Supporting families managing childhood eczema: Developing and optimising Eczema Care Online using qualitative research

Running head: Eczema Care Online for Families

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Parents/carers report multiple barriers to managing childhood eczema, including limited information about eczema and its treatments and child resistance, which could potentially be addressed through online interventions. This paper identifies key issues/challenges for families managing childhood eczema, solutions to consider when supporting them, and describes the development of an online intervention to support families ('Eczema Care Online for Families'). A key finding of this research is that even parents/carers with extensive experience of looking after childhood eczema have gaps in knowledge around treatment, which healthcare professionals could help identify and address, particularly around why, when and how to use emollients and topical corticosteroids. The paper introduces terminology to help clarify the purpose of emollients ('moisturising creams') and topical corticosteroids ('flare control creams') and reflect parents/carers' language.

ABSTRACT

Background: Childhood eczema is often poorly controlled due to under-use of emollients and topical corticosteroids. Parents/carers report practical and psychosocial barriers to managing their child's eczema, including child resistance. Online interventions could potentially support parents/carers; however, rigorous research developing such interventions has been limited.

Aim: To develop an online behavioural intervention to help parents/carers manage and co-manage their child's eczema.

Design and setting: Intervention development using a theory-, evidence- and Person-Based Approach with qualitative research.

Methods: A systematic review and qualitative synthesis (32 studies) and interviews with parents/carers (N=30) were used to identify barriers and facilitators to effective eczema management, and a prototype intervention was developed. Think-aloud interviews with parents/carers (N=25) were then used to optimise the intervention to increase its acceptability and feasibility.

Results: Qualitative research identified that parents/carers had concerns about using emollients and topical corticosteroids; incomplete knowledge and skills around managing eczema; and reluctance to transitioning to co-managing eczema with their child. Think-aloud interviews highlighted that while experienced parents/carers felt they knew how to manage eczema, some information about how to use treatments was still new. Techniques for addressing barriers included: providing a rationale explaining how emollients and topical corticosteroids work; demonstrating how to use treatments; and highlighting that the intervention provided new, up-to-date information.

Conclusions: Parents/carers need support in effectively managing and co-managing their child's eczema. The key output of this research is Eczema Care Online (ECO) for Families; an online intervention for parents/carers of children with eczema, which is being evaluated in a randomised trial.

Key words: atopic eczema, paediatric dermatology, qualitative research, family practice

INTRODUCTION

Eczema affects around one in five children.(1) NICE guidelines recommend daily use of emollients, plus topical corticosteroids (TCS) to treat eczema flare-ups.(1) The main cause of treatment failure is under-use of topical treatments, which can reduce quality of life and increased healthcare costs.(1) Under-use is often due to practical and psychosocial barriers, such as treatment being time-consuming, concerns about TCS, and child resistance.(2–5) Little is known about barriers /facilitators to parents/carers managing and co-managing eczema with older children.(2)

The majority of eczema self-management interventions involve face-to-face education, which can be effective, but their cost-effectiveness is unknown, and uptake can be poor.(6,7) Previous digital interventions targeting parents/carers typically focus on young children,(8) or include multiple components (e.g. education, online monitoring, and face-to-face consultation).(9) Other interventions include written action plans but effectiveness has not yet been evaluated.(10) Systematic reviews show the need for systematically developed evidence-based interventions to support self-management of eczema.(9,11,12)

Key to developing acceptable, feasible, and ultimately effective interventions is understanding the needs, and context of target users.(13,14) The current research aimed to systematically develop an online behavioural intervention for parents/carers of children aged 0-12 years with mild to severe eczema ('Eczema Care Online (ECO) for Families'). It aims to support parental management and parent/child co-management of eczema. Intervention development was informed by qualitative studies that explored parents/carers' a) barriers and facilitators to managing and co-managing eczema; and b) views of the online intervention, its acceptability, and feasibility. This paper describes the research underpinning the development of ECO for Families, which was developed in line with Medical Research Council guidance on developing and evaluating complex interventions.(15,16)

METHODS AND RESULTS

ECO for Families was developed during 2017-2019 using a theory-, evidence and Person-Based Approach (PBA), (13,17,18) which grounded intervention development in an in-depth understanding of target users' needs, challenges and context (i.e. parents/carers of children aged 0-12 years with mild to severe eczema). Five behaviours were targeted, which were agreed through stakeholder consultation as being crucial to effective eczema care;

- Reactive application of TCS to get control of skin inflammation
- Increased use of emollients to keep control of skin inflammation
- Improved management of irritants/triggers
- Reduced scratching (children)
- Improved emotional distress management (children)

