

Supplementary Materials: Final topic guide

Note. This version was used in group of adults with eczema, but this was adopted to refer to “your child’s eczema” in groups with parents

Stage 1: Set up (5 mins)

Informal greetings and indicate when will start

- Introduce self quickly (e.g. Hi I’m Laura and I will be moderating this discussion today.)
- Hi I’m Kim and I will be helping moderate.

You’ll probably get adverts popping up to start with – these should stop after a while so please don’t worry, just ignore them.

I would like to remind you all to respect the other people in the group. The questions we ask will hopefully lead to us all having an open discussion together. There are no right or wrong answers – we are interested in your experience and opinions!

Information you share will not be shared with your doctor or anybody else outside this discussion. The only exception is if we use quotes from you – if we do they will not have you’re your name on them. Please remember that everyone in the discussion is able to see what you are writing, so try and not use confidential information such as your address or date of birth.

The chatroom does not like messages that are too long so if you are going to write more than roughly 100 words please send through the message in stages (I.e. two or three shorter messages). You will receive a pop up telling you if your message was too long. If this does happen just copy and paste parts of your answer into separate, shorter messages to ensure we all receive them.

Is everybody happy to continue?

Wait for responses

If you don’t understand any of the questions as we go along, please do let us know so we can explain a bit more.

Stage 2: Introductions/openings (5-15 mins)

So let’s all introduce ourselves. I’ll make a start.

Hello, my name is Laura and I am a researcher at the Centre of Evidence Based Dermatology at the University of Nottingham. I am interested in your experiences of long-term control of your eczema. In previous groups we have discussed the different words used to describe their long-term control (e.g. flares, bad days, under control) and a whole range of different experiences people have. In the discussion group today we would like to build on what we have learnt so far by using your expertise as patients to focus on two topics in a bit

more depth. We would like discuss how you decide if a treatment is working and how you think we should measure this.

Hello, my name is Kim and I am also a researcher at the Centre of Evidence Based Dermatology at the University of Nottingham.

Now it would be great for everyone else to introduce themselves to the group. You can introduce yourself in as much depth as you feel comfortable with. To start, it would be useful if you could tell us the name you would like to be addressed by and about how your eczema is at the moment.

Now we have all introduced ourselves, let's start our discussion on how you decide if a treatment is working.

Stage 3: Patient experiences (15-60 mins)

How would you decide if a treatment has been working well or not?

(Spend roughly 20-25 minutes on this question)

Possible prompts:

What would trigger you to make changes to your treatment regimen?

If you were having a period where your child's eczema was not well managed, what words would you use to describe this to others?

How would you describe it to your friends, family and colleagues?

What would be the best way to measure if a treatment is working well or not?

(Spend roughly 20-25 minutes on this question)

Possible prompts:

Do you think that a doctor or nurse should measure this or should you measure this?

How often do you think your eczema would need to be measured to fully capture how quickly your eczema changes? Would you say we would need to understand how eczema changes every day, every week or every month?

Why do you think that we need to measure it that often?

Would you be happy to fill out a measure (insert depending on what discussed – e.g. every week, every day)?

Stage 4: Ending (65-70 mins)

We are reaching the end of our discussion now.

Is there anything else you would like to add or any discussions you felt you didn't manage to fully state your opinion on before we end?

Wait for responses

Thank you all so much for taking the time to participate in our discussion. Your opinions are very important in guiding future eczema research. As a mark of our appreciation for you giving up your time today we will send you all a £20 Amazon gift voucher that you will receive via your email in the next few weeks. We will be contacting you via email to send you this gift voucher and provide you with some information in case the discussion today has raised any concerns for you.

(General goodbye)

If you could please close down your browser window now; this will allow you to exit the group.