

Trinity College Dublin
School of Linguistic Speech and Communication Sciences
Participant Information Leaflet

Stigma and Self Image After Glossectomy: Patients Perspectives

Research Site(s)	Trinity College Dublin
Principal Investigator(s) and Co-Investigator(s) (Study Team) (insert names, titles and contact details including Trinity School/Department/Unit)	Principle Investigator: Leah Behan: Behanle@tcd.ie Research Supervisor: Dr. Julie Regan: Juregan@tcd.ie Head of Discipline and Associate Professor in Speech and Language Pathology (Trinity College Dublin)
Data Controller	Trinity College Dublin
Data Protection Officer (Research Data)	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 dataprotection@tcd.ie

We would like to invite you to take part in a study that is being done by Leah Behan at Trinity College Dublin. Before you decide if you want to take part or not, please take some time to read this information leaflet carefully. You should use all of the information on this leaflet to help you make a decision that is right for you. You may want to discuss it with others if you are unsure. If there is anything you are not sure about or you want more information about, feel free to ask us on the email addresses above. Thank you for taking the time to read 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 on costs, funding and approval

Part 4 – future research

Part 5 – further information



Part 1 - The Study

1. Why is this study being done?

We are doing this study to understand the experiences of people that have had a glossectomy (a surgery that is used to remove part or all of the tongue). Studies have not been done on this topic before, and we would like to explore the challenges you face. We really want to look at your challenges regarding self-image and stigma surrounding your surgery.

This project is being done as part of a Final Year Project for an undergraduate degree of Clinical Speech and Language Studies in Trinity College Dublin.

2. Why am I being asked to take part?

You have been identified as somebody that has had part or all of their tongue removed.

We aim to have 8-12 participants in the study.

3. Do I have to take part? Can I leave the study?

You do not have to take part in this study. You can decide whether you want to take part in the study or not. You can change your mind about taking part in the study at any time – even if we have already started. You can opt out of the study and you do not have to give a reason. If you do wish to opt out of the study, please contact Leah Behan, the primary researcher at behanle@tcd.ie and/or Dr Julie Regan, the research supervisor at juregan@tcd.ie who will be able to take you out of the study and give you advice on the management of your data.

You can choose to leave the study at any time up until you have reviewed your interview transcripts and provided any feedback. You will have 3 weeks to do this. After this period, all of the data from all 10 participants will be combined for analysis.

Please note that we will not be able to remove personal data which has been shared or pooled for use in publication before your request for deletion.

4. What does taking part involve?

If you decide to take part, a member of the research team will discuss this information leaflet and consent form with you. You will have to sign a consent form and return it to us. You will be given a copy of your signed consent form and this leaflet to keep.

We will arrange a date and time that suits you to do the interview online via Zoom or in person in Dublin City Centre in a Trinity College building with Leah Behan. I would ask that if you do this interview online, you can do so in a quiet, comfortable place of your liking with strong internet connection. The interview will last approximately 25-40 minutes. As noted in the consent forms, interviews will be audio recorded. During this interview you will be asked



questions about your experience in having part, or all of your tongue removed, and we will discuss any difficulties that you now have. Given that you may experience speech difficulties, the interviewer may ask you to repeat some answers. A whiteboard will also be provided to help you communicate if needed. If you use a communication board/iPad/ anything similar to communicate, this will be welcomed at the interview.

The researchers will then write out what was said in the interview, and you will have 3 weeks to check that you are happy with it.

You are free to withdraw from the study up until this point, as explained in question 4 above.

5. What are the possible benefits of taking part?

Taking part in this study may not directly benefit you. However, we hope that this study may help us to better understand people's experiences who have had their tongue removed. This may result in better care for people like you in the future.

6. Are there any possible disadvantages or risks from taking part?

There are no known risks involved in this study. At all times, your wellbeing takes priority over research activities.

In the event of the interview triggering an emotional event, the interviewer will offer to pause or postpone the interview, and we will try to support you in the best way possible.

