

'Mind the gap': what patients and clinicians believe is 'unknown' about psoriasis

DOI: 10.1111/bjd.19023

DEAR EDITOR, A Priority Setting Partnership (PSP) provides an opportunity for clinicians and patients to jointly decide the research priorities for a specific disease area. The James Lind Alliance (JLA), a non-profit-making initiative established in 2004 that is funded by the National Institute for Health Research (NIHR), have developed a methodology to facilitate PSPs. The JLA believe 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.¹

A PSP invites healthcare professionals (all types of health and social care professionals/clinicians with experience of caring for people with the disease) or those with lived experience of a disease to share those questions they would like to see answered by research. In subsequent stages of the PSP these original submitted questions are themed, grouped and verified as true uncertainties.¹ Thus, the process also enables identification of those questions that have already been addressed by research, that is, they are answered questions

and not uncertainties – 'unrecognized knowns'. Identification of these 'unrecognized knowns' may usefully inform future awareness-raising exercises and education programmes for both patients and clinicians.

The psoriasis PSP, conducted in collaboration with the Psoriasis Association between July 2017 and November 2018, invited healthcare professionals and those with lived experience of psoriasis to identify the most important research priorities for psoriasis.¹ The JLA facilitated the project. A steering group, comprising patients with psoriasis and a multidisciplinary team of healthcare professionals, directed the project. Partner organizations included the British Association of Dermatologists, British Dermatological Nursing Group, Primary Care Dermatology Society and the International Psoriasis Council.¹

In the first stage of the psoriasis PSP process, participants (patients and clinicians) submitted questions they would like to see answered by research (Survey 1).¹ There were 2133 questions submitted by 805 individuals (71% patients, 22% healthcare professionals and 6% others) to Survey 1. The majority of respondents were women (62%) and 10% of respondents were from black and minority ethnic groups.

Of the 2133 questions submitted, 71 questions (3.3%) were identified as having already been addressed by research. These were: 'answered questions' and not true uncertainties; 'unrecognized knowns' (83.1% submitted by those with lived

Table 1 The 'unrecognized knowns' submitted to the psoriasis Priority Setting Partnership by individuals with lived experience of psoriasis and healthcare professionals

Theme 1: Clinical aspects of psoriasis (25%, n = 18)	
Questions from those with lived experience of psoriasis (83%, n = 15; 12 female)	(What are the) different types of psoriasis?
Questions from healthcare professionals (17%, n = 3; 3 female)	Does (psoriasis) spread by contact?
Theme 2: Treatment of psoriasis (47%, n = 33)	
Questions from those with lived experience of psoriasis (85%, n = 28; 16 female)	
General information	Where can I find a patient-focused A-Z of all psoriasis treatments and their long-term benefits and side effects?
Access to treatment	Although there are immune injections now that are helping make people clear, why are they only being given to people who have got very ill after other immune suppressant drugs? If it's known that they are successful why aren't they being given to all (psoriasis) sufferers?
Development of new treatments	What new products are on the market?
Safety	A combination of sun and sea bathing hugely improves my daughter's psoriasis but is it dangerous to spend hours in the hot sun?
Questions from healthcare professionals (15%, n = 5; 3 female)	What are the treatments (for psoriasis)?
Theme 3: Research (18%, n = 13)	
Questions from those with lived experience of psoriasis (85%, n = 11; 7 female)	Is there any research being done (currently)?
Questions from healthcare professionals (15%, n = 2; 1 female)	Can we get (the) Government to fund more research into psoriasis?
Theme 4: Accessing help, advice and support (10%, n = 7)	
Questions from those with lived experience of psoriasis (71%, n = 5; 4 female)	Where is the best place to go to get information about psoriasis? Is there a platform for information?
Questions from healthcare professionals (29%, n = 2; 1 female)	What are the best online advice sites to recommend to patients?

For each theme, indicative questions only are included, as reproducing the whole list is outside the scope of this table.

experience of psoriasis and 16.9% by healthcare professionals). A preponderance of 'unrecognized knowns' were submitted by female respondents (66%), similar to the proportion of overall submissions by respondents to Survey 1. Survey 1 was self-completed and consent was assumed if the form was completed and submitted (online) or returned (paper version). Consent for public surveys of this type is not required by National Health Service research ethics committees.


The 'unrecognized knowns' submitted comprised questions on the following four themes (Table 1): clinical aspects of psoriasis (25%); treatment (47%); research (18%); and accessing help, advice and support (10%). There were no statistically significant differences between themes submitted by healthcare professionals and those with lived experience of psoriasis or between gender groups.

