## Parent Privacy Notice

In order to carry out the SMART Study research project, we will need to collect information about your child, and some of this information will be personal data. Under data protection law, we have to provide you with very specific information about what we do with your child's data and about their rights. We have set out below the key information you need to know about how we will use your child's 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 your child.

What data are we processing and for what purpose will we use it? We will collect and process your child's personal data to conduct the research project, as explained in the Parent Information Sheet.

What is our legal basis for processing your child's data? The legal justification we have under data protection law for processing your child's personal data is that it is necessary for our research, which is of interest to the public. The legal justification we have under data protection law for processing your child's special category data (i.e. information relating to their race, ethnic origin, health) is that it is necessary for scientific or historical research purposes or statistical purposes in the public interest.

Who will my child's personal data be shared with? Your child's 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 any 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 child's data. If personal data are transferred outside the European Union (for example, if one of our partners is based outside the EU or we use a cloud-based app with servers based outside the EU), we make sure that appropriate safeguards are in place to ensure the confidentiality and security of your child's personal data. The research team will consider external requests to gain access to anonymised data. When sharing data for this purpose, a Data Sharing Agreement will be required and it will not be possible to identify your child individually from the data.

**How will my child's 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 child's personal data be kept?** Your child's data will be retained for 10 years. If your child would like to withdraw from the study or you would like to withdraw your child from the study, you can do this up to 4 weeks after the last point of data collection and the information will be deleted. The exception to this is data provided through focus group discussions. If your child is involved in a focus group and withdraws after participating in a focus group discussion, their data will remain in the study and be included in the analyses as it is not possible to separate and remove individual participant data from a focus group discussion.

**Your child's rights in relation to their data** Your child may have the following rights in respect of their personal data:

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

However, your child's rights to access, change or move their information are limited, as we need to manage their information in specific ways in order for the research to be reliable and accurate.

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

The Information Compliance Manager, Legal Services, The University of Birmingham, Edgbaston, Birmingham B15 2TT

Email: dataprotection@contacts.bham.ac.uk Telephone: +44 (0)121 414 3916

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

Nicola Cárdenas Blanco, The Data Protection Officer/Director of Legal Services, The University of Birmingham, Edgbaston, Birmingham B15 2TT

Email: <u>dataprotection@contacts.bham.ac.uk</u> 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 child's personal data. You can make a complaint using the ICO's website.