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*Key finding*

# Europe-wide study finding: Feedback to Patient Research Partners allows for a shared understanding of Impact

## Introduction

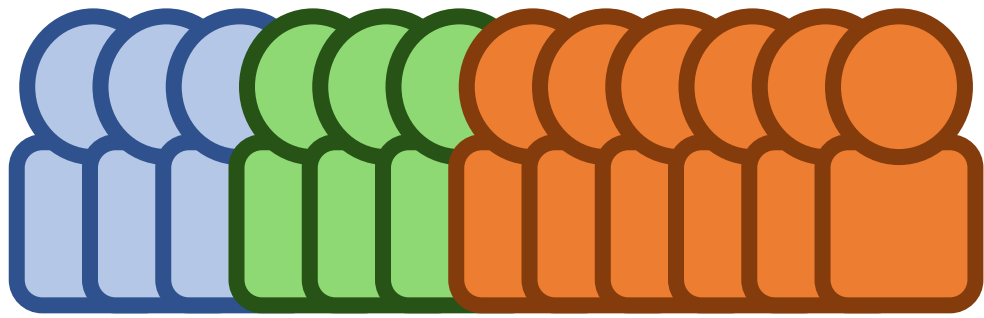
Collaboration with patient research partners (PRPs) in Rheumatology research is actively encouraged, but it is unclear how widely best-practice methods for working with PRPs are implemented.

The Europe-wide iPREPARE study explored the perception of PRP involvement in rheumatology research from PRPs and researchers, identifying barriers to good practice, and potential solutions to better support PRPs in research.

## Methods

### Working group: co-design & analysis

- 3 Study team members
- 3 European Researchers
- 6 European PRPs



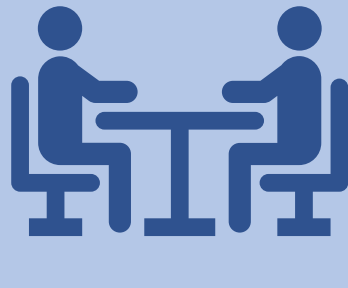
### Co-Design



### Questionnaire



### Interviews



- Questionnaire and interviews carried out with PRPs and researchers across Europe.

## Results

- Questionnaire participants from 16 countries
- Interview participants from 7 countries

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

\*One value missing.

## Questionnaire results

### PRPs

#### Positives

High % trained  
Being involved early  
>50% felt equal

#### Concerns

Low % paid  
Unsure of impact  
Is feedback honest?

### Researchers

#### Positives

PRPs had impact  
Involving PRPs early  
PRPs improve project

#### Concerns

Low % trained  
Low % pay PRPs  
Analysis involvement

## Interview theme examples

### PRPs

Do I make any difference?

A lack of feedback from researchers can lead to PRPs being unsure of the impact of the work.

### Researchers

Delicate relationship

Working with PRPs can be a delicate relationship, managing expectations and power imbalances.

## Moving forward

- Improve researcher feedback
- More training for PRPs and researchers