**SUPPORT Study** **Privacy Notice**

In order to carry out the research described in the SUPPORT Study Participant Information Leaflet, we will need to collect information about you, and some of this information will be your personal data. Under data protection law, we have to provide you with very specific information about what we do with your data and about your rights. We have set out below the key information you need to know about how we will use your personal data.

More information on how the University processes personal data can be found on the University’s website on the page called [‘Data Protection - How the University Uses Your Data’](https://www.birmingham.ac.uk/privacy/index.aspx)

**Who is the Data Controller?**

The University of Birmingham, Edgbaston, Birmingham B15 2TT is the data controller for the personal data that we process in relation to you.

**What data are we processing and for what purpose will we use it?**

We will collect and process your personal data to conduct the research project, as explained in the Participant Information Leaflet.

**What is our legal basis for processing your data?**

The legal justification we have under data protection law for processing your personal data is that it is necessary for our research, which is of interest to the public.

**Who will my personal data be shared with?**

Your personal details will be kept confidential and only persons who are authorised to do so by the research team or the study sponsor will have access to this information. The sponsor may appoint a third party to access your identifiable data, but only for the purposes of monitoring how the research is conducted. We make sure we have appropriate contracts in place with them to protect and safeguard your data.

**How will my personal data be kept secure?**

The University takes great care to ensure that personal data is handled, stored and disposed of confidentially and securely. Our staff receive regular data protection training, and the University has put in place organisational and technical measures so that personal data is processed in accordance with the data protection principles set out in data protection law.

The University has an Information Security Management System based on ISO27001 with a range of controls covering the protection of personal information. Annual security awareness training is mandatory for staff and the University is accredited under the NHS Information Governance Toolkit, the Payment Card Industry Data Security Standard and is in the process of gaining Cyber Essentials Plus for defined services.

In relation to this project, data will be held on password protected computers in secure University of Birmingham buildings. Any paperwork containing personal data will be kept in a locked filing cabinet.

**How long will my personal data be kept?**

All data will be held securely in the custody of the Chief Investigator at the University of Birmingham for 10 years after publication of the main study results, in accordance with the University of Birmingham Research Data Management Policy. At the end of the 10 year period data will be securely destroyed in line with University of Birmingham policy for data disposal at that time. If you withdraw from the project, we will keep the information we have already obtained but, to safeguard your rights, we will use the minimum personally-identifiable information possible.

**Your rights in relation to your data**

You may have the following rights in respect of your personal data:

* The right to access to your data (often referred to as a Subject Access Request).
* The right to correct mistakes in your data.
* The right to erasure of your data (in certain circumstances).
* The right to restrict processing of your data (in certain circumstances).
* The right to complain/disagree about the processing of your data (in certain circumstances).
* The right to ask for your personal data to be transferred electronically to a third party.

However, your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you have taken part in an interview and you decide to withdraw from the study, you can request that your interview data is withdrawn up to 48 hours after the interview has taken place. If you decide to withdraw more than 48 hours after the interview has taken place, your data will still be used in the study for research purposes. If you have taken part in a focus group and you change your mind, you are free to withdraw from the study, however once you have contributed to a focus group discussion, your data will be retained in the study for research purposes.

If you would like more information on your rights, would like to exercise any right or have any queries relating to our processing of your personal data, please contact:

The Information Compliance Manager,

Legal Services,

The University of Birmingham,

Edgbaston,

Birmingham B15 2TT

Email: [dataprotection@contacts.bham.ac.uk](mailto:dataprotection@contacts.bham.ac.uk)

Telephone: +44 (0)121 414 3916

If you wish to make a complaint about how your data is being or has been processed, please contact our Data Protection Officer.

Mrs Carolyn Pike, OBE,

The Data Protection Officer,

Legal Services,

The University of Birmingham,

Edgbaston,

Birmingham B15 2TT

Email: [dataprotection@contacts.bham.ac.uk](mailto:dataprotection@contacts.bham.ac.uk)

Telephone: +44 (0)121 414 3916

You also have a right to complain to the Information Commissioner's Office (ICO) about the way in which we process your personal data. You can make a complaint using the ICO’s website.