



Participant Privacy Notice

The purpose of this document is to explain the ways in which we store and use your data when you agree to join our volunteer panel. Our primary aim is to ensure that any personal data you give us is stored securely and used only for the purposes of scientific research. Your data are not made available to unauthorised third parties and you have the right to request us to remove your data from our system.

The MRC CBU complies with the EU General Data Protection Regulations (GDPR) and the UK Data Protection Act, 2018 (DPA). All data held by the MRC CBU or processed on our behalf will be treated in compliance with this legislation.

What is the purpose and legal basis for processing data?

We will use the personal data you provide to carry out academic research in the public interest.

What data do we collect and what will it be used for?

The data we collect includes your name, gender, email address, telephone number, family characteristics, education and skills, and health/medical data. All data is collected on a voluntary basis and used for the legitimate interests of the MRC CBU in carrying out academic research in the public interest.

Your name, email address, and phone number may be used to identify you on this website. Individual researchers within the MRC CBU may also use your details to contact you about taking part in specific research projects. Your data may also be used to select participants for specific research projects, for example some projects may require participants with particular characteristics such as age or handedness.

We may also use your email or home address to send you information about events such as the CBU Open Day or to keep you up-to-date with Panel news. You can ask for such communications to be limited or to cease.

Individual researchers may request to use your personal data for specific purposes within their own studies. In this case, they will explain the additional ways in which they wish to use your data in a participant information sheet.

Where will my data be kept and who has access to it?

Your data will be available to researchers within the MRC CBU. We will restrict access to your data to those researchers who need it in order to conduct their research (for example to contact you). We will keep a copy of your personal data in a database that is stored on computers within the MRC Cognition and Brain Sciences Unit.

We also use Sona Systems Ltd to process data on our behalf. We use their website (www.sona-systems.com) to collect your data, and a copy of your data will be held on their computer systems located in The Netherlands and Germany. Sona Systems comply with the requirements of GDPR and a copy of their own privacy statement is available here: <https://www.sona-systems.com/privacy.aspx>

On occasion, we may also hire external contractors to work on our database. These contractors will be required to comply with the terms of the GDPR and DPA.

Your personal information will not be disclosed to any other third parties or external organisation. Your data will not be disclosed to state authorities or institutions unless required to do so by UK law.

How long will my data be kept for?

Should you decide that you no longer wish to be a member of the volunteer panel please inform us at this address: panel.office@mrc-cbu.cam.ac.uk.

Should you no longer wish to participate, all personally identifiable information held about you will be immediately deleted from the research panel database and the SONA system.

In addition, we will contact you 5 years after you last took part in a study to see whether you would like to remain on the panel. If you confirm a wish to leave, or we do not manage to contact you, your personal information will be deleted to protect your privacy.

If you take part in an MRI study, the radiographers will retain a copy of the safety screening form that includes your name, address and date of birth. This is kept securely and destroyed after 10 years.

Data Controller

Under the terms of the Data Protection Act 2018 the Data Controller responsible for holding the personally identifiable data you provide when registering as a volunteer is the University of Cambridge. The University of Cambridge privacy notice for research participants can be found here: <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>

Cookies

Like most websites, this site uses cookies which track the IP address of the computer being used (not the details of the person using it) to keep users logged in and to record which pages of the site have been visited. More information about the privacy policy for this website can be found here: <http://www.mrc-cbu.cam.ac.uk/cookies/>

Children's privacy

This site is not open to children. This site does not knowingly collect personal data from children.

Confidentiality and Security

This MRC CBU has implemented security policies and technical measures to protect the personal data under its control from unauthorised access, improper use or disclosure, unauthorised modification, and unlawful destruction or accidental loss.

All employees and data processors, who have access to, and are associated with the processing of personal data, are obliged to respect the confidentiality of visitors' personal data.

Your rights

Under the terms of the GDPR and DPA, you may request access to personal data that we hold about you, request that personal data we hold is erased or rectified, or object to your data being processed. While we will always try to comply with these requests, GDPR and DPA do allow exemptions to these rights under certain conditions (e.g. as set out in Article 89 of GDPR, or Schedule 2, part 6 of the Data Protection Bill), and we may occasionally need to invoke these exemptions if it is important for our research.

Contact information

You must acknowledge and agree to these terms before you may use the system. If you have any questions you should contact Rosemary Dunn, Volunteer Panel Manager at the address below before you acknowledge the agreement: panel.office@mrc-cbu.cam.ac.uk

More information about our current research is available on our website: <http://www.mrc-cbu.cam.ac.uk/>