

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

**Gaining consensus with adults who stutter on the essential elements of therapeutic alliance in
stuttering intervention: An E-Delphi Study**

Site	Clinical speech and language studies department, Trinity College, Dublin
Principal Investigator(s) and Co-Investigator(s) <i>(insert names, titles and contact details. Where relevant, give the name of academic supervisor)</i>	Liadh Furlong – Undergraduate Student furlonli@tcd.ie Dr. Amy Connery – 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 **Amy Connery & Liadh Furlong** 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 five 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 – Future Research
- Part 5 – Further Information

Part 1 – The Study

Why is this study being done?

We are doing this study to gain consensus on the essential elements of therapeutic alliance in stuttering intervention with adults who stutter. This project is being carried out as part of a final year undergraduate degree in clinical speech and language studies.

Why have I been invited to take part?

You have been invited to take part because you are an adult who stutters.

We aim to have 30 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 *speech and language therapy*.

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 *speech and language therapy*. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact *Liadh Furlong* [email: furlonli@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 *Liadh Furlong* (furlonli@tcd.ie) or *Amy Connery*. If you choose not to continue to take part, this will not affect your *speech and language therapy* 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?

The study will take place through three questionnaires sent to you via email. If you decide to participate you will complete the questionnaires at your own convenience.

This research is trying to establish what are the important elements of therapeutic alliance.

This research involves three questionnaires:

- The first questionnaire will include a list of elements identified in previous research as being essential to therapeutic alliance for you to identify if you feel they are essential elements of therapeutic alliance. You will also be asked to add other elements we have omitted.
- The second and third questionnaires will provide a list of the elements that have been identified as being essential to therapeutic alliance and you will be asked to rate them on a scale of 1-5 (disagree to agree).
- More information will accompany the questionnaires

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 therapeutic alliance in the area of stuttering and may result in a definition of therapeutic alliance.

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

There is a risk that the questionnaire will bring up feelings of discomfort. In this case we will supply details of your national stuttering association from which you can seek a support group e.g., for Irish participants we would suggest you seek out support from the Irish Stammering Association

There is a risk that a connection to your identity could be made. 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?

You will receive a second and third questionnaire which are formulated based on the results of the previous questionnaires. The research results will also be disseminated to the gatekeepers of associations on its completion.

Part 2 – Data Protection

How will my data be used?

Data from this research project may be published in the future in scientific / medical / linguistic / educational 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 Liadh Furlong & Amy Connery or to investigators in other academic institutions engaged in similar work if you agree to this.

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

This research will involve gathering personal data such as your name and contact email, this information will be protected by a double encrypted computer for a period of seven years. However, once we have received your responses to the questionnaire pseudonyms will be used to protect your data in the analysis.

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 Liadh Furlong & Amy Connery (co-investigators). All of your personal data will be stored in Ireland. Personal data will only be disclosed to Liadh Furlong & Amy Connery.

If you agree to us sharing this information with other researchers (e.g., by making it available in a data archive) this will be done so without using your personal data, unless you request your personal data be used.

Data that can identify you will be kept for 7 years to allow us as this is the statutory requirement. Anonymised or coded data will be kept for 7 years to allow us to analyse the results and write a paper summarising our results. After this time period your personal data to be destroyed by Amy Connery .

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 accessible only by Liadh Furlong & Amy Connery. If any data is printed the paper copies will be kept securely in the Amy Connery's Trinity College office and will be destroyed after seven years.

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

If something did go wrong we would inform the data protection commission of any data breach within 72 hours of its occurrence.

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
Some data that is defined as more sensitive such as your name is being used for scientific purposes³*

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 Liadh Furlong or Amy Connery 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.

¹ The European General Data Protection Regulation (GDPR)

¹Article 6(1)(e)

³ Article 9(2) (j))

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 04/07/2022.

Who is organising and funding this study?

There is no funding approved for this study

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.

Part 4 – Future Research

Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering future research questions about therapeutic alliance in stuttering intervention. We will ask for your explicit consent for your data to be used in this way. You do not have to agree to have your data available for future research. Future research will only take place if it has research ethics approval.

Part 5 – Further Information

Who should I contact for information or complaints?

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

- *Principal Investigator: Liadh Furlong
Email: furlonli@tcd.ie
Amy Connery
Email: connerya@tcd.ie*
- *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 provide consent at the beginning of the questionnaire. You will be given a copy of this information leaflet to keep. If you consent, we will contact you to conduct a second and third questionnaire. Other than arrangements for the study described, we will only contact you to ask you about future research if you agree.