

## toothPASTE - Empowering Families of Young Children with Autism to Establish Good Oral Health Habits

Family Information Sheet Version: 2, Date: 25.01.22

How do you support your autistic child/family member to have good dental health?

What are your experiences of dental health support from professionals (such as going to the dentist)?

How can we best support you and your family to have good dental health?

*We would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it involves. Please take the time to read this information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.*

Part 1 tells you the purpose of this study and what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

### Part 1 – to give you an overview of the study

#### Why are we doing this study?

Tooth decay is a major health problem. A quarter of five-year-olds have tooth decay. For autistic children, tooth decay can lead to self-harm, sleeping difficulties and disrupted routines. We know that looking after the teeth can be difficult, and we want to find out how we can help. From this, we can make sure any dental health support given by professionals is what families want and need.

This study is carried out by the University of Leeds, who are collaborating with the University of Sheffield, University of Manchester, University of Plymouth, and Bradford Institute for Health Research. We would like to understand how autistic children and their families are supported with their dental health. We would also like to know what you, as a family, would like to see in a dental support package (intervention). The research focuses on the West Yorkshire area, but we will be inviting parents from other areas.

#### Why have I been asked to take part?

You have been asked because we would like to speak to family members who care for an autistic child (aged five years old or younger). They may be diagnosed with autism, or they are on the assessment pathway. **You may be a parent, grandparent, carer or sibling** (over the age of 18).

### Do I have to take part?

No, not at all. It is your choice. Just say if you don't want to join in. Nobody will mind.

If you do want to take part, you do not have to answer every question. If you change your mind, that's ok as well; you can withdraw up until the start of the focus group, or up to the point of writing up if you are taking part in a one-to-one interview. **Whether you take part in the study or not, it will not change any professional support you are currently receiving.**

### What will happen to me if I take part?

#### 1) *We will ask you to sign a form*

This consent form is to say that you understand the study and what will happen. You will be given your own copy of the consent form to keep, as well as this information sheet. You may also wish to fill out a demographic form. This provides us with details of who we have interviewed. It helps us to include autistic children and families with different experiences and backgrounds.

#### 2) *We will ask you some questions in an interview/focus group*

We will ask you some questions about looking after your child/family member's teeth and what kind of support would be helpful to you. This can be with you alone as an interview or with other parents so you can all have a discussion. We will voice record this conversation so we can accurately write what was said. The interview/focus group will last a maximum of 90 minutes to include time for introductions and any questions you may have.

### Where will the interview/focus group take place?

We can arrange a face to face or a video discussion that is most suitable for you. We can speak to you **online** (Zoom/Microsoft Teams), **face-to-face** (at your home/workplace) or **telephone** (Phone call/WhatsApp).

### How do I let you know I want to take part?

If you would like to speak to us **online or by telephone**, please contact the research team ([a.bhatti@leeds.ac.uk](mailto:a.bhatti@leeds.ac.uk) /07841514915), and we will send you a consent form. We will ask you to sign this form and send it back to us by email: [a.bhatti@leeds.ac.uk](mailto:a.bhatti@leeds.ac.uk) (there are other ways to send your consent form if you cannot do this, please see page 4). Once we have received your signed consent form, we will arrange a time and date for the interview/focus group.

If you would like to talk to us **face-to-face**, please contact the research team ([a.bhatti@leeds.ac.uk](mailto:a.bhatti@leeds.ac.uk) /07841514915) and let us know. We will then arrange a time and date for the interview/focus group and send you a consent form. If we are talking to you face-to-face, we will collect your signed consent form on the day.

### Will the study upset or help me?

No - the study will not change any professional support you already receive. There are no disadvantages in taking part, but we will take up a little bit of your time. **For this, you will receive a £10 Amazon gift voucher.** To claim this gift, we ask that you provide an email address so the gift voucher can be sent to you. Once we have confirmed that you have received this voucher, we will destroy your email address. If we are doing a face-to-face interview, we can give your voucher to you on the day. After the interview, we are happy to answer any dental questions you have. If we do not know the answer, we will try and find out.

