



Information Sheet for Parents and Carers of Deaf Children

Note: A British Sign Language version of the Participant Information Sheet & Consent Form is available. Please contact the research team (see contact details below).

Dear Parent/Carer,

Title of study: Longitudinal study of reading development in deaf and hearing children

This study has been approved by the UCL Research Ethics Committee, Project ID 3612/012

We are a team of researchers in the Deafness, Cognition, and Language Research Centre (DCAL) at University College London. We are writing to invite you and your child to take part in the above study, which is looking at early language and emerging reading in hearing and deaf children over three year – from Reception to Year 2. Before you decide if you want to take part, it is important to understand why the research is being done and what it would involve for you. Please read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

1. What is the purpose of the study?

Our research aims to identify the role of visual language inputs (e.g., lipreading; British Sign Language) and other language skills to reading development in deaf and hearing children. Learning to read is challenging for some children, both deaf and hearing. Improving our understanding of the factors that support early reading development will help improve current literacy interventions.

2. Why has my child been invited?

Your child has been invited because we are looking for deaf children to take part in our research and your school has agreed to take part in the study. They have suggested that your child might fit the inclusion criteria below.

3. What are the criteria for taking part?

- Child will be in Reception in the school year 2022/23
- Child was diagnosed as severely or profoundly deaf before the age of 3yrs
- Child has lived in the UK for at least the last 6 months
- Child has no disabilities that would prevent them from completing 30 minutes of tasks on a computer.

4. Does my child have to take part?

Participation in this study is entirely voluntary and we will only include children if they are willing to take part and if you have given consent. If you do decide your child can take part you will be asked to sign a consent form. Your child does not have to take part in this study if you do not want them to, and even if you and your child do agree to take part, you may change your mind and pull out at any time without having to give a reason, and your child's data will be withdrawn from the study unless you agree otherwise. Your child will be made aware that they can indicate at any point during the session that s/he does not want to carry on with the activities and s/he will immediately be taken back to the classroom.

5. What will happen to my child if they take part?

If you agree to take part, you will be notified when we will be visiting your child in school to carry out some tasks measuring language, nonverbal skills and emerging reading skills. These tasks will be carried out with the researcher and are like games and should be fun for your child. The session will be carried out in your child's preferred language (English; BSL; or both) by a researcher who is fluent in the language and experienced in working with deaf children.

The overall session with the researcher will be broken into shorter timeslots to fit with your child's timetable and to ensure that s/he does not get tired. We will record your child's responses on record sheets on the computer. We will also video record your child doing some of the tasks so we can check their scores. We will then come back again to see your child again – once again in Reception, twice in Year 1 and twice in Year 2.

6. Will my child be recorded and how will the recorded media be used?

We will record your child's responses on computer record sheets and we will video record your child doing some of the tests so we can check their scores. Only the research team will watch your child's video and it will be deleted after scoring and checking is completed, usually within 6 months. This is the case unless you specifically say, on the consent form, that we can show it to other researchers and interested professionals for illustration.

7. What are the possible disadvantages and risks of taking part?

Children will be taken out of the classroom for very brief periods to participate in the research: up to 1.5 hrs at 6 points over 3 yrs. The research team will work with the teachers to ensure that this is not disruptive to your child's learning. Care will be taken to make the sessions as interesting as possible and the children will be made to feel at ease. The researchers will at all times follow government guidance and school policies on Covid-19 safety. The project has been given approval from the UCL Research Ethics Committee (project ID 3612/012).

8. What are the possible benefits of taking part?

Your child will try out lots of different tests, the same as other children in their class, and this should be fun. Assessment results will be fed back to teachers and will be helpful in their understanding of children's language and emergent literacy strengths and development needs. The study will help develop our understanding of reading development.

9. What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through UCL's complaints procedure. To complain about the study, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk and inform them that the name of the project is: '*Longitudinal study of reading development in deaf and hearing children*'.

10. Will my taking part in this project be kept confidential?

All personal information about you and your child will be stored securely on the UCL Data Safe Haven. Your child will be given a participant ID. Only anonymous data will be made available on open science platforms. These data will not include the participant ID which will be stored with the research data at UCL. The participant ID key code – linking it to personally identifiable data will be stored in UCL DSH. All non-video research data will be stored alongside this code and not alongside any identifiable data. Your child will not be able to be identified in any reports or publications. Only the research team will watch your child's video for scoring purposes, then the video will be deleted. This will be the case for all videos unless you specifically say (on the consent form) that we can show it to other people.

11. What will happen to the results of the research project?

A summary of the study will be provided to teachers and parents of children who participated. The results will also be written up for publication in an academic journal and presented at conferences/ academic meetings. A copy of any academic publications will be openly available and parents and teachers will be made aware of these via reports/ newsletters. Your child's identity will remain anonymous at all times. Results will be presented in terms of groups of individuals and will not mention individual children.

The research data will be anonymised (made non-identifiable) and may be made available to other researchers to maximise the impact of the data. It will not be possible to identify any child from these data.

