Patient and Public Involvement and Engagement in Evidence Synthesis: a strategy for the NIHR SPCR Evidence Synthesis Working Group

Dr Anne-Marie Boylan (ESWG PPI Lead)

In consultation with Dr Kamal R. Mahtani, Dr Stephen Barclay and Prof Carl Heneghan.

Academic and clinical reviewers: Dr Sophie Park, Dr Stephanie Tierney, Dr Mila Petrova, Ruth Abrams and Dr Geoff Wong.

Public contributor reviewers: Gillian Richards and Brian Goldthorp.

This strategy aims to encourage review teams, researchers and PPI contributors alike, to be innovative, creative and to strive for excellence in public involvement and engagement.

Overview

The NIHR SPCR Evidence Synthesis Working Group has made Patient and Public Involvement (PPI) and Patient and Public Engagement (PPE) key components of its work. This document sets out the strategy to aid in implementing that commitment.

INVOLVE, a national advisory group supporting PPI, defines PPI as active involvement between people who use services, carers and researchers, rather than the use of people as participants in research – research *with* or *by* people who use services rather than *to, about* or *for* them. Whereas engagement refers to the provision and dissemination of information and knowledge about research in ways that engage the public.

The strategy aligns with the INVOLVE guidance for public involvement in systematic reviews and the NIHR's National Standards for Public Involvement in research.

Patient and Public Involvement (PPI) strategy

Involving PPI contributors in evidence synthesis is neither an easy nor obvious task as the vast majority of activities undertaken in this type of work are highly specialist and considered most appropriately conducted by trained researchers. Nonetheless, there are ways to involve contributors to maximise the patient/public benefit of evidence synthesis, ensuring outcomes are relevant and important to patients/public. However, there are many potential benefits to patient and public involvement in systematic reviews:

- Consideration and identification of the key outcomes to be assessed.
- Involvement of members of the public who know about the topic of the review and have first-hand experience of the disease and treatment.
- Researchers and members of the public learning from each other to gain a full understanding of a review and its purpose.

- Ability to deal with specific issues and questions as they arise, for example questions about the specific illness or condition or the findings of the review.
- Adding value to the review, improving quality and relevance to patients.
- Establishing relationships between researchers and the public which may make it easier for researchers to consult people throughout all stages of their research.
- Improving ‘readability’ of scientific language and jargon.
- Contributing to wider dissemination of the review to patients and the public.

The PPI strategy for the ESWG will involve four core elements:

1. Oversight of review conduct and procedure
2. Appropriate involvement in each review
3. Reporting of involvement
4. Development of prioritisation partnerships

1. Oversight of ESWG activities

Two patients or members of the public will be appointed to the ESWG steering committee. They will have experience of involvement in research, preferably in evidence synthesis, and will have an interest in topics relevant to the ongoing ESWG work. They will attend meetings, either in-person or virtually. They will be provided with papers (e.g. progress reports) as relevant in advance of each meeting. They will be invited to comment on any/all aspects of the reviews as they see fit. Any issues concerning review conduct or procedures will be reported at these meetings. PPI contributors will be invited to respond to any such issues arising. These contributors will be supported by the SPCR PPI Officer and the ESWG PPI lead, Anne-Marie Boylan. They will also be involved in the Priority Setting Partnerships (see 4 below) through which they will receive training in systematic reviews.

Priority action: appoint two members – underway

2. Involvement in each review

All reviews will have embedded PPI activity. This may include consultation with contributors on any aspect of the review process. Frequent contact between researchers and contributors is anticipated, although it is acknowledged that this will vary across the life of the review.

This will:

- Increase the scope of researchers’ views
- Provide a helpful means of sense-making and checking throughout
- Ensure relevance of the outputs to patients
- Ensure recommendations are appropriately tailored to the priorities of patients

This strategy does not prescribe how contributors will be involved in each review, but researchers and contributors must work together to agree the terms of involvement. It is acknowledged that the requirements for each review will be different. Review teams are encouraged to be innovative and creative in their approach to PPI, and to strive for excellence.

Priority action: all review leads to ensure PPI is integrated into their reviews from the earliest possible stage. Please produce a lay summary of your review and include planned PPI activity in it. This will be published on the SPCR ESWG website (see below – PPE strategy).

3. Reporting of involvement

All review teams will report (see Appendix 1) their planned involvement strategies in review protocols and include this in any publications or public-facing information, including providing information in PROSPERO registrations, published protocols and papers. This will highlight the significance of PPI to each review and ensure there is a public record of planned activities.

