



Participant Information FAQ: Plain Language Statement (Interview)	
Study title and Researcher Details	
Title: Staging Neurodiverse Sibling Relationships Researcher: Emma Ettinger, PhD student researcher (e.ettinger.1@research.gla.ac.uk) Supervisors: Dr. Graham Eatough (Graham.Eatough@glasgow.ac.uk) and Professor Deborah Cairns (Deborah.Cairns@glasgow.ac.uk) Course: PhD Theatre Studies	
Invitation paragraph	
Thank you for your interest in the <i>Staging Neurodiverse Sibling Relationships</i> project! You are being invited to take part in a research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it will involve. Please take time 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. Take time to decide whether or not you want to take part.	
What is the purpose of the study?	
This study is researching the relationships between autistic adults and their siblings. The researcher will gather real-life stories from interviews to inspire a play about the lives and relationships of a set of fictional characters. The play and an accompanying reflection will be submitted as the researcher's PhD thesis, in Autumn 2025 or 2026. They will be made available for members of the public to read or watch.	
Why have I been chosen?	
You are at least 18 years old <i>and</i> you are either an autistic person with siblings or a person with autistic siblings. (You might also be both.) You may have received an invitation to participate via an autism and/or family services organization you are involved in, via a friend or acquaintance, or by finding a link to the study online.	



Do I have to take part?

It is up to you to decide whether or not to take part. If you do take part, you are free to withdraw at any time and without giving a reason. You may stop the interview at any time and can choose not to answer any questions that make you feel uncomfortable.

Whether or not you participate will have no impact on your grades (if you are a student at the University of Glasgow), nor will it impact your relationship with the researchers or with any organization that you may have heard about the research through.

What will happen to me if I take part?

If you choose to take part, you will be asked a series of questions about yourself and your sibling(s), and to share some memories involving your sibling(s).

You can choose whether to take part via:

- A) an audio-recorded virtual interview (on Zoom or Teams),
- B) an audio-recorded in-person interview, or
- C) a written questionnaire online.

The interview itself should take no more than 90 minutes of your time.

The researcher conducting the interviews is a non-autistic adult with an autistic sibling. Please let me know if there are any accommodations that would help you to take part!

After the interview, you may be invited to take part in a group discussion with other autistic people and/or siblings. You will also have the opportunity to be contacted about future readings or performances of the play. You can opt out of these emails at any time.

Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. Your data will be assigned an ID number, and information about you will have your name and contact details removed.

Please note that if safeguarding concerns or other evidence of potential harm are raised, the University may be obliged to contact relevant statutory bodies/agencies.

You will also be asked to give your sibling(s) a Privacy Notice, to let them know that you will be sharing some information about them with the study. Your sibling(s) have a right to know that we are processing their data, but they will not be able to access any of the information you share with us.



What will happen to the project data and the results of the research study?

Under the UK General Data Protection Regulation (UK GDPR), your personal data (name, contact details, age, location) will be processed under the legal basis of 'task in the public interest'. Where special categories data (about disability status) is recorded, this will be processed under the legal basis that it is 'necessary for archiving purposes in the public interest, or scientific and historical research'.

After your interview, an audio recording and detailed summary will be stored on a secure, encrypted server in the UK. Identifying information will be redacted, and the files will be assigned a pseudonymous ID number, to keep them separate from identifying data like your name, consent form, and contact information. Because your voice may still be recognisable in the audio, a separate identifier document will be maintained in case you wish to exercise your privacy rights.

Your data will be retained on a secure server, maintained by the University of Glasgow, for at least 10 years after the research project is completed. In this time, interview summaries (and, with your permission, audio recordings) may also be consulted by other research teams.

If you opt-in to hearing about project updates and future participation opportunities, your contact information will be maintained (separate from interview data) either until the project's completion or until you opt out.

The researcher will use stories you share during the interview to inspire a fictional stage play, which will be shared with the public. The play will combine stories from many people's interviews along with made-up ideas and events, so no one will be able to identify you. Some of your own words may appear in the final script, but most of the text will be altered or invented. When you consent to participate in this study, you will be asked to assign performance rights in your interview contributions to the researcher.

The researcher will also write a critical reflection on the research and writing process. Things you say in the interview may be referenced here, with your name and any identifying data removed. Parts of this thesis may also be shared in academic conference papers and/or journal articles.

Who is organising and funding the research? (If relevant)

This research is funded by a doctoral scholarship from the University of Glasgow College of Arts. Other organizations may fund portions of the play's development process (ie. so that actors can be hired for readings and/or workshops).

Who has reviewed the study?

The study has been reviewed and approved by members of the College of Arts Research Ethics committee.



How can I access information relating to me or complain if I suspect information has been misused/ used for purposes other than I agreed to?

You can contact the researcher or their supervisor(s) in the first instance if you have any concerns. If you are not comfortable doing this, or if you have tried but don't get a response or if the person in question appears to have left the University, you can contact the College of Arts Ethics Officer (email: arts-ethics@glasgow.ac.uk).

