

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

Provided by:

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How patients and the public were/ are involved

We performed a series of formal qualitative interviews with hip fracture patients and their carers (NIHR RP-DG-1210-10022). We explored the patients' experience of hip fracture and their expectations of recovery from their injury.

We then matched the patients' priorities regarding outcome to existing outcome measurement tools to create a short-list of research tools based on the patients' own views. The patients and their carers were then involved in the consensus meeting where the final UK hip fracture 'core outcome set' was agreed.

The core outcome set is the basis for the current World Hip Trauma Evaluation (WHiTE) cohort study, and the clinical trials embedded in this cohort.

One or more of the patients who contributed during the WHiTE development work is a co-applicant and full member of the research team for each of the embedded trials. The lay co-applicants have first-hand experience of the problems and priorities of patients who sustain a hip fracture, so their views shape every aspect of the trials.

The lay co-applicant is part of the Trial Management Team, with particular responsibility to ensure that all trial procedures and patient-facing information are optimal from the patient perspective. Crucially, towards the end of the trial the lay member leads in the dissemination of the findings to the wider public audience.

Two members of the original patient group now sit on the WHiTE Oversight Committee, to review and guide each and every investigation embedded in the WHiTE project.

The impact of involving patients and public in the study/ your work overall

The core outcome set is based entirely on the patients' expectations and priorities for recovery following a hip fracture; it couldn't have happened without them.

Subsequently, the views of patients have informed and refined all of the WHiTE study, procedures, processes and materials.

The importance of involving patients and the public in research

By involving the patients and their carers right from the beginning, we have ensured that we are addressing the most important research issues from the patients' perspective. This is central to the NIHR philosophy and, of course, the most important aspect of any research project in the NHS.

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

The Lay representatives in each study/trial are supported by the Chief Investigator and the trial coordination team. However, there is a need for ongoing training and peer-support.

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The University of Warwick has the UNTRAP network (University/User Teaching and Research Action Partnership), an organisation which promotes the engagement and involvement of service users and carers in all research and teaching in Health and Social Care. NDORMS may wish to review the UNTRAP model in supporting its own PPI groups.