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UNDERSTANDING CONVERSATION
INFORMATION SHEET FOR PARENTS / GUARDIANS

Ethics Approval Reference: R59912/RE001

We would like to invite your child to be part of this study investigating how we understand conversation. We very much hope you would like your child to take part, but before you decide, it is important that you understand why the study is being done and what it will involve. More information about the project can be obtained by contacting the researcher (contact details above).

What are we trying to find out?

This project is looking at how children understand conversations. We know that vocabulary and grammar are important in understanding conversation, but social communication is likely to depend on more than just these two aspects. For example, people need to understand how context is important in understanding why someone is saying something – for instance, if you say ‘dinner is on the table’, you are not so much telling your family where dinner is, as inviting your family to come and eat! Currently, very little is known about how children develop the ability to understand meaning flexibly in conversation, and so we are exploring this.

Some children seem to have particular problems with social communication, as well as language more generally. We know, for instance, that children with an autism spectrum disorder are more likely than other children to have problems with understanding conversation. Similarly, children with an extra X or Y chromosome are also more likely to have problems with language and social communication. We hope that our findings will be useful in understanding more about the problems experienced by children with communication difficulties.

Why are we receiving this information sheet?

You are receiving this information because you are a parent/guardian of a child with a diagnosis of EITHER an autism spectrum disorder OR an extra X or Y chromosome. We are inviting 50 children with an autism spectrum disorder and 50 children with an extra X or Y chromosome to take part in this research. As for children with an extra chromosome, any child with Klinefelter’s Syndrome (XXY), Triple X or XYY is eligible to take part. All children taking part will need to be aged between 7;0 and 14;11 years and speak English as a first language. The children will also need to have no severe hearing/sight problems and no history of neurological illness, brain injury or any genetic conditions besides the extra chromosome. If your child has an extra X or Y chromosome, we would need them to be aware of this.

Do we have to take part?

It is up to you and your child to decide whether to take part. We suggest that you talk to your child about the study. Please see our Child-friendly Information Sheet, which you can discuss with them.

If you do agree to take part, you will be asked to indicate your consent on a form. You will be asked to do this twice: once when you first decide to participate and then a second time before your child starts the language activities (see below for details). Even when you have consented to take part, you are still free to withdraw at any time, without giving a reason by advising the researcher of your decision (Alexander Wilson. Email: alexander.wilson2@psy.ox.ac.uk. Tel: 01865 271386). A decision to withdraw, or a decision not to take part, would not affect your child's education or medical care in any way. If you decide to withdraw, we will delete all information relating to your child from our research.

It is important to us that your child wants to take part in the study, so before they start the language activities (see below), we will ask them to indicate they are happy to start. If your child decides at any point that they don't want to continue, they are free to stop the activities. To stop, they just click the exit cross in the corner of the computer screen. Our priority is that your child is happy at all times.

What will happen if I give permission for my child to take part?

First of all, we will send you a personalised link over email to a consent form. If you decide to complete the consent form, you will then be presented with some questionnaires. The first questionnaire will check whether your child is suitable for the study. We will ask briefly about their diagnosis, medical history, language and educational history. The questionnaires will also ask more about your child's day-to-day communication. These questionnaires should not take longer than 20 minutes to complete.

In addition, we will ask if there is a good time when we can phone you to have a conversation about your child's development. We will ask a series of questions that should take around 40 minutes.

In the second part of the study, your child would complete some fun language activities on the computer. In the language activities, your child would watch some cartoons and listen to audio, before answering multiple-choice questions about what they have seen and heard by clicking buttons on the computer. The activities are designed to be fun and engaging for children. The activities are all completed in one sitting, and should take around an hour. Before your child starts them, we will check that you still consent to them taking part, and that your child also is willing to do them.

We are happy for your child to complete the language activities EITHER with a researcher present OR without the researcher there. We will follow a slightly different process depending on whether or not the researcher is there; please see below.