Stakeholder consultation throughout intervention development ensured that advice in the intervention was medically correct, evidence-based and presented in an acceptable and accessible way.(19) The intervention development group, which included the intervention development team (KS, ET, KG, MSt, LY, MSa, IM) and stakeholders, comprised 16 experts in dermatology and intervention development: two consultant dermatologists (SML, HW); a

nurse consultant (SL); a Professor of Nursing (FC); two skin researchers (JC, KST); three GPs (MR, MS, ELR) three health psychologists (KG, IM, LY); four research psychologists (DG, KS, MSt, ET); and two patient representatives: two mothers of children with eczema (AR, AA), one of whom was a patient herself and was a patient advocate in eczema. For further detail of how patient and public involvement was used to complement the PBA in ECO for Families see Muller and colleagues.(20)

In keeping with the first two steps of the PBA (Figure 1), ECO for families was developed in two iterative stages: 1) intervention planning, and 2) intervention optimisation. Evidence of potential barriers and facilitators to the behaviours targeted by the intervention, and key factors affecting how families managed and co-managed their child's eczema were explored. The methods and findings at each stage are set out, along with how this evidence was used to plan, develop and optimise the intervention. As per previous intervention development papers using the PBA,(17,21,22) the methods and results are presented together by stage to illustrate how these informed intervention planning and optimisation.

<<<Insert Figure 1 here>>>

Stage 1: Intervention Planning

Stage 1 focused on intervention planning (Figure 1). In ECO, this process was informed by two key studies: a systematic review/qualitative synthesis of the literature,(2) and interviews with parents/carers. Evidence from these studies was used to develop three outputs:

- 'Guiding principles' to inform intervention design. These specified intervention objectives and features for maximising families' engagement with the intervention (Table 2).(13,17,18)
- A behavioural analysis identifying barriers/facilitators to the five target behaviours and potential intervention components and techniques that would address them. Intervention components and techniques were then mapped to theory using a behaviour change framework to ensure no important behaviour change techniques were missed and to systematically describe the intervention (Supplementary Table S1).(23,24)
- A logic model outlining key intervention components and techniques, hypothesised mechanisms of action, and target outcomes.

These key studies and their intervention development outcomes are described below.

1.1. Systematic review/qualitative synthesis of research on families' views and experiences of managing eczema

Methods

A systematic review/thematic synthesis examined patients' and parents/carers' views and experiences of eczema, eczema treatments, and barriers/facilitators to managing eczema, reported in full elsewhere.(2) This review identified 39 papers from 32 studies.(25)

Results

Parents/carers reported substantial physical and emotional impact of caring for their child's eczema, including feeling exhausted, guilty and worried. They reported needing to change behaviours and routines to adapt to managing eczema. Key barriers included:

- Lack of information about eczema and how to use treatments;
- Receiving negative or conflicting advice about topical treatments (particularly TCS);
- Treatment being time-intensive and burdensome, particularly applying topical treatments, and managing irritants/triggers;
- Parents/carers and children disliking topical treatments (due to feel/smell/stinging);
- Child resistance to parents applying topical treatments;
- Concerns about the safety of TCS and 'unnatural' ingredients included in emollients;
- Uncertainty about how and when to use TCS;
- Doubts about the effectiveness of topical treatments.

1.2. Interviews

Methods

Participants were recruited through mail-outs from 16 GP surgeries and opportunistic recruitment in three NHS hospitals. Participants needed to have a child aged 0-12 years with diagnosed eczema and one or more eczema prescriptions in the previous 12 months and be able to communicate in English. Participants received an invitation pack, including an information sheet, and a reply slip to express interest in the study. To gather a diverse range of views and cover a range of developmental stages, participants were purposively sampled on; the child's age, gender, eczema severity, and geographical location. Selected participants were invited to a face-to-face semi-structured interview and consented prior to interview. All interviews were conducted at participants' homes between March and July 2018 by a female research psychologist experienced in qualitative research (ET). Interviews explored parents/carers' views and experiences of managing and co-managing their child's eczema, treatment barriers/facilitators, and terminology used for topical treatments (see Supplementary Box S1 for topic guide). Interviewees received a £10 voucher. Recruitment continued until saturation was reached for main themes.

Interviews lasted 45-60 minutes, were audio-recorded, transcribed verbatim, and analysed using inductive thematic analysis.(26,27) Data were managed in NVivo 12.(28) A coding manual was created by KS and ET, with audit trail. Constant comparison between transcripts, codes, and themes ensured coherency, and diverse cases identified. Analysis was iterative, with codes and themes updated following team discussion and stakeholder consultation. This process facilitated reflexivity by including the perspectives of dermatology and non-dermatology specialists and people with and without lived experience.