A reflective report on PPI activity will be prepared by each review team every six months. These reports will record what PPI activity has occurred (e.g. consultations) and what the impact of the PPI has been. These reflective reports must be completed by researchers and patients. Researchers will be encouraged to reflect on impact in the broadest sense. These reports will be shared across all review teams with a view to promoting shared learning across reviews and encouraging reflection on the impact of involvement.

Publications on patient and public involvement in evidence synthesis will be prepared for submission to peer reviewed journals.

Priority action: write to PROSPERO to highlight the absence of a prompt to report PPI (AMB, KM).

4. Prioritisation partnerships

To ensure there is an element of sustainability in terms of practice and learning, a wider group of patient/public contributors will be formed. This group will be made up of people with relevant experience (e.g. who are registered with a GP and/or who attend their GP reasonably frequently). Efforts will be made to ensure this group is diverse in terms of GP attendance, illness, ethnicity, gender, education/background and age. PPI contributors involved in the current reviews will be invited to join.

Training in evidence synthesis will be led by researchers experienced in evidence synthesis and will be provided to this group online or face-to-face.

The ultimate aim is to create and maintain a group of contributors who are familiar with different types of evidence synthesis and who can:

- Comment on and/or contribute to ongoing projects
- Help set priorities for new projects
- Comment on and/or contribute to new funding applications

Group activities will take place face-to-face and/or electronically (online/phone), and contributors will have to be able to participate in these ways. Contributors will attend meetings with the senior team (or one annual feedback meeting at a minimum) to ensure we are addressing important topics, effectively disseminating our work to the public and involving contributors in our ongoing prioritisation process.

The group will be hosted at the Nuffield Department of Primary Care Health Sciences, University of Oxford, where certain resources can be supplied free of charge. Contributors will be reimbursed for costs and will receive honoraria for their contribution. They will be set up by the SPCR PPI Officer, who will liaise with the ESWG PPI lead.

Priority action: set up group; develop training package. Note training has already been developed by Prof Karina Lovell at Manchester.

Patient and Public Engagement (PPE) strategy

In addition to the involvement activities outlined above, we will undertake PPE activities to ensure widespread dissemination is carried out. These reviews have direct public relevance and will be disseminated widely in order to ensure their findings reach the public.

Each review lead will produce a lay summary of their review for publication on the SPCR ESWG website.

Each review team will undertake additional PPE activities, such as writing blogs in public-friendly language, delivering talks at public events and creating podcasts for key websites (including, for example, SPCR ESWG and the Centre for Evidence Based Medicine CEBM websites, and BMJ Opinion). Teams should strive to work with PPI contributors to co-author or co-present lay dissemination activities.

Review teams should present their findings in a range of accessible ways, considering the audience they are targeting. They may produce infographics that succinctly and clearly demonstrate the outcome of their work. They may produce videos in which they present the findings. They may create podcasts.

Dissemination strategies will be prepared jointly with communications experts to ensure maximum reach. They will employ established communications structures within the NIHR and will be undertaken at existing events, e.g. Evidence Live, an annual conference run by the Centre for Evidence Based Medicine, University of Oxford, or the Oxford Science Festival.

It is essential that all dissemination activities are recorded. Leads should inform the SPCR PPI Officer or ESWG PPI lead, Anne-Marie Boylan, of their activities.

Funding information

	Oct 17 to Mar 18	**Apr 18 to Mar 19**	**Apr 19 to Mar 20**	**Apr 20 to Sep 20**	**Total**
PPI costing	£1,375	£2,250	£1,750	£1,250	**£6,625**

Important links

Stephen Blackburn at Keele is leading some work testing out the NIHR standards for PPI. This work will feed into the current strategy, which may be adapted in response.

Resources

- The SPCR has produced useful resources for PPI that are available on the website:
- INVOLVE's guide to PPI in Systematic Reviews
- The reflective reporting form can be found in Appendix 1 on page 5
- Appendix 2 (page 6) contains a diagram indicating actions to be taken at key milestones

Appendix 1: Reflective reporting form

This form is based on SPCR guidance on reporting Patient and Public Involvement. It should be completed by review teams (including PPI contributors) every six months and returned.

Review name
Review team members
Who is completing this form and why?
What were your goals for PPI in this period?
What PPI activities have been undertaken in this period? *Include meetings, email consultation, document review, discussions, etc.*
What impact has PPI had on the progress of the review? *Please reflect on ways that PPI has made a difference from the perspectives of all team members, including public contributors. This might include changes made across the review, validation of aspects of the review, experiential insights gained, new knowledge for the team members, etc. Report positive and/or negative impacts.*
What are your PPI goals for the next period?
Final comments from PPI contributors
Thank you for completing this form. *Please attach any relevant documents and return to anne-marie.boylan@phc.ox.ac.uk*

Appendix 2: Key milestone action points