

Parent/Guardian Information Statement

My Voice Library: A repository of audio and visual datasets to enable personalised real-time communication

Dr Petra Karlsson (Responsible Researcher)
Program Lead Technology, Adjunct Senior Lecturer
Cerebral Palsy Alliance Research Institute,
The University of Sydney
Building M02C | Level 4 | 88 Mallett Street,
Camperdown, NSW, 2050
Email: pkarlsson@cerebralpalsy.org.au



1. What is this study about?

We are conducting a research study about improving communication for children with cerebral palsy with dysarthria. About one in two children with cerebral palsy find it difficult to speak to friends, family, or anyone in the community. These children mostly rely on an intimate, familiar understanding of gestures and sounds. Children with moderate-severe speech impairments, such as dysarthria, rely on technology solutions, which can translate text or symbols to speech. However, this is time consuming, arduous, and 15-20 times slower than normal speech. Current speech recognition technologies (such as Siri or Alexa) break down even when dysarthria is mild. Therefore, there is a need to improve current technologies to bridge communication difficulties for children with speech impairments. However, high-quality datasets are needed for technology development and evaluation.

The aim of this project is to develop a database of high-quality datasets of voices and videos of children with cerebral palsy through game-based modules. The game-based modules are developed to create an engaging environment for the child to record 150-200 words, sounds and sentences. The dataset collected will be used to develop novel technological solutions for real-time communication devices for children with cerebral palsy, whilst also offering the technology capabilities of online speech assessments, supporting more effective, efficient and accessible disability services for dysarthria.

Your child or the person under your care has been invited to take part. Taking part in this study is voluntary. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

The study is being carried out by the following researchers:

- Lead chief investigator: Dr Petra Karlsson, Cerebral Palsy Alliance, The University of Sydney
- Chief Investigator: Professor Alistair McEwan, The University of Sydney
- Dr Hayley Smithers-Sheedy, Cerebral Palsy Alliance, The University of Sydney
- Assistant Professor Silvia Orlandi, University of Bologna
- Assistant Professor Andrea Bandini, Scuola Superiore Sant'Anna, Pisa, Italy
- Dr Michelle McInerney, The Australian Catholic University
- Mrs Maria Dalmon, Cerebral Palsy Alliance

- Ms Annemarie Murphy, Cerebral Palsy Alliance Research Institute, The University of Sydney

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3. Who can take part in the study?

We are seeking school aged children 8- 18 years with cerebral palsy with moderate or severe dysarthria.

4. What will the study involve?

If you decide that your child or the person under your care can take part in this study, they will do voice activities that are collected through an electronic customisable gamified platform. During the activities, they will be asked to repeat sounds, words, phrases, and sentences. Children will read or hear audio-recorded adult models of each word, sound or sentence. If your child gets tired at any stage, they can leave the activity and resume at a later stage.

Time commitment

- It is anticipated that it will take **10-15 minutes** to set up an account with My Voice Library database. Part of this set up includes information about your child: Country of residency; age; diagnosis; gross and fine motor abilities, hearing and vision; communication and speech ability; language used at home; 3 questions that requires the child to follow a two-step instruction to complete; and if they have access to a laptop or personal computer with a video camera.
- The game-based modules developed to create an engaging environment for children to record the audio and video, under supervision of you as their caregiver, can be completed within **2-3 hours**. However, this estimate is highly individual and you and your child will be given the option to stop a recording and re-visit at a later stage where they can pick up from where you left off.
- After completing the My Voice Library modules, the participating child, with the help from you, will be asked to report on their experiences using two questionnaires (NASA TLX and System Usability Scale). Each questionnaire may take about 10 minutes to complete, in total **20 minutes**.
- Finally, at the end of the user experience surveys, you and your child will be invited to put your contact details into a separate database with the view that future researchers may contact you to invite you to participate in studies where your child will be able to try out technology developed using audio and/or video data from My Voice Library. This section will only take up to **5 minutes** to complete and is not compulsory.

5. Can we withdraw once started?

Being in this study is completely voluntary and your child or the person under your care does not have to take part. They will also be asked if they agree to take part, if you decide they can.

