

Martin J Stevens¹ | Rosemary J Hollick¹ | Gary J Macfarlane¹ | Rebecca Parr¹ | Sella Proven² | Maarten de Wit³, on behalf of the iPREPARE Working Group.

This work was supported by a Research Methods Grant from the European Alliance of Associations for Rheumatology (EULAR)

¹ Aberdeen Centre for Arthritis and Musculoskeletal Health (Epidemiology Group), University of Aberdeen.

² Diakonhjemmet Hospital, Oslo. ³ Chair, EULAR study group for collaborative research, Amsterdam.

Key finding

Feedback to Patient Research Partners is vital to ensure a shared understanding of the value of their work

implementing Patient Research Partner Engagement in Research (iPREPARE)

Rheumatology research embraces collaboration with patient research partners (PRPs). However

- Engagement is often consultative
- Power imbalances exist within teams

The iPREPARE study aimed to

- Identify barriers to PRP involvement
- Examine tokenism
- Explore working relationships with PRPs

Working group: co-design & analysis

3 Study team members
3 European Researchers
6 European PRPs

Co-Design **Questionnaire** **Interviews**

	Questionnaire		Interviews	
	PRPs	Researchers	PRPs	Researchers
Women	71	54	7	3
Men	12	15	1	4
Total	84*	69	8	7
Countries	12	12	7	6

Questionnaire results

PRPs	Researchers
Positives High % trained Being involved early >50% felt equal	Positives PRPs had impact Involving PRPs early PRPs improve project
Concerns Low % paid Unsure of impact Is feedback honest?	Concerns Low % trained Low % pay PRPs Analysis involvement

Interview theme examples

PRPs	Researchers
Do I make any difference?	Delicate relationship
PRPs unsure if they have affected the research.	Managing tensions and power imbalances is not always easy.

Moving forward

Improve researcher feedback
More training for PRPs and researchers