

GRIPP2-Short Form Checklist for the Reporting of Patient Engagement in Research

Section and topic	Item	Reported on page No
1: Aim	<p><i>Report the aim of PPI in the study</i></p> <p>The involvement of more than a dozen patient advocates and patient organization was core to our assessment of a new tool providing information on and access to clinical trials for patients. The aim was to engage a broader and more diverse set of respondents, i.e. not to be limited to patients already presenting at the research hospital. Moreover, their involvement ensured that the insights from our study are relevant and clear.</p>	<p>Page5, Paragraph 2, Line 92 to Page 6, Paragraph 2, Line 116</p>
2: Methods	<p><i>Provide a clear description of the methods used for PPI in the study</i></p> <p>The patient partners played a key role in the recruitment effort. They promoted the survey through their channels (personal connections, e-mail lists, and social media channels). They also provided valuable feedback during the development of the questionnaire, ensuring that all questions were unambiguous, easy to understand and likely to be answered by respondents. Finally, 3 patients tested the online questionnaire to ensure it was fully operational.</p>	<p>Page 6, Paragraph 2, Lines 112-116</p>
3: Study results	<p><i>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</i></p> <p>PPI contributed to the study in several ways, including:</p> <ul style="list-style-type: none"> - Patient partners recruited the majority of participants - Ensured that all questions were clear and easy to understand - Tested the online questionnaire to identify any operational issues before launch 	<p>Page 6, Paragraph 2, Lines 112-116</p>
4: Discussion and conclusions	<p><i>Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects</i></p> <p>The patient partners involvement ensured an unbiased view, compared to involving only patients being treated at the research hospital. The sample is therefore also more reflective of the broader population, whose engagement will be key to democratizing clinical trials. It also provided the researchers with a clearer view on which aspects are important to a patient, helping both to ensure the right focus for the questionnaire, but also the right prioritization of the areas for potential improvement of the trial search tool in the future.</p>	<p>Page 7, Paragraph 2, Line 135 to Page 9, Paragraph 1, Line 169</p>

5: Reflections	<p><i>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience</i></p> <p>Despite the survey being open for multiple weeks, and considerable recruitment efforts of the patients advocates/ organizations and researchers, only 29 responses were received. We suspect that many potential respondents perceived the study as too long (the content page stated an estimated length of 20 minutes).</p> <p>The sample was also not completely representative of the gastrointestinal cancer patient population, being somewhat less ethnically diverse, better educated, and younger. This is likely a reflection of the recruiting channels used and could therefore be resolved by additional activities (e.g. focused on caregivers) in the future.</p>	<p>Page 7, Paragraph 2, Line 135 to Page 8, Paragraph 1, Line 144; Page 8, Paragraph 4, Line 160 - to Page9, Paragraph 1, Line 163, Tables 3-5 (Pages 19-21)</p>
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