Implementing Patient Research Partner Engagement in Research (iPREPARE)

Summary of main findings

iPREPARE Summary Report

November 2025

Martin J Stevens
Maarten de Wit
Peter Böhm
Loreto Carmona
Muriel Elhai
Ricardo Ferreira
Ingrid de Groot
Ingvild Kjeken
Souzi Makri
Rebecca Parr
Eva Petersson
Sella Provan
Jon Skandsen
Tracey Snell
Gary J Macfarlane
Rosemary J Hollick

On behalf of the iPREPARE Working Group

https://doi.org/10.57064/2164/26465

Summary

Background

Rheumatology has a strong history of collaboration with patient research partners (PRPs) to improve research outcomes. However, important gaps remain, particularly in the implementation of patient research partner (PRP) values and principles across the research spectrum. Engagement is often consultative and focused on more applied clinical and qualitative research, with significant power imbalances between researchers and PRPs. This study identified barriers to PRP involvement in Rheumatic and Musculoskeletal Disease (RMD) research, to prevent tokenism and to increase meaningful and sustainable relationships across the RMD research community.

Methods

We undertook a sequential, mixed methods study exploring the perceptions of the roles of PRPs amongst RMD researchers and PRPs. Stakeholders will be involved in all stages of study design and delivery. We co-designed a questionnaire to explore barriers to PRP participation from both PRP and researcher perspectives across the EULAR member community. The questionnaire explored implementation of PRP roles and power imbalances between PRPs and researchers. Semi-structured interviews with PRPs and RMD researchers explored findings from the questionnaire in greater detail. Interviews were thematically analysed to provide greater understanding and clarity around the issues raised.

Deliverables

The report which follows summarise the key findings of the study, including a description of PRP involvement in RMD research and how this varied across contexts (e.g., research settings, countries). It has identified barriers to participation and makes recommendations of what needs to change to ensure high-quality participation across studies in Europe.

https://doi.org/10.57064/2164/26465

Implementing Patient Research Partner Engagement in Research (iPREPARE)

A mixed methods study

EULAR Research Methods Grant

Summary of main findings report

October 2024

https://doi.org/10.57064/2164/26465

Introduction

The iPREPARE study explored the way in which the work of patient research partners (PRPs) in rheumatic and musculoskeletal disease research is perceived by the partners themselves and by researchers.

The iPREPARE working group co-designed two questionnaires which we sent to PRPs and researchers in rheumatology and musculoskeletal disease research. The questionnaires included questions drafted by the working group and other validated questions such as the PEIRS 22 tool (Hamilton et al, 2021).

We received responses from 84 PRPs and 69 researchers with a variety of countries represented as follows:

Country	PRPs	Researchers	Total
UK	31	12	43
Netherlands	21	6	27
Switzerland	6	10	16
Germany	4	9	13
Spain	1	12	13
Sweden	8	4	12
Norway	3	7	10
Portugal	3	2	5
Denmark	3	1	4
Italy		3	3
Greece	2		2
Austria		2	2
Belgium	1		1
Cyprus	1		1
Finland		1	1
Grand Total	**84**	**69**	**153**

https://doi.org/10.57064/2164/26465

59 of the researchers had experience of working with PRPs whilst 10 answered the sub-questionnaire for researchers with no experience of working with PRPs. Most of the results in this report present the results from the 59 researchers with relevant experience.

This was followed up by a co-designed interview phase with 8 PRPs and 7 researchers.

Country	**PRPs**	**Researchers**	**Total**
Switzerland	2	1	3
UK	2	1	3
Netherlands	1	1	2
Denmark		1	1
Italy		1	1
Germany	1		1
Norway		1	1
Portugal	1		1
Spain		1	1
Sweden	1		1
Total	**8**	**7**	**15**

https://doi.org/10.57064/2164/26465

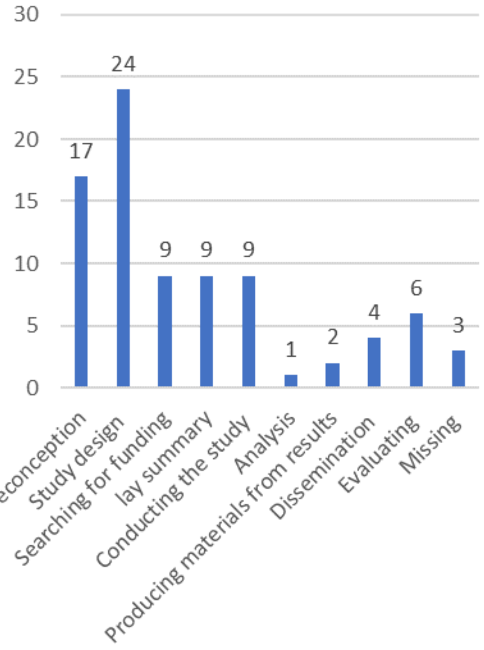
Main findings

Early involvement

A positive result from our study is that PRPs seem to be being involved early in the research cycle, i.e. in study design.

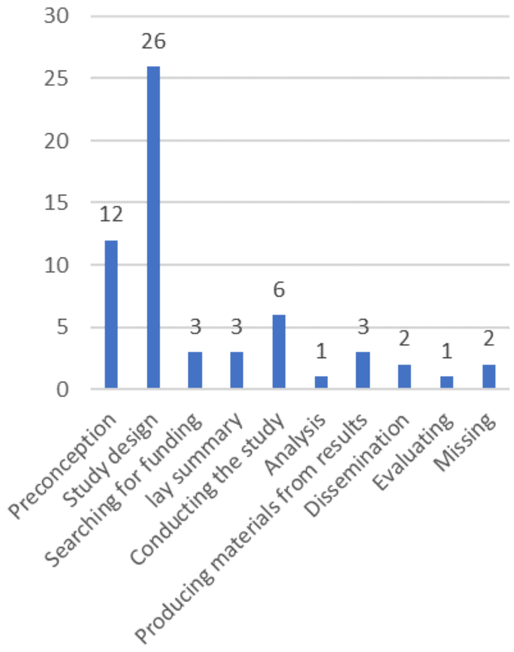
PRPs

In general, at which step of the project were you brought on board?



Researchers

In general, at which step are PRPs brought on board in projects you have worked on?



Number above column denotes number of respondents.

However, in a separate question 10 PRPs (12%) felt they were not brought on board early enough whilst 32 (38%) felt they were only sometimes brought on board early enough. 5 (8%) of researchers felt PRPs were not brought on board early enough whilst 25 (42%) said they were sometimes brought on board early enough. Therefore, we believe there is room for improvement in involving PRPs early on in a research project.

Supplementing these results with the interview results shows that 'early' involvement' was highlighted by both PRPs and researchers as a positive step in working with PRPs. However, 'early' involvement tends to mean two things:

A. Being involved early in the research cycle. i.e. at an early stage in the study design. In our cohort this requirement is generally satisfied. Interviews suggest this is because of funder requirements which seems to have brought about this positive change.

B. Being involved early enough to give a substantive response. In other words, not sending material to PRPs so late that they cannot consider and comment on it. This is an indicator of tokenism and leaves the PRPs feeling that their input is not valued.

In terms of the research cycle there are some very positive results. This shows that funder's requirements to involve PRPs in developing grant proposals are working. However, this can lead to feeling of tokenism if the PRP is not given enough time to respond substantively.

