

## Brief Report



## Public and patient involvement (PPI) in systematic reviews: challenges in Sri Lankan setting and recommendations for the potential way forward

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DOI: <https://doi.org/10.4038/jccpsl.v29i3.8613>

Received on 25 May 2023

Accepted on 12 Aug 2023

### Abstract

**Introduction:** Public and patient involvement (PPI) in systematic reviews is an area of growing interest due to the importance of ensuring that research is relevant, appropriate and acceptable to the people it seeks to benefit.

**Objectives:** To provide an overview of the rationale and methods for involving the public in systematic reviews, as well as identify common and specific challenges associated with it while carrying it out in low-resource setting in a country like Sri Lanka

**Methods:** The report begins with an introduction to PPI and its importance in health research, followed by a description of PPI involvement in each step of a systematic review. The report then explores the resources available to guide researchers on how to incorporate PPI into systematic reviews and identifies the barriers that exist to effective PPI.

**Conclusions & Recommendations:** The report concludes by highlighting the importance of PPI in systematic reviews and the need for more work to promote greater engagement and involvement of patients and the public in research in Sri Lankan context.

**Keywords:** *public and patient involvement, systematic review, Sri Lanka*

## Introduction

Public and patient involvement (PPI) in health research is an essential aspect of ensuring that research is relevant, appropriate and acceptable to the people it intends to benefit. It involves actively engaging patients, their families and members of the public in the research process to ensure that their perspectives, experiences and needs are considered. In the context of systematic reviews, involving the public is particularly important because systematic reviews are used to inform clinical practice, health policy and future research with being at the highest level in the evidence hierarchy (1).

Public and patient involvement in research is widely recognized for its significance. According to systematic reviews, it brings numerous benefits such as improves research outcomes, enhances research quality and relevance, increases the dissemination and uptake of research findings (2-4), increases research relevance and validity, instils patient and public confidence, and aids in the translation of research into practice (3-5). However, few reviews noted barriers to PPI, including limited funding, inadequate training, and resistance from researchers and research institutions (2-3). Inspired by Susan Baxter's master class on involving PPI in literature review, there is a motivation to explore the challenges and methods of engaging patients and the public in literature reviews, particularly in low-resource settings. This includes incorporating the rationale, methods, and resources learned from the master class to ensure meaningful PPI in the review process (6).

### Public involvement in systematic reviews: rationale and methods

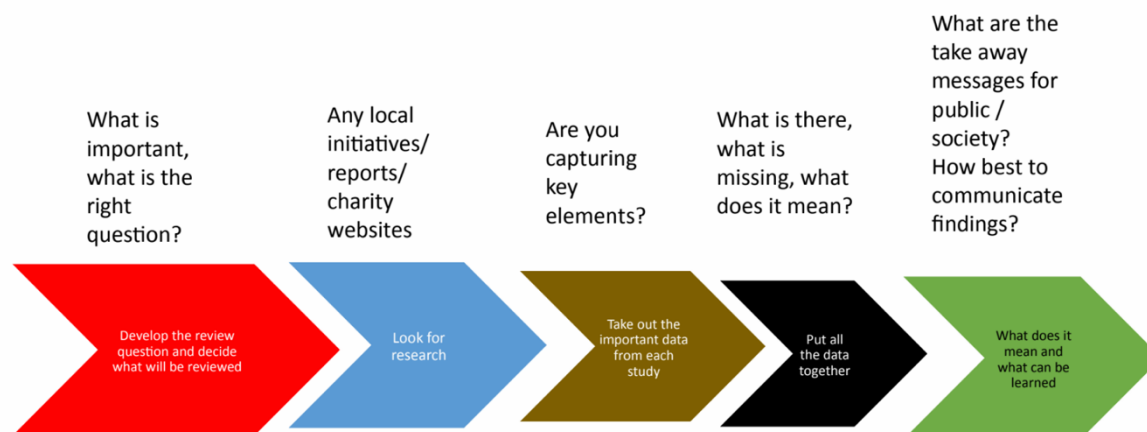
The importance of involving the public in health research, specifically in the context of systematic reviews, has gained recognition in recent years. Public involvement is justified by moral and civil reasons, considering that research is often publicly funded and research topics can have implications for patient care and society (6). In addition to meeting

requirements from funders or supervisors, the real value of public involvement lies in the unique insights and perspectives they contribute to the review process (1, 4, 6).

