

BMJ Open Exploring how patients, carers and members of the public are recruited to advisory boards, groups and panels as partners in public and patient involved health research: a scoping review protocol

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ABSTRACT

Introduction Engaging patients, carers and members of the public in health research has become widely recognised as an important approach for bridging the gap between research, and health and social care by increasing the relevance of research for those who benefit from its findings. Specific approaches to engagement vary, but commonly include advisory boards, groups or patient panels that are active throughout all stages of research. The breadth of and optimal strategies for recruiting patients, carers and members of the public to such boards, groups or panels remains unclear. The objective of this manuscript is to identify the breadth of and optimal strategies used to recruit patients, carers and members of the public to advisory boards, groups or panels, within public and patient involvement (PPI) research.

Methods and analysis This review follows the scoping review framework by Peters *et al*, an elaboration on the framework by Arksey and O'Malley. The search strategy was co-developed among the research team, PPI research experts and a faculty librarian. The review will take place between July 2021 and June 2022. In July and August 2021, eight electronic databases, MEDLINE (PubMed), MEDLINE (OVID), Embase, CINAHL, PsychINFO, Scopus, Web of Science and Cochrane Library, will be explored to capture all available literature. Two independent reviewers will screen articles by title and abstract and then at full text based on predetermined criteria. The data will be presented in a tabular format with a narrative summary discussing how the research findings relate to the overarching research question. A thematic analysis will also be completed using qualitative description, identifying key themes and gaps in the literature.

Ethics and dissemination Ethics is not required for this review. We aim to disseminate the information gathered through presentations at academic conferences, peer-reviewed publications and consultations with lay audiences.

INTRODUCTION

Background

Meaningfully engaging patients, carers and members of the public in health research has become widely recognised as an approach

Strengths and limitations of this study

- The scoping review methodology will follow the most up-to-date framework as proposed by Peters *et al* (an enhancement of Arksey and O'Malley).
- The search of a heterogeneous group of electronic databases will be completed systematically and comprehensively.
- Consultations took place with community, organisational and expert partners before initiating this project to guide the development of the research objectives, research question and the selection of search terms used in preliminary searches.

for bridging the gap between research, and health and social care practices. The National Institute for Health Research defines public and patient involvement (PPI) research as research conducted 'with' or 'by' the individuals it supports.¹ PPI is supported by participatory processes that aim to 'address community issues in a collaborative, consultative, democratic, reflective, reflexive, dialogical and improvement-oriented fashion that builds capacity and creates actionable, ownership of findings'.² This in turn can increase the application and dissemination of research findings, by increasing the relevance and impact of research for those who stand to benefit from its findings.²⁻⁶ Specifically, patients, carers and public stakeholders contribute experiential knowledge, unique perspectives and skills that are essential when designing, implementing and disseminating health research.⁴ Thus, it is recommended that patients, carers and members of the public are meaningfully engaged in research at the earliest stage, ideally the conception of the study.⁷

Approaches to PPI vary but commonly include advisory boards, stakeholder groups or patient panels that are active, ideally, throughout all stages of research. This process of involvement, however, is not easily achievable when recruitment strategies are neither effectively carried out nor well-understood.⁷ Specifically, recruiting patients, carers and members of the public as co-researchers can be a challenging task due to the various recruitment methods and strategies that exist, which also vary depending on context. For example, Burton *et al* discuss recruitment strategies in the context of PPI in dementia research, citing existing dementia research groups, national dementia groups and social services as successful means to identifying potential co-researchers.⁸ While Schlaudecker *et al* described their process of forming a patient and family advisory council by recruiting members via brochures, posters and, most effectively, pocket information cards.⁹ Similarly, Hartling *et al* established a parent advisory group by contacting local/regional parent organisations with subsidiary groups and branches while recruitment posters were also placed at clinics throughout the provincial health system and within the host university's campus.¹⁰

Therefore, although studies exist that discuss varying methods of recruitment of patients, carers and members of the public for advisory boards, groups and panels, the breadth of and optimal strategies for recruiting for such has not yet been extensively explored.

Purpose of conducting the scoping review

This paper seeks to explore the breadth of approaches employed for involving patients, carers and members of the public as partners on health research advisory boards, groups or panels within the context of health and social care services research. Preliminary searches of the literature identified papers discussing selection and engagement strategies in PPI specific to stakeholder groups and advisory groups, but did not reveal any literature reviews outlining the breadth of, and optimal methods and strategies used for such recruitment.^{9–11} Therefore, the objectives of this scoping review are to:

1. Identify the distribution of and context of the recruitment strategies used.
2. Understand the facilitators, barriers and ethical issues of the identified recruitment strategies.
3. Distinguish the varying terms of reference for involvement (ie, panels, boards, individual, etc).
4. Determine whether the individual recruitment strategies are used to address issues of representation or bias.

