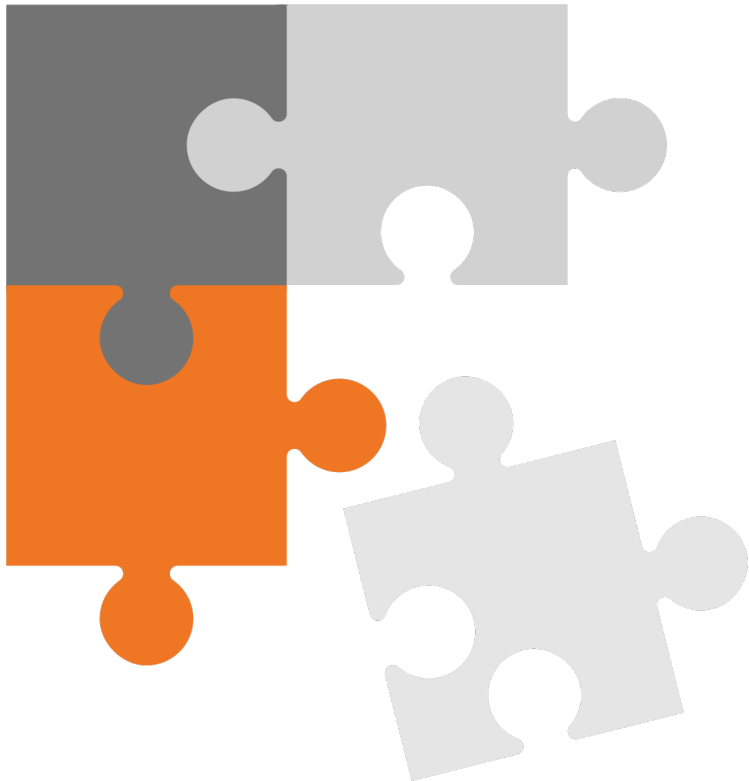


The Top 10 Research Priorities in Psoriatic Arthritis: A James Lind Alliance Priority Setting Partnership



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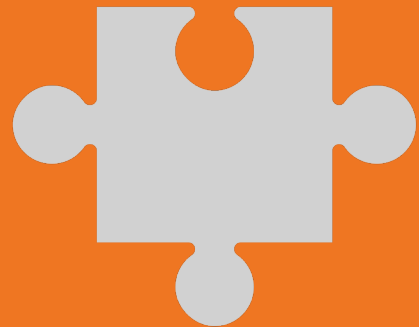
Welcome



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

988 questions



Stage 2
Interim online
survey



Stage 3
Final workshop

Unmet needs in psoriatic arthritis?

How does alcohol affect psoriatic arthritis?

What complimentary therapies help with psoriatic arthritis?

What is the cause of fatigue in psoriatic arthritis?

Is psoriatic arthritis hereditary?

Is damp weather approaching a sign to expect a flare?

Why does it take so long in getting a diagnosis in psoriatic arthritis?

What foods aggravate my condition?

When will personalised, medicine be available for people with psoriatic arthritis?

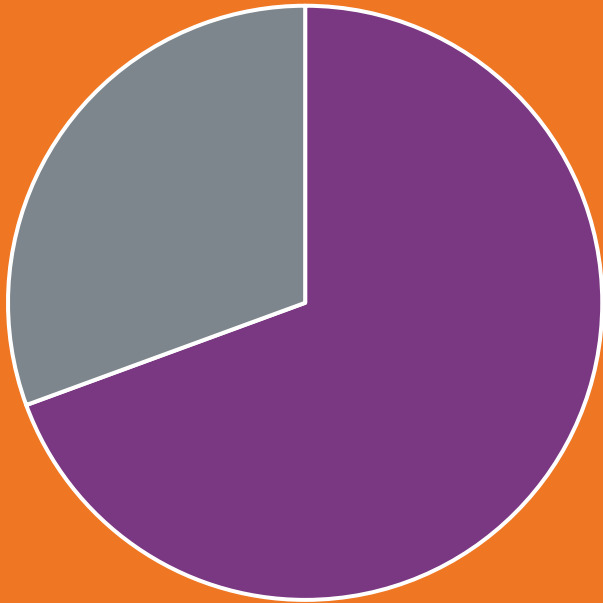
When can we have a specific test for psoriatic arthritis?

How can we best support people to change their lifestyle to manage living with the condition?

Stage 1 – who participated?

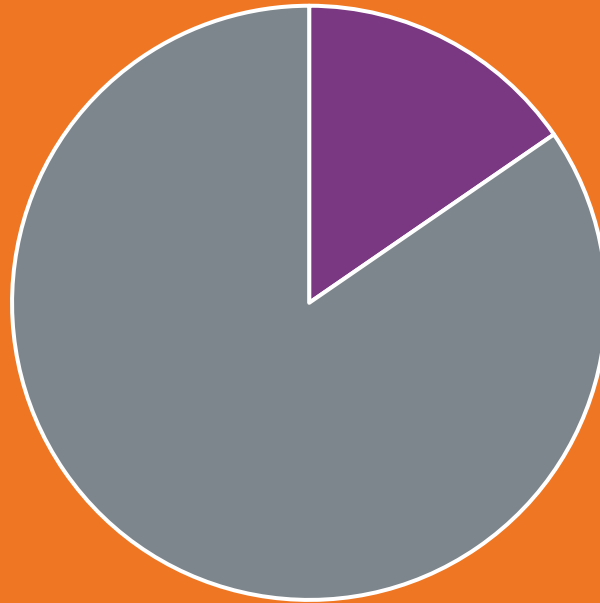
Why are you interested in psoriatic arthritis?

