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"When it goes back to my normal I suppose": online focus groups to explore perceptions of 'control' amongst people with eczema and parents of children with eczema

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Abstract

Objective To inform the development of a core outcome set for eczema by engaging with people with eczema and parents of children with eczema to understand their experiences and understanding of the concept "long-term control".

Design 37 participants took part in a total of 6 semi-structured online focus groups held in a typed chatroom with 5-7 participants per group. Three groups involved adults with eczema and three groups involved parents of children with eczema. Framework analysis was used for data analysis.

Setting A community-based sample was recruited from across the UK via social media and email.

Participants 19 adults aged 17-61 (15/19 female, 16/19 white) and 18 parents of children with eczema aged 9 months-17 years (9/18 female, 18/19 white).

Results Four main themes were identified. 1) "Commonalities and differences in the experiences of long-term control": a reduction in symptoms such as itch and sleep loss characterised eczema control, but what level was acceptable differed across participants. 2) "Eczema control goes beyond the skin": psychological factors, social factors, the constant scratching and the impact on everyday activities are a variety of ways an individual can be impacted. 3) "Stepping up and down of treatment": participants' stepped-up treatment in response to loss of control, but several factors complicated this behaviour. Control needed to be maintained after stepped-up treatment ended to be acceptable. 4) "How to measure long-term control": self-report was generally preferred to allow frequent measurements and to capture unobservable features. Although most thought their eczema needed to be measured frequently, many also felt that this was not always realistic or desirable.

Conclusions Eczema "control" is a complex experience for people with eczema and parents of children with the condition. These experiences could have important implications on how long-term control should be measured in eczema clinical trials and clinical practice.

Strengths and Limitations of this study

- We used qualitative research methods to incorporate perspectives of people with eczema and their parents into discussions informing the development of a core outcome set.
- Explored understandings of the widely used term "eczema control" from the perspective of people with eczema and parents of children with eczema.
- This study used online focus groups, which is a relatively novel methodology that expands on traditional methods for involving patients and parents in the development of outcome measures.

- The online focus groups limited the ability to probe more deeply into participants' experiences compared to face-to-face focus groups.
- The sample mainly included individuals who had attended secondary care for their eczema or their child's eczema so may not represent the views of people living with milder disease who are managed in primary care.

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We have read and understood BMJ policy on declaration of interests and declare that L.H., K.T. and J.C. are members of the Harmonising Outcome Measures in Eczema (HOME) long-term control working group.

Introduction

Eczema is characterised by periods of remission and relapse (1). An international survey of 2002 patients and caregivers found that 75% rated being able to effectively control their eczema as the most important improvement to their quality of life (2). "Long-term control of flares" was included as one of the four domains in the core outcome set for eczema clinical trials by the Harmonising Outcome Measures for Eczema (HOME) initiative (3). There is currently no consensus on how to best capture long-term control of eczema, but it is recognised that it is important to consider the patient perspective in outcome measures in eczema (4).

A systematic review of methods to capture long-term control revealed heterogeneity in how control was captured in published randomised controlled trials (RCTs) (4). Ninety-one percent of RCTs used repeated measurement of eczema outcomes such as clinical signs, quality of life and itch (4). Other ways of measuring long-term control were use of eczema medications (27% of RCTs) and flares (25% of RCTs) (4). This review highlights that measuring “flares” may not be the only method for capturing the long-term control of eczema.

The standardised definition and core outcome measure of long-term control should be driven by patients’ and parents’ experience, as they are best placed to understand whether their disease is being controlled (5). Using qualitative research in the development of a core outcome set can enable meaningful representation of all stakeholders (6). Previous qualitative research has explored the impact of eczema, information needs, attitudes to self-care and views on treatment of parents of children with eczema (7-12). However, very little is known about what people understand by the widely used term eczema ‘control’.

Study objectives

To engage people with eczema and parents of children with eczema to:

(i) determine what long-term control means to them;

(ii) explore what aspects of long-term control are most important to them;

(iii) explore what methods of measuring long-term control are feasible and acceptable.

Methods

This study was approved by the University of Nottingham’s Medical School Research Ethics Committee (F14062016 SoM ROD). All participants provided online consent prior to participation. The protocol is on the Centre of Evidence Based Dermatology’s website (http://www.nottingham.ac.uk/research/groups/cebd/resources/protocol-registration.aspx).

Participant selection

Inclusion criteria were adults aged ≥16 years with self-reported eczema and parents of children with parent-reported eczema. Participants were recruited through the National Eczema Society Facebook page, Twitter posts, and email invitations to people who had consented to being contacted for eczema research and on the University of Nottingham website. Purposive sampling was used to maximise variation in participants relating to characteristics of eczema disease severity, ethnicity, age, sex, previous participation in clinical trials, disease duration and previous experience of healthcare services (13).

Procedure

Six semi-structured, synchronously typed, online focus groups were conducted between August and October 2016. Online methods are becoming increasingly popular in health research due to their ability to reduce costs and the widespread availability of internet access. Predominantly, online typed focus groups have been asynchronous in nature (not occurring in real-time) (14). Whilst asynchronous methods may allow for wider participation, they have been criticized as not being sufficiently responsive to be considered a "focus group" (15). Previous studies using synchronous online focus groups have found that the immediacy and dynamism of face-to-face conversations was mimicked (16, 17).

Participants were allocated to one group only. Groups included either adults (16 years or over) who had eczema, or parents of children with eczema. The recruitment procedure is outlined in Figure 1. Participants joined a group hosted on www.chatstep.com from a location of their choice. Participants entered a nickname of their choice and the room name and password that were provided by email. Between two and four female researchers were present at the discussion to do tasks such as time-keeping, ensuring all participants remained included, responding to technical issues, reading responses and typing responses. L.H. and one other researcher (J.C., K.T. or S.R.) logged into each group to facilitate. All of the research team were introduced simply as “researchers”, although F.C. is a registered nurse and M.S. is a general practitioner. K.T. has had previous experience facilitating online focus groups. Four participants knew some of the researchers prior to the discussions due to involvement in other research activities. L.H. established a relationship with the participants prior to the discussion via email and sometimes telephone contact. Sessions lasted approximately 70-80 minutes.

Focus groups followed a common topic guide (final topic guide in supplementary materials). The questions were revised iteratively based on what was perceived as facilitating engagement and relevant responses during the focus groups (e.g. stopped asking participants to think about going for a check-up as this raised health service issues that were not the subject matter of the study). Questions were framed to elicit everyday experiences of people living with eczema.

The transcript was downloaded after each session. As transcripts were directly typed by participants it was not considered necessary to return transcripts to participants for correction. L.H. made field notes during and after discussions to reflect on her thoughts and feelings relating to the data (18). Participants were sent a debrief email and asked to provide feedback on their experience of taking part shortly after the group. In April 2017 participants were sent a summary of the results and asked for their feedback on the results.

Patient and public involvement

The topic guide was developed with input from two parents of children with eczema and two adults with eczema, three of whom then participated in a group. A ranking activity posted via Twitter and input from the Centre of Evidence Based Dermatology patient panel resulted in the decision to use “long-term management” to describe “long-term control” initially, but the language participants used was subsequently adopted.

Analysis

Framework analysis was used to analyse transcripts (19). Themes were identified at the semantic level and analysis was conducted in an essentialist/realist framework (20). L.H. conducted the analysis, but other team members were involved in refining, interpreting and mapping themes. The thematic framework was driven by familiarisation with the transcripts, however some pre-existing concepts from the literature were considered when developing the framework. Themes were indexed using NVivo 11. The framework was altered to best fit the data. Framework matrices were developed and used for interpreting and mapping the data. Whilst it is acknowledged that different data collection methods may have produced additional data, via the method used no new themes were identified in the final two groups so the researchers were confident data saturation had occurred to the point that additional groups would not have modified the thematic framework (21).

Results

Participant characteristics

Table 1 summarises participant characteristics (N = 37). The majority of participants had been seen in secondary care for their eczema (n = 34/36, 94%). A minority had taken part in clinical trials (n = 4/37, 11%).

Feasibility and acceptability of online focus groups

Out of participants that had provided consent and signed up to a group, the attendance rate was 37/49. 11/37 participants provided feedback on their experience of taking part in the online focus group. Participants liked the convenience of the online method.

> *Preferred online discussion, much more convenient, no need for childcare. (Participant 29, Group 5, parent to son aged 9 months)*

However, some parents were distracted or unable to attend the evening groups (6:30pm – 8:00pm) due to their children's bedtime coinciding with the discussion. One participant commented on this during the discussion:

> *I have a screaming tired 3 year old so let's see if we can do bedtime simultaneously with all her zinc wraps etc ha! Prob not wisest choice of times oops! (Participant 12, Group 2, parent to daughter aged 3)*

Participants liked the group size, privacy, and moderation by the researchers. The method provided anonymity and a non-intimidating platform for all voices to be heard.

> *I thought the discussion group was well moderated and focused, and gave everyone ample opportunities to contribute - and allowed time to think and send responses (Participant 1, Group 1, male aged 33)*

The chatroom indicated when individuals were typing, so the facilitators tried to ensure everyone had responded before advancing discussion. However, typing abilities differed and some said the conversation moved too slowly, whilst others found the conversation pace to be fast.

> *I think the only negative was the conversation became a bit disjointed at times, as it took people time to type. I don't however know how you could address this.. (Participant 28, Group 5, parent to daughter aged 5)*

Main themes on long-term control of eczema

Figure 2 shows how themes 1-3 relate to patient and parent experiences and understanding of eczema "control", which informs how it should be measured (theme 4).

Theme 1: Commonalities and differences in the experiences of long-term control

Normal or out of the ordinary for me

Increased itching, increased redness and less sleep were often cited as indicators of a treatment not working. However, some participants expressed how their symptoms, or their child's symptoms, of uncontrolled eczema have altered over time.

> *I have found some treatments help but he then presents with different types of eczema. Sometimes dry and cracked, other times wet and blistery, some times is spotty and other times is patchy. (Participant 9, Group 2, parent to son aged 7)*

Individuals had different thresholds of acceptable level of control. For some, control was only achieved when there were no symptoms, whilst many viewed control as a reduction in their symptoms to what was "*normal*" for them. For example, one participant described their normal as "*just mild pigmentation marks*". The variation in "normal" for each individual has important implications for measuring long-term control, as alluded to by one participant:

> *Establishing a baseline of what's 'normal' for the person and how this is deviated from – because it is different for everyone! (Participant 2, Group 1, female aged 23)*

Flares vary in size and timing

Variations in the severity of flares were apparent in descriptors of size such as "*small flares*" and "*big flares*". The length of flares also varied both between and within individuals. Some described flares lasting hours, a day or a few days, whilst others described flares that lasted months; described by one participant as a "*chronic flare*".

