

Online Information Sheet for Adult Participants

Title of project: Autism@icn

Department: UCL Institute of Cognitive Neuroscience

Principal Investigator: Prof Antonia Hamilton, Institute of Cognitive Neuroscience, University College London, 17 Queen Square, London WC1N 3AR. Email: a.hamilton@ucl.ac.uk.

Researcher Coordinator: Ms. Ishita Chowdhury, Institute of Cognitive Neuroscience, University College London, 17 Queen Square, London WC1N 3AR. Email: autism.icn@ucl.ac.uk

UCL Data Protection Officer: data-protection@ucl.ac.uk

This project has been approved by the UCL Research Ethics Committee as Project ID 5975/002.

We would like to invite you to take part in our research project. You should only participate if you would like to; choosing not to take part will not disadvantage you in any way. Before you decide whether you would like to take part, it is important for you to read the following information carefully and discuss it with others if you wish. **Please contact us if there is anything that is not clear or if you would like more information. We are happy to answer any questions you may have.**

Information about the project

Why is this study being conducted?

This project is about coordinating research across a series of studies which investigate how people with autism see the world differently and respond differently compared to people without autism. We are creating a research database to store data across many studies and make our research more efficient for both participants and scientists.

Who can participate?

We are recruiting healthy adults aged between 18 and 65 years, with and without autism spectrum condition, to take part in this study. We are recruiting over 100 people to this project over several years.

What does the study involve?

This study is designed to find out how people with autism and people without autism understand the world differently. To take part, you will need to participate in a series of online tasks, where you will be asked to

- Make judgements about images you see and sounds you hear
- Make judgements about social stories or social videos describing everyday events
- Play memory games where you must remember items or events
- Respond rapidly to pictures or words you see on a computer screen

Please note that all these tasks use everyday items and situations (not emotionally stressful or scary situations). The visit will take under **XX** hours, and will include breaks and snacks.

Travel and expenses

You will receive amazon vouchers at the rate of £7.50 per hour as compensation for the time you spend completing the online tasks.

What are the possible benefits of taking part in this research?

There are no immediate benefits to you. In the long term the research will help researchers understand the similarities and differences between people with and without autism. You can learn more about these topics by participating and having the opportunity to ask questions. You can receive a copy of the final report once it has been published in a peer-reviewed journal should you wish.

Do I have to take part?

We would like to emphasize that participation in this research is voluntary. If you choose not to participate, you will not be penalised in any way or lose any benefits to which you are otherwise entitled. If you decide to take part, you will be complete a consent form. Even if you decide to take part, you can withdraw at any time, without giving a reason.

What if something goes wrong?

In the first instance, you should contact the researcher the autism@icn coordinator or the Principal Investigator. If one of these people is the object of complaint, you may wish to contact the ICN Ethics Chair. Participation in this study is covered by the UCL Public Liability Policy for indemnity.

Ishita Chowdhury
Autism@icn
coordinator/researcher
autism.icn@ucl.ac.uk

Dr Antonia Hamilton
Principal Investigator
Email a.hamilton@ucl.ac.uk
Telephone 020 7679 4640

Chair of the UCL Research
Ethics Committee
ethics@ucl.ac.uk

Information about how we use your data

Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. Your responses will be coded by an identifying code, and data will be confidentially secured on our secure servers and our laboratory, and accessed only by our research staff. All data will be collected and stored in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. The results of this study will be seen only by other professional researchers and for teaching purposes. If suitable, results may be published in scientific journals or be presented at scientific meetings. Your name will not be identified in any public forum, and you will not be able to be identified in any ensuing reports or publications.

Limits to confidentiality: Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

What will happen to my data?

When you take part, we collect several different types of data and we use this data in different ways, as described here:

1) Responses in tasks & questionnaires

Data such as responses you make in tasks and questionnaires, your age and a diagnosis code are kept in our autism@icn database which is kept on our secure server in ICN. In this database, your identity is protected by using a code instead of your name. Your name and address are not stored anywhere in the autism@icn database. With your permission, we would like to allow researchers working with the autism@icn group to access this anonymised data for this study and future studies, 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.

