Rheumatology, 2022, **00**, 1–8
https://doi.org/10.1093/rheumatology/keac676
Advance access publication 1 December 2022
Original article

Clinical science

The top 10 research priorities in psoriatic arthritis: a James Lind Alliance Priority Setting Partnership

Louise Hailey [1], Chris Bundy[2], Helen Burstow[3], David Chandler[4], Russ Cowper[5], Philip Helliwell[6], Lucille Joannes[7], Andy Kelly[8], Bronagh Kennedy[9], Suzannah Kinsella[10], Helen McAteer[11], Sandeep Mukherjee[12], Jon Packham[13,14], Elspeth Wise[15], Helen Young [16], Laura C. Coates [1]*

[1]Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford, Oxford, UK
[2]School of Healthcare Sciences, Cardiff University, Cardiff, UK
[3]Rheumatology Service, University Hospitals Dorset NHS Foundation Trust, Christchurch, UK
[4]Psoriasis and Psoriatic Arthritis Alliance (PAPAA), St Albans, UK
[5]Patient Research Partner, Innovation Health, Manchester, UK
[6]Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds, Leeds, UK
[7]Patient Research Partner, Tunbridge Wells, UK
[8]Patient Research Partner, Cardiff, UK
[9]Patient Research Partner, London, UK
[10]James Lind Alliance Adviser and Chair of the Steering Group, Tunbridge Wells, UK
[11]Psoriasis Association, Northampton, UK
[12]Rheumatology Service, University Hospitals Dorset NHS Foundation Trust, Christchurch, UK
[13]Haywood Rheumatology Centre, The Haywood Hospital, Stoke-on-Trent, UK
[14]Clinical associate professor in rheumatology, Academic Unit of Population and Lifespan Sciences, University of Nottingham, Nottingham, UK
[15]Talbot Medical Centre, General Practitioner, South Shields, UK
[16]Centre for Dermatology Research, and Manchester Academic Health Science Centre, The University of Manchester, Manchester, UK

*Corresponding author: Laura C. Coates, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), Botnar Research Centre, Windmill Road, Oxford OX3 7HE, UK. E-mail: laura.coates@ndorms.ox.ac.uk

Abstract

Objectives: To identify and prioritize the top 10 research questions for PsA.

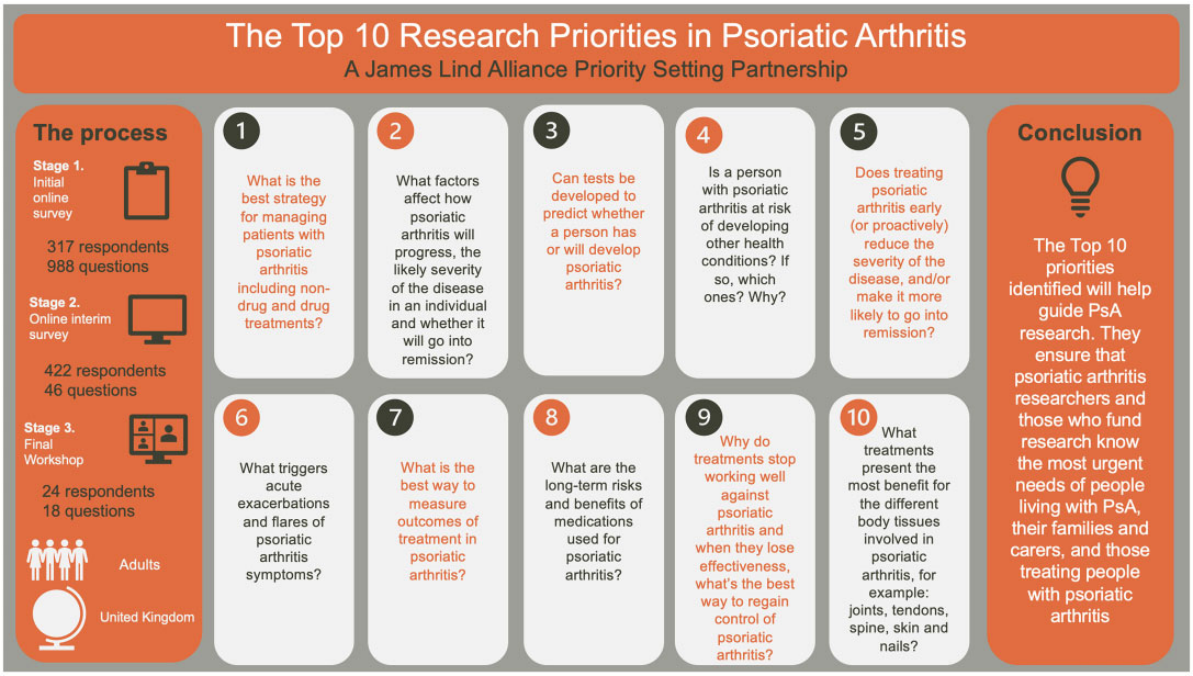
Methods: The British Psoriatic Arthritis Consortium (BritPACT) formed a Priority Setting Partnership (PSP) comprising of people living with PsA, carers and clinicians, supported by the James Lind Alliance (JLA). This PSP followed the established three-stage JLA process: first, an online survey of people living with PsA, carers and clinicians to identify PsA questions, asking, 'What do you think are the most important unanswered questions in psoriatic arthritis research?' The questions were checked against existing evidence to establish 'true uncertainties' and grouped as 'indicative questions' reflecting the overarching themes. Then a second online survey ranked the 'true uncertainties' by importance. Finally, a workshop including people living with PsA and clinician stakeholders finalized the top 10 research priorities.

