

# Developing a protocol to identify and prioritize research questions for psoriasis: a James Lind Alliance Priority Setting Partnership\*

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## Summary

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### Funding sources

This paper presents an independent study funded by the Psoriasis Association and facilitated by the James Lind Alliance.

### Conflicts of interest

None to declare.

Full details of the members of the Psoriasis Priority Setting Partnership Steering Group are listed in Appendix S1 (see Supporting Information).

\*Plain language summary available online

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**Background** Psoriasis affects over two million people in the U.K. It has a significant psychological and social impact on individuals and an associated high economic cost to the U.K. National Health Service. There are many unanswered questions about psoriasis.

**Objectives** To develop a protocol in order to work with patients, families, carers and healthcare professionals to identify psoriasis uncertainties; to agree by consensus a top-10 list of psoriasis uncertainties; and to disseminate prioritized unanswered questions to researchers and funders so as to promote work that will focus on answering the uncertainties considered most important by stakeholders. **Methods** A Psoriasis Priority Setting Partnership has been established to gather psoriasis uncertainties following the transparent methodology advocated by the James Lind Alliance. A steering group composed of stakeholders has disseminated an initial survey to patients, families, carers and healthcare professionals to collect information on important psoriasis questions. After removing duplications, uncertainties will be collated and checked against existing evidence to determine whether any have already been resolved. 'True uncertainties' will be circulated to stakeholders in a second survey where they will be ranked by importance. At a final workshop, information will be distilled to generate a top-10 list of uncertainties.

**Results** By following the protocol outlined in this paper a prioritized list of uncertainties will be identified that will be used to inform the psoriasis research agenda.

**Conclusions** Research targeted to address priorities identified by a range of stakeholders is imperative. This project will inform policy makers and research funding bodies about what really matters to these groups.

### What's already known about this topic?

- Psoriasis is a common immune-mediated inflammatory skin disease affecting over two million people in the U.K.
- Psoriasis has an economic cost to the U.K. National Health Service of £500 million per annum.
- Access to appropriate care can be poor for people with psoriasis who often experience high levels of psychological distress, complex social needs and interconnected physiological symptoms.
- Many unanswered questions about psoriasis remain.

### What does this study add?

- The Psoriasis Priority Setting Partnership is working with patients, their families, carers and healthcare professionals to develop a protocol in order to identify uncertainties about psoriasis and its management.
- A top-10 list of uncertainties will be agreed by consensus. This list will be disseminated to researchers and funders to promote research on those questions that patients, families, carers and healthcare professionals consider most important.

Psoriasis is an immune-mediated inflammatory skin disease that affects two million people in the U.K.<sup>1,2</sup> It has a significant psychological and social impact on affected individuals and costs the U.K. National Health Service at least £500 million per annum.<sup>3</sup> Over the past two decades an expansion in pharmaceutical therapies for psoriasis has enhanced treatment of the disease, particularly for more severe forms. However, access to care that addresses the complex interlinked physiological, psychological and social needs of those who have psoriasis is often poor.<sup>1</sup> There remain many unmet clinical needs and unanswered questions for psoriasis research, which, if addressed, could improve understanding, current care and clinical outcomes and also address the psychological and social needs of patients.

The Psoriasis Priority Setting Partnership (PsPSP) is bringing patients, families, carers and healthcare professionals together to identify uncertainties about psoriasis and to prioritize, by consensus, a top-10 list of these uncertainties. Here on in, patients, families, carers and healthcare professionals will be referred to as the 'key stakeholders'. This information will be disseminated to researchers and research funders in order to promote research, which will answer the questions that key stakeholders consider to be most important. The James Lind Alliance (JLA), which is hosted by the National Institute for Health Research, was responsible for originally setting up the Priority Setting Partnership (PSP) process and is facilitating the PsPSP process.

## Materials and methods

The development of the PsPSP protocol follows the methodology outlined in the *James Lind Alliance Guidebook*.<sup>4</sup> The PsPSP process adopted here involves two surveys; survey 1 was completed in November 2017, and survey 2 is due to start in May 2018.

