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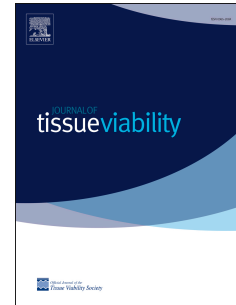
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Synthesising the evidence for patient and public involvement in pressure ulcer research: a scoping review protocol

Abstract

Introduction: There is a growing shift toward greater inclusion of patients and the public in the design, conduct, and implementation of research to ensure it is more meaningful, relevant and impactful. This involvement creates a partnership in which patients and the public contribute to decisions throughout the research lifecycle. While the impact and importance of patient and public involvement (PPI) in research is becoming increasingly recognised, the extent of PPI in pressure ulcer (PU) research has yet to be fully established. This scoping review aims to provide insights into how PPI has been included and reported in PU research, ultimately placing a spotlight on the impact and importance of reporting PPI to guide future PU research.

Methods and analysis: Through synthesising literature from a diverse global landscape, this scoping review aims to achieve the following objectives (1) To explore and map the stage(s) of the PU research cycle where PPI has been incorporated (2) To identify and describe the range of participatory methods, including frameworks, guidelines, or tools, that have been used to facilitate the involvement of patients and the public in PU research. (3) To identify and synthesise reporting impacts of including PPI in PU research, and (4) To map and analyse the terminology commonly used to describe PPI in PU research.

The Joanna Briggs Institute scoping review methodology and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews framework will guide the conduct and reporting of this review. Nine databases will be included in the search strategy and all articles will be independently screened for eligibility by two authors. Data from eligible articles will be extracted using a pre-defined data extraction table, and the results will be analysed and synthesised using the PAGER (Patterns, Advances, Gaps, Evidence for practice and Research recommendations) framework.

Ethics and dissemination: Ethics approval will not be required considering the nature of this scoping review. PPI advisory partners will be consulted for disseminating the results in a format that is accessible and understood by a layperson, in order to communicate the findings to a wide audience and diverse communities. This scoping review will be published in a peer reviewed journal and results will be disseminated at local national and international conferences.

Registration: This scoping review is registered on the Open Science Framework (<https://doi.org/10.17605/OSF.IO/JHT34>). As is typical with scoping reviews, this protocol may evolve over time. Any updates will be documented on the Open Science Framework platform, along with a clear rationale for the changes.

Keywords: Pressure injury, pressure sore, patient engagement, patient and public contribution, patient participation

Strengths and limitations

1. The use of a rigorous, established framework ensures high-quality and consistent results throughout the review process.
2. This review aims not only to list findings but also to analyse the underlying reasons for gaps in evidence and practice.
3. By mapping both existing knowledge and gaps, we will place findings within a theory-driven context, enabling a deeper interpretation of trends and missing evidence in the literature.
4. The review will identify areas in PU research where PPI is being implemented, highlighting its impact on addressing patient needs and preferences.
5. As PPI is a relatively new practice in some regions, much of the available literature may reflect the experiences of “early-adopter” countries, potentially influencing the scope and generalisability of the findings.

Layperson summary of the protocol

What is this review about?

This review will explore research studies that have included people with the lived experience of pressure ulcers (also known as pressure sores). Studies may include

patients, family members, caregivers, or other individuals who are trying to prevent a pressure ulcer, have lived with a pressure ulcer, or have cared for someone with a pressure ulcer. The goal of this review is to understand how much patients and the public have been involved in these studies, what roles they have played, and what difference this has made. Reviewing this information will help summarise what has been done so far and help point to areas where more involvement is needed.

Why is this review important?

Pressure ulcers have a significant impact on the quality of life for those who experience them and for those who care for someone with a pressure ulcer. Including people with lived experience in research can help make the studies more relevant and beneficial for those affected by pressure ulcers. However, we don't know how often or how well individuals are involved in research about pressure ulcers. This review will help identify whether their voices are being heard and how their involvement can be improved.

What type of studies will be included?

We will include studies related to pressure ulcers that have involved patients, caregivers, or others with direct experience of pressure ulcers, in the decisions about how the study will be planned. This could include any research about preventing or treating pressure ulcers in patients of any age and in any place.

What does this review hope to achieve?