Our findings suggest that both patients with psoriasis and healthcare professionals have fundamental gaps in their knowledge about psoriasis and its treatment, potentially limiting clinical outcomes. From a patient's perspective, factors that have a detrimental impact on patients' understanding of psoriasis can lead to dissatisfaction with disease management,² reduced adherence to medication³ and disengagement from healthcare services.² In turn, this can diminish an individual's perceived personal control of psoriasis,² including the risk of developing comorbid disease and the rationale for lifestyle modification.⁴ Previous studies report that clinicians have low confidence in managing psoriasis, and highlight the disproportionately low level of dermatology teaching in medical schools in relation to the significant amount of skin disease seen by physicians.^{5,6} Although exposure to high-quality dermatology teaching across all sectors of healthcare education is improving, increased clinical exposure with a focus on communication techniques to facilitate doctors and patients working in partnership to achieve control of the disease is much needed.⁷

This study demonstrates an appetite for research and clinical innovation for both patients with psoriasis and healthcare professionals. In addition, individuals with psoriasis expressed a desire to participate in research and to raise the profile of psoriasis research in the UK. Patients and healthcare professionals also asked about how to access reliable information, suggesting that although information on psoriasis exists, there is a need for easy access to high-quality information. The hidden nature of information was commented on by a participant thus: 'Not enough information is given to people ... some are too embarrassed to go to a dermatologist ... More information should be made easily accessible such as in chemists, schools, libraries and ... health centres'. Another individual offered the following comment '... The Psoriasis [Association] magazine had someone displaying the condition on the [front] cover. For such a common condition we don't see it enough ...'. Clearly, society needs to embrace a wider understanding of psoriasis in order to improve acceptance and decrease stigmatization of the disease.

In summary, the psoriasis PSP has identified fundamental gaps in the knowledge not only of those who have psoriasis but also those who manage the condition. It is imperative that

the dermatology community address this through public health communications and medical education platforms. Only in this way will it be possible to espouse the challenge made by the World Health Organization to 'address the unnecessary social consequences of psoriasis by challenging the myths and behaviours that lead to the exclusion of patients from health-care settings and daily life'.⁸

R. Majeed-Ariss,¹ M. McPhee,² H. McAteer,³ C.E.M. Griffiths¹ and H.S. Young ¹

¹Department of Dermatology, The University of Manchester, Oxford Road, Manchester, UK; ²Centre of Evidence Based Dermatology, University of Nottingham, King's Meadow Campus, Nottingham, UK; ³Psoriasis Association, Dick Coles House, Northampton, UK

Correspondence: Helen Young.

Email: helen.s.young@manchester.ac.uk

References

- 1 Majeed-Ariss R, McPhee M, McAteer H, et al. The top 10 research priorities for psoriasis in the U.K.: results of a James Lind Alliance psoriasis Priority Setting Partnership. *Br J Dermatol* 2019; **181**:871–3.
- 2 Nelson PA, Chew-Graham CA, Griffiths CEM, Cordingley L. Recognition of need in health care consultations: a qualitative study of people with psoriasis. *Br J Dermatol* 2013; **168**:354–61.
- 3 Thorneloe RJ, Bundy C, Griffiths CEM, et al. Adherence to medication in patients with psoriasis: a systematic literature review. *Br J Dermatol* 2013; **168**:20–31.
- 4 Cordingley L, Nelson PA, Griffiths CEM, Chew-Graham CA. Beyond skin: the need for a new approach to the management of psoriasis in primary care. *Br J Gen Pract* 2012; **62**:568–9.
- 5 Nelson PA, Barker Z, Griffiths CEM et al. 'On the surface': a qualitative study of GPs' and patients' perspectives on psoriasis. *BMC Fam Pract* 2013; **14**:158.
- 6 Chiang YZ, Tan KT, Chiang YN et al. Evaluation of educational methods in dermatology and confidence levels: a national survey of UK medical students. *Int J Dermatol* 2011; **50**:198–202.
- 7 Alahlafi A, Burge S. What should undergraduate medical students know about psoriasis? Involving patients in curriculum development: modified Delphi technique. *BMJ* 2005; **330**:633–6.
- 8 World Health Organization. Sixty-Seventh World Health Assembly, Geneva, 19–24 May 2014, Resolutions and Decisions. Resolution WHA67.9 Psoriasis. Available at: https://apps.who.int/gb/ebwha/pdf_files/WHA67-REC1/A67_2014_REC1-en.pdf (last accessed 19 March 2020).

Funding sources: funded by the Psoriasis Association (grant number R120332). C.E.M.G. is funded in part by the National Institute for Health Research (NIHR) Manchester Biomedical Research Centre.

Conflicts of interest: H.S.Y. has acted as a scientific consultant or has received research funding (outside the submitted work) from Almirall, Aspire Pharma, Janssen-Cilag, Johnson & Johnson, LEO Pharma, Novartis, and UCB Pharma; C.E.M.G. is a NIHR Senior Investigator and is funded in part by the NIHR Manchester Biomedical Research Centre. He has received research funding and/or consultancies from AbbVie, Almirall, Bristol Meyers Squibb, Celgene, LEO Pharma, Lilly, Janssen, Novartis, Sandoz and UCB Pharma.