Author’s response to reviews

Title: A Lung Cancer Research Agenda that Reflects the Diverse Perspectives of Community Stakeholders: Process and Outcomes of the SEED Method

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Author’s response to reviews:

Dear Editors In Chief,

I want to thank the Reviewers for their review and comments of our manuscript. We have reviewed the recommendations carefully and modified the manuscript where appropriate. Below, we have provided our response and detailed the changes made in the manuscript for each reviewer comment. In addition, we have provided the updated manuscript with the modifications in track changes, as well as a clean copy. The line references in the response are referring to lines in the track change document.

REVIEWER 1 COMMENTS:

1. In the plain English summary conceptual models and concept modeling are mentioned but I'm not sure these terms are adequately explained in the summary or elsewhere.

Response: In the body of the manuscript we used the terms “causal model” rather than “concept model”. We have changed the English summary to correspond to the language in the manuscript. We have added an explanation in both the summary, and the body of the manuscript (line 268 – 271). Two references were added in support of this information.
2. SEED was new to me and I note its development was funded by PCORI. I wondered if there was any further explanation to provide detail on how it was developed. Reference 12 and 13 I assume may do this. I was curious to know more. Is there evidence of it being tested anywhere else?

Response: The SEED Method was developed by Dr. Zimmerman, and it’s development is more fully described in reference 12. This manuscript describes the results from the second demonstration of the SEED Method. The Method is currently being applied for a third time in the evaluation of opioid and other substance misuse in a community heavily impacted by this health issue; that study is in progress. There are plans for further dissemination of the Method.

3. The methodology for priority setting partnerships by the James Lind Alliance is mentioned towards the end and I wondered if it any other examples could be mentioned earlier?

Response: We have added a description of other examples in the introduction, lines 131 – 141, with relevant references.

4. Is there an implicit assumption that research questions generated this way will get funded? Is it worth considering the acceptability of evidence generated this way by funders?

Response: This is an important point. Establishing the evidence base for best practices of stakeholder engagement in research question development and prioritization is important to ensure confidence in the validity of the practice. The SEED Method incorporates strategies found to be advantages in the literature including combining several stakeholder engagements methods (consultative, collaborative, and participatory), direct and repeated stakeholder engagement, provision of information and support to stakeholders (research capacity building, etc), data review to identify evidence gaps and avoid duplication of research, and consensus building. It is important that a dissemination plan for the research agenda be part of stakeholder engagement projects and systems in order to link resulting research priorities to potential funders. This is the case for several of the studies and public-clinician partnerships referenced in the manuscript (Nass P, 2012; Madden M, 2016; Haynes SC, 2018), and was part of our process. This information has been added to the discussion in the manuscript. (Line 471 – 474)

5. Reference 4 looks dated. I think there are more recent references that could be used to strengthen this point.

Response: A more recent reference has been added.
6. The term 'causal modeling' is used. Could more explanation be added? I assume that it refers to a logic model approach? It made me think of the Action Effect Method approach we have used with patients and carers which helps to identify factors that contribute to program theory and the testing of causal chains (Reed et al 2014, BMJQS)

Response: We added additional descriptive information about causal modeling with related references (see response to comment 1).

7. The steps involved in the SEED process are clear and helpful in enabling others to test in different settings. I'm concerned about the separation of groups as we generally feel there are benefits of bringing people together. However, your use of group readiness and group dynamic surveys (are these validated?) are an important feature of evaluation that I'd consider using in future. I note with curiosity at the bottom of Table 1 that some questions were not applied to the Topic Groups and I wanted to know why.

Response: The separation of the groups is purposeful, and not without precedent. In fact, the systematic review of studies engaging patients and clinicians in setting research priorities conducted by Stewart, et al. found that the majority of studies had clinicians and patients work separately. The SEED Method chose to have Topic groups of similar stakeholders work independently in order to facilitate group cohesion and open expression, and avoid suppression of ideas and perspectives that is common among mixed patient and provider groups. We have added additional information about the reasons for this method in the discussion (lines 407 - 410)

The Topic Group activities, including the time allocated, method for providing information and coming to consensus are quite scripted. For this reasons, the questions related to these aspects on the group dynamics questionnaire were not relevant for the Topic Group members. The note in Table 1 has been changed to add this information.