Psoriatic arthritis



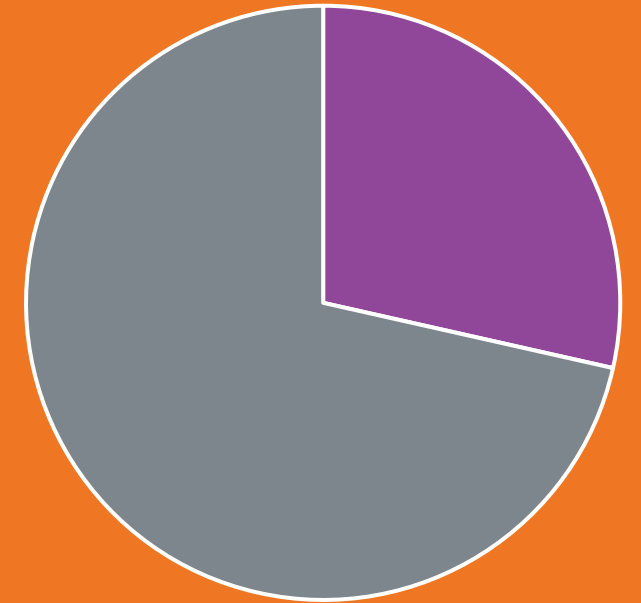
Yes No

Carer, family, friend



Yes No

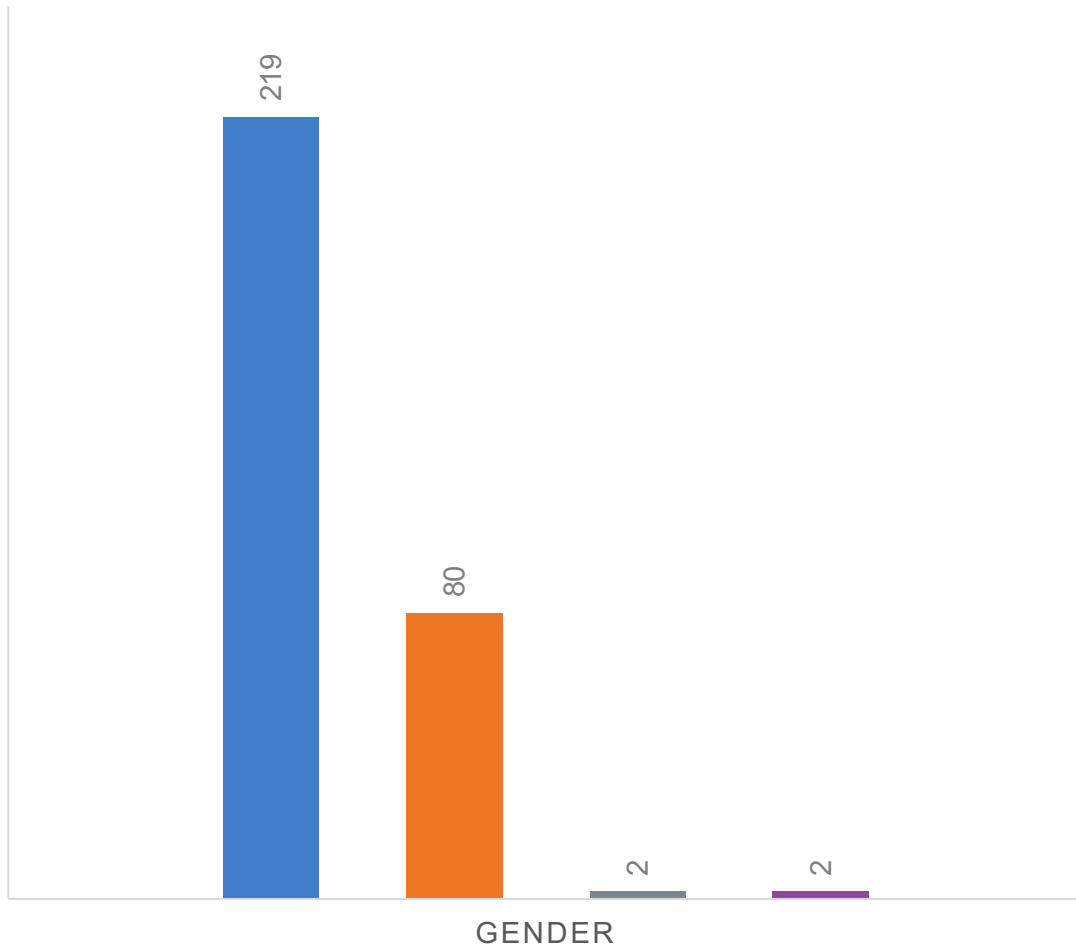
Healthcare professional



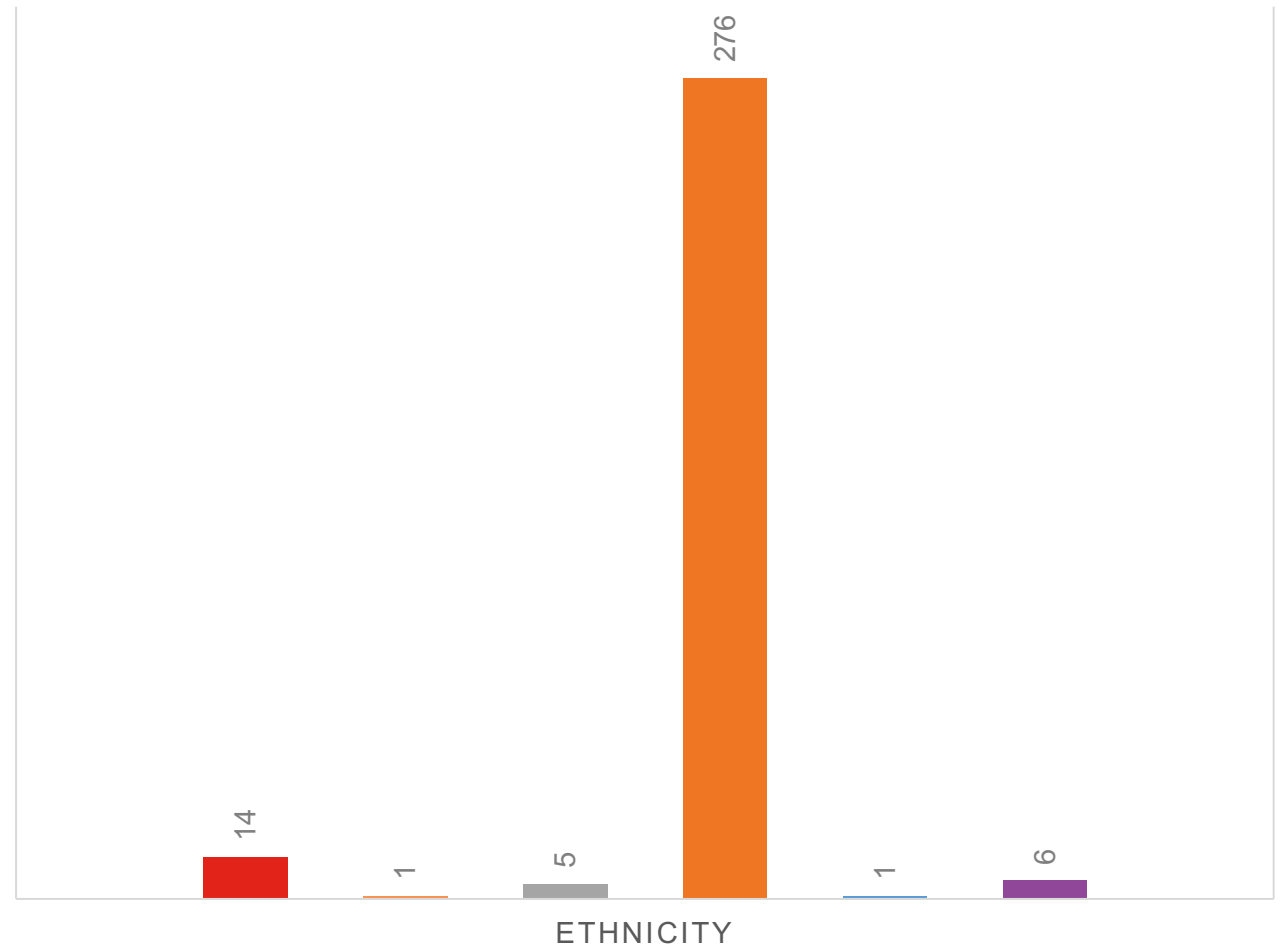
Yes No

Stage 1 - who participated?

