

Participant Information Sheet

Working Title: Adults with ASC and their experiences of therapy: A mixed methods study.

My name is Perri Reed and I am conducting this study as part of my Doctorate in Counselling Psychology dissertation in the School of Psychology. I would like to invite you to take part in a research study aiming to better understand individuals with autism spectrum conditions (ASC) and their past experiences of therapy.

Before you decide whether you wish to take part, read this information sheet carefully. Please don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family, or friends.

This leaflet has 5 main parts:

Part 1: The study

Part 2: Data Protection

Part 3: Costs, Funding, and Approval

Part 4: Future Research

Part 5: Further Information

Contact us at:

Site	Trinity College Dublin (TCD)	
Principal Investigators	Perri Reed Postgraduate student	reedp@tcd.ie
	Dr. Olive Healy Associate Professor, TCD	olive.healy@tcd.ie
Data Controller	Trinity College Dublin (TCD)	
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin, Dublin 2.	dataprotection@tcd.ie .

Why is this study being done?

The aim of this study is to explore how adults with autism spectrum conditions experience therapy. Attending therapy can be a complex experience for some and autistic people sometimes face a number of challenges accessing supports. We hope that this research will contribute to a greater understanding of how therapy can be best provided to support autistic people seeking therapy for experiences of anxiety, depression, OCD and/or ADHD. It is hoped that this research will inform clinicians' awareness and the provision of appropriate support services.

Why have I been invited to take part?

You have been invited to partake in this research because of your unique experience as an autistic person having received therapy for anxiety, depression, OCD and/or ADHD. I am hoping to interview 12-15 individuals over 18 years of age.

Do I have to take part? Can I withdraw?

You do not have to take part in this research. It is entirely your choice to participate. You do not have to give a reason for not taking part or opting out. If you decide to participate and then change your mind, you can email me at reedp@tcd.ie at any point up until the study is published.

What happens if I change my mind?

You can change your mind at any time by contacting me at reedp@tcd.ie. If you choose not to continue to take part, this will not affect you in any way. If you choose to withdraw, please email me. Once I receive your request to withdraw your participation, I will remove your personal data and transcript from the study. I will respond to your email and to confirm when this is done. We will no longer use or share your data for research from this point onwards.

How will the study be carried out?

You will be invited to schedule an individual interview with me at a time that is convenient to you. This interview will be conducted virtually via Microsoft Teams. We will have a conversation about your experiences as an autistic person who has attended therapy for anxiety, depression, OCD and/or ADHD. We anticipate having conversations with between 12 and 15 individuals.

What will happen to me if I decide to take part?

You will be invited to an individual interview with me (Perri). Attached to the email that contains this document, there is another document with a consent form for you to consider. If, after reading the participant information leaflet, you would still like to participate in this study, please email me back with a signed copy of the consent form. If at any time you have any questions, you may contact me by email. Upon receipt of your consent form, I will email you to organise a date and time for an interview.

Interviews will last approximately 60-90 minutes. Interviews will take place online through the conferencing platform 'Microsoft Teams'. On the agreed day you will be emailed a link for the interview and a password for access to the meeting room. At the time of interview, you can click the link and you will be brought to the meeting's virtual waiting room. Once I verify your name, you will be allowed access to the meeting. You are advised not to share the meeting room number or password with others. If you are using a desktop or laptop for the interview, it is advisable to use Google Chrome in Incognito mode for your security. If you are using a mobile phone you are asked to download the app 'Microsoft Teams'. If you would prefer for the interview to take place

over the phone, we will use Teams without the video input so only your voice will be heard. The interview will be recorded so you will be notified when recording begins and ends. It is advisable where possible to use earphones so that you can have privacy. I will be using headphones in a private room to ensure your privacy.

Before the interview, I will ask that you fill out two forms. The first asks you to provide demographic details about yourself (e.g., age, diagnosis, date of diagnosis, country information). The second is a 13-item questionnaire that looks at your overall satisfaction with therapy. During the interview, you will be asked about your experiences of receiving therapy. Interviews will be audio-recorded and written out word for word (transcribed) by myself on a password-protected document. I will change any references to dates, locations, names or job titles to ensure your confidentiality is protected. You have a right to request a copy of this transcript and to change or remove any of your responses until publication of this research. If you would like a copy of this transcript, to change, or to remove any of your responses, please contact me via email.

What will happen with data?

All information you provide for the study will be treated with the utmost respect and with the strictest of confidence. It will be stored safely and securely (please see part 2 for more details). The results from this study will be included in a thesis and used in publications and presentations. Names and other identifiable information (e.g., contact details) will not be used in any of the above.

Are there any risks or benefits to participating in this research?

