



Evaluation of a patient involvement activity in musculoskeletal health research: impact on patients and researchers

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Introduction

- In July 2010 the University of Bristol and North Bristol NHS trust set up a patient involvement group of patients with experience of musculoskeletal conditions and treatment (such as osteoarthritis, osteoporosis, joint replacement surgery and physiotherapy).
- Through facilitated group sessions, the Patient Experience Partnership in Research (PEP-R) group inputs into identification of research topics, refinement of patient materials, intervention development, readability of outcome assessment tools, and dissemination of findings.
- In PEP-R sessions, researchers and patients meet to discuss possible research areas, projects in early design stages and projects that are underway. Sessions are structured and varied. Training is built into sessions and takes place in tailored events.
- There is a need to evaluate the effect of patient involvement activity, but gains provided by patient involvement may be hard to quantify. It has been suggested that an effective way to evaluate patient involvement is to examine impact on stakeholders, particularly patients and researchers. This evaluation assesses impact of the PEP-R activity on stakeholders.

Methods and results

Methods

- The impact of patient involvement was evaluated through completion of a questionnaire by group members and researchers.
- All participants were asked to identify the impact of the PEP-R on themselves and the research.
- 8 patients and 14 researchers completed the questionnaire.
- Responses were analysed using qualitative 'framework' approach¹.



Results

- In the period of evaluation (July 2010 - November 2011), patients met in group sessions 10 times to provide input into 21 studies and study ideas.
- Patients who were group members described their interest in making a contribution, learning about the topics and research in general.
- Patients particularly valued feedback about how their input had shaped studies.
- Researchers identified the benefits of understanding patients' views on the importance, relevance and feasibility of their projects.
- Researchers welcomed discussion of their research with an interested and knowledgeable group, stressing the value of early involvement.

I am impressed with the way all comments, however insignificant they may seem at the time, are taken on board and used. (Patient F)



It helps to be able to give my experience, good or bad, to give advice which might help other people and to feel valued for this. (Patient E)



Discussing the design and reasoning behind my study to a 'lay' panel helped me to think clearly about writing my study proposal; I also thought the enthusiasm the group showed for the study made all the hard work I have had to do far more meaningful. (Researcher T)



As a researcher you can have many ideas for research projects, but without consultation with patients, it can be difficult to know whether these issues are actually of importance to patients. I wanted to engage with PEP-R as it provided an opportunity to ensure that the research was of interest and relevance to patients. (Researcher V)



Conclusions

- The evaluation indicates that musculoskeletal patients and researchers see patient involvement as impacting on research and on them.
- The model used in PEP-R facilitates patient involvement in the design and implementation of research, as well as providing support and training for group members.
- Although resource intensive, the approach used by PEP-R accrues impact and benefit based on co-working towards a common goal.