

Information sheet for relatives of adults on the autism spectrum

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

This booklet contains information about a research project
that you may be interested in

Please read the information inside. If you would like to take
part, please complete the consent form and questionnaires and
send these back to us. Thank you

Autism Spectrum Conditions in Adulthood

Learning about the lives of adults on the autism spectrum

Information Sheet for Relatives

If you would like an EasyRead Information Sheet please email adultautismspectrum@ncl.ac.uk or call us at 0191 282 1380.

Alternatively, you can watch an information video containing all the information given here, on our website www.autismspectrum-uk.com

This research study is called '**Learning about the lives of adults on the autism spectrum and their relatives**'. In this research, we want to know about your experiences as a relative of someone with autism. Our aim is for our research to lead to new knowledge about people's lives, and change to services and support for adults on the autism spectrum and their relatives.

If you agree to join the study, you will be asked to give your contact details, some health and lifecourse information about yourself, some information about your relative's autism spectrum diagnosis, and other information (types of support they receive, their employment opportunities, their home and and information about aspects of their daily life).

Here is information to help you decide whether or not you wish to take part. Please contact us using the contact details at the bottom of this Information Sheet if there is anything you do not understand or if you would like more information. We would also like you to consider whether we can contact you about other autism research projects in the future

We are inviting you to take part in a study that aims to learn much more about the lives of adults on the autism spectrum and their relatives. The term 'autism spectrum' will be used from now on in this Information Sheet.

Research about autism often requires large numbers of participants.

We want to recruit as many relatives of adults on the autism spectrum as possible from across the UK to join our research - a cohort of relatives of adults on the autism spectrum.

A cohort means a group of people with shared characteristics – in this case, relatives of an adult with an autism spectrum diagnosis. If you

agree to take part, as well as contacting you now, we would like to contact you at different times in the future, to make sure we have up-to-date information about you. We hope that the project will continue for at least 10 years – however, you would be free to opt out at any time.

This study will increase our knowledge about what life is like for adults on the autism spectrum and relatives/carers - we will use the results to let people know how adults and relatives might want to be supported, and hope this will lead to people making changes in the services available to adults on the autism spectrum and their relatives.

What are the aims of this study?

- To collect information from relatives of adults on the autism spectrum. This will help researchers, policy makers and those providing services for adults to better understand better the skills and support needs of adults on the autism spectrum
- To ask for updates from time to time to understand in more detail how life experiences change for relatives/carers of adults on the autism spectrum
- To consult with relatives about their priority research questions to be addressed by research
- To help researchers recruit participants for projects that aim to answer important questions which may lead to significant advances in knowledge, opportunities and care.

Why have I been invited to take part?

This study is for any close relative of an adult aged 16 or over, with a diagnosis of autism, atypical autism, autism spectrum disorder/condition, pervasive developmental disorder, high functioning autism or Asperger's Syndrome and people who think s they may have an autism spectrum disorder but have not had a formal assessment.

Relatives/carers of adults on the autism spectrum can have found out about this research in different ways. You may have looked at the website www.autismspectrum-uk.com . Alternatively, health, education, and social care professionals and people from voluntary organisations/community groups have agreed to let relatives of adults on the autism spectrum know about this research study.

How might this study help relatives of adults on the spectrum?

By taking part, you will help us with research that might lead to improvements in services, and support for people from the autism community. The research team includes adults on the autism spectrum, their relatives and professionals. When we designed this study, we spoke to adults on the spectrum and relatives to make sure we are collecting the information needed to better understand peoples' everyday lives.

Will I be asked to participate in other research projects?

In the future, researchers might want to contact relatives of adults on the autism spectrum about other types of research. Our Research Steering Committee, which includes relatives of adults on the autism spectrum, will decide which projects to support, to ensure the studies are of high quality and useful. We will contact you with information about the studies – we won't give other people your details. If you are interested in these studies, you can reply directly to the researchers.

Please note you can take part in the cohort part of the research without being contacted by us about other projects in the future (see the Consent form)

If I am interested in this study, what happens next?

There are two ways you can join this research study.

