NIHR | National Institute for Health and Care Research

Programme Grants for Applied Research

Extended Research Article

Supporting self-care for eczema in the community: the Eczema Care Online research programme including two RCTs

Ingrid Muller,[1*] Beth Stuart,[1,2] Tracey Sach,[3] Lucy Yardley,[1,4] Kate Greenwell,[1] Taeko Becque,[1] Paul Leighton,[5] Laura Howells,[5] Jane Harvey,[5] Julie Hooper,[1] Mary Steele,[1] Katy Sivyer,[1] Daniela Ghio,[1] Emma Teasdale,[1] Emma Axon,[5] Stephanie Lax,[5] Holly Clarke,[3] Mary Onoja,[3] Amina Ahmed,[6] Gareth Griffiths,[7] Hayden Kirk,[8] Sinead Langan,[9] Sandra Lawton,[10] Paul Little,[1] Matthew Ridd,[11] Amanda Roberts,[6] Hywel C Williams,[5] Kim S Thomas[5†] and Miriam Santer[1†]

[1]Primary Care Research Centre, Faculty of Medicine, University of Southampton, Aldermoor Close, Southampton, UK
[2]Centre for Evaluation and Methods, Wolfson Institute of Population Health, Faculty of Medicine and Dentistry, Queen Mary University of London, London, UK
[3]Health Economics Group, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, UK
[4]School of Psychological Science, University of Bristol, Bristol, UK
[5]University of Nottingham, Centre of Evidence Based Dermatology, School of Medicine, University of Nottingham, Applied Health Services Research Building, University Park, Nottingham, UK
[6]Patient and Public Contributor, Centre of Evidence Based Dermatology, School of Medicine, University of Nottingham, Applied Health Services Research Building, University Park, Nottingham, UK
[7]Southampton Clinical Trials Unit, University of Southampton and University Hospital Southampton NHS Foundation Trust, Southampton, UK
[8]Solent NHS Trust Western Community Hospital, William Macleod Way, Southampton, UK
[9]Department of Non-Communicable Disease, London School of Hygiene and Tropical Medicine, London, UK
[10]Nurse Consultant Dermatology, The Rotherham NHS Foundation Trust, UK
[11]Bristol Medical School, University of Bristol, Bristol, UK

[*]Corresponding author I.Muller@soton.ac.uk

[†]Joint programme leads

Published March 2025
DOI: 10.3310/FNHD8546

Scientific summary

Supporting self-care for eczema in the community: the Eczema Care Online research programme including two RCTs

Programme Grants for Applied Research 2025; Vol. 13: No. 3
DOI: 10.3310/FNHD8546

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

Eczema is a common itchy skin condition with a significant impact on quality of life. For most people with eczema, treatments include flare-control creams [topical corticosteroids (TCSs) and topical calcineurin inhibitors] to manage disease exacerbations and daily emollient moisturisers. The main cause of treatment failure is non-use of prescribed treatments for reasons such as treatments being time-consuming to apply; that they may sting when first applied to inflamed skin; concerns about the safety of some treatments; and because people often receive conflicting or insufficient advice about how and when to use them.

Objectives

1. To understand facilitators and barriers to effective eczema management for patients and parents/carers.
2. To update and combine existing evidence around the safety of TCSs and develop knowledge tools for patients and healthcare professionals.
3. To develop online behavioural interventions to support eczema self-care for patients and parents/carers.
4. To determine the clinical and cost-effectiveness of online behavioural self-care interventions compared to standard clinical care.
5. To formulate and initiate an implementation plan for integrating interventions into clinical practice and facilitating their uptake, informed by process evaluation.

Methods

This programme consists of five related workstreams.

1. Understanding barriers and facilitators to effective eczema management

We carried out extensive qualitative work to inform intervention development.

1. We conducted a systematic review and thematic synthesis of qualitative studies to explore the views and experiences of people with eczema and parents/carers of children with eczema.
2. We conducted a secondary analysis of 23 transcripts of interviews with young people aged 16–25 years with eczema collected as part of the HealthTalk.org SKINS project.
3. Primary qualitative research was conducted with (1) children aged 6–12 with eczema, (2) young people aged 13–25 with eczema and (3) parents/carers of children aged 0–12 with eczema. Participants were recruited through primary care and secondary care. Interviews were analysed using thematic analysis.

Analyses in all three of these studies explored views and experiences of topics such as living with eczema, eczema treatments, perceived causes and triggers and experiences of transitioning to co-management or self-management.

