

The World Hip Trauma Evaluation

Case Study

What we did

We performed a series of formal qualitative interviews with hip fracture patients and their carers (NIHR RPDG-1210-10022). We explored the patients' experience of hip fracture and their expectations of recovery from their injury. The patients' priorities regarding outcome were then matched to existing outcome measurement tools to create a shortlist 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 became the basis for the World Hip Trauma Evaluation (WHiTE), and the clinical trials embedded in this study. At least one 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 for ensuring that all trial procedures and patient-facing information are optimal and accessible from the patient perspective. Crucially, towards the end of the trial, the lay member leads in sharing the findings to the wider public audience.

What difference did it make

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 areas of the WHiTE study, including procedures, processes and materials.

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.

Overcoming challenges

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. Our Musculoskeletal Trauma PPI group meets regularly to share information and experiences and are given support from our research team with any issues that arise from these meetings. We are keen to ensure that our PPI group membership is diverse and inclusive and are working to gain wider engagement of patients and members of the public in the UK and increasingly abroad.