As the focus was on understanding parents/carers experiences of managing/co-managing eczema with their child, the analysis focused predominantly on barriers and facilitators to eczema management in order to inform the intervention. Results presented here focus on novel findings that extend those in the systematic review.

Results

Thirty parents/carers (all female) were interviewed. The majority of interviewees (N=28; 93%) were recruited through primary care. See Table 1 for child characteristics.

<<<Insert Table 1 here>>>

Parents/carers typically referred to topical treatments as 'creams', irrespective of their type (gel/ointment/lotion/cream). Emollients were generally called just 'creams', 'emollient creams' or using the brand name. Only a few called them 'emollients' or 'moisturisers'. TCS were usually called 'steroid creams', 'steroids', or occasionally, by product name. One parent/carer called them 'strong creams' when discussing them with her child.

Thematic analysis identified six key themes.

Incomplete knowledge about eczema and its treatments.

Most parents/carers described having received little information explaining eczema and its treatments. Several wanted more information, particularly hints and tips from other parents/carers. Several were unsure what caused eczema flare-ups. A couple wondered how puberty might affect eczema.

> *"when her skin is changing due to teenage-hood… when she wants to start using make-up; does it interfere with eczema?"* ***(Parent/carer29, 12-year-old daughter, moderate eczema)***

A few parents/carers said they weren't sure how best to use emollients, particularly whether they needed to be used regularly. One was unsure if they used them too much.

> *"I stopped using [emollient] because it didn't seem to flare up… if I'd kept using it all winter, would she not have flared up now? Or would she have flared up anyway…?"* ***(Parent/carer9, 18-month-old daughter, mild eczema)***

A few discussed previously using TCS incorrectly or being uncertain about when or how to use them.

> *"I didn't know how much [TCS] to put on…I didn't know what was right and wrong"* ***(Parent/carer5, 2-year-old daughter, moderate eczema)***

Concerns and doubts about the safety and effectiveness of TCS and emollients

Most parents/carers had concerns about TCS. Some described them as a 'necessary evil'; they didn't like them but knew they worked. Some worried about skin thinning. A couple tried to avoid using them and described this as a dilemma.

> *"it was a constant battle between trying not to use them [TCS] and having to use them…Do we need [TCS] or can we get a grip of this without?"* ***(Parent/carer26, 6-year-old daughter, moderate eczema)***

Most parents/carers felt that emollients were effective in reducing itch and keeping control of eczema. However, a few were unconvinced or thought they worked less well over time.

> *"it seems after a certain amount of time [emollients]…lose their magic"* ***(Parent/carer28, 5-year-old daughter, severe eczema)***

Process of trial and error

Most parents/carers described a process of trial and error to work out how best to manage their child's eczema, which might relate to incomplete knowledge around eczema management. This process included; finding the right emollient, developing an emollient routine, and making changes to manage irritants and scratching. A few parents/carers described adapting their regimen over time as their child changed.

*"I have to think ...what's caused this [flare-up] to come on? …I just try and work it out as we go along" (**Parent/carer15, 6-year-old son, mild eczema)***

Several expressed a desire to carry on as usual and to find a balance between managing their child's eczema and leading a 'normal' life.

*"If we have a flare we'll just deal with it at the end of the day… I'm not going to stop her from having a childhood…" **(Parent/carer8, 8-year-old daughter, severe eczema)***

Negative impact of eczema and its treatments on parents

Most parents/carers described treatments as time-consuming, unpleasant, and messy. Some felt exhausted due to treatment burden and sleep deprivation, distressed at seeing their child upset or in pain, or felt they lacked control over their child's eczema.

*"I feel heartbroken, especially when I see their skin quite bad… you feel helpless" **(Parent/carer1, 5-year-old son, mild eczema)***

Child acceptance and rejection of topical treatments

Several parents/carers discussed their child disliking topical treatments. Several felt toddlers were more challenging as they would scream or run away, but some described arguments with older children over delaying or avoiding emollients, and children getting annoyed at parent/carers' prompting them. However, most felt that if their child understood why topical treatments were needed, it helped their child to accept them, and that age-appropriate materials explaining eczema and its treatments would be helpful.

*"books or something like that would be good, or anything…interactive. Colouring on how to apply cream…something that helps them be more educated on what they can do" **(Parent/carer12, 6-year-old son, mild eczema)***

Several felt that examples of other children talking about eczema and how they self-manage might help normalise eczema for their child.

*"videos or clips from other kids who've got it…Then they feel…they're in the same boat, that other people are experiencing that" **(Parent/carer29, 12-year-old daughter, moderate eczema)***

Some felt that establishing a routine helped normalise emollients into their child's day. Others talked about making treatment times more enjoyable with toys or rewards.