2. Evidence for the best and safest way of using topical corticosteroids

We reviewed the scientific evidence of the best and safest ways of using TCSs for eczema through three systematic reviews of the literature.

1. We conducted an umbrella review of systematic reviews of studies using topical steroids for eczema to summarise what is already known about the safety of using TCSs from published systematic reviews.
2. We conducted a Cochrane review of randomised controlled trials (RCTs) evaluating different strategies for using TCSs to examine the safety and effectiveness of different strategies.
3. We conducted a systematic review of the longer-term safety of TCSs for eczema when used for more than a year.

Key findings informed knowledge support tools for patients and health professionals to support the appropriate use of eczema treatments and ensure consistent messaging and signpost to Eczema Care Online (ECO).

3. Developing interventions to support eczema self-care

Two complex behavioural interventions were developed to support eczema management: one for young people aged 13–25 years and other for parents/carers of children aged 0–12 years with eczema. The interventions were online and developed using theory-based, evidence-based and person-based approaches. The interventions were co-produced with an intervention development group which comprised patient and public contributors, dermatologists, nurses, general practitioners (GPs), psychologists and skin researchers. Intervention planning was carried out alongside workstreams 1 and 2 to guide our programme theory and provide us with an in-depth understanding of the key issues, needs and behavioural challenges of our two target groups.

Programme theory was developed for each intervention, including guiding principles, behavioural analysis and an intervention logic model. Intervention materials and prototype interventions were optimised using qualitative think-aloud interviews with participants recruited through database search and mail-outs from eight GP practices. Interviews were analysed using the person-based approach table of changes.

4. Clinical and cost-effectiveness of our online behavioural interventions

Two independent, pragmatic, parallel-group, online RCTs were conducted to determine the clinical and cost-effectiveness of the two online behavioural interventions developed in workstream 3. Participants were recruited through database search and mail-outs from 98 general practices in England. Participants were eligible to take part if they were a young person aged 13–25 years with eczema (trial 1) or a parent/carer of a child aged 0–12 years with eczema (trial 2). People were excluded if they reported very mild or inactive eczema [scoring 5 or less on the patient-oriented eczema measure (POEM)].

Eligible participants were randomised (1 : 1) to receive usual eczema care, or to an online behavioural intervention for eczema plus usual care. Participants in the usual care group were given access to the intervention at the end of the trial period. The primary outcome in both trials was eczema symptoms reported using POEM every 4 weeks for 24 weeks. POEM includes seven questions about the frequency of eczema symptoms over the previous week that are summed to give a score from 0 (no eczema) to 28 (worst possible eczema). Secondary outcomes included POEM scores every 4 weeks over 52 weeks, quality of life, eczema control, itch intensity (young people only), patient enablement, treatment use, adherence problems and intervention use (intervention group only). Service and treatment use data were collected through medical notes review. Separate analyses were carried out for each of the two trials, and according to intention-to-treat principles. Health economic evaluations were conducted from an NHS perspective and included cost–utility and cost-effectiveness analyses.

5. Integrating interventions into clinical practice and facilitating uptake

A qualitative and quantitative process evaluation was nested within the two trials to understand likely causal mechanisms for the interventions, how effects may vary between user groups and settings, and to inform implementation of the interventions. Semistructured qualitative interviews were conducted with a sample of trial participants selected using purposive sampling to ensure a range of ages, gender, ethnicity, eczema severity, socioeconomic status, recruitment site, trial group and intervention usage. Interviews explored views of the website content, delivery features, changes that resulted from the intervention, the impact of the COVID-19 pandemic and reasons for any low intervention usage. Interviews from both groups were analysed together using thematic analysis. Intervention modifications for dissemination were identified using the person-based approach table of changes method.

Intervention usage data were collected to describe patterns of intervention usage for all participants in the intervention arm. Mediation analysis was used to determine whether patient enablement, treatment use or barriers to adherence mediate the intervention effect on eczema severity. Subgroup analysis was carried out to explore whether the intervention effect was different among pre-specified categories of baseline variables. Logistic regression explored associations between higher intervention use and various demographic and baseline factors.

We developed an implementation strategy in consultation with a wide range of stakeholders.

