

Supporting Self-Management of Eczema Through Research

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Conflicts of interest: part of the research teams for the projects discussed, member of the Harmonising Outcome Measures for Eczema (HOME) initiative



What I will talk about today

 Our recent eczema research making a difference for people selfmanaging their eczema



Impact of Eczema Care Online – self-management toolkit



 Rapid Eczema Trials – citizen science project, codesigning trials with patients



 Tracking of eczema to support self-management -EczemaNet / My Eczema Tracker

What is in Eczema Care Online?

- Support effective eczema management through
 - Improved use of topical corticosteroids for flare-ups
 - = flare control creams
 - Regular emollients to prevent flare-ups
 - = moisturising creams
 - Improved management of irritants and triggers



WELCOME TO THE

Eczema Care Online toolkit

Eczema Care Online is a website to help you manage eczema. It will help you to keep your skin healthy and live well with eczema.

Quickly get the best info for you

Take the quiz











Key features of Eczema Care Online

www.EczemaCareOnline.org.uk

- Free, no registration
- Evidence-based, behaviour change intervention
- Suitable for children and adults
- Two RCTs shown improved eczema symptoms and reduced healthcare costs



BMJ 2022; 379 doi: https://doi.org/10.1136/bmj-2022-072007

www.EczemaCareOnline.org.uk – routes to implementation

Eczema charities

- National Eczema Society
- Eczema Outreach Support

Clinical practice

- Primary care electronic systems
- GP and pharmacy training modules (Red Whale, NB Hot Topics)
- Secondary care advice & guidance templates
- National Guidelines

Social media

Advertising on Facebook, Instagram, Google



Being accessed all over the world...over 100,00 visitors



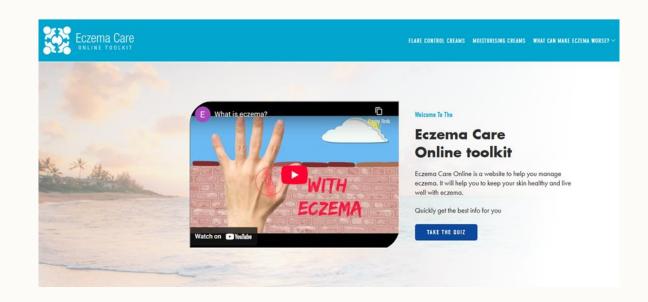


Impact in Australia Feb 2024 to Sept 2025

- 11,682 unique users navigated from Eczema Support Australia website to Eczema Care Online toolkit.
- High demand for practical guides and care plan resources
- Integrated with the Quality Use of Medicines (QUM) Eczema Program
 - government-funded initiative aimed at improving primary care management of eczema.

Eczema Support Australia

https://www.eczemasupport.org.au/eczema-care-online/





Happy to share and avoid duplicated effort

- ECO development took 2 years based on theory and latest evidence
 - Over 100 people with lived experience of eczema
- Currently working with colleagues in The Netherlands, Sweden and France – would love to work with others to make available in your countries too

 Resources can be tailored to local country's needs to be most effective

All publications here





What is the Rapid Eczema Trials project?





Building an eczema citizen-science community

to prioritise, design and run <u>online</u> clinical trials about the self-management of eczema and to share knowledge widely

5-year project (NIHR Programme Grant for Applied Health Research)

So what is so special about the Rapid Eczema Trials Project?



Multiple, efficient trials

Each learning from the one before Master protocol for all trials



Community of people interested in what we are doing

Each contributing in a way that works for them



Eczema Priority Setting Partnership (2012)

Identified FIVE priorities for patients

- What is the best psychological treatment for itching/scratching in eczema?
- Which is the best way for people with eczema to wash?
- What are the best and safest <u>natural products</u> to apply to the skin for eczema?
- How much does <u>avoidance of irritants and allergens</u> help people with eczema?
 Rapid

Creating research together

What is the role of <u>diet</u> in treating eczema



Our first Rapid Eczema Trial.....

Which is the best way for people with eczema to wash?



Co-designed with the eczema community







Prioritization

Intervention Development

Trial Development







9 months to create

13 online meetings

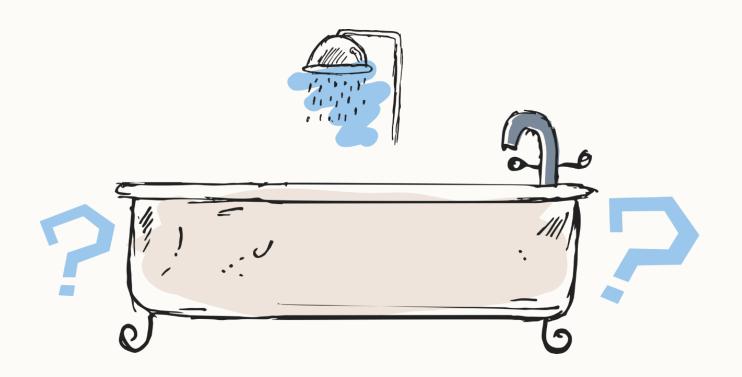
2 community surveys





Our Research Question

Does weekly bathing improve eczema symptoms compared to daily bathing for people with eczema over 4 weeks?