Reluctance to transition to parent-child co-management and child self-management

Some parents/carers talked about letting younger children put their emollients on; however, there were mixed experiences around this. For some it was a deliberate move to teach their child about their emollients. Others described it as a mistake because of the resulting mess .

"I'm quite reluctant to… 'No, let me do it.' Then you've got the handprints all over the mirror and you just find sticky stuff everywhere." ***(Parent/carer10, 5-year-old daughter, moderate eczema)***

Although some parents/carers had positive views of transitioning care to their child, these tended to be older or 'very mature' children. Several felt their child was too young. Some had difficulties letting go of their child's care as they felt that their child would not look after their eczema properly because they weren't physically capable, or they weren't motivated. Some parents/carers managed this by prompting their child or helping them when needed. However, this reluctance to hand over care was apparent even in children close to adolescence who wanted to self-manage.

"I would prefer to be doing it [emollients]…because I know that it'll be getting done properly…she's going through puberty, her body's changing, she doesn't want me coming in…there's been a few arguments, because, sometimes, I don't think she's looking after herself properly" ***(Parent/carer6, 12-year-old daughter, severe eczema)***

Only a few parents/carers talked about TCS in the context of co-management; most felt concerned about letting their child apply TCS or felt they needed to be older, reflecting their concerns about TCS.

*"I don't let her do steroid cream by herself…I'm very conscious that I don't want her putting too much on." (****Parent/carer17, 9-year-old girl, mild eczema)***

Some parents/carers also doubted that other adults would apply emollients as effectively/consistently as they would. A few doubted school would or had had school refuse to manage eczema. Some reported their child feeling uncomfortable using emollients at school. Although a couple of parents/carers described positive experiences at school, this was when there were close links with the school through a school nurse or the parent working there, facilitating eczema management.

1.3 Intervention Development

Key issues influencing intervention design and barriers/facilitators to intervention target behaviours were extracted from the systematic review and interviews and used to inform the guiding principles and behavioural analysis. Key barriers are summarised in Table 2 and Table 3, along with the intervention features/ingredients for addressing them (see Supplementary Table S1 for the full behavioural analysis). An intervention logic model based on the behavioural analysis can be found in Figure 2, outlining key components, techniques, hypothesised mechanisms of action, and target outcomes.(29)

<<<Insert Table 2, Table 3 and Figure 2 here>>>

Initial intervention content was written in Word informed by the guiding principles and behavioural analysis and shared with stakeholders to ensure medical accuracy and obtain patient/parent feedback on acceptability and feasibility prior to think-aloud interviews in Stage 2. This content was then developed into a website using LifeGuide software and

thoroughly tested to ensure functionality across different types of devices (computers, mobile phones, tablets).

A modular intervention was developed with modules focusing on topics related to eczema including treatment use and psychosocial issues (e.g. stress). Parents/carers were initially guided through a short introductory module, which had three key purposes; 1) establish credibility of the intervention, 2) explain eczema and the skin barrier, and 3) briefly explain key treatments (emollients and TCS) and how to use them. This aimed to ensure parents/carers had the basic knowledge/skills for managing eczema

A key aspect of the intervention was the terminology developed for describing emollients, which were called 'moisturising creams', and TCS, which were called 'flare control creams'. This was done to reflect parents/carers own terminology (i.e. 'creams') and to help make clear their different purposes, particularly the role of TCS, and topical calcineurin inhibitors (TCIs), in treating eczema flare-ups.

At the end of the introduction parents/carers could then take a brief quiz to assess their child's eczema, which then recommended one of two core modules; 'getting control using flare control creams' or 'keeping control using moisturising creams'. These provided more information about treatments, addressed common concerns and provided information and photos/video demonstrations of how best to use treatments. Additional modules were provided through drop-down menus (see Figure 3) to allow parents/carers to access a range of topics, including; managing irritants and triggers ('what can make eczema worse'), co-management ('help your child manage eczema'), managing the impact of eczema ('itch, stress and sleep'), and other treatments and related issues ('more about treatments').

<<<Insert Figure 3 here>>>

A full description of the intervention was compiled using TIDieR (Template for Intervention Description and Replication) guidance for reporting intervention development (see Supplementary Box S2).(30)

Stage 2: Intervention Optimisation

2.1. Think-Aloud Interviews

Stage 2 focused on optimising the prototype of the digital intervention using iterative think-aloud interviews with parents/carers. These aimed to elicit feedback on the prototype to inform refining its content and design so that it was more acceptable and feasible for parents/carers to follow. The new terminology around 'moisturising creams' and 'flare control creams' was also assessed.

