

Public involvement in a CLAHRC West research project on evaluating chronic pain peer support groups

Background

Chronic pain affects more than two fifths of the UK population and can impact a person's mobility and independence, and lead to depression.

Pain management or self-management programmes (SMP) can help people manage the effects that pain has on their daily life and improve how they cope with it. These 2-3 month programmes have been shown to have a positive impact on people's ability to manage their pain, but improvements can be harder to sustain over a longer period of time after the programme has finished.

To tackle this problem, North Bristol NHS Trust have developed 'follow-on' peer support groups for people, once they've finished their self-management programme. The idea behind the development of these groups first came from patients and clinicians.

How do peer support groups develop?

In North Bristol NHS Trust self-management programmes are co-facilitated by clinicians and patient tutors. Patient tutors have experience of chronic pain, have attended a self-management programme, and have had further training. After a self-management programme finishes, patient members can develop a new peer support group together, with support from a patient tutor. Groups can meet regularly with informal contact between members, so that people can keep the connections they make with others through the programme and continue to support their self-management of pain.

The research project

North Bristol NHS Trust volunteer patient tutors and clinicians are working in collaboration with University of Bristol researchers from National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West) to evaluate the impact of these peer support groups.

CLAHRC West are interviewing staff who facilitate self-management programmes, patient tutors and patients who've attended programmes about their experiences of these peer support groups. We are also visiting peer support groups to observe them in action. We are exploring different participant's experiences, to understand why peer support groups may, or may not, work for them.

How we involved people

When we started the research, we involved patient tutors through regular research meetings. They really helped the researchers to understand more about the peer support groups, how to design the research and the best ways of inviting people to participate in the research. We also had patient tutors' feedback on the information to send out to people to invite them to take part in the study. Over time we found that patient tutors couldn't always attend these research meetings, as people had busy lives, and could also still be managing their own pain, which can fluctuate and change.

As the research has progressed we have met more patient tutors and people who have taken part in self-management programmes and peer support groups. Many of these were interested in helping us guide the research. We invited those who were interested, to come along to a meeting to ask for people's thoughts on:

- What makes peer support groups successful (or unsuccessful)?
- How to improve questionnaires we're developing to help understand how many people attend these groups?
- What's going to be most useful to know about the research, from a patients' perspective?
- How we can share our findings with everyone?

What people have said so far

Nine patients and patient tutors came along to our first meeting and they shared lots of insights and helped us think these things through. We had some great suggestions to help develop the questionnaire and ideas on how we could share the research findings.

People were interested in linking in with each other's groups and connecting with each other more. Ideas to help this included having a Facebook page so that different groups could find out about each other.



Comments from people who took part in the meeting included:

"I felt relaxed, respected and involved"

"Would be happy to do it again if needed"

"Enjoyed the session"

Everyone who contributed was paid for their time and travel expenses.

We will be hosting future meetings with patients and patient tutors to discuss key findings from the research and how we can best share our findings with everyone.

We're looking forward to the next meeting already.

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