### Stage one: identification and invitation of potential partners

A number of organizations, who advocate for and represent key stakeholders, have made a commitment to support the PsPSP. These include the British Association of Dermatologists (BAD), the Primary Care Dermatology Society (PCDS), the British Dermatology Nursing Group and the International Psoriasis Council.

### Stage two: steering group

A strategically selected steering group comprising individuals from across the U.K. has been convened, including seven patient representatives and seven healthcare professionals. The key stakeholders comprising the steering group collectively represent the breadth of perspectives invested in psoriasis care. For example, the patient representatives are of different ages and both sexes, with personal experience of different types of psoriasis, psoriasis comorbidities and caring for family members with the disease. The healthcare professionals have experience in a variety of healthcare settings including primary, secondary and tertiary care and comprise a number of dermatological roles including medical, nursing and psychological. In addition, there is a PsPSP management team based at the University of Manchester working in close collaboration with the University of Nottingham's Centre of Evidence Based Dermatology, which has significant experience in conducting other dermatology-focused PSPs.<sup>5-7</sup>

At our first steering group meeting, chaired by a JLA advisor, the terms of reference and key milestones for the PsPSP were agreed. The JLA advisor is a key neutral facilitator, who ensures that the PSP process is followed in a fair, transparent way, with equal input from key stakeholders. Detailed discussion enabled the content and layout for survey 1 to be finalized. All steering group members completed a declaration of interests, in order to ensure there were none that may affect their views.

### Stage three: identifying and collating uncertainties

Uncertainties about all forms of psoriasis (with the exception of pustular disease) at all stages of life was collected from key stakeholders. Survey 1 was a self-completion survey, and was used to gather views, largely from the U.K. Although international participants were permitted to complete survey 1, its wording made it clear that it was part of a U.K. funded exercise, wording on the survey made it clear that the survey was part of a U.K. funded exercise and, as such, submitted questions would only inform the research agenda in the U.K. The survey also recorded whether the responder's country of residence was the U.K or elsewhere, thereby ensuring that this variable was taken into consideration during analysis of the data.

Participants will be asked to submit uncertainties either online or by post in an effort to make the process as inclusive as possible. Self-completion surveys are a good method for data collection because it reduces social response effects, which can occur if researchers have to be present while the survey is completed.

The survey 1 was launched at the Annual BAD Meeting (4–6 July 2017, Liverpool, U.K.) in partnership with the Psoriasis Association of Great Britain, who devoted their exhibition space to the PsPSP in order to specifically target healthcare professionals' responses. The Psoriasis Association, who advocate for and represent patients, their families and carers, also promoted the survey at the PCDS Autumn Meeting (21 September 2017, London, U.K.) and the Royal College of General Practitioners Annual Conference (12–14 October 2017, Liverpool, U.K.). In addition, the Psoriasis Association facilitated outreach to patients and their families and carers across the U.K. Dedicated support from the Psoriasis Association has enabled the project to overcome the challenges this type of endeavour presents.

The PsPSP webpage, accessed via the Psoriasis Association website, houses a link to the survey (<https://www.psoriasis-association.org.uk/research/psp>); this allows data to be electronically collected and shared with the PsPSP investigator for analysis. There are also links to the PsPSP webpage from the webpages of the University of Manchester and the University of Nottingham's Centre of Evidence Based Dermatology. Survey 1 closed on 24 November 2017 after it had been determined that responses from, and outreach to, all groups had been maximized.

Partner organizations and members of the steering group have also taken responsibility for signposting individuals and groups from their networks to survey 1. In order to best manage responses, ongoing analyses were being undertaken to determine when theoretical saturation is approached.