> *if I catch a minor flare quickly enough I can sometimes control the irritation before it get completely out of control to what I call a meltdown (Participant 5, Group 1, female aged 20)*

The speed of onset of a flare was variable between participants. An individual's experience could also be variable, for example one participant said, "*it can vary from instant to 12* hours" *(Participant 8, Group 2, parent to daughter aged 4)*. Flares were often described as sudden in onset with limited early signs, whilst others described how the build-up could be gradual. Some parents said their child will know before them that a flare is coming, which could indicate that onset appears quicker for some parents as they do not always notice earlier indicators.

The end of a flare was characterised by better sleep, itching gone or not bleeding on their bedsheets. However, a few commented how it was hard to determine the end of a flare as it never fully went away.

> *with the eczema being so severe a flare never truely ends, it just is better (Participant 7, Group 2, parent to son aged 3)*

Theme 2: Eczema control goes beyond the skin

Psychological impact

Periods of uncontrolled eczema were characterised by negative emotions and low mood for adults, children with eczema and parents. Parents used very emotive language to describe how they felt about periods of uncontrolled eczema, but then reported the psychological impact on their child in broad terms of how it affected the child's general demeanour. The level of control was said to result in either a "*happy child*" or a grumpy/distressed child.

> *Total change in mood. She is happier, carefree and is not frowning. She can play more as not scratching all the time. She sleeps and is not grumpy, less*

> *tantrums as rested, able to concentrate and have patience due to sleeping well. (Participant 13, Group 3, parent to daughter aged 3)*

Some groups discussed how flares were accompanied by apprehension due to lack of certainty of how bad the flare would be and how long it would last. A few participants also recalled that even when they were better they were apprehensive of a flare returning.

> *…fear that it will come back after it's got better is always there (Participant 34, Group 6, female age unknown)*

The vicious itch/scratch cycle

Itchiness to the point that it was difficult not to scratch equated to uncontrolled eczema for many participants. Parents experienced this as needing to constantly supervise their child when eczema is uncontrolled to help them stop scratching.

> *I couldn't even go to the toilet as he would be scratching, face weeping, awful (Participant 29, Group 5, parent to son aged 9 months)*

Some participants described scratching as temporary relief, but expressed concern that scratching made their eczema worse, often leading to more itchiness, broken skin and bleeding, described as a "*vicious cycle*" that needed to be broken to regain control.

> *It feels good to itch – a temporary relief! Although you know it is making it worse! (Participant 36, Group 6, female aged 41)*

Affects ability to do activities of daily living

Participants said uncontrolled eczema can impact almost every aspect of their lives. Sleep disturbance had an impact on concentration the next day. Itchiness and needing to scratch also impaired concentration, however it was clear that tiredness exacerbated this problem.

> *I used to go into work on one hour's sleep…and then I'd spend my time staring into space, itching, feeling sorry for myself and unable to snap out of it (Participant 35, Group 6, female aged 25)*

Uncontrolled eczema and the sleep loss it causes affected the child's behaviour as well as their concentration. For example, the child was described as "*grumpy*" and having "*tantrums*".

Another challenge was the time consumed during a flare period because of what they needed to do differently to normal, although some participants suggested the burden was not limited to flare periods as they engaged in activities to prevent flaring that were also very time consuming.

Adults often felt restricted in clothing due to irritation that certain clothes caused, wanting to cover eczema with clothing, visibility of blood on light fabrics and flaky skin on dark fabrics. Some parents altered their child's clothing, which related to irritation rather than concerns about the visibility of the eczema.

> *I guess what you might be doing differently because of your eczema. Like clothes ... covering up eczema, not black because of dry skin, not too light because I might itch and bleed. (Participant 34, Group 6, female age unknown)*

Washing and exercise were problems for many adult patients due to being unable to face the sensations when cracked or dry skin came into contact with water or sweat. Parents expressed concern about their child's ability to learn, play and interact.

Several adults and parents said impairment to movement was one of the biggest problems faced. Eczema around joint areas, feet or hands impaired their ability to move and do things. Movement was often described as painful.

> *Joints are the worst because it can make you feel helpless and immobile (Participant 5, Group 1, aged 20)*

Affects you socially

Some adults with uncontrolled eczema reported "embarrassment" and "social anxiety". One group suggested this effect was increased when the eczema was more visible.

> *Embarrassing? I often tend to avoid eye contact, as I'm embarrassed with what people might see...and think. I've lost count of the times that I've been asked things like "Who beat you up?", "Dud you cut yourself shaving", and "Ugh, is that contagious?" (Participant 18, Group 4, male aged 43)*

The language used by parents to discuss the social impact of uncontrolled eczema on their child was less detailed than the adults. This may be because parents were unaware of the social impact on their child or were unable to articulate it. However, one parent said reactions can be "unkind".

Both adults and parents expressed feelings of isolation due to the lack of shared experience and understanding from others, rather than from direct social exclusion (although this was apparent for one participant). Some parents expressed concern for their and their child's physical isolation due to preventing exacerbations and treating the eczema reducing socialisation opportunities.

> *How they interact, their developmental markers, how much socialisation they get, for us when his skin is bad it's the socialising and getting out of the house that suffers (Participant 27, Group 5, parent of a male child aged 16 months)*

Theme 3: Stepping up and down of treatment

Responding to a loss of control by "stepping-up" treatment

Most participants altered treatment depending on the level of eczema control. Many ways of measuring long-term control relating to treatment changes were mentioned, including number of treatment prescriptions, use of extra treatments, use of higher strength treatments, time spent using treatments, frequency of treatment and amount of treatment used.

Whilst most discussed visiting the doctor to seek treatment if the eczema was not controlled, stepping-up treatment was complicated by various factors. Not all participants visited a healthcare professional to step-up treatment. Many would use stronger creams they had at home or increase the amount used of the treatment they are already prescribed. Participants often wanted to step-up treatment promptly to prevent further exacerbation of the eczema, but a few felt their doctor did not understand this urgency and would sometimes delay or avoid giving certain prescriptions.

On the other hand, some participants were reluctant to change their treatment in response to worsening of the eczema. Some were fearful that if they use the strongest treatment available, they may have nothing left to use if it gets worse. There were beliefs that a treatment would eventually stop working if you used it too much. Some did not change their treatment as they wanted to try non-pharmacological solutions such as exercise, diet and silk sleeping suits for children. However, sometimes these methods were used in combination with pharmacological treatments.

> *With that in mind we have been trying a lot of other things and we have been reducing the creams down as much as possible so they will be at maximum effectiveness for flare ups, It's a scary prospect isn't it - having nothing to use as an alternative! (Participant 25, Group 5, parent of daughter aged 11 months)*

One participant reported not being able to step-up the treatment because their child was on the maximum treatment available.

> *I'd usually resort to the internet desperately surching for more answers or research. [My child] was on max treatment all the time. (Participant 15, Group 3, parent of daughter aged 17)*

Treatment needs to maintain control in the long-term

It was discussed that control has been gained or a flare has come to an end when you could return to maintenance routines and the eczema symptoms remained controlled.

> *I usually think a flare has ended if I've not had to put steroid cream on that day (Participant 1, Group 1, male aged 33)*

Alternatively, if the worsened eczema returned once stepped-up treatment was ended, this was not considered to be long-term control. Some participants described a continuous cycle of stepping-up and down treatment where the eczema did not remain improved when returning to maintenance treatments. However, it was thought some participants were searching for a “cure” rather than “control”.

> *Sometimes we are advised to use steroids for x long... then as soon as stops everything flares up again. Not a long term solution really (Participant 29, Group 5, parent to son aged 9 months)*

Theme 4: How to measure long-term control

Suggested features of long-term control to be measured were diverse. They can be categorised as observable signs or symptoms (e.g. redness), unobservable symptoms (e.g. itch), treatment used (e.g. escalation of treatment), scratching (e.g. number of times scratched) the effects on the individual’s life (e.g. ability to do everyday activities) and the psychosocial impact (e.g. general mood).

It has to be you

Participants unanimously thought measures should include self-report. Measurement by a doctor was suggested to be too infrequent to capture the fluctuations in eczema.

> *Again it depends on each child, but certainly more frequently than the usual 3 months between consultants visits. we can be fine in the morning as horrendous by bedtime (Participant 30, Group 5, parent of male child aged 11)*

Self-report was also preferred because doctors assess the physical aspects of eczema and not how it affects the individual beyond this. The broad array of ways it can affect individuals is illustrated in theme 2.

> *Has to be you. SO subjective a topic, and nurses' doctors can only observe so much - and not the effects it has personally! (Participant 2, Group 1, female aged 23)*

Some participants suggested they need to be able to make comparisons with previous levels of control for self-report to be meaningful. This links to theme 1, where it was discussed how everyone has different experiences of "normal".

> *it's usually 'compared to what', or on a scale of 1-10, where no number has a real meaning (Participant 22, Group 4, female aged 31)*

Other concerns with self-report included forgetting how the eczema has been if measurements are far apart (i.e. looking back over the last month would be difficult) or “kidding” themselves their eczema is better. Some participants suggested a measure should be quantifiable and percentage of body involvement was suggested. Others thought percentage of body affected would not capture the severity of an area affected or if they felt more burdened by eczema on certain body parts.

Photographs of skin were frequently used. This is maybe surprising since participants highlighted the importance of looking beyond the visual effects of eczema, but it was used to show doctors the eczema fluctuations between visits. Another use for photographs and diaries was self-reflection on eczema changes. Numerous participants said reflecting on how the eczema used to be worse helped them cope. A few were concerned photographs may not show the eczema properly.

It was not questioned whether parents can measure their child’s eczema. One participant suggested it depends on whether the child can vocalise themselves or not. Parents generally seemed confident that they had greater insight into their child’s eczema than doctors.

Ideal versus realistic frequency of measurement

Participants varied hugely in how often their eczema or their child’s eczema needed to be measured from “how about 24 hour watch!!!” to every few months. For many participants at least daily, and sometimes multiple times a day, was deemed necessary. This was to capture a full picture of the disease and to detect flares early. However, many felt that the frequency necessary would not be easily achieved for them due to the burden of recording eczema activity. Reasons for this included being too busy, forgetting or not being disciplined enough.