By reviewing how patients and the public have been involved in pressure ulcer research, we hope to provide examples of how this has been done well and how this has made a difference to the lives of those affected by pressure ulcers. We also plan to review how patients and the public have been supported to be involved and to what extent have they been involved in the research process. Lastly, we plan to look at all the different ways studies across the world are using words to describe patient and public involvement in pressure ulcer research. This review will help show what is missing and what could be done better in the future to make sure that the needs and experiences of those affected by pressure ulcers are included and valued in a meaningful way.

Introduction

Patient and Public Involvement (PPI) is the terminology commonly used across Ireland and the United Kingdom (UK), to describe the contribution of patients, caregivers and members of the public to research^{1, 2}. Globally, there are various different terminologies used to describe PPI, such as in Australia, where consumer involvement is commonly used³. The lack of a universal terminology can create challenges to identify approaches to PPI in research, including the identification of search terms for a review article. PPI stands apart from participation in the research itself, as patients and the public are considered active partners in decision making. This is different from participants in the research, whereby patients and the public are study subjects and provide their data for analysis in the study to reach the objectives. The UK's National Institute for Health Research (NIHR) defines PPI as "research being carried out "with" or "by" members of the public rather than "to" "about" or "for" them"⁴.

Integrating PPI into research design can result in the production of outcomes that are aligned with the needs, values, and preferences of the target population. This is a vital consideration for researchers, as misalignment in what is important to people with the lived experience of a condition can limit the generalisability and subsequent implementation of study findings into practice. A scoping review of 119 studies reporting the purpose and outcomes of PPI in health research, revealed that partnering with patients improved the research design (n=54, 39%) and relevance of the research conducted to those involved (n=37, 24%)⁵. In a reflective approach, Banfield et al.⁶ shared their experience conducting research with advisory groups comprised of mental health patients and caregivers. The authors describe adaptations to the wording of questionnaires and interview protocols, making language more accessible and helped reach under-researched communities such as those from culturally diverse backgrounds⁶. Ultimately these studies demonstrate that PPI is the driving force for the production of relevant and meaningful research that can have a direct impact on those experiencing the condition under study.

PPI can be embedded into any stage of the research cycle, which can range from identifying and prioritising research questions, to evaluating the impact of the research following implementation⁷. Studies introduce PPI into different stages of the research cycle and thus the approach to including PPI is variable across the research

landscape^{8,9}. The NIHR and the United States' Patient-Centered Outcomes Research Institute have highlighted that PPI is more widely reported during the earlier stages of the research cycle, such as during research prioritisation⁸ or research design¹⁰. This is in contrast to the later stages of the research cycle, where involvement activities are less commonly reported, such as during implementation¹⁰ or dissemination⁸. Ultimately, this raises questions regarding the impact of PPI on the research outputs, when involvement can range from one stage of the research cycle, to involvement throughout the entirety of the research cycle.

The inclusion of PPI varies widely depending on the geographical location, research methods, field of study and funding source¹¹. A cross-sectional analysis of PPI reporting in a general health research journal found that the UK had the highest inclusion of PPI (n=591; 44.5% 95% CI: 40.5% to 48.5%)¹¹. Interestingly, the most common funding source for PPI was from the NIHR (57.2%; 95% CI: 51.8% to 62.8%), which denotes that funding is associated with increased PPI inclusion in research¹¹. It is important to note, however, that this study included papers published in the British Medical Journal (BMJ) Open, which may have impacted the reporting of the most common funding source in this analysis. In terms of the research methods and topic, mixed-methods and mental health research were more likely to include PPI¹¹. In an effort to encourage PPI reporting, academic journals such as the Journal of Advanced Nursing and the BMJ open have added a mandatory statement for authors to declare if their research included PPI. However, it is unclear if authors are familiar with the clear distinction between PPI and participation in research¹², which adds further complexity to how PPI is reported or understood in research. Globally, there is a wide variation in the inclusion of PPI throughout research, making it more challenging to synthesise the findings and identify how the lived experience has impacted the research outputs.

