

RESEARCH PRIVACY NOTICE

Participants, Partners and Collaborators – Health and Care Data

London School of Economics and Political Science (LSE) is ranked second in the world and top in the UK and Europe for dedicated social science and management subjects. LSE (the “School”, “We”, “Us”, “Our”) aims to conduct research to the highest standards of research integrity. Our research is underpinned by policies and procedures that ensure we comply with regulations and legislation that govern the conduct of research; this includes the General Data Protection Regulation 2016/679 (GDPR) and the UK Data Protection Act 2018 (DPA). We are a company limited by guarantee, registered in England under company number 70527, whose registered office is at;

London School of Economics and Political Science
Houghton Street
London
WC2A 2AE
United Kingdom

This Notice applies together with any other information the School may provide about a particular use of personal data, for example when collecting data via an online or paper form. For the purpose of any applicable data protection laws enacted in England and Wales, we are the data controller of your personal data and our Data Protection Officer is Rachael Maguire, who can be contacted by post to our address as stated below or via email GLPD.Info.Rights@lse.ac.uk. This notice was last updated in November 2018 and may be amended from time to time.

It should be read in addition to the School’s other relevant policies, including;

- [Data Protection Policy](#)
- [Data Protection and Research](#) (guidance for staff)
- [Information Security Policy, Procedures and Guidelines](#)
- [Research Ethics Policy and Procedures](#)

Introduction

This privacy notice covers personal data processed specifically for research into health. The main [privacy notice for research](#) applies to personal data used for all other research processes.

Our teams work to develop and steward mutually-beneficial relationships with the global philanthropic and corporate sectors. We connect LSE's expertise and ambitions in research, student support and public engagement with partners including trusts and foundations, development banks, and Subject Matter Experts (SMEs) through to multi-national corporates.

We ensure that it is in the public interest when we use personal data from people who have agreed to take part in research and we have the obligation to demonstrate that our research serves the interests of society as a whole. This means that when you agree to take part in a research study, we will use your personal data for that research only in the ways needed to conduct the research and analyse the data.

LSE uses personal data to conduct research to improve health, care and services. We ensure that it is in the public interest when we use personal data from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your personal data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. Most of our health and care research follows the UK Policy Framework for Health and Social Care Research.

What is Research?

Research is a process of methodical investigation that entails collection of data; documentation of critical information; and analysis and interpretation of that data/information, in accordance with suitable methodologies set by specific professional fields and academic disciplines. Sometime it may be conducted in collaboration with commercial organisations and funders.

What is Personal Data?

The GDPR defines “personal data or personal information” as any information relating to an identified or identifiable natural person (a “data subject”); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural, or social identity of that natural person. This includes information which may not explicitly identify you (e.g. where your name has been removed) but which does make it possible to identify you if it is combined with other information that is readily available. For example, this might be because the information available contains a postcode, your gender and date of birth; in these circumstances it might be possible to identify you by using this in conjunction with other information available elsewhere.

Our Responsibilities to Your Data

In most cases, we are the data controller, which means, we will decide how your personal information is collected, used, shared where required, stored and where it is stored, and deleted (processed, conserved and anonymised). We will do so in line with the objectives of the research, ensuring we collect only what is appropriate and necessary, informing you of what we are collecting and how it will be used. For some research projects, the organisation funding the research may make decisions regarding your information. If so, this will be detailed in the participant information sheet you will be given.

We commit to keeping your personal information secure and respect the confidentiality of the personal information that participants in our research provide to us and/or data that we get from other organisations and share with other collaborating organisations as joint controller or our research funders. The School has collaboration agreements and/or contractual arrangements in place which document how we have agreed to share these responsibilities. In these situations, we will be clear with you when we collect your information as to how we intend to use it. We will use your personal data only for the purpose of the research you are participating in and we will not usually use your information or contact you for any purpose other than research unless you have consented to this.