> *but to be honest dont have time when I am a busy workign mother, sometimes it only gets a glance (Participant 4, Group 1, female aged 50)*

Group interactions showed parents wanting to appear willing to help. Therefore, parents were sometimes hesitant to share their reservations with measuring the eczema too frequently, but when prompted with suggestions from previous groups shared this concern.

Whilst a few were prepared to measure controlled eczema, many were prepared to measure at frequent intervals during a flare, but not when eczema was controlled. They did not want to be reminded of the eczema, whereas during a flare they would measure it because they cannot help thinking about it.

> *it's all you think about when it's bad so you'd be prepared to do anything to make it better, like recording its current state, If it was in a bad condition, probably 30 minutes a day but when it's improved I would rather not think about it, so maybe 10 minutes. (Participant 33, Group 6, female aged 17)*

Some suggested frequency should change depending on the stage of treatment. It was thought it would be more necessary to understand fluctuations in periods of uncertainty (e.g. just starting a new treatment, just ending a treatment).

To overcome the problem of the ideal measurement not being realistic, a few suggestions were made that frequency could be flexible to the individual’s needs or measuring tools could be designed so you could skip questions if not needed.

Participant feedback on results

Only 4 participants provided their feedback on the results. All provided general comments that suggested they found the analysis to be accurate and insightful. One participant highlighted again their belief that an assessment of “baseline” and “flaring” should include a holistic appraisal of lifestyle, including mental wellbeing.

Discussion

Main findings

Conducting online focus groups allowed us to explore the experiences and understanding of eczema “control” for a variety of people with eczema and parents of children with eczema across the UK. A loss of eczema control can have varied consequences and impact for an individual and their family. Itching that resulted in scratching, sleep loss, redness, bleeding, impaired psychological wellbeing, feelings of fear and apprehension, impaired daily functioning, social isolation and societal pressures were all prominent features of uncontrolled eczema. The burden of uncontrolled eczema largely reflects findings from previous studies on patient and parent experiences of eczema (7-12). It is well documented that itching and sleep disturbance can impair concentration and have profound effects on patients and parents lives (7-12). Dissatisfaction with treatment that did not control eczema once the treatment was stopped mirrors interviews with parents that found dissatisfaction with the trial and error approach to eczema treatment in primary care (11).

Language used to discuss “long-term control” varies in the literature and it is unclear whether the use of “long-term control of flares” is appropriate. Participants spontaneously used “control” during discussions. They never used “long-term control”, which is likely to be because this is a combination of two concepts; the timeframe and the disease status. Participants frequently used the terms “flare”/”flare-up”. However, what experiences constituted a flare was highly variable. Some people had “chronic” flares lasting for months, whereas some lasted hours or days.

The most common way of measuring long-term control in published RCTs has been repeated measures of clinician-reported signs, usually on a monthly basis (4). Participants talked about how they would measure long-term control as repeated measures of various factors such as quality of life, itch or mood. They preferred self-reported measures due to not all effects being observable by a doctor and frequent measures needed to capture fluctuations in eczema more fully.

Published RCTs have measured flares using number of flares, time to first flare and, to a lesser extent, duration of a flare or remission period (4). The size and length of flares could differ substantially and have varying effects on the individual, which highlights how measures only capturing frequency or length of flares would not capture the impact each flare has on an individual.

Treatment escalation has been used to measure flares and long-term control. Two studies have defined a flare as being: “an episode requiring escalation of treatment or seeking additional medical advice” (22, 23). This measure had good face validity and construct validity (24). However, concerns around resource intensive data management and difficulties pooling data may mean this measure is not suitable for all trials (24). A similar definition has been proposed by the European Task Force on Atopic Dermatitis: “acute, clinically significant worsening of signs and symptoms of atopic dermatitis requiring therapeutic intervention” (25). Another concept of long-term control that has been adopted from asthma research is the concept of well-controlled weeks. A well-controlled week has been defined as occurring when treatment "escalated" for 2 days or fewer plus 2 or more days with a severity score of less than 4 out of 10. Whilst well-controlled weeks have been shown to be valid and reliable, collection requires frequent completion of diaries which may not be suitable for use in all trials (26).

Whilst participants did escalate treatment in response to a flare, there were a number of complexities that could make this difficult to implement as a measure in all trials. The Necessity-Concern Framework suggests patients hold beliefs about how necessary a treatment is to maintain their health and concerns about the treatment having adverse effects, both of which can influence treatment adherence (27). Beliefs expressed by some participants in this study suggest they are concerned about their medication as they were reluctant to step-up treatment. Therefore, lack of treatment adherence may present a problem for using treatment as an indicator of eczema “control”. Alongside changes to treatment, a behavioural response to loss of control many participants cited and suggested measuring was increased scratching, which is one method that has been considered as a way of measuring long-term control (28, 29).

Strengths and limitations

To our knowledge, this is the first qualitative study to consider long-term control of eczema from a patient and parent perspective. The online focus groups reduced barriers of geographical location and time constraints and removed costs for travel, venue and transcription. Previously, online focus groups have been cited as enabling participation by people with visible skin conditions who lack the confidence to attend a face-to-face focus group (4, 7). This is supported by feedback from participants that they liked the anonymous and inclusive nature of the group.

There was a predominance of people of White British ethnicity and of female adults with eczema, despite targeted efforts to recruit male and ethnic minority participants. Only two participants reported never having seen a hospital doctor for their eczema, therefore the sample under-represents experiences for participants treated in primary care, which is the majority of eczema patients in the UK (30).

Online methods present distinct challenges for qualitative research. Language needs to be clear as there is no voice intonation or non-verbal cues. Prior preparation of questions allowed precision in phrasing. Participants valued that typing allowed them to provide considered answers. Threading, where multiple strands of conversation occur in parallel, is typical of online focus groups (16, 17, 31). Addressing an individual's comment whilst simultaneously inviting the whole group to comment on that specific point maintained coherent discussion whilst allowing further exploration a topic.

Qualitative research has the potential to develop both breadth and depth of knowledge (6). Breadth is required to understand the scope of the experience and depth enables understanding the detailed complexities of the experience (6). The method tended to produce brief responses, but prompting was successful at eliciting more detailed responses. Reading responses was difficult when the discussion moved quickly, so having multiple researchers available to engage in different tasks was beneficial.

This study was concerned with individual experiences, whereas RCTs are analysed as group aggregates of outcomes. Future studies need to assess the optimum frequency of measuring outcomes in RCTs. This study highlights that the benefit gained by capturing intra-patient variation needs to be balanced against the burden of collecting this information.

Implications for research and clinical practice

This study investigates an aspect of eczema that has been under-researched from the patient and parent perspective. Box 1 highlights the important ways this study may inform decisions on the best way to measure long-term control in people with eczema. These findings will inform consensus discussions for development of a core outcome set for eczema clinical trials through the HOME initiative (www.homeforeczema.org).

This study is the first stage of an international qualitative research project that will examine cross-cultural variations in how patients view long-term control of eczema in different countries. The methodology is globally accessible and facilitates composite analysis to identify differences across countries. Since online focus groups are a relatively novel method, the lessons learnt from this study will provide guidance for international collaborators.

Conclusions

This qualitative study has shown the complexity of the experience of long-term control for patients and parents. "Eczema control" can have a variety of meanings for people with eczema and their parents, which has important implications for how long-term control may be measured. Overall, this pragmatic online research method was embraced by participants and enabled qualitative research to be conducted effectively with limited resources.

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Contributorship statement: L.H, K.T., J.C. and S.R contributed to the conception of the study. L.H., K.T., J.C, S.R., F.C. and M.S contributed to the design of the work. L.H., K.T., J.C., S.R. and FC. Were involved in data collection. L.H., F.C. M.S. were primarily involved in the analysis process but K.T., J.C. and S.R. were involved in interpretation of data. L.H drafted the work and K.T., J.C., S.R., F.C. and M.S. revised it critically for important intellectual content. All authors gave approval for the final version to be published.

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Data sharing statement: Data sharing requests can be made to the corresponding author.

