The Top 10 Research Priorities in Psoriatic Arthritis:
A James Lind Alliance Priority Setting Partnership

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Welcome
So, what matters to people living with psoriatic arthritis?
The Priority Setting Partnership

“What researchers needed to be answered and patients wanted answering”

Derek Stewart
Patient advocate
The process

Stage 1
Initial online survey

Stage 2
Interim online survey

Stage 3
Final workshop
Stage 1 – initial online survey

Stage 1
317 respondents
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988 questions

Stage 2
Interim online survey

Stage 3
Final workshop
Unmet needs in psoriatic arthritis?

- How does alcohol affect psoriatic arthritis?
- Is psoriatic arthritis hereditary?
- When will personalised medicine be available for people with psoriatic arthritis?
- How can we best support people to change their lifestyle to manage living with the condition?
- What foods aggravate my condition?
- What is the cause of fatigue in psoriatic arthritis?
- Why does it take so long in getting a diagnosis in psoriatic arthritis?
- When can we have a specific test for psoriatic arthritis?
- Is damp weather approaching a sign to expect a flare?
Stage 1 – who participated?

Why are you interested in psoriatic arthritis?

Psoriatic arthritis

- Yes
- No

Carer, family, friend

- Yes
- No

Healthcare professional

- Yes
- No
Stage 1 - who participated?

**Gender**
- Female: 219
- Male: 80
- Prefer not to say: 2
- Other: 2

**Ethnicity**
- Asian: 14
- Black: 1
- Mixed: 5
- White: 1
- Other: 6
- Prefer not to say: 276
Stage 1 – who participated

**Age Distribution**
- 16 & under: 0
- 17-24: 5
- 25-44: 81
- 45-59: 140
- 60-74: 71
- 75+: 6

**Country Distribution**
- England: 236
- Scotland: 9
- Northern Ireland: 2
- Other: 35
Stage 1 - who participated?

<table>
<thead>
<tr>
<th>Clinical Role</th>
<th>Count</th>
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</thead>
<tbody>
<tr>
<td>Rheumatologist</td>
<td>37</td>
</tr>
<tr>
<td>Dermatologist</td>
<td>6</td>
</tr>
<tr>
<td>GP</td>
<td>4</td>
</tr>
<tr>
<td>GP specialist</td>
<td>1</td>
</tr>
<tr>
<td>Hospital doctor</td>
<td>2</td>
</tr>
<tr>
<td>Nurse</td>
<td>6</td>
</tr>
<tr>
<td>AHP</td>
<td>23</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
</tr>
</tbody>
</table>
Evidence check
What questions need answering?

Service design questions

Unrecognised knowns

True uncertainties
Evidence check

- MEDLINE, Cochrane Library and NHS Evidence for systematic reviews and psoriatic arthritis guidelines, using a predefined search strategy, last 3 years

<table>
<thead>
<tr>
<th>Number of references</th>
<th></th>
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<tbody>
<tr>
<td>Total retrieved</td>
<td>473</td>
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<tr>
<td>After screening</td>
<td>153</td>
</tr>
<tr>
<td>Included</td>
<td>101</td>
</tr>
</tbody>
</table>

Against predefined inclusion/exclusion criteria with steering group
Themes

- Treatment
- Diagnosis
- Flares

- Gender
- Psychological, financial and social
- Effects of disease and treatment

- Causes
- Covid-19

Covid-19
Indicative questions

- Does treating psoriatic arthritis early (or proactively) reduce the severity of the disease, make it more likely to go into remission?
- What key social factors are linked to, or associated with, outcomes in psoriatic arthritis such as level of education, employment, loneliness, relationships, age and gender?
- Is a person with psoriatic arthritis predisposed to developing other health conditions? If so, which ones? Why?
- Does having psoriatic arthritis or having treatment for psoriatic arthritis increase your risk of catching COVID-19 or affect its outcome?
- Which psychological interventions improve outcomes in psoriatic arthritis?
- Can tests be developed to predict whether a person has or will develop psoriatic arthritis?
- What triggers acute exacerbations of psoriatic arthritis symptoms?
- What factors affect how psoriatic arthritis will progress, the likely severity of the disease in an individual and whether it will go into remission?

Treatment
Gender
Causes
Covid-19
Psychological, financial and social factors
Diagnosis
Flares
Effects of disease and treatment
Stage 2 – online interim survey

Stage 1
Initial online survey

Stage 2
422 respondents
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46 indicative questions

Stage 3
Final workshop
Stage 2 – who participated?

Why are you interested in psoriatic arthritis?

- 78% I have psoriatic arthritis
- 3% I know someone with psoriatic arthritis
- 1% I'm a carer
- 1% Healthcare professional
Stage 2 - who participated?

GENDER
- Female: 304
- Male: 105
- Prefer not to say: 2
- Other: 2

ETHNICITY
- Asian: 11
- Black: 0
- Mixed: 4
- White: 3
- Other: 4
- Prefer not to say: 2
Stage 2 - who participated?

**AGE**
- Under 20: 27
- 20-29: 130
- 30-49: 222
- 50-69: 33
- 70-80: 0
- Over 80: 1
- Prefer not to say: 0

**COUNTRY**
- England: 328
- Scotland: 7
- Wales: 30
- Northern Ireland: 9
- Other: 39
Stage 2 - who participated?

- Rheumatologist: 27
- Dermatologist: 3
- GP: 4
- GP specialist: 1
- Hospital doctor: 1
- Nurse: 8
- AHP: 25
- Psychologist: 2
- Pharmacist: 0
- Other: 2
Stage 3 – final workshop

Stage 1
Initial online survey

Stage 2
Online interim survey

Stage 3
24 participants
|
18 final questions
Thank you for agreeing to participate in our final workshop. As the workshop is online, we thought we would send you some tea and biscuits to enjoy during the breaks.

We are looking forward to working with you on 12 July 2021. If you have any questions for us before then, including any questions about the workshop information pack, we will send you separately (via email and post).

Contact Louise Halley, PSP coordinator, at Louise.Halley@ndorms.ox.ac.uk.
1. What is the best strategy for managing patients with psoriatic arthritis including non-drug and drug treatments?

2. What factors affect how psoriatic arthritis will progress, the likely severity of the disease in an individual and whether it will go into remission?

3. Can tests be developed to predict whether a person has or will develop psoriatic arthritis?

4. Is a person with psoriatic arthritis at risk of developing other health conditions? If so, which ones? Why?

5. Does treating psoriatic arthritis early (or proactively) reduce the severity of the disease, and/or make it more likely to go into remission?

6. What triggers acute exacerbations and flares of psoriatic arthritis symptoms?

7. What is the best way to measure outcomes of treatment in psoriatic arthritis?

8. What are the long-term risks and benefits of medications used for psoriatic arthritis?

9. 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?

10. 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?
Steering group meeting
What next?
Dissemination

Service design questions

Unrecognised knowns

True uncertainties
Future research
Future research ideas

- NIHR
- Charities
- Other funding bodies
Questions
Acknowledgements