Any decision will not affect current or future relationships with the researchers or anyone else at The University of Sydney, or the Cerebral Palsy Alliance.

If you and your child or the person under your care decide to take part in the study and either of you change your mind, you can withdraw by informing any of the chief investigators.

If you or your child or the person under your care chooses to withdraw, we will not collect any more information. Please let us know at the time of withdrawal what you would like us to do with information we have collected about you, your child or the person under your care up to that point.

If you wish to withdraw any data, please contact the My Voice Library Research Team on myvoicelibrary@cerebralpalsy.org.au. Please note that participant data, collected in My Voice Library, (i.e. not any questionnaires about the experience of using My Voice Library) will be deleted from the active storage only. Previous daily back-ups will not be able to be purged. If, for some reason, a system wide data restore from a daily backup occurs after Data has been deleted but not prior to the backup being overwritten, the My Voice Library Data team will delete the participant data again.

6. Are there any risks or costs?

Aside from giving up time, we do not expect that there will be any risks or costs associated with taking part in this study for you and your child or the person under your care. As a thank you for your child taking part in this study we will give them a \$100 e-gift card when they complete all activities. We will ask you as their parent/carer/guardian for the best contact details to send the e-gift card to.

7. Are there any benefits?

There are no direct benefits for you or your child or the person under your care from being in the study. However, we do hope that researchers will develop technology that can benefit you and your child in the near future. If you sign up to be contacted for further research you may get a study invitation for your child to try out new technology developments.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you and your child or the person under your care for the purposes of this study and for future research use.

a. What personal information do we collect and why?

Cerebral Palsy Alliance (ABN 45 000 062 288) (CPA) is collecting personal information about you (this may include your name, contact details including telephone numbers and email address, location), and your child (this may include your child's name, age, gender, health information such as diagnosis, gross and fine motor abilities, hearing and vision, communication and speech ability, eating and drinking skills, languages used at home, visual recording of your child's face and audio recording of your child's voice, your child's user experience) so that we can:

- develop a data registry which includes personal information that is de-identified that is made available for research being conducted by external researchers;
- assess your or your child's suitability for future clinical trials and contact you about those clinical trials;
- manage our relationship with you; and

- address or respond to any requests from you.

We may also use your personal information for purposes related to those described above which would reasonably be expected by you.

We will not use your information for purposes other than those described above unless we have your consent or as permitted by law (including for law enforcement or public health and safety reasons).

b. How do we collect your personal information?

We generally collect personal information directly from you, through:

- consent forms, questionnaires and interviews; and
- the My Voice Library platform.

c. What happens if you do not provide the information requested?

If you do not provide us with the personal information we have requested, you may not be able to participate in this study.

d. Sharing your personal information

We may disclose your personal information to our related companies, contractors providing services to us and to other third-party service providers we use in conducting this study.

We may also disclose your personal information where we are required or authorised by Australian law to do so, such as child protection laws.

e. Further Information about our Privacy Policy

Further information about how we handle your personal information, including details about how you can access and correct your information and how you can complain about a breach of the Australian Privacy Principles (as well as how we will deal with any complaint) can be found in our Privacy Policy available at <https://cerebralpalsy.org.au/privacy/>.

f. Contact Us

You can contact us about this Privacy Collection Statement by getting in touch with our Privacy Officer, using the following details:

Privacy Officer

Cerebral Palsy Alliance

PO Box 171, Forestville, NSW 2087

Email: privacy@cerebralpalsy.org.au

Phone: 02 9975 8000 (+61 2 9975 8000)

9. Will I be told the results of the study?

You and your child or the person under your care have a right to receive feedback about the overall results of this study.

10. What if I would like further information?

When you have read this information, the following researcher/s will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact:

Dr Petra Karlsson (Responsible Researcher)
Program Lead Technology, Adjunct Senior Lecturer
Cerebral Palsy Alliance Research Institute, The University of Sydney
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11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney HREC Approval No. 2023/263 to the *National Statement on Ethical Conduct in Human Research (2007)*.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep