erase personal details, please consult www.lshtm.ac.uk/dpo or contact dpo@lshtm.ac.uk.