

Mind and Skin - the neurocutaneous axis in severe atopy

Focus group, interviews and surveys exploring how atopic eczema affects your life Participant information sheet – for participants 12-15 years

We would like to ask you if you want to take part in a research study
Please read this information leaflet to find out more
Feel free to ask any questions to help you decide if you want to be
involved

Why are we doing this study?

As you know, atopic eczema (or just eczema) is a very itchy skin condition which causes you to scratch and this often disturbs your sleep. We know that poor sleep can affect your brain in different ways, for example causing difficulty concentrating and understanding school work, and can also affect your mood.

We want to see how having eczema affects your life, and your family's life, their jobs, their education and their sleep.

What does taking part involve?

Focus groups are when people come together to discuss a topic. This can happen in person or online. An interview is where you speak to a person from the research team one-on-one and they talk to you about your experiences. A survey is a set of questions asking you about your experiences and you would complete it online.

We are planning focus groups, interviews and surveys for children and young people with eczema, to study how having a skin condition affects your life, your sleep, your friendships, and if there are things in the environment that might make these things more difficult for people with eczema.

All the people attending the focus group will have eczema and be a similar age to you. They might have similar opinions or different opinions and experiences to you – so it is important to listen as well as to speak. The focus group will last around 1 hour. There will be a facilitator present in the focus groups and interviews who will help make sure everyone has a chance to speak. We may use some art and craft tools to help you express your feelings. There will be a private room to use should you wish to discuss any problems with one of the research team.

After the focus group you will be given the opportunity to speak privately with one of the research team. You will also be provided with a phone number or email to contact should you wish to talk to anyone at a later date about any issues discussed in the focus group.

Do I have to take part?

No. You do not have to take part if you do not want to. If you don't want to speak about certain things – no one will force you.

If you become upset or uncomfortable at any point you can choose to not answer the question or to not continue in the focus group, interview or survey.

If you do not take part you will have the same care and treatment.

If you do decide to take part you will need to sign an assent (agreement) form and your parents/carers will sign a consent form.

You can change your mind at any time and withdraw from the study without saying why and this will not affect your treatment.

Anything else?

A researcher will join the focus groups and interviews to make notes. The focus groups and interviews will also be recorded so we can accurately note what was said. The focus groups, interviews and surveys will be analysed by a researcher to help us to write a report to help tell other people how having eczema affects young people.

We will use the focus groups, interviews and surveys to share stories about living with eczema, which could be shared by a few people or unique to you. The results of the focus groups, interviews and surveys will be shared in medical meetings or journals/books, but your name will not be used. We may use some quotations (repeating exactly what you said), but without using your name. If the recordings are online, we would record the video – we would only ever share the video recordings with other members of the research team.