Results: The initial survey attracted 317 respondents (69% people living with PsA, 15% carers), with 988 questions. This generated 46 indicative questions. In the second survey, 422 respondents (78% people living with PsA, 4% carers) prioritized these. Eighteen questions were taken forward to the final online workshop. The top unanswered PsA research question was 'What is the best strategy for managing patients with psoriatic arthritis including non-drug and drug treatments?' Other top 10 priorities covered diagnosis, prognosis, outcome assessment, flares, comorbidities and other aspects of treatment (https://www.jla.nihr.ac.uk).

Conclusion: The top 10 priorities will guide PsA research and enable PsA researchers and those who fund research to know the most important questions for people living with PsA.

Received: 8 September 2022. **Accepted:** 23 November 2022

Graphical abstract



Keywords: psoriatic arthritis, James Lind Alliance, Priority Setting Partnership, consensus

Rheumatology key messages

- The PsA Priority Setting Partnership is the first completed for a rheumatological disease in adults.
- Using the James Lind Alliance process the most important unanswered research questions in PsA were identified.
- The top 10 questions are important to direct future research efforts into PsA.

Introduction

Psoriasis is a chronic skin condition affecting about 3% of Europeans and North Americans. Some 15–30% of people with psoriasis will develop PsA [1, 2]. PsA is a chronic, complex disease that requires high levels of self-management from those living with the disease. It is associated with many comorbidities, including depression, metabolic syndrome and increased cardiovascular disease risk, and can adversely affect quality of life. There is growing evidence that people living with PsA are significantly affected by poor sleep, fatigue and anxiety [3–5].

PsA is a heterogeneous disease with multiple musculoskeletal manifestations in addition to associated conditions, such as psoriasis. The key to optimal treatment is to consider all aspects of the disease. The more complex patients with PsA require treatment input from multiple specialities to allow optimal management of their condition [6]. As with all complex medical conditions, good communication between specialties and primary care is important for managing treatment.

Unfortunately, many patients with this complex multisystem disease do not receive optimal care and there are several gaps in their management [7]. There is a large unmet need for optimizing management and therapeutic strategy in PsA, and more studies are needed to inform this. There are many unanswered questions regarding both the pharmacological and non-pharmacological management, that, if addressed, could improve current care and clinical outcomes for patients.

Previous studies have demonstrated a mismatch between research priorities identified by people living with a condition, clinicians and researchers [8, 9]. The James Lind Alliance (JLA) works with Priority Setting Partnerships (PSPs) of people living with conditions and clinicians to identify questions about treatments and healthcare interventions and prioritize areas for research [10]. The British Psoriatic Arthritis Consortium (BritPACT), a UK-based consortium of clinicians, researchers and people living with PsA, formed a PSP supported by the JLA. The PSP was formed with the two key UK patient organizations, the Psoriasis and Psoriatic Arthritis Alliance (PAPAA) and the Psoriasis Association, with the British Society of Rheumatology (BSR) as the principal body supporting rheumatologists and allied health professionals in the UK. As with other conditions covered by the JLA, the PsA Priority Setting Partnership (PsA-PSP) aimed to identify the unanswered questions about the diagnosis and management of PsA from the people living with PsA and clinicians' perspectives and then to prioritize those that are the most important. This paper reports on the process and outcome of the PsA-PSP.

Methods

The PsA-PSP process followed six steps; these are illustrated in Fig. 1 showing the flowchart for the PsA-PSP process. The JLA methodology is outlined in the protocol publication (https://www.jla.nihr.ac.uk/documents/psoriatic-arthritis-psp-protocol/24155).