For the purpose of this review, we define 'recruitment' as the identification of and invitation to join boards, panels and committees as project partners or advisors, *not* as study participants, enrollees or subjects. Research partners are defined as 'knowledge users, decision-makers, stakeholders, end-users, service-users, consumers, community members, community of interest, citizens, industry, groups, funders engaged in the research process'.²

METHODS AND ANALYSIS

Given the broad nature of our research question, we want to capture a vast breadth of literature that is comprehensive regarding what is included/excluded.¹² Thus, a scoping review was identified as the most suitable methodology to best answer our four research objectives, in a rigorous and systematic way, that can be replicable in the future. This scoping review will occur between July 2021 and June 2022 and will follow the most up-to-date methodological framework by Peters *et al*, constructed to enhance the framework initially proposed by Arksey and O'Malley.^{13 14} This framework consists of nine stages, underscoring consultation with information scientists, stakeholders and topic-related experts throughout.¹³ The nine stages of this framework include: (1) defining and aligning the objective(s) and question(s); (2) developing and aligning the inclusion criteria with the objective(s) and question(s); (3) describing the planned approach to evidence searching, selection, data extraction and presentation of the evidence; (4) searching for the evidence; (5) selecting the evidence; (6) extracting the evidence; (7) analysis of the evidence; (8) presentation of the results and (9) summarising the evidence concerning the purpose of the review, making conclusions and noting any implications of the findings.¹³ This protocol will outline how each of the nine stages will be addressed.

Stage 1: defining and aligning the objective(s) and question(s)

The topic of interest for this scoping review emerged from informal consultations and requests author JS received over the past few years from other researchers in the field attempting to understand how to optimally recruit patients as co-researchers in PPI research. The initial impetus for the paper was driven by these discussions while consultations with PPI experts further narrowed down research objectives. This was further underscored by the lack of literature that existed comprehensively exploring such strategies. Thus, when formulating the research question, the central concept of recruitment strategies was identified, specifically in the context of advisory boards, groups or panels composed of patients, carers and members of the public. As mentioned above, this type of involvement of patients, carers and members of the public is common in PPI research, yet specific means of recruiting said individuals to boards, groups or panels remains unclear. This led to the formulation of our research question:

What strategies are used to recruit patients, carers and other members of the public as co-researchers, peer-researchers, steering committee members or research advisors, to advisory boards, groups or panels within participatory and public and patient involved health research?

Stage 2: developing and aligning the inclusion criteria with the objective(s) and question(s)

To adequately capture the full scope of available literature to answer our research question and seek out the most relevant literature, we iteratively developed a set of

Table 1 Eligibility criteria

Criterion	Inclusion	Exclusion	Justification
Population and sample	Humans Adults, who are patients, carers or members of the public	Study populations other than humans (animals) Clinicians, managers and other decision-makers Children and youth	Objective is to determine how patients, carers or the public are recruited as co-researchers and partners in health research. The identified recruitment challenges for clinicians, managers, and other decision-makers differed from that of the identified recruitment population or interest. Ethical differences in recruiting and engaging with children and youth in research. As children and youth are defined differently across the literature, mention of either as the population of interest will result in exclusion.
Language	Written in English	Written in another language that is not English	Reviewers are only able to confidently screen in English.
Time period	1995–2021	Years not included in this time period	Able to capture extensive literature within the time that PPI and other participatory health research approaches gained momentum and became more prevalent.
Study focus	Articles that discuss recruitment, retention or identification of patient, carers or members of the public as advisory boards, committees, panels, groups, council, etc for participatory health research Primary study	(A) Other forms of participatory research outside of health and social care; AND (B) Recruitment of patients, carers and public as direct co-researchers, not to boards, panels or committees; AND (C) Patients, carers and members of the public simply as focus group respondents; AND (D) Not reviews or protocols	(A) The area of interest is health and social care research; AND (B) May be different processes for recruitment of patients, carers and public as co-researchers and not to boards, panels or committees. We intend to cover this in a future review. Recruitment to PPI boards, panels and groups is a common way to involve patients, carers and members of the public. Guidance on optimal strategies is lacking in the literature; AND (C) We want to ensure active involvement as partners in research, not as research participants, or sources of data; AND (D) Reviews or protocols will be excluded as we are looking for evidence of PPI in primary studies as the involvement tends to be more intensive and longer duration.
Type of article	Peer-reviewed journal articles and grey literature	Any other literature that is not listed in the inclusion criteria, such as websites	To enable us to capture extensive literature to answer our broad research question as part of the scoping review, grey literature must be included along with peer-reviewed and published literature. Acknowledging feasibility and time constraints, we feel the literature criteria listed would be sufficient in capturing the necessary literature to inform our review.
Geographic location	Any location	None	Public and patient involved health research is a leading research priority worldwide.

