Eczema Monitoring Online

Research Team: Arabella Baker, PhD Student, Centre of Evidence Based Dermatology (CEBD), University of Nottingham (UoN); Professor Kim Thomas, Lead Supervisor and Chief Investigator, CEBD, UoN; Eleanor Mitchell, Co-supervisor and Co-investigator, Nottingham Clinical Trials Unit, UoN.

Study Website: to insert when known. Study Email: eczema@nottingham.ac.uk

Study Title: Eczema Monitoring Online via Questionnaires

PARTICIPANT INFORMATION SHEET (ADULT)

Research Ethics Reference: FMHS 239-0421

Final Version 1.0 Date: 09/04/2021

Thank you for your interest in taking part in this online study. Before agreeing to take part, please take time to read the following information carefully.

Please note "You" refers to adults with eczema and parents/carers of children under 16 years of age with eczema.

What is this study about?

Eczema is an itchy skin condition that affects both children and adults. In eczema research studies, participants often complete questionnaires to tell us about their symptoms and treatment. In this study we would like to evaluate how eczema changes over time by asking participants to complete online questionnaires. This will help to improve how future eczema research is conducted.

Why am I being invited to take part?

You are being invited to take part because you have eczema, or you are the parent or a carer of a child with eczema.

To take part:

- You (or your child) must have been diagnosed with eczema by a health professional (e.g. doctor or nurse)
- You need to be able to and willing to provide informed consent
- You need be able to read and understand written English
- You need to have access to the internet and to an internet-enabled device (e.g. phone, tablet or computer)
- If participating on behalf of a child with eczema, the child should be aged 1-year or older

Do I have to take part?

No. It is up to you to decide if you want to take part in this research study. Even if you do agree to take part, you may withdraw from the study at any time without giving a reason and without any negative consequences, by advising the researchers of this decision via the study email address (above). If you do withdraw, we will keep the research data that you have already provided. This information may be used in the analysis. All data will be reported anonymously.

What will I need to do?

If you choose to take part, you will be asked to complete an online questionnaire during the study. It takes about 10 minutes to complete and you will be in the study for 8 weeks in total. How often you're asked to complete the questionnaire will vary. Some people will be asked to complete the questionnaire every week for a period of 8 weeks, and some people will be asked to complete it at the beginning and end of the study

only. If you are completing the questionnaire on behalf of a child with eczema we would encourage you to discuss the answers with the child.

We will request an email address from you to enable us to send a link to you for the questionnaire. We will also request a mobile phone number from you as we might contact you for the final questionnaire. Upon return of the final questionnaire after 8 weeks, you can choose to be entered into an optional prize draw for a chance to win one of six £20 vouchers as a thank you for taking part. When you have completed the final questionnaire, your participation in this study ends.
Your personal data will be kept confidential and will NOT be shared with third parties.

Are there any risks in taking part?

There are no anticipated risks to your eczema from taking part. You will be able to use your normal eczema treatment throughout this research study.

Are there any benefits in taking part?

There will be no direct benefit to you from taking part, but your participation will help to improve future eczema research. Taking part in this study will allow you to track your eczema symptoms at home, which you may find useful and interesting.

What happens to the data provided?

Once you consent to the study, a unique code/ID will be generated to protect your personal data. All data are kept on password-protected databases sitting on a restricted-access computer system at the University of Nottingham with only the research team having access to the research data. All research data will be kept for a minimum of 7 years after publication of the research. You can find out more about how we use your information and read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx/

Who will have access to your data?

Your data will be used for research purposes only. Under UK Data Protection laws the University is the data controller, which means legally responsible for data security. The Chief Investigator of this study (Prof. Kim Thomas) manages access to the data and responsible for protecting your information and ensuring it is used properly. Responsible members of the University of Nottingham may be given access to data for monitoring and/or auditing of the study to ensure we are complying with guidelines.

What will happen to the results of this study?

The research team will write up the research and publish the results in scientific journals and present at conferences. The research will be also submitted for the doctoral work of Arabella Baker. At the beginning of the study, you will be asked if you'd like to receive a copy of the results. If you agree to this, you will be sent a summary of the results via email. All data will be reported anonymously.

Who has reviewed this study?

This study has been reviewed and given favourable opinion by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (REC ref number: FMHS 239-0421).

What if I have more questions or concerns?

If you have any questions about this project, you may contact the research team.

Email: eczema@nottingham.ac.uk

If you remain unhappy and wish to make a formal complaint, please contact the FMHS Research Ethics Committee Administrator. Email: FMHS-ResearchEthics@nottingham.ac.uk

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PARTICIPANT INFORMATION SHEET (TEENAGER)

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Why am I being invited to take part?

You are being invited to take part because you have eczema.

To take part:

- You must have been diagnosed with eczema by a health professional (e.g. doctor or nurse)
- Your parent or carer needs to be able and willing to provide informed consent for you to take part
- You need be able to read and understand written English
- You need to have access to the internet and to an internet-enabled device (e.g. phone, tablet or computer)

Do I have to take part?

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