> *'Getting a phone call on a Thursday evening over dinner, "Would you be prepared to help with a study?" I'm going to say, "Yes. I look forward to hearing more" and then finding out the following morning my name's been included on the grant proposal. That's cheeky and that doesn't necessarily give me a strong feeling of they're interested in my opinion'* ***PRP06***

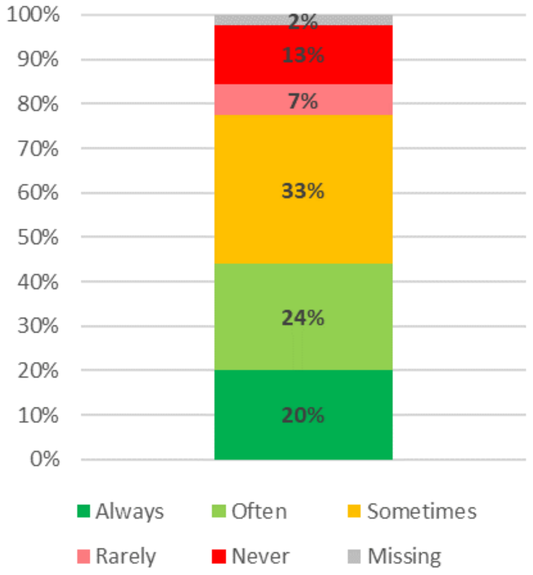
https://doi.org/10.57064/2164/26465

Feedback

An interesting result is that PRPs do not always feel that feedback they receive was honest, whilst researchers do feel that their feedback to PRPs is honest.

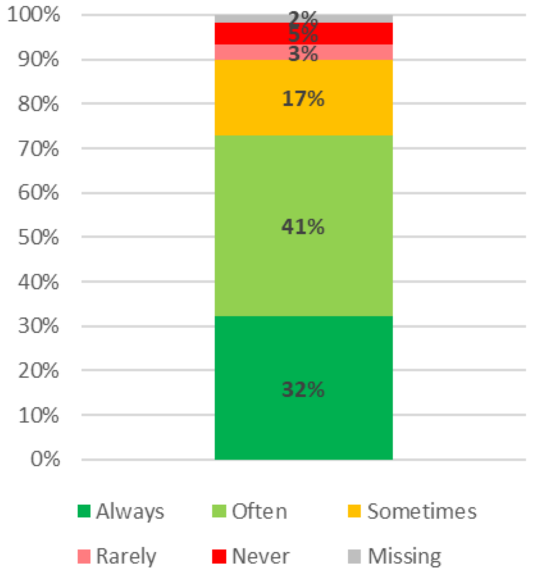
PRP

I was given honest feedback about my contributions



Researchers

PRPs were given honest feedback about their contributions



This result was reinforced in the interviews:

> *'We do get nice encouraging words, thank you for being involved and so on. But it's hard to know whether that's politeness or genuine appreciation and it's hard to quantify the contribution'* ***PRP06***

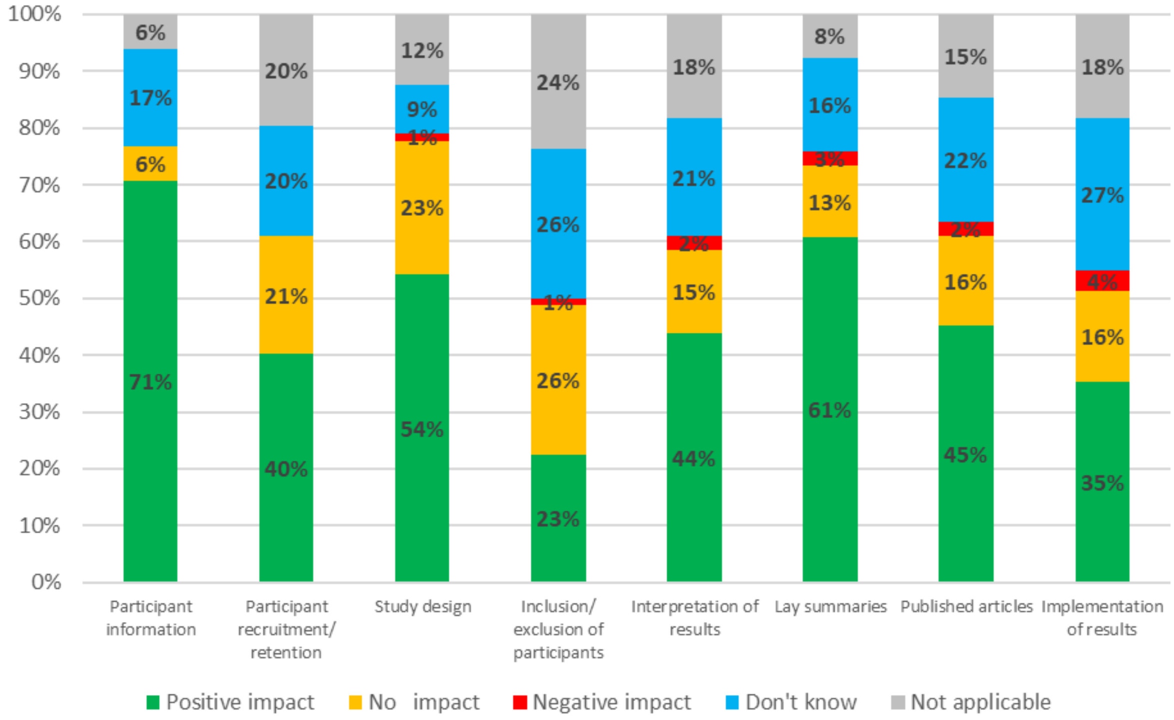
When asked whether feedback was honest a researcher responded:

> *'Yes. Certainly. But always couched in a lot of positive feedback and formulated extremely carefully.'* ***R99***

An important related result was that PRPs consistently rated their own impact on aspects of a study less positively than researchers did. Further a much higher proportion of PRPs did not know if they had an impact.

PRPs

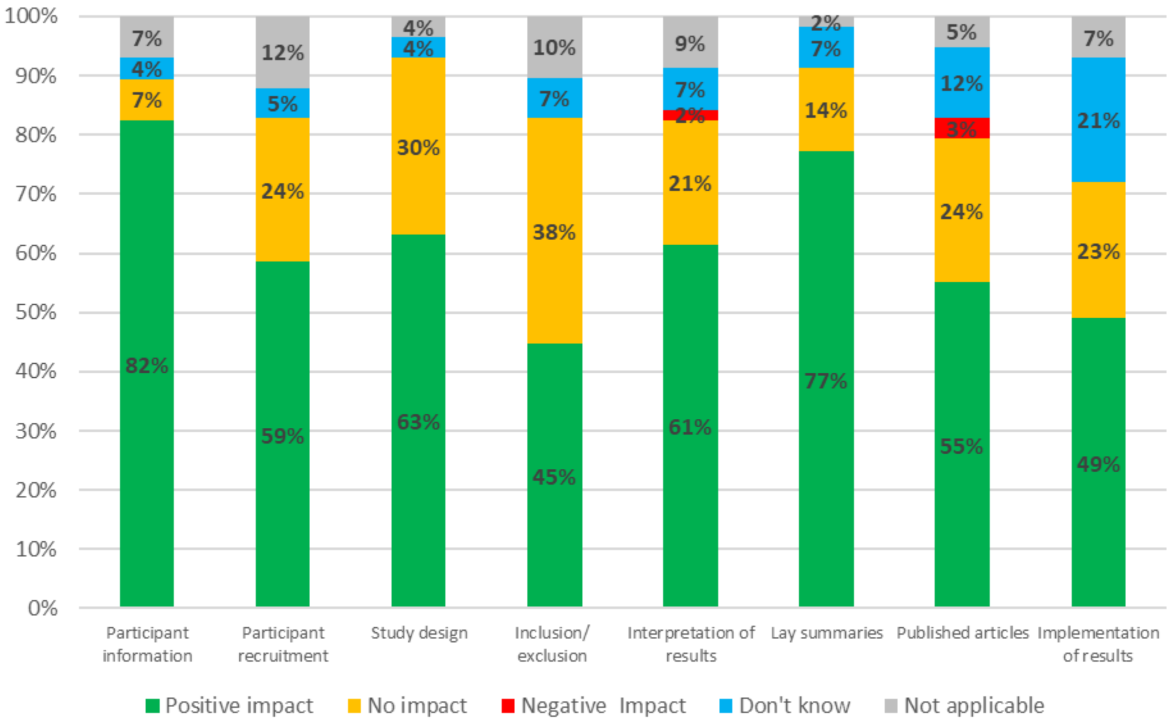
In my work as a PRP, I have had an impact on the following areas of studies