Types of Personal Information We Use within Research Projects

Research project requirements and objectives may vary considerably, therefore, the type of personal information collected and used will depend on the particular research objectives of the project you are taking part in. Whatever data we collect will always be proportionate to achieving those objectives. The Participant Information Sheet will inform you of what information will be collected about you. The categories below are meant to illustrate the breadth of the research data used by the School, which may not apply to the research project you are participating in.

We may collect the following types of personal data about you:

- Your contact and communications information, including:
 - your name(s) and title
 - email address or addresses
 - telephone numbers
 - postal address
 - records of communications and interactions we have had with you

- Work related information, including:
 - your CV and current contractual agreements relating to salary
 - communications sent or received via the School's communication system

LSE may also process some information about you that is considered to be sensitive or which is “special category” personal data. This includes information concerning your:

- details about your health, including
 - Physical health
 - Mental health
 - GP records
 - Hospital records
 - Anything more?

- Personal data of the following groups
 - Doctors, nurses and other staff involved in the recruitment, diagnosis, and treatment of participants taking part in our research studies.
 - Laboratory staff, company employees, and staff from other organisations that are supporting and/or funding the research studies.
 - Members of the public who contribute to the design and conduct of our research or sit on local working groups or committees.
 - Healthcare professionals who contribute to the trial management groups and oversight committees.

- Other biographical, educational and social information, including:
 - ethnicity
 - sexual orientation
 - gender identity, specifically whether your gender identity is the same as the gender originally assigned to you at birth
 - your religious or political beliefs
 - nationality and date of birth
 - your image and likeness, including as captured in photographs taken for work purposes

- information relating to criminal offences
- Any other information relevant to your collaboration with the School or provision of services as part of the School's proposed research activities. For example, information about past criminal convictions. This would, of course, only be collected for a research project dedicated and relevant to that ground. Access to, and the sharing of, this more sensitive personal data is controlled very carefully and you will be specifically informed about this in your Participant Information Sheet.

Your information will usually be shared within the research team conducting the project you are participating in. You will be made aware in the Participant Information Sheet if there are collaborators that are not employed by the University who will also access your information.

All personal information is kept in line with our policies (as listed on page 1 of this document) or any regulatory requirements. Our researchers are asked to anonymise and remove identifiers such as your name and replace this with a unique code or key (pseudonym), or to delete personal information collected as part of their research at the earliest opportunity.

Personal information that we collect from you

Where we collect personal information from you directly, a Participant Information Sheet and/or Privacy Notice will inform you about what information we are using and how we are going to use it. We often ask you for your informed consent when we contact you directly.

Personal information that we collect from other sources

The School also receives data from other sources that may contain your personal data. This could be from NHS records where they make these available to researchers or from other sources of health records or NHS Digital. We would expect that the organisations providing these records will have already sought the relevant consents from you and anonymised or pseudonymised the data so we cannot recognise you if we do not need to for a research project.

Where it is not possible or practical to contact you directly and obtain your consent, we seek approval from the NHS Health Research Authority's Confidentiality Advisory Group (CAG) to obtain your personal information directly from the NHS under a 'Section 251 Exemption'.

Section 251 and the NHS

Section 251 of the NHS Act 2006 came about as it was recognised that there were activities of medical research that required the use of personal information; however, because patient consent

had not been obtained to use patients' confidential information for these other purposes, there was no secure basis in law for doing so.

Section 251 enables the common law duty of confidentiality to be lifted to enable disclosure of confidential patient information for medical purposes, where it was not possible to use anonymised information and where seeking consent was not practical. For information about the CAG and Section 251, please visit: www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/

To find out what choices are available in the way the NHS uses your health records, including opting out, please visit: www.nhs.uk/your-nhs-data-matters/

Your information will usually be shared within the research team conducting the project you are participating in. You will be made aware in the Participant Information Sheet if there are collaborators that are not employed by the University who will also access your information.