There is no risk foreseen outside of risk experienced in everyday life. The interview will explore personal and sensitive topics such as your experience attending therapy. You may refuse to answer questions if you wish. There is no payment for taking part in this research and there is no direct benefit. However, this research may help us to better understand the experiences of individuals with ASC and anxiety, depression, OCD and/or ADHD who have attended therapy – and may result in the development of new ways of supporting autistic people who are seeking therapy. The benefits of the research may not be seen for several years. By participating, you are helping to advance scientific research and psychological interventions.

Part 2 – Data Protection

What information about me (personal data) will be used as part of this study?

You will be asked to give personal information such as your name and contact details. I will also be audio recording the interview about your experiences of receiving therapy. During the interview I will take notes using pen and paper. The audio recording will be classified as personal data because your voice will be recorded. Prior to this, you will be asked to fill in a demographic information form and a 13-item questionnaire.

What will happen to my personal data?

We will use your personal information (name/contact details) to arrange the interview and send out the demographic form and questionnaire. If you agree, I ask that you email your signed consent form to me. Once I receive this, within 24 hours the consent form will be uploaded in a secure, password-protected, encrypted file to TCD's OneDrive and the email with the consent form attached will be destroyed. Your data will be anonymised within 96 hours of collection and the pen and paper notes will be shredded. Four days after the interview your contact details will be deleted. Only data necessary and related to the research question will be collected and

processed. We will retain the anonymised data for a period of 3.5 years after submission of the research thesis. We will retain the consent forms in a soft copy, password-protected, encrypted file for a period of 7 years after

submission of the research thesis. This is in line with Trinity College Research retention policy. After this time, your information will be deleted.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. Only the research team listed on the cover of this information sheet will have access to your personal data and we will never share your personal data with other researchers. There is no guarantee of security when using online technology, however, reasonable steps will be taken to ensure the network is as secure as possible and maintains privacy for you.

We will take the following steps to make sure that we protect your confidentiality and keep your data safe:

- The lead researcher will carry out the online interview in a private, secure room in her home. Earphones will be used to protect your privacy.
- All information we collect from you is solely for the purposes of carrying out this research and will only be kept for as long as is necessary. **Your personal data will not be used in future studies.**
- 'Microsoft Teams' is encrypted end-to-end, meaning that the interview will be as secure as possible. The meeting will be password protected and the waiting room function will only allow you and the interviewer into the meeting.
- A unique study code will be assigned to you. All your information will be gathered, stored and accessed using this code name. Personal information (names, email address) and informed consent forms will be stored separately on One Drive in a password-protected and encrypted file.
- Once the data is at the analysis stage it will be anonymised, therefore there will be no personal data or identifiable information included in the thesis and subsequent publications or presentations.
- Training in data protection law has been provided to the research team.

Will the confidentiality of my data ever be breached or shared with a third party?

Confidentiality may be breached in circumstances in which;

1. The research team has a strong belief or evidence exists that there is a serious risk of harm or danger to either the participant or another individual. This may relate to issues surrounding physical, emotional and/or sexual abuse, concerns for child protection, self-harm, suicidal intent or criminal activity in the future.
2. Disclosure is required as part of a legal process or Garda investigation. In such instances, information may be disclosed to significant others or appropriate third parties without permission being sought.

Where possible, a full explanation will be given to the participant regarding the necessary procedures, as well as the intended actions that may need to be taken.

What is the lawful basis to use my personal data? What are my rights?

By the European General Data Protection Regulation (GDPR) law, we can use your personal information for scientific research (in the public interest). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

You are entitled to:

- Access to your data and receive a copy of it.
- Restrict or object to processing of your data.
- Object to any further processing of the information we hold about you (except where it is de-identified).
- Have inaccurate information about you corrected or deleted.

- Receive your data in a portable format and to have it transferred to another data controller.
- Request deletion of your data.

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting the lead researcher (Perri Reed, reedp@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Part 3 – Cost, Funding, Approval

Has this study been approved by a research ethics committee?

This study has been approved by the School of Psychology, Research Ethics Committee (SPREC) at Trinity College Dublin. Approval was granted on July 19, 2023.

Who is organising and funding this study? Will the results be used for commercial purposes?

There is no funding for this study and there is no grant supporting it. This research will not be used for commercial purposes. I am conducting this research as part of my dissertation for my Doctorate in Counselling Psychology.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying participants to take part in the study and it will not cost you anything to take part.

Part 4 – Future Research

Will my personal data be used in future studies?

No, your personal data will not be used in future studies.

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- **Principal Investigator:** Perri Reed (reedp@tcd.ie)
- **Research Supervisors:** Dr. Olive Healy (olive.healy@tcd.ie)
- **Data Protection Officer, Trinity College Dublin:** Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will then be contacted within one week by the lead researcher to confirm participation, arrange an interview, and complete the demographic form and questionnaire. If you wish to contact me before then, please contact me by email (reedp@tcd.ie). You will also be sent a debrief sheet by email upon the conclusion of the interview.