- Recruited 438 participants
- Aged 1 year and older
- Online trial

See poster #1025 [Sunday: Booth A, poster session 4]

Views from our Citizen Scientists















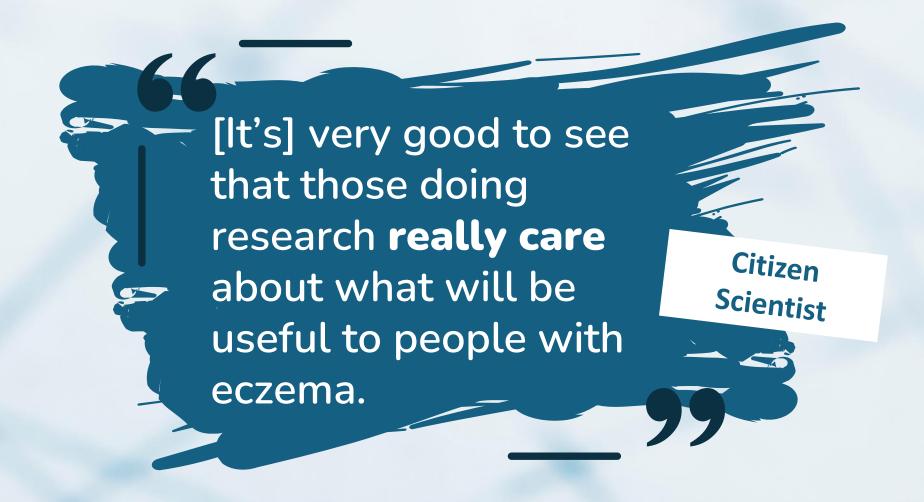
























Coming next





www.RapidEczemaTrials.org



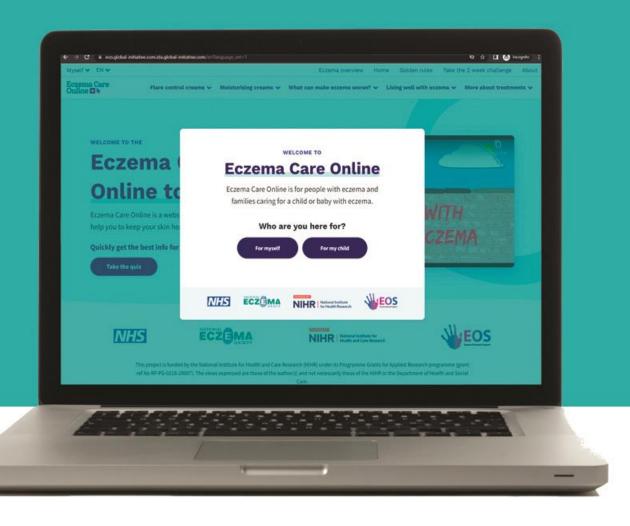
- Does giving advice to treat for 2 days after the eczema looks and feels clear improve eczema control compared to normal care (no specific advice)
- 4-month study
- Now recruiting adults and children



- Does a 3-week online programme to break the itch-scratch cycle improve eczema symptoms compared to usual care?
- 4-month study
- Two RCTs one in children, one in adults
- In set-up (starting 2026)

Everything you need to know to live well with eczema.





EczemaCareOnline.org.uk



Why this is important

 There will always be more questions than answers for people living with eczema

- Patients are often given "well meaning" but conflicting advice due to lack of evidence
 - Erodes trust in healthcare professionals
 - Causes confusion and frustration
 - Promotes to spread of misinformation



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Time to get involved ...

Milk avoidance

- Aaron Drucker et. al.
- Using Rapid Eczema
 Trials methods to
 develop an online RCT in
 Canada / USA
- Aiming to start 2026

Avoidance of triggers

- Danielle Paea et. al. (2025) Australian J of Dermatol (Melbourne)
- Eczema Triggers Identification Questionnaire
- Simple, low-cost intervention



A new dawn for patient-focussed eczema trials

www.RapidEczemaTrials.org



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- Running eczema trials in low- and middle-income countries?
- Running trials in other chronic health conditions eg asthma?