■ Female ■ Male ■ Prefer not to say ■ Other

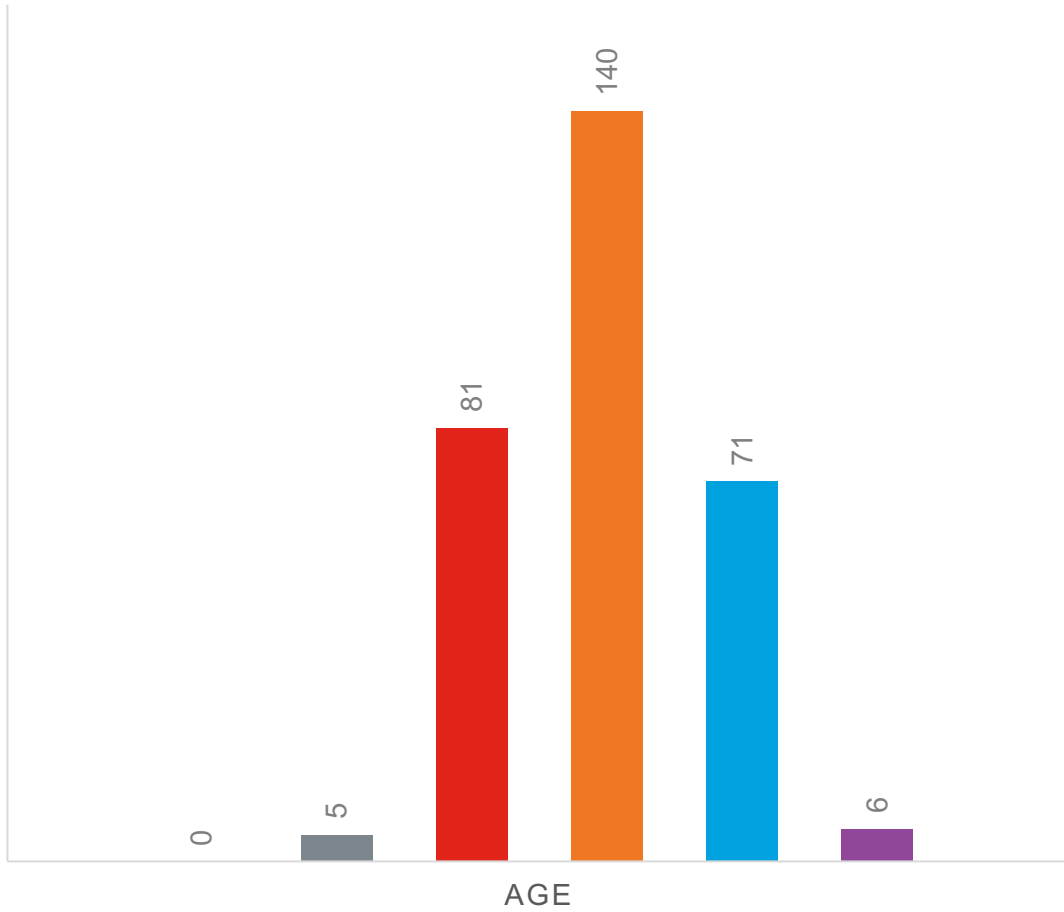


■ Asian ■ Black ■ Mixed ■ White ■ Other ■ Prefer not to say

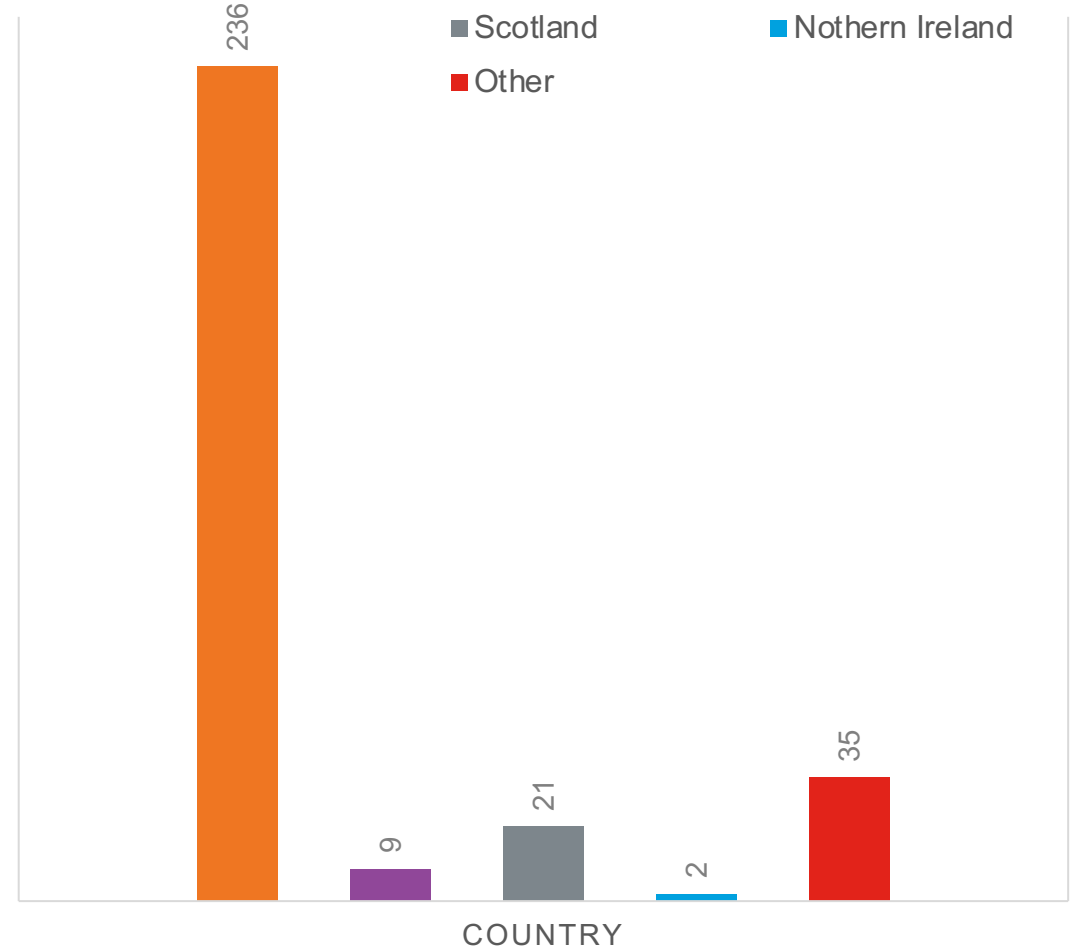


Stage 1 – who participated

■ 16 & under ■ 17-24 ■ 25-44 ■ 45-59 ■ 60-74 ■ 75+

