

## **Exploring experiences of dental care for children with cleft lip and/or palate – Parent or guardian, and child**

*HARMONY: HeAlthieR sMiles fOr childreN with cleft bY improving tooth decay prevention and management: Qualitative Study*

We are researchers from the Bristol Dental School at the University of Bristol. We would like to invite you and your child to take part in a PhD student research study. This information sheet is to let you understand why the research is being done and what it involves if you decide to join the study. If there is anything that does not make sense, please contact us (contact information on last page).

### **What is the purpose of the study?**

We are inviting you to talk with one of our researchers as a parent of a child with a cleft. We want to learn about what support you got regarding your child's teeth, including how to look after them, and your experiences of seeing the dental team, in a local dental practice and with the Cleft team at the hospital.

## **Why have I been invited?**

You have been invited because you have a child with a cleft and we would like to hear about you and your child's experiences with looking after your teeth and going to the dentist.

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

No. It is up to you and your child whether you would like to take part. Choosing to not take part will have no effect on your dental or medical care, or your legal rights.

## **What will happen to me if I take part and what will I have to do?**

You will join an informal meeting with your child and one of our researchers, where we will have discussions regarding going to the dentist, advice you have received about looking after your teeth and your treatment with the Cleft team. The meeting will be recorded so that the researcher can listen back to the conversation as part of the research process.

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

There will be no direct individual benefits, however your experiences will form part of research aimed at improving

dental care for children with a cleft. A £10 gift voucher will be provided as a thank you gesture.

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

There are no recognised disadvantages to taking part, and by participating in the study, your dental, medical and general healthcare will not be affected.

### **What will happen if I do not want to continue with the study?**

You can withdraw from the meeting at any time. If you want to stop, the meeting will be stopped, and you do not have to provide a reason why. Following the meeting, the recording will be anonymised, at this point your data cannot be deleted, but as it is anonymous there will be no link back to you.

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

The results will be written up and presented at scientific conferences and submitted to be published in academic journals so that we can share what we have learned about dental care for children born with a cleft lip or palate. A summary of the results will be sent to all participants.

## **How will we use information about you?**

We will need to use information from you for this research project.

This information will include your initials, name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

## **What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you agree to take part in this study, your data saved from this study may be used for future research.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information:

- at <http://www.bristol.ac.uk/secretary/data-protection/policy/research-participant-fair-processing-notice/>
- by asking one of the research team
- by sending an email to [data-protection@bristol.ac.uk](mailto:data-protection@bristol.ac.uk) , or
- by calling the University's Data Protection Officer on (0117) 3941824.

### **Who is organising and funding the research?**

The research is being conducted by Alexander Gormley at the University of Bristol. The research has been funded by the National Institute of Health and Care Research (NIHR).

## **Who has reviewed this study?**

This study is receipt of an NHS ethical opinion (NHS (24/EM/0114)).

## **What if there is something I am not happy with?**

If you have any concerns or worries about this research, please speak to the research leader (Alexander Gormley, details below) who will do his best to answer your questions.

If you have more general concerns regarding the study, its conduct, or your interactions with any of the study team you can contact [research-governance@bristol.ac.uk](mailto:research-governance@bristol.ac.uk)

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