

National Eczema Society Research Strategy 2024-27

Advancing eczema knowledge and care through research

Introduction

Eczema affects 1 in 5 children and 1 in 10 adults in the UK, and impacts both physical and emotional health. This chronic itchy skin condition is influenced by many factors including the immune system, genetics and environment. It affects people in different ways with varying degrees of severity, symptoms, and triggers. Eczema can be very difficult to live with.

National Eczema Society is a UK charity, working to make life better for people with eczema and their families. We provide information and support, advocating for patients and campaigning for better care. We already play a key role in major eczema research initiatives through promoting patient involvement in surveys and workshops, supporting trial recruitment, and providing patient perspectives as a member of trial steering groups, co-applicant or organisational partner. We are seen as the go-to organisation for PPI involvement in eczema studies but have had to decline many such requests because of lack of resource. We now want to expand our research contributions.

This strategy sets out our plans to leverage the charity's influence and funds to deliver the biggest impact we can for the eczema community.

Shaping eczema research

Despite the number of people affected and the impact on quality-of-life, eczema research remains relatively underfunded. Large-scale eczema projects are often driven by commercial interests. NES wants to support research which is relevant and impactful for the eczema community. We are in a unique position to identify those research questions and to ensure the voices, experiences and priorities of people with eczema are represented in research. We have a national profile that enables us to influence the wider eczema research agenda and are well placed to bring together patients, researchers, clinicians, healthcare providers, regulators and industry.

Identifying research priorities

Priorities for eczema research were explored jointly by patients, researchers and clinicians in a Priority Setting Partnership (PSP) facilitated by the James Lind Alliance (JLA) in 2011. Projects aligning with those priorities have been viewed more favourably by public funding bodies such as NIHR. However, the landscape of eczema research and treatment has evolved considerably since the 2011 PSP. An updated

PSP is critical to ensure that NES's research priorities remain relevant, patient-centred, and aligned with current scientific, healthcare, and societal contexts. Therefore, we propose to invest up to £50k in developing a new PSP, jointly with JLA and other interested parties.

In general, we aim to focus research particularly on neglected aspects of eczema including newer areas such as topical steroid withdrawal, and delivery of care which is often overlooked by larger funding bodies.

Making best use of funds

We are ambitious in our goals but relatively small in research funding terms. We simply do not have the resources to fund large or long-term projects and have to be strategic in how we utilise our funding. So, we will offer innovation and pump-priming grants to encourage new ideas and support pilot or feasibility studies that can be developed into larger trials with funding from other sources. We will also offer PhD studentships to early-career researchers, nurturing scientists for the future.

As a small charity we can achieve more by working in partnership with other charities and funding bodies. By contributing to joint research calls with other organisations, we can leverage resources and expertise to optimise our collective impact. We are willing to work with industry where goals are aligned, for the benefit of the eczema community.

The research budget will be determined each year by the Board of Trustees. Our plans need to be flexible and agile so we can respond quickly to emerging opportunities.

Involving the eczema patient community

We will establish an 'Experts by Experience' Panel to support patient and public involvement in eczema research. Panel members will be able to contribute to the charity's research work and share their lived experiences and views with researchers. We will support our patient panel with comprehensive induction, regular communications and periodic meetings. We want to ensure that research translates into tangible benefits for patients, such as improved self-management and enhanced healthcare delivery.

Awarding grants (See link for full details of application process and terms and conditions.)

Each year we will award one or more of the following:

PhD Studentship: £100,000 for a 24–36-months.

Innovation grant: for £5,000-£20,000 for 12-months.

Pump-priming grant: ranging between £10,000 and £30,000 for 12-months.

There will be one funding round per calendar year.

Call for Proposals Announced: December 2024

Proposal Submission Deadline: Start of March 2025

Review Period: Mid-March 2025

Invited to In-person Presentation for PhD Studentships ONLY: Start of April 2025

Award Announced: Start of May 2025

All complete applications will be anonymised and undergo expert review by NES's Grant Advisory Panel (GAP). NES GAP will include members of Medical Advisory Board, Expert by Experience panel as well other invited external professionals with relevant expertise as needed. Applications will be reviewed and ranked, taking into account strategic fit within NES's research strategy and aims, scientific quality, potential impact to people living with and supporting those with eczema, feasibility, value for money and the expertise of the research team. The top-ranked PhD Studentships will be shortlisted and invited to present their research proposals, in-person, to NES Grant Advisory Panel. The top-ranked pump priming applicants will be invited to give a 10-minute presentation of their proposal, virtually, to the GAP. As an introductory member of the Association of Medical Research Charities (AMRC) NES adheres to sector-wide best practice for expert-review process for funded research.

Publicising NES research

We are committed to disseminating and implementing research findings in an open, accessible manner. Awardees will be encouraged to publish their findings in expert-reviewed journals and at conferences. We ask research partners to formally acknowledge the Society's contribution. We will share the results and impact of NES-supported research with the eczema community through our website, *Exchange* magazine, newsletters and social media platforms.

Updating our research strategy

We will monitor the impact of the research we fund to ensure our research programme is meeting its objectives. We will engage with the eczema community to keep our strategy relevant and impactful. We will review and update our research strategy every three years, to ensure our research programme remains relevant and responsive to new opportunities.

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Next review scheduled: March 2027