Piloting the Patient Experience of Trials measure

Patient experience is increasingly seen as an important aspect of taking part in trials, but there is very little evidence about this issue – our recent scoping review suggested that patient experience is rarely measured.

Our Patient-Centred Trials (PACT) study (funded by the NIHR Research for Patient Benefit programme) aims to develop a short, useable measure that can capture the key issues that impact on patients taking part in trials

We have completed the measure development phase, involving a synthesis of previous studies, qualitative and cognitive interviews, and extensive patient and public involvement.

Pilot Study

The aim of our pilot study is to assess the new measure: is it acceptable to patients, is it useful for staff, and does it have acceptable psychometric performance?

To meet our RfPB timelines, we need to pilot the scale in around 500 patients by the end of April 2019.

To do that, we need to:

1. Identify 'host' trials which could act as pilot sites. We would prefer trials that are close to final follow up of patients, although the measure could be piloted at a number of stages towards the end of a trial

2. We would seek to add our measure to the usual assessment procedures for the trial. We could do a separate, bespoke assessment if that was easier.

3. We would need you to collect and enter the data as part of your routine follow-up – this is the model that we would like to test. Although we only need the questionnaire data and intervention arm for some analyses, it would be helpful to link it to anonymised demographic data (gender and age in years in broad categories) on the patients for further analysis.

4. You would analyse the anonymised data set and we would develop reporting templates for you to use to report the data. We have specific expertise on this through our previous patient experience work at the University of Manchester.

5. We also plan to develop a toolkit to help trial teams to use the measure, and we would like to interview trial teams to understand barriers to the use of the measure, and how it can best be used for quality improvement.

6. We would need host trials to submit an amendment for the use of the measure to the relevant NHS ethics committee where ethical approval is held, and we would assist with that process.

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