All our researchers are asked to de-identify (anonymise), pseudonymise (remove identifiers such as your name and replace this with a unique code or key) or delete personal information collected as part of their research at the earliest opportunity. All personal information is kept in line with our policies or any regulatory requirements.

The Lawfulness of using Your Personal Data

In fulfillment of the GDPR and DPA 2018, we are required to be explicit with you about the legal basis upon which we process your personal information. In the context of research, we will process your personal information in accordance with:

- Art.6 1 (e) *“processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller”*. It is most likely that this will be the lawful basis for processing personal data for research.
- Art.6 1 (a) *“the data subject has given consent to the processing of his or her personal data for one or more specific purposes”*. We will use this lawful basis less often, but may use it when Art.6 1 (e) does not apply. If as such, we will inform you on the Participant Information Sheet provided to you. We will also provide information on how to withdraw your consent where it is permissible, at least, before your data is processed for research.
- Art.9 1(j) *“processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes, shall be subject to appropriate safeguards, in accordance with this Regulation, for the rights and freedoms of the data subject”*. This is for any special categories data used in research, e.g. for health data or ethnicity.

For more information, go to [Data Protection and Research](#)

Sharing Your Information with Others

Your information will usually be shared within the research team conducting the project you are participating in, initially in a way that you can be identified as a participant for the purpose of achieving the research outcomes. However most personal information used in research will be pseudonymised before sharing widely or the outcome is published. You will be made aware in the Participant

Information Sheet if there are collaborators that are not employed by the School who will also access your information. For example;

- other individuals similarly engaged in research activities or in research data collaboration. e.g. third parties processing data on our behalf;
- law enforcement agencies and other government authorities where the School is legally required to do so;
- our advisers where it is necessary for us to obtain their advice or assistance.

The School remains responsible for your personal data and we will ensure there are adequate safeguards in place to secure your information.

Principles and Rights

The School researchers will abide by the six data protection principles that govern how personal data should be processed. Read more about [Data Protection Principles and Research](#) under our Data Protection and Research page. If you want to exercise your rights under these principles, please download our [Data Protection form](#) and email it to GLPD.Info.Rights@lse.ac.uk

You have a right to be informed about the research your data will be used in. This will normally be done either via a written notice (such as a Participant Information Sheet) which you can keep or in the introduction of a survey. Where we are unable to inform you before research is conducted, for example, because we are using secondary data or due to the research project using observation, we will try to brief individuals after the research is finished.

You also have the right to: access information held on you, to have it corrected, in some cases to have it erased, to object to your data being used and to object to automated processing.

How Long is Your Information Kept?

We will retain your personal data for as long as is necessary to conduct a particular research project and/or if we think it will be useful for further research. Research data that is deposited in a data archive at the School or with a third party e.g. the UK Data Archive will be de-identified before deposit. Any keys to research participants, that is, a list of the research participants and a unique identifier used to de-identify individuals within a research data set will be kept separately from that research dataset while the research is ongoing and destroyed prior to deposit.

Consent forms which contain personal information may be kept for a defined minimum number of years after the research has been completed in accordance with:

- any legal, accounting, or reporting requirements;
- any requirement of the funder; and
- in accordance with [LSE Retention Schedule](#) under our Information and Record Management page, unless stated otherwise in a privacy notice.

How to Contact Us

If you want to exercise any of the rights described above or are unhappy with the way we have used your information, you should contact the School Data Protection Officer, **Rachael Maguire** at glpd.info.rights@lse.ac.uk. We will seek to deal with your request without undue delay, and in any

event in accordance with the requirements of the GDPR and related Data Protection Legislation. Please note that we may keep a record of your communications to help us resolve any issues which you raise.

How to Make a Complaint to the Regulator

If you are dissatisfied with our response, or you believe that your data protection or privacy rights have been infringed, you should contact the UK Information Commissioner's Office (ICO), which oversees data protection compliance in the UK. Details of how to do this can be found at:

<https://ico.org.uk/make-a-complaint/>.