



Research Participant Privacy Notice

Introduction

This notice explains how the Liverpool School of Tropical Medicine (LSTM) looks after data about research participants.

This only applies to research where LSTM is the sponsor. If you are a participant in a research study with a different sponsor, please refer to that organisation's privacy notice instead. The sponsor should be named in your Participant Information Sheet.

We sometimes update these notices. You can find the latest notices on our website: <https://www.lstmed.ac.uk/lstm-privacy-statement>

What information is being used?

LSTM sponsors a range of research studies, including clinical trials. Some research only involves LSTM. Sometimes other organisations also work with the research data.

For most research we ask for consent from participants. Consent helps LSTM use information ethically. Consent is not the legal reason for LSTM using your data. The legal reason for LSTM doing research with participant data is described in law as the "performance of a task carried out in the public interest" (GDPR Article 6.1e). Sometimes we need another legal reason. This could be "for the performance of a [research] contract", or "compliance with a legal obligation", or for "vital interests". If you have volunteered to be contacted about future research projects, we use the "legitimate interests" reason (see the [Research Volunteers privacy notice](#) for more information).

Often research at LSTM involves sensitive information about health or ethnicity. When these kinds of data are used, we need another legal reason. The most common legal reason for research is "archiving, research and statistics" (GDPR Article 9.j). This applies to research agreed by a research ethics committee (Data Protection Act 2018, Part I, Schedule I). Other legal reasons might be "explicit consent", "vital interests", "health and social care", or "public health".

Who is using this information, how and why?

We use the information to meet the aims of the research. Your Participant Information Sheet should describe these aims, what information is collected about you, and who will use the data.

Storing and updating your information

It can take years after collecting information to publish the research. Data are usually kept for at least 5 years. Some clinical trials must keep data for over 20 years.

Your consent form contains your name, signature, and other details. This is kept separately from the data analysed by the researchers.

We sometimes share data with other researchers. Unless you give consent for sharing identifiable data, before sharing we remove data that could identify you, like your name and contact details.

Your Participant Information Sheet will outline who to contact about updating your information.

What are your rights over your information?

The Data Protection Act 2018 gives people rights over their information:

- 1. The right to be informed.** The Participant Information Sheet, combined with this privacy notice, meet your right to be informed.
- 2. The right of access**
- 3. The right to rectification**
- 4. The right to erasure** or to 'be forgotten'
- 5. The right to restrict processing**
- 6. The right to data portability.** This is designed for online services and is unlikely to apply to research.
- 7. The right to object**
- 8. Rights around automated decision making and profiling.** If the research involves automated decision making this will be described in the Participant Information Sheet.

You can write to the Data Protection Officer about any of these rights.

Some rights may be limited. These limitations are allowed under the Data Protection Act 2018. The most common limitations are:

- Your rights to access, rectify, or erase your data can be limited if the data is crucial to the research project. For example, if in a research trial is designed so that you do not know whether you are receiving an experimental treatment (and sometimes the researchers do not know either), then we will not be able to give you access to information about which treatment you have taken. You will be allowed access to this information once the treatment each participant took is no longer secret.
- You can restrict or object to your information being used by withdrawing your consent. Sometimes we might continue using your information even if you make this request. For example, we may be allowed to keep your information if we need results from a certain number of people, and if losing your information would take us below that number.

How to contact us

If you wish to exercise any of these rights or ask to see your information, please contact the Data Protection Officer at dataprotection@lstmed.ac.uk. By post: Data Protection Officer, Liverpool School of Tropical Medicine, Pembroke Place, Liverpool, L3 5QA. Telephone: 0151 702 9323

How to complain

If you are unhappy with how your information is being used, first complain to the Data Protection Officer using the contact details above. If you continue to have concerns, you can contact the Information Commissioner:

Helpline: 0303 123 1113

Website: <https://ico.org.uk/for-the-public/raising-concerns/>