



TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES
Participant Information Leaflet
“The Lived experiences of adults with developmental language disorder”.

Site	
Principal Investigator(s) and Co-Investigator(s)	Principal investigator: Rebecca Carey. careyre@tcd.ie Research supervisor: Dr. Amy Connery. connerya@tcd.ie Dr. Amy Connery is an assistant professor of Speech and language pathology, in Trinity College Dublin.
Data Controllers	Trinity College Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 dataprotection@tcd.ie

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

You have to read this information leaflet if you want to take part in the research project.

You have to **understand the risks and benefits** of taking part in this study if you want to take part in the research project.

You are allowed to talk about this leaflet and the project with other people.

Please ask us if there is anything that is not clear to you or if you would like more information.

Take your time to decide if you would like to take part in the research project.

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 because there is **very little research about adults with language difficulties**. We are interested in talking to **adults with language problems and we want to learn if their language problems affect their everyday life**.

This research project is part of my speech and language therapy degree, in Trinity College Dublin.

Why have I been asked to take part?

You have been asked to take part because:

- You have been diagnosed with “**developmental language disorder**”, “**specific language impairment**” or “**language disorder**”, **or you know that you have language difficulties and you have had these difficulties since you were a child**.
- You **attended a speech and language therapist** as a child or teenager or an adult for language therapy
- You **attended a language class or language unit** in primary school

We would like to have 8-10 people take part in this study.

Do I have to take part? Can I withdraw?

You don't have to take part in this study.

It is your choice whether you would like to take part or not to take part.

You can change your mind about taking part in the study and leave the study at any time even if the study has started.

If you want to leave the study, it would not affect you if you ever needed to attend a speech and language therapist now or in the future. You don't have to give a reason for not taking part or for leaving the study.

If you want to leave the study please email Rebecca Carey, at careyre@tcd.ie who will be able to organise this for you.



What happens if I change my mind?

You can ask for any of the information we got from you to be destroyed.

If you ask us to do this, we will destroy all the information that belongs to you.

We will no longer use or share the information we got from you.

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

The study will take place from **September 2023 until January 2024.**

We would like to do one interview with you. The interview would be around 40 minutes long.

We could do the interview online, through “Zoom”, or meet in person in Dublin or a place that is easy for you.

- I will be interviewing you **to learn about your experience as an adult who has difficulties with language.**
- I want to know if your difficulties with language makes it difficult for you to do **or** take part in:
 - work,
 - college or any learning you have done since secondary school,
 - your social life or hobbies
 - And I will ask you questions about this.
- I will be recording our conversation. Only Rebecca Carey is going to listen to the recording.
- I will type out our conversation and pick out “themes” (I want to see if you and the other people who are going to take part have had similar experiences). I will talk about these “themes” in my project.
- **When I have typed out our conversation, I will send you a copy of it. If you want to, you can add information to the typed conversation, or you can ask me to take anything out.**



Are there any benefits to taking part in this research?

If you take part in this study, you will not get anything from doing it.

However, your information may **help us to better understand adults with language difficulties.**

This means we could teach more people about adults with language difficulties and people could be more understanding about it.

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

When I am typing up our interview, **I will be changing your name so other people will not know who you are.**

I don't expect there will be any risks to taking part in the interview.

If anything, negative comes up during the interview, please tell me and I will give you information about support groups/ organisations afterwards.

Please remember the interview will be around 40 minutes long, or longer and if that is too long for you, you do not have to take part in this study.

Part 2 – Data Protection (Data means your information- the consent form you signed, you email address and the recording of the interview)

How will my data be used?

Data from this **research project could be published in future in scientific journals.** When people are reading the study, they will not be able to tell who you are.

The original recording of our interview and the typed copies of the interview will only be heard or read by Rebecca Carey and Dr. Amy Connery (The project supervisor).

What information about me (personal data) will be used as part of this study?

The consent forms, your name and your email address.



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

All the **personal data (information about you)** that we get from you while we are doing this project will be kept **safe and confidential** and only Rebecca Carey and Dr Amy Connery can use your personal data.

All of your personal data will be stored in Ireland.

Your consent form will be kept for 7 years. (This is because of GDPR law).

When I have **typed out the interview**, I will **change your name** so no one will know it is you. This will be kept for until we have finished with the project. **When I am finished with the research project, I will delete the typed interview from my laptop.**

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

We will make sure that other people will not know who you are and we will keep your personal information safe. Here is how we will do this:

- Any information you give us, during this research, that can identify you will be treated confidentially. (This means Rebecca Carey and Amy Connery cannot talk about you or your interview to anyone else).
- All the information you give us will be stored on my laptop in an encrypted and password protected file. (When your information is **encrypted, it means only people with a code can open the file and read your information. It is a way to stop other people from seeing your information**).
- I will change your name 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 that have information that can identify you will then be deleted off my laptop, so that only anonymous data remains.
- Only Rebecca Carey and Dr Amy Connery will be able to see the files.
- Paper copies of the consent forms will be kept **securely in a cabinet and only Dr Amy Connery will be able to access them. The consent forms will be kept in this cabinet for 7 years and then they will be destroyed.**

Rebecca Carey and Dr Amy Connery have done **training in data protection law** and this means **we have to make sure we protect your information and confidentiality.**

If something did go wrong, we would let you know as soon as possible.



We would also report this to the data protection officer.

What is the lawful basis to use my personal data?

According to data protection law¹, we have to tell you of the legal reasons for using your personal data. This research project is in the public interest²

Some information that is more sensitive like; **consent forms, names and contact details** (in line with GDPR) are 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 sent to another organisation or 'data controller'
- The right to tell us how much of your data we can use or ask us to stop using it
- The right to tell us to stop using any of the information we have that is yours.
- The right to have wrong information about you changed or deleted
- The right to tell us to delete your data

By law, you can use any of the rights (mentioned above) about your information (personal data), unless the request would make it impossible or very difficult to conduct the research.

You can **use your rights by contacting Rebecca Carey at careyre@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.

¹ The European General Data Protection Regulation (GDPR)

¹Article 6(1)(e)

³ Article 9(2) (j))



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 – Further Information

Who should I contact for information or complaints?

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

- Principal Investigator: **Rebecca Carey at careyre@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 happy 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 the Consent Form on the next page.

You will be given a copy of this information leaflet and the signed Consent Form to keep.

If you give consent, Rebecca Carey will contact you to arrange a time to do the interview.

You can also ask Rebecca Carey any questions you have, before we do the interview.