Public involvement can occur throughout the different stages of a systematic review, ranging from formulating the review question to disseminating the findings (6). Public contributors play a significant role in identifying relevant literature, prioritizing data, providing diverse perspectives on data synthesis, identifying vulnerable groups and conducting subgroup analyses (6). They can also assist with visual representation, appropriate terminology, summarizing key findings, and contributing to plain language summaries (5-6). Dissemination of review findings can be supported by public contributors through various channels, including videos, presentations, papers, press releases, and blogs (6). To ensure effective public involvement, it is crucial to consider factors such as age, background, location, and the experiences/views of public contributors (6). By incorporating the insights and perspectives of the public, systematic reviews can enhance their relevance, quality, and impact (6-7).

When engaging in PPI in reviews, there are key tips to consider. Firstly, PPI members should be seen as active contributors rather than passive listeners, so that researchers could focus on involving them at various points in the process and clearly communicate their expectations (6). Effective communication is vital, which includes avoiding jargon and acronyms, allowing sufficient time for discussions (as things often take longer than expected), and sharing information and presentations in advance (6). Seeking feedback from PPI members about the meetings and keeping them informed about how their input was utilized is crucial. Researchers should also consider the information needs and training requirements of PPI members, and online training resources like those provided by the University of Sheffield can be beneficial in this

regard (6-7).



**Figure 1: PPI involvement in each step of a systematic review**

*Source: University of Sheffield, School of Health and Related Research, Public Involvement in Research*

### Resources for incorporating PPI in systematic reviews

There are several technical resources available to guide researchers on how to incorporate PPI in systematic reviews. These resources include the UK Standards for Public Involvement, briefing notes for researchers on PPI in NHS, health and social care research, a briefing guide to PPI in funding applications and an interactive course for both new and experienced patient/public reviewers of health and social care research (1, 6-7).

### Challenges of involving PPI in systematic reviews

Several commonly found challenges can arise when conducting PPI in reviews. The number of public contributors needed for a review can vary depending on the complexity of the review. Finding and selecting appropriate public contributors can be challenging processes, but there are strategies available. Finding a good mix of people is important, and researchers should consider selection and advertising strategies. Managing contributions from PPI members can also be a challenge, and researchers should ensure that everyone could share their thoughts. The challenges outlined here pertain to PPI in general rather than exclusively to PPI in systematic reviews. While it may be difficult to

identify challenges specific to reviews, it is important to acknowledge this fact. Another challenge could be the limited scope for PPI in systematic reviews due to the absence of patient recruitment. This limitation hinders the ability to seek input on matters such as optimizing recruitment strategies, reviewing patient-facing documents, or conducting pilot tests. Consequently, the emphasis shifts towards incorporating PPI in formulating the research question, determining which outcomes to extract, and effectively presenting or interpreting the findings in a manner that resonates with the patient community (8-10). In addition, there are challenges specific to developing countries including Sri Lanka. One major challenge is the lack of awareness and understanding of PPI among researchers and the public in Sri Lanka. Many researchers may not be familiar with PPI or may not recognize its value, and the public may not be aware of their potential role in research. This lack of awareness can make it difficult to recruit and engage patients and the public in systematic reviews (11). One other challenge is the limited availability of resources and infrastructure to support PPI in Sri Lanka. This can include limited funding, lack of dedicated staff, and limited access to training and support for PPI activities. These limitations can make it difficult to develop and

implement effective PPI strategies in systematic reviews (12).

