Voice Therapy for Muscle Tension Voice Disorders: Contents and Processes

CLIENT PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study about what Speech Pathologists do in voice therapy. We are interested in exploring the complexities of voice therapy by unpacking the content and interactions that occur between Speech Pathologists and their clients who have Muscle Tension Voice Disorder (MTVD). The findings of this research will help identify, quantify and characterise components of voice therapy used in current clinical practice. It is hoped that this will enhance Speech Pathologists' efforts to systemically approach future research design and reporting standards, clinical practice and professional training.

You have been invited to participate in this study because you are a client of a Speech Pathologist who is treating your voice disorder. The study aims to identify what occurs in voice therapy by completing observations of therapy sessions and interviewing the treating Speech Pathologist for their perspectives of what they did during those sessions. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don’t understand or want to know more about.

You must speak fluent English in order to participate. Participation in this research study is voluntary.
By giving consent to take part in this study you are telling us that you:
✓ Understand what you have read.
✓ Agree to take part in the research study as outlined below.
✓ Agree to the use of your personal information as described.
✓ Agree for your treatment session to be video recorded and for your assessment results to be shared by your speech pathologist with the research team

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers who are all Speech Pathologists:
• Clare Eastwood, PhD Student, Speech Pathologist, The University of Sydney
• Patricia McCabe, PhD Certified Practising Speech Pathologist (CPSP), Associate Professor, The University of Sydney
• Catherine Madill, PhD CPSP, Director of the Voice Research Laboratory, The University of Sydney

STUDENT DECLARATION
Clare Eastwood is conducting this study as the basis for the degree of Doctor of Philosophy at The University of Sydney. This will take place under the supervision of Patricia McCabe, Associate Professor at The University of Sydney.

(3) What will the study involve for me?

This study involves collection of your voice assessment information from your treating Speech Pathologist, video recording your voice therapy session(s) and interview(s) between the treating Speech Pathologist and one of the researchers. We aim to start with your very first therapy session; however, your participation at any stage of your therapy will be appreciated. The number of sessions and interviews will depend on the willingness of you and your Speech Pathologist to participate.

You will need to:

a) Read this participation information statement
b) Inform the researchers if you want to participate
c) Sign consent form

If you wish to have multiple therapy sessions recorded and discussed please indicate the extent you wish to participate on the consent form. You may change your mind on the extent of your participation at any point throughout the study. If you decide you want to increase your participation please contact Clare Eastwood by calling or texting 0434894571 or email clare.eastwood@sydney.edu.au. You may also approach the attending researcher on the day of your therapy session. If you do decide to increase the extent of your participation beyond what you indicate on the initial consent form, you will be asked to sign another consent form.
(4) How much of my time will the study take?

We are not expecting this study to interfere with your time as we will be recording your normal treatment session with your speech pathologist.

(5) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with your Speech Pathologist, the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by contacting Clare Eastwood by calling or texting 0434894571 or email clare.eastwood@sydney.edu.au. Your decision to no longer participate in the study will not affect your current or future relationship your Speech Pathologist, the researchers or anyone else at the University of Sydney.

(6) Are there any risks or costs associated with being in the study?

We do not expect that there will be any risks or costs associated with taking part in this study.

(7) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study.

(8) What will happen to information about me that is collected during the study?

- The video recordings and interviews will be transcribed and analysed by the researchers for the purposes of this project.
- The questionnaires will be de-identified and coded with participant ID numbers. The information collected through the initial questionnaire will be used by the researchers to help evaluate the other data collected in this project.
- During the study, any written information collected about you will be de-identified, coded with ID numbers, scanned and stored on a password protected University owned computer server. The hard copy data will be destroyed immediately after the upload is completed.
- During the study and after its completion, all electronic data will be stored on the University of Sydney Research Drive Storage in a password protected computer.
- Only the researchers will have access to the data.
- The data will be kept for a period of 5 years after the completion of this project. At the end of this time all data will be deleted.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications. Multiple studies may be published from the data collected in this project.
By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research. This information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

(9) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(10) What if I would like further information about the study?

When you have read this information, Clare Eastwood 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 during the study, please feel free to contact Clare Eastwood (PhD student) at clare.eastwood@sydney.edu.au or call 0434894571.

(11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. This feedback will be in the form of a one page lay summary. You will receive this feedback after the study is finished.

(12) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney 2016/055. As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

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 using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

• Telephone: +61 2 8627 8176
• Email: ro.humanethics@sydney.edu.au
• Fax: +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep