Author’s response to reviews

Title: Use of Photovoice to Engage Stakeholders in Planning for Patient-Centered Outcomes Research

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Author’s response to reviews:

We appreciate the insightful comments from reviewers and have incorporated changes that we feel have strengthened the paper as a result. We believe we have incorporated requested organizational changes (Reviewer 3) while maintaining a commentary format as Editors agreed with the authors that the paper is a commentary and not a research paper. We like the current reorganization, and hope that our content revisions, described below, clearly indicate that the paper was not research, per the funders requirements and the intent of the project. We are prepared to revise the headings and organization again to align better with original commentary paper if you so prefer.

Please note that we provide a response (in bold) below to each reviewer comment. To avoid confusion, as formatting can change when comments are uploaded online, we have also placed an asterisk before our responses. We stand ready to revise further if needed.

REVIEWER 1

The article is well written and clear. The article is limited to only 6 participants and as stated anxiety is a serious illness/condition.

*We hope that changes made to the purpose and expectations for our use of Photovoice as an engagement rather than research activity (p. 4, lines 77-84 & lines 87-94) address the concern about the number of participants to “confirm these findings”, which presumably relates to generalizability of findings. These changes made also (we hope) reinforce a primary purpose of engagement in our project -- to “ensure that voices of patients were heard and valued” -- and indicate that this application of photovoice was a patient engagement activity, deemed “non-human subjects research”.

No account appears to have been made or mentioned herein about there any participant chose to submit any photos and why. Explanation of the fact that much of the comments are abstract and
some do not relate directly to the persons condition...Photographs are a powerful tool but I wonder whether the participants were 100% honest in the photos that they took as, with anxiety, fear is often hidden.

*We added a paragraph in the beginning of the discussion section to address the above comments. We revised content to address how photos were chosen or the content of those photos (p.13, lines 285-293), and specifically addressed the abstract content, “Some pictures are concrete images that convey sources of anxiety of coping strategies whereas other pictures reflect abstract representations of what it is like to live with an anxiety disorder from the patient’s perspective” (lines 298-299). The comment regarding the honesty or truth of the photo and caption content is also addressed (lines 293-298) and we have added: “Their photos and captions reveal the truth of their experience from their perspectives. Their photos and captions may not in fact reflect the ‘Truth’ of anxiety disorder from a clinical perspective (citation here), as has been found with narrative-based illness research (Williams, 1984). In other words, the posters reflect the raw truth of patient-partner experiences, which was effective at engaging the clinicians, researchers, and administrators who attended the wrap-up event in discussion about health and healthcare experiences with anxiety.”

One participant mentioned that talking was the cause of her anxiety but group discussions was mentioned with no allowance for this. Photographs are a powerful tool but I wonder whether the participants were 100% honest in the photos that they took as, with anxiety, fear is often hidden.

*We believe you are referring to Figure 6b and its caption. The participant was referring specifically to not wanting to talk with his “girl” after a long, hot day at work. He participated consistently in the project’s group discussions. His lack of desire to talk seems to be specific to his home life. No changes made. Please see p. 11, lines 256-258.

The article is in plain English and has been well written, factors that could have swayed the results, such as participants not taking photos on days they felt anxiety at its highest, has not been mentioned. Because of the limited number of participants (6) a bigger piece of work would need to be completed to confirm these findings.

*Thank you for your comment about plain English. We agree that a bigger piece of work would be needed to understand more about and confirm lived experience with anxiety from a research perspective; however, that is not within the scope of this paper.

REVIEWER 2

This paper is a welcome contribution to patient involvement in research. By focusing on the use of the photovoice method, it provides an example of a method for enabling patients to articulate their tacit knowledge (an essential element in the field that seems to be often overlooked). I am particularly pleased to see that one of the patient partners is also a co-author.

My comments are minor revisions:
Ln 32: add reference to support assertion

*We have revised the abstract to align with the reorganization of the paper. However, to ensure that the relevant information and citations for using Photovoice results ‘to advocate for social justice, health equity, and improvements to policy and practice’ (prior Ln 32) are included in the paper, we have also woven two of the three new references now cited on lines 32-33 into other sections of the paper, e.g. Sanon et al, 2014 is cited on page 16, line 351; and Catalani and Minkler, 2010 is cited on page 14, lines 318-319.