#### Stage four: prioritization – interim priority setting

Once the 'raw' unanswered questions about psoriasis, identified by survey 1, have been collected and cleaned, the uncertainties gathered will be assembled and analysed. This will include content analysis of open-ended questions. Existing sources of information, such as systematic reviews as well as recent clinical guidelines (e.g. those from the National Institute for Health and Care Excellence and BAD), will be identified and checked by the PsPSP investigator. In conjunction with the steering group, the PsPSP investigator will consider to what extent the refined questions have, or have not, been answered by previous research. In addition, a resource developed and updated monthly by the Centre of Evidence Based Dermatology, University of Nottingham, will be used to identify relevant systematic reviews.<sup>8</sup> This resource provides easy access to mappings of systematic reviews by topic for a variety of dermatological conditions and includes a psoriasis map.<sup>9</sup>

It is likely that some uncertainties will be resolved by referring to existing research evidence, that is, they are

'unrecognized knowns' and not uncertainties. This information will be a useful output of the PsPSP per se as it will indicate to what extent existing information is not communicated effectively to those who need it. These 'unrecognized knowns' will be shared with relevant organizations for further dissemination so that these issues may be incorporated into the development of psoriasis information resources.

Questions generated from survey 1 that have not been adequately addressed by previous research will be categorized as 'true uncertainties'. A full list of these 'true uncertainties' will be collated and recorded on a template supplied by the JLA. This data will be submitted to the JLA for publication on its website, ensuring that the PsPSP results are publicly available, which is in line with the principles of this methodology.

As noted in the *James Lind Alliance Guidebook*,<sup>4</sup> consensus development and prioritization methods traditionally employed by the Delphi technique are adapted in the interim priority setting exercise. The interim stage will involve a second survey (survey 2), which will allow the PsPSP to reduce a long list of uncertainties to a shorter list. The steering group has agreed that the long list of uncertainties will be composed of a maximum of 80 most frequently reported items from survey 1. Individuals completing survey 2 will be asked to mark their 10 most important uncertainties from this list (their 'top 10'). As with survey 1, completion of survey 2 may be via post or online. Individuals who have completed survey 1 and agreed to be re-contacted by the PsPSP team will be informed of survey 2 and invited to participate.

#### Stage five: prioritization – final priority setting

The aim of the final priority setting stage is to prioritize, through consensus, the identified uncertainties/specific research questions relating to psoriasis. The 30 most frequently reported items generated by survey 2 will be collated and discussed at a priority setting workshop meeting. This will be conducted in a face-to-face setting, using group discussions and plenary sessions. The JLA advisor will facilitate this final workshop where the top-10 uncertainties will be generated from the longer list of 30. The workshop will be attended by key stakeholders, in addition to those sitting on the PsPSP steering group. The skilled JLA facilitators will ensure all groups are able to contribute equally to a process that is transparent and fair using an adapted nominal group technique.<sup>4</sup> A flowchart of the PsPSP methods is included as Figure 1.

## Results

This PsPSP is working with key stakeholders, using the methods outlined in this protocol, to identify uncertainties about psoriasis and agree on a prioritized list of top-10 uncertainties. It is anticipated that the PsPSP will allow comment on what key stakeholders consider to be the most important unanswered questions for psoriasis.

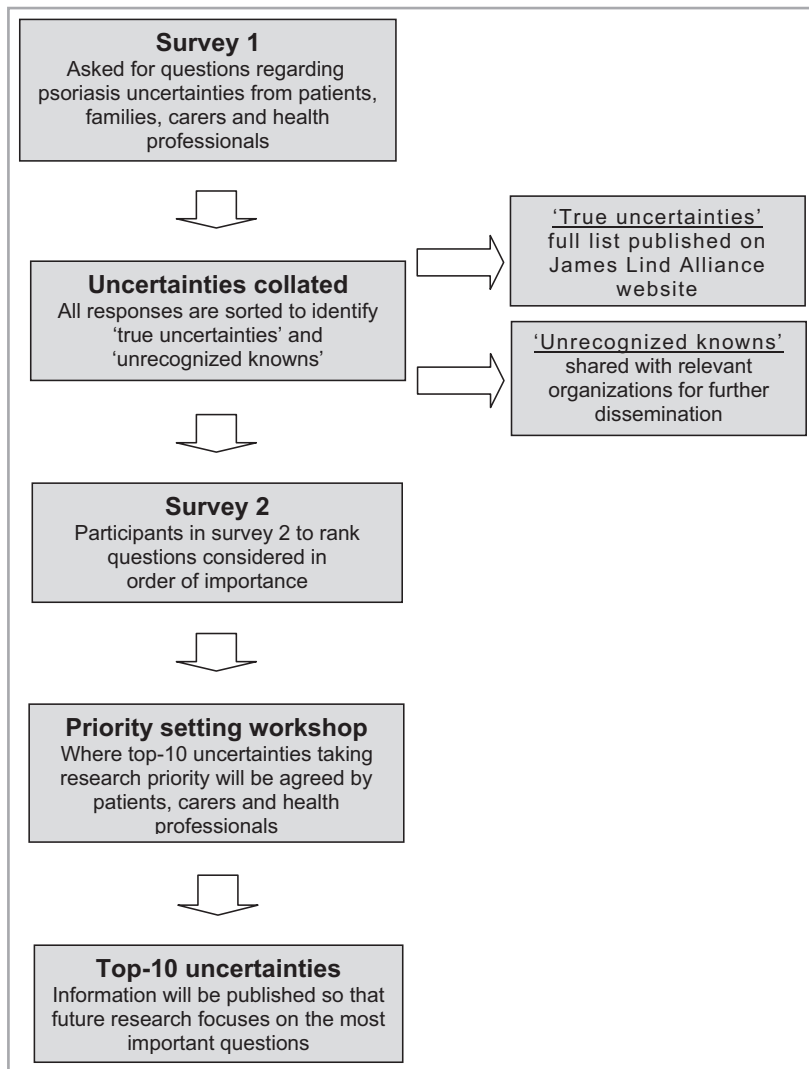


Fig 1. Flowchart of Psoriasis Priority Setting Partnership protocol.

## Discussion

Recent healthcare advancements mean that some people living with psoriasis have access to improved treatments. However, complex unmet needs remain for people with this condition. More targeted research is required to address these needs. With emphasis on limited resources, it is imperative to understand more comprehensively where research is most needed. Traditionally, academic researchers and commercial interests have had pivotal roles in setting the research agenda, with the views of patients given little emphasis. As yet, the most important research questions as agreed by key stakeholders are unknown.

This PsPSP will build on previous efforts to identify gaps and develop the research agenda in psoriasis.<sup>10–12</sup> The most recent work<sup>12</sup> involved a Delphi methodology with 95 experts, most of them being clinical dermatologists. The authors themselves identified a limitation of the work to be its focus on clinicians. The authors suggested future work would

benefit from including the patient voice as is being done by this PsPSP. In addition to patients, this PsPSP includes the voice of other key stakeholders previously unrepresented in work developing the research agenda. The JLA ensures that the views of a multidisciplinary team of experts are heard when developing research priorities, and this supports policy makers and research funders in their management of scarce research resources when prioritizing research.

The PsPSP will ensure the appropriate direction for future psoriasis research. The top-10 list of uncertainties about psoriasis will be disseminated to funding and research agenda setting organizations (such as the Medical Research Council and National Institute for Health Research) as well as the major research funding charities (such as the Psoriasis Association and the British Skin Foundation). By doing this, appropriate research, including clinical trials, will be promoted that will in turn transform the evidence base for psoriasis. PsPSP outcomes will also be disseminated across local and national patient and carer groups using the PsPSP's networks and

subject knowledge. In addition, plain language press releases and social media updates via Twitter and Facebook will be organized.

By following the methods outlined in this protocol, this PsPSP will provide the evidence base from which to develop appropriate and effective evidence-based patient-facing interventions in psoriasis.

Having read this article please do look out for survey 2 which will open in May 2018:

<https://www.psoriasis-association.org.uk/research/psp>.

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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** Psoriasis Priority Setting Partnership Steering Group.

**Video S1** Author video.

**Powerpoint S1** Journal Club Slide Set.