In the Sri Lankan context, cultural factors can pose significant challenges when involving patients and the public in systematic reviews. Cultural norms and expectations surrounding research participation can impact the recruitment and engagement of patients and the public. For instance, there might be cultural beliefs that discourage individuals from actively participating in research or expressing their opinions openly. These cultural factors need to be considered when designing strategies for involving patients and the public in systematic reviews. It is essential to conduct culturally sensitive recruitment. Engaging with community leaders, healthcare providers, and local organizations can help build trust and encourage participation. Involving these stakeholders in the design and implementation of systematic reviews can also enhance cultural acceptability and relevance (13-14). Language barriers can also hinder effective communication with potential PPI contributors. Sri Lanka is a multilingual country, with Sinhala and Tamil being the primary languages spoken. Conducting systematic reviews solely in English may exclude a substantial portion of the population who may not be proficient in the language. Overcoming this barrier requires providing translated materials or utilizing interpreters to facilitate meaningful engagement with patients and the public. This ensures that potential PPI contributors can fully comprehend the information and actively engage in the review process (15). Moreover, the specific context of the research topic can present additional challenges. Certain research areas, such as HIV/AIDS and sexually transmitted diseases (STDs) may be sensitive or stigmatized in Sri Lanka. This stigma can lead to reluctance among individuals to participate in systematic reviews related to these topics. Addressing these sensitivities and assuring confidentiality and privacy protection is crucial for encouraging participation in such research areas. To address sensitive or stigmatized research topics,

creating safe spaces for open and non-judgmental dialogue is crucial. Ensuring confidentiality and privacy protection should be emphasized to alleviate concerns and build trust among participants. Collaborating with patient advocacy groups and NGOs working in these specific areas can provide valuable insights, guidance, and support in navigating the cultural sensitivities associated with these topics (16-17).

If implementing patient and public involvement in systematic reviews in Sri Lanka tomorrow, an effective approach would involve conducting a thorough cultural assessment to identify specific challenges and tailor strategies accordingly. This assessment would provide insights into the cultural nuances, sensitivities, and preferences of the Sri Lankan population, enabling researchers to develop targeted approaches for meaningful involvement of patients and the public in systematic reviews.

## Conclusions & Recommendations

In summary, PPI plays a crucial role in systematic reviews by enhancing the relevance and validity of research, improving patient outcomes, and increasing satisfaction. It is essential for researchers to carefully plan and manage PPI in reviews to ensure successful implementation. By doing so, they can achieve more meaningful and impactful research, ultimately informing policy and practice for the benefit of patients and the broader community. To promote PPI in systematic reviews in Sri Lanka, several strategies can be implemented. These strategies encompass increasing awareness and knowledge of PPI among researchers and the public, offering training and assistance for PPI initiatives and developing culturally appropriate engagement approaches. It is vital to establish a system for compensating individuals involved in PPI and formulate clear guidelines for remuneration. Moreover, evaluating the impact of PPI on the study is crucial. Recognizing and addressing cultural barriers, involving key stakeholders, ensuring

language accessibility, and establishing safe spaces can further enhance the participation of patients and

the public in the process.

**Table 1: Modified sentences patterns of the IAT- original questionnaire**

Item No.	Item in the original version	Item in the modified version
2	“Household chores”	“Educational activities”
3	“Intimacy with your partner”	“Enjoying with your family members”
8	“Job performances”	“Educational performances”

**Table 2: Identified factors, number of items, and items included for each factor**

Identified factor	No. of Items	Included items
Salience	7	15, 12, 7, 19, 10, 11, 4
Excessive use	6	18, 20, 14, 1, 2, 13
Lack of control	3	17, 16, 5
Neglect of work	4	6, 8, 3, 9

### Public Health Implications

- Promoting Patient and Public Involvement in Systematic review in Sri Lanka holds significant potential to positively impact public health outcomes by incorporating diverse perspectives, enhancing research quality, and informing healthcare policies and practices.

### Author Declarations

**Competing interests:** The authors declare that they have no competing interests.

**Ethics approval and consent to participate:** Written based on my experience of conducting a systematic review with PPI and taking part in a master class during my overseers training program.

**Funding:** Self-funded

**Acknowledgements:** Dr Susan Baxter, Senior Research Fellow, University of Sheffield.

**Author contributions:** SL and MS provided resources, feedback to the report and proof reading, BM supported in finalising the Sri Lankan context and proof reading, KN foreign training supervisor, FF initiated and finalised the report.

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