

## **Privacy Notice for Research Participants**

This privacy notice provides information on how the University of Southampton collects and uses your personal information when you take part in one of our research projects. It is important that you read this privacy notice together with the Participant Information Sheet for the study in which you are taking part.

The Participant Information Sheet will explain the purpose of the project and contain more specific details about what information will be collected about you and how it will be used to achieve the project's objectives.

This privacy notice was prepared following the introduction of new data protection laws in May 2018: the General Data Protection Regulation (GDPR); and the UK Data Protection Act 2018 (DPA).

### **1. General Information**

The University of Southampton is a publicly funded organisation which conducts tasks that are considered to be in the public interest such as education and research activities. Our [University Charter](#) states that our research outcomes should be in the public interest. Therefore, unless otherwise stated in the Participant Information Sheet, the legal basis for processing personal information in a research project will be to perform a task in the public interest.

Research may be conducted by staff or students of the University. Most research projects are intended to add to existing knowledge and the outcomes of those projects may be shared through reports and publications. Student projects, however, such as those conducted by our undergraduate students, may not add to existing knowledge but must be undertaken to fulfil their education requirements. Projects undertaken as an educational requirement are also considered a task in the public interest. Therefore, this privacy notice applies to both staff and student research projects.

We always strive to uphold high standards in our research projects. This means that our researchers must follow strict codes of conduct, policies and procedures to ensure the research they conduct under the University complies with regulations and legislation. This includes data protection laws which protect and safeguard the use of personal information. Although many of the principles are the same as previous data protection laws, the GDPR and DPA 2018 have introduced some key changes to further safeguard the use of your personal information.

The principles of data protection law require that your personal data must be:

- Used lawfully, fairly and in a transparent way;

- Collected only for valid purposes that we have clearly explained to you and not used in any way that is incompatible with those purposes;
- Relevant to the purposes we have told you about and limited only to those purposes;
- Accurate and kept up to date;
- Kept only as long as necessary for the purposes we have told you about; and,
- Kept securely.

In the case of Health and Care research, where we have to demonstrate that our research serves the interests of society as a whole, we also do this by following the [UK Policy Framework for Health and Social Care Research](#).

## **2. What is Personal Data (also referred to as ‘Personal Information’)?**

‘Personal Data’ means any information that relates to and is capable of identifying you as an individual. This includes information that identifies you directly such as your name, location or identification number. It can also include data where direct identifiers (such as your name) are not used or have been removed but a person can still be identified by combining the information with other data. For example, a study collecting or using data on music preferences or shopping trends may allow an individual to be indirectly identified when combined with other information such as age or place of work. Research studies that use information that could allow a person to be identified directly or indirectly will be conducted in accordance with data protection laws.

Some research projects may use information about you that is considered ‘sensitive’ (also known as ‘special category’ data). These are information about: your ethnicity; your sexual orientation; your gender identity; your religious beliefs; your genetic data; your biometric data from which you can be uniquely identified; and, your health data. These types of Personal Information require the researchers to take extra care when collecting, storing and using the information. Personal Information relating to criminal convictions must also be treated with extra care.

The types of Personal Information that may be used will depend on the research project. The Participant Information Sheet will tell you if any of these types of personal data will be collected for the study and how it will be used and managed. You should ask a member of the study team if you have any questions or require further clarification. Contact details will be provided on the Participant Information Sheet or the invitation asking you to participate. What our researchers collect and use will always be proportionate to achieving the particular research project objectives.

### **3. Who is responsible for my Personal Information?**

The University of Southampton is the 'Data Controller' when it manages research projects, which means that we are responsible for looking after your Personal Information and using it properly for that project.

Where we work together with other Data Controllers (such as other Universities or our research funders) on a research project, this will be made clear in the Participant Information Sheet provided to you, along with information about how we have agreed to share our responsibilities for handling your data. If you have any further questions about the research collaborations for the project you are taking part in, please contact your project's research team using the contact details on the Participant Information Sheet.

### **4. What safeguards do we have in place to protect your Personal Information?**

All Personal Information is handled according to the University's policies in line with legal and regulatory requirements.

We expect all our staff and students to respect the confidentiality and sensitivity of the Personal Information they use for their research projects from whatever source, whether provided by you, as a participant in our research, or whether received or shared from other organisations

In order to protect your rights and freedoms when using your Personal Information for research purposes, the University will not do anything with your Personal Information that you would not reasonably expect. We will use your personal information only for achieving the objectives of the research you are participating in and we will not usually use your information further or contact you for any purpose other than this research unless you have agreed to this or de-identification processes are applied to your data. We commit to keeping your Personal Information safe and secure.