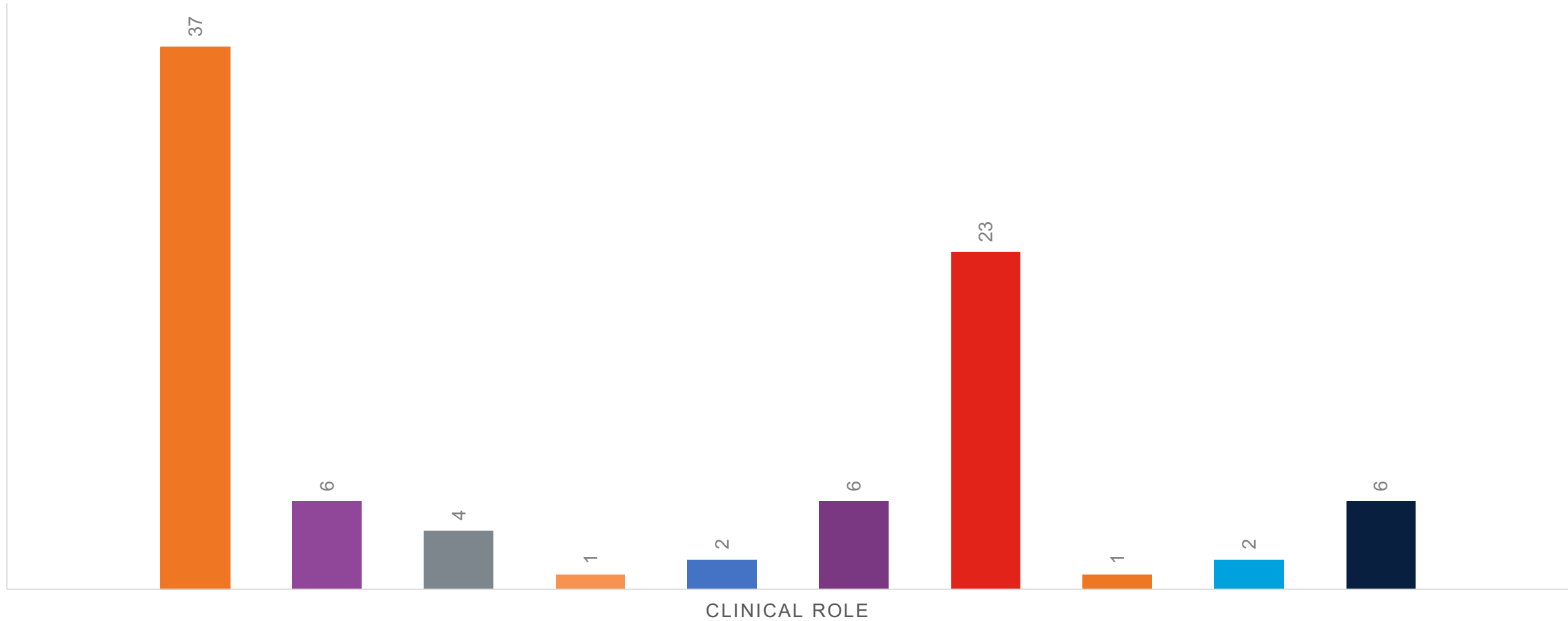


■ England ■ Wales
■ Scotland ■ Northern Ireland
■ Other



Stage 1 - who participated?

■ Rheumatologist ■ Dermatologist ■ GP ■ GP specialist ■ Hospital doctor ■ Nurse ■ AHP ■ Psychologist ■ Pharmacist ■ Other



Evidence check



What questions need answering?

Service design
questions

Unrecognised knowns



True uncertainties

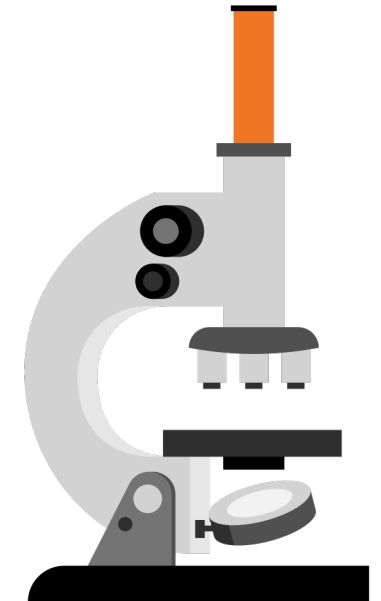


Evidence check

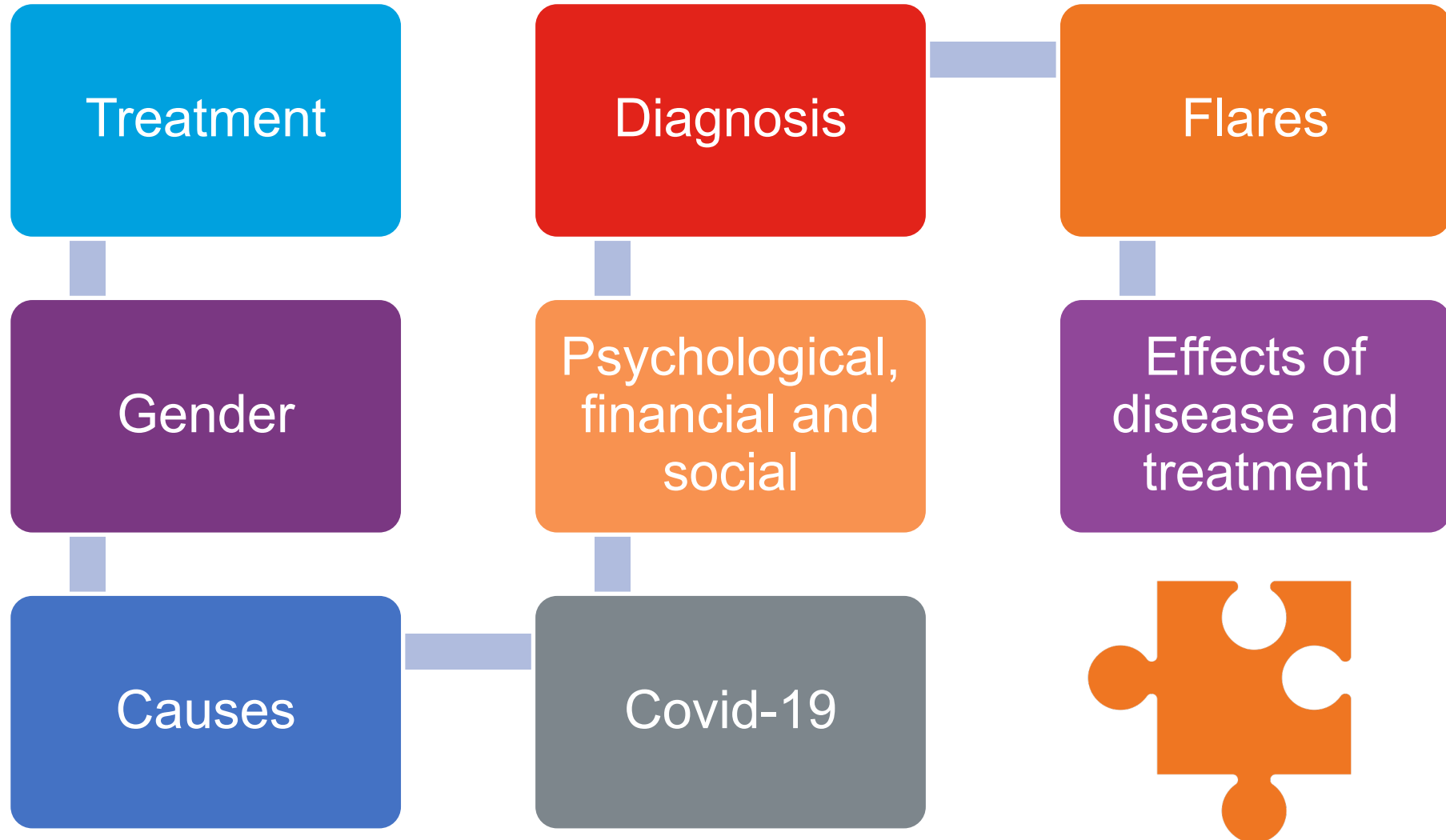
- MEDLINE, Cochrane Library and NHS Evidence for systematic reviews and psoriatic arthritis guidelines, using a predefined search strategy, last 3 years

Number of references	
Total retrieved	473
After screening	153
Included	101

Against predefined inclusion/exclusion criteria with steering group



Themes



Indicative questions

Treatment

Gender

Causes

Covid-19

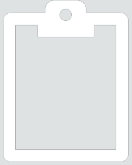
Psychological,
financial and social
factors

Diagnosis

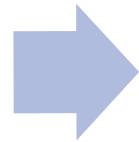
Flares

Effects of disease and
treatment

Stage 2 – online interim survey



Stage 1
Initial online
survey



Stage 2
422
respondents

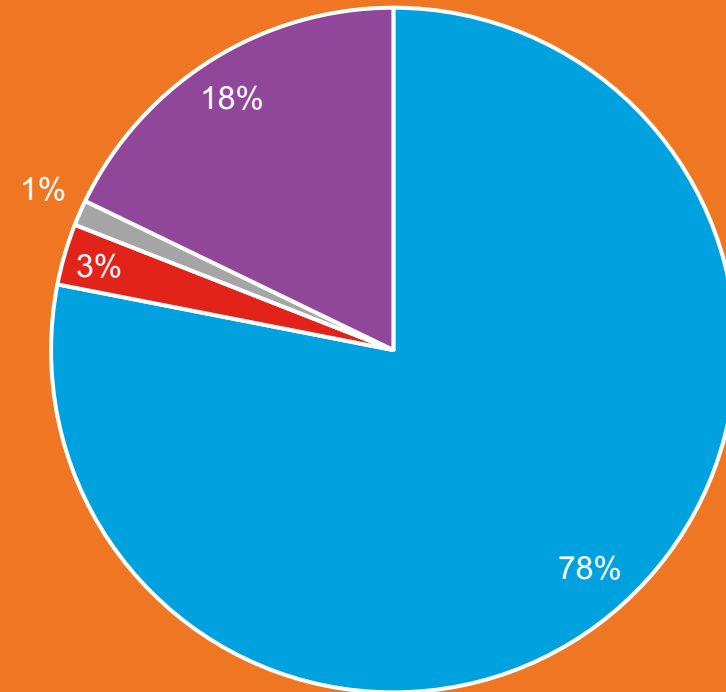
46 indicative
questions



Stage 3
Final workshop

Stage 2 – who participated?

