

Database of developmental speech, language and communication disorder profiles

Participant Information Sheet

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What is this study about?

The aim of this study is to explore how children with speech, language and communication difficulties in childhood have different clinical profiles and how they respond to speech and language therapy. We will do this by carrying out the same assessments for each child with a similar profile that attends the University of Reading Speech and Language Therapy Clinic.

What is involved in participating in the study?

Assessments will be carried out by qualified speech and language therapists or speech and language therapy students (under the supervision of a qualified speech and language therapist) who have undergone an enhanced DBS check and suitable training.

Your child will receive 1-4 assessment sessions. During the sessions, your child will be asked to play with particular toys, point to toys/pictures after a verbal instruction, name or describe pictures, or repeat words/sentences. You as parents will also be asked to complete a few questionnaires about your child's communication, development, behaviour and quality of life. If your child goes on to attend the clinic for therapy some of the assessments may be repeated again after a few months to measure the progress that has been made.

Some of the assessments may be audio or video-recorded for the purposes of scoring the assessments only.

Do I have to take part?

No, your participation in this study is entirely voluntary. If you choose to take part, you will be required to complete an electronic consent form that indicates your willingness to participate. You may withdraw at any point in the study without having to give any reason. If you choose to withdraw your participation, your responses will not be included in the study. Participation in the project will not make any difference to the therapy that is offered to you by the speech and language therapy clinic.

You are welcome to ask any questions that you have about the study at any point.

Data protection and confidentiality

Your data will be held confidentially on secure, password-protected computers. This information will only be accessible by the student researchers, chief investigator, and other qualified members of the School of Psychology and Clinical Language Sciences.

Audio and video recordings will be kept on a secure server and will be accessible only by the researchers and other qualified members of the School of Psychology and Clinical Language Sciences. These recordings will never be made available to the public or put on the internet and will be destroyed 6 months after the end of the study.

Consent forms and any personal data shared will be kept for 5 years following the project within a secure computer system and then destroyed following the University Data Protection Act. Anonymised data may be kept for future research purposes.

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at imps@reading.ac.uk, or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading, RG6 6UR, UK.

The University of Reading collects, analyses, uses, shares and retains personal data for the purposes of research in the public interest. Under data protection law we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest and where it is necessary for scientific or historical research purposes. If you withdraw from a research study, which processes your personal data, dependent on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your personal data.

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data
- Restrict uses of your data
- Object to uses of your data, for example retention after you have withdrawn from a study

Some restrictions apply to the above rights where data is collected and used for research purposes.

You can find out more about your rights on the website of the Information Commissioner's Office at <https://ico.org.uk>

You also have a right to complain to the Information Commissioner's Office if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.

Where can I find out more about the study?

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

If you would like more information about the study, please contact the project supervisor, Dr. Emma Pagnamenta at e.pagnamenta@reading.ac.uk. Any queries regarding the ethical aspects of this project can be directed to the Research Ethics Committee at pcls-ethics@reading.ac.uk.

Thank you for your time. Please feel free to contact us if you have any questions or if you require further information.

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