Results

1. Understanding barriers and facilitators to effective eczema management

Database searches and screening identified 39 papers reporting 32 qualitative studies for review. Thematic synthesis of the data identified four overarching analytical themes: (1) eczema not viewed as a long-term condition; (2) significant psychosocial impact of eczema not acknowledged by others; (3) hesitancy (patient/carer uncertainty) about eczema treatments; and (4) insufficient information and advice about eczema. Review findings informed workstream 3 intervention planning and guided our primary qualitative research.

Qualitative data from 72 participants were analysed in this workstream. The sample included 30 parents of children aged 0–12 years, 14 children aged 6–12 years, 5 young people aged 13–16 years, plus secondary analysis of data collected from 23 young people aged 16–24 years (SKINS project). Findings enabled us to develop an in-depth understanding of the views and experiences of young people and families managing eczema. Key barriers and facilitators were identified, which support the development of our programme theory and behavioural interventions in workstream 3.

2. Evidence for the best and safest way of using topical corticosteroids

Database searches for the umbrella review identified 38 systematic reviews of the safety of TCS in eczema which included 106 studies (77 RCTs and 29 observational studies). No evidence was found that TCSs cause harm when used intermittently 'as required' to treatment eczema flares or as 'weekend therapy' to prevent flares. Adverse events were uncommon with short-term use of TCSs, but high-quality evidence was limited.

The Cochrane systematic review of safety and effectiveness of different strategies of using TCSs for eczema included 104 RCTs with a total of 8443 participants. Key findings included evidence that moderate and potent TCS are better than mild TCSs, that once-daily use of TCSs is as effective as twice daily and that 'weekend therapy' is effective and safe for preventing flares. Reported adverse events were infrequent.

Our systematic review of the long-term safety of TCS for eczema included two RCTs (n = 2570, including 1288 receiving TCS), two cohort studies (all participants received some form of TCS n = 148) and three case-control studies (cases n = 10,322, controls n = 12,201). Overall, the limited body of evidence provides some indication that TCSs used intermittently for eczema are safe over periods of up to 5 years, but gaps remain in our understanding of the lifelong effects of TCS use.

Key findings from this programme were developed into a knowledge tool following extensive stakeholder engagement. The tool signpost to EczemaCareOnline.org.uk and focuses on the primary message of the main interventions, 'two treatments used well', to support consistent messaging around treatment use among health professionals and people and families with eczema.

3. Developing interventions to support eczema self-care

Findings from workstreams 1 and 2 informed the programme theory and evidence base for intervention development. The interventions were developed to target the following key behaviours:

- Improve emollient use.
- Improve the use of TCSs for flare-ups.
- Improve management of irritants and triggers.
- Improve emotional management.
- Reduce scratching.

The online interventions were developed and optimised through qualitative think-aloud interviews with 25 parents/carers of children with eczema and 30 young people aged 13–25 years with eczema. Interviews lasted 45–90 minutes and were recorded and transcribed verbatim. Participants found the information and advice clear, easy to follow, helpful and relatable, particularly the quotes and tips from others like them. Participants found the information on TCSs reassuring. Young people found most content interesting and helpful, whereas parents/carers found the initial prototype

intervention lengthy and repetitive, which led to the content being streamlined and made more interactive, which participants valued and found acceptable and engaging.

4. Clinical and cost-effectiveness of our two online behavioural interventions to support eczema management

Three hundred and forty parents/carers of children (169 usual care; 171 intervention) and 337 young people (169 usual care; 168 intervention) were randomised into the trials. All randomised participants were included in the analyses. Retention was excellent: 92.4% (314/340) parents/carers and 90.2% (304/337) young people at 24 weeks.

Our two brief online behavioural interventions to support eczema management for parents/carers of children and for young people provided a useful benefit in eczema severity at 24 weeks. After controlling for baseline severity and confounders, compared with usual care over 24 weeks, eczema severity (POEM) improved in the intervention groups: −1.5 [95% confidence interval (CI) −2.5 to −0.6] for parents/carers, and −1.9 (95% CI −3.0 to −0.8) for young people. Effects were sustained for 52 weeks in both trials. No harm or unintended effects were identified in either group.

We did not detect a difference in the use of eczema treatments between groups, yet did find statistically significant differences between groups in patient enablement instrument scores. Enablement showed an important difference favouring the intervention group in both trials [adjusted mean difference at 24 weeks −0.7 (95% CI −1.0 to −0.4) for parents/carers and −0.9 (95% CI −1.3 to −0.6) for young people].