There are a wide variety of frameworks, guidelines and tools available to support researchers with conducting high quality PPI, encouraging transparent reporting of the participatory methods used to involve patients and the public. A comprehensive review identified 65 frameworks in existence to support PPI in research, with each having their own intended purpose¹³. Such an example of this are priority-setting frameworks, which include methods for involving patients in setting priorities and translating them

into actionable research questions^{13, 14}. Using participatory frameworks allow for these activities to be planned in a structured and transparent way to ensure diversity and equal inclusion of those involved^{13, 15}. On the other hand, report-focused frameworks such as the GRIPP2 checklist enhances the quality, transparency and consistency of reporting PPI in research¹⁶. Irrespective of these frameworks being available, there is often a discrepancy across studies when reporting each of the steps involved in the framework¹⁷. Various other approaches exist for planning, recording and reporting the impact of PPI alongside reports of challenges experienced when involving patients and the public¹⁸. Thus, there is evidence to suggest that PPI carries both challenges and victories across the research lifecycle. Reporting impacts enables researchers to gain insight into the value and importance of PPI, including strategies to overcome challenges. Thus, considering there are a wide variety of tools, guidelines and frameworks available to support the quality, diversity and inclusion of patients and public participating in research, researchers are in a prime position to leverage these tools in support of greater PPI.

Patient and Public Involvement in pressure ulcer research

Embedding PPI in pressure ulcer (PU) research is integral to producing high quality research that drives relevant and impactful solutions for reducing the heavy burden that PUs place on patients, their families and on the healthcare system¹⁹⁻²³. PUs, defined as localised injuries to the skin and underlying tissue resulting from pressure or a combination of pressure and shear²⁴, remain a persistent challenge in healthcare. While various approaches to risk assessment, early detection, prevention and treatment of PUs have been developed, the inconsistent inclusion of PPI across research studies²⁵ raises questions about the relevance and applicability of research outcomes for patients and caregivers themselves.

A recent study by Muir et al.²⁶ exemplifies the value of PPI in PU research. Their work aimed to develop a multi-component intervention package with PPI, to support PU identification and management for individuals self-managing care at home. One of the eight key themes that emerged focused on learning, emphasising the critical need for enhanced PU awareness and support when seeking help for PU development or deterioration. Importantly, while existing educational materials primarily addressed risk factors, the PPI members highlighted a significant gap: the lack of consideration for

wider contextual issues and strategies for adapting PU management to individual life circumstances. This finding underscores a critical aspect of PPI in PU research, as studies designed with PPI can effectively balance the realities of living with a PU against evidence-based practice. By incorporating the lived experience of patients and caregivers, researchers can ensure their findings are not only scientifically robust but also relevant and implementable in real-world settings. Ultimately, the success of PU prevention and management strategies hinges on their alignment with the daily lives and individual circumstances of those affected by PUs.

Patients are the “real” experts of their condition, as they have the lived experience which offers an enriched perspective based on their own diverse needs, values and preferences². International clinical practice guidelines for the prevention and treatment of PUs involved patients and caregivers (n=1,233) in their development which ultimately emphasised the need for patients to have a more active participation in their care^{23, 24}. In order to make active participation a reality in our healthcare system, PPI must be central to research, thereby giving patients and caregivers a lead role in how research is planned, performed and implemented. Strategies to overcome common barriers associated with PU prevention and treatment are likely to be better understood and addressed when patients and caregivers with experience facing these challenges are listened to²⁷. Thus, a shift in focus towards partnership with patients and caregivers through PPI is a move towards more effective prevention and treatment of PUs across community and healthcare settings.

As the literature involving PPI in PU research has not been comprehensively reviewed, a scoping review was considered the most appropriate approach, considering the heterogeneous and broad nature of the objectives. This scoping review aims to provide insights into how PPI has been included and reported in PU research, ultimately placing a spotlight on the impact and importance of reporting PPI to guide future PU research. The term “advisory partners” will be used throughout this scoping review protocol to refer to patients, caregivers and members of the public involved in the research.

Methods and analysis

The Joanna Briggs Institute (JBI) scoping review protocol methodology guided the development of this protocol²⁸. The scope of this review will accommodate a broad range of methodological approaches, ensuring a comprehensive synthesis of the literature. We will adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR)²⁹ and the JBI guidance for scoping reviews³⁰ to systematically conduct and report the review of published peer-reviewed articles. The review process will include the following stages: (1) development of the research question, (2) formulation of the search strategy, (3) establishment of inclusion and exclusion criteria, (4) data extraction, (5) data analysis and presentation of results, and (6) dissemination of findings. The scoping review will be conducted between 2024 and 2025. Ethical approval is not required for this type of study.

Objectives

Our goal is to synthesise the existing evidence on PPI in PU research. These objectives will be further refined through discussions with the PPI advisory panel. The following objectives will guide this scoping review and aim to map the current landscape of PPI in PU research:

1. To explore and map the stage(s) of the research cycle where PPI has been incorporated into PU research.
2. To identify and describe the range of participatory methods, including frameworks, guidelines, or tools, that have been used to facilitate the involvement of patients and the public in PU research.
3. To identify and synthesise reported impacts of including PPI in PU research, categorising them into key domains of influence.
4. To map and analyse the terminology commonly used to describe PPI in PU research, identifying common terms and any variations across different research contexts.

Eligibility criteria

The inclusion and exclusion criteria were developed following the JBI construct; Population Concept Context (PCC) approach²⁸ and can be seen in table 1.

Table 1. Eligibility criteria

PCC	Inclusion Criteria	Exclusion Criteria
Population	Studies with a primary objective to prevent or treat pressure ulcers in a cohort of patients of any age at risk of developing a pressure ulcer or in patients with a pressure ulcer. This also includes medical-device related pressure ulcers .	Studies that do not explore pressure ulcer prevention or treatment as a primary objective. Studies that do not include patients at risk of developing a pressure ulcer or with a pressure ulcer.
Concept	Studies that actively involve patients, caregivers (relatives), or members of the public with the lived experience of PUs in the planning, development and decision-making process at any stage of the research cycle.	Studies that do not involve patient and public involvement at any stage of the research cycle. Patients, caregivers (relatives), or members of the public that are participants in the research study but do not provide consultation during the research cycle.
Context	In any setting or type of study .	Studies will not be excluded based on study setting or type.

Search strategy

A comprehensive search strategy across nine electronic databases will be performed to identify relevant literature, from inception until March 2025 on each database. The following databases will be chosen to include relevant literature spanning a wide geographical landscape: LILACS PubMed, EMBASE, EBSCO CINAHL, Scopus, Web of Science, ProQuest Dissertation (Web of Science) and Ovid Medline. To identify further published, literature, this scoping review will scan reference lists and citations of all included studies. The following keywords will be used in various combinations (a) "Patient and Public, (b) "Involvement" and (c) "Pressure Ulcer" (Supplementary File: Table 1. Full search strategy). A research librarian (K.W) has already reviewed and provided guidance for the comprehensive search strategy outlined in this protocol.

Types of evidence to be included

The evidence will include original research of all study designs and methodologies, such as quantitative, qualitative, mixed-methods, or multi-methods research. The

literature will be restricted to publications in English, Spanish, and Portuguese due to resource constraints and the authors' limited translation expertise in other languages.

Data management

The final search including all databases were exported to Endnote (version 20, Clarivate, Philadelphia, PA) to exclude duplicates. Following the removal of duplicates, data will be uploaded into Rayyan (<https://new.rayyan.ai/>)³¹ and a second de-duplication process will be conducted. The final identification, screening and inclusion process will be reported by PRISMA flowchart³².

Selection process

Two independent reviewers will conduct the screening, eligibility assessment, and inclusion of articles. The title and abstract screening will be performed independently by both reviewers for all identified articles using Rayyan. Based on predefined inclusion and exclusion criteria, the reviewers will classify each article as 'Yes,' 'No,' or 'Maybe.' Articles classified as 'Yes' or 'Maybe' will proceed to full-text screening. Any discrepancies between the reviewers will be reviewed and resolved by a senior member of the research team. The inclusion and exclusion criteria will be piloted on a randomly selected subset of articles. Once the criteria have been finalised, a different random sample of identified articles will be selected to assess inter-rater reliability using the Kappa coefficient. Testing will continue until a Kappa value of 0.8, indicating strong agreement, is achieved³³. Inter-rater reliability will be regularly assessed throughout the title and abstract screening process to ensure consistency and reliability, providing multiple opportunities for the research team to discuss and resolve any disagreements. During the full-text screening, reviewers will categorise articles as either 'Yes' or 'No,' with any uncertainties being collectively discussed. In cases of discrepancies, adjudication will be made by a senior member of the research team.

Data extraction

Data will be extracted from the full-text articles using a pre-defined data extraction table on Microsoft Excel. To ensure the reliability of the extraction process, a pilot test of the data extraction table will be conducted using the first 10 articles (Supplementary File: Table 2. Data Extraction Table).