Methods

Face-to-face think-aloud interviews(31) were conducted between October 2018 and April 2019 by a female research psychologist experienced in qualitative research (ET) and a medical student (supervised by ET). Participants were recruited using mail-outs from eight GP surgeries using the same eligibility criteria and purposive sampling approach as Stage 1.

Recruitment continued until saturation was reached. Interviewees received a £10 voucher. Interviews lasted 45-90 minutes, used a standard think-aloud interview approach involving minimal prompting to elicit participants' reactions, and were conducted at the participant's home. Participants read sections of the website and said aloud their immediate reactions to the content (see Supplementary Box S3 for topic guide). Interviews were audio-recorded and transcribed verbatim. Data were analysed concurrently to the interviews using a Table of Changes by KS, ET and KG,(32) in which all positive and negative comments were collated, and potential changes identified and prioritised in terms of feasibility of changes and importance of changes in increasing acceptability and feasibility of the intervention. Minor changes to the intervention were agreed within the intervention development team with key issues discussed with stakeholders to support reflexivity and medical accuracy of modified intervention content. Interviews were carried out iteratively; with feedback from earlier interviews informing modifications to optimise the intervention, and later interviews using revised prototype intervention to seek feedback on modifications.

Results

Twenty-five parents/carers (N=23 female; 92%) were interviewed. See Table 1 for child characteristics.

Views of the prototype were generally positive; particularly the new terminology for eczema treatments, wide variety of topics covered, and the videos, parent/carer quotes, and tips. However, participants felt the content was lengthy and repetitive, and wanted quicker access to main modules. A key issue was that many parents/carers initially felt the content was not relevant to them if they had been looking after their child's eczema for a while. Despite this, when going through the content participants still identified things that they had not known, like why and how emollients help keep eczema under control and how to correctly apply treatments (e.g. using TCS until 2 days after the eczema flare-up clears, applying topical treatments in the direction of hair growth). Parents/carers also felt they had gained useful practical tips they had never tried before, such as putting creams in the fridge to make them cool to sooth itching or setting reminders on phones.

> *"I've learnt so much this morning that I didn't know about eczema, and I thought I knew quite a lot!"* ***(Parent/carer16, 2-year-old daughter with mild eczema)***

2.2. Intervention Optimisation

Modules were streamlined and made more interactive to increase user choice and autonomy using optional click-outs and pop-ups. In particular, the core content in the introductory module was cut from 21 to 9 short pages. Readability was improved on individual pages by; 1) highlighting key messages using bold text, 2) using bullet points, and 3) separating text using boxes. Signposting, quotes and tips were added to the introductory module and first page of the core modules to emphasise that:

- the website provided up-to-date information about eczema and its treatments;
- core modules would start basic but then progress;

even parents/carers who had been caring for their child's eczema for a while had learnt new things.

DISCUSSION

Summary

This paper describes the intervention development of ECO for Families, an online behavioural intervention that supports parents/carers to manage and co-manage their child's eczema. A systematic review/qualitative synthesis of the literature and interviews helped identify key barriers that needed to be addressed, including: incomplete knowledge about eczema, its triggers, and its treatment; concerns and doubts about emollients and, especially, TCS; and limited skills for managing and co-managing eczema and its treatments. This information was used to identify appropriate behaviour change techniques and develop a prototype intervention. Think-aloud interviews were used to optimise the intervention.

Strengths and limitations

A strength of ECO for Families is the use of a theory-, evidence- and person-based approach, which ensured development was systematic and informed by in-depth qualitative research and theory.(9) A limitation of the research underpinning ECO for Families was that there were few interviews with parents/carers of children with severe eczema aged under 1 year, particularly in the think-aloud interviews. Most parents/carers were female, so little is known about the views of fathers/male carers. However, there was diversity in child ages, gender, and eczema severities. Interviews were also carried out and analysed by the intervention development team, which may have led to bias. Nonetheless, stakeholder consultation with a wider range of stakeholders, including patient/parent representatives, was used throughout to ensure key aspects were not missed.

Comparison with the existing literature

Existing literature supports the finding that parents/carers feel there is a lack of reliable information about eczema and its treatments,(33,34) and that most parents/carers navigate this through a process of trial and error.(4) The finding that parents/carers report doubts and concerns about topical treatments, particularly TCS, is also supported.(3,5)

To our knowledge, there has been no research into parents/carers' views and experiences of co-managing eczema with children,(2) although research with children suggests conflict between parents/carers and children.(35) The current research suggests that parents/carers may be reluctant to transition care to their child, even when children want to self-manage, which is an issue that has been identified in other long-term health conditions, such as asthma and diabetes.(35) The current intervention supports co-management and provides resources for parents/carers to teach their child about eczema and its treatments. Qualitative research suggests that young people with eczema struggle to make sense of eczema and its treatments despite having it since childhood.(36) This research highlights the importance of information given about eczema and its treatments in childhood, and the potential impact this can have on treatment use. It is hoped that the focus on co-management in ECO for

Families may help parents/carers support their child's transition to self-management as they get older.