Data Breach: There is a very low risk that a connection to your identity may be made, as we have put in place many precautions to prevent this. However, if a breach of confidentiality does occur, we will inform the Data Protection Commission within 72 hours of the breach occurring.

7. What will happen to the results of the study?

You will be sent a copy of the transcription of the interview, and you will be invited to give feedback and make any changes that you wish. You may amend or disregard parts of the interview if you would like. You will have 3 weeks to do this. If you do not give any feedback within these 3 weeks, we will proceed under the assumption that you are happy with the transcription and do not wish to make any changes.

Some quotations from the interview may be used in reports. However, no information which reveals your identity will be disclosed.



Part 2 - Data Protection

8. What information about me (personal data) will be used for this study

We will use the following information about you:

- Your full name
- Your age
- Your clinical diagnosis
- Your contact details (email address)
- Your signature on your consent form
- An audio recording of the interview
- The final transcript of the interview

Your identity will remain confidential, and your name and personal information will not be published.

9. Who will access my personal data?

Your data will be controlled by Trinity College Dublin

Data Protection Officer

Secretary's Office

Trinity College Dublin

Dublin 2

dataprotection@tcd.ie

All of the personal data that we collect about you during this study will be kept strictly confidential and only the research team (Leah Behan & Dr Julie Regan) will be able to access it. All of your personal data will be stored in Ireland.

All of your data will be stored in a SharePoint folder. This requires two factor authentication, a unique username and a strong password. The TCD SharePoint also requires permission to be granted by the owner of the files for them to be accessed.

10. How is the information kept confidential and secure?

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

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

A risk assessment and a data protection impact assessment (DPIA) has been carried out, indicating that this study is of a low risk level.

Consent forms will be deleted immediately following anonymisation of transcriptions. Any information that is gathered during this research which identifies you will be treated confidentially.

We replace your name with a code on all research data. This will be stored on the researchers laptop in a file that is encrypted and password protected..

Any original file with your name will be encrypted and stored on the Trinity College Dublin computer network, in a secure folder. This file will not be stored on the researchers laptop.

All files will only be accessible by Leah Behan (researcher) and Dr Julie Regan (research supervisor)

11. How long will my personal data be needed??

Audio recording: The audio recording of the interview will be retained until it has been transcribed and the content verified after which it will be securely deleted. The transcript will be retained for 3 years after the project end date in line with TCD's retention policy.

Consent forms: Your consent form will be deleted when your data is anonymised.

12. What are my rights under Data Protection law?

You are entitled to:

- object to our use of your personal data or any further use;
- request access to your personal data and to receive a copy of it;
- request inaccurate personal data be corrected or deleted;
- request restriction of our use of your personal data ;
- request deletion of your personal data.

By law you can exercise the above rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the study. For example, if the study is about to be published then we may not be able to delete data as it would impact on the results.

You can exercise these rights by contacting Leah Behan behanle@tcd.ie and/ or Dr Julie Regan juregan@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland.

Email: dataprotection@tcd.ie. Website: <https://www.tcd.ie/dataprotection/>

Part 3 - Approval, Organising and Funding

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 and Communication Sciences on 08/10/2025.

Who is organising and funding this study?

No funding has been obtained for this study.

This study is being undertaken by Leah Behan as part of their undergraduate degree.

Will I be paid for taking part?

No, we are not paying you to take part in the study.

Part 4 - Future Research

Will my personal data be used in future studies?

No. information we collect will only be used for this study.

Part 5 - Further Information

Who should I contact for information or concerns?

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

Primary Researcher: Leah Behan: behanle@tcd.ie

Research supervisor: Dr Julie Regan: juregan@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 raise a concern with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie



Thank you!

Thank you for taking the time to read this Participant Information Leaflet.

If you would like to take part in this study, we will ask you to contact Leah Behan: behanle@tcd.ie or Dr Julie Regan: juregan@tcd.ie and you will be asked to sign the consent form on the next page.

You will be given a copy of this Leaflet and the signed Consent Form to keep. Please retain it for future reference.