

# **Participant Information Sheet**



#### **Allied Health Research**

## University of South Australia – Research Honours Program

Project Title: The Experience of Adults & Teens Undertaking Group

Improv Therapy.

Protocol Number: 205793.

Coordinating Principal Supervisor: Dr. Michelle Swift.

Chief Investigator: Damien Aston.

Associate Investigator: Julia Whittaker.

**Swift Group Improv Therapy** 

Session Coach: Eleanor Brasted.

## Part 1 What does my participation involve?

#### 1 Introduction

You are invited to take part in this research project, which aims to investigate the experiences of adults and teens undertaking a new therapy approach entitled 'Swift Group Therapy'. You have been invited because you are on Swift Speech, Stuttering and Voice client/waiting lists for stuttering therapy or you have responded to an advertisement expressing interest in this project.

Current clients of Swift Speech, Stuttering and Voice are welcome to participate in the study.

This Participant Information Sheet tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent form. By signing it you are telling us that you:

- Understand what you have read
- · Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

Parents are responsible for consent and children can assent or dissent to participating.

You will be given copies of Participant Information Sheet and Consent Form to keep.

#### What is the purpose of this research?

- This research is designed to:
- 1) Collect information about the client experience of participating in an improv and Acceptance and Commitment Therapy (ACT) group for adults or teens who stutter;
- 2) Compare the treatment experience and outcomes of adults and teens;
- 3) Identify Mechanisms and contextual factors that lead to favourable and less favourable outcomes for these clients.
- 4) This study aims to evaluate changes to overall impact rating on the Overall Assessment of the Speakers Experience of Stuttering (OASES) following therapy block.
- 5) This study also aims to thematically analyse participant interview data to determine therapy impact on participant communicative self-efficacy.

The results of this research will be used by the researcher Damien Aston to obtain a Bachelor of Speech Pathology (Research Honours) degree.

This research has been initiated by the Principal Supervisor of Research Project, Dr. Michelle Swift and the University of South Australia. The Principal Supervisor is also the owner of Swift Speech, Stuttering & Voice and the developer of the Swift Group Improv therapy.

Active research will be conducted on location at Swift Speech, Stuttering and Voice Clinic:

- Abergeldie House
   548 Portrush Road
   Glen Osmond, South Australia, 5064
- Or via Zoom

#### 3 What does participation in this research involve?

Consent form will be signed prior to any study assessments being performed. For participants under 18 years old, parental consent is required. The teenager can assent or dissent to participate as indicated on the consent form.

#### ➤ Initial steps:

- Researcher will contact potential participant, to cross check age and stuttering status. If they do not have a formal diagnosis of stuttering, then an appointment with clinician will be arranged to confirm stuttering diagnosis.
- Once participants have been selected, groups will be defined by age parameters (see Section 3). Participants will be notified of session dates/times and to confirm attendance.

#### ➤ Procedures:

- All participants will take part in one block of 'Swift Group Improv Therapy'.
- The block consists of one 60-minute session per week over a 9-week period requiring at minimum 9 individual visits to clinic.
- Prior to first treatment session and at the end of treatment block, two 10-minute speech samples will be collected and 5 stuttering and anxiety related questionnaires will be completed.

- Following the therapy block some participants will be selected and contacted for interviews. These 45 60-minute interviews will take place on location at Swift Speech, Stuttering & Voice Clinic. Teen participants may choose to be interviewed with their parents present if they wish.
- The project aims to be completed and submitted for publication by November 2024.
- Research will be monitored regularly through research team meetings and via University of South Australia's Honours Program.
- Interviews will be audio recorded and transcribed verbatim into written records.
  - Participants will be given the opportunity to review their individual interview transcripts for accuracy.
  - Any video recordings or audio files will be stored electronically on Dr Swift's R: Research
    Drive on the University server. Only members of the research team will have access to
    research data unless the participant consents to sharing it as part of the FluencyBank
    Research database.
  - Written records will be stored in a locked filing cabinet within Dr. Michelle Swift's office.

This research project has been designed to make sure the researchers interpret the results in an appropriate and methodical way ensuring any conclusions resulting from analysis are grounded in the data.

As this is a clinical trial there are no costs associated with participating in the therapy blocks associated with this research project, nor will you be paid.

#### 4 Other relevant information about the research project

- This project will include two separate groups defined by ages.
  - Group 1: 14 17 years of age
  - o Group 2: 18 years of age and above.
- Improv is traditionally a theatre art form where everything that is performed by the actors
  is created in the moment, no scripts and always responding yes to keep the performance
  flowing.
- Improv is seeing increasing use in health fields and 'Swift Group Improv Therapy' uses
  pre-set games and scenarios for participants to engage and explore communication
  feelings in a fun, risk-free and supported environment.
- This study is the first of its kind to combine group improv with evidence based psychological initiatives in the field of advanced stuttering. The project is undertaken in collaboration with Swift Speech, Stuttering and Voice and University of South Australia.
- This project is being conducted in two arms concurrently. Interview data will be analysed
  as part of Damien Aston's research honours project. Secondary analysis using both
  questionnaire data and interview data will be undertaken by Dr. Michelle Swift and
  research partners.

#### 5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and a Consent Form to sign. Copies will be provided to you.

You can choose whether or not you consent to having speech samples and audio recordings uploaded to FluencyBank to assist research into stuttering.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with Swift Speech, Stuttering and Voice. A participant withdrawal form will be provided in this instance.