Figure 1 Recruitment Procedure

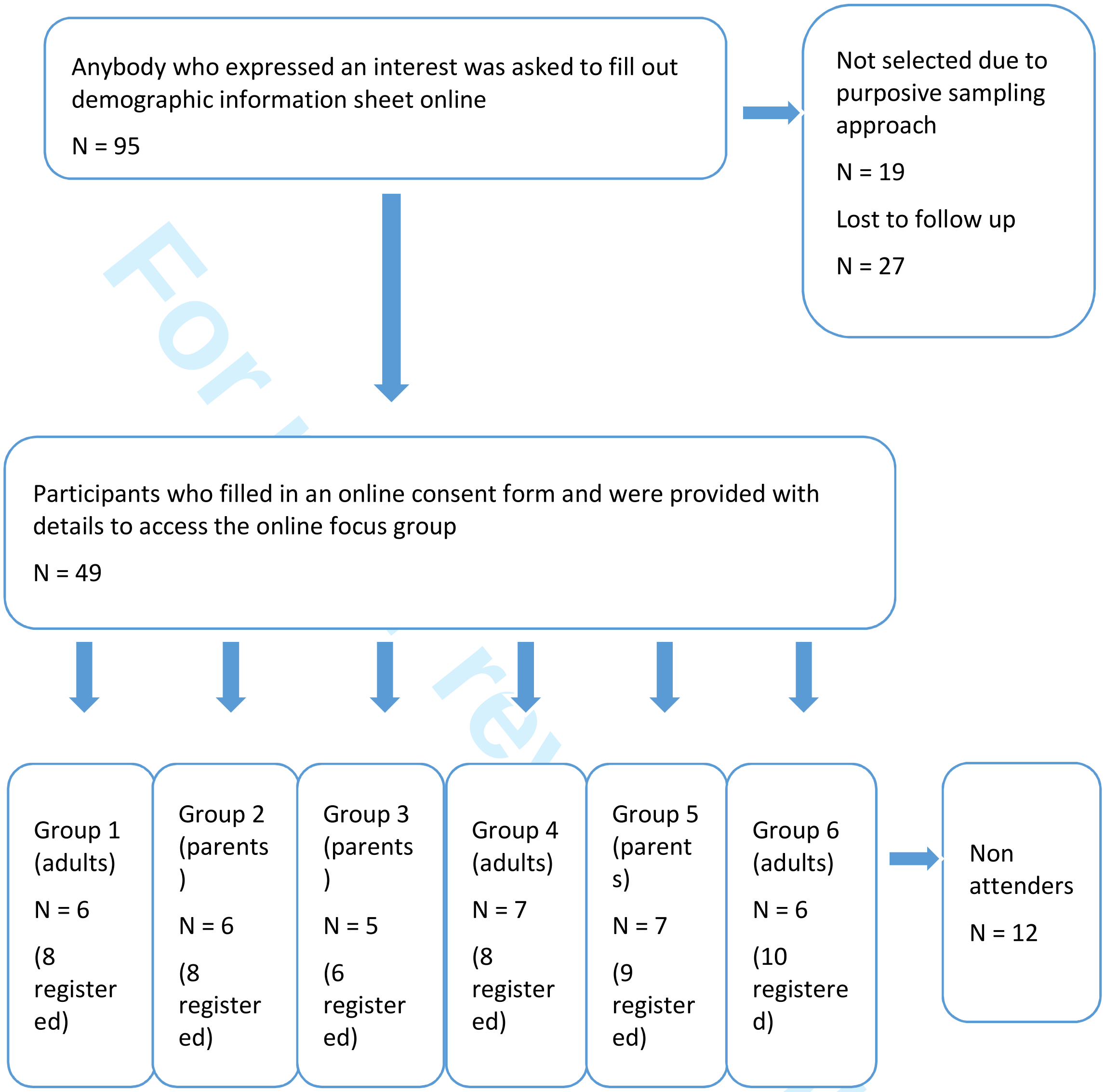
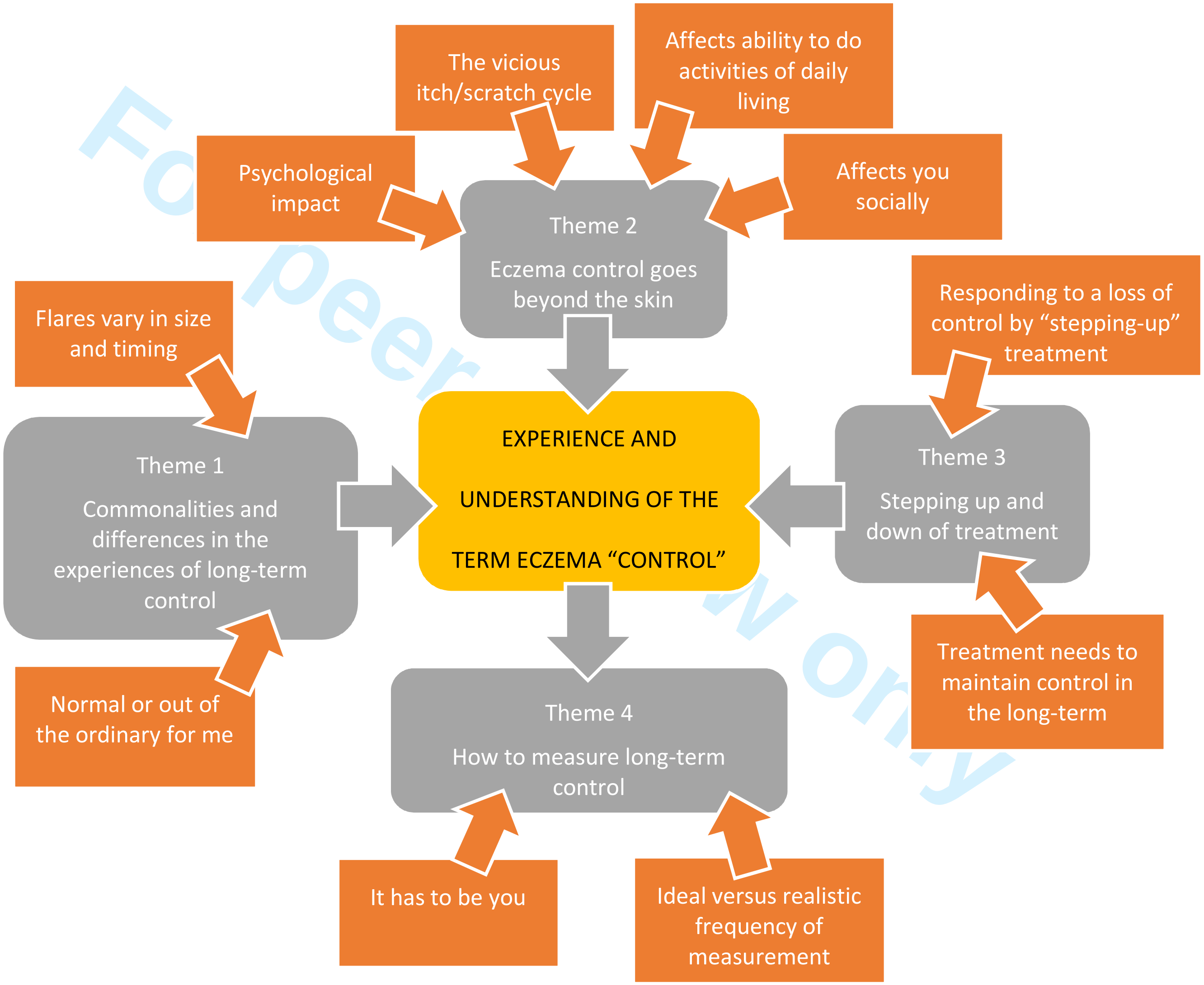


Table 1 Summary of participant and child demographics

	Adults with eczema	Parents of children with eczema	Children with eczema (reported by parents who participated)
N of participants	19	18	-
Sex, n (%)			
Male	4 (21)	-	9 (50)
Female	15 (79)	18 (100)	9 (50)
Age in years, n (%)			
≤5	-	-	12 (67)
6-11	-	-	5 (27)
12-15	-	-	-
16-25	6 (31.67)	1 (6)	1 (6)
26-40	6 (31.67)	15 (83)	-
>40	6 (31.67)	2 (11)	-
unknown	1 (5)	-	-
Ethnicity, n (%)			
White	16 (84)	-	17 (94)
Asian	1 (5)	-	-
Black	-	-	-
Mixed	2 (11)	-	1 (6)
Years since eczema diagnosis			
≤5	1 (5)	-	12 (66)
6-11	2 (11)	-	4 (22)
12-15	-	-	-
16-25	5 (26.34)	-	1 (6)
26-40	5 (26.34)	-	-
>40	5 (26.34)	-	-
unknown	1 (5)	-	1 (6)
Self or parent reported current disease severity, n (%)			
clear	2 (11)	-	-
Almost clear	2 (11)	-	2 (11)
Mild	4 (21)	-	4 (22)
Moderate	9 (47)	-	7 (40)
Severe	1 (5)	-	5 (27)
Very severe	1 (5)	-	-

Figure 2: Mapping of the thematic framework



Box 1 Seven key findings that should be used to inform the measurement of long-term control

From these findings, we recommend the following seven topics be considered when deciding how to measure long-term control of eczema:

1. The need to scratch uncontrollably, the psychological impact, the social impact, symptoms (including itch, pain, sleep), impaired movement, the ability to do everyday activities and treatment used were all indicators of level of control.
2. Understanding the baseline of what is normal for an individual was considered important for understanding long-term control.
3. Not everyone with eczema experiences “flares” or finds it easy to notice changes in their eczema.
4. The behaviour of stepping up treatment for a flare was common, but was complicated by factors such as difficulty getting a prescription and concerns about stepping-up treatment when already using maximum treatment available.
5. For some participants taking treatments that are recommended for short term use, lack of control referred to “rebounds” after the treatment ends. Long-term control measurement should take into account control both during and after treatment.
6. The patient/parent perspective was considered important to fully capture long-term control. The use of parents as a proxy for patient reporting in young children was not questioned by parents.
7. The acceptance of measurement frequency varied between participants and for an individual over time depending on lifestyle and commitments, the treatment stage and level of disease control.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	5
Occupation	3	What was their occupation at the time of the study?	5
Gender	4	Was the researcher male or female?	5
Experience and training	5	What experience or training did the researcher have?	5
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	5-6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5-6
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	3
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5
Sample size	12	How many participants were in the study?	7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	28
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	n/a
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	29
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	5
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	6
Data saturation	22	Was data saturation discussed?	7
Transcripts returned	23	Were transcripts returned to participants for comment and/or	6

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	30
Derivation of themes	26	Were themes identified in advance or derived from the data?	7
Software	27	What software, if applicable, was used to manage the data?	7
Participant checking	28	Did participants provide feedback on the findings?	6
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	7-20
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-20
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-20, 30
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7-20

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

"When it goes back to my normal I suppose": a qualitative study using online focus groups to explore perceptions of 'control' amongst people with eczema and parents of children with eczema in the UK

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“When it goes back to my normal I suppose”: a qualitative study using online focus groups to explore perceptions of ‘control’ amongst people with eczema and parents of children with eczema in the UK

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Abstract

Objective To inform the development of a core outcome set for eczema by engaging with people with eczema and parents of children with eczema to understand their experiences and understanding of the concept “eczema control”.

Design 37 participants took part in a total of 6 semi-structured online focus groups held in a typed chatroom with 5-7 participants per group. Three groups involved adults with eczema and three groups involved parents of children with eczema. Framework analysis was used for data analysis.

Setting A community-based sample was recruited from across the UK via social media and email.

Participants 19 adults aged 17-61 (15/19 female, 16/19 white) and 18 parents of children with eczema aged 9 months-17 years (9/18 female, 18/19 white).

Results Four main themes were identified. 1) “Commonalities and differences in the experiences of control”: a reduction in symptoms such as itch and sleep loss characterised eczema control, but what level was acceptable differed across participants. 2) “Eczema control goes beyond the skin”:

psychological factors, social factors, the constant scratching and the impact on everyday activities are a variety of ways an individual can be impacted. 3) "Stepping up and down of treatment": participants' stepped-up treatment in response to loss of control, but several factors complicated this behaviour. Control needed to be maintained after stepped-up treatment ended to be acceptable. 4) "How to measure control": self-report was generally preferred to allow frequent measurements and to capture unobservable features. Although most thought their eczema needed to be measured frequently, many also felt that this was not always realistic or desirable.

Conclusions Eczema "control" is a complex experience for people with eczema and parents of children with the condition. These experiences could have important implications on how long-term control should be measured in eczema clinical trials and clinical practice.