Economic analysis found that both interventions were low cost and cost-effective with almost all analyses estimating the interventions to be dominant (that is cost saving and more effective than usual care). The exception was the cost–utility analysis for the parent/carer trial where the incremental cost per quality-adjusted life-years was < £20,000.

5. Process evaluation and implementation to integrate interventions into clinical practice and facilitate uptake

Qualitative process evaluation included interviews with 17 parents/carers and 17 young people who took part in the RCTs. Feedback was mostly positive. Participants found the intervention trustworthy and valuable, and participants felt the intervention websites helped them manage their or their child's eczema. Participants reported that ECO helped them to understand and feel confident in managing eczema; improve their use of treatments; avoid irritants and triggers; engage in productive treatment conversations with health professionals; and involve their child in eczema management (parents).

Quantitative process evaluation found that, for parents/carers, about 30% of the intervention effect on the POEM score at 24 weeks was mediated by increasing patient enablement. For young people, about 50% of the intervention effect was mediated by increasing enablement.

Process evaluation showed that the interventions were commonly accessed on smartphones, suggesting the need for an adaptable product and that we needed a stable platform over a few years where software would be updated. As part of our implementation strategy, we therefore decided to redevelop the interventions into a product for dissemination. We worked with a commercial software provider to develop the two interventions into one mobile adaptive website www.eczemacareonline.org.uk. Theory-informed analysis of the qualitative work in this programme and stakeholder consultations also enabled us to identify value propositions (unique identified benefits of the product within the marketplace), target audiences, key stakeholders and avenues for implementation.

Conclusions

We have developed, tested and implemented online interventions to support the self-management of eczema. The benefits on clinical outcomes of using the ECO intervention have been demonstrated in two RCTs, targeting two key user groups: parents of children with eczema and young people learning to manage their own eczema. A within-trial cost-effectiveness analysis suggests that use of the intervention represents value for money for the NHS, resulting in potential cost savings and improved outcomes.

In eczema, self-management support is particularly important due to the complexity and high burden of treatment adherence. By promoting the use of ECO, as well as providing evidence that the interventions improve eczema outcomes, we hope that signposting to self-management support will become increasingly embedded in routine care.

Our two interventions have been redeveloped into one website www.eczemacareonline.org.uk. This resource is freely available in English and Welsh.

Trial registrations

The trial is registered as Current Controlled Trials ISRCTN79282252.

- Workstream 1: systematic review of qualitative studies PROSPERO registration number CRD42018110496.
- Workstream 2: umbrella review PROSPERO registration number CRD42018079409.
- Workstream 2: Cochrane review CD013356.
- Workstream 2: long-term safety review PROSPERO registration number CRD42021286413.
- Workstream 4: trials are registered ISRCTN79282252.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Programme Grants for Applied Research programme (NIHR award ref: RP-PG-0216-20007) and is published in full in *Programme Grants for Applied Research*; Vol. 13, No. 3. See the NIHR Funding and Awards website for further award information.

Programme Grants for Applied Research

ISSN 2050-4330 (Online)

A list of Journals Library editors can be found on the NIHR Journals Library website

Programme Grants for Applied Research (PGfAR) was launched in 2013 and is indexed by Europe PMC, NCBI Bookshelf, DOAJ, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA) and Scopus® (Elsevier, Amsterdam, Netherlands).

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar.

Criteria for inclusion in the *Programme Grants for Applied Research* journal

Manuscripts are published in *Programme Grants for Applied Research* (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Programme Grants for Applied Research programme

The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health and Care Research (NIHR), was established in 2006 to fund collaborative, multidisciplinary programmes of applied research to solve health and social care challenges. Findings are expected to provide evidence that lead to clear and identifiable patient benefits, in the relatively near future.

PGfAR is researcher led and does not specify topics for research; however, the research must be in an area of priority or need for the NHS and the social care sector of the Department of Health and Social Care, with particular emphasis on health and social care areas that cause significant burden, where other research funders may not be focused, or where insufficient funding is available.

The programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director. For more information about the PGfAR programme please visit the website: https://www.nihr.ac.uk/explore-nihr/funding-programmes/programme-grants-for-applied-research.htm

This article

The research reported in this issue of the journal was funded by PGfAR as award number RP-PG-0216-20007. The contractual start date was in September 2017. The draft manuscript began editorial review in March 2023 and was accepted for publication in October 2024. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

This article presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, PGfAR or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the PGfAR programme or the Department of Health and Social Care.

This article was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).