

BOOST: Better Outcomes for Older people with Spinal Trouble

Case Study

Background

This 5-year programme focuses on the management of back pain in older people.

What we did

During the application process we formed a PPI group and worked closely with them. We advertised for PPI representatives via the INVOLVE website and approached other organisations, including the Rotary Club, the British Legion, Age UK, Men's Sheds, BackCare and the British Orthopaedic Associations Patient Liaison Group. We also identified people in the BOOST preparatory interview study and asked contacts in our department to identify older adults. A PPI representative is a co-applicant on the grant, and a PPI representative is member of the Programme Steering Committee. PPI engagement has been 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 and their time.

PPI representatives assisted development of the physiotherapy intervention. Two PPI representatives attended the intervention development day along with clinicians and researchers. A PPI representative carried out the proposed exercise programme in her home to feedback the practicalities of performing the proposed programme; they also helped 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. 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 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 engage with our PPI group regularly and update on the research progress via a six monthly newsletter. We circulate training opportunities as they arise. Work has also begun to develop a website for the study, to allow patients and the public to access information about this research.

What difference did it make?

The presence of PPI representatives ensured the interventions were patient focused and prioritised issues highlighted by them. At the initial PPI meeting people raised issues that the research team acted on; the group queried the age of eligibility (70 years and over) and argued for it to be lowered to 65. They cited the relative poverty of older people as a potential barrier to participation, so access improvements were designed into the programme. They raised the need to broaden the sample of older people with back pain beyond only those who have consulted their GP, so the sampling strategy for the cohort study was changed. 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. PPI input ensured the study questionnaires were readable, understandable and outcomes were relevance.

Researchers and clinicians can become disconnected from the patient's experience of healthcare. The presence of patient voices 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. The PPI representatives played an important role in shaping the intervention we will test in the BOOST Trial.