

## Participant Information Sheet

Exploring the impact of communication difficulties related to cleft lip and/or palate on the individual's mental health.

### 1. Invitation to research

My name is Izzy Binnersley and I am a Speech and Language Therapy student studying at Manchester Metropolitan University. I would like to invite you to take part in my dissertation research project looking at the effects of cleft lip and/or palate on communication and its impact on the individual's mental health.

### 2. Why have I been invited?

You have been invited to take part in this study because you have experienced life growing up and living with a cleft lip or palate.

I am interested in studying this particular population group as I would like to expand and improve awareness on this congenital disorder as well as the effects it can have on the individual's mental health, aiming to improve the quality of service which is currently provided.

### 3. Do I have to take part?

It is up to you to decide. Please read through this information sheet that describes the study. If you are interested in taking part, then please contact us via email at [isabelle.binnersley@stu.mmu.ac.uk](mailto:isabelle.binnersley@stu.mmu.ac.uk) and we will describe the study and go through the information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time during the consent and interview process, without giving a reason. However, from 14 days after the interview, data will have been analysed all data and your right to withdraw will be revoked as the anonymised data will be a part of the research project.

### 4. What will I be asked to do?

You will be asked to take part in one interview between 30 minutes and an hour, over Zoom (or a similar video conferencing tool) which may be carried at your home or in any private confidential space where you feel comfortable. The interview will be between you and the researcher only. It will be informal and in a semi-structured format, meaning there will be a prepared list of questions that will be asked, along with opportunities for discussion around the topics addressed or any others' you wish to share.

During the interview, you will be asked to talk about your experiences of living with a cleft lip and/or palate, about any communication barriers or difficulties you may have faced as a result of this, and about the impact this has had, if any, on your mental health.

With your permission, an audio recording of the interview will be taken to allow for data analysis and will be deleted as soon as the research project is completed and marked. Recordings will not be shared with anybody outside of the research project and confidentiality of any information participants share during the interview is guaranteed.

You will be asked to complete and return the consent form before organising and taking part in the interview.

#### **5. Are there any risks if I participate?**

A potential risk participants may face in this research project could be the possibility of triggering emotions associated with mental health. As this topic is one of the main areas of investigation in the research project, it will likely be included in the majority of questions asked throughout the interview.

#### **6. Are there any advantages if I participate?**

There are no direct advantages or rewards for taking part in this research project, but your contribution of data will add to the already existing body of research looking at the improvement of mental health services in the UK, for those suffering from the condition and also those without.

#### **8. What will happen with the data I provide?**

When you agree to participate in this research, we will collect from you personally identifiable information.

The Manchester Metropolitan University ('the University') is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The University is registered with the Information Commissioner's Office (ICO), and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy.

We collect personal data as part of this research (such as name, telephone numbers or age). As a public authority acting in the public interest we rely upon the 'public task' lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

We will not share your personal data collected in this form with any third parties.

If your data is shared this will be under the terms of a Research Collaboration Agreement which defines use, and agrees confidentiality and information security provisions. It is the University's policy to only publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

We will only retain your personal data for as long as is necessary to achieve the research purpose. Once the research is complete, all interview transcripts and recordings will be disposed of along with any participant personal data or information. Participant anonymity will be adhered to throughout the study and participant confidentiality will be preserved – no names or biographical data will be included in the write up of the study and no data or information will be shared with anyone outside of the project.

For further information about use of your personal data and your data protection rights please see the [University's Data Protection Pages](#).

**What will happen to the results of the research study?**

As this research study is a part of my undergraduate degree in Speech and Language Therapy, it will be submitted to Manchester Metropolitan University for marking.

**Who has reviewed this research project?**

This proposal has been reviewed by the research project supervisor, Simone Bol, at MMU, by academic peers, as well as Ethos ethics committee.

**Who do I contact if I have concerns about this study or I wish to complain?**

General questions about the project may be sent to the researcher, Izzy Binnersley, via email at [isabelle.binnersley@stu.mmu.ac.uk](mailto:isabelle.binnersley@stu.mmu.ac.uk).

The research project supervisor, Simone Bol, may be contacted via email at [s.bol@mmu.ac.uk](mailto:s.bol@mmu.ac.uk), by calling 0161 247 2772 or writing in to: Simone Bol, Senior Lecturer, Faculty of Health, Psychology and Social Care, Birley Campus, 53 Bonsall Street, Manchester, M15 6GX.

(Please note that during the coronavirus pandemic, post boxes are not monitored regularly.)

Faculty ethics: Health, Psychology and Social care may be contacted for concerns/complaints about the project via email at [HPSCEthics@mmu.ac.uk](mailto:HPSCEthics@mmu.ac.uk).

If you have concerns/complaints about the project, please contact the Professor Khatidja Chantler: [K.Chantler@mmu.ac.uk](mailto:K.Chantler@mmu.ac.uk). phone: 0044 161 247 1316, Brooks Building, Manchester Metropolitan University, Manchester, M15 6GX UK

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the [legal@mmu.ac.uk](mailto:legal@mmu.ac.uk) e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: <https://ico.org.uk/global/contact-us/>

**THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT**