

## Lay summary for completed research projects

CCR No and Study Title:	<p>CCR3368</p> <p>A Longitudinal Pilot Study of a Questionnaire Examining Patients' Expectations and Experiences of Participation in Phase I Anti-Cancer Clinical Drug Trials</p>		
CI and Sponsor names:	<p>Dr Natalie Pattison</p> <p>The Royal Marsden NHS Foundation Trust</p>		
Study opening date:	27/05/2010	Study closing date:	30/09/2013
Proposal and Objectives:	<p><b>Background:</b> Successful advances in the treatment of advanced cancer rely on the recruitment of patients into phase I clinical trials of new drugs. Increasingly, clinical trial participation is becoming part of the treatment experience of the individual with cancer.</p> <p>As healthcare professionals we need to understand the experience of patients participating on these trials in order to provide the best practice in the area.</p> <p><b>Design and Objectives:</b> This study used interviews to explore patients' expectations and experiences of participating on phase I clinical trial drug. The interviews were conducted at the outset of the trial and six weeks into treatment. Written informed consent was taken from each patient.</p> <p><b>Sample:</b> A sample of six patients (aged 29-73), chosen to reflect a wide range of experiences, cancers and ages, who were on a phase I anti-cancer clinical drug trial were recruited into the study.</p> <p><b>Methods and Data Analysis:</b> Face-to-face, in-depth interviews using a loosely-structured guide. The audio-recorded interviews were transcribed and analysed for themes.</p>		
Main Findings:	<p><b>Results:</b> Themes emerging from the data included: 'life interrupted'; 'expectations versus experiences'; 'trial participation and the family'; 'the meaning of a trial'; and 'organisational care'.</p> <p>Experiences showed that, whilst there was an expectation of some lifestyle disruption, participation had a greater impact than envisaged. The impact was multi-faceted and related to interruption of daily-life that participants were not always prepared for.</p>		

<p>Implications for practice/future research:</p>	<p>Conclusion: This study contributes to current research about patients' expectations and experiences of participating on phase I anti-cancer clinical trials.</p> <p>It identified mismatches between expectations and experiences and demonstrates the need for nurses to develop a range of flexible educational sessions for pre-trial education, with the continued assessment and provision of information on an individual patient and family basis as the trial progresses and concludes.</p> <p>This will help in ensuring patients' actual experiences of trial participation are congruent with expected ones.</p>
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