2) Name, address & confidential details

If you give permission, we would also like to store your name, contact details and any confidential medical / diagnosis information which you give us in our secure contact list file. This file is kept separate to the autism@icn database on a different secure server with NHS-grade control of data access. Access to this personal data is strictly limited to a small number of named individuals within the autism@icn group (not other linked researchers) and security of this data is strictly maintained. Note that your name will NOT be linked to your task responses. The reason we store your contact details is so we can contact you again if there are future studies you might like to take part in.

3) Consent forms

We store consent forms that include your name and signature, to allow auditing of ethical approval and of our finances. These are kept on our secure server in ICN and are not linked to your task responses.

If you have taken part in previous studies with the autism@icn group, it is helpful if we can link the data from this visit to previous visits. You can give permission for this on the consent form.

What if I want to withdraw from the database after the completion of the study?

If you want to withdraw from this project at any time, just tell [\[name to be confirmed\]](#). 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 database. 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 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.

What will happen after the study?

We will put the results from all the volunteers together for publication. They will be published in reputable scientific journals. Data are typically published for groups (e.g. an average of 20 people) rather than individuals. All data will remain entirely anonymous in the final research papers.

Will you contact me again?

If you agree, we will keep your name and contact details in our secure contact list. This means that we will be able to contact you if we are conducting future studies which might interest you. If you agree, we will also be able to link data from your present participation to any time you participate in our studies in the future. This means that each test session can be shorter and we can use the data we have better.

Further project information

This study is part of the autism@icn project, organised by Antonia Hamilton, Paul Burgess and Sarah White at the ICN. This project is funded by UCL and by research grants to the project leaders. This proposal was reviewed by the UCL ethics board. If you have any comments or concerns about this study, you should discuss these with the project leaders (Antonia Hamilton: a.hamilton@ucl.ac.uk Paul Burgess: p.burgess@ucl.ac.uk; Sarah White: s.white@ucl.ac.uk).

DATA PROTECTION PRIVACY NOTICE

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice, which can be found at: <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

Your personal data will be processed for the purposes outlined in this notice. The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

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. 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/>

Thank you for reading this information sheet and for considering participating in this research.

Online consent Form for Adult Participants

Title of project: Autism@icn

Department: UCL Institute of Cognitive Neuroscience

Principal Investigator: Prof Antonia Hamilton, Institute of Cognitive Neuroscience, University College London, 17 Queen Square, London WC1N 3AR. Email: a.hamilton@ucl.ac.uk.

Researcher Coordinator: Ms. Ishita Chowdhury, Institute of Cognitive Neuroscience, University College London, 17 Queen Square, London WC1N 3AR. Email: autism.icn@ucl.ac.uk

UCL Data Protection Officer: data-protection@ucl.ac.uk

This project has been approved by the UCL Research Ethics Committee as Project ID 5975/002

Thank you for considering taking part in this research. Before you agree to take part, you should have had an opportunity to understand what the project is by going through the Information Sheet. If you have any questions arising from the Information Sheet, please contact the researcher before you decide whether to join in.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

Study items	
	I have read the notes written above and the Information Sheet, and understand what the study involves. I understand the potential risks of participating. No promise or guarantee of benefits has been made to encourage me to take part.
	I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately. I understand that I will be fully compensated even if I choose to withdraw.
	I understand the inclusion and exclusion criteria set out in the information sheet. I do not fall under the exclusion criteria.
	I am aware of who I should contact if I wish to lodge a complaint.
Data Processing Items	
	I understand that my personal information, including responses in tasks & questionnaires, name, contact details, and medical information will be used for the purposes explained to me in the consent form. I understand that according to data protection legislation, 'public task' and 'scientific & historical research' will be the lawful basis for processing.
	I understand that my information may be subject to review by responsible individuals from the University (to include sponsors and funders) for monitoring and audit purposes.
	I agree to be contacted in the future by UCL researchers who would like to invite me to participate in follow-up studies.
	I agree that the autism@icn group can access data from my previous participation and link

	this to my data from my participation this time, and any time I participate in the future.
	I understand that data from this study may be published as a report and I will be able to access a copy on the autism@icn website. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
	I agree that my anonymised research data may be used by others for future research. I am assured that the confidentiality of my personal data will be upheld through the removal of identifiers.
Overall Consent	
	I agree to take part in this study.

By clicking continue, you consent to the above conditions and understand that you can terminate the study at any time, simply by closing your browser.