

## Information Sheet

### Title of Project: Cambridge Autism Research Database

This database has been approved by the University of Cambridge Psychology Research Ethics Committee, project reference: PRE.2024.098

**Principal Investigator:** Professor Simon Baron-Cohen, Director, Autism Research Centre, University of Cambridge, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH.

**Co-Investigators:** (1) Simon Braschi, Database Manager, Autism Research Centre, University of Cambridge, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH. Tel: 01223 465229 (2) Dr Carrie Allison, Deputy Director, Autism Research Centre, University of Cambridge, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH.

We would like to invite you to be part of our Cambridge Autism Research Database. You will only be included if you want to; choosing not to be included will not disadvantage you in any way. Before you decide whether you want to be included, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

At the Autism Research Centre (ARC), we have several research programmes with many different projects to study Autism Spectrum Conditions (ASC) in children, adolescents and adults. This research is conducted by a group of researchers led by Professor Simon Baron-Cohen. This work helps us to understand the biomedical causes of ASC, and develop new and validated methods for assessment and intervention.

Some of the projects involve coming to Cambridge, and some even involve brain-imaging. However, many projects can be completed online at our secure website ([www.autismresearchcentre.com](http://www.autismresearchcentre.com)). We are always looking for people who are willing to participate. We have developed a database of people who are willing to be contacted when projects are looking for eligible individuals.

If you agree to be part of this database, you will be invited to fill in an online registration form which will take approximately 5 minutes per person. We will ask you for your contact details and other personal information. When projects become available, Simon Braschi will contact you and invite you to participate in that project. If you decide to be included in the database, you are under no obligation to take part in any of these studies.

If you agree to be part of this database, we will also ask you to fill out some questionnaires online. Each questionnaire takes approximately 10 minutes to complete. You do not have to complete any of these, but this helps us to capture basic data from all volunteers. You can also stop the questionnaires at any time and complete them at a later date if you wish. You can contact the database manager Simon Braschi at any time to request to be removed from the database and have your data disposed of, without having to give a reason. These data,

in an anonymised form, may be requested for use in a variety of research projects, by members of the Autism Research Centre or external collaborators. Each application needs to be reviewed and approved by the Data Access Committee (made up of members of the ARC as well as members of the autism community who have no affiliation with the university). If approved, a formal Data Transfer Agreement is required between the University of Cambridge and the requestor's institute.

It is up to you to decide whether or not to be part of the database. If you decide to be part of the database, you can print this information sheet and you will be asked to complete an online consent form. It is important that you print and keep your own copy.

If you decide to be part of the database, you can request to be removed from the database at any time and without giving a reason. All data (i.e. contact details and/or results of studies as appropriate) will be collected and stored in accordance with the Data Protection Act 2018 and will not be passed on without your prior, written consent.

From time to time, we may also contact you with information about studies at other research organisations. We consider requests to promote the studies of other research groups very carefully. We may also contact you about news and events that the ARC is involved in, as well as invitations to take part in Patient and Public Involvement and Engagement (PPIE), to help shape and inform research projects.

If you have any questions, please contact Simon Braschi by email ([sb2660@medschl.cam.ac.uk](mailto:sb2660@medschl.cam.ac.uk)).

**Thank you for considering being part of the Cambridge Autism Research Database.**

**Please PRINT this page for your own records.**



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