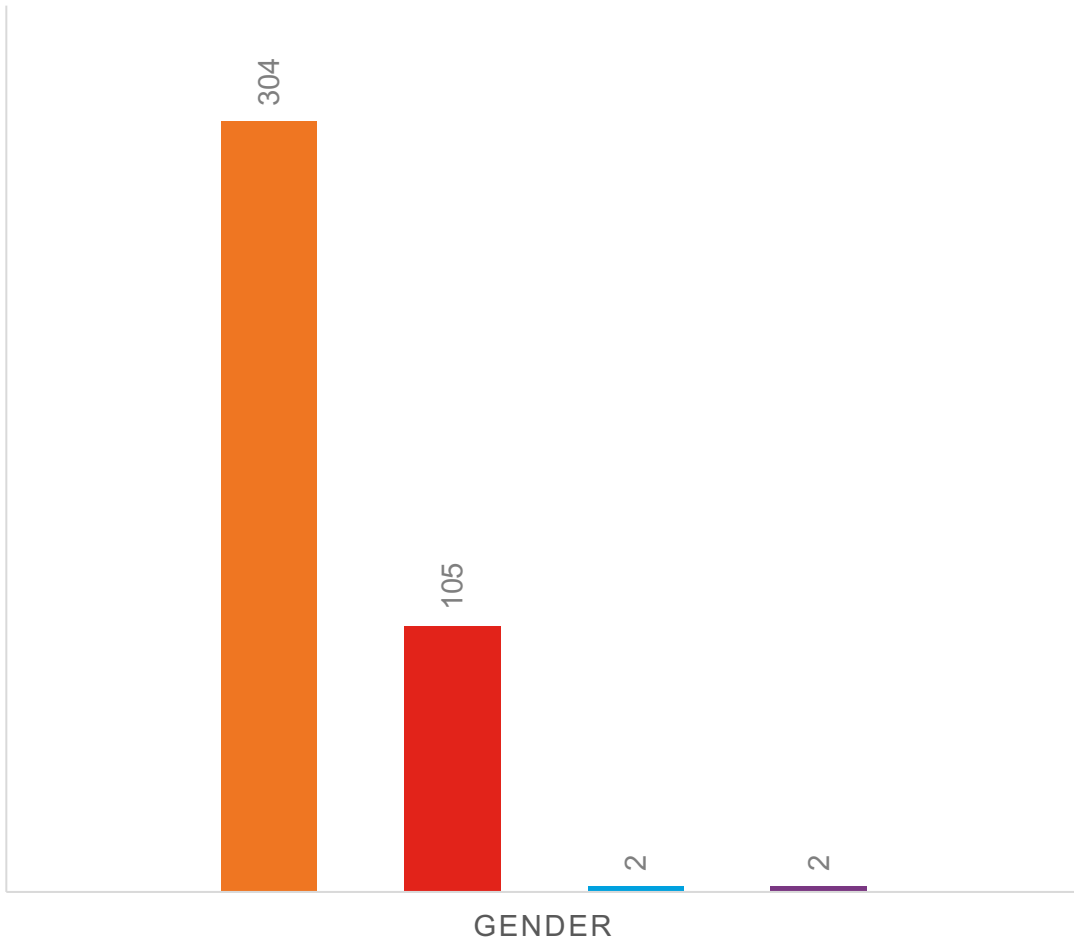
Why are you interested in psoriatic arthritis?



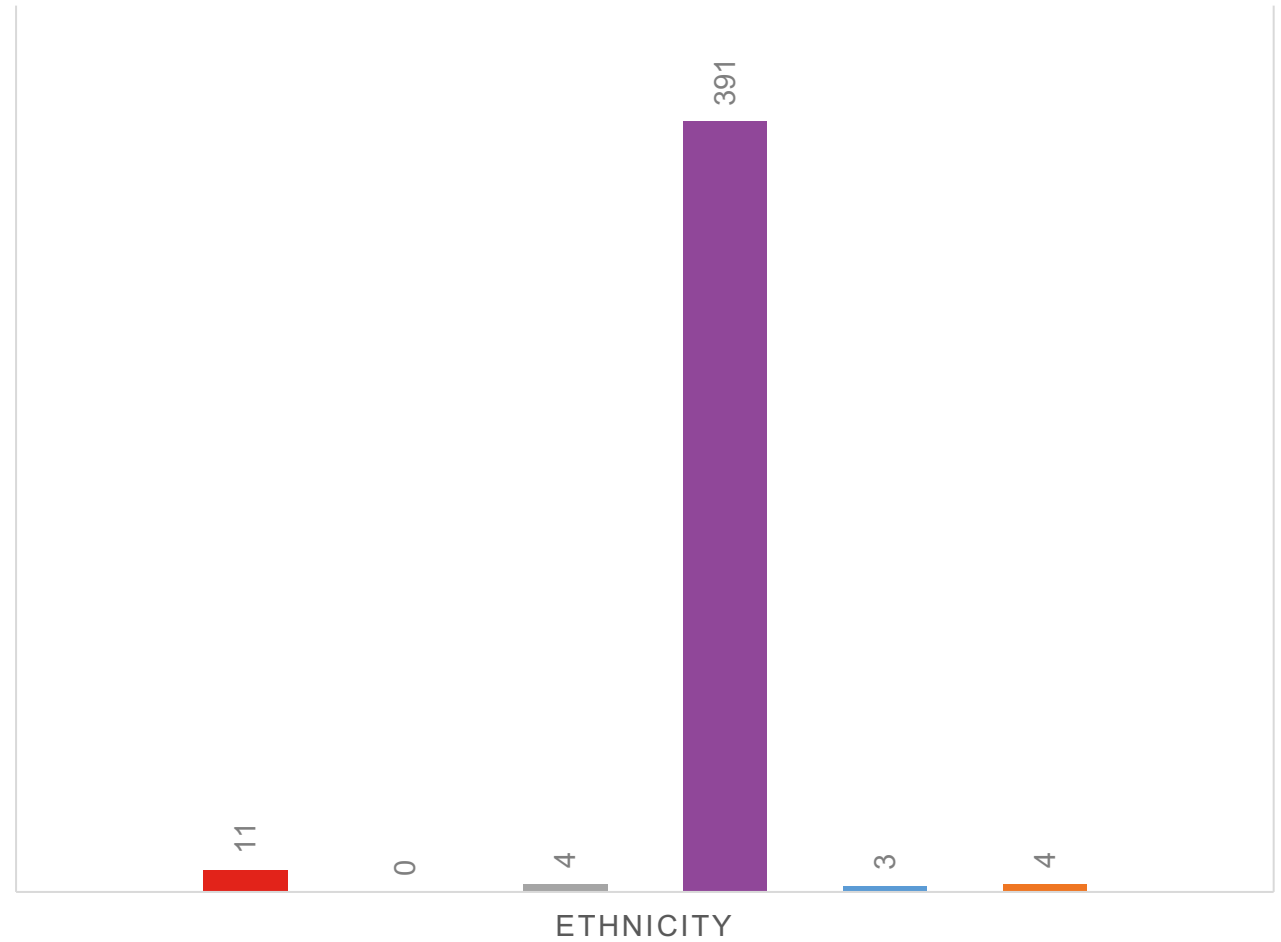
- I have psoriatic arthritis
- I know someone with psoriatic arthritis
- I'm a carer
- Healthcare professional

Stage 2 - who participated?