Ln 43: 'convening' - this is a word I am unfamiliar with, would 'meeting' be better? Perhaps with an adjective or description which conveys a critical quality in the meeting which perhaps would result in it being called a 'convening'

*Thank you for helping us clear up this confusion. We have replaced the word “convening” with “meeting” or “event” throughout

Ln 53: some qualifiers on the assertions in the paper are needed. Eg here, 'was observed to increase cohesion' or 'may have'

*Thank you and we have added qualifiers as noted. When we used the term cohesion in the abstract, we have added the qualifier ‘may have’ as suggested. In the discussion, we removed the term “greater” where it described “group cohesion”

Ln 55 -72: The plain English summary could be much plainer because it is there to capture the broadest literate audience. It might begin with something like: "People with conditions like anxiety may know a lot about what it is like to live day to day with anxiety, but some of that knowledge will be hard to put into words in a way that others can understand it. Photovoice is a method which can help people share that tacit knowledge with others. Sometimes it can even help people know what they know. In this project, people with anxiety used Photovoice to share what they knew about living with anxiety with researchers and health professionals.” I think you will know this from your work, but just a reminder that plain language is not just about using simpler words and shorter sentences, it's about telling a story that readers can connect with (so what) in language that means something to the reader. So sometimes, being more specific (saying something the reader can visual) than a scientific summary (where there is already a lot of agreement on words between reader and writer) can help. Try the plain language summary out on someone not connected to the project. Avoid dehumanising words like 'individuals' or 'one' and jargon like 'symptom burden'.

*Thank you for suggestions to the plain English summary. We have integrated many into our summary with further revisions from our peer-leader co-author so that it now tells more of a story. Please see the revised summary starting on pages 3 and 4, lines 70-84

Ln 84: please add missing reference
*Per Reviewer 3 comments we moved the Photovoice Path to the new methods section, and we have added a reference in the legend specific to Figure 1 (Lorenz & Chilingerian, 2011) – see page 5, line 114).

Ln 270: ‘overwhelmingly positive’ - qualify and temper to note that this and affects in paper were observed or reported.

*We have revised to “a positive effect (p. 14, line 322). We have noted positive effects at the personal level (lines 323-324), group level (lines 324-326) and as patient-partners (lines 335-341)

Finally the paper could be strengthened with some small additions:

1. Explain the approach of incorporating a participant in this paper and not anonymising.

*Following standard Photovoice protocols (Lorenz, 2010 and Wang, 1999), participants have the option of remaining anonymous or having their names known. The co-author who was a peer-leader on the project has benefitted from his leadership role by being awarded a patient scholarship to attend a PCORI conference. Thus, to be named as a co-author is an honor for him and, potentially, will contribute to his future academic and professional career. He did not want to be anonymized.

2. What are the limitations to Photovoice? What is known from evaluations of the method?

*Thank you for these questions. A common limitation to Photovoice research is the small sample size, a problem noted in most Photovoice studies (Hergenrather et al, 2009). This comment may not pertain to our project, as it is not research. A limitation specific to our use of Photovoice as an engagement activity in our project is lack of a formalized approach to elicit feedback from stakeholders who saw the exhibit. We have described this limitation on page 16, lines 348-356.

*As for evaluations: We have not found any evaluations of the Photovoice method. We suggest that review papers in the literature provide a good substitute. These papers are: Hergenrather et al, 2008; Catalani and Minkler, 2010, and Sanon et al, 2013. We have woven insights from Catalani and Minkler, 2010 and Sanon, 2013 in the discussion and Future Improvements section as described above, in particular to show where findings from those review papers support observations from our project.

3. Can you give specific examples of knowledge transferred using it which was omitted from past work?

*A major example of knowledge transferred using photovoice in this project that was omitted from past work is: the contribution of photovoice participation to the quality and level of
stakeholder (particularly patient-partners) engagement and their contributions to future research as described earlier. We hope our response addressed your concern.

4. Did you capture feedback from health professionals and researchers who took part in process? Just to understand the benefits and any issues with this method.

*We discussed capturing health professional and researcher feedback with a pre-test/post-test or general feedback survey, but due to time constraints before the stakeholder event, we did not implement. We have added this recommendation to a brief section “Future Improvements.” Congratulations on this work and taking the time to write it up. I feel it will be very useful to others.

*Thank you.

