

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Exploring Speech and language therapists perspectives of therapeutic alliance building with school aged children who stutter and their parents: a qualitative study

Site	Trinity College Dublin
Principal Investigator(s) and Co-Investigator(s)	Grace McLoughlin – Principal investigator Dr. Fiona Ryan– Academic Supervisor
Data Controllers	Trinity College Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 dataprotection@tcd.ie

You are being invited to take part in a research study that is being done by Grace McLoughlin at Trinity College Dublin.

Before you decide whether or not you wish to take part, please read this information sheet carefully. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

This leaflet has four main parts:

- Part 1 – Information about the Study
- Part 2 – Information on how your data will be used and stored
- Part 3 – Information about Costs, Funding and Approval
- Part 4 – Further Information

Part 1 – The Study

Why is this study being done?

We are doing this study to explore the role of therapeutic alliance in Speech and Language Therapy, with particular attention to stuttering therapy in school aged children. This study wants to specifically explore Speech and Language Therapists perceptions of this topic. This project is being carried out as part of a final year research project in the course of Clinical Speech and Language Studies.

You have been invited to take part because you are a qualified Speech and Language Therapist, with 3 years of working experience including experience with school ages children who stutter.

We aim to have 8-10 people involved in this study.

Do I have to take part? Can I withdraw?

- You don't have to take part in this study. *It is up to you to decide whether or not to take part.* If you decide not to take part it won't affect your current or future career as a Speech and Language Therapist .
- You can change your mind about taking part in the study and opt out at any time even if the study has started. If you decide to opt out, it won't affect your current or future career as a Speech and Language Therapist .
- You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Principal Investigator- Grace McLoughlin @mclougg3@tcd.ie who will be able to organize this for you.

What happens if I change my mind?

You can change your mind at any time by contacting Grace McLoughlin @mclougg3@tcd.ie . If you choose not to continue to take part, this will not affect your *future career as a Speech and Language Therapist* in any way. If you wish, you can ask for your data to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in research studies prior to this time.

What will happen to me if I decide to take part? What will I need to do?

If you decided to take part you will be asked to sign a consent form and contact the principal investigator to confirm an interview time of your preference. The study will take place in one 30 minute interview with Grace McLoughlin, the Principal Investigator. If you decide to participate you will be interviewed in a location of your preference: Zoom call or a meeting in the CSLS building, South Leinster Street, Dublin 01. During the interview you will be asked some questions about your experience working with school aged children who stutter and forming therapeutic alliance.

Are there any benefits to taking part in this research?

Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand the role of therapeutic alliance in Speech and Language Therapy, more specifically in Stuttering Therapy.

Are there any risks to me or others if I take part? What will happen if something goes wrong?

Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.

Will I be told the results of any assessments performed as part of this study that relate to me?

The results of the research will be provided to the participant if they specifically ask for it.

Part 2 – Data Protection

How will my data be used?

Data from this research project may be published in future in scientific journals. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The original recording and all copies will be available only to the present investigators.

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Personal data to be collected and used for this study are:

- Consent forms to provide consent
- Audio recordings to allow researcher to analyse for research purposes.
- Contact details to allow researcher to organise interview times.

Participants medical records will not be accessed.

Identifiable data is needed in order to arrange meetings between you and the principal researcher. Identifiable information will be anonymised when interview analysis is commenced.

Who will have access my personal data? What will happen to my personal data?

All the personal data that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team Principal Investigator: Grace McLoughlin and Academic Supervisor- Dr. Fiona Ryan. *All of your personal data will be stored in Ireland.*

Data that can identify you will be kept for 7 years to adhere with accepted best practice recommendations of secure retention of non- anonymised data. Anonymised or coded data will be kept until 30th of January 2024 to allow us to have time to analyse the interviews to complete the research study. After this time period your personal data to be destroyed by Principal investigator Grace McLoughlin.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

Any information or data which is obtained during this research which identifies you will be treated confidentially. All the data collected will be stored on the researcher's laptop in an encrypted and password protected file. The data will then be made anonymous so as to hide your identity. All original files will be encrypted and transferred to a secure folder in the Trinity College Dublin computer network. Any files containing identifiable information will then be deleted off the laptop, so that only

anonymous data remains. All files will be accessible only by the Principal Investigator: Grace McLoughlin.

All individual researchers involved in this project have been trained in data protection law and are bound by professional code to maintain confidentiality.

What is the lawful basis to use my personal data?

According to data protection legislation¹, we are required to inform you of the legal basis for using your personal data. The tasks we are performing are considered to be in the public interest²

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to have your data transferred to another organisation or 'data controller'
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Grace McLoughlin- Mclougg3@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 30/06/2023.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying participants to take part in the study. It will not cost you to take part in this study.

Part 4 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- *Principal Investigator: Email- Mclougg3@tcd.ie*

¹ The European General Data Protection Regulation (GDPR)

²Article 6(1)(e)

- *Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy. Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.*

Will I be contacted again?

If you would like to take part in this study, you will be asked to sign a Consent Form. You will be given a copy of this information leaflet and the signed Consent Form to keep. If you consent, we will contact you to arrange a time to conduct the interview. Other than arrangements for the study described, we will only contact you if we find clinically relevant results.