

An Investigation into the Effects of Retrieval Practice on Word Learning in Children with Down Syndrome

Participant Information Sheet (PIS)

You are being invited to take part in a research study looking at the effects of retrieval practice on word learning in children diagnosed with Down Syndrome. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➤ Who will conduct the research?

Dr Kelly Burgoyne, Dr Laura Boundy, Emily Croft, and Orlaith Kelly of the Manchester Institute of Education, School of Environment, Education and Development; The University of Manchester.

➤ What is the purpose of the research?

We hope this study will help us identify a potentially beneficial technique for children with Down syndrome to learn language. Retrieval practice, which is repeated testing/recall during the study of new materials, has been shown to successfully improve children's word learning in other populations. Therefore, we aim to see if this can be generalised further by testing this effect in children with Down syndrome. This research has the potential to influence real life language interventions in schools, and to help educators, parents, and schools support learning in children with Down syndrome.

You have been chosen as you expressed interest in taking part and meet the inclusion criteria required. We intend to recruit around 15 participants with Down syndrome and 15 typically developing children to take part in this study.

➤ Is my child suitable to take part?

Inclusion criteria for the study:

Children with Down syndrome

- Age 8-12
- Diagnosis of Down syndrome
- Must be able to communicate spoken language
- English is their main language.
- Normal or corrected to normal vision and hearing

Typically developing children

- Aged 4-6 years
- Must be able to communicate spoken language
- English is their main language.

- Normal or corrected to normal vision and hearing

Exclusion criteria: Children with a (dual) diagnosis of autism spectrum disorder (ASD) are not able to take part

➤ **Will the outcomes of the research be published?**

The outcomes will be published in scientific journals and conferences. It may also be included in a student thesis and on the department webpage. You will not be identifiable in any publications.

➤ **Disclosure and Barring Service (DBS) Check**

All researchers on the project have undergone an enhanced DBS check.

➤ **Who has reviewed the research project?**

The project has been reviewed by The University of Manchester Research Ethics Committee.

What would my child's involvement be?

➤ **What would my child be asked to do if I took part?**

Participants will take part in 4 sessions over Zoom, which will be spread over the space of two weeks (Pre-test screening, Day 1, Day 2 and 1 Week after Day 2) These will be set up by the experimenter at a date and time to suit you, and details will be emailed to you in advance. Zoom sessions will be audio and visual recorded, in order to capture verbal responses, however only the researchers involved in the project will have access to these.

Prior to the study beginning, children will be asked to join a Zoom meeting with their parent to a pre-test screening. This will include a speech production task and a task to assess their receptive vocabulary. This should take no longer than 25 minutes in total.

On Day 1 participants will have the opportunity to learn 6 novel words, each relating to an image of an exotic plant/animal. These will be presented on a PowerPoint slideshow, which will be shared by the experimenter through their screen. On Day 2, they will repeat this and be tested on their memory of these words. At the 1-week mark, they will be tested again on their memory of these words as well as a recognition of the images shown. Each of these sessions should be no longer than 10-15 minutes. We ask for a parent/guardian to accompany the participant during all sessions.

➤ **Will we be compensated for taking part?**

There will be no compensation for taking part.

➤ **What happens if my child does not want to take part or if they change their mind?**

It is up to you to decide whether or not your child takes part. To inform us of your decision please email the contact provided. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. Your child will be asked to give verbal consent at the

beginning of each session. This will be recorded via a verbal assent form. If you decide to take part, you are still free to withdraw your child at any time without giving a reason and without detriment to yourself or them. However, it will not be possible to remove your child's data from the project once it has been anonymised as we will not be able to identify their specific data. This does not affect their data protection rights. If you decide not to take part, you do not need to do anything further.

The audio and visual recording of the Zoom sessions is essential for the study, so you must be willing to agree to this in order to take part. We want you and your child to be comfortable with the recording at all times so you will be free to stop at any point during your participation of the study.

Data Protection and Confidentiality

➤ What information will you collect about me/my child?

In order to participate in this research project, we will need to collect information that could identify you, called "personal identifiable information". Specifically, we will need to collect:

- name
- contact details
- child name
- child date of birth,
- child gender,
- record of consent.

The recorded Zoom meetings will contain both visual and audio recordings of the participant. These will not be shared outside members of the project.

➤ Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

➤ What are my rights in relation to the information you will collect about my child?

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including recordings of sessions.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).

➤ Will my child's participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- Identifying information (name, DoB, contact email address) will be provided on the consent form. The names and contact email address will be stored in a password-protected folder on a secure University of Manchester drive and will be kept separate from participant data. These will be used to provide feedback to parents who express their interest and consent to this. Only the research team will have access to these forms. The date of birth will be used only to calculate his/her exact age on the day of your child's participation in our study. This will be transferred to a password-protected Excel spreadsheet and stored on a secure University fileservers. This spreadsheet will be stored in a separate file location to the consent form and any data.
- Your child's name will never be associated with the data. As we need to collect your child's name, date of birth and gender, this means that your child's personal information is not completely anonymised because they are identifiable. Rather, we will pseudo-anonymise your child's data by assigning them a participant number. We will ensure that your child's name on the consent form cannot be linked back to their gender and date of birth on the Excel spreadsheet, by storing them in separate locations and password protecting them.
- Consent forms and data will be stored in a secure University of Manchester drive for 5 years and then destroyed. No one outside of the project will have access to this.
- Personalised data will not be shared between any other organisation, any data that may be shared will be in an anonymised data set. This may also be deposited into an open data repository at the end of the project.
- The video recordings will be transferred to the University's secure server as soon as possible after the Zoom session. These will be labelled with a participant ID number. The recordings of the sessions will be reviewed by another member of the project in order to test data reliability. The video recordings will be kept for 5 years and then will be deleted.

Your participation in this research will be recorded on Zoom and your personal data will be processed by Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection.

Potential disclosures

- Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.
- In accordance with The University of Manchester Child Safeguarding policy, the researcher may be obliged to break confidentiality if during the course of the study the researcher witnesses something in the background that may be illegal or dangerous. In this eventuality the researcher would be obliged to record this information and inform the appropriate authorities, which would

include our designated member of staff responsible for Child Safeguarding. Parents will be informed of the safeguarding issue following consultation with the designated member of staff.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

➤ Contact details for complaints

If you have a complaint that you wish to direct to members of the research team, please contact:

Dr Kelly Burgoyne

Email: kelly.burgoyne@manchester.ac.uk

Tel: 0161 57208

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#) Tel 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s)

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