Step 1: establishing a steering group/setting up the PSP

PSPs are collaborations between people with a lived experience of a disease and those who care for them. The PsA-PSP steering group (SG) was established with equal representation of people living with PsA, carers and clinicians, and was run as a collaborative effort. The PsA-PSP was overseen by a JLA adviser and chair. The JLA were key to the overall process, working as neutral facilitators of the PSP endeavouring to ensure that the process was conducted in a fair and transparent way, with equal input from the perspectives of all members. The SG met regularly. There was a delay to launching the initial survey due to the pandemic and consequently all the meetings, except for the first SG meeting, were held online.

The PSP engaged with all major national clinician and patient groups to ensure inclusivity in the process. The wide engagement aimed to ensure inclusivity and fair representation of a variety of views of clinicians and people living with PsA/carers. Sixteen stakeholders who agreed to participate in the PSP were asked to complete a declaration of interests, including disclosure of relationships with the pharmaceutical industry. An information specialist was recruited specifically for this project and performed evidence checking specific to the questions identified in the PSP.

Scope

As there had been no earlier PSPs for rheumatological diseases in adults, the intention of the PsA-PSP was to be broad reaching. The planned scope was adult PsA including psoriasis in the context of PsA. It did not extend into PsA in childhood as this is commonly considered as a subtype within JIA. The PsA-PSP did not focus on psoriasis *per se* as this has already been addressed by the psoriasis PSP. During the psoriasis PSP [11], they had received suggestions from people living with psoriasis, carers and clinicians that related specifically to PsA, and these data were shared to ensure that issues identified in that process were not lost. Within adult PsA, the aim was to solicit unmet needs in the key areas of screening and diagnosis, treatment and management of wider psoriatic disease including comorbidities.

Patient and public involvement

Patient and public involvement was a core part of the PSP, from the design, through all stages, to conclusion. From the outset, SG lay members included those with lived experience of PsA (R.C., A.K., L.J., B.K. and D.C.). Both the initial survey and the interim prioritization survey were answered by the public, the majority of whom had lived experience with PsA. Participants at the final prioritization workshop included equal proportions of people living with PsA and their carers, and all others, including representatives from the Psoriasis Association and Psoriasis and PAPAA charities.

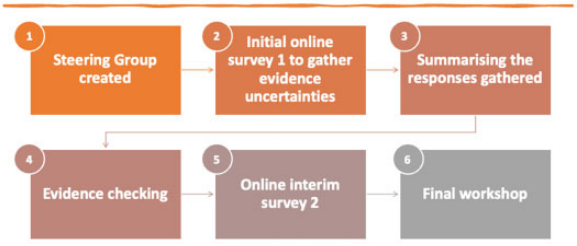


Figure 1. Flowchart of PsA Priority Setting Partnership process

The JLA process works as a partnership with members of the public, the JLA handbook has a specific chapter on consent and ethics [12]. Ethical approval is not usually obtained to run the PsA PSP and no ethical review was sought in this process. PSPs do not normally come under the remit of Health Research Authority approvals, where research priority setting is seen a service evaluation and development rather than research. The people who participated in the online surveys were not asked for written consent but were informed that the questions may be published anonymously. Participation in the online surveys was considered as assumed consent. They were informed that all answers would be anonymous, no identifiable personal data would be published and that they did not have to give their name or contact details. They had access to the study protocol and PSP's terms of reference and were informed that the questions they asked would help shape PsA research.

Raising awareness

It is essential for PSPs to raise awareness of their proposed activity among their people living with the condition, carers and clinician communities, to secure support and participation. This was achieved by using a combination of online meetings, e-mail campaigning, newsletters and widespread use of social media. Awareness raising has several key objectives:

i) to present the proposed plan for the PSP;
ii) to generate support for the process;
iii) to encourage participation in the process; and
iv) to initiate discussion, answer questions and address concerns.

Step 2: initial online Survey 1 to gather evidence uncertainties

The PsA-PSP carried out an initial consultation in the form of a web-based survey to gather questions from people living with PsA, carers, and clinicians. Examples of the questions asked in Survey 1 are listed in Supplementary Table S1, available at *Rheumatology* online. The survey was planned for a paper and online form. However due to advent of the global pandemic in early 2020 the SG took the decision to only run the survey online. The online survey was piloted in March 2020. Due to concerns from the SG about survey responses being overwhelmed by questions about COVID-19 the launch was delayed by 2 months.