All evaluation tools were created by the SEED Evaluation Team for use in the SEED project. We initially consulted the literature on evaluations of community-based initiatives in order to inform creation of our evaluation tools. Where applicable, previously published questions were used and adapted for use, including the Group Readiness assessment and Group Dynamics assessment. We have added sources in the text. (Line 298)

8. There is reference to the use of stakeholder selection called the 7Ps Framework. Assume reference 21 explains further. Why was this used? Were alternatives considered? Could this feature earlier in the methods section? For example from line 201 through to line 208 on page

Response: The reference to the 7Ps Framework in the discussion is provided as evidence for the previous statement that the procedure for selecting the Topic Group members resulted in a
diverse group of people with varying viewpoints. It was not used for the selection of the stakeholders. We have added language to clarify this in the discussion. (Line 401)

9. The methods used to advertise are described but there is no detail about which methods are most successful. If people were not selected to join the group, how was that managed?

Response: Additional information has been added in the methods section to indicate which recruitment methods were most successful and how ineligible candidates were advised. (lines 210 – 213, & 231 – 234)

10. The acronym SCAN is listed but I struggled to understand who this was on page 10.

Response: SCAN participants are those consulted by the Topic Groups through focus groups and key informant interviews to gather information about the health issue in the local context. A definition of the SCAN participants has been added earlier in the manuscript to clarify this. (Line 187)

11. The evaluation methods are comprehensive. I wondered if more could be said about the activity and observation logs and the after-action reviews.

Response: Additional information about these processes have been added. (Lines 301 – 307)

12. Line 356 on p17 refers to other engagement models. Can you be more specific? 12. Line 363 the observation that SEED generates broader questions is well made and important. Could this be made more overt in the abstract?

Response: Clarifying language about the other engagement models has been added. (Line 389).

Language about the broader questions generated by SEED has been added to the abstract. (Line 95)

13. Line 413 on page 19 refers to the lack of technical training and a dearth of capacity building methodologies. Is it implicit that community members need to be trained and informed or could it be considered that researchers need to do more to work with what people know, even if it is uninformed? Is there a deficit-model assumption here or an opportunity for shared learning?
Response: We agree with your statement. One of the principles of the CBPR approach of the SEED Method is that the community members engaged in the project bring experience to the process that is not available to the University team. The intent of the statement on line 413 was that there is a lack of technical training as part of many stakeholder engagement models. The SEED Method specifically incorporates targeted trainings for the community research team (human subjects protection, key informant interviews, and focus group trainings), and the Topic Groups (causal modeling, research question development), to provide them with the skills to perform the tasks requested of them.

We have changed the language to clarify the intent of the statement. (Line 454, 455)

14. Flexibility in the time taken to conduct SEED would be helpful. However, collaboration and participation take time for relationships to form so that they are productive. If there was evidence of more disengagement over time, then consideration of the time becomes more critical.

Response: No response required.

15. I'd consider publishing another paper in the future to follow up on what happened with the questions. Some progress is hinted at and I'd be curious to know more. Finally, I was particularly interested in the faith and religiosity issues that were identified. I have direct experience of losing a close family member to lung cancer which was diagnosed late. My family member refused palliative intervention. This family member had a strong religious faith that with hindsight may have been a factor in delaying seeking help and probably played a part in the refusal of intervention.

Response: I was also interested in the faith and religiosity issues identified, and struck by the fact that this would probably not be a research focus of the research community. We appreciate your advice for a future paper on the project outcomes.

REVIEWER 2 COMMENTS:

This is a well written open and comprehensive description of your research. It is important that other researchers know about and use this method. I could not find any typographical errors which is good and unusual.

Response: We thank Reviewer #2 for their comments and review of the manuscript.
REVIEWER 3 COMMENTS:

The response of the lead author to previous reviewer requests, particularly in the development of the lay summary, appears adequate.

The face to face community based nature of SEED marks it out from the more usual sampling style methods of encouraging participation in the broader based development of research agendas. Its strength lies in its detailed method, its localized and conversational focus, and its potential for creating 'community capacity for sustained research engagement'. Its ability to generate research questions with a wide currency may be limited. However, the approach is both welcome and timely and worthy, as the authors indicate, of further development. Future work may wish to more explicitly explore the political distinctions between 'engagement' and 'involvement' and consider the ethics of co-production in the practice of shaping multi-stakeholder generated research agendas.

Response: We thank Reviewer #3 for their comments, and will consider their recommendations for future work.