We also have the following technical, legal, and organisational safeguards in place to help protect your Personal Information:

- Policies and procedures that our staff and students must follow to collect and use your information safely.
- Training which ensures our staff and students understand the importance of data protection and how to protect your data.

- Security standards and technical measures that ensure your information is stored safely and securely.
- All research projects involving personal data are reviewed and approved by a research ethics committee to ensure the research does not expose you to undue risk or cause you distress (e.g., physical harm, financial loss or psychological distress).
- Contracts are put in place with collaborators on a research project (e.g. companies or individuals not associated with the University) which will include setting out each party's responsibilities for protecting and keeping your personal information confidential.
- The University will carry out data protection impact assessments on high risk projects to ensure that your privacy, rights as an individual, or freedoms, are not affected.
- If we use collaborators outside of the European Economic Area, we will ensure that they have adequate data protection laws, or are part of privacy and security schemes (such as the Privacy Shield self-certification programme in the US).

#### **5. With whom will my Personal Information be shared?**

Your information will usually be shared within the research team conducting the project you are participating in, mainly so that they can identify you as a participant and contact you about the research project. All our researchers are asked to de-identify or delete Personal Information collected as part of their research at the earliest opportunity where it becomes clear that any information held is not necessary to achieve the research project objectives, or it is clearly inaccurate.

Responsible members of the University of Southampton may also be given access to Personal Information used in a research project for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your records. All of these people have a duty to keep your information, as a research participant, strictly confidential.

If we are working with other organisations and information is shared about you, we will inform you in the Participant Information Sheet. Information shared will be on a 'need to know' basis relative to achieving the research project's objectives, and with all appropriate safeguards in place to ensure the security of your information.

Aside from the research project team, most Personal Information used in research will be de-identified before being shared externally with other researchers or publishing the research outcomes. If it is not possible to de-identify your information, we may ask for your consent to share it. Where there is a risk that you can be identified, your data will only be shared in research that has been independently reviewed and approved by an ethics committee. The information cannot be used to contact you or to decide something in relation to you that might affect you. It will not be used to make decisions about future services available to you, such as your care or insurance. If this is relevant to the research you are involved with, you will be provided with information about this in your Participant Information Sheet.

Sometimes researchers will use a third party product or service to support the research project which may require them having access to your Personal Information. If this is the case, the researchers will provide you with details about the third party ('Processor') and their roles and responsibilities on the Participant Information Sheet.

We may also have to disclose your information if required to do so by law in order to comply with a legal obligation, to protect our rights, interests or property and those of others, to act in urgent circumstances to protect the personal safety of our staff, students and the public or to protect us against any legal liability.

## **6. Your rights**

The GDPR and the DPA give you rights in relation to the Personal Information we hold about you. These include rights to request the following:

- Access the information/receive a copy of the information;
- Correct any inaccurate information;
- Have any information deleted;
- Restrict or object to our processing of information; and,
- Move your information ("portability").

Where Personal Information is processed as part of a research project, the extent to which these rights apply varies under the GDPR and the DPA. In particular, your rights to access, change, or move your information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we may not be able to remove the information that we have already obtained. To safeguard your rights, we will use the minimum

personally-identifiable information possible. The Participant Information Sheet will detail up to what point in the study data can be withdrawn.

If you submit a data protection rights request to the University, you will be informed of the decision within one month. If it is considered necessary to refuse to comply with any of your data protection rights, you also have the right to complain about our decision to the UK supervisory authority for data protection, the Information Commissioner's Office.

To note, where the University is no longer in a position to identify you from the information we hold, it will not be possible for the University to implement your rights following a request about such information. In particular, once data collected as part of a research project have been irreversibly anonymised, it will no longer be possible to identify what data we hold about you specifically.

None of the above precludes your right to withdraw consent from participating in the research study at any time.

#### **7. How long is my information kept?**

You will be informed in your Participant Information Sheet how long your Personal Information will be retained. Further details about how long research data collected by the University is kept for can be found in our retention schedule (<http://library.soton.ac.uk/researchdata/retention>).

#### **8. Who can I contact?**

In the first instance, if you have any questions about how your Personal Information is being used in a specific study, you should contact a member of the study team as detailed in the Participant Information Sheet.

If you have any concerns or you wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer ([data.protection@soton.ac.uk](mailto:data.protection@soton.ac.uk)).

If you are not happy with the way your Personal Information is being handled, or with the response received from us, you have the right to lodge a complaint with the Information Commissioner's Office at Wycliffe House, Water Lane, Wilmslow, SK9 5AF (<https://ico.org.uk/>). The University's registration number with the Information Commissioner's Office is Z6801020.