The data items to be extracted from the included studies will encompass several key aspects. Study characteristics such as author, journal and year of publication, country of study, setting, and study design. This will include the outcomes related to the stage of involvement, such as planning, design, implementation, or evaluation. The participatory methods employed will be examined, including frameworks and guides, the number and frequency of involvement in activities, and the specific roles of advisory partners involved. Additionally, information regarding the near-term, intermediate, and long-term impact of PPI for the following key domains of influence will be reported; (1) patients and the public, (2) professional practice, (3) organisations, (4) research quality/relevance and (5) society. The primary and secondary outcomes of interest of each study will be collected and pertaining to the challenges and facilitators of including PPI. Lastly, the terminology used to describe PPI in the included papers will be collected and mapped according to each country.

Critical appraisal of available literature

As this is a scoping review, performing a quality assessment of included studies is not recommended^{29, 30}.

Analysis and presentation of results

For this scoping review, the raw extracted data will be transformed as needed to facilitate the mapping and synthesis of the evidence. This may involve grouping qualitative data into broad categories or summaries, rather than performing a detailed thematic analysis. Quantitative data will be aggregated where appropriate, such as through basic frequency analysis. These transformations will help to standardise the data, enabling comparison across studies and ensuring alignment with the review's objectives. The goal is to provide a clear overview of the data rather than drawing interpretive conclusions from individual studies. To comprehensively outline the scope, characteristics, and synthesis of the reviewed literature, we intend to analyse and present the findings utilising the PAGER framework³⁴. The PAGER framework offers a systematic approach designed to complement existing guidelines, thereby strengthening the methodology of scoping reviews and enhancing the rigor of analysis and reporting. This framework encompasses five key domains: Patterns, Advances, Gaps, Evidence for practice, and Research recommendations³⁴. The PAGER framework includes visual representations of the data through "patterning charts",

offering a clear presentation of themes that clearly identify patterns and gaps across the included studies³⁴. Due to the nature of a scoping review, the decisions around how the data will be presented may evolve and change throughout the conduct of this review.

Patient and public involvement

A PPI advisory partner with lived experience of PUs was involved in the design and writing of this scoping review protocol, ensuring completeness, relevance, and language accessibility for a wider audience, which included the addition of a layperson summary. The research department has established an advisory panel, comprised of people with the lived experience of PUs, to help direct future PU research. Advisory partners will be involved in the conduct, reporting and dissemination of this scoping review. Their involvement will ensure the scoping review includes relevant literature, extracts meaningful data and synthesises results in a patient-centered manner, ultimately helping reach a wider public audience when disseminating the results. The GRIPP II checklist¹⁶ will report PPI in this scoping review.

Ethics and dissemination

Considering the nature of a scoping review, ethics approval will not be required. PPI advisory partners who are experts by experience in this field under study will be involved in the screening, data collection, data analysis and results reporting of this scoping review. Insight and feedback will be sought from advisory partners for disseminating the results in a format that is accessible and understood by a layperson, in order to communicate the findings to a wide audience and diverse communities. This scoping review will be published in peer reviewed publications and results will be disseminated at local national and international conferences. The results will also be communicated through local networks as advised by our advisory partners.

Authors' contributions

HW: Conceptualisation, Methodology, Writing-Original Draft **AB:** Conceptualisation, Methodology, Writing-Original Draft **LT:** Methodology, Writing-Original Draft **PA:** Writing – Review & Editing **LN:** Writing – Review & Editing **ND:** Conceptualization **DN:** Writing-Original Draft **WC:** Conceptualization, Methodology, Writing – Review &

Editing **T'OC**: Writing – Review & Editing **KW**: Methodology **SL**: Writing – Review & Editing **ZM**: Conceptualisation, Methodology, Writing – Review & Editing. Authors' contributions were selected using the contributor Roles Taxonomy (CRediT) author statement³⁵.

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Conflict of interest statement

The authors have no conflict of interest to declare with regards to the content of this scoping review protocol.

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Highlights

- Involving patients and the public in health research has shown to impact the quality of study design and the relevance of research results for those experiencing the condition under study.
- While patient and public involvement (PPI) is recognised as valuable in various healthcare research fields, its specific application and impact in pressure ulcer (PU) research has not been comprehensively reviewed, representing a significant knowledge gap.
- This protocol outlines a scoping review to map the current landscape of PPI in PU research, highlighting opportunities for enhancing the relevance and impact of PU research through PPI, and potentially informing future research practices.
- This protocol was developed with a PPI advisory partner with lived experience of PUs. PPI advisory partners will be involved throughout the review process, ensuring that the findings are relevant and accessible to patients and the public.

Conflict of interest statement

The authors have no conflict of interest to declare with regards to the content of this scoping review protocol.

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