The survey was widely promoted to people living with PsA, their family and carers through the Psoriasis Association and PAPAA. Clinicians were targeted via the BSR. Additionally, it was promoted by the SG, local support groups and colleagues using e-mail, newsletters, websites and social media platforms.

The survey was circulated through the partner organizations (Arthritis and Musculoskeletal Alliance, Arthur's Place, Bath GP Education and Research Trust, Bath Institute for

Rheumatic Diseases, British Association of Dermatologists, British Psoriatic Arthritis Consortium, British Society for Rheumatology, James Lind Alliance, Musculoskeletal Association of Chartered Physiotherapists, National Axial Spondyloarthritis Society, National Rheumatoid Arthritis Society, Podiatry Rheumatic Care Association, Psoriasis Association, Royal College of Nursing, The Barbara Ansell National Network for Adolescent Rheumatology, The College of Podiatry, The Primary Care Rheumatology and Musculoskeletal Medicine Society, The Psoriasis and Psoriatic Arthritis Alliance) for 4 months between June and October 2020. Using the Online Surveys platform [13] survey participants were asked to write up to three questions that they wanted answered by PsA research. Submissions of questions were also taken through e-mail. Before closing the survey, the SG met to discuss if they felt the submissions were saturated (no new types of questions were being submitted) and from as diverse, inclusive group of participants as possible (gender, ethnicity, etc.).

Known existing sources of evidence uncertainties were searched which included Clinical guidelines from the BSR and the National Institute for Health and Care Excellence (NICE). Unmet need from the psoriasis PSP related to PsA were included with the survey results.

Step 3: summarizing the responses gathered

The consultation process produced 'raw' questions and comments indicating areas of uncertainty for people living with PsA, carers and clinicians. These questions were categorized and refined by the information specialist to remove out of scope and duplicate submissions.

The questions (from the online survey, e-mail and reported from NICE) were assigned a unique question code, and then reviewed by L.H. and L.C.C. and thematically grouped.

The survey responses were then sorted into a list of indicative questions under each theme. The aim was to ensure that the indicative questions created were clear, addressable by research and understandable to all. This process resulted in a long list of in-scope summary questions. These are not designed as research questions and to try and word them as such may make them too technical for a non-research audience. They were framed as researchable questions that captured the themes and topics that people suggested. The SG had oversight of this process to ensure that raw data were being interpreted appropriately and that the summary questions were being worded in a way that is understandable to all audiences. The JLA adviser observed the process to ensure accountability and transparency.

Step 4: evidence check (data analysis and verifying uncertainties/refining questions)

The PSP completed the JLA Question Verification Form listed in Supplementary Table S2, available at *Rheumatology* online, which clearly describes the process used to verify the uncertainty of the questions, before starting prioritization. The Question Verification Form included details of the types and sources of evidence used to check uncertainty and has been published on the JLA website. This enables researchers and other stakeholders to understand how the PSP has decided that its questions are unanswered.

A priori the SG considered how it would deal with submitted questions that had been answered, and questions that were out of scope. If there were questions identified that had already been answered with high quality evidence this would be collated and published to identify unmet educational needs for both people living with PsA and clinicians in the field of PsA. Any questions that were outside of the scope (e.g. health services delivery) would also be collated for future analysis and publication. Whilst outside the scope of the PSP, these were still recognized as key issues deserving of future research.

The PsA-PSP summary questions were checked against evidence by the information specialist (L.H.) to determine whether they had already been answered by research. The questions that were not adequately addressed by previous research were collated and recorded. The evidence data summary submitted to the JLA is available in Supplementary Data S1, available at *Rheumatology* online.

Step 5: online interim survey 2

The 'true uncertainties' in the form of 'indicative questions' were taken forward to the interim priority setting stage. Between April and June 2021, the platform SurveyMonkey [14] was used for the second online survey. Participants were asked to select their top 10 uncertainties from a randomized list of 46 indicative questions. Examples of the questions asked in the second survey are listed in Supplementary Table S3, available at *Rheumatology* online.

The SG collated the interim ranked indicative questions. The interim prioritization results were grouped into people living with PsA and/or carers, and clinicians, and separate scores kept ensuring a fair weighting of the different constituent groups. To ensure equal influence of all stakeholders within the groups (including gender, age and ethnicity), regardless of actual numbers of responses received, priorities reported by individual groups, e.g. people living with PsA, men only, ethnic minority groups, carers and clinicians were reviewed. These were used to decide on the final interim prioritized list which consisted of 18 indicative questions, listed in Table 4.