Missing values removed

Researchers

Involving PRPs in our studies had an impact on the following areas of studies



Missing values removed

When asked about this discrepancy in the interviews it was clear that this was a feedback issue. Feedback was very rarely personalised, meaning PRPs could not assess whether they had a positive impact on a study. This may be because researchers wish to preserve the 'delicate relationship' they have with PRPs and perceive that giving negative feedback would not be welcome. However, this also limits PRP's development opportunities and leaves PRPs feeling they need more than a thank you:

> *'We all get the group email, "We're so thankful to our partners and…" yeah but what about in particular or what did we do right? That would be useful.'* ***PRP24***

https://doi.org/10.57064/2164/26465

A possible construction of these two results is that PRP's contributions have more impact than they themselves believe. In turn the researchers feel that their feedback (often non-personalised) is honest. However, the lack of personalised responses means that PRPs do not always understand the huge impact they have and so doubt the honesty of the generic 'thank you' feedback. There is a need for more personalised feedback which will allow PRPs to build more confidence in their own value. In addition, personalised feedback on strengths and weaknesses of contributions will help PRPs to develop their skills.

On some occasions it was clear that no feedback at all had been given to the PRPs:

> *'I was involved in, I think, three or four different types of research. From three, I never heard again. It started and we said, hello and that was it.'* ***PRP03***

Researchers should try and give more personalised and more regular feedback as PRPs seem to appreciate this. However, PRPs can and should feel empowered to ask for more detailed feedback if they want it:

> *'I think as a patient you have to say always, "I want to have updates." Sometimes there is no news but then I want to have update also.'* ***PRP78***

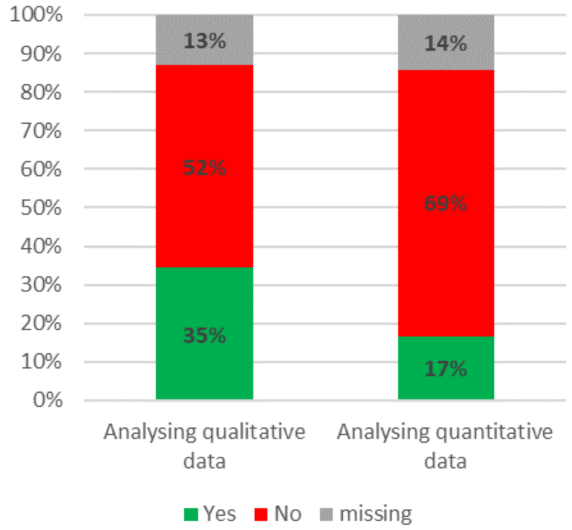
> *'One of these patient research partners said, "But please tell me if I am not doing what you are expecting me to do." This happened only once and actually she has been in all my projects in the last 10 years because I really like that approach because there I perceived the interest in participating also from the other side.'*
> ***R68***

https://doi.org/10.57064/2164/26465

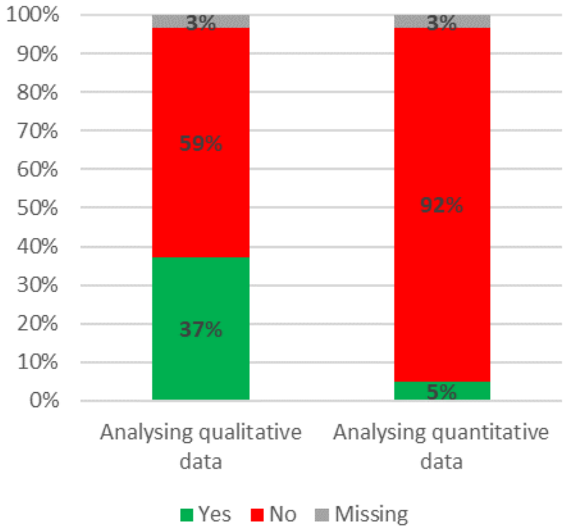
Data analysis and interpretation

It is clear from our questionnaire that PRPs are not generally contributing to data analysis tasks in projects. This clearly contrasts with an overarching ambition of involving PRPs at every stage of a research project. It is also clear that PRPs are more often involved with analysis of qualitative data than quantitative.

PRPs
What research tasks have you contributed to in your role as a PRP?



Researchers
Thinking about projects you've worked on, what research tasks have PRPs been involved in?



In the interviews both PRPs and researchers expressed the view that analysing data (usually interpreted as quantitative/statistical data) is very difficult for PRPs:

> *'I think usually the work is done by a statistician and so at the detailed analysis I think PRPs are not that much involved.'* ***R13***

https://doi.org/10.57064/2164/26465

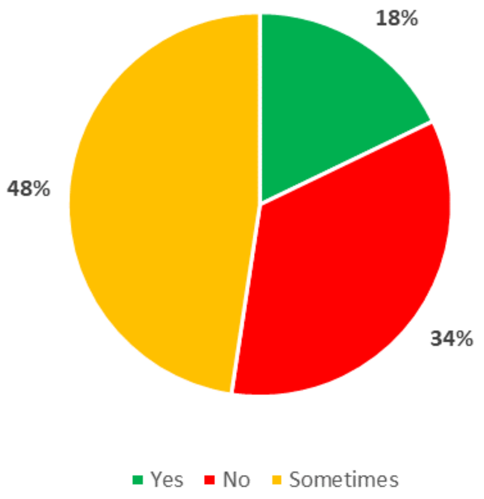
However, both researchers and PRPs expressed the opinions that PRPs can and should contribute to analysis by interpreting the data:

> *'The patient research partners will be essential for discussing how these data are relevant for clinical practice in their particular diseases.'* ***R13***

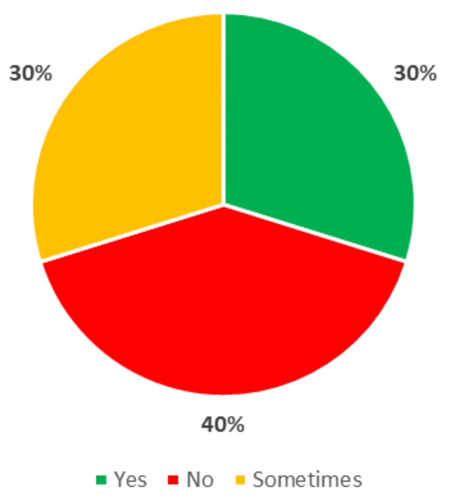
Payment

From our questionnaire it appears that PRPs are regularly not paid for their contributions

PRPs
In general, do you receive any remuneration (payment) for the services you offer as a PRP?



