

Larger studies to confirm the efficacy and long-term effects of high-dose IVIG in grade IV cutaneous aGVHD are warranted.

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The top 10 research priorities for psoriasis in the U.K.: results of a James Lind Alliance psoriasis Priority Setting Partnership

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DEAR EDITOR, Psoriasis is an immune-mediated inflammatory skin disease, with a prevalence of 0.09–11.4%, which affects approximately two million people in the U.K.^{1,2} It has a significant psychological and social impact on affected individuals, is associated with comorbidities such as depression, cardiovascular disease and inflammatory arthritis, and confers a substantial economic burden on the National Health Service.^{1–3} Access to appropriate care that addresses the high healthcare burden and complex interlinked physical, psychological and social needs of those who have psoriasis is often poor.³ There remain many unmet needs and unanswered questions about psoriasis, which, if addressed by research, could improve clinical outcomes for patients.

In order to identify the most important research priorities, from the perspective of both patients and healthcare professionals, a psoriasis Priority Setting Partnership (PSP) was set up. A steering group, comprising patients and healthcare professionals, had oversight of the project and worked in collaboration with key stakeholders including the Psoriasis Association, the major patient support group for psoriasis in the U.K. The James Lind Alliance (JLA) facilitated the project.

Table 1 Top 10 priorities for research in psoriasis, in rank order of priority

1. Do lifestyle factors such as diet, dietary supplements, alcohol, smoking, weight loss and exercise play a part in treating psoriasis?
2. Does treating psoriasis early (or proactively) reduce the severity of the disease, make it more likely to go into remission, or stop other health conditions developing?
3. What factors predict how well psoriasis will respond to a treatment?
4. What is the best way to treat the symptoms of psoriasis: itching, burning, redness, scaling and flaking?
5. How well do psychological and educational interventions work for adults and children with psoriasis?
6. Does treating psoriasis help improve other health conditions, such as psoriatic arthritis, cardiovascular disease, metabolic syndrome and stress?
7. Why do psoriasis treatments stop working well against psoriasis, and when they stop working well, what's the best way to regain control of the disease?
8. To what extent is psoriasis caused by a person's genes or other factors, such as stress, gut health, water quality or change in the weather and temperature?
9. Is a person with psoriasis more likely to develop other health conditions (either as a consequence of psoriasis or due to the effect of treatments for psoriasis)? If so, which ones?
10. What's the best way to treat sudden flare-ups of psoriasis?

The JLA is a non-profit-making initiative established in 2004, funded by the National Institute for Health Research, to support PSPs.⁴ The JLA argue that medical research often overlooks the questions that patients, carers and healthcare professionals consider important and that many areas of potentially important research are therefore neglected and limited research funding wasted.⁵ The JLA functions to enable a dialogue between these groups to prioritize the unanswered questions about prevention, diagnosis, treatments and service delivery for a specific disease of interest.⁶

Throughout the psoriasis PSP, the term 'healthcare professional' was defined as all types of health and social care professionals and clinicians with experience of caring for people with psoriasis.⁶ In keeping with JLA guidance, representatives of the pharmaceutical industry and researchers or scientists who are not also clinicians, patients or carers were excluded from participating in the process.⁶

Using methodology established by the JLA⁶ we gathered questions (uncertainties) using an online and paper-based survey from those with lived experience of psoriasis and healthcare professionals (July to November 2017).⁷ In our first survey, 2133 questions were submitted by 805 individuals, including 71% from patients, 22% from healthcare professionals and 6% from others. Overall 10% were from black and minority ethnic groups and 62% were female. Each submission was appraised to ensure that it had not already been answered by existing research, verifying it as a true uncertainty. The JLA definition of an evidence uncertainty is that (i) no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty exist and/or (ii) up-to-date systematic reviews of research evidence show that uncertainty exists.⁶

We supplemented our survey submissions by including 60 uncertainties identified as 'evidence gaps' or 'research recommendations' from systematic reviews and guidelines published in the last 5 years, while removing uncertainties that were out of scope. For each verified uncertainty, the source of verification was identified and tabulated.⁸ Uncertainties were then refined to produce 55 indicative questions reflecting the overarching themes of the original submissions.

A second survey was conducted, with voting and ranking by 1154 respondents (June to August 2018). Individuals were able to participate in one or both surveys. Participation in survey 2 was not dependent on having previously participated in survey 1. A shortlist of 20 questions was drawn from the highest-ranked priorities from survey 2 by the steering group and used in the final priority setting workshop held in London in September 2018. These shortlisted priorities included the top 10 questions ranked by patients/carers and the top 10 questions ranked by healthcare professionals. Facilitated by three JLA advisors, 26 workshop participants (58% patients, 42% healthcare professionals) reached consensus on the top 10 research priorities for psoriasis (Table 1).⁸

Workshop delegates were drawn from all parts of the U.K. Healthcare professionals attending the workshop included representatives from primary care, secondary and tertiary care dermatology, rheumatology, psychology, community- and

hospital-based nursing, and our partner organizations – the British Association of Dermatologists, British Dermatological Nursing Group, Primary Care Dermatology Society and International Psoriasis Council. Patient representatives (47% men, 53% women) included those with psoriasis or comorbidities of psoriasis, and family members or carers of those with psoriasis. Three individuals – including the PSP information specialist, PSP administrator and U.K. Dermatology Clinical Trials Network, University of Nottingham delegate – attended the workshop but did not participate in priority setting.

The Psoriasis PSP had some limitations. Individuals from black and minority ethnic groups and male patients with psoriasis were relatively under-represented. However, considerable effort was made to enfranchise all views within the psoriasis community and to collect responses from different types of healthcare professionals across a variety of clinical sectors. Collating the large number of submissions in survey 1, for prioritization in survey 2, required grouping of the original submissions into broad themes. However, our survey 1 submissions reached saturation, with no new themes emerging in the later stages of the survey period.

The top 10 priorities, representing the key issues faced by the psoriasis community, will inform the translational research agenda for psoriasis. Addressing these questions will ensure that future research is relevant for the needs of people with psoriasis and result in improved clinical outcomes for patients.

Acknowledgments can be found in Appendix S1 (see Supporting Information).


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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Appendix S1 Acknowledgments.