

## **Privacy Notice - Research Participants *and those invited to participate in research, being undertaken by Health Sciences University.***

The Frascati Manual defines research as comprising "creative and systematic work undertaken in order to increase the stock of knowledge – including knowledge of humankind, culture and society – and to devise new applications of available knowledge." Research at Health Sciences University (HSU) is undertaken by our undergraduate and postgraduate students (working under appropriate staff supervision), our staff or a combination of staff and students. It may be HSU researchers only or working in collaboration with researchers at other organisations. Some research may be conducted in collaboration with funders and commercial organisations.

In order to undertake research and to train students in research methods, staff and students at HSU collect and process various types of personal data. The University is committed to being transparent about how it collects and uses that data and to meeting its data protection obligations. All research activity undergoes ethics approval before it commences and meets the highest standards of research integrity and helps serve the public interest.

### **1. Identity and contact details of the Data Controller**

- 1.1 The Data Controller (the organisation responsible for how your data is processed) is Health Sciences University. The University is registered with the Information Commissioner's Office and it is committed to protecting the rights of individuals in line with data protection legislation.

### **2. Contact details of the Data Protection Officer**

- 2.1 The Data Protection Officer is responsible for advising the University on compliance with data protection legislation and monitoring its performance against it. If you have any concerns regarding the way in which the University is processing your personal data, please contact the Data Protection Officer at [dpo@aecc.ac.uk](mailto:dpo@aecc.ac.uk).

### **3. What information does the University collect?**

- 3.1 The University collects a range of information in order to carry out its research activities. This may include personal data such as name and address, date of birth, or information on your views on specific research topics. The University may also collect special category (sensitive) personal data as defined under data protection legislation such as information about racial or ethnic origin, health, genetic or biometric data (where used for ID purposes).
- 3.2 The University collects this information in a variety of ways. For example, it might be collected via surveys or questionnaires, through interviews of focus groups, or by taking photographs, audio or video recordings.
- 3.3 For each individual research project you will be provided with a Participant Information Sheet, which explains in more detail the kind of information that will be collected, and how this will be done.
- 3.4 All our researchers are required to de-identify (anonymise), pseudonymise (remove

identifiers) or delete personal information collected as part of their research at the earliest possible opportunity.

#### **4. What is the purpose and lawful basis of collecting my data?**

- 4.1 Undertaking research, publishing research and training students to undertake research are tasks that are in the public interest. Universities undertake these activities so that they can fulfil their function as a Higher Education institution. Some types of research will require the collection of personal data including, where appropriate, special category personal data, in order that the aims of the research can be achieved. The University will only collect the information that is necessary to undertake each specific research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.
- 4.2 Where we rely on a different lawful basis such as consent or legitimate interest we will inform you of this in the Participant Information Sheet provided to you.
- 4.3 There is no statutory or contractual requirement to provide your personal data to us through participating in a research project.
- 4.4 The University will not use your personal data for automated decision making or profiling about you as an individual.

#### **5. How and where your data are held**

- 5.1 All research projects involving the collection of personal data are subject to an ethics review, to ensure that appropriate arrangements are made for the secure storage of your data. If you take part in a research project, you will be provided with a Participant Information Sheet that will outline in more detail how and where your data are stored.
- 5.2 All hard copy information is kept in a secure physical location, whilst all electronic information is stored in an HSU password-protected secure network.

#### **6. Who has access to the data?**

- 6.1 Your data will be accessed by members of the research team (including Supervisors of student research projects), however, most personal information used in research will be de-identified or pseudonymised where-ever possible before sharing more widely or publishing the research outcomes. If it is not possible to de-identify your information, we will ask for your consent to share or otherwise make your personal information available to others. Information shared will be on a need to know basis, not excessive and with all appropriate safeguards in place to ensure the security of your information. It may sometimes be necessary to share your personal information with other researchers for the purpose of achieving the research outcomes. Where researchers wish to use any information that would identify you, specific consent will be sought from you.
- 6.2 If it is necessary for anyone else to have access to the data, or for the data to be shared more widely (including any transfers outside the European Economic Area), this will be made clear in the Participant Information Sheet

that will be provided to you before you agree to participate in the research.

- 6.3 At times our research may be audited and access to the data may be required. HSU puts in place safeguards to ensure that audits are conducted in a secure and confidential manner.

## **7. How does the University protect the data?**

- 7.1 In order to protect your rights and freedoms when using your personal information for research and to process special category (sensitive) information, the University must have safeguards in place to help protect that data. The University takes the security of your personal data very seriously and it has policies, procedures, training, technical and organisational measures in place to ensure that your information is protected. All research projects or studies involving personal data that has been identified/deemed higher risk are scrutinised and approved by a research ethics committee.

- 7.2 In accordance with data protection law, we will meet the following standards when we conduct research with your personal information:

- The research will not cause damage or distress to someone (e.g., physical harm, financial loss or psychological pain);
- The research is not carried out in order to do or decide something in relation to an individual person, unless the processing is for medical research approved by a research ethics committee;
- Health Sciences University (as the controller) has technical and organisational safeguards in place (e.g. appropriate staff training and security measures); and
- When we process special category personal data, this is subject to a further public interest test to make sure this particularly sensitive information is required to meet the research objectives

## **8. How long is my data kept?**

- 8.1 If you take part in a research project, you will be provided with a Participant Information Sheet that will outline in more detail how long the data in an identifiable form will be held for and, where applicable, the re- use of the data.
- 8.2 Data will be kept for a minimum amount of time in accordance with research objectives and, in some cases, funder requirements.

## **9. Data Subject's Rights**

- 9.1 Under Data Protection legislation you have the following rights:
- to request access to, and copies of, the personal data that we hold about you;
  - to request that we cease processing your personal data;
  - to request that we do not send you any marketing communications;
  - to request us to correct the personal data we hold about you if it is incorrect;
  - to request that we erase your personal data;
- 9.1.1 to request that we restrict our data processing activities (and, where our processing is based on your consent, you may withdraw that consent, without affecting the lawfulness of our processing based on consent before its withdrawal);
- 9.1.2 to receive from us the personal data you have provided to us, in a reasonable format specified by you, to another data controller;

9.1.3 to object, on grounds relating to your particular situation, to any of our particular processing activities where you feel this has a disproportionate impact on your rights and freedoms.

9.2 It is important to understand that the extent to which these rights apply to research will vary and that in some circumstances a right may be limited when the data is being used for research purposes. It should also be noted that we can only implement your rights during the period upon which we hold personal identifiable information about you. Once the information has been irreversibly de-identified or anonymised and becomes part of the research data set, it will not be possible to access your personal information.

9.3 If you would like to exercise any of these rights or have any questions regarding your rights, please contact the University's Data Protection Officer, using the contact details under Section 10 below.

## 10. How to raise a query, concern or complaint

10.1 If you have questions about the particular research study you are participating in, please use any contact details you have already been supplied with regarding the research study or project.

10.2 If you have general queries, concerns or wish to raise a complaint about how your personal data is used by the University, or if you wish to exercise any of your rights, you should contact the Data Protection Officer in the first instance, using the contact details under Section 2 above.

If you remain dissatisfied, then you have the right to refer the matter to the Information Commissioner's Office (ICO). The ICO can be contacted at:  
Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire, SK9 5AF

Telephone: 0303 123 1113 Website: [www.ico.org.uk](http://www.ico.org.uk)

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