Researchers
In general, do you remunerate (pay) PRPs who are involved in your projects?



*Missing values removed

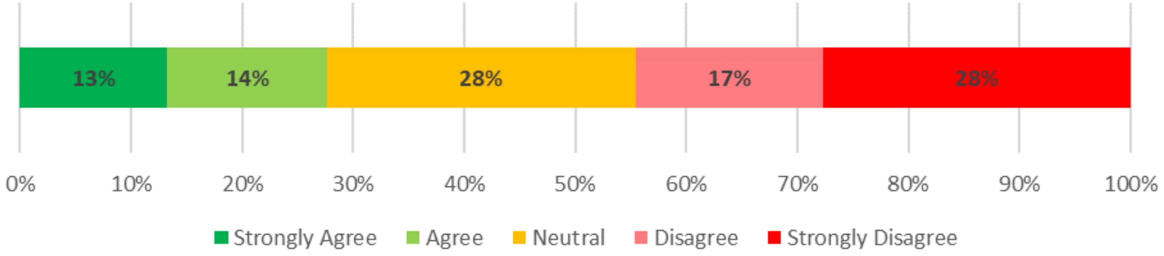
In our questionnaire only 27% of PRPs agreed that remuneration was an important factor when selecting projects. However, when probed further in the interviews it

https://doi.org/10.57064/2164/26465

became clear that this question had been answered mainly in terms of motivation for joining a study. PRPs frequently highlighted other motivations for joining a study and in this context payment was not of paramount importance when making the decision to participate or not.:

PRPs

Remuneration is an important factor when deciding which projects to apply for



Missing values removed.

In the interviews it was clear that the PRP's motivation for participation in research was generally an altruistic desire to help others. In this regard payment was not the primary reason for working on the study because it was outweighed by the desire to help others. When asked about payment one PRP responded:

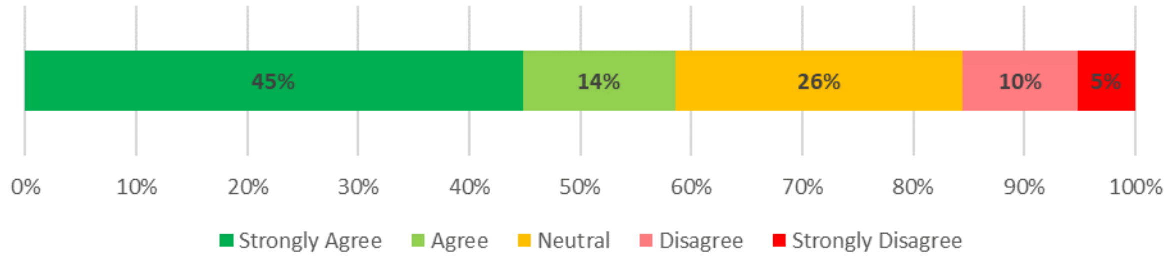
> *'For me, it doesn't make any difference at all. I'll do whatever because I want to and because I want to contribute and anything that helps further along the line people live a better life.'* ***PRP24***

https://doi.org/10.57064/2164/26465

However, in the questionnaire a higher proportion of researchers felt it was important to offer payment:

Researchers

It is important to offer remuneration for PRP roles



Missing values removed

In the interviews it became clear that the importance of payment was being expressed in different ways. Where PRPS had answered in terms of motivation for participation, researchers answered in terms of the utility of contributions and whether the specific input could be considered ‘work’:

> *‘I don’t compensate with money I don’t perceive it as work, I don’t perceive it as, I perceive it as super volunteer’* ***R08***

Despite the above results other PRPs and researchers also felt that payment for PRP work was important:

> *‘I think, nowadays, people would not even volunteer if they thought they weren't going to get paid because this is work and it absolutely must be paid for’* ***R091***

> *‘There must be one or two PRPs in the project and they also have to be paid……. they have to be on the same level.’* ***PRP068***

Further, it seems that lack of payment may discourage some people from becoming PRPs:

> *‘…there are people who then don’t get involved because it’s so many out of pocket expenses.’* ***PRP060***

We should also acknowledge that local rules may prevent PRPs from being paid at all. Also, our sample of PRPs is biased towards the more affluent members of society. Therefore, it is likely that most of our PRP sample do not need financial compensation, and therefore place less value on it. Further we acknowledge that some PRPs are happy to work for free and recognise that lack of funds should not prohibit collaboration with PRPs.

Overall, the issue of payment is complex especially when considering our dataset is across different countries with different localised rules and understanding of payments for PRPs. There is wide range of opinions with strongly held views on either side.

However, we believe that payment for PRP work is a positive step in making PRPs equal partners and reducing power imbalances and therefore should be encouraged. A step towards this would be to always emphasise that PRP work is a provision of expertise, rather than focussing on specific scientific outputs produced by the PRP.

> *‘I can't even imagine how much I'm paid per hour. But £25 per hour for expert opinion seems an absolute basic really’* ***R091***

Finally, in our interviews there was a general support for reimbursement of expenses for PRPs.

https://doi.org/10.57064/2164/26465

Tokenism

We understand tokenism as involving PRPs in research but not allowing or enabling them to influence the research. This could be to satisfy funder requirements or secure other advantages such as enhanced paper publishing opportunities. It is clear from our interviews that PRPs often perceive tokenism in their work, and this is a barrier to constructive PRP work:

> *'I felt someone like… they just needed a person's name, research partner's name on the research'* ***PRP71***

> *'I absolutely came out of it feeling well that was a tick box exercise that was. I need to have this because it looks better, or I need to have this because my tutor says I have to do this to get my PhD or whatever or my research project requires it. But you just knew. It's not what was asked, it's what wasn't asked and what wasn't said that gives the game away I think.'* ***PRP24***

Often tokenism was described by PRPs when the researchers did not allow sufficient time for the PRP to make informed contributions:

> *'Brought in at the oh my god really late stage or the bit where it's okay to do it now because we've got everything else ticked off that we want, and we might not get too many awkward bits at this stage. I think those are the feelings.'* ***PRP24***

https://doi.org/10.57064/2164/26465

Funders requirement to have PRPs involved in research grants seems to have had a positive effect in involving PRPs at an early stage. However sometimes this can lead to tokenism if the researcher does not allow PRPs enough time to comments on proposals:

> *'To be able to apply for public funding….. the researchers have to have patient research partners as part of their grant application. And I think in some cases it's still very much tokenism. We need names of patients. Shit, we haven't got any and we want to submit tomorrow.'* ***PRP60***

Tokenism often seems related to feedback. PRPs in the interviews mention participating in research only to never hear anything back from the researcher

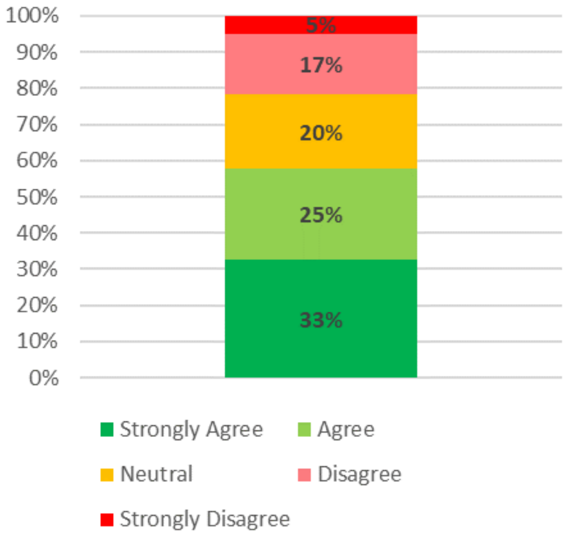
> *'I've been involved in three others that I have no idea what happened after that which is a bit of a shame because you give your all, or maybe they've not finished yet but if so it's taking a long while. But that would be worth knowing.'* ***PRP24***

In these cases, simple feedback, even where grants and/or research is unsuccessful or ends prematurely would be beneficial.

