

## **Kids in Control**

### **Information Sheet for Parents and Carers**

**Chief Investigator: Professor Carsten Flohr**

We would like to invite you to take part in our research study which is funded by the UK Dermatology Clinical Trials Network and led by a team at St John's Institute of Dermatology. This leaflet explains why the research is being done and what it would involve for you and your child.

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

The aim of the study is to develop online support material to help reduce scratching in children with eczema.

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

You have been invited to take part in this study because your child has eczema and you and/or your child have read information via The National Eczema Association or Eczema Outreach Support. We would like to talk to children with eczema of all severities aged 8 - 12 years, who feel that scratching is a problem for them and their parents/carers to get their feedback on our online material. This will help us improve it and make it ideal for this age group. Participants will be purposively sampled to ensure a range of genders, age, ethnic backgrounds and eczema severity are included.

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

No, it is up to you whether you and your child take part and this information sheet can help you decide. Please contact us if you have any questions about the study – contact details are below.

Your child's doctor will not know if you take part or not and your child's care will not be affected. If you decide to take part we will ask you to sign a consent form and your child to sign an assent form online and we will email you a copy to keep.

#### **Incentives**

If you and your child decide to take part and are invited to do an online interview or focus group we would like to give your child a £10 e-gift voucher to say thank you.

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

You and your child will be invited to do an online think-aloud interview. This will involve talking to a researcher via video-call where your child will be shown webpages about eczema, itching and scratching and asked to say all their thoughts out loud. They will also be asked their general thoughts about the information and their experiences of itching and scratching their skin.

Your child may also be invited to take part in a virtual focus group with 2 - 5 other children and their parents or carers. In this focus group you will be shown further information and have a chance to try some of the methods together with other children and will be able to give your feedback.

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

There are no risks to you and your child taking part in this study

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

You and your child may find the online material helpful in reducing scratching behaviour and reducing distress caused by itchy skin.

### **Will my taking part be kept confidential?**

Yes. All information about you and your child will be kept strictly confidential.

Our researcher will be conducting the video interviews online. (at a convenient time to you). Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018).

Your personal information will be shared with the immediate study team. Anonymous information (names and other details removed) will be shared with other researchers including our collaborators at the University of Southampton, or for education.

The video interview and focus group will be recorded, with your consent. This will be shared with a transcription service (with your permission) that will have signed an agreement to ensure confidentiality. Once transcribed all names and identifying information will be removed.

Contact details will be held in a separate secure file on a university computer.

We will ask you if you are happy for us to keep the videos for 3 years, to guide further development of the material, and the anonymised information archived for 7 years to guide future research. In the event that you would prefer the videos are not retained, the interview video will be securely destroyed after transcription is completed.



## **Data Protection Statement**

If you would like more information about how your data will be processed under the terms of UK data protection laws please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

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

We may use quotes with your consent, from interviews and survey in reports but will remove any information that makes it possible to identify you or your child. We can send you a summary of the results at the end of the study if you would like us to.

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

The study is organised by researchers at King's College London, St John's Institute of Dermatology at St Thomas' Hospital and is funded by UK Dermatology Clinical Trials Network.

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

You can withdraw at any time, without giving a reason. You can also request, up to 4 weeks after the interviews or focus groups, that the information you have given is not used in the study and we will no longer retain this. After 4 weeks it will no longer be possible to withdraw your information as it will have been transcribed and anonymised.

In the event that you would prefer the videos are not retained, the individual interview video will be securely destroyed after transcription is completed. Unfortunately, it will not be possible for participants of focus groups to fully withdraw their data as focus group videos will also contain feedback from other participants and hence cannot be destroyed.

## **Who has reviewed the study?**

All research is reviewed by an independent group of people called a Research Ethics Committee. This study has been reviewed and approved by the King's College London Research Ethics Committee.

## **What if there is a problem?**

If you wish to complain, or have any concerns about any aspects of this study, please contact the 'Chair of the BDM REP', E-mail: [rec@kcl.ac.uk](mailto:rec@kcl.ac.uk).



### **What next?**

If you and your child would like to take part, please visit <https://kidsincontrol.org.uk/> to give your details and complete an expression of interest form for the study. A researcher will then get in touch to arrange a time to talk to you and answer any questions you may have.

### **Contact details for further information**

Dr Alpa Kanji, Paediatric & Population-Based Dermatology Research, St John's Institute of Dermatology, St Thomas' Hospital, London SE1 7EH. Email: [KidsinControl@kcl.ac.uk](mailto:KidsinControl@kcl.ac.uk).

**Thank you for reading this information leaflet and for considering taking part in this important research.**