

Establishing and Prioritizing Research Questions for the Treatment of Alopecia Areata: The Alopecia Areata Priority Setting Partnership

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For which topic were research priorities identified?

alopecia areata

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Alopecia areata is a common hair loss disorder that results in patchy to complete hair loss. Many uncertainties exist around the most effective treatments for this condition.

What was the objective?

to identify uncertainties in alopecia areata management and treatment that are important to both service users (people with hair loss, carers and relatives) and healthcare professionals

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

March 2014 - November 2015

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: identification and invitation of potential partners. Step 2: collecting uncertainties: survey asking: Do you have questions about prevention, diagnosis or treatment of hair loss that need to be answered by research?, 2747 responses. Step 3: data processing: reviewing submissions, excluding questions out-of-scope, generating indicative uncertainties, 1015 questions relating to alopecia areata, to reduce large number of indicative uncertainties an interim list was created by steering group by giving weight to questions asked by more than one person and questions asked by both patients and healthcare professionals, resulting in top 51 uncertainties. Step 4: interim ranking: via survey, participants were asked to choose up to ten uncertainties from the interim list, resulting in shortlist of top 25. Step 5: final prioritization: workshop: with nominal group technique, 3 small group discussions and small group rankings, 3 whole group discussions

Which stakeholders took part?

Service users (people with hair loss, carers and relatives) and healthcare professionals. Survey: 912 participants. Interim ranking: 87 participants. Workshop: 19 participants: 7 patients and 12 healthcare professionals (5 dermatologists, 3 trichologists, 3 GPs and 1 psychologist).

How were stakeholders recruited?

Stakeholders were identified through a process of consultation and peer knowledge, building on SG members' networks and existing JLA's affiliates. Through engagement with the various partner organizations, local advertisement and via social media, a range of people with different hair loss conditions, their carers and relatives, and healthcare professions were targeted.

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 4 people with hair loss representing various patient support groups, 4 dermatologists, 1 psychologist, 1 registered trichologist, 1 general practitioner, and 1 JLA advisor. The members oversaw the process, were involved in data processing and interim ranking and participated in the workshop.