REVIEWER 3

Thank you for submitting this extremely interesting article that demonstrates the utility of photovoice. It is written in an understandable way with a lot of relevant detail about how the photovoice method was applied. I found the captions and images presented thought provoking and insightful. It has great potential to add to the existing literature.

*Thank you for highlighting the strengths of this manuscript and we have attempted to maintain the strengths as stated while responding to your insightful and helpful subsequent comments. No changes requested or made in response to this first comment.

However it suffers from structural issues which makes the flow/purpose of the paper confusing in places. I think it would benefit greatly from a re-framing the focus of the paper. It is placed under the headings background, main text, conclusions. Which would suggest that this is a commentary rather than a research/method article which should have Background, methods, results, discussion, conclusions.

*We agree that the flow and purpose needs clarification and improvement to strengthen the manuscript. You are correct that this manuscript was submitted as a commentary rather than research article due to concerns about the funder’s specification that “the P2P award specifically prohibited use of funds for research purposes” that are clarified and elaborated upon (p. 5, lines 99-106). While we sought input from the journal editors via email, in order to submit revisions in a timely fashion we proposed a compromise that reorganized the paper with sub-headings that were aligned with the requested changes. Specifically, we propose major headings to include an Introduction (that contains background information as requested below); a Main Text major heading with sub-headings of Photovoice Background, Photovoice Process (Methods), and Photovoice Results; a Discussion major heading with a sub-heading of Conclusions. We hope that this reorganization, along with responses to suggested content within each (as below) is satisfactory. However, we would be happy to further revise suggested headings to align exactly
with a research article format if requested by editors as long as we keep explicit wording regarding Photovoice as an engagement rather than research activity to comply with funder expectations.

(Please note the 8/15 response from Editors: Dear Dr. Connors, Thank you for your email. Please be informed that the Editors agree with the authors that the paper is a commentary and not a research paper. However perhaps it would be prudent to add something to the background section to make clear that the project was funded by PCORI as an Engagement Activity, and the commentary is on that basis. You may include this advice in the Response To Reviewers, to ensure that it is captured and published alongside the Reviews. Should you have any concerns, please do not hesitate to contact us.)

Also the content of each of these sections needs adjusting: Title: The tile states: 'use of photo voice to engage stakeholders in planning for Patient-centred outcomes research' - Although you mention Patient-centred outcomes in the background you do not define what you mean by this and it not in the aims. - I would re-frame to something like 'use of photo voice to engage stakeholders in planning research to improve care in ED …' or "use of photo voice to increase awareness of anxiety to key stakeholders'. Or 'the benefits of using photo voice to stakeholders in anxiety research' - Alternatively you need to draw out how this links to Patient-centred outcomes research to make the current title more appropriate.

*We chose to follow the alternate recommendation option of keeping the current title, Use of Photovoice to Engage Stakeholders in Planning for Patient-Centered Outcomes Research'; however, improved the link between the application of Photovoice to engaging stakeholders in planning for patient-centered outcomes research throughout. We explicitly state the link in the first line, “This article highlights our unique use of Photovoice methods to engage stakeholders in planning for patient-centered outcomes research (PCOR) focused on informing treatment options for persons with anxiety disorders seeking care in the Emergency Department setting.” (p. 3, lines 67–69) followed by the definition of patient-centered outcomes research as requested, “As defined by the Patient-Centered Outcomes Research Institute, PCOR “helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options”. (p. 3, lines 69–72)

Background: - Figure one and the associated description of the steps of photo voice are methods rather than background - It would be easier to follow if the background started with literature on anxiety and why it is necessary to improve care in EDs for low-risk chest pain patients (more detail about this is needed in general), then move on to your context and the literature around photo voice. - The quote from the patient-partner peer leader is not needed here - rather it is a result/finding

*As requested, we moved Figure One and the associated description of the steps of Photovoice to the Main text/methods section under the sub-heading Photovoice Background. We included a brief background statement of why it is necessary to improve care in the EDs for low-risk chest pain in the Introduction as requested, “In brief, symptoms of an anxiety disorder can be perceived by patients as a heart attack or other serious threat to health and cause patients to seek care in the ED. However, after tests have ruled out a heart attack or other serious event, patients
are commonly discharged without discussion of anxiety as a potential underlying cause of symptoms or a referral for further evaluation and treatment of anxiety.” (p. 4, lines 75-79) and direct the reader to another publication for more information focused on specifics of the problem and potential solution in the ED (i.e., Why an Algorithmic ‘Rule out MI’ Order Set is Necessary but Not Sufficient Care for Chest Pain in the Emergency Department Setting) co-authored by our P2P lead clinician, Dr. Musey (emergency medicine physician) partner who was key in conducting early listening sessions with patients prior to initiation of the Photovoice. We also including the context for the Photovoice component in the introduction and moved the patient-partner quote to Main Text, (p.7, lines 153-156).

