



University of
South Australia

Participant Information Sheet – Clients of Cluttering Treatment

Title	Cluttering treatment: Do client experiences fit with neuro-affirming practice?
Short Title	Cluttering treatment and neuro-affirming practice
Project Number	205589
Project Sponsor	
Chief Investigator/ Principal Investigator	Dr. Michelle Swift
Supervisor	
Associate Investigator(s)	Ms Julia Whittaker Ms Eleanor Brasted Mrs Bianca Wagnitz Ms Anna Bouras

Introduction – What does my participation involve?

You are invited to take part in this research project, which is called ‘Cluttering treatment: Do client experiences fit with neuro-affirming practice?’. You have been invited because you are either a current or past client who has participated in cluttering therapy, either as a teen or adult client or as the parent of a child or teen client. Your contact details were obtained from the client management system used by Swift Speech: Stuttering and Voice, or by responding to an advertisement through Speech Pathology Australia or a Stuttering Special Interest Group.

This Participation 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 such as your doctor.

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 a separate Consent Form. By signing the Consent Form, you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to the use of your information as described
- Will be given a copy of this Participation Information Sheet to keep

What is the purpose of this research?

The aim of this project is to document client experiences of cluttering treatment. Cluttering treatment is often provided within a communication effectiveness framework. Participants' experiences of this framework for treatment will be explored through an interview.

Cluttering is frequently seen in the neurodivergent population (e.g. Autistic individuals, ADHDers) and people with additional diagnoses such as stuttering, language disorder, Down syndrome and Fragile X syndrome. Participants will also be asked about their understanding of neurodiversity affirming practice and whether they found the treatment they received to be neurodiversity affirming. As part of this questioning, clients will be asked whether they have been diagnosed as neurodivergent, or suspect they are neurodivergent. This information is optional for the participant to disclose.

This research is the first phase of a two-phase research study. The second phase will explore the opinions of clients, clinicians and researchers about cluttering treatment and neurodiversity affirming therapy through a conference workshop at the Third World Conference on Cluttering. Preliminary results from this first phase will be presented at the workshop.

What does participation in this research involve?

Consent will be obtained prior to any information being disclosed by you. Participation in this research involves:

- Engaging in a semi structured interview with a research assistant or speech pathologist (who is/was not your treating speech pathologist)
 - This interview will be conducted either face to face, via telephone or telehealth, whichever is more suitable for you.
 - Will take approximately 30-45 minutes.
 - Information provided will be recorded, de-identified, transcribed and analysed.
 - The duration of the project is 2 years.

What are the possible benefits of taking part?

There is no guarantee that you will directly benefit from taking part in this research. However, participating in this research may contribute to the knowledge base of neurodiversity affirming practice and improved cluttering treatment experiences for future clients. This may include yourself if you receive further cluttering treatment in the future.

What are the possible risks and disadvantages of taking part?

This research involves discussing sensitive health information (your cluttering diagnosis and treatment experiences). Most participants will not experience any issues from doing this. For some participants, discussing treatment experiences may be slightly uncomfortable, while others may experience psychological or emotional stress. Some clients may not feel comfortable disclosing their neurotype, which is a voluntary question. The interviewer will not be the client's treating therapist and responses will be de-identified when transcribed so participation will not impact on your relationship with your treating speech pathologist.

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 and you will be given a copy to keep.

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 the University of South Australia or with Swift Speech: Stuttering and Voice.

If you wish to withdraw from the research, a Withdrawal of Consent form will need to be signed and submitted to the Chief Investigator.

What will happen to information about me?

By signing the Consent Form, you consent to the research team collecting and using information about/from you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential and no information which could lead to identification of any individual will be released unless required by law. Information collected or used will be stored as non-identifiable information. Paper-based information will be stored in Dr Michelle Swift's office at UniSA. Electronic data will be stored on the Research Drive at UniSA.

Your information will be used for the purpose of this research project. It will only be disclosed with your written consent, except as required by law.

The interview recordings will also be available for the research team to use in future research into cluttering following ethical review by a Human Research Ethics Committee.

The data will be stored electronically for 5 years after the publication of all relevant papers. After this time, electronic data will be deleted from the Research Drive, and paper based documentation will be shredded.

What if something goes wrong?

Adverse effects are not expected to occur. However, if you do experience discomfort or any other effects from participating in this research, you are advised to contact the Chief Investigator immediately. If you experience psychological or emotional stress from taking part in this research, you can contact Lifeline on 13 11 14 (telephone), 0477 131 114 (SMS) or <https://www.lifeline.org.au/crisis-chat/> (online chat).

What happens when the research project ends?

A summary of project results will be available if requested from the Chief Investigator via email. It is intended that the information obtained from this research will be published.

Who is organising and funding the research?

This research is being conducted by Dr Michelle Swift, who is employed by UniSA and is the business owner of Swift Speech: Stuttering and Voice.

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.

Further information and who to contact

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 on 08 8302 7782 or any of the following people:

Research contact person

Name	Dr Michelle Swift
Position	Chief Investigator
Telephone	08 8302 7782
Email	michelle.swift@unisa.edu.au

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, please contact:

Reviewing HREC name	University of South Australia Human Research Ethics Committee
HREC Executive Officer	Human Ethics Officer
Telephone	+618 8302 6330
Email	humanethics@unisa.edu.au

Reviewing HREC approving this research and HREC Executive Officer details