A partial remedy to tokenism may lie in the use of role descriptions or contracts. Our questionnaire suggested that PRPs were only provided with a role description around 58% of the time. Providing role descriptions in all cases would avoid differences in expectations between researchers and PRPs.

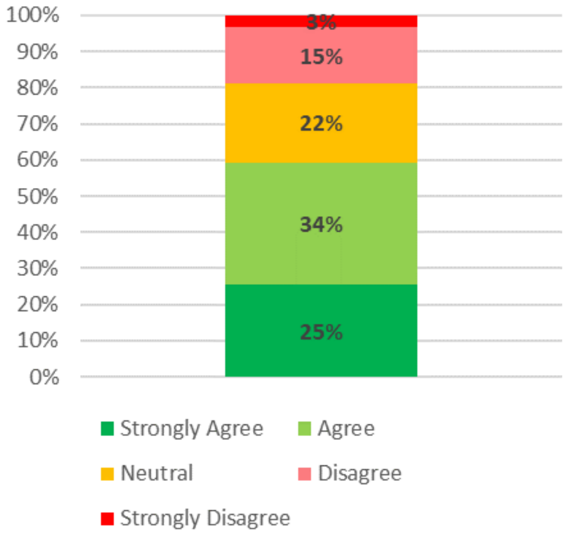
https://doi.org/10.57064/2164/26465

PRPs
I was provided with a role description or contract describing my responsibilities



Missing values removed

Researchers
The PRPs were provided with role descriptions or contract describing their role and/or responsibilities



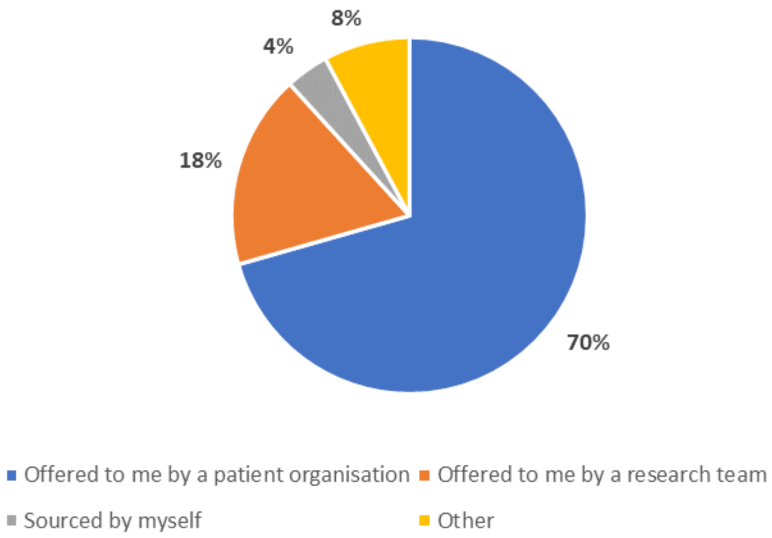
https://doi.org/10.57064/2164/26465

Training

52 (62%) of the PRPs in our questionnaire had received specialist training. Of the 52 with training,

most were provided training by patient organisations.

PRPS
What was the source of the training you received?



*Missing values removed

We acknowledge the potential for a high degree of bias in these answers. We recruited some PRPs from patient organisation mailing lists, which likely explains to the high degree of training received from patient organisations. However, even allowing for this bias 38% of our cohort of PRPs did not have training and those that did only 9 (18%) acknowledged that the training had come from research teams.

In the interviews nearly everyone was very positive about training. Indicating that it was useful or necessary for PRPs to receive training:

https://doi.org/10.57064/2164/26465

> *'The patient needs training for research.'* ***R075***

> *'I did the course….. it's good to prepare the Patient Research Partners and I liked the course, I think it's…..a good design…… it was simple, concise, and practical, I like it.'* ***PRP109***

Further it was noted that training had the potential to reduce power imbalances:

> *'The other is training in making yourself heard in a company of professionals. It's some sort of self, raising the self-esteem to be able to communicate on a level playing field where all these big wig doctors are talking about what they know about the disease etc.'* ***R99***

In contrast, one person felt that the training may detract from PRPs contributions and so should be delivered as neutrally as possible:

> *'I'd be a little bit wary of training because you might be turning out the sort of person that you want, not the sort of person that you need.'* ***PRP24***

62% of our PRP cohort had received training which contrasts with just 22 (37%) of researchers who had training to assist with working with PRPs. When asked about this contrast in interviews, both PRPs and researchers expressed views that there was a need for training for researchers as well.

https://doi.org/10.57064/2164/26465

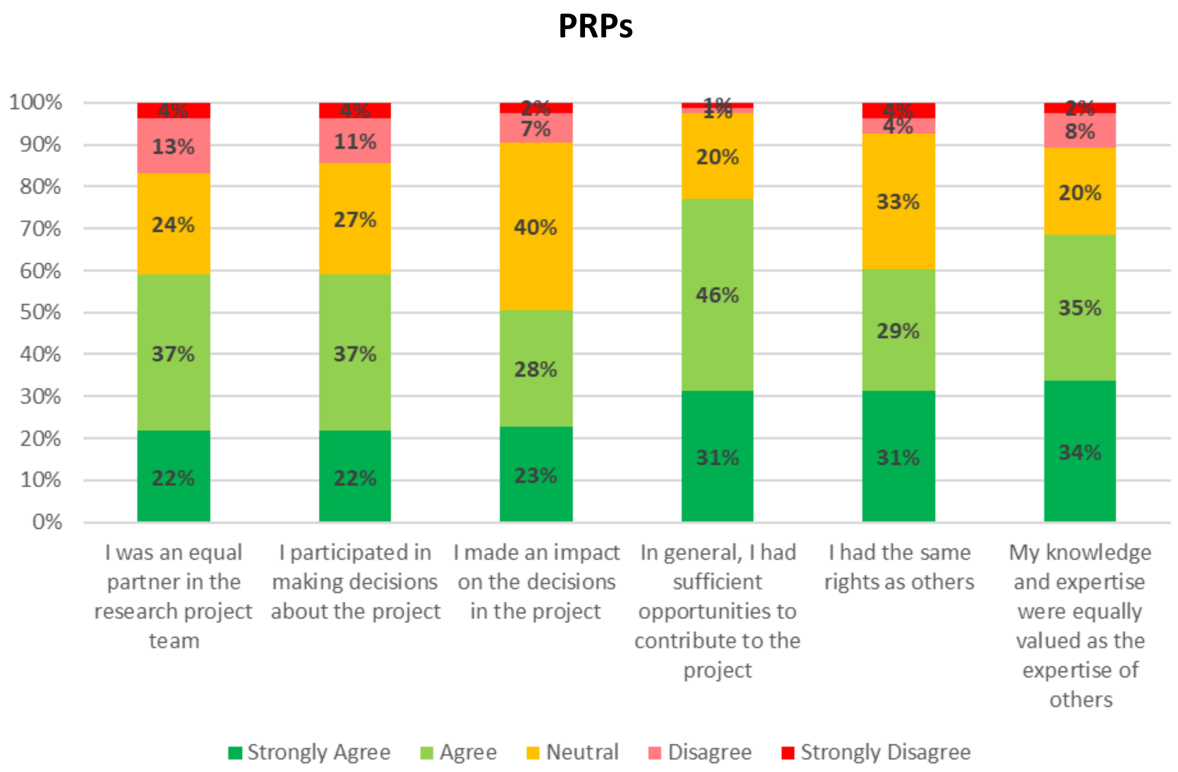
‘I think that there must be a few lessons at the university where they can be told about PRPs and most beautiful would be when a PRP is there and telling what she or he is doing.’ ***PRP078***