Strengths and Limitations of this study

- We used qualitative research methods to incorporate perspectives of people with eczema and parents of children with eczema into discussions informing the development of a core outcome set.
- Explored understandings of the widely used term "eczema control" from the perspective of people with eczema and parents of children with eczema.
- This study used online focus groups, which is a relatively novel methodology that expands on traditional methods for involving patients and parents in the development of outcome measures.
- The online focus groups limited the ability to probe more deeply into participants' experiences compared to face-to-face focus groups.
- The sample mainly included individuals who had attended secondary care for their eczema or their child's eczema so may not represent the views of people living with milder disease who are managed in primary care.

This work was supported by the British Skin Foundation [ref: 8016].

We have read and understood BMJ policy on declaration of interests and declare that L.H., K.T. and J.C. are members of the Harmonising Outcome Measures in Eczema (HOME) long-term control working group.

Introduction

Eczema is characterised by periods of remission and relapse (1). An international survey of 2002 patients and caregivers found that 75% rated being able to effectively control their eczema as the most important improvement to their quality of life (2). “Long-term control” has been voted as one of the four domains in the core outcome set for eczema clinical trials by the Harmonising Outcome Measures for Eczema (HOME) initiative (3). There is currently no consensus on what is meant by “long-term control” of eczema, but it is recognised that it is important to consider the patient perspective in outcome measures in eczema (4). Therefore, this study explores the patient perspective of “long-term control” and adopts the language used by patients to discuss this concept, which were most commonly “control” and “flares”.

A systematic review of methods to capture long-term control revealed heterogeneity in how control was captured in published randomised controlled trials (RCTs) (4). Ninety-one percent of RCTs used repeated measurement of eczema outcomes such as clinical signs, quality of life and itch (4). Other ways of measuring long-term control focused on assessment of use of eczema medications (27% of RCTs) and flares (25% of RCTs) (4). The review highlighted that measuring “flares” may not be the only method for capturing the long-term control of eczema.

The standardised definition and core outcome measure of long-term control should be driven by patients’ and parents’ experience, as they are best placed to understand whether their disease is being controlled (5). Using qualitative research in the development of a core outcome set can enable meaningful representation of all stakeholders (6). Previous qualitative research has explored the impact of eczema, information needs, attitudes to self-care and views on treatment of parents of children with eczema (7-12). However, very little is known about what people understand by the widely used term eczema ‘control’, hence a post meeting questionnaire of the HOME IV delegates indicated that qualitative work to establish what long-term control means to patients was set as an important research priority for the long-term control working group (13).

Study objectives

To engage people with eczema and parents of children with eczema to:

(i) determine what long-term control means to them;

(ii) explore what aspects of long-term control are most important to them;

(iii) explore what methods of measuring long-term control are feasible and acceptable.

Methods

This study was approved by the University of Nottingham’s Medical School Research Ethics Committee (F14062016 SoM ROD). All participants provided online consent prior to participation. The protocol is on the Centre of Evidence Based Dermatology’s website (http://www.nottingham.ac.uk/research/groups/cebd/resources/protocol-registration.aspx).

Participant selection

Inclusion criteria were adults aged ≥16 years with self-reported eczema and parents of children with parent-reported eczema. Participants were recruited through the National Eczema Society Facebook page, Twitter posts, and email invitations to people who had consented to being contacted for eczema research and on the University of Nottingham website. All those who expressed an interest in the study were sent an online survey. Based on the survey responses, purposive sampling was used to maximise variation in participants relating to characteristics of self-reported eczema severity, ethnicity, age, sex, previous participation in clinical trials, disease duration and previous experience of healthcare services (14).

Procedure

Six semi-structured, synchronously typed, online focus groups were conducted between August and October 2016. Online methods are becoming increasingly popular in health research due to their ability to reduce costs and the widespread availability of internet access. Predominantly, online typed focus groups have been asynchronous in nature (not occurring in real-time) (15). Whilst asynchronous methods may allow for wider participation, they have been criticized as not being sufficiently responsive to be considered a “focus group” (16). Previous studies using synchronous online focus groups have found that the immediacy and dynamism of face-to-face conversations was mimicked (17, 18).

Participants were allocated to one group only. Groups included either adults (16 years or over) who had eczema, or parents of children with eczema. The recruitment procedure is outlined in Figure 1. Participants joined a group hosted on www.chatstep.com from a location of their choice. Participants entered a nickname of their choice and the room name and password that were provided by email. Between two and four female researchers were present at the discussion to do tasks such as time-keeping, ensuring all participants remained included, responding to technical issues, reading responses and typing responses. L.H. and one other researcher (J.C., K.T. or S.R.) logged into each group to facilitate. All of the research team were introduced simply as “researchers”, although F.C. is a registered nurse and M.S. is a general practitioner. K.T. has had previous experience facilitating online focus groups. Four participants knew some of the researchers prior to the discussions due to involvement in other research activities. L.H. established a relationship with the participants prior to the discussion via email and sometimes telephone contact. Sessions lasted approximately 70-80 minutes.

Focus groups followed a common topic guide (final topic guide in supplementary materials). The questions were revised iteratively based on what was perceived as facilitating engagement and relevant responses during the focus groups (e.g. stopped asking participants to think about going for a check-up as this raised health service issues that were not the subject matter of the study). Questions were framed to elicit everyday experiences of people living with eczema.

The transcript was downloaded after each session. L.H. made field notes during and after discussions to reflect on her thoughts and feelings relating to the data (19). Participants were sent a debrief email and asked to provide feedback on their experience of taking part shortly after the group. In April 2017 participants were sent a summary of the results and asked for their feedback on the results.

Patient and public involvement

The topic guide was developed with input from two parents of children with eczema and two adults with eczema, three of whom then participated in a group. A ranking activity posted via Twitter (n=75) and input from the Centre of Evidence Based Dermatology patient panel helped us decide what language to use to discuss “long-term control” in advertisements and information about the study, but the language participants used was subsequently adopted.

Analysis

Framework analysis was used to analyse transcripts (20). Themes were identified at the semantic level and analysis was conducted in an essentialist/realist framework (21). L.H. conducted the analysis, but other team members were involved in refining, interpreting and mapping themes. The thematic framework was driven by familiarisation with the transcripts, however some pre-existing concepts from the literature were considered when developing the framework. Themes were indexed using NVivo 11. The framework was altered to best fit the data. Framework matrices were developed and used for interpreting and mapping the data. No new themes were identified in the final two groups so the researchers were confident data saturation had occurred to the point that additional groups would not have modified the thematic framework (22).

Results

Participant characteristics

Table 1 summarises participant characteristics (N = 37). The majority of participants had been seen in secondary care (had been referred to a hospital specialist) for their eczema (n = 34/36, 94%). A minority had taken part in clinical trials (n = 4/37, 11%).

Feasibility and acceptability of online focus groups

Out of participants that had provided consent and signed up to a group, the attendance rate was 37/49. 11/37 participants provided feedback on their experience of taking part in the online focus group. Participants liked the convenience of the online method.

> *Preferred online discussion, much more convenient, no need for childcare. (Participant 29, Group 5, parent to son aged 9 months)*

However, some parents were distracted or unable to attend the evening groups (6:30pm – 8:00pm) due to their children's bedtime coinciding with the discussion.

> *I have a screaming tired 3 year old so let's see if we can do bedtime simultaneously with all her zinc wraps etc ha! Prob not wisest choice of times oops! (Participant 12, Group 2, parent to daughter aged 3)*

Participants liked the group size, privacy, and moderation by the researchers. The method provided anonymity and a non-intimidating platform for all voices to be heard.

> *I thought the discussion group was well moderated and focused, and gave everyone ample opportunities to contribute - and allowed time to think and send responses (Participant 1, Group 1, male aged 33)*

The chatroom indicated when individuals were typing, so the facilitators tried to ensure everyone had responded before advancing discussion. However, typing abilities differed and some said the conversation moved too slowly, whilst others found the conversation pace to be fast.

> *I think the only negative was the conversation became a bit disjointed at times, as it took people time to type. I don't however know how you could address this.. (Participant 28, Group 5, parent to daughter aged 5)*

Main themes on long-term control of eczema

Figure 2 shows how themes 1-3 relate to patient and parent experiences and understanding of eczema “control”, which informs how it should be measured (theme 4).

Theme 1: Commonalities and differences in the experiences of control

Normal or out of the ordinary for me

Increased itching, increased redness and less sleep were often cited as indicators of a treatment not working. However, some participants expressed how their symptoms, or their child’s symptoms, of uncontrolled eczema have altered over time.

> *I have found some treatments help but he then presents with different types of eczema. Sometimes dry and cracked, other times wet and blistery, some times is spotty and other times is patchy. (Participant 9, Group 2, parent to son aged 7)*

Individuals had different thresholds of acceptable level of control. For some, control was only achieved when there were no symptoms, whilst many viewed control as a reduction in their symptoms to what was “*normal*” for them. For example, one participant described their normal as “*just mild pigmentation marks*”. The variation in “normal” for each individual has important implications for measuring control.

> *Establishing a baseline of what's 'normal' for the person and how this is deviated from – because it is different for everyone! (Participant 2, Group 1, female aged 23)*

Flares vary in size and timing

Variations in the severity of flares were apparent in descriptors of size such as "*small flares*" and "*big flares*". The length of flares also varied both between and within individuals. Some described flares lasting hours, a day or a few days, whilst others described flares that lasted months.

> *if I catch a minor flare quickly enough I can sometimes control the irritation before it get completely out of control to what I call a meltdown (Participant 5, Group 1, female aged 20)*

The speed of onset of a flare was varied between individuals and changed for some individuals over time. Flares were often described as sudden in onset with limited early signs, whilst others described how the build-up could be gradual. Some parents said their child will know before them that a flare is coming, which could indicate that onset appears quicker for some parents as they do not always notice earlier indicators.

The end of a flare was characterised by better sleep, itching gone or not bleeding on their bedsheets. However, a few commented how it was hard to determine the end of a flare as it never fully went away.

> *with the eczema being so severe a flare never truely ends, it just is better (Participant 7, Group 2, parent to son aged 3)*

Theme 2: Eczema control goes beyond the skin

Psychological impact

Periods of uncontrolled eczema were characterised by low mood for adults, children with eczema and parents. Parents used emotive language to describe how they felt about periods of uncontrolled eczema, but reported the psychological impact on their child in broad terms of how it affected the child's general demeanour. The level of control was said to result in either a "*happy child*" or a grumpy/distressed child.