Where there appear to have been problems, you can – and indeed may be advised to – submit an 'access request' or an objection to the use of data. As part of the University's obligations under UK General Data Protection Regulation (UK GDPR), participants retain the rights to access and objection with regard to the use of non-anonymised data for research purposes.

1. Access requests and objections can be submitted via the UofG online proforma accessible at: <https://www.gla.ac.uk/myglasgow/dpfoioffice/gdpr/gdprrequests/#>.
2. Access requests and objection are formal procedures not because we mean to intimidate participants into not raising issues, but rather because the University is legally required to respond and address concerns. The system provides a clear point of contact, appropriate support and a clear set of responsibilities.
3. Anyone who submits a request will need to provide proof of their identity. Again, this is not to deter inquiries, but rather reflects the University's duty to guard against fraudulent approaches that might result in data breaches.
4. You also have the right to lodge a complaint against the University regarding data protection issues with the Information Commissioner's Office (<https://ico.org.uk/concerns/>).

Contact for further Information

Emma Ettinger, PhD Researcher: e.ettinger.1@research.gla.ac.uk

Dr. Graham Eatough, Theatre Studies (Primary Supervisor): Graham.Eatough@glasgow.ac.uk

Professor Deborah Cairns, Scottish Learning Disabilities Observatory (Secondary Supervisor): Deborah.Cairns@glasgow.ac.uk

If you have any concerns regarding the conduct of this research project, you can contact the College of Arts Ethics Officer (email: arts-ethics@glasgow.ac.uk).



An Easy Read version of this information can be found at this link:

[Easy Read Participant Information](#)

Privacy Notice for Staging Neurodiverse Sibling Relationships

Your Personal Data

The University of Glasgow and PhD researcher Emma Ettinger will be what's known as the 'Joint Data Controllers' of your personal data processed in relation to *Staging Neurodiverse Sibling Relationships*. This privacy notice will explain how The University of Glasgow and the researcher will process your personal data.

Why we need it

Staging Neurodiverse Sibling Relationships is a PhD research project looking at the relationships between autistic adults and their siblings. The researcher is conducting interviews with siblings in order to inform the writing of a new theatrical play about sibling relationships involving autism.

We are collecting your basic personal data such as name, age, contact details, and place of origin/residence, as well as limited special categories data about your disability status to register your interest in the study and to select participants who meet our selection criteria. For those who are selected, we will use your data to arrange study interviews and to contextualise the experiences you share with us in your interview. We will also use your contact details to send you updates/information about the study and resulting play, if you have consented to receive this.

We will only collect data that we need in order to carry out our research.

Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal bases are that the project constitutes 'a task in the public interest', and that any processing of special category data is 'necessary for archiving purposes in the public interest, or scientific and historical research'.

What we do with it and who we share it with

- All the personal data you submit is processed by the PhD research student and staff at the University of Glasgow in the United Kingdom.
- Your data will be stored in a password-protected file on a secure server, which is only accessible by the student researcher and their supervisors.
- If you participate in the interview phase of this research project, your data will be pseudonymised. An audio recording of your interview, and any other personal data which we collect, will be assigned a Participant ID number and disassociated from your name and contact details. Personally identifiable information will be redacted (bleeped out or replaced with silence in the audio recording), but as audio recordings are difficult to fully anonymise, an identifier document will be maintained in a separate, encrypted and password-protected file, in case you wish to exercise any of your privacy rights.
- At the completion of the project, pseudonymised archival data sets may also be made available to other bona fide research teams.
- Your name or any other identifiable data will not be included in the published output of this research.

How long do we keep it for

Data for potential participants will be retained by the study until all research interviews have been conducted (estimated Spring 2024). If you do not participate in the interview phase of the research project, your data will be securely deleted at this time, except for your contact details if you have indicated that you would like to receive updates about the resulting play. If you do not meet the interview criteria or choose to withdraw from the study, your data will immediately be deleted.

If you do participate in the interview phase of the research project, any unredacted audio recordings and transcripts of your interview will be deleted before the project's completion. Your pseudonymised data (including redacted audio recordings) will be retained by the University for at least 10 years after the project's completion (longer if the materials are consulted during this time). After this time, your data will be securely deleted.

What are your [rights](#)?*

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. You may also have the right to object to the processing of data and the right to data portability.

If you grant us permission to contact you about opportunities for future involvement in this research, you have the right to withdraw that consent at any time.

Your sibling(s) also have a right to information about our processing of their data. A separate privacy notice to be shared with your sibling(s) can be found at the following links:

[Standard Privacy Notice \(for siblings\)](#)

[Easy Read Privacy Notice \(for siblings\)](#)

If you wish to exercise any of these rights, please submit your request via the [webform](#) or contact dp@gla.ac.uk.

**Please note that the ability to exercise these rights will vary and depend on the legal basis on which the processing is being carried out.*

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter.

Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) <https://ico.org.uk/>



An Easy Read version of this information can be found at this link:

[Easy Read Privacy Notice \(participants\)](#)