Researcher present. If you and your child decide to have the researcher present, we can arrange a session in the Department of Experimental Psychology, Oxford University, or at your home, as you prefer. If you decide to travel to Oxford, we can reimburse your travel expenses. It is also possible for us to see your child at school, with the permission of your child's teachers. If we see your child face-to-face, the researcher would plan to have a short conversation with them about child-friendly topics like holidays or hobbies, and we would like to make an audio recording of the conversation. Please note that this conversation is optional, and we will ask you to sign a consent form to indicate that (a) you are still happy for us to give your child the language activities, and (b) you would like us to make the audio recording. If you decide you would prefer us not to make a recording, or your child does not want us to, we will miss out the conversation. We would just do the language activities on the computer.

Researcher not present. It might be more convenient, and your child might be happier, if we send you a link to the language activities over email. Your child should complete the activities in one sitting in their own time. We would just ask that you supervise your child while they do the activities. It is important, of course, that you don't answer the questions for them. You would need a computer with a good internet connection, and your child would need to be able to listen to audio through headphones or a speaker.

What are the advantages / disadvantages of taking part?

There are no direct advantages or disadvantages to your child in taking part. Results from this study will be helpful for us in learning more about the problems some children experience with conversational language.

We will provide your family with a £10 Amazon voucher as a thank you for your time and efforts. Also, if you decide to travel to Oxford to see a researcher, we will reimburse your travel expenses.

What happens to the results of the study?

Results for each child are strictly confidential. Information is identified only by a code number. All results will be kept in spreadsheets on the University server at the University of Oxford. Any paper records will be kept in lockable filing cabinets in a building with swipe-card access. Once all data are collected and analysed, we will make them publicly available in an online data repository, so that they can be used by other researchers. This research data will not include any personally-identifying information. All identifiable data (such as the consent and assent forms, details about your child's development and your email address) will not be made publicly available, and will be destroyed three years following publication or public release of the research. We will ask your permission to keep your email address beyond this period in order to contact you about future research. This is entirely optional.

Generally, we do not give feedback about individual children involved in the research. We cannot provide feedback about the language activities because these are new tasks that will not have completed by many children before. If any concerns/questions arise for you while you are completing the questionnaires, you can get in touch with the research team using the contact details in this document.

The language activities will be displayed using Gorilla, an online platform for presenting tasks and collecting data. Gorilla is fully compliant with all current data protection and security policies, including the Data Protection Act 2018.

The results of the study will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will probably be published open access, meaning that it is available to every internet user. We also aim to publish our findings in scientific journals, but this may be two to three years after the study.

As noted above, we would plan to record a conversation that we have with your child, if we were to see your child in person. This is an optional part of the study, and we will check that you are happy for this to happen. If you are, we would store the recording in an anonymous format on the University server, and would transcribe the conversation, again anonymously. We would not include specific reference to any children in research outputs. We would write about general trends across all the children.

Study documents and data may be accessed by designated individuals from Oxford University for the purpose of research audit.

Who is conducting this research?

The research project is organized by Alexander Wilson of Oxford University, who is a doctoral student in the Department of Experimental Psychology, supervised by Prof. Dorothy Bishop. The research is funded by the European Research Council. This study has been reviewed by, and received ethics clearance through, the University of Oxford's Central University Research Ethics Committee, [R59912/RE001].

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher (Alexander Wilson. Email: alexander.wilson2@psy.ox.ac.uk. Tel: 01865 271386) or their supervisor (Dorothy Bishop. Email: dorothy.bishop@psy.ox.ac.uk. Tel: 01865 271369), who will do their best to answer your query. The research team should acknowledge your concern within 10 working days and give you an indication of how they intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Medical Sciences Inter-Divisional Research Ethics Committee at the University of Oxford (Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). They will seek to resolve the matter in a reasonably expeditious manner.

Data Protection

The University of Oxford is the data controller with respect to your child's personal data, and as such will determine how your child's personal data is used in the study. The University will process your child's personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your child's personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/.

What should I do next?

If you would like to take part in the study, you can click on the link in the email we sent you, which will take you to the consent form. That will allow you to begin the study, as explained above. If you would prefer not to take part in the study, you do not need to do anything. You can simply ignore the email. Please remember that even if you start the study, you may withdraw your child at any time, without penalty and without giving a reason, by notifying the researcher. We will then remove all information relating to your child from the research. If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

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