



Autism Research Centre -Volunteer Database Privacy Policy

Here at the Cambridge Autism Research Centre we take your privacy seriously. All the information you provide to us is confidential. It can only be viewed by members of the ARC for the sole purpose of research. You can instruct us to remove your details from our records at any time and we will carry this out.

The information you provide falls into two main categories - your contact details and demographic information, e.g. diagnosis, date of birth. We need your contact details to enable us to inform you about research projects which you can consider participating in. The demographic information ensures that we only contact you about projects which you are eligible to take part in.

Only two researchers (Paula Smith and Dr. Carrie Allison) and the webmaster (Keith Gravell, Cambridge Web Projects) has access to the personal information (names, addresses) of volunteers who register on the Autism Research Centre database. The data is stored securely and its security is the responsibility of the Autism Research Centre, a part of the University of Cambridge.

Other researchers at the ARC may contact volunteers via Paula Smith to invite them to participate in a specific study. If they reply to that researcher, personal information is only held by that researcher in a secure fashion on one computer for the duration of that study, and then that researcher has the responsibility of deleting it. At no time are personal details stored in the same database as test results, the latter of which are anonymized.

Those registering as volunteers are assumed to be giving explicit consent for their details to be stored electronically on the Cambridgepsychology.com's database of volunteers. The person that registers can also provide details about their children's names and it is that parent's responsibility to check that they have their child's consent or to take this decision to provide such information as a parental choice. In some cases the person that registers is asked to provide anonymous information about adult relatives (such as a spouse) or children over the age of 16. They also have the option to invite such adults to register in their own right.

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.

Data is held on the Autism Research Centre database with full approval from the Psychology Research Ethics Committee.

If you have any concerns about your privacy please **email Paula Smith** (pls28@medschl.cam.ac.uk). For more information about how we treat personal data, see the information below.

What is Personal Data?

Data relating to a living individual who can be identified from that information or from that data and other information in possession of the data controller. Includes name, address, telephone number, id number. Also includes expression of opinion about the individual, and of the intentions of the data controller in respect of that individual.

All processing of personal data is done in accordance with the eight data protection principles below:

1. Personal data shall be processed fairly and lawfully.

Those responsible for processing personal data must make reasonable efforts to ensure that data subjects are informed of the identity of the data controller, the purpose(s) of the processing, any disclosures to third parties that are envisaged and an indication of the period for which the data will be kept. At the Autism Research Centre, University of Cambridge, the data controller is Paula Smith who can be contacted at pls28@medschl.cam.ac.uk or by telephone +44 1223746046.

2. Personal data shall be obtained for specific and lawful purposes and not processed in a manner incompatible with those purposes.

Data obtained for specified purposes must not be used for a purpose that differs from those.

3. Personal data shall be adequate, relevant and not excessive in relation to the purpose for which it is held.

Information, which is not strictly necessary for the purpose for which it is obtained, should not be collected. If data are given or obtained which is excessive for the purpose, they should be immediately deleted or destroyed.

4. Personal data shall be accurate and, where necessary, kept up to date.

Data, which are kept for a long time, must be reviewed and updated as necessary. No data should be kept unless it is reasonable to assume that they are accurate. It is the responsibility of individuals to ensure that data held by the Autism Research Centre are accurate and up-to-date. Completion of an appropriate online registration will be taken as an indication that the data contained therein is accurate. Individuals should notify the Autism Research Centre of any changes in circumstance to enable personal records to be updated accordingly. It is the responsibility of the Autism Research Centre to ensure that any notification regarding change of circumstances is noted and acted upon.

5. Personal data shall be kept only for as long as necessary.

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 research studies or their rights to access services.

6. Personal data shall be processed in accordance with the rights of data subjects under the Data Protection Act.

Data Subjects have the following rights regarding data processing, and the data that are recorded about them:

- To make subject access requests regarding the nature of information held and to whom it has been disclosed.
- To prevent processing likely to cause damage or distress.
- To prevent processing for purposes of direct marketing.
- To be informed about mechanics of automated decision taking process that will significantly affect them.
- Not to have significant decisions that will affect them taken solely by automated process.
- To sue for compensation if they suffer damage by any contravention of the Act.
- To take action to rectify, block, erase or destroy inaccurate data.
- To request the Commissioner to assess whether any provision of the Act has been contravened.

7. Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of data.

8. Personal data shall not be transferred to a country or a territory outside the 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.

