Author’s response to reviews

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

Authors:

Bridie Angela Evans (b.a.evans@swansea.ac.uk)
Alison Porter (a.m.porter@swansea.ac.uk)
Helen Snooks (h.a.snooks@swansea.ac.uk)
Vanessa Burholt (v.burholt@swansea.ac.uk)

Version: 1 Date: 14 Dec 2018

Author’s response to reviews:

Maggie Rahmati and Anne Menard

BMC Medical Research Methodology

December 7th, 2018

Dear Ms Rahmati and Ms Menard

BMRM-D-18-00141

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

Bridie Angela Evans, PhD; Alison Porter; Helen Snooks; Vanessa Burholt

BMC Medical Research Methodology

Please find below our responses to the helpful comments received from reviewers who read our paper A co-produced method to involve service users in research: the SUCCESS model.

Technical comments

- In the ‘Funding’ declaration, please indicate the role of the funding body in: the design of the study; the collection, analysis, and interpretation of data; and the writing of the manuscript.
The funders had no role in: the design of the study; collection, analysis and interpretation of data; writing of the manuscript. We have confirmed this in the Funding declaration. Please see lines 514-515 on p24.

Reviewer reports

Grant D. Huang (Reviewer 1):

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.

Thank you for your recognising the benefits of public and patient involvement in research and how our paper contributes to the evidence base about effective ways to undertake involvement and gain different insights when planning and undertaking health services research. We are grateful for your observations about how we can strengthen our manuscript.

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.
Thank you for this suggestion. We have prepared a process diagram to illustrate the steps in developing the SUCCESS model. Please see figure 1 which we suggest is inserted on p11, line 246.

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.

Thank you for this helpful suggestion. We have provided some specific examples of activities undertaken by SUCCESS members. Please see p14, lines 292-307.

Table 1 provides what is perhaps one 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 a 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?

We have amended Table 1 on p15 to report the total number of times a SUCCESS member was involved. This column now tallies with the 218 research opportunities reported. We have also clarified that individuals were involved more than once and that the number of activities varied according to the work programmes of researchers, timings of funding calls and successful funding awards (p15-16, lines 312-314). We have identified the number of proposals which resulted from activity. Please see lines 319-20, p16. We have amended the discussion to align descriptions of the activities. Please see p18, lines 377-378.

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?

Thankyou for this observation about carers. We recognise this is a limitation and have acknowledged this in the Strengths and Limitations section of the paper at lines 474-479 on p22. We have also provided an explanation for the inactivity of four members at lines 309-312 on p14.

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?

We have considered this issue in the final paragraph of our discussion. But the reviewer’s comments indicate we can explore this point further and we have added some further text to link the literature back to our experiences through the SUCCESS model. Please see p21, lines 443-446.

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?

We have added more detail about how the principles informed operation with additional information in the section about Components of the SUCCESS model (p13, lines 273-74 and 277-79; p17, lines 346-350 and 354-356) and also the discussion (p18, lines 382-83). There were no instances where the principles were required in order to resolve tensions or poor practice.

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.
We have clarified how researchers were aware of, and engaged with, the SUCCESS model. The model was available as one route for accessing public involvement in their work. The additional information is on p13, lines 283-287.

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.

We have added an extra column in Table 1 to show the number of individuals actually involved in the research activities. Please see p15.

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.

The reviewer has highlighted an ongoing debate about how long public member should be involved in research and we are grateful to have the opportunity to strengthen our discussion around this point. Please see p20, lines 414-420. We have also made amendments to the Strengths and Limitations section at p22, lines 462-467.

Reviewer 2 (Reviewer 2):

GENERAL COMMENTS: The paper describes the steps used to develop a model of patient-public involvement in research. It's a good idea to try and describe how this is done as it may serve as guidance (and lessons learnt) to others wishing to do something similar and may reduce some of the 're-inventing the wheel' that occurs for these types of activities. To be useful to others, there are a few more details needed in some steps. There's of course some concern about generalisability of the 'model' created, so this should be readily acknowledged, but is only touched on very briefly.

Thank you for recognising the contribution our paper can make to the evidence base about models of public and patient involvement in research.
REQUESTED REVISIONS:

This paper largely describes the steps/elements of the model that was created and used. There aren't really any results per se (other than numbers of service users participating) or interpretation. The focus is on the methods and as such, every step and every element should be thoroughly described (which the authors acknowledge the importance of in the intro). Some details are missing, such as:

- details of the honorarium provided and types of expenses

We offered an honorarium at the then-recommended rate of £65/half day or £130/day and reimbursed travel expenses, petrol costs and meals. We also covered overnight accommodation when this was required in order to undertake involvement activities. We have included these details on p6-7, lines 136-138.

- was involvement limited to only adults or also parents of children with chronic conditions?

One SUCCESS member was a parent of a child with a chronic condition. We have clarified this detail. Please see p7, line 148 and p9, line 196.

- the actual information provided about the task, role, and resources

We have included the recruitment information as an additional appendix (appendix 1). We provided a handbook to each member. This lengthy document is available from the authors. We have added this information to our paper. Please see p7, line 145-6 and p17, lines 345-46.

- did the workshop only occur once? (if so, at the beginning of the 8 year period described?) how long did it go for?

We have clarified that just one workshop took place at the beginning of the period described and ran between 10.30am-3pm with lunch and refreshment breaks provided. Please see p8, lines 161-163.

- how were service users encouraged/expected to respond to the workshop notes? (which none did) - e.g. by email, phone?

Service uses were invited to respond to the workshop notes by email or telephone. We have clarified this at p11, lines 235-236.
- should the 4 service users who weren't active in any way still be considered members of the panel?

All non-active members were asked whether they wished to remain panel members. All elected to continue receiving information and active members agreed that the four should remain members, with the opportunity to contribute if they wished. We have added this detail on p14, lines 309-312.

- how often were the steering group meetings held?

Meetings were held quarterly. We have added this information on p13, line 269.

ADDITIONAL REQUESTS/SUGGESTIONS:

Other than additional methods detail (examples given above), further acknowledgement of the limitations (and lack of generalisability) is needed - e.g. only 1 carer participated, only adults with particular chronic conditions, members were drawn from existing networks (which many countries don't have), etc

We have added further consideration of the generalisability of our model in the Strengths and Limitations section, as the reviewer helpfully suggests. Please see p22, lines 462-63 and 466-67 and 474-479.

Editorial Policies

Declarations

- Ethics approval and consent to participate
- Consent to publish
- Availability of data and materials
- Competing interests
- Funding
- Authors’ contributions
- Acknowledgements
We have included declarations on all these items in our paper on p23-24, lines 496-524.

We are grateful to the reviewers for their insightful comments and constructive suggestions which we believe have strengthened our revised paper. We hope we have addressed all the points raised and look forward to hearing from you.

Yours sincerely

Bridie Angela Evans