

Improving musculoskeletal research in North Bristol through public participation

By Rachael Gooberman-Hill and Amanda Burston

The need for research in musculoskeletal conditions

Musculoskeletal (muscle and bone) conditions affect millions of people in the UK. They are often very painful and have a great impact on people's lives. It is crucial that the research community works to understand the best ways to provide healthcare for people with these conditions. At the Musculoskeletal Research Unit at the University of Bristol, we are doing research into the best way of treating musculoskeletal conditions such as osteoarthritis and osteoporosis. Public involvement is helping us to shape this research.

Public involvement in musculoskeletal research

Since July 2010, a group of 11 member of the public has met with researchers every six to eight weeks to discuss research ideas and projects. This group is called PEP-R: the Patient Experience Partnership in Research. Group members bring with them knowledge and experience of living with musculoskeletal conditions.

What does PEP-R do?

A PEP-R session lasts for two hours in the evening. A session usually involves discussion of two projects or ideas, but may include more. Researchers come along to discuss ideas with the group, ranging from very early-stage thoughts about topic areas to projects that are already underway. The group has also had the chance to suggest its own ideas for future

research.

Since starting 18 months ago, PEP-R has discussed over 20 projects and ideas including the following:

- An early-stage topic idea was long-term pain after joint surgery. PEP-R identified priority areas for research into improving this pain and researchers are now developing a proposal for a programme of research based on these priorities.
- An example of PEP-R involvement in a project that is already underway is the group's work with the National Institute for Health Research (NIHR) funded Research Studies into the Orthopaedic Experience (RESTORE) research programme. Working with researchers, PEP-R has provided input into patient information materials, the design of interventions and questions to ask patients in research interviews.

How do sessions work?

Session formats include group discussion, presentations, card-sorting tasks and written answer sheets. It is important for researchers to have a written record of the session, so discussions are recorded on a flip chart or written sheets completed by group members. Material is sent out to group members in advance so that they have the chance to read it beforehand. They have the choice of providing their input verbally during a session, or by telephone or email afterwards. This input is collated and passed onto researchers. A light evening meal in the middle of a PEP-R session keeps everyone going!

Who organises the sessions?

The content of PEP-R sessions is worked out by a planning group. This is made up of researchers, a Communication and Patient and Public Involvement (PPI) Manager and a member of PEP-R.

How are PEP-R members supported?

Amanda, our Patient and Public Involvement (PPI) Coordinator is the key contact person for PEP-R members. Training in research is built into the sessions and there has also been the chance for PEP-R members to come to the Research Unit during the working day: to visit labs and offices and to discuss equipment. Members regularly receive feedback on the projects they have discussed.

What is the future for PEP-R?

The planning group is currently conducting an evaluation of PEP-R. Group members and researchers are being asked to describe how PEP-R has impacted on them and whether it has met their expectations. Several PEP-R members now sit on steering groups in the Research Unit. We hope that PEP-R is here to stay!

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