Consent

Wherever possible, personal data or sensitive data should not be obtained, held, used or disclosed unless the individual has given consent. The Autism Research Centre understands "consent" to mean that the data subject has been fully informed of the intended processing and has signified their agreement, whilst being in a fit state of mind to do so and without pressure being exerted upon them. Consent obtained under duress or on the basis of misleading information will not be a valid basis for processing. There must be some active communication between the parties such as completing the registration process on-line and the individual must do this freely of their own accord. Consent cannot be inferred from non-response to a communication. For sensitive data, explicit written consent of data subjects must be obtained unless an alternative legitimate basis for processing exists.

If an individual does not consent to certain types of processing (eg email contact from the autismresearchcentre.com), appropriate action must be taken to ensure that the processing does not take place.

Security of Data

Paula Smith at the Autism Research Centre is responsible for ensuring that any personal data (on others) which is held are kept securely and that they are not disclosed to any unauthorised third party.

All personal data is accessible only to Paula Smith and Dr. Carrie Allison. All personal data is computerised and is password protected. Any hard copy data is kept in a locked filing cabinet in a lockable room with controlled access

Care is taken to ensure that appropriate security measures are in place for the deletion or disposal of personal data. Manual records will be shredded or disposed of as "confidential waste". Hard drives of redundant PCs will be wiped clean before disposal.

The Autism Research Centre ensures that personal data are not disclosed to unauthorised third parties which includes family members, friends, government bodies. This policy determines that personal data may be legitimately disclosed where one of the following conditions apply:

1. the individual has given their consent (eg a volunteer has consented to the Autism Research Centre corresponding with a named third party);
2. where the disclosure is in the legitimate interests of the institution (eg disclosure to staff - personal information can be disclosed to other Autism Research Centre employees if it is clear that those members of staff require the information to enable them to perform their jobs);
3. where the institution is legally obliged to disclose the data (eg ethnic minority and disability monitoring);

The Act permits certain disclosures without consent so long as the information is requested for one or more of the following purposes:

- to safeguard national security*;
- prevention or detection of crime including the apprehension or prosecution of offenders*;
- assessment or collection of tax duty*;
- discharge of regulatory functions (includes health, safety and welfare of persons at work)*;
- to prevent serious harm to a third party;
- to protect the vital interests of the individual, this refers to life and death situations.

* Requests must be supported by appropriate paperwork.

If Paula Smith or Dr. Carrie Allison receive enquiries as to whether a named individual is a member of the Autism Research Centre panel of volunteers, the enquirer should be asked why the information is required. If consent for disclosure has not been given and the reason is not one detailed above (ie consent not required), then Paula Smith and Dr. Carrie Allison will decline to comment. Even confirming

whether or not an individual is a member of the Autism Research Centre panel of volunteers may constitute an unauthorised disclosure.

Unless consent has been obtained from the data subject, information should not be disclosed over the telephone. Instead, the enquirer should be asked to provide documentary evidence to support their request. Ideally a statement from the data subject consenting to disclosure to the third party should accompany the request.

As an alternative to disclosing personal data, the University may offer to do one of the following:

- pass a message to the data subject asking them to contact the enquirer;
- accept a sealed envelope/incoming email message and attempt to forward it to the data subject.

Retention and Disposal of Data

The Autism Research Centre discourages the retention of personal data for longer than they are required. Some data will be kept for longer periods than others.

Disposal of Records

Personal data will be disposed of in a way that protects the rights and privacy of data subjects (eg, shredding, disposal as confidential waste, secure electronic deletion).

Academic Research

Personal data collected only for the purposes of academic research (includes work of staff and students) must be processed in compliance with the Data Protection Act 1998.

Researchers should note that personal data processed ONLY for research purposes receive certain exemptions (detailed below) from the Data Protection Act 1998 IF:

- i. the data are not processed to support measures or decisions with respect to particular individuals AND
- ii. if any data subjects are not caused substantial harm or distress by the processing of the data

If the above conditions are met, the following exemptions may be applied to data processed for research purposes only:

- personal data can be processed for purposes other than that for which they were originally obtained (exemption from Principle 2);
- personal data can be held indefinitely (exemption from Principle 5);
- personal data are exempt from data subject access rights where the data are processed for research purposes and the results are anonymised (exemption from part of Principle 6 relating to access to personal data).

Other than these three exceptions, the Data Protection Act applies in full. The obligations to obtain consent before using data, to collect only necessary and accurate data, and to hold data securely and confidentially must all still be complied with.

Publication

Results of the research will be anonymised when published and no information that is published would allow individuals to be identified. Results of the research can be published on the web or otherwise sent outside the European Economic Area but if this includes any personal data, the specific consent of the data subject must, wherever possible, be obtained.