

# Identifying Acne Treatment Uncertainties via a James Lind Alliance Priority Setting Partnership

Layton et al. (2015)

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## For which topic were research priorities identified?

acne

## In which location was the research priority setting conducted?

Europe - United Kingdom

## Why was it conducted at all?

So far, no PSP has targeted a disease with peak prevalence during adolescence in mainly healthy subjects. Although acne is starting earlier<sup>4</sup> and lasting longer, possibly as a result of lifestyle changes, peak prevalence is between the ages of 16 and 20 years. The age range of acne now spans five decades; few teenagers in Westernised societies are able to avoid acne in one form or other. For reasons that remain poorly understood, postadolescent acne is more common in women than in men. Acne was one of three skin conditions in the top 10 most prevalent diseases worldwide in 2010. However, the most widely used treatments have changed little in the past 30 years. Systematic reviews have consistently shown a paucity of robust evidence from adequately powered randomised controlled trials. When compared with disease burden as estimated by disability-adjusted life years from the Global Burden of Disease 2010 project, acne is under-represented in the Cochrane Database of Systematic Reviews.

## What was the objective?

to identify and rank treatment uncertainties by bringing together people with acne, and professionals providing care within and beyond the National Health Service

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

November 2012 - March 2014

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: setting up PSP: partner organizations contacted, informal meeting held, survey drafted. Step 2: collecting uncertainties: via survey to complement search of research recommendations within recent, relevant and reliable systematic reviews or treatment guidelines undertaken, 8276 questions submitted. Step 3: data processing: responses collated into themes, check against evidence, out-of-scope removed, top 30 most popular themes taken forward. Step 4: interim ranking: participants were asked to choose the three questions they felt were most important and to rank them, steering group appraised ranked scores from patients and professionals and selected 18 uncertainties to be taken forward based on highest ranking by both groups. Step 5: final prioritization: workshop: participants provided with ranks from vote and number of related submissions from survey 1, small group discussions with nominal group technique, small group rankings, plenary discussion

## Which stakeholders took part?

Teenagers and adults with acne, parents, partners, nurses, clinicians, pharmacists, private practitioners. Survey: 2288 participants (1636 patients or family members and 652 professionals). Interim ranking: 2822 participants: 1573 people with acne, 237 family members and 1012 professionals. Workshop: 43 participants: 13 patients, 12 professionals, 13 observers.

## How were stakeholders recruited?

organizational stakeholders were asked to promote the PSP and survey to members via email, via their own website or in any other way they wished. Posters and flyers were sent to local and specialist centres within the UK. In addition, a national chain of community pharmacies distributed flyers via their branches. A dedicated Twitter account was set up. Steering group members were asked to email colleagues and contacts and/or put adverts in local newsletters. Two national health-related organizations, Talk Health and Embarrassing Bodies, promoted the survey via a variety of mechanisms including their own websites. A celebrity agreed to endorse the PSP on the home page of the website and another generated a promotional video. The same methods used to promote the harvesting survey were used to promote the vote.

## 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 representatives of the JLA, people with acne, healthcare and academic professionals involved in treatment delivery, experts in patient and public involvement in research and information management. The members were involved in all steps.



LUDWIG  
BOLTZMANN  
GESELLSCHAFT

LBG Open Innovation in Science Center  
Ludwig Boltzmann Gesellschaft GmbH

Nußdorfer Straße 64, 2. Stock  
1050 Wien, Österreich