## Lay summary for completed research projects

| CCR No and Study Title: | CCR3368  
A Longitudinal Pilot Study of a Questionnaire Examining Patients' Expectations and Experiences of Participation in Phase I Anti-Cancer Clinical Drug Trials |
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| CI and Sponsor names:  | Dr Natalie Pattison  
The Royal Marsden NHS Foundation Trust |
| Study opening date:    | Study closing date:  |
| 27/05/2010             | 30/09/2013 |
| Proposal and Objectives: | Background: 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.  
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.  
Design and Objectives: 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.  
Sample: 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.  
Methods and Data Analysis: Face-to-face, in-depth interviews using a loosely-structured guide. The audio-recorded interviews were transcribed and analysed for themes. |
| Main Findings:          | Results: Themes emerging from the data included: ‘life interrupted’; ‘expectations versus experiences’; ‘trial participation and the family’; ‘the meaning of a trial’; and ‘organisational care’.  
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. |
### Implications for practice/future research:

**Conclusion:** This study contributes to current research about patients’ expectations and experiences of participating on phase I anti-cancer clinical trials.

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.

This will help in ensuring patients’ actual experiences of trial participation are congruent with expected ones.