

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

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Parent Information Sheet Version: 2, Date: 25.1.22

*Your child is being invited to take part in our research study. Before you decide whether you would like your child to take part, we'd like you to understand why the research is being done and what it would involve for you and your child. Talk to others about the study if you wish. Please ask us if there is anything that is not clear.*

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, especially those with little or no verbal communication, tooth decay can lead to self-harm, sleeping difficulties and disrupted routines. We know that looking after autistic children's teeth can be difficult. We want to find out how we can help.

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 the Bradford Institute for Health Research. We want to know how children look after their teeth, what they like and dislike about toothbrushing. We also will ask about what foods and drinks they like and dislike. This will provide us with a better idea of what support autistic children and families want and need. We can use these findings to work with professionals in how they can provide this support.

#### Why has my child been asked to take part?

Your child is being invited to take part in an interview because they have been diagnosed with autism or waiting for an autism assessment. Your child is also aged between 5-14 years old. We would like to speak to them about what they would like help with, and what works for them. Your child can be verbal or non-verbal. If they are able, we will ask your child to write their name to take part to say they are happy to speak to us. Whether they are able or not, we will monitor if your child still wants to speak to us through their words, emotions, or behaviour. If it is clear that your child does not want to take part, the conversation will be ended.

### Does my child have to take part?

No. It is up to you and your child to decide take part in this study. This information sheet explains the study to you. We are happy to answer any questions you have. You are free to withdraw at any time, without giving a reason, up until the point we write up the conversation. Taking part in this research will not affect any professional support you or your child receives.

### What will happen to my child if they take part?

#### *1) We will ask you and your child (where appropriate) to sign a form*

This form records that you and your child want to take part and you understand what is involved. You will be given your own copy of the form to keep, as well as this sheet. The research team will then arrange a time and date for the interview. 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 your child some questions*

We will ask your child some questions about toothbrushing and what they like and dislike. We will ask similar questions about eating and drinking. We will voice record the conversation so that we accurately capture what they say and do. We will use “Talking Mats” within our interview to help us with this. We will take photographs of the Mat for our records as well. If you want to know more about “Talking Mats” and what this involves, please see page 4. If this is not appropriate, please do let us know and we will try our best to work around your child’s communication preference (such as Makaton or Picture Exchange Communication System – PECS). **The discussion will last a maximum of 90 minutes to include time for introductions and any questions you or your child may have.**

### Where will the interview take place?

We would like the interviews will take place at your home. We will work around you and your child with where in your home it would be best to take place.

### Will the study upset or help me or my child?

No – the study will not change any professional support you already receive. We hope that the information from this study will help families and autistic children look after their teeth. There are no disadvantages in taking part, but it will take up some of your time. **For this, your child will receive a £10 Amazon voucher.** You will receive this voucher even if we stop the interview early. 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 with the results of the study?

The results from the interview 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 provide it. The results of this study will guide future research in this area. We will present the findings at academic conferences and write up a report for publication. This will be anonymous, and no names will be used. If you wish to have a copy of the results, please let us know by providing your contact details.

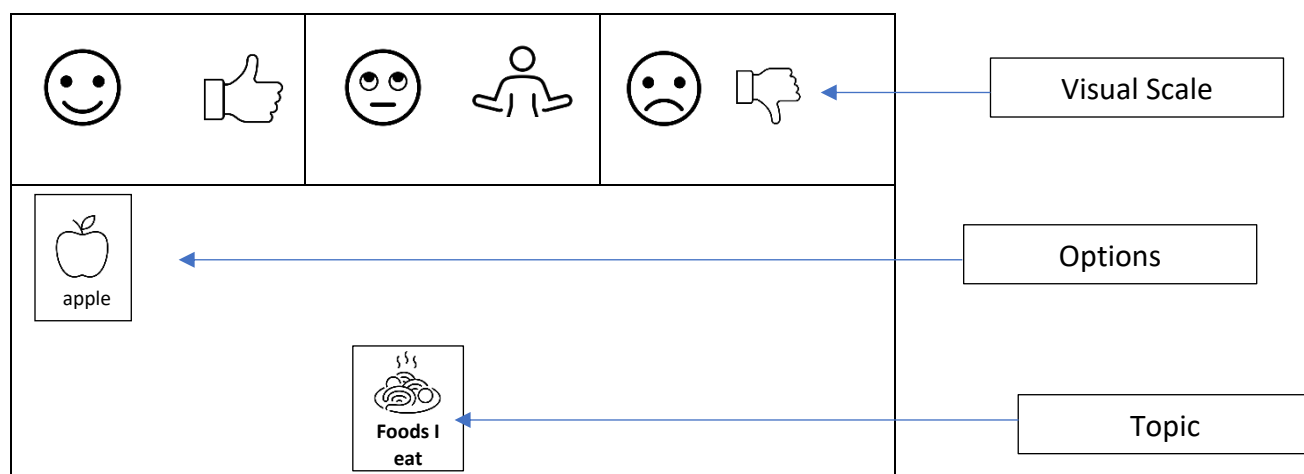
***If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.***

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

### What are “Talking Mats”?

“Talking Mats” are a set of picture symbol cards to help communication. We know that people with Autistic Spectrum Disorder (ASD) can find “Talking Mats” helpful because they allow processing time and communication without speech and can help to express feelings. “Talking Mats” involves three sets of picture symbols: Topic, Options and Visual scale.

The Visual Scale is placed across the top of the mat. This will have symbols which have meaning to your child such as like/not like or happy/not happy. There will also be a mid-point symbol (not sure), if the mid-point is difficult, we will use a two point scale only.



\*THIS DIAGRAM ABOVE MAY BE REPLACED WITH A PHOTO OF THE TALKING MATS USED\*

We will place this mat in front of your child. We will then place the "topic" card at the bottom, such as “food I eat” and hand your child an "option" card (such as an apple) and ask “how do you feel about eating...”. Your child will place the "option" card within the three-/two-point rating scale according to their response (like/not sure/don't like). This will then be taken off the mat and placed onto a separate record mat. We will do this until each “option” has been placed. After this is done, we will ask if they would like to add anything further or if they would like to change their mind on the positionings on the record mat. When we finish with all the cards, we will confirm the mat with your child by going over their “options”. This will provide an opportunity for your child to think about their responses and change their mind if they want. We will then take a photograph of the record mat for our notes and move on to the next topic. Your child can have a copy of these photographs if they wish.

### 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 the 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 and your child are free to discontinue the study at any time without giving any reasons, up until the data is analysed. This would not affect any support you or your child receives.

### 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 within the consent you have given and the 2018 Data Protection Act. Where we need to, your child's information and study data will be shared with our research collaborators (University of Sheffield, University of Manchester, University of Plymouth and the Bradford Institute for Health Research). We will take great care to protect your information. Your consent form, your child's consent form (if taken) and demographic form will be kept on the University of Leeds secure server and will be password-protected. We will label these documents using a code number. Conversations will be audio-recorded, and we will take a picture of the "Talking Mat" 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 will be replaced with a code number so your child will not be identifiable. We will have a document which will have the details of the code numbers. This will be password protected and held in a separate 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 or your child.

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 and photographs of the "Talking Mats") 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 and photographs 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 your child took part in the study.

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

If you are interested for your child to take part in this study or if 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 reading this sheet.***