‘Simply put, they need to learn from the things we did wrong to make the experience for patients as beneficial as possible’ ***R99***

https://doi.org/10.57064/2164/26465

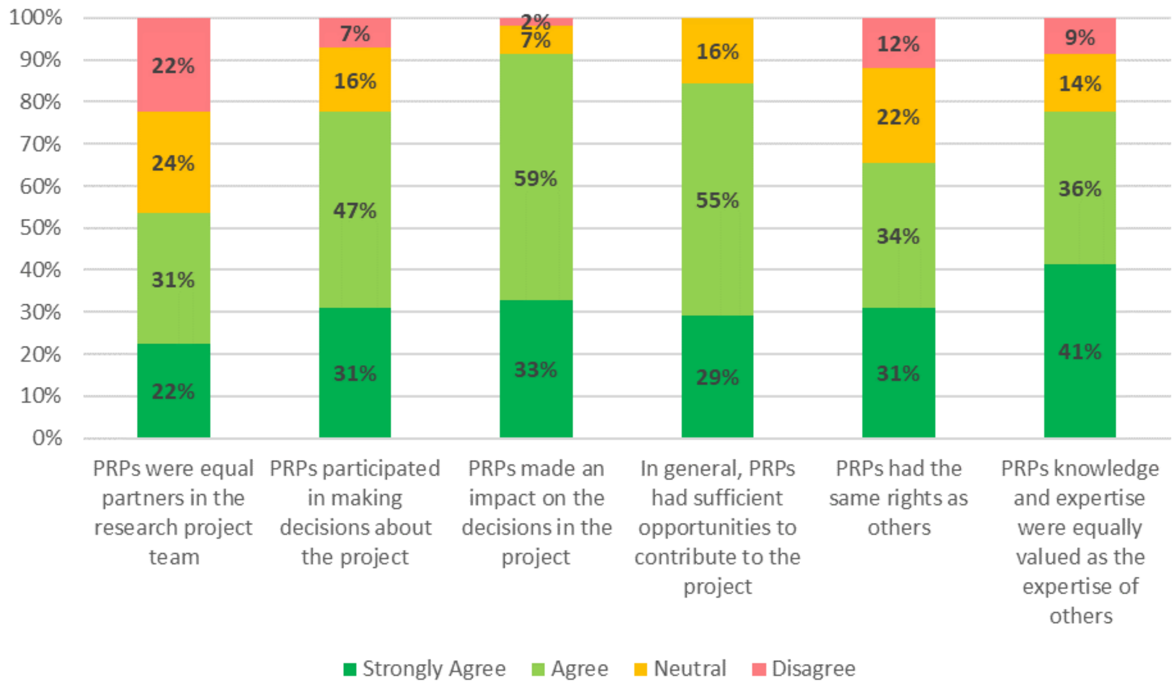
Equal partners

Utilising questions that originated in the PEIRS 22[1] question set, we asked PRPs and researchers whether they felt PRPs were 'equal partners' in research. Almost 60% of our PRPs agreed or strongly agreed that they were equal partners in the research project. However, that also means that 40% of the PRPs could not agree with this statement. Further, this can be contrasted with the fact that only 51% of PRPs felt they had an impact on decisions, whilst 92% of researchers felt that PRPs had an impact on decisions.



Missing values removed

Researchers



Missing values removed

In the interviews it was clear that being an equal partner meant different things to different people. Some strict interpretations of 'equal partner' meant that PRPs could never be considered on an equal footing within a research team:

> *'I don't feel equal. But I'm not necessarily certain I would feel like I needed to be on equal footing with the researchers. It's their study, they're guiding the work. They're running the work. They're the professionals in that.'* ***PRP60***

> *'I don't think it needs to be about equal, it just needs to be about valued. Valued is more important than equal because in some cases you can't be equal'* ***PRP24***

There are still power imbalances which prevent PRPS from feeling like equal partners:

> *'When you're in a team you are feeling quite equal but when you are talking with the professor or with a doctor, researcher, one is very nice and is talking with you on the same level but there are doctors who are thinking they are more'* ***PRP78***

> *'…it's more like a parallel dynamic that it's not exactly the same as the other research collaborators, yet.'* ***R68***

However, our interview participants reported several aspects that could make PRPs feel more equal. These felt relatively simple to adopt on a widespread basis, such as

A: the ability to contribute:

> *'We had, all the time, the possibility to ask questions or to give a statement and I think, then, you are really equal.'* ***PRP55***

B: Respect for expertise:

> *'I hope it will develop to real partnership. You are not on a same level with your knowledge, that's true but you have the other knowledge of the illness. I hope it will be, really, the same.'* ***PRP55***

https://doi.org/10.57064/2164/26465

C: Enhanced communication/feedback:

‘I think the thing that researchers could do is kind of explain they why they’re doing it, what the point of it is, you know? “This is what we’re doing and this why we’re doing it, and this is what we hope to achieve.” Sometimes I feel that we’re left kind of putting those pieces together’ ***PRP61***

‘More training for patients is necessary…. when you give a voice….. you empower them.’ ***R75***

By enhancing aspects like feedback and training we can hope to move towards PRPs working as more equal partners in research:

‘The question indeed becomes as part of the team do you feel that you are given the opportunity to give input and that you feel that your input is being seriously considered and potentially alters the course of the project.’ ***R99***

Being an ‘equal partner’ has different interpretations. However, it seems that relatively simple fixes could increase the feelings of an equal partnership. Involvement of PRPs in research is developing all the time and having a target of a mutual perception of an ‘equal’ partnership seems achievable.

‘Well 20 years ago I couldn’t hear something about Research Partner, they don’t exist, and researchers also think, “I am the research, the knowledge is mine. My plan, my project I don’t want anyone here.” And last five, four, five years it’s different and I’m very, very happy with that. Probably the idea the patient in the centre of the care, the healthcare, maybe changed this idea’ ***PRP109***

https://doi.org/10.57064/2164/26465

PEIRS 22

We included the complete PEIRS 22[1] tool for measuring meaningful patient participation in the PRP questionnaire. We modified these questions slightly to ask the researchers their perspective on the same topics. For example, a question in the PRP questionnaire was 'I had the opportunity to provide input into selecting my tasks for the project.' We modified this for researchers to read 'PRPs had the opportunity to provide input into selecting their tasks for the project.'