All personal data will be stored safely at UCL and destroyed 10 years after the end of the project. We would like to keep your contact details for this long as we would like to contact you again in the future, to follow up on your child's progress. This way we can make sure that we maximise the benefit of the data collected in their early years.

13 . Can I get access to my child's results from the study?

A small number of the tests we will use are standardised tests. The results of these tests will be made available to you and your child's teacher upon request. However, it is important to note that these results will NOT have been administered by a clinician and therefore these scores should not be passed on to others as evidence to support any educational or clinical decisions.

14. Local Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here - https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies](https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and ' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk

15. Who is funding the research?

Wellcome <https://wellcome.org/>

16. Who are the research team and who can I contact for further information?

The research team are listed below. Please feel free to contact any of them to discuss the project further:

Project email address: VisualCR@ucl.ac.uk
Principal Researcher: Prof Mairéad MacSweeney (m.macsweeney@ucl.ac.uk)
Researchers: Dr Tyron Woolfe (tyron.woolfe@ucl.ac.uk)

Department: Deafness, Cognition and Language Research centre (DCAL) & Inst of Cognitive Neuroscience, University College London, 17 Queen Square, London WC1N 3AZ

Thank you for reading this information sheet and for considering taking part in this research study.



Consent form for Parents and Carers of Deaf Children

Note: A British Sign Language version of the Participant Information Sheet & Consent Form is available. Please contact the research team (see contact details below)

Title of Study: Longitudinal study of reading development in deaf and hearing children

Department: Inst of Cognitive Neuroscience

Name of the Principal Researcher: Prof. Mairéad MacSweeney

Name of the Researchers: Dr Tyron Woolfe

Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee, Project ID 3612/012
The Data Protection reference number for this study is - Z6364106/2022/03/57 social research

Thank you for considering taking part in this research. Please ensure you have carefully read the Information Sheet explaining the project before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please contact the researcher before you decide whether to join in. You will be given/ emailed a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. Therefore, please do provide an answer to each question.

		Tick Yes or No
1.	<p>I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction. I understand this will involve:</p> <ul style="list-style-type: none"> • My child being tested by the research team. The researchers will at all times follow government guidance and school policies on Covid-19 safety • Me or my child’s teacher completing a short questionnaire about family background including language use in the home • The researchers knowing about my child’s Language Screen results (Reception) and Phonics Screening results (yr1) • My child being tested by the research team on a set of language and cognitive assessments - twice in Reception, Yr1 and Yr 2 • Testing sessions taking place at my child’s school. On some occasions I am aware that this may need to be online (e.g., new COVID variant) or at home (eg., child illness during term time). The research team will contact me to arrange this if this is necessary. 	<p>Yes/No</p> <p>Yes/No</p> <p>Yes/No</p> <p>Yes/No</p>
2.	I understand that I will be able to withdraw my child’s data up to 4 weeks after the test session	Yes/No
3.	I consent for my child to participate in the study. I understand that my child’s performance on language and literacy assessments and personal data will be used for the purposes explained to me. I understand that according to data protection legislation, ‘public task’ will be the lawful basis for processing, and ‘research purposes’ will be the lawful basis for processing special category data.	Yes/No

4.	I understand that any information I provide is confidential and that all efforts will be made to ensure my child or I cannot be identified. No identifiable personal data will be included in any reports on the project, or disclosed to any other party. Any personal information (e.g., name/ date of birth) will be stored securely on the UCL Data Safe Haven. Anonymised data will also be stored securely at UCL.	Yes/No
5.	I consent to my child being video recorded for the purposes of the research, and understand that the recordings will be: - Stored using password-protected software and will be used for research purposes to check scoring of the assessments. - Deleted within 6months Note: If you do not want your child to be recorded you can still take part in the study. - I consent to the videos of the testing session being shown to other researchers and interested professionals. For example, during a conference presentation. Note: Videos will never be shared online. Note: If you do not want your child's video data to be used in this way you can still take part in the study.	Yes/No Yes/No
6.	I understand that my participation is voluntary and that I, or my child, are free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I or my child have provided up to that point will be deleted unless I agree otherwise.	Yes/No Yes/No
7.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet	Yes/No
8.	I hereby confirm that: (a) I understand the inclusion criteria as detailed in the Information Sheet and (b) My child meets the inclusion criteria.	Yes/No Yes/No
9.	I am aware of who I should contact if I wish to lodge a complaint.	Yes/No
10.	Use of information beyond this project • I agree to my child's anonymous data being used in future research • I understand that other authenticated researchers will have access to my child's anonymised data when archived under the Open Science Framework.	Yes/No Yes/No
11.	Use of data to reduce duplication • If my child is invited to another research study run by DCAL, I agree to some of my child's data being shared with that research team. This is so that my child is not asked to carry out the same assessment more than once. I understand that this means sharing my child's name between teams.	Yes/No
12.	I am happy for my contact details to be retained so I can be contacted in the future to be invited to participate in follow up studies to this project. This will allow the research team to maximise the impact of the data collected. Please note: this may be at any point up to when my child is 16 years old.	Yes/No

Name of Parent/carer

Signature

Date

Email

Postal Address

Mobile phone number