Oxford Biomedical Research Centre

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

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How patients and the public were/ are involved

The BOOST (Better Outcomes for Older people with Spinal Trouble) Programme of Research.

This is a 5 year programme of work funded by the NIHR focusing on the management of back pain in older people. It consists of a cohort study, randomised controlled trial of physiotherapy treatments for older adults with back and leg pain and an embedded qualitative study.

During the application process for this programme of work we assembled a PPI group and we have continued to work closely with them. We advertised for PPI representatives via the INVOLVE website and approached a variety of organisations including the Rotary Club, the British Legion, Age UK, Men's Sheds, BackCare and the British Orthopaedic Associations Patient Liaison Group. PPI representatives were also identified from participants in the BOOST preparatory interview study that was conducted to inform the development of the physiotherapy intervention. We have also utilised personal contacts within our department to identify older adults to assist with PPI activities. An experienced PPI representative is a co-applicant on the grant. We appointed a PPI representative to be an independent member of the Programme Steering Committee. PPI engagement has been undertaken in face-to-face meetings and via emails and phone calls to make it as convenient as possible for the PPI group to contribute. We have supported PPI representatives by paying travel expenses. We have offered to pay for our PPI representatives' time but no one has accepted this offer. Training opportunities offered by the Oxford CLAHRC have been circulated to the group.

PPI representatives have assisted with the development of the physiotherapy intervention. Two PPI representatives attended the intervention development day along with clinicians and researchers. The presence of PPI representatives at this day was integral to ensuring that the interventions were patient focused and prioritised issues highlighted by patients. One PPI representative carried out the proposed exercise programme in her home so she could give feedback on the practicalities of performing the proposed programme. PPI representatives helped us to develop the patient materials for the intervention and even posed as models for the exercise sheets.

Participant information leaflets, consent forms and posters advertising the trial have been reviewed by the PPI group and they have provided feedback on layout and wording to make them user friendly. We have piloted questionnaires with our PPI group. The baseline questionnaire was piloted on 20 PPI representatives including older adults for whom English is a second language to ensure suitability for participants from ethnic minorities. PPI representatives have helped with developing interview schedules for the qualitative study and we will carry out some practice interviews with the PPI representatives prior to undertaking the actual study.

We have endeavoured to engage with our PPI group regularly. We keep them informed with progress of the research via a 6 monthly newsletter. We have circulated training opportunities as they arise. Work has also begun to develop a website for the study and this will allow patients and the public to access information about this research as soon as we receive our favourable opinion from the Research Ethics Committee.

The impact of involving patients and public in the study

At the initial PPI meeting, an overview of the research was given and all in attendance were given an opportunity to generate questions, queries or raise issues. This process raised issues that the research team have acted upon, for example, the group queried the age of eligibility (70 years and over) and argued for it to be lowered to 65. Concerns were voiced around access to the study citing the relative poverty of older people as a potential barrier to participation thus greater emphasis on access issues now informs the design of the programme. The need to broaden the sample of older people with back pain beyond just those who have consulted their GP was raised and the sampling strategy for the cohort study was changed. Further valuable feedback included the importance of the question, their experience of services, the relevance of outcomes, the acceptability of the research methods and the role of PPI input in developing the full application and guiding the programme.

During the set up phase of this research, PPI input has helped to refine the study questionnaires to ensure they were readable, understandable and address issues and outcomes of relevance. We have discussed study procedures to ensure that burden placed on participants is justifiable and well explained, and to identify barriers to recruitment. We have worked collaboratively with the PPI representatives to design information sheets to ensure they engage older people, are easy to understand and address concerns or questions likely to arise in this patient group.

Two PPI representatives attended the intervention development day and this was extremely helpful. Researchers and clinicians can become disconnected from the patient's experience of healthcare. The presence of patient voices at this meeting was a reminder of the purpose of our research (to improve the care of patients) and ensured that our focus was on patient benefit not what is easy to deliver. PPI representatives raised issues such as transport difficulties and were able to give their views on what outcomes were important. The PPI representatives played an important role in shaping the intervention we will test in the BOOST Trial.

The importance of involving patients and the public in research

Early engagement with public and patient representatives was a key part to securing the funding for the programme of research. PPI representatives have contributed in an extremely helpful and meaningful way to the set-up phase of this programme of research. Throughout the remainder of this project we will continue to work with our PPI representatives to get their feedback on the conduct of the studies and their input into the reporting and dissemination strategies.

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

We have not identified any particular difficulties with PPI engagement. We have found people are extremely willing to give their time. We utilised the Research Design Service during the application phase of the research and they were extremely helpful in providing ways to identify PPI representatives and helped to facilitate our initial meeting. I think this has put us in good stead for the rest of the programme of research as they provided us with a framework to structure PPI engagement for the rest of the project.