

## PARTICIPANT INFORMATION SHEET

### **'Parents' experiences of decision-making about orthognathic surgery'**

My name is Jana Safarikova, Trainee Clinical Psychologist at the University of East Anglia. I am carrying out a research study about parents' experiences of decision-making about orthognathic surgery which is conducted as part of my Doctorate in Clinical Psychology course.

Please take time to read through this information sheet. You can ask me for clarification if anything is not clear or if you would like further details.

#### **Why me?**

You are being invited to take part in this study because you are a parent of a young person who was born with cleft lip and/or palate. By taking part in the study, you could help us improve and shape NHS services to deliver the best support for children, young adults and their families.

#### **What is the study about?**

We understand that orthognathic surgery is offered to young people during a transition time when they are expected to be the main decision-makers. It is therefore a significant time for them and consequently for many parents. A recent study addressed the experiences of young people making a decision about this elective surgery but there is limited knowledge about the experiences of parents during the decision-making process. We would like to interview 8-10 parents to share their experiences with us.

#### **Who can take part?**

- Parents of young people who have made a decision about whether or not to undergo orthognathic surgery.
- If the decision is 'yes', the young person is on the treatment pathway to undergo the surgery. It is expected that this decision has been made in the last five years.
- If the decision is 'no', then this decision was made in the last five years as well.

#### **Do I have to take part?**

No, you do not have to take part. Taking part in this research is voluntary, it is up to you whether you want to take part or not. If you decide against taking part, this will in no way affect the care provided to the young person in your family. It is an opportunity for you to share your experiences.

### **What would taking part in this study involve?**

If you are interested in taking part, you should contact me (Jana) using the contact details provided at the end of this information sheet. Once you make contact, I will answer any questions you might have about the study, check that you are eligible to take part and we will arrange our interview via Skype or a similar online platform.

We will start our interview by going through the study details to ensure that you are well informed and agree to take part. We will then read through a consent form to confirm your agreeing to taking part and I will audio record your consent. This might take up to 15 minutes.

During our interview I will start by asking you some basic information about yourself, what type of cleft the young person in your family was born with and how many surgeries they have had (approx. 10 minutes). I will not need to know the gender or name of your child but you can share it with me if you wish. We will then focus on your experience of the decision-making process, how involved you were, what it was like for you and how the decision was reached. The interview is expected to last approximately 45-60 minutes and it will be video and audio recorded. The video recording will be deleted once the audio is confirmed as of satisfactory quality.

### **What will happen to the information I provide?**

Your interview will be transcribed and anonymised so you cannot be identified. Your interview and other parents' interviews will be considered in detail in order to try and understand what the experience of the decision-making process has been like. With your consent I would like to share my findings from the study with other professionals and researchers by publishing the findings, so they and future patients can benefit from your expertise. The Cleft Lip and Palate Service in the NHS will use the information to develop their service and this part of the pathway in particular. If you are interested, you will be able to receive a summary of the anonymised findings.

Following the Data Protection Policy in accordance with GDPR the information you provide (including your non-identifiable data) will be stored securely for 10 years in an encrypted file on a password-protected computer at the University of East Anglia.

The University has a dedicated Data Protection Officer: Ellen Paterson, The Library, University of East Anglia, Norwich Research Park, Norwich NR4 7TJ, [dataprotection@uea.ac.uk](mailto:dataprotection@uea.ac.uk), 01603 592431.

### **What are the benefits of taking part?**

By taking part you will be helping us to understand more about your experiences and you may be able to help other people going through the same process in the future.

### **What are the possible disadvantages and risks of taking part?**

As mentioned above, you will need to offer your time to conduct the study, which might be around 60-80 minutes in total.

Although I hope you will find the interview straightforward, there is a small chance that it might cause you upset as it will address your personal experiences. Ethics committees have to review all planned studies before they can start. The purpose is to protect people taking part by ensuring they do not come to any harm and the studies conducted have value to science and society. This research study has received the required approvals: Health Research Authority (HRA) approval and favourable opinion from West of Scotland REC 5. [REC reference: 20/WS/0034; IRAS project ID: 266133]

### **Can I change my mind?**

Yes, you can change your mind whether you would like to take part in the study. This can be prior to our interview, during our interview or up to a week later. However, after this time the analysis will start and it will *not* be possible to withdraw your data. Hopefully, this approach will offer you enough opportunities to consider your participation and allow you to withdraw in time if you change your mind.

### **Reimbursement**

As a 'thank you' for giving up your time to take part you will receive a £10 voucher.

### **Confidentiality and anonymity**

All information you provide during the interview will be for this research purposes only. However, if you share something in your interview about harming yourself or others, this will need to be shared with CLAPA (or the Police) to ensure that you and others are safe. This would be discussed with you first.

As I will be using your data in the analysis and might use some quotes, full confidentiality of what you share with me cannot be guaranteed. However, all information that identifies you will be changed and therefore your anonymity won't be broken. A pseudonym of your choice will be used to protect your and your child's identity in any data or quotes used in publications.

The University of East Anglia (UEA) is the sponsor for this study based in the United Kingdom. It will be using information from you in order to undertake this study and will act as the data controller for this study. This means that UEA is responsible for looking after your information and using it properly. UEA will keep identifiable information about you for no longer than it is required after the study has finished, e.g. to share a summary of findings with you if you are interested in seeing them.

You can find out more about how we use your information at <https://portal.uea.ac.uk/information-services/strategy-planning-and-compliance/regulations-and-policies/information-regulations-and-policies/data-protection>.

### **General Data Protection Regulation (GDPR) transparency**

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

We will make sure no-one can work out who you are from the reports we write.

### **Interested?**

If you are interested and would like to be interviewed to share your experiences, please contact me and we can arrange a date and time for your interview. Please ask me any questions you may have about participating in this research.

**Complaints**

If you wish to make a complaint about any aspect of this research, please contact Professor Niall Broomfield, Programme Director, Doctorate in Clinical Psychology (n.broomfield@uea.ac.uk).

**How to contact us**

If you have any queries or would like further information, here are the best contact details to get in touch:

Jana Safarikova, Trainee Clinical Psychologist  
j.safarikova@uea.ac.uk  
07434 623207

Dr Paul Fisher  
Registered Clinical Psychologist, Senior Clinical Lecturer in Clinical Psychology at UEA, Supervisor of this research study  
p.fisher@uea.ac.uk

*Thank you for taking time to read through the information and for considering taking part in the research study.*