PPI, public and patient involvement.

eligibility criteria, presented in [table 1](#). While PPI and other participative approaches to knowledge co-creation may involve diverse stakeholders depending on context, we have decided to narrow the research focus to only patient, carers and other non-clinical/non-research partners. This focus emerged from informal consultation with experts in the field, where author JS identified

that researchers had few issues in identifying clinical and decision-maker research partners, but reported difficulty in knowing where to begin to identify and recruit patients, carers and members of the public in an ethical, appropriate and representative way. Thus, the population of interest is adults who are patients, carers or members of the public. Other stakeholders, including clinicians,

managers and other decision-makers will be excluded, as they fall outside the scope of need for this review (table 1). Children and youth are excluded from our population of interest as there are ethical differences in recruiting and engaging with these populations. To be included, studies must therefore be health or social care focused, involve patients, carers or members of the public in the form of advisory boards, groups or panels and be of primary study design.

Stage 3: describing the planned approach to evidence searching, selection, data extraction and presentation of the evidence

A comprehensive literature search of a heterogeneous group of electronic databases is critical to achieving rigour in scoping reviews.¹⁵ After consultation with international PPI experts from a variety of backgrounds (ie, health policy, primary care and global health) and geographical locations (ie, Ireland, UK and Canada), as well as a faculty librarian, the search terms highlighted in online supplemental appendix 1 were identified. Consultations took place with community, organisational and expert partners before initiating this project to guide the development of our research objectives and question. These initial consultations helped to guide selection of search terms used in preliminary searches to ensure the most appropriate body of literature would be captured to answer our question. Search terms (online supplemental appendix 1) will be used to search MEDLINE (PubMed), MEDLINE (OVID), Embase, CINAHL, PsychINFO, Scopus, Web of Science and Cochrane Library. Embase was an added database based on advice from the faculty librarian. While recognising that Scopus captures grey literature, we will also include a search of Open Grey to ensure we capture the breadth of literature available. A supplemental document outlining the search strategy for all databases is available in online supplemental appendix 2. To appropriately cover the research objectives while acknowledging feasibility and time constraints, the literature search criteria was narrowed, removing certain terms like community-based participatory research. The inclusion of this search string would generate an abundance of publications which would render the scoping review infeasible. Furthermore, we will complete the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist, outlined in online supplemental appendix 3, to ensure accuracy in our reporting.¹⁶ The approach to selecting the evidence, data extraction and presentation of the evidence will be discussed in stages 5–8.

Stage 4: searching for the evidence

The search strategy methodology follows the Joanna Briggs Institute Reviewer's Manual three-step process.¹⁷ First, we conducted a preliminary search in MEDLINE (PubMed) to ensure our search terms to be used across all databases adequately captured all keywords and subheadings. We searched and revised our search terms to

capture the most appropriate body of literature. Second, we sought input from a broad community of experts, through formal and informal conversations, to frame our search criteria and to identify any additional keywords for consideration. We will use the identified search terms to search across all of the databases listed in stage 3. Lastly, we will review the references from articles selected for the review and extract any relevant articles. The complete search strategy from CINAHL, one of the major databases used, is outlined in the online supplemental appendix 4.

Stage 5: selecting the evidence

Once searches of each database are complete, the references will be extracted and imported into Distiller SR, a scoping review software.¹⁸ Two independent reviewers (EK and MG) will screen the identified literature by title and abstract following the predetermined inclusion and exclusion criteria, outlined in table 1. Each reviewer will independently complete a selection screening tool, presented in online supplemental appendix 5, to help guide this process. The two reviewers will meet periodically throughout the reviewing process to discuss conflicts. A third reviewer (JS) will arbitrate any remaining conflicts. Inter-rater agreement will be calculated using the kappa statistic. The articles included after title and abstract screening will be screened at full text based on our inclusion criteria and will be used for the final extraction and analysis of the evidence.

