

GRIPP2 short form

		Reported on page No.
<p><b>1: Aim</b></p>	<p><b>Report the aim of PPI in the study</b>            Patients and carers were involved in this study with the aim of ensuring that the survey questions were clear, enabled people to express their own experiences and were of importance to them.</p>	<p>P5</p>
<p><b>2: Methods</b></p>	<p><b>Provide a clear description of the methods used for PPI in the study</b>            Patients and carers involved in the study (AD, RH, JE) were core members of the research team and were involved in the inception of the study or invited to participate at the start of the study. The patients and carers aimed to make substantial contributions to each stage of the research and were included in all study meetings and communications. Patient partners co-produced a poster of the findings for the “NIHR INVOLVE Conference 2017” to aid dissemination of the research to academic and industry research professionals, patients, policy makers, editors, and advocacy groups.            Early drafts of the survey were reviewed and piloted by an additional four BMJ patient reviewers and changes were made to the questionnaire.</p>	<p>P5, P12</p>
<p><b>3: Study results</b></p>	<p><b>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</b>            The patients and carers made substantial contributions to multiple stages of the research.             During questionnaire development and piloting, patient reviewers (and not just those in the research team) helped generate applicable questions of importance to them, suggested the removal of some questions, shortened the questionnaire, changed the wording of questions to clarify meaning, encouraged the use of plain language, and broadened some questions to ensure experiences were captured.             The patients and carers commented on the results and helped write the manuscript for publication. They were key in ensuring the paper was written in plain language. They will help write a plain language summary for dissemination of the results to the study participants and to relevant organisations.</p>	<p>P5</p>

<p><b>4: Discussion and conclusions</b></p>	<p><b>Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects</b></p> <p>PPI influenced all aspects of the study. It increased the relevance of survey questions which was pivotal in engaging patient reviewers to take part in the survey. PPI contributions were constructive, timely and improved the quality of the research conducted and reported.</p>	
<p><b>5: Reflections/critical perspective</b></p>	<p><b>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience</b></p> <p>Involving patients and carers in this study was a very positive experience and input from patients and carers made the project a success. The project demonstrated the feasibility of working with patients and carers to appraise the quality of the research paper. The patients and carers shared research involvement provided a sense of 'ownership'.</p>	