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

The results from your interview/focus groups will be combined with our discussions with professionals who care for autistic children. By doing this, we will find out what kind of support families want and how professionals could help deliver it. The results of this study will be presented at scientific conferences and/or in journals and used to guide future research in this area. This will be anonymous, and no real names will be used. If you wish to have a copy of the results for yourself, please let us know by providing your contact details.

***If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.***

## Part 2 - more detail – information you need to know if you still want to take part.

### What if I cannot email you the consent form?

If you cannot email us the consent form, that is not a problem. You can either take a picture of the form, or you can post it to us. If you want to do a face-to-face interview, you can sign the consent form on the day.

#### *Sending a picture of the consent form*

If you would like to send us a picture of the consent form, please let us know, and we can send you the form by post. Please sign the consent form and send this to Amrit on WhatsApp using the number (07841514915). After receiving the picture, we will securely put this on the University of Leeds secure server and delete the photo on the phone.

#### *By post*

If you would like to post the form, please let us know, and we can send you the form with a pre-paid stamp and our address. After we have received your consent form by post, we will destroy your address details.

### Who is doing and funding the research?

Staff at the University of Leeds are collaborating with the University of Sheffield, University of Manchester, University of Plymouth, and Bradford Institute for Health Research. The research is funded by NIHR (National Institute of Health Research).

### What will happen if I don't want to carry on with the study?

You are free to discontinue the study at any time without giving any reasons. Once the focus group has begun, there will not be an opportunity to withdraw your contribution. If you are taking part in a one-to-one interview, you will have the opportunity to withdraw until the data has been written up.

### What if there is a problem?

If you have any concerns about this study or find aspects of the interview upsetting, you should speak to a member of the research team immediately. If you remain unhappy about any part of this project and wish to complain formally, you can contact Dr Peter Day (Tel. +44 (0)113 343 6139 or email: [p.f.day@leeds.ac.uk](mailto:p.f.day@leeds.ac.uk))

### Who has reviewed this study?

This study has been reviewed by the Dental Research Ethics Committee, at the University of Leeds, to protect your safety, rights and dignity.

### Will taking part in this study be kept confidential?

We take confidentiality very seriously, and any information collected about you will be handled strictly with the consent you have given and the 2018 Data Protection Act. Where we need to, your information and study data will be shared with our research collaborators (the University of Sheffield, University of Manchester, University of Plymouth, and Bradford Institute for Health Research). We will take great care to protect your information. Your consent form and demographic form will be kept on the University of Leeds secure server and password protected. We will label these documents using a code number. Conversations will be audio-recorded so that we can write accurately what was said. The recordings will be typed up (transcribed) by a trusted typist who works with the University of Leeds and stored on the University-approved One Drive. In the typed-up file, all names

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will be replaced with a code number so you will not be identifiable. We will have a document that will have the details of the code numbers. This will be password protected and held in a separate, secure folder on the University of Leeds secure server. Any quotes from the interview that are printed in reports will not be traceable back to you.

Personal data (such your email, telephone number, home address etc) will only be securely shared with research collaborators who will take part in the interview. For analysis and report writing, we may share non-identifiable research data (such as the typed-up interviews) with our research collaborators. These research documents will contain no names or other personal identifiers. Our research collaborators, working at different universities, will follow their organisation's policies for safely storing your study data and personal data.

Once we have finished the study, we will keep the voice recordings for *one year* and written transcripts for up to *five years* so we can check the results and write up our academic papers. We hope to finish the study by March 2023. We will write our reports in a way that no one can work out that you took part in the study.

**If you wish to have a copy of the results, please let us know by providing your contact details.**

#### **What happens now?**

If you are interested in taking part or you have any questions, please contact Amrit Bhatti ([a.bhatti@leeds.ac.uk](mailto:a.bhatti@leeds.ac.uk)) / 07841514915 or Jayne Purdy ([j.purdy@leeds.ac.uk](mailto:j.purdy@leeds.ac.uk)).

***Thank you for taking the time to read this information sheet. If you do decide to take part in this study, we very much appreciate your involvement.***