

PARTICIPANT INFORMATION SHEET

TESTING iCAMPERDOWN: AN ONLINE SPEECH TREATMENT FOR ADULTS WHO STUTTER (UTS HREC REF NO ETH23-8075)

WHO IS DOING THE RESEARCH?

This research is being conducted by Ms Constance Alateras, PhD student at the Australian Stuttering Research Centre, University of Technology Sydney (UTS). This project is being supervised by Associate Professor Robyn Lowe, Professor Mark Onslow, Professor Ross Menzies, Associate Professor Susan O'Brian and Dr Anna Hearne.

WHAT IS THIS RESEARCH ABOUT?

Researchers at the Australian Stuttering Research Centre have developed an online treatment program, iCamperdown, for adults who stutter. iCamperdown is an adaptation of the Camperdown Program, an evidence-based treatment for adults who stutter. iCamperdown is designed to teach adults who stutter to control stuttering, without seeing a speech pathologist.

Eligible adults who stutter will be able to access the online program for six months and work through the seven modules at their own pace. The program includes written, audio and video training materials. The recorded voice of an experienced speech pathologist provides instructions, guidance and encouragement throughout the program.

The treatment involves adults who stutter learning (1) a new way of talking that can help to control stuttering, (2) to identify and set realistic goals for communication, and (3) to self-evaluate for the long-term management of speech and communication goals.

The purpose of this research is to test iCamperdown.

WHY HAVE I BEEN ASKED?

You have been invited to participate in this study because you :

- Are over 18 years of age.
- Have not completed stuttering treatment with a speech pathologist during the previous six months.
- Have good spoken and written English.
- Have access to a private stable internet connection.

FUNDING

Funding for this project has been received from the National Health and Medical Research Council.

IF I SAY YES, WHAT WILL IT INVOLVE?

If you decide to participate you will:

- Complete a set of questionnaires before you start the treatment. In total, completion of these questionnaires should take about 1 hour and can be done over one or more sittings as long as completed before starting treatment.
- Be granted access to iCamperdown for six months.
- Work through the program at your own pace and at times that are convenient to you. You can log in as many times as you like. However, you will get most benefit from the program if you log in a few times each week and allocate time most days to practise your new speech skills.
- You will be taught to speak in a way that can help to control your stuttering and complete problem-solving tasks while you are logged into the program. You will also be encouraged to do some practice activities outside of the program.
- Be asked to complete a questionnaire fortnightly which will take approximately 5 minutes.
- Complete a short set of questionnaires after six months which will take approximately 20-30 minutes to complete. These help us to determine the effectiveness of the program.
- Be contacted after six months by a researcher to discuss your progress and to determine if you require further treatment. If further treatment is required, referral sources will be discussed with you. Any additional treatment services that may be required by you for your stuttering will be at your own expense. At this point your access to iCamperdown will be terminated.

ARE THERE ANY RISKS/INCONVENIENCE?

Yes. This online treatment may not be suitable for all adults who stutter. It may be that some people will not benefit from a reduction in stuttering or achieve as much of a reduction in stuttering as they would like. To minimise the risk, the following features have been incorporated into the program:

- iCamperdown has voiceovers throughout the program. These voiceovers are of an experienced speech pathologist. The content of the voiceovers will coach you through the program.
- You will be taught to set goals for your speech and communication and to evaluate your progress along the way.
- The treatment requires you to practise regularly while logged into the program and outside of the program.
- The program requires that you complete each module in a sequential order. You can repeat any modules and are encouraged to reflect on your progress. You can progress to the next module if you are happy with your progress.
- You will complete a 5-minute questionnaire every two weeks. Based on your response we may contact you to discuss your answers further. This discussion will help to determine if the program itself is not suitable for you or if your continued participation in this study is not recommended.
- If you feel that this program is not the right one for you, or if once started, you are not making progress or your responses to questions within the program indicate that the program is not right for you, a recommendation will be given to see a speech pathologist. In any of these situations, you will be provided with details for where to find a speech pathologist. Any treatment required other than that offered by the online program will be at your own expense.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is totally voluntary. If you decide not to participate in this study, your relationship or future relationship with the researchers or the University of Technology Sydney will not be affected.