Implications for research and practice

A key finding in the think-aloud interviews was that parents/carers who have been caring for their child's eczema for a while may believe that they already know how to use emollients and TCS. However, it was clear that there were still important gaps in their knowledge. This supports NICE recommendations that healthcare professionals refresh parents/carers' knowledge of how to use treatments when they reconsult.(1) The current research suggests that key elements include: when and how to use emollients and TCS and, crucially, their different purposes. Parents/carers' skills can be enhanced by demonstrating how to use treatments and involving children in this could help with transitioning to co-management. Behaviour change strategies for addressing concerns and doubts are also suggested, which include detailed explanation of when and how to use TCS safely.

In conclusion, ECO for Families aims to address key barriers to parents/carers effectively managing their child's eczema. It supports a co-management approach, with the aim of facilitating the child's later transition to self-management. Effectiveness and cost-effectiveness of ECO for Families are being evaluated in a randomised controlled trial, alongside a nested process evaluation to explore parents/carers experiences of the intervention, factors influencing user engagement and outcomes, potential mechanisms of actions, and issues for implementation. A similar intervention, targeting young people with eczema, has also been developed, and is currently being trialled.

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The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

ETHICAL APPROVAL

Ethical approval was given by Wales REC 7 Ethics Committee (ref: 17/WA/0329).

COMPETING INTERESTS:

The authors have no conflicts of interest to declare.

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SUPPLEMENTARY DATA

Supplementary Box S1: Stage 1 Interview schedule

Supplementary Table S1: Behavioural analysis of ECO for Families Intervention using the Behaviour Change Wheel (BCW) and Behaviour Change Techniques Taxonomy (BCTv1)

Supplementary Box S2: Full description of Eczema Care Online (ECO) for Families in accordance with the Template for Intervention Description and Replication (TIDieR) Framework

Supplementary Box S3: Stage 2 think-aloud interview schedule

FIGURE LEGENDS AND NOTES

Figure 1: Overview of the Person-Based Approach (PBA) to intervention development (reproduced with permission from https://www.lifeguideonline.org/pba)

Figure 2. Final intervention logic model outlining key components and hypothesised mechanisms of Eczema Care Online for Families
Note. TCS=topical corticosteroids, TCIs=topical calcineurin inhibitors

Figure 3: Overview of modules and quick access menus in Eczema Care Online (ECO) for Families

TABLES

Table 1: Characteristics of children of parents/carers taking part in the interviews

Child characteristics	**Stage 1.2: Interviews (N=30)**		**Stage 2.1: Think-aloud interviews (N=25)**	
	Number	**Percentage**	**Number**	**Percentage**
Age group				
- Infant (< 1 year)	3	10%	1	4%
- Toddler (1-2 years)	7	23%	5	20%
- Preschool (3-5 years)	5	17%	10	40%
- Younger school age (6-8 years)	7	23%	3	12%
- Older school age (9-12 years)	8	27%	6	24%
Gender				
- Female	15	50%	16	64%
- Male	15	50%	9	36%
Eczema Severity [+]				
- Mild	14	47%	13	52%
- Moderate	10	33%	10	40%
- Severe	6	20%	2	8%

Note. [+] Participants self-reported what they thought their child's eczema severity was (mild, moderate, severe)

Table 1: Guiding principles for intervention design

Issues	**Source[+]**	**Intervention design objectives to address issues**	**Key Features to address issues**
Parents/carers may not have a lot of time; eczema treatment can be time-consuming and may be challenging to fit into their daily routines.	SR; EO	To create an intervention that is engaging and easy to navigate, in which parents/carers can quickly find the relevant information	• Make most intervention content optional so it can be accessed when/if it is needed • Add filtering questions to help signpost parents/carers to relevant modules • Use a modular layout so that parents/carers can quickly identify and select relevant topics • Ensure information is concise, presented in short chunks • Provide information in a range of formats to improve accessibility (e.g. audio-visual features, interactive features)
Parents/carers may feel distressed by the impact eczema has on their child. They may be struggling to manage their child's eczema, may be sleep-deprived or may worry about the long-term impact of eczema on their child. They may also feel distressed by their child's reaction to treatments (e.g. if the child finds it uncomfortable or painful), which may lead them to avoid, delay, stop, or to use treatments less often than needed	PPI; SR; I	To reduce parents/carers' feelings of helplessness, frustration, self-blame, and guilt about their child's eczema	• Validate and normalise parents/carers' feelings around eczema and its management • Emphasise things that parents/carers can do to help manage their child's eczema, including tips and quotes from other parents/carers • Acknowledge that there are precipitating factors that are out of their control and identify what parents/carers can do to manage flare-ups • Avoid messages that may be viewed as blaming parents/carers for eczema flare-ups • Provide emotional management techniques that can help parents/carers manage difficult emotions