Female Male Prefer not to say Other

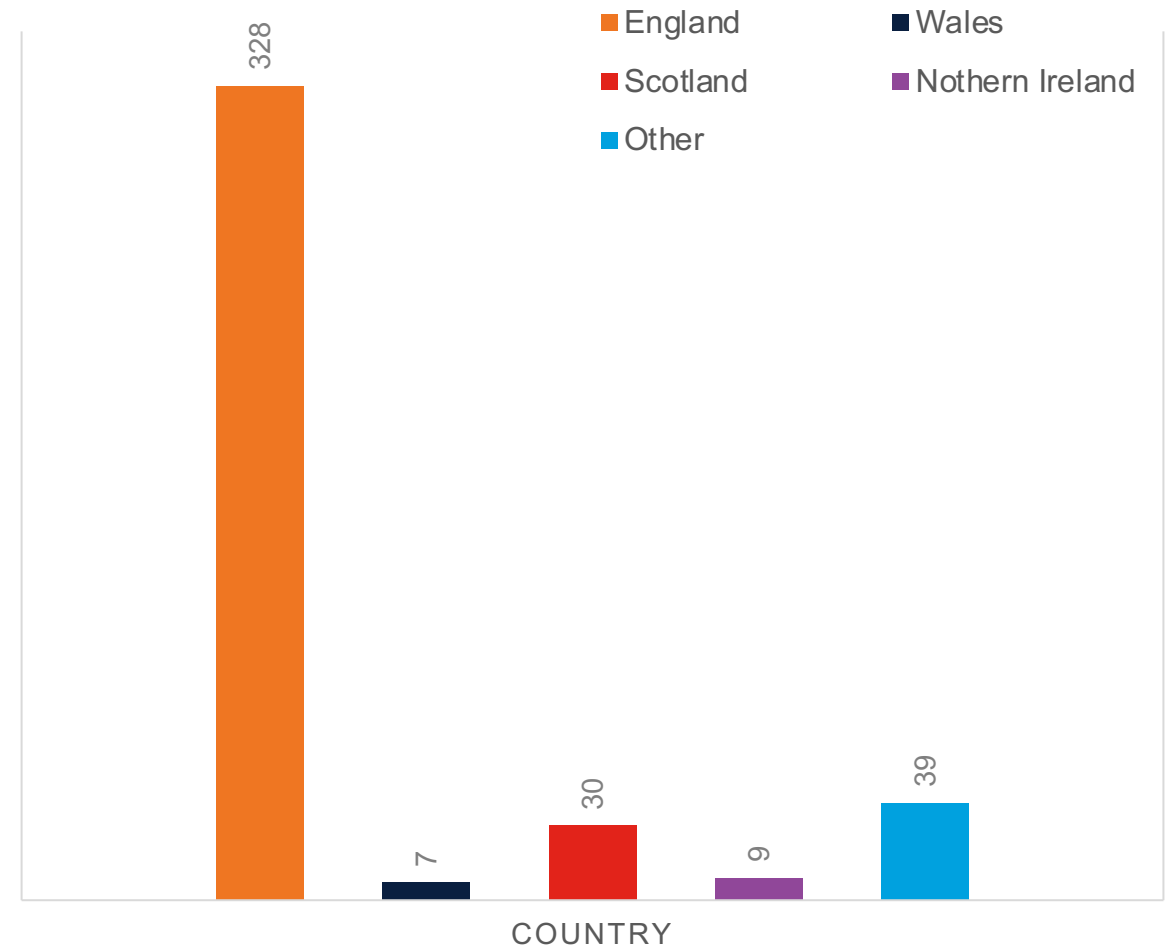
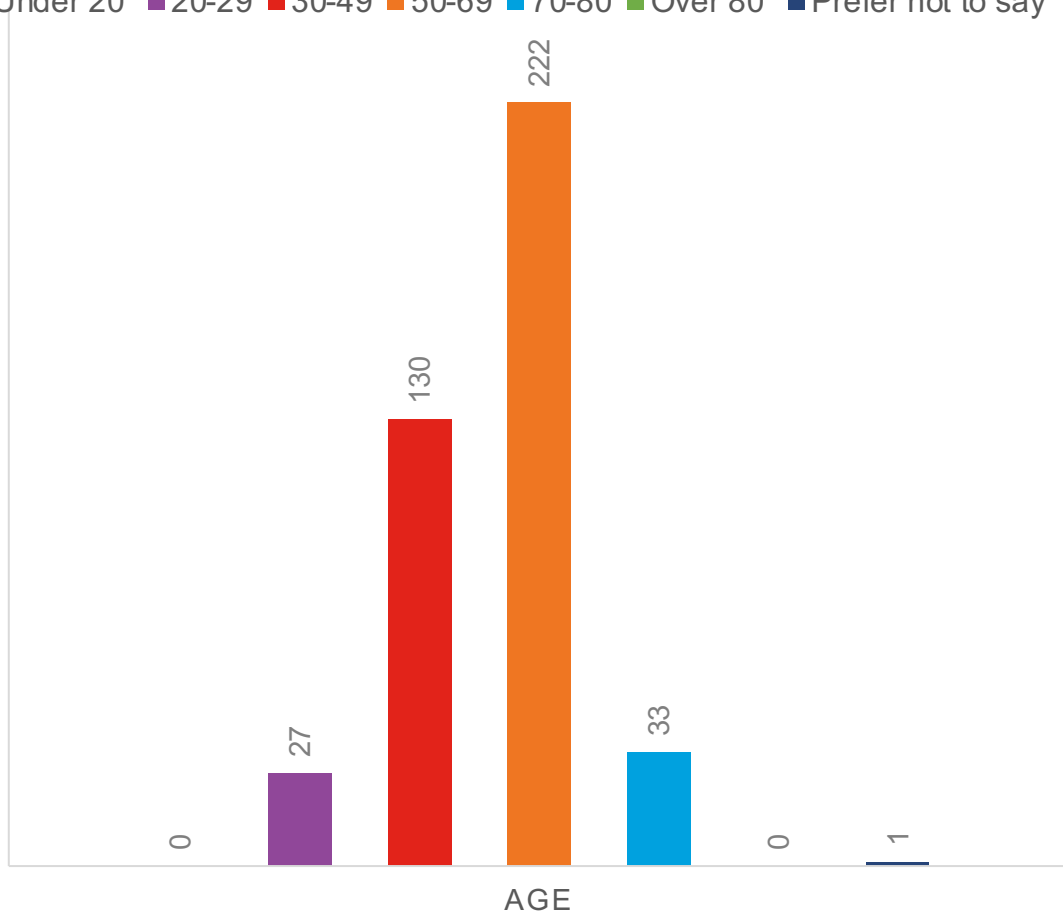


