



## **Autism Research Centre -Volunteer Database Privacy Policy**

### **How we collect data**

Upon registration with the Autism Research Centre (ARC), volunteers provide us with their contact details and demographic information (e.g. date of birth, sex, diagnosis). Any further data that are collected will depend on the specific research study, which is explained in the Participant Information Sheet for each project.

We invite volunteers to take part in research projects, and it is up to each individual to decide whether they wish to take part and contribute their data to the study. We only collect the information that is necessary to undertake the research study, and only when opt-in consent to participation is provided.

We do not receive any data from third parties. Data are held securely on the ARC database with full approval from the Psychology Research Ethics Committee.

### **How we share information and why**

Only the ARC Database Manager and University of Cambridge Clinical School Computing Service Development Team have access to the personally identifiable information (e.g. names, addresses, date of birth) of the volunteers who register. Pseudo-anonymised data will be seen by members of the ARC research team, strictly limited to those researchers who need to see the specific data for their study.

Anonymised Questionnaire or Test data may be shared with the ARC's trusted collaborators, including those who work outside the UK, depending on the consents collected from the participants. We will not share or publish any information that could identify a volunteer who has taken part in a research project.

Personal data will not be transferred to a country or a territory outside the UK/European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

### **Data Retention**

We keep data for as long as it is needed to perform its purpose, or for as long as it is required by law. At the end of the retention period, the data will be deleted or anonymised so that it is no longer personal data.

Research data may be kept for re-use for scientific purposes or statistical analysis, especially if the data underpins scientific publications.

### **Your rights**

Personal information can be deleted at any time on receipt of a request from the person who registered that information, without having to give reasons or without affecting their rights to participate in future studies or access to services.

Furthermore, you have the right to request what data we process about you, obtain a copy of that data, and request the correction of any inaccurate or incomplete information. Please email [support@autismresearchcentre.com](mailto:support@autismresearchcentre.com) if you would like to have your data deleted or updated.

The ARC forms part of the University of Cambridge and supplementary information about data protection rights is published in the University's [general privacy notice](#) as well as one aimed at [research participants](#).