Young children may resist treatments because they dislike them and may not understand why they need them. As children get older, they increasingly encounter situations where they need to take more responsibility for managing their eczema (e.g. starting school, socialising outside the home). They may also want to start to self-manage, so will need to develop their own knowledge and skills for managing eczema.	PPI; SR; I	To facilitate co-management of eczema between parents/carers and their child to support their child's treatment adherence, and support their child's transition towards self-management	• Provide suggestions for ways parents/carers can involve their child in managing their treatment • Provide age-appropriate materials to help children learn about eczema and its management
Children may find eczema painful, itchy, unpleasant, or distressing. They may not understand what eczema is, or why they need to do the things that help them manage their eczema. They may find topical treatments painful, unpleasant, frustrating or boring which may lead them to avoid using treatments or use them less than is needed.	PPI; SR; I	To reduce children's feelings of distress, anxiety, hopelessness, and frustration around eczema and its treatment	• Help parents/carers to understand children's feelings • Provide age-appropriate tools/activities to help children manage difficult emotions related to eczema and its treatment to use on their own or with parents/carers • Provide age-appropriate explanations about eczema and its treatments to help children make sense of eczema and its treatment

Note. [+] SR=systematic review, EO=expert opinion, PPI= patient-public involvement representatives, I=stage 1.2 interviews, TA=stage 2.1 think-aloud interviews

Table 3: Summary of key barriers and intervention ingredients

Key barriers to target behaviours	**Source**[+]	**Key domain targeted**	**Intervention ingredients to address key barriers**
Incomplete knowledge about eczema, its triggers, and its treatment	SR; I; TA	↑Knowledge about eczema and its management	<u>Parents/Carers</u> • Provide information about eczema, its treatment, and triggers • Provide advice about identifying when emollients/TCs are needed for a range of different skin types and severities • Provide information on when to apply emollients/TCSs and when they should use them, and for how long, including advice on identifying the start and end of eczema flare-ups • Provide information about how emollients and TCS differ in terms of their function and how they should be used together • Provide instructional video/photos of how to correctly applying TCSs <u>Children</u> • Explain what eczema is and how it is treated in simple language using videos
Limited skills for managing and co-managing eczema and its treatments (e.g. using creams, supporting transition to child self-management)	SR; I; TA	↑Skills to manage and co-manage eczema with their child	<u>Parents</u> • Use videos to demonstrate how emollients should be applied and how much • Provide suggestions for activities around emollient use to make emollient times more fun and interesting for children (e.g. imaginary games, singing, special toys for emollient times) • Encourage parents/carers to involve their child in applying emollients so they can learn how to do it themselves <u>Children</u> • Use videos to demonstrate how emollients should be applied and how much
Concerns and doubts about emollients and, especially, TCS	SR; I	↑ Positive beliefs about consequences (of using emollients and TCs)	<u>Parents/Carers</u> • Provide a rationale for how emollients and TCs help to manage eczema including when eczema is only mild or not visible on the skin • Provide persuasive and credible information about the effectiveness of emollients and TCs, including scientific evidence, user stories, quotes and videos

Key barriers to target behaviours	Source[+]	Key domain targeted	Intervention ingredients to address key barriers
			• Provide advice about trying out new emollients and finding an emollient that works, including advice on when an emollient should be abandoned to try a new one • Encourage use of a 2-week challenge to evaluate how regular use of an emollient improves eczema symptoms (redness, soreness, itching), and prompt trying a different emollient if it doesn't • Provide advice on how to support child to tolerate the treatments better (e.g. distraction, relaxation) • Provide user stories/quotes about how they dealt with unpleasant reactions in their child • Acknowledge that the process of finding the right emollient can be frustrating/over-whelming/disheartening • Reassure parents/carers that it is ok to ask to change emollients if their child cannot tolerate their current emollient <u>Children</u> • Explain how emollients and TCSs help eczema using easy-to-understand videos

Note. [+] SR=systematic review, EO=expert opinion, PPI= patient-public involvement representatives, I=stage 1.2 interviews, TA=stage 2.1 think-aloud interviews