## What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include:

- Increasing awareness of individual communication abilities and strengths.
- Reduced negative emotions tied to social communication situations.
- Increased ability/motivation to participate in personally relevant social situations.
- Increased acceptance of individual manner of communication.
- Heightened feelings of self-worth, capability and control, leading to positive long-term outcomes for participants.

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

Participating in group situations has the potential to make some individuals self-conscious and uncomfortable. They may feel increased vulnerability. While participants will be supported and guided by professionals at all times, they are encouraged to speak to any member of the research team, or the complaints contact (section 14) who is unattached to the project.

During interviews you may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately.

If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. The research team will link participants to appropriate support services.

All participants who take part in group session will be asked to maintain confidentiality and preserve the anonymity of focus group participants. Please note, however, that given the public nature of group work, this cannot be guaranteed.

#### 8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Participation' form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although 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. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

## 9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as:

- Unavailability/Loss of research team/faculty members.
- Unavailability of sufficient data for ethical analysis.
- Lack of support during data analysis.
- Complications with study design.
- Ethical compliance issue.

## 10 What happens when the research project ends?

If research indicates 'Swift Group Improv' therapy is both beneficial and viable then subsequent therapy blocks will be planned. Following completion of research and individual involvement participants will subsequently have the choice to:

- Enrol in subsequent blocks of 'Swift Group Improv' therapy. Although, the therapy blocks attached to the research project are free of charge for participants, any and all subsequent blocks will carry a cost for participants. The amount will be determined by Swift Speech, Stuttering and Voice.
- See a qualified speech pathologist for one on one standard therapy. Usual fees will apply.
- Cease involvement in any form of stuttering therapy.

Participants can choose to provide their email details to receive a summary of project outcomes. These will be provided once analysis has concluded and project write up has been submitted for publication.

## Part 2 How is the research project being conducted?

### 11 What will happen to information about me?

- Data collected will be individually identifiable for analysis purposes. However, all identities and confidentiality are protected in any and all published materials.
- Hard copies of data will be stored in a locked filing cabinet in Dr. Michelle Swift's office.
   Electronic files will be stored on Dr Swift's R: Research Drive on the University server which is backed up every 24 hours.
- As this is a clinical trial, all raw data including recording of the interviews and group therapy sessions will be kept for 15 years.
- Once files are no longer needed they will be archived in a secure off-site facility as per UniSA archiving processes. After retention time has lapsed hard copies will be shredded and electronic files deleted from Research Drive.
- By signing consent, the participant understands that research data from this project may be analysed in conjunction with the accompanying concurrent related research project/s.
- Your information will only be used for the purpose of this research project and with your consent uploaded to FluencyBank for the purposes of approved research projects in the future. For more information on FluencyBank, please visit <a href="https://fluency.talkbank.org/">https://fluency.talkbank.org/</a>. Information will only be disclosed with your permission, except as required by law.
- The personal information that the research team collect and use include speech samples, information from questionnaires, interview recordings/transcripts and therapy notes concerning 'Swift Group Improv' therapy sessions.

Information about you may be obtained from your health records held at Swift Speech, Stuttering & Voice for the purpose of this research. The treating speech pathologist will make clinical notes relating to the improv group sessions which will be analysed by the research team.

It is anticipated that the results of this research project 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 with your express permission.

In accordance with relevant Australian and/or South Australian privacy and other relevant 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 the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project and for concurrent/future research that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

#### 12 Complaints and compensation

There is a distress protocol in place to ensure participants welfare in all phases of research project. If participants wish to discuss this prior to their participation please contact research team using contact details in Section 14.

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

Complaints regarding conduct of any members of the staff/research team should be directed to the contact details in Section 14.

## 13 Who is organising and funding the research?

This research project is being conducted by Damien Aston. Damien's principal supervisor is Dr Michelle Swift, who is also the owner of Swift Speech, Stuttering & Voice.

Swift Speech, Stuttering and Voice or the University of South Australia may benefit financially from this research project if, for example, the project assists Swift Speech, Stuttering and Voice or the University of South Australia in any commercial enterprise.

You will not benefit financially from your involvement in this research project even if, for example, knowledge acquired from your information proves to be of commercial value to Swift Speech, Stuttering and Voice or the University of South Australia.

In addition, if knowledge acquired through this research leads to discoveries that are of commercial value to Swift Speech, Stuttering and Voice, the University of South Australia or the researchers or their institutions, there will be no financial benefit to you or your family from these discoveries.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

#### 14 Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the University of South Australia as required by the Australian government research requirements, specified in the National Statement on Ethical Conduct in Human Research (2007 - updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher, Damien Aston via email: astdm001@mymail.unisa.edu.au, or any of the following people:

### Research contact person

Name	Dr. Michelle Swift
Position	Principal Supervisor / Director of Swift Speech, Stuttering and Voice
Telephone	0436 202 011
Email	michelle.swift@unisa.edu.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

## **Complaints contact person**

Name	Bianca Wagnitz
Position	Senior Speech Pathologist
Telephone	08 7092 4028
Email	bianca@swiftspeech.clinic

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

## Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	University of South Australia's Human Research Ethics
	Committee
HREC Executive Officer	Executive Officer
Telephone	08 8302 6330
Email	humanethics@unisa.edu.au