Stage 6: extracting the evidence

A tabular chart (table 2) will be used to ensure the most relevant information is extracted from each of the included references. Extracted evidence will be analysed using NVivo software.¹⁹ Authors will use this more formal analytical approach to thoroughly and thematically identify themes that emerge to better understand how they address the four research objectives guiding this review.

Stage 7: analysis of the evidence

A descriptive narrative summary of the varying recruitment methods used across the selected literature will be completed. Thematic analysis will then be conducted to identify key themes, as suggested by Levac *et al*, using qualitative description following the guidance of Braun and Clarke.^{20–22} This will be analysed by all three authors and the same community, organisational and expert partners that were consulted before initiating this project.

It is critical to avoid pre-empting the findings of the scoping review and we will therefore employ strategies from Braun and Clarke, including their '15-point checklist of criteria for good thematic analysis' to ensure precision in collecting and summarising the results.^{22 23} While it is suggested that a board, group or committee should be organised in advance of a study proposal, this is not something that will be explicitly addressed in the scoping review, but may reveal itself in the recruitment challenges uncovered.⁷

Table 2 Preliminary table of charting elements and associated questions for data

Charting elements	Associated questions
Publication details	
Author(s)	Who wrote the study/document?
Year of publication	What year was the study/document published?
Origin/Country of origin	Where was the study/document conducted and/or published?
Publication type	What type of publication is this? (empirical study or grey literature)
General study details	
Aims/Purpose	What were the aims of the study/document?
Methodological design	What methodological design was used for this study?
Study population and sample size (if applicable)	Who is the target population of the study and how many (n) were included in the study?
Methods	What specific methods were used in this study?
Intervention type (if applicable)	Was an intervention used in this study?
Comparator and duration of the intervention (if applicable)	If yes to the intervention type, what was the comparator and duration of the intervention?
Outcomes and details of these (if applicable)	What was the study outcome
<i>Key findings that relate to the recruitment of patients, carers and members of the public to boards, groups and panels</i>	
Type of co-researcher group formed	Was it an advisory board, committee, panel, patient group, etc?
Recruiting co-researchers	How were co-researchers recruited?
Method of recruitment	Were there any stated benefits to this methodology? Were there any stated limitations to this methodology? Were there specific recruitment methods used to address issues of representation or bias?

Adapted from JBI Reviewer's Manual 11.3.7.4, Analysis and Presentation of Results and 11.1, JBI template of evidence details, characteristics and results extraction instrument.^{24 25}

Stage 8: presentation of the results

As discussed in stage 6, a tabular chart will be used to present the results, addressing our five key objectives. The table will be organised by our overarching research objectives, where we will subsequently discuss each included study. We will also present a summary of evidence by a piece of literature included in our review exploring in detail the population, recruitment strategies and outcomes. Findings will be organised into thematic categories including the aims of the retained studies, recruitment design, study design, key findings and gaps uncovered in the literature. Further organisation will include categories that highlight theoretical and operational linkages in the literature.

Stage 9: summarising the evidence in relation to the purpose of the review, making conclusions and noting any implications of the findings

A narrative summary describing the thematic analysis undertaken will be presented in our full scoping review. By understanding the optimal strategies of recruiting patients, carers and members of the public to advisory boards, groups or panels, the development of meaningful research and new partnerships will be strengthened. We expect findings from this scoping review will have

implications in guiding future research recruitment and policy developments.

Public and patient involvement statement

PPI will be integrated throughout this project. International PPI experts, stakeholders and members of the local academic community were consulted to form the search strategy.

ETHICS AND DISSEMINATION

As there will not be consultations with public or patient consultations for this review, only informal feedback with professional stakeholders, ethical approval is not required.

Dissemination of results will be done through presentations at academic conferences, peer-reviewed publications and consultations with lay audiences. We will further solicit suggested dissemination avenues to lay audiences from our patient involvement workshop. We will circle back to researchers who consulted JS regarding recruitment strategies to present our results, aiding them in their research moving forward.

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Contributors All authors have made substantive intellectual contributions to the conceptualisation and development of this protocol. EK co-conceptualised the review approach and drafted the protocol. MG co-conceptualised this review and assisted with writing and critical revision of the intellectual content of the protocol. JS secured funding and contributed to the conceptualisation, writing and critical revision of the protocol. All three authors collaboratively agreed on the final approval of the protocol version to be published.

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Competing interests None declared.

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