



Information sheet for a relative/carer of an adult who is unable to give consent in England or Wales

Learning about the lives of adults on the autism spectrum

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 consultee declaration form and questionnaires and send these back to us. Thank you.

Learning about the lives of adults on the autism spectrum

Information sheet for relative/carer to act as a consultee for an adult on the autism spectrum who is unable to give consent in England / Wales

You have received this information sheet as we understand that your relative/friend/person you care for with an autism spectrum condition is unable to decide for themselves about whether to take part in this research study.

To help us know if it would be appropriate for them to join the research, we would like to you to act as a consultee. A consultee is someone who knows a person with a mental incapacity well and is willing and able to offer an opinion as to what that person's wishes would have been if they were able to decide for themselves. We ask you to read this information and then decide on their behalf whether they should take part, or not. You will of course have your own opinions about this research. However, we are asking you to consider their best interests and what you believe would be their wishes.

If you give your agreement, we will ask you to read and sign the Consultee Declaration Form. We will keep you informed about the research so you can let us know if you have any concerns. In the future, you can request that your relative/friend/person you care for, is withdrawn from the study at any time, without giving a reason and without their health or other care being affected. If you cannot act as a consultee for the research, it will not affect in anyway the standard of care your relative/friend/person you care for receives.

We are keen to offer all adults on the autism spectrum the opportunity to participate in our research, whatever their ability. However, we understand if you do not want to take on the responsibility of being a consultee. If you are unsure about taking on this role, you may wish to seek independent advice such as consulting the Patient Advice and Liaison Service (PALS) in the NHS. If you decide you are unable to make this decision, we ask if you could suggest another person who may be able to act as a consultee on behalf of the adult without the capacity to consent themselves.

Please contact us on 0191 282 1380, or email adultautismspectrum@ncl.ac.uk with any suggestions of another adult we could contact to talk about our research project. Thank you.

Your role is to read this information on behalf of the adult lacking the capacity to give consent. You will be referred to as being a representative of the adult from now on in this information sheet.

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/carers**'. 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 information about the adult you are representing, including their autism spectrum diagnosis, and other information (types of support they receive, their employment opportunities, home, 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. The term 'autism spectrum' will be used from now on in this Information Sheet.

Research about the autism spectrum often requires large numbers of participants. **For this reason we want to recruit as many adults on the autism spectrum as possible from across the UK to join our research - a cohort of adults on the autism spectrum.** A cohort means a group of people with shared characteristics – in this case an autism spectrum diagnosis. If you agree to act as a consultee on behalf of an adult who is unable to give consent to take part themselves, 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 the adult you are representing. 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 – we will use the results to let people know how adults might want to be supported, and hope this will lead to people making changes in the services available to adults on the autism spectrum.

What are the aims of this study?

- To collect information from adults on the autism spectrum and their representatives. This will help researchers, policy makers and those providing services for adults to better understand 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 adults on the autism spectrum
- To consult with adults on the autism spectrum about their priority research questions to be addressed by research
- To help researchers recruit participants for projects that aims to answer important questions which may lead to significant advances in knowledge, opportunities and care.

Why have I been invited to take part?

You are being asked to act as a representative of an adult on the autism spectrum who lacks the capacity to give consent to take part in research. This means you will answer questions on their behalf, as if you were them. We want to include adults 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 they have an autism spectrum disorder but have not had a formal assessment.

You may 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 adults on the autism spectrum and their relatives/carers know about this research study.

How might this study help adults on the autism 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, parents/carers 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 adults on the autism spectrum about other research. Our Research Steering Committee, which includes 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. Then if you are interested, you can reply directly to the researchers.

You can take part in the cohort part of the research without being contacted by us about other projects in the future (see the Consultee Declaration Form)

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

There are two ways you can join this research study.

If you prefer 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 the adult who you will represent. 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, fill in the consultee declaration form 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 adults with autism (including any sources of support, employment opportunities, types of accommodation, and other aspects of everyday activities).

If you would prefer to send the consultee declaration form and questionnaire by post, once you have read this information sheet, please complete the consultee declaration form and the questionnaire. 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 the adult you are representing 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 the document. To find out whether the adults who take part in this research study are representative of all 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 anonymous information which you, a professional or someone who has discussed this research with you, could provide. You will be asked to provide the following information about the adult you are representing: their year of birth, gender, ethnicity, autism spectrum diagnosis and postcode. We ask for their postcode so we can know what type of area in the UK they 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 be asked to complete a consultee declaration form. You will also be asked to complete some questionnaires to give us 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.

We would like your permission to get copies of medical or clinical reports about their diagnosis from the team who made the autism diagnosis. If you do not want to do this, you can still take part in the cohort project – to tell us this, leave box number 5 on the consultee declaration form blank. When we get reports, we will only look at information that is relevant to this autism study and not about anything else. All information we get will be kept securely in a locked cabinet separately from the anonymised research data – we will not give any identifying information on these reports to anyone.

Will my information be kept safe and confidential?

The information you provide on behalf of the adult lacking capacity will be kept safe according to the Data Protection Act 1998. Personal information will be kept separate from the anonymous research data. The research team will store this 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 personal 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 about the adult you are participating on behalf of.** In that case, we will retain information on their year of birth, gender, diagnosis 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 the adult's life, and to answer 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'?

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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