Step 6: final workshop and prioritization of the research questions

The final stage of the PSP process ranked all the shortlisted indicative questions in priority order, identifying the top 10. The 18 top ranked indicative questions were presented at the final 1-day online consensus workshop that took place on 12 July 2021 on Zoom. The workshop followed the JLA guidance [12] for running final consensus workshops online. The SG tried to ensure that the participants in this workshop were representative of geographical diversity and age, and included partners as well as those with lived experience.

Of the 28 stakeholders invited to the final priority setting consensus workshop 24 were able to attend. This diverse group included 13 (5 male, 8 female) people living with PsA and 11 (4 male, 7 female) clinicians made up of rheumatologists, a specialist rheumatology nurse, a podiatrist, physiotherapists and a general practitioner. Participants were divided into four groups with an even distribution of people living with PsA and clinicians, and the groups were facilitated by an independent JLA advisor. Each group was provided with the 18 unanswered research questions and asked to rank the 18 questions. The small group work was an opportunity for different parties to express their views, hear different

perspectives and to think more widely about treating or helping people with PsA. By the end of the workshop the participants reached consensus on the top 10 research priorities in PsA.

Results

A total of 317 people responded to the initial online survey, raising 988 questions. Across all the methods used to gather the initial questions, there were 328 total respondents raising a total of 999 questions. Of these submissions, 268 were from across the UK and 35 were from countries outside the UK. Overall, 69% of the respondents were from people living with PsA, and 15% were friends, relatives or carers of someone affected by PsA. Table 1 shows the categories of respondents who responded to Survey 1 and Table 2 shows the demographics of the people who responded to Survey 1.

Of the original submissions, 860 were in scope and 138 were out of scope. The health information specialist (L.H.) and PSP Lead (L.C.) grouped associated questions generating 46 indicative or summary questions. Supplementary Table S4, available at *Rheumatology* online, shows the original eight themes that were developed and the resulting 46 indicative questions, along with their final ranking. The SG checked the 46 indicative questions against 95 retrieved systematic reviews and five guidelines in the existing literature. None of the 46 indicative questions had been sufficiently answered by current evidence. All 46 indicative questions (uncertainties) were included in the interim survey for prioritization. The 46 indicative questions were prioritized through a second online survey that was completed by 422 respondents. Table 1 shows the categories of the people who responded to Survey 2 and Table 3 shows the demographics of the people who responded to Survey 2.

Data analysis

The 46 indicative questions were refined by L.H., L.C. and S.K. The top 11 ranked questions (22 in total) for both the clinicians and people living with PsA/carer groups were analysed to check for similarity across the groups. The data overlapped for 4 of the top 11 ranked questions across both of the groups. Once questions from both groups were collated and combined a shortlist of 18 questions was produced. These questions were taken through to the final priority setting consensus workshop listed in Table 4. The participants were provided with the 18 unanswered research questions and asked to rank them. The rankings were then combined by the JLA advisor and the workshop participants came together to discuss these rankings, and the top 10 questions were agreed by consensus by all the participants as listed in Table 5.

Discussion

The PsA-PSP enabled the identification and prioritization of 10 key areas of uncertainty. These were identified following the trusted JLA methodology. The 10 priorities identified will help guide PsA research and will support applications for research funding in these key areas. The priorities ensure that PsA researchers and those who fund research know the most urgent needs of people living with PsA, their families and carers, and those treating people with PsA. To our knowledge, this is the first UK PSP for a rheumatological disease and will inform the direction of future research in this area.

Table 1. Categories of respondents to Survey 1 and Survey 2

Category	*n* (%)	
	Survey 1	Survey 2
Person with PsA	211 (69.4)	324 (78.07)
Carer, relative or friend	47 (15.4)	17 (4.09)
Healthcare professional	87 (28.5)	74 (17.83)
Total	345[a]	415[b]
Rheumatologist	37 (42)	27 (36.99)
Dermatologist	6 (6.8)	3 (4.11)
GP	4 (4.5)	4 (5.48)
GP with an extended role	1 (1.1)	1 (1.37)
Hospital doctor	2 (2.3)	1 (1.37)
Nurse	6 (6.8)	8 (10.96)
Allied Health Professional	23 (26.1)	25 (34.25)
Psychologist	1 (1.1)	2 (2.74)
Pharmacist	2 (2.3)	0 0
Other	6 (6.8)	2 (2.74)
Total	88	73

[a] The total number of respondents for Survey 1 does not add up to 317 because the way the questions were structured in the survey meant you could answer multiple questions as yes or no. For example, you could identify as a person with PsA and a healthcare professional working with PsA. In this example you would be a 'yes' for both questions.
[b] The total respondents for Survey 2 was 422, however seven people skipped answering the question that asked if they were a patient, carer, relative, friend or a healthcare professional. GP: general practitioner.