Asian Black Mixed White Other Prefer not to say

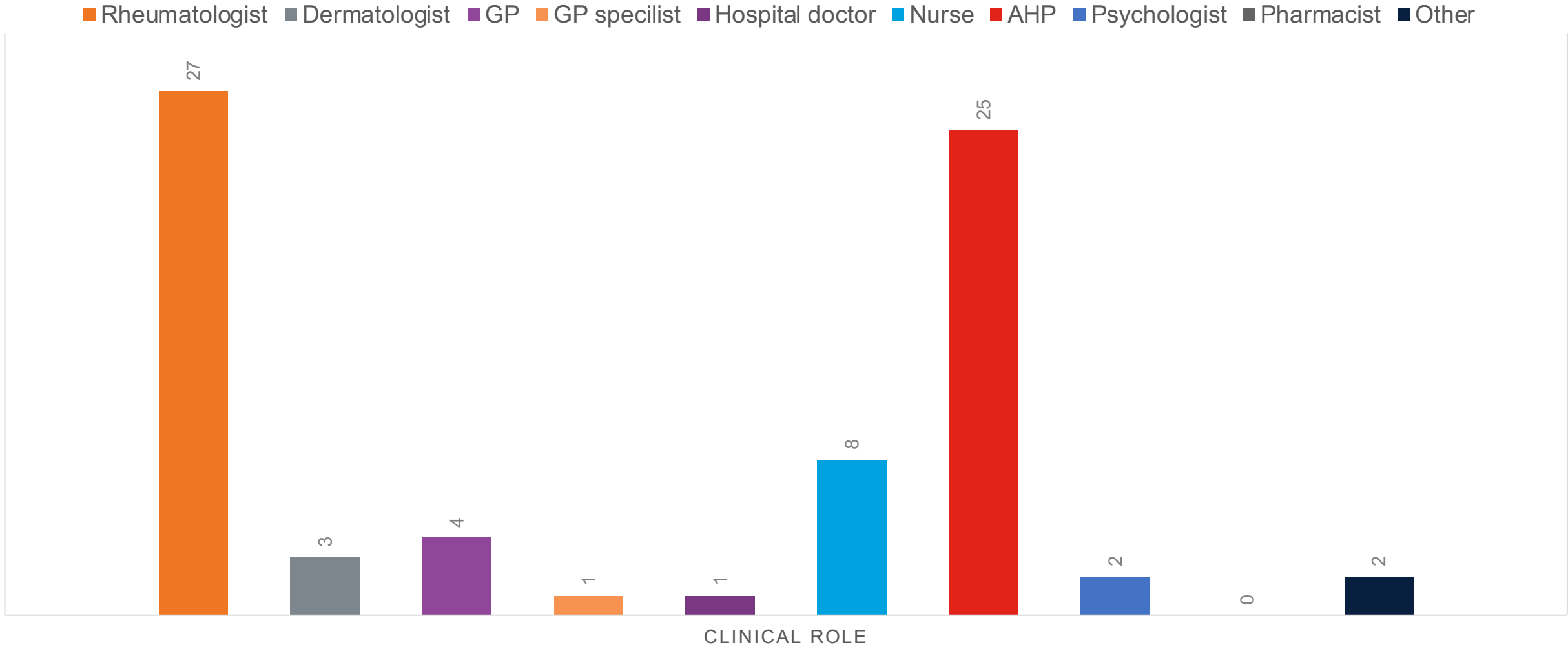


Stage 2 - who participated?

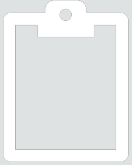
■ Under 20 ■ 20-29 ■ 30-49 ■ 50-69 ■ 70-80 ■ Over 80 ■ Prefer not to say



Stage 2 - who participated?



Stage 3 – final workshop



Stage 1
Initial online survey



Stage 2
Online interim
survey



Stage 3
24 participants

18 final questions

Stage 3 – Final Workshop



Top Ten



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?



Service design
questions

Unrecognised knowns

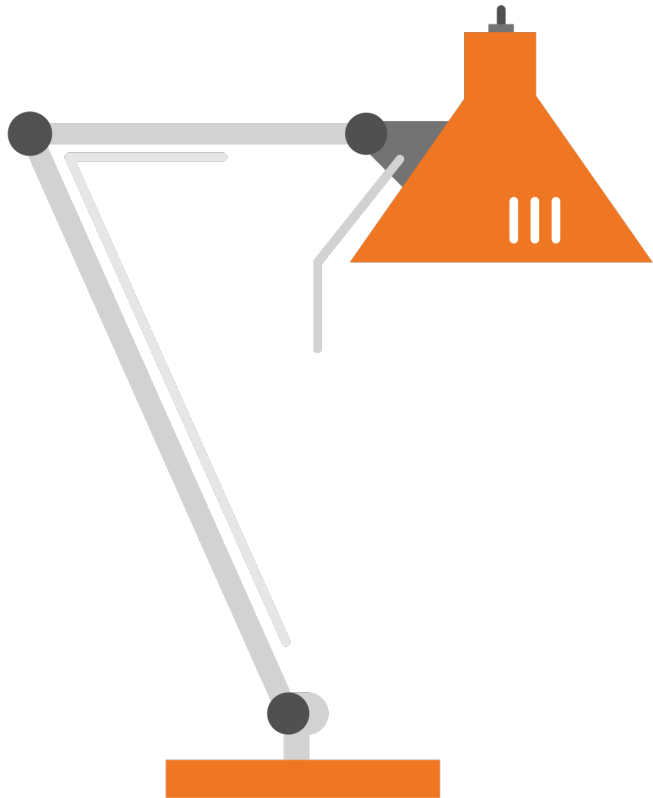
True uncertainties



Future research



Future research ideas



- NIHR
- Charities
- Other funding bodies

Questions



Acknowledgements