> *Total change in mood. She is happier, carefree and is not frowning. She can play more as not scratching all the time. She sleeps and is not grumpy, less tantrums as rested, able to concentrate and have patience due to sleeping well. (Participant 13, Group 3, parent to daughter aged 3)*

Some groups discussed how flares were accompanied by apprehension due to lack of certainty of how bad the flare would be and how long it would last. A few participants also recalled that even when they were better they were apprehensive of a flare returning.

> *…fear that it will come back after it's got better is always there (Participant 34, Group 6, female age unknown)*

The vicious itch/scratch cycle

Itchiness to the point that it was difficult not to scratch equated to uncontrolled eczema for many participants.

> *I couldn't even go to the toilet as he would be scratching, face weeping, awful (Participant 29, Group 5, parent to son aged 9 months)*

Scratching was said to often make the eczema worse, often leading to more itchiness, broken skin and bleeding, described as a "*vicious cycle*" that needed to be broken to regain control.

> *It feels good to itch – a temporary relief! Although you know it is making it worse! (Participant 36, Group 6, female aged 41)*

Affects ability to do activities of daily living

Uncontrolled eczema could impact almost every aspect of people’s lives. Sleep disturbance had an impact on concentration the next day. Itchiness and needing to scratch also impaired concentration, however it was clear that tiredness exacerbated this problem.

> *I used to go into work on one hour's sleep…and then I'd spend my time staring into space, itching, feeling sorry for myself and unable to snap out of it (Participant 35, Group 6, female aged 25)*

Uncontrolled eczema and the sleep loss it causes affected the child’s behaviour as well as their concentration. For example, the child was described as “*grumpy*” and having “*tantrums*”.

Another challenge was the time consumed during a flare period because of what they needed to do differently to normal, although some participants suggested the burden was not limited to flare periods as they engaged in activities to prevent flaring that were also very time consuming.

Adults often felt restricted in clothing due to irritation that certain clothes caused, wanting to cover eczema with clothing, visibility of blood on light fabrics and flaky skin on dark fabrics. Some parents altered their child’s clothing, which related to irritation rather than concerns about the visibility of the eczema.

> *I guess what you might be doing differently because of your eczema. Like clothes ... covering up eczema, not black because of dry skin, not too light because I might itch and bleed. (Participant 34, Group 6, female age unknown)*

Washing and exercise were problems for many adult patients due to being unable to face the sensations when cracked or dry skin came into contact with water or sweat. Parents expressed concern about their child’s ability to learn, play and interact.

Several adults and parents said impairment to movement was one of the biggest problems faced. Eczema around joint areas, feet or hands impaired their ability to move and do things. Movement was often described as painful.

Affects you socially

Some adults with uncontrolled eczema reported “embarrassment” and “social anxiety”. One group suggested this effect was increased when the eczema was more visible.

> *Embarrassing? I often tend to avoid eye contact, as I'm embarrassed with what people might see...and think. I've lost count of the times that I've been asked things like "Who beat you up?", "Dud you cut yourself shaving", and "Ugh, is that contagious?" (Participant 18, Group 4, male aged 43)*

Both adults and parents expressed feelings of isolation due to the lack of shared experience and understanding from others, rather than from direct social exclusion (although this was apparent for one participant). Some parents expressed concern for their and their child’s physical isolation due to preventing exacerbations and treating the eczema reducing socialisation opportunities.

> *How they interact, their developmental markers, how much socialisation they get, for us when his skin is bad it's the socialising and getting out of the house that suffers (Participant 27, Group 5, parent of a male child aged 16 months)*

Theme 3: Stepping up and down of treatment

Responding to a loss of control by “stepping-up” treatment

Most participants altered treatment depending on the level of eczema control. Many ways of measuring control relating to treatment changes were mentioned, including number of treatment prescriptions, use of extra treatments, use of higher strength treatments, time spent using treatments, frequency of treatment and amount of treatment used.

Whilst most discussed visiting the doctor to seek treatment if the eczema was not controlled, stepping-up treatment was complicated by various factors. Not all participants visited a healthcare professional to step-up treatment. Many would use stronger creams they had at home or increase the amount used of the treatment they are already prescribed. Participants often wanted to step-up treatment promptly to prevent further exacerbation of the eczema, but a few felt their doctor did not understand this urgency and would sometimes delay or avoid giving certain prescriptions.

On the other hand, some participants were reluctant to change their treatment in response to worsening of the eczema. Some were fearful that if they use the strongest treatment available, they may have nothing left to use if it gets worse. There were beliefs that a treatment would eventually stop working if you used it too much. Some did not change their treatment as they wanted to try non-pharmacological solutions such as exercise, diet and silk sleeping suits for children. However, sometimes these methods were used in combination with pharmacological treatments.

> *With that in mind we have been trying a lot of other things and we have been reducing the creams down as much as possible so they will be at maximum effectiveness for flare ups, It's a scary prospect isn't it - having nothing to use as an alternative! (Participant 25, Group 5, parent of daughter aged 11 months)*

Treatment needs to maintain control in the long-term

It was discussed that control has been gained or a flare has come to an end when you could return to maintenance routines and the eczema symptoms remained controlled.

> *I usually think a flare has ended if I've not had to put steroid cream on that day (Participant 1, Group 1, male aged 33)*

Alternatively, if the worsened eczema returned once stepped-up treatment was ended, this was not considered to be long-term control. Some participants described a continuous cycle of stepping-up and down treatment where the eczema did not remain improved when returning to maintenance treatments. However, it was thought some participants were searching for a “cure” rather than “control”.

> *Sometimes we are advised to use steroids for x long… then as soon as stops everything flares up again. Not a long term solution really (Participant 29, Group 5, parent to son aged 9 months)*

Theme 4: How to measure control

Suggested features of long-term control to be measured were diverse. They can be categorised as observable signs or symptoms (e.g. redness), unobservable symptoms (e.g. itch), treatment used (e.g. escalation of treatment), scratching (e.g. number of times scratched) the effects on the individual’s life (e.g. ability to do everyday activities) and the psychosocial impact (e.g. general mood).

It has to be you

Participants unanimously thought measures should include self-report. Measurement by a doctor was suggested to be too infrequent to capture the fluctuations in eczema.

> *Again it depends on each child, but certainly more frequently than the usual 3 months between consultants visits. we can be fine in the morning as horrendous by bedtime (Participant 30, Group 5, parent of male child aged 11)*

Self-report was also preferred because doctors assess the physical aspects of eczema and not how it affects the individual beyond this. The broad array of ways it can affect individuals is illustrated in theme 2.

> *Has to be you. SO subjective a topic, and nurses' doctors can only observe so much - and not the effects it has personally! (Participant 2, Group 1, female aged 23)*

Some participants suggested they need to be able to make comparisons with previous levels of control for self-report to be meaningful. This links to theme 1, where it was discussed how everyone has different experiences of “normal”.

> *it's usually 'compared to what', or on a scale of 1-10, where no number has a real meaning (Participant 22, Group 4, female aged 31)*

Other concerns with self-report included forgetting how the eczema has been if measurements are far apart (i.e. looking back over the last month would be difficult) or “kidding” themselves their eczema is better. Some participants suggested a measure should be quantifiable and percentage of body involvement was suggested. Others thought percentage of body affected would not capture the severity of an area affected or if they felt more burdened by eczema on certain body parts.

Photographs of skin were frequently used. This may seem surprising since participants highlighted the importance of looking beyond the visual effects of eczema, but it was used to show doctors the eczema fluctuations between visits. Another use for photographs and diaries was self-reflection on eczema changes. Numerous participants said reflecting on how the eczema used to be worse helped them cope. A few were concerned photographs may not show the eczema properly.

Ideal versus realistic frequency of measurement

Participants varied hugely in how often their eczema or their child’s eczema needed to be measured from “how about 24 hour watch!!!” to every few months. For many participants at least daily-was deemed necessary to capture a full picture of the disease. However, many felt that the frequency necessary would not be easily achieved for them due to the burden of recording eczema activity. Reasons for this included being too busy, forgetting or not being disciplined enough.

> *but to be honest dont have time when I am a busy workign mother, sometimes it only gets a glance (Participant 4, Group 1, female aged 50)*

Analysing group interactions showed parents wanting to appear willing to help. Therefore, parents were sometimes hesitant to share their reservations with measuring the eczema too frequently, but when prompted with suggestions from previous groups they did share this concern.

Whilst a few were prepared to measure controlled eczema, many were prepared to measure at frequent intervals during a flare, but not when eczema was controlled. They did not want to be reminded of the eczema, whereas during a flare they would measure it because they cannot help thinking about it.

> *it's all you think about when it's bad so you'd be prepared to do anything to make it better, like recording its current state, If it was in a bad condition, probably 30 minutes a day but when it's improved I would rather not think about it, so maybe 10 minutes. (Participant 33, Group 6, female aged 17)*

Some suggested frequency should change depending on the stage of treatment. It was thought it would be more necessary to understand fluctuations in periods of uncertainty (e.g. just starting a new treatment, just ending a treatment).

To overcome the problem of the ideal measurement not being realistic, a few suggestions were made that frequency could be flexible to the individual's needs or measuring tools could be designed so you could skip questions if not needed.

Participant feedback on results

Four participants provided feedback on the results. All found the analysis to be accurate and insightful. One participant reiterated their belief that an assessment of “baseline” and “flaring” should include a holistic appraisal of lifestyle, including mental wellbeing.

Discussion

Main findings

Conducting online focus groups allowed us to explore the experiences and understanding of eczema "control" amongst people with eczema and parents of children with eczema across the UK. A loss of eczema control can have varied consequences and impact for an individual and their family: itching, scratching, sleep loss, redness, bleeding, impaired psychological wellbeing, feelings of fear and apprehension, impaired daily functioning, social isolation and societal pressures were all prominent features of uncontrolled eczema. While some of these experiences have been reported elsewhere, this study specifically helps us understand how these experiences relate to the concept of "control" (7-12). Dissatisfaction with treatment that did not lead to controlled eczema once the treatment was stopped mirrors interviews with parents that found dissatisfaction with the trial and error approach to eczema treatment in primary care (11).

The language used to discuss "long-term control" can vary. "Long-term control" is a combination of two concepts; the timeframe and disease activity. There has been international consensus that long-term control should be measured in a clinical trial of eczema treatment that is three months or longer in duration. We did not discuss the trial context with participants in these focus groups as we were interested in their individual and everyday experiences. Participants spontaneously used the term "control" during discussions. Participants also frequently used the terms "flare"/"flare-up", but what experiences constituted a flare was highly variable. Some people had "chronic" flares lasting for months, whereas some lasted hours or days.

