

Learning about the lives of adults on the autism spectrum and their relatives

What is this study about?



You are invited to take part in a research study. In this study, we want to find out about the lives of relatives of adults on the autism spectrum. We also want to find out about how people's lives change over time.

Why have I been asked to take part?



You have been asked to take part because you are a relative of an adult with an autism spectrum diagnosis.

How will it help me?



We hope you will enjoy taking part in the research. We hope that the findings of this research will help people understand more about the lives of adults on the autism spectrum and their relatives. We hope it will lead to some improvements in the services that support adults and their relatives.

What will I have to do?

If you want to take part in this study, there are two ways you can join in.



1. You can fill out the Contact Form and we will send you some other paper forms about the study.

Or



2. You can join by going to the website <http://research.ncl.ac.uk/adultautismspectrum/> and clicking 'Register with the Adult Autism Spectrum Cohort - UK'. You can complete all the forms on this website.

What information will I be asked for?



You will be asked to complete a Consent Form. On this form, you will be asked if you agree to take part in the research.



You will also be asked to fill in a questionnaire. On this questionnaire you will be asked for:

- Information about your daily life
- Information about your relative on the autism spectrum and your experience of being their relative.



Once you have completed the forms we will contact you from time to time. This is because we want you to update the information you gave. We may ask you complete some other forms. We may ask if a researcher can visit you.

Do I have to take part?



No. You choose if you would like to take part, or not. If you do not want to take part that is fine. Choosing not to take part will not affect any care or services you, or your relative gets. If you want to take part, and later change your mind, you can stop at any time.

Will you tell anyone if I take part?



Our research team will know you are taking part. If you agree to us contacting your local health team to get information about your relative's autism diagnosis, they would also know. If you need help filling out the questionnaires, someone who helps you will also know.



Sometimes people have to check the research is being done correctly. If they wanted to do this, they would be able to look at your information, but wouldn't tell anyone about it. We will never give your information to other people. We will never tell anyone you are taking part in the study.

How will I find out the results of the study?



We will send you a newsletter which will show you any interesting results we have found.



Also, you will find this information on our website.

Will I be asked to take part in other research projects?



Some other researchers might want to contact you about other types of research projects in the future. If you are interested in hearing about these projects, we can write to you, or email you. **You do not have to agree to take part in other research projects.**

Who is organising this study?



This study is being run by the autism research team at Newcastle University.



The study is funded by the UK charity Autistica (www.autistica.org.uk).

Can I talk to someone before agreeing to take part?



Yes. If you would like to hear more about the research and/ or have any questions you can contact us by phone or email. Our telephone numbers is 0191 282 1380 and our email address is adultautismspectrum@ncl.ac.uk

Thank you for reading this Information Sheet.