If you prefer to join through the website, once you have accessed www.autismspectrum-uk.com, please click on 'Register with the Adult Autism Spectrum Cohort - UK'. You will be asked to give a small amount of information about yourself and your relative's diagnosis. You will then be emailed your unique password. Once you have entered your email address and the password, you will be able to read information about the study, give your consent and fill in the online questionnaires. We know people take different amounts of time to complete forms – we have designed the forms so you can start them and if you wish, save your information and return later to complete them. This information will help us find out about the experiences of relatives of adults on the autism spectrum as well as some information about their relative's life experience (including any sources of support, employment opportunities, types of accommodation, and other aspects of everyday activities).

If you would prefer to send the consent form and questionnaires by post, once you have read this information sheet, please complete the consent form and the questionnaires. When you have filled them in please send them back to us in the return stamped addressed envelope.

If you have questions for us or concerns about the research, we will be happy to discuss the project with you. Please contact us by email or telephone using the contact details at the end of this information sheet, to arrange a suitable time for us to call you.

Do I have to take part?

No. It is up to you to decide whether or not to join the study. The services you, or your relative, may access now or in the future will not be affected in any way by your decision.

What happens if I decide not to take part?

If you do not want to be contacted again by us, please let us know by contacting the address at the end of this document. To find out whether the relatives who take part in this research study are representative of all relatives of adults on the autism spectrum across the UK, it helps us to have some information about people who don't take part.

For people who don't take part, we would like to keep a small amount of information which you, a professional, or someone who has discussed this research with you, could provide. The information will include your year of birth, gender, ethnicity, postcode, and your relative with an autism spectrum condition's diagnosis. We ask for your postcode so we can know what type of area in the UK you live in. Once we have recorded this information, the last 3 digits of the postcode will be removed by us, so all the information provided is anonymous. If you do not wish to be contacted by us, but are happy to provide us with this information, please complete the reverse side of the contact form and return it to us in the stamped addressed envelope. You do not have to do this, but it helps a lot – thank you.

If I agree to take part, what information will I be asked for?

You will also be asked to complete some questionnaires to give us information about your education, employment, relationship status, health and quality of life. You will also be asked for information on your relative's diagnosis and some information about their autism spectrum

diagnosis, health, living arrangements, level of support needed, access to support, employment, social relationships and lifestyle choices. We would like you to complete as much of the questionnaires as possible – but you can leave questions blank, if necessary. You will not have to give your relative's name or contact details.

Will my information be kept safe and confidential?

Your information will be kept safe according to the Data Protection Act 1998. Your personal information will be kept separate from the anonymous research data. The research team will store your personal information on a secure database at Newcastle University. The database will only be accessed by research staff working on the study and individuals from the relevant agencies or the Northumberland Tyne and Wear NHS Foundation Trust, to check the quality of the research. **No identifying information will ever be released to researchers or anyone else.** Any information that is published will always be anonymised.

What happens if I want to withdraw from this study?

If at any stage you wish to withdraw from this research study, **we will remove all identifiable information.** In that case, we will retain information on your year of birth, gender, diagnosis of your relative and postcode (see section '**What happens if I decide not to take part?**').

What will happen after I have returned the information?

We will contact you from time to time to ask you to update information about your life, and that of your relative on the autism spectrum, and to complete other questionnaires. We may contact you to ask if we can visit you for certain parts of the research – in this case if you do not want a visit, or would like to have someone with you, you could say so. You will be kept informed about the study's progress, and interesting findings, through newsletters and our website www.autismspectrum-uk.com .

Who is organising and funding this research study

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

This study is being run by the autism research team at Newcastle University, working with groups from across the UK. The team includes experienced autism researchers, and researchers who are experts in adulthood and ageing, as well as adults on the autism spectrum and their relatives. For a list of the people involved see the website www.autismspectrum-uk.com . The study is funded by the UK charity

Autistica (www.autistica.org.uk). Autistica aims to fund research that will lead to improved understanding and better outcomes for people with autism across the lifespan.

Who has reviewed this research study?

This research has been looked at by independent committee of people, as part of the National Research Ethics Standards (NRES) procedures. This process has been designed to protect your interests and ensure all research is of a high standard. This study has been reviewed and given a favourable ethical opinion by Wales Research Ethic Committee 5 14/WA/1066 for England, Wales and Northern Ireland and Scotland Research Ethics Committee A 14/SS/1079 for Scotland.

Thank you for taking the time to read this Information Sheet. If you have any questions, please contact the research team, see below:

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