Reviewer's report

Title: A co-produced method to involve service users in research: the SUCCESS model

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Reviewer: Grant D. Huang

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This manuscript describes an effort to enhance the involvement of patients and carers in research and to establish a model for such activities for future health services research. Authors describe the processes for recruiting contributors and the organizational framework for enabling a steering group to work with researchers in various aspects of the research process. In addition to establishing the steering group, this model (called "SUCCESS") enabled 218 research activities over eight years to be conducted. As a report on an overall methodology, no controls were needed for this activity.

The ability to have stakeholders involved and contributing to research has become a vital aspect of the research process. Since investigators may not fully have critical insights for research intended to benefit particular patients, caregivers and providers, other perspectives can greatly help ensure applicability, generalizability, and implementation of research. The authors address an important need for effective ways to obtain such contributions in health services research. This need is highlighted by the relative lack of descriptions of structured approaches and best practices for developing such models. Several insightful details are given for enabling a collaborative approach to addressing chronic illness research. However, there some limitations that need to be addressed that would likely help the manuscript's ability to achieve broader goals of informing the research community on the topic.

The authors provide a significant amount of details about their activities, particularly with recruitment of individuals involved in the steering committee. These efforts are not trivial and the authors should be acknowledged for the amount of work conducted. Furthermore, they highlight what is needed to involve others in research. Perhaps a workflow or process diagram could help illustrate the steps for others desiring to replicate this approach.

Given the focus on describing initial steps in their process, other key details appear to be lacking which may reflect the limited space. For example, having established a steering group, what actual activities were undertaken and what were the results from any contributions (e.g., how were protocols/proposals modified, how did investigators further refine interventions, etc.)? Examples are given but are more general in nature and do not provide a level of insight that most likely helps other researchers understand the value of any contributions provided.
Table 1 provides what is perhaps one of the most critical aspects of the manuscript. However, it is not clear what the relationships are between the number of times an activity was undertaken and the total number of individual involvement opportunities. Are these figures to be considered as a percentage of activities to opportunities or why were there fewer activities undertaken compared to opportunities? Given the various roles listed, it is unclear whether some activities/opportunities were conducted/needed more than others. The elements provide some insights into what was done, but it is difficult to discern the key points to understand from the table.

The authors indicated that 218 research opportunities were involved over eight years. It's not clear how this number was determined. What is confusing is that some opportunities are reported in Table 1 but clearly do not add up to 218 opportunities. Of the activities involved, those described (Discussion, first paragraph) seem similar but not the actual ones provided in Table 1. Also, of these opportunities, how many total protocols/proposals were involved?

It was noted that only one of the service users was a carer (although three were both a patient and a carer). Were there attempts to recruit more carers? Since the final membership was predominantly patients, did the authors attempt to balance subsequent opportunities for contributions from the different subgroups or were they all considered as a single group to be approached despite likely different priorities in any research contributions? Notably 16/20 SUCCESS members were reported to be involved in at least one research activity over eight years. What happened with the other four and were they of a particular subgroup?

Since respondents became aware of the opportunity through various channels, the final membership was a self-selected group that likely had a greater interest in research. Do the authors have any suggestions and/or insights on how they may differ from other types of patients or carers and their perspectives or does it not matter if the key objective simply to involve such stakeholders?

Having principles (Box 2) appears to help provide an important standard for operating among the group. However, can the authors give examples of how these principles translated into the research process by the steering group or helped avoid challenges that may have arisen? E.g., Were there times in which interactions with an investigator had to ensure such principles were used?

Can details be provided on how researchers were given the opportunity to engage the panel? Were they required to use them? Or was it a service offered in which investigators were free to choose to engage them or not? While NIHR expects public involvement, it was not clear if the panel was intended as the sole mechanism for achieving this requirement.
The numbers of individuals actually involved in the various activities should be clarified. As noted previously, 16/20 members were involved in at least one activity. Attendance at steering group meetings was reported to fluctuate between 7 and 14. Perhaps these results can be put into a table to summarize what occurred.

Likely, over an eight-year period, participation fatigue may have been a factor. Besides considering if new members should have been recruited, were some participants more active than others (or have more opportunities to contribute than others)? This point could also suggest a more singular view being consistently provided and potential limitations with the approach. Furthermore, it raises questions of whether maintaining a standing committee is the most effective way for obtaining input given costs and other factors involved by other entities interested in replicating this model.

**Are the methods appropriate and well described?**
If not, please specify what is required in your comments to the authors.

Yes

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

No

**Are the conclusions drawn adequately supported by the data shown?**
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