

The Eczema Priority Setting Partnership: A Collaboration Between Patients, Carers, Clinicians and Researchers to Identify and Prioritize Important Research Questions for the Treatment of Eczema

Batchelor et al. (2013)
<https://doi.org/10.1111/bjd.12040>

For which topic were research priorities identified?

eczema

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Eczema is a common condition, yet there are uncertainties regarding many frequently used treatments. Knowing which of these uncertainties matter to patients and clinicians is important, because they are likely to have different priorities from those of researchers and funders.

What was the objective?

to identify the uncertainties in eczema treatment that are important to patients who have eczema, their carers and the healthcare professionals who treat them

What was the outcome?

a list of 14 research questions

How long did the research prioritization take?

April 2011 - January 2012

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: identification of potential partner organizations and individuals. Step 2: survey: participants invited to submit up to five eczema treatment uncertainties based on the question: What question(s) about eczema treatments would you like to see answered by research?, 1070 submitted questions, 61 uncertainties from U.K. DUETs added. Step 3: data processing: data cleaning, unique questions combined to indicative uncertainties, questions reworded, selecting only treatment uncertainties with more than one submission, 52 indicative uncertainties remained. Step 4: interim ranking: via survey, participants were asked to select top 10 indicative uncertainties. Step 5: review of results by steering group: ranked uncertainties were examined as both a single combined list and for the two groups (patients/carers - HCPs) separately, shortlist of 14 priority areas was created. Step 6: final prioritization: workshop: to formulate research questions based on shared (patient/carer and HCPs) uncertainties, four discussion groups, group members received summary information about each indicative uncertainty, each of the groups was asked to address up to four treatment uncertainties

Which stakeholders took part?

Survey: 493 participants (341 patients/carers, 132 HCPs and 20 unclear). Interim ranking: 514 participants (399 (78%) patients or carers, 106 (21%) HCPs, remaining 9 unclear). Workshop: 40 participants (11 patients, 17 HCPs, seven researchers, 4 facilitators and 1 observer).

How were stakeholders recruited?

Potential partner organizations and individuals were identified through a process of peer knowledge and consultation, using the steering group members' networks and through the JLA's existing register of affiliates. Representation of the following groups was ensured: people who have had eczema; carers of people who have had eczema; and doctors, nurses and professionals allied to medicine with clinical experience of eczema. The survey was advertised through a combination of direct e-mails and newsletters to members of the partner organizations, and through links on relevant websites. Individuals with eczema who had been in contact with the Centre of Evidence-Based Dermatology and the JLA were contacted directly and invited to participate.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process. They were part of a steering group. The steering group consisted of 14 patients and carers (including a representative from the National Eczema Society), 4 healthcare professionals (2 dermatologists, a dermatology nurse specialist and a general practitioner), 3 researchers/administrators at the Centre of Evidence-Based Dermatology. Members were involved in data processing and interim ranking.



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