

Quality of life of autistic adults aged 40+

Study overview

This study is led by researchers from the University of Luxembourg's Lifespan Development, Family & Culture institute. We are interested in what constitutes quality of life for autistic adults aged 40 and older. Many studies use general surveys designed for non-autistic people. However, our research shows these surveys miss key aspects. That is why we have created new questions. We would also like to compare quality of life across the UK, Germany and Luxembourg.

Who can participate?

- Autistic adults (either diagnosed or self-identified) with capacity to provide consent
- Aged 40 or older.
- Living in the UK, Germany or Luxembourg.

Participation steps

To take part, you will complete an online questionnaire. It takes around 25 minutes. Some questions are from existing surveys, while others are new. The new questions are based on research and feedback from autistic adults. Topics include:

- Quality of life
- Mental health (depression, anxiety, loneliness and stress)
- Autistic traits*

**You may have answered these questions before. We need this information to compare diagnosed and self-diagnosed adults.*

Benefits of participation

There might not be immediate benefits for you. However, your input is vital. It helps improve understanding the quality of life of autistic people. It will also help us create a questionnaire which is more relevant for autistic people. This is important because quality of life surveys are often used to show if studies with autistic people were successful.

Risks involved and stopping participation

There are no major risks. However, thinking about quality of life or mental health could be stressful. Participation is voluntary and you can end the survey at any time. You can also skip questions you don't want to answer. If you leave the survey, any shared information will be deleted.

Information collected

We will ask for:

- Age, age of diagnosis/ self-identification, gender, country of residence, education level, employment status, living situation, living arrangement and relationship status.
- Any relevant health issues (e.g. mental health conditions, ADHD)

Data handling

We are not collecting identifiable information (e.g. your name, date of birth or contact details). This means no one will be able to identify you from this data and your data will stay anonymous. We will analyse the data of all participants together to understand what our new survey questions show about quality of life. We will also compare the quality of life of participants across the UK, Germany and Luxembourg. When we publish the results, we would like to put the anonymous data online so that other researchers can check our

work. This helps ensure that research is open, high-quality and trustworthy. We will also ask for your consent to use this data “for further research”. This means carrying out different types of analyses on the same anonymized data as part of our research project. We will not ask you to provide any additional data. For information on how we will protect your data, please read the data protection sheet.

Research results

We will publish the results in scientific papers and share them at conferences. Our papers will be “Open Access”, so you can read them for free. We will also publish the study results on the project website: <https://www.uni.lu/fhse-en/research-projects/autistic-ageing/>.

Thank you for your time.

To participate, please give consent on the survey page.

If you have any questions, email Hannah Viner: hannah.viner@uni.lu

Data protection: information notice about personal data processing

As part of the Research Project, personal data will be collected, processed and analysed to achieve the scientific objectives of the Research Project. This may involve writing dissertations or reports, storing and analysing the data and publishing our research results. Your data may also be important after this Research Project for other research on autism, ageing and quality of life. Please indicate in the consent form below whether you agree to this.

Data collecting and processing : in this study will we ask for your age, age of diagnosis, gender, country of residence, education level, employment status, living situation/ arrangement, relationship status, autism diagnosis and co-occurring health conditions. This personal data will be collected directly from you. All necessary procedures and precautions will be taken to maintain your confidentiality.

Legal basis: Your personal data will be processed in accordance with the General Data Protection Regulation (GDPR) and the Luxembourg Act of 1 August 2018 on Data Protection. The legal basis is stated in Article 6 (1) GDPR “the data subject has given consent to the processing of his or her personal data for one or more specific purposes” : e) processing is necessary for the performance of a task carried out by the University in the public interest; PUBLIC INTEREST.

Sensitive data: This Research Project involves sensitive data regarding your health (autism diagnosis, when applicable and co-occurring health conditions). The processing of personal data is therefore also based on Article 9 (2): (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes. The research mission of the University is laid down in the Act of 27 June 2018 concerning the organisation of the University of Luxembourg.

Data processing: The Data Controller in respect of the processing of your data is the University of Luxembourg, a public institution for higher education and research, acting for the Department of Behaviour and Cognitive Sciences in the Faculty of Humanities, Education and Social Sciences. If you have any requests concerning the processing of your personal data you can contact the University of Luxembourg’s Data Protection Officer by email at dpo@uni.lu, or by post (see address in “your rights” section):

Protecting your data: In order to protect the confidentiality of your data, you will only be identified by a code number (or pseudonym) in the data analysis and in any reports or publications that will be produced by the research team during this research project.

Data storage: Your personal data will be stored on secure password protected servers at the University of Luxembourg. Anonymous data used in scientific publications will be archived in a scientific repository accessible to other researchers.

Data access: The recipients of your personal data are researchers at the University of Luxembourg involved in this research project. Anonymous data used in scientific publications will be archived in a scientific repository accessible to other researchers.

Data transfer: Your personal data will only be processed within the European Union.

Consent form

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I have read and understood:

- ✓ the information sheet.
- ✓ what taking part involves and any risks.
- ✓ That I can email the researchers to ask questions (hannah.viner@uni.lu).
- ✓ My data will be collected and used for this project. My anonymized data will be published in a scientific paper.
- ✓ I can withdraw my consent at any time. I don't have to give a reason. There will be no negative consequences.

Please read the sentences and tick the relevant boxes:

	YES	NO
I consent to the collection and use of my personal data in relation to this research project.		
I agree to the data I provide being stored at the University of Luxembourg.		
I agree for my anonymized data to be used in further research projects on autism, ageing and quality of life.		
I consent to my anonymized data being archived in a scientific repository for other researchers.		
I voluntarily agree to take part in this research project.		