

Patient and Public Involvement (PPI) in Research – Case Study

Provided by:

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How patients and the public were involved

I prepared a funding application for a doctoral fellowship looking at improving methods in research on chronic musculoskeletal conditions. I involved patients with chronic musculoskeletal conditions by:

(i) getting their opinion on the research questions and whether they felt these were important both to them personally and on a wider scale,

(ii) ensuring that the plain English summary of the project was clear and accessible and included all the information they felt to be important, and

(iii) discussing the PPI aspects of the proposed project in terms of whether patients felt the level and type of patient involvement was appropriate and if there were any additional areas that they felt required input from patients and the public.

The impact of involving patients and public in the study

Patients gave some great suggestions on making my plain English summary more lay-person-friendly. It also really boosted my confidence to hear directly from patients about how important the findings would be and how positive they were about the proposed research ideas.

The importance of involving patients and the public in research

I think involving patients and the public in the design, conduct and dissemination of research is of critical importance. We must ensure that the research projects are designed to answer questions that are most relevant and important to the appropriate patient population. Furthermore, the findings from research projects should be presented in a way that is accessible and understandable to the general public.

The biggest challenges in PPI and what might help to overcome them

I think the biggest challenge in PPI is maintaining accessibility. As patients become more involved in research, they can provide useful insights into the patient perspective. However, there will come a point where a patient representative gains so much experience that they lose their 'lay' status. We must try to capture a representative view of the patient group by including a diverse group of patients with varying levels of research experience.