If you choose not to take part in this study and you would like treatment for stuttering, you can find a speech pathologist by contacting Speech Pathology Australia [Find a Speech Pathologist \(speechpathologyaustralia.org.au\)](https://www.speechpathologyaustralia.org.au). Typically, speech pathology services are conducted in a clinic with a speech pathologist or by telepractice, using videoconferencing such as Zoom.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time, without having to give a reason, by contacting Ms Constance Alateras or Associate Professor Robyn Lowe by email: asrc.research@uts.edu.au or phone: 9514 5314.

Withdrawal will not affect your relationship or future relationship with the researchers or the University of Technology Sydney. If you decide to leave the research project, personal information already collected will be retained to ensure that the results of the research project can be measured properly, and to comply with law. At this time, we will ask if you would be prepared to complete two short questionnaires taking around 5-10 minutes in total. One assesses the change in your stuttering so far and the other asks your opinion about the program itself. It is your choice whether or not you complete these. We will not collect any additional personal information from you.

Please be aware that any data collected up until the time you withdraw you will form part of the research project results. If you do not want us to do this, you must inform us before consenting to join this research project.

WHAT WILL HAPPEN TO MY INFORMATION?

By signing the consent form, you consent to the research team collecting and using personal information about you for the research project. All information will be treated confidentially. The following steps are taken to ensure your privacy and confidentiality:

- You will be assigned a unique identifier that will only be known to researchers in this study.
- All your information will be de-identified, where relevant, for data storage and analysis.
- Only researchers directly involved with the research will have access to your information.

We would like to store the information you provide about yourself for future use in research projects that are an extension of this research. In all instances, your information (a) will be treated as confidential, (b) will be stored in a de-identified format where possible, and (c) will be stored on secure University servers. In the event that we wish to use your information for a future research project, we will seek ethical approval to access your data, and only researchers involved with the research will have access to your information.

It is anticipated that the results of this research project and any future research will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except where you give explicit permission.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform one of the research team members named at the end of this document if you would like to access your information.

WHAT IF I HAVE QUERIES OR CONCERNS?

If you have concerns about this research that you think I or my supervisor can help you with, please feel free to contact us on the details listed below.

Ms Constance Alateras or Associate Professor Robyn Lowe

Email: asrc.research@uts.edu.au or phone: 9514 5314

You will be given a copy of this form to keep.

NOTE: This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this

research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated, and you will be informed of the outcome.

CONSENT FORM

TESTING iCAMPERDOWN: AN ONLINE SPEECH TREATMENT FOR ADULTS WHO STUTTER (UTS HREC REF NO. ETH23-8075)

I _____ [participant's name] agree to participate in the research project *Testing iCamperdown: An online speech treatment for adults who stutter* (UTS HREC REF NO. ETH23-8075) being conducted by Ms Constance Alateras, PhD candidate at the Australian Stuttering Research Centre, University of Technology Sydney. This project is being supervised by Associate Professor Robyn Lowe, Professor Mark Onslow, Professor Ross Menzies, Associate Professor Susan O'Brian and Dr Anna Hearne. I understand that funding for this research has been provided by the National Health and Medical Research Council.

I have read the Participant Information Sheet.

I understand the purposes, procedures, and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions, and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described, and I understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I understand that the research data gathered from this project may be published in a form that does not identify me in any way.

I agree that the research data gathered from this project may be used for future research purposes

I am aware that I can contact the researchers named below if I have any concerns about the research:

Associate Professor Robyn Lowe

Ms Constance Alateras

Email: asrc.research@uts.edu.au / Phone: 9514 5314

____/____/____

Name and Signature [participant]

Date