The most common way of measuring long-term control in published RCTs has been repeated measures of clinician-reported signs, usually on a monthly basis (4). Participants talked about how they would measure control as repeated measures of various factors such as quality of life, itch or mood. They preferred self-reported measures due to not all effects being observable by a doctor and frequent measures needed to capture fluctuations in eczema more fully. There are some patient-reported outcome measures that have been previously developed for use in eczema clinical practice and research, but they may not be sufficient to capture all aspects of eczema control from a patient perspective (23-26).

Published RCTs have measured flares using number of flares, time to first flare and, to a lesser extent, duration of a flare or remission period (4). The size and length of flares could differ substantially and have varying effects on the individual, which highlights how measures only capturing frequency or length of flares would not capture the impact each flare has on an individual.

Treatment escalation has been used to measure flares and long-term control. Two studies have defined a flare as being: “an episode requiring escalation of treatment or seeking additional medical advice” (27, 28). This measure had good face validity and construct validity (29). However, concerns around resource intensive data management and difficulties pooling data may mean this measure is not suitable for all trials (29). A similar definition has been proposed by the European Task Force on Atopic Dermatitis: “acute, clinically significant worsening of signs and symptoms of atopic dermatitis requiring therapeutic intervention” (30). Another concept of long-term control that has been adopted from asthma research is the concept of well-controlled weeks. A well-controlled week has been defined as occurring when treatment "escalated" for 2 days or fewer plus 2 or more days with a severity score of less than 4 out of 10. Whilst well-controlled weeks have been shown to be valid and reliable, collection requires frequent completion of diaries which may not be suitable for use in all trials (31).

Whilst participants did escalate treatment in response to a flare, there were a number of complexities that could make this difficult to implement as a measure in all trials. The Necessity-Concerns Framework suggests patients hold beliefs about how necessary a treatment is to maintain their health and concerns about the treatment having adverse effects, both of which can influence treatment adherence (32). Beliefs expressed by some participants in this study suggest they are concerned about their medication as they were reluctant to step-up treatment. Therefore, lack of treatment adherence may present a problem for using treatment as an indicator of eczema “control”. Alongside changes to treatment, a behavioural response to loss of control many participants cited and suggested measuring was increased scratching, which is one method that has been considered as a way of measuring long-term control (33, 34).

Strengths and limitations

To our knowledge, this is the first qualitative study to consider long-term control of eczema from a patient and parent perspective. The online focus groups reduced barriers of geographical location and time constraints and removed costs for travel, venue and transcription. Previously, online focus groups have been cited as enabling participation by people with visible skin conditions who lack the confidence to attend a face-to-face focus group (4, 7). This is supported by feedback from participants that they liked the anonymous and inclusive nature of the group.

There was a predominance of people of White British ethnicity and of female adults with eczema, despite targeted efforts to recruit male and ethnic minority participants. Online recruitment meant that we relied on self-report of eczema diagnosis and eczema disease severity. Only two participants reported never having seen a hospital doctor for their eczema, therefore the sample under-represents experiences for participants treated in primary care, which is the majority of eczema patients in the UK (35).

Online methods present distinct challenges for qualitative research. Language needs to be clear as there is no voice intonation or non-verbal cues. Prior preparation of questions allowed precision in phrasing. Participants valued that typing allowed them to provide considered answers. Threading, where multiple strands of conversation occur in parallel, is typical of online focus groups (17, 18, 36). Addressing an individual’s comment whilst simultaneously inviting the whole group to comment on that specific point maintained coherent discussion whilst allowing further exploration a topic.

Qualitative research has the potential to develop both breadth and depth of knowledge (6). Breadth is required to understand the scope of the experience and depth enables understanding the detailed complexities of the experience (6). The method tended to produce brief responses, but prompting was successful at eliciting more detailed responses. Reading responses was difficult when the discussion moved quickly, so having multiple researchers available to engage in different tasks was beneficial. 11 participants provided feedback on the methodology, however only 4 provided feedback on results. However, all feedback suggested they found the results to be an accurate representation of the discussion.

This study was concerned with individual experiences, whereas RCTs are analysed as group aggregates of outcomes. Future studies need to assess the optimum frequency of measuring outcomes in RCTs. This study highlights that the benefit gained by capturing intra-patient variation needs to be balanced against the burden of collecting this information.

Implications for research and clinical practice

This study investigates an aspect of eczema that has been under-researched from the patient and parent perspective. Box 1 highlights the important ways this study may inform decisions on the best way to measure long-term control in people with eczema. These findings will inform consensus discussions for development of a core outcome set for eczema clinical trials through the HOME initiative (www.homeforeczema.org).

This study is the first stage of an international qualitative research project that will aim to understand long-term control of eczema for patients and parents in different countries to ensure that what is important to patients about the long-term control of eczema is an international perspective. The methodology is globally accessible and facilitates composite analysis to identify differences across countries. Since online focus groups are a relatively novel method, the lessons learnt from this study will provide guidance for international collaborators.

Conclusions

This qualitative study has shown the complexity of the experience of long-term control for patients and parents. “Eczema control” can have a variety of meanings for people with eczema and parents of children with eczema, which has important implications for how long-term control may be measured. Overall, this pragmatic online research method was embraced by participants and enabled qualitative research to be conducted effectively with limited resources.

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Data sharing statement: Data sharing requests can be made to the corresponding author.

Figure 1 Recruitment Procedure

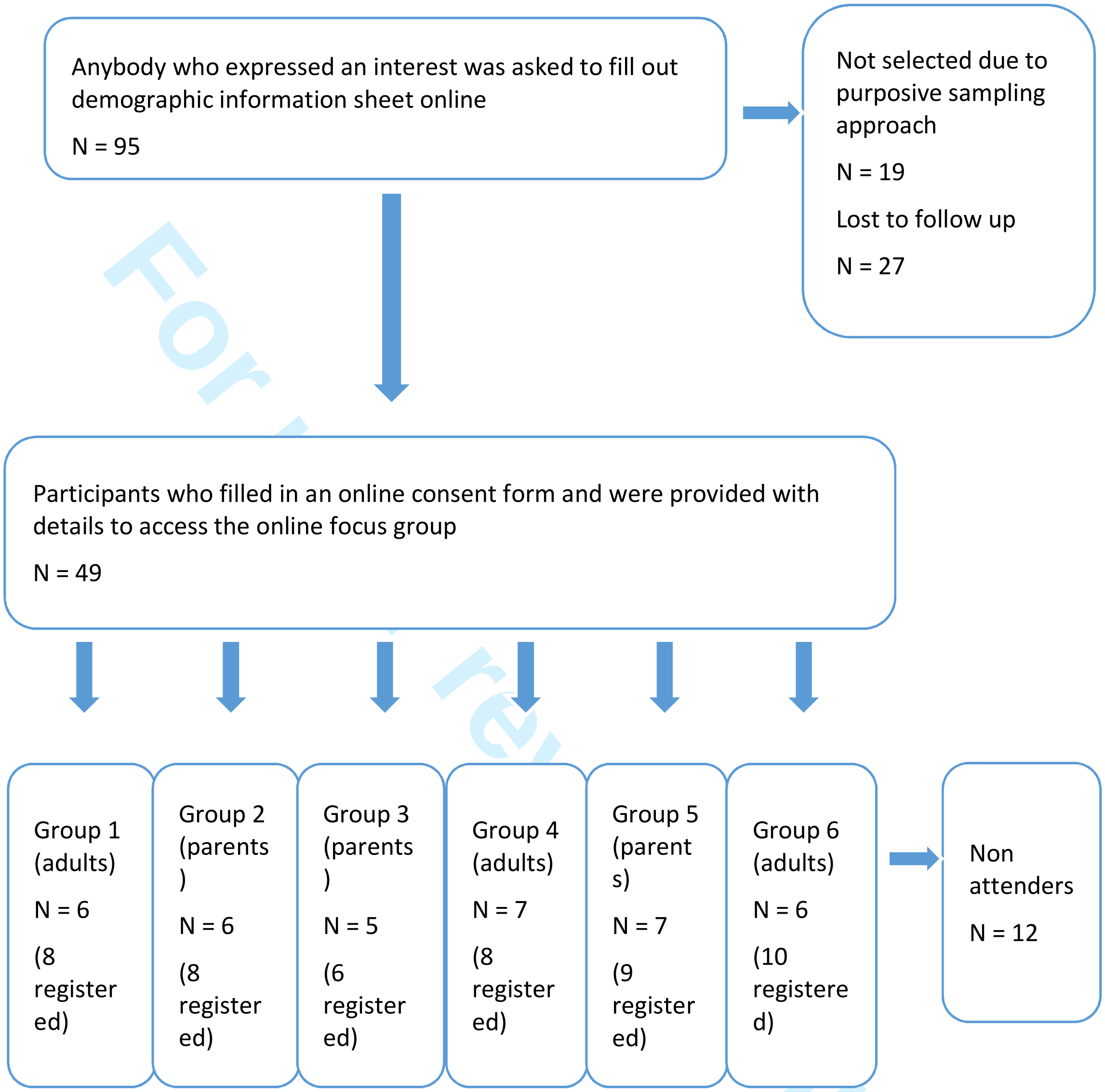
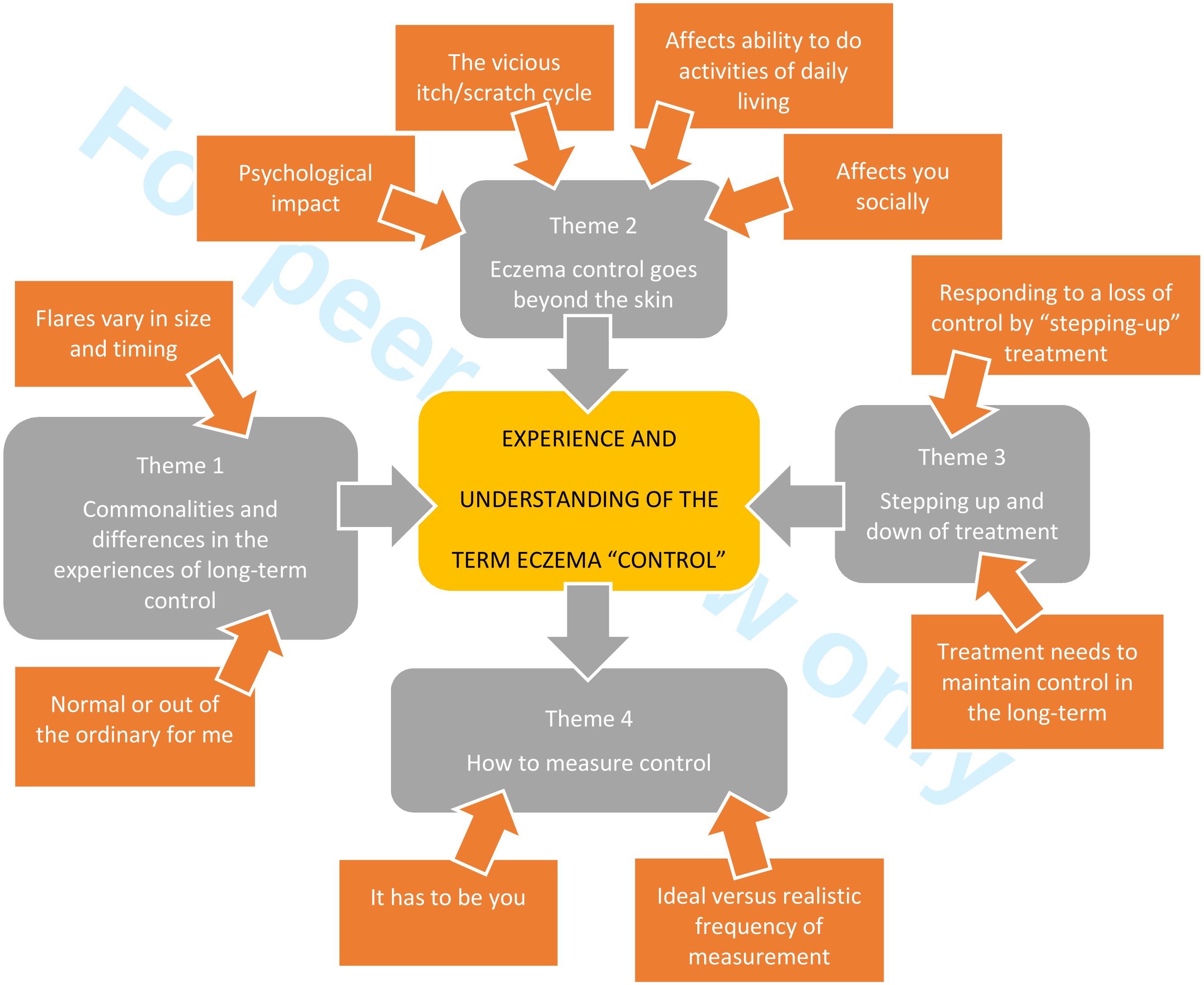