Table 2. Demographics of respondents to Survey 1

Parameter	*n* (%)
Age, years	
<16	0 (0)
17–24	5 (1.7)
25–44	81 (26.7)
45–49	140 (46.2)
60–74	71 (23.4)
>75	6 (2)
Total	303
Gender	
Male	80 (26.4)
Female	219 (72.3)
Other	2 (0.7)
Prefer not to say	2 (0.7)
Total	303
Ethnicity	
White	276 (91.1)
Asian or Asian British	14 (4.6)
Black or Black British	1 (0.3)
Mixed ethnic group	5 (1.7)
Other	1 (0.30
Prefer not to say	6 (2)
Total	303
Country of residence	
England	236 (77.9)
Scotland	21 (6.9)
Wales	9 (3)
Northern Ireland	2 (0.7)
Other	35 (11.6)
Total	303

In total, 988 questions were submitted by 317 individuals.

The key areas of uncertainty identified are not entirely unexpected. A previous exercise, where expert clinicians and people living with PsA conducted round table discussions to identify key unmet needs in PsA, decided the important uncertainties were underdiagnosis and misdiagnosis of PsA, a lack of screening tools, poorly defined treatment algorithms and

Table 3. Demographics of respondents in Survey 2

Parameter	*n* (%)
Age, years	
<20	0 (0)
20–29	27 (6.54)
30–49	130 (31.48)
50–69	222 (53.75)
70–80	33 (7.99)
>80	0 0
Prefer not to say	1 (0.24)
Total	413
Gender	
Male	105 (25.42)
Female	304 (73.61)
Other	2 (0.48)
Prefer not to say	2 (0.48)
Total	413
Ethnicity	
White (British, Irish, other)	391 (94.67)
Asian or Asian British	11 (2.66)
Black or Black British	0 0
Other	3 (0.73)
Prefer not to say	4 (0.97)
Total	413
Country of residence	
England	328 (79.42)
Scotland	30 (7.26)
Wales	7 (1.69)
Northern Ireland	9 (2.18)
Other	39 (9.44)
Total	413

In total, 422 respondents voted in Survey 2.

definitions of treatment response and remission, low awareness of the significant burden experienced by PsA people living with PsA, and the higher risk of comorbidities [7]. In the UK, the NICE guidelines on the diagnosis and treatment of SpA, published in 2017 highlighted lack of evidence in key areas of PsA management, and have listed a research agenda in the areas of diagnosis, treatment and comorbidities [15].

The most important theme in all these studies is treatment, personalized to enable better efficacy and fewer adverse events, and this remains the top priority of people living with PsA and clinicians. Members of BritPACT were instrumental in setting up the current project and are active in the development of national and international management recommendations which will address the identified treatment priorities.

There are strengths and limitations to this project. Firstly, all the key clinical and patient groups involved in the care of PsA in the UK were involved. Secondly, people with lived experience of PsA, and their carers, were included at every stage. However, there are limitations. The co-occurrence of the COVID-19 pandemic required work to be conducted online, potentially limiting inclusion of some participants and increasing the risk of bias. Secondly, despite extensive work to try to increase the diversity of people who participated in the PsA. The participants were not entirely representative of the UK population, particularly with a low proportion of males and participants from Black and Asian minority ethnic groups.

During the PSP process, some survey responses focused on issues around service design rather than clinical needs.

Table 4. Survey 2 submissions that were refined to produce a shortlist of 18 questions from the initial list of 46 indicative questions[a]

Theme	Question	Voting survey ranking		Workshop final ranking
		Clinician ranking	Patient/carer ranking	
Treatment				
	What is the best strategy for managing patients with psoriatic arthritis including non-drug and drug treatments?	1	5	1
	Does treating psoriatic arthritis early (or proactively) reduce the severity of the disease, and/or make it more likely to go into remission?	6	19	5
	What are the long-term risks and benefits of medications used for psoriatic arthritis?	42	3	8
	Why do treatments stop working well against psoriatic arthritis and when they lose effectiveness, what's the best way to regain control of psoriatic arthritis?	23	9	9
	What treatments present the most benefit (considering efficacy, tolerability and safety) for the different body tissues involved in psoriatic arthritis, for example: joints, tendons, spine, skin and nails?	11	11	10
	What factors or tests predict how well an individual with psoriatic arthritis will improve on a treatment?	8	32	11
	What additional treatments (including pain medications, hydrotherapy and pain management) may be helpful to manage symptoms in psoriatic arthritis, such as pain, sleep disruption and fatigue?	24	4	13
	What is the role of non-pharmacological treatments such as physiotherapy, occupational therapy and podiatry in treating patients with psoriatic arthritis?	7	25	16
Causes				
	Is a person with psoriatic arthritis at risk of developing other health conditions? If so, which ones? Why?	17	2	4
	To what extent is psoriatic arthritis caused or affected by internal factors such as genetics and gut health?	12	6	12