Main text/ methods –

Need more details about the 6 patient partners. How were they recruited/ selected. Age range? Gender? Anxiety condition? What is your definition of patient-partner (this means different things in different contexts) - What ethical considerations were taken into account while taking photos? Written or verbal consent for photos of people? - How were the weekly questions developed? - how did you gather / analyse data to determine if the event was successful?

*As requested, we included more information about the 6 patient partners including how they were recruited/selected, overview of demographics and anxiety condition, and definition of patient partner (p. 6, lines 128-139)*As for ethical considerations, patient-partners were expected to ask verbal permission before taking any person’s photograph and to provide consent for including photos in the exhibit. See page 6, lines 142-144. Thank you for prompting us to add this information to the paper. We have copies of the photographers’ written consent forms on file if you wish to see them and would be happy to provide them at the editor’s request.

*We worked with the patient-partner peer leader to develop the questions to be used for photo-taking.

*As noted above in our response to Reviewer 2’s comment #4, “We discussed capturing health professional and researcher feedback with a pre-test/post-test survey, but due to time constraints before the stakeholder event, we did not implement. We have added this recommendation to a brief section “Future Improvements.”

Main text/ Results - You show the data that was presented at the event but there is no interruption or analysis present. – There is also no evidence presented to support that 'awareness was raised' or that it engaged broader stakeholders. Instead this information is in the conclusions - In the results you could give details of the numbers and types of people that attended the event, that there were pledges of money and support.

*As previously stated, Photovoice was undertaken as an engagement rather than research activity. Interpretation or analysis of the data is a big distinguishing feature of research and as such, would likely have required IRB approval. PCORI was quite clear that no activities in the P2P scope of work should require IRB approval. Likewise, we did not do a formal project evaluation on the effects of Photovoice. However, the intended effect of Photovoice as an
engagement activity was to increase awareness of the persistent and high symptom burden associated with anxiety in order to gain stakeholder buy-in for research to address the topic. We strengthened our informal ‘measures of success’ for the project that elaborated on pledges of money and support (p. 14, lines 312-314), and increased health system participation in proposal development (lines 314-315), and quantified the description of the numbers (p. 15, line 314) and types of people (p. 8, lines 171-172) who attended the event. We recommend in the new section “Future Improvements” that formal evaluation measures be used in future.

Examples of stakeholder questions, perceptions of the event from the patient-partners perceptions and their learning about anxiety / group bonding (they are a key stakeholder and benefited to). Was there an evaluation form on the day?

*As previously stated, no formal evaluation was done on the day of the event. We noted this specifically in a brief section on ‘future improvements’ (p. 16, lines 349-356). With help from our patient-partner co-author, we also clarified and expanded on the benefits (e.g., therapeutic) to patient-partners (p. 15, lines 322-341).

Discussion The discussion should not bring in any new information. Rather it should link your findings to the aims and past research. Discuss strengths and limitations of the project and how you / someone else could apply this in the future. You raise complementary epidemiology data, this needs to be explained in the methods or background.

*We treated the discussion section as our reflection on the Photovoice results as we could not link findings to aims as in a research study. However, we did tie our reflections to insights previously described in the review papers. Insights include: collaboration for future research and action (p. 14, lines 320-321), and observed empowerment and engagement of patients (p. 15, lines 346-347). In addition, as noted in a response to reviewer 2 above, small sample sizes are endemic to photovoice projects and thus present a limitation to generalizability. As our paper was not research, generalizability was not a goal of this project (Hergenrather et al, 2008). As noted above, we included future improvements (rather than limitations) in the discussion. We also further complimentary epidemiology data (p. 8, lines 173-174). Finally we did not bring any new information into the conclusions and ensured that our overall conclusion tied back to the title of the article (p. 16, lines 358-361)

LIST OF ABBREVIATIONS ADDED, 9-9-19