Eczema Tracking to support self-management

- Low tech and high-tech solutions
 - EczemaNet uses AI to assess severity from photos
 - My Eczema Tracker validated questionnaires (POEM and RECAP)



Improved remote assessment of eczema severity

EczemaNet uses AI technology to reliably assess eczema severity in all skin tones using uploaded photos

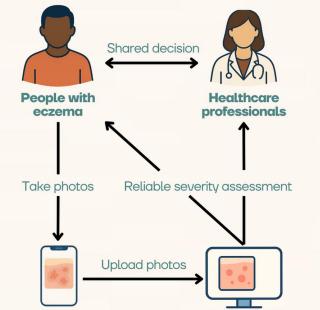
With EczemaNet

people with eczema can

- monitor changes in eczema severity at home
- inform your healthcare provider more effectively about the severity of eczema
- plan the most appropriate treatment more easily

healthcare professionals can

- obtain key information for monitoring eczema severity that can aid shared decision making with patient on a treatment plan
- decide whether specialist referral is needed
- potentially reduce the number of repeat face-to-face appointments





Find out more





Eczema Monitoring Online Trial



Eczema Monitoring Online (EMO)

Eczema Monitoring Online (EMO)

What is EMO?

Taking Part

Meet the Team

Welcome to the EMO study



EMO is a fully online research study looking at how eczema changes over time and how people manage their eczema remotely.

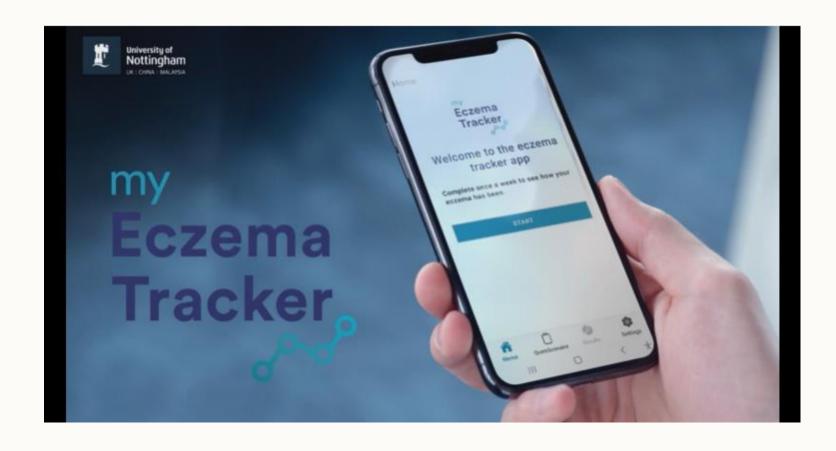
- Online trial with 296 people with eczema randomised to:
 - weekly completion of POEM (7 questions about eczema symptoms)
 - Completion of POEM at baseline and week 8 only



- Found a small but significant difference in eczema symptoms for those who had completed the weekly symptom questionnaires (POEM) compared to usual care
- Average difference between the groups = 1.64 points (95% confidence interval 2.91 to 0.38 points)
 - Small difference, but this is a very simple, self-management intervention



My Eczema tracker



- App for tracking eczema over time
- Includes:
 - Eczema Symptoms (POEM)
 - Eczema Control (Recap)
 - Notes to record treatments and triggers
- Free and no registration needed
- Data remain on personal phone – but can downloaded and shared with healthcare providers

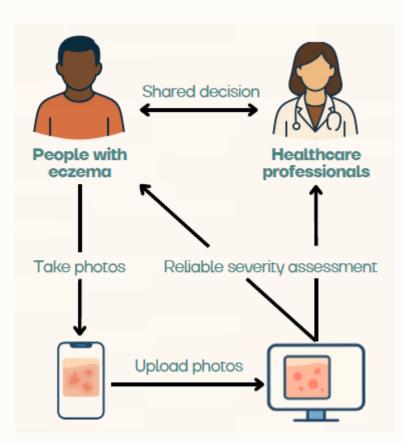


EczemaNet



- Al tool to assess eczema severity from photographs
- Built to be suitable for all skin tones
- Helps patients to understand when to use eczema treatments
- Aids communication between:
 - Patients and healthcare professionals
 - Primary care and secondary care health professionals







What I have covered....

- Three research projects all supporting people to 'live better with eczema'
- All have strong patient input throughout the research journey
- All are making an impact on people's lives
- Really happy to share resources and expertise

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The views expressed are those of the authors and not necessarily those of the NIHR of the Department of Health and Social Care.











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Ezcema Support Organisations











A short story about the impact of eczema...

