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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' among 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 six 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 years (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; and (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 with face-to-face focus groups.
- The sample mainly included individuals who had attended secondary care for their eczema or their child's eczema so it may not represent the views of people living with milder disease who are managed in primary care.

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 per cent 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 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:

1. determine what long-term control means to them
2. explore what aspects of long-term control are most important to them
3. explore what methods of measuring long-term control are feasible and acceptable.

METHODS

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-type focus groups have been asynchronous in nature (not occurring in real time).¹⁵ While asynchronous methods may allow for wider participation, they have been criticised 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. LMH and one other researcher (JR, KST or SR) logged into each group to facilitate. All of the research team were introduced simply as 'researchers', although FC is a registered nurse and MS is a general practitioner. KST 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. LMH established a relationship with the participants prior to the discussion via email and sometimes telephone contact. Sessions lasted approximately 70–80 min.

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 (eg, 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. LMH 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.

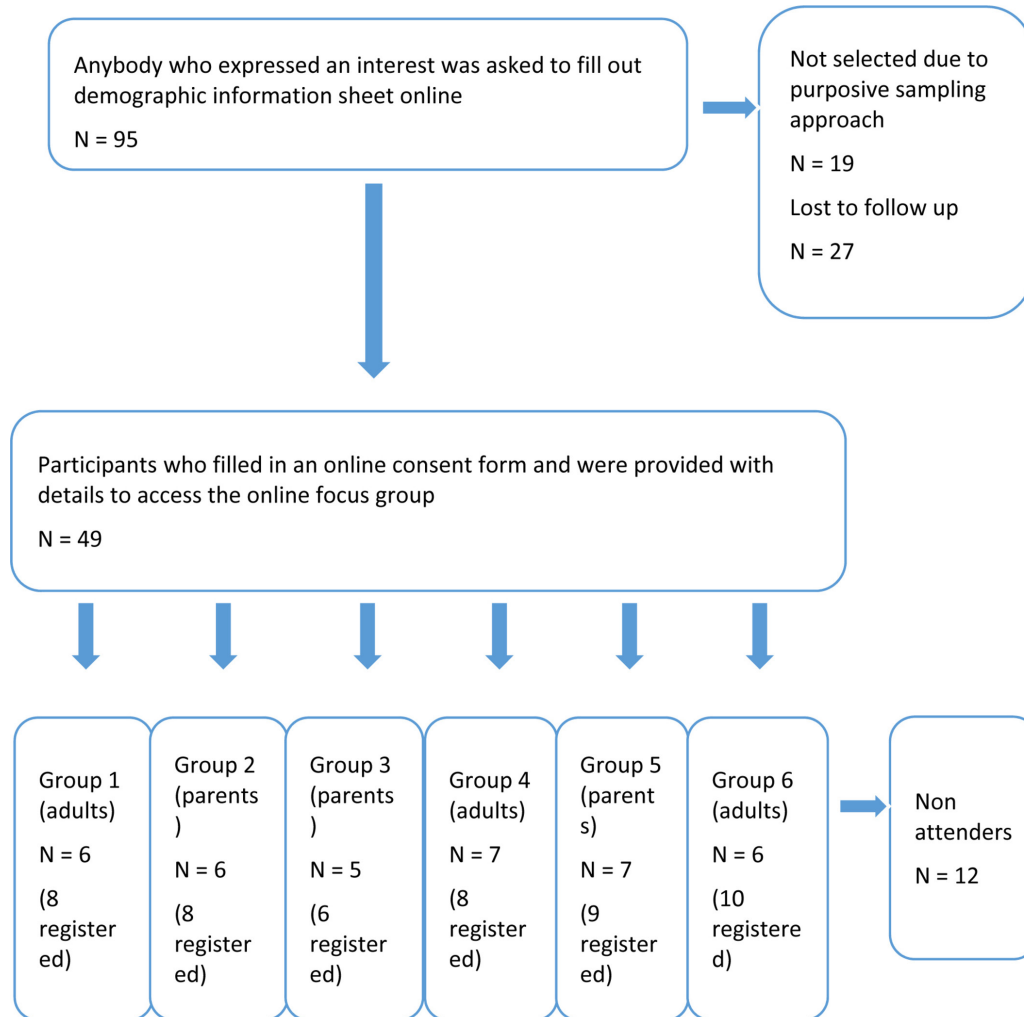


Figure 1 Recruitment procedure.

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 LMH 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 V.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. Eleven of 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)

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, n (%)			
<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)	–	–

However, some parents were distracted or unable to attend the evening groups (18:30–20:00) 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 years)

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 years)

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, while 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 years)

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 years)

Individuals had different thresholds of acceptable level of control. For some, control was only achieved when there were no symptoms, while 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 years)

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, while others described flares that lasted months.



Figure 2 Mapping of the thematic framework.

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 years)

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, while 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 truly ends, it just is better. (Participant 7, Group 2, parent to son, aged 3 years)

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 years)

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 years)

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 years)

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 years)

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.

While 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.

However, 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 years)

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 stepping-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 (eg, redness), unobservable symptoms (eg, itch), treatment used (eg, escalation of treatment), scratching (eg, number of times scratched) the effects on the individual's life (eg, ability to do everyday activities) and the psychosocial impact (eg, 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 years)

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 years)

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 years)

Other concerns with self-report included forgetting how the eczema has been if measurements are far apart (ie, 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 hours 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 don't have time when I am a busy working mother, sometimes it only gets a glance. (Participant 4, group 1, female, aged 50 years)

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.

While 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 min a day but when it's improved I would rather not think about it, so maybe 10 min. (Participant 33, group 6, female, aged 17 years)

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 (eg, just starting a new treatment and 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 well-being.

DISCUSSION

Main findings

Conducting online focus groups allowed us to explore the experiences and understanding of eczema 'control' among 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 well-being, 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 3 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. While well-controlled weeks have been shown to be valid and reliable, collection requires frequent completion of diaries that may not be suitable for use in all trials.³¹

While 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.⁴⁷ 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 while simultaneously inviting the whole group to comment on that specific point helped to maintain a coherent discussion and allow further exploration of the 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. Eleven participants provided feedback on the methodology; however, only four 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 inpatient 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** 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

Box Seven key findings that could inform the measurement of long-term control.

From these findings, we recommend the following seven topics may want to be taken into consideration 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 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 control. The use of parents as a proxy for 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.

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.

Contributors LMH, KST, JRC and SR contributed to the conception of the study. LMH, KST, JRC, SR, FC and MS contributed to the design of the work. LMH, KST, JRC, SR and FC were involved in data collection. LMH, FC and MS were primarily involved in the analysis process, while KST, JRC and SR were involved in interpretation of data. LMH drafted the work, and KST, JRC, SR, FC and MS revised it critically for important intellectual content. All authors gave approval for the final version to be published.

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Competing interests LMH, KST and JC are members of the Harmonising Outcome Measures in Eczema (HOME) long-term control working group.

Ethics approval This study was approved by the University of Nottingham's Medical School Research Ethics Committee (F14062016 SoM ROD).

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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' among people with eczema and parents of children with eczema in the UK

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