(continued)

Table 4. (continued)

Theme	Question	Voting survey ranking		Workshop final ranking
		Clinician ranking	Patient/carer ranking	
Assessment and diagnosis				
	Can tests be developed to predict whether a person has or will develop psoriatic arthritis?	9	23	3
	What role does imaging such as X-ray, MRI and ultrasound play in the diagnosis and management of psoriatic arthritis?	10	28	17
Effects of disease and treatment				
	What factors affect how psoriatic arthritis will progress, the likely severity of the disease in an individual and whether it will go into remission?	4	7	2
	What is the best way to measure outcomes of treatment in psoriatic arthritis?	5	36	7
	What is best way of predicting and preventing joint and soft tissue damage in patients with psoriatic arthritis?	3	14	14
	What factors affect which body tissues (joints, skin, tendons) and which areas of the body (legs, hands, feet) are affected by psoriatic arthritis and why?	16	10	15
Flares				
	What triggers acute exacerbations of psoriatic arthritis symptoms?	2	1	6
Gender				
	How do changes in female hormones, such as during puberty, pregnancy, menstruation, miscarriage, menopause, breast feeding and contraceptive use, trigger or affect psoriatic arthritis and its treatment?	18	8	18

[a] The submissions, verified as 'true uncertainties' supplemented with evidence gaps from systematic reviews and guidelines published in the previous 3 years, were refined to produce 46 indicative questions. Votes cast during Survey 2, on the 46 indicative questions, resulted in a shortlist of 18 questions and prioritization of these was agreed during the final workshop.

Table 5. The top 18 research priorities for psoriatic arthritis in the UK

Question	Final ranking
What is the best strategy for managing patients with psoriatic arthritis, including non-drug and drug treatments?	1
What factors affect how psoriatic arthritis will progress, the likely severity of the disease in an individual and whether it will go into remission?	2
Can tests be developed to predict whether a person has or will develop psoriatic arthritis?	3
Is a person with psoriatic arthritis at risk of developing other health conditions? If so, which ones? Why?	4
Does treating psoriatic arthritis early (or proactively) reduce the severity of the disease and/or make it more likely to go into remission?	5
What triggers acute exacerbations and flares of psoriatic arthritis symptoms?	6
What is the best way to measure outcomes of treatment in psoriatic arthritis?	7
What are the long-term risks and benefits of medications used for psoriatic arthritis?	8
Why do treatments stop working well against psoriatic arthritis, and when they lose effectiveness, what's the best way to regain control of psoriatic arthritis?	9
What treatments present the most benefit (considering efficacy, tolerability and safety) for the different body tissues involved in psoriatic arthritis, for example, joints, tendons, spine, skin and nails?	10
What factors or tests predict how well an individual with psoriatic arthritis will improve on a treatment?	11
To what extent is psoriatic arthritis caused or affected by internal factors such as genetics and gut health?	12
What additional treatments (including pain medications, hydrotherapy and pain management) may be helpful to manage symptoms in psoriatic arthritis, such as pain, sleep disruption and fatigue?	13
What is best way of predicting and preventing joint and soft tissue damage in patients with psoriatic arthritis?	14
What factors affect which body tissues (joints, skin, tendons) and which areas of the body (legs, hands, feet) are affected by psoriatic arthritis and why?	15
What is the role of non-pharmacological treatments such as physiotherapy, occupational therapy and podiatry in treating patients with psoriatic arthritis?	16
What role does imaging such as X-ray, MRI and ultrasound play in the diagnosis and management of psoriatic arthritis?	17
How do changes in female hormones, such as during puberty, pregnancy, menstruation, miscarriage, menopause, breast feeding and contraceptive use, trigger or affect psoriatic arthritis and its treatment?	18

Although outside the scope of the PSP top 10, we recognize the importance of these questions to both people living with PsA and clinicians. BritPACT proposes to assess the evidence around UK service delivery and ways that this may be optimized and highlighting ongoing unmet needs that could be addressed within service delivery.

In conclusion, this project has used a validated technique to identify areas of unmet need, prioritized by people living with

PsA and clinicians. Further work will aim to address these areas in specific research projects.

