



The autism@icn project

Prof Antonia Hamilton  
a.hamilton@ucl.ac.uk  
020 7679 4640

## autism@icn privacy notice

### Introduction

Please read this Privacy Notice carefully – it describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to autism@icn and supplements the following wider [UCL privacy notice\(s\)](#):

- [General privacy notice](#) when you visit UCL's website
- [Research participants for health and care purposes privacy notice](#)

<https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice>

### Who are autism@icn?

The autism@icn project is a collaboration between different research groups at the UCL Institute of Cognitive Neuroscience, which coordinates research into cognition in people with and without autism spectrum conditions.

The principle investigators are:

Antonia Hamilton: [a.hamilton@ucl.ac.uk](mailto:a.hamilton@ucl.ac.uk)

Paul Burgess: [p.burgess@ucl.ac.uk](mailto:p.burgess@ucl.ac.uk);

Sarah White: [s.white@ucl.ac.uk](mailto:s.white@ucl.ac.uk).

The autism@icn project is part of the Institute of Cognitive Neuroscience, which is part of University College London (UCL). UCL is a company incorporated by Royal Charter (number RC 000631) and is the entity that determines how and why your personal data is processed. This means that UCL is the 'controller' of your personal data for the purposes of data protection law.

### How do we use your data?

autism@icn understand the importance of protecting personal data. Our use of data is governed by the General Data Protection Regulations and our research studies are approved by the UCL Graduate School Research ethics board.

We will only use your personal data when the law allows us to. The legal basis that is be used to process your personal data will be *performance of a task in the public interest*. The legal basis used to process special category personal data will be for *scientific and historical research*.

The autism@icn project holds data on people who have signed up to our mailing list and people who have taken part in our research. In the table below, we detail the specific ways which autism@icn processes and uses data.



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Type of data	How is it held?	How is it used?
<b>Mailing list data</b>		
Name, address & interests	This data is kept on a high-security server with two-factor authentication and ISO27001 information security standard. Access is strictly limited to a small number of named individuals within the autism@icn group (not other linked researchers).	To send newsletters about our research to people on our mailing list
<b>Detailed participant information</b>		
Name, address, age and diagnostic details	This data is kept on a high-security server with two-factor authentication and ISO27001 information security standard. Access is strictly limited to a small number of named individuals within the autism@icn group (not other linked researchers).	To contact people and inform them about relevant research projects which they could take part in.
<b>Core scientific data</b>		
Responses in tasks & questionnaires, age & diagnostic code	These data are kept in our <i>autism@icn database</i> which is kept on a secure server in ICN. In this database, personal identities are protected by using a code instead of names. Names and address are not stored anywhere in the autism@icn database.	To conduct our scientific research. The core autism@icn team and other researchers working with us can access this anonymised data, subject to approval from the research ethics committee. This means we can do more with the data, and if you take part in more studies in the future you will not need to repeat tests.
<b>Video &amp; audio of interviews</b>		
Video and audio files	The video recordings are stored on a secure server within ICN and will not be viewed by people outside the autism@icn team. The video files are not linked to your name or to your data files, but you can be identified by your face and voice in these files.	To confirm the quality of our research interviews.



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Type of data	How is it held?	How is it used?
<b>Paperwork (consent forms &amp; payment forms)</b>		
	We store consent forms and payment forms which include your name and signature. These are kept in a locked filing cabinet and are not linked to your task responses.	To allow auditing of ethical approval and of our finances.

### Your rights

Under certain circumstances, you may have the following rights under data protection legislation in relation to your personal data:

- Right to request access to your personal data;
- Right to request correction of your personal data;
- Right to request erasure of your personal data;
- Right to object to processing of your personal data;
- Right to request restriction of the processing your personal data;
- Right to request the transfer of your personal data; and
- Right to withdraw consent.

If you wish to exercise any of these rights, please contact the Data Protection Officer at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

### Any comments or complaints?

You can contact the autism@icn project on [autism.icn@ucl.ac.uk](mailto:autism.icn@ucl.ac.uk)

You can contact UCL by telephoning +44 (0)20 7679 2000 or by writing to: University College London, Gower Street, London WC1E 6BT.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

### What if I want to withdraw from the autism@icn project?

Under the GDPR, the lawful basis for processing your data is *public task* which does not provide an option to withdraw.

Under our ethical approval for our research, you have an option to withdraw from the autism@icn project at any time. If you want to do this, just email [autism.icn@ucl.ac.uk](mailto:autism.icn@ucl.ac.uk). If you withdraw, we will delete all personal data held on our contact list (name / email etc) and all data linked to your participant number in the autism@icn data base. This means that you will not be contacted for future studies and your data will not be used in future data analyses. It will not be possible to remove anonymised data from research analyses which



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have been completed and submitted for academic publication (e.g. PhD theses or research papers). Analyses are typically completed 2 or 3 months after a testing session.

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This privacy notice was updated in July 2018 and may be amended from time to time.