

Managing symptoms of fibromyalgia

Time spent on recruitment helped make public involvement effective for NIHR CLAHRC West

Fibromyalgia is a complex long-term condition where patients experience several symptoms. These include chronic widespread pain, fatigue, sleep that isn't refreshing, mood changes and problems with memory and thinking.

Michelle Farr and Heather Brant are leading a study to discover what health professionals such as GPs, physiotherapists and psychologists understand about fibromyalgia and how confident they are at diagnosing and managing the condition alongside providing support for those with fibromyalgia. They decided early on to make sure people with fibromyalgia had a say in helping to form the questions they needed to ask, provide feedback on some of their findings and to guide them on how best to share the information they have gathered.

Public contributor Collis giving everything careful appraisal



Vicki and Pat giving the benefit of first-hand experience

In January 2018, Heather and Michelle met with PPI facilitator, Mike Bell, to discuss how best to recruit a group of public contributors. They decided the best way was to meet and talk to people with fibromyalgia face-to-face. Mike contacted two support groups for people with Fibromyalgia, one which held daytime meetings in Hanham, Bristol and one that held evening get-togethers in central Bath to ask if the team could visit to explain the research and ask for help. Both groups were keen to assist and so Mike and Heather packed some information leaflets and off they went.



Researcher Heather Brant and public contributor Vicki listening intently

The first PPI meeting was held on Friday 16 March and was attended by six public contributors from as far away as Trowbridge. Everyone was able to contribute fully to the meeting and Heather and Michelle were given a lot of useful feedback. They will be hosting future meetings to discuss key findings from the research and how they can best share their findings with everyone and have received a lot of interest in people who are keen to help the study.

Public contributor, Sharon.



The Hanham group was well attended. Mike and Heather were plied with tea and biscuits before making a short presentation about the study and the important role the group could play as public contributors. There was a good level of interest with many people asking questions and keen to get involved further. The Bath meeting was less busy but the few who attended clearly cascaded the news to other members of the group as, again, there was a lot of interest from people wishing to be involved.