

Autism Spectrum Database-UK (ASD-UK)

Information for Parents/Carers

You are being invited to take part in a project to set up a UK research family database of children diagnosed with an autism spectrum disorder (ASD).

We are including children aged 2 - 16 years, with a diagnosis of autism, atypical autism, autism spectrum disorder, pervasive developmental disorder, or Asperger syndrome. The project is called **Autism Spectrum Database-UK (ASD-UK)**. Research about ASD often requires large numbers of participants. ASD-UK will enable large studies to be undertaken to address important research questions about ASD. At present, the majority of families of children with ASD do not have the opportunity to take part in research studies. A national research database will mean that children and families are more able to participate in research, and have access to research findings.

We would like you to help by agreeing to participate in the ASD-UK project. We are inviting you to give details about your child's diagnosis, and about your family; this will give you the opportunity to take part in ASD research studies. Here is information to help you decide whether or not you wish to take part. Please contact us if there is anything you do not understand or if you would like more information.

Who is organising and funding the project?

This project is being run by a research team at Newcastle University with the help of your child's local health team. The research team includes a child clinical psychologist, a paediatrician specialising in autism and development and a research associate with a health visiting background; all are specialists in autism spectrum disorder. The project is funded by the UK charity Autistica (www.autistica.org.uk). Autistica is committed to ensuring that increased understanding and new scientific knowledge will improve the lives of individuals with ASD and their families.

What are the aims of ASD-UK?

- To help researchers recruit to studies of children with ASD.
- To allow families to take part in research that aims to answer important questions which may lead to significant advances in the care and treatment of children with ASD
- To collect data about your child and family, and allow us to answer some important questions about ASD

Why have I been approached?

Child health professionals from towns and cities across the UK have agreed to inform parents/carers of children with ASD about the ASD-UK project. Your child health team is taking part, and are asking families seen locally whether they would like to be part of this project. This gives you the opportunity to be included on the ASD-UK research database.

How might ASD-UK help us and other children with ASD?

The data that we are able to collect from families participating in ASD-UK will be used by us to answer some important research questions. ASD-UK will also support research studies by other medical researchers in the future. Together, these studies aim to bring about improvements in the quality of life for individuals with ASD and their families in the future. By taking part, you will help with research that might result in improvements for your child now, or improvements for other children with ASD in the future. Any information that is published will be anonymised.

If I am interested in the ASD-UK project, what happens next?

There are two ways you can join ASD-UK. You can go to the ASD-UK website (www.asd-uk.com) and follow the links to the database, or you can join by post.

If you prefer the website, you will be asked to give a small amount of information. You will then be emailed your unique password. Once you have entered your email address and the password, you will be able to give your consent and fill in the online questionnaire. This will take you 20-30 minutes and asks for information about your child's diagnosis. We will also need to send you one questionnaire by post which we will do once you have submitted the consent form. This will take you about 10 minutes to complete. The questionnaire will include a return envelope.

Please go to www.asd-uk.com and click on '**ASD-UK Register**' to join via the website.

If you prefer to receive the consent form and questionnaires by post, once you have read this information sheet, you should complete the '**contact**' form that is included with this information and return to us in the stamped addressed envelope. A member of the child health team may have already done this with you, if the project was discussed with you at a clinic appointment.

After we receive the form, we will contact you by phone, within 2-4 weeks, and discuss the project with you further. If you would like to take part, we will send you the consent form and two questionnaires to complete. The questionnaires ask for information about your child's diagnosis and will take you 30-40 minutes to fill in. When you have filled them in please send them back to us in the return envelope.

Do I have to take part?

Your decision to include your child's details on ASD-UK is entirely voluntary. The services you and your child receive will not be affected in any way by not being included on the database. Where parents do not wish to take part, we have permission from the Ethical Committee to keep a small amount of data which we would like you or your local health team to provide. The Data will include the child's year of birth, gender, ethnicity, local authority, diagnosis and postcode. The postcode will be used so we can look at differences between families who do and do not take part. Once we have recorded the information we need, the last 2 digits of the postcode will be destroyed (this is the part that can identify where you live). If you do not wish to be contacted by us, it would help us if you could complete the reverse of the contact form; **'we would prefer not to be contacted'** and return it to us in the stamped addressed envelope.

If I agree to my child's details being included on ASD-UK, what other information will I be asked for?

In addition to completing the consent form and two questionnaires, we would also like copies of the medical report about your child's diagnosis and the 'statement of special educational needs' (if your child has one). If you don't have copies, your child health team should be able to provide them. When you have all the forms and documents together, you can return them to the research team in the stamped addressed envelope in your pack.

If you are completing the consent form and questionnaire online, we will send you a stamped addressed envelope so that you can send us your child's medical and/or educational reports.

What details will be held about my child?

For each child whose parents/carers consent to them being included on ASD-UK the information will include:

The child's name and date of birth, parents/carers names and dates of birth, address and contact details, the type of ASD diagnosis and other medical conditions, information about your child's communication, developmental skills and behaviour. We would also like to know the school your child attends (if he/she attends one), and a small amount of information about family members, such as siblings names and dates of birth and other family members with a diagnosis of ASD.

Will the data held about my child be kept confidential?

The research team will store your child's data on a secure database at Newcastle University. The data will be password protected and only available to staff working on the project. Consent forms and any paper correspondence will be stored in locked filing cabinets in a secure office. **No identifying information will ever be released to researchers or anyone else.**

Once your child reaches the age of 18, the data will remain on file. However, should your child contact the ASD-UK team at the age of 18 and wish to have all identifiable information removed, then this will be done. We will retain information on year of birth, gender, local authority diagnosis and postcode (see section 'Do I have to take part?').

What will happen after I have returned the data?

The data you send us about your child and family will be used by us to answer important research questions. In addition, we will contact you from time to time to ask you to provide updates about your child's development. You will be kept informed about progress of ASD-UK, and interesting developments, through an annual newsletter and our website: www.asd-uk.com

How will I be contacted to take part in future research projects?

You will not be contacted more than once or twice a year to tell you about a research project. Whether you are contacted more than once will depend upon the length of the study and what is required. A Steering Committee, which includes parent members, makes the decisions about which studies to support. Researchers will not have access to your details. The contact with you will be made by the ASD-UK team and if you are interested you will have the information you need to reply to the researchers. You do not have to take part in any study if you do not wish to.

Thank you for taking the time to read this information. If you would like to participate in the ASD-UK project **please go to www.asd-uk.com** and click on 'ASD-UK Register' to complete the consent form and questionnaire online.

If you prefer to take part by post, please fill in the contact form included with this information sheet and return it to us in the stamped addressed envelope. Once we receive the form a member of research team will phone you in the next 2-4 weeks.

If you have any questions, please contact the research team, see below:

ASD-UK, Institute of Neuroscience, Henry Wellcome Building, Newcastle University, Framlington Place, Newcastle upon Tyne, NE2 4HH.

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