



Participant Information Sheet

Adult Autism Diagnosis and Identity

My name is Colleen Burke, I'm a trainee Clinical Psychologist completing my doctoral thesis in the University of Limerick under the supervision of Professor Patrick Ryan. My interest in the area of adult autism diagnosis was informed by my clinical practice and to contribute to research that may improve understanding and support for adults post-diagnosis.

What is the project about?

The purpose of this study to explore how adults experience receiving an autism diagnosis later in life and how this may relate to identity and self-understanding. Being diagnosed with autism as an adult can sometimes change how a person sees themselves, rather than just a single clinical event. This research aims to contribute to an improved understanding of adult autism diagnosis and inform future clinical practice and research.

What will I have to do?

If you agree to take part, you will be invited to participate in a one-to-one semi-structured interview lasting approximately 30-60 minutes. In this interview you will be asked questions about your experiences of receiving an autism diagnosis, with a focus on identity and adjusting post-diagnosis. You will receive the interview questions beforehand. Depending on your preference, interviews can take place either:

- Audio **or** video recorded (depending on your preference) online via Microsoft Teams recording function
- Audio recorded in person at a safe, private and agreed location via an audio recording device

What are the benefits?

There may be no direct personal benefit, however, some people find value in reflecting on and sharing their experiences of receiving an autism diagnosis in their adulthood. Your participation may also help improve the understanding of adult autism diagnosis. It is hoped that the findings of the study will contribute meaningfully to research in this field and inform health professionals working directly with autistic people post-diagnosis.

What are the risks?

Some people may find that discussing their experiences of receiving an autism diagnosis brings up emotional discomfort. If this happens, you may pause, take a break, skip questions, or stop the interview at any time. You are not required to discuss anything you are uncomfortable sharing.

What if I do not want to take part?

Taking part is completely voluntary. You may choose not to participate or withdraw from the study without giving a reason and without any negative consequences. You can withdraw your data within two weeks of your interview taking place. At that stage, it may not be possible to distinguish your data from that of other participants.

What happens to the information?

The interviews will be recorded and transcribed. Once the interviews are transcribed, the recordings will be permanently deleted. For the first two weeks after transcription, identifiable information will be removed from the transcripts and kept separately. We keep identifiable information for this two-week period so that it is possible to re-identify your transcript if you wish to withdraw from the study. After those two weeks the transcripts will be made anonymous, meaning all identifying details will be permanently deleted so no one can be linked to their interview transcript.

Data will be stored securely on UL's GDPR compliant One-Drive. Anonymised data may be used in the researcher's thesis, publications, and presentations. With your consent, anonymised data may be retained for future research.

Who else is taking part?

Approximately 15-30 adults who received a formal autism diagnosis in adulthood will be invited to take part in this study.

What if something goes wrong?

In the unlikely event that something goes wrong, the interview session will immediately stop until the researcher and participant are ready to restart the session or the session would be stopped completely.

What happens at the end of the study?

At the end of the study all interview data will have been analysed and reported as part of the researcher's thesis and may contribute to academic publications and presentations. Your interview will remain anonymised, and no identifying information will be included in any outputs. Data will be stored securely for 7 years in line with the University of Limericks Data Retention Policy and then securely deleted. With your consent, anonymised data may be retained for future research. If you would like a summary of the findings, the researcher will provide this for you.

What if I have more questions or do not understand something?

If you do not understand any aspect of the research please contact either Colleen or Patrick and discuss any questions that you might have. It is important that you feel completely at ease during the research.

What if I change my mind during the study?

Should you feel at any stage that you want to stop being a participant in the research, you are free to stop and take no further part. You may withdraw participation up to two weeks after completing the interview with no consequence. After those two weeks, the interview

transcripts will be made completely anonymous and it will no longer be possible to re-identify your transcript.

Thank you for taking the time to read this information sheet.

Project Investigator Contact Details:

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Principal Investigator

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This research study has received Ethics approval from the Education and Health Sciences Research Ethics Committee (2026_02_09_EHS).

If you have any concerns about this study and wish to contact someone independent you may contact:

Chair Education and Health Sciences Research Ethics Committee
EHS Faculty Office
University of Limerick
Tel (061) 234101