Supplementary data

Supplementary data are available at Rheumatology online.

Data availability

The data underlying this article are available in the article and in its online supplementary material. Further data and key documents from the priority setting partnership are freely available on the James Lind Alliance website, https://www.jla.nihr.ac.uk/priority-setting-partnerships/psoriatic-arthritis/.

Funding

This work was supported by the British Psoriatic Arthritis Consortium (BritPACT) group who provided funding for the PSP. This group does receive charitable funding from several UK pharmaceutical companies for its educational projects. All of this is though unrestricted funding grants to minimize any conflict of interest. We do not envisage any conflicts of interest where BritPACT could potentially benefit from the results of the PSP apart from encouraging funding for future research in the field of PsA which is in keeping with the BritPACT mission statement.

L.C.C. is funded by a National Institute for Health Research Clinician Scientist award. The work was supported by the National Institute for Health Research (NIHR) Oxford Biomedical Research Centre (BRC). The views expressed are those of the author(s) and not necessarily those of the National Health Service, the NIHR or the Department of Health.

Disclosure statement. There were no conflicts of interest where BritPACT could potentially benefit from the results of the PSP apart from encouraging funding for future research in the field of PsA which is in keeping with the BritPACT mission statement.

Acknowledgements

We acknowledge the people with PsA, their carers and healthcare professionals who formed the steering group, and all the people who responded to the surveys and/or attended the final workshop. Thank you to Suzannah Kinsella, our Priority Setting Partnership chair, for her hard work. Also, to Shona Kirtley, the Knowledge and Information Manager and Senior Research Information Specialist for the EQUATOR Network who kindly agreed to mentor and provide support for the information specialist through the Centre for Statistics in Medicine of at the University of Oxford.

References

1. Coates LC, Savage L, Waxman R *et al.* Comparison of screening questionnaires to identify psoriatic arthritis in a primary-care population: a cross-sectional study. BrJ Dermatol 2016;175:542–8.
2. Mease P, Gladman D, Papp K *et al.* Prevalence of rheumatologist-diagnosed psoriatic arthritis in patients with psoriasis in European/North American dermatology clinics. J Am Acad Dermatol 2013;69:729–35.
3. Gisondi P, Tessari G, Conti A *et al.* Prevalence of metabolic syndrome in patients with psoriasis: a hospital-based case-control study. Br J Dermatol 2007;157:68–73.
4. Husted JA, Thavaneswaran A, Chandran V *et al.* Cardiovascular and other comorbidities in patients with psoriatic arthritis: a comparison with patients with psoriasis. Arthritis Care Res (Hoboken) 2011;63:1729–35.
5. Peters MJ, van der Horst-Bruinsma IE, Dijkmans BA, Nurmohamed MT. Cardiovascular risk profile of patients with spondylarthropathies, particularly ankylosing spondylitis and psoriatic arthritis. Semin Arthritis Rheum 2004;34:585–92.
6. Warren RB, Helliwell PS, Chinoy H. Time for a 'joint' approach? BrJ Dermatol 2013;168:683–4.
7. Helliwell PS, Coates LC, Chandran V *et al.* Qualifying Unmet Needs and Improving Standards of Care in Psoriatic Arthritis. Arthritis Care Res (Hoboken) 2014;66:1759–66.
8. Partridge N, Scadding J. The James Lind Alliance: patients and clinicians should jointly identify their priorities for clinical trials. Lancet 2004;364:1923–4.
9. Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. Obstet Gynecol 2009;114:1341–5.
10. Alliance James Lind. Available from: https://www.jla.nihr.ac.uk (30 November 2022, date last accessed).
11. Alliance James Lind. Psoriasis Top 10. Available from: http://www.jla.nihr.ac.uk/priority-setting-partnerships/psoriasis/top-10-priorities.htm (30 November 2022, date last accessed).
12. Alliance James Lind. The James Lind Alliance Guidebook. Version 10. 2021. Available from: https://www.jla.nihr.ac.uk/jla-guidebook/downloads/JLA-Guidebook-Version-10-March-2021.pdf (30 November 2022, date last accessed).
13. No authors listed. Online surveys UK. 2022. Available from: https://www.onlinesurveys.ac.uk/ (30 November 2022, date last accessed).
14. No authors listed. SurveyMonkey. 2022. Available from: https://www.surveymonkey.com (30 November 2022, date last accessed).
15. National Institute for Health and Care Excellence. Spondyloarthritis in over 16s: diagnosis and management. 2017. Available from: https://www.nice.org.uk/guidance/ng65 (30 November 2022, date last accessed).