The scores are calculated on a scale of 1-100. Higher scores indicate more meaningful participation. The general range of scores tends to be high (anything above 70 is categorised as moderate meaningfulness).

- **PRPs: average score 75.17** (74 PRPS completed all 22 questions)

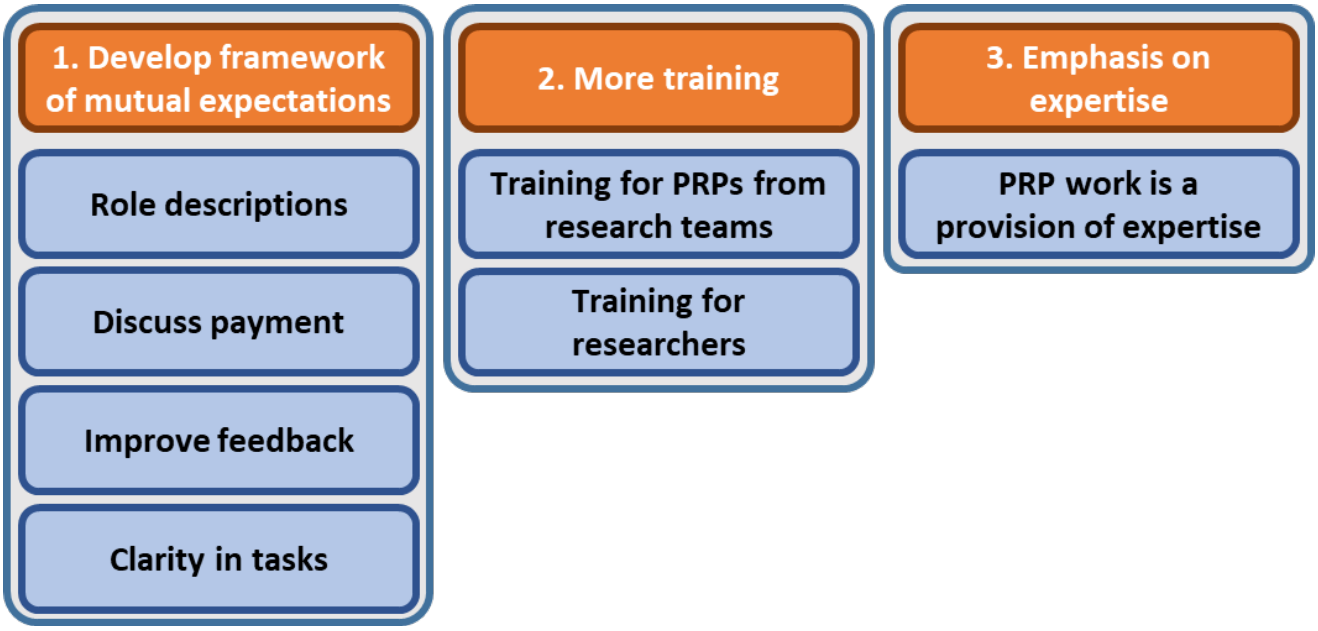
- **Researchers: average score 80.30** (54 researchers completed all 22 questions)

Once again in our cohort, the researchers perceived the participation as more meaningful than the PRPs did. Further, both scores on the recommended cut points indicate that the participation is only moderately meaningful, which means that there is room for improvement throughout the involvement process.

https://doi.org/10.57064/2164/26465

Recommendations

Our study has resulted in three main recommendations with separate components as follows:


1. Develop framework of mutual expectations
Role descriptions
Discuss payment
Improve feedback
Clarity in tasks

2. More training
Training for PRPs from research teams
Training for researchers

3. Emphasis on expertise
PRP work is a provision of expertise

1. We recommend developing a framework to describe mutual expectations between PRPs and researchers

<u>Audience: PRPs, Research funders, Researchers and Research Institutions</u>

The results from iPREPARE clearly demonstrate that PRPs and researchers can have different expectations when collaborating in research. These differing expectations can be barriers to meaningful patient involvement. We recommend that a framework is developed to describe mutual expectations and obligations between researchers and PRPs in a research study. A framework of mutual expectations will allow PRPs to understand what is expected of them and what they will receive in response, whilst also giving them an opportunity to opt out of parts they feel they do not require or want.

The results from the iPREPARE study highlight several areas which could be included in such a framework:

1.1 Role descriptions:

1.1.1 Role descriptions or contracts for PRPs should be available as standard practice.

- Although the majority of PRPs in our cohort had been provided with a role description, there is still a need to increase their usage.
- This will reduce the likelihood of PRPs and researchers holding different expectations from their working relationship which would in turn reduce perceptions of tokenism.
- The role description/contract will also be a good place to specify any payment arrangements.

1.2 Payment:

1.2.1 Before the start of the collaboration opportunities for financial payment for PRP work and reimbursement of costs should be discussed.

- PRPs may join a project because of an altruistic desire to help others. However, this does not mean the PRP should not be paid and/or acknowledged in other ways.
- Widening the possibilities for payment of PRPs may attract a more diverse range of PRPs to involvement work.
- If the role is to be unpaid this should also be specified.
- PRPs reasonable expenses should be re-imbursed.

1.3 Feedback and communications:

1.3.1 Personalised feedback should be made available.

- Feedback from researchers should be more detailed and be personalised to the individual PRP.
- ‘Thank you’ communications are appreciated by PRPs and should be encouraged; however, researchers should consider going beyond a ‘thank you’ to include specifics on the utility of inputs.
- PRPs can ask for more feedback if they feel they are not getting enough.

https://doi.org/10.57064/2164/26465

1.3.2 General communications with PRPs should be increased.

- Researchers should increase the frequency of communications with PRPs, for example letting PRPs know a grant application was unsuccessful or updating PRPs even if there have been no developments for a long period.
- PRPs should be aware they can ask for more study updates if they want them.

1.4 Research tasks

1.4.1. Time to consider and respond.

- Researchers should endeavour to give PRPs enough time to understand and contribute to research projects.
- In many cases PRPs are being involved early in the research cycle, i.e. at design stage. However, sometimes PRPs are not given a reasonable time to consider and prepare responses on individual tasks.
- We understand the timings of research projects which often require delivery at very short notice. However, giving PRPs short response times seems to increase perceptions of tokenism, moving away from an equal partnership.

1.4.2 PRPs can and should be involved in data analysis.

- PRPs and researchers agree that PRPs can contribute to analysis stages in interpreting draft result sets.
- Researchers should think about how best to involve PRPs in data analysis in each individual study so that results are drafted in collaboration with PRPs.
- Researchers could also receive training in how to involve PRPs at the data analysis stage learning from existing good examples/models of involvement.
- Further training 'on the job,' should be given if necessary. For example, researchers should ensure that they have explained the statistical methods to the PRPs in each individual study phase. This will allow greater participation of PRPs in data analysis and will address researcher and PRPs concerns about complexity.

https://doi.org/10.57064/2164/26465

2. We recommend that more training be made available for PRPs and researchers.

Target audience: Researchers and Research Institutions

2.1 More training should be available for PRPs 'on the job' from research teams.

- Research teams should provide/enable (and if necessary secure budget) to train PRPs.
- 'On the job' Training for PRPs within research teams can focus on the skills necessary to deliver any projects that the PRP may be working on. It also creates opportunities for genuine, direct dialogue between PRPs and researchers within a specific project.
- Training could decrease self-doubt of PRPs, decrease power imbalances and enable a more equal partnership.