Figure 1

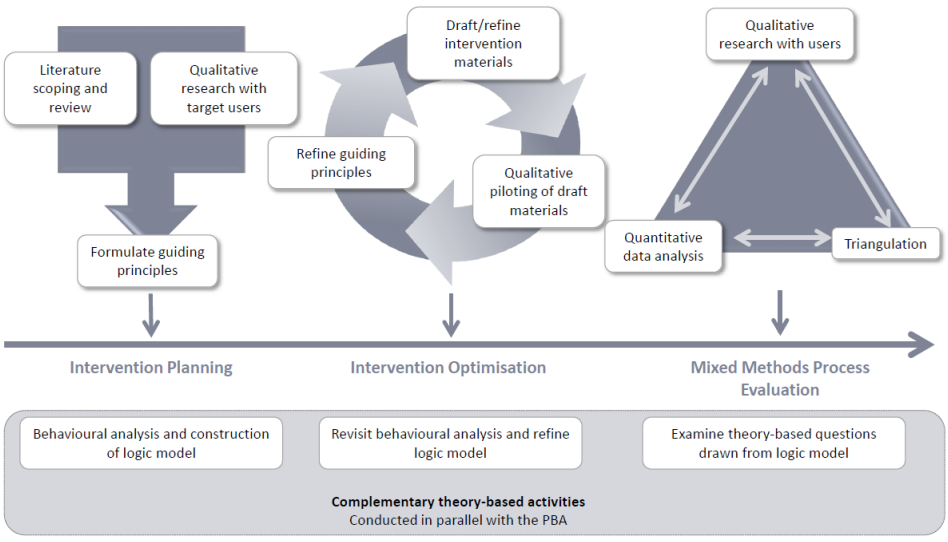

Figure 2

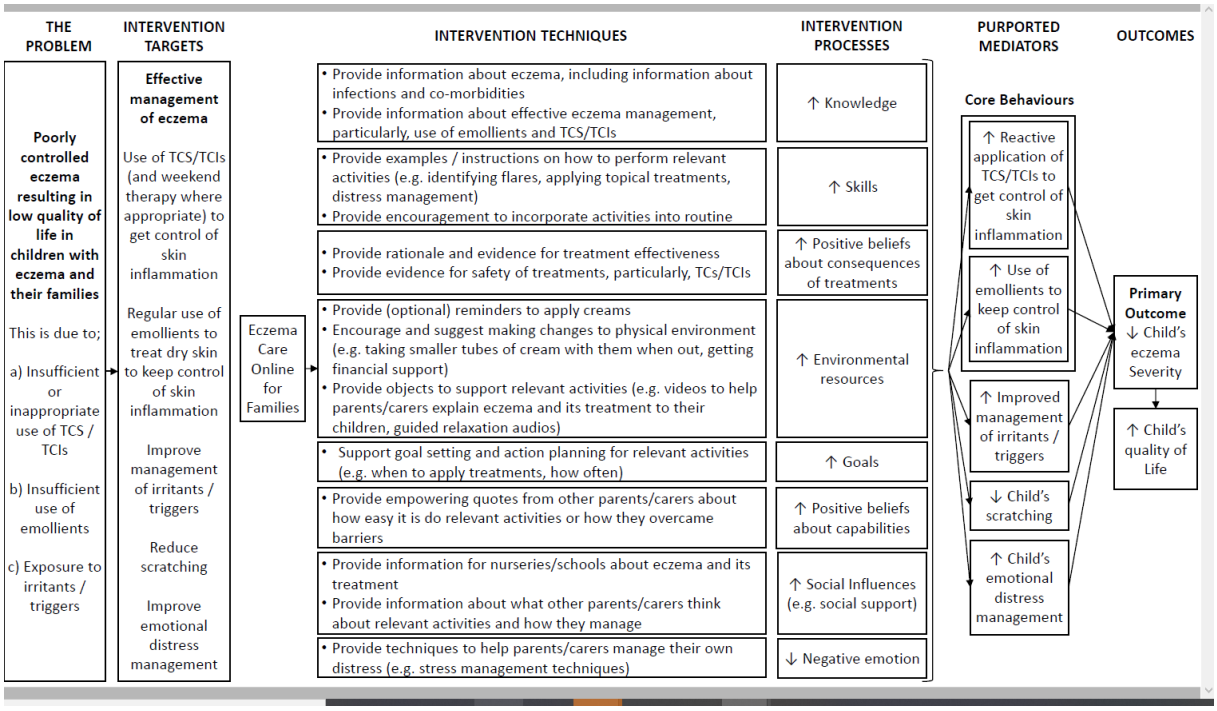

Figure 3