Table 1 Summary of participant and child demographics

	Adults with eczema	Parents of children with eczema	Children with eczema (reported by parents who participated)
N of participants	19	18	-
Sex, n (%)			
Male	4 (21)	-	9 (50)
Female	15 (79)	18 (100)	9 (50)
Age in years, n (%)			
≤5	-	-	12 (67)
6-11	-	-	5 (27)
12-15	-	-	-
16-25	6 (31.67)	1 (6)	1 (6)
26-40	6 (31.67)	15 (83)	-
>40	6 (31.67)	2 (11)	-
unknown	1 (5)	-	-
Ethnicity, n (%)			
White	16 (84)	-	17 (94)
Asian	1 (5)	-	-
Black	-	-	-
Mixed	2 (11)	-	1 (6)
Years since eczema diagnosis			
≤5	1 (5)	-	12 (66)
6-11	2 (11)	-	4 (22)
12-15	-	-	-
16-25	5 (26.34)	-	1 (6)
26-40	5 (26.34)	-	-
>40	5 (26.34)	-	-
unknown	1 (5)	-	1 (6)
Self or parent reported current disease severity, n (%)			
clear	2 (11)	-	-
Almost clear	2 (11)	-	2 (11)
Mild	4 (21)	-	4 (22)
Moderate	9 (47)	-	7 (40)
Severe	1 (5)	-	5 (27)
Very severe	1 (5)	-	-

Figure 2: Mapping of the thematic framework



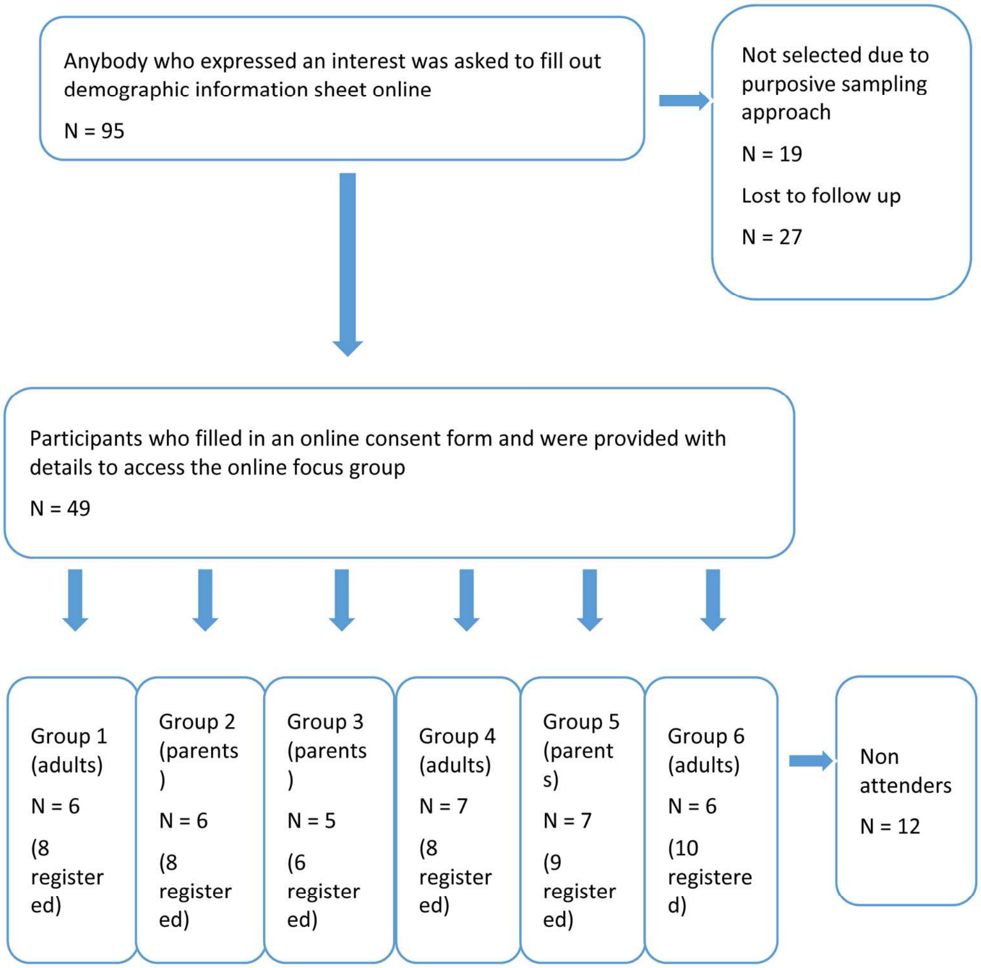


Figure 1. Recruitment procedure

164x164mm (300 x 300 DPI)

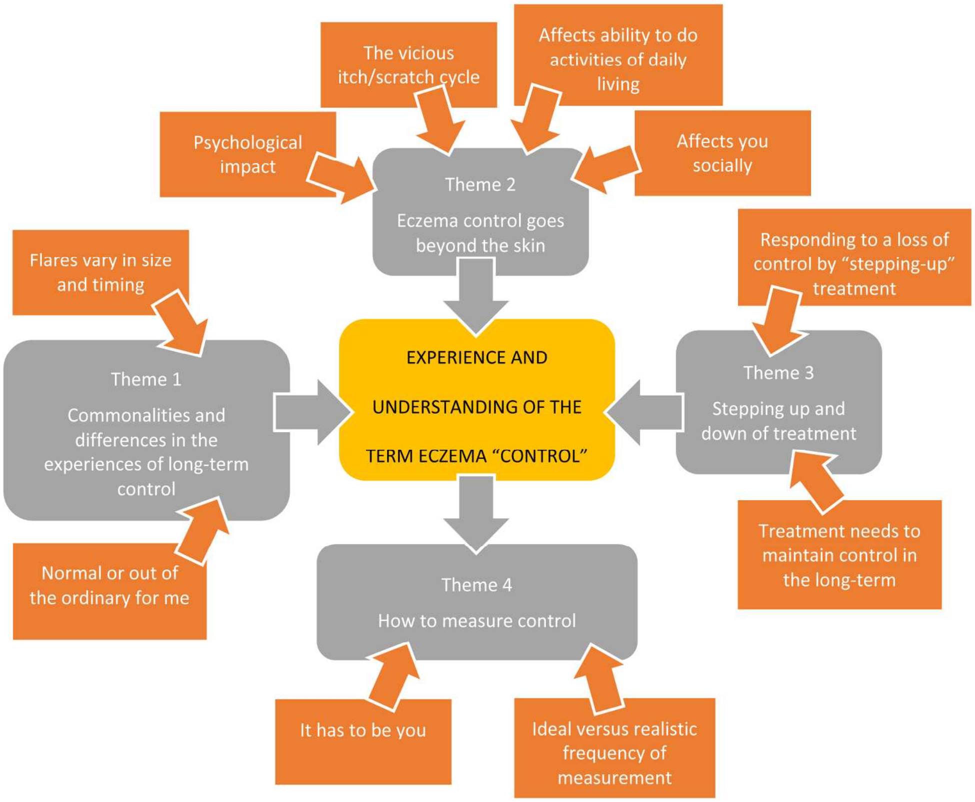


Figure 2. Mapping of the thematic framework

192x166mm (300 x 300 DPI)

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.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	5
Occupation	3	What was their occupation at the time of the study?	5
Gender	4	Was the researcher male or female?	5
Experience and training	5	What experience or training did the researcher have?	5
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	5
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	3
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4-5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	Figure 1
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	n/a
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	5
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	6
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	6

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding tree	25	Did authors provide a description of the coding tree?	Figure 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	6
Participant checking	28	Did participants provide feedback on the findings?	6
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	7-16
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-16
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-16, Figure 2
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7-16

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.