2.2 Training for researchers should be available.

- There is a clear need for researcher training on how to involve PRPs in research.
- Researchers should have training to learn from good models of patient involvement and understand what to do and what not to do.
- It is important that researchers know how to minimise feelings of tokenism and to feedback to PRPs properly so that they understand the value of their contributions.

3. We recommend emphasising that PRP work can be characterised as a provision of expertise

Target audience: PRPs, Research funders, Researchers and Research Institutions

- There is a wide variety of views on payments for PRPs. Many European countries have differing policies and approaches towards payments for PRPs.
- We believe that payments for PRPs are a positive step and can reduce power imbalances and will increase the perceptions of equal partnerships.
- The differing opinions to payments often seem to revolve around whether the contribution can be considered a 'work' output.

https://doi.org/10.57064/2164/26465

- A step forwards would be to emphasise that PRP work can be characterised as a provision of expertise in a medical condition. This provision of expertise can attract payment.
- The value of PRP work should not be based on research outputs alone.

Further research

We recommend conducting further studies exploring the perception of PRP work by PRPs and researchers in larger datasets and other areas of medical research.

- It is likely that the iPREPARE questionnaire can be utilised to understand barriers and facilitators to the work of PRPs in other areas of medical research outside of rheumatology.
- The iPREPARE questionnaire could be repeated to better understand how the work of PRPs changes over time.
- We acknowledge that our results are in a relatively small dataset and are subject to several biases, for example our participants are of a relatively high socio-economic status and were recruited predominantly through patient organisations and networks.
- Any further research should pay particularly attention to recruitment to ensure that potential biases are minimised.

https://doi.org/10.57064/2164/26465

Annex: Interaction with new EULAR recommendations

The iPREPARE study data collection took place before the publication of the new EULAR recommendations for the involvement of patient research partners in rheumatology research (de Wit et al, 2024). However, the results from iPREPARE support and synergise with the new recommendations in several places whilst highlighting other areas that may need extra work. The iPREPARE data can also serve as a baseline measurement of the implementation of the EULAR recommendations.

EULAR Recommendation 1. PRPs should be involved in all types of research, including basic, translational, and clinical research.

iPREPARE results: Although iPREPARE attracted a relatively small dataset it is clear that the involvement of PRPs is less common in some types of research. 12 PRPs from 84 reported experience in basic research and 12 from 84 had experience in translational research, compared to 36 from 84 with experience in implementation research.

EULAR Recommendation 2. Researchers should involve PRPs from the inception of a research project and throughout all its stages

iPREPARE results: See section on main findings: early involvement above. iPREPARE suggests that PRPs are being involved early in the research cycle. The interviews suggested that funder requirements have played a large role in this positive change. However, the requirement to involve PRPs by funders can also lead to tokenism if the PRP is not given enough time to fully consider and contribute to the project before submission.

EULAR Recommendation 3. A minimum of two PRPs should be involved in each project

iPREPARE results: We did not gather data on this particular point.

https://doi.org/10.57064/2164/26465

EULAR Recommendation 4. Recruitment of PRPs should be based on a clear and agreed-upon description of mutual roles and responsibilities and should aim for diversity.

iPREPARE results: See iPREPARE recommendation 1. iPREPARE clearly demonstrates that PRPs and researchers can have different expectations when collaborating in research. We recommend that a framework is developed to describe mutual expectations and obligations between researchers and PRPs in a research study.

EULAR Recommendation 5. The research team must provide a supportive environment and facilitate the contribution of PRPs to research

iPREPARE results: 55 from 84 (65%) of PRPS agreed with the statement ‘I received sufficient support.’ Whilst this suggests that most research teams do provide supportive environments, it is of concern that 35% could not answer this question positively. The specific iPREPARE findings on the lack of PRPs involved in data analysis and that tokenism can manifest itself as a lack of time to contribute to a study, suggest that work remains to be done to actively facilitate contributions of PRPS in research projects.

EULAR Recommendation 6. A designated coordinator should support the collaboration of researchers and PRPs.

iPREPARE results: in iPREPARE 77 PRPs from 84 (92%) agreed that they had a clear point of contact for questions, suggesting the first steps to achieving this recommendation are in place. However, the role of coordinator is clearly wider than being a point of contact. The iPREPARE main findings on the need for improved feedback plus the examples of tokenism suggest that the role of coordinator needs to be developed to address these aspects.

EULAR Recommendation 7. Researchers should have access to training and support, to achieve effective communication and collaboration with PRPs as equal partners

iPREPARE results: See iPREPARE recommendation 2: There was wide support for researcher training so that researchers can learn from good models of patient involvement to improve communication and learn what not to do.

https://doi.org/10.57064/2164/26465

EULAR Recommendation 8. PRPs should have access to training relevant to their roles.

iPREPARE results: see iPREPARE recommendation 2. iPREPARE highlights the needs for more training of PRPs especially 'on the job' training from research teams tailored to the specific study being undertaken.

EULAR Recommendation 9. Researchers and PRPs should regularly evaluate their collaboration and adjust their way of working when needed.

iPREPARE results: Although we did not specifically gather data on this point the results of iPREPARE do suggest that there is a need for evaluation. In the section main findings: feedback, it is clear that PRPs often do not know what impact their contributions have on the research. Regular evaluation of the collaboration would highlight this discrepancy during the project which would allow the study team time to make changes.

EULAR Recommendation 10. The contribution of PRPs must be appropriately recognised, including co-authorship when eligible; financial compensation should be considered

iPREPARE results: Please see iPREPARE recommendation 3. We found that payment policies for PRPs are heterogeneous with different opinions expressed on whether PRPS should be paid. Please see section Main findings: payment. iPREPARE has added to the available data with observations that differing opinions are partially because PRPs discuss payment in terms of motivation for joining a study, whilst researchers discuss payment in terms of study outputs.

https://doi.org/10.57064/2164/26465

Personnel

The iPREPARE co-investigators are:

Martin J Stevens, Rosemary J Hollick, Gary J Macfarlane, Rebecca Parr, Sella Proven, Ingvild Kjeken, Maarten de Wit.

The iPREPARE co-design working group are:

Martin J Stevens, Rosemary J Hollick, Maarten de Wit, Loreto Carmona, Muriel Elhai, Ricardo Ferreira, Souzi Makri, Peter Böhm, Eva Petersson, Tracey Snell, Jon Skandsen, Ingrid de Groot

We also acknowledge input from:

Alessia Alunno, Gwenda Simmons, Paul Studenic, Khadija El Aoufy, Simone Battista

https://doi.org/10.57064/2164/26465

References

1. Hamilton CB, Hoens AM, McKinnon AM, McQuitty S, English K, Hawke LD, et al. (2021) Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. Health Expectations. 2021;24(3):863-79. https://doi.org/10.1111/hex.13227

2. de Wit M, Aouad K, Elhai M, Benavent D, Bertheussen H, Blackburn S, et al. (2024) EULAR recommendations for the involvement of patient research partners in rheumatology research: 2023 update. Annals of the Rheumatic Diseases 2024;83:1443-1453. https://doi.org/10.1136/ard-2024-225566

https://doi.org/10.57064/2164/26465