

Developing a participant experience questionnaire for randomised trials: patient and public involvement for the PAtient Centred Trials (PACT) Study

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Abstract

Introduction

Measuring participant experience is a way of understanding how trial design impacts on trial participants. Yet there is no valid questionnaire that has been developed in partnership with potential participants.

Aims

- 1) To understand participant experience in trials from our patient and public involvement partners;
- 2) To combine insights with our empirical work to ensure our questionnaire captures robust patient-centred data.

Methods

Six patients and members of the public with equal numbers of those with trial experience and those without were invited to attend a questionnaire development workshop.

Topics of concern were broken down into the different stages of a trial to reflect a participant's trial 'journey' from beginning to end.

Insights were tabulated and shared with the wider team to feed into the analyses.

Results

The purpose of the new participant experience questionnaire needs to centre on the 'human connection'; were they treated as a 'person or a subject' by the trial? Was the language personable?

The advantages of being able to capture experience data in stages and in its entirety were emphasised. Insights involved how the trial might 'glam up' the process of taking part heightening expectations; preferences to be allocated to the treatment group might be linked to 'hidden motivations' to take part; and participants might feel 'abandoned' by the trial relationship ending.

Discussion

We applied a novel approach to questionnaire development by involving our PPI group enabling discussions to be focused in a pragmatic way allowing insights to be embedded within our new questionnaire.

Patient and Public Involvement (PPI)

A comprehensive patient and public involvement strategy for the PACT study was co-developed by an experienced PPI Co-ordinator (AD, PRIMER member) and SPCR Fellow (CP) with expertise in PPI Leadership using the Public Involvement Strategy Development Planning Tool (SPCR PRIMER, 2017). In our presentation, we will showcase our learning from both perspectives, including the benefits and challenges of having the engagement strategy in place to aid the development of the questionnaire as described in the abstract. We will also report how we supported a capacity building approach to public involvement having an equal mix of old and new PPI contributors.